Why national medical data infrastructure is necessary for future healthcare challenges

Stefan Thurner

Immediate benefits of national data infrastructure

Keep public HCS affordable

- know true costs in the health care system
- know true services
- reduction of over-medication, over-treatment, and double reporting
- economic benefit of prevention strategies

Keep quality

- actual provision status of HC services
- relation of work conditions and health
- objective and continuous quality control
- build patient participation
- manage data securely

Keep HCS planable

- capacity planning in the HCS
- know infrastructure and capacity and its use

COMPLEXITY SCIENCE HUB VIENNA

Status of Austrian health data landscape

- **Blind spots.** Stakeholders don't know central data in HCS: practitioners don't code diagnosis, outcome-data, Federal institutions don't have information on medication, WahlärztInnen, outpatient care, over-the-counter medication, medication in hospitals
- **Insufficient data flows.** Practically no secondary use → little harmonization. Register data is fragmented and not harmonized (cancer, blood, deaths, etc). Inconsistent pseudonyms → merging not possible
- **Data silos.** Data is not shared between stakeholders and data-owners
- **Speed of data availability.** Insufficient, slow, and intransparent (not automated, not digitalized, manual actions (contact tracing telephone-based, delayed reporting, incompatible software, delays at intermediaries, "Aktengänge", weekends …
- **Data quality.** Insufficient standards, missing control. Counting hospital beds, deaths in pandemic still challenge
- **Data security.** Huge difference in safety standards in different silos

COMPLEXITY SCIENCE HUB VIENNA

Reasons for the current situation

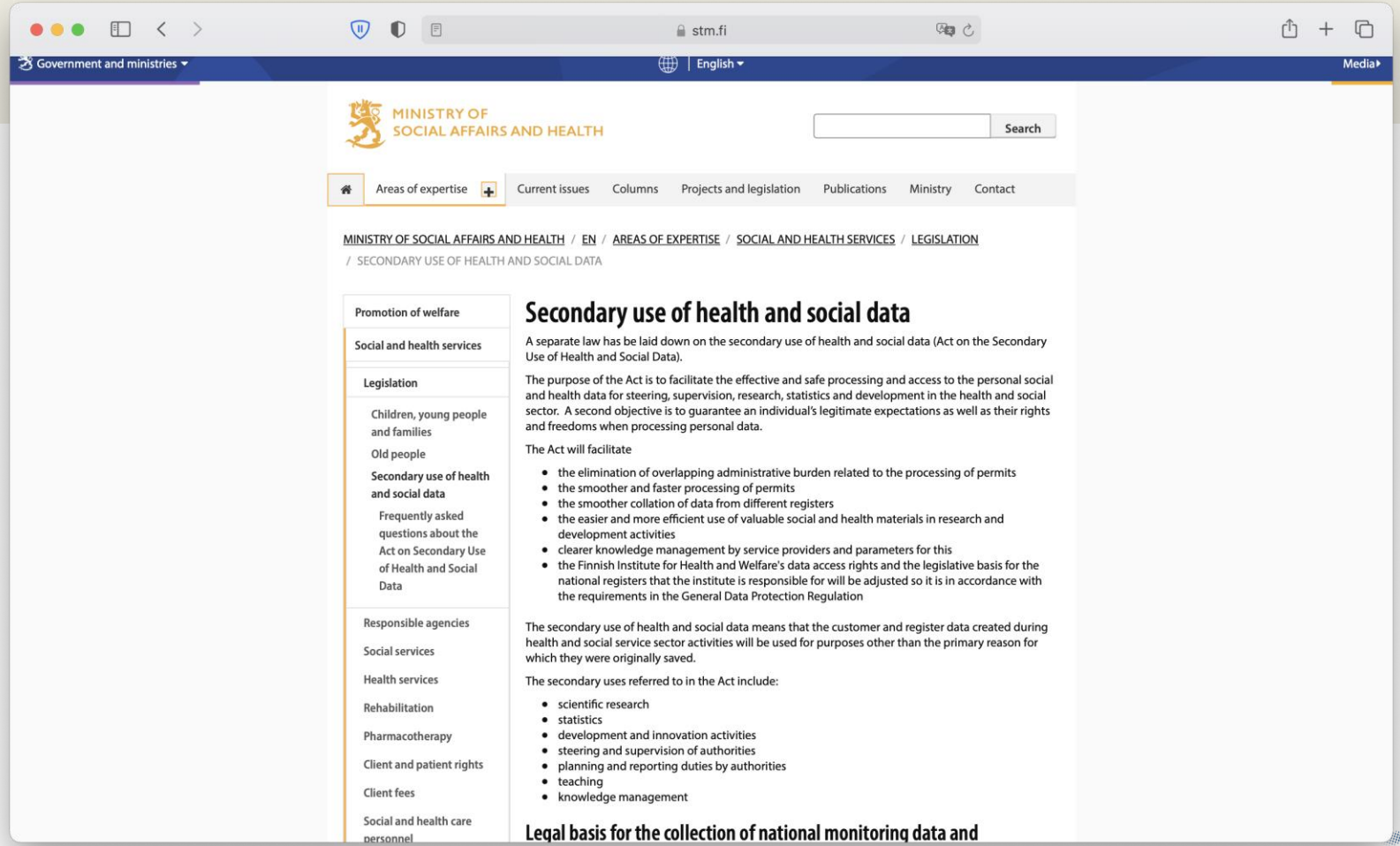
- Health data is **distributed between institutions** with different incentives: social security, insurance, ministries, Statistik Austria, THE provinces, regional health agencies, hospitals, AGES, GÖG, ELGA …
- **No** institution holds **all** data
- Institutions have **no incentives** to share data
- Efforts to pool data have failed in the past 30 years
- Data safety used as an unqualified excuse

Necessary: Independent national medical data institution

- all medical/social data becomes accessible in harmonized way
- all institutions that need data get minimal necessary access to fulfil purpose: from accounting, monitoring, planning, science to patient
- reporting to parliament
- broad governance without veto rights: HC institutions, provinces, patient representatives, Ärztekammer, etc
- highest security standards

Is that possible?

https://stm.fi/en/secondary-use-of-health-and-social-data



COMPLEXITY SCIENCE HUB VIENNA

MINISTRY OF
SOCIAL AFFAIRS AND HEALTH

Act

on the Secondary Use of Health and Social Data

By decision of Parliament, the following is enacted:

Is that possible in Austria?

COMPLEXITY SCIENCE HUB VIENNA

No

Is that possible in Austria?

- deadlock between THE provinces and federal institutions
- conflicting interests between multiple institutions
- must be a top down reform – ministry alone too weak
- political gains marginal or negative

→ **tragedy of the commons**

→ **irony: it has been possible in the past**

Medicine is turning into data science

Imagine that all that happens is recorded

reconstruct history of health care system on personalized basis

→ can watch how medicine works

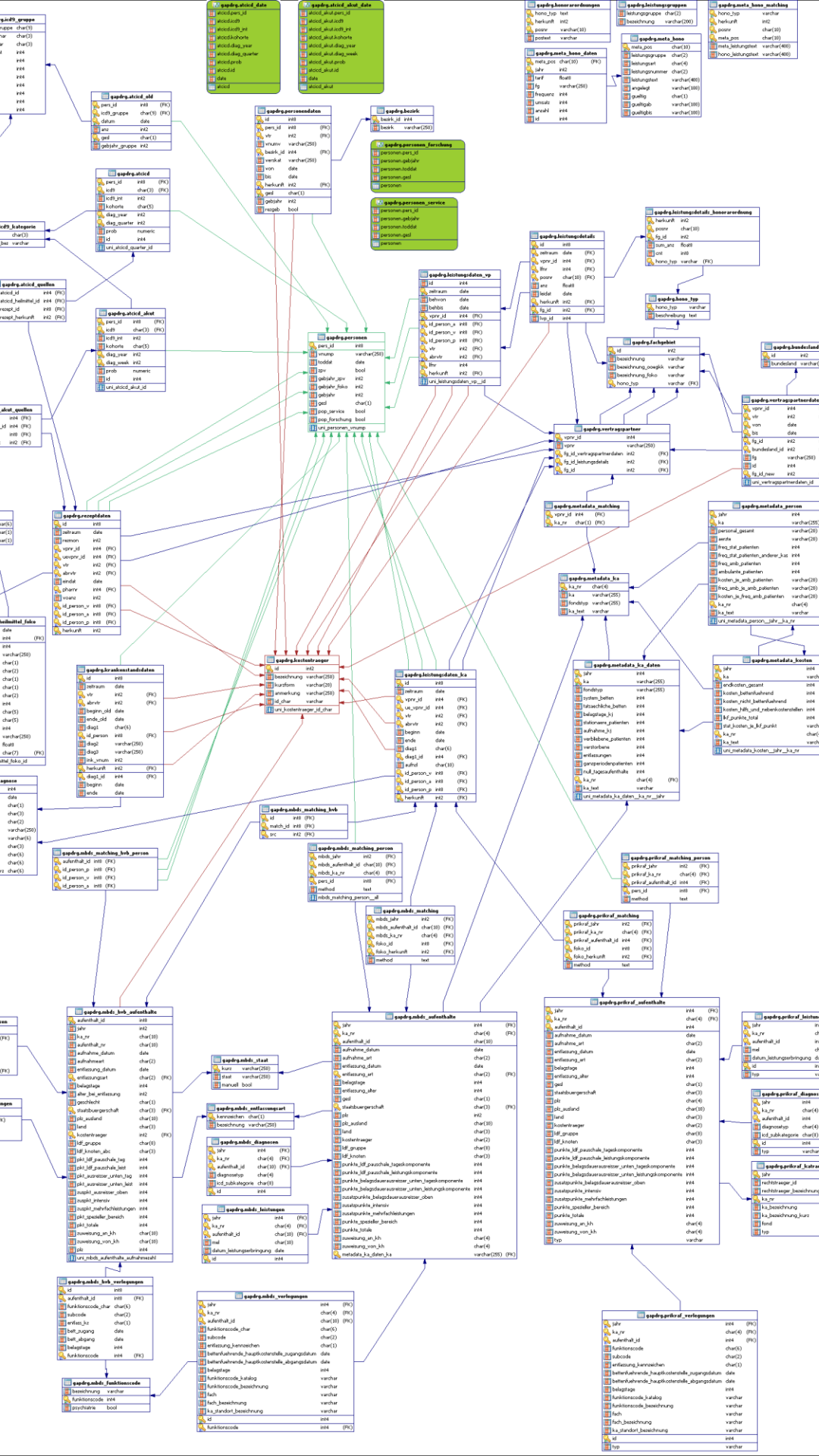
A few words about scientific benefits

- learn patient trajectories
- learn side effects
- learn comorbidities → re-classify diseases
- learn efficiency of treatments
- learn drug efficiency
- learn prevention benefits
- learn resilience of HCS
- learn pandemic management

Example: national re-use data

every medical service → one data line

date |
patient ID |
healthcare practitioner ID |
diagnosis |
side diagnosis |
prescription |
price if generic drug/treatment/therapy |
pharmacy ID |
price of medication |
date of purchase

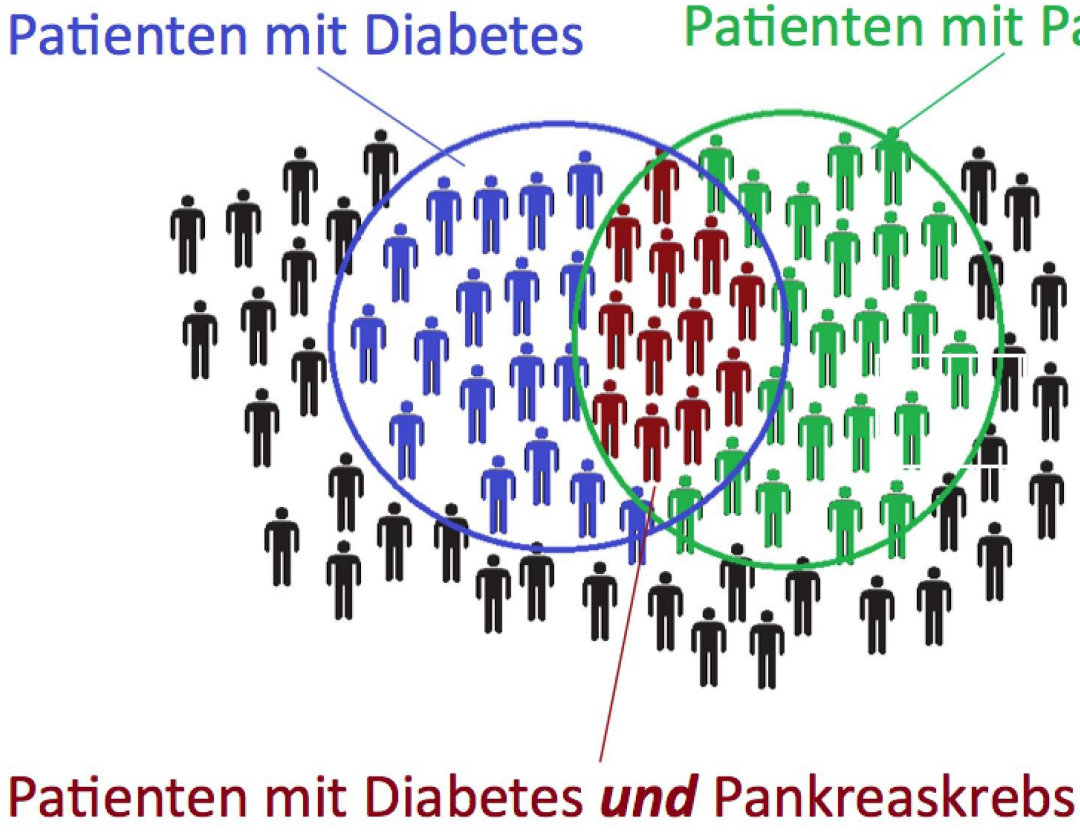


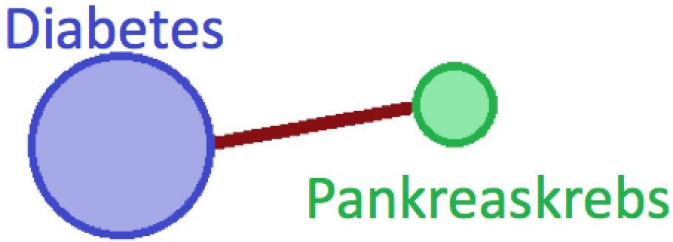
Research data set **2006/2007**

8,000,000	Patients
100,000,000	Patient contacts per year
2,000,000	Hospitalizations per year
12,000	HC providers
6,102	Diseases (ICD10 code)
1,171	Substances (ATC code)
255	Hospitals
1,238	Pharmacies

