

WEBVTT

NOTE duration:"01:21:20"

NOTE recognizability:0.937

NOTE language:en-us

NOTE Confidence: 0.951754628571429

00:00:02.400 --> 00:00:05.120 Well, welcome everyone to tonight's

NOTE Confidence: 0.951754628571429

00:00:05.120 --> 00:00:08.344 webinar from the program from the

NOTE Confidence: 0.951754628571429

00:00:08.344 --> 00:00:10.840 Yale Program for Biomedical Ethics.

NOTE Confidence: 0.9402536

00:00:13.400 --> 00:00:15.492 I'm doctor Jack Hughes,

NOTE Confidence: 0.9402536

00:00:15.492 --> 00:00:19.640 and I will be your host tonight.

NOTE Confidence: 0.9402536

00:00:19.640 --> 00:00:22.476 I, along with my colleague Sarah Hall,

NOTE Confidence: 0.9402536

00:00:22.480 --> 00:00:25.744 am an associate director of the

NOTE Confidence: 0.9402536

00:00:25.744 --> 00:00:28.360 Program for Biomedical Ethics, our.

NOTE Confidence: 0.9301902

00:00:31.510 --> 00:00:36.207 The our our usual host and the director

NOTE Confidence: 0.9301902

00:00:36.207 --> 00:00:39.188 of the Program for Biomedical Ethics,

NOTE Confidence: 0.9301902

00:00:39.190 --> 00:00:41.344 Doctor Mark Mercurio, is out of

NOTE Confidence: 0.9301902

00:00:41.344 --> 00:00:44.030 town and will not be here tonight.

NOTE Confidence: 0.9301902

00:00:44.030 --> 00:00:47.802 But we are pleased tonight to hear

NOTE Confidence: 0.9301902

00:00:47.802 --> 00:00:49.732 from Professor Milger Cho from
NOTE Confidence: 0.9301902

00:00:49.732 --> 00:00:52.574 Stanford University, who will talk to
NOTE Confidence: 0.9301902

00:00:52.574 --> 00:00:55.670 us about the language of difference,
NOTE Confidence: 0.9301902

00:00:55.670 --> 00:01:00.130 inclusiveness and equity. In the,
NOTE Confidence: 0.95132334

00:01:02.170 --> 00:01:06.030 excuse me, increasing equity and
NOTE Confidence: 0.95132334

00:01:06.030 --> 00:01:10.410 inclusion in how we categorize patients.
NOTE Confidence: 0.95132334

00:01:10.410 --> 00:01:13.530 So before I introduce Doctor Cho,
NOTE Confidence: 0.95132334

00:01:13.530 --> 00:01:14.330 I want to tell you,
NOTE Confidence: 0.95132334

00:01:14.330 --> 00:01:17.018 I want to say a few words about
NOTE Confidence: 0.95132334

00:01:17.018 --> 00:01:19.240 the program for biomedical ethics
NOTE Confidence: 0.95132334

00:01:19.240 --> 00:01:22.448 and and also about how we're going
NOTE Confidence: 0.95132334

00:01:22.448 --> 00:01:24.260 to conduct tonight's program.
NOTE Confidence: 0.95132334

00:01:24.260 --> 00:01:25.940 The program for Biomedical Ethics,
NOTE Confidence: 0.95132334

00:01:25.940 --> 00:01:27.818 as many of you are aware,
NOTE Confidence: 0.95132334

00:01:27.820 --> 00:01:31.108 brings speakers on a variety of
NOTE Confidence: 0.95132334

00:01:31.108 --> 00:01:33.790 topics in biomedical ethics on

NOTE Confidence: 0.95132334

00:01:33.790 --> 00:01:37.220 at least once or twice a month.

NOTE Confidence: 0.95132334

00:01:37.220 --> 00:01:41.780 And let me tell you about our

NOTE Confidence: 0.95132334

00:01:41.780 --> 00:01:43.500 a couple of upcoming sessions,

NOTE Confidence: 0.95132334

00:01:43.500 --> 00:01:46.500 one of which will be

NOTE Confidence: 0.90113586

00:01:49.700 --> 00:01:51.499 let me see, I have it down here.

NOTE Confidence: 0.9484301125

00:01:53.700 --> 00:01:56.400 Yes, Professor Jen Miller from Yale

NOTE Confidence: 0.9484301125

00:01:56.400 --> 00:02:00.455 will be talking to us about equity and

NOTE Confidence: 0.9484301125

00:02:00.455 --> 00:02:05.100 biomedical research on April the 19th.

NOTE Confidence: 0.9484301125

00:02:05.100 --> 00:02:09.230 We will be sponsoring a day long

NOTE Confidence: 0.9484301125

00:02:09.230 --> 00:02:12.574 seminar on ethics of the heart justice

NOTE Confidence: 0.9484301125

00:02:12.574 --> 00:02:15.140 considerations in in heart failure.

NOTE Confidence: 0.9484301125

00:02:15.140 --> 00:02:18.900 That will be on May 11th and that is

NOTE Confidence: 0.9484301125

00:02:18.900 --> 00:02:21.220 organized by my colleague Dr. Sarah Fall.

NOTE Confidence: 0.8040452

00:02:23.290 --> 00:02:23.490 So,

NOTE Confidence: 0.819182

00:02:26.170 --> 00:02:30.682 so in tonight's session,

NOTE Confidence: 0.819182

00:02:30.682 --> 00:02:36.930 Professor Cho will speak for approximately

NOTE Confidence: 0.819182

00:02:36.930 --> 00:02:41.930 45 minutes and after which she will

NOTE Confidence: 0.819182

00:02:41.930 --> 00:02:43.758 receive questions and comments.

NOTE Confidence: 0.819182

00:02:43.758 --> 00:02:46.070 Please put your your comments

NOTE Confidence: 0.819182

00:02:46.070 --> 00:02:48.420 and questions into the chat

NOTE Confidence: 0.819182

00:02:48.420 --> 00:02:52.149 function and I will read those to.

NOTE Confidence: 0.819182

00:02:52.149 --> 00:02:55.760 Professor Cho at the time. So

NOTE Confidence: 0.942311317

00:02:58.680 --> 00:03:01.260 Professor Cho is professor of

NOTE Confidence: 0.942311317

00:03:01.260 --> 00:03:03.840 Pediatrics and medicine at Stanford,

NOTE Confidence: 0.942311317

00:03:03.840 --> 00:03:06.768 and she's the director of the Stanford

NOTE Confidence: 0.942311317

00:03:06.768 --> 00:03:09.040 Center for Biomedical Ethics.

NOTE Confidence: 0.942311317

00:03:09.040 --> 00:03:12.088 She's also the principal investigator of

NOTE Confidence: 0.942311317

00:03:12.088 --> 00:03:15.760 the Stanford Center for Integration of

NOTE Confidence: 0.942311317

00:03:15.760 --> 00:03:20.999 Research on Genetics and Ethics. And she is.

NOTE Confidence: 0.925158445

00:03:23.890 --> 00:03:28.770 She is in addition to the director,

NOTE Confidence: 0.925158445

00:03:28.770 --> 00:03:34.250 she's she is professor, and she is the

NOTE Confidence: 0.927582261578948
00:03:38.290 --> 00:03:40.946 her major areas of interest are the ethical
NOTE Confidence: 0.927582261578948
00:03:40.946 --> 00:03:43.658 and social issues raised by new technologies
NOTE Confidence: 0.927582261578948
00:03:43.658 --> 00:03:46.682 such as genetic testing, gene therapy,
NOTE Confidence: 0.927582261578948
00:03:46.682 --> 00:03:49.546 pharmacogenetics and gene patents.
NOTE Confidence: 0.927582261578948
00:03:49.550 --> 00:03:53.722 She also studies how academic industry ties
NOTE Confidence: 0.927582261578948
00:03:53.722 --> 00:03:57.830 affect the conduct of biomedical research.
NOTE Confidence: 0.927582261578948
00:03:57.830 --> 00:04:00.830 She was an undergraduate at MIT,
NOTE Confidence: 0.927582261578948
00:04:00.830 --> 00:04:04.810 obtained her PhD at Stanford.
NOTE Confidence: 0.927582261578948
00:04:04.810 --> 00:04:06.634 And then did a health policy
NOTE Confidence: 0.927582261578948
00:04:06.634 --> 00:04:08.214 fellowship at the University of
NOTE Confidence: 0.927582261578948
00:04:08.214 --> 00:04:09.769 California at the San Francisco.
NOTE Confidence: 0.927582261578948
00:04:09.770 --> 00:04:11.430 She has been at Stanford
NOTE Confidence: 0.927582261578948
00:04:11.430 --> 00:04:13.090 for the past several years.
NOTE Confidence: 0.927582261578948
00:04:13.090 --> 00:04:16.247 She is highly regarded as a mentor.
NOTE Confidence: 0.927582261578948
00:04:16.250 --> 00:04:20.366 She is a productive author and researcher.
NOTE Confidence: 0.927582261578948

00:04:20.370 --> 00:04:22.575 And we are delighted to have her
NOTE Confidence: 0.927582261578948

00:04:22.575 --> 00:04:25.039 here tonight to talk to us about
NOTE Confidence: 0.927582261578948

00:04:25.039 --> 00:04:26.483 the language of difference,
NOTE Confidence: 0.927582261578948

00:04:26.490 --> 00:04:28.762 increasing equity and inclusion
NOTE Confidence: 0.927582261578948

00:04:28.762 --> 00:04:31.602 in how we categorize patients.
NOTE Confidence: 0.927582261578948

00:04:31.610 --> 00:04:33.960 Professor Cho.
NOTE Confidence: 0.927582261578948

00:04:33.960 --> 00:04:36.156 It the the floor is yours.
NOTE Confidence: 0.927582261578948

00:04:36.160 --> 00:04:36.960 Thank you very much.
NOTE Confidence: 0.89553784

00:04:37.080 --> 00:04:38.600 Thank you. Thank you, doctor.
NOTE Confidence: 0.9201268

00:04:56.670 --> 00:05:01.140 So thank you very much for inviting
NOTE Confidence: 0.9201268

00:05:01.140 --> 00:05:03.590 me to join your group today.
NOTE Confidence: 0.9201268

00:05:03.590 --> 00:05:06.158 I'm going to be talking a little bit
NOTE Confidence: 0.9201268

00:05:06.158 --> 00:05:08.613 about the topic that I is not really
NOTE Confidence: 0.9201268

00:05:08.613 --> 00:05:11.430 the focus of my main areas of research,
NOTE Confidence: 0.9201268

00:05:11.430 --> 00:05:17.506 but it's one that I think is important to.
NOTE Confidence: 0.9201268

00:05:17.506 --> 00:05:22.252 Addressed for bioethicists as well As for

NOTE Confidence: 0.9201268

00:05:22.252 --> 00:05:26.390 biomedical scientists and clinicians. So

NOTE Confidence: 0.9100633

00:05:31.860 --> 00:05:36.060 I hope you're able to see my slides here.

NOTE Confidence: 0.875359876

00:05:39.580 --> 00:05:41.620 They look great. OK, good.

NOTE Confidence: 0.941691157142857

00:05:47.200 --> 00:05:50.875 So what I'll be talking about today

NOTE Confidence: 0.941691157142857

00:05:50.880 --> 00:05:53.790 stems from some work that I've

NOTE Confidence: 0.941691157142857

00:05:53.790 --> 00:05:58.198 done on what we call DEI efforts,

NOTE Confidence: 0.941691157142857

00:05:58.200 --> 00:06:00.984 diversity, equity and inclusion

NOTE Confidence: 0.941691157142857

00:06:00.984 --> 00:06:03.184 efforts at Stanford and elsewhere.

NOTE Confidence: 0.941691157142857

00:06:03.184 --> 00:06:05.440 And as many of you know,

NOTE Confidence: 0.941691157142857

00:06:05.440 --> 00:06:08.080 these types of efforts are now

NOTE Confidence: 0.941691157142857

00:06:08.080 --> 00:06:11.096 pervasive in biomedical research

NOTE Confidence: 0.941691157142857

00:06:11.096 --> 00:06:14.866 at at medical institutions and.

NOTE Confidence: 0.941691157142857

00:06:14.870 --> 00:06:17.252 Some of these efforts are aimed

NOTE Confidence: 0.941691157142857

00:06:17.252 --> 00:06:19.533 at increasing diversity of human

NOTE Confidence: 0.941691157142857

00:06:19.533 --> 00:06:22.230 participants in research as well

NOTE Confidence: 0.941691157142857

00:06:22.230 --> 00:06:26.390 as in the research workforce.
NOTE Confidence: 0.941691157142857

00:06:26.390 --> 00:06:28.270 The political and social forces
NOTE Confidence: 0.941691157142857

00:06:28.270 --> 00:06:31.097 driving some of these efforts have been
NOTE Confidence: 0.941691157142857

00:06:31.097 --> 00:06:32.887 comprehensively studied by sociologists
NOTE Confidence: 0.941691157142857

00:06:32.887 --> 00:06:35.629 such as Steven Epstein and others,
NOTE Confidence: 0.941691157142857

00:06:35.630 --> 00:06:40.226 but an under examined issue in DEI is the
NOTE Confidence: 0.941691157142857

00:06:40.226 --> 00:06:43.110 language and the concept of human difference.
NOTE Confidence: 0.941691157142857

00:06:43.110 --> 00:06:45.235 Not just as an exercise
NOTE Confidence: 0.941691157142857

00:06:45.235 --> 00:06:46.510 in political correctness,
NOTE Confidence: 0.941691157142857

00:06:46.510 --> 00:06:49.387 but in looking at DEI as an
NOTE Confidence: 0.941691157142857

00:06:49.387 --> 00:06:51.430 ethical issue more broadly.
NOTE Confidence: 0.941691157142857

00:06:51.430 --> 00:06:53.572 So what I hope to do is to show
NOTE Confidence: 0.941691157142857

00:06:53.572 --> 00:06:55.797 why we need to critically examine
NOTE Confidence: 0.941691157142857

00:06:55.797 --> 00:06:57.707 what we mean by diversity,
NOTE Confidence: 0.941691157142857

00:06:57.710 --> 00:06:59.670 including how we measure it,
NOTE Confidence: 0.941691157142857

00:06:59.670 --> 00:07:02.238 and that we must take care to ensure

NOTE Confidence: 0.941691157142857

00:07:02.238 --> 00:07:06.926 that the language we use to concepts of

NOTE Confidence: 0.941691157142857

00:07:06.926 --> 00:07:09.998 difference are scientifically accurate.

NOTE Confidence: 0.941691157142857

00:07:10.000 --> 00:07:14.038 Clinically useful and not morally offensive.

NOTE Confidence: 0.946962533333333

00:07:20.760 --> 00:07:23.535 So I'll argue that these

NOTE Confidence: 0.946962533333333

00:07:23.535 --> 00:07:25.755 issues are ethical issues.

NOTE Confidence: 0.946962533333333

00:07:25.760 --> 00:07:28.721 So what I'm showing you today is a part

NOTE Confidence: 0.946962533333333

00:07:28.721 --> 00:07:31.717 of a national academies of sciences,

NOTE Confidence: 0.946962533333333

00:07:31.720 --> 00:07:33.875 engineering and Medicine report on

NOTE Confidence: 0.946962533333333

00:07:33.875 --> 00:07:36.504 the use of population descriptors in

NOTE Confidence: 0.946962533333333

00:07:36.504 --> 00:07:38.534 genetics and genomics research that

NOTE Confidence: 0.946962533333333

00:07:38.534 --> 00:07:40.920 was just released earlier this month.

NOTE Confidence: 0.946962533333333

00:07:40.920 --> 00:07:42.575 And it provides recommendations for

NOTE Confidence: 0.946962533333333

00:07:42.575 --> 00:07:44.720 the use of categories such as race,

NOTE Confidence: 0.946962533333333

00:07:44.720 --> 00:07:45.875 ethnicity and ancestry,

NOTE Confidence: 0.946962533333333

00:07:45.875 --> 00:07:48.570 which are built on a framework of

NOTE Confidence: 0.946962533333333

00:07:48.641 --> 00:07:50.496 ethical principles which you can
NOTE Confidence: 0.9469625333333333

00:07:50.496 --> 00:07:53.466 see here in the middle of respect,
NOTE Confidence: 0.9469625333333333

00:07:53.466 --> 00:07:55.678 beneficence, equity and justice,
NOTE Confidence: 0.9469625333333333

00:07:55.680 --> 00:07:58.795 as well as scientific values of validity,
NOTE Confidence: 0.9469625333333333

00:07:58.800 --> 00:07:59.430 responsibility,
NOTE Confidence: 0.9469625333333333

00:07:59.430 --> 00:08:01.320 transparency and replicability.
NOTE Confidence: 0.9469625333333333

00:08:01.320 --> 00:08:05.100 So although this report was intended
NOTE Confidence: 0.9469625333333333

00:08:05.182 --> 00:08:07.658 for genetic research communities.
NOTE Confidence: 0.9469625333333333

00:08:07.660 --> 00:08:09.560 The principles apply to research
NOTE Confidence: 0.9469625333333333

00:08:09.560 --> 00:08:11.460 relevant to humans more generally,
NOTE Confidence: 0.9469625333333333

00:08:11.460 --> 00:08:13.356 and also to categories of human
NOTE Confidence: 0.9469625333333333

00:08:13.356 --> 00:08:14.620 difference other than race,
NOTE Confidence: 0.9469625333333333

00:08:14.620 --> 00:08:16.180 ethnicity, and ancestry.
NOTE Confidence: 0.93723458

00:08:22.060 --> 00:08:24.316 So how I got started into
NOTE Confidence: 0.93723458

00:08:24.316 --> 00:08:25.820 some of these issues,
NOTE Confidence: 0.93723458

00:08:25.820 --> 00:08:28.736 looking at some of these issues,

NOTE Confidence: 0.93723458

00:08:28.740 --> 00:08:34.536 was because of my role on.

NOTE Confidence: 0.93723458

00:08:34.540 --> 00:08:37.305 On the editorial board of a journal

NOTE Confidence: 0.93723458

00:08:37.305 --> 00:08:39.502 called Genetics and Medicine and

NOTE Confidence: 0.93723458

00:08:39.502 --> 00:08:41.674 on a committee for this journal

NOTE Confidence: 0.93723458

00:08:41.674 --> 00:08:44.178 that was called the Idea Committee,

NOTE Confidence: 0.93723458

00:08:44.180 --> 00:08:45.842 the Inclusion, Diversity,

NOTE Confidence: 0.93723458

00:08:45.842 --> 00:08:48.058 equity and Access Committee.

NOTE Confidence: 0.93723458

00:08:48.060 --> 00:08:50.140 As chair of this committee,

NOTE Confidence: 0.93723458

00:08:50.140 --> 00:08:53.776 the EDITORINCHIEF asked us to reexamine

NOTE Confidence: 0.93723458

00:08:53.776 --> 00:08:57.153 the publications that have been put

NOTE Confidence: 0.93723458

00:08:57.153 --> 00:09:00.932 out by the the journal over time.

NOTE Confidence: 0.93723458

00:09:00.932 --> 00:09:04.868 For to look for possible offensive

NOTE Confidence: 0.93723458

00:09:04.868 --> 00:09:07.323 terminology and to think about what

NOTE Confidence: 0.93723458

00:09:07.323 --> 00:09:09.790 we should do about it as a journal.

NOTE Confidence: 0.93723458

00:09:09.790 --> 00:09:11.428 And I know that many other journals,

NOTE Confidence: 0.93723458

00:09:11.430 --> 00:09:12.698 professional societies,
NOTE Confidence: 0.93723458

00:09:12.698 --> 00:09:15.234 publishers and others have
NOTE Confidence: 0.93723458

00:09:15.234 --> 00:09:18.129 been doing similar things,
NOTE Confidence: 0.93723458

00:09:18.129 --> 00:09:21.749 and in particular journals have been
NOTE Confidence: 0.930711184615385

00:09:23.790 --> 00:09:26.140 out. Have been issuing guidelines
NOTE Confidence: 0.930711184615385

00:09:26.140 --> 00:09:29.517 on language such as the American
NOTE Confidence: 0.930711184615385

00:09:29.517 --> 00:09:31.646 Psychological Association which
NOTE Confidence: 0.930711184615385

00:09:31.646 --> 00:09:33.950 you can see up on top has a style
NOTE Confidence: 0.930711184615385

00:09:34.022 --> 00:09:36.185 guide and a major section of the
NOTE Confidence: 0.930711184615385

00:09:36.185 --> 00:09:38.195 Style guide is called Bias free
NOTE Confidence: 0.930711184615385

00:09:38.195 --> 00:09:40.696 language and it has very extensive
NOTE Confidence: 0.930711184615385

00:09:40.696 --> 00:09:42.988 resources and recommendations for
NOTE Confidence: 0.930711184615385

00:09:42.988 --> 00:09:46.825 the for language to be used in
NOTE Confidence: 0.930711184615385

00:09:46.825 --> 00:09:50.340 publications of the society.
NOTE Confidence: 0.930711184615385

00:09:50.340 --> 00:09:51.672 On the bottom right,
NOTE Confidence: 0.930711184615385

00:09:51.672 --> 00:09:54.259 you can see that there have been

NOTE Confidence: 0.930711184615385

00:09:54.259 --> 00:09:56.780 publications and guidance issued by

NOTE Confidence: 0.930711184615385

00:09:56.780 --> 00:09:59.180 biomedical journals such as JAMA.

NOTE Confidence: 0.930711184615385

00:09:59.180 --> 00:10:00.008 In particular,

NOTE Confidence: 0.930711184615385

00:10:00.008 --> 00:10:02.906 this one was an updated guidance focusing

NOTE Confidence: 0.930711184615385

00:10:02.906 --> 00:10:05.649 on reporting of race and ethnicity

NOTE Confidence: 0.930711184615385

00:10:05.649 --> 00:10:07.899 in medical and science journals.

NOTE Confidence: 0.930711184615385

00:10:07.900 --> 00:10:10.140 So what our journal was doing was

NOTE Confidence: 0.930711184615385

00:10:10.140 --> 00:10:14.500 part of sort of a much larger movement.

NOTE Confidence: 0.935222005

00:10:18.080 --> 00:10:20.640 So that was how it started, sort of.

NOTE Confidence: 0.935222005

00:10:20.640 --> 00:10:22.971 Where we got to was publication

NOTE Confidence: 0.935222005

00:10:22.971 --> 00:10:26.157 of an article called words Matter,

NOTE Confidence: 0.935222005

00:10:26.160 --> 00:10:27.994 the language of difference in Human Genetics.

NOTE Confidence: 0.935222005

00:10:28.000 --> 00:10:31.132 And I'll be telling you about that

NOTE Confidence: 0.935222005

00:10:31.132 --> 00:10:33.636 paper through the rest of this talk.

NOTE Confidence: 0.935222005

00:10:33.640 --> 00:10:35.386 And I want to acknowledge my

NOTE Confidence: 0.935222005

00:10:35.386 --> 00:10:37.257 coauthors who some of whom are
NOTE Confidence: 0.935222005

00:10:37.257 --> 00:10:38.877 members of the Idea Committee,
NOTE Confidence: 0.935222005

00:10:38.880 --> 00:10:40.880 with me, in particular,
NOTE Confidence: 0.935222005

00:10:40.880 --> 00:10:44.152 Laura du Galassio and, you know,
NOTE Confidence: 0.935222005

00:10:44.152 --> 00:10:46.060 Laura du Galassio.
NOTE Confidence: 0.935222005

00:10:46.060 --> 00:10:50.412 Who is also a molecular pathologist
NOTE Confidence: 0.935222005

00:10:50.412 --> 00:10:52.260 and laboratory geneticist,
NOTE Confidence: 0.935222005

00:10:52.260 --> 00:10:53.540 as well as Inna Amarillo,
NOTE Confidence: 0.935222005

00:10:53.540 --> 00:10:56.739 who also runs a clinical genetics laboratory.
NOTE Confidence: 0.935222005

00:10:56.740 --> 00:10:57.464 Kevin Mintz,
NOTE Confidence: 0.935222005

00:10:57.464 --> 00:11:00.360 who is not a member of the committee
NOTE Confidence: 0.935222005

00:11:00.438 --> 00:11:02.876 but Disability Rights Scholar who
NOTE Confidence: 0.935222005

00:11:02.876 --> 00:11:06.200 also works on issues of disability
NOTE Confidence: 0.935222005

00:11:06.289 --> 00:11:09.059 as they intersect with genetics.
NOTE Confidence: 0.935222005

00:11:09.060 --> 00:11:11.180 Robin Bennett and Kyle Brothers,
NOTE Confidence: 0.935222005

00:11:11.180 --> 00:11:12.860 who are members of the committee.

