DEMIS
Deutsches elektronisches Meldesystem für den Infektionsschutz
(German electronic reporting system for infectious diseases control)

Project overview at
Aware Machine 2 Machine Communication
Dagstuhl, 29. August 2016
Project lead: RKI/Data Management Unit
Dr. Hermann Claus, Dr. Göran Kirchner
Presenter: Dr. Olga Streibel
Content

- Intro
- Current system
- Goal for DEMIS
- Project steps
- System functions
- Technical insights
- Challenges
- Outlook
Intro

- The Robert Koch Institute (RKI) maintains a database of cases of notifiable diseases, and confirmation of pathogens, reported under the German Protection against Infection Act (Infektionsschutzgesetz, IfSG). SurvStat@RKI 2.0 is an application that allows retrieval of aggregated data from a limited version of the German notification system database. Queries can be created individually or customized from pre-defined queries to generate tables, charts, and maps according to the user's needs.

- The accessible data is updated weekly (generally on Wednesdays) and for some pathogens (§ 7.3 IfSG; e.g. HIV, Syphilis) monthly, respectively.

- The database system is being used for both: public health services (regional and communal health authorities) for registration of new infections and RKI epidemiologists for surveillance of epidemiological situations.
Intro: notifiable evidence of pathogens (IfSG-infection law)

1. Adenovirus
2. Bacillus anthracis
3. Borrelia recurrentis
4. Brucella sp.
5. Campylobacter sp.
6. Chlamydia psittaci
7. Clostridium botulinum
8. Corynebacterium diphtheriae
9. Coxiella burnetii
10. Cryptosporidium sp.
11. Ebolavirus
12. a) EHEC
   b) E. coli, enteropathogenic.
13. Francisella tularensis
14. FSME-Virus
15. Yellow fever virus
16. Giardia lamblia
17. Haemophilus influenzae
18. Hanta virus
19. Hepatitis A virus
20. Hepatitis B virus
21. Hepatitis C virus (non-chronic)
22. Hepatitis D virus
23. Hepatitis E virus
24. Influenza virus
25. Lassa virus
26. Legionella sp.
27. Leptospira sp.
28. Listeria monocytogenes
29. Marburg virus
30. Measles virus
31. Mycobacterium leprae
32. Mycobacterium tuberculosis
33. Neisseria meningitidis
34. Norwalk-like virus
35. Poliovirus
36. Rabiesvirus
37. Rickettsia prowazekii
38. Rotavirus
39. Salmonella Paratyphi
40. Salmonella Typhi
41. Salmonella, sonstige
42. Shigella sp.
43. Trichinella spiralis
44. Vibrio cholerae O 1 and O 139
45. Yersinia enterocolitica
46. Yersinia pestis
1. Other pathogens of hemorrhagic fever
2. Clostridium difficile
3. MRSA
4. Bordetella sp.
5. Measles virus
6. Mumps virus
7. Varicella virus

Report by name has to arrive at the responsible (for the patients) local health authority during 24 hours (§ 9 IfSG)
Current system

- Main software: SurvNet at RKI
- Different databases intern and extern
- Extern:
  - no common shared standards
  - different mechanisms in different federal states
  - third party software with plugins
Current system: GUI for responsible notifiers

- Reports are filled in case by case into the SurvNet

- 35% of health authorities in Germany are using directly the SurvNet 3.0, others a SurvNet-compatible software.
Goals for DEMIS

- Establishing of national electronic reporting system for infectious diseases control under following conditions:
  - law alignment
  - inclusion of all relevant stakeholders
  - circle of experts

- Secure data transfer between the notifier and the Robert Koch Institute
  - Reliable dispatcher service
  - High interoperability
  - Fast responsiveness
Goals for DEMIS

- General architecture approach
System functions (1)

- **Electronic reporting by notifiers**
  - Central reporting at the dispatcher
    → *more convinient for the obligatory notifier*
  - Reporting interface (technical)
    → *flexible and quick adaptation to the emerging exeptional situation*
  - Two approaches
    - 1. Automatic via relevant functionality of the physician’s or medical lab’s system
      → *more convinient for notifiers, faster, more structured*
    - 2. Via web portal (i.e. in shared facilities)
System functions (2)

- Dispatcher service
  - Receiving and confirming notifications
    → standardised and „law-based“ confirmation for obligatory notifiers
  - Forwarding notification to the responsible local health authority
    - ggf. informing further health authorities
    → identifying the responsibility can be adjusted on demand
  - Assignment of complementary reports (i.e. through ?)
    → reducing the workload of local health authorities
  - „Enrichment“ of reports/notifications by further information
    - possible additional reports on the particular person’s case
    - possible additional involved health authorities focusing on the particular case
    - potential relation to an epidemiological outbreak
    - ev. information about „similar“ reports
    → local health authorities receive together with reports further useful information
System functions (3)

