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BJO Online First, published on August 30, 2017 as 10.1136/bjophthalmol-2017-310709

A worldwide survey of retinopathy of prematurity screening

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Received 23 May 2017
Revised 31 July 2017
Accepted 21 August 2017

ABSTRACT

Background To ascertain which countries in the world have retinopathy of prematurity (ROP) screening programmes and guidelines and how these were developed.

Methods An email database was created and requests were sent to ophthalmologists in 141 nations to complete an online survey on ROP screening in their country.

Results Representatives from 92/141 (65%) countries responded. 78/92 (85%) have existing ROP screening programmes, and 68/78 (88%) have defined screening criteria. Some countries have limited screening and those areas which have no screening or for which there is inadequate knowledge are mainly Southeast Asia, Africa and some former Soviet states.

Discussion With the increasing survival of premature babies in lower-middle-income and low-income countries, it is important to ensure that adequate ROP screening and treatment is in place. This information will help organisations focus their resources on those areas most in need.

BACKGROUND

Retinopathy of prematurity (ROP) is a vasoproliferative disorder that affects the developing retinal vessels of premature infants.[1] Appropriate screening of premature infants and subsequent treatment can substantially improve vision outcomes.[2] Babies who are born most premature or have associated neonatal morbidity are at the greatest risk of developing ROP.[3 4] ROP is an increasingly important cause of visual impairment and blindness in children worldwide with an estimated annual incidence (in 2010) of 20 000 children becoming ROP blind with a further 12 300 being visually impaired with the greatest number being in Southeast Asia.[5]

Because ROP is not an externally visible condition, screening programmes must be put in place in order to identify infants with the stages of the disease requiring treatment. Implementation of locally adapted screening and treatment guidelines in conjunction with improvements in the quality of neonatal care have minimised ROP-related blindness in high-income countries.[6]

Currently, the survival rate of premature babies in lower-middle-income and low-income nations is much lower than in wealthier countries. In the poorest countries, only 50% of premature babies born at 28–32 weeks gestation survive in the absence of neonatal intensive care and only about 5% <28 weeks. In contrast, in 2010, in high-income countries with neonatal intensive care units (NICUs), 95% <28 weeks and 50% <25 weeks survived.[7] However, economic development will likely lead to the expansion of neonatal care in lower-middle-income and low-income countries and the expectation is that more babies will survive and need ROP care.[8–11] It is likely that many low-income countries are ill prepared for an increasing incidence of ROP and it would be ideal to anticipate this need and ensure that ROP programmes for screening and treatment are in place when and where they are needed.

While there are many published papers on different aspects of ROP from an increasingly large number of countries, there is little information about where in the world screening is available and where it is not.[12 13] The International Paediatric Ophthalmology and Strabismus Council (IPOSC) (www.iposc.org) sponsored this study to determine the provision of ROP screening around the world and specifically which countries offer screening, which have official screening protocols, how these protocols were established, and to ascertain the degree of prematurity of the babies admitted to NICUs.

METHODS

Ethical approval was obtained through the Ethics Committee of the Royal Australian and New Zealand College of Ophthalmologists. An e-mail database was created with the aim of including a contact with knowledge of ROP programmes in each of the world's 194 countries. This database was generated with the input of members of the IPOSC, their personal contacts and by asking those who completed the survey to provide further contacts in countries for which a representative could not be identified.

The survey was designed by members of the education subcommittee of IPOSC with input from ROP experts from around the world. It was kept deliberately concise so it would not overburden those completing it and ultimately it comprised 14 questions (box 1).

All contacts received an email with an outline of the study and a request that they complete an online survey through the website Survey Monkey (www.surveymonkey.com). The survey was published in English, Spanish and French versions.

If no response was obtained, then at least one reminder email was sent. For some countries, it was possible to contact a second or third person when there was difficulty obtaining data.

To cite: Mora JS, Waite C, Gilbert CE, *et al*. *Br J Ophthalmol* Published Online First: [*please include* Day Month Year]. doi:10.1136/bjophthalmol-2017-310709

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Box 1 Survey questions

1. Name and contact details
2. Position
3. Institution
4. City
5. Country
6. Is retinopathy of prematurity (ROP) screening available in your country?
7. Does your country have defined screening criteria?
8. Who established the criteria in your country?
9. What are your screening criteria?
10. What is the evidence base for your country's ROP screening criteria (choose all that apply)?
    - US (American Academy of) guidelines
    - UK (Royal College of Ophthalmologists) guidelines
    - Other national guidelines (please specify)
    - Cryo-ROP
    - Early Treatment of ROP trial
    - Other papers from literature (please specify)
    - Locally collected data
    - I don't know
    - Other, space for comment below
11. Approximately how many centres/hospitals in the country offer ROP screening?
12. Approximately how many ophthalmologists in your country do the screening?
13. What are the youngest premature babies supported by your neonatal unit by gestational age? For example, do your units support babies of 28, 26 and 23 weeks?
14. If the data are available can you please note the survival rates (as a percentage) for the following birth weight babies:
    - <1000 g
    - 1000–1499 g
    - 1500–1999 g
    - >2000 g

