

east africa open science training

2018 nov

data resources

responsible openness

brian m. bot | principal scientist | sage bionetworks

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why - and what does this mean?

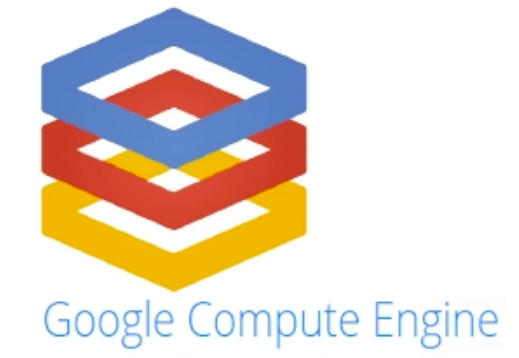
funding agencies looking for maximal return on investment

traditional research conducted only for a single researcher to understand

moving towards an ecosystem where research needs to be conducted for others to consume (beyond just publication)

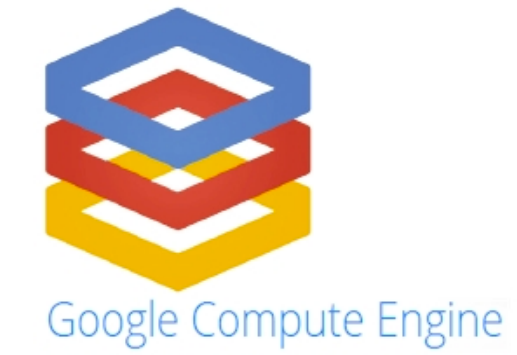
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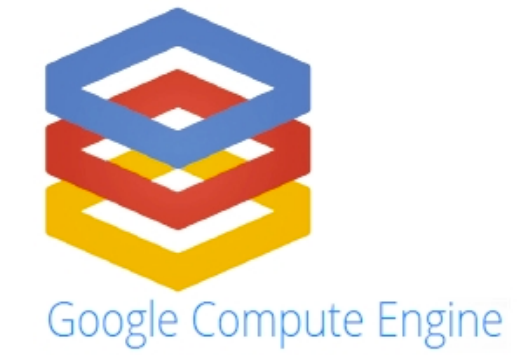


domain specific



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domain specific



results



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domain specific



results



protocols, specimens, university-specific, etc., etc.

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digital object identifier (doi)

a unique identifier which remains fixed over the lifetime of a web-accessible object

metadata, including the object's location, is stored in association with the doi and may change over time

referring to an online document by its doi provides more stable linking than simply referring to a url

ethical issues around 'open' data

responsible openness

human subjects research

“the systematic, scientific investigation that can be either interventional (a "trial") or observational (no "test article") and involves human beings as research subjects”

declaration of helsinki

established in 1964 by the world medical
association, the declaration recommended
guidelines for medical doctors
conducting biomedical research that
involves human subjects

belmont report: 3 standards

beneficence (ethics): maximizing the benefits of research while minimizing any possible risks - and inform participants of both

justice: selection process of the subject is supposed to be fair and not separate due to race, sexual orientation or ethnic group

respect for persons: participants being autonomous and persons with diminished autonomy to be entitled to protection

informed consent

the process of allowing potential participants to make an informed decision about whether or not to join a study

1. description of study
2. risks
3. benefits
4. alternatives to participation
5. compensation (if any)
6. who to contact with questions
7. reiterate that participation is voluntary and providing a procedure for withdrawal

ability to share

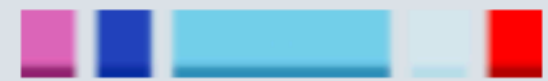
informed consent can dictate extent to which sensitive data can be shared

levels of 'open'

- fully open
- controlled access
 - agree to terms
 - fulfill additional terms (ethical oversight, IRB, etc.)

example of controlled access

nature
biotechnology



Altmetric: 274 Citations: 11

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Commentary | **OPEN**

First, design for data sharing

[John Wilbanks](#) & [Stephen H Friend](#) 

To upend current barriers to sharing clinical data and insights, we need a framework that not only accounts for choices made by trial participants but also qualifies researchers wishing to access and analyze the data.

