

## Perspective

# Retinopathy of prematurity: Overview and highlights of an initiative to integrate prevention, screening, and management into the public health system in India

Clare Gilbert<sup>1</sup>, Rajan Shukla<sup>2</sup>, G V S Murthy<sup>1,2</sup>, Bala V M Santosha<sup>2</sup>, Anirudh G Gudlavalleti<sup>2</sup>, Srividya Mukpalkar<sup>2</sup>, Pavani Yamarthi<sup>2</sup>, Suneetha Pendyala<sup>2</sup>, Anusha Puppala<sup>2</sup>, Supriya Edla<sup>2</sup>, Tripura Batchu<sup>2</sup>, on behalf of the India ROP Partners Implementation Consortium

**Purpose:** In India, more than 800 special newborn care units (SNCUs) have been established since 2008 in government facilities. More preterm infants are now surviving and blindness from retinopathy of prematurity (ROP) is increasing. The aim of the Queen Elizabeth Diamond Jubilee Trust's initiative (2012–2019) was to improve the quality of neonatal care and integrate ROP services into the government health system using expertise in the government and nongovernment sector in four states in a sustainable and scalable manner. **Methods:** State Ministries of Health were engaged and collaboration was established between three government programs (Ministry of Health and Family Welfare, Rashtriya Bal Swasthya Karyakram, and blindness prevention) and relevant professionals. Extensive training took place and equipment was provided. Implementation was guided by a multidisciplinary National Task Force and was monitored by state coordination committees. The Task Force appointed technical expert groups to support implementation through advocacy, information, education and communication materials, operational guidelines, a competency-based training curriculum, and an online database and website. **Results:** Twenty-two ophthalmologists in government facilities were trained to screen for ROP and nine to treat ROP. Almost 13,500 preterm infants were screened in 17 SNCUs and 86% of the 456 infants with sight-threatening ROP were treated. An educational resource using latest pedagogy based on key domain areas for best practices for small and preterm neonates including ROP has been developed and pilot tested and is being evaluated and scaled up. **Conclusion:** All four states are scaling up services or have plans to scale up, and several other states have started the initiatives.

**Key words:** India, integration, retinopathy of prematurity, visual impairment

Retinopathy of prematurity (ROP) became a major cause of blindness in children in the 1990s in many middle- and lower-middle-income countries.<sup>[1,2]</sup> This was the result of increasing survival of babies born preterm due to expansion of intensive neonatal care, coupled with limitations in the quality of care and low coverage of ROP screening and treatment. The same now applies to India, where in 2014 an estimated 3.5 million (uncertainty range 2.9–4.2 million) of the 26 million births were born preterm [gestational age (GA) of less than 37 weeks].<sup>[3]</sup> India has the largest number of preterm births of any country and accounts for almost a quarter (23.4%) of all the 14.8 million preterm births globally. Approximately 14% of all preterm infants are born with a GA of <32 weeks and are at particular risk of ROP. In India, it has been estimated that 490,000 preterm infants are born with a GA of <32 weeks, and at least 5,000

preterm infants require treatment for ROP every year.<sup>[4]</sup> The number of preterm infants requiring treatment for ROP and becoming blind has recently increased in India<sup>[5,6]</sup> in line with the recent expansion of district-level special newborn care units (SNCUs) in government facilities<sup>[7]</sup> and greater provision in the private sector.

Strategies to control visual loss from ROP entail preventing preterm birth and improving the outcomes of preterm birth (e.g., a course of antenatal corticosteroids), high-quality neonatal care from immediately after birth to reduce exposure to known, modifiable risk factors (including hyperoxia, fluctuating hypo-hyperoxia, sepsis, and poor weight gain), and timely screening followed by urgent treatment of infants developing the sight-threatening stages of ROP (ST-ROP) (i.e., type 1 ROP).<sup>[8]</sup> Evidence from high-income countries

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<sup>1</sup>International Centre for Eye Health, Department of Clinical Research, London School of Hygiene and Tropical Medicine, London, UK, <sup>2</sup>Indian Institute of Public Health, Public Health Foundation of India, Kavuri Hills, Madhapur, Hyderabad, Telangana, India

**Correspondence to:** Prof. Clare Gilbert, Professor of International Eye Health, Department of Clinical Research, London School of Hygiene and Tropical Medicine, Keppel Street, London - WC1E 7HT, UK. E-mail: [clare.gilbert@lshtm.ac.uk](mailto:clare.gilbert@lshtm.ac.uk)

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suggests that these strategies can greatly reduce visual impairment from ROP, but not entirely prevent it.<sup>[9]</sup>

