FTDDR Personal Data Use Table 2021

How We Collect Personal Information

Self-Provided Information. The FTD Disorders Registry (FTDDR) collects self-provided information when you register online for the Contact Registry or the Research Registry, complete a survey, and submit an online form.

Automatically Collected Information. Session cookies are used to collect an engagement history of your interactions with the Registry's emails, social media accounts, and website. The Registry's survey software automatically collects certain technical information.

Use of Personal Information

The FTD Disorders Registry is committed to only collecting the information necessary to conduct activities required by law, by consent, and for legitimate interests.

The personal information we collect may be used for one or more of the following purposes:

1. To create and validate your Registry account (i.e. age validation, information required by the NIH to generate a Global Unique Identifier).

2. To track the number of unique FTD cases in the Registry and link-related accounts (dyads/triads).

3. To send automated communications that facilitate your Registry participation such as confirmation emails, survey notifications, study reminders, updates to the Privacy Policy and our Terms and Conditions, technical notices, and other account-related items.

4. To send newsletters and other information regarding frontotemporal degeneration (FTD) that may be of interest to you.

5. To send targeted communications for resolution of account issues or in response to contact/material requests.

6. To provide individualized clinical trial information based on geography and study-specific criteria.

7. To perform population studies within the Registry and/or stratify the Registry population.

8. To inform and shape medical research for FTD by providing de-identified data to projects that pass the Registry's rigorous review process.

9. For research and analysis aimed at improving website user-experience.

10. For research and analysis aimed at improving Registry communications.

11. To troubleshoot user issues with survey software.

12. To respond to law enforcement requests and as required by applicable law, court order, or governmental regulations.

Personal Information We Collect

The categories of personal information we collect and the purposes (from the list above) for which they may be used include:

Identifiers and Contact Information		
Registration Data - Registrant Information **(All Research Registry Accounts)**	Name (First Name, Last Name)	1
	Legal Name at Birth (First Name, Middle Name, Last Name)	1, 2
	Email Address	1, 3, 4, 5, 6
	Username/Password	1
	Postal Address	5, 6
	City of Birth	1, 2
	Phone Number	5

Registration Data - Caregiver Information **(Type 1a and 1b Research Registry Accounts)**	Name (First Name, Last Name)	2
	Email Address	1, 5
	ZIP/Postal Code	5
	Phone Number	5
Registration Data - LAR Information **(Type 1b Research Registry Accounts)**	Name (First Name, Last Name)	1
	Email Address	1, 5
	ZIP/Postal Code	5
	Phone Number	5
Registration Data - FTD-Diagnosed Person's Information (Type 2 and 3 Research Registry Accounts)	Name (First Name, Middle Name, Last Name)	2
	City of Birth	2
Materials Request Form Submissions	Name – Person Ordering Materials (First Name, Last Name)	5
	Name – Person Receiving Materials (First Name, Last Name)	5
	Shipping Address	5
	Email Address	5

	Phone Number	5
Contact Form Submissions	Name	5
	Email Address	5

Demographic Information		
Registration Data - Registrant Information **(All Research Registry Accounts)**	Date of Birth, Year of Birth	1, 2, 6, 7, 8
	Country	1, 6, 7, 8
	Country of Birth	1, 2, 7, 8
	Gender at Birth	1, 2, 6, 7, 8
	Race	7, 8
	Diagnosis	1, 2, 6, 7, 8
Registration Data - LAR Information **(Type 1b Research Registry Accounts)**	Year of Birth	1, 7, 8
	Relationship to Registrant	1, 7, 8
Registration Data - Caregiver Information **(Type 1a and 1b Research Registry Accounts)**	Year of Birth	2, 7, 8
	Relationship to Registrant	2, 6, 7, 8
Registration Data - FTD-Diagnosed Person's Information (Type 2 and 3 Research Registry Accounts)	Date of Birth	2, 7, 8
	Country of Birth	2, 7, 8

	Gender at Birth	2, 7, 8
	Diagnosis	2, 6, 7, 8
	Relationship to Registrant	2, 6, 7, 8
	Deceased	6, 7
Demographic Survey – FTD-Diagnosed Individuals **(Type 1a and 1b Registry Accounts)**	Various demographic information about registrant (FTD-diagnosed person) such as diagnosis, race, location of residence, marital status, gender, employment, age, education level, concurrent research study enrollment, family history, utilization of support resources, research interests	6, 7, 8
	Various demographic information about the caregiver including relationship, degree of interaction	6, 7, 8
Demographic Survey - Caregiver/Spouse/Family/Friend (Type 2 and 3 Accounts)	Various demographic information about the FTD-diagnosed individual such as diagnosis, race, location of residence, marital status, gender, age, concurrent research study enrollment	6, 7, 8

	Various demographic information about registrant (Caregiver, Spouse, Family, or Friend) such as gender, race, location of residence, relationship to affected individual, concurrent study enrollment, family history, utilization of support resources, research interests	6, 7, 8
Disease Impact Survey **(All Accounts)**	General demographic information including age, gender, diagnosis	6, 7, 8
Research Readiness Survey **(All Accounts)**	General demographic information including age, gender, diagnosis	6, 7, 8
Internet or Other Similar Network Activity		
Data Collected via Pardot **(All Accounts)**	Information about how registrants interact with Registry emails	10
	Information about how registrants interact with social media posts	10
	Information about how registrants interact with the Website, including page visit URL, page title, time spend on the page, and the date/time of the visit	9

Data Collected via Alchemer **(Research Registrants)**	Information about how registrants interact with Registry surveys, including time spend on the survey and the date/time that the survey is submitted	11

Device Information

Data Collected via Alchemer **(Research Registrants)**	Browser Type	11
	IP Address	11
	Operating System Type	11
	Device ID	11
	Device Type	11

Geolocation Information

Data Collected via Alchemer **(Research Registrants)**	Physical location where a survey is completed	7

Biometric Information

Demographic Survey – FTD-Diagnosed Individuals **(Type 1a and 1b Registry Accounts)**	Genetic Testing Status and Result	6, 8
	Medications History	6, 8

	Disease Impact	6, 8
	Other Health Information	6, 8
Demographic Survey – Caregiver/Spouse/Family/Friend (Type 2 and 3 Accounts)	Genetic Testing Status and Results of FTD-diagnosed Loved One and Registrant (Caregiver, Spouse, Family, Friend)	6, 8
	Disease Impact for FTD-diagnosed Loved One and Registrant (Caregiver, Spouse, Family, Friend)	6, 8
	Medications History of FTD-diagnosed Loved One	6, 8
	Other Health Information for FTD-diagnosed Loved One	6, 8
Disease Impact Survey **(All Accounts)**	Information to evaluate disease impact including disease presentation, timing of diagnosis, experience throughout diagnostic process, level of independence, symptoms, quality of life	6, 8