

Engaging Stakeholders to Develop a Patient-Centered Research Agenda. Lessons Learned from the Research Action for Health Network (REACHnet)

Haynes et al. (2018)

<https://doi.org/10.1097/MLR.0000000000000785>

For which topic were research priorities identified?

obesity and diabetes

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Patient-centered research requires a focus on the needs and priorities of patients. Because patient engagement can result in the discovery of important topics not currently prioritized by research programs, topic generation, and prioritization activities conducted with patients, caregivers, and other stakeholders are essential. To develop patient-centered research agendas for obesity and diabetes, the Research Action for Health Network conducted topic generation and prioritization activities with multistakeholder research advisory groups.

What was the objective?

to demonstrate how methods for engaging patients in topic generation and prioritization can be implemented in practice for the development of a patient-centered research agenda

What was the outcome?

a ranking list of 8 research topics

How long did the research prioritization take?

July 2014 - August 2015

Which methods were used to identify research priorities?

focus group; meeting; survey

How were the priorities for research identified exactly?

Step 1: focus groups: focus group participants were advisory group members, 2 focus groups focused on diabetes and 2 groups focused on obesity, topic generation process began with an unstructured brainstorming session involving active dialog among all group members, 33 topics for obesity and 24 topics for diabetes were identified. Step 2: data processing: grouping similar topics together, resulting in 19 topics for obesity and 17 for diabetes. Step 3: meeting 1: list presented back to advisory group members to collect their feedback: topics added, eliminated and refined, resulting 2 final lists of 10 topics for obesity and 12 topics for diabetes. Step 4: prioritization survey: advisory group completed prioritization worksheet by identifying the 3-5 research topics most important to them. Step 5: meeting 2: final list shared with advisory group to confirm that the results accurately represented the groups' collective opinion.

Which stakeholders took part?

Patients, family members, clinicians, researchers. Focus group, meeting and survey participants: 64 participants: 41 patients with diabetes or obesity, 2 parents of a pediatric patient with diabetes, 15 clinicians and 6 researchers.

How were stakeholders recruited?

Clinicians were physicians or nurses actively involved in care for patients with diabetes or obesity. Researchers were PhD level research scientists currently studying topics related to obesity or diabetes. Patients were eligible if they were diagnosed with obesity, diabetes, or prediabetes; parents of children diagnosed with diabetes were also eligible to participate. Two different approaches were used to recruit patients. In the first approach, physicians and nurses recruited patients during clinic visits, explaining the purpose of the group and the benefits of participating. In the second approach, patients were recruited from active support groups for managing the condition of interest.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a multi-stakeholder research advisory group. The obesity advisory group consisted of 36 stakeholders, and the diabetes advisory group of 28 stakeholders. The members were involved in all steps of the research prioritization.