

Annual Report 2023  
Institute of Social and  
Preventive Medicine ISPM





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## Director's Letter



Looking back on 2023, I'm once again proud of the many successful and interesting projects and teaching activities conducted by the people of Institute of Social and Preventive Medicine. This report highlights some of these projects. Enjoy reading them!

A year ago, I announced the beginning of a two-year transition phase for ISPM. As we begin this second and final transition year, I also look ahead to the developments 2024 will bring.

By May we will have more concrete information on who the new director of ISPM will be. Also, in January 2024 the university agreed to a new professorship in Climate Impacts on Public Health. The appointment of this professor will happen in the second half of 2024. The research group will be part of ISPM and the professor also will be affiliated with the Oeschger Centre for Climate Change Research (<https://www.oeschger.unibe.ch/>).

As in previous years, the 2023 ISPM annual report shows the very broad thematic range of topics we engage. This diversity is also reflected in the teaching of ISPM lecturers.

And of course, with its approximately 150-160 staff members ISPM could not operate smoothly, if at all, without its dedicated central services staff. I therefore want to end by sending my big "thank you" to all staff members in every domain of activity of ISPM.

Marcel Zwahlen, Director

**Organigram  
Institute of Social and Preventive Medicine  
(ISPM)**

**Directorate**  
 Marcel Zwahlen, Director a.i.  
 Claudia Kuehni, Deputy Director a.i.  
 Christian Althaus  
 Annika Frahsa  
 Brigitte Wanner

**Administration and Services**  
 Personal Assistant to Director  
 Finances  
 Human Resources  
 IT  
 Information and Library  
 Communication  
 Teaching and Course Coordination

**Research Board**

- Research Groups**
- **Cancer**  
Eliane Rohner
  - **Child & Adolescent Health**  
Claudia Kuehni
  - **Climate Change & Health**  
Ana Vicedo-Cabrera
  - **Community Health**  
Annika Frahsa
  - **Environmental & Spatial Epidemiology**  
Ben Spycher
  - **Evidence Synthesis Methods**  
Georgia Salanti
  - **Health Services**  
Marcel Zwahlen
  - **HIV, Hepatitis & Tuberculosis**  
Matthias Egger
  - **INPUT - Interfaculty Platform for Data & Computational Science**  
Christian Althaus
  - **Lifestyle and Behavior**  
Marija Glisic
  - **Mental Health**  
Andreas Haas
  - **Musculoskeletal Health & Rheumatology**  
Stephan Reichenbach
  - **Palliative Care & End of Life**  
Sofia Zambrano
  - **Sexual & Reproductive Health**  
Nicola Low
  - **SwissRDL**  
Adrian Spörri, Mario Morger

**Institute Assembly**  
 all staff

Version 2023-12-11

# ISPM Facts and Figures

as of 31.12.2023

Our research profile covers a wide range of health-related topics across 16 research groups.

We actively participate in university teaching for students of medicine, pharmacy, biomedical engineering, and biomedicine, and are engaged in courses for PhD students and participants in postgraduate training programs as described on the ISPM website.

## People



### Prof. Dr. Marcel Zwahlen

Director a.i.

**Staff members total** 154

**Research** 136

**PhD students** 51

**Admin, technical** 18

**Nationalities** 32

**Research groups** 16

## Education



### Postgraduate courses

- CAS Clinical Research in Health Care Organizations
- CAS Leadership in Health Care Organizations
- CAS Managing Medicine in Health Care Organizations
- MAS in Leading Learning Health Care Organizations
- Swiss Epidemiology Winter School

### Inter University Public Health Education

MPH, DAS, CAS

### Medical Specialist in Prevention and Public Health

Certified training facility

### Bern Lectures in Health Science

10

## Grants



### 2023 our researchers received grants from

- BAG
- Bundesamt für Meteorologie und Klimatologie  
MeteoSchweiz: NCCS-Impact Projects
- Hemmi Stiftung
- Insel
- KLS /KFS
- Krebsforschung Schweiz
- Oxford
- SAMW
- SBFJ
- SNSF: 1 Starting Grant, 1 other grant
- SPHN
- Uni Bern MCID

### 3rd party money spent

SNSF	CHF 2'549'496
Other competitive	CHF 6'263'192
Noncompetitive	CHF 3'350'453

## Teaching



### Total numbers

Courses	73
Course attendees	986
Undergraduate lectures	678

## Publications



Originals in house	94
Original collaborations	109
Reviews in house	14

to be best in a  
point of view.

# Research

search for kn  
examine int  
facts or prin

# Cancer

*We study the occurrence of and risk factors for cancer, and we inform cancer prevention programs. The group currently focuses on the epidemiology of HIV-related malignancies and cervical cancer prevention in sub-Saharan Africa.*

## Key scientific activities

We continued our work analyzing data from the South African HIV Cancer Match (SAM) study—a record-linkage study based on laboratory records from the National Health Laboratory Service and cancer diagnoses from the National Cancer Registry in South Africa. The current SAM study database includes information about more than 5 million people living with HIV. We used data from the SAM study to examine risk factors associated with incident conjunctival cancer among this population. We also worked on updating the SAM database to include data until 2021.

We used a South African medical aid claims database to assess the impact of HIV status on cervical precancer and cancer incidence rates. Using the same database, we examined whether prostate cancer incidence rates differed between men with and without HIV in South Africa. In Zambia, we continued to follow up a cohort of regularly screened women with HIV to examine human papillomavirus and cervical disease dynamics over time. Together with our collaborators in Zambia we retrieved data from various databases that provide information required to model cervical cancer in Zambia. In Zimbabwe, we obtained ethical approval for a prospective cohort study on cervical precancer treatment failure among women with HIV.

## Key academic activities

**Students:** Carole Metekoua started her PhD work on the epidemiology of non-Hodgkin lymphoma in South Africa. John Andoh continued his PhD work developing a mathematical model for assessing comparative effectiveness and cost-effectiveness of different cervical cancer prevention strategies in Zambia.

**Teaching:** We taught and tutored medical students at the University of Bern. Eliane Rohner coordinated the medical specialization program in prevention and public health at ISPM.

**Conferences and Events:** In October 2023, Eliane Rohner held her inaugural lecture together with PD Dr. med. Monika Müller, PhD, from the University Hospital of Psychiatry and Psychotherapy.

**Scientific Talks and Presentations:** Katayoun Taghavi and Eliane Rohner presented research results at the International Papillomavirus Society Conference in Washington, DC. Yann Ruffieux presented his work on imputing the HIV infection date in the SAM study at the International Workshop on HIV and Hepatitis Observational Databases (IWHOD) in Athens, Greece. Carole Metekoua and Eliane Rohner presented research results at the AORTIC Conference on Cancer in Africa in Dakar, Senegal.

**Honors and Awards:** Eliane Rohner received the Research Prize 2023 of the Hemmi Foundation (CHF 25,000).

## Grants

**National Institute of Allergy and Infectious Diseases** (Administrative Supplement to U01AI069924): Human papillomavirus infection and cervical pre-cancer dynamics

among women living with HIV in Zambia: cohort study (USD 96,282. PI Matthias Egger, Project Lead Eliane Rohner; 2023–2024).

**Swiss National Science Foundation** (IZSEZO\_214803): The intersection of cancer and mental health: evidence from South African real-world data (CHF 18,200. Scientific Exchange Chiara Gastaldon, PI Eliane Rohner; 02/2023–07/2023).

## Internal and external collaborations

In Switzerland, we collaborate with the Swiss HIV cohort study (Karoline Aebi-Popp) and the Cancer Registry Bern-Solothurn (Andrea Jordan, Luzius Mader). Internationally, we collaborate with the International epidemiology Databases to Evaluate AIDS—Southern Africa; the National Cancer Registry (Mazvita Muchengeti), South Africa; the University of Cape Town (Gary Maartens), South Africa; the World Health Organization's International Agency for Research on Cancer (Partha Basu), France; the Newlands Clinic (Margaret Pascoe, Tarisai Kufa, Tinei Shamu), Zimbabwe; the Center for Infectious Disease Research (Albert Manasyan, Misinzo Moono), Zambia; and the Molecular Epidemiology Laboratory at the Queen Mary University (Belinda Nedjai), UK.

## Key team members

John Andoh (PhD student), Matthias Egger (head of HIV, Coinfections and Comorbidities research group), Nathalie Fernandez (research fellow), Chiara Gastaldon (research fellow), Carole Metekoua (PhD student), Eliane Rohner (head of research group), Yann Ruffieux (research associate), Katayoun Taghavi (postdoc).

## Selected publications

**Fernández Villalobos NV, Ruffieux Y, Haas AD, Chinogurei C, Cornell M, Taghavi K, Egger M, Folb N, Maartens G, Rohner E. Cervical precancer and cancer incidence among insured women with and without HIV in South Africa.** Int J Cancer. 2024 Jan 15;154(2):273-283.

Dhokotera TG, Muchengeti M, Davidović M, **Rohner E**, Olago V, **Egger M**, Bohlius J. **Gynaecologic and breast cancers in women living with HIV in South Africa: A record linkage study.** Int J Cancer. 2024 Jan 15;154(2):284-296.

**Metekoua C, Ruffieux Y, Olago V, Dhokotera T, Egger M, Bohlius J, Rohner E\***, Muchengeti M\* (\*contributed equally). **Decreasing Incidence of Conjunctival Squamous Cell Carcinoma in People with HIV in South Africa.** J Natl Cancer Inst. 2023 Jun 28;djad119.

# Child and Adolescent Health

## 1. Pediatric Respiratory Epidemiology Group

*The Paediatric Respiratory Epidemiology group studies common and rare respiratory disorders that appear during childhood and may persist throughout life. Our main areas of research include asthma and other wheezing disorders, chronic cough, cystic fibrosis (CF), and primary ciliary dyskinesia (PCD). We examine the roles of environment and behavior on the development of respiratory disorders, analyze phenotypes of diseases, and create diagnostic and prognostic prediction models.*

### Key scientific activities

We conduct population-based and clinical cohort studies and manage pediatric disease registries.

**Swiss Paediatric Airway Cohort (SPAC):** SPAC is a prospective, observational, multicenter clinical cohort study in Switzerland, which currently includes almost 4,200 children referred to one of ten outpatient pediatric pulmonology clinics for wheeze, cough, exertional respiratory symptoms, or sleep-related breathing problems. In 2023 we studied phenotypes of cough among children, evaluated predictors of short-term (1 year) and medium-term (3 year) asthma control, and investigated the reporting of exercise-induced respiratory symptoms by parents versus physicians. We also collaborated with pediatric pulmonologists throughout the SPAC network to create a standardized reporting scheme for childhood obstructive airway disease.

**National physician surveys of asthma diagnosis:** We aim to better understand asthma diagnosis in school-age children. We are designing standardized physician questionnaires in collaboration with national physician societies (pediatrics, general practice, pulmonology, allergology) to survey the healthcare networks in Switzerland, Ukraine, and Mongolia.

**National monitoring of newborn screening (NBS) for CF:** Our research team analyzes the NBS results for cystic fibrosis in Switzerland and monitors the accuracy and efficacy of this screening tool for early detection of CF. In 2023, we evaluated the past 11 years of data and analyzed how possible changes to the algorithm could decrease the false-positive detection rate of CF in newborns.

**Living with PCD (previously known as COVID-PCD):** Living with PCD is an international longitudinal, online participatory study conducted in collaboration with several PCD support groups worldwide. Introduced in May 2020, it now includes more than 750 people of all ages with PCD. Participants periodically complete questionnaires on topics relevant to PCD. In 2023, we investigated physical activity in people with PCD, observed how it changed over a 100-week period, and examined which factors were associated with activity. We studied how feasible it is to collect information about causative genes directly from people with PCD through questionnaires, and investigated associations between clinical characteristics, symptoms, and genotype. We also examined fertility status and the satisfaction with physician-provided fertility counseling among men and women with PCD.

[Link SPAC](#)

[Link Living with PCD](#)



Living with PCD group photo

**Ear-Nose-Throat (ENT) Prospective International Cohort of PCD patients (EPIC-PCD):** EPIC-PCD is a multicenter cohort study focusing on characteristics and prognosis of upper respiratory disease among people with PCD, which currently includes 515 participants from 13 centers in 10 countries. In 2023, we published three articles that rely upon baseline cohort data describing characteristics of otologic disease and sinonasal disease among patients with PCD to study correlation between patient-reported ENT symptoms and objective physical examination findings. We also explored the relationship between upper and lower respiratory disease in PCD.

**Research priorities in PCD:** We lead mixed methods studies that combine qualitative and quantitative analytical approaches to determine future priorities for clinical and epidemiological research on PCD. In 2023, we developed two anonymous surveys: one studying opinions of healthcare professionals and researchers on barriers and priorities for PCD-related research, and a second investigating perspectives of people with PCD and their families on priorities and involvement with PCD-related research. We circulated both surveys internationally with the help of the BEAT-PCD clinical research collaboration, the European Lung Foundation, and PCD support groups worldwide, together reaching more than 500 participants.

**Treatment burden in people with PCD living in Switzerland:** In 2023, we collaborated with representatives of the Swiss PCD support group and psychologists to study the burden of treatments and care management among people with PCD living in Switzerland. Using in-depth interviews and focus groups with adults and adolescents with PCD, and parents of children with PCD, we identified the main sources of burden and problems that arise from PCD management. We are currently developing a nationwide survey to assess treatment burden among persons who have PCD, how it affects quality of life, and to identify factors that have an impact on adherence to prescribed treatments.

**BEAT-PCD Clinical Research Collaboration:** In 2020, the European Respiratory Society (ERS) funded BEAT-PCD Clinical Research Collaboration (CRC), a network of multidisciplinary researchers and clinicians; in 2023 it renewed its support through 2026. The CRC coordinates the translation of basic research to clinical care to improve diagnosis and develop treatments that lead to better long-term outcomes for patients with PCD. Myrofora Goutaki cochairs the network, and Claudia Kuehni and Yin Ting Lam

[Link BEAT-PCD Clinical Research Collaboration](#)



are members of the management committee. Within the BEAT-PCD framework, in 2023 we developed and advanced numerous research projects and published several articles. The network presented bimonthly expert talks, organized a successful international annual meeting and training school for early career researchers in Milan, and co-organized an online annual international conference for people with PCD together with PCD support groups worldwide and the European Lung Foundation.

**Improving diagnosis of PCD:** Our research team has an active role in the improvement and standardization of PCD diagnosis aiming to achieve early, accurate diagnosis for children worldwide who are born with PCD. Claudia Kuehni contributed to the development of a technical standard, supported by the ERS, on nasal nitric oxide measurement in children for the diagnosis of PCD, which was published in 2023. In collaboration with colleagues worldwide and with the support of the ERS and the American Thoracic Society, Myrofora Goutaki contributes to an international Task Force for the development of a joint guideline for the diagnosis of PCD (2023-2025).

**Key academic activities**

**Students:** During 2023, the group included 10 PhD candidates and 2 medical students (one doctoral thesis, one master’s thesis). Three PhD candidates—Daria Berger, Yin Ting Lam, and Maria Christina Mallet—defended their doctoral theses and received PhDs.

**Teaching:** Regular teaching with lectures and tutoring of undergraduate and post-graduate students (University of Bern, Master of Public Health program) by Claudia Kuehni, Myrofora Goutaki, and Eva Pedersen. Yin Ting Lam and Leonie Schreck participated in teaching activities for medical students.

**Conferences and Events:** We co-organized the annual meeting of BEAT-PCD CRC and BEAT-PCD training school in Milan (September 2023) and the 2nd annual online international PCD patient conference (November 2023). We also organized the annual online Swiss PCD meeting (December 2023), and several large project meetings that include the annual meeting of national SPAC collaborators in Bern (November 2023), the annual meeting to discuss CF NBS (March 2023), and the annual online EPIC-PCD collaborators meeting (November 2023). We co-organized a panel discussion webinar through the European Respiratory Society on lung function in epidemiological studies from infancy to childhood with a focus on the urban environment. Finally, we organized bimonthly online expert talks through BEAT-PCD.

**Scientific Talks and Presentations:** As invited speaker, Leonie Schreck presented her talk, “Studie COVID19-PCD – Fruchtbarkeit bei Menschen mit PCD” at the patient congress of the German support group for PCD (Kartagener Syndrom und Primäre Ciliäre Dyskinesie) in April 2023 in Frankfurt, Germany.

In June 2023, Eva Pedersen presented her invited talk “Phenotypes of primary ciliary dyskinesia and their association with genetic mutations and disease progression” at the joint annual meeting of the Swiss Societies of Pulmonology and Cardiology in Basel.

During the ERS BEAT-PCD annual meeting in September 2023 in Milan, Italy, Leonie Schreck presented her invited talk “Infertility among adults with primary ciliary dyskinesia.”

At the online PCD patient conference in November 2023, Myrofora Goutaki presented her invited talk, “PCD research priorities and results from cohort studies.” Myrofora Goutaki and Leonie Schreck were also invited to speak about “Genotype-phenotype associations in PCD” and “Fertility and PCD” at the BEAT-PCD expert talks in October and December 2023, respectively.

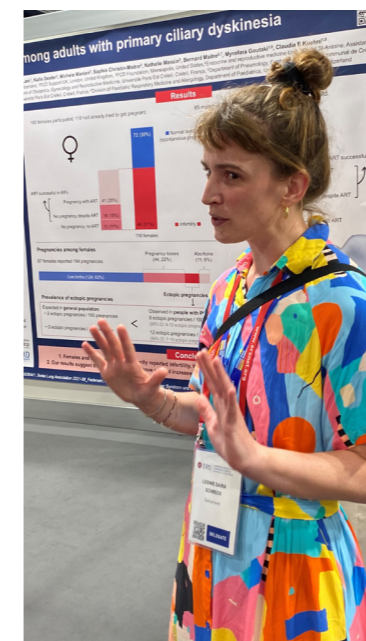
Link  
Guido Falconi Memorial Prize

**Honors and Awards:** At the annual meeting of the Swiss Society of Paediatrics in June 2023, Claudia Kuehni was awarded the prestigious Guido Falconi Memorial Prize for outstanding scientific contributions and significant achievements for the benefit of the health of children and adolescents.

Also at the joint annual meeting of the Swiss Societies of Pulmonology and Cardiology, Yin Ting Lam received the prize for the best oral presentation in pediatric pulmonology for her talk "Association between upper and lower respiratory disease in primary ciliary dyskinesia."



Yin Ting Lam awarded



Leonie Schreck presents her poster at ERS



Claudia Kuehni receives the Fanconi award

### Grants

**Swiss National Science Foundation** (320030B\_192804): Natural history, phenotypes, and disease classification in primary ciliary dyskinesia (phase II). (CHF 447,055. PI Claudia Kuehni; 2020–2023).

**Swiss National Science Foundation** (320030\_212519): Using real-world data for diagnosis and prognosis of childhood asthma. (CHF 1.2 million. PI Claudia Kuehni; 2022–2026).

**Swiss Personalized Health Network**: Using routine health care data to facilitate clinical cohort studies (SPHN-SPAC). (CHF 406,250. PI Claudia Kuehni; 2023–2024).

**Swiss National Science Foundation Ambizione** (PZ00P3\_185923): From the nose to the lungs: the importance of upper respiratory disease in Primary Ciliary Dyskinesia. (CHF 950,341. PI Myrofora Goutaki; 2019–2023).

**Swiss National Science Foundation**: Measures for researchers from Ukraine for PhD student Tayisiya Krasnova. (CHF 110,917. Host Claudia Kuehni; 2022–2024)

**Swiss Lung League**: Phenotypes of Primary Ciliary Dyskinesia and their association with genotypes and disease progression. (CHF 86,082. PI Eva SL Pedersen; 2021–2024).

**Johanna Dürmüller-Bol**: Treatment burden of people with PCD in Switzerland. (CHF 12,646. PI Myrofora Goutaki).

**OM Pharma Clinical Research Grant Agreement**: Assessing the impact of COVID-19 preventive measures on respiratory infections and wheezing episodes in children. (CHF 93,887. PI Claudia Kuehni; 2021–2023).

### Internal and external collaborations

The Paediatric Respiratory Epidemiology group works with an extensive national and international multidisciplinary network of researchers, clinicians, and scientists in the field of pediatric and rare respiratory diseases through SPAC, the CF NBS program, the asthma diagnosis surveys, EPIC-PCD, and BEAT-PCD. We also collaborate closely with patient associations and support groups through Living with PCD.

### Key team members

Daria Berger (PhD candidate), Léa-Zoé Flückiger (research assistant), Maluí Frei (research assistant), Mandukhai Ganbat (PhD candidate), Sarah Glick (postdoc), Myrofora Goutaki (senior researcher), Beatriz Guerra Buezo (PhD candidate), Michelle Hauser (medical student), Mirjam Koller (medical student), Helena Koppe (research assistant), Tayisiya Krasnova (PhD candidate), Claudia Kuehni (head of research group), Yin Ting Lam (PhD candidate), Gia Thu Ly (research assistant), Ronny Makhoul (PhD candidate), Maria Christina Mallet (PhD candidate, subsequently postdoc), Eva Sophie Lunde Pedersen (postdoc), Lara Pissini (research assistant), Franco Romero Gonzalez (PhD candidate), Larissa Rossier (research assistant), Mari Sasaki (postdoc), Leonie Schreck (PhD candidate), Ibrahim Ssekalo (PhD candidate).



