

DIABETIC RETINOPATHY
MEETING OF NON-GOVERNMENTAL ORGANISATIONS

The Imperial Queen's Park Hotel, Bangkok

10.30am - 3.00pm Saturday 6 April, 2013

MINUTES

Co-Chairs:

Kathy Spahn, Helen Keller International
Brian Doolan, The Fred Hollows Foundation

Attendees:

Brien Holden Institute: Prof. Kovin Naidoo
CBM: Dr. Babar Qureshi
The Fred Hollows Foundation: Dr. Richard Le Mesurier, and Di Missen
Helen Keller International: Dr. David Friedman and Nancy Haselow
IAPB: Peter Ackland
ICO: Dr. Bruce Spivey, William Felch and Prof. Hugh Taylor AC
Light for the World: Johannes Trimmel
L'Organisation pour la Prévention de la Cécité: Dr Serge Resnikoff
ORBIS: Dr. Nathan Congdon and Dr. Abu Raihan
Sightsavers: RN Mohanty and Dr.Sandeep Buttan
Lesley Podesta (FHF)-via phone for the Welcome
Bob Mc Mullan (IAPB President) attended for part of Agenda Items 2 and 6.

Apologies:

Operation Eyesight Universal: Brian Foster
Lions Clubs International: Phillip Albano

Key outcomes of the meeting

It was agreed that:

1. The Draft Declaration on Diabetic Retinopathy (Attachment 1) be accepted; and be presented to the IAPB Board of Trustees.
2. A Diabetic Retinopathy Working Group be established with the aim that it be a Working Group of IAPB. Brian Doolan and Kathy Spahn to consider the formation of the Working Group in more detail.
3. Two meetings be scheduled in the next few months; one with a DR program focus and one with a focus on advocacy. Brian Doolan and Kathy Spahn to further discuss meeting arrangements.
4. Online grader training and quality assurance options need to be further explored.
5. Resources and presentations included in the meeting be made available to IAPB for inclusion on its website, subject to the approval of the authors.

1. Welcome and purpose of the meeting

Kathy Spahn and Brian Doolan welcomed everyone to the meeting. Lesley Podesta briefly addressed the meeting (via Skype) acknowledging that it was an historical moment that organisations had come together for the first time to discuss how they could work together to address diabetic retinopathy (DR).

2. Epidemiology of Diabetes and Diabetic Retinopathy - What are we talking about?

Dr. Serge Resnikoff spoke on the extent of the DR challenge.

Key points:

- The complexity of the DR challenge requires a range of responses that are appropriate to particular settings.
- At any given point in time in a population of 1 million people, there will be an estimated 40,000 people with diabetes (4%) who need to be screened. Of these, 35% (14,160) are likely to have some level of DR with 11.7% estimated to have vision threatening DR (4,680) that requires active management.
- Laser treatment is important in resource-poor settings but there is also a need for VR surgery and LV rehabilitation. Apart from anti-VEGF drugs such as Avastin, there are others 'in the pipeline' but at the moment all are unaffordable in low resource settings.
- DR will be a big market for drug companies and will generate both significant interest and require huge investment. Potentially there may be ethical issues similar to those related to HIV/AIDS as well as intellectual property/patent issues. Although such drugs may not be too expensive, given the high number of people who will need to be treated there will be significant cost. On a practical level a drug such as Avastin is packaged in quantities sufficient for 150+ injections so it is critical that there be safe methods to extract it multiple times or manufacturers agree to change the packaging.
- The IDF 2011 Atlas estimates that the number of people in the 20-79 age group with diabetes will be over 500 million by 2030. Interestingly, the projected number of people with diabetes has increased with each new edition of the Atlas.
- Of the top ten countries, all but two of these countries are middle-income countries and rapidly developing. The extent of DR in China and India is an expression of the high number of people, rather than actual prevalence which is higher in countries such as Brazil and Mexico.
- Observational evidence suggests that in regions/countries where the prevalence is already high – such as North America, the Caribbean, Latin America and the Pacific there may be slower rates of increase as numbers are likely to already have reached a plateau. However, the question was raised that if diabetes is increasing it would be reasonable to assume that DR will continue to increase. The biggest changes in the future will be in Africa, followed by the Middle East and North Africa region.
- The high number of people at risk of DR globally reinforces that health systems are not equipped to deal with the rising burden of diabetes and primary prevention is critical.

