



# PMI Cohort Program Update

September 9, 2016

Eric Dishman

Director, PMI Cohort Program

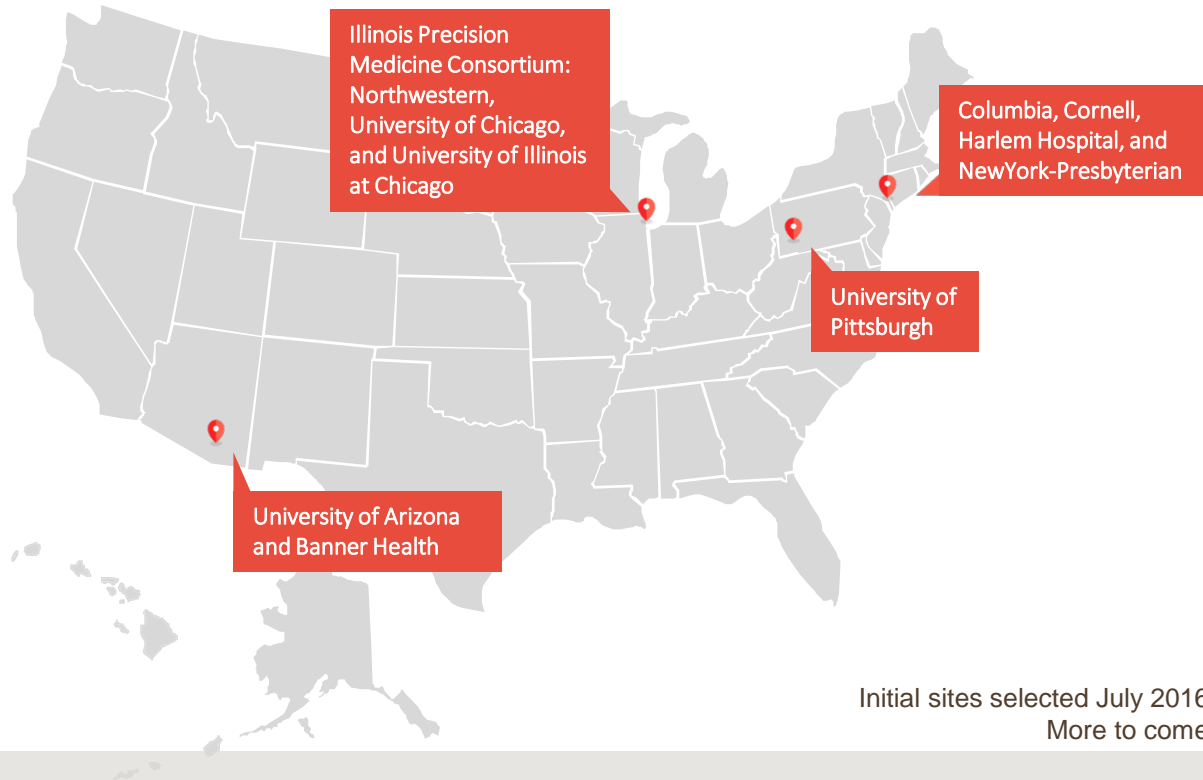
## Key Developments

- Awardees selected
- New HPO funding opportunity
- Governance established
- Survey findings published

