



Diabetes and diabetic retinopathy: Changes in understanding of the disease over the last 25 years and how the UK is helping low-income countries tackle the challenges

BY MARCIA ZONDERVAN, COVA BASCARAN, FRANK SANDI, CHLOE CORNES AND PIPPA WILLIAMS



Diabetes – a historical perspective

Diabetes mellitus (DM) is a chronic disease caused by inherited and / or acquired deficiency in production of insulin by the pancreas, or by the ineffectiveness of the insulin produced. Such a deficiency results in an increased concentration of glucose in the blood, which in turn damages many of the body's systems, in particular the blood vessels and nerves [1]. When diabetes is not well-managed, it is associated with serious complications including heart disease, stroke, blindness, kidney disease and amputations, leading to disability and premature mortality.

Diabetes

dɪə'bɪ:tɪz

noun

noun: **diabetes**; noun: **diabetes mellitus**

1. a disease in which the body's ability to produce or respond to the hormone insulin is impaired, resulting in abnormal metabolism of carbohydrates and elevated levels of glucose in the blood.

The Diabetes Control and Complications Trial (DCCT) was a major clinical study conducted over 10 years in the USA [2]. The publication of its findings 25 years ago significantly changed the management of DM. The study showed that keeping blood glucose levels as close to normal as possible slows the onset and progression of eye, kidney and nerve damage caused by diabetes.

Diabetes, as well as cardiovascular diseases, cancer and other non-communicable diseases, was previously thought to be largely a problem of affluent, industrialised nations. However, by the early 1990s, several reports indicated a high prevalence of diabetes in developing countries, and in diverse groups of ethnic minorities in industrialised countries [3].

This prompted the diabetes programme at the World Health Organization (WHO)

to collate data from many studies. The results led to three conclusions:

1. An apparent epidemic of diabetes had occurred, or was occurring, in adults throughout the world.
2. This trend appeared to be strongly related to lifestyle and socioeconomic change.
3. It was the populations in developing countries, and the minority or disadvantaged communities in the industrialised countries, who faced the greatest risk.

In the early 1990s, for the first time, diabetes in adults was recognised not only as a disease of industrialised countries, but also as a problem in developing nations. All countries needed to develop national policies and programmes for the prevention and control of diabetes.

Diabetes statistics – 25 years ago, today and the future

In the US, the long-established diabetes surveillance system run by the Centers for Disease Control and Prevention (CDC) shows that, in 1993, there were 7.78 million adults who had been diagnosed with DM (a prevalence of 3.06%). In 2015 this had grown to 23.35 million (a prevalence of 7.40%) [4].

The WHO reports that diabetes prevalence has been rising more rapidly in middle- and low-income countries [5]. Africa has the highest proportion of undiagnosed diabetes, with over two-thirds of adults currently living with diabetes unaware of their condition.

Globally, in 2017, 425 million adults (aged between 20 and 79) were living with diabetes compared with 108 million in 1980 [6,7]. Looking ahead, the projected figures for 2045 are that 629 million adults aged between 20 and 79 will be living with diabetes.

The greatest percentage increase will occur in Africa, where numbers are expected to increase from 16 million in 2017 to 41 million in 2045 [6].

Diabetes and its effects on the eye

Diabetic retinopathy (DR) is the leading cause of vision loss in adults of working age [8]. DR occurs as a result of chronic high blood glucose levels damaging the retinal capillaries, leading to capillary leakage and blockage. Approximately one in three people living with diabetes has some degree of DR and 1 in 10 will develop the sight-threatening form of the disease [6].

The vast majority of people who develop DR have no symptoms until the very late stages (by which time it may be too late for effective treatment). Therefore, screening of people with diabetes for DR, and early intervention, are critical [8].

The Diabetic Eye Screening Programme

In the UK, the Royal College of Ophthalmologists published the first set of guidelines for the management of DR in 1997. These have been regularly updated to reflect changes in knowledge and technology. Since that time, advances in retinal imaging, especially high definition optical coherence tomography (OCT) scans, wide field retinal angiography, improved laser technology and intravitreal injections have increased clinical knowledge and treatment options.

In England, the NHS Diabetic Eye Screening programme (DES) was launched in 2003 and covered the whole of England by 2008. In 2015-16 uptake was 82.85% – in practice this means that 2.59 million people with diabetes were offered screening and 2.14 million were screened [9]. The programme is co-ordinated and led nationally, with local screening services provided in line with national quality standards and procedures [10].

