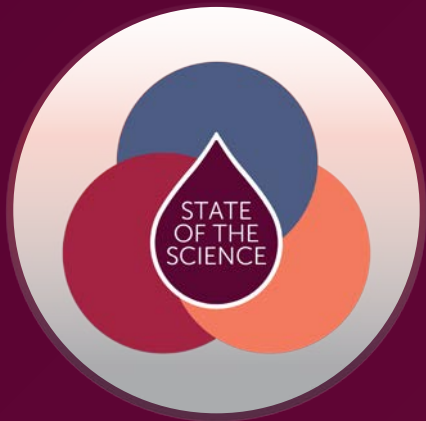




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*for all bleeding disorders*



# State of the Science Research Summit

Working Group 6: Infrastructure



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# Welcome!



- **Co-Chair**
- Children's Hospital Los Angeles,  
University of Southern California



# The working group



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- **Stacy Croteau**, MD, Director, Hemophilia Treatment Center of Boston, Assistant Professor of Pediatrics, Harvard Medical School
- **Randy Curtis**, MBA, Patient Representative
- **Emily Krava**, MPH, CPH, CCRP, Clinical Research Coordinator, Children's Hospital Los Angeles
- **Moses Miles**, Chief Operating Officer, American Thrombosis and Hemostasis Network
- **Lisa Pitler**, JD, MS, RN, CHRC, Healthcare Compliance Professional, Healthcare Regulatory Attorney, Research & Research Administration



# Infrastructure



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**Roads**



**Airports**



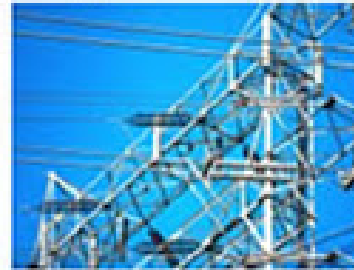
**Harbors**



**Railway systems**



**Energy networks**



**Utility systems**



**Education**



**Healthcare**



**Social Infrastructure**



# Study site infrastructure



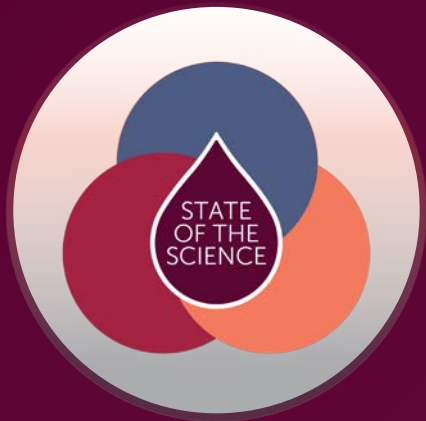
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- Consists of people, processes and tools required to execute a research project at study site
- Two types of processes and tools:
  - Those that are unique to the study site or their larger institution
  - Those that have the potential to be either standardized or centralized between study sites
- The capacity of a study site often determines the ability of the site to participate in a study





