

# Practical issues in health services research in Switzerland: Experience with an end-of-life study in cancer patients.

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## Background

Cancer registries, health insurance companies and administrative bodies can contribute important data for health services research (HSR). However, using and combining data from different sources may be challenging.

## Methods

We describe the process of activating an end-of-life patterns of care study in Swiss cancer patients deceased in 2006-2008 that were enrolled with one health insurance company (Helsana)

To identify cancer patients in the insurance data base, insurance and cancer registry data had to be combined.

In order to complement insurance-based inpatient information, medical records of hospitalized patients had to be reviewed for in-stay use of resources.

These data collection and linkage procedures gave rise to several complicated administrative issues that had to be resolved.

## Results

- In a first step the ethics committees and an advisory body of the Swiss Federal Office of Public Health had to decide on **responsibility for granting permission** to obtain and combine data. This process lasted almost one year. The time line of these procedures is shown in Table 1.
- The **identification of eligible patients** using cancer registry data from four cantons worked well even with diverse database structures.
- Retrieving details on **in-stay resource use** not available from the insurance database required additional approvals. We had to contact 49 hospitals and perform an extensive medical chart review. This applied to 68% of 3873 eligible patients; 94.5% of relevant hospitalization episodes were evaluated in 37 hospitals. The results are shown in Figure 1.

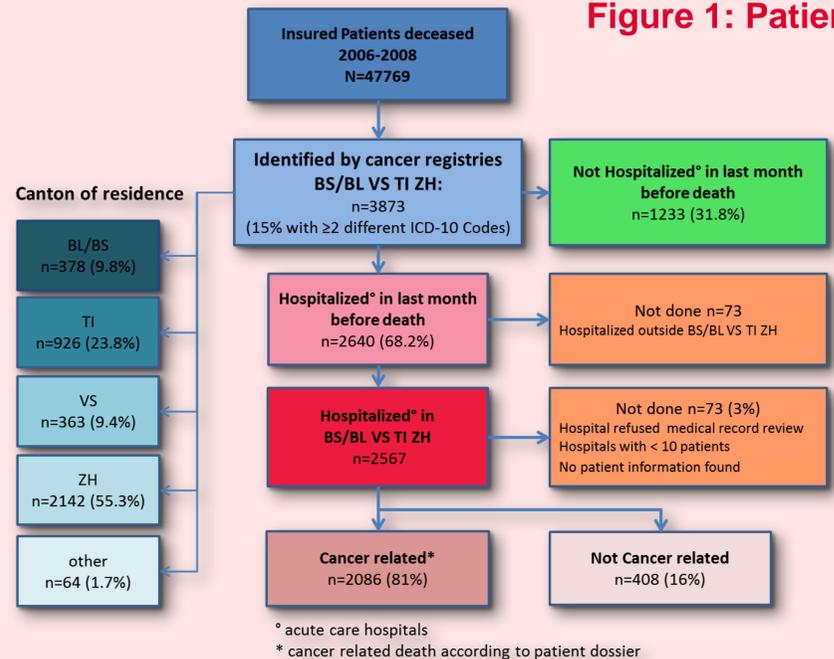
**Table 1: Time-line of the End-of-Life study activation**

Year	Involved parties	Action
2008	Study team: SAKK, Ethics Com, Expert Com, Cancer Reg, Helsana, Hospital	Meeting Helsana and ECPM to discuss possible study
		Study proposal to SAKK
2009		Co-operation proposal to the Foundation National Institute for Cancer Epidemiology and Registration (NICER) and the Swiss cancer registries
		Co-operation agreed with cancer registries Basel (BS/BL), Valais (VS), Ticino (TI), Zürich (ZH)
2010		Study proposal accepted by SAKK
		Start study protocol development
		Request to receive a special permit for data disclosure (SPDD) sent to expert commission dealing with data protection issues (Expertenkommission zum Erhalt einer Sonderbewilligung) at the Federal office of Public Health (BAG)
		Request to receive a SPDD objected by expert commission BAG, ethics committee (EC) approval requested first
		Informal information by the legal expert of the EC in Basel (Ethikkommission beider Basel, EKBB) that he believes EC is not responsible, expert commission BAG has to authorize the study
		Letter to EKBB to ask whether to submit the study to EC or not.
		Answer EKBB: Request for authorization should be submitted. EKBB can be lead EC
		Protocol finalized and signed by SAKK Board
		Submission of study to leading EKBB and EC VS, EC TI, EC ZH
		Contact between legal expert EKBB and expert commission BAG on responsibility to authorize the study
		Invitation by the EKBB to explain study in more detail and answer questions
		Meeting with EKBB
2011		Answer EKBB: study needs adaptation
		Replay to EKBB concerning adaptation requests: study design is defended, requested adaptations are not considered scientific valid
		Positive approval decision by EKBB
		Positive approval decision by EC ZH, VS
		Re-submission request to receive a SPDD to expert commission BAG
		Positive approval decision by EC TI
		Positive decision for SPDD by expert commission BAG
		Data delivery Helsana
		Submission grant application Cancer Research Switzerland (KFS)
		Data linkage BS/BL, VS, TI, ZH
2012		Final database delivery by Helsana for included patients
		Data analysis to identify patients with a hospitalization in last month before death (result see figure 1)
		Grant application KFS approved
		Complementation of Helsana database for missing informationn ambulatory care (last 3 month before death) by reviewing paper bills (Approximately 3500)
		Letter to hospitals (49) with request for reviewing patients medical records for in-stay data collection
2012		Hospitals in Valais refuse insight in patient's medical records and request for extension of the SPDD to allow for data disclosure
		Submission for extension of the SPDD tallow for collection of hospital data to expert commission BAG
		Approval of the extension of the SPDD
2012		Data collection in the hospitals
		Start data analysis