The situation in sub-Saharan Africa and the Caribbean

In sub-Saharan Africa, the scale of the epidemic of DM and DR is only just becoming apparent. In contrast to the developments in industrialised countries

over the last 25 years, screening and treatment for DR is still in its infancy. The time is right for the accumulated knowledge and expertise in the UK to be shared with countries where there is a huge need to tackle DM and DR.

In 2015 the VISION 2020 LINKS Programme established the Diabetic Retinopathy Network (DR-NET) with funding from the Queen Elizabeth Diamond Jubilee Trust [11] to address the growing epidemic of DM and DR in low-income Commonwealth countries in Africa, the Pacific Islands and the Caribbean [12].

More recently, the DR Caribbean project has focused on developing and scaling up national DR screening and treatment programmes in four Caribbean countries – Jamaica, Belize, St Lucia and Dominica [13].

Key areas of sharing knowledge and expertise through DR-NET

The main areas where the DR-NET is making a difference in sub-Saharan Africa and the Caribbean are:

1. Developing clinical skills through training – screening, grading, laser and IV injection treatment
2. Establishing national frameworks and guidelines for development of DR services
3. Use of databases and diabetic registers
4. Acquiring and maintaining essential equipment – lasers and cameras
5. Exchange of knowledge between countries addressing similar issues.

1. Developing clinical skills – screening and grading

Through DR-NET, eye health workers are being trained as screeners and graders. 'Task-shifting' is enabling eye care personnel to be used more efficiently. Ophthalmologists are being trained in the use of laser to halt sight loss from DR.

As well as training and mentorship through the individual VISION 2020 LINKS partnerships, the quality of screening and grading is being enhanced through standardisation of training in screening and grading.

People undertaking a screening / grading role in the hospitals within DR-NET, including DR Caribbean, are being offered the chance to enrol in distance learning courses on Diabetic Retinopathy Screening run by the Gloucestershire Retinal Education Group (GREG) under the leadership of Peter Scanlon [14].

There are three qualifications from which to choose depending on the competencies required of trainees by their programmes:

- Certificate of Higher Education in Diabetic Retinopathy Screening (120 CAT at Level 4)

- University Certificate in Imaging for Diabetic Retinopathy Screening (90 CAT at Level 4)
- University Certificate in Grading for Diabetic Retinopathy Screening (60 CAT at Level 4)

The awards require study for approximately one day a week and continuation of the application of learning in clinical practice, supervised by assessors. Clare Waite, GREG Qualifications Manager, has been instrumental in ensuring the enrolment of screeners from the low-income countries that are part of DR-NET and DR Caribbean. Funding has been provided through a grant from Seeing is Believing (SiB) [15], the Queen Elizabeth Diamond Jubilee Trust and Bayer Pharmaceuticals to GREG.

The main topics covered are:

- an introduction to the study of diabetic retinopathy
- diabetic eye screening programmes, processes and protocols
- preparing the patient for diabetic eye screening
- performing retinal screening
- assessing retinal images.

These are challenging courses for people new to screening, working in a relatively isolated setting where internet access may be limited. Chloe Cornes, Retinal Photography Screener & Grader with the DES Programme in Stafford, is giving her time to support those taking the course by training and mentoring them remotely. She has also been to Belize in late 2017 to support the new group of screener / graders there. After a week's training they all passed the final exam.

To date, 17 people from Ghana, Malawi, Nigeria, Zambia, Belize, Jamaica and Indonesia have passed one of the courses and a further 38 people from Malawi, Tanzania, Zambia, Jamaica, St Lucia, Dominica and Indonesia are undertaking them in 2018. There is enormous value in having screener / graders in these countries who have passed one of the GREG courses and are able to use their expertise to help develop DR screening services, to ensure the quality assurance of the new services, and to train others. The VISION 2020 LINKS Programme is very grateful to the GREG team for enabling so many screener / graders to enhance their skills in this way.

2. Establishing national frameworks and guidelines for DR services

The institutions participating in DR-NET, including DR Caribbean, have been set the challenge of developing a national framework for DR services and specific guidelines for use in their country [16].

At the initial DR-NET Workshop in 2015, as well as the local target to increase DR services in their catchment areas, each participating eye care centre was also charged with developing a national framework for DR services for their country.

There is already progress:

- Botswana has a new National Eye Care Plan in which expanding DR services is a specific objective.
- Zambia is moving forward on expanding the DR services programme nationally, with training for screener / graders from all 10 provinces by Geeta Menon and the team from Frimley Park Hospital.
- The Ministry of Health in Kenya has worked with stakeholders to develop and publish detailed Guidelines for Screening and Management of Diabetic Retinopathy [17].
- Tanzania and Malawi have held stakeholders' meetings and are working towards the preparation of guidelines.

