

CTD Sharing: Looking forward to incentivizing data sharing and reuse, an institutional perspective

Value, responsibility, caring

Sharing CTD, NASEM, 2019-11-19

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* The views expressed herein are those of the presenter and not necessarily her institution.



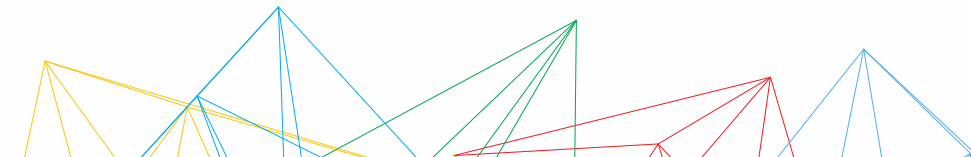
**MIT
Libraries**

Is the value of data sharing worth the cost?

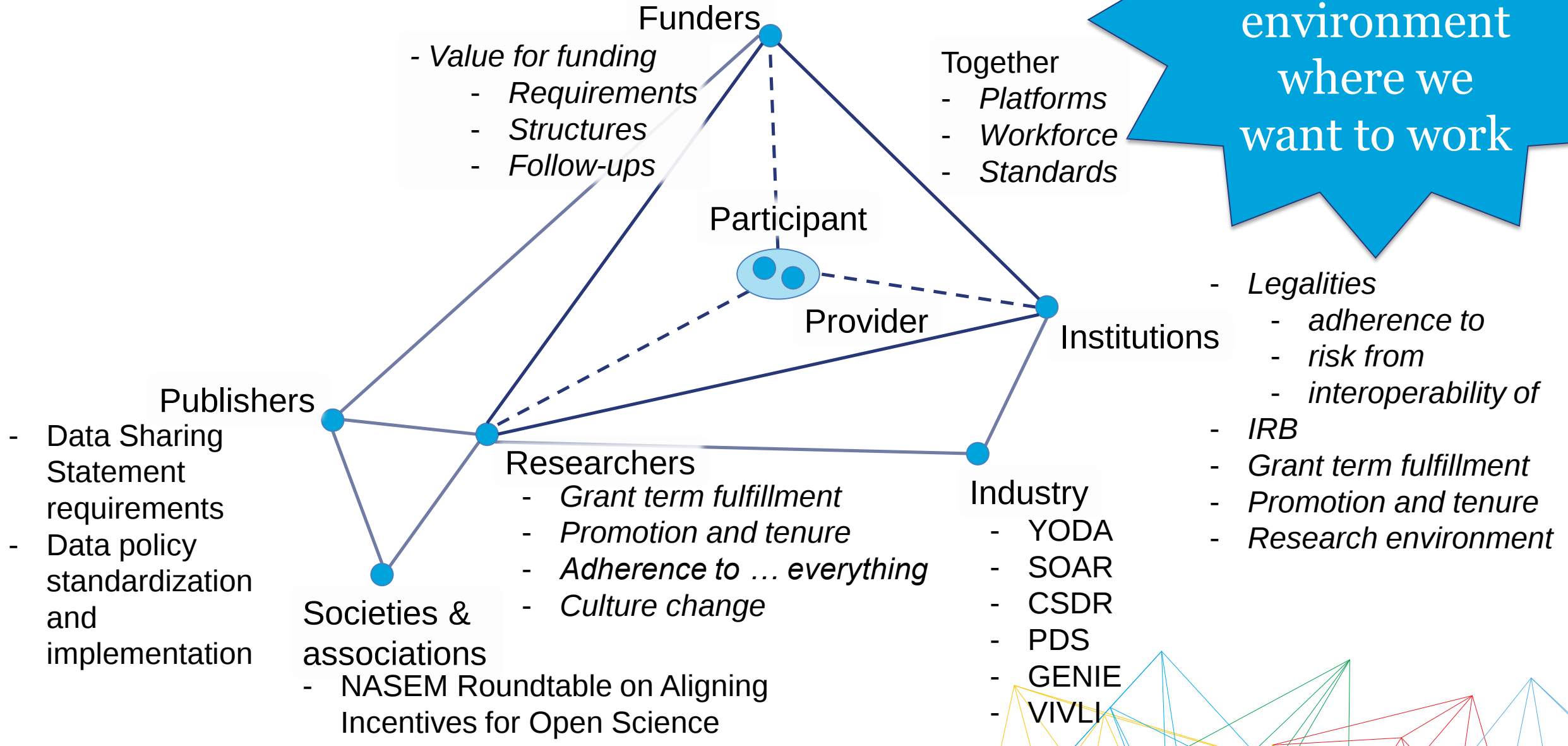
YES! ...but
...not quite yet,
Because we have
some major
Infrastructure debt

Clinical trial data needs to be:

- FAIR
 - Personal Health Train
- Creditable, as a unique product
 - Make Data Count
- Trustable/Fit for use
 - Data Nutrition Project & Data, Responsibly
- Managed by data/inf professionals
 - EDISON



Who's responsible? For what?



