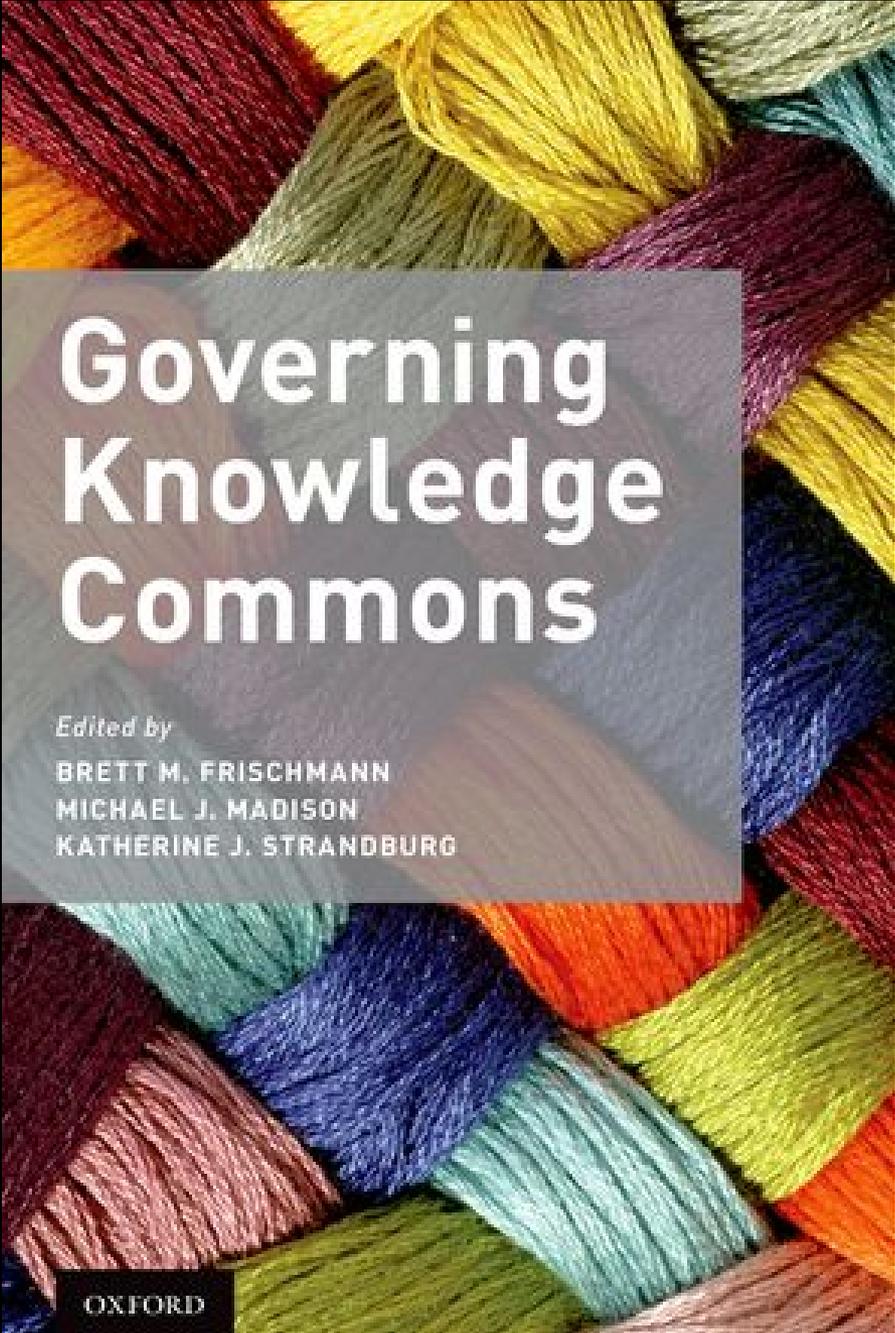


# Infrastructure

*The Social Value of Shared Resources*

Brett M. Frischmann

OXFORD



# Governing Knowledge Commons

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# Background

1. Government intervention
- 2. Commons management is the norm**
3. Positive externalities / large social surplus

# Commons Management

*Commons*  $\leftrightarrow$  *Open Access*

1. Ownership
  2. Community Definition
  3. Degree of Exclusion
- For INFRASTRUCTURE BOOK, we focused on **nondiscriminatory sharing**
    - Various institutional regimes
    - Lack of exclusion & member/nonmember boundaries
    - Not necessarily free

# Commons Management

- **But this focus is not appropriate for broader study of knowledge commons**
- **We'd like to define the resource set very broadly**

# Student Brainstorm Session

**If we define the resource set very broadly to encompass wide range of intellectual resources, can you think of some EXAMPLES????**

**You have three minutes to come up with a list of knowledge commons.**

**Hint: Think about case studies that might be interesting.**

# Open Science Commons

- What is Commons?
- Why Commons?
- How Commons?

