Is India’s policy framework geared for effective action on avoidable blindness from diabetes?

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A B S T R A C T

Background: The growing burden of avoidable blindness caused by diabetic retinopathy (DR) needs an effective and holistic policy that reflects mechanisms for early detection and treatment of DR to reduce the risk of blindness. Materials and Methods: We performed a comprehensive health policy review to highlight the existing systemic issues that enable policy translation and to assess whether India’s policy architecture is geared to address the mounting challenge of DR. We used a keyword-based Internet search for documents available in the last 15 years. Two reviewers independently assessed retrieved policies and extracted contextual and program-oriented information and components delineated in national policy documents. Using a “descriptive analytical” method, the results were collated and summarized as per themes to present status quo, gaps, and recommendations for the future. Results: Lack of focus on building sustainable synergies that require well laid out mechanisms for collaboration within and outside the health sector and poor convergence between national health programs appears to be the weakest links across policy documents. Conclusions: To reasonably address the issues of consistency, comprehensiveness, clarity, context, connectedness, and sustainability, policies will have to rely more strongly on evidence from operational research to support decisions. There is a need to involve multiple stakeholders from multiple sectors, recognize contributions from not-for-profit sector and private health service providers, and finally bring about a nuanced holistic perspective that has a voice with implementable multiple sector actions.

Key words: Chronic disease, diabetes, diabetic retinopathy, health policy, India

INTRODUCTION

The growing prevalence of diabetes as a silent killer in the past two decades has contributed to global cognizance of its public health importance and of its complications, including diabetic retinopathy (DR).¹⁻³ Globally, 1.85 million people go blind due to DR,⁴ and one in five persons with diabetes in India suffers from DR.⁵ Currently, DR is the leading cause of avoidable blindness in the high-income countries and by 2035, it could also be a leading cause of avoidable blindness in low- and middle-income countries, where 80% of the global diabetic population is expected to reside.⁶ India is already one of the diabetes epicenters of the world, projected to have 109 million diabetics in the next 20 years.⁷ Evidence suggests that good glycemic control may arrest the progression of DR.⁸ Early detection and treatment can reduce the risk of blindness from DR by 90%.⁹ The big question is: Is India’s national policy architecture geared to combat the mounting challenge of DR? Delving into policies may highlight...
existing systems, trajectory of approaches, and levers to advance game-changing actions to tackle blindness due to DR.

**Materials and Methods**

A desk review was conducted, which involved identification of documents from a keyword-based Internet search. Key officials at administrative Ministry/Institution(s) were consulted to broaden the scope of the review. Two reviewers independently assessed, retrieved policies, and extracted contextual and program-oriented information as per the following:

**Inclusion criteria**

- Documents/monographs produced and circulars/notifications issued or ratified in the last 15 years (since 2000) when noncommunicable diseases (NCDs) received global attention from the World Health Organization (WHO)
- Provide “policy,” “strategy,” “program,” “plan,” “guidelines,” and “working group recommendations” with reference to DR
- Keywords or reference to “DR,” “diabetes complication/s,” “NCD,” “chronic disease,” “blindness,” “vitreo-retina (VR),” “medical retina,” “cardiovascular disease,” “modifiable risk factor/s,” “lifestyle,” “National Blindness Control Programme,” “National Programme on Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS),” and “5-year plan (hereafter referred to as nth plan).”

**Exclusion criteria**

- Studies (journal articles and gray literature)
- Reports/operational guidelines from national and international private for-profit service providers, Non-Government Organizations (NGO) and hospitals, health clinics, or programs that provide health services
- Evaluation and audit reports (as their focus is on implementation, rather than the policy environment).

Using a “descriptive analytical” method, the results were collated and summarized as per themes to present status quo, gaps, and recommendations for the future.

