The Invisible Woman
Unveiling the impact of advanced breast cancer on women, families, society and the economy across Europe
One of the definitions of survival is ‘that which endures’. I think I fit in this category. I’ve been battling this enemy for five years, through numerous surgeries, lots of radiation and now my second regimen of chemo. Sometimes I feel like a soldier who keeps getting shot, then patched up and sent back on the front lines. I know it’s hard to hear stories like mine – it could have been, might have been, might one day may be you. I pray that it will never be so, for anyone, but the fact remains that, although I am not disease-free, I am alive, and I will do whatever I can to keep going. In spite of the fact that I have serious bone mets, and my prognosis is not very pretty, still I can say I am a survivor, I have endured, I will continue as long as there is breath.

Sandra Yandell

Acknowledgements

The here & now campaign is supported by Novartis Oncology.

The Patient and Carer Survey was carried out by Insight Research Group.

The Here & Now Consumer Poll was carried out by OnePoll.

We thank the European Foundation for the Improvement of Living and Working for the use of the 3rd European Quality of Life Survey data.

The views expressed in this report are those of the author alone, Professor Pamela Abbott, and should not necessarily be taken to represent the views of Novartis or its subsidiaries.
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**Introduction**

Advanced breast cancer (ABC) is not just a personal tragedy – it is a social problem for the people concerned, their families and friends, and society as a whole.

This report raises awareness of ABC across Europe, uncovers insights into the disease and recognises the societal contributions (economic and social) made by women, in particular the 50+ generation.

It draws on existing medical and demographic research, on the European Quality of Life Survey and on two surveys across Europe specially commissioned by Novartis Oncology (Box 1).

The aim of this new evidence is to inform, motivate and bring about a positive change for women with ABC.

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**Box 1**

**A brief summary of data sources**

- **ABC Patient and Carer Survey** - a recruited sample, predominantly via physicians, of 158 ABC patients and 146 carers in nine countries typifying Northern, Eastern, Southern and Western Europe. The survey looked at the impact of the diagnosis of ABC on the psychological, social and economic lives of patients and their families.

- **Awareness of ABC across Europe** - a consumer poll of 2,202 people carried out in 11 countries representative of Northern, Eastern, Southern and Western Europe, exploring perceptions of ABC and the value of the 50+ female generation.

- **A review of selected literature** focusing on the impact of breast cancer and especially ABC on women’s lives, the incidence of breast cancer in Europe, the diagnosis and treatment of breast cancer historically and contemporarily and future expectations and opportunities for treating ABC. The literature was sourced using Google and Google Scholar.

- **A secondary analysis of the European Quality of Life Survey** to uncover the contribution of women aged 50 years or over to paid and unpaid care work in a representative sample of European countries.
Acronyms & Abbreviations

**ABC**  
Advanced Breast Cancer

**EBC**  
Early Breast Cancer

**EQLS**  
European Quality of Life Survey

**HCP**  
Healthcare Professional

**MBC**  
Metastatic Breast Cancer

**ONS**  
Office for National Statistics
Two years ago, in November 2011, I had one of the most extraordinary experiences of my professional life. Following five years of intense work, publications and lobbying, the 1st International Consensus Conference for Advanced Breast Cancer (ABC 1) finally took place.

The difficulties faced during those five years were just a minor reflection of the huge hurdles advanced breast cancer patients face every day. They merely showcase how neglected this group of patients has been for decades.

The Bridge and Silent Voices Surveys and publications, back in 2006, were a painful eye-opener to the suffering that ABC patients had been enduring. I had been helping them fight this terrible disease ever since the beginning of my Medical Oncology residence but in 2006 I had the privilege to start an international and very public fight for them.

Now, seven years down the line, advanced breast cancer is starting to be given more focus. The first truly international consensus guidelines have been developed and they have been presented all over the world, from Canada to Taiwan, in every oncology conference there are now sessions dedicated to a better understanding and a better management of this disease. Breast cancer advocacy groups are now starting to devote attention to advanced patients, lobbying and fighting for their specific needs. Researchers, clinicians and pharmaceutical companies have started to join forces to provide real solutions against this terrible disease instead of ‘speeding’ trials through the metastatic stage in the rush to get to the early setting. The ABC Genome Atlas project is also about to start.
The road is still long and winding... and painful... and very difficult. But, I hope it is now less lonely, that ABC patients feel less abandoned and forgotten, and that we have helped to bring them from “the forgotten heroes” to “the courageous fighters”.

At the opening lecture of ABC 1, author, advocate and breast cancer survivor, Musa Mayer stated a fact that still resonates in my mind today:

“How can we provide the best care for this population if we are not even aware of how many ABC patients exist in the world at a given moment?”

Musa was asking, “please count us!”. The Here & Now campaign is contributing to answering this, but what is really crucial and urgent is a rethinking and re-organisation of cancer registries in all countries to make sure that not only diagnosis and death, but also relapse are registered, and that registries communicate among themselves.

So much more is left to be done: more campaigns, more advocacy, more funding, more research, more trials. The worldwide implementation of ABC guidelines is needed to transform this rapidly fatal disease into a truly chronic one [with sufficiently long-term survival for most patients] and hopefully in the near future, a curable one.

For me it has been an enriching and amazing journey, I have grown as a human being while sharing in the brave fight of so many women and men. Thank you – you are no longer forgotten but you will always be my heroes!

Fatima Cardoso
Director, Breast Unit,
Champalimaud Cancer Center, Lisbon, Portugal
Advanced breast cancer (ABC) affects not only the person diagnosed and their friends and family, but the disease also has a wider social and economic impact.

If they are unable to do some or all of this ‘grey economy’ work, then replacing their unpaid labour has an estimated replacement cost of around €8,767 per year for each woman, a total of €876.5 billion for the 11 European countries considered in this report. This does not take into account that 45 per cent of women aged 50-65 are in paid employment in Europe and make an important contribution to the formal economy.

For many women who are suffering from and coping with ABC, the outcome may be psychological, social and economic hardships. Support and guidance are offered, but they are not sufficient, according to our research, and patients and carers are often unable to get adequate information about ABC. They often feel depressed and worried, and live for the moment as they fear for the future. Many are forced to give up paid employment or reduce the hours that they work and take on less responsibility, at just the time when they face the additional costs of being ill. They are also less able to look after their families. Day-to-day living becomes a struggle to cope and survive.
The hopes for the immediate future include new treatments which need to be accompanied by improved clinical care, better and more tailored access to advice and information, and other measures to improve the quality of life for women with ABC and their families and friends.

Our hope is that this new body of evidence informs and inspires the following groups in order to bring about a positive change for women with ABC. In particular:

• Healthcare professionals to understand they can do more for their patients with ABC;

• Payers, regulators and commissioners to improve their understanding of the ABC landscape and consider their responsibilities when making decisions about access to care;

• Patient support groups to build capabilities and feel empowered to further their support for women throughout their breast cancer journey;

• Health-aware general public to feel proud of this generation of women, recognising their value in society.

And most important of all...

Women with ABC to feel that they are not alone and that together they can achieve more.
Worldwide, about 1.4 million women are diagnosed with breast cancer every year. With 458,000 deaths per year it is the most common cause of female cancer death in many countries in both the developed and developing world. Women in the western world have a one in eight risk of developing breast cancer, with the risk increasing with age. Sixty-five per cent of diagnosed patients were 55 or older, and 88 per cent were 45 or older; only two per cent were younger than 35. Despite advances in treatment and increased chances of survival, the death rate is likely to continue to rise with an aging population.

Breast cancer diagnosis disrupts normally taken-for-granted expectations about our lives and creates uncertainty. The diagnosis affects not just the women themselves but also their families, friends and the communities in which they live. There are economic, social as well as personal costs, not just for the women themselves and their families but also for society more generally. Women are increasing in paid employment across their life course, so at a time when illness may result in extra costs there is the potential loss of earnings negatively impacting a household’s economic well-being, and also the loss of the woman’s talent on the labour market – a loss of skilled and experienced workers. There is also the loss of the non-remunerated and often unrecognised care work that women do in the home and community, looking after children and grandchildren, looking after elderly and disabled relatives and cooking and cleaning. This ‘labour of love’ is nevertheless necessary work that has an economic value – someone else can be paid to do it.

Historically the median survival rate for women with ABC has been two to three years, but with modern treatment regimens there has been an improvement in the rate, with patients occasionally living for a prolonged period of time.

For many women an appropriate use of therapy can translate into years of prolonged survival with a preserved quality of life. Modern oncology for these women has turned a killer disease into a more manageable illness like, for example, diabetes, arthritis or HIV. However, in the Here & Now Patient and Carer Survey, one in two women living with ABC suffered daily pain and only 22 per cent rated their health as ‘good’ or better.
Understanding advanced breast cancer

Breast cancer has become a topic widely covered in the media, with the message generally being a positive one emphasising that with early detection there is a high likelihood of a cure. However, there is little public discussion of advanced breast cancer; a climate of fear, discomfort, isolation and discrimination creates a silence that prevents an understanding of the lives of people living with ABC\textsuperscript{12,13}. There is also a lack of understanding of ABC in the wider community. While 3 in 5 people in the Here & Now Consumer Poll knew someone that has had breast cancer, 43 per cent had not heard of ABC or were unable to define it correctly. Eighty-eight per cent were aware that EBC can be treated so that the patient is free from the disease but only 23 per cent were aware that ABC cannot be treated so that the patient becomes free from the disease.

Although a number of risk factors have been identified for breast cancer, including genetic and lifestyle ones, it cannot be prevented and little is known about the exact cause(s) of the majority of breast cancers, including the metastasis associated with development into ABC\textsuperscript{14}. The common risk factors associated with breast cancer are age, family history of the disease, ethnicity, lifestyle and reproductive history. The higher incidence rate in western European countries compared to those in the south is, at least partly, explained by early detection through screening services and by lifestyle issues in western countries.

There are no measures that can be adopted to prevent metastasis or a reoccurrence of a cancer – or indeed the occurrence of breast cancer in the first place – although lifestyle changes, including physical exercise and a sensible diet, may reduce the cancer risk\textsuperscript{15,16,17}. Other measures that can reduce risk include having children while still young, and breastfeeding\textsuperscript{6}. Early detection is critical; survival rates are higher when the tumour is small and the cancer is asymptomatic at first diagnosis.

