

Patient education and empowerment

Group 1: Adults with diabetes not diagnosed and unaware of DR-related complications

Members

Prof. Dr. Focke Ziemssen, Germany, *Universitäts-Augenklinik Tübingen*

Ms. Doreen Schroeder, Germany, *Bayer*

Dr. Gottlobe Fabisch, Germany, *VDBD-Geschäftsführerin*

Prof. Grzegorz Dzida, Poland, *Medical University of Lublin*

Dr. Teresa Caldas de Almeida, Portugal, *Instituto Nacional de Saude Doutor Ricardo Jorge*


Prof. Rufino Silva, Portugal, *University of Coimbra*

KEEP



CONTACT

KEEP CONTACT

<p>Project Title</p>	<p>KEEP  CONTACT</p> <p>TEAM-COACHING AFTER INDIVIDUALIZED VALUATION</p>
<p>Purpose</p>	<p>Raising awareness of potential eye complications Becoming personal and addressing individualized needs</p>
<p>Objective(s)</p>	<ul style="list-style-type: none"> - Increasing attendance rate of Screening - Involving the GP and the patients without adding more workload - Teamwork with an educated person (medically and psychologically qualified) - Overcome individual barriers: tailor made approach - Enabling differentiation between patient types

The who and the whom:

Stakeholders	GP`s , Nurses, Diabetes assistance, Psychologists, patients
Target Audience	Freshly diagnosed adults with diabetes with low awareness

Actions:

Timeline	Steps
Phase 1	Discuss the project with psychologist and scientist to define groups
Phase 1a	Valuation trial of patients, focus on patients with low awareness (multicentre approach in different countries)
Phase 2	Train the “coaches”
Phase 3	Implementation of the program per country recognizing different local needs

Evaluation and Impact

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

<p>Evaluation Mechanism</p>	<p>Measuring awareness via attendance rate</p>
<p>Impact Measurement (targets, indicators, etc.)</p>	<p>Increasing screening rates</p>

Sustainability, Replicability, and Scalability

<p>Is the program a once-off, or does it require sustaining?</p>	<ul style="list-style-type: none"> - Kick off investment - Reimbursement by local organizations /policy makers
<p>Can the program be replicated in other contexts?</p>	<ul style="list-style-type: none"> - Yes, adapted to local needs
<p>Can the program be scaled up (expanded)?</p>	<ul style="list-style-type: none"> - Yes, dependent on local health system

Patient engagement and empowerment

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

Members

Mr. Tiziano Melchiorre, Italy, *IAPB Italy*

Ms. Cristina Ferrer, Spain, *Bayer*

Dr. Albino Bottazzo, Italy, *FAND*

Dr. Michele Corcio, Italy, *IAPB Italy*

Mr. Giusseppe Castronovo, Italy, *IAPB Italy*

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

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

Patient 2 Patient 4 Eye Health



Patient 2 Patient 4 Eye Health

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