National Diabetic Retinopathy Summit

Hyderabad, April 12-14th 2014

Report

Chaired by: Dr. D Bachani, Deputy Commissioner, Non–Communicable Diseases, Ministry of Health & Family Welfare, Government of India.

Supported by The Queen Elizabeth Diamond Jubilee Trust.

Organised by the Indian Institute of Public Health, Hyderabad, Public Health Foundation of India and the International Centre for Eye Health, London School of Hygiene & Tropical Medicine, UK.

The National Diabetic Retinopathy Summit

The Summit was held in Hyderabad from 12th to 14th April 2014, to develop a national strategy for the prevention, detection and treatment of diabetic retinopathy (DR), a major cause of avoidable blindness. The Summit was supported by The Queen Elizabeth Diamond Jubilee Trust and organised by the Indian Institute of Public Health (IIPH), Hyderabad, Public Health Foundation of India (PHFI) and the International Centre for Eye Health, London School of Hygiene & Tropical Medicine (LSHTM), UK.

EXECUTIVE SUMMARY

The Queen Elizabeth Diamond Jubilee Trust

The Queen Elizabeth Diamond Jubilee Trust (hereafter referred to as the Trust) is a charitable foundation established in 2012 to mark and celebrate the Diamond Jubilee of Her Majesty the Queen. The Trust was set up following a unanimous decision at the Commonwealth Heads of Government Meeting in Perth, in October 2011. With a five year time frame in which to deliver successful programmes across the Commonwealth, the Trust's purpose is to honour Her Majesty the Queen for her 60 year contribution to the Commonwealth.

The Trust focuses on two programmes across the Commonwealth: avoidable blindness and youth leadership. The avoidable blindness programme includes a major trachoma programme in Africa, an Initiative to control visual loss from retinopathy of prematurity (ROP) in India, and support to clinical fellowships, research and studies to explore the role of technology, to strengthen eye care and build capacity across the Commonwealth. As part of the Trust's avoidable blindness programme, an Initiative for the control of diabetic retinopathy (DR) will focus on India, Bangladesh and Pakistan, the Pacific and potentially the Caribbean.

Purpose of the Summit

The purpose of the Summit was to use the experience of delegates and evidence from a recent large scale study supported by the Trust, to identify priority strategies for a programme to control visual loss from DR in India. The programme needs to address existing gaps in service provision, and be sustainable, scalable and integrated into and strengthen health systems.

Background on diabetic retinopathy

Diabetes is a huge and growing problem. In 2013 there were estimated to be 382 million people with diabetes worldwide which is predicted to increase to 592 million by 2035. There are currently estimated to be 60 million people with diabetes in India, 6 million of who have sight threatening DR. Diabetic retinopathy is already an important cause of avoidable blindness, and the number at risk will continue to increase. There is abundant evidence that good control of diabetes as well as early detection and management of DR are the key strategies for controlling visual loss and blindness due to DR. The Government of India has a large scale programme for the control of non-communicable diseases, including diabetes, but control of DR is currently not included in policies.

National DR Summit

In anticipation of the National DR Summit, the Trust recently supported a large scale study in India to provide evidence on current services for the care of people with diabetes and DR, and to evaluate the different approaches being used to detect and treat sight threatening DR. The findings, including gaps in current service delivery, were presented at the Summit.

The Summit brought together agencies and organisations, professional bodies, institutions and policy makers from India and other Commonwealth countries who are involved in the care of people with diabetes or DR. The Summit was attended by 85 delegates including representatives from the Government of India (Deputy Director, General Ophthalmology, National Program for the Control of Blindness (NPCB)); Deputy Commissioner of Non-Communicable Diseases, (NCD)), diabetologists, ophthalmologists, the international non-government organisations (INGOs) who support eye care (Sightsavers India, LCIF, Fred Hollows Foundation, OEU, CBM), and other agencies including IAPB, the International Diabetic Federation (IDF) and VISION2020 India (see Appendix 1).

See Appendix 2 for the Agenda for the Summit.

In the inaugural session Professor GVS Murthy, Director, IIPH, Hyderabad welcomed delegates. Dr Astrid Bonfield, Chief Executive of the Trust, explained how the Trust was established in 2012 to celebrate Her Majesty the Queen's 60 year Commonwealth leadership, and outlined the areas of Trust support. The key note address was presented by Professor K Srinath Reddy, President of PHFI. Dr GN Rao, Chair, LV Prasad Eye Institute, pointed out that DR was not included in VISION2020 programme in 1991. Professor Clare Gilbert explained the objectives and expected outcomes of the Summit, focusing on the need for policy change. The inaugural address was given by Mr LV Subrahmanyam, Principal Secretary, Health, Medical and Family Welfare Department, Government of Andhra Pradesh. Dr Quresh B Masketi, President All India Ophthalmological Society shared the India landscape on diabetes and DR, and Sir Michael Hirst, President, IDF outlined the increasing magnitude of diabetes worldwide. Mr Peter Ackland, on behalf of IAPB, highlighted the importance of a national diabetic programme.

During the first plenary session the IIPH team highlighted the top line findings from the situation analysis of services for diabetes and DR in India (Appendix 3). The main findings were that almost half the patients with DR who were interviewed already had visual loss at the time their DR was detected; there is a need to improve the control of diabetes, to reduce the risk of DR, from the perspectives of service providers and patients; most programmes for the detection and treatment of DR are not integrated into the health system; there was very little communication between physicians caring for diabetics and eye care providers, there is poor information and education about diabetes complications in general and DR in particular for patients, and there is a need to strengthen the government health system for diabetes and DR.

In the second plenary session, Dr D Bachani, Joint Commissioner, Non-Communicable Diseases, Government of India, outlined the government's programme for the control of non-communicable diseases, which extends from communities through to tertiary level care. Dr NK Agarwal, Deputy General (Ophthalmology) highlighted the importance given to DR in the National Program for the Control of Blindness, and Sir Michael Hirst highlighted the key role IDF played in advocating that global attention be paid to the control of non-communicable diseases, including diabetes. Nine eye care institutions outlined their programmes for the detection and treatment of DR.

The presentation by Professor CS Yajnik on the epidemiology of diabetes in plenary session three, highlighted why Indians are at greater risk of diabetes than other populations, introducing the concept of the "thin-fat Indian". Mr Mike Eckstein gave a presentation on the national program for DR in the United Kingdom, highlighting how trained technicians play a key role in screening, and Mr Peter Ackland highlighted the vital importance of taking a health systems perspective when planning programmes for control of DR.

In plenary session four, the INGOs presented their work on DR in India and elsewhere. Two innovative sessions were also held, which included panel discussions with people living with diabetes, which provided insights into their challenges, and with representatives from the media to discuss how to improve communication with the public about diabetes and its complications.

Priority strategies identified

Over the course of the three days there was extensive discussion and several sessions of group work with feedback in plenary. The following strategies were adopted by delegates as priorities for Trust support over the next 4-5 years:

1. Advocacy and communication so that DR is included in all relevant policies and implementation plans
2. Increasing the capacity of physicians to control diabetes, through an educational package
3. Increasing the capacity of patients to control their diabetes, through an educational package
4. Increasing awareness of DR amongst professional groups
5. Development of model programmes at district level for the detection and treatment of DR which are integrated into health systems
6. Monitoring and evaluation
7. Operational Research

8. Dissemination of best practice through a dedicated website

The programme will need to be sustainable within five years and lessons shared widely across the Commonwealth.

A National DR Task Force has been established, to support implementation of the DR programme in India. See Appendix 4 for the suggested Terms of Reference and membership, which are being amended to include wider representation by key policy and decision makers.

In the last session, the draft Hyderabad DR Summit declaration was presented, amendments were made and the Summit Declaration accepted (Appendix 5).

Next steps

After the Summit, the team at PHFI, under the leadership of Professor GVS Murthy, will write a proposal for the Trust, which will be scrutinised initially by the Scientific Advisory Board and then be presented to the Trust's Board of Trustees for approval. The programme will be managed PHFI, who will work with implementing partners. A Programme Advisory Committee and a Programme Implementing Committee will be established to guide the programme.

The Trust will expect the team appointed at PHFI to work closely with VISION2020 India, the Ministry of Health, Government of India, and the National Programme for Blindness Control (NPCB), the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS), and the National DR Task Force to implement the DR Programme. Implementing partners in India will report to PHFI who will be accountable to the Trust.

Inaugural Session

The welcome address and introductions were given by Professor GVS Murthy, Director, Indian Institute of Public Health, Hyderabad.

Dr Astrid Bonfield, Chief Executive, the Trust.
Dr Bonfield explained how the Trust was established in 2012 to celebrate Her Majesty Queen the Queen's 60 years of Commonwealth leadership. Dr Bonfield outlined the areas of work the Trust will support over the next five years, and highlighted the importance of the decisions that would be made during the DR Summit in informing how the Trust support could be used to reduce blindness from DR. The Trust's goal is to make a significant contribution to the elimination of avoidable blindness in Commonwealth countries over a five year period. Funds have been raised by donations from Commonwealth countries and by a grant from the UK government's Department of International Development. The majority of the funding (about 80%) will be for the control of blindness in Commonwealth countries, with 20% to support a youth leadership programme. Trachoma will be the focus in Africa, Australia and the Pacific islands; diabetic retinopathy in India, other countries in Asia, the Pacific and the Caribbean, and retinopathy of prematurity (ROP) in India. Funding is also available to support a fellowships, research and technology initiative, which is providing support to the Commonwealth Eye Health Consortium. As the Trust will run programmes for five years, the activities it wishes to support in relation to DR are those likely to make an incremental difference and which are sustainable, continuing to have an impact beyond the period of funding.

Dr Bonfield highlighted the challenges faced by people with diabetes, and how having all the elements of care they need under one roof would be an efficient and effective way of delivering services.

Dr GN Rao, Chair, LV Prasad Eye Institute,
Professor Rao mentioned that the control of visual loss from DR was not included in the VISION2020 initiative and so has not been prioritized to date. India can learn from the innovation and success of cataract surgical services to improve services for DR.

