

Abstract

Since the introduction of Hollerith machines there have been ideas for the evaluation of time wise massive data collections. However, the main developments started in the sixties based on main-frame computing. Already at that time many dreams were published which took decades to come through. As the delivery of promises and hopes was much less successful than expected many early starters and their institutions were shut down. Driving countries in this competitive game were not only the US and other industrialized countries but also highly funded national institution in many other countries. The complexity of the technology and the dynamics of software development forced most developments out of the competitive game. The US approaches became very dominant due to several "cultural" factors like massive funding resources and well funded disruptive approaches. However, the development of digital research infrastructures in different scientific disciplines has been driven by very specific national factors, of which available IT-power is only one of many im-pact factors. International research competition is more and more based on the management of digital research infrastructures. Easy answers and simple explanations of how to move ahead are not available.



Big Data und Forschungsinfrastruktur - Perspektiven für die Medizin

Deutsche Gesellschaft für Medizinische Informatik,
Biometrie und Epidemiologie e.V.
59. Jahrestagung



Göttingen, 7. bis 10. September 2014
www.gmds2014.de



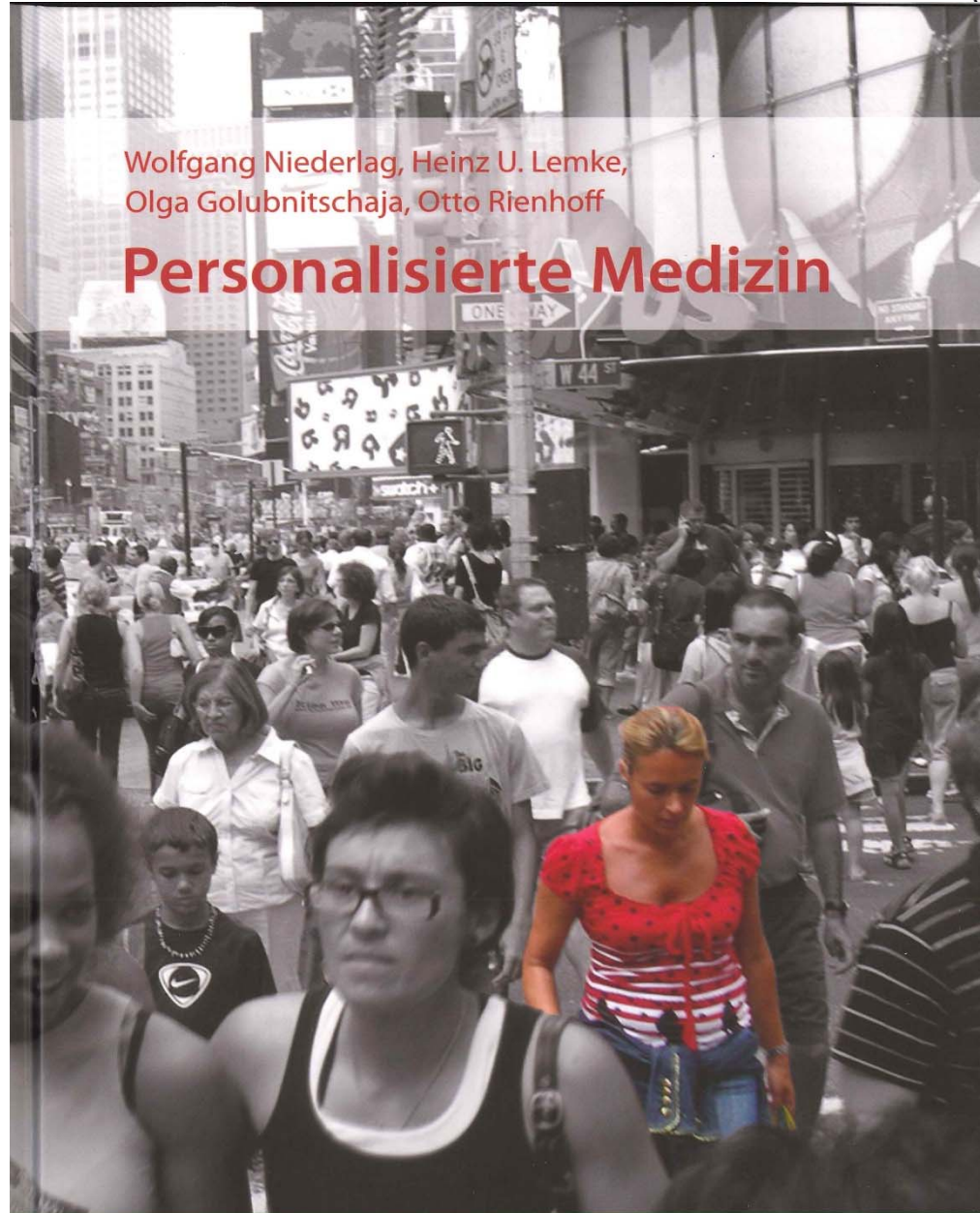
Our way from the past

- Development of IT-Infrastructures started in the last century – with a strong push during WW2.
- The development in different countries was often driven by nationally specific conditions or political targets (e.g. Germany, US, England, Sweden, Israel, Brazil, Cuba).
- Some countries experienced rather continuous developments – others ups and downs in waves (e.g. Denmark, Germany, Greece, South Africa).
- International organizations tend to try to manage the process by overarching funding schemes (e.g. EU) – which only works in internationally established research communities (e.g. astronomy).



