

Influencing the Decision to Share Scientific Data: A Reversal Theory Perspective

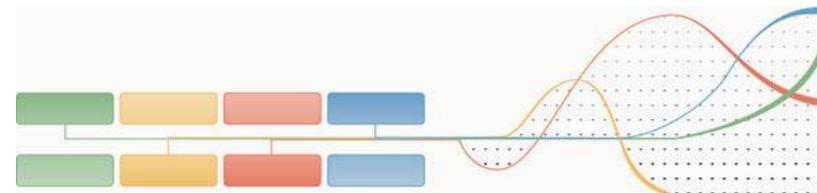


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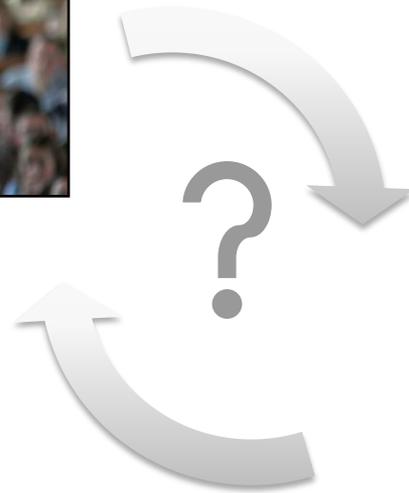


Presentation Overview

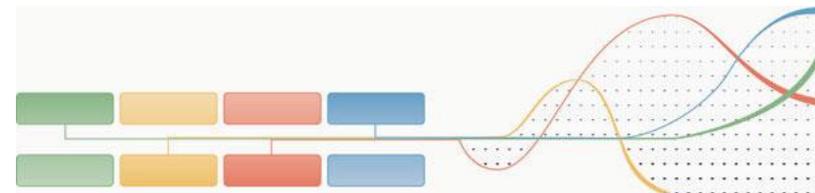
- Research Case Study
- Findings: A Backdrop
- Reversal Theory Perspective
- Questions



Social Norms
Public Discourse
Institutional-Level Arguments



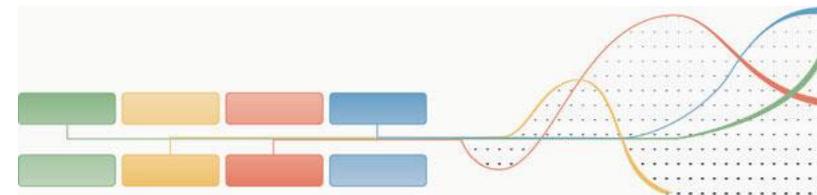
Individual Motives
Individual Beliefs & Sensemaking
Experiences Seen & Heard



The Case Study:

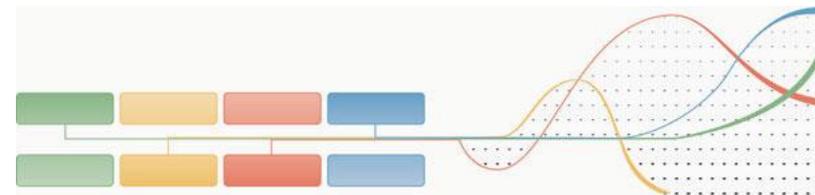
Data Sharing in Cancer Research

- Today's **cancer research** enterprise increasingly relies on **molecular medicine** – the analysis of large data sets that can reveal disease patterns.
- It is argued that this process is best supported when researchers **share data** with others through “team science” – more data sharing leads to more knowledge.
- This evolution is occurring in a highly **decentralized research landscape**, where individual achievement is the emphasis.



