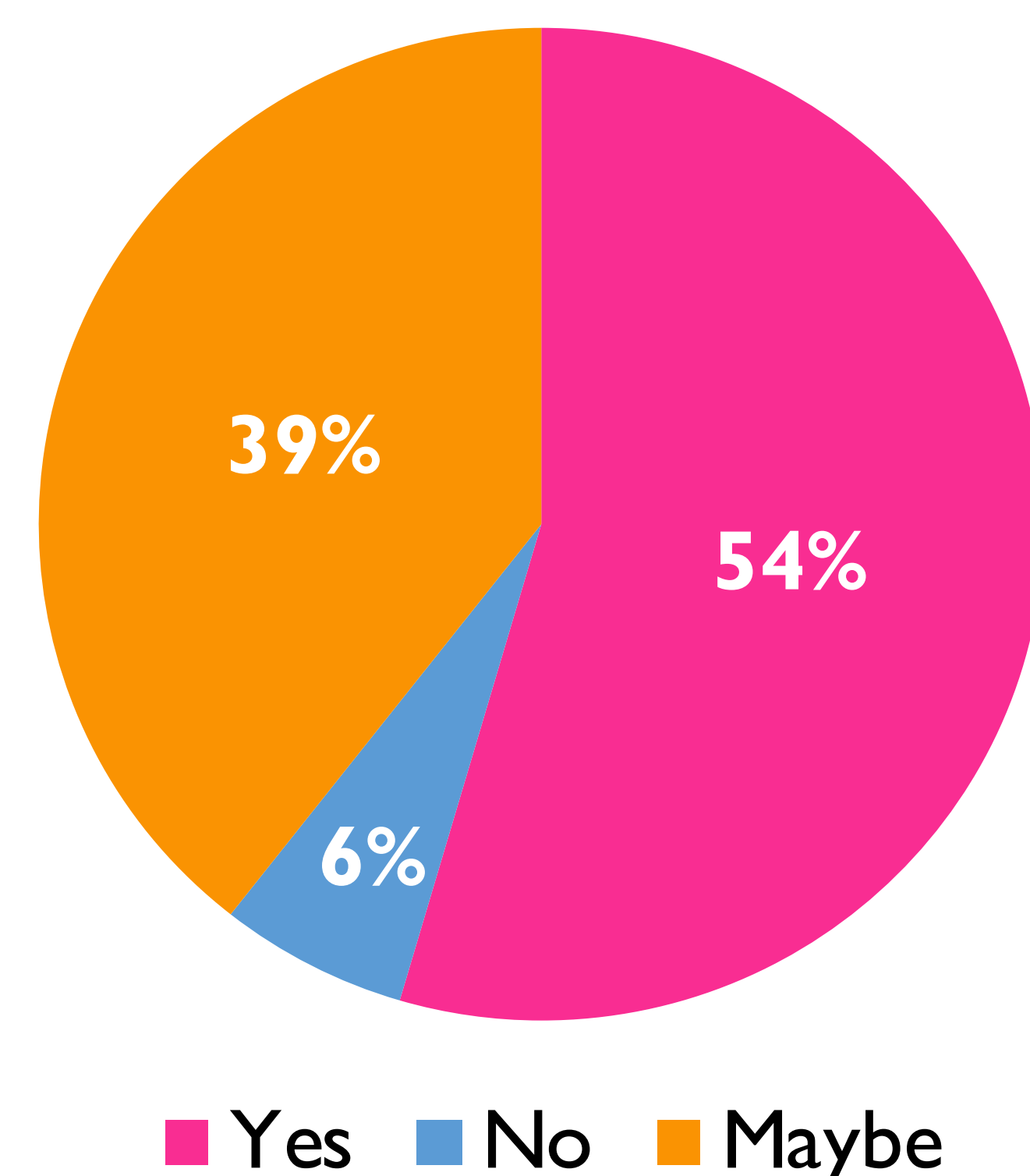


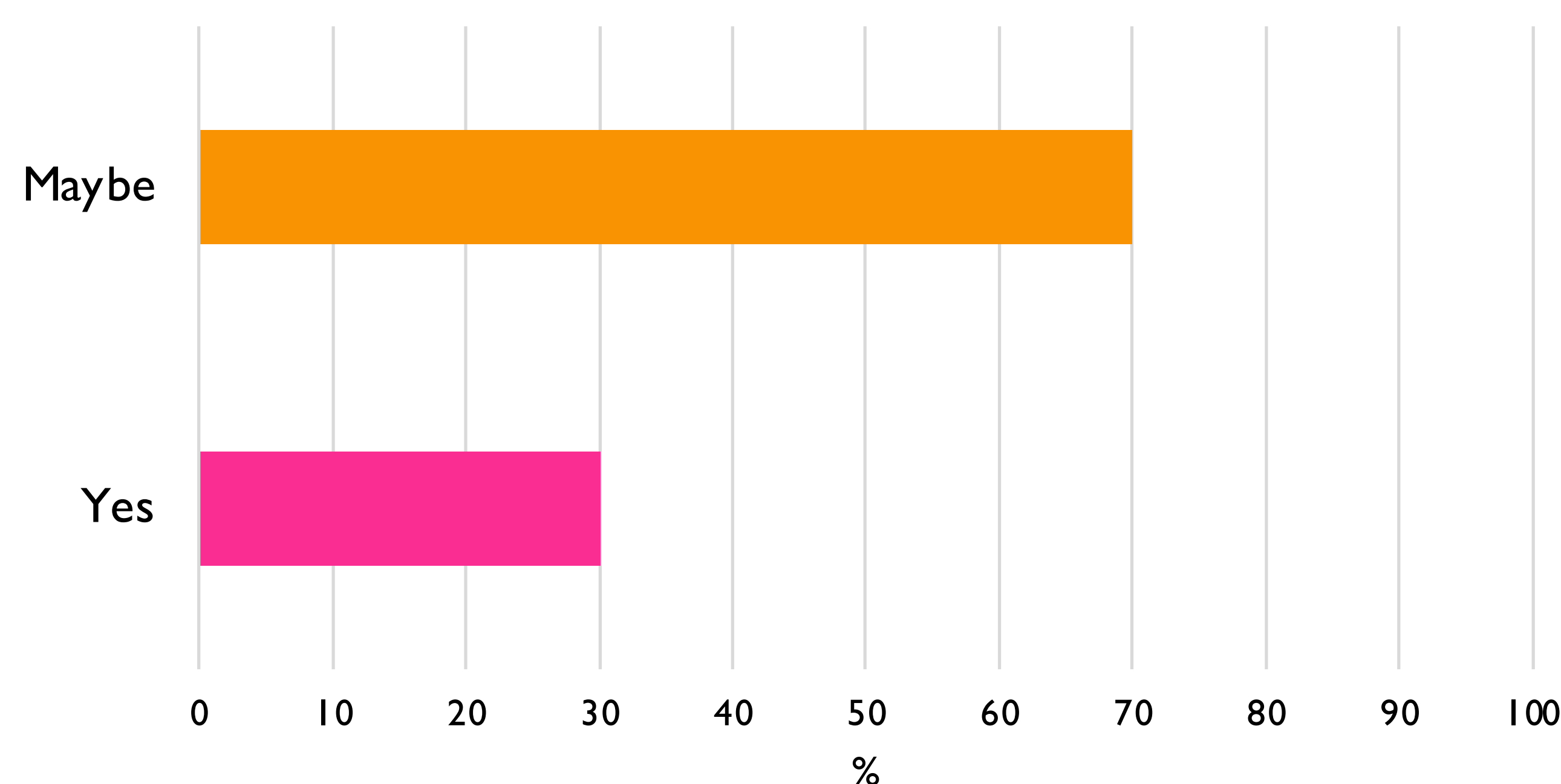
## Only 6% of individuals with familial FTD would not want to participate in a clinical trial

Would you be willing to go into a clinical trial?



## 30% would be willing to go into a gene therapy trial

Would you participate in a gene therapy trial if it meant you could not go into any other trial?



