

Notwendige Infrastrukturen für Transparenz, Effizienz und Nachhaltigkeit in der medizinische Forschung

Prof. Dr. Michael Krawczak

TMF - Technologie- und Methodenplattform
für die vernetzte medizinische Forschung e.V.

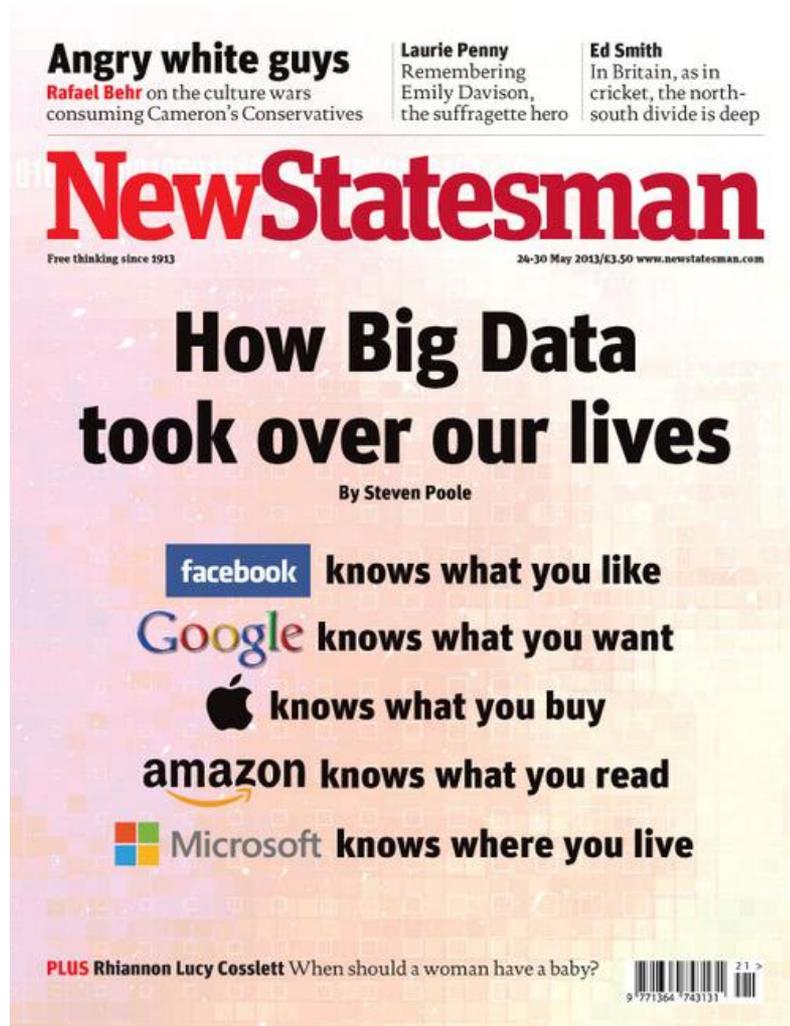
Christian-Albrechts-Universität zu Kiel



Wandmalerei im Grab des Djehutihotep
ca. 1900 v.Chr.

Big Data – Zukunft der Wissenschaft (?)

Big Data – Zukunft der Wissenschaft (?)



“**Big Data** is high-volume, high-velocity and/or high-variety information assets that demand cost-effective, innovative forms of information processing that enable enhanced insight, decision making, and process automation.”

Gartner IT Glossary

Big Data – Zukunft der Wissenschaft (?)

Angry white guys
Rafael Behr on the culture wars consuming Cameron's Conservatives

Laurie Penny
Remembering Emily Davison, the suffragette hero

Ed Smith
In Britain, as in cricket, the north-south divide is deep

NewStatesman

Free thinking since 1913 24-30 May 2013/£3.50 www.newstatesman.com

How Big Data took over our lives

By Steven Poole

facebook knows what you like
Google knows what you want
Apple knows what you buy
amazon knows what you read
Microsoft knows where you live

PLUS Rhiannon Lucy Cosslett When should a woman have a baby?



4 September 2008 | www.nature.com/nature | £10 THE INTERNATIONAL WEEKLY JOURNAL OF SCIENCE

nature

THE BITER BIT
Viral infections for viruses
TROPICAL CYCLONES
The strong get stronger
BLACK HOLE PHYSICS
A new window on the Galactic Centre

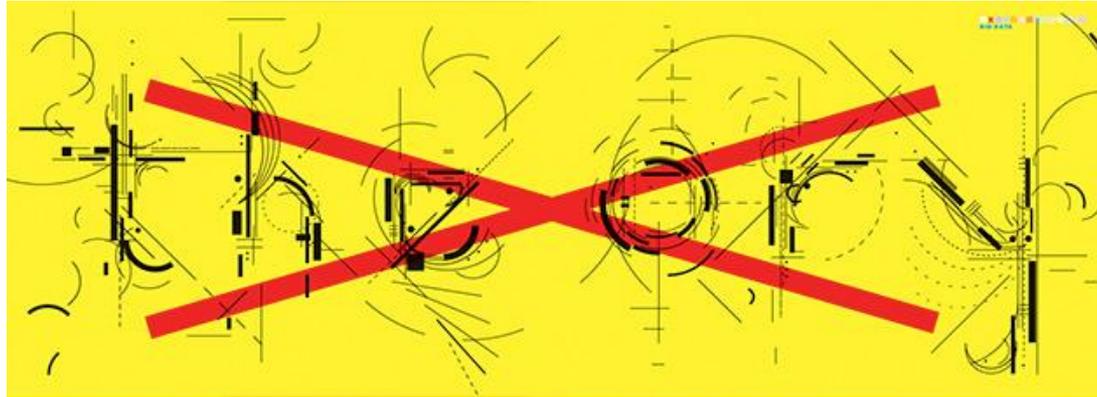
BIG DATA

NATUREJOBS
Minnesota musings

SCIENCE IN THE PETABYTE ERA



Big Data – Zukunft der Wissenschaft (?)