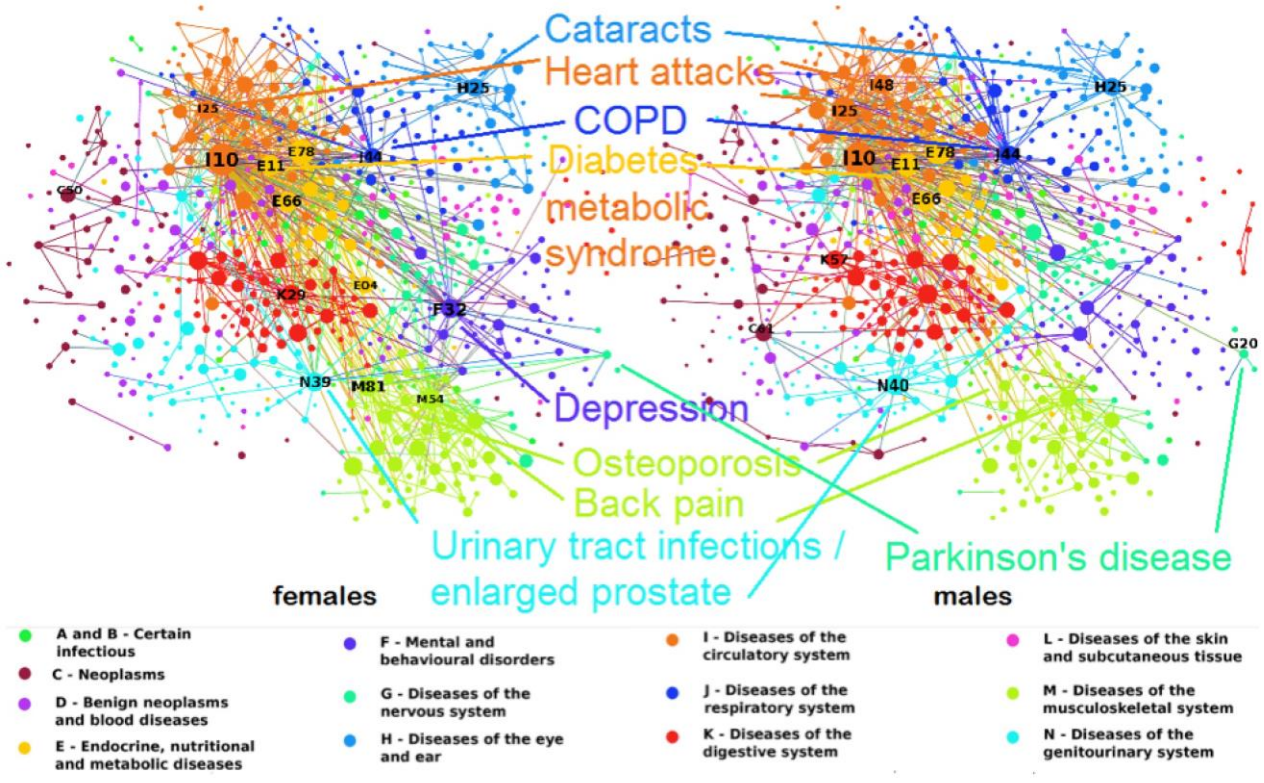
COMPLEXITY SCIENCE HUB VIENNA

Co-morbidity in population





Co-morbidity network



0-8 Jahre

9-16 Jahre

17-24 Jahre

25-32 Jahre

33-40 Jahre

41-48 Jahre

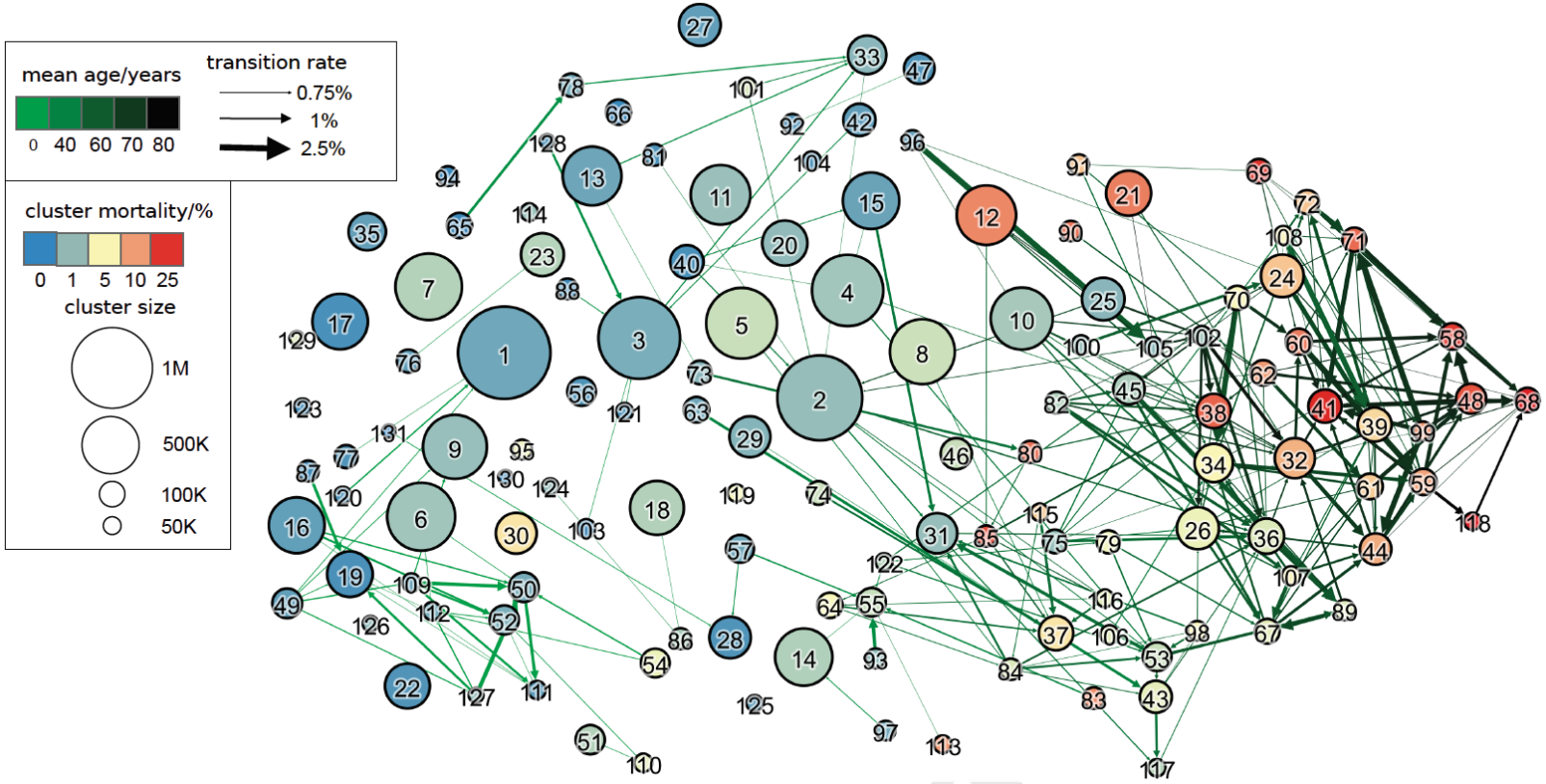
49-56 Jahre

57-64 Jahre

65-72 Jahre

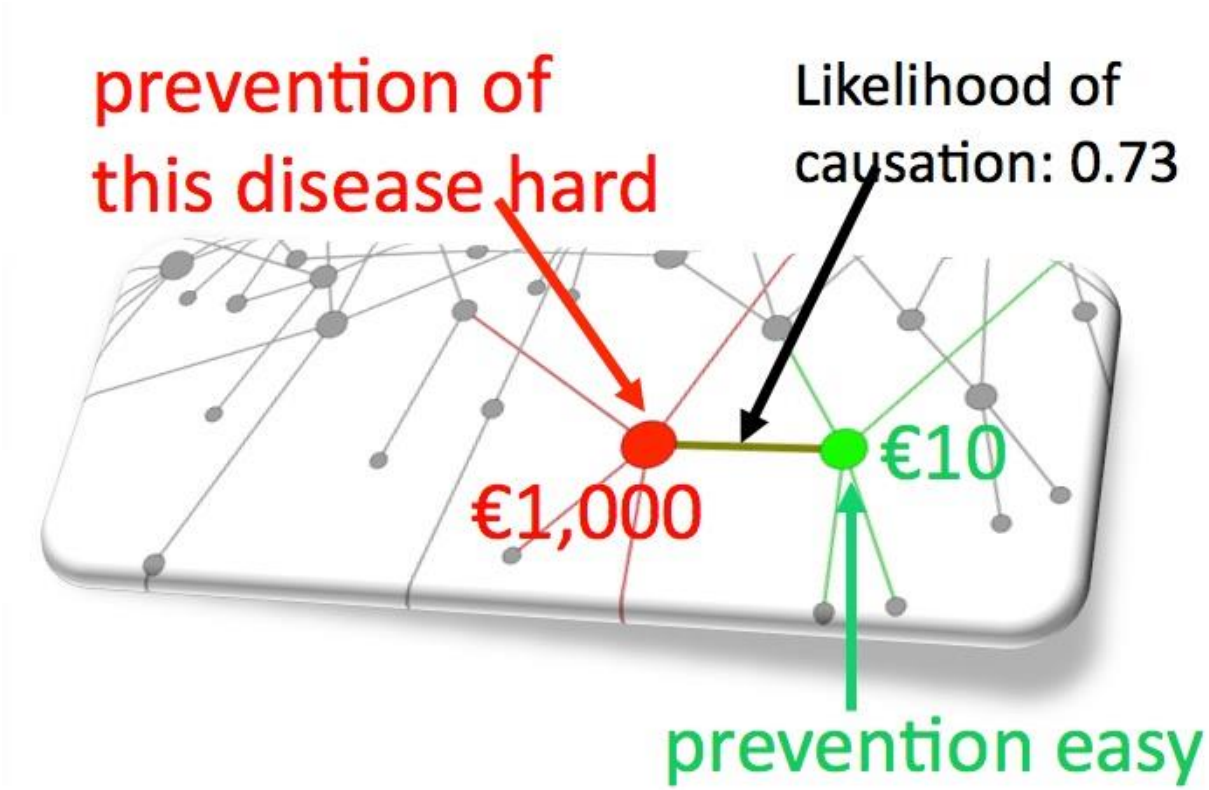
COMPLEXITY SCIENCE HUB VIENNA

Compute health-trajectories



COMPLEXITY SCIENCE HUB VIENNA

How effective is prevention?



COMPLEXITY SCIENCE HUB VIENNA

What therapy works – which doesn’t?

group 1: therapy A
group 2: therapy B

compute all co-morbidities following therapy A
compute all co-morbidities following therapy B

compare: follow up costs, hospital. times, ...

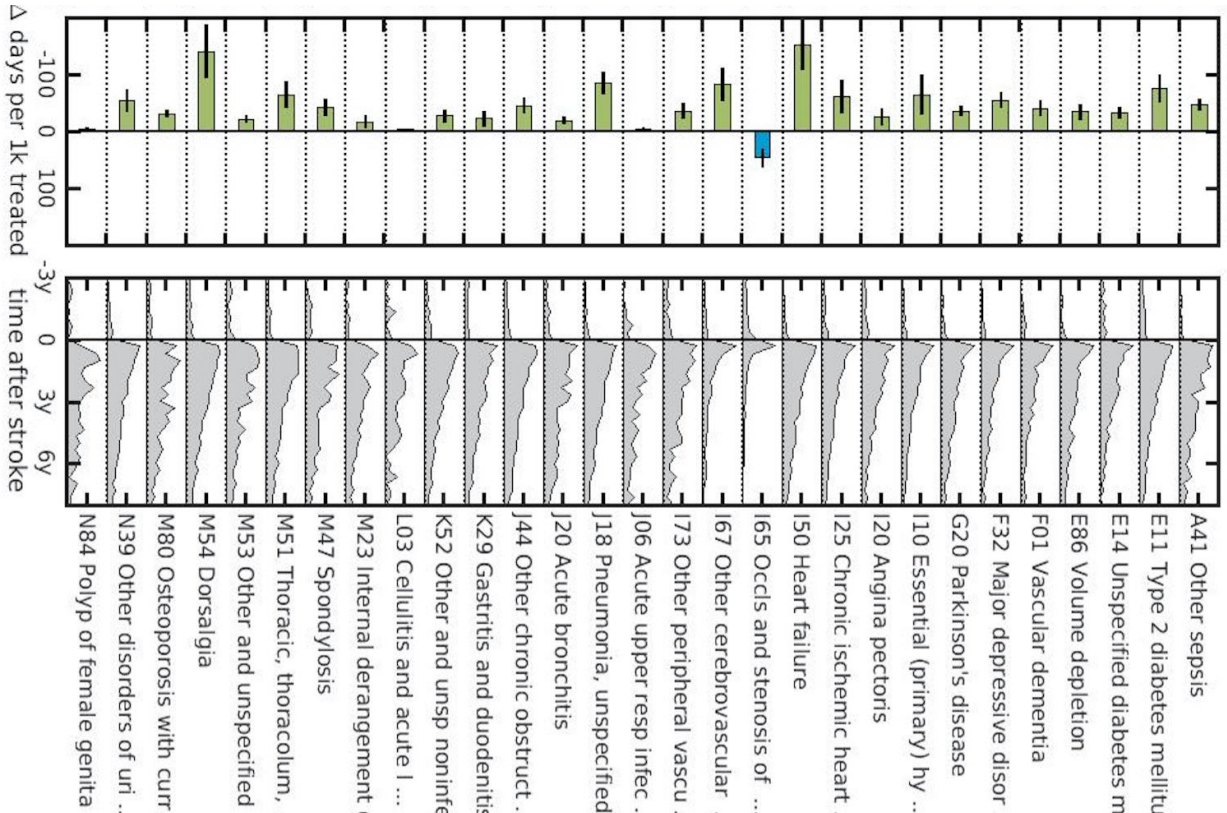
How efficient are stroke-units?

group 1:

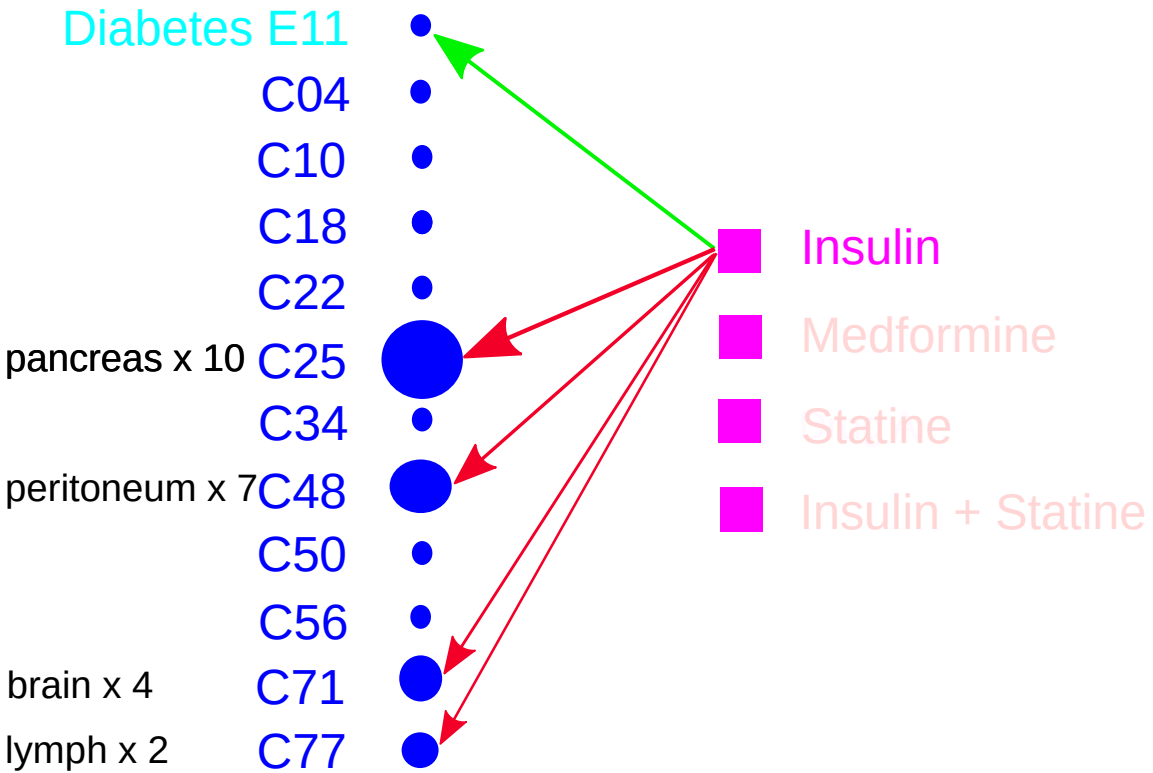
stroke-unit after stroke

group 2:

no special care after stroke

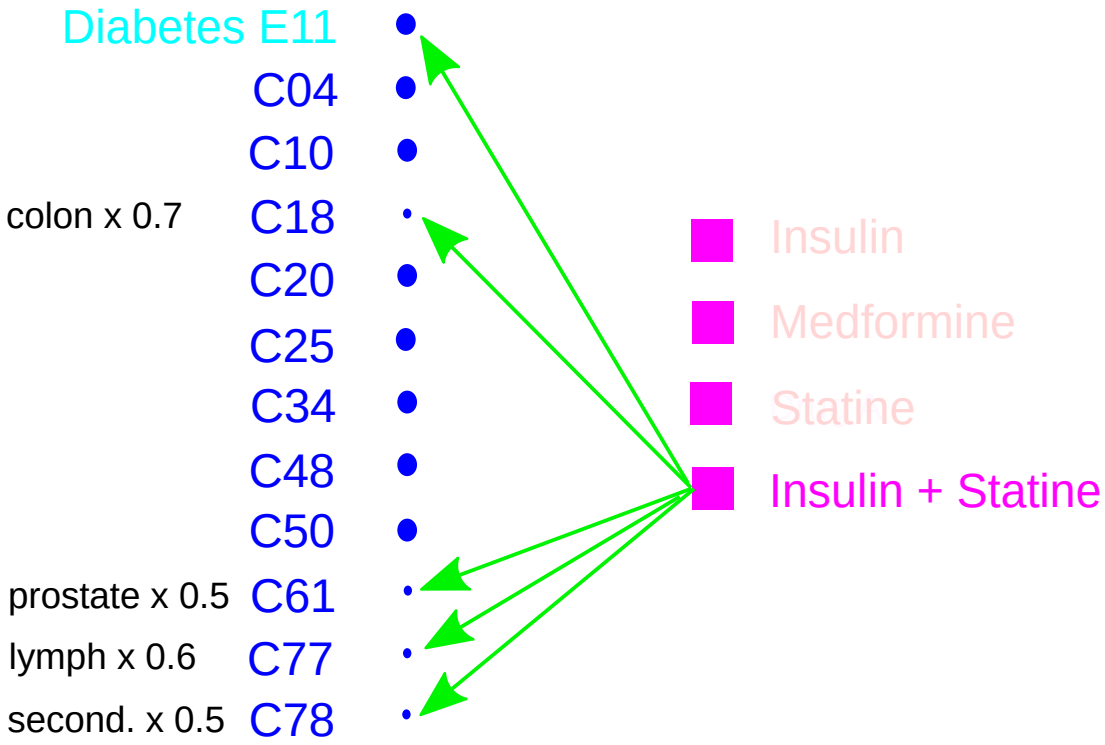


Side effects: insulin



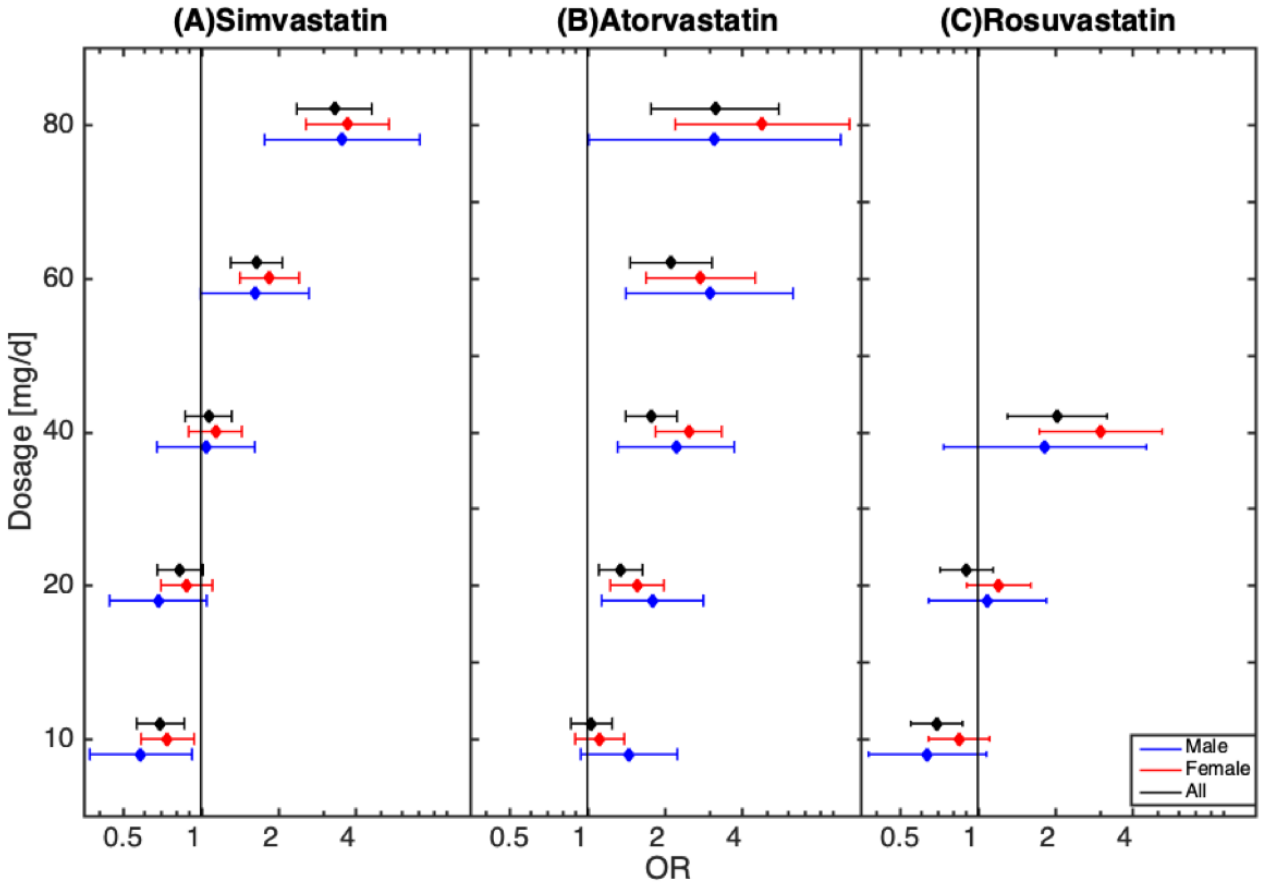
A. Kautzky-Willer, S. Thurner, and P. Klimek, J Internal Medicine 281, 206-216 (2017)

Side effects: insulin + statins



A. Kautzky-Willer, S. Thurner, and P. Klimek, J Internal Medicine 281, 206-216 (2017)

Osteoporosis – statins dosage



Female	Lovastatin	Fluvastatin	Pravastatin	Simvastatin	Atorvasta
0-10 mg	**0.41***	1.00	**0.73***	**0.74***	1.12
CI	0.18--0.89	1.00--1.00	0.53--1.00	0.59--0.94	0.90--1.3
10-20 mg	0.95	**0.59****	0.88	0.88	**1.56****
CI	0.61--1.48	0.40--0.87	0.68--1.14	0.70--1.11	1.23--1.9
20-40 mg	1.80	0.93	1.05	1.14	**2.48****
CI	0.93--3.48	0.73--1.19	0.81--1.37	0.90--1.44	1.84--3.3
40-60 mg		0.98		**1.85****	**2.76****
CI		0.77--1.24		1.42--2.41	1.69--4.5
60-80 mg		1.09		**3.72****	**4.80****
CI		0.85--1.42		2.56--5.39	2.20--10.4
Adj. R^2	0.96	0.95	0.95	0.94	0.96
max.VIF	4.21	3.26	3.04	2.74	2.87

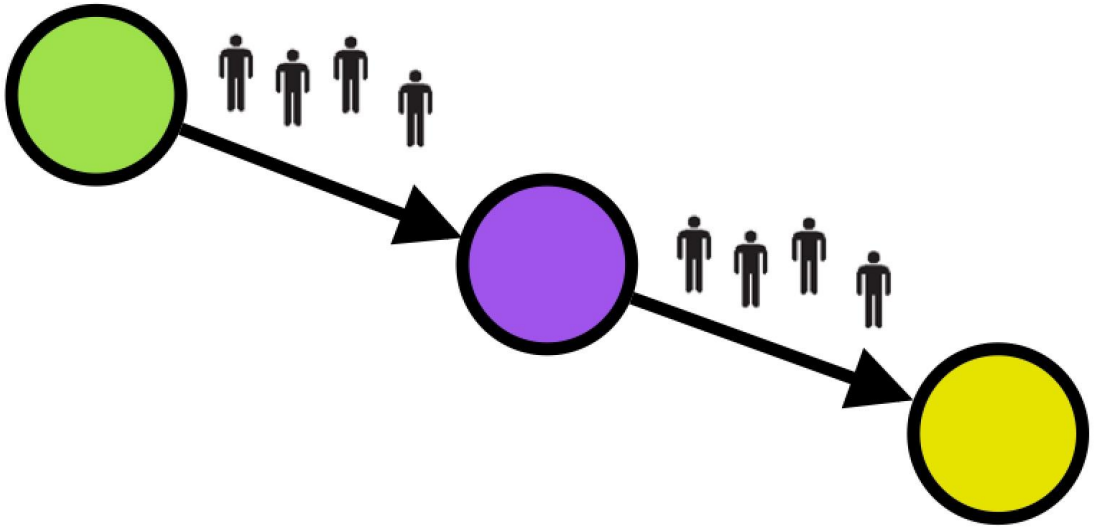
Male	Lovastatin	Fluvastatin	Pravastatin	Simvastatin	Atorvasta
0-10 mg	1.00	1.00	0.71	**0.58***	1.45
CI	1.00--1.00	1.00-1.00	0.40--1.24	0.37--0.92	0.94--2.2
10-20 mg	1.05	0.65	0.94	0.68	**1.79***
CI	0.35--3.09	0.30--1.37	0.59--1.48	0.44--1.05	1.14--2.8
20-40 mg	1.00	0.68	1.08	1.05	**2.21****
CI	1.00--1.00	0.43--1.08	0.68--1.71	0.67--1.62	1.31--3.7
40-60 mg		0.90		1.62	**2.99****
CI		0.57--1.43		1.00--2.63	1.41--6.3
60-80 mg		1.52		**3.54****	**3.13***
CI		0.93--2.49		1.77--7.11	1.01--9.6
Adj. R^2	0.72	0.72	0.73	0.77	0.72
max. VIF	4.21	3.26	3.04	2.74	2.87

