Atlas of variation in risk factors and healthcare for vision in England

Quick user guide Maps **1** Type of statistic **2** Geographic **3** Year of data **4** Rate calculated **5 Optimum values** Low indicates Equal sized quintiles The boundaries lower values are preferential (high number of areas presented (e.g. rate, presented per x number of proportion) people indicates higher values are on the map are divided preferential). Local interpretation equally between the 5 maybe required for some indicators. categories with those with the highest values forming the 'Highest' group etc. Map 1a: Experimental statistic: Variation in rate of all vision outpatient attendances by clinical commissioning group (2019/20) For example, in 2020 there were 135 clinical commissioning groups Directly standardised rate per 100,000 population 4 (CCGs), so 27 CCGs are Optimum value: Requires local interpretation in each category. Darker Significance level compared with England areas have the highest Equal-sized quintiles of geographies values. Higher - 99.8% (70) Highest (18,477 - 24,131) Higher - 95% (2) (16,833 - 18,477) **Significance level** (15,790 - 16,833) Not different (7) compared with England (14,391 - 15,790) Lower - 95% (2) The darkest and lightest Lowest (9,821 - 14,391) Lower - 99.8% (54) shading on map shows CCGs whose confidence intervals do not overlap with the England value. London London The second darkest and lightest colours show areas where the England value falls between the CCG's 95% and 99.8% CI. The number in brackets indicates the number of CCGs in each category. 8 © Crown copyright London is presented as a © Crown copyright separate zoomed in map

for clarity.

Chart, box plot and table

Median

14,990

15,825

15,875

16,231

16,177

16,153

16,194

Significant

Quick user guide



6 For each indicator, data is presented visually in a time series of box and whisker plots. The box plots show the distribution of data.

The line inside each box shows the median (the mid-point, so if the 135 CCGs were sorted in order of value, the value halfway between the CCGs in the 67th and 68th position would give the median). The bottom and top of the blue box represents the values which 25% and 75% of the areas fall below. 50% of the areas have a value within this range.

The whiskers mark the values at which 5% and 95% of areas fall below. The median and maximum values are also shown.

The time series allows us to see how the median has changed over time, but also whether the gap between the extreme values has changed.

The table accompanying the box and whisker plots shows whether there has been any statistically significant change in the median, or in the degree of variation over time.

Sections in the chapter

Context - an overview of why the indicator is of public health interest

Magnitude of variation - commentary in relation to the chart, box plot and table

Options for action – suggestions for best practice

Resources – links to useful documents

Quick user guide

CCG rank position

How were the categories calculated?



Box plot

		percentile	(135 CCGs in 2020)
Box & whisker plot		Max	135
Whiskers Show the extreme values in the dataset. Box 50% of the data values lie between the 25 th and 75 th percentile. The distance between these is known as the inter-quartile range (IQR).	 Maximum The value of the area with the highest value. 95th percentile 95% of areas have values below this. 	95%	Mid value between values of CCGs in ranks 128 and 129
	- 75 th percentile 75% of areas have values below this.	75%	Mid value between values of CCGs in ranks 101 and 102
	The median is the middle value of an Median (50 th percentile)ordered dataset. Half of the observations are below it and half above	50% - Median	Mid value rank 68
	25 th percentile 25% of areas have values below this.	25%	Mid value between values of CCGs in ranks 34 and 35
	 ^{5th} percentile 5% of areas have a value below this. Minimum The value of the area with the lowest value. 	5%	Mid value between values of CCGs in ranks 7 and 8
		Min	1

Diabetic eye screening

Context

The prevalence of diabetes mellitus (diagnosed and undiagnosed) is rapidly increasing in the UK, with an estimated 4.2 million people (aged 16 and over) being affected in England in 2020, with this set to rise to 5.1 million by 2035,¹ making diabetes an urgent public health concern. Studies have documented diabetic eye disease, that is diabetic retinopathy (DR) and diabetic macula oedema (DMO), to affect 48% of type 1 and 28% of type 2 people with diabetes in the UK.² In some cases this may lead to significant visual loss with diabetes accounting for around 14% of blindness certifications in working age adults in England and Wales.^{3,4}

