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Together against cancer

The Swedish Cancer Society’s goal is to defeat cancer. In order to reach this goal, action is required in several different areas, from the research and development of effective patient-centered medical treatment methods to active preventive work that reduces the risk of people being affected by cancer.

The Swedish Cancer Society also carries out active lobbying of authorities, organizations and policy bodies that make decisions on care, health and research policies. This work is paying off and we have today a much more constructive and forward-looking discussion on the cancer issue than we had just ten years ago. Thanks to medical advances and methods for the early detection of certain types of cancer, more and more patients are surviving cancer, or living longer and with a higher quality of life than before.

But we are not resting on our laurels. There is huge potential for improvement in Swedish healthcare and public health policy.

Thousands of cancer patients are still trapped in medically unjustified care queues. Geographical and socio-economic differences in cancer care do not belong in a modern, democratic society. Every year, tens of thousands of young people take up smoking. Overweight and obesity are on the increase in the population, while more and more people, especially young people, are becoming increasingly sedentary. It is also clear that Swedish cancer research is advancing more slowly than in other comparable countries.

These are just a few examples of issues where the responsibility and solutions to the problems lie elsewhere than in medical research or with medical innovators. The Swedish Cancer Society’s policy program highlights the most serious shortcomings in cancer prevention, care and research, as well as measures that could drive development in the right direction.

Our hope is that those reading this program will be inspired and want to help shape even better cancer care and a society where it will be easier for people to avoid lifestyle habits that increase the risk of cancer.

Together we can defeat cancer.

Ulrika Årehed Kågström
Secretary General
Agenda 2030

The UN Resolution Agenda 2030 proposes 17 global goals that aim to drive changes towards a sustainable society. In 2016 the Swedish government determined that we should be a leader in the implementation of this agenda. The implementation entails a gradual transition of Sweden to a modern and sustainable welfare state, both at home and in the global context. This includes work on prevention, research and care, areas where the Swedish Cancer Society is already working towards a more sustainable development.

Agenda 2030 has been adopted by 193 countries around the world and the Swedish government has drawn up an action plan for how Sweden will contribute to achieving the resolution’s objectives. This gives the Swedish Cancer Society a new opportunity to work towards making these issues more visible when political decisions are made. Through an increased focus on sustainability, we create the conditions for positive development in our own country, while at the same time contributing towards and taking responsibility for positive development globally.

Agenda 2030 widens the focus from survival to enabling people to live sustainable, long and healthy lives, as far as is possible. This fits perfectly with the Swedish Cancer Society’s work for more prioritized cancer prevention, high quality, fair and equal cancer care as well as improved conditions for cancer research.
Antibiotic resistance – a threat to progress

Access to effective antibiotic therapy is crucial for treating cancer patients. Even today, large parts of the world lack access to effective antibiotics and resistant bacteria are becoming more common.

Antibiotic resistance does not recognize land borders, so work must be conducted both nationally and globally.

The Swedish Cancer Society believes that:

- Sweden must work to strengthen international commitment to the antibiotic resistance issue, in order to secure global action for everyone’s right to effective antibiotics.
- We need new long-term scientific collaborations and funding models in order to ensure the development of new antibiotics.
- National support for information to the general public and healthcare professionals regarding the correct use of antibiotics must be strengthened.
- Further national work is required regarding the monitoring of antibiotic use.

Antibiotics play a crucial role in the majority of cancer treatments. Whether it’s surgical procedures, cytostatic treatment or stem cell transplants, the availability of antibiotics is crucial to patient survival. Therefore the issue of antibiotic resistance is one of cancer’s major future issues.

Combating antibiotic resistance is primarily about working in parallel in three areas at the same time:
- Developing new effective antibiotics that are used restrictively
- Ensuring proper antibiotic use
- Reducing the spread of already resistant bacteria

By working for the proper use of antibiotics and effective hygiene routines in healthcare, Sweden, unlike large parts of the rest of the world, is in a better position to be able to slow down what is happening. These are efforts that must continue and it is therefore vital that healthcare receives national support to work on these issues. We also need to know more about how prescription and usage differ across the country, so that resources can be properly allocated.

One major problem is that new antibiotics are not being developed at the required rate. There are several reasons for this, of course, not least the major scientific challenges associated with developing antibiotics to combat the most multi-resistant bacteria. There are also challenges in the major efforts required to research new products that can benefit patients, while at the same time the final product must be used to the minimum extent possible, so as to reduce the risk of resistance developing. Therefore, new funding models are needed to ensure that new antibiotics are developed.

Swedish healthcare’s ability to continue to have access to effective antibiotics depends largely on how the world in general manages to slow down the development of resistant bacteria and develop new antibiotics. Sweden must therefore strengthen its already large international commitment to the question of antibiotic resistance. It requires a broad approach that also needs to address, for example, the use of antibiotics in animal farming as well as emissions in manufacturing. Clear global leadership is needed to coordinate and control this work and development.
Our policy programme

Cancer research saves lives

Advances in research are leading to new capabilities in the prevention, diagnosis and treatment of cancer. This has led partly to more people surviving cancer and partly to more people living longer and with improved quality of life.

But innovative research and development cannot be produced to order. It grows out of the researchers’, technicians’ and clinicians’ own drive and curiosity. The role of politicians is to create favorable conditions through, for example, education, clear career paths, funding of projects and creating the right conditions for start-up and developing companies.

Productive medical research and development requires close collaboration between financiers, academia, business, healthcare and patients. The conditions for this collaboration are largely determined by research policy, but also by the way in which healthcare is organized.

A positive business climate is hugely important for the development of cancer care. New treatment methods reach patients faster if there is proximity to the companies that develop them. A strong presence of international companies also increases the opportunities for cancer patients in Sweden to participate in clinical trials with new medicines.

Unfortunately, the last decade has seen Swedish research stagnate. In the 1960s Swedish cancer research was at the forefront and since then it has been in the top-20 list of the world’s leading countries. But in the last decade there has been a clear trend: Sweden’s research is not developing as fast as other, comparable countries. Cancer research has also suffered from this decline.

This is deeply disturbing. There is a clear link between a country’s medical research and the care it can offer patients. When ambitious research activity is integrated with healthcare, patients gain faster access to new diagnostic techniques as well as new treatment methods, care services and medicines. The collaboration has a positive effect on all parts of the care chain, and makes an enormous difference for patients.

Research ethics

Confidence in Swedish research is high among the Swedish population. The fact that research has broad support is important not only for results but also
because it creates willingness to participate in studies and gives insights into the value of priorities. In recent years a great deal of work has been done to make absolutely sure that misconduct does not occur.

The Swedish Cancer Society believes that:

- Clearer regulations must be formulated and implemented to promote good practice and to reinforce methods for dealing with misconduct.

In recent years the media spotlight has been cast on various types of abuse in the research world - everything from cronyism and carelessness to data manipulation and research fraud. These are key issues that need to be monitored closely, because dishonesty must never be tolerated. The rules must be clear and processes must be legal. Not least, researchers must be given all relevant knowledge and support, and universities must take full responsibility for teaching the current regulations. The principle “it must be easy to do the right thing” must be fundamental.

Fortunately, intensive work has been undertaken to improve routines to detect, investigate and prosecute dishonesty more effectively. The New order inquiry to promote good practice and deal with dishonesty in research (SOU 2017:10) proposes clearer laws and the establishment of an independent review structure. These proposals now need to be implemented, with a clear focus on simplifying and clarifying the regulations.

Research conditions

The state must take greater responsibility for the funding of medical research in general and cancer research in particular. This will create both short-term and long-term gains. The majority of research funding should be distributed via national competition. Moreover, the research infrastructure, such as IT support, data storage and biobanks, should be so well coordinated and receive such ample funding that it never constitutes a limitation or source of problems. Sweden must be proactive in increasing Swedish participation in major international collaborative projects, such as the EU framework program.

The Swedish Cancer Society believes that:

- The government must strengthen core funding to universities for research.
- Grants for research distributed via national competition through research councils should be gradually extended.
- The infrastructure for research and research collaboration should be greatly strengthened.
- The proportion of ALF funds distributed in national competition should increase.
- Sweden should broaden its research collaborations both nationally and internationally.
Basic medical research, based on curiosity and empiricism, lies at the heart of all knowledge expansion within health care, but it is rarely profitable in a strictly economic sense. A breakthrough in, for example, tumor biology can cause a considerable stir, but it does not automatically lead to a product that cures patients or to the funding of new research. Commercial players prefer to focus their attention on selected, partially refined, ideas that have already advanced a few steps along the path from laboratory bench to cancer clinic.

Since curiosity-based primary research often receives no funding from the market, responsibility falls instead on the public, and thus in practice on politicians. Sweden needs an aggressive and powerful research policy that guarantees the funding of high quality primary research. Continued large investments and increased funding are necessary. As far as possible, distribution should be via national competition - this also applies to ALF funds.

In parallel with project-based support of research, a massive investment must be made in research infrastructure. This includes IT support in the form of networks, storage capacity, artificial intelligence platforms, patient databases, quality registers as well as blood and tissue banks. This development of infrastructure must also promote collaboration between universities, healthcare, authorities, patients and industry. Naturally accessibility, security and integrity must be ensured not only from a technical perspective, but also in regard to ethics and the law.

The state must take greater responsibility for the funding of medical research in general and cancer research in particular.

