

# Blindness in children - global perspectives

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# Overview

- International Centre for Eye Health
- Challenges of research in developing countries
- What we know about how many children are blind, and why
- How research has strengthened programmes for blinding eye diseases of children:
  - Retinopathy of prematurity (ROP) in Brazil
  - Cataract in Bangladesh





# International Centre for Eye Health

# The International Centre for Eye Health

- Our mission:
  - Research and education to improve eye health and eliminate avoidable visual impairment and blindness, with a focus on low income populations
- WHO Collaborating Centre for blindness prevention
- Activities which focus on major causes of blindness in poor countries:
  - research
  - education
  - information dissemination

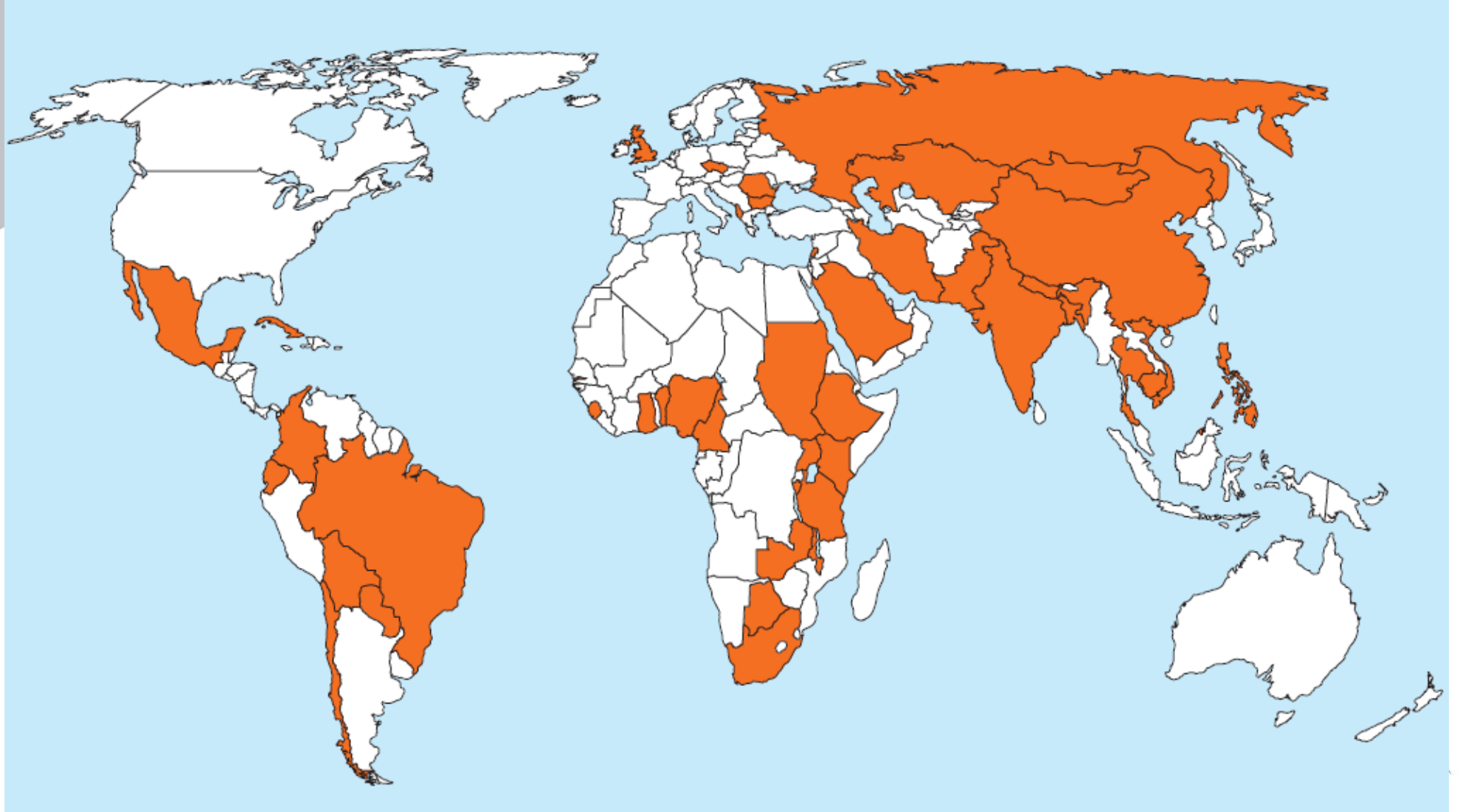


# Types of research

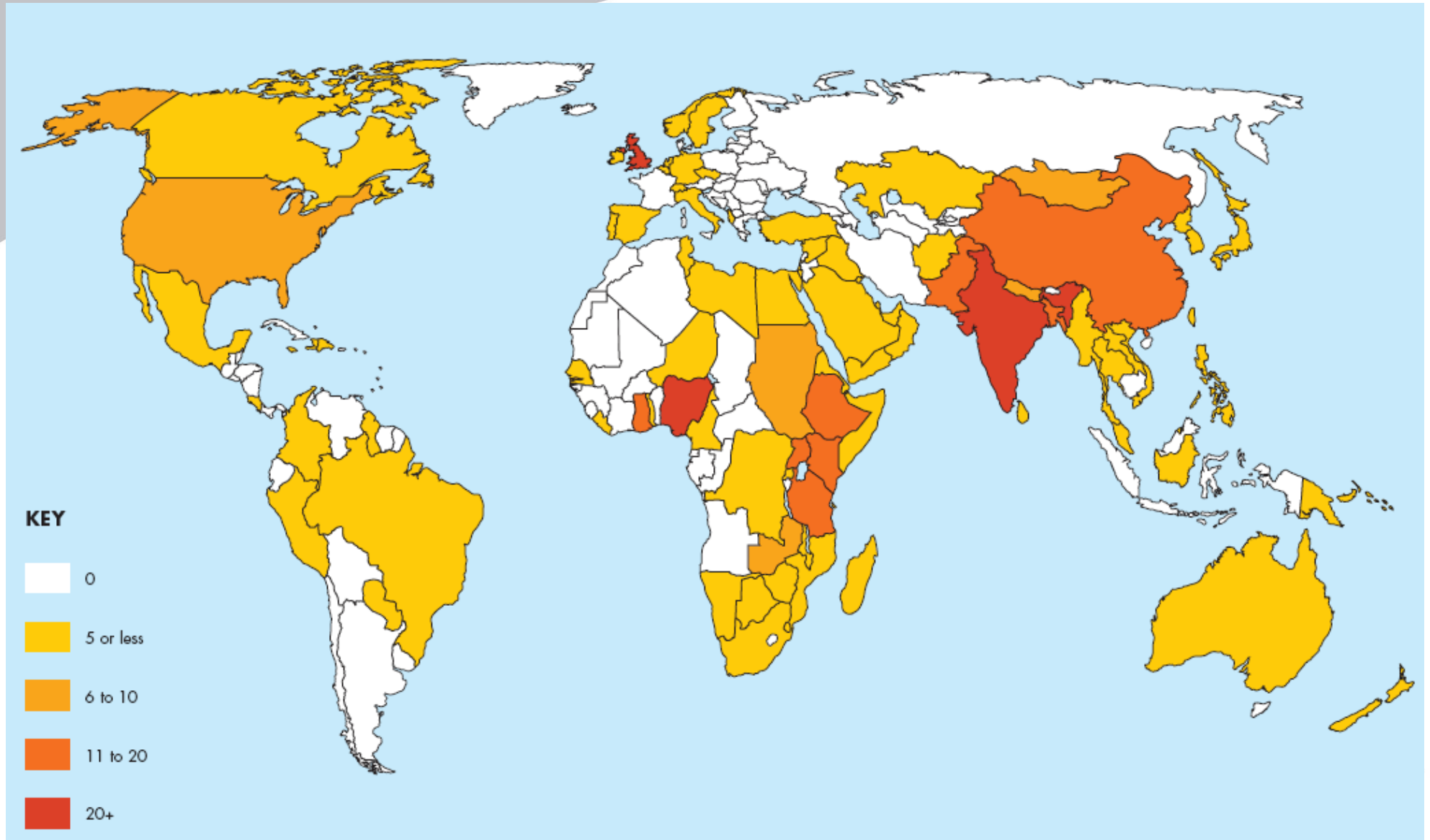
- Epidemiology
- Operational
- Health systems
- Health economics
- Qualitative



# Research: current and recent projects



# Education: masters and diploma students



# Education: Community Eye Health Journal



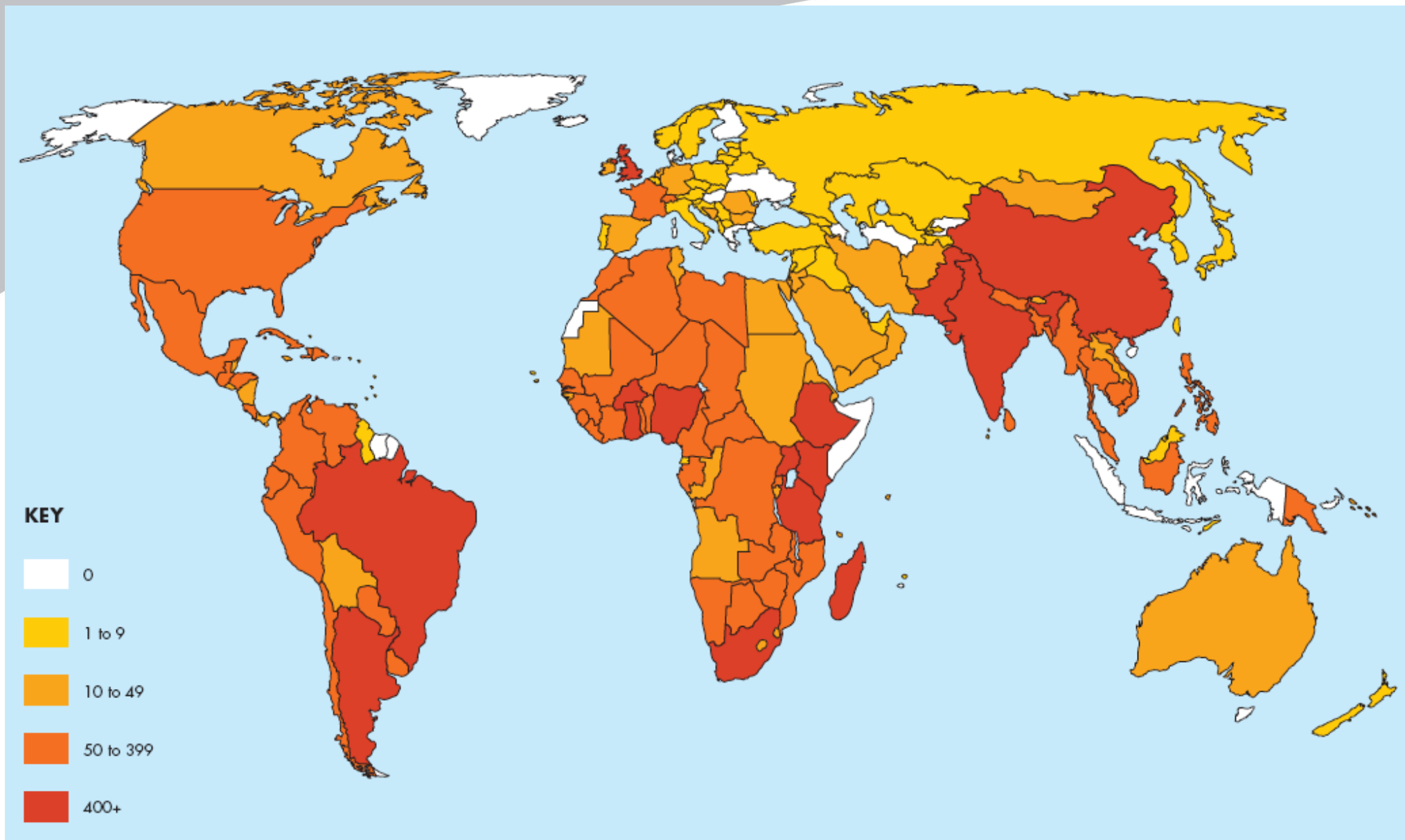
## Readers in 2009:

English	20,204
Chinese	6,000
French	3,541
Portuguese	3,000
Spanish	2,500
<b>Total:</b>	<b>35,245</b>





# Community Eye Health Journal distribution



# Close collaborative relationships with....

- Major international NGOs involved in blindness prevention, and through them to
- Hospitals providing services, and through them to
- Communities and patients in developing countries
- World Health Organization
- International Agency for the Prevention of Blindness
- ...all contribute to our education and research agenda
- ...provide mechanisms for dissemination of results



# Epidemiological research

- How many people in the population have the condition of interest?
  - prevalence (now)
  - incidence (new)
- Who is most affected?
- Why do they have the condition?
- What can be done to prevent or treat it?



# Epidemiology of blindness in children



# Challenges of research in developing countries

- Weak health systems: data not routinely collected
- More than one service provider
- Lack of subspecialty ophthalmology
- Not a research culture
- Lack of research active institutions / individuals
- Research not a priority when needs are so great
- Impact of other research agendas e.g. HIV/AIDS; TB



# Researching blindness in children

- Children do not complain
- They do not like to be examined
- Communication is difficult
- ....standard methods cannot be used
- Blindness is rare so large studies are needed



# Other approaches/sources used

## ➤ Prevalence:

- population based surveys
  - designed for other conditions
- key informant method

## ➤ Causes:

- schools for the blind
- rehabilitation programs
- key informant method



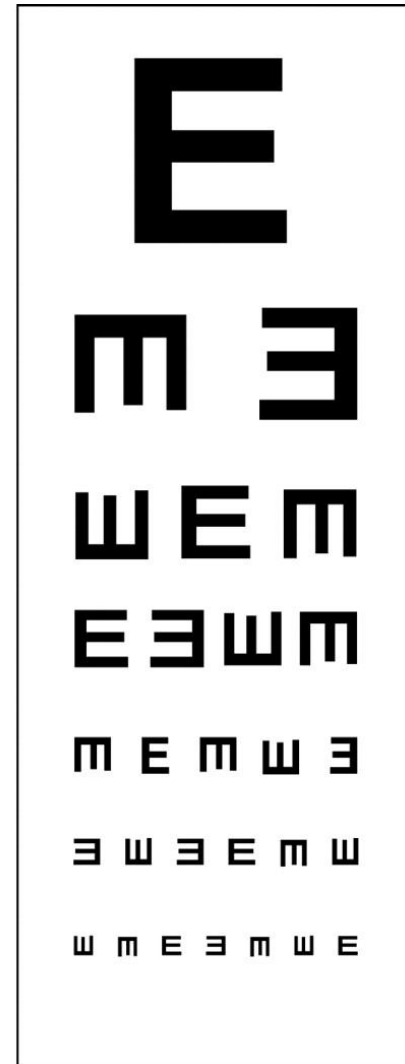
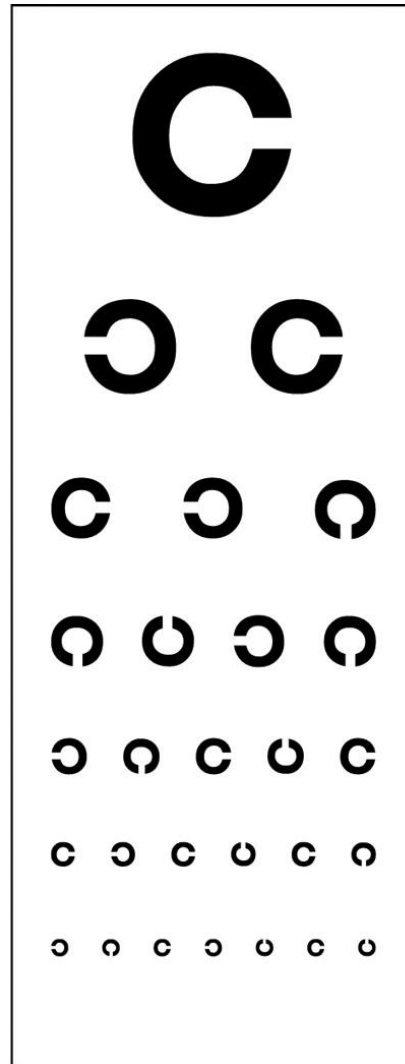
# Definitions

