

BRITISH PAEDIATRIC SURVEILLANCE UNIT

Royal College of Paediatrics and Child Health
5-11 Theobalds Road, London WC1X 8SH

Tel: 020 7092 6173 Email: bpsu@rcpch.ac.uk Web: www.rcpch.ac.uk/bpsu/BCVIS2

BRITISH CHILDHOOD VISUAL IMPAIRMENT AND BLINDNESS STUDY 2 (BCVIS2)

(Short Study Name: Visual Impairment and Blindness in UK children)

Abstract

This study will determine the incidence, causes, mode/context of detection, associated factors, management and short term health and social outcomes of all-cause childhood visual disability. All children aged ≤ 18 years diagnosed during a 1 year period as being severely visually impaired or blind will be identified through their clinicians using national active surveillance independently but simultaneously through the British Paediatric Surveillance Unit (BPSU) and the British Ophthalmological Surveillance Unit (BOSU).

Simultaneously, those children diagnosed with visual impairment (i.e. less severe impairment and thus less likely to present to a paediatrician) will be identified through the BOSU. The merged dataset will then encompass the full spectrum of visual disability.

Expected outcomes include: findings about frequency and current/ emerging determinants to inform prevention and treatment and targeting of screening, a 'map' of clinical and public health services involved in detection and management to inform commissioning and delivery of NHS services, and the compilation of an evidence base about the sociodemographic variations in childhood visual disability to inform national policies.

Principal Investigator

Professor Jugnoo Rahi, Professor of Ophthalmic Epidemiology
UCL Institute of Child Health, 30 Guildford Street, London WC1N 1EH.
Tel: 0207 905 2250 Email: j.rahi@ucl.ac.uk

Co-investigators

Dr Jenefer Sargent, Consultant Paediatrician in Neurodisability, Great Ormond Street Hospital, Great Ormond Street, London WC1N 3JH
Philippa Cumberland, Senior Research Associate; Ameenat Lola Solebo, NIHR Academic Clinical Lecturer; Lucinda Teoh, Research Associate, UCL Institute of Child Health, 30 Guildford Street, London WC1N 1EH
and the British Childhood Visual Impairment Study Group (BCVISG)

Website

www.rcpch.ac.uk/bpsu/BCVIS2

Background

Most children living in the UK with visual impairment or blindness are likely to be affected from birth or infancy and will experience a significant lifelong impact on their development, education, social and emotional wellbeing. Clinical services and public health programmes and policies addressing childhood visual disability require a robust up to date evidence base.

In the UK, this information is unavailable from either previous studies or existing 'routine' data sources. We propose to provide this evidence by conducting a comprehensive epidemiological study of childhood visual impairment and blindness.

Coverage

United Kingdom **excluding the Republic of Ireland**

Duration

October 2015 to October 2016 (13 months of surveillance) with a 12 month follow-up.
Our inter-related questions for the study through BPSU are:

Research Questions	<ul style="list-style-type: none"> ▪ What is the incidence of all-cause severe visual impairment (SVI) and blindness (BL) in children the UK? ▪ How does incidence vary by socio-demographic factors? ▪ What are the disorders causing SVI/BL in children in the UK today? ▪ How are affected children diagnosed/detected and managed and are there variations by socio-demographic factors? ▪ What are the broader short term developmental and health outcomes and are these related to severity of sight impairment and socio-demographic factors?
Case definition	<p>Any child or young person (aged ≤ 18 years) newly diagnosed as being severely visually impaired or blind (SVI/BL) due to any disorder in the UK</p> <p>This includes any child / young person:</p> <ul style="list-style-type: none"> ▪ with corrected distance acuity worse than 6/60 Snellen or LogMAR 1.0 in the better eye OR ▪ is eligible for certification to the national registers of sight impairment OR ▪ with clinical features consistent with SVI/BL OR ▪ assessed as having special educational needs due to SVI/BL.
Reporting instructions	To report any child under the age of 18 seen within the last month who meets the case definition in the UK (excluding Republic of Ireland)
Methods	<p>Active surveillance through BPSU for thirteen months with a one year follow-up.</p> <p>Data will be collected at initial notification and 12 months later using standardised data collection instruments. Forms with postage-paid reply envelopes and covering letters will be posted to reporting clinicians.</p> <p>Non-responders will be contacted by telephone and 1 postal reminder, as required. Information will be collected about socio-demographic variables, general clinical factors and ophthalmic data.</p> <p>The follow up questionnaire will elicit confirmation of visual status and underlying diagnoses as well as key early health and social outcomes.</p>
Funding	Fight for Sight, 9-13 Fenchurch Buildings, Fenchurch Street, London EC3M 5HR
Ethics approval	This study has been approved by NRES Committee – London – Bloomsbury (REC reference: 14/LO/1809; IRAS project ID: 161997) and has been granted Section 251 HRA-CAG permission (CAG Reference: 14/CAG/1028).
Support group	Royal National Institute of Blind People
References	<p>Rahi JS, Cable N; British Childhood Visual Impairment Study Group. Severe visual impairment and blindness in children in the UK. The Lancet. 2003 Oct 25;362(9393):1359-65.</p> <p>Rahi JS, Cumberland PM, Peckham CS; British Childhood Visual Impairment Interest Group. Improving detection of blindness in childhood: the British Childhood Vision Impairment study. Pediatrics. 2010 Oct;126(4):e895-903.</p>

For further information about the study, please contact:

Professor Jugnoo Rahi, UCL Institute of Child Health, 30 Guildford Street, London WC1N 1EH
Email: j.rahi@ucl.ac.uk. **Tel:** 0207 905 2250