

ANCR & NCU Symposium 2016

Gustavelund, Tuusula, Finland
30 August – 1 September 2016

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Organised by

Cancer Society of Finland

Finnish Cancer Registry - Institute for Statistical and Epidemiological Cancer Research

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Program



Tuesday 30 August

12:00 -16:00 ANCR Board meeting (room 6)

14:00-17:00 Presymposium workshops

About 15

Coffee & snack

Presymposium Workshop 1 (meeting room 10), coordinated by Juho Nurmi

Current challenges in cancer coding

Examples of topics that may be discussed are listed below.

- case reports; challenging cases
- multiple primaries in different topographical sites (e.g., colorectal cancer C18-20)

Urinary tract C65-C68

- urothelial neoplasms – urinary papilloma – changes in time; new WHO – urothelial papilloma is benign
- multiple neoplasms – same time – different time – different behavior of tumour at the same
- how your registry deals with

Haematological malignancies

- transformations, how do you code
- multiple neoplasms
- ICD-O-3 vs. WHO classification vs. ENCR 2012 recommendations

Teaching / acquainting of a new coder

How to acquaint a new coder? What kind of knowledge should a new coder have before starting cancer coding (education etc.)? How to organise the work; should it be done by sorting out the organs/topographical sites/ or by diagnoses/cancer types/PADs? How to teach effectively? How to find latest news and to use reference sources?

Presymposium Workshop 2 (meeting room 8), coordinated by Kaius Perttilä

Cancer Registry IT

Examples of topics that may be discussed are listed below.

Big data and Cancer Registries – open discussion regarding the need of a big data approach for cancer registries' future data collection.

- **why** would we want big data, including unstructured and non-required data?
- **will** the collection of big data affect the official mission of cancer registries?
- **who** will, or might, need this data?
- **what** is it going to be used for?
- **when** will there be a need for receiving/processing/providing the data?

16:30-18:30

NORDSCREEN meeting (room 7)

18:00-20:00

Barbeque party with outdoor games

20:00-22:00

Sauna & swim



Wednesday 31 August

7:00-9:00 *Morning sauna & swim*
6:30-9:00 *Breakfast*



ANCR Symposium (Auditorium)

| | |
|-------------|---|
| 9:00-9:10 | Opening |
| | Session 1: Registration (Chair: Gerda Engholm) |
| 9:10-9:30 | Guest presentation <u>Liesbet Van Eycken</u> : 10 Years of Cancer Registry activities in Belgium - descriptive epidemiology and evaluation of quality of care |
| 9:35-9:45 | <u>Helgi Birgisson</u> : Comparison of Icelandic clinical data to data from the regional clinical quality register for colorectal cancer in Uppsala-Örebro region |
| 9:50-10:00 | <u>Stein Aaserud</u> : Web based real-time reporting system for the clinical cancer registries in Norway |
| 10:05-10:15 | <u>Kristine Skovgaard Bossen</u> : Different sources on identical cancer measurements – advantage or disadvantage? |
| 10:20-10:30 | <u>Miriam Elfström</u> : Evidence-based quality indicators of cervical cancer screening and their prioritization |
| 10:35 | <i>Coffee break</i> |
| | Session 2: Aetiology (Chair: Giske Ursin) |
| 10:50-11:00 | <u>Matti Rantanen</u> : Estimating cancer heritability in a young cancer patient family cohort in Finland |
| 11:05-11:15 | <u>Rasmus Hertzum-Larsen</u> : Testicular cancer risk among cryptorchid boys in eastern Denmark |
| 11:20-11:30 | <u>Marte Myhre Reigstad</u> : Risk of cancer after fertility treatment – population-based studies on women treated with and children conceived by assisted reproduction |
| 11:35-11:45 | <u>Allan Jensen</u> : Endometriosis and risks for ovarian, endometrial and breast cancers: a nationwide cohort study |
| 11:50-12:00 | <u>Jorma Sormunen</u> : Physical activity at work and cancer in men, results from the NOCCA project |
| 12:05-12:15 | <u>Kirsti V Hjerkind</u> : Ethnic differences in the incidence of cancer in Norway |
| 12:20 | <i>Lunch break</i> |

Chaired poster tour 1: Screening (Chair: Miriam Elfsröm)

10. Maija Jäntti: The impact of colorectal cancer screening invitation on health-related characteristics of lifestyle in Finland
11. Sanna Heikkinen: Proportion of women with self-reported opportunistic mammography before organized screening
12. Sanni Helander: Lifestyle effects of colorectal cancer screening – population-based survey study in Finland
13. Petra Makkonen: Effect of organized screening and opportunistic testing in cervical cancer in Finland among young women
14. Stefan Lönnberg: Audit of screening histories and the effectiveness of screening
15. Stefan Lönnberg: Randomised intervention to increase cervical screening participation by scheduled screening appointments
16. Mari Nygård: Randomized implementation of primary high risk human papilloma virus testing for cervical cancer screening in Norway
17. Maiju Pankakoski: Cumulative probability of abnormalities in organized cervical cancer screening
18. Deependra Singh: Cumulative risk of false-positive test in relation to breast symptoms in mammography screening: a historical prospective cohort study

Chaired poster tour 2: Statistical methods, information systems

(Chair: Sirpa Heinävaara)

20. Niels Christensen: Big tables with small number cells
21. Gerda Engholm: Prediction of incident cancers in Denmark using NORDCAN
22. Ylva Maria Gjelsvik: Establishing a national system for collection of Patient Reported Outcome Measures (PROMs)
23. Rune Kvåle: Breast and prostate cancer in four Nordic countries: A comparison of incidence and mortality trends between countries and age groups in the period 1975-2013
24. Maarit K Leinonen: Completeness and validity of the cancer data in the Finnish Cancer Registry
25. Joonas Miettinen: Spillover improves survival in non-invited patients of the Finnish colorectal cancer screening programme
26. Janne Pitkäniemi: Estimating regional multilevel variation in excess mortality of cancer patients using integrated nested Laplace approximation
27. Heidi Ryyänänen: Age period cohort incidence model for breast and testis cancer using integrated nested Laplace approximation
28. Wendy Yi-Ying Wu: Estimation of overdiagnosis in breast cancer screening using a non-homogenous multi-state model: a simulation study

Chaired poster tour 3: Other topics (Chair: Laufey Tryggvadóttir)

30. Liv Marit Dørum: Clinical registries in Norway – tools in evaluation of quality of cancer care
31. Merete Ellingjord-Dale: Alcohol, physical activity and breast cancer subtypes in a nested case-control study from the Norwegian Breast Cancer Screening Program
32. Anna Genell: Comparison between observed and expected costs, of health care given to breast-cancer patients in western Sweden 2009 – 2014
33. Tiina Hakanen: Induced abortions and pregnancies in Finnish childhood cancer survivors
34. Lena Holmstrøm: User involvement – unnecessary meddling or obvious necessity?
35. Mats Lambe: Socioeconomic factors and penile cancer risk and mortality; a population-based study
36. Nea Malila: Delays in the patient path of breast cancer in Finland
37. Cecilie Dyg Sperling: Statin use and the risk of endometrial cancer: a Danish nationwide case-control study
38. Håvard Thøgersen: Norwegian immigrants with cancer: Use of health services, treatment and survival
39. Mari-Liis Zimmermann: Recent trends in cancer incidence, mortality and survival in Estonia

Session 3: Patient pathway, survival (Chair: Mats Lambe)

- | | |
|-------------|--|
| 14:20-14:30 | <u>Ole Andersen</u> : The Danish cancer pathways (CPPs) |
| 14:35-14:45 | <u>Anna Genell</u> : The Swedish Multiple Myeloma Registry: Survival exceeds 7 years in patients 65 years and younger, diagnosed 2008-2013 |
| 14:50-15:00 | <u>Yngvar Nilssen</u> : Regional differences in survival in relation to resection: a national population-based study of non-small cell lung cancer in Norway |
| 15:05-15:15 | <u>Jane Christensen</u> : Comparison of the Danish Cancer Register and the Danish Colorectal Cancer Group database |
| 15:20-15:30 | <u>Anna LV Johansson</u> : Tumor characteristics and prognosis in women with pregnancy-associated breast cancer |

15:35 *Coffee & snack*

16:00 *Social-cultural-sportical program*

18:30 *Science discussions at posters, getting beautiful for the dinner*

19:30 *“Las Palmas” gala dinner under the palm trees*

22:00 *Discotheque (voluntary)*



Thursday 1 September

7:00 *Early bird jogging*
7:00-9:00 *Morning sauna & swim*
6:30-9:00 *Breakfast*



NCU Symposium (Auditorium)

9:00-9:10 Opening by the chairman: Sakari Karjalainen

Session 5: Risk factors

9:10-9:30 Hans Storm: Priorities and challenges in primary prevention and risk communication in the Nordic countries

9:35-9:45 Janne Pitkääniemi: Cohort based population attributable fractions for lung, breast and colorectal cancer in Finland

9:50-10:05 Therese Andersson: Avoidable cancer cases in the Nordic countries

10:10 *Coffee break*

Session 6: Screening

10:30-10:40 Views of cancer screening (extended introduction by the chairperson: Nea Malila)

10:45-10:55 Maarit K Leinonen: Cervical cancer screening non-adherence among immigrants in Norway

11:00-11:10 Ilona Siljander: Cumulative probability of false positive results in the Finnish breast cancer screening program

11:15-11:25 Suvi Mäklin: Colorectal cancer screening does not affect long-term health-related quality of life

11:30-11:40 Stefan Lönnerberg: Is there need for broader Nordic collaboration?

11:50-12:00 General discussion

Session 7: Cost of cancer

12:00-12:20 Paulus Torkki: Cost of cancer in Finland – new estimates

12:25 Closing remarks

12:30 *Joint work meeting for NCU & ANCR Boards & Farewell lunch for all others*

13:30-16:00 NCU Board meeting (room 6)

ABSTRACTS

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Web based real-time reporting system for the clinical cancer registries in Norway

Stein Aaserud¹, Huidong Tian¹, Siri Larønningen¹, Ann Helen Seglem¹, Liv Marit Dørum¹, Jan F. Nygård² and Bjørn Møller¹

¹Department of Registration, Cancer Registry of Norway, Oslo, Norway; ²Department of Registry Informatics, Cancer Registry of Norway, Oslo, Norway

Background

Clinicians are required to report extensive amounts of data to the clinical registries for nine cancers in Norway. Until this year, an annual hospital report was the only result from this extensive reporting. Our real-time reporting system, composed of web-based applications developed in R with the *shiny* package, presents administrative and clinical statistics from these registries back to the individual health trusts/hospitals. With this system, which is a part of the Cancer Registry of Norway's electronic reporting service (KREMT), clinicians can get updated statistics for their health trust/hospital.