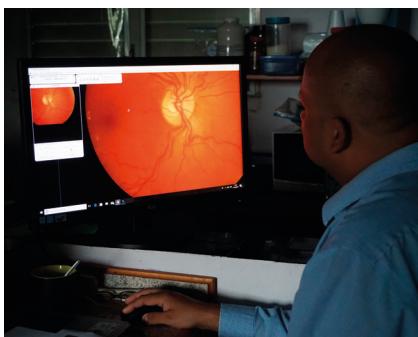
3. Use of databases and diabetes registers

Key learning from the initial DR-NET Workshop was the need to build close links with diabetes departments in order to ensure that patients were aware of the potential for irreversible sight loss due to DR and enable them to have their eyes examined regularly. To foster this, diabetologists and Ministry of Health officials representing eye care and non-communicable diseases (NCDs) participated in the Workshop alongside ophthalmologists and nurses.

Participating eye care teams have strengthened their relationships with diabetologists. Accessing an existing pool of patients already attending a diabetes clinic can be a 'quick win' when establishing a DR service. In some centres, a retinal camera has been installed in the diabetes clinic so that patients can be screened there and then, without needing to find their way to the eye department.

Many of the LINKS institutions prioritised the development of a register of patients with diabetes. As well as using it to record the findings of the screening and any treatment carried out, it also facilitates recall of patients.

Data collection has been put in place to record the numbers of patients screened and treated on a monthly basis by all the partners throughout the five-year period of the funding for DR-NET from the Queen Elizabeth Diamond Jubilee Trust. These data are showing an increase in numbers of patients screened and treated over time [18]. Better data collection provides the evidence needed for advocacy to acquire more resources. Sharing information and



Grading retinal images, Belize.

building up a picture of current and future need is critical.

4. Acquiring and maintaining essential equipment - lasers and cameras

The availability of training for eye care teams through the VISION 2020 LINKS Programme and DR-NET is only valuable if they have access to the equipment needed for screening and treating people with diabetes. Likewise, screening patients in villages on outreach is of limited value if the nearest available treatment is a day's journey away. This is demonstrated in the Case Study from Frank Sandi in Dodoma, over the page.

The need for equipment was one of the issues identified by the participants in DR-NET and several centres have acquired essential items since the network began. Advocacy is key to acquiring more resources and none more so than the purchase of expensive items of equipment by Ministries of Health. The Kitwe-Frimley LINK is an excellent example of the power of advocacy - Geeta Menon underlined the need for DR services in Zambia and encouraged the Ministry of Health to buy a camera and laser for five of the 10 provinces in Zambia. This has enabled a huge step forward in patients



Pippa Williams demonstrating Peek Retina to the Belize team.

being able to access DR services.

Better data collection and statistics produces the evidence needed for advocacy to acquire more resources. Sharing information and building up a picture of current need and projections for future need is critical.

A further need is for equipment to be maintained in good order, so some of the LINKS have included training in equipment and instrument maintenance and repair as part of their partnership priorities. This includes a technician from Nigeria and another from Malawi undertaking training in India.

Summary

Looking back over 25 years shows what huge improvements there have been in the detection and management of DR through developing and successfully implementing Diabetic Eye Screening programmes in the UK and other industrialised countries in response to awareness of the effects of poorly controlled diabetes. The most important way of reducing the risk of complications is to control blood sugar levels to as near to normal as possible. Screening detects DR before the patient notices any loss of vision and enables treatment to stop it getting any worse.

In low-income countries, awareness of diabetes and its complications is low and more health education is needed about the importance of controlling blood sugar levels. Ministries of Health are faced with huge demands on their limited funds and it can be difficult to prioritise providing diabetes and DR services.

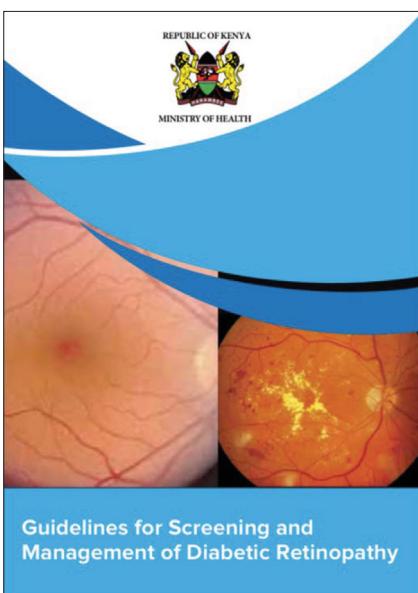
Looking ahead over the next 25 years, it is clear that the number of people living in low-income countries who need regular screening for DR will grow and this will place an increasing burden on health services. The DR-NET partners in 13 Commonwealth countries are benefitting from expertise that is being shared by UK NHS Trusts as they plan and develop national and regional DR services.



