

AllofUs.nih.gov User Testing

Overview

● Objectives:

- Understand prospective participants' and prospective researchers' experiences on AllofUs.nih.gov, including their preferences, needs and any points of confusion
- Gauge reactions to proposed content and navigation
- Identify opportunities to better support user pathways to enroll/register with *All of Us*

● Methods:

- Qualitative interviews
- First-click testing

User Testing: Prospective Participant Segment

PP #	Age Group	Race/ Ethnicity	State	Geographic Area	Household Income	Gender	LGBTQ+	Health Condition/ Disability
1	55–64	African American	MD	Suburban	\$35,000–\$54,999	Female	Lesbian	Congestive heart failure
2	55–64	Caucasian	FL	Rural	\$75,000–\$99,999	Male	No	N/A
3	55–64	Caucasian	NV	Urban	<\$35,000	Male	No	Spinal cord damage, Spasticity
4	25–44	Hispanic Latina	CA	Suburban	\$75,000–\$99,999	Female	No	Asthma
5	30–39	Asian American	WV	Rural	\$55,000–\$74,999	Female	No	N/A
6	45–54	Caucasian	MA	Urban	\$35,000–\$54,999	Female	Lesbian	Hashimoto's disease, Celiac disease
7	45–54	African American	AZ	Suburban	\$75,000–\$99,999	Female	No	N/A

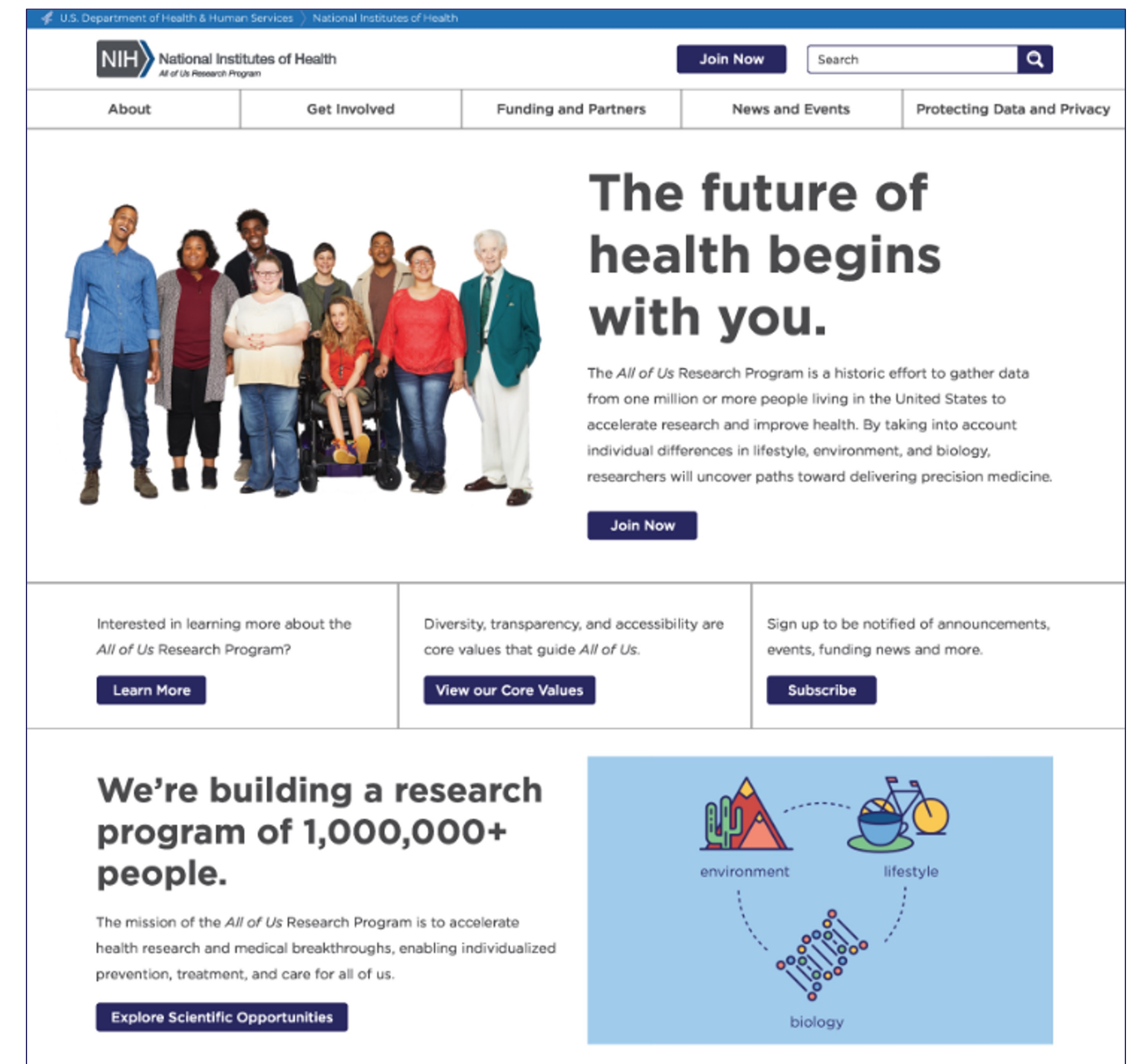
User Testing: Prospective Researchers Segment

