

## Retinopathy of prematurity: Maharashtra state model

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This report describes the goal, activities, and outcomes of the Queen Elizabeth Diamond Jubilee Trust funded retinopathy of prematurity (ROP) program in the state of Maharashtra in collaboration with the Public Health Foundation of India, Hyderabad. The project was initiated in July 2016 with the goal of establishing a sustainable ROP program in the special newborn care units (SNCUs) in public health facilities of five districts. Between 2016 and 2018, ophthalmology and neonatology teams from five district hospitals (DHs) were trained by nongovernment partner hospitals in the state. Infrastructure was developed by procuring equipment for ROP screening/treatment, and awareness generation activities were conducted with a range of stakeholders. Eight ophthalmologists were trained to perform ROP screening (from five DHs and one medical college), and five neonatology teams (pediatricians and nurses) from the project hospitals were trained in best neonatal practices to prevent ROP. The Pune district's hospital was developed as an ROP treatment center. Toward the end of the project period, six new facilities had an established ROP program. The state health department is in the process of scaling up the ROP program to a larger geographic region to ensure universal ROP screening coverage in the state of Maharashtra.

**Key words:** Maharashtra, public sector, retinopathy of prematurity, screening program

With a population of over 120 million, Maharashtra is the second most populous state in India.<sup>[1]</sup> There are 36 special newborn care units (SNCUs) in district hospitals (DHs) with a total bed strength of more than 750.<sup>[2]</sup> In 2015, there were nearly 40,000 admissions to these SNCUs and nearly half (20,000) were preterm infants. Considering an average survival rate of 80%, nearly 16,000 preterm infants need screening for retinopathy of prematurity (ROP) every year. According to recent (2016) estimates for India,<sup>[3]</sup> approximately 20% (3,200) of the surviving preterm infants are likely to develop any ROP and 5% (800) are at the risk of a lifetime of blindness/visual impairment from sight-threatening ROP (ST-ROP). These data provide an estimate of the need for ROP services in the public sector in Maharashtra. However, no data are available from private sector neonatal units, which means that the actual need may be much higher. The devastating impact of ROP blindness on affected children and their families makes a strong and urgent case for the development of ROP services.<sup>[4]</sup>

### Methods

Prior to 2016, there were no ROP screening guidelines from the health ministry and no guidelines on how to establish a structured and universal ROP screening program in the public sector. In 2016, the Maharashtra State Health Department signed a memorandum of understanding with the Queen Elizabeth Diamond Jubilee Trust, United Kingdom (UK) and

the Public Health Foundation of India, Hyderabad to establish ROP services in a limited number of SNCUs. Around the same time, the Rashtriya Baal Swasthya Karyakram (RBSK) introduced the ROP screening guidelines.<sup>[5]</sup> Implementing partners for the Maharashtra ROP project were the H. V. Desai Eye Hospital, Pune (ophthalmology) and K. E. M. Hospital, Pune (neonatology) both of which are nongovernment hospitals. The "model ROP project" was initiated in 2016 with the objective of establishing a sustainable ROP program in five DH SNCUs over 3 years. The development of infrastructure and capacity building of ophthalmology and neonatology teams were the most important activities. Other activities included awareness creation among all stakeholders, such as the public, parents of preterm infants, pediatricians, ophthalmologists, nurses, general practitioners (GPs), and allied ophthalmic personnel.

