Far beyond a "registry," rather, a
Real-World Data (RWD) repository and integrator
designed to
Accelerate Collaborate Research for ME/CFS & Long COVID



Accelerating collaborative research for ME/CFS & Long COVID

### **Clinical Research by Design**

- Parent protocol: an observational study (<a href="https://clinicaltrials.gov/study/NCT04806620">https://clinicaltrials.gov/study/NCT04806620</a>)
- o Covered by a central IRB
- o Flexibility to add sub-studies
- o Positioned for multi-site trials
- o Staffed with a Clinical Data Coordinator



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### **RWD Integration**

- Patient-Reported Outcome (PRO)
- o Electronic Health Record (EHR)
- Activity Tracker/Wearable Data
- Opportunities to include patients with severe diseases





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#### **Customizable**

- Handles any types of trial endpoint data
- Dynamic surveys to capture participants' most current (instead of only historical) conditions
- o Open to receive most types of wearable data



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#### **Precision to the Next Level**

- Participants profiled by clinical diagnostic instruments (DePaul Symptom Questionnaire)
- o Individual symptom-level data enables precision phenotyping
- o Better elucidate responders vs non-responders
- o Expedite trial planning, initiation, and targeted recruitment.



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#### **Empowering Patients**

- Consolidate multi-source health information, including EHRs, wearables, and screening questionnaires
- Automated reports for sharing with clinicians
- User-friendly app to track and pace daily energy usage/spoons
- Opportunities to join clinical studies
- Two-way dialogues with researchers to inform and be informed of clinical trial design/implementation



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**Easy to Join** 



Patient-facing demo for Solve Together: <a href="https://www.youtube.c">https://www.youtube.c</a> <a href="mailto:om/watch?v=Sw684fU">om/watch?v=Sw684fU</a> <a href="mailto:XGhI&t=1470s">XGhI&t=1470s</a>

