

Title:

Methods of ascertainment of children and young people living with diabetes mellitus: a mapping exercise of the NHS diabetic eye screening programmes.

Authors:

Maria Carolina Ibanez-Bruron MD, Ameenat Lola Solebo FRCOphth, Phillippa M Cumberland MSc, Jugnoo Sangeeta Rahi FRCOphth, on behalf of the Diabetic Eye Disease in Childhood Study (DECS) group.

Affiliations of authors:

Institute of Child Health, University College London, London, UK (MC Ibanez-Bruron MD, AL Solebo FRCOphth, PM Cumberland MSc, Prof JS Rahi FRCOphth); Ulverscroft Vision Research Group, London, UK (MCI-B, ALS, PMC, JSR); Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK (ALS, JSR); Moorfields Eye Hospital NHS Foundation Trust, London, UK (ALS, JSR); Institute of Ophthalmology, University College London, London, UK (ALS, JSR).

Corresponding author:

Professor Jugnoo Sangeeta Rahi FRCOphth.
Institute of Child Health UCL, 30 Guildford Street, London, WC1N 1EH.
j.rahi@ucl.ac.uk

Abstract:**Background:**

The aim of diabetic eye screening is to reduce preventable visual loss by identifying and treating of sight-threatening diabetic retinopathy. NICE recommends that annual screening for diabetic retinopathy should start at 12 years of age. However, the National Paediatric Diabetes Audit reported that in 2013/2014 only 52% of eligible children and young people (CYP) underwent screening in England. Complete ascertainment of CYP living with diabetes is essential for effective screening. This study aimed to investigate how eligible CYP are identified in the 70 English diabetic eye screening programmes.

Methods:

In the absence of a centralized/comprehensive list, the contact details of clinical leads or programme managers were manually identified through multiple sources including NHS Trust websites. A postal and electronic survey of the 70 English diabetic eye screening programmes was conducted between October 2015 and February 2016.

Findings:

Of the 42 replying programmes (response rate 60%, 42/70), 43% ($n=18$) use both hospital diabetes clinics and GP registration systems to compile screening lists. In 19% ($n=8$) of programmes, the lists are generated entirely manually e.g. using referral letters from GPs. Frequency of list update is variable ranging from daily to 6 monthly. 31% ($n=13$) actively search for diabetic patients not registered with a GP, and 52% ($n=22$) include patients with diabetes other than type 1 or 2 diabetes mellitus. Information about attendance at hospital eye services following referral is available to 93% ($n=39$) of units. All screening programmes use data management software.

Interpretation:

Current methods of identification of CYP eligible for diabetic eye screening are highly heterogeneous across England. This risks incomplete ascertainment of this population.

In the context of the ongoing Diabetic Eye disease in Childhood Study (DECS), we are doing further work to assess the level of ascertainment of CYP, and to better understand the natural history of diabetic retinopathy in this population, including the incidence of sight-threatening diabetic retinopathy across the English diabetic eye screening programmes. This currently unavailable information is needed to inform ophthalmic services and screening strategies.

Funding:

This work was funded by the Ulverscroft Foundation, the National Institute for Health Research (NIHR) Biomedical Research Centre at University College London Institute of Child Health / Great Ormond Street Hospital NHS Foundation Trust and Diabetes Research & Wellness Foundation.

The funding organisations had no role in the design or conduct of this research.

Contributions:

MCI-B, ALS and JSR contributed to the study design, and data interpretation. MCI-B coordinated the study, analysed the data, and wrote the initial draft of the abstract. All authors made comments on the draft and have approved the final version of the abstract for publication.

Declaration of interests: We declare no competing interests.

Word count: 331

Early career researcher: The first author of the manuscript is a PhD candidate at UCL, Institute of Child Health.