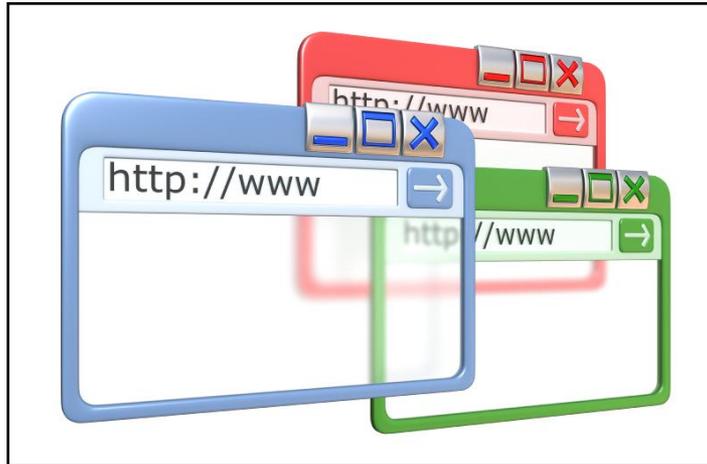
Case Study Questions

- What motives and emotions are linked to a researcher's decision to share cancer research data?
- How do these motives and emotions align, or not align, with social norms and discourse related to the benefits or risks of data sharing?
- **Case Study:** Large cancer research informatics program at the US National Institutes of Health, National Cancer Institute.

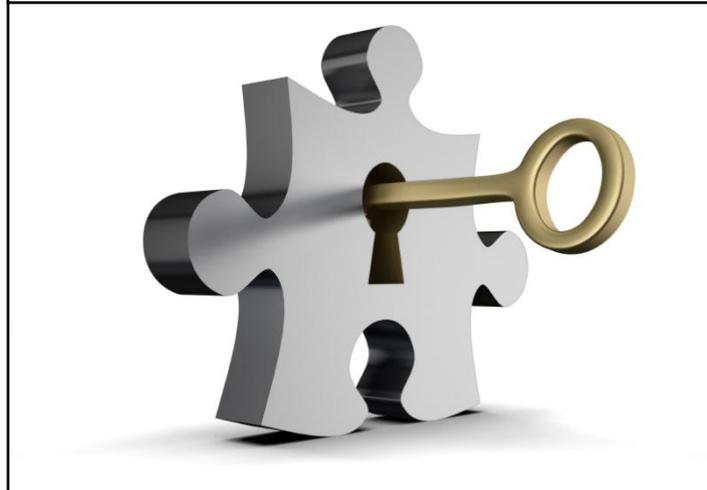


Four Perspectives

Technology



Economic

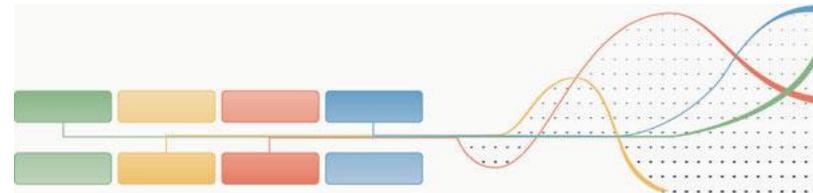


Legal

Personal

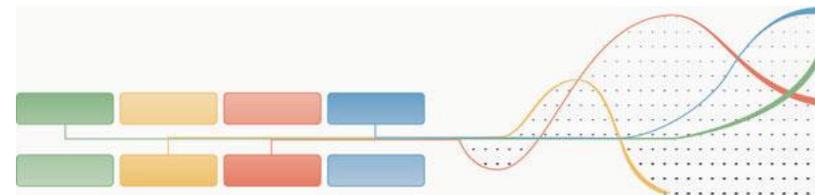
Social Level Arguments... You **Should** Share

- Data sharing encouraged as a means to respond to vast amounts of data being generated by science today.
- Data sharing positioned as good for scientific discovery and progress, and as a vital step towards patient care.
- Emphasis on standards-based sharing, allowing data to be posted and exchanged impersonally on technology grids.
- Institutional rewards are still driven by individual achievement: measured by grants and publications.
- There are some data sharing “strings” attached to large grants – but few measures in place to ensure it happens.
- Regulations and legal requirements complicate ability to share data in the ways advocated.



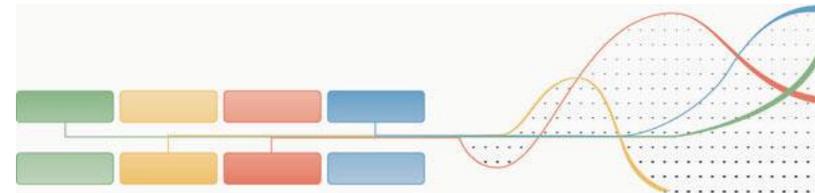
Individual Motives... Why People **Actually** Share

- People share data when it is advantageous to do so: increased sample size, shared publication/grant, or getting something back later.
- They will also generally share if doing so has little cost (data is of perceived low value) and takes little effort.
- Point-to-point data sharing within a trusted collaborative relationship is the norm – “you cannot underestimate the personal element of sharing.”
- Standards-based sharing on technology grids seen as overly burdensome, and by some, even insulting.
- Data are perceived as extensions of oneself and one’s work – to be shared with trusted colleagues and when the terms are clear up-front.
- The greatest fear is being “scooped” – being beat to publication by your own data.



