



ARC and ALL ALS: Two Research Studies, One Shared Goal

NEALS Webinar
January 21, 2026



Today's Speakers

- James Berry, MD
- Courtney Igne
- Fernando Vieira, MD
- Alan Premasiri



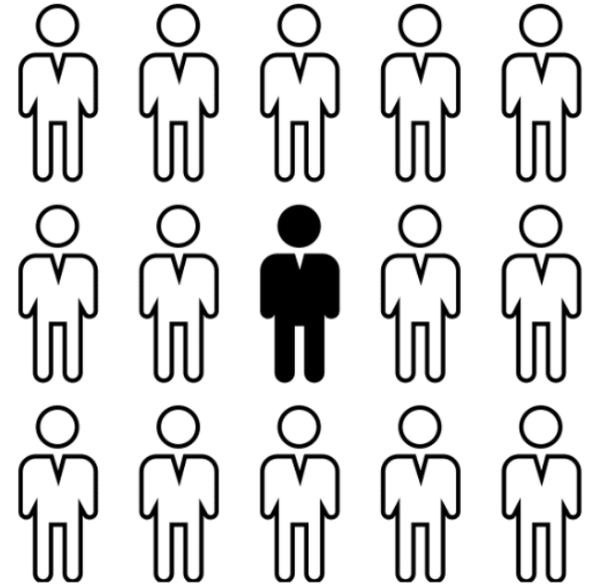
What is a Natural History Study?

- Collects health data, measurements, and biological samples in real-world settings
- Non-interventional: no experimental drugs or treatments
- Helps researchers understand disease onset, diagnosis, and progression
- Provides a foundation for developing better standards of care, drugs, and therapies



Why Natural History Studies Matter in ALS

- ALS looks different in everyone: onset, symptoms, and progression vary widely
- We still don't fully understand how ALS develops or changes over time
- Helps researchers identify early signs, biomarkers, and targets for therapies
- Make more and better experimental drug trials possible and support the development of more effective, targeted treatments



What ARC and ALL ALS Have in Common

- **Natural history studies** that help researchers better understand ALS
- Part of **AMP ALS**, a nationwide effort to accelerate ALS research
- **Remote participation** options available
- Important, multimodal **data collection**, including surveys, speech assessments, digital health measurements, and biosamples
- **Sharing de-identified data securely** with researchers to accelerate breakthroughs
- Designed to **support future ALS therapies** through biomarker identification



ALS Research Collaborative

ALS
THERAPY DEVELOPMENT
INSTITUTE



**ALS
Research
Collaborative**

ALS Research Collaborative (ARC)

- **Inform our drug development efforts**
 - Find new targets relevant to ALS subtypes
 - Develop new models and test potential therapeutics
- **Discover or validate biomarkers to monitor progression**
 - Digital technologies
 - Blood-based biomarkers
- **Share de-identified data to researchers through the ARC Data Commons**



*Unlocking the power of data and
collaboration to end ALS*



Who Can Participate in ARC?

