



EAHIL 2016

Knowledge, Research, Innovation ...



15th EAHIL 2016 Conference 6-11 June, Seville, Spain

Challenges of Open Science and Open Research Data in Health Sciences

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A brief overview...

1. Open Science: meaning and principles
2. Open access: routes and benefits
3. How open is.....
4. Open research data: definition, principles and the data lifecycle
5. Open access policies
6. Europe vs open science
7. 'OA commitments'
8. Open data for other purposes

Meaning of Open Science

“Open Science (OS) offers researchers tools and workflows for **transparency, reproducibility, dissemination** and transfer of new knowledge”

“The conduction of science in a way that others **can collaborate and contribute**, where **research data, lab notes and other research processes** are **freely available, with terms that allow reuse, redistribution and reproduction of the research.** (Open science, http://en.wikipedia.org/wiki/Open_science)

“Open science is the idea that **scientific knowledge of all kinds** should be **openly shared** as early as is practical in the discovery process.”

(Michael Nielsen, <http://openscienceasap.org/open-science/>)

Open science is beyond open access



Principles of Open Science

Open Methodology (Methods, processes, relevant documents)

Open Source (Soft- and Hardware)

Open Data (data free to re-use)

Open Access to scholarly outputs (gratis and libre)

Open Peer Review (transparency in evaluation and quality criteria)

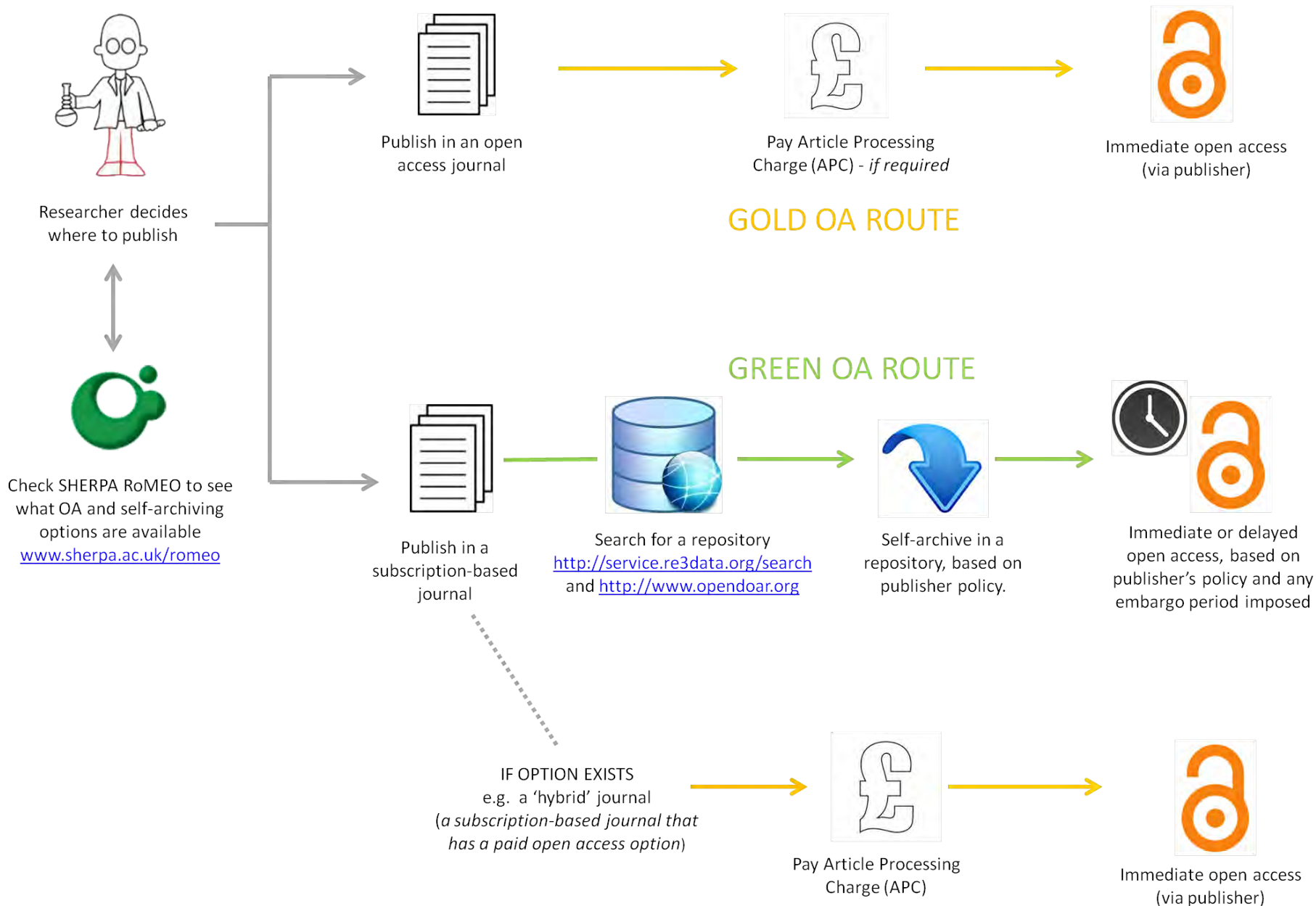
Open Educational Resources (MOOCs, OERs)

<http://openscienceasap.org/open-science/>



“Open-access (OA) literature is digital, online, free of charge, and free of most copyright and licensing restrictions” (Peter Suber)





Benefits of open access to scholarly outputs



How open is.....

Europe's Open Access Champions focuses on highlighting some of *the persons* who are driving Open Access forward in Europe's academic communities.

<http://openscholarchampions.eu>



Europe's Open Access Champions

Inspiration from influential European academics on Open Access & what still needs to be done

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Filter Results

Prof Pearl Dykstra

Professor of Sociology, Director of
Research Department of Public
Administration and Sociology (DPAS)
Erasmus University Rotterdam,
Department of Sociology
The Netherlands



"A little less ideology and a bit more pragmatism is necessary in the Open Access debate"

Ivana Hebrang Grgić

Assistant Professor
University of Zagreb, Faculty of
Humanities and Social Sciences,
Department of Information and
Communication Sciences
Croatia



"Educate all participants of the scholarly communication system on Open Access"

Prof Rune Nilsen

Professor Emeritus in Global Health
University of Bergen
Norway



"Fight academic apartheid to advance equality and quality in the sciences"

Laurent Gatto

Head of the Computational Proteomics
Unit
University of Cambridge
UK



"Focussing on the costs of Open Access is missing the point"

How open is an article based on its license.....

<http://howopenisit.org/lookup/>

HowOpenIsIt? Open Article Gauge

A service to determine the license for journal articles

Researchers and funders often spend inordinate amounts of time trying to figure out what license terms apply to scholarly articles. The Open Article Gauge (OAG) is a service designed to search for, locate, and present the license information for an article – the terms under which it can be accessed and/or reused.

list some DOIs or Pubmed IDs, separated by commas

HowOpenIsIt?

Acknowledge open practices with badges in publications

Open Science Framework

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Badges to Acknowledge Open Practices Files Wiki Analytics Registrations Forks

Home

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View (Current) Sara Bowman: 2014-10-31 20:55:24 UTC

Openness is a core value of scientific practice. There is no central authority determining the validity of scientific claims. Accumulation of scientific knowledge proceeds via open communication with the community. Sharing evidence for scientific claims facilitates critique, extension, and application. Despite the importance of open communication for scientific progress, present norms do not provide strong incentives for individual researchers to share data, materials, or their research process. **Journals can provide such incentives by acknowledging open practices with badges in publications.**

There are circumstances, however, in which open practices are not possible or advisable. For example, sharing some human participant data could violate confidentiality. When badge criteria cannot be met, a description in place of the badge can articulate why. Badges do not define good practice; badges certify that a particular practice was followed. Disclosure makes explicit the conditions under which the ethic of openness is superseded by other ethical concerns. Here, we introduce three badges to acknowledge Open Data, Open Materials, and Preregistration.

VIEW THE BADGES:

OPEN DATA **OPEN MATERIALS** **PREREGISTERED**

How open is a journal based on its 'OA spectrum'

The HowOpenisit? Open Access Spectrum guide illustrates the continuum from more open to less open.

HowOpenisit? Open Access Spectrum Tool

Access	Reader Rights	Reuse Rights	Copyrights	Author Posting Rights	Automatic Posting	Machine Readability	Access
 OPEN ACCESS 	Free readership rights to all articles immediately upon publication	Generous reuse & remixing rights (e.g., CC BY license)	Author holds copyright with no restrictions	Author may post any version to any repository or website	Journals make copies of articles automatically available in trusted third-party repositories (e.g., PubMed Central) immediately upon publication	Article full text, metadata, citations, & data, including supplementary data, provided in community machine-readable standard formats through a community standard API or protocol	 OPEN ACCESS 
	Free readership rights to all articles after an embargo of no more than 6 months	Reuse, remixing, & further building upon the work subject to certain restrictions & conditions (e.g., CC BY-NC & CC BY-SA licenses)	Author holds copyright, with some restrictions on author reuse of published version	Author may post final version of the peer-reviewed manuscript ("postprint") to any repository or website	Journals make copies of articles automatically available in trusted third-party repositories (e.g., PubMed Central) within 6 months	Article full text, metadata, citations, & data, including supplementary data, may be crawled or accessed through a community standard API or protocol	
	Free readership rights to all articles after an embargo greater than 6 months	Reuse (no remixing or further building upon the work) subject to certain restrictions and conditions (e.g., CC BY-ND license)	Publisher holds copyright, with some allowances for author and reader reuse of published version	Author may post final version of the peer-reviewed manuscript ("postprint") to certain repositories or websites	Journals make copies of articles automatically available in trusted third-party repositories (e.g., PubMed Central) within 12 months	Article full text, metadata, & citations may be crawled or accessed without special permission or registration	
	Free and immediate readership rights to some, but not all, articles (including "hybrid" models)		Publisher holds copyright, with some allowances for author reuse of published version	Author may post submitted version/draft of final work ("preprint") to certain repositories or websites		Article full text, metadata, & citations may be crawled or accessed with permission	
 CLOSED ACCESS 	Subscription, membership, pay-per-view, or other fees required to read all articles	No reuse rights beyond fair use/limitations & exceptions to copyright (all rights reserved copyright) to read	Publisher holds copyright, with no author reuse of published version beyond fair use	Author may not deposit any versions to repositories or websites	No automatic posting in third-party repositories	Article full text & metadata not available in machine-readable format	 CLOSED ACCESS 

HowOpenisit? Open Access Spectrum. © 2013 SPARC and F1000, licensed under CC BY

<https://www.plos.org/how-open-is-it>

Open Access Spectrum Evaluation Tool

Scores FAQ Sponsors/Supporters The Data





Administrative Login

96 Investigative Genetics

2041-2223 (Print)
Blomed Central Ltd.

