### **ELSEVIER**





# **Research Data Management**

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# THE LANCET

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### A view on Research Data:

Series

Increasing value and reducing waste: addressing inaccessible research

Dr An-Wen Chan, DPhil<sup>a</sup>. ▲ · ™, Prof Fujian Song, PhD<sup>b</sup>, Andrew Vickers, PhD<sup>c</sup>, Tom Jefferson, MD<sup>d</sup>, Prof Kay Dickersin, PhD<sup>e</sup>, Prof Peter C Gøtzsche, DrMedSci<sup>f</sup>, Prof Harlan M Krumholz, MD<sup>g, h, i</sup>, Davina Ghersi, PhD<sup>j</sup>, H Bart van der Worp, PhD<sup>k</sup>

### Summary

The methods and results of health research are documented in study protocols, full study reports (detailing all analyses), journal reports, and participant-level datasets. However, protocols, full study reports, and participant-level datasets are rarely available, and journal reports are available for only half of all studies and are plagued by selective **reporting of methods and results.** Furthermore, information provided in study protocols and reports varies in quality and is often incomplete. When full information about studies is inaccessible, billions of dollars in investment are wasted, bias is introduced, and research and care of patients are detrimentally affected. To help to improve this situation at a systemic level, three main actions are warranted. First, academic institutions and funders should reward investigators who fully disseminate their research protocols, reports, and participant-level datasets. Second, standards for the content of protocols and full study reports and for data sharing practices should be rigorously developed and adopted for all types of health research. Finally, journals, funders, sponsors, research ethics committees, regulators, and legislators should endorse and enforce policies supporting study registration and wide availability of journal reports, full study reports, and participant-level datasets.

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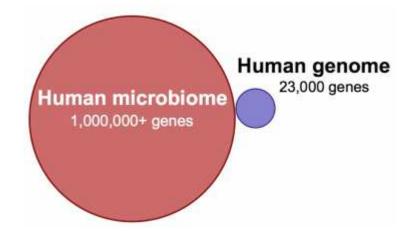
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# What are we really after: Bio & LS

With enough observations, trends and anomalies can be detected:



"Here we present resources from a population of 242 healthy adults sampled at 15 or 18 body sites up to three times, which have generated 5,177 microbial taxonomic profiles from 16S ribosomal RNA genes and over 3.5 terabases of metagenomic sequence so far."

The Human Microbiome Project Consortium, Structure, function and diversity of the healthy human microbiome, Nature 486, 207–214 (14 June 2012) doi:10.1038/nature11234

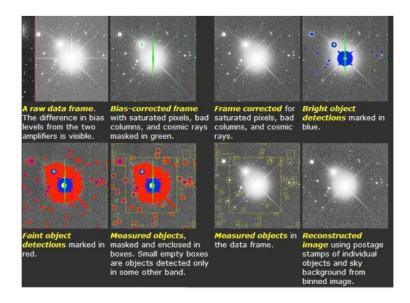
 "The large sample size — 4,298 North Americans of European descent and 2,217 African Americans — has enabled the researchers to mine down into the human genome."

Nidhi Subbaraman, Nature News, 28 November 2012, High-resolution sequencing study emphasizes importance of rare variants in disease.

## What are we really after: astronomy

Extracts from "the top 10 benefits of data sharing in astronomy", from Sloan Digital Sky Survey:

- Early data releases greatly improve the final product, e.g. more people "looking" at the data increases the chance of finding subtle problems, especially important for space missions with finite lifetime, e.g. the ESA's Gaia mission
- More science is extracted from the same dataset, e.g. diversity of ideas: many of the most visible SDSS results were unanticipated in the original project proposal
- Sometimes the only way to secure scarce resources, "easy things" (e.g. those that can be put together by a small number of groups/institutions) have been done in the last century; the "road ahead" requires more substantial merging of research resources, like HST Deep Field, UKIDSS, LSST
- Results in more citations and prestige to the team who produced data; practically all postdocs from the first phase of SDSS hold faculty-level positions today





# What are we really after: malaria



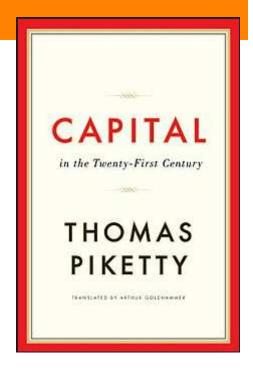
WWARN, the first malaria data sharing network, has used pooled analysis of shared data to provide evidence to **help improve dosing regimens** of malaria treatments

