

# Strategy 2016–2019



**The Norwegian Cancer Society (NCS) is one of the largest organisations in Norway representing the voices of those affected by cancer.** In 2015, the organisation had 113 000 members, 25 000 volunteers and 190 employees, who are all dedicated to promoting the cancer cause.

**NCS works continuously to improve society's attitude to the prevention and treatment of cancer.** We fight cancer locally, nationally and globally through research and preventive measures, information, support, advice and lobbying.

**NCS leads the way.** We have introduced a number of vital improvements within the field of cancer. Mammogram screening, the Norwegian Cancer Registry, the Varde centres for patients and their families, and cancer coordinators in the municipalities are just some of the measures we have initiated.

**NCS receives funding.** The revenues we receive are from bequests, gifts, membership fees and lottery funds.

*Life is a series of moments, most of which are completely routine. Photographer Paal Audestad's pictures for NCS's strategy illustrate how such moments can nevertheless be magical. All photos by Paal Audestad.*

The strategy was approved by NCS's Committee of Representatives on 26 November 2015 and applies to the period 2016–19.

## Introduction

NCS's strategy for the period 2016–2019 has a broad scope and ambitious objectives. Working on this basis, we will continue to produce results that will benefit past and present cancer patients, as well as future generations.

The potential for **prevention** is great – we know that several types of cancer that are becoming more common in Norway are preventable. We plan to continue our efforts in the areas that have the most effect: we will devise targeted campaigns and accurate information, whilst simultaneously working on structural measures aimed at the population. A key word is cooperation – not least between the different sectors of society, such as volunteers, business and the authorities.

The introduction of integrated cancer pathways has been a major step in the right direction for cancer care. Over the next few years, we will closely monitor how the **cancer pathways** are working, and provide constructive input for their improvement. During this period, much of our focus will be on the municipalities – where the patient's journey both starts and ends. The quality of treatment and care in the health service must be improved.

One of our ongoing goals is that more people should **survive** and **live longer with** cancer. This is another area where we endeavour to facilitate closer cooperation between users, research communities and the business sector in order that patients gain quicker access to effective diagnostics, treatment methods and new medicines. More clinical trials are needed, and we will strive to safeguard a better foundation for clinical cancer research.

Another strategic goal is **improved quality of life** for patients and their families. Much of the efforts will be aimed at ensuring compliance with the established rights of patients and their families. We will work to ensure that welfare technology is used where this can help improve quality of life for cancer patients and their families, and we will focus particularly on elderly patients, who often have other health problems in addition to cancer.

More **user-oriented** cancer care is the common thread in all of our activities; patients and their families are at the heart of everything we do. This perspective is highlighted as a specific goal during the strategy period. We will ensure that the user's voice forms the basis for all advances in cancer care, such as in technology and service development, and within research. Greater user involvement in prioritising NCS's own research resources is a vital part of this work.

Finally, a prerequisite for all our work is the goal of a **greater commitment to cancer awareness**. During the four-year period covered by the strategy, donors, members and volunteers will play an invaluable role in our efforts to improve cancer care.

*Anne Lise Ryel, General Secretary*

## NCS's vision

NCS's vision is '**Together we create hope**'.

## NCS's values

NCS's reputation and legitimacy rests on four values that we want the outside world to recognise us by: credibility, transparency, respect and commitment.

- NCS's **credibility** is built upon our knowledge and effective management of funds. We are credible when we communicate our message clearly and uniformly.
- **Transparency** for us means creating a broad and diverse debate about cancer. We also welcome collaboration and new ideas.
- We show **respect** by listening to the experiences and needs of individuals, and by introducing new knowledge and new solutions for the benefit of patients and their families.
- We create and share a **commitment** to cancer awareness, which sees patients and their families benefit from the resources found in society and our own resources.

## NCS's objectives

NCS's objectives as enshrined in the Articles of Association are to work to prevent and reduce the number of cancer cases, and to improve quality of life for patients and their families. These objectives will be realised through the following means:

- broad-based cancer research
- information (on the causes of cancer, manifestation, prevention and treatment)
- cancer care (help for cancer patients and their families)
- serving as a voice for the cancer cause
- international work and collaboration

Cancer patients and their needs are central to NCS's efforts.





