# Submitting Use Cases for the *All of Us* Research Program

<https://www.youtube.com/watch?v=Avh4ggWOGHM>

## Title Slide

Submitting Use Cases for the All of Us Research Program

Logo of the National Institutes of Health

January 12, 2018

@AllofUsResearch #JoinAllofUs

Collage of nine photographs of the faces of people of varying genders and diverse racial and cultural backgrounds.

Voiceover of Dr. Stephanie Devaney speaking.

## Dr. Devaney:

Welcome! I’m Stephanie Devaney, Deputy Director of the *All of Us* Research Program at the National

Institutes of Health. I am joined today by my colleague, Dr. Dianne Babski. We’re here asking for your help…

## Scene Change

Overview: All of Us Research Program

* Mission: To accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.
* How: Deliver a national resource of deep clinical, environmental, lifestyle, and genetic data from one million participants who are consented and engaged to provide data in an ongoing, longitudinal basis (60+ years!).
* Priority: Reflect the broad diversity of the U.S.—all ages, races/ethnicities, gender, SES, geo, and health status—by over-recruiting those underrepresented in biomedical research.
* Priority: Build the tools and capabilities that make it easy for researchers from citizen scientists to premier university labs to make discoveries using the data and biosamples and through ancillary studies with the cohort.

A flow chart consisting of three levels. The first level of the flow chart is a collage of eight photographs of the faces of people of varying genders and diverse racial and cultural backgrounds. On both sides of that photograph is a graphic with four terms: People, Health Status, Data Types, Geography.

Below the photograph are two downward-pointing arrows that lead to the second level of the flow chart. One arrow points to text that reads, “Direct Volunteers.” Below that text are graphic icons: a laptop computer, a smartphone, and a telephone. The second arrow points to text that reads, “Health Care Provider Organizations.” Below that text is a graphic icon of a building with a cross on it.

Beneath this is an arrow that points to the third level of the flow chart, which consists of five graphic icons with accompanying text: an icon of a clipboard and the text, “1. Enroll and Consent (including EHR)”; another icon of a clipboard at a different angle and the text, “2. Surveys, Journals”; an icon of a heart with an electrocardiogram line going through it and the text, “3. Baseline Measurements”; an icon of a drop of blood and the text, “4. Biosamples (blood/urine)”; an icon of a smartphone and the text, “5. Apps, Phones, and Wearables.”

Dr. Devaney speaking.

## Dr. Devaney:

…as we continue to build this bold new program. The *All of Us* Research Program is a historic effort funded by the National Institutes of Health and carried out by more than 80 organizations from across the country.

The mission of *All of Us* is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us. We will do this by engaging 1 million or more individuals for many decades from across the United States who agree to share information about themselves, their lifestyles, their environment, and their health through the sharing of information from their electronic health records, by answering surveys, and providing biological samples, and then making that information available to researchers from across the country.

## Scene change

WE WANT TO HEAR YOUR IDEAS!

Dr. Devaney speaking.

## Dr. Devaney:

But we can’t do this alone. We need your help to identify the best scientific opportunities for a study of this size and scope.

## Scene change

Screen shot of the IdeaScale website home page.

Dr. Devaney speaking.

## Dr. Devaney:

We’re using a crowdsourcing platform called IdeaScale, and Dianne is here to show you how easy it is to submit your ideas.

## Scene change

IDEASCALE LIVE DEMO

Voiceover of Dr. Dianne Babski speaking.

## Dr. Babski:

Thank you, Stephanie, and hello everyone. I’m Dianne Babski from the National Library of Medicine. I’ll be providing a demo of the IdeaScale platform where you can submit your research ideas.

## Scene change

Submit your ideas. Go to <https://allofusresearchpriorities.ideascale.com/>

Dr. Babski speaking.

## Dr. Babski:

So first, how do you get there? There are links posted on the *All of Us* web pages, or you can go to [allofusresearchprioritites.ideascale.com](https://allofusresearchpriorities.ideascale.com/).

## Scene change

Screen shot of a web page of the IdeaScale website, with the All of Us Research Program logo and banner text, “Share Your Ideas.” In the upper right-hand corner of the screen shot is the text, “log in.” Below that is a dropdown box with the text, “When you’re ready. You can register or log in using the link up here.”

A circle with the text, “Click register. If you have an IdeaScale account, log in,” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

To use IdeaScale, you need to have an account. If you have already used IdeaScale, you are ready to go. If not, registering is easy.

