

Country Profile

## Oncology Financing in Sweden

April 2021

BREAKING NEW GROUND

THINKWELL

 ThinkWell  
 @thinkwellglobal  
[www.thinkwell.global](http://www.thinkwell.global)



**Acknowledgements:**

ThinkWell would like to express our sincere gratitude to all individuals and organizations who contributed to the ideas presented in this report.

**Authors:**

This report was prepared by Jens Wilkens, Margaret Cornelius, Ify Jikeme, and Dejan Loncar.

**Recommended Citation:**

Wilkens, Jens, Cornelius, Margaret, Jikeme, Ify and Loncar, Dejan. April 2021. "Oncology Financing in Sweden." Oncology Financing Country Profiles. Washington, DC: ThinkWell.

*This report was produced by ThinkWell, with funding and input from Merck Sharp & Dohme Corp., a subsidiary of Merck & Co., Inc., Kenilworth, New Jersey USA.*

## ACRONYMS & ABBREVIATIONS

COVID-19	Respiratory illness caused by the SARS-CoV-2 virus
EMA	European Medicines Agency
GP	General practitioner
HIS	Health information systems
HPV	Human papillomavirus
HSAN	Medical Responsibility Board (Hälso- och sjukvårdens ansvarsnämnd)
HTA	Health technology assessment
IADL	Instrumental activities of daily living
ICF	International Classification of Functioning, Disability and Health
IVF	In vitro fertilization
IVO	Health and Social Care Inspectorate (Inspektionen för vård och omsorg)
MPA	The Swedish Medical Products Agency
NHS	National Health Service
OECD	Organization for Economic Co-Operation and Development
PREM	Patient-reported experience measures
PROM	Patient-reported outcome measures
PSA	Prostate-specific antigen
RCC	Regional Cancer Center (Regionalt Cancercentrum)
SALAR	Swedish Association of Local Authorities and Regions (Sveriges Kommuner och Landsting)
SBU	Swedish Council on Technology Assessment in Health Care (Statens Beredning för Medicinsk Utvärdering)
SCREESCO	Swedish screening program for colon cancer
SEK	Swedish krona
SIP	Coordinated individual (care) plan (Samordnad Individuell Plan)
SVF	Standardized care processes (Standardiserade vårdförlopp)
TLV	Dental and Pharmaceutical Benefits Agency (Tandvårds- och Läkemedelsförmånsverket)
USD	United States dollar
VHI	Voluntary health insurance
WHO	World Health Organization

## TABLE OF CONTENTS

<b>Executive Summary</b> .....	<b>1</b>
<b>Introduction</b> .....	<b>2</b>
<b>Macroeconomic, Demographic &amp; Cancer Burden Situation</b> .....	<b>3</b>
Macroeconomic & Demographic Outlook.....	3
Burden of Disease.....	4
<b>Health System Structure &amp; Health Financing</b> .....	<b>4</b>
<b>The National Cancer Program</b> .....	<b>7</b>
Program Snapshot.....	7
Cancer Care Continuum.....	8
<b>Oncology Program Financing</b> .....	<b>11</b>
<b>Oncology Financing Challenges</b> .....	<b>15</b>
<b>Options for Improving Oncology Financing</b> .....	<b>17</b>
<b>Summary &amp; Conclusions</b> .....	<b>19</b>
<b>Annex 1 – National Health Agencies</b> .....	<b>20</b>
<b>Annex 2 – Cancer Care Continuum</b> .....	<b>21</b>
<b>References</b> .....	<b>25</b>

## EXECUTIVE SUMMARY

---

### Context

- Over recent years, Sweden’s economic performance has been on par with the average for Europe; the COVID-19 pandemic has less severely impacted the country from an economic standpoint, in large part due to the swift and sizeable government stimulus response.
- Sweden’s 10.1 million population is stable due to relatively high birth rates and net immigration inflows. The annual growth rate of 0.6% is not expected to decrease; the population is projected to reach 11 million by 2040. Like most high-income countries, Sweden has a population that is aging, though not at the same rate as other high-income countries in Europe.
- In 2018, cancer accounted for 25% of Sweden’s 92,000 total deaths. Cancer mortality has declined over the past two decades, although at rates that are slightly slower than for cardiovascular diseases.

---

### Oncology Financing & Performance

- Cancer survival rates are among the highest globally reflecting the generally high medical quality in the Swedish health care system.
- Sweden allocates a large share of its total public resources to health. In 2018, Sweden spent 10.9% of GDP on health, equivalent to SEK 51,996 (USD 5,982) per capita in absolute terms.
- Due to increases in both costs per case and the number of diagnosed cases, cancer care costs have almost doubled over the last 20 years.
- Spending for cancer drugs has grown in absolute and relative terms, but with large variation by type of drug.
- Performance of the oncology continuum is uneven across the country; in particular, waiting times for initiation of treatment vary widely by region.

---

### Key Takeaways

- Sweden can realize the full potential of recent scientific advances in cancer care by centralizing more functions and providing more rapid access to oncology care.
  - The national government can further develop its governance role to ensure increased needs-based allocation of financial resources for cancer.
  - To achieve the national policy objective of equity in access, the central government will need to increase resources proportional to the current and projected burden.
-

## INTRODUCTION

**The global cancer burden is increasing, and countries are grappling with how to sustainably fund comprehensive and high-quality oncology care, including access to new technologies and therapies.** An in-depth understanding of oncology funding flows and the systems and structures that influence them can enable targeted policy efforts to improve financing for national cancer programs.

Cancer care and outcomes in Sweden are among the world's best. Survival rates are among the highest globally (Allemani et al. 2018), reflecting the overall high quality of clinical care in Sweden. However, many Swedish patients still endure long waiting times for diagnosis and treatment initiation, despite many policy measures taken over the years to address these issues.

This country profile is part of a compendium funded by MSD that analyzes how countries finance their oncology programs. It contains valuable information for all stakeholders interested in promoting sustainable and robust financing for oncology care programs and illustrates a variety of ways to engage in realizing this outcome.

# MACROECONOMIC, DEMOGRAPHIC & CANCER BURDEN SITUATION

## MACROECONOMIC & DEMOGRAPHIC OUTLOOK

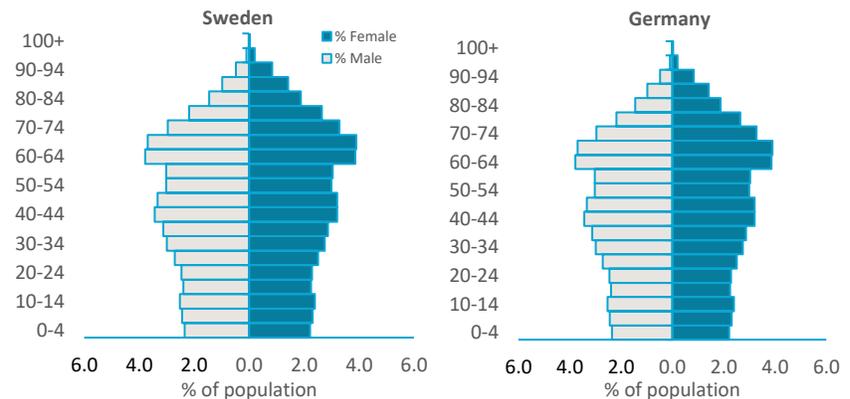
**Sweden is a high-income country recognized globally for its equitable health and social outcomes.** An indication is the relatively low Gini-coefficient (Sweden 27.6, EU average 30.7).<sup>1</sup> Overall, income differences in Sweden are relatively modest, although there are regional differences that affect the ability to collect resources for health services. There is a concentration of high-income groups in regions where high-growth industries are situated, notably the Stockholm and Gothenburg areas. In other areas of the country, large groups in regions with more stagnant industries and large rural populations have lower incomes, caused mainly by higher unemployment but partly also by lower salaries. As local and regional public revenue are generated through personal income taxes, this affects the ability to raise revenues and leads to significant differences in current and future possibilities to fund health and social services. This is perceived as a serious social challenge generally, particularly for equity in health service access, a cornerstone of the national health legislation.

**Sweden's population of 10.1 million is stable due to relatively high birth rates and immigration.** The current annual growth rate at 0.6% is expected to stay positive and population is projected to reach 11 million by 2040. In 2017, Sweden had the second highest fertility rate in the EU after France (Eurostat). Sweden has seen a substantial increase over the last 20 years; the total fertility rate dropped to 1.5 per woman in 1999 but has reached 1.9 in the last decade, partly due to active policies to support families with children (Vollset et al. 2020). In addition to a stabilized fertility rate, Sweden has experienced the largest rate of net immigration in the EU (relative to population size) during the last 10 years.