- research partners from over <u>260 institutions globally</u> have worked with WWARN, and over 120,000 individual patient records have been contributed to the WWARN Data Centre. That equates to around 80% of all the available artemisinin combination therapy trial data.
- Based on the results from the <u>Dihydroartemisinin-Piperaquine (DP) Dose Impact Study Group</u> and pharmacometric modelling of piperaquine, the World Health Organization has revised the recommended dose of DP, a commonly used antimalarial for young children. These <u>revised dose regimens (link is external)</u> are predicted to provide similar piperaquine concentrations across all age groups.
- Similarly, a meta-analysis undertaken by the Artesunate Amodiaquine (ASAQ) Dose Impact Study Group, based on 9,106 patients, found that although the overall efficacy of ASAQ is adequate in most settings, efficacy varies with the formulation and is affected by a range of risk factors including age. The <u>Artemether lumefantrine (AL)</u> <u>Dose Impact Study Group</u> found that cure rates were lowest in young children from Asia, especially those with high parasitemia, and young underweight children from Africa.

## What are we really after: social sciences

**Capital in the Twenty-First Century** is a 2013 book by French economist Thomas Piketty.

- It focuses on wealth and income inequality in Europe and the United States since the 18th century
- Central thesis is that when the rate of return on capital (r) is greater than the
  rate of economic growth (g) over the long term, the result is concentration of
  wealth, and this unequal distribution of wealth causes social and economic
  instability
- All raw data, normalized data, the analysis, and methods have all been made publicly available on a dedicated website <a href="https://www.quandl.com/data/PIKETTY">https://www.quandl.com/data/PIKETTY</a>



"Here are enormous quantities of information distilled from tax rolls, inheritance records, and various other public data sources, laid out in charts that should be readily accessible to the layest of lay readers. Not all of the information in these sections is novel or startling. Having it together in one place, however, is valuable, and even most of the book's fiercest critics respect this achievement." [1]

It also shows data sharing can lead to issues [2]:

- Chris Giles, economics editor of the Financial Times (FT), identified what he claims are "unexplained errors" in Piketty's data, in particular regarding wealth inequality increases since the 1970s. "contain a series of errors that skew his findings"
- Subsequently, Piketty wrote a response defending his findings; the accusation and responses received wide press coverage
- E.g. Scott Winship, a sociologist at the MIPR, claims the allegations are not "significant for the fundamental question of whether Piketty's thesis is right or not"

# **Sharing data – more citations**

OPEN @ ACCESS Freely available online



# Sharing Detailed Research Data Is Associated with Increased Citation Rate



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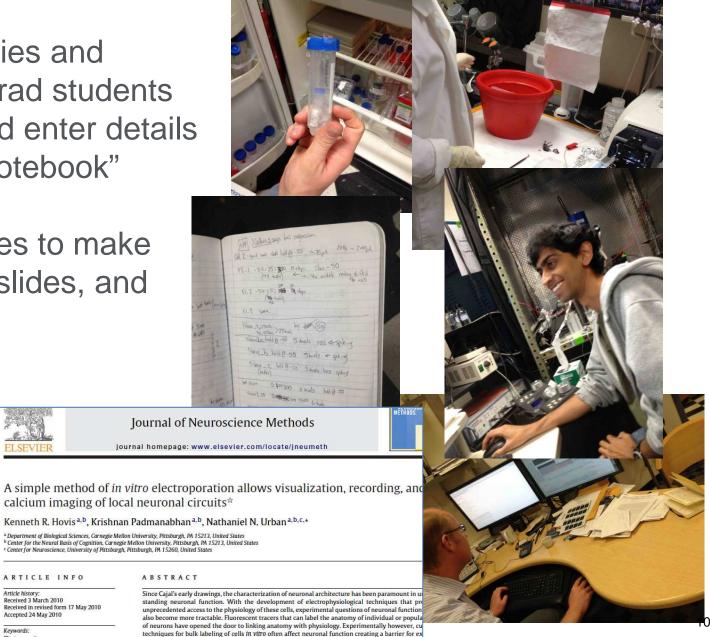
Background. Sharing research data provides benefit to the general scientific community, but the benefit is less obvious for the investigator who makes his or her data available. Principal Findings. We examined the citation history of 85 cancer microarray clinical trial publications with respect to the availability of their data. The 48% of trials with publicly available microarray data received 85% of the aggregate citations. Publicly available data was significantly (p = 0.006) associated with a 69% increase in citations, independently of journal impact factor, date of publication, and author country of origin using linear regression. Significance. This correlation between publicly available data and increased literature impact may further motivate investigators to share their detailed research data.