Journal Homepage
Funder Policy
Sherpa Romeo

Total Score

ACCESS	READER RIGHTS	REUSE RIGHTS	COPYRIGHTS	AUTHOR POSTING RIGHTS	AUTOMATIC POSTING	MACHINE READABILITY	ACCESS
 OPEN ACCESS	Free readership rights to all articles immediately upon publication	Generous reuse & remixing rights (e.g., CC BY license)	Author holds copyright with no restrictions	Author may post any version to any repository or website with no delay	Journals make copies of all articles automatically available in trusted third-party repositories (e.g., PubMed Central, OpenAire, Institutional) immediately upon publication	Article full text, metadata, supporting data (including format and semantic markup) & citations may be accessed via API, with instructions publicly posted	 OPEN ACCESS
	Free readership rights to all articles after an embargo of no more than 6 months	Reuse, remixing, & further building upon the work subject to certain restrictions & conditions (e.g., CC BY-NC & CC BY-SA licenses)	Author retains/publisher grants broad rights, including author reuse (e.g., of figures in presentations/teaching, creation of derivatives) and authorization rights (for others to use)	Author may post some version (determined by publisher) to any repository or website with no delay	Journals make copies of all articles automatically available in trusted third-party repositories (e.g., PubMed Central, OpenAire, Institutional) within 6 months	Article full text, metadata, & citations may be accessed via API, with instructions publicly posted	
	Free readership rights to all articles after an embargo greater than 6 months	Reuse (no remixing or further building upon the work) subject to certain restrictions and conditions (e.g., CC BY-ND license)	-	Author may post some version (determined by publisher) to any repository or website with some delay (determined by the publisher)	Journals make copies of all articles automatically available in trusted third-party repositories (e.g., PubMed Central, OpenAire, Institutional) within 12 months	Article full text, metadata, & citations may be crawled without special permission or registration, with instructions publicly posted	
	Free and immediate readership rights to some, but not all, articles (including "hybrid" models)	Some reuse rights beyond fair use for some, but not all, articles (including "hybrid models")	Author retains/publisher grants limited rights for author reuse (e.g., of figures in presentations/teaching, creation of derivatives)	Author may post some version (determined by publisher) to certain repositories or websites, with or without delays	Journals make copies of some, but not all, articles automatically available in trusted third-party repositories (e.g., PubMed Central, OpenAire, Institutional) within 12 months	Article full text, metadata, & citations may be crawled with permission, with instructions publicly posted	
 CLOSED ACCESS	Subscription, membership, pay-per-view, or other fees required to read all articles	No reuse rights beyond fair use/dealing or other limitations or exceptions to copyright (All Rights Reserved)	Publisher holds copyright, with no author reuse beyond fair use	Author may not deposit any versions to any repositories or websites at any time	No automatic posting in third-party repositories	No full text articles available for crawling	 CLOSED ACCESS

How open is your Institution



SPARC Europe

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SPARC Europe > Events > 2015 > How Open is Your Research? A Checklist for Institutions

How Open is Your Research? A Checklist for Institutions

This checklist is designed to enable research institutions to assess quickly the openness of their research and teaching outputs. It covers the whole process of undertaking and disseminating scholarly and scientific research, and teaching, including for instance the adoption or development of, and adherence to, policies and strategies.

Scoring is either yes/no or on a percentage scale, where 0% signifies no compliance or implementation and 100% signifies full compliance or implementation. For each section the scores are totalled and expressed as a percentage indicating the extent of openness. An overall institutional visualisation is given as a radar chart.

SPARC Europe strategy

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Open Access
What you can do
Related organizations

Post an Event

Upcoming events





Transparency and Openness Promotion (TOP) Guidelines

Transparency, open sharing, and reproducibility are core features of science, but not always part of daily practice. Journals can increase transparency and reproducibility of research by adopting the TOP Guidelines. TOP includes eight modular standards, each with three levels of increasing stringency. Journals select which of the eight transparency standards they wish to adopt for their journal, and select a level of implementation for the selected standards. These features provide flexibility for adoption depending on disciplinary variation, but simultaneously establish community standards.

- Article introducing the TOP Guidelines, *Science*: [Full Text](#) | [Summary](#) | [pdf](#)
- [Summary worksheet of the TOP Guidelines](#)
- [The TOP Guidelines wiki](#)
- [The TOP Guidelines pdf for download](#)
- [Signatories](#)

Signatories

Journals, publishers, societies, repositories, and other organizations with a stake in science are encouraged to join as signatories of the TOP Guidelines.

Journal signatories are:

1. Expressing their support of the principles of openness, transparency, and reproducibility
2. Expressing interest in the guidelines and commit to conducting a review within a year of the standards and levels for potential adoption

Organization signatories are:

1. Expressing their support of the principles of openness, transparency, and reproducibility
2. If relevant, encouraging associated journals to conduct a review of the standards and levels for potential adoption.

Summary of the eight standards and three levels of the TOP guidelines

Levels 1 to 3 are increasingly stringent for each standard. Level 0 offers a comparison that does not meet the standard.

	LEVEL 0	LEVEL 1	LEVEL 2	LEVEL 3
Citation standards	Journal encourages citation of data, code, and materials—or says nothing.	Journal describes citation of data in guidelines to authors with clear rules and examples.	Article provides appropriate citation for data and materials used, consistent with journal's author guidelines.	Article is not published until appropriate citation for data and materials is provided that follows journal's author guidelines.
Data transparency	Journal encourages data sharing—or says nothing.	Article states whether data are available and, if so, where to access them.	Data must be posted to a trusted repository. Exceptions must be identified at article submission.	Data must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
Analytic methods (code) transparency	Journal encourages code sharing—or says nothing.	Article states whether code is available and, if so, where to access them.	Code must be posted to a trusted repository. Exceptions must be identified at article submission.	Code must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
Research materials transparency	Journal encourages materials sharing—or says nothing.	Article states whether materials are available and, if so, where to access them.	Materials must be posted to a trusted repository. Exceptions must be identified at article submission.	Materials must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
Design and analysis transparency	Journal encourages design and analysis transparency or says nothing.	Journal articulates design transparency standards.	Journal requires adherence to design transparency standards for review and publication.	Journal requires and enforces adherence to design transparency standards for review and publication.
Preregistration of studies	Journal says nothing.	Journal encourages preregistration of studies and provides link in article to preregistration if it exists.	Journal encourages preregistration of studies and provides link in article and certification of meeting preregistration badge requirements.	Journal requires preregistration of studies and provides link and badge in article to meeting requirements.
Preregistration of analysis plans	Journal says nothing.	Journal encourages preanalysis plans and provides link in article to registered analysis plan if it exists.	Journal encourages preanalysis plans and provides link in article and certification of meeting registered analysis plan badge requirements.	Journal requires preregistration of studies with analysis plans and provides link and badge in article to meeting requirements.
Replication	Journal discourages submission of replication studies—or says nothing.	Journal encourages submission of replication studies.	Journal encourages submission of replication studies and conducts blind review of results.	Journal uses Registered Reports as a submission option for replication studies with peer review before observing the study outcomes.

Increase effort, transparency and quality

Open Data



Open data must be accessible, useable, assessable and intelligible (extracted from *Science as an Open Enterprise, 2012*)

Accessible

Data must be located in such a manner that it can readily be found and in a form that can be used.

Useable

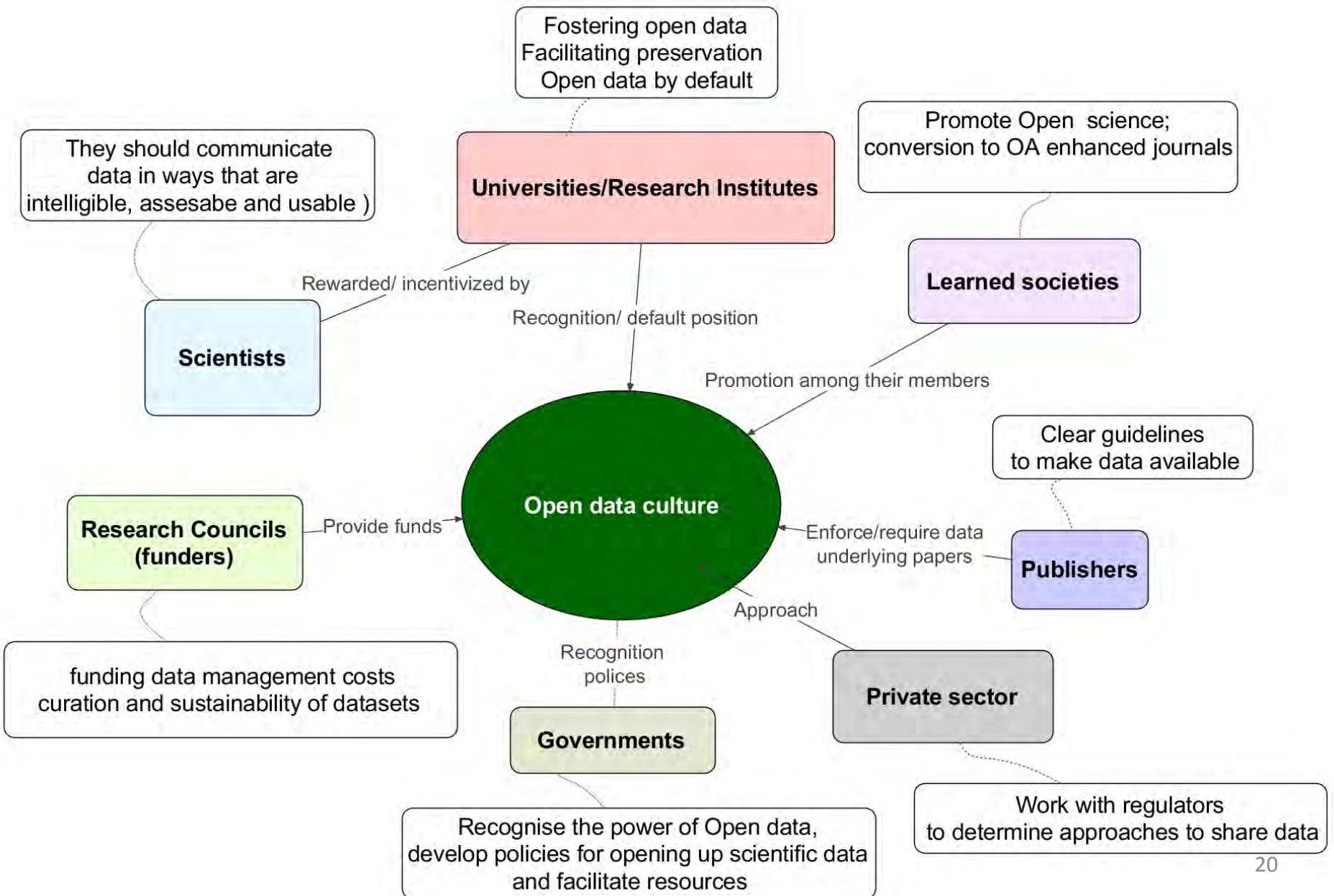
In a format where others can use the data or information. Data should be able to be reused, often for different purposes, and therefore will require proper background information and metadata.

Assessable

In a state in which judgments can be made as to the data or information's reliability.

Intelligible

Comprehensive for those who wish to scrutinise something.



