CAPTURING RARE
YOUTH VOICES

Data Collection August 13, 2020 - October 3, 2020

TREND Community™
Turning Anecdotes Into Evidence™

RARE Youth Revolution
Powering up young voices
Youth magazine

Data Collection Period August 13, 2020 - October 03,2020

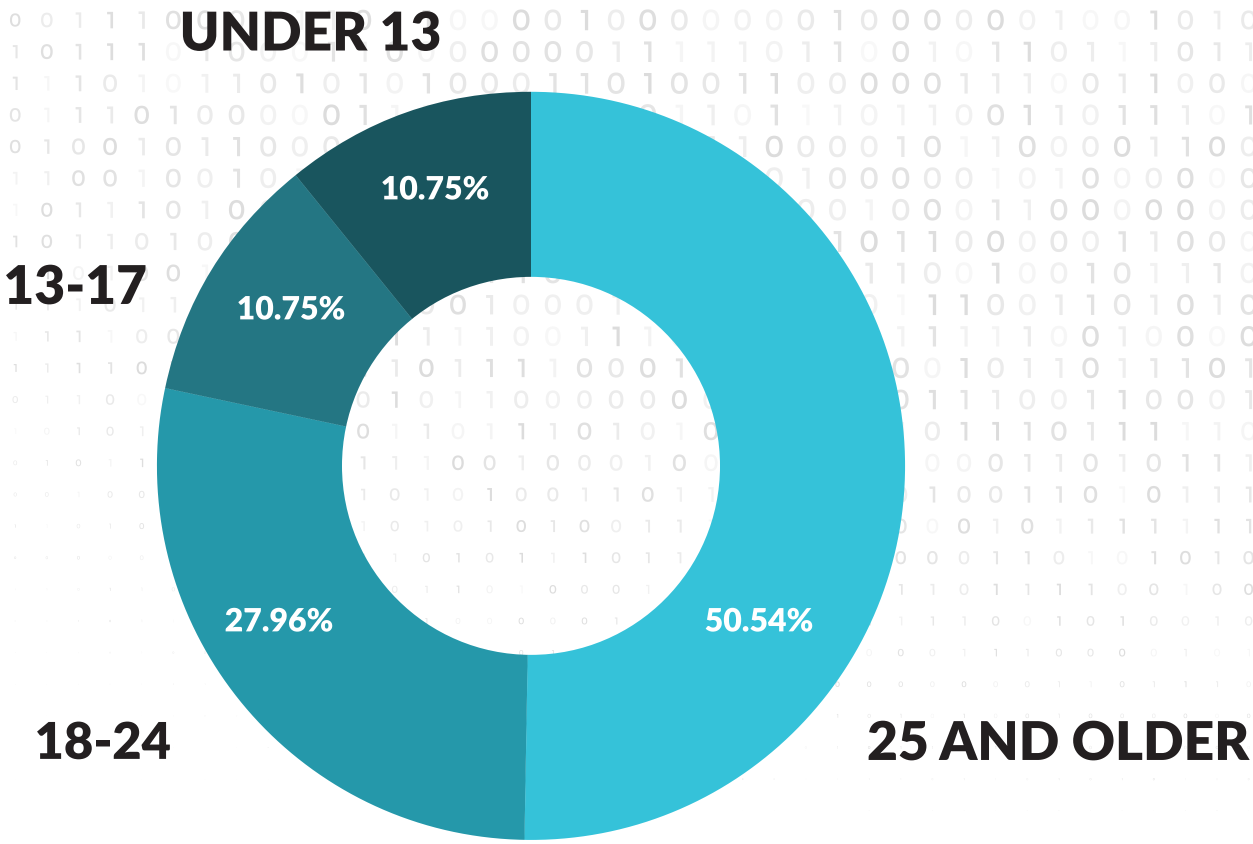
RESEARCH DESCRIPTION

TREND Community, RARE Revolution Magazine and RARE Youth Revolution launched a joint partnership to better understand the perspectives and needs of young people living with rare disease. We wanted to learn how children and young adults living with rare disease are engaging on social media to help us develop strategies to better power up the voices of our youth community. TREND ran a short survey with the hope of collecting information to further aid research into rare diseases and to gather a broader picture of how young individuals with a rare disease or condition are expressing themselves online.

