Using Metrics to inform the Return on Investment (ROI): A Public Funder's Perspective

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NIH Virtual Workshop on Data Metrics
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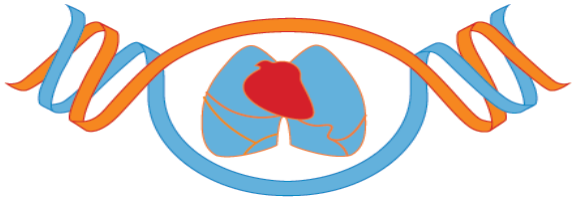
National Heart, Lung, and Blood Institute

NHLBI Data/Materials Sharing

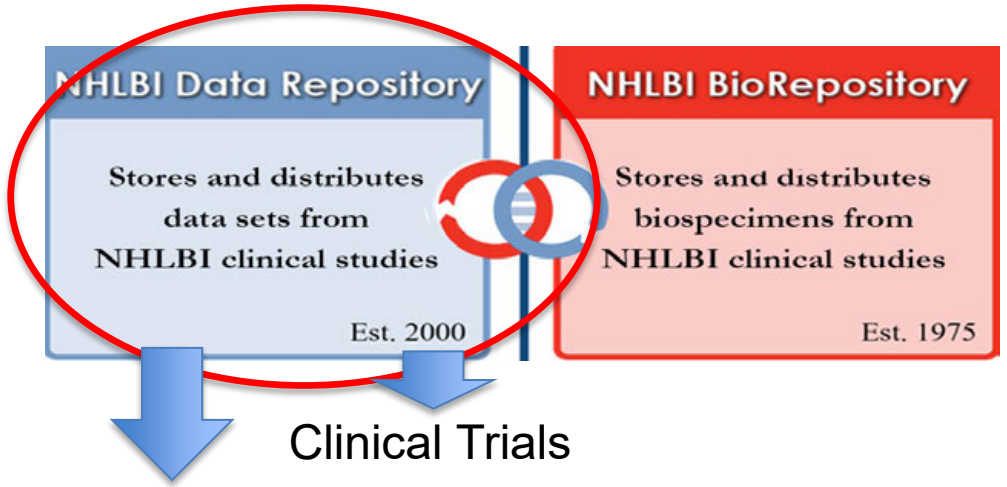
database of Genotypes and Phenotypes (dbGaP), GWAS, microRNA, gene expression profiling

Trans-Omics for Precision Medicine (TOPMed); WGS, metabolic profiles, protein and RNA expression, DNA methylation



BioData Catalyst

Storage, Toolspace, Access and analytics for big data Empowerment



BioLogic specimen & data repositories INformation Coordinating Center (BioLINCC); biospecimens & phenotypic data

