

Research Priorities of People Living with Turner Syndrome

Sandberg et al. (2019)

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For which topic were research priorities identified?

Turner syndrome

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Despite major discoveries, traditional biomedical research has not always addressed topics perceived as priorities by patients and their families. Patient-centered care is predicated on research taking such priorities into account.

What was the objective?

to conduct a survey of affected stakeholders regarding the perceived importance of biomedical versus psychological research in Turner syndrome

What was the outcome?

a list of 3 research areas

How long did the research prioritization take?

April 2016 - May 2016

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey: three questions assessed importance of different areas of research, single most important area of research and willingness to participate in different types of research, the questions were: How important is health research related to TS in the following areas? (medical/physical health problems, emotional/behavioral health problems including difficulty with relationships). The most important health research related to TS should focus on ..., How likely would you be to take part in the following types of health research related to TS?

Which stakeholders took part?

Surveyed women with Turner syndrome, parents of women with ts, parents of younger daughters with ts. 1338 participants: adult women (age 18 and older) with ts (n=543), parents of an adult daughter (age 18 and older) with ts (n=232), and parents of a daughter with ts, age 0-17 (n=563).

How were stakeholders recruited?

Participants were recruited through email lists belonging to the Turner Syndrome Society of the United States (TSSUS) and the Turner Syndrome Global Alliance (TSGA) - totaling 6,468 - and their respective Facebook pages.

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.