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2020 is a year we will never forget. During this pandemic year, we worked from home, encountered uncertainty, learned much, and experienced a year of solidarity with everyone working at ISPM. As specialists with extensive public health experience in prevention, infectious disease epidemiology, and modelling, we are experts who have been sought from the very beginning – not only within Switzerland but also from around the world. All of us have contributed actively and worked very hard to help our colleagues and, above all, everyone who needed our expertise in and beyond the pandemic.

We also have seen how quickly research can become politicized, and how topics that simply were subjects of conversation can cloud debates or even become grounds for conflict. This situation will occupy us for some time to come. Communication of research among researchers, policy makers, and society at large has become more necessary than ever as new pathways for interacting have emerged. We anticipated and are proactively addressing this with a new translation and implementation tier at ISPM that will facilitate utilization and implementation of what we learn. Science, or rather findings from research – especially in public health – must not be ends in themselves but serve and be available to a broad public. We see this as a great responsibility at ISPM. The experience we have gained during this year of challenges will nurture and be incorporated into our capacity to prepare and contribute to a better future.

We look to that future with confidence. Our expertise and research will improve population health everywhere. Our experience and endurance will certainly grow as we transform both the paths toward our goals and obstacles along the way into the goals themselves. What we are learning will better serve the health of our planet and its population, and I personally thank you all for your efforts and commitment in this challenging year.

Oscar H. Franco
Our research profile covers health areas from cardio-metabolic to HIV, cancer, childhood and adolescents, NCDs to environmental influence, with the tiers of development of new methods and lifestyle and behavior reaching across all fields.

We actively participate in University teaching programs for students of medicine, biomedical engineering and biomedicine (including students from the University of Fribourg) and are engaged in PhD and postgraduate programs of the University of Bern and SSPH+.

### Staff

- **Prof. Dr. med. Oscar Franco**
  - Director
- **Prof. Marcel Zwahlen**
  - Deputy Director

Staff members total 135

### Research

- Research 119
- PhD students 28
- Admin, technics 16 (covering 3 institutes)
- Nationalities over 25
- Research groups 15

### 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

- Interuniversity Public Health Education
  - MPH, DAS, CAS

- Medical Specialist in Prevention and Public Health
  - Certified training facility

- Bern Lectures in Health Science
  - 5 monthly seminars plus 7 special talks

### Teaching

- Total numbers
  - Course fees CHF 987'136
  - Courses 94
  - Course attendees 1177
  - Undergraduate lectures 2123

### Grants

- Grants, new in 2020
  - 6 SNSF (total of CHF 3’060’000)
  - 2 Horizon 2020 (total of CHF 890’000)
  - 21 various other projects (total of CHF 3’660’000)

- 3rd Party money spent
  - SNF CHF 3’221’189
  - Other competitive CHF 4’880’743
  - Non-competitive CHF 276’729

### Publications

- Publications total 248
Reports from the Research Groups
Key scientific activities
In July 2020, after returning from a research fellowship at the University of North Carolina at Chapel Hill, Eliane Rohner took over leadership of the group from Julia Bohlius (who moved to Swiss TPH, Basel). The group continued to work on analysing data from the South African HIV Cancer Match (SAM) study, a record-linkage study based on 44 million laboratory records from the National Health Laboratory Services and cancer diagnoses from the National Cancer Registry in South Africa. One such analysis examined the association between CD4 cell counts and the incidence rates of various infection related and unrelated cancers among adults living with HIV. An update of the SAM study to include data through 2019 (with more than 90 million laboratory records in total) was also initiated. Katayoun Taghavi advanced her PhD work, which includes assessing the cervical cancer screening cascade at an antiretroviral therapy clinic in Zimbabwe and examining the diagnostic test accuracy of a portable colposcope for the detection of cervical intraepithelial neoplasia in Zambia. Though the study follow-up was suspended by the COVID-19 pandemic, the group initiated mathematical modelling work to evaluate the comparative effectiveness and cost-effectiveness of different cervical cancer prevention strategies in the high-HIV-burden region of Southern Africa.

Key academic activities
Teaching and tutoring of medical students at the University of Bern.

Internal and external collaborations

Key team members
Eliane Rohner, Katayoun Taghavi, Yann Ruffieux, Rowan Iskandar, Matthias Egger

Selected publications


Cardiometabolic Research

Our research group puts epidemiologic principles into practice in clinical and public health settings to improve prevention and develop detection tools for cardiometabolic diseases. Our research focuses on understanding the role of risk factors and mechanisms underlying the development and prognosis of cardiometabolic diseases.

Key scientific activities
The research group studies the thyroid, diabetes, and cardiovascular disease. We explore the role of epigenetic markers in sex differences in cardiometabolic health and in mediating the diabetogenic effects of statins, and the role of thyroid function, glycemic status, and control of myocardial fibrosis. We have undertaken new studies of women’s health to understand dynamic changes in intermediate cardiovascular risk factors for women across the reproductive stages, dietary changes before and after menopause, causality between age of menopause and blood pressure traits, and the role of iron in sex and menopausal differences in cardiometabolic diseases. Our further activities include assessing cardiometabolic profiles in spinal cord injury patients, the roles of micro-RNAs and inflammation in cardiac involvement in Chagas disease, and clinical phenotyping of patients with heart failure in a tertiary hospital.

Key academic activities
Lectures in sex and gender-specific medicine, clinical epidemiology, public health, systematic reviews and meta-analysis, and GRADE assessment.

Grants
Ongoing:
Swiss National Science Foundation. (ZST20_190277). Spirit grant, noncaloric sweeteners, microbiome, and cardiometabolic risk—a randomized clinical trial of Iranian women. Taulant Muka (co-PI), October 2020-October 2023, CHF 500’000.

Astra Zeneca. Prevalence of Heart Failure in Switzerland. Taulant Muka (PI), April 2020-October 2021, CHF 140’000.

New:
Swiss National Science Foundation (I2L23_200256). Sex and menopausal differences in iron status/biomarkers as potential causative factor contributing to sex differences in cardiometabolic disease (IRONNES). Taulant Muka (PI), July 2021-June 2024, CHF 350’000.

Angiology Department, Bern University Hospital. Genetic variants and unmasking disease pathways in peripheral artery disease. Taulant Muka, September 2020-August 2025, CHF 653’820.


Two PhD Swiss Excellence Scholarships, Taulant Muka (supervisor).

Selected publications


Internal and external collaborations
Department of Cardiology, Inselspital, Bern; Department of Angiology, Inselspital, Bern; Department of Nuclear Medicine, University Hospital Zurich, Zurich; Swiss Paraplegic Research Center, Notvili; CoLaus study, University of Lausanne, Switzerland; Imperial College London, London; Department of Epidemiology, Erasmus Medical Center, Rotterdam, the Netherlands; PREVEND Study, University of Groningen, the Netherlands; Institute of Community Medicine, University of Greifswald, Greifswald; Department of Public Health and Clinical Medicine, Umeå University, Sweden. McGill University, Canada.

Key team members
Taulant Muka, group leader; Oscar H. Franco, Director of ISPM; Ariola Bano, Jessica Laine Carmeli, Faina Wehri, and Marija Glisic, postdocs; Jackie Butts, research fellow; Dante Salvador Jr., Hamidreza Raeisi, Oche Adam Itoho, Peter Francis Reguindin, Valentina Gonzales, and Zayne Roa Diaz, PhD students.
Research Groups

Child and Adolescent Health

1. Paediatric Respiratory Epidemiology Group

The Paediatric Respiratory Epidemiology Group studies common and rare respiratory disorders during childhood and over the life course. Main areas of interest are asthma and other wheezing disorders, chronic cough, cystic fibrosis (CF), and primary ciliary dyskinesia (PCD). We look into the role of environmental and behavioural influences on the development of respiratory disorders, the prediction of clinical course, and phenotypes of diseases such as asthma and PCD.

