WEBVTT

00:00:00.000 --> 00:00:00.730 Nordies

00:00:04.390 --> 00:00:05.850 sorry, the recording of progress.

00:00:05.850 --> 00:00:08.718 I have to say got it.

00:00:08.720 --> 00:00:12.478 Well that's OK. 8.5% unreported,

00:00:12.478 --> 00:00:14.830 so that's the majority of genomic studies.

00:00:14.830 --> 00:00:16.456 But what we have been able

00:00:16.456 --> 00:00:17.830 to accomplish in the NIH,

00:00:17.830 --> 00:00:19.765 all of US research program

00:00:19.765 --> 00:00:20.926 has been unprecedented.

00:00:20.930 --> 00:00:23.070 Today we have over 450,000

00:00:23.070 --> 00:00:25.210 participants enrolled in the study,

00:00:25.210 --> 00:00:27.435 with over 350,000 participants with

00:00:27.435 --> 00:00:29.660 active information in our database.

00:00:29.660 --> 00:00:31.207 And I'll tell you a little bit

NOTE Confidence: 0.726834738

00:00:31.207 --> 00:00:32.449 more about what that means.

NOTE Confidence: 0.726834738

00:00:32.450 --> 00:00:35.096 But what does our all of US

NOTE Confidence: 0.726834738

00:00:35.096 --> 00:00:36.230 research program participant

NOTE Confidence: 0.726834738

00:00:36.302 --> 00:00:38.327 population look like over 80%?

NOTE Confidence: 0.726834738

00:00:38.330 --> 00:00:40.090 Is what we consider underrepresented

NOTE Confidence: 0.726834738

00:00:40.090 --> 00:00:42.857 in biomedical research what we mean by

NOTE Confidence: 0.726834738

00:00:42.857 --> 00:00:44.276 underrepresented biomedical research?

NOTE Confidence: 0.726834738

00:00:44.280 --> 00:00:46.140 We also mean race and ethnicity.

NOTE Confidence: 0.726834738

00:00:46.140 --> 00:00:48.555 We mean great age greater than 65.

NOTE Confidence: 0.726834738

00:00:48.560 --> 00:00:50.936 Those populations that have less than a GED.

NOTE Confidence: 0.726834738

00:00:50.940 --> 00:00:52.505 We think about populations with

NOTE Confidence: 0.726834738

00:00:52.505 --> 00:00:54.838 income less than 25% and we think

NOTE Confidence: 0.726834738

00:00:54.838 --> 00:00:56.920 about sexual and gender minorities as

NOTE Confidence: 0.726834738

00:00:56.985 --> 00:00:59.288 well and also race and ethnicity over

NOTE Confidence: 0.726834738

00:00:59.288 --> 00:01:01.940 80% in the represent that category.

NOTE Confidence: 0.726834738

00:01:01.940 --> 00:01:03.536 But if you look at that category

NOTE Confidence: 0.726834738

00:01:03.536 --> 00:01:04.790 of race and ethnicity,

NOTE Confidence: 0.726834738

00:01:04.790 --> 00:01:08.360 over 50% of our participants right now.

NOTE Confidence: 0.726834738

00:01:08.360 --> 00:01:10.562 Present a racial and ethnic minority

NOTE Confidence: 0.726834738

00:01:10.562 --> 00:01:12.044 with 20% of our participants.

NOTE Confidence: 0.726834738

00:01:12.044 --> 00:01:13.656 For example, being African American and,

NOTE Confidence: 0.726834738

00:01:13.656 --> 00:01:15.949 as was stated at the onset of my talk,

NOTE Confidence: 0.726834738

00:01:15.950 --> 00:01:17.590 I'm a cancer disparities researcher.

NOTE Confidence: 0.726834738

00:01:17.590 --> 00:01:18.140 By training.

NOTE Confidence: 0.726834738

00:01:18.140 --> 00:01:21.089 I was very fortunate to be in a small club.

NOTE Confidence: 0.726834738

00:01:21.090 --> 00:01:22.197 If you will,

NOTE Confidence: 0.726834738

00:01:22.197 --> 00:01:25.070 of of researchers who have received an R1.

NOTE Confidence: 0.726834738

00:01:25.070 --> 00:01:27.149 But when I think about I'm a

NOTE Confidence: 0.726834738

00:01:27.149 --> 00:01:28.553 health disparities research that

NOTE Confidence: 0.726834738

00:01:28.553 --> 00:01:30.377 specifically conducts community based,

NOTE Confidence: 0.726834738

00:01:30.380 --> 00:01:31.274 participatory research,

NOTE Confidence: 0.726834738

00:01:31.274 --> 00:01:34.850 CBPR those of us that know about CDPR.

NOTE Confidence: 0.726834738

00:01:34.850 --> 00:01:36.662 Those of us that do community

NOTE Confidence: 0.726834738

00:01:36.662 --> 00:01:38.898 engaged research. We know the time.

NOTE Confidence: 0.726834738

00:01:38.898 --> 00:01:41.340 It takes to collect primary data,

NOTE Confidence: 0.726834738

00:01:41.340 --> 00:01:42.477 particularly primary data,

NOTE Confidence: 0.726834738

00:01:42.477 --> 00:01:44.372 that is diverse and reflects

NOTE Confidence: 0.726834738

00:01:44.372 --> 00:01:46.019 the diversity of our country.

NOTE Confidence: 0.726834738

00:01:46.020 --> 00:01:47.660 If I if a researcher,

NOTE Confidence: 0.726834738

00:01:47.660 --> 00:01:49.388 if I would have had access to data such

NOTE Confidence: 0.726834738

00:01:49.388 --> 00:01:51.096 as the all of US research database,

NOTE Confidence: 0.726834738

00:01:51.100 --> 00:01:53.025 when I was an early stage investigator,

NOTE Confidence: 0.726834738

00:01:53.030 --> 00:01:54.962 I am very confident that that would

NOTE Confidence: 0.726834738

00:01:54.962 --> 00:01:56.656 have actually speed up my research

NOTE Confidence: 0.726834738

00:01:56.656 --> 00:01:58.282 career and allowed me to ask

NOTE Confidence: 0.726834738

00:01:58.282 --> 00:01:59.543 innovative questions and inclusive

NOTE Confidence: 0.726834738

00:01:59.543 --> 00:02:01.415 questions early on in my career.

NOTE Confidence: 0.726834738

00:02:01.420 --> 00:02:03.457 So I am so excited about the

NOTE Confidence: 0.726834738

00:02:03.457 --> 00:02:05.084 intentionality and the results of

NOTE Confidence: 0.726834738

00:02:05.084 --> 00:02:07.172 that intentionality that we that we've

NOTE Confidence: 0.726834738

00:02:07.172 --> 00:02:09.237 achieved in the all of US research.

NOTE Confidence: 0.726834738

00:02:09.240 --> 00:02:09.520 Program.

NOTE Confidence: 0.76979327875

00:02:16.760 --> 00:02:18.395 So when also thinking about

NOTE Confidence: 0.76979327875

00:02:18.395 --> 00:02:19.376 research and diversity,

NOTE Confidence: 0.76979327875

00:02:19.380 --> 00:02:21.788 as I said earlier, we've been very,

NOTE Confidence: 0.76979327875

00:02:21.790 --> 00:02:24.086 very successful in that all of US

NOTE Confidence: 0.76979327875

00:02:24.086 --> 00:02:25.938 research program of achieving a

NOTE Confidence: 0.76979327875

00:02:25.938 --> 00:02:28.350 participant pool that truly reflects the

NOTE Confidence: 0.76979327875

00:02:28.350 --> 00:02:30.981 diversity of the US with over 80% from

NOTE Confidence: 0.76979327875

00:02:30.981 --> 00:02:32.544 representing underrepresented biomedical

NOTE Confidence: 0.76979327875

00:02:32.544 --> 00:02:35.052 research and 50% racial ethnic minorities.

NOTE Confidence: 0.76979327875

00:02:35.052 --> 00:02:36.936 But in Full disclosure and transparency,

NOTE Confidence: 0.76979327875

00:02:36.940 --> 00:02:38.380 we have a long way to go when

NOTE Confidence: 0.76979327875

00:02:38.380 --> 00:02:39.499 it comes to researchers.

NOTE Confidence: 0.76979327875

00:02:39.500 --> 00:02:43.399 Currently only about 6.9% of our researchers.

NOTE Confidence: 0.76979327875

00:02:43.400 --> 00:02:45.095 Utilize our database.

NOTE Confidence: 0.76979327875

00:02:45.095 --> 00:02:47.232 Our African American about

NOTE Confidence: 0.76979327875

00:02:47.232 --> 00:02:49.000 9% are Asian American,

NOTE Confidence: 0.76979327875

00:02:49.000 --> 00:02:51.624 I mean American Indian,

NOTE Confidence: 0.76979327875

00:02:51.624 --> 00:02:53.770 Alaskan native, 27.7% Asian.

NOTE Confidence: 0.76979327875

00:02:53.770 --> 00:02:56.248 But we still have about 48.4% white

NOTE Confidence: 0.76979327875

00:02:56.248 --> 00:02:58.438 and so we have a long way to go when

NOTE Confidence: 0.76979327875

00:02:58.438 --> 00:03:00.349 we think about making sure that our

NOTE Confidence: 0.76979327875

00:03:00.349 --> 00:03:01.790 researchers reflect the diversity

NOTE Confidence: 0.76979327875

00:03:01.790 --> 00:03:03.270 of our participant population.

NOTE Confidence: 0.76979327875

00:03:03.270 --> 00:03:05.478 We have been very successful in career level,

NOTE Confidence: 0.76979327875

00:03:05.480 --> 00:03:07.748 though ensuring that almost over half of

6

NOTE Confidence: 0.76979327875

00:03:07.748 --> 00:03:09.739 our participants are graduate trainees,

NOTE Confidence: 0.76979327875

00:03:09.740 --> 00:03:11.965 research fellows and our early

NOTE Confidence: 0.76979327875

00:03:11.965 --> 00:03:13.745 career tenure track researchers.

NOTE Confidence: 0.76979327875

00:03:13.750 --> 00:03:15.390 So we want to make sure that the

NOTE Confidence: 0.76979327875

00:03:15.390 --> 00:03:17.026 the level of diversity that we've

NOTE Confidence: 0.76979327875

00:03:17.026 --> 00:03:18.784 achieved in career level is matched.

NOTE Confidence: 0.76979327875

00:03:18.790 --> 00:03:20.911 And when we think about the race

NOTE Confidence: 0.76979327875

00:03:20.911 --> 00:03:23.218 and ethnicity of our our research

NOTE Confidence: 0.76979327875

00:03:23.218 --> 00:03:24.108 research community,

NOTE Confidence: 0.76979327875

00:03:24.110 --> 00:03:26.056 this is an example that I like

NOTE Confidence: 0.76979327875

00:03:26.056 --> 00:03:28.041 to highlight because as a cancer

NOTE Confidence: 0.76979327875

00:03:28.041 --> 00:03:29.136 disparities researcher trained

NOTE Confidence: 0.76979327875

00:03:29.136 --> 00:03:31.090 in cancer prevention and control,

NOTE Confidence: 0.76979327875

00:03:31.090 --> 00:03:33.706 I was very excited and my research ban

NOTE Confidence: 0.76979327875

00:03:33.706 --> 00:03:35.748 across cancer preventions and lung,

NOTE Confidence: 0.76979327875

00:03:35.750 --> 00:03:36.714 prostate, colorectal,

NOTE Confidence: 0.76979327875

00:03:36.714 --> 00:03:39.124 and cervical and breast cancer.

NOTE Confidence: 0.76979327875

00:03:39.130 --> 00:03:42.604 So I was very excited when the in 2012,

NOTE Confidence: 0.76979327875

00:03:42.610 --> 00:03:43.834 when the NIH NCI.

NOTE Confidence: 0.76979327875

00:03:43.834 --> 00:03:45.670 Came out with the national lung

NOTE Confidence: 0.76979327875

00:03:45.739 --> 00:03:46.739 screening trial.

NOTE Confidence: 0.76979327875

00:03:46.740 --> 00:03:48.315 I was excited because for a change

NOTE Confidence: 0.76979327875

00:03:48.315 --> 00:03:49.180 we were going to,

NOTE Confidence: 0.76979327875

00:03:49.180 --> 00:03:51.182 we had got data that showed that

NOTE Confidence: 0.76979327875

00:03:51.182 --> 00:03:53.145 as a result of this national

NOTE Confidence: 0.76979327875

00:03:53.145 --> 00:03:55.560 screening study that there was a 20%

NOTE Confidence: 0.76979327875

00:03:55.560 --> 00:03:58.080 reduction in lung cancer mortality.

NOTE Confidence: 0.76979327875

00:03:58.080 --> 00:03:59.094 That was huge.

NOTE Confidence: 0.76979327875

00:03:59.094 --> 00:04:00.784 But unfortunately the lack of

NOTE Confidence: 0.76979327875

00:04:00.784 --> 00:04:02.540 diversity in clinical trials can

NOTE Confidence: 0.76979327875

00:04:02.540 --> 00:04:04.906 oftentimes lead to a lack of improved

NOTE Confidence: 0.76979327875

00:04:04.973 --> 00:04:06.965 outcomes and high risk population and

NOTE Confidence: 0.76979327875

00:04:06.965 --> 00:04:09.110 lung cancer is one of those areas.

NOTE Confidence: 0.76979327875

00:04:09.110 --> 00:04:11.380 So when we think about this pivotal study,

NOTE Confidence: 0.76979327875

00:04:11.380 --> 00:04:12.760 the national lung screening trial,

NOTE Confidence: 0.76979327875

00:04:12.760 --> 00:04:15.388 the NLST that resulted in 20%.

NOTE Confidence: 0.76979327875

00:04:15.390 --> 00:04:17.314 Production lung cancer mortality

NOTE Confidence: 0.76979327875

00:04:17.314 --> 00:04:20.200 because it showed that screening high

NOTE Confidence: 0.76979327875

00:04:20.274 --> 00:04:22.542 risk populations using a low dose

NOTE Confidence: 0.76979327875

00:04:22.542 --> 00:04:25.049 CT can detect cancers earlier and

NOTE Confidence: 0.76979327875

00:04:25.049 --> 00:04:27.354 prevent mortality from lung cancer.

NOTE Confidence: 0.76979327875

00:04:27.360 --> 00:04:27.729 However,

NOTE Confidence: 0.76979327875

00:04:27.729 --> 00:04:29.943 when we think about the populations

NOTE Confidence: 0.76979327875

00:04:29.943 --> 00:04:31.848 that were included of the 53,000

NOTE Confidence: 0.76979327875

00:04:31.848 --> 00:04:33.012 participants that participate

NOTE Confidence: 0.76979327875

00:04:33.012 --> 00:04:35.340 in the study across 33 sites,

NOTE Confidence: 0.76979327875

00:04:35.340 --> 00:04:37.820 only 4.5% of those participants

NOTE Confidence: 0.76979327875

00:04:37.820 --> 00:04:39.308 were African Americans,

NOTE Confidence: 0.76979327875

00:04:39.310 --> 00:04:41.152 and when I brought this information

NOTE Confidence: 0.76979327875

00:04:41.152 --> 00:04:42.973 back to our Community Health Center

NOTE Confidence: 0.76979327875

00:04:42.973 --> 00:04:44.856 where I used to do my research,

NOTE Confidence: 0.76979327875

00:04:44.860 --> 00:04:45.640 my research.

NOTE Confidence: 0.76979327875

00:04:45.640 --> 00:04:47.590 Embedded in a community primarily

NOTE Confidence: 0.76979327875

00:04:47.590 --> 00:04:50.320 embedded in fairly qualified health centers,

NOTE Confidence: 0.76979327875

00:04:50.320 --> 00:04:52.728 and when I began to look at the

NOTE Confidence: 0.76979327875

00:04:52.728 --> 00:04:54.611 screening guidelines that arose as a

NOTE Confidence: 0.76979327875

00:04:54.611 --> 00:04:56.860 result of the national lung screening trial,

NOTE Confidence: 0.76979327875

00:04:56.860 --> 00:04:58.417 many of the providers that I would speak to,

NOTE Confidence: 0.76979327875

00:04:58.420 --> 00:05:01.297 they would say Kareem the the the

NOTE Confidence: 0.76979327875

00:05:01.297 --> 00:05:02.530 screening screening parameters

NOTE Confidence: 0.76979327875

00:05:02.600 --> 00:05:05.029 that the NLST hat does not reflect

NOTE Confidence: 0.76979327875

00:05:05.029 --> 00:05:07.183 the smoking history that we see

10

NOTE Confidence: 0.76979327875

00:05:07.183 --> 00:05:08.579 in our patient population.

NOTE Confidence: 0.76979327875

00:05:08.580 --> 00:05:11.114 Our our patients may be smoking less,

NOTE Confidence: 0.76979327875

00:05:11.120 --> 00:05:13.176 but they may be smoking for longer years,

NOTE Confidence: 0.811045684444444

00:05:13.180 --> 00:05:15.502 or they may be smoking for less pack years.

NOTE Confidence: 0.811045684444444

00:05:15.510 --> 00:05:16.314 But more cigarettes.

NOTE Confidence: 0.811045684444444

00:05:16.314 --> 00:05:17.654 But are they making spoken?

NOTE Confidence: 0.811045684444444

00:05:17.660 --> 00:05:19.044 Different types of cigarettes

NOTE Confidence: 0.811045684444444

00:05:19.044 --> 00:05:20.774 and tobacco products than what

NOTE Confidence: 0.811045684444444

00:05:20.774 --> 00:05:22.686 was assessed in this NLST study?

NOTE Confidence: 0.811045684444444

00:05:22.690 --> 00:05:24.634 And the other thing that my

NOTE Confidence: 0.811045684444444

00:05:24.634 --> 00:05:25.930 research might clinician community,

NOTE Confidence: 0.811045684444444

00:05:25.930 --> 00:05:27.848 let me know was that the study

NOTE Confidence: 0.811045684444444

00:05:27.848 --> 00:05:30.022 didn't take into account a lot of

NOTE Confidence: 0.811045684444444

00:05:30.022 --> 00:05:31.627 the social determinants of health

NOTE Confidence: 0.811045684444444

00:05:31.627 --> 00:05:33.618 that determine why people smoke and

NOTE Confidence: 0.811045684444444

00:05:33.618 --> 00:05:35.508 how people smoke and the stressful

NOTE Confidence: 0.811045684444444

00:05:35.508 --> 00:05:36.898 situations in which many people

NOTE Confidence: 0.811045684444444

00:05:36.898 --> 00:05:38.614 who smoke in our community clinics

NOTE Confidence: 0.811045684444444

00:05:38.614 --> 00:05:40.270 that they have to deal with.

NOTE Confidence: 0.811045684444444

00:05:40.270 --> 00:05:40.956 So unfortunately,

NOTE Confidence: 0.811045684444444

00:05:40.956 --> 00:05:43.014 while this study was groundbreaking and

NOTE Confidence: 0.811045684444444

00:05:43.014 --> 00:05:45.636 I am so thankful that it was conducted.

NOTE Confidence: 0.811045684444444

00:05:45.640 --> 00:05:47.971 And it did lead to a change in the

NOTE Confidence: 0.811045684444444

00:05:47.971 --> 00:05:50.192 United States Preventive Services Task

NOTE Confidence: 0.811045684444444

00:05:50.192 --> 00:05:53.036 Force guidelines for lung cancer screening.

NOTE Confidence: 0.811045684444444

00:05:53.040 --> 00:05:55.161 What was concerning for me was that

NOTE Confidence: 0.811045684444444

00:05:55.161 --> 00:05:57.429 a the participants in this study did

NOTE Confidence: 0.811045684444444

00:05:57.429 --> 00:05:59.054 not reflect participants who carried

NOTE Confidence: 0.811045684444444

00:05:59.054 --> 00:06:01.068 the highest burden of disease and

NOTE Confidence: 0.811045684444444

00:06:01.068 --> 00:06:03.130 what was also concerning for me was

NOTE Confidence: 0.811045684444444

00:06:03.130 --> 00:06:05.243 that I had to then come in and try

12

00:06:05.243 --> 00:06:07.560 to say that these study results were

00:06:07.560 --> 00:06:09.570 generalizable to high risk populations.

00:06:09.570 --> 00:06:12.650 So I was very happy when I was funded by

00:06:12.729 --> 00:06:16.362 the the NIH D to actually do a similar study.

00:06:16.370 --> 00:06:17.930 Looking at lung cancer screening,

00:06:17.930 --> 00:06:19.680 but taking into account things

00:06:19.680 --> 00:06:20.730 like structural violence,

00:06:20.730 --> 00:06:21.614 structural inequities,

00:06:21.614 --> 00:06:23.382 and other systemic factors

00:06:23.382 --> 00:06:25.150 including systemic racism that

00:06:25.213 --> 00:06:27.145 many of our participants deal with.

00:06:27.150 --> 00:06:29.400 So I I show this as an example to

00:06:29.400 --> 00:06:31.243 remind us that even in efforts

00:06:31.243 --> 00:06:33.189 where we have changed the paradigm

00:06:33.189 --> 00:06:35.639 of what it means for screening in

00:06:35.639 --> 00:06:37.074 in conditions like cancer,

NOTE Confidence: 0.811045684444444

00:06:37.074 --> 00:06:39.276 we must ensure that the participants

NOTE Confidence: 0.811045684444444

00:06:39.276 --> 00:06:41.666 in these trials reflect the populations

NOTE Confidence: 0.811045684444444

00:06:41.666 --> 00:06:44.630 that carry the highest burden of disease.

NOTE Confidence: 0.811045684444444

00:06:44.630 --> 00:06:46.828 So how all of us are doing

NOTE Confidence: 0.811045684444444

00:06:46.828 --> 00:06:47.456 things differently,

NOTE Confidence: 0.811045684444444

00:06:47.460 --> 00:06:49.280 particularly as it thinks to things and

NOTE Confidence: 0.811045684444444

00:06:49.280 --> 00:06:51.288 issues that are important to your center?

NOTE Confidence: 0.811045684444444

00:06:51.290 --> 00:06:51.806 We think of,

NOTE Confidence: 0.811045684444444

00:06:51.806 --> 00:06:52.150 I think,

NOTE Confidence: 0.811045684444444

00:06:52.150 --> 00:06:53.685 about the inclusion of pregnant

NOTE Confidence: 0.811045684444444

00:06:53.685 --> 00:06:54.606 individuals and studies.

