

Patient-Centered Research Priorities: A Mixed-Methods Approach from the Colorado Children's Outcomes Network (COCONet)

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For which topic were research priorities identified?

pediatric health

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Practice-based research networks (PBRNs) perform clinically relevant research designed for immediate translation to patient care. Research questions developed with patients and parents are more likely to be relevant to stakeholders. This case study developed priority areas for patient-centered outcomes research in pediatric health within the context of the Colorado Children's Outcomes Network, a statewide pediatric PBRN, and in collaboration with stakeholders.

What was the objective?

to develop priority areas for patient-centered outcomes research related to child health issues within the context of a statewide pediatric PBRN in collaboration with parents, clinicians, and other stakeholders

What was the outcome?

a ranking list of 6 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

focus group; interview; survey

How were the priorities for research identified exactly?

Step 1: semi-structured interviews and focus groups: to collect research priorities. Step 2: data processing: thematic analysis to identify themes. Step 3: survey: participants were asked to rate importance of each of the 6 topics

Which stakeholders took part?

Parents, adolescent patients, clinicians, researchers, policymakers, community stakeholders. Interview: 52 participants. Focus group: 9 participants. Survey: 75 participants: multiple roles in child health including 47 parents, 32 providers, 22 advocacy staff/ volunteers, 18 health researchers, 11 adolescents, and 32 in other roles.

How were stakeholders recruited?

Participants were identified through a combination of purposive sampling among existing COCONet stakeholders and a snowball recruitment strategy in which stakeholders referred the study team to other potential participants. Recruitment efforts were conducted in partnership private pediatric practices, a family engagement training program, and a local Family Voices chapter. In addition, the study team asked stakeholders at these organizations and in each interview: "Who else should the project team talk to who will tell us something different?" to intentionally seek out stakeholders with differing views, experiences, and perspectives.

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 an advisory board. The advisory board consisted of The advisory board consisted of parents, 3 healthcare providers, 3 researchers, 4 child health advocates, and 1 policy maker.