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Ageing

Leaving No Patient Behind: A 6 Country Scan on Diabetic Eye Disease Educational Materials and Treatment Options

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Introduction

Diabetes is potentially one of the most significant healthcare issues of our time, with wide-ranging social and economic implications for generations to come. Globally, the number of adults living with diabetes has quadrupled since 1980.(1) Currently, more than twice as many Canadians are living with diabetes than in 2000.(1) In 2021, ~2.9 million Canadians aged 20 to 70 years had diabetes and an estimated 6.1% lived with pre-diabetes.(2,3) Those living with diabetes are 25 times more likely to experience vision loss with an estimated 500,000 Canadians living with diabetes-related eye damage that can lead to blindness.(1)

Treatment options for diabetic eye diseases have changed dramatically in recent years as new therapeutics have emerged. Overall, however, there is limited patient education and resources on the available treatment options in Canada and more broadly.

Within an already fiscally constrained health system, there is an urgent need for Canadians at risk of diabetes-related vision complications to be educated and informed of available treatment options for common conditions, such as diabetic retinopathy (DR), diabetic macular edema (DME), cataracts, and glaucoma, all of which can lead to vision impairment or even blindness. There is a need for targeted messages and information for patients and their families concerning the management and access to safe, effective, and appropriate treatment options for their condition as it changes over time. Maintaining and improving the vision of Canadians through appropriate therapeutic interventions is a good return on investment for society across all ages.

The key objective of this study is to improve patient awareness and knowledge of the management and treatments for eye conditions associated with diabetes. The study analyzed patient educational materials related to diabetic eye diseases (DEDs) across six countries (Australia, France, Germany, Spain, Italy, and UK) with the aim of identifying elements of good practices, as well as potential gaps and barriers to successful uptake of the available materials. For each country, various information was obtained, including the key demographics, population living with diabetes, and vision health coverage across national/regional insurance plans. The study also identified the various treatment options for diabetic eye diseases, the availability of patient education materials and information, including the variety of organizations that develop and delivery these resource materials.

The Canadian Context

Healthcare in Canada is delivered through a publicly funded health care system, informally called Medicare.(4) It consists of 13 provincial and territorial insurance plans, which provide universal healthcare coverage to all Canadian residents. Coverage of vision care costs vary across different provincial healthcare plans.(5) Most provinces in Canada do not cover vision care unless the resident is either under the age of 18 or 65 years and older, after which routine eye examination fees are covered. Prescription contact lenses or eyeglasses recommended by an eye doctor are usually not covered by provincial insurance plans. An eye examination may however be covered for any age if it is deemed “medically necessary” (e.g., an eye disease, injury due to trauma, or a possible complication to the eye from a disease like diabetes).(5)

Treatment for diabetic eye diseases

Treatment options for Canadians with DME include laser therapy, intravitreal injections, and surgery. (6) Laser therapy is used when central vision is not involved. Intravitreal injections with anti-VEGF drugs are the first-line therapy in the management of centre-involving DME (i.e., where central vision is involved). Injectable steroids like triamcinolone, dexamethasone and fluocinolone are used as an alternate class of drug in the management of DME if anti-VEGF drugs do not work completely or stop working.(7) Depending on the province of residence in Canada, steroids may not be covered by public health insurance.

Patient education and information

Diabetes Canada

[Diabetes Canada](#) is a national charity whose vision is a world free of the effects of diabetes. The organization emphasizes the importance of eye exams and their roles in helping to detect DEDs quickly. The Diabetes Canada website provides comprehensive information on diabetes including the causes, types, management, and risks. Although there is information on diabetic retinopathy and diabetic macular edema and the available treatment options, this information is directed towards the health-care providers and not patient targeted.(6)

Fighting Blindness Canada (FBC)

Fighting Blindness Canada is Canada's leading private funder of vision research. The organization raises funds to support vision research and education across Canada. An array of patient education resources are available on the site "[Eye diseases](#)" including information on DR and DME, as well as the symptoms and treatment options – laser therapy, surgery, anti-VEGF and steroids.(7) These resources are available mainly in the form of texts with relevant diagrams and a short video to inform patients about DEDs and the complications.

Canadian Association of Optometrists (CAO)

The Canadian Association of Optometrists (CAO) is the national voice of optometry in the country. It is dedicated to collaboratively advancing the highest standard of primary eye care through the promotion of optimal vision and eye health, in partnership with all Canadians.(8)

Although the CAO website does not include information on DME specifically, there is some (very limited) information available on DR, its risk factors, and its treatment, however only laser therapy and intravitreal injections with anti-VEGF are mentioned as treatment options and no information is currently available on the use of steroids. The CAO also provides a short video on DR that mentions DME as a complication of DR. (9)

HealthLink BC

HealthLink BC is a government-funded telehealth service, which provides non-emergency health information and advice to the residents of British Columbia.

The site “[Diabetic retinopathy](#)” contains detailed patient educational information about DR, method of prevention, risk factors, causes, symptoms and treatments. Information on DME is also briefly provided, including the various treatment options – laser treatment, surgery, intravitreal injections with anti-VEGF and steroids.(10) This information is only available online in standard text form.

Summary

In 2021, ~2.9 million Canadians aged 20 to 70 years had diabetes and an estimated 6.1% lived with pre-diabetes. About 500,000 Canadians live with diabetes-related eye damage. If a person is diagnosed with DME, treatment options include laser therapy, intravitreal injections, and surgery.(6) Intravitreal injections with anti-VEGF drugs are the first-line therapy in the management of center-involving DME while injectable steroids like triamcinolone, dexamethasone and fluocinolone are used as an alternate class of drug in the management of DME if anti-VEGF drugs do not work completely or stop working.(7)

While there is substantial information on diabetic retinopathy in Canada, there is limited patient-targeted educational resources on diabetes macular edema and the available treatment options.

