

Principles of Collaboration between SHCS, Cancer Registries, and NICER

1. Background

Partners

The Swiss HIV Cohort Study (SHCS, www.shcs.ch) is a well-known, ongoing multi-centre cohort study of HIV-infected people aged 16 years or older, which was established in 1988. The study has, in over 200 publications, made important contributions to clinical and translational HIV research. The SHCS has recorded AIDS-defining cancers since its inception, and, with non-AIDS defining cancers becoming increasingly important, started to record all cancers in 2000. The ascertainment of non-AIDS defining cancers has, however, been incomplete.

In Switzerland, cancer registration is organised at the cantonal level. At present there are 10 cancer registries, which cover 14 cantons and 4.5 million inhabitants (approximately 62% of the Swiss population), with about 19,000 new cancer cases are recorded each year.

The National Institute for Cancer Epidemiology and Registration (NICER, www.nicer.org) was established in 2008 by the cantonal cancer registries and Oncosuisse, with the contribution of the University of Zürich. NICER is a collaboration of the network of Swiss cancer registries and a national coordinating centre. Its mission is to maintain a combined and harmonised database and to foster epidemiological research, including the linkage of cancer registry data with other databases based on registration regulations.

Brief history

A first linkage between SHCS and the cancer registries took place at the initiative of the Section of Infection of the International Agency for Research on Cancer (IARC, www.iarc.fr) in 2003. It showed that many non-AIDS-defining cancers in SHCS participants were not recorded in the SHCS. The resulting database was held at IARC, and analyzed by IARC scientists. This effort was supported by grants from the SHCS Scientific Board (projects 396, 433, 495) and a grant from Oncosuisse (Jan 2004-Dec 2007). A high-profile paper based on these data was published in *JNCI* in 2005.¹ Several other excellent publications followed.²⁻⁵ The linkage exercise was repeated in 2007, again under the auspices of IARC, in order to increase person-time and to allow analyses of trends in the HAART era. Further analyses are planned within the framework of a recently approved grant from Oncosuisse.

2. Aims and objectives

The aims of the collaboration between the SHCS, the cancer registries and NICER are as follows:

- To regularly merge the SHCS with cancer registry and/or NICER data to create a longitudinal dataset with complete or near complete cancer outcomes based on cancer registry coverage areas.
- To use this dataset to address clinical, epidemiological and public health questions.

- To develop expertise and capacity in cancer epidemiology and linkage studies in Switzerland.

The objective of the present Principles of Collaboration is to clarify the terms of collaboration and roles of the different partners (SHCS, cancer registries, NICER, and IARC) and to define rules for data ownership and access to data.

3. Submission of letters of intent and proposals

The Swiss HIV Cohort Study (SHCS)/Cancer registry/NICER collaboration welcome all types of research projects linked to patients with HIV infection and cancer. NICER, cancer registries, and SHCS are keen to further develop the existing fruitful collaboration with IARC, which will be a preferred partner in future analyses.

The operational rules for data analysis have to be followed according to the Guidelines of the SHCS (see www.shcs.ch) and NICER Guidelines for Scientific Collaboration, Publication, and Authorship (see www.nicer.org). Only analyses based on a full proposal and agreed to by the Scientific Board of SHCS NICER and cancer registries can be performed. Researchers who are formally involved and actively participate in the SHCS, NICER, cancer registries, and IARC preferred partner team may submit research projects.

Proposals have to be submitted at least 3 weeks before the Scientific Board meeting of the SHCS to shcs-submission@hospvd.ch (see www.shcs.ch for meeting dates). All projects aiming to use the NICER/cancer registry/SHCS dataset will be forwarded to ncc@nicer.org for simultaneous consideration by NICER and cancer registries.

4. Confidentiality and ownerships of data

NICER is holder of any linked dataset. In collaboration with the SHCS data centre, the responsible investigator will be provided with the data required for his/her approved project. The data can only be used for the approved project and must be permanently deleted after completion of the project. As a preferred partner, IARC will have access to a copy of the linked dataset, but analyses will have to be approved as described above. All data are to be kept confidential by the responsible investigators, team members, and those involved in the collaboration. SHCS, NICER, and the cancer registries retain ownership of their data.

5. Circulation of publications and presentations before submission

Draft papers and abstracts will be circulated to the SHCS Scientific Board NICER and cancer registries research staff for approval. Revised manuscripts will then be circulated with a time limit for final comments and approval prior to submission for publication.

6. Authorship of publications, reports, conference presentations

For each project a writing group with representatives from SHCS, NICER, and cancer registries will be constituted. All authors will have to meet the guidelines of the International Council of Medical Journal Editors (ICMJE, see www.icmje.org). The key positions on papers should be fairly distributed between collaborators, taking into account authors' contributions.

7. Funding and grant proposals

Projects can be funded through the SHCS small project scheme or through dedicated grants from Cancer Research Switzerland, the Swiss National Science Foundation or other national or international agencies.

Grant applications must be circulated to the Scientific Boards and approved before submission.

If successful, concept sheets for the analyses proposed in the grant must be prepared and approved by the SHCS Scientific Board NICER and cancer registries research staff, as outlined above.

8. Data linkage

Future data linkages will be done by NICER using appropriate privacy preserving data linkage techniques. IARC will provide support and advice. In a first step the pros and cons of different approaches will be explored, and examined in a pilot study. A protocol for future linkages will then be developed.

9. Liaison group

A liaison group will be created, which will consist of one or two representatives each of SHCS, cancer registries, NICER, and IARC. The group will meet over the phone or in person as required. It will be responsible for monitoring progress, including the writing up and publication of analyses, for providing input to the overall direction of the collaboration, and for keeping the relevant bodies at SHCS, cancer registries, NICER, and IARC informed about developments.

References

- (1) Clifford GM, Polesel J, Rickenbach M, Dal Maso L, Keiser O, Kofler A et al. Cancer risk in the Swiss HIV Cohort Study: associations with immunodeficiency, smoking, and highly active antiretroviral therapy. *J Natl Cancer Inst* 2005; 97(6):425-432.
- (2) Polesel J, Clifford GM, Rickenbach M, Dal Maso L, Battegay M, Bouchardy C et al. Non-Hodgkin lymphoma incidence in the Swiss HIV Cohort Study before and after highly active antiretroviral therapy. *AIDS* 2008; 22(2):301-306.
- (3) Clifford GM, Rickenbach M, Polesel J, Dal ML, Steffen I, Ledergerber B et al. Influence of HIV-related immunodeficiency on the risk of hepatocellular carcinoma. *AIDS* 2008; 22(16):2135-2141.
- (4) Franceschi S, Maso LD, Rickenbach M, Polesel J, Hirschel B, Cavassini M et al. Kaposi sarcoma incidence in the Swiss HIV Cohort Study before and after highly active antiretroviral therapy. *Br J Cancer* 2008; 99(5):800-804.
- (5) Clifford GM, Rickenbach M, Lise M, Dal ML, Battegay M, Bohlius J et al. Hodgkin lymphoma in the Swiss HIV Cohort Study. *Blood* 2009; 113(23):5737-5742.