TREND Community™
Turning Anecdotes Into Evidence™

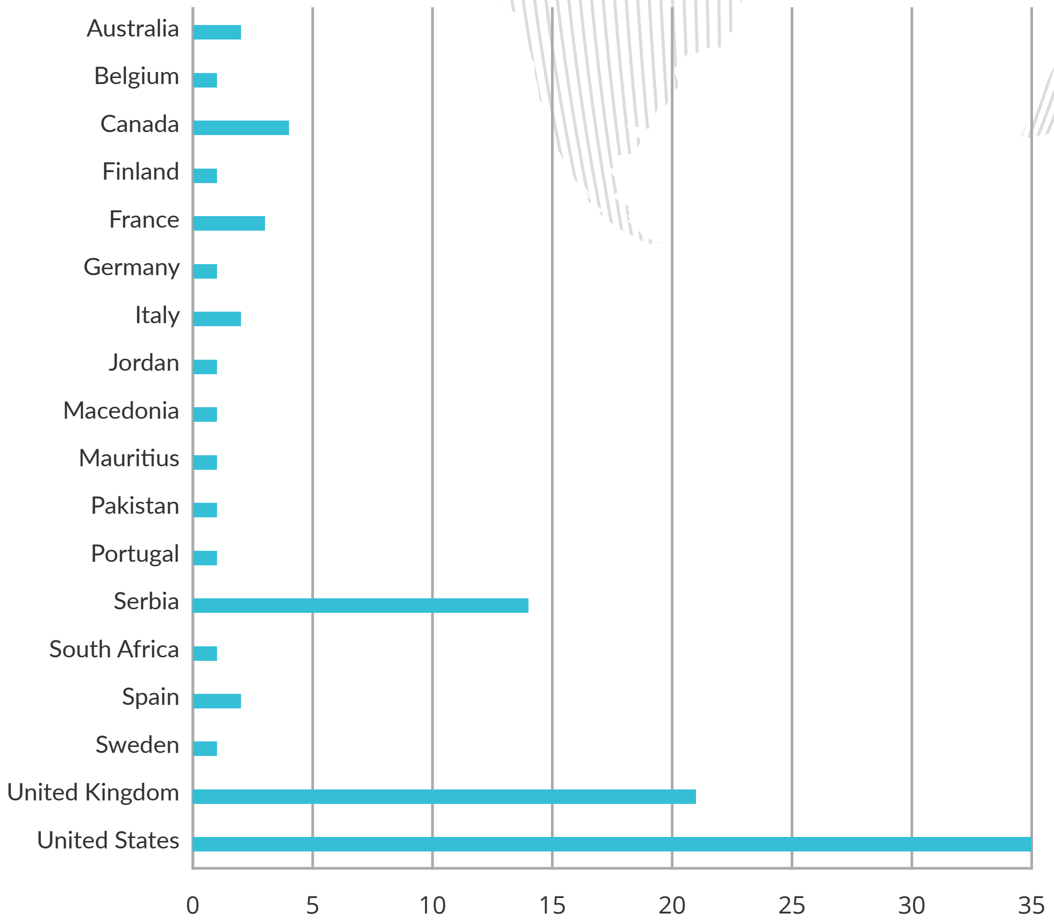
RARE Youth Revolution
Powering up young voices
Youth magazine

HOW OLD WERE RESPONDENTS?



WHERE DO RESPONDENTS LIVE?

