External Evaluation for SiB/CBM project

Childhood blindness in Latin America: planning and implementing programs for the prevention of blindness in children due to retinopathy of prematurity

Evaluation of ROP programs in Rio De Janeiro, Brazil

CONTENT

Part A: Background information

1. *Organization and project*

Name of project organization**:**	CBM
Name and title of responsible person:	Andrea Zin
Title of project	Retinopathy of prematurity in Brazil and Peru
Key project partners	• Instituto Catarata Infantil, PAHO/WHO collaborating centre for childhood blindness prevention, Instituto Fernandes Figueira - FIOCRUZ; • State Secretary of Health (State Government of Rio de Janeiro) • Municipal Secretary of Health (Rio de Janeiro City Hall); • Telemedicine Department of University of Sâo Paulo
Date field activities started:	**January 2010**
2. Evaluator	**ROP programs in Rio de Janeiro, Brazil**
Name of evaluator(s)	Clare Gilbert
Affiliation of evaluator:	London School of Hygiene & Tropical Medicine
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Terms of reference (TOR):

The following outputs are included in the evaluation of ROP programs in Rio:

1. Increasing the coverage of effective programs for detecting and treating ROP, with establishment of programs beyond the city of Rio
2. Management Information system for ROP developed and implemented
3. National and regional workshops held to disseminate best practice and for planning and improving programs in Latin America, and countries in the region visited
4. Development of educational materials on best practices of neonatal care and for the prevention and detection and treatment of ROP for neonatal intensive care personnel

Part B: Executive summary

Provide a brief description of the project, its overlying objectives, and targeted beneficiaries.

Aim of project:

- To decrease ROP as a cause of blindness in children in Peru and Brazil with emphasis on Lima and Rio de Janeiro; to demonstrate scalable models which could be adapted for use in other countries of the region and to develop low vision services in both countries, which could be adapted for use in other countries of the region.

Objectives:

1. Improve neonatal care in Lima and Rio de Janeiro, using the lessons learnt from the current projects in Lima and Rio de Janeiro, Brazil, and materials that have been or will be developed
2. Increase coverage of effective programmes for detecting and treating ROP in Lima and Rio de Janeiro for neonatal units where programmes are not already in place
3. Develop hands-on training programmes for ophthalmologists and neonatologists outside Rio de Janeiro and Lima so that programmes can be established beyond these two cities
4. Develop and implement a management information system to monitor activities
5. Establish low vision clinical training centre in São Paulo (Federal University of São Paulo) and Lima.
6. Establish low vision centres in Peru and Brazil
7. Increase awareness among health care personnel (nurses, neonatologists and ophthalmologists)
8. Expand the lessons learned from this project to other countries in the region through visits (Guatemala, Honduras and El Salvador), national workshops (Brazil, Colombia, Guatemala, Venezuela and Mexico), 2 regional ROP workshops (Nicaragua, Peru) and 1 regional low vision workshop (Paraguay).

The ultimate beneficiaries are preterm infants at risk of visual loss from retinopathy of prematurity..

Key findings

With regard to topic relevance: The project addresses a topic of great relevance to Brazil and Peru, as well as Latin America, where ROP is often the commonest cause of avoidable blindness. Control of ROP blindness is a priority of the Pan American Health Organization for Latin America and the Caribbean.

With regard to project relevance: The approach adopted was highly relevant, entailing primary prevention of ROP through training neonatologists and nurses to improve neonatal care; secondary prevention, by increasing ROP programmes for detection and treatment of infants with the severe stages of ROP, and tertiary prevention, by building the capacity of low vision services to improve visual function, including children with irreversible visual loss from ROP.

With regard to capacity building: The main focus of each component of the project was capacity building, through improving knowledge as well as skills of neonatologists and nurses, ophthalmologists and low vision therapists. Essential equipment was also provided.

With regard to miscellaneous criteria: Sustainability was a key finding as the ROP programmes are fully integrated into government health systems. The State sector did not have programmes and considerable advocacy was required, but this was highly successful, leading to creation of new posts in maternity

hospitals for ophthalmologists who were selected and appointed by the State Ministry. The programme is not, therefore, dependent on the commitment and energy of a few ophthalmologists, but has the potential to be ongoing and hence sustainable as well as to expand to other units.

Lessons learned

What are the most important lessons learned (not more than 5) for future activities?

1. Advocacy with the State Ministry of Health, which led to ROP programs being fully integrated and sustainable.
2. Excellent clinical training and support: high quality ROP programs require motivated and committed ophthalmologists who have had hands-on practical clinical training by ophthalmologists experienced in examining and treating ROP. They also need to be trained in how to set up, run and manage a program, as in this project. The ongoing support, supervision, mentoring and problem solving by the trainers in this project is a model of best practice, maintaining quality as well commitment.
3. Health management information systems for ROP that are integrated into government systems are likely to be used more regularly and have more an impact than stand alone monitoring systems.
4. National and regional multi-disciplinary workshops provide a mechanism for advocacy, planning, networking, team building, sharing knowledge and problem solving. Other regions would benefit enormously from the experiences in Latin America, where Andrea Zin has played a very major role, supported by regional and international facilitators and experts.
5. The online educational materials provide a means of reaching large audiences at little cost to users.

Specific recommendations

What recommendations would you make for the project (not more than 5) to optimize future activities?

ROP programs:

1. An on-line library of images of ROP and its treatment would provide a useful resource during and after training and to create awareness amongst other staff and parents.
2. A network of the ophthalmologists be developed using social media (e.g. Facebook) to provide a mechanism for sharing experiences and knowledge, to discuss new developments in diagnosis and treatment; to design and undertake simple research studies and to disseminate relevant publications for discussion.
3. Monitoring of the ROP programs could be improved, and standard data forms and registers would assist in this. Monitoring should include coverage, the number of infants examined and treated, by birthweight group, follow up rates, and rates of regression after treatment.
4. Awareness of the risk and consequences of ROP needs to be raised amongst parents. State and Municipal health systems need to work with neonatologists, nurses and ophthalmologists to improve communication with parents. Neonatologists should take the responsibility for communicating to parents/carers at discharge if the child needs follow up eye examinations.
5. Advocacy with the State Ministry of Health is needed to improve the long term follow up of preterm infants to detect and manage other ocular morbidity associated with preterm birth and ROP (i.e. high myopia and other refractive errors, strabismus, cortical visual impairment). The State system provides this service but not the Municipal system.

6. Educational materials:

   The online course should be translated into Spanish, for use other countries in Latin America, and English, for other regions (with translation, as required).

Part C: Approach and methodology

What approach was used for the evaluation (desk review, site visit, etc.)?

Site visit

At what project stage the evaluation was conducted?

End of project evaluation.

Who among the project partners and beneficiaries was contacted for the review?

- Representatives of the State Ministry of Health
- Representatives of the Municipal Ministry of Health
- Instituto Fernandes Figueira-FIOCRUZ

What instruments were used to conduct the evaluation (questionnaires, interviews, discussions)?

Interviews and discussions:

- Extensive discussions with Andrea Zin, the Project Manager;
- Semi-structured and in-depth interviews with four of the six ophthalmologists who were trained to screen and treat ROP in the neonatal intensive care units (NICU) where they work;
- Short meeting with ROP trainer, Dr Viviane Lanzelotte;
- Informal discussion with neonatal nurses and neonatologists in the neonatal units visited;
- Discussions with the Director of Health Services, Rio State, Dr Ana Neves;
- Discussions with the Co-oridinator of Neonatal care, Municipal Health services, Dr Nicole Gianini;

Observation:

- All four NICUs which have developed new ROP during this project were visited, as well as two NICUs in the Municipal system where the focus was on nurse training (one has a new ophthalmologist).

Review of documents and other materials:

- Proposal and amendments; logframe
- Ophthalmologist's diaries and registers
- Protocols
- Data recording instruments
- POINTS-ROP online educational materials
- EpiMed State monitoring system

Schedule of visits: I was accompanied by Dr Zin on all occasions.

Sept 2	Sept 3	Sept 4	Sept 5	Sept 6
NICU: Melquiades Calazans; Babara Gomet (O) and neonatal staff Hospital da Mulher Heloneida Studart, to see the new NICU*	NICU: Albert Schweitzer; Renata Cabral (O) and neonatal staff. Reviewed Epi-Med monitoring system	Meeting at IFF to discuss current research for improving nutrition in preterm infants. Reviewed online POINTS-ROP course.	Co-ordinator of neonatal care, Municipal Health services; Dr Nicole Gianini. Trainer in ROP: Dr Viviane Lanzelotte	NICU: Fernando Magalhães. Leonardo Costa (O)
NICU: Adão Pereira Nunes; Leonardo Costa (O)		Director of State Health Services; Dr Ana Neves and her team		

*O = ophthalmologist trained during SCB project; * not a project facility*

Part D: Main findings

Does the project address an issue relevant for public health?

Yes. Retinopathy of prematurity is the commonest cause of avoidable blindness in many countries in Latin America and also in Eastern Europe and SE Asia.

Is the project coherent with the Phase 4 of SiB strategy?

Yes. Priorities for Phase 4 were "to deliver comprehensive and sustainable eye-care services to people living in neglected, marginalized urban areas". The project was undertaken in urban populations in Brazil, focusing on strengthening government services which are accessed by the poor (rather than the NGO or private sectors), which promotes sustainability. The project was comprehensive, covering:

- training neonatal staff in the prevention of ROP in preterm infants;
- expanding programs for detecting and treating the serious stages of ROP;
- providing low vision services for those with irreversible visual loss, including children with ROP. This component of the project has been evaluated by Karin van Dyjk, a low vision expert;
- instituting a health management information system for ROP;
- conducting further national visits and workshops, and conducting one regional workshop

The focus of the different elements of the project in the neonatal care units in Rio are outlined in Table 1.

Table 1. Neonatal care units included in the project in Rio, and main focus

Neonatal unit	System	Focus of SiB project	Comment
Alexander Fleming	M	Neonatal care	Already had an ROP program; Winding down pending closure
Oswaldo Nazareth	M	Neonatal care	Already had an ROP program; Closed in February 2013
Fernado Magalhaes	M	Neonatal care	Already had an ROP program
Herculano Pinheiro	M	Neonatal care	Already had an ROP program
Carmela Dutra [1]	M	Neonatal care; ROP S&T	Needed a new ophthalmologist
Leila Diniz[2]	M	Neonatal care; ROP S&T	No ROP program before
Adao Pereira Nunes[1]	S	Neonatal care; ROP S&T	No ROP program before
Albert Schweitzer[1]	S	Neonatal care; ROP S&T	No ROP program before
Melquiades Calazans[1]	S	Neonatal care; ROP S&T	No ROP program before
Rocha Faria[3]	S	Neonatal care; ROP S&T	No ROP program before
Azevedo Lima[3]	S	Neonatal care; ROP S&T	No ROP program before
Araruama[5]	S	Neonatal care; ROP S&T	No ROP program before
Heloneida Studart[4,5]	S	Neonatal care; ROP S&T	Already had an ROP program

M = Municipal health system
S = State health system
S&T= screening and treatment

1. *NICUs visited and screening ophthalmologists met and interviewed*
2. *Covered by ophthalmologist who screens in Melquiades Calazans*
3. *Two ophthalmologists were trained for S&T for these units but they haven't started ROP programs (see below)*
4. *Covered by ophthalmologist coordinator of ROP program in Municipal government.*
5. *Excluded from the project due to local administrative issues*

A map of the project area is shown in Appendix 1.

