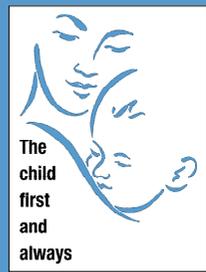


# 4694 'Silent voices' in research with visually impaired children: ethnicity and socio-economic variation in participation in studies of quality of life



Tadić V<sup>1</sup>, Hamblion EL<sup>1,2</sup>, Keeley S<sup>3</sup>, Lewando Hundt G<sup>3</sup>, Moore AT<sup>2</sup>, Rahi JS<sup>1,2</sup>

<sup>1</sup> Centre for Paediatric Epidemiology, UCL Institute of Child Health, London, United Kingdom

<sup>2</sup> Institute of Ophthalmology, UCL, London, United Kingdom

<sup>3</sup> School of Health and Social Studies, University of Warwick, Coventry, United Kingdom

Contact: v.tadic@ich.ucl.ac.uk, j.rahi@ich.ucl.ac.uk

## PURPOSE

To investigate factors influencing the level of participation of visually impaired (VI) children and their families in health services research.

Engaging health service users in research is an important aspect of service planning and provision. However, achieving high levels of participation is an ongoing challenge and the participant's socio-cultural and socio-economic circumstances remain important barriers (Rahi et al., 2003).

## METHODS

We examined the levels of participation overall and by clinical and socio-demographic characteristics of patients who participated and those who did not in two distinct studies of **quality of life (QoL)** in VI children and young people.

### Study 1

**AIM:** To develop a **novel vision-related (VR) QoL instrument** for self reporting in VI children and young people. **METHOD:** Individual **interviews** with VI children and young people about their VR QoL. **ELIGIBILITY CRITERIA:** All children and young people, age 10-15 with VI (visual acuity in the better eye < 6/18, LogMar ≥ .51) due to any disorder, but in absence of other significant impairments. **RECRUITMENT:** By single mailing, followed up by a phone call 2 weeks later.

### Study 2

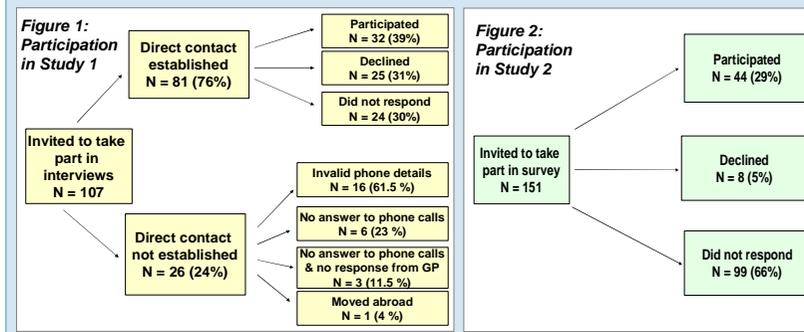
**AIM:** To measure the **health-related (HR) QoL** of children and young people with hereditary retinal disorders. **METHOD:** A cross-sectional **postal survey** of HR QoL of children and young people with hereditary retinal disorders using a generic QoL instrument PedsQL (self-completed, with an exception of 2-4 year old children). **ELIGIBILITY CRITERIA:** All children and young people, age 2-16 years, who are enlisted on the existing cohort of patients with hereditary retinal disorders at Moorfields Eye Hospital, London, UK. **RECRUITMENT:** Invitation letter, followed up by 2<sup>nd</sup> mailing 2-4 weeks later, but no phone contact.

## STATISTICAL ANALYSES

In each study separately, the proportions of **Participants** and **Non-participants** were compared in terms of their age, gender, severity of vision loss, the time of VI onset, ethnicity (using the UK Office for National Statistics classification) and socio-economic background (using the Index of Multiple Deprivation, based on the English postal code).

## RESULTS - Level of participation

In both studies, overall participation was less than 50% and appears to be broadly consistent with the literature in which levels of participation are generally not reported. Identification of a large proportion of participants with whom direct contact cannot be established using the contact details held as 'current' within the health care system (Study 1) highlights an important barrier to engaging users in health services research.



