

# TADDS

Tool for the assessment of diabetic retinopathy  
and diabetes management systems



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# FACTS ON DIABETES AND DIABETIC RETINOPATHY

**Diabetes (DM)** today constitutes one of the emerging threats to public health all over the world:

- 455 million people worldwide have diabetes (2014 estimates).
- In 2012, an estimated 3.8 million people died from the consequences of high fasting blood sugar.
- More than 80% of diabetes deaths occur in low- and middle-income countries.
- WHO projects that diabetes will be the seventh leading cause of death in 2030.

Simple lifestyle measures (healthy body weight; physical activity; healthy diet) have been shown to be effective in preventing or delaying the onset of type 2 diabetes.

Early diagnosis can be accomplished through relatively inexpensive blood testing.

Treatment of diabetes involves lowering blood glucose and the levels of other known risk factors that damage blood vessels.

**Diabetic retinopathy (DR)** is the fifth leading cause of visual impairment and the fourth leading cause of blindness in the world:

- 285 million people worldwide are visually impaired.
- In 2010, an estimated 39.3 million people were blind.
- More than 80% of people with visual impairments live in low-income settings.
- More than 80% of people blind are >50 years old.
- Diabetic retinopathy is the cause of visual impairment for 4.2 million people.

The onset of diabetic retinopathy is the result of long-lasting diabetes; the condition is worse if diabetes is poorly controlled. Prevention of visual impairment from diabetic retinopathy is achieved principally through control of diabetes, early detection of retinal changes, and timely treatment of sight-threatening lesions of the retina once the damage from diabetes is established. Anti-VEGF (vascular endothelial growth factor) agents can reduce the progression of the disease and preserve visual function.

The most critical role of health systems in managing diabetes and preventing irreversible blindness from the disease is cooperation between those responsible for diabetes management and those concerned with diabetic retinopathy. While this may seem obvious, it is not a consistent practice in the health systems of low-income countries, and indeed is often also lacking in middle- and high-income countries.

## PURPOSE OF THE DOCUMENT

In order to assess both management of diabetes and diabetic retinopathy in countries and to estimate the level of cooperation and synergy between these two branches of health care, WHO has designed this assessment tool. The tool will make it possible to carry out situation analysis, define service provision levels, and identify the gaps to be addressed in ensuring universal access to diabetes care and to effective prevention and treatment of diabetic retinopathy.

# CONTENT OF THE TADDS (TOOL FOR THE ASSESSMENT OF DIABETIC RETINOPATHY AND DIABETES MANAGEMENT SYSTEMS)

The WHO Health Systems Framework guided the development of the survey items, which are organized into the following themes<sup>1</sup>:

- 1. Service delivery:** Estimates of needs from available data, priorities, policies and health care programmes for diabetes and diabetic retinopathy; how they are integrated into the public health system and each other (networks); presence and nature of referral pathways between diabetes care and eye care; locations of services; provision of care in public and private services.
- 2. Health workforce:** Cadres, numbers, distribution and training of staff involved in diabetes and eye care services.
- 3. Health information management systems:** Key performance indicators; what information is recorded for the individual patient with diabetes; data collation and communication; patient follow-up systems. Where possible, medical records should be used to assess compliance with regular monitoring of both diabetes and eye examinations.
- 4. Medical products and technologies:** Availability, accessibility and functionality of equipment for diagnosis, management and monitoring by health care providers.
- 5. Health financing:** Government expenditure, health insurance schemes, social security schemes; provision of all stages and types of care for vulnerable population groups (remote rural areas, poor people, elderly people and ethnic minorities).
- 6. Leadership and governance:** Key stakeholders and their roles in management of diabetes and diabetic retinopathy; existence of, and compliance with, guidelines for management of diabetes and diabetic retinopathy.