Research within healthcare

Healthcare must evolve from today’s healthcare provision apparatus to become a fully fledged knowledge organization, which not only applies new knowledge but also creates it. Clinical research and continuous skills development, integrated into day-to-day operations, are crucial if Swedish healthcare is not to fall behind from an international perspective.

The Swedish Cancer Society believes that:
• The regions must take positive action based on research strategies, and the regions’ own budgets for research must increase.
• Healthcare providers’ mandate for healthcare must include research requirements with clear objectives to be followed up.
• The aim should be that every cancer patient is included in a research study, unless they have opted out.
• Opportunities for healthcare professionals to combine clinical activities and research should be improved, for example through research posts and improved career opportunities and employment conditions.
• The infrastructure to promote clinical research must be strengthened, amongst other things through investment in IT support and biobanks.
• The establishment of accredited Comprehensive Cancer Centers and Clinical Cancer Centers at Sweden’s university hospitals must be supported nationally and regionally.
• The Government, through clear assignments, must raise the level of Swedish participation in European supported research programs.
• Democratization of research must be supported by both the authorities and other public bodies - so that citizens become involved in research and innovation and research results are made available.
• Central government and regions must together intensify the work to remove the obstacles that arise in clinical studies as a result of their divided dual responsibility.

The development of cancer care in the coming decades will be guided by a number of trends, the most important of which are the explosion of knowledge in molecular and cell biology, the digital revolution...
and efforts to reduce healthcare costs. Tailor-made treatment based on advanced diagnostics, brand new research findings and real-time data from journals and quality registers will become more common. To achieve full impact, data from large patient groups is needed. International cooperation, not least at European level, will need to be expanded rapidly. Healthcare measures and processes will be continuously analyzed for governance, knowledge acquisition and evaluations. Staff will rely on system-based knowledge provision, such as expert systems based on artificial intelligence.

In this environment, clinical research will be not only an advantage but a necessity in the form of drug testing, healthcare research, studies of surgical methods, new diagnostics and other forms of treatment. Operations must be centered around what we can call “the research clinic”. This means that all healthcare personnel participate in clinical research projects at regular intervals.

In order to attract more clinicians to research, there must be a clear career path and a long-term allocation of resources and responsibilities. This means that access to services, eligibility rules and terms of employment must be reviewed at universities and clinics. More research posts for clinically active doctors and other healthcare professionals will have to be established.

Healthcare business managers should have their own research expertise, as they play an important role in recruiting and supporting research staff and initiating research projects. They should see clinical research as a natural part of budgeting and scheduling at their clinics. Clinical research must also be a part of relevant procurement in healthcare. It is extremely important that the quality of clinical postgraduate education is strengthened and that there is an increased focus on research in undergraduate programs too.

One factor driving the development of clinical operations, research and international collaboration is accredited Comprehensive Cancer Centers and Clinical Cancer Centers, something that has already been established in our neighboring countries Finland, Norway and Denmark. Accreditation or quality assurance in line with the European model (OECI) is a process whereby competence, routines and methods are evaluated so that quality requirements are met according to OECI standards. Happily, accreditation initiatives are already under way in Sweden and should be promoted at both national and regional levels. A first goal must be that all Swedish university hospitals undergo an accreditation process with the aim of providing patients with good and equal care as well as access to clinical studies. These centers also open new doors to European cooperation, where cancer patients in Sweden can be included in large, high-quality studies. Investing in Cancer Centers will mean not only that Sweden sets clear standards and continuously compares itself with the best cancer clinics in Europe. It will also open new doors to international cooperation, where cancer patients in Sweden can be increasingly included in large, high-quality studies. Sweden needs to increase its ambition and commitment to research collaborations outside its borders, not least with regard to the EU framework programs. Research programs such as Horizon 2020 and Innovative Medicines Initiatives (IMI) have allocated enormous resources for strategic research. Work is now under way on the next generation of the EU framework programs and here Sweden must take a strong position, both in terms of participation and influence.

A strong international trend is the democratization of research. The aim is partly to strengthen the direct power and status of citizens when it comes to which research areas are prioritized, and partly to mobilize and involve citizens in research and innovation. It is also about making research results and data more accessible and implementing them faster so that the results can benefit everyone. In the cancer field, this can be achieved in several parallel ways. One example is helping patient associations strengthen their interaction with research, healthcare and society as a whole. Another example is to create stable high-quality conditions for crowdfunding and so-called citizen science. But perhaps the most obvious way is to work from an ambitious vision regarding the number of cancer patients and their relatives who are given the opportunity to participate in clinical research projects.

The goal must be that all cancer patients are included in some form of research study, unless they have opted out. This might include intervention studies, observational studies, diagnostic studies and qualitative studies.

The conditions for clinical research are today determined by both central government and the
Our policy programme

regions, where central government is responsible for the universities and the regions are responsible for health care. Because these two parties have different aims and management structures, a conflict of interest arises. The regions’ main priority is uninterrupted healthcare provision and a balanced budget. The universities, for their part, are often completely dependent on the healthcare system for their clinical research activities.

The result is that this dual responsibility is not particularly fruitful or effective, either from the research or the care perspective. It does not promote the symbiosis needed to drive both care and research forward. To find ways in which this cooperation can function should be a priority for politicians and civil servants in both central government and the regions. They must make strenuous efforts to work together to highlight the obstacles, and to prioritize a functioning effective collaboration.

The regions need to strengthen investment in research, for example by allocating a larger part of their budget for this purpose. There must be clear knowledge objectives for regions and hospital managements. Not least, the regions have an important role to play when it concerns research that is linked directly to monitoring and quality assurance of activities in the healthcare sector, as well as for competence-enhancing projects. Such investments can, for example, lead to better diagnostics, more efficient drug use and fewer unnecessary interventions. Working with clear objectives and monitoring within the framework of the regions’ research strategies leads to greater clarity regarding both the work itself and the priorities and gains that are made.

Life science

Sweden has a long and positive history of collaboration between companies, academia and healthcare. But in the current climate of strong international competition, it is not possible to survive on past achievements. Increased resources and clear incentives are needed to develop these collaborations further.

The Swedish Cancer Society believes that:

- The Government must strengthen the conditions for collaboration in research and innovation within the Life Sciences.
- A Life Science strategy with clear goals must be determined and monitored regularly.
- The funding for research collaborations between academia, healthcare and business must increase.

A positive business climate for the pharmaceutical, medical technology, diagnostics, support products, healthcare services and app industries is of great value for the development of cancer care. Without these companies’ expertise and infrastructure in the areas of research, preparation, clinical trials, product testing, production, distribution and support, many treatment concepts would never see the light of day. Not least, it is vital for Sweden that the international Life Science industry has a strong presence. New methods reach patients more quickly if the companies that develop them are located nearby. Their presence also increases the possibility for cancer patients in Sweden to participate in clinical studies and so be treated with the very latest methods.

In order for Sweden to stand strong in the face of increasingly fierce international competition, work on a national Life Science strategy must be intensified. The strategy needs clear goals and a strong focus on international cooperation. The strategy should also be monitored regularly to ensure that the desired results are being achieved. This also requires clearer incentives and increased funding, including for exploratory projects at an early stage of development.
The Swedish Cancer Society believes that opportunities for healthcare professionals to combine clinical activities and research must be improved.
Cancer prevention reduces cancer risk

Working with prevention is one of society’s most important tasks in the fight to reduce the number of cancer cases. At least a third of all cancer cases could be avoided with preventive measures. Prevention work must be prioritized, to reduce the number of sufferers.

The Swedish Cancer Society believes that:
- We need a national action plan for healthy lifestyles.
- Work on the National Board of Health and Welfare’s national guidelines for the prevention and treatment of unhealthy lifestyles needs to be intensified.

Morbidity is on the increase in Sweden and one explanation is an aging population. Another more worrying explanation is the increase in non-communicable diseases such as cardiovascular disease, diabetes, chronic lung disease and - not least - cancer. In Sweden, these diseases account for 90 percent of all deaths. The diseases have one thing in common, other than being non-communicable: they are largely a consequence of our lifestyle habits such as smoking, alcohol consumption, unhealthy eating habits and insufficient physical activity.

Society’s costs for morbidity are rising. It is estimated that cancer diseases alone will cost society up to SEK 70 billion per year within a couple of decades. At the same time, we know that at least one-third of all cancers could be avoided with preventive measures. More effective and active work for healthier lifestyles would, above all, reduce individuals’ suffering, but also save society huge amounts of money. Despite this, there are major shortcomings in preventive work.

The report How do we create a patient shortage? published in 2015 by the consultancy and audit firm EY, makes it clear that central government, county councils and municipalities together spend SEK 1,400 billion per year mainly in four areas that in one way or another can be linked to public health. But only 1 percent (SEK 14 billion) is allocated to measures aimed at improving individuals’ health behavior, i.e. concrete preventive initiatives such as information and awareness campaigns, counseling, legislation, research, and so on. Monitoring of the national guidelines for
prevention and treatment in unhealthy lifestyles also points in the same direction. Only between 1 and 5 percent of primary care patients have received some form of counseling or advice for better living.

Today there are a number of bodies responsible for preventive work, including Socialstyrelsen (the National Board of Health and Welfare), Folkhälsomyndigheten (the Public Health Authority), Strålskyddsmyndigheten (the Radiation Protection Authority) and Länsstyrelserna (the Regional Administrative Boards). The municipalities and regions are other bodies expected to carry out preventive and public health promotion work, both on their own and through the cooperative organization SKL (Sweden’s municipalities and county councils). But there is no national coordinated action plan with clear guidelines, concrete goals and a consensus on the priorities needed to give citizens the tools for healthier living.

