

The Potential Benefits for Cancer Prevention and Control in Switzerland from a New National Cancer Registration Law

Kerri M. Clough-Gorr, Daniel Bosshard,
Rolf Heusser, Giorgio Nosedà

In accordance with the editorial by Dr. Marti of CLS in the March 2011 issue of the SKB, we at NICER are also pleased and thankful for the news from the FDHA that work on developing a national law for cancer registration will soon begin. This is an important furthering step in cancer control and prevention in Switzerland that when skillfully implemented will positively impact the lives of many and support other important national health policy initiatives.

A cancer diagnosis is one of the most intensive clinical experiences patients may have in their lifetime. It is also one of the most complex, time and resource demanding care services the healthcare industry provides. These simple facts unite all of us in Switzerland, patients, physicians, healthcare staff, planners, health insurance providers, researchers, funders, and the public health community alike by common concerns. Yet our concerns for prevention, and best practice, cost effective, quality cancer care regardless of perspective (e.g. patient, physician, healthcare planner) cannot be addressed without adequate epidemiologic (i.e. disease and treatment) information. We hope the new cancer registration law will provide the necessary platform to address the broadest set of cancer-related concerns and prospective possible.

We are very fortunate in Switzerland to have had for many years the active support of cancer leagues and competent regional cancer registries pioneering and expanding cancer registration and epidemiology in Switzerland without a national mandate. Over time these committed professionals have created a functioning, growing, and ever improving infrastructure for cantonal cancer information. In 2007 NICER was founded as a collaborative network to promote and support national population-based cancer registration and epidemiological cancer research here in Switzerland. Since then cantonal data has been combined to generate updated public use national cancer incidence and mortality statistics (available data coverage approximately 68% of the population, see <http://nicer.org/default.aspx?NavigationID=5&SubNavigationID=35>) including participation in several major international comparative research collaborations (e.g. Concord

Sie finden die deutsche Fassung dieses Artikels auf der NICER Website.

La version française de cet article est disponible sur le site internet de NICER.

<http://nicer.org/default.aspx?NavigationID=5&SubNavigationID=31>

<http://www.ncbi.nlm.nih.gov/pubmed/18639491> and Eurocare <http://www.ncbi.nlm.nih.gov/pubmed/19128955>). It is imperative that the new cancer registration law supports and continues these important national efforts. But no less importantly, the new law should also capitalize on the opportunity to improve population-based cancer registration towards meeting the goals of our existing national health policy initiatives (e.g. SwissDRG, national health prevention, national cancer program).

Currently the lack of a national cancer registration law results in inconsistently available data (not all cantons have coverage or similar procedures and permissions for national data exchange) that severely limits nationwide cancer-related assessments. It also results in paradoxical situations where external initiatives (e.g. Eurocare) have more comprehensive epidemiologic information (e.g. survival) than is nationally available. By international standard we know that the burden of cancer and monitoring of improvements from prevention and care can only be sufficiently measured by complete population-based coverage (new cantonal registries underway) and assessment of all four relevant cancer statistics (prevalence, incidence, mortality, survival – only two currently nationally available). The new national cancer registration law should guarantee that the necessary minimum set of epidemiologic information for valid comprehensive national prevention and control is based on these well-established standards and nationally accessible without requiring active informed consent.

With reasoned implementation the monies spent on the new law could simultaneously target outcomes already mandated by monies spent on existing national health policies. For example, collecting complete-population-based high quality data for all four cancer statistics and establishing an infrastructure to monitor prevention and care of patients in large randomly selected samples would fulfill mandates of the DRG law (i.e. monitoring outcomes and quality of care), national cancer program (i.e. decrease burden of cancer and improve quality of life of cancer patients through prevention, early detection, treatment, epidemiology, and research), and national health prevention law (i.e. measuring health promotion and disease prevention goals nationwide). It would also establish a valuable source of data and nationwide platform for better cancer-related healthcare resource planning while promoting world class collaborative cancer epidemiology research activities.