The Emotions of Data Sharing

- **Anxiety** and **fear** about getting grants in today's competitive funding environment - "sharing pre-published data is academic suicide"
- **Guilt** over delaying sharing data; **Embarrassment** about messy data
- **Frustration** and **irritation** at the legal barriers that stand in the way of sharing
- Feeling **insulted** and **resentment** toward people who underestimate the time required to prepare data for sharing
- **Regret** and **sympathy** about the negative impact of legal requirements on a well-meaning researcher's ability to share
- Potential **humiliation** of getting "scooped" by one's own data
- Concern about sounding **selfish** because data weren't shared
- **Pride** about research projects that had been completed successfully
- **Pleasure** and **caring** about the interpersonal connections that had been developed as a result of data sharing
- **Amazement** and **wonder** at the new possibilities of science

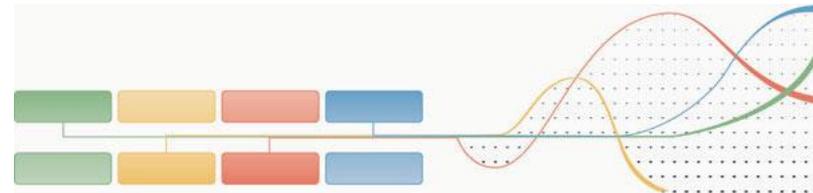
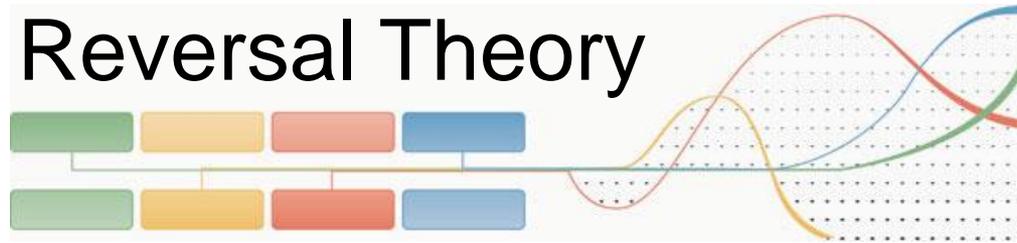