Professor Clare Gilbert, LSHTM
Professor Clare Gilbert explained the objectives and expected outcome of the Summit, and how policy change will be required to develop sustainable, scalable interventions. Close collaboration will also be needed between diabetologists, ophthalmologists, patients and civil society.

Mr LV Subrahmanyam, Principal Secretary, Health, Medical and Family Welfare Department, Government of Andhra Pradesh.
In his Inaugural Address, Mr Subrahmanyam expressed concern about the increasingly sedentary life style in India, particularly among the younger generation which will be reflected in adult life. Changes in diet as well as life style will be required to control the rapid increase in diabetes. He highlighted how managing the emerging NCD issues is wider than just a MoH response, but also encompasses urban design and involvement in education and sport, among other issues. "Convergence" is a key buzzword within the MOH, a confluence of efforts.

Dr. Quresh B Masketi, President All India Ophthalmological Society (AIOS)
Dr. Masketi presented the India landscape on diabetes and DR, and highlighted initiatives taken by AIOS for the prevention of blindness due to DR. In March 2014 a round table meeting was held on DR at the RP Centre, AIIMS attended by representatives from the Government of India and NGOs to formulate an action plan to increase awareness that diabetes can cause blindness. 14-20th November 2014 has been set as Diabetes Awareness Week during which awareness raising events will take place as well as large scale camps for diabetics who will undergo eye examination. Other ways to raise awareness could include social media, phone apps, caller tunes and films in different languages.

Professor K Srinath Reddy, President, PHFI (via webinar).
In his Key Note address, Professor Reddy highlighted policy initiatives and national programmes. Professor Reddy said that the Summit addressed one of the most important challenges to public health in India today.

Vision loss is a major complication of diabetes mainly due to negligence and lack of awareness, which leads to inadequate care by service providers and patients. Existing knowledge on how to control blindness from DR needs to be translated into action. Public health research is required which leads to policy and action: if this does not happen then science and technology are losing their importance. Effective public health requires evidence-based, context specific, resource sensitive, culturally compatible and equity promoting recommendations for policy and practice. The national program for non-communicable diseases includes diabetes, and should also highlight control of DR. An integrated programme for DR should involve NCD, NPCB and NPCDCS.

Operational research will be required to support cost effective programs, including implementation research which links innovation and impact, as innovation is not a true innovation if it stops at the level of discovery. The Summit provides a broad platform for dissemination of knowledge and creates a new pathway for knowledge translation for policy makers and programme managers. However, research alone is not sufficient: engagement of all sectors, including civil society, community based organisations; government, the private sector etc. are required so that an "all society effort" translates knowledge into a transformational endeavour.

Sir Michael Hirst, President, International Diabetic Federation (IDF)
Describing the global burden of diabetes, Sir Michael Hirst presented the following statistics: 1 person is diagnosed with diabetes every 3 seconds; 1 person dies of complications of diabetes every 6 seconds; every 20 seconds a limb is lost because of diabetes. Diabetes is a huge and growing problem. In 2013 there were estimated to be 382 million diabetics which is projected to increase to 592 million by 2035. The figures for pre-diabetes are 316 million in 2013 increasing to 471 million by 2035. In 2013 there were more than 5 million deaths due to diabetes. Diabetes is not just a health issue but also a development issue. Working age people are affected and the costs to society are high and escalating.

Mr Peter Ackland, Chief Executive Officer, IAPB
Mr Ackland highlighted the importance of a national diabetic programme which includes prevention as well as detection and treatment of the complications of diabetes, including DR. In reviewing key documents / guidelines from international ophthalmology and diabetic organisations, he found that presently there is only limited overlap and passing references to DR. Going forward requires a uniform plan, guidelines and strategy with close collaboration between physicians and eye care providers. A national diabetic strategy with guidelines, like the International Council of Ophthalmology guidelines, should be developed.

Plenary Session 1: Main findings of the situational analysis on diabetes and DR services in India.

Chairs **Dr. G. N. Rao and LV Subrahmanyam**

Rationale, purpose and objectives of the study: Dr Rajan Shukla.
There is an emerging epidemic of DR in India. An estimated 60 million people have diabetes and 6 million have sight threatening DR. But much of this visual loss is avoidable as there is a great deal of evidence that good control of diabetes can reduce the risk of sight threatening DR, and early detection and treatment are key to controlling visual loss. Presently there is no organised screening and management program for DR in India, but many eye care providers are running programs, using different approaches and methods. The Trust recently supported a large scale study in India, the purpose of which was to guide decisions made by delegates at the Summit.

The findings of the study will:

- Be used to develop needs-based strategies which can be scaled up in India, the region and globally.
- Provide evidence for expanding the scope of the Government of India's programme for the control of non-communicable diseases (the National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular disease and Stroke (NPCDCS)) and NPCB at national level.
- Provide the basis for inter-sectorial convergence and partnerships for the detection and treatment of DR.

Objectives

1 To review current policies for NCDs, focussing on diabetes and diabetic eye complications;
2 To map large public and private sector diabetic and eye hospitals providing services for diabetes in India;
3 To evaluate existing strategies for DR and referral pathways and to identify best practices for screening and management of DR;
4 To undertake in-depth evaluation of at least 8 models for detecting sight threatening DR which are known to have different approaches, to identify best practices for screening and management of DR.

Methods for situation analysis, Objectives 1-3: Dr Raghupathy Anchala

The 10 largest cities according to the 2011 census were included. Bhubaneswar, Odisha was added to increase representation from the east of the country.

In each city the following were visited:

1. Physicians in government, private-for-profit and private-not-for-profit facilities providing services for diabetics. People with diabetes attending these facilities were also interviewed
2. Eye care providers in government, private-for-profit and private-not-for-profit facilities. People with DR attending these facilities were also interviewed

Cities were first stratified based on their population (more than or less than 8 million) and then service providers were identified and selected in each strata. In each facility five to six patients were recruited for interviews.

Qualitative and quantitative methods were used. Semi structured interviews were conducted with physicians/diabetologists and eye care providers, and structured interviews were conducted with patients. The building blocks of the World Health Organization's health system framework provided the structure. Five teams each comprising two researchers from PHFI under the guidance of a senior faculty member collected the data. In addition, one team from Dr RP Centre, AIIMS collected data from two cities- Delhi and Jaipur.

Methods for evaluation of current programmes for DR, Objective 4

Eye care providers running programmes for the detection and treatment of DR were identified during the situation analysis and more were identified by snow-balling. A detailed questionnaire was developed to collect information on the nature of the programme and to evaluate different aspects e.g. sustainability, integration, coverage, cost effectiveness and responsiveness. Existing definitions for these parameters were used whenever possible, and providers were also asked to categorise their own programme. Two senior researchers (Prof GVS Murthy and B Shamanna) collected the data through face to face interviews.

A total of 837 sampling units in 9 states were included over a 4 month period of data collection. Mumbai and Delhi had the largest number of units. The sampling process was random selection, purposive sampling and snow balling.

Major findings: Professor GVS Murthy.

As the study involved eye units, diabetic units, patients from diabetic and eye clinics and the evaluation of existing DR programmes the findings were presented in five sections.

A. Findings from eye care providers:

- 60% of public and 80% of the private facilities have a retina OPD
- 78% of public and 48% of private facilities lack equipment for diagnosing and/or treating DR
- 50% of eye clinics identified a training need in medical retina
- Public funded facilities were less well equipped to diagnose and treat DR: 20-25% of all facilities lacked laser and fluorescein angiography services. A high proportion lacked OCT
- Only a third of hospitals had a trained retina photographer (lower in public funded hospitals)
- 40% of public and 22% of private facilities are not equipped to provide VR surgery
- Only a fifth had printed protocols for treatment
- Only 10% have written protocols on patient management
- Only half employed a trained counsellor and half have no system in place to track patients for follow up

B. Findings from diabetes clinics

- 11% of public and 54% of private facilities have dedicated clinics for diabetics
- The majority of public funded facilities provide no service for DR
- 70% of all facilities had no dieticians
- 40% of public and 15% of private facilities could not assess HbA1C in house
- 70% of medical staff were not trained in direct ophthalmoscopy
- 80% lacked protocols on the detection and management of complications
- 2/3 of staff were not aware of NPCDCS
- 41% of patients monitor blood sugar at home; 77% find changing diet to be the biggest challenge

C. Patients' perspectives – patients with diabetes

- Family members and friends were the most common source of information
- The complications of diabetes most feared were blindness and renal failure
- 22% did not know the cause of their diabetes; 36% thought it runs in the family.
- 45% understood what was meant by good control of diabetes
- 29% had never had a dilated eye examination; 16% would have their eyes examined if there was a problem and 9% said that there was no need for eye examination

D. Patients' perspectives – patients with DR.

- 45% of patients with DR had visual loss before DR was diagnosed
- Patients rarely reported that their DR was detected in diabetic clinics
- A third of patients with DR received no health education

Quotes from patients

> *"Education programme on complications of diabetes should be covered in the media frequently. Awareness at an early phase of diabetes will improve screening for complications."*
>
> *"Services should be integrated and interlinked so that the poor common man can get facilities very easily in less time"*

E. Findings from the evaluation of existing programmes

Fourteen eye care providers were visited. Several ran more than one programme. Multiple approaches were used a) to identify diabetics, b) to detect DR amongst diabetics, c) as indications for referral, d) for confirmatory diagnosis, e) for the location of treatment and f) to increase follow up.

