Verana Health®

Advancing knowledge and clinical development in Frontotemporal Dementia (FTD) using the American Academy of Neurology's (AAN) Axon Registry®

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Disclosures

This project was led by the Verana Scientific and Medical Teams, and received no outside funding. Verana Health worked with the Association for Frontotemporal Dementia (AFTD).

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FTD is the most common form of dementia for people under age 60, affecting ~60,000 individuals in the U.S.

- FTD refers to a group of disorders brought on by progressive nerve cell loss in the brain's frontal lobe or temporal lobes that leads to
  - deterioration in behavior and personality
  - difficulty with producing or comprehending language
- FTD is frequently misdiagnosed as Alzheimer's, depression, Parkinson's disease, or a psychiatric condition
- Today, there is no known cure for FTD

1 Gainer, G. (2023, February 16). Frontotemporal Degeneration, Dementia - What is FTD? AFTD. https://www.theaftd.org/what-is-ftd/disease-overview/
2 Frontotemporal Dementia. (n.d.). Alzheimer's Disease and Dementia. https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementia
3 Galvin, J. E., Howard, D., Denny, S. S., Dickinson, S., & Tatton, N. (2017). The social and economic burden of frontotemporal degeneration. Neurology, 89(20), 2049–2056. https://doi.org/10.1212/wnl.0000000000004614

How can treatment for FTD be developed?

- ~30% of FTD cases are inherited and ~40% + are familial
- Genetic-based FTD offers an opportunity for early intervention and development of treatments for specific FTD-causing genes

The Association for Frontotemporal Degeneration (AFTD) is an organization focused on advancing research for FTD, providing information, education and support, and raising awareness of this rare and uniquely devastating disease.

1 Gainer, G. (2023, February 16). Frontotemporal Degeneration, Dementia - What is FTD? AFTD. https://www.theaftd.org/what-is-ftd/disease-overview/
2 Gainer, G. (2022, August 3). What Causes FTD? | AFTD. AFTD. https://www.theaftd.org/ftd-genetics/what-causes-ftd/
3 Frontotemporal Dementia. (n.d.-c). Alzheimer's Disease and Dementia. https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementia

Objectives

To evaluate feasibility of a registry-based approach to real-world research and trial recruitment for FTD using the Axon Registry®

Axon Registry®

- Neurology patient registry
- de-identified EHR data
- 3 million unique patients

Verana Health partners with AAN to provide ingestion, mapping and curation of the registry data.

Methods of Identifying Patients with FTD in the Axon Registry®'s Structured Data

FTD Diagnosis

Documented ICD code for Frontotemporal Dementia diagnosis, 9/16/2017 - 9/16/2021

Patients, n = 3,031 (100%)

Age

Patients between the ages of 25-85 at the index date[1]

Patients, n = 2,841 (93.7%)

Other Diagnosis

Patients without a documented ICD code for another significant neurodegenerative disease

Patients, n = 1,754 (61.7%)

Follow-Up Data

At least 12 months of data available following the index date

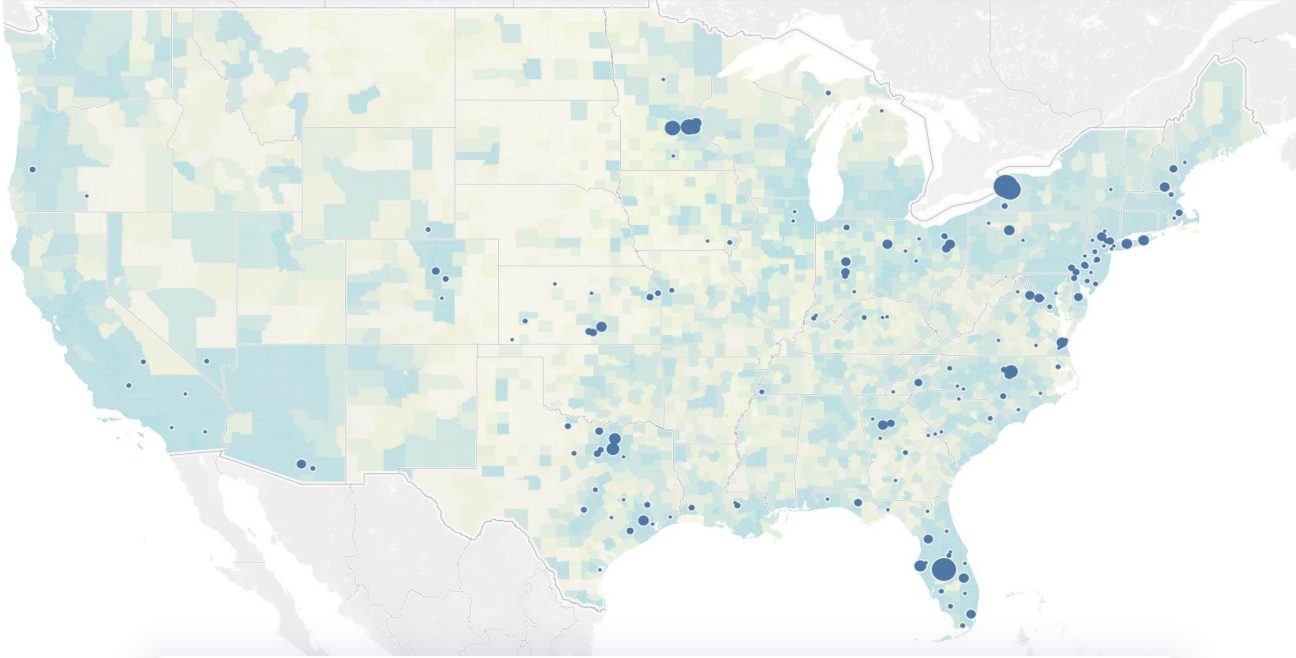
Patients, n = 698 (39.8%)

