MRC Centre of Epidemiology for Child Health

UCL

Overview of childhood visual impairment and blindness

EU Regulatory Workshop - Paediatric Investigation Plans in Ophthalmology
October 2011, EMA

Jugnoo S Rahi
MRC Centre of Epidemiology for Child Health,
Institute of Child Health UCL
and Institute of Ophthalmology UCL.

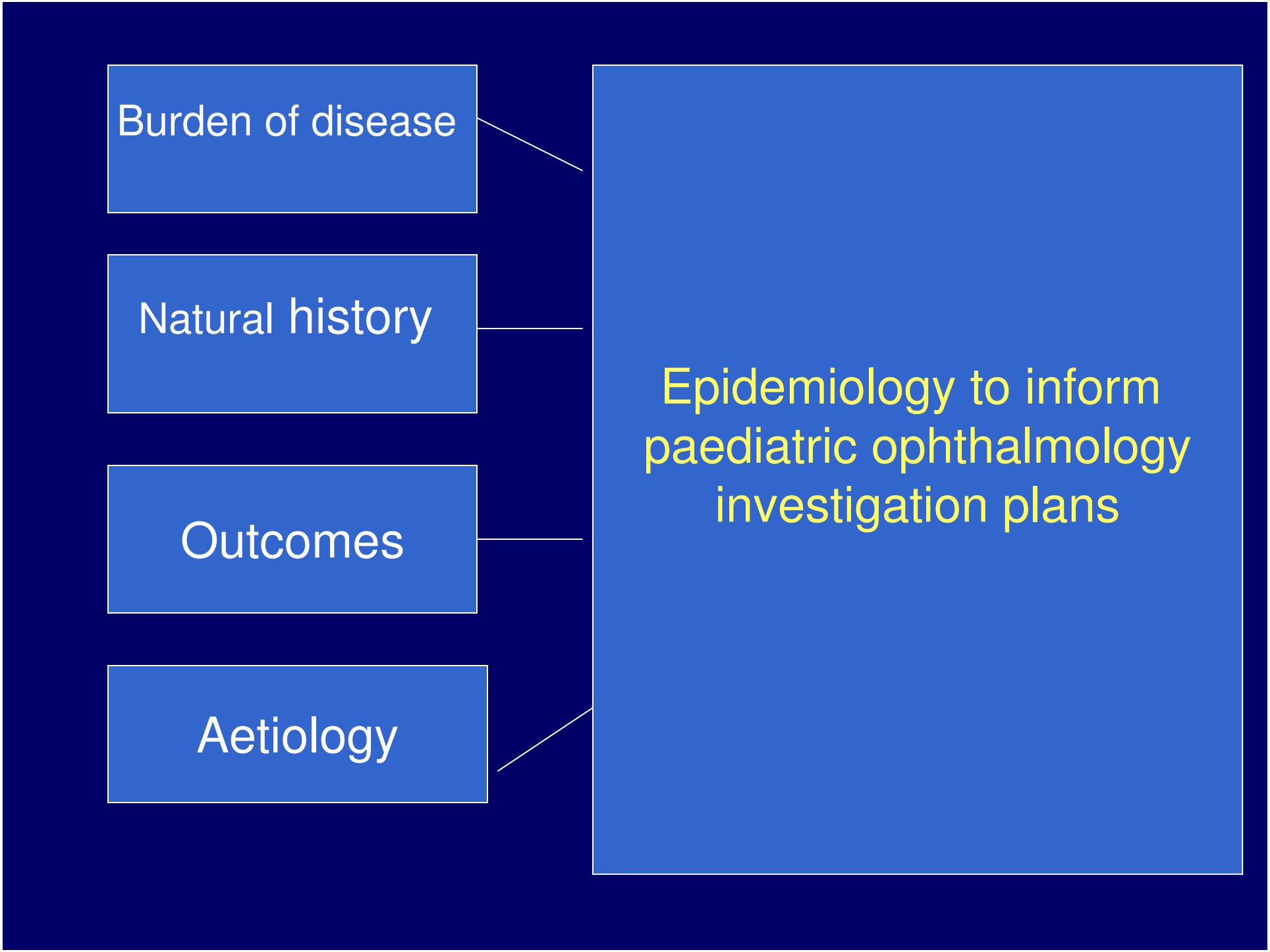
The child first and always

The Ulverscroft Vision Research Group

Outline

Burden and causes of visual childhood impairment and blindness

Epidemiological perspective on *areas of unmet needs* in therapeutic trials


Burden of disease
Natural history
Outcomes
Aetiology
Epidemiology to inform paediatric ophthalmology investigation plans

Paediatric ophthalmology – potential data sources in EU

- *Disorder-specific* population-based prevalence or incidence studies

Paediatric ophthalmology – potential data sources in EU

- *Disorder-specific* population-based prevalence or incidence studies
- ***General* population-based studies** (eg *birth cohort studies)*
- General population-based census or disability *surveys*

Paediatric ophthalmology – potential data sources in EU

- ***Disorder-specific*** **population-based prevalence or incidence studies**
- ***General*** **population-based studies** (eg *birth cohort studies)*
- General population-based census or disability *surveys*
- **National *registers* of visual impairment**
- Disability and special needs registers

Paediatric ophthalmology – potential data sources in EU

- ***Disorder-specific*** **population-based prevalence or incidence studies**
- ***General*** **population-based studies** (eg *birth cohort studies)*
- General population-based census or disability *surveys*
- **National *registers* of visual impairment**
- Disability and special needs registers
- Surveillance schemes (*eg British Ophthalmic Surveillance Unit*)
- Disease/disorder-specific registers & surveillance programmes (*eg congenital anomaly monitoring systems, EUROCAT)*

Paediatric ophthalmology – potential data sources in EU

- ***Disorder-specific*** **population-based prevalence or incidence studies**