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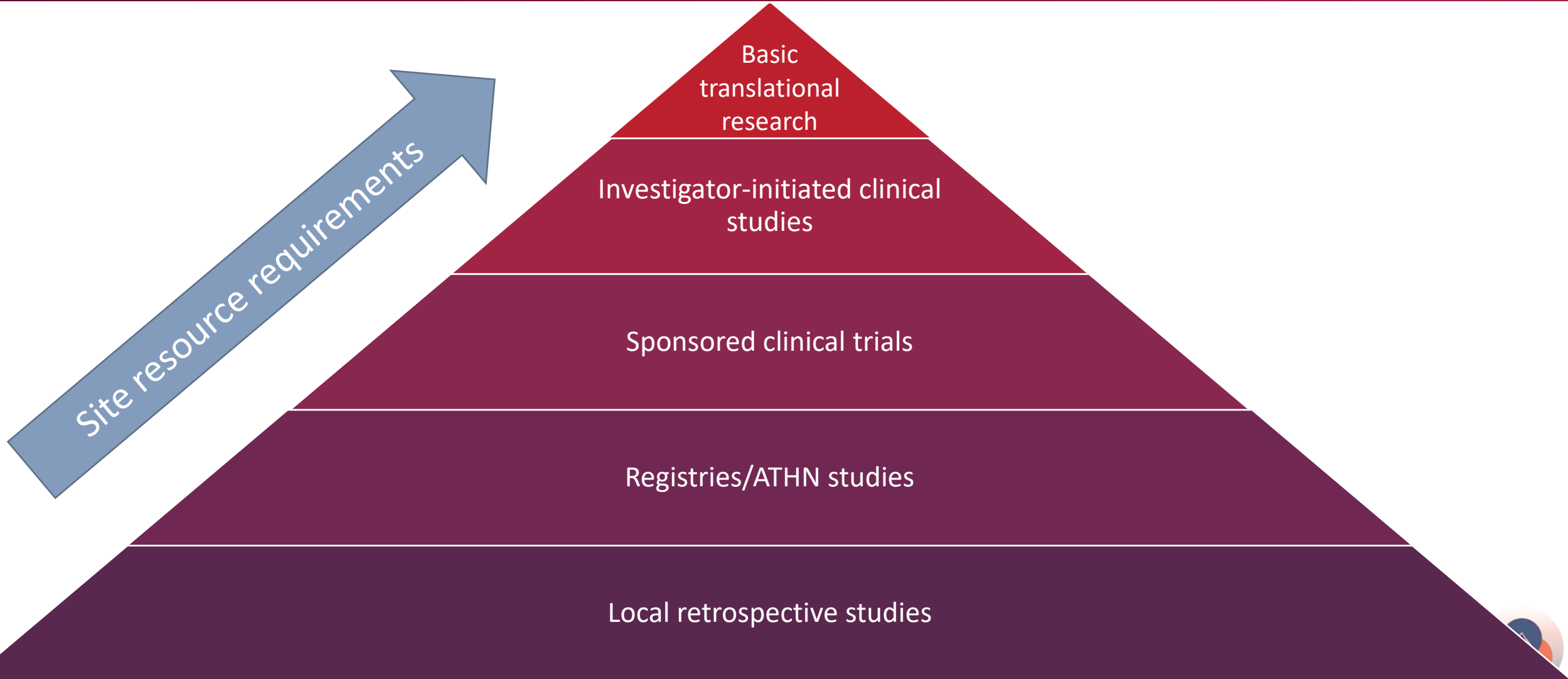