Successful prevention is based on an interaction between efforts at the individual level and overarching measures at the community level. Society bears the responsibility for creating supportive environments that enable healthy lifestyles. An effective prevention policy is based on a combination of efforts that we know, through our experience and research, work well. Policies in the form of taxes, awareness campaigns and marketing regulations are among the effective initiatives that are needed for a successful prevention policy.

Each and every individual can shape their own lifestyle but, if the trend of rising numbers of cancer cases is to be seriously reversed, a powerful and effective prevention policy is needed.

**Tobacco**

Tobacco smoking is the major preventable cause of cancer. In Sweden 5,200 people die annually from cancer as a result of smoking. But other types of tobacco or tobacco-like products also have a negative impact on public health. Not least new products such as e-cigarettes which, in addition to being harmful in themselves, attract young people to start smoking.

The Swedish Cancer Society believes that Swedish tobacco policy - as a minimum - should match the World Health Organization WHO’s demands in the Framework Convention on Tobacco Control and that a realistic plan should be drawn up with the aim of phasing out tobacco smoking from people’s lives.

### The Swedish Cancer Society believes that:

- A concrete action plan for a smoke-free Sweden 2025, with well-defined intermediate targets, must be developed.
- Regular and significant increases in tobacco tax must be implemented.
- The design of tobacco packaging must be neutral and without logos.
- A ban on exposure must be introduced - tobacco packaging should not be visible in stores.
- The regulation of e-cigarettes should be in line with legislation on cigarettes and apply to e-cigarettes both with and without nicotine.
Smoking

Although there has been a reduction in smoking over the past 40 years, every year tens of thousands of young people are attracted to start smoking. Many of them continue into adulthood, exposing themselves to an extremely high risk of suffering from lung cancer and other smoking-related illnesses. Knowledge about smoking’s harmful effects is conclusive, but still almost one in ten adults in Sweden smokes regularly.

High taxes on tobacco are a proven and effective social measure for the reduction of smoking. According to WHO's calculations, a 10 percent tax increase leads to a reduction of smoking by almost 5 percent. Compared with other countries the price of tobacco in Sweden is low - the lowest in the Nordic countries and lower than in both Germany and the UK.

The tobacco industry’s marketing channels are limited. But they still have access to both visible and effective channels, namely the products’ packaging and outlets such as grocery stores, gas stations and other stores where tobacco is sold. Consistent research shows that young people exposed to in-store marketing are at high risk of being attracted to smoking. Habitual smokers are also affected so that they, for example, smoke more or find it harder to quit. Introducing legislation, as several countries have already done, that forces stores to move packaging under the counter or to closed cabinets has proven effective in restricting the recruitment of young smokers. Neutrally designed packaging, without logos and attractive colors, has also proven to be an effective method of reducing the attraction of smoking.

The fact that Sweden supports Smoke-free Sweden 2025 is positive, but it must also be supplemented by an action plan where the necessary policy measures are put in place to reach consumption below 5 percent by 2025. It is absolutely vital both for the individual’s welfare and from a public health perspective to reduce and in the long run completely eliminate the use of tobacco products.

E-cigarettes

E-cigarettes are a relatively new phenomenon that is rapidly growing in scale, especially among young people. Legislation on e-cigarettes is unclear and allows marketing on social media, for example. There is little knowledge about the long-term health effects, but studies in both Sweden and other countries show that there is increased likelihood of young people starting to smoke traditional cigarettes if they use e-cigarettes. Figures from the US, where the use of e-cigarettes has risen sharply in recent years, show that the trend towards a reduction in smoking among adolescents has been reversed and is now on the increase. This development goes completely against what is claimed by e-cigarette advocates and marketers.

A reasonable measure would be to equate e-cigarettes with traditional cigarettes in legislation. Such regulation should include marketing, flavorings and age limits and apply to e-cigarettes both with and without nicotine. Today’s differing regulations for cigarettes and e-cigarettes make supervision more difficult and there is a risk that the differentiated marketing regulations make the law unworkable.

The rapid increase in the use of e-cigarettes, combined with a lack of knowledge about the health effects, is worrying. Parallel to legislation in line with other tobacco regulation, more research is needed on both short-term and long-term health effects.

Snuff

Swedish snuff’s impact on health, and its possible link to cancer, has long been debated. On the basis of existing research, it is true that snuff is a less harmful tobacco product than smoking. But it is absolutely safe to say that snuff is not a health product. There are studies that show a clear connection between snuff and, for example, heart and vascular disease.

Research on the link between snuff and cancer is not as clear-cut. There are research studies that indicate a link between snuff and certain forms of cancer, and there are also studies that indicate that there is no link between snuff and cancer. It is therefore essential, through independent research, that we form a clearer picture of the relationship between taking snuff and increased risk of different types of cancer.

It is not possible to leave snuff out of the discussion on tobacco policy, partly because of the health risks it poses, but also because our EU membership demands a coherent tobacco policy.

Other tobacco products

New tobacco products aimed at attracting new users, especially young people, are under constant development. Manufacturers often use the argument that these products are less harmful to health than normal smoking. In several cases, when these claims are examined in more detail, it has been shown either that they are untrue or that the tests are based on
incorrect assumptions about how the products will be used. An example is so-called “Heat not burn” products where the tobacco is heated and vaporized without burning. According to the manufacturers, this minimizes the risk of absorbing harmful substances. An American independent study demonstrates that this is not true.

The launch of waterpipes with candy flavored smoke is another example of attempts to reach a younger target group. Studies show that young people who use waterpipes take up smoking to a greater extent than those who don’t.

Constant vigilance and monitoring of new tobacco products has to be an important part of tobacco preventive work.

Lifestyle

Everyone has the right to shape their own lives and lifestyles through their own decisions. This is fundamental to a democratic society. At the same time, society has a responsibility to provide the conditions for good living and good health in the population.

Research shows clearly which lifestyle habits we should have in order to reduce the risk of cancer, but improving the general health of the population requires measures and efforts from several different bodies.

Diet

Overweight and obesity increase the risk of several types of cancer. More than half of Sweden’s population is overweight or obese today. The proportion has doubled since the 1980s and continues to increase. Healthy eating habits are linked to a reduced cancer risk and are a crucial element in stopping the negative weight trend at the population level. Unhealthy eating habits are one of the main risk factors for ill health and premature death in Sweden. Despite this, there is a lack of substantial national efforts to reverse the trend.

The Swedish Cancer Society believes that:

• Tax on sugary drinks should be introduced.
• Legislation regarding the marketing of food aimed at children must be tightened and adapted to the new media landscape
• Information initiatives to increase public awareness of the link between unhealthy diet and cancer must be implemented.

Contrary to what many may think, Sweden is not a leading country when it comes to healthy eating. Food habit surveys show that many people ingest too much sugar and salt. Too much processed and red meat is eaten, increasing the risk of cancer. At the same time, most people do not have sufficient quantities of healthy foods such as vegetables, fruits, legumes and whole grains on their plates. Unhealthy eating habits, as well as overweight and obesity, vary between different socio-economic groups.

In the Nordic countries Sweden has the largest proportion of citizens with poor eating habits. 15-year-olds in Sweden are above the EU average for overweight and obesity. 17 percent of young people’s total energy intake comes from empty calories such as sweetened drinks, candy and ice cream. Consumption
Unhealthy eating habits are one of the main risk factors for ill health and premature death in Sweden.
of sweetened beverages has quadrupled since the 1960s, especially among younger people, of whom half drink sweetened beverages several times a week. The relationship between sugary drinks and overweight is scientifically clear. According to WHO, tax on sugar-rich beverages, together with subsidies on vegetables and fruit, is an effective way to have a positive impact on public health. The Nordic Nutrition Recommendations and the EAT Lancet’s report also draw the same conclusions.

Taxing and subsidizing food for public health reasons is not entirely straightforward and its effect varies in different parts of the population. However, this is no argument for not doing it, though it requires the measures to be well thought through and not too cautious. Subsidies have the greatest impact in socio-economically strong groups, while tax increases have a greater effect on consumption in weaker groups. In order to even out inequalities in health, initiatives are needed to focus on creating supportive environments for those with the worst health - the socio-economically weak groups. Several countries, in all parts of the world, have introduced or are in the process of introducing tax and subsidy systems. The changes that have been going for a few years have been scientifically evaluated and published in a variety of scientific journals. Taken together, the results indicate that these changes have been effective. It is important now that the government quickly investigates what such a system might look like in Sweden.

Brand awareness begins at a young age and is linked to differences in eating behavior and weight that are already apparent at the age of four. In Sweden, there are special paragraphs in the advertising laws that regulate advertising aimed at children under the age of twelve. But the new media landscape has changed how marketing is both transmitted and consumed. In order to ensure that we create the right conditions for young people to have healthy eating habits, today’s legislation needs to be both modernized and tightened.

Public knowledge about the link between cancer, obesity and unhealthy food is poor and needs to improve. To change norms and behaviors takes time and requires knowledge, continuous reminders and individual support. Repeating the same message at regular intervals, but in a variety of different ways, increases the chance of achieving lasting change. Here, a great responsibility lies with the authorities whose job it is to ensure a real improvement in public health.

