

NICER Guidelines for Scientific Collaboration, Publication and Authorship

The Foundation National Institute for Cancer Epidemiology and Registration is hereafter referred to as NICER.

This document provides guidelines for research collaboration and related publication involving any NICER-related research. NICER-related research projects are defined as any request to use data held by NICER for purposes other than simple reporting of cancer statistics (e.g. frequencies, proportions, rates).

These guidelines were developed based on current NICER-registry contracts as well as international standards. They are intended to encourage collaborative NICER-related cancer epidemiological research, ensure transparency of processes, and guarantee stakeholders (e.g. patients, investigators, government agencies, funding agencies) the highest standards of research. This document is separated into five main topic-based sections and includes two graphics as follows:

Section 1 – Introduction

Section 2 – Description of request procedures including Appendix 1 and Figure 1

Section 3 – Guiding principals for scientific collaboration

Section 4 – Official acknowledgement citation

Section 5 – Rules for authorship

It is intended for use by the NICER coordinating center (NCC), partner registries, and any other researchers (i.e. external researchers non-NCC or non-registry personnel) conducting NICER-related research. NCC welcomes requests from any person interested in conducting cancer epidemiological research and each NICER-related research request will be approved based on its individual merit and resource availability. This document will be annually updated and it is the responsibility of individual researchers to ensure they are using the most recent copy. Up-to-date versions of NICER-related research guidelines and forms are available via email from contact@nicer.org or on the NICER website www.nicer.org.

1. Introduction

NICER was established to promote and support population-based cancer registration and epidemiological cancer research in Switzerland. Cancer Information is collected by independent canton and regional cancer registries in Switzerland. NCC combines and harmonizes individual registry data to create a central database at the national level (hereafter referred to as NICER database or NICER data). NCC maintains the NICER database as an authoritative national source of cancer information in Switzerland. The NCC in collaboration with partner registries mission is to bring NICER data to the public health and research community. As a result cancer-related data are available for epidemiologic research through the NCC.

2. Requests for NICER-Related Research Projects

NICER-related research request s may involve two distinct categories of data: NICER only data and NICER plus data. NICER only data refers to use of any pooled portion of the NICER database held by NCC under NICER-registry contract agreement. Whereas NICER plus data refers to requests proposing use of any portion of the pooled NICER database plus any additional data outside these (i.e. any data not contained in the NICER database; e.g. date-of-birth for linkage study, treatment

variables for pattern of care study). All requests involving use of NICER data will be processed by NCC in accordance with current NICER-registry contracts and as specified herein.

2.1. Requests: All research projects proposing use of NICER data must be formally submitted using the “NICER Concept Sheet for New Proposals” to the NCC for approval (see Appendix 1 for copy of form). All NICER-related research requests will be logged by NCC with a regularly updated list (including request status in review/approval/decline and reasons for decline or approval) distributed to registries and/or publicly available on NICER website. Upon receipt, each request will be reviewed by NCC for feasibility (analytic, methodological, resources, redundancy with other NICER-related research). Request approval or decline, reasons for decline or approval, and any required modifications will be communicated to requestors by NCC no later than 25 business days after original request submission date. Final copies of all approved requests will be distributed to participating registries. NCC will forward any single registry request (i.e. un-pooled data) to the indicated registry for registry processing. Per specific registry request, however, NCC will approve and fulfill single registry requests on their behalf.

NICER-related research requests may be initiated by NCC or registry-related personnel (Registry Head and/or other registry affiliated personnel publishing with registry affiliation), or external researchers. The expectation is that a representative from NCC and/or at least one registry (based on individual expertise, interest, and availability) will participate as part of the core project team (see Section 3.1 for explanation of core project team) on all NICER-related research projects. For any NICER-related research project Registry Heads may appoint in their place alternate registry-related personnel as a member of the core project team (alternate personnel must have suitable expertise and publish with registry affiliation).

2.2. NICER only data: Any proposed project requiring NICER only data will be forwarded to Registry Heads by NCC. Any NICER only data request initiated by NCC or registry-related personnel will have open invitation to all Registry Heads to participate as part of the core project team. Invitations to participate as part of the core project team for requests using NICER only data from external researchers will be at the discretion of the project leaders. Registry inputs, queries, opposition to projects must be supplied to NCC in writing via email (response time within 15 business days of receipt of the request – NCC will provide email and/or phone follow-up as needed before time elapsed). Any non-response will be considered as approval of the project and refusal of invitation to participate as member of the core project team.

2.3. NICER plus data: Any proposed project requiring NICER plus data must be approved by NCC and all Registry Heads from which data is requested. NCC will circulate all requests for proposed projects requiring NICER plus data via email to all Registry Heads of registries indicated in the request. Registry inputs, queries, approval or refusal to participate in a proposed project must be supplied to NCC in writing via email (response time within 15 business days of receipt of the request – NCC will provide email and/or phone follow-up as needed before time elapsed). Registries must indicate participation preference as both data contributor and/or member of core project team. Any non-

response will be considered decline for inclusion of registry data and non-participation as member of the core project team. All NICER plus data requests will be modified and approved by NCC based on Registry Head approval for data inclusion. For example, if no registries approve data use for a NICER plus data proposed project the project will be declined by NCC. Or when only a subset of registries indicated in the proposed project request approve data use the original request will be modified, by NCC, before approval to include only data from the subset of participating registries.

