


Das Forum für ICT im Gesundheitswesen
Le forum pour les TIC dans le système de santé

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SGMI SSIM SSMI
Schweizerische Gesellschaft für Medizinische Informatik
Société Suisse d'Informatique Médicale
Società Svizzera d'Informatica Medica
Swiss Society for Medical Informatics

**STADE DE SUISSE
BERN**
11.-12. SEPT. 2018

SHCS Scientific Board: Patients incl

David Haerry, Chair, Positive Council Switzerland

 @ Speaker twitter handle

In cooperation with



ehealthsuisse
Nucleo nazionale per il paziente
Organo di coordinazione Confederazione-Cantoni
Organo di coordinamento Confederazione-Cantoni

IHE
SUISSE
Integrating
the Healthcare
Enterprise

pharmaSuisse 

VGIch
Vertragsgesundheitswirtschaft Schweiz



SWISS HIV COHORT STUDY SHCS

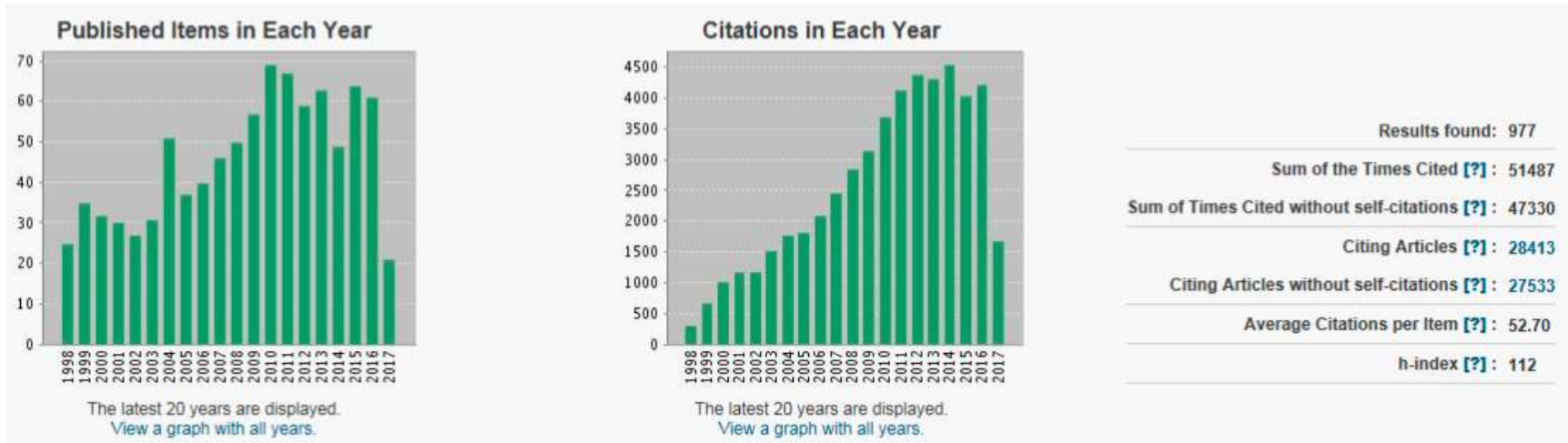
- Systematic longitudinal study enrolling patients with HIV, established 1988
 - Collaboration of all Swiss University Hospital infectious disease clinics, two cantonal hospitals, affiliated laboratories, smaller hospitals & private physicians
 - Represents Swiss HIV epidemic (>70% of ARV sold in CH prescribed within SHCS)
 - Major goal: optimise patient care, reduce HIV transmission & research on HIV treatment, pathogenesis, co-infections, immunology & virus – host interactions
- 2 • Biobank