Physical activity
The link between physical inactivity and an increased risk of cancer is scientifically proven. Modern society, with less physically strenuous work and more sedentary leisure, is a danger to public health. Obesity and overweight are major contributing causes and risk factors for many cancer diagnoses. Physical activity is vital in stopping weight gain at the population level and also has an effect on the individual’s ability to reduce his or her cancer risk.

WHO’s Global Action Plan on Physical Activity has developed a framework with four areas that are identified as effective for increased physical activity: creating active communities, active environments, active individuals and active systems.

The Swedish Cancer Society believes that:

• Initiatives must be taken to increase public awareness of the relationship between physical inactivity and cancer.
• At least 60 minutes of exercise every day should become the norm at school, in addition to sports and health education.
• Social planning should promote increased lifelong physical activity for everyone.

New figures show that fitness has deteriorated sharply in Sweden and far too few reach WHO’s recommendation of 150 minutes of medium-intensity activity and two to three muscle-strengthening sessions a week. The public’s knowledge about the link between cancer and physical activity is poor and needs to improve. To change norms and behaviors takes time and requires knowledge, continuous reminders and individual support. Repeating the same message at regular intervals, but in a variety of different ways, increases the chance of achieving lasting change. Raising the public’s awareness of the link between physical activity and a reduction in the risk of cancer should be one of society’s highest priorities.

Many of our behavioral habits are established during the first years of life. According to WHO recommendations, children should be in motion for at least 60 minutes every day. But only a tiny proportion of the children in Sweden reach this recommended level. Preschool and school are a part of all children’s lives and play an important role for the norms and behaviors that they bring into adulthood.

Physical social planning affects people’s preconditions for physical activity for everyone throughout
their lives. Offering attractive public spaces that encourage exercise, and building an infrastructure that provides opportunities for walking or cycling are some examples of how society can promote physical activity. Employers also have a responsibility to create the conditions for employees to be active during the working day. Internationally, there are several examples of initiatives for increased physical activity in the population, such as tax incentives, grants and motor vehicle-free areas for cycling and walking.

Alcohol
Alcohol is a significant risk factor for many different types of cancer. When alcohol is broken down in the body, a substance called acetaldehyde is formed, which can damage our cells and genes and thus increase the risk of cancer. The link between alcohol and cancer is strongest in relation to cancer of the oral cavity, pharynx, larynx, esophagus, breast, colon, rectum and liver.

The Swedish Cancer Society believes that:

- Information initiatives to increase public awareness of the relationship between alcohol and cancer must be implemented
- Sweden must maintain a restrictive alcohol policy that includes a sales monopoly.
- Health warnings on alcohol packaging should be introduced.
- Legislation regarding the marketing of alcohol must be broadened.
- A significant increase in alcohol tax should be implemented.

The link between alcohol and cancer is scientifically proven. However, knowledge of this is relatively poor in the population. Information initiatives on the relationship between alcohol and cancer are needed to raise awareness of the risks and motivate people to consume less alcohol.

There is strong popular support for the Swedish retail monopoly on alcohol. In fact support has increased in recent years. However, the possibility of exempting micro-breweries and winemakers from the monopoly, and allowing direct sales to consumers at these facilities, is an ever-recurring issue in politics. It has long been known that if the availability of alcohol increases, consumption also increases. From a public health perspective, and with the ambition to reduce the number of cancer cases, such a change would mean a significant deterioration. In addition, exempting certain parts of the business sector from the alcohol monopoly would run counter to the EU’s requirements to allow Systembolaget to have exclusive rights to sales to consumers.

Alcohol advertising has been allowed in Sweden since the beginning of the 2000s, even though it is directly linked to increased alcohol consumption, especially among young people. An advertising ban is also part of WHO’s main recommendations. A public inquiry proposal to ban alcohol advertising by commercial participants in social media is being prepared by the Ministry of Social Affairs. However, it is likely that further measures may be needed to limit alcohol marketing in channels that are in the main as young as their users.

Today, health warnings for alcohol advertising in newspaper advertisements are required. Alcohol producers are allowed to choose their own messages. It is very unusual for them to warn of the link between alcohol and cancer. There is, however, no requirement that packaging, jars, bottles and boxes should contain warning labeling. A requirement for such labeling ought to be as obvious as it is on tobacco packaging. In addition, the warning texts should be selected by an independent body and not by the alcohol industry itself. In Ireland, the government is preparing to introduce mandatory health warning labeling on alcohol packaging.

Raising taxes on harmful substances is an effective way to limit and reduce consumption. Alcohol is no exception to this rule. Since 1998, the real price of alcohol has decreased, even if you count the three tax increases that were implemented between 2008 and 2015. There should therefore be room, and it should be relatively simple, to justify a significant increase in alcohol tax, as this would certainly lead to reduced sales. It is also one of the WHO’s most important proposals for the reduction of alcohol consumption, a proposal that also has other positive effects on public health than reduced cancer risk.

Sun
Sun is life. But too much sun is also the main reason why for several years skin cancer has been the diagnosis group that has shown the largest increase in Sweden. The number of cases of skin melanoma has more than doubled since the mid-1990s. This is a development directly linked to our sun exposure habits.
The Swedish Cancer Society believes that:

• Information initiatives for better sun exposure habits should be carried out regularly.

• Prohibition of sunbed tanning for cosmetic use should be introduced.

• All municipalities must ensure that advice from Boverket (The National Board for Housing, Building and Planning) regarding shaded places at preschools and schools is implemented.

Changing norms, ideals and behaviors takes time and requires knowledge, continuous reminders and individual support. Repeating the same message regularly, and in different ways, increases the chance of a lasting change. In particular, it is important to reach parents of young children, as excessive exposure to sun during the first years of life is particularly harmful. But even adults who sunbathe excessively are at risk. It is not about giving up the sun but about using common sense to enjoy it.

Tanning salons for cosmetic use are a high risk factor for skin melanoma and should be phased out from society entirely. Many international studies have confirmed the link between tanning and skin melanoma. In 2009, IARC, WHO’s organ for cancer research, classified radiation from sunbeds as clearly carcinogenic for humans. The increase in risk is particularly noticeable for young people. Sunbed tanning should be allowed for medical purposes only.

The best way to protect children from skin melanoma in adulthood is to make sure that they never get sunburnt. Parents have a great responsibility here, but children spend a large part of their active waking hours at preschools and schools. In order for the municipalities to better plan and ensure that, for example, school grounds offer sufficient shade, the Swedish Radiation Safety Authority has produced support material designed for all the municipalities. With the use of this material it will now be easier to follow Boverket’s general advice on how outdoor areas for play should be designed.

Environment

It is not just our lifestyles that pose a preventable cancer risk. The internal and external environment, such as workplaces and public spaces, can also increase the risk of cancer in the form of chemicals, radiation and particles in the air and water. Over the past 50 years there have been major improvements. Nevertheless, 600 people in Sweden die every year from cancer caused by exposures in the working environment.

In working life, construction workers still belong to one of the occupational groups that have an increased risk of cancer together with welders, foundry workers, firefighters, painters, chimney sweeps and hairdressers. In these working environments there are substances that have been established to be carcinogenic, or probably carcinogenic, to humans. Examples of such substances are diesel exhaust, rock dust, asphalt, arsenic, dyes, radon and polycyclic aromatic hydrocarbons. Radiation in health care, especially computer tomography, and radon in buildings also have a measurable effect on the number of cancer cases. More needs to be done to ensure that no one is subjected to dangerous exposure in their working life. No one should suffer from cancer as a result of their choice of profession.

In our private lives we are also exposed to cancer risks in the environment around us, including through the heavy metals arsenic and cadmium as well as radon gas found in some older building materials and occurring naturally in the bedrock. Vehicle traffic on the roads is a major contributing cause of carcinogenic substances spreading in the air, from both tire wear and engine exhaust. Calculations show that as many as 200 to 300 people in Sweden each year suffer from lung cancer as a direct result of air pollution, from traffic and other sources.

Cancerfonden anser att:

• The Threshold Limit Values for silica dust in the working environment should be lowered.

• The Threshold Limit Values for diesel exhaust in the working environment should be lowered.

• Information initiatives must be implemented to increase knowledge amongst affected employers and employees of the risks in their working environment.

Dust containing silica particles is a health hazard and is found in many workplaces, for example, where stone is crushed or cut. About 100,000 people in Sweden come into contact with silica through their professions. The Swedish Association of Occupational and Environmental Hygiene, SYMF, has proposed a reduction of the silica Threshold Limit Value to 0.05 mg/m3 from the current 0.1 mg.

There is diesel exhaust everywhere in the community. Particularly vulnerable are the professions where goods are unloaded and loaded, garage work, the construction industry, miners and tunnel workers. SYMF considers it sensible to lower the Threshold Limit Value for diesel.
Cancer care from the person’s viewpoint

In the past decade, a welcome and comprehensive change has taken place in cancer care, based on the national cancer strategy presented in a governmental study in 2009. An important step has been the establishment of the regional cancer centers, RCC, which has driven development forward. Examples of this are progress towards clear and transparent knowledge management, the introduction of standardized care processes and work to concentrate highly specialized cancer care.

At the same time, the fundamental problems that the Swedish healthcare system is facing have also become clear during these years. Much work remains to be done to offer an equitable and high quality cancer care which is based around the patient’s unique situation and which also includes family and children in particular.

Medical progress is not slow. The profession’s knowledge is steadily advancing, as are its methods for diagnosis and treatment. In many respects, the technological advances are astonishing and in several diagnoses survival is clearly on the increase. But the new knowledge often has great difficulty reaching patients. Data and studies that point to obvious shortcomings in healthcare are difficult to convert into effective interventions. Patients, relatives and professionals all feel that things could be much improved.