Material and method

The Cancer Registry of Norway receives clinical notifications electronically from the hospitals in Norway and stores them in a database. Every night our reporting system extracts, preprocesses and transfers the data out of our secure zone to the system server, where users of the Norwegian Health Net (NHN) can access them. The reporting system allows the users to get different reports/analysis for each cancer site and compare their result with those at national level. Higher-level users can also compare the results between lower-level users. The reports/analysis were chosen by our reference groups, consisting of clinicians, pathologists and researchers working with the respective cancer sites.

Results

The presentation will include a demonstration of the reporting system. A demo-version of the system is available at <https://kremt.kreftregisteret.no/> under the tabs "Administrativ Statistikk" and "Klinisk statistikk".

Conclusion

The application is new. However, early feedback has indicated that by reporting cancer statistics back to the reporting health trusts/hospitals immediately, the clinicians get an increased ownership to the information they have reported and a higher motivation for reporting. In addition, the system can be used as a tool in the clinical work.

The Danish cancer pathways (CPPs)

Ole Andersen, consultant, MD, DMSc, MHM

The Danish Cancer Society

Background: In 2007, the times for diagnostic work-up and treatment of Danish cancer patients were long, and survival rates were lower than in other Nordic countries. Thus, the Danish government and the health regions agreed to prepare and implement structured pathways for patients with alarm symptoms of cancer. A CPP is a structured, standardized description of the diagnostic work-up and treatment of each cancer site.

Results: Twenty-six organ-specific CPPs plus a CPP for metastatic cancer of unknown origin and a CPP for patients with non-specific symptoms were prepared in collaboration between health professionals and administrators under the leadership by The Danish Health Authority (Sundhedsstyrelsen). A board of professionals and patient representatives gave advice on the CPPs and an administrative task force was in charge of the implementation in the health regions in 2007-2009. Later work-days in the CPPs were changed into calendar days making a national monitoring of time from referral to initiation of treatment possible from 2013.

Conclusion: CPPs have changed the organization of the patients' courses and stressed the importance of coordination and multidisciplinary collaboration. Time to treatment has decreased especially for the long patient courses, and the Danish survival rates have increased. Successes and challenges of CPPs will be discussed. Denmark was the first country to implement national, structured CPPs. Later Norway and Sweden have followed using the Danish CPPs as models.

Avoidable cancer cases in the Nordic countries

Therese M-L Andersson^{a,b}; Gerda Engholm^a; Elinborg Olafsdottir^c; Eero Pukkala^{d,e}; Magnus Stenbeck^f; Elisabete Weiderpass^{b,g,h,i}; Laufey Tryggvadottir^c; Hans Storm^j

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It is of great importance to quantify how much the cancer burden could be reduced by changing the exposure prevalence of different risk factors. The population-attributable fraction (PAF) provides such a quantification of the total effect of a risk factor on disease burden. However, complete removal of a risk factor is unrealistic and an evaluation of different interventions is of far more use from a public health perspective.

The aim of this project is to quantify the proportion of the current cancer burden in the Nordic countries linked to the risk factors overweight, tobacco, alcohol and low physical activity, and how the cancer burden would change under different prevalence levels for these risk factors. More specifically, we will present the number of avoidable cancer cases during the coming 30 years, in the Nordic countries, under different realistic scenarios of risk factor prevalence.

Preliminary results show that a total of 197 000 cancer cases could be avoided in the Nordic countries over the period 2016-2045 by eliminating overweight and obesity, and even small changes in the prevalence of overweight and obesity would decrease the number of colorectal cancers by 13 000.

The results from this study can be used to understand the potential impact and significance of primary prevention programs targeted towards reducing overweight, tobacco use and alcohol consumption and to increase the level of physical activity in the and Nordic countries.

Comparison of Icelandic clinical data to data from the regional clinical quality register for colorectal cancer in Uppsala-Örebro region

Birgisson H^{1,2}, Tryggvadóttir L^{1,3}, Kristín Alexíusdóttir¹, Fredrik Sandin⁴, Lambe M^{4,5}

¹ Icelandic Cancer Registry; ² Department of Surgical Sciences, Uppsala University, Sweden; ³ Faculty of Medicine University of Iceland; ⁴ Regional Cancer Center Uppsala-Örebro, Sweden; ⁵ Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Sweden

Introduction

The Icelandic Cancer Registry has started the process of implementing clinical registration comparable to the Swedish INCA system.

The aim of this study was to examine whether clinical variables for colon and rectal cancer already recorded in Iceland are comparable to data from the Swedish Colorectal Cancer Register (SCRCR).

Methods

To date, mainly histopathological variables have been registered for colon- and rectal cancer in Iceland. These variables were compared with SCRCR data from the Uppsala-Örebro Region (UÖR) in Central Sweden for the calendar year 2014.

Results

The number of cases with colon (n=115) and rectal cancer (n=51) was on pair with the number reported from the larger hospitals in the UÖR. T1 tumours were more common in Iceland (colon 13%, rectum 16%) compared to UÖR (colon 5%, rectum 8%). While colon T2 cancers were more common in Iceland (20% vs 12 %) a similar pattern was not observed for rectal cancer. The proportion of patients with 12 or more lymph nodes analysed was lower in Iceland (colon 71%, rectum 42%) compared with UÖR (colon 94%, rectum 80%).

Conclusion

These findings indicate that there is place for improvement in the number of lymph nodes analysed from colon and rectal cancer specimens in Iceland. For colon cancer, T1 and T2 tumours were more common in Iceland, possibly reflecting a higher screening activity. For countries implementing a clinical quality register for cancer, it is important to have the possibility to compare and bench-mark clinical data with established registers like those in Sweden.

Comparison of the Danish Cancer Register and the Danish Colorectal Cancer Group database

Christensen J¹, Iversen LH², Ingeholm, P³, Andersen, O¹

¹ Documentation and Quality, The Danish Cancer Society. ² Department of Surgery, Aarhus University Hospital.

³ Department of Pathology, Herlev University Hospital, Chairman of The Danish Colorectal Cancer Group Database

Background

In 2014, The Danish Cancer Register (DCR) reported 5.368 new cases of colon or rectum cancer. In the same year, The Danish Colorectal Cancer Group (DCCG) reported 5,188 new cases of colon or rectum cancer. There is thus a slight discrepancy between the two population-based registers. However, there is variation between the inclusion criteria of the DCR and the DCCG-database and further on information about e.g. stage and time of diagnosis. The significance of these differences on survival has not previously been qualified nor quantified.

Methods

Descriptive statistics will be used for the comparison of data from DCR and DCCG in the period 2004-2014. The inclusion criteria from DCCG will be applied to DCR. For the period, 2013-2014 1-year survival will be calculated using a Cox proportional hazard model for patients with colon or rectum cancer in a) both in DCR and DCCG, b) DCR only, and c) DCCG only.

Results

In the period 2004-2014 DCR registered 42.226 cancer patients and DCCG included 44.179 patients. When combining the two registries we have a total of 46.012 patients diagnosed with colon or rectum cancer. Of these 88% were included in both registers, in addition, 4% were only included in DCR and 8% were only included in DCCG.

Estimates for 1-years survival will be calculated

Conclusion

After using the same inclusion criteria of DCCG on data from DCR we still find discrepancies between the two registers. The consequences for survival estimates will be discussed.

Big tables with small number cells

Niels Christensen, Anne Mette Kejs

Danish Cancer Society, Documentation & Quality

For confidentiality reasons or meaningful interpretation it can be essential to identify table cells with small numbers and make suitable adjustments.

This poster presents a way to do so by algorithms and shows an example of implementation.

The starting point for this work is a table of cancer incidence distributed by 5 age groups and 10 calendar groups. When a table cell with a small number is identified, we will try to adjust this by collapsing neighboring age- and/or calendar groups.

There are rules for collapsing cells and according to the rules, we will identify the patterns of collapsed cells.

Current challenges in cancer coding

Degerlund Henna, Merikivi Minna, Mustonen Susanna, Patriikka Lotta

Finnish Cancer Registry

Background: In the Finnish Cancer Registry we have become aware of challenges to find consensus between different coding rules and recommendations. The coding instructions might vary by registry. When teaching new coders, the general recommendations can be abstruse and even conflicting. Current topics to be discussed exist in hematological malignancies (HM), urothelial-, colorectal- and skin cancers. The questions culminate in decision making: what to do when the disease transforms from benign to malignant, or should these be coded as multiple primaries?

Materials and methods: Our purpose is to collect case reports about challenging cases from ANCR workshop participants. We will discuss these cases and compare decision making between different cancer registries and different recommendations (e.g. Haemacare, ICD-O-3, ENCR). We will also collect information about what information sources registries use to make their coding rules.

Results: We will observe and evaluate differences in coding and sources of information that decision making is based on. We will point out essential complexity of coding rules and information sources and propose needs to harmonize the rules of most common entities. Our output will be a memo after the ANCR meeting.

Conclusions: Purpose of our study is to gather new information about how the coding of cancer cases is done in different registries and what kind of general and international recommendations are used in decision making. Universal and clear coding rules are crucial when new persons are educated as a medical coder. By using updated and common information sources we could standardize the coding and therefore produce comparable statistics.

Clinical registries in Norway – tools in evaluation of quality of cancer care

Liv Marit Dørum, Lena Holmstrøm, Siri Larønningen, Tom Børge Johannesen, Bjørn Møller

Cancer Registry of Norway

Clinical registries at the Cancer Registry of Norway

The Cancer Registry of Norway (CRN) has established national clinical registries for nine different cancer diagnoses. These registries include detailed information on diagnostic measures and therapy such as surgery, radiotherapy and chemotherapy. The clinical registries are integrated in the Cancer Registry's coding and registration activities.

Collaboration with the clinical community

For each clinical registry, we have established reference groups; a panel of multi-disciplinary experts working with the specific cancer diagnosis. The reference groups consist of surgeons, oncologists, radiologist and pathologist covering all four health regions in Norway.

