

# Privacy Policy

Effective as of November 17, 2020.

This Privacy Policy describes how Alzheimer’s Disease Data Initiative, Inc. (ADDI) and our affiliated entities (referred to collectively as “ADDI”, “we”, “us”, or “our”) collects, uses and shares your personal information if you visit <https://www.alzheimersdata.org/> or our other websites or services that link to this Privacy Policy (collectively, the “Services”) or take other actions through the Services such as choosing to contact us, receive our communications or attend our events.

We provide important information for individuals in Europe below.

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## Personal Information We Collect

**Information you provide to us.** Personal information you provide to us through the Services may include:

- **Contact information,** If you request communications from us, we have a form that allows you to provide details, such as your first and last name, email address, and postal or zip code. You are not required to provide any of these other than an email address so that we can fulfill

your request to communicate with you. If you choose to provide a name in your request for communications, you are free to use a pseudonym.

- **Feedback or correspondence**, such as information you provide when you contact us with questions, feedback, or otherwise correspond with us.
- **Usage information**, such as information about how you use the Services and interact with us, including information you provide when you use any interactive features of the Services.
- **Marketing information**, such as your preferences for receiving communications about our products, activities, and publications, and details about how you engage with our communications.
- **Other information** that we may collect which is not specifically listed here, but which we will use in accordance with this Privacy Policy or as otherwise disclosed at the time of collection.

**Information we obtain from data collective platforms.** We may host data for research and other purposes in line with our charitable mission such as the Aridhia DRE. [Aridhia's privacy policy](#) applies to Aridhia's use of any personal data and Aridhia is a service provider of ADDI for this purpose. ADDI will only use and share personal data received as part of the Aridhia DRE to provide the data sharing service and for other purposes that are consistent with and in support of our charitable mission. The type of information ADDI will receive as part of the Aridhia DRE is business card-level information used to register for an account, such as name, email address, and title/organization.

**Information we obtain from social media platforms.** We may maintain pages for ADDI on social media platforms, such as Facebook, Twitter, and LinkedIn. When you visit or interact with our pages on those platforms, the platform provider's privacy policy will apply to your interactions and their collection, use, and processing of your personal information. You or the platforms may provide us with information through the platform, and we will treat such information in accordance with this Privacy Policy.

### **Cookies and Other Information Collected by Automated Means**

We, our service providers, and our business partners may automatically log information about you, your computer or mobile device, and activity occurring on or through the Services. The information that may be collected

automatically includes your computer or mobile device operating system type and version number, manufacturer and model; device identifier; browser type; screen resolution; IP address; the website you visited before browsing to our website; general location information such as city, state or geographic area; and information about your use of and actions on the Services, such as pages or screens you viewed, how long you spent on a page or screen, navigation paths between pages or screens, information about your activity on a page or screen, access times, and length of access. Our service providers and business partners may collect this type of information over time and across third-party websites and mobile applications.

See our [Cookie Policy](#) for more information.

## How We Use Your Personal Information

We use your personal information for the following purposes and as otherwise described in this Privacy Policy or at the time of collection:

**To operate the Services.** We use your personal information to:

- provide, operate, and improve the Services;
- communicate with you about the Services, including by sending you announcements, updates, security alerts, and support and administrative messages;
- understand your interests and personalize your experience with the Services;
- provide support and maintenance for the Services; and
- respond to your requests, questions and feedback.

**For research and development.** We analyze use of the Services to improve the Services and to develop new products and services.

**To send you marketing and promotional communications.** We may send you marketing communications as permitted by law. You can opt out of our marketing and promotional communications as described [below](#).

**To comply with law.** We use your personal information as we believe necessary or appropriate to comply with applicable laws, lawful requests, and legal process, such as to respond to subpoenas or requests from government authorities.

**For compliance, fraud prevention, and safety.** We may use your personal information and disclose it to law enforcement, government authorities, and private parties as we believe necessary or appropriate to: (a) protect our, your, or others' rights, privacy, safety, or property (including by making and defending legal claims); (b) enforce the terms and conditions that govern the Services; and (c) protect, investigate, and deter against fraudulent, harmful, unauthorized, unethical, or illegal activity.

**With your consent.** In some cases we may specifically ask for your consent to collect, use, or share your personal information, such as when required by law.

