World Health Organization
REGIONAL OFFICE FOR Europe

Diabetic retinopathy screening in the WHO European Region: current situation

A survey of professional associations and key informants

Preliminary findings for consultation

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Disclaimer: these are preliminary findings, if you have comments, please contact us: euncd@who.int.

Design: Charlotte Allen.

Contents

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The report was written by: Deborah M. Broadbent, University of Liverpool, United Kingdom; Sue Cohen, WHO Regional Office for Europe; Simon P. Harding, University of Liverpool, United Kingdom; Tunde Peto, Queen's University Belfast, United Kingdom; Pilar Vazquez-Arango, University of Liverpool, United Kingdom; Maria Lasierra Losada, WHO Regional Office for Europe; and Jill Farrington, WHO Regional Office for Europe.

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Acronyms

CME	continuing medical education
DR	diabetic retinopathy
EU	European Union
EU13	members of the European Union after 2004
EU15	members of the European Union before 2004
GP	general practitioner
HICs	high-income countries
LMICs	low- and middle-income countries
OOP	out-of-pocket (payments)
SLB	slit-lamp biomicroscopy
UoL	University of Liverpool
anti-VEGF	anti-vascular endothelial growth factor

Executive summary

WHO recommends diabetic retinopathy (DR) screening, alongside prompt treatment for those who need it, as an effective intervention for all people with diabetes to prevent vision impairment and blindness. DR nevertheless remains a leading cause of vision impairment and blindness across the WHO European Region, with an estimated 950 000 people affected.

The WHO Regional Office for Europe commissioned the University of Liverpool, United Kingdom, to carry out a situational analysis of DR screening in the 53 Member States of the WHO European Region. Of these, 34 are classified as high-income countries/regions (HICs) and 19 are low- and middle-income countries (LMICs), according to the World Bank lending group classification *(1)*.

Views were sought from national professional associations of ophthalmologists and diabetologists, allowing the perspectives of selected organizations and individuals to be gauged rather than those of the national or regional ministry of health.

A survey tool was designed to cover three main areas: organization of screening within a country/region, plans to develop screening in the future, and barriers and facilitators for achieving success. Responses were analysed using quantitative and qualitative techniques. This report covers the findings from responses to the survey on the current situation in each country/region.

Respondents from 45 of the 53 Member States returned surveys. One Member State returned four surveys, one from each of their devolved administrations, so in total, 48 surveys were analysed. It was not always possible to interpret and analyse responses.

Key findings include the following.

- There is evidence of some screening taking place in most countries/regions, with varying degrees of organization.
- Eight respondents reported running systematic[1] DR screening country-/region-wide. Five stated that they had some systematic screening either in a region or a part of their health system, but systematic screening was not available for all people with diabetes. Two respondents stated that their country is in the process of rolling out systematic screening.
- Most respondents (45 of 47 providing information on this point) indicated that ophthalmologists delivered screening wholly or in part in their country/region. Sixteen stated that ophthalmologists were the only professional group involved in screening.
- Surveys from countries/regions with systematic screening in place predominantly reported that technicians, nurses and optometrists undertook screening using retinal photography.
- Six respondents indicated they had a complete list of all people with diabetes in their country they can use for invitations, call–recall and monitoring of screening coverage.
- Seventeen could not provide any information on DR screening coverage or uptake.
- Most ophthalmologists (29 of 36 providing information) received their training for assessment and treatment of DR as part of their primary professional training and then through continuing medical education.
- Many respondents (26 of 48) reported that access to all modalities of treatment was good, but seven indicated that access to treatment including laser was limited.

It was notable that being in a HIC did not necessarily lead to more systematic approaches to screening. Of the 29 HICs in

[1] For a definition of systematic screening, please refer to the main text.

the WHO European Region from which respondents returned surveys, 12 did not have a call–recall system, 15 reported that they did not have any form of quality assurance or audits in place, and 10 said they did not provide patient information leaflets.

This survey provides an important insight into how DR screening is being carried out across the WHO European Region from the perspective of professional organizations and key informants. Although the survey has some limitations, the high response rate enables a picture of what is happening in most Member States in the Region to be obtained.

In summary, this situational analysis demonstrates that there is much countries in the WHO European Region can do to improve the effectiveness of DR screening. By acting, they may reduce the burden of vision impairment and blindness due to DR in their countries.

Reference

World Bank country and lending groups. In: World Bank [website]. Washington (DC): World Bank; 2020 (https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups, accessed 16 December 2020).

Introduction

WHO recommends diabetic retinopathy (DR) screening for all people with diabetes as an effective intervention in tackling a major noncommunicable disease and in prevention of blindness *(1).*

The WHO Regional Office for Europe has developed operational advice for screening and has produced a short guide for policy-makers on screening for various conditions throughout the life-course *(2)*. Building on this general guide, *Diabetic retinopathy screening: a short guide* was published in November 2020 for policy-makers, public health leaders and senior clinicians *(3)*. The guide describes how to improve the effectiveness of DR screening by moving from an unorganized to a more systematic screening approach using the principles of screening as laid out by Wilson & Jungner *(4)* and applying a pathway approach.

The WHO Regional Office for Europe commissioned the University of Liverpool (UoL), United Kingdom, to produce a situational analysis of DR screening provision and capacity plans across Member States of the WHO European Region. The UoL team had been involved in earlier surveys of DR screening conducted under the auspices of a European-wide interest group first established in 2005 *(5).*

The purpose of the situational analysis is to describe the current status of DR screening in the WHO European Region by seeking the perspectives of ophthalmology and endocrinology professional organizations in Member States. It is designed to identify trends and particular approaches to DR screening that may be helpful in informing policy-makers, senior clinicians, public health leaders, professional and patient associations, and other stakeholders involved in planning, designing and implementing DR screening.