**Sweden shares the European challenge of an aging population and managing future funding for public commitments.** However, compared to many other high-income countries in Europe, the age structure has a relatively favorable *shape*.

When compared to Germany, (as projected, Figure 1), Sweden shows a sufficient wage-earning labor force that can sustain publicly financed social welfare programs in the long-term. Nevertheless, Sweden's future outlook may challenge priorities and create strong pressure to further increase health system efficiency and cost-effectiveness in care.

**Figure 1: Age Structure of the Population, Sweden and Germany (2030)**



Source: Populationpyramid.net

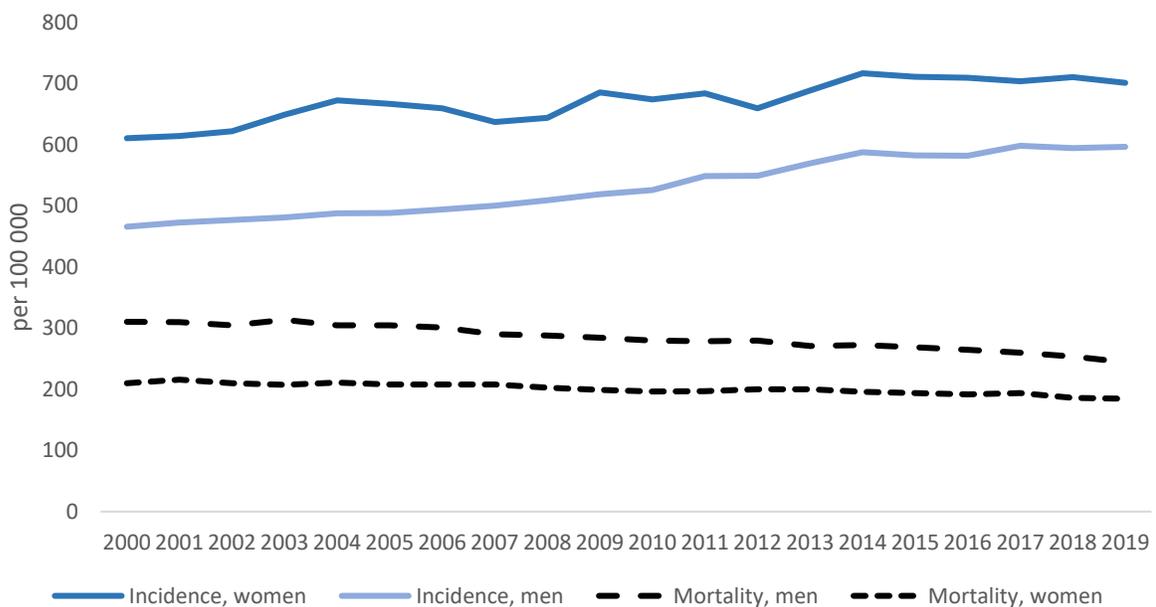
<sup>1</sup> The Gini coefficient is a measure of statistical dispersion representing inequality in income, consumption or wealth within a nation or other group of people. A low number indicates a relatively equal distribution across the population and a high number an unequal distribution. Source: Eurostat.

## BURDEN OF DISEASE

**While cancer mortality has fallen overall, the rate of decline has been slower than for cardiovascular diseases.** In 2018, cancer accounted for 25% and cardiovascular 33% of Sweden's 92,000 deaths, respectively. Breast cancer for women and prostate cancer for men are the most common diagnoses, but lung cancer causes the most deaths overall. Similar to other high-income countries, incidence rates are rising while mortality rates from cancer are falling (). This development varies widely between type of cancer, due to therapy development and life-style factors. For example, since 1970, colon cancer incidence has been steadily increasing while mortality has been declining, for both men and women. For lung cancer, incidence and mortality have declined for men, while they have increased for women. Since 2005, lung cancer is the most common cause of death among cancers for women (Socialstyrelsen 2018).

**Figure 2: Cancer Incidence and Mortality, All Sites**

Number of persons diagnosed and deaths per 100 000, age standardized by Sweden 2000, 2000 - 2019



Source: Swedish cancer registry and Swedish cause of death registry

## HEALTH SYSTEM STRUCTURE & HEALTH FINANCING

**The Swedish health system has three administrative levels, each with separate roles in the health system ().** There is a national commitment to provide equitable health services, and the right to health is guaranteed in the Swedish Constitution. At the same time, most of the funding and provision of services is the responsibility of regional and local administrations accountable to their own respective parliaments.

**A defining characteristic of Swedish public administration is that the national executive government's administration is relatively small and relies heavily on capacity in national expert agencies.** The

national government has a regulatory and normative role, coordinates disease control, and monitors quality, safety, and overall health system performance. The Ministry of Social Affairs has nine expert agencies at its disposal, funded by the national budget, which perform most central government functions (see Annex 1 for description). The Dental and Pharmaceutical Benefits Agency (TLV) has a particularly important role in oncology as it makes decisions about public subsidies for all prescribed medicines and has a growing importance also in assessment of inpatient medicines.

**Purchasing and provision of individual health services is the responsibility of sub-national authority.**

Each of the 21 regions, ranging in size from 60,000 inhabitants (Gotland) to 2,386,000 (Stockholm), have an independent regional health administration responsible for funding and delivering all individual health care services. An overarching structure with six superordinate medical care regions for highly specialized care has emerged to become an additional layer to centralize some functions. The 290 municipalities are responsible for funding and delivery of all social services, long term care (elderly and disabled), and a wide range of population-based services. Regions and municipalities are governed by their own respective parliaments.

**Sub-national authorities are organized under a national association, which has a leading role in national cancer policy development and performance monitoring.** This Swedish Association of Local Authorities and Regions (SALAR) is governed by representatives from the locally elected councils. SALAR is an important party in negotiations with the national government, and under the national cancer strategy (see below) taken a central role in shaping the oncology landscape. In addition, SALAR works to strengthen local self-government and provide local authorities with expert assistance.

**Figure 3: Organization of the Swedish Health System**



Source: Authors

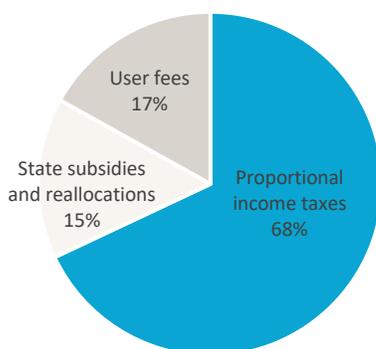
**Sweden allocates a large share of its public resources to health.** In 2018, Sweden spent 10.9% of GDP on health, equivalent to SEK 51,996 (USD 5,982)<sup>2</sup> per capita in absolute terms. The share of GDP spent on health is high in an international comparison and above all Nordic neighbors, but only Norway is a higher spender in absolute terms (also when adjusting for price level). The high spending is partly explained by large amounts allocated to long-term care (26% of total spending). This share is large also relative to most other high-income countries, given Sweden’s investment in formalized elder care. When comparing only hospital, outpatient and pharmaceutical spending, Sweden is an average country for its income bracket.

**A characteristic of Sweden is the relatively high spending on outpatient services and a low proportion spent on inpatient care.** This a consequence of the last 30 years’ transformation of hospital services. Inpatient service provision has been heavily downsized, which is visible by the lowest number of hospital beds per capita in the EU (214 per 100,000 population, EU average 538), short average lengths of stay, and the large share of surgeries performed in outpatient settings.<sup>3</sup> This development has been driven by both efficiency ambitions and the medical professions’ preferences for non-invasive treatments.

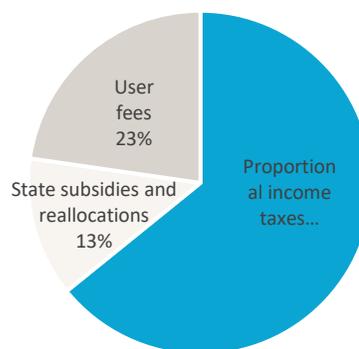
**Revenues for health are mainly raised through regionally determined flat-rate income taxes, leading to a tax structure that does not reflect income levels across the country.** Both regions and municipalities generate revenues from income taxes levied on their respective resident populations, setting tax rates independently (). The municipal tax rate varies from 17.1% (2020) in Österåker (outside Stockholm) to 23.8% in Dorotea (a northern and relatively rural municipality). The regional tax rate varies from 10.8% to

**Figure 4. Revenue sources by administrative level**

**21 regional governments\***



**290 municipalities**



Source: The Swedish Association of Local Authorities and Regions (SALAR)

\* User fees refer to total share of revenue in average for regional and municipal administrations respectively. The fee structure and regulations vary between different sectors. In health, the share of user fees relative to total spending is approximately 15% in regions and 4% in municipalities.