NOTE Confidence: 0.811045684444444

00:06:54.610 --> 00:06:56.618 Historically pregnant individuals have

NOTE Confidence: 0.811045684444444

00:06:56.618 --> 00:06:59.128 been underrepresented in biomedical research,

NOTE Confidence: 0.811045684444444

00:06:59.130 --> 00:07:02.076 and we all understand the reason

NOTE Confidence: 0.811045684444444

00:07:02.076 --> 00:07:04.040 for that underrepresentation right?

NOTE Confidence: 0.811045684444444

00:07:04.040 --> 00:07:05.636 We know that a lot of the

NOTE Confidence: 0.811045684444444

00:07:05.636 --> 00:07:06.939 underrepresentation has do been due to

NOTE Confidence: 0.811045684444444

00:07:06.939 --> 00:07:08.660 a lot and a lot of intervention studies.

NOTE Confidence: 0.811045684444444

00:07:08.660 --> 00:07:11.465 We want to ensure that the benefits

NOTE Confidence: 0.811045684444444

00:07:11.465 --> 00:07:13.880 of a clinical trial outweigh the risk,

NOTE Confidence: 0.811045684444444

00:07:13.880 --> 00:07:15.420 particularly as we think about

NOTE Confidence: 0.811045684444444

00:07:15.420 --> 00:07:16.036 pregnant individuals.

NOTE Confidence: 0.811045684444444

00:07:16.040 --> 00:07:16.432 However,

NOTE Confidence: 0.811045684444444

00:07:16.432 --> 00:07:18.392 our lack of including pregnant

NOTE Confidence: 0.811045684444444

00:07:18.392 --> 00:07:20.321 individuals in large cohort studies

NOTE Confidence: 0.811045684444444

00:07:20.321 --> 00:07:22.372 has not allowed us to have this

NOTE Confidence: 0.811045684444444

00:07:22.372 --> 00:07:24.294 ability to follow pregnant individuals

NOTE Confidence: 0.811045684444444

00:07:24.294 --> 00:07:26.419 and their offspring over time.

NOTE Confidence: 0.811045684444444

00:07:26.420 --> 00:07:27.320 So, for example,

NOTE Confidence: 0.811045684444444

00:07:27.320 --> 00:07:29.420 we have not been able to properly

NOTE Confidence: 0.811045684444444

00:07:29.480 --> 00:07:31.520 assess why African American women,

NOTE Confidence: 0.811045684444444

00:07:31.520 --> 00:07:33.160 despite having some time in

NOTE Confidence: 0.811045684444444

00:07:33.160 --> 00:07:34.144 many instances higher.

NOTE Confidence: 0.811045684444444

00:07:34.150 --> 00:07:35.694 Education status than others

NOTE Confidence: 0.811045684444444

00:07:35.694 --> 00:07:37.624 still have worse birth outcomes,

NOTE Confidence: 0.811045684444444

00:07:37.630 --> 00:07:39.894 so there was a study done by Doctor

NOTE Confidence: 0.811045684444444

00:07:39.894 --> 00:07:41.638 James Collins here in the Chicago

NOTE Confidence: 0.811045684444444

00:07:41.638 --> 00:07:43.576 Land area that showed that an

NOTE Confidence: 0.811045684444444

00:07:43.576 --> 00:07:45.640 African American woman with a JD

NOTE Confidence: 0.811045684444444

00:07:45.707 --> 00:07:48.035 or a PhD was more likely to have

NOTE Confidence: 0.811045684444444

00:07:48.035 --> 00:07:50.092 worse birth outcomes than a white

NOTE Confidence: 0.811045684444444

00:07:50.092 --> 00:07:51.852 European woman with a GED.

NOTE Confidence: 0.811045684444444

00:07:51.860 --> 00:07:53.642 And what that study showed by

NOTE Confidence: 0.811045684444444

00:07:53.642 --> 00:07:55.288 Doctor Collins is that something

NOTE Confidence: 0.811045684444444

00:07:55.288 --> 00:07:57.258 other than social economic factors

NOTE Confidence: 0.811045684444444

00:07:57.258 --> 00:07:58.834 and education levels are

NOTE Confidence: 0.909217589666667

00:07:58.901 --> 00:08:00.938 at play when it comes to African

NOTE Confidence: 0.909217589666667

00:08:00.938 --> 00:08:02.891 American women and women of African

NOTE Confidence: 0.909217589666667

00:08:02.891 --> 00:08:05.010 descent and birth outcomes. So we are.

NOTE Confidence: 0.909217589666667

00:08:05.010 --> 00:08:06.390 I'm really excited that the all

NOTE Confidence: 0.909217589666667

00:08:06.390 --> 00:08:08.393 of US research study has been

NOTE Confidence: 0.909217589666667

00:08:08.393 --> 00:08:09.765 intentional and including pregnant

NOTE Confidence: 0.909217589666667

00:08:09.765 --> 00:08:11.597 women in our pregnant individuals.

NOTE Confidence: 0.909217589666667

00:08:11.600 --> 00:08:13.428 Excuse me in our study, for example,

NOTE Confidence: 0.909217589666667

00:08:13.428 --> 00:08:16.106 we have over 7% of our current

NOTE Confidence: 0.909217589666667

00:08:16.106 --> 00:08:18.286 participants of the 300 + 300

NOTE Confidence: 0.909217589666667

00:08:18.286 --> 00:08:19.896 + 1000 are preg individuals.

NOTE Confidence: 0.909217589666667

00:08:19.900 --> 00:08:21.510 We have a long way to go,

NOTE Confidence: 0.909217589666667

00:08:21.510 --> 00:08:23.232 but I'm hopeful that through conversations

NOTE Confidence: 0.909217589666667

00:08:23.232 --> 00:08:25.019 like that what we're having today,

NOTE Confidence: 0.909217589666667

00:08:25.020 --> 00:08:27.066 researchers like you will be excited

NOTE Confidence: 0.909217589666667

17

00:08:27.066 --> 00:08:29.179 about the database that we have

NOTE Confidence: 0.909217589666667

00:08:29.179 --> 00:08:30.909 and researchers within your center

NOTE Confidence: 0.909217589666667

00:08:30.909 --> 00:08:32.408 who are collecting information

NOTE Confidence: 0.909217589666667

00:08:32.408 --> 00:08:33.996 across the life course.

NOTE Confidence: 0.909217589666667

00:08:34.000 --> 00:08:34.888 We'll see that.

NOTE Confidence: 0.909217589666667

00:08:34.888 --> 00:08:36.664 And all of US research program

NOTE Confidence: 0.909217589666667

00:08:36.664 --> 00:08:37.940 database is an effective tool

NOTE Confidence: 0.909217589666667

00:08:37.940 --> 00:08:39.870 for you to use in your research,

NOTE Confidence: 0.909217589666667

00:08:39.870 --> 00:08:41.963 but in our the top ten conditions

NOTE Confidence: 0.909217589666667

00:08:41.963 --> 00:08:44.101 that we're seeing within our our

NOTE Confidence: 0.909217589666667

00:08:44.101 --> 00:08:46.066 population is looking at complications

NOTE Confidence: 0.909217589666667

00:08:46.066 --> 00:08:47.910 that occurred during pregnancy.

NOTE Confidence: 0.909217589666667

00:08:47.910 --> 00:08:49.374 Third trimester pregnancy,

NOTE Confidence: 0.909217589666667

00:08:49.374 --> 00:08:50.350 unplanned pregnancy,

NOTE Confidence: 0.909217589666667

00:08:50.350 --> 00:08:51.751 second trimester pregnancies.

NOTE Confidence: 0.909217589666667

00:08:51.751 --> 00:08:54.086 But then looking at that

NOTE Confidence: 0.909217589666667

00:08:54.086 --> 00:08:56.268 high risk profile as well.

NOTE Confidence: 0.909217589666667

00:08:56.270 --> 00:08:57.590 And to understand what data

NOTE Confidence: 0.909217589666667

00:08:57.590 --> 00:08:58.910 we have in our database,

NOTE Confidence: 0.909217589666667

00:08:58.910 --> 00:09:00.842 I'm gonna say this this site several

NOTE Confidence: 0.909217589666667

00:09:00.842 --> 00:09:02.210 times throughout the afternoon.

NOTE Confidence: 0.909217589666667

00:09:02.210 --> 00:09:03.158 But please go to

NOTE Confidence: 0.637513576666667

00:09:05.610 --> 00:09:06.699 databrowser.researchallofus.org again. That's

NOTE Confidence: 0.881953386666667

00:09:09.590 --> 00:09:10.766 databrowser.researchallofus.org to learn

NOTE Confidence: 0.881953386666667

00:09:10.766 --> 00:09:13.969 about the several tiers of data that we have.

NOTE Confidence: 0.881953386666667

00:09:13.970 --> 00:09:16.736 So currently within our our database

NOTE Confidence: 0.881953386666667

00:09:16.736 --> 00:09:18.855 we have over 1174 active projects,

NOTE Confidence: 0.881953386666667

00:09:18.855 --> 00:09:21.295 so I talked to you a lot about the

NOTE Confidence: 0.881953386666667

00:09:21.295 --> 00:09:22.970 importance of collecting the data,

NOTE Confidence: 0.881953386666667

00:09:22.970 --> 00:09:25.154 but as a result of collecting the data

NOTE Confidence: 0.881953386666667

00:09:25.154 --> 00:09:27.735 we are now asking researchers like you to

NOTE Confidence: 0.881953386666667

00:09:27.735 --> 00:09:30.507 actually come in on either our public tier,

NOTE Confidence: 0.881953386666667

00:09:30.510 --> 00:09:32.442 our registered tier or our control

NOTE Confidence: 0.881953386666667

00:09:32.442 --> 00:09:35.422 tier of our data to go in and

NOTE Confidence: 0.881953386666667

00:09:35.422 --> 00:09:37.042 ask innovative questions about

NOTE Confidence: 0.881953386666667

00:09:37.042 --> 00:09:39.309 intersectionality so other active projects.

NOTE Confidence: 0.881953386666667

00:09:39.310 --> 00:09:41.056 We have projects that I'm interested

NOTE Confidence: 0.881953386666667

00:09:41.056 --> 00:09:41.929 in your center.

NOTE Confidence: 0.881953386666667

00:09:41.930 --> 00:09:43.533 I think our projects that are looking

NOTE Confidence: 0.881953386666667

00:09:43.533 --> 00:09:45.238 at sickle cell disease and pregnancy.

NOTE Confidence: 0.881953386666667

00:09:45.240 --> 00:09:46.765 Projects that are looking at

NOTE Confidence: 0.881953386666667

00:09:46.765 --> 00:09:47.680 diabetes and pregnancies.

NOTE Confidence: 0.881953386666667

00:09:47.680 --> 00:09:49.470 Projects are looking at hypertensive

NOTE Confidence: 0.881953386666667

00:09:49.470 --> 00:09:51.260 disorders of pregnancies and even

NOTE Confidence: 0.881953386666667

00:09:51.320 --> 00:09:53.318 perinatal stress and and mental health,

NOTE Confidence: 0.881953386666667

00:09:53.320 --> 00:09:55.352 and again for to learn more about the

NOTE Confidence: 0.881953386666667

00:09:55.352 --> 00:09:57.018 research projects in our Active Directory.

NOTE Confidence: 0.881953386666667

00:09:57.020 --> 00:10:00.056 You can go to researchallofus.org for

NOTE Confidence: 0.881953386666667

00:10:00.056 --> 00:10:03.846 its last research projects directly.

NOTE Confidence: 0.881953386666667

00:10:03.850 --> 00:10:05.713 So what are some of the things that are

NOTE Confidence: 0.881953386666667

00:10:05.713 --> 00:10:07.508 our opportunities for collaboration?

NOTE Confidence: 0.881953386666667

00:10:07.510 --> 00:10:09.379 I like to highlight the prep source

NOTE Confidence: 0.881953386666667

00:10:09.379 --> 00:10:10.905 study and it's collaboration with

NOTE Confidence: 0.881953386666667

00:10:10.905 --> 00:10:12.909 the all of US research program.

NOTE Confidence: 0.881953386666667

00:10:12.910 --> 00:10:14.908 Preg source is a longitudinal study

NOTE Confidence: 0.881953386666667

00:10:14.908 --> 00:10:16.526 that pregnant individuals can join

NOTE Confidence: 0.881953386666667

00:10:16.526 --> 00:10:17.936 that is in partnership with the

NOTE Confidence: 0.881953386666667

00:10:17.936 --> 00:10:19.569 all of US research program.

NOTE Confidence: 0.881953386666667

00:10:19.570 --> 00:10:21.945 So what we have done as all of us is that

NOTE Confidence: 0.881953386666667

00:10:21.945 --> 00:10:23.871 we've partnered with another NIH study

NOTE Confidence: 0.881953386666667

00:10:23.871 --> 00:10:25.748 PREG source so that individuals that

NOTE Confidence: 0.881953386666667

00:10:25.748 --> 00:10:28.089 are in the all of US research program.

NOTE Confidence: 0.881953386666667

00:10:28.089 --> 00:10:30.243 Who joined that are pregnant also

NOTE Confidence: 0.881953386666667

00:10:30.243 --> 00:10:32.215 have the opportunity to join Preg

NOTE Confidence: 0.881953386666667

00:10:32.215 --> 00:10:34.168 source because what this would do is

NOTE Confidence: 0.881953386666667

00:10:34.229 --> 00:10:36.343 that this will allow us to capture

NOTE Confidence: 0.881953386666667

00:10:36.343 --> 00:10:38.026 information and to collaborate with

NOTE Confidence: 0.881953386666667

00:10:38.026 --> 00:10:39.966 other researchers that are doing

NOTE Confidence: 0.881953386666667

00:10:39.966 --> 00:10:41.804 research on pregnant individuals so

NOTE Confidence: 0.881953386666667

00:10:41.804 --> 00:10:43.939 we can begin to disentangle some of

NOTE Confidence: 0.881953386666667

00:10:43.939 --> 00:10:45.660 that intersectionality that exists

NOTE Confidence: 0.881953386666667

00:10:45.660 --> 00:10:47.468 between in health outcomes,

NOTE Confidence: 0.881953386666667

00:10:47.470 --> 00:10:49.034 particularly in those high

NOTE Confidence: 0.881953386666667

00:10:49.034 --> 00:10:50.207 risk marginalized populations.

NOTE Confidence: 0.732172548

00:10:52.290 --> 00:10:53.910 And researchers like Doctor Nayed,

NOTE Confidence: 0.732172548

00:10:53.910 --> 00:10:56.712 Noel are exploring reproductive health issues

NOTE Confidence: 0.732172548

00:10:56.712 --> 00:10:58.980 that disproportionately affect black women.

NOTE Confidence: 0.732172548

00:10:58.980 --> 00:11:00.630 So for example, this quote is

NOTE Confidence: 0.732172548

00:11:00.630 --> 00:11:01.730 directly from Doctor Noel.

NOTE Confidence: 0.732172548

00:11:01.730 --> 00:11:03.917 Doctor Noel is an OB GYN I at Boston

NOTE Confidence: 0.732172548

00:11:03.917 --> 00:11:05.154 Hospital and she's leveraging

NOTE Confidence: 0.732172548

00:11:05.154 --> 00:11:07.026 the all of US research program.

NOTE Confidence: 0.732172548

00:11:07.030 --> 00:11:10.318 Data, say data set to to study hypertensive

NOTE Confidence: 0.732172548

00:11:10.318 --> 00:11:13.490 disorders in pregnancy and uterine fibroids.

NOTE Confidence: 0.732172548

00:11:13.490 --> 00:11:15.660 Dr Noel is involved in two demonstration

NOTE Confidence: 0.732172548

00:11:15.660 --> 00:11:17.746 projects right now using the all of U.S.

NOTE Confidence: 0.732172548

00:11:17.750 --> 00:11:20.792 data set and so as a black physician, Dr.

NOTE Confidence: 0.732172548

00:11:20.792 --> 00:11:22.568 Noel says that that I hope that the.

NOTE Confidence: 0.732172548

00:11:22.570 --> 00:11:24.565 All of US research program will work

NOTE Confidence: 0.732172548

00:11:24.565 --> 00:11:26.291 to rewrite the narrative regarding

NOTE Confidence: 0.732172548

00:11:26.291 --> 00:11:28.709 medical experimentation and or the past

NOTE Confidence: 0.732172548

00:11:28.709 --> 00:11:30.416 exclusion of marginalized populations

NOTE Confidence: 0.732172548

00:11:30.416 --> 00:11:32.516 and create more participation in

NOTE Confidence: 0.732172548

00:11:32.516 --> 00:11:34.408 research by these populations to

NOTE Confidence: 0.732172548

00:11:34.408 --> 00:11:36.606 improve health and the fact that we

NOTE Confidence: 0.732172548

00:11:36.606 --> 00:11:38.638 have researchers like Doctor Noel,

NOTE Confidence: 0.732172548

00:11:38.640 --> 00:11:40.026 asking these questions

NOTE Confidence: 0.732172548

00:11:40.026 --> 00:11:40.950 about intersectionality.

NOTE Confidence: 0.732172548

00:11:40.950 --> 00:11:42.889 That's going to really allow us to

NOTE Confidence: 0.732172548

00:11:42.889 --> 00:11:44.459 understand some of these issues.

NOTE Confidence: 0.732172548

00:11:44.460 --> 00:11:46.788 Even some of the women in my own

NOTE Confidence: 0.732172548

00:11:46.788 --> 00:11:49.286 family have had this same issue as

NOTE Confidence: 0.732172548

00:11:49.286 --> 00:11:51.136 it relates to reproductive health

NOTE Confidence: 0.732172548

00:11:51.206 --> 00:11:52.859 and reproductive justice.

NOTE Confidence: 0.732172548

00:11:52.860 --> 00:11:54.852 But Doctor Noel has often cautioned

NOTE Confidence: 0.732172548

00:11:54.852 --> 00:11:56.851 us to understand that while we

NOTE Confidence: 0.732172548

00:11:56.851 --> 00:11:58.669 are in this process of developing

NOTE Confidence: 0.732172548

00:11:58.669 --> 00:12:00.680 a diverse collecting information,

NOTE Confidence: 0.732172548

00:12:00.680 --> 00:12:02.682 we must understand that we have to

NOTE Confidence: 0.732172548

00:12:02.682 --> 00:12:04.805 address a lot of the historical

NOTE Confidence: 0.732172548

00:12:04.805 --> 00:12:06.405 medical mistrust that exists.

NOTE Confidence: 0.732172548

00:12:06.410 --> 00:12:08.335 And I don't like to just say

NOTE Confidence: 0.732172548

00:12:08.335 --> 00:12:08.885 medical mistrust.

NOTE Confidence: 0.732172548

00:12:08.890 --> 00:12:11.026 We heard that term come out a lot

NOTE Confidence: 0.732172548

00:12:11.026 --> 00:12:13.105 when doing the the height of the

NOTE Confidence: 0.732172548

00:12:13.105 --> 00:12:14.992 pandemic as we talked about access

NOTE Confidence: 0.732172548

00:12:14.992 --> 00:12:17.020 to and awareness of the vaccine,

NOTE Confidence: 0.732172548

00:12:17.020 --> 00:12:19.575 we often use the term vaccine hesitancy.

NOTE Confidence: 0.732172548

00:12:19.580 --> 00:12:21.700 But what I like to say when I talk to

NOTE Confidence: 0.732172548

00:12:21.763 --> 00:12:24.288 communities that justified medical mistrust,

NOTE Confidence: 0.732172548

00:12:24.290 --> 00:12:26.024 we think about historical ills and

NOTE Confidence: 0.732172548

00:12:26.024 --> 00:12:27.691 historical mistrust that has happened

NOTE Confidence: 0.732172548

00:12:27.691 --> 00:12:29.527 particularly to marginalized communities.

NOTE Confidence: 0.732172548

00:12:29.530 --> 00:12:31.108 I've had the pleasure for the

NOTE Confidence: 0.732172548

00:12:31.108 --> 00:12:33.252 past six years of working with the

NOTE Confidence: 0.732172548

00:12:33.252 --> 00:12:34.628 family of Henrietta Lacks.

NOTE Confidence: 0.732172548

00:12:34.630 --> 00:12:36.534 When we launched the all of US research

NOTE Confidence: 0.732172548

00:12:36.534 --> 00:12:38.264 program in my former institution at

NOTE Confidence: 0.732172548

00:12:38.264 --> 00:12:40.064 the University of Illinois at Chicago,

NOTE Confidence: 0.732172548

00:12:40.070 --> 00:12:40.415 UIC.

NOTE Confidence: 0.732172548

00:12:40.415 --> 00:12:43.175 At that time I was doing a project

NOTE Confidence: 0.732172548

00:12:43.175 --> 00:12:45.478 that was funded by for Corey,

NOTE Confidence: 0.732172548

00:12:45.480 --> 00:12:47.360 the patient centered Outcomes Research

NOTE Confidence: 0.732172548

00:12:47.360 --> 00:12:50.498 Institute and in that project I was I had

NOTE Confidence: 0.732172548

00:12:50.498 --> 00:12:51.993 cancer survivors and cancer advocates

NOTE Confidence: 0.732172548

00:12:51.993 --> 00:12:54.258 that we were developing and engaging

NOTE Confidence: 0.732172548

00:12:54.258 --> 00:12:56.168 with researchers so that researchers,

NOTE Confidence: 0.732172548

00:12:56.170 --> 00:12:58.613 even if that researcher was a basic

NOTE Confidence: 0.732172548

00:12:58.613 --> 00:13:00.064 science researcher and didn't

NOTE Confidence: 0.732172548

00:13:00.064 --> 00:13:02.080 conduct CBPR research like I do,

00:13:02.080 --> 00:13:04.320 but that we were trying to create

00:13:04.320 --> 00:13:05.834 an environment where participants

00:13:05.834 --> 00:13:07.786 patients could interact with

00:13:07.786 --> 00:13:09.738 researchers so that researchers,

00:13:09.740 --> 00:13:11.510 even those conducting basic science.

