

IAPB DIABETIC RETINOPATHY (DR) WORKING GROUP MEETING Thursday, October 15 2015 from 2:00 pm – 3:30 pm Beijing Marriott Hotel City Wall

Welcome and Introductions

Co Chair: Nick Kourgialis, Helen Keller International Co Chair: Lesley Podesta, Fred Hollows Foundation

WHO Update Regarding DR Related Activities

Silvio Mariotti, World Health Organization

TADDS

- Status
 - o 15 done
 - o 7 underway
 - o 14 planned
- Cost is covered by eye and/or diabetes space
- Involvement of government and broad stakeholder involvement, through institutions
- Useful tool: well received, time limited, size limited assessment
- Raise the issue of DR: raised the need for continued and ongoing care, greater linkages and communication between diabetes and eye care sector. Catalyst for action
- Tool available shortly on WHO Global Observatory

Action: circulate communication from WHO on TADDS through IAPB.

Review of Recent Queen Elizabeth Diamond Jubilee Trust DR Commitments

Astrid Bonfield, The Queen Elizabeth Diamond Jubilee Trust

Working with PHFI and IEH

- Integration of eye care into existing diabetic services
- Proposed outcomes: development of cost effective models in India for those with DR, share learnings, health economics to be used for advocacy, M & E

The Trust, with partners, running programs in Bangladesh, Pakistan, Pacific, Caribbean

 Aim to reduce rates of DR and develop cost effective DR services that can be integrated into existing services

The Trust's long term focus:

- Establish legacy, particularly with government
- Share results: what are the best routes? Start with face to face meeting in Durban
- Commonwealth Eye Health Consortium: share learnings across sector more broadly
- Test what works in different contexts



Update Regarding DR Barometer Project

Joanna Conlon, IAPB

Peter Ackland gave presentation in IAPB Council of Members meeting on the top line information from the DR Barometer study (summary handout provided).

The study represents a glimpse at a point in time of patients and health professionals experience diabetic retinopathy as a complication of diabetes. It is not scientific study and the sample was self-selected. Further analysis is being done and reports at a country level will be provided in 2016. The information will provide valuable insights that can be used to inform advocacy and community awareness campaigns.

DR Alliance Scoping Study

Lesley Podesta, Fred Hollows Foundation

At the DR Working Group discussion In Paris in 2014, there was a broad discussion on the need for further collaboration between the eye and diabetes sector to tackle DR. Teleconference was held to discuss further, followed by volunteers drafting a scope document.

A consultant has been engaged to undertake a Scoping Study (supported by The Queen Elizabeth Diamond Jubilee Trust and The Foundation). Study will include:

- Review of current collaborations and success factors
- Focus of an Alliance: what is the common agenda for change? Priorities?
- Options: membership, governance, funding, measures of success.

The next steps:

• Final report due shortly, explore establishment of Alliance further in 2016.

Diabetes Eye Health Guide for Health Professionals (The Guide)

Linda Hill, Fred Hollows Foundation

- First product of the partnership between the International Diabetes Federation and The Fred Hollows Foundation
- The Guide is a complementary document to ICO Diabetic Retinopathy Guidelines
- Providing eye health guidance for those treating people with diabetes (beyond eye health specialists)
- Developed by a global Working Group with representatives from ophthalmology, optometry, diabetology, endocrinology, diabetes education, primary care
- To be launched at World Diabetes Congress, 1 December 2015
- Promoted throughout 2016 to eye health, diabetes, primary care audiences.

Future Priorities of the IAPB Working Group

Lesley Podesta, Nick Kourgialis

Priorities proposed for 2016:

 Advocacy: urgency to address the rising prevalence of DR and actions to mitigate health, social and economic impacts. Continue collaboration with WHO and support planned global consultation on DR.



- Increase collaboration: across eye and diabetes sectors to adopt a more integrated approach to managing diabetes and DR
- Programming: developing models of care to improve access for people at risk of, or living with diabetic retinopathy to provide adequate information, education, screening and treatment with a particular focus on those in low income settings

The development of a programming 'model'/set of principles was raised as a priority for the DR Working Group in 2016. As many INGO's and other providers are implementing or planning to implement programs to manage DR, consistent and evidence based practice would be useful. While there will be many approaches and need to be context specific, this exercise would be useful to bring together current evidence, different approaches, identification of successful and unsuccessful initiatives and barriers to implementation (such as workforce)

Next steps:

- Linda Hill to develop a draft Terms of Reference
- Form working group with representatives with experience of DR programming and those who may be about to undertake DR programming
- ?Workshop prior to General Assembly in Durban.