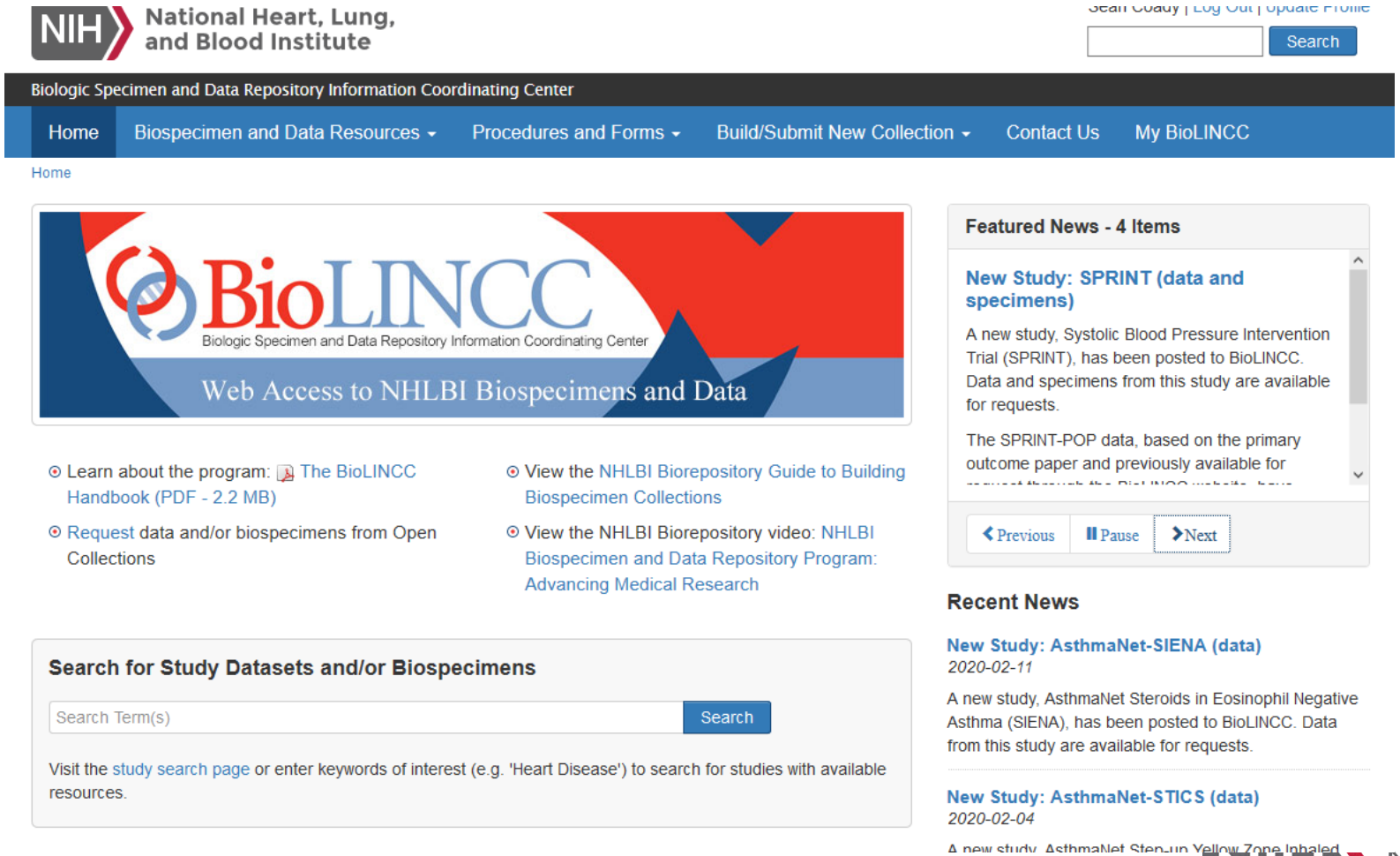
Background – Data Repository

- 1999 NHLBI IRB approves data repository protocol. Website opens in 2000 (NIH IRB # 12-H-N198)

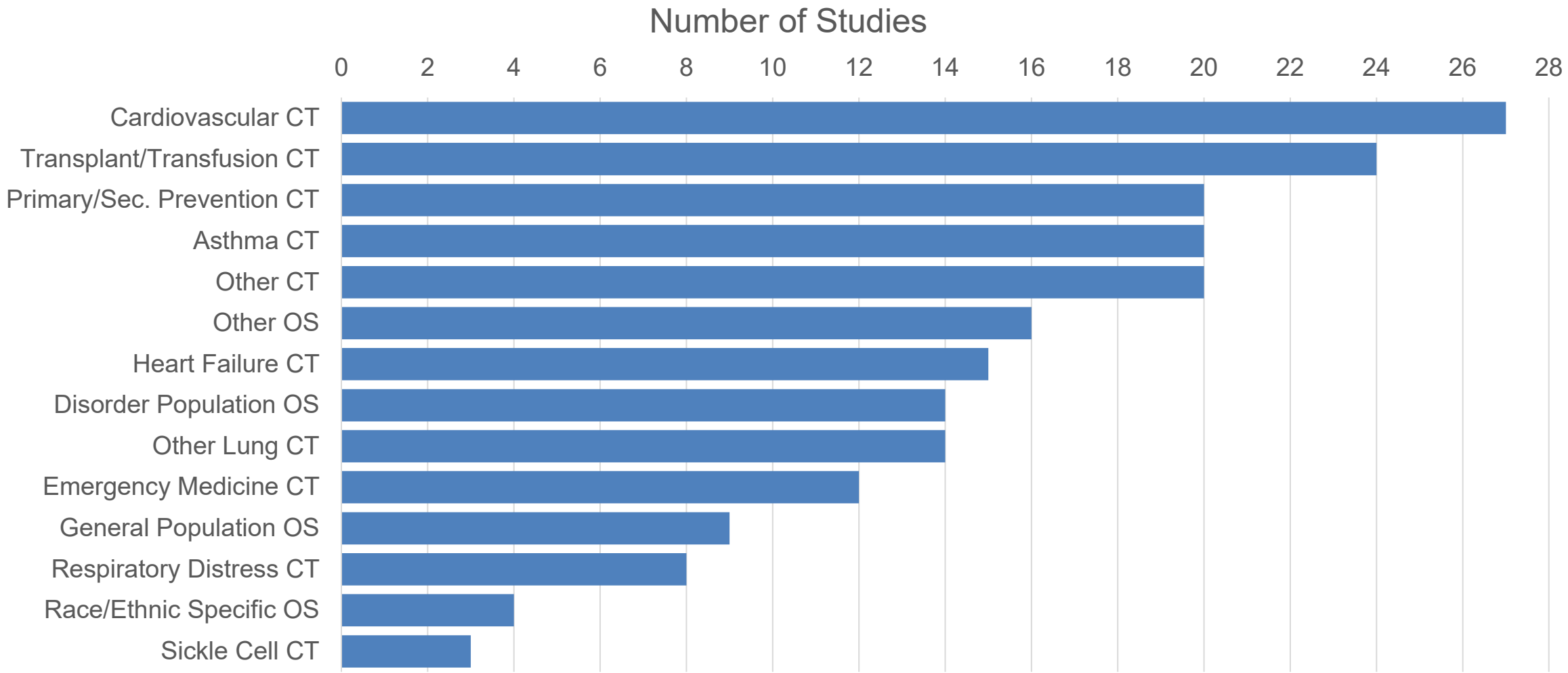
- Purpose:
  In order to take full advantage of NHLBI supported clinical trials and epidemiologic studies and maximize their research value, data should be made available, under appropriate terms and conditions, to the largest possible number of qualified investigators in a timely manner.

Background BioLINCC

BioLINCC established in 2009 to coordinate activities of Data Repository and Biorepository



Current controlled access portfolio: 50 Observational studies (778,732 participants), 157 trials (460,816 participants)



