

WEBVTT

NOTE duration: "00:55:44.384"

NOTE Confidence: 0.7423461

00:00:00.399 --> 00:00:01.599 Good afternoon, and,

NOTE Confidence: 0.9519621

00:00:02.080 --> 00:00:03.860 welcome to everyone to our

NOTE Confidence: 0.83975875

00:00:05.759 --> 00:00:06.259 attention.

NOTE Confidence: 0.592409

00:00:07.120 --> 00:00:09.220 This is Hi, Nice. I

NOTE Confidence: 0.97148144

00:00:10.000 --> 00:00:11.200 hate to interrupt these great

NOTE Confidence: 0.97148144

00:00:11.200 --> 00:00:12.559 conversations, but we have a

NOTE Confidence: 0.97148144

00:00:12.559 --> 00:00:14.080 great speaker. So we'll we'll

NOTE Confidence: 0.97148144

00:00:14.080 --> 00:00:14.900 get to it.

NOTE Confidence: 0.8490879

00:00:15.325 --> 00:00:16.685 Of course. So,

NOTE Confidence: 0.89350444

00:00:18.605 --> 00:00:21.105 welcome everyone to, our first

NOTE Confidence: 0.89350444

00:00:21.244 --> 00:00:22.945 research and progress presentation

NOTE Confidence: 0.9983951

00:00:24.045 --> 00:00:25.325 for twenty twenty six. It's

NOTE Confidence: 0.9983951

00:00:25.325 --> 00:00:26.445 great to see everyone here

NOTE Confidence: 0.9983951

00:00:26.445 --> 00:00:27.965 today, and it's great to

NOTE Confidence: 0.9983951

00:00:27.965 --> 00:00:30.064 have folks online as well.  
NOTE Confidence: 0.999042  
00:00:30.600 --> 00:00:32.040 The CME code for today's  
NOTE Confidence: 0.999042  
00:00:32.040 --> 00:00:34.220 meeting is five five six  
NOTE Confidence: 0.999042  
00:00:34.520 --> 00:00:35.340 five nine  
NOTE Confidence: 0.92725646  
00:00:36.520 --> 00:00:38.300 five five six five nine.  
NOTE Confidence: 0.91992176  
00:00:39.479 --> 00:00:40.680 Just wanted to extend a  
NOTE Confidence: 0.91992176  
00:00:40.680 --> 00:00:42.760 congratulations to Gretchen Berlin who,  
NOTE Confidence: 0.91992176  
00:00:43.000 --> 00:00:44.700 presented her professorial,  
NOTE Confidence: 0.96728927  
00:00:46.165 --> 00:00:47.765 grand rounds this morning, at  
NOTE Confidence: 0.96728927  
00:00:47.765 --> 00:00:48.425 the department.  
NOTE Confidence: 0.87950474  
00:00:49.645 --> 00:00:51.445 It, was in recognition of  
NOTE Confidence: 0.87950474  
00:00:51.445 --> 00:00:52.104 our recent,  
NOTE Confidence: 0.99096644  
00:00:52.965 --> 00:00:54.565 promotion to professor. She just  
NOTE Confidence: 0.99096644  
00:00:54.565 --> 00:00:56.725 did a spectacular job, providing  
NOTE Confidence: 0.99096644  
00:00:56.725 --> 00:00:58.025 an overview of her  
NOTE Confidence: 0.9851631  
00:00:58.370 --> 00:00:59.490 career and many contributions,