Quality of cancer care

The reference groups and CRN cooperate closely in deciding what data to collect in the registry. Historically, the focus of CRN has been research. Now the main focus of the clinical registries is evaluation of the quality of cancer care. The reference groups are responsible for the clinical relevance of the data collected in the registries.

To ensure quality in cancer care, the health authorities require the clinical registries to be used as basis for evaluating the clinical practice for each cancer diagnosis. Results from the clinical registries are reported to the health authorities, the hospitals and the patients annually. These reports include an evaluation of whether the national guidelines for cancer care are followed or not.

The presentation will give a brief introduction to how the Cancer Registry of Norway works together with the clinical community and the health authorities to improve cancer care. Examples from the annual reports will also be given.

Evidence-based quality indicators of cervical cancer screening and their prioritization

K. Miriam Elfström^a, Pär Sparén^a, Peter Olausson^a, Pöran Almstedt^a, Björn Strander^{b,c}, Joakim Dillner^{a,d}

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Background

Quality assurance is an ethical requirement of screening programs. The National Cervical Screening Registry (NKCx) collects all cytologies, HPV tests, invitations and histopathologies taken in Sweden. Program-related causes of cervical cancer, that could possibly be improved, are studied using nationwide audits in case-control format, based on all cases of cervical cancer in the country and population-based controls.

Materials and methods

New indicators are subjected to a rigorous implementation process to ensure that they can be measured objectively and capture impact on cervical cancer incidence and mortality. The value of the indicator is investigated in the national audit database to estimate its relative risk and population attributable proportion for cervical cancer. Indicators are first released to regional screening programs to ensure transparency and buy-in. The following year, the indicator and region-specific results are published in the annual report to compare progress across the country.

Results

A review of the indicators evaluated by the NKCx will be presented with a focus on 2 such QI: i) high grade cervical intraepithelial neoplasia identified in cytology without a follow-up biopsy and ii) non-attendance to cervical screening.

Conclusions

NKCx is a quality register that is entirely based on exports from healthcare databases (no input from individuals is required), allowing for an independent external evaluation of program processes and effect. The QIs are presented on the internet every year (www.nkcx.se/en).

Alcohol, physical activity and breast cancer subtypes in a nested case-control study from the Norwegian Breast Cancer Screening Program

Merete Ellingjord-Dale¹, Linda Vos¹, Solveig Hofvind¹, Steinar Tretli¹, Isabel dos-Santos-Silva², Giske Ursin^{1,3,4}

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⁴University of Southern California, Los Angeles, United States of America

Background: Alcohol increases, while physical activity decreases risk of BC (BC). To what extent these exposures are associated with only certain BC subtypes is unclear.

Methods: We conducted a case-control study nested within a cohort of 344,348 women who participated in the Norwegian Breast Cancer Screening Program (NBCSP) in 2006-2014. We had 5,544 BC cases with information on estrogen receptor (ER), progesterone receptor (PR) and human epidermal growth factor 2 (HER2) and 27 720 controls (matched on year of mammogram and year of birth). We used multinomial logistic regression to estimate odds ratios (ORs) of BC, with 95% confidence intervals (CIs), adjusted for age, body mass index (BMI), education, age at menarche, number of pregnancies and menopausal status.

Results: Alcohol intake was associated with an increased risk of BC overall (p for trend=0.002), and of several subtypes, but statistically significant only for luminal A-like BC. Compared to never drinkers, women with > 6 glasses/week had an OR of luminal A-like BC of 1.46 (95% CI 1.09-1.94), luminal B-like HER2 negative (OR=1.40, 95% CI 0.78-2.49) and triple negative BC (OR=1.32, 95% CI 0.57-3.05). Physical activity was inversely associated with risk of BC overall (p for trend=0.04). Although only the trend for luminal A-like BC approached significance (p for trend=0.05), the ORs were reduced for several subtypes.

Conclusions: Alcohol intake was positively associated, and physical activity negatively associated, with BC overall. Although these associations were statistical significant only for luminal A-like BC, the associations with alcohol and physical activity were similar across several subtypes.

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Prediction of incident cancers in Denmark using NORDCAN

Gerda Engholm, Anne Mette T. Kejs

Department of Documentation & Quality, Danish Cancer Society

Introduction: Long-term prediction of the number of incident cancers is often asked for and presently relevant for the Danish Cancer Plan 4.

Will the capacity in the health care sector for cancer diagnostics, treatment and rehabilitation be sufficient in the future with an aging and increasing population?

Prediction of the Danish incidence up to 2033 will be shown.

Material and methods: The long-term predictions in NORDCAN use age-period-cohort models from the NORDPRED package by Harald Fekjær and Bjørn Møller (Norway) and population forecasts from the statistical bureaus. For some cancer sites like prostate and melanoma of the skin, a continuation of the previous trend is not plausible. Constant rates based on the latest period can then be used, showing the effect of the aging population. Trends differ between sites and the best prediction is probably the sum of predictions and not the prediction of the sum of all sites.

Results. For men incidence increase from 18 000 yearly cases in 2009-2013 to nearly 25 000 in 2029-2033 and from 17 000 to 22 500 for women, 38.5 and 23% increase, respectively. Incidence rates for tobacco dependent cancers like lung and bladder decrease as they do for the unknown and unspecified sites, rectum and ovary, while the risk increases for brain-CNS and especially thyroid cancer.

Conclusion The yearly number of cancer cases in Denmark is expected to increase from 35 000 to more than 47 000 in 2029-2033, a 34% increase. 90% of the increase is due to an aging population.

The Swedish Multiple Myeloma Registry: Median survival exceeds 7 years in patients 65 years and younger diagnosed 2008-2013

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Introduction: The Swedish Multiple Myeloma Registry (SMMR) is a prospective observational register designed to document real-world management and outcomes in newly-diagnosed multiple myeloma (MM), plasmocytoma, and plasma-cell-leukemia since 2008 in Sweden, and to improve MM-patient management quality. Here we present data with focus on survival.

Methods: Data were collected through report-sheets to all clinicians diagnosing MM - at diagnosis, and a year later after follow-up on initial treatment and complications. Using diagnostic data 2008-2013 and follow-up data on symptomatic MM-patients diagnosed 2008-2012, we estimated baseline-characteristics, treatment-distributions and relative survival (RS), with respect to age and ISS-stage at diagnosis.

Results: Clinical baseline-data was available on 3876 patients (coverage 98% compared to the mandatory Swedish Cancer Registry). Median age was 71 years (men 70, women 73). Two thirds of patients were >65 years, 24% were >80. Distribution over ISS-stages I, II, III was 29%, 42%, 29%. Among patients <65 years, 80% received HDM/ASCT (4% >65). One-, three- and five-year RS was 92%, 79%, and 66% for patients <65 years and 79%, 56%, and 39% for patients >65 years. Median RS was 7.3 and 3.7 years for patients <65 years and >65 years. Median RS by ISS-stage was 3.2 and 6.0 years for stages III and II, while not reached for stage I. Early death (<1 year after diagnosis) was observed in 19% of patients.

Discussion: Survival was better in younger patients. Early-death rate 19% compared to 48% years 1964-1968 (ref: Swedish Cancer Registry) illustrates development in the care of MM-patients in Sweden during 50 years.

Comparison between observed and expected costs, of health care given to breast-cancer patients in western Sweden 2009 - 2014

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Introduction

Medical guidelines describe the care breast-cancer patients are expected to receive. This "prognosis" will not reflect care beyond what is planned and resulting prognosis of cost therefore likely to be too low. Previous work indicated cost-of-care for an average breast-cancer patient to exceed the expected by 60 percent, however the result lacked an uncertainty measure necessary for inference. Aims of this study are to consider whether a significant discrepancy exists between the expected and observed care cost for breast-cancer patients and, if so, how large this difference is.

Materials and methods

Health care events were linked to a specific breast-cancer diagnosis using Cost-per-patient data concerning all care given in the Western Sweden Health Care Region 2009-2014 and data from the mandatory cancer registry covering diagnoses from 1958-2014. Events and costs were compared with prognosticated cost according to Guidelines. Data was re-sampled using bootstrap-sampling, average and bootstrap interval for the cost calculated.

Results

Expected cost of care for an average breast-cancer patient was 102 000 SEK. Actual cost (with 95 % bootstrap interval) was estimated at

- 149 143 (146 281 - 152 136) SEK where breast-cancer was main diagnosis
- 167 046 (163 786 - 170 336) SEK where breast-cancer main or contributing diagnosis
- 230 356 (225 779 - 235 132) SEK where breast-cancer in any way related

Discussion

Prognosis based on Guidelines may underestimate events and costs. Actual costs could be 43 to 131 percent higher than expected, however, lack of data on primary care and pharmaceuticals weakens the study.

Establishing a national system for collection of Patient Reported Outcome Measures (PROMs)

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Results on PROMs for cancer patients are not routinely collected across Norway. Therefore, to what extent the patients' perceptions of their medical care and their side effects are similar across hospitals, is not consistently assessed. There is a strong need to assess and evaluate such data.

The Norwegian Prostate Cancer Registry (NoPCR), a clinical registry in the Cancer Registry of Norway (CRN), has received funding from the Movember Foundation to do a pilot study collecting PROMs data from all men recently diagnosed with prostate cancer from 1 January 2017 to 31 December 2019. A control group from the general population matched 1:1 by age and geographic region will also be contacted. We plan to collect the data at baseline, before treatment, and then after 1 and 3 years. If this PROMs collection proves feasible and it becomes a standard source of data for the NoPCR, the patients will be contacted again 5 and 10 years after diagnosis.

The participants in the study will be identified through cancer registry data. They will be invited to participate in the study by either digital mail or regular mail, and they can respond either by paper or electronically. The hospitals who wish to receive a copy of the patient's answers will do so. The infrastructure for the gathering of PROMs will build on, and expand, existing systems used by the CRN. Our aim is to use the same infrastructure for other cancers.

Induced abortions and pregnancies in Finnish childhood cancer survivors

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Background

Due to adverse effects of cancer therapies, childhood cancer survivors (CCS) worry about health of their offspring and risks of having children. Our population-based cohort study aimed to find out whether pregnancies of CCS result in induced abortions more often than pregnancies of female population controls.