<u>Detecting DR:</u>

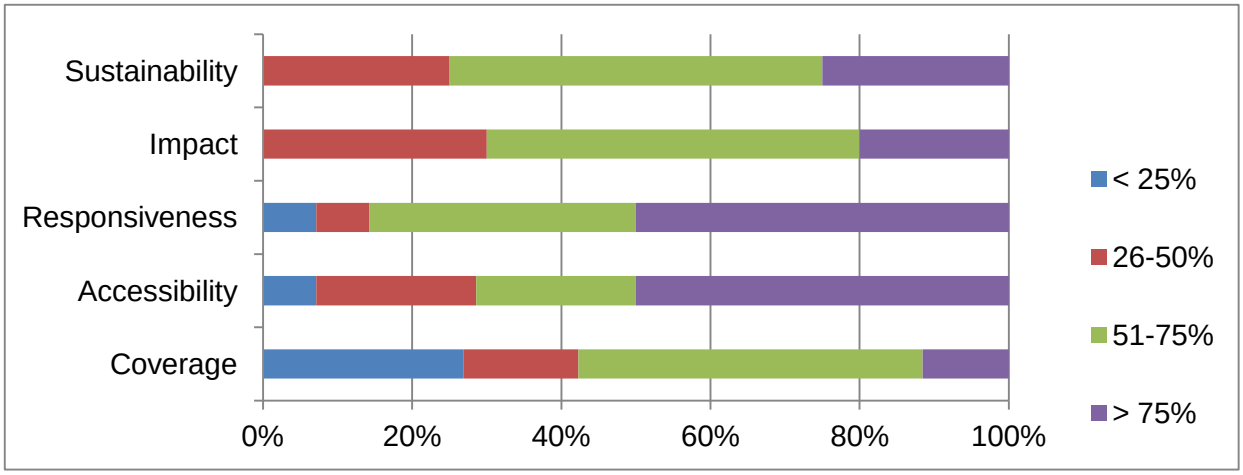
- Community based screening was common e.g., camps; house to house visits to diagnose diabetics; screening in industry and at pharmacies. Facility based screening was undertaken in Vision Centres, at satellite hospitals, in government hospitals, clinicians and Primary health Care Centres. Very few programmes worked with physicians in clinics for diabetics
- 79% of programmes used ophthalmologists or optometrists as primary screeners. Telemedicine was frequently used, often with image interpretation by ophthalmologists at the base hospital
- 50% gave written information to those being screened
- 36% had written protocols for screening
- 64% refer diabetics with any DR to the base hospital, the remainder (36%) refer those with sight threatening DR
- 57% had no mechanism in place for annual screening and 54% lacked systems for follow- up

Confirmatory diagnosis and treatment:

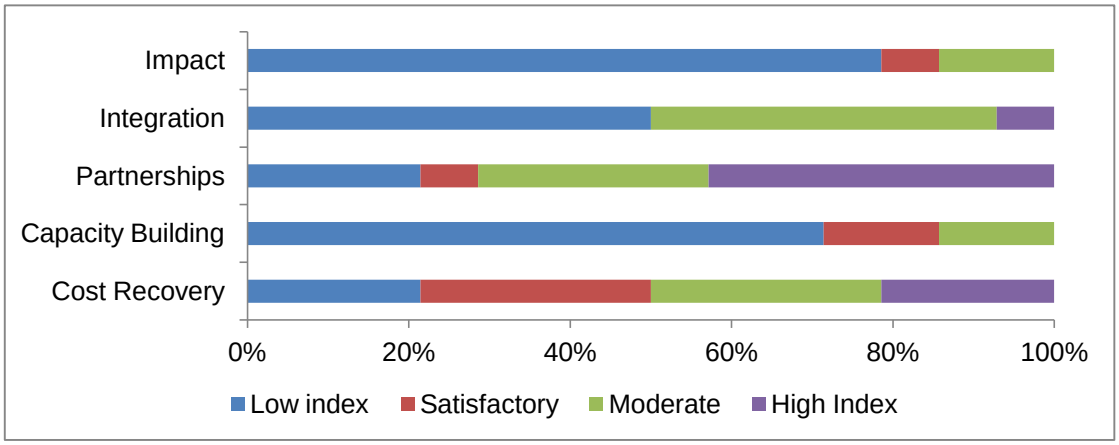
- 57% of providers reported that <50% of those referred attend for confirmatory diagnosis
- 24% had waiting lists for laser treatment

- 33% had written protocols for treatment
- Outreach laser treatment was provided by a few hospitals

Cross cutting issues – self assessed:



Cross cutting issues – assessed by researchers:



Quotes from ophthalmologists:

"Non-clinicians would have a major role in early detection of diabetic retinopathy".

"Screening programme should be done right at the level of the physician or diabetologist because patients with diabetes generally go to their diabetologist or physician first".

"I think that a retinal camera is going to be a major development. As you can manage easily by non-ophthalmologist also"

Implications of the situation analysis and evaluation of DR programmes: Professor Clare Gilbert
The study deliberately focussed on facilities in larger cities, and was not intended to be representative. Service provision is likely to be poorer in facilities in smaller cities. Information was not collected from community members on what they know and do about diabetes and DR as several studies on this topic have already been undertaken in India.

The implications of the findings are that many aspects of the public health system need to be strengthened in order to provide better services for people with diabetes and for those with DR. The role of public-private partnerships for service delivery and for capacity building needs to be explored.

Several DR programmes start by identifying people with diabetes whose eyes are then examined. These approaches are not cost effective, and the Government of India's programme for non-communicable diseases include early detection as one of their priorities. Advocacy at State level may be required to scale up implementation of activities for early detection.

Many of the current programmes for the detection and treatment of DR are not integrated into the health system, which limits their sustainability, cost effectiveness and ability to go scale-up. Much closer collaboration between eye care providers and physicians will be required, with joint planning, implementation, management and monitoring of programs so that initiatives for the detection of DR are integrated into services for people with diabetes.

Many DR programmes use highly skilled personnel to detect DR (i.e. ophthalmologists examine people with diabetes or read and interpret images, or optometrists), which is not an efficient use of human resources. In addition, many programmes refer any degree of DR, rather than referring only those with sight threatening DR. This approach will overload eye care providers, it's not cost effective and unnecessarily increases costs for patients. Consideration should be given to training technicians to take and interpret retinal images, referring only those with sight threatening DR for confirmatory diagnosis and treatment.

A paradigm shift is needed. This will require advocacy for policy change, so that DR is included as an explicit complication of diabetes in all government policies relating to diabetes from community level through to tertiary level. District level model programmes need to be developed and evaluated which are integrated into and which strengthen health systems, which explore task sharing/shifting as a means of improving efficiency and cost effectiveness, and which use public-private partnerships.

Comments from the Chairs

Dr G N Rao commented that the findings corroborate what service providers think to be the reality in India, and introduce some new perspectives. Future programmes should build on what is already in place. The lack of awareness is also not just among the uneducated. Mr Subrahmanyam commented on the importance of task sharing, to free up ophthalmologist's time so they can focus on treating DR. Discussions were also held on how services might be taken closer to people, including exploring technological innovations.

Plenary session II: Overview of programmes for diabetes and diabetic retinopathy

Chairs **Professor Clare Gilbert and Sir Michael Hirst**

National Programme for Non-Communicable Diseases with emphasis on Diabetes: D Bachani, Joint Commissioner, Non-Communicable Disease, Government of India

Dr Bachani presented the global epidemiology of diabetes and stressed the burden contributed by India. Gestational diabetes is also important, requiring better antenatal care. In July 2010 the NCD programmes with 5 key objectives for the control of diabetes were initiated in India in 100 districts in 21 states. The programme will be rolled out in all states by 2017. The programme entails screening adults over the age of 30 years, with strengthening of the health system from sub centre level to higher levels. The programme will foster links with ongoing public health programmes e.g. screening for gestational diabetes as part of reproductive child health, and educating children on risk factors for diabetes as part of school and adolescent health. Dr Bachani advocated for collaborative team work between government, NGOs, INGOs and by establishing public private partnerships.

National Programme for Control of Blindness with emphasis on DR: Dr NK Agarwal, Deputy Director General (Ophthalmology), NPCB, Govt. of India

Dr Agarwal presented the salient features of the programme in the 12th five year plan period (2012-17). The programme provides support for training in the form of retina fellowships, provision of equipment such as lasers, and financial support for laser treatment and VR surgery. He also highlighted the mobile van model for screening and management of DR.

IAPB Global Agenda for DR: Mr Peter Ackland, CEO, IAPB

IAPB global activities related to DR were presented, including highlights of the DR Barometer Project. Other activities initiated were inclusion of DR within RAAB surveys; systems assessment tools developed by WHO/ LIONS; research studies to assess barriers to consistent uptake of DR services by diabetics and factors that help to promote patient adherence for long term care. IAPB is also preparing an essential list of equipment for DR, and a competency framework for screening and grading has been prepared with support from ICO, WCO, IAPB and IDF. Other innovations include a web based system to enable high quality DR screening and grading services, and online training and accreditation systems for programme staff.

VISION2020 India and DR initiatives: Col Madan Deshpande.

VISION 2020 – India activities include development of a costing template for DR screening and management; technician training issues; standards for screening techniques; impact assessment indicators and tools, and continuous advocacy for incorporating DR activities in partner organisations.

Role of professional international & national diabetes agencies in controlling the epidemic of Diabetes: Sir Michael Hirst, President, IDF

IDF is a member association with more than 230 members, including FHF. In India there are 65.1 million people with diabetes and another 21.5 million with pre-diabetes. The number is projected to increase to 109 million people with diabetes by 2035. Half the cases are undiagnosed. One person is diagnosed with diabetes every 3 seconds while 1 person dies of complications of diabetes every 6 seconds globally. IDF is facilitating change and action focusing on prevention and appropriate care and treatment for those who are already diagnosed. IDF plays a key role in compiling and disseminating evidence and has produced the IDF Diabetes Atlas and IDF Guidelines and Task Forces.

IDF played a leading role in advocacy which led to the 2006 United Nations Resolution on Diabetes which was followed by formation of the NCD Alliance (2009) and the UN High-Level Summit on NCDs in 2011 which culminated in global agreement of targets to tackle NCDs (2012) which were approved by the World Health Assembly in 2013. IDF programmes and projects to promote best practice (guidelines), research and action on prevention and care include the Global Network of Parliamentary Champions; Young Leaders in Diabetes Programme; BRIDGES (Translational Research); WINGS (Gestational diabetes); KIDS (Children and Diabetes in School). IDF looks for collaboration and cooperation with others to see progress. The World Diabetes Congress is Bi-Annual, and all are invited.

Support for evidence generation: ICMR research priorities: Drs Tanvir Kaur and R S Dhaliwal

ICMR maintains a registry of diabetics (especially young diabetics), and patients with epilepsy and stroke, in collaboration with partners. The database currently lists 5,500 young diabetics across 8 centres, and the most common complications reported were DR (5%) and nephropathy (3%). She also described the INDIAB study- epidemiological work related to diabetes the aim of which is to provide accurate and comprehensive state- and national-level data on the prevalence of diabetes including older age groups in India. The study includes rural and urban areas and will provide estimates for pre-diabetes, dyslipidaemia, hypertension, obesity, and the level of glycaemic control among the confirmed cases of diabetes. NCD publications are being updated, to be realised later this year.

