

Title page

Title: Vulnerabilities in diabetic eye screening for children and young people in England.

Short running: Vulnerabilities in diabetic eye screening

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Authors contributions:

Ms Ibanez-Bruron and Ms Solebo conceptualized and designed the study, designed the data collection instruments, collected data, carried out the initial analyses, drafted the initial manuscript, and revised the manuscript. Ms Cumberland critically reviewed and provided feedback on the manuscript. Professor Rahi conceptualized and designed the study, supervised data collection, and critically reviewed the manuscript. Professor Rahi is the guarantor. All authors approved the final manuscript as submitted.

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The authors have no conflict of interest to declare

Abstract

Background: Children and young people (CYP) living with diabetes require integrated child-centered care. We hypothesized that suboptimal uptake to diabetic retinopathy screening in CYP may be partly related to the degree of services integration. We investigated the structure of the current pediatric diabetic eye care pathway and associations between service-level characteristics and screening uptake.

Methods: A quality improvement project between January and May 2017 comprising a survey of practice of all 158 pediatric diabetes services (Pediatric Diabetes Units, PDUs) across England and secondary data analysis of routinely collected service data. Generalized linear models for proportional responses were fitted to investigate associations between reported PDU characteristics and screening uptake.

Results: 124 PDUs (78%) responded. In 67% (n=83), patients could be referred directly to screening programs; the remainder relied on primary care for onward referral. 97% (n=120) considered eye screening results useful for counselling patients but only 65% (n=81) reported it was 'easy' to obtain them. Factors independently associated with higher screening uptake were a higher proportion of patients referred from primary care (OR=1.005; 95%CI=1.004-1.007 per 1% of increase), absence of 'out-of-catchment area' patients (OR=1.13; 95%CI=1.04-1.22), and easy access to eye screening results (OR=1.45; 95%CI=1.34-1.56).

Conclusions: There is limited direct communication between the services involved in diabetic eye care for CYP in England. This risks reducing the effectiveness of diabetic retinopathy screening. Similar vulnerabilities are likely to exist in other countries where retinopathy screening for CYP has been 'bolted on' to provision for adults.

Keywords: Ophthalmology, Diabetic Retinopathy, Screening Programs, Child Care, Integrated Health Care Systems

Main text

Introduction

The number of children living with diabetes is increasing worldwide, which puts more people at risk of developing diabetic retinopathy (DR) and permanent visual loss during adulthood.¹ It is currently estimated that over 190,000 Americans aged under 20 years are living with type 1 diabetes, equivalent to a prevalence of 1.92 per 1000.² This disease burden is comparable to other settings such as the UK or Canada, with prevalence estimates of 1.93 and 2.3 per 1000 children respectively.^{3,4} Prevalence of type 2 diabetes in children is also increasing, for example in the US, it was recently reported that more than 2 per 1000 children <18 years are living with type 2 diabetes.⁵ In the UK, the incidence of Type 2 diabetes in children aged <17 years was estimated to be 0.72/100 000 (95% CI 0.58–0.88) in 2015/2016.⁶

Screening programs aimed at detecting and enabling treatment of sight-threatening DR have been successful in reducing visual impairment in adults living with diabetes.⁷ The UK Department of Health recommends that screening for DR should be undertaken in England from the age of 12 years, regardless of disease duration.^{8,9} Similarly, the International Society of Pediatric and Adolescent Diabetes (ISPAD) has recommended DR should start from age 11 years with 2-5 years diabetes duration.¹⁰ Irrespective of precise recommendations, all DR screening programs require a certain level of uptake, i.e. proportion of those offered screening who attend, to be cost-effective. For example, in England, the achievable uptake level for cost-effectiveness of the program is considered 85%.¹¹

The National Pediatric Diabetes Audit (NPDA), which uses data reported routinely by pediatricians caring for children living with diabetes, reported that only 66% of the UK's eligible children were reported to have undergone screening in 2015/2016, with uptake

ranging from 0% to 100% by unit (median: 74%; IQR: 65-81%).^{3, 12} Similar low screening attendance has been reported in the US where 66% of children and young people living with type 1 and 42% of those living type 2 diabetes had undergone retinal examination by 6 years following diagnosis.¹³ Uptake of DR screening decreases during adolescence, especially during transition to adult services,¹⁴ a period when non-adherence to glycaemia control measures. The resultant suboptimal diabetes control is the key risk factor for progression to sight-threatening eye disease.¹⁵