1. Index date is defined as the date in which the FTD diagnosis was first recorded during the index period.
2. Diseases include Alzheimer's Disease, Dementia in Alzheimer disease, Parkinson's Disease, Lewy Body Dementia, Huntington Disease, Paralysis Agitans, Vascular Dementia, Amyotrophic Lateral Sclerosis (ALS)

ICD Codes used for Frontotemporal Dementia diagnosis in the EHR system

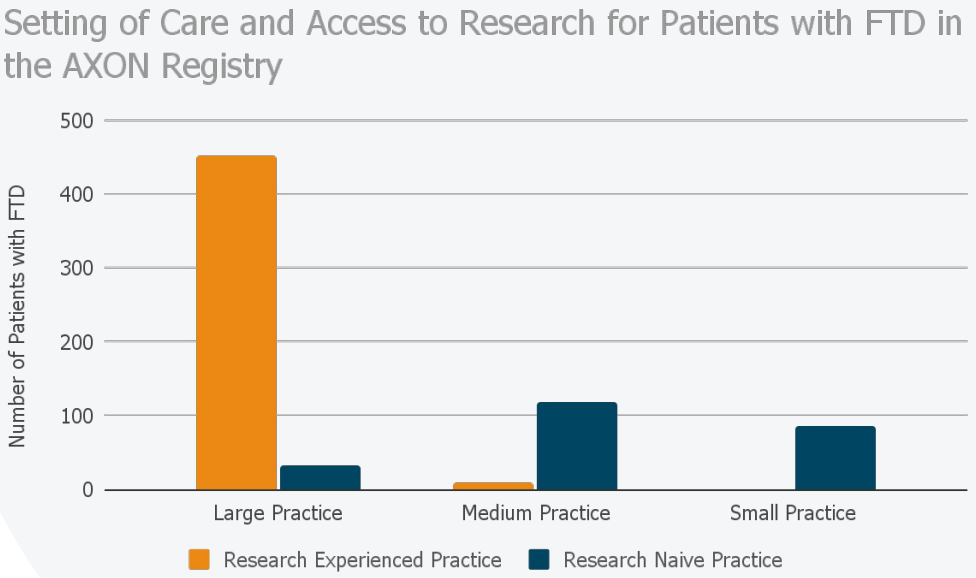
ICD Version	ICD Code	Description for FTD
ICD-10-CM	G31.0	Frontotemporal dementia
ICD-10-CM	G31.09	Other frontotemporal dementia
ICD-10-CM	G31.01	Pick's disease
ICD-9-CM	331.1	Frontotemporal dementia
ICD-9-CM	331.11	Pick's disease
ICD-9-CM	331.19	Other frontotemporal dementia
SNOMED-CT	230270009	Frontotemporal dementia (disorder)
SNOMED-CT	702429008	Frontotemporal dementia with parkinsonism-17 (disorder)
SNOMED-CT	230278002	Progressive aphasia
SNOMED-CT	230280008	Progressive aphasia in Alzheimer's disease (disorder)
SNOMED-CT	716281000	Primary progressive non fluent aphasia
SNOMED-CT	716380002	Logopenic progressive aphasia

Population Density of U.S. Citizens from the 2018 Census vs. Patients with FTD diagnoses in the AXON Registry® in the Index Period

