

National law on cancer registration in Switzerland: Background information from NICER and the cantonal cancer registries regarding the importance of data collected for the purpose of cancer monitoring

Introduction

Cancer is a major public health threat in Switzerland.

Cancer registries help to advance our understanding of the causes, occurrence and outcome of cancer and improve public health by preventing disease and improving health care. The new law on cancer registration will help to consolidate cancer registration processes in Switzerland and support the development of an effective cancer monitoring system. It will be necessary to assure the collection of comparable high quality data in all Swiss cantons.

In the following, NICER presents five examples that demonstrate the high value of systematically collected cancer data for monitoring purposes. Three of the examples are from Switzerland, and two are from cancer registries in the Scandinavian countries, which currently have the most developed cancer registration systems in place.

Annex 1 provides additional examples of valuable knowledge based on data from the cantonal cancer registries of Geneva, Ticino and St. Gallen. Further examples from Europe can be found in a position paper on data protection by the European Network of Cancer Registries¹.

The list is not exhaustive, but the examples presented highlight the kind of valuable information that would be impossible to obtain if unreasonably strict data protection measures prevented systematic and complete collection of cancer monitoring data in Switzerland.

Example 1 (Switzerland): Variation in survival after diagnosis of breast cancer in women

In 2005 breast cancer survival rates in Switzerland were calculated and analyzed in different cantons. Survival rates were found to vary across the Swiss cantons examined, partly explained by different secondary prevention regimes. A subsequent pattern of care study (2009) showed that some of the differences might be also explained by the way patients are cared for across the Swiss regions. The results of these studies were discussed among experts and publicly and resulted in the establishment of mammography screening programmes, accreditation of highly specialized breast centres and discussion on standardized treatment guidelines. The results are relevant for patients, clinicians and the authorities.

Example 2 (Switzerland): Population-based studies on breast cancer screening (Ticino)

Based on Ticino Cancer Registry data, information on screening and cancer diagnosis in the year 2009 was analysed in depth. It was revealed that even well-established opportunistic breast cancer screening is less efficient than a systematic mammography screening program. This study contributed decisively to the Canton of Ticino's decision to introduce a systematic

¹ Eurocourse and ENCR Working Party. Position paper on the Commission's proposal for a General Data Protection Regulation. September 2012. Available at: <http://ieaweb.org/2012/12/data-protection-in-the-eu-an-update/>

mammography screening program. These findings are relevant for women, clinicians and the authorities.

Example 3 (Switzerland): Studies on prognosis of breast cancer in elderly women (Geneva)

Based on Geneva Cancer Registry data, it was discovered that elderly women's survival prognoses were worse than younger women's, despite identical cancer profiles and also after controlling for concomitant diseases. The less favourable prognosis was associated with undertreatment of elderly women. These results reveal a need for changes in the treatment plans for elderly women with cancer. These are important findings for women with cancer and clinicians.

Example 4 (Denmark): Cancer risk and the use of cell phones

In this study, cancer registry data were linked with data on the use of cell phones in Denmark. A large sample of cell-phone users (n = 350,000) was followed for over 10 years. After controlling for confounding variables, analysis of the data showed the following: «In this update of a nationwide study of mobile phone subscribers in Denmark we found no association of an increased risk of tumours of the central nervous system ... Furthermore we found no increased risk in temporal glioma, which would be the most plausible tumour location». These findings are important for the public, the authorities and industry.

Example 5 (Northern European countries): Cancer risk after large-scale accidents (such as nuclear reactor accidents, pollution of drinking water and similar)

In the countries of Northern Europe, cancer registry data made it possible to study the consequences of the Chernobyl nuclear disaster of 1986. Cancer registry data from the period before the accident were compared to the data after the accident. If this study had been bound to the data protection principle of explicit patient consent, the participation rate might well have been higher after the accident than beforehand. This would have led to a distortion of the results. The findings produced by this kind of monitoring are important for the public, practicing physicians, the health care system and the authorities.

