

**James O'Leary, MBA**

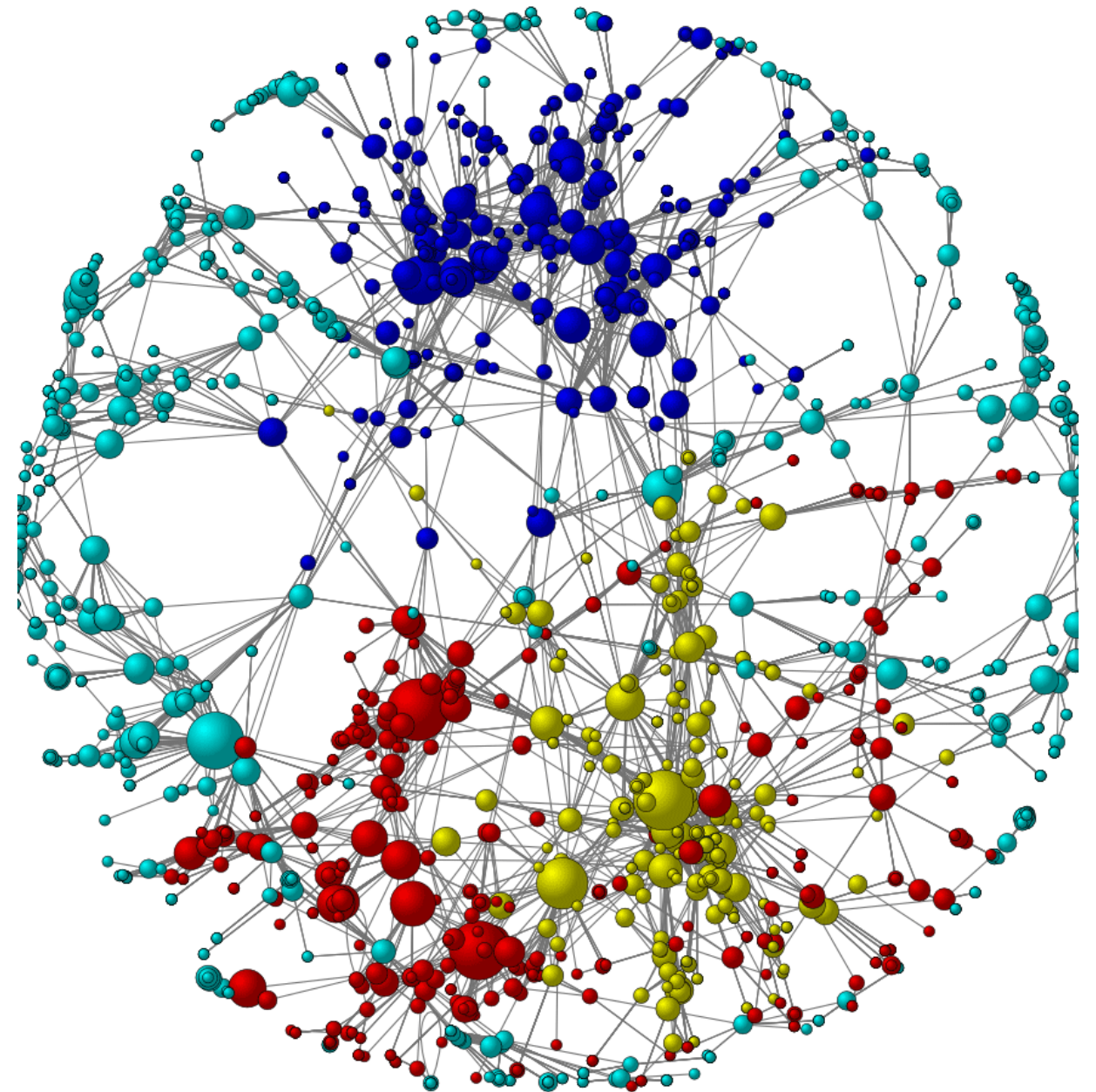
**Presented to the  
Advisory Committee  
on Heritable  
Disorders in  
Newborns and  
Children**