Methodology

The survey was designed to be completed by respondents from professional associations from each Member State of the WHO European Region.

Information for the situational analysis was collected using a survey tool. Additional demographic data were obtained from the WHO Regional Office for Europe European Health Information Gateway *(6).*

The survey instrument was developed by UoL in collaboration with WHO and is based on previous surveys undertaken by the UoL team *(5)*. Questions were designed to cover three main areas: organization of screening within a country/region, plans to develop screening in the future, and barriers and facilitators for achieving success. Respondents were also asked to provide copies of relevant screening policies, clinical guidelines and relevant patient information leaflets.

A list of professional organizations for ophthalmology and diabetes in each country/region was drawn up. A letter was sent by the research team to the professional organizations where these could be identified. Each organization was asked to nominate an ophthalmologist and a diabetologist to complete the survey instrument. Where no professional organizations could be identified, the Regional Office contacted the WHO country offices and/or ministries of health to identify the most appropriate person to respond to the survey.

Responses therefore largely reflect the perspectives of nominated organizations/individuals rather than national/regional ministries of health. The survey tool and responses were in English.

Survey responses were divided into the three topics: current situation, future plans, and barriers and facilitators for success.

Data describing the current method of screening were coded and extracted into an Excel spreadsheet. Responses were coded using an iterative process to ensure consistency. Screening terms were aligned to definitions used in the Regional Office publication *Screening programmes: a short guide (2).* Data were structured according to the four-domain framework described in *Diabetic retinopathy screening: a short guide (3).*

Narratives describing future plans, barriers and facilitators were analysed using a qualitative thematic framework. Findings from these two components will be synthesized and presented in a separate report.

Countries were grouped according to gross national income World Bank criteria *(7)* and recognized political grouping (such as membership of the European Union (EU)) to identify any trends among country responses.

The situational analysis questionnaire is shown in Annex 1, classification of Member States in Annex 2, and participating countries and respondents in Annex 3.

Results

Response to survey

There are 53 Member States in WHO European Region. Respondents from professional associations of 43 Member States returned a completed survey questionnaire. The survey was returned by the ministry of health for two countries (Turkmenistan and Uzbekistan). Eight Member States' professional associations or ministries of health (Belarus, Estonia, France, Iceland, Kazakhstan, Monaco, North Macedonia and Romania) either did not respond to requests or said they could not complete the survey.

The United Kingdom submitted four surveys, one from each of the four devolved administrations: England, Northern Ireland, Scotland and Wales.

Responses therefore were received from 45 Member States, with 48 surveys analysed. Results are presented using the number of submitted surveys as the denominator (48).

Of the 45 Member States that submitted surveys:

- 29 are high-income countries/regions (HICs) and 16 are classified as low- and middle-income countries (LMICs);[2]
- 14 were members of the EU before 2004 and are considered as part of the EU15 group,[3] 11 joined after 2004 and are categorized as the EU13 group (see Annex 2);
- nine belong to the Commonwealth of Independent States grouping; and
- five are members of the South-eastern Europe Health Network.

General observations and limitations on survey responses

There was considerable variation in the way respondents completed the survey. Some provided additional detail and supporting documents, others gave short responses. Sometimes, lack of detail made it difficult to determine how screening was being carried out, although responses to questions about future plans occasionally shed light on current circumstances. In some cases, the survey was completed by more than one person, with different perspectives or answers being provided. This was noted where relevant.

Some survey respondents indicated they could only respond for their hospital or region and could not provide information for the whole country. In these circumstances, this limitation was noted.

Some respondents left questions blank. It was not possible to know whether they did so because they could not answer, did not know the information requested, or had missed the question(s) out. In other cases, answers were unclear or difficult to interpret. In all such circumstances, "No clear response" was recorded for data-extraction purposes. Where respondents replied that they did not know, "Not known" was recorded.

The questionnaire was circulated in English only and required responses in English or Russian. Two submissions were translated from Russian, all others were in English. It was recognized that this was a limitation, as respondents' understanding of the question or their ability to express detail in English may have affected their ability to answer some questions.

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[2] A more detailed income-level classification for LMICs is provided in Annex 2, Table A2.1.

[3] The United Kingdom was not a member of the EU at the time of the survey (2020) but had been a member of the EU before 2004, so is considered as part of the EU15 group for the purposes of this report.

Main findings and interpretation of results

Screening programme design

This section provides information on important design features of screening in countries/regions.

Systematic versus unorganized screening

Screening programmes: a short guide (2) describes how the design of a screening programme profoundly influences its effectiveness. The guide contrasts unorganized with organized or systematic screening. Features of organized or systematic screening that are relevant to DR screening are:

- a pathway is in place, rather than the test being carried out in isolation;
- the test is offered to an identified cohort of people with diabetes at an agreed interval based on a register or list, rather than ad hoc offers being made or relying on individuals to request a test;
- the pathway is governed by protocols and guidelines;
- there are quality standards based on evidence that service providers follow; and
- the screening pathway is supported by an information system that can monitor performance.

For the purposes of this report, systematic or organized screening is defined as DR screening that has these five components in place. Survey responses that provided information on these components were used to categorize a country's/region's approach as systematic or unorganized (Annex 1 lists the questions used).