### Acknowledgements:

We would like to thank all persons involved for their time, co-operation and encouragement.

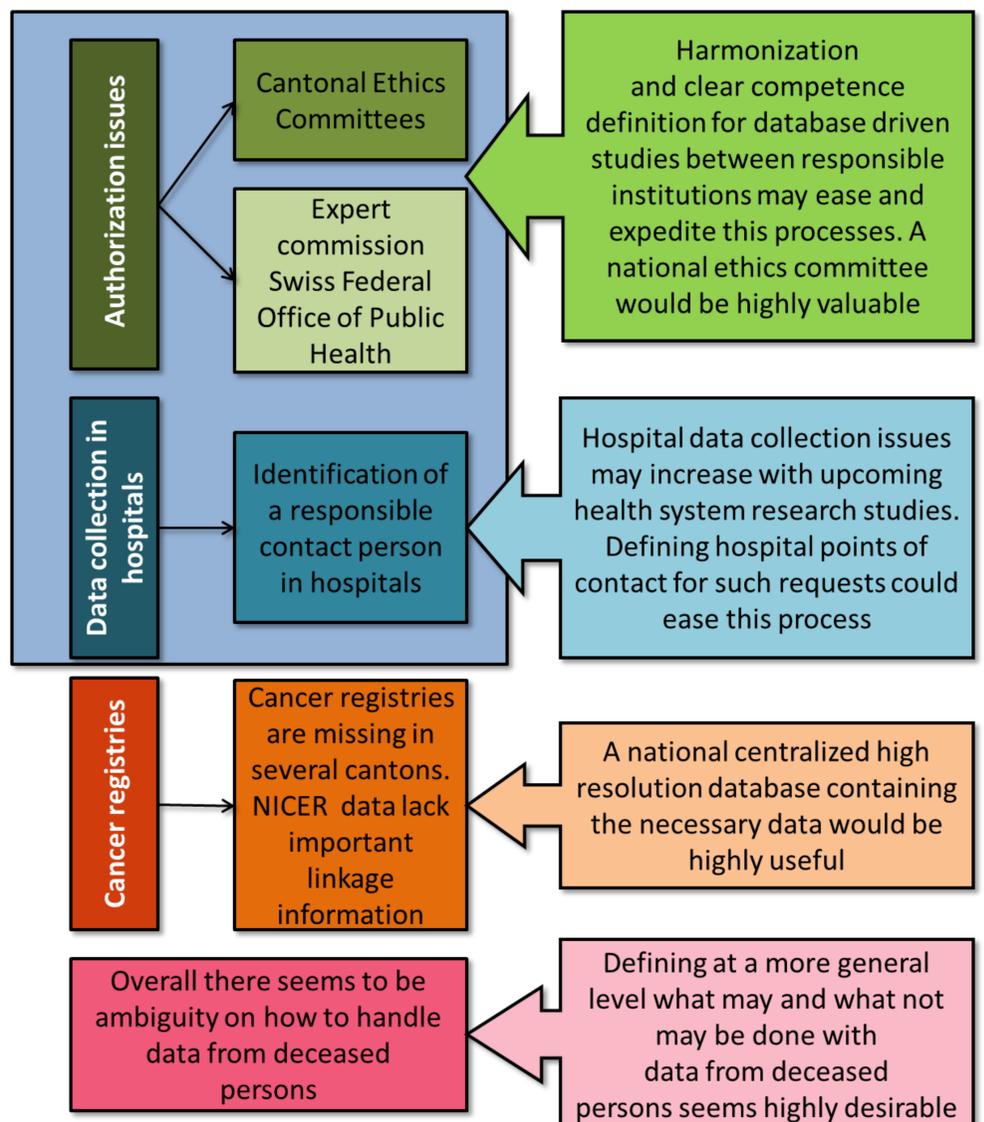
**Figure 1: Patient Flow**



Cancer related death information is only systematically available for those patients who were subject to a medical chart review.

## Discussion

### Time intensive and complicating issues for HTA studies



## Conclusion

HSR studies in Switzerland with large datasets are possible but need perseverance and may involve labor-intensive processes to complement lacking information.

As this type of study will become more common, simplifying and standardizing the process of obtaining permissions and data collection is necessary.