## Scene change

Screen shot of a web page of the IdeaScale website. At the top is the text, “Create Your Account (Already have an account? Log in).”

Below that is the text, “Required fields.”

Below that are three fields for a user to enter information or select from a dropdown menu. The first, labeled with the number 1, is a field labeled “Email Address,” where the user can type in an email address. The text “Demo@mail.com” has been entered into the field. The second is a field labeled “Language,” where the user can select a language from a dropdown menu. “English” has been selected. The third, labeled with the number 2, is a field labeled “Zip Code.” The zip code “20894” has been entered into the field.

Below this is the text, “Send me news and updates about IdeaScale,” with a box marked “OFF” next to it.

Below this is a button with the text, “Register,” which is circled.

A circle with the text, “It’s easy!” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

Just add a working email and your zip code, then click register. Check your email that you used to register, and look for a confirmation email with a link to complete your registration.

## Scene change

Screen shot of the IdeaScale website home page. At the top of the page, the text “IDEAS” is circled.

A circle with the text, “Ready to Submit?” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

So how do you add your ideas to this platform? It’s easy. Once you are logged in and at the main menu, click on “Ideas.”

## Scene change

Screen shot of a web page of the IdeaScale website. The button labeled “Submit New Idea,” which is located at the top right of the screen shot, is circled.

A circle with the text, “Once on the Ideas page, click on ‘Submit New Idea,’” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

On the ideas page, you’ll see the list of ideas already submitted, and in the top right, a “Submit New Idea” button is there; click on that to open a new form.

## Scene change

Screen shot of a web page of the IdeaScale website. The screen shot shows four fields, where users may enter information or select from a dropdown menu. Only three of these fields are highlighted: (1) “Please confirm the language this idea is being submitted in,” (2) “Add a research question that could be uniquely answered by the All of Us Research Program resource,” and (3) “Provide a summary of how you would design a study to address this research question, such as goals, methods, or expected outcomes. Or, if you prefer not to, then please enter N/A.”

There is a toggle button where you may choose to submit your idea anonymously.

The words, “There’s a keyword suggestion utility, just start typing,” which are superimposed over the screen shot and are not a part of the website, are above an optional “Keywords” field.

A circle with the text, “Only three required fields,” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

While we only require three fields to be completed, the more refined you make your submission, the better we can understand what data is needed to address your research questions.

So let’s go through the form. English is the default language for submissions. First, you’ll add your research question. What kind of research can be addressed with the *All of Us* Research Program? Next, we ask for a more detailed summary of how you would design a study to address this research question, such as goals, methods, or expected outcomes or measures. Below that, add some keywords. Just start typing and select from the list. Pick one or many! Later, I’m going to show you that adding keywords provides a convenient way for others to quickly link to your idea.

## Scene change

Data, Methods, and Specifications. Note: You can add up to five for each research idea; there’s a comment box to add more.

Dr. Babski speaking.

## Dr. Babski:

The next part of the form allows you to drill down into data requirements for your study. You can add up to five sets of data requirements. If you need more space, there’s a comment box at the end of the form where you can add additional details about your research idea.

## Scene change

Screen shot of a web page of the IdeaScale website. At the top of the screen is superimposed text that is not part of the website that says, “Select your required Data Item #1, which is most important to your study. This would be an item that needs to be generated and collected from different sources using various procedures, tools, techniques, assays, etc.”

Below this is a field with a dropdown box showing an extensive list of potential data items. An arrow points to a field below this that is labeled, “If Data Item #2 was not in the dropdown, please enter it here.” That arrow is labeled with superimposed text that is not part of the website: “If you don’t see your data type in the list, add it.”

A circle with the text, “What type of data do you want to collect?” is also superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

But first, what data (like diet, used in this example) are needed for your study? For each of the fields, just start typing and select from the list. If you don’t see your item in the list, just add it in the box below. We’ll update the list with your item for all to use.

## Scene change

Screen shot of a web page of the IdeaScale website. At the top of the screen is superimposed text that is not part of the website that says, “By what method will Data Item #1 be obtained? This may include procedures, tools, techniques, assays, and analytical approaches for the collection, measurement, or analysis of data.”

Below this is a dropdown box showing an extensive list of potential data items. An arrow points to a field below this that is labeled, “If you did not find your method for obtaining Data Item #1 in the dropdown selection above, please enter it here.” That arrow is labeled with superimposed text that is not part of the website: “If you don’t see your method it in the list, add it.”