DR in its early stages is largely asymptomatic, and therefore retinopathy screening is crucial to enable early detection of sight-threatening retinopathy, permitting patients to be referred to hospital services for treatment, prior to the onset of significant visual loss. Knowledge regarding earlier stages of retinopathy also informs overall diabetes care and permits risk factor modification.⁵

The countries of the United Kingdom were the first in the world to introduce a national, population-based screening programme to detect diabetic eye disease. The diabetic eye screening programme (DESP) commenced in 2003 and reached population coverage in 2008,⁶ and is now pivotal in the management of diabetic eye disease in the UK.⁷ In England, screening is commissioned by NHS England. Public Health England advises, develops standards and provides specific services that help the local NHS implement and run screening services consistently across the country. DESP along with overall improvement in systemic management and care of people with diabetes has been highly successful as evidenced by the fact that diabetic retinopathy is now no longer the

¹ Public Health England (2015) Diabetes prevalence estimates for CCGs by GP registered populations [Accessed 15 Jun 2021]

² Mathur R, Bhaskaran K, Edwards E and others (2017) Population trends in the 10-year incidence and prevalence of diabetic retinopathy in the UK: a cohort study in the Clinical Practice Research Datalink 2004–2014 BMJ Open. 2017 Feb 28;7(2):e014444 [Accessed 17 Feb 2021]

³ Liew G, Michaelides M, Bunce C (2014) A comparison of the causes of blindness certifications in England and Wales in working age adults (16–64 years), 1999–2000 with 2009–2010 BMJ Open. 2014;4:e004015 [Accessed 16 Feb 2021]

⁴ Rahman F, Zekite A, Bunce C and others (2020) Recent trends in vision impairment certifications in England and Wales Eye (London) 2020 Jul;34(7):1271-1278 [Accessed 16 Feb 2021]

⁵ Harding S, Greenwood R, Aldington S (2003) Grading and disease management in national screening for diabetic retinopathy in England and Wales Diabetic Medicine 2003 Dec;20(12):965-71 [Accessed 17 Feb 2021]

⁶ Scanlon PH (2017) The English National Screening Programme for diabetic retinopathy 2003-2016 Acta Diabetol. 2017;54(6):515-525 [Accessed 16 Jan 2021]

⁷ Scanlon PH (2021) The contribution of the English NHS Diabetic Eye Screening Programme to reductions in diabetes-related blindness, comparisons within Europe, and future challenges Acta Diabetol 2021; 58(4): 521–530 [Accessed 20 Jul 2021]

leading cause for certification of visual impairment in the working age population in England and Wales.^{3,4}

Certifications for diabetic eye disease continue to decline, from 3.6 per 100,000 people aged 12 years or over in the financial year beginning 2010, to 2.9 per 100,000 people aged 12 years or over in the financial year beginning 2019.^{4,8}

Diabetic eye screening is offered every year to all eligible people, aged 12 years and over, with diabetes in England (excluding gestational diabetes). Individuals are required to have light perception as a minimum in at least one eye. People with diabetes already under an ophthalmologist and certain other categories (e.g. those who are terminally ill) are not invited. DESP identifies eligible individuals through an electronic data extraction (GP2DRS)⁹ and by collaborating with GP practices to create, validate and maintain, on at least a quarterly basis, a register of all people with diabetes mellitus.¹⁰

Screening tools for DR grading have evolved over the years in line with technological advances and two field mydriatic digital photography is currently the gold standard for DR screening in England. England uses a feature-based grading system for screening, developed by the Diabetic Retinopathy Grading and Disease Management Working Party,⁵ that is supported by evidence from the Early Treatment Diabetic Retinopathy Study (ETDRS) grading system.