PhDs of the Respiratory group

### Selected publications

**Pedersen ESL, Schreck LD, Goutaki M, Bellu S, Copeland F, Lucas JS, Zwahlen M, Kuehni CE.** Incidence and Severity of SARS-CoV-2 Infections in People with Primary Ciliary Dyskinesia. *Int J Public Health.* 2023; 68:1605561.

**Schreck LD, Goutaki M, Jörger P, Dexter K, Manion M, Christin-Maitre S, Maitre B;** COVID-PCD Patient Advisory Group; **Kuehni CE, Pedersen ESL.** Fertility care among people with primary ciliary dyskinesia. *Pediatr Pulmonol.* 2023. doi: 10.1002/ppul.26743.

**Goutaki M, Lam YT, Alexandru M, Anagiotos A, Armengot M, Boon M, Burgess A, Caversaccio N, Crowley S, Dheyauldeen SAD, Emiralioglu N, Erdem E, van Gogh C, Gunaydin O, Haarman EG, Harris A, Hayn I, Ismail-Koch H, Karadag B, Kempeneers C, Kim S, Lorent N, Ozcelik U, Pioch C, Poirrier AML, Reula A, Roehmel J, Yiallourous P, Yumusakhuylu AC, Papon JF.** Characteristics of Otologic Disease among patients with Primary Ciliary Dyskinesia. *JAMA Otolaryngol Head Neck Surg.* 2023; 149(7):587-596.

**Mallet MC, Pedersen ESL, Makhoul R, Blanchon S, Hoyler K, Jochmann A, Latzin P, Moeller A, Regamey N, Goutaki M, Spycher BD, Kuehni CE;** SPAC Study Team. Phenotypes of cough in children: A latent class analysis. *Clin Exp Allergy.* 2023. doi: 10.1111/cea.14416.

**Ardura-Garcia C, Mallet MC, Berger DO, Hoyler K, Jochmann A, Kuhn A, Moeller A, Regamey N, Singer F, Pedersen ESL, Kuehni CE;** SPAC Study Team. Predictors of asthma control differ from predictors of asthma attacks in children: The Swiss Paediatric Airway Cohort. *Clin Exp Allergy.* 2023; 53(11):1177-1186.

## 2. Paediatric Cancer

### 2.a Childhood Cancer Registry

*ChCR registers diagnoses of cancer among children and adolescents under age 20 in Switzerland and monitors incidence of childhood cancers, quality of care, and long-term outcomes. ChCR data support epidemiological research including studies on causes and outcomes of cancer in young people. Further information can be found on the ChCR website.*

Since the new Cancer Registration Act (CRA) came into force on January 1, 2020, registration of cancer diagnosis has been compulsory. The Federal Office of Public Health (FOPH) gave the mandate to manage the national Childhood Cancer Registry (ChCR) to the consortium of the Swiss Paediatric Oncology Group (SPOG) and the Institute of Social and Preventive Medicine at the University of Bern. For efficiency reasons, the consortium was dissolved at the end of 2023 and the mandate is being taken over by ISPM alone. ISPM will continue to maintain and host the ChCR, to report on cancer in children and adolescents, and provide data for national and international research purposes.

#### Key scientific activities

The data from the ChCR not only provide a basis for routine cancer surveillance in Switzerland but contribute importantly to research on cancer in young people. Our team's core tasks encompass registering, coding, ensuring quality, and processing external requests for data. We routinely report key data quality indicators and cancer statistics including incidence, mortality, and survival on our website.

The ChCR contributes to the following international research and benchmarking initiatives: the CONCORD Program (Global surveillance of cancer survival), the BENCHISTA project (International Benchmarking of Childhood Cancer Survival by Stage) and the CRICCS study (Cancer Risks in Childhood Cancer Survivors). In 2023, the ChCR answered two data requests from international childhood cancer organizations for registry data, and seven data requests for projects on cancer in children and adolescents in Switzerland. The ChCR also replied to 10 requests from patients or their representatives, clinicians, foundations, or journalists.

In 2023 we prepared the data and conducted data analyses for the national Public Health Report 2024, which will focus on the risk of second primary cancers and will be published at the end of 2024.

#### Key academic activities

**Scientific Talks and Presentations:** In November 2023, we participated in the Scientific Conference ENCR 2023 IARC in Granada, Spain. Eleftheria Michalopoulou presented a poster on the "Incidence of cancer in adolescents and young adults (AYAs) in Switzerland".

[Link ChCR website](#)

#### Grants

**Swiss Federal Office of Public Health:** The ChCR is mandated and completely funded by the FOPH. The mandate for the next period 2024 – 2028 has been confirmed by the FOPH.

#### Internal and external collaborations

At ISPM, we collaborate with the Child and Adolescent Health research group. Within Switzerland, we collaborate closely with the FOPH, the National Agency for Cancer Registration, SPOG, Association Suisse des Registres du Cancer, and the FSO.

Outside of Switzerland, we collaborate with the International Association of Cancer Registries, the European Network of Cancer Registries, and the German Childhood Cancer Registry.

#### Key team members

Valentin Bunjaku (assistant RCD), Christina Çinar-Kaufmann (registration and coding), Sophia della Valle (registration and coding), Daniela Dyntar (head RCD), Katharina Flandera (administrative support), Maria Hammer (registration and coding), Ursula Kuehnel (executive coordinator), Claudia Kuehni (head of childhood cancer registry), Eleftheria Michalopoulou (statistics), Shelagh Redmond (consultant data quality), Grit Sommer (head of data requests), Ben Spycher (head of statistics), Gabrielle Vautravers Bayram (administrative support), Mirjam Weiss (registration).



Valentin Bunjaku



Christina Cinar-Kaufmann



Sophia della Valle



Daniela Dyntar



Katharina Flandera



Maria Hammer



Ursula Kuehnel



Claudia Kuehni



Eleftheria Michalopoulou



Sheilagh Redmond



Grit Sommer



Ben Spycher



Gabrielle Vautravers Bayram



Mirjam Weiss

**Selected publications**

Kolodziejczak AS, Guerrini-Rousseau L, Planchon JM, Ecker J, .... **Redmond S**, .... Milde T. **Clinical outcome of pediatric medulloblastoma patients with Li-Fraumeni syndrome**. Neuro Oncol. 2023 Dec 8;25(12):2273-2286. doi: 10.1093/neuonc/noad114 PMID: 37379234; PMCID: PMC10708940.

Wang Y, Ronckers CM, van Leeuwen FE, Moskowitz CS, Leisenring W, ... **Kuehni CE**, ... Teepen JC; **International Consortium for Pooled Studies on Subsequent Malignancies after Childhood and Adolescent Cancer**. **Subsequent female breast cancer risk associated with anthracycline chemotherapy for childhood cancer**. Nat Med. 2023 Sep;29(9):2268-2277. doi: 10.1038/s41591-023-02514-1. Epub 2023 Sep 11. PMID: 37696934; PMCID: PMC10504074.

Link  
Publication

**2.b Childhood Cancer Research Group**

*The Childhood Cancer Research Group studies the effects of childhood cancer over the life course. Our main areas of interest concern long-term outcomes after childhood cancer including prevalence, incidence, and spectrum of somatic and psychosocial late effects such as cardiac and pulmonary function, hearing loss, mental health, educational and social outcomes, health-related quality-of-life, secondary neoplasms, and long-term mortality.*



Childhood Cancer Research group

**Key scientific activities**

We conduct population-based clinical follow-up studies on long-term outcomes after childhood cancer.

**Swiss Childhood Cancer Survivor Study (SCCSS):** This nationwide population-based questionnaire survey continuously enrolls all patients with childhood cancer registered in the Swiss Childhood Cancer Registry who have survived more than five years after their cancer diagnosis. We study the spectrum of somatic and psychosocial outcomes childhood cancer survivors experience, health-related quality-of-life, and health behaviors. We finished the data entry of questionnaires from survivors diagnosed between 2011-2015. We also contacted siblings to compare health outcomes between survivors and their siblings.

**Cardiovascular Late Effects after Childhood Cancer (CardioOnco) Study:** In this prospective longitudinal multicenter study, we compare conventional echocardiography with speckle tracking echocardiography for the early detection of cardiac disease among childhood cancer survivors, conduct cardiopulmonary exercise testing of childhood cancer survivors, and investigate clinical determinants for developing cardiac disease after childhood cancer. The study started in 2016 at the University Hospital of Bern, Inselspital and since 2021 has been expanded to four other centers in Switzerland. The CardioOnco Study has a website to inform survivors ([www.cardiosurvivor.ch](http://www.cardiosurvivor.ch)). To date, 529 childhood cancer survivors have participated in the study.

**Community-based screening program for hearing loss after childhood cancer (HEAR Study):** This prospective study evaluates a novel, low-threshold hearing loss screening program for former childhood cancer patients. We invited adult survivors of childhood cancer at risk of hearing loss for a free hearing test in a local hearing aid shop. Overall, 406 childhood cancer survivors participated in the baseline assessment, 334 participated in the hearing test, and 236 answered the two follow-up questionnaires. The study has a participatory approach through a stakeholder advisory group of former patients, physicians, and hearing experts. We use questionnaires, audiograms, interviews, and group discussions with stakeholders to evaluate the screening program.

**International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG):** In this initiative developing standardized recommendations for follow-up surveillance after childhood cancer, our research group leads a guideline on pulmonary dysfunction, and we are involved in several other guidelines related to ototoxicity, endocrine surveillance, metabolic syndrome, psychosocial problems, and health promotion.

**Pulmonary Late Effects after Childhood Cancer (Pulmo Study, SCCSS FollowUp):** Embedded in regular follow-up visits at pediatric cancer clinics, this prospective longitudinal study at multiple sites compares conventional lung function tests with nitrogen multiple breath washout tests for the early detection of pulmonary disease among survivors of childhood cancer and understanding clinical determinants that lead to the development of pulmonary disease after childhood cancer. This study started in 2022 at Inselspital and the University Children's Hospital of Basel, UKBB and to date 135 children and adolescents have participated. Expansion to Geneva Children's Hospital is in progress.

**Swiss Paediatric Haematology/Oncology Metabank (Biolink):** A project providing a platform to combine data from the SCCSS and two biobanks—the Swiss germline DNA Biobank for Childhood Cancer and the Blood Disorders and the Swiss Pediatric Haematology Oncology Biobank Network—in a privacy-preserving way. The Metabank facilitates project development through the rapid assessment of available data and samples, then links clinical data with biosamples. Biolink enables in-depth research into cancer predispositions, pharmacogenetics, and genetic modifiers of long-term complications after childhood cancer.

**Genetic risks for Complications in Children after Oncological Treatment in Switzerland (GECCOS):** A collaborative project investigating genetic risk factors of complications after childhood cancer as part of the Biolink project, GECCOS improves our understanding of why some people develop second cancers after childhood cancer and others do not. We collected more than 500 germline DNA samples that are stored in the Biobank for Childhood Cancer and Blood Disorders in Geneva. We extracted and sequenced DNA from participants with childhood cancer in Switzerland to contribute to international research collaborations on second cancers.

**Key academic activities**

**Students:** During 2023, the group included three PhD students and one MD-PhD student. Sven Strebel completed his PhD studies.

**Teaching:** Regular teaching with lectures and tutoring of undergraduate and postgraduate students at the University of Bern by Claudia Kuehni, Grit Sommer, Maša Žarković, Philippa Jörger, and Tomáš Sláma.

**Conferences and Events:** Our team members attended the joint Scientific Meeting of the Swiss Pediatric Oncology Group and the Swiss Society of Pediatric Hematology and Oncology in Bern; the Annual Congress of the Swiss Pediatric Society, Interlaken; the Research Day at the University of Basel; the 39th Annual Meeting of the Histiocyte Society, Athens, Greece; and the Brain Tumor Conference, Essen, Germany, giving numerous oral and poster presentations.

**Outreach and Representation:** The SCCSS has a website ([www.swiss-ccss.ch](http://www.swiss-ccss.ch)) through which we report on activities such as our latest publications, with lay summaries, and provide information for study participants. We also regularly report about our projects and results in newsletters published by stakeholder groups (e.g., the newsletter of Childhood Cancer Switzerland), targeting childhood cancer survivors and their families. Our research group and team members are represented in and engaged across scientific as well as stakeholder organizations such as the Swiss Pediatric Oncology Group, the Swiss Society of Pediatric Hematology and Oncology (SSPHO), OncoSuisse, and Childhood Cancer Switzerland.

**Honors and Awards:** Philippa Jörger, Tomáš Sláma, and Maša Žarković received an UniBern Short Travel Grant, which allowed them to visit the renowned childhood cancer research institution St. Jude in Memphis, Tennessee, US, for two weeks.

**Grants**

**Association Jurassienne d'Aide aux Familles d'Enfants atteints de Cancer/AJAFEC:** Quels parcours! – Charity walk during the night in support of pediatric cancer research: Early detection of pulmonary disease after childhood cancer (CHF 34,000. PI Christina Schindera, Nicolas von der Weid; 11/2023-12/2024)

**Swiss Cancer Research and Swiss Cancer League (KLS/KFS-5711-01-2022):** Structural funding for Swiss Childhood Cancer Survivor Study. (CHF 480,000. PI Claudia Kuehni; 01/2023–12/2025).

**Stiftung für krebskranke Kinder, Regio Basiliensis:** Swiss Childhood Cancer Survivor (SCCSS). (CHF 50,000. PI Claudia Kuehni, Nicolas von der Weid; 01/2023-12/2023).

**Stiftung für krebskranke Kinder, Regio Basiliensis:** Prospective Multicenter Cohort Study for Diagnosing Cardiac Dysfunction in Childhood Cancer Survivors. (CHF 16,700. PI Christina Schindera; 01/2023-09/2023).

**Swiss Cancer Research (KFS-5027-02-2020):** Prospective multicenter cohort study for diagnosing cardiac dysfunction among childhood cancer survivors in Switzerland.

Link  
[www.cardiosurvivor.ch](http://www.cardiosurvivor.ch)

Link  
[www.swiss-ccss.ch](http://www.swiss-ccss.ch)

(CHF 336,950. PI Nicolas von der Weid, Co-Applicants, Claudia Kuehni, Christina Schindera; 01/2021–12/2023).

**Swiss Cancer Research** (KFS-4722-02-2019): Dietary intake, overweight, and late effects development in childhood cancer survivors. (CHF 359,450. PI Murielle Bochud, Coapplicant Claudia Kuehni; 07/2019–04/2023).

**Swiss Cancer Research** (HSR-4951-11-2019): Improving access to screening for hearing loss after childhood cancer – a novel community-based approach. (CHF 247,850. PI Claudia Kuehni; 05/2020–10/2023).

**Swiss Cancer Research** (KFS-5302-02-2021): Pulmonary dysfunction after childhood cancer: assessing early-stage disease (phase II). (CHF 369,150. PI Claudia Kuehni; 07/2021–06/2024).

**Kinderkrebs Schweiz:** Dental health problems in childhood cancer survivors. (CHF 15,000. PI Claudia Kuehni; 06/2023-12/2023).

**Kinderkrebs Schweiz:** Early detection of heart disease after treatment for cancer during childhood. (CHF 15,000. PI Christina Schindera, Claudia Kuehni; 01/2023-12/2023).

**University of Basel Research Fund for Excellent Junior Researchers:** Prospective Multicenter Cohort Study for Diagnosing Cardiac Dysfunction in Childhood Cancer Survivors (CHF 80,000. PI Christina Schindera; 11/2021-10/2023).

### Internal and external collaborations

The Childhood Cancer Research Group works with an extensive national and international multidisciplinary network of researchers and clinicians in the field of late effects after childhood cancer. In Switzerland, we collaborate with the nine Swiss Pediatric Oncology Group clinics and the Swiss Childhood Cancer Registry. Internationally, we are partners in several collaborative projects that include the Pan-European Consortia on Late Effects among Long-Term Survivors of Childhood and Adolescent Cancer (PanCareLIFE), and Childhood and Adolescent Survivor Care and Follow-Up Studies (PanCareSurFup), as well as in the International Guideline Harmonization Group (IGHG) for Late Effects of Childhood Cancer.

### Key team members

Fabiën Belle (postdoc), Katharina Fessler (research assistant), Philippa Jörger (PhD candidate), Claudia Kuehni (head of research group), Corinne Matti (project coordinator), Carina Nigg (postdoc), Christina Schindera (postdoc), Tomáš Sláma (PhD candidate), Grit Sommer (research fellow), Sven Strebel (PhD candidate), Leah Weber (research assistant), Maša Žarković (PhD candidate), Andrea Ziörjen (study nurse).



Claudia Kuehni



Fabiën Belle-van Sprundel



Katharina Fessler



Philippa Jörger



Corinne Matti



Carina Nigg



Christina Schindera



Tomáš Sláma



Grit Sommer



Sven Strebel



Leah Weber



Maša Žarković



Andrea Ziörjen

### Selected publications

**Belle FN, Schindera C, Ansari M, Armstrong GT, Beck-Popovic M, Howell R, Leisenring WM, Meacham LR, Rössler J, Spycher BD, Tonorezos E, von der Weid NX, Yasui Y, Oeffinger KC, Kuehni CE.** Risk factors for overweight and obesity after childhood acute lymphoblastic leukemia in North America and Switzerland: A comparison of two cohort studies. *Cancer Med.* 2023;12(20):20423-20439. doi: 10.1002/cam4.6588.

**Kasteler R, Otth M, Halbeisen F. S, Mader L, Singer F, Rössler J, von der Weid NX, Ansari M., & Kuehni CE.** Longitudinal assessment of lung function in Swiss childhood cancer survivors – A multicenter cohort study. *Pediatr Pulmonol.* 2023;1-12. doi: 10.1002/ppul.26738.

Reulen RC, Winter DL, Diallo I, Veres C, Llanas D, Allodji RS, Bagnasco F, Bárdi E, Feijen EAM, Alessi D, Fidler-Benaoudia MM, Høgsholt S, Teepen JC, Linge H, Haddy N, Byrne J, Debiche G, Grabow D, Gudmundsdottir T, Fauchery R, Zrafi W, Michel G, Øfstaas H, Kaatsch P, Vu-Bezin G, Jenkinson H, Kaiser M, Skinner R, Cole T, **Waespe N, Sommer G, Nordenfelt S, Jankovic M, Lähteenmäki Taalas T, Maule MM, van der Pal HJH, Ronckers CM, van Leeuwen FE, Kok JL, Terenziani M, Winther Gunnes M, Wiebe T, Sacerdote C, Jakab Z, Haupt R, Lähteenmäki PM, Zdravec Zaletel L, Kuehni CE, Winther JF, Kremer LCM, Hjorth L, de Vathaire F, Hawkins MM.** Risk Factors for Primary Bone Cancer After Childhood Cancer: A PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies Nested Case-Control Study. *J Clin Oncol.* 2023;41(21):3735-46. doi: 10.1200/JCO.22.02045.

**Sláma T, Belle FN, Strebel S**, Christen S, Högler-Laube E, Rössler J, **Kuehni CE**, von der Weid NX, **Schindera C**. *Prevalence and factors associated with cancer-related fatigue in Swiss adult survivors of childhood cancer*. J Cancer Surviv. 2023. doi: 10.1007/s11764-023-01413-1.

**Strebel S, Mader L, Jörgler P, Waespe N**, Uhlmann S, Von Der Weid N, Ansari M, **Kuehni CE**. *Hearing loss after exposure to vincristine and platinum-based chemotherapy among childhood cancer survivors*. EJC Paediatric Oncology. 2023;1:100017. doi: 10.1016/j.ejcped.2023.100017.

**Strebel S**, Baust K, Grabow D, Byrne J, Langer T, am Zehnhoff-Dinnesen A, **Kuonen R, Weiss A**, Kepak T, Kruseova J, Berger C, Calaminus G, **Sommer G, Kuehni C**. *PanCareLIFE Consortium. Auditory complications among childhood cancer survivors and health-related quality of life: a PanCareLIFE study*. J Cancer Surviv. 2023. doi: 10.1007/s11764-023-01456-4.

de Baat EC, Feijen EAM, Reulen RC, Allodji RS, Bagnasco F, Bardi E, **Belle FN**, Byrne J, van Dalen EC, Debiche G, Diallo I, Grabow D, Hjorth L, Jankovic M, **Kuehni CE**, Levitt G, Llanas D, Loonen J, Zaletel LZ, Maule MM, Miligi L, van der Pal HJH, Ronckers CM, Sacerdote C, Skinner R, Jakab Z, Veres C, Haddy N, Winter DL, de Vathaire F, Hawkins MM, Kremer LCM. *Risk Factors for Heart Failure Among Pan-European Childhood Cancer Survivors: A PanCareSurFup and ProCardio Cohort and Nested Case-Control Study*. J Clin Oncol. 2023;41(1):96-106. doi: 10.1200/JCO.21.02944.

Wang Y, Ronckers CM, van Leeuwen FE, Moskowitz CS, Leisenring W, Armstrong GT, de Vathaire F, Hudson MM, **Kuehni CE**, Arnold MA, Demoor-Goldschmidt C, Green DM, Henderson TO, Howell RM, Ehrhardt MJ, Neglia JP, Oeffinger KC, van der Pal HJH, Robison LL, Schaapveld M, Turcotte LM, **Waespe N**, Kremer LCM, Teepen JC. *The International Consortium for Pooled Studies on Subsequent Malignancies after Childhood and Adolescent Cancer. Subsequent female breast cancer risk associated with anthracycline chemotherapy for childhood cancer*. Nat Med. 2023;29:2268–2277. doi: 10.1038/s41591-023-02514-1.