Details of the total number of births in the maternity units associated with the neonatal units, and the number weighing less than 1500g at birth and their survival rates are shown in Table 2. Neonatal units in this project cover almost 25,000 live births. Survival rates of infants most at risk of ROP (i.e. those <1500gs at birth) vary, ranging from 44% from 83%. The variability can have several causes, but there are two main reasons: some units may admit sicker infants, and levels of neonatal care are likely to vary in quality between units. In industrialized countries survival rates of infants <1500gs is around 90%.

As neonatal care improves it is anticipated that survival will also improve, particularly among those at very high risk of ROP (i.e. <1000gs at birth). At the same time, bigger, more mature infants will be exposed to fewer risk factors for ROP (e.g. infection, poorly administered and inadequately monitored oxygen) and so ROP is likely to become less common in these larger babies.

Table 2. Births in maternity units in the project, and survival of preterm infants most at risk of retinopathy of prematurity

	Population of preterm infants at risk			
	In 2012		Survival <1500g	
	Births	<1500g	%	N
Exisiting ROP Prog				
IMMFM	3963	76	83%	59
HMCD	6120	91	71%	65
HMHP	3353	45	67%	30
HMAF	2619	53	58%	22
Subtotal	**16055**	**265**	**68%**	**176**
New ROP Prog				
HMLD	5417	115	71%	82
HEAPN	2693	97	74%	72
HEMC	1753	43	60%	26
HEAS	4315	87	44%	38
Subtotal	**8761**	**342**	**64%**	**218**
ALL UNITS	**24816**	**607**	**65%**	**394**

Are outputs satisfactory and robust as compared with international quality standards?

Increasing the coverage of effective programs:

The target was to expand ROP programs beyond Rio city, and eight NICUs (7 State, 1 Municipal) were selected based on size, location, and willingness of Directors to develop a program. Two units in the State sector withdrew for administrative reasons. The new ROP programs in four units cover a further 30% of preterm births (60% are in the Municipal system which already had programs and 10% are in private units). 341 babies have been examined in these new programs and 18 (5.3%) treated (Table 3). Overall 1418 babies were examined in NIUCs where SiB has been supporting programs, 55 (3.9%) of whom were treated. Rates of ROP needing treatment varied from 1.9% to 12.2%, reflecting varying case mix, levels of care and survival rates of infants most at risk.

The time period of this project is too short to be able to detect a decline in rates of ROP needing treatment, but rates in existing ROP programs have declined over the last 10 years, when the overall rate was 4.2% (Table 3).

Table 3. rates of severe ROP that was treated in project neonatal units since 2010

	Population of preterm infants at risk				ROP programme 2010			ROP programme 2011			ROP programme 2012			ROP programme 2013 (to June)			2010-June 2013		
	In 2012		Survival <1500g			Treated			Treated			Treated			Treated			Treated	
	Births	<1500g	%	N	Examined	N	%	Examined	N	%	Examined	N	%	Examined	N	%	Examined	N	%
Exisiting ROP Prog																			
IMMFM	3963	76	83%	59	96	4	4,2%	94	2	2,1%	97	5	5,2%	37	1	2,7%	324	12	3,7%
HMCD	6120	91	71%	65	95	3	3,2%	86	0	0,0%	109	2	1,8%	73	2	2,7%	363	7	1,9%
HMHP	3353	45	67%	30	28	1	3,6%	22	4	10,0%	30	3	10,0%	30	3	10,0%	110	11	10,0%
HMAF	2619	53	58%	22	132	3	2,3%	113	3	2,7%	63	2	3,2%	16	0	0,0%	324	8	2,5%
Subtotal	**16055**	**265**	**68%**	**176**	**351**	**11**	3,1%	**315**	**9**	2,9%	**299**	**12**	4,0%	**156**	**6**	**3,8%**	**1121**	**38**	**3,4%**
New ROP Prog																			
HMLD	5417	115	71%	82	Programme not started			55	3	5,5%	62	5	8,1%	57	1	1,8%	174	9	5,2%
HEAPN	2693	97	74%	72	Programme not started			13	1	7,7%	27	4	14,8%	37	1	2,7%	77	6	7,8%
HEMC	1753	43	60%	26	Programme not started			Programme not started			29	2	6,9%	20	1	5,0%	49	3	6,1%
HEAS	4315	87	44%	38	Programme not started			Programme not started			Programme not started			41	0	0	41	0	0,0%
Subtotal	**8761**	**342**	**64%**	**218**				**68**	**4**	**5,9%**	**118**	**11**	**9,3%**	**155**	**3**	**1,9%**	**341**	**18**	**5,3%**
ALL UNITS	**24816**	**607**	**65%**	**394**				**383**	**13**	**3,4%**	**417**	**23**	**5,5%**	**311**	**9**	**2,9%**	**1462**	**56**	**3,8%**

Another positive change over the last 10 years is that the birth weight (BW) and gestational age (GA) of infants treated have also declined over time, suggesting that neonatal care has improved between the earlier study in 2004-6 and June 2012, with bigger, more mature infants being at less risk than previously. The median BW of treated babies was 850g (range 400-1670g) and the median gestational age was 29 weeks (range 23-34), which is close to the values seen in industrialized countries. As no infants were treated who had a gestational age of greater than 34 weeks, consideration could be given to changing the screening criteria to ≤ 34 weeks (rather than the current ≤ 35 weeks) which would considerably reduce the number of babies to be examined.

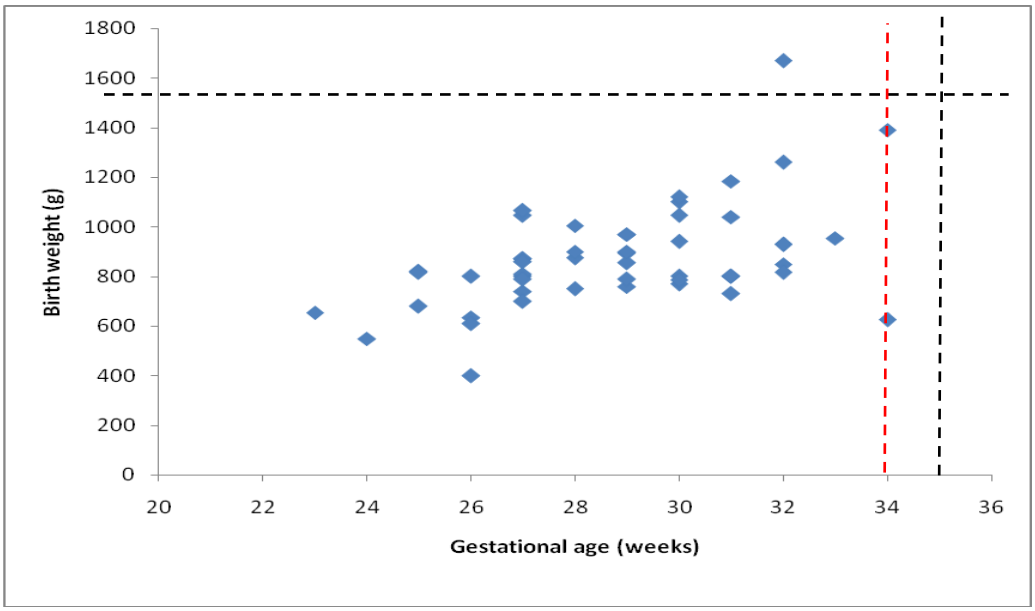


Figure 1. Birth weight and gestational age of infants treated for severe ROP 2010-2013.
Black dotted lines = current screening criteria: Red dotted line, possible revised criteria for gestational age

The programs are of very high quality in terms of training, examination techniques and indications for and methods of treatment (i.e. laser peripheral retinal ablation). The project ophthalmologists reported high response rates to treatment, but this is not currently being monitored.

There is a new, highly controversial treatment for severe ROP which involves injecting an agent into the back of the eye which blocks the growth of blood vessels (an anti-VEGF preparation). Avastin is preparation most frequently used. Although Avastin reduces ROP there are concerns that this may only give short term control of the disease, which can recur months later. It is known that the drug can escape into the blood stream, and there are concerns that there may be unwanted complications in other organs as they develop (e.g. in the brain, lungs and kidneys). Avastin is not available in the government sector in Brazil so the issue of its use does not arise, but it is being used extensively in other countries in the region, often without long term follow up, as it is quick and easy to administer. All the ophthalmologists said they would consider using Avastin but just for the most difficult cases as its safety profile is not yet known.

It was not possible to assess the skills of the ophthalmologists but all have had excellent training, they continue to be supported by the trainers and they work together very well as a team, for example, by discussing difficult cases.

Management Information system for ROP developed and implemented:

Dr Andrea Zin and colleagues were finalizing a stand alone, on-line system for monitoring ROP programs when it became clear that the State Ministry of Health were implementing an online system called Epi-Med. This system was developed by a private company for monitoring intensive care services, including neonatal care, in the State system. Dr Zin gave input to the development of Epi-Med and so data on ROP are being routinely collected. The system is now being rolled out across the State of Rio (population 16 million). Data on ROP is, therefore, now fully integrated into the State monitoring system. The Municipal Health system, which covers the city of Rio (population 10 million) are also considering establishing a monitoring system which would also include ROP.

One area that could be improved is in monitoring the coverage of the program (i.e. the proportion of eligible babies who were actually examined), rates of completed examinations (i.e. babies are examined until they are discharged from the ROP program) and the outcome of treatment. Data are not being collected to allow assessment of coverage, except in one NICU, and review of the ROP register of examined babies in two NICUs showed that 10% and 24% of babies had not attended for all their examinations. Follow up after babies leave the NICU is a problem everywhere, and not unique to Rio. The examining ophthalmologists were aware of the problem and had tried different solutions e.g. calling mothers on their cell phones. A more systematic approach is needed, with neonatologists and nurses being responsible for better communication with mothers, particularly at the time of discharge if their infant requires further eye examinations. (See recommendations and Appendix 2.)

