

Thank you so much for joining the ADLD Research Hub. Together, we can develop a cure for ADLD!

This document will walk you through the steps to share information for [a person diagnosed with ADLD](#). People with ADLD can create their own account with the registry, OR, a family member or caregiver can sign up to enter information on their behalf.

Family members and caregivers of ADLD, we want to hear about your experience too! Please review our family member and caregiver guide for additional instructions.

OPTION 1: Create your own account with the registry as an ADLD patient.

Prefer a video walkthrough? Click [here](#) to see how to join!

1. Sign up for an account with Luna, our registry platform, using [this link](#).
2. Complete the Luna platform consent.
3. Join our first study in the registry, “ADLD Research Hub: Get Started” and complete the study activities. As an ADLD patient, you should complete the following activities:
 - **Your Experience with ADLD: For Patients.** A simple survey about patients’ experience with ADLD and their needs.
 - **Demographics Survey.** Questions about you, your work, and your home life. These details are critical to understanding how our daily lives impact our health.
 - **Electronic Health Records.** An activity to connect your patient portals to the registry and share valuable information about how your health changes over time. You only need to connect your patient portal once - after that, Luna does the rest! *Currently only available for participants in the United States.*

Do not take the “Your Experience With ADLD: For Caregivers and Family Members” survey.

The information you share as part of this study will help us build a picture of the ADLD community and their needs. This study is a starting point: over time, we will collect more detailed information about the ADLD community to aid our efforts to develop a cure. We’ll be in touch with updates about what we’re learning from this first study and what comes next soon!

OPTION 2: Sign up to enter information on behalf of an ADLD patient.

Prefer a video walkthrough? Click [here](#) to see how to join!

Family members or caregivers of ADLD patients can enter information on patients' behalf if patients are unable to do so themselves. To enter information on behalf of a patient as a family member or caregiver, follow these instructions...

1. Create an account to manage a ward with Luna, our registry platform, [using this link](#). Enter your own information then click the blue "CREATE AN ACCOUNT TO MANAGE A MINOR OR WARD."
2. Enter information for the ward. By doing so, you'll create a ward account that's connected to your own account, which you can access using the same login.
3. Complete the Luna platform consent for the ward account.
4. From the ward account, join the first study in the registry, "ADLD Research Hub: Get Started" and complete the study activities. Because you are entering information for an ADLD patient, you should complete the following activities:
 - **Your Experience with ADLD: For Patients.** A simple survey about patients' experience with ADLD and their needs. Fill this out from the perspective of the ADLD patient.
 - **Demographics Survey.** Some basic questions about your ward, their work, and their home life. These details are critical to understanding how our daily lives impact our health. Please be sure to fill this out for your ward, the ADLD patient - and not for you!
 - **Electronic Health Records.** An activity to connect your ward's patient portals to the registry and share valuable information about how their health has changed over time. You only need to connect the patient portal once - after that, Luna does the rest! *Currently only available for participants in the United States.*

Do not take the "Your Experience With ADLD: For Caregivers and Family Members" survey from the ward account. If you'd like to share information about your experience as a family member or caregiver, you can take this survey from your account, instead! For more information on how to do this, please watch this video or review our sign-up guide for family members and caregivers.

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