The Belize DR team, with Chloe Cornes, far left, and Pippa Williams, far right.

References

- WHO Factsheet number 138: Diabetes mellitus www.who.int/mediacentre/factsheets/fs138/en/
- The Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 1993;329(14):977-86.
- King H, Rewers M. Diabetes in adults is now a Third World problem. *WHO Bull* 1991;69:643-8.
- Long-term Trends in Diabetes April 2017. CDC's Division of Diabetes Translation. www.cdc.gov/diabetes/statistics/slides/long_term_trends.pdf
- Diabetes factsheet. Media Centre. WHO: www.who.int/mediacentre/factsheets/fs312/en/
- IDF Diabetes Atlas Eighth Edition 2017. International Diabetes Federation: www.diabetesatlas.org
- WHO Global Report on Diabetes. 2016 http://apps.who.int/iris/bitstream/10665/204871/1/9789241565257_eng.pdf
- Diabetic Retinopathy. The International Agency for the Prevention of Blindness: www.iapb.org/knowledge/what-is-avoidable-blindness/diabetic-retinopathy
- Scanlon PH. The English National Screening Programme for diabetic retinopathy 2003-2016. *Acta Diabetol* 2017;54(6):515-25.
- Diabetic eye screening: programme overview. Gov. uk: www.gov.uk/guidance/diabetic-eye-screening-programme-overview#history
- The Queen Elizabeth Diamond Jubilee Trust: www.jubileetrust.org
- Poore S, Foster A, Zondervan M, et al. Commonwealth nations join forces to prevent blindness from diabetes. *Eye News* 2015;21(5):33-6.
- Williams P, Bailey M, Bascaran C, Zondervan M. VISION 2020 LINKS: collaborating across the Caribbean to tackle diabetic retinopathy. *Eye News* 2018;24(4):26-31.
- Certificate of Higher Education in Diabetic Retinopathy Screening. Gloucestershire Retinal Education and Retinal Research Groups: <http://drscreening.org/pages/default.asp?id=2&ID=3#LongCert-HE>
- Seeing is Believing: <https://seeingisbelieving.org>
- Blows P, Peto T, Philippin H, Zondervan M. Situation analysis of diabetic retinopathy services in eleven countries. *Eye News* 2016;22(4):42-4.
- Ministry of Health, Guidelines for the screening and management of Diabetic Retinopathy in Kenya; 2017. Nairobi, Kenya: www.health.go.ke/wp-content/uploads/2017/11/Guidelines-for-Screening-and-Management-of-Diabetic-Retinopathy-in-Kenya.pdf
- DR-NET data: <https://sites.google.com/site/drnetcomm/activities>
(All links last accessed April 2018)



Kenyan DR Guidelines.

Case Study – need for equipment in Dodoma, Tanzania

"The University of Dodoma Hospital is one of the six referral hospitals in Tanzania and it serves a population of 3.5 million, which is growing fast given that Dodoma aspires to be the capital city of Tanzania. I am Frank Sandi, the Ophthalmologist at the hospital. Recently, I have established a DR screening programme. People with diabetic eye disease needing interventions are referred to the nearest treatment centre, which is about 8-10 hours away by public transport.

The common trend is that most of the patients who are referred are not able to travel for treatment and hence come back at later dates with a severe form of DR. Establishment of treatment services at the hospital in Dodoma will be a paradigm shift in DR management for the Central and the Lake zones of Tanzania.

Screening for DR is among the core services

offered at the hospital and during outreach. I wish to be able to offer treatment for those who are found with DR needing treatment. Without treatment capacity, screening is usually not very effective as most people can't afford to travel all the way to the nearest hospital. My priority is to obtain a fundus camera and a laser so that I can start to carry out DR treatment. This will make a big difference in preventing unnecessary loss of sight in people with diabetes in the 3.5 million population I serve.

I have developed a flier for the Dodoma Diabetic Programme (DDP). Future plans are for this flier to be produced in large volumes and placed in various hospitals in the region to increase awareness of eye screening for DR; this is because most people present to the eye clinic once they start having trouble with their vision."



Ophthalmologist Frank Sandi examining a patient for signs of DR in Dodoma, Tanzania.

