



REPRESENTATION IN CHRONIC PAIN POPULATIONS IN EXPERIMENTAL RESEARCH

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BACKGROUND

- The purpose of clinical research is to further our understanding of the etiology, maintenance, and underlying mechanisms in psychopathology and disease to be better able to prevent, diagnose, and treat such conditions.
- Research requires extensive screening of potential participants to confirm eligibility before recruitment.
- Experimental research focusing on understanding these underlying mechanisms relies on a diverse participant pool.
- For the results of experimental research to be as applicable and generalizable as possible, it is necessary to obtain representative samples from the general population.

Are there meaningful differences in who enrolls in research and who is eligible and chooses to not enroll?

METHODS

Recruitment

- We examined the differences between the youths with chronic pain who decided to enroll in a large multisite biomarker study (Enrolled group), Signature for Pain Recovery IN Teens (SPRINT) at Stanford Children's Hospital, and those who were eligible but decided not to enroll (Not Enrolled group).
- Reasons for not participating included: fear of needles and/or going in the MRI machine, the explicit wish to not enroll, not agreeing to provide consent, or no response to communications from the research team.

Participants

- Adolescents with chronic pain (age M = 15.59y, SD = 1.3y), Enrolled (n= 63) and Not Enrolled (n= 68).

Variables of Interest

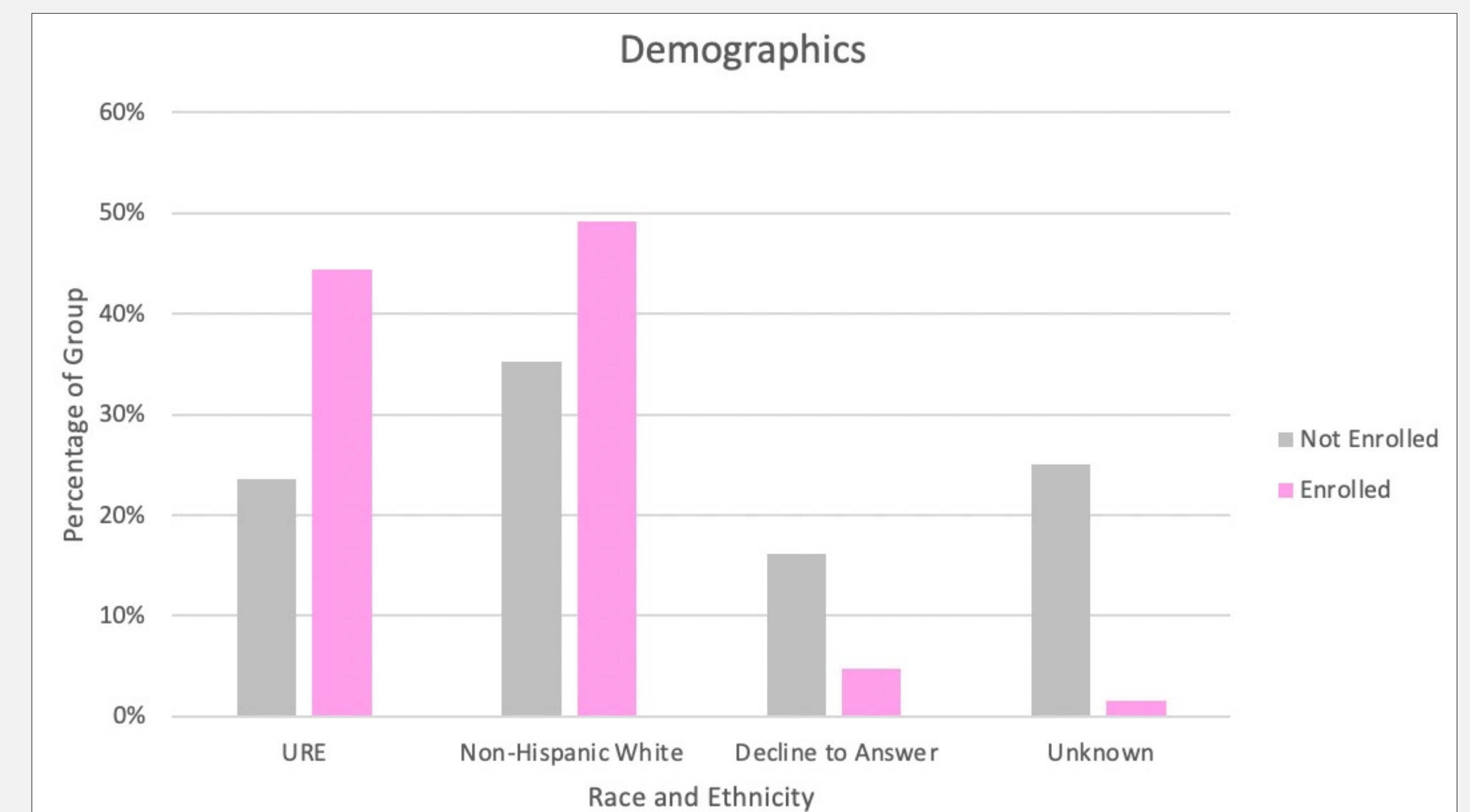
Key Demographics Pain Characteristics Mental Health