Australia

According to Diabetes Australia, the increasing prevalence of diabetes is the nation’s biggest challenge to the health system,(11) with around 1.5 million Australians (6.4%) aged 20-79 years living with condition in 2021.(12) Of those individuals, it is estimated that some 370,000 (25.0%) have undiagnosed diabetes.(12) In 2017-18, the prevalence of diabetes increased with age with rates of those aged 65-74 years being more than 3 times those 45-54 years.(13) On average, 1 out of every 3 people with diabetes are likely to have DR.(14)

In Australia, eye examinations are subsidized through a universal health insurance scheme known as Medicare.(15) The scheme ensures access to a wide range of health and hospital services at low or no direct cost to the individual.

Despite the importance of a proactive self-managed approach, about half of those Australians with diabetes do not have regular eye examinations because many are unaware of the threat of this disease to their vision.(14,16) In response to the low level of awareness, a new national diabetes eye screening program, called KeepSight, was developed by Diabetes Australia.(17) It is being promoted as a once-in-a-generation opportunity to prevent diabetes-related blindness by detecting problems early when they are treatable.(18)

The Australian Government Department of Health (DoH) has policies and programs in place to improve eye health services and prevent and treat eye conditions.(18) Informed by the Macular Disease Foundation Australia (MDFA), the DoH created the [National Strategic Action Plan for Macular Disease](#) in 2019 around the pillars of prevention and early detection; treatment; support; and data and research.(19) The DoH also funds the [Australian Eye and Ear Health Survey](#) following the 2016 national survey.(18)

Treatment for diabetic eye diseases

The entry point to the vision care pathway may start with an optometrist appointment or a referral from a general practitioner to an ophthalmologist. For individuals diagnosed with diabetes, regular eye examinations are recommended for early detection every two years, even if they are asymptomatic.⁽¹⁴⁾ Those with diagnosed diabetic eye diseases (DEDs), such as DME, are advised to have eye examinations at least once every year. ⁽²⁰⁾

Treatment options for Australians with DME include intravitreal injections and laser treatment.⁽²¹⁾ Intravitreal injections are the mainstay treatment, and the usual regime is injections of anti-vascular endothelial growth factor (anti-VEGF) which inhibits the growth and, in some circumstances, allows the restoration of vision. In certain situations, ophthalmologists may also use anti-inflammatory steroids.

Dexamethasone, a glucocorticoid, is approved for the treatment of DME in Australia and is subsidized under the Pharmaceutical Benefits Scheme (PBS). Dexamethasone injections can only be administered by an ophthalmologist skilled in intravitreal injections.⁽²¹⁾

Treatment with dexamethasone occurs through biodegradable, sustained release implants in a solid polymer drug delivery system.⁽²¹⁾ These injections are recommended at 6-month intervals in one eye at a time. There is no current evidence of efficacy or safety of repeat administrations beyond seven implants.⁽²²⁾ If this therapeutic intervention has not improved parameters for the patient, then treatment is discontinued.

Patient education and information

Accurate and up to date information for patients and families is a critical aspect of good eye health and care. In Australia several organisations lead in the development and delivery of general information, symptoms, diagnosis, and treatment of diabetes-related eye conditions.

Macular Disease Foundation Australia

The Macular Disease Foundation Australia (MDFA) is the national peak body representing the interests of 8.5 million Australians living with or at risk of macular disease and their families.⁽²³⁾ As leaders in prevention and early detection, disease management, advocacy, and research, the MDFA aim to reduce the incidence and impact of macular diseases.

Extensive evidence-based information on DEDs – ways to reduce risk, how conditions are diagnosed, the symptoms and treatment options – is available in both hard copy and through the MDFA website. Practical information for the patient, caregiver and family in the form of fact sheets on topics such as [reducing the risk of DED](#), [living with DED](#), [DME](#), and [eye injection](#) costs and rebates can be accessed for free and downloaded.

KeepSight

[KeepSight](#) is a diabetes eye screening program for Australians that encourages people with diabetes to have regular eye exams through specialized reminders and alerts. The program offers general [resources for patients](#) related to Vision health, including information on DR. However, there is no information on treatment options.

Center for Eye Research Australia

The [Center for Eye Research Australia](#) (CERA) is an independent medical research institute and an international leader in eye research that aims to support people affected by vision loss and protect the sight of everyone in need.

CERA offers a plethora of information on research areas, current clinical trials, industry and academic collaboration, and eye conditions. There are also, several [free guides](#) for patients and their families with essential information and research about certain eye conditions. [Information on DEDs](#), including DR and DME includes causes, symptoms, diagnosis, and treatment options.

HealthDirect

[Healthdirect](#) Australia is a national virtual public health information service. It provides free, evidence-based health information and advice that enables Australians to manage their health and well-being. The services help people navigate the broader health system and direct them to appropriate, context-specific healthcare. The services help people navigate the broader health system and direct them to appropriate context-specific healthcare. Searchable engines give access to topics based on symptoms or life stages (figure 1); medical advice and a “service finder” for relevant resources.



Figure 1- Healthdirect website where patients can search health topics in a variety of ways, such as through symptoms or life stages

There is information for patients on [DR](#) including cause, symptoms, diagnosis, treatment, and prevention of the condition.

Vision Initiative

Directed to health care providers, the [Vision Initiative](#) is funded by the Victorian State Government as a public health response to the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss. The Initiative is an integrated eye health promotion program managed by [Vision2020 Australia](#) and operates at the local and state level to promote the importance of regular eye tests by targeting health providers, community, and local media.

The Initiative provides recent information, training, and other resources to primary health care professionals. It also offers basic information to patients on [common eye conditions](#) and resources to support them in the management of certain conditions, including [DR](#).

Summary

In Australia, 1.5 million Australians (6.4%) aged 20-79 years lived with diabetes in 2021.(12) Of those with diabetes, an average 1 of every 3 is likely to develop DR.(14) Those diagnosed with diabetes are recommended to have eye examinations, at least once every two years to detect DR and DME.(14) If a person is diagnosed with DME, treatment options include laser treatment and / or intravitreal injections.(21) There are two types of medications that are commonly used; anti-VEGF medication and steroid implants. In Australia, dexamethasone is approved and is subsidized by the Pharmaceutical Benefits Scheme.(21)

Accurate and up to date information for patients and families is a critical aspect of good eye health and care. In Australia, several organisations lead in the development and delivery of general information, symptoms, diagnosis, treatment, and management information of diabetes-related vision changes. These include the Macular Disease Foundation Australia (MDFA), KeepSight, The Center for Eye Research Australia, HealthDirect, and the Vision Initiative.