Key facts about breast cancer:

Breast cancer is the most common cancer in women worldwide\textsuperscript{5}

The disease burden largely affects women over 50 years and it is estimated that the average age at the time of diagnosis is 61 years\textsuperscript{2}

30\% of women with early breast cancer go on to develop advanced disease, which is currently incurable\textsuperscript{3}

Average life expectancy after ABC diagnosis has changed little in recent decades, remaining at two to three years.\textsuperscript{10}
Women who have ABC experience profound changes in their lives, and they and their families face psychosocial challenges that significantly affect the quality of their lives\(^\text{18}\).

“Sometimes I feel like I am hidden and forgotten.”

*Lynne\(^\text{18}\)*

“Is took me a while to digest the indefiniteness of a metastatic diagnosis. But once I understood, I accepted my reality and was able to continue to ‘start living’ in the moment. That is the challenge.”

*Nazneen\(^\text{19}\)*

“People tend to shy away from me when they find I have the disease.”

*May\(^\text{18}\)*

“Well now I’m very positive day to day – it’s easy when I’m not in pain – I’m determined to live as long as I can, but my doctor says I’m incurable so I accept that sooner or later, and certainly sooner than I want, it’s gonna get me.”

*Karen Caviglia\(^\text{12}\)*
In the Here & Now Patients and Carer Survey, one in two of the respondents thought that society views women with ABC negatively and only eight per cent felt that other people treated them normally.
Making the ‘Invisible’ Visible

The personal, social and economic cost of advanced breast cancer

“Frankly, remission is an awkward place because I am not busy dying. In fact, beyond the normal wear and tear of aging, I now look and feel as well as I did before I became ill. But I have not been able to go ahead with my life simply as though nothing has happened.”

Jenilu Schoolman

Life-threatening illness disrupts our normal assumptions about the roles we can play and the responsibilities we can undertake. It creates uncertainty; it destroys the picture of what life will be like in the future; what tomorrow and next month will bring is always uncertain. Women are generally expected to look after their families, and when they are unable to do so there are financial and social costs as well as personal and psychological ones. There can be loss of income as well as a reduction in the informal care work that they can do. It can be very difficult for women to cope with the diagnosis and they may feel upset, frightened, confused and afraid as they come to terms with it. They may feel angry as they ask ‘why me?’, feel shocked and numb or a sense of bereavement or loss of identity as they begin to feel defined by their disease. At times, they may feel depressed while at others they may feel positive and hopeful. They may have to cope with the side effects of treatment, such as feeling tired and lethargic, and work out how to manage their lives practically.

Hearing that they have breast cancer is difficult news for women but it can be even more of a shock when they learn that it has metastasised. The diagnosis may bring feelings of shock, disbelief, anger, betrayal and sadness. The lack of public awareness of advanced breast cancer often leaves women feeling isolated, misunderstood and unsupported. There may be a loss of trust in doctors or treatments and anger that medicine has failed them. They may fear dying and worry about end-of-life care for themselves and their families.

Messages from women with ABC worldwide say:

• They want to be understood better. Nearly two-thirds feel that no one understands what they are going through and nearly 40 per cent feel isolated from others who don’t have advanced breast cancer.

• They want more information and support available that addresses their needs. Nearly eight in 10 actively seek out information, but 45 per cent think that information on ABC is hard to find and 55 per cent agree that the available information does not meet their needs. Just over half (54 per cent) found it hard to find a support group for ABC and three-quarters would like their healthcare provider to do more to address their emotional needs.

• They want meaningful support that lasts. Although some women get strong emotional support from family and friends, four in 10 say that support declines over time and just over one in two say that they get support from other women with ABC.

* The countries included in Harris Interactive (2013) were the United States, Canada, Mexico, Brazil, the UK, Germany, Russia, India, Taiwan, Hong Kong.
Pan-European patient and carer insights

In the ABC Patient and Carer Survey, eight out of 10 women feel that quality of life is the biggest area in need of improvement for patients. Their economic security and that of their family is threatened, they are not able to care for their families to the extent that they did before they became unwell, and they do not feel in control of their lives. Thirty-seven per cent of patients have lost their confidence and personal identity due to the condition, and half of all patients report daily pain or discomfort and anxiety and depression as a result of ABC.

Patients’ lives are a roller-coaster, alternating between fear of the future and depression on the one hand, and on the other optimism tempered by day-to-day worries about life. Ninety per cent of patients have negative feelings when first diagnosed with early breast cancer and a similar number (92 per cent) experience this again when they are told the cancer has progressed. When asked to give the top five words that describe how they felt about their lives while they were in remission, and how they feel now they have ABC, it is evident that women become more worried and fearful and less confident about the future as their illness progresses. In remission, a third are fearful of a relapse and only just over a third are quietly confident. Around a half are strong, hopeful, optimistic, looking forward or have a positive outlook, only four out of 10 are positively happy and one in three quietly confident. One in four say they live for the present even when in remission.

Patient feelings at different stages of breast cancer

- **EBC Diagnosis**
  - Depressed (41%)
  - Fear (39%)
  - Panic (25%)

- **Remission**
  - Strong (56%)
  - Hopeful (53%)
  - Optimistic (51%)

- **ABC Diagnosis**
  - Fear (30%)
  - Depression (30%)
  - Panic (20%)

- **Day to day life**
  - Depression (31%)
  - Worry (52%)
  - Live in moment (47%)
  - Fear of the future (38%)

Of women living with ABC:

- 30% are depressed when first diagnosed
- Over half are worried and 41% say they are depressed
- Less than a third claim to be ‘strong’, ‘looking forward’ or ‘surviving’
- 50% experience pain that interferes with their daily life
- 50% suffer from discomfort and anxiety
- 37% have lost confidence or a sense of their personal identity since diagnosis
Once patients are diagnosed with ABC, negative feelings are at the forefront of their minds; while nearly one in two patients (46%) were wholly positive while in remission, this falls to only just over one in 10 (12%) when they have ABC.

While only two per cent of patients were negative when in remission, over a quarter (28%) are negative when ABC is diagnosed. One in two women living with ABC are worried or feel like they have to live for the moment, two out of five are depressed or fearful for the future and one in three say they feel sad.

At a time when they are experiencing emotional and physical pain, women living with ABC also need more support from others; as many as one in four feel a sense of withdrawal from colleagues, friends and their extended family and 16 per cent from close family (Figure 1). Forty-four per cent of patients, nearly half, experience daily pain, anxiety or depression and problems with carrying out their usual activities. Around a third have lost confidence in themselves or feel a loss of personal identity, need help with personal care from family and may also have mobility problems.

Sources of information
Healthcare professionals are the main source of information for women living with ABC and are also considered the most useful (Figure 2). Seventy-seven per cent get information from healthcare professionals and 71 per cent find it the most useful. After healthcare professionals, health-related websites are the most used source of information, with nearly four out of 10 using them, but only 18 per cent finding them the most useful of their sources. ABC patients do not typically use patient support groups or online social networks as sources of information.
Nearly nine patients out of 10 thought that they received as much information at advanced diagnosis as they had been given at initial diagnosis, or more, with only 12 per cent saying they were given less. Patients generally said that they had been provided with information on treatment at the time of initial diagnosis (90 per cent) and at advanced diagnosis (88 per cent). However far fewer were given information about sources of support information at initial diagnosis (34 per cent) and at advanced diagnosis (31 per cent).

Well over half of all patients rated the practical information they received on initial diagnosis highly, with 65 per cent, for example, rating the information given on treatment options as ‘very useful’. However, sources of information for psychological support was rated very useful by only 34 per cent of patients and general support by 42 per cent.

**Sources of support**

Support from family and healthcare professionals for women living with ABC is very high, with nearly nine out of 10 being helped by one or both, 60 per cent receiving support from friends, but only a third receiving assistance from support groups and less than one in 10 (seven per cent) from social services. The main source is oncologists, followed by friends, partners and children. While around two thirds of patients are ‘extremely satisfied’ with the support they receive from oncologists and close relatives, they are less satisfied with what more distant relatives, friends, nurses and other members of the healthcare team provide (Figure 3). While levels of satisfaction with oncologists are high, only 72 per cent of patients want more time with their doctors.

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**Figure 2:**
Sources of information used to find out about ABC and its treatment and the ones that were most useful (% of women living with ABC)

**Figure 3:**
Sources of support for women living with ABC and satisfaction with the support
Personal finances

More than one in two (56%) of women living with ABC say that their household has experienced a decline in income as a direct result of their illness. One household in three has faced a decline of more than 30 per cent and one in 10 of more than 50 per cent (Figure 4).

Eighty-seven per cent of ABC patients reported increased living costs as a result of their illness and 62 per cent reported that their financial situation had changed for the worse. Four in 10 women living with ABC suffer from psychological or physical problems as a direct result of the change in their financial circumstances. Increased costs include having to pay for travel to and from check-ups (52 per cent), for additional treatment costs (51 per cent), for help around the house (34 per cent) and for a special diet (22 per cent). In order to cope with the financial pressures of a drop in income and additional costs associated with ABC, four in 10 (38 per cent) cut down on spending not related to healthcare and 24 per cent struggle to pay for things, including 15 per cent who have difficulty in meeting mortgage payments.

Making a difference for women with advanced breast cancer

While patients may ‘put a brave face on it’ or come across as ‘satisfied’ with their treatment and support, much more can be done to support them, improving their quality of life and giving them financial security.

- 65% would feel better informed and 52% more reassured if the doctor gave them more time;
- 79% want improved personal well-being;
- 72% want better access to treatment;
- 68% want better access to healthcare professionals;
- 62% need improved financial support;
- 55% want improved access to counselling services.

Practical support and more information about treatment would make the biggest differences to the lives of women living with ABC. Three-quarters need practical support and three in five need emotional support, while two-thirds need more information about treatment and 57 per cent more information about ABC.