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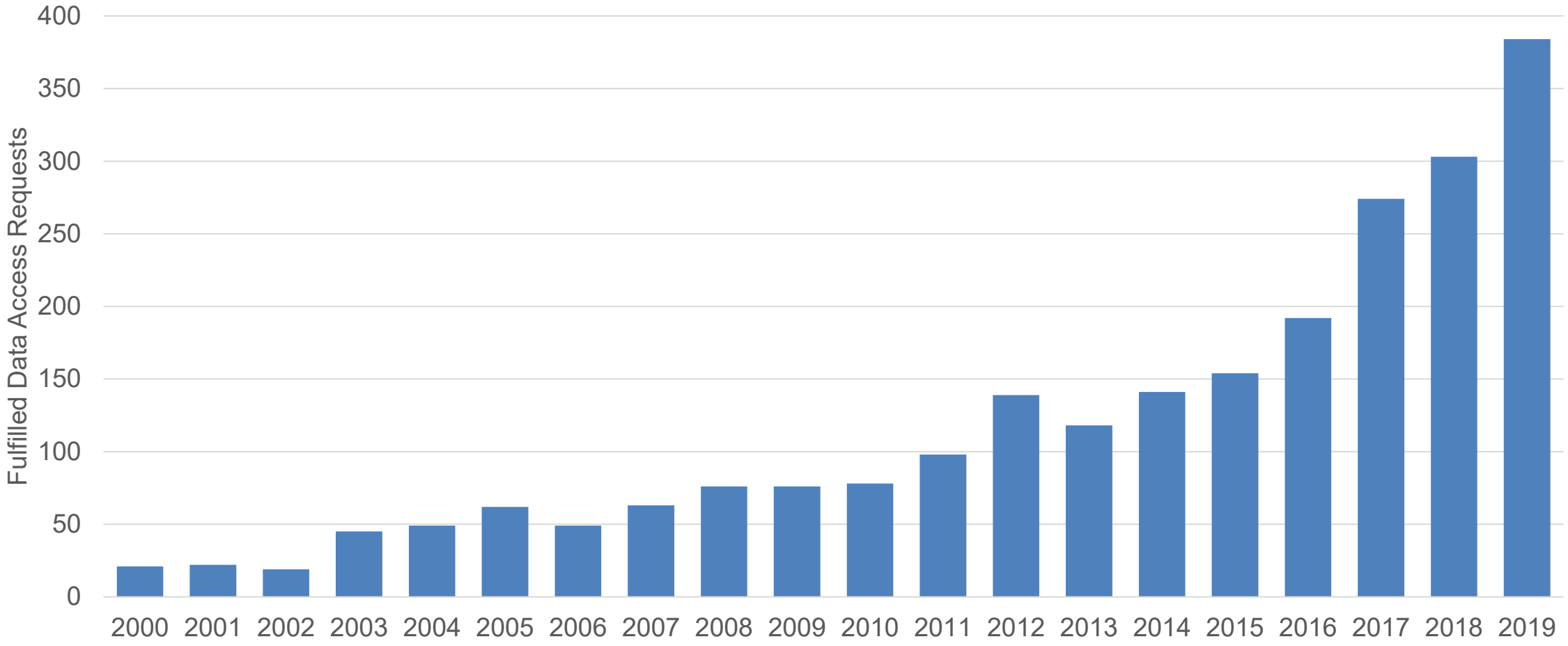
Data Repository Metrics

- Utilization Metrics
- Outcome Metrics
- Effort Metrics
  - Number of interactions and time to complete data access request
  - Support encounters
  - Monitoring

Utilization Metrics: Completed data access requests



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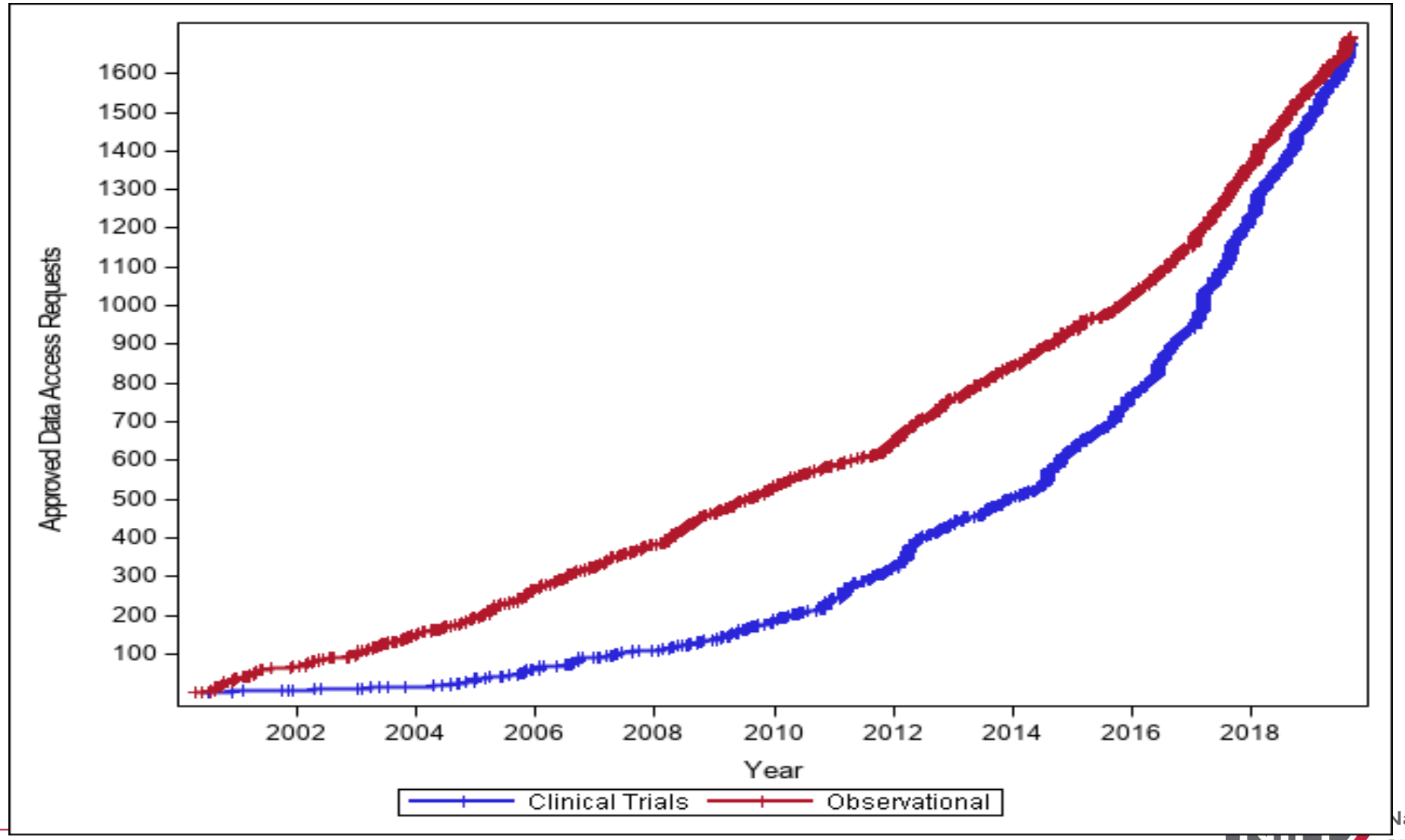
Utilization Metrics: Cumulative data access requests for trial and observational study data (thru, 2019)