Prior to 2012, ROP screening and treatment in India were primarily provided by a small number of nongovernment eye hospitals and apex government tertiary medical institutions who each screened for ROP in a limited number of neonatal units.<sup>[10]</sup> In recognition of the need to scale up ROP services, particularly in government sector SNCUs which serve poor rural populations, the Queen Elizabeth Diamond Jubilee Trust included ROP in India in their 5-year Avoidable Blindness program. To promote scalable and sustainable services, the approach adopted was the integration of ROP into neonatal services in the government sector. The goal of the program was to increase the healthy survival of preterm infants (i.e., without visual loss from ROP), with a target to screen and treat 12,400 and 250 preterm infants, respectively, in 20 neonatal units.

## Methods

Two major activities took place before the project was implemented: a National Summit was held in 2013 at which strategies for support were agreed (i.e., prevention of ROP through a quality improvement initiative and to use existing expertise to build the capacity to screen and treat ROP in government SNCUs) and a desk review and situational analysis to identify states for implementation. A National ROP Task Force (NTF) was established under the Ministry of Health and Family Welfare to guide and monitor implementation. The NTF provided a forum to bring together the relevant national programs for child health [i.e., the Ministry of Health and Family Welfare and Rashtriya Bal Swasthya Karyakram (RBSK)] and for eye care [National Programme for Control of Blindness and Visual Impairment (NPCB&VI)] as well as eye care and neonatal experts and other relevant professional groups and agencies. The NTF established a number of technical expert groups to take forward the quality improvement initiative, to develop and implement an advocacy strategy for policy change and communication, to develop and disseminate health education materials, and to develop operational guidelines, a competency-based training curriculum, software for online data collection and monitoring, and a website. Toward the end of the project, a program coordination committee was also convened. The program was managed by a dedicated team at the Indian Institute of Public Health, Hyderabad, with technical input from the London School of Hygiene & Tropical Medicine [Fig. 1].

The four states to be included in the project were agreed by the NTF (i.e., Madhya Pradesh, Maharashtra, Odisha, and Telangana), based on clear criteria and a situation analysis in eight states. Before the project was implemented, extensive advocacy took place with state governments, and tripartite agreements were signed. Mentoring partners (mostly from the nongovernment sector) with expertise in ROP and in neonatal care were identified for each state. The eye care partners were responsible for initial training and ongoing mentoring of screening and treatment, while the neonatal care partners visited the SNCUs in medical colleges and district hospitals on a regular basis to work with the neonatal teams to improve the quality of care. For ROP screening and treatment, a "hub-and-spoke" approach was adopted, with modifications depending on the local context. The intention

was that a medical college would be the hub, where capacities for ROP screening and treatment would be built, with three to four SNCUs in the surrounding districts as the spokes where screening would take place. All parents/carers provided written informed consent for screening and treatment according to each partner's policies. A dedicated online database (DRROP) was developed for data entry. Each state convened multidisciplinary State Coordination Committees which met to monitor progress and advise on bottlenecks.

The quality improvement initiative for ROP was built on the extensive body of educational materials already developed with support from the National Health Mission. The World Health Organization (WHO) Collaborating Centre for Training and Research in Newborn Care, All India Institute of Medical Sciences (AIIMS), New Delhi, along with the Post Graduate Institute of Medical Education Research, Chandigarh, and the Government Medical College and Hospital, Chandigarh, with the help of nearly 35 leaders in neonatology and nursing champions caring for preterm infants contributed to the development of this educational material. The ROP component of the initiative had two broad areas, the first being the development of a multitude of training materials in 10 modules on topics of relevance to ROP, including videos, webinars, text material, case studies, and self-assessment tools. Novel aspects were team training with use of simulation with mannequins and skills training equipment, and empowering staff to identify and solve problems using Plan, Do, Study, Act (PDSA) cycles.<sup>[11]</sup> The second component was an evaluation of this initiative in Madhya Pradesh based on a Theory of Change. The Theory of Change was used to determine the baseline data to be collected, including processes and outcomes of interest, and to assess assumptions and barriers to implementation among the causal pathways. This was followed by a series of learning sessions and quality improvement projects and a further period of data collection to assess change in practices and outcomes.