# Norway will be a pioneer in cancer prevention

## **BY 2020, NCS AIMS TO:**

- initiate and implement intersectoral measures to prevent cancer, in cooperation with the authorities, the business sector and the voluntary sector
- take steps to make Norway a tobacco-free society
- identify effective measures for groups at risk
- influence the authorities and initiate measures aimed at reducing the prevalence of cancer among groups at risk
- help implement international health obligations, particularly in relation to smoking, and participate in international cooperation and knowledge sharing

The key factors associated with the risk of getting cancer are smoking, diet, inactivity, sunbathing, alcohol, infections, hormones, obesity, genes and factors in the environment and our surroundings, such as radon gas.

Our prevention work entails measures to reduce the risk of cancer and to help ensure a healthier society. As a pioneer, the results of new initiatives that we introduce will see other countries wanting to learn from us.

**INTERSECTORAL MEASURES:** Prevention in the health sector alone is not enough, and improvements are needed in the interaction between different sectors. NCS will initiate cooperation between sectors, levels of government and industry in order to identify solutions that reduce the risk of cancer.

**TOBACCO-FREE NORWAY:** The percentage of daily smokers has halved in the past decade, while the use of moist powder tobacco products (“snus”) has seen a steady increase. The prevalence of lung cancer remains high. NCS will play an active role in promoting measures to reduce tobacco use, particularly among high-risk groups.

**MEASURES AND ACTIVITIES WHERE THEY ARE NEEDED MOST:** Social inequalities in health and the diversity of the population are increasing. Getting the message across and implementing the right measures is therefore a greater challenge than ever before, and we still do not know enough about the effect of measures aimed at people with a low education and income. NCS can procure knowledge that enables more targeted measures.

**COMPLIANCE WITH INTERNATIONAL OBLIGATIONS:** International obligations in relation to tobacco must be complied with and followed up with measures. A concerted international effort is needed to reduce the tobacco industry’s power, and to help ensure that non-infectious diseases are fought globally. NCS can influence international decisions, such as in the UN and the EU, through knowledge and networking.





# Norway will be a pioneer of good patient pathways

## **BY 2020, NCS AIMS TO:**

- help improve the patient pathways for everyone with cancer, with a special focus on reducing inequalities in health
- lead the way in improving the health service and making it more efficient by conducting health service research and supporting innovative projects, and giving the patient more opportunities to spend time at home
- contribute to the greatest degree of equality possible in treatment in the health service, regardless of finances or geographic location
- help improve the quality of treatment and care in the primary health service, with a special focus on nursing homes
- help shorten waiting times for cancer treatment considerably, and to ensure a tailored rehabilitation pathway
- help ensure that all cancer patients and their families receive good support from their doctor, their pathway coordinators in the health trusts and municipalities, and ensure that this work is coordinated effectively

The patient pathway can be described as the road from suspicion to consultation, referral, assessment, treatment, follow-up and rehabilitation. A good patient pathway is characterised by continuity, with coordinated services and short waiting times.

As a pioneer, Norway will demonstrate good results for our patients and their families, which will make other countries want to learn from us.

**IMPROVED PATIENT PATHWAY:** The continuity, quality and interaction in the health service remains unsatisfactory for many cancer patients. NCS will lead the way in improving patient pathways, whilst also helping to reduce social inequalities in health.