Areas of support that would make the biggest difference in the day-to-day life of patients with ABC:

<table>
<thead>
<tr>
<th>Practical Support Needs</th>
<th>Emotional Support Needs</th>
<th>Information on Treatment</th>
<th>Information on ABC</th>
</tr>
</thead>
<tbody>
<tr>
<td>76%</td>
<td>57%</td>
<td>68%</td>
<td>57%</td>
</tr>
<tr>
<td>42% housework</td>
<td>32% from professionals</td>
<td>38% managing side effects</td>
<td>33% managing pain</td>
</tr>
<tr>
<td>37% financial</td>
<td>22% from family/friends</td>
<td>33% treatment expectations</td>
<td>32% what to expect from ABC</td>
</tr>
<tr>
<td>24% sources of financial information</td>
<td>22% sources of psychological support</td>
<td>23% clinical trial participation</td>
<td>50% time to discuss their condition with a doctor</td>
</tr>
<tr>
<td>21% family or friends</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The ‘grey economy’: societal impact of ABC

Across Europe, 50+ women play an important role, cooking and cleaning for their families, and looking after elderly and unwell relatives, children and grandchildren while the parents are at work.20,21,22 When they become ill they may no longer be able to do this ‘grey economy work’.

Family and friends value the support they receive from 50+ women. In the Here & Now Consumer Poll, 56 per cent of respondents said that the inability of a female family member or friend to support them would impact negatively on their lives or the lives of those closest to them. One in five rely on them for financial support. A third of respondents would need to reduce their hours of employment, work part time or hire help – for example, a nanny, tutor, or cleaner – if they no longer had the support of a 50+ family member or friend.

- 56% get support and guidance on day-to-day issues;
- 20% get support with childcare, for example babysitting or doing the school run;
- 19% get financial support.

In the 11 European countries included in the Here & Now Consumer Poll the value of the unpaid care work of women aged over 50 is an estimated €876.5 billion a year*, ranging from €4.7 billion in Denmark to €130 billion in Italy – €8,767 for every woman aged 50+ living in the 11 countries (see Appendix 6 for details for all 11 countries). When a woman becomes sick and is unable to continue to work, or has to reduce the hours that she can work, her family and community suffer; it has a negative impact on the household’s finances at precisely the time when her illness brings additional financial costs.

On average across the 11 countries:

- 51.4% of women in the general population aged 50-64 years are in paid employment
- women spend 22.4 hours a week doing unpaid cooking and cleaning work and caring for children and elderly people;
- 36% of women aged 50 or over look after their own children and or their grandchildren at least several times a week and 18 per cent do so every day;
- 84% do cooking and or housework on a daily basis and 95 per cent at least several times a week;
- 8% look after an elderly or disabled person on a daily basis and 16 per cent at least several times each week;
- 25% do voluntary work in the community at least once a month

* Based on data from the European Quality of Life Survey for 2011, with estimates of the population of women 50 or over from EUROSTAT for 2011 [http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do#] and using the UK minimum wage of £6.36 an hour. See Appendix 4 for more detail about the EQLS.

Do you perform other activities in particular to support your family, friends and society?

I help my son, aged 35, who is suffering from serious depression. I financially support and make contributions to every meal.

France

I give my family financial support. Drive them to hospital and doctor appointments. Drive them to or from work when the train doesn’t turn up.

United Kingdom

I can make others feel better, console them and provide advice. Sometimes I’d support my neighbours not only financially but also with a meal or a friendly chat. I’d also look after their grandchildren or help in the garden. I wouldn’t also say no to someone who’d knock on my door looking for help.

Poland

Visit the elderly in my housing association; take care of my children and grandchildren in the form of trips, holidays, homework.

Denmark

Source: Here & Now Consumer Poll
Women living with ABC are often no longer able to provide the economic, practical, social and emotional support to their families and the wider community that is generally expected of them. This has a negative impact on their families as well as the women themselves. Thirty-four per cent have to pay someone to provide help around the house. A majority of the ABC patients are married (67 per cent) and have children living at home (51 per cent) but they are forced to reduce the time they spend providing practical and emotional support to their families by 41 per cent.

Women living with ABC are less able to take responsibility for domestic work, look after children and other family members and do the emotional work of holding the family together (Figure 5). The proportion of women able to undertake domestic and care work falls significantly as the illness progresses. There is a 65 per cent decline in the proportion of women able to take children to and from activities, for example, and a 56 per cent decline in the proportion able to look after their children or parents at home.

When women do continue to look after their families and to do domestic work, they are forced to reduce significantly the time they spend doing it. ABC has a particularly negative impact on women’s ability to look after children.

- **Housework** reduces from an average of 13 hours a week to five hours
- **Cooking** reduces from an average of 11 hours a week to four hours
- **Looking after family members** reduces from an average of 12 hours a week to three hours
- **Childcare** reduces from an average of 24 hours a week to six hours a week
- **Looking after grandchildren** reduces from an average of 17 hours a week to six hours a week
- **Taking children to/ from activities** reduces from an average of eight hours a week to three hours
- **Looking after parents** reduces from an average of 10 hours a week to four hours

In the Here & Now Patient and Carer Survey:

- **51%** actively looked after the family before diagnosis
- **2/3** actively care for their families post-diagnosis

**ABC patients have children living at home**

- **51%** actively looked after the family before diagnosis
- **1/3** actively care for their families post-diagnosis

Figure 5: Women living with ABC: ability to do domestic and caring work in the home before and after the diagnosis of ABC (%)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Present Day</th>
<th>Before the cancer spread</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping family together</td>
<td>29</td>
<td>40</td>
</tr>
<tr>
<td>Looking after parents</td>
<td>8</td>
<td>18</td>
</tr>
<tr>
<td>Looking after grandchildren</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Taking children to/ from activities</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Childcare</td>
<td>11</td>
<td>26</td>
</tr>
<tr>
<td>Look after other family members</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>Main responsibility for cooking</td>
<td>30</td>
<td>40</td>
</tr>
<tr>
<td>Main responsibility for housework</td>
<td>35</td>
<td>74</td>
</tr>
</tbody>
</table>

**Key**
- Present Day
- Before the cancer spread

Source: Here & Now Patient and Carer Survey; n = 304
ABC also has a negative impact on women’s ability to provide support to the wider community, including providing emotional and practical support to friends and neighbours, and voluntary work and neighbourhood schemes.

**Figure 6:**
Women with ABC providing support in the wider community (%)

<table>
<thead>
<tr>
<th>Activities outside home</th>
<th>Emotional support to friends/neighbours</th>
<th>Practical support to friends/neighbours</th>
<th>Voluntary work</th>
<th>Community schemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before cancer spread</td>
<td>55%</td>
<td>38%</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>After cancer spread</td>
<td>38%</td>
<td>28%</td>
<td>16%</td>
<td>11%</td>
</tr>
</tbody>
</table>

Key
- Red: Before cancer spread
- Yellow: After cancer spread

Source: Here & Now Patient and Carer Survey; n = 304

Although 40 per cent of women living with ABC in the Here & Now Patient and Carer Survey are still in paid employment, half have changed their employment status since their ABC diagnosis, with 18 per cent being forced to give up work completely, 11 per cent to reduce to the number of hours they work and nine per cent to take a less senior role. As a consequence of the reduction in income, many have experienced financial hardship.

| 40% ABC patients are in paid employment | 50% had to make changes to employment | 56% suffered a decline in income | 39% suffered physical/physiological stress due to finances |
A comment on the socio-economic aspects of this report from Fernando Antoñanzas

Until now, there have been few surveys that allow us to understand the variations in lifestyles and the social implications of advanced breast cancer. Furthermore, there are no initiatives that show the consequences of the disease in a broad geographic area such as the one addressed by this current study. For these reasons, the scientific community must welcome this piece of information.

In a previous study in Spain we obtained an aggregate healthcare cost of about €511 million for breast cancer (early and advanced) and €362 million accounting for productivity losses. Interestingly, these productivity losses derived from breast cancer are the largest among all cancers and represent about 10% of total losses from oncologic conditions.

The report does not aim to calculate either healthcare or other economic costs, but to provide some data on changes due to the disease, seen through
the Patient and Carer Survey. The paper does not describe the general situation of women in terms of their patterns of market activities, or their contributions to national income either on absolute values or relative figures. Nevertheless, it is an interesting paper looking at the European picture of the living conditions of these women as well as the changes derived from the condition. It approaches the situation from different perspectives, emphasising the social implications as well as some of the economic consequences.

The contribution of women aged 50 years and over to the national market economy is limited in the general context. However, as highlighted in the survey responses, their involvement in other activities, with some of them belonging to what it is called the ‘grey economy’, is very high. For these reasons, if we were to measure the consequences of the change in the health status of women over 50 years old, in the economy of individual countries, we would need to account for all the activities conducted by these people.
Breast cancer is the most common cancer in women, accounting for 23 per cent of all new cases of cancer in 2008, with 1,380,000 women diagnosed worldwide. In the same year, 458,000 women died from the disease, accounting for 12.7 per cent of deaths amongst women in developing countries and 15.5 per cent in developed ones. Western Europe has the highest age-standardised incidence rate for breast cancer in the world. The estimated number of new cases of breast cancer among women in Europe in 2011 was 464,000, making up 29 per cent of newly diagnosed cases of cancer, and the number of deaths was 131,000 accounting for 17 per cent of all female deaths from cancer.

Breast cancer is the leading cancer in women in all European countries (Appendix 7). There is a threefold variation (49–148 per 100,000) with a clear geographical pattern. Incidence is high in Northern and Western Europe, most notably in Belgium (147.7), France (137), the Netherlands (131), the UK (129) and Scandinavia (Denmark 143, Iceland 131 and Finland 121). In comparison, incidence rates in Eastern Europe are much lower (Figure 7).

There is no clear east-west pattern for mortality rates. Mortality is high in some northern countries – for example Belgium (29 per 100,000) and Denmark (28 per 100,000) – as well as in some Eastern European countries such as Serbia (31 per 100,000) and Macedonia (36 per 100,000), but not in all (Appendix 7). In the former the high mortality rate reflects high incidence rates and in the latter it is a proxy for unfavourable survival rates. It is clear that there are many avoidable deaths amongst women in Eastern and Western Europe.

In Focus: The breast cancer landscape in Europe

Differences in incidence and mortality rates may reflect the availability of accurate statistics or collection methods. For example, there are countries (such as Greece) where there are no cancer registries, making it difficult to assess geographical patterns or to draw conclusions within and across countries.

