

NIH ME/CFS Research Consortium

Research Advisory Committee on Gulf War Veterans' Illnesses

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Presentation contributors

In alphabetical order:

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NIH ME/CFS Research Consortium

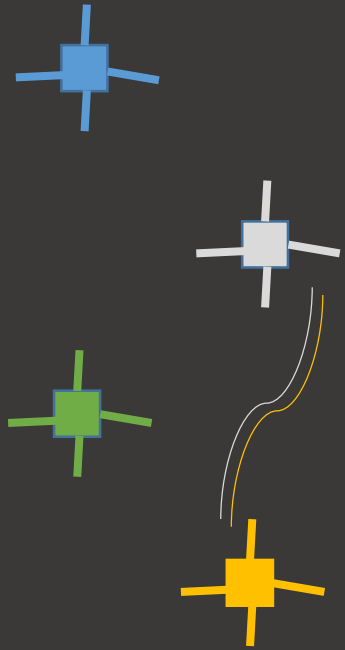
NIH Funding Opportunity Announcement listed 19 research support activities to be provided by the DMCC.

- Clinical data management system
- Data portal with data mining tools
- Distributed computing & database federation
- Data sharing / privacy & confidentiality
- Support for web-based recruitment
- User-friendly resource site
- Logistical & administrative assistance (e.g. planning meetings)
- Consortium organizational support (e.g. Bylaws, SOPs)
- Infrastructure & support for multi-center studies, including protocols, forms, EDC, monitoring/auditing, reporting, Single IRB

