Oncosuisse Initiative M2 - Survey on data collection and data exchange in Swiss cancer centers

Data export 22.9.2022; data analysis done by Dr. Petar Horki, Personalized Health Informatics Group, SIB Swiss Institute of Bioinformatics

1. Starting position

- As part of the Oncosuisse initiative measure 2 "Ensure knowledge transfer", a knowledge gap was identified about the current state of data collection and data exchange in Swiss cancer centers.
- With the aim of closing this gap, the project group, together with Oncosuisse, conducted a survey of Swiss cancer centers.

2. Methods

- The survey was designed by the project group and sent to 49 cancer centers by Oncosuisse, followed by personal reminder emails to complete the survey.
- Cancer centers were identified based on the following criteria:
    1. university hospitals (n = 5)
    2. SAKK members (n = 21), or
    3. SPOG members (n = 9).

  In addition, training centers according to https://www.siwf-register.ch/ (specialty "med. oncology" or "pediatric oncology-hematology"), some hospitals with DKG-certified centers, and other centers known to the working group were included. Efforts were made to identify as many centers as possible, but there is no claim to completeness.
- The survey was sent directly to the clinic directors or equivalent, and they were encouraged to forward it to relevant parties in their institution who could assist in collating the requested information
- The survey was implemented on REDCap Cloud. The survey was not anonymous (so it could be sent further in the institution, see above). The survey could only be completed if all questions were answered; however, some incomplete (unsubmitted, but cached) responses were also evaluated.
- Analysis: descriptive statistics with R, version 4.2.1.

3. Results

3.1 Population:

- Of the 49 centers contacted, 34 completed the survey, including all 5 university hospitals, 4 SPOG members, and 17 SAKK members.

3.2 Documentation:

- The most common hospital information system (HIS) among the responding centers is KISIM (n = 11), followed by CGM Phoenix/G3 (n = 9). Thirteen centers plan to switch HIS in the next few years, including 7 to KISIM.

Figure 1: *The most common hospital information system (HIS) among the respondents.*

- The majority of centers use a tumor documentation system (TDS, n = 24) and almost all centers with TDS (n = 22) have certification according to the German Cancer Society (DKG) or the Q Label. The most common TDS is ODSEasy (n = 15), followed by ONKOSTAR (n = 5). None of the centers without a TDS plan to introduce one.
- Of the semantic references for structured data, only ICD-10 is widely used (n = 23) and ICD-0 (n = 6) is partially used. The rest (SNOMED-CT (n = 2), LOINC (n = 1), ICCC-3 (n = 1)) are used only by individual centers. Six (6) centers do not use semantic references and another seven (7) are uncertain about this.

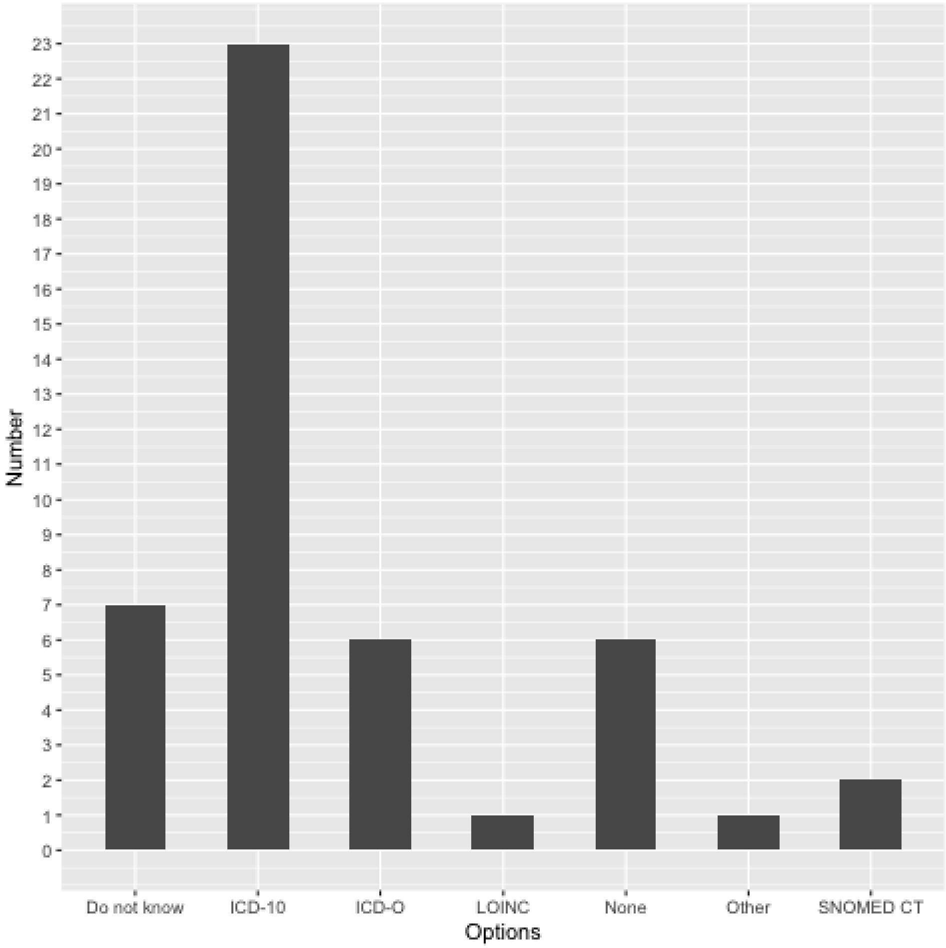

Figure 2: *The most common semantic references for structured data among the respondents.*