**So, how does this apply to  
research in general?**

# So, how does this apply to research in general?



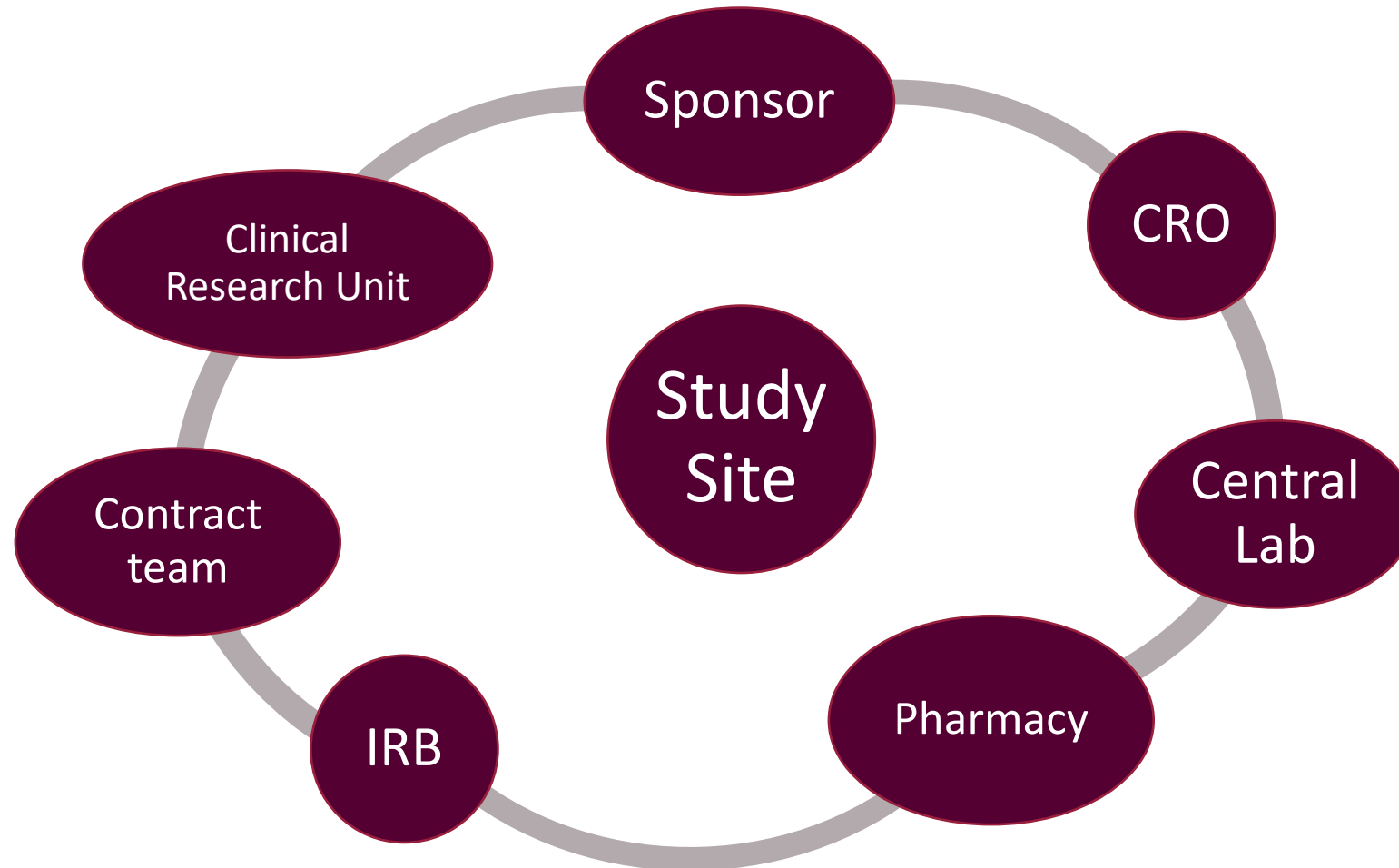
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# The teams