© Wired Magazine

“All models are wrong, but some are useful.”

George Box, Statistiker, University of Wisconsin

“All models are wrong, and increasingly you can succeed without them.”

Peter Norvig, Director of Research, Google Inc.

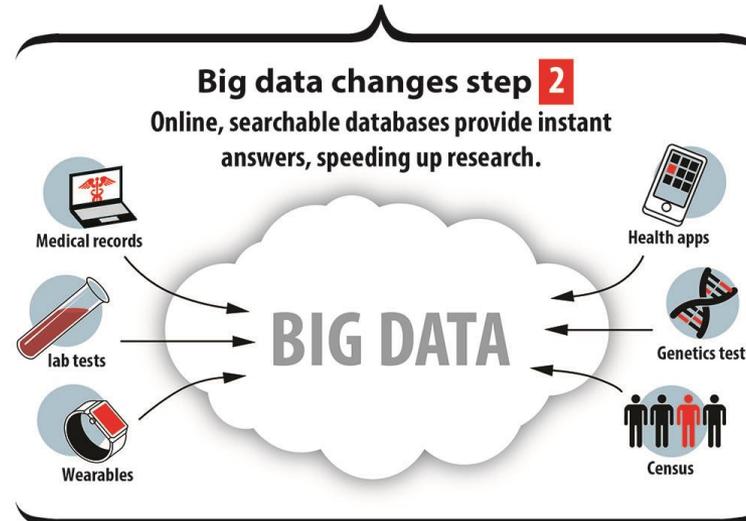
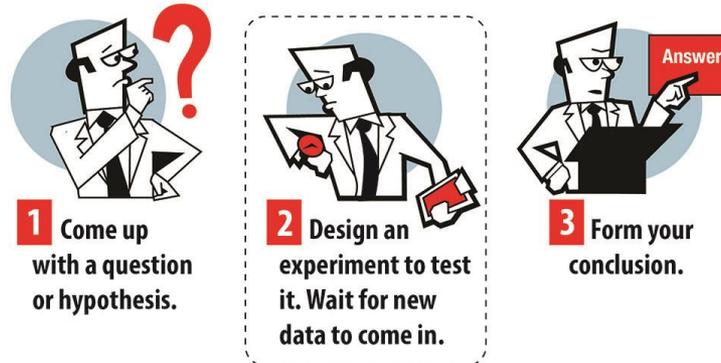
“Correlation supersedes causation, and science can advance even without coherent models, unified theories, or really any mechanistic explanation at all.”

Chris Anderson, Chief Editor, Wired Magazine

Big Data – Zukunft der Wissenschaft (?)

How can big data change science?

Here's how medical research traditionally works:



Big Data – Zukunft der Wissenschaft (?)

Angry white guys
Rafael Behr on the culture wars consuming Cameron's Conservatives

Laurie Penny
Remembering Emily Davison, the suffragette hero

Ed Smith
In Britain, as in

NewStatesman

Free thinking since 1913

How Big Data took over our lives

By Steven Poole

facebook knows what you think
Google knows what you search for
Apple knows what you buy
amazon knows what you buy
Microsoft knows where you live

PLUS Rhiannon Lucy Cosslett When should a woman have a baby?

4 September 2008 www.nature.com/nature £10 THE INTERNATIONAL WEEKLY JOURNAL OF SCIENCE

nature

Viral infection
TROPICAL
The structure of
BLACK
A new

BIG DATA

SCIENCE IN THE PETABYTE ERA

Statistical and Machine-Learning Data Mining

Techniques for Better Predictive Modeling and Analysis of Big Data

Second Edition



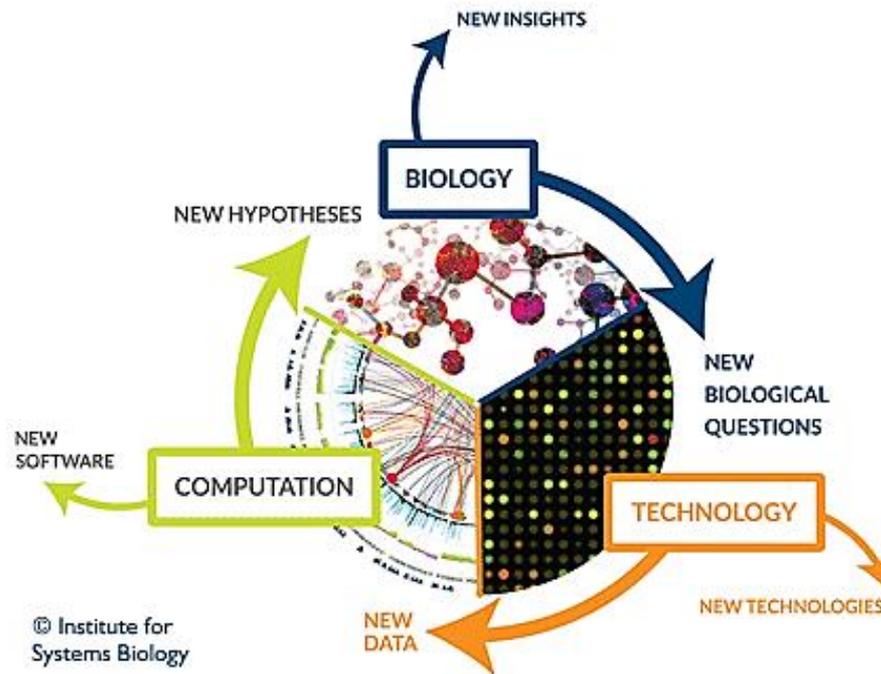
Bruce Ratner

 CRC Press
Taylor & Francis Group

Big Data – Zukunft der Wissenschaft (?)