National and regional workshops:

The target to conduct six workshops has been reached and two (target three) countries have been visited (see Appendix 3). Over 300 professionals attended the workshops, with an almost equal mix of ophthalmologists, neonatologists/pediatricians and nurses. International experts in ROP from Latin America and beyond (ophthalmologists, neonatologists and a neonatal nurse) have facilitated the majority of the workshops with Dr Zin.

Third regional ROP workshop

The third regional workshop was supported by the project. It took place in Cartagena, Colombia on September 11-12th, and Clare Gilbert was one of the international facilitators. The meeting was attended by 53 professionals (neonatologists, ophthalmologists, nurses) from 13 countries in Central and South America (Argentina, Brazil, Bolivia, Colombia, Chile, Cuba, Dominican Republic, El Salvador, Guatemala, Mexico, Nicaragua, Peru, Venezuela), Ministry of Health representatives from Brazil, Colombia and Chile, ORBIS international (who also supported the meeting), Dr Juan Carlos Silva, Director, Program for the Prevention of Blindness, PAHO, and the Dr Alejandro Vasquez de Kartzow, President of the Pan American Association of Ophthalmologists. One Assistant Professor of Pediatric Ophthalmology from Duke University and one ophthalmology resident from University of Pennsylvania, USA, attended as observers. (See Appendix 4 for the agenda.)

The main areas of focus during the workshop were as follows:

- The importance of PAHO and government policies and support in developing ROP programs that are integrated and sustainable;
- Update of data from recent clinical trials on optimal oxygen levels to reduce severe ROP;
- Discussion of the potential role of anti-VEGF preparations in the treatment of severe ROP;
- The importance of data collection and monitoring ROP programs so they can be improved.

Information regarding whether Ministerial Resolutions and/or laws had been passed making eye examination of preterm births mandatory, whether countries had develop their own guidelines, and whether there were systems in pace for monitoring programs. The following were reported by the 13 countries represented:

Ministerial resolutions	6	Argentina, Chile, Colombia, El Salvador, Mexico and Peru
Law	6	Argentina, Chile, Colombia, El Salvador, Mexico and Peru
National guidelines	9	Argentina, Brazil, Chile, Colombia, El Salvador, Mexico, Nicaragua, Peru and Venezuela
Monitoring system	4	Argentina, Brazil, Chile, Colombia and Venezuela

A positive development that emerged during the regional workshop is that planning, organizing and management of ROP workshops in the region in the future will fall under the ROP Society of the PanAmerican Association of Ophthalmologists. Membership of the ROP Society is international and multidisciplinary, with several committees which each have clearly defined areas of activity (e.g. education).

The output of the workshop included:

- Updated regional guidelines in relation to the prevention of ROP through improving neonatal care and for detecting and treating ROP;
- Guidelines on monitoring ROP programs;
- A document on the indications for treatment with anti-VEGF agents, a protocol and informed consent form for parents (to be finalized after further consultation)
- Priorities for action by each country;
- Delineation of the roles and activities of the ROP Society of PAAO;

All these outputs (except for the anti-VEGF document) as well as pdfs of all the presentations given during the meeting are available to all participants on DropBox.

The regional ROP workshop was followed by a seminar at the regional neonatology meeting, SIBEN, on September 11th. The session was attended by about 200 neonatologists and nurses (Agenda Appendix 4).

Educational materials for neonatal care and the prevention of ROP:

The materials are based on an earlier study led by Andrea Zin which involved assessing the effectiveness of training neonatal nurses. The training was called POINTS or Care, as it covered control of **P**ain, **O**xygen, **I**nfection, and improving **N**utrition, **T**emperature control and **S**upportive care. Dr Zin has added control and treatment of ROP. The materials were developed collaboratively with

Andrea Zin, Dr Cynthia Magluta, a public health physician at IFF, and Chao Lung Wen, Department of Telemedicine, University of São Paulo. The content which includes text and DVDs, is all evidence based, up to date and practical, and of exceptionally high quality in terms of the educational approach and presentation. Almost 5,000 people have registered for the on-line, 8 module course which was recently advertised.

Course link: http://neonatal.estacaodigitalsaude.org.br/aia/. Access is limited to those who have registered. See Appendix 5 for screen-captures of some of the web pages.

Has/can the project lead to relevant policy changes?

Control of visual loss from ROP is already a policy of the Pan American Health Organization (PAHO) and is a priority for Brazil. The State Ministry of Health has drafted a law, which is currently under review which would make examination of all preterm infants mandatory. This is likely to have very positive repercussions, leading to greater coverage of ROP programs.

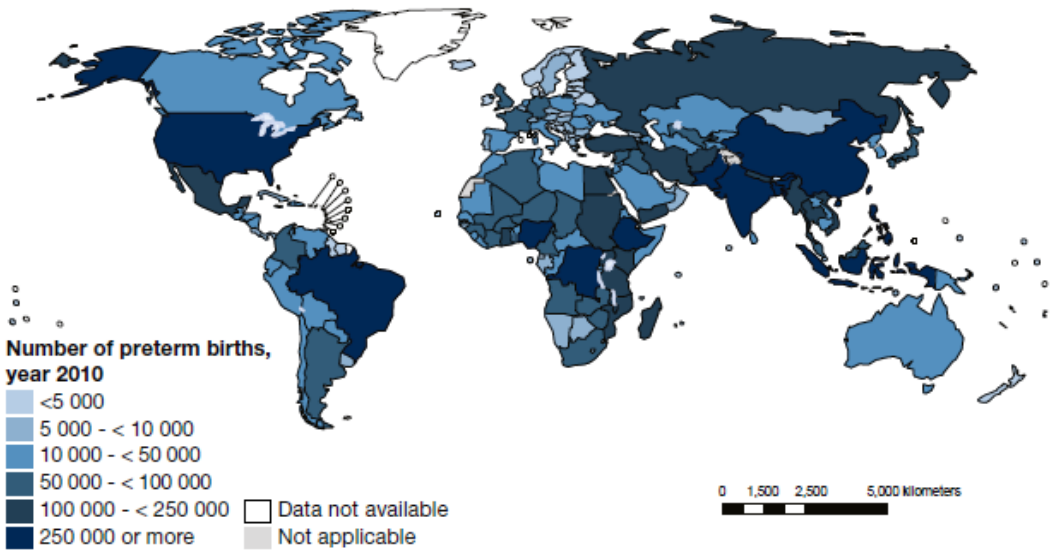
In Rio considerable advocacy was required by Dr Zin to establish ROP programs in the State system. This led to recruitment and employment of ophthalmologists who were subsequently trained in ROP by Dr Zin and Dr Lanzelotte. This project has the potential for replication in other States in Brazil.

In the State health system, long term follow up of preterm infants is not adequate. Infants are referred to general primary health care services, which are not adequately resourced to be able to detect and manage the range of morbidities associated with preterm infants. This issue was raised with the Director of the State Health Services who said that this would be addressed. The same applies to improving care in the first "golden hour" after preterm birth, when gentle resuscitation and avoiding unnecessary oxygen can have a major impact on the development of complications of preterm birth, including ROP. This requires co-ordination between obstetricians, paediatricians and neonatologists.

How relevant are the findings for the regional/international community? Will findings advance the field?

Brazil ranked 10th in terms of the number of preterm births (WHO, Born Too Soon, 2012): controlling blindness from ROP in Brazil, is therefore highly relevant (Table below).

Figure 2.5: Estimated numbers of preterm births in 2010



10 countries account for 60% of the world's preterm births by rank:

1.	India
2.	China
3.	Nigeria
4.	Pakistan
5.	Indonesia
6.	United States of America
7.	Bangladesh
8.	Philippines
9.	Dem. Rep. of Congo
10.	Brazil

ROP programs:
In Brazil, ROP programs are fully integrated into the State and Municipal health systems, including those developed with support of SiB. The ophthalmologists are recruited and employed by the health system, and they receive a regular salary. This means that the programs are sustainable, and can be expanded to other States and Municipal health services in Brazil. Lessons can be learnt by other countries in the region and internationally as in many settings there are too few ophthalmologists willing to screen when this is voluntary. The only way to expand coverage and provide sustainable programs of high quality is for them to be fully integrated into the health system, as is the case in this project.

Educational materials;
The online educational materials have the potential to have a major impact on neonatal care in Brazil and beyond.

Workshops:
The workshops in Latin America have evolved over time, responding to the emerging needs. Initial workshops in the late 1990s and early 2000s focused on ophthalmologists and how they could be trained and how they could set up and manage ROP programs. In subsequent workshops more emphasis was put on prevention of ROP, and so more neonatologists and nurses were invited to participate. As countries move towards the stage were legislation and support of Ministries of Health are needed to improve coverage, representatives from health ministries and policy makers have been invited. A similar evolution may well be needed in countries in Asia, such as The Philippines and Indonesia where ROP control programs are in their infancy.

Lessons learned will contribute to extend capability for new projects in the field?

Comment on management of this project:
This project was managed by Dr Andrea Zin (50% time) with support by Cynthia Magluta (10%, IFF) and a Finance Administrator (20%)(see Appendix 6). The CBM office helped with all financial issues at the central level as well as with financial reporting. CBM also helped with the budget for the Cartagena workshop

Highly complex projects such as this, which had multiple elements, partners and activities, require a full time management team comprising full time experts in program and financial management, with input from those with expertise in eye care and neonatal care. The amount of work this project entailed was far too much for such a small team, which meant that Dr Zin worked way beyond what she was supported to do. Ideally Dr Zin should have provided technical advice to a full time, experienced Program Manager, supported by a full time Administrator, as a minimum.

Has the project significantly contributed to capacity strengthening?
Yes. All elements of the project focus on building the capacity of staff involved in neonatal care and ROP programs. New staff have been trained to detect and treat sight threatening ROP; an educational package has been developed and further national and regional workshops have been held.

Workshops:
One of the purposes of the workshops is to build skills in needs assessment and planning, and to build capacity in areas such as guideline development. Most of those attending the workshops are clinicians who have not previously been exposed to the public health elements of ROP programs.

No other region has national or regional level workshops on ROP, and much can be learnt from the experience in Latin America in other regions, such as Eastern Europe and South East Asia. Although it is difficult to quantify the impact the workshops have had, they have undoubtedly contributed to the development of ROP programs in Brazil and Latin and Central America, which were almost non-existent in the late 1990s. The workshops and visits supported by SCB build on the awareness created since the first workshop in Chile in 1997 when only two ophthalmologists in the whole region were screening for ROP.

Is the project sustainable and potentially apt for scaling up?