Potentially modifiable child and system-level factors related to service organization and delivery can improve the effectiveness of screening or surveillance.¹⁶ Requirements for delivering a cost-effective screening program in children and young people differ from adults because of differences in enablers and barriers for screening attendance.¹⁷ Despite this, in England as in other similar settings and health care systems, DR screening of children and young people living with diabetes has been ‘bolted on’ to, and is undertaken in, services developed for adults and predominantly for those with type 2 diabetes.

In England, the medical care of children living with diabetes involves a diverse range of professionals and services spanning primary/community care as well as specialist (secondary/tertiary/quaternary) care (Figure 1).^{8, 18} Ultimate responsibility for care lies with pediatricians working in secondary care Pediatric Diabetes Units (PDUs). These pediatricians confirm the diagnosis of diabetes, lead management and oversee compliance with preventative care processes such as DR screening. PDUs are also expected to communicate a new diagnosis of diabetes to primary care (family/community) physicians.

A large number of Diabetic Eye Screening Program (DESP) units deliver the national retinopathy screening service, and are independent of pediatric and ophthalmology services.^{18,19} DESPs rely on primary care diabetes registers as the main/sole source of patient

identification, as this is where adults living with diabetes are principally managed. Patients with an abnormal screening result are referred on from the DESPs to ophthalmologists working in tertiary care (Hospital Eye Services) who assess and treat them as required (Figure 1).

We hypothesized that the lack of child-centered screening pathways resulting in suboptimal communication at the interface between the different services delivering diabetic eye care for children in England, may explain the incomplete overall uptake of DR screening by children and young people as well as the regional heterogeneity in uptake. We report here a novel investigation to address this question comprising a survey of PDUs, and an analysis of the association between pediatric diabetes service-level characteristics and screening uptake. This investigation was undertaken in the context of our Diabetic Eye Disease in Childhood Study (DECS) aimed to investigate current recommendations and implementation of DR screening in England, UK, as a model for integrated primary and secondary care provision for children and young people.

Methods

DECS¹⁹ is supported by the DECS group which includes members of the United Kingdom's National Children & Young People's Diabetes Network. This network comprises health professionals including pediatricians/pediatric endocrinologists, pediatric diabetes nurses, dietitians, and psychologists, alongside health care commissioners, voluntary/lay groups and parent representatives, working together to share good practice and maintain high quality standards of care.²⁰ We developed and piloted the survey questionnaire (Supplement file 2) with the Network.

The questionnaire comprised the following sections about usual current practice: sources of patients and referral pathways into their PDU including presence of '*out-of-area*' patients (in

contrast to primary care, PDUs are not responsible for a geographically defined catchment area); data management processes; communication with local (DESPs) including access to screening results; and communication with their local Hospital Eye Services. A specific item on the first communication after a new diagnosis from the PDU to primary healthcare teams was included as this is a step specific to children and young people (versus adults) living with diabetes but is not presently addressed in the NDESP guidelines. An open-ended question sought any additional comments about DR screening in children. The authors reviewed the answers, and specific insights on communication were selected to illustrate survey findings.

All the 158 PDUs in England were invited to participate in this online survey via *SmartSurvey*.²¹ As a quality improvement project under UK Health Research Authority guidance, consent from respondents was not required. The survey was undertaken between 16th January 2017 and 7th May 2017, with 3 reminders sent to non-responders during this period.

