

# The NIH Collaboratory Effort

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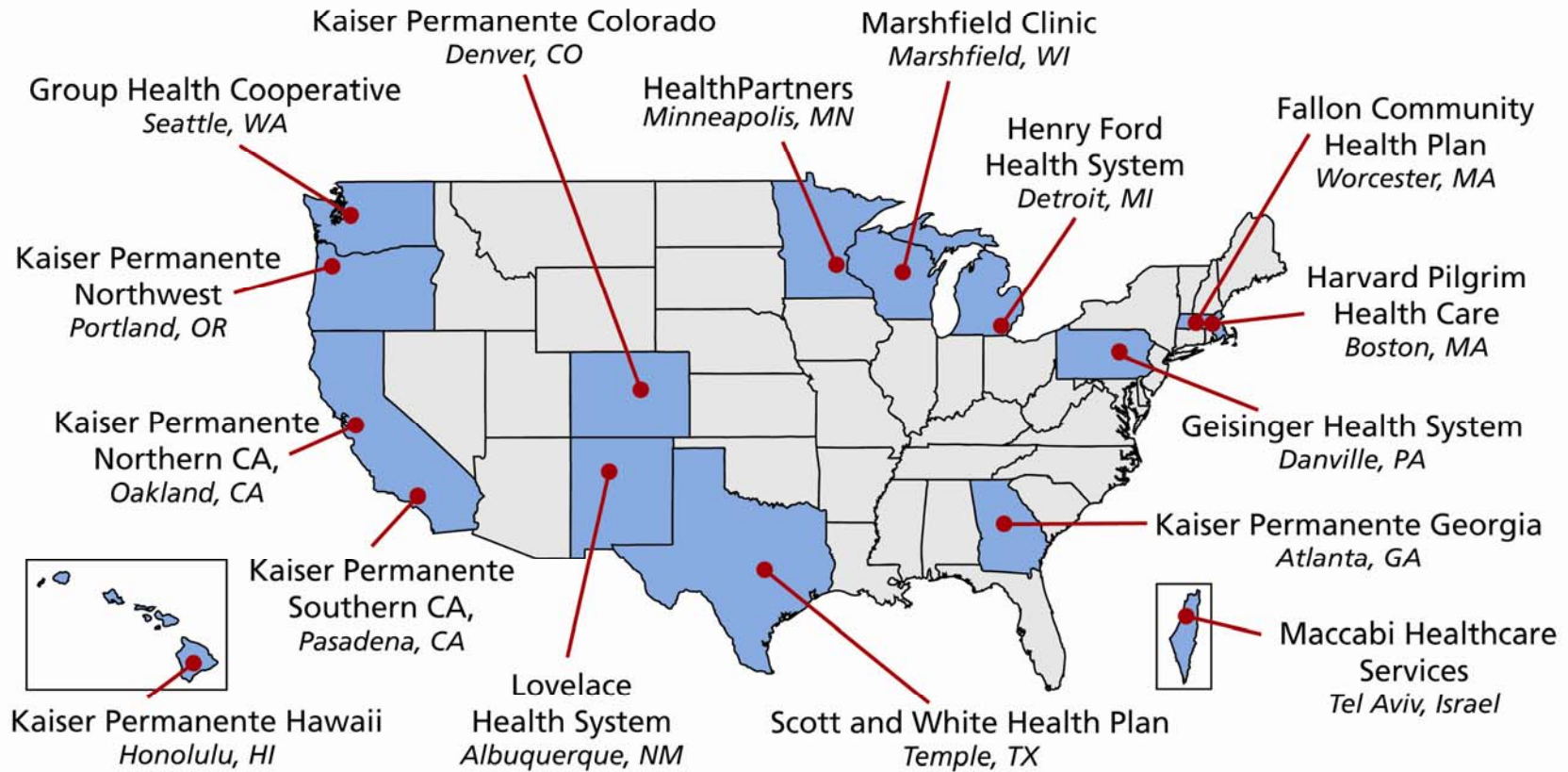
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# NIH's Major Opportunities

- Applying high throughput technologies to understand fundamental biology, and to uncover the causes of specific diseases
- Translating basic science discoveries into new and better treatments
- Putting science to work for the benefit of health care reform
- Encouraging a greater focus on global health
- Reinvigorating and empowering the biomedical research community



# HMO Research Network Members



- 15 U.S. member research sites, 13 million covered individuals
- > 350 multidisciplinary scientists
- Comprehensive data resources including Electronic Health Records, Biobanks (currently under development at several sites), and Virtual Data Warehouse
- Competitive funding from various NIH ICs, AHRQ, CDC, FDA and professional organizations
- Geographic diversity, racial/ethnic diversity, variety of health care delivery models

# Mega-Epidemiology Research:

Can distributed health plans be leveraged to enable large-scale epidemiological studies of disease burden, causes, course, treatment, and prevention?

Can high-throughput technologies for biobanking, genetic and laboratory analyses be cost-efficiently added to existing research resources?

What else is needed in terms of record linkages, standardized data collection and reporting, and improved information technology systems?

## Major HMO-RN Projects: *Large scale epidemiology*

- Vaccine Safety Datalink (CDC) - 8 HMORN sites
  - Long-term monitoring of immunization safety and vaccine-related adverse events, over 75 publications characterizing events, outcomes in various population subgroups
- Mini-Sentinel Network (FDA) – HMORN + other sites; N  $\approx$ 100M individuals (In Progress)
  - Platform for identification and verification of post-marketing adverse events for drugs and devices
- eMERGE *and* Research Program on Genes, Environment & Health (In Progress)
  - Genetic and EHR data to conduct genome wide associations on common traits including dementia, cataracts; eMERGE studying related ethical & social issues; RPGEH building biobank

# The Clinical Trial Enterprise:

Can the large number of typical patients in distributed health plans be leveraged to quickly and efficiently conduct practical clinical trials?

What types of interventions would be optimal to test on a distributed health plan network to inform health care reform?

What are the critical barriers that need to be overcome before such a resource could be realized?

# *Major HMO-RN Projects: Health Care Delivery*

- DEcIDE – Developing Evidence to Inform Decisions about Effectiveness (AHRQ)
  - Umbrella for multiple studies using health system data for comparative effectiveness research
- Demonstration & evaluation projects to inform meaningful health reform
  - Primary Care Medical Home Model
  - CMS Physician Group Practice
- CERT, CERT II, CERT Coordinating Center (AHRQ) - 9 HMORN sites
  - Study pharmaco-epidemiology and outcomes

# IT and Infrastructure

Provide coordinating and data analysis support.

Strengthen the infrastructure for clinical research in domains relevant to mega-epi and clinical trials projects.

- Strengthen the virtual data network.
- Develop tools to query individual health care data networks in domains not currently addressed.
- Enhance methods to capture information from the EMR for research purposes.
- Develop critical assessments of the quality of research data extracted from clinical sources.



# Goals:

Strengthen the infrastructure for clinical research in distributed health plans.

Implement pilot studies and signature projects to determine capabilities of this network for mega-epidemiology studies.

Conduct pragmatic or effectiveness clinical trials that will impact health care delivery.

*Pilot projects and signature projects should be transformative and cross-cutting.*