THE FAIR DATA PRINCIPLES - FOR COMMENT

JOIN IN THE DISCUSSION - LEAVE YOUR COMMENTS BELOW

FAIR Data Principles

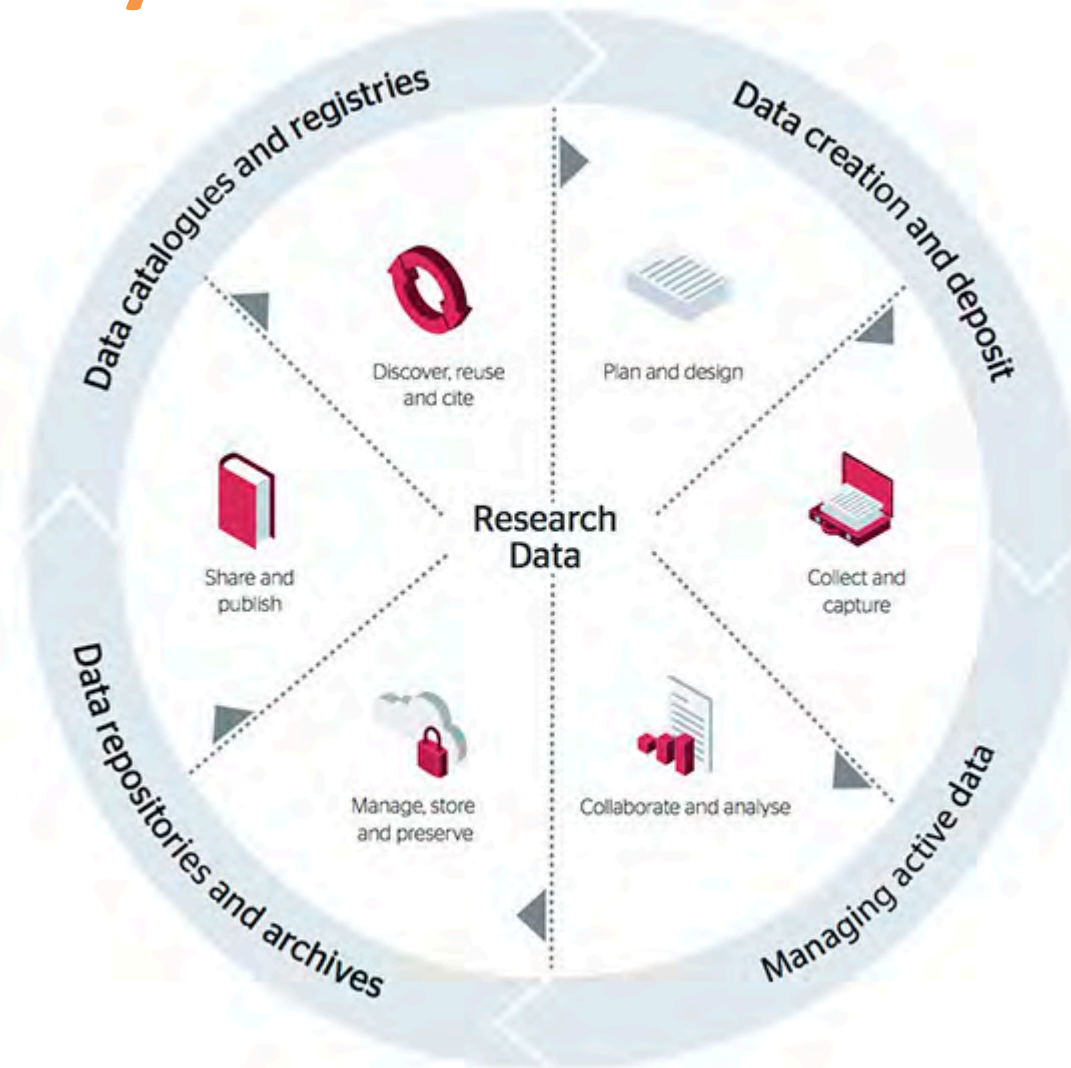
Preamble

One of the grand challenges of data-intensive science is to facilitate knowledge discovery by assisting humans and machines in their discovery of, access to, integration and analysis of, task-appropriate scientific data and their associated algorithms and workflows. Here, we describe **FAIR** - a set of guiding principles to make data **Findable, Accessible, Interoperable, and Re-usable**.

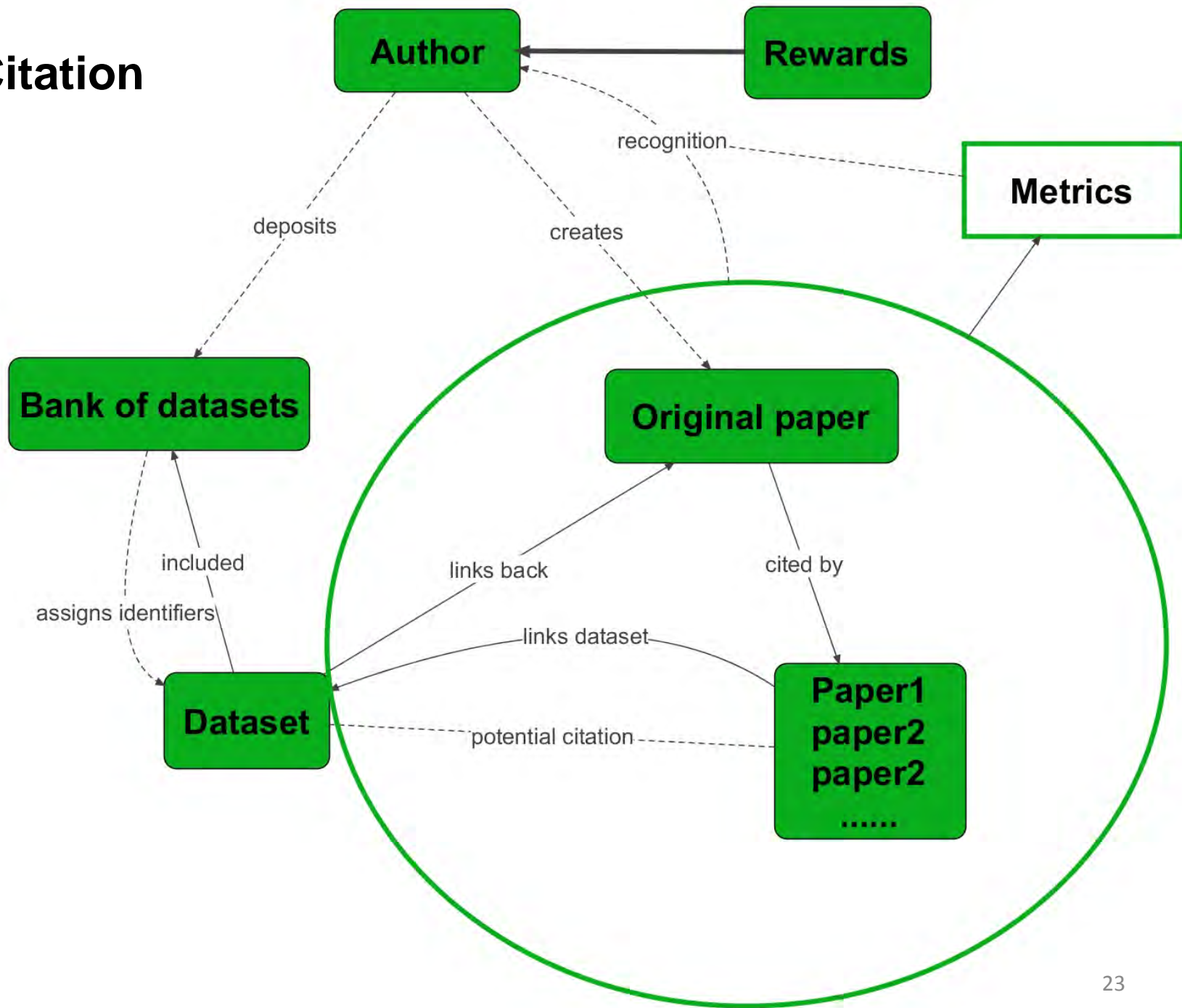
FAIR Data Principles:

- **Findable**
- **Accessible**
- **Interoperable**
- **Re-usable**

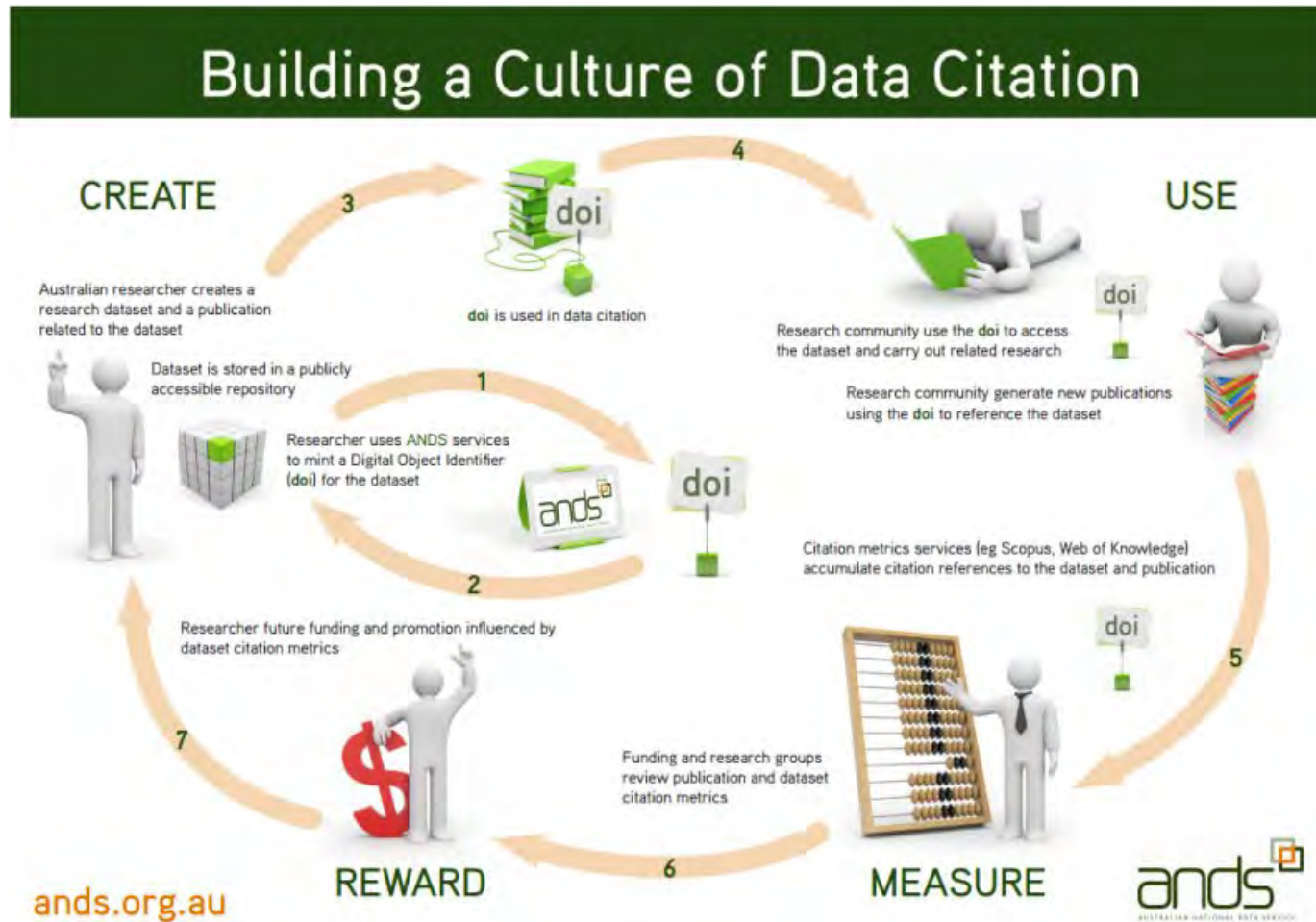
Data lifecycle



Data Citation Cycle

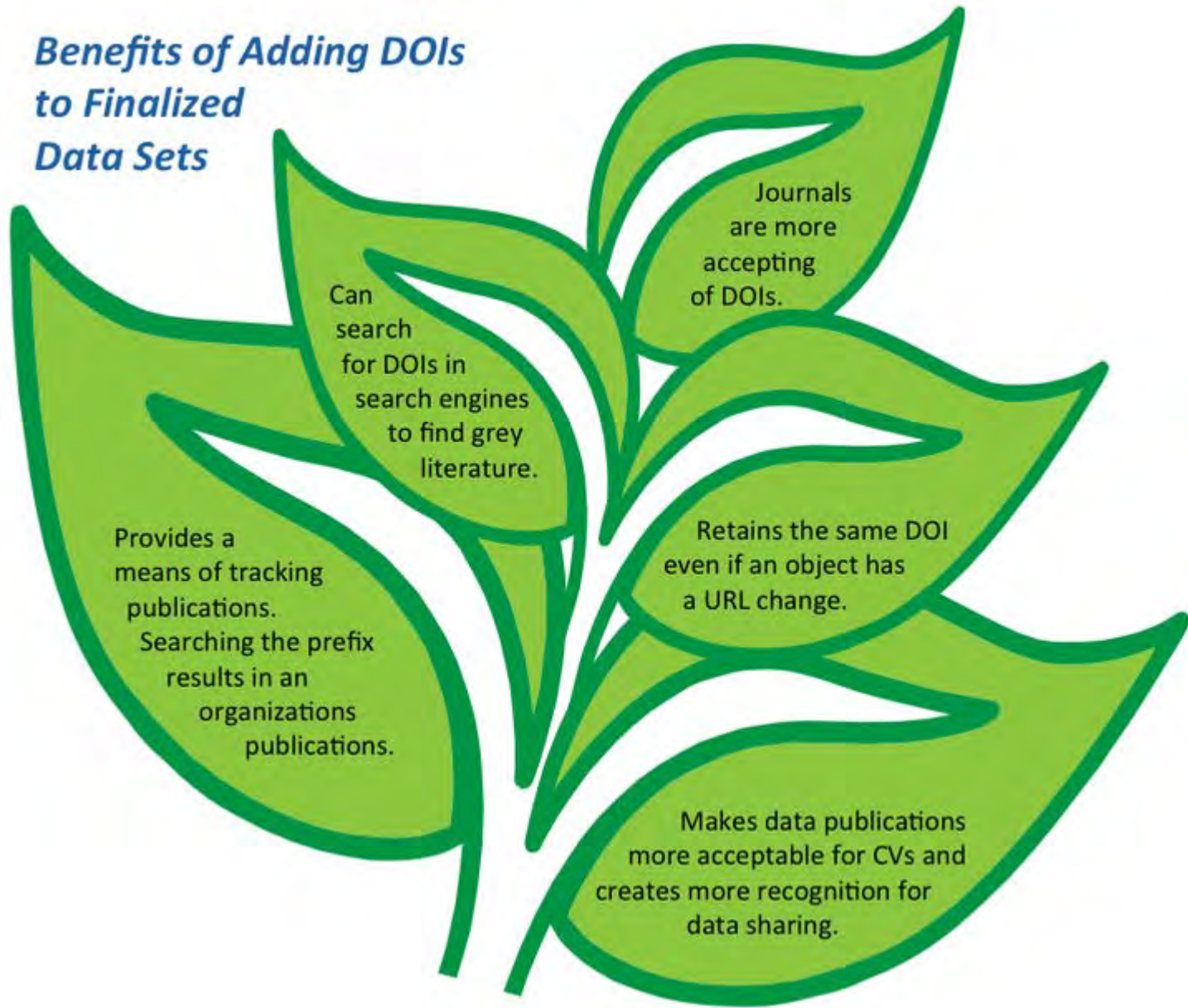


Identification of datasets favours their use and citation



Australian National Data Service. <http://www.ands.org.au/cite-data/index.html>

Benefits of Adding DOIs to Finalized Data Sets



DataCite: Locate, Identify, Cite data



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What do we do?

We want to help make data more accessible and more useful; our purpose is to develop methods to locate, identify and cite data and other research objects. Specifically, support the standards behind persistent identifiers for data, and our members assign

We bring together actors from the research community to address the challenges of objects visible and accessible. Together we constitute a global network of data [Members of DataCite](#) meet in person every six months at summer and winter (collaborate in established [working groups](#).

Through collaboration, we:

- support [researchers](#) by helping them to find, identify, and cite research data and objects with confidence;
- support [data centres](#) by providing persistent identifiers for datasets, workflows and data publication;
- support [journal publishers](#) by enabling research articles to be linked to data/objects.

Currently we are working primarily with organisations that host data, such as [libraries](#).

<https://www.datacite.org/>

Assigning persistent identifiers to datasets

[Northern Circumpolar Soil Carbon Database](#)

[version 1.0.0]

[doi:10.5879/ECDS/00000001](#) Dataset : geospatial

Hugelius, Gustaf

description: The Northern Circumpolar Soil Carbon Database (NCSCD) is a [geospatial](#) database created for the *resourceType:* [geospatial](#)

[Summer temperature gradients in northwest Europe during the Lateglacial to early Holocene t](#)

[doi:10.5258/SOTON/361991](#) Dataset : GeoSpatial

Langdon, Peter • Riddy, Liam • Brooks, Steve

resourceType: [GeoSpatial](#)

[EARTH OBSERVATION DATA: MONITORING MONITORING FLOODS AND DROUGHTS](#)

[doi:10.13140/2.1.3623.7600](#) Text : Book

Amarnath Giriraj

publisher: [Geospatial](#) Today

[Geography Markup Language \(GML\) Encoding Specification v3.1.1](#)

[doi:10.13140/2.1.2846.2401](#)

S Cox • P Daisey • R Lake • C Portele • A Whiteside

publisher: Open [Geospatial](#) Consortium

[Spectral information system development for Australia](#)

[doi:10.5167/UZH-86627](#)

Suarez, Lola • Chisholm, Laurie • Hueni, Andreas • Ong, Cindy • Wyatt, Matthew

rights: School of Mathematical and [Geospatial](#) Sciences

publisher: School of Mathematical and [Geospatial](#) Sciences

[Bayesian spatio-temporal modelling of tobacco-related cancer mortality in Switzerland](#)

[doi:10.5167/UZH-87532](#)

Phuleria, Harish C • Jürgens, Verena • Cerny, Thomas • Früh, Martin • Frick, Harald • (et. al.)

publisher: Global Network for [Geospatial](#) Health

[Comparative Analysis of MODIS SPOT5 and Worldview2 data during wheat growing season](#)

[doi:10.13140/RG.2.1.1558.7920](#)

Ibrar ul Hassan Akhtar

publisher: Global [Geospatial](#) Challenge, Intergraph and Digital Globe

[Geospatial Data](#)

[doi:10.17616/R3Z341](#) Collection : Data Repository Descriptive Record
re3data.org

title: [Geospatial](#) Data

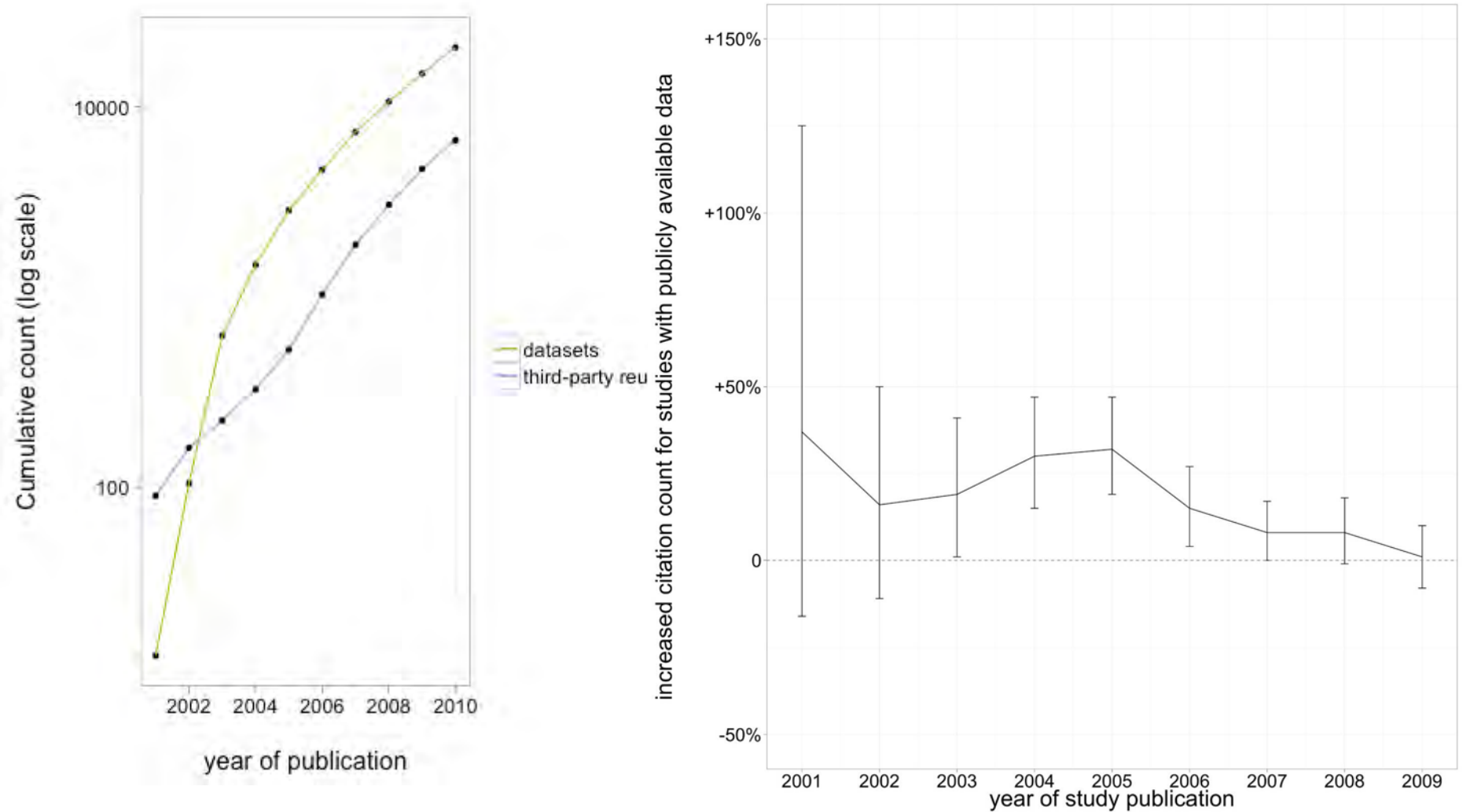
[Verwijzing naar de data van: Nieuwe Kaart van Nederland](#)

[doi:10.17026/DANS-X4D-EW2N](#) Dataset : Dataset

NIROV

subject: [Geospatial](#) sciences

Ver Piowar et al. (2013) Data reuse and the open data citation advantage.
PeerJ PrePrints 1:e1v1 <http://dx.doi.org/10.7287/peerj.preprints.1v1>



Papers of studies that created gene expression microarray data and made them available GEO data (**Gene Expression Omnibus**) received more citations than those for which data were not available

In this section

- [Briefing Papers](#)
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- [Curation Reference Manual](#)
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Disciplinary Metadata

While data curators, and increasingly researchers, know that good metadata is key for research data access and re-use, figuring out precisely what metadata to capture and how to capture it is a complex task. Fortunately, many academic disciplines have supported initiatives to formalise the metadata specifications the community deems to be required for data re-use. This page provides links to information about these disciplinary metadata standards, including profiles, tools to implement the standards, and use cases of data repositories currently implementing them.

