

Piloting the Treatment of Retinopathy in India

Diabetic Retinopathy and Retinopathy of Prematurity

Report of an Independent External Evaluation

Amaltas



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Acknowledgements

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This report has been prepared by Amaltas Consulting Private Limited, India. Amaltas (www.amaltas.asia) is a Delhi based organization with a mission to work within the broad scope of development to provide high quality consulting and research in support of accelerating improvements in the lives of people. The report was written by Dr. Suneeta Singh and Shivanshi Kapoor, Amaltas with support from Dr. Deepak Gupta, Consultant.

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ACRONYMS

AIIMS	All India Institute of Medical Sciences
CCDR	Certificate Course in the Evidence Based Management of Diabetic Retinopathy
DR	Diabetic Retinopathy
DH	District Hospital
IIPH-H	Indian Institute of Public Health - Hyderabad
IDF	International Diabetes Federation
LSHTM	London School of Hygiene and Tropical Medicine
MOHFW	Ministry of Health and Family Welfare
MoU	Memorandum of Understanding
NHM	National Health Mission
NCD	Non-Communicable Diseases
NPCB	National Programme for Control of Blindness and Visual Impairment
NPCDCS	National Programme for Cancer, Diabetes, Cardiovascular Disease and Stroke
NTF	National Task Force
OA/	Ophthalmic Assistant/ Ophthalmic Officer
PHFI	Public Health Foundation of India
PMOOs	Para medical Ophthalmic Officers
QI	Quality Improvement
RBSK	Rashtriya Bal Swasthya Karyakram (National Child Health Scheme)
ROP	Retinopathy of Prematurity
SNCU	Special New-born Care Units
T1DM	Type 1 Diabetes Mellitus
TEG	Technical Expert Group
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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EXECUTIVE SUMMARY

1. The Queen Elizabeth Diamond Jubilee Trust (the Trust) is a charitable foundation set up to mark and celebrate the Queen's 60-year contribution to the Commonwealth. Over the past 4 years, the Trust has funded a programme of work to prevent and treat retinopathy in India. The Trust chose 2 eminent institutions to carry out its work. The Public Health Foundation of India (PHFI) is an autonomous, public-private initiative of the Government of India, and the London School of Hygiene & Tropical Medicine is a renowned centre for research and postgraduate education in public and global health.

2. At the time that the work began, there were no programmes that specifically addressed retinopathy in India. Further, retinopathy diagnosis and treatment requires great skill which was not easily available, particularly in the public system; and identification of retinopathy rests upon a well-equipped and well-functioning health system. What the programme was asked to do was straightforward but challenging: the initiatives must achieve their goals and objectives; they must be scaled up or be likely to be scaled in the near future; and they must be sustained in the long run.

3. The Trust's programme supported and furthered the work of the Ministry of Health and Family Welfare, Government of India. India has considerable experience in this area, however much of the treatment expertise for these conditions resides in eye hospitals in the not-for-profit and private sector, which have limited engagement with the government eye health system. Existing capacity in relevant sectors was proposed to be utilized for the detection, diagnosis, management and follow up of Retinopathy of Prematurity (ROP) and Diabetic Retinopathy (DR) in the public sector.

4. The programme has faced two main setbacks: an initial difficulty in getting buy-in of state governments; and the temporary rescindment of the Foreign Contribution Regulation Act accreditation of the PHFI. The first was responsible for a slow start of the project; and the second led to considerable difficulties, as the primary recipient - PHFI, could no longer receive funds from the Trust. Despite these challenges, we believe that the programme of work initiated by the Trust will leave a lasting legacy for the people of India and the Commonwealth.

Independent External Evaluation

5. In 2019, the London School of Hygiene & Tropical Medicine approached Amaltas, a research and consulting organisation based in India, to carry out the end line review of the project. With the end point of the grant approaching, they were keen to assess (i) the extent to which the initiatives have achieved their goals and objectives; (ii) the extent to which they have been scaled up already or likely to be in the near future; and (iii) their long term sustainability.

6. The independent, external evaluation took a primarily qualitative approach. Objectives of the evaluation were clustered into: (i) a Process and Outcome review; (ii) a Sustainability review; and (iii) a Learning review. Outcomes of each pilot were reviewed as they pertained to practices, programme level improvements and policy changes. More than 150 reports, documents and data were reviewed and over 80 stakeholders interviewed across 9 implementation sites. These include multiple locations in Goa, Gujarat, Kerala, Madhya Pradesh, Rajasthan, Tamil Nadu, Telangana and West Bengal.

Retinopathy of Type 2 Diabetes Mellitus

The DR initiative has been carried forward on the back of a growing non communicable diseases programme. Respondents in all locations remarked on the positive role of the initiative in bringing DR front and centre, and creating the space for it as the programme on diabetes is refined and expanded.



Retinopathy in Type 2 Diabetes Mellitus

Rests on: NCD clinics

Focus: Control of diabetes and annual screening treatment of DR patients

States: Andhra Pradesh, Goa, Gujarat, Karnataka, Kerala, Maharashtra, Odisha, Rajasthan, Tamil Nadu, West Bengal

7. **Outcomes:** Following a Situation Analysis, National DR Summit, and establishment of a National Task Force, partner (Mentoring) institutes for eye care were identified in each state to support the implementation of the programme. By close of the programme, it has been rolled out in 10 of the 11 states

originally identified. The overall goal of the programme was to achieve a reduction in avoidable blindness due to DR by improved control of diabetes, early detection and treatment of sight threatening retinopathy.

8. Pilots that were put in place to address DR relied on identification of patients from among those with diabetes. Diabetes is identified through clinics for non communicable diseases (NCD), which persons with diabetes attend or through line listing following a community survey. Once 'captured' by the system, they are screened by ophthalmic personnel or trained Nurses. The image taken using a camera is thus available for grading by an Ophthalmologist, and sometimes by experienced Ophthalmic Assistants. Diagnosis and treatment of cases takes place usually at tertiary institutions. A variety of models have been followed by these pilots; these have rested upon the differing strength of the health system of the states; the varying geographical and other accessibility issues that the community faces; and the challenges that the identification and treatment of the condition poses.

9. Across the various states involved, the DR Initiative trained 6581 government personnel; these include 41 Ophthalmologists, 183 Ophthalmic Technicians and 6357 frontline workers. In all, 56,799 patients of diabetes were screened for retinopathy, far exceeding the expected targets for the initiative (45,000); and of the 6194 that had changes in their fundus images, 2361 were finally treated. This required investment in equipment; 246 items of equipment were supplied under the initiative in the 10 participating states. Training was also provided to medical graduates through a Certificate Course in Evidence Based Management of Diabetic Retinopathy. This was an open call, partially online course covering the basics of retinopathy identification and treatment which was taken by 578 participants.

10. A key accomplishment of the programme has been to streamline the screening of patients with diabetes for retinopathy. All those with sugar levels in the diabetic range and patients receiving diabetes care undergo ophthalmic examination. Much of this has been enabled by information technology platforms such as the DRROP software created to maintain records of each patient. The programme highlighted the need to track patients, but difficulties encountered were the lack of adequate internet connectivity, complicated functionality and insufficient manpower.

11. There was an increased focus on translating and printing IEC material to create awareness about vision loss due to diabetes leading to increased awareness among the persons with diabetes and their caregivers. Peer Support Groups created in Maharashtra (15), Kerala (4), Gujarat (1) and Karnataka (1). However, more time needed for these groups to deliver the benefits of interpersonal sharing. Energetic efforts were made to develop, publish and disseminate communication collateral to promote interest among the medical fraternity, build awareness among persons attending health facilities, and sensitise the general public.

12. Barriers to treatment are reported to be lack of familiarity with the place at which treatment is available; high cost of transport and caregivers' stay; not enough understanding of the

serious consequences of the condition; and it was speculated, use of private sector services in preference to the distant one provided by the government. Follow up remains a challenge, and a system for repeated follow up is urgently required to be properly piloted. Because the project faced delays, implementation has been of limited duration and a common minimum programme has not fully evolved. This will not doubt emerge expands with the support of state governments.

13. Mentoring Institutes used innovative mechanisms to ensure greater coverage of DR cases such as creating checkpoint at drug stores, people needing screening accompanied by field level workers, utilising state-wide software's to share images, and follow up of cases through field staff etc.

14. PHFI's ability to get government, other policy oriented stakeholders and private sector on board is noteworthy. The National Task Force and State and District Coordination Committees have helped to sensitize the workforce on DR. Involvement of national and state level partners in the programme through the National Task Force and State Coordination Committee meetings helped to keep them updated and ensured buy in. Implementation Partners meetings have disseminated the efforts made and results achieved to state authorities as they were taking place, fostering partnerships.

15. At the policy level, the programme has clocked three major achievements: one, the project has galvanised states to action; two, the project has spotlighted the importance of addressing the complication of retinopathy in the care and management of diabetes; and three, the project has created awareness of other complications of the diabetes. Integration of retinal screening at the NCD clinics has ensured that the DR programme is included in the general health systems.

16. Sustainability: The programme has contributed substantively to the scaling up of services of diabetic retinopathy across various states in the country. Both in immediate and long term plans for sustainability, the accent is on working closely with government to ensure its uptake into the health system of the country. Several state governments that have been involved with the programme have indicated their interest to scale up the programme.

Retinopathy in Type 1 Diabetes Mellitus

Retinal screening was already a part of the T1DM initiative in all three centres under the Initiative. Nevertheless, the initiative has sharpened the focus on DR and provided the opportunity to reflect on strategies to ensure that complications of diabetes among young persons are addressed.

17. The programme envisaged the establishment of a working model for a structured diabetes management programme, cost effective screening facility, referral and follow up services for DR management, provision of free insulin and glucose strips, patient empowerment through peer support groups and behavioural change counselling. The T1DM programme

proposed to test this scope of services and influence changes at the practice, programme and policy level. Funded by the Helmsley Charitable Trust, this project lasted 2 years and was implemented in 3 locations, namely Pushpagiri Vitreo Retina Institute, Hyderabad; AIIMS, Delhi; and Dr. Mohan's Diabetes Specialities Centre, Chennai.

18. Outcomes: Implementation of pilots began in late 2015-early 2016. Apart from DR screening, patients were screened for other microvascular complications and cardiovascular disease risk factors in 2 annual diabetes complication screening camps. Awareness programmes were also organised by all centres; 42 Peer Support Group meetings were held. Under the T1DM Initiative, 1132 young patients of diabetes were registered, 962 screened and 43 treated.

19. Capacity building was undertaken through the a Certificate Course in Evidence Based Management of Diabetic Retinopathy programme. A dedicated 24-hour 7 days a week helpline was also developed and launched. In spite considerable investment, the programme faces challenges with follow up rates even after regular follow up.

20. Outcomes sought which could not be realized in the life of the programme include failure to get T1DM services included in the Rashtriya Bal Swasthya Karyakram guidelines and changes to the Indian Council for Medical Research guidelines for the management of diabetes in T1DM patients.

21. Sustainability: In the centres that were part of the Trust's programme, the T1DM project is eminently sustainable. By the time that the Ophthalmologist sees the patients, they are

already 'triaged' saving both patients' and doctors' time, and enabling the doctor to focus on therapy. This provides a very strong model for sustainability where skills and competence are aligned to the resource.

Retinopathy of Prematurity

The ROP initiative installed a hub and spoke model with a level-3 SNCU as the hub and 4 - 5 SNCUs in neighbouring District Hospitals or other secondary level care institutions as the spokes. It has demonstrated how the treatment of ROP could be undertaken in resource poor settings.

22. A Situation Analysis for ROP was conducted from January - August 2015 to identify gaps in service delivery and select the states in which the programme could be rolled out. The ROP Initiative was eventually rolled out in 4 states. Even more clearly than in the DR programme, the ROP programme has a clear catchment area of patients – the Sick New-born Care Unit (SNCU). The focus on the SNCU, and the increasing rates of institutional delivery and survival, have been a driving force for the ROP programme. This programme has been operational for only a short time, with handover to government systems for intervention having taken place at the far end of the project.

23. The National Task Force set up under the Initiative has succeeded in making this programme a part of the national agenda, not limited to the states in which pilots are being undertaken. PHFI held sensitization/orientation meetings for state officials and multiple stakeholders from the ROP ecosystem. At the central level, the National Task Force has led



Retinopathy in Type 1 Diabetes Mellitus

Rests on: Diabetes clinics and Eye Care Hospital
Focus: Control of diabetes and regular screening and treatment of young patients with T1DM
States: Chennai, Delhi, Hyderabad

Retinopathy of Prematurity

Rests on: Special Newborn Care Units
Focus: Prevention, screening, diagnosis and treatment of very low birth weight neonates
States: Maharashtra, Madhya Pradesh, Odisha, Telangana

the drafting and launch of Operational ROP Guidelines. At the state level, ROP State Coordination Committee has been set up under the chairmanship of the State Health Secretary.

24. Recognising that babies at risk of ROP are mostly admitted to SNCUs, the pilots were sited in SNCU locations with high throughput. The first step of identification of at-risk babies was the responsibility of the SNCU staff. Screening is carried out by Ophthalmologists at the SNCU. As the programme has matured, treatment responsibility has shifted to government Ophthalmologists located at the Medical Colleges. Follow up is a crucial aspect of the programme, with babies to be followed up until their eyes mature fully. The programme has been operation for a short time, with handover to government systems for intervention having taken place at the far end of the project.

25. Targets set by the programme were exceeded in terms of screening of babies; in comparison with an expected 5850 infants to be screened, 10,392 infants could be screened under the ROP Initiative. To do this, 22 Ophthalmologists were trained for screening and another 4 for laser treatment of retinopathy. Further, 186 SNCU teams were trained to make quality improvements in the management of infants admitted to these specialised centres. In total, 106 items of equipment were provided in 8 locations.

26. Outcomes: The initiative helped to set in place a practice of quality improvement, this improving survival of preterm babies, while at the same time, preventing the occurrence of ROP and resulting in at-risk patients being screened. Quality Improvement projects have been carried out focusing on use of oxygen and antibiotics. The package of interventions consisted of over 100 webinars and DVDs and clinical training. The package of interventions was presented at the WHO South East Asia regional meeting in December 2017.

27. The programme was also successful in establishing working relationships between SNCUs and Ophthalmologists. Both government hospitals and partner institutes provide treatment, with specialists visiting the SNCU locations to carry out treatment of ROP when indicated. While a patient management software has been developed, it is not being used consistently for reasons of lack of technical skills, poor internet connectivity and the high workload of data entry operators.

28. The SNCU and nurses from the District Early Intervention Centres at district level play the largest role in the education of mothers and the family of babies at risk of ROP. Despite WhatsApp and phone reminders made to mothers and the family, follow up of at-risk babies remains a challenge due to transport and accommodation costs.

29. The IEC element of the programme is essential and therefore a Technical Expert Group was set up, which developed a communication strategy. Much of the IEC material developed under the programme is being used at the SNCUs, since infants requiring treatment are treated at the SNCU. The material has also been translated into local languages and distributed widely in both public and private sector settings.

30. Three national programmes are involved in addressing the needs of preterm infants for ROP. The DRROP software and paper based recording and reporting systems like ROP dairy, ROP screening registers and ROP management registers were developed to improve follow-up for complete screening and treatment.

31. Sustainability: The ROP initiative has demonstrated that screening and treatment can be successfully integrated into the public health system using a partnership approach in a way that ensures sustainability and fosters comprehensive eye care. This approach could also be used for other potentially blinding conditions. States currently participating in the programme have indicated their intention to scale up the programme. The programme has spotlighted the quality of care at SNCUs at district and medical college levels. The District Early Intervention Centres have also gained confidence in providing follow up care and ensuring that children at risk in their earliest period of life get the care needed to prevent longer term stigma.

32. Yet there are factors that may obstruct the sustainability of the programme. These include staffing issues such as workload and incentive issues of SNCU staff and poor availability of trained Ophthalmologists from government or non-government sectors, follow up once the baby leaves the hospital. SNCUs are not yet using their data to assess and monitor quality. Respondents also cite the need for better educational material for Quality Improvement projects.

Learning from the Programme

Support from the Queen Elizabeth Diamond Jubilee Trust has played an important role in the experimentation with and critical evaluation of pilots to combat avoidable causes of blindness. The pilots have yielded important learning on services to prevent and treat retinopathy for India and the wider Commonwealth of Nations.

33. Change is difficult to institute, and change in bureaucratic systems is especially challenging. The programme required profound changes in government systems and in the way that the work of institutions is carried out. Nonetheless, the programme was able to bring about a broad support for the changes required. Involvement of the top echelons of the national and state administration was critical to facilitating action. It added much to the credibility of the programme and helped to build acceptance of the results of the programme among the decision makers.

34. Reconnecting the primary, secondary and tertiary levels of the healthcare system has been important to reduce the dropout rates. Since retinal specialists are a scarce resource, it was important to free up their time for activities that require their level of skills by introducing para-professionals such as optometrists into the screening process. Coordination between departments was critical in identification, screening, treatment and follow up for DR & ROP to generate the needed understanding and goodwill to persuade all concerned to cooperate.

35. State and District Coordination Committees played a key role in generating the understanding and goodwill needed. The private sector is where the expertise resides while the public sector is catering to a large complement of patients. Partner and Mentoring Institutes readily supported an iterative process of learning. Nonetheless, the process of establishing and operationalising mechanisms for implementation of the programme was often riddled with difficulties.

36. This programme highlighted the need to invest in ancillary staff. Staff such as SNCU nurses, NCD nurses, optometrists, ophthalmic assistants, counsellors etc. were critical – investing in their knowledge and skills as well as their motivation paid dividends. Raising the knowledge and skill levels of persons involved in the programme has been crucial, especially in the health sector where there are frequent advancements in terms of the practices that will promote health. The programme invested in developing clinical guidelines and written protocols for all aspects of diabetic management and newborn care.

37. An important area was the need to increase awareness amongst both relevant professional groups and the general community. Awareness among the general practitioner community is critical to funnel patients into the program and awareness in the community is crucial to increasing the footfall of patients. This was complemented by changing patient behaviour. Attitudinal change among the community was somewhat more complex but was carried out through peer and parent support groups, and IEC material specifically created for them. The experience with peer support groups for adult onset diabetes has been less persuasive and requires further experimentation to be more effective.

38. Traditional methods of maintaining records pose several challenges for consolidation at higher levels leading to inaccuracies. This programme demonstrated how this weakness could be overcome by use of advanced information and communication technology. However, some structural difficulties remain; use was low due lack of adequate internet connectivity, complicated functionality and insufficient manpower training.

39. Creating enthusiasm for the programmes and getting clearances from state governments to go ahead with them required presentation of clear evidence of the requirement and several rounds of discussions. There were unexpected operational challenges that halted progress leading to further delay in the timeline of the programmes. Coordination with the government and other international agencies was crucial to ensure implementation and scale up of the programme. Considerable efforts have been made by PHFI to strengthen the monitoring, audit and feedback mechanisms to improve the programme and also to capture the interest of international agencies.

40. The programme demonstrated that becomes essential to engage concerned bureaucrats, eminent scientists, key functionaries of associations at national, state and district level through meetings, committees etc. This adds much to the credibility of the programme and helps build acceptance of the results of the programme among the decision makers. Programme governance and cross learning between partners has been central to the successful implementation of the programme. PHFI has acted as the glue between the various pilots, providing the momentum, guidance, support and supervision that led to systems involvement and improvements.



