Research Goals

Considerations include: What evidence do we need to test hypotheses? What expertise?

Nature of Collaboration

Considerations include: How sensitive are the data? Who leads negotiation?

Governance Structures

Considerations include: What contract language do we use? What interface?

Pairwise

Open Source

Open Citizen Science

Federated Query

Model-to-Data

Trusted Research Environment

Club/Trust

Governance Design Patterns

IP and Contracts

Data Type

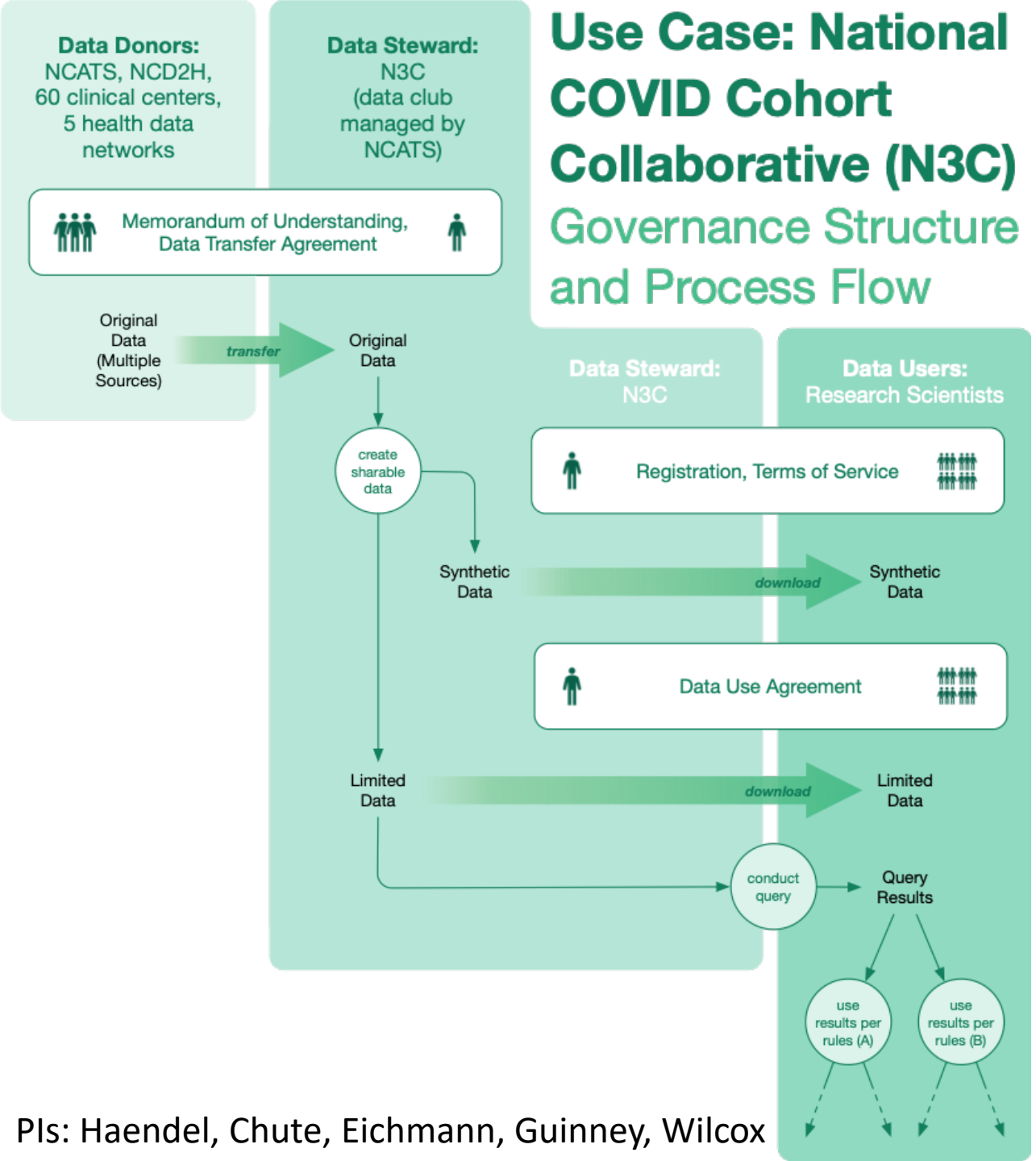
Data Collection Mechanisms

User Qualification Mechanisms

Mathematical Governance Mechanisms

Use Case: National COVID Cohort Collaborative (N3C)

