SWEDISH CANCER SOCIETY REPORT 2026

Next milestone

80 per cent survival

CANCER FONDEN

Contents

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CANCERFONDEN

75

1951 YEARS 2026

TOGETHER AGAINST CANCER

Preface

This year marks the 75th anniversary of the founding of the Swedish Cancer Society, and today we are one of the most important research funders and drivers in the field of cancer in Sweden. When the organisation was founded in the early 1950s, around three in ten people survived their cancer diagnosis. Today, just over seven in ten survive. This is a progression that few could have imagined, and a direct result of research, long-term initiatives, political decisions and strong social engagement.

Behind every percentage point of increased survival rate lies decades of scientific work. Various breakthroughs have transformed cancer from an often fatal disease into something that more and more people can be cured of or live with for a long time. Free academic research has been crucial. Many of today's life-saving treatments originate from discoveries that initially did not have a clear clinical application. Long-term and independent support for research therefore remains one of our most important tasks.

But increased knowledge is not enough. The great challenge of our time is the pace of implementation – how quickly new findings, methods and treatments reach individuals. This can mean that new diagnostic methods are not implemented and cancer is detected at a later stage. For those living with cancer, slow implementation can mean missed opportunities for a cure or maintaining a life with good quality of life. We therefore need to not only continue investing in research, but also to ensure that society and the healthcare system have the capacity to make use of the latest research results.

One of the Swedish Cancer Society's targets for Sweden is for 80 per cent to survive a cancer diagnosis by 2030. In this report, we describe where Sweden stands today and present specific policy proposals that are needed for us to achieve this target.

We know that the trend can be influenced. The last 75 years are proof of that. Let's take the next step together. Because together, we can make the impossible possible.

Ulrika Årehed Kågström
Secretary-General of the Swedish Cancer Society

Summary

Sweden currently has high cancer survival rates by international comparison and strong structural factors in research, care and health data. At the same time, international comparisons show that we face challenges when it comes to translating research results into patient benefit. Reaching the milestone of 80 per cent cancer survival by 2030 requires concrete action right now.

This report describes four areas in which we believe targeted reforms can strengthen the pace of implementation, increase equity and improve Sweden's long-term competitiveness in the field of cancer.

1 Clinical studies – a driver of implementation

Clinical studies are the bridge between research and care. They allow early access to new treatments and strengthen the expertise and innovative capability of healthcare. Despite favourable conditions, Sweden has lost ground in international comparisons, particularly in terms of commercial studies per capita.

Reversing this trend requires clearer national targets, better organisational conditions in healthcare and more equitable opportunities for patients to participate in studies, regardless of where they live.

2 Implementation time – from approval to actual use

There is currently a significant lag between regulatory approval of medicines, medical devices and diagnostics and actual use in healthcare. The processes fulfil important functions, but time spent on administration and lack of coordination risk delaying access to innovations.

Sweden needs to develop more transparent and comprehensive ways of measuring pace of implementation, streamline national and regional processes, and create better incentives for the introduction and monitoring of new methods. A health innovation index can be a practical tool with which to visualise progress and drive improvement.

3 Health data – the foundation on which future research and healthcare development are built

Sweden has unique assets in the form of personal identity numbers, national quality registries and high digital maturity. At the same time, legal frameworks and infrastructure are poorly aligned, hampering the secondary use of health data for research, innovation and use in precision diagnostics.

With the implementation of the European Health Data Space and the development of a national digital infrastructure, there is now an opportunity to take a coordinated and comprehensive approach. Realising the potential requires clearer national coordination, support for data holders and legislative adjustments to enable secure and efficient data sharing.

4 Europe's ability to innovate – the importance of a strong European ecosystem

Sweden's ability to translate research into patient benefit is affected by the broader European innovation climate. Today, the EU is losing ground in the global competition for clinical studies, venture capital and commercialisation of new treatments.

Sweden should actively promote increased harmonisation in the EU, reduced administrative burden and better conditions for investment and scaling-up of profitable and growing innovative companies. At the same time, national structures need to be strengthened so that research, healthcare and business collaborate more effectively.

Terminology

AI-based image analysis
Use of artificial intelligence to analyse medical images, such as X-rays, mammography or pathology images. AI can identify patterns and abnormalities to support diagnostics and treatment decisions.

Biomarkers
Measurable biological characteristics, such as proteins or genetic changes, that can provide information about disease, prognosis or the likely effect of a treatment.

Genetic risk profiling
Analysing a person's genes to assess their risk of developing a particular disease, such as cancer. Can be used to personalise screening or preventive measures.

Basic research
Research aimed at increasing the fundamental understanding of biological mechanisms and disease processes, without the clinical application necessarily being clear from the outset.

Health economics evaluation
An analysis of whether the benefit of a treatment or method is proportionate to its cost. The results are used as a basis for priority-setting and decisions on public funding, for example whether a medicine should be included in the high-cost protection scheme and introduced into publicly funded healthcare.

Interoperability
The ability of different IT systems, databases and technical platforms to communicate, exchange and use information in a structured and secure way. Crucial for effective data sharing within and between healthcare systems.

Clinical research
Research in which people, or health data or tissue samples from people, are studied to generate knowledge about health and disease. The aim is to test new treatments, diagnostic methods or approaches and to evaluate their efficacy and safety in a real healthcare setting.

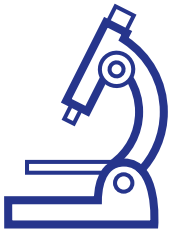
Quality registries
National databases that collect data on diagnosis, treatment and outcomes for patients in different disease areas. The aim is to monitor and improve the quality of care and enable research and development.

Metastases
Daughter tumours that occur when cancer cells spread from the original tumour to other parts of the body. Spread usually takes place through the blood or lymphatic system and usually means that the disease is more advanced.

Precision medicine
An approach in healthcare in which treatment is customised according to the biological, genetic and clinical characteristics of the individual. The aim is to provide the right treatment to the right patient at the right time based on individual circumstances.

Screening
Organised examination of asymptomatic people in a particular age or risk group to detect cancer or its precursors at an early stage. The aim is to reduce mortality and morbidity through earlier diagnosis and treatment.

Liquid biopsy
A method in which tumour-related material, such as DNA fragments (ctDNA), is analysed via blood samples or other body fluids. Enables cancer monitoring and detection of relapse without X-rays or surgical intervention.



80 per cent survival within reach

Cancer survival in Sweden has increased sharply in recent decades, and the majority of all people diagnosed with cancer now survive. These developments show that long-term initiatives in research, care and prevention make a difference.

Where do we stand today?

Since the Swedish Cancer Society was founded, cancer survival rates has more than doubled. In the early 1950s, about three in ten people survived cancer. Today, more than seven in every ten people in Sweden survive a cancer diagnosis. Despite more and more people developing cancer, mainly due to an ageing population but also due to unhealthy lifestyles, cancer mortality has fallen by more than a third since its peak in the mid-1970s. The reduction in mortality is due to more sensitive diagnostic methods, better treatments and preventive measures such as screening and restrictive tobacco policies. In total, it is estimated that around 250,000 lives have been saved in Sweden over the last 50 years thanks to research, healthcare development, improved public health and preventive efforts.*

With its *Europe's Beating Cancer Plan*, the EU has set out its ambition to reduce the negative impacts of cancer through coordinated initiatives in prevention, early detection, treatment and quality of life. In Sweden, the updated national cancer strategy and the Government's strategy for life science have identified research, equitable care and faster implementation as key tools to achieve better treatment outcomes. The ambition is clear: fewer people affected by cancer, earlier detection, higher survival rates, and a high quality of life for everyone living with or beyond a cancer diagnosis.

At the same time, there are still wide differences in survival rates between different cancer types. More than 90 per cent of people who develop prostate or skin cancer now survive. For other cancers, such as pancreatic cancer and some brain tumours, the prognosis is significantly poorer – often around 15 per cent or lower. These cancer types are difficult to detect early and, in metastatic stages, have few or no curative treatment options. What most cancers have in common is that once the disease has spread, the chances of survival are greatly reduced. If colon cancer is detected early, around 90 per cent of patients survive, compared to around 20 per cent when metastases have already formed.

Survival also differs between groups. Women have historically had higher cancer survival rates than men, but today overall survival is roughly the same, or slightly higher in men, a trend largely driven by the high survival rate in prostate cancer. According to statistics from the National Board of Health and Welfare, ten-year survival is just under 72 per cent for women, compared to almost 73 per cent for men.

There are also differences linked to socio-economic factors. For example, survival rates for lung cancer among women in areas with large socioeconomic challenges are around 30 per cent, compared to around 40 per cent in affluent areas.[1] Research shows that these differences can largely be explained by higher co-morbidity in certain groups, which has an impact on treatment options and consequently the chance of a cure.

Furthermore, there are wide differences in survival linked to other factors. For example, women with intellectual or other disabilities run a six times higher risk of dying from breast cancer than the general population. One explanation is that people with intellectual disabilities and autism receive care much later than others and the cancer has then had time to spread to other parts of the body.

Relative survival describes the probability of surviving a cancer disease. It is calculated by estimating the proportion of people receiving a cancer diagnosis who live for a certain time after they have become ill, usually five or ten years, compared with people who do not have cancer. This enables an estimate to be made of how large a part of the mortality rate is due to the cancer disease.

As a risk of recurrence can remain long after treatment has ended, it is often difficult to talk about being completely cured when it comes to cancer. The risk of relapse is highest in the first five years after diagnosis and decreases thereafter. Survival is therefore often reported at five years, but in some cases also after a longer period, such as ten years, to provide a more complete picture of survival.

* Estimate of how many more people would have died of cancer if the death rate had not fallen from its peak in 1975.