- Childhood: 0-15 years
- Blindness:  $<3/60$  in better eye
- Severe impairment:  $<6/60$  in better eye

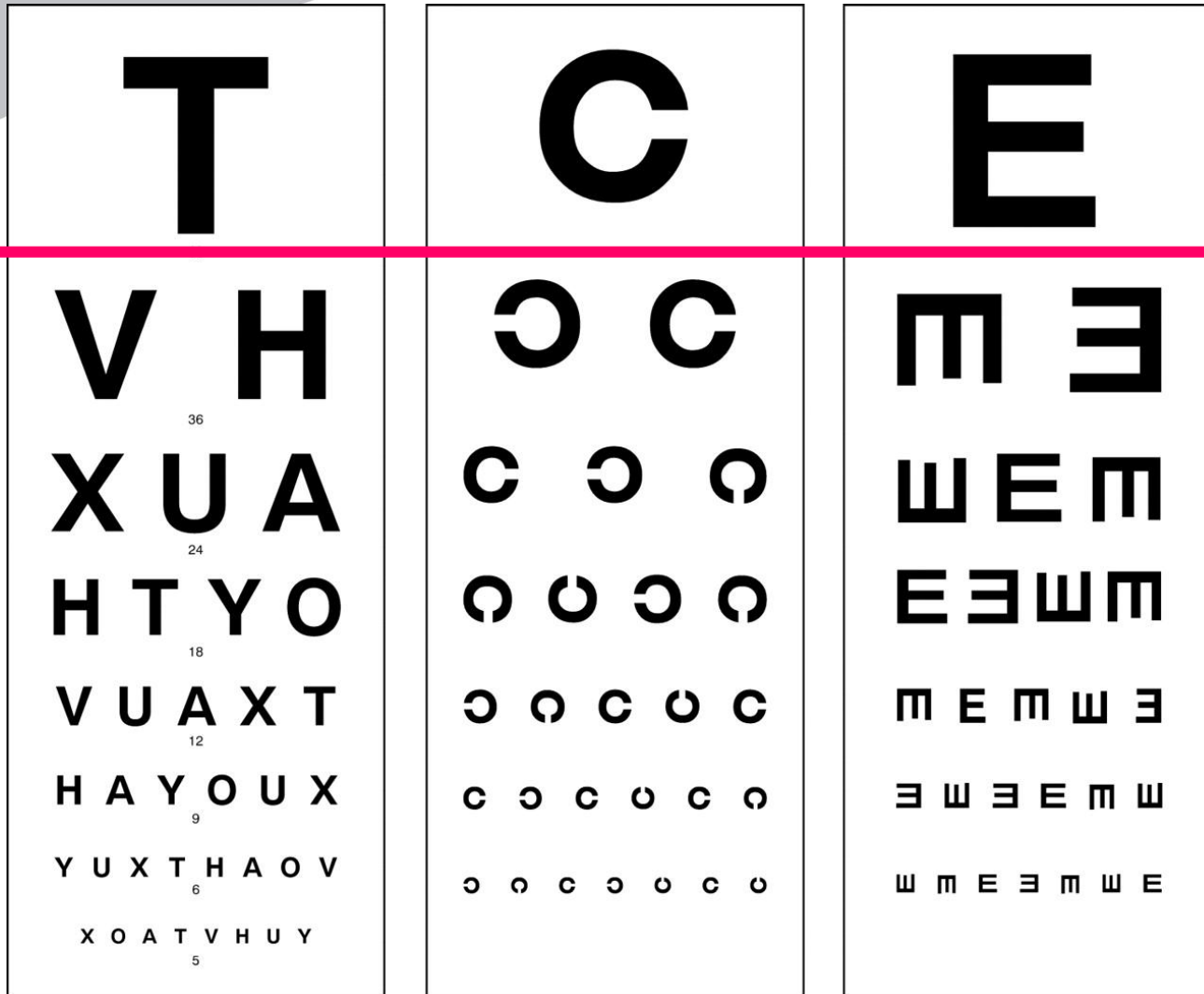




# Visual acuity charts



# Visual acuity charts

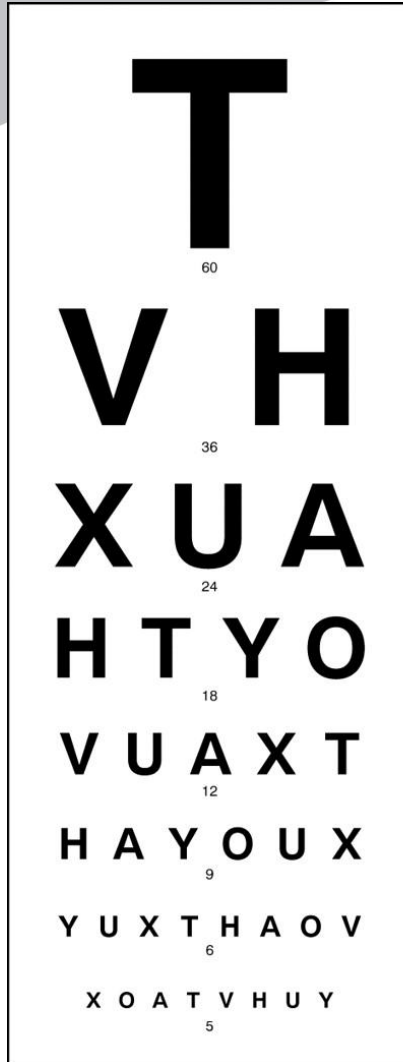


Blind <math><3/60</math>:  
cannot see top  
letter at 3 ms in  
the better  
seeing eye

