Responsible Data

Responsible data are a process, not an outcome.

What are responsible data?

- **Data that are obtained with consent**
- **Data that protect individual privacy.**
- **Data that are stored and shared securely.**
- **Ownership** in information collection, analysis, storage, presentation and reuse of data
- Values of **transparency** and **openness**

Tactics for responsible data processes

- **Future proofing:** Planning technology and data processes in ways that mitigate risks as the landscape changes
- **Red-teaming:** Rigorously considering worst-case scenarios, second- and third-order consequences
- **Human elements of best practice:** Minimize error, ensure consent

There is a wide range of issues related to how to collect, use and analyze the enormous quantities of data that are now available about humans and the planet we live on. How should the data be stored so that it is secure and can't be accessed and used in ways that violate rights, privacy and individual safety? Will storage and security formats selected today be adaptable and/or easily improveable in the future? The above framework, adapted from Alix Dunn of the Engine Room (*www.theengineroom.com*), is a very simple guide to the thinking and practices going on in this arena. In the HIV realm, some of the specific topic areas of relevance include the maintenance and use of digital records that identify people, their HIV status and perhaps also other behaviors/identities that are stigmatized and criminalized; mining of cell phone and internet communications to understand thoughts, questions and priorities of people and populations about new technologies; or screening of biological samples to answer questions or gather information that may not have been mentioned in the original informed consent document or process. Each of these and many other examples have specific complexities, issues and areas that require careful consultation.