NIHR | Moorfields Clinical Research Facility

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Moorfields Eye Hospital NHS Foundation Trust

NHS

Chrissie Adams
EDI Research Associate
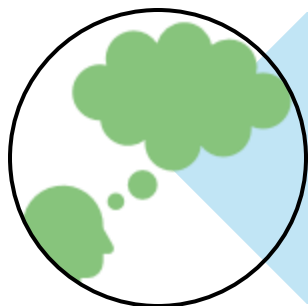
Baseline data has a bigger story: what we can learn from study and system level barriers in data collection
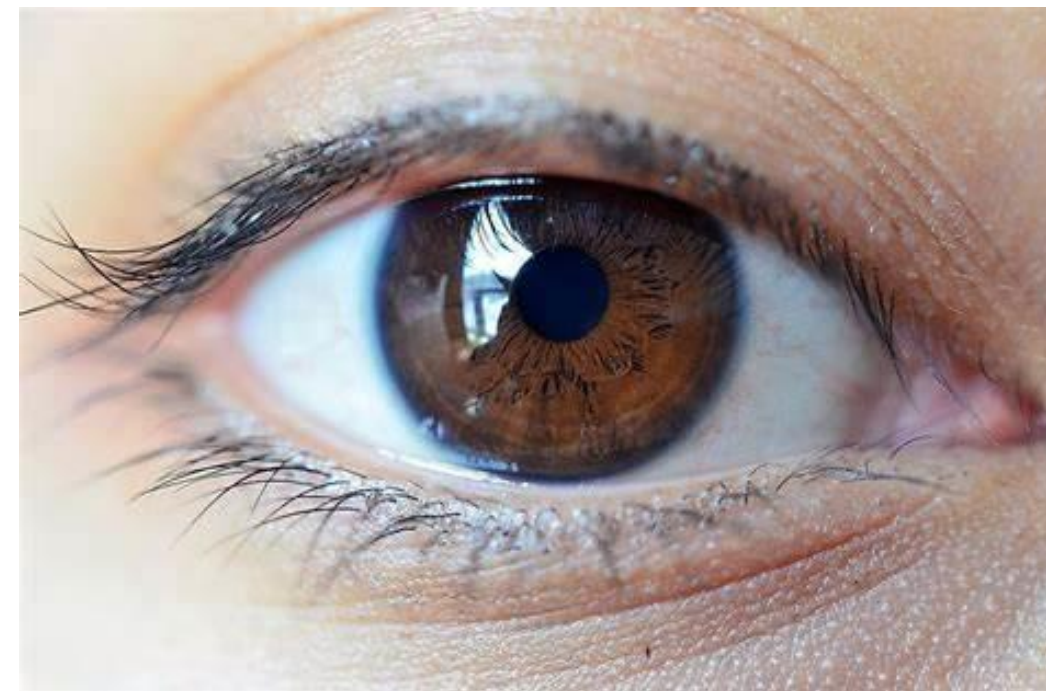
The process of establishing baseline data for our research participants – what is fact and what is fiction?

5 year review showed that we know very little about who has been in our research
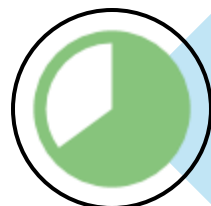
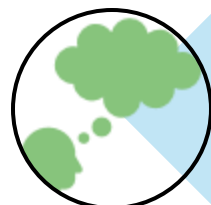Did not show us 'who' was missing- but more 'what' was missing

Chrissie Adams she/her

Equality, Diversity and Inclusion Research Associate
NIHR Moorfields BRC and CRF

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Baseline data has a bigger story: what we can learn from study and system level barriers in data collection
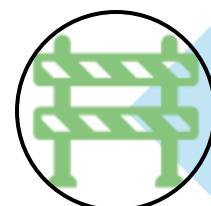
41% of our participants had a 'NOT STATED' code