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<sup>1</sup> [http://www.wpro.who.int/health\\_services/health\\_systems\\_framework/en/](http://www.wpro.who.int/health_services/health_systems_framework/en/)



## OBJECTIVES OF THE ASSESSMENT

The primary objectives of the TADDS are to:

- assess the existence, availability and accessibility of health care services for diabetes mellitus (DM) and diabetic retinopathy (DR) in a given territory or country;
- provide a picture of the existence and effectiveness of links between management of patients with diabetes and management of diabetic retinopathy;
- identify the challenges faced by different levels of a national health system in providing eye care for patients with diabetes;
- inform the government and stakeholders of aspects of a health system that need to be prioritized for future research and development.

The scope of the situation analysis is from a national health systems approach and not to focus on individual care providers or institutions.

# SUGGESTED METHODOLOGY

## DESK-BASED DATA COLLECTION

Prevalence data for both diabetes and vision loss from diabetic retinopathy are required to assist in determining needs at the national level. They can be obtained from recent national or district level surveys (if available); otherwise, the WHO Global Health Observatory<sup>1</sup> by country for diabetic retinopathy may be used. It is estimated that one-third of people with diabetes have some level of vision loss.<sup>2</sup> Data may be requested from the ministry of health on the number and distribution of health services providing diabetes and eye care, and health professional organizations may be contacted for information on the number and distribution of members (e.g. endocrinologists, ophthalmologists) by state or province.

## IDENTIFY ALL RELEVANT STAKEHOLDERS AND KEY INFORMANTS

It is recommended that key informants from the following organizations/departments be interviewed, starting with the ministry of health and the WHO country office:

- Ministry of health
  - secretary or assistant secretary of health
  - division of chronic diseases management /lifestyle
  - division of food and nutrition
- World Health Organization country office
- National prevention of blindness committee
- Local and international nongovernmental organizations (NGOs) involved in the provision of diabetes and eye care
- Professional organizations
  - primary care: general practitioners (primary care/family physicians), primary care nurses

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<sup>1</sup> WHO Global Health Observatory (<http://www.who.int/gho/en/>)

<sup>2</sup> Prevention of Blindness from Diabetes Mellitus ([http://www.who.int/diabetes/publications/prevention\\_diabetes2006/en/](http://www.who.int/diabetes/publications/prevention_diabetes2006/en/))

- diabetes and endocrinology: endocrinologists, diabetologists, internal medicine physicians, primary care diabetes educators, diabetes nurses
- eye care: ophthalmologists, vitreoretinal specialists, optometrists (if available)
- Consumer/patient representative organizations
- Diabetes association

## MAKE APPOINTMENTS TO ARRANGE INTERVIEWS

The situation analysis list of topics should be sent to all individuals to be interviewed so that they can collect any necessary data in advance. TADDS will take approximately one hour to complete but not all sections will be answered by everyone. Group interviews with multiple stakeholders or informants from a similar area of experience or involvement in diabetes or eye care may be appropriate.

## DATA ANALYSIS

Results from key informant interviews can be recorded in hand or computer-written notes or – with the permission of interviewees – as audio files. Responses should be transcribed under the individual section headings of the survey in order to facilitate qualitative analysis. Quantitative data should be summarized by categories used in the TADDS.

# ASSESSMENT TOOL

## *Section 1: Priorities, policies and programmes*

- Existence of and, if known, compliance with the guidelines currently used in the country for diabetes management and for diabetic retinopathy.

## *Section 2: Service delivery*

- National data on the prevalence of diabetes.
- National data on the prevalence and causes of vision impairment.
- National list of public (government) and private hospitals, any information regarding their capacity to provide eye care, and lists of equipment. At least approximate numbers and distribution (by state/province or by level of health system) of health care facilities (village, district, provincial, tertiary hospitals and medical centres).

## *Section 3: Health workforce*

- Estimated number and distribution of registered ophthalmologists (including vitreoretinal surgeons and medical retinal specialists), internal medicine physicians, general practitioners, nurses, optometrists (if national regulations include this professional category).