00:13:11.510 --> 00:13:13.390 Research could share their

00:13:13.390 --> 00:13:15.270 ideas with cancer survivors,

00:13:15.270 --> 00:13:17.615 or they could could create this think

00:13:17.615 --> 00:13:19.071 tank environment where researchers

00:13:19.071 --> 00:13:21.773 were saying that I'm studying not just

00:13:21.773 --> 00:13:23.498 information that's important to me,

00:13:23.500 --> 00:13:25.988 or information that I I study in my

00:13:25.988 --> 00:13:27.340 dissertation several decades ago.

00:13:27.340 --> 00:13:28.930 But research that is important

00:13:28.930 --> 00:13:30.960 to populations who are who carry

00:13:30.960 --> 00:13:32.480 the greatest burden disease.

NOTE Confidence: 0.732172548

00:13:32.480 --> 00:13:35.189 So at this time, when I had this grant,

NOTE Confidence: 0.732172548

00:13:35.190 --> 00:13:36.506 we were getting ready to kick off

NOTE Confidence: 0.732172548

00:13:36.506 --> 00:13:37.980 the all of US research program,

NOTE Confidence: 0.732172548

00:13:37.980 --> 00:13:39.120 and at that time,

NOTE Confidence: 0.732172548

00:13:39.120 --> 00:13:40.830 Oprah Winfrey and the HBO network

NOTE Confidence: 0.793946444

00:13:40.888 --> 00:13:42.508 were getting ready to launch.

NOTE Confidence: 0.793946444

00:13:42.510 --> 00:13:44.512 The movie of Henrietta Lacks and one

NOTE Confidence: 0.793946444

00:13:44.512 --> 00:13:46.088 of the participants in the study.

NOTE Confidence: 0.793946444

00:13:46.090 --> 00:13:47.968 I'll never forget Miss Rosemary Rogers,

NOTE Confidence: 0.793946444

00:13:47.970 --> 00:13:50.103 a breast cancer survivor came to me and said,

NOTE Confidence: 0.793946444

00:13:50.110 --> 00:13:51.895 Karine, I'm very concerned that

NOTE Confidence: 0.793946444

00:13:51.895 --> 00:13:54.040 we're getting ready to launch this.

NOTE Confidence: 0.793946444

00:13:54.040 --> 00:13:55.910 All of US research program,

NOTE Confidence: 0.793946444

00:13:55.910 --> 00:13:57.830 you know and ask people from

NOTE Confidence: 0.793946444

00:13:57.830 --> 00:13:59.110 underrepresented groups and role,

NOTE Confidence: 0.793946444

00:13:59.110 --> 00:14:01.806 but we have not had a community conversation

NOTE Confidence: 0.793946444

00:14:01.806 --> 00:14:04.479 about what it truly means about why

NOTE Confidence: 0.793946444

00:14:04.479 --> 00:14:06.409 populations who have been historically

NOTE Confidence: 0.793946444

00:14:06.479 --> 00:14:08.687 underrepresented do not participate.

NOTE Confidence: 0.793946444

00:14:08.690 --> 00:14:10.614 So, advocates like Miss

NOTE Confidence: 0.793946444

00:14:10.614 --> 00:14:12.538 Rosemary encouraged us to.

NOTE Confidence: 0.793946444

00:14:12.540 --> 00:14:13.748 Have a town hall.

NOTE Confidence: 0.793946444

00:14:13.748 --> 00:14:16.052 That idea led by a patient advocate

NOTE Confidence: 0.793946444

00:14:16.052 --> 00:14:18.985 turned into a community town hall that

NOTE Confidence: 0.793946444

00:14:18.985 --> 00:14:21.543 included over 400 participants from the

NOTE Confidence: 0.793946444

00:14:21.543 --> 00:14:24.378 community and but it also included a

NOTE Confidence: 0.793946444

00:14:24.378 --> 00:14:26.168 panel that included four generations

NOTE Confidence: 0.793946444

00:14:26.168 --> 00:14:28.710 of the family of Henrietta Lacks.

NOTE Confidence: 0.793946444

00:14:28.710 --> 00:14:30.858 It included her great great granddaughter,

NOTE Confidence: 0.793946444

00:14:30.860 --> 00:14:31.796 her great granddaughter,

NOTE Confidence: 0.793946444

00:14:31.796 --> 00:14:33.980 her granddaughter and her daughter in law.

NOTE Confidence: 0.793946444

00:14:33.980 --> 00:14:36.346 Jerry lacks and the importance of the

NOTE Confidence: 0.793946444

00:14:36.346 --> 00:14:38.078 relationships that were built by us.

NOTE Confidence: 0.793946444

00:14:38.080 --> 00:14:39.565 Having that that community town

NOTE Confidence: 0.793946444

00:14:39.565 --> 00:14:40.753 Hall forum is it.

NOTE Confidence: 0.793946444

00:14:40.760 --> 00:14:42.188 Imagine the community impact.

NOTE Confidence: 0.793946444

00:14:42.188 --> 00:14:45.509 When you have the family of Henry at the

NOTE Confidence: 0.793946444

00:14:45.509 --> 00:14:47.723 last speaking to your community members,

NOTE Confidence: 0.793946444

00:14:47.730 --> 00:14:49.540 letting them know that yes,

NOTE Confidence: 0.793946444

00:14:49.540 --> 00:14:52.444 historical ills have taken place in the past,

NOTE Confidence: 0.793946444

00:14:52.450 --> 00:14:53.392 we acknowledge that,

NOTE Confidence: 0.793946444

00:14:53.392 --> 00:14:55.590 but we also acknowledge that it's so

NOTE Confidence: 0.793946444

00:14:55.648 --> 00:14:58.128 important for us to have a seat at the table.

NOTE Confidence: 0.793946444

00:14:58.130 --> 00:15:00.122 The family here at the lack of knowledge

NOTE Confidence: 0.793946444

00:15:00.122 --> 00:15:02.355 that the work that we were doing to

NOTE Confidence: 0.793946444

00:15:02.355 --> 00:15:03.938 advance genomics research by including

NOTE Confidence: 0.793946444

00:15:03.938 --> 00:15:05.998 communities that have been historically

NOTE Confidence: 0.793946444

00:15:05.998 --> 00:15:07.998 represented what's important to them.

NOTE Confidence: 0.793946444

00:15:07.998 --> 00:15:10.434 So imagine the impact of hearing first

NOTE Confidence: 0.793946444

00:15:10.434 --> 00:15:13.137 hand from the family of Henrietta Lacks.

NOTE Confidence: 0.793946444

00:15:13.140 --> 00:15:14.672 About the importance of

NOTE Confidence: 0.793946444

00:15:14.672 --> 00:15:16.204 diversity in clinical trials,

NOTE Confidence: 0.793946444

00:15:16.210 --> 00:15:18.115 that is what I consider

NOTE Confidence: 0.793946444

00:15:18.115 --> 00:15:19.258 true community engagement.

NOTE Confidence: 0.793946444

00:15:19.260 --> 00:15:21.423 Launching our all of US research program

NOTE Confidence: 0.793946444

00:15:21.423 --> 00:15:23.986 off with the with the voice of the lacks

NOTE Confidence: 0.793946444

00:15:23.986 --> 00:15:26.149 family was a gift that is so amazing

NOTE Confidence: 0.793946444

00:15:26.149 --> 00:15:28.065 to me that I'm humbled and honored.

NOTE Confidence: 0.793946444

00:15:28.065 --> 00:15:30.410 And I'm also humbled and honored to

NOTE Confidence: 0.793946444

00:15:30.410 --> 00:15:32.396 continuously work with the the last

NOTE Confidence: 0.793946444

00:15:32.396 --> 00:15:34.280 family to ask those difficult questions.

NOTE Confidence: 0.793946444

00:15:34.280 --> 00:15:35.840 Are we getting it right?

NOTE Confidence: 0.793946444

00:15:35.840 --> 00:15:37.796 What should we be thinking about,

NOTE Confidence: 0.793946444

00:15:37.800 --> 00:15:39.240 especially now in our program,

NOTE Confidence: 0.793946444

00:15:39.240 --> 00:15:41.046 as we think about return of value

NOTE Confidence: 0.793946444

00:15:41.046 --> 00:15:43.240 return of data, we want to think about.

NOTE Confidence: 0.793946444

00:15:43.240 --> 00:15:45.624 Is the data that we were turning to

NOTE Confidence: 0.793946444

00:15:45.624 --> 00:15:47.034 participants important to them and

NOTE Confidence: 0.793946444

00:15:47.034 --> 00:15:48.798 one of the methods and best practices

NOTE Confidence: 0.793946444

00:15:48.853 --> 00:15:50.333 of engaging under representing

NOTE Confidence: 0.793946444

00:15:50.333 --> 00:15:51.813 community and communities and

NOTE Confidence: 0.793946444

00:15:51.813 --> 00:15:53.242 research is community engagement

NOTE Confidence: 0.793946444

00:15:53.242 --> 00:15:55.629 in the all of US research program.

NOTE Confidence: 0.793946444

00:15:55.630 --> 00:15:57.160 We've taken this very important.

NOTE Confidence: 0.793946444

00:15:57.160 --> 00:15:58.060 We've taken this seriously.

NOTE Confidence: 0.793946444

00:15:58.060 --> 00:15:59.410 I'm going to read this quote

NOTE Confidence: 0.793946444

00:15:59.455 --> 00:16:00.260 to you from the CDC.

NOTE Confidence: 0.793946444

00:16:00.260 --> 00:16:01.250 It's older quote,

NOTE Confidence: 0.793946444

00:16:01.250 --> 00:16:02.900 but community engagement is the

NOTE Confidence: 0.793946444

00:16:02.900 --> 00:16:04.401 process of working collaboratively

NOTE Confidence: 0.793946444

00:16:04.401 --> 00:16:06.356 with and through groups of

NOTE Confidence: 0.793946444

00:16:06.356 --> 00:16:08.190 people affiliated by geographic,

NOTE Confidence: 0.793946444

00:16:08.190 --> 00:16:08.672 proximity,

NOTE Confidence: 0.793946444

00:16:08.672 --> 00:16:11.082 special interests or similar situations

NOTE Confidence: 0.793946444

00:16:11.082 --> 00:16:13.630 to address issues affecting the well.

NOTE Confidence: 0.793946444

00:16:13.630 --> 00:16:14.678 Gain of those people.

NOTE Confidence: 0.793946444

00:16:14.678 --> 00:16:16.686 It is a powerful vehicle for bringing

NOTE Confidence: 0.793946444

00:16:16.686 --> 00:16:18.198 about environmental and behavioral

NOTE Confidence: 0.793946444

00:16:18.198 --> 00:16:20.440 change that will improve the health

NOTE Confidence: 0.793946444

00:16:20.440 --> 00:16:22.240 of the Community and its members.

NOTE Confidence: 0.793946444

00:16:22.240 --> 00:16:23.808 And I see here this is a triad

NOTE Confidence: 0.793946444

00:16:23.808 --> 00:16:25.218 that I used to often use.

NOTE Confidence: 0.793946444

00:16:25.220 --> 00:16:27.030 I have community engagement center

NOTE Confidence: 0.793946444

00:16:27.030 --> 00:16:28.840 participants as partners as a

NOTE Confidence: 0.797470171666666

00:16:28.906 --> 00:16:30.768 driving guide, but also diversity

NOTE Confidence: 0.797470171666666

00:16:30.768 --> 00:16:32.548 and researcher workforce and then

NOTE Confidence: 0.797470171666666

00:16:32.548 --> 00:16:34.270 citizen scientists as another concept.

NOTE Confidence: 0.882922914347826

00:16:36.510 --> 00:16:38.724 So in my research and I'll share a little

NOTE Confidence: 0.882922914347826

00:16:38.724 --> 00:16:40.871 bit now about my own research that was

NOTE Confidence: 0.882922914347826

00:16:40.871 --> 00:16:43.029 guided by the social ecological model.

NOTE Confidence: 0.882922914347826

00:16:43.030 --> 00:16:45.118 I did both implementation science as

NOTE Confidence: 0.882922914347826

00:16:45.118 --> 00:16:47.373 well as CBPR, particularly in cancer,

NOTE Confidence: 0.882922914347826

00:16:47.373 --> 00:16:49.378 mentioning control and my team.

NOTE Confidence: 0.882922914347826

00:16:49.380 --> 00:16:51.930 We actually adopted and adapted this

NOTE Confidence: 0.882922914347826

00:16:51.930 --> 00:16:54.447 CDC social ecological model to think

NOTE Confidence: 0.882922914347826

00:16:54.447 --> 00:16:57.051 about how do we engage communities and

NOTE Confidence: 0.882922914347826

00:16:57.051 --> 00:16:59.289 research so at the individual level,

NOTE Confidence: 0.882922914347826

00:16:59.290 --> 00:17:01.168 we engage communities and research by

NOTE Confidence: 0.882922914347826

00:17:01.168 --> 00:17:03.290 thinking about issues of health literacy,

NOTE Confidence: 0.882922914347826

00:17:03.290 --> 00:17:04.140 about knowledge,

NOTE Confidence: 0.882922914347826

00:17:04.140 --> 00:17:06.690 attitudes and beliefs about lung cancer.

NOTE Confidence: 0.882922914347826

00:17:06.690 --> 00:17:08.334 And how screening assessed

NOTE Confidence: 0.882922914347826

00:17:08.334 --> 00:17:09.567 by patient navigators.

NOTE Confidence: 0.882922914347826

00:17:09.570 --> 00:17:12.006 And we also hired patient navigators and

NOTE Confidence: 0.882922914347826

00:17:12.006 --> 00:17:13.875 community health workers that reflected

NOTE Confidence: 0.882922914347826

00:17:13.875 --> 00:17:15.790 the population of the participants.

NOTE Confidence: 0.882922914347826

00:17:15.790 --> 00:17:16.873 We were engaging.

NOTE Confidence: 0.882922914347826

00:17:16.873 --> 00:17:19.400 Then we thought about at the interpersonal

NOTE Confidence: 0.882922914347826

00:17:19.469 --> 00:17:21.714 level what patients supports and

NOTE Confidence: 0.882922914347826

00:17:21.714 --> 00:17:23.510 interpersonal messaging is needed.

NOTE Confidence: 0.882922914347826

00:17:23.510 --> 00:17:25.316 That's going to contribute to the

NOTE Confidence: 0.882922914347826

00:17:25.316 --> 00:17:26.937 social cultural norms about lung

NOTE Confidence: 0.882922914347826

00:17:26.937 --> 00:17:28.747 cancer screening and tobacco cessation.

NOTE Confidence: 0.882922914347826

00:17:28.750 --> 00:17:31.158 We saw a lot of this impacted

NOTE Confidence: 0.882922914347826

00:17:31.158 --> 00:17:31.846 interpersonal care.

NOTE Confidence: 0.882922914347826

00:17:31.850 --> 00:17:34.274 We within the COVID-19 pandemic because

NOTE Confidence: 0.882922914347826

00:17:34.274 --> 00:17:36.909 of social distancing and because of our.

NOTE Confidence: 0.882922914347826

00:17:36.910 --> 00:17:38.870 Need to limit people in the waiting

NOTE Confidence: 0.882922914347826

00:17:38.870 --> 00:17:41.137 rooms and limit people in the exam rooms.

NOTE Confidence: 0.882922914347826

00:17:41.140 --> 00:17:43.348 We saw the impact that that had on

NOTE Confidence: 0.882922914347826

00:17:43.348 --> 00:17:45.773 how certain populations were able to

NOTE Confidence: 0.882922914347826

00:17:45.773 --> 00:17:48.028 make medical decisions because certain

NOTE Confidence: 0.882922914347826

00:17:48.028 --> 00:17:50.349 communities rely on that interpersonal

NOTE Confidence: 0.882922914347826

00:17:50.349 --> 00:17:52.153 that intergenerational family connection

NOTE Confidence: 0.882922914347826

00:17:52.153 --> 00:17:54.248 to make their health care decisions.

NOTE Confidence: 0.882922914347826

00:17:54.248 --> 00:17:55.733 But we also engage communities

NOTE Confidence: 0.882922914347826

00:17:55.733 --> 00:17:57.278 at the organizational level.

NOTE Confidence: 0.882922914347826

00:17:57.280 --> 00:17:58.488 As I stated before,

NOTE Confidence: 0.882922914347826

00:17:58.488 --> 00:17:59.998 my research happened primarily at

NOTE Confidence: 0.882922914347826

00:17:59.998 --> 00:18:01.683 the FQHC and clinical level to

NOTE Confidence: 0.882922914347826

00:18:01.683 --> 00:18:03.764 think about that and so one of the

NOTE Confidence: 0.882922914347826

00:18:03.764 --> 00:18:05.395 things that I did is that anytime

NOTE Confidence: 0.882922914347826

00:18:05.400 --> 00:18:07.160 I developed a community engaged.

NOTE Confidence: 0.882922914347826

00:18:07.160 --> 00:18:08.834 Research project that was going to

NOTE Confidence: 0.882922914347826

00:18:08.834 --> 00:18:10.365 be implemented within our fairly

NOTE Confidence: 0.882922914347826

00:18:10.365 --> 00:18:11.448 qualified Health Center.

NOTE Confidence: 0.882922914347826

00:18:11.450 --> 00:18:12.476 Our community clinic.

NOTE Confidence: 0.882922914347826

00:18:12.476 --> 00:18:14.870 I presented that idea to our Community

NOTE Confidence: 0.882922914347826

00:18:14.927 --> 00:18:16.957 Advisory Board 1st and I presented that

NOTE Confidence: 0.882922914347826

00:18:16.957 --> 00:18:19.427 idea to say hey is the question that

NOTE Confidence: 0.882922914347826

00:18:19.427 --> 00:18:21.231 I'm developing of interest to you.

NOTE Confidence: 0.882922914347826

00:18:21.231 --> 00:18:23.058 B am I thinking about this question

NOTE Confidence: 0.882922914347826

00:18:23.058 --> 00:18:25.480 in a way that would truly drive the

NOTE Confidence: 0.882922914347826

00:18:25.480 --> 00:18:27.350 needle forward for the community?

NOTE Confidence: 0.882922914347826

00:18:27.350 --> 00:18:29.102 I knew that from a scientifically

NOTE Confidence: 0.882922914347826

00:18:29.102 --> 00:18:30.639 rigorous perspective I had developed

NOTE Confidence: 0.882922914347826

00:18:30.639 --> 00:18:32.511 that question the way that would

NOTE Confidence: 0.882922914347826

00:18:32.511 --> 00:18:33.447 move science forward.

NOTE Confidence: 0.882922914347826

00:18:33.450 --> 00:18:35.450 But if we only move science forward in

NOTE Confidence: 0.882922914347826

00:18:35.450 --> 00:18:37.779 a way that's going to be publishable.

NOTE Confidence: 0.882922914347826

00:18:37.780 --> 00:18:38.600 And move our grants.

NOTE Confidence: 0.882922914347826

00:18:38.600 --> 00:18:40.039 For we don't think about moving science

NOTE Confidence: 0.882922914347826

00:18:40.039 --> 00:18:41.497 for it in a way that it will ask.

NOTE Confidence: 0.882922914347826

00:18:41.500 --> 00:18:42.884 You actually answer questions

NOTE Confidence: 0.882922914347826

00:18:42.884 --> 00:18:44.614 that important to the community.

NOTE Confidence: 0.882922914347826

00:18:44.620 --> 00:18:46.678 I believe that we've only moved signs.

NOTE Confidence: 0.882922914347826

00:18:46.680 --> 00:18:48.258 A portion of the way forward.

NOTE Confidence: 0.882922914347826

00:18:48.260 --> 00:18:50.115 And when we think about the policy

NOTE Confidence: 0.882922914347826

00:18:50.115 --> 00:18:51.787 level as a as an early stage investor

NOTE Confidence: 0.882922914347826

00:18:51.787 --> 00:18:53.259 in our first got into research,

NOTE Confidence: 0.882922914347826

00:18:53.260 --> 00:18:54.639 I didn't know that policy was going

NOTE Confidence: 0.882922914347826

00:18:54.639 --> 00:18:56.077 to be something that I would address.

NOTE Confidence: 0.882922914347826

00:18:56.080 --> 00:18:58.248 I didn't know that I would join the

NOTE Confidence: 0.882922914347826

00:18:58.248 --> 00:19:00.083 the Society behavioral medicine and

NOTE Confidence: 0.882922914347826

00:19:00.083 --> 00:19:02.543 learn how to advocate advocate with

NOTE Confidence: 0.882922914347826

00:19:02.543 --> 00:19:04.164 legislators and other policy leaders

NOTE Confidence: 0.882922914347826

00:19:04.164 --> 00:19:06.374 to talk about how that of all the

NOTE Confidence: 0.882922914347826

00:19:06.374 --> 00:19:08.033 lung Cancer Research I can do it.

NOTE Confidence: 0.882922914347826

00:19:08.040 --> 00:19:09.815 We'll talk about the tobacco

NOTE Confidence: 0.882922914347826

00:19:09.815 --> 00:19:10.525 cessation guidelines,

NOTE Confidence: 0.882922914347826

00:19:10.530 --> 00:19:12.336 but there's still a corner store

NOTE Confidence: 0.882922914347826

00:19:12.336 --> 00:19:13.895 in certain neighborhoods in Chicago

NOTE Confidence: 0.882922914347826

00:19:13.895 --> 00:19:15.375 that are selling tobacco products

NOTE Confidence: 0.882922914347826

00:19:15.375 --> 00:19:16.559 to youth that are

NOTE Confidence: 0.829402350952381

00:19:16.617 --> 00:19:18.535 underage. If there are still policies

NOTE Confidence: 0.829402350952381

39

00:19:18.535 --> 00:19:20.393 in place that allow certain messaging

NOTE Confidence: 0.829402350952381

00:19:20.393 --> 00:19:22.073 and signage in certain communities

NOTE Confidence: 0.829402350952381

00:19:22.073 --> 00:19:24.070 in Chicago land to differ from

NOTE Confidence: 0.829402350952381

00:19:24.070 --> 00:19:25.870 what you see in affluent suburbs,

NOTE Confidence: 0.829402350952381

00:19:25.870 --> 00:19:27.590 then that's a policy issue,

NOTE Confidence: 0.829402350952381

00:19:27.590 --> 00:19:29.669 so I had to quickly learn that

NOTE Confidence: 0.829402350952381

00:19:29.669 --> 00:19:32.150 although I may not do Policy Research,

NOTE Confidence: 0.829402350952381

00:19:32.150 --> 00:19:33.398 I wanted to learn.

