

**SEVERE CONGENITAL  
NEUTROPENIA**

# **COVID-19 PATIENT SURVEY REPORT**

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How real patients feel about  
clinical trial participation in  
the midst of a global pandemic

RESULTS FROM A SURVEY CONDUCTED  
**APRIL 2020**



# SEVERE CONGENITAL NEUTROPENIA

x4 Pharmaceuticals partnered with Savvy Cooperative to field a survey to capture patient perspectives in the time of COVID-19 in their ongoing effort to better understand and support the patient communities they serve. The survey was sent to targeted patient communities for whom x4 Pharmaceuticals is actively developing treatments. In particular, x4 Pharmaceuticals wanted to identify patient concerns and areas to improve clinical trials during the global pandemic.

## PARTICIPANTS

**Respondents:** 19 participants

**Ages:** 20-75

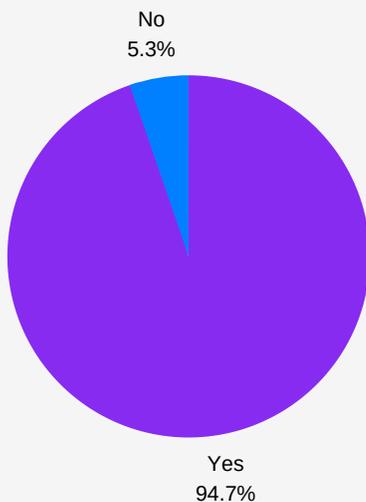
**Geographic Locations:**

*United States:* General, Midwest, East Coast, West Coast

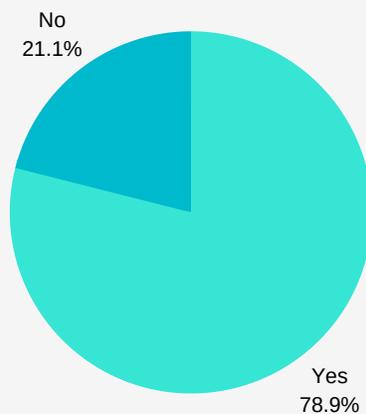
*Ex-US:* United Kingdom

## RESULTS

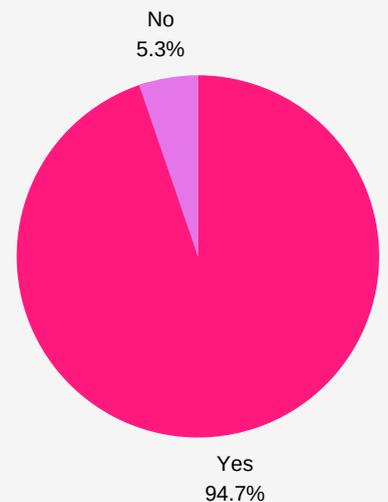
Considering the COVID-19 pandemic, if your doctor said it was safe, would you be willing to go to a hospital or clinical trial site to take part in a clinical trial?



If your doctor said it was safe, would you be willing to take part in a clinical trial if you had to fly in a plane to get to the hospital or clinical trial site?



If all clinical trial-related appointments could be done at doctor offices near you instead of at a hospital or clinical trial site, would you be willing to take part in a clinical trial right now?



### The survey responses revealed the following results:

- Patients skewed to US & UK due to this being an English-language survey
- Super-majority of patients willing to participate and fly if/when doctor says it is safe
- Super-majority of patients willing to participate in a trial with visits conducted locally

# WHAT PATIENTS SAID

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*“I stay at home more, wear a mask, and wash my hands all of the time.”*

*“Staying home and limiting contact with others. Also taking shot every 3 days”*

*“I don't go out unnecessarily. I have family assisting with necessities and I am full-time working from home.”*

*“Working from home 70% of the time. Staying at home, having groceries delivered.”*

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## KEY TAKEAWAYS

### Survey results across different patient communities revealed:

- The majority of patients will participate in a clinical trial at a hospital or trial site if their doctor says it is safe
- The majority of patients will travel if their doctor says it is safe
- The majority of patients will participate in a trial at local doctor's offices

## WHAT COMES NEXT?

### x4 Pharmaceuticals is actively making changes based on your input. Here's what they are doing to address what they learned:

- X4 Pharmaceuticals is incorporating home health visit options to reduce travel as much as possible in its phase 1b clinical study for patients with severe congenital, chronic, and idiopathic neutropenia
- The insights on travel and life during COVID-19 also led X4 Pharmaceuticals to incorporate an at-home testing option for its no-cost genetic testing program for neutropenia (<https://www.invitae.com/en/path4ward/>) to reduce how often a patient has to visit a doctor's office
- To learn more about the clinical trial or the genetic testing program, please contact Michele Rhee at [michele.rhee@x4pharma.com](mailto:michele.rhee@x4pharma.com)