**Results**

A total of 50 documents were reviewed (15 global; 35 national) to assess the policy environment for operationalization of quality, diabetic eye care. The following findings suggest that there is scope to strengthen India’s approach:

**Wide angle: The landscape for India’s policy vision on diabetic retinopathy**

In a nutshell, national policy priorities to accelerate reduction in DR prevalence are largely reflected in the realm of NCD and blindness prevention, detection, and control.

**Early wins: Taking initiative through national programs**

The WHO has led agenda setting and stewardship of global plans and programs for NCD and eye health. India has remained in-step and in some cases preempted World Health Assembly resolutions to confront the range of NCDs and diabetes and eye care [Table 1].

India was the first country in the world to launch a National Programme for Control of Blindness (NPCB) in 1976, before the WHO Programme for the Prevention of Blindness was announced.[10] The National Diabetes Control Programme was rolled out as a pilot (1985–1990) prior to global, landmark resolutions of 1989.[11,12] In 2010, an integrated NPCDCS was approved close on the heels of the WHO Action Plan for Prevention and Control of NCDs in 2008 which called on member states to establish national programs.[1]

**Principal strategies for comprehensive, diabetic eye care and management**

Structures, systems, and services to tackle DR as per the current policy framework are predominantly extended via the NPCB and NPCDCS in India. The National Rural Health Mission (NRHM) subsumed the NPCB in 18 states when it came into existence.[13]

Although it was not an intense part of the original mandate, NRHM, now National Health Mission (NHM) includes the NPCDCS. NPCDCS is currently operational in 152 districts,[14] whereas NPCB is operational across all 640 districts.[11]

Services at each level of care are described below.

**Connecting the dots of primary care**

At all Primary Health Centres, Vision Centres are being established and manned by Para-Medical Ophthalmic Assistants (PMOA)/Ophthalmic Officer (PMOO) to screen and maintain Diabetic Registers (trained to work with fundus photographs). Community Health Centres (CHCs) under NPCB focus on early detection through vision testing and refraction, referral, Information Education and Communication (IEC), and involving the community. In 2010–2011, sanction was provided to 7000 CHC and District Hospitals to create NCD Clinics to screen, diagnose, and manage chronic diseases, including complications.[14]
### Table 1: Areas for action on DR as reflected in policy documents at the global and national level

<table>
<thead>
<tr>
<th>Areas</th>
<th>Level</th>
<th>1970s</th>
<th>1980s</th>
<th>1990s</th>
<th>2000s</th>
<th>2010s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>Global</td>
<td>Health for all by 2000 Primary Health care</td>
<td>Health promotion Healthy cities</td>
<td>Intersectoral approach Task-shifting Community participation</td>
<td>Health systems Healthy lifestyle Renewal of primary health care</td>
<td>Universal health coverage Health systems</td>
</tr>
</tbody>
</table>


Auxiliary Nurse Midwives (ANMs) and Multi-purpose Health Workers (MPWs) are to support detection and referral for NCDs at Type B sub-centers.[15] Field health workers under NPCB, also conduct house-to-house surveys, awareness generation, and referral.[89]

**Strengthening secondary eye care**

Traditionally, district hospitals, notified as base hospitals provide eye care through an out-patient department, dedicated ophthalmic operation theater, and a separate eye ward. NCD clinics have been established at identified district hospitals to provide daily emergency care, screening, counseling, and management of diabetes. District hospital upgradation has also been charted, wherein multipurpose Medical Intensive Care and Stroke Units may be built.[17,18]

The state/union territories are required to develop a referral protocol for cases from the district hospital to tertiary care.

**Transforming tertiary eye care**

Twenty Regional Institutes of Ophthalmology (RIO) provide comprehensive and advanced patient eye care, research, and training at tertiary level.[19] Four RIOs specialize in VR and/or medical retina. Strengthening Government Medical colleges to provide specialized tertiary care facilities, resource centers for training and research in NCDs is an aim of the Ministry of Health, Government of India.[19]

**Critical appraisal of policies to support diabetic eye care**

For clarity of purpose and to commence impactful action on DR, there is a need for elaboration of components within the health systems response, such as clinical guidelines, information systems, quality assurance, manpower planning, and public awareness generation. Only publications from the last decade included measures that address a combination of
program components. Salient features for diabetic eye care were examined across interplay of relevant program components [Table 2].