### Data in the lab

"Using antibodies and squishy bits, grad students experiment and enter details into their lab notebook"

The PI then tries to make sense of their slides, and writes a paper.

End of story.



calcium imaging of local neuronal circuits\*

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ABSTRACT

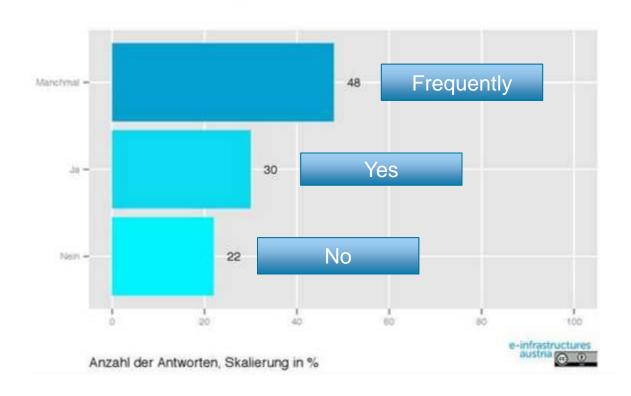
standing neuronal function. With the development of electrophysiological techniques that pr unprecedented access to the physiology of these cells, experimental questions of neuronal function also become more tractable. Fluorescent tracers that can label the anatomy of individual or popula of neurons have opened the door to linking anatomy with physiology. Experimentally however, cu techniques for bulk labeling of cells in vitro often affect neuronal function creating a barrier for ex

# When You Leave Your Institution, What Happens To Your Data?



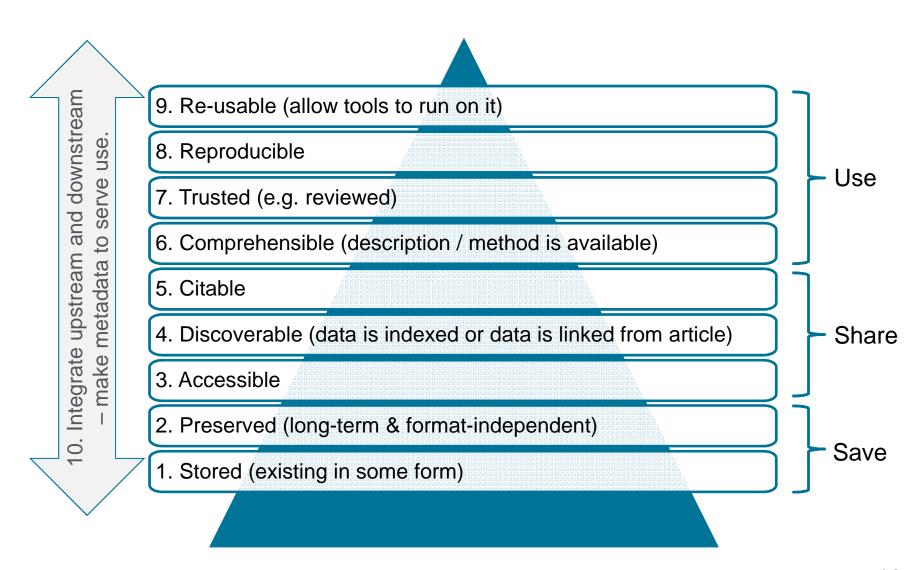
"Forschende und ihre Daten. Ergebnisse einer österreichweiten Befragung (eBook)" E-infrastructures Austria Bauer, B. (Bruno) et all Oct 2015 https://phaidra.univie.ac.at/detail\_object/o:407736