NOTE Confidence: 0.829402350952381

00:19:33.398 --> 00:19:36.090 How can I translate my findings into policy,

NOTE Confidence: 0.829402350952381

00:19:36.090 --> 00:19:37.690 language, or work with Policy

NOTE Confidence: 0.829402350952381

00:19:37.690 --> 00:19:39.290 Research so they can drive?

NOTE Confidence: 0.829402350952381

00:19:39.290 --> 00:19:39.916 Results forward,

NOTE Confidence: 0.829402350952381

00:19:39.916 --> 00:19:42.107 so this is just an example that

NOTE Confidence: 0.829402350952381

00:19:42.107 --> 00:19:44.678 I show of how we were able to

NOTE Confidence: 0.829402350952381

00:19:44.678 --> 00:19:46.116 take Community engaged research

NOTE Confidence: 0.829402350952381

00:19:46.116 --> 00:19:48.276 research and and implement it

NOTE Confidence: 0.829402350952381

00:19:48.276 --> 00:19:50.004 using the ecological approach.

NOTE Confidence: 0.829402350952381

00:19:50.010 --> 00:19:51.430 I also talked about engaging

NOTE Confidence: 0.829402350952381

00:19:51.430 --> 00:19:52.850 citizen science in my research.

NOTE Confidence: 0.882608005263158

00:19:55.090 --> 00:19:56.778 So this is an example of a project

NOTE Confidence: 0.882608005263158

00:19:56.778 --> 00:19:58.788 that I did with citizen scientists

NOTE Confidence: 0.882608005263158

00:19:58.788 --> 00:20:00.703 looking at prostate cancer disparities.

NOTE Confidence: 0.882608005263158

00:20:00.710 --> 00:20:02.470 So this is actually a map of the

NOTE Confidence: 0.882608005263158

00:20:02.470 --> 00:20:04.563 Chicago Land communities in Chicago, IL.

NOTE Confidence: 0.882608005263158

00:20:04.563 --> 00:20:06.928 We have 77 community areas.

NOTE Confidence: 0.882608005263158

00:20:06.930 --> 00:20:08.466 This map right here is from.

NOTE Confidence: 0.882608005263158

00:20:08.470 --> 00:20:10.367 It's a little old, but it does.

NOTE Confidence: 0.882608005263158

00:20:10.370 --> 00:20:12.350 Unfortunately, it still looks this way.

NOTE Confidence: 0.882608005263158

00:20:12.350 --> 00:20:14.326 The darker areas show

NOTE Confidence: 0.882608005263158

00:20:14.326 --> 00:20:15.808 prostate cancer mortality.

NOTE Confidence: 0.882608005263158

00:20:15.810 --> 00:20:18.874 The darker orange or brown areas showed that.

NOTE Confidence: 0.882608005263158

00:20:18.880 --> 00:20:22.120 On the South and West side of Chicago,

NOTE Confidence: 0.882608005263158

00:20:22.120 --> 00:20:23.975 we show that population there's

NOTE Confidence: 0.882608005263158

00:20:23.975 --> 00:20:26.711 52 to 93 per 100,000 people that

NOTE Confidence: 0.882608005263158

00:20:26.711 --> 00:20:28.796 are dying of prostate cancer.

NOTE Confidence: 0.882608005263158

00:20:28.800 --> 00:20:30.728 And if you look at areas over to

NOTE Confidence: 0.882608005263158

00:20:30.728 --> 00:20:32.897 the far right in those light brown,

NOTE Confidence: 0.882608005263158

00:20:32.900 --> 00:20:34.001 almost ivory areas.

NOTE Confidence: 0.882608005263158

00:20:34.001 --> 00:20:36.570 Those are areas such as where institutions

NOTE Confidence: 0.882608005263158

00:20:36.635 --> 00:20:38.591 like northwestern and areas that we

NOTE Confidence: 0.882608005263158

00:20:38.591 --> 00:20:41.139 call the Gold Coast very affluent areas.

NOTE Confidence: 0.882608005263158

00:20:41.140 --> 00:20:43.317 But when you think about where prostate

NOTE Confidence: 0.882608005263158

00:20:43.317 --> 00:20:44.979 cancer mortality was taking place,

NOTE Confidence: 0.882608005263158

00:20:44.980 --> 00:20:46.480 unfortunately our academic centers

NOTE Confidence: 0.882608005263158

00:20:46.480 --> 00:20:48.355 are not in those communities.

NOTE Confidence: 0.882608005263158

00:20:48.360 --> 00:20:49.752 Also, we think about.

NOTE Confidence: 0.882608005263158

00:20:49.752 --> 00:20:51.144 Where prostate cancer mortality

NOTE Confidence: 0.882608005263158

00:20:51.144 --> 00:20:52.230 is taking place.

NOTE Confidence: 0.882608005263158

00:20:52.230 --> 00:20:53.859 Those populations don't

NOTE Confidence: 0.882608005263158

00:20:53.859 --> 00:20:56.530 have access to in clinical,

NOTE Confidence: 0.882608005263158

00:20:56.530 --> 00:20:58.610 clinical trials and or

NOTE Confidence: 0.882608005263158

00:20:58.610 --> 00:21:00.170 innovative screening measures,

NOTE Confidence: 0.882608005263158

00:21:00.170 --> 00:21:02.382 so I sought to engage the Community

NOTE Confidence: 0.882608005263158

00:21:02.382 --> 00:21:03.973 partner called Project Brotherhood to

NOTE Confidence: 0.882608005263158

00:21:03.973 --> 00:21:06.031 think about how can we come together

NOTE Confidence: 0.882608005263158

00:21:06.031 --> 00:21:07.774 to address the prostate cancer

NOTE Confidence: 0.882608005263158

00:21:07.774 --> 00:21:09.862 disparities in the Chicago Land area

NOTE Confidence: 0.882608005263158

00:21:09.870 --> 00:21:11.770 to the citizen scientists concept.

NOTE Confidence: 0.882608005263158

00:21:11.770 --> 00:21:14.011 So what we did is that we use the

NOTE Confidence: 0.882608005263158

00:21:14.011 --> 00:21:15.846 social network theory to engage

NOTE Confidence: 0.882608005263158

00:21:15.846 --> 00:21:17.746 eight African American men that

NOTE Confidence: 0.882608005263158

00:21:17.746 --> 00:21:20.058 were dispersed throughout the city.

NOTE Confidence: 0.882608005263158

00:21:20.060 --> 00:21:21.500 That actually live in population

NOTE Confidence: 0.882608005263158

00:21:21.500 --> 00:21:23.636 lives and lived in parts of the

NOTE Confidence: 0.882608005263158

00:21:23.636 --> 00:21:24.912 city that actually represent

NOTE Confidence: 0.882608005263158

00:21:24.912 --> 00:21:26.188 the highest burden disease.

NOTE Confidence: 0.882608005263158

00:21:26.190 --> 00:21:28.116 Because what we understood is that

NOTE Confidence: 0.882608005263158

00:21:28.116 --> 00:21:29.990 long after our grant was over,

NOTE Confidence: 0.882608005263158

00:21:29.990 --> 00:21:31.784 these men would likely still live

NOTE Confidence: 0.882608005263158

00:21:31.784 --> 00:21:32.980 in these community neighborhoods.

NOTE Confidence: 0.882608005263158

00:21:32.980 --> 00:21:34.800 So by utilizing the citizens

NOTE Confidence: 0.882608005263158

00:21:34.800 --> 00:21:35.528 scientists model,

NOTE Confidence: 0.882608005263158

00:21:35.530 --> 00:21:36.990 we were actually increasing

NOTE Confidence: 0.882608005263158

00:21:36.990 --> 00:21:38.450 the Community knowledge and

NOTE Confidence: 0.882608005263158

00:21:38.450 --> 00:21:40.189 agency within those communities.

NOTE Confidence: 0.882608005263158

00:21:40.190 --> 00:21:42.486 So for a period of six weeks,

NOTE Confidence: 0.882608005263158

00:21:42.490 --> 00:21:44.145 we engage African American men

NOTE Confidence: 0.882608005263158

00:21:44.145 --> 00:21:45.800 and citizen scientists to train

NOTE Confidence: 0.882608005263158

00:21:45.855 --> 00:21:46.869 them on everything.

NOTE Confidence: 0.882608005263158

00:21:46.870 --> 00:21:49.230 In terms of what is a clinical trial,

NOTE Confidence: 0.882608005263158

00:21:49.230 --> 00:21:50.565 why is it important to

NOTE Confidence: 0.882608005263158

00:21:50.565 --> 00:21:51.633 participate in clinical trial?

NOTE Confidence: 0.882608005263158

00:21:51.640 --> 00:21:52.804 Prostate cancer screening.

NOTE Confidence: 0.882608005263158

00:21:52.804 --> 00:21:55.132 101 questions to ask your doctor.

NOTE Confidence: 0.882608005263158

00:21:55.140 --> 00:21:57.084 We even talked about things like the IRB,

NOTE Confidence: 0.882608005263158

00:21:57.090 --> 00:21:58.775 the Institutional Review Board with

NOTE Confidence: 0.882608005263158

00:21:58.775 --> 00:22:00.460 these men and research funding

NOTE Confidence: 0.882608005263158

00:22:00.512 --> 00:22:02.142 because after that training of

NOTE Confidence: 0.882608005263158

00:22:02.142 --> 00:22:03.772 these men and citizen scientists,

NOTE Confidence: 0.882608005263158

00:22:03.780 --> 00:22:05.922 we then asked them to engage their

NOTE Confidence: 0.882608005263158

00:22:05.922 --> 00:22:08.103 social networks to allow us to recruit

NOTE Confidence: 0.882608005263158

00:22:08.103 --> 00:22:09.903 from their social networks for a

NOTE Confidence: 0.882608005263158

00:22:09.969 --> 00:22:11.817 prostate cancer screening study.

NOTE Confidence: 0.882608005263158

00:22:11.820 --> 00:22:14.620 Because I'll tell you when I first

NOTE Confidence: 0.882608005263158

00:22:14.620 --> 00:22:16.844 started my research career and I

NOTE Confidence: 0.882608005263158

00:22:16.844 --> 00:22:18.618 told a former mentor at the time

NOTE Confidence: 0.882608005263158

00:22:18.618 --> 00:22:20.377 that I was interested in doing

NOTE Confidence: 0.882608005263158

00:22:20.377 --> 00:22:21.478 cancer disparities research.

NOTE Confidence: 0.882608005263158

00:22:21.480 --> 00:22:23.015 Particularly focused on minority men

NOTE Confidence: 0.882608005263158

00:22:23.015 --> 00:22:25.249 with the focus on African American men.

NOTE Confidence: 0.882608005263158

00:22:25.250 --> 00:22:27.290 I was told that a it would be

NOTE Confidence: 0.882608005263158

00:22:27.290 --> 00:22:28.951 very difficult to engage African

NOTE Confidence: 0.882608005263158

00:22:28.951 --> 00:22:30.407 American men and research.

NOTE Confidence: 0.882608005263158

00:22:30.410 --> 00:22:32.242 I was told that it be very difficult

NOTE Confidence: 0.882608005263158

00:22:32.242 --> 00:22:34.366 to power my studies in a way that

NOTE Confidence: 0.882608005263158

00:22:34.366 --> 00:22:35.442 would get rigorous findings,

NOTE Confidence: 0.882608005263158

00:22:35.450 --> 00:22:37.226 and I was even told that it'd be

NOTE Confidence: 0.882608005263158

00:22:37.226 --> 00:22:38.912 difficult for me to get funding in

NOTE Confidence: 0.882608005263158

00:22:38.912 --> 00:22:40.729 those areas because of those many things,

NOTE Confidence: 0.816535770909091

00:22:40.730 --> 00:22:42.398 but through collaboration with

NOTE Confidence: 0.816535770909091

00:22:42.398 --> 00:22:44.066 community through adopting this

NOTE Confidence: 0.816535770909091

00:22:44.066 --> 00:22:46.143 citizen scientist model, we were able

NOTE Confidence: 0.816535770909091

00:22:46.143 --> 00:22:47.889 to meet and exceed our enrollment.

NOTE Confidence: 0.816535770909091

00:22:47.890 --> 00:22:49.864 We were also able to understand

NOTE Confidence: 0.816535770909091

00:22:49.864 --> 00:22:52.049 how to engage African American men.

NOTE Confidence: 0.816535770909091

00:22:52.050 --> 00:22:53.706 Research we did innovative things that

NOTE Confidence: 0.816535770909091

00:22:53.706 --> 00:22:55.754 were simple to me but innovative to

NOTE Confidence: 0.816535770909091

00:22:55.754 --> 00:22:57.826 others by making sure that our population,

NOTE Confidence: 0.816535770909091

00:22:57.830 --> 00:22:59.790 the researchers, reflect the population.

NOTE Confidence: 0.816535770909091

00:22:59.790 --> 00:23:01.410 Our partner with Doctor Adam Murphy.

NOTE Confidence: 0.816535770909091

00:23:01.410 --> 00:23:02.566 After the American urologists,

NOTE Confidence: 0.816535770909091

00:23:02.566 --> 00:23:04.600 that was the one of the also

NOTE Confidence: 0.816535770909091

00:23:04.600 --> 00:23:06.064 the lead PI's in the study,

NOTE Confidence: 0.816535770909091

00:23:06.070 --> 00:23:07.342 my My research lab.

NOTE Confidence: 0.816535770909091

00:23:07.342 --> 00:23:07.978 My students.

NOTE Confidence: 0.816535770909091

00:23:07.980 --> 00:23:09.898 I partnered with the medical school to

NOTE Confidence: 0.816535770909091

00:23:09.898 --> 00:23:11.712 engage young African American men that

NOTE Confidence: 0.816535770909091

00:23:11.712 --> 00:23:13.272 were interested in health disparities

NOTE Confidence: 0.816535770909091

00:23:13.272 --> 00:23:14.969 research to join my research team.

NOTE Confidence: 0.816535770909091

00:23:14.970 --> 00:23:17.608 One of those young men is now at

NOTE Confidence: 0.816535770909091

00:23:17.608 --> 00:23:19.684 Cook County Hospital as a urologic.

NOTE Confidence: 0.816535770909091

00:23:19.690 --> 00:23:21.750 The third year urology resident,

NOTE Confidence: 0.816535770909091

00:23:21.750 --> 00:23:22.840 another one that asked them.

NOTE Confidence: 0.816535770909091

00:23:22.840 --> 00:23:24.504 Looking man that was part of my lab

NOTE Confidence: 0.816535770909091

00:23:24.504 --> 00:23:26.451 is now gonna be going off to Tulane

NOTE Confidence: 0.816535770909091

00:23:26.451 --> 00:23:28.266 University to get his PhD because it

NOTE Confidence: 0.816535770909091

00:23:28.266 --> 00:23:29.808 was important to create a pipeline

NOTE Confidence: 0.816535770909091

00:23:29.808 --> 00:23:31.534 of early stage investigators that

NOTE Confidence: 0.816535770909091

00:23:31.534 --> 00:23:33.364 reflected the population that cared.

NOTE Confidence: 0.816535770909091

00:23:33.370 --> 00:23:35.130 The greatest permanent disease.

00:23:35.130 --> 00:23:37.770 And from this citizen scientist model

00:23:37.770 --> 00:23:39.996 we were able to address things address

00:23:39.996 --> 00:23:42.019 this concept of medical mistrust.

00:23:42.020 --> 00:23:43.964 So we asked these citizen scientists

00:23:43.964 --> 00:23:45.737 about medical mistrust and I'm going

00:23:45.737 --> 00:23:47.425 to read a quote from one of the

00:23:47.478 --> 00:23:49.073 citizen scientists that really dispel

00:23:49.073 --> 00:23:51.106 this myth of why certain populations

00:23:51.106 --> 00:23:52.850 don't participate in research.

00:23:52.850 --> 00:23:54.782 Because there's a myth that some

00:23:54.782 --> 00:23:55.748 populations don't participate

00:23:55.748 --> 00:23:57.467 only because of medical mistrust,

00:23:57.470 --> 00:24:00.089 but what we began to find out was that

00:24:00.089 --> 00:24:02.669 medical mistrust can be high and can exist.

00:24:02.670 --> 00:24:04.126 But populations can still

00:24:04.126 --> 00:24:05.218 participate in research.

NOTE Confidence: 0.816535770909091

00:24:05.220 --> 00:24:07.523 It's just a matter of a acknowledging

NOTE Confidence: 0.816535770909091

00:24:07.523 --> 00:24:10.067 that that mistrust and then begin to do

NOTE Confidence: 0.816535770909091

00:24:10.067 --> 00:24:12.041 things to slowly dismantle the systemic

NOTE Confidence: 0.816535770909091

00:24:12.041 --> 00:24:14.096 reasons why that mistrust exists.

NOTE Confidence: 0.816535770909091

00:24:14.100 --> 00:24:15.780 One of the participants said to me

NOTE Confidence: 0.816535770909091

00:24:15.780 --> 00:24:17.690 just because I don't trust the system

NOTE Confidence: 0.816535770909091

00:24:17.690 --> 00:24:19.110 doesn't mean I won't participate

NOTE Confidence: 0.816535770909091

00:24:19.110 --> 00:24:20.775 in research because I trust y'all

NOTE Confidence: 0.816535770909091

00:24:20.775 --> 00:24:22.460 to a certain extent and he let

NOTE Confidence: 0.816535770909091

00:24:22.460 --> 00:24:23.540 me know in a joking way.

NOTE Confidence: 0.816535770909091

00:24:23.540 --> 00:24:24.184 Said Kareem,

NOTE Confidence: 0.816535770909091

00:24:24.184 --> 00:24:26.116 you being a part of the

NOTE Confidence: 0.816535770909091

00:24:26.116 --> 00:24:28.028 system at a big university,

NOTE Confidence: 0.816535770909091

00:24:28.030 --> 00:24:30.480 I'm going to have a certain level of of of

NOTE Confidence: 0.816535770909091

00:24:30.538 --> 00:24:32.925 healthy skepticism about the work you do,

50

NOTE Confidence: 0.816535770909091

00:24:32.930 --> 00:24:34.628 but that doesn't mean that you

NOTE Confidence: 0.816535770909091

00:24:34.628 --> 00:24:36.325 and your team shouldn't put in

NOTE Confidence: 0.816535770909091

00:24:36.325 --> 00:24:38.089 the work to engage me in research

NOTE Confidence: 0.816535770909091

00:24:38.089 --> 00:24:39.824 because I understand the importance

NOTE Confidence: 0.816535770909091

00:24:39.824 --> 00:24:41.609 of participating in research and

NOTE Confidence: 0.816535770909091

00:24:41.609 --> 00:24:42.858 through this citizen scientist

NOTE Confidence: 0.816535770909091

00:24:42.858 --> 00:24:44.930 model we were able to adapt it.

NOTE Confidence: 0.816535770909091

00:24:44.930 --> 00:24:46.610 We started off from prostate cancer.

NOTE Confidence: 0.816535770909091

00:24:46.610 --> 00:24:48.353 We're able to adapt it from prostate

NOTE Confidence: 0.816535770909091

00:24:48.353 --> 00:24:49.668 cancer to engage African American

NOTE Confidence: 0.816535770909091

00:24:49.668 --> 00:24:51.216 men and colon cancer to right

NOTE Confidence: 0.816535770909091

00:24:51.216 --> 00:24:52.730 before I left the university,

NOTE Confidence: 0.816535770909091

00:24:52.730 --> 00:24:54.680 we adapted it for lung cancer.

NOTE Confidence: 0.816535770909091

00:24:54.680 --> 00:24:56.941 And this model taught me that when

NOTE Confidence: 0.816535770909091

00:24:56.941 --> 00:24:58.319 you intentionally engage communities

NOTE Confidence: 0.816535770909091

00:24:58.319 --> 00:25:00.419 in the development of your research

NOTE Confidence: 0.816535770909091

00:25:00.419 --> 00:25:02.428 question and you began to in a

NOTE Confidence: 0.816535770909091

00:25:02.428 --> 00:25:04.111 head on way in a respectful way,

NOTE Confidence: 0.816535770909091

00:25:04.111 --> 00:25:05.435 address why certain populations

NOTE Confidence: 0.816535770909091

00:25:05.435 --> 00:25:07.640 have not been engaged in research,

NOTE Confidence: 0.816535770909091

00:25:07.640 --> 00:25:09.254 you really begin to dispel some

NOTE Confidence: 0.816535770909091

00:25:09.254 --> 00:25:11.255 of those myths about why certain

NOTE Confidence: 0.816535770909091

00:25:11.255 --> 00:25:12.560 populations don't participate,

NOTE Confidence: 0.816535770909091

00:25:12.560 --> 00:25:14.065 because in all of my research career,

NOTE Confidence: 0.912058748333333

00:25:14.070 --> 00:25:15.426 I'll be very honest with you.

NOTE Confidence: 0.912058748333333

00:25:15.430 --> 00:25:18.518 I've never had an issue of enrolling diverse,

NOTE Confidence: 0.912058748333333

00:25:18.520 --> 00:25:20.488 diverse participants in research.

NOTE Confidence: 0.912058748333333

00:25:20.488 --> 00:25:22.628 Why, because a I've conducted

NOTE Confidence: 0.912058748333333

00:25:22.628 --> 00:25:24.276 those studies in place.

NOTE Confidence: 0.912058748333333

00:25:24.280 --> 00:25:25.980 Where populations get their

NOTE Confidence: 0.912058748333333

00:25:25.980 --> 00:25:28.105 health care because place matters.

NOTE Confidence: 0.912058748333333

00:25:28.110 --> 00:25:30.007 So going to communities that are diverse

NOTE Confidence: 0.912058748333333

00:25:30.007 --> 00:25:31.750 and engage with those communities.

