

Speak up)) about tech

A STUPID CANCER + SYNEOS HEALTH RESEARCH INITIATIVE

What does the AYA Community have to say about digital health technologies?

What's working? What's not? And what's yet to be imagined?

There's lots of buzz around benefits and challenges that come from innovations in mobile health, health information technology and wearable devices. Knowing that the AYA community has unique needs and experiences, Syneos Health and Stupid Cancer teamed up to create Speak Up About Tech in AYA Cancer Care.

We're listening to and learning from Stupid Cancer community members so we can create tools that can help you address big picture questions around preferences, efficacy and efficiency in digital health and related concerns around access and inequity.

AYA ambassadors led the way.

What's working? What's not? And what's yet to be imagined?

Representation is important and unfortunately lacking in many spaces. I want people from underrepresented groups to be given a voice. Also, our age group is often forgotten about in cancer spaces. I want our opinions to be heard and shared.
– **Chrystle**

What I found most interesting hearing from fellow AYAs was how the participants shared their experience and it brought healing for others because they felt seen, heard and valued because of how similar their experiences were.
– **Nazanin**

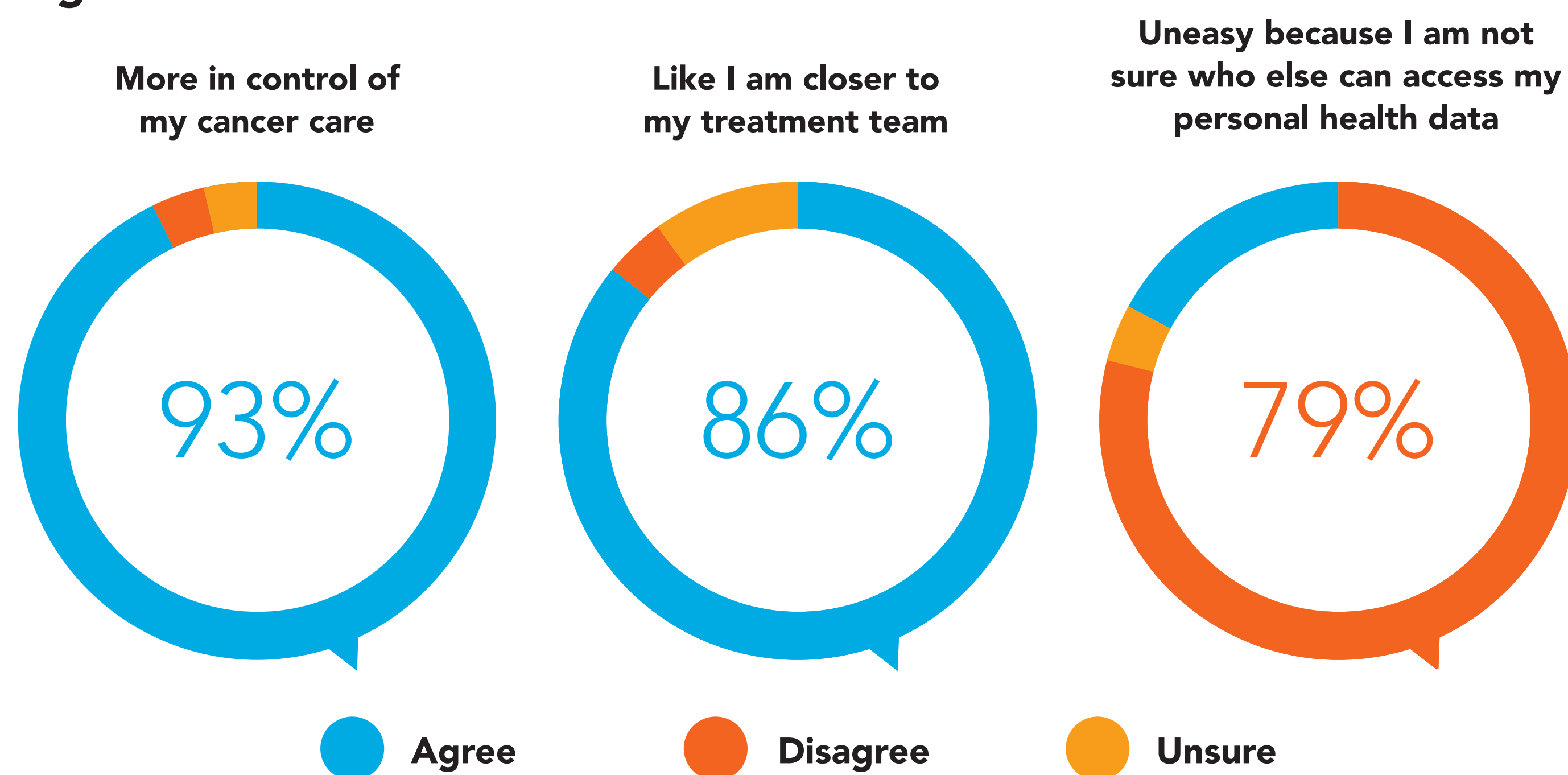
I think it's important that young adults have their voices and opinions heard. I always enjoy these types of things so I can learn about other people, get to know them and their experiences and provide any resources, help or guidance that I can.
– **Michael**