# Open Science Commons

- What is Commons?
  - Commons are resource management /governance institutions that enable sustainable shared use of certain resources within a community.
- Why Commons?
- How Commons?

# Open Science Commons

- **What is Commons?**
  - **Commons are resource management / governance institutions that enable sustainable shared use of certain resources within a community.**
- **Why Commons?**
  - **Open Science is a complex resource system.**
  - **Many shared resources are infrastructural.**
  - **The scientific community defines and is defined by commons.**
- **How Commons?**

# Open Science Commons

- What is Commons?
  - Commons are resource management / governance institutions that enable sustainable shared use of certain resources within a community.
- Why Commons?
  - Open Science is a complex resource system.
  - Many shared resources are infrastructural.
  - The scientific community defines and is defined by commons.
- How Commons?
  - Open access works for some resources.
  - But for most, governance is complex, contextual, resource-specific and community-specific.
  - Much more than “openness.”

# MOTIVATION FOR THE KNOWLEDGE COMMONS PROJECT

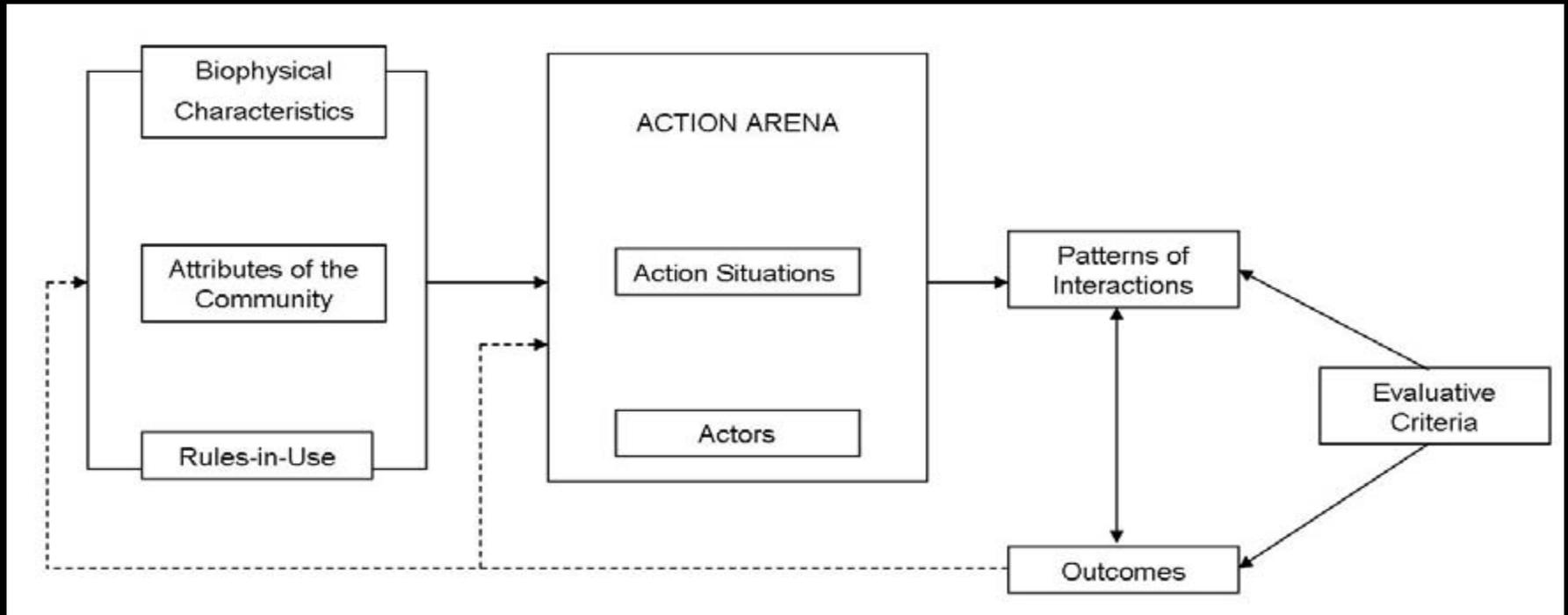
- **Standard IP theory overly-simplistic**
  - Dichotomy btw property/ “public domain”
  - Incentive/free rider story
  - Difficulty making useful predictions – empirically unresolved balancing
- **Not markets/not public domain/not firms**
  - Approaches to creating intellectual resources that are
    - Collective/collaborative
    - Governed informally or formally by private ordering
- **Cooperative/collaborative modes of creativity**
  - String of “one-off” case studies reveals important of norms, governance

**How to systematize the inquiry?**

# The Ostrom Approach

- Construct a **framework** for analyzing various case studies to identify and categorize potentially important variables
  - Organizes empirical inquiry by specifying general sets of variables and relationships to each other
  - Allows integrated and comparative inquiry across domains
  - Useful when one needs to identify and build theories
  - Initial goal is to map our parameter space

