

ALL ALS Consortium: A Centralized Participant-Interest Form and Patient Navigation Workflow to Increase Recruitment and Remote Participation



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Background

The Access for ALL in ALS (ALL ALS) Consortium is a NIH-funded observational research program that consists of 2 coordination centers, Massachusetts General Hospital (MGH) and Barrow Neurological Institute (BNI), and 36 clinical sites across the US.

ALL ALS implemented a Participant-Interest Form (PIF) on the ALL ALS Website in December 2025 that collects basic personal information from people interested in participating in the study or seeking additional information. A general ALL ALS email inbox was launched January 2025. A Patient Navigation (PN) team collects, reviews, and follows-up on PIF/email submissions. If requested, the PNs refer potential participants to ALL ALS sites for screening and potential enrollment.

PIF Objectives

- Increase overall recruitment in ALL ALS.
- Expand community engagement to locations throughout the US without active sites.
- Reduce site staff burden by managing initial potential participant communication and coordinating site referrals.
- Improve enrollment consistency across sites by connecting potential remote participants with low-enrolling sites.

Methods

The PIF collects name, location, contact info, interest level, and referral source. The PIF also obtains explicit consent from submitters for ALL ALS to store their submitted data within an internal database and share their data with ALL ALS site staff. Upon PIF/email submission, the PNs reconfirm interest, collect background information, answer questions, and refer to sites, if applicable.

The PNs evaluate the best site for referral based on the interested person's location, time zone, and cohort interest, as well as each site's research policies and enrollment numbers. Referrals are generally sent once a week. PNs follow-up on site response time and referral outcome once a month.

Results

As of October 2025, 439 PIFs have been submitted, with 236 individuals referred to sites. Of 1047 people enrolled, 103 were referred via the PIF. Of the 6 sites that have received the most PN-referrals, 5 have been consistent or semi-consistent low-enrollers.

As of October 2025, the average age of individuals enrolled in ASSESS Onsite was 61 yrs, ASSESS Remote was 62 yrs, ASSESS Control was 52 yrs, and PREVENT was 45 yrs.

