UCSF Open Access Policy Deposits

Title Ethics and Open Science

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Ethical Questions in Open Science

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About Me

Data Services Librarian

Data Management

UCSF Library's Data Science Initiative provides data management support for students, faculty, and staff. We offer consultations and teach general and curriculum-integrated classes to help UCSF researchers better organize and manage data for reproducibility. Topics covered include locating public datasets, organizing files, documenting data, and publishing research data to meet journal requirements.

Meet our data management expert

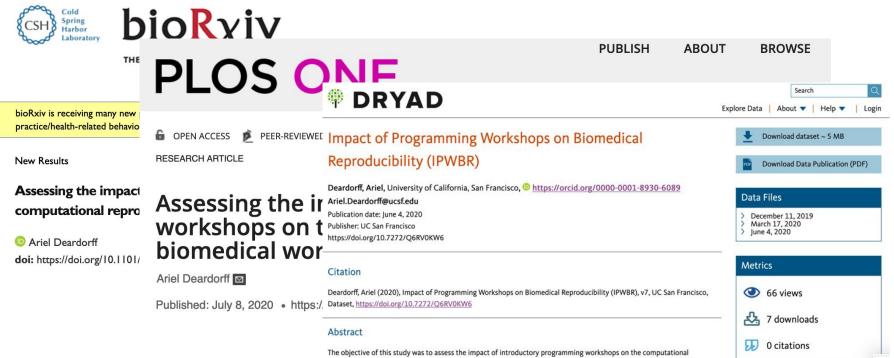


Ariel Deardorff

Ariel has worked as a librarian in academia, healthcare, and was a Fellow at the NIH. She is very familiar with funder and journal policies for data management, and can help researchers comply with these new requirements and integrate open science tools and methods into their research practice.



Open Science Researcher



reproducibility of biomedical research workflows. This mixed methods study consisted of in-depth interviews with 14

Situated in the Library's Data Science Team

Data Science

UCSF Library's Data Science Initiative (DSI) serves as a campus hub for education and support in data science. Our mission is to build computational and data skills in the UCSF community by providing education and resources to trainees, faculty, and staff. Come learn fundamental research skills, connect with others, and be empowered to engage in cutting edge biomedical research. See the **catalog for a list of core Data Science workshops** and materials. There are also additional materials online for self-study.

Programming Workshops and Tools

Find helpful resources for installations and tutorials, or register for one of our weekly workshops on Python or R, SQL, and more.

Bioinformatics and Statistical Analysis

Learn how to analyze data from bioinformatics or clinical research projects by attending a specialized workshop.

Finding, Sharing, and Managing Data

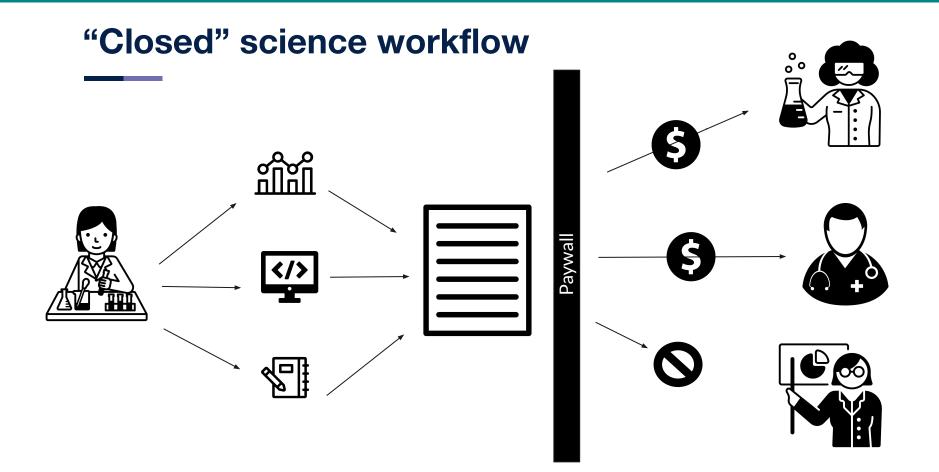
Learn how to properly organize, document, and share your research data for reproducibility.