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|----------------------|------------|----------------|
| • Age | • Pain | • Depression |
| • Gender | • Mobility | • Anxiety |
| • Race and Ethnicity | • Fatigue | • Fear of Pain |

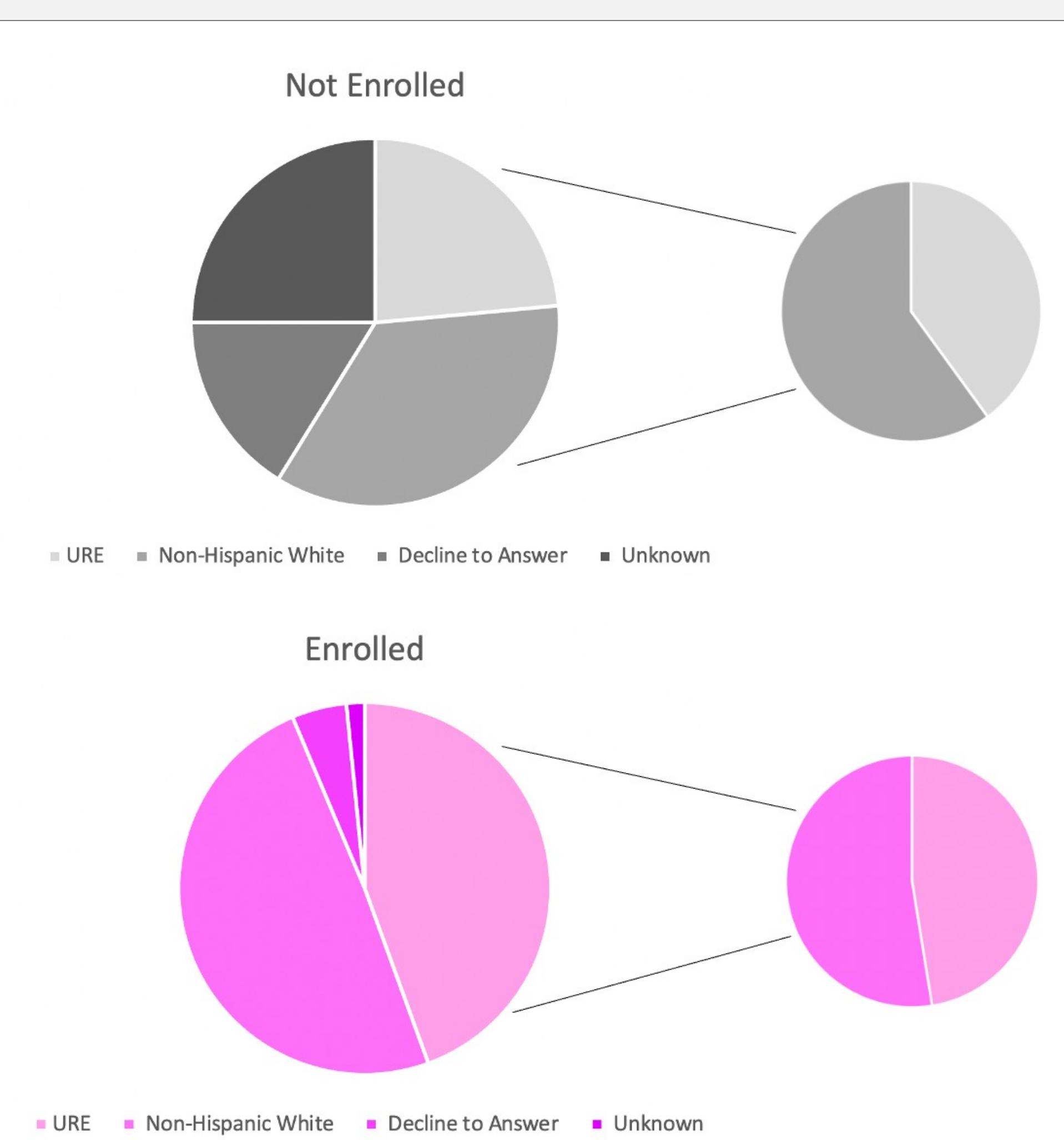
School Functioning Parent Health Family Status

- | | | |
|--------------------------|------------|-----------------------|
| • School quality of life | • Physical | • Hollingshead scores |
| | • Mental | |
| | • Pain | |