Governance Structure and Process Flow



PIs: Haendel, Chute, Eichmann, Guinney, Wilcox

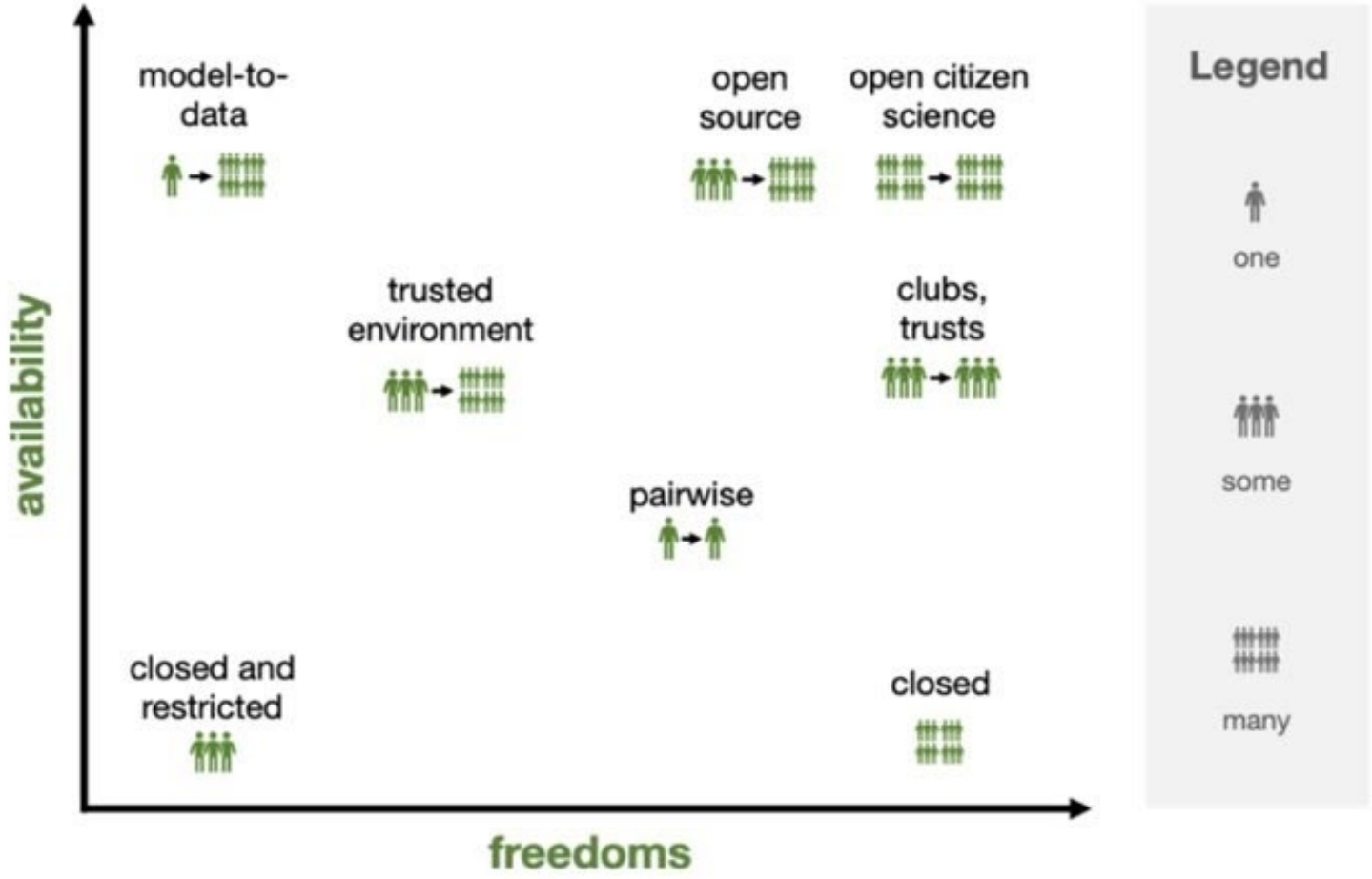
Integrating data across systems:

Data interoperability between health systems and data linkage across sources requires increased investment in data quality standards

Care evaluation often requires integration of lived experience beyond data captured in the medical system

- Clinical care in impacted by factors not captured in the medical record
- Individual lived experience is highly private and sensitive information

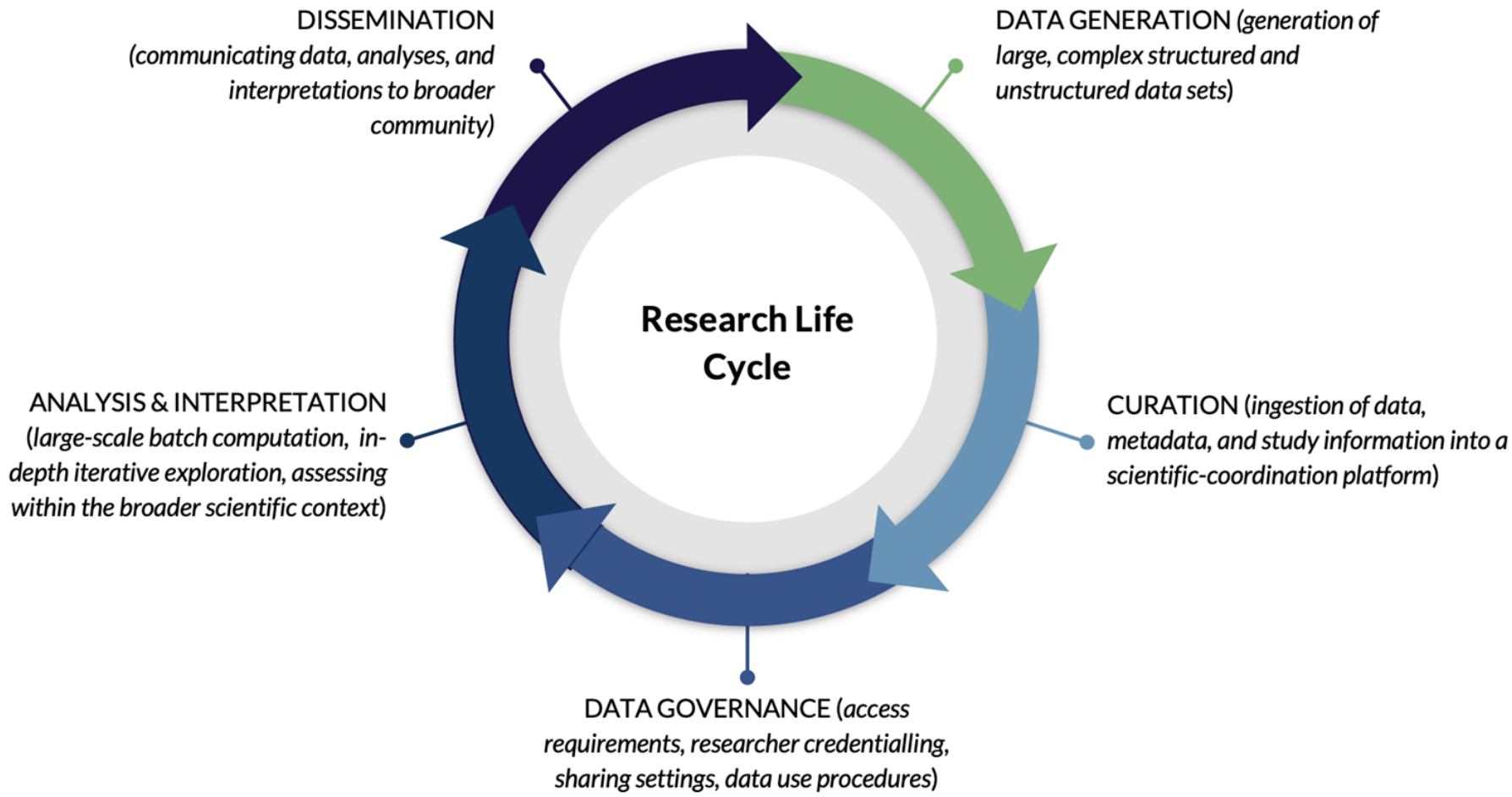
Who acts as steward for our research data?



