

Exploring Research Priorities of Parents Who Have Children with Down Syndrome, Cleft Lip with or Without Cleft Palate, Congenital Heart Defects, and Spina Bifida Using ConnectEpeople: A Social Media Coproduction Research Study

<https://doi.org/10.2196/15847>

For which topic were research priorities identified?

children with down syndrome, cleft lip with or without cleft palate, congenital heart defects and spina bifida

In which location was the research priority setting conducted?

Africa - South Africa; Asia - India; Asia - Turkey; Asia - United Arab Emirates; Europe - Bulgaria; Europe - Croatia; Europe - Germany; Europe - Ireland; Europe - Lithuania; Europe - Netherlands; Europe - Poland; Europe - Portugal; Europe - Spain; Europe - United Kingdom; North America - USA; South America - Panama; South America - Peru

Why was it conducted at all?

Establishing a linked European Cohort of Children with Congenital Anomalies (EUROlinkCAT) is a European project with a number of aims, one of which is connecting researchers and families of children with specific congenital anomalies (CAs), such as Down syndrome (DS), cleft lip with or without cleft palate (CLP), congenital heart defects (CHD), and spina bifida (SB), under the banner of ConnectEpeople. The aim of this project was to actively involve parents in setting research priorities and ensuring that research results are disseminated in a meaningful way by establishing a sustainable electronic forum (e-forum), called ConnectEpeople, to provide regional, national, and international support to families through maintaining the links between the European Surveillance of Congenital Anomalies' (EUROCAT) registries and families.

What was the objective?

to determine the research priorities of parents who have children with Down syndrome, cleft lip with or without cleft palate, congenital heart defects, and spina bifida

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: research questions identified with RAPs using Facebook, WhatsApp, Skype, and video chat, participants asked: "Is there a research question that you already have that you would like an answer to?", questions compiled and reviewed. Step 2: survey: survey seeking verification on research questions. Step 3: data analysis of survey: research questions reported as really important and important were combined, Facebook groups were then consulted to seek consensus on relevance and rating

Which stakeholders took part?

Parents of a child with CLP, DS, CHD or SB. Step 1: 32 participants. Step 2: 80 participants.

How were stakeholders recruited?

Parents who had a child with 1 of the 4 CAs were actively recruited via social media to participate in an online research forum using secret Facebook groups. Participating parents were known as research-aware parents (RAPs). Parent support organizations across 9 European countries identified by the research team were contacted. Those who agreed to act as gatekeepers provided information about the ConnectEpeople project to their members via their social media profiles, via group newsletters, in person, on the telephone, and via other communication networks.

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.