# Developing a sustainable and scalable control programme for Retinopathy of Prematurity in Kenya: a health system perspective

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## ABSTRACT

Disease-control programmes have an important role to play in strengthening health systems to deliver the interventions they recommend. In low and middle income countries, there is a shortfall in the coverage of interventions for primary, secondary and tertiary interventions for the control of Retinopathy of Prematurity (ROP)-related childhood blindness and visual impairment. We need strong health systems to ensure prevention, timely diagnosis and access to effective care for ROP. If a health system strengthening approach is employed as ROP interventions are being planned, health system issues that will affect implementation and outcomes can be identified.

**Key words:** Retinopathy of Prematurity, Health systems, Kenya

## The challenge of ROP

Retinopathy of Prematurity (ROP) is a sight-threatening disease associated with abnormal vascularization of the retina in premature infants. Each year, 15 million babies are born preterm worldwide, and over 30,000 of them become visually impaired or blind from ROP[1]. A recent study in Nairobi, Kenya found that 41.7% of premature babies screened for ROP in one hospital had ROP[2]. The main risk factors for ROP are gestation of ≤32 weeks (term gestation is 37-42 weeks), and very low birth weight (VLBW, ≤1500g)[3,4]. ROP is not present at birth, but develops in the first few weeks of life in infants at risk. Although blindness from ROP is avoidable, vision lost from ROP usually cannot be restored. The affected neonates risk life-long blindness with high costs, including reduced quality of life[5].

With the increase in the survival of preterm babies in most parts of the world, ROP has become a leading cause of preventable childhood blindness[6]. Low and Middle-Income Countries (LMICs) are particularly vulnerable to rapid increase in the burden of ROP, because improved access to neonatal services has led to increased survival of VLBW and premature babies[7]. The health systems in LMICs are already overstretched, for instance due to a severe health workforce crisis. This means that neonatal services for screening, detection and treatment of ROP are often less than optimal, which in turn increases the risk of sight-loss from ROP. These trends draw attention to the role of context in ROP control programmes, and the necessity of strengthening health systems.

Good antenatal perinatal and neonatal care, early detection and treatment are key to controlling ROP-related visual loss. The path to developing sustainable ROP control programmes that model these interventions particularly in LMIC is multi-pronged. Investment in the different aspects of the health system would determine the extent to which such a programme will be successful. In Kenya, a technical working group is taking forward the agenda of the Kenya retinopathy of prematurity control programme. This includes development of national clinical practice guidelines. The deliberations of this group have provided an opportunity for convergence and reconciliation of both health system perspectives and technical ROP-specific perspectives. In this article we consider the vital importance of taking a health system perspective when planning programmes for control of ROP.

## How can we strengthen the health system for prevention of blindness from ROP?

What does it take to prevent one premature/VLBW infant from blindness from ROP? Primary prevention of ROP can

be achieved through optimal neonatal care[8]. Secondary prevention of ROP is also achievable through:- screening for ROP within the first 30 days of life, urgent treatment for babies with sight-threatening ROP and appropriate follow-up to identify other conditions that can cause vision loss, such as refractive error or strabismus. Tertiary prevention includes surgical procedures for advanced ROP.

The overall goal of an ROP control programme is to reduce the prevalence and incidence of avoidable blindness and visual impairment caused by ROP in the population. A successful disease control programme strengthens the existing health system to enable it to deliver the programme interventions[9]. The World Health Report in 2000 defined a health system as 'all organizations, people and actions whose primary intent is to promote, restore or maintain health'[10]. The World Health Organization's (WHO) health systems framework has identified six inter-related building blocks of a well-functioning health system (Figure 1): leadership and governance; medicines and technologies, health management information systems; the health workforce; service delivery and financing. This framework is widely used, and has already been found to be a useful tool for planning for eye care services such as cataract services and diabetic retinopathy services[9,11].

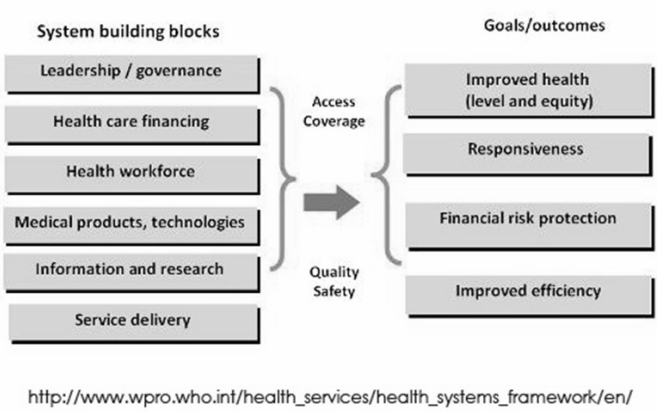


**Figure 1:** The WHO Health Systems Framework

Building on the WHO framework, Kenya has added two other building blocks in the Kenya Health Policy Framework (2014-2030), (health infrastructure, research and development)[12]. A recent Eye Health System Assessment (EHSA) in Kenya identified lack of capabilities to mobilise resources for implementation and sustenance of eye care services as one of the key weaknesses[13]. The health system of each country is unique, and unrecognized weaknesses in the building blocks can be a barrier to an effective national response to ROP. The following considerations emerged during the discussions of the ROP technical working group.

*Leadership and governance:* Is crucial for stakeholder coordination, mobilisation of resources, effective decision-making and accountability of all the actors. Some of the questions the ROP programme has considered are: What should be included in the clinical practice guidelines? How can teamwork be fostered between neonatal services and eye care services? As managing ROP is broader than just a public sector response, how can public –private institutional partnership be implemented to improve access to services? Advocacy is particularly an important facilitator for mobilising the necessary equipment for neonatal care, including oxygen delivery and monitoring systems. The targeted actors will include policy makers; professional societies; managers of neonatal and eye care programmes; private practitioners, training institutions, and parents of newborn babies.