Key scientific activities

We conduct population-based and clinical cohort studies and registries:

Swiss Paediatric Airway Cohort (SPAC): The SPAC (https://spac-study.ch/) is a prospective observational national multcenter clinical cohort study, which includes over 2500 children referred to paediatric respiratory outpatient clinics due to wheeze, recurrent cough, exercise- and sleep-related respiratory problems. In 2020 the focus was on diagnosis of exercise-induced symptoms, the diagnostic accuracy of algorithms and objective tests in asthma, and factors driving adjustment of asthma treatment in children. We included new questions in the monthly follow-up online questionnaire related to COVID-19 and preventive measures such as social distancing to assess how these may have affected the number of respiratory symptoms and infections in this group of children.

Luftibus in the School is a population-based study on respiratory health in school-aged children in the Canton of Zurich. In 2020, the focus was on validation of reference values for lung function parameters and analyses related to chronic cough.

Swiss PCD survey: We developed a national survey nested in the Swiss PCD registry (CH-PCD) to study symptoms and health-related behaviours of PCD patients. The survey was based on the standardised FOLLOW-PCD patient questionnaire and had an excellent response rate (82%). Currently, we focus on analysing prevalence and severity of upper and lower respiratory symptoms and their associations with physical activity.

COVID-PCD: This online longitudinal participatory study follows people with PCD during the COVID-19 pandemic. It started recruitment on 30 May, is available in five languages, and uses weekly questionnaires to collect information about infections, symptoms, and health behaviours. In 2020, the cohort recruited more than 600 persons with PCD from over 40 countries. We study number of people with a SARS-CoV-2 infection, severity of disease, and number of people vaccinated against COVID-19. Results are published weekly on the study website (www.covid19pcd.ispm.ch).

Ear-Nose-Throat (ENT) Prospective International Cohort of PCD patients (EPIC-PCD): The EPIC-PCD is a multicenter cohort on characteristics and prognosis of upper respiratory disease in patients with PCD. Recruitment started in nine countries and already includes more than 100 patients.

Research priorities in PCD: This is a mixed-methods study combining qualitative and quantitative analysis approaches to determine future priorities for clinical and epidemiological research on PCD. In 2020 we held semistructured interviews with experts in the field. We will expand the study to patient representatives in Switzerland and the UK.

BEAT-PCD Clinical Research Collaboration: The BEAT-PCD Clinical Research Collaboration (CRC), a network of multidisciplinary researchers and clinicians, was funded in 2020 by the European Respiratory Society (ERS). The network is coordinating research from basic
science to clinical care to improve diagnosis and develop treatments that lead to better long-term outcomes of patients with PCD. Myrofora Goutaki co-chairs the network, Claudia Kuehni is a member of the management committee, and Yin Ting Lam is a PhD representative at the advisory board.


**Key academic activities**

**Students:** During 2020, the group included 6 PhD candidates (of whom Carmen de Jong and Eva Pedersen defended their PhDs in February and March 2020) and two medical students working on their MD theses.

**Organization of conferences:** Co-organization of the inaugural meeting of the BEAT-PCD CRC (September 2020)

**Fellowships/Prizes:** Myrofora Goutaki was elected chair of the paediatric epidemiology scientific group of the ERS (2021-2024). Cristina Ardura-Garcia was selected as an early career editor for the European Respiratory Journal through its mentoring programme.

**Teaching:** Regular teaching with lectures and tutoring in undergraduate and postgraduate students (University of Bern, MPH program) by Claudia Kuehni, Myrofora Goutaki, Cristina Ardura-Garcia, Eva Pedersen.

**Grants**

*Swiss National Science Foundation (SNSF 320030B_192804):* Natural history, phenotypes and disease classification in primary ciliary dyskinesia (phase 2) (CHF 447’055; 05/2020-04/2023; PI: Claudia Kuehni)

*Swiss National Science Foundation (SNSF 32003_182628):* Phenotypes and prognostic modelling in childhood asthma moving towards clinical applications (Phase II) (CHF 904’000; 10/2018 – 09/2022; PI: Claudia Kuehni)

*Swiss National Science Foundation (SNSF P30093_185923 Ambizione):* From the nose to the lungs: the importance of upper respiratory disease in Primary Ciliary Dyskinesia (CHF 950’341; 10/2019-09/2023; PI: Myrofora Goutaki)

*Swiss Lung League: Predicting asthma attacks in Swiss children: SPAC-Attacks, a clinical cohort study (CHF 67’300; 07/2019-06/2021; PI Cristina Ardura-Garcia)*

**Internal and external collaborations**

The Paediatric Respiratory Epidemiology Research Group has an extensive national and international multidisciplinary network of researchers, clinicians and scientists in the field of paediatric and rare respiratory diseases, through several collaborative projects, such as the BEAT-PCD CRC.

**Key team members**

Claudia Kuehni (group leader), Myrofora Goutaki (senior researcher), Cristina Ardura-Garcia (Postdoc), Eva Sophie Lunde Pedersen (Postdoc), Rebeca Mozun (PhD candidate), Maria Christina Mallet (PhD candidate), Yin Ting Lam (PhD candidate), Daria Berger (PhD candidate), Helena Koppe (Research assistant), Natalie Messerli, Gia Thu Ly (Research assistant).
2. Paediatric Cancer

We host the national Childhood Cancer Registry (ChCR, section 2.a) and conduct research into the epidemiology of childhood cancer over the life course (section 2.b).

2.a Childhood Cancer Registry

Endowed with a mandate by the Swiss Confederation, we are the national centre for registering data on cancer occurring in young people up to 19 years of age in Switzerland. Physicians, hospitals, laboratories, and other health institutions are obliged to report to us all cases of cancer in children, adolescents, and young adults that they diagnose and treat.

The registry collects a vast array of clinical data on cancer, including diagnoses, treatment, follow-up care, late effects, predispositions, previous diseases, and comorbidities. In coding the data, we adhere to international standards and national norms. Our longstanding collaboration with clinics caring for children and adolescents with cancer and many years of experience in cancer registration help to ensure the provision of comprehensive and high-quality data.

As part of our responsibilities for public health reporting, we regularly inform the public about the most recent trends in cancer incidence, prevalence, mortality, and survival among young people. Upon request, we carry out statistical analyses that provide researchers, public health authorities, media professionals, and many others with the information they need for their work.

The data we collect, process, make available and publish will help to improve the understanding of cancer in young people. They will also help to improve quality of cancer prevention, screening, treatment, and care.

Key scientific activities

We conducted a survey to learn more about how healthcare professionals in clinics inform patients about cancer registration and report cases and the challenges they face in carrying out these activities.

We registered and coded new cases, updated information on registered cases, and conducted quality checks.

We migrated the data collected from 1976 to 2019 to the new register software.

We drafted a concept for public health reporting on cancer in 2024, 2027 and 2030 and defined the methods and means of publication of statistical analyses together with other stakeholders.

We conducted routine statistical analyses, with the results being published on the Federal Statistical Office web portal «Krebs bei Kindern» and our webpage «Figures: Incidence, survival, mortality».

We provided third parties with statistical analyses or data extractions.

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Selected publications


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Figure 1: Receiver operating characteristics (ROC) curve of clinical tests to diagnose asthma.
Key academic activities
Conferences talks:
Wissenschaftliches Symposium 40 Jahre Deutsches Kinderkrebsregister: «Childhood Cancer Registry Switzerland – Facts, Plans, Challenges», talk by Verena Pfeiffer (January 24, 2020; Mainz)
Swiss Oncology and Haematology Congress (SOHC): «Ergebnisse Befragung der meldenden Personen & Herausforderungen Kinderkrebsregistrier», talk by Cornelia Stadter and Verena Pfeiffer (November 19, 2020; Zurich)

Grants
Swiss Federal Office of Public Health (FOPH): CHF 840'000

Internal and external collaborations
The ChKCR collaborates closely with the Federal Office of Public Health, the National Agency for Cancer Registration, the Swiss Association of Cancer Registries, and the ISPM Paediatric Cancer Epidemiology Group.