Material and methods

Using registry data of four national registers (Finnish Cancer Registry, Central Population Register, Finnish Medical Birth Register, and Register of Induced Abortions), we identified induced abortions and deliveries in 1,575 female CCS (diagnosed with cancer between 1971 and 2012 at 0-14 years of age in Finland) and in 10,416 population controls. Incidences, incidence proportions, and hazard ratios (HR) of induced abortions and pregnancies were compared between CCS and population controls over the follow-up period between 1987 and 2013. HRs with 95% confidence intervals (CI) were estimated using Cox proportional hazards regression modeling.

Results

We identified 227 induced abortions and 1,156 pregnancies in CCS, and 1,726 induced abortions and 10,481 pregnancies among population controls. Probability of becoming pregnant was significantly lower among CCS compared to population controls (HR 0.81, 95%CI 0.76-0.86). According to our preliminary results, pregnancies of CCS were more likely to result in induced abortions among CCS in comparison with population controls (HR 1.19, 95%CI 1.04-1.37).

Conclusions

Our preliminary results suggest that CCS may be more likely to terminate their pregnancies by choice in comparison with population controls. Such difference between CCS and population controls should be considered in pregnancy counseling of CCS.

Proportion of women with self-reported opportunistic mammography before organized screening

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In Finland, organized nationwide breast cancer (BC) screening is biennially offered for women aged 50-69 years. The aim was to estimate the proportion of women having opportunistic mammography at age <50 years and to investigate the role of BC family history and educational level for having opportunistic mammography.

The study material comprises two self-administered, population-based questionnaires from altogether 9845 women without cancer and aged less than 50 years; 4666 women in Women's Health and Use of Hormone-study (WHH), and 5179 in Breast Cancer Screening, Lifestyle and Quality of Life-study (EET). We report estimated proportions of women with self-reported opportunistic mammography at age <50 years in percentages.

Response percentages were 53% in WHH survey and 52% in EET survey. Percentage of women with self-reported opportunistic mammography was 66.7% and 60.4% in the two questionnaires, respectively. Regarding family history of BC, 76.5% and 68.5% of women with BC family history in a first degree relative reported having had a mammography, in contrast to that of 65.5% and 59.4% of women without BC family history. Opportunistic mammography was also more common in women with >12 years of education than women with ≤12 years of education.

Overall, some two thirds of women reports of having had a mammography before organized screening. Opportunistic mammography was more likely among women with positive family history of BC in first degree relative as well as >12 years of education. Regardless of low response activity, the observed popularity of opportunistic mammography before organized screening gives ground for further evaluation of related health care practices.

Lifestyle effects of colorectal cancer screening – population-based survey study in Finland

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Mass Screening Registry, Finnish Cancer Registry

Background

CRC mortality can be reduced with screening, but it is yet unclear if CRC screening affects various lifestyle related factors. A national programme for CRC screening with repeated faecal occult blood (FOB) testing followed by colonoscopy for test positives has been running in Finland since 2004. We aim to clarify if screening is introducing harmful effects on colorectal cancer risk related life style.

Methods

A population-based random sample of 10648 Finnish adults born in 1951 living in the municipalities voluntary involved in CRC screening programme were sent a lifestyle questionnaire in 2010. In 2011, the 60-year old cohort was independently randomised (1:1) for their first ever CRC screening (invited) or control group (not contacted). The questionnaires were repeated in 2012 for all. From both survey rounds, 2508 pairs of completed questionnaires were available for analysis from the screening group and 2387 from the control group. The outcome was 2-year change in total lifestyle score of CRC risk related lifestyle factors (smoking, alcohol consumption, physical activity, diet and BMI).

Results

There were only minor changes in total lifestyle score and these occurred likewise in the screening group and in controls. There was no difference by participation, either: the change in score did not differ significantly in those participating screening compared to those invited, but not participated screening.

Conclusions

Present study found no changes in total lifestyle in the studied age group due to CRC screening. Life style effects seem not to reduce the potential benefit of an otherwise feasible screening programme.

Testicular cancer risk among cryptorchid boys in eastern Denmark

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Danish Cancer Society

Introduction

Cryptorchidism is a risk factor for testicular cancer in adult life. It remains unclear how prepubertal surgery for cryptorchidism intervene development of adult testicular cancer. The aim of study was to investigate tools to identify the cryptorchid boys who later develop testicular cancer.

Methods

The study cohort consisted of 1403 men operated prepubertally and pubertally for undescended testis between 1971 and 2003. At surgery testicular biopsies were taken from the cryptorchid testes. The boys were followed for occurrence of testicular cancer. The testicular cancer risk was compared to the risk in the Danish Population. Testicular biopsies from the boys who developed testicular cancer underwent histological examination with specific diagnostic immunohistochemical markers for germ cell neoplasia. The immunohistochemical staining of biopsies from the cancer cases was compared with identical stainings of consecutive testicular biopsies from 417 cryptorchid boys.

Results

The cohort of 1403 boys was followed for 33,627 person years at risk. We identified 16 cases with testicular cancer in adulthood. The standardized incidence ratio was 2.66 (95%CI; 1.52-4.32). In the biopsies from at time of surgery new immunohistochemical stainings indicated Intratubular Germ Cell Neoplasia (ITGCN) in two of these 16 cancer cases. One had syndromic cryptorchid and developed seminoma, and another showed non-syndromic cryptorchidism and developed embryonic terato-carcinoma. Totally, ITGCN was diagnosed in 0.24% (1/417)-0.50% (7/1403) of prepubertal cryptorchid boys, whereof 62.5% (5/8) in syndromic cryptorchidism.

Discussion

ITGCN is predominantly observed prepubertally in boys with syndromic cryptorchidism. In non-syndromic cryptorchidism testicular cancer develops postpubertally, generally not based on dormant germ cells of ITGCN caused by an early fetal maldevelopment.

Ethnic differences in the incidence of cancer in Norway

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Introduction

Disparities in cancer risk patterns across ethnic groups and between immigrants and native populations have been reported previously. However, since medical records in Norway do not record country of birth or origin, there has been no monitoring of cancer incidence among different immigrant groups.

Methods

This project links data from the Cancer Registry of Norway with data from Statistics Norway to examine age-specific and age-standardized overall and site-specific cancer incidence rates in different immigrant groups and compare them to rates among persons born in Norway to Norwegian-born parents, using the age distribution from the world standard population.

Results

Analyses of 850 333 immigrants show that 10 334 women and 9 158 men developed cancer in the period 1990-2012. During this period, incidence rates per 100 000 person-years were 235 for women and 267 for men. Among 4 882 955 persons born in Norway to Norwegian-born parents, 230 099 women and 258 333 men developed cancer during the same period, and the incidence rates were 248 women and 298 for men. Cancer in the lung, liver, stomach, prostate, and cervix was more common in specific immigrant groups.

Conclusions

This study found differences in cancer incidence between immigrants and persons born in Norway to Norwegian-born parents. Identifying and monitoring cancer types among immigrants that are rare in the Norwegian population are important for early detection, and to ensure appropriate health care. Additionally, identifying lifestyle-related cancers which are less common among immigrants could help prevent lifestyle changes that may occur after migration.

User involvement – unnecessary meddling or obvious necessity?

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Cancer Registry of Norway (CRN)

Background

User involvement in every aspect of health care, research, and clinical registries is one of the main priorities in Norway. “No decision about me without me” being one of the mantras. Patients are becoming more active decision makers regarding their own health care, but user involvement is not yet a natural part of research and registry work. Colleagues have argued that patients shouldn’t meddle in research and registry work, because it demands knowledge and an objective view that patients can’t be expected to have.

User involvement at CRN

Patients’ views on research and registry work is important, because it will help us to focus on what is important for cancer patients. The CRN is working with the Norwegian cancer society (NCS) to involve users in our clinical registries. Mid September this year we will participate at a patient representative seminar hosted by NCS. We will suggest organising a panel of patient representatives to give them a voice in registry work to improve cancer care.

User involvement in research is also expected and when applying for grants describing user involvement is often an explicit demand. How can user involvement in research be done and what part of research should have user involvement?

We would like to give a short presentation and open up for comments and experiences from the audience.

The impact of colorectal cancer screening invitation on health-related characteristics of lifestyle in Finland

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Background

Previous research implies that colorectal cancer (CRC) screening might have a negative effect on lifestyle and possibly leading to changes in health. The aim of the study was to evaluate the effects of CRC screening on self-rated health (SRH) which is a good estimate for one's health, even for death. We are the first to our knowledge to provide information on the effects of CRC screening on SRH.

Methods

In the population based health services study the target population (n=31951) of Finnish men and women born in 1951 and eligible for colorectal cancer screening for the first time in 2011 was randomized 1:1 for CRC screening and control groups in 2010. A random third were sent the same questionnaire in 2010 and in 2012. The study population (n=4895) responded both years. SRH, healthiness of diet (diet) and physical fitness were assessed and modelled using calendar time (2010, 2012), screening invitation (yes/no) and sex as covariates.

Results

Physical fitness, diet and SRH increased in calendar time (OR 1.45, CI 1.30-1.61, OR 1.25, CI 1.09-1.43 and OR 1.29, CI 1.16-1.43, respectively). CRC screening invitation had no effect (OR 1.09, CI 0.87-1.37, OR 0.95, CI 0.75-1.20 and OR 0.90, CI 0.74-1.10, respectively).

Conclusions

CRC screening invitation had no effect on physical fitness, diet or SRH when adjusted for calendar time and sex. According to our results invitation to CRC screening did not have a negative effect on self-rated health. The randomized setting enables us to generalize the results to the target population.

Endometriosis and risks for ovarian, endometrial and breast cancers: a nationwide cohort study

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OBJECTIVE

A growing body of evidence suggests that endometriosis increases the risk for ovarian cancer, but it is less well studied whether the excess risk is confined to certain histotypes. Furthermore, it is not fully resolved if endometriosis is associated with endometrial- and breast cancer. The aim was to study overall- and histotype-specific risks for these hormone-dependent cancers in women with endometriosis.

METHODS

In the National Patient Register, we identified 45 790 women with a clinical diagnosis of endometriosis during 1977–2012. We linked the cohort to the Danish Cancer Register and calculated standardized incidence ratios (SIRs) with corresponding 95% confidence intervals (CIs).