3.3 Data transmission/interfaces

- Data transfer from HIS to TDS is mainly manual: at 15 centers, more than half of the data is transferred manually, while at two centers only 0-10% of the data transfer is manual.
- At 16 centers, at least the transfer of master data such as name and date of birth is done directly into the TDS via an HIS interface, but only 4 centers report that clinical data are also transferred.
- Data delivery to the cantonal cancer registry is mainly in report form (see Figure and Table 1). Twenty six (26) centers send only reports, six (6) only structured data and two (2) a mixed form (structured data and reports). The most common transmission method is email (n = 23), but thirteen (13) centers send at least part of the data by interface, while four (4) centers still send (part of) the data by fax or mail.
- Of the nine (9) centers that send structured data, four (4) have the data stored in HIS, three (3) in TDS, and the remaining two (2) in other systems.
- Most (= 22) participants do not know which exchange format is used to send data to third parties, and another seven (7) state that they do not use any exchange format. Only four (4) indicate that they use FHIR. Six (6) others plan to implement FHIR in the next 1-5 years.

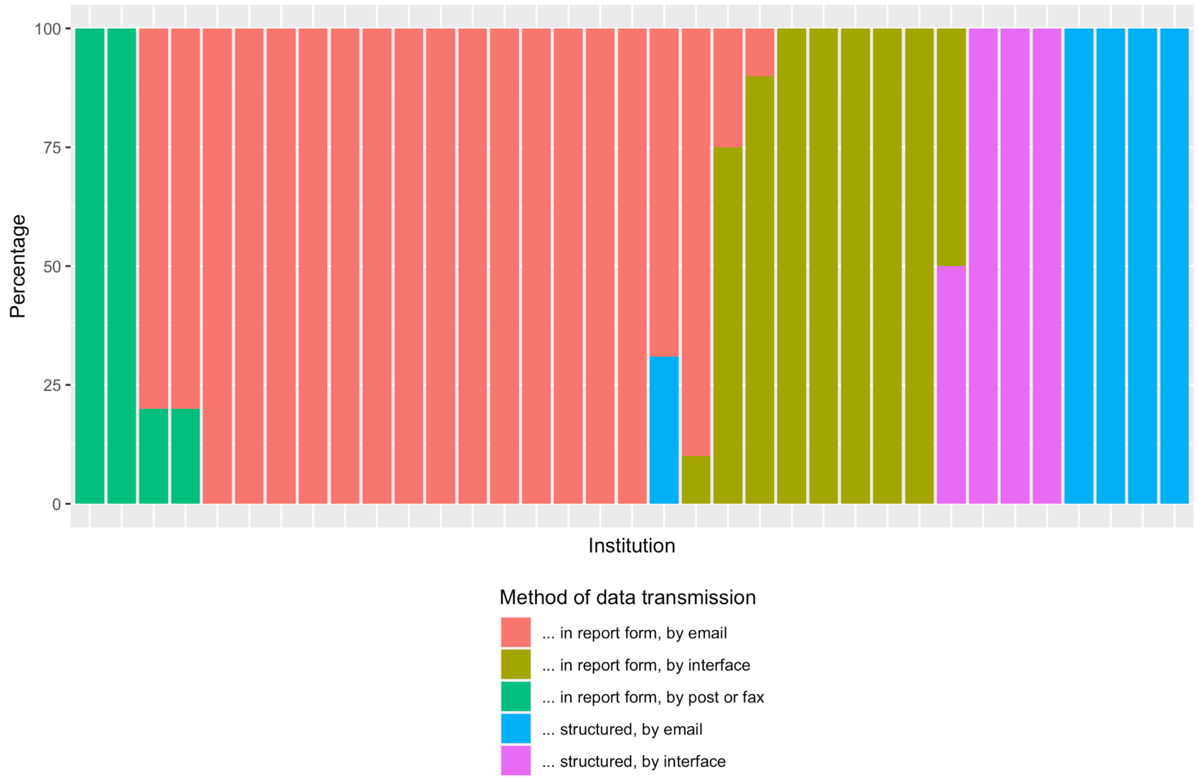

Figure 3: *Sending data to the cantonal cancer registry.*

Table 1: *Sending data to the cantonal cancer registry.*

Contents	**Method**	**Number**
Report form	E-Mail	14
Report form	Interface	5
Report form	E-Mail & Interface	3
Structured	Email	3
Structured	Interface	3
Report form	Fax or Post	2
Report form	Fax or Post & email	2
Report form & Structured	Email	1
Report form & Structured	Interface	1