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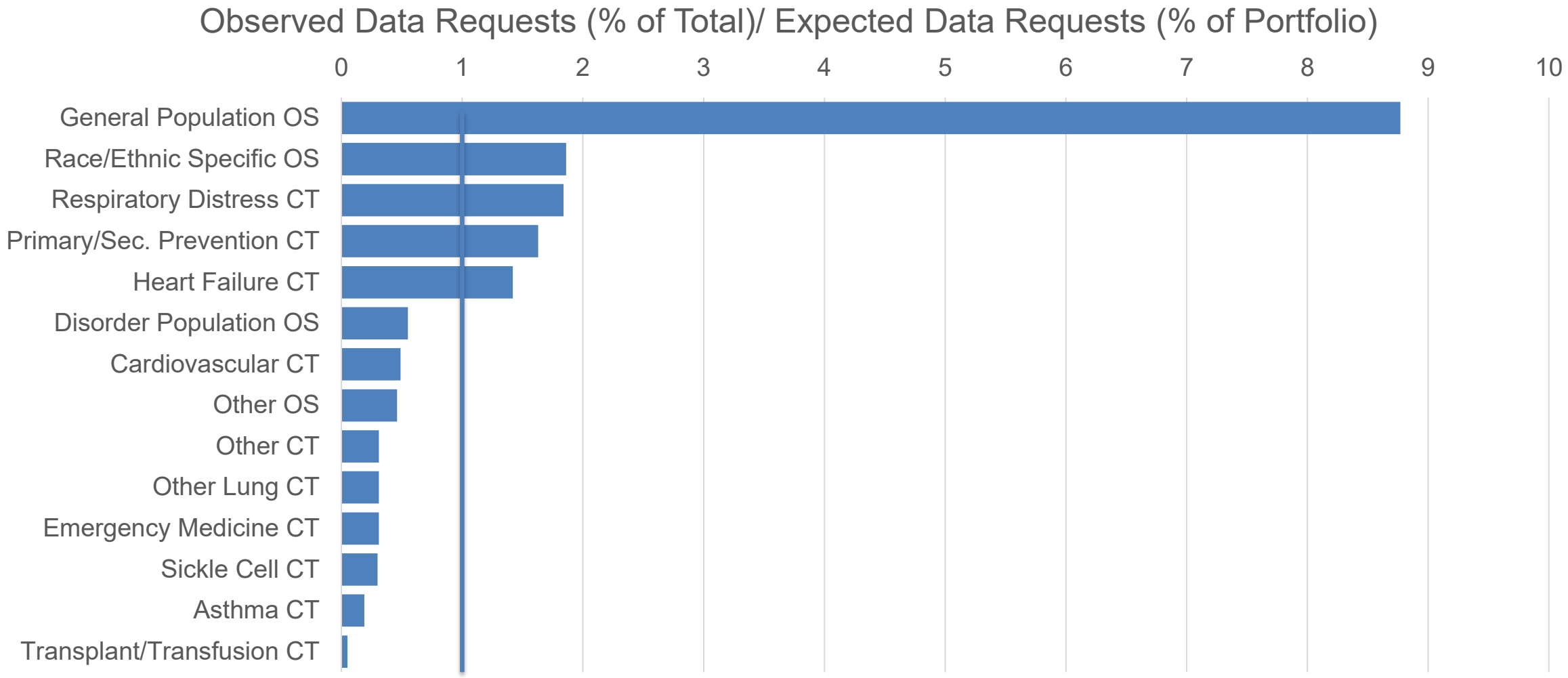
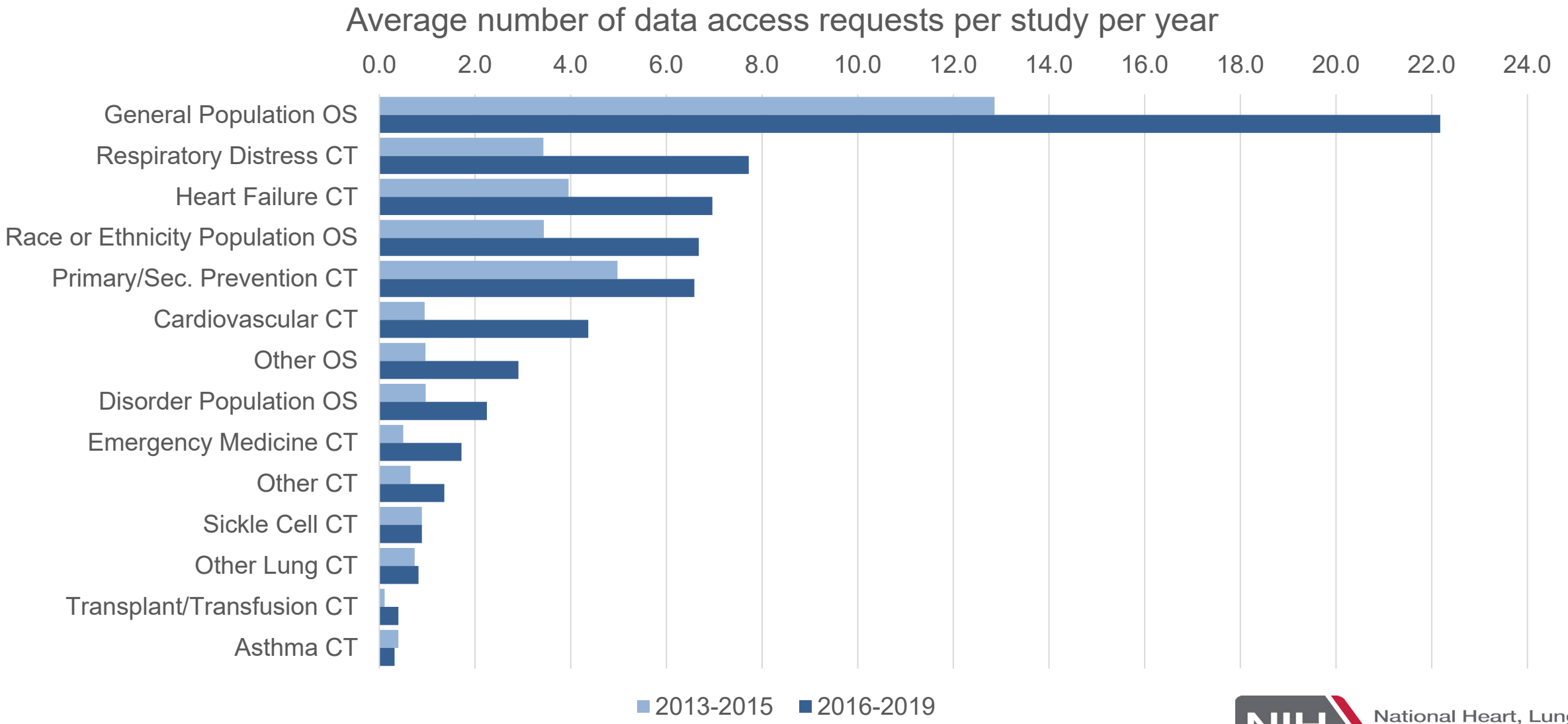
Utilization Metrics: Observed / Expected Utilization by study type