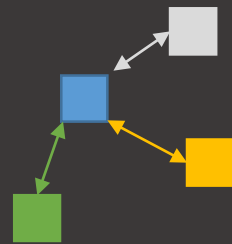
Scalable infrastructure

Models of collaborative research

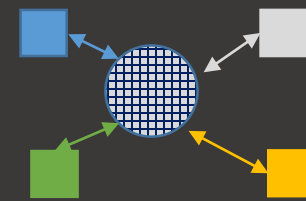
Single site



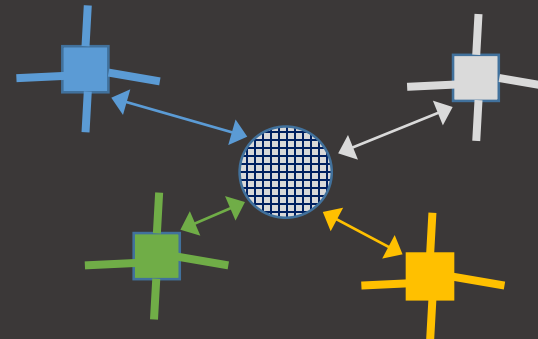
Classic Multisite



Multisite with DMCC

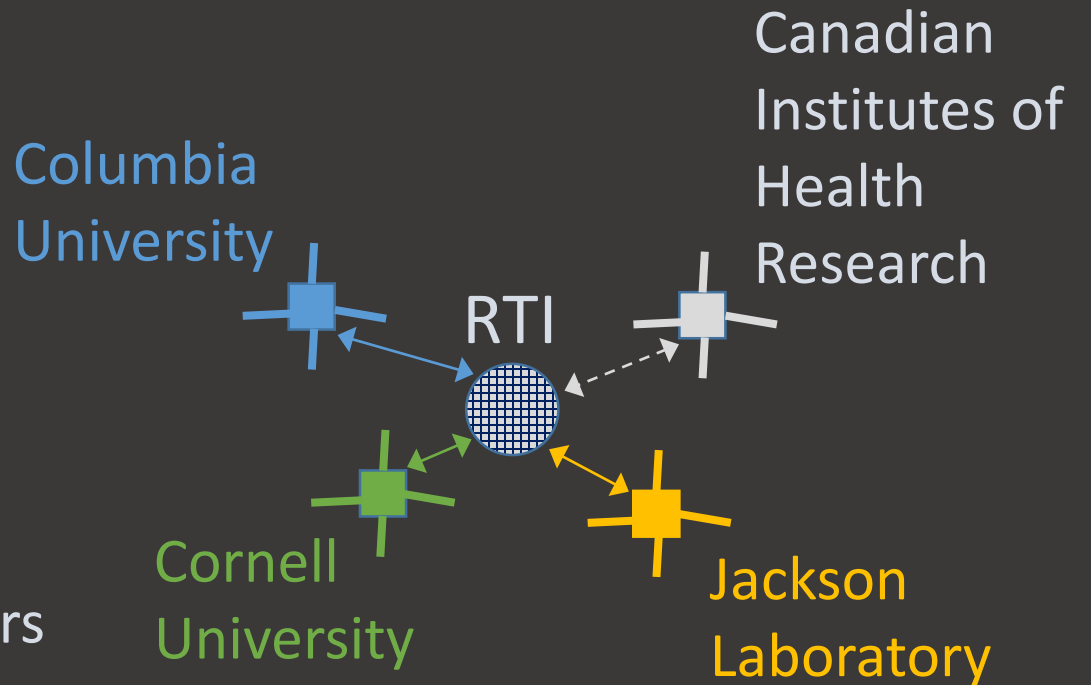


Collaborative Research Consortium

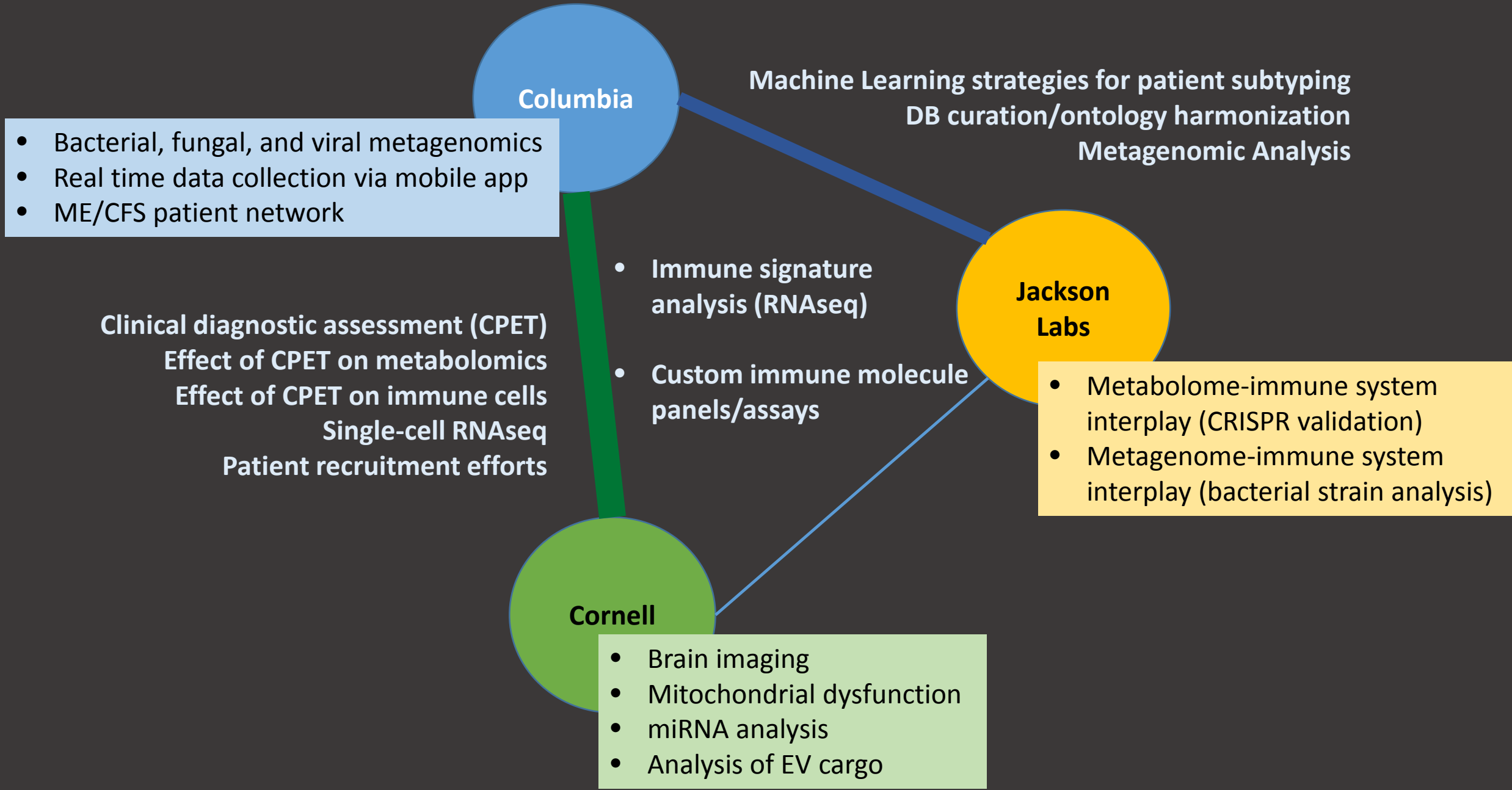


Consortium structure

- Supported by NINDS and NIAID
- Partnerships with several patient advocacy groups
- Multisite recruitment
 - Collaboration with clinical researchers
- Governed by Consortium Steering Committee
 - CRC and DMCC PIs, NINDS & NIAID Scientific Officers
- Consortium Charter



