

Priority Capability Discussion and Decisions



Russ Waitman, facilitator
October 26, 2021 9 am

Areas from Thursday (besides Proposal milestones)

- Deeper health system engagement
 - Need to socialize with our health systems better so they understand how integral their partnership is to research.
 - Frustration among PIs that they can't move forward due to health system barriers
- Build upon NET-PRO rare cancer trial (ancillary studies)
 - Also address NAACCR file format changes
- Genomic integration (VCF, BAM)
- Mom/baby linkage and maternal health

Areas from Thursday (continued)

- Blood pressure control pragmatic trial
 - Utah related weight loss retention also home devices
- Data quality and push every site's ability to recruit to prospective trials.
- Leverage GROUSE platform and data linkage and subscription model is intriguing
- Infectious disease, build on public health
- Health equity, broad phenotyping
- Neuromuscular trials (CSPN)

Other items outside milestones

- Front door refresh
- TRAC/google docs improvements/platform?
- PASC likely to prioritize some data domains
- Have a AWS/Snowflake follow up socialization with some sites

Discussion

- Betsy: dealing with home medications/medication reconciliation (PREVENTABLE impact as well as BESTMED)
 - Jim: also implications of surescripts, careeverywhere
- See paper
- Jim Besides Neuro and Cancer, other embedded labs like BP control, DM, sleep, Obesity/Bariatric/DM
 - Continued work in COVID (Betsy)
 - Lindsay linking viral genome sequencing (UNMC also funded to do it for N3C); incident autoimmune disease post covid (PASC crossover); genomic variants in immune genes. Also has a targeted list of genes that also may be associated with variability across demographic groups.

From the proposal, potential areas

- Data expansion (notes, SDOH, PASC crossover)
- Linkage, DataVant/Snowflake, non-profit and industry (VINCI with Dr. Kean) licensing quarterly
 - Payor engagement?
- Deeper health system engagement value proposition
- EHR-REDCap Integration at 'vanguard sites'
- GROUSE (CMS + other claims/linkages, SDOH)
- Coordinating Center Scopes (see following)