<sup>2</sup> 2018 (WHO Global Health Expenditure Database, who.int/nha/database, accessed 25/01/2021)

<sup>3</sup> ec.europa.eu/eurostat/data/database, accessed 25/01/2021

12.1%.<sup>4</sup> Combined, these rates vary from 29.2% to 35.1%, with generally lower income tax in affluent parts of Stockholm and higher taxes in low-income rural parts of the country.<sup>5</sup>

**A re-allocation system and state subsidies are increasingly important in reconciling fiscal space differentials across the country.** Central government block grants and earmarked subsidies for specific types of care have grown in importance the last decade. Still more significant is the nationally imposed equalization system used to adjust for structural factors, such as differences in age, income, and population density, which for some parts of the country, plays a decisive role for health care funding. This system managed by the central level government and is crucial in mitigating the imbalances in overall resource availability for financing health care.

**User fees are applied to almost all health services, but the system provides strong financial protection due to exemptions and annual ceiling amounts (caps) per patient.** Of all resources spent on health, 84% is from public budget sources. User fees make up the remaining ~15% of total spending and are highly differentiated by type of service.<sup>6</sup>

## THE NATIONAL CANCER PROGRAM

### PROGRAM SNAPSHOT

**In 2009, the government endorsed *A National Cancer Strategy for the Future*, which has strongly influenced policy since.** The strategy emphasized a holistic approach with strengthened primary and secondary prevention, improvement of early discovery, diagnosis and treatment, as well as palliative care (SOU 2009). The strategy was initiated in recognition of an increasing number of Swedes at risk of being diagnosed with cancer due to longer life expectancy rates, but also to prepare for managing cancer as a chronic condition due to increasing survival rates.<sup>7</sup> The cancer strategy was also a response to the waiting time problems, especially in the early phases of the care continuum. The National Cancer Strategy has served as the guiding document in national cancer policy formulation since its adoption.

#### Box 1. The National Cancer Strategy

**The National Cancer Strategy outlines five over-arching objectives:**

- 1) reduce the risk of developing cancer
- 2) improve the quality of cancer patient management
- 3) prolong survival times and improve quality of life after a cancer diagnosis
- 4) reduce regional differences in survival time after a cancer diagnosis
- 5) reduce differences between population groups in morbidity and survival time.

---

<sup>4</sup> Note that these administrations also have other commitments than health. Municipalities are responsible for a wide range of services, e.g., childcare and schools. However, in the regional budget, health care makes up 90% of spending.

<sup>5</sup> In addition to local flat rate income taxes, a national flat-rate payroll tax and a national progressive income tax generate public revenues.

<sup>6</sup> Regions charge a single fee for primary care varying from SEK 200 to 350 (USD 24 to 41) and twice as much for specialist care. For inpatient services the fee is typically SEK 100 (USD 8.50) per day. Fee levels and specific age and service exceptions are set by regions; there are nationally regulated caps on the totals per patient over a 12-month period. Currently the caps are: SEK 1100 (USD 130) for inpatient care; for outpatient prescribed medicines and medical devices, patients pay the full price up to SEK 1125 (USD 133), after which they are entitled to an increasing level of state subsidy. The cap for medicines, currently set at SEK 2250 (USD 266).

**While cancer care is the responsibility of the 21 regional administrations, an important feature in operationalizing the National Cancer Strategy was the establishment of six regional cancer centers (RCCs) and a national coordination of the centers hosted by SALAR.** With the mandate to guide and supervise, the RCCs have evolved into knowledge hubs by engaging predominantly with medical professionals. Funding and provision of care have not changed in any fundamental way and are still responsibilities of the regional administrations. Nevertheless, the RCCs have enabled concentration and coordination of cancer services by segmenting care in clinical levels of required skills and resources (Schmidt et al. 2018).

## CANCER CARE CONTINUUM

**The Swedish oncology care continuum benefits from a strong tradition of health promotion and disease prevention policies, which play an important role in cancer outcomes.** These promotion and prevention policies range from supporting awareness campaigns to tax policies, and are directed at improving healthy behaviors and lifestyles. Successful screening for breast cancer and the recently implemented HPV vaccination program are also indications of these prevention efforts.

**Early diagnosis of cancer is one of the main objectives of the Swedish National Cancer Strategy; however, implementation of these guidelines falls to the regional administrations and progress has been uneven.** Screening for colorectal and lung cancer, as well as other early detection and diagnostic services are not widely promoted or prioritized. In fact, the early part of the care continuum is probably the most criticized and worst performing compared to peer countries. Box 2 provides greater detail about how benefits are organized under the Swedish system and the impact this design has on oncology. Annex 2 provides a more detailed review of the care continuum, including the growing influence patient perspectives on care and outcomes, greater emphasis on rehabilitation due to higher survival rates, and the relatively advanced but fragmented data and monitoring system of care processes and outcomes in Sweden.

**Box 2. Benefit entitlement design in the Swedish health system, implications for oncology**

**Entitlement to publicly funded health services is residency based on 100% coverage among formal residents. No link between contributions and entitlements exists regarding public funds for health.** Entitlements for undocumented immigrants and asylum seekers have been subject to debate and changes over the years. Swedish nationals with foreign residency are not covered.

Services covered **Publicly financed benefits are only explicitly defined for outpatient medicines, outpatient medical devices and dental care (by TLV). For all other services, there is no national list of service coverage.** The regions' autonomy does have consequences for equity in service coverage, although public and political pressure to limit differences is high. SALAR works to align entitlement rules, which has for example led to harmonized rules for IVF. Indirectly, the introduction of a purchaser-provider split in the regional administrations in the 1990s, and practice of DRGs and similar description has led to lists of covered services, although these are not effectively communicated to the population.

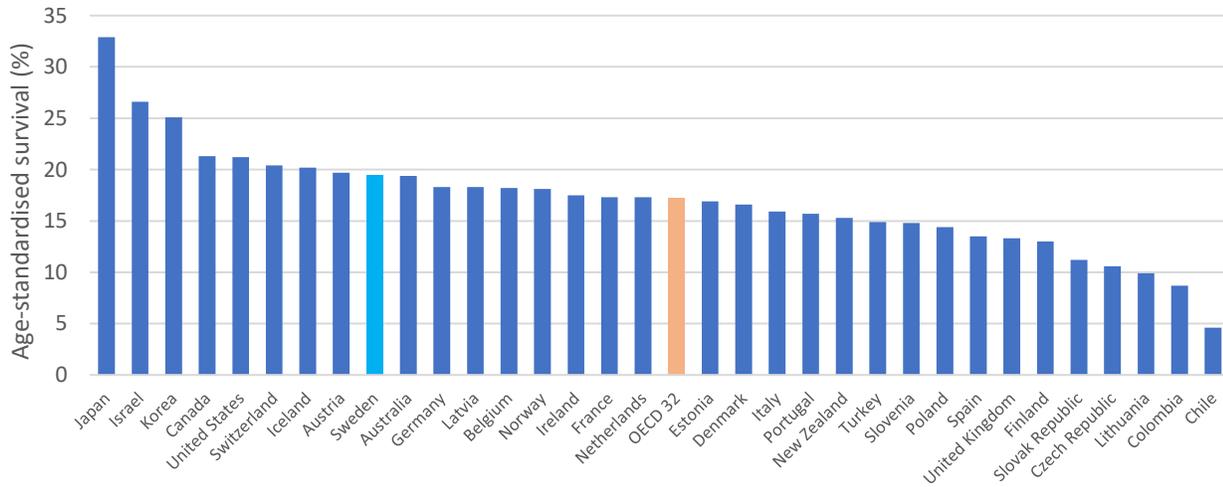
Services excluded **Although Sweden does not explicitly define what is not funded publicly, a strong tradition of evidence-based medicine and local hospital budget autonomy often leads to exclusions and late introductions, a frequent occurrence of expensive cancer drugs.** These delays to access are often caused by additional reviews after decisions on a national level, both on a regional level, hospital level and clinic level. A recent example is CAR T-cell therapy in haematology. The New Therapies Council (see below) approved a drug for adult lymphoma and another for acute leukaemia with children (for specific indications) in 2019 (EMA approval in 2018). Skåne university hospital (region Skåne) was first to use the lymphoma drug in regular care in January 2020. During the same year, Sahlgrenska university hospital (region Västra Götaland) however, did not approve funding for this drug in their local HTA decision process. Another much-debated example is that so far only Stockholm conducts colorectal cancer screening. A national recommendation is not yet issued, due to ambiguous evidence on effectiveness.

**Sweden attains high-level clinical outcomes, but the timeliness of services is sub-optimal.** Survival rates are among the highest globally (Allemani et al. 2018), which reflects the generally high clinical quality in the Swedish health system. Sweden has led the development of improved survival following cancer diagnosis for decades. Breast cancer 5-year survival is now 88.8%, the fifth highest among OECD countries. Lung cancer generally has lower survival rates; for this condition, Sweden ranks lower with the 9th highest survival rates. Long waiting times for diagnosis and initiation of treatment remain, with large differentials across the country, despite several policy measures over the years (Figure 5).