** p<0.01; *p<0.05

COMPLEXITY SCIENCE HUB VIENNA

Treatment paths

„Schulbuch“-Beispiel



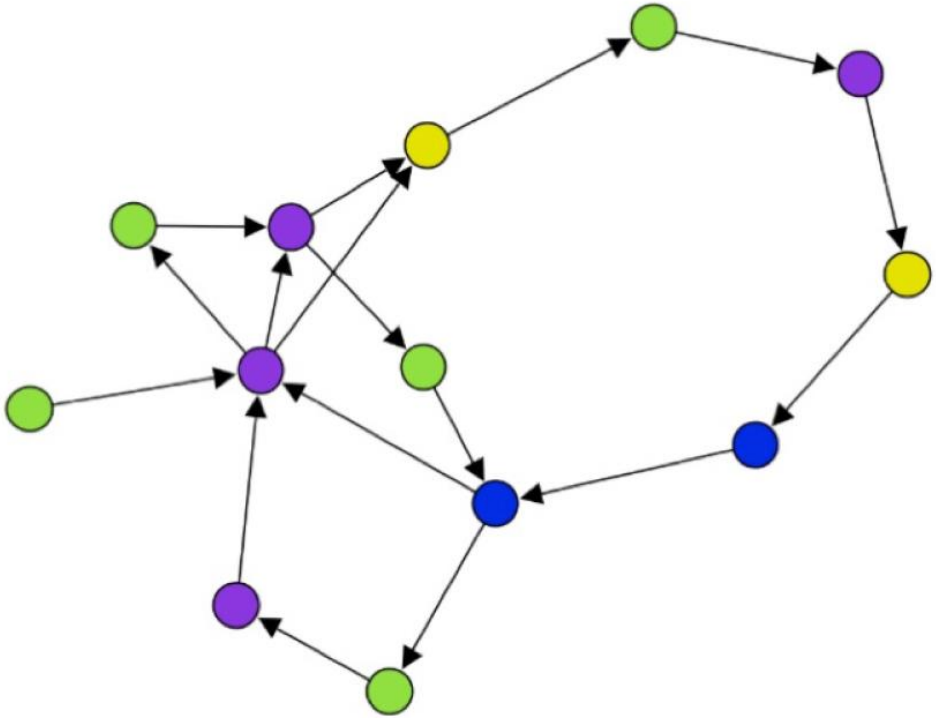
Allgemeinmediziner

Facharzt

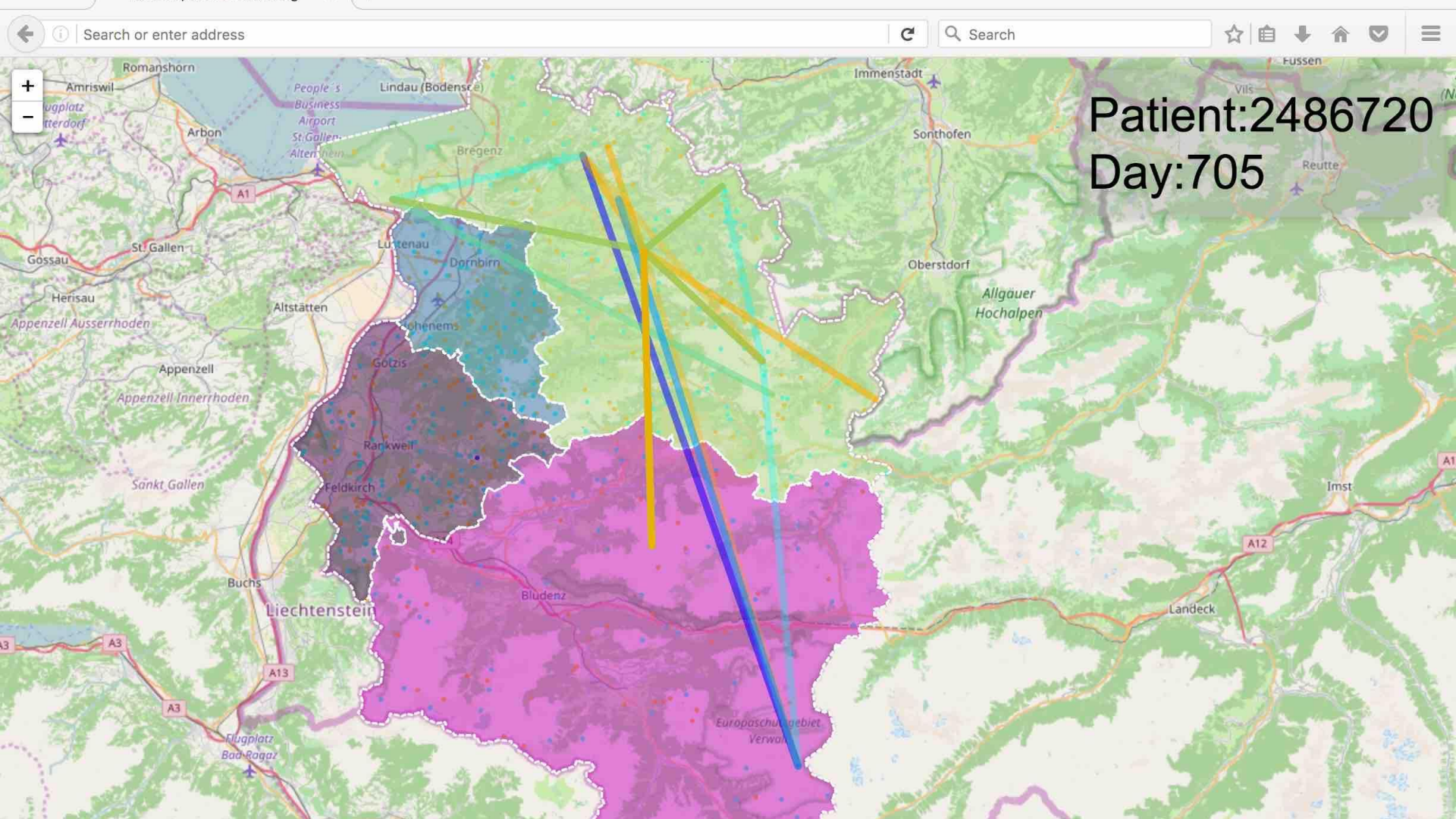
Apotheke

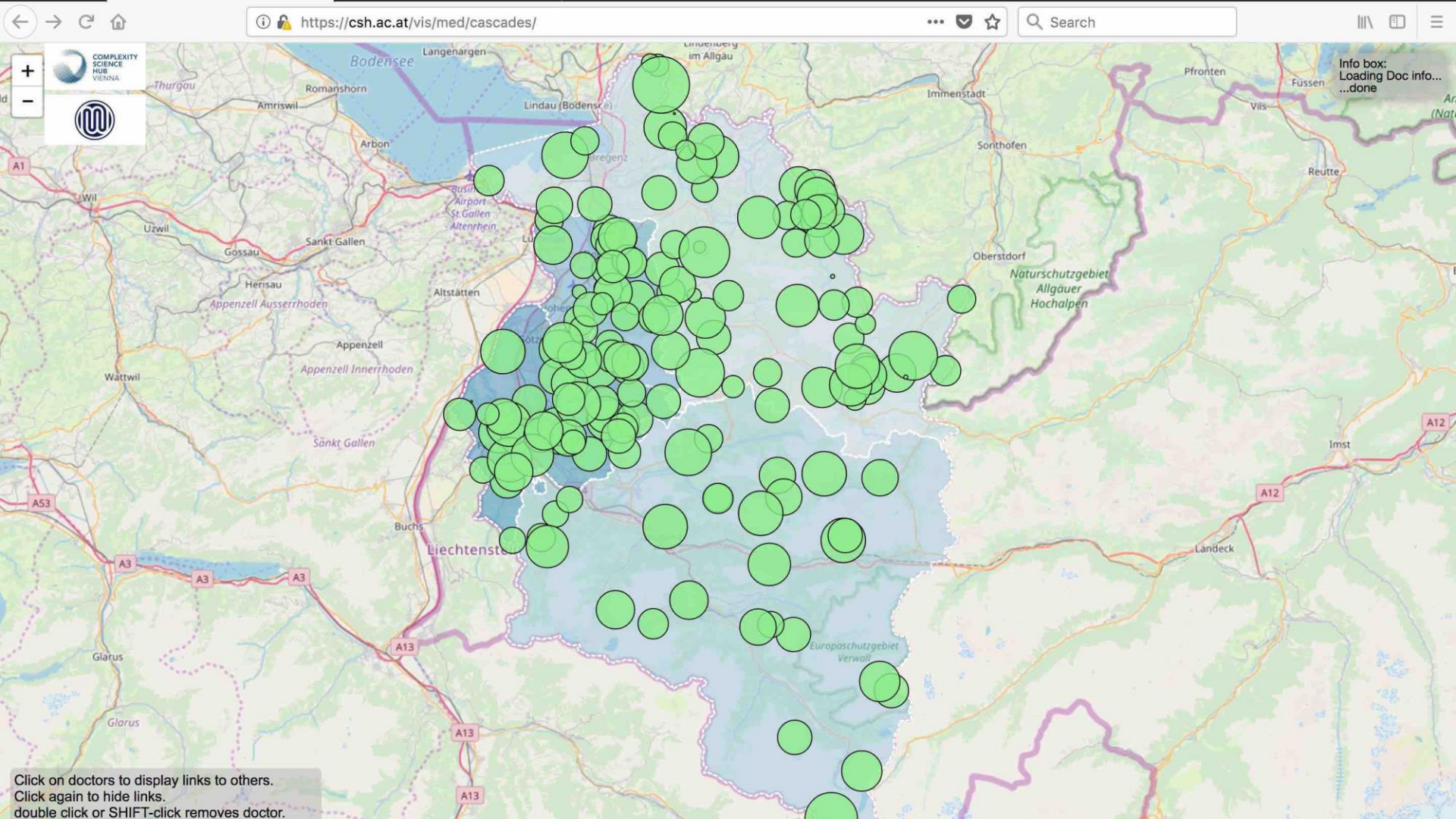
COMPLEXITY SCIENCE HUB VIENNA

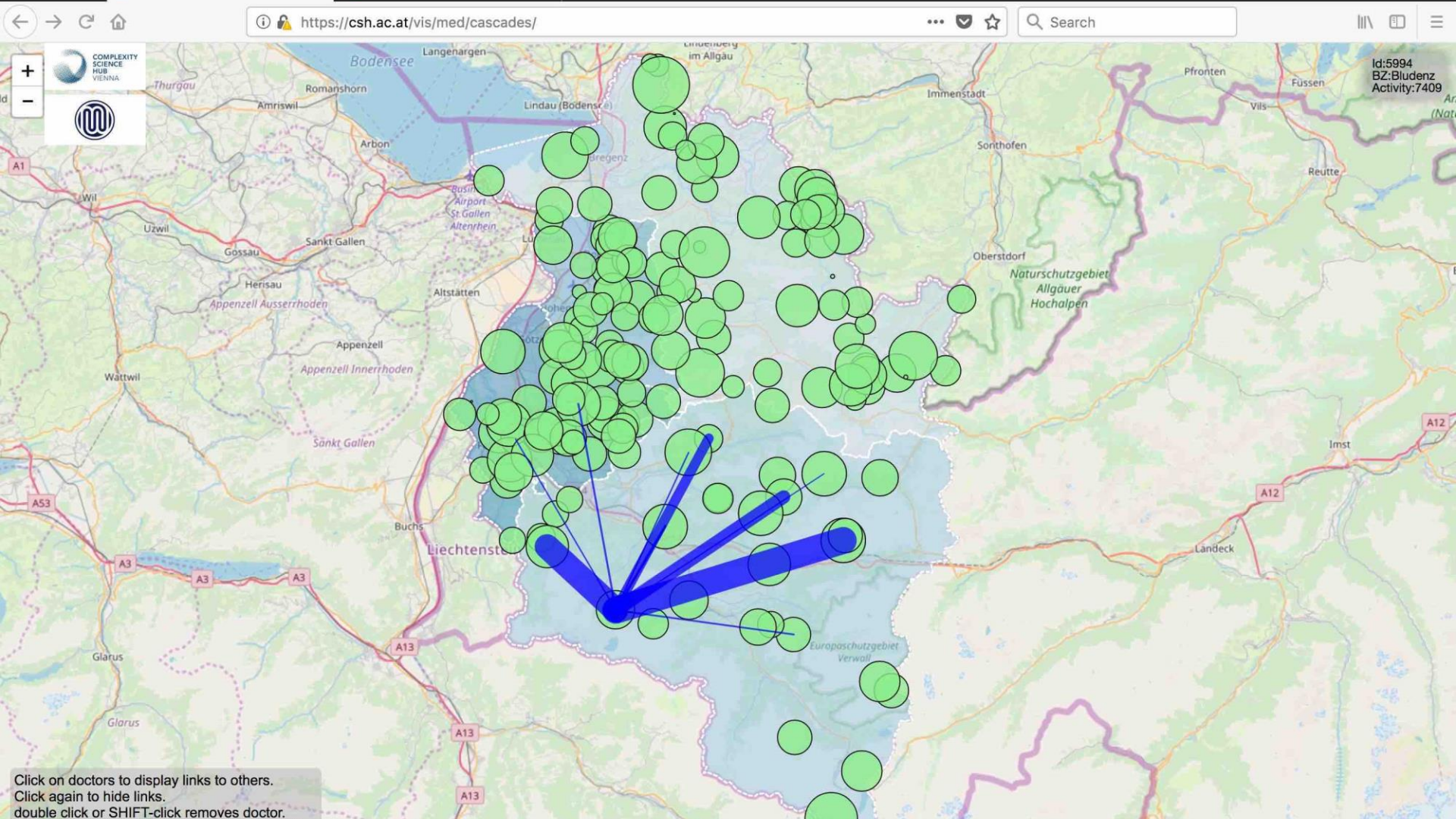
Treatment paths

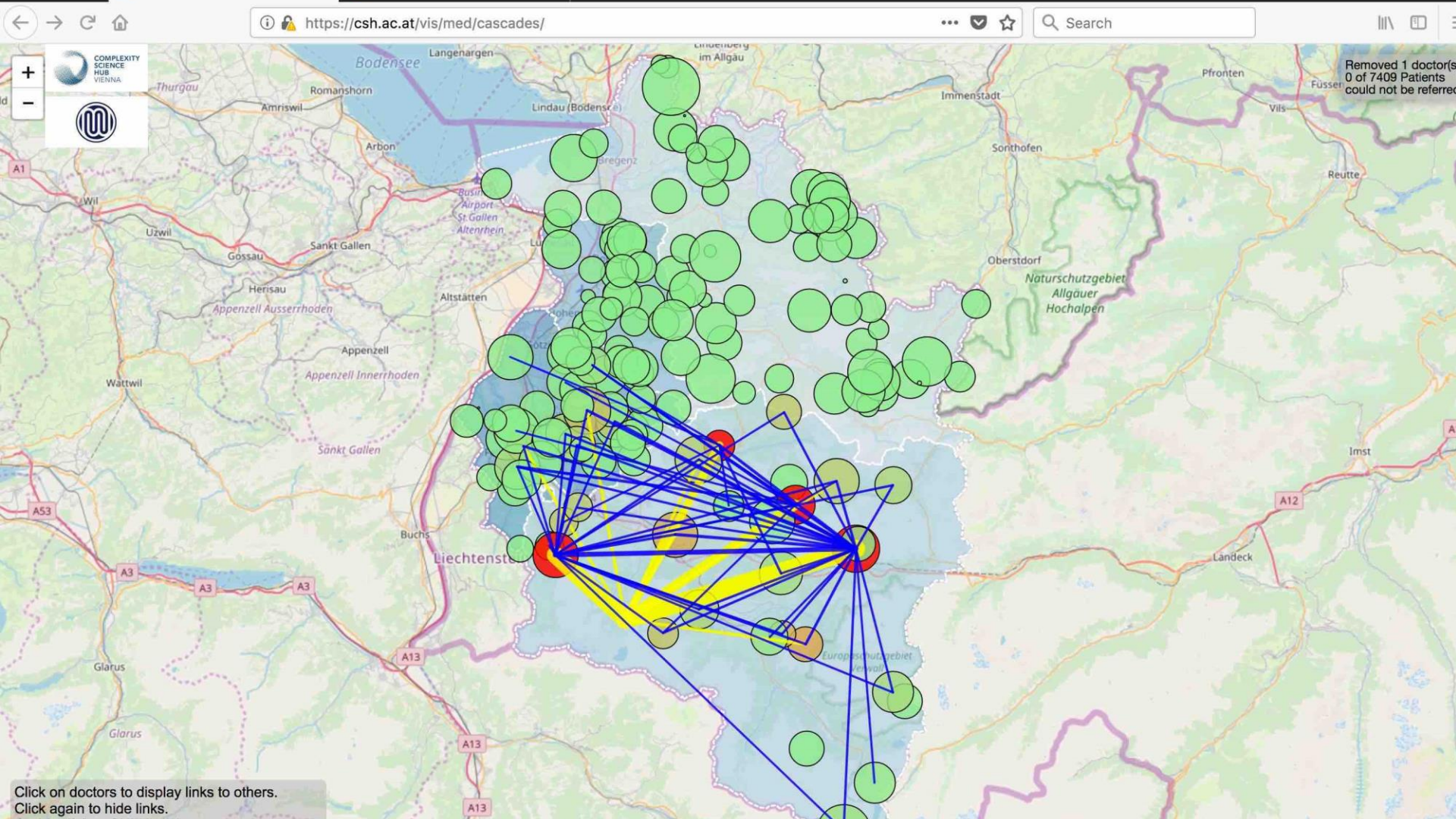


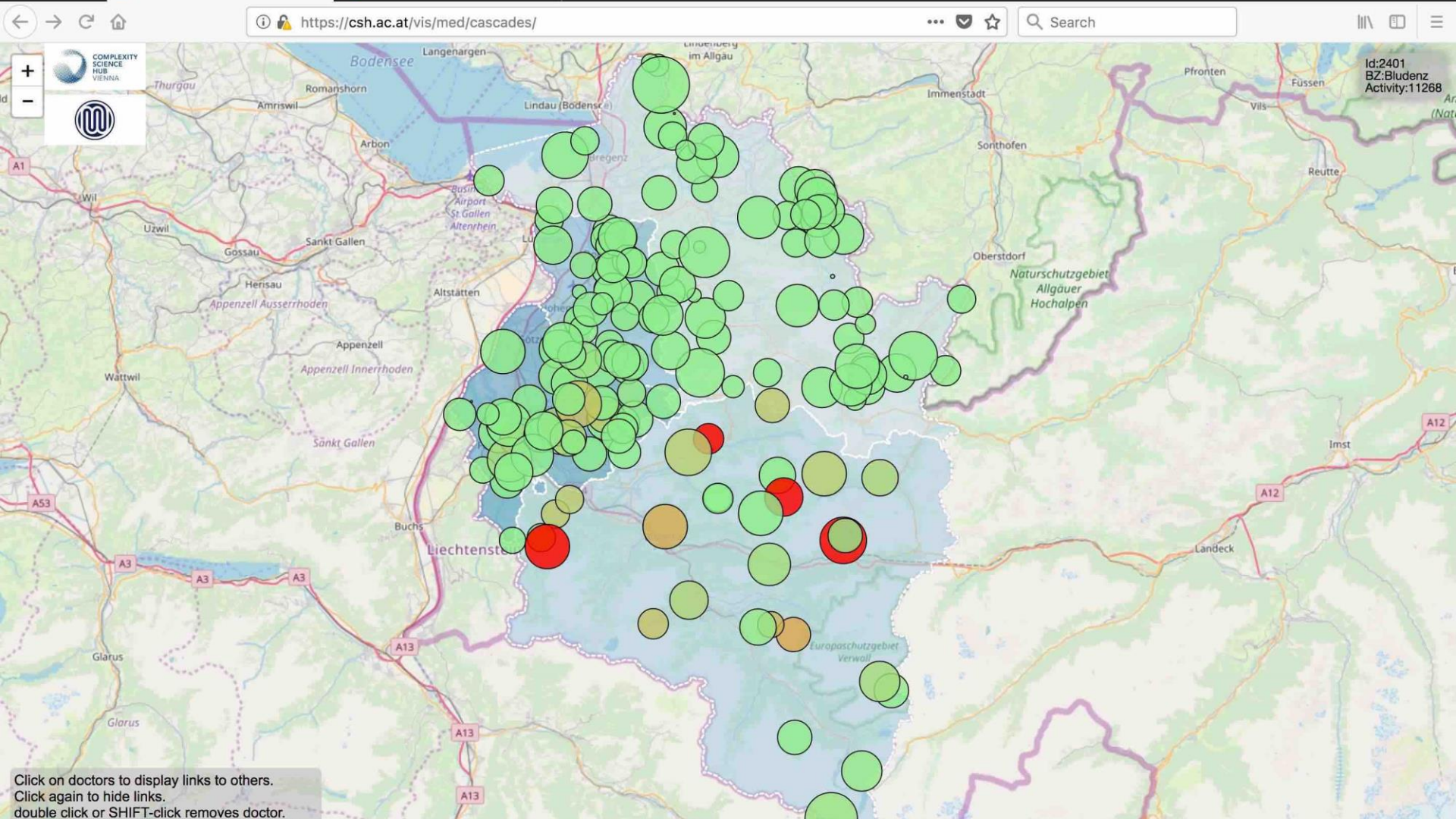
GP
specialist
pharmacy
hospital


Patient:2486720
Day:705
Romanshorn
Amriswil
Arbon
Lindau (Bodensee)
Immenstadt
Sonthofen
Bregenz
Reutte
Oberstdorf
Allgauer Hochalpen
Gossau
St. Gallen
Herisau
Altstätten
Appenzell Ausserrhoden
Appenzell
Appenzell Innerrhoden
Sankt Gallen
Dornbirn
Götzis
Rankweil
Feldkirch
Buchs
Liechtenstein
Bludenz
Landeck
Imst
A1
A3
A12
A13

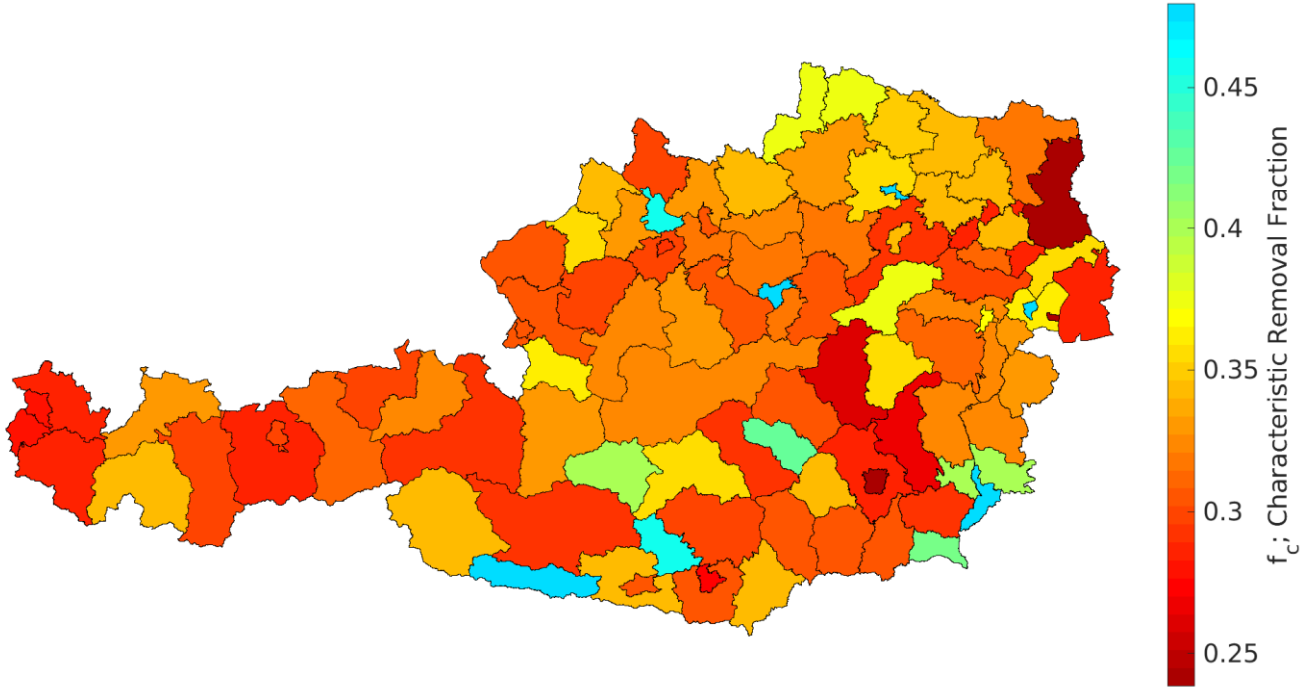

https://csh.ac.at/vis/med/cascades/
Search
COMPLEXITY SCIENCE HUB VIENNA
Info box:
Loading Doc info...
...done
Bodensee
Langenargen
Thurgau
Romanshorn
Amriswil
Lindau (Bodensee)
Arbon
Immenstadt
Pfronten
Füssen
Vils
Sonthofen
Reutte
Wil
Uzwil
Gossau
Sankt Gallen
Herisau
Appenzell Ausserrhoden
Altstätten
Oberstdorf
Naturschutzgebiet Allgäuer Hochalpen
Appenzell
Appenzell Innerrhoden
Wattwil
Sankt Gallen
Imst
Buchs
Landeck
Glarus
Glarus
A1
A53
A3
A13
A12
Click on doctors to display links to others.
Click again to hide links.
double click or SHIFT-click removes doctor.


https://csh.ac.at/vis/med/cascades/
Search
COMPLEXITY SCIENCE HUB VIENNA
Id:5994
BZ:Bludenz
Activity:7409
Bodensee
Langenargen
Thurgau
Romanshorn
Amriswil
Lindau (Bodensee)
Arbon
Immenstadt
Pfronten
Füssen
Vils
Sonthofen
Reutte
Wil
Uzwil
Gossau
Sankt Gallen
Herisau
Appenzell Ausserrhoden
Altstätten
Oberstdorf
Naturschutzgebiet Allgäuer Hochalpen
Appenzell
Appenzell Innerrhoden
Wattwil
Sankt Gallen
Buchs
Liechtenstein
Imst
Landeck
Glarus
Glarus
Europaschutzgebiet Verwall
A1
A53
A3
A13
A12
Click on doctors to display links to others.
Click again to hide links.
double click or SHIFT-click removes doctor.