Utilization Metrics: Trends in Utilization by Study Type



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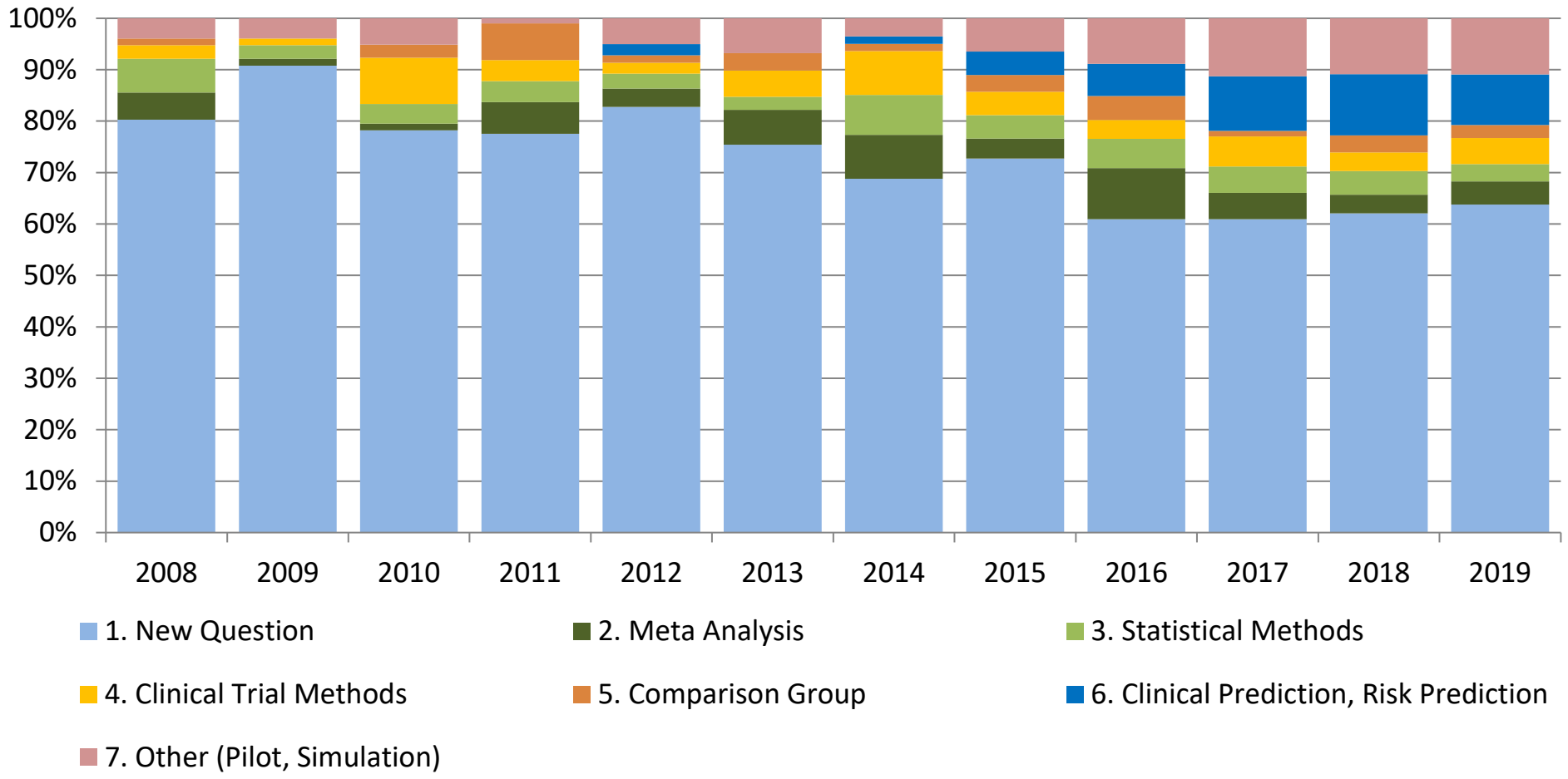
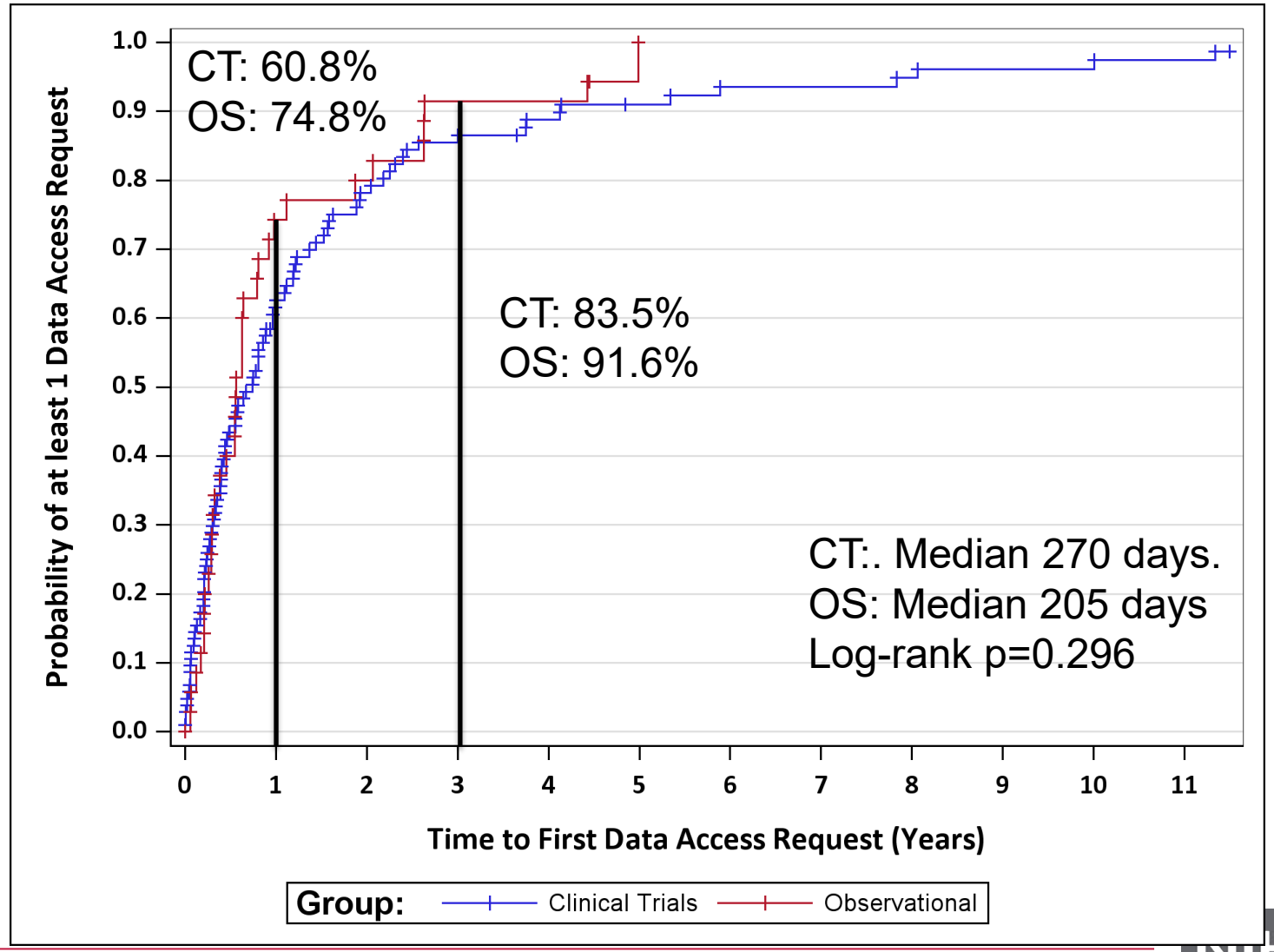
Utilization Metrics: Primary reason for data access request