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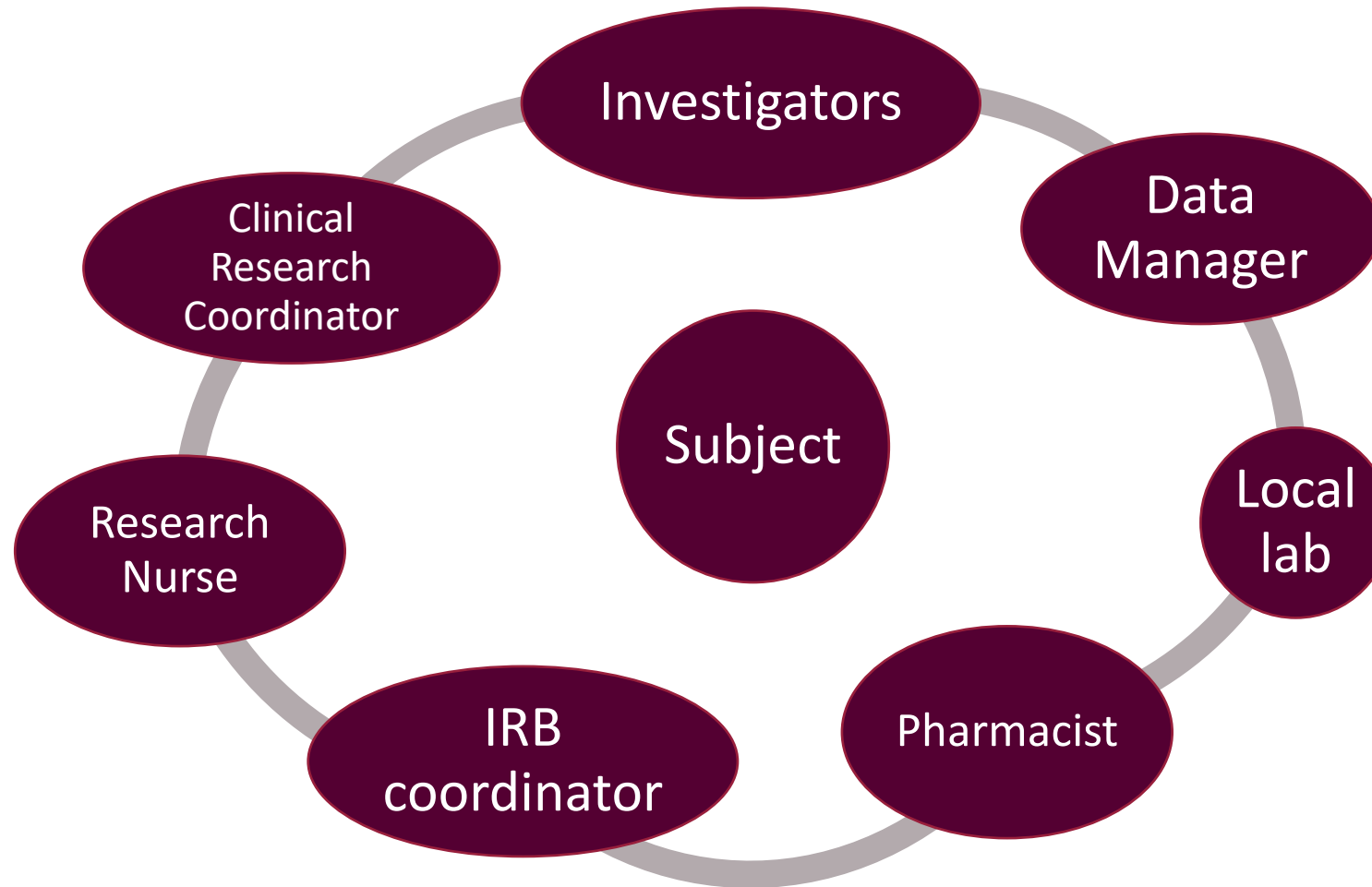