The ability to coordinate and jointly tackle the major challenges facing cancer care will be crucial to whether cancer care will be able to progress from healthcare production apparatus to becoming a fully fledged knowledge organization that not only applies, but also creates, new knowledge.

The person at the center

Putting the person at the center of care may sound as if it goes without saying, but it actually requires a high level of awareness in the profession, with excellent routines and clear working methods. It also needs the organization to be properly adapted to it. Although research, debate and the profession have focused attention on the issue in recent decades, much remains to be done in order for such a working method to have a full impact in healthcare.

Person-centered care is seeing the patient as a person and not as a disease. It is based on a working
method where patients and their viewpoints, experiences, knowledge and participation are included in all aspects of care. But not only that, it is also about care that takes into account existential, social and psychological needs to the same extent as physical needs. Patients become equal partners in the care team and can thus actively participate in their own care and health.

The benefits are clear. Patients and relatives become active participants and have the opportunity to influence the situation. Both patients and relatives often feel greater satisfaction with the care. Care personnel experience increased job satisfaction and reduced stress, and care times are often shorter.

**Person-centered care**
Understanding of the value of making the patient the centerpoint when cancer care is organized and planned has grown in recent years. Starting from each patient’s unique situation and involving patients in their own care have educational, psychological and medical benefits.

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**The Swedish Cancer Society believes that:**

- Healthcare managers must make overarching decisions to provide person-centered care, thus establishing legitimacy and fairness.
- Cancer care must work consistently to ensure that care for all cancer patients is person-centered.
- All cancer patients should be involved in developing a written individualized care plan.
- All patients should be offered a named contact nurse at the time of diagnosis.
- Patient representatives must always be involved in decisions regarding healthcare.
- Effective methods for national assessments of participation and influence need to be created and used in the development and improvement of care.

Adapting healthcare to the patient rather than the other way round is a positive development where everyone is the winner. Participation in everything from planning to implementation and follow-up gives patients greater security and increases the likelihood that they will follow the recommended treatment.

A great deal of work is required by the healthcare system if patients are to be kept informed and involved. Procedures for how best to utilize the resource that patients constitute are not fully developed. Finding methods for patient participation at a structural level is an important challenge, while at the same time patient organizations need to become better at
collaborating and raising common interests. Patients with cancer are faced with a very complex care system with many different contacts, from initial symptoms to treatments and rehabilitation or palliative care. To help navigate through the care, coordinate efforts and discuss the disease, all cancer patients should have access to a contact nurse. Many cancer patients still do not have access to this resource. This is not acceptable and the issue must be given higher priority. It should also be possible for patients to change the contact nurse if they do not feel comfortable with the one they have been assigned to.

Written individual care plans contribute to participation and communication around the planning and implementation of care interventions, and ensure that the patient’s unique situation and needs are the determining factors.

The care system needs to establish more effective methods to improve the work of building patient participation and influence. Experience shows that it is vital for healthcare management, through overarching orientation policies, to create the right conditions and to give staff a mandate for making care person-centered. Improved and validated indicators are also needed that highlight the patient’s perspective on care, and are comparable at the national level.

Self-care
Self-care is a relatively new concept in healthcare and the interpretation of its meaning may be different for different healthcare providers and different patients. Providing cancer patients with the support and conditions for self-care can in many cases greatly contribute to improved quality of life.

According to the National Board of Health and Welfare, self-care is defined as “when someone in the healthcare system has assessed that a person can, on their own or with the help of someone else, perform a healthcare measure”. A self-care program consists of three different components: medical management, i.e. handling medication and any side effects of treatment on a daily basis; behavior management, i.e. maintaining, changing or creating new meaningful behaviors and skills to coordinate one’s care and health; and emotional management, i.e. finding strategies to reduce the emotional strain.

For this to work, healthcare needs to establish functioning models to support those patients who to some extent have responsibility for their own self-care. Such models must be person-centered. There is also a great value in using digital tools to facilitate, for example, health reporting and to coordinate healthcare. This is an area where there are considerable opportunities to make advances in cancer care.

Another development area is support provided to patients by healthcare regarding lifestyles. Research shows that smoking, physical activity, nutrition and alcohol consumption can affect the effectiveness of treatment and the risk of relapse. Therefore all patients should be offered information, skills and support based on their needs.

Self-care is about utilizing the patient’s own capabilities. It must always be based on the patient’s circumstances and must never jeopardize patient safety, lead to poorer medical results or lower the quality of life.

Waiting times
Long waiting times that are not medically justified are one of the major problems of cancer care. Being forced to wait for a diagnosis, treatment and other interventions during the care process creates frustration and worry for patients and relatives. Over the past four years, standardized care programs, SVF, have been established for more than 30 cancer diagnoses. No dramatic improvements have yet been made.
The Swedish Cancer Society believes that:

• Organizational deficiencies that, despite standardized care processes, cause unnecessarily long waiting times must be identified and addressed.
• Improvement initiatives must be prioritized with regard to diagnoses where waiting times are longest.
• Care units that measurably contribute to reducing unnecessary waiting for cancer patients should be rewarded.
• All regions’ efforts to reduce waiting times should be made jointly, so that following up of the SVF process can be efficient and reliable, and national assessments and comparisons can be carried out continuously.

The most common explanation for long waiting times is a lack of various types of resources, in particular the lack of specialist expertise in key functions such as pathologists, radiologists and urologists. But this is not a complete explanation and there are many examples of how relatively simple organizational changes can make a big difference within the framework of existing resources. Finding different ways to encourage and reward such work at the clinics is a responsibility that rests with healthcare principals. Experience shows that good results can be achieved in a short time.

In order to rectify unjustified waiting times, managers need to identify the bottlenecks that aggravate and delay standardized care procedures. It is also essential that the work to implement standardized care processes and shortened waiting times receives the necessary support and resources. It is vital that all regions monitor the waiting time situation continuously and that investments are made so that data can be analyzed and compared at national level.

Ensuring competence provision in parallel through increased training and recruitment strategies is an obvious necessity, but it takes longer to show results. Similarly, digitization of healthcare will have effects in this area.

Rehabilitation
The number of cancer patients and people surviving after cancer treatment will increase sharply over the next few decades. This is essentially a positive challenge, but it will place great demands on monitoring and rehabilitation in connection with cancer treatments. To meet this, it is essential that the national rehabilitation program is followed throughout the country. It will also require closer cooperation between specialist care and primary care.

A cancer diagnosis is life-changing for both patients and their families. Ingrained everyday routines, jobs, leisure time, relationships and more are subjected to great stress.

In the National Cancer Rehabilitation Program, rehabilitation is defined as a way to prevent and reduce the physical, psychological, social and existential consequences of cancer and its treatment. Rehabilitation is still a neglected area in cancer care, despite the fact that both the human and socioeconomic value of rehabilitation is becoming increasingly apparent. A Swedish study has shown that 5,000 SEK invested in rehabilitation resulted in 50,000 SEK in lower care costs.

It’s difficult for rehabilitation to find its place in today’s cancer care. The resources available are insufficient and unevenly distributed across the country. Some clinics and hospitals provide high-quality rehabilitation, while others fall short. The consequence is that only a limited number of patients have access to the latest expertise regarding the best possible rehabilitation.

It is therefore important that the National Cancer Rehabilitation Program be introduced across the country. It is about safeguarding patients’ physical, mental, existential and social needs. It is also about achieving the best possible treatment results and using society’s and healthcare’s resources effectively. At the same time, more research is needed on which interventions give the best results based on the patient’s specific situation.

Care equality
Sweden is not an equal country when it comes to health. There’s a difference of five years in average life
expectancy between upper income people with university-level education and those with a low income and no more than compulsory education. For women in the lowest socioeconomic group, average life expectancy has for several years seen an even greater decline.

The differences, which in some respects are significant, are dependent on both geographical and socioeconomic patient groupings. In one part of the country, it is not uncommon for a man with prostate cancer to be forced to wait over seven months for treatment, while men in another part wait just three months. In total, around 2,900 lives a year would be saved if all socioeconomic groups had the same pattern of cancer onset and mortality as those with post-secondary education.

There is no simple explanation for the large differences in mortality between the socioeconomic groups. However, in the studies that have been undertaken, and based on today’s knowledge, one can see three main influencing factors: individual conditions, the care provider’s actions and healthcare and social policy. All three factors need to be taken into account if inequality is to be reduced.

When it comes to regional differences in cancer care, these appear to be “unwelcome and overly loyal companions”. Despite the fact that there is data pointing to regional differences, work to iron them out is slow. Good praxis and successful work seem to clump together in isolated islands and it is proving difficult to spread them more evenly over wider areas. Regional differences are still large, for example in terms of diagnostics and access to recommended treatments.

Another perspective which needs further investigation is whether or not there are inequalities amongst recent immigrants, and if so, what sort of inequalities.

When it comes to the introduction of new drugs, much has certainly been done to reduce the existing differences. At the same time, much work remains in this area. There are major differences between different medicines in terms of how quickly they reach the patient. In addition, there are continuing differences between regions and socioeconomic groups in terms of access.

Efforts to achieve fair and equal care require focus and great commitment.