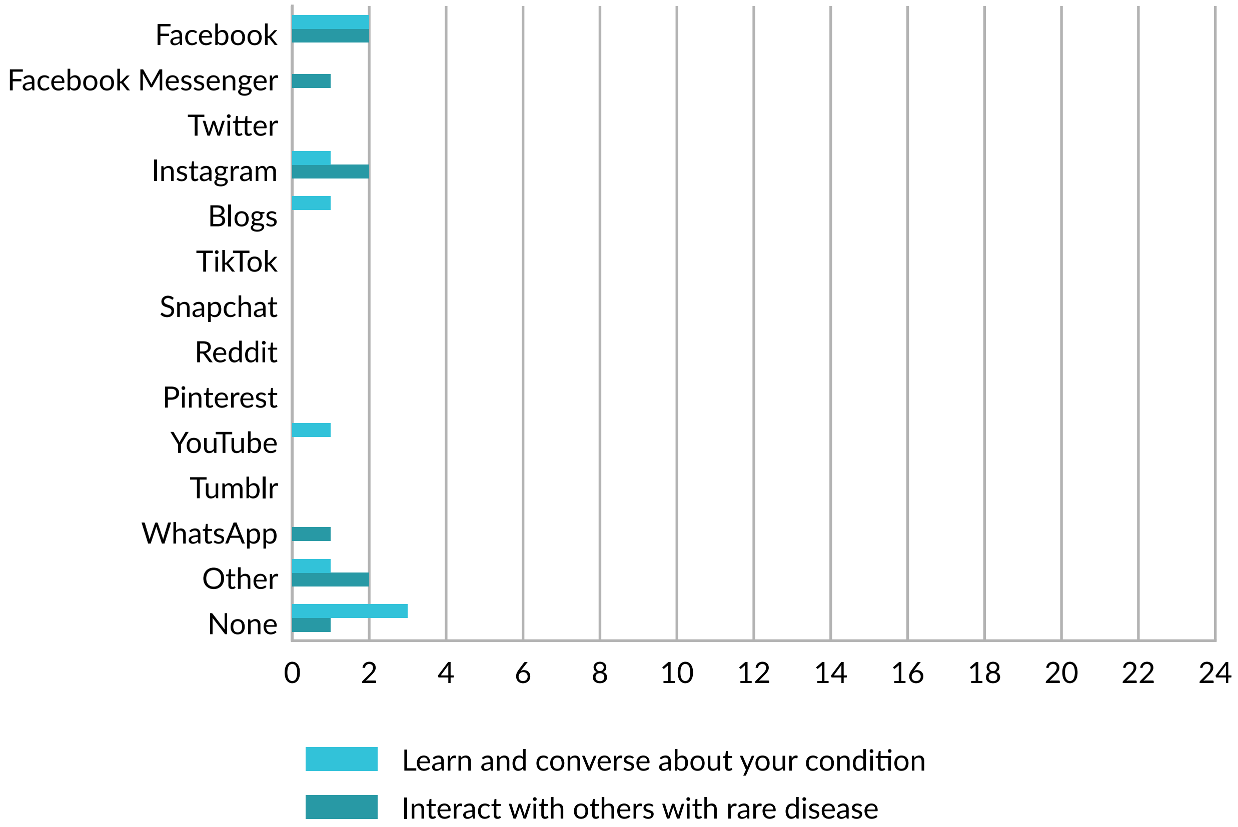
We had a truly diverse number of responses from countries around the world.



SOCIAL PLATFORM USE FOR RESPONDENTS UNDER 13

Which social media platforms do you use most to **learn** and converse about your condition?