**To create anonymous data.** We may create aggregated and other anonymous data from your personal information and other individuals whose personal information we collect. We make personal information into anonymous data by removing information that makes the data personally identifiable to you. We may use this anonymous data and share it with third parties for our lawful business purposes, including to analyze and improve the Services and promote our business.

## How We Share Your Personal Information

We do not share your personal information with third parties without your consent, except in the following circumstances or as otherwise described in this Privacy Policy:

**Business Partners.** We may share your personal information with Gates Ventures, LLC, which helps ADDI by providing technical support, such as troubleshooting site issues and administrative assistance, for purposes consistent with this Privacy Policy.

**Service providers.** We may share your personal information with third-party companies and individuals that provide services on our behalf or help us operate the Services (such as customer support, website troubleshooting,

hosting, analytics, email delivery, marketing, and database management services).

Examples of some of our current service providers (with links to their privacy policies and/or legal terms) as of the date of posting this privacy policy are:

- Microsoft (we use Microsoft Azure for websites and most databases, as well as CRM services; all long-term data backups are held within Azure). <https://privacy.microsoft.com/en-us/privacystatement>
- Atlassian (to support collaboration/internal support from Gates Ventures and Velir) <https://www.atlassian.com/legal/privacy-policy>
- Velir (web developer) <https://www.sitecore.com/trust/privacy-policy>
- Altriva Solutions (CRM vendor) <http://altriva.com/Privacy>
- Sendgrid (email services) <https://sendgrid.com/policies/privacy-2016/>
- Click Dimensions (email automation for CRM, email analytics) <https://clickdimensions.com/about/privacy-policy/>
- Akamai (CDN/content delivery network to help distribute content for site performance) <https://www.akamai.com/us/en/multimedia/documents/akamai/akamai-privacy-statement.pdf>
- Adobe Analytics <https://www.adobe.com/privacy/policy.html>
- Google Analytics <https://policies.google.com/privacy?hl=en-US>
- Site 24x7 (external site monitoring) <https://www.site24x7.com/privacypolicy.html>
- Qualys, Inc. (external security monitoring) <https://www.qualys.com/company/privacy/>
- Optiv Security Inc. (external security partner) <https://www.optiv.com/privacy-policy>

Partners. See our [Cookie Policy](#) for more information about third parties that collect information through our Services with cookies and similar technologies.

Professional advisors. We may disclose your personal information to professional advisors, such as lawyers, bankers, auditors, and insurers, where necessary in the course of the professional services that they render to us.

For compliance, fraud prevention and safety. We may share your personal information for the compliance, fraud prevention and safety purposes described above.

Government Requests. Notwithstanding anything to the contrary in this policy, we may preserve or disclose your information if we believe that it is reasonably necessary to comply with a law, regulation, or legal request or to protect the safety, property, or rights of ADDI or others. However, nothing in this policy is intended to limit any legal defenses or objections that you may have to a third party or government request to disclose your information.

Corporate transfers. We may transfer or otherwise share some or all of our business or assets, including your personal information, in connection with a (potential) organizational transaction such as a merger, consolidation, reorganization, or in the event of dissolution.

## Your Choices

In this section, we describe the rights and choices available to all users. Users who are located within Europe can find additional information about their potential rights [below](#).

**Opt out of marketing communications.** You may opt out of marketing emails by following the unsubscribe instructions at the bottom of the email. You may continue to receive service-related and other non-marketing emails.

**Cookies & browser web storage.** For information on how to disable cookies and similar technologies used in the Services, see our [Cookie Policy](#).

**Do Not Track.** Some Internet browsers may be configured to send “Do Not Track” signals to the online services that you visit. We currently do not respond to “Do Not Track” or similar signals. To find out more about “Do Not Track,” please visit [www.allaboutdnt.com](http://www.allaboutdnt.com).

**Choosing not to share your personal information.** Where we are required by law to collect your personal information, or where we need your personal information to provide the Services to you, if you do not provide this information when requested (or you later ask to delete it), we may not be able to provide you with the Services or certain features. We will tell you what information you must provide to receive the Services by designating it as required at the time of collection or through other appropriate means. In some cases, you may provide a pseudonym, such as when you sign up for our email list.

