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

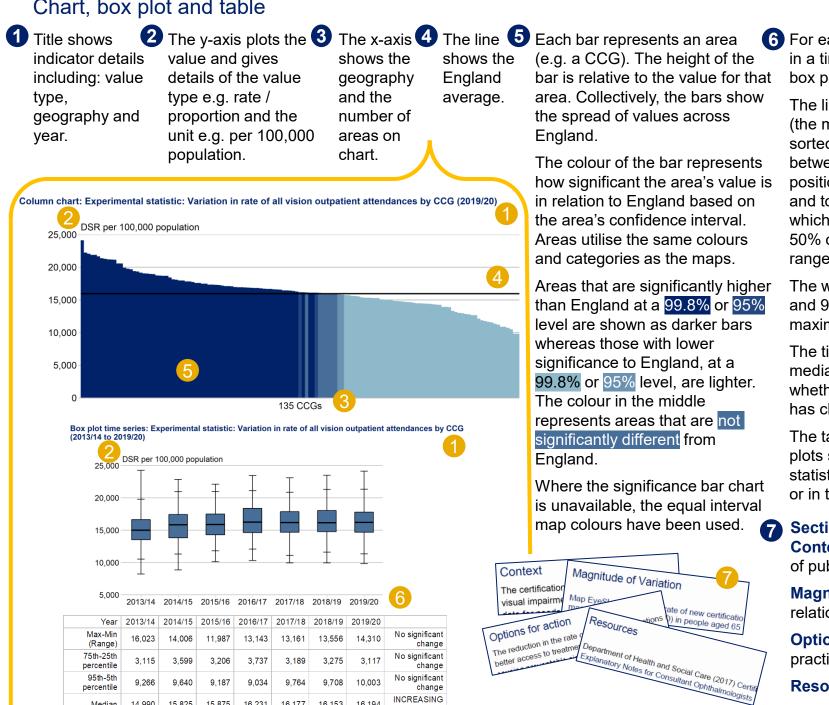
16,177

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 67<sup>th</sup> and 68<sup>th</sup> 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

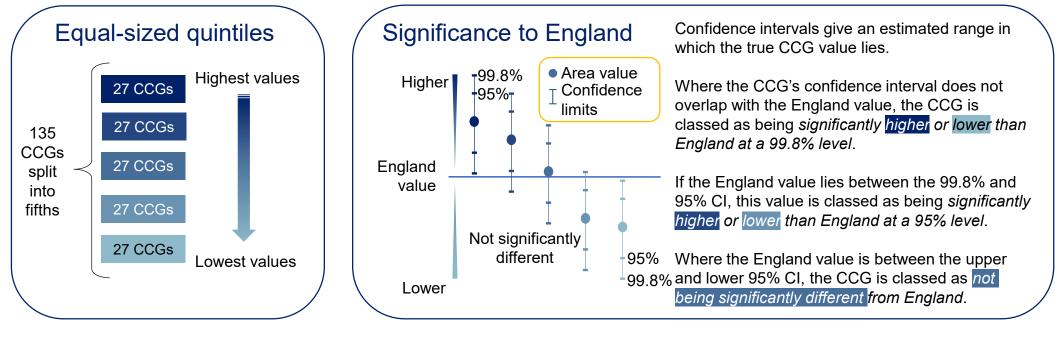
**Options for action** – suggestions for best practice

**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 Maximum The value of the area 95 <sup>th</sup> percentile 95% of areas ha	, i i i i i i i i i i i i i i i i i i i	95%	Mid value between values of CCGs in ranks 128 and 129
values in the dataset. Box 75 <sup>th</sup> percentile 75% of areas ha	ave values below this.	75%	Mid value between values of CCGs in ranks 101 and 102
50% of the data values lie between the 25 <sup>th</sup> Median (50 <sup>th</sup> percentile) <sub>ordered</sub>	dian is the middle value of an dataset. Half of the observations w it and half above.	50% - Median	Mid value rank 68
The distance between 25 <sup>th</sup> percentile 25% of areas ha		25%	Mid value between values of CCGs in ranks 34 and 35
these is known as the inter-quartile range (IQR).		5%	Mid value between values of CCGs in ranks 7 and 8
		Min	1

# Eye cancer

## Intraocular and ocular surface cancers

## Context

Despite being the most common primary intraocular cancer in adults, uveal melanoma is still relatively rare. The estimated incidence of uveal melanoma in Europe is approximately 2 to 8 per million per year.<sup>1</sup> In races with brown eyes the incidence is significantly lower. Eye preserving treatment in the form of radiotherapy can be used to treat the majority of small or medium sized melanomas. Large melanomas are treated by enucleation (eye removal). Survival following treatment for uveal melanoma can be predicted based on American Joint Committee on Cancer (AJCC) stage, genetic changes within the tumour, particularly changes in chromosome 3 and 8, and histological changes within the tumour. Overall, 50% of patients with uveal melanoma are limited and the majority of patients with metastatic uveal melanoma die within one year of diagnosis.<sup>2</sup>

