

Jahrestagung 2019 der AG für Medizinisches Bibliothekswesen

# FAIR Data Management als gemeinsame Herausforderung

**Prof. Dr. Ulrich Sax**

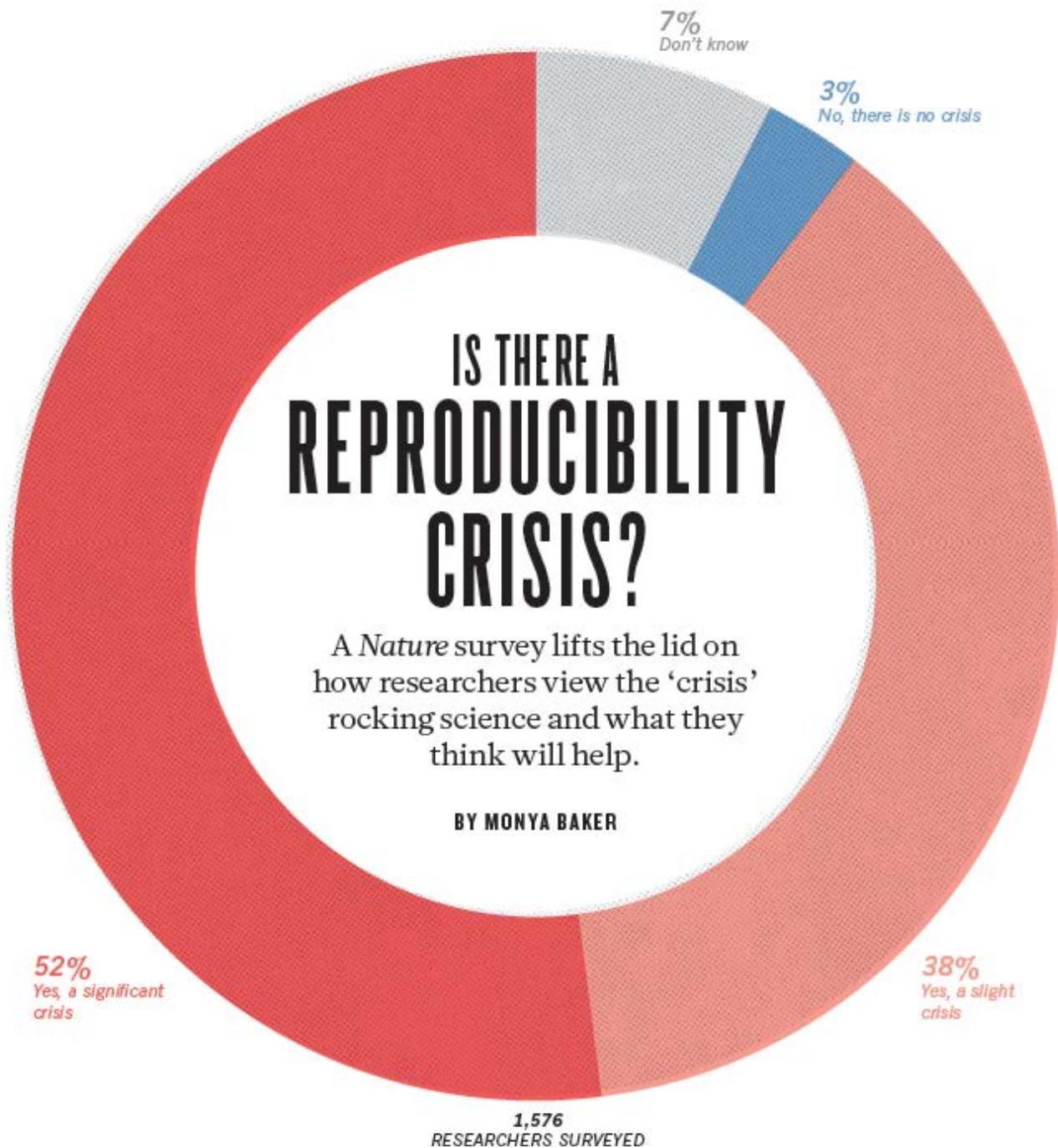
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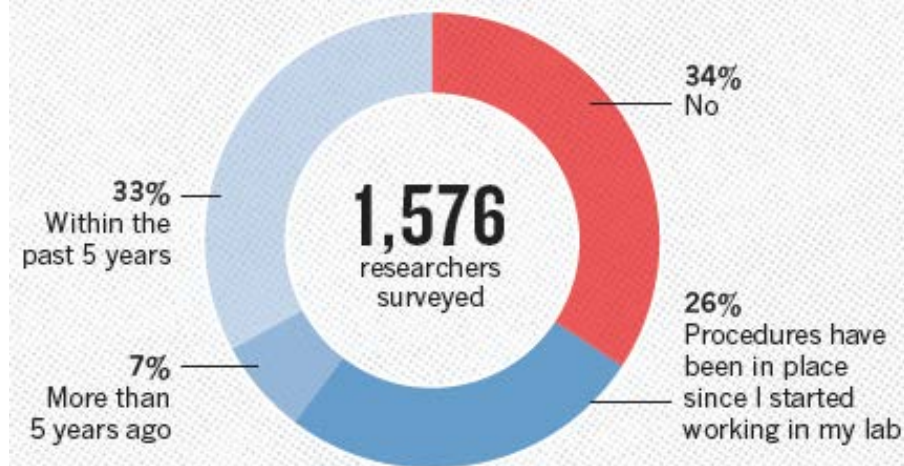
<http://orcid.org/0000-0002-8188-3495>