Eight respondents (from Finland, Ireland, Spain, Sweden, and United Kingdom (England), United Kingdom (Northern Ireland), United Kingdom (Scotland) and United Kingdom (Wales),[4] which are all HICs and members of the EU15)[3] provided evidence that country-/region-wide systematic screening was in place. Seven respondents (from Belgium, Denmark, Georgia, Germany, the Netherlands, Portugal and the Russian Federation) stated that some systematic screening was occurring either in a region or part of the health system. For example, five (from Belgium, Denmark, Georgia, Germany and the Netherlands) stated that systematic screening was offered if patients were referred to a hospital, used insulin or were enrolled in a management programme for people with diabetes. In all such cases, this did not cover all people with diabetes; in some, systematic screening covered only a minority of people with diabetes in a country. Two respondents (from Malta and Slovenia) reported that systematic screening was in the process of being rolled out across the country, and one (from Norway) that plans for a systematic DR screening programme had been agreed and a pilot should be starting shortly.

Of the eight respondents reporting that they had systematic country-/region-wide screening in place, all except one (from Sweden) reported using digital retinal cameras to screen, with either non-clinical trained technicians, nurses or general practitioners (GPs) grading images. Sweden has an ophthalmologist-delivered service. Respondents reporting partial systematic screening or systematic screening being rolled out presented a mixed picture of some retinal camera use with technicians, and some ophthalmologist-delivered screening.

Two respondents (from Hungary and Israel) did not provide sufficient information to ascertain whether they had systematic screening in place either partially or countrywide. Of the remaining 28 surveys analysed, screening in the

[4] For convenience, hereafter referred to simply as England, Northern Ireland, Scotland and Wales.

country/region was considered to be unorganized. In all but one, screening is ophthalmologist-delivered. There is one exception (Italy), which has unorganized screening and a mixed approach of ophthalmologist-delivered DR and technicians using retinal cameras.

Frequency of screening

Of the 48 surveys submitted, 30 responses reported that screening is offered annually. One response (from Albania) reported that screening was done two yearly and another (Uzbekistan) that the country offered screening every five years. Nine respondents reported variable screening intervals depending on findings at screening. Five of these (from Armenia, Germany, Norway and Spain, and Scotland) described using two-yearly intervals for people with no DR and at least annual intervals for people with DR. Three responses reported extending the interval to three years for people with diabetes who had no DR, either type 2 diabetes and no DR (Finland and Sweden), or two consecutive examinations showing no DR (the Netherlands). Six respondents reported using factors other than retinopathy alone, including measures of glycaemic control (Austria, Denmark, Spain and Sweden), type (Denmark, Finland and Sweden) or duration of diabetes (Austria, Denmark and Israel). One response (from Denmark) reported being in the process of rolling out a personalized variable interval based on a risk-calculation algorithm that includes an interval of four years. Two respondents (from Greece and Turkmenistan) did not provide any information on screening intervals.

Resources and infrastructure

Screening test

Respondents were asked to indicate which tests were available to undertake screening. There was inconsistency in the way this question was answered. Some respondents appeared to indicate what was available, while others identified which test predominantly was used for screening. At times it was not clear whether a particular modality was widely available or could be accessed only in some parts of the country/region or, for example, just in the private sector. The question asked whether the test was available rather than whether capacity currently was adequate. Caution therefore must be taken in interpreting these results.

Of the 48 respondents:

- 14 (from Denmark, Finland, Ireland, Malta, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, and England, Northern Ireland, Scotland and Wales) indicated that retinal photography was the main method used for DR screening (notably, these respondents are all from HICs);
- 13 (from Albania, Austria, Azerbaijan, Bosnia and Herzegovina, Croatia, Georgia, Israel, Montenegro, Serbia, Slovakia, Tajikistan, Turkey and Uzbekistan) reported that slit-lamp biomicroscopy (SLB) was the predominant method used, although four of these respondents (from Albania, Azerbaijan, Israel and Turkey) reported that retinal photography was used but was not widespread (of these 13 respondents, nine are from LMICs);
- 18 indicated that all three modalities of direct ophthalmoscopy, SLB and retinal photography were available, but it was not possible to ascertain how much each test was being used or whether it was available across the country; and
- three (Greece, Luxembourg and Turkmenistan) did not provide information.

Direct ophthalmoscopy was reported as being in use in several countries and being used as an important method of screening in one (Ukraine).

Staffing

Respondents were asked about the number of ophthalmologists available and trained to treat DR. Some provided information on the total number of ophthalmologists in the country/region (at times distinguishing between private and public sectors), while others gave information on those who were medical retina specialists and trained to treat DR.

Twenty-nine respondents provided information on the total number of ophthalmologists working in the country/region. Results are presented as number of ophthalmologists per 100 000 population *(6)*. Countries/regions have been grouped based on their rate:

- four respondents (from Montenegro, Albania, Uzbekistan and England) had rates of fewer than 5 per 100 000 (England is part of a HIC);
- 14 had rates between 5 and 10 per 100 000 (10 are HICs (Andorra, Belgium, Croatia, Czechia, Finland, Germany, Hungary, Slovenia, Spain and Sweden) and four LMICs (Azerbaijan, the Republic of Moldova, Turkey and Ukraine);
- 10 had rates between 10 and 15 per 100 000 (eight are HICs (Austria, Cyprus, Lithuania, Luxembourg, Norway, Poland, Portugal and Switzerland) and two LMICs (Armenia and the Russian Federation); and
- one respondent, from a small HIC (San Marino), had a rate of 30 per 100 000.

Nineteen respondents provided information on the total number of ophthalmologists who were medical retina specialists or were described as being trained to treat DR:

- four (from Serbia, Tajikistan, Turkey and Uzbekistan) reported rates of fewer than 0.5 per 100 000 (these are LMICs);
- six (Georgia, Lithuania, the Republic of Moldova, the Russian Federation, and England and Wales) reported rates of between 0.5 and 1 per 100 000 (Lithuania is a HIC and England and Wales are part of a HIC; the other three are LMICs);
- three (Belgium, Cyprus and Croatia) reported rates of 1–1.5 per 100 000 (all are HICs);
- three (Denmark, Israel and Spain) reported rates of 1.5–2 per 100 000 (all are HICs); and
- three (Latvia, Malta and Portugal) reported rates greater than 2 per 100 000 (all are HICs).

