

FTD Disorders Registry (FTDDR) Participants: Understanding Social Risk Factors in Research Participation

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Background

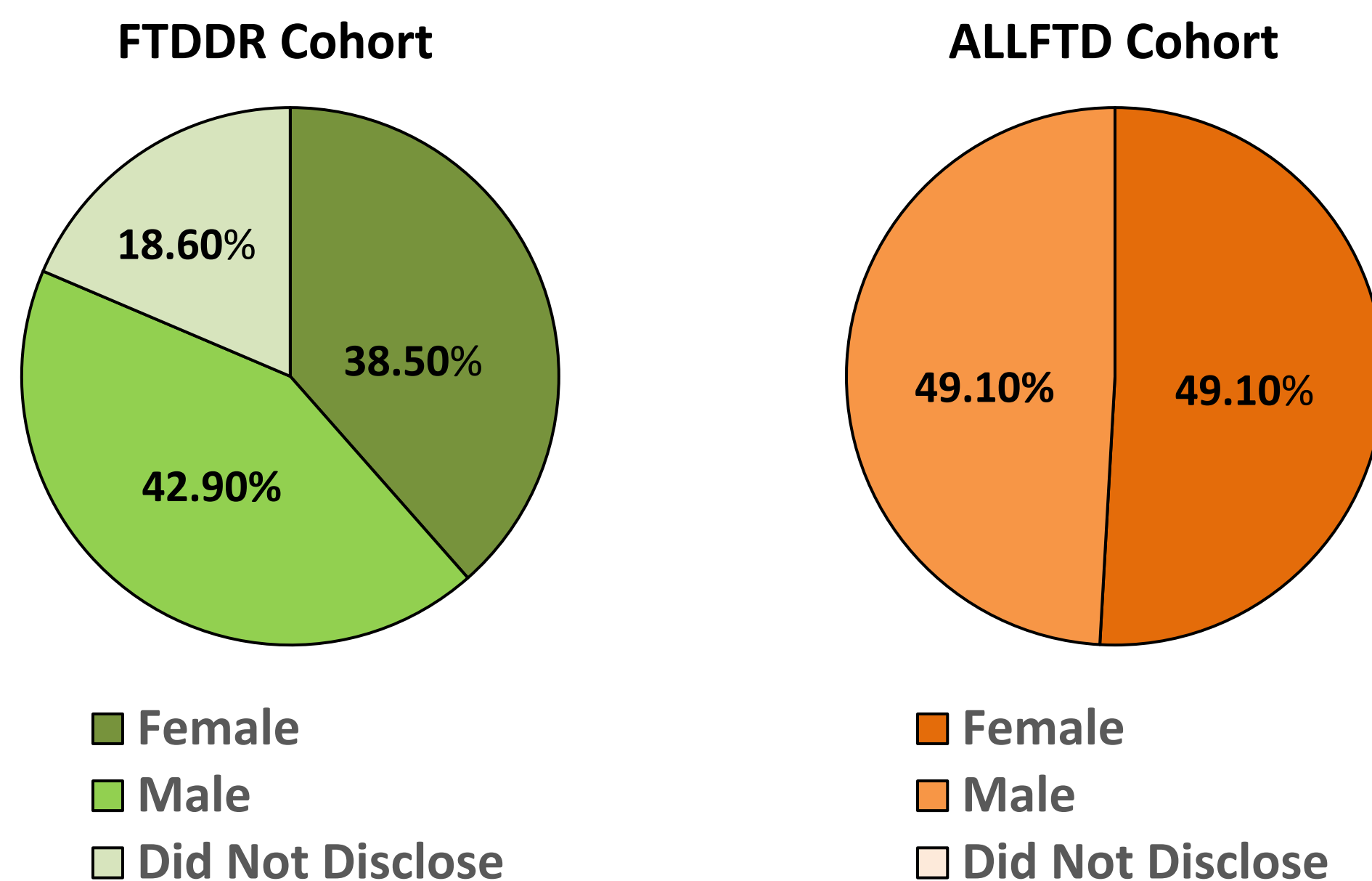
Frontotemporal degeneration (FTD) is an umbrella term encompassing a range of rare neurodegenerative disorders that cause progressive changes to behavior, personality, language, and movement with onset typically before age 60. The FTD Disorders Registry (FTDDR) is a compliant, web-based registry that facilitates FTD research with over 6,000 participants. Currently, several potential FTD therapies are under investigation, underscoring the need for increased diversity in research participation.