- ***General*** **population-based studies** (eg *birth cohort studies)*
- General population-based census or disability *surveys*
- **National *registers* of visual impairment**
- Disability and special needs registers
- Surveillance schemes (*eg British Ophthalmic Surveillance Unit*)
- Disease/disorder-specific registers & surveillance programmes (*eg national congenital anomaly monitoring systems)*
- Multi-disciplinary visual impairment teams
- Community-based rehabilitation programmes
- Service-linked databases / registers

Incomplete picture of childhood visual impairment

- few *disease-specific* national prevalence or incidence studies
- few reliable routine national sources of incidence data eg national registers of sight impairment - *under-ascertainment and imprecision*
- limited *recent* national population-based data on causes
- difficult to assess secular trends

non-comparability of data from different sources due to variation in taxonomies (*visual impairment and aetiology)*

UNICEF Child 0 – 15 years

WHO:

Dual anatomical and aetiological taxonomy for ‘causes’ VI / BL

Visual impairment **(VI)** *< 6/18, LogMAR 0.5 in better eye*

Severe visual impairment and blindness **(SVI/BL)**

<6/60, LogMAR 1.0 in better eye

Global: 1.2 million blind (BL) children

(50% in very low income countries, prevalence c. 15 / 1000)

In high income / industrialised populations:

Blindness →

0.5 / 1000

Visual impairment

1.5 / 1000 ↙

British Childhood Severe Visual Impairment / Blindness Study (BCVIS)

through the

British Childhood Visual Impairment Study Group

Aim:

To determine incidence and cause(s) of severe visual impairment or blindness in children in the UK

Lancet 2003;362:1359-65

Supported by British Council for Prevention of Blindness; Children Nationwide Medical Research Fund; National Eye Research Centre

BCVIS – METHODS

Population-based, prospective, observational study:
national active surveillance undertaken
British Ophthalmological Surveillance Unit (BOSU)
British Paediatric Surveillance Unit (BPSU)
for one year (2000)