RESULTS

Endometriosis was associated with increased risks for ovarian cancer (SIR 1.34; 95% CI: 1.16–1.55), due primarily to endometrioid (SIR 1.64; 95% CI: 1.09–2.37) and clear-cell types (SIR 3.64; 95% CI: 2.36–5.38). An excess risk was also observed for endometrial cancer (SIR 1.43; 95% CI: 1.13–1.79), primarily of type 1 (SIR 1.54; 95% CI: 1.20–1.96); and the risk for breast cancer was increased among women aged ≥ 50 years at first diagnosis of endometriosis (SIR 1.27; 95% CI: 1.12–1.42).

CONCLUSIONS

The results corroborate previous findings of increased risks for endometrioid and clear-cell ovarian cancer in women with endometriosis. As the first cohort study to date, we observed a significantly increased risk for endometrial cancer in women with a diagnosis of endometriosis. The increased breast cancer risk among women with endometriosis diagnosed at ≥ 50 years of age should be studied further.

Tumor characteristics and prognosis in women with pregnancy-associated breast cancer (PABC)

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Background

There is evidence of poor prognosis in women with pregnancy-associated breast cancer (PABC) diagnosed during pregnancy or within 2 years of delivery. We examined clinicopathologic features (TNM stage, grade, hormone receptor status) and mortality in women with a current or recent pregnancy at breast cancer diagnosis.

Materials & methods

We followed a cohort of women identified in the Swedish Cancer Register with a diagnosis of invasive breast cancer (BC) between 1992 and 2009 at ages 15 to 44 years (n=9,441). Information on tumour characteristics was retrieved from 6 regional Breast Cancer Quality Registers (BCQR) and available for 95% of the women (n=9,006). Dates of childbirths were obtained from the Swedish Multi-Generation Register. Age-standardized distributions of tumor stage (TNM), Elston grade and ER/PR/HER2 status were compared between nulliparous women and women with breast cancer during pregnancy and up to 10 years post-delivery. Adjusted hazard ratios (HR) for mortality were estimated using Cox regression.

Results

We identified 1,661 nulliparous women with BC, 778 women with PABC, and 3598 with BC during 2-10 years post-delivery. Compared to age-standardized nulliparous women, women with PABC had more advanced T and N stage, and higher proportions of ER/PR negative, HER2 positive and triple-negative tumors, in particular in women diagnosed 0-12 months post-delivery. A poorer survival was observed in women diagnosed within 5 years of delivery after adjustment for age, year, education and region. Following adjustment for tumor characteristics, hazard ratios were attenuated and non-significant, with the exception of women diagnosed 2-5 years post-delivery which remained significant.

Conclusion

The poorer prognosis observed in women with pregnancy-associated breast cancer appears to be largely explained by more adverse tumor characteristics at diagnosis.

Breast and prostate cancer in four Nordic countries: A comparison of incidence and mortality trends between countries and age groups in the period 1975-2013

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Background

In the Nordic countries organised screening programs are implemented for breast but not for prostate cancer. Extensive prostate-specific antigen (PSA) testing has, however, been performed. The aims of the present study were to compare breast and prostate cancer incidence and mortality trends by age in four Nordic countries, and to identify differences in the effects of organised mammography screening vs non-organised PSA testing on the trends.

Methods

Breast and prostate cancer incidence and mortality rates by age for the period 1975–2013 in Norway, Sweden, Denmark and Finland were obtained from the NORDCAN database. Joinpoint regression models were fitted to the rates to identify linear changes in the trends.

Results

A much less prominent increase in breast than prostate cancer incidence was observed. The total reduction in mortality from the period 1994-96 to the period 2011-13, ranged from 36% in Norway to 16% in Finland for breast and from 29% in Finland to 6% in Denmark for prostate cancer. The decreases in breast cancer mortality were largest in the youngest age group in all four countries. In the age group 55-74 the decline in mortality was larger for prostate than for breast cancer in all countries except Denmark.

Conclusions

The decrease in breast cancer mortality in the youngest suggests that other measures than organised screening are responsible for the favourable mortality trends. The large increase in prostate compared to breast cancer incidence, alongside similar mortality decreases, indicates that a higher proportion of prostate than breast cancer cases are overdiagnosed.

Socioeconomic factors and penile cancer risk and mortality; a population-based study

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Objective

To investigate possible associations between socioeconomic status (SES) and penile cancer risk, stage at diagnosis and mortality.

Materials and methods

Population-based register study including men in Sweden diagnosed with penile cancer between 2000 and 2012 (n=1676) and randomly chosen controls (n= 9872). Data were retrieved from the National Penile Cancer Register (NPECR) and several other population-based healthcare and sociodemographic registers. Educational level, disposable income, marital status, and number of individuals in the household were assessed as indicators of SES.

The risk of penile cancer and penile cancer death in relation to SES were estimated using logistic regression and proportional hazards models, respectively. Cumulative cause-specific mortality estimates by SES were calculated using the Kaplan-Meier method.

Results

Low educational level and low disposable income was associated with invasive penile cancer. Furthermore, low educational level was associated with more advanced primary tumor stage. Divorced and never married men had a generally increased risk of penile cancer and were diagnosed with more advanced primary tumor stages. However, neither educational level nor marital status was associated with lymph node or distant metastases. Also, men in single-person households had an increased risk of both non-invasive and invasive disease. In men with invasive penile cancer, no significant associations of indicators of SES and cause specific mortality were found.

Conclusions

Low educational level, low disposable income, being divorced or never married and living in a single-person household all increase the risk of advanced stage penile cancer, but not lymph node or distant metastases. The assessed indicators of SES did not influence penile cancer specific mortality. In conclusion, our study indicates that SES influences the risk and stage of penile cancer, but not survival.

Cervical cancer screening non-adherence among immigrants in Norway

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Background

Available data on migrants' health in Norway is limited. Access to and use of cervical cancer services is an important factor for cancer prevention. Immigrants often lack screening programs in their home countries and may face barriers in adopting norms and values of the receiving society. We assessed the screening uptake among immigrants and native Norwegians, and estimated factors that predicted non-adherence among immigrants.

Methods

The study population consisted of 1 157 537 (84%) native Norwegians and 222 972 (16%) immigrants. Non-adherence was defined as no registered cytology within the last screening interval of three years. We modelled non-adherence by Poisson regression using socio-demographic, health care, and migration –related explanatory variables.

Results

55.3% of immigrants and 31.7% of native Norwegians were not screened in 2008–2012. Non-adherence rate varied substantially across immigrant groups. It was lowest among migrants from Nordic countries, 42.3%, and highest among migrants from Baltic countries, 78.7%. Screening uptake also varied significantly by region. Living less than 10 years in Norway was the strongest determinant of non-adherence (prevalence ratio adjusted for age and parity at screening 1.60, 95% CI 1.61-1.64). Also being outside of the workforce or unemployed, having a male general practitioner (GP), having a young or foreign GP, and distance to GP's office predicted non-adherence.

Conclusions

Immigrants face special barriers to screening some of which are religious, cultural and language related. Barriers related to the health care system can be reduced by programme and health care -targeted interventions. Screening options that are acceptable across immigrant groups need to be studied and feasible options implemented to reduce disparities in cervical screening.

Completeness and validity of the cancer data in the Finnish Cancer Registry

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Background

The Finnish Cancer Registry (FCR) has a long tradition of collecting data and monitoring the cancer burden in the country. Completeness for solid tumours has been close to 100% but the estimate is based on cases diagnosed thirty years ago. Thus, we aimed to provide a comprehensive data quality assessment at the FCR.

Methods

Established quantitative and semi-quantitative techniques with a special focus to review cases diagnosed in 2009-2013.

Results

The FCR's database for the period 2009-2013 comprised 150 405 incident cases. Childhood cancer incidence rates for both genders were close to the upper limit of the reference interval. Overall, 93.0% of all new cancer cases were morphologically verified. There was great variation according to the cancer site, %MV being lowest of 43% for the site uterus, other (C55). Independent case ascertainment using hospital discharges and mortality to incidence ratios indicate that particularly tumours without histological verification, such as benign or borderline tumours of brain and central nervous system and eye tumours, are missing from the FCR.

Conclusions

In spite of slight violations from the recommended rules by the European Network of Cancer Registries, registration and coding routines in place at the FCR yields comparable data of high quality. Registration of tumours without histological verification is incomplete and warrants an active trace-back using external data sources like hospital discharges.

Audit of screening histories and the effectiveness of screening

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Background

Screening programme audits are recommended in European Guidelines and considered an ethically required part of population-based screening. We conducted a systematic programmatic audit in order to identify the significance of different screening failures on the residual cervical cancer burden in Norway.

Methods

The case population consisted of all invasive cancers recorded in the Cancer Registry of Norway with incidence dates in 1996-2013, and amounted to 5432 cases. Ten age-matched controls per case were drawn from the National Population Register. Screening history was categorised by participation, result of primary screening test and management of positive tests from individual linkage to the screening register. Odds ratios for cervical cancer according to screening history were calculated with 95% confidence intervals (CIs).

Results

About half (51%) of the case women had participated in screening in the five-year interval before diagnosis compared with 63% of the controls, with an associated OR of 0.45 (95% CI 0.43-0.48). Of the cases, 32% had a negative last primary cytology compared with 59% of the controls, with an associated OR of 0.31 (95% CI 0.29-0.33). The risk for cervical cancer was much higher for women with a borderline (OR 10.0, 95% 9.0-11.1) or high-grade primary cytology (OR 16.0, 95% CI 13.5-18.8) compared to those with normal smears.

Conclusions

Non-participation was the most important contributor to cervical cancer risk in Norway. However, women with positive screening tests had significantly elevated risks of cervical cancer, indicating possibilities for improvement also in the management and treatment of screen-positive women.

Randomised intervention to increase cervical screening participation by scheduled screening appointments

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Background

The main barrier to optimal effect in many established population-based screening programmes against cervical cancer is low participation. In Norway, a routine health service integrated population-based screening programme has been running since 1995, using open invitations and reminders. The aim of this randomised health service study was to pilot scheduled appointments and assess their potential for increased participation in the local setting.

Methods

We randomised 1087 women eligible for screening and overdue for their 3-yearly screening test to receive either a standard reminder (control) or an invitation with a given appointment for smear taking (intervention). Letters were sent 2-4 weeks before the scheduled appointments at three centres: a mid-wife clinic, a public health care centre, and a GP centre. The primary outcome was participation at 6 months of follow-up. Secondary outcomes were participation at 1 and 3 months.