The most common intraocular cancer in childhood is retinoblastoma with a worldwide incidence of between 1:15,000 and 1:20,000.<sup>3</sup> Eighty per cent of cases of retinoblastoma occur in the developing world.<sup>4</sup> Untreated, retinoblastoma is universally fatal. With modern multimodal treatment, survival from retinoblastoma can reach almost 100%.<sup>5</sup> The genetics of retinoblastoma are well understood and key to the management of children with retinoblastoma and their families is good genetic testing and counselling. Due to a lack of treatment resources and because of late presentation there is huge disparity in survival between regions of the world. In the developing world, retinoblastoma survival is predicted to be around 30%.<sup>6</sup> The main treatment for retinoblastoma is chemotherapy, which can be delivered systemically, to the eye by intra-ophthalmic artery chemotherapy or into the vitreous. Local treatments such as

<sup>&</sup>lt;sup>1</sup> Jager MJ, Shields CL, Cebulla CM and others (2020) Uveal Melanoma Nature Reviews. 2020 apr;6(24):1-25 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>2</sup> Virgili G, Gatta G, Ciccolallo L and others (2008) Survival in patients with uveal melanoma in Europe Arch Ophthalmol. 2008 Oct;126(10):1413-1418 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>3</sup> Kivelä T (2009) The epidemiological challenge of the most frequent eye cancer: retinoblastoma, an issue of birth and death Br J Ophthalmol 2009 Sep;93(9):1129-1131 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>4</sup> Global Retinoblastoma Study Group (2020) Global retinoblastoma presentation and analysis by national income level JAMA Oncol 2020 May;6(5):685-695 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>5</sup> Shields CL, Bas Z, Tadepalli S and others (2020) Long-term (20-year) real-world outcomes of intravenous chemotherapy (chemoreduction) for retinoblastoma in 964 eyes of 554 patients at a single centre Br J Ophthalmol. 2020 Nov;104(11):1548-1555 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>6</sup> Ancona-Lezama D, Dalvin LA, Shields CL (2020) Modern treatment of retinoblastoma: A 2020 review Indian Journal of Ophthalmology 2020 Nov;68(11):2356-2365 [Accessed 21 Jun 2021]

laser, cryotherapy or plaque radiotherapy may be needed. However, advanced disease is still treated by enucleation of the eye.<sup>7</sup>

Ocular surface cancers most commonly arise from either conjunctival squamous cells or from conjunctival melanocytes. Both tumours often arise from precursor non-malignant lesions. Sunlight appears to be a significant risk factor for the development of ocular surface squamous neoplasia (OSSN). HIV and HPV infection are also implicated. The incidence of OSSN is highest in equatorial regions and in older white men. In the USA the incidence is between 0.3 and 8.4 per million people per year.<sup>8,9</sup> In Australia it is 19 per million people per year.<sup>10</sup> In a UK based 12 month prospective observational study, the reported incidence of OSSN was 0.53 cases per million people per year.<sup>11</sup> The incidence of worldwide conjunctival melanoma is increasing and is estimated to be between 0.24 to 0.8 cases per million.<sup>12</sup> Again, sunlight has been proposed as a risk factor for its development but the evidence for this is equivocal.

The main treatment for ocular surface tumours is surgery. Topical chemotherapy and radiotherapy can be used as adjuvant treatments. Systemic monitoring for metastatic spread is particularly important for conjunctival melanoma. The frequency of systemic metastasis in conjunctival melanoma is around 19%.<sup>12</sup>

## Data quality

This is the first publication of intraocular and ocular surface cancer incidence with a geographical breakdown from Public Health England's National Cancer Registration and Analysis Service (NCRAS) data. The data have been carefully quality assured and the analysis accurately reflects the data stored in the national disease registration database, however as with any new publication it is possible that variation in the reported incidence may reflect previously undetected variation in the quality of submissions to the registry (for example, if one Trust did not submit eye cancer patients, the rates in their area may appear artificially low). The indicator was chosen through multiple discussions with clinicians and NCRAS staff. All the data used was supplied by NCRAS.

