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Diabetes
Federation



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The Diabetic Retinopathy Barometer Project is a new multi-country study – and the first of its kind in the world – focused on diabetic retinopathy and diabetic macular edema. Diabetic retinopathy is one of the most common complications of diabetes and one of the major causes of adult blindness.

Results from the study will be used to inform policy and decision-making locally and globally. The project will culminate in a comprehensive report and a set of resources, including a country toolkit, related to diabetic retinopathy, diabetic macular edema, and vision loss.

To undertake the study, surveys need to be conducted to gather new and much needed information. Your guidance and insights are requested to identify providers who may be willing to (a) complete a survey and/or (b) assist in recruiting patients that may be willing to take part in a survey. We would also appreciate support to identify organizations that may help recruit people with diabetes to take part in the survey.

Surveys generally take about 20-30 minutes to complete and can currently be completed in English but will be available in additional languages in the coming weeks. Taking part in this project is voluntary and responses will be anonymous. The Ethical Review Boards of partner organizations have reviewed and approved the study protocol.

It would be greatly appreciated if the enclosed survey link could be shared with colleagues and people with diabetes. The link can be emailed or posted on websites of appropriate organizations. For your information, in each of the 42 countries, participation from 30 providers is sought in various specialties (e.g., primary care, eye specialist, diabetes specialist) and 70 people with diabetes in various stages of disease progression (i.e., diabetes only, diabetic retinopathy or diabetic macular edema).

Patient survey: https://nyam.qualtrics.com/SE/?SID=SV_3CTWkyeZAdYXhGd

Provider survey: https://nyam.qualtrics.com/SE/?SID=SV_ePZhgyikrGabTaR

If you have questions about the study or the survey please contact Linda Weiss PhD (lweiss@nyam.org), Study Director, or Ebele Benjamin-Gardner (ebenjamin@nyam.org), Study Manager. Thank you in advance for your consideration.

Yours sincerely,

Nicole Waldston

Project Officer
International Federation on Ageing

DIABETIC RETINOPATHY BAROMETER SURVEY PROJECT

EXECUTIVE SUMMARY

The *International Diabetes Federation (IDF)*, the *International Federation on Ageing (IFA)*, and the *International Agency for the Prevention of Blindness (IAPB)*, working in collaboration with *The New York Academy of Medicine (NYAM)*, have launched a new project to gather information on awareness, policy, health care, and other services for people with diabetes, diabetic retinopathy, and diabetic macular edema across 42 countries.

Diabetic retinopathy is one of the most common complications of diabetes and one of the major causes of adult blindness.

The study is using multiple research methods and information sources including literature reviews, modeling of trends, and surveys.

Phase one is almost complete and includes patient and provider interviews in eight countries: Germany, Saudi Arabia, Japan, Romania, Mexico, Argentina, Uganda, and Bangladesh.

In phase two, patients and providers in 42 countries will be surveyed to ascertain their perceptions and experience with diabetes and diabetic retinopathy.

Results from the project will be used to inform policy and decision-making around this common and serious complication of diabetes. It will culminate in a comprehensive report with country specific results and a set of resources related to diabetic retinopathy, diabetic macular edema, and vision loss in particular countries and around the world.

For particular countries, there will be a country toolkit with background, resource listings, and recommendations focused on diabetic retinopathy and its prevention, screening, treatment, and supportive services. Our goal is to develop products for individual countries, and globally, that are most relevant and useful for people with diabetes and people that care for them.

To increase our understanding of country-level issues and practices, we are seeking engagement from member organizations, other non-governmental organizations, providers, and people with diabetes. Agencies collaborating in this work will be acknowledged in the final report.

Bayer Pharma AG has funded and facilitated this research, acted as an advisor to the participating organizations and will assist in the dissemination of the research findings. Bayer Pharma AG has no involvement in collection or analysis of data relating to this research.