<http://www.mi.med.uni-goettingen.de>



## HAVE YOU ESTABLISHED PROCEDURES FOR REPRODUCIBILITY?

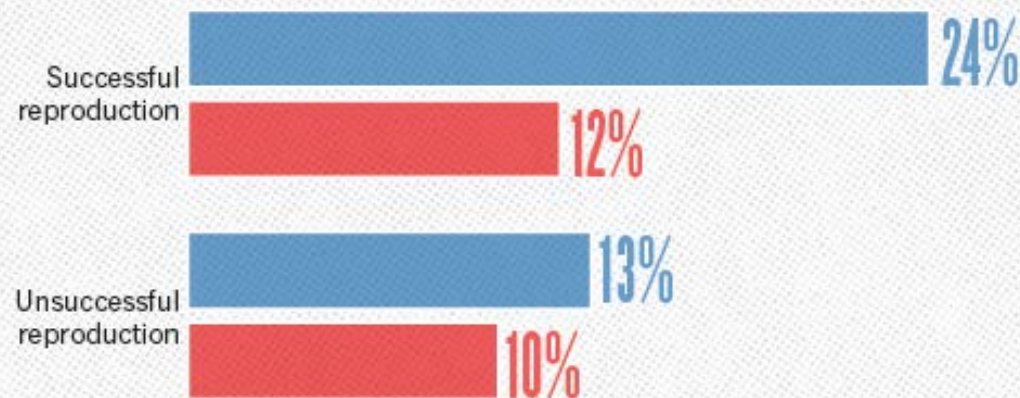
Among the most popular strategies was having different lab members redo experiments.



## HAVE YOU EVER TRIED TO PUBLISH A REPRODUCTION ATTEMPT?

Although only a small proportion of respondents tried to publish replication attempts, many had their papers accepted.

● Published ● Failed to publish

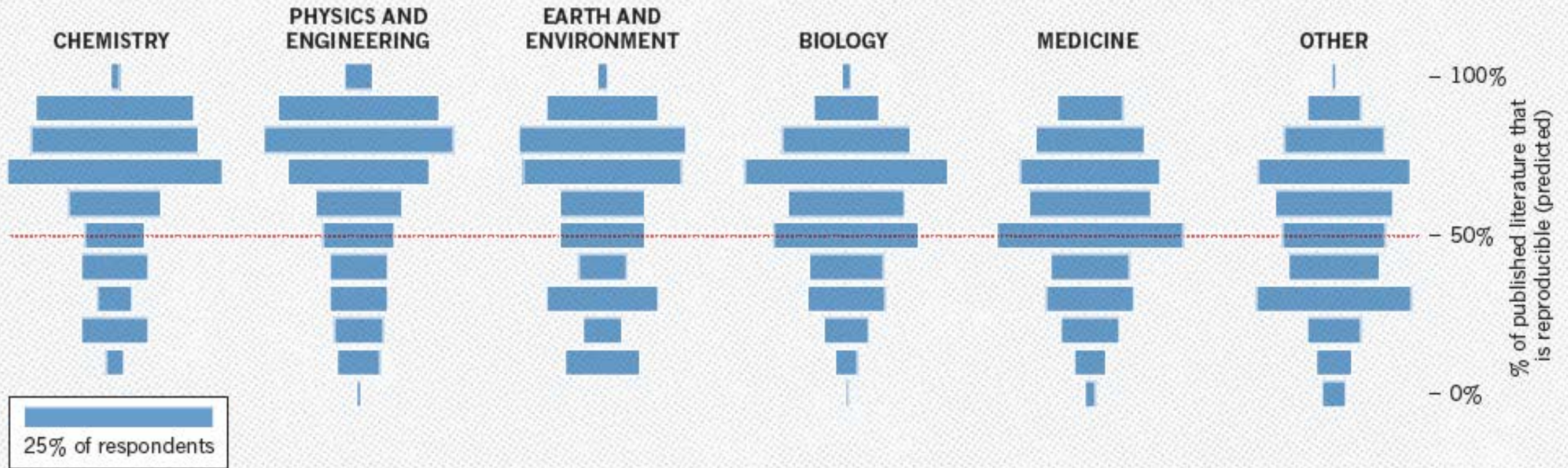


# A 'CRISIS' IN NUMBERS

Nature surveyed 1,576 scientists online to get their thoughts on reproducibility in their field and in science in general. See [go.nature.com/2vjr4y](http://go.nature.com/2vjr4y) for more charts and access to the full data.

## HOW MUCH PUBLISHED WORK IN YOUR FIELD IS REPRODUCIBLE?

Physicists and chemists were most confident in the literature.



# SCIENTIFIC DATA

OPEN

## Comment: The FAIR Guiding Principles for Scientific Data Management

Mark D. Wilkinson *et al.*#

There is an urgent need to improve the set of stakeholders—representing academia, industry, and government—to come together to design and jointly implement the FAIR Data Principles. The FAIR Principles put specific requirements on how to find and use the data, in addition to the formal publication of the FAIR Principles and their implementation in the community.