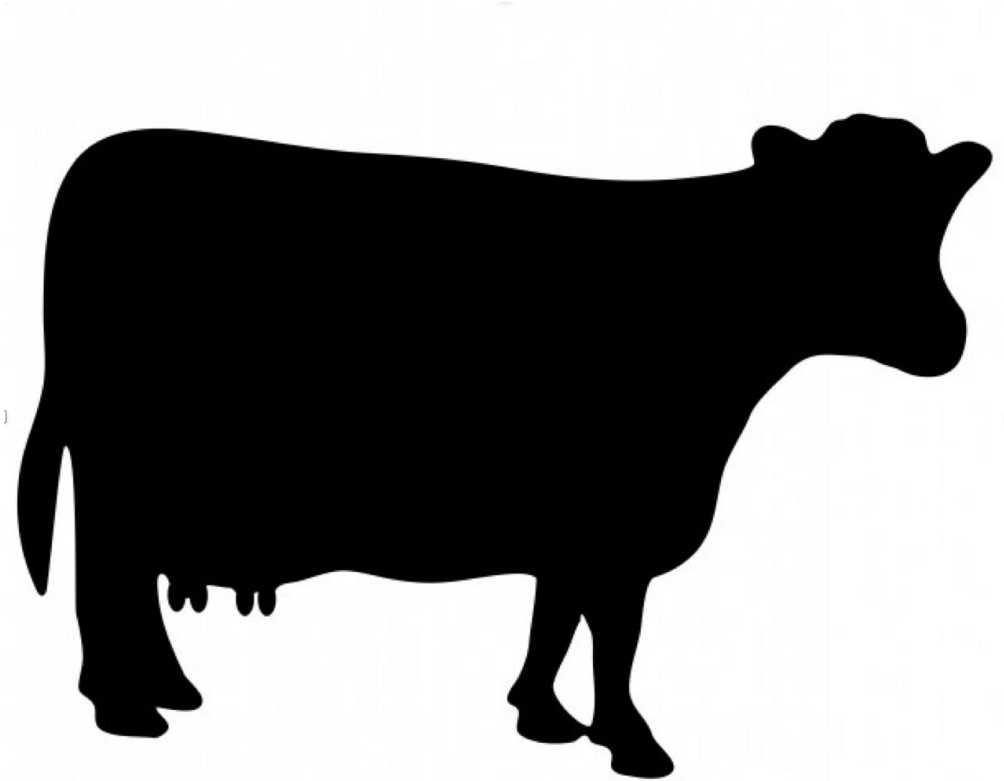

https://csh.ac.at/vis/med/cascades/
Search
COMPLEXITY SCIENCE HUB VIENNA
Removed 1 doctor(s)
0 of 7409 Patients
could not be referred
Click on doctors to display links to others.
Click again to hide links.


https://csh.ac.at/vis/med/cascades/
Search
COMPLEXITY SCIENCE HUB VIENNA
Id:2401
BZ:Bludenz
Activity:11268
Bodensee
Langenargen
Thurgau
Romanshorn
Amriswil
Lindau (Bodensee)
Arbon
Immenstadt
Pfronten
Füssen
Vils
Sonthofen
Reutte
Wil
Uzwil
Gossau
Sankt Gallen
Herisau
Appenzell Ausserrhoden
Altstätten
Oberstdorf
Naturschutzgebiet Allgäuer Hochalpen
Appenzell
Appenzell Innerrhoden
Wattwil
Sankt Gallen
Buchs
Liechtenstein
Imst
Landeck
Glarus
Glarus
Europaschutzgebiet Verwall
A1
A53
A3
A13
A12
Click on doctors to display links to others.
Click again to hide links.
double click or SHIFT-click removes doctor.

How resilient is the health care system?



COMPLEXITY SCIENCE HUB VIENNA



Multilayer **A**nimal **D**isease Network for **cows**

- 2,000,000 cows
- 150,000 genomes including parents, grandparents, …
- geolocation, social life, farm/herd/family....
- complete history of food intake
- complete health care records, diagnoses, treatment, vaccines, dosage
- 80 diseases
- complete metabolic information
- sensor data
- tissue samples

COMPLEXITY SCIENCE HUB VIENNA

Pandemic control?

CSH COVID-19 strategy (March 2020)

Corona Ampel

+ testing

+ mobility monitoring

+ digital contact tracing

+ ranking of NPI

+ Co-morbidity tracking

+ Capacity monitoring of HCS

+ Strategies for special sectors: nursing homes + schools

= Logistic control (without vaccine)

COMPLEXITY SCIENCE HUB VIENNA

Where will the journey go?

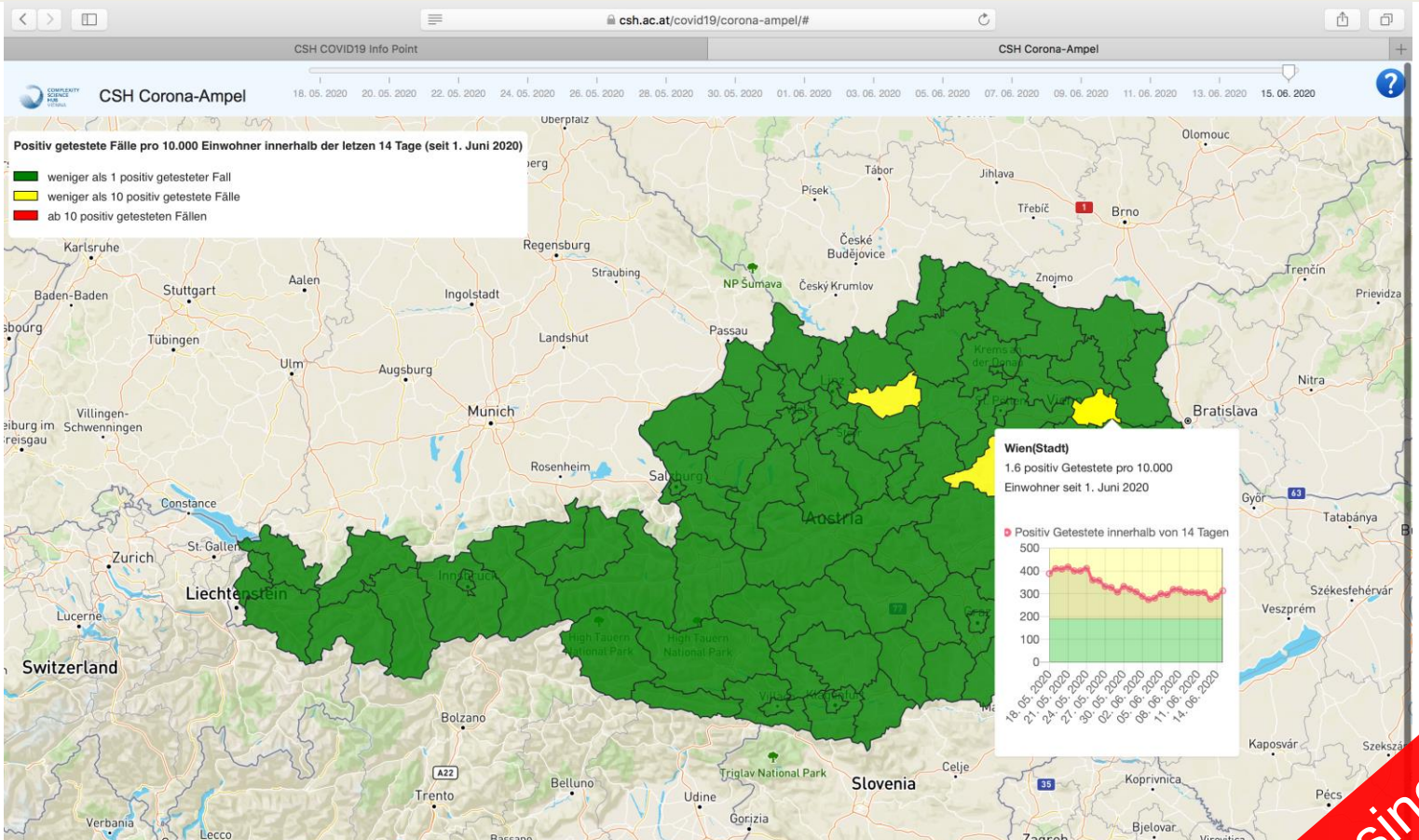
Time never goes back

Must live with Big Med data – in retrospect we will have wanted that

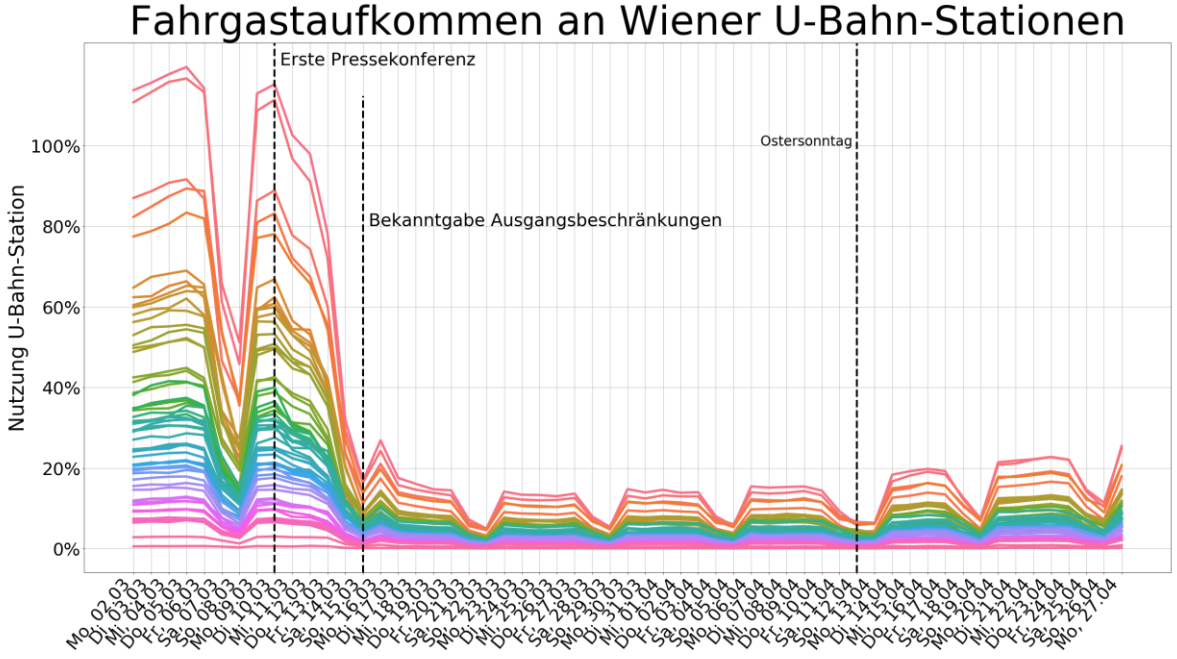
- **Danger of missed reform.** Public HCS lose connection to digital reality
- **Data-cooperation.** Without it – lose abilities to run **public** HCS. Necessary: *Unabhängige Nationale Medizindatenstelle*
- **Safety.** No data-risks for citizens
- **Transparency.** Quality control / avoid cost explosion
- **Transparent** cooperation with science and industry

COMPLEXITY SCIENCE HUB VIENNA

Corona Ampel



Mobilität der Österreicher:innen



Station
Landstrasse
Karlsplatz
Praterstern
Volkstheater
Westbahnhof
Schwedenplatz
Vorgartenstrasse
Suedtirolerplatz
Nestroyplatz
Herrengasse
Rochusplatz
Kettenbrueckengasse
Stubentor
Rossauerlaende
Burggasse
Reumannplatz
Philadelphiabruecke
Keplerplatz
Messegelaende
Dresdnerstrasse
Zentrum_Kagran
Friedensbruecke
Erdberg
Johnstrasse
Gasometer
Linie18_Matzleindsdorfer_Platz
Spittelau
Linie18_Kliebergasse
Troststrasse
Stephansplatz
Kendlerstrasse
Altes_Landgut_U1
Grossfeldsiedlung
Simmering

Policy Brief

COMPLEXITY SCIENCE HUB VIENNA

Lockdown – Compliance

Bundesland	Lockdown 1	Lockdown 2	Lockdown 3	Nach 2 Wochen in Lockdown 3	Nach 3 Wochen in Lockdown 3
B	–79 %	–48 %	–42 %	–31 %	–16 %
K	–68 %	–41 %	–21 %	–15 %	–4 %
NÖ	–78 %	–47 %	–37 %	–28 %	–14 %
OÖ	–69 %	–38 %	–28 %	–21 %	–11 %
S	–64 %	–33 %	–12 %	–11 %	–9 %
St	–72 %	–44 %	–22 %	–18 %	–10 %
T	–67 %	–37 %	–13 %	–11 %	–11 %
V	–57 %	–30 %	–22 %	–16 %	–15 %
W	–80 %	–50 %	–35 %	–29 %	–16 %

Policy Brief

COMPLEXITY SCIENCE HUB VIENNA

Testen: optimal-pooling Formel

$$Q = \frac{1}{\omega}\left(r(1 - P_+^*) + (r + \omega)P_+^*\right)$$

Use arrow keys left <- and right -> on keyboard to finetune sliders.

Test Sensitivity 99.4 %

Test Specificity 98 %

Expected Positive Rate 0.4 %

Found Optimum

Metric	Value	Unit
Optimal Pool Size	17	Count
Gain (effective no. persons/test, PPT)	8	Count
Max. number of missed infectious (FNPT)	0.003	Fraction

Plot

Policy Brief

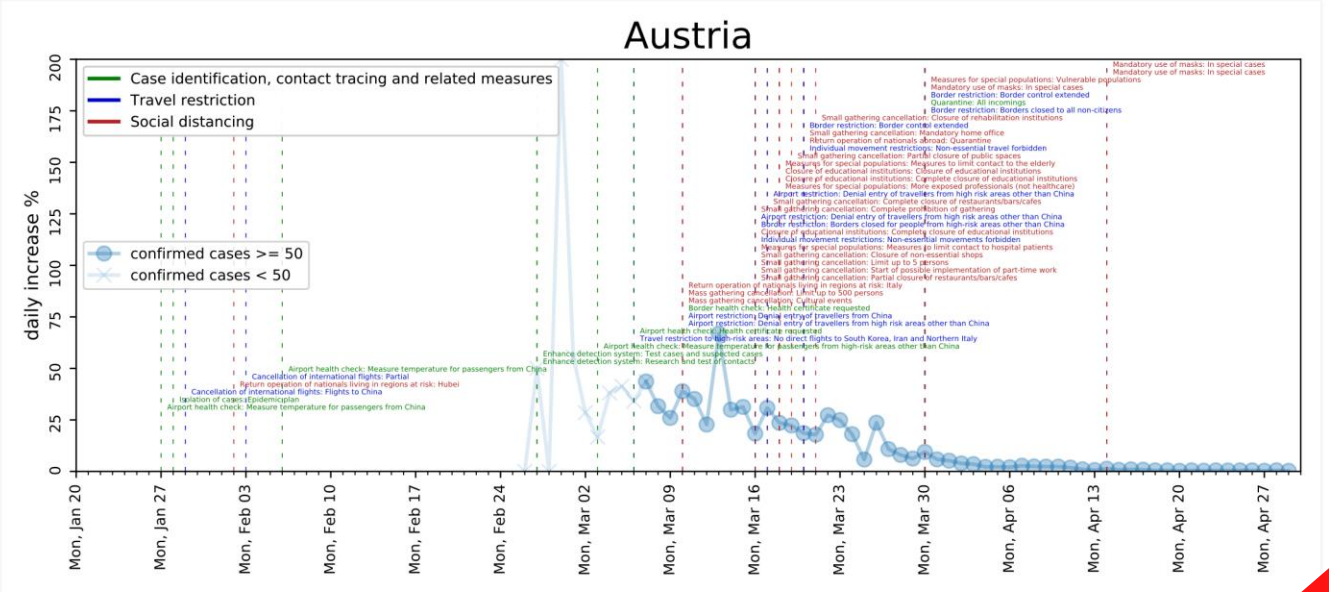
COMPLEXITY SCIENCE HUB VIENNA

Globaler Datensatz der Massnahmen

covid19-interventions.com

CSH COVID19 Info Point | COVID-19 Interventions Data – COVID-19 Interventions Data