3.4. Data Usage and Sharing, Data Governance

- All but four (4) centers use data systematically (at least occasionally) within their research institution.
- Most also share data as part of multicenter research projects (7 frequently, 23 sometimes). Of the remaining seven (7), three (3) are interested in doing so in the future.
- All thirty seven (37) participants would in principle be willing to share clinical data for research purposes as part of nationwide initiatives.
- The Swiss Centralized Oncology Real-world Evidence Data (SCORED) data initiative of the Swiss Association for Clinical Cancer Research (SAKK) is known to most (n = 33). The majority are also aware of the Swiss Personalized Health Network (SPHN, n = 20) and a minority of Personalized Health and Related Technologies (PHRT, n = 6).
- The basic willingness to share data for research purposes with non-academic partners, such as industry or health insurance companies, is also present among the majority (n = 22), but is much smaller than with academic partners. Reasons given for not wanting to share data included reservations about data protection (n = 14) or ethics (n = 6).
- Of the centers, the majority (n = 24) use a general consent (GC): seventeen (17) their own, six (6) from Swissethics, and one (1) unknown. The patients' agreement with the GC is summarized in Figure 4 and Table 2.

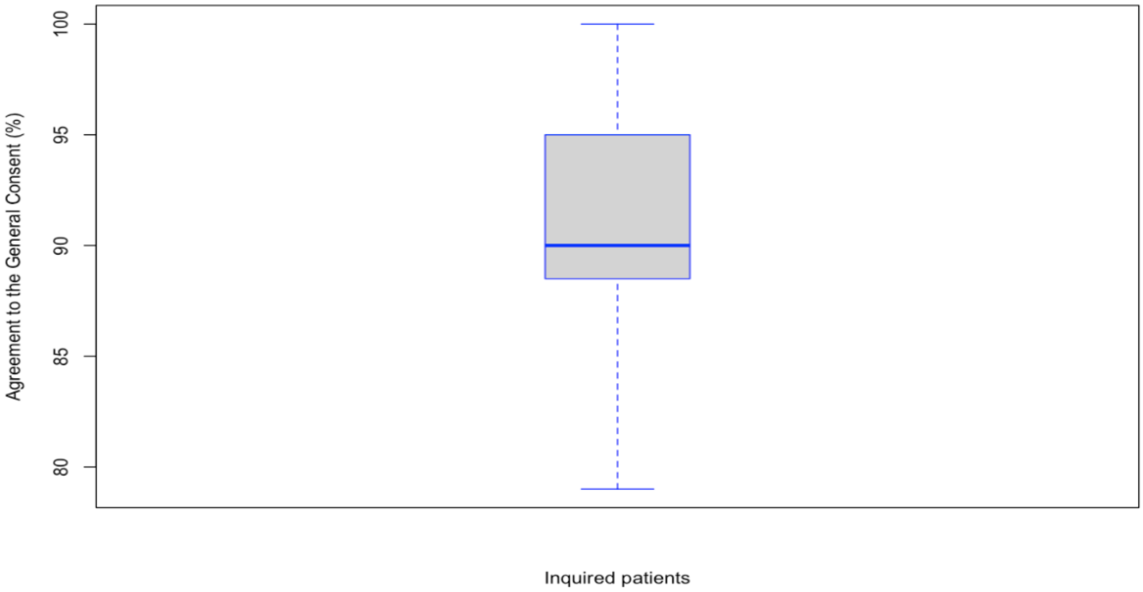

Figure 4: *Summary of the patients' agreement with the General Consent (GC).*

Table 2: *Summary of the patients' agreement with the General Consent (GC).*

Agreement to the GC (%)	
Mean	90.8
Median	90.0
Standard Deviation	6.3
Min	79.0
Max	100.0
Lower Quartile	88.5
Upper Quartile	95.0

- Seventeen (17) centers have also already conducted research projects in which the GC served as patient consent.
- The majority of respondents stated that permission to share encrypted data with third parties is granted by internal guidelines (n = 22) and/or the legal department (n = 17); in one case, the data governance board was mentioned. Some (n = 4) respondents do not know how sharing is regulated or stated that there is no regulation for it (n = 3).
- The clinical trial unit (CTU) was most frequently cited as the primary point of contact for both internal and external data requests (n = 14 each). Other contact points mentioned are summarized in Table 3 for internal and Table 4 for external data requests.

Table 3: *Summary of primary point of contact for internal data requests.*

Primary point of contact for internal data requests	n
Clinical Trials Unit (CTU)	14
Clinical Data Warehouse (IT-Department)	6
Other*	12
Do not know	4

*... Ethics committee, internal research commission, clinic (secretariat), medical controlling, oncology center / research department, legal service, study coordination.

Table 4: *Summary of primary point of contact for external data requests.*

Primary point of contact for external data requests	n
Clinical Trials Unit (CTU)	14
Clinical Data Warehouse (IT-Department)	2
Other*	11
Do not know	9

*... Ethics committee, internal research commission, responsible clinic (secretariat), medical controlling, oncology center, legal service, study coordination.

3.5 Other

- Multiple respondents from pediatric cancer centers fed back that the questionnaire was primarily aimed at adult oncology.

4 Acknowledgements

- We would like to thank the participating hospitals for the time and effort invested in filling out the survey.