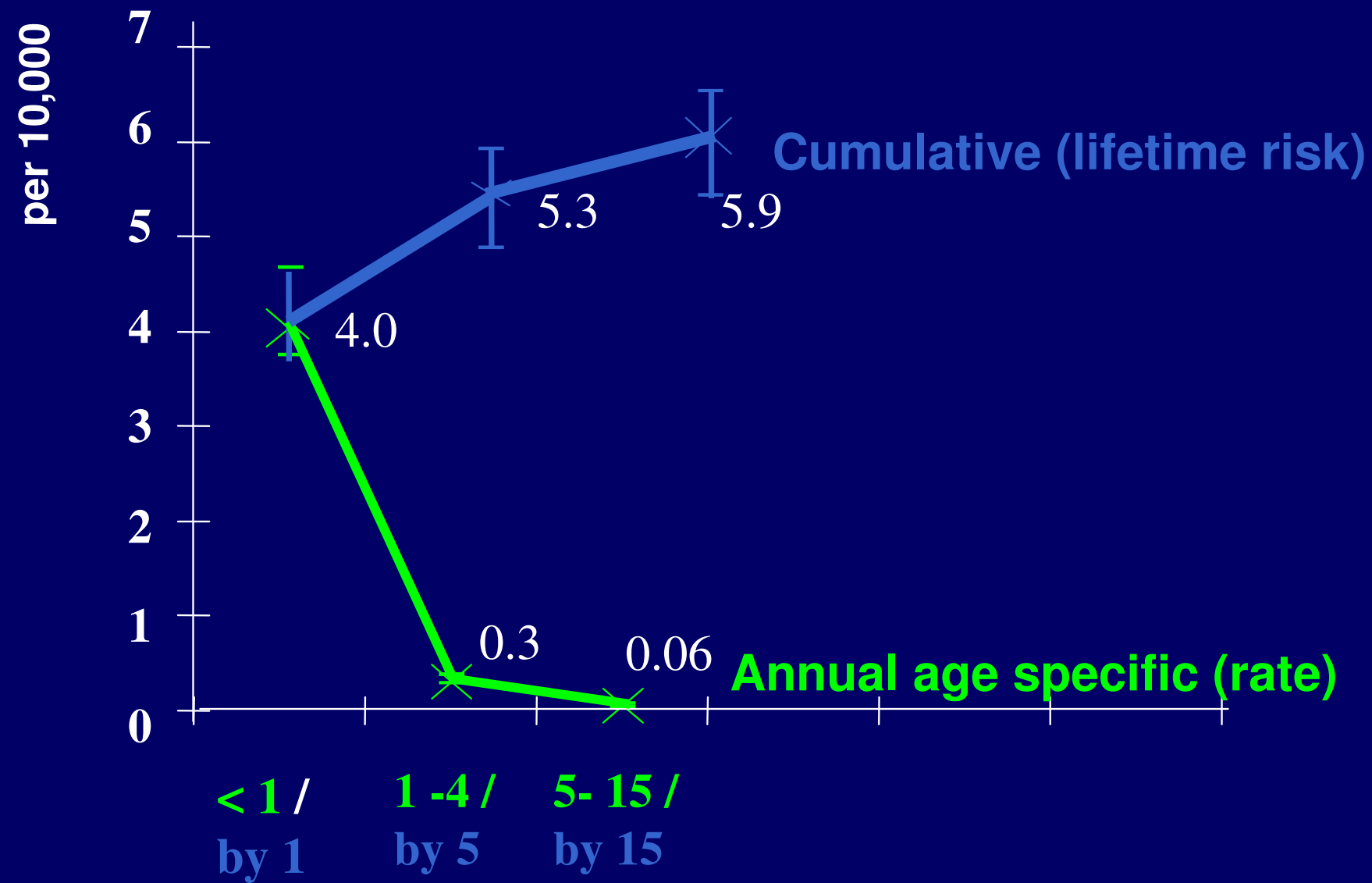
All children <16 years in UK n*ewly diagnosed* as *severely visually impaired or blind due to any disorder*