NOTE Confidence: 0.912058748333333

00:25:31.750 --> 00:25:33.526 The other thing is that I was present

NOTE Confidence: 0.912058748333333

00:25:33.526 --> 00:25:35.409 in the communities before I need to

NOTE Confidence: 0.912058748333333

00:25:35.409 --> 00:25:37.595 engage in research and I'm sure you all

NOTE Confidence: 0.912058748333333

00:25:37.595 --> 00:25:39.324 see that in your child's syndrome is

NOTE Confidence: 0.912058748333333

00:25:39.330 --> 00:25:41.266 that if you want to engage with parents,

NOTE Confidence: 0.912058748333333

00:25:41.270 --> 00:25:43.027 if you want to engage in research,

NOTE Confidence: 0.912058748333333

00:25:43.030 --> 00:25:44.710 you must build relationships

NOTE Confidence: 0.912058748333333

00:25:44.710 --> 00:25:46.390 before that research question,

NOTE Confidence: 0.912058748333333

00:25:46.390 --> 00:25:47.968 and you also must be present

NOTE Confidence: 0.912058748333333

00:25:47.968 --> 00:25:49.364 in those communities after your

NOTE Confidence: 0.912058748333333

00:25:49.364 --> 00:25:50.548 research question is over,

NOTE Confidence: 0.912058748333333

00:25:50.550 --> 00:25:52.601 I cannot tell you the many of

NOTE Confidence: 0.912058748333333

00:25:52.601 --> 00:25:54.289 church basements that I've been in.

NOTE Confidence: 0.912058748333333

00:25:54.290 --> 00:25:55.750 Talking about prostate cancer

NOTE Confidence: 0.912058748333333

00:25:55.750 --> 00:25:56.845 on Father's Day,

NOTE Confidence: 0.912058748333333

00:25:56.850 --> 00:25:58.460 but many of pulpits that I've been

NOTE Confidence: 0.912058748333333

00:25:58.460 --> 00:26:00.141 talking that I've been in African

NOTE Confidence: 0.912058748333333

00:26:00.141 --> 00:26:01.711 American churches talking about breast

NOTE Confidence: 0.912058748333333

00:26:01.711 --> 00:26:03.099 cancer screening on Mother's Day,

NOTE Confidence: 0.912058748333333

00:26:03.100 --> 00:26:04.927 and I've also shared my own death

NOTE Confidence: 0.912058748333333

00:26:04.927 --> 00:26:06.217 experience with with with the

NOTE Confidence: 0.912058748333333

00:26:06.217 --> 00:26:07.806 community to let them know that when

NOTE Confidence: 0.912058748333333

00:26:07.806 --> 00:26:09.539 I talk about cancer disparities.

NOTE Confidence: 0.912058748333333

00:26:09.540 --> 00:26:10.980 I'm not just talking about it

NOTE Confidence: 0.912058748333333

00:26:10.980 --> 00:26:11.940 from a scientific perspective,

NOTE Confidence: 0.912058748333333

00:26:11.940 --> 00:26:13.753 and I'm also talking about it from

NOTE Confidence: 0.912058748333333

00:26:13.753 --> 00:26:15.247 my lived experience losing my mother

NOTE Confidence: 0.912058748333333

00:26:15.247 --> 00:26:17.180 at a very young age to breast cancer.

NOTE Confidence: 0.912058748333333

00:26:17.180 --> 00:26:18.892 My biological mother then,

NOTE Confidence: 0.912058748333333

00:26:18.892 --> 00:26:19.320 unfortunately,

NOTE Confidence: 0.912058748333333

00:26:19.320 --> 00:26:20.972 losing my bonus mom to lung cancer

NOTE Confidence: 0.912058748333333

00:26:20.972 --> 00:26:22.750 at the height of the pandemic and

NOTE Confidence: 0.912058748333333

00:26:22.750 --> 00:26:24.280 just last year losing my brother

NOTE Confidence: 0.912058748333333

00:26:24.337 --> 00:26:25.369 to colorectal cancer.

NOTE Confidence: 0.912058748333333

00:26:25.370 --> 00:26:27.484 So as I was engaging those African

NOTE Confidence: 0.912058748333333

00:26:27.484 --> 00:26:29.793 American men a year and a half

NOTE Confidence: 0.912058748333333

00:26:29.793 --> 00:26:31.458 ago in colorectal cancer from

NOTE Confidence: 0.912058748333333

00:26:31.458 --> 00:26:33.529 research program on citizen science,

NOTE Confidence: 0.912058748333333

00:26:33.530 --> 00:26:35.226 I didn't have to think about what does

NOTE Confidence: 0.912058748333333

00:26:35.226 --> 00:26:37.204 it mean to engage after the American

NOTE Confidence: 0.912058748333333

00:26:37.204 --> 00:26:38.704 men and colorectal cancer screening.

NOTE Confidence: 0.912058748333333

00:26:38.710 --> 00:26:41.689 I have my own lived experience to draw from,

NOTE Confidence: 0.912058748333333

00:26:41.690 --> 00:26:43.020 and I think as researchers,

NOTE Confidence: 0.912058748333333

00:26:43.020 --> 00:26:44.189 we have to do more of that.

NOTE Confidence: 0.912058748333333

00:26:44.190 --> 00:26:45.886 We have to be willing to bring our

NOTE Confidence: 0.912058748333333

00:26:45.886 --> 00:26:47.312 full and our own authentic selves

NOTE Confidence: 0.912058748333333

00:26:47.312 --> 00:26:49.398 to this work so that we can have

NOTE Confidence: 0.912058748333333

00:26:49.398 --> 00:26:50.622 relatability to the communities

NOTE Confidence: 0.912058748333333

00:26:50.622 --> 00:26:52.549 that we're serving so that we can.

NOTE Confidence: 0.912058748333333

00:26:52.549 --> 00:26:54.180 They can see that the questions that

NOTE Confidence: 0.912058748333333

00:26:54.232 --> 00:26:56.087 we're asking are not only important to.

NOTE Confidence: 0.912058748333333

00:26:56.090 --> 00:26:57.419 US as researchers,

NOTE Confidence: 0.912058748333333

00:26:57.419 --> 00:27:00.520 but they're important to us as individuals.

NOTE Confidence: 0.912058748333333

00:27:00.520 --> 00:27:02.480 And in the all of US research program,

NOTE Confidence: 0.912058748333333

00:27:02.480 --> 00:27:04.420 we've also been intentional about

NOTE Confidence: 0.912058748333333

00:27:04.420 --> 00:27:06.360 this concept of community engagement.

NOTE Confidence: 0.912058748333333

00:27:06.360 --> 00:27:08.058 And there's a chief engagement officer.

NOTE Confidence: 0.912058748333333

00:27:08.060 --> 00:27:10.346 I'm very proud of the engagement

NOTE Confidence: 0.912058748333333

00:27:10.346 --> 00:27:12.719 ecosystem that we've developed as a program.

NOTE Confidence: 0.912058748333333

00:27:12.720 --> 00:27:14.400 Our engagement ecosystem consists

NOTE Confidence: 0.912058748333333

00:27:14.400 --> 00:27:16.080 of our frontline staff,

NOTE Confidence: 0.912058748333333

00:27:16.080 --> 00:27:17.928 people that you often forget about

NOTE Confidence: 0.912058748333333

00:27:17.928 --> 00:27:19.522 those frontline staff that check

NOTE Confidence: 0.912058748333333

00:27:19.522 --> 00:27:21.077 the participants in that check,

NOTE Confidence: 0.912058748333333

00:27:21.080 --> 00:27:23.078 check the patients in that actually

NOTE Confidence: 0.912058748333333

00:27:23.078 --> 00:27:24.077 may become participants.

NOTE Confidence: 0.912058748333333

00:27:24.080 --> 00:27:25.152 We actually conduct research

NOTE Confidence: 0.912058748333333

00:27:25.152 --> 00:27:26.224 and focus groups with.

NOTE Confidence: 0.912058748333333

00:27:26.230 --> 00:27:27.558 Those populate those staff

NOTE Confidence: 0.912058748333333

00:27:27.558 --> 00:27:29.218 members to say you know.

NOTE Confidence: 0.912058748333333

00:27:29.220 --> 00:27:30.336 How could we be doing this?

NOTE Confidence: 0.912058748333333

00:27:30.340 --> 00:27:33.210 Already better does the is this study

NOTE Confidence: 0.912058748333333

00:27:33.210 --> 00:27:35.429 diverting from your normal standard of care?

NOTE Confidence: 0.912058748333333

00:27:35.430 --> 00:27:35.882 If so,

NOTE Confidence: 0.912058748333333

00:27:35.882 --> 00:27:37.238 how can we make it better?

NOTE Confidence: 0.912058748333333

00:27:37.240 --> 00:27:39.190 We partner with Community partners

NOTE Confidence: 0.912058748333333

00:27:39.190 --> 00:27:40.750 and and national organizations.

NOTE Confidence: 0.912058748333333

00:27:40.750 --> 00:27:42.772 We have partnered with the organization

NOTE Confidence: 0.912058748333333

00:27:42.772 --> 00:27:45.188 called Pignus Pixis Partners to have a

NOTE Confidence: 0.912058748333333

00:27:45.188 --> 00:27:46.544 community provider Gateway initiative.

NOTE Confidence: 0.745870598

00:27:46.550 --> 00:27:48.790 We have innovative engagement awards.

NOTE Confidence: 0.745870598

00:27:48.790 --> 00:27:50.578 We have participant engagement core party

NOTE Confidence: 0.745870598

00:27:50.578 --> 00:27:52.350 with the National Library of Medicine.

NOTE Confidence: 0.745870598

00:27:52.350 --> 00:27:54.843 But what I want to talk about next is

NOTE Confidence: 0.745870598

00:27:54.843 --> 00:27:58.031 the the fact of our intentionality and

NOTE Confidence: 0.745870598

00:27:58.031 --> 00:27:59.923 including participants as partners.

NOTE Confidence: 0.745870598

00:27:59.930 --> 00:28:01.568 So since the beginning of the program,

NOTE Confidence: 0.745870598

00:28:01.570 --> 00:28:03.930 the all of US Research program has been

NOTE Confidence: 0.745870598

00:28:03.930 --> 00:28:05.622 intentional in ensuring that participants

NOTE Confidence: 0.745870598

00:28:05.622 --> 00:28:08.290 are actually guiding the work that we do.

NOTE Confidence: 0.745870598

00:28:08.290 --> 00:28:10.405 So this is an example of over our 47

58

NOTE Confidence: 0.745870598

00:28:10.405 --> 00:28:12.082 Member participant advisory boards

NOTE Confidence: 0.745870598

00:28:12.082 --> 00:28:13.926 that are actually participants.

NOTE Confidence: 0.745870598

00:28:13.930 --> 00:28:16.100 This is much bigger and and more

NOTE Confidence: 0.745870598

00:28:16.100 --> 00:28:17.971 intentional than the Community Advisory

NOTE Confidence: 0.745870598

00:28:17.971 --> 00:28:19.727 Board because these participants

NOTE Confidence: 0.745870598

00:28:19.727 --> 00:28:21.915 actually sit at various decision

NOTE Confidence: 0.745870598

00:28:21.915 --> 00:28:23.770 making levels in the program.

NOTE Confidence: 0.745870598

00:28:23.770 --> 00:28:25.828 Some of them serve on our IRB

NOTE Confidence: 0.745870598

00:28:25.828 --> 00:28:26.710 Institutional Review Board.

NOTE Confidence: 0.745870598

00:28:26.710 --> 00:28:28.726 Some of them serve on our steering committee,

NOTE Confidence: 0.745870598

00:28:28.730 --> 00:28:29.996 some of them, many of them.

NOTE Confidence: 0.745870598

00:28:30.000 --> 00:28:32.124 We'll serve in our program's ability

NOTE Confidence: 0.745870598

00:28:32.124 --> 00:28:34.214 to develop ancillary staff studies from

NOTE Confidence: 0.745870598

00:28:34.214 --> 00:28:36.377 our from our data and our participants

NOTE Confidence: 0.745870598

00:28:36.377 --> 00:28:38.222 and ambassadors reflect the diversity

NOTE Confidence: 0.745870598

00:28:38.222 --> 00:28:40.442 of the population that we serve.

NOTE Confidence: 0.745870598

00:28:40.450 --> 00:28:41.196 For example,

NOTE Confidence: 0.745870598

00:28:41.196 --> 00:28:42.688 participant Ambassador Joyce Winkler,

NOTE Confidence: 0.745870598

00:28:42.690 --> 00:28:45.266 while highlight here is from South Carolina,

NOTE Confidence: 0.745870598

00:28:45.270 --> 00:28:47.754 and Joyce was a nurse for over 40 years,

NOTE Confidence: 0.745870598

00:28:47.760 --> 00:28:48.540 holding positions,

NOTE Confidence: 0.745870598

00:28:48.540 --> 00:28:49.710 administrative and management,

NOTE Confidence: 0.745870598

00:28:49.710 --> 00:28:51.675 and then teaching and until

NOTE Confidence: 0.745870598

00:28:51.675 --> 00:28:53.247 retirement in in 2018.

NOTE Confidence: 0.745870598

00:28:53.250 --> 00:28:55.290 Joyce is bathing based in Columbia,

NOTE Confidence: 0.745870598

00:28:55.290 --> 00:28:57.404 SC at a fairly qualified Health Center,

NOTE Confidence: 0.745870598

00:28:57.410 --> 00:28:59.132 and I had the pleasure of

NOTE Confidence: 0.745870598

00:28:59.132 --> 00:29:00.650 meeting Joyce back in 2017.

NOTE Confidence: 0.745870598

00:29:00.650 --> 00:29:00.915 2018,

NOTE Confidence: 0.745870598

00:29:00.915 --> 00:29:02.770 when she was working in the FQHC

NOTE Confidence: 0.745870598

00:29:02.770 --> 00:29:04.806 and one of the quotes that Joyce

00:29:04.806 --> 00:29:06.797 gave us recently that she said the

00:29:06.797 --> 00:29:09.031 mission is so near and dear to me as

00:29:09.031 --> 00:29:10.486 it relates to transformative health

00:29:10.486 --> 00:29:12.627 and the potential to impact on the

00:29:12.627 --> 00:29:13.851 potential impact on individuals

00:29:13.851 --> 00:29:15.420 and families and communities.

00:29:15.420 --> 00:29:17.996 We are all interconnected in some way.

00:29:18.000 --> 00:29:19.992 So imagine the impact that participant

00:29:19.992 --> 00:29:21.604 ambassadors like Joyce have when

00:29:21.604 --> 00:29:23.436 they go out to talk to the computer,

00:29:23.440 --> 00:29:24.560 their communities,

00:29:24.560 --> 00:29:27.360 about the importance of diverse

00:29:27.360 --> 00:29:29.040 participation in research.

00:29:29.040 --> 00:29:30.604 And as a nurse,

00:29:30.604 --> 00:29:32.559 Joyce also brings that that

00:29:32.559 --> 00:29:34.400 understanding of different career,

NOTE Confidence: 0.745870598

00:29:34.400 --> 00:29:36.158 different research types of the program.

NOTE Confidence: 0.745870598

00:29:36.160 --> 00:29:37.567 Joyce lets us know like what it

NOTE Confidence: 0.745870598

00:29:37.567 --> 00:29:38.360 was like for us,

NOTE Confidence: 0.745870598

00:29:38.360 --> 00:29:40.243 for her to be a frontline staff

NOTE Confidence: 0.745870598

00:29:40.243 --> 00:29:41.050 working with participants.

NOTE Confidence: 0.745870598

00:29:41.050 --> 00:29:43.258 And she brings that lived experience

NOTE Confidence: 0.745870598

00:29:43.258 --> 00:29:45.140 to the program as well.

NOTE Confidence: 0.745870598

00:29:45.140 --> 00:29:46.724 And we think about I talked

NOTE Confidence: 0.745870598

00:29:46.724 --> 00:29:47.516 earlier about this.

NOTE Confidence: 0.745870598

00:29:47.520 --> 00:29:48.920 I'm really excited about this.

NOTE Confidence: 0.745870598

00:29:48.920 --> 00:29:51.125 Just last week we had our second

NOTE Confidence: 0.745870598

00:29:51.125 --> 00:29:53.200 annual minority Student Research Symposium.

NOTE Confidence: 0.745870598

00:29:53.200 --> 00:29:55.174 What we call MSRM and our science

NOTE Confidence: 0.745870598

00:29:55.174 --> 00:29:56.872 date because another thing that we're

NOTE Confidence: 0.745870598

00:29:56.872 --> 00:29:58.734 committed to in the program is not

NOTE Confidence: 0.745870598

00:29:58.792 --> 00:30:00.827 just diversifying the participant pool,

NOTE Confidence: 0.745870598

00:30:00.830 --> 00:30:02.540 but also diversifying and engaging.

NOTE Confidence: 0.745870598

00:30:02.540 --> 00:30:03.676 Diverse cohort of research.

NOTE Confidence: 0.745870598

00:30:03.676 --> 00:30:05.380 And these are just four examples

NOTE Confidence: 0.745870598

00:30:05.429 --> 00:30:07.151 of of the research scholars that we

NOTE Confidence: 0.745870598

00:30:07.151 --> 00:30:09.099 have through the all of US research

NOTE Confidence: 0.745870598

00:30:09.099 --> 00:30:10.259 program we're partnering with.

NOTE Confidence: 0.745870598

00:30:10.260 --> 00:30:11.908 Historically black colleges and

NOTE Confidence: 0.745870598

00:30:11.908 --> 00:30:13.968 universities HBC US and minority

NOTE Confidence: 0.745870598

00:30:13.968 --> 00:30:15.409 serving institutions MSI.

NOTE Confidence: 0.745870598

00:30:15.410 --> 00:30:17.426 To ensure that we give students

NOTE Confidence: 0.745870598

00:30:17.426 --> 00:30:19.553 from across the country access an

NOTE Confidence: 0.745870598

00:30:19.553 --> 00:30:21.707 opportunity to engage in our database

NOTE Confidence: 0.745870598

00:30:21.710 --> 00:30:23.747 so that they hopefully one day can

NOTE Confidence: 0.745870598

00:30:23.747 --> 00:30:25.630 become interested in genomics research.

NOTE Confidence: 0.745870598

00:30:25.630 --> 00:30:27.676 Across the the wide spectrum of

NOTE Confidence: 0.745870598

00:30:27.676 --> 00:30:29.475 genomic research and hopefully they

NOTE Confidence: 0.745870598

00:30:29.475 --> 00:30:30.963 can contribute to diversifying

NOTE Confidence: 0.745870598

00:30:30.963 --> 00:30:32.079 the research tool.

NOTE Confidence: 0.79601026

00:30:32.080 --> 00:30:33.448 And now I'll I'll end with.

NOTE Confidence: 0.79601026

00:30:33.450 --> 00:30:35.410 I'll spend the next 5 minutes or so

NOTE Confidence: 0.79601026

00:30:35.410 --> 00:30:36.793 talking about our pediatric enrollment

NOTE Confidence: 0.79601026

00:30:36.793 --> 00:30:39.457 plan because I do want to leave some time

NOTE Confidence: 0.79601026

00:30:39.457 --> 00:30:41.606 for discussion and questions, but we are.

NOTE Confidence: 0.79601026

00:30:41.606 --> 00:30:43.580 I'm excited because the all of US

NOTE Confidence: 0.79601026

00:30:43.647 --> 00:30:46.216 research program is really at this point.

NOTE Confidence: 0.79601026

00:30:46.220 --> 00:30:48.092 Thinking about how we are uniquely

NOTE Confidence: 0.79601026

00:30:48.092 --> 00:30:49.751 positioned to address the following

NOTE Confidence: 0.79601026

00:30:49.751 --> 00:30:51.526 areas of of health disparities.

NOTE Confidence: 0.79601026

00:30:51.530 --> 00:30:53.360 Because we think about pediatric health,

NOTE Confidence: 0.79601026

00:30:53.360 --> 00:30:54.716 pediatric health disparities,

NOTE Confidence: 0.79601026

00:30:54.716 --> 00:30:56.088 physical environment, exposures,

NOTE Confidence: 0.79601026

00:30:56.088 --> 00:30:57.492 social environment and

NOTE Confidence: 0.79601026

00:30:57.492 --> 00:30:58.896 longitude and biomarkers.

NOTE Confidence: 0.79601026

00:30:58.900 --> 00:31:00.643 So thinking about children that are living

NOTE Confidence: 0.79601026

00:31:00.643 --> 00:31:02.310 with asthma in certain communities.

NOTE Confidence: 0.79601026

00:31:02.310 --> 00:31:04.366 We are equipped to ask questions not just

NOTE Confidence: 0.79601026

00:31:04.366 --> 00:31:06.348 about the biological aspect of asthma,

NOTE Confidence: 0.79601026

00:31:06.350 --> 00:31:08.450 but about the physical and lived environment.

NOTE Confidence: 0.79601026

00:31:08.450 --> 00:31:09.830 We're equipped to think about this,

NOTE Confidence: 0.79601026

00:31:09.830 --> 00:31:10.358 the school,

NOTE Confidence: 0.79601026

00:31:10.358 --> 00:31:11.414 the learning environment that

NOTE Confidence: 0.79601026

00:31:11.414 --> 00:31:12.470 those youth live in,

NOTE Confidence: 0.79601026

00:31:12.470 --> 00:31:14.678 but then also think about what

NOTE Confidence: 0.79601026

00:31:14.678 --> 00:31:16.569 and connect that information to

NOTE Confidence: 0.79601026

00:31:16.569 --> 00:31:18.344 longitudinal biomarkers that may be

NOTE Confidence: 0.79601026

00:31:18.344 --> 00:31:20.770 present in some of those children.

NOTE Confidence: 0.79601026

00:31:20.770 --> 00:31:22.374 And our programmatic objectives.

NOTE Confidence: 0.79601026

00:31:22.374 --> 00:31:23.577 For pediatric enrollment,

NOTE Confidence: 0.79601026

00:31:23.580 --> 00:31:26.370 we're hoping to enroll our first

NOTE Confidence: 0.79601026

00:31:26.370 --> 00:31:28.714 pediatric cohort in early 2023 and

NOTE Confidence: 0.79601026

00:31:28.714 --> 00:31:30.408 our objectives for this year is that

NOTE Confidence: 0.79601026

00:31:30.408 --> 00:31:31.989 we're underway to hire Directive,

NOTE Confidence: 0.79601026

00:31:31.990 --> 00:31:33.052 director of Pediatrics,

NOTE Confidence: 0.79601026

00:31:33.052 --> 00:31:35.530 and then we're also on our way

NOTE Confidence: 0.79601026

00:31:35.598 --> 00:31:38.076 of approving our IBO our IRB

NOTE Confidence: 0.79601026

00:31:38.076 --> 00:31:39.728 protocol for pediatric enrollment,

NOTE Confidence: 0.79601026

00:31:39.730 --> 00:31:41.501 and our approach is to take a

NOTE Confidence: 0.79601026

00:31:41.501 --> 00:31:42.976 phase family based approach to

NOTE Confidence: 0.79601026

00:31:42.976 --> 00:31:45.265 recruitment which I think is really a

NOTE Confidence: 0.79601026

00:31:45.265 --> 00:31:46.920 conversation that I hope to to engage

NOTE Confidence: 0.79601026

00:31:46.920 --> 00:31:48.478 you all in over the future because

NOTE Confidence: 0.79601026

00:31:48.478 --> 00:31:50.130 we want to begin with the pilot.