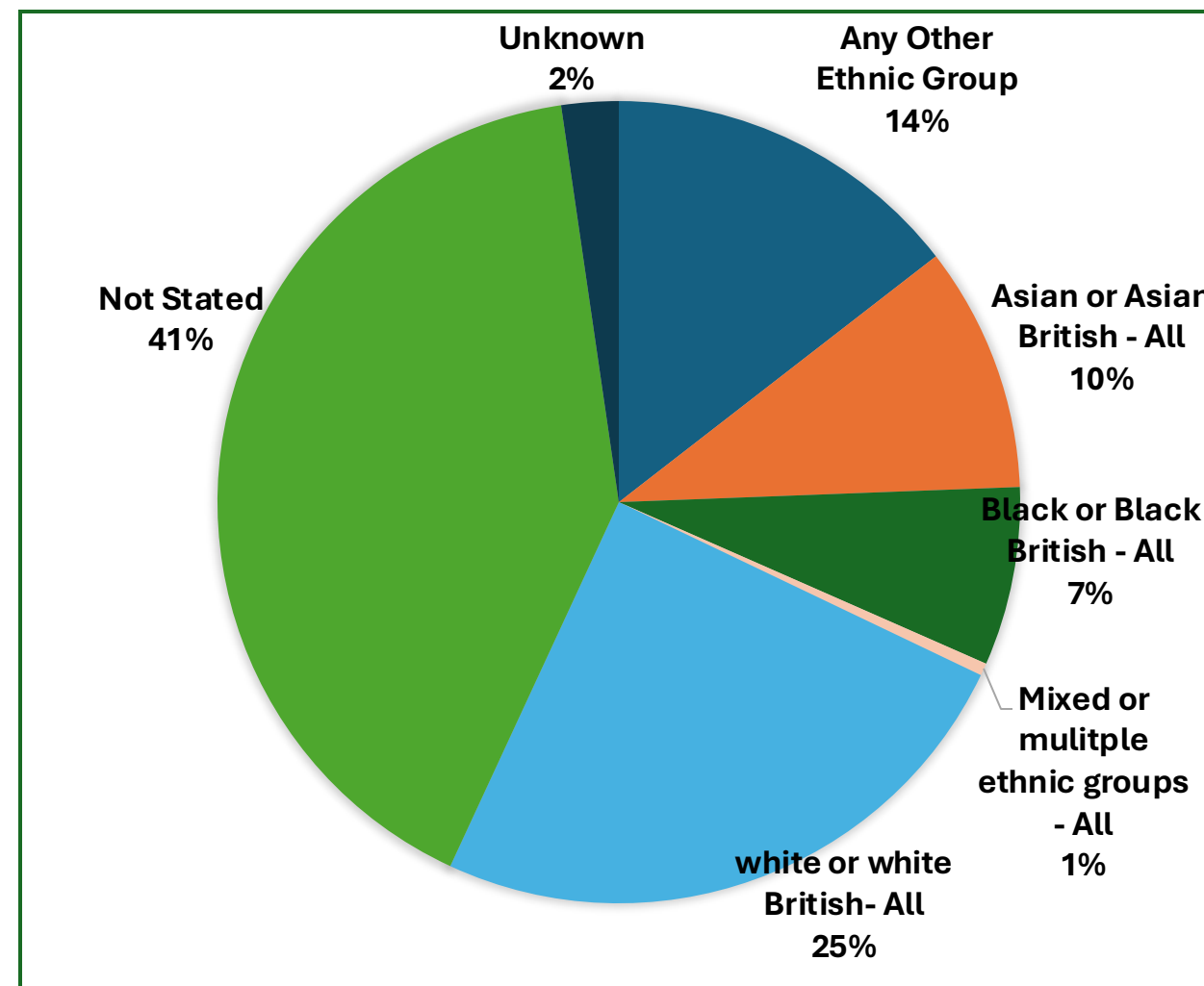57% of our research participants had an unknown ethnic background

This had increased by 14% from 2022 – with an impact post covid due to switching from calling to qualify patient details, to in-person

Baseline Data Collection = significant barriers in data collection at

System Level   **Study Level**

Patient Level

Pie chart:
- Unknown 2%
- Any Other Ethnic Group 14%
- Asian or Asian British - All 10%
- Black or Black British - All 7%
- Mixed or mulitple ethnic groups - All 1%
- white or white British- All 25%
- Not Stated 41%

Chrissie Adams
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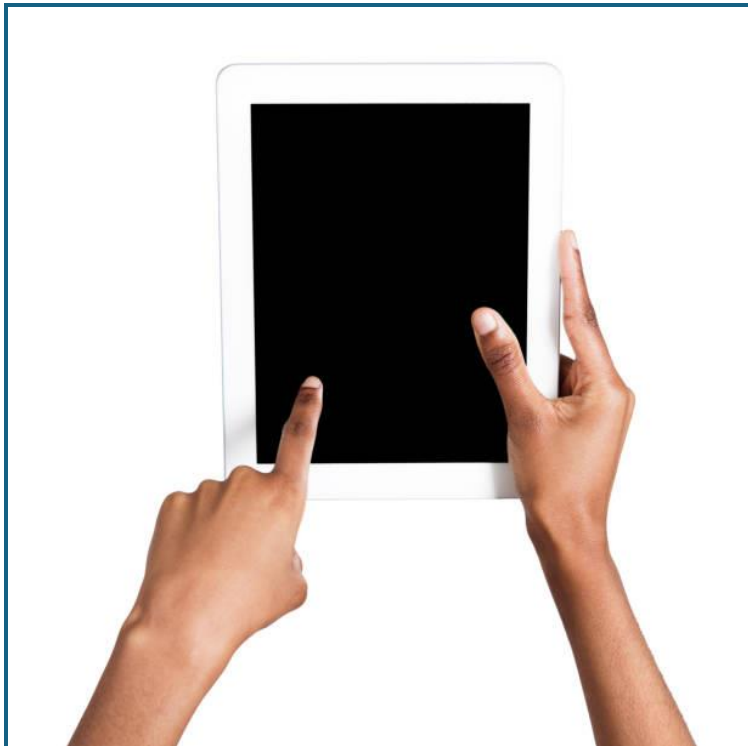| System Level Barrier	Study Level Barrier
• PAS data quality issue- Trust level • Research Level -We are not recording things centrally. • We have multiple ways of retaining ethnicity data, and multiple data bases • We have varied terms/language/forms and no centralised mandated recording	• We are not mandating that this be collected. • It is not compulsory • Commercial studies vary • We are not prioritising this • Time is not being allocated to data input post study • Time is not being allocated to reviewing PIS, CRF, Consent forms through an Inclusion Lens

Chrissie Adams
EDI Research Associate

Take back control at a local level. Inclusion work should be about creating new ways of doing things. Don't expect the existing systems to 'fit' people within them – that's not equity.

Changed EDGE profile options

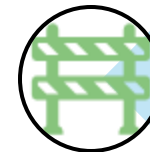Ran Education Sessions

Accountability

Equality Questionnaire for iPad

Self Service option and private space

Accessibility for sight loss

No Patient Level Barrier

(unless you want to know someone's income**)**