Results

At 6 months, 20% of the 510 women in the control-group and 37% of the 526 women in the intervention-group had participated in screening, excluding 51 women from analysis due to screening just before invitation. The adjusted RR was 1.8 (95% CI 1.5-2.2). There was no significant heterogeneity between centres or age-groups. Previous participation was significantly associated with current participation (RR 3.4; 95% CI 2.3-5.2). The RRs for participation at 1 and 3 months were 4.0 (95% CI 2.6-6.2) and 2.6 (95% CI 2.0-3.4), respectively.

Conclusions

Replacing the standard reminder by invitations to screen with a given appointment significantly increased screening participation among women overdue for screening.

Effect of organized screening and opportunistic testing in cervical cancer in Finland among young women

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Background

Screening under 25 years old women has been shown to have little or no impact on the risk of cervical cancer and clear effects have been observed above 40 years. In Finland an extensive opportunistic screening practice that concentrates on younger women exists alongside the national screening program. The aim of this study is to clarify the effect of opportunistic testing and organized screening on the risk of cervical cancer among young women in Finland.

Methods

In the Finnish Cancer Registry there were 280 cervical cancer cases diagnosed in 2004-2009 and screened below age of 40 the year 1997 onward. Screening histories for these women and their 1680 age-matched controls were derived by linkage to the mass screening register. The data was further linked with opportunistic testing data available. OR's and 95% confidence intervals for the association of cervical cancer diagnosis and participation in organized screening and opportunistic testing 0,5-5,5 years before the diagnosis were estimated using unconditional logistic regression. Results were corrected for self-selection bias and attendance rate.

Results

OR of cervical cancer for screening below age 25 was 1.04 (95% CI 0.30-3.58). Participation in organized screening at 25 to 40 resulted in OR 0.62 (0.41-0.98), participation only in opportunistic testing 0.89 (0.57-1.37) and participation in both in OR 0.39 (0.18-0.88).

Conclusion

According to initial results opportunistic testing showed no clear additional benefit on preventing cervical cancer. The study supports previous findings about the lower effect of screening in younger age groups compared to older ones.

Delays in the patient path of breast cancer in Finland

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Survival of cancer patients is related to early diagnosis and therefore any delays in the diagnostics and treatment path should be minimized. The aim was to study potential delays in the patient path among cancers of breast (BC), colorectum (CRC), and prostate (PC) in the specialist care in Finland.

Data on BC was retrieved from the Finnish Cancer Registry (FCR) from the diagnostic year 2013 (n=4 791). The patients were linked with the hospital discharge register (HILMO) to receive data on referral, first visit, date of queuing for treatment, and first treatment between 2012 and 2014.

Some 77 cases were missing from HILMO, no cause for queuing was given in 1029 cases, 1395 cases were urgent (within 3 weeks) and in 1713 cases the patient was in the normal queue (within 6 weeks). The remaining 577 cases had various other reasons, e.g. regular control, patient related cause. In urgent cases the average delay from referral to treatment was more than 3 weeks in 68% and in non-urgent cases more than 6 weeks in 23%. The time from referral to first visit was within the national guidelines in 62% of urgent cases and in 90% of non-urgent cases. Some 666 cases had to be removed from this analysis due to missing dates or negative time from visit to referral.

Results on CRC and PC will be presented at the meeting.

We measured the time from referral to the first visit and first treatment in specialist care for most of the BC patients diagnosed in 2013. We are concerned about the fact that waiting times exceeded the national guidelines in close to a third of patients. However, there were substantial problems in the data due to missing an illegal dates that had to be solved before the data can be used for routine benchmarking.

Colorectal cancer screening does not affect long-term health-related quality of life

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Background: Screening for colorectal cancer (CRC) has been recommended by EU and several national institutes. Yet the effects of screening on health-related quality of life (HRQOL) are not well known. This study evaluates whether the generic HRQOL is affected by screening.

Methods: The Finnish CRC Screening programme is based on biennial faecal occult blood test (FOBT) targeted to 60-69 -year old men and women. The population was randomized to screening and control groups by municipality, age and gender. The HRQOL was assessed by self-administered postal survey using a generic instrument, the 15D. The HRQOL was estimated one year prior to screening invitation and again, approximately one year after the screening invitation and at similar time points for controls.

Results: The screening group reported HRQOL 252 days before, and again 428 days after screening, on average. The pre-screening 15D score was similar in the screening and control groups, and corresponded well to the age-specific population values. The post-screening scores were similar in both groups and no differences were observed within any of the 15 dimensions. Women with a positive FOBT had a lower score than the female control group ($p < 0.05$) both before and after screening. There were no statistically significant differences in transition probabilities between the screening and the control group in transition between health states from 2010 to 2012.

Conclusion: CRC screening using FOBT seems to have no long-term impact on the generic HRQOL. The observed lower HRQOL in women with positive FOBT existed already before screening.

Spillover improves survival in non-invited patients of the Finnish colorectal cancer screening programme

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The Finnish Cancer Registry

Randomized controlled trials (RCTs) on screening for colorectal cancer (CRC) have consistently shown a CRC mortality reducing effect (16 % on average). In 2004 the Finnish CRC screening programme was initiated and found, in contrast to the RCTs, a nonsignificant increase in CRC mortality (4 %).

In our paper (currently under review with the BMJ) we discuss spillover, i.e. the overall indirect influence a cancer screening programme has on the non-invited population. This influence can occur through changes in material and immaterial resources and in the behaviour of the public and medical personnel, as well as other factors.

To study changes in survival occurring simultaneously with adopting the programme we estimated Cox model CRC mortality hazard ratios (HRs) and Ederer II relative survival curves. This was done in three periods of diagnosis (1999-2003, 2004-2008, 2009-2013) in patients not invited to screening diagnosed in early and late adopter municipalities (programme adoption in 2004-2008 and 2009-2013, respectively).

We then estimated the crude spillover effect as the average change in CRC mortality occurring simultaneously with programme adoption. The net spillover effect was estimated as the difference between the crude spillover effect and the period effect. In the paper we report a net spillover effect of 11% (95 % CI: 2—19 %). Our paper has implications for future cancer screening programmes, as programmes are evaluated based on their total effectiveness in the population, and the spillover effect can create a significant bias in comparisons of invitees to controls.

Estimating age-specific mortality rates from incidence and survival data

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Background: Cancer mortality rates are based on cause of death information. Earlier studies comparing cause specific and relative survival indicate that in some older patients, cancer is incorrectly reported as cause of death. The aim of this study is to compare age specific mortality rates calculated from information on cause of death to lifetable-derived mortality rates (LTM) to examine the accuracy of the former rates.

Material and Methods: Observed age-specific mortality and incidence rates were obtained from NordCan for various cancer sites. The lifetable-derived age-specific mortality rates were estimated as the sum of the product of the probability of being alive at the beginning of an interval times the probability of dying of the cancer of interest during the interval times the annual age-specific incidence rate. Overall and net survival were estimated using data from the Cancer Registry of Norway.

Results: The difference between the LTM and the observed mortality rates was increasing with increasing age. The LTM was always lower than the observed mortality rates for the oldest age groups.

Conclusion: LTM rates indicate that cancer mortality rates are over-estimated in older age groups.

Regional differences in survival in relation to resection: a national population-based study of non-small cell lung cancer in Norway

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Background: Survival and resection rates vary between places of residence for lung cancer patients. However, it is unknown if differences in survival can be explained by varying resection rates.

Methods: National population-based data from the Cancer Registry of Norway, Statistics Norway, and the Norwegian Patient Register were linked for all non-small cell lung cancer (NSCLC) patients diagnosed during 2002-2011 (n=20,365). Five-year relative excess risk (RER) of death was adjusted for case-mix (year and age at diagnosis, sex, education, personal income, topography, smoking status and comorbidity) and resection rate. All analyses were stratified by localised and regional spread at diagnosis.

Results: The overall resection rate for all NSCLC patients were 21.2%. Significant differences in RER of death were observed between health trusts both for patients with localised (p=0.01) and regional spread (p<0.01), however, these could not be explained by the differences in resection rates. For patients with regional disease, it was indicated that some health trusts might perform too many surgeries, which may be seen through a high proportion of pathological stage III patients. No such trend was observed among patients with localised disease.

Conclusions: There are indications of differences in the quality of care delivered in Norway since differences in RER of death still exist between regions after adjusting for case-mix and the proportion resected.

Randomized implementation of primary high risk human papilloma virus testing for cervical cancer screening in Norway

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Background / Objectives: Improved understanding of the natural history of cervical carcinogenesis, and knowledge of the relative performance of different screening tests implies superiority of the high risk human papillomavirus (hrHPV) test over cytology in cervical cancer screening. Starting from February 1st, 2015, a five-year hrHPV testing in primary screening was implemented to gradually replace a triennial Pap-smear screening of women 34-69 years of age.

Methods: In 2014, the same HPV test, biobank solutions, similar communication strategies etc., were adapted by screening units implementing new cervical cancer screening technology for approximately 1/4 of eligible Norwegian female population (in four counties). Based on date of birth (odd and even days) about 50% of 34-69 years old women were allocated to receive a cytology and 50% a hrHPV test in screening.

Results: By the June 30th 2016, about 90,000 women were screened with either hrHPV or cytology; screening attendance rates were comparable; the overall hrHPV positivity rate in HPV arm was 6.5%; reflex cytology in triage of those hrHPV positives indicated high proportion of severe abnormalities (close to 40%), leading to increased colposcopy referral in HPV screening as compared to cytology screening; there was significantly more CIN2+ diagnosed in the HPV arm. Altogether, 59 cervical cancers were diagnosed, of which 24 were in the cytology and 35 in the HPV arm.

Conclusions: Gradual and randomized implementation allows direct comparison of effect indicators between two screening modalities and alleviates workload increase for the colposcopy and pathology services.