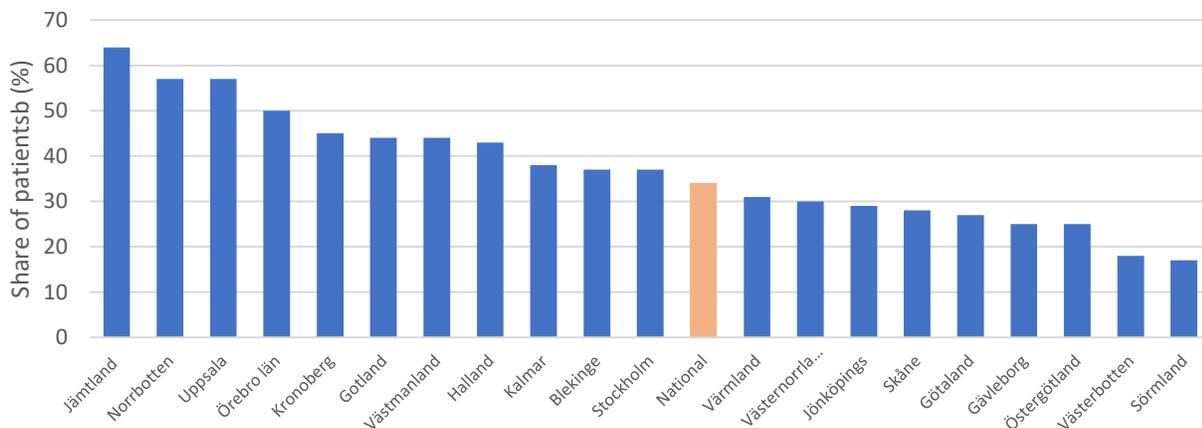
**Once the patient gains access to care, efficiency and effectiveness is high.** Treatment outcomes are strong in Swedish cancer care, as indicated by standard effectiveness indicators such as survival rates. Clinical practice has developed quickly, though there is room for improvement: clinicians interviewed for this study indicate Swedish tradition in evidence-based medicine possibly holds back some of the larger scale adoption of new technologies and methods, such as biomarkers and genetic profiling.

**Figure 5. Sweden has excellent medical outcomes in cancer (A) but waiting times for treatment are long and varying across the country (B).**

**A. Age-standardised five-year net survival (%), lung cancer, OECD countries 2010-14**



**B. Share of patients referred with lung cancer suspicion starting treatment within national norm (30-40 days depending on type of treatment), by Swedish region 2020**



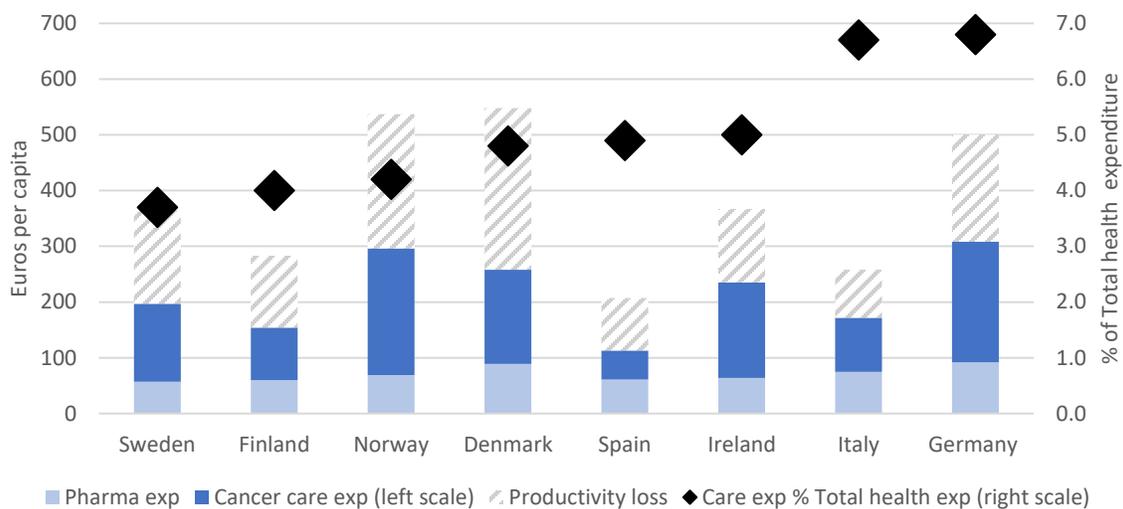
Source: OECD Health Care Quality Indicators and Regional Cancer Centers Sweden

## ONCOLOGY PROGRAM FINANCING

### Total Public Oncology Expenditures

**Although Sweden spends relatively sizable resources on health generally, spending on cancer is lower than other countries.** Due to increases in both costs per case and the number of diagnosed cases, costs for cancer care have almost doubled over the last 20 years,<sup>8</sup> yet health spending generally has not increased proportionally. As a result, Sweden stands out among high-income countries, with cancer care costs responding to only 3.7% of total health spending (Figure 6). In absolute terms, the gap is highest compared to higher income countries such as Norway, but also to countries like Germany, where inpatient care is more dominant in oncology.<sup>9</sup>

**Figure 6. Costs for cancer, by services, medicines, productivity losses, and as a share of health spending, Sweden and selected countries (2018)**



Source: The Cost of Cancer in Europe 2018 (Hofmarcher et al. 2020)

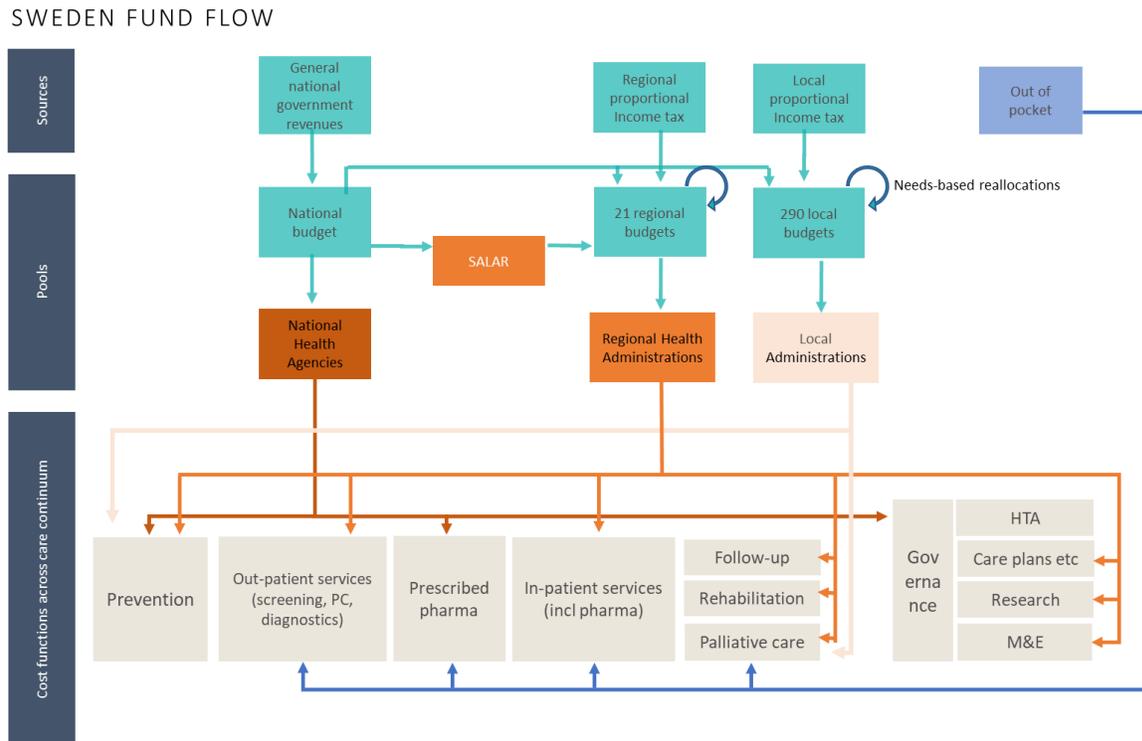
Comparing across OECD European high-income countries, the costs for productivity losses in society are almost on par with costs incurred by providing care. These societal costs related to mortality are moving downwards as survival rates improve (Hofmarcher et al. 2020).

<sup>8</sup> <https://svenskfarmaci.se/lakemedel/kostnaden-for-cancerlakemedel-okar-snabbt/>

<sup>9</sup> Cross-country comparative disease-specific health expenditure data is rare. Comparisons between countries rely on cost-of-illness studies, which are not available on a regular basis, nor produced using standardized methodology.