SUBJECT CATEGORIES

- » Research data
- » Publication characteristics

Received: 10 December 2015

Accepted: 12 February 2016

Published: 15 March 2016

### Box 2 | The FAIR Guiding Principles

#### To be Findable:

- F1. (meta)data are assigned a globally unique and persistent identifier
- F2. data are described with rich metadata (defined by R1 below)
- F3. metadata clearly and explicitly include the identifier of the data it describes
- F4. (meta)data are registered or indexed in a searchable resource

#### To be Accessible:

- A1. (meta)data are retrievable by their identifier using a standardized communications protocol
  - A1.1 the protocol is open, free, and universally implementable
  - A1.2 the protocol allows for an authentication and authorization procedure, where necessary
- A2. metadata are accessible, even when the data are no longer available

#### To be Interoperable:

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
- I2. (meta)data use vocabularies that follow FAIR principles
- I3. (meta)data include qualified references to other (meta)data

#### To be Reusable:

- R1. meta(data) are richly described with a plurality of accurate and relevant attributes
  - R1.1. (meta)data are released with a clear and accessible data usage license
  - R1.2. (meta)data are associated with detailed provenance
  - R1.3. (meta)data meet domain-relevant community standards

Wilkinson et al. 2016

SCIENTIFIC DATA

3:160018 | DOI:

10.1038/sdata.2016.18

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DAVIDE BONAZZI/SALZMAN ART

## A solution to psychology's reproducibility problem just failed its first test

By [David Adam](#) | May. 23, 2019, 10:00 AM

Behavior change is difficult—just ask any psychologist. A new study shows behavior change among psychologists is no different. Efforts to improve the robustness of research by asking psychologists to state their methods and goals ahead of time, a process called preregistration, have stumbled at the first hurdle.

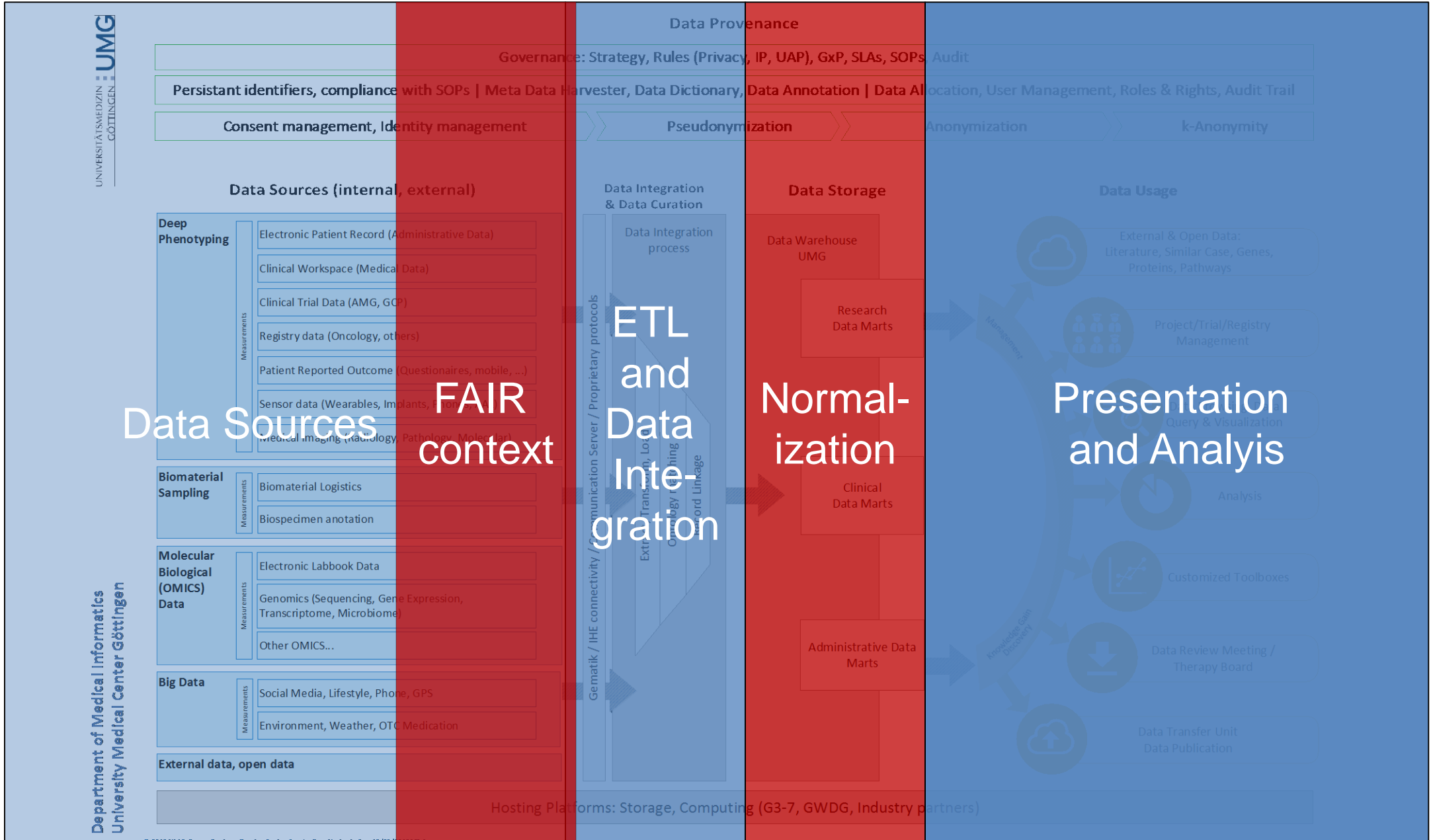
### Unmet plans

Of 27 studies in a psychology journal, just one followed its preregistered plan to a T. Researchers identified deviations from plans in eight categories.