Aravind Eye Care System Approach to DR: Dr P Namperumalsamy, Chairman: Aravind Eye Care System has undertaken extensive work in relation to DR over the last 20 years, including epidemiological studies, screening camps, mobile screening, awareness creation, training ophthalmologists and the development of a low cost laser. The Aravind Diabetic Technology Model uses technicians for fundus photography at Vision Centres and base hospitals. Teleophthalmology allows access to patients in rural centres to high quality opinions and advice through mobile vans, low cost fundus camera and cell phone transmission of images. Aravind Eye Care System has recently started working with physicians to detect DR.

LVP Model for DR: Dr TP Das, Regional Chair, IAPB

LV Prasad Eye Institute runs several different programmes and research projects for DR in the southern and eastern part of India. LV Prasad has a pyramidal model for eye care delivery and systems are in place which link vision centres to tertiary care. LVP has worked on IEC materials for diabetic patients and a DR manual for doctors. They are researching new fundus cameras and automatic grading. Vittala Eye Institute Model for DR: Dr Krishna R Murthy

One of the challenges of outreach approaches to detecting patients with sight threatening DR is the lack of access to laser treatment. Vittala Eye Institute is addressing this by taking a laser and other diagnostic equipment on outreach in a specially designed van, with support from World Diabetes Federation. The need for integrated screening for diabetic patients has been recognised, to include laboratories and a foot clinic etc.

RP Centre Model for DR: Dr Praveen Vashisht, AIIMS

The RP Centre is running a project for DR in the slums of Delhi, working closely with community based volunteers and in partnership with community based organisations as key drivers for effective community based screening programmes. In this programme, which is supported by Sightsavers, screening is performed by optometrists using handheld non-mydriatic cameras.

Sankara Nethralaya Model for DR: Dr Rajiv Raman

Dr Rajiv highlighted the epidemiological evidence created by the SNDREAMS study and 54 publications have been published in peer reviewed journals. Sankara Nethralaya runs a tele-ophthalmological model for detecting DR as well as training fellowships for DR and other capacity building initiatives.

Aditya Jyot Model for DR: Dr Radhika Krishnan

Dr Radhika presented the epidemiological studies undertaken by Aditya Jyot- DRUMSS- a study of DR in Mumbai slums. The model they use for the DR programme involves local health workers, who understand the local context and constraints. They have a mobile van with support from WDU.

Divyajyoti Model for DR: Dr Uday Gajiwala

The DR programme in Gujarat is undertaken in tribal areas, and entails house to house visits with blood sugar examination to identify diabetics followed by eye examination. Educational materials have also been developed in the local language. It was acknowledged that this approach is resource intensive and lack of field workers impedes field based operations on regular basis.

C H Nagri Hospital, Ahmedabad DR Model: Drs Usha K Vyas and Tejas Ben Desai

Team work is an essential component of the DR programme run by this municipal corporation hospital, which delivers community based DR services. Link workers have been trained who support the ophthalmologists and optometrists who undertake screening in camps. Only 5-10% is referred from diabetologists, with majority being self-referred. Outreach at the primary level is needed, and a comprehensive model with all services under one roof.

H V Desai Hospital, Pune, DR Model: Dr Kuldeep Dole

Strategies for control require awareness creation, based on current knowledge and practices. Screening can be opportunistic or in organized screening in clinics or camps. Capacity building is usually required as well as subsidizing costs. In Pune mass media was effective at increasing enrolment in screening, and use of protocols and screening in physicians' clinics was the most effective approach. Treatment should include all modalities to improve credibility. Poor uptake of treatment was a major problem as was lack of understanding of the disease. Epidemiological, operational and clinical research has an important role in strengthening implementation.

Plenary Session III Management and Cost issues for DR

Chairs **D Bachani and C S Yajnik**

Dr C.S. Yajnik, Yajnik Diabetes Centre, Pune

India is the world capital of both diabetes and under-nutrition. This apparent paradox is explained by the "thin-fat Indian" as Indians have a higher proportion of body fat for a given body mass index than Caucasians. The biological explanation is that under-nutrition during pregnancy can alter genetic material in the developing foetus and the way genes are subsequently expressed in childhood and adult life, building on Dr Barker's ideas of foetal programming. This predisposes to insulin-resistance and an increased risk of diabetes. A life cycle approach to control of diabetes is, therefore needed, starting with reducing under-nutrition during adolescence and pregnancy. Focusing on the early life cycle, age 0-3 years is also more cost-effectiveness.

Dr Mike Eckstein, UK Regional Manager of the NHS DR programme

The UKs' National Health Service has a national program (since 2005) for screening and treating DR which costs approximately £23 ($37) per diabetic patient. Evidence suggests this is being successful as DR is no longer a leading cause of blindness. In England in 2013, 2.36 of the 2.6 million diabetics were invited for annual screening: 1.91 (81%) million were screened, 74,000 (3%) were referred to eye departments and 4,600 (6.2% of those referred) were treated. Only 0.2% of all those screened were treated with laser. Lists of diabetics are obtained from GPs (family doctors) who are invited for screening. Trained screener/graders, usually non-medical personnel, take and interpret retinal images in the community, only referring those with poor images or sights threatening DR. Retinal specialists oversee referrals.

The Revised English Diabetic Eye Screening Programme Grading Classification defines different stages and referral criteria, with an online image library. The Quality and Outcomes Framework (QOF) provides financial incentives to GP surgeries and the programme is prescriptive in the way programmes collect and grade images and manage onward referrals. The programme is very closely monitored. The following factors need to be considered in relation to cost effectiveness: who is screened and what are they screened for; the screening interval; how and who should do the screening; is there an education component to increase awareness of DR; how DR is to be graded; referral criteria etc. The standardised system allows comparisons to be made across centres throughout the country. An important element of the UK programme is to keep diabetics with DR out of eye departments unless they need assessment for treatment.

Mr Peter Ackland, IAPB:

All aspects of the health system need to be strengthened to provide services for the control of visual loss from DR, strengthening each of the six building blocks: leadership and governance; medicines and technologies, health management information systems; the health workforce; service delivery and financing. Mr Ackland recommended building on and strengthening existing health systems.

Mr R D Thulasiraj, Aravind Eye Care System, via video presentation

The majority of patients with DR only require examination and a few investigations; fewer require laser treatment or intraocular injections, and even fewer need surgery. Services for DR are therefore primarily non-surgical and many costs are the same in district and tertiary facilities but the latter may have more expensive equipment. As most equipment and staff will not be specific to DR, marginal costing is appropriate, costing service provision for a period (year) rather than for each unit of service. Costs should be included for equipment, training, space and human resources for case finding, service delivery and maintenance of equipment.

Annual cost of providing DR services includes capital costs and depreciation plus the costs of providing care. In the Aravind Eye Care System the annual costs translate to 240$ per day, assuming 50 patients are seen a day, with 25% being new patients. The Aravind group have produced a manual on DR programmes with support from Sightsavers and Lions. Many systems are under-utilised, with low awareness and low referral rates. IEC / community work is required. Improving uptake will improve cost-effectiveness.

Discussion:
It was suggested that a one stop shop where all complications of diabetes can be managed will be ideal for reducing costs for patients.

Plenary Session IV - INGO support for diabetes and DR

Chair **Dr NK Agarwal**

Dr Agarwal pointed out role of INGOs in infrastructure development, provision of equipment, supporting laboratory testing, payment for operations and IEC and research activities.
Several INGOS presented their work in different parts of country and worldwide in relation to eye care and DR. Representatives of INGOS highlighted the role of collaboration, developing culturally relevant programmes, the importance of pilot testing, translating knowledge and evidence of sustainability and dissemination of learning.

Panel discussion 1: An eye on patient and caregiver perspectives

Chair **Dr K Viswanath, Pusphagiri Eye Institute**

In this session people with diabetes were asked what they knew about diabetes and DR and how being diabetic has affected them. All panel members belonged to the Diabetic Self Care Foundation, Hyderabad, most had been diabetic for more than 20 years, all but one were male, with an average age of 75. Two panel members had lost vision in one eye from poor cataract surgery and one had DR. The Foundation has been in place for 20 years and its aim is to promote self-care and monitoring. On every fourth Sunday, a medical professional interacts with members.

Panel members said that diabetes and DR were not a financial problem for them personally. They felt that physical activity was very important for control, and that meeting other people with diabetes is very helpful. Most knew that diabetes can affect the vision and that an annual eye examination is required. The group thought that the cost of treatment and compliance with medication were major challenges faced by people with diabetes. The panel recommended that the government should take steps to provide insulin/ oral medications at affordable prices, or free, and that medical professionals need to provide greater guidance to people with diabetes.

Panel discussion 2: Spreading the word on diabetic retinopathy

Chairs **Dr Usha Raman and Mr Jonathan Dunbar**

In this session several health care professionals and professionals from the media shared their experiences, both good and bad, and discussed opportunities provided by working with the media.

The need to demystify DR was highlighted and as a first step. It was felt that sustained conversations between professionals in the media, eye/diabetes health specialists and the public had an important role to play in improving the understanding of DR among the population. Mainstream and mid-level media were identified as natural partners and several recommendations were made to strengthen the relationship for information-sharing with the public. Specific ideas included working with script writers of soap operas and setting up a media information hub at PHFI to develop regular press releases. It was acknowledged that other health education and promotion avenues will also be necessary which will need to be ongoing and run in a sustained manner.

Plenary Session V - Identifying priority areas for the control of DR in India

Theory of Change, Prof Clare Gilbert

Theories of Change are increasingly used by researchers and programme planners as they define and describe all the interconnected elements needed to bring about a given long-term goal or positive change using a causal pathway. The long term goal is defined first, and working back from this, the inputs and interventions, activities and processes can be then described in a logical manner. A Theory of Change also allows assumptions to be articulated (e.g., there is a low turnover of the cadre of staff being trained) and to identify possible barriers to implementation (e.g., staff do not have autonomy or independence to deliver what they have been trained to do).

