# Data Sharing: Why is it still so hard?

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### Data Types

### Raw

- GT3X
- CWA
- Bin files

### Raw-ish

- HDF5
- CSV gzipped vs. not



Some need applications/licenses - ideal to have open source solutions to open

# Data Types

### Interpolated/Filtered/Aggregated

- What epoch?
  - 1 second?
  - 5 second?

- Measure to use?
  - $r = \sqrt{(x^2 + y^2 + z^2)}$
  - Mean of x, y, z?
  - Variance?

Can't invert these - can't go back!



### **RAW**

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  - 5 second?

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### **Journals: Guidelines**

- Data Availability Upon Request

- Have it "somewhere"

OR





### But where?

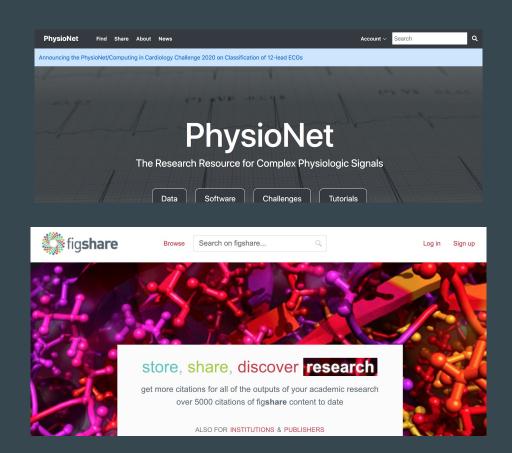
Example of biologically-related repos

- Physionet

#### General data

- Figshare
- Zenodo
- Synapse
- Datacite

What are your other favorites?



# Get a Digital Object Identifier (DOI)

Make sure it's

- FAIR - Findable, Accessible, Interoperable, and Reusable

But our commodity is paper/citations (it's true, so needs):

- Citable



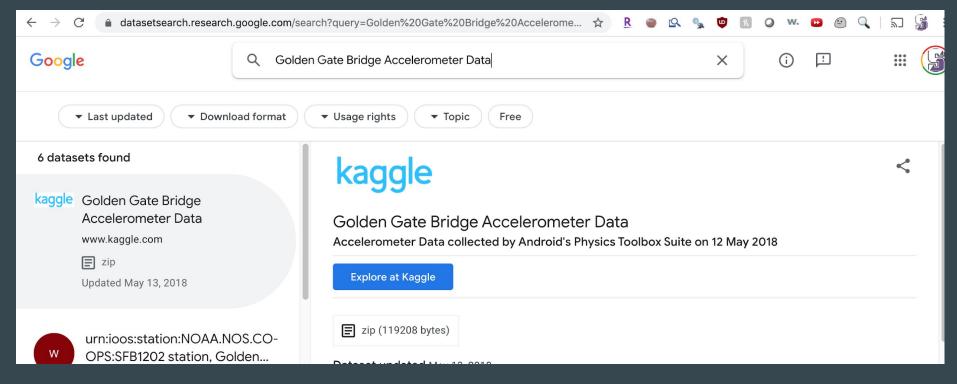
# **Funding Agencies**

- No central repository
- Other fields (e.g. genomics) have one that you \*need\* to put in
  - dbGaP https://www.ncbi.nlm.nih.gov/gap/

One of the main issues starting one: funding



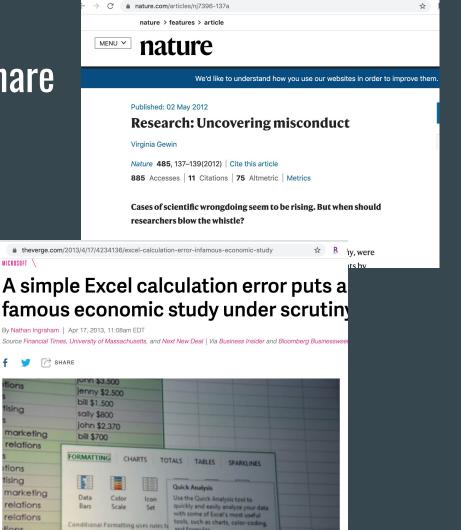
# Searching can be hard: https://datasetsearch.research.google.com/



# Downsides: Why people don't share

### Issue with non-replicability

- People see if your results replicate
- High-profile examples of errors
  - https://www.theverge.com/2013/4/ 17/4234136/excel-calculation-erro <u>r-infamous-economic-study</u>
  - https://www.nature.com/articles/n i7396-137a
- It's a Legitimate concern, but
  - Want to do good science or not be wrong?



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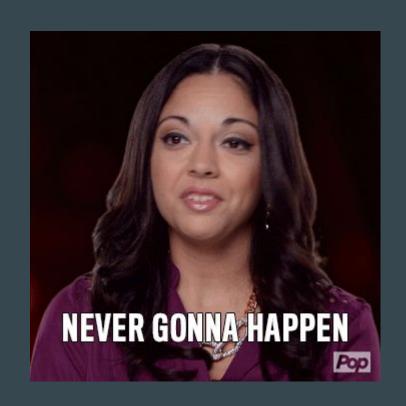
# **Downsides: Why people don't share**