“**Systems Biology** is the computational and mathematical modeling of complex biological systems. [...] Systems Biology is a biology-based interdisciplinary field of study that focuses on complex interactions within biological systems, using a holistic approach (instead of the more traditional reductionism) to biological and biomedical research.”

Wikipedia



Big Data – Zukunft der Wissenschaft (?)



e:Med **Konsortien** Demonstratoren Nachwuchsforschung Querschnitt International



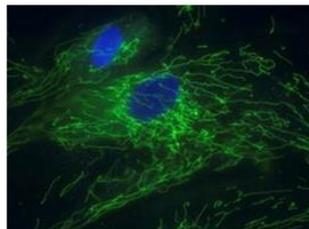
Home **Konsortien**

CancerTelSys
CAPSyS
CLIOMMICS
e:AtheroSysMed
e:Kid
IntegraMent
Multiscale HCC
PANC-STRAT
SMOOSE
SYSIMIT
SysINFLAME
SysMedAlcoholism
SYSMED-NB
SYS-Stomach

Modul I

Konsortien der Systemmedizin

Das e:Med Modul I mit aktuell 14 interdisziplinären Forschungskonsortien der Systemmedizin ist die zentrale Maßnahme des Forschungs- und Förderkonzepts. Für Forschungsgruppen an 42 wissenschaftlichen Einrichtungen in 28 deutschen Städten sowie 3 Universitäten außerhalb Deutschlands stellt das BMBF für die ersten drei der vorgesehenen fünf Förderjahre einen Betrag von 52,3 Mio.€ zur Verfügung.



Diese interdisziplinären Forschungskonsortien bearbeiten in zahlreichen Teilprojekten an unterschiedlichen Standorten jeweils eine gemeinsame krankheitsbezogene Fragestellung anhand eines systemmedizinischen Forschungsansatzes. Hierbei arbeiten klinische Arbeitsgruppen, hochdurchsatzorientierte Teams der biomedizinischen Grundlagenforschung sowie Experten für Informationstechnologien zusammen. Sie untersuchen komplexe physiologische und pathologische Prozesse verschiedener Krebsarten, neurologischer Krankheiten und Entzündungs- sowie Herz-Kreislauf-Erkrankungen. Zentral sind hierbei die funktionelle Annotation, das Formulieren von Modellen des



Mitglieder

Hier entsteht in Kürze der e:Med Mitgliederbereich.



AKTUELLES

- [Genomforschung – Quo vadis, Deutschland?](#)
- [Schlussbericht PerMediCon 2015](#)

VERANSTALTUNGEN

- [Sep. 26-30, 2015: HUPO, Vancouver](#)
- [Nov. 16-18, 2015: IHEC, Tokio](#)

mehr

<http://www.sys-med.de//>

Forderungen



Research: increasing value,

How to increase value and priorities are set

Jain Chalmers, Michael B Bracken, Ben Djafarzadeh, Silvio Garattini, Sandy Oliver

Lancet 2014; 383: 156-65
 Published Online January 8, 2014
[http://dx.doi.org/10.1016/S0140-6736\(13\)27291-1](http://dx.doi.org/10.1016/S0140-6736(13)27291-1)
 This is the first in a Series of five papers about research

of waste cannot be justified. In this report, we discuss achievements, partly because some studies are done have relevance for human health. Additionally, good as the way in which these ideas are prioritised for should not be deemed wasteful; they are simply an im- funding to achieve a defined mission are often referred to as 'big science'. Successful big science projects should have a clearly defined goal, a possible means to achieve it and a strong sociological rationale to justify public funding of such endeavors. Similarly, the type of project that can be widely supported beyond the scientific community depends on societal needs at the time. Although most biology has been and continues to be small science, the Human Genome Project and other genome projects are considered big science in biology. A defining feature of these projects is a large-scale engineering effort designed in support of a specific scientific aim. Projects involving particle colliders and genome sequencing are essentially equipment-driven data-acquisition projects, and such projects will continue to provide new findings through equipment advances.

Recommendations

- 1 More research on research should be done to identify factors associated with successful replication of basic research and translation to application in health care, and how to achieve the most productive ratio of basic to applied research
 - Monitoring—periodic surveys of the distribution of funding for research and analyses of yields from basic research
- 2 Research funders should make information available about how they decide what research to support, and fund investigators of the effects of initiatives to engage potential users of research in research prioritisation
 - Monitoring—periodic surveys of information on research funders' websites about their principles and methods used to decide what research to support
- 3 Research funders and regulators should demand that proposals for additional primary research are justified by systematic reviews showing what is already known, and increase funding for the required syntheses of existing evidence
 - Monitoring—audit proposals for and reports of new primary research
- 4 Research funders and research regulators should strengthen and develop sources of information about research that is in progress, ensure that they are used by researchers, insist on publication of protocols at study inception, and encourage collaboration to reduce waste
 - Monitoring—periodic surveys of progress in publishing protocols and analyses to expose redundant research

