Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

Schweizerische Pädiatrische Onkologie Gruppe
Groupe d'Oncologie Pédiatrique Suisse
Gruppo d'Oncologia Pediatrica Svizzera
Swiss Paediatric Oncology Group

UNIVERSITÄT BERN

# Childhood Cancer Registry Data Utilisation

**SOHC 19. November 2021, Zurich**

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ISPM, University of Berne

# ChCR – national and international roles

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- mandated by the FOPH (BAG)
- national cancer registry
  - for people aged 0-19 years at Dx
- national reporting and data delivery
  - for people diagnosed before age 20 years
- international collaboration (international data calls)
  - for people diagnosed before age 20 years

# Cancer Registration Act (01.01.2020)

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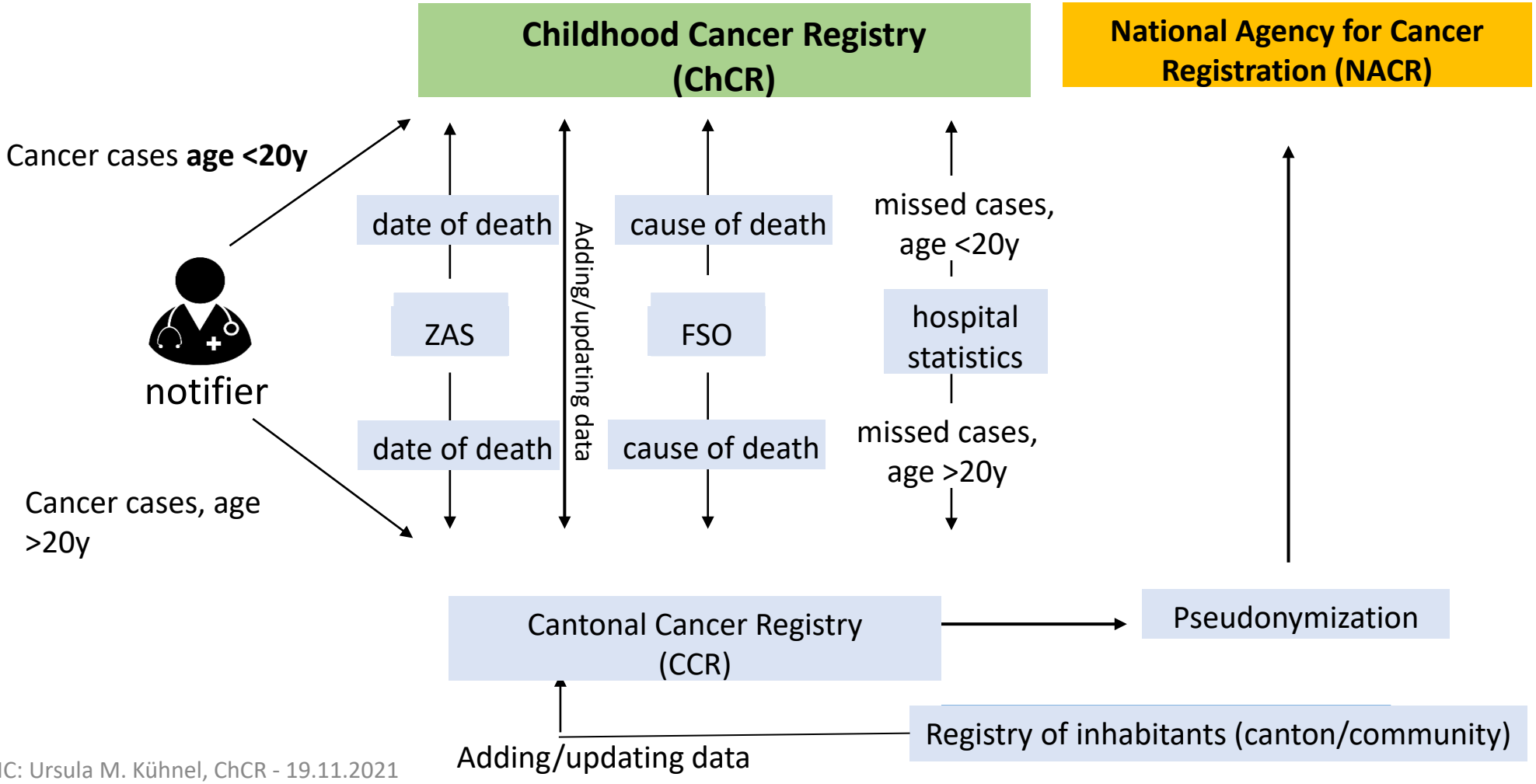