These differences underscore the importance of targeted initiatives for early detection and equitable care. However, despite variations between cancer types and demographic groups, overall survival continues to rise. If the trend continues at the same rate as in recent years, it is entirely possible to achieve the Swedish Cancer Society's target for Sweden in 2030, namely a 80 per cent survival rate by 2030. This is a milestone we can reach if the positive trend towards reduced cancer deaths we have seen in recent years continues. In practice, this would mean 6,300 more lives saved.**

This ambition is in line with both the EU cancer plan and Sweden's national cancer strategy.

But the target will not be reached by itself. It requires continued efforts to enable earlier detection and new treatments capable of curing even metastatic and difficult-to-treat cancer, for example. It requires new knowledge to be put into practice more quickly, so that every breakthrough actually benefits patients.

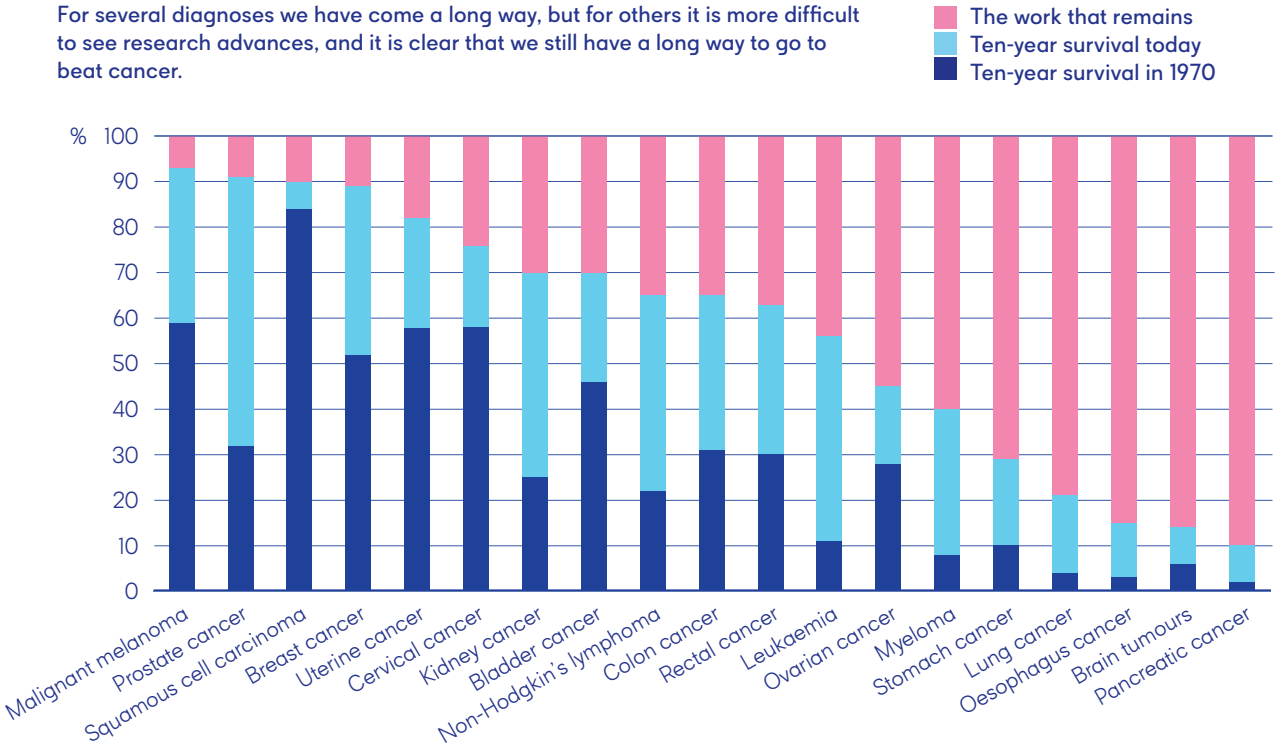
Swedish survival by international comparison

Sweden has high cancer survival rates compared to the rest of the world. According to the OECD, the age-standardised cancer mortality in Sweden is the third-lowest in the EU, at 207 deaths per 100,000 people, compared to an EU average of 235.[2] If other countries in Europe achieved the same survival rates as Sweden, around 200,000 deaths could be avoided every year in the EU, a potential highlighted in a report by the Swedish Institute for Health Economics (IHE).[3] Survival rates in Sweden are the highest in the Nordic Region for several cancers, such as prostate and breast cancer.[4]

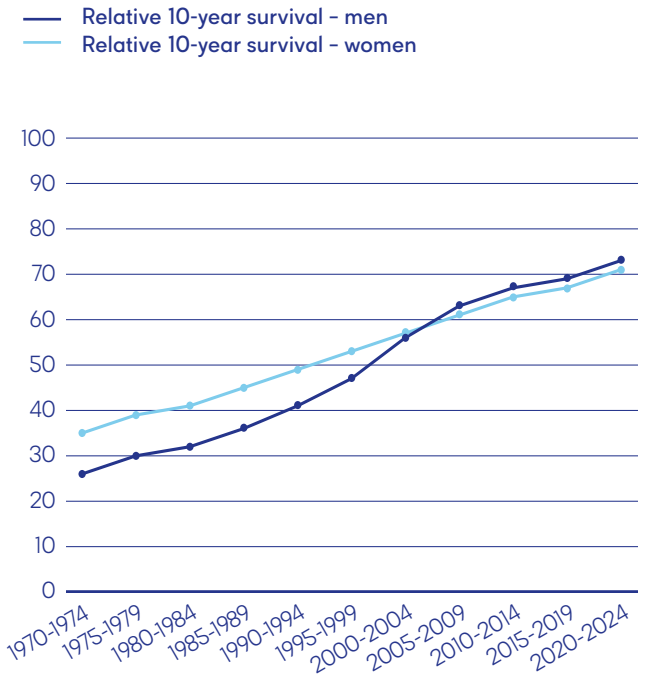
** The figure quoted is an estimate of the difference between cancer death rates continuing to decline at the same rate as in the last 15 years and remaining at the current level until 2030, based on Statistics Sweden's population projections and the National Board of Health and Welfare's mortality statistics.

Anything is possible – if research is prioritised

For several diagnoses we have come a long way, but for others it is more difficult to see research advances, and it is clear that we still have a long way to go to beat cancer.



Steady increase in survival



Examples of important breakthroughs since 1950

1950s

An important breakthrough in knowledge was that researchers were able to link tobacco smoking to cancer for the first time.

In 1951, Ebba Andersson and Morri Nidén founded the Swedish Cancer Society.

1960s

Screening for cervical cancer is introduced in Sweden in stages between 1966 and 1977.

1970s

New chemotherapy medicines are developed that, combined with radiotherapy, provide more effective cancer treatment. In breast cancer, the first hormonal therapy medicine, tamoxifen, starts to be used, as well as breast-conserving surgery. A large amount of research at this time also focuses on what are known as oncogenes, genes that can turn healthy cells into cancer cells.

1980s

A range of techniques are developed to analyse the genome. As early as the 1970s, the Swedish healthcare system introduced mammography to enable breast tumours to be detected early. In the 1980s, the National Board of Health and Welfare issues general advice on regular mammography screening.

From an international perspective, Sweden also stands out in a positive sense in terms of gender equality. The difference in cancer death rates between women and men is the lowest in the EU. At the same time, there are clear socio-economic differences.

Sweden's strengths lie in a well-developed public healthcare system, preventive measures, health data and quality registries and many years of experience with national screening programmes. Participation in organised screening programmes in Sweden is high, with the result that death rates for several major cancers are falling faster than the EU average. At the same time, there are challenges regarding waiting times and unequal participation in the various screening programmes, both regionally and between demographic groups. The OECD also highlights other weaknesses, including in the field of radiotherapy, where Sweden lags behind many comparable countries, and identifies regional differences in access to rehabilitation and palliative care.

The relatively low level of cancer deaths in Sweden means that prevalence, that is to say. the number of people living with or after cancer, is the highest in Europe. This makes greater demands on effective follow-up and rehabilitation to also ensure quality of life after treatment has ended.

Our capabilities have never been greater and are developing rapidly

The options currently available to analyse the origin and development of malignant tumours have fundamentally altered the conditions for cancer research and cancer care. Thanks to scientific and technological advances, the genetic and biological characteristics of tumours can be mapped with high precision. As a result, many cancer diagnoses can now be divided into distinct subgroups with differing prognoses and treatment needs. This has an impact on the prospects of developing new treatments and making customised treatment choices.

Development is highly technology- and data-driven. Large-scale DNA sequencing (analysis of DNA), access to biobank specimens, health data registries and advanced analytical methods make it possible, for example, to link patient information at the molecular level to diagnoses, treatment results and other clinical outcomes. It has laid the foundation for molecular diagnostics and the development of targeted medicines, immunotherapies and cell-based treatments. This has led to better survival rates and treatment outcomes.

Overall, this is driving a paradigm shift from broad, general treatment strategies to more personalised interventions, collectively known as precision medicine. Treatment choices are increasingly based on the molecular profile of the tumour rather than solely on the tissue of origin or stage, placing new demands on diagnostic capacity, infrastructure and healthcare expertise.

In parallel, technology in imaging, radiotherapy and surgery is being rapidly developed. Advanced radiology and pathology enable more precise treatment planning. Liquid biopsies allow for repeated and sparing analyses of tumours during and after treatment. Modern radiotherapy can be customised with high precision, and new surgical techniques reduce complications and recovery time. Together, this contributes to earlier detection and more effective and non-aggressive treatments.

At the same time, the role of patients is changing through greater access to information and involvement, strengthening their ability to participate in decisions concerning their

1990s

Sweden has a strong public health tradition and also unique health data registries. This has laid the foundation for successful population-based cancer research, known as cancer epidemiology, which is now becoming more widely used. In the late 1990s, targeted treatment is developed. Specific antibodies start to be used as treatments for different cancer types.

2000s

The entire human genome has been mapped through the HUGO project. This information can be used to customise treatments.

Girls gain access to a human papillomavirus (HPV) vaccine in 2010.