The ABC landscape in Europe

It is estimated that up to one in three of all breast cancer cases will become metastatic with a median survival rate of three years and a five-year survival rate of just 26 per cent. In addition, one in 10 women will already be at an advanced stage when first diagnosed, with a five-year survival rate of less than 20 per cent.

The exact prevalence of ABC is currently unknown, since in almost all countries cancer registries include diagnosis and death but not relapse; because women live with ABC for several years and every year there are new relapses, the prevalence (number of women living with ABC at a certain time point) is unknown. This has huge implications for the organisation of support and care for these patients.
Figure 7: Estimated European breast cancer incidence in 2008

Figure 8: Estimated breast cancer mortality in Europe in 2008
Historical Perspective

There have been significant advances in the treatment of breast cancer, including ABC, over the last 20 or so years. Survival rates have increased and there are improvements in quality of life. Breast cancer was one of the first cancers to be recognised as a disease dating back to Hippocrates ca. 460 BC to ca. 370 BC and with surgical cases being recorded as early as the first century AD. In the 15th century it was recognised that cancer cells spread through the body and metastasised. This paved the way for understanding the limitations of surgery for ABC. However, until the mid-twentieth century the main treatment was a mastectomy – the surgical removal of one or both breasts, partially or completely.

Since the 1950s, advances in detection and routine screening with early diagnosis have improved survival rates, and, for women with early breast cancer, local incision and radiotherapy has become routine. Changes in mortality data show that improvements in screening and treatment have had a positive impact on outcomes. There has been a decline in breast cancer mortality in most European countries – see Figure 9 - with a median decline of 21.3 per cent between 1989 and 2006. Changes vary by country, however, ranging from a decline of 45 per cent in Iceland to a 17 per cent increase in Romania. The decrease was greater than 30 per cent in three countries, between 20 and 30 per cent in 12 countries, and continued to increase in only four countries, all of which were in Eastern Europe. Countries with high mortality in 1987-9 tended to have had the largest reductions in mortality.

Younger women have benefitted more than older ones, with mortality declining more for women under 50 than for older women and declining for younger women in all the countries. Mortality actually increased in four countries for women aged 50-69 and in 13 countries for women aged 70 or over. The median change for women under 50 years of age was -37 per cent, ranging from -76 per cent in Iceland to -14 per cent in Latvia. For women aged 50-69 the median change was -21 per cent, ranging from -40 per cent in England and Wales to 14 per cent in Romania, and for women aged 70 or over the median change was -2 per cent, ranging from -42 per cent in Iceland to 80 per cent in Greece. Again, caution should be used with the interpretation of these figures given the variation in the collection and availability of reliable data for this group of patients.

Advances in ABC have been slow and median overall survival has improved only slightly in the last decades – from 14 months in the 1990s to about 22 months in the early 2000s and between 24-36 months more recently. These changes are different according to the ABC subtype, with HER-2 positive disease seeing the biggest improvement. Most treatments available for ABC help to control the disease and improve quality of life but do not substantially impact on survival.
Figure 9:
Changes in breast cancer mortality between 1989 and 2006 in European countries ranked according to decline in mortality, overall decline.

Source: Autier et al 2010
Breast cancer remains a significant scientific and clinical challenge, although advances have been made in diagnosis and treatment, including the management of ABC (see Figure 10). However, despite surgery, radiotherapy, chemotherapy and endocrine therapy, metastatic breast cancers are still incurable. Treatment aims to weaken the cancer, manage the symptoms and side effects and prevent the cancer from spreading further. The aim is to enable women to carry on with their normal daily activities for as long as possible.

There is no proven value for routine testing or screening of women with early-stage cancer for ABC, but new detection techniques may allow detection of very early advanced disease.

Women generally feel overwhelmed as they grapple with practical treatment decisions. Treatment is generally dependent on the type of cancer and should take into account the psychosocial implications for the women themselves, their partners and their families.

Women who have progressed from EBC to ABC will have undergone a number of treatments as the disease has progressed. In the ABC Patient and Carer Survey, 76 per cent of the 304 women living with ABC had had chemotherapy, 73 per cent surgery, 50 per cent radiotherapy, 26 per cent hormonal therapy and five per cent other treatments. In addition, five per cent had been given complementary treatments and two per cent could not recall what treatments they had received.

- **Stage 3 cancers** tend to be treated, in the majority of cases, with systemic therapy (chemotherapy or endocrine therapy) pre-operatively, followed by surgery and post-operative radiation and where the receptors allow, hormone therapy.

- **Stage 4 cancer** treatment aims to control the symptoms, improve quality of life and prolong life as much as possible. Women diagnosed with Stage 4 may be treated with chemotherapy, hormone therapy, targeted therapy or a combination of these depending on a number of factors (such as organs involved, tumour biology, disease volume, severity of symptoms, previous treatments used, patient preference etc). They may also receive radiotherapy depending on the certain types of metastases.

There are few treatments able to prolong survival for ABC, but many that are effective at controlling the disease. Treatments change over time as the cancer adapts and builds resistance and therefore stops responding to the prescribed therapy.

Women living with ABC can also have a range of symptoms that need to be controlled, such as pain, breathing difficulties, cough, constipation, sickness, high blood calcium levels, pressure on the spinal cord, fluid retention and swelling, loss of appetite, difficulty sleeping, tiredness and weakness. Nowadays, there are many effective therapies to control these symptoms, particularly pain, which can be controlled in over 90% of cases32.

**Types of treatment for metastatic breast cancer**

**Hormonal therapies** can stop or slow down the growth of the cancer and reduce symptoms; they work best with oestrogen receptive positive cancers and are more appropriate to slow-growing cancers.

**Chemotherapy** can also stop or slow down the growth of cancer. It is used when the cancer does not have oestrogen receptors, when hormone therapy is no longer controlling the cancer or when the disease is rapidly progressing or associated with many symptoms.

**Radiotherapy** uses high energy rays to destroy cancer cells and is used to treat certain types of metastases such as those in the breast, bones, skin, lymph nodes or brain.

**Targeted therapy** is directed against specific molecules of the cancer cell such as the HER-2 receptor or the mTOR protein and can keep the cancer under control for some time.

**Surgery** removes the original or metastatic tumour.
Figure 10: Key milestones in the treatments of ABC

1940-1960
- Ovarian and hormone suppression found to improve breast cancer outcomes
- The world’s first clinical trial testing tamoxifen (Novaldex®) as a breast cancer treatment was carried out in the UK

1970-1975
- Oestrogen receptor status proven to predict risk of breast cancer recurrence
- Taxanes emerge as vital chemotherapy option for ABC
- BRCA1 and BRCA2 gene mutations linked to increased breast cancer risk

1975-1980
- Chemotherapy drug doxorubicin (Adriamycin®) found to be effective in shrinking ABC tumors
- Bone-building bisphosphonates help reduce complications of ABC and its treatment

1994
- Targeted drug denosumab (Xgeva®) helps prevent common bone-related complications in ABC

1996
- EU approval of bevacizumab (Avastin®) for use in ABC

2000
- Sentinel lymph node biopsy introduced to assess breast cancer spread

2001
- New class of drugs, aromatase inhibitors, introduced for ABC

2004
- Targeted drug eribulin mesylate (Halaven®) found to improve survival for ABC

2007
- EU approval of trastuzumab (Herceptin®) for use in ABC

2008
- EU approval of lapatinib (Tyverb®) for use in ABC

2009
- EU approval of letrozole (Femara®) for use in ABC

2010
- EU approval of capecitabine (Xeloda®) for use in ABC

2012
- Bone-building bisphosphonates help reduce complications of ABC and its treatment

The Future: Expectations and Opportunities for Treating ABC

The potential for further significant scientific advances in the prevention, detection, treatment and management of breast cancer is high, building on the findings from research in recent years. However, this will require increased funding of research, increased cross-disciplinary collaboration, improved clinical trial methodologies and the translation of research findings into clinical practice\textsuperscript{12}. In Europe, on average, only five per cent of cancer research funding is spent on investigating metastasis even though 90 per cent of cancer deaths are due to it\textsuperscript{33}.

The immediate hope for the next five years is to use existing scientific knowledge to improve clinical care and to carry out targeted research, focusing on identified gaps. A recent expert review has identified ten major gaps that can be prioritised\textsuperscript{14}, including the diagnosis and treatment of ABC. A key concern is finding out how breast cancer spreads and evades therapy. General awareness of what it is like to live with ABC, for example, or at least awareness among the medical profession, would improve the quality of life of women living with the disease and their families. One of the challenges in the management of ABC is developing optimal treatment strategies, including psychosocial support, and the management of the consequences of treatment, as women survive for longer.

The hope for the future is that a cure is found for all breast cancer, with developments in targeted therapy. Screening and early detection are important, since the earlier the cancer is diagnosed the higher the chances of cure and lower the chances of developing metastatic disease. However, even some early detected cancers can relapse and lead to metastases.

Breast cancer is not a single disease but is made up of different subtypes associated with different clinical outcomes. Understanding this heterogeneity is the key for the development of targeted cancer-preventative and therapeutic interventions. Advances in science mean that specific proteins or genetic abnormalities that propagate the cancer are being identified and can be targeted with medicines to stop growth. The challenge is to translate the findings into clinical practice\textsuperscript{33}.
Advanced technologies, including genomic technologies, will be used to improve early detection and define individual risk for breast cancer better. While the exact aetiology of breast cancer is unknown, genetic risk factors are increasingly being discovered which can be used to identify women with a higher risk of developing breast cancer. These women could potentially be candidates for cancer prevention therapies and increased surveillance.

The rapidly increasing knowledge in the fields of cancer genomics and cell biology can be used to develop more effective and less toxic treatments for breast cancer and to improve the ability to identify cancers that are more likely to recur. Genetic testing can also be used to individualise patient care and genetic techniques developed to repair or replace harmful genes before breast cancer occurs. Gene expression analysis, for example, has led to the identification of five subtypes of breast cancer that have distinct biological features, clinical outcomes and responses to chemotherapy. This knowledge may be used to develop treatment strategies based on the specific characteristics of a woman’s tumour. Research has already shown that a woman’s response to chemotherapy is influenced by inherited variations in genes that affect the body’s ability to absorb, metabolise and eliminate drugs. The growing knowledge of the genetic characteristics of tumours will make it possible to predict tumour responses to chemotherapy drugs as well as the likelihood of severe adverse reactions to them. This knowledge will aid the development of more individualised treatments and permit the design of more effective and less toxic drugs. Similarly, the increasing knowledge about the way in which the immune system works can be used to develop ways of enhancing the body’s ability to recognise and destroy cancer cells, building on the work already underway testing breast cancer treatment vaccines.