France

In France, about 3.94 million adults (8.6%) had diabetes in 2021.(24) Of these, some 1.10 million people are living with undiagnosed diabetes, and 2.7% are affected by DR.(25) The prevalence of diabetes is increasing, particularly in men, people under 20 years of age, and those 80 years of age and over. (26) France has a rapidly ageing population, with older people projected to represent one-quarter of the population by 2025.(26) In terms of the health care burden, more than 1 in 4 people aged 75 years and over has diabetes in France.(26) In 2021, the nation was the 7th highest country in the world for health expenditures due to diabetes with a total diabetes-related health expenditure in adults aged 20-79 equalling USD 22.7 billion.(24)

The Ministry of Social Affairs and Health (Ministère des Solidarités et de la Santé) oversees the health system (which has both private and public arms) and is based on a holistic model that incorporates health, medico- social, and social components.(27) The objective is to prevent, treat, and support patients and residents in a comprehensive and continuous manner.(27) To meet these objectives, the public authorities act on a national, regional, and local level.

Starting in 2001, Public Health France (Santé Publique France) created a diabetes surveillance program to track the frequency, severity, and evolution of diabetes.(28) Along with the surveillance program, it conducts national studies on diabetes to better understand the needs and necessary follow-up required for people with diabetes in France.(28)

Treatment for diabetic eye diseases

The High Health Authority (HAS; haute autorité de santé) recommends that the optimum treatment for DEDs is prevention through regular visits to an ophthalmologist, achieving glycaemic balance, controlling blood pressure, and a “healthy lifestyle”.(29,30) When an individual is first diagnosed with diabetes, an ophthalmological exam is conducted that includes the measurement of visual acuity and the examination of the retina to detect early stages of DR.(30) Further examinations are recommended every 1 to 2 years, depending on the initial results.(30) If a person with diabetes experiences a sudden reduction in visual acuity, an emergency ophthalmological consultation is required.(30)

While the progression of DME can be well managed through the control of glycemia and blood pressure,(31) with advanced DME there are three main treatment options: laser treatment, intravitreal injections, or surgical treatment.(30) Laser treatment remains the reference treatment for individuals with significant DME, but this treatment does not improve visual acuity, but rather prevents it from worsening.(30,31) Treatment through intravitreal injection is via anti-VEGF medication or steroid implants in patients who have a vision acuity loss of $\leq 5/10$ consecutive and whom the management of diabetes has been optimized.(31,32) Finally, surgical treatment may be approved in some severe cases of DME.(30)

Anti-VEGF medications appears to be a first-line treatment when visual loss is associated with a diffuse form of DME or in the event of leaks near the centre of the macula.(31,32) There are two types of steroid implants approved for use: dexamethasone and fluocinolone acetonide.(31) Both treatments are in consultation with the patient and can require monthly follow-up, repeated intensively for several years.(33) Treatment using Dexamethasone can be considered a first-line treatment in patients who have had cataract surgery, for those where non-steroid treatment is not suitable, or there is a suboptimal response.(31)

Patient education and information

In France, patient education and information is focused on DR, rather than DME. However, it can be argued that the strong emphasis on prevention of DR may also impact the prevalence and early detection, management, and treatment of DME.

Fédération Française des Diabétiques

The Fédération Française des diabétiques (FFD) or the French Diabetics Federation, is an association of patients, at the service of patients, and lead by patients representing more than 4 million individuals with diabetes.(34) The mission of FFD is to inform, support, and prevent; to defend patients individually and collectively; and to support research and innovation.(34)

Resources, mainly in the form of text and videos, are available through the website to inform patients about diabetes and the complications, including DEDs.(35) For example, the video diabetic retinopathy and eye complications targeted to patients and their families explains in some detail not only the risks but also the importance of assessment and treatments. From the review, no educational material and resources were located on DME.

Syndicat National des Ophtalmologistes de France

The Syndicat National des Ophtalmologistes de France (SNOF), or the National Union of Ophthalmologists of France is the representative union of ophthalmologists - both public and private - working in metropolitan France and overseas.(36)

The SNOF provides videos and guides for patients on different eye diseases, including DR and DME. In addition the “encyclopaedia of sight” has specific sections on vision health, eye diseases, and treatment options.(37)

Le Guide de la Vue

Created by Cydonia d., an independent publishing company, Le guide de la Vue (figure 2) is a source of information for the general public that is dedicated to vision health, sight, optics and hearing.(38) Information on diabetic eye diseases in the form of short paragraphs and [blog posts](#) with relevant pictures and diagrams is available on the website. Information on diabetic eye diseases in the form of short paragraphs and blog posts with relevant pictures and diagrams is available on the website.



Figure 2 - The Vision Guide with information on Diabetic Retinopathy stages

Summary

In 2021, ~3.94 million adults (8.6%) had diabetes in France.(24) As France has a rapidly ageing population with older people projected to represent 25% of the population by 2025, the prevalence of diabetes is also increasing as more than 1 in 4 people aged 75 years and over has diabetes.(26) When an individual is first diagnosed with diabetes, an ophthalmological exam is planned to detect early stages of DR.(30) Depending on the results of this exam, subsequent examinations will be recommended every 1 to 2 years.(30)

In France, there is a strong emphasis on prevention, so first line of action is to achieve glycaemic balance and control blood pressure through a healthy lifestyle.(29,30) If an individual has advanced DME, treatment options include laser treatment, intravitreal injections, or surgical treatment are indicated.(30)

Patient education and information is focused on DR, rather than DME. Organizations with resources for patients, caregivers and families include the French Diabetics Federation, the National Union of Ophthalmologists of France, and the Vision Guide.

