

Health System Research Priorities for Children and Youth with Special Health Care Needs

<https://doi.org/10.1542/peds.2019-0673>

For which topic were research priorities identified?

children and youth with special health care needs

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

In 2017, the Health Resources and Services Administration MCHB established a cooperative agreement to create a national research network, the Children and Youth with Special Health Care Needs National Research Network (CYSHCN) (<http://www.cyshcn.org>). CYSHCN is an interdisciplinary, multisite, collaborative network to lead, promote, and coordinate national research activities to inform a highquality system of care for CYSHCN. The network's initial charge was to create a research agenda reflective of multistakeholder priorities. This agenda could help (1) prioritize the most important health system questions facing stakeholders, (2) define research goals for issues of greatest importance, and (3) provide a blueprint for research that CYSHCN investigators and other stakeholders can follow.

What was the objective?

to establish priorities for a national research agenda for children and youth with special health care needs

What was the outcome?

a list of 96 research topics

How long did the research prioritization take?

February 2018 - April 2018

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: collecting research priorities: survey: participants were asked to identify one or two things that they would most like to see improved in the approach to health for children and youth with special health care needs (CYSHCN), and what research with or about CYSHCN they would like to see in a national research agenda, 2835 responses. Step 2: data processing: coding, editing, and combining submissions into 86 unique research topics. Step 3: stakeholder organizations were asked to submit articles perceived to guide future CYSHCN research directions. Step 4: Delphi round 2: appropriateness ratings via survey, participants were asked to rate priority topics. Step 5: Delphi round 4: via meeting: discussing the round 1 ratings, participants were asked to re-rate, final plenary discussions

Which stakeholders took part?

CYSHCN families, health care providers, researchers, policymakers. Survey: 269 participants: 24% CYSHCN or family members, 73% health professionals, including primary (28%) and specialty (26%) care providers, behavioral health providers and therapists (10%), administrators and policy experts (13%), and researchers (15%). RAM panelists: members of the CYSHCN Executive, Steering, and Advisory Committees (each of which included family members of CYSHCN), the network's MCHB Division of Research project officers, and members of the MCHB services branch for CYSHCN.

How were stakeholders recruited?

Members of stakeholder organizations were identified by the CYSHCN Executive Committee.

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.