One ophthalmologist from each of the five DHs was selected for a 2-weeks training at the H. V. Desai Eye Hospital, Pune. Essential equipment was provided to the DHs and the mentoring center. Each trainee was administered a pretraining questionnaire to assess his/her training needs (knowledge and skill levels). Training started with practicing binocular indirect ophthalmoscopy on dummy eyes after a didactic lecture and demonstration by the trainer. This was followed by indirect ophthalmoscopy on adult eyes. Once the trainees were confident in examining adults, they were exposed to ROP screening under supervision, followed by independent screening. Trainees visited six SNCUs on two occasions

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(12 visits), screening more than 30 babies independently over 2 weeks. The training also included Microsoft PowerPoint presentations, demonstrations, hands-on practice, and discussions using an image bank of at least 100 images with the full range of clinical findings seen in ROP. At the end of the 2 weeks, a post-training questionnaire was administered to assess the change in knowledge and skill levels. The questionnaire consisted of basic ROP knowledge questions, as well as those eliciting their level of skills. Mentoring support continued with weekly visits to the Pune DH team for 6 months as this center was to be developed as a nodal center for ROP treatment in public health facilities. The trainers made quarterly visits to other centers to monitor activities and help resolve challenges.

The Pune DH ophthalmologist was also trained in laser treatment of ROP as this hospital was designed to be a nodal treatment center, and a green retina laser (Topcon Corporation, Tokyo, Japan) was provided. However, because of the long distances between the SNCUs [Fig. 1] in the four other districts, treatment was provided by ophthalmologists in the private sector. Private ophthalmologists were selected based on their training and experience in ROP care and engaged after signing a memorandum of understanding (MOU). The private providers were reimbursed through RBSK funds.

The neonatology mentoring team at the K. E. M. Hospital, Pune, primarily, imparted training to the neonatal teams from the project hospitals. The neonatologists and nurses were educated about best practices that can reduce the incidence of ROP. The neonatal teams attended a week-long training program at the K. E. M. Hospital, Pune, where they were trained in supplemental oxygen monitoring practices, hand hygiene to prevent infection, kangaroo mother care, and breast-feeding and nesting practices. In addition, the ophthalmologist mentors trained nursing teams from each DH SNCU in the documentation and maintaining a ROP register, counseling parents to improve follow-up visits, etc. A Microsoft PowerPoint presentation on ROP was also shown. These nurses were administered pre and posttraining questionnaires to assess the change in their knowledge and skills after training.

## Results

The five district SNCUs included in the project, as recommended by the State Health Department, were Nagpur, Nashik, Osmanabad, Pune, and Thane [Fig. 1], Thane, Pune, and Nagpur are the most populous districts in the state with a combined population of 30.3 million.<sup>[1]</sup> The initial intention had been to include a government medical college, but the State Health Department decided later to only include DH SNCUs.

Three-quarters of the trainee ophthalmologists were above the age of 45 years. Pre and posttraining assessment showed an improvement in knowledge (timing of first screening, need of multiple examinations, risk of visual impairment despite treatment, and need for long-term follow-up) from 40% to 100% and improvement in skills (binocular indirect ophthalmoscopy in adults and infants) from 20% to 40%.

In four of the project hospitals, private ophthalmologists visited every week to provide screening/treatment support. Based on the physical stability of the baby and convenience, babies were treated either in the SNCU or at the private facility.

Outcomes and outputs of the ROP project in Maharashtra are shown in Table 1. This also includes one medical college that started ROP screening independently in the first quarter of the project. Table 2 shows district-wise outputs. Despite the best possible efforts and communication with the parents, compliance with follow-up screening after discharge was less than 60%. The uptake of treatment was over 90%.

**Table 1: Outcomes and outputs during ROP project period**

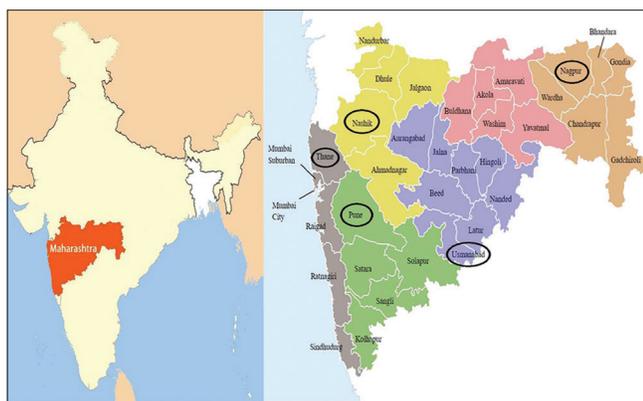
Activities (No of.)	Outputs
Districts with ROP screening facilities	5
Health facilities providing ROP screening	6 (5 DH, 1 medical college)
Ophthalmologists trained in screening	8
Ophthalmologists trained in the treatment	1
Preterm infants screened	2465
Infants detected with ROP	275 (11.1% of screened)
Infants treated	43 (1.7% of screened; 15.5% ROP detected)
CMEs/workshops	25
Health care professionals sensitized	1105