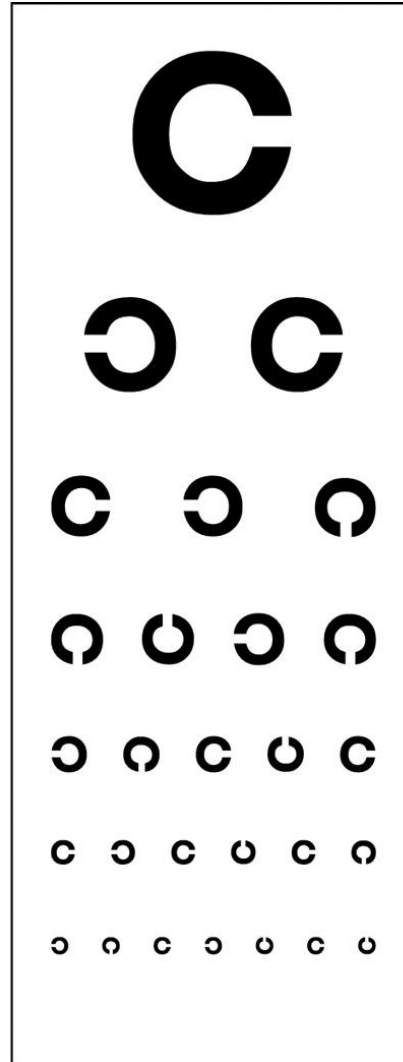


# Visual acuity charts

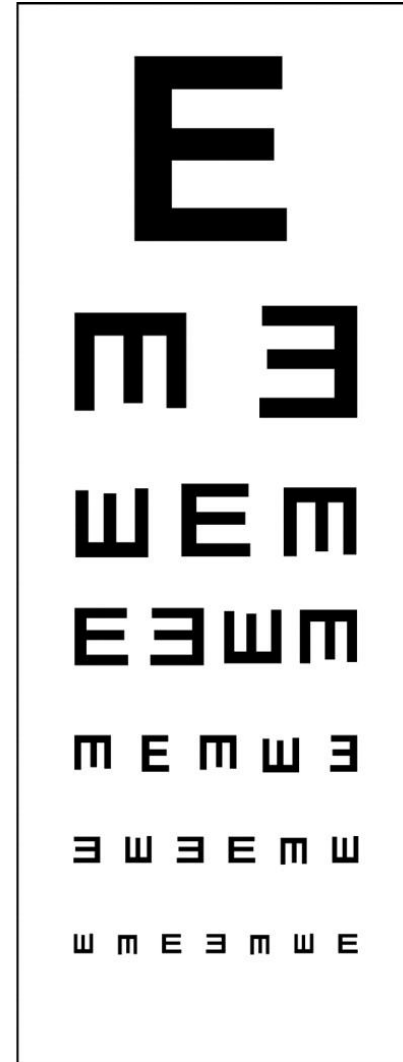
10+ years



5+ years



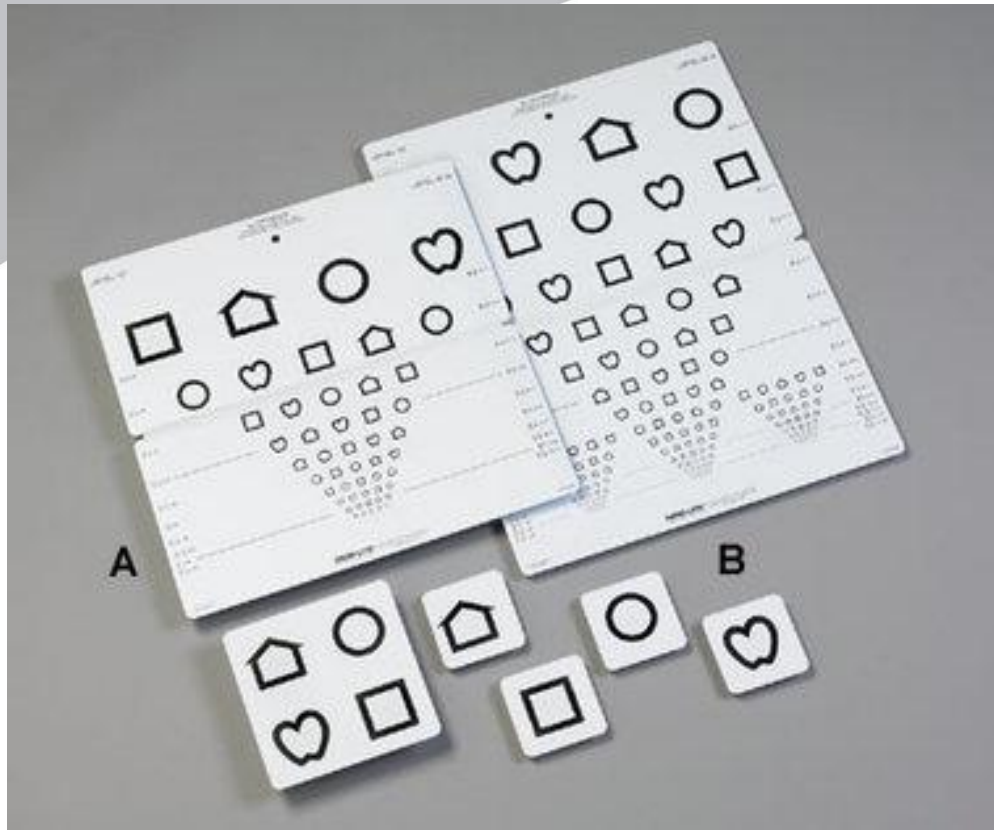
5+ years



Age at which children can be tested using standard charts



# Testing vision in young children: different tests are needed.....



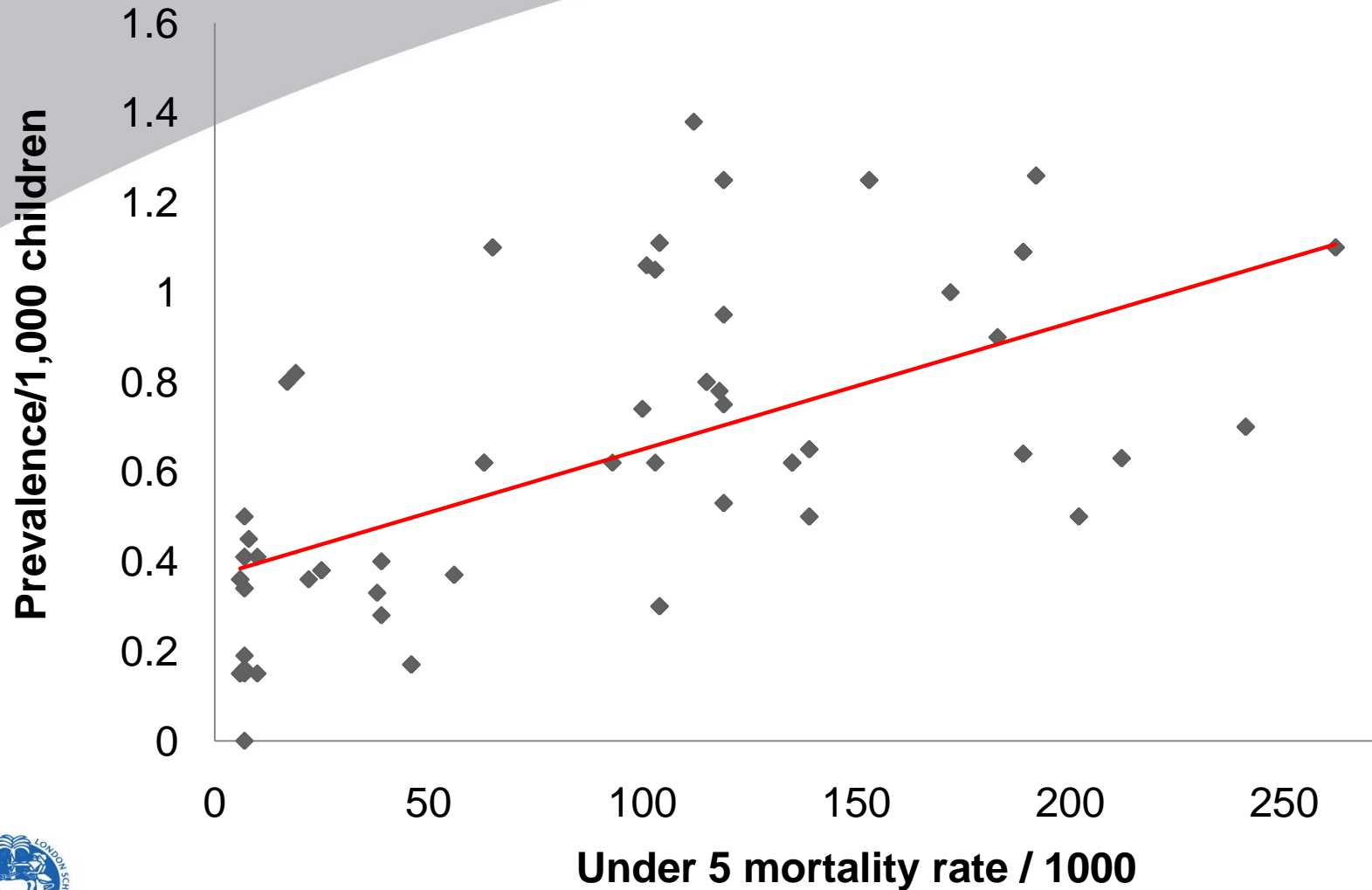
....and lots of toys



# What do we know about the epidemiology of blindness in children?



# Available data on the prevalence of blindness, by under 5 mortality rate



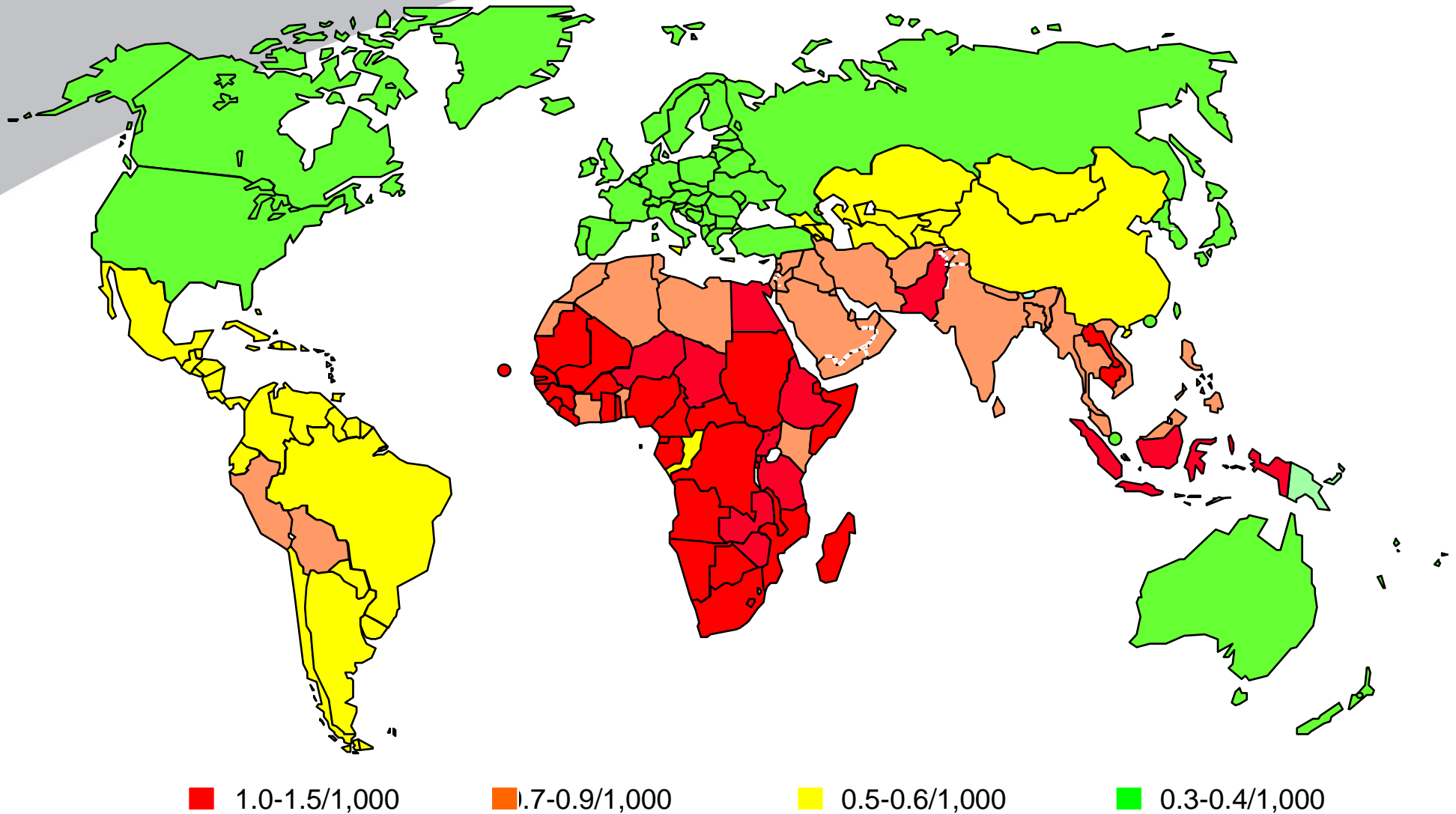
# Under 5 mortality rates as a proxy for blindness in children: rationale

- Under 5 mortality rates reflect
  - poverty and social determinants of health
  - female education
  - access to services which prevent blindness and mortality e.g.
    - measles immunization
    - vitamin A supplementation
  - Being used to predict whether vitamin A deficiency is a public health problem

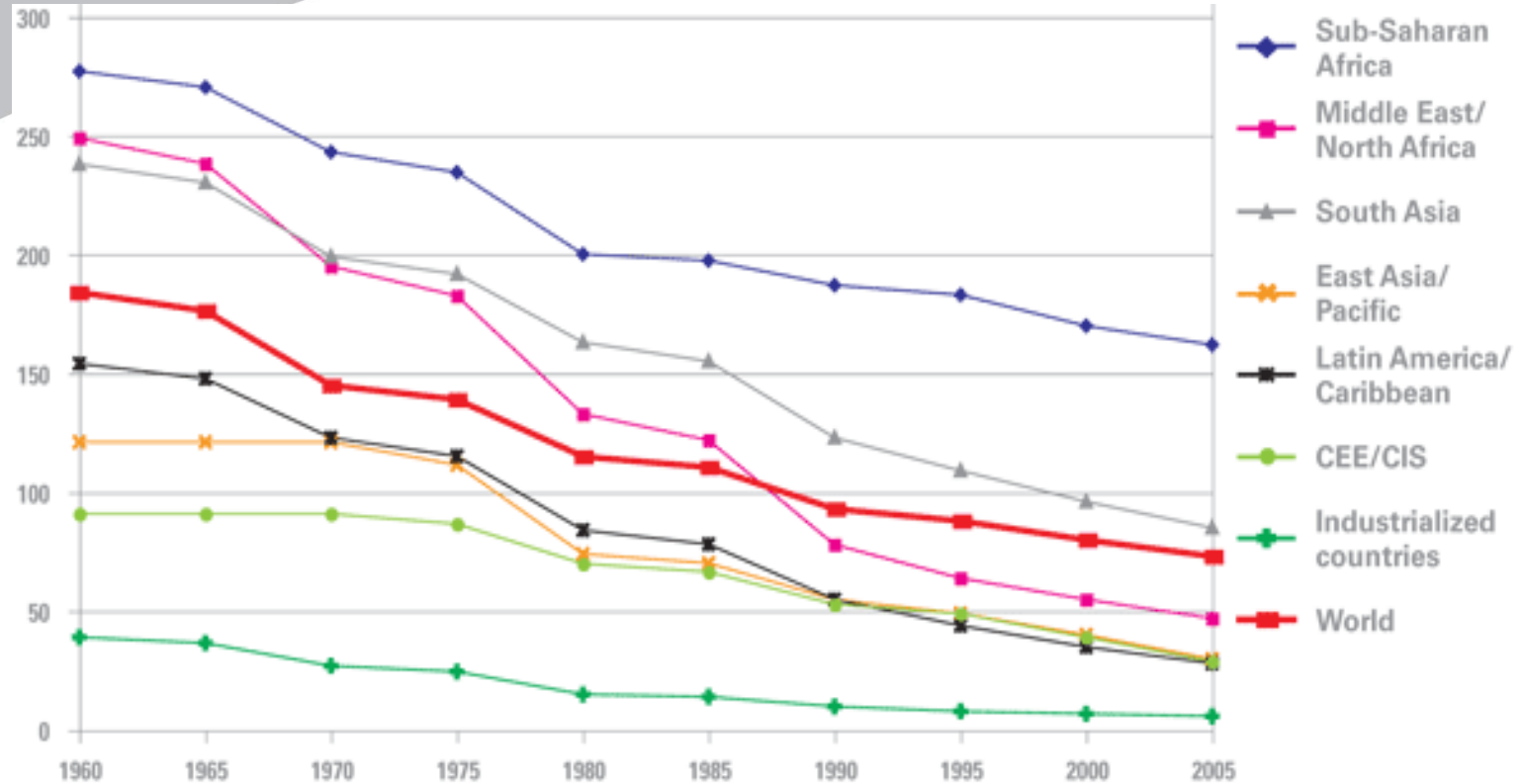




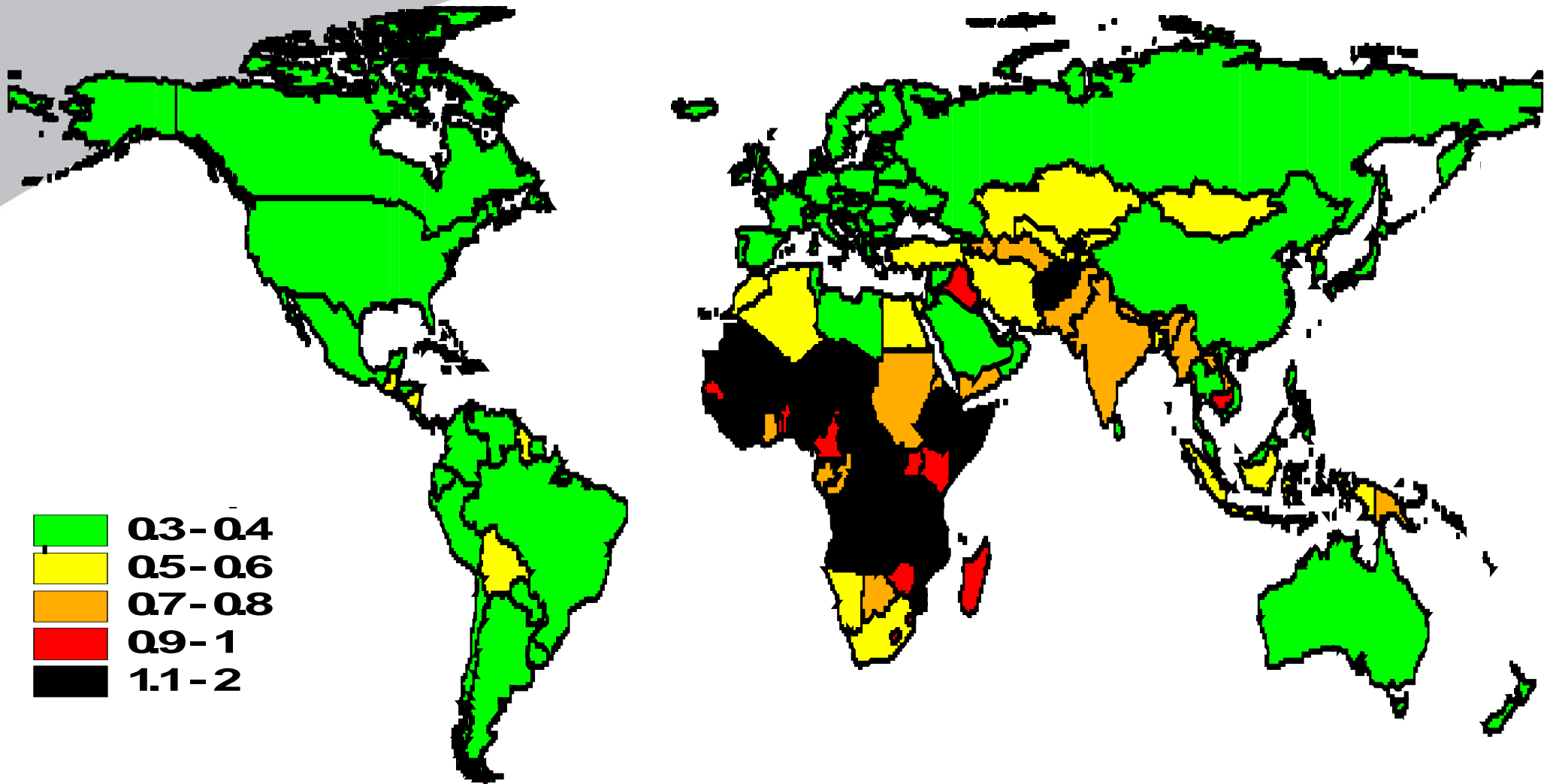
# Prevalence of blindness in children: using under 5 mortality rates 1999 estimate