From Analysis to Action: Two Tools

Metaphor

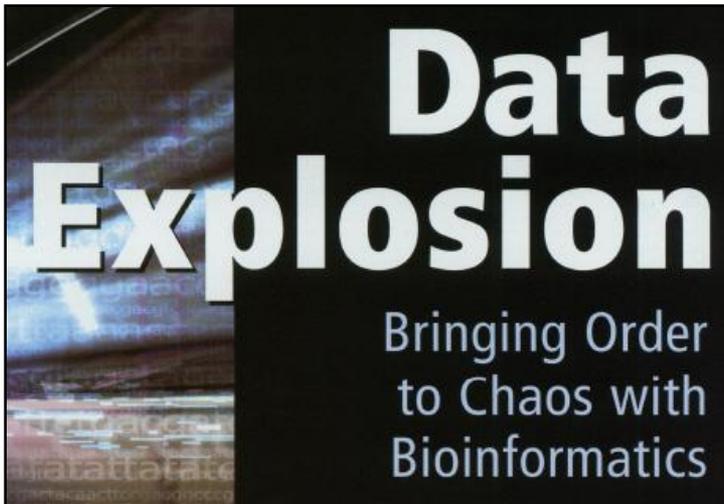


Reversal Theory



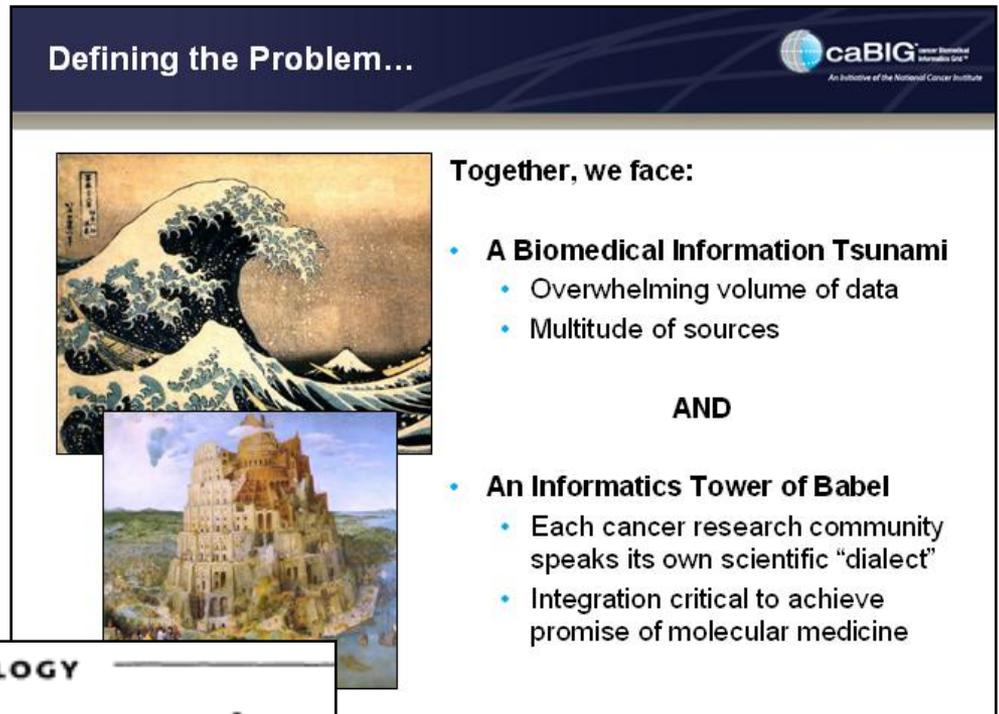
Why Share Data?

Mastering the Chaos...OR



Data Explosion
Bringing Order to Chaos with Bioinformatics

The graphic features a dark background with a glowing blue and white light effect on the left side, suggesting data or a digital interface. The text is in a bold, white, sans-serif font.



Defining the Problem...

caBIG
An Initiative of the National Cancer Institute

Together, we face:

- **A Biomedical Information Tsunami**
 - Overwhelming volume of data
 - Multitude of sources

AND

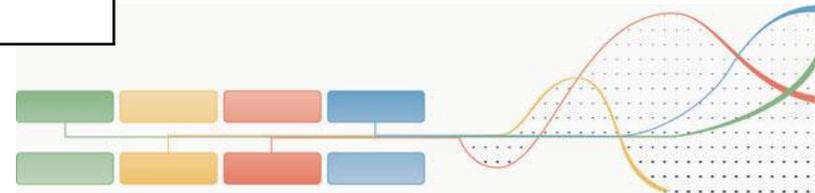
- **An Informatics Tower of Babel**
 - Each cancer research community speaks its own scientific “dialect”
 - Integration critical to achieve promise of molecular medicine

The slide has a dark blue header with the caBIG logo. Below the header, there are two images: the Great Wave off Kanagawa and the Tower of Babel. The text is in a white, sans-serif font.