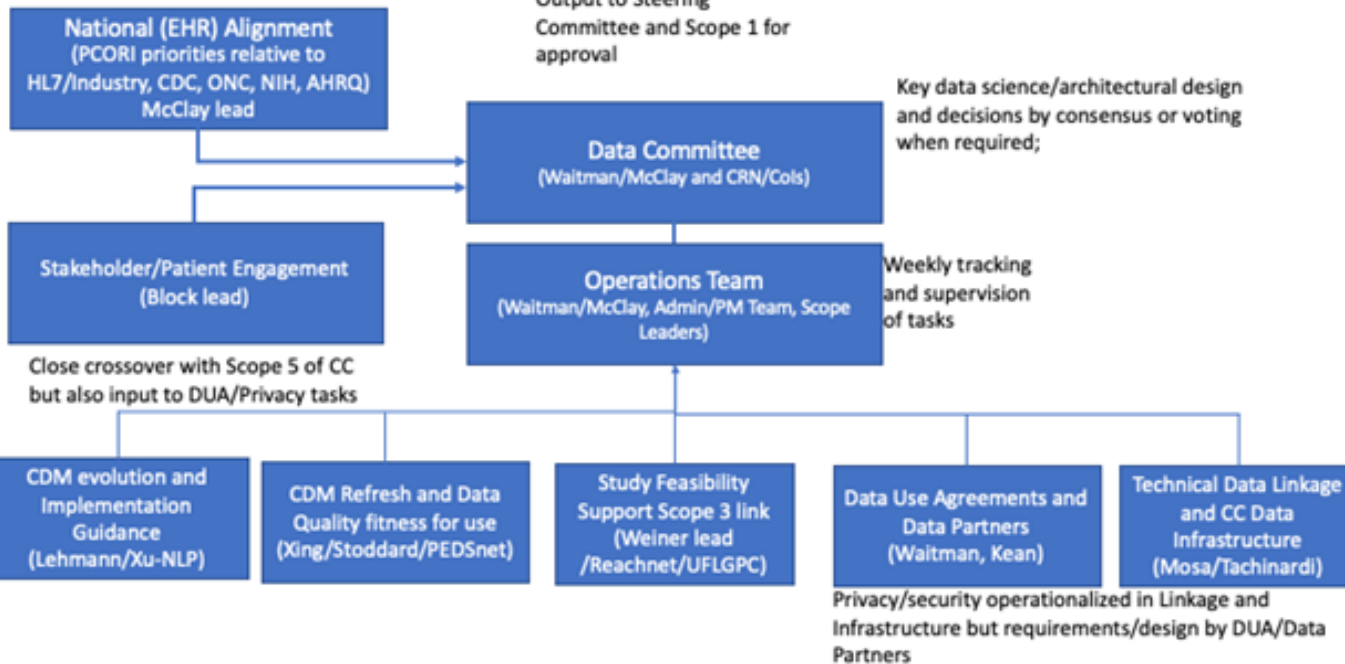
PCORnet Coordinating Center Scopes

- \$3.0 million - Scope 1: PMO to Facilitate PCORnet Governance, Collaboration, and Operations to Enable Multi-network PCORnet Research of Definitive Studies of National Scope
- \$5.0 million - Scope 2: Maintenance and Development of the PCORnet Common Data Model, Data Characterization, and Privacy Preserving Record Linkage
- \$6.5 million Scope 3: PCORnet Designated Study Consultation and Query and Analytic Tool Development to Enable Multi-network PCORnet Research
- \$1.5 million - Scope 4: PCORnet Communications
- \$2.0 million - Scope 5: Highly Engaged Patients, Researchers, Clinicians, Health Systems, and Health Plans