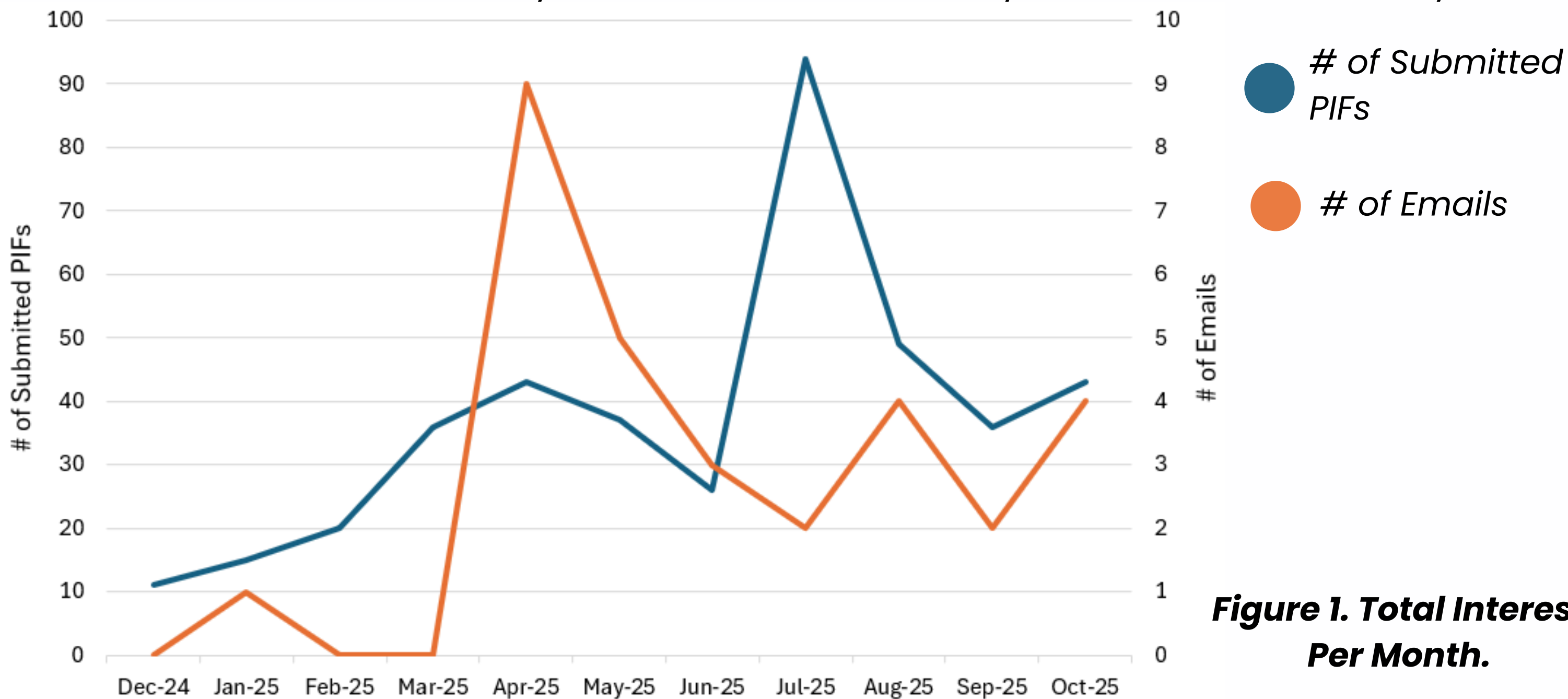


Figure 1. Total Interest Per Month.

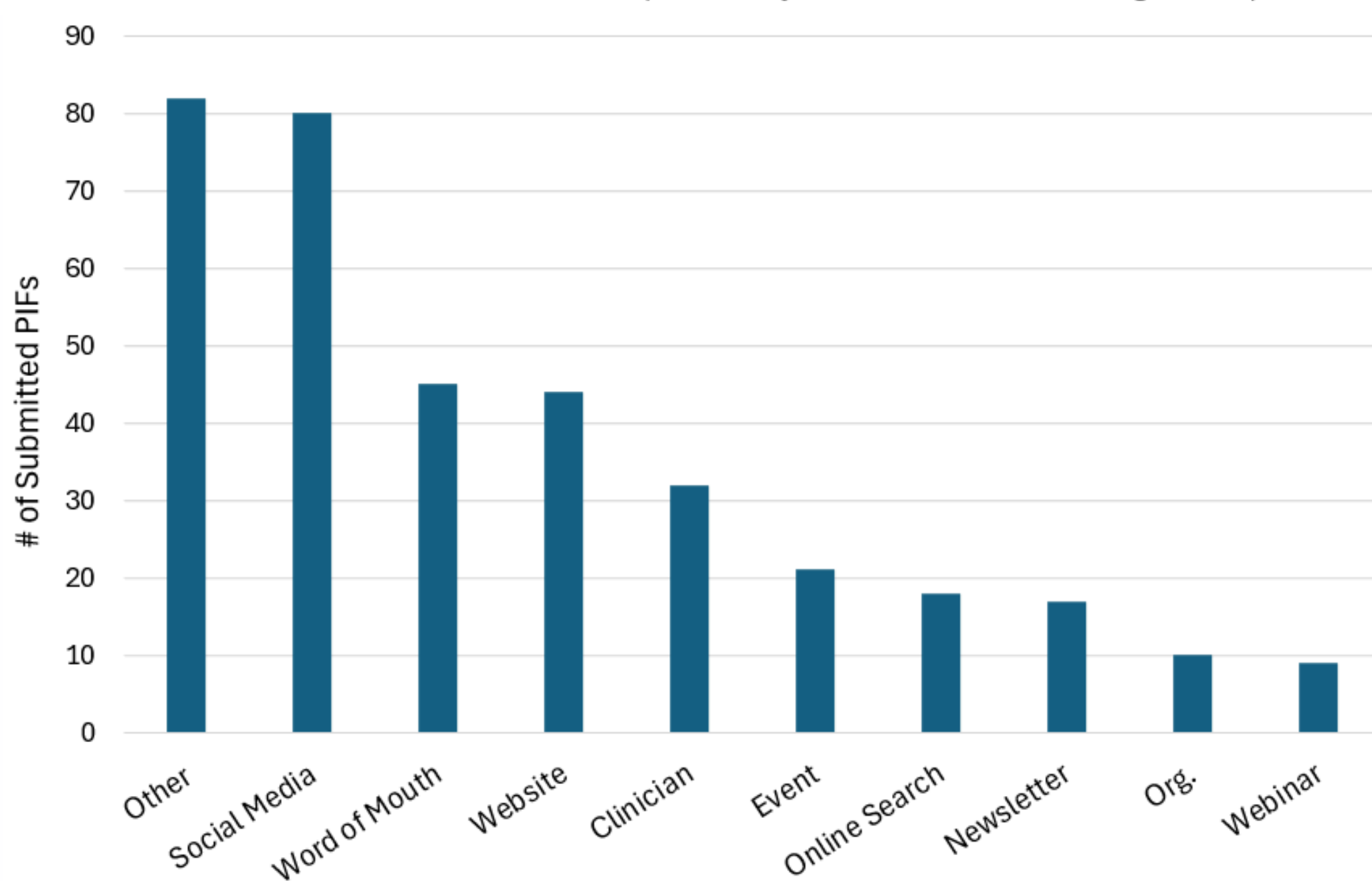


Figure 2. PIF Referral Source. "Other" is often self-reported as other ALS research studies, ALS clinics/clinicians, family member(s), and ALS organizations. "Organization" (Org.) only added to PIF form in August 2025.