Today's Talk

- Explore Open Science
- COVID-19 & Open Access
- COVID-19 & Open Data
- Unpack Ethical Issues

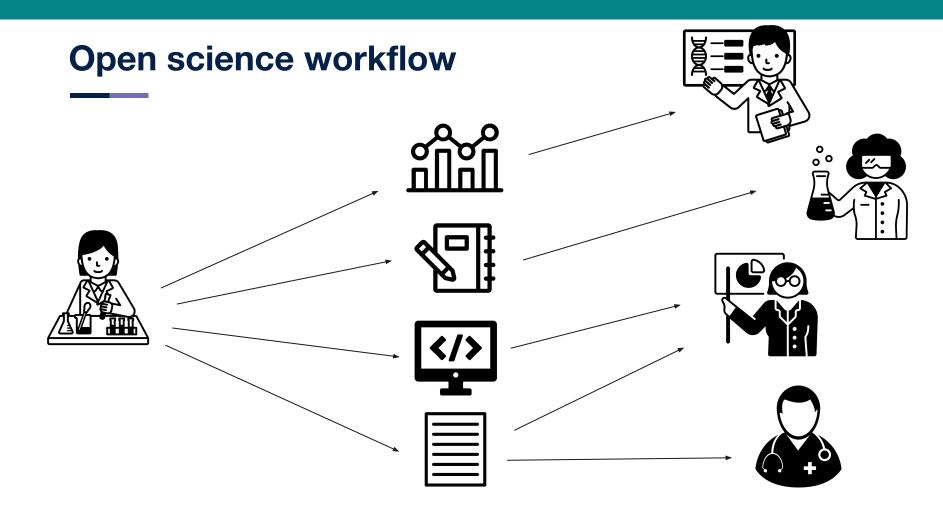
What is open science?

(slides from Open Science 101 co-developed with Anneliese Taylor)



"Open science is the movement to make scientific research, data, and dissemination accessible to all levels of an inquiring society."

- FOSTER Open Science



Open Science =

Open Access Open Data Open Methods Open Protocols Open Source Open Code Open Educational Resources **Open Pedagogy**

Why practice open science?

Requirements - this is an evolving area!

- Funders:The NIH has had an open access mandate for
publications since 2008 and a genomic data sharing
mandate since 2014. Will likely have a comprehensive
data sharing mandate by the end of 2021.
- Institutions: The University of California also has an open access mandate
- Journals: Several journals (PLOS, Nature, Science) now require open data to publish.

Get Credit for your Work!

You work hard on your data, code, and methods and they should be recognized as citable research outputs that go on your CV

Making your work open leads to more citations for your articles:

- <u>Piwowar et al.</u> found that articles published as open access receive
 18% more citations than average
- <u>A study from Colavizza</u> et al. showed that studies that provide access to underlying **data** are **cited up to 25% more often** than those that don't.

Reproducibility

"A second barrier to computational reproducibility is the lack of sharing or insufficient sharing of the full compendium of artifacts necessary to rerun the analysis, including the data used, the source code, information about the computational environment, and other digital artifacts."

- National Academy of the Sciences report on Reproducibility and Replicability (p 57)

To promote equity and social justice

- Not everyone can afford access to paywalled content
- Consider international and unaffiliated researchers, clinicians, journalists, citizen scientists, members of the public!
- UCSF's mission "Advancing health worldwide"
- PRIDE values: professionalism, respect, integrity, diversity, excellence

COVID-19 & Open Access

Preprints take the stage



THE PREPRINT SERVER FOR BIOLOGY

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bioRxiv is receiving many new papers on coronavirus SARS-CoV-2. A reminder: these are preliminary reports that have not been p practice/health-related behavior, or be reported in news media as established information.

COVID-19 SARS-CoV-2 preprints from medRxiv and bioRxiv

6243 Articles (4967 medRxiv, 1276 bioRxiv)

Preprint about COVID-19 preprints

Preprinting a pandemic: the role of preprints in the COVID-19 pandemic

🔟 Nicholas Fraser, 🔟 Liam Brierley, ២ Gautam Dey, ២ Jessica K Polka, ២ Máté Pálfy, ២ Jonathon Alexis Coates

doi: https://doi.org/10.1101/2020.05.22.111294

This article is a preprint and has not been certified by peer review [what does this mean?].

"in just 4 months following the first case of COVID-19, 2,527 preprints have been posted to bioRxiv and medRxiv alone, and >40% of the total COVID-19 literature to date has been posted via preprints"

The literature unlocked!



The NEW ENGLAND JOURNAL of MEDICINE

SPECIALTIES TOPICS MULTIMEDIA CURRENT ISSUE LEARNING/CME AUTHOR CENTER

Welcome to Elsevier's Novel Coronavirus In find expert, curated information for the res SARS-CoV-2 (the novel coronavirus) and CC

All resources are free to access and include patients.

Coronavirus (Covid-19)

A collection of articles and other resources on the Coronavirus (Covid-19) outbreak, including clinical rep

All Journal content related to the Covid-19 pandemic is freely available.