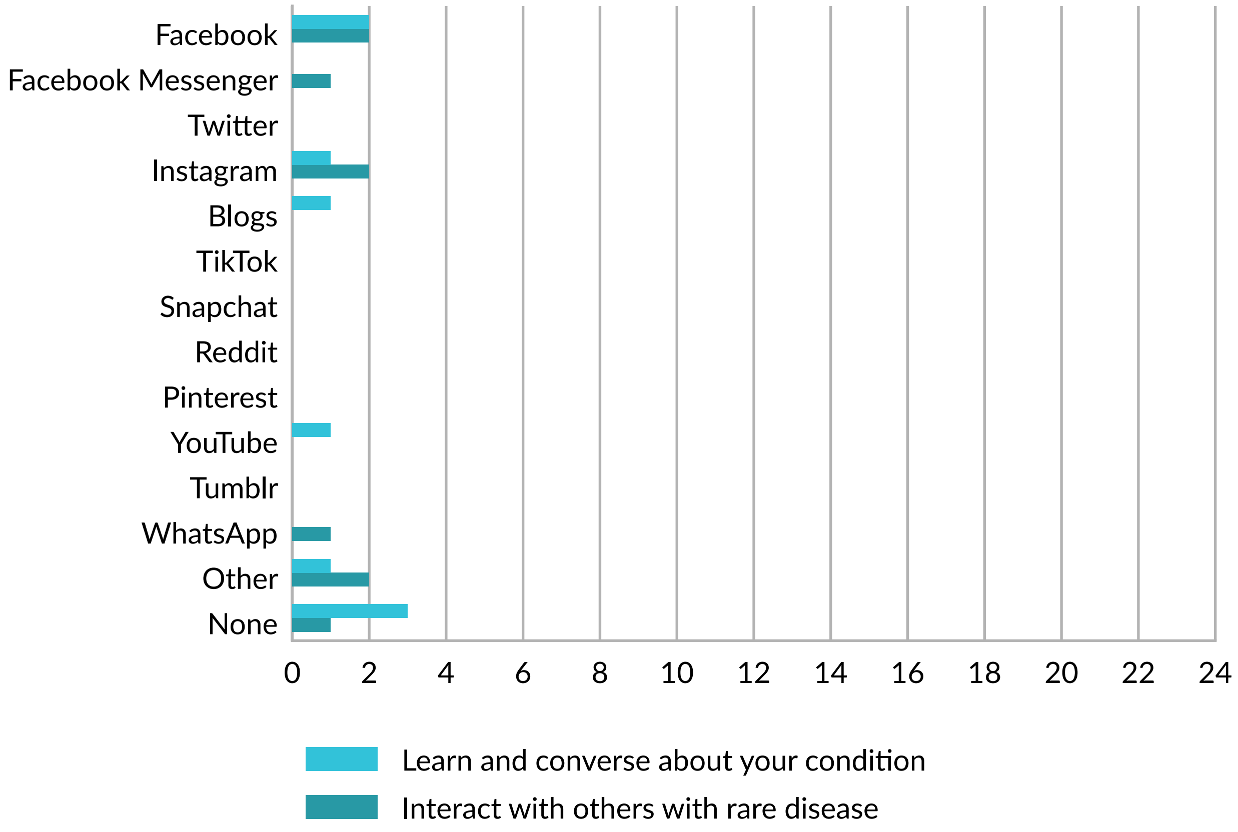
Which social media platforms do you use to **interact** with others living with rare disease?



SOCIAL PLATFORM USE FOR RESPONDENTS AGES 13-17

Which social media platforms do you use most to **learn** and converse about your condition?

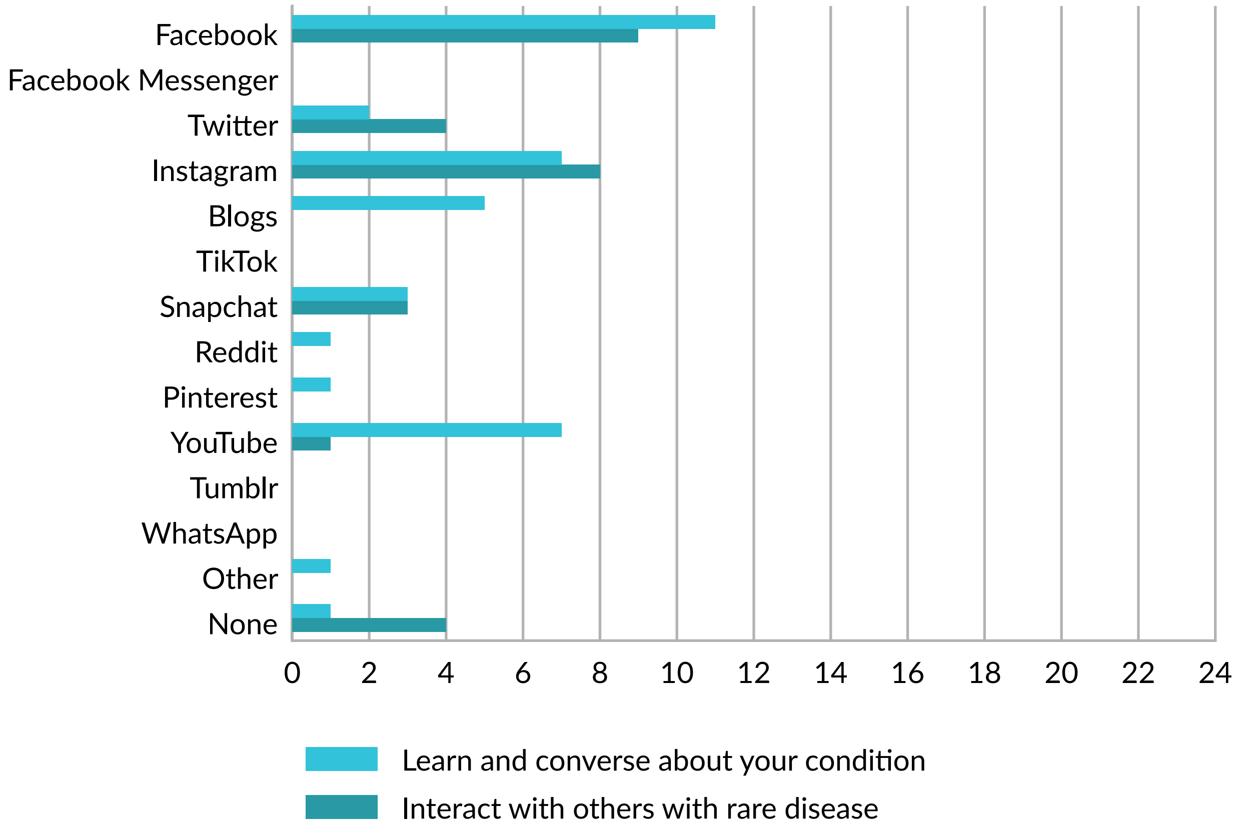
Which social media platforms do you use to **interact** with others living with rare disease?