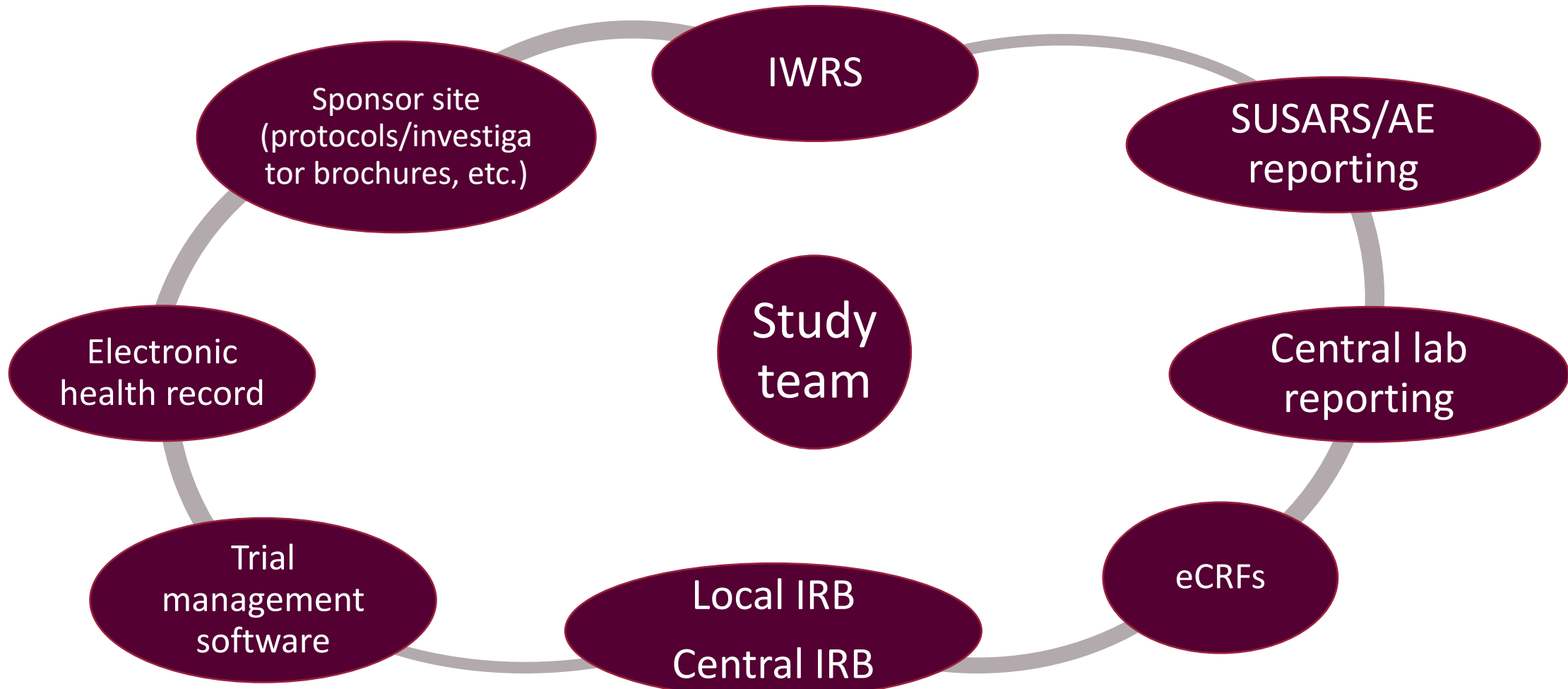
# The players



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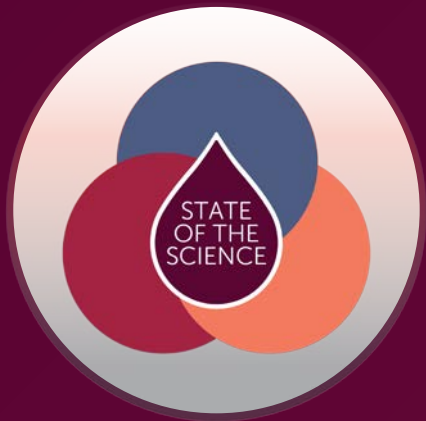


# The interfaces/websites (the short list)





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# So, how does this apply to research in the HTC?

# Hemophilia center types



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Federally-supported Academic Centers  
(University-based adult and pediatric  
hospitals)

Federally-supported Non-university  
Adult and Children's Hospitals

HTC and ATHN affiliates

Federally-supported Non-hospital  
affiliated private HTCs

Non Federally-supported centers



# Research resources vary

[Sources of funding can include grants (HRSA/340B, CDC, other Federal grants, other grants), sponsored studies (pharma), philanthropy]



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- Centers with significant resources for research
  - Many staff (CRCs, CRNs, IRB coordinator, research lab, etc.)
  - Can participate in most if not the full pyramid
- Centers with some funding for research
  - Some staff sufficient for some of the pyramid
- Centers with 1-2 staff members who perform double duty e.g. clinical nurses who function as research nurses
  - Generally, only participate in ATHN/CDC studies
- No dedicated research staff
  - May participate in some research (ATHN/CDC) volunteering their time