Of the 48 surveys received, 45 responded that ophthalmologists carried out the screening examination. It appears, however, that this question may have been answered in different ways, with some respondents including ophthalmologists involved in management as well as assessment and treatment. No response was given for one country (Greece) and two respondents (from England and Wales) said ophthalmologists did not do DR screening. Sixteen reported that only ophthalmologists carried out screening and of these, five stated that only ophthalmologists were mandated to conduct screening in their countries (Albania, Croatia, Georgia, Montenegro and Poland).

Seventeen respondents said that endocrinologists also undertook screening. There was no clear pattern to which countries used endocrinologists in addition to ophthalmologists; of the 17 respondents, 11 were HICs, with a mix of EU15 and EU13 Member States.

Three surveys (from the Netherlands, Spain and Ukraine) reported GPs undertaking screening. In some cases (such as Spain), it appears that GPs have been trained to perform primary grading using retinal photography, while in others (such as Ukraine), they are using direct ophthalmoscopy.

All 14 respondents that reported using retinal photography as their main method of screening stated they used technicians, optometrists or nurses in some capacity either to take images or take and grade images.

Across all 48 respondents, 18 reported some use of technicians, 14 optometrists and four nurses.

There does not appear to be any relationship between the number of ophthalmologists per 100 000 population in each country/region and the use of technicians for screening.

Treatment

Respondents were asked to comment on access to laser, intraocular injections (anti-vascular endothelial growth factor (anti-VEGF) and steroids) and vitrectomy. Some confirmed that all treatment modalities were widely available, and others indicated that all or some of these treatment modalities were available but may not always be accessible for the whole population. Where respondents did not make qualifications or provide further detail, it was not possible to assess the availability or capacity of treatment services and results should be interpreted with caution.

Twenty-six surveys reported that they had comprehensive access to all three treatment modalities and did not remark on any problems with capacity; 25 of them are HICs and one (Turkey) is an LMIC.

Twelve surveys reported some problems with access to one or more of the treatments. Of the 12 responses, five were from HICs that are members of the EU13 (Croatia, Czechia, Greece, Poland and Slovenia) and seven (Albania, Armenia, Azerbaijan, Kyrgyzstan, the Republic of Moldova, Tajikistan and Uzbekistan) are LMICs, of which six are in the Commonwealth of Independent States.

Three surveys (from Armenia, Kyrgyzstan and Tajikistan) reported that treatments were limited and often required patients to pay out of pocket (OOP) for them. Another three (from Albania, Azerbaijan and Uzbekistan) reported problems with access to vitrectomy, three more (Albania, Azerbaijan and Poland) mentioned difficulty providing anti-VEGF, and one (Uzbekistan) cited difficulty in providing laser treatments. Respondents from five countries (Croatia, Czechia, Greece, the Republic of Moldova and Slovenia) reported long waiting lists for treatment which in some cases resulted in patients paying OOP to get treatment.

New technologies

Respondents were asked to comment on whether any new technologies, such as optical coherence tomography, automated grading and electronic data-transfer systems (including telemedicine and digital surveillance), had been introduced into screening. Some commented that it was available even if limited to, for example, a university hospital or as part of research, while others replied positively only if it was used routinely. The responses below indicate any use of new technology.

Twenty-eight of 48 respondents said optical coherence tomography was in use in their country/region. Some replied specifically, however, that it was available as part of a screening programme while others commented that it was used only for patients being managed for diabetic macular oedema; others did not specify how it was used. Of the 28 respondents, 18 are from HICs and 10 from LMICs.

Eleven respondents (from Armenia, Austria, Belgium, Finland, Latvia, the Netherlands, Norway, Portugal, Spain and Switzerland, and Scotland) reported some use of automated grading or artificial intelligence software. Terminology was not clear, so it is not possible to distinguish between these two types of technology from responses. These are all (or are part of) HICs, other than Armenia, an LMIC whose use of automated grading was made available as part of a donor-funded project.

Eight respondents (from Albania, Bulgaria, Denmark, Finland, Israel, Latvia, Norway and the Russian Federation) reported use of telemedicine, but again it was not clear exactly what respondents meant by telemedicine or how widespread was its use in the country.

Pathways

Policies and guidelines

Respondents were asked about national policies and clinical guidelines for DR screening and many provided links or full downloads. Some respondents gave examples of general policies for diabetes management that included references to DR screening, while others had specific policies for DR screening. When asked for policies, some respondents provided clinical guidelines from professional associations. Results below try to distinguish policies produced by a national or regional government from clinical guidelines produced by a professional association. Responses in some cases were not clear.

Twenty-six of 48 respondents reported that their country/region had a national policy covering some elements of DR screening. Eleven of these respondents (from Denmark, Ireland, Israel, Norway, Portugal, Slovenia and Sweden, and England, Northern Ireland, Scotland and Wales) had screening-specific policies in place. It is notable that apart from one country (Israel), these countries/regions have some form of systematic screening in place or under development. Two respondents (from Lithuania and Norway) said that their countries currently are developing a policy. The remaining 20 respondents said their country did not have a policy or did not answer the question.

Thirty-two of 48 respondents reported that their country/region had clinical guidelines. The scope included guidelines for diabetes as well as screening. Eight respondents (from Andorra, Azerbaijan, Czechia, Malta, Montenegro, Serbia, Tajikistan and Ukraine) said they had adopted clinical guidelines from other countries or international organizations, including the American Association of Ophthalmologists, the American Diabetes Association, the European Society of Retina Specialists, the International Council of Ophthalmologists, the Russian Federation and the United Kingdom.

