

Patient education and empowerment

Group 3: Adults with diabetes who have just been diagnosed with diabetic macular edema

Members

Ms. Angela Burns, Canada, *International Federation on Ageing*

Prof. Sehnaz Karadeniz, Turkey, *International Diabetes Federation Europe*

Prof. Dr. Sema Oruc Dundar, Turkey, *Turkish Ophthalmological Society Medical Retina Unit Executive Board*

Prof. Dr. Domagoj Ivastinovic, Austria, *Medizinische Universitat Graz*

Dr. Christiana Tsomidou, Greece, *General Clinic of Piraeus Hippocrates*

Prof. Malgorzata Pacholec, Poland, *AMD Retina Poland*

Ms. Elzbieta Szeratics, Poland, *AMD Retina Poland*

Ms. Karolina Opasek, Poland, *Bayer*

Project Title	DME: You Can Save Your Vision
Purpose	<ol style="list-style-type: none">1. To inform the patients with DME about the next steps after diagnoses2. To improve and maintain patient compliance with recommended care

Upon diagnoses, the ophthalmologists have a conversation with the patient and provide:

- A postcard with a link to a website which includes videos, information, newsletter sign-up
- A fridge magnet
- Written materials available (bulletin/flyers)

Key message for ophthalmologist to say to patient:

If we follow the recommended treatment plan, we can help you maintain your vision. There is hope!!

Key information topics:

- **Potential functional changes**
- **Support options:** patient groups, psychology, disability benefits and patients rights
- **Therapy options:** injections/laser, process for receiving it, frequency and duration of therapy, follow-up procedures, rehabilitation options including vision aids
- **Diabetes Management:** prompt to visit GP or internist
- **Key consideration:** accessibility (reading level and vision function)

The who and the whom:

Clarify the stakeholders of the project and the target audience.

<p>Stakeholders</p>	<p>Patients Families and caregivers Professional Organizations and Societies NGOs – vision health, diabetes - develops the messaging Pharmaceutical companies – funder Health Ministry</p>
<p>Target Audience</p>	<p>Patients with new diagnoses of diabetic macular edema (new and long-term) and their families Ophthalmologists</p>

Actions:

Determine actions for each objective, and when and how these will be implemented and who is responsible.

Timeline	Steps
8 months	<p>Develop materials in collaboration with patient organizations and ophthalmologist societies:</p> <ul style="list-style-type: none"> • Website with information and a YouTube video series with different perspectives, short (1 min), catchy titles, key messages, simple language – could be translated to short podcast • Written materials including booklets, digital information, texts/emails (some materials may already exist)
4 months	Contact stakeholders (ophthalmologist societies, patient organizations) to provide postcards and information package
Ongoing (every 3 months)	Update online content Distribute newsletters to mailing list
6 months	<p>Evaluation</p> <ul style="list-style-type: none"> • Patient perspective • Ophthalmologist perspective

Evaluation and Impact:

Outline mechanism for evaluating progress and how the impact of the program will be measured.

<p>Evaluation Mechanism</p>	<ul style="list-style-type: none"> • Monitoring of dissemination: follow-up with ophthalmologists to see how they are using the information resources • Online patient questionnaire • Ophthalmologist questionnaire online via email • Monitor website visits (duration of visit, clicks per page)
<p>Impact Measurement (targets, indicators, etc.)</p>	<ul style="list-style-type: none"> • Proportion of patients who proceed through the recommended treatment regimen • Real-life indicators: how many injections required, how many visits, duration of treatment, visual function measurements, OCT findings) • Increased regulated HBAC1 and improved lifestyle

Sustainability, Replicability, and Scalability

<p>Is the program a once-off, or does it require sustaining?</p>	<p>It must be continuously implemented</p>
<p>Can the program be replicated in other contexts?</p>	<p>Yes – developed first in one country but could be adopted for other countries (including language and health system)</p>
<p>Can the program be scaled up (expanded)?</p>	<ul style="list-style-type: none"> • It could start from one city and be expanded across the country