The oncology fund flow reflects a centralized ‘inflow’ where taxes are collected at national, regional and local levels, and a decentralized ‘outflow,’ where pooling and purchasing functions are completely devolved to the regional level and down. In effect, Sweden’s health system (Figure 7) is comprised of 21 distinct regional health administrations, each of which has its own capacity to raise revenues, organize care delivery, and manage population health.

Figure 7. Oncology Fund Flow in Sweden



Source Authors

### Sources

All public resources for health originate from budget revenues at each respective administrative level, with the regional income tax being the largest source of health funds overall. Health priorities are set at the discretion of the central, regional, and local governments, respectively. Since regional authorities have few responsibilities beyond health, the regional income tax can be viewed as a tax to support health services, although no formal earmarks exist for health. Regional health administrations are also purchasers with an active role in all levels of care, with the exception of a few specific functions purchased by national health agencies and local administrations.

**National government funding plays a minor role in health, with prescribed pharmaceuticals being an important exception for oncology.** Because the central government funds prescribed reimbursed medicines, its budget plays an important role in oncology financing policy. Outpatient drugs represent approximately half of the central government budget line for health.<sup>10</sup> Formally, these resources are pooled by the regional authorities, but the expense is forecasted in detail (modelled by need, not actual

<sup>10</sup> After excluding government support for people with functional variations (mostly personal assistance, IADL).

consumption) and subject to *post hoc* adjustments. In effect, the central government is the third-party payer for all prescribed drugs, with a limit, then the regions take over. But the latter seldom happens, primarily because the projections of how much will be prescribed are quite precise and accurate. Effectively, funding of prescribed pharmaceuticals works as an earmarked budget contribution from the central level. In addition, targeted programs (in psychiatry, oncology, and public health), have grown in importance for regions' ability to fund health care, although they only represent a few percent of total public spending on health. The remainder of the national budget for health is channeled through the national health agencies, mostly for normative, regulatory, and monitoring functions.

**An important feature of pooling resources for health in Sweden is the needs-based allocation and reallocation scheme.** Based on national regulation, these formulas are imposed on regional and local governments, to equalize the ability to provide health services. The reallocation formula is the subject of some debate, with a popular argument that national government subsidies should proportionally be larger for less well-off regions. These lower-income areas fund a substantial portion of their respective budgets through revenues from state subsidies and reallocations (see Figure 4).

**Patient fees and other out-of-pocket payments for oncology are very minor.** Although user fees have an important role in Swedish health care from a utilization management standpoint, in practice oncology treatment and drugs are close to free as patients are likely to have met user fee caps by the time they have entered the care pathway. However, for the early stages of the care continuum, fees can still apply. Under a recent agreement with SALAR (REF Ds 2018:25), the national government imposed new regulations to ensure zero fees for cervical cancer testing, providing funding to cover the additional costs. This is one of many recent examples of how national government funding is used to drive national priorities via the decentralized health system structure.

### Pools and Purchasers

**For hospital inpatient services, the regional health administrations are single payers and decisive for the overall oncology resource envelope.** Hospital contracting is increasingly strategic, with surgery and oncology cases shared between hospitals. This profiling is typically manifested in long-term agreements. In large regions with several hospitals, oncology is located selectively. In smaller regions, oncology treatment is contracted out to sites in other regions. Resources are typically allocated in medium-term budget agreements, recognizing specialization and profile of the hospitals, with target volumes by type of care. The specific reimbursement method varies between regions and even specific hospitals within a region, as some profiles are more prone to global budget type of arrangements (e.g., acute care) and other case-based payment (e.g., elective surgery).

### Hospital services

**Most public hospitals in Sweden are semi-autonomous with a contractual relationship to the regions, but in practice the purchaser-provider split works within a political process, which influences all major decisions.** Since the 1990s, hospitals have been generally organized as formal independent public corporations, or divisions within the regional administrations with independent budget responsibility. However, autonomy and accountability are in most cases not separate from the political process and the regional purchasing entity. Investments in both infrastructure and high-cost equipment are typically strategic regional decisions and part of medium-term budget agreements between hospitals and regional budget authorities. Staffing and day-to-day oversight fall to hospital management. The case is different for primary care, where the regional purchasing entity uses capitation and performance-based payments for primary care providers, who thus operate with a sizable degree of autonomy in terms of care management.

## Pharmaceuticals

**Pricing and procurement of pharmaceuticals for inpatient and outpatient drugs follows two separate processes, with implications for how drugs are introduced into the system.** Outpatient prescribed drugs are introduced to the market in a strictly value-based pricing structure, in which an application to TLV with a cost-effectiveness appraisal is the decisive step. Also note that costs for these drugs do not fall directly on the regions (as illustrated in the fund flow map). For inpatient medicines, in principle, all regions independently purchase these in public procurement processes. Pharmaceuticals make up a substantial proportion of hospital budgets, especially for inpatient care. Decision-making varies between regions, with budget responsibility shared in various ways between the regional administration level, hospitals, and specific clinics. For high-cost oncology drugs, *ad hoc* requests to the central budget are made on exceptional basis and have been one of the ways to handle trade-offs between cost-containment, efficiency, and equity.

**In the last few years, hospital procurement has taken important steps toward a centralized process of value appraisals similar to how prescribed drugs are managed.** With TLV and SALAR as core partners, the New Therapies Council is emerging as an important stakeholder in pricing and market entry. This development is likely to continue: the more complex oncology treatment becomes, and the more budget impact pharmaceutical drugs have (see Box 3). In the pharmaceutical therapy area of oncology, a 35% increase in costs is forecasted from 2019 to 2022 (Socialstyrelsen 2020). However, inpatient medicine procurement is difficult to coordinate, as purchasing power and opportunities vary largely between regions, depending on size. For new oncology pharmaceuticals, managed entry agreements between companies and regions play a decisive role for actual costs, with implications for volume and equity in availability. With the regional structure of the health system and costs for inpatient medicines falling on regional budgets, national coordination will remain a guiding mechanism, rather than a new procurement structure.

**Costs for cancer drugs increase in absolute and relative terms, but with large variation by type of drug.** Total sales of cancer pharmaceuticals have increased several times in the last two decades. But the increase in traditional types of drugs (cytostatic and hormones) has been modest and below the general cost increase in health care. Hormones are still growing in total sales but less so than other costs. Costs for cytostatic, still used in large volumes (especially for breast cancer treatment) but with expired patents, have decreased over the last decade, even in absolute terms. The largest increase is instead seen for targeted drugs, including immunotherapy drugs which increased from 40 to 71% of total sales between 2008 and 2016. Note that assessing actual costs is difficult, e.g., because of confidential net price agreements, which gives lower costs than indicated by official price lists (see Box 3).

**The difference in inpatient and outpatient use means future increasing costs will fall on different budgets.** In inpatient settings, the dominant drugs are cytostatic, immunotherapies and monoclonal

### Box 3. Challenges in estimating oncology costs.

The rising costs of cancer medicines receive a lot of political and media attention; the five products with highest sales volume currently make up about 40% of total oncology drug costs.

However, total costs are difficult to estimate. Accounting for all spending on national level is difficult as many special agreements with regions do use confidential prices, sometimes linked to volumes and/or outcomes. Cost-attribution of a specific drug is also difficult. Many cancer drugs are used for other indications, e.g., in rheumatology.

In addition, new precision medicine is not only about drugs but about diagnostic methods including biomarkers. The ascent of personalized medicine and special budget lines for expensive drugs will impact traditional costing methods that rely on average costs per patient or diagnosis. Thus, payment modalities like diagnosis related groups may become increasingly obsolete.

antibodies. At the turn of the 21<sup>st</sup> century, outpatient drugs made up 70% of total costs of cancer drugs. The dominant prescribed cancer drugs in outpatient care (approximately 46% of total drug costs) are instead hormones and kinase- and signal inhibitors. With the introduction of antibodies in hospital cancer treatment, this share fell to 35% in 2013. Since then, the share of prescribed drugs has increased again, due to, for example, increased use of hormone-based therapies in prostate cancer care and kinase inhibitors in leukemia (Vårdanalys 2017). As long as Sweden maintains its dual system of introduction and funding of inpatient and outpatient (prescribed) drugs, incentives to apply and integrate new drugs in treatment will differ depending on how they are applied. For example, new drugs that can be administered orally at home carry costs that fall on the national medicines budget, as opposed to drugs administered in hospital clinics, which fall on regional budgets.