Key team members
Verena Pfeiffer (co-director), Claudia Kuehni (co-director), Shelagh Redmond (head, registration & data quality), Ben Sprecher (head, statistics), Meltem Altun (clinical data manager), Enka Brantschern Berezlaz (clinical data manager, medical coder), Katharina Flanderer (administrative assistant), Anna Glenc (statistical data manager), Christina Huf (data protection consultant), Erika Minder (medical coder), Eleftheria Michalopoulou (statistician), Anna Muller (IT system administrator), Ursina Roder (statistical data manager), Cornelia Stadter (coordinator).

Selected publications


2.b Paediatric Cancer Epidemiology Group
The Paediatric Cancer Epidemiology Group studies the epidemiology of childhood cancer over the life course. Our main areas of interest relate to long-term outcomes after childhood cancer. This includes prevalence, incidence, and spectrum of somatic and psychosocial late effects such as cardiac and pulmonary dysfunction, somatic health, mental health, educational and social outcomes, health-related quality of life, secondary neoplasms, and cause-specific long-term mortality.

Key scientific activities
We conduct the following population-based clinical follow-up studies on long-term outcomes after childhood cancer:

Swiss Childhood Cancer Survivor Study (SCCSS): The SSCCS is a nationwide population-based questionnaire survey continuously including all childhood cancer patients registered in the Childhood Cancer Registry who survived 5 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 behaviours. Currently, we are contacting all survivors diagnosed between 2011-2015. SSCSS-Nutrition is a sub-study of the SSCCS which collects dietary information via self-reported questionnaires and urine samples of survivors.

Cardiovascular Late Effects after Childhood Cancer (CardioOnco Study): The CardioOnco study is a prospective longitudinal multicentre study. It compares conventional echocardiography with speckle tracking echocardiography for the early detection of cardiac disease in childhood cancer survivors to try to understand the clinical determinants for the development of cardiac disease after childhood cancer. The study started in 2016 at the University Hospital in Bern and in 2021 will expand to four other centres in Switzerland.

Community-based screening program for hearing loss after childhood cancer: This prospective study evaluates access to novel, low-threshold hearing tests for former childhood cancer patients. We will invite childhood cancer patients at risk of hearing loss for a free hearing test in a local hearing aid shop. Results will improve our knowledge on the overall burden of hearing loss in childhood cancer survivors and relevant factors. We will use questionnaires, interviews, and group discussions with all stakeholders to evaluate the screening program.

Swiss Paediatric Haematology/Oncology Metabank (Biolink): The Metabank project builds a platform to combine data from the Childhood Cancer Registry and two biobanks, the Swiss germline DNA Biobank for Childhood Cancer and Blood Disorders (BSKIDS) and the Swiss Paediatric Haematology Oncology Biobank Network (SPHO) in a privacy cohering way. The Metabank facilitates project development through rapid assessment of available data and samples and links clinical data with biosamples. Biolink will enable in depth research in the fields of cancer predispositions, pharmacogenetics, and genetic modifiers of long-term complications after childhood cancer.

Genetic Risks for Complications in Children after Oncological Treatment in Switzerland (GenECOS): The aim of the GECCOS project is to find genetic risk factors of complications after childhood cancer. We have collected more than 500 germline DNA samples in the BSKIDS biobank. We extracted and sequenced DNA of Swiss childhood cancer patients in order to contribute to international research collaborations on second cancers. This will help us...
better understand why some patients develop second cancers after childhood cancer and others not.

International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG; www.ighg.org): This initiative develops standardised recommendations for follow-up surveillance after childhood cancer. Our research group leads a guideline on pulmonary dysfunction and is involved in several other guidelines related to ototoxicity, metabolic syndrome, and psychosocial problems.

Key academic activities
Students: In 2020, the group included six PhD students. Christina Schindera defended her PhD in November 2020. One medical student completed her Master thesis.

Teaching: Regular teaching with lectures and tutoring in undergraduate and postgraduate students (University of Bern, MPH program) by Claudia Kuehni and Nicolas Waespe.

Grants
Swiss National Science Foundation (31BLS0_185396): The Swiss Pediatric Hematology/ Oncology Metabank – a network for precision medicine research (CHF 583’638; PI Jean-Pierre Bourquin, co-PI Marc Ansari and Claudia Kuehni)

Swiss Cancer Research, Swiss Cancer League (KLS/KFS-4825-01-2019): Structural funding for Swiss Childhood Cancer Survivor Study (CHF 480’000; 01/2020-12/2022; PI Claudia Kuehni)

Swiss Cancer Research (KFS-4722-02-2019): Dietary intake, overweight, and late effects development in childhood cancer survivors (CHF 359’450; 07/2019-06/2022; PI Murielle Bochud, co-PI Claudia Kuehni)

Swiss Cancer Research (KFS-5027-02-2020): Early detection of heart disease after treatment for cancer during childhood (CHF 336’950; 01/2021-12/2023; PI: Nicolas von der Weid)

Swiss Cancer Research (HSR-3686-16-2019): Improving access to screening for hearing loss after childhood cancer – a novel community-based approach (CHF 247’850; 05/2020-04/2023; PI: Claudia Kuehni)

Kinderkrebshilfe Schweiz: The Swiss Childhood Cancer Survivor Study (SCCSS) (CHF 480’000; 01/2020-12/2022; PI Claudia Kuehni)

Swiss Cancer Research (KFS-4722-02-2019): Dietary intake, overweight, and late effects development in childhood cancer survivors (CHF 359’450; 07/2019-06/2022; PI Murielle Bochud, co-PI Claudia Kuehni)

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Swiss Cancer Research (KFS-5027-02-2020): Early detection of heart disease after treatment for cancer during childhood (CHF 336’950; 01/2021-12/2023; PI: Nicolas von der Weid)


Kinderkrebshilfe Schweiz: The Swiss Childhood Cancer Survivor Study (SCCSS) (CHF 480’000; 01/2020-12/2022; PI Claudia Kuehni)

Lung League Bern: Pulmonary function in long-term childhood cancer survivors after hematopoietic stem cell transplantation (CHF 33’570; 08/2020-02/2021; PI: Maria Otth)

Stiftung für krebskranke Kinder, Regio Basiliensis (2019-P012): Early detection of cardiac dysfunction in survivors of childhood cancer (01/2020-06/2020; CHF 28’773; PI Christina Schindera)

Loss after childhood cancer - a novel community-based approach (CHF 247’850; 05/2020-04/2023; PI: Claudia Kuehni)

Hematopoietic stem cell transplantation (CHF 33’570; 08/2020-02/2021; PI: Maria Otth)

Kinderkrebshilfe Schweiz: The Swiss Childhood Cancer Survivor Study (SCCSS) (CHF 480’000; 01/2020-12/2022; PI Claudia Kuehni)

Swiss Cancer Research (KFS-4722-02-2019): Dietary intake, overweight, and late effects development in childhood cancer survivors (CHF 359’450; 07/2019-06/2022; PI Murielle Bochud, co-PI Claudia Kuehni)

Swiss Cancer Research (KFS-5027-02-2020): Early detection of heart disease after treatment for cancer during childhood (CHF 336’950; 01/2021-12/2023; PI: Nicolas von der Weid)

Swiss Cancer Research (HSR-3686-16-2019): Improving access to screening for hearing loss after childhood cancer – a novel community-based approach (CHF 247’850; 05/2020-04/2023; PI: Claudia Kuehni)

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Lung League Bern: Pulmonary function in long-term childhood cancer survivors after hematopoietic stem cell transplantation (CHF 33’570; 08/2020-02/2021; PI: Maria Otth)

Stiftung für krebskranke Kinder, Regio Basiliensis (2019-P012): Early detection of cardiac dysfunction in survivors of childhood cancer (01/2020-06/2020; CHF 28’773; PI Christina Schindera)

Internal and external collaborations
The Paediatric Cancer Epidemiology Research Group has an extensive national and international, multidisciplinary network with researchers and clinicians in the field of late effects of childhood cancer. In Switzerland, we collaborate with the nine paediatric oncology clinics of the Swiss Paediatric Oncology Group (SPOG). Internationally, we collaborate with PanCareSurFup (http://www.pancaresurfup.eu) and PanCareLIFE (http://www.pancarelife.eu). PanCareSurFup investigates the burden and risk factors of the most severe and life threatening late effects after childhood cancer, namely secondary neo-

plasms, cardiovascular disease, and premature death. PanCareLIFE focuses on hearing loss, infertility and quality of life.