INTRODUCTION

INTRODUCTION

In 2013, the Queen Elizabeth Diamond Jubilee Trust began funding a 4 year programme of work in India addressing important challenges in eye health namely, diabetic retinopathy (DR) and retinopathy of prematurity (ROP). The grant managed by the Public Health Foundation of India (PHFI), specifically the Indian Institute of Public Health-Hyderabad (IIPH-H)¹ has sought to establish models of sustainable and scalable services for reducing avoidable blindness in India. In addition the Trust mobilised funding for DR in Type 1 Diabetes (T1DM) from the Helmsley Charitable Trust.

Vision provides an immeasurable extension of the capabilities of a human to go about everyday tasks, earn a livelihood and avoid injury and death. The opposite of sightedness is visual impairment and blindness.^{2,3} At the global level, in 2010, the World Health Organisation (WHO) estimated that 253 million people of all ages are visually impaired, of whom 36 million are blind.⁴ About 89% of them live in low and middle-income

countries.⁵ The chief causes of visual impairment are uncorrected refractive errors and un-operated cataract.⁶ The foremost causes of blindness worldwide are cataract, glaucoma, age-related macular degeneration, DR and trachoma.⁷ ROP has emerged as an important cause of blindness in children in lower middle income countries, along with cataract.

Both DR and ROP can be sight threatening: ROP causes blindness soon after birth; DR secondary to T1DM during adolescence/ young adulthood and in Type 2 Diabetes Mellitus during adulthood. There are windows in the natural history of disease of each in which retinopathy can be prevented or halted. Primary prevention, screening, diagnosis, treatment and follow up efforts must be made early within the windows of opportunity for the best results to be obtained. Failure to do so results in a high price being paid by those affected.

The Queen Elizabeth Diamond Jubilee Trust Programme in India

The Trust has been working to combat 3 major avoidable causes of blindness namely DR, Retinopathy of Prematurity (ROP) and Trachoma. The DR Initiative of the Trust is supporting programmes in 13 countries across the Commonwealth including India. The Trust's Trachoma Initiative does not support work in India, but does so in 11 countries of the Commonwealth. ROP initiatives are being supported only in India.⁸

The first engagement of the Trust in India was to support the National Summit on ROP in 2013. The Summit brought together experts who could assist the Ministry of Health and Family Welfare (MOHFW) in improving neonatal care to reduce the risk of ROP and through new initiatives for the detection and treatment of sight threatening ROP. In the same year, the Trust funded PHFI and LSHTM to conduct a Situation Analysis on DR to assess the provision of services for screening and treatment of DR in the largest cities across India. In a scenario in which approximately half of all persons with diabetes who present to eye care facilities have some vision impairment before being

diagnosed, the Situation Analysis found that both government and private diabetes clinics do not provide early screening for DR.⁹

The Trust has chosen to engage with two of the most relevant institutions in its work. PHFI is an autonomous institution set up as a public-private initiative of the Government of India. It was set up with the aim of filling the deficit of public health professionals and building institutional capacity for training, research and policy development in the area of public health. The London School of Hygiene & Tropical Medicine (LSHTM) is a renowned centre for research and postgraduate education in public and global health. One of the world's leading public health institutes, it makes significant contributions to public and global health research, education and translation of knowledge into policy and practice. This 120 year old institution was ranked University of the Year by Times Higher Education Awards for 2016.

¹ For the remainder of the report, we shall refer to the implementing institute as IIPH-H.

² Bourne RA. et al. on behalf of the Vision Loss Expert Group. Causes of vision loss worldwide, 1990–2010: a systematic analysis. *Lancet Glob Health*. 2013 Dec;1(6):e339-49

³ WHO. Blindness and Vision Loss. Accessed at: <http://www.who.int/topics/blindness/en/> on 07 May 2019

⁴ WHO. Global data on visual impairment 2010. Accessed at <https://www.who.int/blindness/publications/globaldata/en/>

⁵ Bourne RA. et al. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. *Lancet Glob Health*. 2017

⁶ WHO. Visual impairment and blindness. Available at: <http://www.who.int/mediacentre/factsheets/fs282/en/> (Accessed on 29th June 2019)

⁷ WHO. Causes of blindness and visual impairment. Available at: <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment> (Accessed on 29th June 2019)

⁸ Personal communication, Dr Andrew Cooper, The Queen Elizabeth's Diamond Jubilee Trust

⁹ The Queen Elizabeth Diamond Jubilee Trust's, Public Health Foundation of India and London School of Hygiene and Tropical Medicine (2014) Report on National Diabetic Retinopathy Summit. Available at: https://phfi.org/images/home/dr_summit_report.pdf

A Partnership with India

India has considerable experience in both neonatal care and the management of diabetes. It also has expertise in detection and management of retinopathy due to diabetes and prematurity; however much of the treatment expertise for these conditions resides in eye hospitals in the not-for-profit and private sector, which have limited engagement with the government eye health system. The Trust supported programme proposed to use existing capacity in these sectors to build capacity of government sector physicians and endocrinologists (for DR) and paediatricians and neonatologists (for ROP), of ophthalmologists and eye care teams, and a variety of ancillary staff in the detection, diagnosis, management and follow up of ROP and DR. The approach proposed was potentially scalable and sustainable, if supported by policy and financial commitment by the Government of India and State governments.

The Trust's programme supports and furthers the work of the MOHFW, Government of India. The MOHFW is responsible for running health programmes addressing public health problems such as the National Health Mission (NHM), Prevention and Control of Non-Communicable Diseases (NPCDCS), Rashtriya

Bal Swasthya Karyakram (RBSK) and National Programme for Control of Blindness and Visual Impairment (NPCBVI) among others.

Subsequent to the establishment of the Trust funded programmes in IIPH-H and due to advocacy undertaken by PHFI, the MOHFW set up National Task Forces (NTFs) for both ROP and DR with the aim to bring policy makers, programme managers, eye care and public health professionals together to guide implementation of activities in the country. Within the Task Forces are Technical Expert Groups (TEGs) that have been set up to provide expertise in particular areas. It is hoped that both these Task Forces will continue to guide implementation in India beyond the life span of the Trust supported project.

Mapping of Programme Areas

In the national summits held on ROP and DR and attended by government, International/ National NGOs and private players working to reduce avoidable blindness, priority strategies were

identified for the Trust's support. The Grant proposals identified several programme areas that the programmes would address. These can broadly be clubbed into 5 broad activity areas:

Table 1: Grouping of programme areas into broad activity areas

	Retinopathy of Type 2 Diabetes Mellitus	Retinopathy of Type 1 Diabetes Mellitus	Retinopathy of Prematurity
I. Advocacy with government	<i>Programme Area 1:</i> Execute an advocacy and communication strategy	<i>Programme Area 1:</i> Advocacy with the Ministry of Health for inclusion of T1DM in policy documents and for inclusion of services for T1DM in Rashtriya Bal Swasthya Karyakram	<i>Programme Area 5:</i> Advocacy with Ministries of Health and other stake holders <i>Programme Area 1:</i> Situational Analysis and Service Mapping
II. Capacity building	<i>Programme Area 2:</i> Improve capacity of Physicians, Dieticians and Counsellors <i>Programme Area 6:</i> Build capacity in operational/ implementation health economics research	<i>Programme Area 4:</i> Increase capacity of service providers regarding the prevention, detection and management of the complications, including DR, among patients with T1DM <i>Programme Area 2:</i> Standardised Operational Guidelines for the prevention, early detection and management of DR in T1DM patients.	<i>Programme Area 3:</i> Increase the capacity of neonatal health care teams to deliver high quality clinical care for prevention and early detection of ST Retinopathy of Prematurity. <i>Programme Area 2:</i> Increase capacity of ophthalmologists at district hospital and medical colleges to screen and treat ST ROP
III. Information, Education & Communication	<i>Programme Area:</i> Improve capacity of persons with diabetes to improve control of their diabetes <i>Programme Area:</i> Increase awareness of professionals by publishing and disseminating findings of situational analysis <i>Programme Area:</i> Create a website for dissemination to various audiences	<i>Programme Area:</i> Promote peer-to-peer and family support groups for people with T1 diabetes and their families, which foster interactions with service providers. <i>Programme Area:</i> Helpline	<i>Programme Area:</i> Develop and implement an information, communication and education strategy to support parents <i>Programme Area:</i> Increase awareness among relevant professional groups <i>Programme Area:</i> Dissemination through dedicated website
IV. Piloting the programmes	<i>Programme Area:</i> Implement and evaluate integrated district models for the control of DR that strengthen health systems	<i>Programme Area 5:</i> Integrate detection and treatment of DR into existing health systems by establishing health system capacity and linkages for screening and management of DR complications in T1DM patients.	<i>Programme Area:</i> Develop or strengthen ROP programs in Medical Colleges and District level SNCUs in selected States, and in large government neonatal units
V. Monitoring & Evaluation	<i>Programme Area 7:</i> Monitoring and evaluation	<i>Programme Area 7:</i> Monitoring and evaluation	<i>Programme Area 7:</i> Monitoring and evaluation

Management of the Grant

The Grant provides support of just over 8 million pounds to PHFI (IIPH-H) and LSHTM for the ROP and DR (Type 1 and Type 2) programmes. This includes GBP 60,000 for the Situation Analysis on DR, GBP 3.34 million for the ROP programme and GBP 4.05 million for the DR programme. The Trust has mobilised funding for DR in Type 1 Diabetes (T1DM) from the Helmsley Charitable Trust.

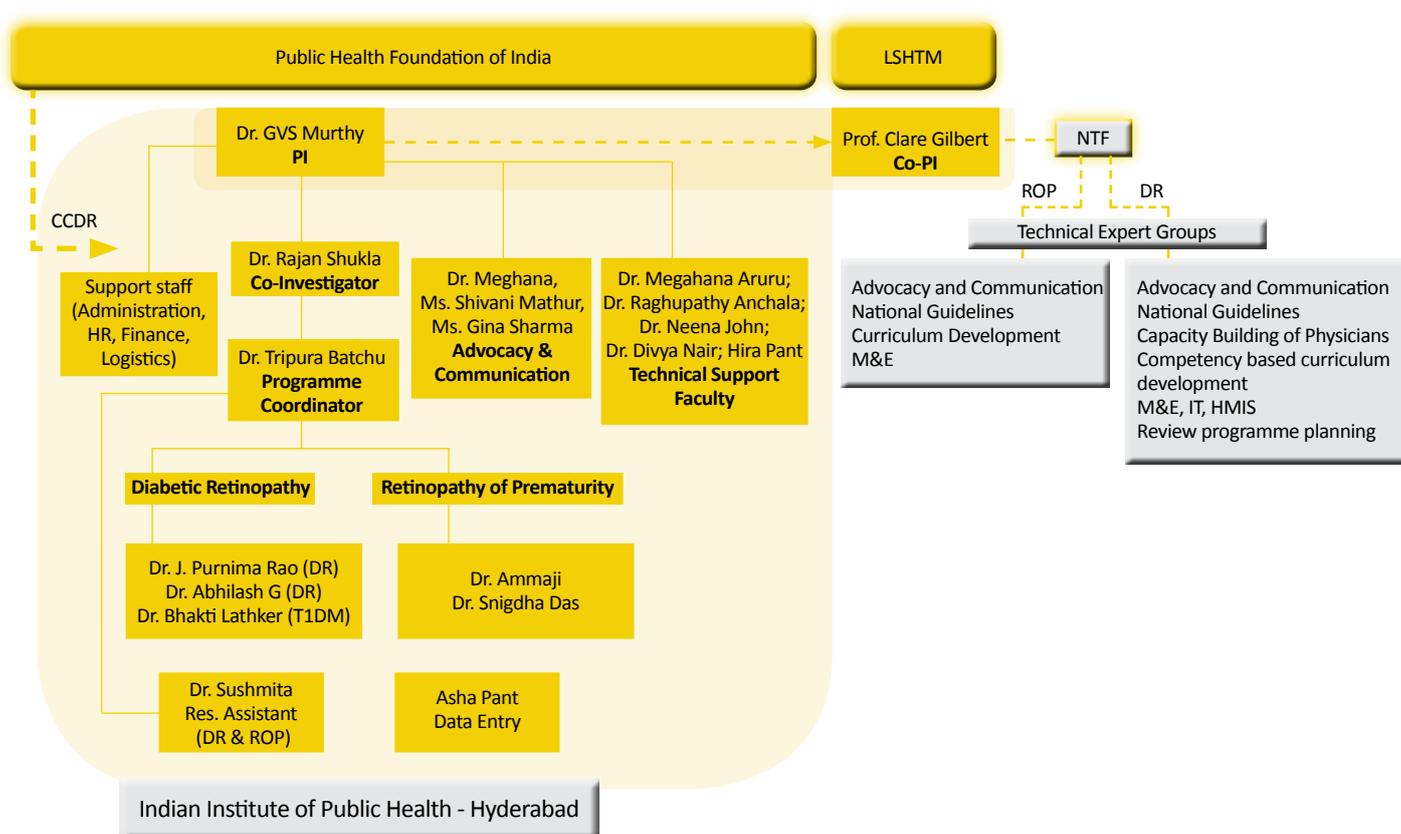
The Grant has been made to PHFI with Dr. GVS Murthy, Director IIPH-H as the Principal Investigator (PI) of the Grant and Dr. Clare Gilbert, LSHTM as the Co-Principal Investigator. The day-to-day supervision is the task of Dr. Rajan Shukla who is an Investigator on the programme.

and district coordination committees have been constituted to review progress, address problems and recommend mid-course corrections.

Communication between the Trust and IIPH-H are mediated by Mr. Jonathan Dunbar (early phase of the project), Dr. Andrew Cooper and Mr. Matt Little on the Trust's side and Dr. Murthy, Dr. Shukla and Dr. Gilbert on the grantee side.

The Trust envisages that the programme will leave a lasting legacy for the people of the Commonwealth. The effort has thus been able to create pathways for sustainability through programmes

Figure 1: Organogram of the programme team



Dr. Tripura Batchu is the coordinator for all the component programmes who leads the team working on the programme. This team coordinates directly with partner institutes and hospitals, while government level communications are handled primarily by Dr. Murthy and Dr. Shukla. The advocacy and communications team, and the programme officers are placed directly under Dr. Murthy. The Certificate Course in the Evidence Based Management of Diabetic Retinopathy (CCDR) is handled at the central PHFI office in Gurgaon, which coordinates with the programme. IIPH-H sends monthly and 6 monthly reports to the Trust after consolidation of information from the partners. Mechanisms have been put in place to guide decisions on implementations. The National Task Forces, state coordination committees

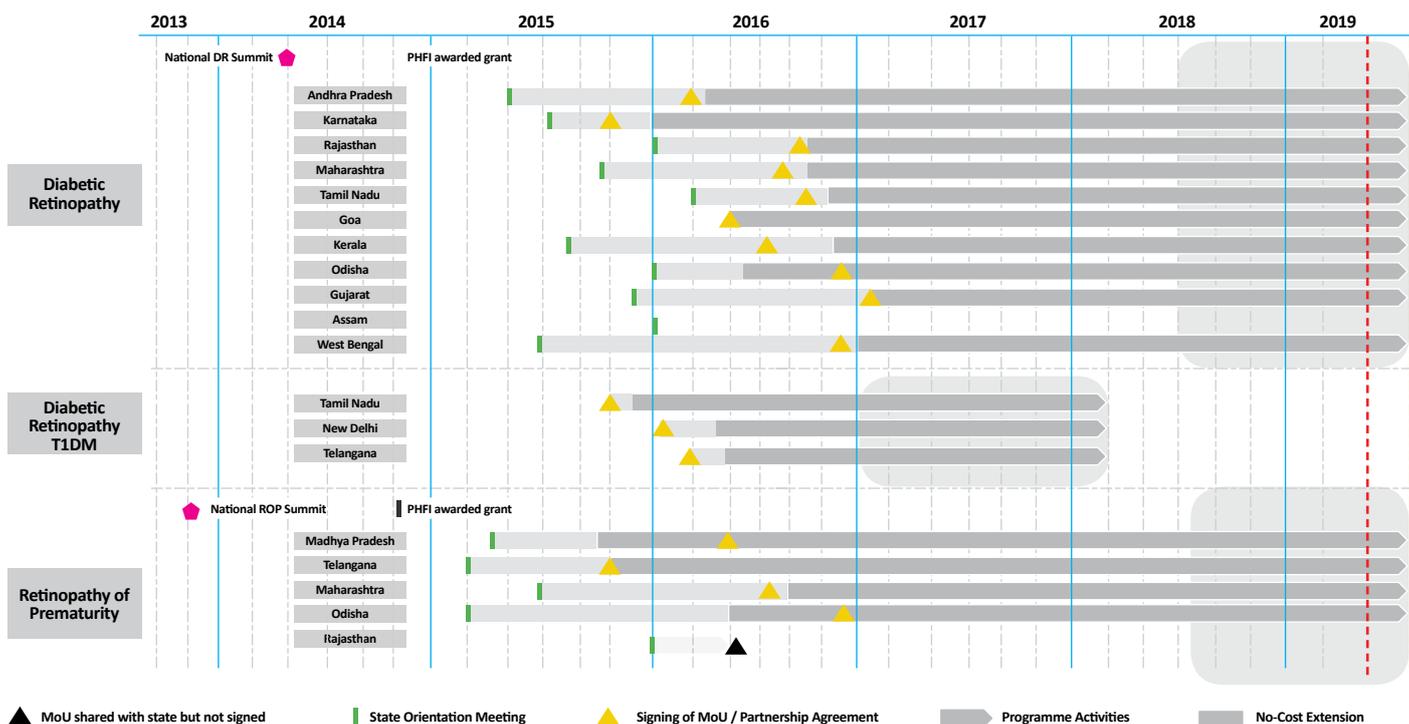
that focus on policy, capacity building in the government sector and the development of competency based training and national guidelines to support the scaling up of the services for ROP and DR well beyond the period of Trust support.

The programme has faced two main challenges: an initial difficulty in getting buy-in of state governments; and the rescindment of the Foreign Contribution Regulation Act accreditation of the PHFI for a period of time. The first was responsible for a slow start of the project. At the time of the midline review, a Memorandum of Understanding (MoU) had been signed for DR with only two states, with six more taking place in 2016 and another two (Gujarat and West Bengal) in 2017 and for ROP MoUs were signed for two (Madhya Pradesh and

Telangana) in 2015 and another two (Odisha and Maharashtra) in 2016. The second led to considerable difficulties, as the primary recipient – PHFI, could no longer receive funds from the Trust. This meant that funds could not be provided to partnering institutes as before, nor could procurement of equipment be carried out under the project. It took close to a year for the matter to be resolved; in the meantime, funding

had to be provided by the Trust to various partnering institutes through the LSHTM who in turn provided funds to partnering institutes which had FCRA approvals. In sum, the project suffered not only due to the sudden blockage of funds, but also because precious staff time was diverted to other concerns. It also led to large attrition among contract staff deployed by IIPH Hyderabad for the programme.