# More data collected for children and adolescents

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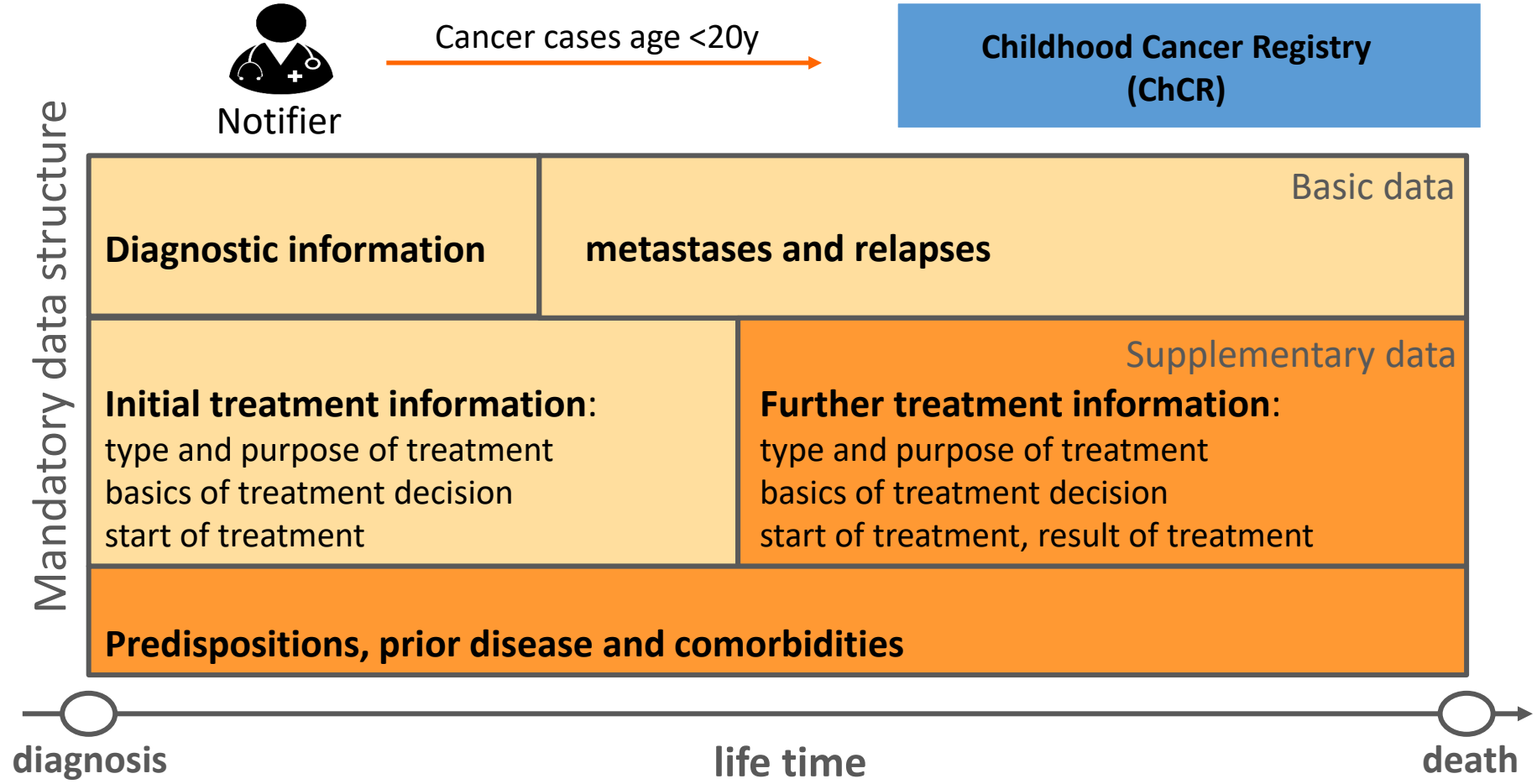