## ETHNICITY

Figure 5: Ethnic variation in Study 1

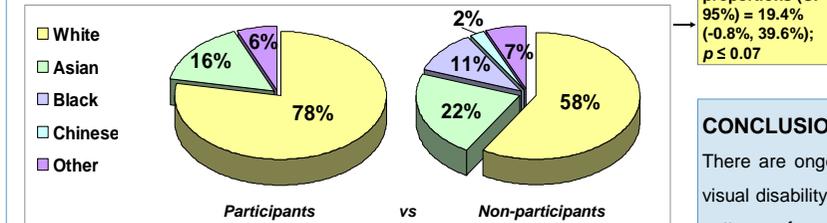
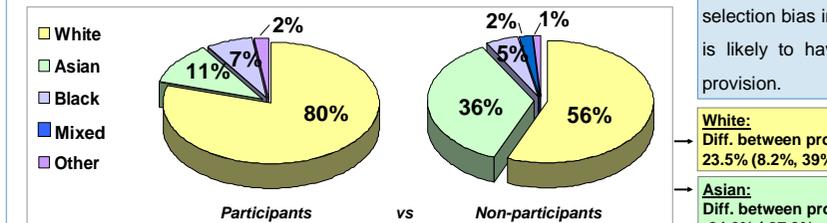


Figure 6: Ethnic variation in Study 2



## RESULTS - Participation barriers

The participants from ethnic majority (white) backgrounds and from more affluent socio-economic backgrounds were significantly over-represented. The level of participation did not vary by 'clinical' characteristics - age, gender, visual acuity and the time of VI onset in either study ( $p$  values > .05).

## SOCIO-ECONOMIC BACKGROUND

Figure 3: Socio-economic variation in Study 1

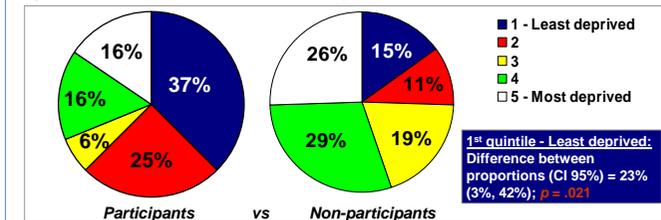
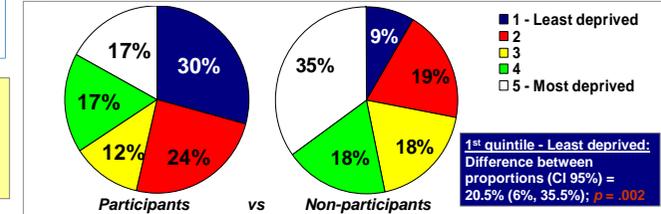


Figure 4: Socio-economic variation in Study 2



## CONCLUSIONS

There are ongoing barriers to participation in child and family centred research on childhood visual disability for individuals from socio-economically deprived or ethnic minority groups. Such patterns of participation seem to be consistent across studies that differ in design, recruitment procedure and demands placed upon participants. We urge assessment and reporting of selection bias in health services research on childhood disability, as failure to elicit 'silent voices' is likely to have important implications for equitable and appropriate service planning and provision.

**White:** Diff. between proportions (CI 95%) = 23.5% (8.2%, 39%);  $p = 0.007$

**Asian:** Diff. between proportions (CI 95%) = -24.6% (-37.9%, -11.4%);  $p = 0.003$

### Acknowledgements:

This research was supported by the Guide Dogs Association for the Blind. The Centre for Paediatric Epidemiology and Biostatistics at ICH also benefits from funding support from the Medical Research Council in its capacity as the MRC Centre of Epidemiology for Child Health. This work was undertaken at UCL Institute of Child Health / Great Ormond Street Hospital and Moorfields Eye Hospital / UCL Institute of Ophthalmology, both of which receive a proportion of funding from the Department of Health's NIHR Biomedical Research Centres funding scheme.