Figure 2: Progress of programme activities



Evaluation of the Programmes

This independent, external endline evaluation of the work of the Grant has been carried out by Amaltas, an India based research and consulting organisation. Over 150 documents were reviewed and more than 80 interviews conducted in 9 field sites to carry out the present review. A brief on the methodology adopted for the endline is appended at Annexure I.

For each of the programmes, the evaluation looked at Outcomes and Sustainability of the programme. As part of the Outcomes, it reviewed the changes brought about by the pilots at (i) the ‘practice level’ which reviewed how activities were changed by

the pilots; (ii) the ‘programme level’ for changes to systems and guidelines; and (iii) the ‘policy level’ for changes in the environment in which the programmes were operating. Finally, the evaluation also reviewed the Learning that the three programmes offer to programming of retinopathy and other difficult public health problems in India, as well as to other countries in the Commonwealth. The sections that follow describe the findings of the evaluation in this order for each of the three programmes supported by the Grant.



RETINOPATHY IN TYPE 2 DIABETES MELLITUS

RETINOPATHY IN TYPE 2 DIABETES MELLITUS

Among the microvascular complications of diabetes, is Retinopathy that occurs as a result of damage to blood vessels in the retina. If left untreated, DR can lead eventually to blindness. However vision loss can be avoided if it is detected early and managed in tandem with diabetes.

Globally, ~93 million persons live with and 1.85 million are blinded by DR. Every person with diabetes Type 1 and 2 is at risk of the condition. In India, Type 2 diabetes is the major public health concern. According to the International Diabetes Federation Diabetes Atlas 2017, there are an estimated 425 million adults worldwide who have diabetes. Of these, India has about 72.9 million persons with diabetes, making it the country with the second-highest number of people living with diabetes. The magnitude of diabetes among adults in India is projected to increase exponentially to 134 million by 2045.¹⁰ As reported in a recent paper in Lancet, the prevalence of diabetes has increased in every State of India bar one since 1990.¹¹ It is predicted that if the proportion of people with sight threatening DR (10%) remains constant over time, an additional 10 million persons with sight threatening DR will be added in the country by 2035.¹²

The Government of India has indicated its commitment to controlling diabetes and other non-communicable diseases (NCD) by establishing the NPCDCS in 2010. The programme operates through NCD clinics at the Primary Health Centre (PHC) upwards. However, the NCD programme has not

identified the detection and treatment of DR as a part of its service delivery at these centres.

The Trust funded programme proposed to work with the NPCDCS and NPCBVI to increase awareness of the retinal complications of diabetes including retinopathy and the need for regular eye examinations, provided the following:¹³

- Diabetic retinopathy is included in the Government health system at every level
- Commitment to the implementation of a comprehensive programme for control of diabetes where early detection and management to prevent vision loss from diabetic retinopathy is assured
- National guidelines for detection and management of diabetic retinopathy are established and used widely across the country.
- Capacity of physicians and health support staff is enhanced for improved control of diabetes and reduction of vision loss due to diabetic retinopathy.
- People with diabetes and their family carers are empowered and enabled to control their diabetes through lifestyle changes, dietary modification and compliance with medication.
- Effective integrated models of comprehensive district programmes for screening and management of diabetic retinopathy amongst people with diabetes are adopted by the Government for scaling up at the end of the project.

Outcomes

The Trust's engagement on DR began with a Situation Analysis commissioned in October 2013. A National DR Summit was held in April 2014 after which an NTF for DR was established in 2014. The NTF included representatives from the Government of India (Deputy Director General-NPCB, Deputy Director General-NCD, National Health Mission (NHM) officials); professionals from leading academic institutions; representatives of professional organizations, International Diabetes Federation, WHO, VISION 2020 India, civil society organisations, PHFI and the Trust's Scientific Advisory Board.

The Queen Elizabeth Diamond Jubilee Trust's larger grant to the DR programme began in November 2014 and comes to an end in June 2019 after a no-cost extension of 6 months.



Figure 3: States shortlisted for DR pilots

¹⁰ International Diabetes Federation. India Country Report. Diabetes Atlas Eighth edition 2017. Available at <https://diabetesatlas.org/resources/2017-atlas.html>

¹¹ Bourne RA. et al. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. Lancet Glob Health. 2017

¹² The Queen Elizabeth Diamond Jubilee Trust, Public Health Foundation of India and London School of Hygiene and Tropical Medicine. The Emerging Epidemic of Diabetic Retinopathy in India: Report of a Situation Analysis and Evaluation of Existing Programmes for Screening and Treatment for Diabetic Retinopathy Available at: <https://icsh.lshtm.ac.uk/situation-analysis-and-evaluation-of-existing-programmes-for-screening-and-treatment-for-dr/>

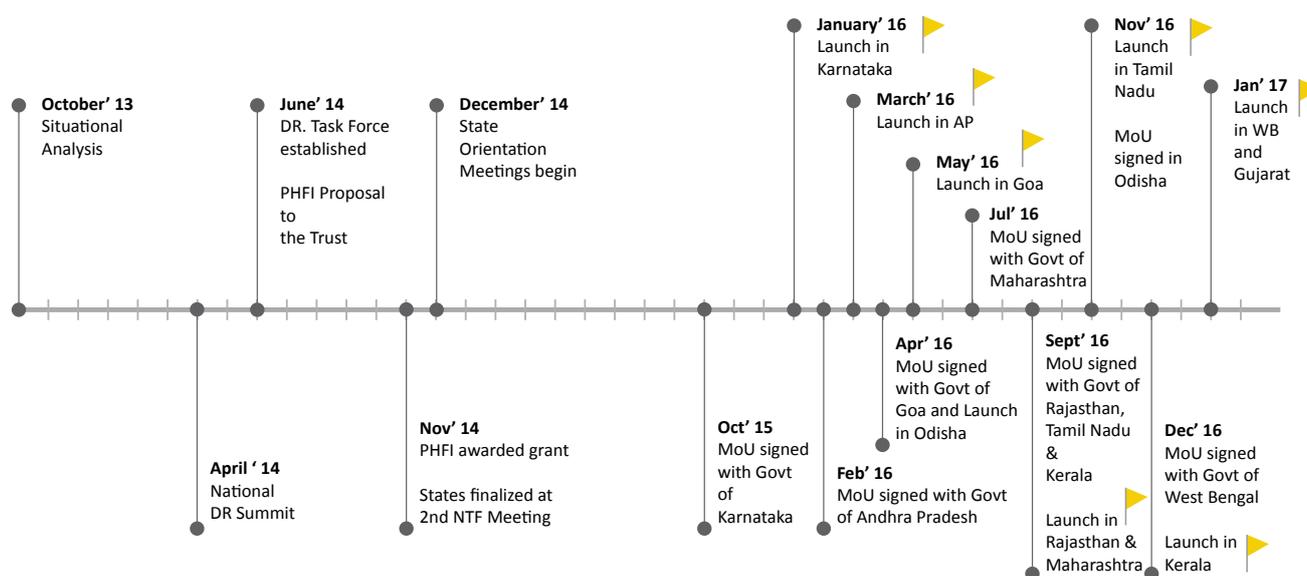
¹³ The Queen Elizabeth Diamond Jubilee Trust. Reducing blindness from diabetic retinopathy in India: Generating and using evidence for policy change and programme development Draft 2.0. 2014

IIPH-H and LSHTM submitted a proposal for the DR programme to the Trust in June 2014, which was awarded in November of the same year. The states in which the DR pilots were to begin were finalised by the NTF at the 2nd NTF meeting held in November 2014. Eleven states were finalised where the NPCDCS programme had been functional for at least 2 years and mentoring eye care partners were available. These were Andhra Pradesh, Assam, Goa, Gujarat, Karnataka, Kerala, Maharashtra, Odisha, Rajasthan, Tamil Nadu and West Bengal. Assam was dropped in 2016 as the government was not ready to be on board and financial allocation was not made to the state.

It took over a year for the first state to begin the programme in January 2016. At the midline, the programme had taken off in 2 of the 10 states and by this endline, it is operational in all 10 states.

The DR programme presumes that there is a functioning NCD program in the district which identifies persons with diabetes and addresses their diabetes treatment needs; developed services to reliably screen this population annually for DR; and provision of treatment in case of need. In the first instance, much of the initial work relied largely on the partner institutes. It was known that control of DR was not a part of service

Figure 4: Timeline for the DR programme



State orientation meetings began soon after the award of the grant. Partner institutes were identified in each state to support the implementation of the programme. It has been planned to also find physicians willing to take on a mentoring role. However, it was difficult to find motivated physicians to take on this task.

delivery at the NCD clinics. Since then, several changes have been instituted with a gradual embedding of the programme into state systems.

Table 2: DR programme locations, partner institutes and status

State	Partner Ophthalmology	Start Date	District	No. of facilities
Karnataka	Vittala International Institute of Ophthalmology	January 2016	Tumkur	5
Andhra Pradesh	Pushpagiri Vitro Retina Institute	March 2016	Vizianagaram	4
Goa	Goa Medical College, Goa & PBMA's H V Desai Eye Hospital	May 2016	North & South Goa	7
Gujarat	Divya Jyoti Trust, Tejas Eye Hospital, Surat	February 2017	Surat	5
Kerala	Little Flower Trust	December 2016	Thrissur	5
Maharashtra	Mahatma Gandhi Institute of Medical Sciences	October 2016	Wardha	4
Odisha	LV Prasad Eye Institute	April 2016	Khurda	4
Rajasthan	Global Hospital	August 2016	Pali	5
Tamil Nadu	Aravind Eye Hospital	November 2016	Tirunelveli	6
West Bengal	Vivekananda Mission Ashram Nethra Nirman Niketan, Paschim Medinipur	January 2017	Paschim Medinipur	8

Today, the programme identifies patients who might have DR through PHCs, NCD clinics at Community Health Centres (CHC), Sub-District Hospitals (SDH) and District Hospitals (DH). Screening for DR takes place by trained government staff in NCD clinics PHCs, CHCs and sometimes in DHs. Diagnosis and treatment take place in ophthalmology centres of the DH or Medical College; and by or at the Mentoring Institute. Images of the fundus of the eye are transferred electronically to the location of the Ophthalmologist. Basic reading is done by the

duty health staff such as auxiliary nurse midwives (ANMs) and Accredited Social Health Activists (ASHAs) have also been co-opted to the programme to generate awareness on DR and encourage screening and treatment uptake for DR.

Different models of screening and treatment have been tested in each state. An overview of the systems adopted in different states is at Table 5.

Table 3: Models adopted for DR programme

	Screening for DR		Image grading	Diagnosis and treatment	Follow up	
	Where *	Who	Who	Where and who	Where	Who
AP	NCD clinics in CHC and DH	PMOOs	Ophthalmologist of DH #	Ophthalmologists at DH # and Mentoring Hospital	Mentoring Hospital DH	Mentoring Hospital staff and
GOA	NCD clinics in PHC, CHC and SDH	OAs Ophthalmologist (2 centers)	Ophthalmologist of DH #	Ophthalmologists at Medical College #	MC	Project Coordinator OAs and
GUJ	NCD clinics in CHC and DH	OAs	Ophthalmologist	Ophthalmologists at Mentoring Hospital and DH # (x1)	CHC	Ophthalmologist OAs and
KN	NCD clinics in CHCs	PMOOs OAs Ophthalmologist of Mentoring Hospital	OAs of Mentoring Hospital	District Ophthalmologist# at CHC in Mobile Eye Unit of Mentoring Hospital (Nayana)	Mentoring Hospital CHC	Ophthalmologist Mentoring Hospital staff
KER	NCD clinics in CHCs	OAs Ophthalmologist team of Mentoring Hospital	Ophthalmologist of Mentoring Hospital	Ophthalmologists at Medical College	Mentoring Hospital	Mentoring Hospital staff
MAH	NCD clinics in CHCs/ PHCs. Patients transported from community to PHCs and CHCs.	NCD nurses OAs	Ophthalmologist of Mentoring Hospital (earlier by District Ophthalmologist #)	Ophthalmologists at Mentoring Hospital only (as local Ophthalmologist transferred)	Mentoring Hospital	NCD nurses & ASHA
ODI	NCD clinic in CHCs (recent)	Ophthalmologist of Mentoring Hospital OAs	Ophthalmologist of Mentoring hospital	Ophthalmologists at Mentoring Hospital and Capital Hospital (DH) #	Capital Hospital Mentoring Hospital	OA & Ophthalmologists
RAJ	Clinics in CHCs (no NCD clinics)	OAs from Mentoring Hospital	Ophthalmologist of Mentoring Hospital	Ophthalmologists at Mentoring Hospital	CHC DH	Mentoring Hospital staff
TN	NCD clinics in CHCs	NCD nurses with help of Field Coordinator of Mentoring Hospital. NHM staff replaces NCD nurses in their absence.	Ophthalmologist of Medical College# and Mentoring Hospital	Ophthalmologists at Medical College # and Mentoring Hospital	Mentoring Hospital	Medical officer
WB	NCD clinics in CHCs and DHs	OAs from Mentoring Hospital, and local OAs	Ophthalmologist of Mentoring Hospital	Ophthalmologists at Medical College # and Mentoring Hospital	Medical College Mentoring Hospital	OA & Ophthalmologists

Ophthalmologists trained and equipped to diagnose and treat DR *Diabetic patients who attend hospitals also have an eye examination

Ophthalmic Assistant (OAs)/ Ophthalmic Officers (OO) and image is uploaded/transferred on software for detailed reading at Ophthalmology centres at the DH, Mentoring Institutes or the tertiary level Government Hospital identified in several of the states. Finally, if treatment is required it is provided at the DH, GH, Medical College or the Mentoring Institutes. In addition, the partnering Mentoring Institutes also provide training to NCD nurses, optometrists (variably called PMOOs and OAs) for DR screening, to Graders for diagnosis, and to Ophthalmologists for screening and treatment of DR. General

All pilots rely on identification of patients with DR at NCD clinics which persons with diabetes attend. These newly established NCD clinics are located at DH and SDHs as in the case of AP, Goa, Gujarat and West Bengal; or at Community Health Centres in all states with the exception of Rajasthan which has not yet established NCD clinics. In Maharashtra and Goa, they are also identified through line listing following a survey in the community. Patients with diabetes are provided transportation to the PHCs/ CHCs in Maharashtra. At these centres, they are screened by ophthalmic personnel such as Ophthalmic Officers,

OAs, or Ophthalmologists from the centres or Mentoring Institutes. In Maharashtra and Tamil Nadu, NCD nurses have also been trained and provide this service. In the case of Tamil Nadu, the NCD nurse (or NHM staff when s/he is not present) is assisted by the Field Coordinator of the Mentoring Institute.

Once the image of the fundus is captured, the image is graded to review whether treatment is immediately required. This takes place for the most part by Ophthalmologists located at either the Government (Medical College/ District) Hospital or the Mentoring Institute. Mentoring Institutes extend support in several (7) states for this function. In Karnataka, experienced OAs of the Mentoring Institute undertake this job.

Diagnosis and treatment of cases takes place usually at tertiary institutions such as Medical College Hospital and Mentoring Institutes. In AP, Gujarat and Odisha, this function is carried out at the DHs as well. As of now, this takes place only in the Mentoring Institutes in Rajasthan and Maharashtra. In Karnataka, the District Ophthalmologist diagnoses cases at the CHC in the Mobile Eye Unit of the Mentoring Hospital. Follow up takes place at CHC or DH in AP, Gujarat, Karnataka and Rajasthan; at the Medical College in Goa and also in the Mentoring Institute in AP and Gujarat. In two states, namely, in Kerala and Maharashtra, follow up takes place solely in the Mentoring Institutes.

The variety of models followed by these pilots rest upon the differing strength of the health system of the states; the varying geographical and other accessibility issues that the community faces; and the challenges that the identification and treatment

of the condition poses. The NCD programme and its roll out has had a profound effect in making the public aware of the need to take care of their own health including through regular eye examination. With the advent of new technology, identification of DR has gained from the fall in prices of fundus cameras; the ease with which these can be deployed; and their ability to communicate with other digital devices. This has made the capturing of fundus images and their transfer to a grading centre easier, freeing up highly skilled personnel to take up other important work. It has also made possible the centralisation of the image reading centre and addressed patient convenience by making grading available within minutes. The next step in the patient pathway is one fraught with challenges – patients have to be motivated to access the highly specialised service of diagnosis and treatment at a centre far away from where they live, leaving room for drop out. This drop out is significant, and in the absence of a system for capturing private sector data, can leave out many of those deemed to require treatment. Barriers to treatment are reported to be lack of familiarity with the place at which treatment is available; high cost of transport and caregivers' stay; not enough understanding of the serious consequences of the condition; and it was speculated, use of private sector services in preference to the distant one provided by the government. Follow up remains a challenge, and a system for repeated follow up is urgently required to be properly piloted. Experimentation with peer support groups, and drug distribution only after check-up is verified, are some efforts that have been made in this direction. Because the project faced delays, implementation has been of limited duration and a common minimum programme has not fully evolved. This will not doubt emerge expands with the support of state governments.

Practice

The DR programme has been carried forward on the back of a growing NPCDCS programme. Respondents in all locations visited remarked on the positive role played by the Trust's programme to bring DR to the notice of NCD work on diabetes, and create the space for it as the programme is being refined and expanded. As the DR programme has rolled out across the 10 states, changes at the practice level have been instituted.

Screening for retinopathy A process to identify and track patients for DR is becoming streamlined. In pilot locations, lists of patients with high blood sugar identified through a survey carried out 2 -3 years ago are being invited to visit government health facilities to check current blood sugar levels; walk in patients over 40 years of age are also being systematically checked. All those with blood sugar levels in the diabetic range are advised retinal screening as are those with visual symptoms. This is being done at PHC, CHC, SDH and DH of the government. Further, patients receiving diabetes care are now being referred for ophthalmic examination. In some locations such as Maharashtra, even patients of private practitioners are being solicited to have regular retinal screening.

However, the programme has not yet been able to ensure that these patients systematically find their way to the screening location – better coordination between the outpatient/ NCD area and the eye clinic is needed. In a few locations, the ophthalmic outpatient department (OPD) has been moved closer to the NCD clinic; in others the fundus camera used to take retinal images has been moved to the NCD clinic and NCD nurses trained to take images. Still others, like Karnataka have adopted a mobile facility approach employing a mobile van to go to facilities with NCD clinics. In Maharashtra, a van is used to transport patients from the community to the NCD where they are screened to increase uptake.

Staffing at the government health facilities is crucial to the success of the programme. Staff vacancy particularly in Rajasthan and Odisha has led to increased workload on the existing staff. Involvement of social health workers like ASHAs, and female health workers/ANMs has led to an increased footfall of patients in Kerala, Maharashtra and Andhra Pradesh. However, once the programme ends, they will need to be incentivised to take up these additional responsibilities.

IT platforms An online data entry system (DRROP software) was created by the programme. After initial difficulties in its use, it has been upgraded and is being used to maintain the records of each visit of the patient. This has reportedly helped to improve record keeping. Difficulties are posed by lack of adequate internet connectivity, complicated functionality and insufficient manpower. In places where the software could not be used, manual recording is being done and separate DR registers have been maintained. An important outcome of the programme is that data of DR cases screened and treated outside the programme is also now being maintained by the government hospitals.