Four respondents (from Croatia, Cyprus, Georgia and Greece) reported having neither national policies nor clinical guidelines for DR screening or management.

Identification and invitation of eligible cohort

The survey asked respondents about how people with diabetes were identified for screening, how they were advised to attend, and whether there was a formal call–recall system in place. Respondents were prompted to identify if registers were in use. These questions were answered in different ways, so accurately and consistently interpreting responses proved difficult.

Twenty-four respondents stated that all or some of their country/region had some form of call–recall system in place for some of the population. Of these, six appear to have complete lists of people with diabetes (Ireland and Malta, and England, Northern Ireland, Scotland and Wales). They reported that when a person was diagnosed with diabetes, it was automatically transferred to a list/register that generated letters to invite people for screening, and a call–recall system was in place. Although not explicitly stated in responses, the assumption is that a diagnosis of diabetes is coded to electronic medical records and this coding is used to generate a list or register that is used for a call–recall system for subsequent appointments.

Among other respondents in the group of 24:

- one (from Israel) appeared to have complete lists of people with a diagnosis of diabetes based on GP coding, with the GP expected to make the referral for patients to be screened, rather than using automatic call–recall systems;
- two (from Spain and Sweden) reported having near complete registers of people with diabetes, but it was not clear how this operated in relation to DR screening or whether there was an associated systematic call–recall system in place;

- four respondents (from Georgia, Germany, Portugal and Turkey) stated they used electronic records to identify people with diabetes and had call–recall in place for those who were identified, but the systems did not appear to pick up everyone who had a diagnosis of diabetes;
- 10 (from Armenia, Belgium, Denmark, Finland, Italy, the Netherlands, Norway, Poland, Switzerland and Uzbekistan) reported some form of call–recall system in place once people with diabetes had been referred for screening, based on registers held by endocrinology clinics, GPs or screening services, or some mix of these; and
- one respondent (from San Marino, which has a very small population) stated that a single diabetes clinic operated in the country and was used to ensure all people with diabetes undergo DR screening.

The remaining 24 respondents said that people with diabetes were identified by their GP or by endocrinologists (or both) and were then referred (verbally or by letter) to an ophthalmologist who would arrange screening. There were some examples of patients self-referring to an ophthalmologist, but no call–recall system was in place. Twelve of this 24 are HICs (Andorra, Austria, Croatia, Cyprus, Czechia, Greece, Hungary, Latvia, Lithuania, Luxembourg, Slovakia and Slovenia) and 12 are LMICs (Albania, Azerbaijan, Bosnia and Herzegovina, Bulgaria, Kyrgyzstan, Montenegro, the Republic of Moldova, the Russian Federation, Serbia, Tajikistan, Turkmenistan and Ukraine).

Two respondents (from Hungary and Kyrgyzstan) remarked that public awareness campaigns were in place to encourage people with diabetes to have their eyes checked, as other mechanisms to identify and invite them to attend screening were inadequate.

Quality of screening

Assuring quality

Seven respondents (from Denmark, Ireland, Portugal, and England, Northern Ireland, Scotland and Wales) reported that they had some form of quality-assurance system in place. All these countries/regions have systematic screening, either country-/region-wide or in part of the health system.

Nine respondents (from Azerbaijan, Belgium, Croatia, Finland, Malta, the Russian Federation, San Marino, Spain and Sweden) reported undertaking some form of audit, both ad hoc and regular.

Twenty-seven respondents, 15 of whom were from HICs, stated explicitly that they did not have any system in place to assess the quality of screening or testing.

Fail-safe system

The survey asked if there was a system in place to monitor if people attend and follow-up non-attenders (a fail-safe system).

Eleven respondents stated that they had a fail-safe system in place, including the eight respondents with country-/region-wide systematic screening plus three additional respondents (from Israel, Malta and Portugal). Five respondents (from Armenia, Poland, Slovenia, Switzerland and Turkey) reported having fail-safe systems in places such as individual hospitals, but not across all of the health system.

Twenty-three respondents stated that there was no fail-safe system in place. This included 11 from HICs, five of which (Belgium, Denmark, Germany, Italy and the Netherlands) are in the EU15 group.

Training and education

The survey asked what training and competence assessment systems were available for professionals, including technical personnel. Some respondents gave details of general training for residents in ophthalmology and others also provided details of continuous medical education (CME).

Some respondents gave details of training specifically designed for DR. This appeared predominantly to be for technicians or non-medical staff.

For the purposes of this report, responses have been analysed according to whether training and/or accreditation was part of general training and CME or whether the country/region had specific training and/or accreditation for DR screening.

Twelve respondents (from Armenia, Finland, Ireland, Malta, the Netherlands, Norway, Portugal and Spain, and England, Northern Ireland, Scotland and Wales) reported that they had specific training and/or accreditation in place for DR screening. These are all from HICs, with one exception (Armenia).

Twenty-nine of the 36 respondents providing a response indicated that training for DR screening was part of general training for ophthalmologists. Examples were provided of CME available for DR. Seven respondents did not provide any clear information on training and accreditation.

Equity

Access to DR screening

Eleven of 48 respondents (from Denmark, Finland, Ireland, Israel, Portugal, San Marino and Sweden, and England, Northern Ireland, Scotland and Wales) said they could provide accurate coverage statistics (the proportion of the eligible population that has been screened). Six of these provided the data (for Denmark, Ireland, Israel and Portugal, and England and Wales). Coverage reported by these respondents was between 62% and 75%. They are all from HICs.