BCVIS - Results

439 children newly diagnosed as SVI/BL in 2000

- 54% Male
- 72% White, 16% South Asian, 4% Black, 7% Other
- 76% additional non-ophthalmic disorder(s) or impairment(s) - 'SVI/BL plus'
- 24% low birth weight (<2500g)
- 40% in most socio-economically deprived quintile
- 10% died within a year of diagnosis (Infant mortality in SVI/BL 20x greater then general UK population)

BCVIS: Incidence SVI/BL in UK in 2000



Annual Incidence of SVI/BL 0-15 years in UK, 2000

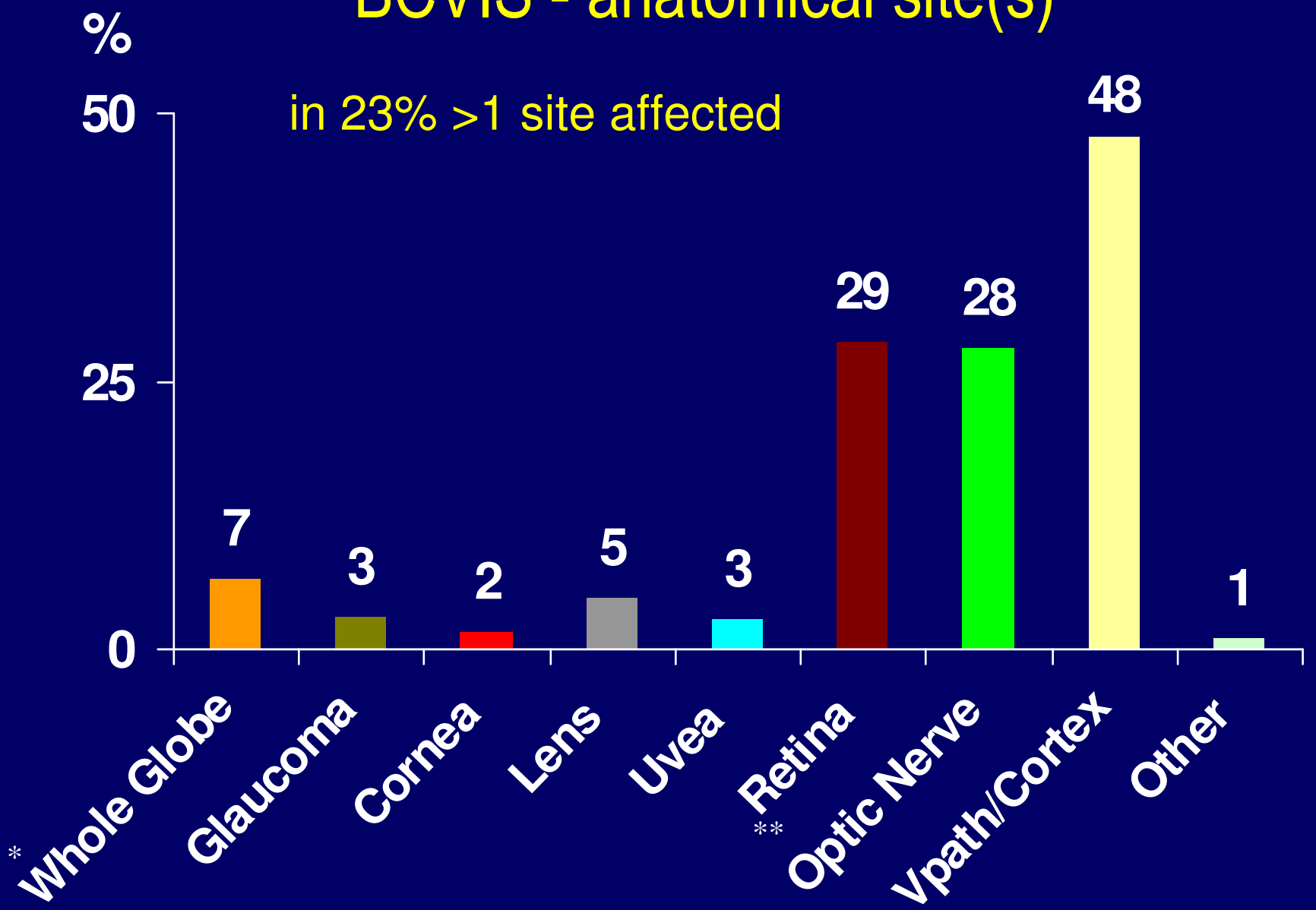
Age	Number of Cases	per 10,000 per year (95%CI)
All	420[1]	0.35 (0.31, 0.38)
SVI/BL Plus	328	0.27 (0.24, 0.30)
SVI/BL Isolated	90	0.08 (0.06, 0.09)