A Theory of Change can be modified in light of preliminary studies or changing priorities, and identifies what needs to be monitored or assessed in terms in inputs, outputs, outcomes and impact. A draft Theory of Change for the DR programme was shown (Appendix 6) showing the possible causal pathways which could lead to the goal of less blindness from DR.

Group work session 1

Seven strategies were identified from the different causal pathways in the Theory of Change all of which could contribute to the goal of reducing visual loss from DR. The seven areas were:

1. Address the underlying drivers of the “thin-fat” Indian
2. Prevention of diabetes and other non-communicable diseases
3. Early detection and treatment of people with diabetes
4. Prevention of DR and other complications in people with diabetes through better management
5. Early detection and treatment of DR
6. Sight restoring VR surgery
7. Low vision care/rehabilitation

Four groups were asked to prioritize these as potential strategies for Trust support, bearing in mind that the Trust’s programme:

- Is time bound (4-5 years)
- Needs to be sustainable after the period of funding
- Needs to be scalable, and hence integrated into and strengthen health systems
- Should leave a lasting legacy
- Cannot just be “business as usual”

The four areas that were prioritised by at least one group were:

1. Building the capacity of physicians to improve the control of diabetes in their patients, to reduce complications, including DR;
2. Building the capacity of patients to improve the control of their diabetes, to reduce complications, including DR;
3. Detecting and treating sight threatening DR
4. Improving access to sight restoring VR surgery

All groups also gave some degree of priority to interventions to reduce diabetes and to detect and treat people with diabetes. However, it was acknowledged that these activities are now being prioritised by the Government of India’s Programme for non-communicable diseases, and support from the Trust should be used to ensure that control of the complications of diabetes, including DR, is included in policy, operational plans and budgetary allocation at all levels of service delivery. This will require an advocacy and communication strategy. These are summarized below.

		Gp 1	Gp 2	Gp 3	Gp 4	Activities
1	Reduce drivers of the "thin-fat" Indian					Advocacy for policy change, so that DR is included
2	Prevention of diabetes and other NCD					Advocacy for policy change, so DR is included
3	Detection and treatment of diabetes					Advocacy for policy change, so that DR is included
4	Prevention of DR/complications in diabetics					Build capacity of physicians and patients
5	Early detection and treatment of DR					Develop/strengthen detection & treatment of DR which is integrated into and which strengthens health systems
6	Sight restoring VR surgery					
7	Low vision care/rehab					

High priority
Low priority
Moderate priority
Already covered by eye care providers

Group work session 2

In this session, the four groups worked on the areas which had been prioritized in the first session of group work, taking account of the gaps identified in the situation analysis;

Group 1 — What approaches and activities are needed to support physicians for improvement of control of diabetes to reduce the risk of complications, including DR?

Group 2 — What approaches and activities are needed to support patients to improve control of their diabetes to reduce the risk of complications, including DR?

Groups 3 and 4 — What approaches and activities are needed to increase capacities and capabilities for the detection and treatment of DR in government facilities?

Group 1: Approaches and activities needed to support physicians to improve the control of diabetes to reduce the risk of complications, including DR.

The situation analysis showed gaps in the existing system: there are no guidelines for physicians in relation to prevention of DR but the ICMR DM guidelines can be a model. There are knowledge and implementation gaps and a lack of referral pathways. No online courses are available. A Theory of Constraints (ToC) can be used to identify the activities needed to bring about change in behaviour and/or functioning to improve effectiveness at health system and at PHC level. Health system level constraints include lack of distance learning / technology platforms for education; no screening and management protocols; inadequate linkages for referral; no network for comorbidities; no IEC activities.

Constraints at PHC level are governance, training, access to drugs and delivery systems.
Strategies to address the gaps include CME on diabetes care and on the prevention, detection and management of complications including DR; message for patients should be that type 2 diabetes is a lifestyle disease; influence physicians to think beyond medicines; counsellors or dieticians should be part of the team; different levels of training will be required for the different levels of physicians. Attitudinal and compliance issues are also problematic (implementation gap).

Other suggestions on capacity building included training laboratory staff, electronic patient records, connecting tertiary care / NGO sector to secondary and primary care for skills transfer, strengthening referral linkages and supportive supervision. Improving the knowledge and skills of staff will involve collaborative

curriculum development, training master trainers, linking district and state training centres with the CCEBDM and an e-government portal for information / awareness.

Group 2: Approaches and activities needed to support <u>patients</u> to improve the control of diabetes to reduce the risk of complications, including DR.

The situation analysis showed that the main challenges diabetics face in controlling their disease were changing their diet, inability to exercise, cost of investigations, keeping all clinic appointments due to loss of wages and remembering to take their medication.

Strategies to address changing diet included simple dietary education, family counselling DM support groups and making non-diabetic food more available. A suggestion for increasing exercise requires awareness, a simplified exercise schedule, workplace provision for exercise, celebrity role models and group exercises. Reducing the cost of investigations and medication could entail advocacy to reduce tax on diabetic medicines and for home blood glucose testing kits, improving health insurance cover for diabetics, including diabetic medicines in the basic package care. Strategies to improve adherence to medication and follow up include use of smart 'Diabetic Health Cards' for appointment management, family education, providing all care under one roof (ideal), smartphone based kits for self-monitoring and management, identifying a pool of physicians trained in general DM care using standard protocols, effective referral network with diabetologists, weekly pill boxes to improve adherence and evening or Sunday clinics to prevent loss of wages.

Groups 3 and 4. Approaches and activities needed to increase capacities and capabilities for the detection, diagnosis and treatment of DR in government facilities

Sight threatening DR should be defined for awareness raising, screening, diagnosis and management. Integrated services for diabetes and DR need to be prioritised within the NBCP and NPCDCS.

Screening needs to be integrated into NCD services at every level, building on the existing eye care system at different levels. As per NPCB policies, staff at PHC/CHC level can be trained to screen using direct ophthalmoscopy or fundus photography with image analysis at district level. A mobile van may be required to take the camera and technician to different clinics. Outreach strategies are required. ASHA/ ANM workers can sensitise the community about DR and assess visual acuity, but incentives may be required. Capacities to improve the management of diabetes and for the screening, diagnosis management and of DR may be needed in Medical Colleges, as well as development of clear referral pathways to eye care providers with sub-specialisation in medical or surgical retina. An online registry for reminders and patient follow-ups was suggested, with a barcode scanner on a patient held chronic disease book for identification.

Clear mapping of services in urban areas, including the private sector, will be required to prevent duplication and identify where capacity building is required. Technicians can be trained for many NCD activities e.g. for laboratory investigations as well as fundus photography and grading. Integrating DR into existing structures and systems should be in Districts where NCD services are already established.

Group work session 3

In this session, each group was asked to come up with a clear and concise statement of the goal of the Trust's support for control of DR. Groups were also asked to address some specific cross cutting issues which had been identified as important gaps in the situation analysis:

Group 1	How to operationalise an integrated district model for diabetes and DR 1) approach to be adopted and 2) criteria for selection of districts e.g. geographical location/level of development/availability of services etc.
Group 2	Need for accreditation; capacity building guidelines; screening and treatment guidelines at each level

Group 3 Need for HMIS at all levels; indicators to be collected at each level

Group 4 Outline an advocacy and communication strategy

Group 1: Integrated district model for diabetes and DR

A sustainable, accessible, scalable and integrated district model within the existing government facilities is recommended for prevention of DR focussing in the first instance on districts where the Government's programme for non-communicable diseases has already been rolled out, with geographical representation. Other criteria should be the availability of ophthalmic services (ophthalmologists, RIO and medical College) in the same or neighbouring district. The model should include a mixture of NCD, non-NCD clinics and work with private practitioners who are more numerous in urban areas. The DR Task Force can advocate for this model.

Group 2: Need for capacity building, guidelines for screening and treatment at different levels, supportive mechanisms and accreditation.

Activities will be needed at all levels, from sub-centre level, PHC, CHC, district, RIO and Medical Colleges. Short-term tasks will include development of human resources (Para clinical/clinical/IEC) at all levels. Building the infrastructure / facilities and providing equipment for screening, diagnosis, and medical and surgical management of DR will be needed. Referral mechanisms will be needed to manage other complications of diabetes. Awareness rising will be required regarding diabetes and its complications, including DR. Long-term tasks will include ongoing service delivery as well as monitoring and evaluation.

Capacity building: A competency based framework is needed for screening, treatment and rehabilitation at each level.

Guidelines: An initial review of existing guidelines is required (e.g., VISION2020 and ICO documents), to assess their suitability and to identify areas where more guidelines are needed at different levels. New guidelines should be developed via a collaborative process. Guidelines will need to cover screening methods (e.g. imaging based system), for referral for confirmatory diagnosis, for indications for and methods of treatment, and for referral from district level to tertiary level where more advanced eye care will be available. Guidelines should also be available for referral for low vision care and rehabilitation.

Accreditation: The recommendation is to develop a governance structure with accreditation (both institutional as well as individual) being one of its roles.

Group 3: Need for Health Management Information System (HMIS) at all levels; indicators to be collected at each level.

Health education on diabetes and DR for the community should be based on their knowledge, attitudes and practices.

An HMIS is needed at primary, secondary and tertiary level based on existing national and international guidelines, with modification if required. This will be required for the screening/ case detection and treatment elements of the program.

Electronic Medical Record (EMR):
Existing EMRs for diabetes and DR need to be reviewed, and amended if required. The EMR could be integrated into and maintained by the existing NPCB network integrated system. The EMR could act as a register to document details of patients, visual acuity over time, quality of images (for programmes using retinal imaging), type of DR, treatment given, and attendance for follow up.

Group 4: Advocacy and Communication

The following target audiences were identified: policy makers at National and State levels; professional societies; managers of programmes at national, state and district level (for non-communicable diseases and blindness control); private practitioners, the community and the media. Other relevant ministries include Education, Transport, Food and Leisure/Parks. For each target group suggestions were made for the key messages, the strategies to be adopted, and the timing of implementation.

