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

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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.[1,2] 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].[3] 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.[4] The number of preterm infants requiring treatment for ROP and becoming blind has recently increased in India[5,6] in line with the recent expansion of district-level special newborn care units (SNCUs) in government facilities[7] 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).[8] Evidence from high-income countries

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

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.\[10\] 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 (RBK)] 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.\[11\]

The four states to be included in the project were agreed by the NFT (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 bottle necks.

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 (PDCA) cycles.\[11\] 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 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 n | Per month n | n | %     | n | %     |
| 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),[12] 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.[13] 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 DRROP software for program data collection, a
dedicated website was developed where many of these outputs
can be accessed.[14] 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.

References
1. Blencowe H, Lawn JE, Vazquez T, Fielder A, Gilbert C.
Preterm-associated visual impairment and estimates of retinopathy
of prematurity at regional and global levels for 2010. Pediatr Res
2013;74(Suppl 1):35–49.
2. Gilbert C, Fielder A, Gordillo L, Quinn G, Semiglia R, Visintin P,
et al. Characteristics of infants with severe retinopathy of
prematurity in countries with low, moderate, and high levels
of development: Implications for screening programs. Pediatrics
2005;115:e518–25.
3. Chawanpaiboon S, Vogel JP, Moller AB, Lumbiganon P, Peiztold M,
Hogan D, et al. Global, regional, and national estimates of levels
of preterm birth in 2014: A systematic review and modelling analysis.
Lancet Glob Health 2019;7:e37–46.
4. Blencowe H, Moxon S, Gilbert C. Update on blindness due to
retinopathy of prematurity globally and in India. Indian Pediatr
2016;53(Suppl 2):S89–92.
5. Azad R, Chandra P, Gangwe A, Kumar V. Lack of screening
underlies most stage-5 retinopathy of prematurity among
cases presenting to a tertiary eye center in India. Indian Pediatr
2016;53(Suppl 2):S103–6.
6. Agarwal K, Balakrishnan D, Rani PK, Jalali S. Changing patterns
of early childhood blinding conditions presenting to a tertiary eye
center: The epidemic of retinopathy of prematurity in India. Indian
J Ophthalmol 2019;67:8168.
7. Shah HD, Shah B, Dave PV, Katariya JB, Vats KP. A step toward
healthy newborn: An assessment of 2 years’ admission pattern and
treatment outcomes of neonates admitted in Special Newborn Care
Units of Gujarat. Indian J Community Med 2018;43:14–8.
8. Chan-Ling T, Gole GA, Quinn GE, Adamson SJ, Darlow BA.
Pathophysiology, screening, and treatment of ROP: A multi-disciplinary
perspective. Prog Retinal Eye Res 2018 62:77e119.
9. Adams CG, Bunce C, Xing W, Butler L, Long V, Reddy A, et al.
Retinopathy of prematurity in the United Kingdom: Retreatment
rates, visual and structural 1-year outcomes. Eye (Lond) 2018;32:1752–9.
10. Gilbert C, Shukla R, Kumar R, Khera A, Murthy GV. Services for the detection and treatment of retinopathy of prematurity in major Indian cities: The 11-city 9-state study. Indian Pediatr 2016;53(Suppl 2):S112-7.

11. National Health Service, UK. Plan, Do, Study, Act (PDSA) cycles and the model for improvement Available from: https://improvement.nhs.uk/documents/2142/plan-do-study-act.pdf. [Last accessed 2019 Nov 06].

12. Point of Care Continuous Quality Improvement, Department of Pediatrics, All India Institute of Medical Sciences, Delhi. Available from: https://www.pocqi.org/. [Last accessed 2019 Nov 06].

13. Special issue on ‘better healthcare through quality improvement’, Indian Peds 2018;55. Available from: https://www.indianpediatrics.net/sep2018/current.htm. [Last accessed 2019 Oct 28].

14. Website for Queen Elizabeth Diamond Jubilee Trust programme on diabetic retinopathy and retinopathy of prematurity in India. Available from: https://drropindia.org/. [Last accessed 2019 Oct 28].