RESULTS

Representatives from a total of 141 countries were contacted. Thirty countries not contacted were small island nations and in 23 countries, no individual could be identified to contact. Of the 141 countries contacted, 92 completed the survey (65%) (figure 1). The survey response rate was poorest in Africa (table 1).

Seventy-eight of the 92 responding countries (85%) have screening for ROP in at least some centres (table 1). The 14 countries without screening are Moldova, Laos, Cambodia and 11 African countries. No data were available from 49 countries and these were mainly in Africa and former Soviet states (figure 1).

Sixty-eight countries have defined national screening guidelines (figure 1) and in almost half (31/68, the guidelines were developed by a collaboration between paediatric and ophthalmology societies. Fifteen national protocols were created by ophthalmologists alone, 18 were produced at a local hospital level and 4 were unspecified. The most commonly used source of evidence for guideline development was data from the Early Treatment of ROP trial (23 countries), followed by the American Academy of Ophthalmology guidelines (14 countries) and the UK's Royal College of Ophthalmology guidelines (12 countries). Ten countries cited the Cryotherapy for ROP study and two used material from the International Agency for the Prevention of Blindness. Some countries used a combination of these resources and 35 countries used locally collected data, in addition to other resources, to assist in preparing guidelines. Countries without defined guidelines reported that they use a combination of the sources outlined above to guide indications for screening.

The number of centres in each country offering ROP screening varies widely (1–100) as does the number of doctors screening (1–250). There are seven countries with only one or two screening centres. These are Azerbaijan, Bosnia and Herzegovina, Lithuania, Montenegro, Myanmar, Bahrain and Qatar. Three countries have only one or two ophthalmologist screeners. These are Montenegro (one for a population of 626 000 and 3400 births per year), Macedonia (one for a population of 2 080 000 and 10 600 births per year) and Bosnia and Herzegovina (two for a population of 3,870,000 and 15 800 births per year).

The gestational age (GA) of babies admitted to NICUs ranges from 22 to 28 weeks. Eight countries admit only babies of ≥28 weeks, and 69 stated that babies <28 week GA are admitted. The screening criteria range from <30 to 37 weeks GA and from <1000 to 2500 g birth weight (BW). The oldest babies routinely screened are in Egypt and Serbia (<37 weeks GA, <2000 g BW), Ukraine (<37 weeks GA, <1500 g BW) and the Dominican Republic (<35 weeks GA, <2500 g BW).

DISCUSSION

The final response rate of this survey was satisfactory at 92/141 (65%) varying from 94% (33/35) in Asia and Oceania to 33% (15/46) in Africa. The low response rate in Africa may be due to a relative lack of ophthalmologists with a paediatric interest, and/or because there is low awareness of ROP as services for neonatal care have not yet expanded.

The majority of countries who responded offer some ROP screening (78/92, 85%) and most have established ROP screening criteria (68/78, 88%). These criteria vary widely from GA of <30–37 weeks and BWs of <1000–2500g. Variation in screening criteria are both inevitable and desirable. In areas with lower standards of neonatal care, larger more mature infants are at risk and for countries setting up screening, it is important to be conservative and use broader criteria.[8 14–16] Local audits can then guide refinements to the screening criteria, with modifications based on evidence of a change in the characteristics of babies treated for ROP over time. As levels of neonatal care can vary substantially within countries, it is important that modifications to screening criteria are based on data from as many NICUs as possible, to reduce the risk of bias if data from only better performing units are used.[13 16]

The number of ophthalmologists who screen varies widely between countries as do the ophthalmologists per number of live births, suggesting that there are considerable differences in the level of service provided, and some are likely to be inadequately resourced for their populations. Table 2 depicts the numbers of live births per screener in countries classified as high-income, upper-middle-income and lower-middle-income.[17 18] There is a trend for wealthier countries to have more screeners per live births but accurate comparisons are difficult as data were not collected on the number of NICUs nor on the number of preterm infants who would require screening. There are currently no benchmarks or recommendations regarding the number of ophthalmologists with the skills to screen per head of population or according to the number of live or preterm births. Such an exercise would be challenging given the variation in screening