Briefly the nomenclature describes:

- R0- No retinopathy
- R1- Background retinopathy
- R2- Pre-proliferative retinopathy
- R3- Proliferative retinopathy
 - R3A: Active proliferative retinopathy
 - o R3S: Stable treated proliferative retinopathy
- M0- No maculopathy
- M1- Maculopathy present
- P0- Photocoagulation absent
- P1- Photocoagulation present
- U- Ungradable

Retinopathy grading then determines further management,¹¹ with patients deemed to have R0, R1 or M0 called for annual review by the DESP, those with R2 or M1 being

⁸ Public Health England (2021) Public Health Profiles: Indicator ID 41203 [Accessed 16 Jun 2021]

⁹ NHS Digital (2021) GP2DRS (Diabetic eye screening programme) [Accessed 20 Jul 2021]

¹⁰ Public Health England with NHS England and NHS Improvement (2019) NHS public health functions agreement 2019-20 Service specification no.22 NHS Diabetic Eye Screening Programme [Accessed 16 Feb 2021]

¹¹ Public Health England (2017) NHS Diabetic Eye Screening Programme – Grading definitions for referable disease [Accessed 16 Jun 2021]

referred to hospital eye services and patients with R3 disease requiring urgent referral to hospital eye services for consideration of panretinal photocoagulation/laser treatment.

Quality assurance of grading and graders is measured and maintained in the Test and Training (TAT) system, recognised to be a valid indicator in assuring high quality grading in diabetic eye screening. This is achieved by setting minimum standards of >85% sensitivity and >80% specificity to detect referable diabetic retinopathy (M1, R2 and R3A).^{11,12}

Each local screening provider is responsible for continually monitoring and collecting data regarding its delivery of the service. This enables benchmarking between areas within the eligible screening programme population using several standards¹³ and key performance indicators (KPI) as outlined below. The acceptable level should be achieved as a minimum by all programmes.⁶

KP1: The proportion of those offered routine digital screening who attend a digital screening event where images are captured. Acceptable \geq 75.0% Achievable \geq 85%

KP2: Time between routine digital screening/digital surveillance/slit lamp biomicroscopy and printing of results letters to the person with diabetes, GP and relevant health professionals. Acceptable: 85% < 3 weeks and 99% < 6 weeks.

KP3: Time between screening event and first attended consultation at hospital eye services or digital surveillance

- Urgent Acceptable: ≥ 80% 6 weeks
- Routine Acceptable: ≥ 70% 13 weeks Achievable: ≥ 95% 13 weeks

In the financial year beginning 2018, the England DESP invited 2.8 million people with diabetes for retinopathy screening with an uptake of 82.6% (2.3 million). 9,053 (0.3% of patients screened) were urgently referred to hospital eye services (R3, proliferative retinopathy), and 83,137 (3.2%) routine referrals were made for patients with R2 and

¹² Keenan TDL, Johnston RL, Donachie PHJ and others (2013) United Kingdom National Ophthalmology Database Study: Diabetic Retinopathy; Report 1: prevalence of centre-involving diabetic macular oedema and other grades of maculopathy and retinopathy in hospital eye services Eye (London) 2013 Dec;27(12):1397-404 [Accessed 17 Feb 2021]

¹³ NHS Screening Programmes: Diabetic Eye (2016) The management of grading quality: Good practice in the quality assurance of grading [Accessed 16 Feb 2021]

M1.¹⁴ Review of these patients by hospital eye services within specified timescales is imperative so that treatment can be offered, as appropriate, to minimise the risk of visual loss.

Diabetic eye screening during the COVID-19 pandemic

More recently, the coronavirus (COVID-19) pandemic has posed many challenges to DESP with nationwide screening being temporarily suspended. Furthermore, the population of people with diabetes being at higher risk meant many were shielding and restrictions to transportation services have led to understandably poorer uptake, which will impact outcomes in the financial year beginning 2020 and beyond.

