

Patient education and empowerment

Group 2: Adults with diabetes who have just been diagnosed with DR

Members

Mr. Giuseppe Castronovo, Italy, *IAPB Italy*

Mr. Tiziano Melchiorre, Italy, *IAPB Italy*

Dr. Michele Corcio, Italy, *IAPB Italy*

Dr. Albino Bottazzo, Italy, *FAND*

Ms. Cristina Ferrer, Spain, *Bayer*

Dr. Manuel Serrano-Gil, Spain, *Global Alliance for Self Management for Self Management Support, Servicio Murciano de Salud*

Dr. Susana Bettencourt, Portugal, *Associação Protectora dos Diabéticos de Portugal*

Patient 2 Patient 4 Eye Health



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Help people with diabetes when diagnosed with DR to know what to do and to support them

Objectives:

- Create awareness and acceptance within the community that patients can take an active role in helping other patients to improve their eye health
- PwD diagnosed with DR understand what they can still do in their normal life and maintain/improve their eye sight
- Recruit and train expert patients with special training on DR to provide practical and emotional support on how to deal with the situation and become a protagonist of their own success
- Establish different tactics and tools co-created by patients to support the patients on their journey

The who and the whom

Stakeholders:

- **Patients/Advocacy groups**
- **Patient mentors**
- **Professional Associations**

- Ophthalmologists
- Diabetologists
- GPs/PCP
- Optometrists/Opticians
- Pharmacists

Target Audience:

People with Diabetes diagnosed with DR and their families

- Mostly older
- Don't always use the internet
- Don't always have family

2 Pillars of Support



National Register
for DR for
measuring success

1

Mentor Programme

- Offline
- Expert Patients trained in DR
- Various options to engage and interact:
 - F2F meetings
 - Telephone
 - What's app
 - Group meetings
- Utilise existing programmes e.g. hotline in Italy, magazines

Lead by PAGs
to ensure
trust

2

Patient Information Platform

- Online
- Content co-created by patients:
 - Patient videos
 - Patient stories
 - Tools
 - (local) best practice programmes
- Use other media to inform: e.g. TV, patient congresses, PGA, Pharmacies to reach bigger population

Initiate a pilot (IT, PORT, ESP)

1. Establish Steering Committee:
 - global + national for pilot countries
 - Include all stakeholders
(professional associations, patient groups, industry etc.)
2. Audit of existing resources/assets to identify synergies and identify gaps
3. Review links and needs for other programmes required e.g. screening programme
4. Financial analysis incl. health economic impact per country
5. Understand feasibility issues and find ways to overcome them (e.g. funding)
6. Define the content for the information and mentor training
7. Develop detailed programme and role out plan

How we see we are successful

Prior to role out

- Engagement of stakeholders and local authorities

Success measurement

- Programme Uptake: Numbers of patients participating + mentors signing up
- Impact on Patient QoL: 2nd DR Barometer study
- Impact on Patient Motivation/Engagement: QoL Questionnaire (Time/Benefit ratio)
- Clinical Benefit: Decreasing progression of DR (clinical data)
- Impact on Health Economics: Cost-Benefit analysis

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