# Other tumours in children and adolescents

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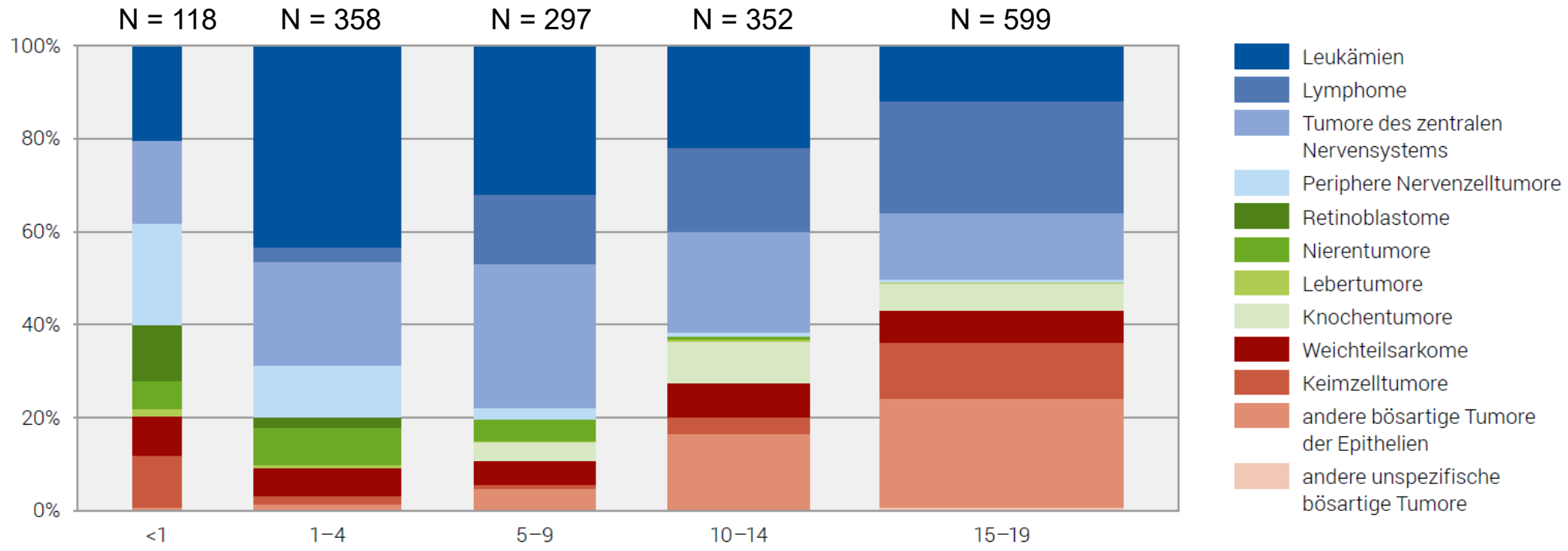


$N_{total}$ = 1724

- Adults: Carcinoma (Lung, Breast, Prostate, Colon)
- Children: Leukemia, embryonal Tumors, CNS Tumors
- Adolescents: Lymphoma, epithelial Tumors, CNS Tumors, Leukemia