2010s

Studies show that lifestyle has an impact on cancer risk. Sunbeds are also linked to an increased risk of skin cancer, and in 2018 an age limit of 18 is introduced in Sweden.

Further development of a range of different kinds of immunotherapy, with for example new medicines being approved for lung cancer and skin cancer.

2020s

CAR-T cell therapies are gradually established in clinical practice and are creating new treatment options, particularly for certain difficult-to-treat blood cancers. At the same time, important advances are being made in treatment follow-up, with blood-based analyses enabling earlier detection of relapses and more personalised treatment.

80%
survive a cancer diagnosis.

own care. This strengthens both the quality of care and the relevance of research.

Together, these changes are driving new approaches and more person-centred care. Healthcare will eventually move from standardised flows towards more dynamic and personalised processes integrating biological, clinical and personal factors. This creates great opportunities, but also places increased demands on coordination, infrastructure, skills supply and equitable implementation throughout the healthcare system.

Taking all these factors into account, what this means for patients is better opportunities for early and accurate diagnostics, more effective and personalised treatments, and in the longer term higher survival rates and improved quality of life.

Continued commitment to research is crucial

The breakthroughs that are transforming diagnostics and treatment today are the result of long-term investments in research, often dating back decades. The major steps forward we are seeing the results of today would not have been possible without basic and clinical research. Making the next generation of breakthroughs a reality will therefore require continued and greater investment in research, from basic research in the laboratory to research on patients in the healthcare system.

This is where independent research plays a crucial role. Independent research means researcher-initiated research where the questions are formulated by the researchers themselves based on scientific curiosity, gaps in knowledge and new hypotheses, not on short-term political priorities or immediate commercial targets. This is research that is often driven by a desire to understand different phenomena without the clinical application being clear from the outset.

History shows that many of the most successful treatments today originate in research of this nature. Discoveries in fields such as molecular genetics and cell biology were made long before anyone could foresee the development of immunotherapies, targeted medicines or advanced diagnostic tests. Safeguarding independent research is therefore an investment in future opportunities, even when the benefits are not yet evident.

At the same time, this development is taking place in an increasingly competitive international research landscape.

According to the Swedish Research Council's *Research Barometer 2025*, Sweden is one of the world's most research-intensive countries. Total spending on research and development in 2023 amounted to around SEK 223 billion, equivalent to 3.6 per cent of GDP, placing Sweden among the top three OECD countries. At the same time, the barometer shows that the increase that has taken place is mainly driven by industry. According to the Swedish Research Council, the resources of the higher education sector have been eroded in real terms in recent years, as a result of inflation and unchanged grant levels.

Since 1951, the Swedish Cancer Society has invested more than SEK 18 billion in Swedish cancer research and is the largest single non-governmental funding body in the field today. Research funding is based on open calls for proposals, peer review and a long-term approach. It covers the whole spectrum of cancer research, from basic research to clinical and point-of-care research, and aims to create the best possible conditions for new breakthroughs.

At a time when scientific understanding is advancing rapidly and global competition for skills, investment and research infrastructure is intensifying, there are strict demands for

stability and a long-term approach. For Sweden to continue to be a leading research nation in the future, stable and predictable funding, clear national priorities and favourable conditions for researchers to work and develop in are required. This is a responsibility shared between central government, regions, higher education institutions, funding bodies and industry.

What is just around the corner

Rapid development in the field of cancer means that we can expect new methods, treatments and approaches to have a major impact on cancer survival and quality of life in the near future if they are implemented in healthcare.

In the area of treatment, the development of targeted therapies and immunotherapy medicines is continuing at a high pace and is expected to enable more cancers to be treated more effectively and with fewer side effects for the individual. At the same time, intensive research is underway on cancer vaccines that aim to strengthen the body's own immune response to tumours and could eventually transform the treatment options for several diagnoses.

Equally rapid development is taking place in the area of diagnosis. Liquid biopsies, where small amounts of DNA fragments from tumours can be analysed through blood tests, allow for earlier detection, closer follow-up and more dynamic adaptation of treatment over time. Combined with advanced imaging and molecular pathology, this creates the conditions necessary to identify cancer at earlier stages, when treatment is often more effective and successful.

Screening is another area with great potential. With new biomarkers, genetic risk profiling and AI-based image analysis, future screening can be both more accurate and more personalised. This provides opportunities to detect cancer earlier in those at greatest risk, while reducing unnecessary tests for others. For several major cancers, such as breast and lung cancer, developments are already under way that may lead to expanded or entirely new national screening programmes.

In parallel, we are gaining a deeper understanding of how cancer arises, develops and interacts with its biological environment. Research on the microenvironment of tumours, the role of the immune system, lifestyle factors and co-morbidity is contributing to a more cohesive picture of the disease. This increased understanding of disease lays the foundation for more effective combinations of prevention, early detection and treatment.

Taken together, this means that we are facing a period where several lines of development converge: better biological understanding, more powerful diagnostics and more precise treatments. It is at the point where these areas intersect that the major improvements in survival are expected to occur in the coming years. The challenge will be to ensure that these advances benefit all individuals quickly, equitably and systematically.

Without long-term investment in independent academic research, we risk undermining our ability to achieve new breakthroughs, with direct consequences for future patients and societal development.

Malin Sund, Chair of the Swedish Cancer Society's Research Committee

The pace of implementation needs to increase

The ability to transfer research findings to clinical practice is crucial for patient benefit, quality of healthcare and its long-term development capability. When new findings, methods and treatments are delayed in the transition from research to care, this has direct consequences for individuals living with or at risk of developing cancer.

Unnecessarily slow implementation can mean, among other things:

- Delayed access to early detection methods, which can lead to cancer being diagnosed at later stages, with a poorer prognosis and lower survival.
- Delayed access to new treatments, which may mean that patients miss out on therapies with better efficacy or fewer side effects.

A slow pace of implementation can also lead to unnecessarily high societal costs, for example, in terms of diagnostics and early detection. Identifying cancer at an early stage increases the chances of effective treatment and cure, also leading to a lower burden on healthcare systems.

At the same time, implementation capacity affects the entire research and innovation system. Countries and regions that can rapidly deploy new solutions become more attractive for clinical studies, investments and international collaborations. This strengthens innovation and makes it easier to attract researchers, healthcare staff and businesses wishing to work in a setting where new knowledge actually has an impact. In the long run, this will improve both scientific excellence and the quality of care, to the direct benefit of patients.

Also central to the introduction of new methods and treatments, however, is the systematic phasing-out of methods and treatments that lack evidence or the benefits of which are no longer proportionate to the costs and risks. Initiatives such as *Kloka kliniska val (Wise clinical choices)* show that there is significant potential to free up resources by phasing out actions that persist mainly for historical reasons despite a lack of evidence or questionable efficacy. This is essential in creating scope for new, more effective solutions.

Long and winding road to patient benefit

The path from scientific breakthrough to practical patient benefit is often long and complex. In practice, this means that it can take ten to fifteen years, sometimes longer, from a scientific breakthrough to broad clinical use.

The process from research to clinical implementation involves many stakeholders, and each step plays an important role in ensuring quality, safety and equitable access at a cost that society can sustain. At the same time, this means that the journey is often long and difficult to overview, with the risk of unnecessary waiting times that ultimately risk affecting patients.

Scientifically published results need to be reproduced, further developed and validated through continued studies.

Medical devices and medicinal products also need to go through regulatory and health economic processes before they can be used in routine care and included in care programmes and standardised care pathways.

In the case of medicines, health economic assessments are at the core of decisions on whether to introduce new treatments into publicly funded healthcare. The aim is to ensure that healthcare resources are used responsibly, taking into account survival, quality of life and severity of disease. At the same time, these assessment processes currently clearly delay the introduction of new cancer medicines in Sweden.

Time spent on administrative procedures for evaluating the health economics of new cancer medicines more than doubled between 2020 and 2024. This is partly because the evaluations have become more complex and the number of cases has increased, while capacity and ways of working have not kept pace with the rate of innovation in the field of cancer.[5]

In addition, infrastructure and expertise need to be built up in healthcare before new methods can be fully utilised. This may signify investments in laboratory capacity, advanced imaging diagnostics, digital data management systems and secure health data sharing solutions. New diagnostic tests or treatments often require specialised training for doctors, nurses and other healthcare staff, as well as the development of new procedures for taking samples, interpreting results and follow-up. Working methods need to be integrated into existing care processes to work effectively.

Another challenge is the fact that, in Sweden, decisions on the introduction of new treatments, diagnostic methods

and technical solutions are often taken at national level, while financial decisions, implementation and follow-up take place at regional level. This makes it difficult to ensure that recommended methods are actually implemented, followed up and further developed throughout the country. The result is variation in both pace and scale, with differences in access that cannot always be justified on the basis of patient needs.

A preliminary study under the project *Faster implementation of innovation in Swedish healthcare* (SIISH) shows that a lack of coordination and a lack of clarity in the roles of healthcare organisations, purchasing, legal affairs and suppliers often hinder innovation and implementation. When the dialogue between different stakeholders comes late in the implementation process, joint development and implementation becomes more difficult, even though the need in healthcare is clear.

Time to implementation needs to be reduced where possible

The fact that the development and introduction of new methods takes time is not a problem in itself – it is necessary to ensure that these methods are safe, effective and available at a cost that society can sustain. However, delays in the process due, for example, to cumbersome administration, long processing times, legal uncertainties, difficulties in accessing health data and lack of opportunities and incentives for clinical research need to be addressed.

The Swedish Cancer Society has identified four areas in which we believe Sweden needs to do more and where targeted improvements can have a major impact on the pace of implementation and thus have effects for the individual patient. These are presented in the following sections.

Access to new diagnostics and treatment should not be determined by where in the country someone lives. For patients, equitable implementation is about equity – and about lives.

Eva Backman, Chair of the patient association PALEMA

Four key areas for Sweden

In this chapter, we highlight four areas in which targeted reforms can make a particularly big difference in terms of achieving the 80 per cent cancer survival target by 2030.