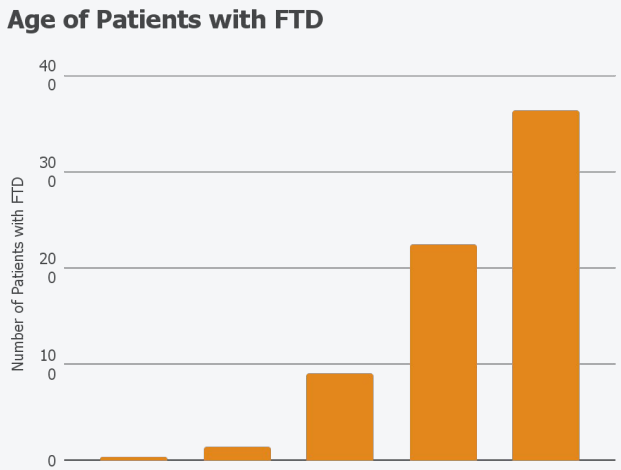


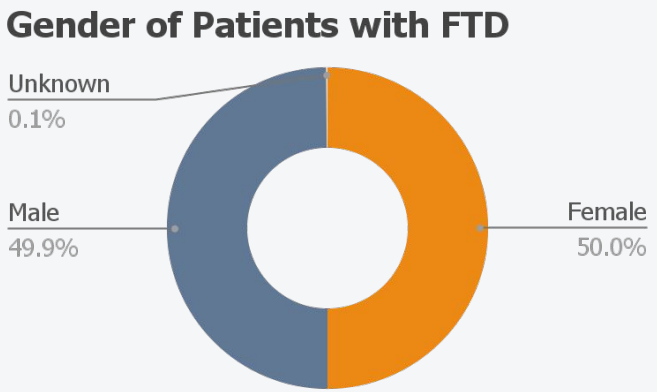
1 US Census Bureau. (2022b, August 6). Historical Population Density Data (1910-2020). Census.gov. https://www.census.gov/data/tables/time-series/dec/density-data-text.html

Demographics of Patients with FTD



Demographics of Patients with FTD

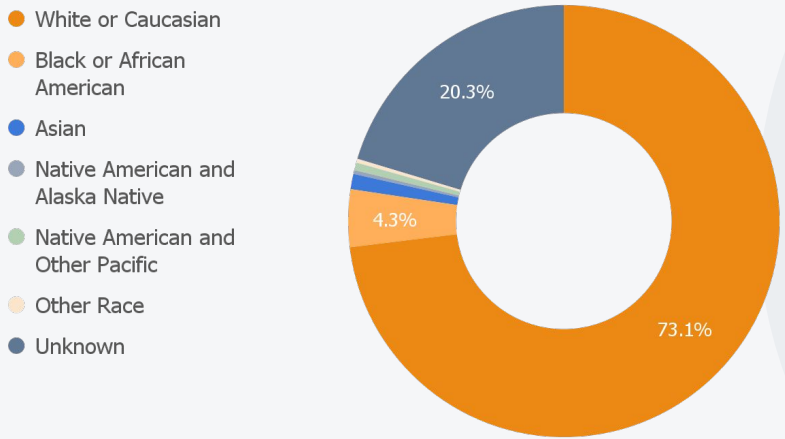




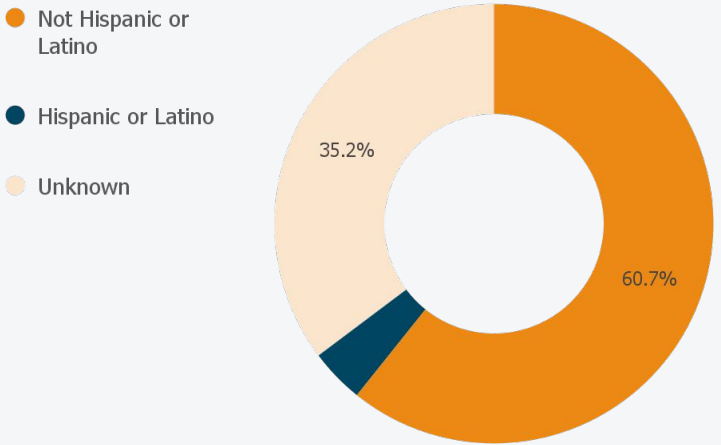
1 Fast Facts about Frontotemporal Degeneration, AFTD. https://www.theaftd.org/wp-content/uploads/2009/02/Fast-Facts-Final-6-11.pdf