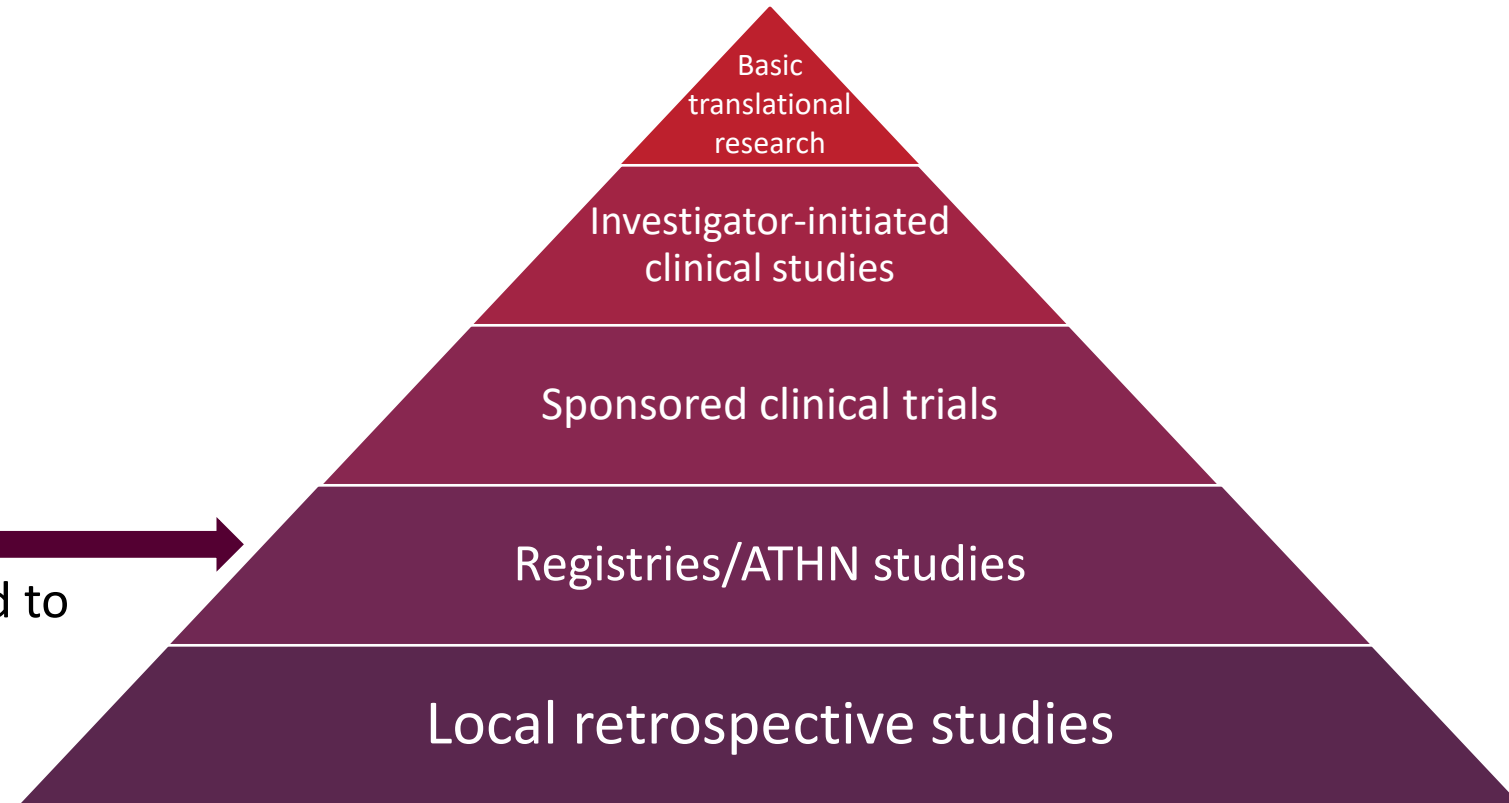


# What should be the expectations?



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- Not all centers can do all research
- Goal should be for **every** HTC to at least be able to participate in CDC Community Counts/ATHN dataset/ATHN Transcends
  - Funding and other support is required to achieve this



# How do we get there?



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- Dr. Ragni's group will discuss funding sources
- NHF/ATHN should work with the centers to achieve some semblance of equity. For example:
  - More funds allocated to smaller centers in order to get everyone to the second layer of the pyramid
  - Assistance with “start up” for centers that are not achieving the second level
  - Development of a “centralized” research hub for services aimed at increasing the capacity of center to participate in research
  - Provision of educational opportunities/training