### **Oncology services beyond what most Swedish stakeholders define as ‘traditional’ health care**

**Municipalities have a wide responsibility for prevention and rehabilitative care and estimates point to that municipalities in Sweden spend large amounts on support to cancer patients.** Municipal community services are approved and commissioned based on needs for support in daily activities. Therefore, disease-specific data on how much is spent by local authorities for community services are very sparse. Approximate estimates for general cancer care are possible by combining the ICF (International Classification of Functioning, Disability and Health) used in describing the need and the IADL (Instrumental Activities of Daily Living) classes for interventions (Lindholm et al. 2013). This approach has been used to estimate cancer care costs for municipalities using the three IADL classes accommodation (institutional), home support, and home health care. The costs per cancer case for these services exceeds the regionally funded medical cancer care costs per case in 7 of the 12 largest cancer diagnoses (Feldman<sup>11</sup>).

## **ONCOLOGY FINANCING CHALLENGES**

**Waiting times are by far the most commonly cited challenge in Swedish cancer care, which relates to how the system is financed as there is no explicit incentive for accelerating access to care.** For some diagnoses, waits are very long. In 2017, the median waiting time from primary care referral to a specialist at suspicion of prostate cancer to start of treatment (radiotherapy, not pharmaceutical or combination) varied from an average of 134 days in the region with the shortest waiting-times (Kronoberg) to 333 days in the region with the longest (Jämtland).

**Long wait times are in effect a rationing mechanism within the Swedish health system.** In oncology, it was argued for many years that the negative impact on health outcomes was marginal by pointing to high survival rates. This excuse is losing momentum as evidence contrary to specific Swedish studies is emerging (Hanna et al. 2020). Also, patient experience and the quality-of-life aspects in outcomes are increasingly prevalent in Swedish quality assessments of health care.

**Availability and access to pharmaceutical treatment is similarly a crucial component of care, which needs to be more equitable.** Similar to waiting times, but with less visibility in public debate, pharmaceutical consumption varies widely across the country. Ultimately, differences in regional fiscal space, budget processes, and HTA capacity across regions works against national objectives to achieve equitable utilization of health care.

---

<sup>11</sup> [https://www.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/prevention/cpk/cpk\\_teknisk\\_rapport\\_19maj16.pdf](https://www.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/prevention/cpk/cpk_teknisk_rapport_19maj16.pdf)

**Sweden's globally recognized leadership in clinical research has lost ground in recent years, partly due to poorly integrated health information and focus on service outputs instead over outcomes.** Local information systems are very advanced in that measuring health service production has been a guiding star for 20 years development of contracting and payment mechanisms. However, Swedish health information systems (HIS, including electronic health records and health registers) are in general not well-integrated, contributing to a fragmented patient experience in both diagnosis and treatment. Notably interviews with key informants for this report also confirm that these inadequacies contribute to the difficulties for hospital clinics to engage in clinical research.

**Regional revenue collection is unlikely to meet a growing demand for advanced cancer therapies.** Relying on regional capacity to generate new funds could also increase the risk of deepening inequities in access, as wealthier regions would in theory be more capable than lower-income areas of the country to generate new resources for oncology. Dissatisfaction with long waits and anxiety about whether the public system will meet its obligations has already taxed public trust in the public system.

**The use of voluntary health insurance (VHI) as supplemental cover is currently limited but rapidly growing.** Premiums for VHI currently account for less than 1% of total health spending. Though this share is minimal, the number of people carrying VHI has increased tenfold in 20 years, from 67,000 to 681,000 people.<sup>12</sup> Until now, VHI has played a supplementary role, mainly to allow policy holders to access relatively simple outpatient services faster than is provided in traditional care. However, the range of services is growing and recently, a specialized cancer care insurance entered the market (alivia.se), for which pre-existing conditions is a factor in access and pricing. The VHI market has become a politically sensitive topic and the government has recently initiated a public inquiry to seek options for regulation.<sup>13</sup> Although not common, greater numbers of people are also seeking provider alternatives abroad.

#### **Box 4. The potential impact of COVID-19 on oncology financing**

Key informants in interviews for this report noted the impact on cancer burden of disease, given the delays in oncology diagnosis and treatment.

Elderly care provides a strong case in point for needed structural and accountability reforms. Guidance from national agencies is provided, but the translation and adaptation to local context and challenges make them difficult to apply and has contributed to surge in COVID-related mortality. Among 1,700 elderly care homes, differences in local governance, medical support from regional administrations and many other factors varies considerably.

The COVID-19 pandemic was described as a catalyst for structural and accountability reforms in Swedish health care. The highlighted need for structural reforms can support discussions also about access and equity in cancer treatment, including medicines.

Sources: Key Informant Interviews

---

<sup>12</sup> [www.svenskforsakring.se](http://www.svenskforsakring.se) (accessed 25/11/2020)

<sup>13</sup> [www.regeringen.se/rattsliga-dokument/kommittedirektiv/2020/08/dir.-202083/](http://www.regeringen.se/rattsliga-dokument/kommittedirektiv/2020/08/dir.-202083/)

## OPTIONS FOR IMPROVED ONCOLOGY FINANCING

---

### **Option 1**      **Increases in oncology medicines spending requires additional public resources.**

---

**Policy intervention logic**      While the share of cancer-specific spending has not increased over time, the relative increase caused by the introduction of effective but expensive treatment options, has been offset by a reduction in inpatient service costs. Thus far, this has largely been due to a transition within hospitals budgets, which in Sweden has been supported by a parallel radical shift in all hospital care from inpatient to outpatient services.

---

**Technical and administrative feasibility**      Efficiency gains in hospitals have likely reached their maximum, and reallocation of resources from other areas of care is unlikely. More resources for cancer care will therefore require additional funding, although this is largely a political choice.

---

**Political acceptability**      There are very strong equity arguments for this. However, awareness about relative priority to different health care areas is low and advocacy work is needed to build support.

---

### **Option 2**      **Move more functions to the national level. This can include selected funding responsibilities such as hospital oncology drugs.**

---

**Policy intervention logic**      In several important aspects, the governance of cancer care has been nationalised during the last 10 years. Still, the national level works mainly normatively and implementation on regional and facility levels are discretionary. Expertise from all levels work jointly on TLV and RCC recommendations, but the current tradition of consensus agreements may not be sufficient to deliver transformative change for oncology care and access. For example, delays in implementation are often used as a rationing mechanism to elevate or downgrade jointly agreed policies.

---

**Technical and administrative feasibility**      Regional and hospital resource decisions are outputs of local political processes and clinical facility priorities, making adaptation and implementation of national priorities scattered and piecemeal. National responsibility to fund critical functions, e.g., expensive but cost-effective oncology medicines, would increase equity and the ability to fund innovative medicine. The mechanisms already exist and are practiced selectively in the current Swedish health care system.

---

**Political acceptability**      There is growing support for strengthening national leadership in the health sector. Although restricted by several influential regional administrations, lifting more decision-making to the national level will be required to keep high equity ambitions. As long as this means the national level takes on more funding responsibilities, resistance is likely to be limited.

---

---

<b>Option 3</b>	<b>Increase the use of regional and clinical performance success stories through stronger national governance and accountability regulation.</b>
<b>Policy intervention logic</b>	In clinical practice, Sweden is characterized by considerable differences– with no one clinic or region top performing across all areas of oncology. For providers, no real incentives program exists, and regions apply new knowledge on a voluntary basis. Instead, the system builds on trust in the medical professions, effectiveness of the bureaucracy, and for prevention and early detection, health literacy of the population. The system would benefit from the stronger promotion of best practices across regions and providers.
<b>Technical and administrative feasibility</b>	The RCCs give cancer visibility in the overall governance structure of the Swedish health system, but they serve multiple clients and thereby interests. Ultimately, regional administrations need to be accountable and national government would need to enforce stronger regulations and incentives for this.
<b>Political acceptability</b>	Suggestions that move decision-making from regional authorities are likely to meet resistance. But the high potential impact on best-practice dissemination is an opportunity that might appeal to non-governmental organizations or other key government stakeholders who can influence the dialogue.

---

<b>Option 4</b>	<b>Increase flexibility in hospital budgets and empower medical professionals in decisions about the rational use of resources in individualised treatment.</b>
<b>Policy intervention logic</b>	Historically, pharmaceuticals were a marginal input in hospital oncology treatment. Being an increasing part of treatment and costs in modern cancer care, the cost implications of how pharmaceuticals are reimbursed have come into sharper focus. Testing and applying new drugs in a DRG system developed with an old relative cost structure is expensive for the clinic. More flexibility and autonomy for clinical managers will enable more rational use of funds and can support clinical research.
<b>Technical and administrative feasibility</b>	In Sweden, global budgets are ascendant and there is momentum for moving away from case-based payments. Per key informants, this shift may stem from a desire among clinicians fatigued with registration requirements for all interventions, even beyond what is medically justified, and a temporary shift caused by major reconstructions of hospitals in large regions.
<b>Political acceptability</b>	Currently, there appears to be high political acceptability and support to move toward global budgets, but implementation will remain a challenge given uneven capacity across the regions. <i>Value-based reimbursement</i> dialogue is currently also shifting toward <i>individual care</i> .