Annual Incidence SVI/BL 0-15 years by ethnic group and sex

Category	Incidence per 10,000 per year	Relative Rate (95% CI)
Ethnic group†		
White	0.23 (0.21, 0.26)	**Base**
South Asian	1.2 (0.92, 1.49)	5.1 (3.9, 6.7)
Indian	*0.5 (0.2, 0.8)*	*2.1(1.2, 3.6)*
Pakistani or Bangladeshi	*1.6 (0.1, 2.1)*	*6.7(4.9, 9.1)*
Black	0.5 (0.3, 0.8)	2.3 (1.4, 3.7)
Other	0.7 (0.4, 0.9)	2.9 (1.9, 4.3)
Sex		
Female	0.3(0.28, 0.37)	**Base**
Male	0.4(0.32, 0.42)	0.9 (0.7, 1.1)

† Great Britain only

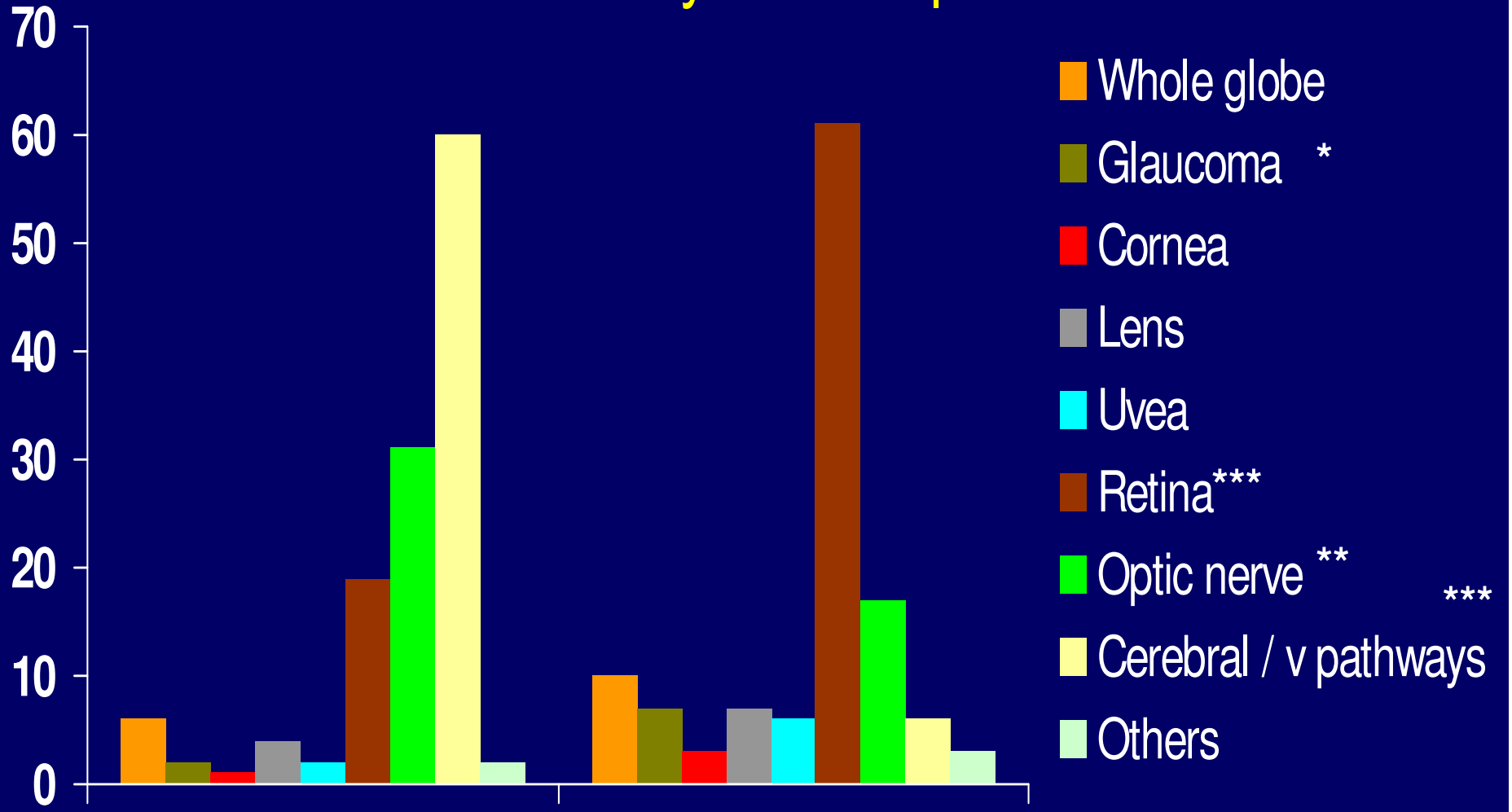
BCVIS - anatomical site(s)