NOTE Confidence: 0.79601026

00:31:50.130 --> 00:31:51.042 And scale up,

NOTE Confidence: 0.79601026

00:31:51.042 --> 00:31:52.258 we're gonna enroll participants,

NOTE Confidence: 0.79601026

00:31:52.260 --> 00:31:53.511 hopefully by age,

NOTE Confidence: 0.79601026

00:31:53.511 --> 00:31:55.179 birth to six years,

NOTE Confidence: 0.79601026

00:31:55.180 --> 00:31:57.315 7 to 12 and 13 to 17.

NOTE Confidence: 0.79601026

00:31:57.320 --> 00:31:58.995 But even thinking about this

NOTE Confidence: 0.79601026

00:31:58.995 --> 00:32:00.670 concept of family based diet

NOTE Confidence: 0.79601026

00:32:00.734 --> 00:32:02.499 or triad enrollment for birth,

NOTE Confidence: 0.79601026

00:32:02.500 --> 00:32:04.404 that can be but participants can be

NOTE Confidence: 0.79601026

00:32:04.404 --> 00:32:06.279 enrolled even without a parent or guardian.

NOTE Confidence: 0.79601026

00:32:06.280 --> 00:32:07.447 Also being enrolled.

NOTE Confidence: 0.79601026

00:32:07.447 --> 00:32:09.781 But I'm excited about the pediatric

NOTE Confidence: 0.79601026

00:32:09.781 --> 00:32:11.605 enrollment because that really will

NOTE Confidence: 0.79601026

00:32:11.605 --> 00:32:13.663 allow us to collect this longitude

NOTE Confidence: 0.79601026

00:32:13.721 --> 00:32:15.636 information over the life course.

NOTE Confidence: 0.79601026

00:32:15.640 --> 00:32:17.640 But even prior to our

NOTE Confidence: 0.79601026

00:32:17.640 --> 00:32:18.840 pediatric enrollment launch,

NOTE Confidence: 0.79601026

00:32:18.840 --> 00:32:21.368 because the all of US research program does

NOTE Confidence: 0.79601026

00:32:21.368 --> 00:32:23.480 interface with electronic health records,

NOTE Confidence: 0.79601026

00:32:23.480 --> 00:32:25.530 we actually have legacy pediatric

NOTE Confidence: 0.79601026

00:32:25.530 --> 00:32:27.580 data that's available from the

NOTE Confidence: 0.79601026

00:32:27.646 --> 00:32:29.720 EHR from as far back as 1980.

NOTE Confidence: 0.79601026

00:32:29.720 --> 00:32:33.242 So we have about 19,729 participants with

NOTE Confidence: 0.79601026

00:32:33.242 --> 00:32:35.860 what we call legacy pediatric EHR data.

NOTE Confidence: 0.79601026

00:32:35.860 --> 00:32:38.303 And we have projects that are underway

NOTE Confidence: 0.79601026

00:32:38.303 --> 00:32:40.704 already in our database that are

NOTE Confidence: 0.79601026

00:32:40.704 --> 00:32:42.844 looking at different questions that

NOTE Confidence: 0.79601026

00:32:42.844 --> 00:32:45.550 are related to this legacy information.

NOTE Confidence: 0.79601026

00:32:45.550 --> 00:32:47.135 On pediatric projects being studied

NOTE Confidence: 0.79601026

00:32:47.135 --> 00:32:48.720 in the research workmen's currently

NOTE Confidence: 0.79601026

00:32:48.768 --> 00:32:49.838 are looking at type one,

NOTE Confidence: 0.79601026

00:32:49.840 --> 00:32:50.774 diabetes, transitions,

NOTE Confidence: 0.79601026

00:32:50.774 --> 00:32:52.642 childhood obesity and also

NOTE Confidence: 0.79601026

00:32:52.642 --> 00:32:54.043 metabolites and cancer,

NOTE Confidence: 0.79601026

00:32:54.050 --> 00:32:56.550 just to name a few.

NOTE Confidence: 0.79601026

00:32:56.550 --> 00:32:58.006 So that is what I wanted to

NOTE Confidence: 0.79601026

00:32:58.006 --> 00:32:59.538 talk to you all about today.

NOTE Confidence: 0.79601026

00:32:59.540 --> 00:33:00.821 I want to thank you for your

NOTE Confidence: 0.79601026

00:33:00.821 --> 00:33:01.850 time and your attention,

NOTE Confidence: 0.79601026

00:33:01.850 --> 00:33:03.722 and I want to open it up to questions

NOTE Confidence: 0.79601026

00:33:03.722 --> 00:33:05.312 right now and hopefully this will

NOTE Confidence: 0.79601026

00:33:05.312 --> 00:33:06.898 not be my last conversation with

NOTE Confidence: 0.79601026

00:33:06.898 --> 00:33:08.522 you all as we can think about how

NOTE Confidence: 0.79601026

00:33:08.522 --> 00:33:10.368 can we get you all excited about our

NOTE Confidence: 0.79601026

00:33:10.368 --> 00:33:11.753 database and how it can hopefully

NOTE Confidence: 0.79601026

00:33:11.753 --> 00:33:13.669 be a tool that you all will be able

NOTE Confidence: 0.79601026

00:33:13.669 --> 00:33:15.237 to use both in your center and in

NOTE Confidence: 0.8117102175

00:33:15.240 --> 00:33:16.480 your own research endeavors.

NOTE Confidence: 0.854217251

00:33:24.530 --> 00:33:25.914 Thank you so much,

NOTE Confidence: 0.854217251

00:33:25.914 --> 00:33:28.557 Doctor Watson and really that was a

NOTE Confidence: 0.854217251

00:33:28.557 --> 00:33:31.052 wonderful overview of your extensive

NOTE Confidence: 0.854217251

00:33:31.052 --> 00:33:33.048 experience and community engagement.

NOTE Confidence: 0.854217251

00:33:33.050 --> 00:33:37.019 Really a wonderful how to guide and you know,

NOTE Confidence: 0.854217251

00:33:37.020 --> 00:33:38.406 every time I hear about the all of U.S.

NOTE Confidence: 0.854217251

00:33:38.410 --> 00:33:40.454 court, I can't hear about a new

NOTE Confidence: 0.854217251

00:33:40.454 --> 00:33:42.370 component that I wasn't aware of.

NOTE Confidence: 0.854217251

00:33:42.370 --> 00:33:44.015 I wasn't aware of the legacy pediatric

NOTE Confidence: 0.854217251

00:33:44.015 --> 00:33:46.090 data and I just want to emphasize for

NOTE Confidence: 0.854217251

00:33:46.090 --> 00:33:48.130 anyone here in the Community that you know.

NOTE Confidence: 0.854217251

00:33:48.130 --> 00:33:50.272 All it takes is just to to register online.

NOTE Confidence: 0.854217251

00:33:50.280 --> 00:33:52.904 To be able to use the resource and

NOTE Confidence: 0.854217251

00:33:52.904 --> 00:33:55.419 that Yale already has a data use

NOTE Confidence: 0.854217251

00:33:55.419 --> 00:33:57.724 agreement in place and so essentially

NOTE Confidence: 0.854217251

00:33:57.724 --> 00:34:00.783 we have ready access to these data.

NOTE Confidence: 0.854217251

00:34:00.790 --> 00:34:02.398 For anyone that would want to use them.

NOTE Confidence: 0.854217251

00:34:02.400 --> 00:34:04.135 So I'd encourage anyone notice

NOTE Confidence: 0.854217251

00:34:04.135 --> 00:34:06.270 to unmute if you're on zoom,

NOTE Confidence: 0.854217251

00:34:06.270 --> 00:34:07.596 or if we've got any questions

NOTE Confidence: 0.854217251

00:34:07.596 --> 00:34:09.220 in the room for Doctor Watson.

NOTE Confidence: 0.811495005

00:34:19.670 --> 00:34:21.206 While we're waiting, you did address.

NOTE Confidence: 0.811495005

00:34:21.210 --> 00:34:23.352 My first question is that I was

NOTE Confidence: 0.811495005

00:34:23.352 --> 00:34:24.819 hoping that researchers would know

NOTE Confidence: 0.811495005

00:34:24.819 --> 00:34:26.779 that I want to talk about the the

NOTE Confidence: 0.811495005

00:34:26.835 --> 00:34:28.837 various levels of data that we have.

NOTE Confidence: 0.811495005

00:34:28.840 --> 00:34:30.597 Currently we have 3 levels of data.

NOTE Confidence: 0.811495005

00:34:30.600 --> 00:34:32.550 We have the publicly available data

NOTE Confidence: 0.811495005

00:34:32.550 --> 00:34:34.499 that anyone can get access to,

NOTE Confidence: 0.811495005

00:34:34.500 --> 00:34:36.096 and as a former faculty member

NOTE Confidence: 0.811495005

00:34:36.096 --> 00:34:38.019 in the School of Public Health,

NOTE Confidence: 0.811495005

00:34:38.020 --> 00:34:40.169 I actually was excited about the publicly

NOTE Confidence: 0.811495005

00:34:40.169 --> 00:34:42.007 available data because it's just a

NOTE Confidence: 0.811495005

00:34:42.007 --> 00:34:43.735 large secondary data set with with

NOTE Confidence: 0.811495005

00:34:43.735 --> 00:34:45.179 predominantly descriptive statistics,

NOTE Confidence: 0.811495005

00:34:45.180 --> 00:34:46.308 but that young researchers

NOTE Confidence: 0.811495005

00:34:46.308 --> 00:34:47.718 can use like I would.

NOTE Confidence: 0.811495005

00:34:47.720 --> 00:34:49.900 I was using it to teach in the MPH courses,

NOTE Confidence: 0.811495005

00:34:49.900 --> 00:34:50.146 right?

NOTE Confidence: 0.811495005

00:34:50.146 --> 00:34:51.622 You think about students who are

NOTE Confidence: 0.811495005

00:34:51.622 --> 00:34:53.319 learning how to do secondary data

NOTE Confidence: 0.811495005

00:34:53.319 --> 00:34:54.535 analysis that publicly available

NOTE Confidence: 0.811495005

00:34:54.535 --> 00:34:55.899 data is important for that,

NOTE Confidence: 0.811495005

00:34:55.900 --> 00:34:57.600 but also for communities for

00:34:57.600 --> 00:34:59.300 communities that want to know.

00:34:59.300 --> 00:35:00.144 You know what is?

00:35:00.144 --> 00:35:02.137 What does the all of us program look

00:35:02.137 --> 00:35:04.482 like for this particular disease that I'm

00:35:04.482 --> 00:35:06.368 passionate about that I'm interested in?

00:35:06.370 --> 00:35:07.749 What does the data set look like?

00:35:07.750 --> 00:35:09.556 How many participants in the all of

00:35:09.556 --> 00:35:11.368 US program are impacted by cancer?

00:35:11.370 --> 00:35:15.162 How many are impacted by low birth weight

00:35:15.162 --> 00:35:16.896 preterm preterm infant deliveries?

00:35:16.896 --> 00:35:18.468 How many participants are

00:35:18.468 --> 00:35:19.647 impacted by diabetes?

00:35:19.650 --> 00:35:21.869 That's information that you can get from

00:35:21.869 --> 00:35:23.808 our aggregated publicly available data set.

00:35:23.810 --> 00:35:25.568 But then there's the registered tier,

00:35:25.570 --> 00:35:26.704 the registered tier.

NOTE Confidence: 0.811495005

00:35:26.704 --> 00:35:28.216 If you're affiliated with

NOTE Confidence: 0.811495005

00:35:28.216 --> 00:35:29.960 Yale College of Medicine.

NOTE Confidence: 0.811495005

00:35:29.960 --> 00:35:32.018 Yellow already has a data use agreement,

NOTE Confidence: 0.811495005

00:35:32.020 --> 00:35:33.676 so as a researcher at Yale,

NOTE Confidence: 0.811495005

00:35:33.680 --> 00:35:35.228 you should have pretty easy access

NOTE Confidence: 0.811495005

00:35:35.228 --> 00:35:37.413 to be able to go and register to

NOTE Confidence: 0.811495005

00:35:37.413 --> 00:35:39.057 get access to that register tier

NOTE Confidence: 0.811495005

00:35:39.116 --> 00:35:40.300 at that register tier.

NOTE Confidence: 0.811495005

00:35:40.300 --> 00:35:42.250 You can get more detailed information

NOTE Confidence: 0.811495005

00:35:42.250 --> 00:35:44.856 that can begin to look at the EHR data,

NOTE Confidence: 0.811495005

00:35:44.860 --> 00:35:46.415 pull information from the electronic

NOTE Confidence: 0.811495005

00:35:46.415 --> 00:35:48.274 health record you begin to look

NOTE Confidence: 0.811495005

00:35:48.274 --> 00:35:50.038 at data from our social terms of

NOTE Confidence: 0.811495005

00:35:50.038 --> 00:35:51.611 health survey even though over

NOTE Confidence: 0.811495005

00:35:51.611 --> 00:35:52.971 the 100,000 participants that

NOTE Confidence: 0.811495005

00:35:52.971 --> 00:35:54.590 completed our COVID-19 cope survey,

NOTE Confidence: 0.811495005

00:35:54.590 --> 00:35:56.655 you can get access to that date.

NOTE Confidence: 0.811495005

00:35:56.660 --> 00:35:58.460 You can get access to data

NOTE Confidence: 0.811495005

00:35:58.460 --> 00:36:00.400 around a myriad of questions.

NOTE Confidence: 0.811495005

00:36:00.400 --> 00:36:02.065 Physical measurements how many patients

NOTE Confidence: 0.811495005

00:36:02.065 --> 00:36:04.662 we have in our database to have elevated

NOTE Confidence: 0.811495005

00:36:04.662 --> 00:36:06.408 blood pressure to how many patients

NOTE Confidence: 0.811495005

00:36:06.408 --> 00:36:08.653 we have that are 19 to 25 you you know,

NOTE Confidence: 0.811495005

00:36:08.660 --> 00:36:09.704 while it's young adulthood,

NOTE Confidence: 0.811495005

00:36:09.704 --> 00:36:11.553 but that may be a really important

NOTE Confidence: 0.811495005

00:36:11.553 --> 00:36:13.361 data set for you to ask to have

NOTE Confidence: 0.811495005

00:36:13.361 --> 00:36:15.097 may have elevated blood pressure.

NOTE Confidence: 0.811495005

00:36:15.100 --> 00:36:16.608 Elevated blood sugars that's

NOTE Confidence: 0.811495005

00:36:16.608 --> 00:36:17.739 in the information,

NOTE Confidence: 0.811495005

00:36:17.740 --> 00:36:18.566 for example,

NOTE Confidence: 0.811495005

00:36:18.566 --> 00:36:21.457 and even wearable date we have about

NOTE Confidence: 0.811495005

00:36:21.460 --> 00:36:23.330 1411 thousand participants who have

NOTE Confidence: 0.811495005

00:36:23.330 --> 00:36:25.200 participated in the Fitbit pilot

NOTE Confidence: 0.811495005

00:36:25.255 --> 00:36:26.959 that have wearable data for us.

NOTE Confidence: 0.811495005

00:36:26.960 --> 00:36:29.960 But then there's a genomics that we recently.

NOTE Confidence: 0.811495005

00:36:29.960 --> 00:36:31.924 At least 100,000 participants

NOTE Confidence: 0.811495005

00:36:31.924 --> 00:36:34.379 genomic sequence data to researchers

NOTE Confidence: 0.811495005

00:36:34.379 --> 00:36:36.487 didn't get access to that leg,

NOTE Confidence: 0.811495005

00:36:36.490 --> 00:36:37.630 and that's at the controlled

NOTE Confidence: 0.811495005

00:36:37.630 --> 00:36:39.080 tier and at the control tower.

NOTE Confidence: 0.811495005

00:36:39.080 --> 00:36:41.224 You can also get 3 level zip code

NOTE Confidence: 0.811495005

00:36:41.224 --> 00:36:42.688 information and as a researcher,

NOTE Confidence: 0.811495005

00:36:42.690 --> 00:36:44.350 that information was very important

NOTE Confidence: 0.811495005

00:36:44.350 --> 00:36:47.121 to me because I wanted to be able to

NOTE Confidence: 0.811495005

00:36:47.121 --> 00:36:48.783 geocode and think about how someone's

NOTE Confidence: 0.811495005

00:36:48.783 --> 00:36:50.901 neighborhood where they live could be

NOTE Confidence: 0.811495005

00:36:50.901 --> 00:36:52.970 impacted by certain health conditions.

NOTE Confidence: 0.861867096666667

00:36:55.820 --> 00:36:57.320 Fantastic and I, you know I.

NOTE Confidence: 0.861867096666667

00:36:57.320 --> 00:36:59.216 I just wondered if you could speak a

NOTE Confidence: 0.861867096666667

00:36:59.216 --> 00:37:01.058 little bit to the recruitment strategy

NOTE Confidence: 0.861867096666667

00:37:01.058 --> 00:37:03.026 because I know with large initiatives

NOTE Confidence: 0.861867096666667

00:37:03.082 --> 00:37:04.797 such as the UK Biobank in general,

NOTE Confidence: 0.861867096666667

00:37:04.800 --> 00:37:05.864 you know there is.

NOTE Confidence: 0.861867096666667

00:37:05.864 --> 00:37:07.004 There's been, you know,

NOTE Confidence: 0.861867096666667

00:37:07.004 --> 00:37:08.514 kind of more well educated,

NOTE Confidence: 0.861867096666667

00:37:08.520 --> 00:37:10.932 more well off people that have

NOTE Confidence: 0.861867096666667

00:37:10.932 --> 00:37:12.540 just naturally gravitated towards

NOTE Confidence: 0.861867096666667

00:37:12.612 --> 00:37:14.500 these large scale initiatives.

NOTE Confidence: 0.861867096666667

00:37:14.500 --> 00:37:16.190 I'm wondering what procedures are

NOTE Confidence: 0.861867096666667

00:37:16.190 --> 00:37:18.657 in place to ensure that that all

NOTE Confidence: 0.861867096666667

00:37:18.657 --> 00:37:20.437 of us remains and representative.

NOTE Confidence: 0.92327339625

00:37:21.360 --> 00:37:23.240 I thank you so much for that question.

NOTE Confidence: 0.92327339625

00:37:23.240 --> 00:37:25.088 I think one of the biggest things that

NOTE Confidence: 0.92327339625

00:37:25.088 --> 00:37:27.047 we did to ensure diverse participation

NOTE Confidence: 0.92327339625

00:37:27.047 --> 00:37:29.207 is having diversity in our recruitment

NOTE Confidence: 0.92327339625

00:37:29.259 --> 00:37:30.699 and in our enrollment sites.

NOTE Confidence: 0.92327339625

00:37:30.700 --> 00:37:33.356 So we for example we have groups of

NOTE Confidence: 0.92327339625

00:37:33.356 --> 00:37:35.582 clinics like fairly qualified health and

NOTE Confidence: 0.92327339625

00:37:35.582 --> 00:37:38.497 you've heard me talk a lot about FQHC's

NOTE Confidence: 0.92327339625

00:37:38.497 --> 00:37:40.039 fairly qualified health centers and I

NOTE Confidence: 0.92327339625

00:37:40.039 --> 00:37:42.519 talk a lot about things because they're

NOTE Confidence: 0.92327339625

00:37:42.519 --> 00:37:44.179 historically underrepresented in research.

NOTE Confidence: 0.92327339625

00:37:44.180 --> 00:37:46.742 Over 25% of our nation's most underserved

NOTE Confidence: 0.92327339625

00:37:46.742 --> 00:37:49.406 get their care at fairly qualified health

NOTE Confidence: 0.92327339625

00:37:49.406 --> 00:37:52.040 centers and a large portion of them.

NOTE Confidence: 0.92327339625

00:37:52.040 --> 00:37:54.240 It's just they get their treatment and care.

NOTE Confidence: 0.92327339625

00:37:54.240 --> 00:37:56.358 FQHC's are also racial and ethnic

NOTE Confidence: 0.92327339625

00:37:56.358 --> 00:37:58.270 minorities or populations with carrying

NOTE Confidence: 0.92327339625

00:37:58.270 --> 00:38:00.475 huge disparities in chronic conditions.

NOTE Confidence: 0.92327339625

00:38:00.480 --> 00:38:02.480 But FQHC's are historically

NOTE Confidence: 0.92327339625

00:38:02.480 --> 00:38:03.980 underrepresented in research,

NOTE Confidence: 0.92327339625

00:38:03.980 --> 00:38:05.876 so at the onset of the all of

NOTE Confidence: 0.92327339625

00:38:05.876 --> 00:38:06.880 US research program,

NOTE Confidence: 0.92327339625

00:38:06.880 --> 00:38:09.195 we actually piloted out recruitment

NOTE Confidence: 0.92327339625

00:38:09.195 --> 00:38:11.400 and enrollment at FQHC'S to ensure

NOTE Confidence: 0.92327339625

00:38:11.400 --> 00:38:13.290 that we ask questions of how do

NOTE Confidence: 0.92327339625

00:38:13.356 --> 00:38:15.486 you build up research capacity and

NOTE Confidence: 0.92327339625

00:38:15.486 --> 00:38:17.420 interest at Community health centers?

NOTE Confidence: 0.92327339625

00:38:17.420 --> 00:38:18.792 So that's one thing,

NOTE Confidence: 0.92327339625

00:38:18.792 --> 00:38:20.850 and that pilot allowed us to

NOTE Confidence: 0.92327339625

00:38:20.920 --> 00:38:22.108 grow the the the.

