Swiss Paediatric Asthma Cohort

Claudia Kuehni, Eva Pedersen, Alban Ramette

ISPM, University of Bern
claudia.kuehni@ispm.unibe.ch

C Casaulta and P Latzin (Bern), A Möller and F Singer (Zürich), J Barben (St Gallen), G Hafen (Lausanne), N Regamey (Luzern), U Frey (Basel)…
Why a Clinical Cohort?

Asthma: many unanswered questions

- **Scientific**
  - Phenotypes? how are they distinguished?
  - Response to treatment - differ by phenotype?
  - Prediction of long-term outcome?

- **Clinical**
  - Do novel diagnostic tests improve management?
  - Asthma control

- **Public health**
  - Usefulness & Implantation of guidelines? Equal access? Environmental exposures?
Why a Clinical Cohort?
Not all we see is asthma: few data on

- Chronic cough
  - cough-variant asthma, ENT disease, other aetiologies
  - risk factors, natural history, treatment and prevention
- Exercise-induced dyspnoea
  - vocal cord dysfunction, EIA, other causes
- Sleep-disordered breathing, snoring
- United airways
Previous Research – mostly from

- **Birth cohort studies**
  - 90% healthy children, 10% with disease, 1% not «mild»
  - risk factors for incidence
  - limited power for diseased children (phenotypes, prognosis)
  - self-reported data
  - Few data on other than asthma (chronic cough, etc)

- **Small clinical cohorts** (monocentric)
  - Non-representative

- **For clinical implications, we need research from real patients in our healthcare system** - multicentric representative studies
The Swiss Paediatric Asthma Cohort
(revise name)

A representative longitudinal study of children and adolescents seen in the Swiss health care system for recurrent:
- wheeze, dyspnoea, cough, exercise- and sleep-related problems

Standardised central collection of routine clinical data
- Patient history (questionnaire)
- clinical data (examination, diagnostics, diagnoses, treatment)
- Purely observational – no test done «for the study»

Follow-up via repeated visits and postal questionnaires
Who will be included?

Patients: aim for 3000

- Respiratory outpatient referrals for “asthma”, wheeze, cough, exercise- and sleep problems
- Age 0-16
- Excluded: specific severe disease (CF, PCD, …)

Partners/setting:
- **Phase 1** (2016): Bern, Lausanne, St.Gallen, Zurich
- **Phase 2**: (depends on funding):
  - Other centres: Basel, Luzern, Geneva? Other?
  - Paediatric practices (1ary care)
Flow chart – study participation

**Clinic**
- First visit
- Signed consent form
  - Study information and questionnaire
- **Clinic**
- First visit
- No signed consent form
  - Study information and questionnaire

**Baseline data**
- Personal data
  - Names, addresses, telephone numbers demographics
- Questionnaire:
  - Current symptoms, history of symptoms, family history of symptoms, environmental factors
- Results of clinical tests
  - Lung function
  - Allergy test
  - Blood test
  - Oxygen saturation
  - Etc.

**Follow-up data**
- Update of Addresses
- Follow-up questionnaire:
  - Current symptoms, medication, environmental factors
- Intermediate visits to clinic
  - Results of clinical tests

**Trust Center, ISPM Bern**

**Linkage with Routine data, ISPM Bern**
- Medizinischen Krankenhaustatistik des BFS
- Einwohnerkontrollen
- Geburtenstatistik
- Todesursachenstatistik
- Swiss National Cohort

**Data analysis, ISPM Bern**

**Medizinische Datenbank, ISPM Bern**
Aims and Impact

Real-life study in contemporaneous health care settings

- **Clinical epidemiology**: Better understanding of asthma phenotypes, chronic cough and non-specific respiratory problems in children
- Spectrum and natural history, asthma prediction
- Healthcare research
- Sampling frame for nested studies
- Opportunity to standardise procedures across centres
Data rights and access

**Redcap database (internet-based)**
- Personal data separated from medical
- Data entered by data manager
- **Centres can download own data** anytime
- **Agreements and concept sheets** for
  - analyses using data from several centres
  - nested studies with additional data collection

**Ethics: “registry permission”, allowing to**
- Collect data from records & questionnaires
- link routine data
- Analyse data for a set of pre-specified aims
Timeline

- June 16: Ethics, questionnaires
- Oct 16: Start in pilot centres
- From 2017: First analyses, possibility for other centres

Funding

Allergie-Stiftung Ulrich Müller
SNF
Lungenligen Bern & St.Gallen

Centres need local funding
Questions?
Die Swiss National cohort
an anonymous dataset of all inhabitants
Linkage SPAC - SNC

- Belastet
- Nicht belastet
  - Erkrankt
What data will we collect?

Baseline data (first visit to clinic)

- **Personal information** (names, addresses, date of birth, consent)
- **Questionnaire** to family/patient (standardized history)
  - Current & past symptoms & treatments
  - Environmental and socio-economic exposures
- **Hospital records:** diagnoses, prescriptions and test results
  - Lung function tests, FeNO, SaO
  - Allergy tests, blood tests, imaging, …

Follow-up data

- Follow-up clinical visits where available
- Short postal questionnaire to parents

“Swiss routine data” (obtained by data linkage)

- Birth and mortality statistics, hospital episode statistics, census