3. Scoping Diabetic Retinopathy: What's happening now?

Each representative spoke about their organisation's current DR activities. (Only particular aspects are noted in this section, for more information please refer to the *Diabetic Retinopathy: Background Paper*, which gives an overview of organisations' current work based on a questionnaire completed prior to the meeting).

LFTW: Johannes Trimmel identified that partnerships have been very important in its DR program development; they have been established between the Universities of Jimma, Ethiopia and Graz/Austria to build up capacity to treat DR. A particular challenge is the transfer of skills especially for ophthalmologists. LFTW is also working in north-east India. It was asked if there were any issues with people travelling across the border to the program in Burundi; this was not seen as a problem.

CBM: Dr Barbar Qureshi identified that most of CBM's focus has been on the secondary level with some primary prevention and some tertiary level work. Significant work has been undertaken in Pakistan – collaboratively with WHO, IAPB, FHF and regional partners - particularly through the Pakistan DR Taskforce. CBM is also piloting a small screening project in India.

ORBIS: Dr Abu Raihan explained that DR is one of ORBIS's emerging priorities in its Asia programs. Three key strategies are HR development, technology adoption and health system strengthening through the integration of ophthalmologists, endocrinologists and general physicians in the management of diabetes and retinopathy. Since 2008 ORBIS has developed three DR projects: Bangladesh - in partnership with Diabetic Association of Bangladesh (DAB) where three northern district hospitals have developed an integrated approach to screening and treatment; China- in partnership with Zhongshan Ophthalmic Center to strengthen county level hospitals for screening; and India - in partnership with HV Desai Eye Hospital to promote behavior change among population prone to DR and to increase awareness and knowledge of DR and utilization of DR services.

Advocacy with Ministries of Health, public education and operational research are key ongoing activities in these projects. Additionally, with collaboration of Ministry of Health in China ORBIS is currently designing a four year project to develop a model program for DR screening and treatment among four rural provinces.

ORBIS: Dr. Nathan Congdon explained the CREST Project which is a model of diabetic eye care in rural China treating both DR and glaucoma. Due to the lack of understanding of DR by patients and doctors and the lack of symptoms it is estimated that over 90% of people with DR are undiagnosed and/or untreated. The model aims to create clinical excellence through training, providing equipment and effective IT systems, patient education, as well as advocacy and research. The project has used cell phone messaging to improve long-term compliance. He referred to an article in JAMA titled *Attitudes of Doctors, Patients and Village Health Workers Toward Glaucoma and Diabetic Retinopathy in Rural China*.

HKI: Nancy Haselow spoke about two pilot projects - Bangladesh (based at Chittagong Eye Hospital) and Indonesia (Rumah Sakit Cipto Mangunkusumo Hospital) where HKI has worked collaboratively with local and regional organisations. Making DR screening a basic component of the medical evaluation for all diabetes patients is a key aim. Early identification and follow up are critical components of being able to establish an efficient system which can also triage effectively. Given HKI's overarching emphasis on malnutrition, prevention strategies are also being trialled.

FHF: As the organisation's DR work in Bangladesh, Pakistan and Nepal was summarised in the background paper, Dr. Richard Le Mesurier focused on the work being done in the Pacific where the prevalence of DR is very high; estimated at over 41% (Fiji). The Pacific Eye Institute (PEI) has been particularly effective in human resource development initiatives. As an example, DR screening and monitoring has now been fully integrated into the ophthalmic nurse Diploma of Eye Care programs at

PEI, where eye nurses learn to use a non-mydratic fundus camera and interpret the subsequent images for reassurance, further monitoring or referral as appropriate.

BHI: Prof. Kovin Naidoo identified that Aboriginal people have 14 times higher rate of blindness. BHI aims to bring together a public health approach combined with innovative technology. A key component is the EyeQ system - trialling an affordable high-resolution retinal camera which will provide automated, same-visit detection and interpretation of retinal images. It is likely that the cameras will be available in 2014. The work done in KwaZulu – Natal shows that rural Africa requires a different model. Training of optometrists in diabetic eye disease monitoring has been undertaken in Vietnam and Africa.