**Socioeconomic inequality**

The socioeconomic inequalities in cancer care are judged to be greater than the regional ones, and they are far more complex to deal with. Researchers in, for example, sociology and social medicine have for decades highlighted these inequalities with the support of scientific studies and unambiguous statistics. Despite improved medical technology and skills, and despite knowing that care is unfair and unequal, society has failed to bridge the gaps between the socioeconomic groups.

**The Swedish Cancer Society believes that:**

- National measurable goals must be established for the reduction of socioeconomic differences in cancer care.
- Regional cancer centers must be given the special task of creating Open Comparisons of inequalities in cancer care as well as the task of developing and evaluating effective initiatives for equal cancer care.
- Healthcare staff’s skills in dealing with patients from different backgrounds and social conditions must be improved through training and continuing education.

One effective way to bring about change is to have a clear objective as to what you want to achieve. All regions should quickly set concrete and measurable goals for what they want to achieve in their work to reduce socioeconomic disparities in healthcare. These goals should also include preventive work, such as participation in screening and vaccination programs. Monitoring of the goals should be open and accessible to both employees and the general public.

Thus, some of the differences are due to factors that operate before cancer is diagnosed, such as those that affect the risk of contracting certain types of cancer or the disposition to participate in screening studies for early diagnosis. But it is indisputable that the differences also depend on different treatment outcomes once the diagnosis has been made, and that some of these depend on what care is received.

An evaluation carried out by the National Board of Health and Welfare has made it clear that people with shorter education have poorer access to the diagnostic measures recommended in the national guidelines. For example, highly educated men with prostate cancer are offered skeletal examination to a greater extent than less educated. Highly educated people with lung cancer have shorter waiting times from referral to diagnosis. The studies also show that different demographic and socioeconomic groups are offered different treatment. For example, the National Board of Health and Welfare has established that people with shorter education generally have poorer access to the treatment recommended in the national guidelines. In order to reduce these socioeconomic gaps,
To reduce socioeconomic inequality, healthcare professionals must have the right tools to work with.
healthcare professionals must have the right tools to work with. Being able to adapt care to each patient’s individual conditions is a crucial factor. It might, for example, be a matter of how communication with the patient takes place, or how staff can work to gain awareness of their own unwanted and unconscious behaviors. These are issues which must be included in healthcare professionals’ training and which also need to be worked on continuously.

Patients from vulnerable groups often need special support to enable them to navigate healthcare. When individuals perceive that they are in a position of weakness in relation to community institutions such as care, they need appropriate support. This is important because the disposition to seek care and participate in screening programs differs between different groups. People with only primary school education are more reluctant to seek care and there are indications that people in lower socioeconomic groups participate in screening to a lesser extent. The ability to make demands on healthcare providers also differs between different groups. Previous research has shown that people with higher education are generally given more time for questions and requests when meeting with healthcare personnel. Models for what the individual support might look like need to be developed and implemented at all levels of care. It might, for example, be a matter of offering personal support to patients to help them understand their situation and their rights. Good examples of this can be found all over the country.

The government needs to initiate work at the national level to develop new ways to increase accessibility in healthcare. Examples of this are flexible opening hours, different ways to book times, access to interpreters and coaches as well as information.

Regional inequality
Since the beginning of the 2000s, the Swedish Cancer Society has repeatedly demonstrated that there are major regional differences in cancer care. Waiting times, access to diagnostic methods, treatments, follow-up and even survival are affected by the place and region in which the patient lives. Regional inequality must be eliminated. Cancer patients must be able to feel confident that they will receive the best possible cancer care regardless of where they live.

Colon cancer behaves no differently in Norrbotten than in Östergötland. Nevertheless, statistics and measurements in the national Quality Registries show clearly that patients with the same diagnosis are treated in different ways in different parts of the country. Some regions place great importance on patients being evaluated at so-called multidisciplinary conferences, while others do not. Some regions prioritize giving their patients a special form of aftercare that reduces the risk of relapse, while other regions choose not to.

It is not a matter of healthcare consciously choosing to provide inferior treatments. Everyone acts in ways that they have learnt work best. So comparing oneself with others, and thus gaining insight into methods other than those one uses oneself, is extremely valuable.

Since the regional inequalities began to receive serious attention, not least in the report by the Swedish Cancer Society, Quality Registries and other sources have become more open about reporting these differences. Regional inequalities can for the most part be attributed to organizational causes. Thus, healthcare management bears a clear responsibility to create the right organizational conditions for the best possible cancer care.

Medicines
The differences that still exist between different regions and socioeconomic groups when it comes to the use of new cancer drugs are completely unacceptable. Considerable efforts have been made to reduce the differences, but there is still much to be done to ensure that all cancer patients have speedy access to new and effective drugs.
The Swedish Cancer Society believes that:

- All cancer patients must be guaranteed good, equal access to effective medicines.
- All cancer patients should be offered diagnostics with testing that maps the tumor’s genetic profile so that the right treatment can be given.
- Work on the national process for a fairer and more equal introduction of medicines must be continued and followed up in a structured and effective way.
- New cancer drugs should be financed through a national fund that ensures access based on patients’ needs.
- Support for collaboration between healthcare, academia, industry and public authorities, enabling more effective monitoring of medicines, should be strengthened.

For many years the pharmaceutical industry has invested a large part of its research and development resources on developing new cancer drugs. Several new cancer drugs have been introduced to the market in recent years, many of them with remarkably good results.

In order to defeat cancer, new treatments must be used and evaluated in clinical practice. A drug that on average prolongs survival by a number of months may extend some patients’ lives by many years, while for others it has no effect whatsoever. To find the subgroups that really benefit from a new drug, it must be tested on many patients. This requires healthcare, academia and industry to collaborate more closely. In addition, testing that maps the genetic profile of tumors needs to be offered to all patients in order to find the right treatment. Vinnova’s initiative “Genomic Medicine Sweden” is a commendable initiative to establish testing in everyday healthcare.

Many of the drugs that emerge in these new processes are expensive compared to older treatment methods and not all patients respond to them. As a result, many clinics and regions restrict their usage and in some cases reject them entirely. This has created an unfair situation where place of residence has become a deciding factor for who does or does not receive treatment with a particular drug. In order for all cancer patients to have equal access to new cancer drugs, work on introducing drugs fairly and equitably must continue to be given priority. A special focus needs to be placed on monitoring so that experience can be used to optimize the correct use of drugs.

The Swedish Cancer Society also proposes the establishment of a national fund to finance new cancer drugs during an introductory phase. This is necessary to ensure that all cancer patients have access to the new drugs they need.

Monitoring of the new system is absolutely crucial. It is important that the results are made available to academia and industry so that there is a clear feedback.

Early detection

Early detection of cancer increases the chances of cure. Rapid detection and rapid treatment increase the chances of survival. Cancer sufferers and their families are the primary winners, but there are also socioeconomic benefits. Early detection and diagnosis together with prompt treatment are therefore the most important areas to strengthen in order to increase survival.

These are the three most important areas: Firstly, to identify through various methods, via screening, precursors to cancer or cancer at a very early stage. Secondly, vaccination to reduce the risk of cancers caused by human papillomavirus (HPV), such as cervical cancer. Thirdly, it is important to be alert and aware when people seek medical care with symptoms that may be signs of cancer.

An important factor in efforts to detect cancer early through screening, or to prevent the disease through vaccination, is to encourage as many people as possible in the target group to participate. Through the organized screening programs that have long been active in Sweden - gynecological cell sampling and mammography - we know that some groups are more difficult to persuade to take part than others. One goal of screening and vaccination is the constant development of methods to achieve the highest possible participation.

For most cancer diagnoses, there are currently no reliable methods for conducting organized screening programs. Research to develop such methods must be encouraged. However, the biggest challenge is to strengthen primary care’s ability to detect cancer at as early a stage as possible.

Primary care

Primary care is the front line in Swedish healthcare. This is where most patients begin their journey through the care system. This applies to a great extent to cancer patients. 70 percent of all those who receive a cancer diagnosis have their initial investigations in primary care. Providing primary care with tools such as better routines, training and skills when it comes to quickly identifying symptoms that may be due to cancer, as well as prompt and accurate referrals, are important parts of early detection.
It must be easy for patients to see their doctor and to see the same doctor on a regular basis. This increases the chances of detecting suspected cancer at the earliest possible stage.
The Swedish Cancer Society believes that:
• Primary care should be strengthened to ensure quality and continuity.
• Regular training initiatives should be implemented to increase primary care competence in the early detection of cancer and standardized care processes.
• The regions should offer effective and up-to-date knowledge support for the early detection of cancer.
• Initiatives are required to ensure that primary care carries out the standardized care processes in the same effective manner throughout the country.

Based on the number of doctors working in hospitals per capita, Sweden is the best in the world. Unlike in many other countries, Swedish healthcare expansion has been achieved mainly by building a large number of large hospitals. To some extent, this has been at the expense of primary care in the form of health centers and GPs. On the other hand, primary care’s responsibility for detecting the early symptoms of serious illnesses, and for keeping those patients who are least in need of care away from hospitals, remains the same and has been reinforced in some cases.

As a result primary care is now to a large extent under-dimensioned and underskilled, and so finds it difficult to fulfill its basic remit. Its staff are under severe pressure and there is a high turnover of employees, particularly doctors.

The standardized care programs, SVF, have increased the chance that patients with suspected cancer will be referred more quickly for further investigation and specialist care. But in order for it to function fully, primary care needs to have the proper tools to work with. Since 2018 Project CaPrim has been running in the Stockholm healthcare region, tasked with training primary care personnel and developing the required tools. Such initiatives are needed throughout the country.