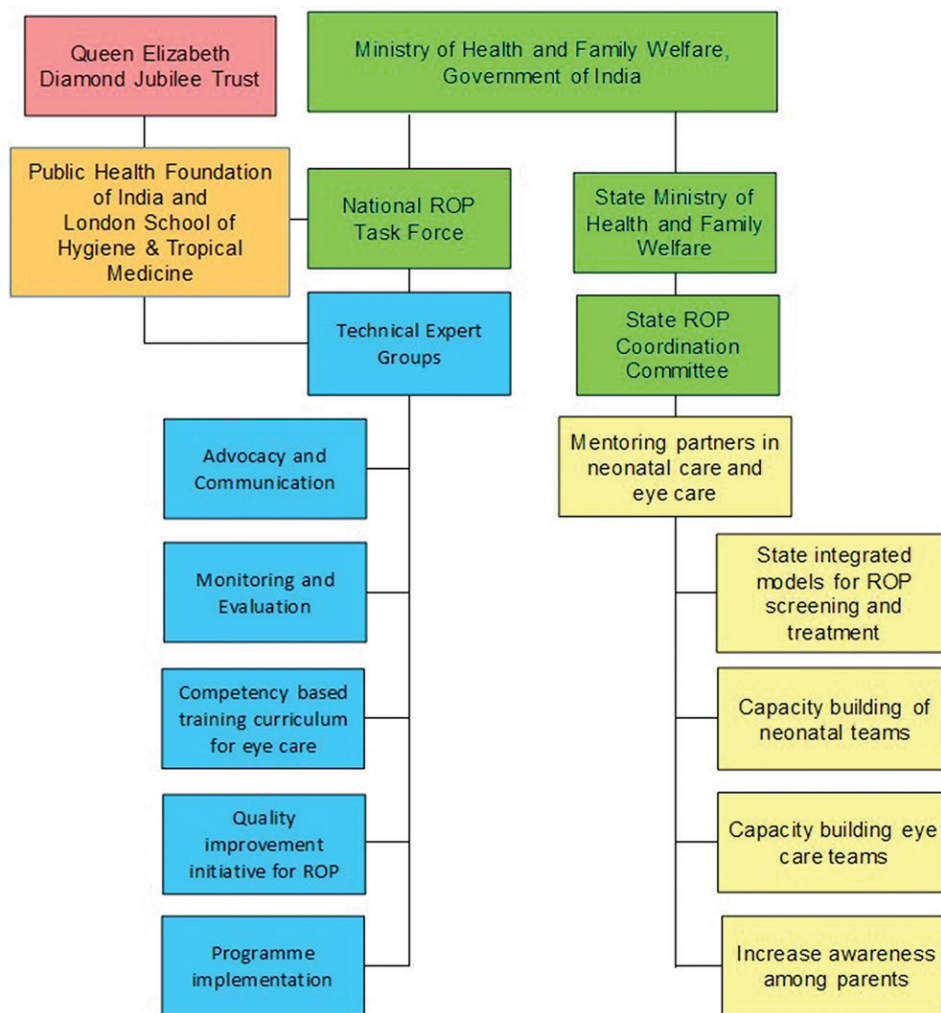
## Results

### Screening and treatment

During the period of implementation (November 2015–May 2019), 13,438 preterm infants were screened in 17 SNCUs in the four states [Table 1]. The highest number screened was in Telangana (3,896), but the average number screened per month was very similar across states (range 86–97). A total of 456 (3.4%) infants were identified with STROP (i.e., type 1 ROP, aggressive posterior ROP, or Stage 4 or 5 ROP), which ranged from 1.7% to 4.0% of babies screened, 317 (86%) of whom were treated.

During the project, 22 ophthalmologists in government district hospitals and medical colleges were trained to screen for ROP using binocular indirect ophthalmoscopy, several of whom required preliminary training on adults before learning how to screen infants. Nine ophthalmologists from medical colleges were also trained to treat ROP (laser and anti-vascular endothelial growth factor injections). Critical equipment required for screening and treatment were provided by the Trust. A large number of other personnel were trained or orientated on ROP, including obstetricians, neonatal nurses, midwives, and Accredited Social Health Activists (ASHAs).

The model of delivery varied somewhat from state to state depending on the local circumstances and state preferences. For



**Figure 1:** Structure of the Trust-supported project for the control of visual loss from retinopathy of prematurity in India

**Table 1: Number of preterm infants screened and treated by states (as of May 2019)**

State	Date started	Infants screened		Treatment needed for STROP		Infants treated	
		Overall <i>n</i>	Per month <i>n</i>	<i>n</i>	%	<i>n</i>	%
Telangana	November 2015	3,896	91	154	4.0%	154	100%
Madhya Pradesh	March 2016	3,801	97	142	3.7%	85	60%
Odisha	April 2016	3,276	86	117	3.6%	112	96%
Maharashtra	April 2017	2,465	95	43	1.7%	43	100%
Total		13,438	92	456	3.4%	394	86%

STROP=Sight-threatening ROP, i.e., type 1

example, in one state there was a lack of ophthalmologists in the government sector who could treat ROP, and this was addressed by commissioning private ophthalmologists. In another state, the SNCUs were dispersed, and an ophthalmologist in each location was identified and trained to treat. In some locations, the optometrist from the RBSK District Early Intervention Centre assisted during screening.