ANNEX 1: Importance of cancer registry data

A) Examples from the Geneva Cancer Registry

Christine Bouchardy, Head Cancer Registry of Canton of Geneva

Surveillance of risk factors among the population

Study: *Recent increase of breast cancer incidence among women under the age of forty*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, social class, country of birth, method of detection, diagnostic confirmation and family history of breast cancer. **Main results and conclusions:**

The risk of breast cancer in women <40 years old has doubled since 2002. This increase is not fully explained by the arrival of new immigrants, by better surveillance/screening of young women with a strong family history of breast cancer, or by better assessment through new diagnostic methods such as the magnetic resonance imaging (MRI). **Impact and consequences:**

This increase in incidence of breast cancer among young women, recently confirmed also at the European level, requires careful further surveillance and research on the rise of exposure to new or already well-established cancer risk factors. **Target audience:** General population, public health authorities and researchers. **Published in:** *British Journal of Cancer*, 2007.

Study: *Changing pattern of age-specific breast cancer incidence in Geneva*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, social class, country of birth, method of detection and the use of hormone replacement therapy (HRT) at menopause obtained from a specific health survey conducted among the Geneva population. **Main results and conclusions:**

Among peri- and postmenopausal women breast cancer occurrence increased over the years, showing a peak in 2002, and started to decline thereafter, with at least 50 fewer breast cancers cases per year. This trend corresponded to the time of a change in the use of HRT in Geneva: in fact, a significant decrease in the use of HRT in Geneva was observed after the release of scientific publications in 2000 showing an association between use of HRT and increased breast cancer risk. Therefore, the changes in HRT use are likely to be at the origin of the observed decrease in breast cancer incidence in Geneva. **Impact and consequences:** Women should be fully informed on both the benefits and risks of HRT. **Target audience:** General population, public health authorities. **Published in:** *Breast Cancer Research and Treatment*, 2010.

Study: *Cancer risk by occupation and socio-economic group among men: a study by the Association of Swiss Cancer Registries*

Country/region involved: Switzerland. **Source of information and data used:** Data from five Swiss cancer registries (Basel, Geneva, St. Gallen/Appenzell, Vaud and Zurich) including age, marital status, degree of urbanization, nationality and type of diagnosis confirmation. Occupation at the time of diagnosis was used to build a variable for socioeconomic status

(SES). **Main results and conclusions:** Large SES differences in cancer risks were observed. The impact of SES is particularly high for alcohol-, tobacco- and poor nutrition-related cancers such as lung, upper aerodigestive tract, oesophagus and stomach cancers, more frequent among less favoured groups. Occupation is an important risk factor for some cancers, such as lung, pleura, nose and sinuses, bladder, lympho-hematopoietic system, bladder, thyroid cancer and melanoma. **Impact and consequences:** This study provides interpretable results for additional research, public health actions, epidemiologic surveillance of health inequalities and occupational-related risks in Switzerland. **Target audience:** General population, public health authorities, occupational medical professionals, insurance companies (SUVA, etc.) **Published in:** Scandinavian Journal of Work, Environment & Health, 2002.

Study: *Cancer incidence near the waste incinerator of Les Cheneviers*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, sex, social class, period of diagnosis, municipality of residence, ecologic and geographic data, including distance of the municipality of residence from the incinerator, emission of pollutants, winds, etc. **Main results and conclusions:** We observed no increase of risk of sarcoma and lymphoma, the two tumours known to be linked to waste incineration. **Impact and consequences:** This study provides reassuring results, a lack of cancer increase among residents living near the incinerator. **Impact and consequences:** Continuous evaluation of cancer risk around incinerators or other dangerous environmental sources by cancer registries is required. **Target audience:** General population, public health authorities, professionals. **Publication:** Rapport d'évaluation sur l'incidence des cancers à proximité de l'usine d'incinération des ordures des Cheneviers, Department of Regional Affairs, Economy and Health, Geneva, 2008.

