

Privacy Information for all study participants

What shapes quality of life of visually impaired children and young people

IRAS ID: 255525

University College London Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor and data controller for this research study, so is responsible for looking after your information and using it properly.

To identify eligible study participants, researchers collect information like your child's name, vision diagnosis, date of birth, sex and ethnicity from NHS Trust patient record systems. We will use the smallest amount of personally identifiable information.

If you withdraw from the study, we cannot remove personal information we have already collected as this would make the research invalid.

When the study finishes, we will delete or de-identify personal information. We will keep information about you and/or your child securely for 15 years after the study has finished.

Under the General Data Protection Regulation (GDPR), the legal basis for processing your information is for the performance of a task carried out in the public interest.

If you have any questions about how your personal information is used, or wish to exercise any of your rights, please consult the University's data protection webpage <https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>.

If you need further assistance please contact the university's Data Protection Officer data-protection@ucl.ac.uk. You can contact UCL by telephoning +44 (0)20 7679 2000 or by writing to University College London, Gower Street, London WC1E 6BT.

If you wish to complain about the use of your personal data, you can contact the university's Data Protection Officer who will investigate the matter.

If you are not satisfied with the Data Protection Officer's response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (<http://www.ico.org.uk>).