# The IAD Framework for structured case study analysis



Players (ages, skill level), rules, soccer field, weather

Soccer game

League season

Skill, team-building, fun, revenue

**E.g. soccer league, fishery, agricultural cooperative**

- **Results of Ostrom's Approach:**
  - **Design Principles for Governing Sustainable Resources**
    - Clearly defined boundaries
    - Proportional equivalence btw benefits and costs
    - Governance by those affected
    - Monitoring
    - Graduated sanctions
    - Conflict-resolution mechanisms
    - Minimal recognition of rights for self-organization
    - Nested enterprises

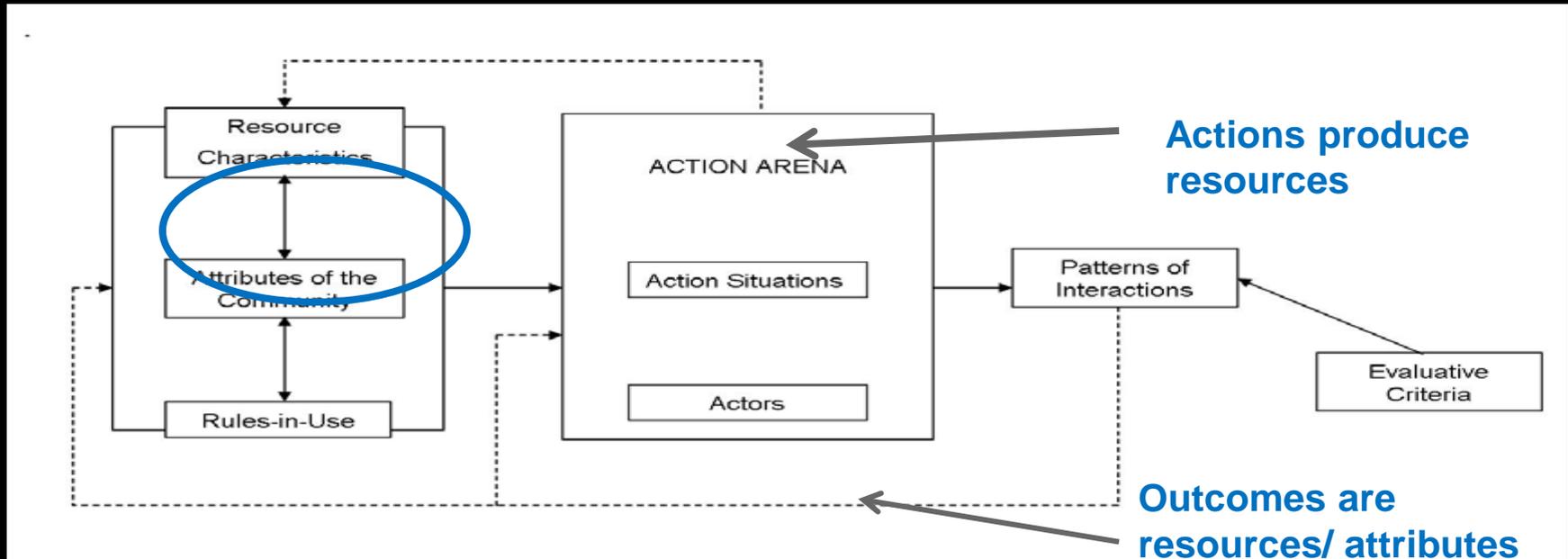
**Our Proposal: Apply a similar approach to study knowledge commons**

We **do not** anticipate uncovering the **same** design principles because intellectual resources are **different** in important ways –

- Nonrivalry
- Resources must be created, not just managed

# MAPPING TO THE CULTURAL ENVIRONMENT:

- IAD Framework must be adapted
  - In natural resource context resource characteristics are primarily exogenous, actions focus on use
  - In cultural context resources are human-made, actions focus on production *and* use



## **I. Background Environment**

- A. What is the background context (legal, cultural, etc.) of this particular commons?
- B. What is the “default” status of the resources involved in the commons? Patented? Copyright? Open?

## **II. Attributes of the Commons**

### **A. Resources**

- i. What resources are pooled and how they are created or obtained?
- ii. What are the characteristics of the resources, such as whether they are rival or non-rival, whether they are tangible or intangible,
- iii. What technologies and skills are needed to create, obtain, maintain and use them?

### **B. Community Members**

- i. Who are the community members and what are their roles?
- ii. What are the degree and nature of openness of the community with respect to each type of community member and the general public?

### **C. Goals and Objectives**

- i. What are the goals and objectives, including obstacles or dilemmas to overcome?
- ii. What are the history and narrative of the commons?

## **III. Governance**

- A. What are the governance mechanisms of the commons (e.g., membership rules, resource contribution or extraction standards and requirements, conflict resolution mechanisms, sanctions for rule violation)?
- B. Who are the decision-makers and how are they selected?
- C. What are the institutions that govern decision-making?
- D. What informal norms govern the commons?
- E. How do nonmembers interact with the commons? What institutions govern those interactions?
- F. What legal structures (including intellectual property rules, subsidies, contract and licensing law, antitrust provisions) govern the functioning of the commons?