1 Clinical studies
– a driver of implementation

Clinical research often bridges the gap between basic research and actual application in healthcare. It is in this part of the research chain that new medicines, treatments, diagnostics and approaches are tested in healthcare and with patients. How well this link works has a direct bearing on treatment outcomes and the potential to continue improving cancer survival.

For patients, participation in clinical studies can provide early access to treatments under development that have not yet received marketing authorisation. This is particularly important when established treatment options are lacking or have been exhausted. In such situations, clinical studies may offer the possibility of a cure or a significantly improved prognosis. Clinical studies are therefore an important part of cancer care throughout the course of the disease, in both the curative and palliative phases. They already have an impact on individual treatment outcomes today, not just on future care at group level.

Furthermore, clinical research helps to develop healthcare capacity. When studies are conducted, expertise, ways of working and infrastructure are built up in the clinical organisation. This strengthens implementation capacity and improves the chances of new treatment options being introduced when they become available. This is essential if medical advances are to have an equitable and systematic impact on healthcare.

Clinical studies also have a strong bearing on society and the wider economy. Good conditions for clinical research are an important part of a strong life science sector and affect Sweden's attractiveness as a research and innovation country. When pharmaceutical and medical device companies choose to conduct their trials in Sweden, opportunities are created for patients and healthcare, but also for investment, jobs and long-term knowledge building. A system for clinical studies that runs smoothly is therefore a strategic resource for both healthcare and Swedish society at large.

To investigate the attitudes of cancer patients towards clinical studies, the Swedish Cancer Society conducted an online survey that was sent to around twenty patient organisations. The results suggest that there is strong interest among patients in participating in clinical studies, but that many are currently not given the opportunity or do not know how to proceed.* Of respondents living with metastatic cancer, around eight out of ten say they have not been asked to participate in a clinical study. At the same time, almost as many in this group respond that they would like to participate if given the opportunity. In addition, around 85 per cent

Proposals on clinical studies

- **Target for Sweden to be ranked in the top 5 in the EU.** Decide on a target for Sweden to rank among the top 5 in the EU in terms of the number of commercial clinical trials per capita.
- **Simplify patient recruitment through direct contact.** Adapt legal frameworks, ensure secure systems and introduce common procedures. These should enable healthcare providers to directly contact patients identified through registries with an enquiry about their interest in participating in a clinical study, if the patient has not actively declined such contact.

* Online survey conducted by the Swedish Cancer Society in February 2026 and distributed through patient organisations. A total of 260 respondents, 143 of whom reported living with metastatic cancer. The respondents represented more than ten different types of cancer and all regions.

of all respondents say they do not know who to turn to to find a clinical study in which to participate.

Current ranking

International comparisons show that Sweden currently ranks in the lower half of several comparable countries in terms of industry-funded clinical trials. Of the 30 countries in the EEA (EU Member States plus Norway, Iceland and Liechtenstein), Sweden ranks 16th in terms of the number of commercial clinical studies per capita, with 0.84 studies per capita (100,000). In contrast, Denmark has the highest rate with 2.00 studies per capita (100,000).[6]

Beyond this ranking, the trend over time shows a clear decline. While the number of commercial clinical studies has declined in all European countries over the past five years, Sweden is among the countries where the decline has been the greatest. Only four countries have experienced a

Quotes from the survey

Taking part in studies would bring hope... I'd rather my doctors tried to find something for me and that my participation could also help others.

Patient with metastatic liver, bile duct or pancreatic cancer who had not been asked to participate in a clinical study.

I wanted to participate in a clinical study but had not been given the opportunity. The doctors kept putting it off, saying we'll have to look at it in a few months, after the summer. After the summer, it was too late.

Patient with metastatic liver, bile duct or pancreatic cancer who had not been asked to participate in a clinical study.

Highly skilled, very pleasant staff. I felt safe as I was being closely monitored and precise blood tests were done to make sure the treatments were right. I felt I could get in touch at any time if there was any reason to.

Patient with metastatic gynaecological cancer who participated in a clinical study of new medicines.

greater decline. In 2023, 88 commercial clinical trials were conducted in Sweden, compared with 138 in 2018, representing an overall decrease of around 36 per cent. This represents an average annual decline of 8.6 per cent over the period 2018-2023. The corresponding average annual rate of change in the EEA was 6 per cent over the same period.

At the same time, a national review by the collaborating Regional Cancer Centres (RCCs) presented in the report *Clinical Studies in Cancer Care* shows that the extent of clinical research varies between regions and hospital types. Almost all organisations in the survey report conducting academic studies, while around 60 per cent also have industry-sponsored studies. Study activity is clearly concentrated in university hospitals, while smaller hospitals have a more limited share of industry-sponsored studies.

Since 2024, the Network of Oncology and Haematology Trial Units of University Hospitals (NASTRO) has been compiling annual statistics on the number of patients in Sweden participating in pharmaceutical studies at their units. In 2024, 648 patients participated in pharmaceutical studies, and the corresponding figure for 2025 is 740 patients. This represents an increase of around 14 per cent. The figures also include patients participating in the studies' control groups.

Sweden can do better

At present, there are major differences in how many cancer patients participate in clinical studies depending on where in Sweden they live. Regions with university hospitals as a rule have more participating patients and a higher proportion of ongoing studies relative to the number of cancer patients. At the same time, there are also significant differences within regions. One explanation is that clinical research is prioritised and organised differently, both between regions and within regions. In some parts of organisations, clinical studies are an integral part of the healthcare mission, while in others they rely heavily on the initiative of individuals.

In order for more clinical studies to be conducted, healthcare professionals need to be given what is actually needed to conduct research as part of the organisation's mission. Today, research is not given sufficient scope in healthcare, while governance and follow-up are inadequate.[7] In addition, healthcare is characterised by high pressure of care, which means that clinical research often takes a back seat to day-to-day patient care. The report *Clinical Studies in Cancer Care* from the RCCs in collaboration shows that only half of staff in cancer care regard research as a prioritised aspect of their work.

One challenge is that many organisations lack sufficient time, resources and organisational support to combine clinical service with research, which means that research grants cannot always be fully utilised. At the same time, the proportion of postdoctoral doctors has been decreasing in Sweden since the early 2000s. This is problematic, as postdoctoral doctors often play a key role in bringing new knowledge into everyday clinical practice. When fewer doctors combine research with working with patients, there is a greater risk that new findings, treatments and approaches will reach the healthcare system at a slower rate.

At the same time, the RCCs show in their report that the development of clinical studies is not clear-cut. Where the study organisation has been strengthened, recurring factors highlighted include a more strategic approach in which research has been given a clear role, access to medical doctors with PhDs and associate professorships, clear objectives that are monitored, and effective procedures in asking patients to participate. Access to research nurses and conversion from a county hospital to a university healthcare centre are also highlighted as important.

I have been diagnosed with both colon cancer and endocrine tumours. I have not been asked about a clinical study but would like to have participated.

Patient with stomach or bowel cancer who had not been asked to participate in a clinical trial.

In general, there is very little information about ongoing clinical studies at doctors' appointments. You have to do your own research and ask questions, as well as participate in gynaecology-related webinars with lectures by senior doctors, senior lecturers or professors.

Patient with metastatic gynaecological cancer who had been asked to but had not participated in a clinical study.

More studies are needed for my rare cancer and I would like to be involved to ensure more treatments are developed.

Patient with metastatic endocrine tumours who had not been asked to participate in a clinical study.

In organisations where the number of studies have instead decreased, lack of staff, time and resources and an increased administrative burden are identified as key reasons. The possibility of including patients in clinical studies also varies geographically. In northern healthcare regions, a significantly higher proportion of patients report that they could not be included due to distance than in metropolitan regions. The patient's place of residence thus has a direct impact on the possibility of participating in clinical studies.

Industry reports decreased interest in conducting clinical studies in Sweden. For pharmaceutical and medical device companies, clinical studies are an integral part of global development programmes, with different countries competing to host research. The choice of study country is based on such factors as when studies commence, the opportunity to recruit patients in sufficient numbers, and implementation capacity.

Against this background, Sweden is currently regarded as less competitive than several comparable countries. The lack of nationally coordinated approaches means that clinical studies often need to be organised separately in each region, with different contact routes, processes and administrative requirements. In addition, the regulatory framework for the use of patient data is felt to be unclear, with varying regional practices. For companies, this leads to longer start-up times, higher costs and increased uncertainty around study implementation.

The picture that emerges is that Sweden has favourable conditions for clinical studies, but that these are not being fully utilised. Differences in organisation, prioritisation and implementation mean that the potential is exploited differently in different parts of the country. At the same time, experience from organisations in which clinical studies work well shows that targeted efforts and clear structures can make a big difference.

This means that there is considerable room for manoeuvre. Under the right conditions, clinical studies can play an even greater role in patient benefit, healthcare development and Sweden's position as a research nation.

The necessary conditions exist

Sweden has internationally recognised universities and a strong academic tradition in medical research. Although the proportion of postdoctoral doctors has decreased over time, there is still a good supply of medical doctors holding PhDs, especially at the university hospitals. In addition, research nurses represent a key and specialised skill set in cancer care, with great significance in the practical implementation of clinical studies. However, access to such nurses varies between different parts of the country. This means that the skills exist, but they need to be utilised and strengthened.