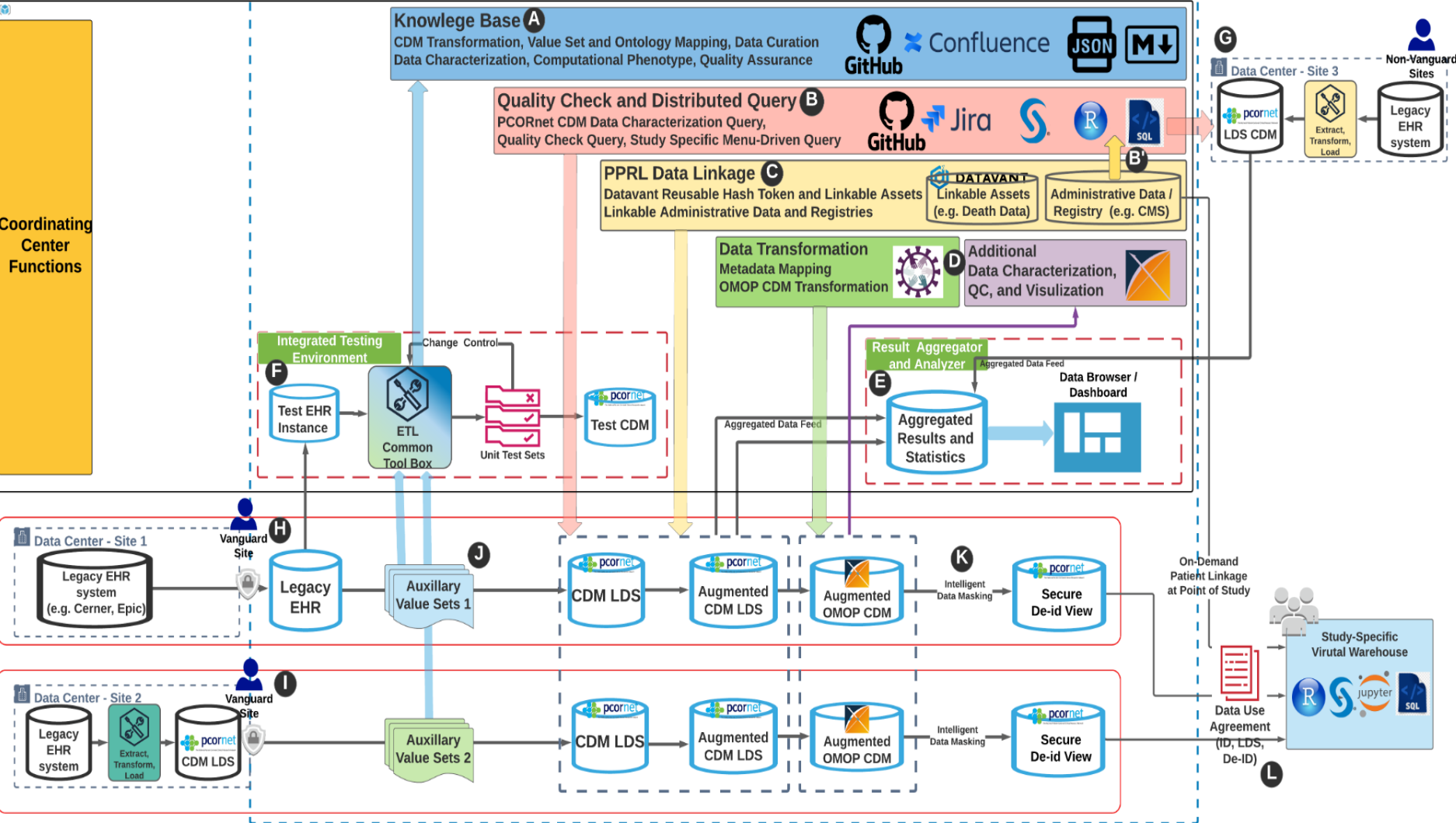
Scope 2: Data and Linkage, HEDWIG

- Mizzou, MCW, Houston, Indiana, Nebraska, Utah, CHOP, Hopkins, ADVANCE,

Key input to all Scope 2 tasks and Scope 3

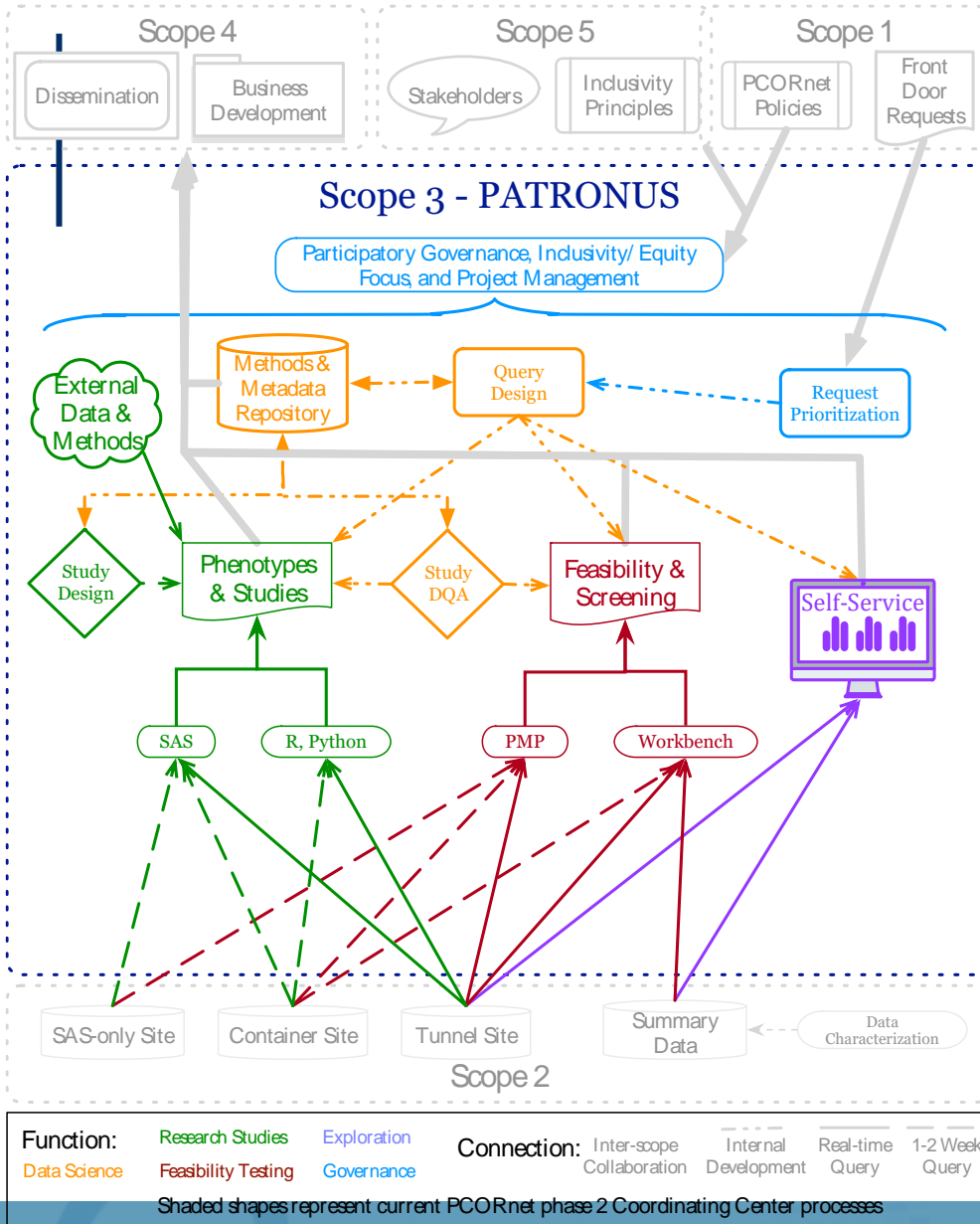


PCORnet Scope 2 - AWS/Snowflake Virtual Private Cloud meeting HIPAA and NIST-800-53 for Federal Security Requirements