	All deviations disclosed	Undisclosed deviations	No deviations
Hypothesis/ research question	3	5	19
Variables	0	4	23
Direction of effect	0	6	21
Operational- ization of variables	4	3	20
Sample size	5	10	12
Exclusion criteria	3	15	9
Procedure	2	1	24
Statistical model	6	13	8

The lack of transparency is troubling, but understandable, Vanpaemel says: Some researchers might fear their paper won't be published if they admit to not having entirely followed their preregistration. "As soon as we see more papers being published [with] transparent changes, these concerns will be hopefully lessened."

doi:10.1126/science.aa1207



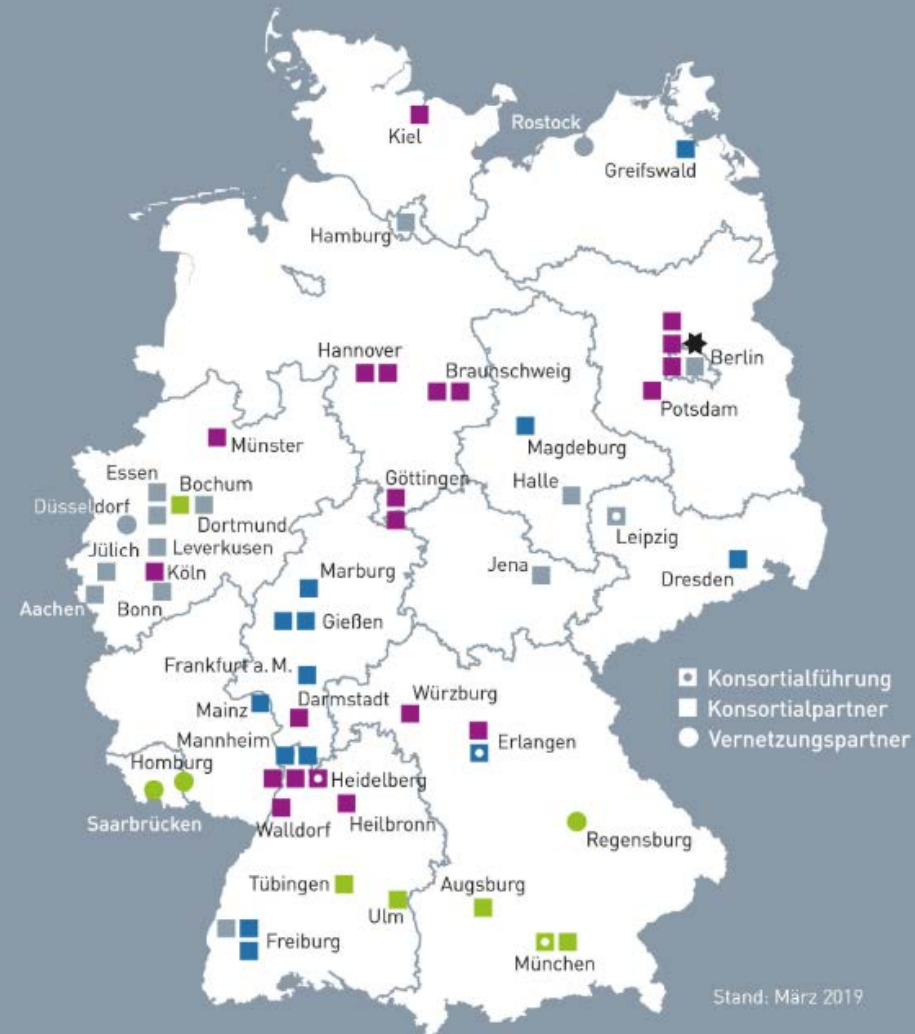


# Vernetzen. Forschen. Heilen.

Forschung stärken, Versorgung verbessern.  
Medizininformatik.

Um Daten aus Krankenversorgung und Forschung besser nutzbar zu machen, hat das Bundesministerium für Bildung und Forschung die Medizininformatik-Initiative mit 100 Millionen Euro gefördert. Die Fördermaßnahme soll die medizinische Forschung stärken und die Patientenversorgung verbessern.

## Geförderte Konsortien und Standorte während der Aufbau- und Vernetzungsphase





Jahrestagung der GMDS  
08. – 11.09.2019  
Dortmund



**Vorträge aus den Arbeitsgruppen des Nationalen Steuerungsgremiums**

# **AG Interoperabilität: erste Erfolge und künftige Herausforderungen**

Thomas Ganslandt<sup>1</sup>, Martin Boeker<sup>1</sup>, Björn Schreiweis<sup>2</sup>, Birger Haarbrand<sup>2</sup>, Danny Ammon<sup>3</sup>, Silke Haferkamp<sup>3</sup>, Holger Stenzhorn<sup>4</sup>, Karoline Buckow<sup>5</sup>, Ulrich Sax<sup>2</sup>

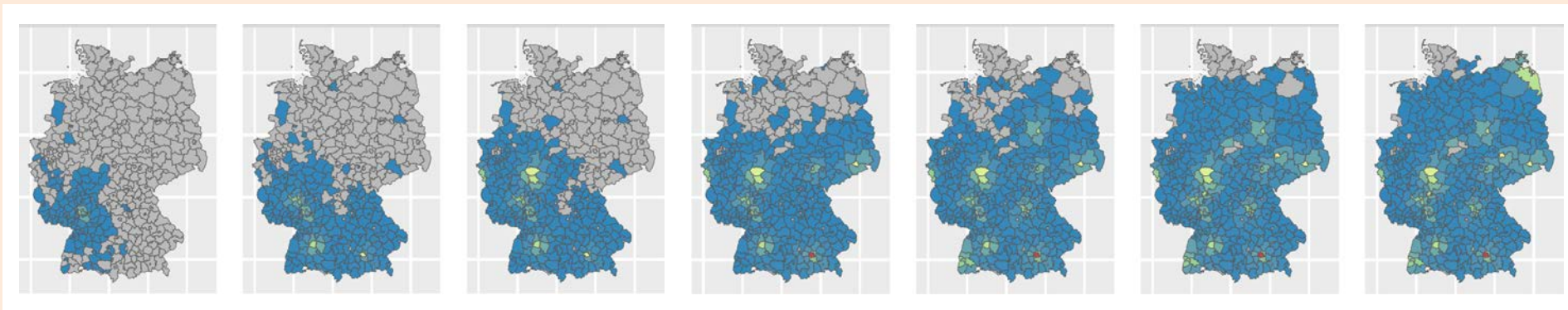
<sup>1</sup> miracum, <sup>2</sup> HiGHmed, <sup>3</sup> SMITH, <sup>4</sup> DIFUTURE, <sup>5</sup> Koordinierungsstelle des NSG (TMF)