Overview of research domains

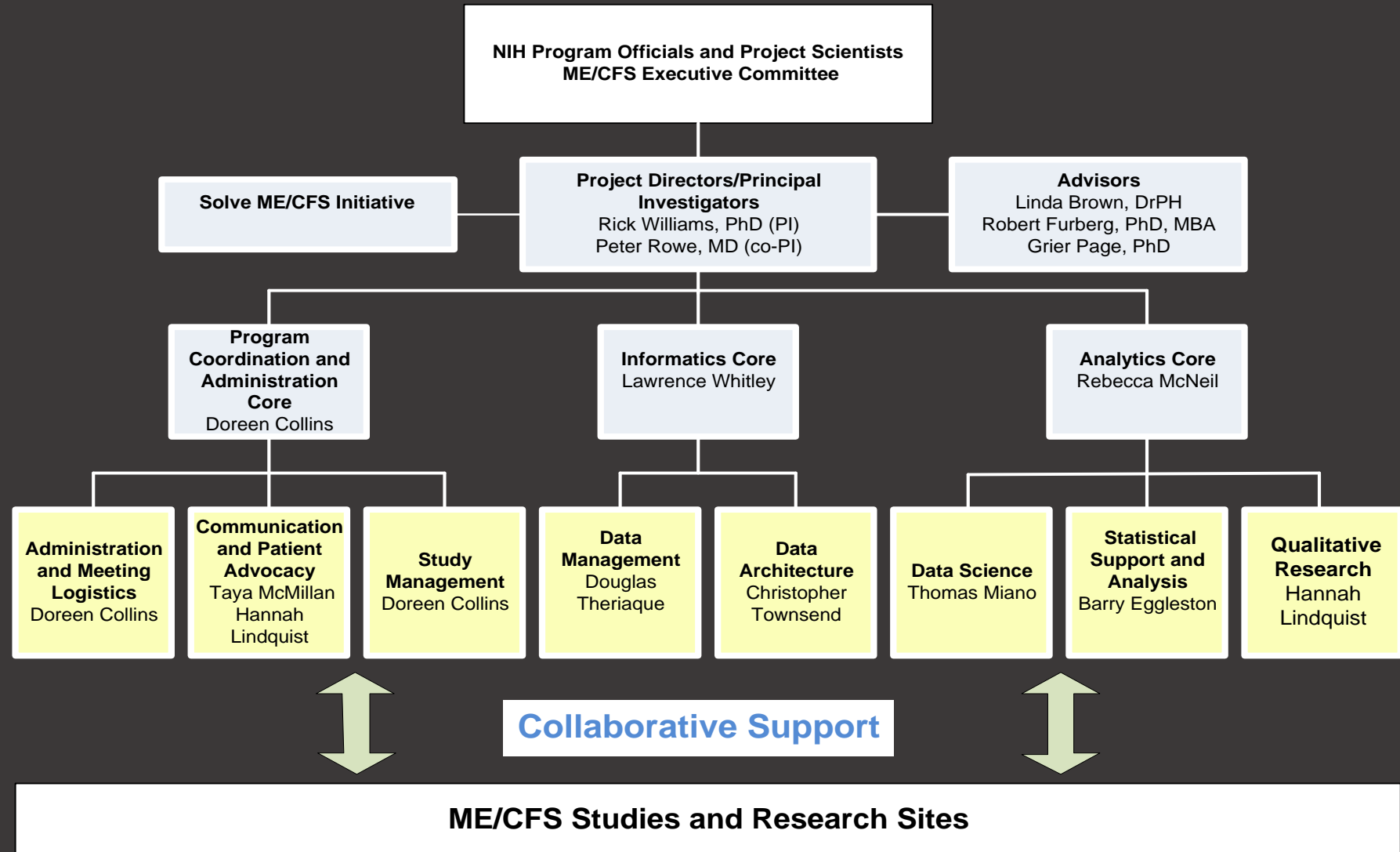


Working groups

Formed as needed to efficiently engage expertise across Consortium

- Community outreach
- Clinical data collection
- Bioinformatics

DMCC organization



delivering the promise of science
for global good



RTI International is an independent, nonprofit research institute dedicated to improving the human condition. We combine scientific rigor and technical expertise in social and laboratory sciences, engineering, and international development to deliver solutions to the critical needs of clients worldwide.