Evaluation of care and access to good practice

Study: *Impact of obesity on diagnosis and treatment of breast cancer*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, nationality, weight, height, family history of breast cancer, method of detection, diagnosis confirmation, treatment including surgical margin and duration of hospitalization. **Main results and conclusions:** Obese women are less often screened, have more advanced stage at diagnosis, less frequently have access to latest diagnostic methods such as MRI and are at increased risk of prolonged hospital stay. **Impact and consequences:** Obesity, which is a public health problem in Switzerland, has a direct impact on breast cancer diagnosis, treatment and consequently prognosis. **Target audience:** General population, public health authorities, professionals. **Published in:** *Breast Cancer Research and Treatment*, 2010.

Study: *Social class is an important and independent prognostic factor of breast cancer mortality*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, period, nationality, country of birth, occupation, sector of care, method of detection, diagnosis confirmation, stage, tumour characteristics, detailed treatments, survival and cause of death. Occupation was used to build a variable for

socioeconomic status. **Main results and conclusions:** Compared to patients with high socioeconomic status, patients with low socioeconomic status had an increased risk of dying of breast cancer. These women were more often foreigners, less frequently had screen-detected cancer and were at a more advanced stage at diagnosis. They less frequently underwent breast-conserving surgery, hormonal therapy and chemotherapy, in particular in case of axillary lymph node involvement. **Impact and consequences:** Socioeconomic differences in diagnosis and treatment are strong in Geneva, despite its affluence and high-quality health structures. Socioeconomic status should be considered an independent prognostic factor for breast and other cancers and women with low socioeconomic status should be offered intensified support and surveillance. **Target audience:** General population, public health authorities, professionals. **Published in:** *International Journal of Cancer*, 2006.

Study: *Undertreatment strongly decreases prognosis of breast cancer in elderly women*

Country/region involved: Canton of Geneva. **Source of information and data used:** Geneva Cancer Registry data including age, nationality, presence of co-morbidities, patient's or family's refusal of treatment, method of detection, diagnosis confirmation and treatment including surgical margins. **Main results and conclusions:** Contrary to physicians' belief, elderly patients have tumours with similar aggressive profiles as younger patients'. Half of elderly patients are undertreated or treated with non-established protocols. This sub-optimal treatment is not explained by a patient's co-morbidities or refusal of treatment. As a consequence, elderly women experience important breast cancer over-mortality. **Impact and consequences:** In the aging population of Switzerland, cancer treatment for elderly patients is a public health priority. Treatments need to be adapted to the elderly but at the same time should offer them the best chance of cure. **Target audience:** General population, public health authorities, professionals. **Published in:** *Journal of Clinical Oncology*, 2003.

Evaluation of adverse effects of care

Study: *Excess of cardiovascular mortality among node-negative breast cancer patients irradiated for inner-quadrant tumours*

Source of information and data used: Geneva Cancer Registry data including age, year of diagnosis, nationality, occupation, detailed treatment, survival and exact cause of death.

Main results and conclusions: Patients with inner-quadrant breast cancers had a more than doubled risk of cardiovascular mortality compared with patients with outer-quadrant tumours. The risk was particularly increased in the calendar period with higher boost irradiation levels. Patients with left-sided breast cancer had no excess of cardiovascular mortality compared with patients with right-sided tumours. **Impact and consequence:** Radiotherapy of inner-quadrant breast cancer is associated with an important increase of cardiovascular mortality, most probably a result of higher irradiation of the heart. For patients with inner-quadrant tumours needing radiotherapy, the heart should be protected from radiation. **Target audience:** General population, public health authorities, professionals, insurance. **Published in:** *Annals of Oncology*, 2010.