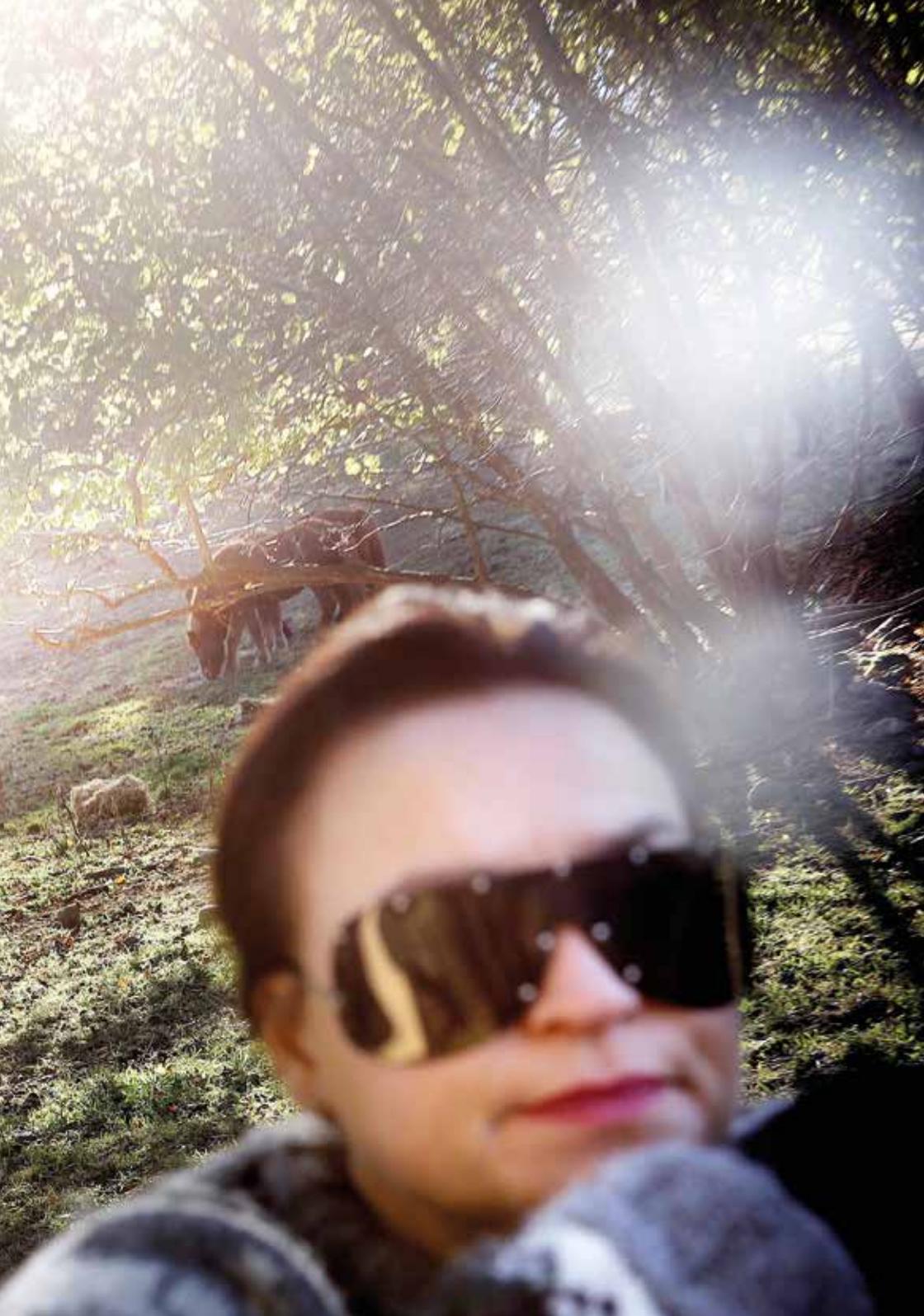
**SMARTER SOLUTIONS:** We are familiar with the challenges associated with organisation, task-sharing and new technical solutions in the health service. In the next strategy period, NCS will foster greater knowledge and help to initiate or stimulate innovative, collaborative projects.

**IMPROVING THE PRIMARY HEALTH SERVICE AND NURSING HOMES:** The Coordination Reform has meant greater responsibility for the primary health service in the treatment and care of the seriously ill. NCS will promote improvements to the follow-up of cancer patients in the municipalities. Nursing homes can be an intermediate stop between hospital and the home, and we will help to raise the status and quality of nursing home care.

**SHORTER WAITING TIMES AND MORE DIVERSITY IN REHABILITATION PATHWAYS:** Waiting times for cancer treatment must be reduced further. In addition, the rehabilitation of patients should be tailored to their needs. NCS will be a driving force in this area. In addition, we will continue to develop our own initiatives, such as the Varde centres for patients and cancer coordinators in the municipalities.