RESULTS



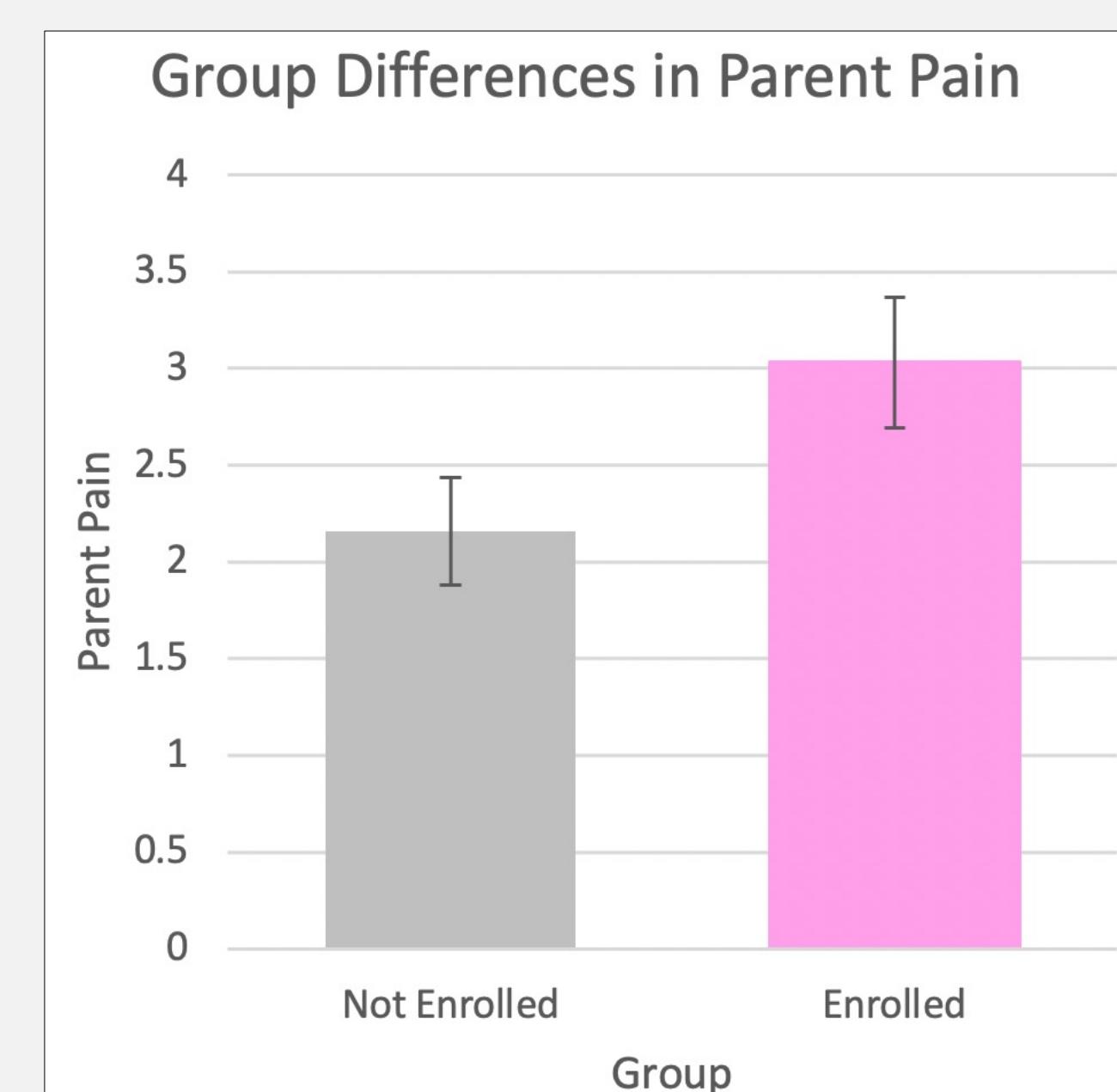
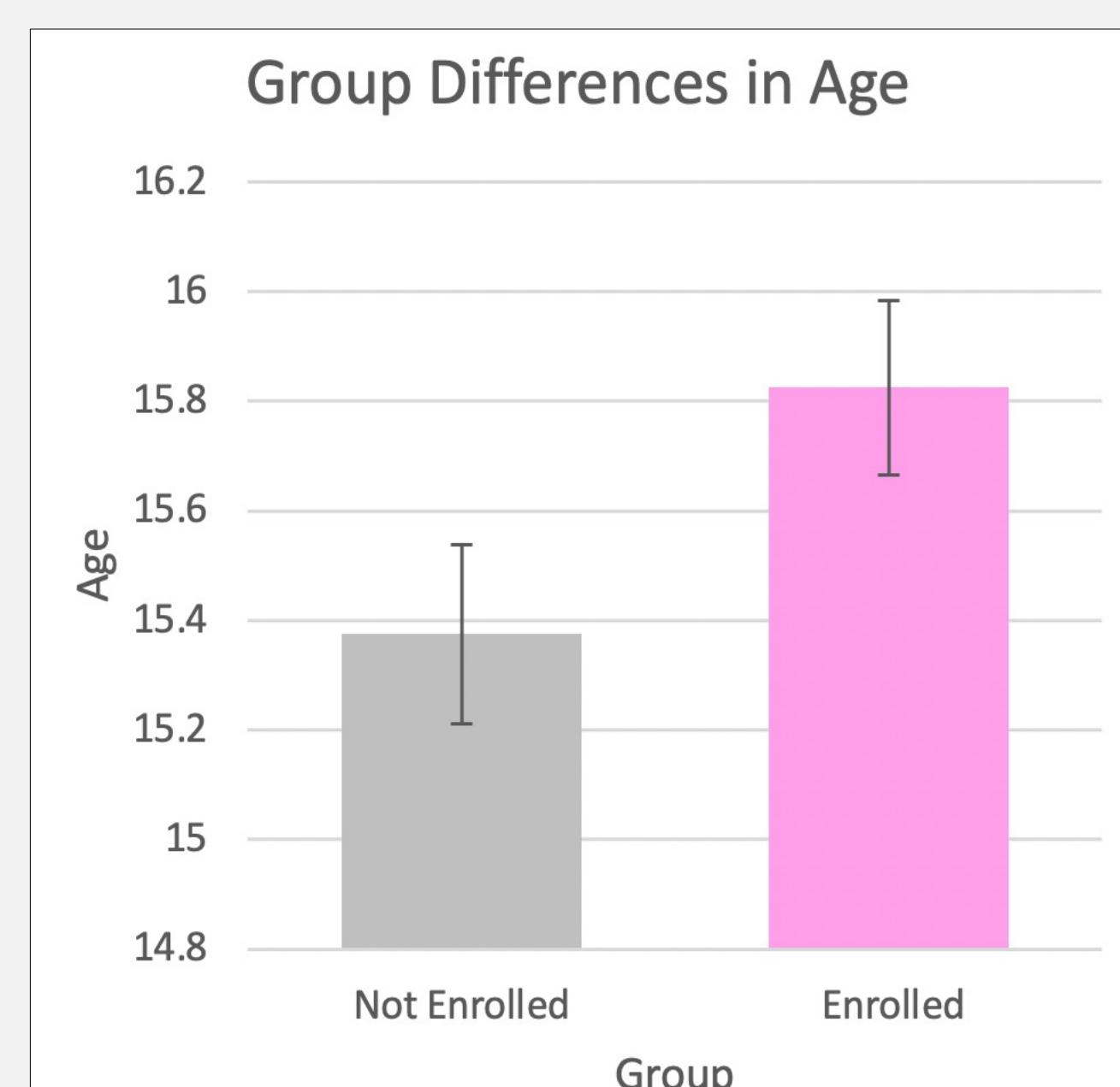
Our initial analyses revealed significant group differences when we examined race and ethnicity. Specifically, more patients who declined to answer or skipped the question decided to not participate in research, [$\chi^2(1)=22.8, p<.001$].