Sightsavers: RN Mohanty and Dr Sandeep Buttan identified that SS's approach to DR encompasses developing partnerships with like minded organizations, developing demonstration approaches that can be replicated and building local capacity as well as advocacy. It is important to integrate DR programs into the wider health system. SS has a focus on India and SE Asia; it financially supported the development of the Aravind DR Guidelines. Some of the key challenges identified include a lack of region specific data to assist program planning, inadequate workforce and lack of training; inadequate evidence on cost - effective community based screening models and inadequate health care infrastructure.

ICO: Dr. Bruce Spivey explained that key DR work includes: the development of Technical Guidelines for DR; curriculum development for subspecialty training in DR and establishment of an ICO Taskforce on DR. ICO is also examining public health system development in relation to DR.

Lions: Dr. Serge Resnikoff (spoke on behalf of Lions) stated that since 2008, 22 projects have been funded by Lions to support the strengthening of existing eye care units and linking them with diabetes management programs; the underpinning philosophy being that eye care needs to be integrated into the diabetes approach – not stand alone. A multi-level agreement has been developed between Lions and WHO to develop tools to assess how diabetes and DR systems are working and the Centre for Eye Health Research (Aust.) is involved in this project. He suggested the Lions Sightfirst (SF) Grants Program may be an option for organisations seeking funding for DR projects. He also briefly mentioned that OPC had quite a negative experience in eye care screening in France. For more information on SF Grants go to: http://www.lcif.org/EN/files/pdfs/LCIF_40.pdf

IAPB: Peter Ackland identified that IAPB in collaboration with the Standard Chartered Bank has directed funding to the Seeing Is Believing (SiB) Program which has contributed to the development of a number of DR projects.

As part of the general discussion it was recognised that a number of organisations are working in the same countries so there is scope to better collaborate. As an example four organisations are conducting DR work in Pakistan.

4. Workforce challenges and opportunities in diabetic retinopathy care

Prof. Hugh Taylor gave an overview of some of the challenges. Key points:

- It is important to have a whole system in place; systems development is critical.
- 'The patient journey is a 'leaky pipe – it needs to be better managed.
- People with diabetes are six times more likely to have cataracts.
- Up-skilling the ophthalmological workforce is critical; but also need to train eye care teams, focused on meeting community needs.

- Workforce capacity will be enhanced as technology gets cheaper; it is important to invest in training in the use of technology. There is also scope for drugs such as Avastin to be cheaper but currently the application of such drugs is not necessarily affordable or easy.
- With appropriate laser treatment 98% of blindness could be prevented. 'We must not let the best get in the way of the good.'
- On the basis of calculations in the *Closing the Gap* report it is estimated that for a population of 10,000 people, 8.3 EFTs need to be involved in the patient journey to provide good quality care.
- ICO would like to know what to do in terms of further identification and development of good workforce development models to learn from and replicate.

5. Developing and implementing DR Programs: Challenges to Success

Dr. David Friedman provided an overview of challenges based on HKI's experiences.

- Screening has to happen repeatedly so ideally the cost of screening has to be low. While treatment will prevent vision loss it will not restore it so these are important considerations from both a patient and program perspective.
- There is a need for a comprehensive set of patient educational materials that could be translated to country specific needs.
- It is challenging to identify and maintain relationships with good partners – important to know the personnel involved and recognise that good project management is essential.
- There is a need to be able to create a revenue stream for treatment of DR otherwise staff will be shifted to other areas; the downstream income of care provided is not recognised.
- HKI's experience demonstrates that staff training is a challenge given the staff turnover. HKI has developed quite sophisticated IT but for it to be effective local staff need to know how to use it. Enthusiasm for new technology needs to be tempered with the logistics of training; before large investment is made it is important to identify scope and useability of technology (such as cameras etc).
- It is important to establish effective ways to grade images and there are many problems in transferring images despite scope of automated grading systems.
- There was discussion about the on-line training system for graders. Dr.Friedman noted that an on-line system has already been developed for NHS (by Peter Scanlon) that could be made available to NGOs at an estimated price of \$85,000 with an annual fee of about \$95 per year, per grader.
- Some key priorities for effective program development include: the need for centralized training and certification process; inexpensive and simple tracking software; an effective way to universally identify and track patients; ways to generate revenue so programs can expand; and low cost, high quality, portable fundus cameras.