**BETTER INTERACTION AND MORE CONTINUITY:** In order to address the lack of continuity and coordination of services, NCS will strive to ensure a systematic collaboration between the patient's doctor, the pathway coordinator and the cancer coordinator.





# More will survive or live longer with cancer

## **BY 2020, NCS AIMS TO:**

- initiate collaboration between users, research communities, the authorities, the business sector and innovation environments. Promote quick patient access to new and improved methods of treatment, medicines and screening programmes
- conduct research on cancer, its causes and treatment, with a special focus on learning about cancer patients who have other additional health problems
- help improve the foundation for clinical trials and for more clinical trials to be conducted
- help ensure that patients are given a more precise diagnosis and more tailored treatment
- ensure that larger parts of the population and more professionals are familiar with the warning signs of cancer

An increased survival rate means that the number of years of quality life lost due to cancer will be reduced. When cancer is detected early, the treatment options are greater. New cancer medicines and treatment methods means that patients who cannot be cured can have a good quality of life for longer. Research, innovation and new technologies are instruments that drive medical advances.

Research is and must remain an important strategic priority for NCS and constitute the largest part of NCS's resource use. NCS is drawing up an action plan for research.

Living longer with cancer means that patients who cannot be cured can have a good quality of life for longer. Patients must also be given the opportunity to decline treatment that does not contribute to their quality of life.

**POOLING RESOURCES TO HASTEN THE DISSEMINATION OF NEW KNOWLEDGE TO PATIENTS:** When it comes to adopting new knowledge and technology, Norway is lagging behind. We also have room for improvement in terms of introducing new cancer medicines, treatment methods and screening programmes. Cancer treatment requires specialist expertise, but the expertise is scattered. NCS will be a driving force in linking research and innovation communities, the authorities and users, ensuring that all parties interact with a view to developing new treatment methods and medicines.

**KNOWLEDGE AND TREATMENT OF CANCER AND OTHER SERIOUS ILLNESSES:** We need more research on cancer, cancer treatment and effects of treatment. Many cancer patients, however, also have other serious illnesses that impact upon the patient pathway. NCS will help gain more knowledge on this.

**CLINICAL TRIALS:** A prerequisite for using new treatments and medicines is good clinical trials documenting efficacy. In Norway, the foundation for clinical trials is inadequate. In addition to funding various studies, NCS must be an active proponent of better conditions for clinical research.

**TAILORED DIAGNOSTICS AND TREATMENT:** We are about to progress from more or less the same treatment for all patients with the same cancer diagnosis to treatment that is adapted to the individual patient. NCS can fund research and serve as a strong advocate of tailored treatment.

**WARNING SIGNS OF CANCER:** There are still too many people who are not familiar with the warning signs of cancer. The result is that cancer is detected at a late stage, and the prognosis is therefore not as good. GPs have a key role to play here, and NCS will help this target group to recognise the warning signs.





# Better quality of life for patients and their families

## **BY 2020, NCS AIMS TO:**

- strengthen patients and their families' rights to health and welfare services, and increase their opportunities for participating in society and working life
- improve patients and their families' ability to cope during and after illness by developing good care provisions and new welfare technology
- provide more information on and research into how to improve quality of life and living conditions, especially for those living with incurable cancer or late effects after treatment
- improve quality of life for cancer patients, with a particular focus on the elderly with several health problems

Home life, family relations, education, finances, physical and mental health along with specific late effects of a serious illness are all factors that affect quality of life. Improving quality of life enables past and present cancer patients to have the best quality of life possible despite having a serious illness, and this also applies to their families and bereaved relatives.

**RIGHT TO HEALTH AND WELFARE SERVICES:** In certain areas, the rights of patients and their families are not strong enough. Nor is it always the case that the authorities comply with the statutory rights of patients and their families. In general, the provision of financial guidance for patients is inadequate. NCS will develop its own provision in addition to serving as a proponent of safeguarding and strengthening the rights of patients and their families.

**RIGHT TO WORK AND BE PART OF SOCIETY:** Going back to work can be a challenge after cancer treatment. Work has a major impact on a person's quality of life and on the economy. NCS will lead the way in helping patients to combine work, illness and treatment, and to ensure that cancer patients are helped to integrate into society after treatment.