Key team members
Claudia Kuehni (group leader), Fabiën Belle (Postdoc), Luzius Mader (Postdoc), Christina Schindera (Postdoc), Nicolas Waespe (PhD candidate), Maria Otth (PhD candidate), Sven Strehel (PhD candidate), Tomas Slama (PhD candidate), Fabienne Luzi (PhD candidate), Selma Riedo (Research assistant), Cornelia Stadter (BioLink project manager)

Selected publications


3. Paediatric and Rare Diseases Registries Group

The Paediatric and Rare Diseases Registries Group (SRDR) is a national, population-based registry for children and adults with rare diseases. The SRDR aims to collect a core data set from all people with rare diseases in Switzerland, approximately 500,000 people. The SRDR will constitute a platform for rare disease enabling clinical and epidemiological studies and facilitating patient’s participation in national and international trials.

In autumn 2020, the Federal Office of Public Health (FOPH) approved funding under article 24 of the national law on cancer registration. This financial support allows the employment of a project manager and an IT staff member. Specific measures of data transfer from University Hospitals Children’s Hospitals, and Centres for Rare Diseases to the SRDR are being implemented.

Key scientific activities
The Paediatric and Rare Disease Registries Group coordinates platforms, national registries and cohort studies:

Swiss Rare Disease Registry (SRDR): The SRDR is a national, population-based registry for children and adults with rare diseases. The SRDR aims to collect a core data set from all people with rare diseases in Switzerland, approximately 500,000 people. The SRDR will constitute a platform for rare disease enabling clinical and epidemiological studies and facilitating patient’s participation in national and international trials.

In autumn 2020, the Federal Office of Public Health (FOPH) approved funding under article 24 of the national law on cancer registration. This financial support allows the employment of a project manager and an IT staff member. Specific measures of data transfer from University Hospitals Children’s Hospitals, and Centres for Rare Diseases to the SRDR are being implemented.

SwissPedRegistry is a research platform for paediatric registries. It is part of SwissPedNet (https://www.swisspednet.ch/de/willkommen/), the Swiss research network of clinical paediatric hubs. SwissPedRegistry provides expertise and advice for the development and conduct of epidemiological and clinical registries collecting data on children or persons of any age. It develops regulatory frameworks, methodologies and instruments for registries and participates in national discussions and meetings on registry relevant issues.

Swiss Registry for Neuromuscular Disorders (Swiss-Reg-NMD): The Swiss-Reg-NMD is a national registry of children and adults diagnosed with Duchenne-Becker Muscular Dystrophy, Spinal Muscular Atrophy, and LAMA2-related Muscular Dystrophy. The registry aims for the inclusion of patients in current clinical trials and the long-term follow-up of patients with these disorders. The Swiss-Reg-NMD completed a report on the effect of Nusinersen in treating SMA patients for the Federal Social Insurance Office.

Swiss Cerebral Palsy Registry (Swiss-CP-Reg): The Swiss-CP-Reg is a national registry that investigates health-related issues in people with cerebral palsy. It includes all children, adolescents, and adults who are diagnosed with cerebral palsy. The aim is to improve the future care and well-being of individuals with cerebral palsy.

Swiss Growth Study (SGS): The SGS is a national registry that evaluates efficacy and long-term effects of growth hormone treatment in Switzerland.

Swiss Pediatric Inflammatory Brain Disease Registry (Swiss-Ped-IBrainD): The Swiss-Ped-IBrainD collects medical data on paediatric patients with inflammatory brain diseases. The dataset includes information on the diagnosis, disease course, and treatments of inflammatory brain diseases. The registry promotes communication and collaboration between specialists who will implement the acquired knowledge in the best interest of their patients. The registry aims to improve medical care and quality of life of children with inflammatory brain diseases.

Key team members
Claudia Kuehni (group leader, head of SwissPedRegistry, PI, SwissPedData), Ben Spycher (Co-PI SwissPedData), Anne Tschetter (senior researcher, project lead SwissPedRegistry and Swiss-CP-Reg), Dominique Baumann (project manager Swiss-Reg-NMD), Michaela Fux (Project manager, Swiss Rare Disease Registry), Grit Sommer (project manager SwissPedStudienzentrum).

Grants
Swiss Federal Office of Health (FOPH): Financial support of the Swiss Rare Disease Registry under article 24 of the national law on cancer registration (CHF 250’000 per year; 1/2020-10/2025; PI: Claudia Kuehni)

Universität Zürich, Abteilung für Stoffwechselkrankheiten, Kinderspital Zürich: Setup of Swiss Rare Disease Registry (CHF 332’000; 07/2020-12/2020; PI: Claudia Kuehni)

SwissPedNet: SwissPedRegistry, a research platform for paediatric registries (CHF 284’000; 1/2017-12/2020; PI: Claudia Kuehni)

Schweizerische Stiftung für das Cerebrale gelähmte Kind: Swiss Cerebral Palsy Registry (CHF 200’000; 4/2020-6/2023; PI: Anne Tschetter)

Patient organisations (CHF 33’500 for 2020) and pharmaceutical companies (sponsored research agreements and unconditional grants: CHF 205’000 for 2022) support the Swiss-Reg-NMD.

Swiss-Ped-IBrainD received financial aid from the Swiss Multiple Sclerosis Society and the pharmaceutical industry (CHF 380’000 for 2020-2022).

Key academic activities
Teaching: Regular teaching with lectures and tutoring in undergraduate and postgraduate studies (University of Bern, MPh program) by Claudia Kuehni and Ben Spycher.

Internal and external collaborations
Representatives of the Paediatric and Rare Diseases Registries Group attended national and international meetings with relevant stakeholders, participated in working groups, developed instruments, and represented the needs and interests of paediatric registries. The group collaborates closely with Swiss RDL, the medical Registries and Data Linkage centre at ISPM Bern, in particular for data linkage and software development.
Climate Change and Health

The Climate Change and Health group works to advance knowledge of the impact of climate change and related environmental stressors on health. The main lines of research include (1) quantification of impacts due to nonoptimal temperatures and evaluation of vulnerability patterns, (2) projections of health impacts under composite climate change scenarios, (3) intersection between urban environment and climate change, (4) assessment of etiological mechanisms explaining the association between temperature and specific health outcomes such as cardiovascular diseases and mental disorders, (5) the impact of changing environment on the elderly, in particular focusing on the link between healthy aging and climate change.

Selected publications


Research Groups

Climate Change and Health

The Climate Change and Health group works to advance knowledge of the impact of climate change and related environmental stressors on health. The main lines of research include (1) quantification of impacts due to nonoptimal temperatures and evaluation of vulnerability patterns, (2) projections of health impacts under composite climate change scenarios, (3) intersection between urban environment and climate change, (4) assessment of etiological mechanisms explaining the association between temperature and specific health outcomes such as cardiovascular diseases and mental disorders, (5) the impact of changing environment on the elderly, in particular focusing on the link between healthy aging and climate change.

Selected publications


Key scientific activities

Coordination of international collaborations within the Multi-country Multi-city Collaborative Research network.
Participation in international meetings, such as the annual meeting of the International Society for Environmental Epidemiology (online), InDust workshop (COST action, Barcelona, January 2020).
Invited speaker in national and international meetings, such as the General Assembly of the Swiss Society for Meteorology and European Geoscience Union (November 2020).
Participation in the preparation of the 6th Assessment Report of the Intergovernmental Panel on Climate Change, as contributing author in Chapter 16.

Key academic activities

Lectures for medical students on climate change, planetary health, and sustainability (Mensch und Umwelt).
Participation with several lectures in the MSc Climate Science (University of Bern) including two seminars and a full course on «Environmental epidemiology applied to climate sciences.»
Supervision of two PhD students (Marvin Bundo, Evan de Schrijver), an MSc student (Christoph Kestenholz), and a doctoral thesis (Séverine Bär).