FINAL PLENARY SESSION

Goal of the Trust's programme for DR:

The goal/impact of the program will be finalised in consultation with the Trust

Top line indicators as measures of success:

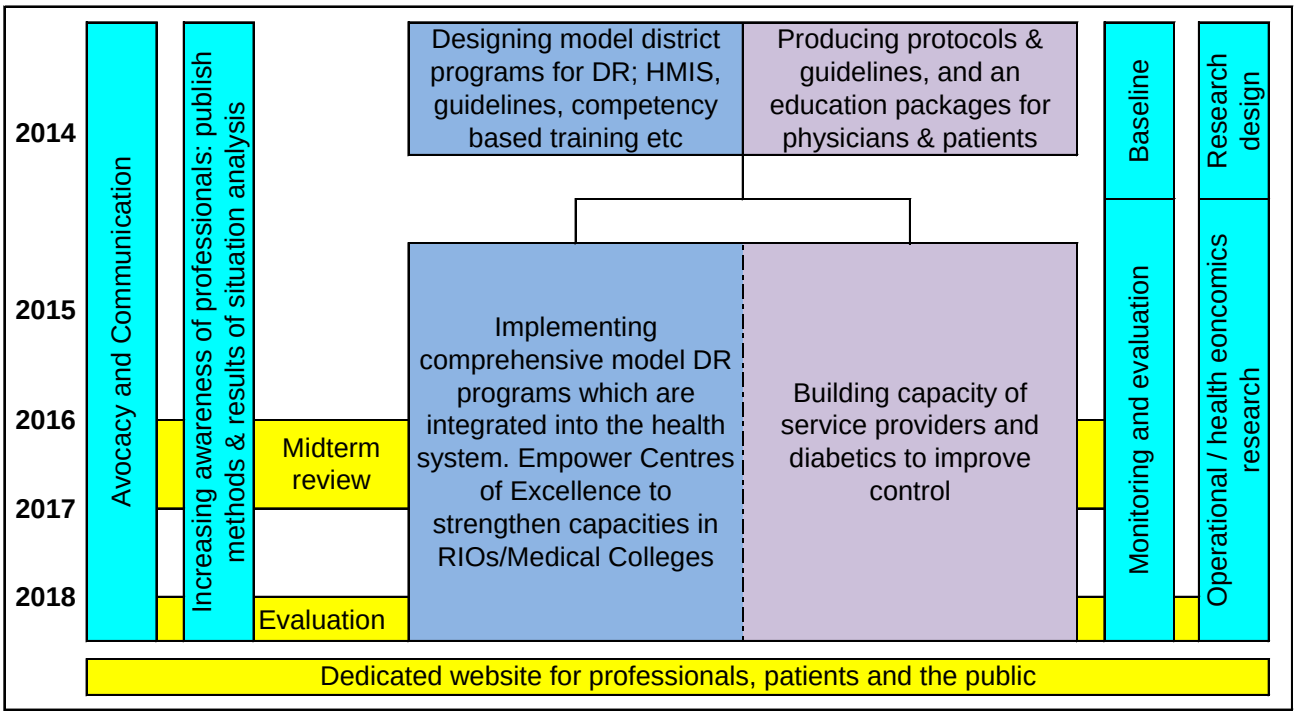
Four or more "top-line" indicators will be identified, in consultation with the Trust, to assess the impact of the program overall.

1. Advocacy leads to policy change so that DR is included in programs for the control of non-communicable diseases in India
2. Physicians have enhanced capacities to manage diabetes, leading to a reduction in sight threatening diabetic retinopathy
3. Patients have enhanced capacities to manage diabetes, leading to a reduction in sight threatening diabetic retinopathy
4. Greater coverage of programmes for the detection and treatment of DR that are integrated into and strengthen health systems

The following eight areas for Trust support were agreed by delegates

1. Advocacy and communication strategy
2. Improve the capacity of physicians to improve control of diabetes
3. Improve the capacity of people with diabetes to improve control of diabetes
4. Implement and evaluate district models for DR control that strengthen and are integrated into health systems
5. Increase awareness of professionals, by publishing and disseminating the findings of the situation analysis
6. Operational / health economics research
7. Monitoring and evaluation
8. Website for dissemination to different audiences

Proposed timeline and relationship between the different elements



Preliminary budgetary allocation

The following % allocation of the operations budget was agreed by delegates (This excludes the program management costs).

	Program area	**Allocation %**
1	Advocacy and communication	5%
2	Improving control: physicians	10%
3	Improving control: patients	
4	DR district programs + guidelines/protocols/HMIS etc.	75%
5	Increasing awareness of professionals	2%
6	Research	2%
7	Monitoring and evaluation	4%
8	Website	2%
		100%

Next steps

Dr GVS Murthy, his team at PHFI and Prof Clare Gilbert will write a proposal for scrutiny by the Scientific Advisory Board of the Trust. Following this the proposal will be reviewed by the Board of Trustees later in the year when a decision regarding support will be made.

The Management structure developed at PHFI to manage the Trust's ROP program in India will also apply to the management of the DR program, and dedicated staff will be appointed for different roles.

Appendix 1: Delegates

	Name	Designation	email ID
	Government of India/ Government of Andhra Pradesh		
	Shri L.V. Subrahmanyam	Principal Secretary (Health), Govt. of Andhra Pradesh, Hyderabad	prlsecy_hmfw@ap.gov.in
	Dr. D. Bachani, CHAIR	Deputy Commissioner, NCD, Govt. of India, New Delhi	dr.bachani@gmail.com
	Dr. N.K. Agarwal	Deputy Director General (Ophthalmology), NPCB, Govt. of India, New Delhi	nknindia@gmail.com; nknd@gmail.com
	Dr Geeta Prasadini	Joint Director, NCD Program, Andhra Pradesh, Hyderabad	drprasadini@yahoo.co.uk
	Academic Institutions / Research Bodies, India		
	Dr Tanvir Kaur	ICMR, Delhi	kaurt@icmr.org.in
	Dr RS Daliwal	ICMR, Delhi	dhaliwalrs@icmr.delhi.nic.in
	Dr BR Shamanna	Associate Professor, UoH, Hyderabad	brsham@gmail.com
	Dr Usha Raman	HoD, Dept of Communications UoH, Hyderabad	usha.raman@gmail.com
	Dr Praveen Vashist	Additional Professor, AIIMS, New Delhi	praveenvashist2007@gmail.com
	Dr Sumit Malhotra	AIIMS, New Delhi	drsumitaiims@gmail.com
	Dr Noopur Gupta	AIIMS, RP Centre, New Delhi	noopurgupta@hotmail.com
	Dr. K. Srinath Reddy**	President, PHFI, New Delhi	ksrinath.reddy@phfi.org
	Ms Kavitha Chauhan	PHFI, Delhi	kavita.chauhan@phfi.org
	Dr GVS Murthy	Director, IIPH, Hyderabad	murthy.gvs@iiphh.org
	Dr Raghupathy Anchala	IIPH, Hyderabad	raghupathy.a@iiphh.org
	Dr AT Joteeswaran	IIPH, Hyderabad	jothees.at@iiphh.org
	Dr Vivek Singh	IIPH, Hyderabad	vivek.singh@iiphh.org
	Dr Tutul Chakravarthy	IIPH, Hyderabad	titirchakravarti@gmail.com
	Mr Hira Ballab Pant	IIPH, Hyderabad	hira@iiphh.org
	Mr K Nanda Kishore	IIPH, Hyderabad	nandu.k@iiphh.org
	Mr Souvik Bandopadhyay	IIPH, Hyderabad	sauvik.kumar@iiphh.org
	Dr M Jayaram	IIPH, Hyderabad	jayaram.m@iiphh.org
	Dr S Sri Krishna	IIPH, Hyderabad	srikrishna.sr@iiphh.org
	Ms Shivani Mathur	IIPH, Hyderabad	shivani.mathur@phfi.org
	Dr Rajan Shukla	IIPH, Hyderabad	rajan.shukla@iiphh.org
	Dr Suresh Munuswamy	IIPH, Hyderabad	s.munuswamy@iiphh.org
	Dr Samiksha Singh	IIPH, Hyderabad	samiksha.singh@iiphh.org
	Mr D Mahesh	IIPH, Hyderabad	mahesh.d@iiphh.org
	Dr Komal Allagh	IIPH, Hyderabad	komal.allagh@iiphh.org
	Ms Jayanti Sagar	IIPH, Hyderabad	jayanthi.sagar@iiphh.org
	Non-Government Organizations		
	Dr C.S.Shetty	Technical Advisor, Lions SightFirst, South India, Bengaluru	drscshetty@gmail.com
	Dr Sara Varughese	Regional Director, CBM, SARO Bengaluru	sara.varughese@cbmsaro.org
	Dr Harpreet Kapoor	CBM, Bangalore	harpreet_kapoor@hotmail.com
	Dr RN Mohanty	Chief Executive Officer, Sightsavers, India, Delhi	rnmohanty@sightsavers.org
	Dr Sandeep Bhuttan	Sightsavers Technical Advisor, New Delhi	sbuttan@sightsavers.org