**Integrated service delivery: Shall the twain meet?**

Clear treatment guidelines for DR are required. The NPCDCS provides scope for inclusion of management of DR as a complication. While the WHO-Indian Council of Medical Research has developed guidelines for diabetes, including its complications, they have not been updated or adopted nationally. Neither do they provide details for screening and referral for the treatment of DR. The Vision 2020: Right to Sight initiative in India has recently published a visually-rich manual of clinical guidelines for comprehensive management of DR in India, building on International Council of Ophthalmology guidelines developed in 2008. Both of these are a step in

<table>
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<tr>
<th>Table 2: Components relevant to diabetic eye care delineated in national policy documents</th>
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<tbody>
<tr>
<td>Component</td>
</tr>
<tr>
<td>Clinical guidelines</td>
</tr>
<tr>
<td>Targets</td>
</tr>
<tr>
<td>Human resource Health Management Information Systems (HMIS)</td>
</tr>
<tr>
<td>Monitoring and Evaluation</td>
</tr>
<tr>
<td>Convergence</td>
</tr>
<tr>
<td>Quality assurance</td>
</tr>
<tr>
<td>Equipment</td>
</tr>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>Health education Budgetary allocation</td>
</tr>
<tr>
<td>Evidence used</td>
</tr>
<tr>
<td>Identification of good practice</td>
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<tr>
<td>Identification of good practice</td>
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</table>

*Basic contours and mechanisms are outlined. †Mention of the word or statement of need. Responsibilities for action are described. NCD: Noncommunicable diseases, NPCDCS: National Programme on Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke, DR: Diabetic retinopathy, NGO: Non-Government Organizations, PMOA: Para-Medical Ophthalmic Assistants, RIO: Regional Institutes of Ophthalmology, VR: Vitreo-retina; LVPEI: Lakshmi varasadasprad eye institute, ICARE: International centre for advancement of rural eye care
the right direction, featuring assessments, equipment, patient education, specialist support, and timing of follow-up, but require to be owned by both ophthalmologists and physicians.

The goal of collaborative care remains to be fully conceptualized and detailed across the primary, secondary, and tertiary levels of care. Better coverage and follow-up rates for DR are achievable only when eye care is provided jointly with diabetic care at the same healthcare facility. However, while the same facility offers eye and NCD services in India, each package under NPCDCS and NPCB is a stand-alone package, without information-sharing or a defined intra-facility or clear inter-facility referral pathway from the ophthalmologist to the physician or the endocrinologist and vice versa. A literature-based mapping of DR-relevant service delivery points and referral linkages are presented [Figure 1].

Human resource management
Establishing national coordinating mechanisms at health ministries and development of an eye health workforce, including paramedical professionals and community health workers has received global emphasis. In India, adequacy and competency of overall human resources for comprehensive eye care is questionable. A clear system to plan supply of human resources, particularly for NCDs is required. While manpower guidelines prescribing minimum requirements have been articulated for contractual doctors and staff, skills and competencies of various health workforce cadres are lacking.

Affixing responsibilities for DR care is required. For example, CHCs are required to facilitate intensive glycemic control, retinopathy screening, and photocoagulation, but the “when” “how” “by whom” and “where” are not provided. NPCDCS operational guidelines bear only slightly more detail regarding staffing and roles within the NCD Cell as in the National Programme for Health Care of the Elderly.

Capacity building
Building a cadre for primary eye care, comprising surgeons, nurses, and requiring refresher training for PMOAs/PMOOs, Medical Officers, Accredited Social Health Activist (ASHA), and integrated child development scheme (ICDS) workers and one for NCDs, comprising 32,000 district physicians, nurses, and consultants has been recommended.