Communication Taking a cue from the IEC material created by IIPH-H, both Mentoring Institutes and the government programme are now translating and printing IEC material to create awareness about vision loss due to diabetes. Several strategies are being considered for the distribution of this material. This includes using ASHA workers for distribution of the material to households, display of posters at hospitals and public places like Gram Panchayat or meeting places of village elders, approaching pharmacists association for distribution of IEC in pharmacies etc. FM Radio and Doordarshan advertisements are also being run to increase mass awareness. These strategies could lead to increased awareness among the persons with diabetes and their caregivers, and in turn increase the footfall for DR screening.

Peer support groups Apart from the communication material, the programme has encouraged formation of peer support groups that provide an opportunity for people to share personal experiences. Peer support groups have been formed in the states of Maharashtra (15), Kerala (4) and Gujarat (1) and Karnataka (1).



Programme

The overall goal of the programme is to achieve a reduction in avoidable blindness due to DR by improved control of diabetes, early detection and treatment of sight threatening retinopathy. To achieve this, implementation has used a strategic mix of programme areas.

Table 4: Meetings held of the NTF for DR

National Task Force Meeting	Date
NTF Meeting 1	7 August 2014
NTF Meeting 2	21 November 2014
NTF Meeting 3	2 November 2015
NTF Meeting 4	30 July 2016
NTF Meeting 5	28 February 2017

¹⁴ The situational analysis was conducted by IIPH-H, PHFI, and the International Centre for Eye Health, London School of Hygiene & Tropical Medicine, UK

¹⁵ The Queen Elizabeth Diamond Jubilee Trust, Public Health Foundation of India and London School of Hygiene and Tropical Medicine. The Emerging Epidemic of Diabetic Retinopathy in India: Report of a Situation Analysis and Evaluation of Existing Programmes for Screening and Treatment for Diabetic Retinopathy Available at: <https://iceh.lshtm.ac.uk/situation-analysis-and-evaluation-of-existing-programmes-for-screening-and-treatment-for-dr/>

¹⁶ National DR Summit – Available at: <https://blogs.lshtm.ac.uk/iceh/files/2015/01/DR-Summit-Report.pdf>

Goa and Andhra Pradesh are expecting to begin soon. The main themes of their discussion have been on diet, nutrition, exercise, management of emergencies and medication management. While the intention has been good, these groups will need more time to deliver the benefits of interpersonal sharing. For the moment, they remain largely didactic and participation is being incentivised by drug distribution.

Innovation In addition to the IEC material, Mentoring Institutes are using innovative mechanisms to ensure greater coverage of the DR cases. For example, Maharashtra and Tamil Nadu are making smart use of the distribution of drugs as an incentive for patients to participate. A checkpoint has been created at government pharmacies to ensure that only the patients who have completed DR screening are provided drugs. In Maharashtra, patients needing screening are mobilised by ASHA workers, and accompanied to the screening sites, and then accompanied back to their communities. Tamil Nadu is utilising the Aravind Diabetic Retinopathy Evaluation Software (ADRES) of the Mentoring Institute to send images from CHCs to the base hospital to detect DR. Similarly availability of green laser in West Bengal has enhanced footfall in the Ophthalmology units. As the programme has expanded in each state, some states such as Kerala (and soon Gujarat), have chosen to use their e-health systems to track patient care. Several refinements to ensure adequate patient tracking, not only of initial screening but also of follow up screening, are proposed in various states; this will add to the programme’s effectiveness once implemented. In some states such as Maharashtra, Kerala and others, incipient systems based on ASHA and ANMs are beginning to emerge, but much of this is work-in-progress and will require more attention as the listing of persons with diabetes grows longer.

Advocacy with Government Under the programme, advocacy was undertaken by IIPH-H primarily with the MOHFW and other policy oriented stakeholders.

The Situation Analysis for DR carried out in 2013 ¹⁴ helped to set the agenda for the DR Summit and NTF to get government involved. The output of the Summit was the identification of priority strategies for a programme to control visual loss from DR in India. Findings from the Situation Analysis have been summarized in a report and published in a special issue of the Indian Journal of Endocrinology and Metabolism. ¹⁵

The NTF for DR was set up in June 2014 following the DR Summit in April 2014. The Task Force was convened by Dr. D. Bachani, Deputy Commissioner NCDs, MOHFW, chaired by Dr. Atul Kumar, Chief (Dr R.P. Centre, AIIMS) and Advisor

(Ophthalmology), Government of India, and co-chaired by Dr. Nikhil Tandon, Professor of Endocrinology, AIIMS. The NTF reports to the MOHFW, Government of India and is supported in its operations by a Secretariat based at IIPH-H. The role of the NTF is to support any development of the evidence base on DR, provide advice for policy makers on the best ways for government investment in DR prevention, advice on the most effective strategies for targeting prevention in high risk and underserved populations groups, provide guidance to strengthen DR screening and management services, advice to government on options for better integration of DR services into the NHM and support the development of inter-departmental and multi-sectorial partnerships on DR.¹⁶

The NTF has a wide representation from the government and private sector. Doctors, both endocrinologists and ophthalmologists, are members. It is through the efforts of the NTF that the Additional Secretary was brought on-board, and sent letters to Departments of Health in States selected for the implementation of this programme. The NTF has made this programme a national agenda, widening it beyond the states where pilots will be run. The NTF has had 5 meetings till date. Details of the meetings are provided in Table 3.

Once the grant had been awarded to IIPH-H, orientation meetings with states identified by the NTF were held. In these meetings that were attended by government representatives such as the Principal Secretary Health, State Programme Officer (NCD), Deputy Commissioner (MOHFW, Government of India), partner institutes, IIPH-H communicated the purpose of the programme, the Trust, the NTF, the Partner Organization and the contributions that the programme would make to the public health system. These meetings helped to sensitize the audience to the issue of DR, and clarify with them the support that the programme is willing to offer them. Possible approaches for implementing the programme were also discussed at this stage. These state orientation meetings have been undertaken in 9 states with the exception of Maharashtra and have helped to generate government buy-in for the programme.

At the beginning of programme activities, a State Coordination Committee and District Coordination Committee were constituted. These committees were expected to meet regularly to review the activities of the programme, increase awareness and guide as an advocacy tool for DR. However, the committee meetings often did not take place due to the unavailability of the government officials and last minute cancellations. The maximum number of State Coordination Committee meetings has been held in Goa (5). While there has been no state meeting in Maharashtra, one state meeting in Rajasthan is scheduled for May this year. District Coordination Committee meetings have been held in Goa, Gujarat, Kerala, Karnataka, Andhra Pradesh, West Bengal, Odisha and Maharashtra. There have been no district coordination meetings in Tamil Nadu and Rajasthan.

Implementation of Pilots The DR programme has been piloted in ten states. For the implementation of pilots, a partner (Mentoring Institute for eye care) was selected in each state. Hands-on training of Ophthalmologists, skill upgradation of the Ophthalmic Surgeon, Ophthalmic Officers, ASHA, ANMs, NCD clinic nurses and Physicians has been provided by these partners. Instruments, equipment and machines have been provided by the programme over a period of 4 years and most have already been handed over to the public sector hospitals. The target set for the Trust's programme has been exceeded for DR. While the target was to screen 45,000 persons with diabetes in the period of 4 years, the programme screened 62,000.

While the programme has had considerable achievement, some challenges had to be addressed in the process. At the pilot implementation level, availability of Ophthalmologists in the districts had emerged as the major challenge. Government Ophthalmologists are overburdened with cataract surgeries and complain that they do not find time to deal with DR. Even though OAs are in place but their low status reduces their effectiveness as service providers in the eyes of patients. In addition to lack of manpower, transfers of NCD nurses and Optometrists trained in DR screening poses another challenge.

Table 5: Status of people trained by state

State	Ophthalmic technicians trained for screening	Ophthalmologist trained for treatment	ASHA/health workers oriented on DR
Karnataka	5	9	1186
Andhra Pradesh	16	3	289
Kerala	65	8	463
Tamil Nadu	33*	4	102
Odisha	4	4	70
Rajasthan	9	2	236
Gujarat	48	4	1142
Goa	19	4	0 [§]
Maharashtra	11	1 [#]	645
West Bengal	6	2	2224
Total	183	41	6357

* Nurses trained to take images

§ No ASHA workers

Trained ophthalmologist transferred; no replacement

States have not yet been able to come up with an effective system to facilitate patient movement from NCD clinic to DR screening. One reason is that there is no list of patients with diabetes who attend the NCD clinic. Another is that in several states, screening takes place only on particular days of the week as the OAs have other field roles. Persons with diabetes visiting the centre on non-screening days are advised to visit the centre on the screening days leading to patients being missed out. Once screened, getting the patients to the base hospital for treatment is another challenge due to the poor socio economic condition of the patients. Lack of awareness among people about diabetes and issues associated with it, makes follow ups a challenge. The problem is aggravated when they come without any form of identity proof or attendant, making it difficult to

as internet connectivity and low battery strength. In addition, there have been concerns about the poor maintenance of the equipment's particularly in Rajasthan. Suggestions have been made for the provision of annual maintenance contract of equipment for long run. It was seen that the states that have decided to either support or extend the project are taking responsibility of the maintenance of equipment supplied under the project. The details of the equipment supplied, their status and maintenance is attached in Annexure V

Capacity Building Under the pilots, capacity building is taking place for OAs/OOs (and optometrists), NCD clinic Nurses and Ophthalmologists for screening, grading of images and treatment of DR. However, transfer of staff trained in DR screening and

Table 6: Status of people screened and treated by state

State	Registered with diabetes	Patients Screened	Failed Screening (referred)		Patients Treated	
Karnataka	7428	5697	1930	34%	608	10.7%
Andhra Pradesh	5788	4867	283	6%	55	1.1%
Kerala	10,368	17,616	1901	11%	359	2.0%
Tamil Nadu	8360	6215	157	3%	61	1.0%
Odisha	1488	1488	130	9%	6	0.4%
Rajasthan	3292	2836	79	3%	18	0.6%
Gujarat	2279	1426	491	34%	89	6.2%
Goa	7164	4990	555	11%	833	16.7%
Maharashtra	7618	7618	203	3%	108	1.4%
West Bengal	4511	4046	465	11%	224	5.5%
Total	58,296	56,799	6194	11%	2361	4.2%

enter their contact details in the system. In 3-4 states, staff at the screening centres was not motivated to take up screening under the programme and most of the DR screening was solely done by the mentoring team right from maintenance of equipment, screening of patients, grading of images, patient counselling, treatment of referred cases until the follow up of patients for annual repeat screening. Need is felt to increase involvement of in house faculty of the government medical team (Medical officers, NCD nurses, OAs and Ophthalmologists).

The well-established field plan has helped to build local partnerships since a partner institute (mentoring partner for eye care) was selected in each state for implementation of the pilots. Hands-on training of Ophthalmologists, skill upgradation of the retinal surgeons, PMOOs and physicians has been provided by the Mentoring Institutes. However, trained staff is sometimes posted out for a variety of reasons such as personal issues, transfer to other hospitals etc. Staff coming into the programme area received training in many places.

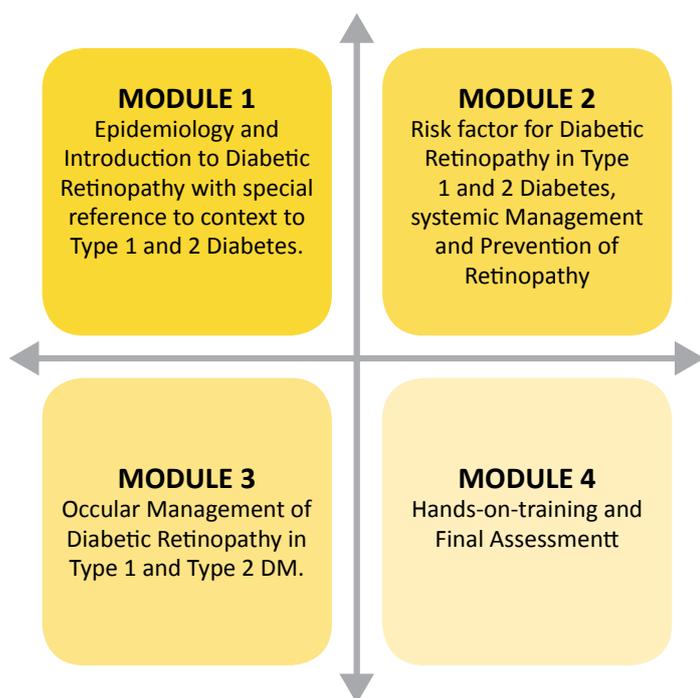
Instruments, equipment and machines have been provided by the programme over a period of 4 years, and most have already been handed over to the public sector hospitals. However, there have been issues with the use and maintenance of the equipment. Tablets that have been provided for registration of patients referred for DR screening is not being used in most states due to lack of understanding, and technical issues such

delay in appointment of contractual optometrists has led to untrained staff being in position in certain locations. The TEG on Capacity Building of Ophthalmologists has developed a DR Management Manual for Ophthalmologists. This will serve as a standard training guide for those working in DR. In addition, they have also developed technical, and operational guidelines for DR that is anticipated to be available by the end of June.

ASHAs are playing a crucial role in increasing awareness in the community and increasing the footfall of the patients. DR orientation sessions have been organised for ASHA's in Andhra Pradesh, Goa, Kerala, Gujarat, West Bengal, Karnataka, Maharashtra and Odisha. However, their engagement in the programme after the Trust funding comes to an end is unsure since they need to be incentivised to take up additional responsibilities.

In addition PHFI has launched a Certificate Course in Evidence Based Management of Diabetic Retinopathy to build capacity among Physicians. This course is run in collaboration with academic partners Dr. Mohan's Diabetes Education Academy and the Aravind Eye Care System. The objective of the course is to enhance the knowledge, skills and core competencies of practicing primary care physicians in the management of diabetes to reduce the risk of DR. This course is supported by funding from the Helmsley Charitable Trust for 4 cycles of 4 months each. The CCDR also aims to develop a standard teaching protocol and module for evidence based learning on DR, build a

Figure 5: Module wise representation of the CCDR



a period of 4 months. The course requires attendance in all contact sessions, plus clearance of final written assessment for completion. Three cycles of the English-medium course will be conducted in over 10 sites across the country with regional faculty at each centre before June 2019. Faculty comprises of an endocrinologist and a retina specialist who deliver the course under the leadership of National Experts.

A total of 578 participants have taken part in the CCDR so far. Of these, 388 have successfully completed the course and the remaining are to complete the fourth module. Nominations for the CCDR course have required constant follow up as doctors were committed to other government programmes.

An endline evaluation of the course was conducted by PHFI at the end of the course in June 2016 and the feedback on the course was overall positive. However, no other report has been released after the completion of other modules of the CCDR training. The one factor that all participants have consistently rated as one of the best has been the faculty. The participants have attributed the value of the sessions to the high quality of faculty selected for this course. The faculty have kept the course flexible to participants' common convenience, have responded well to queries and have been able to provide an enabling environment for learning.

A CCDR 'e-learning Module' for physicians and counsellors/

Table 7: Profile of participants of the CCDR

	CCDR 1	CCDR 2	CCDR 3	CCDR 4
Total Participants	186	138	121	133
Gender				
Female	51	47	44	62
Affiliation				
Government	77	52	58	98
Private	95	82	56	26
Other	13	4	7	9
Qualification				
PG (MD, MS, DNB)	83	71	40	11
PG Diploma	12	0	0	0
MBBS	62	63	74	114
Diploma Ophthalmology	29	4	7	8
Geographic Spread				
North	17	9	12	13
South	87	47	28	51
East	45	27	4	0
West	22	55	56	49
Central	15	0	21	20
Completed	162	122	104	On going

network of primary care physicians and specialists in the field of diabetes and retinopathy and to update practicing/primary care physicians with the latest advancements in the field of DR. Physicians from the pilot districts are being encouraged and supported by the Trust supported projects to attend this course. CCDR is a 4 module course, spanning 4 contact sessions over

High level of patient communication /counselling is being carried out.

- State Government Stakeholder

dieticians on evidence based management of diabetes with a focus on screening, referral and management of DR is in the final phase and will soon be completed. Additional funding has been secured for this initiative which will greatly increase access to the course.

Capacity building through operational/ implementation health economics research has also been undertaken. Two operations research workshops and 8 operations research projects have been completed and are being readied for submission for publication.

Information, Education and Communication The programme has made genuine effort to develop, publish and disseminate communication collateral to promote interest among the medical fraternity, build awareness among persons attending health facilities, and sensitise the masses. While there was no standardized IEC material for patients and caregivers at time of the mid-term assessment, a large amount of material has been created since 2017 to create awareness among different target audiences. The list of IEC material that has been produced is attached in Annex III.

An integrated logo for both ROP and DR was launched at the NTF in July 2016 which sends out the common message of 'early screening and timely intervention to reduce avoidable blindness'. This has been widely used in all the IEC material that has been created.

IEC includes infographics, advertisement, radio jingles, posters and standees for the general population; flipbooks for ASHAs; give-away material like fact sheets, posters, stickers and danglers for health care professionals; and policy briefs for policymakers. Posters, videos, brochures and leaflets have been translated into local languages by state governments and are being extensively used. Posters are pasted at prominent public places, hospitals and CHCs and information leaflets are shared at CHCs and PHCs. These have helped in increasing the overall awareness regarding DR amongst not only patients of diabetes, but also other patients frequenting the hospital.

The website that was to be put up for dissemination has been delayed by three years and will now become operational by end of the programme. It was gathered that this delay has been due the issues that IIPH-H has faced with respect to foreign

funding receipts. As a substitute, content to create awareness among the general populations has been posted on Facebook and Twitter regularly. Similarly, a mobile phone application or online system for diabetic care was to be created to allow patients to set (alarm) reminders to take medication and doctor appointments, annual eye examination, and provide a means of logging blood test results. This is underway, but has not yet been completed.

To spread information on the gravity of the issue of DR among professional groups, the Situation Analysis was released at the National DR Summit in April 2014. A special issue of the Indian Journal of Endocrinology published 11 papers from the situation analysis and systematic reviews. The report is available in the public domain.¹⁷ In addition IIPH-H and Queen's Trust have presented work done under the programme at several national and international forums. This includes Screening for Diabetic Eye Disease in A Diabetic Clinic organised by Apollo Hospital, Hyderabad; WHO Consultation on DR, 21-23 September 2016, Switzerland; the Commonwealth DR Symposium, Durban; International Agency for the Prevention of Blindness (IAPB) meeting, Kathmandu; Satellite Symposium, Abu Dhabi; Meeting of Minds-Experiences from Field, Mumbai etc. The researchers have also published 11 articles on DR in peer reviewed journals. This includes Indian Journal of Ophthalmology, Indian Journal of Endocrinology, and Bulletin of the WHO.

Lessons learned from the programme in India have been presented at the following platforms:

- BioAsia National Conference, Hyderabad, 2016
- Commonwealth Eye Health Consortium – DR-NET, Durban, 2016.
- World Congress of Optometry, Hyderaabd, 2017
- World Diabetes Congress Satellite Symposium, Abu Dhabi, 2017.
- Tata Trust's Meeting of Minds Conference, Mumbai, 2017
- Indian Public Health Association Annual Conference, 2018
- Vision2020 India Annual Conference, Tiruvanthapuram, 2018
- Telangana Public Health Conference, Hyderabad, 2019
- Vision 2020 India Conference, Chennai, 2019.