#BeFAIRandCARE

C – Collective benefit: Data ecosystems shall be designed and function in ways that enable the participant community to derive benefit from the data

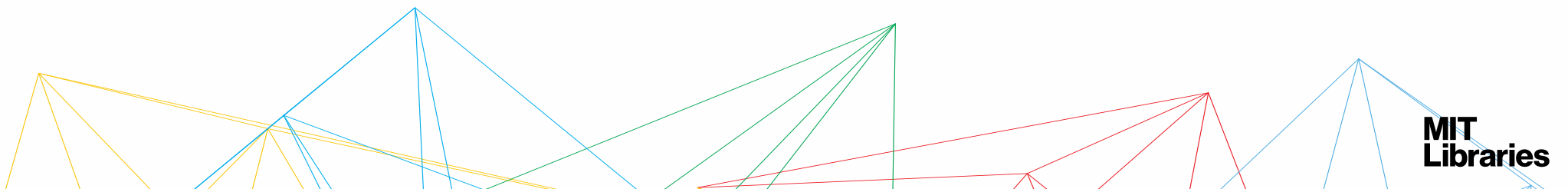
A – Authority to control: Participant community's rights and interests in their data must be recognised and their authority to control such data be empowered. The participant community's data governance enables the participant community and governing bodies to determine how the participant community, as well as their lands, territories, resources, knowledges and geographical indicators, are represented and identified within data.

R – Responsibility: Those working with the participant community's data have a responsibility to share how those data are used to support the participant community's self-determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to the participant community.

E – Ethics: The participant community's rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

WHAT ARE WE WILLING TO LOSE?

Thank you.



Sources & Resources

Territorial acknowledgement: <https://native-land.ca/>

Ranganathan's Five Laws of Library Science:
https://en.wikipedia.org/wiki/Five_laws_of_library_science

Definition of data management: "If the data you need still exists..." by Rex Sanders
<https://rexsanders.weebly.com/if-the-data-you-need-still-exists.html>

Personal Health Train (Dutch Techcentre for Life Sciences): [WARNING! Link hacked. Maybe fixed now?] <https://www.dtls.nl/fair-data/personal-health-train/>

Getting credit for data (via specific citation!): <https://makedatacount.org/>

Achieving human and machine accessibility of cited data in scholarly publications
<https://doi.org/10.7717/peerj-cs.1>

Data Nutrition Project: <https://datanutrition.media.mit.edu/index.html>

Data, Responsibly: <https://dataresponsibly.github.io/>

Education for Data Intensive Science to Open New science frontiers (EDISON): <http://www.uazone.org/demch/presentations/edison2019-07-slides-deck-v06.pdf> &
https://github.com/EDISONcommunity/EDSF/blob/master/data-science-professional-profiles/EDISON_DSPP-release3-v07.pdf

ICMJE data sharing statement requirements: Taichman, D. B., Sahni, P., Pinborg, A., Peiperl, L., Laine, C., James, A., ... & Frizelle, F. A. (2017). Data sharing statements for clinical trials: a requirement of the International Committee of Medical Journal Editors. *Annals of Internal Medicine*, 167(1), 63-65.
<https://www.nejm.org/doi/full/10.1056/NEJMe1705439>

Data policy standardization: <https://www.rd-alliance.org/groups/data-policy-standardisation-and-implementation-ig>

Roundtable on Aligning Incentives for Open Science:
<https://www8.nationalacademies.org/pa/projectview.aspx?key=51293>

MIT Open Access Task Force recommendations: <https://open-access.mit.edu/sites/default/files/OA-Final-Report.pdf>

Time spent on data sharing: Wilhelm, E. E., E. Oster, and I. Shoulson. 2014. Approaches and costs for sharing clinical research data. *JAMA* 311(12):1201-1202. doi:10.1001/jama.2014.850.

European Commission numbers:
https://ec.europa.eu/research/openscience/pdf/realising_the_european_open_science_cloud_2016.pdf#view=fit&pagemode=none & <http://e-irg.eu/news-blog/-/blogs/we-need-500-000-respected-data-stewards-to-operate-the-european-open-science-cloud>

CARE Principles: <https://www.gida-global.org/care>

Twitter comment: <https://twitter.com/ImmunoFever/status/1194677460714917888>

The data cartoon: Data Sharing and Management SNAFU in 3 Short Acts
<https://www.youtube.com/watch?v=N2zK3sAtr-4> by NYU Health Sciences Library, CC By

Research Data Alliance (where data conversations are happening!): <https://www.rd-alliance.org/>