NOTE Confidence: 0.935222005

00:11:12.860 --> 00:11:15.540 Robin is a genetic counselor.

NOTE Confidence: 0.935222005

00:11:15.540 --> 00:11:18.445 Who has been working on guidelines for

NOTE Confidence: 0.935222005

00:11:18.445 --> 00:11:21.272 terminology for the National Society of

NOTE Confidence: 0.935222005

00:11:21.272 --> 00:11:24.288 Genetic Counselors for almost 30 years now,

NOTE Confidence: 0.935222005

00:11:24.288 --> 00:11:25.419 and Kyle Brothers,

NOTE Confidence: 0.935222005

00:11:25.420 --> 00:11:29.536 who is a pediatrician and also

NOTE Confidence: 0.935222005

00:11:29.540 --> 00:11:32.066 an LC scholar who is works

NOTE Confidence: 0.935222005

00:11:32.066 --> 00:11:33.096 on the committee with me.

NOTE Confidence: 0.9201268

00:11:37.460 --> 00:11:41.596 So some of the premises of this paper are

NOTE Confidence: 0.9201268

00:11:41.596 --> 00:11:44.530 that in biomedical research and medicine.

NOTE Confidence: 0.9201268

00:11:44.530 --> 00:11:46.470 Language that defines the boundaries

NOTE Confidence: 0.9201268

00:11:46.470 --> 00:11:48.410 of human difference is pervasive.

NOTE Confidence: 0.9201268

00:11:48.410 --> 00:11:52.330 In fact, some of this language is critical,

NOTE Confidence: 0.9201268

00:11:52.330 --> 00:11:54.352 and the concepts behind them are

NOTE Confidence: 0.9201268

00:11:54.352 --> 00:11:56.085 critical to conducting biomedical

NOTE Confidence: 0.9201268

00:11:56.085 --> 00:11:58.410 research and to clinical practice.
NOTE Confidence: 0.943863262666667

00:12:01.010 --> 00:12:03.596 But the use of these categories
NOTE Confidence: 0.943863262666667

00:12:03.596 --> 00:12:05.976 in research and clinical practice
NOTE Confidence: 0.943863262666667

00:12:05.976 --> 00:12:08.256 does reify those boundaries.
NOTE Confidence: 0.943863262666667

00:12:08.260 --> 00:12:10.910 And the classification schemes that
NOTE Confidence: 0.943863262666667

00:12:10.910 --> 00:12:14.223 they imply confer power and privilege
NOTE Confidence: 0.943863262666667

00:12:14.223 --> 00:12:17.098 to some and marginalize others,
NOTE Confidence: 0.943863262666667

00:12:17.100 --> 00:12:20.075 which was very well described in the
NOTE Confidence: 0.943863262666667

00:12:20.075 --> 00:12:23.242 seminal book by Jeff Bakker and Susan
NOTE Confidence: 0.943863262666667

00:12:23.242 --> 00:12:26.734 Lee star called Sorting Things Out.
NOTE Confidence: 0.943863262666667

00:12:26.740 --> 00:12:28.575 And these classification schemes can
NOTE Confidence: 0.943863262666667

00:12:28.575 --> 00:12:31.020 also lead to poor health outcomes,
NOTE Confidence: 0.947771011111111

00:12:37.420 --> 00:12:41.392 so. Let's ask ourselves some questions
NOTE Confidence: 0.947771011111111

00:12:41.392 --> 00:12:43.378 about categorizing difference,
NOTE Confidence: 0.947771011111111

00:12:43.380 --> 00:12:44.991 because these categories
NOTE Confidence: 0.947771011111111

00:12:44.991 --> 00:12:47.139 do make a difference.

NOTE Confidence: 0.9477710111111111
00:12:47.140 --> 00:12:49.378 What do we mean by diversity?
NOTE Confidence: 0.9477710111111111
00:12:49.380 --> 00:12:52.477 Why do we classify according to certain
NOTE Confidence: 0.9477710111111111
00:12:52.477 --> 00:12:56.419 features of difference and not others?
NOTE Confidence: 0.9477710111111111
00:12:56.420 --> 00:12:58.620 An important part of biomedical
NOTE Confidence: 0.9477710111111111
00:12:58.620 --> 00:13:00.380 research and clinical practice
NOTE Confidence: 0.9477710111111111
00:13:00.380 --> 00:13:02.590 is creating and classifying.
NOTE Confidence: 0.9477710111111111
00:13:02.590 --> 00:13:04.546 According to these categories of difference,
NOTE Confidence: 0.9477710111111111
00:13:04.550 --> 00:13:06.590 in order to delineate,
NOTE Confidence: 0.9477710111111111
00:13:06.590 --> 00:13:08.630 delineate normal from abnormal,
NOTE Confidence: 0.9477710111111111
00:13:08.630 --> 00:13:10.922 pathogenic, from non pathogenic,
NOTE Confidence: 0.9477710111111111
00:13:10.922 --> 00:13:14.360 and other features which are necessary
NOTE Confidence: 0.9477710111111111
00:13:14.444 --> 00:13:17.189 to identify correlates of disease.
NOTE Confidence: 0.9477710111111111
00:13:17.190 --> 00:13:19.165 However, we know that classification
NOTE Confidence: 0.9477710111111111
00:13:19.165 --> 00:13:21.310 schemes privilege some, marginalize others,
NOTE Confidence: 0.9477710111111111
00:13:21.310 --> 00:13:24.670 and confer power and control to those
NOTE Confidence: 0.9477710111111111

00:13:24.670 --> 00:13:27.909 who devise the classification schemes.
NOTE Confidence: 0.9477710111111111

00:13:27.910 --> 00:13:30.129 So what I'll discuss today is why
NOTE Confidence: 0.9477710111111111

00:13:30.129 --> 00:13:32.388 it's important to ask questions about.
NOTE Confidence: 0.9477710111111111

00:13:32.390 --> 00:13:35.000 Why we are categorizing diversity and
NOTE Confidence: 0.9477710111111111

00:13:35.000 --> 00:13:38.178 how those categories are derived and why?
NOTE Confidence: 0.9477710111111111

00:13:38.178 --> 00:13:40.348 These are also ethical questions
NOTE Confidence: 0.9477710111111111

00:13:40.350 --> 00:13:46.012 and what I'm showing here is one
NOTE Confidence: 0.9477710111111111

00:13:46.012 --> 00:13:49.264 example of a categorization in the
NOTE Confidence: 0.9477710111111111

00:13:49.270 --> 00:13:51.808 international classifications of
NOTE Confidence: 0.9477710111111111

00:13:51.808 --> 00:13:55.822 diseases which has a category that is
NOTE Confidence: 0.9477710111111111

00:13:55.822 --> 00:13:58.030 called struck by Orca initial encounter.
NOTE Confidence: 0.946291579

00:14:04.530 --> 00:14:07.862 So one major reason that the application
NOTE Confidence: 0.946291579

00:14:07.862 --> 00:14:12.970 of the categories medically harmful for is,
NOTE Confidence: 0.946291574

00:14:17.450 --> 00:14:20.267 for example, an example of how they can be
NOTE Confidence: 0.946291574

00:14:20.267 --> 00:14:22.567 medically harmful is through the practice,
NOTE Confidence: 0.946291574

00:14:22.570 --> 00:14:25.849 for example, of race norming or

NOTE Confidence: 0.946291574

00:14:25.849 --> 00:14:28.963 that these categories can lead to

NOTE Confidence: 0.946291574

00:14:28.963 --> 00:14:31.609 discrimination and access to services.

NOTE Confidence: 0.946291574

00:14:31.610 --> 00:14:33.890 Another way these categories can be

NOTE Confidence: 0.946291574

00:14:33.890 --> 00:14:37.133 harmful is if they're morally offensive by

NOTE Confidence: 0.946291574

00:14:37.133 --> 00:14:39.883 reinforcing injustice and showing disrespect.

NOTE Confidence: 0.946291574

00:14:39.890 --> 00:14:42.263 The categories in the labels used to

NOTE Confidence: 0.946291574

00:14:42.263 --> 00:14:44.360 describe them are often value laden

NOTE Confidence: 0.946291574

00:14:44.360 --> 00:14:46.733 and often assigned by people who not

NOTE Confidence: 0.946291574

00:14:46.796 --> 00:14:48.926 do not belong to those categories.

NOTE Confidence: 0.946291574

00:14:48.930 --> 00:14:51.234 Finally, when categories that are used

NOTE Confidence: 0.946291574

00:14:51.234 --> 00:14:53.654 or derived from social or political

NOTE Confidence: 0.946291574

00:14:53.654 --> 00:14:56.517 purposes are used in clinical practice or

NOTE Confidence: 0.946291574

00:14:56.517 --> 00:14:59.010 biomedical research for different purposes,

NOTE Confidence: 0.946291574

00:14:59.010 --> 00:15:00.698 they can be harmful

NOTE Confidence: 0.946291574

00:15:00.698 --> 00:15:01.964 because they're inaccurate.

NOTE Confidence: 0.946291574

00:15:01.970 --> 00:15:04.470 And lead to inappropriate aggregation
NOTE Confidence: 0.946291574

00:15:04.470 --> 00:15:06.970 or disaggregation of data and
NOTE Confidence: 0.946291574

00:15:07.049 --> 00:15:09.290 eventually health disparities.
NOTE Confidence: 0.946291574

00:15:09.290 --> 00:15:11.270 I'll discuss several different
NOTE Confidence: 0.946291574

00:15:11.270 --> 00:15:13.745 types of classification and the
NOTE Confidence: 0.946291574

00:15:13.745 --> 00:15:15.847 language used to describe them,
NOTE Confidence: 0.946291574

00:15:15.850 --> 00:15:19.810 including disability and severity of disease,
NOTE Confidence: 0.946291574

00:15:19.810 --> 00:15:22.526 sex and gender, and race and ethnicity.
NOTE Confidence: 0.946291574

00:15:22.530 --> 00:15:26.170 And I think this may be a good time to
NOTE Confidence: 0.946291574

00:15:26.170 --> 00:15:28.714 give people a trigger warning that I will
NOTE Confidence: 0.946291574

00:15:28.714 --> 00:15:31.460 be using terms that are considered slurs.
NOTE Confidence: 0.946291574

00:15:31.460 --> 00:15:32.831 Throughout this talk,
NOTE Confidence: 0.946291574

00:15:32.831 --> 00:15:35.116 because they're commonly used in
NOTE Confidence: 0.946291574

00:15:35.116 --> 00:15:37.900 medical and scientific parlance today,
NOTE Confidence: 0.946291574

00:15:37.900 --> 00:15:40.154 and it's necessary to identify them in
NOTE Confidence: 0.946291574

00:15:40.154 --> 00:15:42.846 order to call them out as inappropriate

NOTE Confidence: 0.946291574

00:15:42.846 --> 00:15:45.336 and also to present alternative language.

NOTE Confidence: 0.946291574

00:15:45.340 --> 00:15:49.580 And I say this also knowing that from my

NOTE Confidence: 0.946291574

00:15:49.580 --> 00:15:52.419 role as on the editorial board of a journal,

NOTE Confidence: 0.946291574

00:15:52.420 --> 00:15:54.616 a scientific journal that every day.

NOTE Confidence: 0.931672972727273

00:15:56.630 --> 00:15:59.227 I am asked to look at manuscripts

NOTE Confidence: 0.931672972727273

00:15:59.227 --> 00:16:02.072 that are submitted to the journal that

NOTE Confidence: 0.931672972727273

00:16:02.072 --> 00:16:04.142 still continue to use terminology

NOTE Confidence: 0.931672972727273

00:16:04.142 --> 00:16:07.870 that are considered slurs.

NOTE Confidence: 0.931672972727273

00:16:07.870 --> 00:16:11.214 So I think it's important to start

NOTE Confidence: 0.931672972727273

00:16:11.214 --> 00:16:14.510 a conversation about educating,

NOTE Confidence: 0.931672972727273

00:16:14.510 --> 00:16:16.103 educating various communities

NOTE Confidence: 0.931672972727273

00:16:16.103 --> 00:16:19.289 about how and why these are

NOTE Confidence: 0.931672972727273

00:16:19.289 --> 00:16:21.309 considered inappropriate now.

NOTE Confidence: 0.936380874666667

00:16:25.570 --> 00:16:28.994 So let's start with the concept of disability

NOTE Confidence: 0.936380874666667

00:16:28.994 --> 00:16:31.889 and looking at some definitions of it.

NOTE Confidence: 0.936380874666667

00:16:31.890 --> 00:16:35.305 The first one is from the ADA,
NOTE Confidence: 0.936380874666667

00:16:35.305 --> 00:16:39.050 which defines a person with a disability
NOTE Confidence: 0.936380874666667

00:16:39.050 --> 00:16:41.834 as a person who has a physical or
NOTE Confidence: 0.936380874666667

00:16:41.834 --> 00:16:43.480 mental impairment that substantially
NOTE Confidence: 0.936380874666667

00:16:43.480 --> 00:16:46.560 limits one or more major life activity.
NOTE Confidence: 0.936380874666667

00:16:46.560 --> 00:16:48.317 The second one comes from the CDC,
NOTE Confidence: 0.936380874666667

00:16:48.320 --> 00:16:50.215 which defines disability as any
NOTE Confidence: 0.936380874666667

00:16:50.215 --> 00:16:52.520 condition of the body or mind.
NOTE Confidence: 0.936380874666667

00:16:52.520 --> 00:16:54.314 That makes it more difficult for
NOTE Confidence: 0.936380874666667

00:16:54.314 --> 00:16:56.280 the person with the condition to
NOTE Confidence: 0.936380874666667

00:16:56.280 --> 00:16:58.060 do certain activities and interact
NOTE Confidence: 0.936380874666667

00:16:58.060 --> 00:16:59.880 with the world around them.
NOTE Confidence: 0.936380874666667

00:16:59.880 --> 00:17:01.735 So you can perhaps imagine how these
NOTE Confidence: 0.936380874666667

00:17:01.735 --> 00:17:03.719 definitions have an element of subjectivity,
NOTE Confidence: 0.936380874666667

00:17:03.720 --> 00:17:07.536 but also that they focus on biological and
NOTE Confidence: 0.936380874666667

00:17:07.536 --> 00:17:09.640 physical characteristics of individuals.

NOTE Confidence: 0.9553487
00:17:14.510 --> 00:17:17.060 The Who published an international
NOTE Confidence: 0.9553487
00:17:17.060 --> 00:17:18.590 classification of functioning,
NOTE Confidence: 0.9553487
00:17:18.590 --> 00:17:20.744 disability and Health to give some
NOTE Confidence: 0.9553487
00:17:20.744 --> 00:17:23.030 help to the concepts of function,
NOTE Confidence: 0.9553487
00:17:23.030 --> 00:17:25.238 activity and participation levels,
NOTE Confidence: 0.9553487
00:17:25.238 --> 00:17:28.550 and perhaps to reduce some subjectivity.
NOTE Confidence: 0.9553487
00:17:28.550 --> 00:17:29.652 More importantly,
NOTE Confidence: 0.9553487
00:17:29.652 --> 00:17:32.407 the ICF implicitly acknowledges the
NOTE Confidence: 0.9553487
00:17:32.407 --> 00:17:35.316 role of environmental conditions in
NOTE Confidence: 0.9553487
00:17:35.316 --> 00:17:38.286 essentially creating disability by raising
NOTE Confidence: 0.9553487
00:17:38.286 --> 00:17:41.366 barriers to activity and participation.
NOTE Confidence: 0.9553487
00:17:41.370 --> 00:17:42.682 Thus, it acknowledges that
NOTE Confidence: 0.9553487
00:17:42.682 --> 00:17:44.650 disability is not just a biological
NOTE Confidence: 0.9553487
00:17:44.712 --> 00:17:46.408 characteristic of an individual,
NOTE Confidence: 0.9553487
00:17:46.410 --> 00:17:48.165 but includes a component of
NOTE Confidence: 0.9553487

00:17:48.165 --> 00:17:49.569 interaction with the environment,
NOTE Confidence: 0.9553487

00:17:49.570 --> 00:17:51.298 an idea that is central to
NOTE Confidence: 0.9553487

00:17:51.298 --> 00:17:52.162 the disability critique.
NOTE Confidence: 0.922523846666667

00:17:58.210 --> 00:17:59.678 So because biomedical researchers
NOTE Confidence: 0.922523846666667

00:17:59.678 --> 00:18:01.880 play a big role in defining
NOTE Confidence: 0.922523846666667

00:18:01.943 --> 00:18:04.168 categories of disability and disease,
NOTE Confidence: 0.922523846666667

00:18:04.170 --> 00:18:05.882 and because these definitions
NOTE Confidence: 0.922523846666667

00:18:05.882 --> 00:18:08.487 are value laden, it's the job.
NOTE Confidence: 0.922523846666667

00:18:08.487 --> 00:18:10.682 Of researchers and bioethicists as
NOTE Confidence: 0.922523846666667

00:18:10.682 --> 00:18:13.619 well to take a thoughtful approach
NOTE Confidence: 0.922523846666667

00:18:13.619 --> 00:18:16.583 and guard against and combat ableism
NOTE Confidence: 0.922523846666667

00:18:16.664 --> 00:18:18.939 in the act of classification.
NOTE Confidence: 0.922523846666667

00:18:18.940 --> 00:18:20.664 Ableism is discrimination against
NOTE Confidence: 0.922523846666667

00:18:20.664 --> 00:18:23.250 and stereotyping of whole groups of
NOTE Confidence: 0.922523846666667

00:18:23.315 --> 00:18:25.345 people based on incorrect assumptions
NOTE Confidence: 0.922523846666667

00:18:25.345 --> 00:18:27.877 that people with typical or normal

NOTE Confidence: 0.922523846666667

00:18:27.877 --> 00:18:30.499 abilities are superior to those with

NOTE Confidence: 0.922523846666667

00:18:30.499 --> 00:18:32.650 disabilities and that the disabled state

NOTE Confidence: 0.922523846666667

00:18:32.650 --> 00:18:34.940 is undesirable and something to be fixed.

NOTE Confidence: 0.951754628571429

00:18:37.440 --> 00:18:38.952 Unfortunately, ableist tendencies

NOTE Confidence: 0.951754628571429

00:18:38.952 --> 00:18:41.472 are deeply embedded in our

NOTE Confidence: 0.951754628571429

00:18:41.472 --> 00:18:43.878 society and in science as well.

NOTE Confidence: 0.951754628571429

00:18:43.880 --> 00:18:46.036 Most of you have heard about the

NOTE Confidence: 0.944726222222222

00:18:48.160 --> 00:18:50.825 \$1927.00 versus Bell decision by

NOTE Confidence: 0.944726222222222

00:18:50.825 --> 00:18:54.067 the US Supreme Court in which the

NOTE Confidence: 0.944726222222222

00:18:54.067 --> 00:18:56.281 court upheld a Virginia statute that

NOTE Confidence: 0.944726222222222

00:18:56.281 --> 00:18:58.533 provided for the sterilization for

NOTE Confidence: 0.944726222222222

00:18:58.533 --> 00:19:00.345 of people considered genetically

NOTE Confidence: 0.944726222222222

00:19:00.345 --> 00:19:03.536 unfit and paved the way for laws.

NOTE Confidence: 0.944726222222222

00:19:03.540 --> 00:19:06.036 That were similar to that in 30 States

NOTE Confidence: 0.944726222222222

00:19:06.036 --> 00:19:08.086 and leading to an estimated 65,000

NOTE Confidence: 0.944726222222222

00:19:08.086 --> 00:19:10.216 Americans being sterilized without consent.

NOTE Confidence: 0.93883274

00:19:12.300 --> 00:19:14.260 It's the categorization of Carrie

NOTE Confidence: 0.93883274

00:19:14.260 --> 00:19:16.220 Buck as being genetically unfit

NOTE Confidence: 0.9301349325

00:19:18.340 --> 00:19:20.865 based on being labeled as

NOTE Confidence: 0.9301349325

00:19:20.865 --> 00:19:22.380 feebleminded and promiscuous

NOTE Confidence: 0.9402536

00:19:24.420 --> 00:19:26.940 that was central to this case,

NOTE Confidence: 0.9402536

00:19:26.940 --> 00:19:29.160 and this alleged promiscuity

NOTE Confidence: 0.9402536

00:19:29.160 --> 00:19:32.130 led her to having a child.

NOTE Confidence: 0.9402536

00:19:32.130 --> 00:19:34.380 And then the famous quote 3

NOTE Confidence: 0.9402536

00:19:34.380 --> 00:19:36.750 generations of imbeciles are enough.

NOTE Confidence: 0.954789558888889

00:19:38.830 --> 00:19:41.950 However, there was no evidence for

NOTE Confidence: 0.954789558888889

00:19:41.950 --> 00:19:43.510 this family's feeblemindedness.

NOTE Confidence: 0.954789558888889

00:19:43.510 --> 00:19:45.442 Carrie Buck was known to be an

NOTE Confidence: 0.954789558888889

00:19:45.442 --> 00:19:47.189 avid reader of the newspaper,

NOTE Confidence: 0.954789558888889

00:19:47.190 --> 00:19:49.311 and her school record in fact indicated

NOTE Confidence: 0.954789558888889

00:19:49.311 --> 00:19:51.269 that she was not feebleminded.

NOTE Confidence: 0.954789558888889
00:19:51.270 --> 00:19:53.110 Carrie's daughter Vivian was at
NOTE Confidence: 0.954789558888889
00:19:53.110 --> 00:19:54.950 worst A/B student in school,
NOTE Confidence: 0.954789558888889
00:19:54.950 --> 00:19:57.390 and even on the honor roll one year
NOTE Confidence: 0.954789558888889
00:19:57.390 --> 00:20:00.390 Carrie's socalled promiscuity was actually.
NOTE Confidence: 0.954789558888889
00:20:00.390 --> 00:20:02.565 The relabeling of her rape
NOTE Confidence: 0.954789558888889
00:20:02.565 --> 00:20:03.870 by Clarence Garland,
NOTE Confidence: 0.954789558888889
00:20:03.870 --> 00:20:06.666 a relative of her foster parents,
NOTE Confidence: 0.954789558888889
00:20:06.670 --> 00:20:07.633 however, Harry Laughlin,
NOTE Confidence: 0.954789558888889
00:20:07.633 --> 00:20:09.559 director of the Eugenics Record office
NOTE Confidence: 0.954789558888889
00:20:09.559 --> 00:20:11.390 at Cold Spring Harbor Laboratory,
NOTE Confidence: 0.954789558888889
00:20:11.390 --> 00:20:13.230 was the scientific expert who
NOTE Confidence: 0.954789558888889
00:20:13.230 --> 00:20:15.070 nonetheless opined that Carrie Buck
NOTE Confidence: 0.954789558888889
00:20:15.128 --> 00:20:17.060 should be sterilized based on the
NOTE Confidence: 0.954789558888889
00:20:17.060 --> 00:20:19.150 assessment that she was feebleminded.
NOTE Confidence: 0.954789558888889
00:20:19.150 --> 00:20:21.270 Those categorizations that were key
NOTE Confidence: 0.954789558888889

00:20:21.270 --> 00:20:23.390 to allowing infringement of critical

NOTE Confidence: 0.954789558888889

00:20:23.458 --> 00:20:25.110 individual rights and liberties

NOTE Confidence: 0.954789558888889

00:20:25.110 --> 00:20:27.175 were absolutely not evidence based

NOTE Confidence: 0.954789558888889

00:20:27.175 --> 00:20:29.773 and were but were protected by a

NOTE Confidence: 0.954789558888889

00:20:29.773 --> 00:20:31.189 veneer of scientific authority.