¹⁷ Endocrine Society of India. Indian Journal of Endocrinology and Metabolism. Available at <http://www.ijem.in/>

Policy

At the policy level, the programme has clocked three major achievements: one, the project has galvanised states to action; second the project has spotlighted the importance of addressing the complication of retinopathy in the care and management of diabetes; and three, the project has created awareness of other complications of the diabetes.

Initiative has had a lot of clarity with plenty of future thinking. So that states can take it up after they can see the effects.

- State Government Stakeholder

Embedment into NPCDCS programme The Trust funding has seeded the government machinery with the notion that it is possible to organise to address this complication of what is an exponentially growing disease. Retinal problems have always been considered difficult to tackle, as they require services that are highly specialised. By breaking down the detection and treatment cycle into manageable bytes, reserving specialist care for those requiring intervention through triage, this problem has become more or less resolved. Integration of retinal screening at the NCD clinics has ensured that the DR programme is included in the government health systems. The programme has generated considerable interest in policymaking levels within the government, which are cognizant of the coming epidemic of diabetes and the possibility of increasing disability due to loss of vision.

Attention to other complications Another achievement has been the space that this has created to treat other complications of diabetes, both at state level as well as at national level. Respondents have spoken about the need to address other complications of diabetes, notably diabetic foot care and kidney disease secondary to diabetes. Several states have chosen

to include these in their NPCDCS response. The programme in Goa for example, supports screening and management of complications like peripheral neuropathy and nephropathy. A new information system to capture and track patients of diabetes and hypertension that is presently being piloted has fields for these complications.

State action States are seized of the problem of DR - and they see the possibility for addressing the problem. In addition to the meetings of the State Coordination Committees, considerable efforts have been made over the last year to support the implementing partners and state governments by conducting implementing partners meetings. Approximately four such meetings have been conducted and have been extremely useful in fostering ownership. Several have taken steps already to work closely with the Trust programme to embed their own systems with programme capabilities. But more remains to be done. For example, DR is mentioned in NPCB documentation, but it is not addressed in NPCDCS documents.

The involvement of national and state level partners in the programme through the NTF and State Coordination Committee meetings has helped to keep them updated about the pilot projects and ensure buy in. The National Guidelines for detection and management of DR developed by the TEG established under the programme will be used widely across the country.

Effective integrated models of comprehensive district programmes for screening and management of DR has led to increased commitment to the DR programmes over the last few years. The Government of AP decided to retain (not transfer) the PMOOs and Ophthalmologists trained under the project beyond the project area while the Government of Goa agreed to cover annual maintenance charges for the equipment. Government of Odisha has decided to implement eye screening programs across the whole state.

Sustainability

The DR programme facilitated by IIPH-H has contributed substantively to the scaling up of services of DR across various states in the country. The programme has immediate and longer term plans for sustainability. In either case, the accent is on working closely with government and to ensure its uptake into the health system of the country.

Although the control of DR is not included in the NPCDCS policy, efforts have been made to create pathways for sustainability. In order to do this, the focus of the programme has been on policy, capacity building in the government sector and the development of competency based training and national guidelines, all of which will support the scaling up of the

services for DR well beyond the period of Trust support. State and District Coordination Committees have been constituted where the pilot projects are in place to review the activities, increase awareness and act as an advocacy tool for DR. This has helped ensure that the state government is able to feed into the work being proposed and sees value in the activities being carried out. As a result, state government buy-in is high where pilot projects are in place. The ultimate value of the pilots has been to showcase and test various options available to the government for scale up.

An unexpected pathway for sustainability that has opened up is because of the expanding NPCDCS programme. Diabetes

care is an integral part of the NPCDCS programme, and the avenues opened up under the Trust programme for integration of DR have provided a segue into sustainable DR care. Tools developed for the Trust programme are expected to play a role as the programme expands to districts that are not yet covered e.g. training curricula, education materials, clinical guidelines, trained staff, new and installed equipment, etc.

Several state governments that have been involved with the programme have indicated their interest to scale up the programme. With increasing scale, there has also been modification of some systems; many of these modifications were piloted as part of the roll out of the programme in the states.

The Karnataka government has taken the decision to roll out DR activity to 2 more districts and 5 taluks (sub-province units) in Tumkur district with technical support from Vittala (Mentoring Institute). The Mukhya Mantri Eye Kendram (Chief Minister's Eye Centre) in Andhra Pradesh piloted DR screening in 7 districts in the state, but plans are in place to extend this to the entire state. Andhra Pradesh has already placed fundus cameras in all CHCs under the Chief Minister's Focus Districts programme. The Gujarat government is planning a modest scale up initially to 2 more districts, but has included it for state-wide scale up in its next annual request for funds under the NHM. The state has involved chemists in the programme and plans to approach the Retina Surgeons' Association to develop a private-public partnership model. Kerala has already made plans for state wide expansion to all its 14 districts with state and central funds. Taking a cue from this and another Trust funded programme, Kerala has integrated DR screening into its e-health portal via which DR images are sent to a state grading cell set up in the Regional Institute of Ophthalmology. They are also incentivizing ASHAs to undertake activities under the programme. Tamil Nadu has proposed a tele-ophthalmology network for all its DH and Medical College hospitals in its annual request for funds.

Another reason for optimism with respect to sustainability is the increased awareness that the programme has generated among people visiting local health facilities. The widespread availability of IEC materials and the use of mass media such as radio has led to a surge of awareness, noticed in the increase in patients seeking DR screening to health facilities. This suggests that the programme can be scaled with less effort to other PHCs and CHCs nearby as patients are motivated to get screened for DR.

Nevertheless, several instances of concern did come to the notice of the team. The West Bengal programme has been unable to establish local partnerships to ensure continuity of the programme. Similarly, lack of ophthalmic resources at the DHs in Maharashtra and Rajasthan could also act as a dampener to plans for scaling up in these states.

Legacy has been created in a number of ways. Academic evidence has been amassed and reported in peer-reviewed journals. It has built understanding within the government of the need to be cognizant of downstream conditions. The programme has animated the community of patients and caregivers in the retinopathy space to demand services. NTFs have been established for DR involving the full range of pertinent specialities creating a resource that the government can draw upon for advice. A large body of work has already been carried out to develop the materials needed and training programmes required to put a robust system into play. This will support future efforts in this direction. Professional groups have been sensitised to the subject through a variety of ways. The programme has established a recent precedence of collaborative work between government and non-government entities in delivering an ophthalmological programme of work.



RETINOPATHY OF TYPE 1 DIABETES MELLITUS

RETINOPATHY OF TYPE 1 DIABETES MELLITUS

The Helmsley Charitable Trust has been associated with type 1 diabetes mellitus since the launch of its T1DM programme in 2008. The goal of its programme is to have a positive impact on people living with T1DM. The Helmsley Charitable Trust had been working in India with a few select partners prior to its affiliation with the Trust's work, after which it started working with the government.

T1DM is one of the most common paediatric endocrine illnesses. It is characterized by the inability of the pancreas to produce insulin. It is estimated that there are 500,000 children with T1DM below the age of 15 years globally and of these, more than 50% are from low and middle income countries. India has a disproportionate share of T1DM, with 112,000 children living with T1DM. According to a recent IDF estimate, the incidence of T1DM in India is 4.2/100,000/year.¹⁸ Persons with T1DM are at a higher risk for developing long term complications of diabetes due to their younger age at onset and longer duration of disease.¹⁹

DR is one of the several complications that persons with T1DM face. It is also one of the most frequent causes of new cases of blindness among these children and young adults. Vision

threatening retinopathy is not very common in the first few years of diabetes, but almost all T1DM patients are expected to develop DR over a period of time.²⁰

In India, the majority of T1DM patients are unaware of the requirement for regular screening and therefore are unaware of their DR status.²¹ The Indian Council of Medical Research funded Registry of Persons with diabetes in India with young age at onset was started in the year 2006 with 10 collaborating centres across India.²² The Registry provides an overview of diabetes in the young.

To address the special needs of persons with T1DM and their families, and to reduce preventable blindness from DR in persons with T1DM, the Trust programme aims to:

1. Test the feasibility, usability and utility of a digital camera model for point of care screening of Diabetes Retinopathy (DR) in patients with T1DM at the diabetic clinics
2. Establish peer to peer and family support groups for a cohort of T1DM.
3. Advocate for inclusion of services for T1DM into Rashtriya Bal Swasthya Karyakram (RBSK)

Outcomes

The programme envisages the establishment of a working model for a structured diabetes management programme, cost effective screening facility, referral and follow up services for DR management, provision of free insulin and glucose strips, patient empowerment through peer support groups and behavioural change counselling. Funded by the Helmsley Charitable Trust, this project was for about 2 years and implemented in 3 locations. IIPH-H was awarded a grant in February 2015.

IIPH-H reviewed and finalised the proposal submitted to it by an expert committee at PHFI after due ethical approval, followed by signing a MoU. In Hyderabad, Pushpagiri Vitreo Retina Institute (PVRI) submitted the proposal jointly with Sivananda Rehabilitation Home (SRH) and worked together on the project. AIIMS (Delhi) and Dr. Mohan's Diabetes Specialities Centre (Chennai) submitted the proposals independently.



Figure 6: Cities shortlisted for T1DM pilots

The T1DM programme has contributed substantively to testing a scope of services and resulted in significant changes at the practice, programme and policy level.

¹⁸ International Diabetes Federation. DF Diabetes Atlas, 6th edn. Brussels, Belgium; 2013. Accessed at <http://www.idf.org/diabetesatlas> on 05 May 2019

¹⁹ Walsh MG, Zgibor J, Borch-Johnsen K, Orchard TJ. A multinational comparison of complications assessment in type 1 diabetes: The DiaMond substudy of complications (DiaComp) level 2. *Diabetes Care* 2004;27:1610–1617.

²⁰ Prasanna Kumar K, Saboo B, Rao P, et al. Type 1 diabetes: Awareness, management and challenges: Current scenario in India. *Indian J. Endocrinol. Metab.* 2015;19:6. Available at: <http://www.ijem.in/text.asp?2015/19/7/6/155339>

²¹ Ramasamy K, Raman R, Tandon M. Current state of care for diabetic retinopathy in India. *Curr. Diab. Rep.* 2013;13:460–468.

²² Praveen, P. A., Madhu, S. V., Mohan, V., Das, S., Kakati, S., Shah, N., ... Tandon, N. (2016). Registry of Youth Onset Diabetes in India (YDR): Rationale, Recruitment, and Current Status. *Journal of diabetes science and technology*, 10(5), 1034–1041. doi:10.1177/1932296816645121

Table 8: T1DM programmes under Trust's funding

State	Centre	Start Date	Close Date
Tamil Nadu	Dr. Mohan's Diabetes Specialities Centre, Chennai	October 2015	March 2018
Delhi	AIIMS, New Delhi	January 2016	June 2018
Telangana	Pushpagiri VitreoRetinal Institute (PVRI) & Shivananda Rehabilitation Home (Ramdev Rao Hospital), Hyderabad	February 2016	September 2017

Practice

Retinal screening was part of the routine followed by all three centres under their T1DM programme. However, the programme has sharpened the focus on DR secondary to T1DM and given the opportunity to reflect and develop a strategy to ensure that complications of diabetes among children are addressed.

Under the DR programme on T1DM, a trained Optometrist at the diabetes centre carries out fundus screening and images are transferred to the Ophthalmology centre through a software developed in the pilot. An Ophthalmologist grades the images and detailed printed reports are provided to the patient on the next visit. Patients who require further examination or treatment are contacted to visit the centre. During the screening visit, patients are told about the importance of screening and treatment for DR. They are counselled by a diabetes educator on diet, calorie counting, regular physical activity, injection technique, sick day management and risk factors such as

hypertension and dyslipidaemia. Free glucometers, glucose strips, insulin and insulin syringes are distributed to the eligible patients registered under the programme. The T1DM program has also instituted a strong follow up mechanism in which an alert is sent to the patient every three months through SMS. Phone calls are used to track patients.

At AIIMS, in addition to routine OPD services, the centre organises an “Annual Diabetes of Young Camp” to which all T1DM patients are invited to come. At the Camp they are provided with single window access to blood sugar testing and screening of the retina as well as other complications of diabetes. Although a hard clinical outcome is more downstream for patients with Type 1 diabetes mellitus registered in the programme, it can reasonably be assumed a greater coverage with screening leads to earlier intervention and thereon to a better vision outcome.

Programme

Implementation of Pilots Pilots began in late 2015-early 2016. There were some delays noticed during midterm assessment – some of it due to ethical approvals required with respect to proposal submission and finalisation. But the programme did not face the initial delays seen in Type 2 diabetes work, as it did not require an MoU to be signed with the government. The exception was at AIIMS where the delay was mainly due to its (lengthy governmental) processes for procurement and recruitment.

In Hyderabad, the Ramdev Rao Hospital of the Shivananda Rehabilitation Home has a dedicated Diabetes of Young clinic. In all, 337 patients were recruited and screened for DR in SRH through detailed ophthalmic examination. Fundus photography was carried out using a non mydriatic fundus camera and images sent to PVRI by wireless transfer. An Ophthalmic consultant at PVRI graded the images and identified suspected DR patients.

At the Mohan's Diabetes Specialities Centre, the criteria for inclusion in the study were: current age above 10 years with

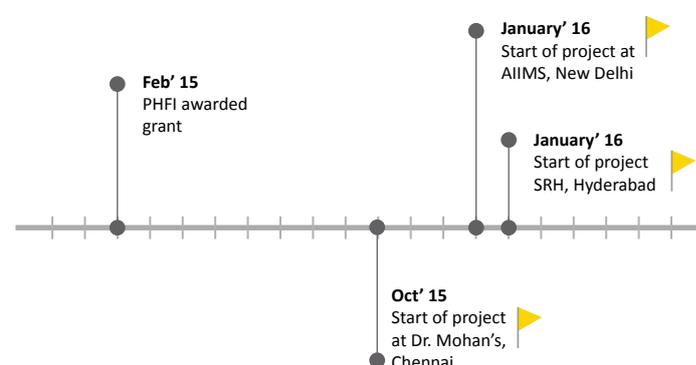


Figure 7: Timeline for the T1DM Programme

type 1 diabetes (insulin), minimum duration for diabetes should be 3 years and patient was willing to undergo retinal colour photography. In total, 313 patients were recruited under this program but only 212 could be screened. Retinal colour photography done by using digital retinal camera and grading of

DR of both eyes was done using the modified Early Treatment DR Study grading system. Free glucometers, insulin, syringes and strips were also provided to the patients under program. Of the 212 patients studied, 22 patients with STDR alone underwent laser photocoagulation treatment and attended regular 3 months follow-up.

At AIIMS, the programme pilot tested in the Diabetes of Young clinic under the Department of Endocrinology and Metabolic

and three times respectively during project period. In spite considerable investment, the programme faces challenges with follow up rates even after regular follow up.

Awareness generation Awareness programmes were also organised by all centres. In the Shivananda programme, 267 patients incentivised by free insulin kits, attended an awareness programme at the Diabetes Research Society. Further, 28 peer-to-peer and family support groups for people with T1DM

Table 9: Status of screening, treatment and peer group meetings at T1DM centres

Centre	Patients registered /recruited	Patients screened	Patients Treated	Peer Group Meetings
Dr. Mohan's, Chennai	313	212	22	11
AIIMS, Delhi	482	413	20	3
Shivananda Rehabilitation Home, Hyderabad	337	337	1	28
Total	1132	962	43	42

Diseases. In all, 482 T1DM patients were registered and 413 were screened after excluding 69 patients (they had less than 10 years at registration or with cataract) under T1DM program. Patients were screened for the presence or absence of DR. Visual acuity of the patients were measured using Early Treatment DR Study visual acuity charts and an optometrist took the retinal photographs using digital fundus imaging system (non-mydratric digital camera). The photographs were graded by an ophthalmologist at the Dr. R. P. Centre for Ophthalmic Sciences at AIIMS. Of those screened, 13.1% patients were diagnosed with any form of retinopathy and 4.1% of them underwent treatment. Apart from DR screening, patients were screened for other microvascular complications and cardiovascular disease risk factors in two annual diabetes complication screening camps. Patients registered under the project were also provided with glucometers, glucose strips, insulin and insulin syringes. AIIMS also distributed the procured materials beyond the project period.

Follow up rates Follow up rates have not been as good as were hoped for. In the Shivananda Rehabilitation Home programme, 84.9% attended the first follow up and only 3.8% attended the second follow up. 17.8% patients were referred to visit PVRI for detailed eye examination but only 12.7% visited in spite of timely communication with these patients. Ultimately, 1 patient was identified with sight threatening DR and underwent intervention at PVRI. In Dr. Mohan's 74.5% patients were identified who attended the first annual follow up and at AIIMS, 34.9% and 33.4% patients underwent DR screening twice

were established to support their education and learning. Dr. Mohan's Centre established 11 peer-to-peer groups of T1DM patients to provide support by group therapy and create awareness about diabetes and DR. AIIMS too, established 3 peer-to-peer groups under the T1DM program incorporating elements of self-management, nutritional advice and lifestyle modification. During the screening visit, patients with T1DM

Creating peer support groups has been one of the best strategies with respect to T1DM. The problem is best understood when communicated by a peer. Patients work as better ambassadors than doctors.

- Service Provider

were educated about the need for screening and treatment for DR. They were counselled by a diabetes educator on diet, calorie counting, regular physical activity, injection technique, sick day management and risk factors such as hypertension, dyslipidaemia. AIIMS also organized two diet awareness exhibitions as part of the annual diabetes complication screening camps. The programme has ensured that case studies of successful coping strategies, retinopathy, eye complications, and nurturing practices along self-management were the essential elements of support group activities.

Capacity Building Service providers are becoming more aware of T1DM after connecting with the programme through pilots and the CCDR. Capacity building under the grant is being undertaken through the CCDR which is common for both the DR and T1DM programme.

A strong follow up mechanism has been created- A pop up SMS is generated every three months and an alert goes to the patient.

- Service Provider

The programme has provided the centres access to OAs for screening and treatment through establishment of partnerships. The pilot has also resulted in the development of software at AIIMS for transfer of images from screening to an ophthalmologist for grading. However, there has been little sharing of such developments across institutions involved in the programme.

Helpline A dedicated helpline (24*7) was developed and launched by the eminent cricketer Mr VVS Laxman. This helpline was developed for patient support activities and a dedicated telephone number has been obtained for this. A lot of work has gone into popularizing this dedicated telephone number through FM radio, social media and chat shows. The same portal is meant for both T1DM and T2DM.

IEC Materials and collaterals Janrise Advertising Agency along with IIPH-H team has developed a brochure for T1DM patients and their parents along with healthcare providers. These have been distributed to partner institutes. Partner institutes have also used their own IEC materials for T1DM patients. Shivananda Rehabilitation Home, Hyderabad and AIIMS, Delhi have developed brochures, posters and pamphlets for distribution to patients and caregivers. AIIMS also has a room dedicated to imparting information about T1DM.

Policy

Advocacy with the government A major focus of the programme has been to getting T1DM services included in the RBSK guidelines. Such inclusion would facilitate the delivery of T1DM services at public health systems. Several rounds of discussion have been held with government officials, but with little effect.