## **IV. Patterns and Outcomes**

- A. What benefits are delivered to members and to others (including innovations and creative output, production, sharing, and dissemination of those innovations and output to a broader audience, and social interactions that emerge from the commons?)
- B. What costs and risks are associated with the commons, including, for example, any negative externalities?

## **I. Background Environment**

- A. What is the background context (legal, cultural, etc.) of this particular commons?
- B. What is the “default” status of the resources involved in the commons? Patented? Copyright? Open?

## **II. Attributes of the Commons**

### **A. Resources**

- i. What resources are pooled and shared?
- ii. What are the characteristics of the resources? Tangible or intangible, physical or digital, etc.
- iii. What technologies and skills are needed to use the resources?

### **B. Community Members**

- i. Who are the community members? Who are the contributors?
- ii. What are the degree and nature of interactions between members and the general public?

### **C. Goals and Objectives**

- i. What are the goals and objectives of the commons?
- ii. What are the history and nature of the commons?

## **III. Governance**

- A. What are the governance mechanisms? Rules, norms, standards and requirements for resource extraction and use?
- B. Who are the decision-makers and who are the enforcers?
- C. What are the institutions that govern the commons?
- D. What informal norms govern the commons?
- E. How do nonmembers interact with the commons?
- F. What legal structures (including property rights and antitrust provisions) govern the commons?

## **IV. Patterns and Outcomes**

- A. What benefits are delivered to members and nonmembers? Production, sharing, and dissemination of knowledge, social interactions that emerge, etc.
- B. What costs and risks are associated with the commons? Externalities?

**Don't worry about  
the content of this  
slide.**

**Too much text!!!**

**Just note the  
structure and  
approach.**

Author	Title	Commons
Cole, Daniel	Learning from Lin: Lessons and Cautions from the Natural Commons for the Knowledge Commons	Theory
Benkler, Yochai	Between Spanish Huertas and the Open Road: A Tale of Two Commons?	Theory
Contreras, Jorge	Constructing the Genome Commons	Gene data
Von Overwalle, Geertrui	Van Overwalle, Geertrui, Governing Genomic Data: Plea for an 'Open Commons'	Gene data
Strandburg, Frischmann, & Cui	The Rare Diseases Clinical Research Network and the Urea Cycle Disorders Consortium as Nested Knowledge Commons	Rare disease research
Madison, Michael	Commons at the Intersection of Peer Production, Citizen Science, and Big Data: Galaxy Zoo	Astronomical data
Schweik, Charlie	Toward the Comparison of Open Source Commons Institutions	OSS
Morell, Mayo Fuster	Governance of online creation communities for the building of digital commons	Online creation communities
Shah, Sonali and Moody, Cyrus	Creating a Context for Entrepreneurship: Examining How Users' Technological & Organizational Innovations Set the Stage for Entrepreneurial Activity	User Innovation
Meyer, Peter	An inventive commons: Shared sources of the airplane and its industry	Airplane invention
Murray, Laura	Exchange Practices Among Nineteenth-century US Newspaper Editors: Cooperation in Competition	Journalism
Piper, Tina	How War Creates Commons: General McNaughton and the National Research Council, 1914-1939	Military Technology
Fagundes, David	Labor and/as Love: Roller Derby's Constructed Cultural Commons	Roller derby names
Daniels, Brigham	Legispedia	Congress

# Themes from case studies

1. Knowledge commons may confront ***diverse obstacles or social dilemmas***, many of which are not well described or reducible to the simple free rider dilemma.
2. Complex relationships between knowledge commons and the systems within which they operate and/or are nested. (***complex, nested systems***)
3. Knowledge commons often depended on ***shared infrastructure***
4. ***Informal governance*** institutions, and especially trusted leadership, often played key roles
5. Commons governance often evolved over time, and commons seemed to play an important role in early stages of some industries (***evolution***)
6. Knowledge commons governance often did not depend on one strong type or source of individual motivations for cooperation. (***many motivations; complex***)

# Future

- IASC meeting on knowledge commons in Paris in October 2016
- Workshop for study of knowledge commons
  - Check out the website
- Case study database; coding manual; possible experiments ... plenty to do!!!

# Cambridge Studies on Governing Knowledge Commons

- Next book in series:  
**Governing Medical Research Commons (2016)**
- Currently planning future conferences and books to expand our knowledge base

# *Rare Disease Research Consortia as Nested Commons*

*Series of case studies using the modified  
IAD framework*

- (1) Urea Cycle Disorder Consortium
- (2) North American Mitochondrial Disease Consortium

more to come ...

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Murray, Laura	Exchange Practices Among Nineteenth-century US Newspaper Editors: Cooperation in Competition	Journalism
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# The Rare Disease Problem

- Few patients per disease (officially < 200K in US, often only a few thousand globally)
- No “blockbuster” pharma profits
- Patients are geographically scattered
- Latest science: many diseases “rare” in the sense that treatments must be personalized?