---

## SUMMARY & CONCLUSIONS

**Securing sufficient resources for *equitable provision of quality cancer care* and access to lifesaving medicines will be a challenge for all countries, regardless of income status.** Though a relatively wealthy country, Sweden will face critical decisions as it confronts an increasing burden and greater demand for new treatment modalities and technologies. This country profile presents potential options for consideration, considering the organization of the Swedish health system and the opportunities and constraints the structure poses for oncology financing.

Areas for further study include the root causes of the long wait times, which were referenced by many of the key informants interviewed for this study. Other potential areas for further study include evaluating which functions might be adopted by the national level in terms of increasing access to cancer care and treatment and determining how differing administrative arrangements can impact the performance of the cancer care continuum.

The limitations to this study include limited availability of expenditure data by cost category and at the sub-national level. Quantifying the amount spent on the different components of the cancer continuum could give additional visibility into how public resources are being used to deliver comprehensive cancer care to the Swedish population.

## ANNEX 1 – NATIONAL HEALTH AGENCIES

The Ministry of Health and Social Affairs has nine government agencies directly involved in health. The following five agencies have important governing roles relevant to oncology financing:

- **The National Board of Health and Welfare** develops norms and standards, such as clinical guidelines (which are voluntary to implement as the regions are responsible for service delivery) and classification systems. It also collects a wide range of data through its health data registers (e.g., death, cancer, pharmaceutical, and health service provision registers), which are analysed in house but also disseminated to researchers. It is also the licensing authority for all medical professions that are working under such regulation.
- **The Swedish Medical Products Agency (MPA)** is the Swedish national authority responsible for the regulation and surveillance of the development, manufacture and sale of drugs and other medicinal products. All drugs sold in Sweden must be approved by and registered with the MPA.
- **The Dental and Pharmaceutical Benefits Agency (TLV)** approves all medicines and medicinal products to be included in the pharmaceutical benefits scheme (public subsidy of prescribed medicines) and is responsible for monitoring activities in the pharmacy market. It also decides which dental services should be subsidized.
- **The Public Health Agency of Sweden** has the overall responsibility for health promotion, diseases prevention, and communicable disease control. This agency provides policy advice to all levels of government and funds campaigns implemented by civil society organizations.
- Health insurance schemes do not fund Swedish health services. However, **the Swedish Social Insurance Agency (Försäkringskassan)** is an important health authority as it administers a wide range of insurance benefits for loss of income allowances, such as sickness and parental leave.

The other four are the Medical Responsibility Board (HSAN), the Swedish Agency for HTA (SBU), the Health and Social Care Inspectorate (IVO), and the Swedish Agency for Health and Care Services Analysis.

## ANNEX 2 – CANCER CARE CONTINUUM

**A guiding principle of the National Cancer Strategy and implementation design is strengthening the patients' perspective, by recognizing patients' needs for consistency and accessibility.** Several concrete tools have been implemented in the framework of the strategy and development of the RCCs, e.g., patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in outcomes data collection. Several reforms have also more generally enforced stronger care coordination, e.g., national-wide implementation of individual cancer care plans (later also adopted in other areas of care), and development of dedicated contact nurses for cancer patients. Clinical practice in the early stages of the care continuum has received a lot of attention, with increased use of multidisciplinary decision-making and a nationally imposed standardized care pathways system (SVF, standardiserade vårdförlopp) with more emphasis on reducing waiting times than traditional clinical guidelines (Wilkins et al. 2016).

**The SVF system has meant nationally implemented guidelines and reporting systems for a defined continuum of cancer care.** Developed and managed by the RCCs, the SVFs adhere to national medical guidelines with a specified process for close to all cancer diagnoses, clarifying at what point a particular treatment is warranted along the continuum. The specific time-point of entry into an SVF is called “justified suspicion,” and differs in detail between the specific cancer diagnoses. In the later part of a cancer continuum, rehabilitation can be part of the SVF description, but is most often not. Palliative care is also not included. The SVF program has led to some improvement in terms of waiting times for specific parts of the care pathway, but not yet alleviated lengthy care processes and inequity in access.

### 1. Prevention

**Sweden is a top performer in life-style factors for cancer prevention, partly due to health promotive policies for many decades.** In all global comparisons, Sweden sets an excellent example on factors conducive to strong prevention, such as low prevalence of smoking, overweight and obesity, regular physical activity, and healthy diets. These positive lifestyle patterns are partly due to a long tradition of strong policy levers, including taxation on harmful consumption (EU State of Health, 2019). Still more can be done, and risk factors vary in importance for prevention by cancer diagnosis (Colditz et al. 2000; Institute of and National Research Council National Cancer Policy 2003). It is estimated that 28% of Sweden's cancer cases in 2018 were related to lifestyle and lack of immunization. This share is higher among women (31% vs 25% for men), not due to differences in risk behaviors, but because mortality is higher in diagnoses more prevalent among women (ref IHE, 2020).

### 2. Screening

**Like other health services in Sweden, screening is governed by national guidance while funding and service responsibilities are regional.** Sweden's two national screening programs for cervical and breast cancers are effectively mandates that the regions are required to fully implement. Colorectal and prostate cancer are screened, but not yet with national coverage on population basis. Coverage rates are relatively high in a European perspective (except colorectal cancer).

**Cervical cancer screening** is rolled out nationally with high uptake. All regions cover Pap test for women between 23 to 64. HPV screening is standard depending on age group and indication. The frequency varies by age group, women between the ages of 23 to 49 are recommended for screening every three years; 50 to 64 every seven years.

**Mammography screening** is offered by all Swedish regions and has high national coverage. Among women aged 50–69, 90% report they have had a breast examination in the past two years (Eurostat). The

screening program is more generous than most comparable countries: screening is offered free of charge for all ages between 40 and 69, and in most regions also for the next five-year age group. This priority was set based on emerging evidence of cost-effectiveness in higher age groups (Mao, Nyström, and Jonsson 2020).

**Colorectal cancer** does not yet have a national screening program, which explains the relatively low coverage in Sweden (33% of people aged 50–74, EU average 50%). Only the Stockholm region has implemented screening, where all men and women age 60-69 are referred for testing every second year. More regions are currently planning to follow suit, based on new recommendations from both the National Board of Health and the RCCs. A large study is currently underway that will help to increase the evidence base about form of screening, target age population, and cost-effectiveness in the Swedish context (see SCREESCO [study](#)).

There is also an active debate and research in the medical professions about the benefits and harms of population screening for **prostate cancer**. Currently, the National Board of Health does not recommend implementation of PSA-testing. It is however available upon request at any primary care centre at the standard patient fee. RCCs in collaboration with regions are implementing more organised testing on a pilot basis. When PSA-testing can be effectively complemented, this policy is likely to develop further.

### 3. Diagnosis

**Early diagnosis of cancer is one of the main objectives of the Swedish National Cancer Strategy, but progress is still unsatisfactory.** In Sweden, more than seven out of 10 cancer patients have their first contact in the primary care setting, yet it is estimated that a general practitioner sees only 3-4 patients per year who later receive a cancer diagnosis.<sup>14</sup> Primary care as the entry point is a corner stone in the Swedish health system and SVFs provide guidance for coordination in the early stages of diagnoses. Even so, patient, doctor and system delays are common.

### 4. Treatment

**Once the patient is inside the health care system, efficiency and effectiveness are high.** Despite dissatisfaction with how the early phases of the care continuum works, treatment outcomes are overall strong in Swedish cancer care, as indicated by standard effectiveness indicators such as survival rates. Clinical practice has developed rapidly, driven by the medical professions. In addition, outpatient and less invasive surgery, which improve life expectancy and patients' functional abilities, has also been driven by structural reforms and cost-containment efforts in the regional administrations. Hospital contracting is increasingly strategic (see section on inpatient funding below). As noninvasive treatments options have increased both in quantity and access, the need for surgical capacity and infrastructure has sharply declined.

**Precision medicine necessitates the integration of radiation- surgery- and oncology treatment, and Swedish cancer care can evolve to accommodate these new therapeutic methods.** Personalized medicine is driven both by diagnostics and treatment itself. Clinicians interviewed as key informants for this study indicate the Swedish tradition in evidence-based medicine possibly holds back some of the larger scale adoption of new innovations, such as biomarkers and genetic profiling. Knowledge, skills and funding priorities are not likely to hold this back, but rather impose a high bar for outcome quality for new therapies.

