

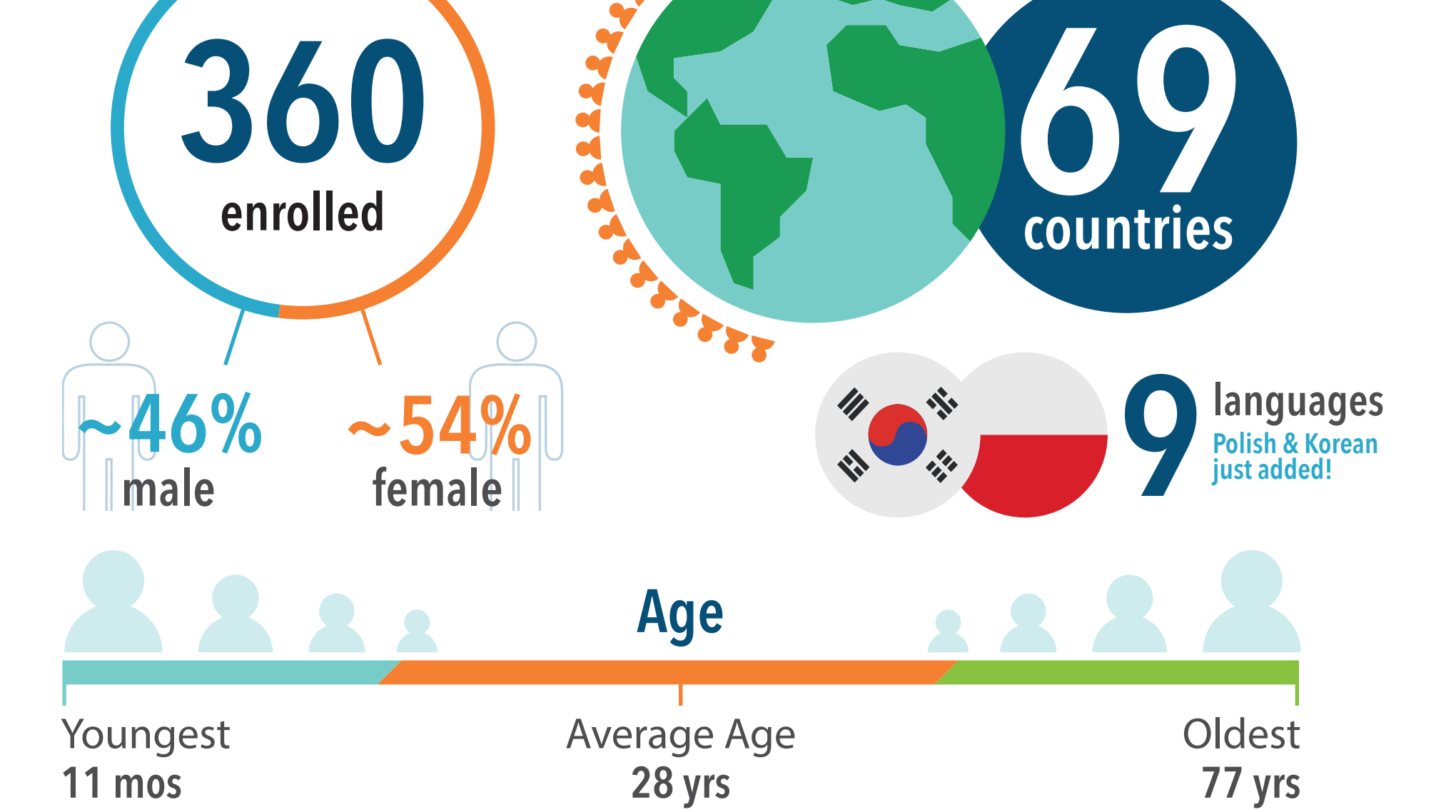
What is the FOP Registry?

It's the largest and most detailed collection of medical information about people with FOP.