## *Section 4: Health technology*

- Description of equipment for diagnosis and monitoring of diabetes.
- Inventory of ophthalmic equipment across all hospitals.

## *Section 5: Health information management systems*

- Details from locally or nationally aggregated data on use of diabetes and eye care services based on diagnosis or type of service.
- Information on methods of sharing patient data between providers of health care services.
- Details from any national registers for chronic diseases and/or vision impairment.
- Use of reminder systems to recall patients with diabetes or diabetic retinopathy for review appointments.

### ***Section 6: Health promotion for diabetes and diabetic retinopathy***

- Titles and details of public health materials used for community awareness or patient education.
- Use of World Sight Day and World Diabetes Day for major awareness initiatives.

### ***Section 7: Health financing***

- Coverage (% of population) of population with government health insurance for diabetes detection, monitoring and treatment.
- Coverage (% of population) of population with private health insurance.
- List of items/services that can be claimed under government health insurance for diabetes and eye care.

# ETHICS

Ethics approval for this assessment might need to be obtained in accordance with government (ministry of health) regulations and protocols in individual countries as a final assessment report is expected to be published.

All information should be recorded anonymously: the source of information is important but individuals should not be named.

The perspectives of different stakeholders should be retrievable for analysis.

**PLEASE USE THE QUESTIONNAIRE PROVIDED TO COMPLETE THE REQUIRED INFORMATION. ANY ADDITIONAL TABLE OR DOCUMENT CAN BE PROVIDED AS AN ANNEX ENSURE THAT THE GRADING AT THE END OF EACH SECTION IS DULY COMPLETED.**

**SUMMARIES OF REPLIES RECEIVED BY INTERVIEWEES SHOULD BE PROVIDED IN ORDER TO APPROPRIATELY REPRESENT THE SITUATION IN DIFFERENT PLACES OF THE COUNTRY.**

# PRIORITIES, POLICIES AND PROGRAMMES

## NATIONAL DIABETES PLAN/PROGRAMME

1. Is diabetes listed as a national health priority?

Yes

No

2. Is diabetic retinopathy (DR) listed as a priority in the national prevention of blindness plan?

Yes

No

3. Does your country have a national diabetes plan?

Yes

No

4. If so, what does this national plan cover?

Primary prevention of diabetes

Complications (including vision impairment)

Community awareness and patient education

Clinical care, services, and supplies

Remarks:

5. Is there a national policy on food and/or nutrition?

Yes

No

6. Is there a national programme on food and/or nutrition?

Yes

No

Name of programme:

Lead organization responsible for the programme:

7. Is there a national policy on diabetes prevention?

Yes

No

8. Is there a national diabetes prevention programme?

Yes

No

Name of programme:

Lead organization responsible for the programme:

9. Is there a national diabetes association?

Yes

No

a. What does it do?

Patient education and awareness

Clinician education and awareness

Policy development and advocacy

Networks between service providers and people with diabetes

b. What health promotion and patient education strategies are used by the diabetes association?

**Select the number<sup>1</sup> below that best represents the situation in the country:**

Existence of priority, policies and programmes for DM:	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
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<sup>1</sup> Key:

1 – DM is not a priority; there is no national plan and no national programme.

2 – DM is listed as a priority; there is a national plan but no programme has been implemented.

3 – DM is listed as a priority; a national plan has been formulated and a programme is in place but does not cover the whole country.

4 – DM is listed as a priority; both a plan and a programme are in place and there is national coverage.



## CLINICAL MANAGEMENT GUIDELINES

10. Are there guidelines for the management of diabetes?

Yes

No

***(If yes, please give the full title of the clinical management guidelines most commonly used and provide a copy.)***

a. Is diabetic retinopathy included as a component of these guidelines?

Yes

No

b. For what levels of the health care system (primary, secondary, tertiary) are the guidelines applicable?

c. What is the intended target audience (e.g. primary care workers, specialists) for the guidelines?