- 2.4. Data usage:** Once a request is approved, the responsible investigator must return a signed completed “NICER Data Use Agreement” for each project with analyses being conducted outside NCC before data preparation and/or delivery can occur. The responsible investigator will be provided by NCC only the NICER data elements required for his/her approved project (i.e. project-specific dataset). The project-specific dataset can only be used for the approved project and must be permanently deleted after completion of the project. No individual (non-NCC) researcher will be given access to the complete NICER database. Any project requiring use of the complete NICER database must be conducted in conjunction with NCC.

3. Scientific Collaboration

All NICER-related research projects should follow the guiding research principals outlined below.

- 3.1. Research participation:** Each NICER-related research request must specify project leaders along with the core project team as known at time of request submission. Project leaders are defined as any of the following: responsible investigator/requestor, first and/or senior/last authors. The core project team defines the writing group (i.e. authors) and all persons actively participating in the research. Project leaders are responsible for planning and organization of all research-related activities. All core project team members take responsibility for the study and agree on methodology. Agreement for project participation implies that members of the core project team accept the criteria for authorship as stated below (Section 5.2) and will have adequate access to the project-specific dataset and all preliminary and final results to participate as agreed upon within the core project team. The project leaders must inform NCC of any changes to the core project team that occur at any time before completion of the project. NCC will regularly update individual project information (via website and/or email distribution) to guarantee up-to-date NICER-related research communication and transparency.
- 3.2. Research responsibilities and conduct:** The core project team responsibilities are: study design, data analysis, data interpretation, planning for associated presentations, and preparation of project-related manuscripts. All members of the core project team must meet author guidelines (Section 5.2 below) and the team is collectively responsible to ensure compliance. Project leaders will seek as much input as possible from every core team member on all areas (study design, data analysis, data interpretation, planning and preparation of presentations and manuscripts). The project leaders are responsible for all necessary ethic committee approval as well as ensuring proper data protection methods which must be documented to NCC before any data can be delivered. Furthermore, all project leaders of approved projects are expected to guide the research process to ensure scientific and ethical integrity, avoid and/or minimize conflicts, and are responsible to

objectively arbitrate and manage any core project team related conflicts that do arise in a constructive manner to resolution.

4. Acknowledgment Citation

All publications resulting from any use of NICER data must include acknowledgement of NICER and each individual contributing registry as source of the data.

- 4.1. Official citation:** The following text, up-to-date as of 2016, should be used in the acknowledgment section verbatim but modified to reflect the canton data actually used in the analyses:

The Swiss cancer data used in these analyses was supplied by the Foundation National Institute for Cancer Epidemiology and Registration (NICER) and its partner registries in cantons Aargau, Basel, Bern, Fribourg, Geneva, Glarus & Graubünden, Luzern, Neuchâtel & Jura, St. Gallen & Appenzell, Thurgau, Ticino, Valais, Vaud, Zürich & Zug.

5. Authorship

There are two distinctive types of authorship associated with NICER-related research projects: NICER Working Group and individual authorship. Each type of authorship has unique criteria and specifications as detailed below.

- 5.1. NICER Working Group:** All NICER-related research publications using NICER data that include NCC or registry personnel as core project team members must also include “NICER Working Group” in some position of authorship preferably at end. The individual members of the NICER Working Group whenever possible (i.e. depends on individual Journal guidelines) should be listed as “contributors” for all NICER-related publications. The format, up-to-date as of 2016, should be as follows:

In author list: *Author A, Author B, Author C and the NICER Working Group**

As affiliation notation: **Composition of NICER Working Group by individual contributors listed in acknowledgment section*