NOTE Confidence: 0.98412573  
00:01:00.930 --> 00:01:01.970 both here at Yale and  
NOTE Confidence: 0.98412573  
00:01:01.970 --> 00:01:03.030 nationally. So,  
NOTE Confidence: 0.99768585  
00:01:03.650 --> 00:01:05.090 just a great congratulations to  
NOTE Confidence: 0.99768585  
00:01:05.090 --> 00:01:06.610 her. If you missed it,  
NOTE Confidence: 0.99768585  
00:01:06.610 --> 00:01:07.730 there is a recording of  
NOTE Confidence: 0.99768585  
00:01:07.730 --> 00:01:09.170 it available on the department  
NOTE Confidence: 0.99768585  
00:01:09.170 --> 00:01:09.670 website.  
NOTE Confidence: 0.9416773  
00:01:13.475 --> 00:01:14.515 Okay. And,  
NOTE Confidence: 0.98293215  
00:01:15.155 --> 00:01:16.994 our weekly reminder about our  
NOTE Confidence: 0.98293215  
00:01:16.994 --> 00:01:17.494 retreats.  
NOTE Confidence: 0.9356455  
00:01:18.194 --> 00:01:19.314 Our next retreat is going  
NOTE Confidence: 0.9356455  
00:01:19.314 --> 00:01:20.755 to be February six, at  
NOTE Confidence: 0.9356455  
00:01:20.755 --> 00:01:21.954 the Yale West Campus, the  
NOTE Confidence: 0.9356455  
00:01:21.954 --> 00:01:23.575 professional development retreat.  
NOTE Confidence: 0.98561907  
00:01:24.160 --> 00:01:25.700 Abba Black has put together  
NOTE Confidence: 0.98561907

00:01:25.760 --> 00:01:26.900 a wonderful program.  
NOTE Confidence: 0.9706072

00:01:27.440 --> 00:01:28.720 She'll probably tell us more  
NOTE Confidence: 0.9706072

00:01:28.720 --> 00:01:29.760 about it perhaps at next  
NOTE Confidence: 0.9706072

00:01:29.760 --> 00:01:30.980 week's faculty meeting.  
NOTE Confidence: 0.97104275

00:01:32.160 --> 00:01:33.600 And, it'd be great to  
NOTE Confidence: 0.97104275

00:01:33.600 --> 00:01:34.959 see as many as many  
NOTE Confidence: 0.97104275

00:01:34.959 --> 00:01:35.920 of you there as possible.  
NOTE Confidence: 0.97104275

00:01:35.920 --> 00:01:37.220 It's always a wonderful  
NOTE Confidence: 0.996766

00:01:37.920 --> 00:01:39.780 experience that Abba puts together.  
NOTE Confidence: 0.9161749

00:01:42.375 --> 00:01:44.215 Here's our weekly reminder, at  
NOTE Confidence: 0.9161749

00:01:44.215 --> 00:01:45.174 least for this time of  
NOTE Confidence: 0.9161749

00:01:45.174 --> 00:01:47.194 year, around the, FDAC,  
NOTE Confidence: 0.994218

00:01:47.735 --> 00:01:48.235 process.  
NOTE Confidence: 0.8763073

00:01:49.174 --> 00:01:50.775 Again, we're at step one,  
NOTE Confidence: 0.8763073

00:01:50.775 --> 00:01:51.275 which  
NOTE Confidence: 0.9708536

00:01:52.220 --> 00:01:53.820 goes until February second. Now

NOTE Confidence: 0.9708536  
00:01:53.820 --> 00:01:55.260 I heard from Vivian, I  
NOTE Confidence: 0.9708536  
00:01:55.260 --> 00:01:56.800 think, that so far,  
NOTE Confidence: 0.9905542  
00:01:57.260 --> 00:01:58.620 our response numbers are on  
NOTE Confidence: 0.9905542  
00:01:58.620 --> 00:01:59.760 the low side.  
NOTE Confidence: 0.961546  
00:02:00.860 --> 00:02:02.220 But last year, we ended  
NOTE Confidence: 0.961546  
00:02:02.220 --> 00:02:03.600 up with one hundred percent.  
NOTE Confidence: 0.961546  
00:02:03.740 --> 00:02:05.119 I'm sure we'll get there,  
NOTE Confidence: 0.9924061  
00:02:06.285 --> 00:02:08.065 as well this year. So  
NOTE Confidence: 0.9966888  
00:02:08.605 --> 00:02:10.445 please don't forget to complete  
NOTE Confidence: 0.9966888  
00:02:10.445 --> 00:02:12.285 your FDAC documents and follow  
NOTE Confidence: 0.9966888  
00:02:12.285 --> 00:02:12.945 the steps  
NOTE Confidence: 0.9947321  
00:02:13.725 --> 00:02:14.705 on this slide.  
NOTE Confidence: 0.9395734  
00:02:15.965 --> 00:02:18.125 And then, next week, for  
NOTE Confidence: 0.9395734  
00:02:18.125 --> 00:02:19.580 our grand rounds,  
NOTE Confidence: 0.8446891  
00:02:20.280 --> 00:02:21.500 Ashley, Lussier  
NOTE Confidence: 0.97129095