<sup>&</sup>lt;sup>7</sup> Dimaras H, Corson TW, Cobrinik D and others (2015) Retinoblastoma Nature reviews Disease primers. 2015 Aug;1, 15021 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>8</sup> Emmanuel B, Ruder E, Lin SW and others (2012) Incidence of squamous-cell carcinoma of the conjunctiva and other eye cancers in the NIH-AARP Diet and Health Study Ecancermedicalscience. 2012 May;6:254 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>9</sup> Sun EC, Fears TR, Goedert JJ Epidemiology of squamous cell conjunctival cancer. Cancer Epidemiol Biomarkers Prev. 1997;6(2):73–77 [Accessed 03 Aug 2021]

<sup>&</sup>lt;sup>10</sup> Lee GA, Hirst LW. Incidence of ocular surface epithelial dysplasia in metropolitan brisbane: A 10-year survey. Archives of Ophthalmology. 1992;110(4):525–527 [Accessed 03 Aug 2021]

<sup>&</sup>lt;sup>11</sup> Kiire CA, Stewart RMK, Srinivasan S, and others (2019) A prospective study of the incidence, associations and outcomes of ocular surface squamous neoplasia in the United Kingdom Eye (Lond). 2019 Feb;33(2):283-294 [Accessed 21 Jun 2021]

<sup>&</sup>lt;sup>12</sup> Wong JR, Nanji AA, Galor A and others (2014) Management of conjunctival malignant melanoma: a review and update Expert Rev Ophthalmol. 2014 Jun;9(3):185-204 [Accessed 21 Jun 2021]

NCRAS codes cancer according to the International Classification of Diseases for Oncology Third Edition (ICDO3) and provides a mapping for all cancers to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD10) Version for 2010. For this indicator only the coding system of ICD10 was used. This group is what we considered traditionally as being 'eye' cancers and are treated by eye cancer specialists. They include cancers coded to C69.0 to C69.4 in ICD10 (see Table 6.1 below for full description).

The registration of these cancers follows the recommended principles for the registration process which relies on multiple data sources, enhanced follow-up with trusts and expert processing by cancer registration officers.<sup>13</sup> We expect population level coverage of all eye cancers in England. Cancer registration has very complete data, the very small number of cases missed tend to be clinically diagnosed untreated cancers where the patient is still alive, or cases treated entirely outside the NHS.

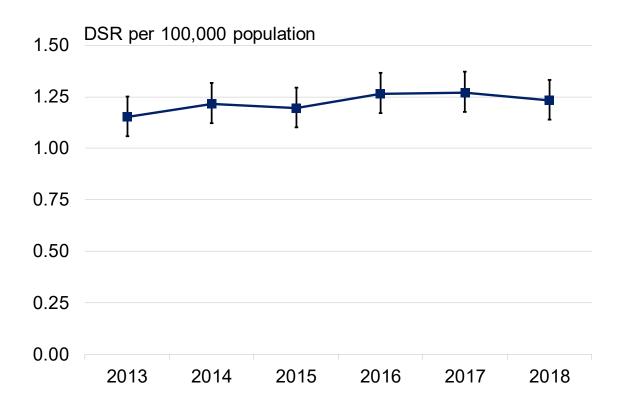
Imprecise coding could affect this indicator. If cases of the eye are coded to C69.9 (Eye, not otherwise specified) they would not be included in this indicator. However, numbers of these cases are small.

ICD10 Code	Description
C69.0	Malignant neoplasm of conjunctiva
C69.1	Malignant neoplasm of cornea
C69.2	Malignant neoplasm of retina
C69.3	Malignant neoplasm of choroid
C69.4	Malignant neoplasm of ciliary body

#### Table 6.1: Indicator codes and description

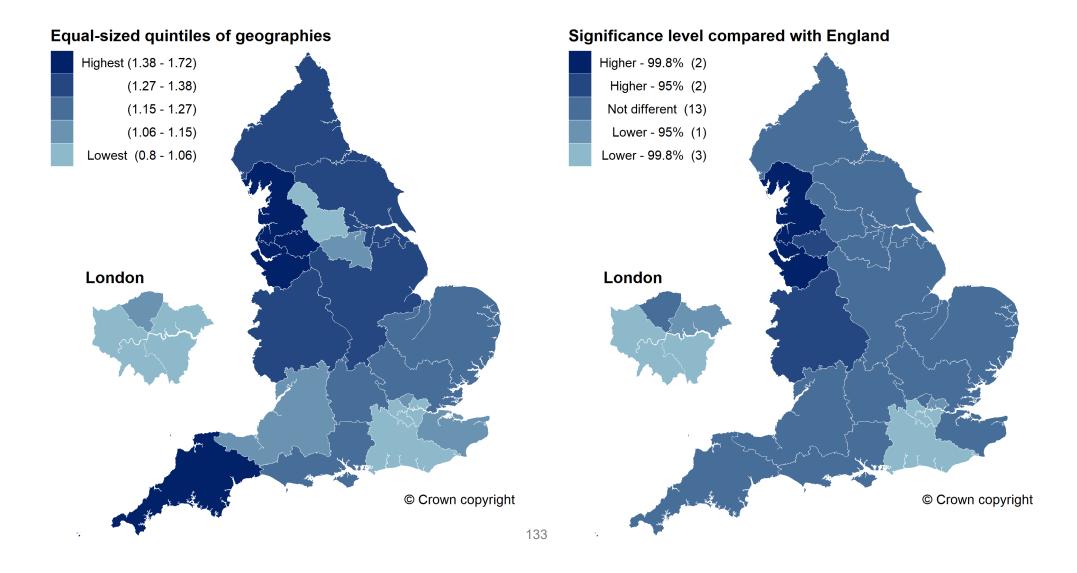
<sup>&</sup>lt;sup>13</sup> Henson KE, Elliss-Brookes L, Coupland VH and others (2020) Data Resource Profile: National Cancer Registration Dataset in England International Journal of Epidemiology, Volume 49, Issue 1, February 2020, Pages 16–16h [Accessed 05 August 2021]