Data on overall uptake of DR screening by PDU were extracted from the 2015/2016 NPDA.²² Uptake was defined as the percentage of children aged 12 years or older with type 1 diabetes with a complete year of care (i.e. eligible for DR screening) reported as receiving DR screening.³

Statistical methods

The unit of analysis of screening uptake was PDU. Using data from NPDA, respondent PDUs were compared with non-respondent PDUs by service-level characteristics that might influence screening uptake using t-tests or Wilcoxon rank-sum tests depending on the distribution of the variables. Logarithmic transformation of the unit size, defined as the number of children registered in the PDU, was performed to compare the mean size by participation status. NPDA does not disclose the precise number of children undergoing

screening in a given PDU if fewer than five such individuals attend (to avoid potential for identification of the patients), so the five PDUs in this category were assigned the maximum possible number i.e. four children.

Descriptive statistics were used to characterize survey responses. Presence of out-of-area patients was dichotomized as 'Yes' or 'No'. Access to eye screening results was categorized as 'easy access', 'difficult access' and 'no access'.

Generalized linear models for proportional responses (binomial error model) were fitted to explore the association between reported characteristics of PDUs and their DR screening uptake. Only PDUs with complete data on relevant variables were included in final regression analyses (n=108, 87%). Factors found to be statistically significant in univariable analysis (P-value<0.1) were entered in the initial multivariable model, and backward stepwise regression was conducted to select the final model (P-value<0.05 threshold for statistical significance). Odd ratios (ORs) with their 95% confidence intervals (95% CI) were calculated as a measure of the magnitude of the association with screening uptake. All statistical analyses were conducted using R software.²³

Results

124 of the 158 (78%) English PDUs completed the survey. Participating and non-participating PDUs were similar with respect to the number, age, ethnicity, and quality of glycaemic control of children cared for in PDUs as well as overall DR screening uptake (Table 1). The NPDA does not reported on individual-level characteristics such as level of education or socio-economic status by PDU.

Referral sources pathways into PDUs and data management

In 85% of PDUs, primary care services were the main (i.e.>50%) source of referral for patients who were suspected to have diabetes (table 2), followed by emergency rooms in 13%

of PDUs, reflecting the potentially acute presentation of diabetes in children. The median percentages of referrals from primary care and emergency rooms were 83% (IQR, 70-95%) and 15% (IQR, 5-29%), respectively (Figure 2). Median percentage of patients diagnosed with diabetes after developing diabetic ketoacidosis was 25% (IQR, 20-33%). 75% PDUs reported having some 'out-of-area' patients, i.e. living outside their catchment area.

All but one PDU had a formal database / register of patients and 78% used computer software for patient data management.

Feed-back to primary care when a new child is diagnosed with diabetes in PDU

Most PDUs (n=117; 94%) reported always communicating with primary care when a new patient was diagnosed with diabetes, providing details on diagnosis and treatment plan along with requests for repeat medication prescriptions. 45 (36%) PDUs had an automatic electronic feedback system for this whilst the others used letters or telephone calls to inform primary care. Additionally, 31 PDUs reported telephoning primary care colleagues when prior opportunities of diagnosis appeared to have been missed.

DR referral pathways from PDUs

Only 67% (n= 83) of PDUs had a mechanism for referring children *directly* to a local Diabetic Eye Screening Program (DESP) as shown in Figure 2. Four units reported specific arrangements with their local DESPs to facilitate screening completion e.g. dedicated paediatric slots, annual screening sessions where eye screening and blood tests are done at the same visit, special immediate appointments for hard-to-reach children. Children younger than 12 years i.e. below the UK age threshold for DR screening, had been referred to DESPs by 31% (n=39) of PDUs; and 19% (n=24) of PDUs reported referral of these younger children directly to secondary/tertiary Hospital Eye Services for DR screening. The most common reason for referral of these younger children was diabetes duration greater than 5 years.

Availability of diabetic eye screening results to pediatricians at the PDU

Almost all responding PDUs (97%, n=120) considered knowledge of DR screening results to be useful for their clinical practice, with one respondent commenting *“It is essential we have the results of retinopathy screening automatically as families want to discuss these and their significance.”* However, only 77% (n=96) of PDUs reported routinely having access to these results, 65% (n=81) and 12% (n=15) reporting easy and difficult access respectively (Figure 2 & Table 2).