## Requirements for research and treatment advances:

- Patient recruitment for studies and drug trials
- Protocol standardization and data aggregation
- Cooperation among widely scattered researchers

# What is the Rare Disease Clinical Research Network?

- Established in 2003 by NIH
- Peer-reviewed grants of about \$1.25M/yr
- Now 19 Consortia (each dealing with a different cluster of rare diseases)

## Goals:

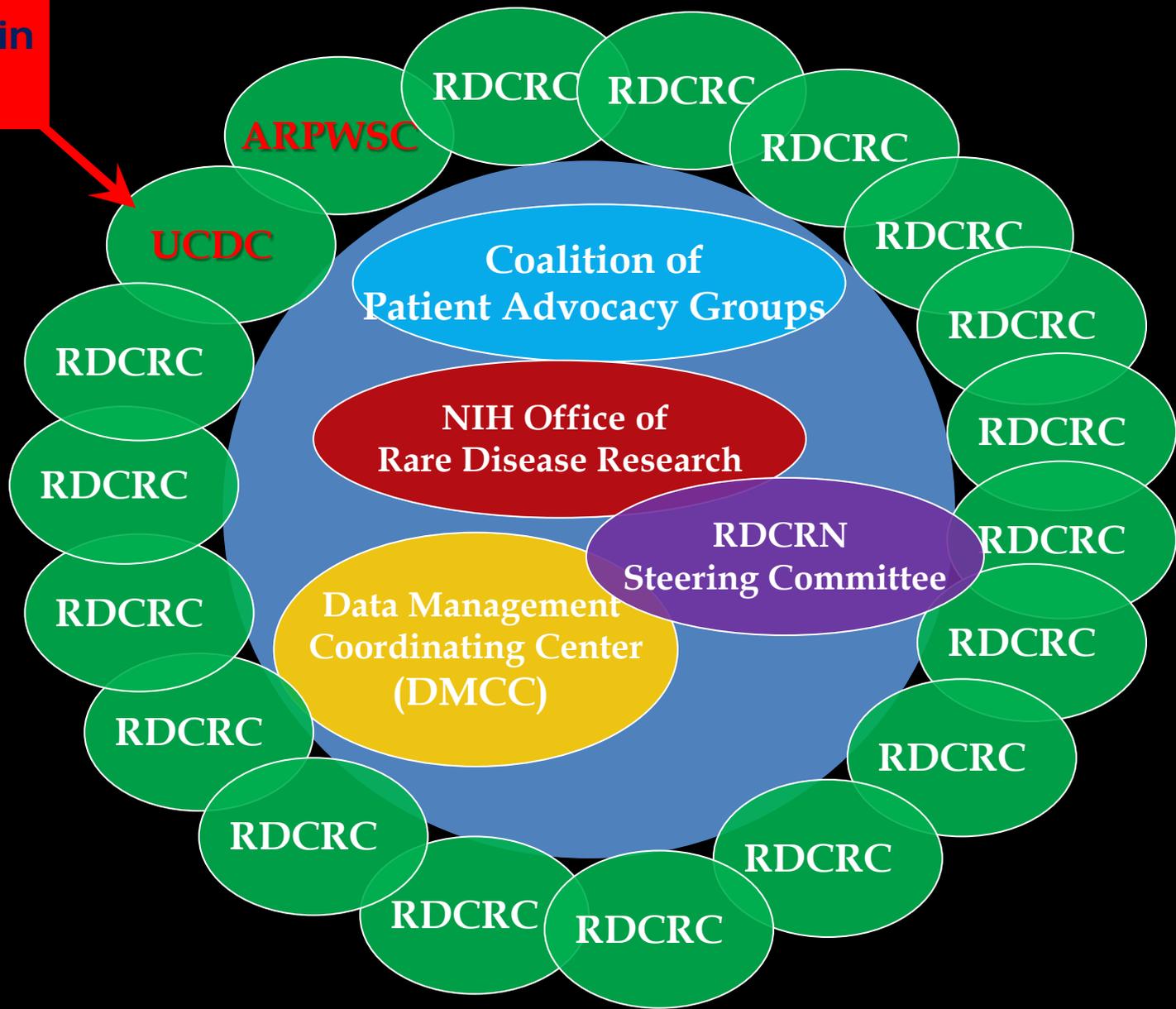
- Explore methods for rare disease research
- Overcome obstacles of small numbers/geographical isolation
- Establish shared resources for rare disease research and treatment development