¹⁴ Public Health England (2020) Diabetic eye screening: 1 April 2018 to 31 March 2019 data table [Accessed 14 Jun 2021]

Map 5a: Variation in percentage of those offered diabetic eye screening who attend a routine digital screening event (where images were captured) in people aged 12 years and over by clinical commissioning group (2018/19)

Optimum value: High

Performance thresholds



Column chart: Variation in percentage of those offered diabetic eye screening who attend a routine digital screening event (where images were captured) in people aged 12 years and over by CCG (2018/19)



Note: Column chart colours correspond to indicator performance thresholds

Map 5b: Variation in percentage of urgent referrals for diabetic eye disease (referred proliferative diabetic retinopathy [R3A]) seen within 6 weeks of screening event in people aged 12 years and over by DESP area (2018/19)

Optimum value: High

Performance thresholds



Column chart: Variation in percentage of urgent referrals for diabetic eye disease (referred proliferative diabetic retinopathy [R3A]) seen within 6 weeks of screening event in people aged 12 years and over by DESP area (2018/19)



Note: Column chart colours correspond to indicator performance thresholds

Map 5c: Variation in percentage of routine referrals for diabetic eye disease (referred pre-proliferative diabetic retinopathy [R2] or maculopathy [M1]) seen within 13 weeks of screening event in people aged 12 years and over by DESP area (2018/19)

Optimum value: High

Performance thresholds



Column chart: Variation in percentage of routine referrals for diabetic eye disease (referred pre-proliferative diabetic retinopathy [R2] or maculopathy [M1]) seen within 13 weeks of screening event in people aged 12 years and over by DESP area (2018/19)



Note: Column chart colours correspond to indicator performance thresholds

Magnitude of Variation

Map 5a: Variation in percentage of those offered diabetic eye screening who attend a routine digital screening event (where images were captured) in people aged 12 years and over by clinical commissioning group

The map and column chart display the latest period (2018/19), during which clinical commissioning group (CCG) values ranged from 73.8% to 92.1%, which is a 1.2-fold difference between CCGs.

The England value for 2018/19 was 83.2%.

Overall, uptake of diabetic eye screening met the acceptable standard in 2018/19 177 out of 180 CCGs (for which data were available) meeting this level, and 66 out of 177 meeting the achievable standard.

A number of factors are known to adversely affect the uptake of diabetic screening, including both younger and older age groups, social deprivation, being of an ethnic minority background, poorer blood sugar control, smoking and a lack of awareness of the risk of visual loss.^{15, 16, 17, 18}

A large number barriers to screening have been reported including accessibility to the screening clinic, time (such as competing demands), scheduling and referral difficulties, doctor-patient communication, lack of awareness of the condition, lack of awareness of screening and confusion between this and routine eye tests, absence of symptoms and perceived necessity of screening.^{16,19}

¹⁵ Hwang J, Rudnisky C, Bowen S and others (2015) Socioeconomic factors associated with visual impairment and ophthalmic care utilization in patients with type II diabetes Canadian Journal of Ophthalmology 2015 Apr;50(2):119–26 [Accessed 20 May 2021]

¹⁶ Kliner M, Fell G, Gibbons C and others (2012) Diabetic retinopathy equity profile in a multi-ethnic, deprived population in northern England Eye 2012;26(5):671–7 [Accessed 20 May 2021]

¹⁷ Moreton RBR, Stratton IM, Chave SJ and others (2017) Factors determining uptake of diabetic retinopathy screening in Oxfordshire Diabetic Medicine. 2017 Jul;34(7):993-999 [Accessed 20 May 2021]

¹⁸ Graham-Rowe E, Lorencatto F, Lawrenson JG and others (2018) Barriers to and enablers of diabetic retinopathy screening attendance: a systematic review of published and grey literature Diabetic Medicine 2018 Oct;35(10):1308-1319 [Accessed 20 May 2021]

¹⁹ Lindenmeyer A, Sturt JA, Hipwell A, and others (2014) Influence of primary care practices on patients' uptake of diabetic retinopathy screening : a qualitative case study British Journal of General Practice, 64 (625): e484-e492 [Accessed 05 Aug 2021]

Map 5b: Variation in percentage of urgent referrals for diabetic eye disease (referred proliferative diabetic retinopathy [R3A]) seen within 6 weeks of screening event in people aged 12 years and over by DESP area

The map and column chart display the latest period (2018/19), during which DESP area values ranged from 33.3% to 94.6%, which is a 2.8-fold difference between DESP areas.