### 3. Paediatric and Rare Disease Registries

*The Pediatric and Rare Disease Registries group hosts several medical registries and conducts studies in different areas of pediatric epidemiology such as endocrinology, gastroenterology, nephrology, neurology, pneumonology, and rare diseases. We collect data to better understand and treat diseases to improve patient quality of life.*

We help answer specific research questions, recruit patients for clinical studies, and coordinate postmarketing surveillance of drugs. We promote the usability of medical data for research in pediatrics and foster communication between researchers nationally and internationally and thus disseminate knowledge.

#### Key scientific activities

We coordinate platforms, national registries, and cohort studies.

**SwissPedRegistry** is a research platform for pediatric registries and also part of SwissPedNet—the Swiss research network of clinical pediatric hubs. We provide expertise and advice for the development of and conducting epidemiological and clinical registries that collect data on children or persons of any age. We develop regulatory frameworks, methodologies, and instruments for registries and participate in national discussions and meetings on registry-relevant issues. With our work, we are a driving force in infrastructure development for clinical research in pediatrics (see SwissPedHealth and SwissPedData).

**Swiss Rare Disease Registry (SRDR)**: SRDR is a national, population-based registry for children and adults with rare diseases. SRDR collects a core dataset from everyone with a rare disease in Switzerland—around 500,000 people. The SRDR constitutes a platform enabling clinical and epidemiological studies of rare diseases and facilitating patient participation in national and international trials. In 2023, we focused on restructuring the registry organization as a multicentric study. The registry's priority remains patient self-registration, which we facilitate through an online platform for self-registration developed in collaboration with SwissRDL.

**Swiss Registry for Neuromuscular Disorders (Swiss-Reg-NMD)**: Swiss-Reg-NMD is a national patient registry for children and adults diagnosed with Duchenne-Becker muscular dystrophy (BMD/DMD), spinal muscular atrophy (SMA), LAMA2-related muscular dystrophy (LAMA2-RD), and collagen-VI-related myopathy (COL-6). The registry collects detailed health-related information from medical records and occasionally from patient surveys. In 2023, data from the first SMA gene therapy were analyzed, showing that this therapy is an effective treatment for SMA and has a particularly positive effect on the motor development of the treated patients. In the DMD cohort, we have learned from our patient survey that the Covid-19 pandemic has had a direct impact on the education and participation in social life of young people with DMD.

**Swiss Cerebral Palsy Registry (Swiss-CP-Reg)**: Swiss-CP-Reg is a national registry investigating health-related issues among people with cerebral palsy (CP). It includes all individuals with CP born, treated, or living in Switzerland. The aim is to improve

future care and the wellbeing of individuals with CP. In 2023, we analyzed our first national survey on concerns in the daily life of families with children and adolescents with CP. Together with researchers from Inselspital, ZHAW, and Kinder-Reha Schweiz, we also launched the project entitled “Parti-CP: Barriers and facilitators for participation in children for cerebral palsy, their siblings and families in Switzerland.”

**Swiss Pediatric Inflammatory Brain Disease Registry** (Swiss-Ped-IBrainD): Swiss-Ped-IBrainD collects medical data from people with inflammatory brain diseases of pediatric onset. The data set includes information on the diagnosis, course, and treatment of inflammatory brain diseases. The registry promotes collaboration between specialists through the Swiss-Ped-IBrainD Task Force. The working group consists of all principal investigators involved in Swiss-Ped-IBrainD and other experts in the field. They implement the knowledge gained in the best interest of their patients. Ultimately, the registry aims to improve the medical care and quality of life of children with inflammatory brain diseases in Switzerland.

**Swiss Primary Ciliary Dyskinesia Registry** (CH-PCD): CH-PCD is a national registry for people with primary ciliary dyskinesia who live or receive care in Switzerland. The registry collects information both from participants and health care professionals and provides a valuable national research platform. In 2023, we analysed data collected directly from participants through a nationwide survey. We investigated the prevalence of neonatal problems, changes in respiratory symptoms over time, and associations of upper and lower airway symptoms with lung function. In a nested study, we interviewed registry participants about the burden of their treatment.

### Key academic activities

**Students:** In 2023, Mirjam Koller started her medical doctoral thesis (CH-PCD). Lena Bischoff completed her medical doctoral thesis (Swiss-CP-Reg and Ostschweizer Kinderspital, St. Gallen). Selina Gredig started her PhD thesis (Swiss-CP-Reg and Inselspital, Bern). M. Fasciati started her medical masters thesis (Swiss-Ped-IBrainD). Nora Laube started her medical doctoral thesis (Swiss Paediatric Renal Registry at ISPM, supported by SwissPedRegistry).

**Teaching:** Regular teaching with lectures and tutoring of undergraduate and postgraduate students (University of Bern, Master of Public Health Program) by Claudia Kuehni, Myrofora Goutaki, and Sandra Bigi.

**Conferences and Events:** CH-PCD co-organized the annual online Swiss PCD meeting in December 2023. Swiss-CP-Reg co-organized the Swiss Academy of Childhood Disability Research Day (January 2023).

**Scientific Talks and Presentations:** Myrofora Goutaki presented CH-PCD work on neonatal problems of people with PCD at the Joint annual meeting of the Swiss Societies of Pulmonology and Cardiology (June 2023) and at the conference of the European Respiratory Society (September 2023, Milan). Sandra Hunziker presented preliminary results on topics of concern at the Research Day of the Swiss Academy of Childhood Disability and at the Annual Meeting of the European Academy of Childhood Disability (January 2023 and May 2023, Swiss-CP-Reg). Sandra Bigi presented the Swiss-Ped-IBrainD and its first year experience as a poster at the MS State of the Art Symposium 2023. Lorena Hulliger presented on first insights into epidemiology of pediatric-onset inflammatory brain diseases at the annual meeting of the German Society of Neuropediatrics (Jahrestagung der Gesellschaft für Neuropädiatrie). At the ProRaris Rare Disease Day, Michaela Fux and Natalie Bayard-Guggisberg presented the SRDR, addressing challenges and opportunities of patient involvement in clinical research and healthcare. Cheryl von Arx gave a presentation on “What can the Rare Disease Registry contribute to postmarketing surveillance (drawbacks and proposed solutions)” at the Multi-Stakeholder Workshop of the Rare Disease Action Forum.

**Outreach and Representation:** Representatives from the group attended national and international meetings with relevant stakeholders, participated in working groups, and represented the needs and interests of pediatric registries. We conducted science communication and outreach activities related to rare diseases in general and neuromuscular disorders in particular with various patient organizations and foundations, university and cantonal hospitals, and representatives of the pharmaceutical industry. We represented the interests of pediatric registries in working groups of the FOPH, which are responsible for developing the content of the work prioritized by the specialist group conference (AG Registerübersicht, AG Strukturierte Datenerfassung).

### Grants

**SwissPedNet:** SwissPedRegistry in general (CHF 80,000 per year; PI Claudia Kuehni; 1/2021–12/2024) and research collaboration with SwissPedRegistry to advance the development of the infrastructure with focus on rare diseases (CHF 98,000. PI Claudia Kuehni; 12/2023-12/2024).

**Swiss Federal Office of Public Health:** Financial support for the Swiss Rare Disease Registry under article 24 of the national law on cancer registration. (CHF 250,000 per year; PI Claudia Kuehni; 11/2020–10/2025).

**Zwillenberg-Foundation:** Development of the SRDR self-registration platform (CHF 20,000).

**Patient organizations and pharmaceutical companies:** See Swiss-Reg-NMD for more information.

**Swiss National Science Foundation** (20030\_212587): A mixed-methods study identifying barriers and facilitators for participation in children with cerebral palsy in Switzerland – a family perspective. (CHF 916,368. PI Sebastian Grunt, Co-PIs Anne Tschertter, Hubertus J.A. van Hedel, Christina Schulze; 2023–2026).

**Schweizerische Stiftung für das Cerebral gelähmte Kind and Anna Mueller Grocholski-Stiftung:** Swiss Cerebral Palsy Registry. (CHF 299,045. PI Anne Tschertter; 2020–2024).

**Swiss Multiple Sclerosis Society, Johanna Dürmüller-Bol Stiftung, Anna Mueller Grocholski-Stiftung and several pharmaceutical companies:** Swiss-Ped-IBrainD. (CHF 735,102 peer and non-peer reviewed funding; PI Sandra Bigi; 2020–2024).

### Internal and external collaborations

At ISPM, we collaborate closely with medical Registries and Data Linkage (SwissRDL), particularly for data linkage and software development. Within Switzerland we work with colleagues at university and cantonal hospitals, hubs of SwissPedNet, centers for rare diseases, the kosek—Coordination Rare Diseases Switzerland, patient organizations, and others. Outside of Switzerland, we collaborate with Surveillance of CP in Europe, TREAT-NMD Neuromuscular Network, and with the BEAT-PCD network. In addition, the Swiss-Ped-IBrainD team collaborated with a clinic in Datteln (Germany) on a project on prepubertal multiple sclerosis.

### Key team members

Dominique Baumann (project manager Swiss-Reg-NMD), Natalie Bayard-Guggisberg (research assistant SRDR), Sandra Bigi (medical head Swiss-Ped-IBrain-D), Anna Born (data manager Swiss-Reg-NMD, Swiss-CP-Reg), Isabella Christen (research assistant Swiss-Ped-IBrainD), Katharina Flandera (assistant), Michaela Fux (project manager SRDR), Myrofora Goutaki (senior researcher, co-lead of CH-PCD), Selina Gredig (PhD student, Swiss-CP-Reg), Susanne Hofer (data manager Swiss-Ped-IBrainD), Lorena



Hulliger (project manager Swiss-Ped-IBrainD), Sandra Hunziker (research assistant Swiss-CP-Reg and SwissPedRegistry), Claudia Kuehni (head of research group, SwissPedRegistry, and SwissPedHealth), Nadine Lötscher (data manager and assistant Swiss-Reg-NMD), Andrea Mathis (project manager Swiss-Reg-NMD), Anne Tschertner (senior researcher, project lead SwissPedRegistry and Swiss-CP-Reg), Cheryl von Arx (project manager SRDR).

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### Selected publications

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Stettner GM, Hasselmann O, **Tschertner A**, Galiart E, Jacquier D, Klein A. *Treatment of spinal muscular atrophy with Onasemnogene Apeparovvec in Switzerland: a prospective observational case series study*. *BMC Neurology*. 23(1):88.

Gruebner O, van Haasteren A, Hug A, Elayan S, Sykora M, Albanese E, Stettner GM, Waldboth V, Messmer-Khosla S, Enzmann C, **Baumann D**, von Wyl V, Fadda M, Wolf M, von Rhein M. *Mental health challenges and digital platform opportunities in patients and families affected by pediatric neuromuscular diseases—experiences from Switzerland*. *DIGITAL HEALTH*. 2023;9:1-11.

**Hunziker S**, Morosoli F, Zuercher K, **Tschertner A**, Grunt S, on behalf of the Swiss Cerebral Palsy Registry Group. *Prescription Practices of Cannabinoids in Children with Cerebral Palsy Worldwide—A Survey of the Swiss Cerebral Palsy Registry*. *Children* 2023;10(12):1838.

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The Pediatric and Rare Disease Registries group

## 4. Pediatric Swiss Personalized Health Network

*The Pediatric Swiss Personalized Health Network group is a key national stakeholder aiming to develop a sustainable data infrastructure for data-driven and personalized health research in children.*

### Key scientific activities

We coordinate and contribute to projects to make health-related data on children in Switzerland findable, accessible, interoperable, and reusable at a national level. Through our work, we drive infrastructure development for clinical research in pediatrics with the involvement of patients, families, and the public.

**Pediatric personalized research network Switzerland (SwissPedHealth)** is a joint national data stream funded by Swiss Personalized Health Network (SPHN) and Personalized Health and Related Technologies (PHRT). SwissPedHealth is a multidisciplinary collaboration between the five Swiss university pediatric hospitals in Basel, Bern, Geneva, Lausanne, and Zurich and the two cantonal hospitals in Luzern and St. Gallen with the aim of ensuring that routine clinical data in pediatrics are interoperable, standardized, quality-controlled, and ready for research. The Child and Adolescent Health research group is one of the key actors in this national data stream. ISPM leads two nested research projects, which investigate growth and obesity in Swiss children (NP1, **SwissPedGrowth**), and effectiveness and quality of cancer registration in Swiss children (NP2, **SwissPedCancer**). The project builds on **SwissPedData**—a national pediatric, harmonized core dataset defined through an SPHN infrastructure development project. The harmonized set of data collected during routine inpatient and outpatient visits improves the quality of data collected during encounters with patients. It will allow fast, almost real-time use of the data for high quality research. The dataset currently is being implemented in clinics.

**SwissPedHealth–Personalized Pediatric Primary care (SwissPedHealth–PREPP)** is a collaborative project between three Swiss pediatric university hospitals and three pediatric primary care practices. It is funded by the federal initiative SPHN and aims to improve the quality of pediatric health care by exchanging hospital and primary care data through real-time data sharing. It specifically aims to demonstrate the feasibility of linking databases of pediatric primary care practices and hospitals, and testing the benefit of the newly built infrastructure in four real-world use cases. In use case 2, which is led by ISPM Bern, we will explore how primary care data (longitudinal anthropometric measurements) could complement hospital data to improve obesity management.

**SPHN-Swiss Pediatric Airway Cohort (SPHN-SPAC)** is a demonstrator project funded by SPHN and involves the three children’s hospitals in Bern, Zurich, and Lucerne. For large cohort studies like the SPAC study, which is a hospital-based, longitudinal clinical cohort study of more than 4,500 patients with respiratory symptoms, the workload associated with manual data collection and entry of clinical data becomes increasingly unsustainable and costly. Therefore, this project aims to investigate whether routine healthcare data from hospitals can assist or supplement data collection for the SPAC study. Specifically, we will explore, set up, validate, and implement procedures enabling automatic data extraction from hospitals; assess the data quality of the automatic data extraction; support physicians to standardize labelling of common respiratory diagnoses; compare study participants to nonparticipants; and study respiratory health over time and analyze repeated lung function

tests. More information on SPAC can be found in 6.1 Pediatric Respiratory Epidemiology Group.

### Key academic activities

**Students:** During 2023, the group included 2 MD-PhD candidates.

**Teaching:** Regular teaching with lectures and tutoring of undergraduate and postgraduate students (University of Bern) by Claudia Kuehni, Eva Pedersen, and Fabiën Belle.

**Conferences and events:** Our team members attended several workshops organized by SPHN, the National Data Streams symposium & monitoring meetings in Lausanne, the Kinderklinik Research Day in Bern, the annual congress of the Swiss Society of Paediatrics in Interlaken, and the European Respiratory Society International Congress in Milan. We also set up kickoff meetings for SwissPedGrowth and SPHN-SPAC with all executive board members and other stakeholders.

**Scientific talks and presentations:** During the Kinderklinik Research Day of the University Hospital of Bern, Inselspital in November 2023, Lorenz Leuenberger presented his work “Height, weight, and BMI in Swiss children: the SwissPedGrowth project.” Christina Mallet presented her work “Diagnosis in children with prolonged or recurrent cough: findings from the Swiss Paediatric Airway Cohort” at the annual congress of the Swiss Society of Paediatrics (June 2023), the European Respiratory Society International congress (September 2023), and the Kinderklinik Research Day of Inselspital (November 2023).

**Honors and awards:** Lorenz Leuenberger received the prize for the best oral presentation for clinical research for his talk on “Height, weight, and BMI in Swiss children: the SwissPedGrowth project” at the Kinderklinik Research Day of Inselspital (November 2023).

### Grants

**Swiss Personalized Health Network (SPHN) and the Personalized Health and Related Technologies (PHRT):** Pediatric Personalized Research Network Switzerland (SwissPedHealth) – a Joint Pediatric National Data Stream. (CHF 5 million with CHF 1.083 million dedicated to ISPM; PIs Luregn Schlapbach and Julia Vogt, Coapplicant Claudia Kuehni; 09/2022–08/2025).

**Swiss Personalized Health Network (SPHN):** SwissPedHealth–Preparing PERsonalizEd PEdiatRic PRimaRy caRE (PREPP). (CHF 490,221. PI Jan Bonhoeffer, Coapplicant Claudia Kuehni; 04/2023–09/2024).

**Swiss Personalized Health Network (SPHN):** Using routine health care data to facilitate clinical cohort studies (SPHN-SPAC). (CHF 406,250. PI Claudia Kuehni; 04/2023–09/2024).

### Internal and external collaborations

We collaborate within Switzerland with university and cantonal hospitals, clinical data warehouses, research groups, and primary care practices to combine resources, expertise, and knowledge for cutting-edge medical research. Outside of Switzerland we collaborate with PEDSnet, a clinical network in the US that conducts research across multiple children’s hospital health systems.

### Key team members

Fabiën Belle-van Sprundel (project manager SwissPedHealth, member PREPP), Claudia Kuehni (head of research group, coapplicant SwissPedHealth, coapplicant SwissPed-

Health-PREPP, PI SPHN-SPAC), Lorenz Leuenberger (PhD student SwissPedHealth–SwissPedGrowth, member PREPP), Christina Mallet (project manager SPHN-SPAC), Eva Pedersen (PI SPHN-SPAC), Franco Romero (PhD student SPHN-SPAC), Mari Sasaki (project manager SPHN-SPAC), Yara Shoman (Postdoc SwissPedHealth–SwissPed-Cancer).



The Pediatric Swiss Personalized Health Network group

# Climate Change and Health

*The Climate Change and Health research group advances knowledge of the impact of climate change and related environmental stressors on human health. Our main research lines develop along the intersection of epidemiology and public health with climate sciences.*

These include (1) health impact assessments of extreme weather events at different geographical scales and historical periods, and under future climate change scenarios, (2) identification of profiles of vulnerability to climate-related health risks, (3) the impact of climate change on urban populations, modulating factors, and connections with existing challenges such as social inequalities and ageing in cities, (4) quantification of health impacts attributed to human-induced climate change, and (5) evaluation of health risks associated with compound and cascading weather events.

### Key scientific activities

Coordination of international collaborations within the Multi-country Multi-city Collaborative Research Network (based at the London School of Hygiene and Tropical Medicine) to advance knowledge of the impact of weather-related factors on mortality.

Kickoff and development of the activities of the first year of the two research projects NCCS-Impacts-Health and SNSF Starting Grant ACTUAL.

### Key academic activities

**Students:** Supervision of five PhD and four masters students.

**Teaching:** Lectures at the University of Bern in the first year of medical study on climate change, planetary health, and sustainability (Mensch und Umwelt); the MSc in climate science including two seminars and a full course on environmental epidemiology applied to climate sciences; and in the introductory course of Module 2 of the Public Health Sciences Course Program.

**Conferences and events:** National and international scientific events such as the annual meeting of the European Geoscience Union.

**Scientific talks and presentations:** Presenter at the Autumn seminar series “Was is gesundheit?” Collegium Generale of the University of Bern, presenter at Meeting of the German Perinatal Health Association, CLIMACT series of EPFL, keynote at the Autumn Plenary meeting of the Oeschger Center for Climate Change Research.

**Outreach and representation:** National and international scientific committees, such as the European Chapter of the International Society for Environmental Epidemiology and Environment and Health committee of the European Respiratory Society.

### Grants

**Swiss National Foundation:** SNSF Starting Grant ACTUAL: Advancing research on extreme humid heat and health. (CHF 1.7 million. PI Ana M. Vicedo-Cabrera; 06/2023–05/2028).

**National Center for Climate Services:** NCCS-Impacts: Health Decision Support for Dealing with Climate Change in Switzerland: A cross-sectoral approach—impacts of climate change on health, well-being, and performance of humans and animals and

on food safety in Switzerland. (CHF 760,000. PI Ana M. Vicedo-Cabrera; 02/2023–12/2025).

**EPFL:** Extended-range warnings for heatwaves in Switzerland (HEATaware). (CHF 60,000. Coapplicant Ana M. Vicedo-Cabrera; 01/2023–12/2023)

**The Heart & Stroke Foundation of Canada:** Exploring the relationship between high temperatures and cardiovascular disease-related morbidity and mortality: Differences across vulnerable groups and geographic areas in Canada (\$193,325. Collaborator Ana M. Vicedo-Cabrera; 07/2023–06/2026).

**Swiss National Foundation:** SNSF Cost Action FAIRNESS: Urban Green Space and Climate in a Network of Urban Climate Networks. (CHF 319,981. Collaborator Ana M. Vicedo-Cabrera; 05/2023–04/2027).

### Internal and external collaborations

University of Bern collaborators: Stefan Brönnimann (Climatology), Olivia Romppainen-Martius (Department of Geography), Christoph Raible (Department of Physics), Thomas Müller (University of Bern), Sandra Eckert (Center for Development and Environment), Edouard Davin (Wyss Academy).

Swiss Tropical and Public Health Institute (Martina Ragetti), ETH Zurich Switzerland (David Bresch, Erich Fischer, Sonia Seneviratne), London School of Hygiene and Tropical Medicine UK (Antonio Gasparrini, Sir Andy Haines), CICERO Oslo Norway (Jana Sillman and Kristin Aunan), Norwegian Institute of Public Health (Shilpa Rao), University of Valencia Spain (Carmen Iñiguez), University of Bristol UK (Dann Mitchell and Eunice Lo).