But without an adequate national cancer registration law specifying a minimum dataset and corresponding infrastructure that meets cantonal requirements, national health policy needs, and international standards, Switzerland will not be able to effectively meet the myriad cancer-related concerns from any perspective. Hence, we at NICER look forward to continually working with our cantonal and federal partners in furthering national cancer control and prevention efforts; and warmly welcome a new cancer registration law drafted to maximize benefits to all (e.g. minimize fragmentation, produce nationwide statistics and transparency for quality and effectiveness of prevention and care). A more detailed description of the NICER and cantonal registries' position on the new cancer registration law is available on the NICER website (<http://nicer.org/default.aspx?NavigationID=5&SubNavigationID=31>).

Kerri M. Clough-Gorr, *Research Director*
Daniel Bosshard, *Fiduciary*
Rolf Heusser, *Director*
Giorgio Nosedà, *President*

nicer

National Institute for Cancer Epidemiology and Registration
Nationales Institut für Krebs epidemiologie und -registrierung
Institut National pour l'Épidémiologie et l'Enregistrement du Cancer
Istituto Nazionale per l'Epidemiologia e la Registrazione del Cancro

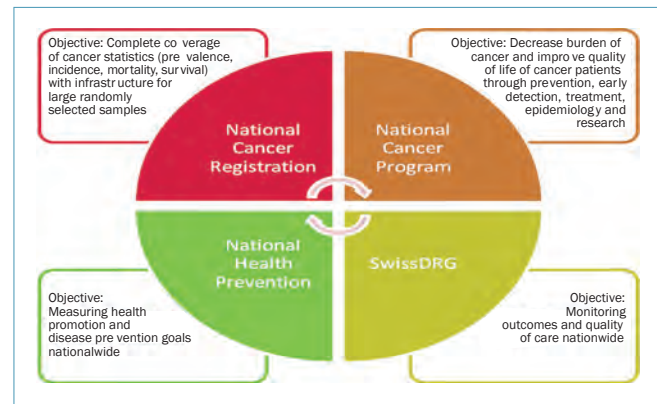


Figure 1: Potential synergistic overlap of objectives of existing national healthcare policy initiatives with a new cancer registration law.

Please note: German and French versions of this article are available on the NICER website at <http://nicer.org/default.aspx?NavigationID=5&SubNavigationID=31>

Correspondence:

Kerri M. Clough-Gorr, DSc, MPH
National Institute for Cancer Epidemiology and Registration (NICER)
University of Zürich
Seilergraben 49, CH-8001 Zürich
kerri.clough-gorr@nicer.org

Die der Universität Zürich angegliederte Stiftung NICER (National Institute for Cancer Epidemiology and Registration) koordiniert die Sammlung von Krebsdaten in der Schweiz und fördert die epidemiologische Forschung.

Wir suchen per 1. August 2011 oder nach Vereinbarung eine/einen

Datenbankmanagerin/Datenbankmanager (60%)

Ihr Aufgabengebiet

- Aufbau, Verwaltung und Pflege einer Datenbank
- Zusammenführen und Validieren von Daten zu Krebs
- Statistische Aufbereitung von Daten
- Mitarbeit bei epidemiologischen Projekten im Bereich der Krebsforschung

Ihr Profil

- Abgeschlossene universitäre Grundausbildung auf Bachelor oder Masterstufe, vorzugsweise in Gesundheitswissenschaften und/oder Statistik
- Erfahrung in der Verwaltung von SQL-Datenbanken
- Flair für statistische Fragen, vorzugsweise Programmiersprache Stata
- Selbstständige Arbeitsweise und Teamfähigkeit

Wir bieten

- Eine spannende Aufgabe im kleinen und gut eingespielten Team
- Flexible Arbeitszeiten und attraktiver Arbeitsort an zentraler Lage
- Eine entwicklungs- und ausbaufähige Stelle

Bewerbungsunterlagen mit Foto senden Sie bitte bis 30. Juli an:

Foundation National Institute for Cancer, Epidemiology and Registration (NICER), c/o Universität Zürich, ISPM
Nina Pupikofer, Seilergraben 49, 8001 Zürich, T: 044 634 53 74, nina.pupikofer@nicer.org, www.nicer.org