NOTE Confidence: 0.92327339625

00:38:22.110 --> 00:38:24.710 Both of our FQHC season enrolled to date.

NOTE Confidence: 0.92327339625

79

00:38:24.710 --> 00:38:26.796 I believe we have over 7 fairly

NOTE Confidence: 0.92327339625

00:38:26.796 --> 00:38:28.230 qualified health centers enrolled,

NOTE Confidence: 0.92327339625

00:38:28.230 --> 00:38:30.252 including a new FQHC in Hawaii

NOTE Confidence: 0.92327339625

00:38:30.252 --> 00:38:32.917 that allows us to think about the

NOTE Confidence: 0.92327339625

00:38:32.917 --> 00:38:35.401 engagement of agent of of Pacific

NOTE Confidence: 0.92327339625

00:38:35.401 --> 00:38:37.229 Islanders and research study.

NOTE Confidence: 0.92327339625

00:38:37.230 --> 00:38:39.530 Another population that has been

NOTE Confidence: 0.92327339625

00:38:39.530 --> 00:38:41.370 historically underrepresented research but

NOTE Confidence: 0.92327339625

00:38:41.370 --> 00:38:43.983 also we have a lot of academic medical

NOTE Confidence: 0.92327339625

00:38:43.983 --> 00:38:46.089 centers that serve diverse populations.

NOTE Confidence: 0.92327339625

00:38:46.090 --> 00:38:48.114 So we have packing the medical centers that

NOTE Confidence: 0.92327339625

00:38:48.114 --> 00:38:50.547 may be more brutal located that are engaged.

NOTE Confidence: 0.92327339625

00:38:50.550 --> 00:38:51.910 We have some active Medical

NOTE Confidence: 0.92327339625

00:38:51.910 --> 00:38:52.998 Center in urban areas.

NOTE Confidence: 0.92327339625

00:38:53.000 --> 00:38:55.569 But when I look at the NLST,

NOTE Confidence: 0.92327339625

00:38:55.570 --> 00:38:56.590 the national inspiring trial,

00:38:56.590 --> 00:38:58.960 which is a study I was really proud of.

00:38:58.960 --> 00:39:01.381 But we could learn a lot from studies and

00:39:01.381 --> 00:39:03.635 thinking about where are those sites located?

00:39:03.640 --> 00:39:05.572 And there has to be intentionality

00:39:05.572 --> 00:39:07.599 in that recruitment of those sites.

00:39:07.600 --> 00:39:09.427 And you have to think about that.

00:39:09.430 --> 00:39:11.126 So if you're launching a study you want

00:39:11.126 --> 00:39:13.018 to do it within a community setting.

00:39:13.020 --> 00:39:15.366 There may be some groundwork and

00:39:15.366 --> 00:39:17.958 relationship building that you may have to

00:39:17.958 --> 00:39:20.212 start long before you launch that study.

00:39:20.220 --> 00:39:22.026 You may think about how do I

00:39:22.026 --> 00:39:23.430 ensure this community has access?

00:39:23.430 --> 00:39:24.466 When I think about,

00:39:24.466 --> 00:39:26.407 you know the resources at that at

00:39:26.407 --> 00:39:28.042 that Community Center within that

NOTE Confidence: 0.92327339625

00:39:28.042 --> 00:39:29.685 Community setting and some other

NOTE Confidence: 0.92327339625

00:39:29.685 --> 00:39:31.365 things that we're doing we're doing

NOTE Confidence: 0.92327339625

00:39:31.365 --> 00:39:33.974 in the study is we call it recruit to

NOTE Confidence: 0.92327339625

00:39:33.974 --> 00:39:35.950 retain when we recruit a participant.

NOTE Confidence: 0.92327339625

00:39:35.950 --> 00:39:37.894 We think about what were some of the

NOTE Confidence: 0.92327339625

00:39:37.894 --> 00:39:39.931 things that that were needed to engage

NOTE Confidence: 0.92327339625

00:39:39.931 --> 00:39:41.426 and or recruit that participant,

NOTE Confidence: 0.92327339625

00:39:41.430 --> 00:39:42.060 for example,

NOTE Confidence: 0.92327339625

00:39:42.060 --> 00:39:45.190 in order right now to log onto our website,

NOTE Confidence: 0.92327339625

00:39:45.190 --> 00:39:46.228 mean to enroll in our study,

NOTE Confidence: 0.92327339625

00:39:46.230 --> 00:39:47.868 you have to have an email address.

NOTE Confidence: 0.92327339625

00:39:47.870 --> 00:39:48.255 Well,

NOTE Confidence: 0.92327339625

00:39:48.255 --> 00:39:50.950 if if a research coordinator has to

NOTE Confidence: 0.92327339625

00:39:50.950 --> 00:39:53.551 help participant get an email address, then.

NOTE Confidence: 0.92327339625

00:39:53.551 --> 00:39:54.273 It may.

NOTE Confidence: 0.92327339625

00:39:54.273 --> 00:39:56.700 You may think that I I often tell

NOTE Confidence: 0.92327339625

00:39:56.700 --> 00:39:57.435 the research coordinator.

NOTE Confidence: 0.92327339625

00:39:57.440 --> 00:39:59.526 You may have to spend more time

NOTE Confidence: 0.92327339625

00:39:59.526 --> 00:40:00.899 engaging that participant if you

NOTE Confidence: 0.92327339625

00:40:00.899 --> 00:40:02.571 had to set them up with the email

NOTE Confidence: 0.863772098095238

00:40:02.631 --> 00:40:04.265 address. You may need to call

NOTE Confidence: 0.863772098095238

00:40:04.265 --> 00:40:05.480 them 30 days after enrollment,

NOTE Confidence: 0.863772098095238

00:40:05.480 --> 00:40:06.668 60 days after enrollment,

NOTE Confidence: 0.863772098095238

00:40:06.668 --> 00:40:08.863 six months and even 12A year after

NOTE Confidence: 0.863772098095238

00:40:08.863 --> 00:40:10.623 enrollment to continue the engagement

NOTE Confidence: 0.863772098095238

00:40:10.623 --> 00:40:12.810 with that with those participants.

NOTE Confidence: 0.863772098095238

00:40:12.810 --> 00:40:14.405 And somebody said Kareem that

NOTE Confidence: 0.863772098095238

00:40:14.405 --> 00:40:16.000 requires a lot of effort,

NOTE Confidence: 0.863772098095238

00:40:16.000 --> 00:40:19.200 a lot of FTE, a lot of times it does.

NOTE Confidence: 0.863772098095238

00:40:19.200 --> 00:40:21.636 I'm not saying that in engaging and

NOTE Confidence: 0.863772098095238

00:40:21.636 --> 00:40:23.900 recruiting and retaining diverse populations.

NOTE Confidence: 0.863772098095238

00:40:23.900 --> 00:40:26.570 It's easy, but it's essential.

NOTE Confidence: 0.863772098095238

00:40:26.570 --> 00:40:28.858 And when you think about how do you

NOTE Confidence: 0.863772098095238

00:40:28.858 --> 00:40:30.369 research studies up at the onset,

NOTE Confidence: 0.863772098095238

00:40:30.370 --> 00:40:32.110 we have to think about resourcing

NOTE Confidence: 0.863772098095238

00:40:32.110 --> 00:40:33.656 studies as well as researchers

NOTE Confidence: 0.863772098095238

00:40:33.656 --> 00:40:35.600 appropriately to allow them to do

NOTE Confidence: 0.863772098095238

00:40:35.600 --> 00:40:37.690 this type of intentional engage.

NOTE Confidence: 0.90004325

00:40:40.130 --> 00:40:40.680 Fantastic.

NOTE Confidence: 0.781216061428572

00:40:48.890 --> 00:40:51.365 And I you know that there's a lot of

NOTE Confidence: 0.781216061428572

00:40:51.365 --> 00:40:54.030 people here that are doing a lot of

NOTE Confidence: 0.781216061428572

00:40:54.030 --> 00:40:56.130 interesting research in terms of child

NOTE Confidence: 0.781216061428572

00:40:56.130 --> 00:40:58.660 development and in terms of, you know,

NOTE Confidence: 0.781216061428572

00:40:58.660 --> 00:41:00.685 trying to understand the developmental

NOTE Confidence: 0.781216061428572

00:41:00.685 --> 00:41:02.850 influences on health and well being.

NOTE Confidence: 0.781216061428572

00:41:02.850 --> 00:41:05.410 And so if people are interested in trying

NOTE Confidence: 0.781216061428572

00:41:05.410 --> 00:41:08.330 to get involved in the pediatric cohort,

NOTE Confidence: 0.781216061428572

00:41:08.330 --> 00:41:10.370 or maybe even suggesting measures,

NOTE Confidence: 0.781216061428572

00:41:10.370 --> 00:41:12.120 what is the process for for for

NOTE Confidence: 0.781216061428572

00:41:12.120 --> 00:41:13.766 trying to kind of engage with

NOTE Confidence: 0.781216061428572

00:41:13.766 --> 00:41:15.434 the all of us pediatric cohort?

NOTE Confidence: 0.78345445

00:41:15.760 --> 00:41:17.080 That is a great question.

NOTE Confidence: 0.78345445

00:41:17.080 --> 00:41:18.560 So one of the things this is the

NOTE Confidence: 0.78345445

00:41:18.560 --> 00:41:20.448 perfect time for us to be having this

NOTE Confidence: 0.78345445

00:41:20.448 --> 00:41:21.432 question about suggesting measures.

NOTE Confidence: 0.78345445

00:41:21.440 --> 00:41:23.690 You can send an email to.

NOTE Confidence: 0.885506414

00:41:28.740 --> 00:41:30.830 Joinjoinallofus.org if you go to

NOTE Confidence: 0.885506414

00:41:30.830 --> 00:41:32.290 joinallofus.org the research allofus.org

NOTE Confidence: 0.885506414

00:41:32.290 --> 00:41:34.761 that will take you directly to a

NOTE Confidence: 0.885506414

00:41:34.761 --> 00:41:36.117 way that you can send information

NOTE Confidence: 0.885506414

00:41:36.117 --> 00:41:37.982 and as a researcher when you send

NOTE Confidence: 0.885506414

00:41:37.982 --> 00:41:39.680 an information let us know go.

NOTE Confidence: 0.885506414

00:41:39.680 --> 00:41:40.748 I would encourage researchers

NOTE Confidence: 0.885506414

00:41:40.748 --> 00:41:42.660 from this Community to 1st go to

NOTE Confidence: 0.885506414

00:41:42.660 --> 00:41:43.980 our publicly available data set.

NOTE Confidence: 0.885506414

00:41:43.980 --> 00:41:45.611 Kind of browse around and look at

NOTE Confidence: 0.885506414

00:41:45.611 --> 00:41:47.709 some of the type of data that we're

NOTE Confidence: 0.885506414

00:41:47.709 --> 00:41:49.680 collecting or even going and register and

NOTE Confidence: 0.885506414

00:41:49.680 --> 00:41:51.960 to see what type of data we're collecting.

NOTE Confidence: 0.885506414

00:41:51.960 --> 00:41:53.604 And if you don't see data

NOTE Confidence: 0.885506414

00:41:53.604 --> 00:41:54.426 that we're collecting,

NOTE Confidence: 0.885506414

00:41:54.430 --> 00:41:55.900 that's going to be important to the

NOTE Confidence: 0.885506414

00:41:55.900 --> 00:41:56.990 research that you're conducting.

NOTE Confidence: 0.885506414

00:41:56.990 --> 00:41:58.886 Send this a message and say you know,

NOTE Confidence: 0.885506414

00:41:58.890 --> 00:42:00.798 I know it's early on and you are thinking

NOTE Confidence: 0.885506414

00:42:00.798 --> 00:42:02.229 about your pediatric enrollment.

NOTE Confidence: 0.885506414

00:42:02.230 --> 00:42:04.566 Have you thought about this type of question?

NOTE Confidence: 0.885506414

00:42:04.570 --> 00:42:06.230 Have you thought about these

NOTE Confidence: 0.885506414

00:42:06.230 --> 00:42:07.226 types of surveys?

NOTE Confidence: 0.885506414

00:42:07.230 --> 00:42:08.938 And but the other beautiful opportunity that

NOTE Confidence: 0.885506414

00:42:08.938 --> 00:42:11.010 we have is pilot research opportunities.

NOTE Confidence: 0.885506414

00:42:11.010 --> 00:42:13.385 There will be opportunities for

NOTE Confidence: 0.885506414

00:42:13.385 --> 00:42:15.285 researchers to develop ancillary

NOTE Confidence: 0.885506414

00:42:15.285 --> 00:42:17.548 studies from our data set as well,

NOTE Confidence: 0.885506414

00:42:17.550 --> 00:42:18.696 but they'll be able to pose.

NOTE Confidence: 0.885506414

00:42:18.700 --> 00:42:20.681 And we're about two years out from

NOTE Confidence: 0.885506414

00:42:20.681 --> 00:42:22.210 that ancillary study development.

NOTE Confidence: 0.885506414

00:42:22.210 --> 00:42:24.226 But that's also something I'm excited about.

NOTE Confidence: 0.885506414

00:42:24.230 --> 00:42:27.317 But we're at a really important time.

NOTE Confidence: 0.885506414

00:42:27.320 --> 00:42:28.904 When we think about our social

NOTE Confidence: 0.885506414

00:42:28.904 --> 00:42:30.566 terms of health study that was

NOTE Confidence: 0.885506414

00:42:30.566 --> 00:42:32.204 helped to develop by a researcher,

NOTE Confidence: 0.885506414

00:42:32.210 --> 00:42:34.130 doctor Cheryl Clark from Boston

NOTE Confidence: 0.885506414

00:42:34.130 --> 00:42:34.898 Medical University,

NOTE Confidence: 0.885506414

00:42:34.900 --> 00:42:36.909 developing that that that that social terms

NOTE Confidence: 0.885506414

00:42:36.909 --> 00:42:38.870 of health survey and doctor Clark said,

NOTE Confidence: 0.885506414

00:42:38.870 --> 00:42:39.262 you know,

NOTE Confidence: 0.885506414

00:42:39.262 --> 00:42:40.634 as an intern and she wanted to

NOTE Confidence: 0.885506414

00:42:40.634 --> 00:42:42.253 make sure that we were collecting

NOTE Confidence: 0.885506414

00:42:42.253 --> 00:42:43.628 measures that would intersect with

NOTE Confidence: 0.885506414

00:42:43.672 --> 00:42:45.152 the biological information that we

NOTE Confidence: 0.885506414

00:42:45.152 --> 00:42:46.632 were collecting that could really

NOTE Confidence: 0.885506414

00:42:46.640 --> 00:42:48.120 begin to look at some of those health

NOTE Confidence: 0.885506414

00:42:48.120 --> 00:42:48.979 disparities that we're seeing.

NOTE Confidence: 0.894203752222222

00:42:52.620 --> 00:42:54.292 So a lot of people taking notes as

NOTE Confidence: 0.894203752222222

00:42:54.292 --> 00:42:55.982 you're trying to as you were mentioning

NOTE Confidence: 0.894203752222222

00:42:55.982 --> 00:42:57.428 that email address, so I might

NOTE Confidence: 0.795592585

00:42:57.440 --> 00:42:58.706 I'll put it back up again,

NOTE Confidence: 0.795592585

00:42:58.710 --> 00:43:00.397 and I'm sorry I'll say it slower.

NOTE Confidence: 0.795592585

00:43:00.400 --> 00:43:02.992 The probably eat the easiest place to go

NOTE Confidence: 0.795592585

00:43:02.992 --> 00:43:05.678 to is probably all of us that nih.gov.

NOTE Confidence: 0.795592585

00:43:05.678 --> 00:43:07.706 That's probably the most simple website

NOTE Confidence: 0.757584365555556

00:43:10.560 --> 00:43:11.118 againthatsallofus.nih.gov. Thank you.

NOTE Confidence: 0.757584365555556

00:43:11.118 --> 00:43:12.234 Someone put it in the check.

NOTE Confidence: 0.866238286

00:43:14.230 --> 00:43:16.114 Very, very efficient.

NOTE Confidence: 0.866238286

00:43:16.114 --> 00:43:18.084 That's wonderful. And you know,

NOTE Confidence: 0.866238286

00:43:18.084 --> 00:43:20.310 I I know I've been having the question,

NOTE Confidence: 0.866238286

00:43:20.310 --> 00:43:21.566 so if anyone else wants to jump in,

NOTE Confidence: 0.866238286

00:43:21.570 --> 00:43:24.314 please feel free to unmute and and

NOTE Confidence: 0.866238286

00:43:24.314 --> 00:43:27.256 ask questions as obviously I just I'm

NOTE Confidence: 0.866238286

00:43:27.256 --> 00:43:30.327 fascinated by the resource and one other

NOTE Confidence: 0.866238286

00:43:30.327 --> 00:43:33.045 very critical component of research is

NOTE Confidence: 0.866238286

00:43:33.045 --> 00:43:35.985 funding and so do you know if there

NOTE Confidence: 0.866238286

00:43:35.985 --> 00:43:38.800 will be rfas or what the will there.

NOTE Confidence: 0.866238286

00:43:38.800 --> 00:43:41.056 Will there be specific competitions to

NOTE Confidence: 0.866238286

00:43:41.056 --> 00:43:43.697 try and encourage use of all of us and?

NOTE Confidence: 0.866238286

00:43:43.700 --> 00:43:45.350 Can we get any insight scoop

NOTE Confidence: 0.8349281975

00:43:46.440 --> 00:43:47.952 that is a great question and you

NOTE Confidence: 0.8349281975

00:43:47.952 --> 00:43:49.718 know at at the NIH, we're not.

NOTE Confidence: 0.8349281975

00:43:49.718 --> 00:43:52.350 We're not able to talk about the potential

NOTE Confidence: 0.8349281975

00:43:52.414 --> 00:43:54.712 for RFA's before before they come out

NOTE Confidence: 0.8349281975

00:43:54.712 --> 00:43:56.120 before they're publicly available,

NOTE Confidence: 0.8349281975

00:43:56.120 --> 00:43:58.307 but what I can say is that we have

NOTE Confidence: 0.8349281975

00:43:58.307 --> 00:44:00.621 I can think about our Community

NOTE Confidence: 0.8349281975

00:44:00.621 --> 00:44:03.083 grants that we've given we've given

NOTE Confidence: 0.8349281975

00:44:03.083 --> 00:44:05.435 over over 100 awards to Community

NOTE Confidence: 0.8349281975

00:44:05.435 --> 00:44:07.577 partners to engage in this research,

NOTE Confidence: 0.8349281975

00:44:07.577 --> 00:44:09.810 and we are actively thinking about what

NOTE Confidence: 0.8349281975

00:44:09.875 --> 00:44:11.861 resources are needed for researchers to

NOTE Confidence: 0.8349281975

00:44:11.861 --> 00:44:14.139 engage with the use of our database.

NOTE Confidence: 0.8349281975

00:44:14.140 --> 00:44:16.338 As well, but I also want to

NOTE Confidence: 0.8349281975

00:44:16.338 --> 00:44:16.966 encourage researchers.

NOTE Confidence: 0.8349281975

00:44:16.970 --> 00:44:18.182 While the all of US program

NOTE Confidence: 0.8349281975

00:44:18.182 --> 00:44:18.990 is thinking about that.

NOTE Confidence: 0.8349281975

00:44:18.990 --> 00:44:21.350 But if you're doing research with a different

NOTE Confidence: 0.8349281975

00:44:21.350 --> 00:44:23.147 institute and a center at the Oliver,

NOTE Confidence: 0.8349281975

00:44:23.150 --> 00:44:24.870 I mean at the NIH,

NOTE Confidence: 0.8349281975

00:44:24.870 --> 00:44:27.383 think about using the all of US

NOTE Confidence: 0.8349281975

00:44:27.383 --> 00:44:29.573 research program database as a data

NOTE Confidence: 0.8349281975

00:44:29.573 --> 00:44:31.308 set for your research application.

NOTE Confidence: 0.8349281975

00:44:31.310 --> 00:44:31.918 For example,

NOTE Confidence: 0.8349281975

00:44:31.918 --> 00:44:34.670 if you're applying to the NIH to the NCI,

NOTE Confidence: 0.8349281975

00:44:34.670 --> 00:44:36.066 the National Cancer Institute,

NOTE Confidence: 0.8349281975

00:44:36.066 --> 00:44:37.811 and you're looking at certain

NOTE Confidence: 0.8349281975

00:44:37.811 --> 00:44:38.610 pediatric cancers,

NOTE Confidence: 0.8349281975

00:44:38.610 --> 00:44:40.808 feel free to to write into your

NOTE Confidence: 0.8349281975

00:44:40.808 --> 00:44:42.413 proposal that we are proposing

NOTE Confidence: 0.8349281975

00:44:42.413 --> 00:44:44.499 to use for one of our aims.

NOTE Confidence: 0.8349281975

00:44:44.500 --> 00:44:45.977 Or from some of our background data.

NOTE Confidence: 0.8349281975

00:44:45.980 --> 00:44:48.428 The all of US research program data set.

NOTE Confidence: 0.8349281975

00:44:48.430 --> 00:44:49.698 We are encouraging people,

NOTE Confidence: 0.8349281975

00:44:49.698 --> 00:44:51.600 no matter where you're applying to,

NOTE Confidence: 0.8349281975

00:44:51.600 --> 00:44:53.148 for your funding to think about

NOTE Confidence: 0.8349281975

00:44:53.148 --> 00:44:55.230 using all of US research data set.

NOTE Confidence: 0.8349281975

00:44:55.230 --> 00:44:57.432 But we are thinking very intentional

NOTE Confidence: 0.8349281975

00:44:57.432 --> 00:44:59.390 about what resources are needed.

NOTE Confidence: 0.766493352222222

00:45:04.290 --> 00:45:06.027 And if I may ask just one more question,

NOTE Confidence: 0.766493352222222

00:45:06.030 --> 00:45:08.770 you know I I was noticing on your CV that

NOTE Confidence: 0.766493352222222

00:45:08.845 --> 00:45:11.629 you were part of the lead for community

NOTE Confidence: 0.766493352222222

00:45:11.629 --> 00:45:13.938 outreach and engagement of your CSA.