SOCIAL PLATFORM USE FOR RESPONDENTS
AGES 18-24

Which social media platforms do you use most to **learn** and converse about your condition?

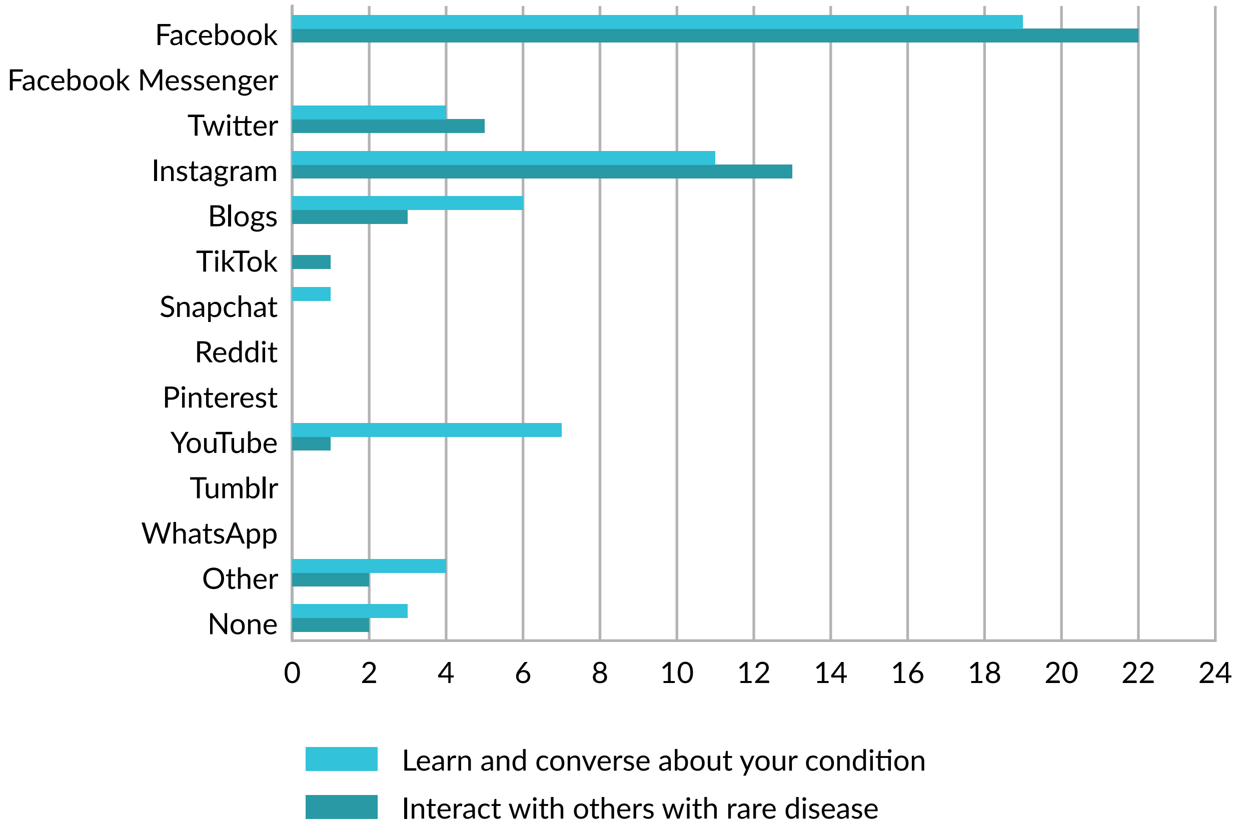
Which social media platforms do you use to **interact** with others living with rare disease?