11. Are evidence-based guidelines available for the management of diabetic retinopathy?

Yes

No

***(If yes, please give the full title of the clinical management guidelines most commonly used and provide a copy.)***

a. Do they cover:

prevention of vision loss from diabetic retinopathy?

treatment?

follow-up?

b. For what levels of the health care system are the guidelines applicable?

Primary

Secondary

Tertiary

c. The guidelines are:

Evidence-based

Consensus-based

Mixture of both

If consensus-based, who (stakeholders) was involved in guideline development?

12. Are the guidelines being used?

Subjective rating scale: 1 = unused, 12 = widely used (click the appropriate number)

1    2    3    4    5    6    7    8    9    10    11    12

13. Describe how the intended audience is made aware of the existence of the guidelines? How were they disseminated (e.g. in print, by website)? In what languages are they produced?

**Select the number<sup>1</sup> below that best represents the situation in the country:**

Guidelines for clinical management of DM:    **1**    **2**    **3**    **4**

Guidelines for clinical management of DR:    **1**    **2**    **3**    **4**

<sup>1</sup> Key:

- 1 – There are no ministry of health-recommended guidelines.
- 2 – Ministry of health guidelines have been formulated but health professionals are unaware of their availability and thus they are not widely used.
- 3 – Ministry of health guidelines are available and known to the appropriate audience but they are not widely followed.
- 4 – Ministry of health guidelines have been formulated and are commonly followed.

*Additional information for Section 1*

## NETWORKS AND LINKAGES

14. Describe how people with newly diagnosed diabetes are identified.
  - a. Where are the services located (village, district, regional, provincial, tertiary levels of care)?
  - b. The facilities are:  
Private                      Public
  
15. Describe how ongoing care of people with diabetes is performed.
  - a. Where are the facilities located (village, district, regional, provincial, tertiary levels of care)?
  - b. The facilities are:  
Private                      Public
  
16. Describe the access to care services for people with diabetes.
  - a. What proportion of the population can access this service?
  
  - b. What are the barriers that prevent access to services?
  
17. What services are available at the community level for people with diabetes?
  - a. Clinical services:  
for patient identification and risk assessment
  - b. Patient education and support services:  
for diabetes  
for diabetic retinopathy

18. Is there a specialist diabetes centre?

Yes

No

a. If yes, what services does it provide?

b. What proportion of the population has access to these services?

Select the number<sup>1</sup> below that best represents the situation in the country:

Location of DM services and accessibility to population in need:    1    2    3    4

<sup>1</sup> Key:

1 – Services available in few places and to few people.

- Services are not available everywhere; they can be found only in large hospitals and are accessible only to those who can pay.

2 – Some services are available to part of the population.

- Services are available in regional hospitals or health centres and are partly paid by the patients. Populations in rural areas cannot reach services easily; transport to the health facilities and the cost of service are the main barriers.

3 – Services are available everywhere but do not reach some of the population.

- Services are available in most rural and urban areas providing care at district, regional, provincial and tertiary levels; however, costs and transport are barriers for some patients.

4 – Services are available everywhere for the whole population.

- Services are available in all locations and costs are paid by insurance schemes, are subsidized by the state, or are available free of charge.

## DIABETIC RETINOPATHY SCREENING

19. Are people with diabetes routinely referred for eye examinations?

Yes

No

a. Does this include referral of people who are asymptomatic?

Yes

No

b. Are people referred only if they report symptoms of vision loss?

Yes

No

c. Is an eye examination incorporated into the annual cycle of care for people with diabetes?

Yes

No

20. Is there a community screening programme for diabetic retinopathy?

Yes

No

a. How are people with diabetes recruited for screening?

b. What personnel are involved?

c. Is any outreach screening provided?

Yes

No

d. Coverage of screening?

e. Who pays for the screening?