Grants

As principal investigator:

As coapplicant or contributor (funded):
EU Joint Research Centre-Seville: «Revisiting temperature-mortality associations using climate reanalysis data». PI: Antonio Gasparini (London School of Hygiene and Tropical

**Canadian Institutes of Health Research (CIHR):** «Climate change-related health inequalities in Canada: How hot temperatures affect vulnerable groups living in large urban centres». PI: Piotr Wilk. Role: Co-applicant. $489,600. Oct 2020-Sept 2024.

**Internal and external collaborations**

**Internal:**
Jakob Zscheischler (Climate and Environmental Physics, University of Bern), Stefan Brönnimann (Climatology, University of Bern), Thomas Müller (Psychology unit, University of Bern).

**External:**
Swiss Tropical and Public Health Institute (Martina Ragettli), ETH Zurich (David Bresch, Erich Fischer), London School of Hygiene and Tropical Medicine (Antonio Gasparrini, Sir Andy Haines), Yale University (Kai Chen), CICERO Oslo (Jana Sillman and Kristin Aunan), Norwegian Institute of Public Health (Shilpa Rao), University of Valencia (Carmen Íñiguez), University of Bristol (Dann Mitchell and Eunice Le).

**Key team members**
Ana M. Vicedo-Cabrera (head), Evan de Schrijver (PhD student), Marvin Bundo (PhD student), Christoph Kestenholz (MSc Student), Séverine Bär (doctoral student).

**Selected publications**


Environmental and Spatial Epidemiology

We study potential effects of environmental exposures on human health with a focus on cancer by exploring both spatial and temporal variation in cancer incidence and mortality.

Key scientific activities
In an SNF-funded project on low-dose ionizing radiation and childhood cancer, we developed a map of terrestrial gamma radiation in Switzerland based on an extensive dataset of airborne gamma-spectrometry measurements. Linking this map to data from the Swiss National Cohort study and the Childhood Cancer Registry, we investigated associations between incidence of childhood cancers and external background radiation. As part of the EU-funded project RadioNorm, we initiated a multinational collaborative study of natural background radiation and the risks of childhood leukemia and tumors of the central nervous system together with partners in Finland, Denmark, Norway, and France. We published results of simulation studies comparing methods for Bayesian spatial modelling and disease mapping. Using these methods, we investigated the spatial distribution of childhood cancer incidence in Switzerland for different cancer types and the extent to which this variation was explained by previously studied environmental factors. We also published results of a study on parental occupational exposure to pesticides and the risk of childhood cancer in Switzerland.

Key academic activities
We give lectures in environmental epidemiology and health effects of nonionizing radiation for medical students; Ben Spycher coteaches a postgraduate SSPH+ course on applied logistic regression, and he is a member of the academic board of Public Health Weiterbildung. We presented results of our research at a symposium on the environment and cancer organized by the Swiss Cancer League at the Swiss Public Health Conference, and at the symposium of the Graduate School for Health Sciences.

Grants
Swiss National Science Foundation (No. 320030_176218): Low dose ionising radiation and the risk of childhood cancer. (Ben Spycher PI, 1/2018-12/2021, CHF 572’000).

Internal and external collaborations
Internal: Swiss National Cohort (SNC), Swiss Childhood Cancer Registry (SCCR), Child and Adolescent Health Group, SwissRDL – Medical Registries and Data Linkage.
External: UniSante, Université de Lausanne; Swiss TPH Basel; University of Tampere, Finland; French National Institute of Health and Medical Research (INSERM); Danish Cancer Society Research Center; UCLA Fielding School of Public Health; Swiss Paediatric Oncology Group (SPOG); Swiss Federal Nuclear Safety Inspectorate (ENS); Paul Scherrer Institute (PSI); Institute for Occupational Safety and Health of the German Social Accident Insurance (IFA); MRC Center for Environment and Health of Imperial College London; Unite INSERM Centre Leon Berard, Lyon.

Key team members
Ben Spycher, group leader; Christian Kreis and Astrid Coste, postdoctoral researchers; Antonella Mazzei and Christophe Folly, PhD student.

Selected publications
ESTHER Switzerland
Network for the promotion of Institutional Health Partnerships

Our work at ESTHER Switzerland coordinates institutional health partnerships (IHP) between organizations in Switzerland and low- and middle-income countries (LMIC). At ESTHER Switzerland, we regard long-term international collaboration as an opportunity for healthcare institutions to share best practices and learn from each other.

ESTHER Switzerland brings many benefits to its partners, both nationally and internationally. LMIC’s gain experience in health service management and develop clinical and leadership skills. Partners from Switzerland learn to work in more resource efficient ways and learn about healthcare issues, which they normally do not encounter at home. Both partners contribute to and may benefit from implementing research.

A distinctive difference between ESTHER-funded partnerships and more traditional development projects is that ESTHER breaks down conventional roles and power structures in favor of peer-to-peer partnerships, which enables collaborative needs assessment, shared accountability, and mutual learning. ESTHER Switzerland applies the IHP approach developed by the World Health Organization (WHO) called the Twinning Partnerships for Improvement (TPI) initiative. ESTHER Switzerland is the only official partner of the WHO’s TPI in Switzerland.

Through ESTHER, long-term, mutually beneficial collaborations between healthcare institutions are made possible, which contribute to the goal of Universal Health Coverage.

Key activities
The year 2020 has been marked by the COVID-19 pandemic. Nevertheless, we launched the call for proposals. The newly composed Steering Committee selected five full proposals and five start-up proposals with partners in Tanzania, Madagascar, Mozambique, Zambia, South Africa, Guinea Conakry, Uganda, Malawi, Bangladesh, and Uzbekistan.

We developed a clear strategic direction for ESTHER Switzerland, as well as a more attractive web appearance, and a clearer communication style.

Throughout 2020, we shared best practices from ESTHER Switzerland through three main channels: a new website, online events, and a WHO learning hub.

Grants
Swiss Agency for Development and Cooperation: https://www.esther-switzerland.ch/partnerships/

Internal and external collaborations
ESTHER Switzerland members actively contributed to several online events throughout the year, including events that provided opportunities to promote the approach of IHPs for Swiss and international partners, such as the Tropical Health and Education Trust (THET) and ESTHER Alliance conference «Partnerships in a Time of COVID-19» on April 25, 2020 and the ESTHER Alliance’s «Health Partnerships during the Pandemic: Contributions and Lessons» on August 28, 2020 (with participation by Olimjon Saidmamatov from the 20SU06 start-up partnership).

ESTHER Switzerland also participated in an online event that provided an opportunity to hear about partnerships funded by other ESTHER country programmes, interact with other ESTHER country members, and promote ESTHER Switzerland’s new strategic direction during ESTHER Ireland Partnerships Forum’s «A Bright Future for Health Partnerships» on November 11, 2020.

The joint ESTHER Alliance-WHO live webinar event, «Improving Health Service Quality through Health Partnerships» on December 2, 2020, was the first event organized together with the WHO – an important partner in promoting ESTHER standards among Swiss and international institutions.

Key team members
Dörte Petit (head of programme), Oscar H. Franco (chair), Luc Guex (head of finance and controlling), Christian Wyniger (web master), Judith Safford (communications and fundraising).
Evidence Synthesis Methods

The Evidence Synthesis Methods research group develops advances, applies, and disseminates methodology for synthesizing evidence from studies of the efficacy and safety of healthcare interventions. We work on pairwise and network meta-analysis, and we do research on methods to address publication bias, the role of nonrandomized studies in evidence synthesis, multivariate meta-analysis models, and methods to synthesize data about rare safety outcomes.