### Is Your Research Data Useful To Others?

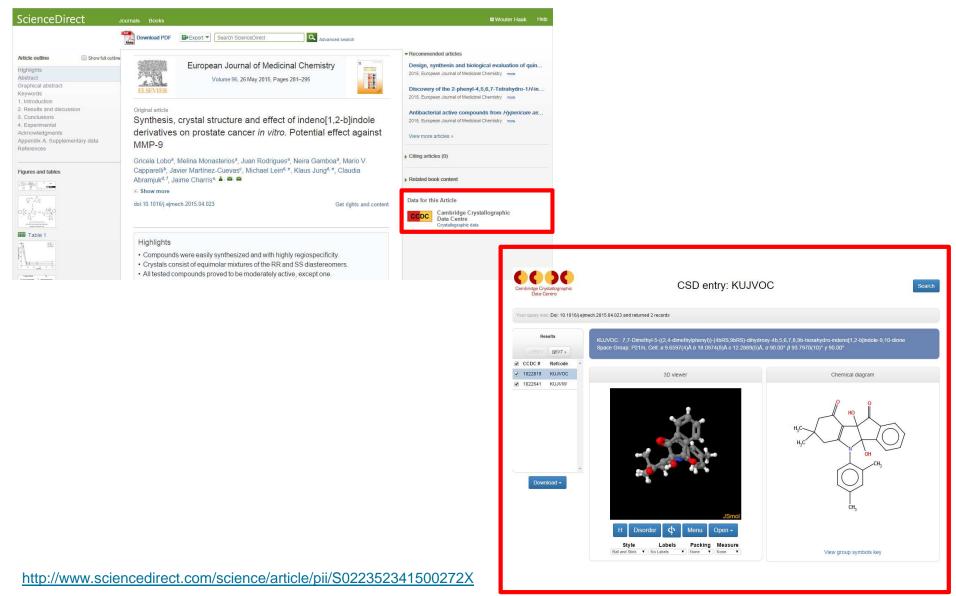


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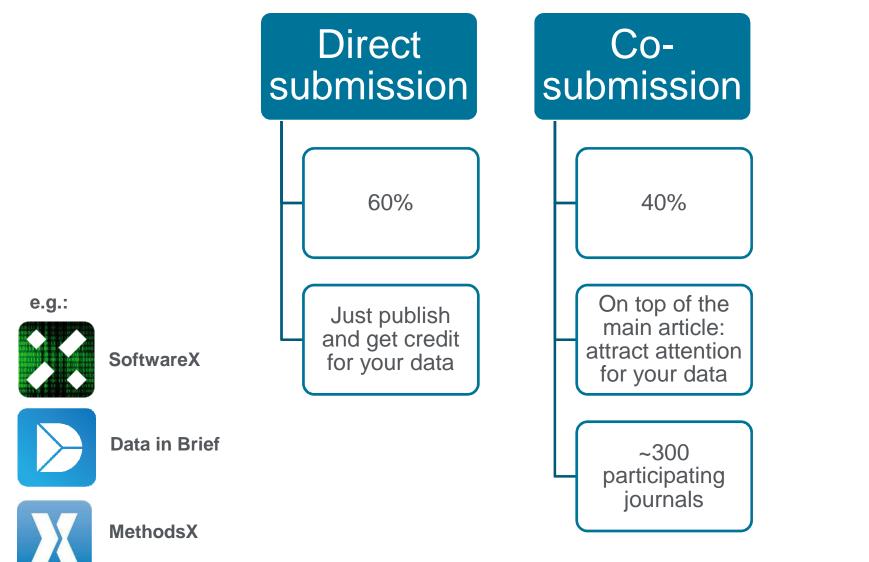
# Elsevier's approach; climbing the data pyramid



## 1. Research Data linking – linking articles to external datasets

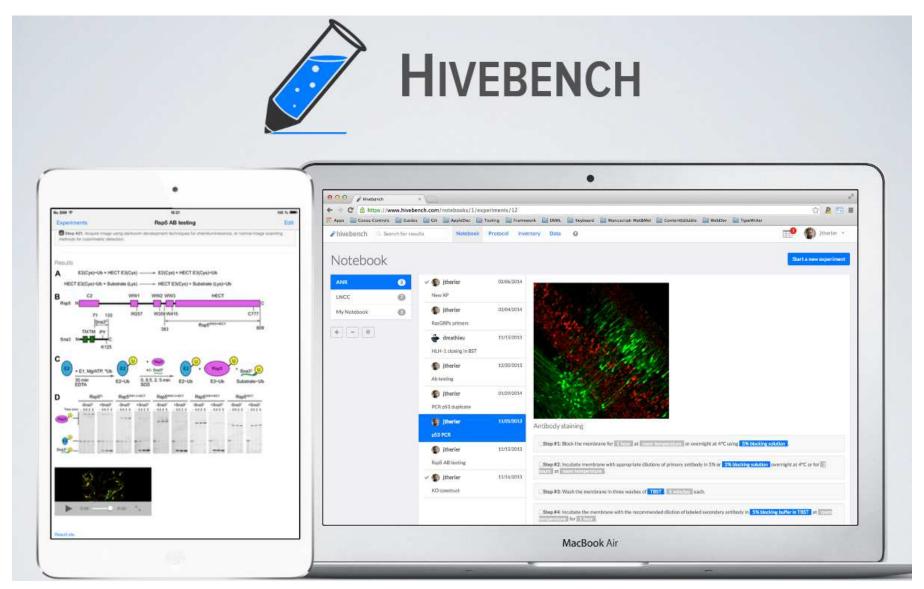


2. Gold OA reviewed **data journals**, software journals, materials & methods journals (collectively called "Research Elements")