Utilization Metrics: Time from availability of study to first access request



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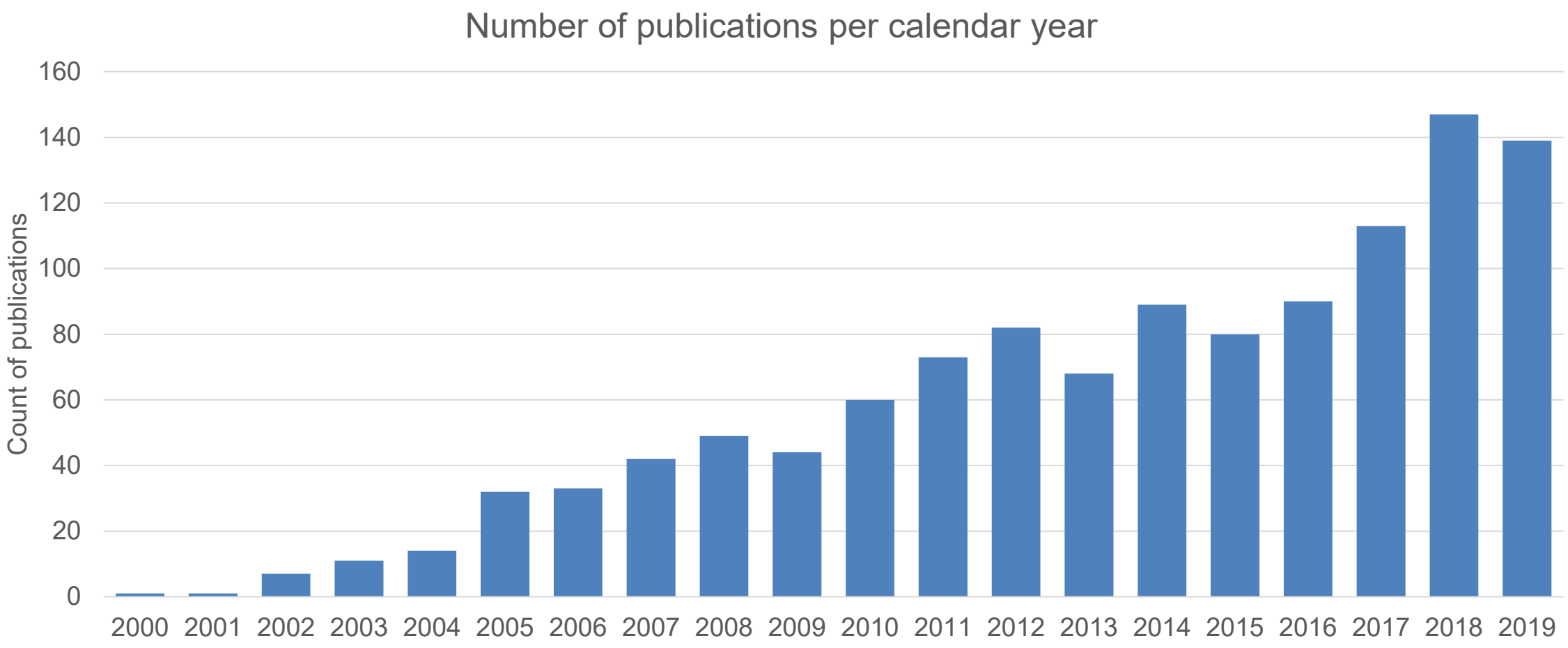
Outcome Metrics: Publications



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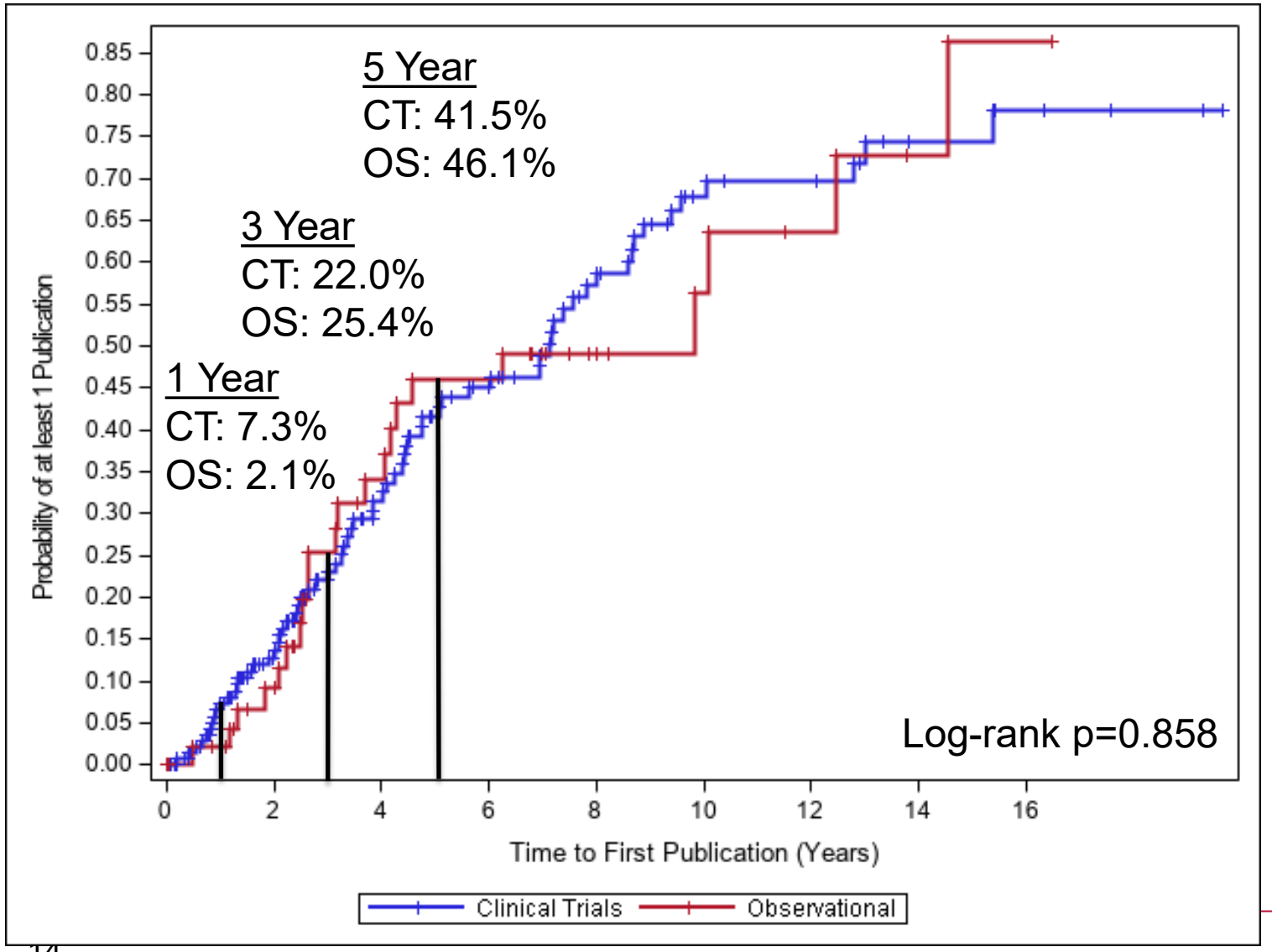
Outcome Metrics: Time to “Incident” publication by type of study (through 2019)