*inc ant seg dysgenesis, multiple colobomas

** Inc albinism

BCVIS: anatomical site by other impairment/disorder

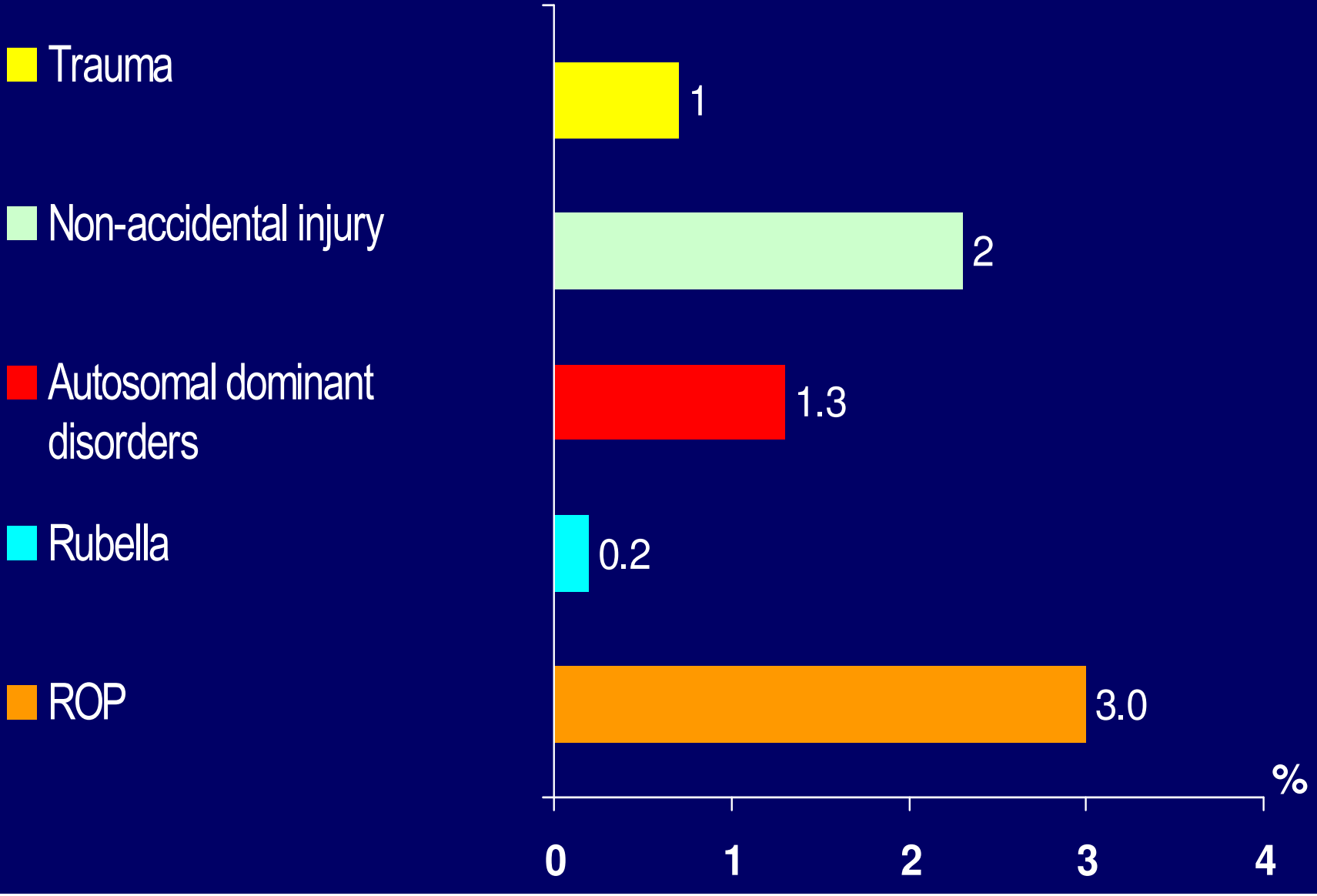


* p <0.05, ** p<0.01, *** p <0.001

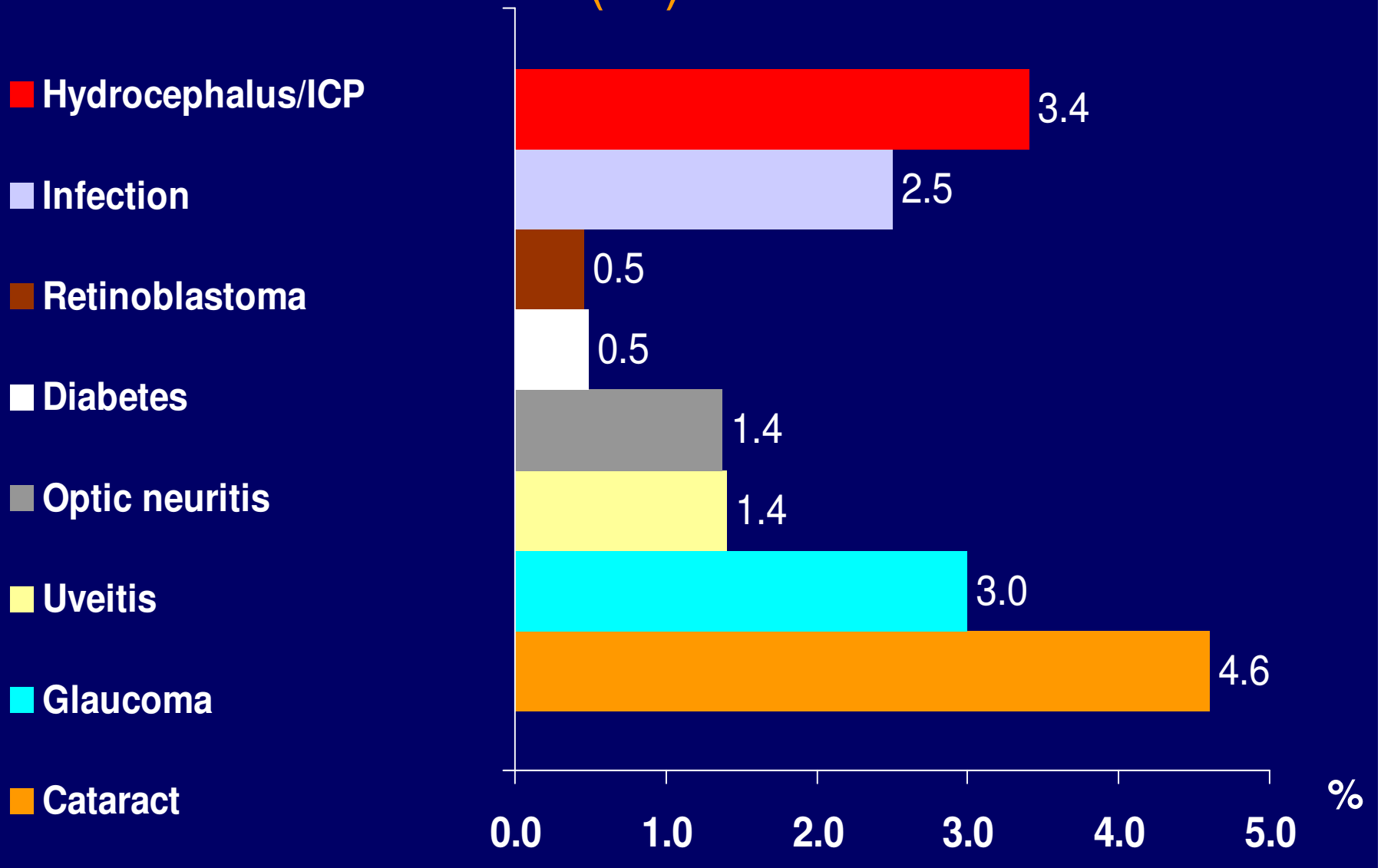
25%

SVI / BL
is preventable or treatable
with current knowledge

BCVIS: Potentially preventable causes of SVI/BL
7.5% (33)



BCVIS: Potentially treatable causes of SVI/BL 17.1% (75)



Implications for intervention studies

- Two ‘ target’ populations’ of **SVI/BL** children – ‘isolated’ or ‘plus’ non-ophthalmic impairments / disorders
- Incidence varies with age, presence of non-ophthalmic impairments, ethnicity and birthweight, socio-economic status
- CVI ‘main’ cause, but disorders are diverse, patterns (anatomical sites and aetiology) vary by presence of non-ophthalmic impairments, birthweight and ethnicity
- Scope for further primary and secondary prevention limited with current knowledge
- Require novel treatments eg for CVI

Gaps in knowledge (1)

Population of children with visual impairment (vs SVI/BL)

- Incidence unknown - likely to be at least twice that of SVI/BL
- Pattern of ‘causes’ unknown - likely to differ significantly from SVI/BL

Implications for planning intervention studies

Gaps in knowledge (2)

Long-term outcomes / natural history

Limited information about

- long term visual function / morbidity

- social (eg education, occupation) impact
- general and mental health
- quality of life (or other patient-reported outcomes)

of affected individuals and families

Implications for assessing impact of interventions

Gaps in knowledge (3)

Health economics of childhood visual impairment

- Limited work on ‘costs’ (financial and opportunity) and benefits of different treatment and prevention strategies

Implications for resource allocation (research and care /services)

MRC | Centre of Epidemiology for Child Health

UCL

Thank you!

j.rahi@ucl.ac.uk

The Ulverscroft Vision Research Group