Yes, the ROP programs in Rio are completely sustainable, and so can be scaled up within the Sate and Municipal health systems.

How could international network be improved? Is there potential for wider knowledge sharing / capacity strengthening within region and beyond?

The workshops provide an ideal opportunity for networking, sharing knowledge and experiences. Facilitators at workshops could transfer their skills and use their experiences to develop workshops in other regions. Indeed, workshops have already been held in Eastern Europe and workshops are planned for Indonesia and the Philippines.

The 4th World Congress of ROP is due to be held in Mexico in 2014, providing an opportunity to share experiences from this project to a very wide audience.

Provide 3-5 best practices that can be taken from the project.

1. Advocacy with Ministries of health, which led to ROP programs being fully integrated and sustainable.

2. Excellent clinical training and support: Providing high quality ROP programs requires motivated and committed ophthalmologists who are exposed to extensive, hands-on practical clinical training by ophthalmologists experienced in examining and treating preterm infants. They also need to be trained in how to set up, run and manage a program, as in this project. The ongoing support, supervision, mentoring and problem solving by the trainers in this project is also a model of best practice, maintaining quality as well commitment.

3. Health management information systems for ROP that are integrated into government systems are likely to be used more regularly and have more an impact than stand alone ROP monitoring systems.

4. National and regional multi-disciplinary workshops provide a mechanism for advocacy, planning, networking, team building, sharing knowledge and problem solving. Other regions would benefit

enormously from the experiences in Latin America, where Andrea Zin has played a very major role, supported by regional and international facilitators and experts.

5. The online educational materials provide a means of reaching a very large audience at little cost to the end user.

Provide 3-5 recommendations for project in moving forward.

ROP programs:

1. An on-line library of images of ROP and its treatment would provide a useful resource during and after training. The images could also be used for to create awareness amongst other staff and parents. The library could include annotated images of the following: different stages of ROP (typical and atypical presentations), what adequate laser treatment looks like, when and how to retreat infants etc.

2. A network of the ophthalmologists be developed using social media (e.g. Facebook) to provide a mechanism for sharing experiences and knowledge, to discuss new developments in diagnosis and treatment; to design and undertake simple research studies and to disseminate relevant publications for discussion.

3. Monitoring of the ROP programs could be improved, and standard data forms and registers would assist in this. Monitoring should include coverage, the number of infants examined and treated, by birthweight group, follow up rates, and rates of regression after treatment.

4. Awareness of the risk and consequences of ROP needs to be raised amongst parents so they realize the importance of eye examinations, particularly after their infant has left the NICU. State and Municipal health systems need to work with neontaologists, nurses and ophthalmologists to improve communication with parents. Every opportunity should be taken to talk to parents by all members of the team, supported by written information that is simple and clear, as many mothers are extremely young, unmarried, and not well educated. Neonatologists should take the responsibility for communicating to parents/carers at the time of discharge if the child needs follow up eye examinations.

5. Advocacy with the State Ministry of Health is needed to improve the long term follow up of preterm infants to detect and manage other ocular morbidity associated with preterm birth and ROP (i.e. high myopia and other refractive errors, strabismus, cortical visual impairment and visual perceptions problems). The State system provides this service but not the Municipal system.

7. Educational materials:

   The online course should be translated into Spanish, for use other countries in Latin America, and English, for other regions (with translation, as required).

Part E: Context analysis

1. Has the situation in the country changed since the project's inception (particularly: new risks)?

Were certain issues either over- or under-estimated?

The State and Municipal systems are both restructuring, with closure of some units, and the development of new units. The reason is to concentrate expertise, and to improve the link between maternal health and neonatal care. These are very positive developments.

The State system is embracing public-private partnerships, with the staff in State facilities being employed and managed by private companies. Salaries have been increased, and management has improved.

Advocacy with the State Ministry of health took longer than anticipated which delayed the appointment and training of ophthalmologists in the State system. This meant that the target number of preterm infants to be examined (30%) could was only reached by early 2013.

Two of the six ophthalmologists identified for training are not running programs. One has taken on a leadership role in his Eye Department, and the other ophthalmologist did not attend for training. Reasons are not known.

Change in leadership in the neonatal units led to some lack of continuity.

Were initial project assumptions correctly assessed by project team?

The original intention had been that ROP programs would be developed in Sao Paulo, the assumption being that there was willingness and commitment. However, it became clear after a year that little could be achieved, and so the project was relocated to Rio. This was another cause of delay.

2. Provide an assessment of the project activities & project partner's relationship with others who are active in the field.

Define areas of cooperation and coordination. Describe any problems?

Some neonatologists were not very supportive of the new ROP programmes to begin with; for example, they did not allocate a nurse to assist the ophthalmologist. However, this changed over time as they came to appreciate what the ophthalmologists were doing.

There was surprisingly little communication or co-ordination between the Municipal and State health systems. Dr Zin has developed very good working relations with both, and provided a mechanism where each could hear about the positive elements in the other.

CBM have supported ROP programs in Brazil in the past, and were the implementing partner for this project. No other NGOs support ROP programs in Brazil.

3. In the project proposal, was the strategy clearly defined and appropriate?

Was the appropriate target population identified?
Yes

Was the strategy appropriately defined at the time of project inception?
Yes

4. In the project proposal, were the strategy and methodology clearly defined and appropriate?
Was the methodology appropriately defined at the time of project inception in terms of timing, responsibilities, etc.?

Yes, but a change of site from Sao Paulo to Rio meant that there was a change in partners as well as timing.

5. Milestones and achievements

Have the milestones so far been achieved and are on track? If not, please assess why.

1. Increased coverage of effective programs for detecting and treating ROP, with establishment of programs beyond the city of Rio.
   The target was to implement ROP screening and treatment program in 6 NICUs from State government and 1 Municipal. One State NICU withdrew due to administrative problems. Although 2 ophthalmologists were trained, they left the program and for this reason 2 State units still do not have the program in place. The State government is looking for suitable candidates to replace the professionals that left. The program is now being implemented 9 of of the 11 NICUs of the project.

2. Management Information system for ROP developed and integrated into the State government system. The Municipal government is considering the best way to incorporate ROP into their MIS.

3. Six workshops (national and regional) were held, to disseminate best practice and for planning and improving programs in Latin America, and 2 countries in the region were visited. One country was not visited due to security issues (Honduras)

4. Educational materials on best practices for neonatal care and for the prevention, detection and treatment of ROP for staff caring for preterm infants was developed and disseminated through a web based course.

6. Impact and outcome measures

What outputs/measurable indicators have been achieved over the project's lifetime?

- ROP programmes were extended outside the city of Rio
- A further 30% of preterm infants are now in units with ROP programs

- The system for monitoring ROP is embedded the Municipal governments HMIS for intensive system. The State system is considering adopting a integrated system of monitoring
- A online educational systems on neonatal care is available in Portuguese and the first course has started
- National and regional workshops took place as planned.

What expected outputs have not been achieved, and is it reasonable that they have not been?

- Country visits were not undertaken by Dr Zin, for security reasons. Another country was not selected because of competing demands

What impact has been seen with the achievements so far?

Assessing the impact of programs where the focus is prevention can be very challenging, requiring baseline data, and clear indications that any inputs and outcomes have directly led to the impacts.

In Rio there was no base line data on the number of infants become ROP blind each year, as there is no system for surveillance. After discussion with Dr Zin it became clear that this would be very challenging to set up in Rio, as there is no tertiary referral eye department where infants with advanced ROP (Stages 4 and 5) are assessed or operated upon. Indeed, there is no vitreo-retinal surgeon in the city who operates on Stage 4 ROP (Stage 5 being considered inoperable by most experts). In addition, infants who are blind from ROP may have other disabilities, and so not be captured in data for children enrolled in inclusive education. There is only one school for the blind in Rio, which only caters for blind children who have no other impairment, and so data from this source are likely to be biased and under-estimate the magnitude of the problem.

What can be said with certainty is that at least 25% of the infants treated for ROP during this project would have become totally blind without treatment, and more infants would have become visually impaired.

7. Reducing global inequities

What have been the project's activities and achievements in reducing gender disparities, either in terms of education of girls or advancement of women?

There are no gender differences in the rates or severity of ROP, and all infants were examined regardless of gender. There are no gender differences in access to NICUs.

What impact has the project had on improving the situation for the most disadvantaged in society?

This project was undertaken in the government health system, which caters for the poor. There are a large number of private NICUs in the city, but these were not included in the program. Teenage pregnancy and low socio-economic status are known to increase the risk of preterm birth, and a high proportion on mothers of the babies examined in this project were very young and uneducated.

Having a blind child puts considerable strain on parents and families in terms of psychological, emotional and economic impacts. As a result of this project infants have been prevented from becoming blind or visually impaired from ROP, so avoiding further disadvantage.

8. Resource management

In terms of human resources, were clear roles and responsibilities defined and utilized for project staff? Have any changes been made throughout the project?

After the project moved from São Paulo to Rio de Janeiro, a new staff had to be appointed. Responsibilities and roles were clearly established.

Project staff:

- Coordination/Management: Andrea Zin, Cynthia Magluta, Regina Fialho
- Nurse trainers: Margareth Dutra, Edneia Oliveira, Marcelle Campos
- Ophthalmology Training: Andrea Zin and Viviane Lanzelotte
- Development of elearning resource Andrea Zin, Cynthia Magluta, Edneia Oliveira, Marcelle Campos, Margareth Dutra, Olga Bonfim, Jose Roberto Ramos, Maria Elizabeth Moreira, Maria de Fatima Junqueira Marinho and Daniela Verzoni withinput from experts from the University of Sao Paulo

In terms of infrastructure, has the project equipment been appropriately allocated and adapted for the context? Are there any discrepancies from the original plan?

The only equipment provided was for examining babies, so that each NICU has its own, and one laser, which is being shared by several ophthalmologists.

9. Sustainability & scale-up

How likely is this project to be sustained? Have activities already been or are being carried out with regards to replication or scale up?

The ROP programs are highly sustainable as they are integrated into the health systems.

The ROP programs will continue after funding from this project ceases, and are likely to expand.