GEFÖRDERT VOM



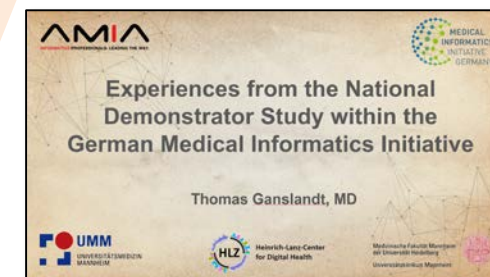
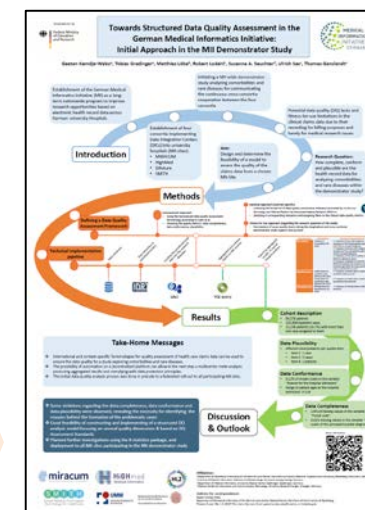


# Demonstrator-Studie



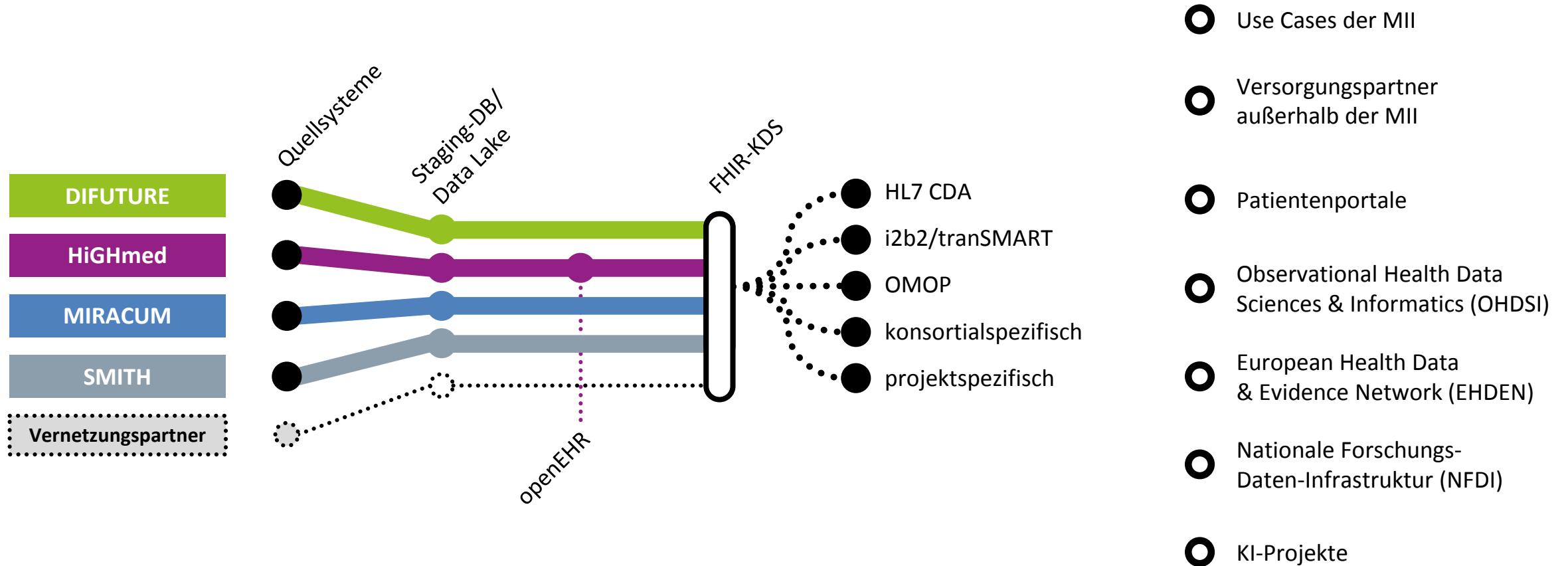
Einzugsgebiet im Verlauf der Datenbereitstellung (09/2018 - 03/2019)

## MEDINFO 2019 Lyon (Poster)



## AMIA 2019 Washington (Vortrag)

# Konvergenz durch Nutzung des MII-Kerndatensatzes









# Nationale Forschungsdaten- infrastruktur (NFDI) DFG

Die nationale Forschungsdateninfrastruktur (NFDI) soll die Datenbestände von Wissenschaft und Forschung systematisch erschließen, nachhaltig sichern und zugänglich machen sowie (inter-)national vernetzen. Sie wird in einem aus der Wissenschaft getriebenen Prozess als vernetzte Struktur eigeninitiativ agierender Konsortien aufgebaut werden.