### Key team members

Carole Bouverat (masters student), Marvin Bundo (PhD candidate), Evan de Schrijver (PhD candidate), Mirjam Gerber (masters student), Lilian Goepp (PhD candidate), Katia Hidalgo (masters student), Sujung Lee (PhD candidate), Nadine Löstcher (project manager assistant), Sidharth Sivaraj (PhD candidate), Ana M. Vicedo-Cabrera (head of research group), Adrienne Wehrli (masters student).

### Selected publications

Blattner CE, **Vicedo-Cabrera AM**, Frölicher TL, Ingold K, Raible CC, Wyttenbach J. **How science bolstered a key European climate-change case.** Nature. 2023 Sep;621(7978):255-257. doi: 10.1038/d41586-023-02809-w.

**Vicedo-Cabrera AM**, Melén E, Forastiere F, Gehring U, Katsouyanni K, Yorgancioglu A, Ulrik CS, Hansen K, Powell P, Ward B, Hoffmann B, Andersen ZJ. **Climate change and respiratory health: a European Respiratory Society position statement.** Eur Respir J. 2023 Sep 3;62(2):2201960. doi: 10.1183/13993003.01960-2022.

Lüthi S, Fairless C, Fischer EM, Scovronick N, Ben Armstrong, Coelho MSZS, Guo YL, Guo Y, Honda Y, Huber V, Kyselý J, Lavigne E, Royé D, Rytí N, Silva S, Urban A, Gasparrini A, Bresch DN, **Vicedo-Cabrera AM.** **Rapid increase in the risk of heat-related mortality.** Nat Commun. 2023 Aug 24;14(1):4894. doi: 10.1038/s41467-023-40599-x.

**de Schrijver E**, Royé D, Gasparrini A, Franco OH, **Vicedo-Cabrera AM.** **Exploring vulnerability to heat and cold across urban and rural populations in Switzerland.** Environ Res Health. 2023 Jun 1;1(2):025003-25003. doi: 10.1088/2752-5309/acab78.

Salvador C, Nieto R, Vicente-Serrano SM, García-Herrera R, Gimeno L, **Vicedo-Cabrera AM**. **Public Health Implications of Drought in a Climate Change Context: A Critical Review**. *Annu Rev Public Health*. 2023 Apr 3;44:213-232. doi: 10.1146/annurev-publhealth-071421-051636.



## Community Health and Health(care) Systems

*We apply theory-driven social science methodology to understand and explain contextual conditions of health and promote and improve community health and health(care) systems. We apply the knowledge gained to influence social determinants of health and policymaking and contribute to health equity and well-being locally and internationally.*

### Key scientific activities

We explored innovative research methods such as photovoice to study the promotion of physical activity in nursing homes. We applied qualitative methods to explore the integration of primary care and public health in medical education in the Philippines, knowledge brokering in urban health interventions, and the hospice setting through an actor-based, health equity lens. We also continued or finished rapid, scoping, and systematic reviews on vulnerability among children, adolescents, and the elderly; participation and community health; smoking and migration; science-policy interaction in public health emergencies; and global health accountability.

### Key academic activities

**Students:** Our team included three PhD candidates working on science-policy interaction (Sophie Meyer), migrant health and smoking (Kris Schürch), and health, illness, and societal division in pandemic contexts (Cristopher Kobler Betancourt). One student finished his masters thesis and several students continued working on their masters and MD theses.

**Teaching:** We taught and tutored undergraduates and postgraduates studying medicine and pharmacy at the University of Bern, as well as students in the master of public health and the Public Health Sciences Course programs. Annika Frahsa co-led the core methods and health promotion modules in the UniBe PHS Course Program and gave external guest lectures and seminars on physical activity and health promotion.

**Conferences and Events:** Harvy Liwanag organized and facilitated a session on dialogical reflexivity to decolonize global health as part of the Network for Education and Research on Peace and Sustainability (NERPS) Conference in Bangkok (February 2023). Liwanag joined collaborators from Nepal, the Philippines, and USA for a workshop in Kathmandu to develop a framework for assessing organizational capacities in health policy and systems research (August 2023).

**Scientific Talks and Presentations:** Oral presentation at the D-A-CH Public Health3 conference (Lindau, Sophie Meyer), poster presentations at the European Implementation Event (Basel, Harvy Liwanag, Sophie Meyer), oral presentation at the Virtual Conference on Migrant Health hosted by LMU Munich, Pettenkofer School of Public Health (Cristopher Kobler Betancourt).

**Outreach and Representation:** Mandate by Health Promotion Switzerland to support the development of the cantonal action programs on health promotion and prevention, consultation for the Federal Office of Public Health on psychosocial determinants of health. Harvy Liwanag joined the editorial board of Health Research Policy and Systems as Associate Editor. Annika Frahsa was appointed to the core team of Gesunde UniBE and continued as steering committee member of PartNet – D-A-CH network on participatory health research.

### Grants

**Health Promotion Switzerland:** Expertise on vulnerable groups (PI Annika Frahsa; 09/2023-04/2024).

**UniBE Travel Grant:** Research Visit to the University of Melbourne (Harvy Liwanag; 4/2024).

**Multidisciplinary Center for Infectious Diseases and the Vinetum Foundation:** The pandemic society in Switzerland: Polarization and public health, (CHF 719,572. PI Annika Frahsa, Co-PI Nicola Low; 04/2022–03/2025).

**German Federal Ministry of Health Research (FKZ 2519FSB114):** BaSAlt—Physical activity promotion in nursing homes (approx. EUR 1.0 million. Co-PI Annika Frahsa; 06/2019–06/2023).

**United States Agency for International Development (R4D-001482-001):** Forum for Advancing Better Health Policy and Systems Research Institutions (FAB HPSRIs), (USD 67,658. Co-PI Harvy Liwanag; 11/2022–08/2023).

### Internal and external collaborations

At ISPM, we work closely with the Palliative Care and End of Life research group, focusing on qualitative methods. We collaborate with BReady and the Institute of Political Science to explore societal polarization, marginalization, and COVID-19. Cooperation with the Institute of Sport Science addresses worksite health promotion. In Switzerland we collaborate with Unisanté and the University of Lausanne, consult for BAG and Health Promotion Switzerland, as well as the Association Hospice Bern. Internationally we cooperate with the Univ. of Tübingen, FAU Erlangen-Nuremberg, and the University of Eastern Finland. We also collaborate with institutions in the Global South that include the Department of Health in the Philippines and HERD International in Nepal.

### Key team members



Lucia Bühlmayer (research assistant), Andrea Flükiger (personal assistant), Annika Frahsa (head of research group), Cristopher Kobler Betancourt (PhD candidate), Marina Köhli (research assistant), Harvy Joy Liwanag (postdoc), Gia Thu Ly (research assistant), Sophie Meyer (PhD candidate), Kris Schürch (PhD candidate),

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### Selected publications

**Mesa-Vieira C, Gonzalez-Jaramillo N, Díaz-Ríos C, Pano, O, Meyer S, Menassa M, Minder B, Lin V, Franco O, Frahsa A.** *Urban Governance, Multisectoral Action, and Civic Engagement for Population Health, Wellbeing, and Equity in Urban Settings: A Systematic Review.* International Journal of Public Health 2023; 68: 1605772. DOI: 10.3389/ijph.2023.1605772.

**Frahsa A.** *Ethische Überlegungen in der bewegungsbezogenen Gesundheitsförderung.* In: Thiel A, Tittlbach S, Sudeck G, Wagner P, Woll A, editors. *Handbuch Bewegungsbezogene Gesundheitsförderung.* Beiträge zur Lehre und Forschung im Sport 199. Schorndorf: Hofmann; 2023. p. 106-116.

**Frahsa A, Trüb D, Thiel A.** *The Applicability of Photovoice in Pseudo-total Institutions – Methodological Insights from an Exploratory Study on Physical Activity in Nursing Homes.* International Journal of Qualitative Methods 2023; 22: 160940692311616. DOI: 10.1177/16094069231161602.

**Liwanag HJ, James O, Frahsa A.** *A Review and Analysis of Accountability in Global Health Funding, Research Collaborations and Training: Towards Conceptual Clarity and Better Practice.* BMJ Global Health 2023; 8(12): e012906. DOI: 10.1136/bmjgh-2023-012906.

## Environmental and Spatial Epidemiology

*We study the potential effects of environmental exposures such as ionizing radiation and traffic-related air pollution on human health with a primary focus on cancer. We also explore spatial variation and temporal trends in cancer incidence and mortality.*

### Key scientific activities

In a project funded by the Swiss Cancer League, we conducted the first comprehensive analysis of the incidence and mortality for cancers among adolescents and young adults (AYA, ages 15–39 years) in Switzerland. As part of the EU Horizon 2020 project RadoNorm, we set up a collaborative study with partners from Denmark, Finland, France, and Norway on exposure to natural background radiation and the risks of childhood leukemia and tumors of the central nervous system. We completed analyses for several studies focusing on sun exposure in children and the association between residential UV exposure and childhood cancers in children and adults. We also contributed to an international study of childhood leukemia risk among children living in homes with built-in electrical transformers. Manuscripts presenting these results are in preparation or have been submitted.

In a study funded by the Federal Office for the Environment, we evaluated different methodological approaches for detecting changes in cancer trends potentially resulting from increased exposure to non-ionizing radiation from mobile phone use.

In collaboration with the partners at the University Hospital Bern and the Institute of Mathematical Statistics and Actuarial Science of the University of Bern, we contributed to setting up two studies that will investigate the usefulness of wearables data for personalized predictions of infectious and chronic diseases in postmenopausal woman. A methodological paper covering a data-driven framework for personalized sequential classification (and its application for preclinical diagnosis of dementia) was published in a peer-reviewed journal.

### Key academic activities

**Students:** One medical student completed his MD thesis. Four psychology students are doing an internship in our group.

**Teaching:** Ben Spycher taught courses in biostatistics that are part of the new PhD course program in Public Health Sciences. He also taught courses in biostatistics for the medical faculty at the University of Fribourg and at Bern University of Applied Sciences. Lectures in environmental epidemiology and tutoring for first-year medical students at the University of Bern were given by Ben Spycher and Christian Kreis.

**Scientific Talks and Presentations:** Poster presentations at the 55th Congress of the International Society of Paediatric Oncology (SIOP), 2023, Ottawa, Canada and at the European Network of Cancer Registries—International Association of Cancer Registries Scientific Conference, 2023, Granada, Spain (Presenters: Céline Bolliger, Eleftheria Michalopoulou).

**Outreach and Representation:** Ben Spycher is member of the Scientific Council of the International Agency for Research on Cancer, and also a member of the academic board of Public Health Weiterbildung.

Link  
RadoNorm

### Grants

**Swiss Cancer League** (KLS-5432-08-2021). The epidemiology of cancer in adolescents and young adults (AYA) in Switzerland (CHF 337,400. PI Ben Spycher; 01/2022–12/2024).

**Multidisciplinary Center for Infectious Diseases.** menobalance App: Use of [artificial intelligence] methods to design a personalized chronic and infectious disease management medical device (CHF 956,890. Coapplicant Ben Spycher; 01/2022–12/2024).

**European Commission Horizon 2020** (900009). RadoNorm. (CHF 271,700. Subtask leader Ben Spycher; 9/2020–8/2025).

**Federal Office for the Environment** (FOEN, 19.0094.PJ / 63372F472). Erarbeitung der Methodik für das Monitoring von Tumoren im Rahmen des NIS-Gesundheitsmonitorings [Development of the methodology for monitoring tumors as part of the NIR health monitoring]. (CHF 129,900. PI Ben Spycher; 7/2022–12/2023)

### Internal and external collaborations

At the Institute of Social and Preventive Medicine, we collaborate with the Swiss National Cohort, Swiss Childhood Cancer Registry, the Child and Adolescent Health research group, and SwissRDL—Medical Registries and Data Linkage. Within Switzerland, we collaborate with the University Hospital Bern Inselspital (Philipp Latzin, Petra Stute); Unisanté, University of Lausanne (David Vernez, Jean-Luc Bulliard); University of Lucerne (Katharina Roser, Céline Bolliger); Swiss TPH Basel (Martin Rööfli); and the Swiss Pediatric Oncology Group.

Internationally, we collaborate with University of Tampere, Finland (Anssi Auvinen, Jad Abuhamed, Wafa Alimam); French National Institute of Health and Medical Research (INSERM), France (Stephanie Goujon); Danish Cancer Society Research Center, Denmark (Ole Raaschou-Nielsen); Norwegian University of Life Sciences, Norway (Geir Aamodt); UCLA Fielding School of Public Health, USA (Leeka Kheifets).

### Key team members

Christian Kreis (postdoc), Eleftheria Michalopoulou (statistician), Ben Spycher (head of research group), Patric Wyss (scientific collaborator).

### Selected publications

**Mallet MC, Pedersen ESL, Makhoul R,** Blanchon S, Hoyle K, Jochmann A, Latzin P, Moeller A, Regamey N, **Goutaki M, Spycher BD, Kuehni CE;** SPAC Study Team. **Phenotypes of cough in children: A latent class analysis.** Clin Exp Allergy 2023 Nov. doi: 10.1111/cea.14416. Online ahead of print.

**Belle FN, Schindera C,** Ansari M, Armstrong GT, Beck-Popovic M, Howell R, Leisenring WM, Meacham LR, Rössler J, **Spycher BD,** Tonorezos E, von der Weid NX, Yasui Y, Oeffinger KC, **Kuehni CE.** **Risk factors for overweight and obesity after childhood acute lymphoblastic leukemia in North America and Switzerland: A comparison of two cohort studies.** Cancer Med 2022;12:20423-20436. doi: 10.1002/cam4.6588.

Frauchiger BS, Ramsey KA, Usemann J, Kieninger E, Casaulta C, Sirtes D, Yammine S, **Spycher BD,** Moeller A, Latzin P. **Variability of clinically measured lung clearance index in children with cystic fibrosis.** Pediatr Pulmonol 2023;58:197-205. doi: 10.1002/ppul.26180.



**Wyss P**, Ginsbourger D, Shou H, Davatzikos C, Klöppel S, Abdulkadir A. **Adaptive data-driven selection of sequences of biological and cognitive markers in pre-clinical diagnosis of dementia**. Scientific reports 2023; 13(1); 6406. doi: 10.1038/s41598-023-32867-z



## Evidence Synthesis Methods

*The Evidence Synthesis Methods research group develops, applies, and disseminates methodology for synthesizing study evidence to answer important public health questions. We also work with prediction models to inform decision-making and support health technology assessments and guidelines.*

Link  
GALENOS

### Key scientific activities

We work on GALENOS—the Global Alliance for Living Evidence on aNxiety, depression and pSychosis—a project funded by the Wellcome Trust (UK) that allows us to create and maintain a new living evidence resource for prioritizing early phase research in mental health. Within this project, we work on the synthesis of evidence from early phase studies in humans and the synthesis of results from animal studies. We plan a meeting in early 2024 to triangulate the evidence from animal and human studies and evaluate the role of TAAR1 agonists in alleviating the symptoms of psychosis. We also work in GALENOS on methodological developments that include advanced multivariate, multilevel models for animal studies, statistical models for the synthesis of data and a framework to evaluate the risk of bias in mediation studies, and methods to evaluate the applicability of findings from animal studies to humans.

We also continue developing methods for health technology assessment. In particular, we develop methods for combining prognosis research and evidence synthesis methods using machine learning or statistical methodology, and present various applications of our models to make predictions about treatment effects in psychiatry, neurology, cardiology, and rheumatology. We are also working on a personalised perspective for cost-effectiveness analysis.

### Key academic activities

**Students:** Bohua Chen completed her MSc thesis in applied statistics in the Faculty of Mathematics; she was cosupervised by our team. Currently, Wanda Rölofs is working on her masters thesis, “Evaluating guidelines for the pharmacological treatment of depression: are they evidence based?” in the Faculty of Medicine.

**Teaching:** Members of the group teach postgraduate courses at the University of Bern in the CAS in clinical research in health care organisations, the Public Health Sciences PhD Program, and in the Master of Public Health Program. We also contribute to teaching in the Master of Biomedical Sciences Program and the Swiss Epidemiology Winter School.

We also organize and participate in national and international short courses in, e.g., the masters program in biostatistics at the University of Zurich and the annual course on network meta-analysis at the University of Oxford.

### Grants

NRP 78 project funding from the Swiss National Science Foundation successfully concluded for the project “[What works best? Methods for ranking competing treatments in network meta-analysis.](#)”

Funding from the European Commission continues for our Horizon 2020 [HTx project](#), and from the UK’s Wellcome Trust for the [GALENOS project](#).

Virginia Chiocchia received a mobility grant from the University of Bern to go to the University of Oxford for two months in 2024.

### Internal and external collaborations

Within the Institute of Social and Preventive Medicine, we collaborate with the Sexual and Reproductive Health, Mental Health, and the HIV, Coinfections and Comorbidities research groups. We have numerous collaborators around the globe from many universities including the University of Oxford, University College London, and University of York, UK; University of Kyoto, Japan; University of Freiburg, Germany; and many more.

### Key team members

Virginia Chiocchia (postdoctoral researcher), Orestis Efthimiou (PD, senior researcher), Matthias Egger (head of HIV, Coinfections and Comorbidities research group), Chiara Gastaldon (senior researcher), Robin Guelimi (visiting fellow), Georgia Salanti (head of research group), Thomy Tonia (senior researcher).

### Selected publications

**Tonia T, Buitrago-Garcia D, Peter NL, ... Salanti G.** [Tool to assess risk of bias in studies estimating the prevalence of mental health disorders \(RoB-PrevMH\).](#) *BMJ Ment Health.* 2023 Oct;26(1):e300694. doi: 10.1136/bmjment-2023-300694. PMID: 37899074; PMCID: PMC10619100.

**Chalkou K, Vickers AJ, Pellegrini F, Manca A, Salanti G.** [Decision Curve Analysis for Personalized Treatment Choice between Multiple Options.](#) *Med Decis Making.* 2023 Apr;43(3):337-349. doi: 10.1177/0272989X221143058. Epub 2022 Dec 13. PMID: 36511470; PMCID: PMC10021120.

**Hamza T, Chalkou K, Pellegrini F ... Salanti G.** [Synthesizing cross-design evidence and cross-format data using network meta-regression.](#) *Res Synth Methods.* 2023 Mar;14(2):283-300. doi: 10.1002/jrsm.1619. Epub 2023 Feb 22. PMID: 36625736.

Fischer U, Koga M, Strbian D ... **Salanti G** ....[Early versus Later Anticoagulation for Stroke with Atrial Fibrillation.](#) *ELAN Investigators. N Engl J Med.* 2023 Jun 29;388(26):2411-2421. doi: 10.1056/NEJMoa2303048. Epub 2023 May 24.

**Chiocchia V, Holloway A, Salanti G.** [Semi-automated assessment of the risk of bias due to missing evidence in network meta-analysis: a guidance paper for the ROB-MEN web-application.](#) *BMC Med Res Methodol.* 2023 Oct 7;23(1):223. doi: 10.1186/s12874-023-02038-9. PMID: 37805460; PMCID: PMC10559514.

**Efthimiou O, Hoogland J, Debray TPA ... Egger M**.... [Measuring the performance of prediction models to personalize treatment choice.](#) *Stat Med.* 2023 Apr 15;42(8):1188-1206. doi: 10.1002/sim.9665. Epub 2023 Jan 26. PMID: 36700492.

Links Teaching:

CAS in clinical research in health care organisations

Public Health Sciences PhD Program

Master of Public Health Program

Master of Biomedical Sciences

Swiss Epidemiology Winter School

Masters program in biostatistics at the University of Zurich

Network meta-analysis at the University of Oxford

# HIV, Coinfections and Comorbidities

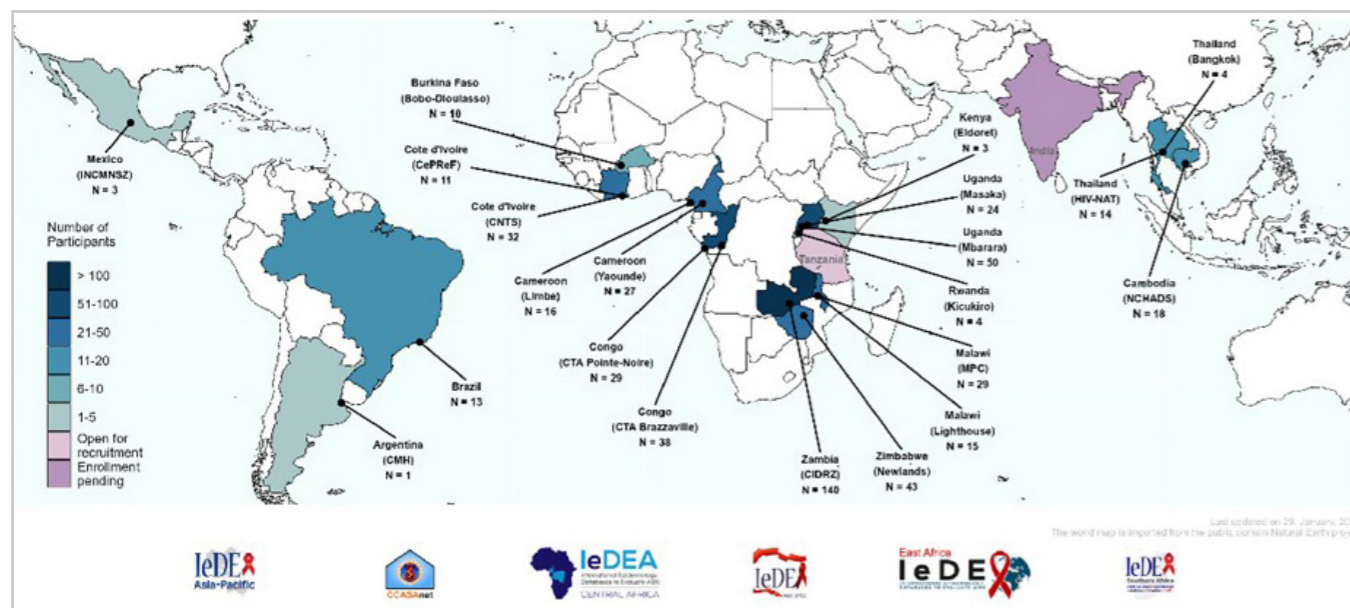
Our research group examines the clinical and public health epidemiology of HIV and coinfections and comorbidities, focusing on Southern Africa and other countries in the global South, and of COVID-19, focusing on Switzerland. We conduct fieldwork, analyze large databases, develop mathematical models, and work on methodological issues.