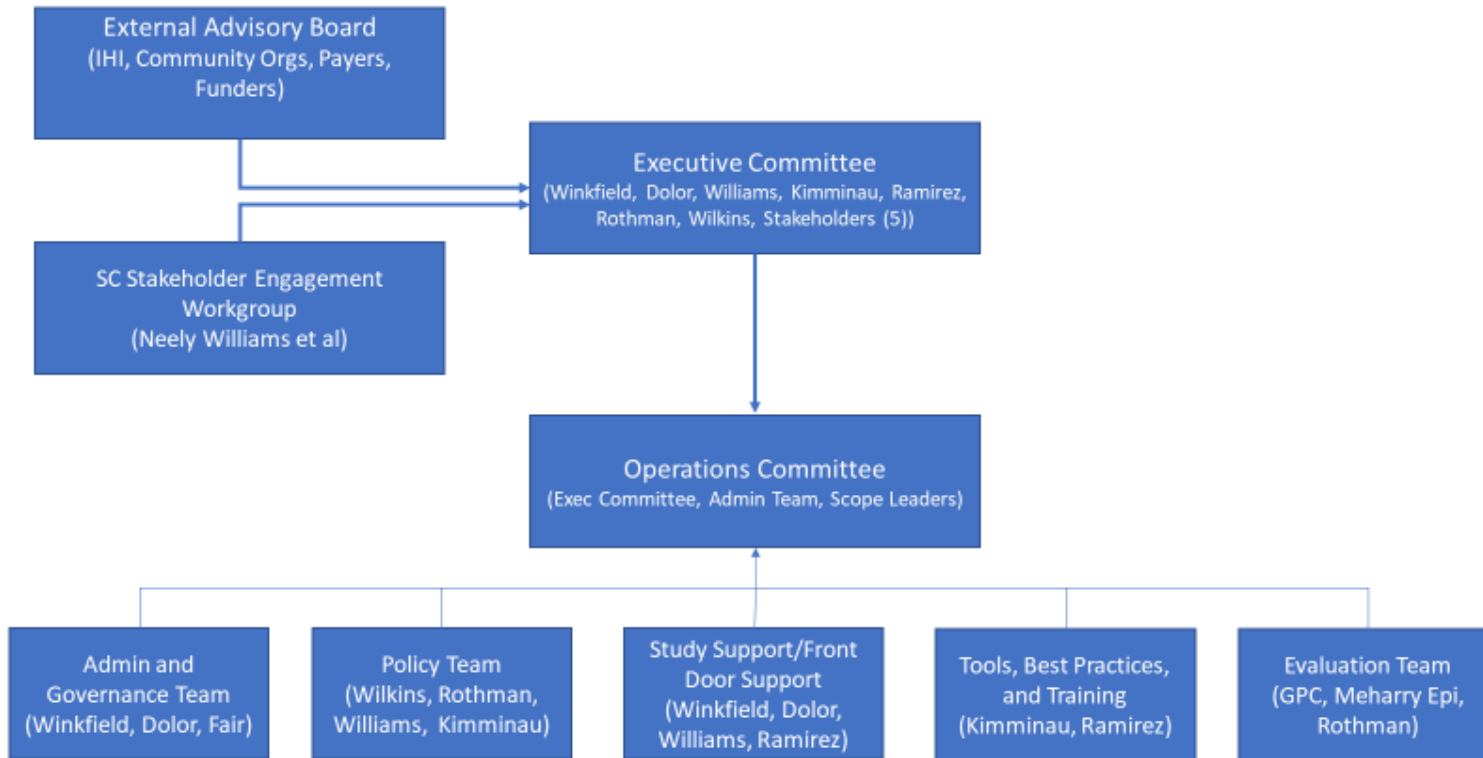
Scope 3

- **CHOP**, Cornell, Pitt, Mizzou, Iowa, Hopkins, OCHIN, Northwestern/Lurie



Scope 5: Engagement

- Vanderbilt/Star, San Antonio, Mizzou



Thank you.



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