Case Study – development of DR services in St Lucia

St Lucia launched its National Diabetic Retinopathy Screening Service in February 2018. The inauguration was held in the Vieux Fort Primary Care Centre and officially opened by The Honourable Minister of Health and Wellness, Senator Mary Isaac. DR screening takes place in two primary health centres, Castries Polyclinic in the north and Vieux Fort Polyclinic in the south of the island.



Senator Mary Isaac opening the St Lucia National Diabetic Retinopathy Screening Service.

The total population of the island is approximately 180,000. The prevalence of DM in adults in St Lucia is believed to be about 11% [6]. The estimated number of adults on the island who should be screened annually for DR is 12,800: over 1000 adults with DR could require treatment today.

So far the screening is taking place one day a week in each location, with a view to increasing these sessions as the demand increases. The screening is conducted by the eight screener-graders who were trained by their Frimley Park Hospital LINK partners in December 2017 and have now formally enrolled in the Certificate of Higher Education in Diabetic Retinopathy Screening [14].

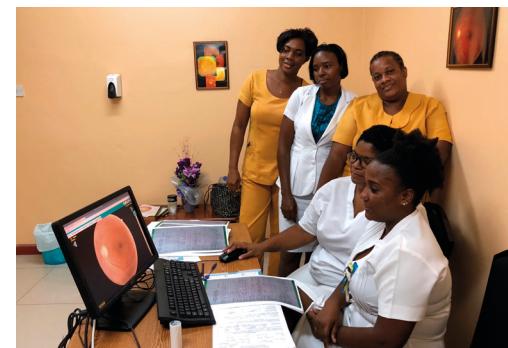
The programme is led by Dr Sharon Belmar-George of the Ministry of Health and the service is fully integrated within St Lucia's health system and its health management information system (HMIS). A referral mechanism has been set up whereby all the country's primary health

centres can register diabetic patients for screening. This system also allows for image storage, which can be accessed remotely over a network. If needed, patients can then be booked for laser treatment by Dr Darra Burt, the national Ophthalmologist, who trained in laser treatment through the programme. Dr Burt runs one laser clinic per month which will move to weekly sessions as the number of referrals increases.

This is a great achievement for St Lucia and a testament to the strong leadership at the Ministry of Health and the partnership established through the LINK (St Lucia Ministry of Health and Frimley Park Hospital) that delivered training and mentoring activities over the preceding months. It is also thanks to funding from the Queen Elizabeth Diamond Jubilee Trust, via the Commonwealth Eye Health Consortium, to the VISION 2020 LINKS Programme for the development of DR services in 13 Commonwealth countries in Africa and the Caribbean [13].



DR screening and treatment services underway in St Lucia.



Diabetic Retinopathy Screening courses by GREG – student testimonials

"Acquiring a certificate of higher education in Diabetic Retinopathy screening has really improved my practice as a principal ophthalmic nursing officer, after graduation. The five modules offered by the University of Gloucestershire have been simplified for students to understand the contents. The staff assigned to me were very helpful because I received my modules via email on time and helped me to schedule my exam timetable with my supervisor. In fact, I didn't experience any challenges in pursuing this course. I would therefore recommend this course to anybody who is interested in pursuing it because it is very educative and interesting to have special expertise in diabetic retinopathy screening." *Provided by a student from Ghana*

"I would like to express my sincere gratitude for the tremendous support that Gloucestershire Hospitals NHS Foundation Trust and all team members have provided through my course. In my opinion the course was understandable and productive, as well as the teaching techniques, studying materials and website itself. The course helped increase my performance in my field of work and give me more confidence. Now, I'm so competent in what I'm doing, I'm looking forward to increasing my knowledge further." *Provided by a student from Tanzania*

AUTHORS



Marcia Zondervan,

Programme Manager,
VISION 2020 LINKS
Programme, International
Centre for Eye Health,
LSHTM, UK.



Frank Sandi,

Consultant
Ophthalmologist, The
University of Dodoma and
Benjamin Mkapa Teaching
Hospital, Dodoma,
Tanzania.



Cova Bascaran,

Research Fellow &
Programme Director,
Public Health for Eye Care,
International Centre for Eye
Health, LSHTM, UK.



Chloe Cornes,

Retinal Photography
Screener & Grader,
Staffordshire and Stoke on
Trent Partnership NHS Trust,
Diabetic Eye Screening
Programme, Stafford, UK.



Pippa Williams,

Research Assistant & Project
Coordinator, International
Centre for Eye Health,
LSHTM, UK.

Correspondence:

Marcia Zondervan,
VISION 2020 LINKS Programme Manager,
International Centre for
Eye Health,
LSHTM, Keppel Street,
London, WC1E 7HT.

E: marcia.zondervan@lshtm.ac.uk
www.iceh.org.uk

