Culture(s) of Data Sharing

IOM Workshop: Sharing Clinical Research Data
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Value of Trust

Trust is the foundation for all productive relationships. How do you build trust?

Managing Research Relationships

Contractual:

Relational:

Building Trust

We share core values and interests

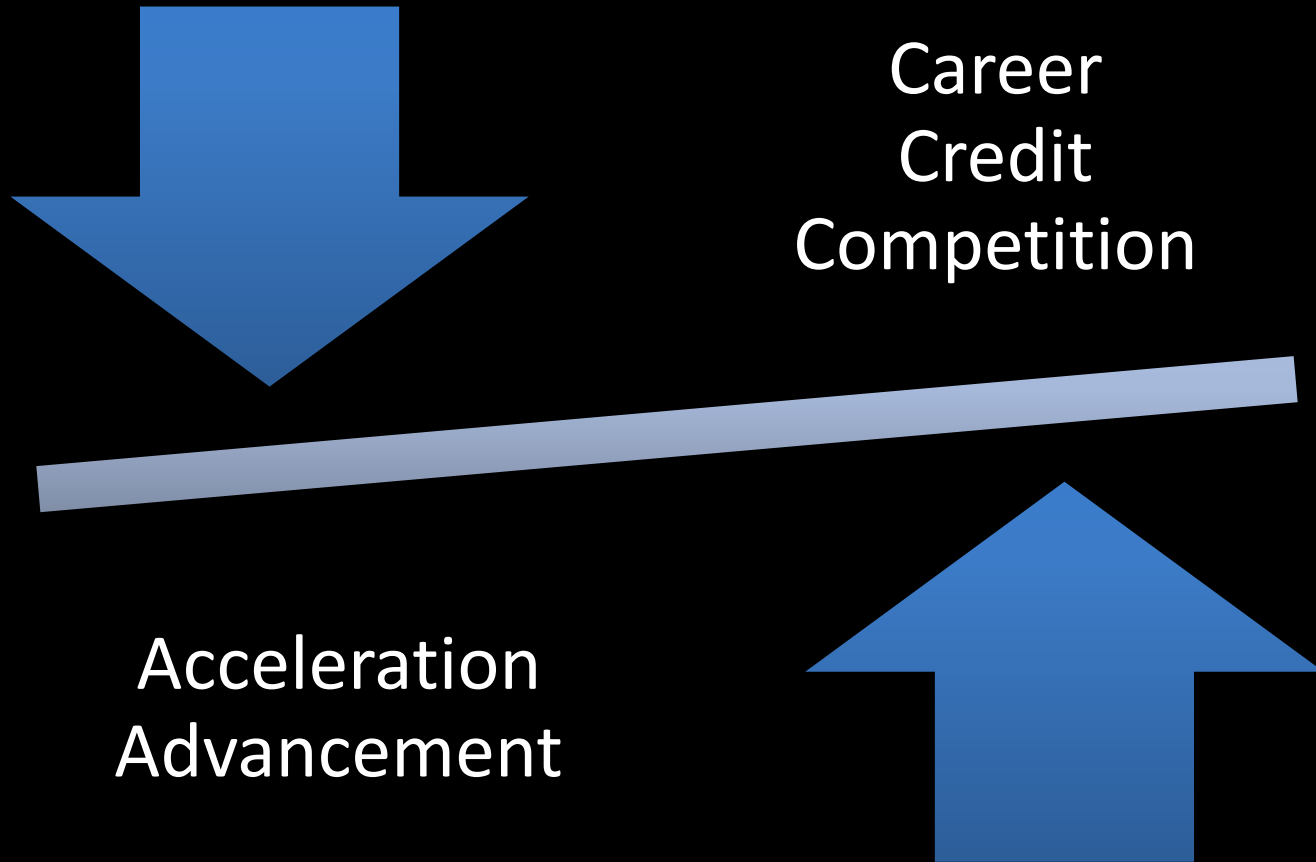We are committed to a common cause

You have my best interest in mind

Your rules are transparent and consistent (or logical)

Someone I trust, trusts you

Data Sharing: What is at stake?

Career
Credit
Competition

Acceleration
Advancement

Cultural Divide in Research

Academic Research

- Competitive environments can lead to closed doors

Open Science

- Competition happens in open-space.

Culture is Changing Everywhere

Old World

- **IT (expert) driven**
- **Static tools**
- **Laptop**
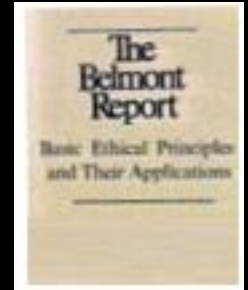- **On-premise**
- **Limited few**

New World

- User driven
- In-context collaboration
- Actionable apps
- Mobile
- Cloud
- Everyone

Bhorowitz.com Blogpost
"Revolution at the Edge"

Returning to Old Fashioned Research Ethics

- Respect for Persons

  – How can our research processes enact respect?

- Beneficence

  – How can we assure our research is achieving benefits? And clear benefits for whom?

- Justice

  – How can we proceed equitably and fairly?

What can respect look like?

- Partnership
  - Acknowledgement
  - Gratitude
  - Exchange
  - Benefit sharing

- Communication
  - Asking permission
  - Feedback
  - Updates

We need to reach for Standards of Excellence

Data Sharing Policies Provide The Ladder

Regulations set the floor

Learning from advocacy-run research practices

– Building Better Biobanks Working Group, 2012

History says, don't hope
On this side of the grave.
But then, once in a lifetime
The longed-for tidal wave
Of justice can rise up,
And hope and history rhyme.

- Seamus Heaney, "Doubletake"