Cumulative probability of abnormalities in organized cervical cancer screening

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A large amount of screening tests are performed every year by national cervical cancer screening programmes. Although regular screening and follow-up is the key to cancer prevention, screening inevitably detects mild or borderline abnormalities that would never progress to a more severe stage. We analysed the cumulative probability and recurrence of cervical abnormalities in the Finnish screening programme during a 22-year follow-up, concentrating on the difference between borderline and more severe abnormalities. Screening histories were collected for 364 487 women born in 1950-1965. Data consisted of 1 207 017 routine screens and 88 143 follow-up screens during 1991–2012. Probabilities of cervical abnormalities by age were estimated using logistic regression and generalized estimating equations (GEE) methodology. The probability of experiencing any abnormality at least once at ages 30–64 was 34.0% (95% CI: 33.3-34.6%). The number was 5.4% (95% CI: 5.0-5.8%) for results warranting referral and 2.2% (95% CI: 2.0-2.4%) for results with histologically confirmed findings. Previous occurrences were associated with an increased risk of detecting new ones, specifically in older women. Our results refer to a notable overdiagnosis of borderline results. The lifetime risk of having any cervical abnormalities could be even higher in countries where the screening interval is smaller than five years. Re-evaluation of diagnostic criteria concerning mild abnormalities would improve screening efficacy. Also, special monitoring of women with recurrent abnormalities especially at older ages may be needed.

Estimating regional multilevel variation in excess mortality of cancer patients using integrated nested Laplace approximation

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Background

Models of excess mortality with random effects can be used to estimate regional variation in cancer survival. Statistical inference for these models based on the Markov chain Monte Carlo (MCMC) methods is computationally intensive and, therefore, not feasible for routine analyses of cancer register data. This study assesses the performance of the integrated nested Laplace approximation (INLA) in monitoring regional variation in cancer survival.

Methods

Poisson regression model of excess mortality including both spatially correlated and unstructured random effects was fitted in to the follow-up data of patients diagnosed with ovarian and breast cancer in Finland in 1953–2012. We estimated standard deviations associated with i) variation between hospital districts, ii) variation between municipalities within hospital districts and iii) total variation between municipalities. Posterior estimates based on the INLA approach were compared to those based on the MCMC simulation.

Results

Variation within hospital districts dominated in the total variation between municipalities. In 2003–2012, variation between hospital districts was only 14% (95% posterior interval: 2–54%) and 12% (2–37%) of the total variation in ovarian and breast cancer, respectively. The posterior estimates were similar between the INLA approach and the MCMC simulation. Inference based on the MCMC simulation was considerably time-consuming.

Discussion

In the estimation of regional variation in excess mortality of cancer patients, the INLA approach is accurate, fast and easy to implement by using the R-INLA package. Based on our results INLA-based estimates can be part of the routine reporting in the Finnish Cancer Registry.

Cohort based population attributable fractions for lung, breast and colorectal cancer in Finland

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Population attributable fraction (PAF) estimates the population impact of cancer risk factors. Development of PAF estimation for cohort studies¹ inspired us to develop a hierarchical Bayesian model for cohort-PAF (c-PAF) accounting for competing risk of death as well as for more traditional net-PAF.

We combined data from eight FINRISK-project cohorts from 1972 to 2007 with 64,038 subjects and 7,499 first cancers in lung, breast, colon and rectum. Subjects were followed from the date of survey until first cancer, death or Dec 31 2013. Risk factor information included indicators for smoking and alcohol use interaction, overweight (BMI>25), physical activity, factory working, infectious disease, and eating red meat.

The c-PAF for lung cancer in males was 88% (95% CI: 79% ; 95%) and for females 63% (45%;78%), smoking being the most significant risk factor with c-PAF 82% in males and 59% in females. The c-PAF for breast cancer in females was 6% (-6%; 16%). The net-PAF estimates were 1–2% larger. In males the c-PAF for colorectal cancer was 33% (3%; 57%) and in females 21% (1%; 39%). The net-PAF was 41% in males and 24% in females, indicating the more pronounced effect of competing mortality in males than females. Use of alcohol (21% c-PAF) and overweight (16% c-PAF) were most significant factors for colorectal cancer in males and overweight (c-PAF 13%) in females.

Competing mortality has big impact on PAF in late onset cancers like colorectal cancer. Competing mortality is often elevated among persons with high risk for cancer.

Reference:

¹Laaksonen MA, Härkänen T, Knekt P, Virtala E, Oja H. Estimation of population attributable fraction (PAF) for disease occurrence in a cohort study design. *Stat Med* 2010;29(7-8):860–74.

Estimating cancer heritability in a young cancer patient family cohort in Finland

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Background

The Finnish young cancer patient family cohort was used to estimate familial aggregation and heritability of breast cancer (BC) and digestive organ cancer (DOC). Young cancer patients were diagnosed between 1970 and 2012 under the age of 40. Their families were collected from the Population Register Centre and linked to the cancer registry data. The BC cohort consists of 3949 families with 29 132 individuals and 743 familial breast cancers. There were 2712 families in the DOC cohort and 19 136 individuals with 577 familial DOCs.

Methods

Heritability was estimated using a hierarchical Bayesian Poisson random effects regression model for the cancer incidence ratio (SIR). Variance was splitted into three components from which the proportion of the additive genetic variance, i.e. heritability, was estimated. We also assessed both the ascertainment and follow-up bias present in the design.

Results

Simulation studies showed that the size of the data was sufficient and adjustment for ascertainment bias was appropriate for estimating variance components correctly. Familial aggregation was present in both cancers. SIR for BC family members was 1.80 (1.67-1.94) and for DOC 1.60 (1.47-1.73). The heritability of BC and DOC were 25% (0-56%) and 69% (45-92%), respectively.

Discussion

This is the first study in Finland to assess cancer heritability in families with early onset cancer cases. The breast cancer heritability estimated is in line with previous findings from Nordic studies. Digestive organ cancer heritability is higher than expected. Study shows that heritabilities can be estimated from cancer registry combining family data reliably.

Risk of cancer after fertility treatment – population-based studies on women treated with and children conceived by assisted reproduction

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Background

Increasing use of assisted reproduction (ART) means that growing numbers of women are exposed to a variety of fertility drugs. Some studies have shown elevated risks of ovarian, breast and other cancers in women treated with fertility drugs. Several studies suggest increased risk of cancer in children conceived by ART.

Method

This study used data from the National Registry, the Medical Birth Registry of Norway (MBRN), the Norwegian Prescription Database (NorPD) and the Cancer Registry of Norway (CRN), to calculate hazard ratios (HR) and 95% confidence intervals (CI) in women treated with and children conceived by fertility drugs, compared to those not. The observational period spans 1984 through 2014 for both groups. The study assessed all site cancer, as well as common cancers in women in this age group. Childhood cancers were assessed by sites, as specified by the International Classification of Childhood Cancers.

Results

Most estimates on site-specific cancer were not elevated for treated women. However, in nulliparous women treated with fertility drugs, risk of ovarian and endometrial cancer was elevated, HRs 2.24 (95% CI 1.14-4.40) and 4.59 (95% CI 2.68-7.84) respectively. In parous women treated with ART risk of breast and central nervous system cancers were elevated, HR 1.20 (95% CI 1.01–1.42) and 1.50 (95% CI 1.03-2.18) respectively. The risk of all-site childhood cancer was not elevated for ART conceived children, but the risk of leukemia was 1.67 (95% CI 1.02-2.73) and Hodgkin lymphoma was 3.63 (95% CI 1.12-11.72).

Conclusion

Although there were risk elevations among subgroups of women treated for infertility, the findings are reassuring for women and children exposed to fertility treatments in Norway. However, follow up time is still short, particularly for children. Findings warrant continued observation of women treated with fertility drugs, particularly concerning ovarian cancer.

Age period cohort incidence model for breast and testis cancer using integrated nested Laplace approximation

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Finnish Cancer Registry

Age period cohort models are important in epidemiological research. However, there is an identification problem in traditional Poisson regression analysis because *period* equals *cohort plus age*. One traditional frequentist approach to the identification problem is to leave one variable out but then estimates can be biased. Another traditional frequentist approach is to set restrictions to the parameters which can lead to very different estimates. In Bayesian approach there is no need to set restrictions to the parameters if weakly informative priors are used.

In my master's thesis I used integrated nested Laplace approximation. The main benefit of integrated nested Laplace approximation is computational compared to Markov chain Monte Carlo sampling. In my master's thesis I used first and second order random walk priors and different gamma hyperpriors.

Age, period and cohort had effect on breast cancer risk and on testis cancer risk. Breast cancer is common cancer among women so the choice of priors and the choice of hyperpriors didn't have much effect on the breast cancer results. However, the testis cancer is rare so the choice of priors and the choice of hyperpriors had quite large effect on the testis cancer results.

Cumulative probability of false positive results in the Finnish breast cancer screening program

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Finnish Cancer Registry, Mass Screening Registry

Background

A false-positive result represents harm in mammography screening. In this study we estimate the cumulative risk of a false-positive (FP) test result during 10 biennial screening examinations for women aged 50 to 69 years.

Methods

A retrospective cohort study was performed for 84,475 women aged 50—51 years at the time of their first invitation to mammography screening in 1992—1995. These women underwent altogether 477,047 screening mammograms in the Finnish 20-year breast cancer screening program. Generalized estimating equations were used to estimate the cumulative probability of a false-positive result. Age, regularity of attendance and a previous FP result were taken into account in the modelling. The cumulative risk was calculated from the parameter estimates by using the Bayes rule.

Results

Out of all screening attendees, 2.8 % were recalled for further examinations and of these 82.0 % received a false positive result. The estimated cumulative risk of at least one FP result during the screening program was 17.2 % (95 % CI: 16.8—17.5 %). Irregular screening attendance and previous FP findings increased the risk of (another) FP results.

Conclusions

Approximately one in every six women will be recalled for further examination with at least one negative outcome, provided they attend the biennial mammographic screening program between ages 50 to 69 years. Understanding the burden of false positive results to the target population helps in analyzing the viability of the screening program.

Cumulative risk of false-positive test in relation to breast symptoms in mammography screening: a historical prospective cohort study

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Background

In Finland, collecting self-reported symptoms information and inspection of breasts by the radiographer are the part of mammography screening program. We estimated the cumulative probability of false positive screening test results with respect to symptom history reported at screen.

Methods

A historical prospective cohort study was done using individual screening data from 413,611 women aged 50-69 years with 2,627,256 invitations for mammography screening between 1992 and 2012 in Finland. Symptoms (lump, retraction and secretion) were reported at 56,805 visits and 48,873 visits resulted in a false positive mammography result. Generalized linear models were used to estimate the probability of at least one false positive test and true positive in women with and without symptom at screening visit.