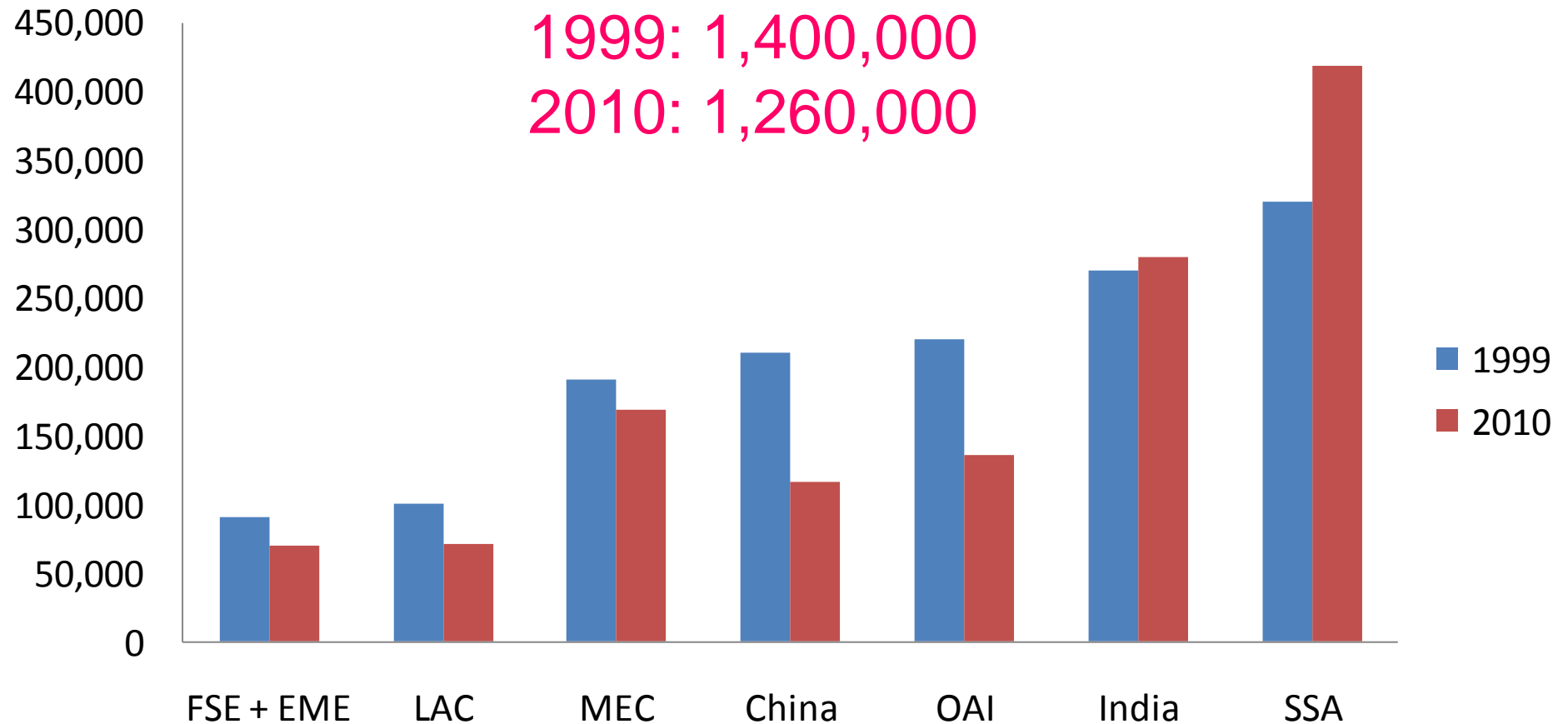
# Under 5 mortality rates are declining



# Prevalence of blindness in children: using under 5 mortality rates 2010 estimate



# Magnitude estimates in 1999 and 2010, by World Bank region



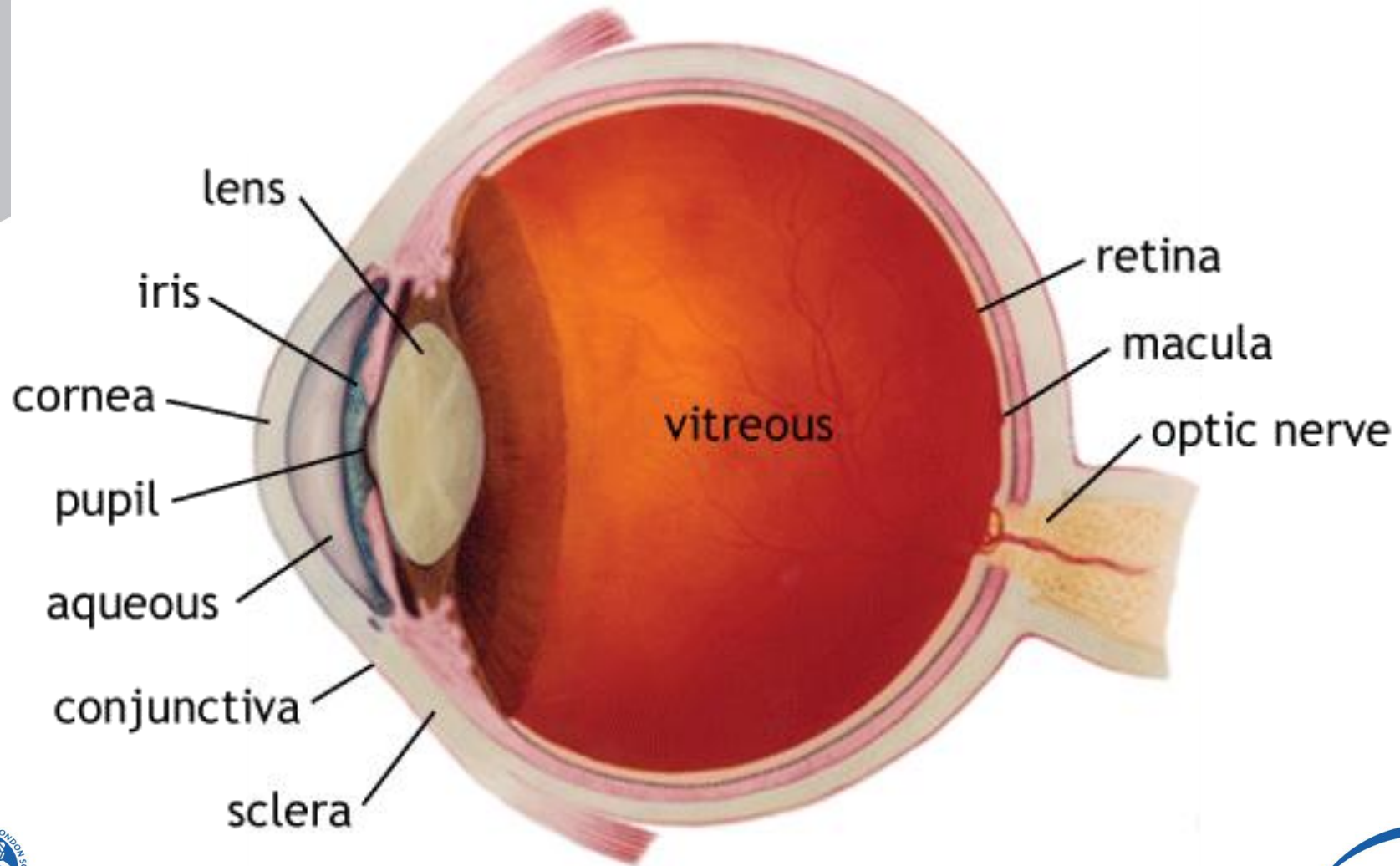
# Causes of blindness in children

## Classification system:

- Developed by ICEH in 1993
- Adopted by WHO
- Anatomical site of abnormality
  - site in visual pathways most affected
- Aetiology
  - time of onset of condition



# Parts of the eye



# Cause by time of onset: life-course approach



**Adolescence**



**Pregnancy**



**Delivery**



**Neonate**



**Childhood**

# Cause by time of onset: life-course approach



## Adolescence

Genetic conditions



## Pregnancy

Infections; genes controlling eye development



## Newborn

Brain damage



## Neonate

Conjunctivitis of the newborn; if premature, ROP



## Childhood

Corneal scarring: VADD / measles / TEM; refractive errors; injury; infections



# Complex range of interventions and strategies needed for control: from community through to tertiary level



## Adolescence

Genetic conditions



## Pregnancy

Infections; genes controlling eye development



## Newborn

Brain damage



## Neonate

Conjunctivitis of the newborn; if premature, ROP



## Childhood

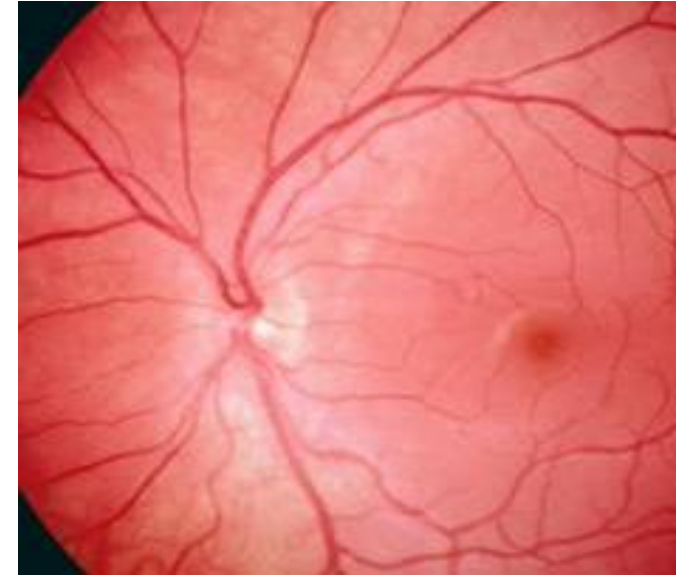
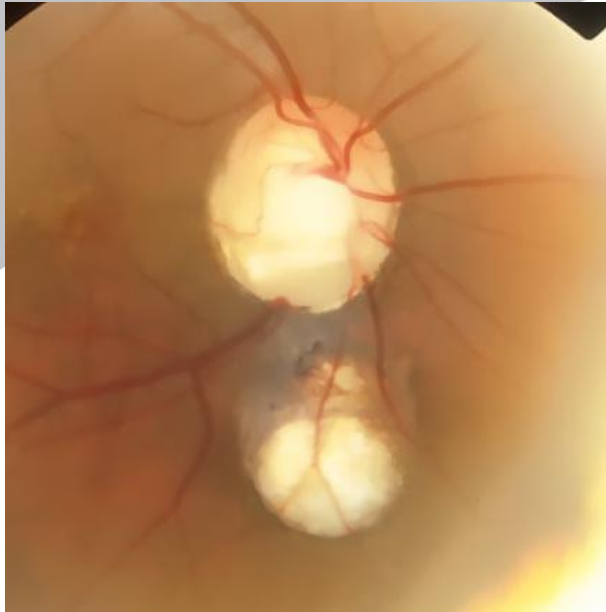
Corneal scarring: VADD / measles / TEM; refractive errors; injury; infections

# Causes of blindness in children

- Data on 32,000 children from 43 countries
- Marked variation in the major causes



# Magnitude and causes: rich communities



10 million

20% 0-15 = 2 mill

Prev = 0.3/ 1,000  
**600 blind**

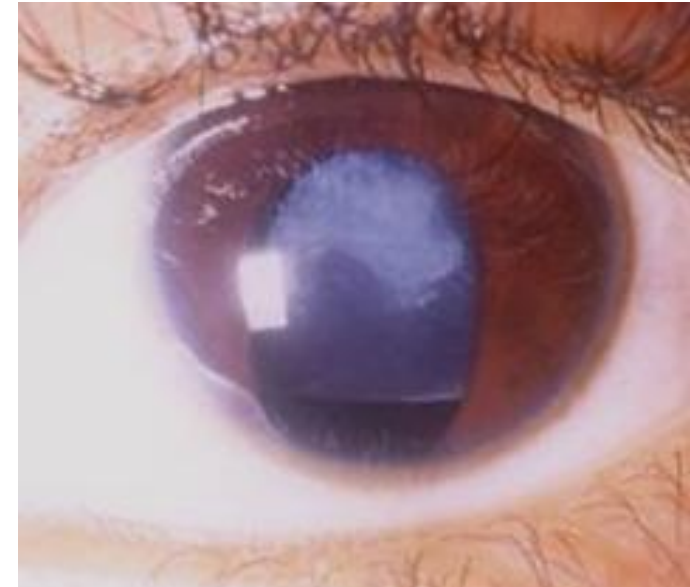
Scar 0%

Cat/gl 10%

ROP 10%

**Others 80%**

# Magnitude and causes: middle income



10 million

30% 0-15 = 3 mill

Prev = 0.6/ 1,000  
**1,800 blind**

Scar 0%

Cat/gl 20%

**ROP 25%**

**Others 55%**

# Magnitude and causes: poor communities



10 million

40% 0-15 = 4 mill

Prev = 0.9/1,000  
**3,600 blind**



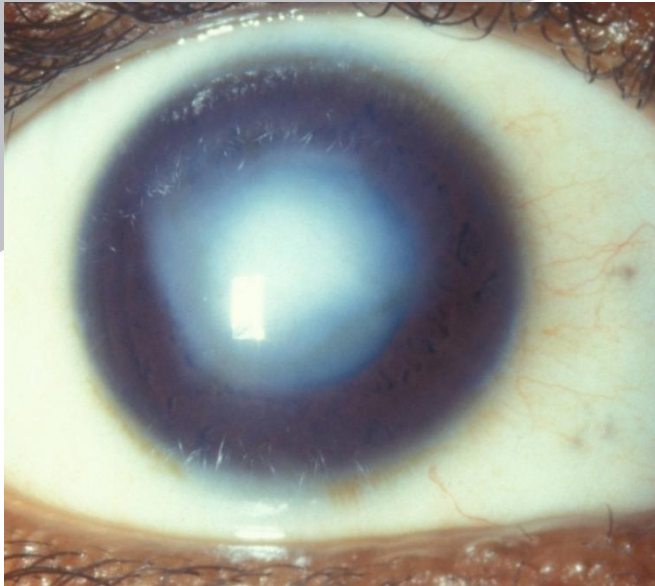
**Scar 20%**

**Cat/gl 20%**

ROP 0%

Others 60%

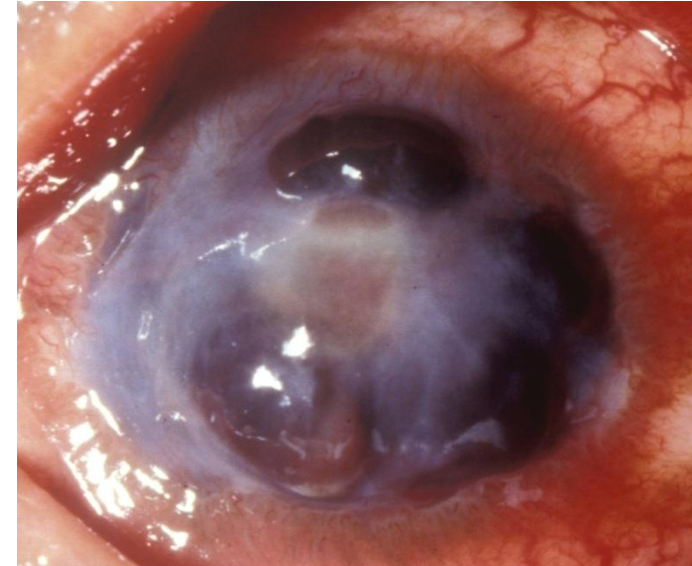
# Magnitude and causes: very poor African countries