The England value for 2018/19 was 77.9%.

The mean England value for review of urgent referrals within 6 weeks was slightly below the acceptable standard of 80%. However, there is large variation across regions. Approximately half, 33 out of 61 (for which data were available), DESP areas met the acceptable standard.

Map 5c: Variation in percentage of routine referrals for diabetic eye disease (referred preproliferative diabetic retinopathy [R2] or maculopathy [M1]) seen within 13 weeks of screening event in people aged 12 years and over by DESP area

The map and column chart display the latest period (2018/19), during which DESP area values ranged from 15.3% to 88.4%, which is a 5.8-fold difference between DESP areas.

The England value for 2018/19 was 53.2%.

The mean England value for review of routine referrals within 13 weeks was below the acceptable standard of 70%, with marked variation across England. Only 11 out of 61 (for which data were available) DESP areas met the acceptable standard.

The factors described above with regards to screening uptake, such as social deprivation,¹⁶ also affect patient attendance at secondary care appointments. Patients referred with proliferative or pre-proliferative retinopathy, or maculopathy (outcomes Map 5b and Map 5c) may have poorer glycaemic control as reflected by their stage of retinopathy, which could also result in other comorbidities, illness and hospital admissions that would reduce their attendance in the hospital eye service. Studies have demonstrated end organ involvement and depression as risk factors for failure to attend appointments.²⁰ Other barriers reported include long waiting times, other medical conditions, forgetting, and inability to leave work.²¹

²⁰ Chen AJ, Hwang V, Law PY and others (2018) Factors Associated with Non-compliance for Diabetic Retinopathy Follow-up in an Urban Safety-Net Hospital Ophthalmic Epidemiology 06 Aug 2018, 25(5-6):443-450 [Accessed 20 May 2021]

²¹ Lu J, Chen J, Hwang V and others (2019) Analysis of Patient-Reported Barriers to Diabetic Retinopathy Follow-Up Ophthalmic Surgery Lasers and Imaging Retina. 2019 Feb 1;50(2):99-105 [Accessed 20 May 2021]

A further important factor is a lack of hospital capacity to accommodate appointments in a timely manner, given increasing pressure on medical retina clinics in the hospital eye service, that are required to also accommodate urgent referrals for other conditions such as age-related macular degeneration. This may result in cancellations or delays in appointments in hospital eye services due to inadequate staffing and or resources to meet the increasing prevalence and burden of diabetes mellitus.

Delays in timely review of routine referrals (outcome Map 5c), with less than a fifth of DESP areas meeting the acceptable standard, may particularly impact patients with diabetic maculopathy (M1) who may require treatment. Studies have shown that delayed treatment for diabetic macular oedema may potentially reduce gains in vision that might be achieved with existing NICE approved anti-VEGF therapy.^{22,23}

Options for action

Given the diversity of factors that have been identified to affect uptake of screening and attendance at hospital eye appointments, improving outcomes requires a multi-faceted approach. However, common themes in many studies are a lack of awareness regarding the disease and the importance of recommendation by other healthcare professionals.^{16, 17, 18, 20, 21, 22, 24}

Patient education is therefore key to improve an understanding of the risks of diabetes and diabetic retinopathy, the need for pre-symptomatic identification and early treatment of eye disease, and to address any concerns. NICE guidance for type 2 diabetes advises offering patients structured education around the time of diagnosis with annual review.²⁵ Rates of offering structured education (approximately 50% in people with type 1 diabetes and over 80% in people with type 2 diabetes), and attending (approximately 15% in each group), have changed little over the past few years, though both increasingly occur sooner after diagnosis, and ongoing work is required to improve engagement with this.²⁵ Engagement with patient organisations is important and specific efforts should be targeted at reaching out to younger patients and ethnic minority communities via community networks and disseminating information in different languages.