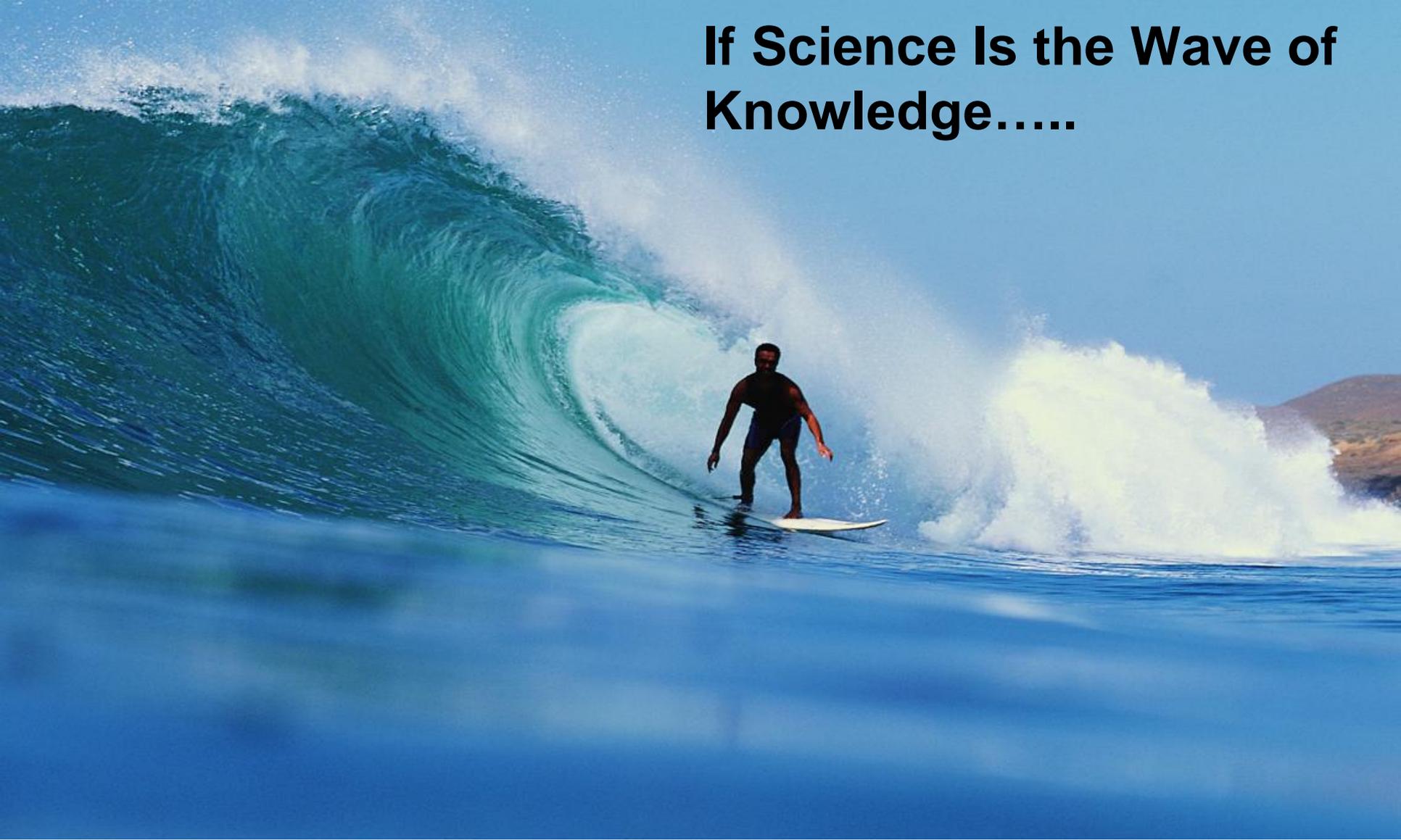
FUTURE DIRECTIONS: COMPUTATIONAL BIOLOGY

Bioinformatics—Trying to Swim in a Sea of Data

The text is in a bold, black, sans-serif font on a white background.



If Science Is the Wave of Knowledge.....



“We’re all little waves bouncing around in the inside of a kiddie pool.”

Only then will it be possible to fully exploit the information as compressed **reams of data**. We are in the midst of an **explosion of knowledge** about cancer as a disease. However, in cancer research there exists a **'Tower of Babel'** problem.

Applications that **talk to each other**;
Let Data Speak to Data.

Advocacy
Encouraging Data Sharing
(Motivators)

Data sharing is like **dating**; data sharing is a **scientific marriage**; Data sharing occurs in **scientific marriages** we are all in the **middle** of.

Embracing the individual diversity of members and connecting them

"A lung image database is **breathing life into** 'medical grid' vision"

The caBIG technologies will also allow researchers to **tap into an ocean** of raw published data

Think of it as an **organic bank account**. You put your biomaterial in and earn medical **interest** in the form of knowledge and therapies that grow out of that **deposit**

caBIG provides **libraries of resources or banks** for cancer research

Technology
As Central Agent

People
As Central Agent

Scale-Less Metaphor (Form-Less)

"Raw" data is **raw** and is additional stuff you have to **wade** through.

Advocacy for
Data Sharing **Concerns**
(Demotivators)

Data sets are something to be **"squeezed" (or "wring it out")** until there is only the left behind "freeware" to then share.