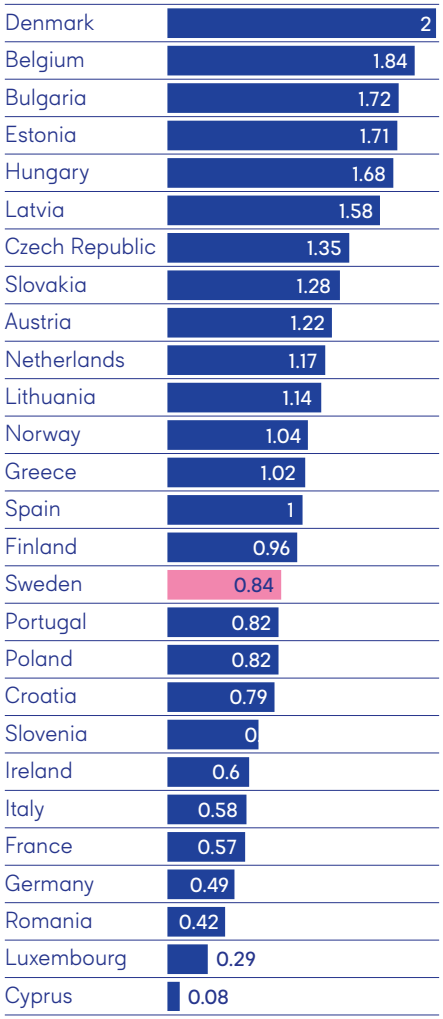
There is also strong interest among patients in Sweden in participating in clinical research, particularly in cancer care. There are established procedures for informing patients and consulting them about their interest in participating in clinical studies, although the extent to which this is done today varies depending on different resources, awareness and approaches. Overall, this means that patient engagement is a key strength, but that its potential needs to be better harnessed to fully contribute to the recruitment, implementation and follow-up of clinical studies in Sweden.

Another strength is the well-developed quality and health data registries that exist in the country. Sweden has around 150 national quality registries used for monitoring, development and research in healthcare. The health data registries that exist in Sweden are a key strength for clinical research and enable registry-based studies, effective follow-up and long-term knowledge building. Internationally, there are few comparable schemes with equivalent coverage and quality.

Furthermore, Sweden has long had digital medical records and administrative systems in healthcare, which is crucial for clinical studies. Access to digital information creates opportunities to identify potential study participants and to integrate clinical studies in ordinary healthcare activities in a way that is not possible in all countries. At the same time, maturity, functionality and use vary between regions and systems, meaning that clear challenges remain in this area. ■

Ranking of clinical trials

Sweden lags behind many comparable countries. Clinical trials per capita (100,000) in 2023.



Source: Clinical Trial Repository (retrieved 30 April 2024) Notice: Liechtenstein, Malta and Iceland are not included in the comparison as data coverage for these countries is limited.

Clinical research makes us better and faster

Gunilla Enblad is a professor and senior physician in oncology at Uppsala University and Uppsala University Hospital. Her work spans the entire chain from patient encounters to research and teaching. The combination is key, she says, particularly for the development of new treatments in cancer care.

“I work with patients, research and teaching. These elements are closely linked and reinforce one another,” she says.

An important part of healthcare

For Gunilla, the value of clinical research is undeniable, both for patients and for healthcare at large. It is not something on the sidelines of healthcare, but is instead essential for the continued development of healthcare.

“It contributes a huge amount. Conducting research in a focus area makes you very skilled in it. Through national and international cooperation, you learn more and stay at the leading edge. It also allows for faster uptake of new treatments and often provides the opportunity to participate in studies of new therapies.”

The ability to access new treatments at an early stage is one of the major benefits of clinical research. When healthcare staff participate in studies, they learn how treatments work in practice, how to manage side effects and which patients benefit most from them.

“The significance is enormous. These studies help us to understand how best to use the new treatments.”

A clear example is the development of CAR-T cells, a form of immunotherapy that has been described as a breakthrough in cancer care.

“CAR-T cells are a new immunotherapy for cancer. You rebuild the patient’s own immune cells, T cells, so that they can attack the cancer by recognising a surface structure on the cancer cells,” Gunilla explains.

In Sweden, this form of treatment is currently used for lymphoma, leukaemia and myeloma, but development is progressing rapidly. Uppsala University and Uppsala University Hospital were the first in Europe to treat patients with CAR-T cells, starting back in 2014. The clinical studies conducted there included patients from all parts of the country and became an important knowledge platform.

“Through the studies, we learnt a lot about how best to use CAR-T cells and how to manage the side effects.”

Knowledge exchange is key

In parallel, national cooperation was built up. Online meetings were held every two weeks to discuss all the patients and share experiences.

“This has played a major role in the subsequent introduction of CAR-T throughout the country. It has also made Sweden suitable to participate in more studies.”

Today, there is also a Swedish-produced CAR-T treatment from Uppsala. Patients from all parts of the country are treated in Uppsala and Stockholm, while the cells are produced at Vecura in Stockholm, a clear example of national collaboration.

“The experience gained in the work on CAR-T cells offers important lessons for the future,” says Gunilla.

“When we introduce a new treatment, the national cooperation has been incredibly valuable. Building regulatory and research expertise in advanced therapies has also been very important.”

At the same time, she is aware of areas for development.

“We ought to simplify the reporting and follow-up of our results, so that we can demonstrate more clearly the results we are achieving. Sweden has great potential to bring together expertise of international importance.”

2 Implementation time
– from approval to actual use

As described earlier in the report, decisions on the approval, funding and introduction of new treatments, technologies and methods involve multiple levels and participants. For medicinal products, regulatory marketing authorisation is done at EU level by the European Medicines Agency (EMA). Such authorisation means that the medicines have been deemed safe and effective and can be sold in the EU. However, this does not mean that patients will have immediate access to the treatment.

In Sweden, EU marketing authorisation is followed by national and regional processes for health economics evaluation, price negotiation and decisions on implementation in routine care. These steps are of key importance to responsible and cost-effective use of resources, and the Swedish Dental and Pharmaceutical Benefits Agency (TLV) plays a crucial role in this work. At the same time, the process means that there can be a significant delay between authorisation and actual use in healthcare. During this period, the treatment is formally available on the market but in practice is unavailable to patients.

An equivalent, and sometimes even more protracted, process can be seen for medical devices and diagnostic methods. CE marking under EU regulations means that the product may be marketed, but introduction into healthcare depends on regional decisions, procurement and budget priorities. For advanced imaging, radiotherapy or molecular diagnostics, introduction may also require investment in infrastructure, skills and changes in working practices. In these cases, introduction may be delayed not only by financial reviews but also by organisational and practical obstacles.

The time lag is also influenced by how well the coordination between national and regional levels works. Differences in priorities, resources and organisational preparedness mean that access varies across the country. Access to modern cancer care is therefore determined not only by regulatory decisions, but by how efficiently the whole system works and how different stakeholders interact. This, in turn, has implications for the development of care, the possibility of earlier detection and access to new treatments – and ultimately for the survival and quality of life of people affected by cancer.

Proposals for increasing the pace of implementation

› **Establish a health innovation index** Mandate the government agency concerned to establish a health innovation index to provide an overview of which new treatments and selected technologies are being used, how quickly they are being adopted and where there may be potential for further initiatives.

Current ranking

Reducing the time gap between authorisation and actual use requires not only efficient processes but also the possibility of measuring and monitoring the speed of uptake of new treatments and technologies in a systematic and comparable way. When the introduction of new innovations is not monitored and made visible, there is a risk of the issue not being prioritised in the governance of healthcare. The lack of combined and transparent implementation metrics therefore means that the pace of implementation is not given the same weight in monitoring and governance as other parts of healthcare.

Today, there is no uniform and comprehensive European review of how quickly new innovations actually reach patients. The closest thing that exists is the summary of access to new medicines by the European Federation of Pharmaceutical Industries and Associations (EFPIA) through its Waiting to Access Innovative Therapies (W.A.I.T.) indicator. This indicator measures the time from EU approval to actual availability at national level.

For medicinal products launched in Sweden, the average time from EU approval to a decision on availability is around one year. For cancer medicines, the lead time is longer, around 448 days on average, placing Sweden behind several comparable countries such as Denmark, Finland and the Netherlands, according to EFPIA's 2024 summary.

However, international comparisons are complex. In some countries, uptake is faster, but often through individual decisions for individual patients rather than group decisions covering all or part of patient groups. Sweden mainly takes decisions at group level, which strengthens equality but can affect how quickly new treatments reach the healthcare system.

A further limitation is that existing rankings only cover medicinal products. There is no

equivalent systematic follow-up for medical devices, diagnostics, radiotherapy or surgical methods. As a result, there is no combined, comprehensive way of measuring how well healthcare systems are putting medical advances into practice. The pace of implementation in these areas can be significant, but is currently difficult to compare between countries and over time.

The lack of broad and common indicators means that the pace of implementation remains largely an indirect or implicit issue in the governance of healthcare.

Creating clear incentives for rapid and equitable access to innovation requires the development of more comprehensive and transparent metrics, encompassing not only regulatory decisions, but actual use in clinical practice. Such metrics could help to improve comparability across countries and regions, strengthen accountability and increase system improvement over time.

Sweden can do better

Experience shows that implementation processes can be influenced. Processing times at government agencies are affected by how cases are prioritised, how early a dialogue is conducted on the design of the documentation and the extent to which resources and working methods are adapted

to the increased complexity. Shortening lead times is therefore not about lowering requirements, but about creating better conditions for informed decisions that can be taken in a reasonable time. At the same time, the time to implementation is affected by the interest of pharmaceutical companies in launching their products on the Swedish market.

Increased focus on implementation studies is also necessary. Even when new treatments or diagnostic methods are assessed as valuable, their introduction into healthcare may be delayed. One reason is that the evidence base is often built on controlled clinical studies, while knowledge of how the methods work in everyday clinical practice is more limited. This may relate to how they fit into existing care flows, what resource requirements they entail or which patients benefit most in practice.

When such knowledge is lacking, uncertainty about use, efficacy and costs increases. This can lead to longer decision-making processes or more restrictive recommendations, which in turn means that patients have to wait for new methods. More systematic work on implementation studies can contribute to faster and more accurate decisions and reduce differences in introduction between regions.

At the same time, the culture and governance of healthcare need to encourage development and implementation to a greater extent. In many organisations, the introduction of new approaches, techniques or methods is still seen as something that happens alongside their core mission. Implementation and innovation consequently compete with ongoing healthcare provision for time, resources and management attention.