NOTE Confidence: 0.954789558888889

00:20:31.190 --> 00:20:33.255 While this Supreme Court case

NOTE Confidence: 0.954789558888889

00:20:33.255 --> 00:20:34.907 perpetrated many moral injuries,

NOTE Confidence: 0.954789558888889

00:20:34.910 --> 00:20:36.548 I think it's also an example,

NOTE Confidence: 0.954789558888889

00:20:36.550 --> 00:20:39.150 albeit perhaps an extreme example,

NOTE Confidence: 0.954789558888889

00:20:39.150 --> 00:20:40.975 of how categorization is misused

NOTE Confidence: 0.954789558888889

00:20:40.975 --> 00:20:42.070 to great harm.

NOTE Confidence: 0.939628550588235

00:20:47.990 --> 00:20:50.126 A different way that values are

NOTE Confidence: 0.939628550588235

00:20:50.126 --> 00:20:52.348 embedded in categories is in the

NOTE Confidence: 0.939628550588235

00:20:52.348 --> 00:20:54.178 terminology used to describe them.

NOTE Confidence: 0.939628550588235

00:20:54.180 --> 00:20:55.780 Efforts by disability rights

NOTE Confidence: 0.939628550588235

00:20:55.780 --> 00:20:57.780 groups and people with lived

NOTE Confidence: 0.939628550588235
00:20:57.780 --> 00:20:59.299 experience with disabilities,
NOTE Confidence: 0.939628550588235
00:20:59.300 --> 00:21:00.380 as well as their families,
NOTE Confidence: 0.939628550588235
00:21:00.380 --> 00:21:02.570 have led the way towards greater
NOTE Confidence: 0.939628550588235
00:21:02.570 --> 00:21:04.635 inclusivity of language to signal
NOTE Confidence: 0.939628550588235
00:21:04.635 --> 00:21:06.258 respect and trustworthiness.
NOTE Confidence: 0.939628550588235
00:21:06.260 --> 00:21:07.904 There's evidence that for
NOTE Confidence: 0.939628550588235
00:21:07.904 --> 00:21:09.137 those with disabilities,
NOTE Confidence: 0.939628550588235
00:21:09.140 --> 00:21:12.260 lack of inclusivity and respect are
NOTE Confidence: 0.939628550588235
00:21:12.260 --> 00:21:15.300 ongoing barriers to receiving healthcare,
NOTE Confidence: 0.939628550588235
00:21:15.300 --> 00:21:18.919 so these signals are more than symbolic.
NOTE Confidence: 0.939628550588235
00:21:18.920 --> 00:21:20.625 Some specific actions that have
NOTE Confidence: 0.939628550588235
00:21:20.625 --> 00:21:22.666 been taken include the passing of
NOTE Confidence: 0.939628550588235
00:21:22.666 --> 00:21:24.316 Rosa's law in the United States,
NOTE Confidence: 0.939628550588235
00:21:24.320 --> 00:21:26.220 which changes references to mental
NOTE Confidence: 0.939628550588235
00:21:26.220 --> 00:21:28.120 retardation of federal law to
NOTE Confidence: 0.939628550588235

00:21:28.187 --> 00:21:30.327 intellectual disability and changing
NOTE Confidence: 0.939628550588235

00:21:30.327 --> 00:21:32.436 mentally ***** to individual
NOTE Confidence: 0.939628550588235

00:21:32.436 --> 00:21:34.508 with an intellectual disability
NOTE Confidence: 0.939628550588235

00:21:34.508 --> 00:21:37.360 taking a first person approach.
NOTE Confidence: 0.939628550588235

00:21:37.360 --> 00:21:41.350 Families in the European fragile X
NOTE Confidence: 0.939628550588235

00:21:41.350 --> 00:21:43.866 network have also recently led the
NOTE Confidence: 0.939628550588235

00:21:43.866 --> 00:21:48.930 charge to rename the FM R1 gene.
NOTE Confidence: 0.939628550588235

00:21:48.930 --> 00:21:52.446 To the fragile X messenger ribonuclear
NOTE Confidence: 0.939628550588235

00:21:52.446 --> 00:21:56.410 ribonuclear protein 1 gene.
NOTE Confidence: 0.939628550588235

00:21:56.410 --> 00:21:56.702 However,
NOTE Confidence: 0.939628550588235

00:21:56.702 --> 00:21:58.746 in order to make good on the
NOTE Confidence: 0.939628550588235

00:21:58.746 --> 00:22:00.770 principles of respect and beneficence,
NOTE Confidence: 0.939628550588235

00:22:00.770 --> 00:22:03.524 it's important to look to disability
NOTE Confidence: 0.939628550588235

00:22:03.524 --> 00:22:05.785 communities to understand when and
NOTE Confidence: 0.939628550588235

00:22:05.785 --> 00:22:07.879 for whom taking the first person
NOTE Confidence: 0.939628550588235

00:22:07.879 --> 00:22:10.168 approach is or is not preferred.

NOTE Confidence: 0.939628550588235
00:22:10.170 --> 00:22:11.088 For example, many,
NOTE Confidence: 0.939628550588235
00:22:11.088 --> 00:22:12.924 but not all individuals who are
NOTE Confidence: 0.939628550588235
00:22:12.924 --> 00:22:15.037 deaf or who live with autism
NOTE Confidence: 0.939628550588235
00:22:15.037 --> 00:22:16.437 spectrum disorder prefer being
NOTE Confidence: 0.939628550588235
00:22:16.437 --> 00:22:18.130 referred to as deaf or autistic,
NOTE Confidence: 0.939628550588235
00:22:18.130 --> 00:22:19.782 symbolizing that they consider
NOTE Confidence: 0.939628550588235
00:22:19.782 --> 00:22:22.260 themselves part of a distinct cultural
NOTE Confidence: 0.939628550588235
00:22:22.320 --> 00:22:24.078 group or have a distinct identity
NOTE Confidence: 0.939628550588235
00:22:24.078 --> 00:22:26.449 on the basis of their disabilities.
NOTE Confidence: 0.939628550588235
00:22:26.450 --> 00:22:26.781 However,
NOTE Confidence: 0.939628550588235
00:22:26.781 --> 00:22:28.767 this begs the question about whether,
NOTE Confidence: 0.939628550588235
00:22:28.770 --> 00:22:29.303 when,
NOTE Confidence: 0.939628550588235
00:22:29.303 --> 00:22:31.435 and how researchers and
NOTE Confidence: 0.939628550588235
00:22:31.435 --> 00:22:33.567 clinical professionals should be
NOTE Confidence: 0.939628550588235
00:22:33.567 --> 00:22:35.990 categorizing conditions people for
NOTE Confidence: 0.939628550588235

00:22:35.990 --> 00:22:38.190 research and clinical purposes.
NOTE Confidence: 0.939628550588235

00:22:38.190 --> 00:22:40.566 And categories for new for scientific
NOTE Confidence: 0.939628550588235

00:22:40.566 --> 00:22:43.388 purse should also be used for medical,
NOTE Confidence: 0.939628550588235

00:22:43.390 --> 00:22:46.350 social policy and political purposes.
NOTE Confidence: 0.943128782857143

00:22:49.790 --> 00:22:54.270 So moving on here to another example
NOTE Confidence: 0.943128782857143

00:22:54.270 --> 00:22:57.535 of categorization of severity of
NOTE Confidence: 0.943128782857143

00:22:57.535 --> 00:22:59.510 disease, I'll show you a recent
NOTE Confidence: 0.95031692

00:23:01.830 --> 00:23:04.150 example which is the product
NOTE Confidence: 0.95031692

00:23:04.150 --> 00:23:06.006 of value based decisions.
NOTE Confidence: 0.95031692

00:23:06.010 --> 00:23:07.972 In this case, decisions made by
NOTE Confidence: 0.95031692

00:23:07.972 --> 00:23:09.709 clinicians and criticized not only
NOTE Confidence: 0.95031692

00:23:09.709 --> 00:23:11.209 for the categories themselves,
NOTE Confidence: 0.95031692

00:23:11.210 --> 00:23:13.540 but for the process by
NOTE Confidence: 0.95031692

00:23:13.540 --> 00:23:15.404 which they were generated.
NOTE Confidence: 0.95031692

00:23:15.410 --> 00:23:17.230 So in this example,
NOTE Confidence: 0.95031692

00:23:17.230 --> 00:23:21.021 I'm showing you here an article which

NOTE Confidence: 0.95031692

00:23:21.021 --> 00:23:23.649 represents guidelines for carrier

NOTE Confidence: 0.95031692

00:23:23.649 --> 00:23:27.368 genetic carrier screening issued by the

NOTE Confidence: 0.95031692

00:23:27.368 --> 00:23:30.123 American College of Medical Genetics.

NOTE Confidence: 0.95031692

00:23:30.130 --> 00:23:32.572 And these guidelines were meant to

NOTE Confidence: 0.95031692

00:23:32.572 --> 00:23:34.200 address equitable distribution of

NOTE Confidence: 0.95031692

00:23:34.263 --> 00:23:36.298 the benefits of genetic screening.

NOTE Confidence: 0.95031692

00:23:36.300 --> 00:23:37.936 These guidelines expanded the

NOTE Confidence: 0.95031692

00:23:37.936 --> 00:23:39.981 populations that were recommended to

NOTE Confidence: 0.95031692

00:23:39.981 --> 00:23:42.187 get genetic screening for conditions

NOTE Confidence: 0.95031692

00:23:42.187 --> 00:23:46.592 that are have been associated with

NOTE Confidence: 0.95031692

00:23:46.592 --> 00:23:49.780 specific population subpopulation.

NOTE Confidence: 0.95031692

00:23:49.780 --> 00:23:52.700 So prior to this update,

NOTE Confidence: 0.95031692

00:23:52.700 --> 00:23:54.188 genetic screening guidelines

NOTE Confidence: 0.95031692

00:23:54.188 --> 00:23:56.172 recommended that cystic fibrosis

NOTE Confidence: 0.95031692

00:23:56.172 --> 00:23:58.487 screening be offered to those

NOTE Confidence: 0.95031692

00:23:58.487 --> 00:24:00.376 of Northern European ancestry or
NOTE Confidence: 0.95031692

00:24:00.376 --> 00:24:02.156 sickle cell disease be offered
NOTE Confidence: 0.95031692

00:24:02.156 --> 00:24:04.260 to those of African ancestry,
NOTE Confidence: 0.95031692

00:24:04.260 --> 00:24:05.104 for example.
NOTE Confidence: 0.95031692

00:24:05.104 --> 00:24:07.636 So the update recognized that these
NOTE Confidence: 0.95031692

00:24:07.636 --> 00:24:09.211 populations are not accurately
NOTE Confidence: 0.95031692

00:24:09.211 --> 00:24:11.521 respective of who is likely to be
NOTE Confidence: 0.95031692

00:24:11.521 --> 00:24:14.028 a carrier of the associated genes,
NOTE Confidence: 0.95031692

00:24:14.030 --> 00:24:16.214 so the recommendations were no longer
NOTE Confidence: 0.95031692

00:24:16.214 --> 00:24:17.670 limited to specific populations,
NOTE Confidence: 0.935836339411765

00:24:20.070 --> 00:24:21.108 however well-intentioned,
NOTE Confidence: 0.935836339411765

00:24:21.108 --> 00:24:23.184 these guidelines were criticized
NOTE Confidence: 0.935836339411765

00:24:23.184 --> 00:24:26.243 in part because of how categories
NOTE Confidence: 0.935836339411765

00:24:26.243 --> 00:24:28.055 of disease severity were
NOTE Confidence: 0.935836339411765

00:24:28.055 --> 00:24:30.598 defined in these guidelines.
NOTE Confidence: 0.935836339411765

00:24:30.600 --> 00:24:32.838 Disease severity is typically a key

NOTE Confidence: 0.935836339411765

00:24:32.838 --> 00:24:35.599 factor in public health screening criteria,

NOTE Confidence: 0.935836339411765

00:24:35.600 --> 00:24:38.000 as well as disease prevalence,

NOTE Confidence: 0.935836339411765

00:24:38.000 --> 00:24:39.096 analytic validity,

NOTE Confidence: 0.935836339411765

00:24:39.096 --> 00:24:41.288 availability of treatment for

NOTE Confidence: 0.935836339411765

00:24:41.288 --> 00:24:43.480 diagnostic or reproductive options.

NOTE Confidence: 0.942540736363636

00:24:47.160 --> 00:24:49.712 You can see some of the categories of

NOTE Confidence: 0.942540736363636

00:24:49.712 --> 00:24:51.569 disease severity used in these guidelines

NOTE Confidence: 0.942540736363636

00:24:51.569 --> 00:24:54.080 on the right side of the screen here,

NOTE Confidence: 0.942540736363636

00:24:54.080 --> 00:24:57.312 including categories called profound,

NOTE Confidence: 0.942540736363636

00:24:57.312 --> 00:25:00.910 severe, and moderate.

NOTE Confidence: 0.942540736363636

00:25:00.910 --> 00:25:02.830 In a blog late last year,

NOTE Confidence: 0.942540736363636

00:25:02.830 --> 00:25:05.455 the genetic counselors Katie Stoll

NOTE Confidence: 0.942540736363636

00:25:05.455 --> 00:25:08.080 and Robert Resta highlighted the

NOTE Confidence: 0.942540736363636

00:25:08.159 --> 00:25:10.852 categories of disease severity and

NOTE Confidence: 0.942540736363636

00:25:10.852 --> 00:25:12.562 noted that it's concerning that

NOTE Confidence: 0.942540736363636

00:25:12.562 --> 00:25:14.363 the study puts conditions that
NOTE Confidence: 0.942540736363636

00:25:14.363 --> 00:25:15.843 are associated with intellectual
NOTE Confidence: 0.942540736363636

00:25:15.843 --> 00:25:18.060 disability in the same group as
NOTE Confidence: 0.942540736363636

00:25:18.060 --> 00:25:19.878 those that are associated with death
NOTE Confidence: 0.942540736363636

00:25:19.878 --> 00:25:21.756 and infancy or early childhood.
NOTE Confidence: 0.942540736363636

00:25:21.756 --> 00:25:25.137 Also, if we look across the lifespan.
NOTE Confidence: 0.942540736363636

00:25:25.140 --> 00:25:28.228 Many if not most of us will experience
NOTE Confidence: 0.942540736363636

00:25:28.228 --> 00:25:30.596 some features that could be counted
NOTE Confidence: 0.942540736363636

00:25:30.596 --> 00:25:33.540 in the severe and or moderate buckets.
NOTE Confidence: 0.942540736363636

00:25:33.540 --> 00:25:34.398 So importantly,
NOTE Confidence: 0.942540736363636

00:25:34.398 --> 00:25:37.401 stolen Resta went on to critique how
NOTE Confidence: 0.942540736363636

00:25:37.401 --> 00:25:40.020 the categories of disease severity
NOTE Confidence: 0.942540736363636

00:25:40.020 --> 00:25:43.054 were just were actually derived being
NOTE Confidence: 0.942540736363636

00:25:43.054 --> 00:25:45.812 based on a single limited survey of
NOTE Confidence: 0.942540736363636

00:25:45.812 --> 00:25:47.832 healthcare providers that was conducted
NOTE Confidence: 0.942540736363636

00:25:47.832 --> 00:25:49.777 by the company called Council,

NOTE Confidence: 0.942540736363636
00:25:49.780 --> 00:25:52.725 now called Myriad Genetics because
NOTE Confidence: 0.942540736363636
00:25:52.725 --> 00:25:55.670 they were bought by Myriad.
NOTE Confidence: 0.942540736363636
00:25:55.670 --> 00:25:59.534 And this survey was limited to 192
NOTE Confidence: 0.942540736363636
00:25:59.534 --> 00:26:01.550 genetic counselors and physicians,
NOTE Confidence: 0.942540736363636
00:26:01.550 --> 00:26:03.811 and did not include those with lived
NOTE Confidence: 0.942540736363636
00:26:03.811 --> 00:26:05.222 experience with the conditions
NOTE Confidence: 0.942540736363636
00:26:05.222 --> 00:26:07.270 included on the ACMG panel.
NOTE Confidence: 0.9508201065
00:26:12.510 --> 00:26:14.855 So let's look at some recent examples
NOTE Confidence: 0.9508201065
00:26:14.855 --> 00:26:16.858 of changes to language describing
NOTE Confidence: 0.9508201065
00:26:16.858 --> 00:26:19.654 categories of sex and gender in
NOTE Confidence: 0.9508201065
00:26:19.654 --> 00:26:22.291 clinical documents, such as laboratory
NOTE Confidence: 0.9508201065
00:26:22.291 --> 00:26:24.559 requisition forms and reports.
NOTE Confidence: 0.9508201065
00:26:24.560 --> 00:26:26.804 Part of the rationale for these
NOTE Confidence: 0.9508201065
00:26:26.804 --> 00:26:28.792 suggested changes in language is
NOTE Confidence: 0.9508201065
00:26:28.792 --> 00:26:30.937 that the pathologization of these
NOTE Confidence: 0.9508201065

00:26:30.937 --> 00:26:32.653 characteristics and identities of
NOTE Confidence: 0.9508201065

00:26:32.717 --> 00:26:34.679 these groups adds to the stigma,
NOTE Confidence: 0.9508201065

00:26:34.680 --> 00:26:35.728 harassment, violence,
NOTE Confidence: 0.9508201065

00:26:35.728 --> 00:26:37.300 and healthcare inequities
NOTE Confidence: 0.9508201065

00:26:37.300 --> 00:26:39.396 these groups already face.
NOTE Confidence: 0.9508201065

00:26:39.400 --> 00:26:40.940 With very poor health outcomes
NOTE Confidence: 0.9508201065

00:26:40.940 --> 00:26:43.493 and leads to lack of trust in the
NOTE Confidence: 0.9508201065

00:26:43.493 --> 00:26:45.078 healthcare system as a whole.
NOTE Confidence: 0.91961395

00:26:47.360 --> 00:26:49.360 These changes to category names
NOTE Confidence: 0.91961395

00:26:49.360 --> 00:26:51.360 represent a major shift that's.
NOTE Confidence: 0.91961395

00:26:51.360 --> 00:26:53.484 Can signal respect for gender and
NOTE Confidence: 0.91961395

00:26:53.484 --> 00:26:56.191 sex and sex minority communities and
NOTE Confidence: 0.91961395

00:26:56.191 --> 00:26:58.639 trustworthiness of healthcare providers,
NOTE Confidence: 0.91961395

00:26:58.640 --> 00:27:00.854 but more work needs to be done to fully
NOTE Confidence: 0.91961395

00:27:00.854 --> 00:27:03.099 and adopt inclusive language throughout
NOTE Confidence: 0.91961395

00:27:03.099 --> 00:27:05.519 the research and healthcare enterprises.

NOTE Confidence: 0.960033493793103
00:27:11.240 --> 00:27:13.012 Other medical professional groups
NOTE Confidence: 0.960033493793103
00:27:13.012 --> 00:27:15.227 working with patient advocates have
NOTE Confidence: 0.960033493793103
00:27:15.227 --> 00:27:17.409 also instituted changes to language
NOTE Confidence: 0.960033493793103
00:27:17.409 --> 00:27:19.504 describing sex and gender minorities
NOTE Confidence: 0.960033493793103
00:27:19.504 --> 00:27:21.822 to make categorization more expansive
NOTE Confidence: 0.960033493793103
00:27:21.822 --> 00:27:24.117 and more inclusive of differences.
NOTE Confidence: 0.960033493793103
00:27:24.120 --> 00:27:26.275 In particular, terms that imply
NOTE Confidence: 0.960033493793103
00:27:26.275 --> 00:27:27.999 that only cisgendered individuals
NOTE Confidence: 0.960033493793103
00:27:27.999 --> 00:27:30.246 are normal while others are
NOTE Confidence: 0.960033493793103
00:27:30.246 --> 00:27:31.994 abnormal have been discontinued.
NOTE Confidence: 0.960033493793103
00:27:32.000 --> 00:27:35.080 Again, this inclusivity is not just symbolic.
NOTE Confidence: 0.960033493793103
00:27:35.080 --> 00:27:38.008 It facilitates the collection of clinically
NOTE Confidence: 0.960033493793103
00:27:38.008 --> 00:27:40.360 relevant biological and social data,
NOTE Confidence: 0.960033493793103
00:27:40.360 --> 00:27:42.480 as well as signaling respect,
NOTE Confidence: 0.960033493793103
00:27:42.480 --> 00:27:44.106 trustworthiness and affirmation
NOTE Confidence: 0.960033493793103

00:27:44.106 --> 00:27:46.274 of a diverse identity,
NOTE Confidence: 0.960033493793103

00:27:46.280 --> 00:27:49.292 and conclude to increase clinic visits
NOTE Confidence: 0.960033493793103

00:27:49.292 --> 00:27:53.830 and seeking access to care according to.
NOTE Confidence: 0.960033493793103

00:27:53.830 --> 00:27:55.550 A large number of empirical
NOTE Confidence: 0.960033493793103

00:27:55.550 --> 00:27:57.270 studies that have documented this.
NOTE Confidence: 0.96138674

00:28:01.510 --> 00:28:03.410 There's another example from the
NOTE Confidence: 0.96138674

00:28:03.410 --> 00:28:05.310 National Society of Genetic Counselors,
NOTE Confidence: 0.96138674

00:28:05.310 --> 00:28:08.322 which last year changed its standardized
NOTE Confidence: 0.96138674

00:28:08.322 --> 00:28:10.330 pedigree nomenclature in response
NOTE Confidence: 0.96138674

00:28:10.406 --> 00:28:13.017 to quote a growing awareness of the
NOTE Confidence: 0.96138674

00:28:13.017 --> 00:28:15.228 nonbinary nature of sex and gender,
NOTE Confidence: 0.96138674

00:28:15.230 --> 00:28:18.303 as well as respect for the importance
NOTE Confidence: 0.96138674

00:28:18.303 --> 00:28:21.324 in clinical settings of a person's
NOTE Confidence: 0.96138674

00:28:21.324 --> 00:28:23.488 selfidentified gender and sexuality.
NOTE Confidence: 0.96138674

00:28:23.490 --> 00:28:27.228 And this this article explicitly cites
NOTE Confidence: 0.96138674

00:28:27.228 --> 00:28:30.944 evidence linking patients access to health

NOTE Confidence: 0.96138674

00:28:30.944 --> 00:28:33.764 records with better health outcome.

NOTE Confidence: 0.96138674

00:28:33.770 --> 00:28:35.528 You can see in this diagram.

NOTE Confidence: 0.96138674

00:28:35.530 --> 00:28:37.050 Or maybe, maybe you can't,

NOTE Confidence: 0.96138674

00:28:37.050 --> 00:28:39.930 but I hope you can see that there are

NOTE Confidence: 0.96138674

00:28:39.930 --> 00:28:42.315 there's some new nomenclature symbols

NOTE Confidence: 0.96138674

00:28:42.315 --> 00:28:45.539 which now includes a diamond shaped symbol

NOTE Confidence: 0.96138674

00:28:45.539 --> 00:28:48.806 at the bottom row there in addition to

NOTE Confidence: 0.96138674

00:28:48.806 --> 00:28:51.518 the previously used squares and circles.

NOTE Confidence: 0.96138674

00:28:51.520 --> 00:28:53.680 And note that symbols represent

NOTE Confidence: 0.96138674

00:28:53.680 --> 00:28:55.840 gender identity as opposed to

NOTE Confidence: 0.96138674

00:28:55.914 --> 00:28:58.039 phenotypic gender and not sex.