---

<sup>14</sup> The Swedish Cancer Society report 2020 <https://static-files.cancerfonden.se/cancerfondsrapporten-cancervard-2020.pdf>

## 5. Rehabilitation

**Patient-centered rehabilitative care for cancer as a chronic condition is emergent.** With cancer increasingly becoming a chronic condition, rehabilitation is a growing area of concern and attention. In areas with very high survival but long-lasting treatment this is especially important, such as pediatric cancer survivors. Rehabilitation is commonly organised in outpatient hospital clinics in close collaboration with hospital treatment, although the organization and ownership vary considerably. Fragmented service delivery is hampering coordinated care when funding for services is spread across hospitals, primary care clinics, and municipal institutions. Swedish health care has worked for many years to overcome this fragmentation in administrative levels and varying types of provider organisation by developing various tools for coordination and sharing responsibility. A national cancer rehabilitation care program is updated every second year, including structured consultations with all regional administrations. In Sweden, the *Coordinated Individual (Care) Plan (SIP)* has gained momentum in cancer care. More recently, specific primary care clinics licensed to care for cancer patients have been suggested, but this has not yet materialized. Part of the problem is that many services rely on the separate hospital, primary care, and municipal institutions. At the same time funding responsibility follows with the type of service provision, not the patient.

## 6. Governance

**As with the Swedish health system as a whole, cancer care is governed in multiple layers of administration and suffers from a lack of accountability.** The recent addition to this structure, the RCCs, receive part of their assignments from the national government and others from its respective regions. In addition, the RCCs are not authorized to advance clinical practice, but rather reactively implement standardized norms and guidance. Data and knowledge sharing based on collaborative initiatives have instead been the stronghold in governing the system, building peer-to-peer and public pressure by benchmarking. Data is still in abundance (see Box 5), but no longer cutting edge and organized to cater to modern cancer services (see section *Ongoing Challenges in Oncology Financing*).

### Box 5. Swedish health and disease specific registries

Sweden has a long tradition of building national medical registries, of which the cancer register is a center piece. The National Board for Health and Welfare (see Annex 1) hosts the main registers, such as the national patient register (tracks all visits in specialist care), the birth register and prescribed drugs register, and the Swedish Cancer Register, founded in 1958. It is compulsory by law for every health care provider to report newly detected cancer cases, including diagnoses from clinical settings, laboratories, and autopsies. The registry and it consequently covers the whole population with approximately 60,000 malignant cases of cancer is registered every year.

Medical specialist groups have developed disease specific quality registers, which have received much national support and international attention in the last 10 years. The various quality registries have traditionally been initiated by specialized clinicians with the purpose to build data and evidence in support of clinical quality improvement. Content (variables and data coverage) varies by register, but all include individual level diagnosis, interventions, and outcomes. With time, these registers have gained large traction in public policy as they are used extensively in research and national enquiries, but their commercial value has also built up over time as they constitute a large repository of data for product development and verification. These are motives for the government to support the institutionalization and coordinated management of these originally almost civil society data collection.

Since 2018, health care providers in Sweden submit data on utilization of cancer pharmaceuticals to a new quality register designated to monitor new cancer medicines nationally. The new register implemented by SALAR and TLV jointly is a corner stone in the implementation plan for the national medicine strategy. This strategy was formed in 2011 by a broad group of government agencies and interest organizations, and has been periodically updated to meet evolving challenges in effective and equitable use of medicines. The new cancer drug registry is a response to macro trends such as the exponential increase in new effective but expensive medicines for several cancer diagnoses and the difficulties in monitoring the long-term cost effectiveness. The registry is funded by the national government. Similar to earlier support to quality registers, part of these funds is allocated via SALAR down to clinics with an incentive system to encourage data sharing of high quality.

Source: [www.kvalitetsregister.se](http://www.kvalitetsregister.se)

## REFERENCES

- Allemani, C., T. Matsuda, V. Di Carlo, R. Harewood, M. Matz, M. Nikšić, A. Bonaventure, M. Valkov, C. J. Johnson, J. Estève, O. J. Ogunbiyi, E. Silva G. Azevedo, W. Q. Chen, S. Eser, G. Engholm, C. A. Stiller, A. Monnereau, R. R. Woods, O. Visser, G. H. Lim, J. Aitken, H. K. Weir, and M. P. Coleman. 2018. "Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries." *Lancet* 391 (10125):1023-1075. doi: 10.1016/s0140-6736(17)33326-3.
- Colditz, G. A., K. A. Atwood, K. Emmons, R. R. Monson, W. C. Willett, D. Trichopoulos, and D. J. Hunter. 2000. "Harvard Report on Cancer Prevention Volume 4: Harvard Cancer Risk Index." *Cancer Causes & Control* 11 (6):477-488. doi: 10.1023/A:1008984432272.
- Hamilton, W., T. Green, T. Martins, K. Elliott, G. Rubin, and U. Macleod. 2013. "Evaluation of risk assessment tools for suspected cancer in general practice: a cohort study." *Br J Gen Pract* 63 (606):e30-6. doi: 10.3399/bjgp13X660751.
- Hanna, Timothy P., Will D. King, Stephane Thibodeau, Matthew Jalink, Gregory A. Paulin, Elizabeth Harvey-Jones, Dylan E. O'Sullivan, Christopher M. Booth, Richard Sullivan, and Ajay Aggarwal. 2020. "Mortality due to cancer treatment delay: systematic review and meta-analysis." *BMJ* 371:m4087. doi: 10.1136/bmj.m4087.
- Hofmarcher, Thomas, Peter Lindgren, Nils Wilking, and Bengt Jönsson. 2020. "The cost of cancer in Europe 2018." *European Journal of Cancer* 129:41-49. doi: <https://doi.org/10.1016/j.ejca.2020.01.011>.
- Institute of Medicine, and Board National Research Council National Cancer Policy. 2003. *Fulfilling the Potential of Cancer Prevention and Early Detection*, edited by S. J. Curry, T. Byers and M. Hewitt. Washington (DC): National Academies Press (US)
- Copyright 2003 by the National Academy of Sciences. All rights reserved.
- Lindholm, C., A. Gustavsson, L. Jönsson, and A. Wimo. 2013. "Costs explained by function rather than diagnosis--results from the SNAC Nordanstig elderly cohort in Sweden." *Int J Geriatr Psychiatry* 28 (5):454-62. doi: 10.1002/gps.3844.
- Mao, Zheng, Lennarth Nyström, and Håkan Jonsson. 2020. "Effectiveness of Population-Based Service Screening with Mammography for Women Aged 70–74 Years in Sweden." *Cancer Epidemiology Biomarkers & Prevention*. doi: 10.1158/1055-9965.EPI-20-0523.
- OECD, WHO, Eurostat. *A System of Health Accounts 2011: Revised edition*: OECD Publications Centre. Online
- Electronic document.
- Schmidt, Ingrid, Johan Thor, Thomas Davidson, Fredrik Nilsson, and Christina Carlsson. 2018. "The national program on standardized cancer care pathways in Sweden: Observations and findings half way through." *Health Policy* 122 (9):945-948. doi: 10.1016/j.healthpol.2018.07.012.
- Socialstyrelsen. 2018. *Cancer i siffror 2018 (Eng: Cancer in numbers 2018)*. Stockholm: The National Board of Health and Welfare and The Swedish Cancer Society.

Socialstyrelsen. 2020. Läkemedelsförsäljning i Sverige – analys och prognos 2020–2023. Stockholm.

SOU. 2009. A National Cancer Strategy for the Future. Swedish Government Inquiries.

Vollset, Stein Emil, Emily Goren, Chun-Wei Yuan, Jackie Cao, Amanda E. Smith, Thomas Hsiao, Catherine Bisignano, Gulrez S. Azhar, Emma Castro, Julian Chalek, Andrew J. Dolgert, Tahvi Frank, Kai Fukutaki, Simon I. Hay, Rafael Lozano, Ali H. Mokdad, Vishnu Nandakumar, Maxwell Pierce, Martin Pletcher, Toshana Robalik, Krista M. Steuben, Han Yong Wunrow, Bianca S. Zlavog, and Christopher J. L. Murray. 2020. "Fertility, mortality, migration, and population scenarios for 195 countries and territories from 2017 to 2100: a forecasting analysis for the Global Burden of Disease Study." *The Lancet* 396 (10258):1285-1306. doi: 10.1016/S0140-6736(20)30677-2.

Vårdanalys. 2017. Cancerläkemedel – ett kunskapsunderlag om införande, användning och uppföljning. Stockholm: Swedish Agency for Health and Care Services Analysis.

Wilkens, J., H. Thulesius, I. Schmidt, and C. Carlsson. 2016. "The 2015 National Cancer Program in Sweden: Introducing standardized care pathways in a decentralized system." *Health Policy* 120 (12):1378-1382. doi: 10.1016/j.healthpol.2016.09.008.