(Prof) S Garattini, PhD, Department of Hematology and Department of Health Outcomes and Behavior, H Lee Moffett Cancer Center and Research Institute, Tampa, FL, USA (Prof) B Bracken, PhD, Istituto di Ricovero e Cura a Carattere Scientifico Istituto di Ricerche Farmacologiche Mario Negri, Milan, Italy (S Garattini MD), RAND Tampa, Cambridge, UK (S Garattini), UNDP/INFPA/UNICEF/WHO World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP), WHO, Geneva, Switzerland (A M Gilman PhD), Florry Institute of Neuroscience and Mental Health, Melbourne, VIC, Australia (S W Hoare PhD), Stanford Prevention Research Center, Department of Medicine (Prof) J A Chalmers MD, and Division of Epidemiology, Department of Health Research and Policy (Prof) J A Ioannidis, School of Medicine, Stanford University, Stanford, CA, USA (Department of Statistics, School of Humanities and Sciences, Stanford University, Stanford, CA, USA (Prof) J A Ioannidis and Meta-Research Innovation Center at Stanford (METRICS), Stanford University, Stanford, CA, USA

commentary

Social engineering for virtual 'big science' in systems biology

Hiroaki Kitano, Samik Ghosh & Yukiko Matsuoka

A new type of big science is emerging that involves knowledge integration and collaboration among small sciences. Because open collaboration involves participants with diverse motivations and interests, social dynamics have a critical role in making the project successful. Thus, proper 'social engineering' will have greater role in scientific project planning and management in the future.

Scientific projects with large amounts of funding to achieve a defined mission are often referred to as 'big science'. Successful big science projects should have a clearly defined goal, a possible means to achieve it and a strong sociological rationale to justify public funding of such endeavors. Similarly, the type of project that can be widely supported beyond the scientific community depends on societal needs at the time. Although most biology has been and continues to be small science, the Human Genome Project and other genome projects are considered big science in biology. A defining feature of these projects is a large-scale engineering effort designed in support of a specific scientific aim. Projects involving particle colliders and genome sequencing are essentially equipment-driven data-acquisition projects, and such projects will continue to provide new findings through equipment advances.

There is a related desire to obtain a comprehensive understanding of specific cellular systems and biological processes through high-throughput methods. Emergence of systems biology as mainstream biology is accelerating this tendency, because it often requires measurements and analysis of various large-scale and multifaceted data. At the same time, new knowledge critical for in-depth and precise understanding of systems is often derived from small science. This means that a new type of big science is needed that consolidates data and knowledge not only from large-scale projects, but also from discoveries by small science.

It is therefore inevitable that a 'virtual' big science will form, connecting large numbers of researchers around the globe to attain large-scale knowledge integration in an emergent manner. The implication is that such an initiative must have widely acceptable objectives, leadership and proper sociological design to make it sustainable.

There is an impossible number of problems that have yet to be resolved in the biomedical field, and some of these would benefit from being included in big science projects, either in a deliberate and organized or in a more emergent manner. For example, in the numerous cases of diseases for which effective cures are not available but are being proposed and developed, problems remain. Indeed, the cost of drug discovery is so high that it puts severe pressure on the public medical system and impedes access to drugs for underprivileged segments, which in turn prevents development of drugs for rare diseases or those that are prevalent in the poorest areas of the world.

The rising cost of drug discovery affects all segments of society. With increased understanding of individual genomic variations and their impacts on drug efficacy and side effects, we can envision an era of personalized medicine in which patients are selected on the basis of genetic and biochemical differences that underlie different responses to drugs. This would help patients minimize side effects and help health-care systems eliminate considerable misdirected cost. At the same time, it may also mean substantial revenue reduction for pharmaceutical companies. Research and development (R&D) as an industry, and thereby the ability to find possible cures for orphan diseases, may not be sustainable unless drastic reductions in R&D costs are achieved.

Cost and access to medical services is a critical factor for the base-of-the-pyramid segment of the population. For example, tuberculosis is still a major killer in developing countries, as 9.27 million new infections were reported in 2007 globally, with a significant percentage of them being multidrug resistant and some being extensively drug resistant¹. Yet only a handful of drug-discovery projects exist because

of the mismatch between the investment of R&D and the ability of countries where tuberculosis is prevalent to afford treatment. Unless cost-effective drug development can be achieved, those who suffer from neglected diseases will not be saved. Developing technologies to substantially mitigate these problems is socially valuable.

Knowledge integration at all levels
 One of the fundamental causes of low productivity in drug discovery is a lack of in-depth understanding of the complexity of biological systems and a means of predicting potential outcomes of candidate compounds when used in cells, model animals and patients (<http://www.fda.gov/downloads/ScienceResearch/SpecialTopics/CriticalPathInitiative/CriticalPathOpportunitiesReports/ucml13411.pdf> and <http://www.pwc.com/govt/pharma-life-sciences/pharma-2020/pharma-2020-vision-path.html>). Proper introduction of a system- and network-oriented approach to drug discovery, with prediction capabilities even at the cellular level, is expected to rectify the situation by providing a better understanding of the biology that underlies diseases and, ultimately, by enabling us to use precise computational models of cells, organs and patients. Already, several systems biology efforts are under way and being planned.

Development of precise biological models requires integration of knowledge and data at all levels, from genomics and proteomics to imaging and physiology. Various data from high-throughput experiments provide us with genome-wide characteristics, but small-sciences data must be incorporated to gain an understanding of the detailed mechanisms. For both financial and sociological reasons, no single large-scale project can address a systems-level problem truly comprehensively. For instance, even if a large-scale project is

© 2011 Nature America, Inc. All rights reserved.