Primary challenges to ME/CFS research

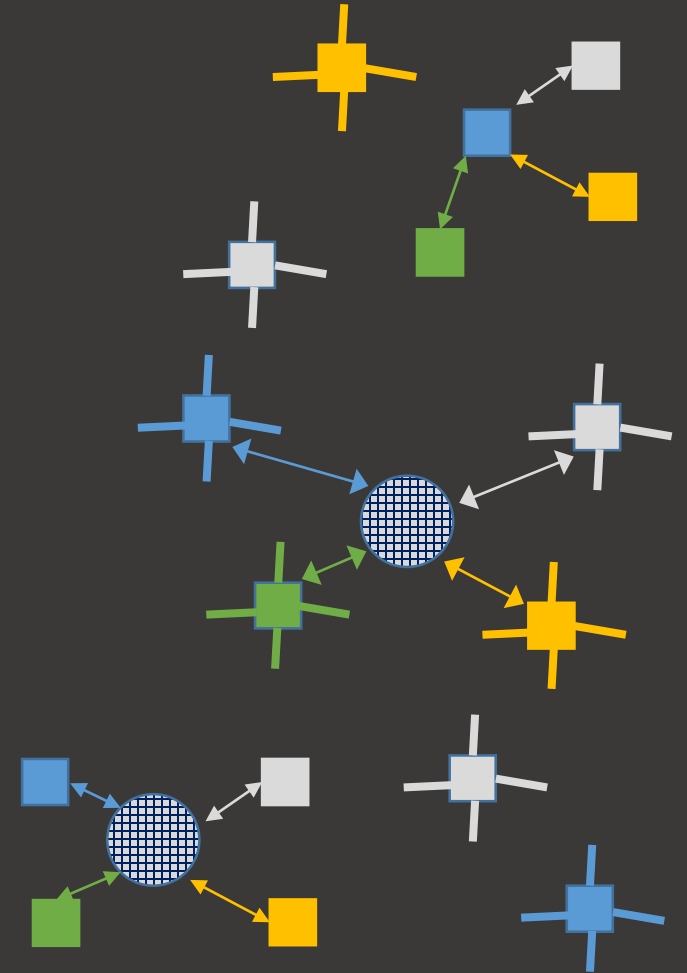
- Outdated clinician beliefs
 - Patient trust & access to care
- Dearth of clinical researchers
- Technology & computational capacity
- Limited funding
- Multiple case definitions
 - Need objective measures
 - Biomarkers?
 - Cardiopulmonary exercise testing?

Within the VA/GWI setting ... similar challenges

- Outdated clinician beliefs
 - Patient trust
 - *Inconsistent uptake of education*
 - *Inconsistent service-connection*
- Dearth of clinical researchers
 - *Few specialists; WRIISCs at capacity*
 - *Primary care gatekeeping*
- Technology & computational capacity
 - *Access to novel test approaches*
 - *Few VA-approved computing tools*
- Limited funding
 - *Improved with GW portfolio*
- Multiple case definitions
 - Need objective measures
 - Biomarkers?
 - Cardiopulmonary exercise testing?
- *Identifying potential participants*
 - *Historically, no GW flag*
 - *Medical record data mixed*
 - *Improvements being made*

Within the VA setting ... strong foundations!

- All models of multisite research can occur in the VA
 - Many single-site studies
 - Some multi-site studies
 - Fewer multi-site studies with a DMCC
 - *Research consortia?*
- Cooperative Studies Program (CSP)
 - Robust DMCC infrastructures for multi-site trials
 - *Could build DMCC out to Consortium scope*
- WRIISCs
 - *Could there be more WRIISCs?*
- *Centers of Excellence for GWI?*



Tools for building

- Building knowledge and trust
 - TMS trainings
 - Webinars
 - Grand rounds and academic partnerships
- Building research infrastructure
 - Existing registry and cohorts
- Electronic records system tools
 - Clinical reminders structured could be triggered for existing registry participants → update core patient characteristics
 - Leverage clinic visits to expand registry and biorepository (MVP-style)

Many logistical questions

- Operations vs research
- IT approvals and support
- Resources
 - Financial support of clinical and research effort
 - Clinic space
 - Support of hospital leadership
- Integrated care considerations: GI, neuro, dermatology, rheumatology
- Integration of community health providers

questions
and
discussion