**Quality improvement**

The package of preterm care quality improvement training materials which included ROP was initially developed and

pilot tested in six SNCUs in Madhya Pradesh. The initiative, known as the Point of Care Continuous Quality Improvement (POCQI),<sup>[12]</sup> was launched by the WHO South East Asia Regional Office and UNICEF in December 2017 with sharing of training material which included the ROP component. The package was initially rolled out in Madhya Pradesh where neonatal teams in 13 neonatal units were oriented on quality improvement. A further 18 teams had been trained by the end of May 2019 in the other three states. The positive impact of quality improvement using PDSA cycles on different aspects of neonatal care of relevance to ROP, such as optimising oxygen

delivery, increasing kangaroo mother care and the use of breastmilk, and the uptake of ROP screening, for example, can be found in a special issue of Indian Pediatrics 2018, volume 55.<sup>[13]</sup> The neonatal mentoring partners also made multiple visits to the SNCUs in their respective states to support quality improvement.

### Outputs of technical expert groups

The technical expert groups produced a range of outputs including a policy brief and educational materials for parents (posters and leaflets), standard operating procedures for nurses, and public awareness materials. Other groups produced Operational Guidelines and a competency-based training curriculum and assessment package for ophthalmologists. In addition to the DRRROP software for program data collection, a dedicated website was developed where many of these outputs can be accessed.<sup>[14]</sup> Peer support groups for parents were also pilot tested.

## Discussion

Key lessons learnt were that engaging state governments, which is critical for sustainability and scaling up, can take time and that technical expert groups can develop initiatives which bring about positive change and produce outputs which support implementation and scaling up. As has been recognized elsewhere, ROP services need to be integrated into neonatal care services, and members of the neonatal team have a key role to play in ensuring that all eligible babies are screened and that engagement of families/parents is essential. Training ophthalmologists in ROP screening may require initial training in indirect ophthalmoscopy, and competencies beyond clinical skills are required, such as communication, leadership, keeping up to date with technical advances, and management skills. Given the lack of ophthalmologists in the government sector, the private (both for-profit and not-for-profit) sector can successfully fill the gap, particularly for the treatment of ROP. A way to address this gap would be to ensure that all postgraduate training in ophthalmology includes ROP.

Using an online data entry system can be challenging due to variable Internet connectivity, and resources need to be allocated to track babies through the system to ensure timely screening, with repeated screening and treatment if required. This particularly applies to infants who have been discharged from the SNCUs.

Several of the four states have plans or have already scaled up services for ROP based on learning from the Trust-supported project. In Odisha, ROP services are expanding to eight other SNCUs and in MP ROP services for five more SNCUs are included in RBSK's National Health Mission plans. In Maharashtra, state services are expanding to 10 further SNCUs in collaboration with HV Desai Eye Hospital with support from the State Health Department. New States, such as Tamil Nadu, in collaboration with Aravind Eye Care System, has expanded screening to 10 SNCUs with a grant from an international organization, and in Kerala the Ministry of Health is developing services for all government SNCUs. Haryana, Punjab, and Himachal Pradesh are also implementing ROP services in several SNCUs under the mentorship of PGIMER, Chandigarh. There are also plans to scale up the quality improvement initiative.

## Conclusion

The initiative exceeded expectations in terms of the target number of preterm infants screened and treated, and brought together neonatologists, pediatricians, neonatal nurses, and ophthalmologists from across the country on a common platform to tackle ROP. This in large part was due to the active engagement of the national and state governments, the work of the NTF and state coordination committees, and the dedication and commitment of all those implementing the project. The initiative demonstrates what can be achieved by integrating services into the government sector through partnerships between different national programs, professional groups, and sectors of healthcare delivery. The findings of the evaluation of the quality improvement initiative are awaited, but the findings from the quality improvement initiative using PDSA cycles are very encouraging. Efforts by the state governments to expand ROP services across the state and development of services in new states are important outcomes of the program and are in large part due to the active efforts of partnering institutions.

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### Conflicts of interest

There are no conflicts of interest.

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A nurse in the neonatal intensive care unit of Fernandez Hospital, Hyderabad, with a premature baby she has just fed. ©Poulomi Basu, The Queen Elizabeth Diamond Jubilee Trust