

# Towards the Creation of a National Institute for Cancer Epidemiology and Registration (NICER)

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## Summary

Cancer epidemiology based on cancer registry data permits to measure cancer burden, to survey the disparities of occurrence, to evaluate efficacy of public health actions and health care systems, as well as generate insights into the mechanisms of cancer causation.

In Switzerland, nine population-based cancer registries cover 56% of the population. The Association of Swiss Cancer Registries (ASCR) started in 1978 with the main objective to harmonise data collection, create an intercantonal data set, and promote cancer epidemiology at a national level. At the end of the 1990s, evaluations of the ASCR clearly established that cancer epidemiology remains marginalised in Switzerland and that the present subsidy and structure must change in order to permit an adequate development of the discipline. With the support of the Federal Office for Education and Science the need and the utility of cancer epidemiology is being recognised progressively.

The aim of this report is to establish the main objectives of cancer epidemiology in Switzerland and to propose a general structure and a budget for a «National Institute for Cancer Epidemiology and Registration (NICER)» adapted to reach these objectives. The creation of such an institute would present many advantages.

The intended Institute would be a centre of information, surveillance, evaluation, and research regarding cancer epidemiology. It would participate in the elaboration of national programs against cancer. It would establish continuous monitoring of the disease and would permit public health authorities,

clinicians and politicians to evaluate the efficacy of their actions. As it is already the case in most developed countries, cancer epidemiology could this way develop into the most promising cancer control discipline in Switzerland with a direct benefit for future patients, health professionals and society. It should be recalled that in all industrialised countries, cancer is the leading cause of premature death.

## 1. Utility of cancer registration and population-based cancer epidemiology

Population-based cancer epidemiology is the scientific approach to measure cancer burden, plan and evaluate public health actions, to survey, as well as generate insights into the mechanisms of cancer causation. Epidemiological research based on comprehensive cancer registration therefore remains the most valid and efficient way to plan and evaluate all these aspects of cancer control.

The primary task of a cancer registry is to register all cancer cases occurring in a defined population. Information on patients is collected continuously and systematically from various sources. The data items recorded are patient characteristics, as well as clinical and pathological tumour characteristics, and the way of discovery has also to be taken into account. The information is collected according to guidelines set by relevant international and European organisations (International Agency for Research on Cancer, World Health Organization, European Network of Cancer Registries). The registries publish comparative incidence data in **Cancer Incidence in**

**Five Continents**, a series published by the International Agency for Research on Cancer (IARC) (1). Information from cancer registries is the primary resource for epidemiological research on cancer determinants, as well as for planning and evaluating health services for prevention, diagnosis, and treatment of the disease. Specific studies based on cancer registry data also permit to evaluate environmental risk factors, adverse effects of treatment, particularly on a long-term basis, as well as the global efficiency of the health care system and the degree of generalisation of good practice in medical care. Cancer registries can also be used for monitoring occupational risks, for surveillance of individuals with various exposures and as a convenient source for clinical studies (2-4). Thus, cancer registration is a necessary part of a modern health information system.

Population-based epidemiology based on cancer registration allows answering many questions formulated by public health authorities, clinicians, as well as by patients and the general population (5). Which cancers are particularly frequent in Switzerland? Is it true that the number of cancers is increasing? Is mortality from breast cancer decreasing? If yes, is it due to screening? Is mortality decreasing in all cantons? What is the proportion of curable cancers? Is cancer survival better in Switzerland than in other European countries? Which women still develop invasive cervix cancer? Which cancer has the greatest impact in terms of years of life lost? What is the effect of the Chernobyl catastrophe on childhood cancer in Switzerland? How efficient is the national program of melanoma screening and prevention?

Are occupational cancers an important problem in Switzerland? How many cases of professional malignant mesothelioma are not recognised by the SUVA? Are workers in the pharmaceutical industries at increased risk of cancer? How many men live with the diagnosis of prostate cancer in Switzerland? Do Swiss German-speaking cantons diagnose breast cancer at a more advanced stage than the French-speaking ones? How many colon cancers are discovered by Hemocult® screening? How is localised prostate cancer treated? Is the treatment similar in the different cantons? Why do unskilled workers have the poorest prognosis after upper aero-digestive cancer? Does leukaemia remain the most frequent cause of death by cancer among children? Is the efficacy of the private health care sector similar to that of the university hospitals? Is breast cancer treated according to the Standards, Options & Recommendations (SOR)? Is this the case in all cantons? How are elderly breast cancer patients treated? What are the importance and consequences of undertreatment of these patients? How many patients with stomach cancer undergo surgery performed by surgeons with an experience of less than two similar operations per year? What is the risk of second cancer after radiochemotherapy for Hodgkin's disease? Does mitoxanthrone increase the risk of acute myeloid leukaemia? What is at the origin of the dramatic increase of lobular breast cancer? What determines lung cancer cure? Where do cancer patients die? Are Asian immigrants at higher risk of liver cancer? Does pregnancy after breast cancer decrease the prognosis? What is the risk of cancer in persons infected with HIV? These numerous questions are only some examples of possible studies, which can be carried out by the cancer registries.