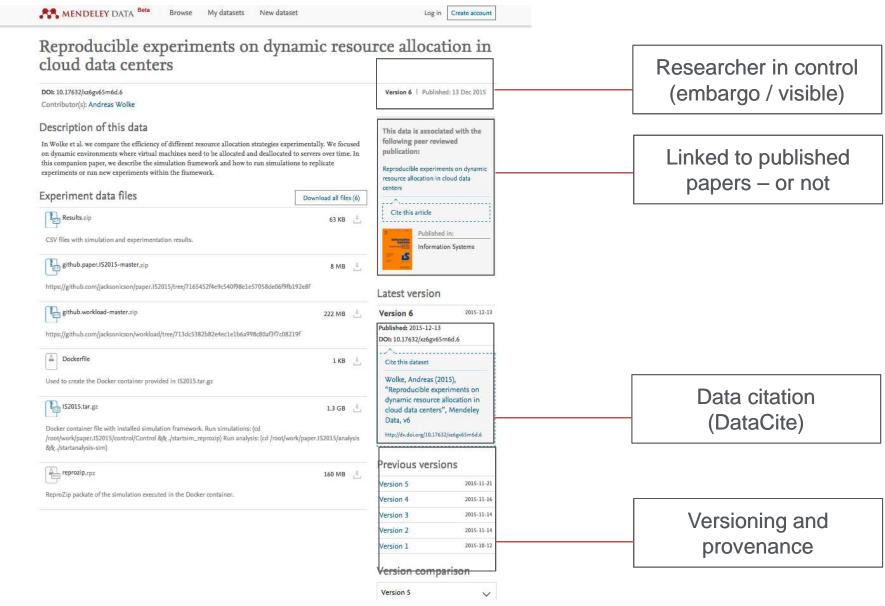


https://www.elsevier.com/books-and-journals/research-elements

# 3. Development Partnership (France) – Lab Data Tool: structure in the lab <a href="https://www.hivebench.com">www.hivebench.com</a>



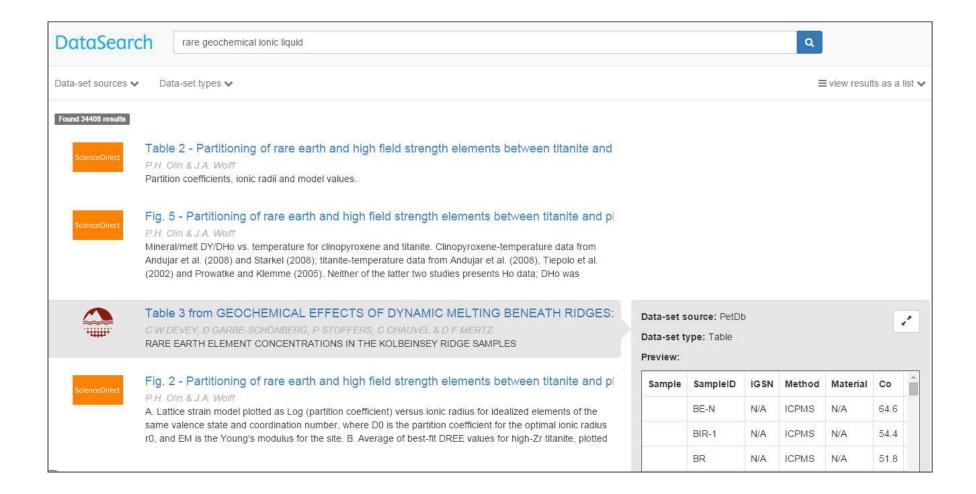
# 4. Manage, Store: Mendeley Data launched Dec 2015