# Why Study the RDCRN?

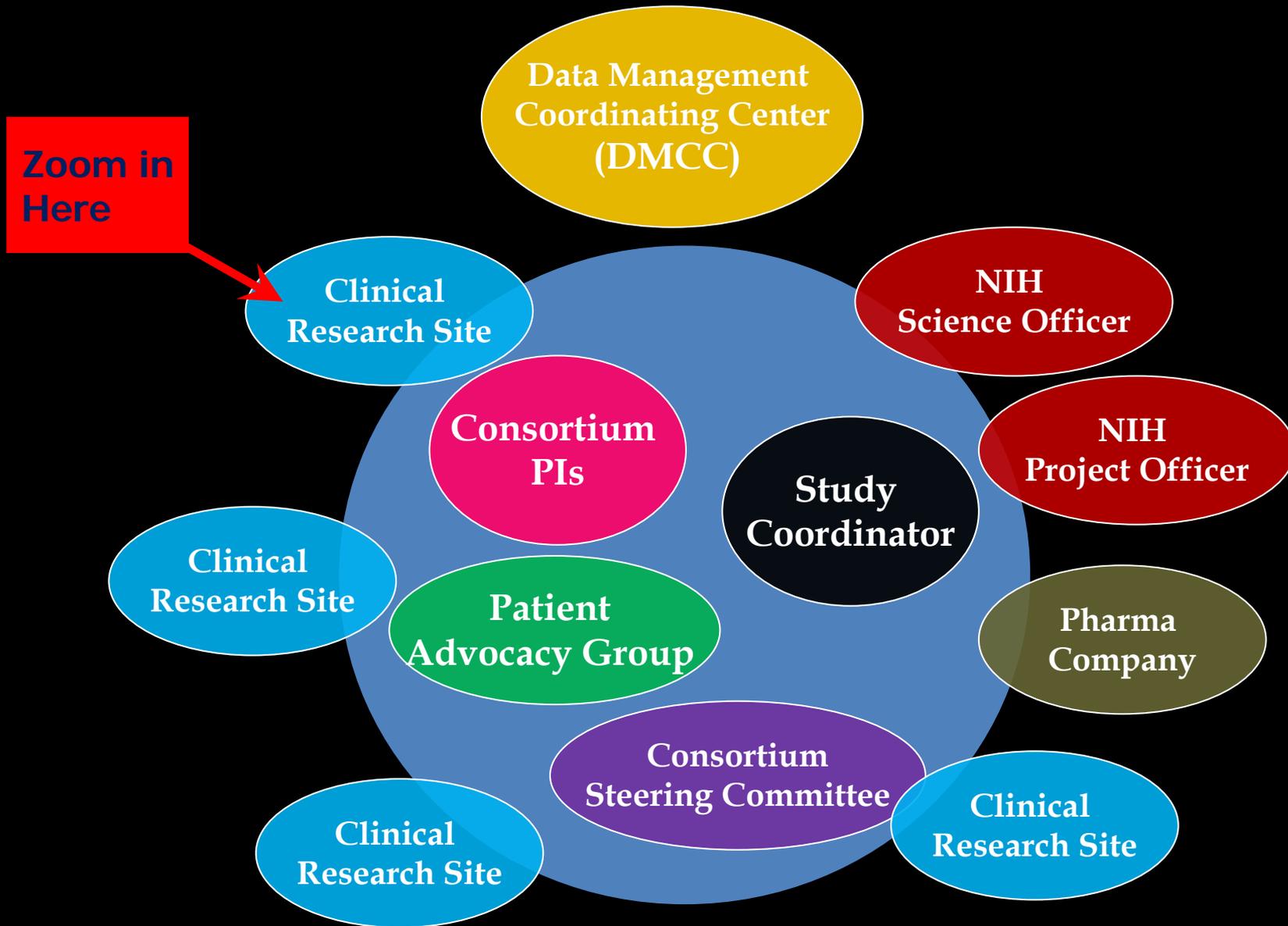
- Obvious importance of rare disease research
- Good test bed for the framework/methodology
  - Several consortia to be compared
  - Nested structure
- Began by studying one consortium in depth: UCDC (Urea Cycle Disorders Consortium)
- **Starting a second RDR case study:** ARPWSC (Angelman, Rett & Prader-Willi Syndromes Consortium)
- **Planning NIH proposal**