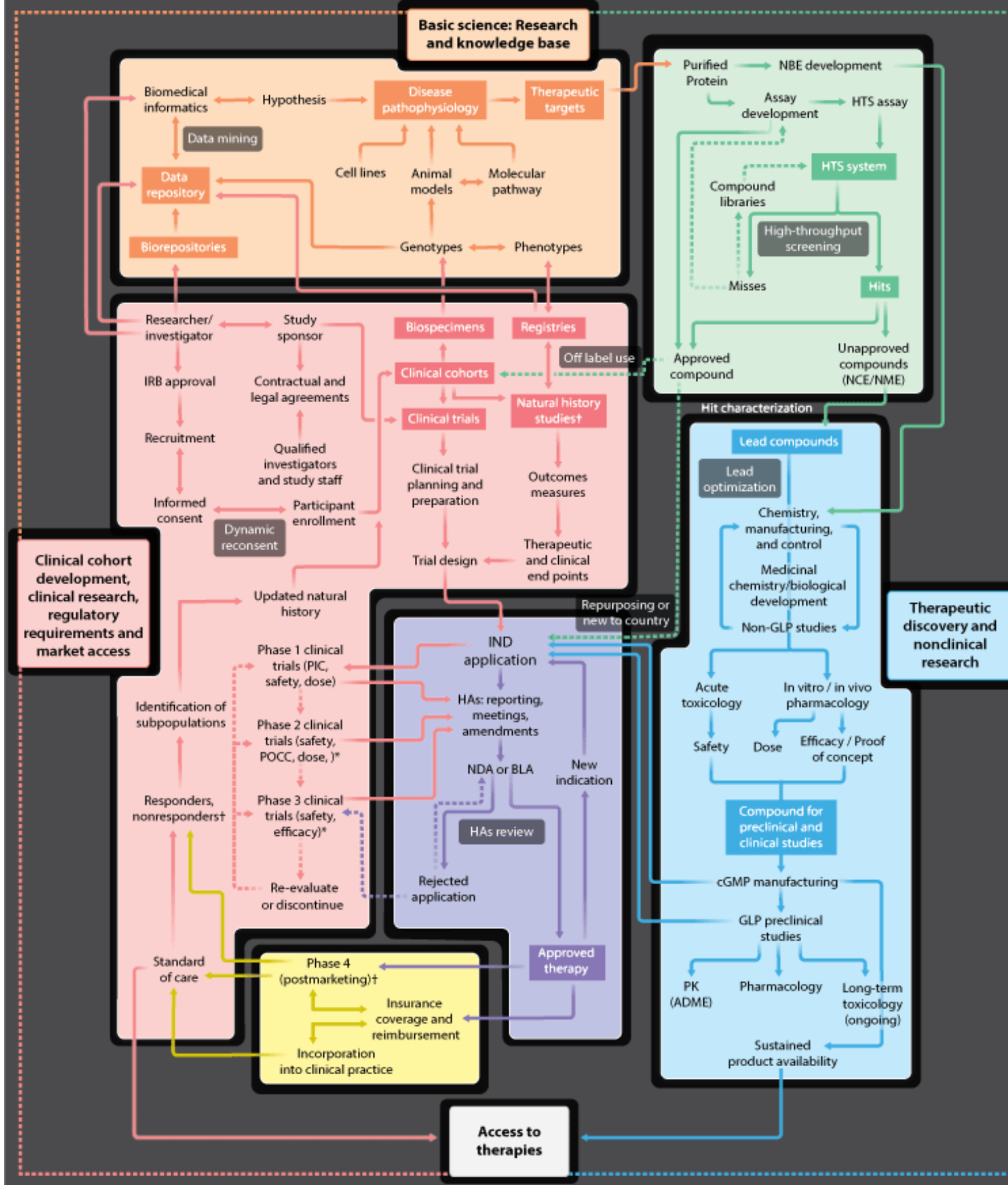
**March 22, 2019**

# Resources for Facilitating Rare Disease Research

# Diversity of Resources

- Information
- Expertise
- Templates
- Tools
- Platforms
- Programs
- Data
- Investment





- What is the purpose of the registry?
- What type of data/samples are collected?
- Who contributes data/from where is the data collected?
- Is the data longitudinal?
- Is the data de-identified?
- National or international?
- How is the registry governed?
- Who owns the data?
- What happens to the data/data use plan?
- How were the questions generated?
- How does the data get to where it is needed most?

# Reality of Registries

- Cost/resources
- Data quality
- Data access
- Policy/regulatory
- Partnership



Cartoon by xkcd at <http://xkcd.com/883/>

A photograph of a road with two yellow center lines and two white arrows pointing left and right. The text "Where is direction needed?" is overlaid on the road.

Where is direction needed?

# Contact

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