

Report on Research Compliance Volume 15, Number 6. June 30, 2018 National Launch Complete, 'All of Us' Moves Focus to Research Topics, Portal

By Theresa Defino

“We’re all united by a common goal: Building an amazing research resource that will make possible the next great discoveries in health and medicine,” NIH Director Francis Collins told those assembled at the historic Abyssinian Baptist Church. Collins was at the pulpit in Harlem to officially kick off the start of open enrollment in the agency’s All of Us precision medicine research project.

The May 7 launch involved live events in a total of six additional locations, including Kansas City and Detroit. Prior to that date, individuals had to be invited to join the study, which hopes to enroll 1 million people (*RRC 2/18, p. 1*).

During a press event a few days earlier, Collins said All of Us was the realization of an idea that “might have seemed like a pipe dream 15 years ago.” He called the program “unprecedented,” “unique” and a “historic effort to advance precision medicine.”

“The result will be a massive public resource open to all researchers from citizen scientists to academics to commercial labs that can help science answer important questions about today’s health mysteries,” Collins said at the press briefing.

Currently, the protocol for All of Us is fairly limited. Participation consists of completing three health surveys, allowing access to the electronic health record, and visiting a facility to have body measurements taken along with blood and urine samples. More surveys and other research protocols will be added.

NIH began the restricted enrollment last summer as part of what it called the “beta testing phase.”

In January, Eric Dishman, program director, reported that All of Us had 18,508 participants “who are started somewhere in the process of registering, consenting and starting their survey modules and then over 11,500 who have finished the entire protocol.”

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