For those disciplines that have not yet settled on a metadata standard, and for those repositories that work with data across disciplines, the General Research Data section links to information about broader metadata standards that have been adapted to suit the needs of research data.

Please note that a [community-maintained version of this directory](#) has been set up under the auspices of the Research Data Alliance.

Search by Discipline



[Biology](#)



[Earth Science](#)



[General Research Data](#)



[Physical Science](#)



[Social Science & Humanities](#)

http://www.re3data.org/



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geospatial

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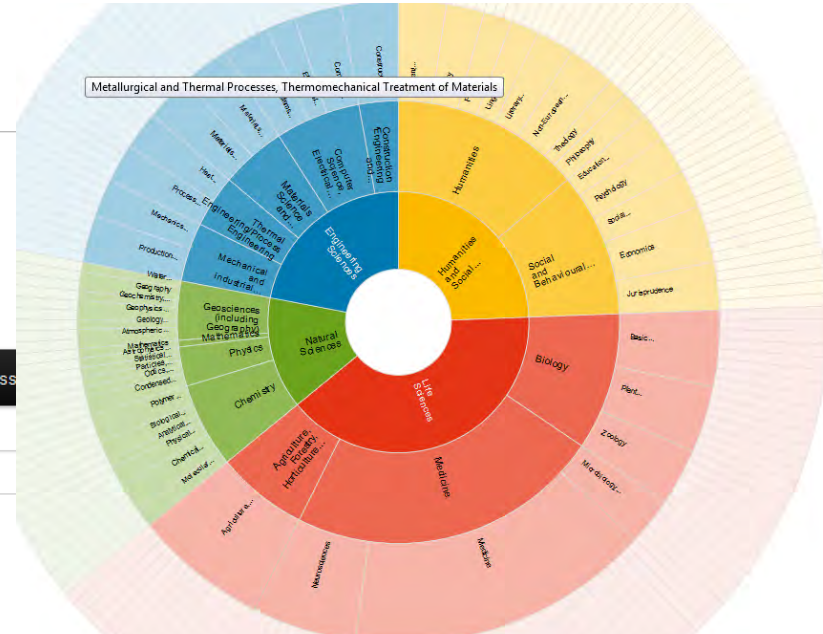
Polar Geospatial Center PGC

Subject(s) Geosciences (including Geography) Geology and Palaeontology
Geodesy, Photogrammetry, Remote Sensing, Geoinformatics, Cartography
Geochemistry, Mineralogy and Crystallography Natural Sciences
Geophysics and Geodesy

Content type(s) Standard office documents Images Raw data other

Country United States

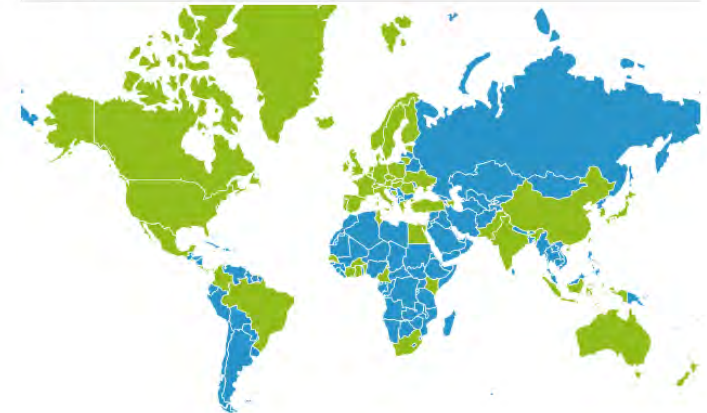
The Polar Geospatial Center provides geospatial support, mapping, and GIS/remote sensing solutions to researchers and logistics groups in the polar science community.



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Graphical Text



Four Rodent and Vole Biodiversity Models for Europe

William Wint¹, David Morley², Neil S. Alexander³

1. Senior Research Associate, Environmental Research Group Oxford (ERGO), Department of Zoology, Oxford, United Kingdom
2. Research Assistant, Environmental Research Group Oxford (ERGO), Department of Zoology, Oxford, United Kingdom
3. Research Assistant, Environmental Research Group Oxford (ERGO), Department of Zoology, Oxford, United Kingdom

The Journal publishes peer reviewed data papers describing public health datasets with high reuse potential

(3) Dataset Description

Object Name

volebiodiv2.zip

Data Type

Primary data, Processed data, Interpretation of data.

Format Names and Versions

JPG, TIF, TFW, XML

Creation Dates

15/08/2012 – 15/08/2012

Dataset Creators

William Wint, David Morley, Neil S. Alexander.

Repository Location

<http://dx.doi.org/10.5061/dryad.771gr>

Publication Date

08/07/2013

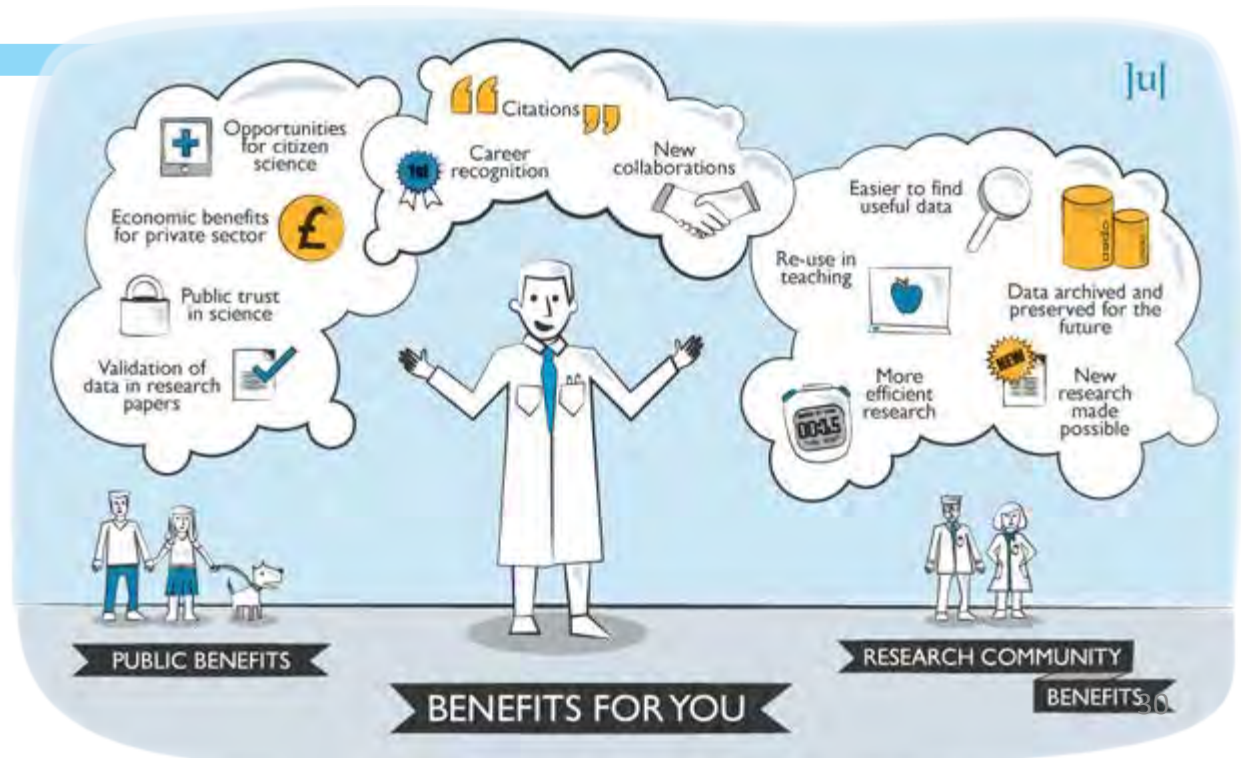
language

English

License

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Data Availability

The following policy applies to all of PLOS journals, unless otherwise noted.