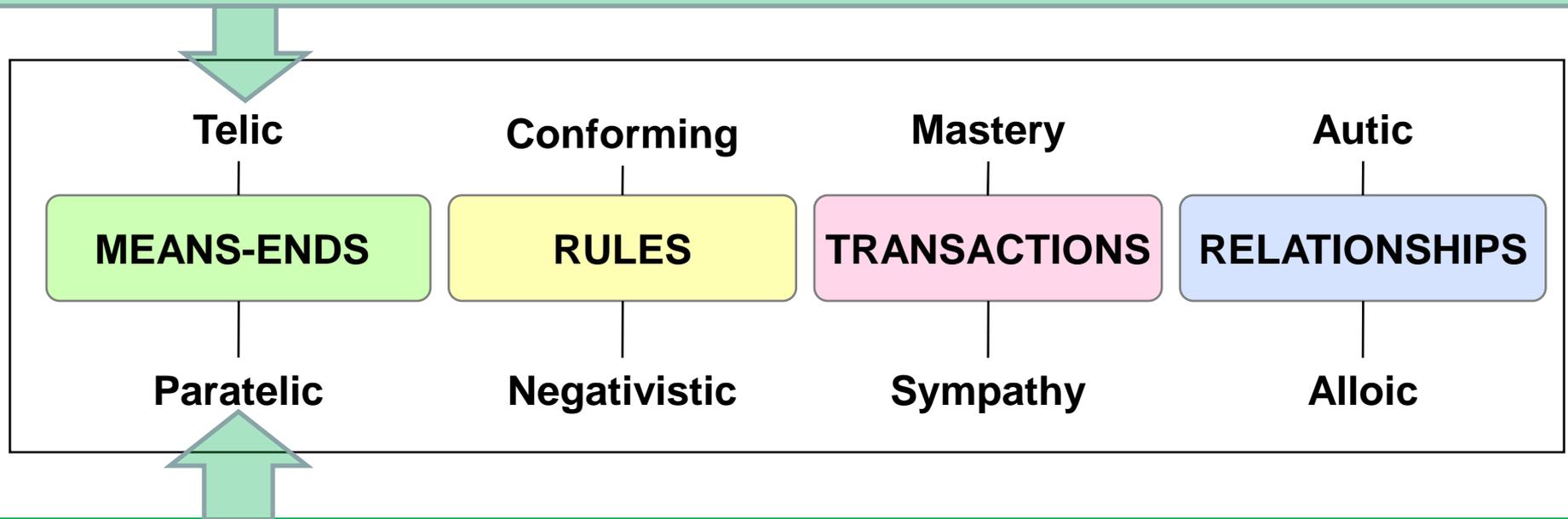
Researchers are afraid of getting **scolded** for sharing their data.

Small Scale Metaphor (Control Based)

Gaps in Motivational Potential...

Social Messaging: Telic imagery and threats, communicated through large-scale fear metaphor and grant requirements.

Individual Reaction: Skepticism that sharing data actually helps achieve goals



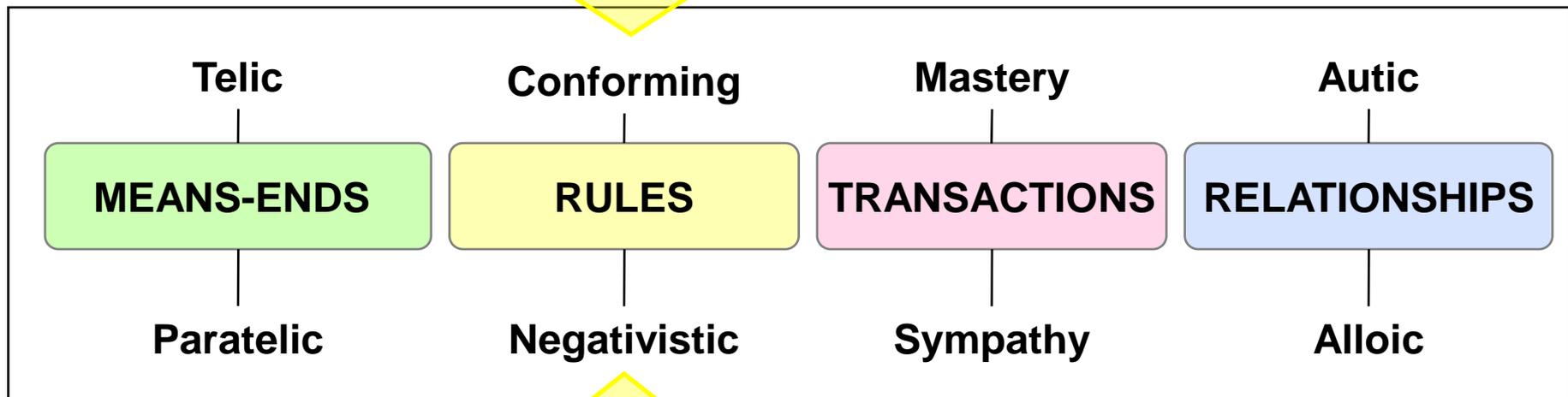
Individual Reaction: Paratelic reaction to grant requirement – often made fun of during interviews.