## Other Sites, Mobile Applications, and Services

The Services may contain links to, or content or features from, other websites and online services operated by third parties. These links are not an endorsement of, or representation that we are affiliated with, any third party. In addition, our content may be included on web pages or in mobile applications or online services that are not associated with us. We do not control third-party websites, mobile applications, or online services, and we are not responsible for their actions. Other websites and services follow different rules regarding the collection, use, and sharing of your personal information. We encourage you to read the privacy policies of the other websites and mobile applications and online services you use.

## Security Practices

The security of your personal information is important to us. We employ a number of organizational, technical and physical safeguards designed to protect the personal information we collect. However, security risk is inherent in all internet and information technologies and we cannot guarantee the security of your personal information.

Some of our current security practices as of the date of this privacy policy include: Data is stored within a secured facility that limits physical access. Data at rest is stored in an encrypted state. Vendors must receive individual, per-instance authorization before being able to access our data stored within their facility (which access is only allowed as part of troubleshooting). All administrative accounts are protected by multi-factor authentication and, in most cases, access is also limited by IP address. All administrative actions are audited. An automated security review is undertaken on a regularly

scheduled basis. A specific and targeted security review is conducted bi-annually or more often as dictated by the needs and changes introduced in the services offered. An SDLC (software development lifecycle) program is used by the development partners to manage security practices and data handling during the development and maintenance cycles.

## International Data Transfers

We are headquartered in the United States and have service providers in other countries, and your personal information may be transferred outside of your state, province, or country to the United States or other locations where privacy laws may not be as protective as those in your state, province, or country.

## Children

The Services are not directed to, and we do not knowingly collect personal information from, anyone under the age of 16. If we learn that we have collected personal information of a child without the consent of the child's parent or guardian, we will delete it. We encourage parents with concerns to contact us at [support@alzheimersdata.org](mailto:support@alzheimersdata.org).

## Changes to this Privacy Policy

We may amend this Privacy Policy at any time by posting the amended version on the Services and indicating the effective date of the amended version. We may announce any material changes to this Privacy Policy through the Service and/or via email if we have your email address. In all cases, your continued use of the Services after the posting of any modified Privacy Policy indicates your assent to the amended Privacy Policy.

## How to Contact Us

If you have any questions or comments about this Policy or ADDI's privacy practices, email us at [support@alzheimersdata.org](mailto:support@alzheimersdata.org).

## Your California Privacy Rights

California has recently passed a new law called the California Consumer Privacy Act (CCPA). If the CCPA is applicable to us and to you, you have the right to:

1. know the categories of personal information collected about you in the prior 12 months and its sources and business purpose;
2. know whether your personal information is sold or disclosed, and to whom, in prior 12 months;
3. access and then delete your personal information (subject to exceptions); and
4. equal service and price (non-discrimination) if you exercise your privacy rights.

Please submit any requests to [support@alzheimersdata.org](mailto:support@alzheimersdata.org). You will need to verify your identity but confirming the details that you originally provided to us receive communications. If you did not request communications, you will need to verify the personal information that is related to your request. If you are an agent

For purposes of CCPA, “Personal Information” is defined to include information that identifies, relates to, describes, or is capable of being associated with a particular consumer or household. This includes (among other types of personal information) IP addresses, geolocation data, biometric information, and “unique identifiers” such as device and cookie IDs, Internet activity information like browsing history, commercial information such as products or services purchased or consuming histories or tendencies, and characteristics concerning an individual’s race, color, sex (including pregnancy, childbirth, and related medical conditions), age (40 or older), religion, genetic information, sexual orientation, political affiliation, national origin, disability or citizenship status. Inferences drawn from personal information “to create a profile about a consumer reflecting the consumer’s preferences, characteristics, psychological trends, preferences, predispositions, behavior, attitudes, intelligence, abilities, and aptitudes” are also considered “personal information.”

## Your Nevada Rights

You may review and request changes to your information or opt-out of the sale (if applicable) of your personal information at [support@alzheimersdata.org](mailto:support@alzheimersdata.org).

## Notice to European Users

The information provided in this section applies only to individuals in the [European Economic Area](#) and United Kingdom (collectively, “Europe”).

Personal information. References to “personal information” in this Privacy Policy are equivalent to “personal data” governed by European data protection legislation.

Controller and Representative. ADDI is the controller of your personal information covered by this Privacy Policy for purposes of European data protection legislation.

The contact information for our representative in Europe is: [Europesupport@alzheimersdata.org](mailto:Europesupport@alzheimersdata.org).