Of 80 social media-referred PIFs, 32 submitted in Jul and 15 in Aug. Of the 80, 35 have known cohort of interest: ASSESS (20) and PREVENT (15).

Results Cont.

- ASSESS On-Site
- ASSESS Remote
- PREVENT
- Unknown

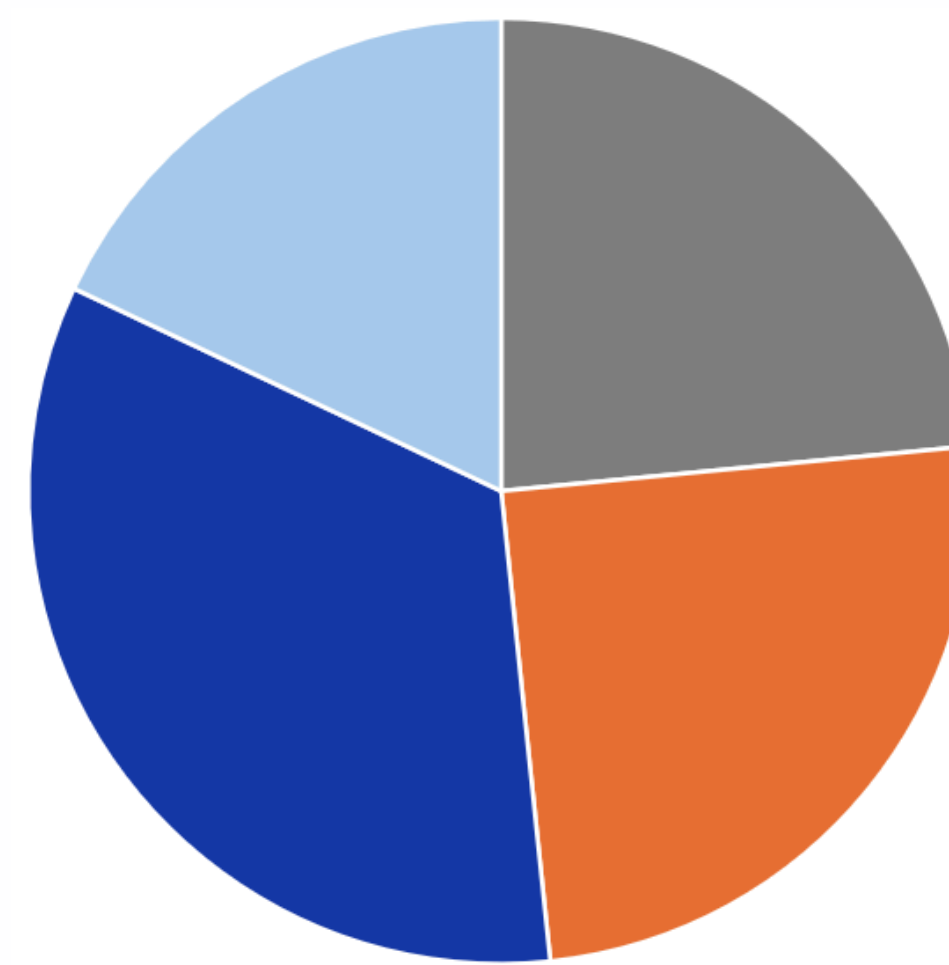


Figure 3. Cohort Interest. On-site (23%), Remote (25%), PREVENT (34%), Unknown (18%).