### Key scientific activities

Highlights in 2023 included the first publication and recruiting of the first 500 people living with HIV globally into the DTG RESIST study. DTG RESIST investigates dolutegravir resistance in people living with HIV who are experiencing virologic failure on dolutegravir-based ART within the International epidemiology Databases to Evaluate AIDS (IeDEA). It is the only large international study to prospectively examine emergent resistance to the integrase strand transfer inhibitor (INSTI) dolutegravir in diverse settings characterized by different HIV-1 subtypes, provision of ART, and guidelines on resistance testing. DTG RESIST is a collaboration between ISPM Bern and colleagues at the Universities of Zurich, Bristol, and KwaZulu-Natal.

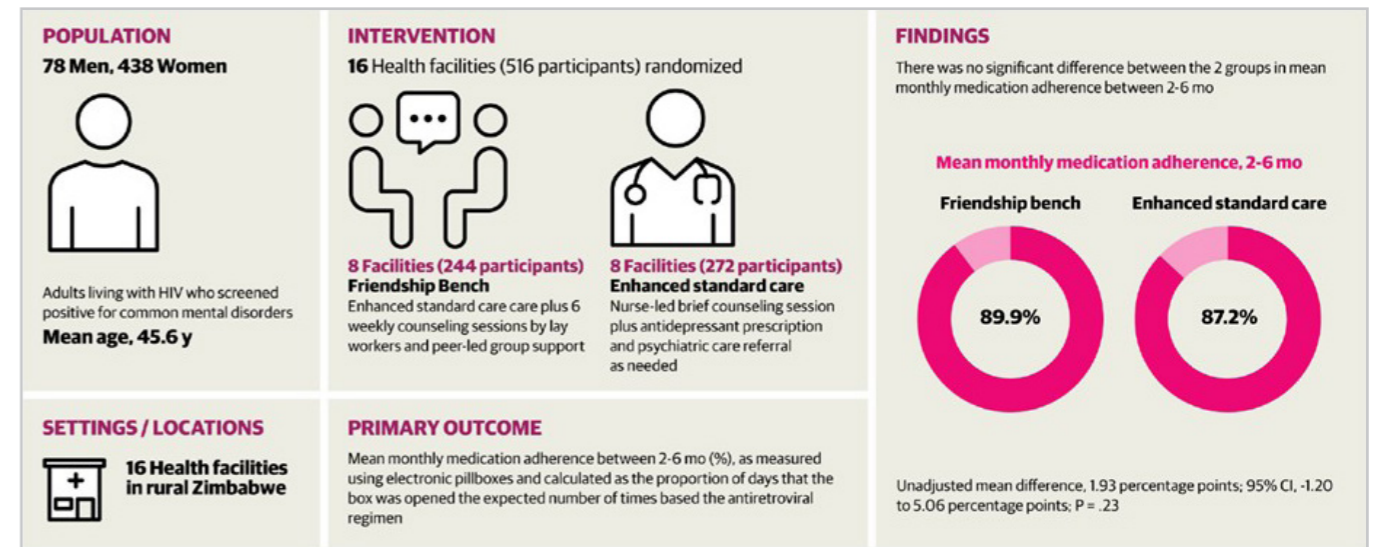
DTG RESIST has two parts: the first is a collaborative analysis of existing data from HIV cohort studies that has recently been published. In this analysis of eight large cohort Studies from Europe, Canada, and South Africa, we identified INSTI drug resistance mutations (DRMs) in 86 (14%) of 599 people living with HIV with a genotypic resistance test while viremic on dolutegravir-based ART. Resistance to nucleoside reverse transcriptase inhibitor substantially increased the risk of dolutegravir resistance, which is of concern, notably in resource-limited settings. Exposure to first-generation INSTI drugs was associated both with more resistance mutations and higher levels of dolutegravir resistance, but the association with dolutegravir resistance was not statistically significant. A wide range of INSTI DRMs was present.

The prospective part of the study is ongoing, aiming to recruit 1500 participants by mid-2025. The map below shows progress as of the end of 2023.



DTG RESIST: map of participating countries and recruitment of eligible people living with HIV as of end of 2023. The logos below the graph represent the six regions of the IeDEA participating in the study.

Other highlights included the publication of a cluster randomized trial examining the effect of the Friendship Bench intervention on antiretroviral therapy outcomes and mental health symptoms in rural Zimbabwe. Common mental disorders, including depression and anxiety, are prevalent among people living with HIV and are associated with suboptimal adherence to antiretroviral therapy and less favorable outcomes. The Friendship Bench is a community-based mental health intervention designed to address common mental disorders such as anxiety and depression, particularly in low- and middle-income countries. It was initially developed in Harare, Zimbabwe, by psychiatrist Dixon Chibanda and has since been adopted in other regions. The intervention's core is the use of trained community health workers, often laypersons known as "grandmothers," who deliver problem-solving therapy to individuals in the community. These sessions typically occur on wooden benches in discreet areas of clinics or under trees, which is how the intervention got its name. The infographic below (from JAMA Network Open) summarizes the study population, intervention and findings. The Friendship Bench intervention did not affect adherence and viral suppression, possibly due to the absence of skill-based adherence training and a ceiling effect.



Together with the School of Public Health, University of Cape Town, South Africa our group serves as the data center for the Southern African region of the International epidemiology Databases to Evaluate AIDS (see [www.iedea.org](http://www.iedea.org)). This global health consortium collects data on over 2.2 million people living with and at risk for HIV in 44 countries. In 2023 our group contributed to over 20 articles from the Southern African region of IeDEA.

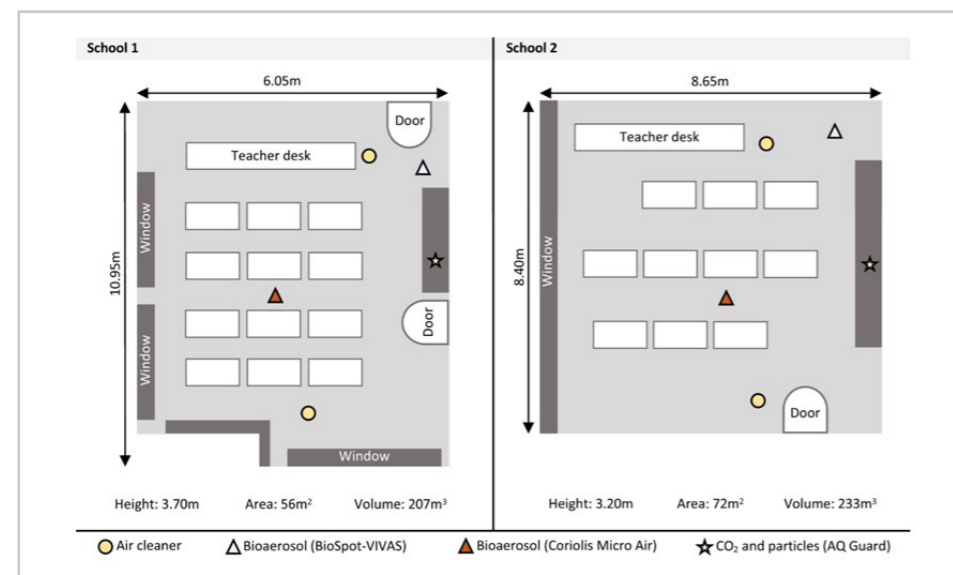
In a bibliographic study, we analyzed authorship in the IeDEA Southern Africa publication output. Studies have shown that women and authors from low-income and middle-income countries are under-represented in the first and last authorship positions compared with their colleagues from high-income countries. Authorship parasitism, defined as articles without authors from the countries where the study was conducted, is common in some countries. In contrast to previous studies, in IeDEA Southern Africa women were more likely to be first authors than men. However, the proportion of female authors declined when moving from first to last

author. Authors from high-income countries, including from ISPM Bern, tended to occupy the first and last positions. All publications originating in the Southern African region of leDEA included authors from participating countries. In other words, there was no evidence of authorship parasitism. This analysis led to a vivid debate within leDEA on how to make authorship more equitable. Indeed, global health research collaborations should include a process of review and reflection on equity in roles, responsibilities, and authorship.

A prospective study in Lusaka, Zambia, compared adults with chronic hepatitis B virus (HBV) infection, with and without HIV, to gain a better understanding of HIV's impact on the natural history of HBV in high-burden countries. The team measured HBV DNA levels, hepatitis B e antigen (HBeAg), and liver disease via transient elastography and serum alanine aminotransferase (ALT). In multivariable analyses, we evaluated the association of HIV overall and by level of CD4+ count on these markers. Among 713 adults analyzed, HIV coinfection was associated with five-fold increased HBV DNA levels and two times the odds of HBeAg-positivity. HIV was not associated with markers of fibrosis or ALT. The study showed that HIV's impact on HBV natural history likely depended on the degree and duration of immune suppression and supports the notion that HBV DNA should be monitored in people with HBV/HIV coinfection and immune suppression.

An experimental study triangulating epidemiological, environmental, and molecular data examined SARS-CoV-2 transmission with and without mask-wearing or air cleaners in schools in Switzerland. The team collected epidemiological (cases of Coronavirus Disease 2019), environmental (CO<sub>2</sub>, aerosol, and particle concentrations), and molecular data (bioaerosol and saliva samples) during the March 2022 Omicron wave in two secondary schools. Molecular analysis of students' saliva and airborne samples detected SARS-CoV-2 throughout the study, whereas other respiratory viruses were detected only occasionally. Compared to no intervention, the transmission risk was substantially lower with mask mandates but comparable with air cleaners. The transmission model estimated that wearing masks could have prevented between 2 and 19 infections during the study period. The original multiple-measurement approach of this study could be used to continuously monitor the transmission risk of respiratory infections and examine the effectiveness of infection control measures in other congregate settings.

The figure below shows the setup of the study in the two classrooms.



Schematic study setup of classrooms where environmental data was collected in each school. One air cleaner was placed in the front and the other in the back of the classrooms. All devices were placed at the head level of students when they were seated.

**Key academic activities**

**Students:** Belinda Chihota defended her PhD thesis.

**Teaching:** We contributed to topics including problem-based learning, critical appraisal of studies, biostatistics for medical students, epidemiology book club, database and central data monitoring, introduction to R, systematic reviews and meta-analysis, prognostic research/basics to modelling, and clinical epidemiology in undergraduate and postgraduate teaching, as well as to courses for PhD and MPH students.

**Conferences and events:** In October 2023, Eliane Rohner held her inaugural lecture with PD Dr. med. Monika Müller, PhD, from the University Hospital of Psychiatry and Psychotherapy.

**Scientific Talks and Presentations:**

• **Conference on Retroviruses and Opportunistic Infections, February 2023**  
Regional (leDEA Southern Africa):  
**Long-term hepatitis B outcomes in Zambia with tenofovir-treated HBV/HIV coinfection** (poster). Vinikoor M, Hamusonde K, Muula G, Asombang M, Bhattacharya D, Sinkala E, Lauer G, Chung R, Mbewe W, Egger M, Bosomprah S, Wandeler G.

**Virologic failure after routine switching to DTG-Based first-Line ART** (poster). Whitesell Skrivankova V, Huwa J, Chiwaya GD, Buleya S, Chintedza J, Kalua T, Muula G, Banda E, Chihota B, Bolton-Moore C, Hossman S, Kouyos R, Lessells R, Wandeler G, Egger M.

Multiregional (leDEA Global):  
**Transition to dolutegravir-based ART in low- and middle-income countries in leDEA** (poster). Elizabeth Zaniewski et al.

• **International Workshop on HIV and Hepatitis Observational Databases, March 2023**  
**Hypertension among people living with HIV after starting or switching to DTG, EFV, or ATV/r-based ART at Newlands clinic, Zimbabwe** (oral). Shamu T, Egger M, Mudzviti T, Chimbetete C, Manasa J, Anderegg N.

**Estimating HIV infection dates and cancer incidence rates in the South African Cancer Match study, a simulation approach** (poster). Ruffieux Y, Muchengeti M, Bohlius J, Dhokotera T, Olago V, Metekoua C, Egger M, Rohner E.

**eGFR change after transitioning to dolutegravir-based antiretroviral therapy among people living with HIV at Newlands Clinic, Zimbabwe: a longitudinal study** (poster). Shamu T, Egger M, Mudzviti T, Manasa J, Chimbetete C, Anderegg N.

**Prevalence and predictors of multimorbidity among adults with and without HIV infection in urban Zambia and Zimbabwe** (poster). Muula G, Mandiriri A, Varaidzo Chihota B, Mumba A, Bosomprah S, Bolton-Moore C, Egger M, Davies Mary-Ann, Chimbetete C, Wandeler G, Riebenschahm C.

• **International Aids Society, July 2023**  
**Depressive symptoms and metabolic syndrome among people living with and without HIV in urban Zambia and Zimbabwe.** Mandiri, A, Chichota B, Muula G, Nyamutowa H, Bosomprah S, Bolton-Moore C, Haas A, Egger M, Wandeler G, Chimbetete C.

- **International Papillomavirus Society Conference, April 2023**

**Frequent discordance between HPV detection in cytological and histopathological samples among women living with HIV in Zambia** (oral). Taghavi K, Moono M, Glass A, Basu P, Mwanahamuntu MH, Manasyan A, Low N, Rohner E.

**Assessing cervical cancer incidence in 517,574 women living with and without HIV in South Africa** (poster). Ruffieux Y, Haas A, Boshomane TMG, Taghavi K, Egger M, Folb N, Maartens G, Rohner E.

- **African Organization for Research and Training in Cancer Conference, November 2023**

**Incident prostate cancer among privately insured men with and without HIV in South Africa** (oral). Ruffieux Y, Fernandez Villalobos N, Chinogurei C, Maartens G, Folb N, Rohner E.

**Declining incidence of Burkitt lymphoma with improved antiretroviral treatment access in South Africa (1986-2021)** (poster). Metekoua C, Rohner E, Ruffieux Y, Bohlius J, Muchengeti M, Wiggill T.

- **The Union World Conference on Lung Health, November 2023**

**Cardiac involvement in tuberculosis patients at the start of treatment: echocardiography results from two ongoing tuberculosis cohorts in South Africa and Zambia** (oral). Muula G, Samim D, Chibomba D, Bolton-Moore C, Banholzer N, De Marchi S, Günther G, Egger M, Pilgrim T, Fenner L.

**Honors and Awards:** Eliane Rohner received the Research Prize 2023 of the Hemmi Foundation (CHF 25,000).

### Grants

**National Institute of Allergy and Infectious Diseases** (U01AI069924): International epidemiology Databases to Evaluate AIDS—Southern Africa (USD 16 million. PI Matthias Egger; 2021–2026).

**National Institute of Allergy and Infectious Diseases** (R01AI152772): HIV-1 subtype, specific drug resistance in patients failing Dolutegravir-based 1st, 2nd or 3rd line regimens: the International epidemiological Databases to Evaluate AIDS (USD 2.4 million. PI Matthias Egger; 2021–2024).

**Multidisciplinary Center for Infectious Diseases:** Preparedness for surveillance in school rooms in pandemic and epidemic situations: multiple measure approach to estimate transmission and interventions for COVID-19 and seasonal influenza (PI Lukas Fenner).

**Multidisciplinary Center for Infectious Diseases:** Core activity BReady cohort (PIs Gilles Wandeler, Nicola Low).

**Multidisciplinary Center for Infectious Diseases:** Early detection for early action: integrating multiple data sources for monitoring the SARS-CoV-2 epidemic in near real-time (Coapplicant Julien Riou).

### Internal and external collaborations

We work with colleagues in Switzerland at the University of Zürich, ETH Zürich, the Swiss Tropical and Public Health Institute, the Department of Clinical Research at the University of Basel, and the Clinical Trials Unit of the University in Bern.

Within the Institute of Social and Preventive Medicine, we collaborate with the Cancer, Mental Health, Sexual and Reproductive Health, Interfaculty Platform for Data and Computational Science, and Evidence Synthesis Methods research groups.

Internationally, we collaborate with the Joint United Nations Program on HIV/AIDS and the World Health Organization; the Centre for Infectious Disease Epidemiology and Research at the University of Cape Town and the Kwazulu-Natal Research Innovation and Sequencing Platform, South Africa; and many other collaborators within IeDEA. Academic collaborations also exist with the London School of Hygiene and Tropical Medicine and the University of Bristol, UK.

### Key team members

John Andoh (PhD student), Marie Ballif (postdoc), Nicolas Banholzer (postdoc), Belinda Chihota (PhD student), Cam Ha Dao Ostinelli (clinical data manager), Christiane Didden (research associate), Orestis Efthimiou (research fellow), Matthias Egger (head of research group), Lukas Fenner (senior research scientist), Nathalie Fernandez (research fellow), Chiara Gastaldon (postdoc), Pauline Göller (MD student), Andreas Haas (head of Mental Health research group), Fabrice Helfenstein (research fellow), Leonie Heron (research fellow), Ardele Mandiri (PhD student), Santiago Martinez (student aid), Sophie Oblette (administrative project coordinator), Ipek Çelikağ Özer (administrative project coordinator), Selma Riedo (scientific collaborator), Eliane Rohner (head of Cancer research group), Yann Ruffieux (research associate), Mamatha Sauermann (project manager), Allison Scarlotta (program management assistant), Tiana Schwab (PhD student), Konstantinos Seintaridis (student aid), Lilian Smith-Wirth (project coordinator), Katayoun Taghavi (postdoc), Per von Groote (program manager), Gilles Wandeler (adjunct researcher), Veronika Whitesell Skrivankova (research fellow), Elizabeth Zaniewski (research fellow), Marcel Zwahlen (Director a.i.).

### Selected publications

Loosli T, **Hossmann S**, Ingle SM ... **Egger M** .... **HIV-1 drug resistance in people on dolutegravir-based antiretroviral therapy: a collaborative cohort analysis**. *The Lancet HIV*. 2023;10:e733–41.

**Haas AD**, Kunzekwenyika C, Manzero J ... **Egger M**. **Effect of the Friendship Bench Intervention on Antiretroviral Therapy Outcomes and Mental Health Symptoms in Rural Zimbabwe: A Cluster Randomized Trial**. *JAMA Network Open*. 2023;6:e2323205.

**Skrivankova VW**, **Hossmann S**, Cornell M ... **Egger M**. **Authorship inequalities in global health research: the IeDEA Southern Africa collaboration**. *BMJ Glob Health*. 2023;8:e013316.

Muula GK, Bosomprah S, Sinkala E ... **Wandeler G** .... **Hepatitis B viral replication markers and hepatic fibrosis in untreated chronic hepatitis B virus infection with and without HIV coinfection in Zambia**. *AIDS*. 2023;37:2015–20.

**Banholzer N**, **Zürcher K**, Jent P ... **Fenner L**. **SARS-CoV-2 transmission with and without mask wearing or air cleaners in schools in Switzerland: A modeling study of epidemiological, environmental, and molecular data**. *PLoS Med*. 2023;20:e1004226.

## INPUT—Interfaculty Platform for Data and Computational Science

*The Interfaculty Platform for Data and Computational Science is a collaboration between the Institute of Social and Preventive Medicine and the Center for Space and Habitability (CSH) that fosters interdisciplinary research at the intersection of statistics, and data and computational science. We apply statistical and machine learning to large data sets and use high-performance computing to make simulation-based inferences in epidemiology, medicine, and the natural sciences. A major focus of this research is infectious disease modeling and outbreak analysis.*

### Key scientific activities

In 2023 we completed our study on the importation of viral variants of concern (VoCs) during the SARS-CoV-2 epidemic in Switzerland. Using a novel phylogenetic approach, we estimated there were between 383–1,038 imports of Alpha and 455–1,347 imports of Delta into Switzerland. We then modeled different counterfactual intervention scenarios and found that implementing border closures after the announcement of VoCs would have had limited impact on mitigating the spread of VoCs. In contrast, increased surveillance of travelers could be effective in delaying the spread of VoCs in situations in which their severity is unclear.

