

# ALL ALS Consortium: A Site Engagement Model to Strengthen Outreach, Recruitment, and Participation Across a National Network

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## Background

The **Access for All in ALS (ALL ALS) Consortium** is a nationwide initiative comprised of two clinical coordinating centers and 37 clinical research sites (Figure 1) dedicated to advancing ALS research through the longitudinal collection of clinical data, biospecimens, and digital health measures. To increase study awareness and participant enrollment, the ALL ALS Outreach Team provides recruitment resources, outreach guidance, and site-specific support across the consortium.

Despite these efforts, recruitment across a national research network presents unique challenges. Participating sites vary in available resources, outreach experience, community partnerships, and local engagement opportunities. While centralized recruitment initiatives provide broad support, site-specific barriers often require individualized strategies tailored to each site's needs.

To address these challenges, the ALL ALS Outreach Team developed a structured **Site Engagement Model** that provides targeted support through collaborative site visits. The model focuses on assessing recruitment practices, identifying barriers and opportunities, strengthening community partnerships, and developing tailored outreach strategies to enhance participant engagement across the ALL ALS network.



Figure 1. ALL ALS Site Map

## Objectives

- Evaluate current recruitment and outreach practices
- Identify site-specific barriers and challenges to enrollment
- Assess existing community partnerships and engagement activities
- Share available ALL ALS recruitment resources and tools
- Develop tailored recruitment and outreach strategies
- Strengthen collaboration between site teams and the central Outreach Team
- Identify successful practices that could be shared across the consortium

## Methods

To strengthen site-level recruitment and outreach efforts, the ALL ALS Outreach Team implemented a structured Site Engagement Model consisting of in-person site visits and targeted strategy discussions. The Outreach Team conducted visits at **8 ALL ALS research sites**, spending approximately 1–2 days at each site engaging with study coordinators, site principal investigators, research assistants, nurses, and other personnel involved in ALL ALS outreach and recruitment activities.

### Site Selection:

ALL ALS research sites were selected for visits based on outreach support needs, enrollment capacity, and opportunities to strengthen recruitment infrastructure. Selection considered each site's outreach activities, recruitment performance, and potential benefit from individualized support. Figure 2 highlights the geographic location of sites selected.