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SHCS ORGANISATION



SHCS PUBLICATION RECORD





SHCS, PERSONAL & SUBJECTIVE

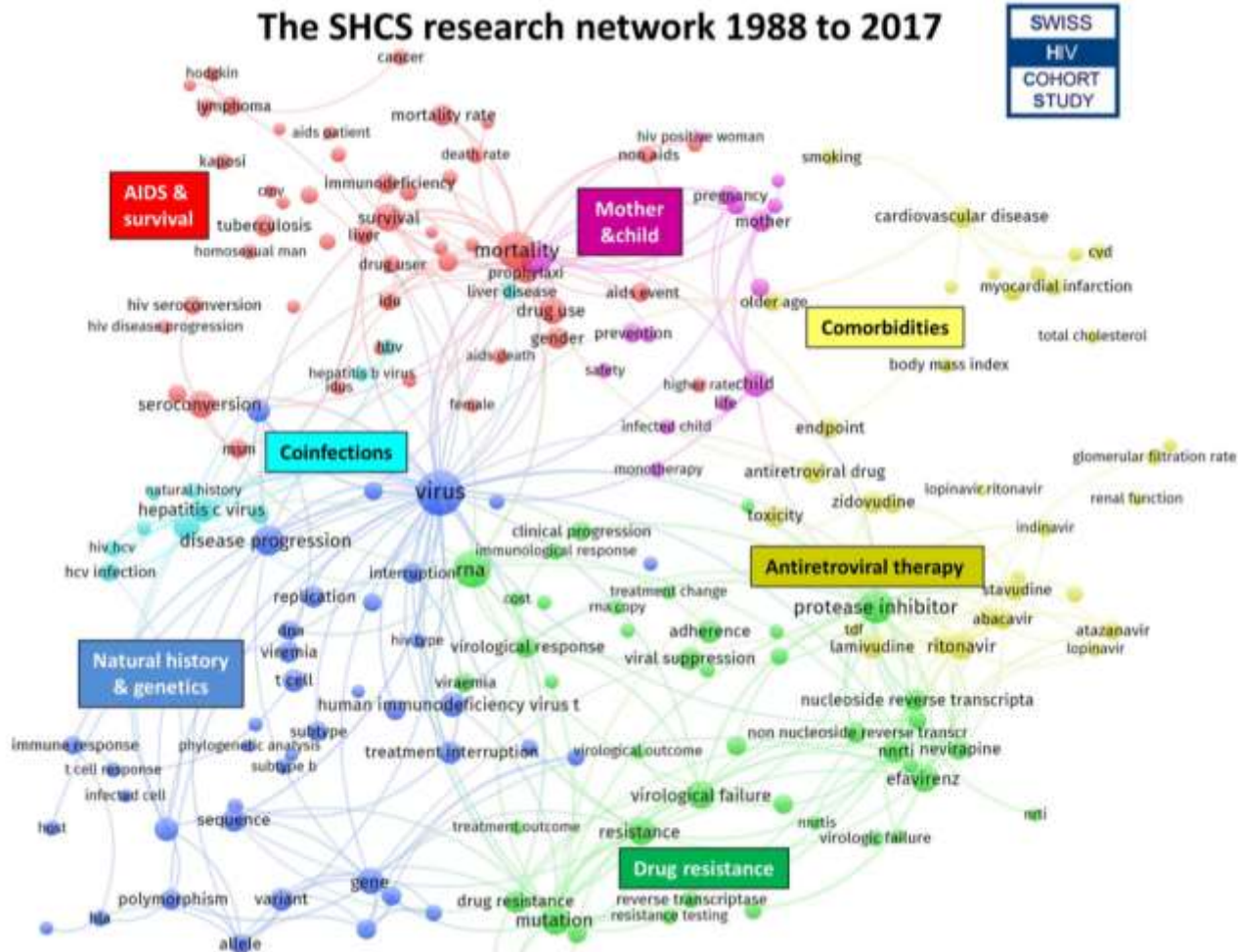
- General and personal quality of HIV care: enormous impact
- Life expectancy at 60 vs 30 years ago at diagnosis
- Learned handling diverse patient populations – IDU, migrants, gay men
- On heterogeneous care delivery structures: big impact in the absence of national guidelines, but room for improvement
- Adapting to new challenges – see next slide
- Collaboration between universities, smaller hospitals and private practitioners: enormous impact for two reasons
 1. Joint research & publications within SHCS
 2. Annual virology meeting since 29 years