qualified researcher program core principles

- balance privacy with participant's desire for reuse
- emphasize transparency
- cultivate a clear set of norms for working with participant-donated data
- assess data requester's knowledge of basic research ethics
- emphasize return of information to participants and the research community

qualified researcher process

- demonstrate awareness / understanding of data-sharing framework and applied ethics
- validate identity
- a public statement of intended data use (transparency for participants)
- agree to a 'contract' of data sharing, including conditions specific to data collected (i.e. 'do not attempt to re-identify participants')

qualified researcher process: example

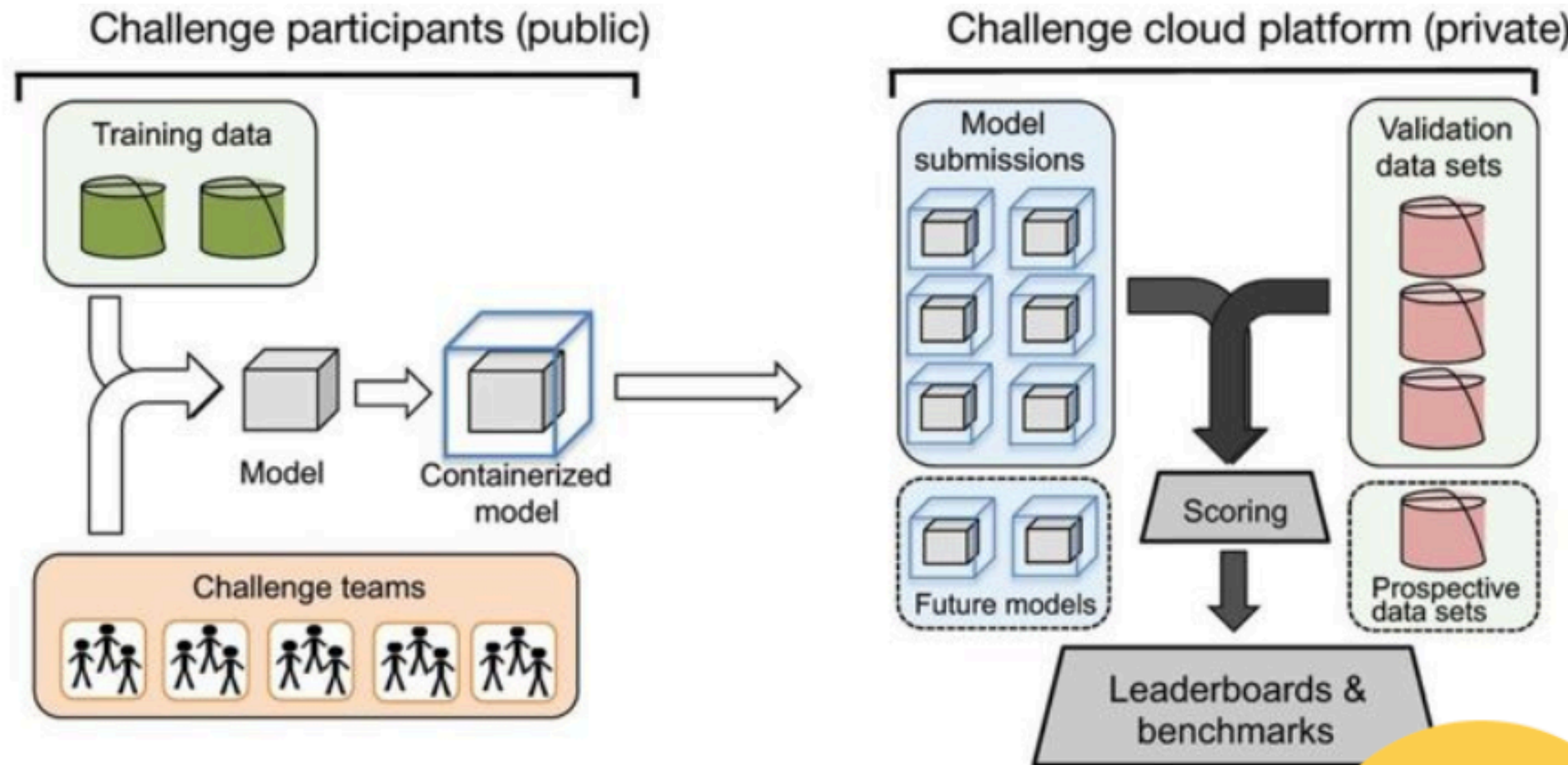
after lunch topic ;)

ways of 'accessing' sensitive data

model-to-data = model portability + model scalability



ways of 'accessing' sensitive data



"alternative models for sharing confidential biomedical data." guinney & saez-rodriguez. nature biotech 2018