Our Multidisciplinary Center for Infectious Diseases (MCID) project saw its first scientific output with a newly developed dynamic transmission model of SARS-CoV-2 in Switzerland that leverages both the daily number of laboratory-confirmed cases and seroprevalence data to uncover the true epidemic curve. When we applied this model to laboratory-confirmed SARS-CoV-2 cases and two seroprevalence studies from the canton of Geneva in 2020, we were able to obtain detailed estimates of how the transmission rate and the ascertainment of cases changed over the year. These results will improve assessment of the impact of nonpharmaceutical interventions, behavioral changes, and seasonal effects on the SARS-CoV-2 epidemic in Switzerland.

To improve future pandemic preparedness in Switzerland, it will be important to integrate newly developed tools into the existing surveillance systems and decision-making processes. To this end, we organized the Swiss Meeting for Infectious Disease Dynamics (SMIDDY), which focused on infectious disease modeling and its role in policymaking. Representatives of several research institutes from Switzerland and abroad and the Federal Office of Public Health discussed the current challenges and opportunities to improve surveillance systems for infectious diseases.

### Key academic activities

**Students:** From January to November, Martina L. Reichmuth conducted research at Stellenbosch University in South Africa supported by a UniBE Doc.Mobility grant.

**Teaching:** Lectures on infectious disease epidemiology and modeling at bachelors and masters degree levels at the University of Bern; courses on core methods (basic statistics and projects in R, introduction to epidemiology and study design, diagnostic test evaluation) in the newly developed Public Health Sciences Course Program.

**Conferences and Events:** Emma B. Hodcroft was on the organizing committee of the 30th International Dynamics & Evolution of Human Viruses conference in Heidelberg.

**Scientific Talks and Presentations:** Oral and poster presentations at Epidemics, the 9th International Conference on Infectious Disease Dynamics, in Bologna; the 30th International Dynamics & Evolution of Human Viruses conference in Heidelberg; the SNSF Corona Research Conference in Thun; the Bern Data Science Day; the Bits to Breakthroughs Symposium in Bern.

**Outreach and Representation:** Swiss Meeting on Infectious Disease Dynamics on “Modelling infectious diseases during the pandemic: advances in methods and its role for policy making.”

### Grants

**Multidisciplinary Center for Infectious Diseases:** Early detection for early action: integrating multiple data sources for monitoring the SARS-CoV-2 epidemic in near real-time. (CHF 492,063 [of total 949,088] awarded to ISPM. PI Christian L. Althaus, Co-PI Julien Riou; 03/2023–2/2026).

**Horizon Europe and State Secretariat for Education, Research and Innovation (101095619):** ESCAPE—Efficient and rapidly SCALable EU-wide evidence-driven Pandemic response plans through dynamic Epidemic data assimilation. (CHF 400,257 [of total EUR 3,187,746] awarded to ISPM. Co-PI Christian L. Althaus, Emma B. Hodcroft, Nicola Low; 01/2023–12/2026).

**Federal Office of Public Health and Federal Food Safety and Veterinary Office:** Impacts of climate change on health, well-being and performance of humans and animals and on food safety in Switzerland. (CHF 754,000. PI Ana M. Vicedo-Cabrera, Co-PI Christian L. Althaus, Julien Riou; 01/2023–2/2025).

**UniBE:** Doc.Mobility, Analyzing transmission characteristics of SARS-CoV-2 variants using genomic surveillance data from different regions and communities in South Africa and Switzerland. (CHF 55,936. PI Martina L. Reichmuth; 01/2023–12/2023).

**Swiss National Science Foundation (196046):** Tracking the COVID-19 epidemic in Switzerland: phylogenetics and epidemiological modeling. (CHF 295,487. PI Christian L. Althaus; 06/2020–10/2023).

**Horizon 2020 (101003688):** EpiPose—Epidemic intelligence to minimize 2019-nCoV’s public health, economic and social impact in Europe. (EUR 513,304 [of total 4,548,391] awarded to ISPM. Co-PI Christian L. Althaus, Nicola Low; 03/2020–04/2023).

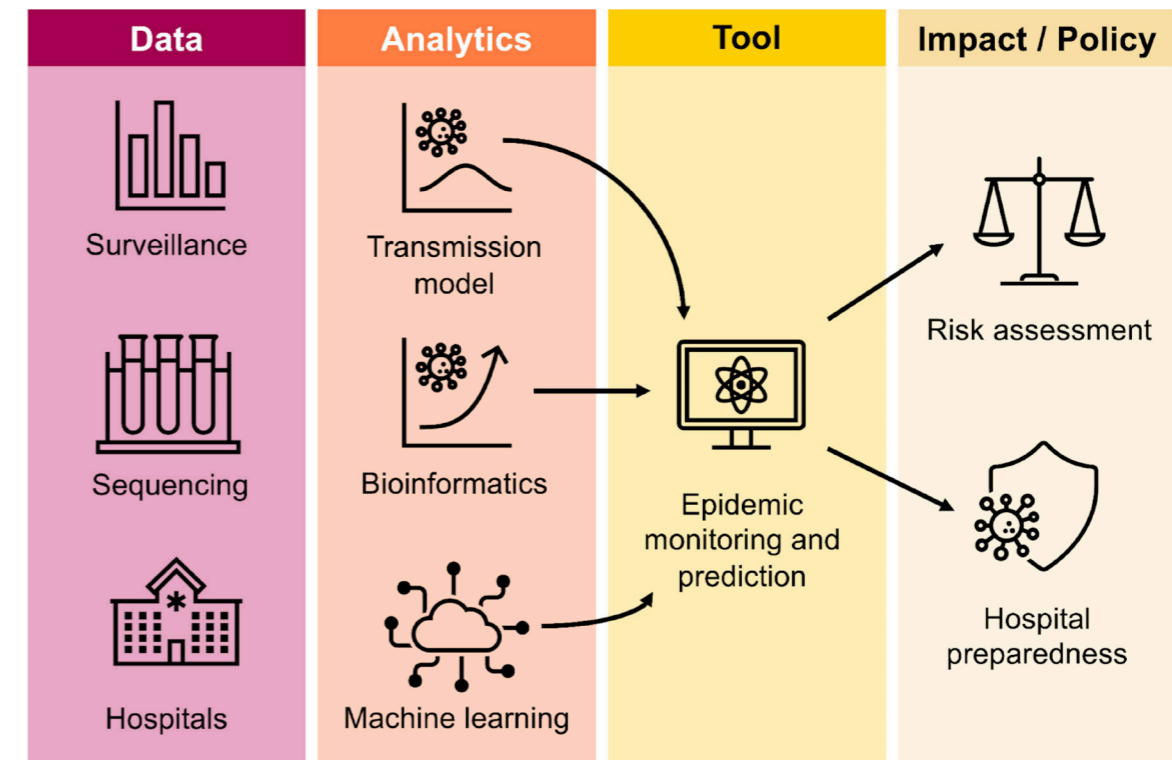
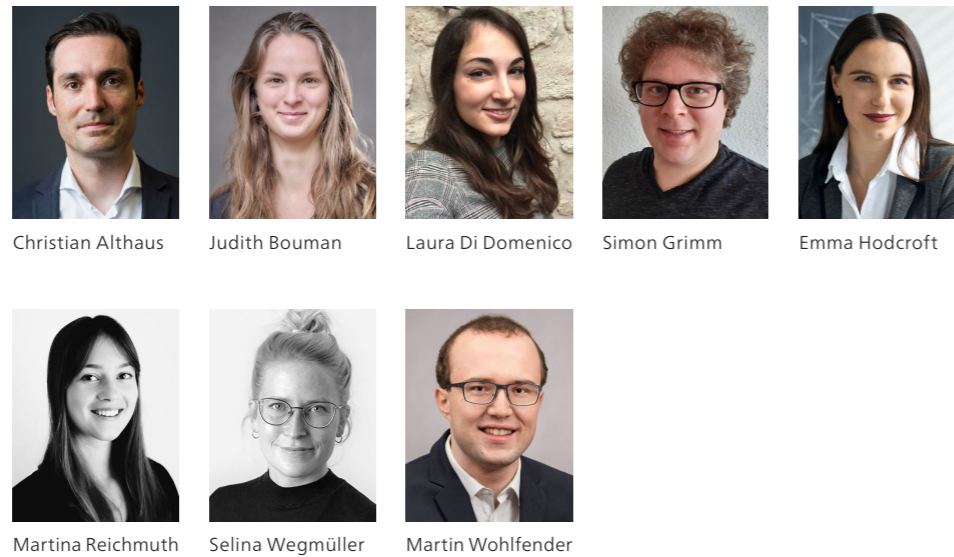
### Internal and external collaborations

INPUT continues as a collaboration between ISPM and CSH focusing on developing and applying computational methods in epidemiology, medicine, and the natural sciences. Within MCID we collaborate with the Bern University Hospital (G. Beldi, A. Leichtle), the Institute for Infectious Diseases (A. Ramette), and the KPM Center for Public Management (C. Schlaifer). At ISPM we collaborate with members of the research groups Climate Change and Health; HIV, Coinfections and Comorbidities; and Sexual and Reproductive Health.

Internationally, we worked intensively with Nextstrain and our European partners from the EpiPose and ESCAPE projects on SARS-CoV-2-related research.

**Key team members**

Christian L. Althaus (head of research group), Judith A. Bouman (postdoc), Laura Di Domenico (postdoc, arrived in 2023), Simon L. Grimm (research fellow, left in 2023), Emma B. Hodcroft (postdoc, left in 2023), Martina L. Reichmuth (PhD student), Selina Wegmüller (project manager), Martin Wohlfender (PhD student).



Development and impact of a tool to track the spread of SARS-CoV-2 and potentially other respiratory infections in Switzerland.

**Selected publications**

**Reichmuth ML, Hodcroft EB, Althaus CL.** Importation of Alpha and Delta variants during the SARS-CoV-2 epidemic in Switzerland: Phylogenetic analysis and intervention scenarios. *PLoS Pathog.* 2023;19(8):e1011553.

**Reichmuth ML, Heron L, Riou J, Moser A, Hauser A, Low N, Althaus CL.** Socio-demographic characteristics associated with COVID-19 vaccination uptake in Switzerland: longitudinal analysis of the CoMix study. *BMC Public Health.* 2023;23(1):1523.

Wong KLM, Gimma A, Coletti P, **CoMix Europe Working Group**, Faes C, Beutels P, Hens N, Jaeger VK, Karch A, Johnson H, Edmunds W, Jarvis CI. **Social contact patterns during the COVID-19 pandemic in 21 European countries—evidence from a two-year study.** *BMC Infect Dis.* 2023;23(1):268.

Jit M, Ainslie K, **Althaus C**, Caetano C, Colizza V, Paolotti D, Beutels P, Willem L, Edmunds J, Nunes B, Namorado S, Faes C, **Low N**, Wallinga J, Hens N. **Reflections On Epidemiological Modeling To Inform Policy During The COVID-19 Pandemic In Western Europe, 2020-23.** *Health Aff (Millwood).* 2023;42(12):1630-1636.

Kadelka S, **Bouman JA**, Ashcroft P, Regoes RR. **Correcting for Antibody Waning in Cumulative Incidence Estimation from Sequential Serosurveys.** *Am J Epidemiol.* 2023:kwad226.

Viana R, Moyo S, Amoako, DG ... **Althaus CL** .... **Rapid epidemic expansion of the SARS-CoV-2 Omicron variant in southern Africa.** *Nature.* 2022;603(7902):679–86.

## Mental Health

*The Mental Health research group studies the epidemiology of mental illness, the interplay between mental and physical health, the impact of mental health complications on treating physical comorbidities, and the provision of mental health services.*

### Key scientific activities

International multicohort study on mortality and mental health in people living with HIV: We conducted international multicohort studies in North America and South Africa comparing excess mortality associated with mental health and substance use disorders among people living with HIV. Our work documents substantial excess mortality among people living with HIV and mental health complications in North America and South Africa.

Causal pathways to excess mortality among people with mental health complications: A major focus of our research has been exploring the causal pathways that lead to excess mortality, including increased suicide rates, in people with mental health complications. We have identified key factors that include a higher incidence of physical illness like major cardiovascular events and suboptimal adherence to chronic medication regimes among individuals with mental health disorders. These findings underscore the need for comprehensive care strategies that address both mental and physical health needs.

Formative research on intervention strategies: Our team conducted formative research on potential interventions that can be implemented in low- and middle-income countries to reduce excess mortality among people with mental health complications. We have evaluated approaches for identifying individuals at high risk of suicide to be prioritized for targeted suicide prevention interventions.

Innovative approaches to medication adherence: Aiming to address the challenge of suboptimal medication adherence of people with mental health complications, we conducted quasi-experimental studies to explore the effectiveness of innovative medication delivery methods. These include courier delivery services and longer durations for prescription refills.

Prospective cohort study on mental disorders and mental health care in South Africa: Our team is undertaking a prospective cohort study across three public sector clinics in South Africa. The focus of this study is to ascertain the prevalence of mental disorders, identify existing gaps and barriers in mental health care, and validate mental health screening tools. Our ultimate goal is to improve the provision of mental health care in South Africa's public primary care sector.

Investigation into postpartum depression: We conducted a large cohort study to investigate the incidence of postpartum depression and its risk factors in South Africa's private health care sector. This study aims to improve the management of postpartum depression in South Africa's private health care sector.

### Key academic activities

**Students:** Cristina Mesa Vieira successfully defended her PhD thesis, "Psychosocial risk factors of mental disorders and cardiovascular disease," in the Graduate School for Health Sciences, University of Bern. Christiane Didden is currently in her final year at LMU Munich working on her thesis, "Methods of causal inference for investigating social and epidemiological questions with observational data." Mpho Tlali, at the

University of Cape Town, is in the second year of her PhD program focusing on treatment of mental health and substance use disorders in South Africa's public and private sector health care systems.

**Teaching:** Our group contributed to tutoring medical students at the University of Bern and lectured on the epidemiology of suicide.

**Scientific Talks and Presentations:** Our group presented abstracts at the Conference on Retroviruses and Opportunistic Infections in Seattle and the International Workshop on HIV and Hepatitis Observational Databases in Athens.

**Honors and Awards:** Andreas Haas has been awarded his habilitation in epidemiology from the Faculty of Medicine at the University of Bern. He has also been appointed as an Honorary Research Associate at the Centre for Infectious Disease Epidemiology and Research at the University of Cape Town.

### Grants

**National Institute of Allergy and Infectious Diseases** (U01AI069924): International epidemiology Databases to Evaluate AIDS—Southern Africa (USD 16 million. PI Mattias Egger; 2021–2026).

**Swiss National Science Foundation** (193381): Pathways from mental disorders to the burden of disease: Causal mediation analysis of big data from South Africa (CHF 924,952. PI Andreas Haas; 2021–2025).

### Internal and external collaborations

Within the Institute of Social and Preventive Medicine, we collaborate with the research groups HIV, Coinfections and Comorbidities; Cancer; and Evidence Synthesis Methods.

Our group leads the mental health research portfolio of IeDEA-SA—a global research collaboration funded by the National Institutes of Health.

In South Africa, our collaborations include the Centre for Infectious Disease Epidemiology and Research and the HIV Mental Health Research Unit at the University of Cape Town, the Department of Psychiatry at the University of Stellenbosch, the South African Medical Research Council, the Western Cape Department of Health, and a private-sector medical insurance administration and health risk management company.

### Key team members

Christiane Didden (statistician), Chiara Gastaldon (postdoctoral researcher), Andreas Haas (head of research group), Yann Ruffieux (statistician), Mpho Tlali (PhD student at University of Cape Town), Cristina Mesa Vieira (PhD student), Veronika Skrivankova Whitesell (research fellow).

### Selected publications

**Haas AD, Kunzekwenyika C, Manzero J, Hossmann S, Limacher A, van Dijk JH, Manhibi R, von Groote Per, Hobbins MA, Verhey R, Egger M. Effect of the Friendship Bench intervention on antiretroviral therapy outcomes and mental health symptoms in rural Zimbabwe: A cluster randomized trial. JAMA Netw Open. 2023 Jul 3;6(7):e2323205.**



**Ruffieux Y, Wettstein A,** Maartens G, Folb N, **Mesa Vieira C, Didden C,** Tlali M, Williams C, Cornell M, Schomaker M, Johnson LF, Joska JA, **Egger M, Haas AD.** *Life-years lost associated with mental illness: a cohort study of beneficiaries of a South African medical insurance scheme.* J Affect Disord. 2023 Nov 1;340:204-212.

**Haas AD, Lienhard R, Didden C,** Cornell M, Boshomane TMG, Folb N, Salazar-Vizcaya L, **Ruffieux Y,** Nyakato P, **Wettstein AE,** Tlali M, Davies MA, **von Groote P,** Wainberg M, Maartens G, Joska JA. *Mental health, longitudinal ART adherence, and viral suppression among adolescents and adults living with HIV in South Africa: a cohort study.* AIDS Behav. 2023 Jun;27(6):1849-1861.

Parcesepe AM, Stockton M, Remch M, Wester CW, Bernard C, Ross J, **Haas AD,** Ajeh R, Althoff KN, Enane L, Pape W, Minga A, Kwobah E, Tlali M, Tanuma J, Nsonde D, Freeman A, Duda SN, Nash D, Lancaster K. *Availability of screening and treatment for common mental disorders in HIV clinic settings: data from the global International epidemiology Databases to Evaluate AIDS (IeDEA) Consortium, 2016-2017 and 2020.* J Int AIDS Soc. 2023 Aug;26(8):e26147.

## Musculoskeletal Health and Rheumatology

*The Musculoskeletal Health and Rheumatology research group is involved in research projects on musculoskeletal disorders, especially osteoarthritis, giant cell arteritis, and osteoporosis. Our research includes studies on prevalence, incidence, diagnosis, and natural history, as well as systematic reviews and randomized controlled trials (RCT). We collaborate with the Clinic for Rheumatology and Immunology at the University Hospital of Bern, Inselspital.*

### Key scientific activities

We established a new collaboration with the Institute for Biomechanics at ETH Zürich in 2022. We already have obtained preliminary results from this collaboration on new biomechanical treatment options for knee osteoarthritis that influence knee loading via personalized orthotic footwear.

We consolidated our collaboration with the primary and secondary health care system-based registry on osteoporosis and giant cell arteritis. In addition we host the cohort on Takayasu arteritis—a Swiss registry.

We continue to analyze and publish results from the 10-year follow-up of the inception cohort study (Sumiswald cohort) to understand the role of femoroacetabular impingement in the development of osteoarthritis of the hip. We also continue to publish secondary analyses from the multicenter RCT comparing arthroscopic hip surgery to physiotherapy-led care for femoroacetabular impingement (Australian FASHIoN trial). And we are analyzing long-term follow-up results on the rapid induction of remission with high-dose glucocorticoids among patients with giant cell arteritis (GUSTO trial).

### Key academic activities

**Habilitation:** Dr med Judith Everts received her degree in 2023.

**Teaching:** We offer regular teaching activities at the undergraduate and postgraduate levels that include seminars and talks.

**Conferences and Events:** Group members are regularly invited to speak and present work at national and international conferences.

**Scientific Talks and Presentations:** Group members presented posters and talks at the two large rheumatology conferences: the European League Against Rheumatism and the American College of Rheumatology.

**Outreach and Representation:** Stephan Reichenbach is board member for the Foundation of Physical Therapy Science, Switzerland.

### Grants

**Innosuisse—Swiss Innovation Agency** (104.374 IP-LS): Personalized orthotic footwear for relieving knee pain and retarding progression of knee osteoarthritis through balancing dynamic knee loading (CHF 77,066 [of total 737,240] awarded to ISPM. PI Stephan Reichenbach; 12/2022–12/2025).

### Internal and external collaborations

Within Switzerland, we collaborate with University Hospital of Bern, Inselspital; Swiss Institute for Translational and Entrepreneurial Medicine (sitem-insel); University of Bern, CTU; OsteoRheuma Bern (Dr. Judith Everts-Graber), and ETH Zürich (Prof. Bill Taylor).

Outside of Switzerland, we collaborate with the University of Sydney, Australia (Prof. David Hunter); Boston University, USA (Prof. David Felson); and Rotterdam University, The Netherlands (Prof. Fernando Rivadeneira).

### Key team members

Stephan Reichenbach (head of research group)

### Selected publications

Everts-Graber J, Bonel H, Lehmann D, Gahl B, Häuselmann H, Studer U, Ziswiler HR, **Reichenbach S**, Lehmann T. **Comparison of anti-fracture effectiveness of zoledronate, ibandronate and alendronate versus denosumab in a registry-based cohort study.** Osteoporos Int. 2023;34(11):1961-1973.

Christ L, Gloor AD, Kollert F, Gaber T, Buttgereit F, **Reichenbach S**, Villiger PM. **Serum proteomics in giant cell arteritis in response to a three-day pulse of glucocorticoid followed by tocilizumab monotherapy (the GUSTO trial).** Front Immunol. 2023;14:1165758.

Iudici M, Hemmig AK, Stegert M, Courvoisier DS, Adler S, Becker MO, Berger CT, Dan D, Finckh A, Mahr A, Neumann T, **Reichenbach S**, Ribi C, Seitz L, Villiger P, Wildi L, Daikeler T; Giant Cell Arteritis SCQM Study Group. **Management of giant-cell arteritis in Switzerland: an online national survey.** Swiss Med Wkly. 2023;153:40051.