Value, reducing waste 3 Reducing waste in biomedical research

Elina Hemminki, Robert S Phillips, Julian Savulescu, Malcolm Macleod, Janet Wistley

Question and selection of an appropriate study design, waste can arise in management of biomedical research. Obtaining regulatory and governance some and disproportionate to the conceivable risks to research participants. Intentions that are assumed to be justified in the interests of patients and the efficiency of these interests. Inefficient management of the procedural conduct of in poor recruitment and retention of participants in well designed studies sources of waste can be minimised if the following four recommendations their influence to reduce other causes of waste and inefficiency in research. All work with researchers, patients, and health professionals to streamline guidelines, and processes that govern whether and how research can be done, the plausible risks associated with the research. Third, researchers and efficiency of recruitment, retention, data monitoring, and data sharing in known to reduce inefficiencies, and further research should be done to fully, everyone, particularly those responsible for health-care systems, should day clinical practice. Regulators and researchers should monitor adherence publish metrics.

research, which are elaborated upon in this Series. After identification of an important research question and selection of an appropriate study design, waste can be noticeable and quantifiable from the way in which research is regulated and managed? Furthermore, foreknowledge of regulatory and management requirements can affect researchers' choice of research question and study design, resulting in unnoticed and unquantifiable waste, such that important research is identified but never addressed. Ultimately, waste arises from questions being overlooked or unnecessarily addressed, research being underpowered or done too slowly, and research being too costly. A consensus on the need to regulate biomedical research arose from Nazi research atrocities² and abuses of people in mainly non-therapeutic research,^{3,4} such that by the 1980s, the need for ethics review and preclinical regulation of biomedical research involving human beings was not controversial. Similarly, published revelations of maltreatment of experimental animals in preclinical research led to it becoming more regulated⁵. Nowadays, permission to do biomedical research (regulatory approval) is needed in accordance with requirements of national or regional laws or professional authorities. Research ethics committees are independent regulators of most types of biomedical clinical research, whereas additional specific regulators oversee research involving data, devices, drugs, embryos, radiation, and tissue, among others. Regulatory functions are also undertaken by institutional bodies concerned with biomedical research governance, which is

Forderungen

Ioannidis JPA, et al. (2014) Lancet 383: 166–175.

- Standardisierung von Ressourcen und Prozeduren
- hohe methodologische Anforderungen an Publikationen
- mehr Anreize für Sorgfalt und Qualität
- Offenlegung von Methoden, Registrierung von Daten
- Anreize für Datenteilung schaffen
- Pflicht der Förderer zur Sicherung von Qualität
- Replikation fördern, Duplikation vermeiden
- bessere Ausbildung der Forscher
- bessere Kommunikation zwischen Forschern

“To maximise motivation for change, reductions of waste in research will need behavioural changes, not only from researchers, but also from publishers and regulators. These changes will need external pressure from stake holders such as funding agencies.”

Forderungen

Al-Shali Salman R, et al. (2014) Lancet 383: 176–185.

- Reduzierung des administrativen Aufwands
 - Aufsichtsbehörden
 - Ethikkommissionen
 - Förderanträge
 - rechtliche Rahmenbedingungen
- konsistente Anforderungen
 - angegliche Regeln und Verfahren

Chalmers I, et al. (2014) Lancet 383: 166–165.

- Forschung über Forschung
 - Faktoren für erfolgreiche Replikation und Translation
- Informationsquellen über Forschung

Forderungen

Kitano H, et al. (2011) Nat Chem Biol 7: 323–326.

- Konsolidierung von Daten und Wissen der “Small Science”
- Vermeidung einzelner Mega-Projekte
 - finanzielle und soziologische Gründe
- Vernetzung von Forschern zwecks Wissensintegration
- akzeptierte Ziele
- Führung und angemessenes soziologisches Design
- Anreize für die Beteiligung an gemeinschaftlichen Anstrengungen

“Social engineering will be recognized as an indispensable part of research activity in the coming years for large-scale and complex big science, because it is the people who do science, not technology or machines..”

Herausforderungen

Herausforderungen

- keine übergreifenden Konzepte (weder lokal noch national)
- mangelhafte Interoperabilität
- Fehlen von Standards
- heterogene Datentypen (meist unstrukturiert)
- wenig Nutzung von Versorgungsdaten und -biomaterialien
- unklare ELSI Rahmenbedingungen
- mangelhafte institutionelle Einbettung (finanziell, strukturell)
- starke Abhängigkeit von Drittmitteln

Herausforderungen



Beispiele

Beispiele

United States
National Library of Medicine
National Institutes of Health

NLM > NCBI > Human Genome Resources

Browse your genome

Click on a chromosome to show

Genes

1 2 3 4 5 6 7 8
9 10 11 12 13 14 15 16
17 18 19 20 21 22 X Y

Find A Gene
Search for
from Any species

The NCBI Handbook
An online guide to the use of NCBI resources. Titles of selected chapters that refer to human genome resources are shown below.

The Single Nucleotide Polymorphism Database (dbSNP) of Nucleotide Sequence Variation
Adrienne Kitts and Stephen Shery

Online Mendelian Inheritance in Man (OMIM): A Directory of Human Genes and Genetic Disorders
Donna Maglott, Joanna S. Amberger, and Ada Hamosh

Human Genome Resources

A challenge facing researchers today is that of piecing together and analyzing the plethora of data currently being generated through the Human Genome Project and scores of smaller projects. NCBI's Web site serves an integrated, one-stop, genomic information infrastructure for biomedical researchers from around the world so that they may use these data in their research efforts. [More...](#)

Genes and Human Health

- ▶ **Gene Database**
A new database of genes and associated information is now available for searching in Entrez.
- ▶ **OMIM**
A guide to human genes and inherited disorders maintained by Johns Hopkins University and collaborators.
- ▶ **dbSNP**
A database of single nucleotide polymorphisms (SNPs) and other nucleotide variations.
- ▶ **dbGaP**
The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the results of studies that have investigated the interaction of genotype and phenotype.