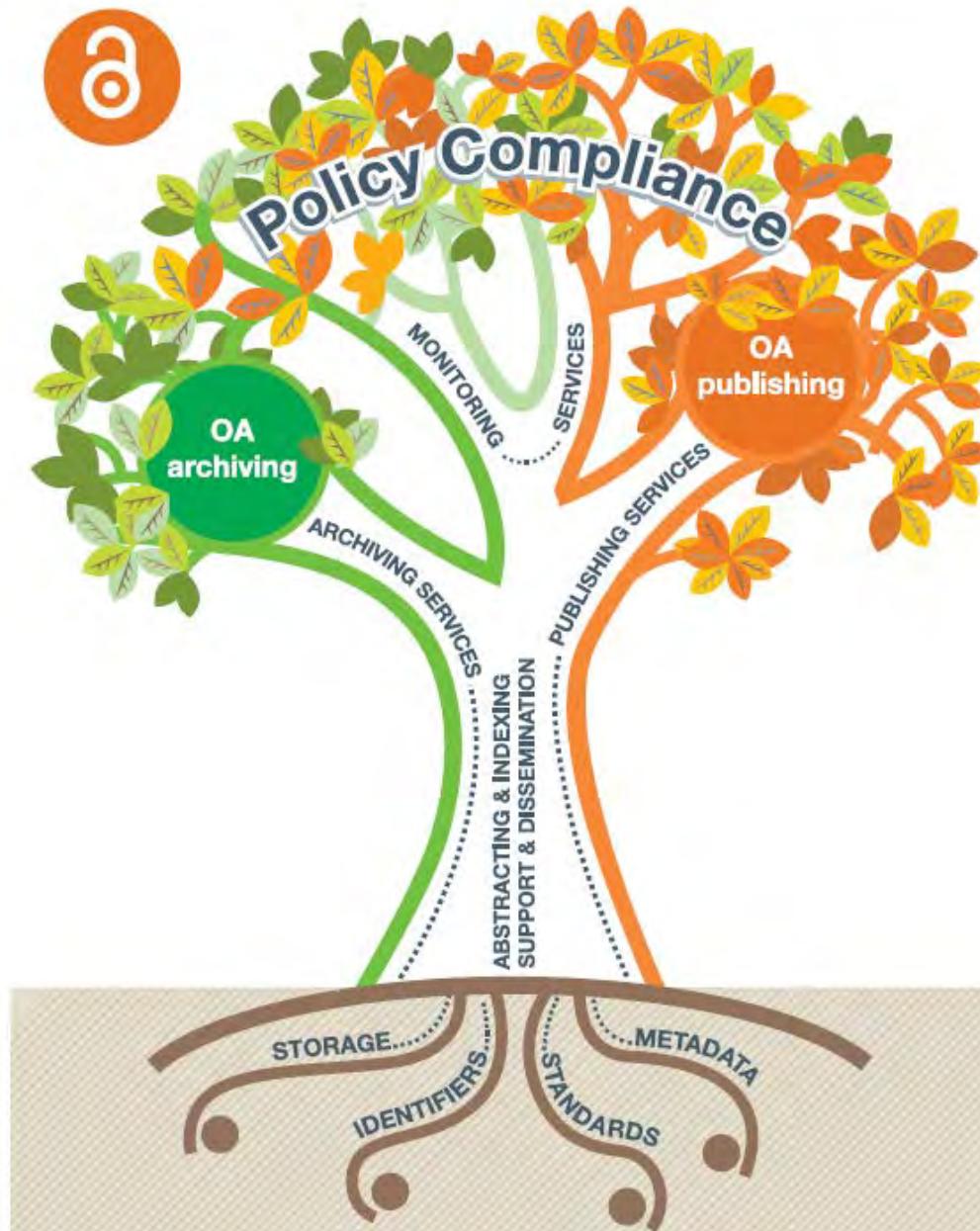
PLOS journals require authors to make all data underlying the findings described in their manuscript fully available without restriction, with rare exception.

When submitting a manuscript online, authors must provide a *Data Availability Statement* describing compliance with PLOS's policy. If the article is accepted for publication, the data availability statement will be published as part of the final article.

Refusal to share data and related metadata and methods in accordance with this policy will be grounds for rejection. PLOS journal editors encourage researchers to contact them if they encounter difficulties in obtaining data from articles published in PLOS journals. If restrictions on access to data come to light after publication, we reserve the right to post a correction, to contact the authors' institutions and funders, or in extreme cases to retract the publication.

OA policies

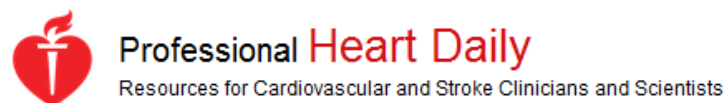
Figure 1: How OA services enable OA publishing, OA archiving and policy compliance



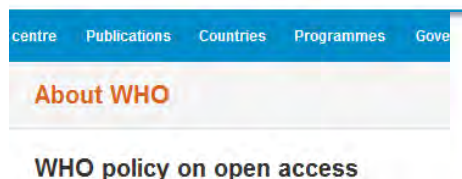
Putting down roots Securing the future of open access policies

Workshop 10 November 2015
Report dated January 2016

Agencies/funders requiring public access to publications and data (some examples)



Open Access Policy concerning UNESCO publications



The Analytic and Translational Genetics Unit (Massachusetts General Hospital)

Publication Policy

“As human geneticists, our primary goal is to determine the genetic causes of rare and common diseases in order to facilitate both the diagnosis of individual patients and the discovery of disease processes that may provide new therapeutic insights. Particularly since we receive public and private funds to deliver on this mission, **we are committed to the key ethical principle that any genetic discoveries pertaining to human diseases, and any tools or resources we generate** that may help others in this endeavor, **must be made available as freely and rapidly as possible...**”

“We believe that it is **only a matter of time** before the **concept of restricted access to the products of scientific research becomes an anachronism**, and we hope that the human genetics and genomics community can play a leading role in the transition to more enlightened models”



EDITORIAL

Sharing Clinical Trial Data — A Proposal from the International Committee of Medical Journal Editors

Darren B. Taichman, M.D., Ph.D., Joyce Backus, M.S.L.S., Christopher Baethge, M.D., Howard Bauchner, M.D., Peter W. de Leeuw, M.D., Jeffrey M. Drazen, M.D., John Fletcher, M.B., B.Chir., M.P.H., Frank A. Frizelle, M.B., Ch.B., F.R.A.C.S., Trish Groves, M.B., B.S., M.R.C.Psych., Abraham Haileamlak, M.D., Astrid James, M.B., B.S., Christine Laine, M.D., M.P.H., Larry Peiperl, M.D., Anja Pinborg, M.D., Peush Sahni, M.B., B.S., M.S., Ph.D., and Sinan Wu, M.D.
N Engl J Med 2016; 374:384-386 | January 28, 2016 | DOI: 10.1056/NEJMe1515172

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Article | References | Citing Articles (16) | Letters | Metrics

The International Committee of Medical Journal Editors (ICMJE) believes that there is an ethical obligation to responsibly share data generated by interventional clinical trials because participants have put themselves at risk. In a growing consensus, many funders around the world — foundations, government agencies, and industry — now mandate data sharing. Here we outline the ICMJE's proposed requirements to help meet this obligation. We encourage feedback on the proposed requirements. Anyone can provide feedback at www.icmje.org by 18 April 2016.

The ICMJE defines a clinical trial as any research project that prospectively assigns people or a group of people to an intervention, with or without concurrent comparison or control groups, to study the cause-and-effect relationship between a health-related intervention and a health outcome. Further details may be found in the *Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals* at www.icmje.org.

The ICMJE **proposes to require authors to share with others the de-identified individual-patient data (IPD) underlying the results presented in the article no later than 6 months after publication.**

Sharing clinical trial data, including de-identified IPD, requires planning to ensure appropriate ethics committee or institutional review board approval and the informed consent of study participants.



Around half of clinical trials have never been reported.
This is the story of the campaign to find them—
and to fix medicine.

[Read the AllTrials story](#)


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March 17, 2016

American Medical Association Joins AllTrials Campaign for Clinical Trial Transparency

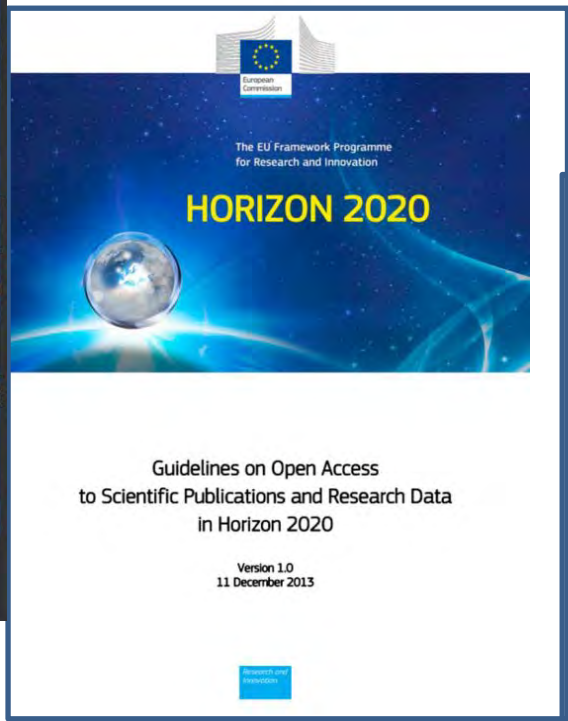
For immediate release:
March 17, 2016

The AMA strongly supports improving the timeliness and accessibility of clinical trial data to reduce the duplication of research and help inform future research—ultimately improving health outcomes for patients," said AMA President Steven. J. Stack. "The AMA is pleased to join the AllTrials initiative to continue efforts aimed at ensuring open access to clinical trial data for physicians, researchers and patients.

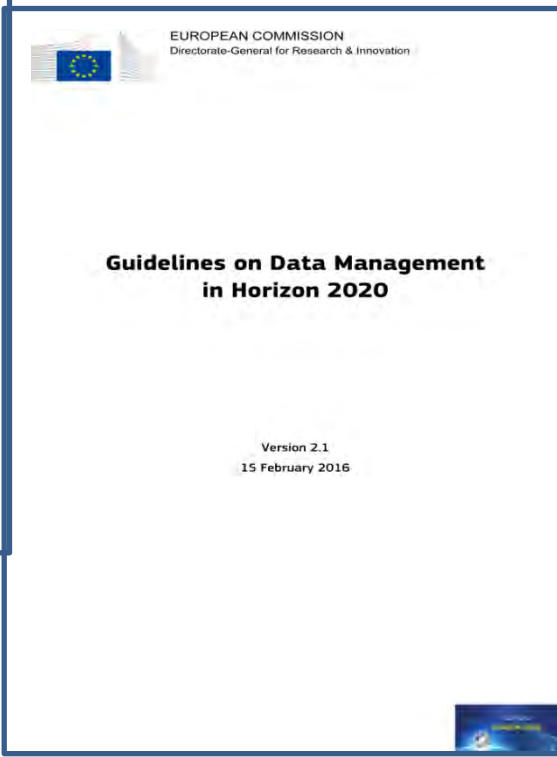
Europe vs Open science.....