A circle with the text, “How would you collect data?” is also superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

Next, you can refine the data element you just added. What are the methods for obtaining the data you selected (like surveys)? Again, if you don’t see your item in the list, add it in the box below.

## Scene change

Screen shot of a web page of the IdeaScale website. At the top of the screen is superimposed text that is not part of the website that says, “Are there specifications that apply to the method by which Data Item #1 will be obtained, e.g., is the measurement taken once a year, every month, or some other variation.”

Below is a dropdown box showing an extensive list of potential time intervals and methods to obtain data.

Below this are two fields. The first field has a dropdown box and is labeled “Specification #2.” An arrow points to the second field, which is labeled, “If Specification #2 was not in the dropdown, please enter it here.” That arrow is labeled with superimposed text that is not part of the website: “If you don’t see a specification for your method in the list, add it.”

A circle with the text “Specifications?” is also superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

And even more refinement: Are there any other specifications needed for the data method you selected? In this example, our data was diet, collected via surveys, and once a year. If you don’t see your item in the list, add it in the text box below.

## Scene change

When done, click submit or save as a draft to finish later.

Dr. Babski speaking.

## Dr. Babski:

A reminder that you can add up to five sets of data requirements. If you need more space, use the comment box at the end of the form. When you’re done, click submit or save as a draft to edit and submit later.

## Scene change

Screen shot of a web page of the IdeaScale website. A navigation bar, which has links labeled “Recent,” “Popular,” and “My Ideas,” is circled. Also circled is a field on the right of the web page labeled “Search ideas” and a group of keywords beneath the heading “What we’re discussing.”

A circle with the text, “How to browse ideas,” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

One of the nice things about IdeaScale is that it provides the opportunity to see what everyone else is adding as research ideas. You can look at recent or popular ideas, search in the text box, or even click on the keywords to see a set of related ideas.

## Scene change

Screen shot of the web page from the previous slide. A box in the center of the screen shot with the text “1 vote” is circled, and the text, “Add your comment,” which is at the bottom of the screen shot, is circled.

A circle with the text “Interact” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

Another fun feature is the ability to vote on your favorite ideas or even comment on submissions.

## Scene change

Screen shot of a web page of the IdeaScale website. The tab labeled “Comments” is active. A comment by Alison Cernich (username @alison.cernich), made on 2 Nov 2017, labeled “A,” is displayed and reads as follows: “If this is tied to another idea, is there a way to group them or do they have to retain order they are submitted?” A user may either reply to this comment or report it as abuse.

Below this is a field, labeled “D,” with the text, “Will you consider additional environmental factors in this research?”

Below this is a dropdown field labeled “Your Language.” “English” has been selected.

Below this is a button labeled “Submit Comment.”

A circle with the text, “Comment on other submissions; reply to those commenting on yours,” is superimposed over the screen shot of the web page.

Dr. Babski speaking.

## Dr. Babski:

Commenting is a great way to start a dialogue with other submitters!

## Scene change

Still have questions? [AoURPW@nih.gov](mailto:AoURPW@nih.gov)

Dr. Babski speaking.

## Dr. Babski:

And that’s it! This is a unique opportunity for you to share your ideas with the *All of Us* Research Program community. I encourage you to add your ideas soon and bookmark the URL and come back often to see what’s been added. If you have any questions, please send them to [AoURPW@nih.gov](mailto:AoURPW@nih.gov). We look forward to your submissions!

## Scene change

RESOURCES

Dr. Devaney speaking.

## Dr. Devaney:

Thank you, Dianne. For more information about…

## Scene change and Closing slide

Text: More Information

* Provide feedback about the IdeaScale tool for submitting Use Cases
  + Send an email to [AoURP@nih.gov](mailto:AoURP@nih.gov)
* Where to Submit a Use Case
  + IdeaScale Research Priorities homepage: <https://allofusresearchpriorities.ideascale.com/>
* General information about the NIH All of Us Program
  + Visit: <https://allofus.nih.gov/>
* Information about the current All of Us research protocol
  + Visit: <https://allofus.nih.gov/news-events-and-media/announcements/all-us-research-program-initial-protocol>

See the NIH Director’s Blog!

<https://directorsblog.nih.gov/2018/01/11/got-a-great-research-idea-all-of-us-wants-to-hear-it/>

Dr. Devaney speaking.

## Dr. Devaney:

…*All of Us* or IdeaScale, or to submit a use case, please see the resources below. We look forward to seeing your ideas!