The Indian Council for Medical Research has produced guidelines for the management of diabetes in T1DM patients, but these reportedly do not mention the DR component. The programme had intended to revise these guidelines through an Expert Group so that they cover DR and other eye complications in detail. But this has not happened.

Sustainability

In the centres that were part of the Trust's programme, the T1DM project is eminently sustainable. Each of the centre's has a different format and focus of attention: Dr Mohan's is a diabetes centre, Shivananda Rehabilitation Home is also diabetes care centre, and AIIMS is a general duty hospital and eye centre. All have a vested interest in continuing services to their clientele.

In AIIMS, the Annual Camp plays a crucial role and acts as an annual review mechanism. Patients have become aware of the benefits it provides and see it as a one stop shop for all their screenings. In Hyderabad, the partnering institute has indicated its intention to provide services of screening and treatment to young patients with T1DM even after the Trust funding comes to an end.

The programme provided the space to create a system for referral from the diabetes clinic to the specialities that the patient requires, including the eye clinics. By parsing out the process into sections that can be carried out by more or

Screening is now done by non-physicians health care providers (optometrist) who can do this. You are aligning skills and competence with the resource. Very good model for sustainability.

- National Government Stakeholder

less skilled personnel, the system has become more efficient. Screening done by non-physicians health care providers like optometrist. The hospital can buy cameras from their funds as camera's cost have fallen significantly.

Patients are already 'triaged', which saves both the patients and doctors their time and enables the doctor to focus on therapy. Ophthalmologists are glad to get patients who need treatment on priority. This provides a very strong model for sustainability where skills and competence are aligning with the resource.



RETINOPATHY OF PREMATURITY

RETINOPATHY OF PREMATURITY

In India, about 300,000 children are estimated to be blind, and ~10% of this number is attributed to ROP. Much can be done to control blindness due to ROP by reducing its incidence by improving quality of neonatal care and by its early detection and treatment.

The RMNCH+A approach document outlines measures to set up Special New-born Care Units (SNCU) to strengthen care for premature, low birth weight new-borns and sick children. Around 750 SNCUs have been set up across the country. Although Neonatal Intensive Care Units (NICU) play an important role in increasing the survival of premature babies, they bring a significant risk of ROP from the use of supplemental oxygen among neonates less than 34 weeks of gestation and/or whose weight is 2000 grams or less at the time of birth. Further, acidosis, sepsis and respiratory distress syndrome can also cause ROP. ROP of a severity requiring treatment is likely to develop only in ~10% preterm babies receiving neonatal care. Once vision has been lost, it usually cannot be restored.

The National Neonatology Forum of India guidelines for neonatal care state that screening for ROP should be performed in all preterm neonates born <34 weeks gestation age and/or <1750 grams birth weight. Larger babies can also be screened till 34-36 weeks gestation age or 1750-2000 grams birth weight if

they have risk factors for ROP.²³ Since infants who develop this condition have stayed as preterm babies in SNCUs and NICUs, the ROP programme has involved obstetricians, neonatologists, neonatal nurses as well as ophthalmologists.

The ROP Programme is directed to building awareness regarding complications of preterm births including ROP and the need for screening and treatment, beginning with SNCUs in the government health system. It aims to achieve this through:

- Prevention of ROP by improving quality of care provided at the SNCU through capacity building of neonatal care teams and building capacity of the ophthalmologists and providing equipment at DHs for screening ROP in preterm admissions in the SNCU/ NICU.
- Integration of retina screening at the SNCUs in the government sector within 30 days of birth by capacity building and providing equipment at DHs and Medical Colleges.
- Integration of treatment services into the government health systems by capacity building and providing equipment at Medical Colleges, as well as developing the capacity of Medical Colleges to meet future training needs in the state.

Outcomes

Following the ROP Summit in 2013 and the establishment of the NTF for ROP in April 2014, IIPH-H submitted a proposal to the Trust in June 2014 which was accepted in September 2014.

It is widely acknowledged that more needs to be done to improve the quality of care for infants at risk of ROP in India. Since most of the ROP programs are in private or non-government hospitals, this means that government SNCUs where the majority of preterm infants are being cared for, either rely on the private sector or that they do not have ROP programs in place. Improvements in maternal care has swollen the numbers of surviving babies, especially babies that are preterm and therefore at greater risk of ROP. But beyond survival, the focus must also be on the best outcomes for babies that survive as a result of greater coverage of neonatal care.

The first task that IIPH-H undertook under the grant was a Situation Analysis. The Situation Analysis for ROP was conducted from January - August 2015 to identify gaps in



Figure 8: States shortlisted for ROP pilots

service delivery and select the states in which the programme could be rolled out.

²³ National Neonatology Forum, India. Evidence Based Clinical Practice Guidelines. 2010. Available at :<https://retinopathyprematurity.com/rop/nnf-screening-guidelines/>

To begin with, ten states on the online SNCU database were studied for inclusion in the programme. A detailed and transparent process was undertaken to select the states for the model programmes. States were finalised based on:

- States with an online SNCU database
- High volume SNCUs where rate of premature admissions and survival rate was high
- Where willingness had been shown by the state in the sensitization meeting
- Presence of a medical college willing to take a lead role in treatment and mentoring and clusters of SNCUs around it

The start of the programme in states has been contingent on the signing of the MoU, which on an average has taken around 5-6 months from initiation of talks with the government. The states of Madhya Pradesh, Maharashtra, Rajasthan, Telangana and Odisha

were selected to take on the programme. Despite efforts made to initiate the programme and a tri party agreement being formulated, the programme could not begin in the state of Rajasthan.

Each state adopted a different model; these were tested and evaluated for sustainability and scalability. The broad elements were the same: in each State, a hub and spoke model has been adopted with the Government Medical College with a level-3 SNCU as the hub with 4 - 5 SNCUs in neighbouring DHs or other secondary level care institutions as the spokes. Partner Institutes willing to train, support and mentor the government health facilities have been identified in each state. See table 9. The ROP programme facilitated by IIPH-H has contributed substantively to the scaling up of services for ROP in the country.

It has led to several changes at the practice, programme and policy level

Figure 9: Timeline for the ROP Programme

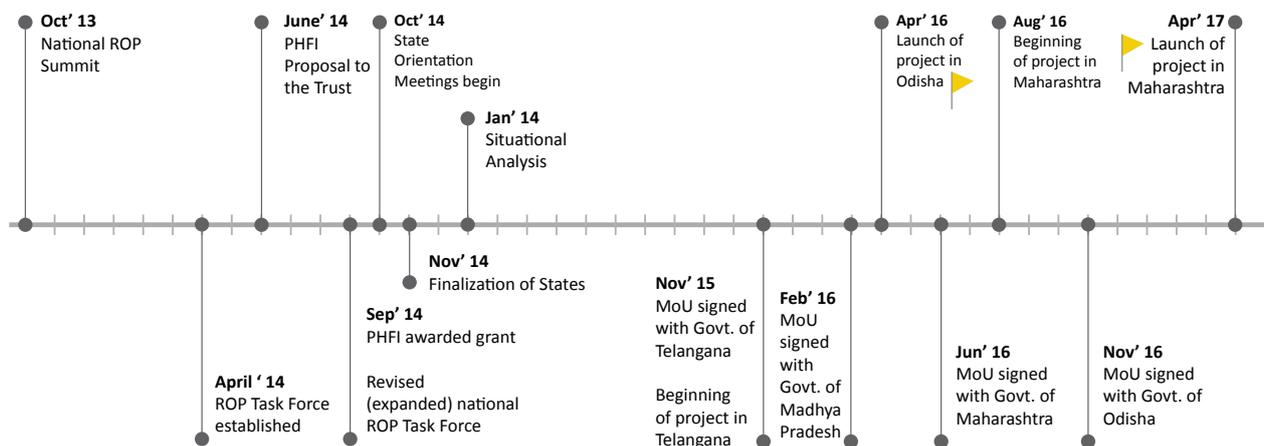


Table 10: Models adopted by ROP programme

State	Identification of babies to be screened		Preparing infants for screening		Screening		Grading of images		Babies treated	Babies followed up	
	Where	Who	Where	Who	Where/how	Who	Where	Who	Who / Where	Where	Who
MAH	SNCU	Paediatrician	SNCU	SNCU nurses	SNCU by indirect ophthalmoscopy	Ophthal-mologist	-	-	Ophthalmologist GOI and private, DHs Mentoring hospital	Eye clinic in DEIC	DEIC staff OA Mentoring partner staff
MP	SNCU	Nurses supervised by Paediatrician	SNCU	SNCU nurses	SNCU by indirect ophthalmoscopy	Ophthal-mologist	-	-	Ophthalmologist, Medical Colleges	SNCU and OPD	ROP Nurses
ODI	SNCU	Paediatrician	SNCU	SNCU nurses	SNCU by indirect ophthalmoscopy	Ophthal-mologist	-	-	Ophthalmologist, Medical College; Mentoring hospital;	SNCU	Mentoring partner staff OA Optometrist Postgraduate Paediatric students
TEL	SNCU	SNCU staff	SNCU	SNCU nurses; OAs Mentoring team	SNCU by indirect ophthalmoscopy. Imaging by nurses in 2 SNCUs being piloted	Ophthal-mologist SNCU nurses	SNCU and Mentoring Hospital	Nurses Ophthal-mologist	Ophthalmologist, Medical College* Mentoring hospitals	SNCU	Mentoring partner staff OA Optometrist

Recognising that babies at risk of ROP are mostly admitted to SNCUs, the pilots were sited in SNCU locations with high throughput. The first step of identification of at-risk babies and preparing them for screening was invariably the responsibility of the SNCU staff with Paediatricians taking the lead in Maharashtra and Odisha; and SNCU staff in MP and Telangana. SNCU nurses took responsibility for preparing the infant for ROP screening in all states; in Telangana, they received assistance from the OA from the Mentoring Institution. Screening itself is generally carried out by Ophthalmologists at the SNCU. However in Telangana, imaging by SNCU nurses is being piloted in 2 SNCUs with images being graded by SNCU nurses and by Ophthalmologists of the Mentoring Institution.

As the programme has matured, treatment responsibility has shifted to government Ophthalmologists located at the Medical Colleges with the remainder being mopped up by Ophthalmologists at the Mentoring Institutions. In the case of Maharashtra, the Ophthalmologist at the DH carries out treatment as well as Private Ophthalmologists who are co-opted by the programme, apart from the Mentoring Institution. Follow up is a crucial aspect of the programme, with babies to be followed up until their eyes mature fully. SNCU still remain the site of follow up with babies returning to them for their check-ups. Mentoring Institute staff work alongside OAs and Optometrists to this; in Odisha they are supported by postgraduate paediatric students. In MP, in addition babies also report to the Ophthalmology outpatient department of the hospital, and in Maharashtra, to the eye clinic in the DEIC where they are attended to by Mentoring Institute staff in addition to DEIC staff and OAs.

Even more clearly than in the DR programme, the ROP programme has a clear catchment area of patients – the SNCU. High risk babies admitted to the SNCU are the universe from which babies requiring treatment are to be identified. The focus on the SNCU provided by the reproductive, maternal and child health programme and the increasing rates of institutional delivery and survival have been a driving force for the ROP programme. In the case of the ROP programme, a clear focus was kept on prevention of ROP through quality improvement in the functioning of SNCU; an area in which the role of SNCU staff was paramount. Thus an emphasis on good practice basics such as hand hygiene, early breastfeeding, kangaroo mother care, temperature monitoring, limited oxygen use, etc. have ensured that the SNCUs are able to limit the number of babies who require intervention. This has led to benefits that go well beyond the gains realised by ROP treatment alone. Challenges that the programme faces have much to do with the constraints faced by families once they leave the hospital facility. Follow up visits fall off dramatically, and co-optation of the field based ASHA is still patchy. Constraints include a failure of families to appreciate the consequences of not taking action; adverse climatic conditions; traditional beliefs; and distance and high cost of transportation. This programme has been operation for a short time, with handover to government systems for intervention having taken place at the far end of the project. It would not at this stage be possible to make definitive statements comparing the various pilots.

Practice

Two pronged approach Improvements in the SNCUs are being promoted through development of Premature Baby Educational Package and Quality Improvement (QI) approach and ROP services are being integrated into District Early Intervention Centres (DEIC) and working relationships between SNCUs and Ophthalmologists.

Ophthalmologists in the government medical colleges and DHs were trained and equipped to treat vision threatening ROP. The following SNCUs and Partner Institutes have been involved in the programme:

Table 11: ROP programme locations, partner institutes and status

State	Partner Ophthalmology	Partner Neonatology	Start Date	Location of SNCUs
Madhya Pradesh	Postgraduate Institute of Medical Education and Research, Chandigarh	Postgraduate Institute of Medical Education and Research, Chandigarh	Mar 2016	Indore, Ujjain, Dhar, Sehore
Maharashtra	HV Desai Eye Hospital, Pune	KEM Hospital, Pune	April 2017	Nashik, Thane, Pune, Osmanabad,
Odisha	LV Prasad Eye Institute, Bhubaneswar	Capital Hospital, Bhubaneswar	April 2016	Nagpur
Rajasthan	AIIMS, Delhi	AIIMS, Delhi	Did not take off	Mayurbhanj, Cuttack, Ganjam, Balasore,
Telangana	LV Prasad Eye Institute, Pushpagiri Vitro Retina Institute, Hyderabad	Fernandez Hospital, Hyderabad	Nov 2015	Jaipur, Bharatpur, Alwar Sangareddy, Nalgonda, Gandhi, Niloufer

Quality Improvement projects Apart from the institutionalisation of the Operational Guidelines, there has been a concerted effort to train nurses and doctors working in SNCUs to improve the quality of care of preterm infants. Key areas of intervention address the main risk factors for ROP. In almost all SNCUs, QI ‘projects’ have led to the identification of a causal pathway for poor outcomes and simple ways that the outcome could be improved without an outlay of significant funding. Several such QI projects have been carried out focusing on use of oxygen and antibiotics for very preterm or low birth weight, hand hygiene, kangaroo mother care, initiation of breastfeeds etc. The package of

lack of a retina specialist in many of these places. Nevertheless, available Ophthalmologists have been recruited to carry out screening of new-borns for ROP using indirect Ophthalmoscopy. At district SNCUs and in view of the poor availability of Ophthalmologists’ time, fundus photography is being carried out by OAs even SNCU nurses using ROP-specific, wide-field digital imaging systems. Where this is taking place, the actual reading of

Ophthalmologists have a number of other responsibilities – medicolegal cases, night duties, cataract targets, glaucoma surgery, admin duties which makes it difficult for them to take on additional responsibilities.

- Programme Management

District level SNCU have implemented QI. Changes monitored on-line. E.g. – antibiotic use change, consumption of oxygen.

PGI has also observed change in practice

- State Government Stakeholder

interventions consisted of over 100 webinars and DVDs and clinical training using simulators in Delhi and in two locations in Chandigarh. A team of neonatologists who have extensive experience of QI and adult education at AIIMS; PGIMER, Chandigarh and the DH, Chandigarh developed the materials. The package of interventions was presented at the WHO South East Asia regional meeting in December 2017 where they were endorsed, and have been presented and are already being used in other countries in the region, such as Bangladesh.

images is being done by Ophthalmologists of the district health service or the MCs. This initiative, while promising, has not had the length of operationalization that would permit comment on its effectiveness, sustainability and scalability. Nonetheless, should this be successful in a longer run, it would offer a possible solution to the dire shortage of ophthalmologists that many countries in the commonwealth face.

Both government hospitals and partner institutes provide treatment, with specialists visiting the SNCU locations to carry out treatment when indicated. This has led to increasing numbers of at risk patients being screened and treated for ROP. The targets set for the Trust’s programme have been exceeded for ROP as well. While the target was to screen 5850 infants

Table 12: Status of infants screened and treated by state

State	Infants screened		Infants recommended for laser		Infants treated when laser recommended	
	N	N	% recommended laser of those screened	N	% treated of those screened	% uptake
Madhya Pradesh	3396	133	3.9%	78	2.3%	59%
Maharashtra	2127	39	1.8%	39	1.8%	100%
Odisha	2897	109	3.8%	93	3.2%	85%
Telangana	3642	146	4.0%	146	4.0%	100%
Total	10,392	427	4.1%	317	3.1%	74%

Several SNCUs are reporting significantly better outcomes in terms of survival rates and processes leading to savings in antibiotic and oxygen costs at the institutional level. Several papers have been published in this regard in peer reviewed journals and presentations made at neonatology and other forums. Nurses and doctors showed good understanding of the high quality SNCU care; however it was also observed that these improvements had not yet become fully embedded in several level-3 and district SNCUs. These QI projects began quite late in the life of the programme and may be the reason that they are not fully internalised by staff in several locations.

Partnerships with the private sector Training of Ophthalmologists from the districts in which these SNCUs are located has been undertaken. In MCs, Ophthalmologists are generally available; however a challenge that has been faced is the

in the period of 4 years, the programme has screened almost double the number i.e. 10392 infants.

Follow up plays a critical role once babies at risk are discharged from the SNCU, but their eyes are yet to mature fully. To ensure that babies at risk do not drop out of treatment, the DEIC and SNCU staff have come up with several innovations. This includes communication on WhatsApp, frequent reminders over telephone, showing videos on use of SNCU to mothers etc. While some of these have reportedly been effective, dropout rates continue to be high in some locations, notably in Madhya Pradesh.

A patient management software has been developed to capture details of infants eligible for ROP screening and their treatment and follow-up. However, this software is not being used consistently in the states for reasons of lack of technical skills,

poor internet connectivity, increased workload on DEOs, etc. Madhya Pradesh is using the patient management software.

Communication Most of the IEC material developed under the programme is being used at the SNCUs since infants requiring treatment are at SNCU and are treated at SNCU/NICU. It must be acknowledged that SNCU and DEIC nurses are playing a big role in the education of mothers and the family of babies who are at risk of ROP. A large amount of materials have been developed by the TEG for Advocacy and Communication for the ROP programme in different formats and for diverse audiences. This includes guidelines, SOPs, banners, brochures, factsheets, leaflets

infographics, policy briefs, documentaries and case studies to target groups such as general population, professionals and government. Much of this material has been translated into local languages and distributed widely in both public and private sector settings. The list of IEC material has been attached in Annex III.

*Communication component requires much more attention
but it needs to be decided that who should manage it*
- Programme Management

Programme

Advocacy with government Initial advocacy with the government by IIPH-H cited the evidence from the Situation Analysis. A court case in the Hon. High Court of Tamil Nadu, wherein a patient who had become blind from ROP was awarded a hefty compensation, also helped to trigger greater attention to the programme among governments.

Table 13: NTF meetings for ROP

National Task Force Meeting	Date
NTF Meeting 1	18 February 2014 (Convened by AIIMS)
NTF Meeting 2	8-9 October 2014
NTF Meeting 3	4 November 2015
NTF Meeting 4	28 July 2016
NTF Meeting 5	28 February 2017

NTF on ROP Following the ROP Summit, a broad based NTF was established in April 2014. The role of the NTF is to support development of the evidence base on ROP, provide advice for policy makers on the best ways for government investment in prevention of blindness from ROP, provide guidance to strengthen ROP screening and management services, advise government on options for better integration of ROP services into the NHM and support the development of inter-departmental and multi-sectorial partnerships on ROP. The NTF oversees programme activities and serves as a platform for discussions, new ideas, and driving new policies. The NTF has representation from the government, ophthalmologists, neonatologists, nurses, the Trust, Federation of Obstetric and Gynaecological Societies of India, PHFI and non-government institutes working in eye health. The NTF was originally chaired by the Joint Secretary (RMNCHA+), MOHFW and co-chaired by the Chief, Dr R.P. Centre, AIIMS. There was a handover of change of the Chair in 2016 and it is now chaired by the new Chair and Professor of Ophthalmology, R.P. Centre at AIIMS.

