

Patient Engagement in Type 2 Diabetes Mellitus Research: What Patients Want

Simacek et al. (2018)

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For which topic were research priorities identified?

diabetes type 2

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

As patients are the ultimate stakeholder in their health, their perspectives should be included along with researchers, providers, and funders of research design, execution, and interpretation. Despite the high prevalence of type 2 diabetes mellitus (T2DM), patients are rarely directly included in these decisions.

What was the objective?

to determine areas of research most important to patients with type 2 diabetes mellitus (T2DM), to identify ways through which patients with T2DM want to engage in research, and evaluate online patient research networks as a source for obtaining patient perspectives on research engagement

What was the outcome?

a list of 4 research topics

How long did the research prioritization take?

May 2015 - December 2015

Which methods were used to identify research priorities?

group discussion

How were the priorities for research identified exactly?

Step 1: online patient community forum (PatientsLikeMe) to host two asynchronous moderated discussions: three to four prompted posts to start discussions among members of the T2DM community, participants were asked what research they felt was most important for people with T2DM, how they felt that current research applies to them, and why they look for information about T2DM. Step 2: data processing: thematic analysis

Which stakeholders took part?

Patients. 88 participants.

How were stakeholders recruited?

Online forum recruitment was augmented through direct messages sent to all patients with T2DM through the PLM private message system. For each of the two events, three types of messages were sent. The first was an introduction to the upcoming event with a general description of the topics to be covered. The second was a preview message sent through the PLM website with shortened versions of the starter posts. Finally, to further encourage participation, reminder messages were sent along with several quotes from actual posts from participants.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.