Thirumaran AJ, Murphy NJ, Eyles JP, Linklater JM, **Reichenbach S**, Schmaranzer F, Lerch TD, Venkatesha V, Heller G, O'Donnell J, Hunter DJ. **Do patients with femoroacetabular impingement syndrome who undergo hip arthroscopy display improved alpha angle (magnetic resonance imaging) and radiographic hip morphology?** Int J Rheum Dis. 2023;26(2):354-359.

## Palliative Care and End of Life

*The interdisciplinary Palliative Care and End of Life research group applies expertise in qualitative as well as quantitative methods to undertake clinical, psychosocial, and health services research. We draw upon affiliation with both the Institute of Social and Preventive Medicine and the University Center for Palliative Care at the University Hospital of Bern, Inselspital to study aspects of palliative care that include clinician well-being and emotions, communication, community care, and cost analyses.*

### Key scientific activities

In 2023 our key research activities focused on 1) establishing a core outcome set for the care of dying people, 2) understanding the public perspective on physician communication styles during serious illness conversations, 3) developing an advance care planning course with and for older adults and caregivers, 4) evaluating and establishing societal model procedures for proactive planning for the end of life, 5) economic evaluations of palliative care, 6) evaluating telemedicine in palliative care, and 7) consolidating Eccellenza projects on physician emotions and communication.

### Key academic activities

**Students:** Luca Emmenegger received his Dr. med degree with the thesis "Differences in medication profile through palliative care interventions in hospitalized patients at the end of life." Florence Liaudet received her master in medicine on the topic "Compassion training: Towards a better understanding of patients through self-exposure."

**Teaching:** We continue to give all lectures and seminars on palliative medicine for medical students in years 4–6. Our teaching covers symptom assessment and management as well as psychosocial topics such as grief and communication about dying and death, and ethical topics including hastening of death in older age and self-determination.

Since 2017 our center has been responsible for the postgraduate certificate of advanced studies in Interprofessional Specialized Palliative Care at the University of Bern.

Through our research we also are developing and evaluating innovative teaching models for medical students, nurses, healthcare professionals, and the general Swiss population.

Outside of end-of-life and palliative care topics, Sofia Zambrano coteaches three postgraduate courses with Annika Frahsa on qualitative research in the Public Health Sciences Course Program.

**Conferences and events:** We organized a palliative care specialist symposium (August) and the 8th edition of the summer school in palliative medicine (June).

**Scientific talks and presentations:** We gave oral presentations at the World Congress of the European Association of Palliative Care (June), The National Palliative Care congress (November), the Nursing Conference for General Medicine (November), and the Deutsche Gesellschaft für Palliativmedizin symposium (April).

In total, we presented our research 29 times at medical or scientific events in the form of oral presentations, workshops, or posters.

Link  
Bärn treit

**Outreach and representation:** Together with "Bärn treit," we performed a variety of outreach activities to increase public knowledge and awareness of end-of-life and health care challenges including an annual palliative care movie festival in Bern, book readings on dying, death cafés, and other open activities.

Bärn treit aims for sustainable development of Bern as a compassionate city. Compassionate City Bern is a community palliative care network that disseminates evidence-based knowledge to the public. Bern was selected as the host city for the 8th Public Health International Palliative Care Conference (October 22–25, 2024).

**Honors and Awards:** Monica Fliedner was elected to the board of directors of the European Association of Palliative Care for the period 2023–2027. We won best abstract recognition for "Integration of specialized palliative care during fatal hospitalizations: heart failure vs. cancer," and "Supporting family carers at the end of life: participatory action research" at the National Palliative Care Conference (November).

### Grants

**Krebsforschung Schweiz** (KFS-5738-02-2023) Psychological harm as patient safety concern in advanced cancer care. (CHF 368,900. PI David Schwappach, Coapplicant Sofia Zambrano; 02/2024–08/2026)

**Gesundheitsförderung Schweiz** Concurrent Care (CoCa), Implementation of structured and needs-orientated advance care planning as part of the follow-up care of cancer patients according to 'iplan'. (CHF 879,444. PI Monica Fliedner; 01.01.2024–31.12.2027)

**Swiss Academy of Medical Sciences** (KZS 15/22): The sources and impact of moral distress on Swiss junior physicians: A mixed methods study to develop a framework to foster resilience, ethical competence, and wellness in junior physicians. (CHF 95,994. PI Sofia Zambrano; 06/2023–10/2024).

**Swiss National Science Foundation** (PCEFP1-194177): Eccellenza Professorial Fellowship: The risks and benefits of integrating emotions in end-of-life communication. (CHF 1,826,322. PI Sofia Zambrano; 11/2021–11/2026).

**Swiss National Science Foundation** (33IC30\_207041): DigiPALL; a randomized controlled trial of digital patient reported outcomes and biomarker monitoring in palliative care. (CHF 704,038. Co-PI Steffen Eychmüller; 08/2022–08/2026).

**Swiss National Science Foundation** (10531G\_212822): Cost data of patients dying in the hospital: does Palliative Care matter? — A retrospective cross-sectional study of complete hospital costs of deceased patients in a Swiss university hospital over five years. (CHF 149,011. PI Maud Maessen, Co-PI Steffen Eychmüller, Luca Emmenegger, Monika Hagemann; 12/2022–12/2024).

**St.Gallen Latinamerica House:** Compassionate communities in Colombia, Argentina, and Switzerland. How to assess their effectiveness? (CHF 23,000. PI Steffen Eychmüller, Coapplicants Valentina González, Andri Christen, Sofia Zambrano; 01/2022–01/2024).

**Lindenhof Foundation, Bern:** Plattform Palliative Care (CHF 1.48 million. PI Steffen Eychmüller; 09/2020–08/2023).

**Horizon 2020** (825731): I-LIVE: Living well, dying well. A research program to support living until the end. (EUR 394,750 [of 4,017,817 awarded to University of Bern. Work package lead Steffen Eychmüller, Sofia Zambrano; 01/2019–12/2023]).

### Internal and external collaborations

We collaborate with an extensive network of local, regional, national, and international partners from a diverse range of areas and sectors. As an example, the i-LIVE consortium is composed of 14 health and research institutions in 11 European countries and Australia, New Zealand, and Argentina.

Within the Eccellenza, we collaborate internally with the Berner Institute für Hausarztmedizin (BIHAM) and Institut für Medizinische Lehre at the University of Bern. Within Switzerland we collaborate with Zürich University Hospital and the University of Fribourg. Outside of Switzerland we collaborate with Vrije Universiteit Brussel, Belgium, and Duke University, Stanford University and the University of Rochester in the USA. We also conduct qualitative subprojects within SNF funded studies internally with BIHAM, and externally with the Department of Infectious Diseases at Inselspital and the Palliative Care Service at Lausanne University Hospital, CHUV.

### Key team members

Andreas Ebnetter (research collaborator), Martina Egloff (research assistant), Luca Emmenegger (research collaborator), Steffen Eychmüller (adjunct professor), Sibylle Felber (research collaborator), Monica Fliedner (postdoc), Valentina González (postdoc), Monika Hagemann (research collaborator), Barbara Janina Kieszun (research collaborator), Anna Lange (PhD candidate), Maud Maessen (senior postdoc), Yvonne Mattmann (research assistant), Katrien Moens (PhD candidate), Maya Monteverde (research collaborator), Robert Staeck (PhD candidate), Cornelia Stähli (research assistant), Sofia Zambrano (head of research group).

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### Selected publications

**Felber SJ**, Guffi T, Brem BG, Schmitz FM, Schnabel KP, Schär SG, **Eychmüller S**, **Zambrano SC**. [Talking about dying and death: Essentials of communicating about approaching death from the perspective of major stakeholders](#). Palliative & Supportive Care. 2023 Nov 6:1-0.

**Staeck R**, Streit S, **Zambrano SC**. [Gesunde Ärztinnen und Ärzte für eine gesunde Versorgung](#). Primary and Hospital Care. 2023 Apr 5;23(4):106-7.

**González-Jaramillo V**, Krikorian A, Tripodoro V, Jorge M, **Zambrano SC**, López F, Vélez MC, Noguera T, Orellana S, Montilla S, **Christen-Cevallos Rosero A**, **Eychmüller S**. [Compassionate communities: How to assess their benefit? A protocol of a collaborative study between different countries](#). Palliat Care Soc Pract. 2023 May 8;17:26323524231170885. doi: 10.1177/26323524231170885

van Eenennaam RM, Kruithof W, Beelen A, Bakker LA, van Eijk RPA, **Maessen M**, Baardman JF, Visser-Meily JMA, Veldink JH, van den Berg LH. [Frequency of euthanasia, factors associated with end-of-life practices, and quality of end-of-life care in patients with amyotrophic lateral sclerosis in the Netherlands: a population-based cohort study](#). Lancet Neurology. 2023 Jul;22(7):591-601. doi: 10.1016/S1474-4422(23)00155-2.

Bernardis A, **Gonzalez-Jaramillo V**, **Ebnetter AS**, **Eychmüller S**. [Palliative care and COVID-19: a bibliometric analysis](#). BMJ Support Palliat Care. 2023 Jan 26. doi: 10.1136/spcare-2022-004108.

## Patient Safety in Health Services

*We study hazards in health care in a variety of clinical contexts with different methodologies and data sources.*

### Key scientific activities

One stream of our research applies a patient safety indicator to routine longitudinal hospital data to estimate rates of unintentionally retained foreign objects after surgery (RFO). This indicator is currently used for international comparisons of healthcare system performance. In a qualitative expert study, we explored key national stakeholders' views on RFO as a safety problem, its preventability, and need for action in Switzerland. Our epidemiological analyses revealed that the annual RFO rate more than doubled between 2000 and 2019 and coincided with increasing coding intensity in routine hospital data. These results raise serious doubts about using this particular patient safety indicator for comparing hospitals, countries, and years.

Patient safety research has a long history investigating and describing preventable physical harms to patients or caregivers such as infections or injuries, whereas emotional or psychological harm is usually beyond its scope. However, for patients and caregivers these invisible injuries are very important. One reason for lack of attention to them is the problem of defining and assessing preventable psychological harm. In our upcoming study, conceptual work and empirical studies will investigate this in the context of cancer care.

Another focus of our research is on the opportunities and hazards associated with the digital transformation of health care. In particular, the usability of electronic medical records can have both direct and indirect impact on patients. In our research, we assess usability issues and their impact on patient safety with the goal of informing how these digital systems should be improved. In one study, we analysed patient-misidentification incidents and identified screen layout as a risk factor. Currently, we are developing and adapting instruments to assess clinical usability of electronic health record systems in inpatient and outpatient health care. In a new study, we investigate the effects of electronic health records on antibiotic ordering errors and are integrating a human factors approach to understand how the electronic ordering system may have contributed to the errors.

### Key academic activities

**Students:** Two MD theses were supervised.

**Teaching:** David Schwappach teaches patient safety in the medical faculty at the University of Bern and a module on patient safety in the MPH program. He is also a lecturer and member of the program board of the new CAS Medication Safety at the University of Bern. In the new Public Health PhD Program, he is the co-lead and responsible for course development of the Health Systems and Policy stream.

**Conferences and events:** Member of scientific committee, DXcom—a workshop on communication in diagnostic error (funded by SNF), Bern. Member of program committee, European Implementation Event (EIE2023), Basel.

**Scientific talks and presentations:** 5th global ministerial summit on patient safety, Montreux; Onkologidagarna, Kalmar Sweden; Swiss eHealth Forum Bern; European Society For Emergency Medicine, Quadrimed, Crans-Montana; Annual Congress of the Swiss Society of Senology, Zürich.

**Outreach and representation:** David Schwappach leads the patient safety jury for the annual Innovation Qualité, the Swiss Prize for Quality in healthcare awarded by the

Swiss Medical Association. As a member of a designated expert group mandated by the Swiss Medical Association and the Swiss Institute for continued medical education, Schwappach developed core competencies for patient safety for medical training and continuing education.

### Grants

Psychological harm as patient safety concern in advanced cancer care.

Effects of electronic health record EHR transitioning on antibiotic ordering errors in an academic hospital setting (ABOXER).

### Internal and external collaborators

Prof. Sofia Zambrano (ISPM Bern)  
 Prof. Wolf Hautz, Prof. Gert Krümmrey (Universitäres Notfallzentrum Inselspital Bern)  
 Dr. Philipp Jent (Spitalhygiene Inselspital Bern)  
 Raj Ratwani, PhD (Medstar Health, Georgetown University School of Medicine USA)  
 Prof. Maria Wertli (Kantonsspital Baden)  
 Dr. Yvonne Pfeiffer (harmfree healthcare)  
 Dr. Michael Havranek (University of Lucerne)  
 Prof. Laurent Audigé, Prof. Andreas Müller (University Hospital Basel)  
 Helena Ullgren, PhD (Karolinska Institute, Sweden)

### Key team members

David Schwappach (head of research group), Lara Dreismann (postdoctoral research fellow).

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### Selected publications

**Schwappach D, Havranek MM. Are temporal trends in retained foreign object rates after surgery in Switzerland impacted by increasing coding intensity? A retrospective analysis of hospital routine data from 2000 to 2019. BMJ Open 2023; doi: 10.1136/bmjopen-2023-075660.**

Pfeiffer Y, Atkinson A, Maag J, Lane MA, **Schwappach DLB**, Marschall J. **Preventing Surgical Site Infections: Are Safety Climate Level and Its Strength Associated With Self-reported Commitment To, Subjective Norms Toward, and Knowledge About Preventive Measures?** Journal of Patient Safety 2023. doi: 10.1097/PTS.0000000000001111.

## Public Health and Primary Care Library

*The Public Health and Primary Care Library team provides research support services primarily for researchers and PhD students at the Institute of Social and Preventive Medicine, the Clinical Trials Unit Bern (CTU), and the Institute of Primary Health Care (BIHAM). As embedded librarians, we provide personalized and timely research support and collaborate closely with research teams on their projects.*

Our main expertise is conducting thorough literature searches for all types of evidence synthesis research. We also offer assistance throughout the process of publishing research findings; monitor ISPM, CTU, and BIHAM research output and open access compliance; and instruct master of public health (MPH) and PhD/CAS students on systematic literature searching.

### Key scientific activities

Following the Cochrane Handbook for Systematic Reviews, we developed high quality, state-of-the-art search strategies across a wide range of databases to ensure the accuracy and completeness of evidence used for literature reviews. As coauthors on several resulting articles, we took responsibility for correctly reporting the search process according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline. Additionally, to ensure international quality standards we offered peer review for search strategies built by the researchers themselves. We perform our peer review following the Peer Review of Electronic Search Strategies (PRESS 2015) guideline. To help review teams monitor new studies as they analyse data, we set up database search alerts on request and keep teams informed of new developments.

As expert searchers on systematic review teams, our goal is to streamline the systematic review process by eliminating time-consuming and repetitive tasks. One such task is removing duplicate records from databases with overlapping content. The use of our fully automated deduplication tool Deduklick, developed in collaboration with Risklick, a spin-off of the University of Bern, saved a significant amount of time. This time was then invested in implementing regular peer review of complex search strategies. Thanks to a new license for Covidence, acquired by the Medical Library, we were able to introduce this useful systematic review tool to researchers. This tool allows us to directly upload search results as well as article full texts, thus simplifying the process for the researchers. Additionally, we started to explore the potential of AI-driven tools to further unburden the systematic review process.

### Key academic activities

**Teaching:** We taught systematic literature search methods in modules of the MPH program as well as the University of Bern's PhD and CAS programs. We also created a curated and constantly updated collection of (self-)learning materials for conducting systematic literature searches in medical and health sciences on ILIAS—the university's central teaching and learning platform. This collection is publicly accessible and intended to serve students, course participants, and other interested individuals. We also gave researchers and PhD students guidance on selecting suitable journals for submitting their manuscripts, obtaining funding for article processing charges, and identifying journals or publishers with predatory practices or tendencies.

**Conferences and Events:** Doris participated in the European Association for Health Information and Libraries (EAHIL) annual conference in Trondheim, Norway—the main European platform for meeting other expert searchers and medical information specialists—while Beatrice attended a series of live webinars on systematic literature search for experts by Cochrane Germany and Austria. Throughout the year, we have expanded and updated our professional knowledge and skills by participating in online webinars and workshops.

**Scientific Talks and Presentations:** Together with Poorya Amini from Risklick, Beatrice represented our deduplication tool Deduklick at the Dutch Deduplication Days, where Deduklick was compared to other widely used tools. Since the introduction of Deduklick in 2022, the tool has been continually improved and delivers excellent quality and reliability.

### Internal and external collaborations

At the University of Bern, we collaborate with the Medical Library's Research Support Services (systematic review services), the Open Science/Open Access team (publishing support), and the Medical Faculty's publications team (research evaluation).

We maintain close communication with other information specialists in the medical field and exchange knowledge and ideas at national and international meetings organized by the Swiss Academy of Medical Sciences (SAMS), EAHIL, Cochrane, and the Arbeitsgemeinschaft für medizinisches Bibliothekswesen (AGMB), and via specialized mailing lists and book clubs.

### Key team members

Doris Kopp-Heim and Beatrice Minder are medical information specialists.



Doris Kopp



Beatrice Minder  
Wyssmann

### Selected publications

**Menassa M, Stronks K, Khatami F, Roa Diaz ZM, Pano O, Gamba M, Itodo OA, Buttia C, Wehrli F, Minder B, Velarde MR, Franco OH.** *Concepts and definitions of healthy ageing: a systematic review and synthesis of theoretical models.* *EClinicalMedicine.* 2023;56:101821.

**Mesa-Vieira C, Gonzalez-Jaramillo N, Diaz-Rios C, Pano O, Meyer S, Menassa M, Minder B, Lin V, Franco OH, Frahsa A.** *Urban Governance, Multisectoral Action, and Civic Engagement for Population Health, Wellbeing, and Equity in Urban Settings: A Systematic Review.* *Int J Public Health.* 2023;68:1605772.

Stojic S, **Minder B**, Boehl G, Rivero T, **Zwahlen M**, Gemperli A, **Glisic M.** *Systematic review and meta-analysis use in the field of spinal cord injury research: A bibliometric analysis.* *J Spinal Cord Med.* 2023:1-11.

## Sexual and Reproductive Health

*We examine questions about etiology, epidemiology, prevention and control, diagnosis, and social and cultural aspects of sexually transmitted infections (STI) and emerging infectious disease threats in Switzerland and internationally. Our studies include field epidemiology, synthesis of published evidence, and methodological research. We are committed to open science principles and the production of living evidence.*

### Key scientific activities

In 2023 pandemic preparedness became increasingly important as the emergency phase of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic ended. The “Bern, get ready” (BEready) cohort study team successfully enrolled 108 households, including children and pets, in a pilot study. This cohort study will investigate existing and emerging infectious disease threats and enhance pandemic preparedness in Switzerland. BEready is a core activity and future resource for the Multidisciplinary Center for Infectious Diseases (MCID) members. As investigators in the new ESCAPE project, we started reviewing evidence to define the scope of pandemic preparedness cohort studies like BEready. We are one of eight members of this Horizon Europe-funded consortium, which aims to develop efficient, scalable pandemic response plans for Europe. With the end of our COVID-19 Open Access Project and the EpiPose projects, Leonie Heron led the publication of our experience of keeping a living systematic review alive during a pandemic.

Our international project on the global challenge of the political prioritization of the prevention and control of STI came to an end with the publication of a final report and video disseminated by the Swiss Network of International Studies. The Women and Newborn Trial of Antenatal Intervention and Management (WANTAIM, meaning “together”) in Papua New Guinea released a preprint of its main findings, for which antenatal point-of-care STI screening did not reduce the incidence of preterm birth or low birthweight when compared with syndromic management. Ranjana Gigi received her MD and completed enrolment of 604 pregnant women in a cohort study for the Philani Ndiphile project (meaning “be healthy, and I will be healthy”) in South Africa. The International mpox research consortium project, led by the University of Manitoba held its kickoff meeting in Kinshasa and found the first cluster of clade I monkeypox virus infections linked to sexual contact in the Democratic Republic of the Congo.

Our methodological work on prevalence studies continued with Diana Buitrago-Garcia submitting her PhD thesis.

### Key academic activities

**Students:** Our group included two PhD students and two MD students.

**Teaching:** Our group contributed to teaching for undergraduates in medicine and biomedical sciences, and PhD students and postgraduates studying for certificates of advanced studies. Teaching subject areas included writing for publication and protocol development, gender studies, infectious disease epidemiology, public health ethics, and global health.

**Conferences and events:** We conducted an interdisciplinary meeting with international experts in research and policy to discuss the findings of the WANTAIM trial in Papua New Guinea and the global political prioritization of STI in November 2023. This event included a webcast seminar with a global audience.

We held a training school and workshop on risk of bias assessment in prevalence studies supported by the Harmony European Union COST Action in Athens, Greece in May 2023.

**Scientific talks and presentations:** Nicola Low was an invited speaker and Ranjana Gigi and Nicola Low gave oral presentations at International Society for STD Research congress, Chicago, July 2023.

**Outreach and representation:** Nicola Low was vice-chair of the International Health Regulations emergency committee on the multicountry outbreak of mpox until the end of the public health emergency of international concern in July 2023.

