

People with CP and their Family's Preferences about Genomics Research

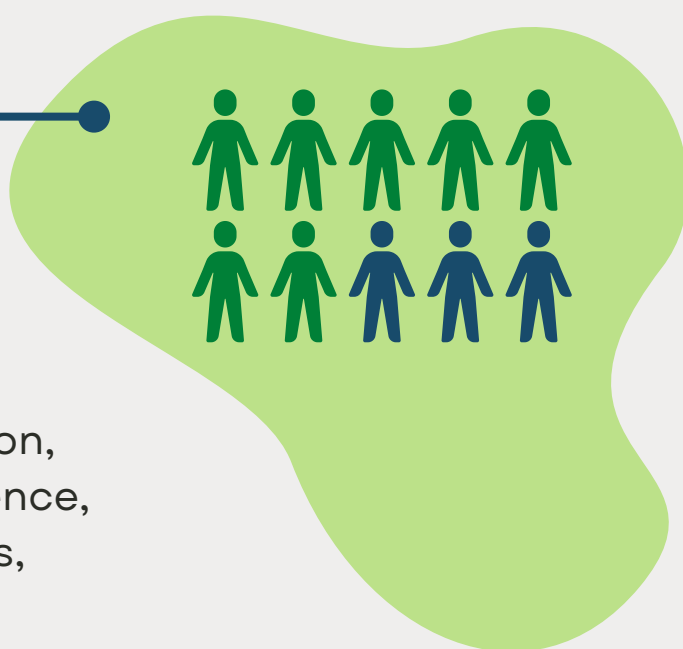
This study captured the views of people with CP and their family's about genomics research, biobanking, and how genomic data is used and stored.

145 people participated in the electronic survey - majority of participants were mothers of individuals with CP.

Willing to Participate

68% of participants were willing to participate in a CP genomics research study.

Willingness to participate was associated with tertiary education, previous genetic testing experience, increased awareness of genetics, and trust in international researchers



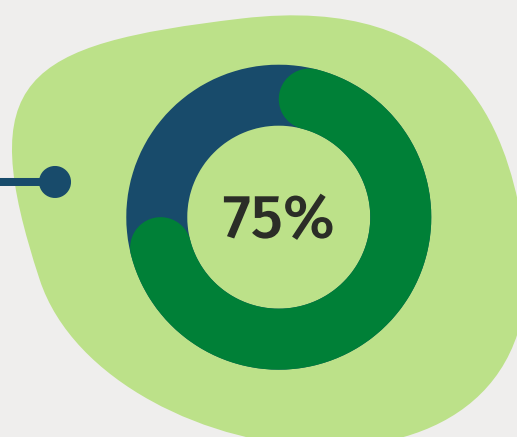
Data Sharing

82% were willing to share their de-identified genomics and clinical data



Biobanking

75% were willing to participate in sample sharing via biobanks



What Information is important when considering participation

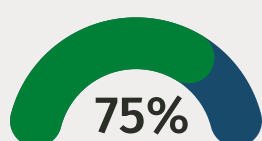
Purpose

The purpose of the study was important for both participation in the original study (94% indicated important), as well as for any studies their data was being accessed/shared (83%).

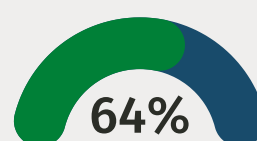
Data security

The steps taken to anonymize their information for data sharing (88%), keeping their information confidential (87%), and what would happen in the event of a breach (86%) were also important.

Communication



Wanted to hear from researchers once a year if enrolled in a study.



Wanted to be notified when their data had been shared.

Find the full text manuscript published in [Public Health Genomics](#)

Wilson YA et al., (2021). People with cerebral palsy and their family's preferences about genomics research. Public Health Genomics, 1-10.