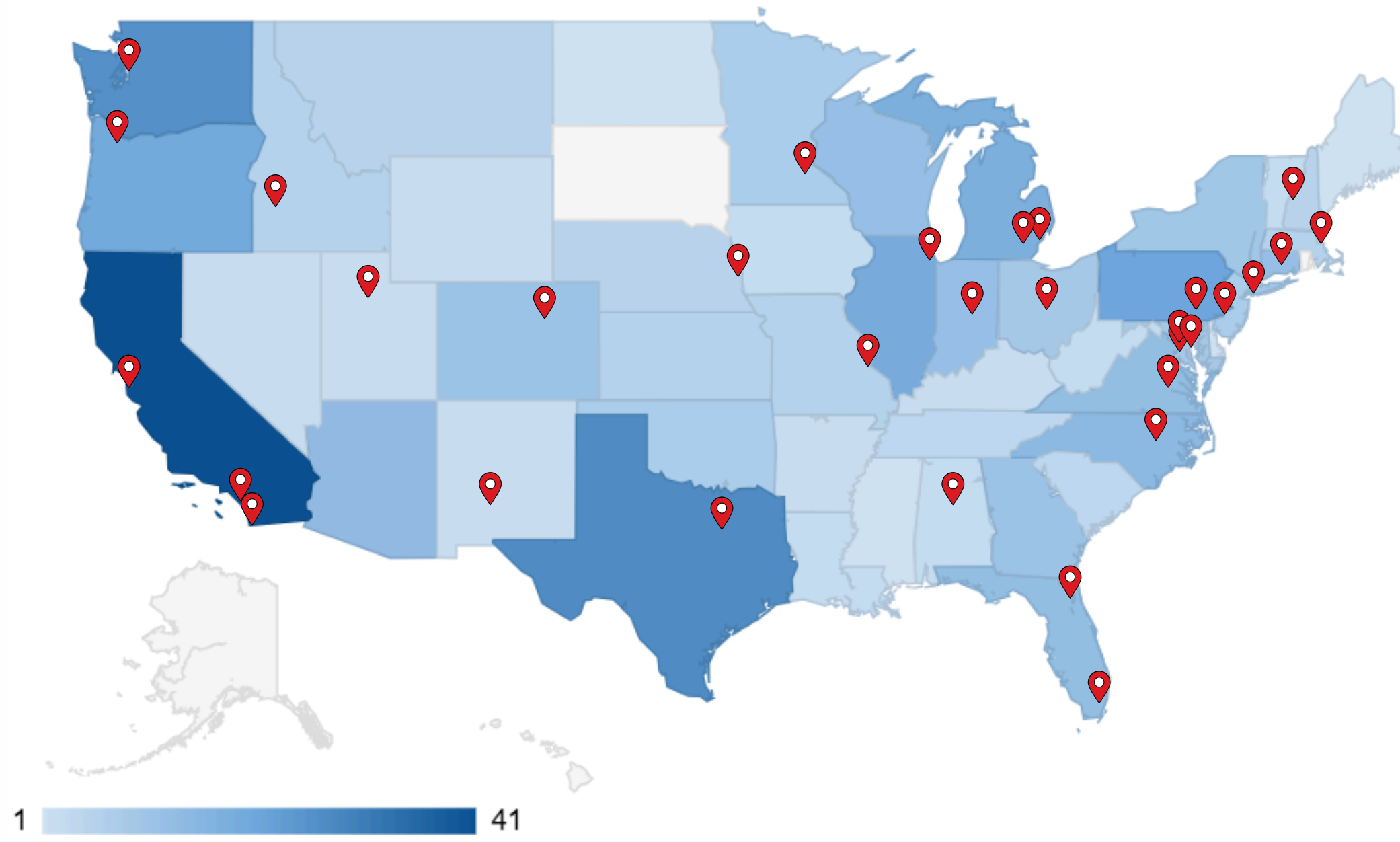


Figure 4. Heat Map of PIF Interest. The darker the blue, the more PIFs/emails submitted from a person self-reporting as a resident of that state. 5 PIFs and 3 emails from non-US residents. 15 unknowns. States/territories with no interest: AK, HI, SD, and Puerto Rico (not shown).

Discussion

- Effect of outreach initiatives on interest and recruitment can be evaluated through analysis of PIF/email submission data. Future outreach initiatives can be adjusted accordingly. However, PIF/email data can be unreliable.
- States with no interest lack an ALL ALS site, highlighting the need for outreach initiatives that recruit outside of established site patient populations.
- A large influx of PIF submissions followed the release of an organization-led Facebook video campaign in July, which may indicate that social media campaigns are highly effective at increasing interest and recruitment. Although social media usage for healthcare-related purposes has been found to decrease with increasing age, more ASSESS-interested PIFs were submitted post-Facebook video campaign (Marsh et al., 2021). More social media initiatives must be completed and tracked to validate findings.
- PREVENT may be the cohort with the most PIF interest because multiple people from one family can participate and there are fewer research opportunities and accessibility issues for the at genetic risk community. There may be more interest in the ASSESS Remote than ASSESS Onsite cohort because onsite participants are often recruited directly from site patient populations.
- Successful PN workflow requires site-specific customization. The workflow has increased general enrollment and enrollment at low-enrolling sites, improved enrollment consistency, decreased site recruitment burden, and has allowed PNs to collect information on and develop materials that address FAQs, common concerns, and areas of improvement.

Future Directives

- Use PIF submission data to guide outreach initiatives focused on increasing overall ALL ALS recruitment and community engagement, particularly in US states of low interest.
- Modify recruitment, enrollment, and retention practices and resources based on potential participant questions, concerns, and feedback.

References

Marsh H., Almekdash M. H., Rossettie S., John A., Pelham K., Magers B. (2021). Implications of Age on Social Media Utilization in Health Care Practice Development: Cross-sectional Survey Study. Jmir Human Factors, 8(3). <https://doi.org/10.2196/27528>

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