Germany

In 2021, there were some 6.2 million people (10%) in Germany with diabetes and of those, ~1.3 million people had been undiagnosed.(24) Germany ranks 4th in the world for total health expenditure due to diabetes, spending ~ USD 41.3 billion.(24) It is also estimated that the incidence of DR in patients with Type 2 diabetes is nearly 29.9%.(39)

The National Health Care Guidelines (NVL) developed by the German Medical Association (BÄK), the National Association of Statutory Health Insurance Physicians (KBV), and the Working Group of Scientific Medical Societies (AWMF) is a decision-making tool for the appropriate medical approach to special health problems within the framework of structured medical care.(40) The NVL publishes guidelines on many diseases, including diabetes and associated complications.

Treatment for diabetic eye diseases

The NVL makes specific management and treatment recommendations for eye health depending on whether the diagnosis is based on Type 1 and Type 2 diabetes.(40) Comprehensive eye examinations including that of the fundus are recommended for those with Type 1 diabetes and patients over 11 years of age or 5 years after initial diagnosis.(41,42) For Germans with Type 2 diabetes, the recommendation is an initial eye exam immediately following diagnosis.(41,42) Depending upon the results of this assessment regular eye check-ups are recommended at various intervals.

If a person with diabetes:

1. is at low risk of eye complications and there is no damage to the retina detected, check-ups are recommended every 2 years.
2. is at high risk of eye complication and there is no damage to the retina detected, check-ups are recommended every year.
3. has damage to the retina, check-ups are recommended annually or more frequently depending on the ophthalmologist's advice.(42)

In Germany, it is believed that an effective treatment for DEDs has two important parts: (1) diabetes management through the control of blood sugar and blood pressure which helps to prevent the development of retinal damage; and (2) screening for eye complications then management and treatment specifically by an ophthalmologist.(41,42) The nature of the treatment will depend upon the severity and progression of the DR. Laser treatment, intravitreal injections, and surgery are all approved for DEDs depending on the disease progression.

Anti-VEGF medications approved for use in Germany are the first line of treatment and have the potential to not only stop the deterioration of vision, but also to improve the vision.(41,42) In patients where the condition does not improve, steroid medications may be offered and will also be administered through an intravitreal injection.(41,42) The dexamethasone implant is approved for patients with DME who have visual impairment and have had cataract surgery and / or have not responded to other treatment options. The fluocinolone acetonide implant is approved for patients with vision impairment and chronic DME who have not responded to other treatment options.

Patient education and information

The German Diabetes Aid

The German Diabetes Aid (DDH; Deutsche Diabetes Hilfe) is an organization that advocates for people with diabetes, their families, and individuals at risk of developing diabetes. Helping to influence and shape policy to improve quality of care through early detection and expansion of research, and the implementation of a national diabetes plan is a core mechanism.(43) The organization also offers various resources such as a guide to preventing eye diseases, brochures, and printouts with information on diabetes and the steps needed to maintain personal health and well-being. Other materials explain treatment options at different stages of the disease.(44)

The German Diabetes Society

The German Diabetes Society (DDG; Deutsche Diabetes Gesellschaft) is a medical and scientific society that focuses on the research, therapy, and prevention of diabetes. While services and advice from physicians, non-medical specialists, and actors from civil society is available on the website, the Society is not a patient organization.(45)

In addition to scientifically tested information, there is information on the diabetes health passport, practices and clinics with the DDG seal of approval, and advice and support from associations and like-minded individuals.(46) However, there is a lack of information on DEDs.

The Diabetes Health Passport

Created as a collaboration by the German Diabetes Aid the German Diabetes Society, the [Diabetes Health Passport](#) is a guide for individuals with diabetes to keep track of medical appointments (figure 3).

The Passport includes information on common complications, such as DR, and encourages individuals to attend regular check-ups to prevent such complications. There is no specific information on treatment options for DEDs.

“Diabetes - Damage to the Retina: Prevent and Treat” Patient Guideline

The recommendations of the NVL for the prevention and therapy of retinal complications of diabetes are illustrated in the patient guidelines.(42)

This guide aims to help patients and their families gain a deeper understanding of how diabetes can affect their eye health by damaging their retina and the various lines of treatment available (figure 4) depending on the progression of the DR.



Figure 3 - The diabetes health passport, created as a joint collaboration by the German Diabetes Aid the German Diabetes Society

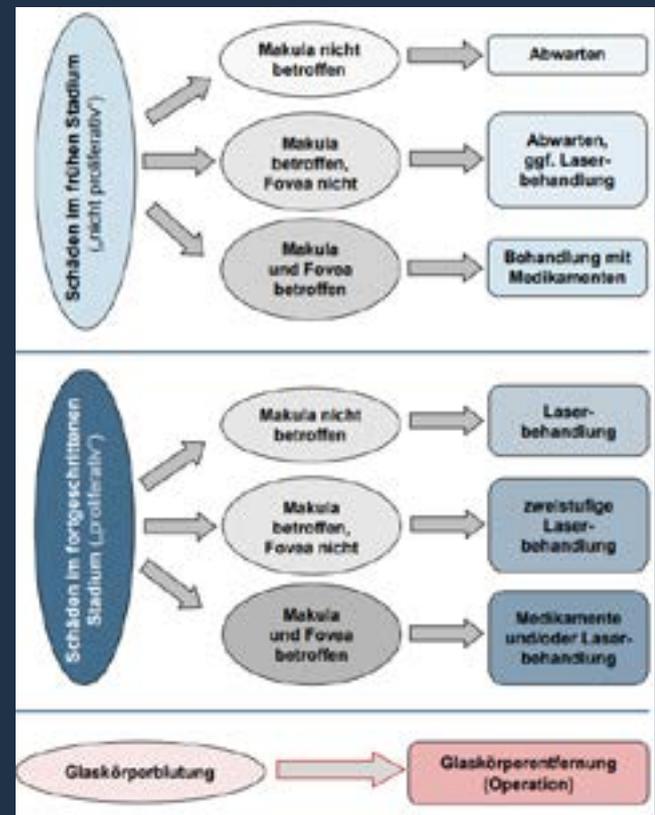


Figure 4 - The various lines of treatment depending on the progression of DR

Summary

An estimated 6.2 million people (10.0%) had diabetes in 2021 in Germany.(24) In patients with Type 2, the incidence is ~29.9%.(39) The NVL has different screening and treatment recommendations depending upon the type of diabetes.(42)

Effective treatment in Germany for individuals with DEDs starts with prevention and disease management.(42) Laser treatment, intravitreal injections, and surgery are all approved depending on the severity of the disease.