## Absichtserklärungen zum Aufbau der NFDI

Bis zum 4. Juli 2019 sind die Absichtserklärungen für eine Antragstellung im Jahr 2019 in Form von verbindlichen Voranmeldungen sowie für eine Antragstellung in den Jahren 2020 und 2021 in Form von unverbindlichen Absichtserklärungen in der DFG-Geschäftsstelle eingegangen.

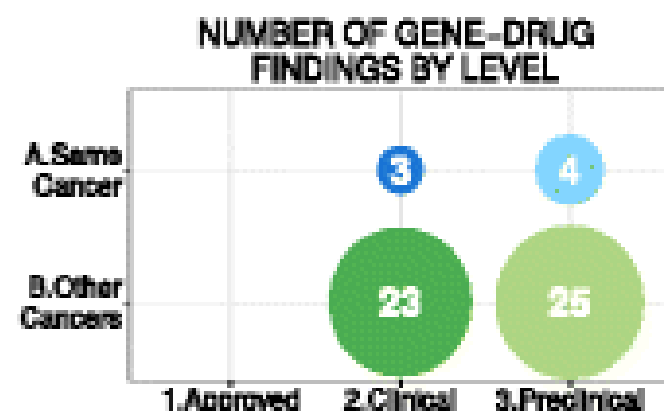
Verbindliche Voranmeldungen für eine Antragstellung im Jahr 2019:

- [NFDI letters of intent - National Research Data Infrastructure for Personal Health Data \(NFDI4Health\) \(PDF | 96 KB\)](#) 
  - [NFDI letters of intent - Nationale Forschungsdateninfrastruktur für die Ingenieurwissenschaften \(NFDI4Ing\) \(PDF | 350 KB\)](#) 
  - [NFDI letters of intent - Consortium of the Medical Informatics Initiative \(MII\) and the German Centers for Health Research \(DZG\) \(NFDI4Medicine\) \(PDF | 185 KB\)](#) 
  - [NFDI letters of intent - National Research Data Infrastructure for Mobility Technology \(NFDI4MobilTech\) \(PDF | 170 KB\)](#) 
  - [NFDI letters of intent - National Research Data Infrastructure for Materials Science and Engineering \(NFDI4MSE\) \(PDF | 414 KB\)](#) 
  - [NFDI letters of intent - Particle, Astroparticle, Hadron and Nuclear Physics accelerates the NFDI \(PAHN-PaN\) \(PDF | 259 KB\)](#) 
  - [NFDI letters of intent - Text+: Language- and Text-Based Research Data Infrastructure \(Text+\) \(PDF | 157 KB\)](#) 
- 
- [NFDI letters of intent - Mathematical Research Data Initiative \(MaRDI\) \(PDF | 169 KB\)](#) 
  - [NFDI letters of intent - NFDI for Agricultural Sciences \(NFDI4Agri\) \(PDF | 270 KB\)](#) 
  - [NFDI letters of intent - Biodiversity, Ecology & Environmental Data \(NFDI4BioDiversity\) \(PDF | 249 KB\)](#) 
  - [NFDI letters of intent - NFDI for Catalysis-Related Sciences \(NFDI4cat\) \(PDF | 136 KB\)](#) 
  - [NFDI letters of intent - Fachkonsortium Chemie für die Nationale Forschungsdateninfrastruktur \(NFDI4Chem\) \(PDF | 240 KB\)](#) 
  - [NFDI letters of intent - Consortium for research data on material and immaterial ... \(NFDI4Culture\) \(PDF | 338 KB\)](#) 
  - [NFDI letters of intent - Consortium Earth System Science / NFDI Konsortium Erdsystemforschung \(NFDI4Earth\) \(PDF | 312 KB\)](#) 

Gene	Patient's Variant	Level of Evidence	Seg. Mean	Size (Mb)
AURKA	ampl.	B3	0.58	39.2
BIRC7	ampl.	B3	0.58	39.2
BRCA1	del.	A2 ,B2 ,A3 ,B3	-0.84	2.6
CCNE1	ampl.	A3 ,B3	0.73	15.2
CDK12	del.	A3	-0.87	1.9
FANCA	del.	B2	-0.71	59.8
FRS2	ampl.	B3	0.73	6.5
MDM2	ampl.	B2	0.73	6.5
NF1	del.	B2 ,B3	-0.85	2.6
PALB2	del.	B2 ,B3	-0.70	17.5
RICTOR	ampl.	B2	1.56	12.5
SUZ12	del.	B3	-0.87	4.5
TOP1	ampl.	B2	0.58	39.2
TSC2	R505X,del.	B2 ,B3	-0.78	11.2

**Levels of Evidence:** Findings are classified into 6 levels of evidence combining the axis A-B and the axis 1-2-3. Level A means evidence in the same cancer type. Level B means evidence in any other cancer type. On the 1-2-3 axis, level 1 means evidence supported by drug approval organizations or clinical guidelines, level 2 contains clinical evidence (clinical trials, case reports) and level 3 consists of preclinical evidence. The distribution of findings into levels is summarized in the right figure

**Table of Results:** All the predictive associations are detailed in this table. The results are sorted by 1) drug frequency, 2) levels of evidence (A1-B1-A2-B2-A3-B3). To allow a quick interpretation, the type of association (response, resistance) is colored (green, red) and new variants are gray and underlined.