All except one of those with access to screening result (n=95) received them directly from DESPs, in 38% (36/95) through paper (e.g. letters or printed lists) based rather than electronic feedback. Additionally, 28% (27/96) and 5% (5/96) reported that they received results through their patients or from primary care, respectively. For example, one respondent commented *“Usually we have to write to the general practitioner (family doctors) for a copy of the result and/or ask the patient to bring the result with them to clinic.”* One third (31/96) of PDUs with access to screening results, reported direct online access to the DESP databases from their clinics.

Thus overall, 35% (n=43/124) of PDUs reported *not* having direct access (n=28) or difficulty in accessing results of diabetic eye screening (n=15). Differences in geographical catchment areas between PDUs and DESPs were indicated as a source of difficulty, with one respondent commenting *“it's not always obvious which area the patient falls into”*.

Availability to pediatricians in PDUs of outcome of assessment in the hospital eye service

Only 62% (n=77) PDUs reported *routinely* receiving information from ophthalmologists in Hospital Eye Services about the outcome of the ophthalmology review for patients referred from DESP following an abnormal screening result (Figure 2).

PDU-level characteristics associated with DR screening uptake

Table 3 shows the associations between PDU characteristic as reported by unit, and diabetic eye screening uptake as reported in the NPDA 2015/2016. Factors positively associated with DR screening uptake were higher proportion of patients referred to the PDU from primary care (OR, 1.005; 95%CI, 1.004-1.007 per 1% of increase), the absence of ‘out-of-catchment area’ patients (OR, 1.13; 95%CI, 1.04-1.22), and reporting having easy access to screening results (OR, 1.45; 95%CI, 1.34-1.56, versus difficult/no-access).

Discussion

Our study has identified important variations in communication between pediatric health services and diabetic eye screening programs, which are associated with DR screening uptake by children and young people living with diabetes. Most notably, easy access to DR screening results was associated with a near doubling of odds of screening attendance whilst caring for ‘out-of-catchment area’ patients was associated with a 13% increased risk of failing to attend. These findings suggest sub-optimal integration of services and identify vulnerabilities in the current care provision that are also likely to exist in other countries and might be usefully addressed.

In England, as elsewhere, pediatricians are the key professionals responsible for the care of children and they provide the link to other services and teams.¹⁷ Therefore, their views and experiences are critical to understanding how to improve diabetic eye screening.

Nevertheless, our study comprises perception rather than direct evaluation of services and is cross-sectional in design, thus observed associations between better communication and higher screening uptake are not necessarily causal.

Current international guidelines on management of children living with diabetes recommend that retinal examination should be performed by eye care professionals.^{10, 17} However,

diabetic eye care guidelines for these professionals often overlook the pediatric population,²⁴ as they only represent a small fraction of their patients, and furthermore are mostly free of treatment-requiring retinopathy. Diabetic eye care for children, therefore, is currently delivered in a health care landscape designed for and primarily serving adults living with diabetes.^{9, 18, 25} In England, for example, the predominant model is a two-way partnership between primary care, where adults living with diabetes are cared for, and DESPs. By contrast, children, who are largely diagnosed and looked after in secondary or tertiary care by pediatricians, enter DESPs through an indirect pathway with no a children-specific route for returning their screening results to those involved in their clinical diabetes management.

In line with the American Diabetes Association's recent Standards of Medical Care in Diabetes focus on coordinated system delivery,²⁶ we suggest expanding the current recommendation of ensuring an adequate and timely referral for ophthalmologic care of those with abnormal screening results,²⁴ to ensuring an adequate integration of diabetic eye screening within the care of patients. This will contribute to the development of "*eye care professionals with expertise in diabetic retinopathy and experience in counseling the pediatric patient and family on the importance of early prevention and intervention*" as recommended by the ADA guidelines in children and adolescents.²⁷ Integration of diabetic eye screening into paediatric care is also crucial if retinal health is to be incorporated as a marker of other comorbidities in children living with type 1 diabetes.²⁸

Our findings of limited direct communication of screening results between the screening program and pediatricians, with results instead directed to the individual's primary care physician and the additional issue of the mismatch in geographical "catchment" areas served by primary, and therefore screening programs, and secondary health care services point to the real risk of actions being delayed or omitted. Receiving pediatric diabetes care and diabetic

eye screening from services that are not locally connected risks the high level of coordination that is necessary for effective delivery of care.