In Germany, there appears limited patient educational material on treatment options, yet resources available are very thorough such as the Diabetes – Damage to the Retina: Prevent and Treat Patient Guideline.(42)

Italy

In 2021, there were ~4.5 million adults (9.9%) aged 20-79 years with diabetes in Italy and of those cases, some 1.5 million people are undiagnosed.(2) Worldwide, Italy is one of the top ten countries with a high total health expenditure due to diabetes, spending an estimated USD 14.7 billion in 2021. (2) The diabetes-related expenditure per adult with diabetes aged 20-79 years was ~USD 3,280.80 in 2021. It is estimated that of those with diabetes, about 30% of them are affected by DR.(47)

To treat diabetes and related conditions, such as DEDs, the Diabetes Medical Association (AMD; Associazione Medici Diabetologi) and the Italian Society of Diabetology (SID; Società Italiana di Diabetologia) created the Italian Standards for the treatment of diabetes mellitus.(47)

The servizio sanitario nazionale (SSN; national health service) is a system of structures and services that aim to guarantee all citizens, in conditions of equality, universal access to the equitable provision of health services.(48) It is a public health care system that subsidizes medical care for Italian citizens and Italian permanent residents.

Treatment for diabetic eye diseases

To reduce the risk of DR and associated complications, the primary focus is on maintaining appropriate blood sugar levels and low blood pressure while being aware of potential complications, specifically nephropathy and changes in vision.(49)

At the time of diagnosis patients have a comprehensive eye examination to establish baseline data. (49) If retinopathy is not detected, patients are recommended to be assessed at least once every 2 years.(49) In the presence of a mild, non-proliferative retinopathy, the frequency of screening increases to every 12 months whereas if moderate, non-proliferative retinopathy is identified, then the patient is examined for changes every 6 months.(49) With advanced retinopathy, the frequency of screening will be determined between the patient and ophthalmologist.(49)

The primary treatments for DR and DME are laser treatment, anti-VEGF injections, and steroid injections. Anti-VEGF injections, which are reimbursed by the SSN, are approved in conjunction with laser treatment to improve health outcomes when recommended by an ophthalmologist.(49) Approved steroid medications (fluocinolone acetonide and dexamethasone) are used to treat DME when other available treatments have not proven effective.

Fluocinolone acetonide is administered as a single injection into the eyes.(50) It is also recommended to monitor these patients at least every 3 months to look for the appearance of complications, such as cataracts, due to the prolonged duration of the release of the medication.(50) Dexamethasone is used to treat adult patients with DME who have already undergone cataract surgery when other available treatments have not proven effective.(51)

Patient education and information

Diabete.it

Created by the Associazione medici diabetologi (AMD; association of Diabetologists), diabete.it is an online space dedicated to people with diabetes, their families, and all people involved or affected by diabetes.(52) It is intended to promote more efficient communication between patients and diabetes teams, providing people with scientifically verified information that has been elaborated and explained in simple language.(52)

The site provides general information about the maintenance of health, how to prevent diabetes, as well as the treatment options. There is limited information on diabetes complications, such as DR and DME.

“Detto Danoi” Watch out for diabetes

Created by Diabete Italia, “Detto Danoi – Watch out for diabetes: What do I really need to know about diabetic retinopathy” is a publication for people with diabetes on prevention, risk, and treatment of DR at various stages of the disease and is available on the Diabete Italia website.(49)

Agenzia Italiana del Farmaco (AIFA)

Detailed fact sheets are produced by AIFA for both patients and health care professionals on approved therapeutics medications which then form part of the consent process.(49,50) Information describes what the medication is used for, what patients need to know before being given the medication, method of administration, possible side effects, and how to store the medication.

Summary

In Italy, there were ~4.5 million adults (9.9%) aged 20-79 years with diabetes in 2021.(2) Of those with diabetes, about 1 in 3 are affected by DR.(47) Italian guidelines emphasize prevention and early detection in the management of DEDs. Laser treatment, and intravitreal injections (anti-VEGF and steroids) are approved treatments reimbursed by SSN.

Although there are limited patient educational resources on treatment for DME, the resources that do exist are comprehensive. The “Detto Danoi – Watch out for diabetes: What do I really need to know about diabetic retinopathy” publication in particular is a useful tool for any person that has been diagnosed with diabetes. It has information ranging from recommendations for individuals with an initial diagnosis to those with advanced DR and DME.(49)

Spain

In 2021, there were ~5.1 million adults (10.3%) in Spain with diabetes and a further 1.56 million that were undiagnosed.(53) Since 2019, diabetes has increased by 42%.(53) Diabetes disproportionately affects older adults, affecting 21.29% of those aged 65 years of age and over.(54) After 75 years of age, there is the sharpest increase in cases with almost 1 in every 4 people having diabetes.(54)

In Spain, the National Health System (SNS; Sistema nacional de salud) subsidizes health services. Every person with Spanish nationality and foreigners who have established their residence in Spain can access health care. (55)

The SNS released a Diabetes Strategy in 2006, which was updated in 2012. No further updates appear available. This strategy has the general objective of halting and reversing the trend in the incidence of diabetes in Spain, improving the quality of life of patients, and reducing mortality from diabetes.(56) Recommendations include diabetes screening of populations at risk and promoting accessibility of healthcare services for early detection of DR and prevention of blindness.(56) To collect information on the prevalence of diabetes, the SNS Diabetes Strategy uses data from the National Health Survey of Spain (ENSE; Encuesta nacional de Salud España) and the European Health Survey in Spain (EES; Encuesta Europea de Salud en España).(56)