IDU = Injecting drug users

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The SHCS research network 1988 to 2017

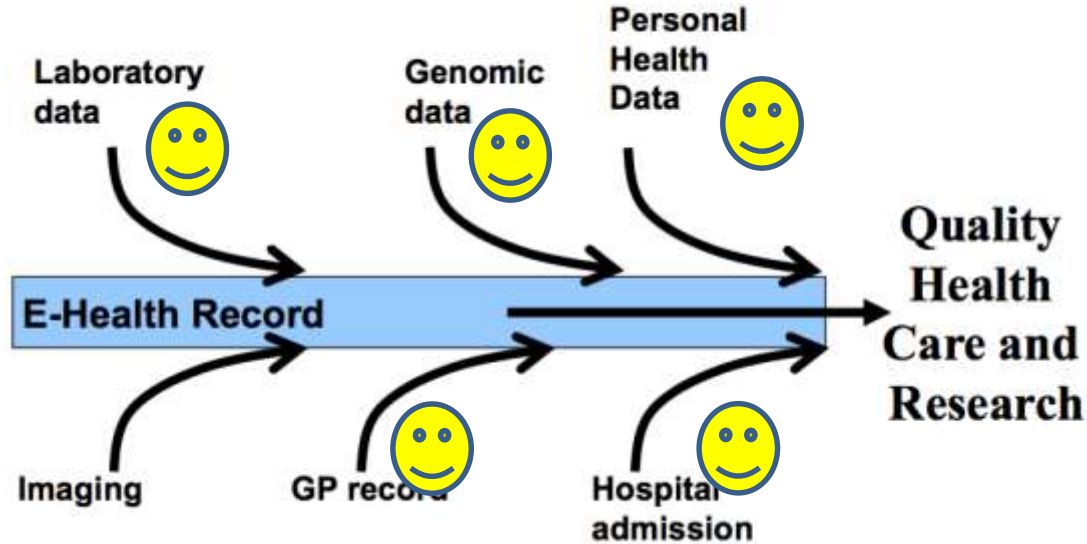


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11.-12. September 2018

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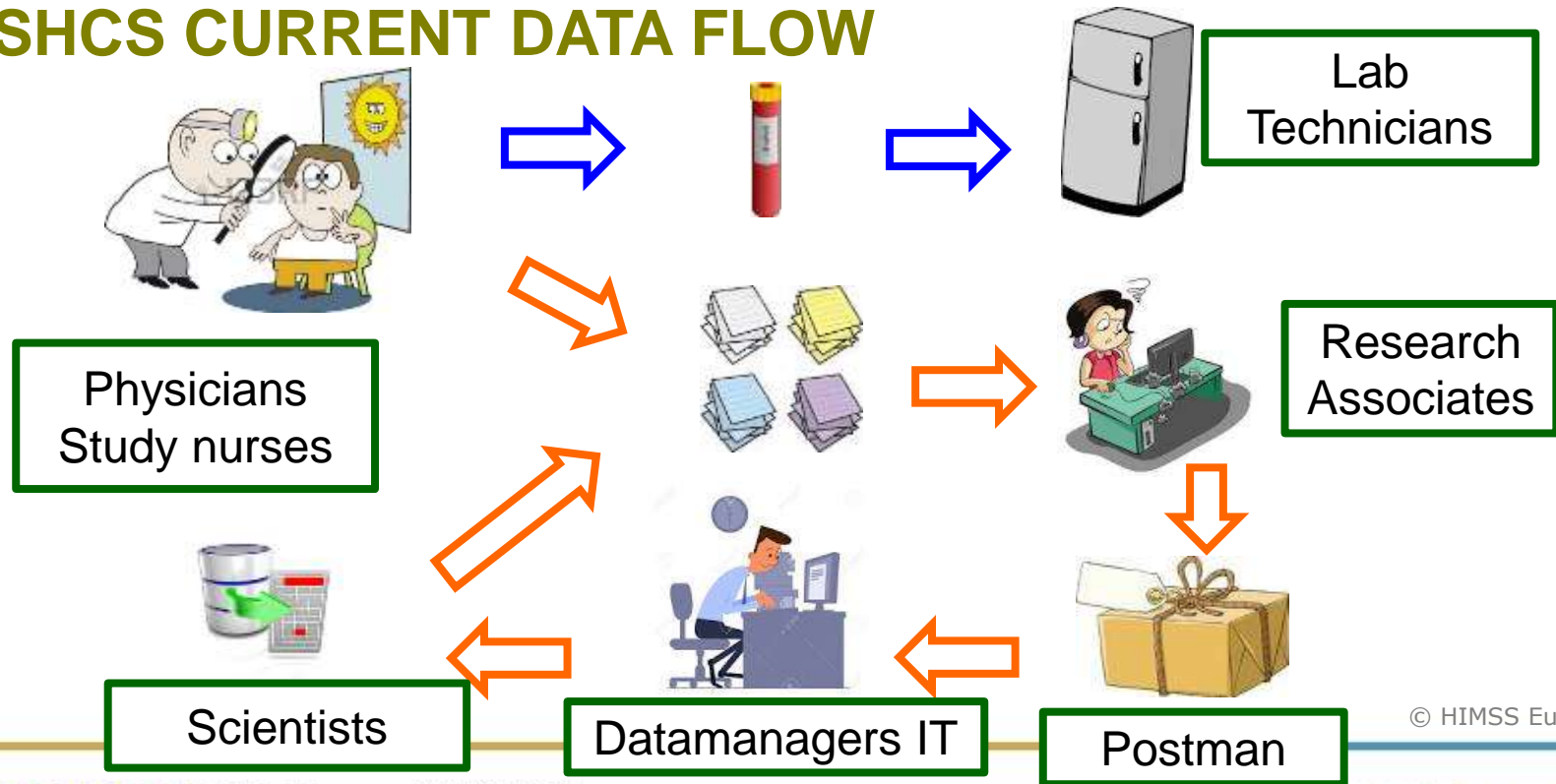
INTEGRATION OF PATIENT AND HETEROGENEOUS DATA - ESSENTIAL FOR THE FUTURE OF MEDICINE



7 Slide courtesy Andrew Morris

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SHCS CURRENT DATA FLOW





SHCS DATA MANAGEMENT

- Safe data handling & collaboration between CH centres
 - Participants anonymised with 5-digit ID number
 - Only documents with ID number leave clinics, never a name
 - Only treating physician/institution knows linkage
 - Paper CRFs sent in secured boxes to data centre (centralized)
 - Data centre: data processed, database shared with participating institutions once per month via secure server
 - Some information suppressed (e.g. date of birth & nationality)



SHCS DATA MANAGEMENT

- International collaborations
 - SHCS Scientific Board decides about participation. Projects required to be within SHCS IC
 - Data exchange in standardised format (<http://www.hicdep.org/>) via a secured server



CHALLENGES

- Current static IC model insufficient
 - Authorising collection, rather than use of data
- Impact of digitalisation on health research
- Genomic privacy vs genomic openness
- Can people access their data?
- New Swiss General Consent: important step – is it enough, does it help or hinder research?
- Trust and its perception

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WHEN IS PATIENT INPUT PARAMOUNT?