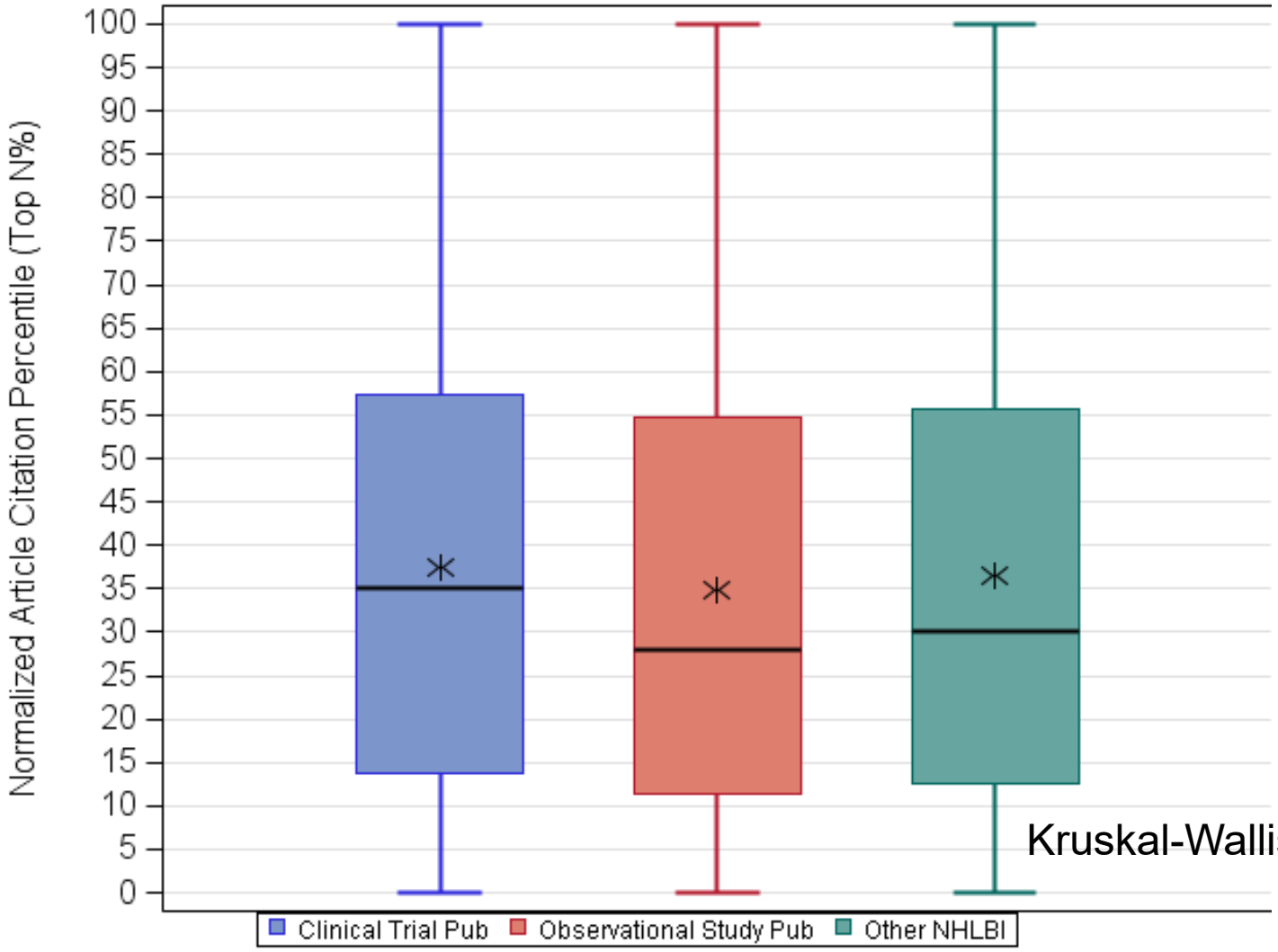


1179 publications
596 Included data from 1 or more trials

69 Trials 1+ publications

506 investigators have published at least once. Mean number of publications per investigator publishing=3.0

Outcome Metrics: Citation Percentile (Top N%) publications using repository trial data, observational data and 10% random sample of all NHLBI supported articles (Articles thru May 2015)



Kruskal-Wallis Test p=0.333

Outcome Metrics: Workforce training

- 23% of completed data access requests indicate primary user has 0-5 years of research experience

- QVR search of NIH grant applications found only two training applications (1 K01, 1 K99) mentioned BioLINCC

Messages from the metrics

- Demand for secondary use of data from clinical strudies continues to steadily increase
- Growing demand for data from clinical trials
- Metrics can suggest gap areas
- Data from repositories fulfill a range of purposes
- Unclear if publication rates are low
- Citation metrics suggest quality of publications utilizing repository data are similar to publications supported directly by the Institute
- Need to better assess role of repositories in training new investigators