NOTE Confidence: 0.96138674

00:28:58.040 --> 00:29:00.590 The nomenclature also relies heavily on

NOTE Confidence: 0.96138674

00:29:00.590 --> 00:29:03.279 annotation to add details of chromosome,

NOTE Confidence: 0.96138674

00:29:03.280 --> 00:29:05.060 complement and family relationships

NOTE Confidence: 0.96138674

00:29:05.060 --> 00:29:07.285 that are relevant to clinical

NOTE Confidence: 0.96138674

00:29:07.285 --> 00:29:08.680 interpretation of the pedigree,
NOTE Confidence: 0.96138674

00:29:08.680 --> 00:29:11.960 such as adoption, the use of donor gametes,
NOTE Confidence: 0.96138674

00:29:11.960 --> 00:29:13.720 or gender affirming surgeries.
NOTE Confidence: 0.9394149833333333

00:29:16.320 --> 00:29:18.258 So this represents a major shift
NOTE Confidence: 0.9394149833333333

00:29:18.258 --> 00:29:20.540 and I think a move towards.
NOTE Confidence: 0.9394149833333333

00:29:20.540 --> 00:29:23.460 Both being more respectful
NOTE Confidence: 0.9394149833333333

00:29:23.460 --> 00:29:25.476 of patients identities,
NOTE Confidence: 0.9394149833333333

00:29:25.476 --> 00:29:29.356 but also seeking to be more
NOTE Confidence: 0.9394149833333333

00:29:29.356 --> 00:29:31.258 clinically and scientifically
NOTE Confidence: 0.9394149833333333

00:29:31.258 --> 00:29:34.196 accurate in capturing data in
NOTE Confidence: 0.9394149833333333

00:29:34.196 --> 00:29:36.500 and interactions with patients.
NOTE Confidence: 0.9413717033333333

00:29:40.620 --> 00:29:42.840 So move on to categories
NOTE Confidence: 0.9413717033333333

00:29:42.840 --> 00:29:44.616 of race and ethnicity.
NOTE Confidence: 0.9413717033333333

00:29:44.620 --> 00:29:47.098 Why do we use race and ethnicity
NOTE Confidence: 0.9413717033333333

00:29:47.098 --> 00:29:48.783 as categories in biomedical
NOTE Confidence: 0.9413717033333333

00:29:48.783 --> 00:29:50.979 research and clinical care?

NOTE Confidence: 0.9413717033333333

00:29:50.980 --> 00:29:53.304 In part, it's based on the assumption

NOTE Confidence: 0.9413717033333333

00:29:53.304 --> 00:29:55.894 that people of different races or

NOTE Confidence: 0.9413717033333333

00:29:55.894 --> 00:29:57.934 ancestries have different Physiology.

NOTE Confidence: 0.9413717033333333

00:29:57.940 --> 00:30:00.180 However, this is potentially dangerous.

NOTE Confidence: 0.9413717033333333

00:30:00.180 --> 00:30:03.400 It's led to practices such as race

NOTE Confidence: 0.9413717033333333

00:30:03.400 --> 00:30:05.428 norming that I mentioned before,

NOTE Confidence: 0.9413717033333333

00:30:05.428 --> 00:30:07.780 that have been criticized because of

NOTE Confidence: 0.9413717033333333

00:30:07.852 --> 00:30:10.204 their inaccuracy and the potential to

NOTE Confidence: 0.9413717033333333

00:30:10.204 --> 00:30:12.626 lead to under diagnosis and treatment,

NOTE Confidence: 0.9413717033333333

00:30:12.626 --> 00:30:14.741 or under under treatment or

NOTE Confidence: 0.9413717033333333

00:30:14.741 --> 00:30:16.624 withholding of benefits from

NOTE Confidence: 0.9413717033333333

00:30:16.624 --> 00:30:18.259 already disadvantaged groups.

NOTE Confidence: 0.9444466833333333

00:30:20.630 --> 00:30:23.228 Another example of how this can

NOTE Confidence: 0.9444466833333333

00:30:23.228 --> 00:30:26.070 be this thinking is dangerous is

NOTE Confidence: 0.9444466833333333

00:30:26.070 --> 00:30:28.839 from the infamous study based on

NOTE Confidence: 0.9444466833333333

00:30:28.839 --> 00:30:30.475 assumptions of differences between
NOTE Confidence: 0.9444466833333333

00:30:30.475 --> 00:30:33.070 blacks and whites in their Physiology
NOTE Confidence: 0.9444466833333333

00:30:33.070 --> 00:30:35.470 of response to infectious disease,
NOTE Confidence: 0.9444466833333333

00:30:35.470 --> 00:30:37.225 which you've probably heard of
NOTE Confidence: 0.9444466833333333

00:30:37.225 --> 00:30:38.980 the socalled Tuskegee study of
NOTE Confidence: 0.9444466833333333

00:30:39.043 --> 00:30:41.110 untreated syphilis in the ***** male.
NOTE Confidence: 0.9427608656666667

00:30:48.540 --> 00:30:50.860 But I and dozens of others have argued
NOTE Confidence: 0.9427608656666667

00:30:50.860 --> 00:30:53.217 that using social categories of race and
NOTE Confidence: 0.9427608656666667

00:30:53.217 --> 00:30:55.435 ethnicity are as proxies for biological
NOTE Confidence: 0.9427608656666667

00:30:55.435 --> 00:30:57.187 characteristics such as Physiology
NOTE Confidence: 0.9427608656666667

00:30:57.187 --> 00:30:59.793 or genetics or correlates of disease,
NOTE Confidence: 0.9427608656666667

00:30:59.793 --> 00:31:01.858 is extremely inexact at best,
NOTE Confidence: 0.9427608656666667

00:31:01.860 --> 00:31:05.340 and does not comport with evidence.
NOTE Confidence: 0.9427608656666667

00:31:05.340 --> 00:31:07.500 As a very simple example,
NOTE Confidence: 0.9427608656666667

00:31:07.500 --> 00:31:09.414 clinicians are taught to think of
NOTE Confidence: 0.9427608656666667

00:31:09.414 --> 00:31:11.419 sickle cell disease as a disease

NOTE Confidence: 0.942760865666667

00:31:11.419 --> 00:31:13.089 of blacks or African Americans.

NOTE Confidence: 0.942760865666667

00:31:13.090 --> 00:31:14.770 But the highest rates of sickle cell

NOTE Confidence: 0.942760865666667

00:31:14.770 --> 00:31:16.528 disease are in some areas of Africa,

NOTE Confidence: 0.942760865666667

00:31:16.530 --> 00:31:19.370 but also include India, Sicily,

NOTE Confidence: 0.942760865666667

00:31:19.370 --> 00:31:21.074 Greece and southern Turkey.

NOTE Confidence: 0.942760865666667

00:31:21.074 --> 00:31:23.204 And on the African continent,

NOTE Confidence: 0.942760865666667

00:31:23.210 --> 00:31:25.085 the prevalence of sickle cell

NOTE Confidence: 0.942760865666667

00:31:25.085 --> 00:31:26.960 trait in specific areas ranges

NOTE Confidence: 0.942760865666667

00:31:27.026 --> 00:31:29.038 from less than 1% to 45%.

NOTE Confidence: 0.942760865666667

00:31:29.038 --> 00:31:31.408 So typological thinking can be

NOTE Confidence: 0.942760865666667

00:31:31.408 --> 00:31:33.923 very misleading when applied to

NOTE Confidence: 0.942760865666667

00:31:33.923 --> 00:31:36.448 clinical care in some situations.

NOTE Confidence: 0.94981383

00:31:41.940 --> 00:31:43.720 However, until very recently,

NOTE Confidence: 0.94981383

00:31:43.720 --> 00:31:45.500 there's been little challenge

NOTE Confidence: 0.94981383

00:31:45.500 --> 00:31:47.604 in biomedicine to the very idea

NOTE Confidence: 0.94981383

00:31:47.604 --> 00:31:49.332 of the category of race itself.
NOTE Confidence: 0.94981383

00:31:49.340 --> 00:31:52.298 For example, in its recently updated
NOTE Confidence: 0.94981383

00:31:52.300 --> 00:31:54.673 2021 guidance on the use of racial
NOTE Confidence: 0.94981383

00:31:54.673 --> 00:31:56.820 and ethnic terms in publications,
NOTE Confidence: 0.94981383

00:31:56.820 --> 00:31:59.312 JAMA recommended replacing the
NOTE Confidence: 0.94981383

00:31:59.312 --> 00:32:01.804 term Caucasian with white.
NOTE Confidence: 0.94981383

00:32:01.810 --> 00:32:04.258 Only stating that it quote is
NOTE Confidence: 0.94981383

00:32:04.258 --> 00:32:06.335 technically specific to people from
NOTE Confidence: 0.94981383

00:32:06.335 --> 00:32:08.579 the Caucasus region in Eurasia and
NOTE Confidence: 0.94981383

00:32:08.579 --> 00:32:11.319 thus should not be used except when
NOTE Confidence: 0.94981383

00:32:11.319 --> 00:32:13.641 referring to people from this region.
NOTE Confidence: 0.94981383

00:32:13.650 --> 00:32:15.720 However, the guidance does not refer
NOTE Confidence: 0.94981383

00:32:15.720 --> 00:32:18.501 to the fact that Caucasian was at one
NOTE Confidence: 0.94981383

00:32:18.501 --> 00:32:20.914 point one of two categories of humans
NOTE Confidence: 0.94981383

00:32:20.914 --> 00:32:23.114 that were and this the Caucasian
NOTE Confidence: 0.94981383

00:32:23.114 --> 00:32:25.370 group was considered white skinned and

NOTE Confidence: 0.94981383

00:32:25.439 --> 00:32:27.773 beautiful in contrast to the other

NOTE Confidence: 0.94981383

00:32:27.773 --> 00:32:30.005 category that was considered Mongolian.

NOTE Confidence: 0.94981383

00:32:30.005 --> 00:32:34.142 Who were devoid of virtue or later.

NOTE Confidence: 0.94981383

00:32:34.142 --> 00:32:36.047 Caucasian was one of five

NOTE Confidence: 0.94981383

00:32:36.047 --> 00:32:38.327 categories of human races which

NOTE Confidence: 0.94981383

00:32:38.327 --> 00:32:39.934 represented God's original creation,

NOTE Confidence: 0.94981383

00:32:39.934 --> 00:32:42.082 in contrast to the other four

NOTE Confidence: 0.94981383

00:32:42.082 --> 00:32:43.751 which were considered degenerate

NOTE Confidence: 0.94981383

00:32:43.751 --> 00:32:46.253 versions of the original human form,

NOTE Confidence: 0.92922091

00:32:53.440 --> 00:32:55.540 so also in 2021.

NOTE Confidence: 0.92922091

00:32:55.540 --> 00:32:58.964 My colleagues on the Idea Committee of

NOTE Confidence: 0.92922091

00:32:58.964 --> 00:33:00.608 the Journal of Genetics and Medicine,

NOTE Confidence: 0.92922091

00:33:00.610 --> 00:33:03.028 Kyle Brothers and Robin Bennett and

NOTE Confidence: 0.92922091

00:33:03.028 --> 00:33:04.640 I proposed principles supporting

NOTE Confidence: 0.92922091

00:33:04.699 --> 00:33:07.045 anti racism in publication of Human

NOTE Confidence: 0.92922091

00:33:07.045 --> 00:33:08.609 Genetics and Genetics research

NOTE Confidence: 0.92922091

00:33:08.610 --> 00:33:13.210 which were went a little further but

NOTE Confidence: 0.92922091

00:33:13.210 --> 00:33:15.655 beyond previous recommendations.

NOTE Confidence: 0.92922091

00:33:15.655 --> 00:33:17.915 And addressed appropriate and

NOTE Confidence: 0.92922091

00:33:17.915 --> 00:33:20.740 inappropriate uses of entire categories

NOTE Confidence: 0.92922091

00:33:20.812 --> 00:33:22.717 of race and genetic ancestry.

NOTE Confidence: 0.92922091

00:33:22.720 --> 00:33:25.447 And you can see in a couple of the

NOTE Confidence: 0.92922091

00:33:25.447 --> 00:33:27.321 principles out of the 8 principles

NOTE Confidence: 0.92922091

00:33:27.321 --> 00:33:31.400 that we described in this article

NOTE Confidence: 0.92922091

00:33:31.400 --> 00:33:34.010 that we tried to make distinctions

NOTE Confidence: 0.92922091

00:33:34.010 --> 00:33:39.380 between the use of race as a social

NOTE Confidence: 0.92922091

00:33:39.380 --> 00:33:43.200 political category and genetic

NOTE Confidence: 0.92922091

00:33:43.200 --> 00:33:46.520 ancestry as well as ethnicity.

NOTE Confidence: 0.95157486375

00:33:54.580 --> 00:33:56.890 So the recent guidance of the

NOTE Confidence: 0.95157486375

00:33:56.890 --> 00:33:58.872 national academies that I mentioned

NOTE Confidence: 0.95157486375

00:33:58.872 --> 00:34:01.296 previously on the use of population

NOTE Confidence: 0.95157486375

00:34:01.296 --> 00:34:02.720 descriptors goes even further.

NOTE Confidence: 0.95157486375

00:34:02.720 --> 00:34:03.740 It's more specific,

NOTE Confidence: 0.95157486375

00:34:03.740 --> 00:34:07.505 outlining particular types of genetic

NOTE Confidence: 0.95157486375

00:34:07.505 --> 00:34:11.340 research and where categories of race,

NOTE Confidence: 0.95157486375

00:34:11.340 --> 00:34:12.350 ethnicity, ancestry,

NOTE Confidence: 0.95157486375

00:34:12.350 --> 00:34:15.885 indigeneity or geography should not be used

NOTE Confidence: 0.95157486375

00:34:15.885 --> 00:34:18.779 because they offer no scientific benefit,

NOTE Confidence: 0.95157486375

00:34:18.780 --> 00:34:21.460 yet can cause social harm,

NOTE Confidence: 0.95157486375

00:34:21.460 --> 00:34:23.359 this report cites.

NOTE Confidence: 0.95157486375

00:34:23.359 --> 00:34:27.790 Many tones of evidence of such harm,

NOTE Confidence: 0.95157486375

00:34:27.790 --> 00:34:28.696 and so it's.

NOTE Confidence: 0.95157486375

00:34:28.696 --> 00:34:30.810 I highly recommend reading it if you

NOTE Confidence: 0.95157486375

00:34:30.879 --> 00:34:33.345 would like to use it as such a resource,

NOTE Confidence: 0.95157486375

00:34:33.350 --> 00:34:36.546 but I'll also show you some some other

NOTE Confidence: 0.95157486375

00:34:36.546 --> 00:34:39.892 examples that we had described in our

NOTE Confidence: 0.95157486375

00:34:39.892 --> 00:34:42.588 article as well as in other venues.
NOTE Confidence: 0.93622824

00:34:45.870 --> 00:34:48.894 So here is an example that shows the way
NOTE Confidence: 0.93622824

00:34:48.894 --> 00:34:51.750 that shows that the way we group people
NOTE Confidence: 0.93622824

00:34:51.750 --> 00:34:54.390 into categories shapes what we learn about
NOTE Confidence: 0.93622824

00:34:54.390 --> 00:34:56.628 the groups and potentially causes harm.
NOTE Confidence: 0.93622824

00:34:56.630 --> 00:34:59.828 In a retrospective analysis of over
NOTE Confidence: 0.93622824

00:34:59.830 --> 00:35:01.990 85,000 patients tested for COVID-19
NOTE Confidence: 0.93622824

00:35:01.990 --> 00:35:05.129 in the New York City Public Hospital
NOTE Confidence: 0.93622824

00:35:05.129 --> 00:35:07.384 system in spring of 2020,
NOTE Confidence: 0.93622824

00:35:07.390 --> 00:35:09.705 researchers analyzed COVID-19 outcomes of
NOTE Confidence: 0.93622824

00:35:09.705 --> 00:35:12.510 Asian ethnic subgroups compared to Asians.
NOTE Confidence: 0.93622824

00:35:12.510 --> 00:35:16.600 Overall, the.
NOTE Confidence: 0.93622824

00:35:16.600 --> 00:35:19.240 And other racial groups shown
NOTE Confidence: 0.93622824

00:35:19.240 --> 00:35:21.880 in in various colors here,
NOTE Confidence: 0.93622824

00:35:21.880 --> 00:35:23.848 so I'm not telling you which
NOTE Confidence: 0.93622824

00:35:23.848 --> 00:35:25.160 ones they are yet,

NOTE Confidence: 0.93622824

00:35:25.160 --> 00:35:27.452 but the researchers found that there

NOTE Confidence: 0.93622824

00:35:27.452 --> 00:35:28.980 were differences between groups

NOTE Confidence: 0.93622824

00:35:29.040 --> 00:35:30.840 of patients classified as white,

NOTE Confidence: 0.93622824

00:35:30.840 --> 00:35:32.452 black, Hispanic, and Asian.

NOTE Confidence: 0.93622824

00:35:32.452 --> 00:35:34.870 But they also found that the

NOTE Confidence: 0.93622824

00:35:34.944 --> 00:35:37.878 use of the Asian category masked

NOTE Confidence: 0.93622824

00:35:37.878 --> 00:35:39.834 important differences in mortality.

NOTE Confidence: 0.93622824

00:35:39.840 --> 00:35:42.400 So in this chart.

NOTE Confidence: 0.93622824

00:35:42.400 --> 00:35:44.521 The group that was called White is

NOTE Confidence: 0.93622824

00:35:44.521 --> 00:35:46.600 indicated here in orange on the left,

NOTE Confidence: 0.94427896

00:35:49.040 --> 00:35:53.026 showing a larger number of negative

NOTE Confidence: 0.94427896

00:35:53.026 --> 00:35:55.822 outcomes than the other groups shown

NOTE Confidence: 0.94427896

00:35:55.822 --> 00:35:58.800 in green, yellow, purple, and blue,

NOTE Confidence: 0.958703166666667

00:36:02.200 --> 00:36:06.265 and those other categories were

NOTE Confidence: 0.958703166666667

00:36:06.265 --> 00:36:10.088 representing these other other groups.

NOTE Confidence: 0.958703166666667

00:36:10.090 --> 00:36:13.234 Black, Hispanic and Asian
NOTE Confidence: 0.958703166666667

00:36:13.234 --> 00:36:16.690 in purple, respectively.
NOTE Confidence: 0.958703166666667

00:36:16.690 --> 00:36:20.538 But what's what is being shown in the
NOTE Confidence: 0.958703166666667

00:36:20.538 --> 00:36:24.071 bar that is in red is the rates of
NOTE Confidence: 0.958703166666667

00:36:24.071 --> 00:36:27.323 death in patients classified as Chinese,
NOTE Confidence: 0.958703166666667

00:36:27.330 --> 00:36:30.130 which are included in the purple bar.
NOTE Confidence: 0.958703166666667

00:36:30.130 --> 00:36:32.974 But when you separate them
NOTE Confidence: 0.958703166666667

00:36:32.974 --> 00:36:34.884 out into their own category,
NOTE Confidence: 0.958703166666667

00:36:34.890 --> 00:36:37.445 the death rates go up much higher.
NOTE Confidence: 0.913204113333333

00:36:45.590 --> 00:36:48.691 In another example, a US study of
NOTE Confidence: 0.913204113333333

00:36:48.691 --> 00:36:51.589 over 6 million patient records,
NOTE Confidence: 0.913204113333333

00:36:51.590 --> 00:36:53.270 researchers found similar differences
NOTE Confidence: 0.913204113333333

00:36:53.270 --> 00:36:55.370 between Asian subgroups and also
NOTE Confidence: 0.913204113333333

00:36:55.370 --> 00:36:56.870 between Hispanic subgroups,
NOTE Confidence: 0.913204113333333

00:36:56.870 --> 00:36:58.730 which included people who indicated
NOTE Confidence: 0.913204113333333

00:36:58.730 --> 00:37:00.590 they were of Puerto Rican,

NOTE Confidence: 0.913204113333333

00:37:00.590 --> 00:37:03.190 Mexican, Cuban, South American,

NOTE Confidence: 0.913204113333333

00:37:03.190 --> 00:37:05.790 or Central American origin.

NOTE Confidence: 0.913204113333333

00:37:05.790 --> 00:37:07.596 For example, they found that the

NOTE Confidence: 0.913204113333333

00:37:07.596 --> 00:37:09.160 prevalence of chronic liver disease

NOTE Confidence: 0.913204113333333

00:37:09.160 --> 00:37:11.008 was almost three times higher than.

NOTE Confidence: 0.913204113333333

00:37:11.010 --> 00:37:13.295 For Mexican patients compared to

NOTE Confidence: 0.913204113333333

00:37:13.295 --> 00:37:15.546 patients of Cuban ancestry, however,

NOTE Confidence: 0.913204113333333

00:37:15.546 --> 00:37:17.626 there were also significant differences

NOTE Confidence: 0.913204113333333

00:37:17.626 --> 00:37:19.717 based on whether you patients

NOTE Confidence: 0.913204113333333

00:37:19.717 --> 00:37:21.889 were US born versus foreign born.

NOTE Confidence: 0.913204113333333

00:37:21.890 --> 00:37:23.618 So cancer prevalence was twice as

NOTE Confidence: 0.913204113333333

00:37:23.618 --> 00:37:25.867 high among those who were US born than

NOTE Confidence: 0.913204113333333

00:37:25.867 --> 00:37:27.650 those who were born outside the US,

NOTE Confidence: 0.913204113333333

00:37:27.650 --> 00:37:30.650 thus confirming the immigration paradox.

NOTE Confidence: 0.913204113333333

00:37:30.650 --> 00:37:31.238 These studies,

NOTE Confidence: 0.913204113333333

00:37:31.238 --> 00:37:33.002 and many others like them suggest
NOTE Confidence: 0.913204113333333

00:37:33.002 --> 00:37:34.799 that race and ethnicity categories
NOTE Confidence: 0.913204113333333

00:37:34.799 --> 00:37:36.335 can mask health differences.
NOTE Confidence: 0.913204113333333

00:37:36.340 --> 00:37:38.220 And also indicate other variables,
NOTE Confidence: 0.913204113333333

00:37:38.220 --> 00:37:40.740 such as immigration or socioeconomic status,
NOTE Confidence: 0.913204113333333

00:37:40.740 --> 00:37:43.428 that might be more relevant but
NOTE Confidence: 0.913204113333333

00:37:43.428 --> 00:37:46.060 often not collected or analyzed.
NOTE Confidence: 0.913204113333333

00:37:46.060 --> 00:37:48.412 But does the routine routinized use
NOTE Confidence: 0.913204113333333

00:37:48.412 --> 00:37:49.980 of entrenched categories distract
NOTE Confidence: 0.913204113333333

00:37:50.046 --> 00:37:52.436 from the search for the most relevant
NOTE Confidence: 0.913204113333333

00:37:52.436 --> 00:37:54.340 category for the most relevant categories?
NOTE Confidence: 0.9201268

00:37:56.380 --> 00:37:56.500 So
NOTE Confidence: 0.950317

00:37:59.800 --> 00:38:01.876 here I'll switch to another example,
NOTE Confidence: 0.950317

00:38:01.880 --> 00:38:04.752 an old one, that shows how the entire
NOTE Confidence: 0.950317

00:38:04.752 --> 00:38:07.179 category of race is conceptually
NOTE Confidence: 0.950317

00:38:07.179 --> 00:38:09.355 bereft for scientific purposes.

NOTE Confidence: 0.950317

00:38:09.360 --> 00:38:11.430 In this case, because it's conflated

NOTE Confidence: 0.950317

00:38:11.430 --> 00:38:13.752 with ethnicity, intellectual ability,

NOTE Confidence: 0.950317

00:38:13.752 --> 00:38:16.200 and physical appearance.

NOTE Confidence: 0.950317

00:38:16.200 --> 00:38:19.985 So some of you may have may be familiar

NOTE Confidence: 0.950317

00:38:19.985 --> 00:38:23.383 with paper that was published in 1866,

NOTE Confidence: 0.950317

00:38:23.383 --> 00:38:25.555 the original paper describing

NOTE Confidence: 0.950317

00:38:25.555 --> 00:38:29.200 what is now called Down syndrome,

NOTE Confidence: 0.950317

00:38:29.200 --> 00:38:33.260 and in this paper Langdon proposed a

NOTE Confidence: 0.950317

00:38:33.260 --> 00:38:35.211 classification of the feeble-minded.

NOTE Confidence: 0.950317

00:38:35.211 --> 00:38:37.039 By arranging them around

NOTE Confidence: 0.950317

00:38:37.039 --> 00:38:38.410 various ethnic standards,

NOTE Confidence: 0.950317

00:38:38.410 --> 00:38:40.447 and that's a quote in the paper.