Nineteen respondents provided an estimate of coverage. It should be noted that respondents sometimes indicated it was an estimate based on their personal experience, so numbers should be treated with considerable caution:

- four respondents (from Azerbaijan, Hungary, Slovenia and Poland) estimated that coverage was less than 30% of people with diabetes;
- six (Bulgaria, Croatia, Norway, the Russian Federation, Slovenia and Tajikistan) estimated that coverage was between 30% and 50%;
- four (Latvia, the Netherlands and Switzerland, and Northern Ireland) estimated that coverage was between 50% and 70%; and
- five (Belgium, Finland, San Marino, Spain and Sweden) estimated that coverage was greater than 70%.

Some respondents provided estimates of uptake (the proportion of those invited who are screened) and estimates of the proportion of people with diabetes who were invited to screening.

Of note is that 17 respondents did not provide any data. Of these, eight (from Andorra, Austria, Cyprus, Czechia, Greece, Lithuania, Luxembourg and Malta) are from HICs. One respondent (from Malta) said their system was under development and chose not to provide estimates.

Health literacy

The survey's exploration of support for health literacy was limited to one question about whether countries/regions had any eye leaflets for people with diabetes. Some respondents sent in examples, others said these were often locally produced, and others remarked that most information was available online.

The following reports on whether patient information leaflets were available.

Twenty-four respondents stated that patient leaflets were available: 18 respondents were from HICs, and six were from LMICs (Albania, Armenia, Azerbaijan, the Republic of Moldova, the Russian Federation and Turkey).

Sixteen respondents, 10 of which were from HICs (Andorra, Croatia, Cyprus, Latvia, Malta, the Netherlands, Poland, San Marino, Slovakia and Sweden) stated there were no eye leaflets for people with diabetes.

Operational infrastructure

Financing

Respondents were asked to complete a table indicating the funding source for screening, call–recall system and treatment. They were also asked to indicate whether the patient was expected to contribute either through a co-payment or by OOP payments.

Funding systems were categorized as either publicly funded from central or devolved government, insurance-based (either social or private insurance) or OOP. It should be noted that health system funding can be complex, and some systems have multiple sources of funding; this categorization therefore may be a simplification of actual systems. If co-payments were required, this was recorded. Some respondents indicated whether certain treatments, such as anti-VEGF injections, were excluded from publicly funded or insurance schedules. This also was noted.

Responses were sometimes difficult to interpret, as some respondents appeared to indicate what should happen (for example, screening or treatment should be publicly funded), while others seemed to describe what actually happened (such as people choosing to pay OOP because of long waiting lists or difficultly accessing treatment). Results should therefore be interpreted with caution.

Twenty-seven respondents indicated that DR screening in their country/region was paid from public funds. Six of these respondents (from Albania, Andorra, Cyprus, Latvia, Norway and Sweden) said that patients made some form of co-payment. Five of the 27 (from Armenia, Greece, Hungary, Poland and Tajikistan) reported that patients sometimes made an OOP payment to obtain screening. Twenty-one of the 27 respondents were from HICs.

Sixteen respondents reported that DR screening predominantly was funded through health insurance. Six of the 16 (from Belgium, Croatia, Czechia, Georgia, the Netherlands and Switzerland) reported that patients also needed to make a co-payment, and two of the 16 (from Bulgaria and the Republic of Moldova) indicated that some patients made OOP payments to access screening. Respondents from two countries (Kyrgyzstan and Uzbekistan), both of which are LMICs, stated that screening was available only if patients paid OOP.

Twenty-two respondents indicated that treatment for DR was funded from public funds. Four of these (from Andorra, Cyprus, Latvia and Norway) stated that co-payments were required, and three (from Greece, Hungary and Poland) that some patients made OOP payments to obtain treatment.

Twenty respondents stated that treatment for DR was funded through insurance. Of these, four (from Belgium, Georgia, the Netherlands and Switzerland) required co-payments. Seven respondents (from Albania, Armenia, Bulgaria, Croatia, the Republic of Moldova, Serbia and Ukraine, six of which are LMICs) indicated that patients made OOP payments to obtain treatment when insurance was not available.

Three respondents (from Kyrgyzstan, Tajikistan and Uzbekistan, all of which are LMICs) stated that the only way to obtain treatment was to pay OOP.

Discussion

The response rate to the survey across the WHO European Region was high, with professional organizations from 45 of 53 Member States providing information on the current position of DR screening in their country. Further findings from the survey, examining how countries are planning for the future and what barriers and facilitators they encounter in taking forward DR screening, will be reported at a later stage.

Any future surveys on this topic would benefit from considering how varied responses have been and how best to capture the complexity of DR screening in different countries/regions.

Although there have been limitations on what can be inferred from some of the data because of inconsistencies in the way the survey was answered, it is still possible to draw meaningful and useful conclusions.

There is wide variability in the way screening is carried out across the Region. This may in part be due to lack of direction from policy-makers. Although respondents from most countries/regions reported some kind of clinical guidelines that covered DR screening, many (20) were unable to point to national/regional policy documents that addressed DR screening.

Few respondents (eight) provided evidence that DR screening was carried out systematically country-/region-wide. Some indicated that systematic screening was in place in part of their health system or for some people with diabetes, but it was not universally available. The few countries/regions that run systematic screening are all HICs that predominantly use retinal photography and technicians to undertake screening.

Much screening in the WHO European Region appears to be unorganized and relies on ad hoc referrals of people with diabetes to ophthalmologists for their eyes to be tested.

Retinal cameras are available in most countries/regions, but SLB appears to be in widespread use as a method of screening across the Region.

This lack of systematic screening and an inability to identify people with diabetes for screening means that few respondents from countries/regions (11) were able accurately to monitor the proportion of people with diabetes who were being screened. Without this basic information, it will be difficult for policy-makers to design, implement and monitor the effectiveness of future DR screening programmes.