**MANAGING A SERIOUS ILLNESS:** Cancer can make it difficult to manage everyday life. NCS can help improve patients' management of the illness through tailored provisions from NCS's volunteers and the municipality, and by adopting new ICT tools.

**LEARNING ABOUT WHAT WORKS:** We understand the patients' needs, but are not as familiar with the measures needed to improve quality of life, especially for those living with incurable cancer and those suffering from late effects after treatment. NCS can initiate systematic procurement of knowledge on measures that have a positive effect on quality of life.

**RISING NUMBERS OF ELDERLY:** The elderly population is growing, and the level of knowledge on cancer treatment and care for the most elderly patients needs to be stepped up. NCS can help to provide knowledge and propose solutions that are tailored to the needs of this group.





# More user-oriented cancer care

## **BY 2020, NCS AIMS TO:**

- ensure user involvement in prioritising and distributing NCS's research funds
- help ensure that the user's voice sets the terms for prioritisation and development of new technologies, services and research
- procure systematic knowledge of patients and their families' needs
- facilitate support for cancer patients and their families to make difficult choices, by providing good information, tools and opportunities for dialogue, and to make decisions together with health personnel

Patients and their families should provide input to the development of cancer care. This includes helping to devise measures and the right to make decisions about their own lives.

**USER INVOLVEMENT IN RESEARCH:** User involvement in research can make research more relevant. NCS can contribute to user representation in its own research allocations, and influence others to listen to the users.

**SYSTEMATIC USER REPRESENTATION:** Some councils, boards and committees in the health and welfare sector still have no user representation. NCS can provide expertise on patients and their families' experiences and can promote greater user representation.

**SYSTEMATIC KNOWLEDGE ON USER NEEDS:** In order to promote effective services and relevant research, we need to learn more about actual needs. NCS will contribute through a user panel and a close dialogue with cancer patients and their families, and will commission research and investigations.

**HELP TO MAKE DIFFICULT CHOICES:** Cancer patients and their families are often faced with difficult choices. NCS can provide information and useful tools that make it easier to make choices in line with their own values and preferences. We will continue to be a preferred source of support and information about cancer.





# Greater commitment to cancer awareness

## **BY 2020, NCS AIMS TO:**

- increase support for and awareness of cancer among the population, politicians, policy-makers, professionals and researchers
- engage members, donors, sponsors, volunteers and the population in general in supporting the cancer cause
- reach out to a large audience with our message and activities by being the preferred organisation for volunteers
- increase support for and awareness of cancer by developing an organisation that is portrayed as innovative, informative and cost-effective, as well as the most attractive employer in the voluntary sector

NCS creates and shares a commitment to cancer awareness, which sees patients and their families benefit from society and our own resources.

**CANCER AWARENESS ON THE AGENDA:** Cancer is one of the fastest growing diseases in the world, and is the number one killer of the under 75s. Cancer awareness is rightfully an important item on the political agenda, and attracts highly competent professionals and researchers. By being a constructive and collaborative contributor, NCS will ensure that the interest is maintained, whilst paving the way for solutions that also benefit other diseases.

**SUPPORT AMONG THE POPULATION:** NCS works continuously to maintain its solid reputation. The wide popular support we receive enhances our standing and is essential for increasing membership and revenues. NCS will create arenas that make it easy to get involved.

**REVENUES:** The competition for members, sponsors, gifts and public funds is always tough. NCS must continue its efforts to secure income and, in particular, must attract contributors by effectively promoting its various projects and activities.

**VOLUNTEERS:** Norway needs a large commitment from the voluntary sector in order to address the future challenges in the health and welfare sectors. NCS can develop a multitude of meaningful and sought-after activities for the benefit of the cancer cause. We need dedicated and skilled volunteers to undertake this work. In order to be the preferred organisation for volunteers, we must be attractive to those who choose to spend their time on our cause.

**TOP OF THE CLASS:** NCS will serve as a social contributor that is able to think creatively and initiate innovative measures. We are developing this skill through competent and dedicated employees and good leadership. NCS will reach out even farther afield, and must better reflect the diversity of the population. We must ensure that we are an attractive employer that attracts a diverse pool of competent employees.



NORWEGIAN  
**CANCER SOCIETY**