

PERSPECTIVES ON THE RECOGNISED PROJECT FROM PEOPLE LIVING WITH DIABETES

RECOGNISED is a Horizon 2020-funded research project which seeks to determine whether events taking place in the retina in people living with Type 2 Diabetes (T2D) can be used as a marker of changes occurring in the brain signalling cognitive impairment and dementia. For this purpose, a four-year research project is being conducted, consisting of experimental and clinical studies.

We spoke to six Spanish participants in the clinical studies, to gain further insights into their experiences of living with their condition and their reasons for joining the RECOGNISED trials.

The men and women we interviewed have all been living with T2D for more than a decade and most were over the age of 70. For some, early signs of short-term memory loss were mentioned during the interviews.

The participants interviewed managed their diabetes either through oral medication or with insulin. There was a common perception that the general population is not adequately informed about Type 2 Diabetes and its complications:



“

Apart from people who are close to someone with diabetes, people don't really know what diabetes is. There are a lot of people who have very little information about what diabetes is.

”

Sara*, RECOGNISED participant

Among the six participants interviewed, the majority had eye problems such as cataracts. A few mentioned memory loss issues that were particularly worrying to them. This was an important reason behind their involvement in the RECOGNISED project trials.

“

Sometimes I go to a room to get something and when I get to the room, I don't remember what I was going to get. This happens to me more often now than before and this worries me more. If scientists could help me with this, I would be interested.

”

Juan*, RECOGNISED participant

Another interviewee stated *“The only thing I can say is that I do forget things more than I used to. For example, I go somewhere and suddenly I find that I don't remember where I was going”*. Some people felt at a loss to explain what was happening to them:

“I would just like to ask the doctors and scientists why I don't remember things sometimes. I know I am not a child, but I would like to know why that happens to me”.

Raquel*, RECOGNISED participant.

The interviewees also provided further insights into the reasoning behind their involvement in the RECOGNISED project. Most commonly, people living with diabetes decided to participate in the project with the aims of improving their health and learning more about their conditions: *“I hope that my participation in RECOGNISED will help me improve my eyesight. I think it is good to participate in this project to try to improve my health”*. Leonie*, RECOGNISED participant.



Contributing to science and helping others through their contribution was also a major driving force: *“As they explained to me when they proposed to me to be part of this project: it will serve to go deeper into the problem, see if the situation I am in can be improved, what can be done, and also help ensure that all this can be transferred to other people with the same problem”*.

Another participant stated ***"I am happy because they have done some tests on me that they would not have done otherwise. And also, I entered the study really thinking that it was something of service I could do for research; it seemed perfect to me"***.

One interviewee mentioned his trust and love for science as the main reason behind his participation in the project:

"I decided to participate in this project because I trust science. Scientists have saved my wife's life who also has type 2 diabetes. She was about to lose an eye due to diabetes and she was able to recover thanks to them. Miguel*, RECOGNISED participant"

An interviewee also expressed a feeling of self-fulfilment and pride in participating in a project for the greater good: ***"I tell people that I am doing this project and that I am happy, if I can help in the research, then I am delighted"***.

All the people interviewed considered that such research projects were important for the advancement of treatments and to make living with the conditions easier for all. When asked whether they would encourage others to volunteer in such clinical trials, all of the interviewees gave a positive answer to the effect that: ***"I believe that all of us***

who are affected should collaborate, if we intend to improve our quality of life and solve the problems as much as possible. If we do not collaborate, we will not be able to know if an improvement is possible, a solution, whatever it can be". Pablo*, RECOGNISED participant



The participants showed interest in joining future studies and wanted to be kept up to date with the latest development concerning diabetes management ***"I would like to know what topics are being researched. I would like to know more, to receive more information. And if there is something new about diabetes, I would like to know about it, I would be pleased if they would explain it to me"***.

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**All names have been changed to protect the identities of RECOGNISED participants*



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