Determination of public health priorities and evaluation of prevention

Study: *Cancer in Switzerland: situation and development from 1983 to 2007*

Source of information and data used: NICER and mortality data from the Swiss Federal Statistical Office (FSO) and international data on incidence, mortality and survival. **Main results and conclusions:** As compared to the rest of the world, Switzerland presents very high risk for prostate cancer, breast cancer, melanoma, lymphoma and testicular cancer. European comparisons show that survival after cancer is high in Switzerland for most cancers, due to early diagnosis and effective treatment provided by the health system. However, important disparities still exist between the cantons, linked to differences in prevention and screening strategies. For each cancer, this monograph provides information on risk factors and preventive measures or screening actions that help to decrease the impact of each cancer among the Swiss population. **Impact and consequences:** This monograph shows that cancer registries are a unique and an indispensable source of information for cancer monitoring, determining public health priorities and evaluating the efficacy of prevention and screening actions. **Target audience:** General population, public health authorities, researchers, physicians. **Publication:** Federal Statistical Office, NICER, Swiss Childhood Cancer Registry. *Swiss Statistics* series, #14 Health, published by the Federal Statistical Office (FSO), 2011.

B) Examples from the Ticino Cancer Registry

Andrea Bordoni, Head Cancer Registry of Canton of Ticino

Quality of cancer care evaluation

Case study: *Variation in survival after diagnosis of breast cancer in Switzerland*

Date, country involved: 2005, Switzerland, selected cantons. **Source(s) of information:** Cancer registry data, pathology cancer patient reports, hospital cancer patient documents and cantonal office of inhabitant. **Data used during analyses:** Tumour type, specific stage with quality control in medical documentation, age, date of incidence, date of death, specific morphology to exclude tumour types not breast specific (lymphoma and melanoma). **Main results:** After adjustment for age and stage, some cantons have higher survival probability than others. **Conclusions:** There are inter-cantonal differences in survival probability. **Potential impact areas:** Quality of care. **Target audience:** Patients, clinicians and health authorities. **Effects/consequences:** Promotion of additional studies on cancer care, organisation of high-quality cancer units. **Published in:** *Annals of Oncology*, 2005.

Case study: *POC, patterns of breast cancer care in Switzerland*

Date, country involved: 2007, Switzerland, selected cantons. **Source(s) of information:** Cancer registry data, pathology cancer patient reports, hospital cancer patient documents, public and private physicians and cantonal office of inhabitant. **Data used during analyses:** Similar to example just above but more detailed data, including biological characterization of tumours (morphology, hormonal receptors, etc.), different prognostic and predictive factors,

detailed treatment modality, etc. **Main results:** There are different treatment modalities in different cantons. **Conclusions:** Some of the observed survival differences can be explained by different treatment modalities. **Potential impact areas:** Quality of care. **Target audience:** Patients, clinician and health authorities. **Effects/consequences:** Organization of high quality cancer units, standardization of care according to guidelines.

Case study: *Impact on survival of neo-adjuvant treatment of locally advanced rectal cancers at population based level*

Date, country involved: 2011, Southern Switzerland, Ticino. **Source(s) of information:** Cancer registry data, pathology cancer patient reports, hospital cancer patient documents, public and private physicians, radiotherapy reports, cantonal office of the inhabitant. **Data used during analyses:** Biological characteristics of tumours (morphology, differentiation, etc.), different prognostic and predictive factors, detailed treatment modality, follow-up, etc. **Main results:** Confirmation (similar results in another study, but this is the only study at the population-based level) of benefit in terms of survival of patients with rectal cancer receiving neo-adjuvant radiotherapy. **Conclusions:** Neo-adjuvant treatment of locally advanced rectal tumours should be encouraged. **Potential impact areas:** Quality of care. **Target audience:** Clinicians. **Effects/consequences:** We observed an increase in number of patients treated according to the described modality in recent years. **Published in:** *European Journal of Cancer Prevention*, 2012

