CONSIDERATIONS FOR COMMUNITY ENGAGEMENT IN GENOMICS FOR INDIGENOUS PEOPLES

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Avoid “Engagement Washing”

ETHICS WASHING

Making false or misleading claims by **adopting language resembling ethical behavior** to improve public perception **while perpetrating unidirectional or ‘top-down’ power authority.**

It can involve being vocal about ethics without taking meaningful action.

ENGAGEMENT WASHING

When researchers recognize the ethical and epistemological imperative to engage with stakeholders but **<u>pursue such engagement only to satisfy reputational aims to maintain the status quo</u>.** This compromises processes of moral inquiry and often results in stakeholders being engaged with in a limited, perfunctory, or tokenized manner.

Example: Using “engagement” to describe recruitment but not changing decision-making authority

Buskell A, Tsosie KS. *Amer J Biol Anth.* Pending.

IN PRACTICE:

Community engagement can be challenging:

- Lack of researcher training in engagement methods and qualitative training
- Lack of local research infrastructure
- Difficult to identify local key experts
- Lack of consensus when many communities involved
- Conflicting institutional (e.g. university, NIH) vs community policies

Situating engagement within current practices can be challenging:

- Publish-or-perish
- Grant funding does not adequately fund engagement
- Researchers not cross-trained in community engagement

<u>IN PRACTICE:</u>

It is much easier to default to minimum standards than actual engagement.
But is this truly ethical?

SCIENCE ADVANCES | RESEARCH ARTICLE

HUMAN GENETICS

Identifying a living great-grandson of the Lakota Sioux leader Tatanka Iyotake (Sitting Bull)

Ida Moltke[1†], Thorfinn Sand Korneliussen[2,3†], Andaine Seguin-Orlando[2,4,5†], J. Víctor Moreno-Mayar[2], Ernie LaPointe[6], William Billeck[7], Eske Willerslev[2,8,9,10*]

