

# Collaborating across the Caribbean to tackle diabetic retinopathy

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The VISION 2020 LINKS Programme has been running since 2004, with a focus on improving the quality and quantity of eye care training in low-income countries [1]. In 2014, the Diabetic Retinopathy Network (DR-NET) was established [2]. This is a network of 17 VISION 2020 LINKS in 10 countries, all working on reducing visual loss from the growing burden of diabetic retinopathy. In 2014 the first VISION 2020 LINK in the Caribbean was established in Jamaica. The University Hospital of the West Indies was linked with Moorfields Eye Hospital and the Homerton Hospital in London, UK [3]. Financial support for the DR-NET comes from the Queen Elizabeth Diamond Jubilee Trust [4].

Within the Caribbean region many countries do not have national Diabetic Retinopathy Screening Programmes. Shortly after we reported on the mid-way stage of the DR-NET [5] there was an opportunity to collaborate further across the Caribbean region which had also received funding from the Queen Elizabeth Diamond Jubilee Trust. The development of the Caribbean DR-NET involves building on the existing link in Jamaica and forming three new LINK partnerships; with Belize, Dominica and St Lucia (listed in Table 1).

The North American and Caribbean (NAC) region has seen a rise in diabetes prevalence in line with global increase in prevalence. The World Health Organization (WHO) reports that in 2014, 422 million people in the world had diabetes – a prevalence of 8.5% among the adult population [6]. The NAC region has the second highest prevalence of diabetes per capita worldwide, with one in eight adults having the disease. The estimated age-adjusted diabetes prevalence for adults aged 20-79 specifically in the four countries initiating the Caribbean DR-NET ranges from 10.9% to 16.5% [7].

The rise in diabetes in the region is a concern for those involved with eye healthcare, as diabetes is a major cause of visual impairment and blindness. People with Type 1 or Type 2 diabetes are at risk of developing diabetic eye disease. Regular screening and early treatment is important to prevent unnecessary loss of vision. Many people with diabetes are unaware that they have the condition and often, by the time their vision deteriorates, it is too late for treatment. In addition, within the Caribbean islands, the spending on care per person with diabetes is currently low, at less than USD 2000 per year compared with USD 10,902 per capita in the US [7].

The need to support the strengthening of screening and treatment services in the region is high. In addition to the high

prevalence of diabetes in the region, forming an arm of DR-NET specific to the Caribbean region acknowledges the different context of delivering healthcare here. The creation of a Caribbean DR-NET creates a forum to share experiences and knowledge on the specific challenges and opportunities the region faces. Some of these challenges were drawn into stark context recently, with the impact of Hurricane Irma and Hurricane Maria in the region, which in particular seriously affected our partners in Dominica.

The development of the Caribbean DR-NET uses the same model that has been successful in DR-NET [2]. As such, the main objective of the Caribbean DR-NET is to implement a comprehensive model for screening, referral and treatment of diabetic retinopathy in each of the participating countries. There is also an opportunity to take learning from the LINKS already active and build this into action in the Caribbean.

Following the DR-NET model, representatives of the participating organisations in the Caribbean recently gathered for a stakeholders' planning workshop to kick-start the Network. The representatives from Dominica were unable to travel to the workshop, due to Hurricane Maria, but remained, and still do, in the thoughts of everyone involved in the Caribbean DR-NET. This article aims to explain the stakeholder workshop in more depth and share insight into the planning process that the VISION 2020 LINKS Programme goes through to address diabetic retinopathy.

## Aim and description of workshop

Jamaica was selected to host the Diabetic Retinopathy (DR) Caribbean Regional Workshop (25-27 September 2017) at the invitation of the Permanent Secretary in the Jamaican Ministry of Health. The three-day workshop was held at the University of the West Indies Regional Headquarters in Kingston. The workshop was chaired by Professor Allen Foster and had about 60 participants from St Lucia, Belize, Jamaica, including the UK LINK Partners. Locally there was representation from the Ministry of Health in Jamaica, three of the four Jamaica Regional Health Authorities (SERHA, SRHA and NERHA), the Pan American Health Organization (PAHO) and the Diabetes Association of Jamaica. The Ministry of Health in Jamaica received co-sponsorship for the workshop from PAHO. The workshop brought together multidisciplinary country teams and LINK partners for the first time within the Caribbean.

**Table 1: LINKS partnerships formed as part of the Caribbean DR-NET.**

Caribbean participating institution	UK LINK partner
Belize Council for the Visually Impaired, Belize	Brighton and Sussex University Hospitals
Ministry of Health, Dominica	Brighton and Sussex University Hospitals
Ministry of Health, Jamaica	Homerton and Moorfields
Ministry of Health, St Lucia	Frimley Park Hospital



These included policy makers, ophthalmologists, diabetologists, optometrists, screener / graders and information management systems personnel.

The aim of the workshop was for each country, or region, to create an action plan that will assist in establishing a national screening programme within the public health system, which will in turn lead to a reduction in the incidence of blindness due to DR.

The objectives of the workshop were:

- To promote the development of good practice guidelines for DR
- To provide guidance for planning and the implementation of DR services
- To identify indicators to monitor activities.

To achieve this the workshop involved plenary sessions on diabetes management; screening and treatment for diabetic retinopathy and training health workers for service delivery. Following this, the LINKS worked together in interactive group sessions to conduct needs assessments and develop an action plan for the next two years.