At the same time, the medical, nursing and social-work professions need to know more about what it means for a woman to have breast cancer, and particularly the implications of ABC. The professionals need time to listen to women when they talk about how they are feeling, and also when they say that their financial position and their households are suffering. Women need guidance and reassurance on how to deal with the uncertainty and loss of control that ABC causes, and their families need to better understand how they are likely to be feeling and what their future lives are likely to hold. The household needs financial support as well as emotional if the quality of everyone’s lives is to be maintained. Furthermore, it should be possible to rethink job descriptions to keep more ABC patients in productive paid work, as has happened with people with mobility and sensory problems, and the country’s economy can ill afford to lose so many of its most experienced workers. Beyond medical advances, therefore, it is necessary to advocate political and social advances and to keep this vulnerable group in the eye of the public and policy-makers.
References


Appendices

Appendix 1:
The European environment: country-specific overviews
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. **70% of women surveyed in Denmark living with ABC feel worried by their condition** although a significant number (40%) are hopeful about life and an additional 70% state they are living for the moment.
- As a direct result of ABC, 40% of ABC patients and carers in Denmark experienced anxiety or depression, while 20% state they have lost their sense of personal identity.
- Some women living with ABC in Denmark have become withdrawn from their close family (10%) and friends (10%) due to their condition.
- In addition to the emotional impact of ABC, 30% of patients experience daily pain and discomfort.

Traditional work and contributions

- A fifth (20%) of women living with ABC who were surveyed in Denmark are working full time.
- **78% of employed patients and carers have had to make a change to their employment status as a direct result of ABC.**
  - Out of the patients and carers surveyed in Denmark who have had to make a change to their employment status, 25% have had to give up work for a period of time and 38% have been forced to give up work completely.
- **Of all ABC patients and carers surveyed in Denmark, 60% have experienced a decline in their household income**
  - 30% of patients and carers had additional expenditure as a direct result of spending more on medication and 10% had increased expenditure as a result of complementary treatments.
  - As a result of this, many have experienced stress (10%) and psychological problems (20%).

The socio-economic impact of ABC

Perceptions

- **40% of ABC patients and carers surveyed in Denmark believe they are perceived negatively by society.** This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and supported by society.

Support needs of ABC patients

- However, after, only 20% of women were responsible for keeping the family together and only 10% responsible for taking children to and from activities.

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis.

- Before an ABC diagnosis, 37% of patients and carers in Denmark provided emotional support and 27% provided practical support to friends/neighbours. However, this drops to 27% and 17% respectively following diagnosis and as a direct result of their illness.

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfil an active role in their home life falls significantly.

- Before, 40% of women surveyed were responsible for keeping the family together and 30% responsible for taking children to and from activities.

In Denmark, 70% of patients and carers surveyed said they received emotional or practical support from their oncologist compared to just 10% from patient groups or charities.

In relation to services offered to ABC patients, 60% of patients and carers surveyed in Denmark feel it is necessary to improve personal well-being/quality of life while 70% think it is important to improve access to treatment and interactions with healthcare professionals.

Please note that for Denmark, the sample size is not statistically robust, therefore this statistics sheet provides an overview of the findings only.
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. **Half of women surveyed in France (50%) living with ABC feel depressed most of the time, while 57% say they are fearful of the future**
- As a direct result of ABC, **65% of ABC patients and carers in France say they have experienced anxiety or depression, with 42% stating they have lost their sense of personal identity**
- A number of women living with ABC in France have become withdrawn from their close family (27%), friends (40%) and colleagues/co-workers (53%) due to their condition
- In addition to the emotional impact of ABC, **77% of patients experience daily pain and discomfort**

Traditional work and contributions

- **Almost a third (30%) of women living with ABC who were surveyed in France are working full time**
- **58% of employed patients have had to make a change to their employment status as a direct result of ABC**
  - Out of the patients and carers surveyed in France who have had to make a change to their employment status, 40% have had to give up work for a period of time and 20% have been forced to give up work completely
  - **Of all ABC patients and carers surveyed in France, 47% have experienced a decline in their household income, with 17% of patients saying their income has reduced by half**
  - 55% of patients and carers had additional expenditure as a direct result of spending more on further medication and 37% had increased expenditure as a result of complementary treatments
  - As a result of this, 37% have experienced stress and 50% have suffered from psychological problems

The socio-economic impact of ABC

Perceptions

- **62% of ABC patients and carers surveyed in France believe they are perceived negatively by society.** This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfil an active role in their home life falls significantly

- **Before an ABC diagnosis, 60% of patients in France provided emotional support and half provided practical support to friends/neighbours. However, this drops to 40% and 30% respectively following diagnosis** and as a direct result of their illness

Support needs of ABC patients

- **Only 17% of women living with ABC have received support from patient groups following an ABC diagnosis** while almost a third (30%) have received support from the breast cancer community (ABC and EBC)
- In France, patients receive more support from their friends (67%), children (40%) and spouse/partner (43%) than their oncologist (33%)
- In relation to services offered to ABC patients, **88% of patients surveyed in France feel it is necessary to improve personal well-being/quality of life while two-thirds (76%) also think it is important to improve access to and interactions with healthcare professionals**

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis

- **Before an ABC diagnosis, 60% of patients in France provided emotional support and half provided practical support to friends/neighbours. However, this drops to 40% and 30% respectively following diagnosis** and as a direct result of their illness

- **However, after, only 37% are able to conduct housework, 23% are responsible for childcare and just 7% are able to look after their grandchildren**
The personal impact of ABC

• ABC has a significant emotional impact on women in their day-to-day life. Around a third (31%) of women surveyed in Greece living with ABC feel depressed most of the time, while an additional 34% are fearful for their future

• As a direct result of ABC, 31% of ABC patients and carers in Greece feel they or their patient have experienced anxiety or depression, with 31% stating they have lost a sense of personal identity

• Some women living with ABC in Greece have become withdrawn from their close family (27%), friends (31%) and colleagues/co-workers (14%) due to their condition

• In addition to the emotional impact of ABC, 17% of patients experience daily pain and discomfort

Traditional work and contributions

• Approximately a fifth (21%) of women living with ABC who were surveyed in Greece are working full time

• 55% of employed patients and carers have had to make a change to their employment status as a direct result of ABC

• Out of the patients and carers surveyed in Greece who have had to make a change to their employment status, 56% have had to give up work for a period of time and 19% have been forced to give up work completely

• Of all ABC patients and carers surveyed in Greece, 73% have experienced a decline in their household income

• 24% of patients and carers had additional expenditure as a direct result of spending more on further medication and 21% had increased expenditure as a result of complementary treatments

• As a result of this, 10% have experienced stress and 21% have suffered from psychological problems

Support needs of ABC patients

• However, after, these numbers fall, with 72% responsible for the housework, 69% responsible for cooking and 38% responsible for ‘keeping the family together’

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis

• Before an ABC diagnosis, 10% of patients in Greece provided emotional support to friends/neighbours. However, this drops to 3% following diagnosis as a direct result of their illness

The socio-economic impact of ABC

Perceptions

• 59% of ABC patients and carers surveyed in Greece believe they are perceived negatively by society. This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfill an active role in their home life falls significantly

• Before, 86% of women surveyed were responsible for the housework, 83% responsible for the cooking and 48% were responsible for ‘keeping the family together’

• Only 7% of women living with ABC have received support from patient groups following diagnosis while 15% have received support from the breast cancer community (ABC and EBC)

• In relation to services offered to ABC patients, around three-quarters (79%) of patients and carers surveyed in Greece feel it is necessary to improve interactions with healthcare professionals while three-quarters (75%) think it is important to improve financial support
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. 40% of women surveyed in Italy living with ABC feel depressed most of the time, while 17% say they are fearful of the future.
- As a direct result of ABC, **58% of ABC patients and carers in Italy say they have experienced anxiety or depression**, with 40% stating that they have lost their sense of personal identity.
- Only a small number of women living with ABC in Italy become withdrawn from their close family (7%), friends (13%) and colleagues/co-workers (17%) due to their condition.
- In addition to the emotional impact of ABC, 40% of patients experience daily pain and discomfort.

Traditional work and contributions

- **Almost half (47%) of women living with ABC who were surveyed in Italy are working full time**.
- **63% of employed patients and carers have had to make a change to their employment status as a direct result of ABC**.
  - Of the patients and carers surveyed in Italy who have had to make a change to their employment status, 52% have had to give up work for a period of time and 21% have been forced to give up work completely.
  - Of all ABC patients and carers surveyed in Italy, **53% have experienced a decline in their household income**, with 10% of patients saying their income has reduced by over half.
- **Only 3% of women living with ABC have received support from patient support groups following an ABC diagnosis** while 13% have received support from the breast cancer community (ABC and EBC).

The socio-economic impact of ABC

Perceptions

- **47% of ABC patients and carers surveyed in Italy believe they are perceived negatively by society**. This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and supported by society.

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfil an active role in their home life falls significantly.
- Before, 80% of women surveyed were responsible for the housework, 30% responsible for childcare and 17% looked after their grandchildren.

Support needs of ABC patients

- **However, after, only 7% are responsible for the housework, 13% responsible for childcare and none are able to look after their grandchildren**.
- **Before an ABC diagnosis, 23% of patients in Italy provided emotional support and 20% provided practical support to friends/ neighbours. However, this drops to 17% and 13% respectively following diagnosis and as a direct result of their illness**.
- **Only 3% of women living with ABC have received support from patient support groups following an ABC diagnosis while 13% have received support from the breast cancer community (ABC and EBC)**.
- **In relation to services offered to ABC patients, 85% of patients and carers surveyed in Italy feel it is necessary to improve personal well-being/ quality of life while 64% also think it is important to improve access to and interactions with healthcare professionals**.
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. More than a quarter of women surveyed in Poland (27%) living with ABC feel depressed most of the time, while 30% say they are fearful of the future.
- As a direct result of ABC, 33% of ABC patients and carers in Poland say they have experienced anxiety or depression, with 28% stating they have lost their sense of personal identity.
- A number of women living with ABC in Poland have become withdrawn from their close family (13%), friends (13%) and colleagues/co-workers (7%) due to their condition.
- In addition to the emotional impact of ABC, 40% of patients experience daily pain and discomfort.