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MATERIALS AND METHODS

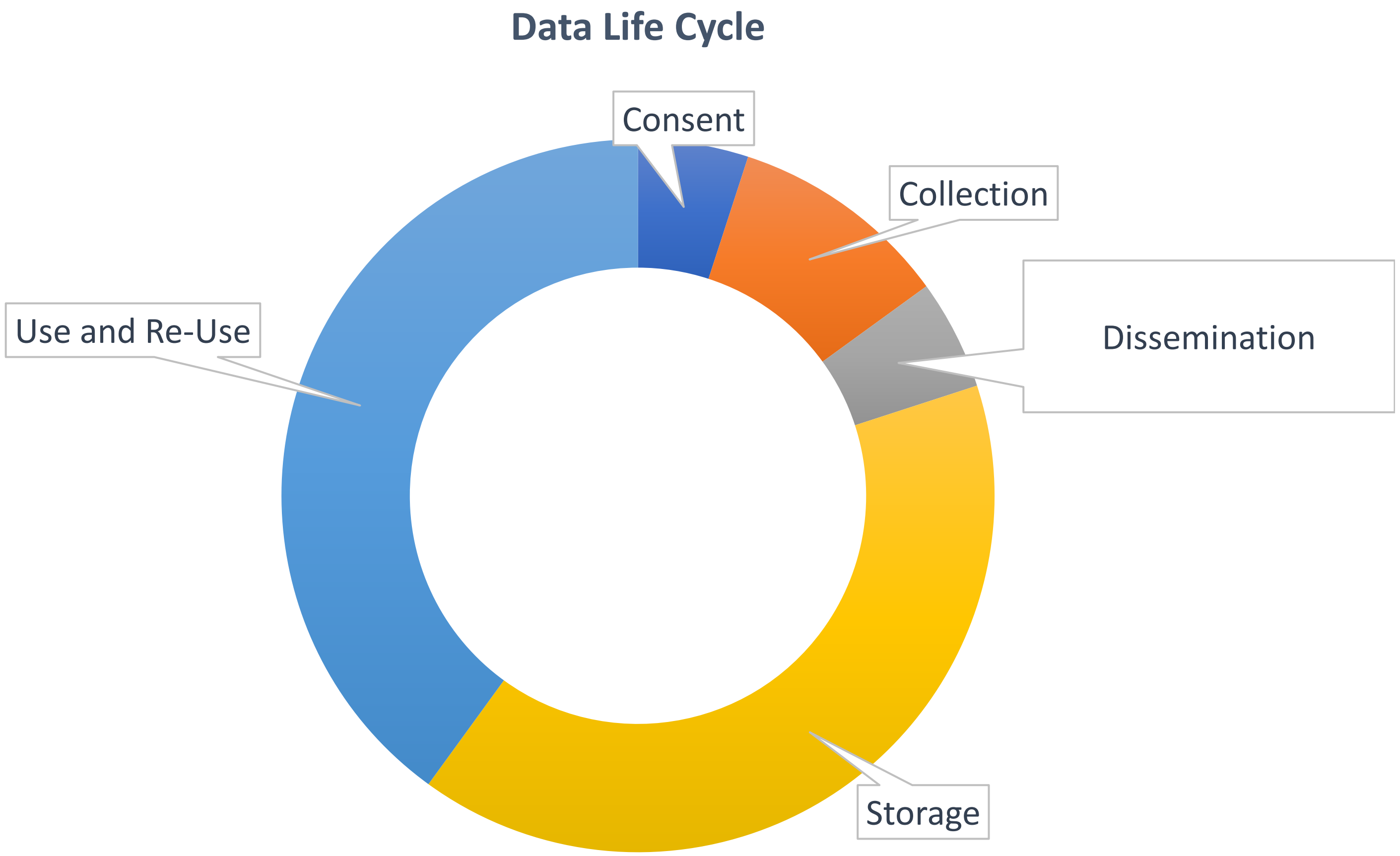
Ethics statement

We note that permission or consent for the study was not sought from the Standing Rock Sioux Tribe, which would be the modern-day tribe of Sitting Bull. However, the Tribal Chair and the Tribal Historic Preservation Officer of the Standing Rock Sioux Tribe **were informed of the study and its results in <u>August 2020 via email. They have not replied.</u>**

- Sometimes, community engagement is treated as a spectrum, in which one act of including community in the research process is still called ”engagement”
- Tribal Nations have been aware of this language bait-and-switch
- Advocate for community-driven research as opposed to community engaged research

Tribal disengagement	Tribal-trust relationship	Non-tribal partnership	Tribal partnership	Tribally-driven research
Tribe Does Not Engage in Research	**Tribe Has NO or LITTLE Ownership or Stewardship**	**Tribe Has SOME Ownership or Stewardship**	**Tribe Has COMPLETE Ownership or Stewardship**	**Tribe Has COMPLETE Ownership or Stewardship**
Tribe actively chooses not to participate in research.	An outside entity makes the decisions on the collection, storage, and usage of data from the Tribe.	The Tribe might contract or partner with an outside entity to assist with collection, storage, and usage of data.	Native 3rd party works for Tribe. Confidentiality, trust. Full ownership of data. Education and expertise needed.	The Tribe retains control and responsibility over the collection, storage, and usage of data.
No data collected from the Tribe to regulate.	Tribal leaders and members have no to little input on this process.	Tribal leaders and members have some control over this process.	Tribal leaders have control over this process.	Tribal leaders have total control over this process.
NULL MODEL	MODEL 1	MODEL 2	MODEL 3	MODEL 4