Consolidation of curricula from the NHM, NPCB, and the NPDCS is necessary to lend structure to continuing education and skills development programs relevant to DR. Health services research and strengthening existing national and local training institutions on priority (RIOs, medical colleges, and district and sub-district hospitals) may facilitate more effective training programs.

Task-shifting emerges as a strong undercurrent, with training also being suggested for counselors, social workers, practitioners of Indian Systems of Medicine, Registered Medical Practitioners, ANMs, MPWs, and other locally available human resources. Since 2009, efforts to equip the ASHA as a “lay diabetes facilitator” are ongoing, but evidence has not translated into policy directions.

Infrastructure and equipment
There is a shortfall in equipment for the treatment of common eye diseases as well as surgical services. Policy debates highlight challenges in the availability of good screening and diagnostic equipment, need for modern surgical tools and intraoperative patient care, full asepsis at all levels to prevent postoperative infection, and high quality presterilized drugs and surgical consumables.

Guidelines and norms for assistance under NPCB have shown some inconsistencies. For example, fundus cameras are available at Vision Centres in the NGO sector, but there is no mention of the same under relevant documents for grants-in-aid or NRHM Programme Implementation Plan (PIP).
Real-time surveillance, health management information systems and monitoring

Reliable and timely consolidation of information from NPCB and NPCDCS at national, state, and district levels may potentially strengthen planning of DR programs. Global calls to establish monitoring mechanisms and coordinating agencies date back to the World Health Assembly resolution of 2003 in eye care,[43] through the Moscow Declaration in 2011 for NCDs.[44] Risk factors, outcomes, social and economic determinants of health, and health system responses should ideally be surveyed.[45-47]

The last two 5-year plan sketch a number of disparate mechanisms, but what would be most useful is to suggest how they may work together [Table 3].

Table 3: Monitoring and surveillance mechanisms mentioned in national policy documents

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>Task</th>
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<tbody>
<tr>
<td>Integrated Surveillance Project (IDSP)</td>
<td>Collect risk factor and morbidity prevalence on NCDs in seven states. No information on mortality, complications or expenditure</td>
</tr>
<tr>
<td>Sentinel Surveillance Units</td>
<td>Monitor, survey and study ocular morbidity</td>
</tr>
<tr>
<td>NCD Cells</td>
<td>Gather data for an epidemiological database on NCDs</td>
</tr>
<tr>
<td>Technical Resource Group (TRG)</td>
<td>Provide dedicated oversight and independent evaluation</td>
</tr>
<tr>
<td>Nutrition monitoring</td>
<td>Identify trends and initiate interventions on diabetes</td>
</tr>
<tr>
<td>Disease Registry</td>
<td>Collect secondary data related to specific diagnosis, condition, or procedure</td>
</tr>
<tr>
<td>Involve medical colleges</td>
<td>Operational and evaluation research</td>
</tr>
<tr>
<td>Health Impact Cell</td>
<td>Proactively understand the health impact of policies</td>
</tr>
</tbody>
</table>
| Community-based Monitoring Committees | By Panchayati Raj Institutions (PRI), community based organizations (CBO), voluntary organizations (VO) and NGOs | NCD: Noncommunicable diseases, NGO: Non-Government Organizations

While the NHM is designed to monitor all programs under a single administrative system, its separation of accountabilities (design of the standard formats/software and training of management information system staff at the center, analysis of performance and expenditure by states, and compilation of data and monitoring of performance at the block level) does not provide sufficient tools for information-sharing, joint planning, and coordination or concurrent monitoring.