10. Monitoring and dissemination

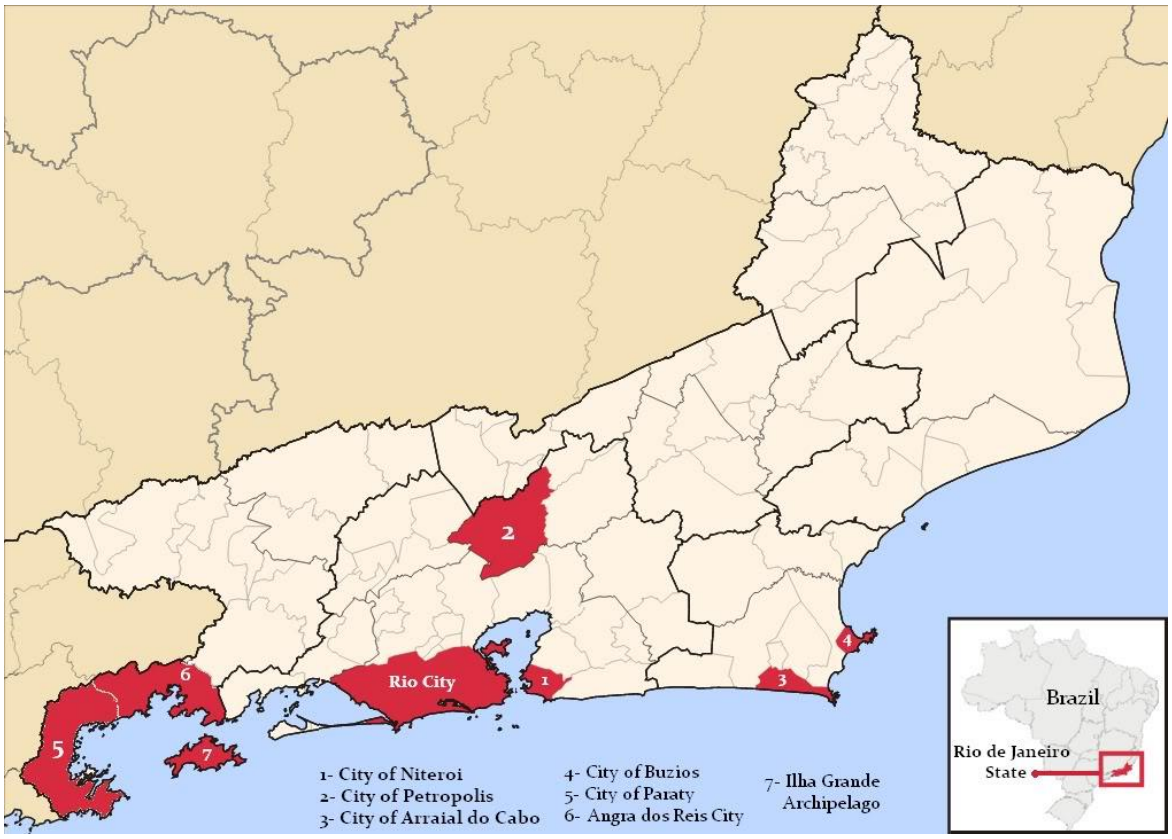
What monitoring tools are being used and who is in charge of these? Were they appropriate?

Ophthalmologists were asked to report to Dr Zin every six months on the number of babies examined, the number treated and their characteristics. These were appropriate indicators. As indicated above, other indicators such as coverage, follow up rates and response to treatment would allow problems needing action to be identified.

What activities have been undertaken to disseminate knowledge gained by the project – please provide a quantitative and qualitative report on publications, presentations or other dissemination activities/tools.

The activities undertaken and preliminary results of the project have been presented in several meetings organised for the Municipal and State Health Departments (2 meetings/year/Health Department), meetings of the Brazilian Neonatal Research Network (2011 and 2012), one National ROP workshop (Peru, Aug 2012), one Regional ROP workshop (Colombia, September 2013) and at the Standard Chartered Bank office in New York City (October 2012).

APPENDIX 1. Map of Project area



<u>Cities included in ROP programs:</u>

Duque de Caxias, Nilópolis and Niterói (program could not be established)

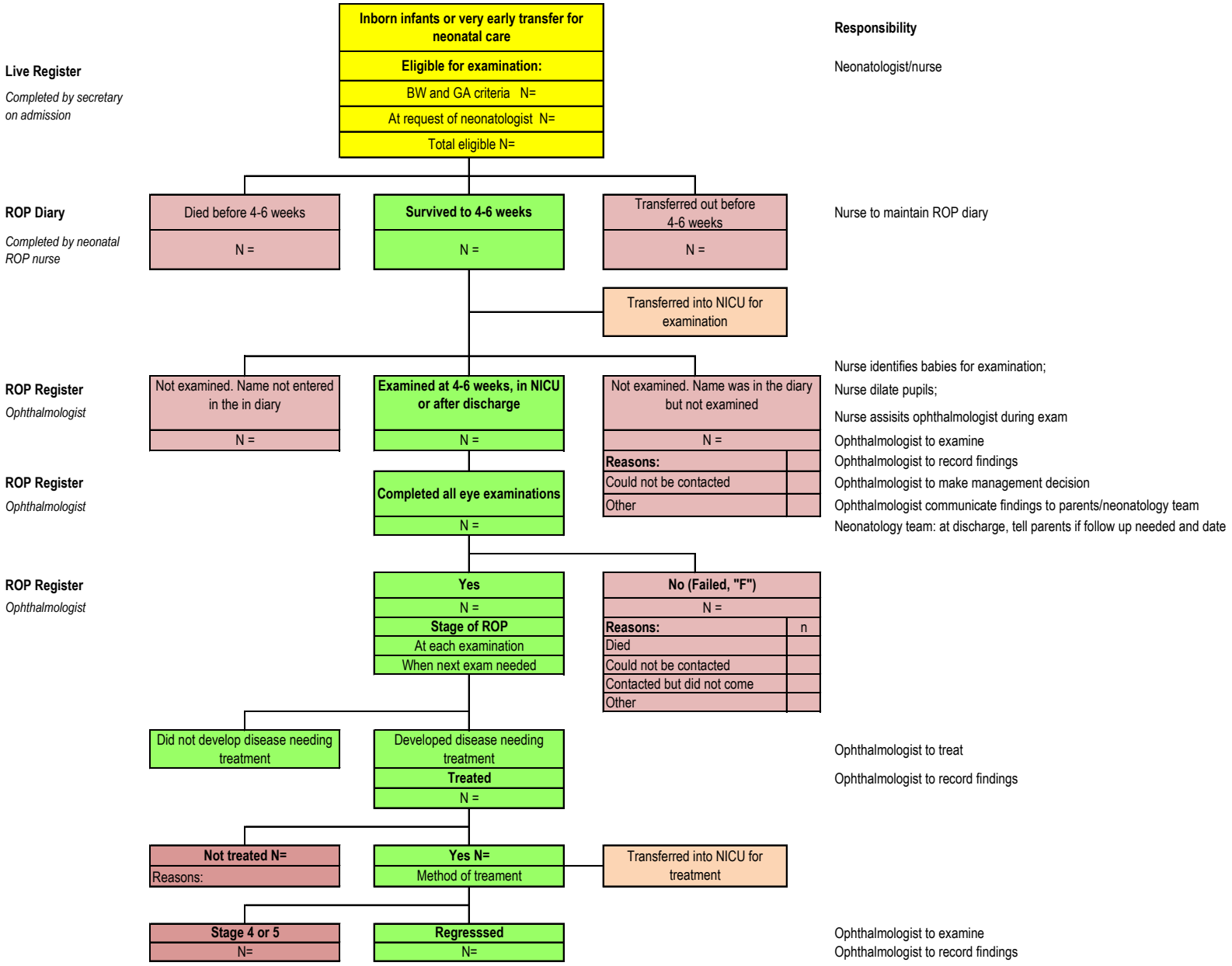
Population in 2011

Whole state of Rio de Janeiro	16,112,678	100%
Metropolitan region Rio de Janeiro	11,909,897	74%
Cities outside Rio Metropolitan region	4,202,781	26%

Units in the SiB project are responsible for approximately 30% (450/1,500) of preterm babies born annually in the Metropolitan with birth weights <1,500 eligible who require examination for ROP.

APPENDIX 2. MONITORING ROP PROGRAMS

Flow chart – see next page


Responsibility
Live Register
Completed by secretary on admission
Inborn infants or very early transfer for neonatal care
Eligible for examination:
BW and GA criteria N=
At request of neonatologist N=
Total eligible N=
Neonatologist/nurse
ROP Diary
Completed by neonatal ROP nurse
Died before 4-6 weeks
N =
Survived to 4-6 weeks
N =
Transferred out before 4-6 weeks
N =
Nurse to maintain ROP diary
Transferred into NICU for examination
ROP Register
Ophthalmologist
Not examined. Name not entered in the in diary
N =
Examined at 4-6 weeks, in NICU or after discharge
N =
Not examined. Name was in the diary but not examined
N =
Reasons:
Could not be contacted
Other
Nurse identifies babies for examination;
Nurse dilate pupils;
Nurse assisits ophthalmologist during exam
Ophthalmologist to examine
Ophthalmologist to record findings
ROP Register
Ophthalmologist
Completed all eye examinations
N =
Ophthalmologist to make management decision
Ophthalmologist communicate findings to parents/neonatology team
Neonatology team: at discharge, tell parents if follow up needed and date
ROP Register
Ophthalmologist
Yes
N =
Stage of ROP
At each examination
When next exam needed
No (Failed, "F")
N =
Reasons:
n
Died
Could not be contacted
Contacted but did not come
Other
Did not develop disease needing treatment
Developed disease needing treatment
Treated
N =
Ophthalmologist to treat
Ophthalmologist to record findings
Not treated N=
Reasons:
Yes N=
Method of treament
Transferred into NICU for treatment
Stage 4 or 5
N=
Regresssed
N=
Ophthalmologist to examine
Ophthalmologist to record findings

MONITORING ROP PROGRAMMES

<u>EXCLUDE</u> babies transferrred to the NICU just for ROP treatment

Name of NICU _____

Name of examining ophthalmologist(s) _____

Reporting period Year _____

Note: Report for the period ending 6 months earlier

Months _____ to _____

	Total admitted in reporting period	Died/transferred before 1st exam	Survived to date of 1st exam			
Number of babies eligible for examination *(from Live Register)*				**A**		
Extras added by neonatologist				**B**		
TOTAL who should have been examined				**C = A + B**		
Number and proportion of babies having first eye examination *(from ROP Register)*					**D**	**% (D/C x100)**
Number and proportion of babies who should have had a first examination but did not:					**E (C-D)**	**% (E/Cx100)**
Number and proportion of babies completing ALL examination					**F**	**% (F/C x100)**
Number and proportion of babies NOT completing all examinations					**G (C-F)**	**% (C/F x100)**

Reasons:

Died	
Could not be contacted	
Contacted but did not come	
Other	

Stages of ROP by birthweight group (maximum stage of ROP in worst eye at only/last examination)

	No ROP	No ROP	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	AP-ROP
	Fully vasc	Immature vs						
<1000gs								
1000-1499								
1500-1749								
1750-1999								
2000 or more								