6. Setting the Advocacy Agenda - Where to from here?

Discussion centred on the future role, membership and next steps for the Group.

- All of the organisations represented have common challenges and interests, from technology to human resource constraints to compliance and follow-up issues.
- It was generally agreed that the right combination of organisations were present 'around the table' but there is a need to identify the Group's potential advocacy role. It was raised as to whether the Group would have enough status to be able to influence the IDF as a large global organisation. There is a need to create an interface with the IDF and build on the IDF's willingness to take up the issue of DR but not to include it as part of this Group.
- In considering the key issue/s on which to advocate there is a need for: a good evidence base; clarity about the key DR priorities; more comprehensive program input; and a framework for defining and identifying effective models encompassing both cost and quality of care. It is not only an issue of evidence but one of competition - there is a need to position DR on the NCD agenda. The Group needs to engage more with the diabetes sector and use diabetes as a platform to advocate on DR issues.
- It was raised whether the article *Cost-effectiveness of detecting and treating diabetic retinopathy* by Dr. Jonathon Javitts (1996) which demonstrated that prevention of DR is cost effective for governments was sufficient, or whether proven and tested models for DR prevention and treatment were needed before we could advocate with governments.
- The ICO, IAPB and World Council of Optometry could work jointly – allowing for organisations to share their knowledge and skills.
- Patient educational materials - content and key messages could be standardised in a template though information would need to be tailored for different countries and languages.
- In terms of human resource development it was emphasised that a transfer of skills not just systems is essential. To improve training for graders there is the option of potentially utilising an established on-line training system (such as the one previously referred to, developed by Peter Scanlon). Alternatively, it could start 'de novo' and an open access system could be created as was done for trachoma. This issue requires further exploration.
- Various gaps in knowledge were identified such as some analysis of the various cameras that are available or in development.

In summarising the discussion Kathy Spahn identified **six general areas of focus**:

- Technology
 - Cameras
 - Grading
 - Online training and ongoing quality assessment for grading
- Materials and resources
 - Universal key messages for patient education, to be customized per location
 - DR program management guidelines
- Clinical training and education
- Advocacy (global and national), including resource mobilization
- Cost and financing issues
- Collaboration, i.e., using this group as a platform to promote collaboration

Brian Doolan spoke briefly about the upcoming IDF's World Diabetes Congress, 2-6 December 2013 which is an excellent forum to raise the profile of DR. He will be chairing The Fred Hollows Foundation

session on DR; other opportunities also exist at the Congress to promote the prevention of DR and organisations were encouraged to attend.

7. Outcomes

It was recognised that there was scope for the Group to continue working on the priority issues and to formalise its status. Some key strategies were identified for immediate action.

1. It was agreed that the Draft Declaration (circulated prior to the meeting) which commits organisations to continue to work together as a coalition be accepted and presented to the IAPB Board of Trustees.
2. Two half - day meetings should be scheduled in the next few months to discuss:
 - Program issues: including patient education materials, management guidelines, cost issues and financing – involving program staff from represented organisations
 - Advocacy: to explore the kind of evidence base that is needed and share any current evidence and research relevant to DR.

Brian Doolan and Kathy Spahn to discuss future meeting arrangements and also identify how on-line grader training options and quality assurance options could be further explored.

Some representatives indicated that they would like to be involved in both meetings and it was agreed that the invitation to attend should be extended to others such as those involved in research, advocacy and program development.

3. It was agreed that a Diabetic Retinopathy Working Group could be established with the intent that it be a Working Group of IAPB.
4. It was agreed that resources and presentations included in the meeting be made available to IAPB for inclusion on its website, subject to the approval of the authors.

Brian Doolan and Kathy Spahn thanked everyone for their participation.