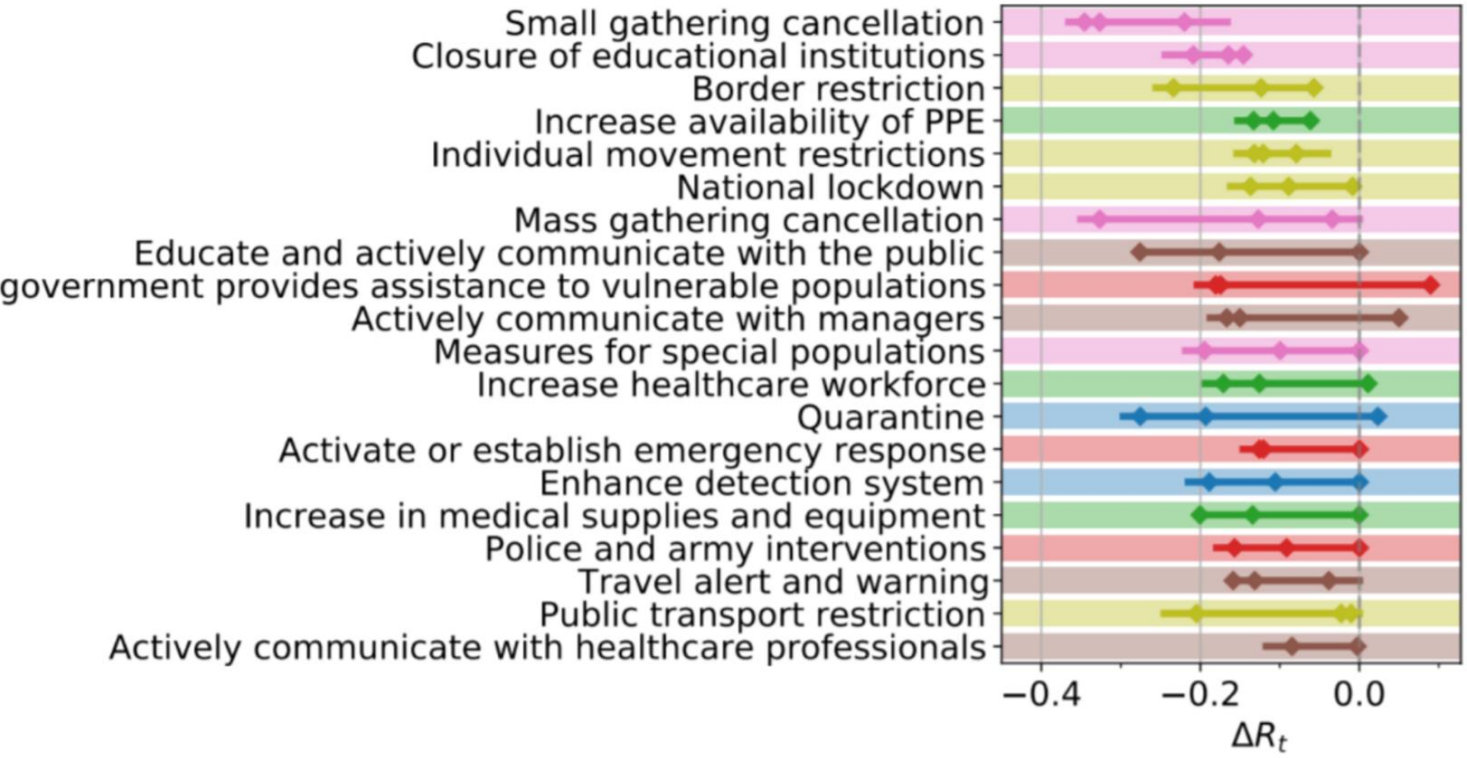
Austria Albania Belgium Bosnia and Herzegovina Brazil Canada Croatia Czech Republic Denmark Ecuador El Salvador Estonia
Finland France Germany Greece Honduras Hong Kong Hungary Iceland India Indonesia Ireland Italy Japan Kazakhstan Kosovo
Kuwait Lithuania Malaysia Mauritius Mexico Montenegro Netherlands New Zealand North Macedonia Norway Poland Portugal
Romania Serbia Singapore Slovakia Slovenia South Korea Spain Sweden Switzerland Syria Taiwan Thailand United Kingdom



used by WHO

COMPLEXITY SCIENCE HUB VIENNA

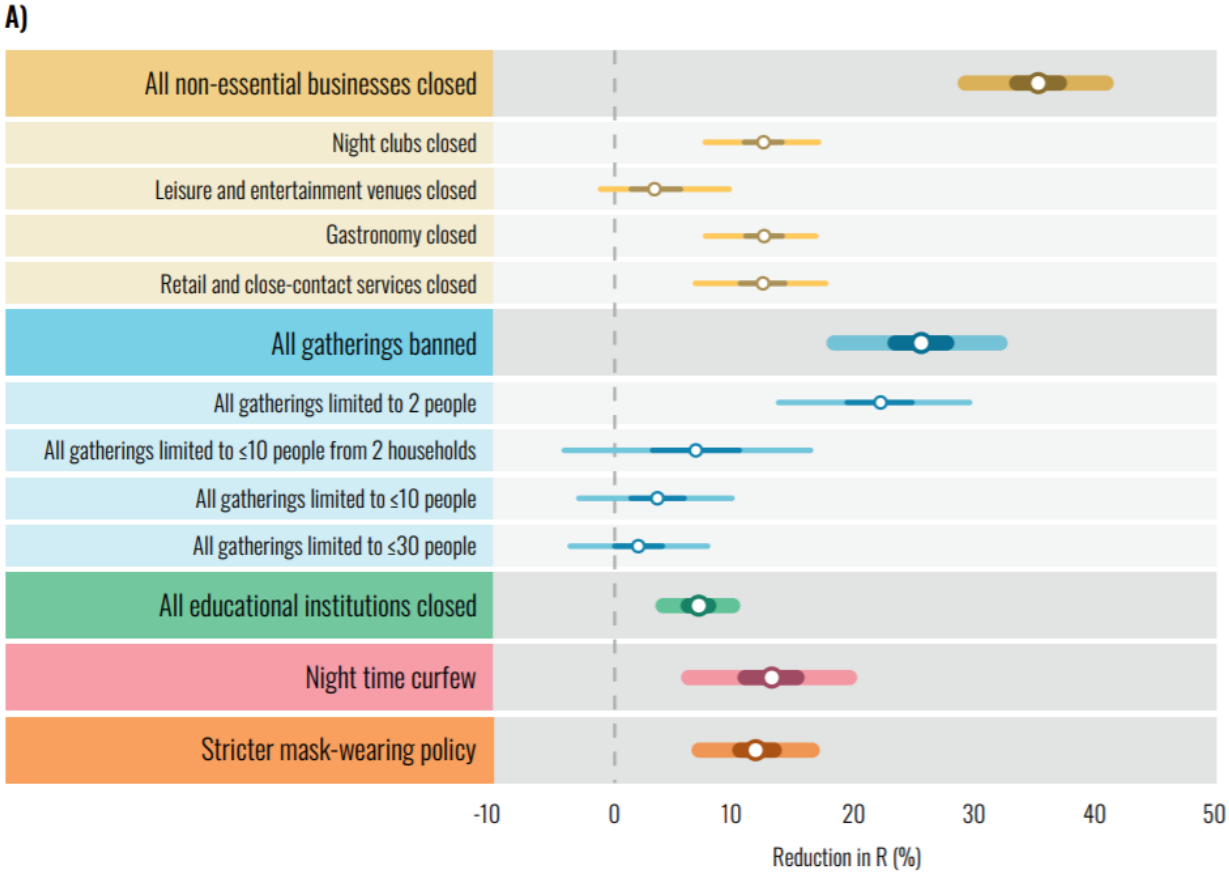
Wie gut funktionieren welche Massnahmen?