*Service delivery:* What is the coverage of interventions such as antenatal corticosteroids given within 48 hours before preterm delivery? How can neonatal care be improved? How can mothers be encouraged to play their role in the care of the infant, such as breastfeeding or kangaroo care? What ROP screening and treatment criteria will apply in the country? How can absence or interruptions in these services be avoided? How can adverse outcomes at screening and treatment be monitored? What are the referral pathways for ROP?

*Human resource for health:* Are there sufficient numbers of neonatologists/paediatricians, paediatric ophthalmologists/general ophthalmologists or vitreo-retinal surgeons, and nurses? Are staff distributed where their services are needed? How do we embark on capacity-development at pre-service? Can an education package be provided as on-job training locally to increase the capacity of the health workers? How can we be sensitive to the time constraints and competing priorities that will be faced by these clinicians?

*Health finance:* How much does ROP screening and treatment cost? Cost is often a significant barrier to access and quality of care. How can we advocate for funding to meet any finance gaps? How can the cost of retinal laser, anti-Vascular Endothelial Growth Factor (anti-VEGF) treatment or vitreo-retinal surgery be driven down? What about the cost of equipment, training, space and human resources for the ROP programme - how can additional and sustainable financing be invested in these areas? Can technology such as telemedicine reduce the costs and improve efficiency in the programme? How do we measure the allocative and technical efficiency of these investments?

*Pharmaceuticals and other medical products:* Access to drugs and laser must be considered. How can supply-chain management for the drugs be improved? The majority of the neonates at risk will only require a screening examination; but this also requires medicines such as topical analgesics and mydriatics. Fewer of the neonates require retinal laser treatment or intraocular injections, and even fewer need surgery. However these

services need to be available at short notice, which calls for flexibility in the supply chain and availability of the equipment.

*Health Management Information System (HMIS):* What data needs to be collected in the programme? How is this data captured in the registers or other records? Some of the process indicators are: percentage of babies meeting the screening criteria who receive at least one ROP screening examination; percentage of babies meeting the treatment criteria who receive the appropriate intervention; and percentage of babies needing ROP treatment who are treated within 48 hours of the decision to treat. How will the monitoring and evaluation framework be implemented?

*Health infrastructure:* Optimal neonatal care requires adequate equipment in the newborn unit, such as temperature monitors, oxygen blenders, pulse oximeters and technologies for infection control. The screening examination requires the use of cameras, indirect ophthalmoscopes, lenses, and eye speculums. Sterilization facilities, sterile facilities for administration of anti-VEGF, and indirect laser facilities are also required.

*Research and development:* There is need to advance research, beginning with a nationwide needs assessment for ROP services in newborn units. The number needed to screen for one infant with sight-threatening ROP to be identified in this population needs to be investigated. The research agenda should also include innovative approaches to implement the ROP programme in a country with inadequate neonatologists, ophthalmologists and nurses. As most of the equipment and human resource required need not be specific to ROP, research is necessary to determine marginal cost of the programme. It is also important to identify the contribution of the programme to reducing the ROP burden and strengthening national capacity to handle ROP.

## Sustainability and scaling up of the ROP programme

The main outputs of the health system for ROP are increased access and improved quality of care. To achieve these, the ROP programme will need to be sustainable in all the health system building blocks. Strong and sustainable health systems focus on primary care, which in the case of ROP includes strengthening antenatal care (to reduce premature or VLBW births), neonatal care and ROP screening. Interventions to improve neonatal care are essential to the programme as they reduce the development of the disease. More importantly, optimal neonatal care reduces the risk not only of developing ROP, but also other causes of neonatal morbidity and mortality. Similarly, screening provides an opportunity for identifying and treating other sight-threatening conditions such as congenital cataract and retinal diseases, besides ROP.

*Three main issues are likely to contribute to the success of the ROP programme:* integration with the health system, collaboration between neonatal and ophthalmic services, and leadership (Figure 2). As these factors are vital to the long-term success of the programme, the way they will be implemented should be well articulated. The success of the ROP programme should also be measured not just on the medical benefits but also on the health system benefits.

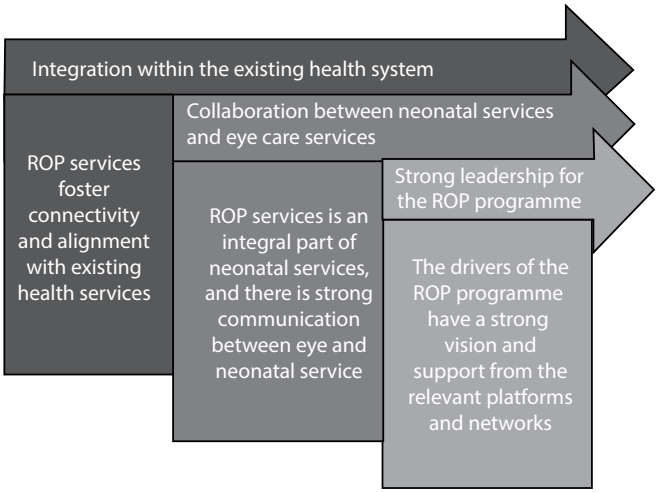


**Figure 2:** Potential success factors for the Kenya ROP programme

## CONCLUSION

Delivering ROP care through the ROP programme must be pragmatic, synergistic, and simultaneously advance both medical and health system goals. Given that other countries are also developing national programmes for ROP, sharing the health system perspective can help address potential barriers to implementation and scale up of the programmes.

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