

## **Current state of clinical data research networks & GPC (Waitman, Fennel, McClay)**

- I. Russ shared PCORI's overview of the network
  - a. PCORnet is very complex and ambitious
    - i. Integrated billing & clinical data – significant accomplishment
    - ii. Heightened coordination between regulatory and informatics teams
    - iii. Researchers & patients coming together to improve research
  - b. GPC and national network...are behind schedule
    - i. Massive studies underway while infrastructure under development has revealed obstacles & misalignment and challenges relationships
  
- II. Update from national PCORnet meeting
  - a. PCORnet invested over \$300 million in infrastructure
  - b. 3 coordinating centers: Duke Clinical Research institute, Harvard Pilgrim HCl, Genetic Alliance (patient advocacy org)
  - c. Russ serves on PCORnet executive committee
  - d. Over 130 health systems across the country
  - e. Over 80 data marts
  - f. Work to standardize to a common data model – goal to put data in standard format
  - g. Research demonstration projects include – ADAPTABLE (aspirin), Antibiotics & Excess Weight Gain (do antibiotics cause excess weight gain in children), Bariatric Surgery (outcomes of 3 main surgical treatment options for 1, 3, 5 years)
  - h. High integration of data & ability to scale network – PCORnet wants to be in this space
  - i. How PCORnet differentiates itself from other organizations – patient-focused research agenda that addresses needs of society
  - j. PCORnet sustainability goal – create a sustainable better, faster, cheaper platform
  - k. Key market is clinical trials
  - l. To establish PCORnet entity as a 501(c)(3)
    - i. PCORI up for reauthorization next year by Congress
    - ii. Future of PCORI depends on sustainability plan
    - iii. Patient recruitment – a key area of opportunity
    - iv. PCORnet Front Door – entryway for engagement
  - m. Recruitment for ADAPTABLE is way behind
  
- III. Network development
  - a. Data use for “two masters” – trial recruitment & big picture for observational studies
  
- IV. GPC charge - help leadership consider the best path:
  - a. for you (individual),
  - b. your “site”,
  - c. your regional partners,
  - d. the GPC,
  - e. and PCORnet.