- 59% of employed patients and carers have had to make a change to their employment status as a direct result of ABC.
  - Out of the patients and carers surveyed in Poland who have had to make a change to their employment status, 21% have had to give up work for a period of time and 50% have been forced to give up work completely.
  - Of all ABC patients and carers surveyed in Poland, 65% have experienced a decline in their household income, with 17% of patients saying their income has reduced by over half.
- 75% of patients and carers had additional expenditure as a direct result of spending more on further medication and 50% had increased expenditure as a result of complementary treatments.
  - As a result of this, 50% have experienced stress and 50% say they have suffered from a combination of psychological or physical problems.

The socio-economic impact of ABC

Perceptions

- 47% of ABC patients and carers surveyed in Poland believe they are perceived negatively by society. This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society.

Traditional work and contributions

- 13% of women living with ABC who were surveyed in Poland are working full time.

- However, after, only 40% remained responsible for housework, just 3% had the main responsibility for childcare and 47% for cooking family meals.

Support needs of ABC patients

- Only 10% of women living with ABC have received support from patient groups following an ABC diagnosis while 30% have received support from the breast cancer community (ABC and EBC).
- 83% of patients surveyed in Poland felt their oncologist offered them support, with 89% of this group claiming they were satisfied with the support that was provided.
- In relation to services offered to ABC patients, three-quarters (75%) of patients and carers surveyed in Poland feel it is necessary to improve access to and interactions with healthcare professionals while more than two thirds (69%) also think it is important to improve personal well-being/quality of life.

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis

- Before an ABC diagnosis, 37% of patients in Poland provided emotional support and 27% provided practical support to friends/neighbours. However, this drops to 27% and 17% respectively following diagnosis and as a direct result of their illness.

Societal contributions (the grey economy)

- Following an ABC diagnosis, patients’ ability to fulfil an active role in their home life falls significantly.
  - Before, 83% of women surveyed were responsible for the housework, 30% responsible for childcare, and 80% for cooking family meals.
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. Almost a third (27%) of women surveyed in Spain living with ABC feel depressed most of the time, while 17% say they are fearful of the future.
- As a direct result of ABC, 45% of ABC patients and carers in Spain say they have experienced anxiety or depression, with 35% stating they have lost their sense of personal identity.
- Some women living with ABC in Spain have become withdrawn from their close family (10%), friends (20%) and colleagues/co-workers (20%) due to their condition.
- In addition to the emotional impact of ABC, 53% of patients experience daily pain and discomfort.

Traditional work and contributions

- A fifth (20%) of women living with ABC in Spain who were surveyed are working full time.
- 45% of employed patients and carers have had to make a change to their employment status as a direct result of ABC.
  - Out of the patients and carers surveyed in Spain who have had to make a change to their employment status, 38% have had to give up work for a period of time and 71% have been forced to give up work completely.
  - Of all ABC patients and carers surveyed in Spain, almost half (48%) have experienced a decline in their household income.
  - 55% of patients and carers had additional expenditure as a direct result of spending more on further medication and 22% had increased expenditure as a result of complementary treatments.
  - As a result of this, almost a third (30%) have experienced stress and over two-thirds (69%) have suffered from psychological problems.

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfil an active role in their home life falls significantly.

- Before, 73% of women were mainly responsible for housework, 67% responsible for cooking and 37% of women are responsible for ‘keeping the family together’.
- However, after, only 57% of women were mainly responsible for housework, 43% responsible for cooking and 23% mainly responsible for ‘keeping the family together’. Only 7% are responsible for taking children to and from activities compared to 23% before diagnosis with ABC.

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis.

- Before an ABC diagnosis, 40% of patients in Spain provided emotional support and one third provided practical support to friends/neighbours. However, this drops to 33% and 23% respectively following diagnosis and as a direct result of their illness.

Support needs of ABC patients

- Only 13% of women living with ABC have received support from patient support groups following an ABC diagnosis while 43% have received support from the breast cancer community (ABC and EBC).
- In relation to services offered to ABC patients, almost all (93%) patients and carers surveyed in Spain feel it is necessary to improve personal well-being/quality of life while 58% also think it is important to improve financial support.

The socio-economic impact of ABC

Perceptions

- 52% of ABC patients and carers surveyed in Spain believe they are perceived negatively by society. This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society.

SPAIN
The personal impact of ABC

- ABC has a significant emotional impact on women in their day-to-day life. Three-quarters (75%) of women surveyed in Sweden living with ABC feel depressed most of the time, while 50% of women say they are fearful for their future.

- As a direct result of ABC, 85% of ABC patients in Sweden say they or their patient have experienced anxiety or depression, with 50% stating they have lost their sense of personal identity.

- Many women living with ABC in Sweden have become withdrawn from their close family (35%), friends (45%) and colleagues/co-workers (65%) due to their condition.

- In addition to the emotional impact of ABC, 70% of patients experience daily pain and discomfort.

Traditional work and contributions

- A fifth (20%) of women living with ABC who were surveyed in Sweden are working full time.

- 80% of employed patients and carers have had to make a change to their employment status as a direct result of ABC.
  - Out of the patients and carers surveyed in Sweden who have had to make a change to their employment status, 23% have had to give up work for a period of time and 46% have had to give up work completely.

- Of all ABC patients and carers surveyed in Sweden, 65% have experienced a decline in their household income.
  - 20% of patients and carers had additional expenditure as a direct result of spending more on further medication and 20% had increased expenditure as a result of complementary treatments.
  - As a result of this, 35% have experienced stress and 30% have required help from the state or insurance.

Societal contributions (the grey economy)

Following an ABC diagnosis, patients’ ability to fulfill an active role in their home life falls significantly.

- Before, 45% of women surveyed were responsible for the housework, 50% responsible for the cooking and a fifth were responsible for ‘keeping the family together’.

- However, following an ABC diagnosis, only 5% are still responsible for the housework, 20% responsible for the cooking and 5% were still responsible for ‘keeping the family together’. Only 5% remain mainly responsible for looking after their children and 0% are able to look after their grandchildren.

Women’s wider contributions to society, outside of the family, decrease following an ABC diagnosis.

- Before, 15% of patients in Sweden provided emotional support and 30% provided practical support to friends/neighbours. However, this drops to 15% following diagnosis and as a direct result of their illness.

Support needs of ABC patients

- Only 25% of women living with ABC have received support from patient support groups following an ABC diagnosis while 20% have received support from the breast cancer community (EBC and ABC).

- In relation to services offered to ABC patients, 90% of patients and carers surveyed in Sweden feel it is necessary to improve personal well-being/quality of life while an additional 65% think it is important to improve access to treatments.

The socio-economic impact of ABC

Perceptions

- 30% of ABC patients and carers surveyed in Sweden believe they are perceived negatively by society. This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society.

Please note that for Sweden, the sample size is not statistically robust, therefore this statistics sheet provides an overview of the findings only.
Appendix 2: Author and report contributor

About the author

Professor Pamela Abbott works as a senior researcher at the University of Aberdeen UK. She graduated in sociology from the University of London in 1970, and was awarded a master’s degree in 1975 in sociology with politics, and a PhD in 1982. She has worked in several universities in the UK as a lecturer, senior lecturer, professor, dean and pro vice-chancellor; she was vice rector academic in two African universities and foundation director of the Rwandan Council for Higher Education. She has also been director of research at a think tank in Rwanda devoted to the study of public policy. She is a member of the Academy of Social Sciences and has served as honorary general secretary and later chair of the British Sociological Association.

Her research interests are in gender, social class, wellbeing and health. She has published extensively in peer-reviewed journals and is also recognised as an expert on social research methods. In addition to her academic publications, she has published in policy and practice-related journals and been commissioned to write reports setting out the findings of policy-related research and policy analysis in the health and welfare fields. Recent major research projects include Work and Care in the EU with Claire Wallace, and Health in Times of Transition in the former Soviet Union with Christian Haerpfer.

Report contributor

Fernando Antoñanzas is professor of applied economics at the University of La Rioja, Spain, and was formerly research director of SOIKOS (research institute on health economics in Barcelona). He has participated in several post-graduate programmes from different universities related to health economics and his research activities have focused on quantitative economics applied to the health sector. Professor Antoñanzas has published many papers on economic evaluation of health technologies, co-authored several books and is a member of the editorial committee for three different journals. Professor Antoñanzas is a former president of the Spanish Health Economics Association.
Appendix 3:
Here & Now campaign ambassadors

Professor Mario Campone, MD PhD
Professor Mario Campone is currently an in-hospital practitioner and oncology specialist at l’Institut de Cancérologie de l’Ouest. He holds a doctorate in medical oncology, as well as an LBA in cell biology and a university diploma in life science and health. He has been a professor of medical oncology at the University of Angers since September 2012.

His research interests involve studies to determine the prognostic factors in breast cancer, as well as factors predictive of response to targeted therapies. He has also been the coordinator and principal investigator in numerous clinical studies of new therapeutic agents in breast pathology and glial tumours.

Dr Fatima Cardoso, MD
Dr Cardoso is the director of the breast cancer unit of the Champalimaud Cancer Center in Lisbon, Portugal. Dr Cardoso earned her medical degree at the University of Porto in Portugal and completed fellowships in the translational research unit of the Jules Bordet Institute (JUB) in Brussels, Belgium, and the department of molecular and cellular oncology at MD Anderson Cancer Center in Houston, Texas. She then worked for ten years as assistant professor at the Medical Oncology Clinic of the JUB where, besides her clinical work, she was active in the translational research unit and was responsible for phase II-III trials in breast cancer. She is board certified in medical oncology and internal medicine.