When follow-up and reimbursement systems focus primarily on short-term production, there is little incentive to invest in new solutions, even when they can improve quality and patient outcomes in the longer term.

The necessary conditions exist

Sweden already has much of what is needed to monitor the introduction of new treatments and technologies in cancer care. There are extensive registries, national compilations and coordination functions that show which methods are used and to what extent. In the field of medicines, there are established registries and data sources that enable monitoring of use and introduction, including the registry for cancer medicines and regular national compilations from the RCCs. These structures provide a basis for monitoring the uptake of new treatments, although coverage, timeliness and comparability between regions vary.

Infrastructures in precision diagnostics have also been developed. Genomic Medicine Sweden (GMS) compiles and coordinates information on genomic analyses and molecular diagnostics, creating a better overview of the availability and use of advanced precision diagnostics in the country. This provides a basis for national monitoring even in areas that have traditionally been more difficult to measure than use of medicines.

There are also national quality registries, care programmes and knowledge management structures that can help monitor the introduction of new methods in areas such as surgery, radiotherapy and diagnostics. Although these systems are not primarily designed to measure pace of implementation, they provide an important information base for developing more systematic indicators over time.

Sweden has additionally established national processes for reimbursement decisions and recommendations for medicines, as well as structures for national knowledge management. These contribute to a relatively coordinated model for implementation, although regional decisions continue to play a key role. The combination of national decisions and regional implementation provides both opportunities for equitable governance and variation in implementation.

In addition, Swedish cancer care is notable for a high level of medical expertise, strong research links and many years of experience of introducing new treatments and methods. There are established stakeholders in healthcare, academia, government agencies and industry who are fundamentally well placed to contribute to the development, evaluation and implementation of innovations in clinical practice.

Overall, this means that the necessary conditions exist, both organisationally and in terms of data, to develop more comprehensive and comparable metrics for how quickly new innovations are adopted in different parts of Sweden. The challenge therefore lies not primarily in the absence of structures, but in how existing systems can be coordinated and used more strategically to create transparency, incentives and improvement over time. ■

The goal is to make genetic profiling available to all cancer patients

Richard Rosenquist Brandell is Professor of Clinical Genetics at Karolinska Institutet and a senior physician at Karolinska University Hospital. Much of his career has been devoted to developing precision diagnostic methods in healthcare, particularly in cancer genetics. He is also the director of Genomic Medicine Sweden (GMS), a national initiative that brings together the country's seven university hospitals and seven medical faculties in the development of precision medicine, with the aim of more patients receiving the right diagnosis and treatment in time.

National collaboration for the future of healthcare

Genomic Medicine Sweden (GMS) was launched in 2017, with the aim of making advanced genetic diagnostics available throughout the country, a technology that has developed very rapidly over the last 10 years. Today, technology makes it possible to read a person's complete genome in less than 24 hours. The answers can then be used to provide more accurate diagnostics and treatment based on the individual's unique circumstances. By coordinating laboratories, expertise and infrastructure, GMS has built a national structure enabling it to offer the technology to more patients. In cancer, this work has had three distinct tracks: blood cancers, childhood cancers and solid tumours. In both blood cancers and solid tumours, the focus has been on developing national gene panels that analyse hundreds of selected genes, and today there are three such gene panels: two for blood cancers and one for solid tumours.

"We do not examine the entire genome, but focus on genes that are particularly important in cancer and known to be significant for prognosis and treatment. It can help us assess prognosis, determine if there is a targeted treatment and sometimes detect if the cancer is hereditary," Richard explains.

In some areas, such as childhood cancers, a further step has been taken with the introduction of whole genome sequencing. i.e. analysing the entire genome. Since May, all children being treated for cancer have been offered such analysis. The possibility of introducing whole genome sequencing for some other patient groups, such as those with sarcomas and leukaemia, is currently being examined.

"It is likely that in the future there will be more cancers for which we use whole genome analysis."

The goal is equitable access

In order to receive precision treatment, the cancer patient's genome must first be profiled. The possibility of this varies depending on where in the country the patient lives. To enable equitable access to precision diagnostics, GMS has established seven Genomic Medicine Centres at university hospitals. In the national cancer strategy, the National Board of Health and Welfare has also been tasked with developing a five-year implementation programme for more equitable implementation of precision diagnostics across the country. According to the latest inventory, around 25,000 genetic cancer analyses are currently performed per year. This is a substantial increase compared to previous years, and the trend is for steady progress. But there is more to be done.

"There are around 70,000 new cancer cases every year in Sweden. My aim is to make genetic profiling available to all cancer patients, wherever in the country they live. We are not there yet, but I am optimistic that we will get there as the costs of sequencing fall."

New clinical studies to broaden treatment options

Alongside the expansion of diagnostics, more clinical studies in precision medicine are needed. A recent example is the national study FOCU.SE, supported by the Swedish Government. The study will test medicines outside their traditional areas of use – treatments that are normally used for a particular cancer, but which may also work for other tumours. The hope is to be able to offer more patients effective treatment, while gathering valuable knowledge for the future.

3 Health data
– the foundation on which future research and healthcare development are built

Health data is information that describes an individual's health status. It can include data from quality registries, patient records, clinical trial protocols, genetic and biological information from tests, and lifestyle data from apps and other digital tools. Health data is not only used for the care of the individual the data relates to (primary use), but can also be used for other purposes, such as the care of other patients, research and care development (secondary use).

Proposals for increased use of health data

- **Enable secondary use of health data** Adapt national legislation to enable secondary use of health data, both for research and innovation and for the widespread adoption of precision medicine across the country.
- **Support data holders in existing and future regulatory frameworks** Provide guidance and legal support to regions and other data holders to help them navigate the current regulatory framework and the implementation process of EHDS and the national digital infrastructure.

Health data is crucial, for example, for diagnostics, treatment decisions, patient follow-up and care planning decisions, with the information contributing to better prioritisation, resource use and risk management. For research and innovation, health data is an invaluable resource. By analysing data from large groups of patients, researchers can better understand diseases like cancer and develop and evaluate new treatments. For example, health data is a fundamental component of precision medicine. It makes it possible to identify which patients are likely to benefit most from a given treatment based on biological and clinical factors. Providing the right treatment to the right patient at the right time leads to improved care outcomes, reduces the risk of side effects and contributes to more sustainable healthcare systems. All in all, health data is a key driver of medical innovation, improved patient care and a more sustainable and knowledge-driven healthcare system.

Current ranking

International comparisons of countries' development in the field of health data are complex, but indicators from the report on *Further use of health data for care and clinical research* (SOU 2023:76) show that Sweden has relatively good data access compared with other countries. At the same time, the results are less favourable in areas such as interoperability and infrastructure. The inquiry points out that the pace of development in Sweden has been lower than in comparable countries, and that Sweden is at a level that several pioneering countries reached about 7–15 years ago.

One example of a global pioneer in health data is Estonia. As long ago as 2008, a national health data system was established, linking healthcare providers and bringing patient information together in a common, secure platform. Estonia also has a national biobank with over 210,000 participants, which is a key resource for medical research and innovation. In parallel, Estonia has created a clear legal framework for the integration of genomic data from the biobank into healthcare, as part of the introduction of precision medicine. One of the first concrete steps is that women with an increased genetic risk of breast cancer are identified earlier and offered screening up to ten years before the ordinary programme, with the aim of detecting disease at an earlier and more treatable stage. In the longer term, pharmacogenetics will also be integrated to enable more personalised medicine choices and dosages. Overall, Estonia illustrates the great potential of strategic use of health data.

At the same time, this type of interconnected and data-heavy system places very high demands on information security, cyber protection and privacy protection.

Another example is Finland. Finland was the first country in Europe to introduce specific legislation allowing secondary use of health data for research. At the heart of the Finnish system is the Finnish Social and Health Data Permit Authority (Findata), a government agency that acts as a central gateway to data from national registries, the national electronic patient record system, biobanks and university hospitals, among other sources. Each year, Findata receives around 300 applications, which are closely scrutinised. Accepted data is made available via a secure server, and Findata collates, combines and pre-processes the data and provides tools for analysis.

Sweden can do better

Several different laws govern how health data can be shared, including the Patient Data Act, public access to information and secrecy legislation and the General Data Protection Regulation (GDPR). These regulatory frameworks aim to protect the privacy of individuals and ensure that sensitive health data is handled in a legally secure and responsible manner. This is crucial in maintaining the trust of patients in the healthcare system.

At the same time, present-day legal support to enable safe and effective secondary use of health data is perceived to be complex. In relation to data sharing for research and development, this often leads to uncertainty and sometimes restrictions on what data can and cannot be shared. Interpretation of the legislation varies between different data holders (those responsible for storing and managing data, such as government agencies and regions), creating lengthy processes and a lack of clarity. Moreover, there is no national infrastructure to coordinate access to data, which means that those wishing to use data for research and development often have to approach each individual data holder.

The challenges are even greater with regard to data sharing for the care of patients other than the person the data relates to, for example in precision medicine, where information, such as medical history, genetic and biological factors, from many individuals needs to be combined to enable treatments to be personalised. In other words, there is a need to be able to share personal data in a secure way, which is not clearly legislated for today.

In 2024, the European Health Data Space (EHDS) Regulation was adopted with the aim of establishing a common framework for using and sharing health data within the European Union, including for research and innovation. This Regulation will entail new legislation and adaptations to existing regulatory frameworks in Sweden, and extensive preparatory work is under way at the government agencies concerned.

The EHDS has great potential to simplify access to health data through clear definitions of and requirements for data holders and data users, as well as the establishment of a national operator responsible for enabling and managing data access. This function will also maintain a national catalogue that provides a combined overview of available health data.

In parallel, and in line with the EHDS, the Government is investing in a national digital infrastructure for healthcare. Such an infrastructure is essential for gathering and structuring healthcare data, which is an important building block for research and development of future treatment methods. The report *A national digital infrastructure in healthcare* (SOU 2026:6) also shows that some legislative adjustments may be necessary to fully unlock the potential of health data, for example to enable precision medicine.