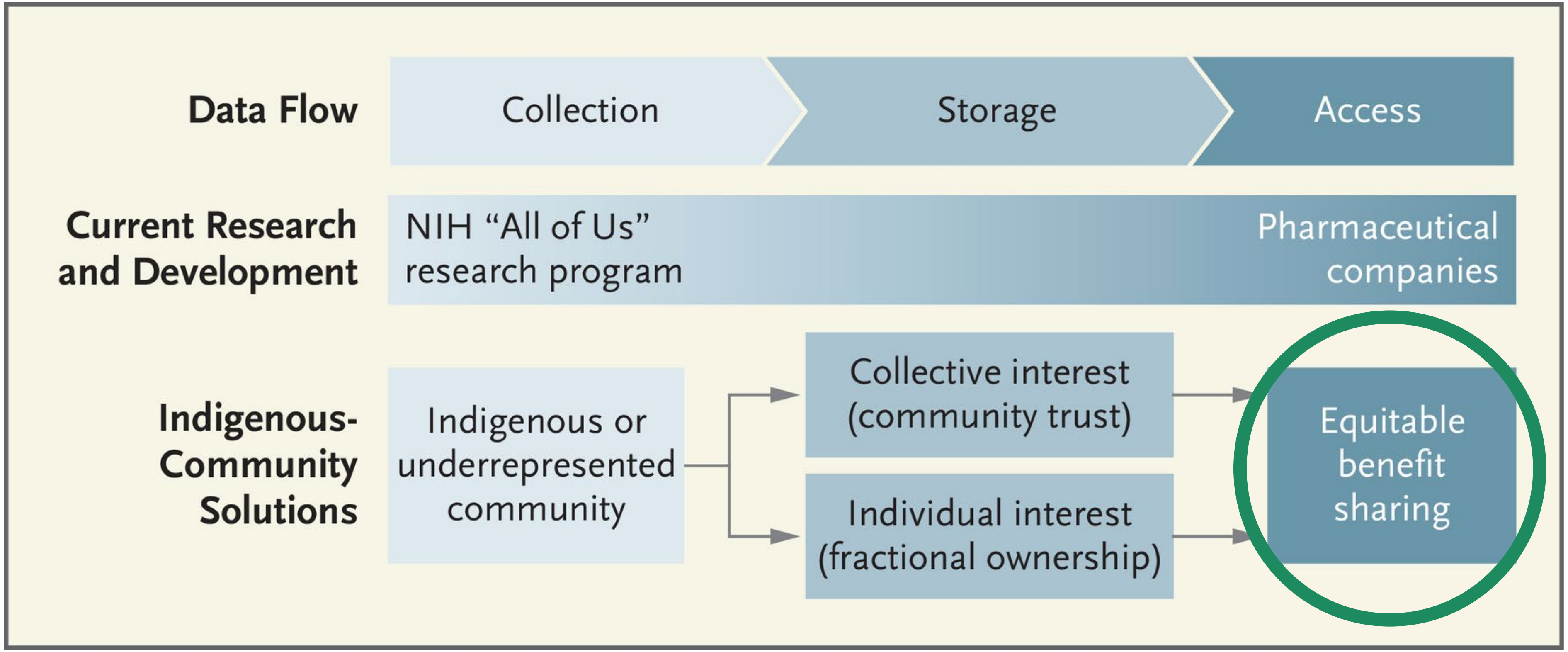
Tsosie KS, Yracheta JM. Pending.



- Community engagement must consider that, for much of the lifespan its lifespan, data persists in the dissemination/storage/use/re-use stage
- Therefore, we cannot consider engagement for only the initial steps of the data lifecycle
- The risks for small, underrepresented groups related to genomics data (e.g., re-identifiability, genomic racial profiling, and circumvention of group consent) is higher than other data types.

CONSIDER WHETHER THE BENEFITS OF RESEARCH ARE EQUITABLE

Credit: Fox 2020



Data Flow: Collection → Storage → Access

Current Research and Development: NIH “All of Us” research program → Pharmaceutical companies

Indigenous-Community Solutions: Indigenous or underrepresented community → Collective interest (community trust) / Individual interest (fractional ownership) → Equitable benefit sharing

- In considering the data lifecycle, the rules of access and innovation solely benefit universities (Baye-Dole Act) and industry, not communities
- If communities are contributing data that bring innovation, they should also benefit

Selling the Next Innovations in Precision Medicine as a Benefit Does Not Work for Communities Who Do Not Have Equitable Access to Preventative Health

"In 2018, Indian Health Services spent an average of $3,779 per patient.
The national spending per capita that same year was $9,409"
National Indian Health Board

Cycle of Victim-Blaming and Coercion

Indigenous people are told they will miss precision health benefits if they do not engage, without changes to power imbalances creating research harms

Indigenous people disengage from genomic research due to research harms

Open Peer Commentaries

We Have "Gifted" Enough: Indigenous Genomic Data Sovereignty in Precision Medicine

Krystal S. Tsosie, Joseph M. Yracheta, Jessica A. Kolopenuk & Janis Geary

Pages 72-75 | Published online: 07 Apr 2021

Merely making clinical genetic tests available is not going to solve the equity problem.

It is not “profit-generative” to use Indigenous peoples’ DNA to create therapeutics that specifically impact Indigenous peoples.