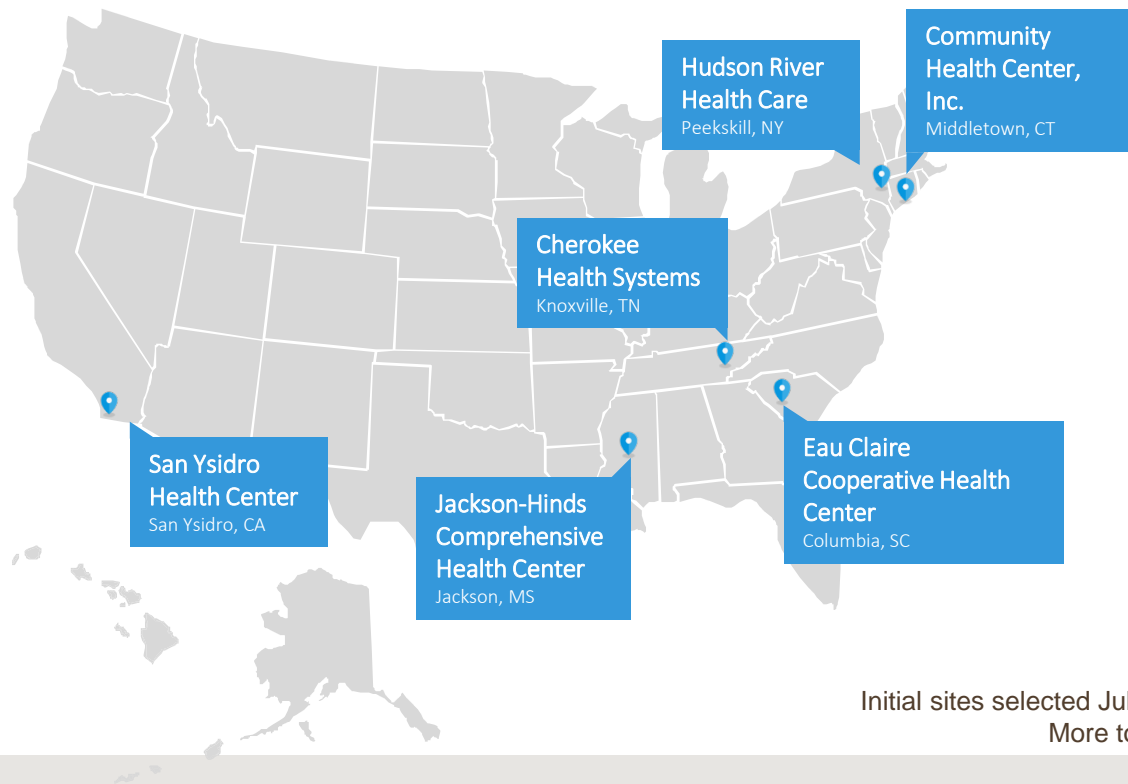
## Awardees Selected

- **Biobank:** Mayo Clinic
- **Data and Research Support Center (DRC):** Vanderbilt University Medical Center and Verily
- **Participant Technologies Center (PTC):** Scripps Research Institute and Vibrent Health