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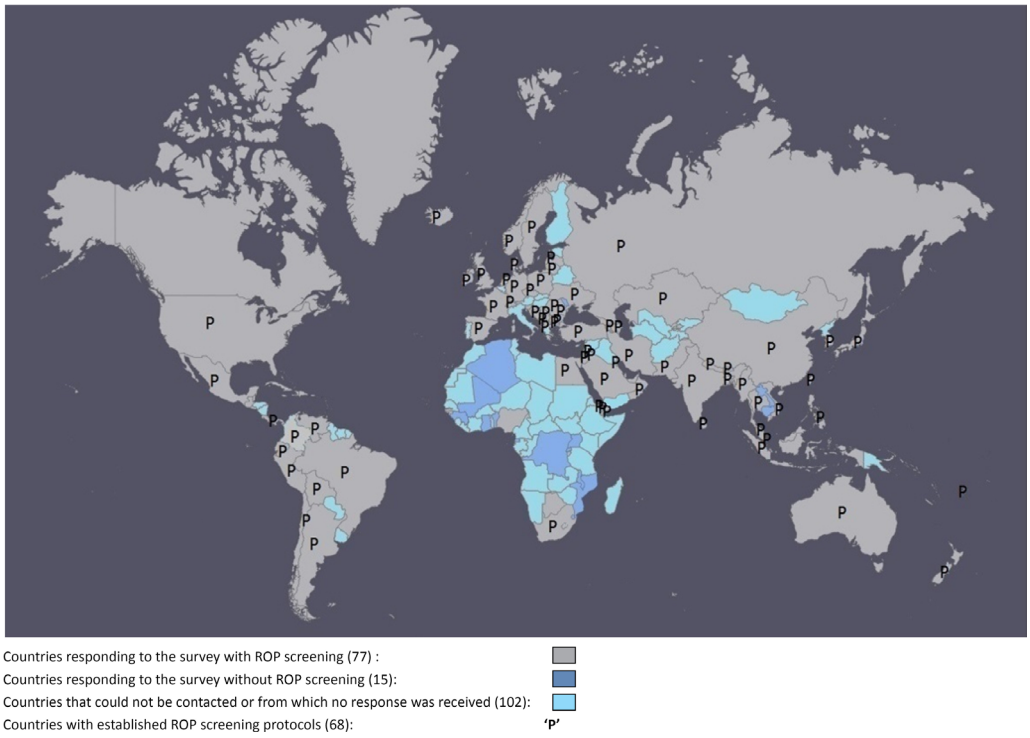

Figure 1 Countries with and without screening for ROP and those with ROP screening guidelines. ROP, retinopathy of prematurity.

criteria which can have a big impact on the number of infants to be screened and hence the workload.[13]

Countries without screening for ROP are listed in table 3 with their respective United Nations Development Indices, birth rates and infant mortality rates.[17–19] Algeria ranks the highest at 83 (out of 188 countries) and 11 of the other 13 countries without ROP screening are in the lowest quartile of countries in terms of development. Nine of these countries are in Africa, the region which currently has the lowest estimated annual incidence of visual loss from ROP.[5] Infant mortality rates are also high in these countries, reflecting standards of maternal and neonatal care. As preterm birth is an important cause of neonatal and infant mortality,[6] the high infant mortality rates in these countries suggest that a high proportion of preterm infants either do not have access to neonatal care, or the care provided is inadequate. Indeed, in a recent review of 51 papers on neonatal surgery in Africa, 59% of studies reported an absence of neonatal care; in 63%, there was a shortage of trained personnel and 77% reported delayed presentation and inadequate facilities.[20]

A limitation of this study is that not every country in the world was contacted, and among those contacted, the response rate was 65%. Of the 35% who did not respond 8 (6%) were wealthy European nations who are likely to have ROP programmes but 31 (22%) were African nations. Survey information was provided by a single contact in each country and it is not possible to be certain that the information is completely accurate. Furthermore, in some cases, the survey was not fully completed. For example, not everyone was able to detail how many centres or how many ophthalmologists were involved in screening. It is not possible therefore to provide worldwide data on the number of screeners per head of population. This information could

Table 1 Survey responses in different regions of the world

		Contacted		Completed	
Region	**Total**	**No.**	**%**	**No.**	**%**
North/Central America	22	12	55	7	58
South America	13	10	77	8	80
Europe	47	38	81	29	76
Asia and Oceania	58	35	60	33	94
Africa	54	46	85	15	33
	194	**141**	**73**	**92**	**65**

Table 2 Number of live births for every ophthalmologist screener

Country/economic status*, †	Total population (million)	Number of screeners	Live births (1000s)‡	Live births per screener
High income				
Sweden	9.9	60	115	1916
New Zealand	4.5	16	61	3800
United Kingdom	65	147	770	5200
Upper middle income				
Brazil	210	80	3150	40 000
South Africa	55	15	1099	73 267
China	1382	100	18 440	184 400
Lower middle income				
Indonesia	260	40	4420	110 500
Guatemala	16.7	4	480	120 000
Egypt	74.9	15	1901	126 700

*World Bank region.[17]
†Nepal was the only country ranked in the World Bank low-income group that responded to the survey and which has ROP screening. The number of screeners was not provided.
‡UNICEF data.[18]
ROP, retinopathy of prematurity; UNICEF, The United Nations Children's Fund.

