



2020-2024

Strategy for The Cancer Registry of Norway



# The Cancer Registry of Norway: Strategy for 2020-2024

## Executive summary

The Cancer Registry of Norway was established in 1952 and is one of the oldest national cancer registries in the world. All medical doctors in the country are required by law to notify the Cancer Registry of new cancer cases, including suspected cases without a verified diagnosis, and cases identified during autopsy. These established routines yield data that are timely, accurate, and close to complete.

The core objective of the Cancer Registry is to establish knowledge and disseminate information which contributes to reducing the burden of cancer in Norway. The Cancer Registry Regulation (Kreftregisterforskriften, kgl. res. 21. December 2001), which is in turn grounded in the Personal Health Data Filing System Act, describes the main objectives of the Cancer Registry thusly:

- **Registration:** Collect and, within the bounds of the regulations, process data on cancer patients in Norway to map the occurrence of cancer in the country and monitor changes over time.
- **Research:** Conduct, promote, and provide a basis for research to develop new knowledge about the causes of cancer, diagnosis, cancer prevention, natural history, and treatment effects.
- **Information on cancer health care:** Provide advice on preventive measures and cancer health care.
- **Cancer prevention:** Provide advice and information on cancer preventive measures to the government and to the general population.

The Cancer Registry is also responsible for Norway's national breast and cervical cancer screening programs: BreastScreen Norway and CervicalScreen Norway. The goal of these programs is to prevent cancer death through the early detection and treatment of cancerous or precancerous lesions. In 2012, the Cancer Registry of Norway was also given the responsibility to coordinate and oversee a pilot program of colorectal cancer screening. This pilot program is to be expanded and rolled out as a national screening program in 2021.

The Cancer Registry consists of about 200 people, including 40 researchers with backgrounds in fields such as medicine, statistics, informatics, and psychology, and it is organized into departments and sections: Department of Registration, Department of Registry Informatics, Department of Research, Department of Administration, and three Screening Sections: Section of cervical cancer screening, Section of breast cancer screening and Section of colorectal cancer screening.

The Cancer Registry of Norway is organised as a division under Oslo University Hospital Trust, with its own strategic advisory council. The core activity of the Cancer Registry of Norway is financed through the state budget while research conducted is typically supported by research grants and fund from different sources.

## Our mission

To contribute to a reduction in the burden of cancer

## How we work to accomplish our mission

### Prevention

- Develop new knowledge on causes of cancer and cancer prevention
- Provide evidence-based advice and information on cancer prevention
- Evaluate prevention strategies

### Early detection

- Investigate different approaches for early detection of cancer
- Improve the existing cancer screening programs
- Establish a national colorectal cancer screening program
- Further develop national and international expertise within cancer screening

### Improvement of cancer care

- Use Cancer Registry data for quality control and improvement of the health services
- Gain knowledge about cancer outcomes reported by patients and the long-term effects of cancer treatment

## Our main tasks

- To register all cancer cases in Norway
- To make cancer data and statistics available for planning, quality control, and research
- To conduct epidemiological cancer research of high international quality
- To manage, monitor, quality assure, and further develop national cancer screening programs
- To advise health authorities and the public on measures that can prevent cancer and reduce the cancer burden

## Focus areas for 2020-2024

### Research and methods

- To explore personalized cancer prevention
- To use new methods to eliminate cervical cancer
- To apply machine learning methods in epidemiology and cancer screening
- To use biobanks to identify new molecular markers
- To identify inequities in cancer care

### **Infrastructure and dissemination**

- To facilitate automated reporting on the use of cancer drugs
- To establish a national colorectal cancer screening program
- To include patient-reported outcome measures in all clinical registries
- To communicate advice on cancer prevention
- To make cancer data easily accessible to different user groups

## **Aims and focus areas by Department / Section**

### **Department of Registration**

- To ensure minimum 80% completeness of clinical reports to all quality registries
- To establish a data extraction solution / data warehouse
- To use patient-reported outcome measures in research projects

### **Department of Registry Informatics**

- To provide a digital platform for secure data handling and efficient workflow

### **Department of Research**

- To focus on personalized cancer prevention
- To conduct applied research on modifiable risk factors for cancer
- To explore molecular markers in cancer prevention using biobanks

### **Department of Administration**

- To contribute to keeping the Cancer Registry relevant and agile through the recruitment of highly competent researchers and professionals, as well as through the provision of necessary administrative support

### **Section of cervical cancer screening**

- To implement human papillomavirus screening nationally and establish self-sampling options within the screening program CervicalScreen Norway

### **Section of breast cancer screening**

- To contribute to increased knowledge about breast cancer screening, and implement the knowledge gained in the screening program BreastScreen Norway

### **Section of colorectal cancer screening**

- To establish a national colorectal cancer screening program ColorectalScreen Norway

## Criteria we depend on in order to succeed

### **Relevant competence**

- Preserve and establish new collaborations with internationally recognized research institutions
- Create and maintain a community of leading researchers within the fields of cancer epidemiology, screening, and statistics
- Obtain competence in recent artificial intelligence- and machine learning methods in cancer Epidemiology

### **Accurate communication**

- Make registry statistics easily accessible and adapted for different user groups
- Improve public knowledge about cancer and cancer prevention
- Adapt advice and information to different target groups of the public

### **Adequate funding**

- Secure sufficient funding from the state budget to ensure regular activities
- Develop a strategy to secure basic as well as additional funding from the state budget for modernization of the breast cancer screening program
- Secure sufficient funding for continuous maintenance and further development of the quality registries
- Develop a strategy for research and project funding

### **Interdisciplinary digitization**

- Establish new information and technology platform for the screening programs
- Ensure appropriate data flow, from the receipt of cancer notifications to the dissemination of data
- Adapt internal data models to international standards
- Migrate all cancer data to the new information and technology platform
- Develop a data warehouse



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