# HPOs: Regional Medical Centers



# HPOs: FQHC Pilot Sites



## HPOs: VA Medical Centers

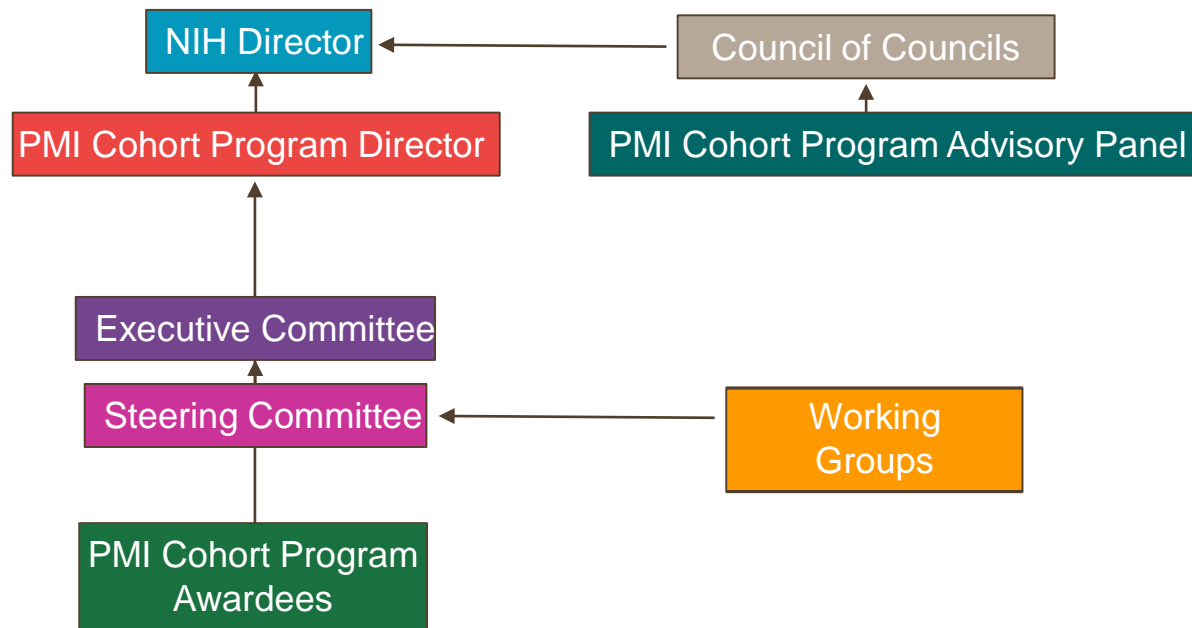


- Participating VA medical centers TBD
- Collaboration with Million Veteran Program

## New Other Transaction Award

- Precision Medicine Initiative® Cohort Program Regional Medical Center Healthcare Provider Organizations (OT2)
  - <https://www.nih.gov/sites/default/files/research-training/initiatives/pmi/20160728-hpo.pdf>
  - Applications due Aug. 29; award by Sept. 29 (FY2016)
  - Intend to fund 3 awards
- OT mechanism – partnerships with non-traditional applicants
  - Prioritizing integrated delivery networks
  - Prioritizing HPOs that can enhance geographic coverage of the consortium

# Governance





# Executive Committee

- **Co-chairs**: Eric Dishman, NIH; Josh Denny, M.D., Vanderbilt Univ. Medical Center (DRC)
- **Participants**: Martha Daviglus, M.D., Ph.D., University of Illinois at Chicago
- **PTC**: Eric Topol, M.D., Scripps
- **Biobank**: Stephen Thibodeau, Ph.D., Mayo Clinic
- **HPOs**:
  - **FQHCs**: Wanda Montalvo, Ph.D., R.N., CHC, Inc.
  - **Regional Medical Centers**: David Goldstein, Ph.D., Columbia
  - **VA**: Chris O'Donnell, M.D., Harvard, VA Boston, Brigham and Women's
- **NIH**:
  - **Clinical**: Michael Lauer, M.D., NIH Deputy Director for Extramural Research
  - **Program**: Joni Rutter, Ph.D., Director for Program and Strategic Implementation, PMI Cohort Program, NIH
  - **Technology**: James McClain, Ph.D., Interim Technology Lead, PMI Cohort Program, NIH

## Working Groups

- Consent
- Data Privacy and Security
- Data Sharing with Participants/Return of Information and Value
- Electronic Health Records
- Engagement and Communications
- Participant-provided Information
- Physical Evaluation and Biospecimens
- Program Coordinators
- Protocol Integration
- Publication, Access, and Policies
- Scientific Vision

## ■ Survey Suggests Broad Public Support for Program

- 2,601 responses analyzed
- 79% supported the program after reading short description; 54% said they would definitely or probably participate if asked—not predictive of enrollment #'s, but encouraging
- Little variability among demographic groups
- Most important incentive for participation: learning about one's health information

Kaufman DJ, Baker R, Milner LC, Devaney S, Hudson KL (2016) A Survey of U.S Adults' Opinions about Conduct of a Nationwide Precision Medicine Initiative® Cohort Study of Genes and Environment.

PLoS ONE 11(8): e0160461. doi:10.1371/journal.pone.0160461

## Working Toward Launch

- Launch to occur in phases, beginning later this year
- Detailed launch plan developed
  - Program implementation details—protocol and policies
  - IT system development and testing
  - Stakeholder engagement



**Thank you!**  
**Questions?**