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Table 3 Level of development, number of births and infant mortality rate for countries which reported no ROP screening

Country	UNHDI*	UNHDI ranking†	World Bank region‡	Annual number of births (1000s)§	Infant mortality rate (per 1000 live births)*
Republic of Moldova	0.693	107	Lower middle	42	13.3
Cambodia	0.555	143	Lower middle	389	32.5
Laos People's Dem. Rep.	0.575	141	Lower middle	181	53.8
Algeria	0.736	83	Lower middle	952	21.6
Benin	0.480	166	Low income	376	56.2
Dem. Rep. of Congo	0.433	176	Low income	2889	86.1
Ghana	0.579	140	Low income	800	52.3
Guinea	0.411	182	Low income	434	64.9
Malawi	0.445	173	Low income	652	44.2
Mali	0.419	179	Low income	723	77.6
Mozambique	0.416	180	Low income	1005	61.5
Rwanda	0.483	163	Low income	414	37.1
Swaziland	0.531	150	Lower middle	37	55.9
Uganda	0.483	163	Low income	1626	43.8

Dem. Rep=Democratic Republic.
*UNHDI 2014 data. UNHDI is a calculation based on life expectancy, schooling and gross national income. Norway has the highest UNHDI (0.944) and Niger the lowest (0.348).[19]
†The UNHI ranking ranges from 1 (highest) to 188 (lowest).[19]
‡Country wealth level grouping by the World Bank.[17]
§UNICEF data.[18]
Dem. Rep, Democratic Republic; ROP, retinopathy of prematurity; UNHDI, United Nations Human Development Index; UNICEF, The United Nations Children's Fund.

perhaps be obtained through the paediatric ophthalmology societies of those countries which have such groups and might allow more accurate comparisons of the availability of ROP screening and treatment services.

This survey focused on screening. Information on the indications for and methods of treatment for ROP was not requested. While it is not ethical to establish screening programme unless there are ophthalmologists able to provide treatment, exploring the method of treatment of ROP in low-income and middle-income countries was beyond the scope of this study.

The information obtained through this survey has led IPOSC to consider the following objectives. First, to create guidelines to assist countries to develop multidisciplinary, evidence-informed national guidelines for ROP. Second, the method of screening needs to be considered particularly given the limited number of paediatric ophthalmologists in many developing nations and the success of telemedicine programmes, notably in India.[21] Third, to undertake a further survey of the indications being used for treatment and treatment modalities. Fourth, to produce an electronic ROP screening database and audit tool to allow countries to adjust their screening criteria and to monitor the quality of treatment over time. Lastly, to continue adding additional paediatric ophthalmologists and information to the database to ensure IPOSC representation in as many countries as possible. This will help to provide a resource for advocacy for all paediatric ophthalmology services including ROP programmes.

A blind child has a higher likelihood of delayed development, poorer socioeconomic status, and having more frequent hospitalisations and higher mortality than those that are not blind.[22] ROP is a potentially avoidable cause of blindness that is likely to become more prevalent in the decades ahead. This study has clarified which parts of the world do not yet have ROP screening and will allow Ministries of Health and other agencies and organisations involved in the prevention of blindness in children to direct their efforts to those areas most in need as services for preterm infants expand in low-income countries.

Acknowledgements The authors wish to thank all those who assisted in creating the database for this study and in particular IAPB Africa, CBM, Drs Sonal Farzavandi, Anthony Murray, Branislav Stankovic and all the IPOSC members who provided contact information. Special thanks to Graham Quinn, Gill Adams and Nicoline Schalij-Delfos who assisted with the survey design, to Dr Luis Ospina who translated the survey into French and to all those who completed the survey.

Contributors JM: the guarantor for the paper and was involved in all aspects of its design, conception, analysis, manuscript creation and editing. CW: involved in project design, analysis, manuscript creation and editing. CEG: involved in data analysis, manuscript creation and editing. BB: involved in project design. JJS: involved in project conception and design, data analysis and manuscript editing.

Funding This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement There is no unpublished data.

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