

I AM ALS presents ALS Signal: A Clinical Trials Dashboard

Created by patients and caregivers to educate the ALS community about global ALS clinical trials

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Background:

Advances in neuroscience have led to an increased number of clinical trials available to ALS patients. However patients are often either not informed of these trials or advised to search for clinical trial opportunities on their own. This can lead to patients not enrolling in trials as registries can be challenging to navigate or provide limited information. To remedy this, a team of patients and caregivers from I AM ALS' Clinical Trials Team created ALS Signal, a clinical trials dashboard that brings together disparate information and presents opportunities in a digestible manner.

Objective:

According to a 2019 survey of 551 ALS patients conducted by Ipsos on behalf of I AM ALS, 30% of ALS patients either did not know about clinical trials or did not know how to find information on clinical trials (1). To address this, I AM ALS volunteers sought to create a unique patient-centric dashboard to educate the ALS community about global therapeutic interventional trials, create more informed patients and increase trial participation.

Methods:

I AM ALS Clinical Trials Community Team members reviewed international registries for current and upcoming clinical therapeutic interventional ALS trials. The team debated which specific trial information was of most interest to the ALS community based on their own journey as patients, caregivers and loved ones. They collected this information for each active and upcoming trial.

The data was compiled within a spreadsheet, which was exported to create a dashboard containing ten clinical trial filters to customize search functions (see Figure 1). A U.S. trial finder was developed within the dashboard with five additional filters to help people find trials near them (see Figure 2). In addition, ALS Signal has a section listing registered and unregistered expanded access programs (see Figure 2). The I AM ALS Scientific Advisory Council, patients, caregivers, clinician-scientists and other stakeholders reviewed the dashboard's content and format prior to publication.

Results:

ALS Signal: A Clinical Trials Dashboard was introduced to the ALS community on July 25, 2020. It is available at <https://iamals.org/alssignal/>. ALS Signal had a total of 6,645 page views between July 25 and November 1, 2020. Currently, the dashboard contains 80 clinical trials with 73 trials listed on clinicaltrials.gov and seven trials from other registries. Updates are made at least every two weeks to reflect new information from registries, press releases and correspondence with sponsors and researchers.

Figure 1: First page of ALS Signal, the dashboard

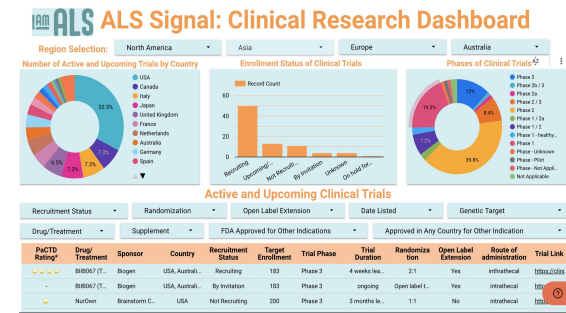
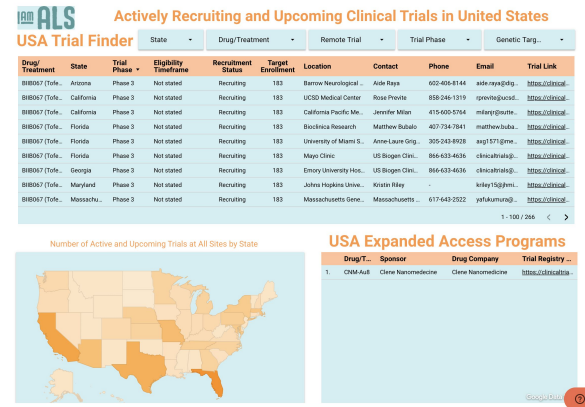


Figure 2: Second page of ALS Signal, the trial finder



Discussion

The creation of a centralized dashboard with filters, a trial design rating system and a trial finder allows patients and caregivers an opportunity to personalize their search for clinical trials. The goal of this dashboard is to provide hope and facilitate discussions between patients and their health care providers.

Conclusion

ALS Signal brings together clinical trial data. It is an important tool in empowering patients and enrolling participants in clinical trials.

References

1. Ipsos, Clinical Trials Survey, 2019