NOTE Confidence: 0.950317

00:38:40.450 --> 00:38:42.410 And the paper goes on to say,

NOTE Confidence: 0.950317

00:38:42.410 --> 00:38:44.748 the number of idiots who arrange themselves

NOTE Confidence: 0.950317

00:38:44.748 --> 00:38:46.687 around the Mongolian type is so great,

NOTE Confidence: 0.950317

00:38:46.690 --> 00:38:48.944 and they present such a close resemblance

NOTE Confidence: 0.950317

00:38:48.944 --> 00:38:50.890 to one another in mental power,

NOTE Confidence: 0.950317

00:38:50.890 --> 00:38:53.344 that I shall describe an idiot

NOTE Confidence: 0.950317

00:38:53.344 --> 00:38:55.770 Member of this racial division.

NOTE Confidence: 0.950317

00:38:55.770 --> 00:38:58.227 So you can see the the conflation

NOTE Confidence: 0.950317

00:38:58.227 --> 00:39:00.730 of all these different concepts

NOTE Confidence: 0.950317

00:39:00.730 --> 00:39:02.610 here in these sentences.

NOTE Confidence: 0.925594876333334

00:39:06.210 --> 00:39:08.316 In the 1950s, it was recognized

NOTE Confidence: 0.925594876333334

00:39:08.316 --> 00:39:10.146 that this inaccurate conflation of

NOTE Confidence: 0.925594876333334

00:39:10.146 --> 00:39:11.986 race with the condition associated

NOTE Confidence: 0.925594876333334

00:39:11.986 --> 00:39:13.887 with variations of cognitive and

NOTE Confidence: 0.925594876333334

00:39:13.887 --> 00:39:15.379 learning abilities was inappropriate

NOTE Confidence: 0.925594876333334

00:39:15.379 --> 00:39:18.220 and led to the replacement of the

NOTE Confidence: 0.925594876333334

00:39:18.220 --> 00:39:20.645 term ***** with Down syndrome.

NOTE Confidence: 0.925594876333334

00:39:20.650 --> 00:39:23.580 Although this terminology arose centuries

NOTE Confidence: 0.925594876333334

00:39:23.580 --> 00:39:27.686 ago and was also replaced decades ago,

NOTE Confidence: 0.925594876333334
00:39:27.690 --> 00:39:30.105 it still persists in medical
NOTE Confidence: 0.925594876333334
00:39:30.105 --> 00:39:32.520 terminology to the present day.
NOTE Confidence: 0.925594876333334
00:39:32.520 --> 00:39:35.600 My my colleague Laura du Glazio alerted
NOTE Confidence: 0.925594876333334
00:39:35.600 --> 00:39:38.080 me several months ago to the idea,
NOTE Confidence: 0.925594876333334
00:39:38.080 --> 00:39:40.582 or to the fact that a quote from the
NOTE Confidence: 0.925594876333334
00:39:40.582 --> 00:39:42.681 original Langdon down article was
NOTE Confidence: 0.925594876333334
00:39:42.681 --> 00:39:44.437 very unproblematically presented in
NOTE Confidence: 0.925594876333334
00:39:44.437 --> 00:39:46.767 the header of the entry for twice
NOTE Confidence: 0.925594876333334
00:39:46.767 --> 00:39:48.788 semi 21 in the medical textbook
NOTE Confidence: 0.925594876333334
00:39:48.788 --> 00:39:51.928 Smith's recognizable patterns of human
NOTE Confidence: 0.925594876333334
00:39:51.928 --> 00:39:53.768 malformation in last year's edition,
NOTE Confidence: 0.925594876333334
00:39:53.768 --> 00:39:55.278 which is the newest edition.
NOTE Confidence: 0.960380335
00:39:57.440 --> 00:39:58.960 However, the underlying concepts
NOTE Confidence: 0.960380335
00:39:58.960 --> 00:40:00.480 are harmful in healthcare,
NOTE Confidence: 0.960380335
00:40:00.480 --> 00:40:02.465 especially when the categories they
NOTE Confidence: 0.960380335

00:40:02.465 --> 00:40:04.450 represent are assumed to represent
NOTE Confidence: 0.960380335

00:40:04.508 --> 00:40:06.720 clinical clinically relevant groupings.
NOTE Confidence: 0.908771043913044

00:40:13.760 --> 00:40:15.317 Furthermore, the underlying
NOTE Confidence: 0.908771043913044

00:40:15.317 --> 00:40:17.912 assumption of racial typologies is
NOTE Confidence: 0.908771043913044

00:40:17.912 --> 00:40:20.801 delineating pure or distinct and non
NOTE Confidence: 0.908771043913044

00:40:20.801 --> 00:40:23.031 overlapping groups also causes both
NOTE Confidence: 0.908771043913044

00:40:23.031 --> 00:40:24.799 scientific and ethical damage.
NOTE Confidence: 0.908771043913044

00:40:24.800 --> 00:40:27.170 In this article, the authors call
NOTE Confidence: 0.908771043913044

00:40:27.170 --> 00:40:29.720 out the category of multiracial.
NOTE Confidence: 0.908771043913044

00:40:29.720 --> 00:40:32.020 Being used as the justification
NOTE Confidence: 0.908771043913044

00:40:32.020 --> 00:40:34.238 for removing data relevant to
NOTE Confidence: 0.908771043913044

00:40:34.238 --> 00:40:36.752 those individuals in the name of
NOTE Confidence: 0.908771043913044

00:40:36.752 --> 00:40:38.640 quality control in a database,
NOTE Confidence: 0.908771043913044

00:40:38.640 --> 00:40:41.120 which is a common practice.
NOTE Confidence: 0.908771043913044

00:40:41.120 --> 00:40:43.280 This does unnecessarily unnecessary
NOTE Confidence: 0.908771043913044

00:40:43.280 --> 00:40:45.980 violence to both the scientific

NOTE Confidence: 0.908771043913044

00:40:45.980 --> 00:40:49.496 analysis and as well leaves out a

NOTE Confidence: 0.908771043913044

00:40:49.496 --> 00:40:51.480 growing population from research.

NOTE Confidence: 0.95836782

00:40:57.480 --> 00:41:01.250 So how should biomedical researchers?

NOTE Confidence: 0.95836782

00:41:01.250 --> 00:41:03.556 And clinicians be more inclusive, respectful,

NOTE Confidence: 0.95836782

00:41:03.556 --> 00:41:06.112 and accurate in their description and

NOTE Confidence: 0.95836782

00:41:06.112 --> 00:41:08.090 categorization of human difference.

NOTE Confidence: 0.95836782

00:41:08.090 --> 00:41:10.010 There are many ongoing efforts,

NOTE Confidence: 0.95836782

00:41:10.010 --> 00:41:11.970 many of which I've mentioned here today,

NOTE Confidence: 0.96239308

00:41:15.450 --> 00:41:18.690 with specific recommendations on language

NOTE Confidence: 0.96239308

00:41:18.690 --> 00:41:21.450 study design and reporting in journals,

NOTE Confidence: 0.96239308

00:41:21.450 --> 00:41:24.130 but also on considerations for

NOTE Confidence: 0.96239308

00:41:24.130 --> 00:41:26.822 data collection and analysis.

NOTE Confidence: 0.96239308

00:41:26.822 --> 00:41:29.978 I shows some of the recent.

NOTE Confidence: 0.96239308

00:41:29.978 --> 00:41:31.786 Guidelines and resources here.

NOTE Confidence: 0.96239308

00:41:31.790 --> 00:41:34.670 A common theme in these recommendations

NOTE Confidence: 0.96239308

00:41:34.670 --> 00:41:36.506 about race and ethnicity is that
NOTE Confidence: 0.96239308

00:41:36.506 --> 00:41:38.872 it should be not it should not
NOTE Confidence: 0.96239308

00:41:38.872 --> 00:41:40.667 be used as biological variables,
NOTE Confidence: 0.96239308

00:41:40.670 --> 00:41:44.110 but only as social variables, and that
NOTE Confidence: 0.95635504

00:41:46.150 --> 00:41:49.510 how race and ethnicity are ascertained
NOTE Confidence: 0.95635504

00:41:49.510 --> 00:41:51.750 should be accurately reported.
NOTE Confidence: 0.95635504

00:41:51.750 --> 00:41:54.216 Importantly, why race and ethnicity is
NOTE Confidence: 0.95635504

00:41:54.216 --> 00:41:56.486 used should be carefully considered
NOTE Confidence: 0.95635504

00:41:56.486 --> 00:41:58.730 rather than done unquestionably.
NOTE Confidence: 0.95635504

00:41:58.730 --> 00:42:00.938 You know, whether they or other
NOTE Confidence: 0.95635504

00:42:00.938 --> 00:42:02.410 variables such as education,
NOTE Confidence: 0.95635504

00:42:02.410 --> 00:42:04.374 economic status or environmental
NOTE Confidence: 0.95635504

00:42:04.374 --> 00:42:07.320 factors are actually the most important
NOTE Confidence: 0.95635504

00:42:07.388 --> 00:42:09.568 to answering the study question.
NOTE Confidence: 0.95635504

00:42:09.570 --> 00:42:13.134 The National Academies report also talks
NOTE Confidence: 0.95635504

00:42:13.134 --> 00:42:15.707 about transparency and reproducibility.

NOTE Confidence: 0.95635504

00:42:15.707 --> 00:42:19.002 However, I also believe that

NOTE Confidence: 0.95635504

00:42:19.002 --> 00:42:22.047 bioethicists have a role to play here,

NOTE Confidence: 0.95635504

00:42:22.050 --> 00:42:25.658 as well as scientists.

NOTE Confidence: 0.95635504

00:42:25.660 --> 00:42:27.910 The report also places responsibility

NOTE Confidence: 0.95635504

00:42:27.910 --> 00:42:30.160 on research institutions and recommends

NOTE Confidence: 0.95635504

00:42:30.221 --> 00:42:32.429 that they offer tools such as

NOTE Confidence: 0.95635504

00:42:32.429 --> 00:42:34.388 educational modules for inclusion in

NOTE Confidence: 0.95635504

00:42:34.388 --> 00:42:36.468 human research protection, training,

NOTE Confidence: 0.95635504

00:42:36.468 --> 00:42:39.700 education and fostering interdisciplinary

NOTE Confidence: 0.95635504

00:42:39.700 --> 00:42:42.932 collaborations between scientists and,

NOTE Confidence: 0.95635504

00:42:42.940 --> 00:42:45.739 for example, sociologists,

NOTE Confidence: 0.95635504

00:42:45.740 --> 00:42:47.348 anthropologists and others,

NOTE Confidence: 0.95635504

00:42:47.348 --> 00:42:50.028 and for and with facilitating

NOTE Confidence: 0.95635504

00:42:50.028 --> 00:42:51.100 community engagement,

NOTE Confidence: 0.95635504

00:42:51.100 --> 00:42:52.099 among other things.

NOTE Confidence: 0.939338681818182

00:42:54.660 --> 00:42:57.586 So I'll show I have some slides
NOTE Confidence: 0.939338681818182

00:42:57.586 --> 00:43:03.060 here which have other resources for
NOTE Confidence: 0.939338681818182

00:43:03.060 --> 00:43:06.740 recommendations on more inclusive
NOTE Confidence: 0.939338681818182

00:43:06.740 --> 00:43:09.736 language here based on sex and gender
NOTE Confidence: 0.86267414

00:43:12.380 --> 00:43:16.220 and on the next slide for disability.
NOTE Confidence: 0.936899076666667

00:43:23.550 --> 00:43:26.950 So I'll just finish here
NOTE Confidence: 0.936899076666667

00:43:26.950 --> 00:43:29.148 by raising some questions.
NOTE Confidence: 0.9402536

00:43:31.940 --> 00:43:34.276 And to say that to make our research
NOTE Confidence: 0.9402536

00:43:34.276 --> 00:43:36.342 more diverse, equitable and inclusive,
NOTE Confidence: 0.9402536

00:43:36.342 --> 00:43:38.812 these are questions that researchers
NOTE Confidence: 0.9402536

00:43:38.812 --> 00:43:41.428 and clinicians should ask about how
NOTE Confidence: 0.9402536

00:43:41.428 --> 00:43:43.378 we are defining human difference.
NOTE Confidence: 0.9402536

00:43:43.380 --> 00:43:45.697 So what is the evidence that racial,
NOTE Confidence: 0.9402536

00:43:45.700 --> 00:43:46.942 ethnic, sex, gender,
NOTE Confidence: 0.9402536

00:43:46.942 --> 00:43:49.012 or other differences are essential
NOTE Confidence: 0.9402536

00:43:49.012 --> 00:43:51.395 to the research question and

NOTE Confidence: 0.9402536

00:43:51.395 --> 00:43:53.379 relevant to clinical practice?

NOTE Confidence: 0.9402536

00:43:53.380 --> 00:43:55.708 And are there other types of

NOTE Confidence: 0.9402536

00:43:55.708 --> 00:43:57.920 difference that are being overlooked?

NOTE Confidence: 0.9402536

00:43:57.920 --> 00:44:00.650 What's the evidence that the differences

NOTE Confidence: 0.9402536

00:44:00.720 --> 00:44:03.370 are accurately measured or ascertained?

NOTE Confidence: 0.9402536

00:44:03.370 --> 00:44:06.232 Is the validity of the classification

NOTE Confidence: 0.9402536

00:44:06.232 --> 00:44:09.089 systems based on assumptions or evidence?

NOTE Confidence: 0.9402536

00:44:09.090 --> 00:44:11.610 Are the category labels respective,

NOTE Confidence: 0.9402536

00:44:11.610 --> 00:44:14.250 respectful, accurate, and derived

NOTE Confidence: 0.9402536

00:44:14.250 --> 00:44:18.210 from or reflective of community input?

NOTE Confidence: 0.9402536

00:44:18.210 --> 00:44:20.055 However, to the extent that

NOTE Confidence: 0.9402536

00:44:20.055 --> 00:44:21.900 categorization and language should be

NOTE Confidence: 0.9402536

00:44:21.956 --> 00:44:24.170 based on ethical principles of respect,

NOTE Confidence: 0.9402536

00:44:24.170 --> 00:44:25.835 beneficence, and justice.

NOTE Confidence: 0.9402536

00:44:25.835 --> 00:44:29.720 I submit that these are also questions

NOTE Confidence: 0.9402536

00:44:29.814 --> 00:44:32.940 for the bioethics community as well.
NOTE Confidence: 0.9402536

00:44:32.940 --> 00:44:36.374 I'll just leave you with a quote
NOTE Confidence: 0.9402536

00:44:36.374 --> 00:44:39.836 from Paul Starr which I thought
NOTE Confidence: 0.9402536

00:44:39.836 --> 00:44:41.500 was relevant to this
NOTE Confidence: 0.938576325

00:44:43.540 --> 00:44:49.498 and it's from it's from some
NOTE Confidence: 0.938576325

00:44:49.500 --> 00:44:55.340 writings that he he in which he.
NOTE Confidence: 0.938576325

00:44:55.340 --> 00:44:57.980 Put forth the concept of cultural
NOTE Confidence: 0.938576325

00:44:57.980 --> 00:45:01.700 authority and talk and spoke about
NOTE Confidence: 0.938576325

00:45:01.700 --> 00:45:06.296 how clinicians can use this cultural,
NOTE Confidence: 0.938576325

00:45:06.300 --> 00:45:07.188 cultural authority.
NOTE Confidence: 0.938576325

00:45:07.188 --> 00:45:10.296 And he says here that patients consult
NOTE Confidence: 0.938576325

00:45:10.296 --> 00:45:12.099 physicians not just for advice,
NOTE Confidence: 0.938576325

00:45:12.100 --> 00:45:13.516 but first of all to find
NOTE Confidence: 0.938576325

00:45:13.516 --> 00:45:14.900 out whether they are, quote,
NOTE Confidence: 0.938576325

00:45:14.900 --> 00:45:17.980 really sick and what their symptoms mean.
NOTE Confidence: 0.938576325

00:45:17.980 --> 00:45:19.804 Cultural authority in this

NOTE Confidence: 0.938576325

00:45:19.804 --> 00:45:22.084 context is antecedent to action.

NOTE Confidence: 0.938576325

00:45:22.090 --> 00:45:23.506 The authority to interpret

NOTE Confidence: 0.938576325

00:45:23.506 --> 00:45:24.568 signs and symptoms,

NOTE Confidence: 0.938576325

00:45:24.570 --> 00:45:26.610 to diagnose health or illness,

NOTE Confidence: 0.938576325

00:45:26.610 --> 00:45:28.242 to name diseases,

NOTE Confidence: 0.938576325

00:45:28.242 --> 00:45:31.770 and I emphasize that in bold myself,

NOTE Confidence: 0.938576325

00:45:31.770 --> 00:45:33.286 and to offer prognosis,

NOTE Confidence: 0.938576325

00:45:33.286 --> 00:45:35.560 is the foundation of any social

NOTE Confidence: 0.938576325

00:45:35.635 --> 00:45:38.050 authority the physician can assume.

NOTE Confidence: 0.938576325

00:45:38.050 --> 00:45:39.890 By shaping the patient's understanding

NOTE Confidence: 0.938576325

00:45:39.890 --> 00:45:41.362 of their own experience,

NOTE Confidence: 0.938576325

00:45:41.370 --> 00:45:43.710 physicians create the conditions under

NOTE Confidence: 0.938576325

00:45:43.710 --> 00:45:46.050 which their advice seems appropriate.

NOTE Confidence: 0.938576325

00:45:46.050 --> 00:45:48.054 And I thought that this quote

NOTE Confidence: 0.938576325

00:45:48.054 --> 00:45:49.146 seemed appropriate for.

NOTE Confidence: 0.938576325

00:45:49.146 --> 00:45:51.709 The issues that I hope we'll be
NOTE Confidence: 0.938576325

00:45:51.709 --> 00:45:53.551 talking about further for the rest
NOTE Confidence: 0.938576325

00:45:53.551 --> 00:45:55.486 of the for the rest of my time here.
NOTE Confidence: 0.9402536

00:45:57.650 --> 00:45:58.210 All right,
NOTE Confidence: 0.950317

00:45:59.450 --> 00:46:02.690 wonderful. Thank you very much.
NOTE Confidence: 0.950317

00:46:02.690 --> 00:46:07.250 And I will at first before I throw the
NOTE Confidence: 0.950317

00:46:07.250 --> 00:46:10.406 session over for comments and questions,
NOTE Confidence: 0.950317

00:46:10.410 --> 00:46:11.880 I have to correct a couple
NOTE Confidence: 0.950317

00:46:11.880 --> 00:46:13.330 of statements I made earlier.
NOTE Confidence: 0.950317

00:46:13.330 --> 00:46:16.790 First of all, put your questions and
NOTE Confidence: 0.950317

00:46:16.790 --> 00:46:20.590 comments in the Q&A, not in the chat.
NOTE Confidence: 0.950317

00:46:20.590 --> 00:46:26.046 And second, the our next speaker,
NOTE Confidence: 0.950317

00:46:26.046 --> 00:46:27.870 Jen Miller will appear.
NOTE Confidence: 0.950317

00:46:27.870 --> 00:46:30.470 I don't I think I gave you the wrong date.
NOTE Confidence: 0.950317

00:46:30.470 --> 00:46:35.310 She will, she will be here on April the 12th.
NOTE Confidence: 0.950317

00:46:35.310 --> 00:46:40.322 So Doctor show, I want to ask what use

NOTE Confidence: 0.950317

00:46:40.322 --> 00:46:43.304 the prerogative of the chair or the

NOTE Confidence: 0.950317

00:46:43.304 --> 00:46:47.890 host to ask you do you have a sense of?

NOTE Confidence: 0.950317

00:46:47.890 --> 00:46:51.775 With all these journals revising

NOTE Confidence: 0.950317

00:46:51.775 --> 00:46:53.329 their policies,

NOTE Confidence: 0.950317

00:46:53.330 --> 00:46:57.538 do you have a sense of how effective

NOTE Confidence: 0.950317

00:46:57.538 --> 00:47:02.690 they've been or how well they've adhered

NOTE Confidence: 0.950317

00:47:02.820 --> 00:47:06.050 to their own their own guidelines?

NOTE Confidence: 0.950317

00:47:06.050 --> 00:47:08.290 And first of all,

NOTE Confidence: 0.950317

00:47:08.290 --> 00:47:11.188 it sounds like many journals have have

NOTE Confidence: 0.950317

00:47:11.188 --> 00:47:14.128 created their own sets of of guidelines.

NOTE Confidence: 0.950317

00:47:14.130 --> 00:47:14.930 Do you have a sense?

NOTE Confidence: 0.950317

00:47:14.930 --> 00:47:16.469 So I should.

NOTE Confidence: 0.950317

00:47:16.470 --> 00:47:18.350 Make this a two-part question.