- **Information service**
  - 'signal' detection in potential data bursts / emergency situations
  - Consideration of data from registration possible
    → *fast automatic contentwise interpretation of data*
  - Edits' history of every single fall (also for obligatory registrants)
  - Further processing of data (SurvStat@RKI)
  - Manifold possibilities for situations-suited and personalised
- **informations- and service offer for obligatory notifiers**, i.e.
  - uptodate epidemiological information
  - disease compliant advisory and recommendations
  - patients‘ information material
Example: intelligent and adaptive knowledge base (i.e. terminology server)

Example: enhanced 'signal' analysis
Technical insights (general)

- Functionalities as **webservices**
  - Convenient integration into physicians’ or medical labs systems and software of communal public-health-authorities feasible
- Hosting through BVA (federal computing center, ITZBund-federal IT service provider)
- Further development of SurvNet@RKI
- Several accompanying projects
  - standards for registration content (terminology-server)
    - z.B. consistent encoding of medical labs techniques and results
    - Migration into ICD-11 (International Classification of Diseases)
    - Standards for reports
  - (HL7-FHIR = Fast Healthcare Interoperability Resources format)
Technical insights (general)

- **Shared, distributed data storage** from all local health authorities, federal authorities, Robert Koch Institute
  - *content-based and technical changes can be provided much faster*
- Data access via user authorization
- Personal data encryption: data is for the responsible local health authority *encrypted*; Access possible for this authority only.
- Forwarding of the case between local health authorities
  - = data encryption for the next responsible authority
  - central **automatic deletion rule** for personal data
    - *consistent and confident handling of personal data*
Project steps

- Technical concept
- Creating legal foundation by law
  (IfSG-German 'Act on the Prevention and Control of Infectious Diseases')
- Inclusion of stakeholders
- Extension levels:
  - shared distributed database
  - notification portal for notifications and reports
  - digital notification by medical labs
  - digital notification by physicians
  - digital notification according to § 7 Par. 3 IfSG
  - (anonymous notifications through medical lab with reports from physicians)
- Integrating further data exchange in DEMIS
  - Affects other infectious-epidemiologic relevant data exchange between the same corresponding participants (med.labs, physicians, hospitals, ÖGD (public health services))
  - molecular surveillance
- Use of the telematic-infrastructure functionalities from e-health card
Project challenges

- Law based
- Stakeholders

Technical:
- Automatic adaptability to the exceptional situations
- Secure data exchange between obligatory notifiers and the receivers
- Intelligent, adaptive and reliable knowledge service
- Fast response in emergent situations
Some of stakeholders by geographic regions

- Bezirksamt Eimsbüttel, Fachamt Gesundheit
- Gesundheitsamt / Landeskompetenzzentrum Bremen
- Region Hannover
- Gesundheitsamt Rhein-Kreis Neuss
- Gesundheitsamt Fulda
- Gesundheitsamt Breisgau-Hochschwarzwald
- Landesamt für Gesundheit und Lebensmittelsicherheit
- Gesundheitsamt Kreis Schleswig-Flensburg
- Gesundheitsamt Hansestadt Rostock
- Landesamt für Gesundheit und Soziales Berlin
- Landesamt für Verbraucherschutz Sachsen-Anhalt
- Gesundheitsamt Greiz
- Landesamt für Gesundheit und Lebensmittelsicherheit
Outlook and discussion:

- Relevant research issues ( ?):
  - interpretation of data in the context of law and epidemiology.
  - intelligent and adaptive (public health) data management.

- interoperability on the data level
- semantical enrichment of the data
Outlook

- SurStat @ RKI
  https://survstat.rki.de/

- Terminology server

- Epidemiological information

- Epidemiological yearbook
  http://www.rki.de/EN/Content/infections/epidemiology/inf_dis_Germany/infectious_diseases_in_Germany_node.html
Thank you!

Data Management (Unit 31) @ RKI:

The main tasks of unit 31 'Data Management' of Department 3 (Infectious Disease Epidemiology) include the administration and editing of all infection-related epidemiological data (e.g., surveillance data regulated by the Protection against Infection Act (IfSG) and the Transfusion Law (TFG), Sentinels, ...)

http://www.rki.de/EN/Content/Institute/DepartmentsUnits/InfDiseaseEpidem/Div31/div31_node.html