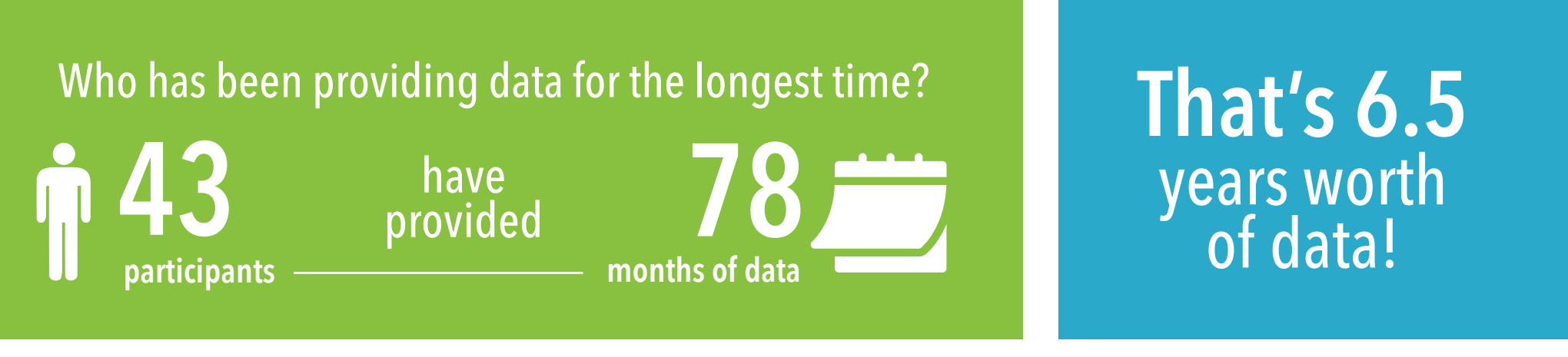
People living with FOP from around the world, and their doctors, are contributing to this important resource.

Information from the FOP Registry is used to improve clinical care and speed the development of treatments.

Who's Taking Part in the Registry?

