



2016-2019

Strategy for The Cancer Registry of Norway

The Cancer Registry of Norway

Strategy 2016 – 2019

Our Mission

The Cancer Registry will fight cancer and the challenges that are caused by this disease.

Our Main Tasks

Recording of all cancer cases in Norway is central to the Cancer Registry's activities. All medical practitioners are required by law to notify the Cancer Registry of new cancer cases, and as a result the reporting since 1953 is nearly complete. The combination of a unique personal identification number for each individual Norwegian resident and linkage with population-based registries enable tracking of trends of cancer incidence, cancer survival and cancer mortality within the entire population over time.

In addition to recording data on cancer the main goals are to

- Perform epidemiological research of high international standard within the following areas:
 - Incidence, trends and predictions of cancer cases
 - Causes of cancer (primary prevention)
 - Cancer screening (secondary prevention)
 - Natural history, diagnosis and effect of treatment (tertiary prevention)

Manage, evaluate and further develop the cancer screening programs

Provide advice and guidance regarding cancer prevention measures and cancer health care.

Primary Prevention

Primary Prevention is to prevent cancer from occurring. The Cancer Registry of Norway is mapping the incidence of cancer and contributes to knowledge on causes of cancer.

The Cancer Registry will drive cancer epidemiological research at high international level within:

- Cancer incidence, -survival, -mortality and predictions (descriptive cancer epidemiology)
- Causes of cancer
 - Lifestyle factors
 - Occupational hazards / external exposures
 - Hereditary factors and frailty
- Biomarkers for early detection of cancer
- Cancer prevention among high-risk groups
- HPV-vaccination and HPV-related cancers

The Cancer Registry will ensure optimal conditions for primary prevention by

- Maintaining high data quality
- Presenting results and statistics that portray a picture of cancer in Norway both today and tomorrow, including comparisons with other Nordic countries
- Contributing to reducing differences in cancer incidence by pointing out inequalities in socioeconomics, residence, and country of origin
- Increasing the number of externally financed research projects, as well as working towards establishing a research centre of excellence
- Initiating, leading and participating in national and international research projects and consortia
- Further developing information and communication technologies (ICT) solutions for effective data flow

Secondary Prevention

Secondary prevention includes detection and treatment of precancers, and early cancer intervention. The Cancer Registry administers, undertakes quality control, and performs research-based evaluation of the screening programs.

The Cancer Registry will continue to ensure that the best possible screening program is offered to the population by:

- Maintaining high quality in all parts of the program through continuous quality assurance, evaluation and by performing research based on timely data
- Establishing validated quality targets to ensure high quality in all parts of the program/pilot project and subsequent treatment
- Establishing additional services for the population “innbyggertjenester”, with particular focus on access to test results and screening history
- Developing a joint communication strategy for the screening programs
- Investigating opportunities and consequences of personalising the screening programs based on risk profiles (stratified screening)
- Further developing the collaboration with clinical experts
- Developing and implementing a new ICT platform for the screening programs

The cervical cancer screening program will also

- Increase attendance to the program
- Facilitate implementation of HPV testing as primary screening
- Achieve 100% electronic reporting from the laboratories and hospitals

The breast cancer screening program will also

- Investigate the knowledge base for and consequences of a potential change in target group for the program
- Contribute to the knowledge base for assessing whether digital tomosynthesis (3D-picturing) is suitable as a new breast cancer screening method

Pilot project for national colorectal cancer screening program

- Contribute to the knowledge base to enable a decision whether to establish a national colorectal cancer screening program
- Propose solutions for logistics and IT-solutions for a national program

The Cancer Registry will contribute to increasing knowledge regarding early detection and prognostic factors by:

- Performing research on
 - Early biomarkers for cancer
 - Genetics and epigenetics
- Increasing utilisation of the Janus serum biobank
- Participating in the development and testing of new screening methods including stratified screening
- Considering additional new screening programs
- Mapping the use of screening outside of the organised screening programs

Tertiary Prevention

Tertiary prevention is to minimise and reduce the negative consequences of cancer by offering cancer patients the best available examination, treatment and follow-up. The Cancer Registry contributes with knowledge and competence about the health services which can reduce cancer mortality and increase survival.

The Cancer Registry will have high quality data

- Maintain >98% completeness on data regarding cancer incidence
- Achieve 90% completeness on data from the established clinical registries regarding diagnosis, treatment and follow-up
- Further develop the Cancer Registry ICT platform with respect to reporting and operation of the registries to ensure both efficient receipt of data on cancer, as well as accessibility for statistical analyses and research
 - Further develop electronic solutions for clinical reporting to the Cancer Registry and sending out reminder letters, by
 - Establishing structured reporting of pathology reports through use of pathology templates
 - Make updated clinical statistics available to those who report
 - Increase repurposing of data to minimise duplet recordings of data
 - Collect data from other registries and systems within the hospital sector
 - Work towards integration of cancer reporting using structured electronic patient journals
 - Investigate repurposing of data from other sources
 - The Cancer Registry will actively participate in decision making forums regarding national ICT-solutions, to ensure that the needs of the Cancer Registry are covered

The Cancer Registry will contribute to improving the quality of the health service by:

- Ensuring continuous reporting of results from the hospitals for local quality assurance, to reduce unwanted discrepancies in the health service
- Improving accessibility of statistics for the full patient history
- Further developing relevant quality measures to ensure improvement of the health service
- Making updated national statistics available as soon as possible
- Establishing at least eight new clinical registries, to contribute to improved quality for several groups of cancer patients

The Cancer Registry will establish user involvement for the Clinical Registries

- The Cancer Registry will initiate collaboration with patient organisations to obtain advice regarding design of reports and information, as well as targets for the clinical registries to work towards
- The Cancer Registry will generate solutions for collecting patient reported outcome measures for the clinical registries

The Cancer Registry will perform research and provide competence within clinical epidemiology by

- Performing research on the effect of diagnosis, treatment and follow-up of the cancer patients, in collaboration with the clinical research areas, including population-based studies of the use and effectiveness of new cancer drugs
- Documenting whether equivalent health service is offered to all inhabitants, independent of socioeconomics, residence, country of origin and other factors

Advice and information

The Cancer Registry will be visible and clear in public. We will contribute to improving the knowledge base on cancer incidence, causes of cancer and how to prevent cancer

We will do this by

- Working towards measures that can prevent cancer and lead to better prognosis following a cancer diagnosis
- Generating a foundation enabling the screening target group to undertake informed choices regarding participation in screening
- Demonstrating why cancer statistics, the Cancer Registry's population-based research and results from the various clinical registries make an important foundation for decision making within cancer care
- Contributing with professional competence within the public space



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