# Nested Structure: RDCRN Level

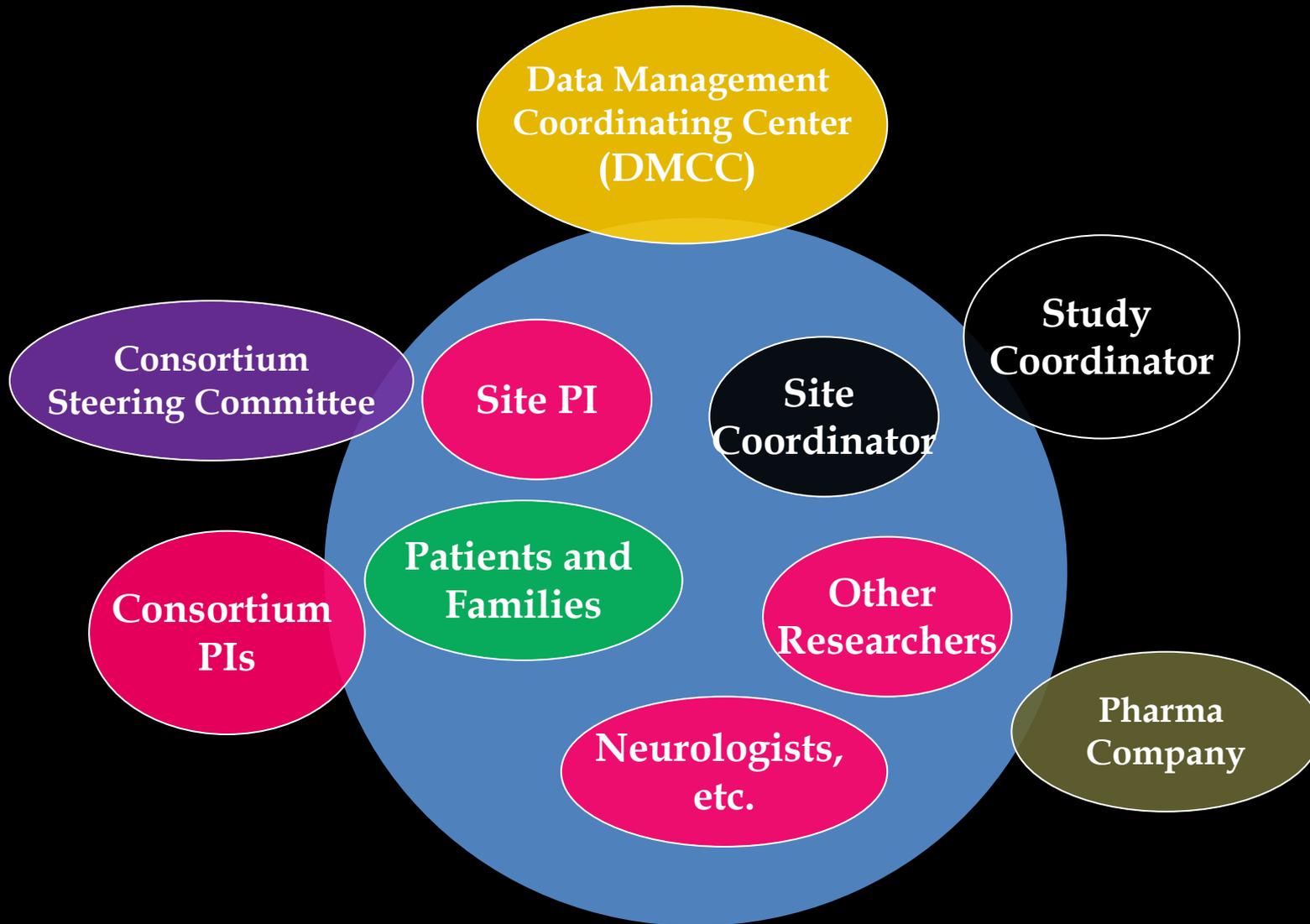
Zoom in Here



# Nested Structure: Consortium Level



# Nested Structure: Site Level



# Methodology (UCDC study)

- Literature review, incl. policies, industry agreements, minutes
- 16 Semi-structured interviews with NIH officials, researchers, administrator, pharma representative, patient advocacy group representative
- Attend annual consortium meeting
- Survey consortium members

# Analysis

- **RDCRCs involve *many* resources and outcomes**
  - Funding, patients as research subjects, DMCC, knowledge about the disease and about research practice, publications, research and treatment protocols, drugs, data, website (public and researcher only) ...
- **RDCRCs involve *many* types of actors**
  - MD/PhD researchers (pediatricians, metabolic and genetic specialists), Study PIs, Site PIs, study coordinator, site coordinators, patients, patient advocacy group, NIH officials, pharma representatives ...
- **RDCRCs involve *many* action situations**
  - Longitudinal Study (required by NIH), other research projects, clinical trials, treatment of patients, training of junior researchers (required by NIH), production of publications, protocols, website

# Main Objectives

1. Create a pool of research subjects and patient data
2. Sustain and grow community
3. Promote knowledge sharing within community (and to outside communities)
4. Cooperate with patients in setting research priorities and communicating results
5. Translate research into treatment (pharma)

# Analysis

- Differences from default “typical NIH-funded medical research” environment

## **Need to recruit large fraction of all patients**

- Important role of patient advocacy groups and importance of relationship to patients

## **Need to involve many clinical sites**

- Importance of recruiting researchers to participate despite potential issues: researcher competitiveness or researcher disinterest/lack of career potential
- Governance and leadership issues

## **Difficulty attracting pharmco interest**

- Cost/benefit issues for small patient pool

# How Does UCDC Meet These Challenges to Achieve Objectives?

- **Underlying incentives**
- **Longitudinal Study**
- **Leadership and informal governance**
- **Close-knit core group/inclusiveness**
- **Publication Policy**