PR #	Age Group	Race/Ethnicity	State	Geographic Area	Gender
1	40–49	Asian American	OH	Urban	Male
2	40–49	Hispanic Latino	RI	Urban	Female
3	30–39	Hispanic Latina / African American	MA	Urban	Female
4	30–39	Caucasian	DC	Urban	Male
5	40–49	Caucasian	VA	Suburban	Female
6	30–39	African American	MA	Urban	Female
7	40–49	Caucasian	KY	Rural	Female

What Works Well: First Impressions

- Prospective Participant and Prospective Researcher groups both liked the focus on diversity.
- Prospective Participant users were interested in the Core Values CTA.
- Prospective Researcher users were interested in a study with 1,000,000+ participants.

“When you see a company has core values, you can see if they align with yours. If they did, I’d be more likely to join.”



What Works Well: Helpful Pages

- ◎ All Prospective Participants found the following pages helpful:
 - Program Overview
 - Core Values
 - Participation

- ◎ The majority of Prospective Researchers found the following pages helpful:
 - Program Overview
 - What Makes *All of Us* Different?
 - Protocol
 - Scientific Opportunities

What Works Well: Identifying JoinAllofUs.org and Research Hub Links

- ◎ When asked, “Where would you click to sign up?”
 - Five Prospective Participants selected a JoinAllofUs.org text link or CTA.
 - One clicked “Participants as Partners.”
 - One clicked “Consent Process.”
 - All Prospective Researchers selected a Research Hub link.



Areas of Improvement: Readiness to Join

First Impressions

*“The Future of Health Begins with You’ is interesting. There’s a button below that says ‘Join Now.’ **I would not click on Join Now yet, but that headline grabs my attention.**”*

Final Thoughts

- ◎ By the end, all Prospective Participants expressed a tentative interest in joining *All of Us*, but said **they would need more information before deciding to join.**
- ◎ Before being asked where they *would* click *if* they decided to enroll, only three clicked a JoinAllofUs.org link unprompted.
- ◎ Questions remained about:
 - Eligibility and cost
 - What commitments participation requires
 - Who’s involved
 - What people are saying about the program

Areas of Improvement: Improving Clarity

◎ Purpose and Eligibility:

- Prospective Participants were confused about the purpose of the study and eligibility in regard to health status.
- Only one Prospective Researcher identified precision medicine as the focus of the program on the homepage.

Recommendation: Clarify program purpose and eligibility on the homepage.

◎ “Scientific Opportunities” label:

- Prospective Participants expected this to be synonymous with “Participation” label.
- Prospective Researchers expected to find grant proposal opportunities.

