

# **A review of breast cancer care and outcomes in 18 countries in Europe, Asia, and Latin America**

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## **REPORT SUMMARY AND KEY FINDINGS**

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The full report is available at: [www.comparatorreports.se](http://www.comparatorreports.se)

## Summary

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- **The health burden of breast cancer is high with 1.2 million women affected worldwide each year; the cost to society is significant, particularly the indirect cost as most women affected are of working age.**
- **Dramatic improvement has been seen in the long-term prognosis for breast cancer patients over the last 30 years - largely attributable to earlier diagnosis due to screening and the introduction of adjuvant treatment.**
- **A multidisciplinary approach encompassing different medical specialties is the best way to handle the complexities of breast cancer.**
- **Patient surveys repeatedly demonstrate that many breast cancer patients feel that the communication with the treating physician regarding their disease and treatment options is insufficient.**
- **Treatment of metastatic disease is an important part of breast cancer care and an area of intensive research as it is the stage where new drugs are often first introduced, yet little attention is given to the situation for women with metastatic breast cancer.**
- **It is important to have a holistic approach in the evaluation of novel technologies so that demonstratedly effective new medical interventions can be introduced to patients with minimal delay.**

## Introduction

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This document summarises the key findings and recommendations from the first international study looking at the burden and cost of breast cancer and patterns of care and outcomes across 18 countries in Europe, Latin America, and Asia. The report highlights that there have been significant improvements in outcomes over the last 20-30 years; yet the burden of breast cancer remains high. Outcomes vary significantly between countries which indicate that there is considerable room for improvement and that best practices in prevention and treatment need to be assessed and adopted more consistently.

Data were collected from primary and secondary sources with primary data collected from specially prepared questionnaires for both experts and patients and secondary data largely from literature reviews and databases. The primary objective was to review the current evidence-based best practices in breast cancer management and to understand the elements of care that are driving improvement in outcomes.

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## **Key findings**

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### **→ The burden of breast cancer**

Breast cancer is the most common form of cancer in women with approximately 1.2 million women worldwide affected each year. Over the last 50 years incidence rates have increased in developed countries but are now also rapidly increasing in many newly industrialised countries due mainly to lifestyle changes reflective of those in developed countries. Although the risk of developing breast cancer increases with age, most breast cancer cases occur in women of working age i.e. younger than 65 years. The indirect costs of breast cancer are therefore considerable, as much as twice the direct costs, based on recent assessments in some European countries, and possibly even higher in developing countries where mortality rates are greater and the average age of affected women is lower. Direct costs of breast cancer are also significant, though they vary greatly between countries depending on overall spending on healthcare.

In many of the study countries the true burden of breast cancer is difficult to assess due to the lack of comprehensive clinical and epidemiological data. A broad approach is needed across countries in order to make registration more encompassing and relevant.

### **→ Outcomes of breast cancer care**

Long-term prognosis has improved significantly over the last 50 years; 10-year survival rates are now 80% in those countries with best outcomes compared to just over 50% 50 years ago. The largest improvements are due to earlier diagnosis as a consequence of population-based mammography and the introduction of adjuvant therapy. However for patients with advanced disease there has been limited improvement in long-term survival over the past 50 years although the length of survival has been prolonged.

Quality of life is also an important outcome of breast cancer care. One area so far largely neglected, is the evaluation of quality of life in women that are cured. There is for some women a cost of cure, long term side effects of treatment, that can be significant. However, it is in advanced breast cancer patients that the quality of life impact is the most significant, as reflected in a Swedish patient survey. The results showed that women with recurrent or metastatic disease had a pronounced reduction in health status compared to the general female population, regardless of age. Women younger than 60 years that had been diagnosed with breast cancer had a lower health status than the general population of similar age regardless of current state, however women in the survey over 60 years who were relapse-free following treatment had better health status than the general female population in Sweden aged over 60.

## → Treatment patterns in the study countries

### **Organisation of care**

A multidisciplinary team approach - encompassing the relevant medical specialties such as surgeons, radiotherapists, medical oncologists, gynaecologists, specialised nurses, etc. - is the recommended model for breast cancer care, and it has been demonstrated that decisions made by a multidisciplinary team are more likely to be in accordance with evidence-based guidelines than those made by individual clinicians.

### **Guidelines**

Adherence to evidence-based treatment guidelines that are in line with internationally accepted standards and regularly updated is key to promoting best use of existing resources and equity in access to treatment services. Countries with established cancer registries, detailed guidelines and mechanisms in place to audit clinical practice against guidelines enjoy the best outcomes of care. Another initiative which has been proposed but is not readily implemented in breast cancer care is care quality registries that capture the diagnosis, the treatment provided, and the outcome for all patients treated within a country or region, which would allow for comprehensive evaluation of the care provided in relation to outcomes. Inclusion of well defined patient-focused criteria for outcome assessments is an important part of this.

