emerge network

genda: Steering Committee Meeting

Thursday, June 6th, 2024

Venue: Le Meridien Philadelphia | 1421 Arch Street, Philadelphia, PA 19102

The Trumbauer Ballroom Meeting Room:

Breakout Room: Abele Library 8:30-9:00 AM

9:00-9:15 AM NHGRI Program official report | Robb Rowley (NHGRI)

Announcements & opening remarks | Rex Chisholm (SC Chair, Northwestern) 9:15-9:30 AM

9:30-10:45 AM Panel: End of recruitment & GIRA return targets | Sites

Site report outs (5 minutes/site)

Moderators Gail Jarvik (UW), Iftikhar Kullo (Mayo), Cindy Prows (CCHMC) | Discussion (15 minutes)

Networking Break 10:45-11:05 AM

Workgroup breakout session one 11:05-12:15 PM

Recruitment & Return (CARE, R2/ELSI/sIRB, & QA/QC Taskforce) (The Trumbauer Ballroom)

Secondary use of data (GRID) (Abele Library)

Working Lunch 12:15-12:45 PM

12:45-1:05 PM Considerations for Return of Polygenic Risk Scores to Pediatric Research Participants in eMERGE 4 | Sharice

Wood (CCHMC) & Jasmine Purcell (CHOP)

1:05-2:15 PM Workgroup breakout session two

• Outcomes collection & analysis (Provider Uptake & Outcomes, Phenotyping, & QA/QC Taskforce) (The

Trumbauer Ballroom)

Ethical, social, & legal issues of data utilization (ELSI) (Abele Library)

2:15-2:35 PM **Networking Break**

2:35-2:55 PM Sample updates & Clinical operations | Swaroop Aradhya (Invitae) & Katie Larkin (Broad)

2:55-3:00 PM Closing Remarks | Rex Chisholm (SC Chair, Northwestern)

3:00 PM **Adjourn**

4:00 PM Tour of Penn Museum (Penn Museum, 3260 South St, Philadelphia, PA 19104)

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Friday, June 7th, 2024

Venue:

Meeting Room:	The Trumbauer Ballroom
8:30-9:00 AM	Breakfast
9:00-9:20 AM	Overall outcomes analysis plan discussion Nita Limdi (UAB) & Dave Veenstra (UW)
9:20-10:50 AM	Outcomes report outs: Adult conditions Sites Condition report outs (10 minutes/condition) Moderators: Nita Limdi (UAB) & Dave Veenstra (UW) Discussion (10 minutes)
10:50-11:10 AM	Networking Break

10:50-11:10 AM	Networking Break
11:10-11:30 AM	Outcomes report outs: Pediatric conditions Cindy Prows (CCHMC), Hakon Hakonarson (CHOP), Jeff Roizen (CHOP)
11:30-11:50 AM	Capturing outcomes via phenotyping Wei-Qi Wei (VUMC) & Shawn Murphy (MGB)
11:50-12:30 PM	Working Lunch
12:30-1:00 PM	QA/QC data, progress, and next steps Lisa Martin (CCHMC) & Jen Pacheco (Northwestern)
1:00-1:20 PM	Secondary use of data on AnVIL Adam Gordon (Northwestern) & Matt Lebo (MGB)
1:20-1:40 PM	CIRT Manuscript Proposal Emma Perez (MGB) & Bob Freimuth (Mayo)
1:40-2:25 PM	Timelines, publications, & network goals Leadership: Robb Rowley (NHGRI), Josh Peterson (CC/VUMC), Rex Chisholm (Northwestern).
2:25-2:30 PM	Closing Remarks Rex Chisholm (SC Chair, Northwestern)

2:30 PM

Adjourn