Demographics of Patients with FTD

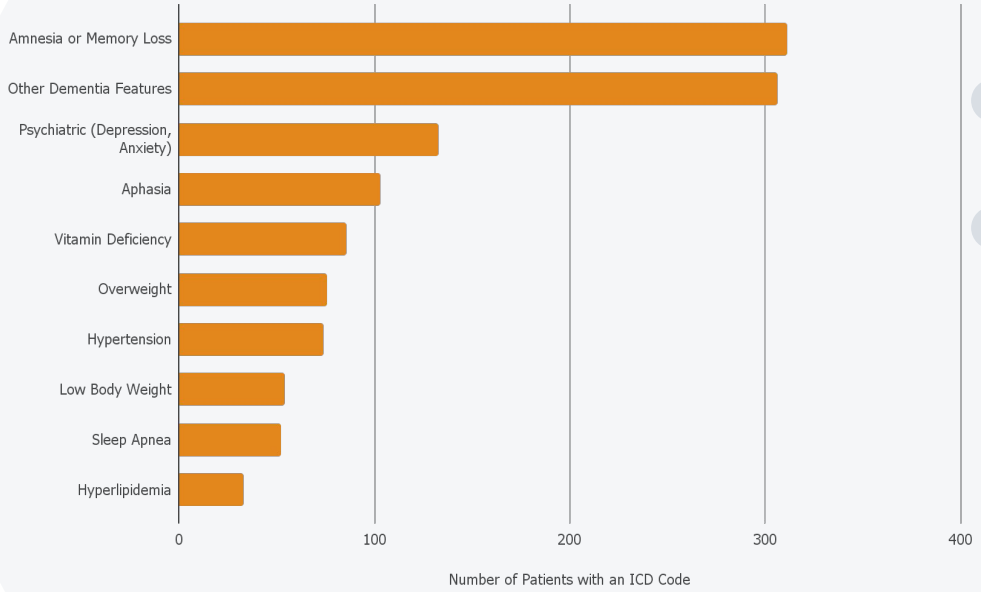
Race of Patients with FTD



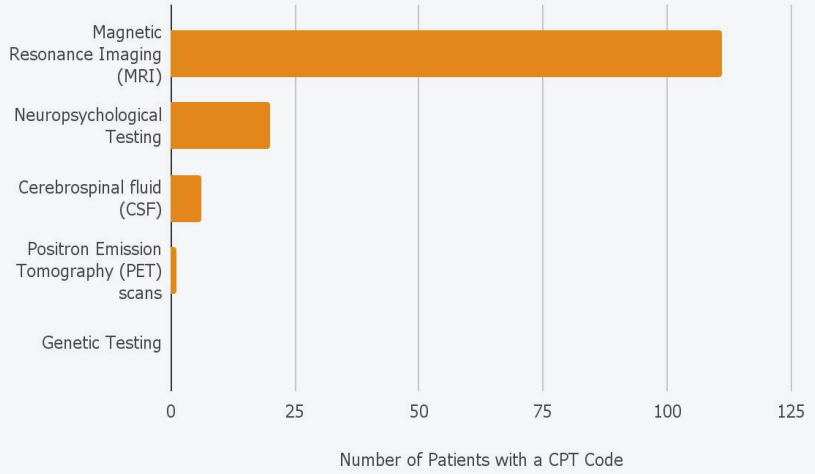
Ethnicity of Patients with FTD



What are the top Concomitant Diagnoses of Patients with FTD?



What are the top procedures documented in the structured fields of Patients with FTD?



Limitations

The Axon Registry is not a population sample

Diagnosis based on ICD codes

Concurrent diagnoses and misdiagnoses

Demographic data is EHR derived with missingness and misclassification

Patients Excluded from the cohort due to a concomitant diagnosis	Number of Patients
Exclude patients[1] with documentation of an ICD diagnosis for another significant neurodegenerative disease*	1,087
Pre Index Date Diagnosis of Neurodegenerative Disease	866
Post Index Date Diagnosis of Neurodegenerative Disease	663

*Diseases include Alzheimer's Disease, Dementia in Alzheimer disease, Parkinson's Disease, Lewy Body Dementia, Huntington Disease, Paralysis Agitans, Vascular Dementia, Amyotrophic Lateral Sclerosis (ALS)
1 Patients diagnoses for other neurodegenerative diseases are not mutually exclusive; a patient may have a diagnosis before and after their FTD diagnosis that excludes them from the cohort

Conclusions

To support the discovery of new medicines, we need to improve the diagnosis experience access to genetic counseling, and access to diagnosis.

Pairing the Axon Registry with provider outreach and education can surface patients with FTD and expand access to clinical trials.