Guinney J, Saez-Rodriguez J. Nat Biotechnol. 2018 36(5):391-392.

Green Paper – Wilbanks, Sen, Mangravite
https://sage-bionetworks.github.io/governanceGreenPaper/

The representativeness of the practice of research itself



Graphic adapted from Ben Logsdon

MindKind STUDY

Identify what self-management strategies work for who and why in global youth with anxiety or depression

Figure by Carly Marten, Sage Bionetworks

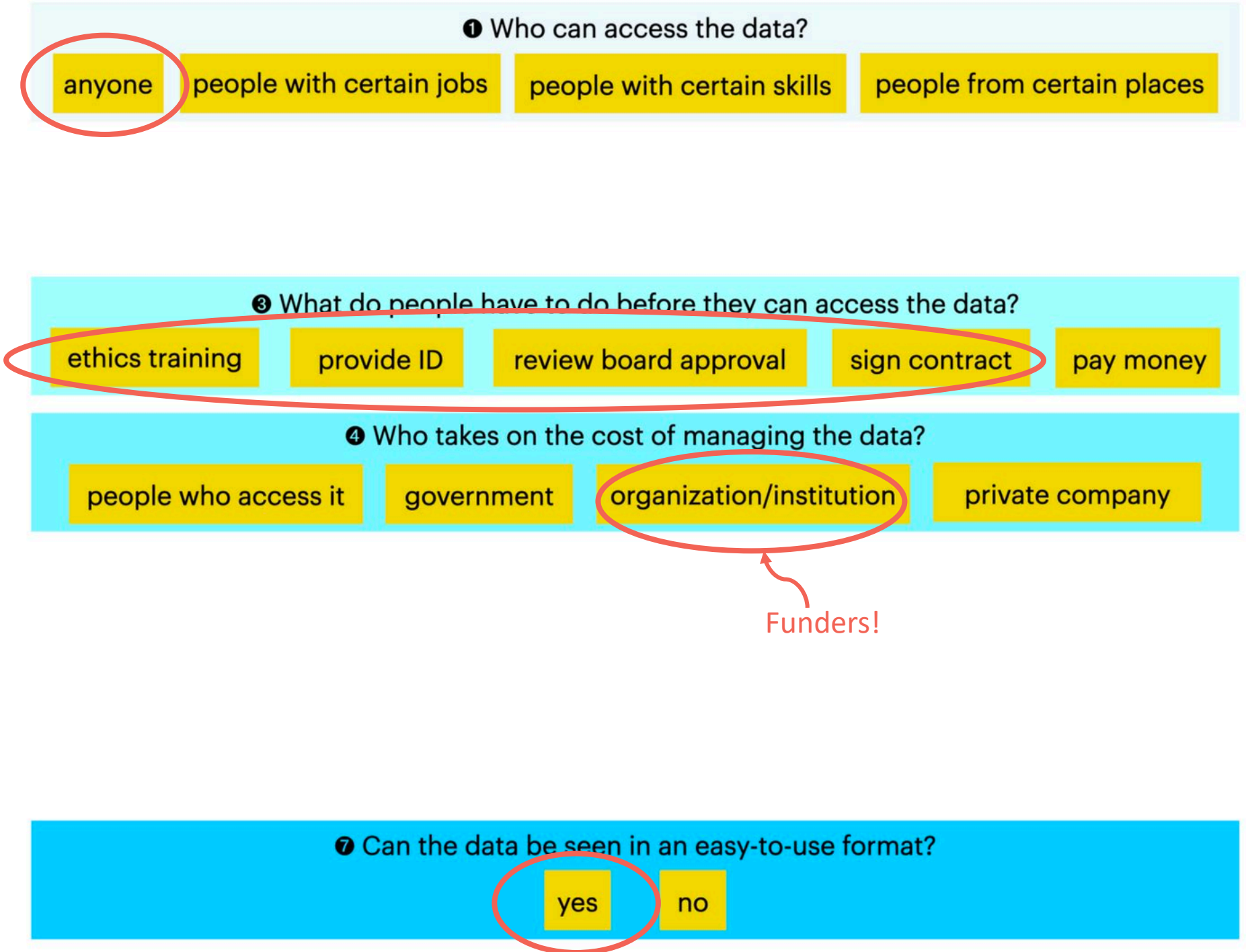


Figure by Carly Marten, Sage Bionetworks