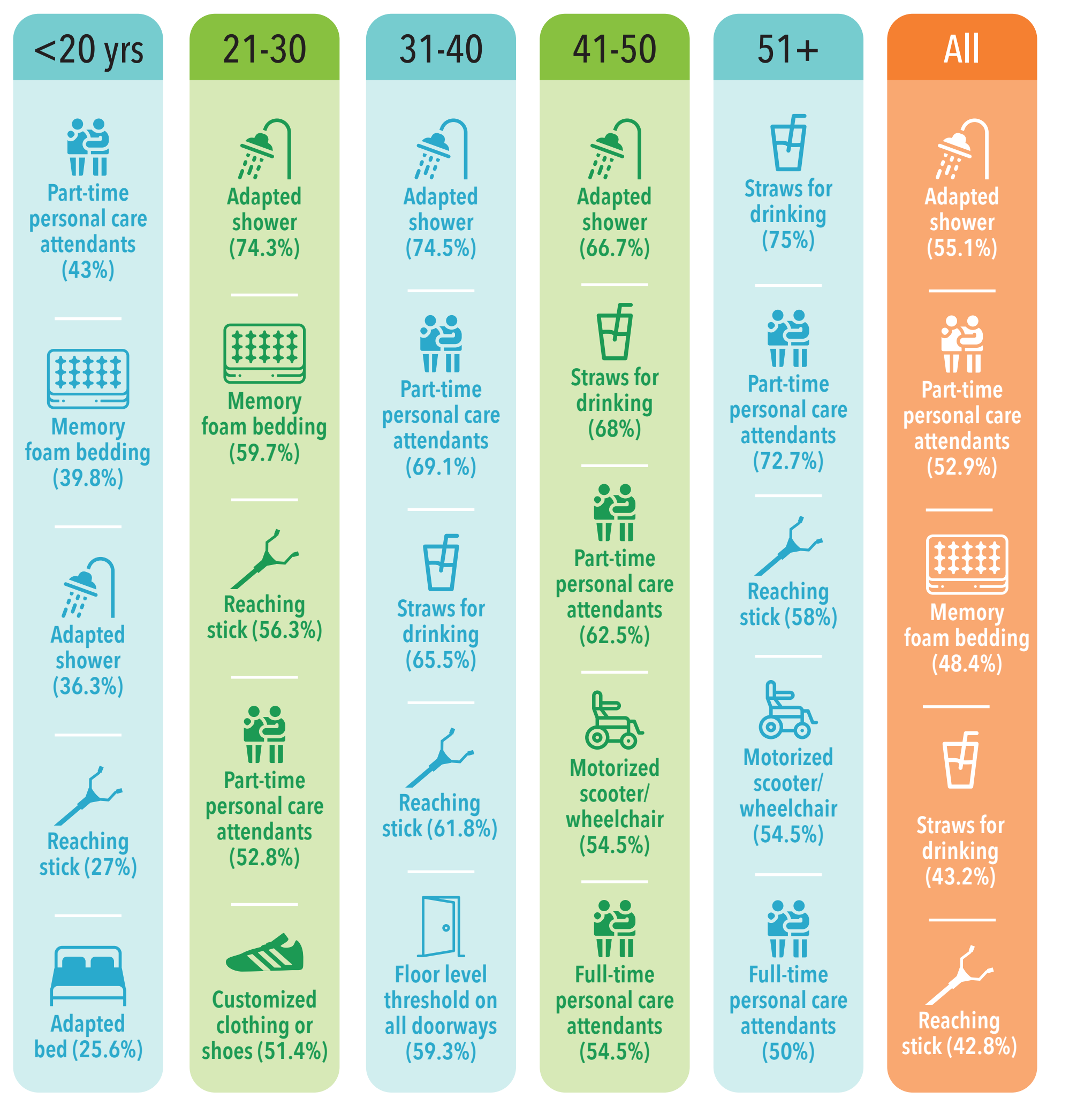


After completing the Enrollment Survey, participants are invited to complete Follow-up Surveys every 6 months. Here's what we're learning:



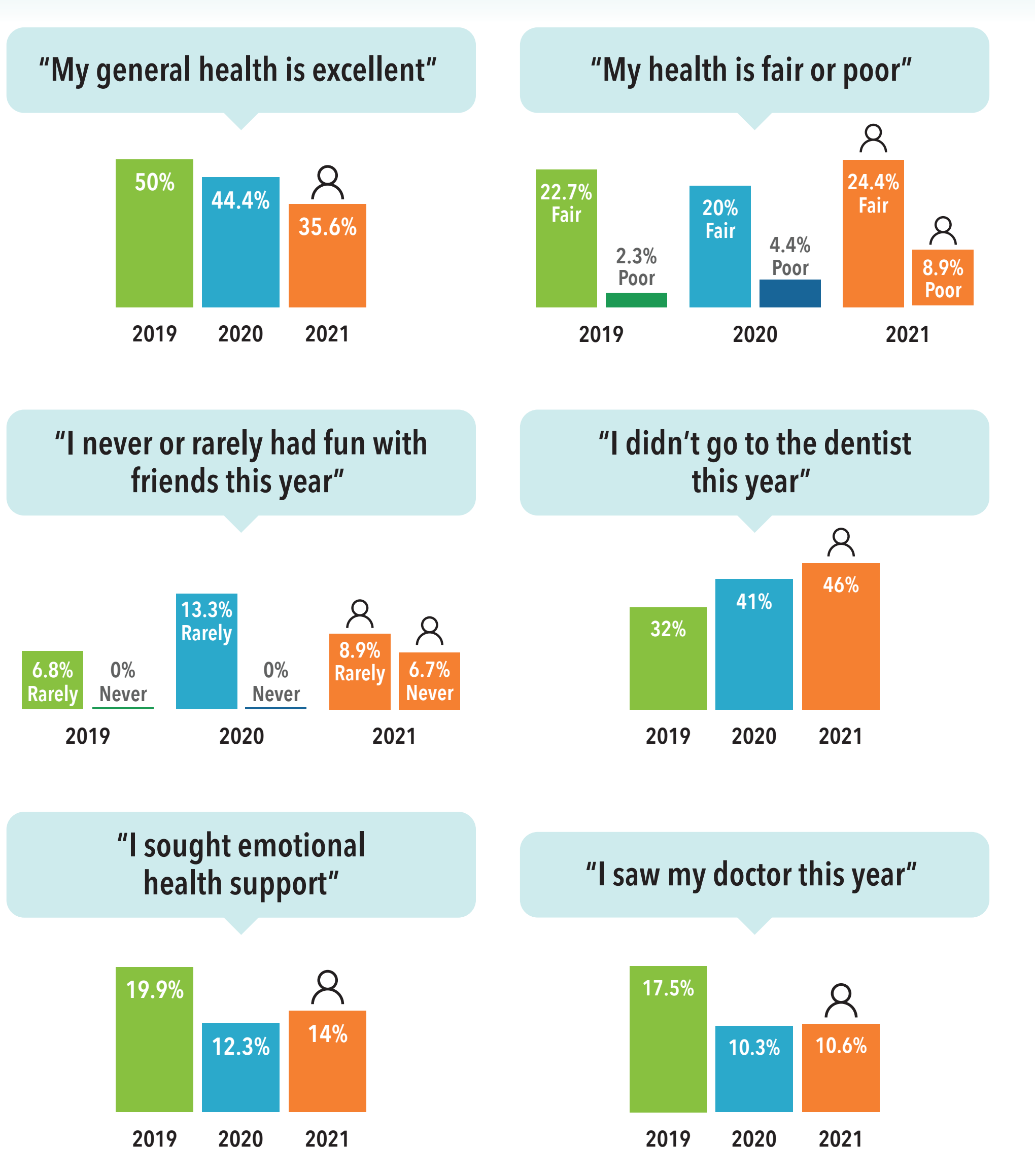
Who's Using Aids, Assistive Devices and Adaptations (AADA)?