21. Where are eye examinations for diabetic retinopathy performed most commonly in villages, at district, regional, provincial, tertiary levels of care)?

a. What proportion of the population can access this service (no one, 30%, 60%, 90%, 100%)?

b. What are the barriers that prevent access to services?

c. The services are:

Private

Public

Select the number <sup>1</sup> below that best represents the situation in the country:				
Location of DM services and accessibility to population in need:	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<sup>1</sup> Key:  1 – Services available in few places and to few people. <ul style="list-style-type: none"><li>• Services are not available everywhere; they can be found only in large hospitals and are accessible only to those who can pay.</li></ul> 2 – Some services are available to part of the population. <ul style="list-style-type: none"><li>• Services are available in regional hospitals or health centres and are partly paid by the patients. Populations in rural areas cannot reach services easily; transport to the health facilities and the cost of service are the main barriers.</li></ul> 3 – Services are available everywhere but do not reach some of the population. <ul style="list-style-type: none"><li>• Services are available in most rural and urban areas providing care at district, regional, provincial and tertiary levels; however, costs and transport are barriers for some patients.</li></ul> 4 – Services are available everywhere for the whole population. <ul style="list-style-type: none"><li>• Services are available in all locations and costs are paid by insurance schemes, are subsidized by the state, or are available free of charge.</li></ul>				

22. Describe the networks between services for diabetes care and eye care.

a. Stakeholders

b. Referral pathways (one-way, reciprocal)

c. What information is shared between practitioners?

23. Are any nongovernmental organizations (NGOs) involved in the care of people with diabetes and diabetic retinopathy?

Yes

No

If so, what roles do they perform in diabetes and in eye examination for people with diabetes (health promotion, screening, laser, vitreoretinal surgery)?

Select the number<sup>1</sup> below that best represents the situation in the country:

Networks between the care providers for DM and DR:    **1**    **2**    **3**    **4**

<sup>1</sup> Key:

1 – There is no known collaboration between separate providers of care for DM and DR.

2 – Few centres provide patient-centred care.

3 – Some centres provide patient-centred care by means of collaboration between DM and DR services.

4 – Most centres provide patient-centred care based on collaboration between DM and DR services.

### *Additional information for Section 2*

24. What categories of health professionals (endocrinologist; ophthalmologist; primary care physician; general, diabetes or ophthalmic-trained nurse; dietitian; etc.) are available to care for people with diabetes?

What is the ratio of providers to patients at each level of the health system?

25. What aspects of diabetes management are included in the teaching curriculum for primary health care workers (nurses and primary care physicians)?

Awareness of complications of diabetes – specifically, vision loss from diabetic retinopathy

Health education for patients

Need for and timing of referral for eye examination

Management of diabetic retinopathy

26. How is continuing medical education provided to primary health care workers?

Formal training by government, university, professional organizations

Regular informal updates

Workshops

Updates on guidelines

Select the number<sup>1</sup> below that best represents the situation in the country:

Training opportunities and quality for DM and DR care providers:    **1**    **2**    **3**    **4**

<sup>1</sup> Key:

1 – Largely inadequate.

2 – Few training opportunities; consequently fewer human resources than needed.

3 – Training available only in large cities and hospitals.

4 – Training for DM and DR is appropriate and of good quality.



27. Are the following investigations/equipment available?

Biochemical laboratory tests for HbA1c (glycated haemoglobin), lipids, creatinine, urinary protein

Blood glucose meter (owned/kept by patients with diabetes or by the health service)

Slit lamp

Direct ophthalmoscope

28. What technologies are used to perform retinal examination for diabetic retinopathy?

Dilated eye examination by ophthalmologist

Dilated eye examination by refractionist/optometrist

Retinal imaging – mydriatic camera

Retinal imaging – non-mydriatic camera

29. Where are these technologies available (villages, district, regional, provincial, tertiary levels of care)?

Select the number<sup>1</sup> below that best represents the situation in the country:

Accessibility of health technology:    **1**    **2**    **3**    **4**

<sup>1</sup> Key:

1 – Modern examination technology not available to the majority of patients.