NOTE Confidence: 0.950317

00:47:18.350 --> 00:47:20.245 What proportion of major journals

NOTE Confidence: 0.950317

00:47:20.245 --> 00:47:22.516 do you think have instituted these

NOTE Confidence: 0.950317

00:47:22.516 --> 00:47:24.707 kind of policies and second of all,
NOTE Confidence: 0.950317

00:47:24.710 --> 00:47:27.040 how successful have they been
NOTE Confidence: 0.950317

00:47:27.040 --> 00:47:28.904 in implementing those policies?
NOTE Confidence: 0.9419308333333333

00:47:32.940 --> 00:47:35.100 I don't know how many journals,
NOTE Confidence: 0.9419308333333333

00:47:35.100 --> 00:47:37.180 I haven't really looked specifically.
NOTE Confidence: 0.9419308333333333

00:47:37.180 --> 00:47:39.273 I know that the the JAMA guidelines
NOTE Confidence: 0.9419308333333333

00:47:39.273 --> 00:47:41.339 seem to be very influential,
NOTE Confidence: 0.9419308333333333

00:47:41.340 --> 00:47:43.538 as well as the APA style guidelines.
NOTE Confidence: 0.9419308333333333

00:47:43.540 --> 00:47:45.339 The APA has been working on those
NOTE Confidence: 0.9419308333333333

00:47:45.339 --> 00:47:46.740 style guidelines for a long time,
NOTE Confidence: 0.9419308333333333

00:47:46.740 --> 00:47:48.342 and they've added and and it's
NOTE Confidence: 0.9419308333333333

00:47:48.342 --> 00:47:49.980 sort of a living document,
NOTE Confidence: 0.9419308333333333

00:47:49.980 --> 00:47:52.620 so it's been revised.
NOTE Confidence: 0.9419308333333333

00:47:52.620 --> 00:47:55.658 In many ways over over the years.
NOTE Confidence: 0.9419308333333333

00:47:55.660 --> 00:47:57.664 So I think that other journals
NOTE Confidence: 0.9419308333333333

00:47:57.664 --> 00:47:59.685 defer to that those style guidelines

NOTE Confidence: 0.9419308333333333
00:47:59.685 --> 00:48:02.582 as as well as now to the the JAMA
NOTE Confidence: 0.9419308333333333
00:48:02.582 --> 00:48:04.106 guidelines which originally came
NOTE Confidence: 0.9419308333333333
00:48:04.106 --> 00:48:06.459 out many years ago and this up,
NOTE Confidence: 0.9419308333333333
00:48:06.460 --> 00:48:08.164 this latest update was
NOTE Confidence: 0.9419308333333333
00:48:08.164 --> 00:48:09.780 a significant revision.
NOTE Confidence: 0.9318674333333333
00:48:12.060 --> 00:48:15.060 But I know that you know,
NOTE Confidence: 0.9318674333333333
00:48:15.060 --> 00:48:17.340 having worked with some.
NOTE Confidence: 0.9318674333333333
00:48:17.340 --> 00:48:19.194 Genetics journals nearly 20
NOTE Confidence: 0.9318674333333333
00:48:19.194 --> 00:48:21.336 years ago where they did make
NOTE Confidence: 0.9318674333333333
00:48:21.336 --> 00:48:22.954 recommendations on the use
NOTE Confidence: 0.9318674333333333
00:48:22.954 --> 00:48:24.208 of terminology specifically
NOTE Confidence: 0.9318674333333333
00:48:24.208 --> 00:48:25.880 around race and ethnicity
NOTE Confidence: 0.9486397666666667
00:48:28.400 --> 00:48:31.743 that they know from their analysis after
NOTE Confidence: 0.9486397666666667
00:48:31.743 --> 00:48:33.801 the guidelines were released that there
NOTE Confidence: 0.9486397666666667
00:48:33.801 --> 00:48:36.359 was very little change in the publication,
NOTE Confidence: 0.9486397666666667

00:48:36.360 --> 00:48:41.960 so there is going to require more.
NOTE Confidence: 0.9670893333333333

00:48:45.280 --> 00:48:50.492 More concerted efforts at the level of,
NOTE Confidence: 0.9670893333333333

00:48:50.492 --> 00:48:53.216 you know, the editorial staff in
NOTE Confidence: 0.9670893333333333

00:48:53.216 --> 00:48:55.820 insisting on changes and 1st identifying
NOTE Confidence: 0.9670893333333333

00:48:55.892 --> 00:48:57.956 which changes need to be made,
NOTE Confidence: 0.9670893333333333

00:48:57.960 --> 00:49:02.998 which are not that easy. It's, you know,
NOTE Confidence: 0.9670893333333333

00:49:03.000 --> 00:49:07.013 it's it's very it requires very
NOTE Confidence: 0.9670893333333333

00:49:07.013 --> 00:49:09.359 close reading of of manuscripts to
NOTE Confidence: 0.882768072

00:49:11.400 --> 00:49:13.200 understand some of these subtle,
NOTE Confidence: 0.882768072

00:49:13.200 --> 00:49:15.600 subtle concepts.
NOTE Confidence: 0.882768072

00:49:15.600 --> 00:49:21.035 So I think there's there was some hope,
NOTE Confidence: 0.882768072

00:49:21.040 --> 00:49:23.476 I think I can speak for our journal,
NOTE Confidence: 0.882768072

00:49:23.476 --> 00:49:25.860 that we were waiting to see what the
NOTE Confidence: 0.882768072

00:49:25.923 --> 00:49:28.478 National Academies of Medicine had to say.
NOTE Confidence: 0.882768072

00:49:28.480 --> 00:49:31.189 And indeed they have a whole section
NOTE Confidence: 0.882768072

00:49:31.189 --> 00:49:33.838 of their report that is devoted to,

NOTE Confidence: 0.915549205
00:49:37.560 --> 00:49:40.380 devoted to specific measures
NOTE Confidence: 0.915549205
00:49:40.380 --> 00:49:43.200 that institutions should take.
NOTE Confidence: 0.915549205
00:49:43.200 --> 00:49:45.920 To implement the recommendations
NOTE Confidence: 0.915549205
00:49:45.920 --> 00:49:49.676 that that the academies have made.
NOTE Confidence: 0.915549205
00:49:49.676 --> 00:49:53.108 So I think it's going to
NOTE Confidence: 0.915549205
00:49:53.108 --> 00:49:56.128 require sort of multilayered,
NOTE Confidence: 0.915549205
00:49:56.128 --> 00:49:57.760 multilevel efforts,
NOTE Confidence: 0.915549205
00:49:57.760 --> 00:50:01.330 not just leaving it all to individual
NOTE Confidence: 0.915549205
00:50:01.330 --> 00:50:04.718 researchers or or individuals at all,
NOTE Confidence: 0.915549205
00:50:04.720 --> 00:50:08.120 and that institutions have to
NOTE Confidence: 0.915549205
00:50:08.120 --> 00:50:12.668 provide resources for education.
NOTE Confidence: 0.915549205
00:50:12.670 --> 00:50:17.448 And and and things like perhaps
NOTE Confidence: 0.915549205
00:50:17.448 --> 00:50:19.920 things like prior institutional
NOTE Confidence: 0.915549205
00:50:19.920 --> 00:50:22.392 review of publications to
NOTE Confidence: 0.915549205
00:50:22.392 --> 00:50:25.307 help people by people who have
NOTE Confidence: 0.915549205

00:50:25.310 --> 00:50:29.470 expertise in in in these areas
NOTE Confidence: 0.9603804

00:50:31.510 --> 00:50:34.422 to help people individual
NOTE Confidence: 0.9603804

00:50:34.422 --> 00:50:35.828 researchers who may not
NOTE Confidence: 0.94629164

00:50:38.110 --> 00:50:40.700 have that kind of expertise.
NOTE Confidence: 0.94629164

00:50:40.700 --> 00:50:42.535 You know, before everybody's educated
NOTE Confidence: 0.94629164

00:50:42.535 --> 00:50:45.684 and on the same page about these types
NOTE Confidence: 0.94629164

00:50:45.684 --> 00:50:48.340 of terminologies that are considered
NOTE Confidence: 0.94629164

00:50:48.340 --> 00:50:50.260 acceptable and not acceptable,
NOTE Confidence: 0.94629164

00:50:50.260 --> 00:50:52.480 that there's some resources that
NOTE Confidence: 0.94629164

00:50:52.480 --> 00:50:54.256 are provided by institutions.
NOTE Confidence: 0.9288678664

00:50:55.420 --> 00:50:57.450 So you would put at least some
NOTE Confidence: 0.9288678664

00:50:57.450 --> 00:50:59.763 more of the burden on the
NOTE Confidence: 0.9288678664

00:50:59.763 --> 00:51:01.131 individual institutions and
NOTE Confidence: 0.9288678664

00:51:01.131 --> 00:51:03.405 therefore on the authors rather
NOTE Confidence: 0.9288678664

00:51:03.405 --> 00:51:05.431 than on the journals themselves,
NOTE Confidence: 0.9288678664

00:51:05.431 --> 00:51:07.024 which is understood.

NOTE Confidence: 0.9288678664

00:51:07.024 --> 00:51:08.998 The journals are certainly.

NOTE Confidence: 0.9288678664

00:51:08.998 --> 00:51:10.510 Sufficiently burdened but is

NOTE Confidence: 0.9288678664

00:51:10.510 --> 00:51:12.400 that am I interpreting your

NOTE Confidence: 0.9288678664

00:51:12.459 --> 00:51:13.869 your statement correctly.

NOTE Confidence: 0.937293708235294

00:51:15.350 --> 00:51:18.150 So I think we have to kind of spread the

NOTE Confidence: 0.937293708235294

00:51:18.220 --> 00:51:20.950 efforts out because it's going to take,

NOTE Confidence: 0.937293708235294

00:51:20.950 --> 00:51:22.926 it's going to take this is a major

NOTE Confidence: 0.937293708235294

00:51:22.926 --> 00:51:25.192 these are major changes that that are in

NOTE Confidence: 0.937293708235294

00:51:25.192 --> 00:51:27.348 this report and that also that I think

NOTE Confidence: 0.946291578

00:51:29.590 --> 00:51:31.846 it's not just about race and

NOTE Confidence: 0.946291578

00:51:31.846 --> 00:51:34.270 ethnicity but other things you

NOTE Confidence: 0.946291578

00:51:34.270 --> 00:51:38.290 know if you think about how.

NOTE Confidence: 0.946291578

00:51:38.290 --> 00:51:42.250 You know laboratory reports are structured,

NOTE Confidence: 0.946291578

00:51:42.250 --> 00:51:44.968 it's going to take some major,

NOTE Confidence: 0.946291578

00:51:44.970 --> 00:51:50.970 major efforts to to align you know

NOTE Confidence: 0.946291578

00:51:50.970 --> 00:51:53.490 all are the majority of clinical
NOTE Confidence: 0.946291578

00:51:53.490 --> 00:51:56.346 laboratories so that they are they have
NOTE Confidence: 0.946291578

00:51:56.346 --> 00:52:00.370 some kind of similarities in how they
NOTE Confidence: 0.946291578

00:52:00.370 --> 00:52:03.089 are implementing inclusivity guidelines.
NOTE Confidence: 0.9503169

00:52:05.610 --> 00:52:06.090 Thank you.
NOTE Confidence: 0.9251585

00:52:08.180 --> 00:52:11.330 Now we have a what I consider a very
NOTE Confidence: 0.9251585

00:52:11.330 --> 00:52:13.060 good question from our colleague Dr.
NOTE Confidence: 0.9251585

00:52:13.060 --> 00:52:14.452 Chadi Tol Walker,
NOTE Confidence: 0.9251585

00:52:14.452 --> 00:52:17.236 who says Stanford published a language
NOTE Confidence: 0.9251585

00:52:17.236 --> 00:52:19.990 guide that was attacked and ridiculed
NOTE Confidence: 0.9251585

00:52:19.990 --> 00:52:23.100 in the media and eventually taken down.
NOTE Confidence: 0.9251585

00:52:23.100 --> 00:52:25.648 We at Yale and Doctor Tol Walker
NOTE Confidence: 0.9251585

00:52:25.648 --> 00:52:27.660 was instrumental in this effort,
NOTE Confidence: 0.9251585

00:52:27.660 --> 00:52:29.472 have developed an inclusive
NOTE Confidence: 0.9251585

00:52:29.472 --> 00:52:31.737 language guide for our community.
NOTE Confidence: 0.9251585

00:52:31.740 --> 00:52:34.170 Yale School of Medicine we have.

NOTE Confidence: 0.9251585

00:52:34.170 --> 00:52:36.032 We have it behind a firewall so

NOTE Confidence: 0.9251585

00:52:36.032 --> 00:52:37.810 that it's helpful to our community,

NOTE Confidence: 0.9251585

00:52:37.810 --> 00:52:41.770 but would like to release it more widely.

NOTE Confidence: 0.9251585

00:52:41.770 --> 00:52:45.046 Any tips for navigating potential criticism,

NOTE Confidence: 0.9251585

00:52:45.050 --> 00:52:48.488 especially that made in bad faith?

NOTE Confidence: 0.9352219

00:52:50.530 --> 00:52:51.730 Yeah, wow.

NOTE Confidence: 0.88458451125

00:52:54.090 --> 00:52:56.170 Yeah, this is quite the subject of many,

NOTE Confidence: 0.88458451125

00:52:56.170 --> 00:53:00.090 many faculty meetings, I think.

NOTE Confidence: 0.93019031

00:53:06.360 --> 00:53:09.786 I'm not sure I have any really

NOTE Confidence: 0.93019031

00:53:09.786 --> 00:53:12.316 effective tips for navigating criticism,

NOTE Confidence: 0.93019031

00:53:12.320 --> 00:53:17.920 but I do think that it it may be helpful to

NOTE Confidence: 0.951231962727273

00:53:21.400 --> 00:53:24.700 to provide more scaffolding so rather

NOTE Confidence: 0.951231962727273

00:53:24.700 --> 00:53:27.840 than just releasing a document.

NOTE Confidence: 0.951231962727273

00:53:27.840 --> 00:53:29.766 Which has no context, which doesn't

NOTE Confidence: 0.951231962727273

00:53:29.766 --> 00:53:32.064 have sort of the opportunity for

NOTE Confidence: 0.951231962727273

00:53:32.064 --> 00:53:33.960 discussion and explanation and
NOTE Confidence: 0.9805072

00:53:38.120 --> 00:53:39.520 providing context
NOTE Confidence: 0.934503085714286

00:53:42.160 --> 00:53:46.240 that it may be more helpful to have
NOTE Confidence: 0.924689523529412

00:53:49.520 --> 00:53:51.745 have the document be discussed
NOTE Confidence: 0.924689523529412

00:53:51.745 --> 00:53:55.102 it with the sort of in the
NOTE Confidence: 0.924689523529412

00:53:55.102 --> 00:53:57.707 environment of a more interactive.
NOTE Confidence: 0.924689523529412

00:53:57.710 --> 00:54:02.210 You know educational setting probably
NOTE Confidence: 0.924689523529412

00:54:02.210 --> 00:54:04.430 multiple educational settings.
NOTE Confidence: 0.924689523529412

00:54:04.430 --> 00:54:07.056 So that because these are
NOTE Confidence: 0.924689523529412

00:54:07.056 --> 00:54:08.584 pretty nuanced issues and
NOTE Confidence: 0.94276945

00:54:10.670 --> 00:54:12.638 and I think that's something that's
NOTE Confidence: 0.94276945

00:54:12.638 --> 00:54:14.850 an issue that was faced by these
NOTE Confidence: 0.94276945

00:54:14.850 --> 00:54:16.847 journals that we're putting out language
NOTE Confidence: 0.94276945

00:54:16.847 --> 00:54:18.629 guidelines is because you can't really.
NOTE Confidence: 0.94276945

00:54:18.630 --> 00:54:20.910 It's very hard to make sort of blanket
NOTE Confidence: 0.94276945

00:54:20.910 --> 00:54:22.782 statements about how you should use certain

NOTE Confidence: 0.94276945

00:54:22.782 --> 00:54:25.284 words and and not and you could see that

NOTE Confidence: 0.94276945

00:54:25.284 --> 00:54:27.090 in the National Academies report where.

NOTE Confidence: 0.94276945

00:54:27.090 --> 00:54:28.749 You know you can't make a rule

NOTE Confidence: 0.94276945

00:54:28.749 --> 00:54:30.648 and say you can't use race ever,

NOTE Confidence: 0.94276945

00:54:30.650 --> 00:54:32.580 because sometimes it you actually

NOTE Confidence: 0.94276945

00:54:32.580 --> 00:54:34.124 should be using race.

NOTE Confidence: 0.94276945

00:54:34.130 --> 00:54:37.049 For example, you can't study end of.

NOTE Confidence: 0.94276945

00:54:37.050 --> 00:54:38.421 So for example,

NOTE Confidence: 0.94276945

00:54:38.421 --> 00:54:41.163 the very reason why the government

NOTE Confidence: 0.94276945

00:54:41.163 --> 00:54:44.148 came up with the O MB categories

NOTE Confidence: 0.94276945

00:54:44.148 --> 00:54:46.922 of race and ethnicity back in the

NOTE Confidence: 0.94276945

00:54:46.922 --> 00:54:49.779 70s was in response to and so they

NOTE Confidence: 0.94276945

00:54:49.779 --> 00:54:52.320 could in order to make it possible

NOTE Confidence: 0.94276945

00:54:52.398 --> 00:54:54.450 to measure discrimination.

NOTE Confidence: 0.94276945

00:54:54.450 --> 00:54:56.496 And so you can't measure discrimination

NOTE Confidence: 0.94276945

00:54:56.496 --> 00:54:58.170 without social categories of race.
NOTE Confidence: 0.94276945

00:54:58.170 --> 00:55:00.599 So the problem comes in is when
NOTE Confidence: 0.94276945

00:55:00.599 --> 00:55:02.418 you're using categories that are
NOTE Confidence: 0.94276945

00:55:02.418 --> 00:55:04.390 mismatched with the uses, right?
NOTE Confidence: 0.94276945

00:55:04.390 --> 00:55:08.170 So if you're trying to capture biological,
NOTE Confidence: 0.94276945

00:55:08.170 --> 00:55:09.898 biological features and you're
NOTE Confidence: 0.94276945

00:55:09.898 --> 00:55:12.490 using social categories to do that,
NOTE Confidence: 0.94276945

00:55:12.490 --> 00:55:13.186 you're, you're,
NOTE Confidence: 0.94276945

00:55:13.186 --> 00:55:16.150 you're really going to have problems there.
NOTE Confidence: 0.94276945

00:55:16.150 --> 00:55:17.980 And that's where.
NOTE Confidence: 0.94276945

00:55:17.980 --> 00:55:19.624 But those are kind of nuanced
NOTE Confidence: 0.94276945

00:55:19.624 --> 00:55:21.419 issues that you can't really just.
NOTE Confidence: 0.94276945

00:55:21.420 --> 00:55:24.220 It's hard to just sort of make
NOTE Confidence: 0.94276945

00:55:24.220 --> 00:55:26.848 guidelines about and and also to to
NOTE Confidence: 0.94276945

00:55:26.848 --> 00:55:29.552 explain I think you know there are
NOTE Confidence: 0.94276945

00:55:29.552 --> 00:55:32.090 certain terms where it seems more

NOTE Confidence: 0.94276945

00:55:32.175 --> 00:55:34.885 obvious than others why they're

NOTE Confidence: 0.94276945

00:55:34.885 --> 00:55:37.445 considered offensive now but you'd

NOTE Confidence: 0.94276945

00:55:37.445 --> 00:55:38.215 be surprised.

NOTE Confidence: 0.94276945

00:55:38.215 --> 00:55:40.770 Some people really have no you know

NOTE Confidence: 0.94276945

00:55:40.770 --> 00:55:42.660 especially when you know a place

NOTE Confidence: 0.94276945

00:55:42.660 --> 00:55:44.765 like Yale or less like Stanford

NOTE Confidence: 0.94276945

00:55:44.765 --> 00:55:46.520 which has people coming from.

NOTE Confidence: 0.94276945

00:55:46.520 --> 00:55:49.568 A wide variety of cultures globally

NOTE Confidence: 0.94276945

00:55:49.568 --> 00:55:52.480 and different traditions and practices.

NOTE Confidence: 0.894690144444444

00:55:54.840 --> 00:55:58.080 You know, I think it it it means that

NOTE Confidence: 0.894690144444444

00:55:58.080 --> 00:56:00.222 these discussions have to give people

NOTE Confidence: 0.894690144444444

00:56:00.222 --> 00:56:03.216 space to ask questions and not feel like

NOTE Confidence: 0.894690144444444

00:56:03.216 --> 00:56:05.091 they're being criticized for asking

NOTE Confidence: 0.894690144444444

00:56:05.091 --> 00:56:07.320 questions because they don't understand.

NOTE Confidence: 0.9301903125

00:56:08.840 --> 00:56:11.400 Thank you. I I will say that the

NOTE Confidence: 0.9301903125

00:56:11.400 --> 00:56:13.758 that the Yale document actually it
NOTE Confidence: 0.9301903125

00:56:13.758 --> 00:56:16.698 does attempt and I think it does
NOTE Confidence: 0.9301903125

00:56:16.698 --> 00:56:19.771 reasonably well to provide context
NOTE Confidence: 0.9301903125

00:56:19.771 --> 00:56:24.400 and to provide explanations the the
NOTE Confidence: 0.9301903125

00:56:24.400 --> 00:56:27.208 the question and I can certainly
NOTE Confidence: 0.9301903125

00:56:27.208 --> 00:56:30.160 understand the concern is that how,
NOTE Confidence: 0.9301903125

00:56:30.160 --> 00:56:33.301 how are we going to get people to pay
NOTE Confidence: 0.9301903125

00:56:33.301 --> 00:56:36.820 attention to the document and to actually.
NOTE Confidence: 0.9301903125

00:56:36.820 --> 00:56:40.660 Incorporate the the context and the
NOTE Confidence: 0.9301903125

00:56:40.660 --> 00:56:43.700 explanations and the history all of
NOTE Confidence: 0.9301903125

00:56:43.700 --> 00:56:46.019 which is in there in a in a fairly
NOTE Confidence: 0.9301903125

00:56:46.019 --> 00:56:48.812 succinct form but I think but it's
NOTE Confidence: 0.9301903125

00:56:48.812 --> 00:56:51.820 it's a very nice job so far but yeah
NOTE Confidence: 0.9125667533333333

00:56:52.820 --> 00:56:54.900 I'd love to see it actually sounds very
NOTE Confidence: 0.9402535455555556

00:56:54.900 --> 00:56:57.912 well we will we will send
NOTE Confidence: 0.9402535455555556

00:56:57.912 --> 00:56:59.418 it along absolutely.

NOTE Confidence: 0.940253545555556
00:56:59.420 --> 00:57:03.326 So that's that's that's very helpful.
NOTE Confidence: 0.940253545555556
00:57:03.330 --> 00:57:05.850 I I have to apologize once again.
NOTE Confidence: 0.940253545555556
00:57:05.850 --> 00:57:08.526 Apparently I have screwed up my,
NOTE Confidence: 0.940253545555556
00:57:08.530 --> 00:57:13.890 my, my dates so that I I this
NOTE Confidence: 0.940253545555556
00:57:13.890 --> 00:57:16.130 will take just a moment.
NOTE Confidence: 0.940253545555556
00:57:16.130 --> 00:57:20.325 But I said that doctor Doctor Miller
NOTE Confidence: 0.940253545555556
00:57:20.325 --> 00:57:23.304 would be appearing on April the 12th
NOTE Confidence: 0.940253545555556
00:57:23.304 --> 00:57:25.536 and it looks like she's actually
NOTE Confidence: 0.940253545555556
00:57:25.536 --> 00:57:28.287 going to be here on April the 19th.
NOTE Confidence: 0.940253545555556
00:57:28.290 --> 00:57:30.070 The Cardiology Ethics Symposium
NOTE Confidence: 0.940253545555556
00:57:30.070 --> 00:57:32.660 will be on Friday, may the 11th.
NOTE Confidence: 0.940253545555556
00:57:32.660 --> 00:57:34.010 It will be on Friday,
NOTE Confidence: 0.940253545555556
00:57:34.010 --> 00:57:36.970 may the 12th and that will be an all day
NOTE Confidence: 0.940253545555556
00:57:37.044 --> 00:57:39.928 session on the ethics of heart failure.
NOTE Confidence: 0.940253545555556
00:57:39.930 --> 00:57:43.250 So let let me proceed.
NOTE Confidence: 0.870464770714286

00:57:46.890 --> 00:57:49.739 Okay, so here's a a question from
NOTE Confidence: 0.870464770714286

00:57:49.739 --> 00:57:51.929 an anonymous attendee how can I I,
NOTE Confidence: 0.870464770714286

00:57:51.930 --> 00:57:54.482 a student at the Yale PA program
NOTE Confidence: 0.870464770714286

00:57:54.482 --> 00:57:55.850 physician associate program,
NOTE Confidence: 0.870464770714286

00:57:55.850 --> 00:57:59.162 enlist the help of the biomedical
NOTE Confidence: 0.870464770714286

00:57:59.162 --> 00:58:02.571 ethics department to ensure the legacy
NOTE Confidence: 0.870464770714286

00:58:02.571 --> 00:58:05.331 of unscientific categorizations at at
NOTE Confidence: 0.870464770714286

00:58:05.331 --> 00:58:09.440 Yale ends in our medical Ed curriculum?
NOTE Confidence: 0.870464770714286

00:58:09.440 --> 00:58:12.800 I have seen outdated genetics terminology,
NOTE Confidence: 0.870464770714286

00:58:12.800 --> 00:58:14.820 outdated guidelines,
NOTE Confidence: 0.870464770714286

00:58:14.820 --> 00:58:17.360 suggestions regarding regarding
NOTE Confidence: 0.870464770714286

00:58:17.360 --> 00:58:19.960 ACE inhibitors in black patients,
NOTE Confidence: 0.870464770714286

00:58:19.960 --> 00:58:23.728 and incorrect terms used for describing
NOTE Confidence: 0.870464770714286

00:58:23.728 --> 00:58:27.280 geographic anxiety and population difference.
NOTE Confidence: 0.870464770714286

00:58:27.280 --> 00:58:31.200 How do I enlist your help to
NOTE Confidence: 0.870464770714286

00:58:31.200 --> 00:58:34.109 update our curriculum so?