Epigenomics

- ▶ **NIH Epigenomics Roadmap**
Reference epigenomic maps and studies on new epigenetic mechanisms and their relevance to human health.
- ▶ **Roadmap Epigenomics Data**
A comprehensive listing of all NIH Roadmap Epigenomics datasets submitted to GEO and SRA.

The Genomic Sequence

- ▶ **Download DNA sequence**
Download the complete DNA
- ▶ **BLAST the Genome**
Compare your sequence to the

<http://www.ncbi.nlm.nih.gov/genome/guide/human/resources.shtml>

Beispiele

HOME ABOUT US SERVICES DC DESK CONTACT US Search Site

University of Pittsburgh
Center for Research on
Health Care
Data
Center

"Your advice and support have been instrumental to the success of the project. I really appreciate everything you've done to help us along the way!"
-Michelle Freeman, MD



Statistics
Statistical Analysis of Clinical, Translational, and Other Medical Studies

- Collaboratively discuss/revise research objectives
- Develop overall statistical strategies
- Design clinical trials and other experimental studies
- Develop sampling approaches for survey/observational studies
- Calculate sample sizes through refining measures of clinical/scientific effects
- Determine/implement randomization and treatment assignment strategies

[Read more about our Statistics Services](#)

Data Management

Web Design

Graphic Design

Qualitative Research Services

Where Research and Technology Come Together!

Over the past ten years, the Center for Research on Health Care (CRHC) Data Center has been the go-to solution for University of Pittsburgh researchers. Our talented team of faculty and staff members provides quality statistical analysis, database development, website design, and other graphic design services. With over 500 research projects in our portfolio, we offer both experience and innovative technology.

We develop all of our data management systems to provide data integrity and accuracy. Our technology team maintains current knowledge of all security measures that should be employed for both data and servers. To that end, our team implements the security recommendations of the FDA 21 CFR Part 11 regulations on all our data management systems. We also ensure that our servers utilize 128-bit SSL security for online real time data entry. All of our servers are housed in a secure location and can only be accessed through strict firewall rules. Routine backups ensure that all data are secure.

CRHC Data Center Report is now online



We are very excited to share with you the Center for Research on Health Care Data Center Report.

[Read the Report](#) 

Center for Research on Health Care Data Center - 200 Meyran Avenue, Suite 200 - Pittsburgh, PA 15213-3221 Web Design & Maintenance by CRHC Data Center

<http://www.crhc.pitt.edu/>

Beispiele

The image displays three overlapping screenshots of the SND Swedish National Data Service website. The leftmost screenshot shows the 'Find and order data' page with a search bar and a list of categories. The middle screenshot shows the same page with a search result for 'The Cohort of Swedish Men, COSM'. The rightmost screenshot shows the detailed page for 'The Cohort of Swedish Men, COSM', including a description, title, principal investigator, purpose, abstract, and topic classification.

SND Swedish National Data Service

Find data Deposit data Researchers' support

Home > Find and order data

Find and order data

Order data
Question bank (beta)
SND Online Analysis
SND Nesstar Server
International data
Swedish party programmes and election manifestos
Archaeological GIS Data
The Swedish Gallup archive 1942-1954
Data of the Month
Accessibility levels

Search

List all

886 1
26 1
267 1
246 2
22 3
138 3
3 3

To the top

FUNDED BY
Vetenskapsrådet

SND Swedish National Data Service

Find data Deposit data Researchers' support

Home > All studies in our catalogue > All studies

Find and order data

Order data
Question bank (beta)
SND Online Analysis
SND Nesstar Server
International data
Swedish party programmes and election manifestos
Archaeological GIS Data
The Swedish Gallup archive 1942-1954
Data of the Month
Accessibility levels

Start

För mer

SND Swedish National Data Service

Find data Deposit data Researchers' support Grants and courses Projects About us

SEARCH Search webpage >>

Home > Find and order data > The Cohort of Swedish Men, COSM

Site map

Find and order data

Order data
Question bank (beta)
SND Online Analysis
SND Nesstar Server
International data
Swedish party programmes and election manifestos
Archaeological GIS Data
The Swedish Gallup archive 1942-1954
Data of the Month
Accessibility levels

The Cohort of Swedish Men, COSM

Description Documentation Publications Related studies

Study number: EXT 0015

Title: The Cohort of Swedish Men, COSM

Principal investigator(s): [Alicja Wolk, Karolinska Institute, Institute of Environmental Medicine \(IMM\)](#)
[Karolinska Institute, Institute of Environmental Medicine \(IMM\)](#)

Purpose: To study the causes of chronic diseases as cancer, myocardial infarction, diabetes, osteoporosis, cataract and obesity, and also the causes of longer or shorter longevity.

