

## Member Owned Platform

Data Analysis

Interconnected Registries

External Data Sets

Patient Reported Outcomes  
Gene Panels

Exomes

Electronic Health Records  
Genomes  
Wearables

## Collect, Structure, and Organize Data

- Cohort ID
- Longitudinal
- Visualization

Biomarkers  
Natural History  
Practice Guidelines  
New Interventions

Retrospective Controls  
Comparative Effectiveness  
Disease Correlation

Transparency  
Training

Data Stewardship:  
Privacy + Security

## Registry Nourishment

Registries are nourished by multiple sources—EHR, wearables, exomes, gene panels, patient reported outcomes, and more—that strengthen the data canopy and create a powerful, interconnected network with people of the center.

100+ validated instruments

## Data Canopy

Registries are interconnected and provide a wealth of accessible data. As new registries are onboarded the canopy expands and data grows, opening up new possibilities for people-powered research.

25+ active registries 55k+ participants

## Fruitful Insights

Enterprise analysis tools generate customized results from your sandbox, based on your research question—such as biomarkers, natural history, disease correlation and more—helping accelerate medical discoveries and breakthroughs.

100+ studies

## Community Cultivation

Onboarding and training is available to ensure your registry is effectively set-up, managed, and maintained to produce better member outcomes. The community is non-exclusive and open to all data sets and researcher collaboration.

25 years experience

## Secure Foundation

Data privacy and security is a bedrock of the registry infrastructure. We are governed by community leaders, subject to the oversight of our ethics advisory board, and have approval from the Genetic Alliance IRB. We are GDPR and HIPAA compliant.

250 IRB approvals



## Program for Engaging Everyone Responsibly

Join the ever-growing nexus of support groups, registries and foundations building people-powered data sharing communities to uncover the solutions that matter.

### FEATURES + FUNCTIONALITY

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Registry Branding

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Plug-and-Play Set Up

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Libraries of Validated Instruments, Surveys, and Questionnaires

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Enterprise Analysis Tool

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Cross-registry Data Access and Communication

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EHR Portal Connection

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Genomic Information Sharing

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Data Standardization

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### Build your registry.

Your Registry. Your Research. Your Results.

### How it Works



#### Create a Registry

Establish and grow your registry with our self-guided, proven resource that takes you from concept to community—including IRB support, biobank resources, off-the-shelf validated surveys, and more.



#### Connect Health + DNA Data to Drive Research

Leverage APIs that empower your participants to securely upload and store data including electronic health records, health surveys, genomic/genetic information, and more.



#### Advance Science + Accelerate Health Discovery

Execute research questions and query the de-identified, encrypted data to answer your research questions and operate in compliance with GDPR and consumer privacy laws.



#### Reward Your Members with Shares for Sharing

Participants can earn shares for their data contribution and may choose to donate them to your organization. Proceeds earned from research flow back in the form of dividends, ensuring everyone shares in the value created.