Social Messaging: Data sharing helps scientific discovery in general.
Individual: What if I get scooped?

Gaps in Motivational Potential...

Social Messaging: Data sharing should be done using shared standards – data formatted is more easily shared.

Individual Reaction: Conforming occurs within the personal sharing relationship, not on Grids.



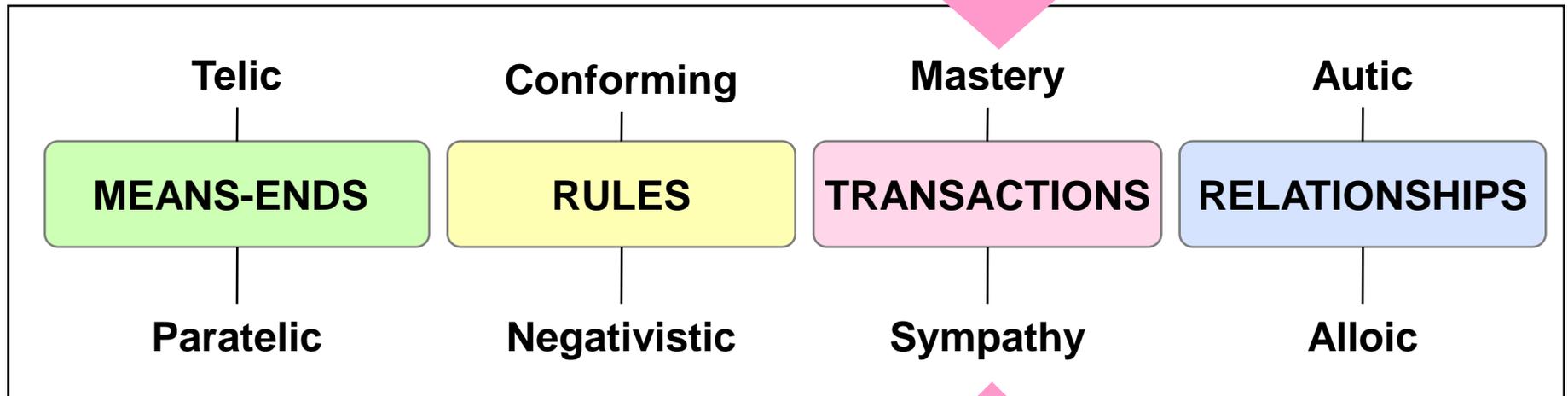
Individual Reaction: People want freedom to choose; and feel boxed in by standards.

Social Messaging: Grid sharing is the cool new thing! (When will it be the new norm?)

Gaps in Motivational Potential...

Social Messaging: Data sharing enhances scientific outcomes and the power and ability to cure cancer.

Individual Reaction: How will data sharing help me get my next grant or publication?