Legal bases for processing. The legal bases of our processing of your personal information as described in this Privacy Policy will depend on the type of personal information and the specific context in which we process it. However, the legal bases we typically rely on are set out in the table below. We rely on our legitimate interests as our legal basis only where those interests are not overridden by the impact on you (unless we have your consent or our processing is otherwise required or permitted by law). If you have questions about the legal basis of how we process your personal information, contact us at [support@alzheimersdata.org](mailto:support@alzheimersdata.org).

Processing purpose. Details regarding each processing purpose listed below are provided in the section above titled “How We Use Your Personal Information”.	Legal basis
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To operate the services	Processing is necessary to perform the contract governing our provision of the Services or to take steps that you request prior to signing up for the Services. If we have not entered into a contract with you, we process your personal information based on our legitimate interest in providing the Services you access and request.
For research and development To send you marketing communications For compliance, fraud prevent, and safety To create anonymous data	These activities constitute our legitimate interests.
To comply with law	Processing is necessary to comply with our legal obligations.
With your consent	Processing is based on your consent. Where we rely on your consent you have the right to withdraw it any time in the manner indicated when you consent or in the Services.

**Use for new purposes.** We may use your personal information for reasons not described in this Privacy Policy where permitted by law and the reason is compatible with the purpose for which we collected it. If we need to use your personal information for an unrelated purpose, we will notify you and explain the applicable legal basis.

**Sensitive personal information.** We ask that you not provide us with any sensitive personal information (e.g., social security number, government-issued identification, payment card information, information related to racial or ethnic origin, political opinions, religion or other beliefs, health, biometrics or genetic characteristics, criminal background or trade union membership) on or through the Services, or otherwise to us.

## Retention

We retain personal information where we have an ongoing legitimate business need to do so (for example, to provide you with a service you have requested; to comply with applicable legal, tax or accounting requirements; to establish or defend legal claims; or for fraud prevention). When we have no ongoing legitimate business need to process your personal information, we will either delete or anonymize it or, if this is not possible (for example, because your personal information has been stored in backup archives), then we will securely store your personal information and isolate it from any further processing until deletion is possible.

“Live” user data (username, email, sign-in information [whether a link to a Facebook or Twitter ID or a password if the user is using our internal authentication]) is stored without any active plans on purging old or inactive data.

Backup data (which may contain the above user-specific information) is retained for up to 1 year.

A user may request, in accordance with standards such as GDPR, to have their data removed from our live system, and it will eventually expire out of the backups once the retention period has ended.

## Your rights

European data protection laws give you certain rights regarding your personal information. If you are located within Europe, you may ask us to take the following actions in relation to your personal information that we hold:

- **Access.** Provide you with information about how we process your personal information and give you access to your personal information.
- **Correct.** Update or correct inaccuracies in your personal information.
- **Delete.** Delete your personal information.
- **Transfer.** Transfer a machine-readable copy of your personal information to you or a third party of your choice.
- **Restrict.** Restrict the processing of your personal information.

- **Object.** Object to our reliance on our legitimate interests as the basis of our processing of your personal information that impacts your rights.

Please [contact us](#) to submit these requests. We may request specific information from you to help us confirm your identity and process your request. Applicable law may require or permit us to decline your request. If we decline your request, we will tell you why, subject to legal restrictions. If you would like to submit a complaint about our use of your personal information or our response to your requests regarding your personal information, you may [contact us](#) or submit a complaint to the data protection regulator in your jurisdiction. You can find your data protection regulator [here](#).

### **Cross-Border Data Transfer**

If we transfer your personal information from the European Economic Area to a country outside of it and are required to apply additional safeguards to your personal information under European data protection legislation, we will do so. Please [support@alzheimersdata.org](mailto:support@alzheimersdata.org) for further information about any such transfers or the specific safeguards applied.

## **Cookie Policy**

Effective as of November 17, 2020.

This Cookie Policy explains how Alzheimer’s Disease Data Initiative, Inc. and our subsidiaries and affiliates (collectively, “**ADDI**”, “**we**”, “**us**” or “**our**”) uses cookies and similar technologies in connection with [website] and any other website that we own or control and which posts or links to this Cookie Policy (collectively, the “Sites”).

### **What are cookies?**

Cookies are small data files that are placed on your computer or mobile device when you visit a website. Cookies serve different purposes, like helping us understand how a site is being used, letting you navigate between pages efficiently, remembering your preferences and generally improving your browsing experience.