But in the long term, some form of paradigm shift is also needed that strengthens the role of primary care and increases the status of doctors and nurses working with general medicine close to the general public.

Functioning primary care is central to success in the fight against cancer. Counseling on health issues, medical follow-up and rehabilitation are all examples of important tasks which have to be performed in primary care, in addition to early detection. The accessibility and continuity of primary care must therefore be strengthened. It must be easy for patients to see their doctor and to see the same doctor on a regular basis. This increases the chances of detecting suspected cancer at the earliest possible stage.

Screening
For many years, two successful national screening programs have been conducted for the early detection of cancer. Both are aimed at women: mammography for breast cancer and gynecological cell sampling for cervical cancer. The National Board of Health and Welfare also recommends screening for colon cancer using a method that has been developed and implemented in the Stockholm healthcare region since 2008.

The Swedish Cancer Society believes that:
• All regions should target programs towards women who have not been screened.
• Participation in screening programs must be free of charge.
• All regions should introduce screening for colon cancer.
• The benefit of screening for other cancers should be investigated.
• Age ranges should be continuously evaluated on the basis of population development and new research.
• More research to find new, more effective screening methods should be encouraged, with the further aim of reducing the risk of overdiagnosis.

For breast cancer and cervical cancer, it is possible through screening to find preliminary stages and tumors even before the body shows symptoms of disease. A third program that enables early detection of colon and rectal cancer is recommended by the National Board of Health and Welfare. The configuration and forms of this screening are also being examined in a national study that includes all the regions except Stockholm and Gotland, which have already introduced the program, and Västernorrland, which decided not to be included in the study. It is hoped that this national study will pave the way for an orderly introduction of screening for colon and rectal cancer, something which the EU has been recommending for ten years.

Studies have shown that lung cancer screening is effective in some groups and saves lives. The Regi-
Our policy programme

Onal Cancer Center Stockholm-Gotland has taken an important initiative by offering women who smoke daily low-dose computed tomography screening of the lungs as well as smoking cessation support, a method that has been shown in several studies to lead to early detection and improved prognosis. This work can hopefully lead to an improved capability to detect lung cancer at an earlier stage.

For the cancer type that affects most people, prostate cancer, there is at present no scientific support for national screening. However, the issue is being investigated further. It is important that active investigative work is carried out in order to introduce screening as soon as the scientific support is available. It is also important that research into effective methods for screening of other cancers is encouraged.

High participation in controlled screening programs is important if more lives are to be saved. Mammography screening is a contributing factor to increased breast cancer survival. Since gynecological cell sampling was introduced in the mid-1960s, the number of cases of cervical cancer has halved. Screening for colon and rectal cancer can reduce mortality in these types of cancer by 15 percent.

Participation in the screening programs is voluntary. You are invited to an examination and choose whether or not you wish to participate. Unfortunately it has been found that there are large differences between different groups in terms of the degree of participation. In mammography screening and gynecological cell sampling, women in socioeconomically weak groups, and women with immigrant backgrounds, are underrepresented. This means that these women have less chance of being diagnosed early and thus less chance of being cured. Therefore, it is important to take steps that increase participation, such as free examinations, annual recalls, telephone contact, the offer of help in making an appointment and the offer of a gynecological self-test by mail.

For the last couple of years there has been a national program relating to steps the regions should take to persuade women who have not taken part in gynecological cell sampling to do so. It is important that this program is followed as it improves the chance of increasing participation. The regions can also get better at learning from each other. There are regions that have achieved almost 100 percent response and so may have work methods and routines that others can be inspired by.

Vaccination

Every year, over 300 men and over 700 women in Sweden suffer from HPV-related cancer. Among men, it is mainly cancer of the throat, penis and anus. In women, it is mainly cervical and pharyngeal cancer. Currently it has been decided that children in the age-group 10-12 should be vaccinated. Efforts are needed both to disseminate information and to provide support to healthcare professionals and others to ensure that as many people as possible are aware of the importance of vaccination.

The Swedish Cancer Society believes that:

• As soon as possible the government must take the decision that boys should also be offered vaccination against HPV within the general vaccination program for children.
• Price per dose should not be the most important argument in the purchase of vaccines. Rather the strongest long-term benefit for man and society should be prioritized.
For a number of years, girls aged 10-12 have been vaccinated against HPV 16 and 18, two viruses that can cause cervical cancer. These viruses account for about 70 percent of all cases of cervical cancer in Sweden. The vaccination rate is at a stable level of around 80 percent. To increase protection rates, boys should also be vaccinated.

If boys are given the opportunity to be vaccinated on the same terms as girls, they will have their own protection against HPV and the cancers linked to the virus. In addition, the spread of the virus is expected to decrease, providing greater indirect protection for unvaccinated boys and girls.

It is estimated that three quarters of the cancer caused by HPV can be prevented with today’s girls’ vaccination program. A further 120 cancer cases per year can be prevented if boys are vaccinated against HPV.

A proposal to expand the vaccination program to include boys is on the government’s table pending approval. The program must be implemented quickly. When purchasing a new vaccine, it is important to choose a vaccine that provides the best possible long-term protection against HPV.

### Organization

Medical progress is advancing rapidly and the pace is increasing. Over the past two or three decades, successful research, new drugs, more accurate diagnoses and thus more effective treatments as well as modern healthcare methods have created opportunities to rapidly improve cancer care. In the best of worlds, Sweden’s cancer healthcare would have been able to concentrate on one crucial task: to ensure that patients quickly gain access to these advances. But for decades, the entire health care system has instead been wasting time and resources on a number of permanent problems.

The debate about shortcomings and challenges in Swedish cancer care and healthcare as a whole has rarely been about poor medical results, incompetent surgeons or unskilled nurses. Debates are, naturally, not about things that work but about things that don’t work. About IT systems that make communication between care units more difficult, about staff who struggle with extra shifts and overtime and yet still do not have time to carry out their duties. Or unnecessarily long waiting times because, for example, there’s a lack of the right skills at the right place at the right time. All of this affects patients.

One factor that has contributed to the Swedish healthcare being a costly and in many ways inefficient organization, with major difficulties in adapting to the rapid development of the world, is the model with 21 independent regions (formerly county councils). Each and every one of them has to formulate their own personnel policy, procure medical records and buy medical equipment, instead of coordinating at national level. What is being done well in one part of the country, which could and ought to serve as a model for the entire healthcare organization, gets stuck there and does not spread to the other regions.

Since 2010 the regional cancer centers RCC have, through a number of improvement projects, been the driving force for a more nationally coordinated cancer care. But RCC’s mandate is limited and there is no long-term perspective regarding funding and targets. With RCC as the driving force, the regions have certainly become better at collaborating, but there is still a long way to go to the modern, fast-moving, knowledge-driven organization that the healthcare system must become in order to meet the challenges facing cancer care.

### Stronger national control

The division of Sweden into 21 autonomous regions is based on an outdated structure which does not serve today’s cancer patients well. In fact the organization of care is itself acting as a brake, holding development back when it comes to ensuring equal, research-based and knowledge-based care. National challenges require national solutions, and an ever-faster development requires stronger national control so that all cancer patients can be offered the best care.

**The Swedish Cancer Society believes that:**

- The current healthcare organization with 21 autonomous regions must be reviewed, with particular focus on its effect on patients.
- There must be stronger national control and coordination of cancer care.
- The national cancer strategy must be updated and it must include long-term, clear and monitorable goals.

The argument that care should be managed and performed by an organization in the patients’ geographical proximity has become increasingly hollow as society has developed. Proximity at the expense of quality is not sustainable. From the patient’s perspective, it is
National challenges require national solutions, and increasingly fast developments demand stronger national control so that all cancer patients can be offered the best possible care.
preferable that those who make decisions about the organization and focus of care are close to medical and organizational expertise, rather than close to the local hospital. Over the years there have been a number of reviews and proposals regarding reorganization of the regions. But nothing has actually been done.

Cancer-related research leading to new medicines, new treatment methods and the development of care is rushing along at breakneck speed. New technology and digitization are ready and waiting impatiently to improve and streamline healthcare. It goes without saying that it takes longer to modernize and introduce new methods in 21 organizations than in one.

It is high time that the issue is tackled from a patient perspective, and that the organization is adapted to what best benefits the patient and provides the best opportunity to offer equal, research-based and knowledge-based care.

At the same time, the development of cancer care needs strong national coordination, which can drive essential development work and coordinate specific issues related to cancer care.

Regional Cancer Centers
Regional Cancer Centers (RCC) began as a cautious knowledge-enhancing unit under SKL, Sweden’s municipalities and county councils. With great commitment and clear goals, they have grown steadily and had a measurable effect on cancer care. RCC are needed for cancer care to continue to develop, and with clearer mandates and responsibilities progress will be made.

The Swedish Cancer Society believes that:

- Agreement between central government and the regions is required for a permanent funding of RCC.
- RCC must be given clear, long-term goals and mandates to strengthen national control and coordination of cancer care.
- RCC must be given special responsibility to work towards enabling more cancer patients to be included in clinical studies.

Today, RCC lead the work on all care programs in the cancer field, managing the Quality Registries and the standardized care processes. RCC are also responsible for the process of moving the patient from the periphery to the center, the establishment of contact nurses and not least the important issue of a multi-level structured cancer care.