It was notable that income level did not determine the extent of organization or systems in place to provide effective DR screening. Respondents from many HICs reported lack of organization, with those from 12 HICs not having a call–recall system, 15 reporting that they did not have any form of quality assurance or audits in place, and 10 that they did not provide patient leaflets. Of the 16 responses received from respondents in LMICs, six provided evidence of some systems being in place to identify people with diabetes and moves towards a more systematic approach to screening being underway.

In summary, this situational analysis demonstrates that there is much that countries/regions in the WHO European Region can do to improve the effectiveness of DR screening and, by doing so, reduce the burden of vision impairment and blindness across the Region.

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Annex 1. Situational analysis questionnaire

Diabetic Eye Screening – a Situational Analysis for the WHO European Region

Country/reigon	Income	EU Group[a]	Other group
Albania	Upper middle income	NA	SEEHN
Andorra	High income	NA	–
Armenia	Upper middle income	No	CIS
Austria	High income	EU15	–
Azerbaijan	Upper middle income	NA	CIS
Belarus	Upper middle income	NA	CIS
Belgium	High income	EU15	–
Bosnia and Herzegovina	Upper middle income	NA	SEEHN
Bulgaria	Upper middle income	EU13	–
Croatia	High income	EU13	–
Cyprus	High income	EU13	–
Czechia	High income	EU13	–
Denmark	High income	EU15	Nordic
Estonia	High income	EU13	–
Finland	High income	EU15	Nordic
France	High income	EU15	–
Georgia	Upper middle income	NA	–
Germany	High income	EU15	–
Greece	High income	EU15	–
Hungary	High income	EU13	–
Iceland	High income	NA	Nordic
Ireland	High income	EU15	–
Israel	High income	NA	SEEHN
Italy	High income	EU15	–
Kazakhstan	Upper middle income	NA	CIS
Kyrgyzstan	Lower middle income	NA	CIS
Latvia	High income	EU13	–
Lithuania	High income	EU13	–
Luxembourg	High income	EU15	–

Country/reigon	Income	EU Group[a]	Other group
Malta	High income	EU13	–
Monaco	High income	NA	–
Montenegro	Upper middle income	NA	SEEHN
Netherlands	High income	EU15	–
North Macedonia	Upper middle income	NA	SEEHN
Norway	High income	NA	Nordic
Poland	High income	EU13	–
Portugal – Central Region[b]	High income	EU15	–
Republic of Moldova	Lower middle income	NA	CIS
Romania	High income	EU13	SEEHN
Russian Federation	Upper middle income	NA	CIS
San Marino	High income	NA	–
Serbia	Upper middle income	NA	SEEHN
Slovakia	High income	EU13	–
Slovenia	High income	EU13	–
Spain	High income	EU15	–
Sweden	High income	EU15	Nordic
Switzerland – Lausanne[b]	High income	NA	–
Tajikistan	Low income	NA	CIS
Turkey	Upper middle income	NA	–
Turkmenistan	Upper middle income	NA	CIS
Ukraine	Lower middle income	NA	CIS
United Kingdom[c]	High income	EU15[d]	–
Uzbekistan	Lower middle income	NO	CIS

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Please answer these questions consulting with other colleagues as needed to ensure the answers describe, as best you can, the current situation in your country. If data don't exist, we kindly ask you to please indicate this.

Your country's population

- Number of ophthalmologists available trained to treat diabetic retinopathy and maculopathy
- Number of people with diabetes-related blindness, where known (please provide source, e.g., blindness register, national organization supporting people with visual impairment/collecting data)

Current status of screening in your country

If your country has a federated or regional health system, please kindly describe any variation.

- Do you have national policies/frameworks/performance indicators/clinical guidelines on diabetic retinopathy screening/management? If so, please share their links or files (in original language if not available in English).
- How do you identify people who are eligible for screening (e.g., diabetes register, GP register, dispensing records)?
- How are people advised to attend for screening (formal written invitation, verbal recommendation, telephone invitation, patient request, informal, other – please describe)?
- Is there a formal call–recall system?
- Can you estimate what proportion of your diabetic population is invited for screening?
- What proportion of these attend for screening? How have you estimated this?
- Is there a system to monitor if people attend (fail-safe system)?
- What screening methods are available (indicate all that apply)?

Direct ophthalmoscopy		Optometrist	
Retinal photography		Technician	
Slit-lamp biomicroscopy		Endocrinologist	
		Ophthalmologist	

- What is the frequency of screening?
- Many countries recommend screening every year. Have you introduced longer intervals between screening (e.g., two years)? If so, is this risk-based (please identify risk factors used)?
- What systems do have in place to maintain the quality of the screening programme? Do you carry out audits of grading? Do you have any quality standards that you monitor?
- Do you have any clinical guidelines – if so, can you share?
- What training and competence assessment is available for professionals, including technical personnel? (Can you consider technicians, optometrists, ophthalmologists?)
- What access is there to treatments including laser, intraocular injections (anti-vascular endothelial growth factor, steroids) and vitrectomy?
- Have you have introduced any new technologies into screening, such as optical coherence tomography, automated grading, electronic data transfer systems (including telemedicine), digital surveillance?
- Do you have any eye-screening leaflets for people with diabetes? If so, can you share these with us?
- Who pays for screening – insurance, private, co-payment, central budget? Does the person with diabetes pay? Please complete table.

	Screening	Call–recall system	Retinopathy treatment
Insurance, private, co-payment, central budget, other			
Any patient contribution required? Yes/No			

Developing screening for the future

- What would be the ideal model for screening for diabetic retinopathy suitable for your country context?

- What are the principle requirements you need to develop your ideal national screening programme? What do you consider are the barriers to implementation at present?
- What has been your experience of engaging with health providers (commissioners, health insurance companies, private and public sector) and patients so far?
- How do you currently evaluate the success of your programme if you have one?
- What are your tips for success? Please tell us about some of the key achievements that you've had.