Journal List > World J Gastroenterol > v.24(43)



World J Gastroenterol. 2018 Nov 21  
 Published online 2018 Nov 21

### Pancreatic cancer: treatment and outcomes

Andrew McGuigan, Paul Kelly,

Author information Article

This article has been cited by

#### Abstract

This review aims to outline treatment and outcomes, wh malignancy. Pancreatic ader the second leading cause of contributes to poor five-year of prognostic outcomes for this disease is essential to in preventive and/or early dete screening to detect pre-mali papillary mucinous neoplas screening test has yet to be i introduction of new surgical adjuvant chemoradiotherapy identification of novel biom cancer therapy can be tailor consequences on quality of development of new agents burden associated with panc pancreatic adenocarcinoma needed to bring breakthrough

**Keywords:** Pancreatic can cancer treatment

16.09.2019

World J Gastroenterol

pancreatic cancer

suchen

### Suchergebnis

Treffer 1 - 10 von insgesamt 6019!

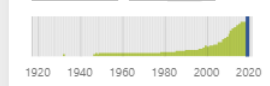
« 1 2 3 4 5 »

#### Filtermöglichkeiten

Freier Zugang 27279

Jahr

von bis



Fachgebiet

Medizin, Gesundheit 48309

Ernährung 4420

▼ mehr

Dokumenttyp

Artikel 60199

Online 31069

Konferenzbeitrag 367

Audio / Video 7

Forschungsdaten 1

▲ weniger

Sprache

Englisch 54162

Japanisch 1720

▼ mehr

Artikel x

List By Topic

Hide Filters

#### Filters

Apply Clear

#### Status

- Recruitment ⓘ :
- Not yet recruiting
  - Recruiting
  - Enrolling by invitation
  - Active, not recruiting
  - Suspended
  - Terminated
  - Completed
  - Withdrawn
  - Unknown status†

Expanded Access ⓘ : +

#### Eligibility Criteria

Age ⓘ :

years OR

1 Lichtenstein, Gary R  
**Artikel: Pancreatic C**

Gastroenterology & hepatology  
 2017 Band 13, Heft 5, Seite(n) 25

Zusatzmaterialien ▶

2 **Artikel ; Online: Panc**

Nature reviews. Disease primers  
 2016 Band 2, Seite(n) 16023

Zusatzmaterialien ▶

3 **Artikel ; Online: Panc**

Kamisawa, Terumi / Wood, L

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Go to Genes & Variants Go! BROWSE SEARCH ACTIVITY ADD

## GENE KRAS

Last Modified by NickSpies Last Reviewed by NickSpies

Mutations in the RAS family of proteins are frequently observed across cancer types. The amino acid positions that account for the overwhelming majority of these mutations are G12, G13 and Q61. The different protein isoforms, despite their raw similarity, also behave very differently when expressed in non-native tissue types, likely due to differences in the C-terminal hyper-variable regions. Mis-regulation of isoform expression has been shown to be a driving event in cancer, as well as missense mutations at the three hotspots previously mentioned. While highly recurrent in cancer, attempts to target these RAS mutants with inhibitors have not been successful, and has not yet become common practice in the clinic. The prognostic implications for KRAS mutations vary between cancer types, but have been shown to be associated with poor outcome in colorectal cancer, non-small cell lung cancer, and others.

Sources: [Prior et al., 2012, Cancer Res.](#) [DGIdb Details](#)

**Name:** KRAS proto-oncogene, GTPase

**Entrez Symbol:** KRAS **Entrez ID:** 3845

**Aliases:** C-K-RAS, CFC2, K-RAS2A, K-RAS2B, K-RAS4A, K-RAS4B, KI-RAS, KRAS1, KRAS2, NS, NS3, RALD, RASK2

**Chromosome:** 12 **Start:** 25357723 **End:** 25403870 **Strand:** -1 (GRCh37)

**Protein Domains:** P-loop containing nucleoside triphosphate hydrolase, Ran GTPase, Small GTP-binding protein domain, Small GTPase superfamily, Small GTPase superfamily, Rab type... (2 more)

**Pathways:** telomeres telomerase cellular aging and immortality, Bisphosphonate Pathway, Pharmacodynamics, EGFR Inhibitor Pathway, Pharmacodynamics, Pathway\_PA165959425, Sorafenib Pharmacodynamics... (203 more)

[View MyGene.info Details](#)

### KRAS Variants & Variant Group

Filter by name Display Options

A146P A146T A146V AMPLIFICATION EXON 2 MUTATION G12 G12/G13 G12A G12C G12D G12R G12S G12V G13 G13D G13V MUTATION Q22\* Q61 Q61H RS61764370

**EGFR TKI Resistance Group**

G12A (KRAS) G12C (KRAS) G12D (KRAS) T790M (EGFR)