10 million

50% 0-15 = 5 mill

Prev = 1.2/1,000  
**6,000 blind**



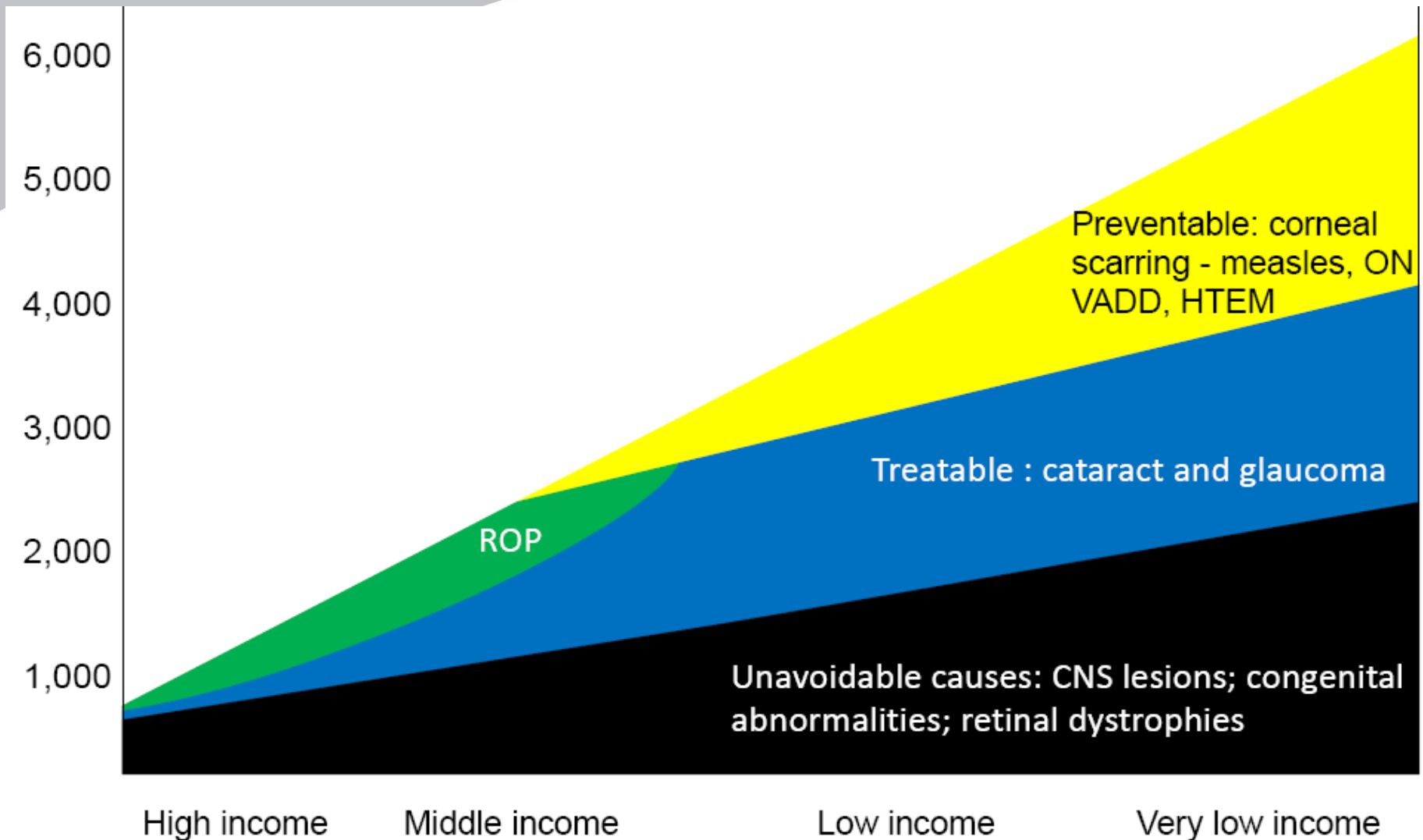
**Scar 50%**

**Cat/gl 15%**

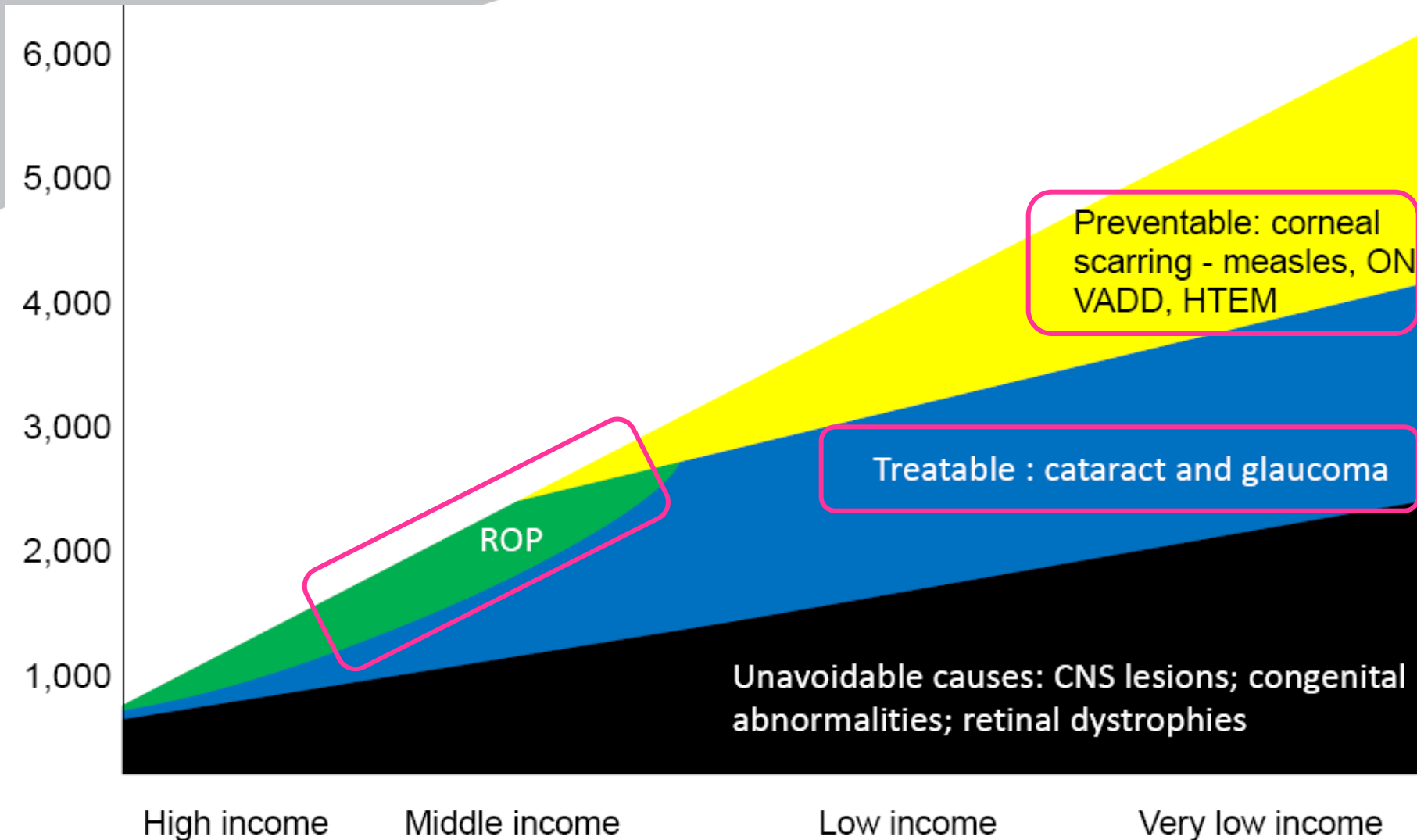
ROP 0%

Others 35%

# Number of blind children/10 million pop, by cause and level of development

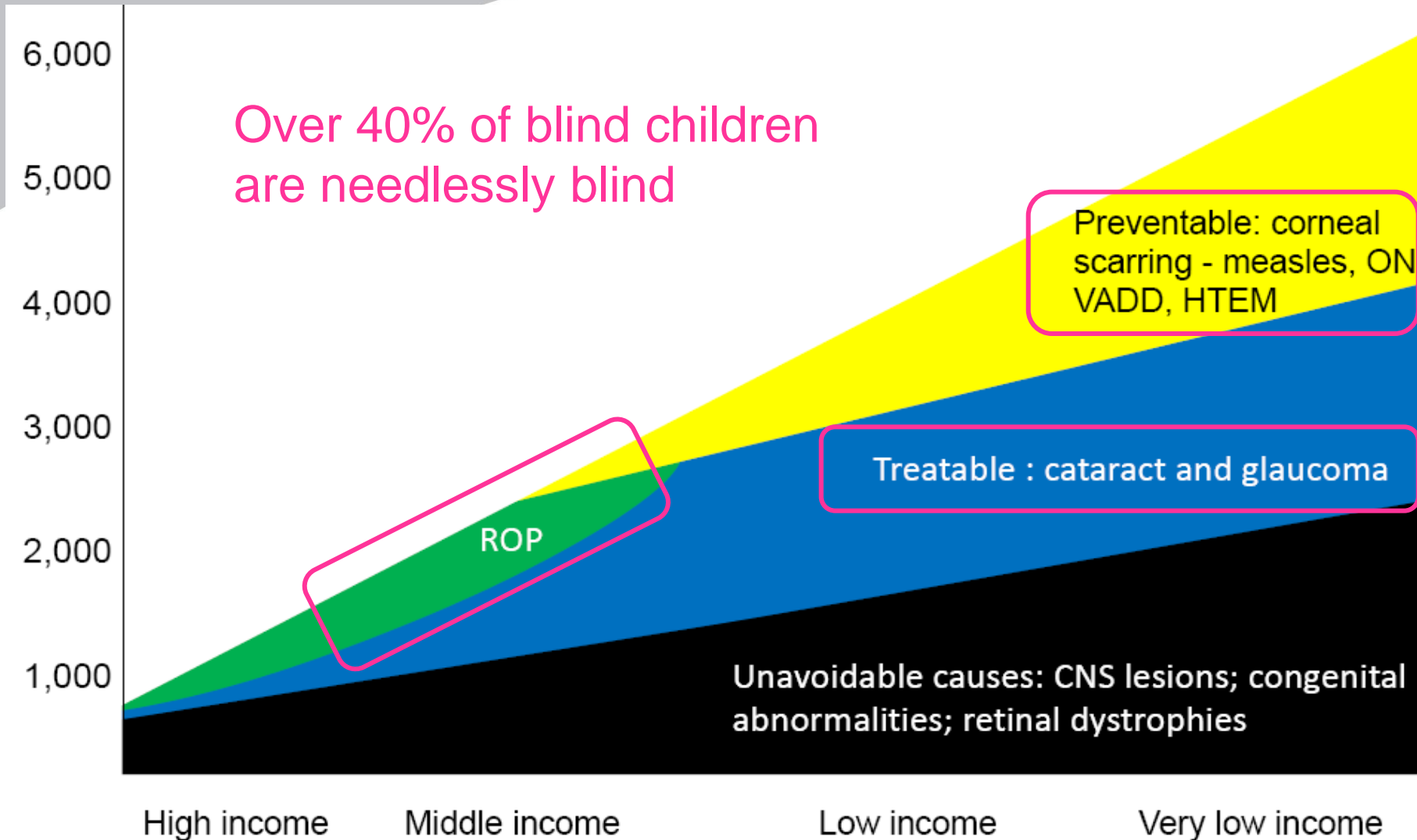


# Main avoidable causes





# Main avoidable causes



# Impact of blindness in childhood

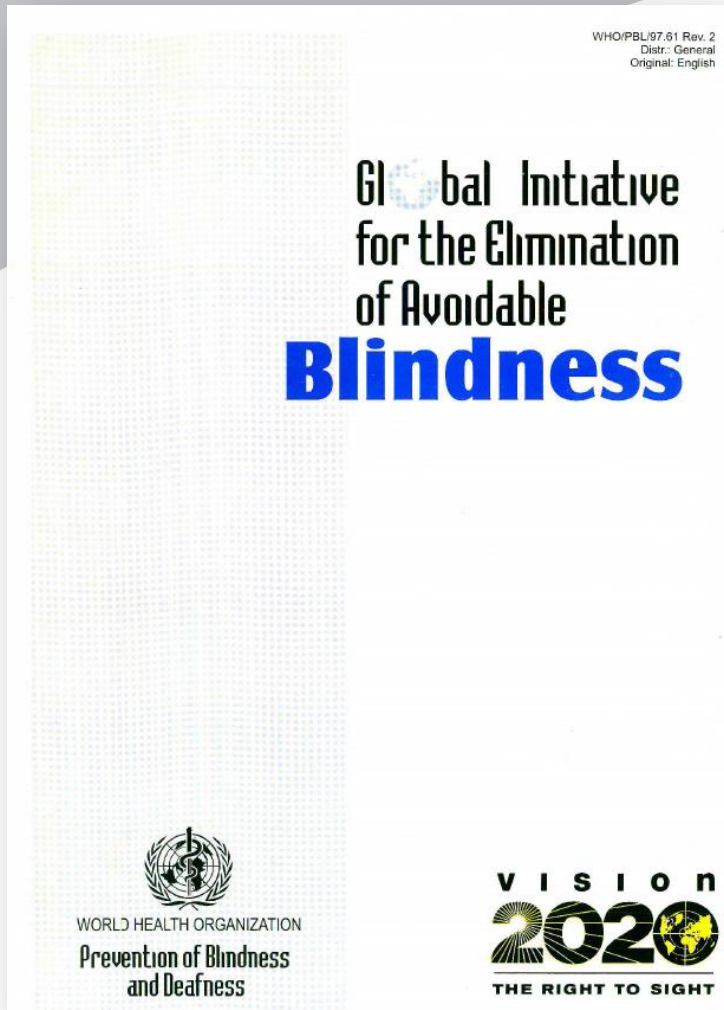
- Can have profound consequences on the child, their family and community
  - developmental delay
  - no schooling
  - family breakdown
  - loss of income



What is being done about it?



# VISION2020: The Right to Sight



- Global initiative for the elimination of avoidable blindness by 2020
- Launched in 1999
- Childhood blindness is a priority....

16

**Cause: CHILDHOOD BLINDNESS**

**Aim:** To eliminate avoidable causes of childhood blindness



WORLD HEALTH ORGANIZATION  
Prevention of Blindness and Deafness

WHO/PBL/00.77  
Distr.: General  
Original: English



WORLD HEALTH ORGANIZATION  
Prevention of Blindness and Deafness

WHO/PBL/00.77  
Distr.: General  
Original: English

## Preventing blindness in children

Report of a WHO/IAPB scientific meeting

Hyderabad, India, 13-17 April 1999



WORLD HEALTH ORGANIZATION  
Prevention of Blindness and Deafness  
Geneva, Switzerland

INTERNATIONAL ALLIANCE  
FOR THE PREVENTION OF BLINDNESS  
HYDRABAD, INDIA

# Preventing blindness in children

Report of a WHO/IAPB scientific meeting



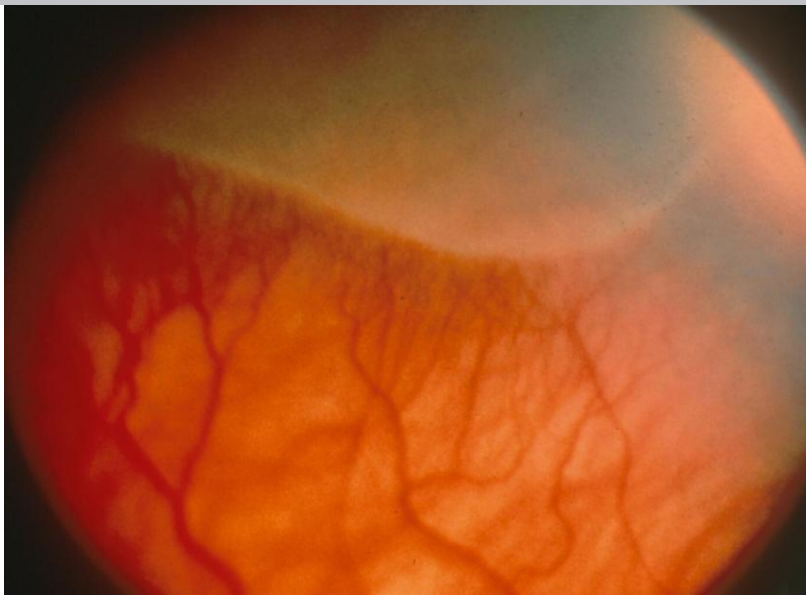
# How research has strengthened programmes and influenced policy

- Retinopathy of prematurity (ROP) in Brazil and Latin America
- Childhood cataract in Bangladesh