Wolfgang Niederlag, Heinz U. Lemke,
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Personalisierte Medizin





DER SPIEGEL

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Deutschland €4,60

4 190700 704608 50

Total vermessen

Wir werden gläserne Patienten – und hoffen auf ewige Gesundheit

The cover features a woman with long dark hair, looking directly at the camera. She is holding a blue, credit-card-sized health card. The card has a yellow chip on the left and a small photo of the woman on the right. The card displays various medical data points and a heart rate monitor line. The background of the card is a grid with faint text and numbers.

Visible text on the health card:

- Hämoglobin g/dl 13,8-17,3 13,7
- Hämatocrit % 40-53 42
- MCV fL 80-96 84
- MCH pg 28-33 34
- MCHC g/dl 33-36 34,8
- RBC /mm³ 4,0-5,0 4,8
- WBC /mm³ 4,0-10,8 6,2
- Neutrophils % 40-70 62
- Lymphocytes % 20-40 29
- Monocytes % 2-10 3
- Eosinophils % 1-5 0,6
- Basophils % 0-1 0,6
- Platelets /mm³ 150-400 16,000
- Urea nitrogen mg/dl 7-20 11,4
- Creatinine mg/dl 0,6-1,2 0,6
- BUN/Creatinine ratio 10-20 19,0
- Glucose mg/dl 70-100 87,6
- Hemoglobin A1c % 5,7-6,4 5,9
- Cholesterol mg/dl 125-200 154
- LDL cholesterol mg/dl 70-130 89
- HDL cholesterol mg/dl 35-65 59
- Triglycerides mg/dl 15-150 114
- Uric acid mg/dl 3,5-7,0 5,3
- Serum iron mcg/dl 50-150 114
- Alkaline phosphatase U/L 40-120 104
- Aspartate aminotransferase U/L 0-37 29
- Alanine aminotransferase U/L 0-37 29
- Bilirubin mg/dl 0,1-1,2 0,2
- Prothrombin time sec 11-14 12,4
- Partial thromboplastin time sec 28-35 31,4
- Fibrinogen g/dl 2,0-4,0 3,14
- D-dimer ng/mL <0,5 0,2
- Prostate-specific antigen ng/mL 0-4,0 3,14
- Testosterone ng/dL 300-1000 514
- Estrone pg/mL 10-40 21,4
- Estradiol pg/mL 10-40 21,4
- Testosterone/estrone ratio 10-100 24,0
- Testosterone/estradiol ratio 10-100 24,0

Personal data on the card:

- Geschlecht: weiblich
- Alter: 29
- Gewicht: 54 kg
- Blutdruck: 120/70 mmHg

Small text at the bottom of the card:

Bei erhöhtem Wert (→) zu hoch, bei niedrigem Wert (←) zu niedrig.
 Bei niedrigem Wert (←) zu hoch, bei erhöhtem Wert (→) zu niedrig.

The analyses of the German Council for Research Information Infrastructures

- Focus on „research data“ – addressing material collections as well digital data resources.
- Both are seen in closest connection and interdependence.
- It is perceived that both types of research infrastructures have to be promoted and substantially developed together.
- There is no simple recipe how to do it.
- Currently several working groups active (more infos at the end of the talk).

Types of `Research data`

Collections

- archive documents
- books
- bio specimen
- drilling probes
- archaeological artefacts
- ...

Digital data

- raw data measurements
- metadata
- data utilization process documentation
- published data
- ...

Database, 2016, 1–11 doi: 10.1093/database/baw125
Original article

Original article
**The Global Genome Biodiversity
Network (GGBN) Data Standard
specification**

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M. Doering⁸, P. Flemons⁹, B. Gemeinholzer¹⁰, A. Günther¹, T. Hollowell²,
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Disruption as principle of advance ?

- Simple messages pay off in the political discussion.
- The belief in the advantages of „disruption“ follows the idea of transplanting success-stories in other countries into the own environment (e.g. Silicon Valley to Berlin).
- Historical examples support such argumentations (e.g. US Liberty Sip Production).
- However, they need changes in the political set-up to work (e.g. Singapore).
- Societal areas which are highly legally defined will be difficult to disrupt (e.g. health care in Germany).

Résumé: still a long way to go or: the complexity of social change

- Strategic planning of research data-infrastructure needs societal developments to move consequently ahead.
- Leapfrogging by disruption may only help if tipping-points are reached.
- Thus, it is extremely difficult to foresee the dynamics of the future development.
- However, more data without reliable scientific results may lead to negative political reactions.
- Strategic planning has to manage this kind of development and focus on social aspects rather than just extending IT-hardware resources.