Methods

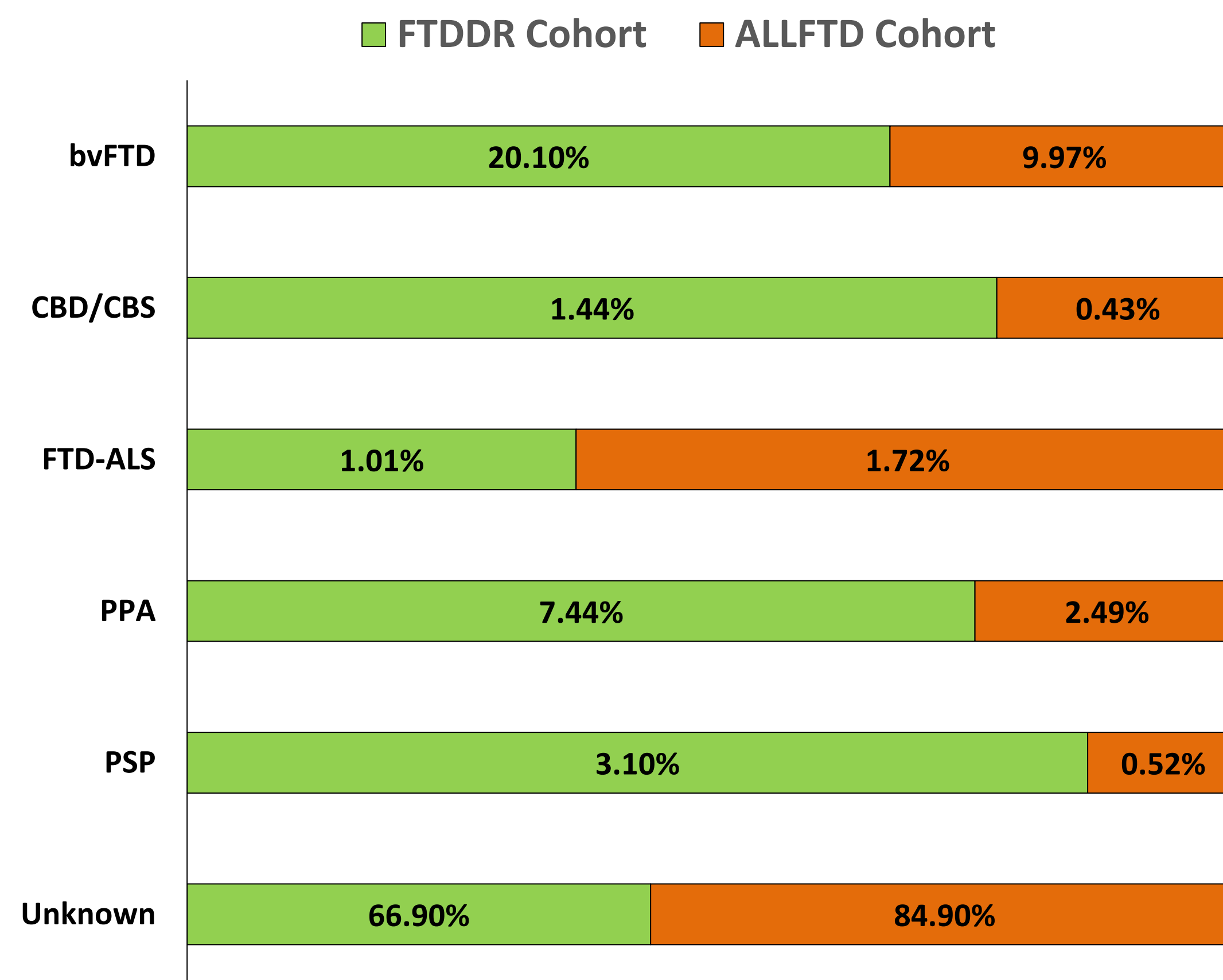
Two validated scores describe socioeconomic and geographic factors that may impact willingness to participate in research. The Area Deprivation Index (ADI) assesses socioeconomic disadvantages and captures social determinants of health. The Rural-Urban Commuting Area Codes (RUCA) measures population density, urbanization, and daily commuting to determine individuals living in urban vs rural communities. Both scores are for United States (U.S.) residents only.

FTDDR U.S. participants were divided into two cohorts: (1-FTDDR) enrolled in FTDDR only and (2-ALLFTD) enrolled in FTDDR through the ALLFTD Study, a longitudinal natural history study. ADI percentiles were calculated using self-reported zip codes for 1392 cohort 1 and 983 cohort 2 participants. RUCA scores were calculated using self-reported zip codes for 4565 cohort 1 and 1174 cohort 2 participants.

Participant's Gender



Participant's FTD Diagnosis



Participant's Socioeconomic Disadvantage (ADI)

1-25 Percentile	26-50 Percentile	51-75 Percentile	76-100 Percentile
40.5% (n=564)	32.9% (n=458)	19.7% (n=274)	6.9% (n=96)

Low Disadvantage ← High Disadvantage

1-25 Percentile	26-50 Percentile	51-75 Percentile	76-100 Percentile
49.3% (n=485)	28.3% (n=278)	16.7% (n=164)	5.7% (n=56)

Low Disadvantage ← High Disadvantage

Participants Living in Urban vs Rural Communities (RUCA)

Score 1-3	Score 4-7	Score 8-10
87.9% (n=4014)	8.9% (n=410)	3.2% (n=141)

Urbanized Area ← Rural Area

Score 1-3	Score 4-7	Score 8-10
85.8% (n=1007)	11.0% (n=129)	3.2% (n=38)

Urbanized Area ← Rural Area

Discussion

The FTDDR cohort had 18.6% of participants who chose not to disclose their gender while all participants in the ALLFTD cohort disclosed their gender. Additionally, more PSP and CBD/CBS diagnosed individuals were within the FTDDR cohort vs. ALLFTD cohort. ADI analysis indicated a low percentage (6.9% FTDDR, 5.7% ALLFTD) of participants lived in a highly disadvantageous communities. 40.5% of FTDDR cohort and 49.3% of ALLFTD cohort lived in communities considered "low disadvantage," suggesting they may have fewer socioeconomic risk factors or impediments to research participation. Additionally, RUCA analysis indicated most participants in both cohorts lived in urban areas (87.9% FTDDR, 85.8% ALLFTD) and only 3.2% for both cohorts lived in rural communities. A barrier to both ADI and RUCA analysis is the lack of validation for self-reported zip codes and missing participant zip codes in ADI and RUCA datasets.

Conclusions

Socioeconomic and geographic factors may play a role in accurate diagnosis, access to medical centers, and ability to participate in research. ADI and RUCA analyses indicate that the majority of FTDDR participants, including those actively enrolled in FTD research, live in less disadvantageous neighborhoods and in urban areas, highlighting the needs for outreach to more disadvantaged and rural communities. FTDDR developing and executing an engagement strategy to identify, recruit, and retain diverse individuals willing to participate in research could accelerate advancements in FTD research.