NOTE Confidence: 0.870464770714286
00:58:34.110 --> 00:58:36.348 This is, this is obviously a
NOTE Confidence: 0.870464770714286
00:58:36.348 --> 00:58:39.108 problem we have to deal with here,
NOTE Confidence: 0.870464770714286
00:58:39.110 --> 00:58:41.595 but do you have some
NOTE Confidence: 0.870464770714286
00:58:41.595 --> 00:58:43.583 suggestions for our students?
NOTE Confidence: 0.861307466666667
00:58:45.310 --> 00:58:48.732 Yeah, great question. Yes.
NOTE Confidence: 0.861307466666667
00:58:48.732 --> 00:58:51.148 I mean if if you were at Stanford,
NOTE Confidence: 0.861307466666667
00:58:51.150 --> 00:58:53.630 what would I tell you? I would say,
NOTE Confidence: 0.945844377777778
00:58:56.070 --> 00:58:59.772 you know, probably similarly at Yale
NOTE Confidence: 0.945844377777778
00:58:59.772 --> 00:59:04.240 there are now sort of a plethora of.
NOTE Confidence: 0.945844377777778
00:59:04.240 --> 00:59:08.006 Committees that are dealing with DEI
NOTE Confidence: 0.945844377777778
00:59:08.006 --> 00:59:12.426 or Jedi or idea or whatever acronym
NOTE Confidence: 0.945844377777778
00:59:12.426 --> 00:59:15.946 they want to use that are supposed
NOTE Confidence: 0.945844377777778
00:59:15.946 --> 00:59:18.238 to be dealing with these issues.
NOTE Confidence: 0.945844377777778
00:59:18.240 --> 00:59:22.300 And I would imagine there is a
NOTE Confidence: 0.945844377777778
00:59:22.300 --> 00:59:24.880 curriculum committee that is thinking
NOTE Confidence: 0.945844377777778

00:59:24.880 --> 00:59:28.520 about how to make the curriculum more
NOTE Confidence: 0.945844377777778

00:59:28.520 --> 00:59:32.390 inclusive and improve it in many ways.
NOTE Confidence: 0.945844377777778

00:59:32.390 --> 00:59:36.828 In terms of all kinds of related
NOTE Confidence: 0.945844377777778

00:59:36.830 --> 00:59:39.170 features or characteristics.
NOTE Confidence: 0.945844377777778

00:59:39.170 --> 00:59:43.750 So that's where I would go and to,
NOTE Confidence: 0.945844377777778

00:59:43.750 --> 00:59:46.014 you know, raise, raise these,
NOTE Confidence: 0.945844377777778

00:59:46.014 --> 00:59:46.958 these issues,
NOTE Confidence: 0.945844377777778

00:59:46.958 --> 00:59:49.790 I imagine that there are also
NOTE Confidence: 0.950317

00:59:52.910 --> 00:59:57.094 efforts at the national level and I
NOTE Confidence: 0.950317

00:59:57.094 --> 00:59:59.874 know that the one of the recommendations
NOTE Confidence: 0.950317

00:59:59.874 --> 01:00:02.329 from the National Academies report.
NOTE Confidence: 0.950317

01:00:02.330 --> 01:00:08.245 Was to form a clearinghouse of resources
NOTE Confidence: 0.950317

01:00:08.250 --> 01:00:12.354 and also of you know guidelines and
NOTE Confidence: 0.950317

01:00:12.354 --> 01:00:15.488 and that sort of thing, but also of
NOTE Confidence: 0.957864441666667

01:00:17.730 --> 01:00:21.174 things like curriculum changes and and
NOTE Confidence: 0.957864441666667

01:00:21.174 --> 01:00:24.929 educational modules that are being developed.

NOTE Confidence: 0.957864441666667

01:00:24.930 --> 01:00:28.702 So sort of a sharing, a locus of

NOTE Confidence: 0.957864441666667

01:00:28.702 --> 01:00:31.846 sharing of these kinds of materials.

NOTE Confidence: 0.957864441666667

01:00:31.850 --> 01:00:34.125 Although that's that report was just issued,

NOTE Confidence: 0.957864441666667

01:00:34.130 --> 01:00:38.778 I don't know of any such body right now,

NOTE Confidence: 0.957864441666667

01:00:38.778 --> 01:00:41.658 but I imagine that there

NOTE Confidence: 0.957864441666667

01:00:41.658 --> 01:00:44.346 will be some movement in that

NOTE Confidence: 0.957864441666667

01:00:44.346 --> 01:00:47.130 direction may be led by you know,

NOTE Confidence: 0.957864441666667

01:00:47.130 --> 01:00:49.404 a group like the double AMC, right,

NOTE Confidence: 0.957864441666667

01:00:49.404 --> 01:00:52.008 the American Academy of Medical Colleges,

NOTE Confidence: 0.910745981818182

01:00:53.770 --> 01:00:57.228 right. And I would add that we

NOTE Confidence: 0.910745981818182

01:00:57.228 --> 01:00:59.870 certainly have a structure.

NOTE Confidence: 0.910745981818182

01:00:59.870 --> 01:01:03.182 That is meant to deal with DEI here

NOTE Confidence: 0.910745981818182

01:01:03.182 --> 01:01:05.954 on the medical school campus and that

NOTE Confidence: 0.910745981818182

01:01:05.954 --> 01:01:08.828 should apply to the PA program as well.

NOTE Confidence: 0.910745981818182

01:01:08.830 --> 01:01:13.824 So and if that should be an Ave.

NOTE Confidence: 0.910745981818182

01:01:13.830 --> 01:01:16.788 for redress and if it's not,
NOTE Confidence: 0.910745981818182

01:01:16.790 --> 01:01:19.508 we have work to do. So thank you.
NOTE Confidence: 0.9754755

01:01:21.990 --> 01:01:24.830 Another question.
NOTE Confidence: 0.9754755

01:01:24.830 --> 01:01:26.550 Some people express frustration
NOTE Confidence: 0.9754755

01:01:26.550 --> 01:01:29.130 at the imperative to use precise
NOTE Confidence: 0.9754755

01:01:29.200 --> 01:01:31.881 language due to the perception that it
NOTE Confidence: 0.9754755

01:01:31.881 --> 01:01:34.309 changes so quickly and so frequently.
NOTE Confidence: 0.9754755

01:01:34.310 --> 01:01:36.102 Of course, the nature of language is
NOTE Confidence: 0.9754755

01:01:36.102 --> 01:01:38.508 that it is always changing and evolving,
NOTE Confidence: 0.9754755

01:01:38.510 --> 01:01:42.668 but this is some people's concern.
NOTE Confidence: 0.9754755

01:01:42.670 --> 01:01:44.947 Can you speak a bit more to this point?
NOTE Confidence: 0.926698920714286

01:01:47.880 --> 01:01:49.656 This is an issue that I talked about
NOTE Confidence: 0.926698920714286

01:01:49.656 --> 01:01:51.320 with my coauthors of the paper,
NOTE Confidence: 0.926698920714286

01:01:51.320 --> 01:01:53.224 knowing that as soon as it was
NOTE Confidence: 0.926698920714286

01:01:53.224 --> 01:01:55.319 published it was going to be outdated.
NOTE Confidence: 0.926698920714286

01:01:55.320 --> 01:01:57.938 But I think how we dealt with

NOTE Confidence: 0.926698920714286
01:01:57.938 --> 01:02:00.718 that or tried to reconcile this,
NOTE Confidence: 0.934215514
01:02:03.840 --> 01:02:05.880 you know, with our own
NOTE Confidence: 0.934215514
01:02:05.880 --> 01:02:12.880 publication, was that the act of
NOTE Confidence: 0.93824086
01:02:15.160 --> 01:02:19.596 keeping up with sort of. The the
NOTE Confidence: 0.93824086
01:02:19.596 --> 01:02:22.326 Times in terms of understanding
NOTE Confidence: 0.95836772
01:02:24.490 --> 01:02:29.410 both where language and categorization
NOTE Confidence: 0.95836772
01:02:29.410 --> 01:02:33.075 are doing scientific and clinical
NOTE Confidence: 0.95836772
01:02:33.075 --> 01:02:37.205 damage and and also where it is doing
NOTE Confidence: 0.9704438
01:02:39.890 --> 01:02:45.210 causing causing disrespect
NOTE Confidence: 0.9704438
01:02:45.210 --> 01:02:47.082 of various communities.
NOTE Confidence: 0.9704438
01:02:47.082 --> 01:02:52.077 Just the very act of of doing that
NOTE Confidence: 0.9704438
01:02:52.077 --> 01:02:56.298 is in itself a virtuous activity,
NOTE Confidence: 0.9704438
01:02:56.298 --> 01:03:00.100 so signaling trustworthiness and signaling
NOTE Confidence: 0.89714026625
01:03:02.340 --> 01:03:03.590 open mindedness.
NOTE Confidence: 0.89714026625
01:03:03.590 --> 01:03:07.340 And to some extent I think
NOTE Confidence: 0.89714026625

01:03:07.340 --> 01:03:10.870 part of the frustration is
NOTE Confidence: 0.89714026625

01:03:10.870 --> 01:03:15.220 due to the underlying sort of.
NOTE Confidence: 0.89714026625

01:03:15.220 --> 01:03:16.820 Movement that is happening here,
NOTE Confidence: 0.89714026625

01:03:16.820 --> 01:03:21.580 which is that it means sort of
NOTE Confidence: 0.89714026625

01:03:21.580 --> 01:03:24.620 admitting that professional groups
NOTE Confidence: 0.89714026625

01:03:24.620 --> 01:03:29.046 may not be the ones in power
NOTE Confidence: 0.89714026625

01:03:29.046 --> 01:03:31.506 anymore and with the authority
NOTE Confidence: 0.89714026625

01:03:31.506 --> 01:03:34.722 to make these decisions and and
NOTE Confidence: 0.89714026625

01:03:34.722 --> 01:03:37.778 that some of that power has to be
NOTE Confidence: 0.89714026625

01:03:37.778 --> 01:03:40.739 ceded to communities and patients,
NOTE Confidence: 0.9201268

01:03:44.020 --> 01:03:49.609 so. And so that means I think that this is,
NOTE Confidence: 0.9201268

01:03:49.610 --> 01:03:51.634 this is even though the language is changing
NOTE Confidence: 0.9201268

01:03:51.634 --> 01:03:53.208 and evolving and that's frustrating.
NOTE Confidence: 0.9201268

01:03:53.210 --> 01:03:56.634 I think the there's a bigger thing that's
NOTE Confidence: 0.9201268

01:03:56.634 --> 01:03:58.316 evolving underneath that fundamentally,
NOTE Confidence: 0.9201268

01:03:58.316 --> 01:04:00.646 which is a power shift.

NOTE Confidence: 0.950317

01:04:03.730 --> 01:04:05.368 Thank you. Very good.

NOTE Confidence: 0.933544666666667

01:04:07.410 --> 01:04:11.370 I would like to just.

NOTE Confidence: 0.899149198571429

01:04:13.910 --> 01:04:16.066 Read a response from Doctor Paul Walker.

NOTE Confidence: 0.899149198571429

01:04:16.070 --> 01:04:19.335 He says thank you. That's how we're

NOTE Confidence: 0.899149198571429

01:04:19.335 --> 01:04:20.910 using it internally right now,

NOTE Confidence: 0.899149198571429

01:04:20.910 --> 01:04:22.809 contextualizing narrow educational

NOTE Confidence: 0.899149198571429

01:04:22.809 --> 01:04:25.341 slash research slash clinical

NOTE Confidence: 0.899149198571429

01:04:25.341 --> 01:04:28.310 settings to foster conversation.

NOTE Confidence: 0.899149198571429

01:04:28.310 --> 01:04:31.794 I've read some bad faith out of

NOTE Confidence: 0.899149198571429

01:04:31.794 --> 01:04:33.604 context criticism of the Stanford

NOTE Confidence: 0.899149198571429

01:04:33.604 --> 01:04:35.820 guy that I suspect deliberately

NOTE Confidence: 0.899149198571429

01:04:35.820 --> 01:04:38.450 ignored the context in the

NOTE Confidence: 0.899149198571429

01:04:38.450 --> 01:04:42.000 interest of sensationalism is that.

NOTE Confidence: 0.899149198571429

01:04:42.000 --> 01:04:44.880 Do you think that's the case or yeah,

NOTE Confidence: 0.887207543333333

01:04:44.920 --> 01:04:47.638 I I think that's that's true.

NOTE Confidence: 0.887207543333333

01:04:47.640 --> 01:04:49.720 But I think it does point out that
NOTE Confidence: 0.948879322857143

01:04:52.640 --> 01:04:55.279 even guidelines like this on language use
NOTE Confidence: 0.950316927142857

01:04:57.840 --> 01:05:01.879 are highly and should be highly contextual,
NOTE Confidence: 0.950316927142857

01:05:01.880 --> 01:05:04.536 right? I mean, you can use the exact
NOTE Confidence: 0.950316927142857

01:05:04.536 --> 01:05:07.210 same word in different setting. Right.
NOTE Confidence: 0.950316927142857

01:05:07.210 --> 01:05:10.080 And we're talking about usage in research,
NOTE Confidence: 0.950316927142857

01:05:10.080 --> 01:05:13.120 usage in patient doctor communications,
NOTE Confidence: 0.950316927142857

01:05:13.120 --> 01:05:16.594 in publications in the news in, you know,
NOTE Confidence: 0.950316927142857

01:05:16.594 --> 01:05:18.673 all these different settings and the exact
NOTE Confidence: 0.950316927142857

01:05:18.673 --> 01:05:20.787 same term can have different meanings
NOTE Confidence: 0.950316927142857

01:05:20.787 --> 01:05:22.840 in those different settings, right. So
NOTE Confidence: 0.938815971428571

01:05:26.080 --> 01:05:29.594 not to say that the criticism was,
NOTE Confidence: 0.938815971428571

01:05:29.600 --> 01:05:32.008 you know, I think the criticism was
NOTE Confidence: 0.938815971428571

01:05:32.008 --> 01:05:34.649 really in the interest of sensationalism
NOTE Confidence: 0.938815971428571

01:05:34.649 --> 01:05:36.200 as as as you mentioned and.
NOTE Confidence: 0.92616484

01:05:41.280 --> 01:05:43.620 But I think it is. That's why I think

NOTE Confidence: 0.92616484

01:05:43.620 --> 01:05:46.512 it's important to provide these types

NOTE Confidence: 0.92616484

01:05:46.512 --> 01:05:51.384 of recommendations in the with a very

NOTE Confidence: 0.92616484

01:05:51.384 --> 01:05:55.520 clear context alongside it. Well,

NOTE Confidence: 0.923363584615385

01:05:55.520 --> 01:05:57.896 I'm going to speculate that some

NOTE Confidence: 0.923363584615385

01:05:57.896 --> 01:06:01.258 of the some of the criticisms that.

NOTE Confidence: 0.923363584615385

01:06:01.260 --> 01:06:04.662 We we we might say we're not

NOTE Confidence: 0.923363584615385

01:06:04.662 --> 01:06:06.926 particularly reasoned or balanced

NOTE Confidence: 0.923363584615385

01:06:06.926 --> 01:06:10.040 or thoughtful perhaps. All right.

NOTE Confidence: 0.923363584615385

01:06:10.040 --> 01:06:12.490 We're part of a understandably

NOTE Confidence: 0.923363584615385

01:06:12.490 --> 01:06:14.435 human reaction to change.

NOTE Confidence: 0.923363584615385

01:06:14.435 --> 01:06:16.375 We don't like change.

NOTE Confidence: 0.923363584615385

01:06:16.380 --> 01:06:18.510 We don't like being even having

NOTE Confidence: 0.923363584615385

01:06:18.510 --> 01:06:20.359 it implied that we've been

NOTE Confidence: 0.923363584615385

01:06:20.359 --> 01:06:22.164 incorrect in what we've been

NOTE Confidence: 0.923363584615385

01:06:22.164 --> 01:06:24.419 doing for load these many years.

NOTE Confidence: 0.923363584615385

01:06:24.420 --> 01:06:25.578 And so I
NOTE Confidence: 0.92616484

01:06:27.660 --> 01:06:31.880 I, I sort of under, I think I understand.
NOTE Confidence: 0.92616484

01:06:31.880 --> 01:06:34.085 I when I've been, when when it's
NOTE Confidence: 0.92616484

01:06:34.085 --> 01:06:36.393 been brought to my own attention of
NOTE Confidence: 0.92616484

01:06:36.393 --> 01:06:39.120 something that I had not even considered.
NOTE Confidence: 0.92616484

01:06:39.120 --> 01:06:41.916 And my first reaction is defensive.
NOTE Confidence: 0.92616484

01:06:41.920 --> 01:06:46.480 And I want to, I want to argue.
NOTE Confidence: 0.92616484

01:06:46.480 --> 01:06:48.440 But but I have.
NOTE Confidence: 0.92616484

01:06:48.440 --> 01:06:50.890 I'm fortunately surrounded by colleagues
NOTE Confidence: 0.92616484

01:06:50.890 --> 01:06:53.816 who are are fair thinkers and reasonable
NOTE Confidence: 0.92616484

01:06:53.816 --> 01:06:56.480 people and have a calming influence.
NOTE Confidence: 0.92616484

01:06:56.480 --> 01:07:00.136 But so I I think I understand how.
NOTE Confidence: 0.92616484

01:07:00.140 --> 01:07:02.813 These, these reactions are
NOTE Confidence: 0.92616484

01:07:02.813 --> 01:07:05.410 generated and I wonder if it's not
NOTE Confidence: 0.92616484

01:07:05.486 --> 01:07:07.616 to a certain extent inevitable.
NOTE Confidence: 0.92616484

01:07:07.620 --> 01:07:09.564 And I guess that's what we're

NOTE Confidence: 0.92616484

01:07:09.564 --> 01:07:11.100 trying to minimize with all of this.

NOTE Confidence: 0.946765211764706

01:07:12.340 --> 01:07:14.236 I think it's also important that as part

NOTE Confidence: 0.946765211764706

01:07:14.236 --> 01:07:16.213 of the educational process that we've

NOTE Confidence: 0.946765211764706

01:07:16.213 --> 01:07:18.100 been talking about, and I'm sure that

NOTE Confidence: 0.881810494

01:07:20.980 --> 01:07:23.892 doctor tall Walker is, is is

NOTE Confidence: 0.881810494

01:07:23.892 --> 01:07:27.436 using these guidelines for that.

NOTE Confidence: 0.881810494

01:07:27.436 --> 01:07:30.068 You know, it's part of what can

NOTE Confidence: 0.881810494

01:07:30.068 --> 01:07:32.157 be helpful here I think is,

NOTE Confidence: 0.940253548

01:07:34.720 --> 01:07:38.006 you know, an understanding of how

NOTE Confidence: 0.940253548

01:07:38.006 --> 01:07:42.874 the language is not just, you know,

NOTE Confidence: 0.940253548

01:07:42.874 --> 01:07:46.044 it's not just political correctness that the

NOTE Confidence: 0.940253548

01:07:46.044 --> 01:07:49.151 language use has clinical impacts, right.

NOTE Confidence: 0.940253548

01:07:49.151 --> 01:07:51.888 And it has, it can have very

NOTE Confidence: 0.940253548

01:07:51.888 --> 01:07:53.858 negative clinical impacts and so.

NOTE Confidence: 0.940253548

01:07:53.860 --> 01:07:55.700 Part of what we tried to do in our paper

NOTE Confidence: 0.940253548

01:07:55.752 --> 01:07:57.456 is sort of cite some of the evidence,
NOTE Confidence: 0.940253548

01:07:57.460 --> 01:07:59.140 but we couldn't really cite all of it.
NOTE Confidence: 0.940253548

01:07:59.140 --> 01:08:01.556 But there is a lot of evidence out
NOTE Confidence: 0.940253548

01:08:01.556 --> 01:08:04.171 there that shows how that makes
NOTE Confidence: 0.940253548

01:08:04.171 --> 01:08:06.107 connections between language and
NOTE Confidence: 0.940253548

01:08:06.107 --> 01:08:08.019 categorization and actual harms.
NOTE Confidence: 0.940253548

01:08:08.020 --> 01:08:11.388 So I think that's important to convey that
NOTE Confidence: 0.940253548

01:08:11.388 --> 01:08:14.680 this isn't just sort of like an empty,
NOTE Confidence: 0.940253548

01:08:14.680 --> 01:08:18.088 you know, empty cry of wokeness, right?
NOTE Confidence: 0.940253548

01:08:18.088 --> 01:08:20.176 That there's actual people get hurt.
NOTE Confidence: 0.91952675

01:08:23.450 --> 01:08:26.730 Yes. And and it seems to me that when you,
NOTE Confidence: 0.91952675

01:08:26.730 --> 01:08:28.655 when you when you're able to provide
NOTE Confidence: 0.91952675

01:08:28.655 --> 01:08:30.609 examples they can be really compelling.
NOTE Confidence: 0.91952675

01:08:30.610 --> 01:08:32.962 Some of the examples you provided in
NOTE Confidence: 0.91952675

01:08:32.962 --> 01:08:36.970 in your talk just just now I think
NOTE Confidence: 0.91952675

01:08:36.970 --> 01:08:39.076 could be could be really compelling

NOTE Confidence: 0.91952675

01:08:39.076 --> 01:08:41.638 and maybe it it has something maybe

NOTE Confidence: 0.91952675

01:08:41.638 --> 01:08:44.650 the strategy has to be that it has

NOTE Confidence: 0.91952675

01:08:44.650 --> 01:08:48.165 to be introducing small amounts

NOTE Confidence: 0.91952675

01:08:48.165 --> 01:08:51.785 with very compelling narratives.

NOTE Confidence: 0.91952675

01:08:51.790 --> 01:08:56.830 In order to tone down these reactions,

NOTE Confidence: 0.91952675

01:08:56.830 --> 01:08:59.070 but I'm just speculating,

NOTE Confidence: 0.936740485454546

01:09:01.430 --> 01:09:03.824 Dr. Tall Walker has a further

NOTE Confidence: 0.936740485454546

01:09:03.824 --> 01:09:08.050 contribution to the PA student. The.

NOTE Confidence: 0.936740485454546

01:09:08.050 --> 01:09:10.050 And I will try, if I can figure it out,

NOTE Confidence: 0.936740485454546

01:09:10.050 --> 01:09:12.306 I'll try to figure out how to put

NOTE Confidence: 0.936740485454546

01:09:12.306 --> 01:09:14.248 this into the chat or the Q&A.

NOTE Confidence: 0.936740485454546

01:09:14.250 --> 01:09:15.450 It's well actually if you look in the

NOTE Confidence: 0.93220288

01:09:17.730 --> 01:09:21.528 Q&A, m.yale.ed U slash language and

NOTE Confidence: 0.93220288

01:09:21.528 --> 01:09:23.436 that's the website that the student

NOTE Confidence: 0.93220288

01:09:23.436 --> 01:09:26.291 can bring up to the PA curriculum group

NOTE Confidence: 0.93220288

01:09:26.291 --> 01:09:28.126 to help forward the conversation.
NOTE Confidence: 0.93220288

01:09:28.130 --> 01:09:30.888 So that's our local local problem here.
NOTE Confidence: 0.963734866666667

01:09:33.490 --> 01:09:36.690 Another question from our faculty.
NOTE Confidence: 0.930190315

01:09:39.430 --> 01:09:42.460 Hold on. In response to the question
NOTE Confidence: 0.930190315

01:09:42.460 --> 01:09:44.997 of how to deal with teaching faculty
NOTE Confidence: 0.930190315

01:09:44.997 --> 01:09:46.629 using inappropriate language,
NOTE Confidence: 0.930190315

01:09:46.630 --> 01:09:48.508 I would say the course directors
NOTE Confidence: 0.930190315

01:09:48.508 --> 01:09:50.667 try very hard to address these
NOTE Confidence: 0.930190315

01:09:50.667 --> 01:09:52.772 issues with individual faculty and
NOTE Confidence: 0.930190315

01:09:52.772 --> 01:09:54.857 also provide them with resources
NOTE Confidence: 0.930190315

01:09:54.857 --> 01:09:57.107 to update the language they use.
NOTE Confidence: 0.930190315

01:09:57.110 --> 01:10:01.212 So I agree. I think, I think we're,
NOTE Confidence: 0.930190315

01:10:01.212 --> 01:10:02.923 we're working on this, we're,
NOTE Confidence: 0.930190315

01:10:02.923 --> 01:10:05.270 we're trying to do better. So.
NOTE Confidence: 0.7916372

01:10:07.580 --> 01:10:10.620 And and and so my
NOTE Confidence: 0.9352219

01:10:13.980 --> 01:10:18.488 as part of what we've been been

NOTE Confidence: 0.9352219

01:10:18.488 --> 01:10:22.473 talking about this this whole idea of

NOTE Confidence: 0.9352219

01:10:22.473 --> 01:10:26.633 you know can you think of of the the

NOTE Confidence: 0.9352219

01:10:26.633 --> 01:10:30.146 larger strategy for how we implement

NOTE Confidence: 0.9352219

01:10:30.146 --> 01:10:34.376 these suggestions these these changes.