06.10.2016

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The one and only key: social/legal development by education and training

- Countries have to identify their typical national route ahead.
- There will be massive changes for social groups on that route. Leading to fights for resources, social recognition, and power.
- Countries will manage these distribution fights differently.
- These effects are the stronger the more the sector/discipline is entangled in national traditions.
- They will have a strong impact on big data IT-infrastructures.
- Driving factors in the societal process will be national interests (e.g. Iceland, Israel, Estonia) in respect to the management of research data and research material collections.



Digitale Agenda 2014 – 2017

Nationaler **IT** Gipfel



Rat für
I n f o r m a t i o n s
I n f r a s t r u k t u r e n

Position Paper 2016

ENHANCING RESEARCH DATA MANAGEMENT: PERFORMANCE THROUGH DIVERSITY

Recommendations regarding structures, processes, and
financing for research data management in Germany

CURRENT SITUATION: Research Data Management (RDM) in Germany

- Dramatic increase in the quantity/heterogeneity of research data in Germany
- Numerous informative statements regarding RDM, but there is still an "implementation deficit"
- Substantial financial and personnel requirements
- Numerous hurdles inhibit the transformation
 - Heterogeneous funding landscape, a lack of coordination, orientation towards technology instead of processes, cultural diversity among the disciplines, unclear quality assurance and reputation mechanisms, as well as uncertainty of the stakeholders in terms of strategic investments

RECOMMENDATIONS

... for policymakers and science

- Changing funding policy – sustainability through the orderly transition of project-based initiatives into suitable sponsoring organisation
- Ensuring efficiency and coordination based on a (distributed) national research data infrastructure (NFDI)
- Roadmaps as a tool for coordination and financial planning of the NFDI
- Linking the NFDI with monitoring and quality assurance systems
- Promoting various aspects of a "research data culture"
- Progressing the development of expertise/personnel at all levels
- Promoting international networking (in the EU and globally)

RECOMMENDATIONS

... for scientific organisations

- Promoting evaluation concepts for RD infrastructures
- Developing guidelines for long-term archiving
- Disseminating standards and quality criteria (and in doing so: working towards fulfilling the needs of users)
- Establishing binding rules of conduct
- Designing attractive training and education programmes for new occupations and career paths
- Establishing dedicated data publication services in science
- Providing guidance during the establishment of the NFDI

RECOMMENDATIONS

... for researchers and their scientific societies + communities

- Developing RD standards appropriate to the discipline while considering establishing connections to existing services (i.e. ensuring interoperability)
- Planning how to handle data in good time, triggering a scientific discourse regarding archiving periods
- Coordinating the interests in the triangle formed by data users, data producers, and infrastructure centres
- Recognising digitality as a field of expertise of researchers + management, actively initiating a discussion regarding critical points
- Leading a discourse on responsibility for data and data security
- Contributing locally from the bottom up to the establishment of an NFDI

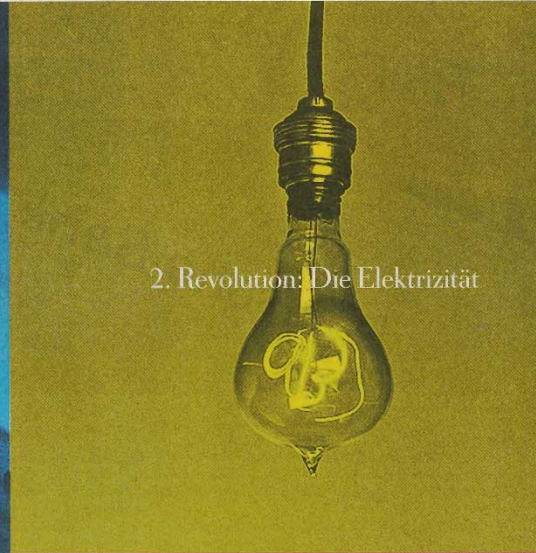


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WIRTSCHAFT



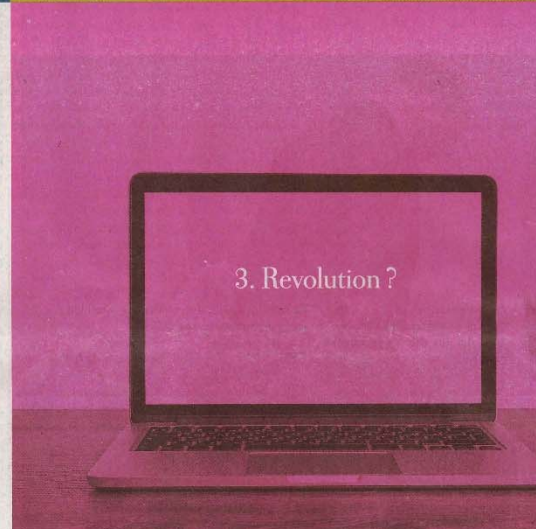
1. Revolution: Die Dampfmaschine



2. Revolution: Die Elektrizität

Ist der Computer überschätzt?

Ökonomen kritisieren das Internet: Viel Hype,
wenig Nettogewinn! THOMAS FISCHERMANN glaubt, dass sie
die aktuellen Revolutionen schlecht verstehen



3. Revolution ?