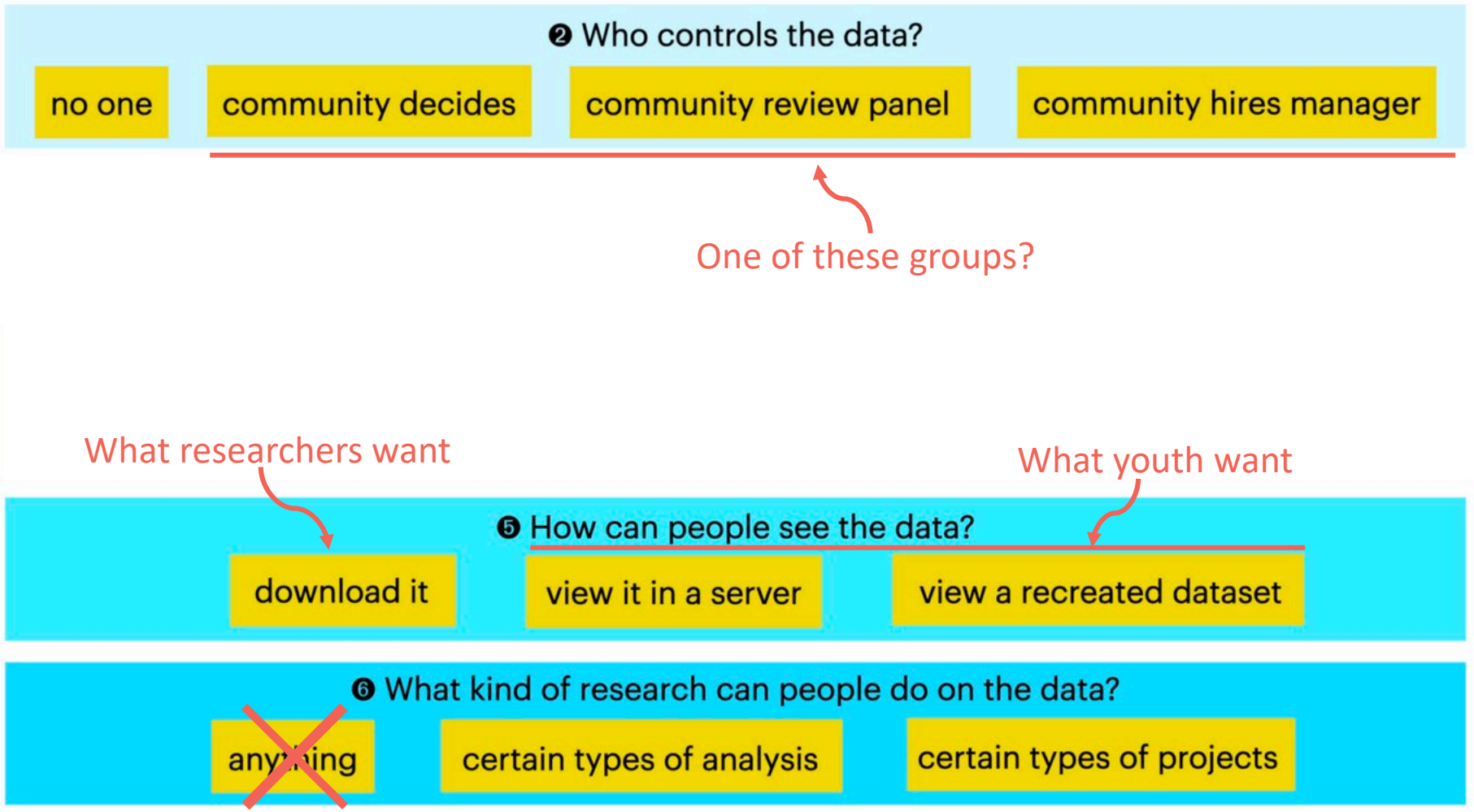


Figure by Carly Marten, Sage Bionetworks

Recommendations

- **Enable integration of data across systems:**
  - Data interoperability between health systems and data linkage across sources requires increased investment in data quality standards
- **Integrate participants into the research lifecycle**
  - Enable richer understanding of lived experience
  - Support alignment of research questions with community needs
  - Supports capacity building for translating research outcomes into action