- Survival data, global cohorts collaboration opening access to private insurance (life) – partnership with SwissRe
- PARTNER studies: proof of non-infectiousness of patients with undetectable viral load; applies to hetero- and homosexual couples
- General: research questions related to quality of life

RECENT CHALLENGE

Data mining and predictive modeling for morbidity- and mortality-related parameters in HIV infection

A novel methodological approach with outcome-related clusters

Authors: [REDACTED]; Swiss HIV Cohort Study

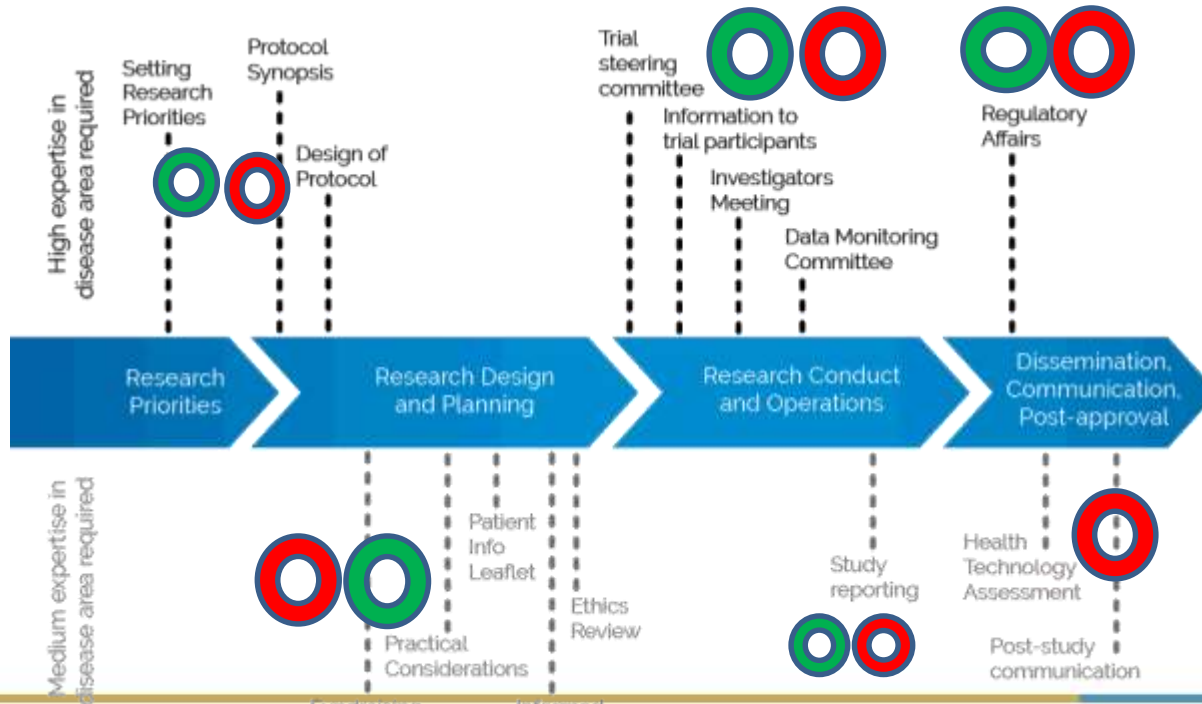
- * First authorship
- † Senior authorship

1 [REDACTED]

² IBM Research — Zurich Laboratory, Ruschlikon, Switzerland

[REDACTED]

PATIENT INVOLVEMENT EUPATI



HIV
HCV

2 EUPATI PATIENT EXPERT TRAININGS

- 98 Alumni, 3 from CH
- 58 Indications
- 3rd Course ongoing,
3 from CH
- Contact alumni
<https://www.eupati.eu/eupati-training-course/>





THANKS

- Prof Huldrych Günthard, Zürich University Hospital, President SHCS
- Prof Andri Rauch, Inselspital Bern, Chair Scientific Board SHCS
- Dr Alexandra Scherrer, Zürich University Hospital, Head SHCS Data Centre
- Prof Andrew Morris, Scottish Government Health Directorate, Chief Scientist