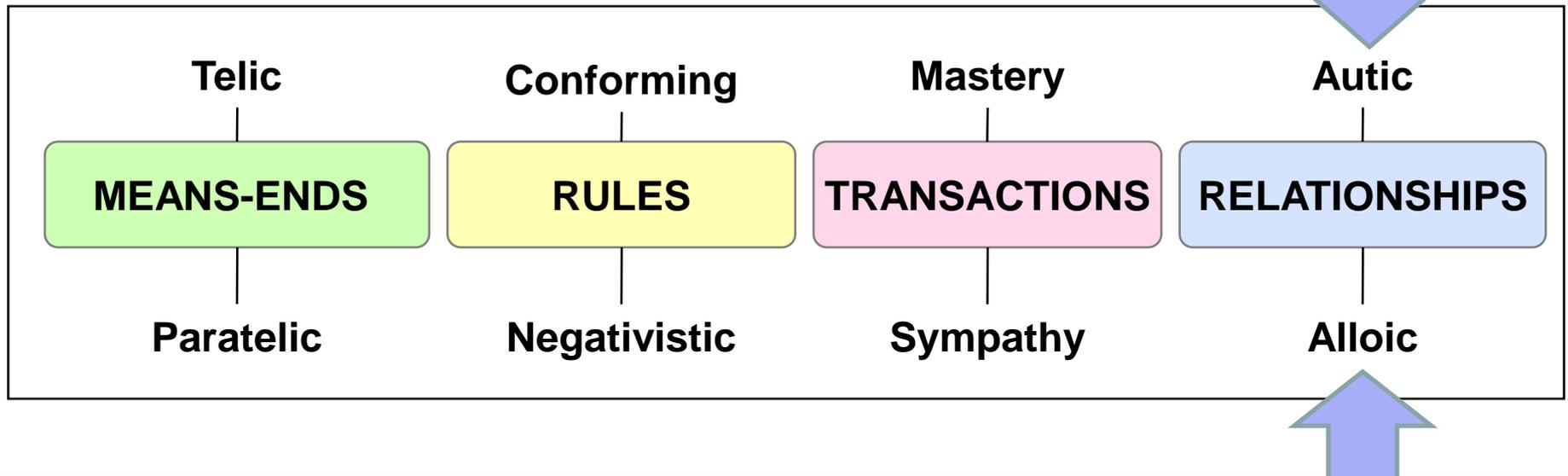
Individual Reaction: Interpersonal connections and relationships are essential in establishing the trust to share.

Social Messaging: Data sharing is needed to help *patients*.
Individual: Patients are not in mind on a daily basis.

Gaps in Motivational Potential...

Social Messaging: MISSING! The norms of science emphasize the “bigger than all of us” nature of science – personal gain not often acknowledged at social level. ~~WHFM?~~

Individual Reaction: Getting grants, publication, and gain in relationships critical to sharing.



Individual Reaction: I'll share because I care about or want to help another researcher.

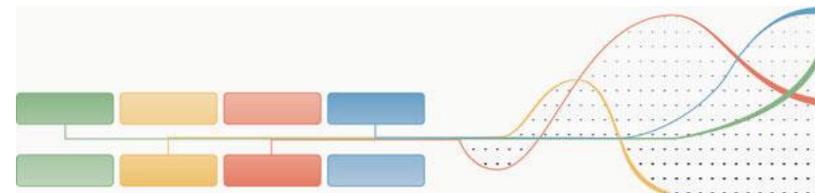
Social Messaging: Sharing should be done to benefit the greater good of science and patient care.

And Differences in Scale

State	Small Scale, Near Proximity – More Effective	Large Scale, More Distant – Less Effective
Telic	Sharing data is important for career advancement *	Sharing data is important to achieve scientific advances
Paratelic	Emerging bioinformatics tools are interesting and will help you explore new areas	The bioinformatics field allows for the extension of science into endless areas of exploration
Conforming	Creating interoperable data sets will save time over the course of a long-term project	Interoperable data sets facilitate large-scale data sharing
Negativistic	Data sharing will separate you from the rest of the pack *	Data sharing is needed to revolutionize science
Mastery	Data sharing will help you compete for grants and get published *	Data sharing makes science better
Sympathy	Data sharing develops trust with other researchers, leading to long-term collaborative relationships.	Data sharing is needed to support the development of cures for patients
Autic	If you share data now, you'll probably get something back later	Data sharing increases your visibility and success
Alloic	Data sharing will help another researcher who needs you	Data sharing supports the greater good

Implications and Conclusions

- More investigation into differences in scale, and relationships to the reversal process
- Further investigation into the close linkages between reversal theory and metaphor
- Practical implications for changing data sharing discourse
- Supporting Patient Advocates in navigating the research motivational system
- Further demonstrations of role and power of reversal theory at both personal and social levels – for both analysis and intervention



Discussion/Questions

