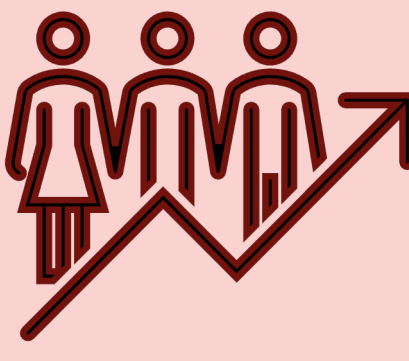


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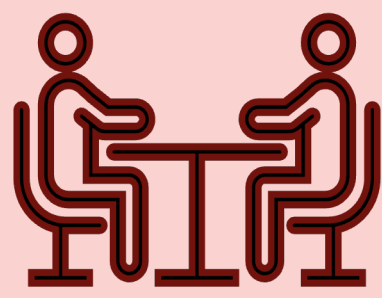
BACKGROUND



In recent years, regulatory authorities, pharmaceutical companies and other clinical trial Sponsors have shifted to a more patient-centric approach, incorporating their input into medicine development decisions [1].



There remains a significant gap in research concerning the diversity of PAs and the extent to which they can truly represent the patient populations they are meant to represent.



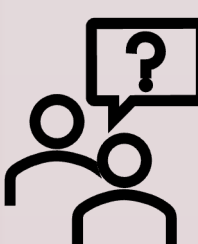
Patient Advocates (PAs) play an essential role in representing that patient voice and their wishes.



This study has examined the representativeness of self-identified PAs in medicine development against the known demographics.



To what extent do self-identified patient advocates on the professional network LinkedIn reflect the demographic and clinical characteristics of the disease populations they represent in the UK, compared to national disease demographics?



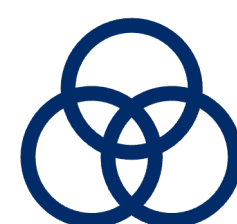
METHOD



This research employed descriptive observational methods to assess the demographic representativeness of self-identified PAs based in the UK.



Data were collected from LinkedIn profiles using specific inclusion criteria between May and August 2024.



The collected data were classified according to age, sex, ethnicity, and educational background. A comparative analysis was conducted between the demographics of PAs and the known demographics of the patient populations they represent.



The methodology relied on visual assessments of publicly available information, acknowledging limitations in data accessibility and potential observer bias, particularly in the classification of demographic characteristics.