Abstract: COSM is a population based cohort of men borned 1918-1952 (45-79 years old) who lived in the counties of Västmanland and Örebro in 1997. 48860 of these 100303 men (48.7%) responded and filled in a questionnaire with questions about lifestyle and environment such as diet, smoking and alcohol habits, physical activity at work and leisure time, use of diet supplementation and certain medication. There were also questions about subjectively judged health and different diseases and health problems for men only. It was also asked about chronic diseases as cancer (especially in prostate, colon, lungs and kidneys), myocardial infarction, diabetes, osteoporosis, cataract and obesity. In 2008 a new questionnaire with health related questions was sent to all participants, the participation rate was 77%. In 2009 they also got a questionnaire on lifestyle, 90% of the participants answered. . 2010 collection of biomaterials (blood, urine, fat biopsies) and antropometric measures started . More than 1000 men had spring 2012 participated in this collection which is ongoing.
The questionnaires used in COSM are

...

more

Topic classification: [Cancer and Oncology](#), [Cardiac and Cardiovascular Systems](#), [Clinical Medicine](#), [Endocrinology and Diabetes](#), [Health, Medical and Health Sciences](#), [Specific diseases and medical conditions](#)

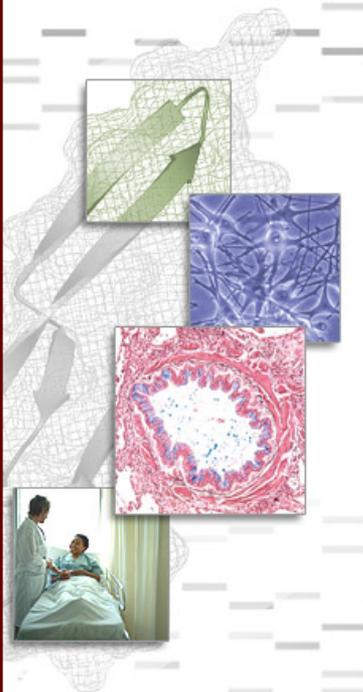
Beispiele

i2b2

A National Center for Biomedical Computing

Informatics for Integrating Biology & the Bedside

[About Us](#) | [Driving Biology Projects](#) | [Software](#) | [Resources](#) | [Events](#) | [Training](#) | [News](#) | [Collaborations](#) | [Publications](#)



MISSION

i2b2 (Informatics for Integrating Biology and the Bedside) is an NIH-funded National Center for Biomedical Computing based at Partners HealthCare System. The i2b2 Center is developing a scalable informatics framework that will enable clinical researchers to use existing clinical data for discovery research and, when combined with IRB-approved genomic data, facilitate the design of targeted therapies for individual patients with diseases having genetic origins. This platform currently enjoys wide international adoption by the CTSA network, academic health centers, and industry. i2b2 is funded as a cooperative agreement with the National Institutes of Health.

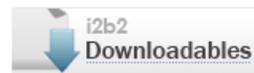
DRIVING BIOLOGY PROJECTS

- :: [Overview](#)
- :: [Current DBPs](#)
 - :: [Autoimmune/CV Diseases](#)
 - :: [Diabetes/CV Diseases](#)
- :: [Past DBPs](#)
 - :: [Airways Diseases](#)
 - :: [Hypertension](#)
 - :: [Type 2 Diabetes Mellitus](#)
 - :: [Huntington's Disease](#)
 - :: [Major Depressive Disorder](#)
 - :: [Rheumatoid Arthritis](#)
 - :: [Obesity](#)

RESOURCES

- :: [Overview](#)
- :: [Computational Tools](#)
- :: [Software](#)
- :: [NLP Research Data Sets](#)
- :: [NLP Shared Tasks](#)
- :: [Academic Users' Group](#)
- :: [Publication Data](#)

SOFTWARE



Beispiele

DE | EN | Zugang beantragen | Login

Deutsches Biobanken-Register

Home Über uns Biobanken User Portal News Projektportal Symposium

Symposium 2015



Nationales Biobanken-Symposium

9. - 10. Dezember 2015
Call for Papers
endet am 30.09.2015

Call for Papers

Am 9. und 10. Dezember findet das 4. Nationale Biobanken-Symposium mit dem Schwerpunktthema **Biobanknetzwerke als Schrittmacher der medizinischen Forschung** statt. Wir laden Sie herzlich ein, sich mit Ihren Beiträgen aktiv an der inhaltlichen Ausgestaltung der Veranstaltung zu beteiligen.

Weitere Informationen dazu finden Sie hier:
www.biobanken.de/symposium/callforpapers

News

IBBL 2015 Biospecimen Proficiency Testing (PT) programme

Registrations for IBBL's 2015 Biospecimen Proficiency Testing (PT) programme...
→ mehr

Termine

12. Jahrestagung der Deutschen Vereinten Gesellschaft für Klinische Chemie und Laboratoriumsmedizin

14.10.2015 - 17.10.2015
→ mehr

Sitzung der AG Biomaterialbanken (Leipzig)

14.10.2015
→ mehr

BioMedBridges Symposium: Open bridges for life science data

17.11.2015 - 18.11.2015
→ mehr

GEFÖRDERT VOM



Bundesministerium für Bildung und Forschung

BETRIEBEN DURCH



TMF

IBBL 2015 Biospecimen Proficiency Testing (PT) programme

Registrations for IBBL's 2015 Biospecimen Proficiency Testing (PT) programme are now open.
→ mehr



IBBL
INTEGRATED BIOMARK OF LIFE SCIENCES
FOR NEXT GENERATION HEALTHCARE

BBMRI-ERIC DIRECTORY 1.0 NOW AVAILABLE

29.07.2015. Die erste Version des neuen Europäischen Biobanken-Kataloges ist nun online-geschaltet.
→ mehr



BBMRI-ERIC
BioBanking and BioMolecular resources
Research Infrastructure

Mustertext Patienteneinwilligungen für Biobanken jetzt auch auf Englisch verfügbar