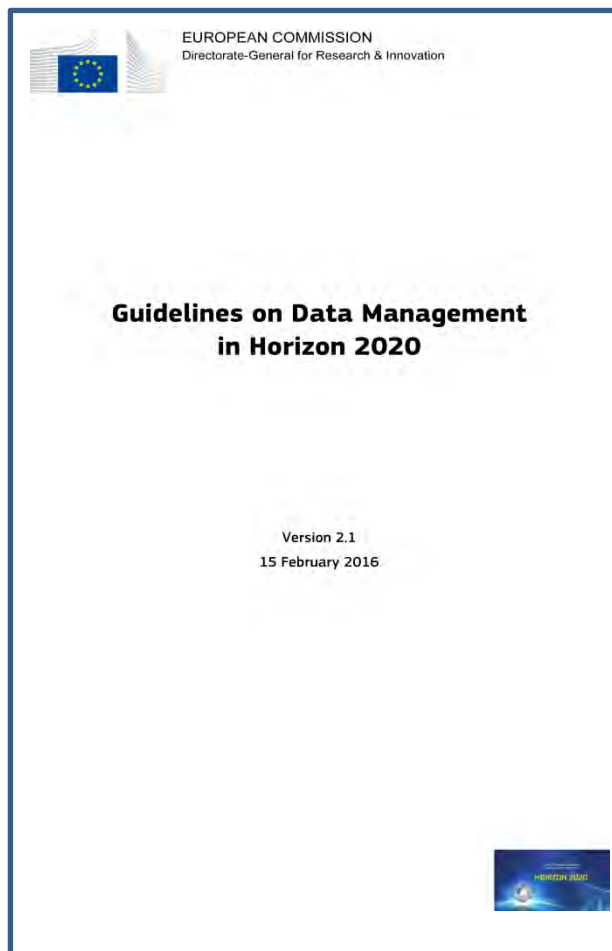


2007-2013



2014-2020





Research Data Pilot in H2020

A novelty in Horizon 2020 is the Open Research Data Pilot which aims to improve and maximise access to and re-use of research data generated by projects. The legal requirements for projects participating in this pilot are contained in the optional article 29.3 of the Model Grant Agreement.

http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf

*In a research context, examples of data include **statistics**, **results of experiments**, **measurements**, **observations** resulting from fieldwork, **survey** results, **interview recordings** and **images**. The focus is on research data that is available in **digital form**.*

Types of data covered by the Open Research Data Pilot:

1. The data, including associated metadata (i.e. metadata describing the research data deposited), **needed to validate the results presented in scientific publications as soon as possible** ("underlying data")
2. Other data (for instance curated data not directly attributable to a publication, or raw data), including associated metadata, as specified and within the deadlines laid down in the data management plan that is, according to the individual judgement by each project

For the 2016-2017 Work Programme, the areas of Horizon 2020 participating in the Open Research Data Pilot are:

- Future & Emerging Technologies
- Research infrastructures
- Leadership in enabling & industrial technologies – Information & Communication Technologies
- Nanotechnologies, Advanced Materials, Advanced Manufacturing & Processing, & Biotechnology – 'nanosafety' & 'modelling' topics
- Societal Challenge – Food security, sustainable agriculture & forestry, marine & maritime & inland water research & the bioeconomy - selected topics as specified in the work programme
- Societal Challenge – Climate Action, Environment, Resource Efficiency & Raw Materials – except raw materials
- Societal Challenge – Europe in a changing world – inclusive, innovative & reflective societies
- Science with & for Society
- Cross-cutting activities – focus areas – part Smart & Sustainable Cities

Projects in other areas can participate on a voluntary basis

Opting out partially or entirely from the Pilot on Open Research Data Projects can opt out at any stage if:

- Participation is **incompatible** with the Horizon 2020 obligation to protect
- Results that can reasonably be expected to be **commercially or industrially exploited**
- Participation is incompatible with the need for **confidentiality** in connection with **security issues**
- Participation is incompatible with rules on **protecting personal data**
- Participation would mean that the **project's main aim might** not be achieved
- The project will **not generate / collect** any research data
- There are **other legitimate reasons** not to take part in the Pilot (at proposal stage - free text box provided).

EC announces Open Science Cloud and open research data by default

Updated on 24 May 2016

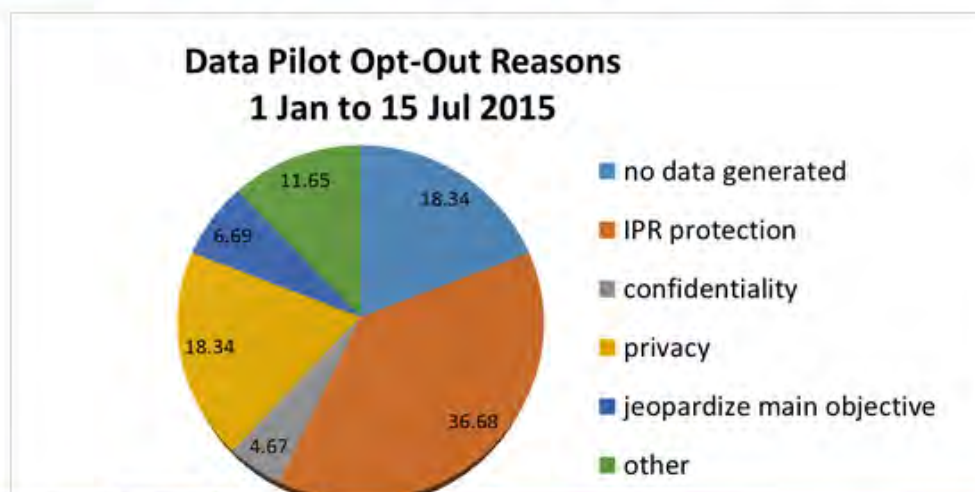


The "European Cloud Initiative – Building a competitive data and knowledge economy in Europe" aims to strengthen Europe's position in data-driven innovation, improve its competitiveness and cohesion, and help create a Digital Single Market in Europe. Towards this the EC will make Open Data the default for funded projects by 2017.

On April 19th the European Commission presented its blueprint for cloud-based services and world-class data infrastructure. The planned European Open Science Cloud (EOSC) aims to create a trusted environment for hosting and processing research data to support EU science in its global leading role. It will give Europe's 1.7 million researchers and 70 million science and technology professionals a virtual environment to store, share and re-use their data across disciplines and borders. It will provide a secure environment where privacy and data protection must be guaranteed by design, based on recognised standards, and where users can be confident concerning data security and liability risks.

To develop the EOSC and take the lead in data-sharing the Commission will make all scientific data produced by Horizon 2020-funded projects open by default by 2017. This will extend the [current pilot](#), whereby projects implement data management plans to make it easier to find, access and re-use research data. However, existing opt-out facilities will be preserved, to take into account for example the sensitiveness of certain data from domains such as security or data that are very close to market.

Introduced at the start of 2015, covering just seven work programme areas, the Horizon 2020 Open Research Data Pilot has been a big success. In the first six months of the pilot, about a third of projects (65.4%, 431 signed grant agreements) that were part of the pilot chose to opt out. The most common reasons for opting out were: (1) concerns over intellectual property (37%), (2) the project did not expect to generate any data (18%), and privacy/data protection concerns (18%). Of those projects that were not originally part of the pilot, 11.9% (3268 projects) nonetheless have voluntarily opted in. For further details, see: <https://open-data.europa.eu/data/dataset/open-research-data-the-uptake-of-the-pilot-in-the-first-calls-of-horizon-2020>



EUDAT: the collaborative Pan-European infrastructure providing research data services, training and consultancy for



Researchers



Research Communities



Research Infrastructures & Data Centres

B2DROP
Sync and Exchange Research Data
[Read more!](#)
use

B2SHARE
Store and Share Research Data
[Read more!](#)
use

B2SAFE
Replicate Research Data Safely
[Read more!](#)

B2STAGE
Get Data to Computation
[Read more!](#)

B2FIND
Find Research Data
[Read more!](#)
use

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STATISTICS
OA, PROJECTS, TOPICS

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Science. **Set free.**

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Datasets

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- 23 March 2016 **Dataset** **Open access** [View](#)

Trophic-meta-analysis: First release of tritrophic meta-analysis data and code
Monica Granados

First release of data and code associated with "Interaction strength and the impact of introduced omnivores: A meta-analysis of introduced aquatic invasive species" manuscript

Uploaded by Monsauce on 23 March 2016.
- 22 March 2016 **Dataset** **Open access** [View](#)

Huntingtin linker sequence determination by computational methods - correspondence with Alex Holehouse
[Holehouse, Alex](#); [Pappu, Rohit](#); [Harding, Rachel](#)

Huntingtin open lab notebook project

Uploaded by racheljaneharding on 22 March 2016.
- 28 August 2014 **Dataset** **Open access** [View](#)



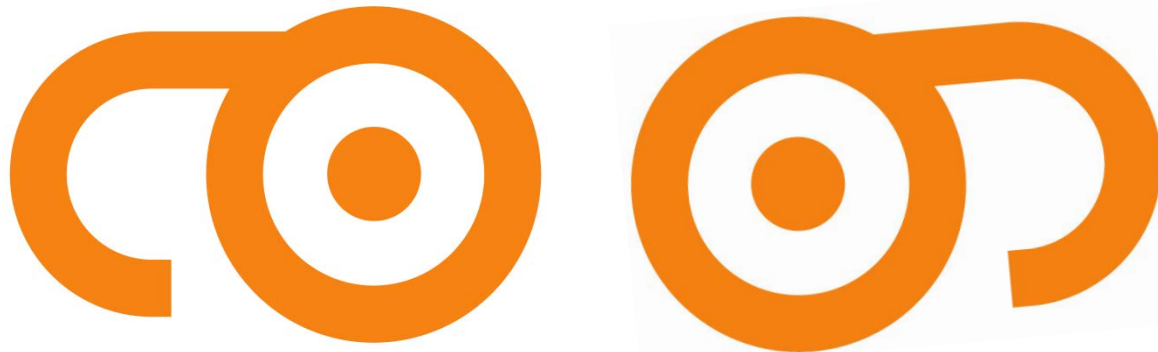
Draft European Open Science Agenda. 26 February 2016

DIRECTORATE-GENERAL FOR RESEARCH AND INNOVATION (RTD)

Based on 5 policy actions:

- Foster Open Science
- Remove barriers to Open Science
- Develop research infrastructures for Open Science
- Mainstream Open Access to research results
- Embed Open Science in Society

From vision to action





This document is a living document reflecting the present state of open science evolution. It is based on the input of many participating experts and stakeholders of the Amsterdam Conference ‘Open Science – From Vision to Action’, hosted by the Netherlands’ EU Presidency on 4 and 5 April 2016.

Formulated to reach two important pan-European goals for 2020:

- 1. Full open access for all scientific publications**
- 2. A fundamentally new approach towards optimal reuse of research data**

To reach these goals by 2020 we need flanking policy:

- **New assessment, reward and evaluation systems**
- **Alignment of policies and exchange of best practices**

<http://english.eu2016.nl/documents/reports/2016/04/04/amsterdam-call-for-action-on-open-science>

Brussels, 27 May 2016
(OR. en)

9526/16

RECH 208
TELECOM 100

OUTCOME OF PROCEEDINGS

From:	General Secretariat of the Council
To:	Delegations
No. prev. doc.:	8791/16 RECH 133 TELECOM 74
Subject:	The transition towards an Open Science system - Council conclusions (adopted on 27/05/2016)



Science ministers from European Union nations AGREED last month to **make publicly funded research publications freely available by 2020**. Each country will implement its own publication policy.

The Council:

UNDERLINES the principle for the optimal reuse of research data should be: “**as open as possible, as closed as necessary**”.

EMPHASIZED that the opportunities for the optimal reuse of research data can only be realised if data are consistent with the FAIR principles (findable, accessible, interoperable and re-usable) within a secure and trustworthy environment

OA Commitments

Essential medicines and health products

Developing Global Norms for Sharing Data and Results during Public Health Emergencies

A longer statement of principles arising from the 1-2 Sep 2015 consultation is available

Leading international stakeholders from multiple sectors convened at a WHO consultation in September 2015, where they affirmed that timely and transparent pre-publication sharing of data and results during public health emergencies must become the global norm.

WHO seeks a paradigm shift in the approach to information sharing in emergencies, from one limited by embargoes set for publication timelines, to open sharing using modern fit-for-purpose pre-publication platforms. Researchers, journals and funders will need to engage fully for this paradigm shift to occur. (Point 3 from summary points)

http://www.who.int/medicines/ebola-treatment/data-sharing_phe/en/

NEWS

Sharing data during Zika and other global health emergencies

We're joining over 30 global health bodies in calling for all research data gathered during the Zika virus outbreak, and future public health emergencies, to be made available as rapidly and openly as possible.