RESULTS

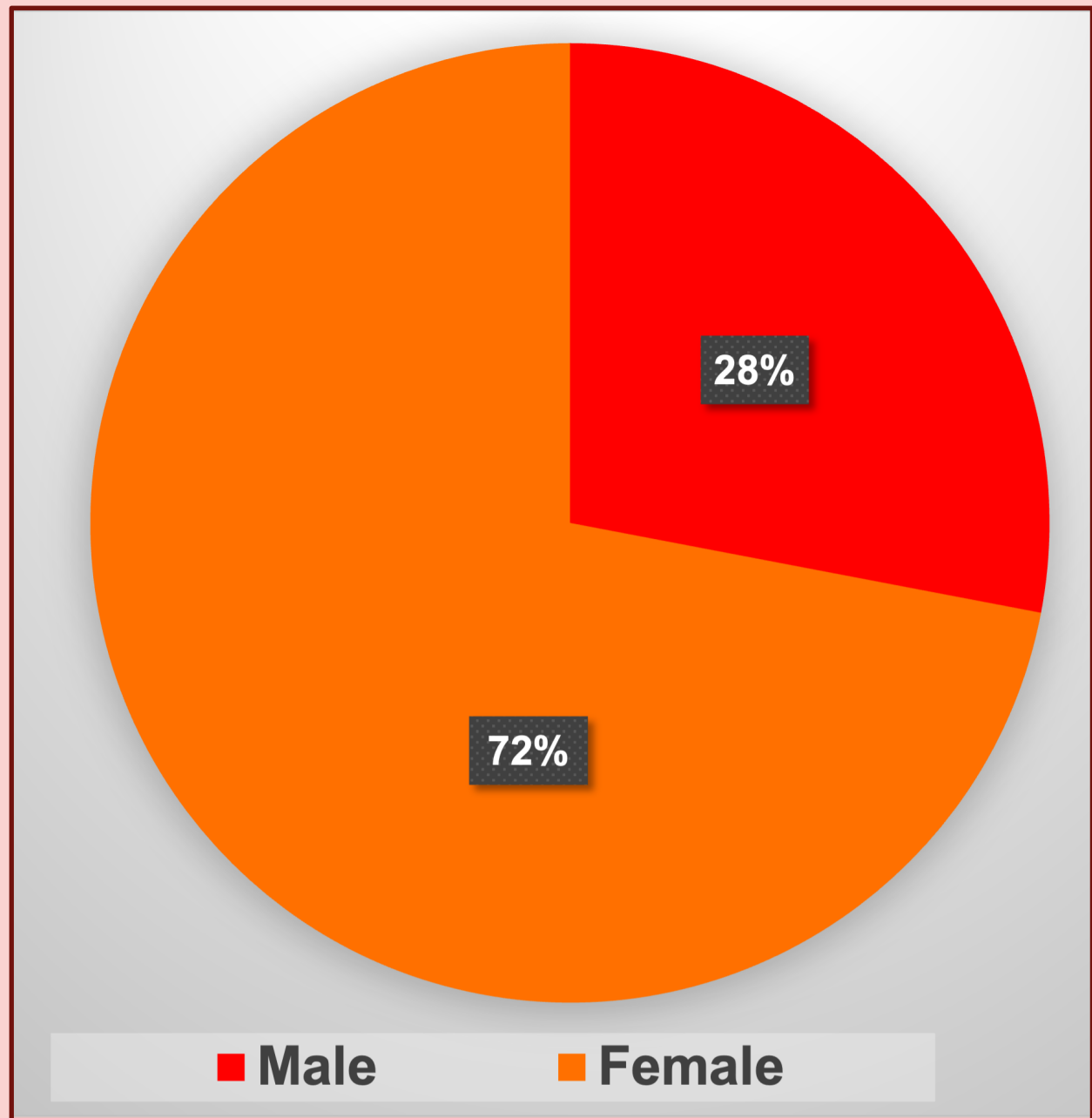


Figure 1: Distribution of Sex Demographics among PAs with (n=174, after exclusion of “unknown” profiles n=30)