Most Common Tools Used (by age)



Who's Still Feeling the COVID Impact?

Here's What People Are Saying



2021 FOP Registry Accomplishments

Medical Portal

The FOP Registry has a Medical Portal where FOP doctors can enter data on their FOP patients! We now have active Medical Portal sites in these countries: Argentina, Australia, Brazil, Mexico and the United States. FOP patients must consent to having their data entered.

Height and Weight Survey

Launched a Height and Weight Survey to help develop clinical trials.

FOP-PROMPT Symptom Tracker

In 2020, the IFOPA developed the FOP-PROMPT, a daily FOP symptom tracker. In 2021, the IFOPA engaged with the FDA and continued to develop and validate the tracker so that it can be included in clinical trials. The FOP-PROMPT is now being integrated into an upcoming clinical trial to help researchers understand the effects of a study drug on FOP symptoms and flares.

New Data Published

Data on Caregiver Support in FOP was published in the Journal of Rare Diseases Research & Treatment.

A collaboration with the University of California, San Francisco resulted in an article on the Impact of COVID-19 on People Living with FOP in the Orphanet Journal of Rare Diseases.

Registry data was incorporated in a publication on the Prevalence of FOP in the United States, published in the Orphanet Journal of Rare Diseases.

FOP Registry Video

We created a video that helps explain the FOP Registry and how people living with FOP can get involved! It will soon be translated into 8 languages.

Languages Added

The FOP Registry added Polish and Korean translations to the Registry surveys, and now has 9 languages.

Thank You to Our Registry Sponsors

Thanks to funding support from our sponsors, the FOP Registry has continued to serve the FOP community.

Visionary Partner:
Incyte Pharmaceuticals

Collaborating Partners:
BioCryst Pharmaceuticals
Ipsen
Regeneron Pharmaceuticals

The FOP Registry would not be possible without our Medical Advisory Board members, Participant Board members, and our Registry participants.

Special Thanks To:

Radiant Hope Foundation for the initial vision and funding support of the FOP Registry.

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FUND RESEARCH. FIND A CURE. SUPPORT FAMILIES... WORLDWIDE

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