Dr Cardoso’s research interests include biology of breast cancer, prognostic and predictive markers of response to systemic therapy, and new anticancer agents. She is actively involved in a number of phase I-II breast cancer clinical trials and served as the scientific director of the international research network TRANSBIG for seven years. Dr Cardoso is actively involved in numerous professional organisations such as European Society for Medical Oncology (ESMO), European CanCer Organisation (ECCO), European Organisation for Research and Treatment of Cancer (EORTC), American Society of Clinical Oncology (ASCO), and American Association for Cancer Research (AACR) where she serves on several committees, including the ECCO board of directors, and is the current EORTC secretary general and vice-chair of the EORTC-Breast Cancer Group. She is the breast cancer program coordinator of the European School of Oncology and co-chair of the Advanced Breast Cancer International Consensus Guidelines Conference (ABC). Dr Cardoso is editor-in-chief of The Breast Journal, associate editor of the European Journal of Cancer, and has authored over 200 publications.
Dr Javier Cortes graduated in medicine and surgery from the Autonomous University of Madrid in 1996. He went on to specialise at the University of Navarra’s department of medical oncology where he then worked full time as doctor in medical oncology from 2002. Since 2003, he has also worked in the department of medical oncology at the Vall d’Hebron University Hospital, Barcelona, where he is coordinator of the teaching and training programme for residents in oncology and senior specialist in breast cancer with a particular interest in new drugs development. He is head of the breast cancer unit and melanoma unit.

Dr Cortes is the author of numerous publications, with a strong focus on breast tumours and novel treatments. He actively participates in the development of several national and international clinical investigations, especially in relation to drugs directed against molecular targets and new chemotherapy agents.

Dr Michael Gnant graduated with a medical degree from the University of Vienna in 1988 before going on to specialise in surgery and surgical oncology. He enjoyed a two-year research period as fellow and visiting scientist at the National Cancer Institute in Bethesda, USA, before returning to Europe to become a professor of experimental surgical oncology in 2004. In 2008, he was appointed professor of surgery at Vienna Medical University, where he presently serves as director of the department of surgery, and co-directs the Comprehensive Cancer Center. Since 2005, he has been president of the globally successful Austrian Breast and Colorectal Cancer Study Group.

Dr Gnant’s research interests include a variety of surgical oncology fields, in particular breast cancer and pancreatic cancer, endocrine intervention and bone targeted treatment. He has published more than 350 original papers in peer-reviewed journals, held numerous national and international talks, and served as principle investigator in many national and international clinical trials. He has received numerous awards for his work including the Grand Central European Award for Clinical Cancer Research, and the coveted Claudia von Schilling Prize. He is a frequent speaker at meetings such as ASCO, SABCS, ECCO, and EBCC, and has served as panellist at the St. Gallen Consensus since 2007.
Victoria Harmer is team leader and clinical nurse specialist in breast care at Imperial College Healthcare Hospital NHS Trust. She qualified in nursing with an award for distinction in practice, and has 18 years’ oncology experience. Currently studying for her doctorate at King’s College, she is also a trustee for Against Breast Cancer, a member of the Clinical Experts Reference Group for Breakthrough Breast Cancer, an executive committee member for Europa Donna UK, the nurse representative on the Association of British Surgery Education and Training Committee, a steering committee member of the RCN Cancer and Breast Care Forum and co-chair of the London Cancer Alliance breast nurses group.

Victoria has worked with Marks & Spencer on their swimwear design for the post-mastectomy body and has assisted scriptwriters on a variety of high profile TV programmes to ensure medical correctness when a character had breast cancer. She is proactive in raising breast cancer awareness and runs a monthly support group for breast cancer survivors. Her main passions are in the arena of surgery and sexuality. She recently came third in the ‘British Journal of Nursing Awards, 2013’ in the ‘Oncology and Haematology Nurse of the Year’ category, and is shortlisted for the ‘Cancer Nurse’ and ‘Nurse of the Year’ categories for the Nursing Times Awards 2013.

Stephen Johnston is professor of breast cancer medicine and consultant medical oncologist at the Royal Marsden NHS Foundation Trust & Institute of Cancer Research, London. He was the first director of the UK’s National Institute for Health Research (NIHR) biomedical research centre for cancer at the Royal Marsden. He graduated in 1983 from Trinity College at The University of Cambridge, and in 1986 from the medical school at The University of Newcastle upon Tyne. He trained in general medicine at St Bartholomew’s Hospital and Hammersmith Hospital in London, and subsequently in medical oncology at the Royal Marsden Hospital. He gained his PhD from the Institute of Cancer Research at the University of London, and took up his current position as medical oncologist on the breast unit at the Royal Marsden Hospital in 1997.

He has a specialist interest in the treatment of metastatic breast cancer, and his major research interests lie in understanding mechanisms of endocrine resistance in breast cancer. He is actively involved in facilitating the interface between basic and applied research, and is chief investigator of several phase II-III trials of novel therapeutic approaches in advanced disease, including new endocrine therapies and targeted signal transduction inhibitors. He has published over 230 breast cancer-related articles in peer-reviewed journals, and is a member of several scientific committees and advisory boards, a faculty member at the American Society for Clinical Oncology, the deputy-editor of the international journal Breast Cancer Research, and a former trustee of the UK charity ‘Breast Cancer Campaign’ having also been chairman of their scientific advisory board.
Diane Mackie, BSc

Diane is a clinical nurse specialist in secondary breast cancer at the Royal Marsden NHS Foundation Trust in London. Diane has over 25 years’ oncology nursing experience. In 1997 she became, along with a colleague as part of a job share, the first UK clinical nurse specialist for secondary breast cancer. This post at Charing Cross Hospital, London, was supported by the UK cancer charity, Macmillan Cancer Support, to improve the emotional and psycho social support for patients with secondary breast cancer. Diane has been actively involved in the development of services for patients with secondary breast cancer locally and nationally, including contributing to NICE documents and membership of Breast Cancer Care’s Secondary Breast Cancer Taskforce. Her role supports dissemination of best practice, locally, nationally and internationally. Recent publications have included a specialist supportive care chapter written by Diane and her colleague Melissa Warren in the Handbook of Metastatic Breast Cancer by Prof Johnston and Dr Swanton and a poster presenting nurse-led research based on the needs of patients with metastatic breast cancer at San Antonio Breast Cancer Symposium 2012.

Diane’s teaching and presenting commitments include work as an associate lecturer on the management of metastatic breast cancer as part of the breast cancer care module (BSc and MSc) at the school of nursing and rehabilitation at the Royal Marsden Hospital.

Dr Konstantinos Papazisis, MD PhD

Dr Konstantinos Papazisis is a medical doctor and researcher in the field of oncology. He obtained his medical degree from Ioannina University School of Medicine in November 1989 and his certification of internal medicine specialisation in 2001 after five years specialising as a clinical registrar in internal medicine, infectious diseases, haematology and oncology. He is currently a consultant medical oncologist at the Euromedica General Klinik in Thessaloniki. His clinical and research interests include experimental and molecular oncology, signal transduction and molecular targets in cancer therapeutics.
Novartis has also commissioned two pieces of original research to broaden and deepen the available information: a Consumer Poll of Awareness of ABC in the general public across Europe and the ABC Patient and Carer Survey, a survey of patients with advanced breast cancer and carers. Sampling was difficult in both studies, for ethical and humanitarian reasons and because of some reluctance to collaborate on the part of doctors, patients and carers, therefore, a variety of sampling techniques had to be used to obtain a sufficient number of responses for the results to be interpretable; percentages in the studies should not be taken to represent the underlying populations with precision. The samples are by no means randomly selected – the preferred method for accurate representation of percentages in the population – and the second survey reached only a relatively small number of people in each country. However, the samples do cover a full range of ages and conditions and they allow the ‘voice’ of the patients and carers to be heard. The most probable bias in the data is that those who are not represented are those in most distress and most at risk of mortality, so the real situation is likely to be worse than this account portrays rather than better.

European Quality of Life Survey 2011

The 3rd European Quality of Life Survey was carried out in 2011 in 27 EU countries and in seven non-EU countries, including the 10 countries sampled for this report. The EQLS is carried out by the European Foundation for the Improvement of Living and Working Conditions. It uses a multistage probability sampling design with the target population being adults 18 years and over who have been resident in the country for at least six months at the time of the survey. In the EU there were 35,516 achieved interviews. In the 10 countries from which data was used for this report 1,032 interviews were achieved in Austria, 1,024 in Denmark, 1,004 in Greece, 1,512 in Spain, 2,270 in France, 2,259 in Italy, 1,008 in the Netherlands, 2,262 in Poland and 1,007 in Sweden. The response rate for the 10 countries varied from 61.6 per cent in Poland to 32.4 per cent in the Netherlands. Selection probability and post-stratification weights are applied to correct for the unequal probability of being selected and to ensure that the data is representative of the population of adults in each country in terms of key variables such as age, gender, urbanisation level, region and household size.

For more detail on sampling see:

For more detail on survey methods see:
Anderson et al (2013) Appendix 1
### Awareness of ACB across Europe

This was a consumer poll carried out in eleven countries: Austria, Denmark, France, Germany, Greece, Italy, the Netherlands, Poland, Spain, Sweden and the United Kingdom. The countries chosen represent a range of different public welfare regimes and availability of medical and health services and differ markedly in their history and their economic circumstances. The achieved sample was 2,202 – roughly 200 respondents in each country. Males and females are equally represented. The selection criteria were that potential respondents were over 18 and had not been diagnosed as having breast cancer. The aim of the consumer poll was to explore consumer perceptions of advanced breast cancer and of the value of the 50+ female generation economically, domestically, and in terms of mentorship and support.

Further details on the sampling method and the questionnaire are available from Novartis Oncology.

### ABC Patient and Carer survey

This was a survey of Advanced Breast Cancer cases across Europe, with an achieved sample of 304 informants – 158 patients and 146 carers. The criteria for inclusion were that potential respondents were over 18, had been diagnosed as having cancer which had spread beyond the breast or had metastasised, or were caring for a patient with this diagnosis, and were aware of the diagnosis.

Sampling was carried out in nine countries which, again, represent between them a range of welfare regimes and economic circumstances (see Table 1.1 below). The target was: 60 informants in four countries – France, Italy, Poland and Spain; 40 in Greece; 20 informants in four countries – Austria, Denmark, the Netherlands and Sweden. The desired quota was fully achieved in France, Italy, Poland, Spain and Sweden, about 75% in Greece (where the refusal rate among carers was high) and 50% in Denmark (with refusals split equally between patients and carers); response was very low in the Netherlands (15%) and Austria (10%).