Top 100 papers 2020

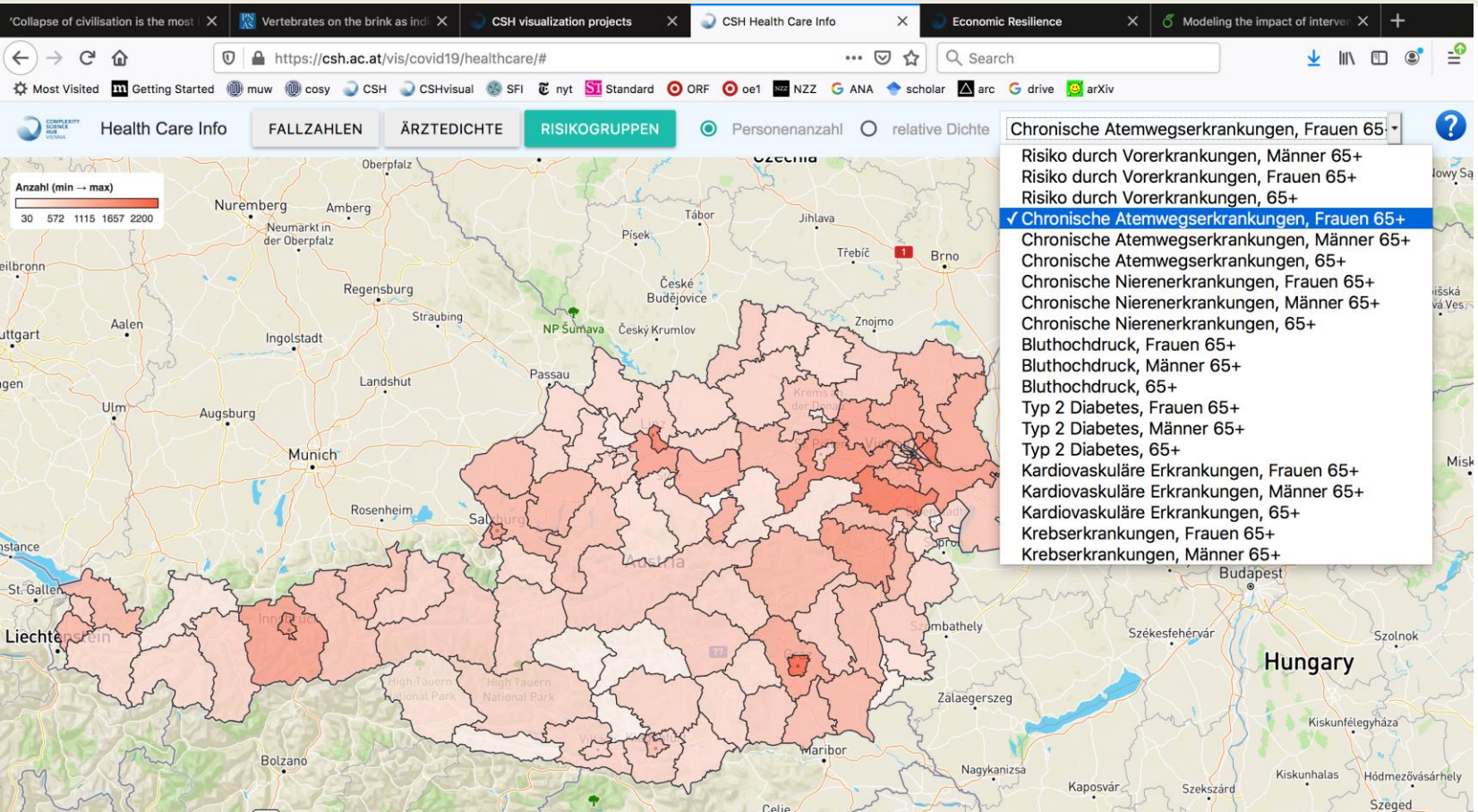
COMPLEXITY SCIENCE HUB VIENNA

Confirmation in 2nd wave



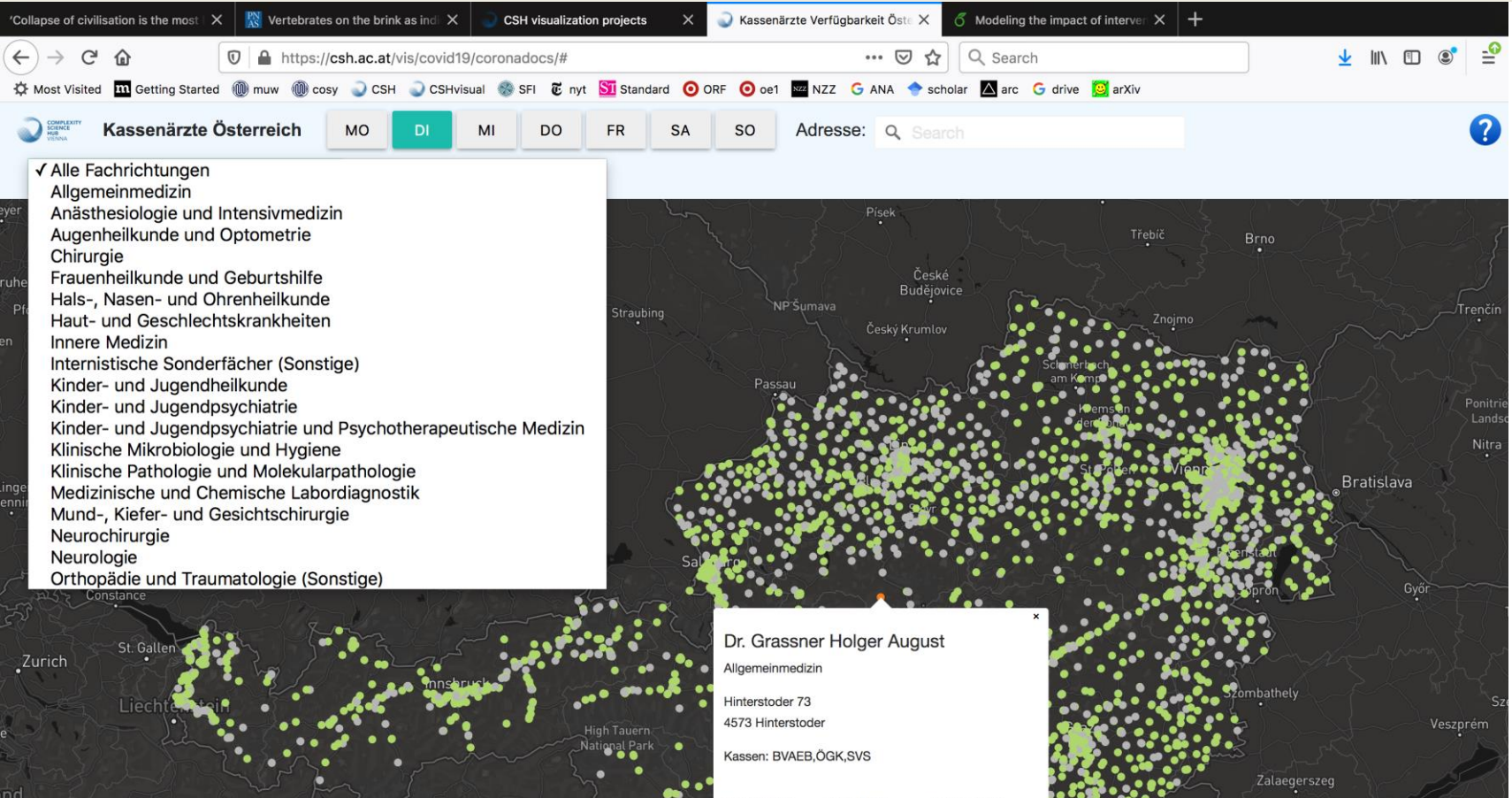
COMPLEXITY SCIENCE HUB VIENNA

Klinische Vorerkrankungen



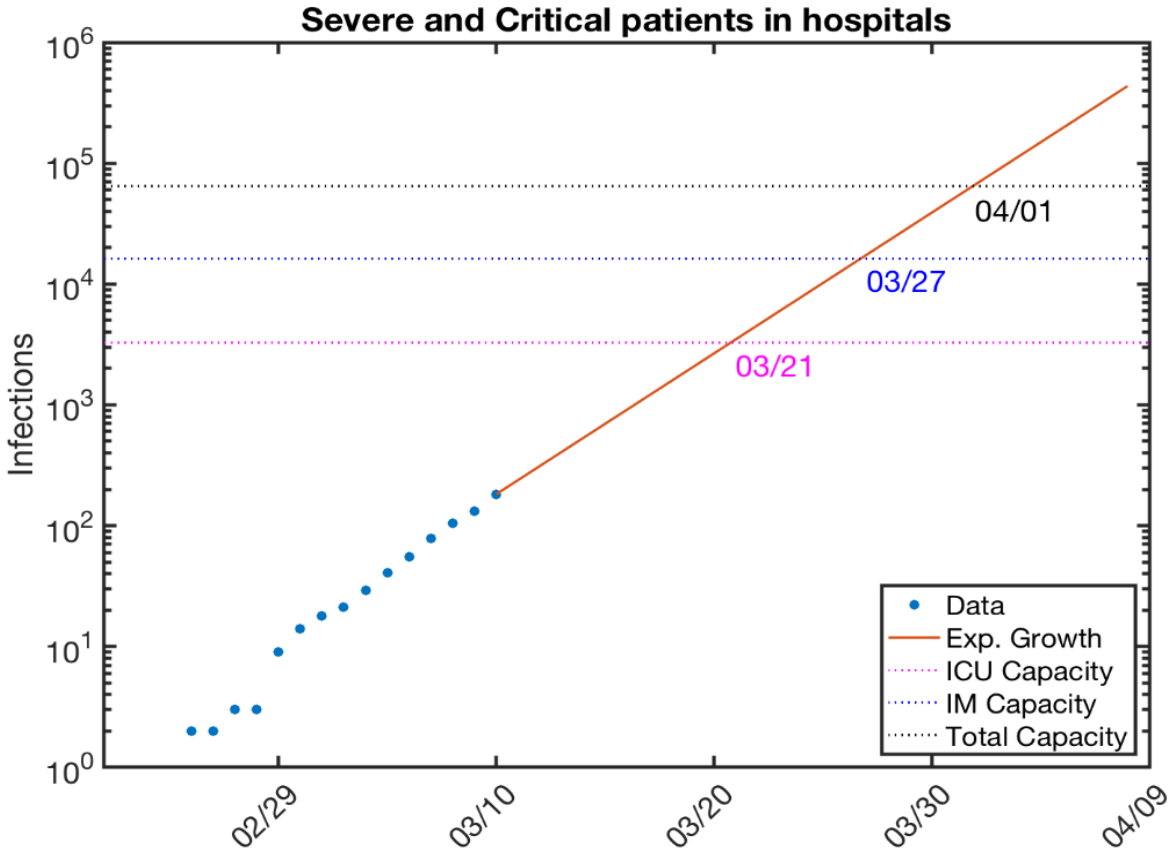
COMPLEXITY SCIENCE HUB VIENNA

Kapazitätsmonitoring des Gesundheitssystems



COMPLEXITY SCIENCE HUB VIENNA

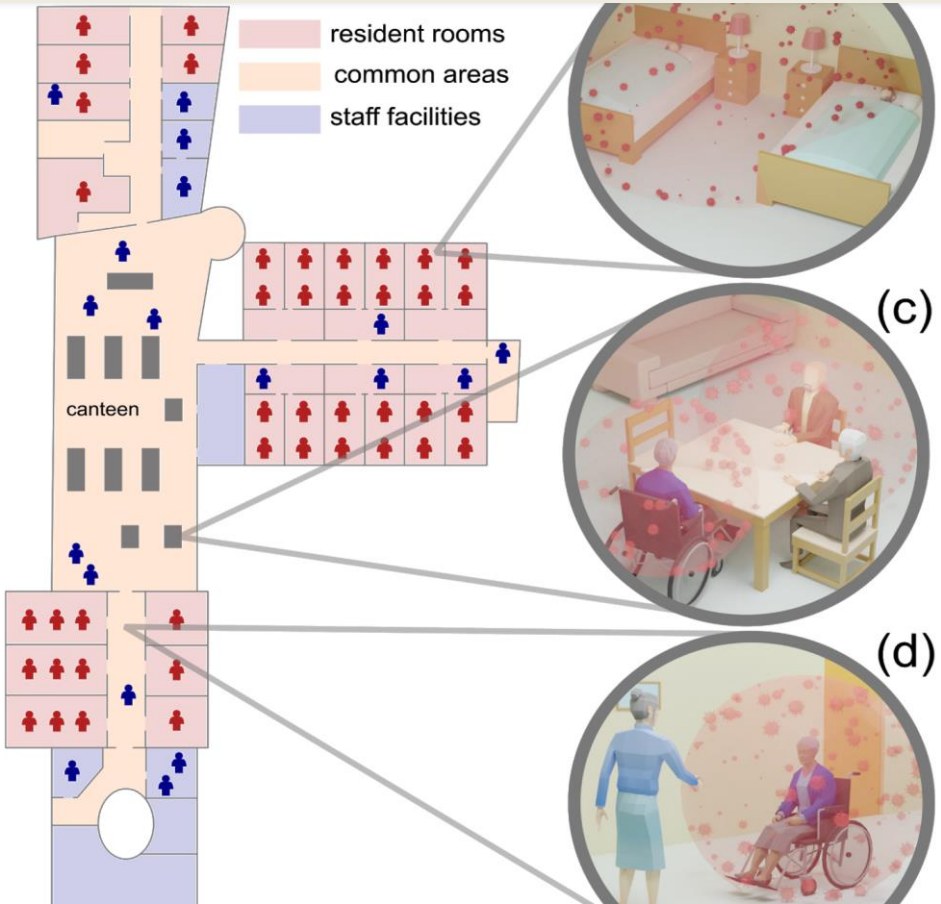
Warnung 10. März 2020



Policy Brief

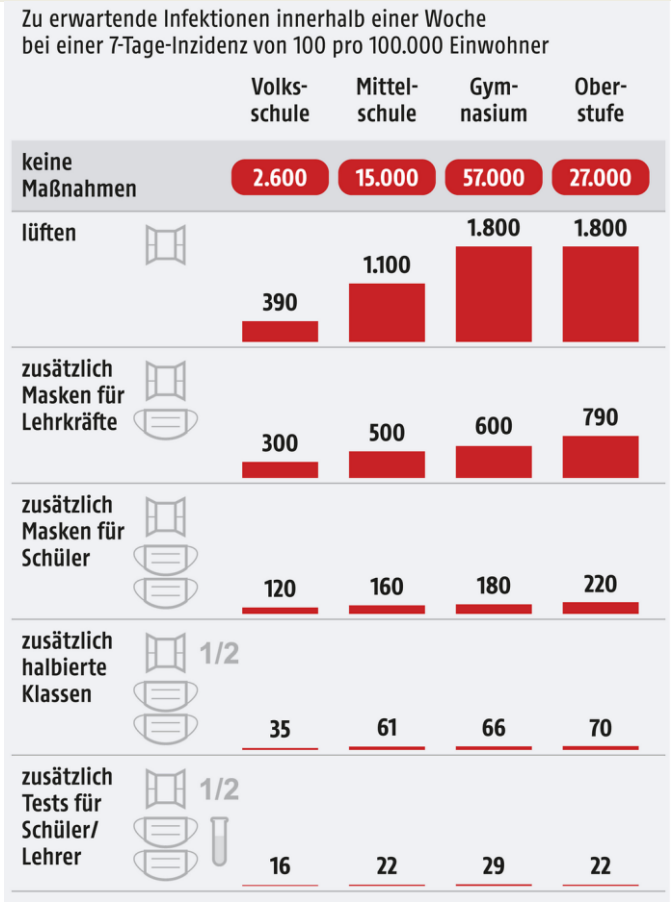
COMPLEXITY SCIENCE HUB VIENNA

Optimale Teststrategie für Altersheime



COMPLEXITY SCIENCE HUB VIENNA

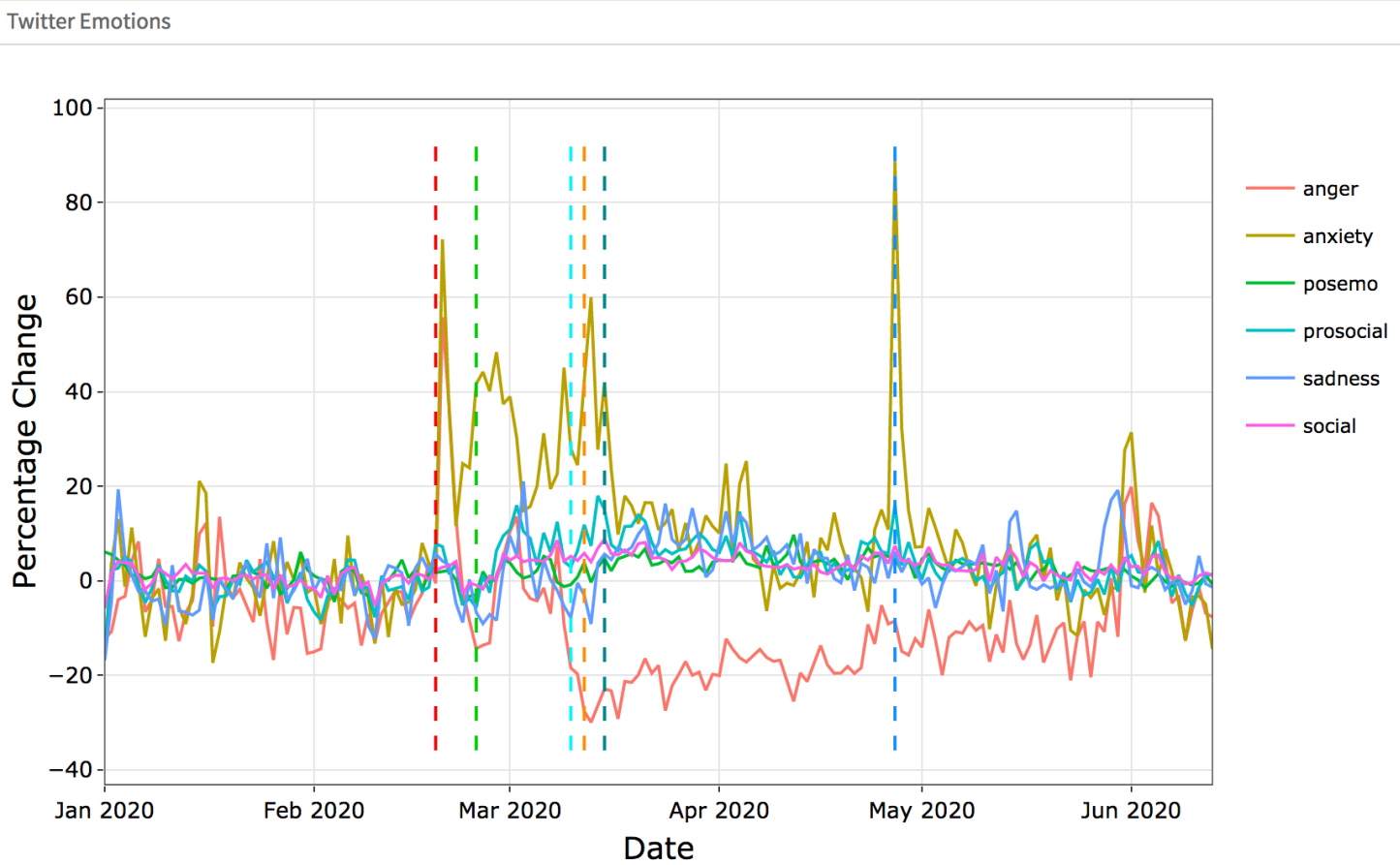
Schulöffnungen durch NPIs



Policy Brief

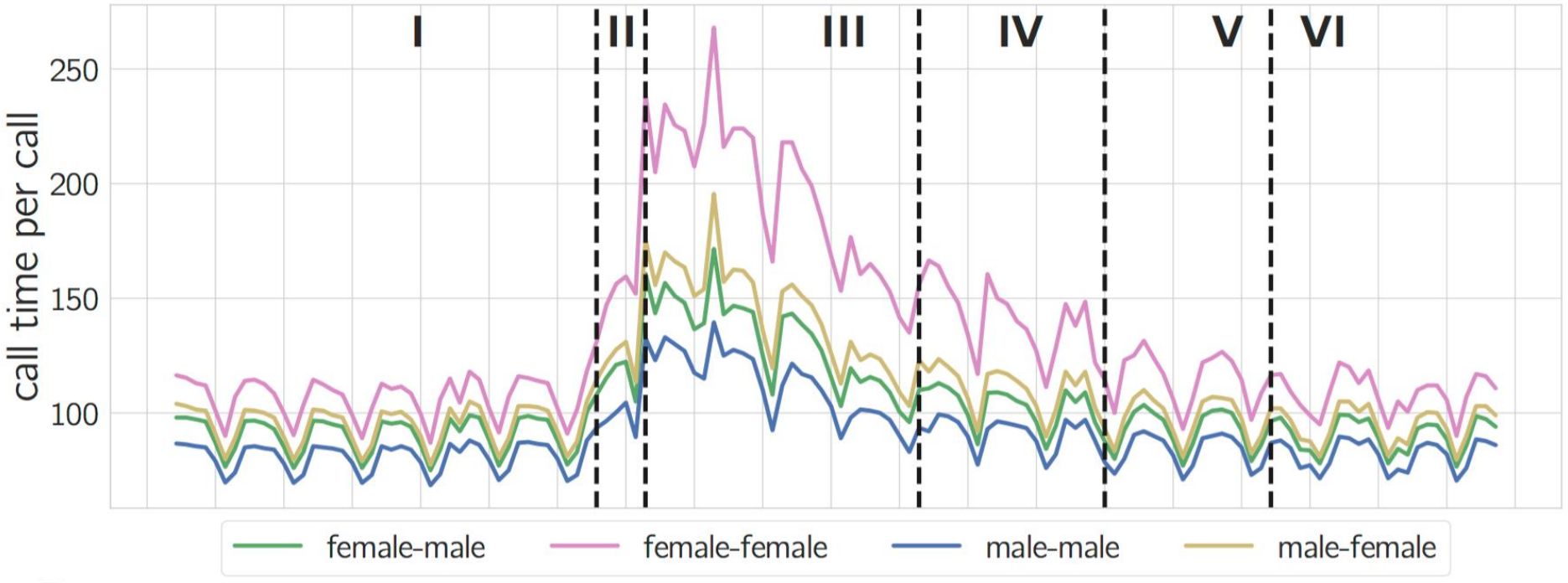
COMPLEXITY SCIENCE HUB VIENNA

Emotionen in der Bevölkerung



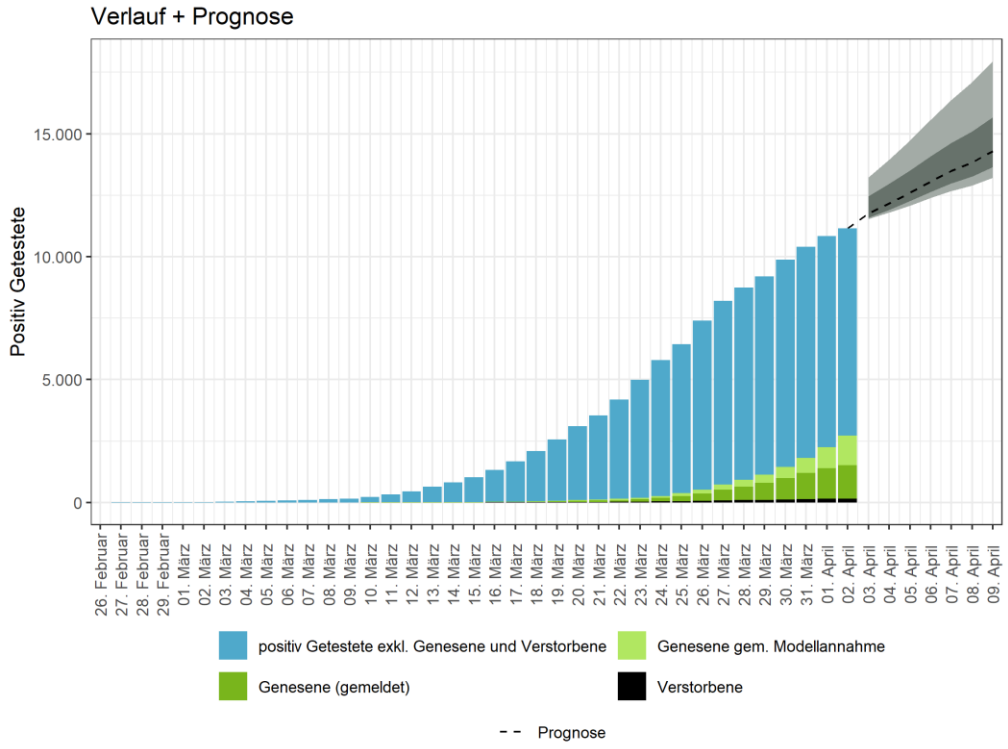
COMPLEXITY SCIENCE HUB VIENNA