We suggest the international emphasis on the need for integration of healthcare, particularly for children with complex chronic conditions,²⁹⁻³¹ provides an opportunity to address the vulnerabilities our survey has identified in England, and which are likely to exist in other settings where diabetic eye care is delivered outside pediatric services. Like all children with chronic medical conditions,³² those living with diabetes require the input of multiple specialists and services but also face the additional challenge of comprising only a small proportion of the total population with this condition and consequently are at risk of receiving adult-centered care when they are seen by non-pediatric specialists.³³

New approaches will require primary research to identify the modifiable factors associated with screening uptake in children and young people, and there is currently a dearth of evidence in this area.³⁴ Mixed methods studies of the ‘person-level’ and ‘system-level’ factors including communication between all those involved in care and affected individuals are likely to be fruitful. Alongside this, implementation research, assessing the challenges of delivering existing guidelines into real world practice, is required to ensure a positive balance between benefits and harms of a screening programme,^{35,36} so that screening for DR, whose efficacy is proven,³⁷ is also effective in children and young people.

Finally, in the exciting new health informatics landscape, the use of technology including electronic patient medical records,^{38,39} and digital clinical information systems (e.g. diabetes registries), should ensure that it is possible to ‘*make patients’ medical information available to the right clinicians wherever they are*’ so as ‘*to ensure that patients get the right care in the most appropriate location*’³⁰ The ophthalmic care of children living with diabetes provides a particularly suitable test case for the power of health data science to deliver better health.

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Tables

Table 1. Comparison of participating and non-participating Pediatric Diabetes Units (PDUs).

Characteristic of PDUs[†], (n of units with available information[‡])	Participating PDUs (n=124)	Non- participating PDUs (n=24)	p-value
Number of registered patients in PDU (n=158) <i>log transformed mean (sd)</i>	5.0 (0.5)	5.0 (0.4)	0.51 [§]
Percentage of White ethnicity children (n=155) <i>Median [IQR]</i>	86 [62-94]	78 [58-96]	0.59 [¶]
Percentage of children with Type 1 diabetes in the PDU (n=157) <i>Median [IQR]</i>	97 [95-98]	97 [94-98]	0.56 [¶]
Age group of children managed in the PDU			
0-4 years, <i>mean (sd) (n=157)</i>	6 (0.02)	6 (0.02)	0.27 [§]
5-9 years, <i>mean (sd) (n=158)</i>	21 (0.04)	22 (0.04)	0.16 [§]
10-14 years, <i>mean (sd) (n=158)</i>	40 (0.05)	40 (0.06)	0.85 [§]
15-19 years, <i>mean (sd) (n=158)</i>	33 (0.07)	31 (0.08)	0.33 [§]
Mean HbA1c (mmol/mol) among children managed in the PDU (n=157) <i>Mean (sd)</i>	68 (3.6)	68 (4.6)	0.95 [§]
Overall uptake of diabetic eye screening reported by the PDU (n=155) <i>Median [IQR]</i>	74 [63-82]	74 [70-80]	0.98 [¶]
Percentage of normal eye screening (n=155) <i>Median [IQR]</i>	80 [73-89]	78 [71-86]	0.35 [§]
Percentage of missing data on eye screening result (n=142) <i>Median [IQR]</i>	1.9 [0.0-5.4]	3.3 [1.4-19]	0.09 [§]

[†] reported in the NPDA 2015/2016.

[‡] some PDUs did not report data to avoid re-identification (less than 5 participants in the category).

[§] t-test

[¶] Wilcoxon rank-sum tests

Table 2. Summary of survey findings regarding diabetic eye care pathways in children from 124 Pediatric Diabetes Units (PDUs) in England.