The NTF has been instrumental in turning attention towards ROP as an issue. The NTF has succeeded in making this programme a part of the national agenda, not limited to the

states in which pilots are being undertaken. So far, 5 NTF meetings have been held.

Certain areas remain weak. It is felt that the NTF consists predominantly of ophthalmologists, with only a very limited number of neonatologists, only 1 nurse (President of the Nurses Association of India) and only 1 obstetrician (President of Federation of Obstetric and Gynaecological Societies of India). By design the ROP Task Force has remained independent of other Task Forces for eye diseases, as the nature of the problem in ROP is very different. Another problem is the shortage of neonatologists in the public health force. However, the NTF has been enormously successful in giving the programme the direction it needs.

To address the concerns raised in the midterm review regarding the NTF meetings focussing on the Trust's programme rather than on national issues, the Project Steering Committee was reinvigorated for the full participation of partners and managers of the programme. These meetings have provided a forum to track progress and to detect, discuss and find solutions to problems. In all, 3 meetings of the Project Steering Committee have been held so far wherein partners were brought together to learn from each other.

State level sensitization/orientation meetings IIPH-H has held sensitization/orientation meetings for state officials and multiple stakeholders from the ROP ecosystem in the selected 4 states to increase buy-in from the government for such a programme. IIPH-H staff meeting with state officials introduced them to the programme; these meetings were chaired by the Mission Director, NHM or the Director, Directorate of Health Services, and attended by other government, district officers and other stakeholders, allowing IIPH-H to have an active dialogue on the need of ROP control. At these meetings, the states were informed of the Trust and the programme, the NTFs, the TEGs and their roles, and the need to make the programme scalable and sustainable.

Following this, IIPH-H initiated the process of getting a MoU signed between the government, partner institutes and

themselves. Some governments received the programme very well and were extremely quick in getting things rolling on the ground such as Madhya Pradesh and Telangana. However in other states like Odisha, the signing of the MoU took 9 months after the talks were initiated in February 2016.

At the central level, the NTF has led the drafting and launch of Operational ROP Guidelines. These guidelines will serve as both, a handbook for care givers and as a resource for program managers to effective planning, implementation and evaluation of their programs. It is unanimously felt that IIPH-H has been instrumental in positioning ROP as a priority issue in the country today. It has also contributed to bringing together the NGO and government sector to work in an organized manner. Apart from advocating for ROP as an issue, IIPH-H has also created ownership among both ophthalmologists and neonatologists for this programme.

A tripartite agreement Four states participated in the piloting of the ROP programme. Rajasthan did not sign the tripartite agreement and so was dropped. Under the tripartite agreement, governments of these four states committed to identify this programme as a health systems strengthening

SNCUs and ophthalmology departments of implementation sites, Representatives of Partner Institutes, representatives from PHFI). The State Coordination Committees were required to meet twice every year. However this has not happened due to the FCRA issue. In all, 3 meetings have been held in Madhya Pradesh and Telangana; and 2 each in Odisha and Maharashtra.

Capacity building The National ROP Operational Guidelines have helped to streamline processes for comprehensive management of preterm babies. The expectation is that these Guidelines will be integrated into the existing child healthcare facilities in SNCUs guidelines under the RBSK.

With regard to the Quality Improvement initiative, the first step was to create a Premature Baby Educational Package. AIIMS, Delhi along with Postgraduate Institute of Medical Education & Research and Government Medical College & Hospital, Chandigarh, have collaborated to create an educational package to cater to the needs of nurses and doctors in SNCUs and MCs. This package caters to the care needs of premature new-borns and was not previously available. It has buy in from WHO and UNICEF, two leading United Nations agencies concerned with the subject. The package has been disseminated in SNCUs and

Table 14: Status of people trained by state

State	Ophthalmologists trained on screening	Ophthalmologists trained for treatment	SNCU teams trained
Madhya Pradesh	6	1	37
Maharashtra	5	1	50
Odisha	6	1	25
Telangana	5	2	74
Total	22	4	186

project and provide necessary directives and circulars. The state was responsible to nominate doctors for training, and that the trained doctors contribute significantly to ensure sustainability. The government also committed to ensuring an enabling environment to experiment with innovative methods for sustainability of the district project, and scaling it up at the end of the project period. The ophthalmic and neonatal Partner Institutes committed to working in collaboration with the government and IIPH-H, by providing training to SNCU staff (neonatal partner) for prevention of ROP and Ophthalmologists (ophthalmology partner) for screening and treatment of ROP. The Partner Institutes committed to developing and implementing strategies to build the capacity of the nodal DH as a centre of training and treatment.²⁴

At the state level, ROP State Coordination Committee has been set up under the chairmanship of the State Health Secretary. The members of this committee are State Health Mission Director, Commissioner of Health, Director of Health Services, Development Partners (UNICEF in Maharashtra and Madhya Pradesh), Representatives from RCH Programme, State SNCU coordinator, State Blindness Control Officer, State RBSK Coordinator, Implementing partners (Head of Departments of

MCs where screening and treatment are being implemented as a means of reducing the incidence of ROP.

In addition to this package, wide collaboration of 25 leading paediatric practitioners from across the country with leadership from AIIMS, Delhi led to the development of a QI module. The module explains the steps that can lead to the identification of the reasons for a particular poor outcome that participants (in this case, SNCU and MC nurses and doctors) would wish to change and guides brainstorming ways to address the reasons with out-of-the-box thinking. The module takes the Plan-Do-Study-Act approach and explain how to do what is required. The QI module is accessible online and available for free to professionals. Although the initial plan was to develop and test the POCQI and preterm package in MP and then roll it out in other project states through simulation skill labs training by mentoring institution, this got delayed. The local neonatal mentoring partners in each state were thus charged with the responsibility of building the QI capacity in the respective states. Capacity building for quality of care emphasises the responsibility of neonatologists and SNCU staff working as a teams to prevent ROP. At pilot sites, SNCU staff has been trained for better quality of care practices to reduce the incidence of ROP in premature babies. Papers in several peer reviewed journals,

²⁴ Memorandum of Understanding signed between Government of Maharashtra, PHFI and HV Desai Eye Hospital.

presentations at various national and international conferences, and visits to the SNCUs testify to the effect that these quality of care efforts are having on preterm survival rates, the process improvements that are taking place, and their screening and treatment for ROP.

Staffing concerns However some concerns continue to beset the system. In high load SNCUs with low human resource counts, maintaining a high quality of care poses a challenge. Staff turnover at project sites leads to untrained nurses being in place, reducing overall project impact. Albeit that contractual staff under the NHM (SNCU nurses, DEIC nurse and paediatrician) makes staff continuity possible, this cannot substitute for longstanding paediatric nurses familiar with SNCU practice. A concern has been the readiness of nurses to take up SNCU duties in the absence of additional 'hardship' incentives over and above usual pay scales.

Another area of concern is the screening of pre term babies for ROP at the right time. The SNCU ROP Nurse/ DEIC Optometrist has been identified in most centres as having the responsibility for checking the age of the preterm babies in the SNCU and ensuring their screening. Ophthalmologists at DHs are being trained in indirect ophthalmoscopy for ROP screening and treatment in leading government and NGO eye care institutions. However, Ophthalmologists trained are usually overburdened by additional (administrative) duties leaving little time for clinical practice. Other factors include the fact that babies may be discharged from the SNCU before the due date for screening. Further, ROP screening may not have taken place before discharge, and in most cases, the baby is likely to require further screening sessions. This is now being aligned to the RBSK's DEIC where the DEIC nurse/ SNCU data entry operator is being charged with making telephonic reminder calls. ASHAs and ANMs are being roped in to support the process of follow up. In addition, as suggested in the mid-term report, a protocol for process counselling for ROP, screening and its treatment may be beneficial. This protocol needs to be part of the SNCU programme.

Information, education and communication The IEC element of the programme is essential to spread knowledge and awareness about ROP. In recognition of its importance to the overall outcome, a TEG has been set up for this purpose which has developed a communication strategy. Quite a lot of IEC material has been developed by the IIPH-H office, and translation, printing and distribution of materials has been undertaken by the Mentoring Institutes. This includes banners, brochures, factsheets and leaflets to target different groups such as general population, professionals and government. Much of this material has been translated into local languages and distributed widely in both public and private sector settings.

Nurses and ophthalmologists are being educated by partner institutes on the pre-counselling aspect of screening of ROP, however it is not very evident in practice. While posters have reportedly been put up for ROP screening in SNCUs, they were not easy to be found. The role of ASHA workers to improve follow up and create awareness regarding ROP is an attractive avenue that remains to be fully explored under the programme.

Finally, several activities were conducted both by IIPH-H and Partnering Institutes on World Sight Day, World Diabetes Day and World Prematurity Day. Events included street plays, walkathons, Continuing Medical Education session and training. These have led to increased awareness among patients.

Dissemination The NTF has emphasised the need to increase awareness among professional groups, with the idea that paediatricians can connect with local ophthalmologists to get screening and treatment at their SNCUs. The programme has developed a Database of Retina Specialists to link SNCUs to retina capabilities throughout the country. The thinking is that once screening is carried out, doctors can refer them to retina specialists in the nearest vicinity for treatment, so that travel does not cause hesitation among caregivers for follow up.

The programme has made sincere efforts to disseminate their models. The first conference that was targeted was the 53rd Annual Conference of Indian Academy of Paediatrics (PEDICON) in January 2016. This platform was utilized to spread the message on ROP through a speech by the President of Federation of Obstetric and Gynaecological Societies of India on the role of nurses in preventing ROP. The ROP team utilized several opportunities to create awareness about screening and treatment of ROP such as inauguration of 'Women's Wing' of the Indian Association of Paediatrics, State Conference of Andhra Pradesh Obstetrics and Gynaecology Society etc. Furthermore, the programme has supported a special issue of 'Indian Paediatrics'. A full list of conferences and papers are provided at Annexure III.

Mass awareness was not an element of the envisaged programme, as it was not thought appropriate to increase awareness among the public when services were not yet widely available in the government sector. However, IIPH-H has had the opportunity to get the ROP project covered and aired by NDTV through a documentary. In addition, infographics, short films and radio jingles have been created to increase awareness. Additional communication activities that have been planned before the end of the programme in June 2019 include completion of a documentary film on the DR&ROP programme, the first phase of which has been completed; finalisation and populating the website, the content of which is being drafted; planning for a peer support group facilitator guide, short films on peer support groups and planning for events like the World Prematurity Day etc.

Challenges of the programme While much has been achieved in the pilots, they have also highlighted several challenges. First, limited awareness of the risk of ROP amongst SNCU nurses, high workload and resource constraints means that work in the SNCU does not always meet the highest standards of care. Second, continuing but diminishing lack of understanding and trust between the public sector where most preterm babies are treated, and the not-for-profit and private sectors which are providing the initial expertise. And finally, synergy and coordination between neonatal care and eye care services has been difficult to achieve in some locations.

At the treatment level, the main challenge remains the availability of Ophthalmologists at the district level. Ophthalmologists available are burdened with other duties and with meeting cataract surgery targets. The government hospitals are sometimes not able to release Ophthalmologists for training programmes, and in some places, Ophthalmologists were not keen to take the training. Follow up continues to be a

major challenge. Parents do not come back for follow up due to personal reasons or due to failures of the follow up system. In some states this may be because treatment is only available in far-off urban centres. Madhya Pradesh faced a peculiar challenge: while a highly skilled offsite mentor for ophthalmology provided screening using indirect ophthalmoscopy; treatment handholding became difficult because of the distance.

Policy

A key area of concern to policy for ROP is the lack of instruction on ROP in SNCU settings. The programme has endeavoured to ensure that ROP is identified early and addressed in government systems by creating coordination between the SNCU and treating hospitals.

Three intersecting programmes Three national programmes are involved in addressing the needs of preterm infants and ROP. The National RMNCHA+ programme is responsible for intensive neonatal care for all preterm and low birth weight new-borns; RBSK covers health screening and early intervention services for children; and the NPCB is mandated to prevent avoidable blindness and strengthen capacity for screening and treatment. The project has sought to create synergy between these programs to bolster the ability of the health services to provide effective ROP services, and this is very visible in discussion at the state with programme leadership. The Operational Guidelines clearly articulate the role of each programme at state level and each functionary at hospital level to improve coordination.

The DROP software and paper based recording and reporting systems like ROP dairy, ROP screening registers and ROP management registers have been developed to improve follow-up for complete screening and treatment. The problems of the DROP software are because of the failure to update SNCU online database at the SNCU regularly as the ROP software relies on Inputs from SNCU software and availability of data entry operator at the SNCU. Although the position is sanctioned under NHM, the person is engaged with multiple office responsibilities and often not available/ interested in updating the SNCU database.

Scale up models A central result of the pilots has been to create models that have been iteratively developed and tested to work. States have developed models based on their own contexts and state experience to develop capacity for QI at SNCUs; track babies requiring screening and get screening organised; develop

systems to provide diagnosis and treatment as needed; and ensure follow up. In Madhya Pradesh for example, it is the Rewa Medical College and Bhopal Medical College which are main treatment centres. Similarly, in Telangana, the SNCU nurse is being co-opted to undertake fundus imaging for screening for ROP. In Maharashtra's Nagpur, Nasik and Thane districts, the private sector has been engaged through contracts to provide laser treatment for ROP.

Incentivising intensive care An interesting consequence of the programme has been the attention to incentives for intensive health care functions. Incentives for specialised duties such as in the SNCU may be required to motivate nurses to take these up. Madhya Pradesh expects that this will take place through budget sharing of payments under Ayushman Bharat schemes for intensive care. Other states too will have to create the wherewithal to retain crucial staff in highly demanding settings.

Aligning district and tertiary care capabilities A policy area that needs to be addressed as the country come to grips with the issues of prematurity including ROP, is the pre service training of nurses and doctors engaged in treating preterm babies. This training is to take place at Medical and Nursing Colleges but will require a 'practice area' in the form of a high functioning SNCU at a tertiary level facility such as those attached to a Medical College. A leadership training has been undertaken at PGIMER, Chandigarh. Other facilities must be upgraded so that pre service staff is exposed from the start to the highest levels of quality of care. At present, colleges are often under resourced as funding streams favour district level facilities.

Hard to detect, hard to treat Wider availability of ROP services has led to improvements in awareness of professionals and community, at least in districts in which the project has been implemented. Policy intervention is required to ensure that an awareness of ROP is injected into the doctors' community, increasing demand and making services more widely available.

Sustainability

As the programme draws to a close, it is clear that the ROP pilot has already led to major benefits: there is greater awareness of the need for systematic screening of small preterms at risk with the need for coordination between RMNCHA+, RBSK and NPCB clearly evident.

An immediate effect has been that screening has been introduced in non participating districts, where some state governments have provided equipment to non participating SNCUs and have extended the hub-and-spoke model by drawing in additional organisations into the task. The pilot has given non-governmental organizations the confidence to offer support to the public health sector. The NPCBVI also plans to fund capacity strengthening of public sector MCs to screen and treat ROP and expand the programme in this way.

States currently participating in the programme have indicated their intention to scale up the programme. Madhya Pradesh plans to include all institutions associated with Ayushman Bharat programme to extend screening and treatment services for small preterm infants. In fact, in order to ensure that other institutions not linked to the Ayushman Bharat programme are also available to support preterm screening, support will be provided under the RBSK. Maharashtra is planning to scale up the programme to all 36 SNCUs in the state and integrate ROP into the DEIC in these centres. The Odisha team is planning for expansion of the ROP screening program to 5 additional districts around LV Prasad Eye Institute's secondary centre in Odisha. These include Rajgangpur, Keonjhar, Anugul, Rayagada and Berhampur. Telangana plans to provide technical support to scale up ROP activities (both quality new-born care and screening and; treatment for ROP) to all the 21 SNCUs in the state, starting with a cluster of SNCUs around MGM Hospital, Warangal.

Introduced eye check up for every child in postnatal ward – this is now all under Ayushman Bharat. But if some hospitals are not linked to Ayushman Bharat (due to not meeting those norms) they will receive under RBSK.

- State Government Stakeholder

Non participating states such as Tamil Nadu encouraged by the technical support available and compelled by the growing small preterm population, have begun ROP programmes with the help of non-government organisations working in the eye sector. UNICEF, a technical UN agency for child health, has included ROP in their plans for support over the next five years.

It must also be added that while this may not have been the ultimate focus, the programme has spotlighted the quality of care at SNCUs at district and MC levels. There is greater ownership of the responsibility or better quality of care by the staff of these units, and growing confidence that they are able to deliver it. In certain SNCUs, staff has improved quality of care to the extent that preterm babies are more likely to survive than before, they are able to document reductions in costs, and mothers and fathers give testimony to the care that they have received.

The DEICs, while playing a part in the programme, have also gained confidence in providing follow up care and ensuring that children at risk in their earliest period of life get the care needed to prevent longer term stigmata.

Yet there are factors that may obstruct the sustainability of the programme. These include staffing issues such as workload and incentive issues of SNCU staff and poor availability of trained Ophthalmologists from government or non-government sectors. SNCUs are not yet using their data to assess and monitor quality. Respondents also cite the need for better educational material for QI projects.

A major problem remains follow up. Once the baby leaves the hospital, follow up is dependent on the empowerment of the family to take action on reminders; this depends entirely on their motivation and family situation. With inputs of the internal audits conducted by IIPH-H, and facilitation with ROP diary, ROP stamps and ROP register, the processes are improving but still leave a lot to be done.

The pilot programmes on ROP have demonstrated that screening and treatment can be successfully integrated into the public health system using a partnership approach in a way that ensures sustainability and fosters comprehensive eye care. This approach could also be used for other potentially blinding conditions.



LEARNING AND CONCLUSION

LEARNING FROM THE PROGRAMME

Two sight threatening retinopathies were addressed by the programme, DR secondary to adult onset diabetes and early onset diabetes, and ROP among early pre term new-borns. Each comes with a very different epidemiology and natural history, and hence a very different point of intersection with the health services. The idea of the programme was to pilot the changes within the health services of the country in several different contexts, offering the opportunity not only to make adjustments to the pilots as they went along, but also to study as implementation science, their evolution in the health system. Pilots for DR (adult onset DM) were experimented with in 10 disparate states; for DR (T1DM) in 3 dissimilar centres; and for ROP in 4 different states.

It was quite clear from the start that the pilots themselves would not have the length of play to ‘fully’ test the approaches. Added to this was the difficulty posed by the temporary withdrawal of accreditation of PHFI to receive foreign funds, leading to a trough in the timeline of operations. It is to the credit of all the partners -the Trust, IIPH-H and PHFI, LSHTM, and partnering institutes- that the project was completed having met its original targets. Many lessons can be derived from these pilots.

