

**“National Breast Cancer Quality Register: A Powerful Tool to Improve Treatment”**  
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**Sweden: Background of the Cancer Picture**

Sweden is a country of 10 million inhabitants. In 2012 50 hospitals performed breast surgery in Sweden, and local county councils have the power to decide local healthcare policies. The Swedish Cancer Registry was established in 1958 to cover whole population and registers 50,000 new cases per year. Sweden runs national screening programmes for women aged 40-74 years old with a 75-80% compliance rate and because of its long history, cancer screening has become a natural part of women’s lives. Screening is important because it can often detect cancers at early stages, which increases the possibility of the cancer being cured and less aggressive treatment is required. Because parts of Sweden are scarcely populated, mobile mammography buses are used to facilitate breast cancer screening in rural areas.

In 2009, a national inquiry for cancer strategy was carried out [which Professor Sandelin contributed to]. The purpose of this was to better understand the bigger picture of cancer care in Sweden. Ultimately, the inquiry showed that Sweden had fragmented care and unexplained regional differences. This highlighted that primary prevention of cancers need to be spearheaded by the public. This national inquiry led to the establishment of regional cancer centres which functioned as regional coordinators of cancer care.

Today, there are six regional cancer centres in Sweden. The law requires all diagnosticians to register all primary cancers. In addition national quality registers were established and these are in contrast to the cancer register person bases registers. Patients have the right to opt out and have their information withdrawn from the national breast cancer quality register, however, the process is such that unless patients intentionally opt out, their data will automatically be entered into the quality register. This system enables Sweden to maintain a comprehensive set of data regarding all breast cancer incidences and outcomes within the country. The trends and analysis regarding this data are published and disseminated by hospital, county and regional levels in their national reports, which highlight how Sweden’s breast cancer detection and care system has been successful as well as areas where it needs improvement.

**Similarities and differences between the Swedish and Hong Kong Breast Cancer Registries**

	<b>Sweden</b>	<b>Hong Kong</b>
Similarity	Steering group with patient representatives: this is incredibly helpful and gives patients ownership to support each other and inform the process for breast cancer care	
Differences	99% completion	Partial completion
		Epidemiologic data
	Includes quality indicators by National Board of Health	Risk factors
	Describes in detail the breast process from diagnosis to first occurrence.	Describes breast process
	National and international target levels, surgical indicators	Patients reported outcome measure
	Morbidity reported	Glossary
	Government funded	NGO

**Aims of the Swedish National Breast Cancer Quality Register**

- To report on target levels according to national and international guidelines.
  - o Communication between different stakeholders are important to improve care process
- To follow trends in management and care.
- To identify regional differences and thereby suggest improvements for healthcare providers, particularly trends that could not previously be explained.
- To provide a comprehensive report to healthcare professionals, policy makers, and non-professional stakeholders.

Although the Register has very high completion rates regarding the primary pathway, the data for medical treatment and follow-up have been less complete.

## ***Reconstruction register***

1. Immediate reconstruction and oncoplastic procedures
2. Late reconstruction after primary breast cancer operation
3. Risk reducing mastectomies in asymptomatic women
4. Secondary reconstructions after immediate and or late reconstruction

The register reports on which reconstructive procedures are more and less frequently used within the country and describes the type and number of procedures performed. The majority of reconstructions and oncoplastic surgeries are done in the Stockholm area and in Southern Sweden. This has led to a survivorsq initiative that supports every woman . regardless of where she lives . in her right to access reconstruction. By highlighting the regional differences, health providers are empowered to redirect resources to ensure a more equitable access to health.

## ***Lessons from the Swedish National Breast Cancer Quality Register***

Professor Sandelin went on to give some examples from the data of regional disparities and lessons we can learn from different procedures. For example, around half of the breast cancer cases in the total population were detected through mammography screening and the rates of screen-detected cases varied across different regions. The biological subtypes based on immunohistochemical (IHC) analysis of breast cancer also varied across different regions within the country. Furthermore, regional disparities were also observed in the rates of achieving the national target levels. Apart from regional disparities, the trend of using different types of treatment could also be observed using the data from the registers.

## ***Consequences of the Register***

- The concentration of surgical units decreases each year (from 60 to 50 between 2008 - 2012) which points to more equitable access to care throughout the country.
- Compliance with the indicators has increased
- Benchmark care: regional differences can be highlighted
- Transparency: data is updated in real time
- It has become the source for many national collaborative research projects which have meaningful practical implications in alerting other regions if they are not meeting certain benchmark indicators.

Overall, the National Quality Breast Cancer Register in Sweden is incredibly useful and important. The data it collects and enables medical and academic practitioners to learn from the trends in breast cancer detection and care, making changes in the health systems to benefit patients.

## ***Swedish National Breast Cancer Quality Register: Looking Ahead***

Although breast cancer quality registries have many positive attributes, they are still very resource demanding and continuously modified. Looking to the future, Professor Sandelin pointed to how technological innovations could revolutionise how the breast cancer register may run. For example synoptic reports of pathology data, a patients medical chart could automatically be downloaded into the register. Patients may be able to start reporting symptoms via social media and be advised electronically on the best course of action for their context. Supported by the Ministry of Health and Welfare and the local/regional authorities, much more can yet be done to and through the breast cancer quality register to prevent and control cancer across Sweden.