https://data.mendeley.com/datasets/xz6gv65m6d/6

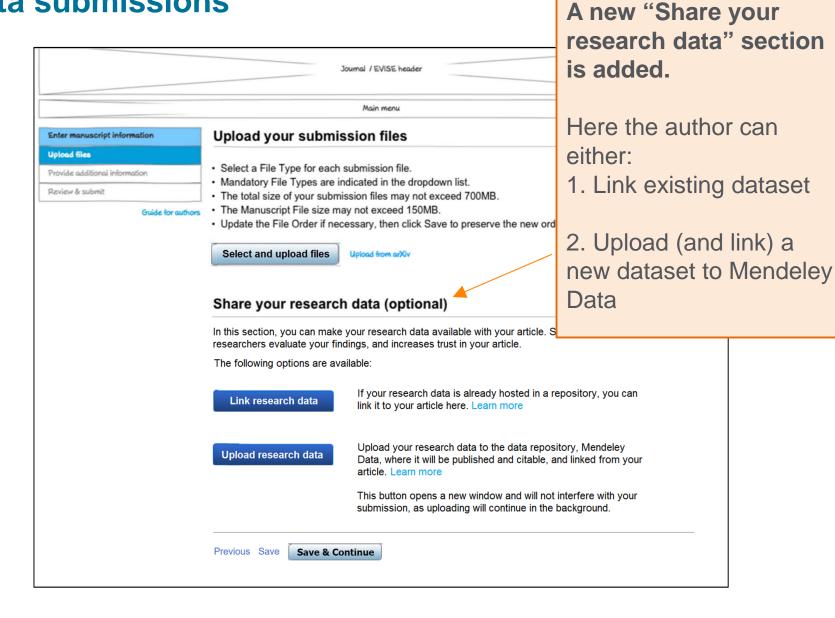


## 5. Prototype: Research Data Search

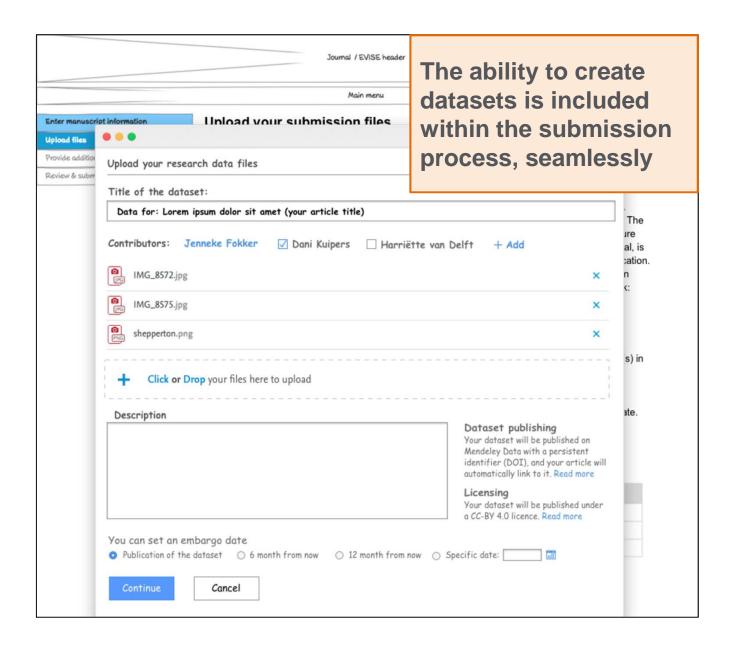


(prototype under username / password. Upon request) search for "rare geochemical ionic liquid" or "mantle calcium variation"

## **Data submissions**



### **Data submissions**



### **Co-submission of Research Elements**

#### Share your research data (optional)

Articles associated with available datasets have a citation advantage. Make your research data accessible by uploading it, linking to it and/or submitting an additional article about your data. Read more about data sharing options

[Journal X policy section]

Add link(s) to an external repository to make your data more discoverable

If your data is already hosted in a repository you can link it to your article here. Learn more about database linking

Upload your research data to link and visualize it within your article You can post your data - inlouding raw and processed data, directly in the Journal X repository in Mendeley Data, making it more discoverable, accessible and citable.

- · Your data will be then linked with your article and
- Supported data formats will be visualized within your article automatically. Read more

All data files can be posted; for visualization, this journal encourages: 3D Molecular Models 3D Neuroimaging Data

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This may not be the final structure - currently being user tested.

### The 10 components for and how Elsevier can help effective research data 10. Integrate upstream and downstream 9. Re-usable make metadata to serve use. 8. Reproducible Lab notebook 7. Trusted partnership 6. Comprehensible Data iournals / 5. Citable Research Data Linking **Elements** (Elsevier) Data Search (Elsevier) 4. Discoverable (agnostic) Mendeley data 3. Accessible repository (agnostic) 2. Preserved 1. Stored **Metrics / improvement program (agnostic)**

**Pro-active researcher adoption program (agnostic)**