See our directory of all Elsevier's COVID-19 resources >

For Now



ICOLC COVID19 Complimentary Expanded Access Specifics 🛛 🔅 🙆

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27	EDP Sciences	31 August 2020	https://www.edpsciences.org/en// privacy-policy	Fri Apr 3 2020	ISP Respor	
28	Elsevier	31 August 2020	https://privacy.elsevier.com/	Sun 15 Mar 2020	ISP Respor	
29	Érudit	To be determined	https://apropos.erudit.org/en/imp lementation-of-a-privacy-policy/	Mon Mar 30 2020	ISP Respor	
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Who decides when the COVID-19 literature is no longer open?

Why COVID-19 and not Ebola? Cancer? Alzheimer's?

COVID-19 & Open Data

Explosion in COVID-19 public data

COVID-19 Research and Information Resources

Search this Guide Search

A guide to COVID-19 research resources and datasets

Home COVID-19 Data and Dashboards

COVID-19 Literature & Multimedia
Research Data
Genomic Data
Epidemiological Data + Dashboards
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Patient Information

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Ariel Deardorff

Clinical Data

UCSF COVID-19 Clinical Data

UCSF COVID-19 Research Data Mart with IRB approval (IRB #20-30545, COVID-19 collaborative study for prospective and retrospective computational analysis). This will facilitate access for UCSF researchers who would like access to these identified data for research. Data extracts from the UCSF Electronic Health Record System (APeX) include patients who have been tested for or diagnosed with COVID-19.

Vivli

Clinical trial data repository - working on adding and curating data from COVID-19 trials

ClinicalTrials.gov COVID-19 Trials

A collection of registered clinical studies related to COVID-19

• Coronavirus Clinical Trials Explorer

Interactive map and database of clinical trials related to COVID-19

STAT's COVID-19 Drugs and Vaccines Tracker

STAT's guide to some of the most talked-about efforts to treat or prevent coronavirus infection, with details on the science, history, and timeline for each endeavor.

Epidemiological Data + Dashboards

San Francisco COVID-19 Data

Data and reports from the city of San Francisco related to COVID-19 including cases and deaths, demographics, lab

Submissions increasing to data repositories



CAREER FEATURE · 19 MAY 2020 · CORRECTION 28 MAY 2020

Six tips for data sharing in the age of the coronavirus

Researchers are rushing to pool resources and data sets to tackle the pandemic, but the new era of openness comes with concerns around privacy, ownership and ethics.

New Incentives for sharing

More than 2,800 observational clinical trials for COVID-19 treatments are currently listed by the global Cochrane COVID-19 Study Register; Humphreys says that a switch to greater sharing is key to developing a successful treatment by the end of 2020. "Researchers are more worried now about making sure their data are available, so their profile is raised as opposed to their not getting credit for it," she says.

But speed can come with a cost

Anonymize personal information. When depositing data concerning human study participants, make sure you have the appropriate ethical and legal approvals, says Lowenberg. The data must be properly anonymized and de-identified. "A majority of submissions of COVID-19 data have required major revisions because they contained tons of personally identifying information," she says – such as patients' names and entire health records. This information cannot be shared, and must be removed.

Speed and questionable data

THE LANCET

COMMENT | VOLUME 395, ISSUE 10240, P1820, JUNE 13, 2020



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PDF [42 KB]

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Retraction—Hydroxychloroquine or chloroquine with or without a macrolide for treatment of COVID-19: a multinational registry analysis

Mandeep R Mehra 🖾 🛛 Frank Ruschitzka 🔹 Amit N Patel

Published: June 05, 2020 • DOI: https://doi.org/10.1016/S0140-6736(20)31324-6 •



Check for updates

Log in

COVID-19 pressures exacerbate ongoing issues

- How are research participants consenting to data sharing?
- How do we correctly de-identify research data?
 - Qualitative data?
 - Genomic data?
- Who is curating the data? Is it usable?
- Who owns research data? Who benefits from research?
- Who can access data? Everyone? Researchers?
- Is it ethical to keep research data locked away?

How do we balance participant privacy, research collaboration, and speed?

Questions for you

- 1. How does openness fit into your research goals?
- 2. Has COVID-19 changed your relationship with preprints and open data?
- 3. What other ethical questions surround open science?

How can the Library Help?

Want to learn more about open science, data sharing, data management, publishing, literature searching, or data science? Why not:

- Sign up for a workshop
- <u>Check out class materials online</u>
- Meet with a librarian
- Sign up for a monthly newsletter

Got an ideas for other ways to collaborate? Get in touch!



Anneliese Taylor, Head of Scholarly Communication, UCSF Library Jill Barr-Walker, Clinical Librarian, UCSF Library

Questions for me?

Let's chat! ariel.deardorff@ucsf.edu