Key scientific activities
In a systematic review and network meta-analysis, we showed that alcoholic formulations of 4–5% alcoholic chlorhexidine gluconate are safe and twice as effective as povidone-iodine solutions in preventing infection after clean surgery in adults. (The Comparative Efficacy of Chlorhexidine Gluconate and Povidone-iodine Antiseptics for the Prevention of Infection in Clean Surgery. doi: 10.1097/SLA.00000000000004076)

Using data from a mega-trial in depression, we developed a machine-learning algorithm for personalizing the choice of antidepressant therapy. (Can personalized treatment prediction improve the outcomes, compared with the group average approach, in a randomized trial? Developing and validating a multivariable prediction model in a pragmatic mega trial of acute treatment of major depression. doi.org/10.1016/j.jad.2020.05.141)

We explored the level of agreement of the treatment hierarchies from different ranking metrics in network meta-analysis. We found that the pairwise agreement was high for all rankings and it decreased when there are imprecise estimates or large imbalances in the variance estimates, though such networks were rare in practice. (Agreement between ranking metrics in network meta-analysis: an empirical study. doi.org/10.1136/bmjopen-2020-037744)

We proposed a hierarchical dose-response meta-analysis model in a Bayesian framework. We compare our approach to the one-stage dose-response meta-analysis model in a simulation study. We also illustrate the method by reanalyzing an antidepressant dataset. (A Bayesian Dose-Response Meta-Analysis Model: Simulation Study and Application. doi.org/10.1177/0962280220982643)

We examined the relative contribution of network paths of different lengths to estimates of treatment effects. We found that on average one-third of evidence comes from direct effects and another half from paths of length 2. (In network meta-analysis, most of the information comes from indirect evidence: empirical study. doi.org/10.1016/j.jclinepi.2020.04.009)

Key academic activities
Members of the team teach CAS and SSPH+ postgraduate courses and contribute to undergraduate teaching at the University of Bern. We also participate and organize international short courses.

Orestis Efthimiou was appointed honorary member of the Psychiatric Department of Oxford University.

New members joined our team: Jacqueline Kolb, Thomy Tonia and Alex Holloway.

Adriani Nikolakopoulou received an SNF postdoc travel fellowship and went to Freiburg.

Selected publications


CINeMA: An approach for assessing confidence in the results of a network meta-analysis. A Nikolakopoulou, JPT Higgins, T Papakonstantinou, A Charnani, C Del Giovane, M Egger, G Salanti PLOS Medicine 2020 17 1-19


Key team members
Georgia Salanti, Konstantina Chalkou, Virginia Chiocchia, Orestis Efthimiou, Tasnim Hamza, Jacqueline Kolb, Theodoros Papakonstantinou, Michael Sea, Thomy Tonia

Grants
Georgia Salanti received a grant from NRP 78 «Covid-19» for the MHCOVID project for a continuously updated meta-ecological study of the effects of the COVID-19 pandemic on mental health, alcohol/substance abuse, and violence in the general population. https://mhcovid.ispm.unibe.ch

Internal and external collaborations
We collaborate with the Sexual and Reproductive Health and the HIV, Hepatitis, and Tuberculosis teams from ISPM. We have numerous collaborators around the globe in different universities: the University of Oxford, the University of Kyoto, Monash University of Sydney, the University of Oulu.
Our research group engages the clinical and public health epidemiology of HIV and coinfections with hepatitis B/C and tuberculosis in sub-Saharan Africa. We focus on the long-term outcomes of antiretroviral therapy (ART), the impact of ART on HIV transmission and coinfections, mathematical modelling, and methodological aspects of the analysis of longitudinal data.

We conduct analyses for international organizations such as UNAIDS, the Clinton Health Access Initiative, the World Health Organization, the Gates Foundation, UNITAID, the World Bank, and other external partners. We also collaborate closely with international partners as well as ISPM's own research groups.

Key scientific activities
The TB genomics project came to the end of a successful 8-year international collaboration with partners in the International epidemiology Databases to Evaluate AIDS (IeDEA) and others in the USA, Peru, Ivory Coast, Nigeria, Kenya, Tanzania, DRC, South Africa, Thailand, and Switzerland. The project combined classical epidemiology, microbiology, and next generation sequencing technology to answer clinical questions about the impact of underdiagnosed drug-resistant TB on mortality. This ambitious, transdisciplinary project led to eight high level publications.

Key academic activities
PhD: Nanina Anderegg, «People living with HIV worldwide: from start of ART to retention in care and death.»
Postdoc: Andreas Haas, SNF Ambizione 2021-2024, «Pathways from mental illness to the burden of disease: Causal mediation analysis of big data from South Africa.»

Grants
National Institute of Allergy and Infectious Diseases (NIAID), U01AI069924 (2016-2021): International Epidemiology Databases to Evaluate AIDS (IeDEA-SA), ($14,000,000, PI Egger)

Internal and external collaborations
ISPM research groups:
Cancer, Sexual and Reproductive Health, Climate Change and Health

External:
CTU Bern, University of Bern; Center for Development and Environment, University of Bern; University of Geneva; University of Zürich; Swiss TPH; Swiss School of Public Health (SSPH+); International epidemiology Database to Evaluate AIDS (IeDEA) network; World Health Organization.


Screening test accuracy of portable devices that can be used to perform colposcopy for detecting CIN2+ in low- and middle-income countries: a systematic review and meta-analysis. K Taghavi, E Rohner, P Basu, N Low, A Rutjes et al. BMC Women’s Health, 2020.

Key scientific activities
In 2020, members of our research group have made significant contributions to the understanding of the SARS-CoV-2 pandemic:
• We published one of the first estimates of the basic reproduction number and on superspreading of SARS-CoV-2 which considerably impacted the global discourse on the risk for a pandemic (ref. 1).
• We collaborated on the first epidemiological assessment of digital contract tracing for SARS-CoV-2 worldwide, demonstrating that digital contact tracing reaches exposed contacts, who then test positive for SARS-CoV-2 (ref. 2).

Key academic activities
• Member of the Swiss National COVID-19 Science Task Force (C. Althaus)
• Science communication and outreach activities related to the COVID-19 pandemic at various organizations, academic institutes and the media

Grants
Horizon 2020: EpiPose - Epidemic intelligence to minimize 2019-nCoV’s public health, economic and social impact in Europe, € 2’933’913 (€ 505’593 to ISPM), Co-PI: C. Althaus (with N. Low)

Swiss National Science Foundation (SNSF): Tracking the COVID-19 epidemic in Switzerland: phylogenetics and epidemiological modeling, CHF 295’487, PI: C. Althaus

Internal and external collaborations
We strengthened our collaboration with the Center for Space and Habitability (CSH) on topics related to mathematical modelling and simulation-based inference (refs. 3-4), which led to the creation of the Interfaculty Platform for Data and Computational Science (INPUT). INPUT aims at developing and applying computational methods in epidemiology, medicine and the natural sciences, and will officially launch in 2021 with various activities. In addition, we had successful collaborations on mathematical modelling with members of the following research groups: Cardiometabolic Health, Sexual and Reproductive Health, and HIV, Hepatitis and Tuberculosis.

Key team members
PD Dr. Christian L. Althaus (head of research group)
Dr. Emma B. Hodcroft (postdoc since November 2020)
Martina L. Reichmuth, M.Sc. (PhD student since December 2020)
Dr. Maurane Riesen (PhD student until January 2020)
The Musculoskeletal Health research group is involved in research projects on musculoskeletal disorders, especially osteoarthritis and giant cell arteritis. This includes studies of prevalence, incidence, diagnosis and natural history, as well as systematic reviews and randomized controlled trials. The group collaborates with the Clinic for Rheumatology and Immunology of the University Hospital Bern.

Key scientific activities

Peter Villiger and Stephan Reichenbach together with the CTU Bern set up the CORONACT trial, a double-blind, randomized, controlled phase II trial on the efficacy and safety of tocilizumab in the treatment of coronavirus induced disease (COVID-19). The multicenter study also included the University Hospitals of Zurich, Lausanne, and Lugano, and it started on 28 April (NCT04335071, https://clinicaltrials.gov/ct2/show/NCT04335071?term=Reichenbach+Stephan&draw=2&rank=3). The primary outcomes were ICU admission, intubation, and death. Through the end of the first epidemic wave, six persons had been included.

We are performing a 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. All original 1080 participants were mailed a validated self-reported questionnaire focusing on the development of hip pain and any surgical procedures performed during the previous 10 years. All participants initially evaluated with MRI were asked to undergo repeat clinical examination and MRI.