Results

The estimated cumulative probabilities were 18% and 6% for false positive and true positive results respectively. In women with a history of a lump, the cumulative probabilities of false positive test and true positive were 45% and 16% respectively, compared to 17% and 5% with no reported lump. In women with a history of any given symptom, the cumulative probabilities of false positive test and true positive were 38% and 13%. Likewise, women with a history of a 'lump and retraction' had the cumulative false positive probability of 56%.

Conclusion

The study showed higher cumulative risk of false positive tests and more cancers detected in women who reported symptoms compared to women who did not report symptoms at screen. The risk varies substantially, depending on symptom types and characteristics. Information on breast symptoms influences the balance of absolute benefits and harms of screening.

Different sources on identical cancer measurements – advantage or disadvantage?

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Documentation & Quality, Danish Cancer Society

Background

The Danish Cancer Registry has existed since 1943 monitoring basic cancer epidemiology in the Danish population. More recently, several clinical databases have been established for specific cancer sites monitoring the quality of cancer care. These databases use specific clinical or morphological inclusion criteria.

Two data sources can coexist, if they supplement each other on different items and have identical information on the intersection. However, we have observed differences between the Cancer Register and two clinical databases, i.e. populations, TNM-stage data, and date of diagnosis (see abstract from Christensen et al.) Hence, estimates of key measures such as survival differ depending on use of Cancer Register or the clinical database.

Results

We have set up a collaboration between the clinical researchers in charge of three clinical databases, officials in charge of the Cancer Register and Danish Cancer Society to resolve differences and how to minimize them. We report on how we work and the methods used.

Conclusion

National population registers and clinical databases often coexist. This makes sense if they have identical intersections. If not, it leads to biased estimates in research and policy analyses and causes a lot of confusion and controversies. The ultimate goal is to have identical data on identical cancer measurements in Denmark.

Physical strain at work and incidence of colon and prostate cancers

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We studied the association of perceived physical workload (PPWL) at work and the incidence of colon (CC) or prostate cancer (PC) in a case-control setting in the Nordic Occupational Cancer (NOCCA) data. Data from Finland, Iceland, Norway and Sweden were used for CC and data from Finland and Sweden for the PC study. Five population controls were selected for each cancer patient. Cumulative PPWL exposures were estimated from the census occupations using the NOCCA job exposure matrix. The group of professions with no significant exposure to PPWL was used as the reference in odds ratio (OR) calculation.

PPWL showed a stronger protective effect on CC for males than for females. The OR's in the highest PPWL decile were 0.74 (95% confidence interval: 0.72-0.77) and 0.87 (0.81-0.95), respectively. The highest decrease was seen in the cancer of descending part of the colon (OR 0.61, 0.54-0.69) in the highest PPWL decile in males.

For PC the highest decrease was seen in the moderate PPWL category (50th-90th percentiles): the OR was 0.88, (0.87-0.89), and after adjustment for socioeconomic status (SES) 0.94 (0.92-0.95). The OR for the highest PPWL decile was 0.97 (0.95-0.99) after adjustment for SES.

Our studies show that increased PPWL at work is associated with decreased incidence of CC, especially in men. The protective effect varies by location of colon. PPWL has little or no effect to the incidence rate of PC.

Statin use and the risk of endometrial cancer: a Danish nationwide case-control study

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Objective

To examine the association between statin use and the risk of endometrial cancer in a nationwide register-based case-control study.

Methods

Cases were all female residents of Denmark with a primary diagnosis of endometrial cancer during 2000-2009. For each case, 15 controls matched on age (± 1 month) were randomly selected by risk-set sampling. Information about statin use was obtained from The Danish Prescription Registry, where 'ever use' of statin was defined as ≥ 2 prescriptions on separate dates. Conditional logistic regressions were used to estimate odd ratios (OR) and 95% confidence intervals (95 % CI), adjusting for potential confounders including parity, HRT, obesity, diabetes, chronic obstructive pulmonary disease and education. Furthermore, we examined whether the risk of endometrial cancer varied by duration and intensity of statin use and stratified by endometrial cancer type and potential effect measure modifications.

Results

The study population included 5,382 cases and 72,127 controls. Ever use of statin was not associated with the risk of endometrial cancer (OR 1.03, 95 % CI 0.94-1.14). In addition, the duration and intensity of statin use did not influence the risk of endometrial cancer, and we found no strong associations when stratifying intensity by short- and long-term use. These results were consistent for both type I (OR 1.03, 95 % CI 0.93-1.15) and type II (OR 1.03, 95 % CI 0.80-1.35) endometrial cancer.

Conclusion and discussion

We found no association between use of statins and risk of endometrial cancer although, that we cannot fully exclude residual confounding from obesity/BMI.

Norwegian immigrants with cancer: Use of health services, treatment and survival

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Cancer Registry of Norway

Background

In countries where ethnic minorities have been present for a longer time, e.g., the US, disparities in cancer care between ethnic groups are well documented. As the immigrant population in Europe is aging and cancer incidence is expected to increase, it is important to conduct similar research in a relevant context.

Aim

Our objective is to conduct a series of studies assessing disparities in cancer care between immigrants in Norway and the general Norwegian population for the quality indicators: Stage at diagnosis (*Study 1*), time to treatment and treatment patterns (*Study 2*) and survival (*Study 3*).

Methods

A nationwide cohort study of subjects diagnosed with cancer from January 1990 to December 2014 will be identified from the population-based Cancer Registry of Norway (CRN). Immigrant information and relevant variables is to be obtained by linkage with Statistics Norway and the Norwegian Patient Registry. Further, immigrants are assigned to country groups using the standard WHO country categorization, with some modifications. Subsets will be created for the most common cancer types. Descriptive statistics and regression modeling will be applied to test for differences within common cancers, as well as for groups of cancers when relevant. The studies have been approved by the local ethics committee.

Results

We are currently awaiting data and plan to present preliminary results from *Study 1*.

10 years of Cancer Registry activities in Belgium - descriptive epidemiology and evaluation of quality of care

Liesbet Van Eycken

Belgian Cancer Registry

The Belgian Cancer Registry (BCR; www.kankerregister.org) is in charge of producing and monitoring the Belgian statistics on cancer incidence (incl. spatiotemporal trends), prevalence and survival. The Health Law of December 2006 provides a legal basis for the Cancer Registry and describes the clinical and pathological anatomy pathway for data collection. Data are routinely gathered in these two settings allowing most of first-way missed cases to be declared by the other one. The law also provides the authorisation to use the national number (social security number) for the patient identification. The use of this unique number facilitates linkage with other available medical and/or administrative data (e.g. nomenclature, death certificates, hospital discharge and pharmacological data) and hence longitudinal research. Such a linkage not only requires the authorization of the Privacy Commission but also implies severe measures and rules for privacy protection and confidentiality.

The Flemish region achieved a full coverage and completeness since the year of incidence 1999; the data were published in 'Cancer Incidence in Five Continents', volume VIII and IX. From 2004 on, data are complete for the whole country: they were recently published in 'Cancer Incidence in Five Continents', volume X. Data are now available for 10 consecutive incidence years, 2004-2013. Cancer incidence data 2014 will be published in September 2016. The progress made during the last years, is clearly related to the legislation activities, new initiatives on clinical registration in the Flemish, Brussels and Walloon hospitals, and the sustained registration efforts of the pathology laboratories.

Although incidence, survival, prediction and prevalence figures represent a very important output of a cancer registry, this can only be considered as a first deliverable in a multi-step process. Cancer registries indeed see their role more and more extended in cancer control.

The increasing involvement of the clinicians and pathologists in quality of care studies, the introduction of a national cancer plan and the active participation of patient organisations demonstrate a growing interest in cancer control. Cancer control not only aims to reduce the incidence, morbidity, and mortality of cancer but also wants to improve the quality of life of cancer patients through the systematic implementation of evidence-based interventions in prevention, early diagnosis, treatment, and palliative care. These studies should result in optimizing treatment strategies, reducing variability in treatment and improving the prognosis of cancer patients. The BCR is increasingly involved in the evaluation of quality of care studies and provides individual feedback reports to all Belgian hospitals involved in cancer diagnosis and treatment.

Estimation of overdiagnosis in breast cancer screening using a non-homogenous multi-state model: a simulation study

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Background

Overdiagnosis is regarded as a major harm of mammography screening but published estimates of the frequency of overdiagnosis vary widely. This discrepancy might be due to different study designs, estimation methods and lead time adjustment methods. The aim of this study is to develop a non-homogenous multi-state model for estimation of overdiagnosis, to validate the model by a simulation study in which the true frequency of overdiagnosis can be identified and to compare our estimate with the classical cumulative incidence method.

Methods

We constructed a four-state model to describe the natural history of breast cancer. The invisible latent disease progression of breast cancer for each individual and the observed disease states were simulated assuming a breast screening trial with biennial invitation of women 50-69 years. A non-homogenous Markov process was developed to estimate the expected number of detected non-progressive cases. One hundred repetitions of the simulation with one million women were done to evaluate the performance of the multi-state model. One sample was randomly selected for illustration.

Results

Based on the 100 repetitions of simulation, the mean value of the true frequency of overdiagnosis was 12.5% and the average estimates by the cumulative incidence method and multi-state model were 12.9% (interquartile=2.46%) and 13.4% (interquartile=2.16%), respectively. The multi-state model had larger bias than the cumulative incidence method but the variation of the estimates was smaller.

Conclusions

We showed that a non-homogenous multi-state model produces a proper estimate of the frequency of overdiagnosis comparable to the cumulative incidence method.

Recent trends in cancer incidence, mortality and survival in Estonia

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Aim

To analyse 20-year trends in incidence and mortality, and recent relative survival for selected cancer sites in Estonia.

Methods

Temporal trends in age-standardised (World) incidence (1994–2013) were examined using Cancer Registry data on cases of colorectal, lung, breast (women), cervical and prostate cancer and skin melanoma. Trends in age-standardized mortality (1994–2014) were analysed using data from the Causes of Death Registry. Five-year relative survival ratios (RSR) for 2010–2014 were calculated using period-hybrid analysis (cases diagnosed in 2005–2012 and followed through 2014).

Results

Since 1994, both the incidence and mortality of male lung cancer have declined steadily, while among women, the incidence has increased slightly during recent years. Breast cancer incidence has increased continuously, while mortality has been decreasing since 2000. Cervical cancer incidence is still rising with no change in mortality. Continuous upward trends are apparent in the incidence of prostate and colorectal cancer as well as skin melanoma, while there is no significant change in mortality.

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