

We want your input!

If your child with Down syndrome is younger than 22 years old, you are eligible to fill out our **SURVEY** and help us in developing a **Health Instrument for Individuals with Down syndrome**.

WHO

Dr. Stephanie Santoro MD (right) is a medical geneticist at Massachusetts's General Hospital's Down Syndrome Program (MGH DSP). Dr. Santoro and the MGH DSP team are creating an instrument that directly assesses health in individuals with Down syndrome.

WHAT

The survey is **up to 100 questions** and should take **less than 40 minutes**. The survey will ask questions about your child with Down syndrome and their health.

WHEN

Survey 1: Now!
Survey 2: 2-4 Weeks after taking Survey 1

WHY

There are over 200,000 individuals with Down syndrome living in the United States and studies to date have focused on outcomes outside of health. It is important to accurately measure the health of all individuals with Down syndrome and there aren't similar tools available for this population. Creating such an instrument will provide a measure of the current state of health for an individual with Down syndrome and be helpful in future research aimed at improving the health and happiness of individuals with Down syndrome.



SCAN THIS QR TO GO
TO THE SCREENING
FORM!



You can also access the screening form at

<https://redcap.partners.org/redcap/surveys/>

by entering the following code

A7CYA4WN3

Participation is voluntary and you have the right to withdraw at any time

IRB Contact: "If you'd like to speak with someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Partners Human Research Committee at (857) 282-1900"

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If you have any questions, please contact
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