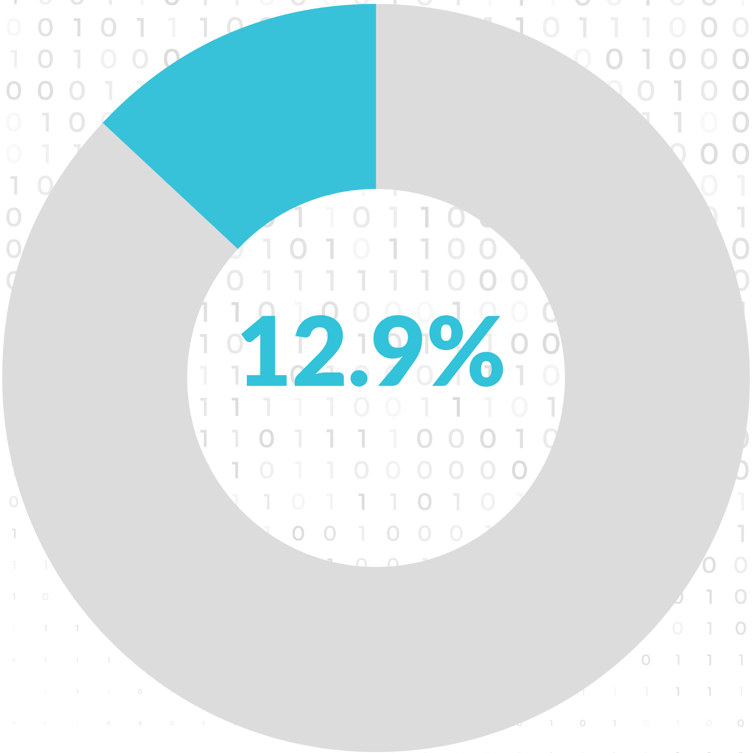
SOCIAL PLATFORM USE FOR RESPONDENTS 25 AND ABOVE

Which social media platforms do you use most to **learn** and converse about your condition?

Which social media platforms do you use to **interact** with others living with rare disease?



WHAT PERCENTAGE ARE UNDIAGNOSED?



12.9% of respondents mentioned being undiagnosed (12 out of 93 respondents).This is a universal unmet need when it comes to rare disease. Patients and caregivers often spend years simply trying to get a correct diagnosis.

HOW ARE RESPONDENTS PERSONALLY AFFECTED BY RARE DISEASE?

I have a rare disease diagnosis	59
I have an undiagnosed medical condition	11
I am a young caregiver for someone with a rare disease diagnosis	4
I am the sibling of someone with a rare disease diagnosis	6
I am a child of a parent, or other family member with a rare disease	13

IN CONCLUSION

As communication evolves, TREND Community, RARE Revolution Magazine and RARE Youth Revolution believe that stakeholders need to meet people where they are. Today's youth do not communicate in the same way their parents did, and they don't use the same means of communication. As we continue to create more surveys and make more discoveries, it is our hope that we can create a more inclusive community of patients, advocates, caregivers, and stakeholders. Capturing the patient voice of youth communities is a critical part of this mission. There is so much to be gained when we talk, and understating the dynamics of how young people interact is crucial to fostering those conversations for everyone.

TREND Community™
Turning Anecdotes Into Evidence™

RARE Youth Revolution
Powering up young voices
Youth magazine