# Using GENFI participant engagement to inform observational research and clinical trials

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## 1. Background

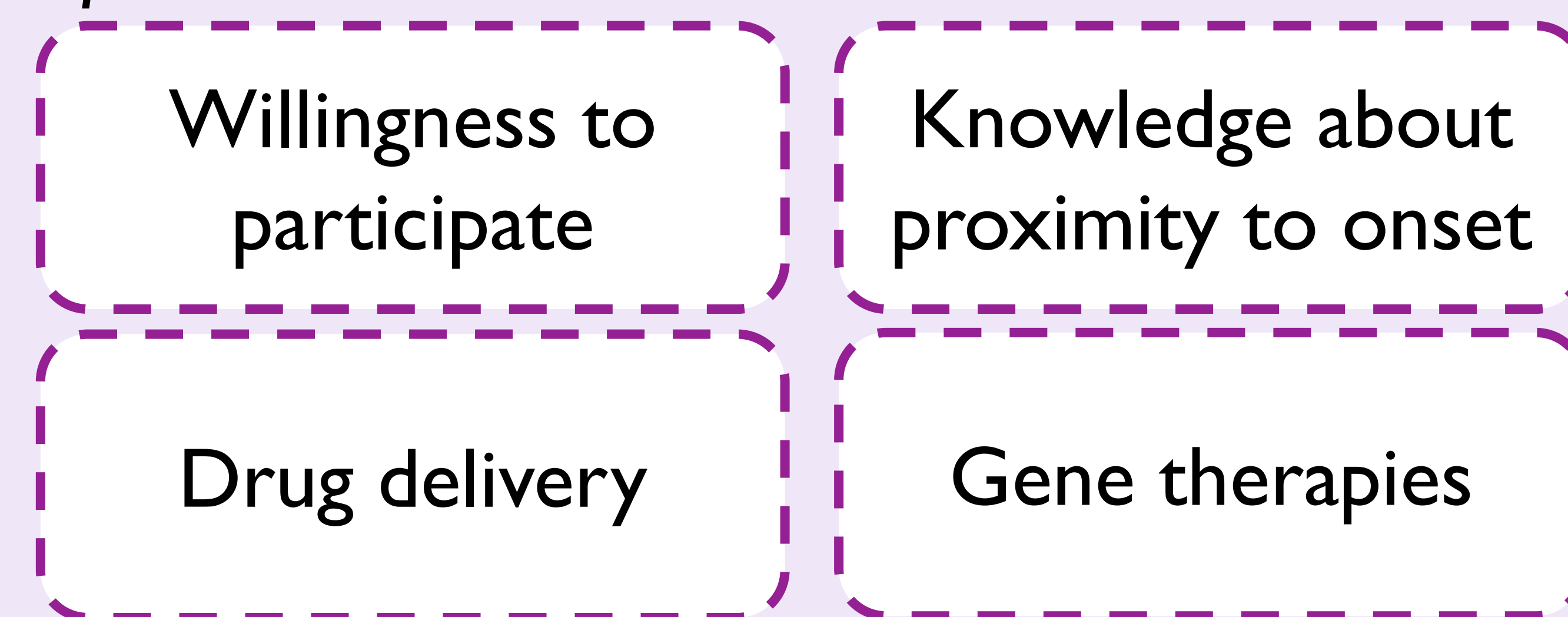
It is vital that we include the views of individuals with frontotemporal dementia (FTD) and their families in the development and design process of clinical trials for FTD. This study aims to establish what types of trials and treatments individuals with familial FTD would like to participate in.

## 2. Methods

135 participants in the GENFI study (34% known carriers), completed an online structured questionnaire about FTD clinical trials and research.