Treatment for diabetic eye diseases

According to the Spanish Ministry of Health, regular preventative examinations are a fundamental part of an effective diabetes treatment plan and includes regular, periodic eye examinations.(57) Adults with diabetes are recommended to visit an ophthalmologist and at the time of diagnosis to have an eye examination of the fundus for early detection of DR and DME.(57,58) Depending on the results of the initial eye examination assessments every 1 to 2 years are recommended.(58)

The most common cause of vision loss in adults with diabetes is DME. Treatment decisions are based on the progression of the disease. For patients with no changes in visual acuity and without central involvement, laser therapy is recommended.(59) Conversely with decreased visual acuity and central involvement, intravitreal injections are recommended, of which there are two main therapeutic interventions, anti-VEGF and steroids. (59) In more severe cases, surgical treatment through vitrectomy should be considered.(59)

The use of anti-VEGF medications is approved in Spain and financed as a treatment option for DME and involves several consecutive injections administered monthly, until vision acuity is maximized. (60) For patients who are not suitable for or have an insufficient response to anti-VEGF medications, there are two approved steroid medications.(59) Dexamethasone is administered as an intravitreal implant that releases the medication over a period of 4 to 6 months.(61) If other treatments are considered insufficient, the fluocinolone acetonide implant can be administered as a third line of treatment for chronic DME.(61)

Patient education and information

Sociedad Española de diabetes (SED; Spanish Society of Diabetes)



Figure 5 - An article from FSED's "Diabetes" magazine, which is intended to share recent scientific, medical, and care advances with people with diabetes, their families, and the public.

The Spanish Society of Diabetes (SED) is a non-profit organisation with the goal of improving the hope and quality of life of patients with diabetes.(62) SED created a Foundation (FSED) that offers general information about diabetes, and factsheets for patients including eye care. Information is not available on eye complications such as DME.(58)

The Foundation also publishes a magazine bimonthly (figure 5) with the most recent scientific, medical, and care advances related to diabetes for people with diabetes, their families, and the general public.(63)

The Hospital Clínic de Barcelona

The Clínic de Barcelona is a leading public health centre with a desire for excellence in its three main action areas: care, research, and training.(64) Detailed information in various forms (e.g., infographics, videos and written descriptions) is available on diabetes and its complications including [DR and DME](#). For DR and DME, a description of the disease, diagnosis, treatment options, disease evolution, how to live with the disease, and current research is presented.(65)

Sociedad Española de Retina y Vítreo (SERV)

The Spanish Society of the Retina and Vitreous (SERV; Sociedad Española de retina y vítreo) is a non-profit scientific organization that promotes the study of diseases of the retina, choroid, and vitreous. SERV has numerous publications related to [DR and DME](#), some intended for patients and others for healthcare professionals.(66)

The "If you want to conserve your sight: Watch out for diabetes (Si quieres conservar la vista, ¡OJO con la DIABETES!)" publication is of particular relevance.(66) This guide includes detailed information (e.g., including illustrations, practical examples of vision loss, and retinal photographs) on how diabetes can affect the eyes, preventative measures, treatment options, and effectiveness of treatments. (66)

Summary

In Spain, the prevalence of diabetes in 2021 was 10.3%, representing ~5.1 million people.(53) The Ministry of Health recommends that at time of diagnosis, patients have an eye examination of the fundus for early diagnosis of DR and DME.(57,58) Depending on the results from the initial examination, a follow-up exam will be required every 1 to 2 years.(58)

Approved treatment options include laser therapy, intravitreal injections and, in the more severe cases, surgical treatment.(59) There are two main types of intravitreal injection medications: anti-VEGF medications as a first line of treatment and steroid implants for patients who have had an insufficient response to anti-VEGF medications.(59,60)

There are some patient education materials on DME in Spain. The Barcelona Clinic and the Spanish Society of the Retina and Vitreous in particular have created many resources on DR and DME and include a description of the disease, diagnosis, treatment options, disease evolution, how to live with the disease, and current research is presented.(65,66)

United Kingdom

As of 2019,ⁱ Diabetes UK estimates that there are over 4.9 million people with diabetes in the United Kingdom;(67) and of that number, an estimated ~1 million have undiagnosed diabetes.(61) In addition, there is an expected 13.6 million people at an increased risk of developing Type 2 diabetes.(67) It is also probable that over 1700 people in the UK have their vision seriously affected by diabetes each year; this is more than 30 people each week.(69)

Health services in the UK are subsidized by the National Health Service (NHS).(70) The NHS expends at least £10 billion a year on diabetes, accounting for 10% of its entire budget.(67) As the number of people living with diabetes increases, so will the necessary budget to treat them. England, Northern Ireland (NI), Scotland, and Wales-as the United Kingdom each have a distinct government funded NHS and as such there are variations in the policies and diabetes programmes.

Treatment for diabetic eye diseases

To support those with diabetes, the NHS funds certain checks, tests, and services to assist in self-management and the prevention of serious diabetic complications.(71) As an example the diabetic eye screening programme (DES) aims to protect the vision of anyone over the age of 12 years with diabetes.(65) The DES is intended to be a preventative strategy to detect eye problems before vision changes and specifically focuses on DR and associated complications, such as DME.(69)

When first diagnosed with diabetes, the patient is invited to an annual screening for early detection of eye complications. Depending on the results and risk factors, the frequency of examinations may change to once every 2 years. Since the tests focus on DR, patients are also encouraged to continue regular eye tests with opticians who will check for other conditions such as glaucoma and cataracts which are beyond the scope of the DES.(69)

Sight tests in the UK are recommended for everyone at least once every 24 months. These appointments are not free for everyone; however, they are subsidized for certain cohorts including adults 60 years of age and over and anyone diagnosed with diabetes.(73)