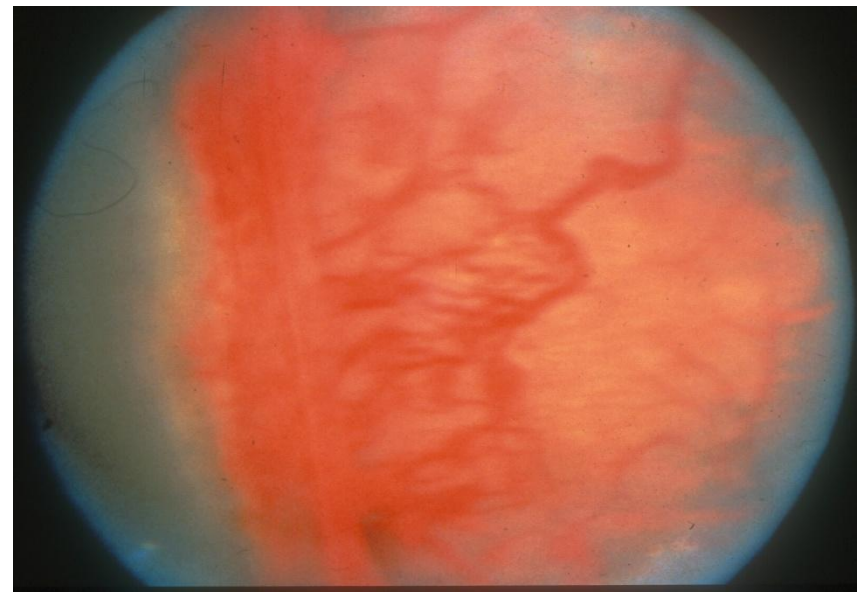


# Retinopathy of prematurity (ROP)

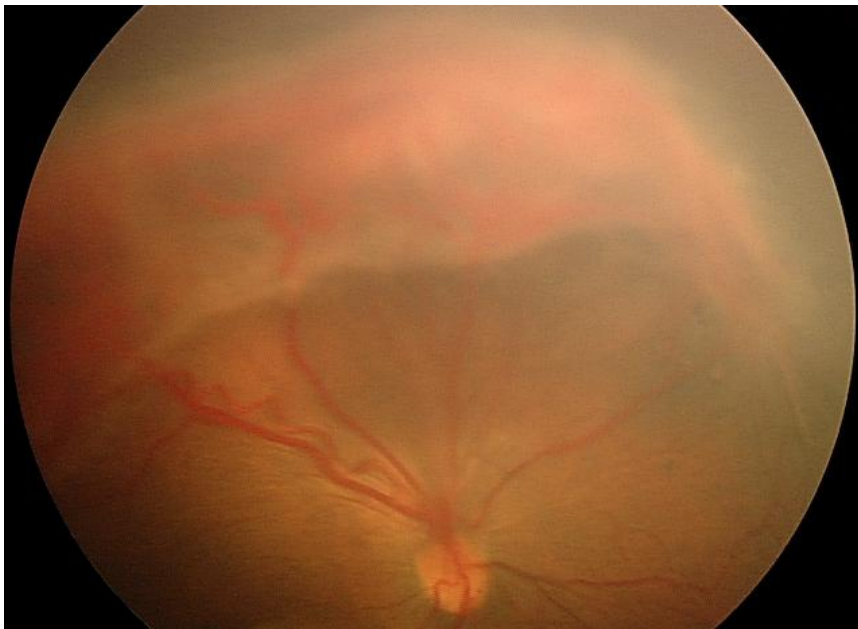




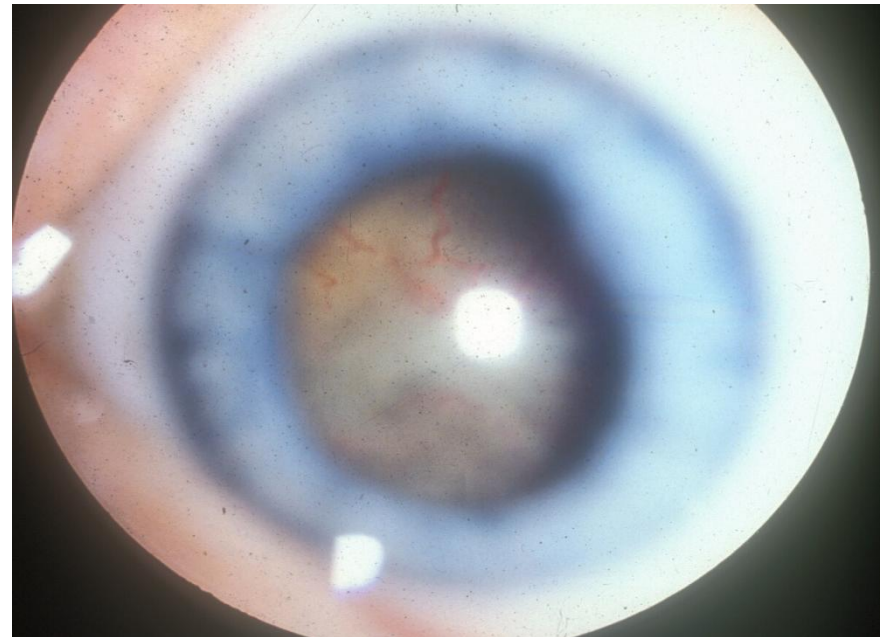
Stage 2: ridge



Stage 3: vascular ridge



Stage 4: subtotal detachment



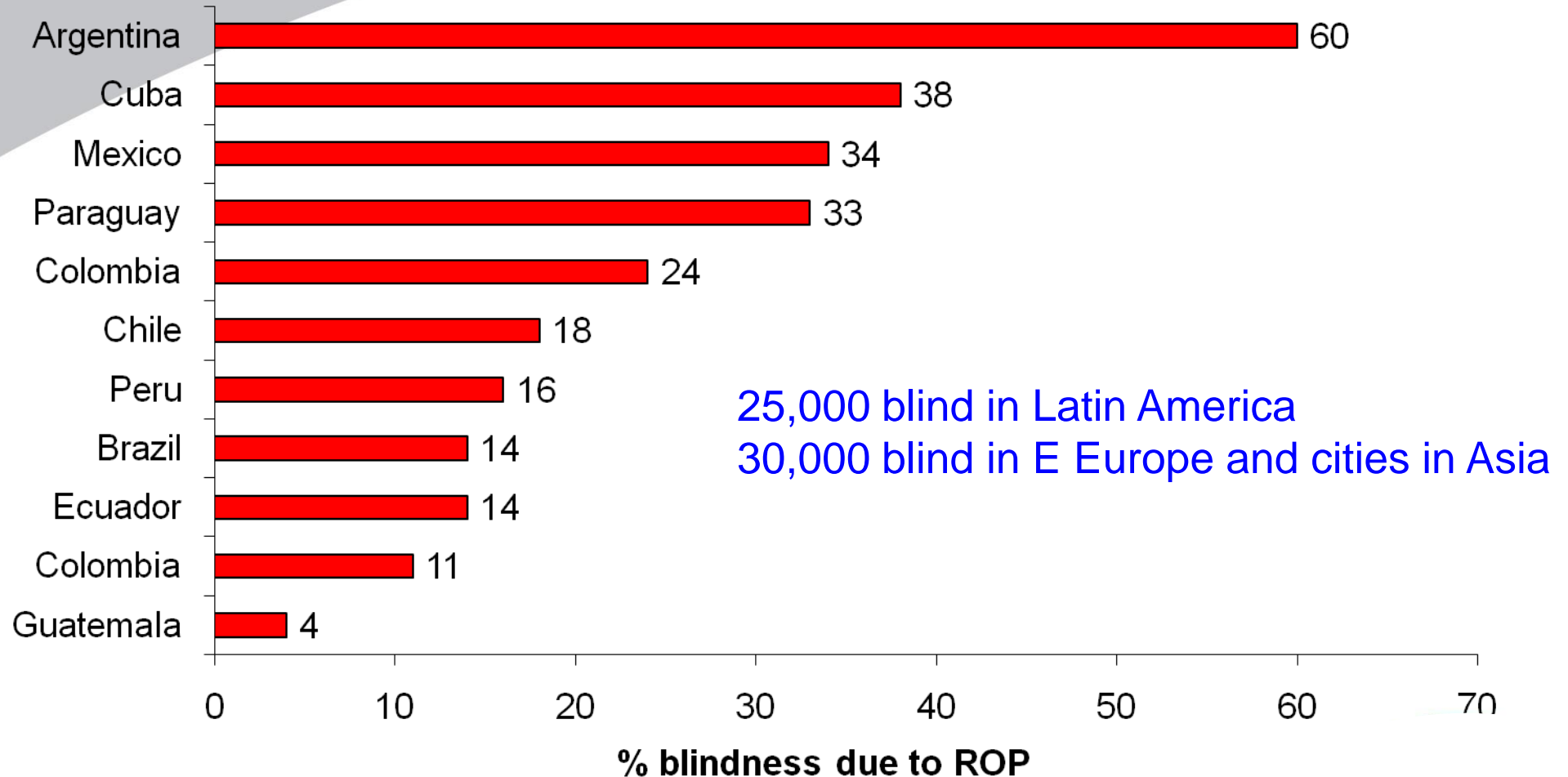
Stage 5: Total detachment



# Examining children in Chile...



# ROP as a cause of blindness in Latin America (%)



# Risk factors for ROP

- Prematurity, prematurity, prematurity!
- But also:
  - inadequately controlled oxygen
  - infection
  - poor early weight gain
- Inadequate services
  - poor staff numbers
  - poor training and low motivation
  - inadequate equipment

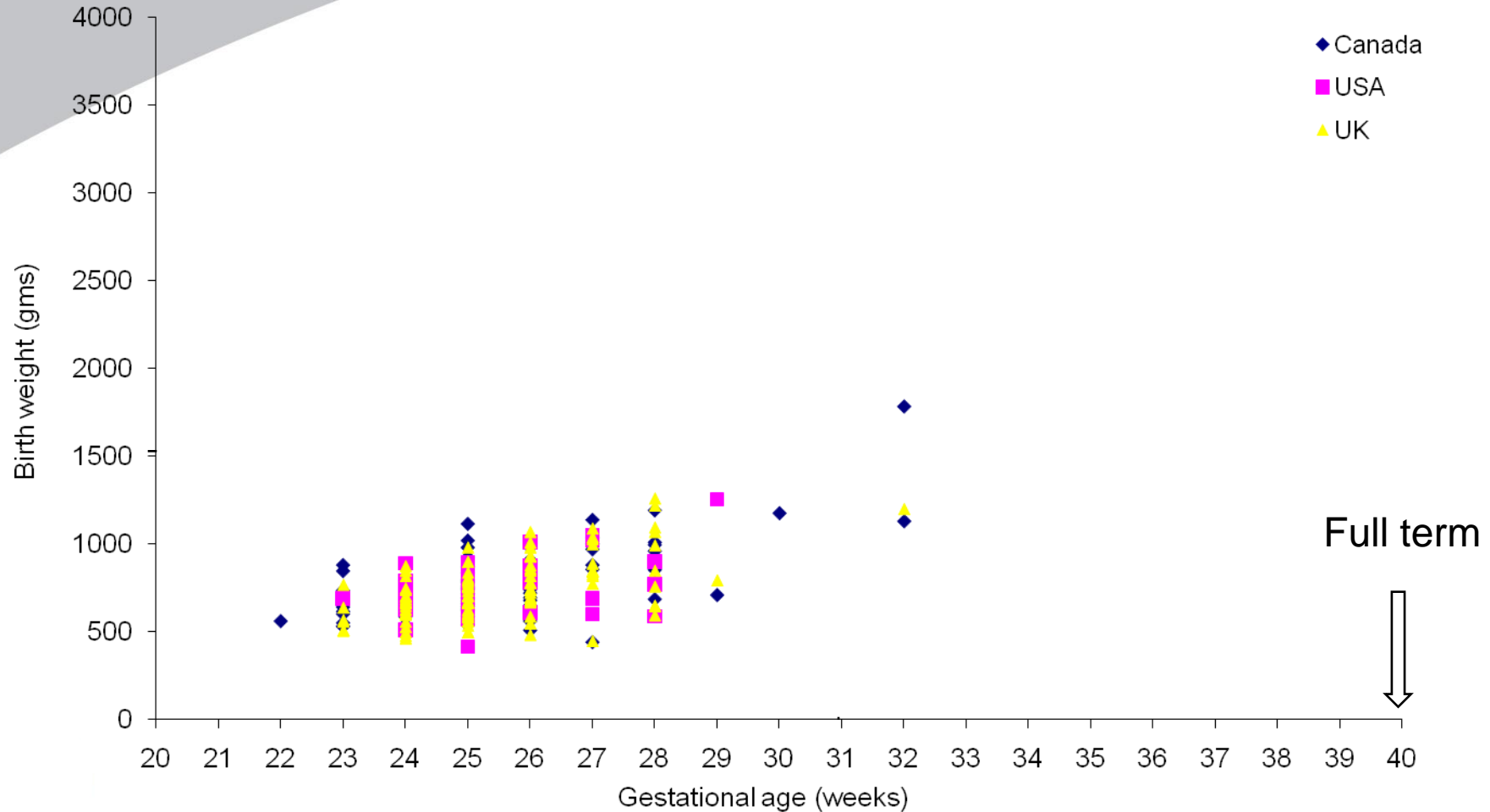


# Prevention of blindness from ROP

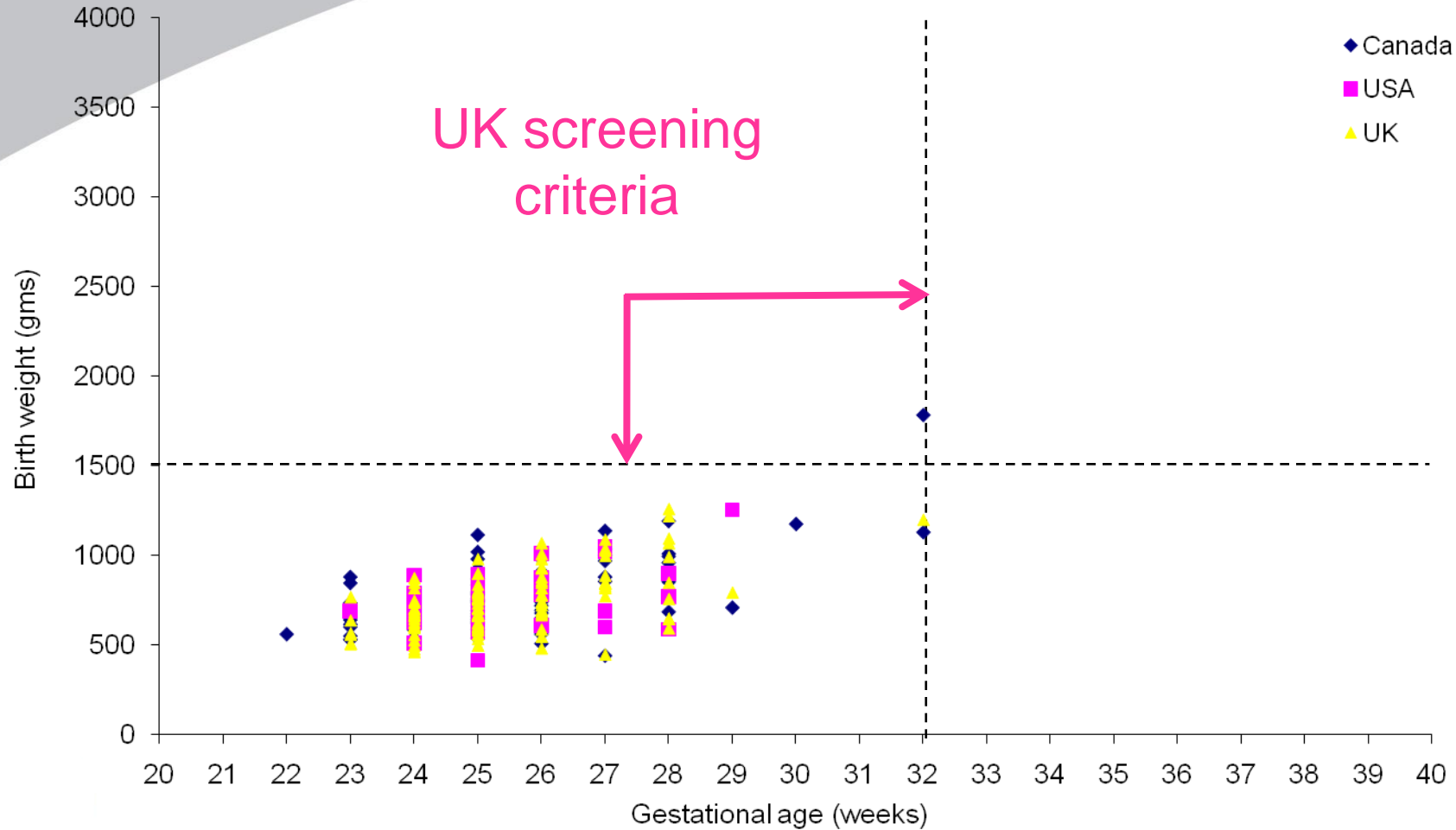
- Prevent preterm birth (2% in L America)
- Antenatal steroids
- Excellent neonatal care
- Screening of premature babies at risk by eye doctors
  - treat those with advanced disease by laser
  - highly effective at preventing blindness
- ? Which babies should be examined