It follows a [consensus statement](#) arising from a WHO consultation in September 2015, in which leading international stakeholders affirmed that timely and transparent pre-publication sharing of data and results during public health emergencies must become the global norm. The statement is published in full below.

Statement on data sharing in public health emergencies

The arguments for sharing data, and the consequences of not doing so, have been thrown into stark relief by the Ebola and Zika outbreaks.

In the context of a public health emergency of international concern, there is an imperative on all parties to make any information available that might have value in combatting the crisis.

We are committed to working in partnership to ensure that the global response to public health emergencies is informed by the best available research evidence and data, as such:

- Journal signatories will make all content concerning the Zika virus free to access. Any data or preprint deposited for unrestricted dissemination ahead of submission of any paper will not pre-empt its publication in these journals.
- Funder signatories will require researchers undertaking work relevant to public health emergencies to set in place mechanisms to share quality-assured interim and final data as rapidly and widely as possible, including with public health and research communities and the World Health Organization.



Tim Ellis, Wellcome Images

Published: 10 February 2016

Author: Hannah Isom

Topics: [Influencing policy](#), [Data sharing](#), [Zika](#)

Notes for editors

If your organisation would like to become a signatory to the statement, please email [Katherine Littler](#).

Signatories to the Statement


- Academy of Finland
- Academy of Medical Sciences, UK
- Bernhard Nocht Institute for Tropical Medicine
- Bill and Melinda Gates Foundation
- Biotechnology and Biological Sciences

http://f1000research.com/channels/arbovirus

Open access channel for papers and data

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Zika & Arbovirus Outbreaks



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Articles (15) Posters (24) Slides (3)

in All

ABOUT THIS CHANNEL TRACK

The *Zika & Arbovirus Outbreaks* channel is publishing research and clinical findings, data, protocols and presentations on all topics relating to Zika, other arboviruses and their vectors, without limitation of article size, type or perceived impact. All articles published in this channel will have their Article Processing Charges (APCs) waived. See the accompanying [blog](#) for more details.

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Statement on Data Sharing in Public Health Emergencies

Statement on Data Sharing in Public Health Emergencies

BioMed Central is part of Springer Nature, which has signed the following global statement on data sharing. All our research is free to access at all times.

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- Any data or preprint deposited for unrestricted dissemination ahead of

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The Yale University Open Data Access (YODA) Project at the Center for Outcomes Research and Evaluation advocates for the **responsible sharing of clinical research data**. The Project is committed to open science and **data transparency**, and **supports research attempting to produce concrete benefits to patients, the medical community, and society as a whole...**The mission of the YODA Project is to **not only increase access to clinical research data, but to promote its use to generate new knowledge.**

Open data for different goals



PARTNERSHIP

SERVICES

PUBLICATIONS

TOOLS

DATA

BLOG

NEWS

Our goal is to increase the supply of and demand for open aid data, building the capacity of our stakeholders to collaboratively leverage it for the improved ability to plan, manage, and coordinate aid-related decision making, leading to enhanced development outcomes.



PARTNERSHIP

SERVICES

PUBLICATIONS

TOOLS

DATA

OPEN DATA FOR DEVELOPMENT Solution Briefs

Lead Authors: Joel Gurin and Laura Manley

SUSTAINABLE DEVELOPMENT GOALS



WATER AND SANITATION

SUSTAINABLE DEVELOPMENT GOALS



AGRICULTURE AND FOOD SECURITY

SUSTAINABLE DEVELOPMENT GOALS



HEALTH

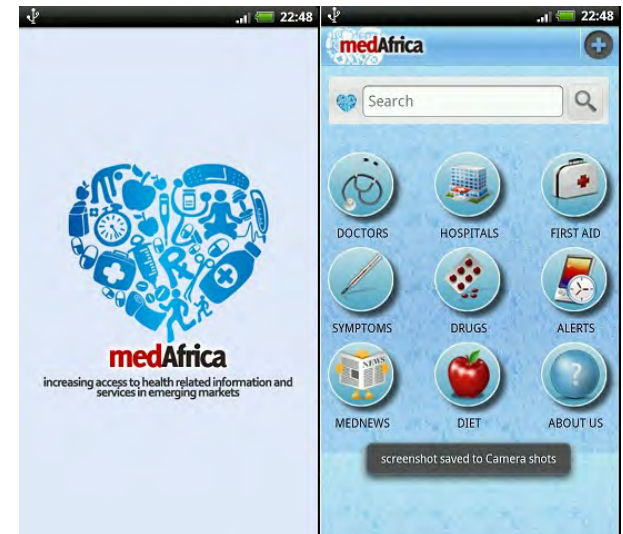


HOW OPEN DATA HELPS IMPROVE HEALTH

Open Data connects patients to healthcare providers, provides a check on healthcare quality, keeps medical costs in check, enables health education, and helps prevent and treat infectious disease. Specifically:

1. Applications built on Open Data can help consumers find healthcare providers to meet their needs.
2. Researchers, policymakers, and healthcare administrators can use Open Data to make healthcare more efficient and less expensive.
3. Health Open Data can support programs to improve public health research and clinics.
4. Programs using Open Data can promote health education for vulnerable populations.

<http://openaidpartnership.org/publications/briefs/sectoral/>





DOCUMENT
[GODAN Governance Report](#)



NEWS
[Open call for GODAN partners to be part of an original...](#)



DOCUMENT
[How can we Improve agriculture, food and nutrition...](#)



DOCUMENT
[Open Data and Farming 101](#)

The Global Open Data for Agriculture and Nutrition (GODAN) initiative seeks to support global efforts to make agricultural and nutritional relevant **data available, accessible, and usable for unrestricted use worldwide**. Launched in October 2013.

<http://godan.info/>



Welcome to HealthData.gov

This site is dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all.

Learn More



Community



Health



Quality



Medicare



Hospital



Inpatient



National



State

This site is dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all.



About

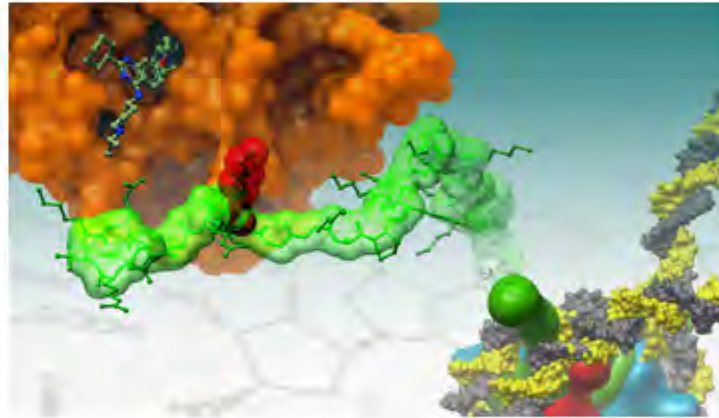
Science

A public-private partnership that supports the discovery of new medicines through open access research.

Home » About » Mission and Philosophy

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Pioneering Science to Inspire Pioneering Medicines



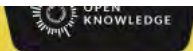
The SGC catalyses research in new areas of human biology and drug discovery by focusing explicitly on less well-studied areas of the human genome.

The SGC accelerates research in these new areas by making all its research output available to the scientific community with no strings attached, and by creating an open collaborative network of scientists in hundreds of universities around the world and in nine global pharmaceutical companies.

Together, this network of academic and industry scientists is driving a new scientific and drug discovery ecosystem whose primary aim is to advance science and is less influenced by personal, institutional or commercial gain.

The SGC (Structural Genomics Consortium) is a not-for-profit, public-private partnership with the directive to carry out basic science of relevance to drug discovery. <http://www.thesgc.org/>

Global Open Data Index
<http://index.okfn.org/>



Tracking the state of government open data.

The first initiative of its kind, the Global Open Data Index provides the most comprehensive snapshot available of the global state of open data.

Compare countries

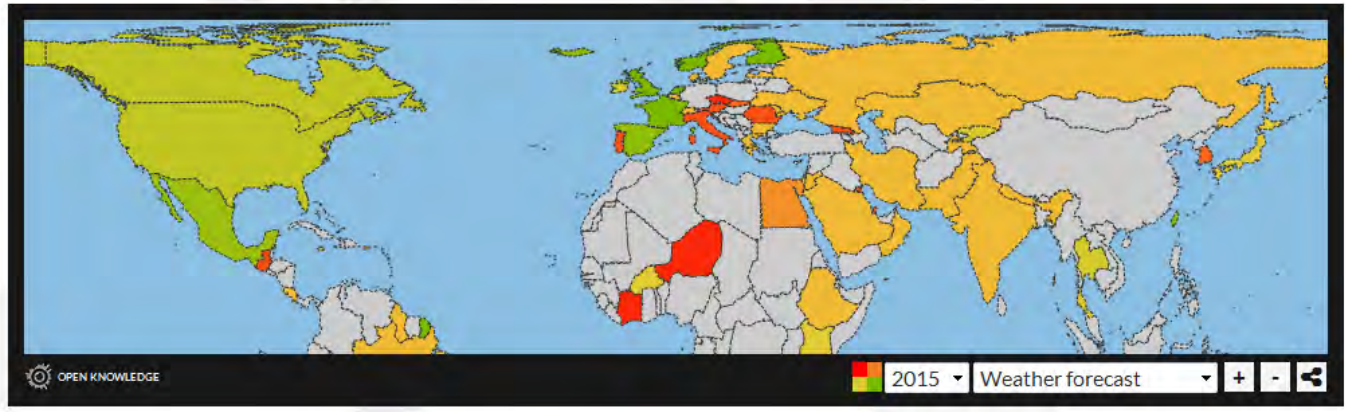
See insights

122

PLACES IN THE INDEX

Up from 97 in 2014

See the open data scores for the currently selected dataset(s), from 0 to 100.





Putting the World's Vulnerable People on the Map

Each year, disasters around the world kill nearly 100,000 and affect or displace 200 million people. Many of the places where these disasters occur are literally 'missing' from many maps and first responders lack the information to make valuable decisions regarding relief efforts. Missing Maps is an open, collaborative project in which you can help to map areas where humanitarian organisations are trying to meet the needs of vulnerable people.

GET INVOLVED

[Missing Maps](#) is a joint effort between the American & British Red Cross, the Humanitarian OpenStreetMap Team and Doctors Without Borders.

The objective is to map the most vulnerable places in the world so that NGOs & communities can use the maps and data to better respond to crises affecting the areas.

Missing Maps takes an open, collaborative, and community-based approach. It is powered by the enthusiasm and hard work of digital/remote volunteers both at home and abroad.

Step 1
Remote volunteers
trace satellite imagery
into OpenStreetMap



Step 2
Community volunteers add local
detail such as neighborhoods, street
names, and evacuation centers



Step 3
Humanitarian organizations use
mapped information to plan risk
reduction and disaster response
activities that save lives



Data licensing allows knowing how to reuse your data



Open Data Licensing Animation - OERIPR Support
https://www.youtube.com/watch?v=Tvwp5LK_Wko

Thank you!