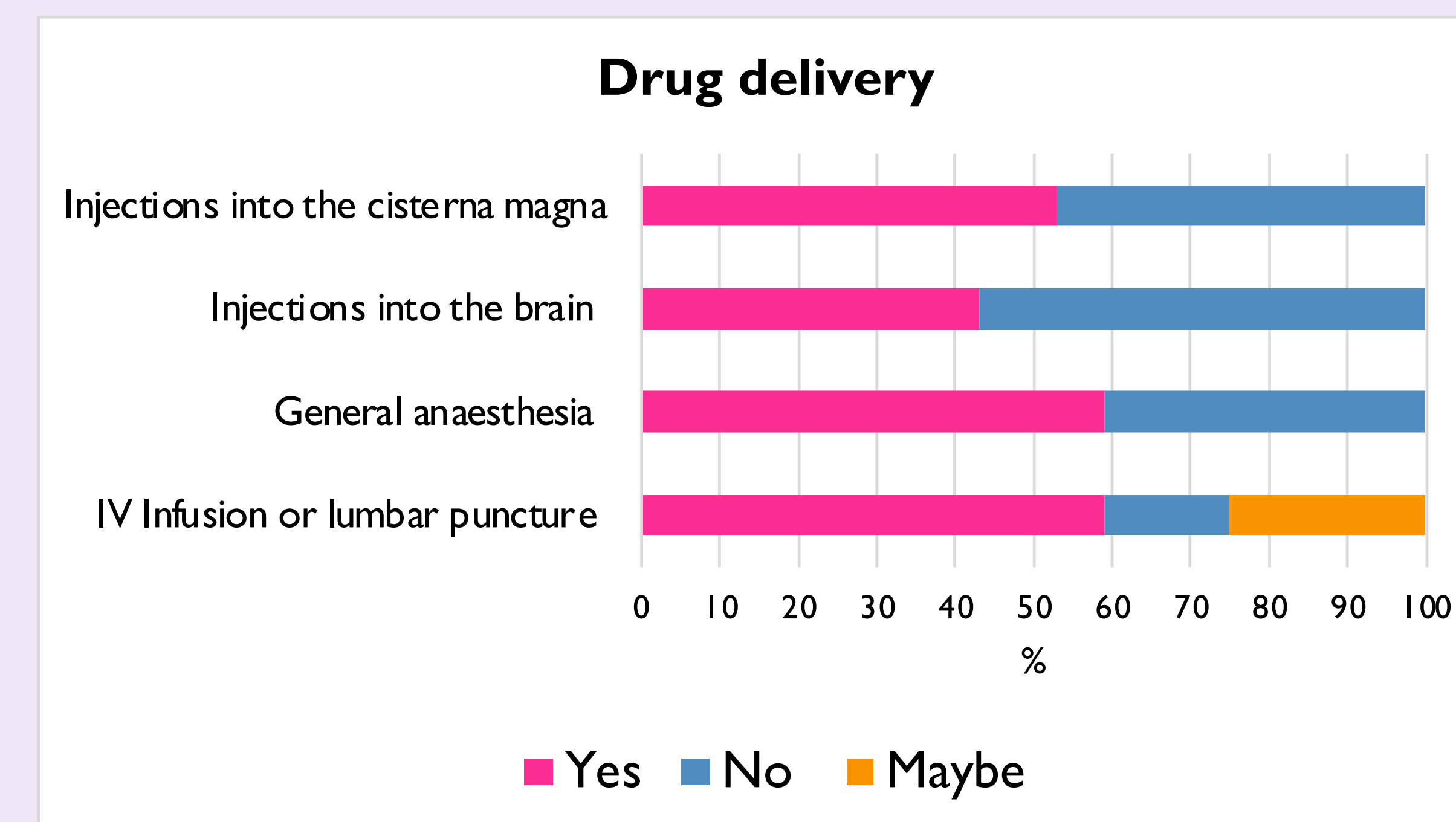
- 27 questions
- Multiple choice & free text

Topics included:



## 3. Results

Overall, individuals expressed an interest in participating in clinical trials, with 86% willing to travel to be in a trial. 50% of individuals would participate if it meant having to find out whether they were approaching symptom onset. However, 85% of people said they would be willing to find out their neurofilament light protein level.



## 4. Conclusion

Observational studies and clinical trials are designed to make a difference to people's lives, and they must be considered throughout the development of treatments and research. Future work in this area should continue to include the patient voice to ensure we continue in a direction that patients and families are happy with.