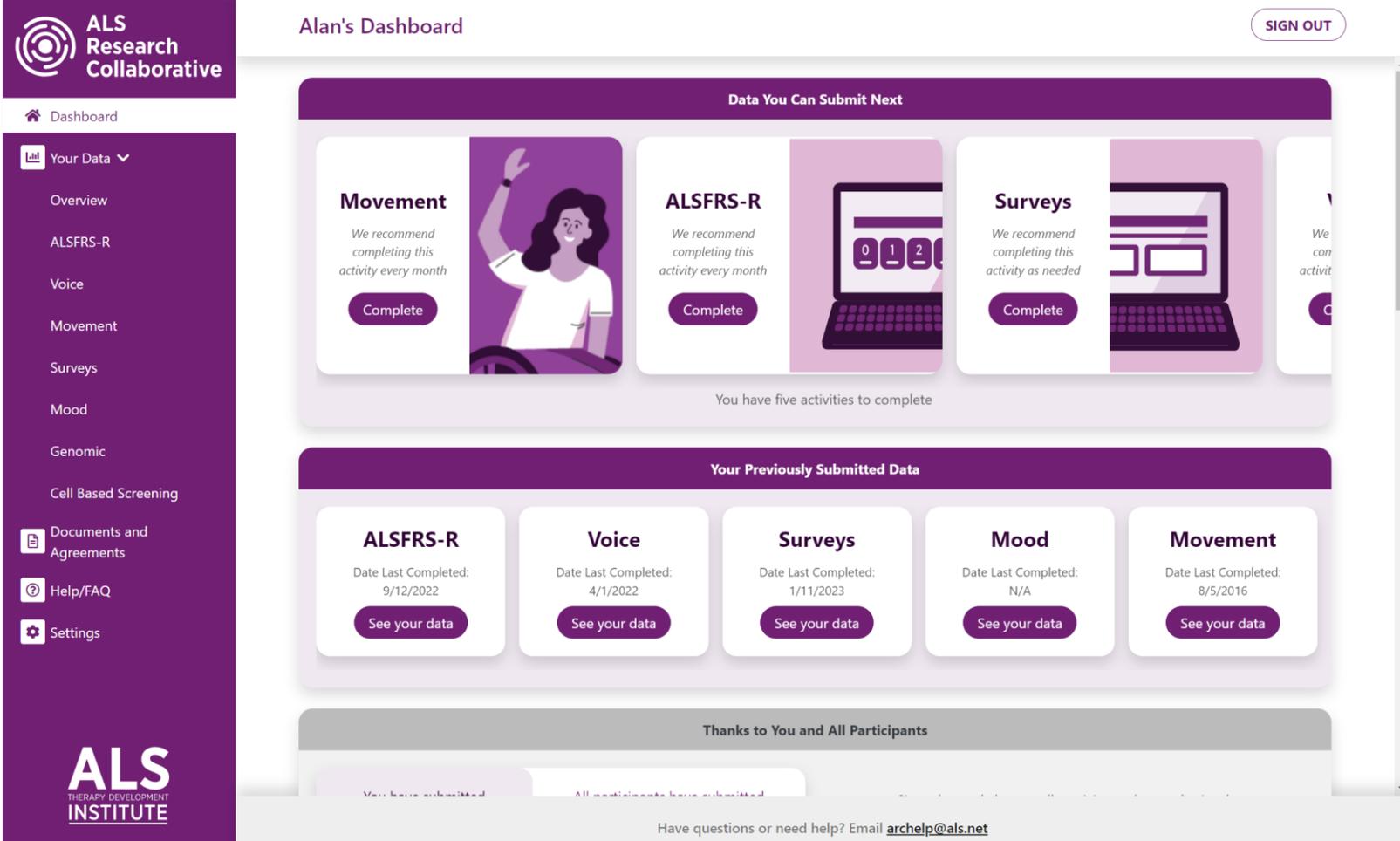
Sign up at arc.als.net

Inclusion Criteria:

- Have an ALS diagnosis or be an asymptomatic gene carrier of an ALS associated mutation or be a healthy volunteer.
- 18 years of age or older
- Can communicate in written English

Complete the consent process at your own pace.

Can participate from any country but may be limited to certain tasks.



The screenshot shows a user's dashboard for the ALS Research Collaborative. The dashboard is titled "Alan's Dashboard" and includes a "SIGN OUT" button in the top right corner. The main content is divided into two sections: "Data You Can Submit Next" and "Your Previously Submitted Data".

Data You Can Submit Next

Activity	Recommendation	Action
Movement	We recommend completing this activity every month	Complete
ALSFRS-R	We recommend completing this activity every month	Complete
Surveys	We recommend completing this activity as needed	Complete