# Underlying Incentives / Motivations

- Patient care as primary driver
  - “We are pediatricians”
- Participants enjoy collaborating, sharing knowledge
- **These characteristics**
  - Help to overcome coordination/ free rider/ conflict issues
  - Help with patient recruitment

# Longitudinal Study

- 80% agreed every rare disease consortium should have LS
- >50% agreed LS is most important UCDC project
- **Patient recruitment**
  - Non-invasive, low risk
  - Monitoring/displaying recruitment numbers incentivizes recruitment, addresses “free rider” issues
  - Funding for study coordinators
- **Many clinical sites**
  - Low entry barrier for researchers (“pre-fab” study, DMCC)
  - Data source for independent projects (balance between cooperation and competition)
- **Pharma involvement**
  - Well-characterized population of research subjects

# Leadership and Informal Governance

- **Patient recruitment**

- NUCDF/Cynthia Le Mons relationship
- Study coordinator/site coordinator leadership

- **Many clinical sites**

- Leadership, collegiality ranked most important
- Leadership characteristics: dedicated, trustworthy, determined
- Ranked most important and described current leaders
- Hierarchical democratic governance
- “UCDC decisions made by leadership”, “UCDC is hierarchical”  
**and**
- “UCDC decisions made by consensus,” “UCDC decisions made by majority vote”

# Close-Knit Group/Inclusiveness

- **Patient Recruitment**

- Longstanding relationship with NUCDF
- Annual meeting with NUCDF

- **Many clinical sites**

- Longstanding personal relationships between core researchers
- Trust important to informal governance
- Inclusiveness efforts
  - At annual meeting (e.g. introductions)
  - Monthly teleconferences

- **Pharma interest**

- Personal relationships with small pharma
- Inclusion at annual meeting

# Publication Policy

- Important to PIs – all were familiar with it, nearly all stated input was important
- Only formal governance structure that seemed very important to interviewees, survey respondents
- **Many clinical sites**
  - Important way to avoid disputes over credit allocation
  - All PIs agreed authorship assigned fairly
  - But publication policy not used in a formal way, more as a norm setting device

# Potential Challenges for UCDC

- **Leadership transition**

- Can be difficult for institutions with informal governance / centralized trust-based decisionmaking

- **Growth in number of sites**

- Challenge for informal decisionmaking/conflict resolution
- Greater say in decisions? (Survey)
  - Site PIs: 33% respondents agreed, only 8% disagreed
  - Non-PI researchers: 33% agreed, only 14% disagreed
  - Study coordinators: 40% agreed, only 18% disagreed

# Potential Challenges for UCDC

- **IP/ Data Sharing / Pharma Relationships**
  - As research moves toward application these areas may become more important
  - Survey showed some differences in views on these issues
  - Nearly all PIs agreed:
    - IP licensing policy should be established by Steering Committee
    - Input into policy was important
  - Potential for disagreements with patients on these issues
  - Potential for disagreements re involvement of Big Pharma v. small pharma
  - **More formal policies might help to avoid conflict (cf. publication policy)**

# Measures of Success:

- **Pool of research subjects and patient data**
  - **Patient recruitment and site expansion**
- **Acquiring additional funding**
- **Publications**
- **Data available for further studies**
- **Pharma interest**
- **Treatment improvements**

# Learning from Our Case Study

- **UCDC is highly successful among RCDCs**
  - Highest score in NIH peer review process
  - Meets NIH and its own goals and objectives
  - Still, we don't have independent evaluative criteria or a basis for comparison
- **UCDC in-depth study provides testable hypotheses regarding success factors**

# Hypotheses Based on Study: Important

- **Strong Leadership:** Dedication, collegiality, fundraising capability, respected decisionmaker, scientific credentials, sincere interest in patients (pediatrician)
- **Strong study coordinator leadership and site coordinator training:** direct patient contact
- **Close-knit core researcher group:** plus conscious integration of newcomers
- **Strong PAG with good relationship with PIs**
- **Longitudinal study:** “cheap” way for site PIs to get involved in (and publish) UCD research, also important for involving pharma companies by creating a pool of well-characterized patients
- **Monthly teleconferences, annual gatherings**
- **Protocol standardization and central data collection:** through DMCC
- **Formal publication policy**

# Hypotheses Based on Study: Unimportant

- Formal conflict resolution policy or procedure
- History of involvement by all site PIs in UCD research
- Central patient contact registry at DMCC
- Public-facing website for RCDC (PAG website is important)

# Conclusions

- **Scarce resources in the rare disease context:**
  - Patient data and participation
  - Publication credit to “go around”
  - Funding
- **Scarce resources must be “created” (not just managed) by RCDC**
  - Patient recruitment
    - Importance of site coordinators, importance of relationship with PAG, permitting PAG to help set research agenda
- **Community itself must be “created” (not just governed)**
  - **Site recruitment:** Finding funding for additional sites, Training site personnel, Ensuring sufficient effort/results by sites, Dealing with publication credit issues