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Screening for diabetic retinopathy in children and young people in the UK: potential gaps in ascertainment of those at risk.

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Short running title: Improving screening for diabetic retinopathy in childhood.

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Guidelines in the UK recommend that children and young people living with Type 1 DM and Type 2 DM undergo annual screening for diabetic retinopathy from the age of 12 years.[1] This is currently delivered though a large number of regional diabetic eye screening programmes (DESPs) which are responsible for identifying eligible children and young people and inviting them to a screening appointment (Fig. 1). In 2014/2015 the National Paediatric Diabetes Audit, based on secondary (hospital-based) care data for over 27,600 children, revealed that only 64% of eligible English children and young people had been recorded as having undergone diabetic retinopathy screening during the last audit year, of whom, 13% were reported to have at least background diabetic retinopathy.[2] One potential cause of low screening coverage is incomplete ascertainment of the eligible population. There has been no systematic investigation of how this population is identified in the English DESPs.

Through multi-disciplinary collaborative clinical research network—the Diabetic Eye disease in Childhood Study (DECS) group – we are undertaking a multi-faceted research programme to address the current paucity of information about the frequency and natural history of childhood diabetic eye disease, in order to inform service planning including diabetic eye screening. From this programme we report here a survey (both postal and electronic approaches) of the 70 English DESPs which was conducted between October 2015 and February 2016. In the absence of a centralised register, contact details of programme leads were manually identified through multiple sources, and at least two reminders were sent to non-responding DESPs.

Questionnaires were received from 42 programmes (response rate = 60%). All programmes used primary care (family practitioner) registration systems to compile their screening lists. Eighteen (43%) also drew on information from hospital diabetes clinics (secondary care) as a complementary source. Less than a third of programmes (*n*=13) actively searched for eligible patients not registered with a family practitioner, group classified as hard to reach by the DESPs. 52% (*n*=22) included patients with "syndromatic"/secondary diabetes such as Wolfram Syndrome. In 19% (*n*=8) of programmes, screening lists were generated entirely manually e.g. using referral letters from family practitioners, and in 24% (*n*=10) combined manual and electronic methods were used. Frequency of list update varied, from daily to 6 monthly. Information about attendance at Hospital Eye Services following referral for an abnormal screening result was routinely fedback to 93% (*n*=39) of DESPs.

We report significant heterogeneity and some potential vulnerabilities in the means by which children and young people eligible for diabetic retinopathy screening are identified by DESPs. This may be a risk

to complete screening coverage in this population. Differences in methods of ascertainment of children and young people living with diabetes might explain in part the high regional heterogeneity in diabetic retinopathy screening coverage reported by the National Paediatric Diabetes Audit 2014/2015, which ranges from 0% to 100% (median: 77%; interquartile range: 58-91%).[2] Since children and young people living with diabetes are largely diagnosed and managed in secondary care, we suggest it is crucial that both secondary and primary care patient information/registration systems are used to identify this population.

Whilst treatment-requiring paediatric diabetic retinopathy is thought to be uncommon,[3] abnormal retinal vascular findings are present in 6% and 24% of 12 and 18 year olds respectively,[2] and may be the first indicator of microvascular disease.[4] Although there is limited understanding of the natural history of diabetic retinopathy in children and young people, in particular the outcome of the abnormal retinal findings, it is well-recognised that vasculopathy is the main cause of the increased mortality seen in individuals diagnosed with T1 DM in childhood.[5] This, along with the projected doubling European incidence of Type 1 DM between 2005-2020,[6] and the rising incidence of paediatric Type 2 DM,[7] calls for collaborative efforts to increase the diabetic retinopathy screening uptake, ensure integrated paediatric diabetes care, and increase our understanding of paediatric diabetic retinopathy. Other aspects of DECS should provide evidence to support these developments so as to reduce the risk of preventable visual loss and vascular complications in early adulthood.

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Figure 1. Points of care of children and young people living with diabetes.

Family Practitioners

(Primary care)

Referral of CYP the DESPs at 12 years old.

Paediatric Diabetes Units

(Secondary hospital care)

DM diagnosis confirmation, registration, monitoring complications, and providing data for the national audit.

Diabetic Eye Screening programmes (DESPs, n=70)

Identification eligible population and invitation to diabetic eye screening. Referral cases of sight-threatening retinopathy to HES.

Hospital Eye Services (HES)

(Tertiary care)

Conducting diabetic eye screening in selected cases, diagnosis confirmation and treatment of referred cases from DESPs.

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