You have five activities to complete

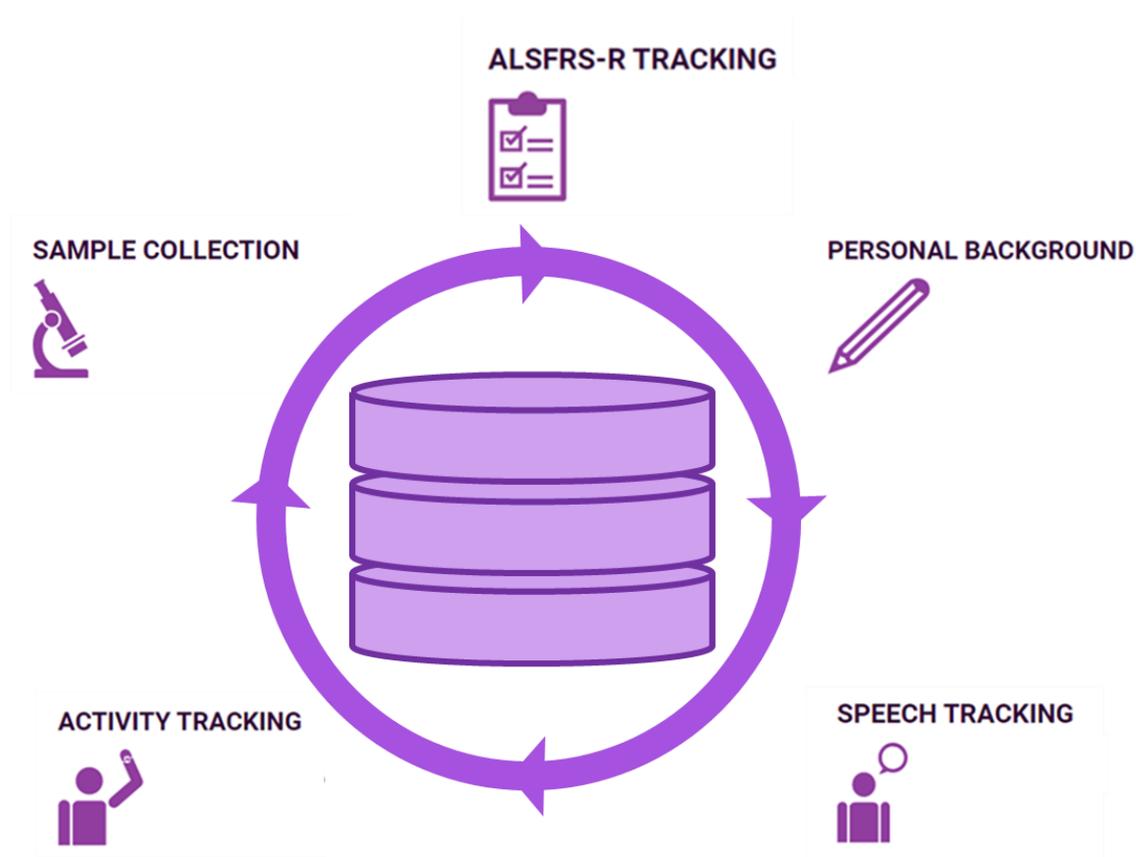
Your Previously Submitted Data

Activity	Date Last Completed	Action
ALSFRS-R	9/12/2022	See your data
Voice	4/1/2022	See your data
Surveys	1/11/2023	See your data
Mood	N/A	See your data
Movement	8/5/2016	See your data

Thanks to You and All Participants

Have questions or need help? Email archelp@als.net

What Participants Can Expect: ARC



- Tasks are completed once, quarterly, or monthly
- All tasks are optional with flexible scheduling
- Remote participation
- View your data in the participant portal
- Opportunity for long-term contribution to research



Access for ALL in ALS



ALLALS
Access for ALL in ALS

Access for ALL in ALS (ALL ALS)

- NIH-funded, Natural History study, consisting of **36 Clinical Sites across the U.S. and Puerto Rico**
- Collects clinical data and biosamples
- Shares de-identified data through the ALS Knowledge Portal (and biosamples through BioSEND Biorepository)
- Designed to **accelerate biomarker discovery and treatment development**
- Offers **remote participation** options for individuals living with ALS