ⁱ It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

Treatment options for DME in the UK include laser therapy and intravitreal injections, depending upon the stage of the disease.(74) The goal of laser treatment is to prevent the worsening of vision, and to have full effect (which may only be seen after many months), several sessions may be needed. (74) Depending upon the progress of the condition, intravitreal anti-VEGF injections, an approved line of treatment in the UK, may be scheduled once per month until the vision begins to stabilise.(74)

Steroid medications (fluocinolone acetonide and dexamethasone funded by the NHS) are used as a second line of treatment if anti-VEGF medications are not suitable or not effective.(74) While both are administered through intravitreal injections, fluocinolone acetonide is injected in a steroid-releasing implant while dexamethasone is injected as a dissolving steroid.(74) The dexamethasone injection will work over a period of 3-6 months, while fluocinolone acetonide will operate over a period up to 3 years. Since the steroid medications have an associated risk of cataract, current NHS guidance states that these treatments should be for those patients who have already had cataract surgery.(75)

Patient education and information

Moorfields Eye Hospital NHS Foundation Trust

The UK Moorfields Eye Hospital NHS Foundation Trust is a world-class centre of excellence for ophthalmic research, education, and services.(76) A comprehensive array of patient information and resources is available on the site "[Your eye health](#)" and includes not only general information on eye conditions, such as [DME](#) and [DR](#) but also detailed brochures that explain the condition, how to reduce risk, and the general treatment options.

A more detailed brochure for patients on [anti-VEGF](#) treatment includes information about the eye conditions that might require such treatment, how the treatment works, aftercare, risks associated, and who to contact should there be further questions. It should be noted that there is no specific information on the therapeutic treatments of steroid medications.

Diabetes UK

[Diabetes UK](#) is the leading national diabetes charity whose vision is a world where diabetes can do no harm. The organisational ethos is to lead the fight against the biggest growing health crisis in the country by sharing knowledge and influencing policies to improve practice.

The organisation aims to prevent Type 2 diabetes by raising awareness, and campaigning for support to those affected by diabetes.(77) [Managing eye problems when you have diabetes](#) is series of practical steps outlined on the Diabetes UK. The organisation encourages early detection through eye screening, managing background and pre-proliferative retinopathy, understanding the differences between various stages of the conditions as well as the kinds of treatment that may be discussed between the patient and treating physician.

i It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

The Royal National Institute of Blind People

The Royal National Institute of Blind People (RNIB) is a registered charity in England, Wales, Scotland, and the Isle of Man and Northern Ireland that plays a critical role in minimizing the barriers that people experiencing sight loss face.

[Understanding eye conditions related to diabetes](#) is a comprehensive publication that begins with the condition – what is diabetes and what are the different types. Next is a brief description of how the eye works, and how diabetes affects vision going on to describe the different types of retinopathies. In addition to the actions to reduce risk various treatments are explained including laser, anti-VEGF, steroid implants, and vitrectomy surgery depending upon the condition and its progression.

NHS Inform

[NHS inform](#) is Scotland's national health information service that aims to provide accurate and relevant health-related information. With respect to diabetes and eye complications basic information is available on diabetic eye screening and the management and treatment of [DR and DME](#) including laser therapy, eye injections (anti-VEGF treatment and steroid implant injections), and eye surgery.(78)

Summary

In 2019, there were an estimated 4.9 million people with diabetes in the UK.(60) Every year, more than 1700 people in the UK have their vision seriously affected by diabetes.(69) To protect the vision of anyone over the age of 12 years with diabetes, the NHS funds the diabetic eye screening programme (DES).(69) Through this program, patients are first invited to an annual screening at the time of diagnosis and, depending on the results, will be advised to return every 1 to 2 years.(69) Treatment options for DME in the UK include laser therapy and intravitreal injections (anti-VEGF treatment and steroid medications), depending upon the stage of the disease. While anti-VEGF medication is the first line of treatment, steroids are used in patients who either are not suitable for or did not yield the anticipated results with the anti-VEGF treatment. (75)

There is a plethora of patient education and information on treatment for DME in the UK. Organizations such as the Moorfields Eye Hospital NHS Foundation Trust, Diabetes UK, the Royal National Institute of Blind People, and NHS Inform release many different patient resources.

ⁱ It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

A Comparative Analysis of the Study Findings

		Canada	Australia	France	Germany	Italy	Spain	UK
Comprehensiveness	Patient educational material is reflective of all available treatment options. (e.g., Anti-VEGF drugs, Injectable steroids etc.)	Orange	Orange	Red	Orange	Orange	Green	Green
	Patient educational materials describe the benefits and contexts in which treatment options, including alternative treatment such as steroids should be used.	Orange	Orange	Orange	Orange	Orange	Orange	Green
	Patient educational materials contain information for every stage of diabetic eye diseases.	Orange	Orange	Red	Orange	Orange	Orange	Green
Multiple channels and media of dissemination	Available information is disseminated through online channels: internet, websites	Green	Green	Green	Green	Green	Green	Green
	Messages are disseminated offline e.g., printout (brochures, leaflets)	Red	Green	Red	Green	Red	Red	Green
Well-defined audience	Patient information is disseminated using various forms or media e.g., video and infographics	Orange	Green	Orange	Green	Orange	Orange	Green
	Dedicated information for specific at-risk populations	Orange	Green	Green	Green	Green	Green	Green
	Tailored to various levels of fluency.	Orange	Orange	Orange	Orange	Orange	Green	Green
	Clearly states the intended target audience (e.g., health care professionals, patients, or the general population)	Green	Green	Green	Green	Green	Green	Green
	Educational materials are directed towards a variety of target audiences	Orange	Green	Orange	Orange	Green	Green	Green

i It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

Sources of information Information on diabetic eye diseases is provided by a variety of sources including:

Independent/not-for-profit organizations	Well developed	Well developed	Well developed	Partially developed	Well developed	Well developed	Well developed
Professional bodies	Well developed	Partially developed	Well developed	Well developed	Well developed	Well developed	Well developed
Government	Partially developed	Well developed	Not yet developed	Partially developed	Well developed	Well developed	Well developed
Charity organizations	Well developed	Well developed	Not yet developed	Not yet developed	Not yet developed	Not yet developed	Well developed

Table 1: Environmental Scan Results

■ Not yet developed
 ■ Partially developed
 ■ Well developed

Information gathered through the environmental scans highlighted four components essential for the development of effective patient educational materials.