### Knowledge sharing

The plenary sessions refreshed everyone's knowledge around the topics of diabetes and diabetic retinopathy and presented information which would inform the planning activities. Andrew Smith of Brighton started the sessions, providing the overall context and summarising the key points regarding the prevention and management of diabetes mellitus. Following this, Dawn Sim of Moorfields Eye Hospital presented a recap of the principles of a screening programme and also highlighted the importance of looking past screening as the test. In particular, it was stressed that screening can be seen as a process or pathway which identifies a referable case that needs treatment now or may need treatment in the near future. Professor Geeta Menon gave a session on the successful screener-grader training that has been run in Zambia

through the Kitwe-Frimley LINK, providing an opportunity to share learning from the DR-NET.

Covering treatment options for diabetic retinopathy, presentations were given by Angela Mattis, Jeannine Imoru, Zubin Sainan and Mike Eckstein, covering laser treatment, anti-VEGF and surgery. These presentations also considered which of these treatment options was the most suitable to the context within the Caribbean in terms of resources and ability to deliver. Lizette Mowatt rounded up the plenary sessions by providing an overview of the training options for treatment available in the region. The presentations updated everyone on the planned outcomes of the Network; what a screening service should look like, what treatment options are feasible in the context and the training methods to build the skills needed to run a service.

### Assessing the need

The DR-NET Toolkit revised specially for the Caribbean workshop provided a guide to working through the process of assessing and clarifying the need. In working groups, each partnership worked through a situational analysis, beginning with calculating the prevalence of diabetes mellitus, diabetic retinopathy and vision-threatening diabetic retinopathy (VTDR) within their region. This gave them a target of where they needed to be in terms of service delivery; estimating how many people need regular screening and how many people need treatment to prevent visual loss from diabetic eye disease.

The next step was to assess each region's current screening and treatment statistics. This provides a statement of where each is now, which, when compared against where they need to be, gives an indication of how far they have to travel. For every country, this step highlighted the importance of building services to prevent and treat diabetic eye disease in the region.

**Table 2: The results of the working groups and an estimated overview of the need in the Caribbean DR-NET at present.**

	Population	Number of people who need regular eye examination	Number of people with VTDR who require treatment to prevent visual loss
Belize	380,000	21,000	2,100
Dominica	70,000	5,000	500
Jamaica	2,800,000	200,000	20,000
St Lucia	170,000	12,000	1,200
<b>Caribbean DR programme</b>	<b>3,420,000</b>	<b>238,000</b>	<b>24,000</b>



### Planning actions

The following day was spent in LINK working groups, focused on planning how each country would get from where they are now, to where they want to be. Three main priorities were identified across the region in order to move towards national screening services.

- Priority 1: How to increase the number of people living with diabetes who are being screened.
- Priority 2: How to reduce the number of people with vision-threatening diabetic retinopathy.
- Priority 3: How to create more awareness of diabetic retinopathy and the need for regular eye examinations.

The countries all started the planning activity by reviewing what resources were available within their context. Next, the countries set about identifying the major challenges they were facing, which impeded the ability to set up a national screening service. For each of the three priorities the partnerships then worked through what the major constraints were specifically within their region or country and they proposed solutions.

The next important step was to consider what could be done in the next one to two years and from this develop an action plan. In approaching the planning section, it was important for each LINK to break down their plans into small achievable targets, with steady increases towards the end goal.

Each country ended the workshop with a two-year plan, specific to their context, working step-by-step towards a national screening service. On the final day, each LINK presented this action plan to the other participants, which provided a forum for feedback.

This important step drew on experience from other regions in the Caribbean and also from the wider DR-NET, and was important in setting realistic targets and identifying opportunities for collaboration. One example is the invitation from the Jamaican Ministry of Health to the biomedical engineer in St Lucia to join their training workshop planned for later 2017.

### Partnership through LINKS

An important step for strengthening collaboration with the Caribbean region is the formalisation of VISION 2020 LINK partnerships. The workshop was an initial step in building these relationships and exploring together how support can be provided through the LINK partnerships.

Representatives from Belize Council for the Visually Impaired, Belize:

"The national eye care programme in Belize is provided not by the government, but by a non-profit organisation, the Belize Council for the Visually Impaired (BCVI) which has been in existence since 1981. Over the years, BCVI's services have expanded to include primary, secondary and rehabilitative services, with its most recent programme launched in 2013 to reduce the incidence of blindness due to diabetic retinopathy.

We have successfully set up three screening centres and started seeing and treating patients. Over the years, thanks to support from the World Sight Foundation and Mike Eckstein and Nick White of Brighton and Sussex University Hospitals, we have been able to strengthen the programme and identify areas in need of support, such as increasing patient uptake, further training in grading for screeners, further specialist training for our ophthalmologist, and data collection and management.

With the newly-implemented Caribbean DR-NET providing BCVI with a formalised LINK with the Brighton and Sussex DR team, we are very much looking forward to strengthening the national service to be able to identify and treat more Belizeans with sight-threatening DR.

The DR-NET Workshop was an excellent opportunity for BCVI's team to meet and discuss the way forward along with the Brighton team. The sessions gave us an opportunity to personalise our plans based on our country's situation, while learning from other partners in our region. The result? Realistic goals and targets with a more holistic approach to on-the-ground support."

If any ophthalmologists, medical retinal trainees or screeners are interested in volunteering to join the Caribbean DR-NET and help its activities within the Caribbean over the next 18 months, please contact Marcia Zondervan (see below).

If anyone has a Laser Eye Model such as the type made by Eyetech and would be willing to donate or lend it to the Caribbean DR-NET for training, please let Marcia know ASAP.



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