### Many excuses

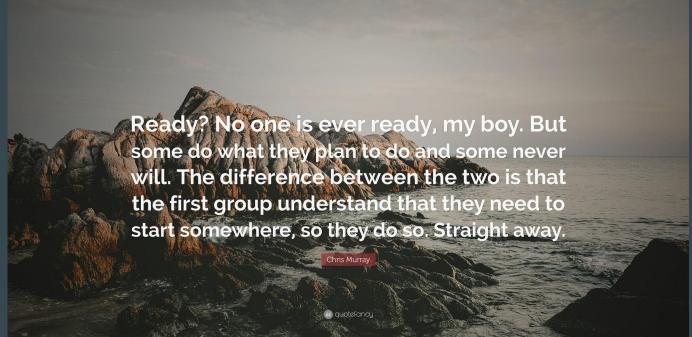
- "I wanted to do that analysis", but
   many times →
- They'll scoop me

# PRIMARY DATA COLLECTORS SHOULD GET PRIORITY

- But the embargo time can't be ∞
- 5 years?
- What if publicly-funded?



# Why people don't share: I'm not ready yet



https://quotefancy.com/quote/1655560/Chris-Murray-Ready-No-one-is-ever-ready-my-boy-But-some-do-what-they-plan-to-do-and-some

### **Upside: Why should you still share**

### Replication

 Other researchers are helping identifying issues in your dataou with your data

#### More citations

- Hopefully good ones or people finding new things
- Consortia UK Biobank

### Pushing science



# **Upside: Why should you still share**

### Data Aggregation

- You have data X, I have data Y
- Can show better out-of-sample validity,
   or .... you can have MORE POWER:





### Consent

Make sure your study documents have this in the language

- Talk to your local IRB
- Ask others
- Ask the repository
- Ask the funders



### De-identification/Anonymization

LOADS of open questions - what is "identifiable"?

HIPAA stuff obviously,
 but what about

Gait?

GPS?

Data also hides in things sometimes (e.g. header of gt3x)



See

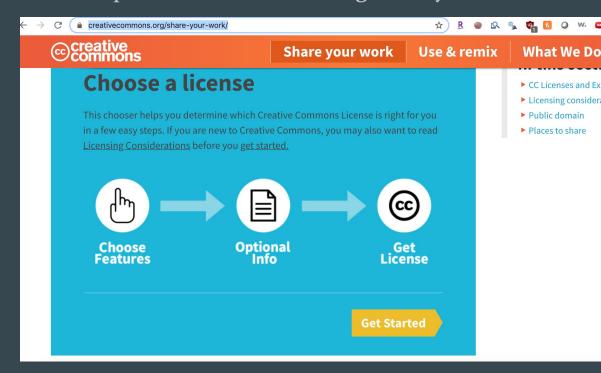
### Licenses:

https://help.data.world/hc/en-us/articles/115006114287-Common-license-types-for-datasets for help

Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0)

- MIT
- Apache
- BSD
- GPL

https://creativecommons.org/share-your-work/



### Open Data

Upper limb activity of twenty myoelectric prosthesis users and twenty healthy anatomically intact adults.

- <a href="https://springernature.figshare.com/collections/Upper\_limb\_activity\_of\_twenty\_m">https://springernature.figshare.com/collections/Upper\_limb\_activity\_of\_twenty\_m</a>
<a href="your springernature.figshare.com/collections/Upper\_limb\_activity\_of\_twenty\_m">your springernature.figshare.com/collections/Upper\_limb\_activity\_of\_twenty\_m</a>
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Newcastle polysomnography and accelerometer data

- https://zenodo.org/record/1160410

### Open Data: Why I care

Having open data allows us to make tutorials/workflows for:

- 1. Our Students
- 2. Students in our courses
- 3. Software packages
- 4. Collaborators
- 5. The rest of science

(But maybe gives away "secret sauce")



# If you're releasing data, see if

- Can you read it open source
  - gt3x files (R: <u>AGread</u>, <u>read.gt3x</u>,
    - Python: <u>ActiGraph-ActiWave-Analysis</u>)
  - Most other file types: <u>GGIR</u> (e.g. Axtivity CWA)
  - Everything can read CSV
  - Mostly everything can read HDF5 can do ALL of these
- Data Structure/naming convention: BIDS
  - https://www.openmhealth.org/schemas/omh\_acceleration/



# Gifs/Images

- https://imgur.com/gallery/Cr2L8s1
- https://painepublishing.com/measurementadvisor/wp-content/uploads/sites/4/2018/03/too-much-data.jpg
- <a href="https://medial.giphy.com/media/G5X63GrrLjjVK/giphy.gif?cid=ecf05e4780a131d84268014d0b5604c95823">https://medial.giphy.com/media/G5X63GrrLjjVK/giphy.gif?cid=ecf05e4780a131d84268014d0b5604c95823</a> <a href="mailto:e8fc843a62e2&rid=giphy.gif">e8fc843a62e2&rid=giphy.gif</a>
- https://media.giphy.com/media/9LZpYKd2CmV6ICxs17/giphy.gif
- https://media.giphy.com/media/3oz8xRD1irfRHMnVD2/giphy.gif
- https://media.giphy.com/media/3orifdO6eKr9YBdOBq/giphy.gif
- https://media.giphy.com/media/l41Yr7JNU9U7upjNu/giphy.gif
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- https://media.giphy.com/media/26AHPxxnSw1L9T1rW/giphy.gif
- https://media.giphy.com/media/WUCeN3kP3X3JZu52vg/giphy.gif

# Thanks!