# Other data providers

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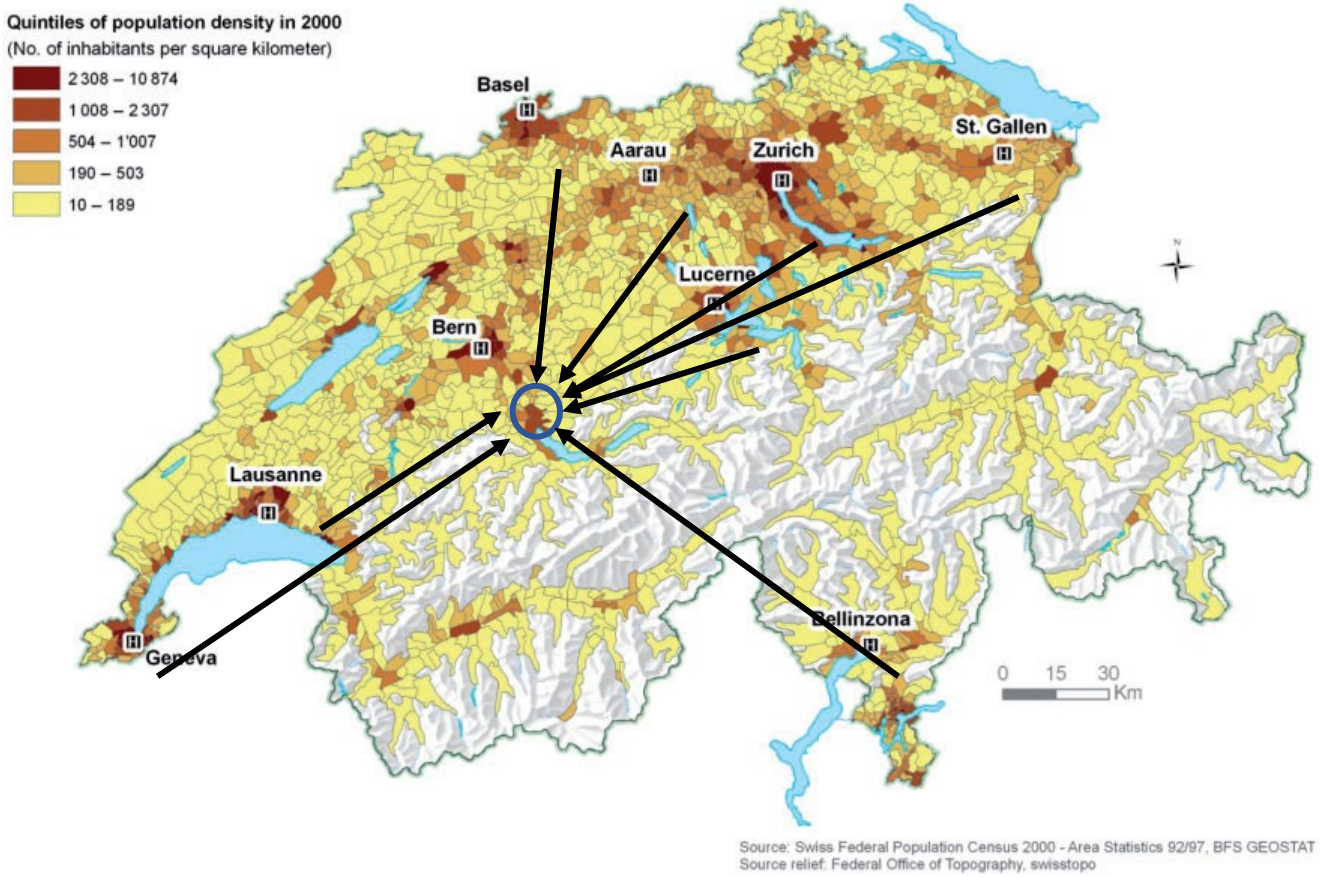


**National Cancer Registry – Notifications by:**

- 9 specialised clinics for children
  – SPOG Network
  (75% of cases)

- many clinics for adolescents of 15-19 yoa

# Data requests (Q1 - Q3 2021)

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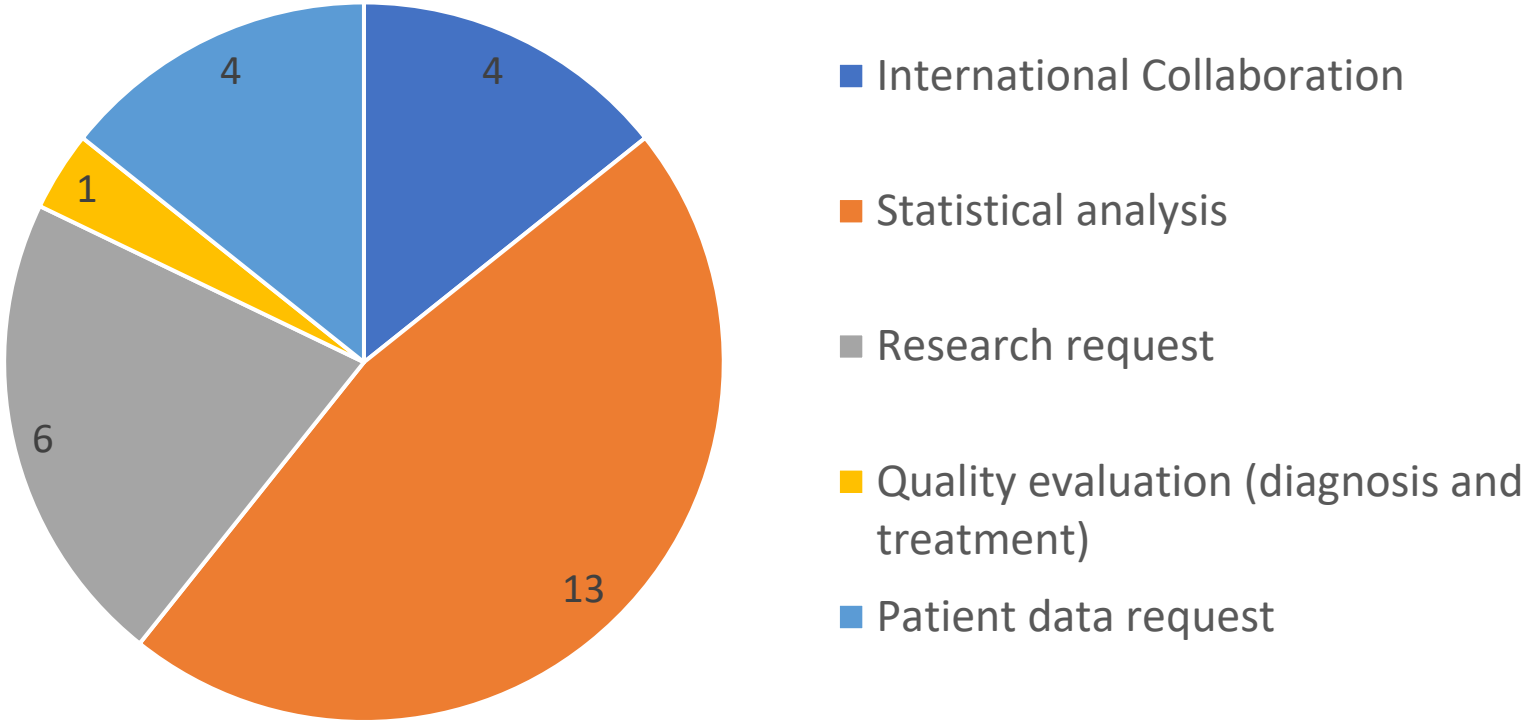