## 2. Cancer registration and population-based epidemiology in Switzerland

Nine population-based cancer registries are now operating in Switzerland. They cover a population of 4.2

millions (i.e. 56% of the Swiss population) and 13 of the 26 cantons or half-cantons. These cancer registries are independent units, producing their own statistics and research at cantonal or regional levels. Some of them are efficient research centres regularly performing descriptive, etiological, surveillance, and evaluation studies.

The Association of Swiss Cancer Registries (ASCR) started in 1978 with the main objective to harmonise the data collection, create an intercantonal data set, and promote cancer epidemiology at a national level. Later on, the ASCR was incorporated into the Swiss Institute for Applied Cancer Research (SIK) and receives currently an annual subsidy of about 730'000 SFr from the Swiss Confederation. This subsidy covers only 8% of the total costs of cancer registration at the peripheral level and the part-time salaries of an epidemiologist (25%), a secretary (10%) and the full-time salary of a computer-scientist/bio-statistician (100%) at the small co-ordination centre. The major part of the total costs is covered by the cantonal budgets and cancer leagues

In Switzerland, like in other countries, the need for information, results and skills in cancer epidemiology is increasing. This is especially true for the evaluation of the effectiveness of national programs against cancer, the epidemiological surveillance of the population, and the evaluation of health-care output. In addition to the increasing number of cancer cases occurring in the ageing Swiss population, there is a growing demand on the cancer registries to increase the information collected and to provide useful and interpretable statistics for public health authorities, health insurances, professionals, and researchers. Therefore, in addition to tumour main characteristics, numerous additional data are requested today. For example, Swiss cancer registries need to collect data 1) on occupation to monitor occupational cancers and on social class to evaluate inequalities in risk, prevention and health care access, 2) on the way of discovery and stage to study diagnostic precocity, in particular the effect of screening, 3) on the type of treatment to evaluate disparities of care and

generalisation of good practice, 4) on survival to evaluate the prognosis and the global efficacy of care, 5) on second tumour occurrence to evaluate putative iatrogenic effects of treatments. It is now the moment to modify the structures of the ASCR. At cantonal levels, several cancer registries meet financial difficulties and lack political support. The number of cases registered per year has more than doubled since the 1970s. Additionally, the number of medical records as well as other sources of information consulted for cancer registration has grown dramatically due to increased investigations, expansion of treatment centres, development of private practice, and the mobility of patients consulting several services. Despite the increasing number of cancer registries and registered cancer cases the federal subvention slightly increased but was never adapted, neither to this growth nor to the new objectives. Contrary to most other branches involved in cancer research, epidemiological research does not benefit from grants from the pharmaceutical industry because it has no direct financial impact. The means at disposal for epidemiological research are about 20 times less than for clinical or biological cancer research.

At the end of the 1990s, the ASCR conducted an evaluation of its objectives, means and internal functioning. A Committee of evaluation and reorganisation including national and international experts was constituted. A largely distributed report was published in 1999 (6). In the context of the global evaluation of the Swiss Institute for Applied Cancer Research (SIK) into which the ASCR is integrated, the ASCR was also evaluated by another international scientific committee (7). These two evaluations clearly established that cancer epidemiology remains marginalized in Switzerland (6,7). The report «Additional funding for the Swiss cancer registries' network and population epidemiology», established details on the financial needs for basic registration in August 2000 (8).

These evaluations emphasised the necessity to improve the integration and collaboration with the different authorities and institutions concerned, in particular with the Swiss Federal Office

for Public Health, the Swiss Federal Statistical Office, and the future National Health Observatory. It was also concluded that epidemiology must be represented as a discipline *per se* within institutions in charge of research coordination, such as Oncosuisse. The links with international organisations (WHO, etc.) have to be strengthened. A legal basis for cancer registration was recognised as an imperative factor for the development of cancer registration. As regards financial support, only permanent and adequate resources can permit continuous and valid registration corresponding to the needs of research and teaching. A fixed funding quota for specific epidemiological cancer research projects should be awarded.

The needs of cancer epidemiology and registration were explained on several occasions to the SIAK, the Swiss Federal Statistical Office, the Swiss Federal Office for Public Health and more recently to the Federal Office for Education and Science (OFES). With the support of the OFES, presently in charge of the ASCR subsidy, the needs of cancer epidemiology have been progressively recognised and a great interest in epidemiological and public health research has been generated. The moment has come for political decisions to create a structure able to monitor cancer, to evaluate the effect of ongoing and future national programs against cancer and to develop epidemiological research. The present report gives the main objectives and the general structure of what we can call the «National Institute for Cancer Epidemiology and Registration (NICER)». It should be considered as the working document to be used for future discussion.