Our Sites may use both session cookies (which expire once you close your web browser) and persistent cookies (which stay on your computer or mobile device until you delete them).

We use two broad categories of cookies: (1) first party cookies, served directly by us to your computer or mobile device, which we use to recognize your computer or mobile device when it revisits our Sites; and (2) third -party cookies, which are served by service providers or business partners on our Sites, and can be used by these parties to recognize your computer or mobile device when it visits other websites. Third party cookies can be used for a variety of purposes, including site analytics, advertising and social media features.

On the Sites, we use cookies and similar technologies in the following categories described in the table below.

Type	Description	Who serves the cookies (link to privacy policy/site)	How to control them
Analytics	These cookies help us understand how our Services is performing and being used. These cookies may work with web beacons included in emails we send to track which emails are opened	<a href="#">Google</a> <a href="#">Analytics</a> <a href="#">Hubspot</a> <a href="#">Salesforce</a> <a href="#">Pardot</a>	See 'your choices' below. Google Analytics uses its own cookies. You can find out more information about Google Analytics cookies <a href="#">here</a> and about how Google protects your data <a href="#">here</a> . You can prevent the use of Google Analytics relating to your use of our Sites by

	and which links are clicked by recipients.		downloading and installing a browser plugin available <a href="#">here</a> .
Essential	These cookies are necessary to allow the technical operation of our Services (e.g., they enable you to move around on a website and to use its features).	ADDI	See 'your choices' below.
Functionality/performance	These cookies enhance the performance and functionality of our Services.	<a href="#">Google Tag Manager</a>	See 'your choices' below.

## Other technologies

In addition to cookies, our Sites may use other technologies, such as Flash technology and pixel tags to collect information automatically.

### *Web Beacons*

We may also use web beacons (which are also known as pixel tags and clear GIFs) on our Sites and in our HTML formatted emails to track the actions of users on our Sites and interactions with our emails. Unlike cookies, which are stored on the hard drive of your computer or mobile device by a website, pixel tags are embedded invisibly on webpages or within HTML formatted emails. Pixel tags are used to demonstrate that a webpage was accessed or that

certain content was viewed, typically to measure the success of our marketing campaigns or engagement with our emails and to compile statistics about usage of the Sites, so that we can manage our content more effectively.

Currently, examples of beacons we use are fb pixel

<https://pixel.facebook.com/about/privacy/>, LinkedIn Insights Tag

<https://www.linkedin.com/legal/privacy-policy>

[https://www.linkedin.com/legal/cookie\\_policy?src=or-](https://www.linkedin.com/legal/cookie_policy?src=or-search&veh=www.google.com)

[search&veh=www.google.com](https://www.linkedin.com/legal/cookie_policy?src=or-search&veh=www.google.com), Twitter Universal Website Tag

<https://help.twitter.com/en/rules-and-policies/twitter-cookies>.

## Your choices

Most browsers let you remove or reject cookies. To do this, follow the instructions in your browser settings. Many browsers accept cookies by default until you change your settings. Please note that if you set your browser to disable cookies, the Sites may not work properly.

For more information about cookies, including how to see what cookies have been set on your computer or mobile device and how to manage and delete them, visit [www.allaboutcookies.org](http://www.allaboutcookies.org). If you do not accept our cookies, you may experience some inconvenience in your use of our Sites.

Users may opt out of receiving targeted advertising on websites through members of the Network Advertising Initiative by clicking [here](#) or the Digital Advertising Alliance by clicking [here](#). European users may opt out of receiving targeted advertising on websites through members of the European Interactive Digital Advertising Alliance by clicking [here](#), selecting the user's country, and then clicking "Choices" (or similarly-titled link. Please note that we also may work with companies that offer their own opt-out mechanisms and may not participate in the opt-out mechanisms above.

If you choose to opt out of targeted advertisements, you will still see advertisements online but they may not be relevant to you. Even if you do choose to opt out, not all companies that serve online targeted advertising are included in this list, and so you may still receive some cookies and tailored advertisements from companies that are not listed.

For more information about how we collect, use, and share your information, see our [Privacy Policy](#).

## **Changes**

Information about the cookies we use may be updated from time to time, so please check back on a regular basis for any changes.

## **Questions**

If you have any questions about this Cookie Policy, please contact us at [support@alzheimersdata.org](mailto:support@alzheimersdata.org).