What pharmaceutical companies told Indigenous scientists

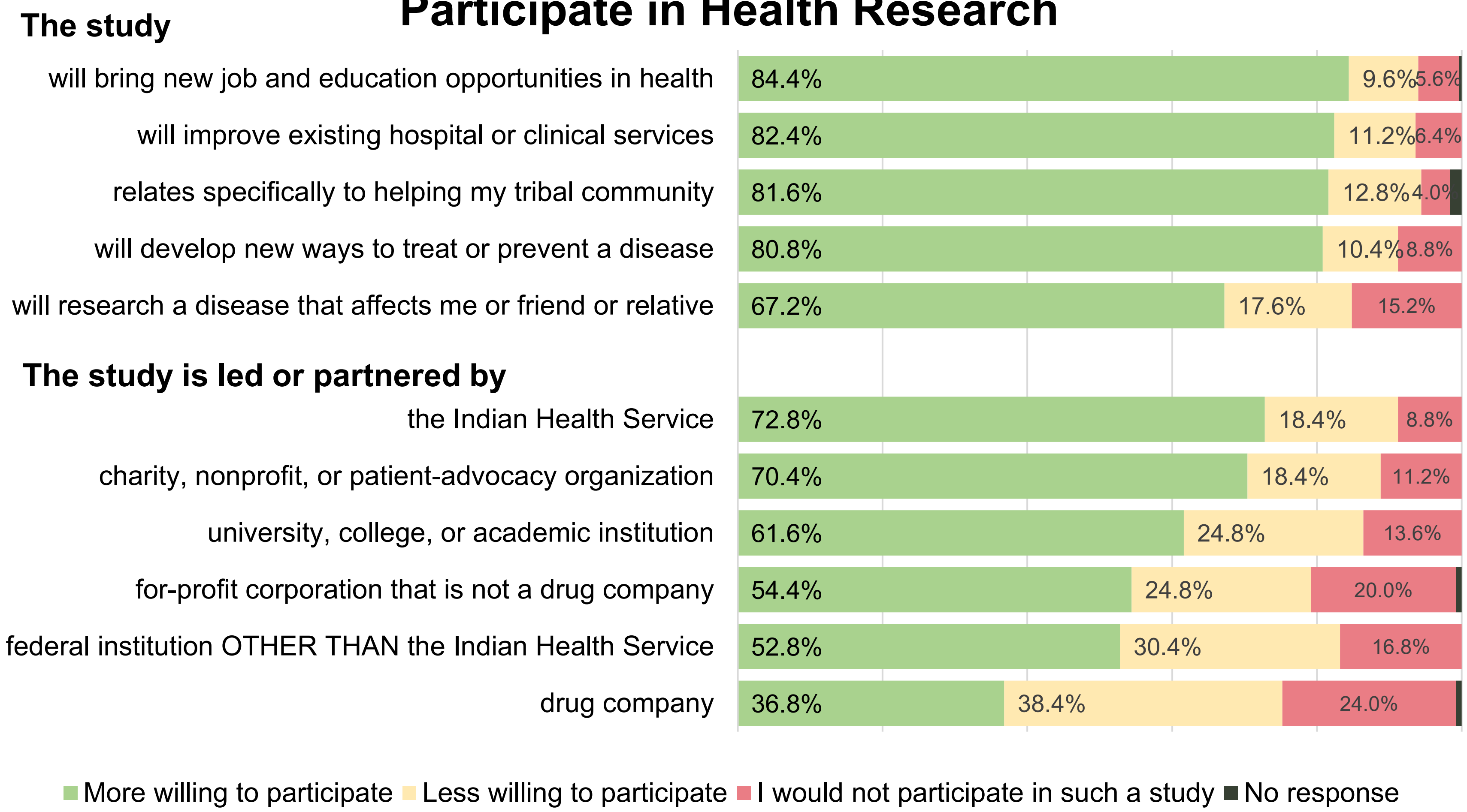
Recruiting more Indigenous peoples into datasets is not going to solve the health inequity problem.

Dropping genetic tests into our communities is not going to solve the health inequity problem.

- Tribal community member rated job and education opportunities created by health research higher than benefits from researching a disease or condition.
- Pharmaceutical companies and federal biomedical institutions were rated last in terms of trustworthiness.

Factors Considered when Deciding Whether to Participate in Health Research

Tsosie et al 2022



Tribal Non-Profit Governance of Tribal Data

- Many US Tribes do not participate in federally-funded research
- A Tribally-managed biorepository could change that trust dynamic (“data trusts”)
- Tribal organization, under geographic and legal jurisdiction of Cheyenne River Sioux Tribe, houses and governs data from Tribal members of partner communities
- Research oversight by Sitting Bull College IRB, a TCU-based entity
- Board of Directors and Community Advisory Board are Indigenous scientists and members

Native BioData consortium

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Tsosie Lab for Indigenous Genomic Data Equity and Justice