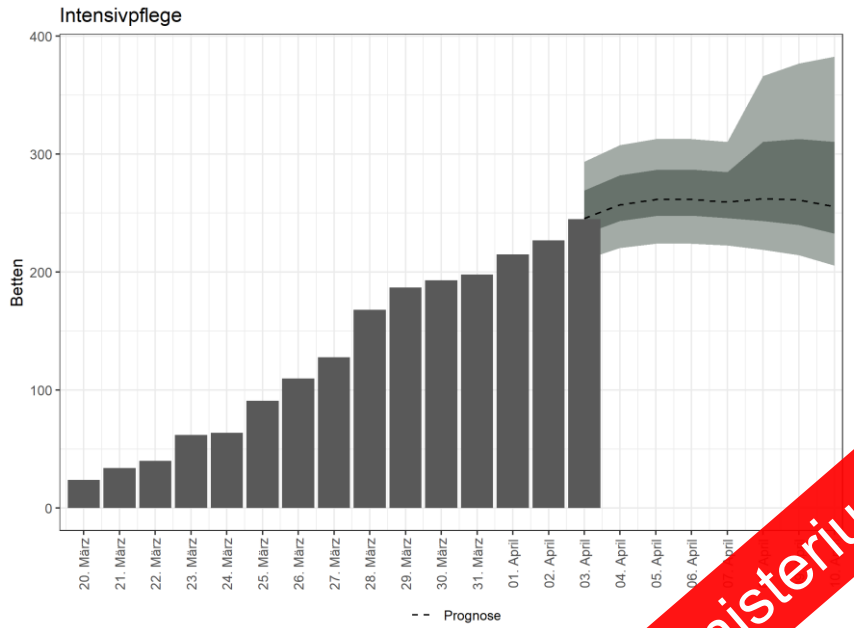
Gender-Unterschiede in der Krise



COMPLEXITY SCIENCE HUB VIENNA

Prognose-Konsortium

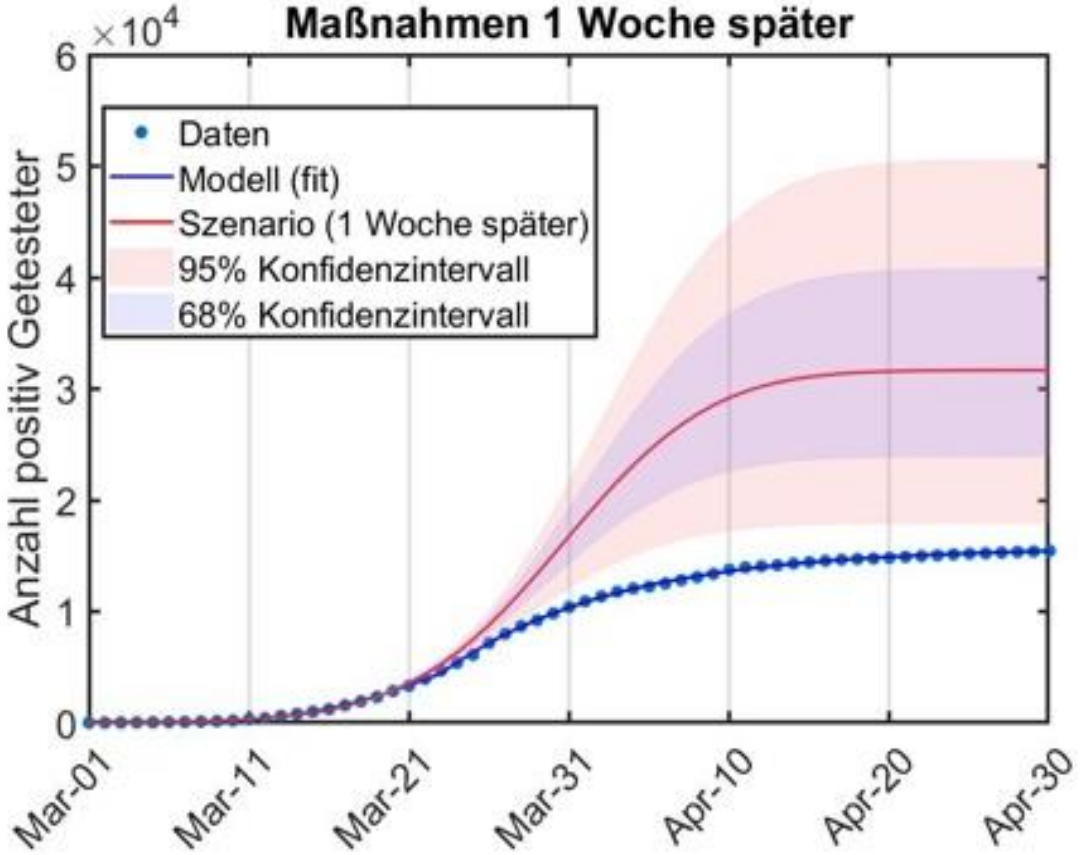




Sozialministerium

COMPLEXITY SCIENCE HUB VIENNA

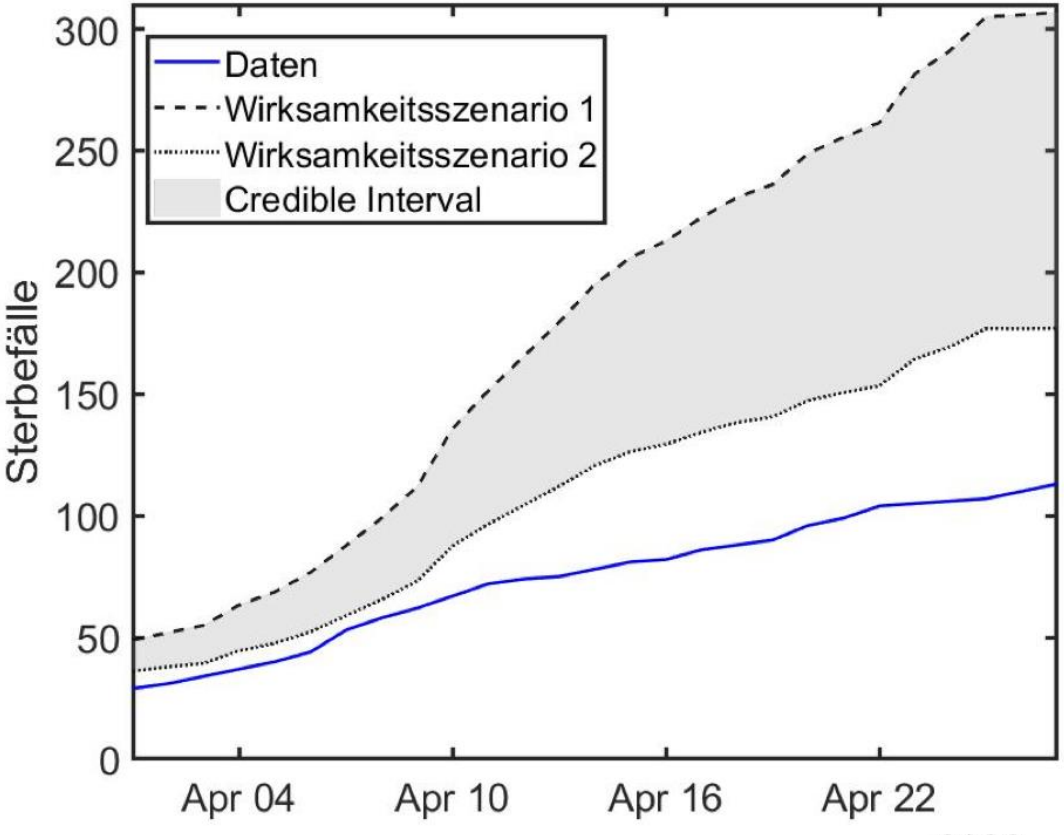
Was, wenn Lockdown 1 Woche später?



Policy Brief

COMPLEXITY SCIENCE HUB VIENNA

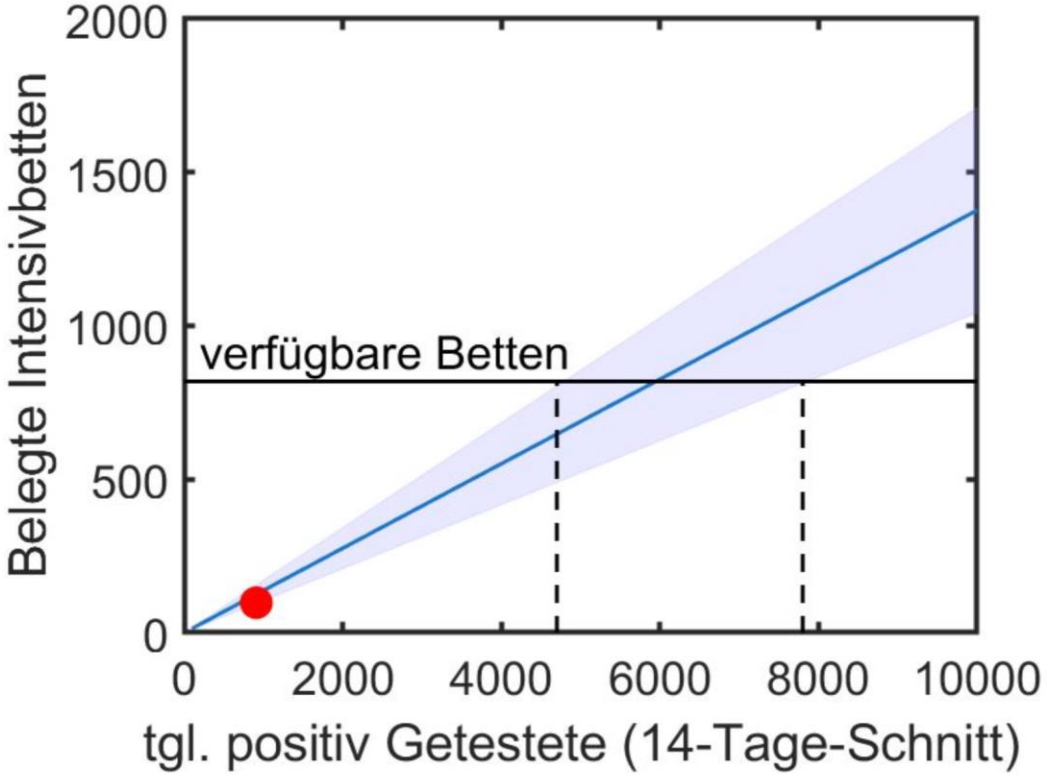
Rolle des Ärztefunkdiensts?



Policy Brief

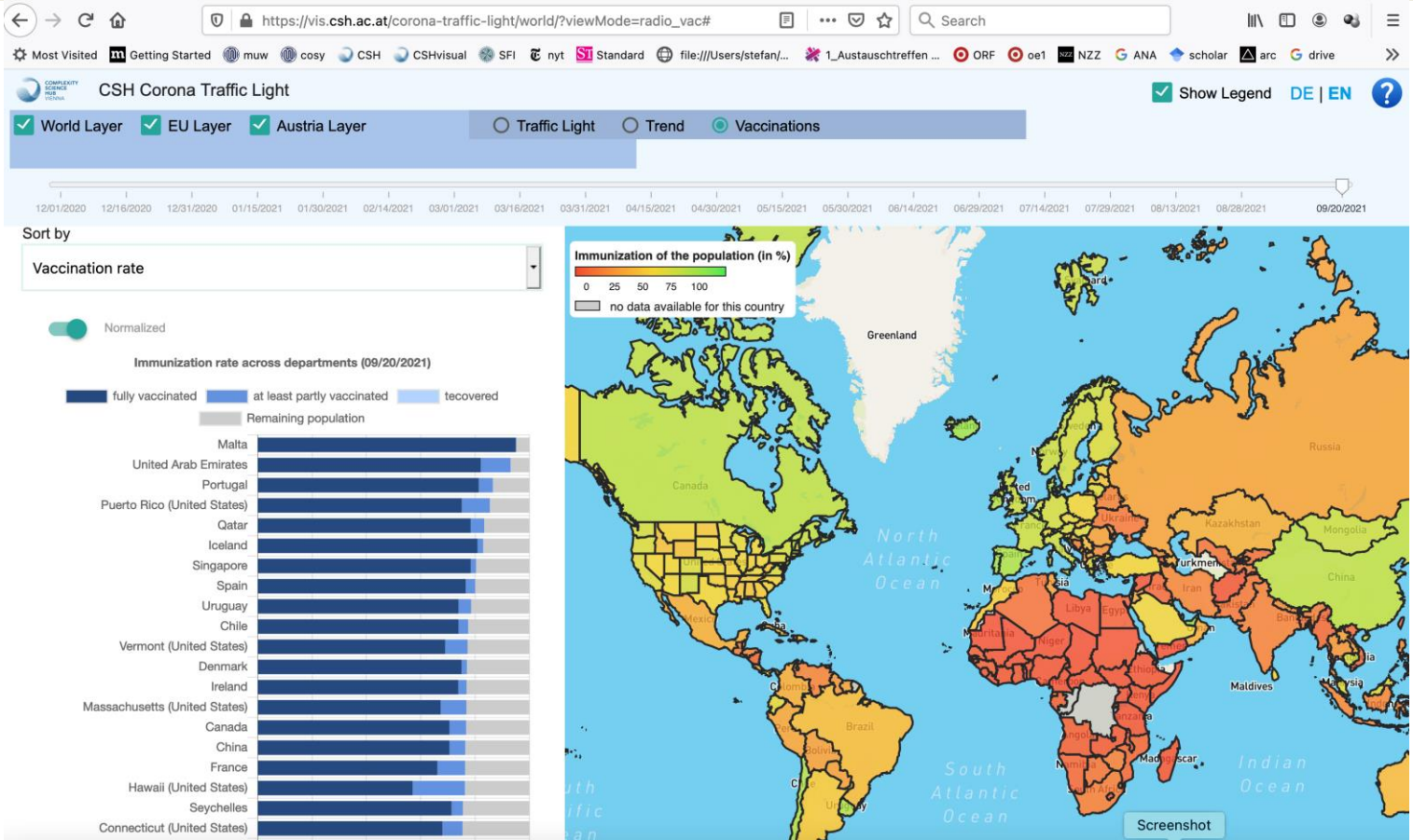
COMPLEXITY SCIENCE HUB VIENNA

Warnung im Oktober 2020



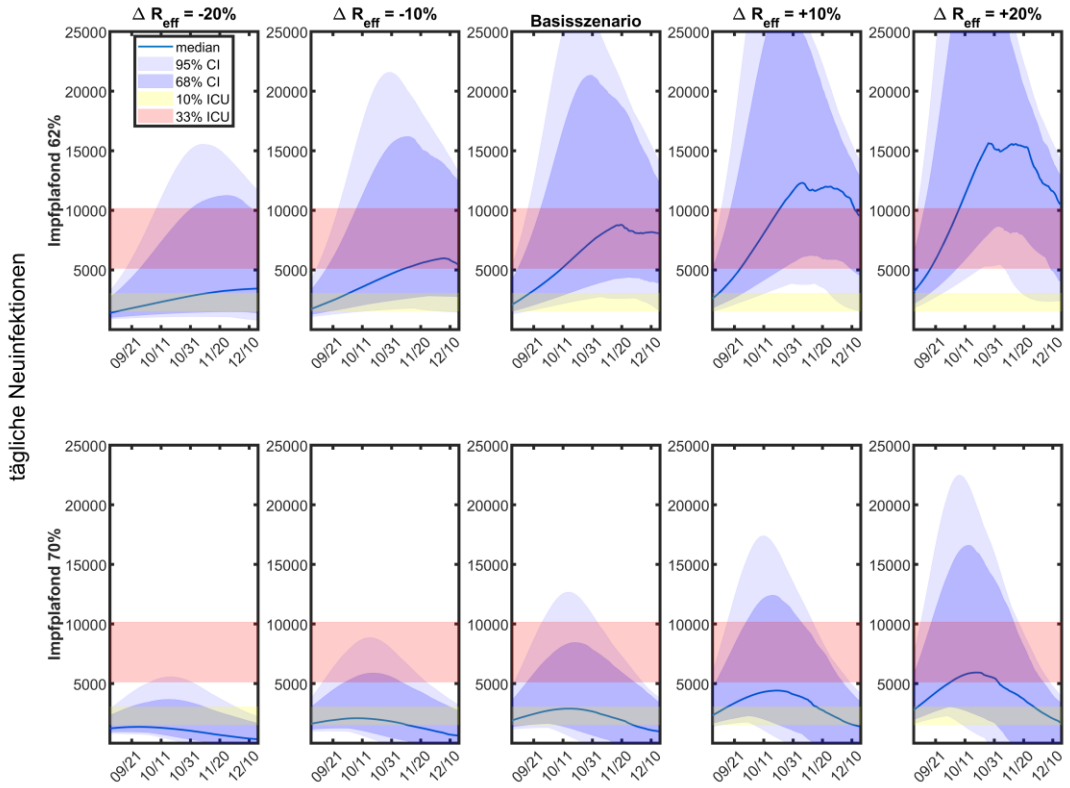
COMPLEXITY SCIENCE HUB VIENNA

Impfampel + Reisemonitoring



COMPLEXITY SCIENCE HUB VIENNA

Outlook nächste 100 Tage

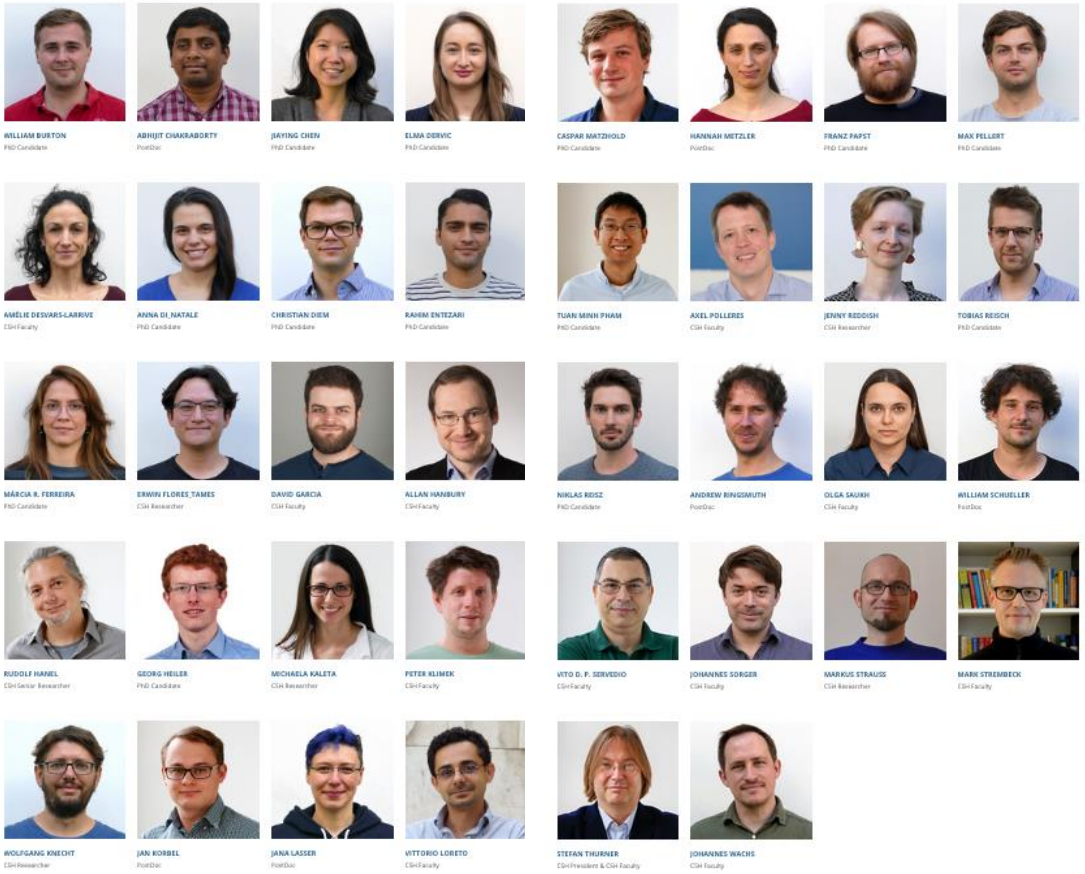


Base-line Scenario:

Herbst 2021: NPIs und saisonale Effekte so wie 2020

COMPLEXITY SCIENCE HUB VIENNA

Team



COMPLEXITY SCIENCE HUB VIENNA