00:02:21.800 --> 00:02:23.580 is presenting on bronchiectasis,  
NOTE Confidence: 0.9993482

00:02:24.200 --> 00:02:24.700 specifically  
NOTE Confidence: 0.9817289

00:02:25.400 --> 00:02:26.200 when to think of it  
NOTE Confidence: 0.9817289

00:02:26.200 --> 00:02:27.420 in primary care.  
NOTE Confidence: 0.9978407

00:02:28.120 --> 00:02:29.800 And next Thursday at noon,  
NOTE Confidence: 0.9978407

00:02:29.800 --> 00:02:31.340 we'll have our monthly section  
NOTE Confidence: 0.97370696

00:02:31.800 --> 00:02:33.240 faculty and staff meeting, and  
NOTE Confidence: 0.97370696

00:02:33.240 --> 00:02:34.300 I know there's a  
NOTE Confidence: 0.9885321

00:02:34.655 --> 00:02:35.855 great agenda for that meeting  
NOTE Confidence: 0.9885321

00:02:35.855 --> 00:02:36.495 as well. So,  
NOTE Confidence: 0.983289

00:02:37.055 --> 00:02:38.014 and we'll send out an  
NOTE Confidence: 0.983289

00:02:38.014 --> 00:02:39.775 announcement with that agenda early  
NOTE Confidence: 0.983289

00:02:39.775 --> 00:02:40.435 next week.  
NOTE Confidence: 0.98428947

00:02:41.055 --> 00:02:42.334 Look forward to seeing everyone  
NOTE Confidence: 0.98428947

00:02:42.334 --> 00:02:42.834 there.  
NOTE Confidence: 0.99424314

00:02:43.535 --> 00:02:45.775 Here's our disclosure slide, and

NOTE Confidence: 0.99424314  
00:02:45.775 --> 00:02:47.215 I have the privilege now  
NOTE Confidence: 0.99424314  
00:02:47.215 --> 00:02:48.675 of turning over the podium  
NOTE Confidence: 0.99424314  
00:02:48.735 --> 00:02:49.394 to your  
NOTE Confidence: 0.85313356  
00:02:50.020 --> 00:02:51.460 vice chief of research, Carrie  
NOTE Confidence: 0.85313356  
00:02:51.460 --> 00:02:52.440 Gross. Carrie.  
NOTE Confidence: 0.9417483  
00:02:55.700 --> 00:02:57.220 Thanks, Patrick, and happy New  
NOTE Confidence: 0.9417483  
00:02:57.220 --> 00:02:58.980 Year, everyone. And, yeah, again,  
NOTE Confidence: 0.9417483  
00:02:58.980 --> 00:03:00.680 I wanted to reiterate our,  
NOTE Confidence: 0.71303606  
00:03:01.139 --> 00:03:01.639 congratulations  
NOTE Confidence: 0.9308747  
00:03:01.940 --> 00:03:02.900 to Gretchen. It was a  
NOTE Confidence: 0.9308747  
00:03:02.900 --> 00:03:04.500 really an amazing grand rounds.  
NOTE Confidence: 0.9308747  
00:03:04.500 --> 00:03:05.794 And, actually, I feel like  
NOTE Confidence: 0.9308747  
00:03:05.794 --> 00:03:07.815 Jen Miller, our speaker today  
NOTE Confidence: 0.9308747  
00:03:07.955 --> 00:03:08.194 is,  
NOTE Confidence: 0.9850136  
00:03:09.635 --> 00:03:11.474 has followed footsteps that are  
NOTE Confidence: 0.9850136

00:03:11.474 --> 00:03:13.474 illustrative of the importance of  
NOTE Confidence: 0.9850136

00:03:13.474 --> 00:03:15.555 partnership and change from within  
NOTE Confidence: 0.9850136

00:03:15.555 --> 00:03:17.315 as opposed to just changing  
NOTE Confidence: 0.9850136