### **Prevention and early diagnosis**

Most breast cancer risk factors are not subject to primary prevention interventions. However approximately 5% of breast cancer cases occur in women with an highly increased hereditary risk to developing breast cancer; these women may be identified and provided with more intensive follow-up, and in some cases treated with preventive measure such as surgery or chemoprevention, although this is still an area under debate and issues remain in targeting the right at-risk populations.

Mammography screening to enhance early detection is increasingly available in the study countries. However, many women still do not have access to screening and in developing countries, with limited healthcare resources, breast cancer is still often detected in more advanced stages. Initial steps to promote earlier diagnosis include initiatives to increase awareness of breast cancer and endorse regular clinical breast examinations.

### **Treatment of early breast cancer**

Breast cancer surgery has developed into a specialty in many countries and the introduction of breast conserving surgery has resulted in improved quality of life. Radiotherapy added to surgery can decrease the risk of relapse by two-thirds but there is still limited access in many countries. Adjuvant therapy with chemotherapy, endocrine and now also biological therapy has produced a major contribution to the improvement in outcomes for breast cancer over the

last 20-30 years. However, access to adjuvant therapy continues to vary, despite the availability of evidence-based guidelines about their use. With improved outcomes of breast cancer treatment the need for rehabilitation, both physical and psychosocial, has increased. Patient organisations can play an important role in supporting breast cancer patient rehabilitation.

### **Treatment of advanced breast cancer**

In spite of the advances seen in the treatment of early breast cancer, a significant number of women will suffer a relapse and develop metastatic disease. Metastatic breast cancer constitutes a large part of breast cancer care and is also an area of intensive research not least because most new drugs are introduced in patients with metastatic disease. The major focus is on medical treatment, still insufficient evidence exists for the best treatment strategies. The costs associated with metastatic disease are considerable and, therefore, well organised and evidence-based care of these patients will have a significant impact on the total burden of disease. The outcomes of treatments for advanced breast cancer need to be evaluated from several standpoints together with the patient taking into account quality of life considerations. In the palliative treatment of metastatic breast cancer, although guidelines are available in several of the study countries, the majority of countries do not have adequate specialised palliative care facilities.

### **→ The patient perspective**

The evidence-base for the design and implementation of patient-focused cancer care is limited. It is recommended that systematic feedback is obtained from patients through surveys and that patients should be engaged in decision-making regarding the design and development of cancer care. Increased involvement in treatment decisions requires patients to be well informed and it has been shown that patients who participate in treatment decisions will have more realistic expectations from their treatment. Patient-physician communication is a very important channel of information for patients, and access to information needs to be facilitated throughout the care process, especially in the transfer between different care units in order to streamline the patient pathway through the care organisation and avoid unnecessary waiting time.

It is important that a healthcare system is able to produce outcome data that are regularly updated and relevant for patient care. Patients should be able to compare the outcome, standard times for diagnosis, and treatment provided in their treatment setting with that of other centres in order to know what to expect in terms of care and also when the situation is not in line with standard practices. It is recommended that health-related quality of life and patient satisfaction are captured in the clinical follow-up and made available in quality registries, and patient groups could play a significant role in endorsing this.

## → Introduction and diffusion of new medical interventions

The introduction of new technology in diagnostics, surgery, radiotherapy and medical treatment into clinical practice is often delayed, even as clinical evidence of effectiveness is available. Many countries lack formal processes for evaluation of the cost-effectiveness of novel technologies, and large variations in access exist across countries. It is important that new medical interventions are introduced with a perspective on the total care of the patient, from prevention to palliation, in order to optimise use of resources.

## **Conclusion**

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It is very important that regulation, prioritisation, funding and organisation of breast cancer care are coordinated to provide all patients with the most appropriate, cost-effective and evidence-based treatment with minimal delays.

## **Recommendations**

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**It is clear that all stakeholders must work together in ensuring that breast cancer care practices and guidelines are coordinated to provide patients with the best care and countries should take action to:**

- **Increase epidemiological and clinical data for breast cancer to capture not just incidence and mortality but also more detailed parameters that allow for evaluation of treatment patterns in relation to outcome.**
- **Ensure evidence-based treatment guidelines are regularly updated in line with internationally accepted standards and that practice is routinely audited to ensure they are applied. This is key to promoting the best use of existing services and equity in access to treatment and care.**
- **Develop and improve formal health technology assessment processes to evaluate all new technology throughout the total chain of care in order to optimise use of resources and access to care.**
- **Address quality of life using appropriate instruments both in patients with recurrent or metastatic disease and in those who are cured, taking into account long-term unwanted effects of treatment.**
- **Develop patient-focused care programmes that fully take into account the patient perspective; including meeting patients' information needs, getting systematic feedback from patients through surveys, and engaging patients in the decision-making process.**
- **Healthcare services need to produce up to date information for patients so that patients can recognise the standard of care they should expect to receive.**