Promoting outreach activities and public awareness

The key messages, approaches, and arrangements for IEC are embedded in policies as an overlapping, fluid menu of options [Table 4]. Development of application-oriented strategies, that take a life course approach and tailor different approaches to varied contexts and target groups would further their utility. Vision 2020 has conducted workshops and roundtable meetings to develop an action plan in this realm.[49]

Global policies envision a leadership role for an adequately staffed and funded health promotion unit within the Ministry of Health,[1] but this is yet to be realized via the Central Health Education Bureau or a new National Institute for Health Promotion and Control of Chronic Diseases.[17] They may explore inclusion of NCD and blindness control activities into primary health care as aligned to the Moscow Declaration, potentially via Village Health Sanitation and Nutrition Committees and other avenues.

Budgetary allocations

There is nearly a 6-fold jump in NPCB allocations since the Ninth Plan and close to a 5-fold jump in NPCDCS funding in a short span since 2010–2011 [Figure 2]. NPCDCS funding has increased on account of increasing geographical coverage. As a proportion of the total healthcare budget,
the NPCB allocations remain nearly at the same level whereas NPCDCS allocation has doubled.

The Twelfth Plan initiated bold interventions under NPCDCS up to the district level [Table 5]. This confirms the level of commitment accorded to blindness and NCD control activities. Data on the proportion of total outlay on diabetes are not available since the Eleventh Plan, after merger of pilot programs. A limited provision of INR 1500 for DR laser and INR 5000 for VR surgeries has been made. No strategies or incentive mechanisms have been devised for greater uptake of DR services at secondary care facilities. No provisions on financing for vulnerable populations were found.

Changes in the ratio of sharing between the Centre and State Government from 80:20 to 75 in the last two 5-year plan may influence fiscal planning. In addition, from 2013 to 2014, NPCB expenditure falls under the NCD flexi pool, under the recently approved NHM umbrella. The 2015 budget cuts in the health sector, attributed to large unutilized sums may impact these plans.

Interconnectedness with other policies
Global health resolutions call for strengthening partnerships, with a view to share responsibilities, coordinate for resource mobilization, advocacy, capacity building, and collaborative research. They highlight the importance of intersectoral policies, regulations, and appropriate measures to minimize the effect of the major risk factors of NCDs. India’s plans echo this sentiment. However, the nature and extent of engagement among multiple stakeholders, especially at the state and local level remains to be fleshed out.

Many national policies from nonhealth sectors have an impact on DR, through modification of lifestyle-related risk factors, and the interplay of social determinants of health and built environment for diabetes. Opportunities to incorporate prevention of diabetes, blindness, and visual impairment in schemes for the development of women and children, nutrition, National Urban Renewal Mission, school health programs, transportation, tobacco control, poverty reduction strategies, and relevant socioeconomic policies have been initiated and show promise. Policies must move beyond the usual suspects to apply across sectors, such as agriculture and food safety, finance (pricing and taxation), trade, environment, education, disability, alcohol, youth and sports, and local governance vide Panchayati Raj Institutions, Civil Society Organizations, and self-help groups.

The fine print: Policy commitments of direct relevance to diabetic retinopathy

Only a handful of national documents, out of the 35 reviewed, bear details for public health action on DR care and management. The Ninth Plan (1997–2002), issued while “VISION 2020” was being prepared, was the first to call for inclusion of other causes of blindness. The Tenth Plan squarely stated that NPCB would tackle DR, following Vision 2020’s inclusion of it as a priority eye condition. The plan provided for screening of diabetics for retinopathy estimated the prevalence of DR at 20% among diabetics. Prior to the Tenth Plan, it appears that strategies for reduction in the prevalence of cancer were given greater priority vis-à-vis other NCDs.

Budgetary guidelines relevant to DR were developed by NPCB from 2008 onward. Recurring grant-in-aid sums were established for complete treatment of DR by voluntary organizations, NGOs, or private practitioners in fixed facilities and for VR surgery. Patient eligibility, evidence, maintaining a DR register and submission of monthly reports on cases screened, treated, and operated in prescribed formats, and payments are mentioned, but without details.

For nonrecurring grant-in-aid for the development of mobile ophthalmic units with tele-ophthalmic network and fixed tele-models (up to maximum of INR 0.6 million), at least one eye surgeon in the base hospital is required to perform 1200 DR procedures in 2 years.