²² Sadda SR, Campbell J, Dugel PU and others (2020) Relationship between duration and extent of oedema and visual acuity outcome with ranibizumab in diabetic macula oedema: A post hoc analysis of Protocol I data Eye (London) 2020 Mar;34(3):480-490 [Accessed 20 May 2021]

²³ National Institute for Health and Care Excellence (2013) Ranibizumab for treating diabetic macular oedema Technology appraisal guidance (NICE guideline [TA274]) [Accessed 15 Jun 2021]

²⁴ van Eijk KND, Blom JW, Gussekloo J and others (2012) Diabetic retinopathy screening in patients with diabetes mellitus in primary care: incentives and barriers to screening attendance Diabetes Research and Clinical Practice 2012;96(1):10–6 [Accessed 20 May 2021]

²⁵ NHS Digital (2020) National Diabetes Audit Diabetes Prevention Programme- Quarterly Report: 1 January to 31 December 2020 [Accessed 15 Jun 2021]

Communication between the different groups of healthcare professionals involved in care of people with diabetes is also pivotal. Strengthening ongoing interaction between DESP, hospital eye services and professionals in primary and secondary care managing people with diabetes will encourage the latter groups to promote retinopathy screening and attend hospital appointments. In many regions there are close links between DESP and hospital eye services, and in regions where Map 5b and Map 5c outcomes fall below the acceptable standard, these links could be used to identify local factors for intervention to improve uptake and attendance at hospital appointments. A lack of capacity or resources within hospital eye services such as space, medical and administrative staff may also need to be evaluated.

Studies also identify convenience as a barrier to attendance for both screening and hospital appointments. Improving the accessibility of hospital eye services, providing more flexibility and integrating diabetes care have all been proposed as enablers of uptake,¹⁸ although these are more challenging to achieve given the need for funding and infrastructure change. An important development is the introduction of more digital surveillance clinics within DESP for monitoring of low risk maculopathy which does not require referral to hospital eye services. This is done via the use of optical coherence tomography (OCT) assessments, which are not currently included in NHS England commissioned DES services. Public Health England has recently provided guidance (July 2020) on provision of the use of OCT.²⁶ A more widespread, consistent commissioning of DESP OCT surveillance across England will help refine routine referrals (Map 5c) and prioritise those that need specialist intervention for treatment in hospital eye services, thus reducing delays in starting treatment for high risk maculopathy. This would aid managing COVID-19 related backlogs in hospital eye services, as well as being aligned with the NHS long term plan.^{27,28} The COVID-19 pandemic has also accelerated the use of imaging or virtual appointments within hospital eye services,²⁹ which may also reduce the delays, be more cost effective and improve patient experience.

Resources

Public Health England (2020) Diabetic eye screening standards valid for data collected from 1 April 2019 [Accessed 22 Feb 2021]

²⁶ Public Health England (2020) Optical coherence tomography (OCT) in diabetic eye screening (DES) surveillance clinics [Accessed 20 May 2021]

²⁷ Leal J, Luengo-Fernandez R, Stratton IM and others (2019) Cost-effectiveness of digital surveillance clinics with optical coherence tomography versus hospital eye service follow-up for patients with screen-positive maculopathy Eye (London) 2019 Apr;33(4):640-647 [Accessed 20 May 2021]

²⁸ NHS England (Jan 2019) NHS Long Term Plan [Accessed 29 Jul 2021]

²⁹ Faes L, Fu DJ, Huemer J and others (2020) A virtual-clinic pathway for patients referred from a national diabetes eye screening programme reduces service demands whilst maintaining quality of care Eye (London) 2020 Oct 30:1-10 [Accessed 20 May 2021]

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Published August 2021 PHE gateway number: GOV-8023



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