Stages of ROP by gestational age (maximum stage of ROP in worst eye at only/last examination)

	No ROP	No ROP	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	AP-ROP
<26 weeks	Fully vasc	Immature vs						
26-28								
>28-30								
>30-32								
>32-34								
>34								

Number of babies treated in study period: inborn ____ AP-ROP ____ ET-ROP ____ **TOTAL**

Note: exclude infants referred from other units just for ROP treatment :

Birthweight & gestational age of treated babies								**Characteristics of babies**		**Method of treatment**	**Regresssed**	
Baby 1	PMA**		wks	BW		GA					Yes	No
Baby 2	PMA**		wks	BW		GA					Yes	No
Baby 2	PMA**		wks	BW		GA					Yes	No
Baby 3	PMA**		wks	BW		GA					Yes	No
Baby 4	PMA**		wks	BW		GA					Yes	No
Baby 5	PMA**		wks	BW		GA					Yes	No
Baby 6	PMA**		wks	BW		GA					Yes	No
Baby 7	PMA**		wks	BW		GA					Yes	No
Baby 8	PMA**		wks	BW		GA					Yes	No
Baby 8	PMA**		wks	BW		GA					Yes	No
Baby 10	PMA**		wks	BW		GA					Yes	No

***PMA=post menstrual age at treatment*

Stages of ROP by birthweight group (maximum stage of ROP in worst eye at only/last examination)

	No ROP	No ROP	Stage 1	Stage 2	Stage 3	Stage 4a/b	Stage 5	AP-ROP
	Fully vascularized	Immature vessels						*Do NOT include in Stage 2 or 3*
<1000gs								
1000-1499								
1500-1749								
1750-1999								
2000 or more								

Stages of ROP by gestational age (maximum stage of ROP in worst eye at only/last examination)

	No ROP	No ROP	Stage 1	Stage 2	Stage 3	Stage 4a/b	Stage 5	AP-ROP
	Fully vascularized	Immature vessels						*Do NOT include in Stage 2 or 3*
<26 weeks								
26-28								
>28-30								
>30-32								
>32-34								
>34								

Number of babies needing treatment in study period: inborn ____ AP-ROP ____ ET-ROP ____ **TOTAL**

Number of babies actually treated in study period: inborn ____ AP-ROP ____ ET-ROP ____ **TOTAL**

Note: exclude infants referred just for ROP treatment :

Birthweight & gestational age of treated babies

		Characteristics of babies						Method used	Regresssed	
Baby 1	PMA**		wks	BW		GA			Yes	No
Baby 2	PMA**		wks	BW		GA			Yes	No
Baby 2	PMA**		wks	BW		GA			Yes	No
Baby 3	PMA**		wks	BW		GA			Yes	No
Baby 4	PMA**		wks	BW		GA			Yes	No
Baby 5	PMA**		wks	BW		GA			Yes	No
Baby 6	PMA**		wks	BW		GA			Yes	No
Baby 7	PMA**		wks	BW		GA			Yes	No
Baby 8	PMA**		wks	BW		GA			Yes	No
Baby 8	PMA**		wks	BW		GA			Yes	No
Baby 10	PMA**		wks	BW		GA			Yes	No

***PMA=post menstrual age at treatment*

Data to be collected to register babies eligible for eye examination at the time of admission ("Live register")

	Mothers name	Date admitted	Date of birth	Inborn or referral (outborn)	Birthweight	Gestational age	Date when will be 4 weeks of age	Still in NICU at 4 weeks (Yes/No)	If not, why not: died, transferred; discharged
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									

etc

APPENDIX 3. WORKSHOP UNDERTAKEN DURING PROJECT PERIOD

Workshops

1. Target: To organize 6 workshops in 3 years (Venezuela, Mexico, Brazil, Peru, Nicaragua and Colombia)
2. Output: 6 workshops organized from 2010-1013. Brazil workshop was cancelled due to local management difficulties. El Salvador workshop was performed

Country visits:

1. Target: To perform 3 visits: Honduras (year 1) and El Salvador (year 2), other (year 3)
2. Output: 2 visits were performed - El Salvador and Argentina. Honduras was cancelled due to local management difficulties and Argentina was chosen because of a successful neonatal country intervention.

2010

Workshops:
Colombia: October 20-23, 2010.
Nicaragua: November 15-17, 2010.

Visit:
Guatemala (not El Salvador) was visited in Nov 18-19, 2010 by Dr Brian Darlow

2011

Workshops:
Venezuela: July 22-23 (Follow-up workshop + strategic planning)
18 ophthalmologists, 10 pediatricians, 5 nurses and 2 Low Vision experts from 11 states of the country attended this workshop.
CBM and the Venezuelan Society of Ophthalmology supported this event.
Facilitators:

- Dr. Luz Gordillo, Ophthalmologist, ROP expert from Lima
- Dr. Ana María Villanueva, pediatrician from Lima.

El Salvador: Sept 1-2 (1st national workshop – situation analysis)
Seventy-seven individuals representing 16 cities from across El Salvador attended the Workshop consisting in 13 ophthalmologists, 31 neonatologists/pediatricians, and 33 NICU nurses as well as representatives from the MOH and USAID. Also present were Dr. Marina Estela Avalos, Director of Health from the Ministry of Health and Dr Roberto Sanchez Ochoa , director of the maternity hospital.
Facilitators:

- Eduardo H.Bancalari, MD, Miller School of Medicine, University of Miami, USA
- Graham Quinn MD, MSCE, The Children's Hospital of Philadelphia, University of Pennsylvania School of Medicine, USA
- Ana Quiroga, Escuela de Enfermería, Universidad Austral, Argentina
- International observer: Luxme Hariharan, Resident Physician, University of Pennsylvania

Mexico: Aug 31-Sept 2 (Advocacy meeting)
90 participants (50 ophthalmologists, 20 neonatologists and 20 nurses) attended this workshop,
Facilitators:

- Dr. Brian Darlow, neonatologist, Christchurch School of Medicine, New Zealand,
- Dr. M de la Fuente, ophthalmologist Yucatán and others.

2012

Peru, Lima: August 8-10
Purpose:
A follow-up workshop for strategic planning and to revise the national ROP guidelines

70 participants: 22 ophthalmologists, 20 neonatologists/ pediatricians, 18 registered nurses, 1 medical technician and 9 representatives from the health authorities, MINSA and EsSalud.
Facilitators:

- Prof. Clare Gilbert (International Centre for Eye Health (ICEH), London School of Hygiene and Tropical Medicine (LSHTM), United Kingdom);
- Dr. Andrea Zin (Fernandes Figueira Institute, FIOCRUZ, Brazil, PAHO Collaborative Centre for thePreventionofChildhoodBlindness, CBM advisor for ChildhoodBlindness);
- Prof. Brian Darlow (University of Otago, New Zealand);
- Dr Karin Van Dijk (CBM, global advisor for low vision, Low vision specialist Netherlands).

Conclusions:
1. Good collaboration between nurses, neonatologists, ophthalmologists and institutions;
2. ROP programs been set up in many centres outside of Lima;
3. Legislation which makes examination for ROP mandatory for ROP and which guarantees payment to hospitals is having a significant impact;
4. Babies are still being referred with advanced ROP. Reasons need to explored and how best to expand ROP programs and improve the quality of existing programs to prevent these cases;
5. Many NICUs still lack key items of equipment, mainly for oxygen delivery. There also inadequacies in labour wards, intermediate care nurseries and operating theatres;
6. There is a lack of trained ophthalmologists to treat ROP and a lack of lasers in some centres;
7. Nurse-infant ratios are less than optimal in many centres;
8. Low vision services are being implemented, both in Lima and in the provinces, and there is a need to network these services with neonatal follow-up facilities.

Honduras: Cancelled because of local difficulties.

Argentina visited by Dr Luxme Hariharan, MD, MPH, Resident Physician, University of Pennsylvania.

Purpose: To explore the role UNICEF and others played in bringing about the improvement in neonatal care that has taken place in Argentina, and to evaluate the impact in terms of rates of blindness due to ROP.

2013

III Regional ROP Workshop Cartagena, Colombia, September 9-10

40 participants (neonatologists, nurses, ophthalmologists)
8 facilitators; 7 international observers from CBM, Orbis, PAHO, Clarity, FIOCRUZ

Outputs:
1. Revised regional ROP guidelines for prevention of ROP, taking account of the findings of recent clinical trials on optimum oxygen saturation targets, and for examination and treatment of ROP, taking account of the controversial new treatment with Avastin.
2. Strategic plan for the region defined

APPENDIX 4. Agenda for the regional ROP workshop in Cartagena, Colombia

III Taller Latinoamericano de Retinopatía del Prematuro (ROP)
Hotel Capilla del Mar
Cartagena, Colombia
9-11 de septiembre de 2013

Facilitadores:

Prof. Clare Gilbert, FRCOphth, MD. MSc. Centro Internacional de Salud Ocular, Escuela de Londres de Higiene y Medicina Tropical, Londres, Reino Unido

Prof. Brian Darlow, MD, Universidad de Otago, Christchurch, Nueva Zealand

Graham Quinn MD, MSCE, Hospital de Niños de Filadelfia, Universidad de Pensilvania, Facultad de Medicina, EE.UU.