# Figure 6.1: Incidence rate of uveal, retinal and conjunctival cancers for England (2013 to 2018)

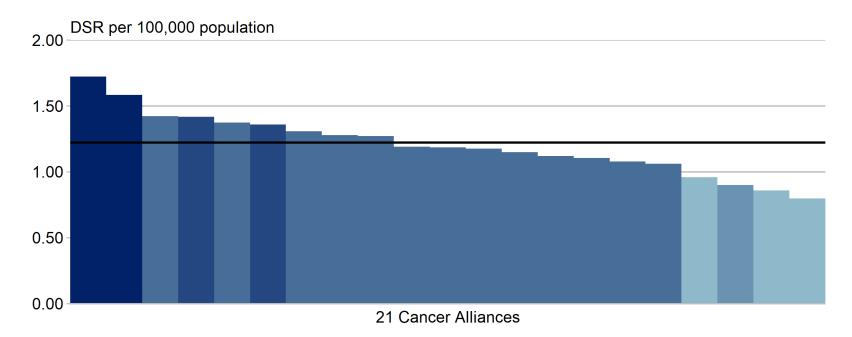


# Map 6: Variation in incidence rate of uveal, retinal and conjunctival cancers by cancer alliance (2013-2018)

Directly standardised rate per 100,000 population Optimum value: Requires local interpretation



# Column chart: Variation in incidence rate of uveal, retinal and conjunctival cancers by Cancer Alliance (2013-2018)



## Magnitude of Variation

Map 6: Variation in incidence rate of uveal, retinal and conjunctival cancers by cancer alliance

The maps and column chart display the latest period (2013-2018), during which cancer alliance values ranged from 0.8 per 100,000 population to 1.7 per 100,000 population, which is a 2.2-fold difference between cancer alliances.

The England value for 2013-2018 was 1.2 per 100,000 population.

Ethnicity and skin type are important risk factors for ocular tumours in adults. The variation seen within England may be partly explained by differences in demography throughout the country and in differences in patient's willingness to seek hospital care.

An important consideration in uveal tumours is that they are rarely diagnosed by biopsy. Instead, clinicians use multimodal imaging (for example ultrasound, photography and optical coherence tomography) to give clues as to the likely diagnosis. Distinguishing between small melanomas and benign naevi using imaging can be difficult, subjective and open to geographic variation in opinion. There are three adult ocular oncology centres in England based in Liverpool, Sheffield and London. The variation in incidence seen within the country may partly be due to differences between centres, and between ophthalmologists and optometrists who refer to these centres, in where the line is drawn between benign naevi and melanomas.

## Options for action

Continuing collaboration between English ocular oncology centres to agree on defined criteria for distinguishing between naevi and melanomas may help in reducing variation in incidence. Educating non-ocular oncologist ophthalmologists and optometrists so they know when and how to refer patients may also be helpful.

In the future, the best option for reducing subjectivity in diagnosis and thus some of the variation in incidence would be to have a biochemical test that was non-invasive with no side effects that could distinguish between a benign choroidal naevus and melanoma. Liquid biopsies of blood to detect circulating melanoma DNA or circulating melanoma cells hold promise in this area.<sup>14</sup>

Local areas are recommended to review their own data and identify if rates look unusual or unexpected, noting any associated data quality issues and exploring the potential reasons for variation and suggested options for action. Areas are encouraged to contact

<sup>&</sup>lt;sup>14</sup> Jin E, Burnier JV (2021) Liquid Biopsy in Uveal Melanoma: Are We There Yet? Ocul Oncol Pathol. 2021 Mar;7(1):1-16 [Accessed 21 Jun 2021]

the National Cancer Registration and Analysis Service (NCRAS) to discuss any data issues arising from this.

### Resources

Royal College of Ophthalmologists (2019) Referral pathways for adult ocular tumours [Accessed 21 Jun 2021]

The College of Optometrists (2020) Clinical Management Guidelines Guidance on Pigmented Fundus Lesions [Accessed 21 Jun 2021]

OcuMelUK Welcome page [Accessed 22 Jul 2021]

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