These processes present significant opportunities for transnational European research and innovation while helping to address many of the challenges faced in Sweden through clearer responsibilities, improved coordination and more appropriate regulatory frameworks. At the same time, there are strict demands on stakeholders to ensure

interoperability, comply with data standards, maintain data protection and privacy, and have trained staff and functioning IT systems. Realising the potential of ongoing initiatives requires implementation processes to be adequately resourced and all stakeholders to work together and be supported in their roles and responsibilities. Sweden's ambition should not only be to implement the EHDS, but to go further and become a pioneer in the area.

The necessary conditions exist

Sweden has many strengths that provide a unique opportunity to raise the level of ambition in the field of health data. The Swedish system of personal identity numbers makes it possible to monitor care and health outcomes over time and to collate knowledge at population level. Our extensive national health data registries, such as the cancer registry, provide a unique foundation for both population studies and precision medicine. The country's high level of digital maturity facilitates the collection, storage and analysis of data in a secure and structured way. In addition, the Forska!Sverige opinion survey shows that a large majority of the population (84 per cent in 2025) are in favour of their health data being used for research purposes, which provides strong societal support. ■

Using data that already exists to improve care, strengthen research and save lives

Mats Nilsson, chair of the inquiry to enable a national health data infrastructure. How will Sweden adapt its laws and organisation to the new EU legislation on health data? And what might this mean for research, innovation and ultimately patient survival? Mats Nilsson, has a key role in providing answers to these questions.

Preparing Sweden for new European legislation

Mats Nilsson is a lawyer by profession and has spent most of his professional life working on healthcare issues at the Ministry of Health and Social Affairs and related government agencies. He was involved in the development of the first national cancer strategy. He currently chairs a government inquiry on a national digital health data infrastructure. Alongside this role, Mats is also the deputy director general of Forte, one of the government research councils.

"I am the chair of the inquiry on national digital health data infrastructure. We are analysing how Swedish legislation needs to be adapted to the EU's new Regulation on a European Health Data Space (EHDS) and are developing proposals for new or amended laws," says Mats. The inquiry began in early 2024 and is due to present its final report on 30 November 2026. In the meantime, several interim reports have been issued.

"Our second interim report dealt with what is known as the secondary use of health data and how responsibility should be shared between Swedish government agencies. It led to the Government tasking the National Board of Health and Welfare, Statistics Sweden and the Health and Social Care Inspectorate (IVO) with preparing for their role as health data access bodies under the EHDS. These government agencies are due to submit a final report in June 2026."

What is the EHDS – and why is it important?

The European Health Data Space (EHDS) is a new EU Regulation that aims to make it easier to share and use health data within the European Union, both for the care of individual patients and for purposes such as research, statistics and innovation. A key part of Mats' work is concerned with the latter, also referred to as secondary use.

"The EHDS requires Member States to introduce supplementary national provisions. These include the obligations of data users and holders and the rights of patients," he explains.

This may include, for example, how a person should be informed about what are referred to as significant clinical discoveries, i.e. findings in research data that may have an impact on the individual's health.

"The Regulation requires there to be national rules on how such information is to be provided, either directly to the person or through healthcare staff. At the same time, individuals should have the right to say that they do not wish to be informed."

The inquiry will also analyse how the right of someone to oppose the use of their health data for secondary purposes, known as an opt-out, should be regulated in Swedish law.

Can secondary use save lives?

A question that is often raised is how data collected on one patient can help improve survival for others.

"If large amounts of medical records and registry data can be analysed across national borders, it will be possible to identify more quickly which treatments result in better survival. It is also possible to highlight differences in outcomes between different healthcare providers," says Mats. In practice, this means that experience with patients in one country can benefit patients in another. This can be particularly important in rare diseases, where each country has few cases.

Great potential for research and innovation

Mats sees significant opportunities for Swedish research and healthcare development.

"The EHDS means, among other things, that those responsible for health data, and covered by the rules, must disclose health data collected in healthcare and stored in medical records if someone requests it for secondary use. This does not apply solely at national level – data from all EU countries can be made available within the system."

This provides a better basis for comparative studies between countries and for research on rare diagnoses. It also introduces requirements for data to be made available within three months of an application being approved, and for it to be quality labelled. The National Board of Health and Welfare is already working to improve access to data from health data registries for research purposes and to reduce processing times.

"While it is still difficult to make precise economic calculations, in our first interim report we judge that the EHDS can lead to significant cost savings and contribute to more patient-safe and effective care."

The benefits of secondary use are often more long-term and indirect than those related to the individual patient's care right now. But they can be just as important. Mats mentions two examples:

Better access to data provides a stronger scientific basis for political and administrative decisions in healthcare, and creates the conditions needed for more effective clinical studies. Reusing health data already collected reduces the costs of research and development while allowing for faster and more accurate work.

What can already be done now?

Although the EHDS has not yet been fully implemented, preparations are under way at several levels.

"The work required for Sweden to comply with the EHDS Regulation is extensive. We need a functioning regulatory framework and a clear division of roles between government agencies. It must be clear who is responsible for what," says Mats.

For secondary use, the National Board of Health and Welfare, the Health and Social Care Inspectorate and Statistics Sweden (SCB) already have specific governmental mandates. The eHealth Agency has a key responsibility for the national digital infrastructure, which is crucial for the EHDS to work in practice. At the same time, regions, municipalities, other healthcare providers and data holders need to adapt their organisations, both technically and organisationally. For the healthcare sector, this signifies a major transition, as Tomas Werngren, who was the national coordinator of the national digital infrastructure inquiry, emphasised in his final report.

"Staff need to be aware of the new rights patients will gain and the obligations of the healthcare system. It is important that requirements and timelines are clear well in advance."

For Mats, it is clear that the EHDS is not just about technology and law, but about creating better conditions for knowledge.

"Ultimately it's a matter of using data that already exists to improve care, strengthen research and in the long run save lives."

4 Europe's ability to innovate
– the importance of a strong European ecosystem

The countries of Europe are each relatively small and have limited ability to compete globally. However, together they represent one of the world's largest populations and markets, offering the potential to maintain and strengthen Europe's leading position in life science. In an increasingly global and competitive context, other regions have been overtaken, showing that renewed and coordinated initiatives at EU level are crucial to regain a prominent position. To this end, in 2025 the European Commission adopted a strategy for life science, with the ambition of making the European Union the most attractive location for research, development and innovation by 2030.

A favourable innovation climate is a key requirement for strong and competitive cancer research and the ability to translate this into patient benefit. An ecosystem that works smoothly drives scientific breakthroughs and strengthens the development capacity of both academia and industry. At the same time, it helps patients gain faster access to new treatments, not least through clinical trials and early implementation of innovations in healthcare. Moreover, a strong life sciences industry is an important part of the wider economy, contributing to employment, growth and strategic autonomy.

Proposals for increased European capability

› **Promote greater harmonisation** Ensure that research and innovation are given clear political priority in both Nordic cooperation and the EU, and work to harmonise regulatory frameworks, increase cooperation and reduce administrative burden in the areas of health data sharing, clinical trials, ethical testing, product approval and evaluation.

Current ranking

The innovation gap between the EU and other leading regions, such as the United States and China, is widening. Globally, the number of commercial clinical trials funded by the pharmaceutical industry has increased by 38 per cent over the last ten years. At the same time, the EU's share of these trials has fallen from 22 per cent in 2013 to 12 per cent in 2023, while Asia established itself as a major centre for clinical research over the same period, with China's share of newly initiated trials rising from 8 per cent to 29 per cent.[8] Of the top ten best-selling biologicals in Europe in 2022, only two were launched by EU-based companies.[9] The EU's business climate is not sufficiently favourable to bring new products to market quickly and at scale. As a result, many innovative companies are seeking venture capital and expansion opportunities outside Europe. Around 60 per cent of all global scaleups are located in North America, compared to only 8 per cent in the EU. The EU's share of global venture capital is only 5 per cent, while the corresponding figures for the United States and China are 52 per cent and 40 per cent respectively.[10]

The EU can do better

The EU regulatory framework, together with the 27 national systems, which additionally differ, creates a complex environment for innovators. Rules are not always designed to favour innovation or rapid market access. For example, parallel ethical reviews are often required in each Member State to obtain authorisation to start clinical studies, creating significant administrative burdens. The regulatory authorisation process is also complex, as both European and national government agencies are involved. This increases the administrative burden, lengthens timelines and increases costs. There are several initiatives and proposals to simplify processes, which are welcome steps, but implementation is often difficult. A clear example is the EU's Clinical Trials Regulation, where technical problems and a greater administrative burden have created additional challenges for many stakeholders.

There are major challenges when it comes to enabling seamless cooperation between countries, especially when it comes to sharing and using health data. Despite common data protection rules, these are interpreted differently between and within Member States, generating uncertainty about what is permitted in international data sharing. In addition, differences in data systems, coding and registry formats make it difficult to combine and analyse data across borders. The lack of common standards for data quality makes comparability between countries difficult. The European Health Data Space, mentioned earlier and now being implemented in the Member States, is a response to several of these problems.

Strengthening Europe's innovative capacity also requires increased investment in research and development, both from public funds and private operators. Long-term public funding for universities and research infrastructures generates fundamental knowledge and platforms at national level,

and strengthens independent research. European research programmes act as a driver of cross-border knowledge exchange. At the same time, investment from private operators is crucial to enable research results to be converted into commercial products. Despite this, European start-ups and scale-ups (profitable and fast growing companies) face significant challenges. These include limited access to capital, lower risk appetite on the part of investors compared to other regions, slow uptake of innovations in health systems and untapped potential in public procurement.