These components include:

1. Comprehensiveness
2. Multiple channels of dissemination
3. Well-defined audience
4. Sources of information

Component 1: Comprehensiveness

While patient educational materials typically provide a comprehensive overview of the treatment options, there are often gaps in understanding the benefits and contexts in which alternative treatment options such as steroids should be used. Also, there is often increased attention within education materials on diabetic retinopathy versus diabetic macular edema.

Patient educational materials on DEDs should be comprehensive and reflective of all available treatment options and should clearly explain the contexts wherein each treatment option is employed and include information for every stage and type of the disease. This is important to ensure that patients are well informed about their disease, so that they are active in their own care.

Component 2: Multiple Channels of Dissemination

To improve the uptake of the educational information, it is crucial for the messages to be distributed through multiple online and offline channels of dissemination and tailored to various levels of literacy and fluency. Such channels include internet, websites, radio, tv, printouts (leaflets and brochures), etc. Broadening the channels of dissemination can increase both the ways in which the message is communicated and the audiences that can be targeted and this will ultimately improve patients' access to the information, ensure their comprehension and improve health outcomes.

i It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

Component 3: Well-defined Audience

The target audience for the patient educational materials vary from country to country. In some countries, educational materials are targeted exclusively towards patients and their families, while in other countries materials are tailored towards the public, in addition to patients and their families. While the universality of messages for the general population seems reasonable, this type of messaging can often fail to reach and resonate with individuals most at-risk and those with differing levels of literacy and fluency. To further improve patient awareness and knowledge of DEDs and the available treatment options, it is imperative that at-risk populations are at the center of the message development.

Component 4: Sources of Information

Improving patient knowledge and awareness of DEDs is a collective effort involving many stakeholders. Each country has several organizations that lead in the development of information on DEDs including patient advocacy organizations, medical and scientific societies, independent medical and scientific knowledge publishing companies, and the governments.

Having different sources of information can help reach a wider audience, improve the access to and the uptake rates of the educational information. This will eventually maximize the impact of the messages being disseminated.

Policy Recommendations

Diabetes and diabetic eye diseases contribute to severe socioeconomic burdens on individuals, communities, and the nation's health system. Canadians are increasingly at risk of vision loss with complications related to their diabetes. The lack of awareness of the current treatment options for DEDs, as well as the non-adherence to treatment and follow-up regimens could lead to the loss of vision in this growing group of Canadians. The findings of this study show that patient educational materials on diabetic eye diseases can exclude at-risk groups who need the information the most. Given the low levels of awareness of the treatment options for diabetic eye diseases, there is a clear need to understand the factors impeding patient awareness. Strategies to address these issues include:

- Support the training and integration of diabetes educators within the clinics of primary care providers and specialists.
- Establish a patient advocacy group to improve the knowledge of DEDs based upon the needs expressed by patients.
- Support and encourage the use of diverse media types and channels of dissemination including online and offline materials.
- Leverage the voices and lived experience of patients in the development of educational materials to increase impact and resonance and decrease fear associated with treatment.
- Support and encourage the amplification of messaging around diabetes and diabetic eye diseases across diverse stakeholders (government, patient advocacy organizations, medical and scientific societies, clinicians, and patients).

ⁱ It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

- Establish and invest in strategies towards mitigating the fear associated with the treatment options for diabetic eye diseases.

These recommendations could help to mitigate the identified gaps and lead to significant improvement in outcomes for Canadians with diabetes-related eye damage.

Conclusion

Globally, there is a rapidly ageing population. Similarly, the incidence of diabetes has rapidly increased with the number of adults living with diabetes quadrupling since 1980. Individuals living with diabetes are much more likely to experience diabetes-related eye damage, so much so that diabetes is a leading cause of blindness in Canadians.

It is crucial that patient educational materials for those with diabetic eye diseases are: accurate and up to date, including all available treatment options whilst emphasizing prevention; easily accessible through various channels and media to ensure that all patients and their families can be well informed; tailored to various levels of literacy taking into consideration images and languages; and comprehensive evidence-based information for every stage of diabetic eye diseases.

The findings of this six-country study highlight the significant and concerning gap in patient education and targeted materials for at-risk populations on diabetic eye diseases across countries; and the need to identify best practices that can inform the improvement of Canadian patient awareness and education of vision health conditions and their respective treatments.

Patients with DMEs have three main options: surgical treatment, laser treatment and intravitreal injections with anti-VEGF or steroids. These treatment options are informed by the progression or severity of the condition. Anti-VEGF drugs like Ranibizumab, Aflibercept and Bevacizumab are used as first-line therapy in the management of centre-involving DME. On the other hand, injectable steroids e.g., triamcinolone, dexamethasone and fluocinolone acetonide are used in patients who are not suitable for or have an insufficient response to anti-VEGF medications. While there is a high degree of consistency in the treatment options across the six countries their awareness and integration of these treatment options within patient education materials varies broadly.

Despite Australia being a leader in the production of evidence based educational materials on DEDs with increased access to treatment which is subsidized, about half of Australians with diabetes do not have regular eye examinations because they are unaware of the threat of DEDs to their vision. The findings from Australia therefore pose a very important conclusion that the availability of patient educational materials is only half of the puzzle. Information needs to be tailored and disseminated in a manner to ensure/increase uptake.

Canadians need targeted patient educational material for those with DR and DME that is easy to access, consistent, and addresses the various levels of health literacy. It is important to ensure that patients have all the required information to safe, effective, and appropriate treatment options for their conditions, as it evolved over time. There is a need to prioritize patient educational material to ensure that no patient is left behind.

ⁱ It should be noted that the most recent data for the UK was from 2019/20. Although there are more recent statistics for England and Northern Ireland, as of December 2021, Wales and Scotland have yet to publish their most recent statistics.

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