The BEready project team won an award from the Franxini Innovation Hub to improve communication between science and politics. We received training, wrote a blog and hosted a briefing for members of the Canton of Bern parliament.

### Grants

**European Commission Horizon Europe** (101095619): Efficient and scalable EU-wide pandemic response plans through dynamic epidemic data assimilation (ESCAPE). (EUR 3.2 million. Coapplicants Nicola Low, Christian L. Althaus, Emma Hodcroft; 01/2023–12/2026).

**Multidisciplinary Center for Infectious Diseases** (core activity): The BEready cohort. (CHF 1.8 million. PI Nicola Low with Gilles Wandeler; 05/2022–04/2025).

**Multidisciplinary Center for Infectious Diseases** (MA\_21): Divided pandemic society and public health: Polarization in the COVID-19 pandemic response in Switzerland. (CHF 720,000. PI Annika Frahsa, Coapplicant Nicola Low; 05/2022–04/2025).

**Swiss Cancer Research** (9346): Cervical pre-cancer treatment failure among women living with HIV in Zimbabwe: A cohort study. (CHF 372,100. PI Eliane Rohner, Coapplicant Nicola Low; 01/2022–12/2025).

**Swiss National Science Foundation** (320030\_197831): Influence of sexually transmitted infections, genital tract infections and the vaginal microbiome on preterm birth. (CHF 720,000. PI Nicola Low; 10/2021–09/2025).

**European Commission Horizon 2020** (101003688): Epidemic intelligence to minimize COVID-19’s public health, economic and social impact in Europe (EpiPose). (EUR 2.9 million. Coapplicants Nicola Low, Christian L. Althaus; 03/2020–03/2023).

**Swiss Network of International Studies** (19/63): Political prioritisation of the prevention and control of sexually transmitted infections: A global challenge. (CHF 246,000. PI Nicola Low; 01/2020–07/2023).

### Internal and external collaborations

At the Institute of Social and Preventive Medicine, we collaborate with the Cancer; Child and Adolescent Health; Community Health and Health Care Systems; HIV, Coinfections and Comorbidities; Interfaculty Platform for Data and Computational Science; and Evidence Synthesis research groups. At the University of Bern, we work with MCID, and elsewhere in Switzerland with colleagues at the University of Zurich.

We work internationally with the Foundation for Professional Development, South Africa; Papua New Guinea Institute of Medical Research; University of New South Wales and University of Melbourne, Australia; Hasselt University, Belgium; University

College London, UK; London School of Hygiene and Tropical Medicine, UK; Shenzhen University, China; and the World Health Organization.

#### Key team members

Diana Buitrago-Garcia (PhD student), Ranjana Gigi (MD student), Leonie Heron (postdoc), Eva Maria Hodel (project manager), Christian Kosok (MD student), Aziz Mert Ipekci (PhD student), Nicola Low (head of research group), Gilles Wandeler (co-PI).

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#### Selected publications

**Heron L, Buitrago-Garcia D, Ipekci AM, Baumann R, Imeri H, Salanti G, Counotte MJ, Low N.** [How to update a living systematic review and keep it alive during a pandemic: a practical guide.](#) *Systematic Reviews* 2023-09-02 DOI: 10.1186/s13643-023-02325-y

**Gigi RMS, Buitrago-Garcia D, Taghavi K,** Dunaiski CM, van de Wijgert JHHM, Peters RPH, **Low N.** [Vulvovaginal yeast infections during pregnancy and perinatal outcomes: systematic review and meta-analysis.](#) *BMC Women's Health* 2023;23:116 <https://doi.org/10.1186/s12905-023-02258-7>.

**Gigi RMS,** Mdingi MM, Jung H, Claassen-Weitz S, Butikofer L, Klausner JD... **Low N.** [Genital tract infections, the vaginal microbiome and gestational age at birth among pregnant women in South Africa: a cohort study protocol.](#) *BMJ Open* 2023;13:e081562. DOI: 10.1136/bmjopen-2023-081562.

Jit M, Ainslie K, **Althaus C,** Caetano C, Colizza V, Paolotti, D, Beutels P, Lander W, Edmunds J, Nunes B, Namorado S, Faes C, **Low N,** Wallinga J, Hens N. [Reflections On Epidemiological Modeling To Inform Policy During The COVID-19 Pandemic In Western Europe, 2020–23.](#) *Health Affairs* 2023;42(12):1630-36 <https://doi.org/10.1377/hlthaff.2023.00688>.

Mengi A; Vallely LM, Laman M, Jally E, Kulimbao J, Warel S, Enman R, Aipit J, **Low N,** Riddell MA. [The use of newborn foot length to identify low birth weight and preterm babies in Papua New Guinea: A diagnostic accuracy study.](#) *PLOS Global Public Health* 2023 DOI: 10.1371/journal.pgph.0001924.

**Low N,** Bachmann LH, Ogoina D, McDonald R, **Ipekci AM,** Quilter LAS, Cevik M. [Mpox virus and transmission through sexual contact: Defining the research agenda.](#) *PLOS Medicine* 2023 DOI: 10.1371/journal.pmed.1004163.

Knafou J, Haas Q, **Borissov N,** Counotte M, **Low N,** Imeri H, **Ipekci AM,** **Buitrago-Garcia D,** **Heron L,** **Amini P,** Teodoro D. [Ensemble of deep learning language models to support the creation of living systematic reviews for the COVID-19 literature.](#) *Systematic Reviews* 2023;12:94 <https://doi.org/10.1186/s13643-023-02247-9>.



## Spinal Cord Injury, Cardiometabolic Diseases, Lifestyle and Behavior

*The Lifestyle and Behavior group takes a transdisciplinary and life-course approach to understanding complex associations between modifiable lifestyle factors and major noncommunicable diseases in the context of healthy ageing. The main research streams over the past year focused on identifying (i) potential causal pathways underlying lifestyle-related chronic diseases, and (ii) the role of lifestyle in rehabilitation and health maintenance after neurotrauma.*

### Key scientific activities

In a series of articles, we explored the burden of cardiometabolic diseases during the initial rehabilitation stay following spinal cord injury (SCI). Approximately 5.5 months postinjury, one-third of people with SCI are classified as moderate to high risk for cardiovascular disease (CVD), with over 60% being overweight and almost 40% having metabolic syndrome. We linked rehabilitation outcomes, measured through improved respiratory function, higher hand grip strength, and mobility, to a more favorable cardiometabolic risk profile. The major focus of our future work will be to develop screening and preventive strategies targeting central obesity as the key modifiable cardiovascular risk factor. In light of this, together with SCI and nutrition experts we published a systematic review of the literature, which mapped the most promising dietary interventions linked with improved health outcomes following the injury. Together with Jivko Stoyanov, we studied a complex association between microbiome, diet, and cardiometabolic risk factors in elite Swiss para-athletes. Healthy diet remains the most promising approach to influencing central obesity, cardiometabolic risk, and overall health and well-being in the SCI population. Marija Glisic is therefore organizing a large international survey among health professionals to prioritize nutrition research in people with SCI that emphasizes its benefits beyond weight management. This will offer a macroscopic overview of perceived research priorities guiding us toward future investigations aimed at individuals aging with SCI.

In a large systematic literature review, we provided a comprehensive overview and analysis of sixty-five theoretical models to define healthy aging. It is evident that a uniform model or definition of healthy aging is not practical considering the diverse nature of the concept across various populations, dimensions, and contexts. Our classification system may serve as a foundation for further standardizing the use of conceptual terms and dimensions as well as establishing theoretical frameworks specific to healthy aging dimensions, and it can help guide research and facilitate comparisons of empirical findings.

### Key academic activities

**Students:** Three PhD candidates successfully completed their PhD studies: Oche Adam Itodo, Magda Gamba, and Marilyn Menassa. Under supervision of Marija Glisic, Muriel Handelman handed in her thesis as part of the continuing education program in public health of the Universities of Basel, Bern, and Zurich.

**Teaching:** At the University of Bern, Marija Glisic teaches epidemiology in the undergraduate chemistry and biochemistry curriculum, and clinical epidemiology and health technology assessment in the biomedical engineering program. She also teaches in the Certificate of Advanced Studies program in Sex- and Gender-specific Medicine at the University of Zurich. Glisic also teaches translational medicine and evidence-based medicine with Jivko Stoyanov at the University of Lucerne.

Links:  
SwiSCI  
Swiss BioRef  
ANDRONET

**Scientific Talks and Presentations:** In 2023 we presented our work to the Deutschsprachige Medizinische Gesellschaft für Paraplegiologie (DMGP), International Spinal Cord Society (ISCOS), European Society of Cardiology, and at the annual meeting of the Cardiovascular Research Cluster Bern.

**Outreach and Representation:** Marija Glisic has become a research officer of the International Spinal Cord Society (ISCOS) Special Interest Nutrition Group. Glisic and Jivko Stoyanov are members of the Swiss SCI Cohort consortia's biomedical interest group, as well as the Swiss BioRef for personalized reference values for precision medicine. Marija Glisic also is a member of ANDRONET—the European andrology network for research coordination, education, and public awareness—a European COST action.

### Internal and external collaborators

Our group collaborates with a broad national and international multidisciplinary network of researchers, clinicians, and other professionals in the field of cardiometabolic diseases, lifestyle, and SCI.

### Key team members

Magda Gamba (PhD candidate), Marija Glisic (head of research group), Oche Adam Itodo (PhD candidate), Leonidas G Karagounis (adjunct professor), Marilyn Menassa (PhD candidate), Jivko Stoyanov (titular professor).

### Selected publications

Raguindin PF, Mueller G, Stoyanov J, Eriks-Hoogland I, Jordan X, Stojic S, Hund-Georgiadis M, Muka T, Stucki G, Glisic M. **Burden of Cardiovascular Risk in Individuals With Spinal Cord Injury and Its Association With Rehabilitation Outcomes: Results From the Swiss Spinal Cord Injury Cohort.** *Am J Phys Med Rehabil* 2023, 102 (12), 1043-1054.

Raguindin PF, Stoyanov J, Eriks-Hoogland I, Stucki G, Jordan X, Schubert M, Franco OH, Muka T, Glisic M. **Cardiometabolic risk profiling during spinal cord injury rehabilitation: A longitudinal analysis from the Swiss Spinal Cord Injury (SwiSCI) cohort.** *Pm r* 2023, 15 (6), 715-730.

Valido E, Bertolo A, Hertig-Godeschalk A, Flueck JL, Ruettimann B, Glisic M, Stoyanov J. **Characteristics of the gut microbiome of Swiss elite athletes with a spinal cord injury: An exploratory study.** *J Spinal Cord Med* 2024, 1-9.

Stojic S, Eriks-Hoogland I, Gamba M, Valido E, Minder B, Chatelan A, Karagounis LG, Ballesteros M, Diaz C, Brach M, Stoyanov J, Diviani N, Rubinelli S, Perret C, Glisic M. **Mapping of Dietary Interventions Beneficial in the Prevention of Secondary Health Conditions in Spinal Cord Injured Population: A Systematic Review.** *J Nutr Health Aging* 2023, 27 (7), 524-541.

Menassa M, Stronks K, Khatmi F, Roa Díaz ZM, Espinola OP, Gamba M, Itodo OA, Buttia C, Wehrli F, Minder B, Velarde MR, Franco OH. **Concepts and definitions of healthy ageing: a systematic review and synthesis of theoretical models.** *EClinicalMedicine* 2023, 56, 101821.

# SwissRDL—Medical Registries and Data Linkage

*SwissRDL is a research and service unit covering all activities in the field of medical registries. Our work includes planning, setting up, operating, and maintaining about 20 small regional, national, and international medical registries. To ensure high data quality, we offer support through monitoring visits and central data monitoring. Registry success is demonstrated by detailed reports, statistical analyses, and publications.*

In collaboration with external partners such as medical associations and foundations, we develop, implement, operate, and maintain national and international medical registries and multicenter outcome studies. We ensure high quality, secure data in our center by applying strict validation rules, monitoring data regularly, and monitoring on site.

Our support team offers help for registry issues and data entry by phone, email, and webinars, and we are in contact with more than 180 hospitals in Switzerland. We also develop and offer full-range support for patient-recorded outcome measures on tablets and websites. Our statisticians and project managers create regular, high quality reports for registries such as quarterly reports for hospitals, annual scientific reports (e.g., the report of the national hip and knee registry), benchmark reports for clinics, operator-specific reports, implant reports for industry, and summaries for the public. Our data managers and statisticians also analyze data for scientific publications and posters.

Another core area of SwissRDL excellence is data linkage. We have longstanding experience building large cohorts in which data are linked using probabilistic record linkage methodology. Our experience led to our expertise linking data without available unique identifiers when simple merging is not possible. We also developed and apply privacy-preserving methods for record linkage. Record linkage procedures are also used to link registry data with federal mortality data.

### Key scientific activities

**Acquisition of new registries and projects:** SIRIS Shoulder (incl. patient reported outcome measures, PROMs), national PROMs project for SIRIS Hip and KneeRegistry, Osteoporosis Registry.

**Go-live of new registries:** SwissCare, Swiss Heart Surgery, Swiss Rare Disease Registry.

**Analyses, research, and reporting:** Expansion of central data monitoring and PROMs reporting, new statistical reports, and linking the SIRIS Hip and Knee Registry with the Swissnoso SSI Registry.

**Realization of new technical tools:** Extending the core registry system with new applications, e.g., a PROMs-dashboard with R shiny.

**Planning a new registry system:** Finalization of the detailed design and concept for the new registry system HERES (Health Registry System); start of the realization phase.

### Key academic activities

**Teaching:** Adrian Spörri regularly teaches undergraduate and postgraduate students about medical statistical software, medical registries, and probabilistic record linkage

methodology at the University of Bern and for international partner organizations. Christian Brand is involved in undergraduate teaching of biostatistics.

**Conferences and Events:** We participate in International Society of Arthroplasty Registries meetings and conferences.

**Outreach and Representation:** Through implant registries, we are in touch with medical device suppliers and offer scientific support for reports and studies. We are members of expert committees for the Swiss National Association for Quality Development in Hospitals and Clinics.

### Grants

**Bundesamt für Gesundheit/Federal Office of Public Health.** Schweizerisches Register für seltene Erkrankungen/Swiss Registry for Rare Diseases. (2020–2024).

**Eidgenössische Qualitätskommission/Federal Quality Commission.** Qualitätsverbesserung bei orthopädischen Implantatinfektionen: Analyse, Grundlagen und Ausarbeiten von Interventionen durch Verlinkung der nationalen Registern Swissnoso und SIRIS (2022-2023).

**Eidgenössische Qualitätskommission/Federal Quality Commission.** Entwicklung und Pilotierung des national verpflichteten Implantatregister SIRIS Schulter.

**Eidgenössische Qualitätskommission/Federal Quality Commission.** Nationale Einführung PROMs für das Schweizerische Implantat-Register SIRIS Hüfte und Knie.

### Internal and external collaborations

Within Switzerland, SwissRDL supports researchers at University Hospital of Bern, Inselspital to create and operate medical registries.

Additionally, we collaborate with medical associations and foundations to operate and maintain their registries such as the SIRIS Foundation and their national hip and knee implant registry with more than 150 hospitals, and Swissnoso for surgical site infections with more than 170 hospitals delivering data to SwissRDL.

We also collaborate with the Swiss National Association for Quality Development in Hospitals and Clinics. Supporting data management and reporting for more than 200 Spitex organizations, SwissRDL oversees the Home Care Data platform from Spitex Schweiz.

New registries include the Swiss Cardiology Registry and the Swiss Heart Surgery Registry. We also developed different projects for cantonal health administrations and for hospital groups.

Outside of Switzerland, we are in close contact with international registry providers such as the National Joint Registry, UK, and the Endoprothesenregister Deutschland, Germany.

### Key team members

Tanja Aegerter (project manager and monitor), Camille Blochet (project manager and monitor), Lilianna Bolliger (project manager and monitor), Andreas Boss (project manager and statistician), Christian Brand (statistician), Nathanaël Cottin (senior software engineer), Martin Drees (senior software engineer), Cyrille Dubray (head of development), Milena Kovatsch (project manager and IT assistant), Mario Morger (co-head SwissRDL), Anna Müller (system administrator), Stefanie Paerschke (adminis-

#### Links:

SIRIS foundation

Swissnoso

Swiss National Association for Quality Development in Hospitals and Clinics

Spitex Schweiz

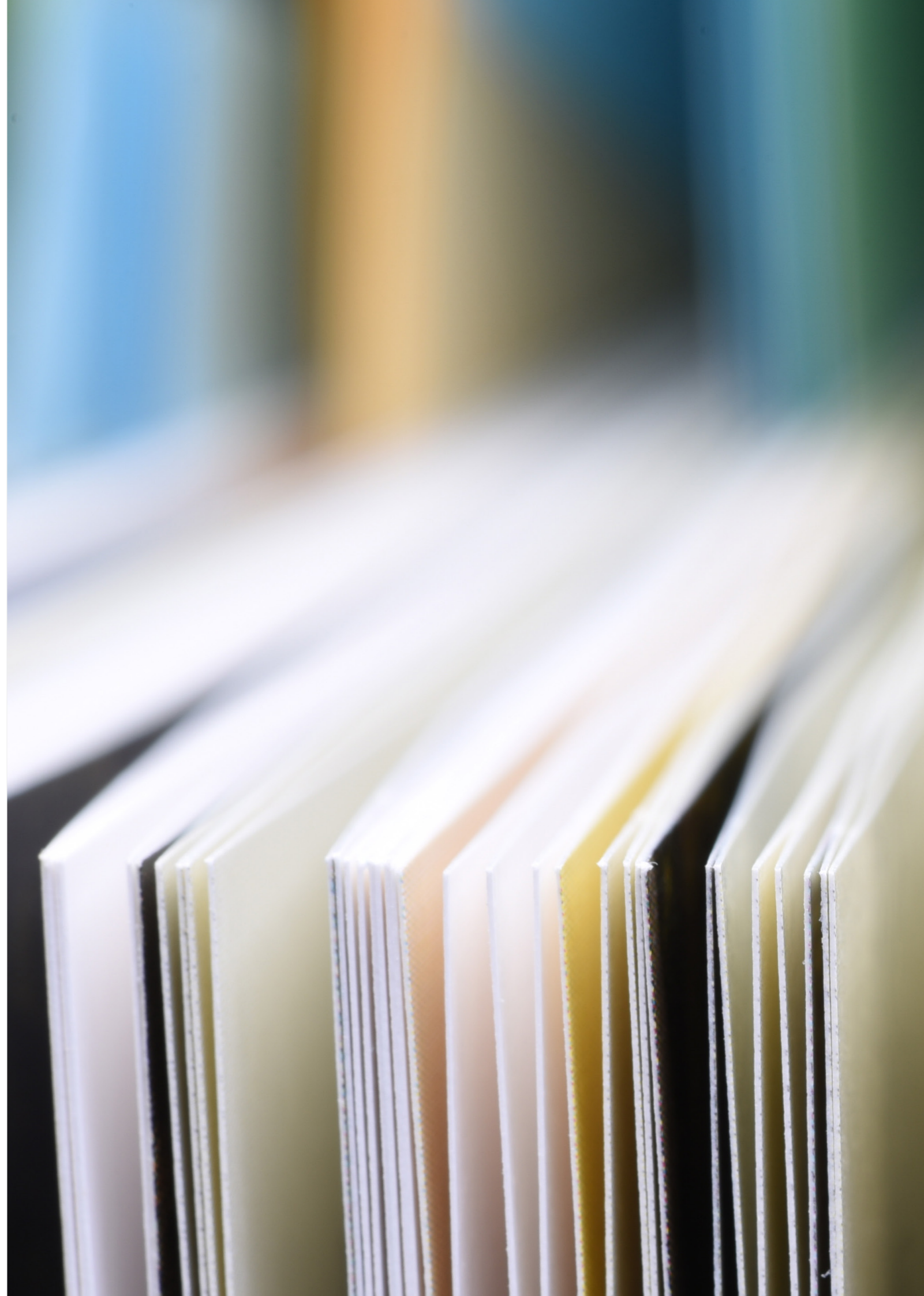
Link  
SIRIS Report 2023

tration), Jonas Ryser (DevOps), Kurt Schmidlin (senior research fellow), David Sossavi (senior software engineer), Adrian Spörri (co-head of SwissRDL), Lucas Tauschek (project manager).

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### Selected publications

Leta, Tesfaye H; Fenstad, Anne Marie; Lygre, Stein Håkon L; Lie, Stein Atle; Lindberg-Larsen, Martin; Pedersen, Alma B; W-Dahl, Annette; Rolfson, Ola; Bülow, Erik; Ashforth, James A; Van Steenberghe, Liza N; Nelissen, Rob G H H; Harries, Dylan; De Steiger, Richard; Lutro, Olav; Hakulinen, Emmi; Mäkelä, Keijo; Willis, Jinny; Wyatt, Michael; Frampton, Chris; ... (2023). [The use of antibiotic-loaded bone cement and systemic antibiotic prophylactic use in 2,971,357 primary total knee arthroplasties from 2010 to 2020: an international register-based observational study among countries in Africa, Europe, North America, and Oceania](#). Acta orthopaedica, 94, pp. 416-425. Medical Journals Sweden AB 10.2340/17453674.2023.17737



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www.ispm.unibe.ch

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Christopher Ritter

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