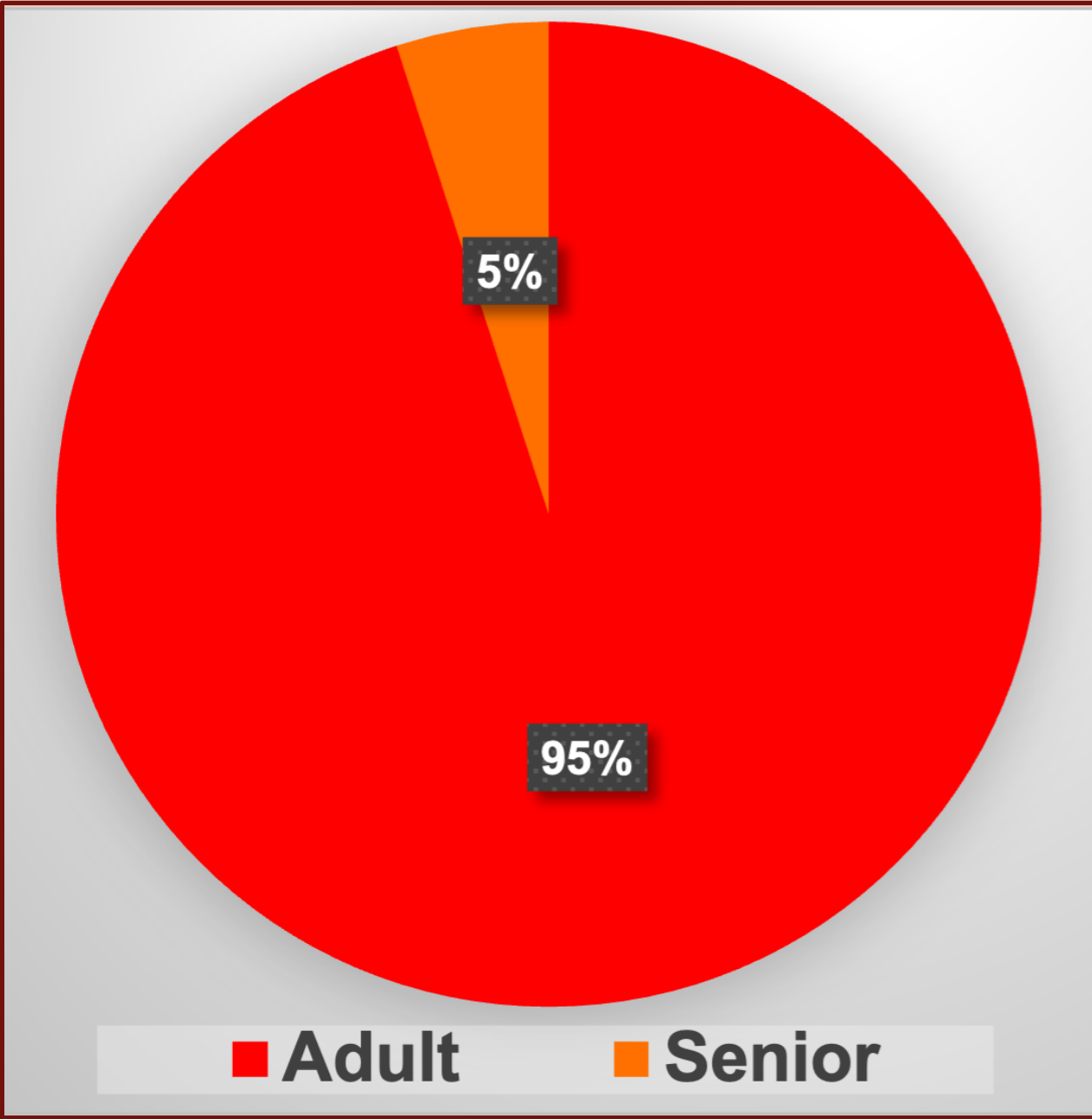


Figure 2: Distribution of Age Demographics among PAs with (n=170, after exclusion of “unknown” profiles n=34)

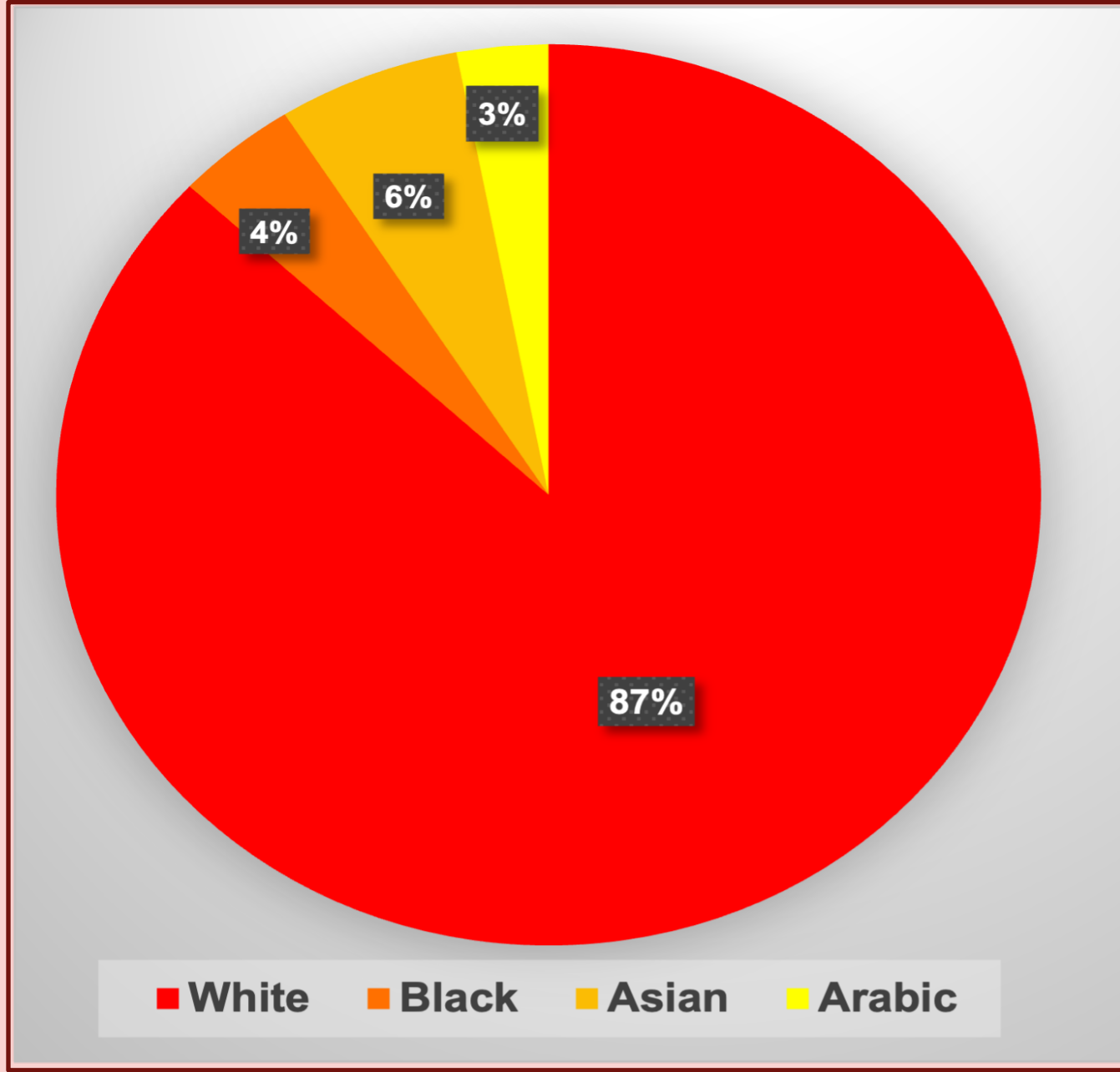


Figure 3: Distribution of Ethnicity Demographics among PAs with (n=157, after exclusion of “unknown” profiles n=47)