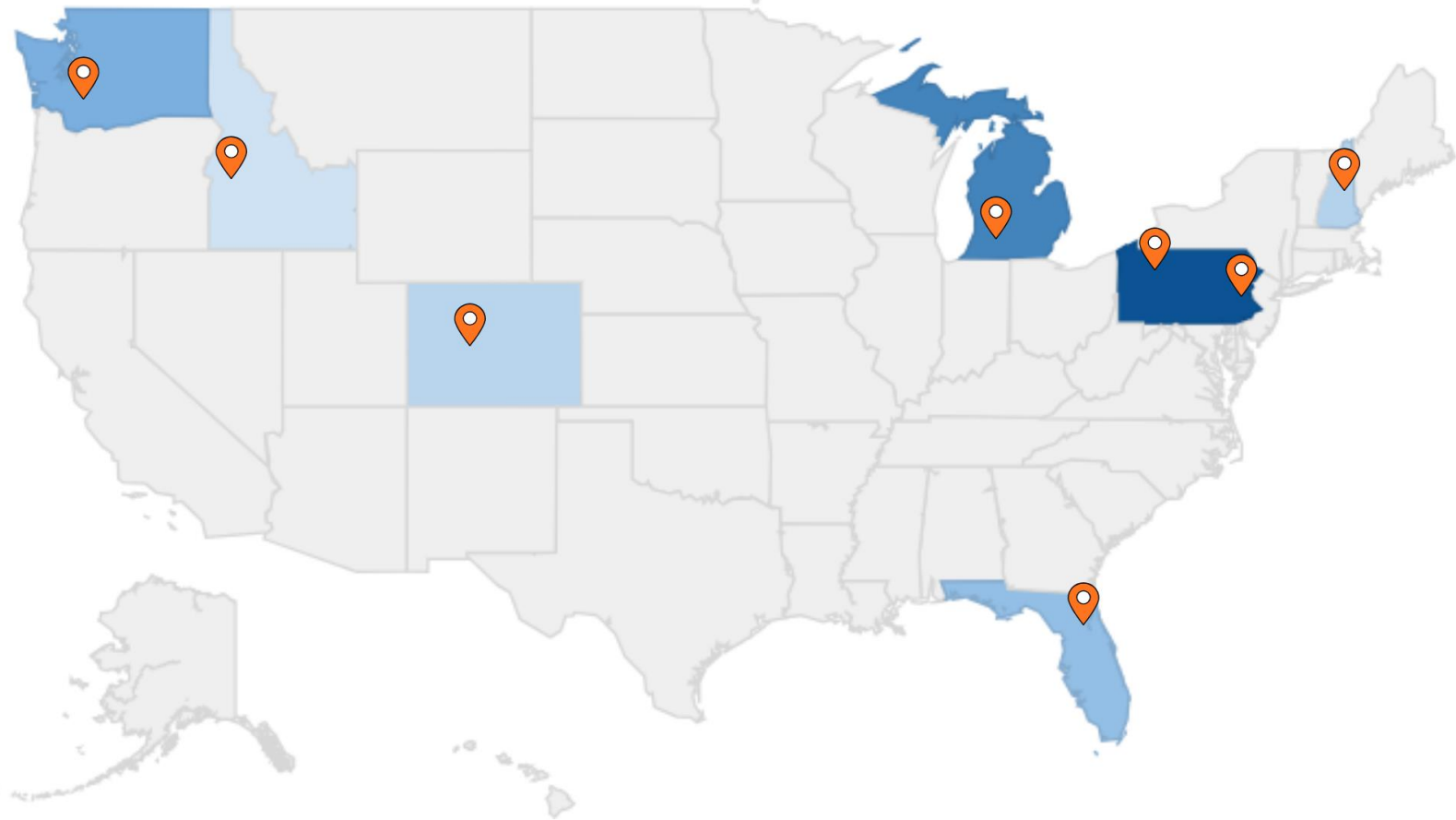


Figure 2. Sites Selected for Visits  
University of Washington, University of Colorado Anschutz Medical Campus, Saint Alphonsus Regional Medical Center, Henry Ford Health, Dartmouth Hitchcock, Temple University, and Nova Southeastern University were selected for visits.

## Site Engagement Model

### Site Visit/Engagement Model

Each visit focused on understanding site-specific recruitment approaches, identifying barriers and opportunities, and collaborating with site teams to develop actionable outreach strategies. In some instances visits included observation of research conversations between study teams and patients to support strengthening study conversations. Discussions followed the five steps shown in figure 3.

| Step           | Engagement Activity                                                                                                                  | Purpose                                                                |
|----------------|--------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|
| 1. Assess      | Evaluate current recruitment practices, outreach activities, community partnerships, clinic processes, and site-specific challenges. | Understand site needs, strengths, and barriers impacting recruitment.  |
| 2. Collaborate | Engage site teams in discussions to identify local needs and opportunities for improvement.                                          | Build alignment between site teams and the central Outreach Team.      |
| 3. Strategize  | Develop customized recruitment and outreach action plans based on site capacity and community resources.                             | Create targeted approaches tailored to each site's unique needs.       |
| 4. Implement   | Support sites in executing outreach activities, utilizing resources, and strengthening community engagement.                         | Translate recruitment strategies into actionable outreach efforts.     |
| 5. Evaluate    | Share lessons learned, identify successful strategies, and incorporate site feedback.                                                | Improve future outreach approaches and inform network-wide strategies. |

Figure 3. Site Engagement Visit Model

## Results & Discussion

Site engagement visits provided a better understanding of the unique recruitment strengths, challenges, and outreach needs across participating ALL ALS sites. Through discussions with site teams, the Outreach Team identified opportunities to strengthen recruitment workflows, expand community outreach, and increase awareness of available study resources. In several cases, the visits led to new collaborations with local clinics, community organizations, and institutional marketing teams that could support future recruitment efforts. Site teams also shared successful outreach strategies that can be adapted by other consortium sites.

Feedback from participating sites also demonstrated the value of ongoing collaboration, leading to the development of the ALL ALS Study Coordinator Support Network to support continued communication, resource sharing, and dissemination of recruitment and retention best practices across the consortium.

One limitation of the Site Engagement Model was that, while visits identified recruitment opportunities and site-specific strategies, implementation depended on each site's available staffing, resources, and institutional capacity. Several sites had limited time or personnel dedicated to outreach, making it difficult to adopt additional recruitment activities despite recognizing their potential value. These findings underscore the importance of ongoing consortium support to help sites overcome barriers and sustain recruitment efforts.

## Future Directives

- Establish the ALL ALS Coordinator Support Network to provide ongoing outreach support and foster collaboration across sites.
- Broaden the outreach program to include participant retention support.