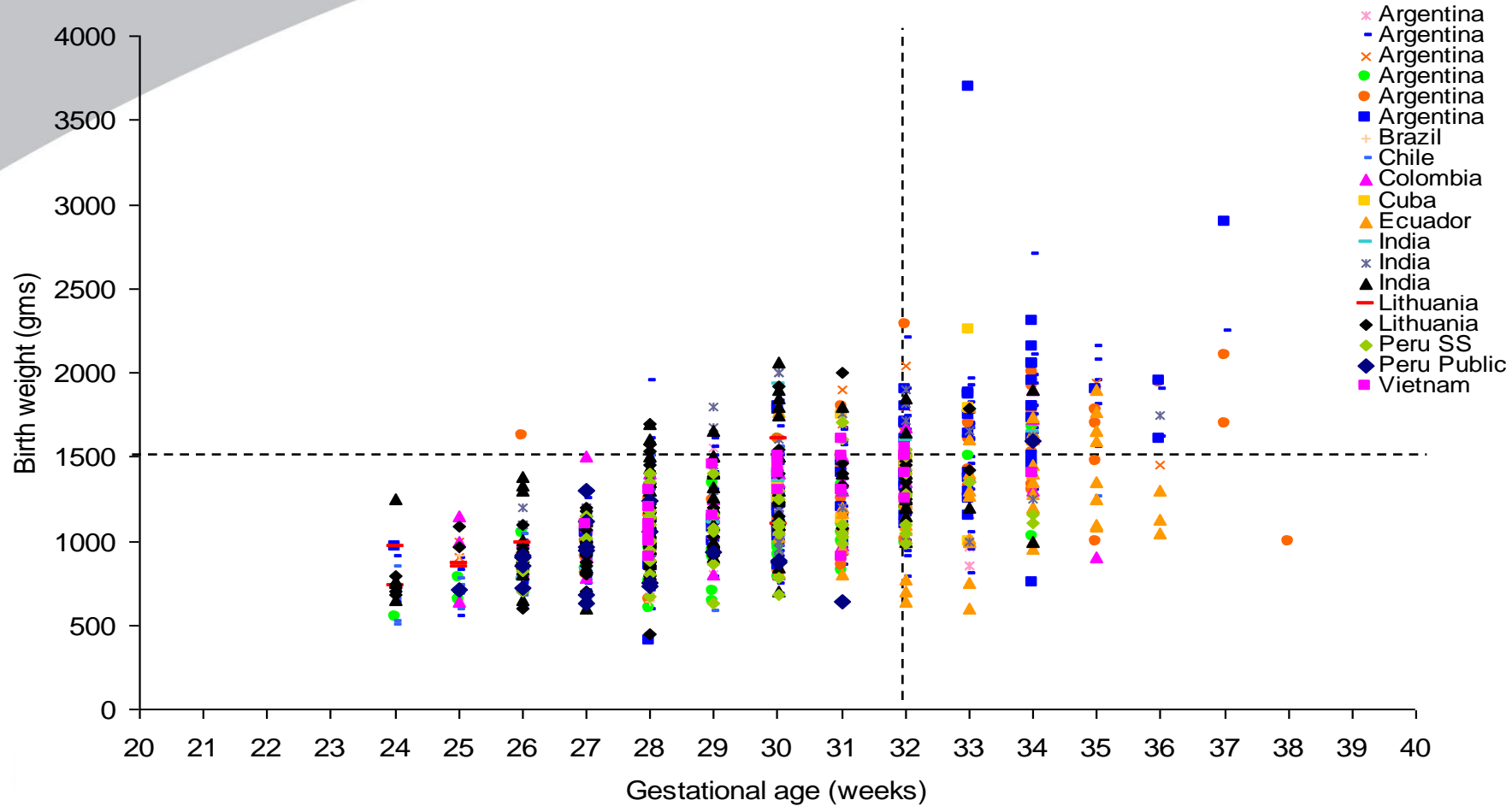
# Characteristics of babies with “severe” ROP in UK, USA and Canada



# Characteristics of babies with “severe” ROP in UK, USA and Canada



# Characteristics of babies with “severe” ROP in low/middle income countries



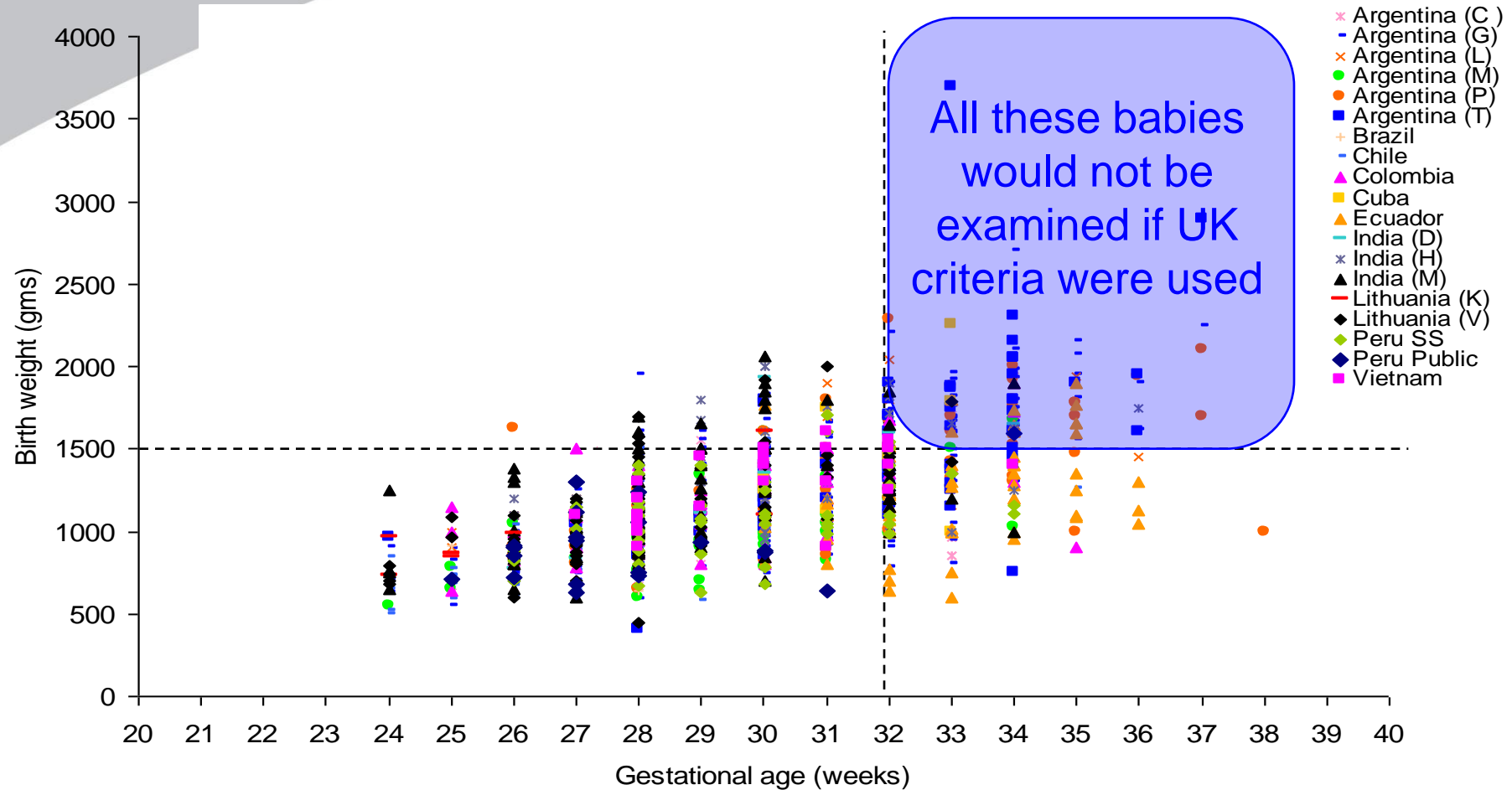


Varying neonatal care in India  
- variation in exposure to risk  
factors for ROP

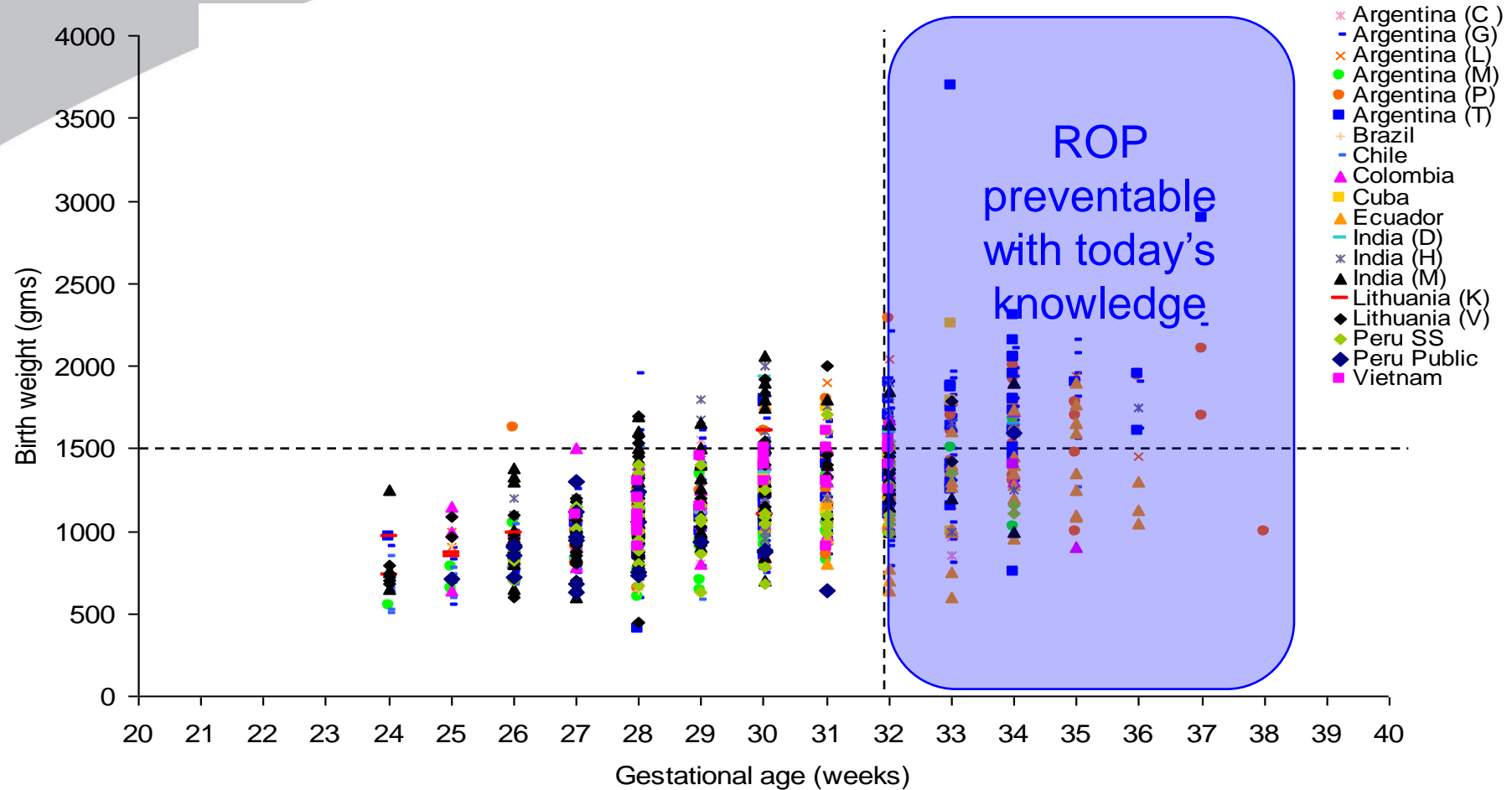




# Implications of variability in babies at risk in low / middle income countries



# Implications of variability in babies at risk in low / middle income countries





# Two projects in Rio de Janeiro

## Questions:

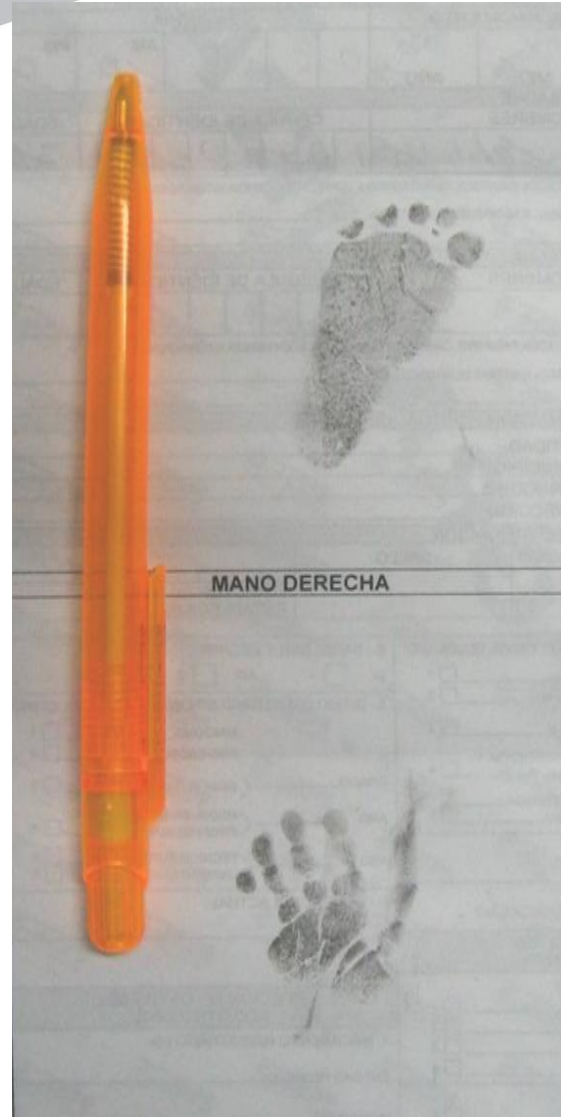
- Which criteria should be used in Brazil for eye examination?
- Can ROP be prevented by increasing the knowledge and skills of nurses?