We are evaluating the morphological changes on hip X-ray within the framework of a multicenter, randomised controlled trial comparing arthroscopic hip surgery to physiotherapy-led care for femoroacetabular impingement (the Australian FASHIoN trial).

We are conducting a clinical trial on rapid induction of remission with high-dose glucocorticoids in patients with giant cell arteritis (GUSTO trial).

We are establishing a register of patients with giant cell arteritis at the University Hospital Bern and within the Swiss Clinical Quality Management in Rheumatic Diseases Registry (SCQM).

Key academic activities

Regular teaching at the undergraduate and postgraduate levels, including seminars and talks.

Grants

Swiss National Science Foundation 32473B_160153

Internal and external collaborations

University Hospital of Bern (Inselspital)
Swiss Institute for Translational and Entrepreneurial Medicine, Bern (siteinSEL AG)
CTU Bern, University of Bern
University of Toronto, Canada (Prof. Peter Juni)
University of Sydney, Australia (Prof. David Hunter)
Boston University, Massachusetts, USA (Prof. David Felson)

Selected publications


As the number of older people with chronic and complex conditions increases, the need for research in end-of-life palliative care has never been greater. An estimated 19 million people are in need of specialised palliative care worldwide each year. Therefore, finding what works best to provide relief from symptoms for persons near the end of life and offer support to those close to them has become essential.

Because human beings with physical, social, and spiritual needs are at the center of such research, the priority is less fighting disease than it is preserving quality of life, dignity, and self-determination. Research in palliative care thus requires a multidimensional, interdisciplinary approach to open up unimagined possibilities.

The Covid-19 pandemic only reinforces the importance of many aspects of palliative care, which include symptom treatment at the end of life, decision-making and advance care planning, and support for relatives.

Key scientific activities
The University Centre for Palliative Care (UZP) is a well-connected regional, national, and international center for specialised palliative care. The research group of the UZP, which also is affiliated with ISPM, studies end-of-life and palliative care with a research focus on advance care planning, care for the dying, and community/primary palliative care. The research activities range from the determination and definition of an international core outcome set of care at the end of life, primarily defined by patients themselves and their relatives, to the evaluation and establishment of model societal procedures in proactive planning for the end of life.

Key academic activities
Teaching: The UZP covers all topics related to palliative and end-of-life care in medical school years four to six. Since 2016, our center has been responsible for the postgraduate CAS in specialised interprofessional palliative care at the University of Bern. In addition, the center increasingly supervises master’s theses and dissertations, and participates in postdoctoral programs.

Academic achievements: Steffen Eychmüller was appointed associate professor at the University of Bern on 1 May, 2021, and Sofia Zambrano was awarded the SNSF Eccellenza Professorial Fellowship in 2020. She will start her position as an assistant professor in October, 2021.

Grants
Lindenhof Foundation, Bern (09/2020 – 08/2023): Platform Palliative Care, (CHF 1’480’000, Eychmüller)

Horizon 2020 (01/2019-01/2023): iLIVE: Living well, dying well. A research programme to support living until the end (Grant agreement no: 825731) (Total EUR 4’017’817 of which Bern EUR 394’750, Eychmüller and Zambrano)

Swiss National Science Foundation (02/2018-07/2022): PROAKTIV: A cluster trial of palliative needs assessment and care in general practice (SNF 407440_167501) (CHF 559’431, Maessen, Eychmüller)

Swiss National Science Foundation (04/2017-03/2020): Determinants of End of Life discussions in Non-Malignant Illness: An International, Multicentre, Qualitative Study to Understand the Key Perspectives of Bereaved Families and Medical Specialists (10001.C_1698871) (CHF 57’602, Zambrano)


Gesundheitsförderung Schweiz, (1/2020 - 31.12.2022): Projekt «Co-Lab» Compassionate city (Total CHF 300,000 of which CHF 125’000 for PCEOL-research group, (Eychmüller, Lead, Dr. Claudia Michel).

Internal and external collaborations
Rotterdam (+12 countries including Argentina and New Zealand) in iLIVE (Horizon 2020); Brisbane, San Francisco (SNSF); Geneva, Zurich

Key team members
Maud Maessen, Sofia Zambrano, Monica Fliedner, Barbara Affolter, Marina Maier, Jelena Baumann, Monika Hagemann, Martina Egloff, Valentina Gonzalez, Steffen Eychmüller, Andreas Ebner, Andri Christen

Selected publications
- Does Time for (in)Direct Nursing Care Activities at the End of Life for Patients With or Without Specialized Palliative Care in a University Hospital Differ? A Retrospective Analysis. MC Fliedner, M Hagemann, S Eychmüller, C King, C Lohrmann, RJG Halfens, JMGS Schols. Am J Hosp Palliat Care, 2020

- Unmet device reprogramming needs at the end of life among patients with implantable cardioverter defibrillator: A systematic review and meta-analysis. V Gonzalez-Jaramillo, P Sobanski, JA Calvoche, LF Arenas-Ochoa, OH Franco, L Huzniker, S Eychmüller, M Maessen. Palliat Med. 2020
In 2020 the key objective of the sexual and reproductive health research group was to contribute to prevention of and research about coronavirus disease 2019 (COVID-19) and the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) while maintaining our involvement in sexual and reproductive health research.

We also aimed this year to make sure that everyone felt safe and supported while working.

**Key scientific activities**

**COVID-19**

Living Evidence ([https://ispmbern.github.io/covid-19/](https://ispmbern.github.io/covid-19/), @evidencelive) was a major achievement for 2020. We started, out of interest, a systematic search for scientific publications on 17 January, 2020, when 19 publications about the novel coronavirus 2019 had been indexed. We expected to see a trend similar to what we had seen with Zika virus infection. Our Zika Open Access Project had found about 60 publications per week. For SARS-CoV-2COVID-19 (figure – see below), as of 21.05.2021 we had indexed 173'095 publications – 2'000 per week. The COVID-19 Open Access database is updated daily, is searchable, and is helping us and others with systematic reviews and living systematic reviews. The latest results of our living systematic review of asymptomatic SARS-CoV-2 infection (Buitrago-Garcia et al.) suggest that a minority of people with SARS-COV-2 will remain asymptomatic throughout the course of their infection, and that asymptomatic infections are about one-third as transmissible as symptomatic infections. Michel Counotte, Hira Imeri, Mert Ipekci, Dianne Egli-Gany, and Diana Buitrago-Garcia worked on this project with a crowd of volunteers (see photo), with support from the EpiPose project (Horizon2020) and the Swiss National Science Foundation.

We also contributed to systematic reviews of the accuracy of diagnostic testing for SARS-CoV-2 infections with partners in the Cochrane Collaboration and in mental health (Buitrago-Garcia, Low).

**The science of prevalence**

Prevalence, as a measure of the frequency of a condition, is deceptively simple and under-appreciated. In her PhD project, Diana Buitrago-Garcia is investigating numerous biases in the measurement of prevalence and deficiencies in reporting in individual studies and systematic reviews.

**Sexually transmitted infections**

The Women and Newborns Trial of Antenatal Intervention and Management (WANTAIM, meaning ‘together’ in Tok Pisin) is a cluster-randomised crossover trial in two provinces in Papua New Guinea investigating the effect of point-of-care testing for curable sexually transmitted infections. Our substudy examines newborn infections and development. With a target of 2'000, we had enrolled 1,824 newborn babies by April 2021. The first analyses are due in the second half of 2021. Dianne Egli-Gany worked on this project, with support from the Swiss National Science Foundation.

Philani Ndiphile (Be healthy and I will be healthy). An individually randomised controlled trial in Eastern Cape province in South Africa, this trial also investigates point-of-care testing for curable sexually transmitted infections. For her MD-PhD, Ranjana Gigi will conduct a cohort study within the main trial to examine the influence of the vaginal microbiome and other vaginal and sexually transmitted infections on preterm birth, with support from the Swiss National Science Foundation. The study plans enrolment starting in March 2021.
Systematic reviews of associations between reproductive tract and sexually transmitted infections. We have completed reviews for Neisseria gonorrhoeae, Mycoplasma genitalium, and other genital mycoplasmas. We are still doing the review for vaginal yeast infections.