Characteristic reported by PDU in survey. (<i>n</i> of responses)	Category	Participating PDUs <i>n</i> (%)	
Main source (>50%) of patients referred to PDU. (<i>n</i> =110)	Primary care	94 (85)	
	Accident & emergency rooms [†]	15 (14)	
	Other sources [‡]	1 (1)	
Any of 'out-of-area' patients managed by PDU. (<i>n</i> =120)	Yes	90 (75)	
Existence of register of all patients managed in PDU. (<i>n</i> =124)	Yes, electronic	100 (81)	
	Yes, paper based	2 (1)	
	Yes, electronic and paper-based	21 (17)	
	No	1 (1)	
Use of clinical information management software. (<i>n</i> =124)	Yes	97 (78)	
Direct referral from PDU to DESP possible. (<i>n</i> =124)	Yes	83 (67)	
Any children referred to diabetic eye screening before <12 years of age. (<i>n</i> =124)	at DESP (main reason)	Yes (diabetes duration >5 years)	18 (15)
		Yes (ensuring registration at DESP)	15 (12)
		Yes (suboptimal diabetes control)	4 (3)
		Yes (other diabetic complications)	2 (1)
		No	85 (69)
	at Hospital Eye Services (main reason)	Yes (diabetes duration >5 years)	13 (10)
		Yes (presence of other eye problems)	6 (5)
		Yes (parent anxiety)	1 (1)
		Yes (suboptimal diabetes control)	1 (1)
		Yes (no reason stated)	3 (2)
No	100 (81)		
Direct access for PDU to diabetic eye screening results. (<i>n</i> =124)	Easy access	81 (65)	
	Difficult access	15 (12)	
	No-access	28 (23)	

[†] Including four PDUs reported 50% from primary care and from 50% accident & emergency rooms.

[‡] Transfers of care from other PDUs, self-referrals of siblings of registered children, or referrals from other pediatric specialties.

Table 3. Association between characteristic of Pediatric Diabetes Units (PDUs) and diabetic eye screening uptake (No. = 108 PDUs with complete data on all variables)

Characteristic by PDU	Odds ratio	(95% CI)	p-value
Univariable binomial regression			
NPDA REPORT 2015/2016[†]			
Proportion patients with type 1 diabetes – <i>1% increase</i>	2.44	(1.22-4.97)	0.013
Proportion 5-9 years old patients – <i>1% increase</i>	0.33	(0.13-0.80)	0.014
DECS SURVEY			
Proportion referrals from primary care – <i>1% increase</i>	1.006	(1.004-1.008)	<0.001
Out-of-area patients managed in PDU – <i>no</i>	1.23	(1.13-1.33)	<0.001
Feed-back route to primary care – <i>automatic</i>	1.08	(1.01-1.16)	0.022
Direct contact to primary care if early diabetes diagnosis appeared to have been missed – <i>yes</i>	1.10	(1.02-1.19)	0.011
Register of patients – <i>Electronic only vs paper-based/no register</i>	0.92	(0.84-0.997)	0.043
Use of data management software – <i>yes</i>	0.96	(0.89-1.04)	0.349
Direct referral to DESP possible – <i>yes</i>	1.16	(1.08-1.25)	<0.001
Referral to DESP of children under 12 years old – <i>yes</i>	1.06	(0.99-1.14)	0.091
PDU access to DESP screening results – <i>easy access vs difficult or no access</i>	1.49	(1.38-1.60)	<0.001
Multivariable binomial regression			
Proportion referrals from primary care – <i>1% increase</i>	1.005	(1.004-1.007)	<0.001
Presence of out-of-area patients – <i>no</i>	1.13	(1.04-1.22)	0.005
Feed-back route to primary care – <i>automatic</i>	1.06	(0.99-1.14)	0.094
PDU access DESP screening results – <i>easy access vs difficult or no access</i>	1.45	(1.34-1.56)	<0.001

[†] Proportion of White children was not available for all PDUs.

Figure legends

Figure 1. Diabetic eye care pathways in children and young people in England.

Figure 2. Survey findings regarding diabetic eye care pathway in children and young people in England. Italics fonts and dashed lines were used to indicate study findings.

† In addition to DESP, primary care and patients themselves were sources of screening results. 23% of units reported not having routinely access to screening results.