2 – Modern examination technology available only in major hospitals and private clinics.

3 – Modern examination technology available in most provincial hospitals and clinics.

4 – Modern examination technology available to all patients.

*Additional information for Sections 3 and 4*

30. What nationally agreed health population indicators of diabetes are monitored?

Prevalence

Incidence

Not measured

How often are they measured?

31. What nationally agreed health population indicators of diabetic retinopathy are monitored?

Prevalence of vision impairment and blindness

Not measured

How often are they measured?

32. Describe the methods used (surveys, hospital data, health insurance statistics) to collect this information.

33. Describe how the information is collated and reported (standardized data set).

34. What information about individual patients with diabetes is recorded in their patient medical records in hospitals?

Risk factors

Complications – including diabetic retinopathy

Previous eye examination for diabetic retinopathy

Treatments

Follow-up

35. Is there a recall system for people with diabetes to have follow-up eye examination?

Yes

No

Communication methods: personal record books, information cards

mHealth: text messaging reminders using mobile phones

Select the number<sup>1</sup> below that best represents the situation in the country:

Knowledge of disease burden:    1       2       3       4

<sup>1</sup> Key:

1 – Prevalence of DM and DR is neither known nor estimated; information about patients is inadequate.

2 – Prevalence of DM is known but not the prevalence of DR.

*or*

Prevalence of DR is known but not the prevalence of DM, and patients' records are not utilized.

3 – Prevalence of both DM and DR is known or has been estimated; patients' records are used to analyse data at national level.

4 – Prevalence of both DM and DR is known or has been estimated; patients' records are collated, analysed and regularly published.

### *Additional information for Section 5*

# HEALTH PROMOTION FOR DIABETES AND DIABETIC RETINOPATHY

# 6

SECTION

36. Is information provided to the community about diabetes?

Symptoms and signs

Risk factors

Complications

Management

Where to seek help

37. Is information provided to the community about diabetic retinopathy?

Yes

No

38. How is community education regarding diabetes delivered?

Print media

mHealth: text messaging reminders using mobile phones

Radio/television

39. What is the coverage of health promotion and patient education?

National

Provincial

District

40. Are people with diabetes made aware of diabetic patients' organizations?

Yes

No

How are patients' support organizations made accessible to disadvantaged groups of the population:

In rural locations?

In what languages/dialects?

For people with disabilities?

41. Give examples of how initiatives such as World Diabetes Day and World Sight Day are used to educate people and medical professionals on vision impairment from diabetes.

Select the number<sup>1</sup> below that best represents the situation in the country:

Information and education provided to the community and to patients on DM and DR:

1      2      3      4

<sup>1</sup> Key:

- 1 – Little information is provided to the community and little education to patients .
- 2 – Information to the community is provided occasionally and only through national-level media; not all patients receive education.
- 3 – Information is provided at national and provincial level; most patients receive education.
- 4 – Information is provided to the community at all levels; all patients receive education and patients' organizations are actively involved.

*Additional information for Section 6*

## HEALTH FINANCING

42. How are interventions for people with diabetes financed?

Activity	% of cost funded by government	% of cost funded by private insurance	% of cost funded by patient (out-of-pocket)	% of cost funded by NGO	% of cost funded by others (please specify)
Medical treatment					
Hospital treatment					
Medications					
Laboratory tests					
Other:					

43. How are interventions for people with diabetic retinopathy financed?

Activity	% of cost funded by government	% of cost funded by private insurance	% of cost funded by patient (out-of-pocket)	% of cost funded by NGO	% of cost funded by others (please specify)
Prevention (retinal screening)					
Laser photocoagulation					
Vitreoretinal surgery					
Other:					

*Additional information for Section 7*

## PEOPLE WHO PARTICIPATED IN THE ASSESSMENT

NAME

POSITION/ORGANISATION

EMAIL









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