The original sampling design involved recruiting patients via physicians, with a cash incentive in five of the countries (none was offered in Greece, and a charitable donation was made instead in France and the Netherlands). Healthcare practitioners were often reluctant to offer contact details, however, because they saw their patient as too physically and emotionally vulnerable, and many of the contacts provided did not result in completed interviews. In order to boost numbers, therefore, a variety of strategies were used:

- Contact details for additional healthcare practitioners were provided by local partners;
- Additional recruitment agencies were employed in the Netherlands, Austria and Denmark;
- Consumer recruiters were employed in Greece;
- Advertisements were placed in newspapers (including on their websites), on patient support websites and in Facebook for the above four countries;
- A local public relations partner in Denmark recruited patients and carers.

For a copy of the questionnaire used, please contact Novartis Oncology.

### Demographic characteristics of the sample

- 80% of the patients in sample were age 40-69; 7% were younger than this and 13% older.
- Two-thirds were married or in a relationship, and about 70% had children living at home. Of the households that had children, 1 in 5 had children under 5, about the same number had children aged 12-17, and the rest of the children were 18 or older.
- 74% of the carers were aged 40-69; nearly 20% were younger than this and only 5% older.
- 73% were married, and 35% were the spouse of a patient; 21% were the patient’s mother. Overall, about 80% were related to the patient by blood or marriage.
- 40% of the patients were still in employment, as reported by them or their carers, but over half had experienced a loss of income.
Table A1.1: Sampling design and achieved sample in the survey

<table>
<thead>
<tr>
<th>Total Sample</th>
<th>Target</th>
<th>Achieved</th>
<th>Achieved as %</th>
</tr>
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<tbody>
<tr>
<td>Patients</td>
<td>180</td>
<td>158</td>
<td>88%</td>
</tr>
<tr>
<td>Carers</td>
<td>180</td>
<td>146</td>
<td>81%</td>
</tr>
<tr>
<td>Total</td>
<td>360</td>
<td>304</td>
<td>84%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Austria</th>
<th>Target</th>
<th>Achieved</th>
<th>Greece</th>
<th>Target</th>
<th>Achieved</th>
<th>Poland</th>
<th>Target</th>
<th>Achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>10</td>
<td>1</td>
<td>Patients</td>
<td>20</td>
<td>20</td>
<td>Patients</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Carers</td>
<td>10</td>
<td>1</td>
<td>Carers</td>
<td>20</td>
<td>9</td>
<td>Carers</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
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<td>Total</td>
<td>40</td>
<td>29</td>
<td>Total</td>
<td>60</td>
<td>60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Denmark</th>
<th>Target</th>
<th>Achieved</th>
<th>Italy</th>
<th>Target</th>
<th>Achieved</th>
<th>Spain</th>
<th>Target</th>
<th>Achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>10</td>
<td>6</td>
<td>Patients</td>
<td>30</td>
<td>30</td>
<td>Patients</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Carers</td>
<td>10</td>
<td>5</td>
<td>Carers</td>
<td>30</td>
<td>30</td>
<td>Carers</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>10</td>
<td>Total</td>
<td>60</td>
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<td>Total</td>
<td>60</td>
<td>60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>France</th>
<th>Target</th>
<th>Achieved</th>
<th>Netherlands</th>
<th>Target</th>
<th>Achieved</th>
<th>Sweden</th>
<th>Target</th>
<th>Achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>30</td>
<td>30</td>
<td>Patients</td>
<td>10</td>
<td>2</td>
<td>Patients</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Carers</td>
<td>30</td>
<td>30</td>
<td>Carers</td>
<td>130</td>
<td>1</td>
<td>Carers</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>60</td>
<td>Total</td>
<td>20</td>
<td>3</td>
<td>Total</td>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>
Breast cancer is the uncontrolled growth of breast cells and occurs as a result of mutations in the genes responsible for regulating the growth of cells and keeping them healthy.

The malignant tumour, if left unchecked, can spread to other parts of the body. The breast cancer stages refer to how far the tumour has spread beyond its original site. Breast cancer is always caused by a genetic abnormality, a mistake in the genetic material, but only between five and ten per cent of cancers are due to an abnormality inherited from parents; most are due to the ageing process and the general ‘wear and tear’ of life.

### Stages of breast cancer

<table>
<thead>
<tr>
<th>STAGE</th>
<th>DEFINITION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Cancer cells remain inside the breast duct, without invasion into normal adjacent breast tissue.</td>
</tr>
<tr>
<td>Stage 1</td>
<td>A tumour that measures no more than 2 cms or cells no larger than 2 mm, found in the axillary lymph nodes, or both.</td>
</tr>
<tr>
<td>Stage 2a</td>
<td>Cancer cells are found in the axillary lymph nodes with no tumour in the breast, or the tumour measures less than 2 cms and has spread to the axillary lymph nodes or the tumour is between 2 and 5 cms and has not spread to the axillary lymph nodes.</td>
</tr>
<tr>
<td>Stage 2b</td>
<td>The tumour is between 2 and 5 cms and has spread to the axillary lymph nodes or the tumour is larger than 5 cms but has not spread to the axillary lymph nodes.</td>
</tr>
<tr>
<td>Stage 3a</td>
<td>No tumour is found in the breast but cancer is found in the axillary lymph nodes, which are sticking together or to other structures, or the tumour is any size and has spread to the axillary lymph nodes which are sticking together or to other structures, or the tumour is larger than 5 cm and has spread to the axillary lymph nodes.</td>
</tr>
<tr>
<td>Stage 3b</td>
<td>The tumour is any size and has spread to the chest wall and/or the skin of the breast and may have spread to axillary lymph nodes that are clumped together. Inflammatory breast cancer is considered at least Stage IIIb.</td>
</tr>
<tr>
<td>Stage 3c</td>
<td>There may or may not be a tumour but the cancer has spread to lymph nodes either above or below the collarbone and may have spread to axillary lymph nodes and/or the chest wall and/or the skin of the breast.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>The cancer has spread or metastasised to other parts of the body.</td>
</tr>
</tbody>
</table>

Source: breastcancer.org
Appendix 6:
The grey economy of the 50+ woman in Europe

Value of care and domestic work done by women per annum in 11 representative European countries in 2011 in UK £ billions based on UK minimum wage

<table>
<thead>
<tr>
<th>Country</th>
<th>Value (£ billion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italy</td>
<td>£110</td>
</tr>
<tr>
<td>Germany</td>
<td>£109.5</td>
</tr>
<tr>
<td>UK</td>
<td>£92.2</td>
</tr>
<tr>
<td>Spain</td>
<td>£86.4</td>
</tr>
<tr>
<td>France</td>
<td>£60.6</td>
</tr>
<tr>
<td>Poland</td>
<td>£25</td>
</tr>
<tr>
<td>Greece</td>
<td>£19.3</td>
</tr>
<tr>
<td>Netherlands</td>
<td>£12.6</td>
</tr>
<tr>
<td>Austria</td>
<td>£9.1</td>
</tr>
<tr>
<td>Sweden</td>
<td>£4.7</td>
</tr>
<tr>
<td>Denmark</td>
<td>£2.8</td>
</tr>
</tbody>
</table>

Source: author’s analysis of EQLS 2011 and EUROSTAT population data

Proportion of women 50 years and over in paid employment in 11 representative European countries in 2011

<table>
<thead>
<tr>
<th>Country</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>44</td>
</tr>
<tr>
<td>Denmark</td>
<td>59</td>
</tr>
<tr>
<td>France</td>
<td>58</td>
</tr>
<tr>
<td>Germany</td>
<td>58</td>
</tr>
<tr>
<td>Greece</td>
<td>35</td>
</tr>
<tr>
<td>Italy</td>
<td>62</td>
</tr>
<tr>
<td>Netherlands</td>
<td>29</td>
</tr>
<tr>
<td>Poland</td>
<td>28</td>
</tr>
<tr>
<td>Spain</td>
<td>74</td>
</tr>
<tr>
<td>Sweden</td>
<td>88.5</td>
</tr>
<tr>
<td>UK</td>
<td>28.5</td>
</tr>
</tbody>
</table>

Source: author’s analysis of EQLS 2011

Mean hours women 50 years and older do care and domestic work a week in 11 representative European countries in 2011

<table>
<thead>
<tr>
<th>Country</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>22.6</td>
</tr>
<tr>
<td>Denmark</td>
<td>13.4</td>
</tr>
<tr>
<td>France</td>
<td>18.3</td>
</tr>
<tr>
<td>Germany</td>
<td>19.3</td>
</tr>
<tr>
<td>Greece</td>
<td>25.8</td>
</tr>
<tr>
<td>Italy</td>
<td>24.2</td>
</tr>
<tr>
<td>Netherlands</td>
<td>18.4</td>
</tr>
<tr>
<td>Poland</td>
<td>24.3</td>
</tr>
<tr>
<td>Spain</td>
<td>15.3</td>
</tr>
<tr>
<td>Sweden</td>
<td>84.2</td>
</tr>
<tr>
<td>UK</td>
<td>74.8</td>
</tr>
</tbody>
</table>

Source: author’s analysis of EQLS 2011
Proportion of women 50 years and older that look after children on a regular and occasional basis in 11 representative European countries in 2011

<table>
<thead>
<tr>
<th>Country</th>
<th>At least occasionally</th>
<th>At least several times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>37.6</td>
<td>28</td>
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<td>UK</td>
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Source: author’s analysis of EQLS 2011

Proportion of women 50 years and older that look after elderly/disabled relatives on a regular and occasional basis in 11 representative European countries in 2011

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<th>At least occasionally</th>
<th>At least several times a week</th>
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<td>18.1</td>
</tr>
</tbody>
</table>

Source: author’s analysis of EQLS 2011
Appendix 7:
The breast cancer landscape in Europe

Estimated age standardised cancer incidence for breast cancer in women in Europe in 2012 per 100,000

Source: Ferlay et al 2013
Estimated age standardised cancer mortality rates for breast cancer in women in Europe in 2012 per 100,000

Source: Ferlay et al 2013