Augusto Sola, MD, St. Jude Medical Center, EE.UU, Presidente del Siben

Juan Carlos Silva, Asesor Regional, Organización Panamericana de Salud (OPS)

Prof. Claudia Zuluaga- Botero MD, Universidad del Valle y Instituto Para Niños Ciegos y Sordos del Valle del Cauca, Colombia

Luz Consuelo Zepeda Romero MD MSc CEH, Hospital Civil de Guadalajara Universidad de Guadalajara, México

Andrea Zin, MD, PhD, Instituto Fernandes Figueira, FIOCRUZ, OPS/OMS Centro de Colaboración para la Prevención de la Ceguera Infantil, Río de Janeiro, Brasil

Patrocinadores:

Christoffel Blindness Mission (CBM)
Orbis
OPS
Clarity
Iridex

Día 1		
8:00-8:30	Presentación de posters	
8:30	Bienvenida y presentación de los participantes	Sola/Zuluaga/ Watson/Peñuela
8:50	Objetivos del taller	Zin
9:00-9:20	ROP como causa de ceguera	Gilbert
9:20-9:40	Prevención de ceguera por ROP: Enfoque multidisiplinario (Intervenciones para prevenir la ROP)	Darlow
9:40-10:00	Presentación de las guías regionales actualizadas sobre detección y tratamiento de ROP	Quinn/Darlow
10:00-12:00 (habrá Café disponile)	Muestra de los posters de: Argentina, Bolivia, Brasil, Chile, Colombia, Costa Rica, Cuba, República Dominica, Ecuador, El Salvador (Actualización de los planes nacionales, políticas y legislación, logros y los obstáculos en los programas nacionales que se llevan a cabo desde la última reunión regional de ROP (Mar del Plata)	
12:00-14:00	Almuerzo	
14:00-14:30	Plan de Prevención de la Ceguera de la OPS. Rol de los Ministerios de Salud. (¿Es alcanzable para los gobiernos?)	OPS
14:30-16:30 (habrá Café disponile)	<u>Sesión 1 de trabajo en grupo y retroalimentación</u> 1. Limitaciones de los programas actuales y su superación 2. Sustentabilidad delos programas de ROP incluyendo un proyecto de Ley (delinear los componentes esenciales de una ley) 3. Monitoreo y Evaluación: MIS	

	Sesión 2a de trabajo en grupo y retroalimentación – oftalmólogos (2 grupos) Identificar entre los temas a continuación, cuáles son las principales fortalezas y debilidades de los programas de ROP. Hacer sugerencias para superar las barreras 1. Información para los padres y para el personal de salud que brinda tratamientos, los riesgos reales al usar antiangiogénicos 2. Criterios de selección 3. Tiempo, método, frecuencia y lugar de los exámenes, así como asegurar el seguimiento 4. Digitalización de imágenes para documentar los hallazgos y / o para la detección a través de telemedicina 5. Método de tratamiento, y seguimiento después del tratamiento, antiangiogénicos 6. Capacitación en exámenes y tratamientos 7. Acceso a cirugía vítreo-retiniana 8. Seguimiento de los bebés prematuros 9. Derivación a programas de baja visión / rehabilitación de niños con discapacidad visual por ROP 10. Datos recogidos para el seguimiento y evaluación de los programas Sesión 2b de trabajo en grupo y retroalimentación – neonatólogos / enfermeros Análisis de los lineamientos regionales: cómo aplicar en su país 1. Estándares mínimos aceptables para el monitoreo del oxígeno 2. Monitoreo a todos los pacientes que reciben oxígeno 3. Identificación y registro de los bebés que necesitan exámenes (quién y cómo) 4. Cuidados durante el examen, laser / crio, tratamiento antiangiogénico en cuidados intensivos 5. Asegurar que los bebés dados de alta y tratados son sujetos de seguimiento 6. Componentes pediátricos y seguimiento del desarrollo de los bebés tratados con antiangiogénicos 7. Mejores prácticas en cuidado neonatal: el control de la temperatura, dolor, infección Sesión 2b de trabajo en grupo y retroalimentación - Formuladores de políticas 1. Abogacía e información para los responsables de hacer políticas 2. Rol de los Ministerios de Salud, acceso a los programas de ROP 3. Política, legislación 4. Planificación de un programa de cobertura universal de ROP a. Disponibilidad de recursos humanos (oftalmólogos) b. Capacitación sobre el examen y tratamiento, obligatorios para todos los programas de residencia en oftalmología c. Disponibilidad de equipos de diagnóstico y tratamiento 5. ¿Cómo lidiar con la necesidad de contar con mayor cobertura de atención neonatal 6. Sistemas de gestión de la información (conjunto mínimo de datos) planificación, monitoreo y evaluación de programas 7. Prevención de la retinopatía del prematuro mediante educación y concienciación de las enfermeras y neonatólogos

Reunión SIBEN – Sept 11 2013

ROP en Latino América: Dónde estamos y a dónde vamos?

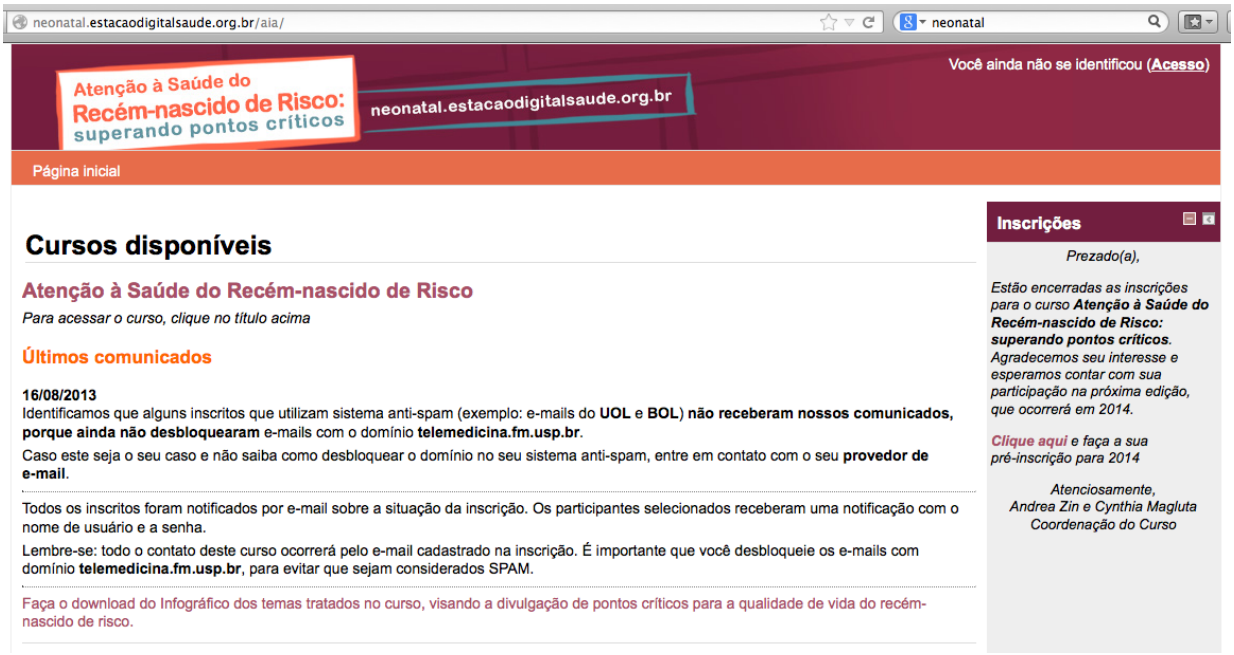
Facilitadores: Gilbert, Sola, Darlow, Quinn, Silva, Zuluaga, Zepeda, Zin

8:30-8:40	Bienvenida y Presentación	Sola and Zuluaga
8:40-9:00	ROP como causa de ceguera: Una perspectiva internacional	C Gilbert
9:00-9:20	ROP como un indicador de la calidad de los cuidados neonatales	B Darlow
9:20-9:40	Monitoreo del oxígeno en recién nacidos prematuros: evitando confusión y malos entendidos en la práctica cotidiana	A Sola
9:40-10:00	Detección de retinopatía grave: métodos actuales y alternativos	G Quinn
10:00-10:20	Coffee break	
10:20-10:40	Opciones actuales de tratamiento	C Zepeda
10:40-11:00	Rol de los Miniserios de Salud	JC Silva
11:00-11:20	Cuáles son los siguientes pasos? Conclusiones y recomendaciones	A Zin
11:20-12:00	Discusión	A Zin