# Dr Zin examined preterm babies in the 7 largest units in Rio de Janeiro



# Almost 4,000 babies were examined over 30 months



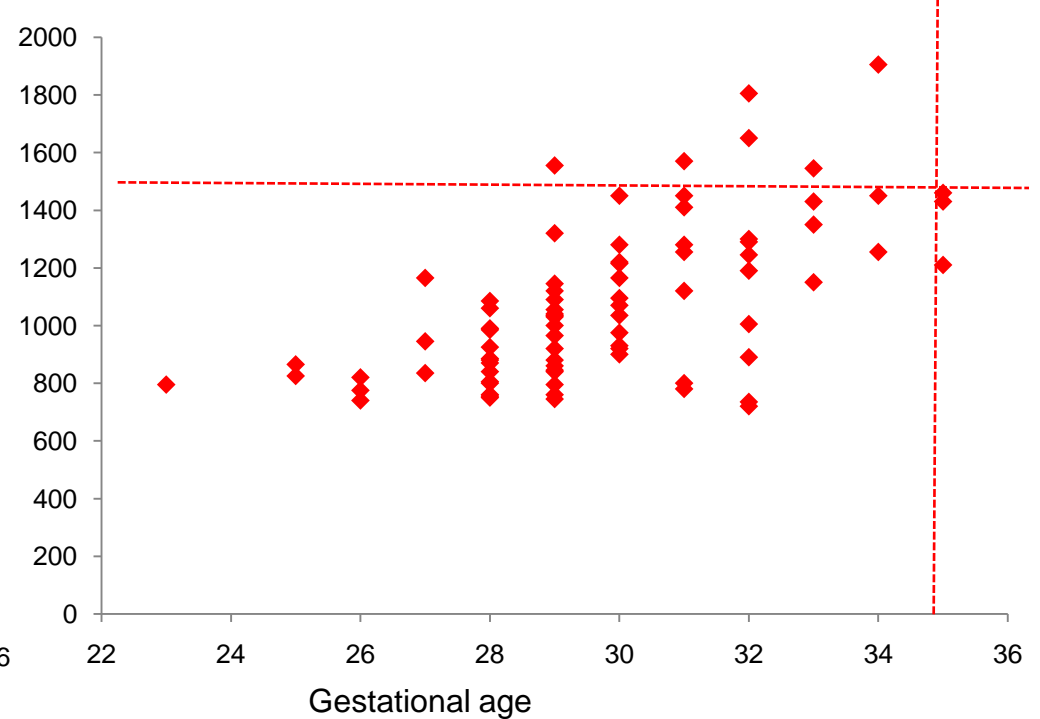
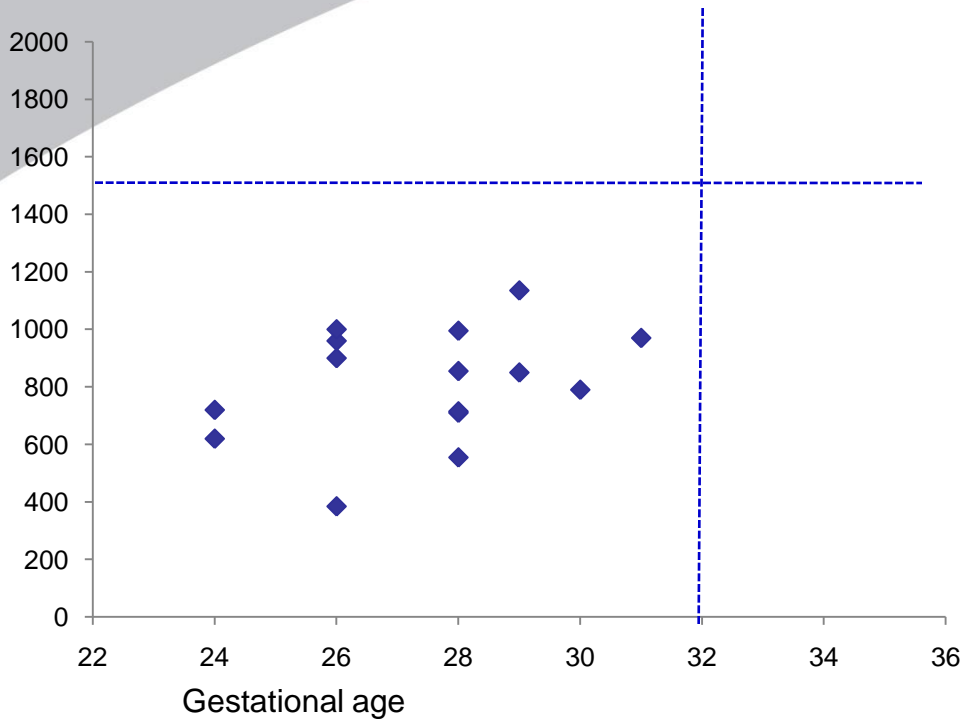
.....some were very  
small indeed

# Characteristics of treated babies

## Survival of <1500g babies

2 units high survival

5 units low survival

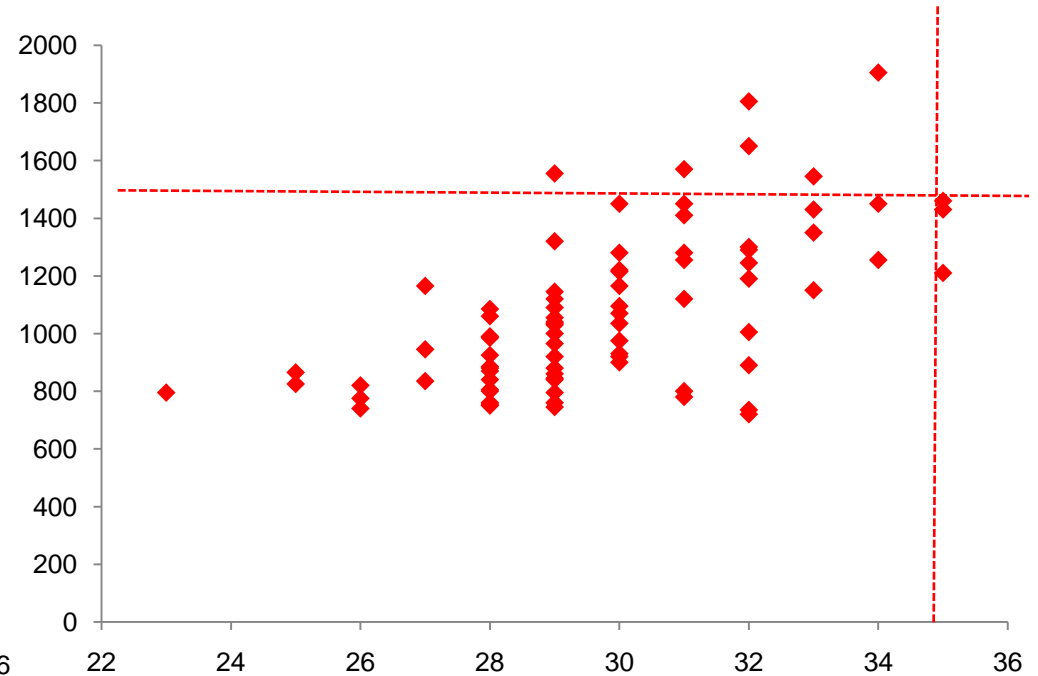
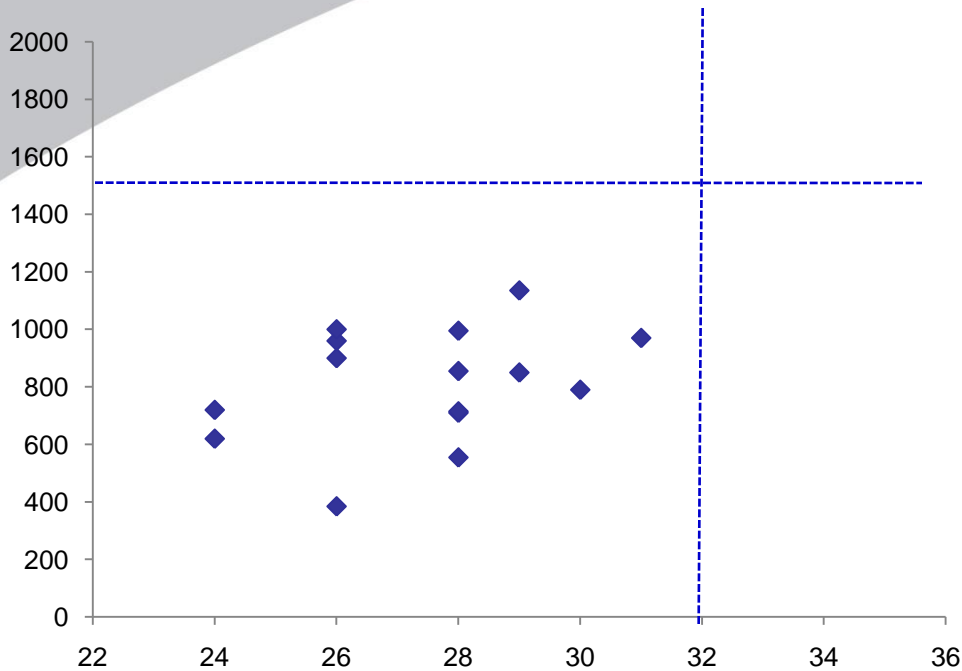


# Characteristics of treated babies

## Survival of <1500g babies

2 units high survival

5 units low survival



Criteria:  $\leq 1500\text{g}$  or <32 weeks

Criteria:  $\leq 1500\text{g}$  or <35 weeks





# Workload implications of different criteria

- Applying the wide criteria to all units ( $\leq 1500\text{g}$  and  $\leq 35$  weeks):
  - 20% more babies to be examined but only
  - 12% more examinations



# POINTS of Care study (PoC)

## ➤ Question:

- Does training nurses and providing minimal essential equipment improve neonatal outcomes, including ROP?

## ➤ Methods:

- 1 year pre-intervention data collection
- POINTS of Care training of nurses and equipment
- 1 year follow up data collection



# POINTS of care intervention in 6 units in Rio de Janeiro



Pain

Oxygen

Infection

Nutrition

Temperature

Supportive care



# Preliminary results

- No change in ROP or other outcomes
- BUT better nurse practices e.g.
  - monitoring oxygen: 23% correct before training  
52% correct after training
- Exploring reasons:
  - internal “brain drain” of neonatologists and nurses due to staff shortages outside urban areas



# Programmes for ROP in Latin America

In 1997:

- No awareness that ROP was a major cause of blindness
- Workshop in Chile:
  - only a handful of ophthalmologists screening in 2 countries in the region



# Situation now in Latin America

- >30 workshops over last 12 years
- National guidelines and committees in many countries; programmes in virtually all
- NGO support for training, equipment and treatment
- Government policies in Chile, Argentina, Brazil and Peru making examination of preterm babies essential
- PAHO: control of ROP blindness the 2<sup>nd</sup> Goal in the blindness prevention strategy for the region.....

## **GOAL 2: REDUCE BLINDNESS AND VISUAL IMPAIRMENT IN CHILDREN**

**Objective 2.1: Reduce blindness in premature babies due to retinopathy of prematurity (ROP)**

# ....and beyond

- Lithuania            2007            1<sup>st</sup> World ROP Congress
- India                    2009            2<sup>nd</sup> World ROP Congress
- China                    2012            3<sup>rd</sup> World ROP Congress
- National guidelines in China (2004) and India (2010) and programmes expanding
- Eastern Europe – a big challenge....





Baby treated in India:  
12 weeks premature;  
weighed 1.1 kg







# Childhood cataract in Bangladesh

## Questions:

- How many children are blind?
- What are main the causes of avoidable blindness?
- What can be done about it?



# Study undertaken by Dr Muhit

## Steps:

- Development/refinement of “key informant method”
- Applied to populations of 100,000 in all 64 districts
- Used to estimate prevalence
- Provided data on causes



# Training Key Informants: community volunteers



# Key informants identify children with eye/visual problems in the community



# Children identified by Key Informants examined in the community



# Children identified by Key Informants examined in the community





# Health education and counselling



# Cataract blind children referred for surgery



# Summary of findings

- 1,935 blind children examined
- Prevalence estimate:
  - 0.75/1,000 children
  - same as estimate using U5MR as a proxy
- Main causes:
  - unoperated cataract            31%\*
  - corneal scarring                27%
  - other causes                    42%
  - \* beliefs that blind children cannot be treated



# Estimates of numbers blind and causes

- 40,000 blind children in Bangladesh
- 12,000 from bilateral cataract
  
- In 2004
  - only 1 eye surgeon trained in paediatrics
  - only 3 centres could manage children, 2 in Dhaka
  - less than 300 child cataract operations/year



# Bangladesh Childhood Cataract Campaign: 2004-2010

- Collaborative project: Sightsavers, ORBIS etc
- Targets:
  - find 40,000 blind children
  - operate on 10,000 children with bilateral cataract
  - establish 8-10 Child Eye Care Centres
- Case finding approaches for whole country
  - 1. key informant method
  - 2. house to house visits by volunteers
  - 3. community based rehabilitation



# End of project evaluation (2010)

- 16 trained paediatric ophthalmologists
- 8 Child Eye Care Centres established
- 32,641 blind children found - 9,383 from cataract
- 24,500 cataract operations on children
- Awareness raised as many more children presenting for surgery















Back in  
action!



# Further studies using key informants

- **Blindness in children:**
  - Ghana, Iran and Malawi
- **Other disabilities in children:**
  - Bangladesh





## What next?

- Policy research for ROP in Latin America
- Evaluate the impact of integrating child eye health into government health systems
- Scaling up.....

# Acknowledgements

## Colleagues:

Ophthalmologists who examined children in schools for the blind

Andrea Zin + colleagues, Brazil

Brian Darlow + colleagues

M Muhit and CSF team

## Funding:

CBM

Sightsavers

Thrasher Medical Research Trust

Optimus Foundation

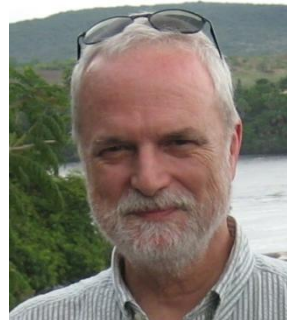
BDF New Life

Muslim Aid



# The NO-ROP International group









# The Great ICEH Team!