ALL ALS Clinical Site Map



WEST

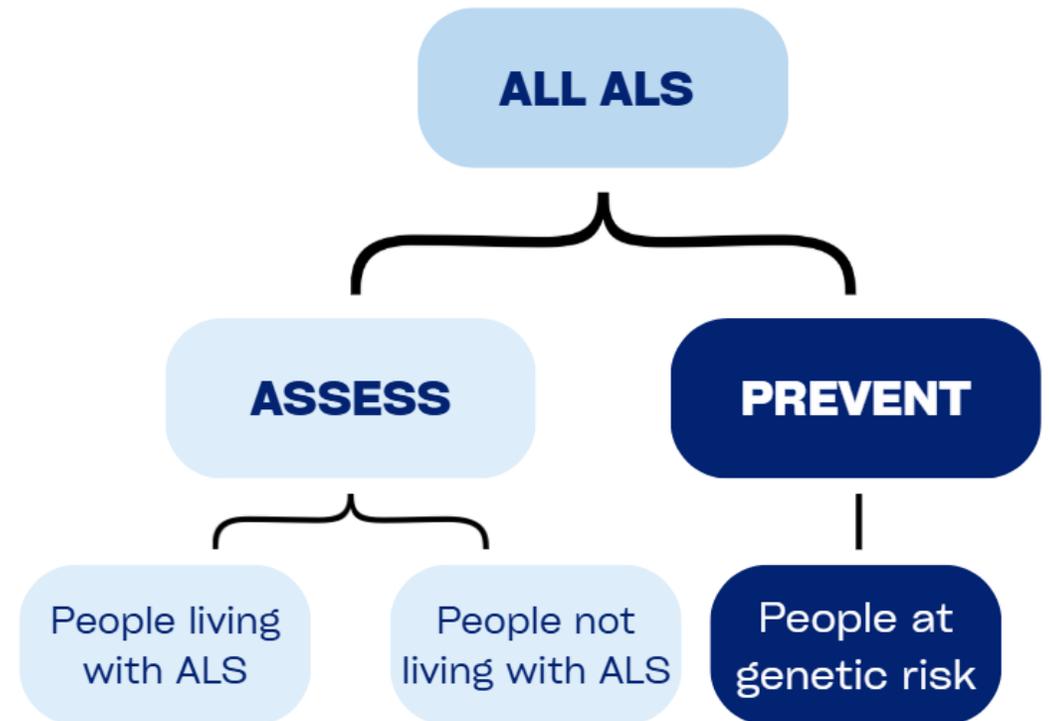
- Barrow Neurological Institute
- Columbia University
- Washington University
- Georgetown University
- University of Washington
- University of California, San Diego
- Northwestern University
- Mayo Clinic
- Massachusetts General Hospital
- University of Colorado Denver
- Ohio State University
- Universidad de Puerto Rico
- Saint Alphonsus Regional Medical
- Henry Ford Health
- University of Michigan
- University of Minnesota
- University of California, Irvine
- Providence Brain and Spine
- University of Utah

EAST

- Texas Neurology
- Virginia Commonwealth University
- Temple University
- Pennsylvania State Medical Center
- Duke University
- Dartmouth Hitchcock
- University of Nebraska Medicine ALS Center
- Indiana University ALS Center
- Nova Southeastern University
- Hospital for Special Care
- University of California, San Francisco
- University of Alabama, Birmingham
- John Hopkins University
- NIH/NINDS
- UCLA
- Vanderbilt
- UPenn

Who Can Participate in ALL ALS?

- **People living with ALS**
- **People without ALS (controls)**
- **Individuals with increased genetic risk (where applicable)**
- **Participation is focused on individuals living in the U.S. and Puerto Rico**
- All participants must be 18 years or older



What Participants Can Expect: ALL ALS

	Person Living with ALS	Control	Person at Genetic Risk
Study Length	2 years	2 years	3 years
# of Total Visits	7	3	10
Remote Option?	Yes	No	No
Lumbar Puncture (Spinal Tap)	<i>Optional</i>	<i>Optional</i>	<i>Optional</i>

**Physical Tests
(Breathing &
Muscle)**

Blood Draws

Questionnaires

**Digital Surveys
& Speech
Assessments**

How ARC & ALL ALS Work Together

- Prioritizing the community by making ALS research **accessible** and **participant-centered**
- Collecting **complementary natural history data** from across the ALS spectrum
- Building **broad, representative datasets** that lead to more accurate understandings of ALS
- Promoting collaborative ALS research by securely sharing data and samples with researchers



What This Means for You

- Contribute to research that could improve quality of life and lead to effective drugs and treatments
- Flexible options: in-person or remote visits; remote biospecimen collection
- Access to personalized data in the ARC portal and an *upcoming* ALL ALS dashboard
- Join a community of people making a difference in ALS research

All Research is Valuable

- If you have a strong preference, participate in the one that best suits your circumstances
- You can also participate in *both!*
- Two sets of your data can be very helpful in validating research methods and findings
- **There's no wrong choice. All participation is valuable and makes an impact.**



How to Get Involved

- Check eligibility
- **Contact study team:**
 - ARC: archelp@als.net
 - ALL ALS: info@all-als.org
- Ask questions about participation
- Participation is voluntary and flexible!

Questions?

Contact Us:

ARC



info@als.net



www.als.net/arc/



@alstdi

ALL ALS



info@all-als.org



www.all-als.org



@all_als_