## VARIANT ACTIVATING MUTATION

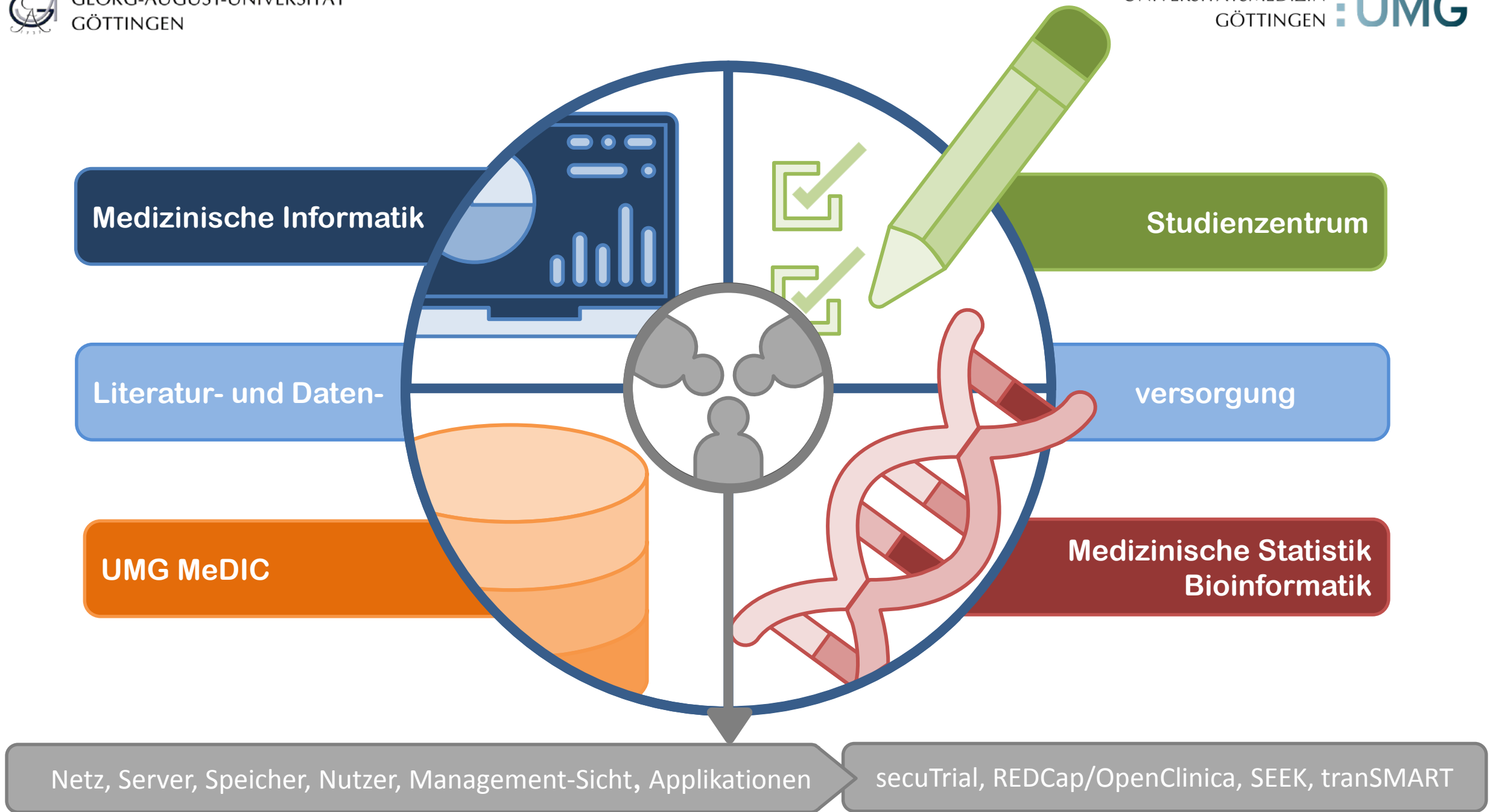
Variant Summary Variant Talk

3  Recruiting [Systematic Hereditary Pancreatic Cancer Risk Assessment and Implications for Personalized Therapy](#)

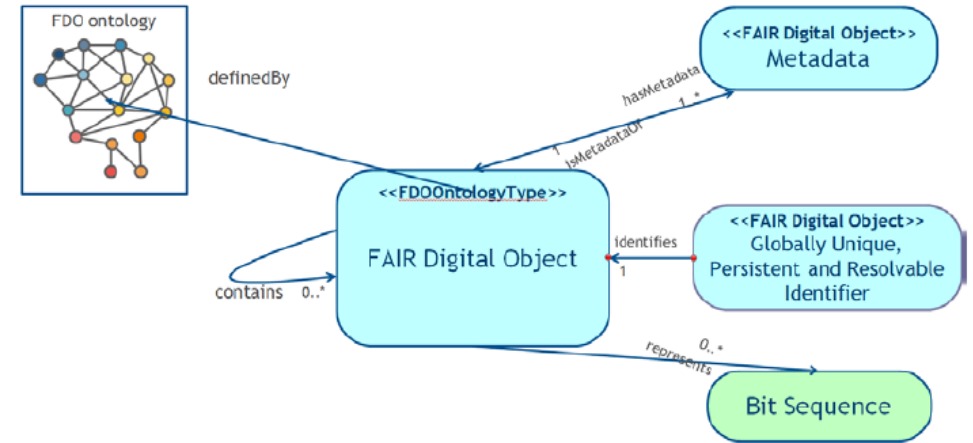
4  Recruiting [Losartan and Nivolumab in Combination With FOLFIRINOX and SBRT in Localized Pancreatic Cancer](#)

5  Recruiting [Study of Gemcitabine, Nab-paclitaxel, and Ficlutuzumab \(AV-299\) in Patients With Advanced Pancreatic](#)

13



## ■ Modell für FAIR Digital Objects



## ■ FAIR Assessment Frameworks

# Zusammenfassung

- Biomedizinische Daten sind der Motor für die klinische und biomedizinische Forschung. Entscheidend für die Nutzbarkeit der Daten ist es, den Kontext bzw. Zweck der Datenerhebung (Provenance) zusammen mit den Daten vorzuhalten.
- Für die Interpretation der Daten müssen ähnliche Fälle bzw. Erkenntnisse aus öffentlichen Datenbanken bzw. der Literatur mit herangezogen werden.
- Das ist eine gemeinsame Herausforderung der Lebenswissenschaften und der Bibliothekswissenschaften.
- Eine disziplinübergreifende Agenda zu den FAIR guiding principles würde helfen:
  - Systematische automatisierte Literatursuche
  - Übergang von wissenschaftlichen Publikationen zu verbundenen Datenpublikationen
  - Nachhaltige Findbarkeit und Zugänglichkeit von Daten und Publikationen (!)



# Department of Medical Informatics

Retreat 2018



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