Recommendation: Change “Scientific Opportunities” to “Researcher Opportunities” or “Opportunities for Researchers.”

Areas of Improvement: Improving Clarity, Continued

◎ “Participants as Partners” vs. “Funding and Partners”

- Prospective Participants expected funding to play a role in participation.

Recommendation: Use labels to differentiate “Program Partners” from “Participants as Partners” terms.

◎ Who Is “*All of Us*?”

- Most Prospective Participants were not familiar with NIH or did not understand the connection.

Recommendation: Explain the program’s connection to NIH on the “Who We Are” page and link to NIH.gov.

Areas of Improvement: Enhancing Prominence

● Program Overview

- Users found “How Can *All of Us* Make a Difference?” heading and bullets particularly compelling and suggested moving this to the top of the page.

Recommendation: Revise the page to move this content up.



***All of Us* Research Program Overview**

***All of Us* and Precision Medicine**

The National Institutes of Health formed the [Precision Medicine Initiative Working Group of the Advisory Committee to the Director](#) in March 2015. The group concluded its work in September 2015 with a [detailed report \(PDF | 1.05 MB\)](#). The report provided a framework for setting up the *All of Us* Research Program.

Precision medicine:

- Is based on you as an individual
- Takes into account your environment (where you live), lifestyle (what you do), and your family health history and genetic makeup
- Gives health care providers the information they need to make customized recommendations for people of different backgrounds, ages, and regions
- Helps you get better information about how to be healthier

All of Us is part of a new era in which researchers, health care providers, technology experts, community partners, and the public work together to develop individualized health care. Learn more about [who is involved](#).

How Can *All of Us* Make a Difference?

Too often, health care is one size fits all. Treatments meant for the “average” patient may not work well for individual people. Health care providers may find it difficult to coordinate care among specialists or to access all of a patient’s health information. Researchers may spend lots of time and resources creating new databases for every study.

All of Us is working to improve health care through research. Unlike research studies that focus on one disease or group of people, *All of Us* is building a diverse database that can inform thousands of studies on a variety of health conditions. This creates more opportunities to:

- Know the risk factors for certain diseases.
- Figure out which treatments work best for people of different backgrounds.
- Connect people with the right clinical studies for their needs.
- Learn how technologies can help us take steps to be healthier.

Learn about what makes the *All of Us* Research Program different.

