Electronic Medical Records and Genomics (eMERGE) Network

consortiapedia.fastercures.org/consortia/emerge/

Research Areas

Tool Development
Interoperability

Data-Sharing Enabler

At a Glance

- Status: **Active Consortium**
- Year Launched: **2007**
- Initiating Organization: **NHGRI**
- Initiator Type: **Government**
- Location: **North America**

Abstract

The Electronic Medical Records and Genomics (eMERGE) Network was announced in September 2007 (RFA HG-07-005). It is a National Institutes of Health (NIH)–organized and –funded consortium of U.S. medical research institutions. The Network brings together researchers with a wide range of expertise in genomics, statistics, ethics, informatics, and clinical medicine from leading medical research institutions across the country to achieve its overall goals.

Mission

eMERGE is a national network organized and funded by the National Human Genome Research Institute (NHGRI) that combines deoxyribonucleic acid (DNA) biorepositories with electronic medical record (EMR) systems for large-scale, high-throughput genetic research in support of implementing genomic medicine. eMERGE studies and pilots genomic medicine translation through discovery, implementation, tools, and policy. During Phase I and II, the Network deployed more than 40 electronic phenotype algorithms across more than 55,000 subjects with dense genomic data. Returning clinical results has been implemented or planned for pilot at sites across the Network. A large-scale survey of patient attitudes regarding data sharing is being sent to 90,000 clinic patients across the country. A multicenter pilot of returning genome sequence information to EMRs for use in healthcare is almost

complete. Themes of genomics, bioinformatics, genomic medicine, ethnics, data sharing, privacy, and community engagement are of particular relevance to eMERGE.

eMERGE is openly interested in collaborations. Current external collaborations include the U.S. Air Force, ENCODE, IGNITE, and the larger ELSI (Ethical, Legal, and Social Issues) community. eMERGE is dedicated to developing tools, identifying best practices, and communicating results for participant consent, data sharing, and returning genomic research results, to benefit the broader medical and scientific communities and the general public.

The current project portfolio for eMERGE includes patient recruitment, biobank research survey, genomics, phenotyping, privacy, EHRI, precision prescribing, return of results, and patient education.

Consortium History

eMERGE was initiated in 2007 and included five biorepositories linked to EMRs. The network demonstrated that EMR phenotyping to develop cohorts for genome-wide studies was a robust approach to genetic discovery, defined approaches for enhancing privacy of shared EMR data, and engaged patients and communities in consent and data sharing. eMERGE expanded to include seven clinical sites in 2011 and two pediatric sites in 2012.

Structure & Governance

The Steering Committee is the governing body of eMERGE and consists of principal investigators from each institution and the NIH project scientist.

An External Scientific Panel provides input to the NHGRI director about the progress and direction of the Network.

The Coordinating Center provides centralized support and infrastructure for eMERGE Phase II programs.

The Genotyping Centers provide genotyping service under Clinical Laboratory Improvement Amendments (CLIA) certification for clinical actionable genetic variants.

The Consent, Education, Regulation, and Consultation (CERC) group explores models for informing patients, physicians, and the public about the proper use of genomic data and return of clinically relevant findings.

The Electronic Health Records Integration group focuses on creating standards for representing genomic data and developing clinical-decision support tools for its use.

The Genomics workgroup reviews site-specific genotyping data, performs quality control procedures, and imputes genotyping data for inclusion in network-wide analyses.

The Phenotyping workgroup identifies efficient, effective, and transportable phenotyping methods in order to complete Network phenotyping.

The Return of Results workgroup defines standards for clinical actionability and determines what genetic variants meet these standards.

The eMERGE-PGx Initiative is a Network collaboration with Pharmacogenomics Research Network (PGRN) that seeks to return pharmacogenomic variants of known significance to EMRs for clinical care and to identify pharmacogenomic variants of unknown significance.

Impact/Accomplishment

Two objectives are to share resulting best practices, expertise, and experience within and outside of the Network, and to disseminate association findings, tools, and best practices to the scientific community. The following list is a subset of informatics-based tools used by multiple eMERGE institutions. These tools are publicly available and shareable with other institutions or consortia.

Links/Social Media Feed

Other website	http://www.genome.gov/27540473
Homepage	https://emerge.mc.vanderbilt.edu/
Twitter	https://twitter.com/eMERGENetwork_

LinkedIn	https://www.linkedin.com/groups?mostRecent=&gid=5137057&trk=myg_ugrp_dis

Points of Contact

Rongling Li
NHGRI
phone: 301-594-6524
fax: 301-435-1580
email: lir2@mail.nih.gov

Jacqueline Odgis
NHGRI
phone: 301-496-7531
email: jacqueline.odgis@nih.gov

General Inquiries
Melissa Basford, Program Manager
phone: 615-343-0121
email: melissa.basford@vanderbilt.edu

Website Inquiries
Adam Hardebeck, Program Coordinator
phone: 615-343-8477
email: adam.hardebeck@vanderbilt.edu

Sponsors & Partners

Center for Inherited Disease Research
Children's Hospital Boston
Cincinnati Children's
Columbia University
Essentia Health
Geisinger

Group Health
Marshfield Clinic
Mayo Clinic
Mount Sinai School of Medicine
National Human Genome Research Institute
National Center for Biotechnology Information
Northwestern University
Penn State University
The Children’s Hospital of Philadelphia
University of Washington Medical Center
Vanderbilt University

Updated: **04/14/2016**