Questions used to assess whether screening was organized/systematic or unorganized

- Do you have national policies/frameworks/performance indicators/clinical guidelines on diabetic retinopathy screening/management? If so, please share their links or files (in original language if not available in English).
- How do you identify people who are eligible for screening (e.g., diabetes register, GP register, dispensing records)?
- How are people advised to attend for screening (formal written invitation, verbal recommendation, telephone invitation, patient request, informal, other – please describe)?
- Is there a formal call–recall system?
- Can you estimate what proportion of your diabetic population is invited for screening?
- What proportion of these attend for screening? How have you estimated this?
- What systems do have in place to maintain the quality of the screening programme? Do you carry out audits of grading? Do you have any quality standards that you monitor?
- Do you have any clinical guidelines – if so, can you share?

Annex 2. Classification for Member States of the WHO European Region

Table A2.1 shows the classification used in the survey for Member States.

Table A2.1. Classification used in the survey for Member States

Table A2.1 contd

EU: European Union.
NA: not applicable.
[a] EU15: Member of the EU before 2004; EU13: Member of the EU after 2004.
[b] Respondents answered questions for their region or hospital rather than providing a national perspective.
[c] The United Kingdom submitted four surveys, one from each devolved administration: England, Northern Ireland, Scotland and Wales.
[d] The UK was not a member of the EU at the time of the survey (2020) but is considered part of the EU15 group for this report.
Source: WHO Regional Office for Europe (2020). Health for All explorer. In: European Health Information Gateway [online database]. Copenhagen: WHO Regional Office for Europe (https://gateway.euro.who.int/en/hfa-explorer/, accessed 16 December 2020).

The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

Member States

Albania
Andorra
Armenia
Austria
Azerbaijan
Belarus
Belgium
Bosnia and Herzegovina
Bulgaria
Croatia
Cyprus
Czechia
Denmark
Estonia
Finland
France
Georgia
Germany
Greece
Hungary
Iceland
Ireland
Israel
Italy
Kazakhstan
Kyrgyzstan
Latvia
Lithuania
Luxembourg
Malta
Monaco
Montenegro
Netherlands
Lithuania
Luxembourg
Malta
Monaco
Montenegro
Netherlands
North Macedonia
Norway
Poland
Portugal
Republic of Moldova
Romania
Russian Federation
San Marino
Serbia
Slovakia
Slovenia
Spain
Sweden
Switzerland
Tajikistan
Turkey
Turkmenistan
Ukraine
United Kingdom
Uzbekistan

World Health Organization Regional Office for Europe,
UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark
Tel.: +45 45 33 70 00 Fax: +45 45 33 70 01
Email: eurocontact@who.int Website: www.euro.who.int

Annex 3. Participating countries and respondents

Participating countries and respondents are shown in Table A3.1.

Table A3.1. Participating countries and respondents

Country	Respondent(s)
Albania	Julinda Jaho Mimoza Meco Florian Toti
Andorra	Miquel Álvarez Marfany Xavier Avellanet Viladomat
Armenia	Diana Andreasyan Naira Gogyan Nune Yeghiazaryan
Austria	Felix Aberer Sonja Karst
Azerbaijan	Mushfig Karimov
Belgium	Christophe De Block Werner Dirven
Bosnia and Herzegovina	Halida Basić Amina Godinjak Meliha Halilbašić Amra Nadarević Vodenčarević
Bulgaria	Alek Oscar Galateya Tsvetkova
Croatia	Dario Rahelić Martina Tomić
Cyprus	Andreas Kontos
Czechia	Terezie Pelikanova Tomas Sosna
Denmark	Toke Bek Jakob Grauslund Marit Jørgensen
Finland	Nina Hautala Henna Cederberg-Tamminen Paula Summanen
Georgia	Ana Apulava Elena Shelestova Lika Tsutskiridze
Germany	Hansjürgen Agostini Hans-Peter Hammes Klaus Lemmen Focke Ziemssen
Greece	Maria Niskopoulou
Hungary	Miklós Resch
Ireland	David Keegan
Israel	Irit Hochberg Gabriel Katz Naim Shehadeh
Italy	Roberto Perilli Massimo Porta
Kyrgyzstan	Nazgul Omurakunova
Latvia	Guna Laganovska
Lithuania	Vilma Jurate Balciuniene Edita Prakapiene
Luxembourg	Sandra Cardillo
Malta	Alastair Bezzina John Grech Hardie Mario Vella
Montenegro	Sreten Kavaric Emir Muzurovic
Netherlands	Yvonne de Jong-Hesse Reinier Schlingemann Erik Serné
Norway	Dag Fosmark Per Medbøe Thorsby
Poland	Elżbieta Bandurska-Stankiewicz Wojciech Matuszewski Sławomir Teper
Portugal	João-Filipe Raposo José Cunha-Vaz

Table A3.1 contd

Country	Respondent(s)
Slovakia	Viera Donicova Zbynek Schroner Jana Stefanickova
Slovenia	Mojca Urbančič
Spain	Rodrigo Abreu Iñaki Llorente Gomez Alicia Pareja Ríos
Sweden	Karl-Johan Hellgren Johan Jendle
Switzerland	Lazaros Konstantinidis Anne Wojtusciszyn
Tajikistan	Salomat Kasymova Hakim Karimzade
Turkmenistan	Ministry of Health
Turkey	Z. Sehnaz Karadeniz
United Kingdom	Sanjiv Banerjee Hamish Courtney Michael Gavin David Owens Tunde Peto Sam Philip Peter Scanlon John Wilding
Ukraine	Andrii Korol Yana Saienko
Uzbekistan	Ministry of Health