NOTE Confidence: 0.766493352222222

00:45:13.940 --> 00:45:15.780 Basically the which many here

NOTE Confidence: 0.766493352222222

00:45:15.780 --> 00:45:18.156 people here would be able to

NOTE Confidence: 0.766493352222222

00:45:18.156 --> 00:45:20.028 know the clinical investigation,

NOTE Confidence: 0.766493352222222

00:45:20.030 --> 00:45:23.230 which is our kind of CSA center here at Yale.

NOTE Confidence: 0.766493352222222

00:45:23.230 --> 00:45:24.515 And then obviously you've had

NOTE Confidence: 0.766493352222222

00:45:24.515 --> 00:45:26.119 a meteoric rise now to chief

NOTE Confidence: 0.766493352222222

00:45:26.119 --> 00:45:27.727 engagement officer of all of us.

NOTE Confidence: 0.766493352222222

00:45:27.730 --> 00:45:29.706 I was wondering if you could tell us

NOTE Confidence: 0.766493352222222

00:45:29.706 --> 00:45:31.510 about critical points in your transition,

NOTE Confidence: 0.766493352222222

00:45:31.510 --> 00:45:32.530 particularly for the.

NOTE Confidence: 0.766493352222222

00:45:32.530 --> 00:45:34.910 The trainings that are on the line

NOTE Confidence: 0.766493352222222

00:45:34.971 --> 00:45:36.954 and what we're kind of very pivotal

NOTE Confidence: 0.766493352222222

00:45:36.954 --> 00:45:39.498 moments as you as you moved from from

NOTE Confidence: 0.766493352222222

00:45:39.498 --> 00:45:40.693 from different stages across your

NOTE Confidence: 0.766493352222222

00:45:40.693 --> 00:45:42.406 career that you might be able to share

NOTE Confidence: 0.766493352222222

00:45:42.406 --> 00:45:43.770 with the trainees in the audience.

NOTE Confidence: 0.756255433583333

00:45:44.230 --> 00:45:45.578 That's a great question.

NOTE Confidence: 0.756255433583333

00:45:45.578 --> 00:45:47.982 One of the critical moments I would

NOTE Confidence: 0.756255433583333

00:45:47.982 --> 00:45:50.478 say is meant for me being mentored by

NOTE Confidence: 0.756255433583333

00:45:50.478 --> 00:45:52.607 having a really intentional mentor.

NOTE Confidence: 0.756255433583333

00:45:52.610 --> 00:45:54.380 My idea? My postdoc with Doctor

NOTE Confidence: 0.756255433583333

00:45:54.380 --> 00:45:56.538 Robert Wynn who's now the cancer and

NOTE Confidence: 0.756255433583333

00:45:56.538 --> 00:45:58.374 director at the VCU Massey Cancer

NOTE Confidence: 0.756255433583333

00:45:58.374 --> 00:46:00.186 Center and and during my postdoc,

NOTE Confidence: 0.756255433583333

00:46:00.190 --> 00:46:02.297 even even the development of my postdoc,

NOTE Confidence: 0.756255433583333

00:46:02.300 --> 00:46:03.572 was a leadership postdoc.

NOTE Confidence: 0.756255433583333

00:46:03.572 --> 00:46:05.162 Which is not heard of.

NOTE Confidence: 0.756255433583333

00:46:05.170 --> 00:46:06.805 You don't hear many postdocs

NOTE Confidence: 0.756255433583333

00:46:06.805 --> 00:46:08.440 that are actually intended on

NOTE Confidence: 0.756255433583333

00:46:08.497 --> 00:46:10.017 developing you as a leader.

NOTE Confidence: 0.756255433583333

00:46:10.020 --> 00:46:11.466 So Doctor Wynn had my postdoc

NOTE Confidence: 0.756255433583333

00:46:11.466 --> 00:46:12.968 focus on both my leadership

NOTE Confidence: 0.756255433583333

00:46:12.968 --> 00:46:14.896 development and cancer disparities,

NOTE Confidence: 0.756255433583333

00:46:14.900 --> 00:46:17.196 as well as my cancer disparities career

NOTE Confidence: 0.756255433583333

00:46:17.196 --> 00:46:19.519 and as mentors as faculty and staff.

NOTE Confidence: 0.756255433583333

00:46:19.520 --> 00:46:20.856 You actually have potential

NOTE Confidence: 0.756255433583333

00:46:20.856 --> 00:46:22.860 agency to develop the type of

NOTE Confidence: 0.756255433583333

00:46:22.920 --> 00:46:24.620 postdocs you want to develop,

NOTE Confidence: 0.756255433583333

00:46:24.620 --> 00:46:26.538 so be creative and innovative when you

NOTE Confidence: 0.756255433583333

00:46:26.538 --> 00:46:28.220 develop those postdocs for your students.

NOTE Confidence: 0.756255433583333

00:46:28.220 --> 00:46:29.780 So that was a huge piece of it.

NOTE Confidence: 0.756255433583333

00:46:29.780 --> 00:46:31.761 But the other thing was that while

NOTE Confidence: 0.756255433583333

00:46:31.761 --> 00:46:33.979 it may appear to be a meteoric rise.

NOTE Confidence: 0.756255433583333

00:46:33.980 --> 00:46:36.860 In my my world I have been doing community

NOTE Confidence: 0.756255433583333

00:46:36.860 --> 00:46:38.979 engaged research for over 23 years.

NOTE Confidence: 0.756255433583333

00:46:38.980 --> 00:46:41.171 Since the onset of my research career

NOTE Confidence: 0.756255433583333

00:46:41.171 --> 00:46:44.032 and it was truly that commitment to

NOTE Confidence: 0.756255433583333

00:46:44.032 --> 00:46:46.347 community engaged research doing that

NOTE Confidence: 0.756255433583333

00:46:46.347 --> 00:46:48.901 research for and with communities instead

NOTE Confidence: 0.756255433583333

00:46:48.901 --> 00:46:51.181 of on communities that really allow

NOTE Confidence: 0.756255433583333

00:46:51.181 --> 00:46:53.189 me to gain that trust in the insight.

NOTE Confidence: 0.756255433583333

00:46:53.190 --> 00:46:53.748 For example,

NOTE Confidence: 0.756255433583333

00:46:53.748 --> 00:46:55.701 the work that I did with citizen

NOTE Confidence: 0.756255433583333

00:46:55.701 --> 00:46:57.163 science and African American

NOTE Confidence: 0.756255433583333

00:46:57.163 --> 00:46:58.667 men were project brotherhood.

NOTE Confidence: 0.756255433583333

00:46:58.670 --> 00:47:01.106 I had a partnership with that community

NOTE Confidence: 0.756255433583333

00:47:01.106 --> 00:47:02.834 based organization for seven years

NOTE Confidence: 0.756255433583333

00:47:02.834 --> 00:47:05.018 before we enter into a research there.

NOTE Confidence: 0.756255433583333

00:47:05.020 --> 00:47:07.309 Seven years, that means that I was

NOTE Confidence: 0.756255433583333

00:47:07.309 --> 00:47:09.380 coming to health fairs with them.

NOTE Confidence: 0.756255433583333

00:47:09.380 --> 00:47:11.472 Grassroots organizations with them,

NOTE Confidence: 0.756255433583333

00:47:11.472 --> 00:47:12.518 basketball tournaments.

NOTE Confidence: 0.756255433583333

00:47:12.520 --> 00:47:13.780 With them, you name it.

NOTE Confidence: 0.756255433583333

00:47:13.780 --> 00:47:14.752 And I was.

NOTE Confidence: 0.756255433583333

00:47:14.752 --> 00:47:16.696 And I also looked at project

NOTE Confidence: 0.756255433583333

00:47:16.696 --> 00:47:18.308 Brotherhood as being just as

NOTE Confidence: 0.756255433583333

00:47:18.308 --> 00:47:20.138 important to my training and my

NOTE Confidence: 0.756255433583333

00:47:20.206 --> 00:47:22.558 education as my tenured faculty work.

NOTE Confidence: 0.756255433583333

00:47:22.560 --> 00:47:24.051 It was just important for me to

NOTE Confidence: 0.756255433583333

00:47:24.051 --> 00:47:25.596 learn from the community as it was

NOTE Confidence: 0.756255433583333

00:47:25.596 --> 00:47:27.345 for me to learn from those basic

NOTE Confidence: 0.756255433583333

00:47:27.345 --> 00:47:28.599 and translational researchers,

NOTE Confidence: 0.756255433583333

00:47:28.600 --> 00:47:30.000 and I think that's something

NOTE Confidence: 0.756255433583333

00:47:30.000 --> 00:47:31.400 we forget to tell researchers.

NOTE Confidence: 0.756255433583333

00:47:31.400 --> 00:47:33.371 And it was also my role and my work

NOTE Confidence: 0.756255433583333

00:47:33.371 --> 00:47:35.290 with Community campus partnerships.

NOTE Confidence: 0.756255433583333

00:47:35.290 --> 00:47:37.790 Health CCPH and National Organization

NOTE Confidence: 0.756255433583333

00:47:37.790 --> 00:47:38.790 International Organization,

NOTE Confidence: 0.756255433583333

00:47:38.790 --> 00:47:40.939 which I was the board chair that

NOTE Confidence: 0.756255433583333

00:47:40.939 --> 00:47:43.088 allowed me to help develop Internet

NOTE Confidence: 0.756255433583333

00:47:43.088 --> 00:47:44.520 national guidelines for community

NOTE Confidence: 0.756255433583333

00:47:44.520 --> 00:47:46.615 engaged research and I worked with

NOTE Confidence: 0.756255433583333

00:47:46.615 --> 00:47:48.145 the all of US research program.

NOTE Confidence: 0.756255433583333

00:47:48.150 --> 00:47:50.274 Actually at the onset of its

NOTE Confidence: 0.756255433583333

00:47:50.274 --> 00:47:51.690 community engagement work with

NOTE Confidence: 0.756255433583333

00:47:51.750 --> 00:47:53.700 Doctor Consuelo Wilkins out of

NOTE Confidence: 0.756255433583333

00:47:53.700 --> 00:47:55.650 Wilkins out of Meharry Vanderbilt,

NOTE Confidence: 0.756255433583333

00:47:55.650 --> 00:47:57.130 who was one of my mentors as well.

NOTE Confidence: 0.756255433583333

00:47:57.130 --> 00:47:59.153 So I've been very blessed to have

NOTE Confidence: 0.756255433583333

00:47:59.153 --> 00:48:01.642 a group of mentors that have been

NOTE Confidence: 0.756255433583333

00:48:01.642 --> 00:48:03.970 doing this work for several decades.

NOTE Confidence: 0.756255433583333

00:48:03.970 --> 00:48:05.674 That actually brought me up in the ranks.

NOTE Confidence: 0.756255433583333

00:48:05.680 --> 00:48:07.215 And brought me alongside even

00:48:07.215 --> 00:48:08.750 things that Doctor Lynn did.

00:48:08.750 --> 00:48:10.844 That was things like bringing me

00:48:10.844 --> 00:48:13.528 to the NIH as a mentor review.

00:48:13.530 --> 00:48:15.840 It changed the way I wrote grants

00:48:15.840 --> 00:48:16.830 and many researchers.

00:48:16.830 --> 00:48:18.405 Many of us that are funded through the night,

00:48:18.410 --> 00:48:20.462 and we get invited to the NIH grant review.

00:48:20.470 --> 00:48:21.926 We don't even know that we can

00:48:21.926 --> 00:48:22.550 bring a mentee

00:48:22.601 --> 00:48:24.580 on that grant. Review with us when when

00:48:24.580 --> 00:48:26.613 you get invited to review a journal

00:48:26.613 --> 00:48:28.557 publication and that there's an opportunity

00:48:28.557 --> 00:48:30.808 for you to have that a mentor review.

00:48:30.810 --> 00:48:33.204 Take it, give that training of yours,

00:48:33.210 --> 00:48:34.830 opportunity to review that paper.

00:48:34.830 --> 00:48:36.220 Give that training. Of yours,

NOTE Confidence: 0.840915882307692

00:48:36.220 --> 00:48:38.268 an opportunity to come to the NIH review

NOTE Confidence: 0.840915882307692

00:48:38.268 --> 00:48:40.440 or any other grant review, you know,

NOTE Confidence: 0.840915882307692

00:48:40.440 --> 00:48:43.296 I just gave a talk at our minority Student

NOTE Confidence: 0.840915882307692

00:48:43.296 --> 00:48:45.183 Research symposium with Doctor Wynn,

NOTE Confidence: 0.840915882307692

00:48:45.183 --> 00:48:46.749 so it was a talk with

NOTE Confidence: 0.840915882307692

00:48:46.749 --> 00:48:48.099 Doctor Wynn is my mentor,

NOTE Confidence: 0.840915882307692

00:48:48.100 --> 00:48:50.011 and then I had Alexander Kimbro one

NOTE Confidence: 0.840915882307692

00:48:50.011 --> 00:48:52.009 of my mentees with me, and we talked,

NOTE Confidence: 0.840915882307692

00:48:52.009 --> 00:48:53.347 and I talked about the importance

NOTE Confidence: 0.840915882307692

00:48:53.347 --> 00:48:54.719 of being mentored and being,

NOTE Confidence: 0.840915882307692

00:48:54.720 --> 00:48:57.240 and and and being a mentee,

NOTE Confidence: 0.840915882307692

00:48:57.240 --> 00:48:58.682 and one of the things that Doctor

NOTE Confidence: 0.840915882307692

00:48:58.682 --> 00:49:00.288 Wynn talks about is the difference

NOTE Confidence: 0.840915882307692

00:49:00.288 --> 00:49:01.540 between mentorship and sponsorship.

NOTE Confidence: 0.840915882307692

00:49:01.540 --> 00:49:02.904 And sponsorship is actually

NOTE Confidence: 0.840915882307692

00:49:02.904 --> 00:49:04.268 giving someone a seed.

NOTE Confidence: 0.840915882307692

00:49:04.270 --> 00:49:06.790 The table when you have received the table.

NOTE Confidence: 0.840915882307692

00:49:06.790 --> 00:49:08.212 Because there may be places where

NOTE Confidence: 0.840915882307692

00:49:08.212 --> 00:49:09.809 I would never have been invited.

NOTE Confidence: 0.840915882307692

00:49:09.810 --> 00:49:10.834 If Doctor Winden say,

NOTE Confidence: 0.840915882307692

00:49:10.834 --> 00:49:13.190 you know what I'm gonna turn down this talk,

NOTE Confidence: 0.840915882307692

00:49:13.190 --> 00:49:14.738 but I'm gonna let my trainee

NOTE Confidence: 0.840915882307692

00:49:14.738 --> 00:49:16.408 Kareem come and give this talk

NOTE Confidence: 0.840915882307692

00:49:16.408 --> 00:49:18.438 and he talks about the level of

NOTE Confidence: 0.840915882307692

00:49:18.438 --> 00:49:20.050 vulnerability it takes to be a mentor,

NOTE Confidence: 0.840915882307692

00:49:20.050 --> 00:49:22.210 the level of trust it takes to be a mentor,

NOTE Confidence: 0.840915882307692

00:49:22.210 --> 00:49:24.016 but also the intentionality it takes.

NOTE Confidence: 0.688965974111111

00:49:25.550 --> 00:49:27.179 It's representation, mentorship,

NOTE Confidence: 0.688965974111111

00:49:27.179 --> 00:49:30.437 inclusion, key themes we have and

NOTE Confidence: 0.717578656

00:49:30.450 --> 00:49:32.090 and intentional, and I can't

NOTE Confidence: 0.717578656

00:49:32.090 --> 00:49:33.730 and diversity and inclusion and

NOTE Confidence: 0.717578656

00:49:33.789 --> 00:49:35.759 representation does not just happen.

NOTE Confidence: 0.717578656

00:49:35.760 --> 00:49:37.116 You have to be intentional with.

NOTE Confidence: 0.770063407

00:49:38.120 --> 00:49:41.592 We we did have one question come in

NOTE Confidence: 0.770063407

00:49:41.592 --> 00:49:43.608 from Alec, Alex Kurtzman and will

NOTE Confidence: 0.770063407

00:49:43.608 --> 00:49:45.677 recruitment of children into all of us

NOTE Confidence: 0.770063407

00:49:45.677 --> 00:49:47.429 provide for linkage of children's data

NOTE Confidence: 0.770063407

00:49:47.429 --> 00:49:49.448 to their families and extended families.

NOTE Confidence: 0.770063407

00:49:49.450 --> 00:49:51.262 I guess. How far will those

NOTE Confidence: 0.770063407

00:49:51.262 --> 00:49:52.470 electronic health records extend

NOTE Confidence: 0.756741578

00:49:52.620 --> 00:49:54.996 it? Will it in terms of linkage to it

NOTE Confidence: 0.756741578

00:49:54.996 --> 00:49:57.385 you I won't say that provide linkage

NOTE Confidence: 0.756741578

00:49:57.385 --> 00:49:59.608 but whatever in that child's electronic

NOTE Confidence: 0.756741578

00:49:59.608 --> 00:50:02.760 medical record is what you have access to.

NOTE Confidence: 0.756741578

00:50:02.760 --> 00:50:05.046 For example, say what if in that child they

NOTE Confidence: 0.756741578

00:50:05.046 --> 00:50:07.442 have a history of type one diabetes and in

NOTE Confidence: 0.756741578

00:50:07.442 --> 00:50:09.446 their their record it also talks about?

NOTE Confidence: 0.756741578

00:50:09.450 --> 00:50:10.329 Other family members.

NOTE Confidence: 0.756741578

00:50:10.329 --> 00:50:12.811 You will then be able to get a

NOTE Confidence: 0.756741578

00:50:12.811 --> 00:50:14.631 disaggregated report about the family

NOTE Confidence: 0.756741578

00:50:14.631 --> 00:50:16.560 history of that child. You know,

NOTE Confidence: 0.756741578

00:50:16.560 --> 00:50:17.970 history of diabetes and their family,

NOTE Confidence: 0.756741578

00:50:17.970 --> 00:50:19.278 but not necessarily access

NOTE Confidence: 0.756741578

00:50:19.278 --> 00:50:20.586 to that family's records,

NOTE Confidence: 0.756741578

00:50:20.590 --> 00:50:21.960 because you could only get

NOTE Confidence: 0.756741578

00:50:21.960 --> 00:50:23.330 access to records to someone.

NOTE Confidence: 0.756741578

00:50:23.330 --> 00:50:25.256 For someone who has consented or

NOTE Confidence: 0.756741578

00:50:25.256 --> 00:50:27.636 to a parent who has consented for

NOTE Confidence: 0.756741578

00:50:27.636 --> 00:50:30.023 their their child to be in study.

NOTE Confidence: 0.756741578

00:50:30.030 --> 00:50:31.458 And I also saw a question

NOTE Confidence: 0.756741578

00:50:31.458 --> 00:50:32.172 about parallel data.

NOTE Confidence: 0.756741578

00:50:32.180 --> 00:50:34.208 Yes, the same information that we're

NOTE Confidence: 0.756741578

00:50:34.208 --> 00:50:36.390 collecting on adults, for example,

NOTE Confidence: 0.756741578

00:50:36.390 --> 00:50:38.130 biospecimen information information,

NOTE Confidence: 0.756741578

00:50:38.130 --> 00:50:39.670 such example height, weight,

NOTE Confidence: 0.756741578

00:50:39.670 --> 00:50:42.410 blood samples will be collected in urine.

NOTE Confidence: 0.756741578

00:50:42.410 --> 00:50:44.678 Samples were more than likely be collected

NOTE Confidence: 0.756741578

00:50:44.678 --> 00:50:47.270 on on youth as well as saliva as well,

NOTE Confidence: 0.756741578

00:50:47.270 --> 00:50:49.020 and then that information from

NOTE Confidence: 0.756741578

00:50:49.020 --> 00:50:50.070 Biosample specimen collection

NOTE Confidence: 0.756741578

00:50:50.070 --> 00:50:51.996 will be available as whether as

NOTE Confidence: 0.756741578

00:50:51.996 --> 00:50:53.754 well as the genetic analysis will

NOTE Confidence: 0.756741578

00:50:53.812 --> 00:50:55.457 be available to researchers too.

NOTE Confidence: 0.8362648775

00:50:57.790 --> 00:50:58.819 That's incredibly exciting.

NOTE Confidence: 0.8362648775

00:50:58.819 --> 00:51:00.534 Well, you know Doctor Watson.

NOTE Confidence: 0.8362648775

00:51:00.540 --> 00:51:02.388 I just wanted to really thank you

NOTE Confidence: 0.8362648775

00:51:02.388 --> 00:51:04.080 again for sharing a really amazing

NOTE Confidence: 0.8362648775

00:51:04.080 --> 00:51:06.040 how to in terms of engaging community

NOTE Confidence: 0.8362648775

00:51:06.096 --> 00:51:07.626 and getting the community involved

NOTE Confidence: 0.8362648775

00:51:07.626 --> 00:51:09.434 in research and also for sharing

NOTE Confidence: 0.8362648775

00:51:09.434 --> 00:51:11.352 your why and when you talked about

NOTE Confidence: 0.8362648775

00:51:11.352 --> 00:51:13.247 your family history and and really

NOTE Confidence: 0.8362648775

00:51:13.247 --> 00:51:14.857 have that motivation your science.

NOTE Confidence: 0.8362648775

00:51:14.860 --> 00:51:16.450 So we really appreciate you being

NOTE Confidence: 0.8362648775

00:51:16.450 --> 00:51:18.632 with us today and we look forward

NOTE Confidence: 0.8362648775

00:51:18.632 --> 00:51:20.056 to continuing this conversation,

NOTE Confidence: 0.8362648775

00:51:20.060 --> 00:51:21.860 hopefully here in New Haven at some point.

NOTE Confidence: 0.8362648775

00:51:21.860 --> 00:51:23.010 So thank you. Once again.

NOTE Confidence: 0.741145069285714

00:51:23.240 --> 00:51:25.860 Yeah, we hope to come back and do a data

NOTE Confidence: 0.741145069285714

00:51:25.931 --> 00:51:28.140 demonstration project for you. We'd

NOTE Confidence: 0.7852135625

00:51:28.150 --> 00:51:29.858 love that you again.

NOTE Confidence: 0.870871683333333

00:51:30.310 --> 00:51:30.979 Thank you all.