Table 5: Significant budgetary initiatives relevant to DR in the Twelfth Plan

<table>
<thead>
<tr>
<th>Area</th>
<th>Budget (in crore INR)</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health education</td>
<td>12</td>
<td>Triple the previous amount</td>
</tr>
<tr>
<td>Target 1.2 lakh DR cases</td>
<td>18</td>
<td>Recurring expenditure (8% of total NPCB outlay @ Rs. 1,500 per case)</td>
</tr>
<tr>
<td>VR surgery for 0.45 lakh cases</td>
<td>22.5</td>
<td>Recurring expenditure (3% of total NPCB outlay @ Rs. 5,000 per case)</td>
</tr>
<tr>
<td>Assistance for RIOs</td>
<td>30</td>
<td>Five times the previous amount</td>
</tr>
<tr>
<td>Mobile Ophthalmology vans</td>
<td>2506</td>
<td>First-time investment</td>
</tr>
</tbody>
</table>

DR: Diabetic retinopathy, RIO: Regional Institutes of Ophthalmology, VR: Vitreoretina, NPCB: National Programme for Control of Blindness, INR: Indian Rupee

Figure 2: Outlays as per Indian 5-year plans (Indian Rupees in Crores)
be experienced in DR. Currently, the PIP for 2013–2014 includes active DR screening of the population above 50 years at eye camps and transportation of operable cases to care facilities.

**CONCLUSION**

The policy literature is unanimous on the importance of strengthening functional linkages among primary, secondary, and tertiary care centers for integrated treatment of diabetes mellitus, hypertension, and heart disease. However, “universal eye health” as a backdrop for the systems’ response and governance structures suggests that there are many ways to significantly improve early detection, treatment, and management of DR in India.

Recommendations of the World Health Report in 2008 on primary health care sought to breathe life into the aims of the Alma Ata Declaration, translating public policy for health systems strengthening and governance at the lowest level. India’s policies have begun to shape a stronger primary eye care infrastructure and cadre, such that patients with simple eye conditions do not require to access services at secondary or tertiary hospitals.

A lack of focus on building sustainable synergies and sketchy details appear to be the weakest links across policy documents. Many of them lack the “how to” mechanisms for collaboration within the health sector and with other sectors. Operational research is required to identify mechanisms of convergence between NPCDCS and NPCB programme activities. To reasonably address the issues of consistency, comprehensiveness, clarity, context, connectedness, and sustainability, policies will have to rely more on evidence to support decisions and present essential actions. Current policies also need to expand their view of contributions by the not-for-profit sector and private health service providers to holistically address the situation. At the moment, limited innovations and voices are reflected.

There is a growing recognition of the need for multi-sectoral actions, if the commitment to tackle DR is to be adequately reflected in the policy realm. This is evident from reflections on policy formulation processes through working group notes and active revisions in the last decade. This is, especially crucial as the key tasks to prevent and control DR include improving dietary intake, reducing high levels of stress and lack of physical activity, as well as managing rapid urbanization and concomitant lifestyle change. As Vision 2020 is less than 5 years away, it is these factors and a responsive, nuanced policy architecture that may pave the way for vital change.

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**Conflicts of interest**

There are no conflicts of interest.

**REFERENCES**


20. WHO-ICMR, Guidelines for Management of Type 2 Diabetes, Prepared as an outcome of the WHO-ICMR Workshop on Guidelines for Management of Type 2 Diabetes, 2-4 May 2003, Chennai; 2005.


25. National Programme for Control of Blindness, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, Guidelines for Operationalization of Multi-Purpose District Mobile Ophthalmic Units under the National Programme for Control of Blindness, 12th Five Year Plan; 2013.


44. First Global Ministerial Conference on Healthy Lifestyles and Non communicable Disease Control Moscow, Moscow Declaration: Preamble, 28-29 April, 2011.