	Dr. Shivam Mani	Technical Advisor, OEU, Kanpur	mainis@operationeyesight.com
	Dr B Kashinath	Senior Director, International Programs, OEU, Hyderabad	bhoosnurmathk@operationeyesight.com
	Dr Rahul Ali	ORBIS International, Gurgoan	Rahul.Ali@orbis.org
	Dr Rishi Raj Borah	India Country officer, ORBIS International, Gurgoan	rishiraj.borah@orbis.org
	Dr GV Rao	The HANS Foundation, Delhi	gvrao59@gmail.com
	VISION2020 India/IAPB		
	Dr Madan Deshpande	President, VISION 2020 India, Pune	president@vision2020india.org
	Mr R. D. Thulasiraj**	Vision2020 India; IAPB; Aravind Eye Care System, Madurai	thulsi@aravind.org
	Dr T.P. Das	IAPB Regional Chair, Hyderabad	tpd@lvpei.org
	Physicians		
	Dr C S Yajnik	Yajnik Diabetes Centre and KEM Pune	csyajnik@hotmail.com
	Dr S M Sadikot	President Indian Diabetic Federation, Ahmedabad	smsadikot@gmail.com
	Dr Hussain Siddique	Physician (Retd Govt doctor), Hyderabad	
	Dr PV Rao	Sr. Professor and Head, Department of Endocrinology, NIMS, Hyderabad	diabetology@eth.net; diabetes@bsml.in
	Ophthalmologists / Eye Care providers		
	Dr. Quresh B. Maskati	President, AIOS, India, Delhi	qureshmaskati@gmail.com
	Dr P Namperumalsamy	Aravind Eye Care System, Madurai	dr.nam@aravind.org
	Dr GN Rao	Chair LVPEI, Hyderabad	gnrao@lvpei.org
	Dr R Rajlakshmi	Dr Mohan Diabetes Centre, Chennai	drraj@drmohans.com
	Dr Rajiv Raman	VR Services, Sankara Netralaya, Chennai	rajivpgraman@gmail.com
	Dr Radhika Krishnan	Aditya Jyot Foundation, Mumbai	drradhika.ajftle@gmail.com
	Dr Sunita Mohan	Aditya Jyot Foundation, Mumbai	dr.sunitamohan282@gmail.com
	Dr Mohita Sharma	Tirupathi Eye Institute, Noida	drmohita@tirupatieye.org
	Dr Smitha Jasper	Department of Ophthalmology, Christian Medical College, Vellore	smithajasper@gmail.com
	Dr Sheshadri Mahajan	Spark Eye Care Hospitals, Hyderabad	drsheshadri@gmai.com
	Dr. Uday Gajiwala	Divya Jyot Trust, Surat	umadevang@yahoo.co.in
	Dr Usha K Vyas	CH Nagri Hospital, Ahmedabad	ushavyas@yahoo.com
	Dr Tejas Ben Desai	CH Nagri Hospital, Ahmedabad	dr_tejasdesai@yahoo.com
	Dr K. Vishwanath	Director, PVRI Institute, Hyderabad	pvri.india@gmail.com
	Mr R Govind Hari	PVRI Institute, Hyderabad	pvri.india@gmail.com
	Dr Kuldeep Dole	HV Desai Eye Hospital, Pune,	kuldeepdole@yahoo.co.in
	Dr Manisha Aggarwal	Shroff's Hospital, Noida	manisha@sceh.net
	Dr Krishna Murthy	Vittala Eye Hospital, Bangalore	krmjr2000@gmail.com
	Dr Padmaja Rani	LVPEI, Hyderabad	rpk@lvpei.org
	Dr. S. Narsimhulu	District Hospital, Ananthapur	
	Other institutions/Organizations		
	Ms Dipti Acharjee	Sr. Skills & Education Advisor, Deputy High Commission, British High Commission, Hyderabad	diptiukti30@gmail.com
	Mr K.Chandrasekhar	Forus Health, Bangalore	kc@forushealth.com
	Mr R Guru Moorthy	PVRI Institute, Hyderabad	rgurumoorthy@yahoo.com
	Mr. Prabhat Kumar Sinha	Programme Manager- NCD partnerships, Eli Lilly and Company (India), Gurgaon	sinha_prabhat_kumar@lilly.com

	International delegates		
	Dr Astrid Bonfield	Chief Executive, The Queen Elizabeth Diamond Jubilee Trust, London	astrid.bonfield@qejubileetrust.org
	Jonathan Dunbar	Programme Officer, The Queen Elizabeth Diamond Jubilee Trust, London	jonathan.dunbar@qejubileetrust.org
	Dr Sir Michael Hirst	President, International Diabetes Federation, Edinburgh	michael.hirst@pagodapr.com
	Dr Petra Wilson	CEO, International Diabetes Federation, Brussels	petra.wilson@idf.org
	Mr Peter Ackland	CEO, IAPB, London	packland@iapb.org
	Dr Sally Crook	Seeing is Believing Programme Manager, IAPB, London	scrook@iapb.org
	Professor Clare Gilbert	Co-Director ICEH, LSHTM, London	clare.gilbert@lshtm.ac.uk
	Mr Mike Eckstein	Brighton and Sussex University Hospital, Brighton, UK	michael.eckstein@bsuh.nhs.uk
	Dr Satya Prabha Kotha	Senior Program Manager- Eye Health, HKI, Jakarta, Indonesia	skotha@hki.org
	Dr Lizette Mowatt	Consultant Ophthalmologist, Senior Lecturer, University of the West Indies, Jamaica	lizettemowatt@yahoo.com
	Dr Zareen Khair	Country Manager Bangladesh, Fred Hollows Foundation, Bangladesh	zkhair@hollows.org
	Dr. Megan Verry	Manager Global Partnerships, Fred Hollows Foundation, Australia	mverry@hollows.org
	Ms Nimrata Khuman	Fred Hollows Foundation, Australia	nkhuman@hollows.org
	Dr Laura Healy	Project Officer, Global Partnerships, Fred Hollows Foundation, Australia	lhealy@hollows.org
	Secretariat		
	Ms B. Vijayalaskmi	IIPH, Hyderabad	vijaya.b@iiphh.org
	Ms B Madhavi	IIPH, Hyderabad	madhavi.sunil@iiphh.org
	Mr P Chaitanya Kumar	IIPH, Hyderabad	chaitanya.p@iiphh.org
	Mr R Someswar Rao	IIPH, Hyderabad	someshwer.r@iiphh.org
	Mr T Siva Nageswara Rao	IIPH, Hyderabad	siva.nrao@iiphh.org
	Ms Gina Sharma	PHFI, Delhi	gina.sharma@phfi.org
	** Did not attend in person. Gave presentations by electronic media		

Appendix 2: Agenda for the National DR Summit

Diabetic Retinopathy Summit
Agenda

Developing a national strategy for the prevention, detection and treatment of a major cause of avoidable blindness

12-14 April 2014, Hyderabad

PUBLIC HEALTH FOUNDATION OF INDIA

THE QUEEN ELIZABETH DIAMOND JUBILEE TRUST

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Supported by The Queen Elizabeth Diamond Jubilee Trust and organised by IIPH, Hyderabad & the International Centre for Eye Health, London School of Hygiene & Tropical Medicine

Chair: D Bachani, Deputy Commissioner, Non-Communicable Disease, Governmentof India
Facilitators: Clare Gilbert, GVS Murthy, R D Thulasiraj
Rapporteurs: BR Shamanna, Rajan Shukla, Raghupathy Anchala, AT Jotheeswaran, Praveen Vashisht

Saturday, 12th April 2014

8.30 – 9.30	**Registration**	
9.30 – 10.45	**Inaugural session**	
	Welcome and Introductions	GVS Murthy, Director, Indian Institute of Public Health-Hyderabad
	Diabetic retinopathy in focus: The case for action	Astrid Bonfield, Chief Executive Officer, The Queen Elizabeth Diamond Jubilee Trust
	Building a roadmap for the future	G N Rao, Chair, LV Prasad Eye Institute
	Summit objectives and expected outcomes	Clare Gilbert, Professor and Co-Director, International Centre for Eye Health, London School of Hygiene and Tropical Medicine
	Inaugural Address	L V Subrahmanyam & Ajay Sawhney, Principal Secretary, Health, Medical and Family Welfare Department, Government of Andhra Pradesh
	Sharing the India landscape: AIOS initiatives	Quresh B Maskati, President, All India Ophthalmological Society
	Key Note Address: : Policy initiatives and national programmes - Direction for translating evidence and experience to responsive policy	K Srinath Reddy, President, Public Health Foundation of India
	Message from IDF	Sir Michael Hirst, President, International Diabetes Federation
	Message from IAPB	Peter Ackland, IAPB
	Vote of Thanks	M Jayaram, Academic Registrar and Senior Administrative Officer, Indian Institute of Public Health - Hyderabad

10.45-11.15	**Tea/Coffee**
11.15-13.15	**Plenary Session-I: Top line findings of the situational analysis on diabetes and DR services in India** **Chairs:** G N Rao, Chair, LV Prasad Eye Institute and L V Subrahmanyam, Principal Secretary, Health, Medical & Family Welfare Department, Government of Andhra Pradesh Purpose and Objectives of the Study — Rajan Shukla Methodology — Raghupathy Anchala Coverage of Sample — Vivek Singh Major Findings from the Study — GVS Murthy Implications of the Study — Clare Gilbert
13.15-14.00	**Lunch**
14.00-15.30 **(6 mins per speaker)**	**Plenary Session-II: Overview of programmes for diabetes and diabetic retinopathy** **Chairs:** Clare Gilbert, Professor and Co-Director, International Centre for Eye Health, London School of Hygiene and Tropical Medicine and Sir Michael Hirst, President, International Diabetes Federation National Programme for Non Communicable Diseases with emphasis on Diabetes — D Bachani, Deputy Commissioner, Non - Communicable Disease, Government of India National Programme for Control of Blindness with emphasis on DR — N K Agarwal, Deputy Director General (Ophthalmology), NPCB, Govt. of India IAPB Global Agenda for DR — Peter Ackland, CEO, IAPB Vision 2020 India and DR initiatives — Madan Deshpande Role of professional international & national diabetes agencies in controlling the epidemic of Diabetes — Sir Michael Hirst, President, International Diabetes Federation Support for evidence generation: ICMR research priorities — Tanvir Kaur and R S Dhaliwal Aravind Eye Care System Approach to DR — P Namperumalsamy, Chairman, Aravind Eye Care System LVP Model for DR — TP Das, Regional Chair, IAPB Vithala Eye Institute Model for DR — Krishna Murthy RP Centre Model for DR — Praveen Vashisht, AIIMS Sankara Nethralaya Model for DR — Rajiv Raman Aditya Jyot Model for DR — Radhika Krishnan Divyajyoti — Uday Gajiwala C H Nagri Hospital, Ahmedabad — Usha K Vyas and Tejas Ben Desai H V Desai Hospital, Pune — Kuldeep Dole

5.30-16.00	**Tea/Coffee**
6.00-16.30	**Plenary Session-II continues**
6.30-17.30	**Panel discussion - An eye on patient and care-giver perspectives** **Chair:** K Viswanath, Pushpagiri Eye Institute