Antimicrobial resistance in Neisseria gonorrhoeae. We are investigating the emergence of resistance to antimicrobials used to treat gonorrhoea. Ceftriaxone is the last antimicrobial that is recommended as a first-line treatment worldwide. Julien Riou led the development of a mathematical model which we fitted to data from England. Soushieta Jagadesh joined this project to extend the model to data from South Africa and to investigate how strategies for diagnostic testing will affect the timing of emergence of ceftriaxone resistance, with support from the Foundation for Innovative Diagnostics.

Partner notification. We are part of the Limiting Undetected Sexually Transmitted Infections to Reduce Morbidity (LUSTRUM) programme. In 2020 the cluster-randomised crossover trial to evaluate accelerated partner therapy (APT) for people with chlamydia completed enrolment, a new classification of sexual partner types was completed, and the mathematical model that will be used to evaluate the long-term impact and cost-effectiveness of APT was published as a preprint. Nicola Low and Christian Althaus lead the LUSTRUM work package on mathematical modelling.

Global political prioritisation of sexually transmitted infections. Funded by the Swiss Network of International Studies, we continued investigating the burden of disease due to sexually transmitted infections in a collaboration with the World Health Organization and Institute of Health Metrics and Evaluation. We are also examining points of view about the importance of sexually transmitted infections from the grassroots to global stakeholders. The spread of SARS-CoV-2 has, however, delayed our qualitative fieldwork in Papua New Guinea and Zambia.

Key academic activities

Vaccines against sexually transmitted infections. Nicola Low, Julien Riou and Christian Althaus have been part of a World Health Organization global consultation on vaccines for gonorrhoea.


Grants


Foundation for Innovative Diagnostics. 2020-10 to 2021-12: Mathematical modelling of the development and spread of antimicrobial-resistant Neisseria gonorrhoeae and the impact of new diagnostics and treatments in South Africa.

European Commission. 2020-03 to 2023-03. GRANT_NUMBER: 101003688: Epidemic intelligence to minimize 2019-nCoV’s public health, economic and social impact in Europe (EpiPose).

Internal and external collaborations

At ISPM, the Sexual and Reproductive Health group collaborates closely with the Immunepoepidemiology, HIV, and Evidence Synthesis research groups.

LUSTRUM consortium (Limiting Undetected Sexually Transmitted Infections to Reduce Morbidity. https://www.lustrum.org.uk/), led by Professor Claudia Estcourt, from Central

& North West London NHS Trust and University College London. LUSTRUM is a five-year programme of research funded by the National Institute for Health Research under its Programme Grants for Applied Research.

EpiPose consortium (Epidemic intelligence to minimize 2019-nCoV’s public health, economic, and social impact in Europe, https://www.uhasselt.be/epipose). EpiPose aims to provide urgently needed answers about the epidemiological characteristics of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)

WANTAIM study (Women and Newborns Trial of Antenatal Interventions and Management, http://wantaim.org/), led by Professor Andrew Vallely of the Kirby Institute, University of New South Wales, Australia and Papua New Guinea Institute of Medical Research.

Key team members

Nicola Low, research group lead
Diana Buitrago Garcia, PhD student
Ranjana Gigi, PhD student
Hira Imeri, research assistant
Soushieta Jagadesh, postdoc
Julien Riou, postdoc

Selected publications


Innovative contributions to theory and data in social inequality and health research.

Key scientific activities
Theory and measurement development, mostly in the areas of social determinants of health, cultural capital and health, health literacy, and health care utilization.

Key academic activities
Research, internal and external teaching, expert activities: research evaluation and assessment, advisory boards, and public health consultancy services. Establishing a new professorship for community health at ISPM.

Grants
NFP 74 Gesundheitsversorgung (04/2017–08/2020): Migrant Women’s Health Care Needs for Chronic Illness Services in Switzerland (Miwoca) (Projekt-Nr. 167428) (CHF 485'879)

Internal and external collaborations
Geneva, Zug (YASS consortium); Geneva, Tübingen, Istanbul (Miwoca); Vancouver (Cultural capital), Atlanta, Montreal, Jyväskylä

Key team members
Thomas Abel, Richard Benkert, Sophie Meyer, Romaine Farquet

Selected publications


SwissRDL – Medical Registries and Data Linkage

SwissRDL is a research and service unit offering all-round support to medical registries that includes the planning, set-up, operation, and maintenance of small regional, national, and international medical registries. To ensure high data quality, we provide monitoring visits and central data monitoring, and detailed reports, statistical analyses, and publications that demonstrate registry success.

Key objectives
In collaboration with external partners that include medical associations and foundations, SwissRDL develops, implements, operates, and maintains national and international medical registries and multicenter outcome studies. We ensure high quality data in a secure data center applying strict validation rules and regular, on-site monitoring.

The support team is in contact with more than 180 hospitals in Switzerland to offer help with registry issues and data entry via phone, email, and webinars. We have installed a comprehensive implant library for the identification and categorization of implants such as those for hips and knees, and support barcode-scanner-based data entry and web services for direct data transfer from hospitals.

SwissRDL offers full-range support for patient-reported outcome measures (PROMs) on tablets and websites, and a team of statisticians and project manager regularly creates quarterly hospital reports and comprehensive annual reports.

A further SwissRDL core excellence is data linkage. Longstanding experience in building large cohorts such as the Swiss National Cohort (www.swissnationalcohort.ch), in which large datasets were linked using probabilistic record linkage methodology, led to our expertise in linking data for which no unique identifier is available and simple merging is not possible. We also have developed and applied privacy preserving methods for record linkage.

Key scientific activities
SwissRDL creates high quality scientific reports such as the annual report of the national hip and knee registry (www.siris-implant.ch). Additionally, we produce benchmark reports for clinics, which allow comparison of core outcomes between hospitals using funnel plots. SwissRDL participates in several research projects analysing registry data, and supports the linkage of additional data. For medical device suppliers we offer implant reports for specified products, and our data managers and statisticians analyze data for scientific publications and posters.

SwissRDL supports national and international record linking projects and in Africa, for example, has linked HIV data with cancer registry data.

Key academic activities
Dr. Adrian Spörrì regularly teaches medical statistical software, medical registries, and probabilistic record linkage methodology to undergraduate and postgraduate students at the University of Bern and to international partner organizations. Dr. Christian Brand is involved in undergraduate teaching in biostatistics.

Grants
SNF 2019-2021: The Swiss Pediatric Hematology/Oncology Metabank – a network for precision medicine research, Federal Office of Public Health: Swiss Rare Disease Registry

BAG 2020-2024: Schweizerisches Register für seltene Erkrankungen

Internal and external collaborations
SwissRDL supports researchers at at the University of Bern and the University Hospital of Bern, Inselspital, to create and operate medical registries. Additionally, we collaborate with medical associations and foundations to operate registries such as the SIRIS foundation (www.siris-implant.ch) for the national hip and knee implant registry, with more than 150 hospitals involved, and Swissnoso (www.swissnoso.ch) for surgical site infections, with more than 170 hospitals delivering data to SwissRDL. We collaborate with the Swiss National Association for Quality Development in Hospitals and Clinics ANQ (https://www. anq.ch/en/) and offer support as members of expert committees. SwissRDL is in charge of the Home Care Data platform of Spitex Schweiz (www.spitex.ch) supporting data management and reporting for close to 100 Spitex organizations. Internationally, we are in close contact with registry providers that include the National Joint Registry in UK and the Endoprothesenregister Deutschland, and participate in meetings and conferences of the International Society of Arthroplasty Registries. Through implant registries we are in touch with medical device suppliers and offer scientific support for reports and studies.

Key team members
Dr. Adrian Spörrì, head of SwissRDL
Dr. Christian Brand, statistician
Dr. Kurt Schmidlin, statistician and record linkage
Dr. Andreas Boss, project manager and record linkage
Martin Drees, head of development team, programmer
Lilianna Bolliger, project manager, monitoring and support
Stefanie Paerschke, project management support