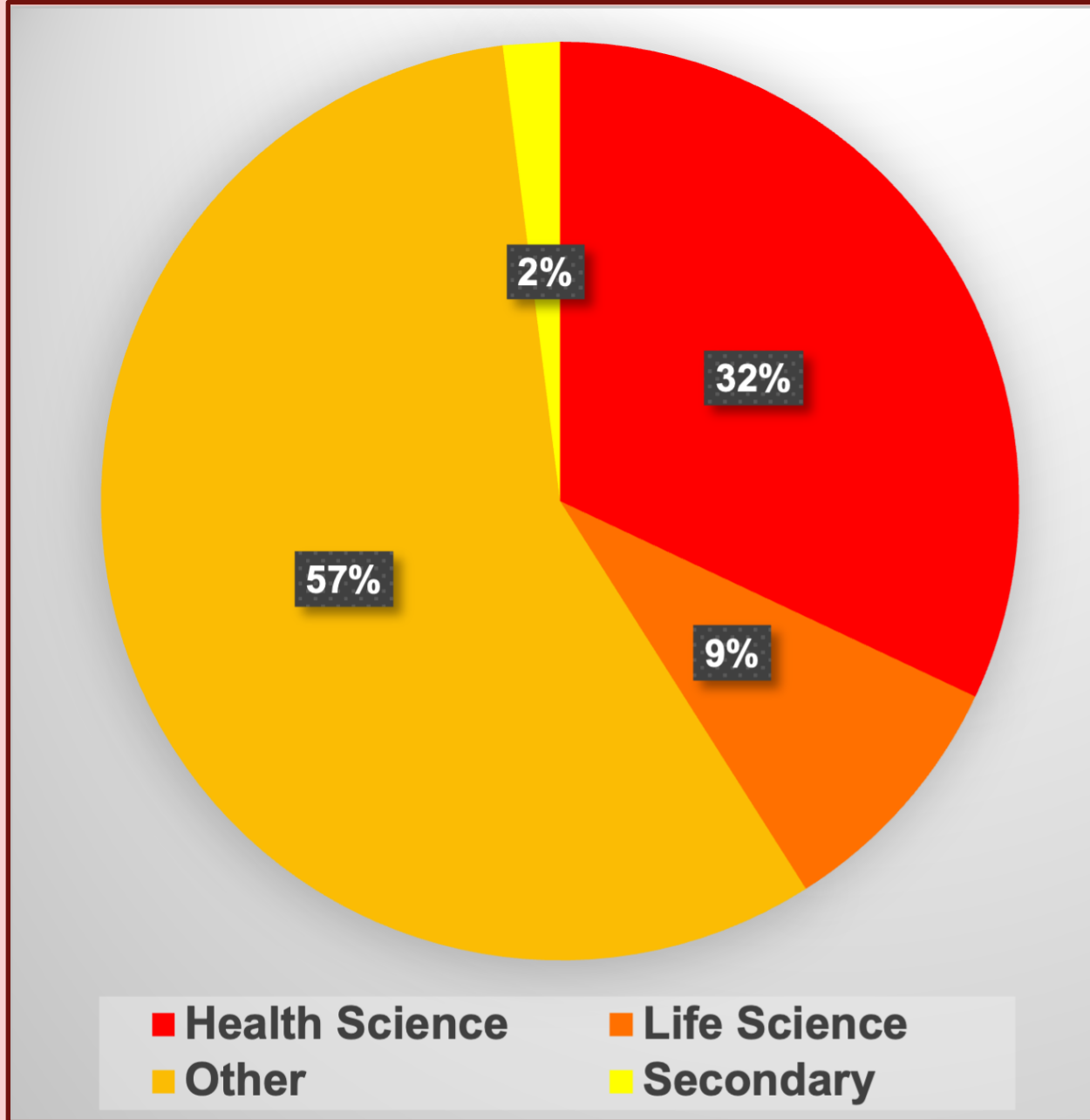
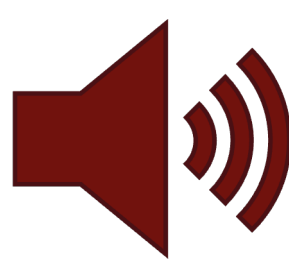


Figure 4: Distribution of Educational Background among PAs with (n=134, after exclusion of “unknown” profiles n=70)

CONCLUSION



Inequities and a lack of diversity among self-identified PAs in the UK.



Whilst this research was limited to just the LinkedIn database, the results do indicate that there needs to be actions to ensure that there is a wider patient representation in the provision of input into medicine development decision-making.

FUTURE DIRECTION