NOTE Confidence: 0.96289617625

01:10:36.700 --> 01:10:37.975 Through academic medicine,

NOTE Confidence: 0.96289617625

01:10:37.975 --> 01:10:40.100 but through medicine in general.

NOTE Confidence: 0.96289617625

01:10:40.100 --> 01:10:42.124 And that's a very large question and I

NOTE Confidence: 0.96289617625

01:10:42.124 --> 01:10:44.177 think you've partially addressed it so far.

NOTE Confidence: 0.96289617625

01:10:44.180 --> 01:10:47.385 But if you have any thoughts about the,

NOTE Confidence: 0.96289617625

01:10:47.385 --> 01:10:49.660 the grand strategy, if if you will.

NOTE Confidence: 0.944278888

01:10:52.860 --> 01:10:54.612 Yeah, I haven't really thought that

NOTE Confidence: 0.944278888

01:10:54.612 --> 01:10:56.808 much about sort of broader changes,

NOTE Confidence: 0.944278888

01:10:56.808 --> 01:11:00.406 how to sort of implement broader changes

NOTE Confidence: 0.944278888

01:11:00.406 --> 01:11:04.177 in medicine writ large that that's huge.

NOTE Confidence: 0.944278888

01:11:04.180 --> 01:11:06.236 I mean, obviously education.

NOTE Confidence: 0.944278888

01:11:06.236 --> 01:11:09.320 And the medical education process is,
NOTE Confidence: 0.944278888

01:11:09.320 --> 01:11:14.960 is is you know, an obvious target of efforts
NOTE Confidence: 0.942266398

01:11:18.880 --> 01:11:22.592 and there are I think there are some
NOTE Confidence: 0.942266398

01:11:22.592 --> 01:11:24.945 some resources that are aimed at sort
NOTE Confidence: 0.942266398

01:11:24.945 --> 01:11:27.279 of in the growing set of resources.
NOTE Confidence: 0.942266398

01:11:27.280 --> 01:11:30.264 I'm sorry I don't have them sort of
NOTE Confidence: 0.942266398

01:11:30.264 --> 01:11:32.888 off the tip of my tongue right now,
NOTE Confidence: 0.942266398

01:11:32.888 --> 01:11:35.240 but there are resources on sort of.
NOTE Confidence: 0.840793568888889

01:11:38.930 --> 01:11:41.660 For example, anti racism and
NOTE Confidence: 0.840793568888889

01:11:41.660 --> 01:11:43.844 anti ableism in medicine,
NOTE Confidence: 0.840793568888889

01:11:43.850 --> 01:11:46.450 how to institutionalize those,
NOTE Confidence: 0.930420142857143

01:11:50.050 --> 01:11:51.390 you know, that's that's a
NOTE Confidence: 0.930420142857143

01:11:51.390 --> 01:11:52.450 different story. I think
NOTE Confidence: 0.948080688888889

01:11:55.450 --> 01:11:58.225 in terms of research there
NOTE Confidence: 0.948080688888889

01:11:58.225 --> 01:12:00.445 are some leverage points.
NOTE Confidence: 0.948080688888889

01:12:00.450 --> 01:12:02.034 Some of which are mentioned in

NOTE Confidence: 0.948080688888889
01:12:02.034 --> 01:12:03.090 that National Academies report.
NOTE Confidence: 0.948080688888889
01:12:03.090 --> 01:12:04.910 And although the report really
NOTE Confidence: 0.948080688888889
01:12:04.910 --> 01:12:07.490 is focused on race and ethnicity,
NOTE Confidence: 0.948080688888889
01:12:07.490 --> 01:12:10.334 I think these leverage points are
NOTE Confidence: 0.948080688888889
01:12:10.334 --> 01:12:12.530 really valid for all research.
NOTE Confidence: 0.948080688888889
01:12:12.530 --> 01:12:15.110 So one of them is obviously
NOTE Confidence: 0.948080688888889
01:12:15.204 --> 01:12:17.568 through journal publication.
NOTE Confidence: 0.948080688888889
01:12:17.570 --> 01:12:19.545 Another one that they pointed
NOTE Confidence: 0.948080688888889
01:12:19.545 --> 01:12:21.125 to is research funders,
NOTE Confidence: 0.948080688888889
01:12:21.130 --> 01:12:25.229 and they provide a even a sort
NOTE Confidence: 0.948080688888889
01:12:25.229 --> 01:12:27.194 of checklist of things that
NOTE Confidence: 0.948080688888889
01:12:27.194 --> 01:12:28.829 research funders should ask.
NOTE Confidence: 0.948080688888889
01:12:28.830 --> 01:12:32.195 Before they provide funding to
NOTE Confidence: 0.948080688888889
01:12:32.195 --> 01:12:35.325 researchers to assure that they have
NOTE Confidence: 0.948080688888889
01:12:35.325 --> 01:12:40.416 gotten education on issues regarding racism,
NOTE Confidence: 0.948080688888889

01:12:40.416 --> 01:12:42.148 ableism, etcetera,
NOTE Confidence: 0.948304226

01:12:44.590 --> 01:12:47.440 as well as. Pretty specific
NOTE Confidence: 0.948304226

01:12:47.440 --> 01:12:50.290 questions they could be asking.
NOTE Confidence: 0.948304226

01:12:50.290 --> 01:12:53.410 Funders could be asking of researchers
NOTE Confidence: 0.948304226

01:12:53.410 --> 01:12:56.574 in in their in Grant proposal right
NOTE Confidence: 0.948304226

01:12:56.574 --> 01:13:00.460 in terms of study design and asking
NOTE Confidence: 0.948304226

01:13:00.460 --> 01:13:04.050 for methodological rigor in in
NOTE Confidence: 0.948304226

01:13:04.050 --> 01:13:06.810 their use and and even questioning.
NOTE Confidence: 0.948304226

01:13:06.810 --> 01:13:09.138 Do you need to use categories
NOTE Confidence: 0.948304226

01:13:09.138 --> 01:13:10.930 such as race altogether?
NOTE Confidence: 0.948304226

01:13:10.930 --> 01:13:11.980 Maybe you don't.
NOTE Confidence: 0.948304226

01:13:11.980 --> 01:13:13.730 Maybe it would be inappropriate.
NOTE Confidence: 0.923000405882353

01:13:15.900 --> 01:13:18.714 So there's there's lots of sort of
NOTE Confidence: 0.923000405882353

01:13:18.714 --> 01:13:21.655 levers that can be pushed there and
NOTE Confidence: 0.923000405882353

01:13:21.655 --> 01:13:23.566 and that there's institutionally some
NOTE Confidence: 0.923000405882353

01:13:23.566 --> 01:13:25.897 of the things they talked about were

NOTE Confidence: 0.9301902

01:13:27.940 --> 01:13:34.420 at the level of the IRB for example and

NOTE Confidence: 0.9301902

01:13:34.420 --> 01:13:40.408 you know although that might end up by.

NOTE Confidence: 0.9301902

01:13:40.410 --> 01:13:42.660 In the form of more requirements

NOTE Confidence: 0.9301902

01:13:42.660 --> 01:13:44.658 for training, like HIPAA training,

NOTE Confidence: 0.9301902

01:13:44.658 --> 01:13:47.550 you know, but that is one of

NOTE Confidence: 0.9301902

01:13:47.550 --> 01:13:49.610 the suggestions that they made.

NOTE Confidence: 0.9301902

01:13:49.610 --> 01:13:52.370 And, you know, requiring that

NOTE Confidence: 0.9301902

01:13:52.370 --> 01:13:55.130 there be some education before

NOTE Confidence: 0.9301902

01:13:55.130 --> 01:13:58.330 researchers are allowed to use

NOTE Confidence: 0.9301902

01:13:58.330 --> 01:14:00.050 samples from human subjects,

NOTE Confidence: 0.9301902

01:14:00.050 --> 01:14:02.200 or to access human subjects

NOTE Confidence: 0.9301902

01:14:02.200 --> 01:14:03.929 at all in their research.

NOTE Confidence: 0.94780115

01:14:09.160 --> 01:14:10.960 They also talked about

NOTE Confidence: 0.948639766666667

01:14:14.680 --> 01:14:16.689 I think there were there were other

NOTE Confidence: 0.948639766666667

01:14:16.689 --> 01:14:18.719 issues that were really institutional

NOTE Confidence: 0.93365423125

01:14:21.080 --> 01:14:23.546 beyond education but you know there's
NOTE Confidence: 0.93365423125

01:14:23.546 --> 01:14:26.255 there's sort of many different places
NOTE Confidence: 0.93365423125

01:14:26.255 --> 01:14:28.840 pressure points that that where
NOTE Confidence: 0.95434236

01:14:32.160 --> 01:14:34.208 faculty for example at
NOTE Confidence: 0.95434236

01:14:34.208 --> 01:14:35.800 academic organizations.
NOTE Confidence: 0.917653326315789

01:14:38.840 --> 01:14:42.172 You know are are subject to pressure
NOTE Confidence: 0.917653326315789

01:14:42.172 --> 01:14:46.320 from from the institution and and the
NOTE Confidence: 0.917653326315789

01:14:46.320 --> 01:14:49.600 institution and can have requirements.
NOTE Confidence: 0.917653326315789

01:14:49.600 --> 01:14:51.904 The other one that I mentioned
NOTE Confidence: 0.917653326315789

01:14:51.904 --> 01:14:54.346 was you know review of protocols
NOTE Confidence: 0.917653326315789

01:14:54.346 --> 01:14:57.064 for example or maybe of articles
NOTE Confidence: 0.917653326315789

01:14:57.064 --> 01:14:59.104 and obviously they're these are
NOTE Confidence: 0.917653326315789

01:14:59.104 --> 01:15:01.480 probably going to come up against.
NOTE Confidence: 0.92154553

01:15:05.170 --> 01:15:07.050 Criticisms in terms of academic
NOTE Confidence: 0.92154553

01:15:07.050 --> 01:15:08.930 freedom and and so forth.
NOTE Confidence: 0.92154553

01:15:08.930 --> 01:15:12.530 But I think that there are

NOTE Confidence: 0.92154553
01:15:12.530 --> 01:15:16.083 some good ethical reasons why,
NOTE Confidence: 0.92154553
01:15:16.083 --> 01:15:18.527 at the very least,
NOTE Confidence: 0.92154553
01:15:18.530 --> 01:15:21.854 researchers should be asked
NOTE Confidence: 0.92154553
01:15:21.854 --> 01:15:24.474 to demonstrate some type of
NOTE Confidence: 0.92154553
01:15:24.474 --> 01:15:26.570 competency and knowledge about
NOTE Confidence: 0.951754628571429
01:15:28.690 --> 01:15:33.128 the use of categories for scientific reasons.
NOTE Confidence: 0.951754628571429
01:15:33.130 --> 01:15:34.950 I think that you know.
NOTE Confidence: 0.951754628571429
01:15:34.950 --> 01:15:37.694 The way that we use the categories
NOTE Confidence: 0.951754628571429
01:15:37.694 --> 01:15:40.284 of human difference that are related
NOTE Confidence: 0.951754628571429
01:15:40.284 --> 01:15:43.846 to social identities are used in ways
NOTE Confidence: 0.951754628571429
01:15:43.846 --> 01:15:46.622 that are very methodologically sloppy,
NOTE Confidence: 0.951754628571429
01:15:46.622 --> 01:15:50.514 and we would not allow other medical
NOTE Confidence: 0.951754628571429
01:15:50.514 --> 01:15:52.949 variables to be used in this way,
NOTE Confidence: 0.951754628571429
01:15:52.950 --> 01:15:54.732 right, if you think about when
NOTE Confidence: 0.951754628571429
01:15:54.732 --> 01:15:55.623 you're making measurements.
NOTE Confidence: 0.951754628571429

01:15:55.630 --> 01:15:57.961 Of things are certain things that are
NOTE Confidence: 0.951754628571429

01:15:57.961 --> 01:15:59.854 related to rigor and reproducibility.
NOTE Confidence: 0.951754628571429

01:15:59.854 --> 01:16:02.146 You know, when you measure a blood pressure,
NOTE Confidence: 0.951754628571429

01:16:02.150 --> 01:16:04.350 you need to know it's a blood pressure.
NOTE Confidence: 0.951754628571429

01:16:04.350 --> 01:16:05.510 And what is blood pressure?
NOTE Confidence: 0.951754628571429

01:16:05.510 --> 01:16:08.870 You have to have definitions of that,
NOTE Confidence: 0.951754628571429

01:16:08.870 --> 01:16:11.117 you know, and we don't treat these
NOTE Confidence: 0.951754628571429

01:16:11.117 --> 01:16:12.728 identity categories or these social
NOTE Confidence: 0.951754628571429

01:16:12.728 --> 01:16:14.786 categories in the same way at all.
NOTE Confidence: 0.94427896

01:16:16.910 --> 01:16:19.390 So you know, that's another,
NOTE Confidence: 0.94427896

01:16:19.390 --> 01:16:20.428 that's another issue.
NOTE Confidence: 0.9402536

01:16:23.030 --> 01:16:25.406 And then finally one of the things that.
NOTE Confidence: 0.9402536

01:16:25.410 --> 01:16:29.083 I've been talking about is including
NOTE Confidence: 0.9402536

01:16:29.083 --> 01:16:35.490 these issues in analysis of research
NOTE Confidence: 0.9402536

01:16:35.490 --> 01:16:39.130 ethics consultation cases. So
NOTE Confidence: 0.9095679748

01:16:41.370 --> 01:16:43.362 I have a long list of things that

NOTE Confidence: 0.9095679748

01:16:43.362 --> 01:16:45.581 I am now requiring our trainees

NOTE Confidence: 0.9095679748

01:16:45.581 --> 01:16:47.646 who are trained getting training

NOTE Confidence: 0.9095679748

01:16:47.646 --> 01:16:49.544 and research ethics consultation

NOTE Confidence: 0.9095679748

01:16:49.544 --> 01:16:52.490 to read so that they can include

NOTE Confidence: 0.9095679748

01:16:52.490 --> 01:16:54.090 these considerations as their.

NOTE Confidence: 0.9095679748

01:16:54.090 --> 01:16:57.770 Reviewing protocols or study designs

NOTE Confidence: 0.9095679748

01:16:57.770 --> 01:17:00.230 that are presented in the context

NOTE Confidence: 0.9095679748

01:17:00.302 --> 01:17:02.490 of research ethics consultation.

NOTE Confidence: 0.93019015

01:17:04.970 --> 01:17:05.610 The the,

NOTE Confidence: 0.899789710952381

01:17:08.330 --> 01:17:11.235 the idea, or the the notion of

NOTE Confidence: 0.899789710952381

01:17:11.235 --> 01:17:13.768 requiring people to demonstrate some

NOTE Confidence: 0.899789710952381

01:17:13.768 --> 01:17:16.758 confidence in these matters before

NOTE Confidence: 0.899789710952381

01:17:16.758 --> 01:17:19.716 they can participate in in submitting

NOTE Confidence: 0.899789710952381

01:17:19.716 --> 01:17:21.528 research or submitting documents.

NOTE Confidence: 0.931051435833333

01:17:24.390 --> 01:17:27.468 Do you I I assume that runs the risk

NOTE Confidence: 0.931051435833333

01:17:27.468 --> 01:17:30.974 of generating resentment and people at,
NOTE Confidence: 0.931051435833333

01:17:30.974 --> 01:17:33.954 you know, doing the functory checklist,
NOTE Confidence: 0.931051435833333

01:17:33.954 --> 01:17:37.769 learning as little as possible to get
NOTE Confidence: 0.931051435833333

01:17:37.769 --> 01:17:41.108 by through the process of getting their
NOTE Confidence: 0.931051435833333

01:17:41.108 --> 01:17:45.010 grants submitted and funded and getting
NOTE Confidence: 0.931051435833333

01:17:45.010 --> 01:17:48.430 their documents reviewed and accepted.
NOTE Confidence: 0.931051435833333

01:17:48.430 --> 01:17:52.016 But, and that troubles me to an extent, but.
NOTE Confidence: 0.931051435833333

01:17:52.016 --> 01:17:55.666 On the other hand, once people understand
NOTE Confidence: 0.931051435833333

01:17:55.666 --> 01:17:58.960 what the what's the, what's required,
NOTE Confidence: 0.934662822222222

01:18:01.680 --> 01:18:05.502 we seem to adapt and it becomes
NOTE Confidence: 0.934662822222222

01:18:05.502 --> 01:18:08.520 part of part of what life is about.
NOTE Confidence: 0.934662822222222

01:18:08.520 --> 01:18:11.250 And so this would be part of what
NOTE Confidence: 0.934662822222222

01:18:11.250 --> 01:18:12.800 academic life would be about.
NOTE Confidence: 0.934662822222222

01:18:12.800 --> 01:18:15.344 Perhaps eventually we get to where this is
NOTE Confidence: 0.934662822222222

01:18:15.344 --> 01:18:18.924 part of what clinical practice is all about.
NOTE Confidence: 0.934662822222222

01:18:18.924 --> 01:18:21.585 And so maybe, at least initially,

NOTE Confidence: 0.934662822222222

01:18:21.585 --> 01:18:25.320 we don't care if people believe avidly in

NOTE Confidence: 0.934662822222222

01:18:25.320 --> 01:18:29.660 all the things that you've been advocating,

NOTE Confidence: 0.934662822222222

01:18:29.660 --> 01:18:31.820 but at least they can fake

NOTE Confidence: 0.934662822222222

01:18:31.820 --> 01:18:33.580 it until they make it.

NOTE Confidence: 0.934662822222222

01:18:33.580 --> 01:18:36.100 Now, does that sound just too cynical,

NOTE Confidence: 0.934662822222222

01:18:36.100 --> 01:18:40.220 or is is that a possible approach?

NOTE Confidence: 0.936228332

01:18:41.620 --> 01:18:43.564 Well, yeah, I think.

NOTE Confidence: 0.936228332

01:18:43.564 --> 01:18:45.766 Yeah, for some people they're, you know,

NOTE Confidence: 0.936228332

01:18:45.770 --> 01:18:47.730 these practices are very entrenched.

NOTE Confidence: 0.936228332

01:18:47.730 --> 01:18:48.714 When, you know,

NOTE Confidence: 0.936228332

01:18:48.714 --> 01:18:50.682 when somebody does a case presentation,

NOTE Confidence: 0.936228332

01:18:50.690 --> 01:18:52.125 what they, what do they start with?

NOTE Confidence: 0.936228332

01:18:52.130 --> 01:18:53.890 They start with, you know,

NOTE Confidence: 0.936228332

01:18:53.890 --> 01:18:56.690 this is a 35 year old black male with blah,

NOTE Confidence: 0.936228332

01:18:56.690 --> 01:18:58.226 blah, blah, blah blah.

NOTE Confidence: 0.936228332

01:18:58.226 --> 01:19:00.410 And without any sort of thought about,
NOTE Confidence: 0.936228332

01:19:00.410 --> 01:19:01.310 well, what is that?
NOTE Confidence: 0.936228332

01:19:01.310 --> 01:19:02.210 Why is that relevant?
NOTE Confidence: 0.936228332

01:19:02.210 --> 01:19:03.970 Is that relevant at all in this case,
NOTE Confidence: 0.936228332

01:19:03.970 --> 01:19:05.330 what does black mean?
NOTE Confidence: 0.936228332

01:19:05.330 --> 01:19:07.370 I mean that the National Academy
NOTE Confidence: 0.936228332

01:19:07.433 --> 01:19:09.109 report actually recommends not
NOTE Confidence: 0.936228332

01:19:09.109 --> 01:19:11.204 using the term black anymore.
NOTE Confidence: 0.936228332

01:19:11.210 --> 01:19:13.010 It also recommends not using
NOTE Confidence: 0.936228332

01:19:13.010 --> 01:19:14.810 the term white anymore because
NOTE Confidence: 0.936228332

01:19:14.881 --> 01:19:16.406 what does that even mean?
NOTE Confidence: 0.936228332

01:19:16.410 --> 01:19:19.290 What does that even mean in the context of,
NOTE Confidence: 0.936228332

01:19:19.290 --> 01:19:19.690 you know,
NOTE Confidence: 0.936701811764706

01:19:23.610 --> 01:19:25.474 well, I mean, we could go on for
NOTE Confidence: 0.936701811764706

01:19:25.474 --> 01:19:27.148 hours just about that question in
NOTE Confidence: 0.936701811764706

01:19:27.148 --> 01:19:30.302 and of itself, but we do a lot of

NOTE Confidence: 0.936701811764706
01:19:30.302 --> 01:19:31.794 things without thinking, right?
NOTE Confidence: 0.936701811764706
01:19:31.794 --> 01:19:33.890 And so I think just asking
NOTE Confidence: 0.936701811764706
01:19:33.890 --> 01:19:36.050 people to pause for a moment.
NOTE Confidence: 0.930397261538461
01:19:42.550 --> 01:19:45.734 And if that means that there has to
NOTE Confidence: 0.930397261538461
01:19:45.734 --> 01:19:49.230 be sort of educational requirements,
NOTE Confidence: 0.94226628
01:19:53.950 --> 01:19:55.798 you know, I think those are
NOTE Confidence: 0.94226628
01:19:55.798 --> 01:19:57.030 going to cause resentment,
NOTE Confidence: 0.94226628
01:19:57.030 --> 01:20:03.998 but also once if these kinds of issues
NOTE Confidence: 0.94226628
01:20:03.998 --> 01:20:07.641 get incorporated at levels like.
NOTE Confidence: 0.94226628
01:20:07.641 --> 01:20:12.209 At places like in the grant review process,
NOTE Confidence: 0.94226628
01:20:12.210 --> 01:20:16.370 in the paper review process,
NOTE Confidence: 0.94226628
01:20:16.370 --> 01:20:18.002 that means that they will be
NOTE Confidence: 0.94226628
01:20:18.002 --> 01:20:19.489 inevitable and people will have to
NOTE Confidence: 0.93220288
01:20:23.010 --> 01:20:24.090 do more than fake it.
NOTE Confidence: 0.9402536
01:20:26.970 --> 01:20:29.930 They they can't just talk to talk,
NOTE Confidence: 0.9402536

01:20:29.930 --> 01:20:31.498 they have to be.
NOTE Confidence: 0.9402536

01:20:31.498 --> 01:20:33.850 Eventually they will walk the walk,
NOTE Confidence: 0.9402536

01:20:33.850 --> 01:20:37.210 as you said in some circles.
NOTE Confidence: 0.9402536

01:20:37.210 --> 01:20:41.140 Well, this has been a
NOTE Confidence: 0.9402536

01:20:41.140 --> 01:20:43.810 delightful session and we really
NOTE Confidence: 0.9402536

01:20:43.810 --> 01:20:45.690 appreciate you joining us.
NOTE Confidence: 0.9402536

01:20:45.690 --> 01:20:49.146 Do you have any further remarks
NOTE Confidence: 0.9402536

01:20:49.146 --> 01:20:50.886 you'd like to conclude with?
NOTE Confidence: 0.93270605

01:20:54.730 --> 01:20:55.690 I don't think so.
NOTE Confidence: 0.914403282222222

01:20:57.970 --> 01:21:00.658 Just want to thank you for
NOTE Confidence: 0.914403282222222

01:21:00.658 --> 01:21:02.622 inviting me to see your group,
NOTE Confidence: 0.914403282222222

01:21:02.622 --> 01:21:04.050 even though I can't really see them.
NOTE Confidence: 0.936479825

01:21:04.830 --> 01:21:06.210 Yes, all right. Well,
NOTE Confidence: 0.936479825

01:21:06.210 --> 01:21:08.538 thank you so much. This has been,
NOTE Confidence: 0.936479825

01:21:08.538 --> 01:21:10.750 this has been terrific and we really
NOTE Confidence: 0.936479825

01:21:10.811 --> 01:21:12.666 appreciate you you joining us.

NOTE Confidence: 0.936479825

01:21:12.670 --> 01:21:14.710 So have have a good evening.

NOTE Confidence: 0.9402536

01:21:15.910 --> 01:21:16.310 Thank you.