Case study: *Quality indicators of cancer care in Southern Switzerland*

Date, country involved: 2011–2013, Ticino. **Source(s) of information:** Cancer registry data, pathology cancer patient reports, hospital cancer patient reports, public and private physicians, cantonal office of inhabitant. **Data used during analyses:** All data relating to quality from the diagnosis to the end of treatment. **Main results:** We are analysing the percentage of patients that benefit from treatment according to guidelines and up-to-date knowledge on cancer for colorectal, prostate, ovary, uterus and lung cancer. The project is ongoing. **Conclusions:** The results will be presented at the population-based level, to facilitate comparison with other cantons in Switzerland. **Potential impact areas:** Quality of care. **Target audience:** Clinicians, patients, patient associations. **Effects/consequences:** The objective is to obtain an additional increase of quality of care.

Cancer screening strategy evaluation

Case study: *Assessment of breast cancer opportunistic screening by clinical-pathological indicators: a population-based study*

Date, country involved: 2009, Southern Switzerland, Ticino. **Source(s) of information:** Ticino Cancer Registry data, pathology cancer patient reports, hospital cancer patient documents, public and private physicians, cantonal office of the inhabitant. **Data used during analyses:** Similar to first example above but more detailed data, including biological characterization of tumours (morphology, hormonal receptors, etc.), different prognostic and predictive factors, detailed treatment modality, etc. **Main results:** Well-implemented breast cancer

opportunistic screening strategy is less efficient than programmed screening. **Conclusions:** Programmed screening program is necessary in the cantons without it. **Potential impact areas:** Secondary screening. **Target audience:** Patients, clinicians and health authorities. **Effects/consequences:** Implementation of screening program in Ticino has been approved by the government. **Published in:** *British Journal of Cancer*, 2009

Cancer prognostic predictive factors

Case study: *Breast cancer classification according to immune-histochemical markers: clinic-pathologic features and short-term survival analysis in a population-based study from the South of Switzerland*

Date, country involved: 2009, Southern Switzerland, Ticino. **Source(s) of information:** Ticino Cancer Registry data, pathology cancer patient reports, hospital cancer patient documents, public and private physicians, cantonal office of the inhabitant. **Data used during analyses:** Biological characteristics of tumours (morphology, differentiation, etc.), different prognostic and predictive factors, detailed treatment modality, follow-up, etc. **Main results:** We provide strong evidence that the molecular classification is useful for clinical management and superior to World Health Organization classification in terms of short-term prognostic value. **Conclusions:** Molecular breast cancer classification is beneficial for efficient treatment decisions. **Potential impact areas:** Quality of care. **Target audience:** Clinicians, patients. **Effects/consequences:** We observed an increase in patients classified according to the described modality in recent years. **Published in:** *Annals of Oncology*, 2009

C) Examples from the Cancer Registry of Canton of St. Gallen/Appenzell

Silvia Ess, Head Cancer Registry of Canton of St. Gallen/Appenzell

Title of case study: *Patterns of care of breast cancer in Switzerland*

Date, country involved: 2005, Switzerland. **Source(s) of information:** Cancer registries, pathology reports, patient records. **Data used during analyses:** 150 additional variables collected for the study. **Main results:** There are regional differences in the way patients with breast cancer are cared for in Switzerland; case load related to state-of-the-art management; participation of teams in clinical research is predictor for state-of-the-art management. **Conclusions:** Importance of specialization and research in the quality of care, necessity to reduce regional disparities. **Potential impact areas:** Centralization of care, accreditation of centres to aid patient choice of provider. **Target audience:** Patients, health authorities, physicians. **Effects/consequences:** Start of accreditation system of breast centres in Switzerland by the Swiss Cancer League. **Publications in:** *Cancer Epidemiology* 2009, *Annals of Oncology* 2010, *Clinical Breast Cancer* 2012, *Swiss Medical Weekly* 2012