22.07.2015. Die Arbeitsgruppe Biobanken des Arbeitskreises medizinischer Ethikkommissionen stellt den im November 2013 verabschiedeten Mustertext zur Spende, Einlagerung und Nutzung von Biomaterialien sowie zur Erhebung, Verarbeitung und Nutzung von Daten in Biobanken jetzt auch in englischer Sprache zur Verfügung. Der Text beruht auf deutschem Recht und den hiesigen ethischen Auffassungen.
→ mehr



Beispiele

 **Deutsches Register
Klinischer Studien**
German Clinical
Trials Register

- Home
- Wir über uns
 - Ziele
 - Team
 - Internationale Vernetzung
 - Zusammenarbeit mit den Ethikkommissionen
- Studien suchen
- Studien registrieren
- Benutzerregistrierung
- Veröffentlichungen
- Nützliche Links
- Glossar
- Beschreibung der Eingabefelder
- FAQ
- Kontakt
- Impressum
- Barrierefreiheit

Herzlich willkommen beim Deutschen Register Klinischer Studien (DRKS)

Das Deutsche Register Klinischer Studien (DRKS) bietet Ihnen die Möglichkeit, Informationen zu laufenden und abgeschlossenen klinischen Studien in Deutschland zu [suchen](#) oder eigene Studien über die [Registrierung](#) anderen zugänglich zu machen.

Zu jeder Studie finden Sie bei uns Eckdaten wie Studientitel, Kurzbeschreibungen, Ein- und Ausschlusskriterien, Studienstatus und Endpunkte.

Für die Suche nach Studien können Sie Ihren Suchbegriff direkt in die Suchbox eingeben. Die [erweiterte Suchfunktion](#) ermöglicht Ihnen eine zusätzliche Eingrenzung Ihrer Suche. So können Sie beispielsweise gezielt nach Studien suchen, die im Moment Patienten einschließen.

Das DRKS ist kostenfrei und öffentlich zugänglich. Das Projekt wird vom Bundesministerium für Bildung und Forschung ([BMBF](#)) gefördert und von einer non-Profit-Institution verwaltet.

Seit Oktober 2008 ist das [DRKS](#) als [WHO-Primär-Register](#) anerkannt.
Mit einer Registrierung im [DRKS](#) sind damit die Anforderungen des [ICMJE](#) als Voraussetzung für eine Veröffentlichung erfüllt.

Bitte beachten Sie unabhängig von der Forderung der medizinischen Zeitschriften bei international durchgeführten Studien etwaige nationale Regularien, welche in einzelnen Ländern noch eine zusätzliche Registrierungspflicht meist beschränkt auf Arzneimittelstudien in bestimmten Registern vorsehen.

 Wir befolgen den [HONcode Standard](#) für vertrauenswürdige Gesundheitsinformationen.
Überprüfen Sie dies [hier](#).

Letzte Änderung: 04.05.2015

Kontakt | Impressum | [Zum Seitenanfang](#) | 

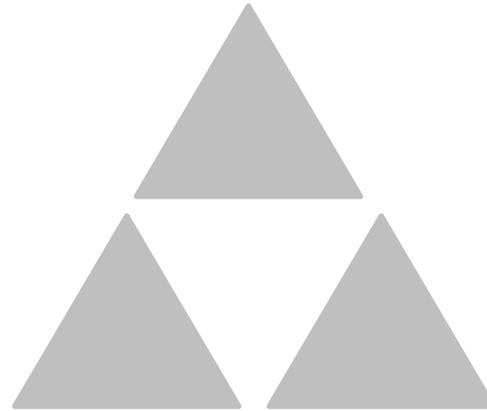
Notwendigkeiten

Notwendigkeiten

- Entwicklung lokaler und nationaler Integrationskonzepte
- Definition und Etablierung konsentierter Datenstandards
- Qualitätskontrolle für Daten und Biomaterialien
- bessere Nutzbarkeit von Daten und Biomaterialien
- Etablierung versorgungsintegrierter Forschungsinformatik und Biobanken
- generische und konsistente Antworten auf ELSI-Fragen
- strukturelle Einbindung von Medizininformatik und Biobanken
- nachhaltige Finanzierung
- Änderung der Förderungs- und Publikationsanreize
- bessere Aus- und Weiterbildungsangebote
- übergreifende Kommunikations- und Abstimmungsplattformen

Notwendigkeiten

Verfügbarkeit



Verwertbarkeit

Verknüpfbarkeit

Perspektive

Perspektive



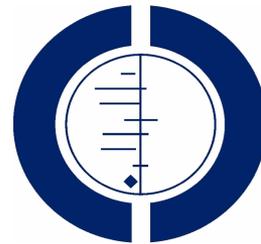
Bundesministerium
für Bildung
und Forschung

Nationale Initiative Medizininformatik

Workshop, 18. März 2015, Berlin

Konzept: Eils, Hahn, Jahns, Kroemer, Tolxdorf, von Kalle

- kleine Anzahl multiregionaler Kompetenzzentren
- Konzentration auf wenige Krankheiten
- Entwicklung einer forschungsorientierten Versorgungs-IT
- aktive Rolle der Krankenversorger (finanziell, strukturell)
- Definition und Abstimmung gemeinsamer Datenstandards
- Definition von Interoperabilitäts-Kriterien
- Lotsenfunktion bei der zukünftigen Auswahl von Standards und Verfahren



Cochrane
Deutschland

Herzlichen Dank für Ihre Aufmerksamkeit !