The necessary conditions exist

Europe has several strengths and assets to build on, including high quality in academia and education and a strong commitment to academic freedom. There are also several ongoing initiatives and there is political will to promote harmonisation between Member States and take steps towards a true Union with fewer barriers and greater interaction and co-operation. In this respect, it is important that Sweden plays an active role in the policy processes at EU level and pushes for research and innovation in the field of health to remain a high priority.

There is also untapped potential in Nordic cooperation, which could provide a point of departure on a smaller scale. For example, by coordinating and harmonising our national quality registries, the populations can be larger and the data sets more robust, improving the prospects for clinical research and follow-up. Closer cooperation can also stimulate cross-border studies and trials. The Nordic countries have similar health care systems, creating favourable conditions for effective joint initiatives. ■

Europe is favourably placed to re-take the lead

With a background as a medicinal products developer and entrepreneur in oncology, **Jessica Martinsson,** CEO of SwedenBIO, moves between academia, start-ups and global pharmaceutical companies. Her experience in both big pharma and smaller, nimble-footed companies has provided her with a clear picture of Sweden's position in the international life science sector.

"I know what Sweden is good at, but also what works less well in the Swedish ecosystem. This what drove me to take on the role of CEO at SwedenBIO," she says.

SwedenBIO is Sweden's trade organisation for life science companies and brings together around 300 member companies. By creating effective interfaces between industry operators, building knowledge and giving companies a strong voice in public debate, the competitiveness of the Swedish sector will be strengthened.

A key element in this work is to support companies in their internationalisation journey and give them global visibility, while ensuring that experiences and lessons learned are shared within the membership.

"If we at the office don't have the answer to a question, one of our companies almost always does. In our member community there is a unique sense of participation and support."

A strong EU with untapped potential

Europe has significant strengths. It has a strong research and innovation base, world-leading academic environments and a pharmaceutical industry with high exports.

In particular, Jessica Martinsson highlights access to health data as offering huge potential.

"Many countries, especially Sweden, are sitting on a digital gold mine with their health registries. The EU has a huge research opportunity here, but it requires data to be made much more accessible than it is today. There is an opportunity for Sweden to take the lead, but in addition to technological development, this requires political will and structures for responsible and effective use of data."

Cooperation as a competitive tool

In a global competitive environment in which the United States and China are advancing their positions, it is becoming increasingly clear that Europe needs to join forces and cooperate more strategically across national borders.

"The only way to be the best is to work with the best," says Jessica.

"The EU has long had strong support programmes to promote cooperation between industry and academia. But Europe's former leadership role in industry is increasingly being challenged. If the EU is to regain its leading position, it needs a Europe that is prepared to invest more in excellence and sometimes put national interests aside," says Jessica.

"Europe must re-take the lead so that medicinal products and medical devices can be developed, produced and used here. By re-establishing a strong industry, we are also building the economic foundations for world-class healthcare for the citizens of Europe."

Capital and regulatory simplification important for the future

One of the greatest challenges for European companies is access to capital. The global turmoil of recent years has made the funding climate tougher, not least for life science growth companies. According to Jessica, there is an untapped opportunity in Europe's pension capital.

"There is great potential in European pension capital that could help build next-generation companies."

At the same time, she points to the administrative burden as a brake on innovation.

"The EU has, perhaps with good intentions, introduced regulatory frameworks that in practice complicate and delay the development of businesses."

She regards the European life science strategy and proposed regulatory simplifications, such as under the EU Biotech Act, as important steps in the right direction.

"We need to stop putting obstacles in the way of European innovation."

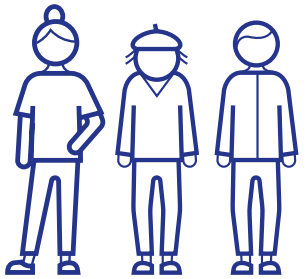
For SwedenBIO CEO Jessica Martinsson, the way forward is clear: "With better coordination, more capital and a simpler regulatory framework, Europe is favourably placed to re-take the lead. If Europe succeeds in this, we will not only strengthen our competitiveness, but also ensure that future medical innovations benefit patients."

The way forward

There is a substantial need for further policy development in the four areas covered in this report, and much is already in progress. In the report, the Swedish Cancer Society highlights a number of proposals judged to be particularly effective. These are mainly aimed at the national level.

These proposals are not exhaustive but represent initiatives that can create better conditions for research and innovation and contribute to shorter implementation times.

1 Clinical studies – a driver of implementation	› Decide on a target for Sweden to rank among the top 5 in the EU in terms of number of commercial clinical trials per capita. › Simplify patient recruitment through direct contact. Adapt legal frameworks, ensure secure systems and introduce common procedures. These should enable healthcare providers to directly contact patients identified through registries with an enquiry about interest in participating in a clinical study, if the patient has not actively declined such contact.
2 Implementation time – from approval to actual use	› Mandate the government agency concerned to establish a health innovation index to provide an overview of which new treatments and selected technologies are being used, how quickly they are being adopted and where there may be potential for further initiatives.
3 Health data – the foundation on which future research and healthcare development are built	› Adapt national legislation to enable secondary use of health data, both for research and innovation and for the widespread adoption of precision medicine across the country. › Provide guidance and legal support to regions and other data holders to help them navigate the current regulatory framework and the implementation process of EHDS and the national digital infrastructure.
4 Europe's innovation capacity – the importance of a strong European ecosystem	› Ensure that research and innovation are given clear political priority in both Nordic cooperation and the EU, and work to harmonise regulatory frameworks, increase cooperation and reduce the administrative burden in the areas of health data sharing, clinical trials, ethical testing, product approval and evaluation.



Currently, there are a number of national initiatives and strategies in Sweden addressing key issues in research, life science, clinical trials and precision medicine, making the division of responsibilities for this work increasingly complex and unclear. These include the updated national cancer strategy, the research bill, the final report of the Healthcare Responsibility Committee and the national strategy for life science. Here, we see a risk of compartmentalisation and lack of cohesion. It therefore needs to be clearer who has coordinating national responsibility for research and life science issues.

At the same time, initiatives are needed at several levels. Regions have a key role to play in enabling clinical research and supporting the implementation of research results, while the day-to-day work of individual healthcare units is crucial in ensuring that these measures are effective for patients and organisations. The 2023 Swedish Cancer Society report, *Clinical research: Everyone's and no-one's responsibility*, analyses in depth what is needed at regional level to make research an integral part of healthcare, and it largely relates to the need for increased political accountability.

The role of the Swedish Cancer Society

The Swedish Cancer Society is a non-profit organisation established in 1951 with the aim of beating cancer. Since we started, we have been one of the most important funders of Swedish cancer research, contributing to breakthroughs in prevention, diagnostics, treatment and rehabilitation.

Our vision is clear: a society in which fewer people get cancer and where more people are cured or are able to live a long life, with good quality of life. Our objective is clear – by 2030, 80 per cent will survive their cancer diagnosis, and everyone living with or after cancer will have the opportunity for good quality of life. At the same time, preventable cancer cases will be reduced by 30 per cent, with one third of all cancers being detected at an earlier stage.

In 2024, the Swedish Cancer Society reached a historic milestone by deciding to distribute a total of SEK 1 billion in research funding in a single year. This also happened in 2025. It is due to public trust and a long-term strategy to strengthen Swedish cancer research. By funding independent academic research, we make a contribution to the next breakthrough.

At the same time, we have taken clearer responsibility to ensure that research results benefit patients faster. In recent years, we have invested heavily in clinical studies to strengthen Sweden's capacity and position in this area, thereby improving patients' early access to new or improved treatments and increasing the country's attractiveness as a research nation. We have also strengthened support for patient-centred care research, research that develops approaches, rehabilitation and care for those living with or after cancer.

We also fund implementation projects in healthcare to prepare for the broad introduction of new diagnostics, for example. And to further reduce the gap between scientific breakthroughs and patient benefit, we are developing initiatives that support the further development of promising research results towards utilisation through commercialisation or direct implementation in healthcare.

The Swedish Cancer Society also actively promotes greater international cooperation and harmonisation. By strengthening Sweden's role in European and other international research and innovation partnerships, we are contributing to more multinational clinical studies, more effective knowledge development and a more coherent European approach to cancer.

As a civil society stakeholder, the Swedish Cancer Society has a special role to play. We are politically independent, which allows us to take a long-term approach, take risks at an early stage and put patients' needs at the centre. We can identify gaps in the system, mobilise resources and act where the need is greatest. By combining research funding, knowledge dissemination, advocacy and cooperation, we contribute to strengthening the entire cancer chain – from preventive initiatives and early detection to advanced treatment and good quality of life after care has been completed.

Beating cancer requires perseverance, cooperation and the courage to invest in both the solutions of today and the breakthroughs of tomorrow. The Swedish Cancer Society accepts its responsibility: for research, for patients and for Sweden to remain at the forefront of the fight against cancer.

The Swedish Cancer Society was founded in 1951 by Ebba Andersson and Morri Nidén. Since then, cancer survival rates have more than doubled. At that time, about three in every ten people survived cancer. Today, more than seven in every ten people in Sweden survive a cancer diagnosis.

The Swedish Cancer Society's four targets for Sweden by 2030

30%
reduction in preventable cancer cases.

1/3
of all cancer detected at an earlier stage.

80%
survive a cancer diagnosis.

100%
of people living with and after a cancer diagnosis enjoying good quality of life.

Annex
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The Swedish Cancer Society's vision is to beat cancer. We are working to ensure that fewer people develop cancer and more people survive cancer by funding cutting-edge research, spreading awareness of cancer and influencing decision-makers on important issues.

The Swedish Cancer Society is an independent, non-profit organisation without government support. Our work relies entirely on bequests and donations from private individuals and companies.

We are one of the largest funders of Swedish cancer research. Since 1951, we have awarded more than SEK 18 billion to the leading research projects in Sweden.
Cancer survival rates have more than doubled over the same period.

Thanks to research advances, seven out of every ten people who develop cancer now survive.
We have come a long way, but we are not there yet.

#togetheragainstcancer

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