We conducted a poll at Digital CancerCon.

Here's what respondents had to say:

- **75.9%** use digital health tools very often
- **93.1%** for easier communication with their treatment team
 - **65.5%** to monitor health issues
 - **100.0%** use a patient portal and **86.2%** have telehealth appointments
- **17.2%** do not have consistent or affordable internet/broadband access at home

Digital health makes me feel



We held listening sessions.

Here's what we heard

In two listening sessions we dug deeper through small group discussions organized around age and representative across cancer types and demographic background.

Group 1 AYAs 20-27 years old

Group 2 AYAs 27-39 years old

Group 1 had slightly greater exposure to a variety of digital health tools. Across both age groups, participants feel assumptions are made about their access and comfort with technology as young people. AYAs overall report not receiving much communication or support around their digital healthcare.

Digital health cannot replace the human connection. The AYAs shared seeing their providers face-to-face in addition to virtually helps them to feel treated as a real person, not a figure on a screen. Most participants preferred receiving significant news, such as a diagnosis, in-person rather than through a call or a patient portal message.

From insights to action, AYAs shared:

Viewing lab test results before discussion with a provider can create confusion and anxiety

Create a patient/provider checklist and discussion guide that include topics on communication to help increase dialogue. Patients can have upfront conversations regarding their preferences for receiving test results (e.g., opt-out of notifications) and other important health information (in-person vs. patient portal) to mitigate potential stressors.

Independently researching for the best digital health apps to use because care team is not providing recommendations

Develop a resource that provides community ratings for currently available digital health applications. Creating a rating system that is geared towards AYAs with cancer can facilitate easier navigation and reduce the fatigue of constant trial-and-error while testing apps.

We asked the community to imagine

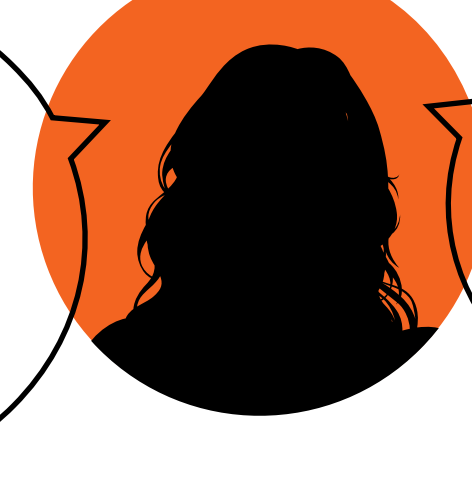
If you could create a digital health solution that would help you or the broader AYA community, what would it be?

"There are a **billion support groups for AYA**, but do you think they know about each other? They don't. Even in my same city, I'm a part of four and I'm like this could be one."



"I told my oncologist once I wish there was like a **dating app for people that are doing this**, you could like kind of match with people and sort of connect with them. I think **community is one of the most important things to utilize and to have in your arsenal for your care.**"

"Because a lot of times with young adult cancer, it's our first big medical thing and we have to learn on the job, how to advocate. It would be better if we had **something teaching us how to advocate as we go through it.**"
"We all crave these instruction manuals."



"Think if MyChart portals and things like that had the apps that we were saying that we used like logging your medications, but if they had an **app that integrated and helped you kind of track your symptoms, track your medications, and reminders that were in the portal.**"

We're still listening.

SPEAK UP: WHAT'S YOUR IDEA?

Raise your voice and share your insights before the end of CancerCon 2023.

Top Themes for Digital Health Solutions

- A "one-stop shop" patient portal
- A more engaging and connected AYA platform
- A roadmap for navigating cancer treatment and advocacy



If I could create a digital health solution, I would...
Scan the QR code to answer