### 3. The National Institute for Cancer Epidemiology and Registration (NICER)

#### 3.1. The role of the Institute

This intended Institute would provide, for the first time in Switzerland, an adequate system of information, surveillance, planning, and evaluation in the field of cancer. Its role would be based on the objectives defined by the Com-

mittee of evaluation and reorganisation (6). The first objective would be to establish basic information on cancer burden in Switzerland, in terms of incidence, mortality, survival, prevalence, geographical disparities, trends and perspectives. The second objective would be to establish an adequate system of information adapted to the needs of public health authorities in order to better define priorities, to evaluate efficacy of public health actions and of the health care system, to survey the effect of environmental and occupational risks and social inequalities. The third objective would be to develop optimal epidemiological research to permit the conduct of population-based studies and to promote adequate teaching to remedy the lack of epidemiologists in Switzerland.

The tasks of this future Institute would be the following:

#### *Management of a permanent intercantonal data base*

- Set guidelines for the Swiss cancer registration, compatible with the International guidelines in the field (definition, codification, registration and validation of variables, timetable, etc.) according to priorities defined at a national level.
- Monitor regularly the quality (validity, comparability, completeness, delays, etc.) of Swiss cancer registration with the help of international experts.
- Promote cancer registration and accredit new regional registration centres.
- Facilitate linkage between cancer registries and other data files in order to increase available information on various aspects of cancer.

#### *Information system adapted to the needs of public health and professionals*

- Publish regularly interpretable statistical data, in particular for the National Observatory of Health, Swiss Federal Statistical Office and the Swiss Federal Office for Public Health.
- Evaluate general efficacy of the health system.
- Contribute to plan public health actions for cancer control.

- Evaluate the efficacy of implemented public health actions, in particular ongoing and future national programs against cancer.
- Evaluate generalisation of good preventive screening and health care practices.
- Surveillance of adverse environmental effects (ecology, occupation etc.) and treatment (iatrogenic effect of drugs or radiotherapy).
- Assess cancer prognosis and determinants of cure.
- Assess cancer causes, notably by cohort linkage studies of exposed individuals.
- Increase potential of research in genetic epidemiology, cost of health palliative care, and quality of life by establishing links with other data sources.
- Provide expertise on cancer in the fields of public health and epidemiology.

#### *Promotion of research and teaching*

- Develop all fields of epidemiological research, from statistical methods to cancer causation and controls.
- Train new epidemiologists in the field of cancer.
- Represent and promote cancer epidemiology within different authorities, plan cancer research and public health strategies.

#### 3.2 The global structure of the Institute

The Institute would be administrative and financially independent. An important first step to expand the idea of a National Institute is to develop efficient managerial structures. In any case, close and official collaboration should exist with the Swiss Federal Statistical Office, the National Health Observatory, the Universities, the Swiss Federal Office for Public Health, as well as the Federal Office for Education and Science. In particular, one can envision the Institute to be affiliated to the National Health Observatory, at least for routine statistics on cancer occurrence. This Institute would closely collaborate with Oncosuisse in which it would represent the epidemiological and public health aspects of the cancer control. Close partnership with the SIAK must also be estab-



lished in order to ascertain true collaboration and develop multidisciplinary research. The existing working structures of the co-ordination office, employing a statistician and a part-time epidemiologist, should continue as a natural development. The Institute should develop into a Centre of competence (as defined by the Swiss National Science Foundation) proficient to receive subsidies and mandates from the Swiss Confederation, as well as private subsidies from Oncosuisse, the Swiss National Science Foundation, or the Cancer Leagues for specific research. A Scientific Committee consisting of international experts in registration, epidemiology, research on cancer and public health would supervise the activities of the Institute. The Swiss public health authorities, in collaboration with this Scientific Committee, will have to define research priorities. The Scientific Committee will also decide who would receive grants or training.

Cancer registries would remain independent structures at a cantonal level, but would be closely linked to the Institute for all activities and decisions at a national level. They would continue to be financed mainly by cantonal authorities. The share of the federal subsidy would depend on the number of cases registered and on details provided on patient and tumour characteristics. The Institute would provide the regional registries with training (internships, courses, grants, etc.), methodological and infrastructure supports (computer programs, statistical packages, etc.). The Institute is in close contact with the cantonal authorities in order to guarantee the continuity of local subsidies. It is possible to conceive that

the cantons where there are no cancer registries contribute financially to the intercantonal cancer information system. According to the activities of the Institute, financial sources could be diversified and involve different authorities such as the Swiss Federal Statistical Office, Swiss Federal Office for Public Health, Federal Office for Education and Science, Cancer Research Switzerland, as well as the National Health Observatory.

#### 4. Perspectives

Cancer epidemiology based on population data is an essential part of any rational cancer control program. Without such monitoring system, public health professionals, clinicians and politicians will be unable to evaluate the efficacy of their actions. The type of information emerging from this Institute could be adapted to national needs and interests, bearing in mind the importance of international comparability. This Institute projected would be a centre of competence able to cover a wide variety of research areas, from determination of etiological factors to evaluation of effect of care. With close collaboration with other institutions, it could develop promising areas of research such as biomolecular and genetic epidemiology. As it is already the case in most developed countries, cancer epidemiology will then become the most promising cancer control discipline in Switzerland with a direct benefit for individuals, patients and society. A budget detailing the necessary means for this project has been drawn up for the attention of the federal institutions interested.

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