This difference seems to be driven by the Enrolled group being more willing to answer the race and ethnicity questions compared to the Not Enrolled group. When comparing those who answered, there was no significant differences in Underrepresented Racial and Ethnic (URE) and Non-Hispanic White patients between groups, [$\chi^2(1)=0.537, p=0.464$].

CONCLUSIONS

There were no significant differences observed in pain characteristics: average pain intensity, mobility, and fatigue. We compared patient mental health and found no significant differences in anxiety, depressive symptoms, pain catastrophizing, or child fear of pain. We examined patient functioning and found no significant difference between groups in school functioning. For parent health demographics we observed no significant difference in physical or mental health.



We did not observe any significant group differences in gender. There was a significant difference in age - those who were in the Enrolled group were significantly older than the Not Enrolled group, [$t(125)=1.977 p=0.05$, Enrolled M(\pm SD)=15.825(\pm 1.264), Not Enrolled M(\pm SD)=15.375(\pm 1.303)].

We did observe significantly higher parent pain in the Enrolled group compared to the Not Enrolled group [$t(120)=-1.997 p=0.048$, Enrolled M(\pm SD)=3.032(\pm 2.682), Not Enrolled M(\pm SD)=2.156(\pm 2.234)].

FUTURE DIRECTIONS

We propose that future research should encompass **similar assessment points throughout the recruitment and enrollment process** to examine differences between enrolled and not enrolled but eligible cohorts to ensure that there is **no systematic bias** in recruitment procedures introduced by the study team and that the population participating in all research, specifically chronic pain research, is representative and **generalizable**. This is particularly important because **equitable** and **representative** enrollment and participation in research will lead to improved patient care.

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