Finnish Cancer Society/Finnish Cancer Registry

NORDSCREEN within NIASC February 2016

Project: Interactive joint NORDic database on performance and outcome indicators of cervical cancer SCREENing (NORDSCREEN)

Aim

The NORDSCREEN project aims to develop a publicly available web-based interactive tool/application to access standardised, and as far as possible, evidence-based, performance and outcome indicators of cervical cancer screening, based upon up-to-date Nordic cancer screening register data.

Background

The five Nordic countries (four of which are represented in NIASC) have national screening registers with high completeness on organised screening invitations and results. The screening programmes differ to some extent with respect to policy and direct comparison of actual performance and outcome of screening across programmes is currently difficult. Such direct comparison could prove immensely informative and produce valuable data to support screening policy development and implementation. The Nordic setting is uniquely suited for further research on screening impact and optimisation.

Link to the NIASC application work plan

In accordance with the aims of NIASC, this project will develop a method and platform to refine and capitalize on the unique existing national screening registries in the Nordic countries. A joint Nordic effort to standardize reporting of performance and outcome indicators and make these publicly available will have the potential to stimulate quality improvement in screening and management of screen-positives, which may translate into improved health outcomes.

Work plan

Key performance indicators in cervical cancer screening have been described in the European Guidelines for QA in cervical cancer screening 2nd ed. The indicators have been elaborated on, together with the data items needed to calculate them, in European collaborations (deliverables of WP5 in EUROUCOURSE; http://www.eurocourse.org). The Nordic cervical cancer screening network (restarted in 2014) has already provided some input on the practical aspects of data retrieval and the calculation of indicators. Based on previous work, this project will develop and implement a standardised set of key performance and outcome indicators, and a set of scripts for standardised retrieval (/export) of the required data items from the different collaborating screening registers. The resulting data will be in aggregate form. Finally, a web-based application will be developed for easy, flexible and public access to these data. All methodological work will be performed in the

Finnish Cancer Registry. The web-based application is to be built up in and funded by Karolinska Institutet.

As data on spontaneous, or opportunistic, screening (not prompted by a programme invitation and outside of the framework defined by the screening policy), is an essential part of the testing activity, it is important that this is also included in the data set providing the basis for performance and outcome monitoring. In particular, systematic registration of opportunistic cervical smear testing should be advocated and planned together with experience from those countries where this has already been achieved. Reaching data coverage of all opportunistic testing will require the definition and clearance of remaining logistic and organisational barriers, including issues concerning the legal framework, data repository, data flow and use of data.

Timelines

The project would be active from 1.5.2016 to 31.12.2018. The development of both platform and the evidence-base and consensus definition of indicators would proceed in parallel, also the development of export scripts would proceed in parallel when feasible.

Interaction with other NIASC groups or Stakeholders

The project will draw upon established networks of screening managers and researchers in each country, the Nordic cancer registries, European collaborators, and IARC, in order to reach a consensus on data structure, retrieval, choice and definition of indicators, for maximum relevance to the end-user in the Nordic region and beyond.

The main collaborators in the project will be the Finnish Cancer Registry, Karolinska Institutet, and the Cancer Registry of Norway. The Icelandic Cancer Registry and the Danish Cancer Society / Danish Quality Database for cervical cancer screening will also be involved in the project.

Conclusion

The proposal involves the harnessing of the potential of the existing rich national registries of cancer screening in the Nordic countries. A first requirement of fully exploiting the potential of data is to make it accessible to potential exploiters. Comparison of indicators with Nordic peers, would highlight areas of suboptimal screening performance in individual programmes or regions, and thereby help to direct efforts to improve screening implementation. The joint data repository with publicly available standardised indicators may also motivate programmes to develop and improve their routines for screening data collection and monitoring. The ready availability of performance indicators, not only for the own country, but for comparator programmes as well, would also greatly ease the provision of relevant and tailored data to decision-makers, the press, and screening providers (as exemplified by NORDCAN and GLOBOCAN in the field of cancer burden). The screening data repository could also be useful for identifying areas needing further quality assurance research and attention, thereby acting as a seeding ground for the development of new research projects and quality improvement for better health outcomes in years to come.