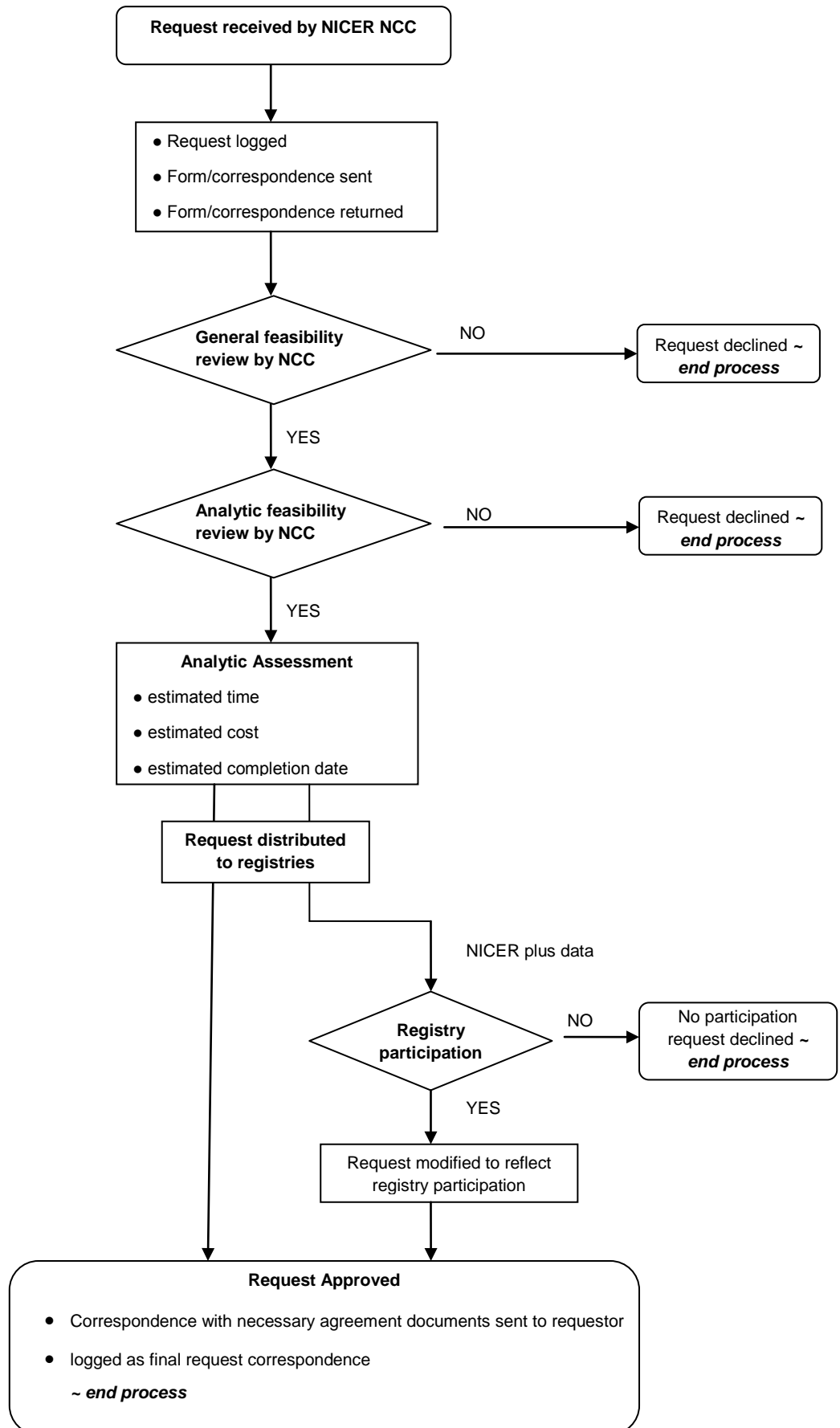
In acknowledgement section modified to reflect registries that contributed data:
Members of the NICER Working Group for these analyses included: Aargau- M. Adam & I. Curjoric, Basel- M. Mousavi, Bern- A. Perren, Fribourg- B. Camey, Geneva- C. Bouchardy, Glarus & Graubünden- H. Frick, Luzern- J. Diebold, Neuchâtel & Jura- M. Bochud, St. Gallen & Appenzell- H. Frick, Thurgau- A. Schmidt, Ticino- A. Bordoni, Valais- I. Konzelmann, Vaud- M. Bochud, Zürich & Zug- S. Rohrmann

- 5.2. Individual authorship:** NICER authorship guidelines for individual authorship (not NICER Working Group) are based on and must comply with the latest guidelines of the International Committee of Medical Journal Editors (ICMJE “Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publications”) published online at <http://www.icmje.org/recommendations>. Authorship position is determined by the core project team and usually based on level of active participation. Individual authorship should be based on the following conditions:

1. Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data.
2. Drafting the article or revising it critically for important intellectual content.
3. Final approval of the version to be published.
4. Authors should meet conditions 1, 2, and 3 above.

Acquisition of funding, collection of data, or general supervision of the research group or individual members, alone, does not justify authorship. All individuals designated as authors should qualify for authorship, and all those who qualify should be listed. Each author should have participated sufficiently in the work to take public responsibility for appropriate proportions of the content. The core project team should collectively make decisions about contributors/authors at the start of the project whenever soonest possible but certainly before the first draft of any manuscript is completed. The project leaders and/or corresponding author should be prepared to explain the presence and order of authors to any journal submission or other inquiries related to publication. It is not the role of anyone outside the core project team (e.g. journal editors, funding agencies, non-participating registries, NICER Scientific Advisory Board, NICER Registry Advisory Board, NICER Foundation Board) to make authorship decisions or to arbitrate conflicts related to authorship.

Figure 1: NICER-Related Research Request Flowchart



Requests

NCC welcomes requests for NICER-related research from any person interested in conducting cancer epidemiological research. Each request will be approved based on its individual merit and resource availability.

If you wish to **request NICER-related research collaboration or data** please complete the [NICER CONCEPT SHEET FOR NEW PROJECTS](#) .

If you wish to get **simple counts defined by some user specified criteria** (e.g. number of incident colorectal cancers 1998 in men 35-55 years old in all cantons available) please complete the [NICER REQUEST FOR SIMPLE CANCER STATISTICS](#) .