## → Examples of data requests to the ChCR

# Patient data request

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aim: informed decisions for the treatment of a 2nd primary neoplasm
patient developed a 2nd primary neoplasm

Request: treatment data for 1st cancer case
(medical records for had been lost)

- ChCR – extracted all available information for this patient
and sent it to the patient or his physician (patient's preference)

➢ No ethics approval needed

➢ Type of data: detailed data from one patient

# Patient identifying data

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aim: new setting up of an interdisciplinary late effects clinic

- Request: medical person (head of clinic) wants to invite former patients with high risk of late effects
- ChCR – identified former patients (based on inclusion criteria) and sent names and addresses to the former clinic

➢ Approval from local data security official (canton and hospital) (ethics committee: "application not necessary")

➢ Type of data: patient identifying data only

# Individual Patient Data for a Research Project

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aim: Research Project by an interdisciplinary follow-up care clinic on health problems and QoL (patients participating in a research study)

- Request: data on tumor and previous treatments – to be related to observed health outcomes
- ChCR – received a list of patients who gave informed consent for this study and sent data on tumor and treatment to the PI

➢ Ethics committee approval, written informed consent which explicitly allows to retrieve information from the ChCR

➢ Type of data**:** individual medical data (tumor and treatment) which can be linked to study dataset

# Aggregated Data for a Research Project (detailed data and complex analyses)

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aim: external PI plans an epidemiological study on a certain brain tumor (incidence, diagnostic features, time trends, survival)

- ChCR – performed the analyses and sent only aggregated data (tables and figures)
- The PI paid for the analysis time and invited ChCH statisticians as co-authors.

➢ No approval needed, only aggregated data

➢ Type of data: aggregated data (anonymized)

Alternatively (discussed with PI): Submission for an ethics approval by the PI to receive an anonymous or pseudonymous dataset and perform the analysis himself

# Research on the risk of cancer (analyses by PI, supervision by ChCR)

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aim: comparison of the risk of cancer in children exposed to different levels of ionizing radiation from the environment
comparison group = Swiss National Cohort Dataset

- ChCR – extracted data on place of residence (geocoded address)
  – and on few relevant characteristics (type of tumor, age, sex)
  – supervision of analyses by head statistician
  The analyses were performed by the team of the PI.

➢ Ethics committee approval, but no informed consent needed

➢ Type of data: data potentially identifying
(place of residence, no names and addresses )

# In summary

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ChCR data can serve broad aspects of

- monitoring (epidemiology, health care provision)
- enabling research and supporting clinical care
- performing benchmarking

→ specific processes have to be followed,
purpose specific agreements have to be made and
ethics approval to be clarified

- Collecting data without using them is unethical.
(Cancer Registration Act, Art. 2)

# Data requested from the ChCR

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- **if –** data are stratified by age and include age groups diagnosed below age 20 years or only data for patients diagnosed below age 20 years
- childhoodcancerregistry@ispm.unibe.ch
  kinderkrebsregister@ispm.unibe.ch
- the data request forms will be available on the ChCR Website soon

- Thank you !