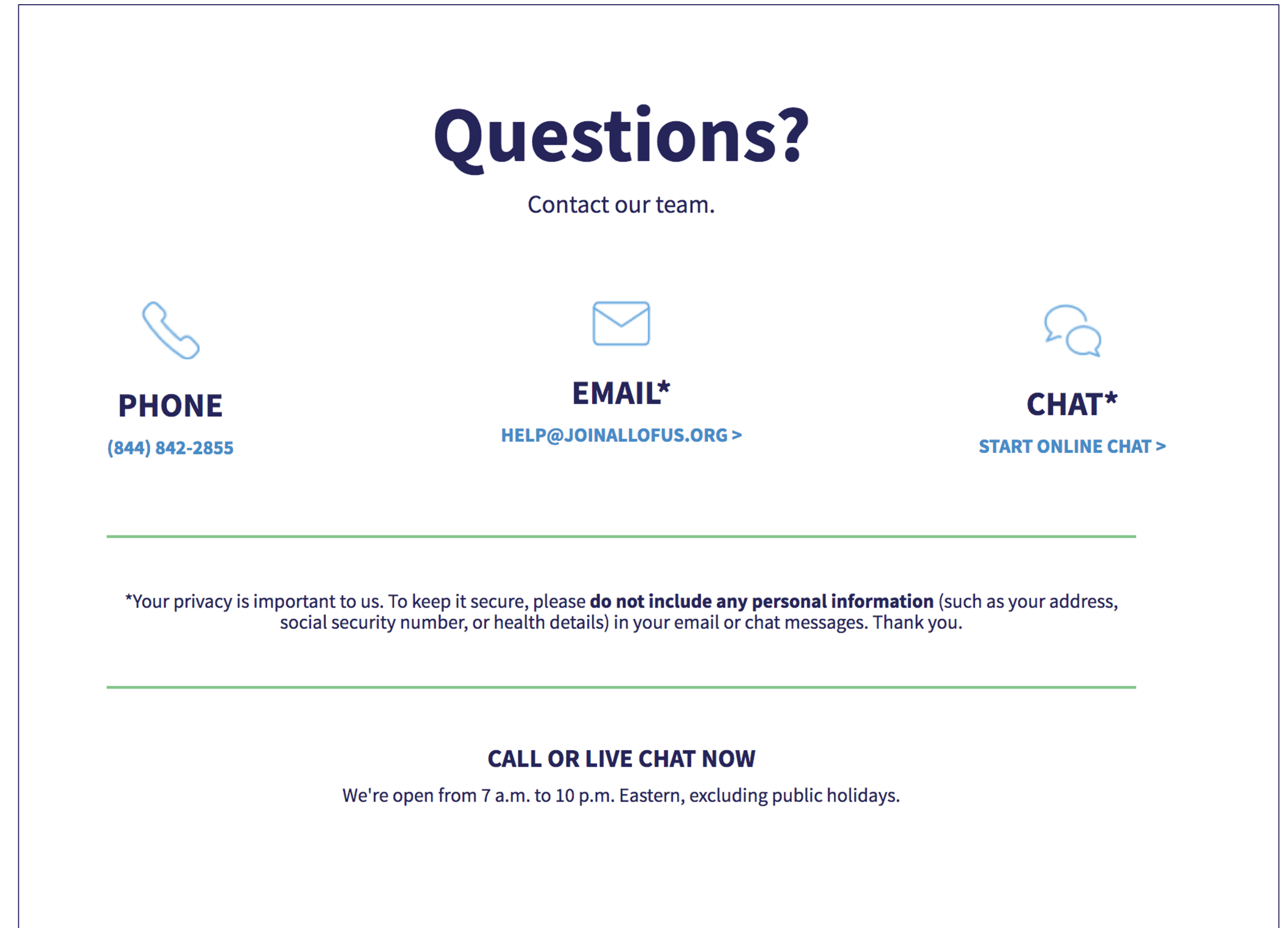
[Learn More](#)

Areas of Improvement: Enhancing Prominence, Continued

● Contact information

- Users wanted contact information to appear more prominently on several pages.

Recommendation: Add a contact callout that links to the *All of Us* Customer Service Portal.



Areas of Improvement: Enhancing Prominence, Continued

● Protocol Key Points

- Users wanted to see the Protocol Summary first and to see details about data types and process on this page.

Recommendation: Surface key points from the Protocol on the page and switch the Summary and Protocol links.

● Surfacing Details

- Users wanted more specific information on the “About,” “Get Involved,” and “Participation” pages.

Recommendation: Surface details on “About” and “Get Involved” from child pages in these sections.

Recommendation: Revise the “Participation” page to incorporate details from “What You Would Need to Do” and “Benefits of Taking Part” pages on JoinAllofUs.org.

Additional Opportunities: Stories and Milestones

- Prospective Participants demonstrated a strong interest in Stories.

“‘Stories’ add that human element that helps a reader connect and relate.... ‘Stories,’ to me, would involve patients or people with health issues that were somehow impacted. When you read stories like that, it helps you connect.”

“[I’d click ‘Stories,’ because] everything else seems like it’s just going to be a bunch of information, like things I can’t connect with, like ‘Protocol,’ ‘Program and Scientific Milestones.’ All that sounds overwhelming, and I don’t know enough about the program yet to dive into that, but I like stories.”

- Both groups demonstrated an interest in seeing program results and successes.
 - Program and Scientific Milestones