ROP=Retinopathy of prematurity, No=Number, DH=District hospital, CMEs=Continuing medical education

**Table 2: District-wise details of ROP screening and treatments**

District	Infants screened	Any ROP		No. treated	
		n	Incidence* (%)	n	Incidence* (%)
Nagpur	1233	21	1.7	6	0.5
Nashik	502	192	38.2	26	5.2
Osmanabad	231	1	0.4	1	0.4
Pune	302	46	15.2	7	2.3
Thane	197	15	7.6	3	1.5
Total	2465	275	11.1	43	1.7

\*Denominator for calculation is "infants screened", ROP=Retinopathy of prematurity, No. = Number



**Figure 1: ROP project districts from the state of Maharashtra (circled in Black)**

## Discussion

This project, to improve ROP care in public SNCUs in Maharashtra, was novel as it entailed collaboration between government, nongovernment, and private providers, as well as a collaboration between eye care and child health. The public-private partnership (PPP) model ensured the utilization of skilled resources in a timely manner (crucial to prevent blindness from ROP) as parents did not have to travel a long distance to reach the specialists, saving both time and meager financial resources.

There was a wide variation in the number of infants screened and the incidence of any ROP/treatable ROP by districts. Several factors could explain this variation. This data could have a bias, as overall compliance to follow-up was poor (60%). Potential variation in the quality of neonatal care, likely referrals of more sick infants from nearby tribal districts, could be responsible for higher incidence of ROP in some SNCUs. Data on proportion of aggressive posterior ROP (AP-ROP) could have served as a proxy measure of supplemental oxygen management. However, these data could not be accessed.

The project had many challenges, and each challenge proved to be a learning experience. Only one ophthalmologist was conversant with binocular indirect ophthalmoscopy and almost all found it difficult to become confident in ROP screening within 2 weeks. Most trainees needed support for a few months with frequent visits from mentors or local experts in the private sector. Hence, training should be for at least 1 month for ophthalmologists without skills in binocular indirect ophthalmoscopy, and we recommend deputing younger ophthalmologists for training to reduce the learning curve.

A persistent challenge was the low uptake of screening after discharge, which may be improved by sensitizing and training primary health care workers (accredited social health activists and auxiliary nurse midwives) to engage with parents.

As ROP screening services strengthen across the state, more babies with ROP-associated visual loss are likely to be identified, and a strong network of the district early intervention centers will assume an important role in habilitation. This would ensure good integration of visually impaired babies with their families and society.

The most positive impact of the program is the planning of ROP care in the state of Maharashtra. In the last year of the project (2018), the implementing partners (the H. V. Desai Eye

Hospital and K. E. M. Hospital) along with the State Health Department started planning to scale-up the ROP services to two new districts. In 2019, the State Health Department is taking the lead to scale-up ROP services to 29 districts, using either the PPP model or complete public facility model. At the time of writing, wide-field pediatric retinal imaging devices (3nethra neo, Forus Health, Bangalore, India) have been provided to further four DHs, and the H V Desai Eye Hospital, Pune, is training local teams.

## Conclusion

To summarize, this project in Maharashtra spearheaded a very important movement of ROP screening across several districts. With the current momentum, we hope that the state of Maharashtra could significantly reduce ROP-related blindness over the next few years.

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## Conflicts of interest

There are no conflicts of interest.

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