



2023 Quality of Life Survey - FAQs

If you have additional questions please reach out to the survey administrator at gretchen@csrf.net.

Q: Who is conducting this survey?

A: Cushing's Support & Research Foundation (CSRF) and the World Alliance of Pituitary Organizations (WAPO) are collaborating on design, translation, distribution, and analysis of the data collection. CSRF is a US-based, non-profit organization that began in 1995 and has been patient-led since inception. WAPO is a global pituitary organization that was formed in 2014 to support new and existing pituitary patient groups everywhere. You can find more information on websites csrf.net and wapo.org.

Q: What is the main objective of this survey and how will the collected data be utilized?

A: We wish to gain insights into global patient experiences with diagnosis, treatment, and quality of life. Our ultimate goal is to improve care and support to Cushing's patients worldwide. Our findings will be used and shared in many ways that include the following:

- A live presentation by CSRF at the WAPO Summit 2023 held October 6-8 in Buenos Aires, Argentina
- An article in our newsletter
- A report that we will share at professional conferences and on our website
- Summaries on social media that will link back to the full data
- Live presentations and/or professional posters for conferences in 2024

Q: How will you protect my identity and other personal information?

A: None of your personal data will ever be shared, rented, or sold to anyone for any reason. The results of the survey will be deidentified and shared as averages, percentages, graphs, and other aggregate summaries that do not name any individual. SurveyMonkey, the program used

to create the survey and collect the data, has a robust privacy policy that can be viewed here: <https://www.surveymonkey.com/mp/legal/privacy/>.

Q: How long will it take for me to complete this survey?

A: The survey consists of 142 “yes or no” questions about treatments, diagnosis, and quality of life plus seven demographic questions. It will take approximately 15-20 minutes to complete. We understand this is a substantial commitment, and we appreciate your time.

Q: Can I exit the survey and return to it later, or do I need to complete it in one session?

A: Please plan to complete the survey at the same time you start it because there is no option to save and return later. If you are unable to complete it, you can discard your work and return later to start over again.

Q: Why is this survey asking me about things I don't often get asked, or see mentioned in research or in the doctor's office?

A: We believe that people who have experienced Cushing's have a unique opportunity to educate patients, providers, and others in our community. Even our best doctors and researchers are limited in what they can explore. When we identify our commonalities and validate the complex aftermath of Cushing's, especially details related to long-term recovery and quality of life, we create priceless data that cannot be collected in any other way. CSRF has convened a patient committee three times since 2020 to review and update the survey's contents. Every person taking this survey is participating in valuable research, and the finished products will be effective tools that will help tell our stories to a global audience.