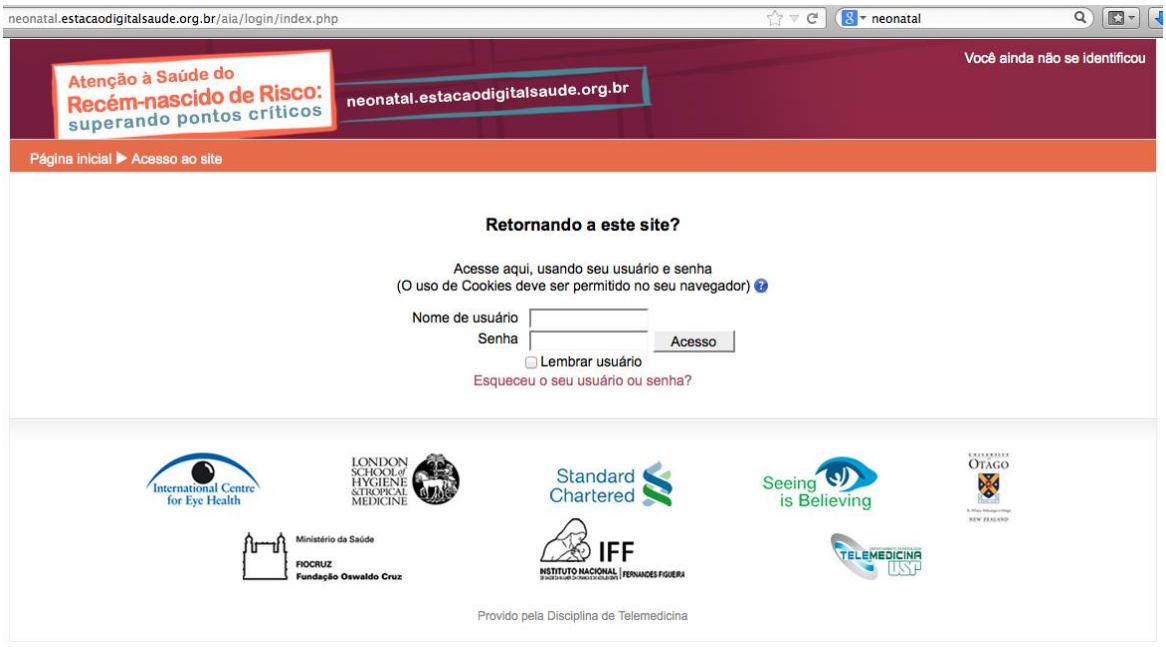
APPENDIX 5. eLEARNING RESOURCE FOR ROP

Internet screen print outs of the POINTS-ROP online course

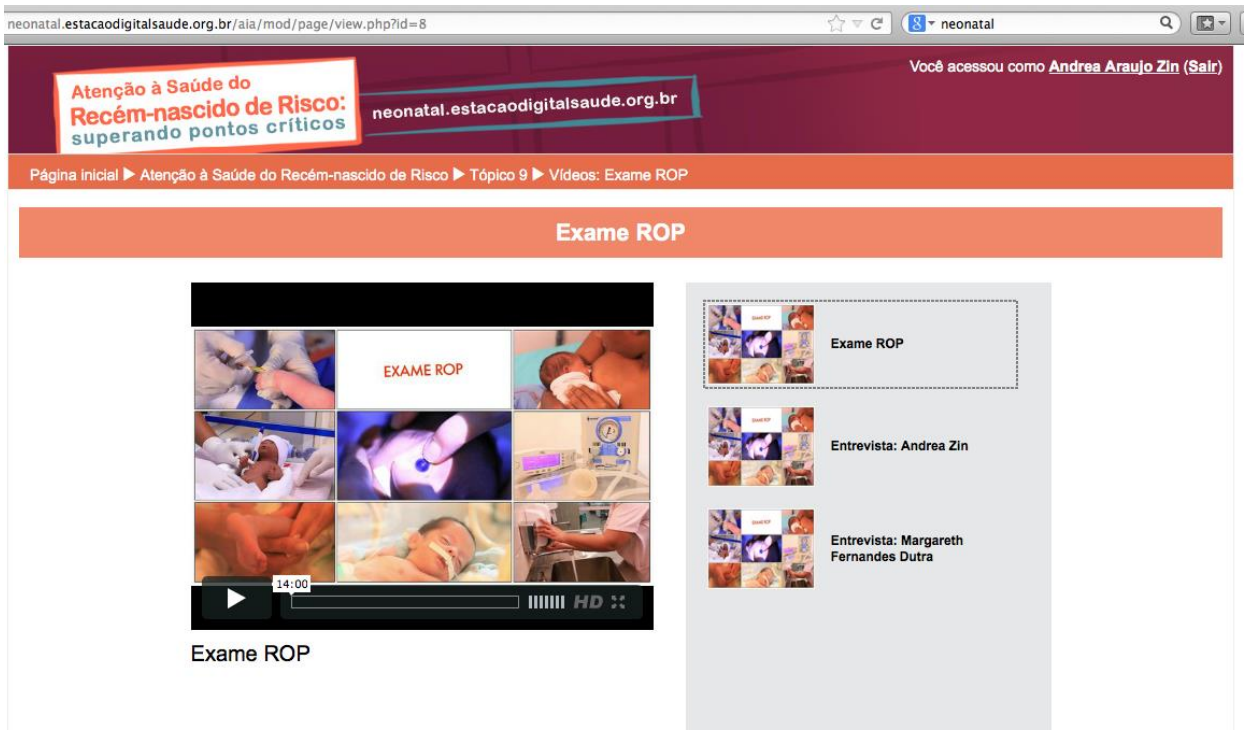
http://neonatal.estacaodigitalsaude.org.br/aia/



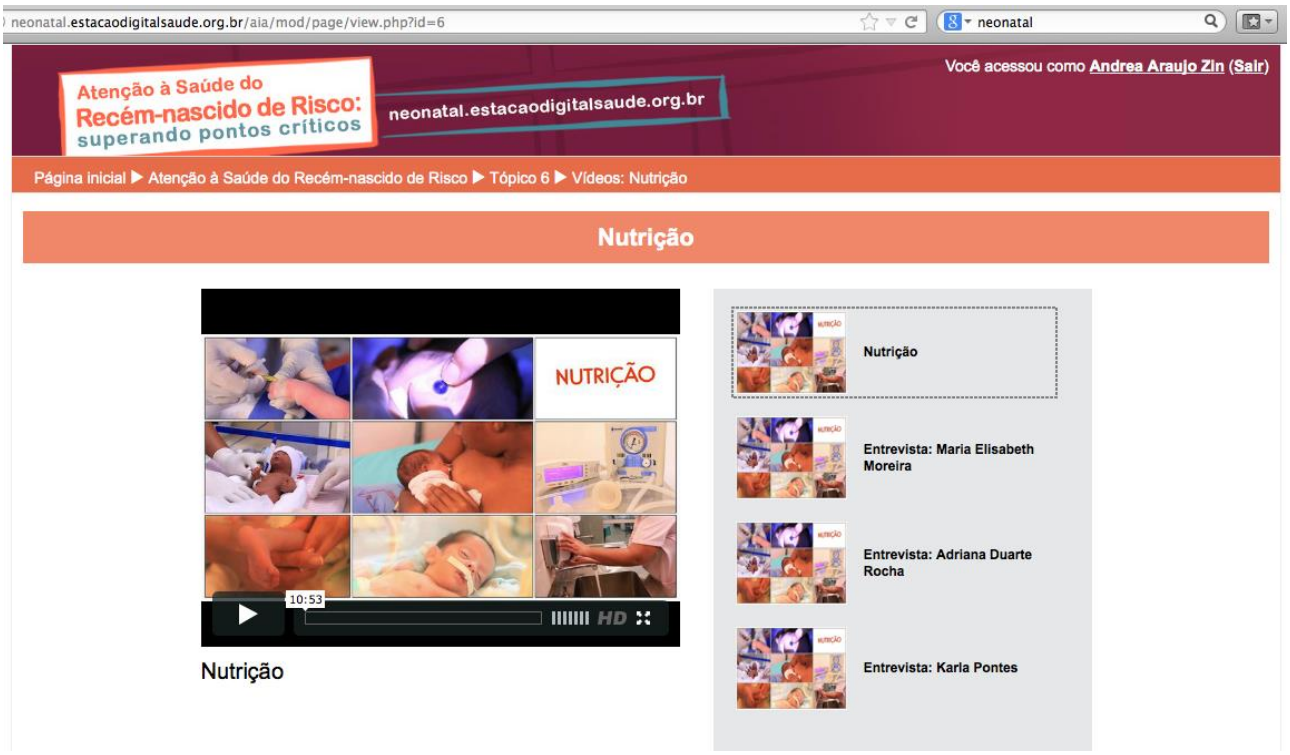
Front page



Collaborating institutions logos



Page where DVD on ROP can be accessed



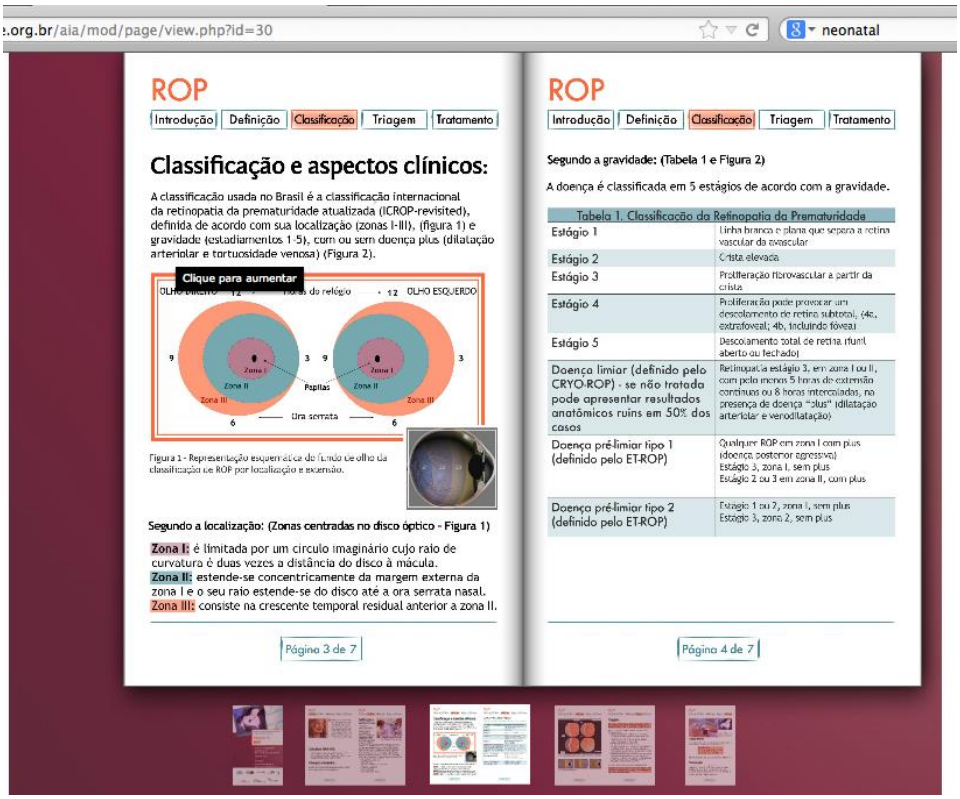
Page where DVD on nutrition can be accessed

Page where DVD on delivery and monitoring oxygen can be accessed

First page of reading material on control of infection

Pages 3 and 4 of the text on supportive care

Pages 3 and 4 of the text on delivery and monitoring oxygen



ROP

Introdução | Definição | Classificação | Triagem | Tratamento

Classificação e aspectos clínicos:

A classificação usada no Brasil é a classificação internacional da retinopatia da prematuridade atualizada (ICROP-revisited), definida de acordo com sua localização (zonas I-III), (figura 1) e gravidade (estadiamentos 1-5), com ou sem doença plus (dilatação arteriolar e tortuosidade venosa) (Figura 2).

Clique para aumentar

OLHO DIREITO ... Horas do relógio ... 12 OLHO ESQUERDO

9 3 9 3

Zona I Zona I Zona II Zona II Zona III Zona III

Papilas

6 Ora serrata 6

Figura 1 - Representação esquemática do fundo de olho da classificação de ROP por localização e extensão.

Segundo a localização: (Zonas centradas no disco óptico - Figura 1)

Zona I: é limitada por um círculo imaginário cujo raio de curvatura é duas vezes a distância do disco à mácula.
Zona II: estende-se concentricamente da margem externa da zona I e o seu raio estende-se do disco até a ora serrata nasal.
Zona III: consiste na crescente temporal residual anterior a zona II.

Página 3 de 7

ROP

Introdução | Definição | Classificação | Triagem | Tratamento

Segundo a gravidade: (Tabela 1 e Figura 2)

A doença é classificada em 5 estágios de acordo com a gravidade.

Tabela 1. Classificação da Retinopatia da Prematuridade

Estágio 1	Linha branca e plana que separa a retina vascular da avascular
Estágio 2	Crista elevada
Estágio 3	Proliferação fibrovascular a partir da crista
Estágio 4	Proliferação pode provocar um descolamento de retina subtotal, (4a, extrafoveal; 4b, incluindo fóvea)
Estágio 5	Descolamento total de retina (funil aberto ou fechado)
Doença limiar (definido pelo CRYO-ROP) - se não tratada pode apresentar resultados anatômicos ruins em 50% dos casos	Retinopatia estágio 3, em zona I ou II, com pelo menos 5 horas de extensão contínuas ou 8 horas intercaladas, na presença de doença "plus" (dilatação arteriolar e venodilatação)
Doença pré-limiar tipo 1 (definido pelo ET-ROP)	Qualquer ROP em zona I com plus (doença posterior agressiva) Estágio 3, zona I, sem plus Estágio 2 ou 3 em zona II, com plus
Doença pré-limiar tipo 2 (definido pelo ET-ROP)	Estágio 1 ou 2, zona I, sem plus Estágio 3, zona 2, sem plus

Página 4 de 7

Pages 3 and 4 of the text on ROP

Poster illustrating the POINTS-ROP topics

APPENDIX 6. PROGRAM MANAGEMENT