Broad support for change

Change is difficult to institute, and change in bureaucratic systems is especially challenging. Each of the programmes initiated under the grant has required profound changes in government systems and in the way that the work of institutions is carried out. For example, under the DR project, it has required NCD nurses to take on fundus imaging; in the T1DM project for peer support groups to be established; In the ROP project, for expedited transfer of preterm babies from the labour room to SNCUs. Not only that, ways of working have also been intensely affected. Nurses in SNCUs have learnt to investigate the reasons for high infection rates, while DEIC nurses have learnt to create the weekly examination lists of preterm babies identified for screening. The programme has challenged everyone from the bureaucrats in administration to ward boys in SNCUs to change their mindset. That it has succeeded in doing so is a true achievement of the programme.

Bureaucratic will

Involvement of the top echelons of the national and state administration has been critical to facilitating action. The National Task Forces and State Coordination Committees constituted under the programmes have helped to iron out differences between departments. Painstaking work with

the programmes have ensured that in the states involved, coordination between the national and state programmes has been worked out with resource (re-)allocation taking place in an optimal manner. Thus the programme has not only required greater work on the ground and in the wards, but also greater work at the district and state where programme managers and bureaucrats are located. Programmes such as the RBSK, RMNCHA+, NPCDCS and NPCB have drawn upon the Trust’s programme to develop future plans for expansion and translation into state initiatives.

Interdepartmental convergence

Interdepartmental coordination is critical in identification, screening, treatment and follow up for DR and ROP. The programmes called for convergence between the departments of Paediatrics, Obstetrics, Endocrinology, General Medicine, and Ophthalmology at the hospital level. Convergence of siloed departments is a daunting task for any administrator and has required great persistence and administrative will at all levels within the system to work through.

This has meant that there had to be discussions between these departments, within district health systems and within the state health systems. State Coordination Committees and District Coordination Committees played a key role and helped generate the needed understanding and goodwill to persuade all concerned to cooperate.

Private public partnership

Another layer of coordination that this programme demanded was that between the private sector in which expertise resided and the public sector which was catering to a large complement of patients. The process of establishing and operationalising mechanisms for implementation of the programme was riddled with difficulties. Partner and Mentoring Institutes in all projects provided expertise and a readiness to support an iterative process, improvements in both the capacity and systems of government institutions. At the start of the programme, these private sector institutions often had to take on a delivery role as well, which prepared them to transfer skills and knowledge to public institutions. As the programme proceeded and became more embedded in the government system, they were able to for the most part, gently ease out of the delivery role while continuing to provide backup services and take care of spill

over as needed. The complementarity of the expertise of private sector and willingness of the government sector to absorb capacity helped to make this mechanism work.

However, it must be mentioned that this did not take place entirely smoothly. In some places capacity transfer did not take place, in others clashes between views led to failure to coordinate, while in still others success was personality driven rather than systems led. Where there was lack of commitment or focus and resources were lacking or not assigned, the programme did not take off as envisaged.

Streamlining management of resources

Adult onset diabetes is a common disease. Thus the need for services is high and the volume of screening to be done is likewise high, especially because it is to be done multiple times over a lifetime. Both ROP and retinopathy secondary to T1DM are relatively uncommon. However in the first, a possibility exists of capturing the target population from SNCUs where most of the at risk babies are attended, while in the second, these young people remain interspersed in the general population and there are no field programmes (except the RBSK) that explicitly target that group.

Thus capturing the population that requires retinopathy treatment requires a combination of broad based and targeted strategies, and use of available human resource in a tactical manner. In addition to financial resources, resource constraints at both bureaucratic and government medical facilities as well as preoccupation of government departments in addressing their pre-existing priorities has been a challenge. ASHAs are a resource that have been tried out under the programme and proven to be quite useful, but need to be incentivised. Likewise, contractual DEIC nurses under the RBSK have also been co-opted. However indications are that they would need to be motivated to take on additional responsibilities, as would auxiliary nurse midwives.

Investing in ancillary staff

This programme has also brought another important aspect of the health care system into the spotlight. Because so much of the programmes rely on the capabilities of ancillary staff – SNCU nurses, NCD nurses, optometrists, OAs, counsellors etc., as they do on the capabilities of the doctors and specialists, the programme has highlighted the role that ancillary staff plays. It has made it impossible to ignore the need to upgrade their skills as the health profile of the catchment population's change, and the need to find ways to motivate them as a way to improve quality of care. While the programme has already made this

clear in the case of these two conditions, it has important lessons for the wider healthcare system and implications for how India organises itself for the ensuing epidemiological transition.

Capacity building efforts

A challenge to the programme has been the transfer of staff already trained in screening and treatment. This is a problem in some states more than others where staff transfer policies are less tough. Various states have taken different approaches to resolving this: in Maharashtra's ROP programme, staff at all SNCUs have been trained, while in others, frequent training has been done to ensure that new staff is trained; while in still others, supportive supervision and short training approaches have been attempted to bring new staff up to speed.

Raising the knowledge and skill levels of persons involved in the programme is crucial, especially in the health sector, where there are frequent advancements in terms of the practices that will promote health. In addition, there is a need for clinical guidelines and written protocols for all aspects of diabetic management and new-born care.

Integrating the healthcare chain

The programme has done much to reconnect the primary, secondary and tertiary levels of the healthcare system. Developments over the course of years have laid emphasis on one at the cost of the others. Because this project is based on field detection and requires medical services to be delivered at every level within the system, it has helped to re-connect these levels. Thus a person with diabetes is detected at the PHC or CHC. Under the DR programme, s/he would need to have a fundus image at the centre, which would require a specialist to read the image; and then s/he would require further investigation or treatment at a tertiary care facility. ROP presents a similar story where the degree of specialisation is even more acute given the challenges of treating a small pre term new-born.

Retina specialists are far and few between. Efforts have been made under the programme to create systems to bridge the gaps and ensure that specialised services are available closer to the patients' homes. Nonetheless, this has been difficult to do so far. Training general duty ophthalmologists has not fully solved that deficiency especially in the public sector where they are often required to take on administrative duties as well. But better equipment and falling prices is making treatment of retinal diseases easier, and is gradually moving the needle from the complex to the routine.

Until that happens, this has meant that the onus is on the patient to seek out specialised services and not only once, but

until the problem is resolved. As a result, the numbers indicate a high drop out between screening and treatment. Facilitation of patients to reach treatment services is urgently required.

Creating awareness

An area of need has been increasing awareness amongst relevant professional groups and the general community. Awareness among the general practitioner community is critical to funnel patients into the program and awareness in the community is crucial to increasing the footfall of patients. Awareness among professional groups has relied for the most part on training, and publications and presentations made at conferences and consultations.

It might also be added that an increased flow of patients was needed to initially create the will among staff to do what is expected. The DR programme helped to do this by providing value-added services at PHC level which in the opinion of those involved, has led to increasing demand at that level.

Changing patient behaviour

Attitudinal change among the community is somewhat more complex, making treatment and follow up a challenge. There has been some effort to increase awareness among the general community through radio jingles, TV ads, newspapers, etc.; community education and awareness promotion campaigns have also been undertaken. Patient behaviour has been sought to be changed through peer and parent support groups and materials developed for the facilitation of the meetings. A key stakeholder for whom not enough material appeared to be available was the parents of young adolescents, and sons and daughters of older patients with diabetes.

The formation of peer support groups was tried out under the programme under the general wisdom that peers make better advocates than professionals. These worked out well in some centres in the case of T1DM, but had to be linked to distribution of drugs to draw attendance. The experience with peer support groups for adult onset diabetes has been less persuasive and perhaps requires further experimentation to be more effective.

Technology, an agent for change

Traditional methods of maintaining records pose several challenges for consolidation at higher levels leading to inaccuracies. The use of advanced information and communication technology helps

to overcome this challenge. The programme has demonstrated the use of technology in the form of DRROP software that has enabled one-point entry of data on each visit of the patient and its immediate transmission to the mentoring hospital for grading, saving a lot of time and effort. However some difficulties were encountered in its usage due lack of adequate internet connectivity, complicated functionality and insufficient manpower training. Once these challenges are dealt with, such advances in technology, particularly for screening and its linkage to uptake of referral and treatment, can lead to greater coverage.

Some states chose to go with their existing platforms such as E-Health in Kerala and Tamil Nadu, while others are in the process of creating a mobile based platform with advanced functionalities such as Gujarat. In either case, the effort is to digitise patient records in a way that facilitates recording of health data and ensures and facilitates follow up of all patients once registered in the system.

Programming for results

At the national level, the programme established NTFs under the chairmanship of the concerned bureaucrats and eminent scientists, incorporating key functionaries of associations and scientific luminaries. This added much to the credibility of the programme and helped build acceptance of the results of the programme among the decision makers. A key role was played by the Implementation Partners Steering Groups which proved instrumental, due to the eminence of the partners and the influence they exerted with national and state governments.

At the state level, the State Orientation Meetings created the space to discuss the programme, and present evidence as to why it was required. State Coordination Committees were constituted to deal with policy decisions that would need to be taken and create the basis for local level changes. Participation by key state functionaries in this important forum also helped set the stage for exit planning as time went on. The District Coordination Committees provided a more directive role, helping to solve local issues and freeing up time of functionaries to undertake training.

Partnerships for sustainability

A key role was also played by the IIPH-H team and Partners to coordinate with the government. This helped to support the implementation and scale up of the programme. Considerable efforts were made by them to strengthen the monitoring, audit and feedback mechanisms to improve the programme. It may also be noted that considerable efforts were made to capture the interest of international agencies. Agencies such as UNICEF were

brought on board in several states and have played an important role during programme implementation and have committed to driving this forward as the programme draws to a close.

Governance and cross learning

IIPH-H acted as the glue between the various pilots, providing the momentum, guidance, support and supervision that led to systems involvement and improvements. The role played by Dr GVS Murthy and his team at IIPH-H, and that played by Dr Clare Gilbert at the LSHTM, has been central to the successful implementation of the programme. Programme governance was helped by the high levels of communication that was maintained between IIPH-H and the Implementing Partners and Partnering and Mentoring Institutes and the Trust.

Although each state has a slightly different health system and context, and adopts a customised approach to fight the disease, there are also enough similarities for there to be ample room for cross learning. Several forums were created to create synergy. Every attempt was made to ensure good communication and cross learning between partners through regular Partners meetings. These helped to raise doubts and have them answered as well as learn from others' experience.

A sustainable programme

Clearly evident in the programme's timeline is the slow start that it has had. Creating enthusiasm for the programmes and getting clearances from state governments to go ahead with them required presentation of clear evidence of the requirement and several rounds of discussions. Some states demonstrated greater appetite for the programmes and began the process earlier, but these were only a handful by the midterm of the Trust's grant. And just as the midterm of the programme was past, there was an unexpected operational challenge, halting progress for the time being and leading to further delay in the timeline of the programmes.

Despite these difficulties, the programmes have been able to cover the 10 states planned for the DR programme, 3 centres for the T1DM programme, and 4 of 5 states for the ROP programme. In the very short time that they have had to play out, the programmes have been able to generate enough evidence and documentation to convince a large number of decision makers of the utility of the programmes. Several reports and publications later, most of the programme states have made commitments to continuing the work begun already and to expanding the remit of the programmes, in some cases to the entire state, and new States have also come on board.

CONCLUSION

The DR & ROP programme funded by Queen Elizabeth Diamond Jubilee Trust has been implemented by PHFI (IIPH-H) and the London School of Hygiene & Tropical Medicine along with partnering institutes over the last 4 – 5 years. The programme has, as envisaged, yielded important learning for the introduction of wide scale services to prevent, detect and treat retinopathy into the health services of India, and through that for the wider Commonwealth of Nations.

Support from the Queen Elizabeth Diamond Jubilee Trust has played an important role in the experimentation with and critical evaluation of pilots to combat two major avoidable causes of blindness namely, DR and ROP. Given responsibility of the grant, IIPH-H and LSHTM have nurtured a programme of work by partnering institutes and government collaborators that has exceeded the targets set out for the programme at its start.

Despite initial teething problems and after overcoming funding challenges, the programme has been able to entrench itself into government systems in a large set of states and facilities. The

fact that the scope of the pilots is not small not only adds to the strength of their results, but also to the learning that they have been able to generate. A large volume of scientific evidence has been generated drawing upon programming under the grant. Despite the short period of time in which the pilots have been in operation in several states, they have been able to demonstrate real results that are convincing to state authorities.

The grant leaves a lasting legacy in the form of capacity building tools, guidelines and standard operating procedures, equipment and systems and IEC materials that have been transferred to the administration. The national and state governments have indicated their intention to continue the work initiated under the grant and expand it in several cases. This is a remarkable achievement and a testimony to the hard work put into the programme.



ANNEXURES

ANNEXURE I : BRIEF METHODOLOGY

In 2014, PHFI and LSHTM were awarded a grant to “to establish models of sustainable and scalable services for reducing avoidable blindness in India”.

In 2019, they approached Amaltas to carry out the endline review of the project. With the end point of the grant approaching, they are keen to assess (i) the extent to which the initiatives have achieved their goals and objectives; (ii) the extent to which they have been scaled up already or likely to be in the near future; and (iii) their long term sustainability.

Specific objectives of the evaluation are to:

- Assess achievements in relation to originally stated goals and objectives.
- Identify outstanding gaps and explanations thereof.
- Summarize the processes adopted and the advantages/disadvantages of such approaches.
- Assess level of buy-in by government and all other major stakeholders.
- Assess whether the initiatives brought about policy change.
- Identify key lessons for other states of India and low & middle income countries which are yet to begin such programs.

Monitoring reports and other documentation maintained by IIPH-H have been used in the evaluation. The evaluative assessment has been guided by the information gathered from IIPH-H as well as through meetings with key stakeholders of the programme.

Data Collection

The evaluation took a primarily qualitative approach. The evaluative assessment clustered the objectives into 3 reviews namely: (i) process and outcome covering specific objectives 1-3; (ii) sustainability covering specific objectives 4-5; and (iii) learning covering specific objective 6.

The guiding document has been the Information Needs Matrix (attached below) constructed from the documentation of the programmes and finalised in consultation with IIPH-H. Data collection took place during March-May 2019.

Work Stream 1: Review of Secondary Data

Over 150 reports, documents and programme data have been reviewed to capture indicators of interest. The following documents have been of particular interest:

- Programme documents of the Trust-funded programme
- Programme Proposals made to the Trust
- Proposals submitted by Partners
- Reports generated during the period of implementation of the project
- Minutes of Meetings such as State Orientation / Sensitization meetings, NTF Meetings, Technical Expert Group Meetings, State Coordination Committee meetings
- Monthly and 6 monthly reports sent to the Queen’s Trust
- Monitoring indicators
- End Line Evaluation of the CCDR
- Policy and programme documents from Ministry of Health & Family Welfare and State Departments of Health pertaining to ROP and DR
- Report(s) of NTF on ROP and DR

Work Stream 2: Qualitative data collection from Stakeholders and Service Providers

Over 80 stakeholders have been interviewed in this evaluation, using specific interview guides designed for each set of stakeholders. Key areas of discussion included status of achievements; what worked and what didn’t; what has changed in terms of practice, programme and policy; level of buy-in; and key lessons for other states that are yet to begin such programmes. In order to assess the current status of programme implementation, selected DR, ROP and T1DM implementation sites were visited in Goa, Gujarat, Kerala, Madhya Pradesh, Rajasthan, Tamil Nadu, Telangana and West Bengal,

During these visits, qualitative data were gathered from service providers: key staff of the institutions involved in providing services and service providers at the intervention sites namely, neonatal care team members, ophthalmologists, endocrinologists, NCD clinic personnel and eye care personnel. A list of interviewees is given in Annexure II.

Figure 10: The Evaluation Approach



Specific objectives	Areas of inquiry	Methods	Source
REVIEW OF OUTCOMES			
<ul style="list-style-type: none"> ▪ Assess achievements in relation to originally stated goals and objectives ▪ Identify outstanding gaps and explanations thereof ▪ Summarize the processes adopted and the advantages/ disadvantages of such approaches. 	<ul style="list-style-type: none"> ▪ To what extent has the programme carried out expected activities? ▪ To what extent has the programme met expected timeline? ▪ To what extent have initiatives focused on marginalized groups? ▪ What has worked and not worked? ▪ Have users of DR and ROP services benefitted from the interventions? ▪ Were the risks mitigated or not? ▪ What are the main barriers to implementation? ▪ What impact have these had? ▪ To what extent have the governance mechanisms for both programmes contributed to the results? ▪ How has the programme changed practice? What changes had been made in the training, monitoring, and management of DR and ROP? ▪ To what extent has there been cross learning between implementing partners and the programmes? 	<ul style="list-style-type: none"> ▪ Document review ▪ Analysis of quantitative data on achievements based on programme Logframe ▪ Site visits and interviews with service providers ▪ Interviews with senior management of the project ▪ Interviews with members of the National Task Forces and Expert Groups ▪ Interviews with service users 	<ul style="list-style-type: none"> ▪ Documents ▪ Programme Manager ▪ Service providers at implementation sites / institution at which services provided ▪ IIPHH staff ▪ IIPHH & LSHTM management ▪ Members of the National Task Forces and Expert Groups ▪ Service users
REVIEW OF SUSTAINABILITY			
<ul style="list-style-type: none"> ▪ Assess level of buy-in by government and all other major stakeholders. ▪ Assess whether the initiatives brought about policy change. 	<ul style="list-style-type: none"> ▪ What actions have been taken by IIPHH/PHFI to facilitate inclusion of DR and ROP into policies and programmes? ▪ Has evidence for action been disseminated? ▪ To what extent do the Trust's programmes for DR and ROP have the support of the Government? ▪ Is control of visual loss from DR and ROP seen as public health priority at state and central levels? ▪ What actions have been taken by the Ministry of Health at state/ central levels to include DR and ROP into policies and programmes of NCDs and child health? ▪ To what extent will initiatives for prevention, screening, treatment, and follow up, be sustained when Trust funding comes to an end? ▪ What has been done to ensure sustainability after Trust funding comes to an end? ▪ How do implementing partners view their role in making the programme sustainable? 	<ul style="list-style-type: none"> ▪ Document review ▪ Interviews with manager and senior management of the project ▪ Interviews with members of the National Task Forces and Expert Groups ▪ Interviews with officials of central/ state Ministry of Health 	<ul style="list-style-type: none"> ▪ Documents ▪ Programme Manager ▪ IIPHH & LSHTM management ▪ Members of the National Task Forces and Expert Groups ▪ Officials of central/ state Ministry of Health
REVIEW OF LEARNINGS			
<ul style="list-style-type: none"> ▪ Identify key lessons for other states of India and low & middle income countries which are yet to begin such programs. 	<ul style="list-style-type: none"> ▪ Have non-project states shown interest in take up and scaling up of the initiatives on? ▪ To what extent have lessons learned in the 'programme states' been shared with other states and Commonwealth countries in the region? ▪ What can be done to share learning from the programme with other states/ countries in and outside the Commonwealth? 	<ul style="list-style-type: none"> ▪ Interviews with stakeholders in managerial positions 	<ul style="list-style-type: none"> ▪ Documents ▪ Programme Manager ▪ IIPHH & LSHTM management ▪ Members of the National Task Forces and Expert Groups ▪ Officials of central/ state Ministry of Health