RCC are financed through an agreement between the state and SKL, which is renewed for four-year periods. This is an unsatisfactory solution that limits the long-term perspective of RCC’s work. A prerequisite for maintaining RCC’s strengths and impetus for developing cancer care is that RCC are made permanent and given a clearer and stronger mandate in the national development and management of cancer care. The uncertainty that lies in the relatively short funding periods acts as a brake on progress. Moreover, there is a risk that the government, in making grants to the RCC, places conditions on the funds through assignments which are designed to satisfy short-term political opinion, but which divert focus away from major, necessary improvement efforts.

One very important task in cancer care is to bring the research community and medical care closer together. Today, astonishingly little clinical research is carried out at Swedish hospitals, in part because the healthcare system has great difficulty offering clinically active doctors and nurses time and space for research. More active research in the hospital environment would be of enormous benefit, not least for the patients, who would thus be closer to medical advances and care development. Another positive effect would be the opportunity to transform the hospital environment from a care facility to a knowledge organization, which is almost certainly a prerequisite for the maintenance of care quality and continued treatment results that stand up well in international competition. With a clearly stated mission, RCC would be able to take the lead in a systematic and long-term increase in the number of patients given the opportunity to be included in clinical trials.

Skills provision
The right expertise in the right place is an ambition that cancer care has for a long time found it difficult to live up to. The lack of pathologists, urologists and specialist nurses, among others, bedevils the clinics and creates unnecessarily long waiting times. But it is also an anomaly that is constantly draining for staff who, regardless of how many overtime hours they work, always feel inadequate.
The Swedish Cancer Society believes that:

- A long-term national recruitment strategy for cancer care needs to be developed.
- All employee groups within cancer care must have excellent employment conditions including during further education.
- Together the regions must develop a national model for how cancer healthcare can become an attractive employer for new and existing personnel so that the long-term skills supply is secured.
- All regions must jointly carry out steps to ensure that all competences are used in the best possible way within cancer care.

The lack of key competences in healthcare is often reduced in the debate to a question of the need for more staff. And in many cases that is what it is all about. But it is not the only factor. There are other aspects to the issue of skills provision, for instance how the business is planned, what the organization at the clinic looks like, and the ability or inability to collaborate between clinics, hospitals and even regions across the country. The ability and willingness to adopt new technology and embrace the opportunities offered by digitization are also related to what an optimal solution for both patients and staff can look like.

However, there are many job vacancies that need to be filled, and a more cohesive, national recruitment strategy must therefore be introduced to provide the necessary overview and foresight. Regional strategies are not enough, and national responsibility is needed.

One urgent task is to create attractive workplaces that will both attract new staff and retain existing ones. This is about the terms of employment offered by the employer, i.e. the regions, including opportunities for professional development through continuing and further education, and whether or not time spent on such education is paid for. Stimulating work exchanges, customized and individually prepared schedules and research opportunities are other features that employers must offer. Competition for skilled labor is fierce and is unlikely to decrease, and so it is important to create attractive workplaces suited to today's highly qualified employees.

An underestimated and underused method is to look up and see how others have solved their problems. There are examples of clinics that have transformed and streamlined their operations in ways that have both increased the well-being of staff and removed unnecessary patient waiting times, without the need for additional resources, either in the form of more staff or technology investments. This is quite simply learning from those who have achieved greater success. A systematic review of how tasks are distributed among the various professional groups within healthcare has also proved to be an excellent way to improve efficiency and free up time for patient care.

Highly specialized cancer care

Gathering together expertise and experience for the treatment of complicated, resource-demanding or unusual cancers has long been one of the Swedish Cancer Society's most important demands, so that all patients can benefit from the best possible care, regardless of where they live. The work of concentrating and centralizing highly specialized cancer care has gained momentum in recent years through the efforts of RCC, but much remains to be done.

The Swedish Cancer Society believes that:

- The patient’s needs should be top priority when making decisions about centralization.
- Decisions on centralization need to be firmly anchored with both staff and patients.
- The National Board of Health and Welfare should handle the process of centralization in a transparent and constructive way.
- The National Board of Health and Welfare should accelerate the process regarding the centralizing of cancer diagnoses.

A surgeon needs to perform a certain number of procedures of a specific type in order to maintain and develop expertise in this particular area. Statistics show a clear relationship between the number of procedures performed and the treatment results.

The question of centralization is sensitive because it affects other activities, such as emergency surgery. A hospital that is unable to offer patients planned surgery to a large enough extent risks having surgeons on the payroll who have too little to do. There are concerns in these hospitals that in such cases they will be forced to close their emergency departments, which is not an easy decision to make. In many cases, it will turn out to be a process of winners and losers, where experienced staff have to accept handing over activities they have been doing for years to colleagues in other parts of the country. But as long as the process creates better care for patients, the professional demands must take a back seat. The opposite also
applies: if the result is not better care, then there is no reason to change what works.

Prestige is also certainly a factor in resistance to centralization. Not being able to operate certain conditions can be perceived as a diminishing of one’s own professional pride. It is therefore vital when making preparations for centralization to consider all angles and let all voices be heard. Through an open and constructive dialogue with all parties, it is possible to avoid deadlocks and conflicts that are difficult to resolve and which ultimately affect patients. It is not about winning or losing, but about starting from a clear patient perspective to build a healthcare system that treats everyone at the appropriate level and leads to the best results.

Today, advanced diagnostics and treatment for ten diagnostic areas within cancer are concentrated and distributed across the country’s seven university hospitals. When the National Board of Health and Welfare places cancers into the unit for highly specialized care, it is important that the tempo in the centralization of cancer remains high. There are still a large number of diagnoses where patients would benefit greatly from being treated by dedicated specialists. This is an important part of the work to achieve more equal and equitable care.

Digitization
Healthcare’s ability to utilize digital technology in its interaction with patients and for the internal streamlining of communication and processes has been neglected and is a long way from the revolution that is taking place in the rest of society. People are quickly embracing the benefits of digital interfaces and information retrieval. The fact that healthcare is not keeping pace with the development of the rest of society is a source of frustration for many patients and a weakness in healthcare’s relationship with the public.

The Swedish Cancer Society believes that:

• The government and the regions must jointly and immediately make the priorities and investments necessary for the effective digitization of healthcare.

• The government and the regions must agree on a plan to create a national joint system for information exchange and medical records management.

• Management roles must be established with responsibility for digital development in healthcare management organizations.
Digitization, which is happening at a furious pace, is really a sub-process in a major technological process consisting of three phases: digital skills, digital awareness and digitization. Digital skills can be defined, somewhat simplified, as knowledge of how to use the internet and manage a computer. Digital awareness is about understanding and being able to utilize and develop the benefits that you can achieve with your digital skills. And what is happening now is that the process, or the technological evolution, is moving into digitization. That is, it is taking the step from merely reinforcing and supporting existing methods and behaviors to enabling innovations that do not necessarily have direct reference to things that we recognize and can relate to.

Healthcare’s position in this process is somewhere between phase one and phase two. They have learned how to use the computer but cannot yet take full advantage of it.

In 2016 an agreement was reached between central government and Sweden’s municipalities and county councils, SKL, jointly promoting the vision that Sweden should be the best in the world at e-health by 2025. This agreement is the guiding document for work on digitization in all welfare sectors. So far there has been no public evaluation of how the work is progressing, but the impression, almost three years after the start, is that it has not come very far, and it is difficult to see how the vision for 2025 can be fulfilled.

There’s a huge need to develop healthcare’s digital capacity. Digital interfaces with functions relevant to patients would contribute to both increased accessibility and increased participation. National platforms for records management and administration would streamline many internal processes and free up resources for working with patients. Something that has proven to work well and speed up the work on digitization is to appoint executives in management positions responsible for digital development. There are also good reasons for more actively developing techniques where the actual care is performed digitally, for example in self-care, where patients themselves carry out some of the tasks that are otherwise done by healthcare professionals.

In parallel with this, research is pushing ahead in leaps and bounds. Today, the tumor’s characteristics can be mapped in detail through basic research. Large amounts of data on the individual tumor provide new opportunities for precision medicine and targeted treatment. Another example is the possibility of using artificial intelligence to examine data and detect early stages of cancer. But healthcare is finding it difficult to absorb the great gains made by research.

Concern is sometimes expressed about the possible negative consequences digitization might have for healthcare. For instance, it is suggested that patients’ personal integrity and security is at risk in the digital environment. Others warn against overconfidence in the possibility that digital functions will be able to replace some of the tasks currently performed by healthcare professionals.

Of course, misgivings of this sort must be taken seriously. There are always pitfalls associated with major changes and a constant ongoing impact assessment is necessary to avoid them. But avoiding risks by doing nothing is not a reasonable approach. On the contrary, everyone, from principals and hospital managers to clinics and professionals, must embrace the opportunities, roll up their sleeves and jointly accelerate the work of taking care into the digital age.
TOGETHER AGAINST CANCER

The Swedish Cancer Society’s vision is to defeat cancer. By funding the most advanced research, disseminating knowledge about cancer and lobbying decision-makers on important issues, we work to reduce the number of cancer sufferers and increase the number of cancer survivors. The Swedish Cancer Society is an independent, non-profit organization which receives no state support. Our work is entirely dependent on bequests and gifts from individuals and companies. We are one of the largest funders of Swedish cancer research. Since 1951, we have distributed SEK 11 billion to the leading research projects in Sweden. Cancer survival has more than doubled during this period. Today, thanks to research progress, two out of three people who have cancer survive. We’ve come a long way, but we’re not there yet.