Sunday, 13th April 2014

00-10.00 mins per peaker; llowed by uestions)	**Plenary Session-III: Management and cost issues for DR** **Chairs:** D Bachani, Deputy Commissioner, Non - Communicable Disease, Government of India and C S Yajnik, Director, Diabetes Unit, King Edward Memorial Hospital and Research Centre	
	Epidemiology of Diabetes	C S Yajnik
	Cost-effectiveness of services for Diabetic Retinopathy	Mike Eckstein
	Global initiatives for Diabetic Retinopathy- IAPB Five-Year Action Plan	Peter Ackland, CEO, IAPB
	Cost & Sustainability of DR Services	R D Thulasiraj, Vision 2020 India; IAPB; Aravind Eye Care System
0.00-11:00 mins per peaker; llowed by uestions)	**Plenary Session-IV: INGOs support for diabetes and diabetic retinopathy** **Chairs :** N K Agarwal, Deputy Director General (Ophthalmology), National Programme for Control of Blindness, Government of India and R D Thulasiraj, Vision 2020 India; IAPB; Aravind Eye Care System	
	CBM	Harpreet Kapoor
	ORBIS	Rahul Ali
	Sightsavers	Sandeep Bhuttan
	LCIF	C S Shetty
	Fred Hollows Foundation	Megan Verry
	International Diabetes Federation	Petra Wilson
	OEU	Shivam Maini/B Kashinath
1.00-11.30	**Tea/ Coffee**	
1.30-13.00	**Plenary Session-V: Listing priority areas for DR management in India**	
	Theory of change Formation of Break Out groups	Clare Gilbert, Professor and Co-Director, International Centre for Eye Health, London School of Hygiene and Tropical Medicine
3.00-14.00	**Lunch**	

Appendix 4: Terms of Reference for the National DR Task Force

The Task Force will be under the Ministry of Health, NCD Program

Membership

- The Taskforce will be appointed for a term of five years by the MoHFW.
- The Taskforce will be:
    - Convened by Dr. D. Bachani, Deputy Commissioner, Non Communicable Diseases (NCDs), Ministry of Health and Family Welfare (MoHFW).
    - Chaired by Dr Y.R. Sharma, Chief, Dr R.P. Centre, AIIMS and Advisor(Ophthalmology), Govt. of India
    - Co-chaired by Dr. Nikhil Tandon, Professor of Endocrinology at All India Institute of Medical Sciences (AIIMS).

Other members of the Taskforce will include:

- Representative from National Program for Control of Blindness (NPCB)
- President Vision2020
- President, All India Ophthalmic Society (AIOS)
- President, Association of Physicians of India (API)
- Representative National Health Mission (NHM)
- Regional Chair for International Association for Preventable Blindness (IAPB)
- Representative from Civil Society
- Representative from World Diabetes Association (WDA)
- Representative from World Health Organization – India Country Office, NCD Focal Point
- Dr. GVS Murthy, Public Health Foundation of India – Member Secretary
- Dr. Clare Gilbert, Special Advisor for The Queens Diamond Jubilee Trust

Terms of Reference

Tasks

The DR Taskforce will provide evidence-based advice to the government and health providers – both public and private – on DR prevention, control and management programmes and support the development of a national model DR prevention strategy which is sustainable, accessible, scalable and integrated in the national health mission.

The Strategy will provide a blueprint for tackling the burden of preventable blindness currently caused by diabetes. It will be directed at the overall health sector in the model districts with a special focus on strengthening community awareness, screening and management at primary and secondary levels of health care.

The Taskforce will also:

1. Support further development of the evidence base on DR, to inform the model DR strategy;
2. Provide advice for policy makers on the best ways for government investment in DR prevention;
3. Provide advice on the most effective strategies for targeting prevention in high risk and underserved populations groups;
4. Provide guidance to strengthen DR screening and management services, particularly in primary and secondary care settings;
5. Provide advice to government on options for better integration of DR services into the NHM; and
6. Support the development of inter-departmental and multi-sectorial partnerships on DR.

Accountability and deliverables

The Taskforce will report to the MoHFW, Govt. of India. The Taskforce will use a multidisciplinary approach, operate in a collaborative, open and consultative manner, and work in partnership with existing agencies and

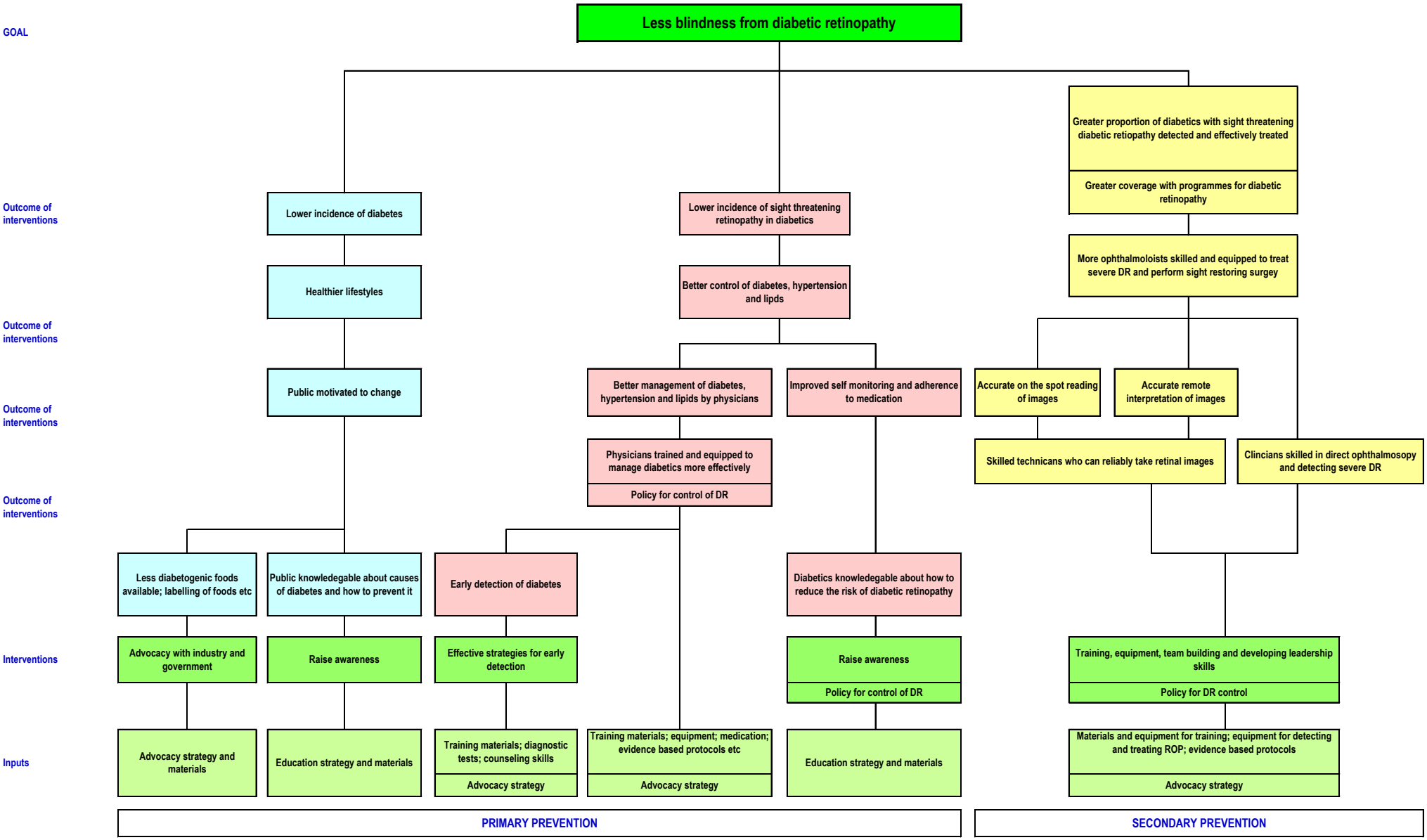
bodies working in associated departments.

The Taskforce will provide:

- Advise on the framework for the DR prevention project partnership between the Trust, PHFI, MoHFW and the states;
- A five year work programme;
- Steering of the operations in the district models through the district health societies;
- Oversight and technical advice for project operations;
- Advice on such matters as may be referred to the Taskforce from time to time by the MoHFW, Govt. of India, and
- Inputs for a long term DR prevention strategy for the country;

The Taskforce shall be supported in its operations by a Secretariat based at the Public Health Foundation of India's premises in New Delhi.

Appendix 6. Draft Theory of Change for the control of DR in India (next page)


GOAL
Less blindness from diabetic retinopathy
Outcome of interventions
Lower incidence of diabetes
Lower incidence of sight threatening retinopathy in diabetics
Greater proportion of diabetics with sight threatening diabetic retiopathy detected and effectively treated
Greater coverage with programmes for diabetic retinopathy
Outcome of interventions
Healthier lifestyles
Better control of diabetes, hypertension and lipds
More ophthalmoloists skilled and equipped to treat severe DR and perform sight restoring surgey
Outcome of interventions
Public motivated to change
Better management of diabetes, hypertension and lipids by physicians
Improved self monitoring and adherence to medication
Accurate on the spot reading of images
Accurate remote interpretation of images
Outcome of interventions
Physicians trained and equipped to manage diabetics more effectively
Policy for control of DR
Skilled technicans who can reliably take retinal images
Clincians skilled in direct ophthalmosopy and detecting severe DR
Outcome of interventions
Less diabetogenic foods available; labelling of foods etc
Public knowledegable about causes of diabetes and how to prevent it
Early detection of diabetes
Diabetics knowledegable about how to reduce the risk of diabetic retinopathy
Interventions
Advocacy with industry and government
Raise awareness
Effective strategies for early detection
Raise awareness
Policy for control of DR
Training, equipment, team building and developing leadership skills
Policy for DR control
Inputs
Advocacy strategy and materials
Education strategy and materials
Training materials; diagnostic tests; counseling skills
Advocacy strategy
Training materials; equipment; medication; evidence based protocols etc
Advocacy strategy
Education strategy and materials
Materials and equipment for training; equipment for detecting and treating ROP; evidence based protocols
Advocacy strategy
PRIMARY PREVENTION
SECONDARY PREVENTION

PHOTOGRAPHS OF THE DR SUMMIT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Diabetic Retinopathy Summit


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