00:03:17.315 --> 00:03:17.635 from,  
NOTE Confidence: 0.8614472

00:03:18.549 --> 00:03:19.209 from outside.  
NOTE Confidence: 0.84903693

00:03:20.069 --> 00:03:20.569 Jen,  
NOTE Confidence: 0.925077

00:03:20.870 --> 00:03:21.909 I didn't realize you were  
NOTE Confidence: 0.925077

00:03:21.909 --> 00:03:23.689 a physics major undergrad.  
NOTE Confidence: 0.7903589

00:03:24.790 --> 00:03:26.889 And then, after your under  
NOTE Confidence: 0.7903589

00:03:26.950 --> 00:03:27.849 Jen Miller's  
NOTE Confidence: 0.91436166

00:03:28.150 --> 00:03:31.049 undergraduate training, she proceeded to  
NOTE Confidence: 0.91436166

00:03:31.189 --> 00:03:32.889 get graduate training in  
NOTE Confidence: 0.9665822

00:03:34.525 --> 00:03:35.805 international health and business, but  
NOTE Confidence: 0.9665822

00:03:35.805 --> 00:03:37.085 really then focusing more on  
NOTE Confidence: 0.9665822

00:03:37.085 --> 00:03:38.445 bioethics where she went on  
NOTE Confidence: 0.9665822

00:03:38.445 --> 00:03:39.645 to get her PhD in



NOTE Confidence: 0.9665822  
00:03:39.645 --> 00:03:40.145 bioethics,  
NOTE Confidence: 0.9143204  
00:03:41.405 --> 00:03:43.245 from, let's get this name,  
NOTE Confidence: 0.9143204  
00:03:43.485 --> 00:03:45.585 the Pontypical University of Regina  
NOTE Confidence: 0.9143204  
00:03:45.725 --> 00:03:46.225 Apostolatorum,  
NOTE Confidence: 0.9997475  
00:03:47.120 --> 00:03:47.780 as well  
NOTE Confidence: 0.78476423  
00:03:48.319 --> 00:03:49.700 as post doctoral trainings,  
NOTE Confidence: 0.99919003  
00:03:50.159 --> 00:03:51.219 from both Duke  
NOTE Confidence: 0.9528669  
00:03:51.519 --> 00:03:53.040 and Harvard, and then was  
NOTE Confidence: 0.9528669  
00:03:53.040 --> 00:03:54.560 at NYU for quite some  
NOTE Confidence: 0.9528669  
00:03:54.560 --> 00:03:56.159 time. And we're very lucky  
NOTE Confidence: 0.9528669  
00:03:56.159 --> 00:03:57.620 to recruit her to Yale.  
NOTE Confidence: 0.9660192  
00:03:58.480 --> 00:03:59.359 So what I was alluding  
NOTE Confidence: 0.9660192  
00:03:59.359 --> 00:04:00.239 to when I was talking  
NOTE Confidence: 0.9660192  
00:04:00.239 --> 00:04:02.905 about Jen's skill and, in  
NOTE Confidence: 0.9660192  
00:04:02.905 --> 00:04:03.405 forging  
NOTE Confidence: 0.99965966

00:04:03.785 --> 00:04:04.285 partnerships  
NOTE Confidence: 0.9727828

00:04:05.385 --> 00:04:07.245 really focuses on this idea  
NOTE Confidence: 0.9727828

00:04:07.305 --> 00:04:09.625 of, empiric bioethics to try  
NOTE Confidence: 0.9727828

00:04:09.625 --> 00:04:10.445 to understand  
NOTE Confidence: 0.97243774

00:04:11.145 --> 00:04:12.585 what different parties are doing  
NOTE Confidence: 0.97243774

00:04:12.585 --> 00:04:14.045 with regard to the ethical  
NOTE Confidence: 0.97243774

00:04:14.105 --> 00:04:15.950 conduct of research. And then  
NOTE Confidence: 0.97243774

00:04:16.170 --> 00:04:17.450 unlike many of us in  
NOTE Confidence: 0.97243774

00:04:17.450 --> 00:04:18.830 academia where we,  
NOTE Confidence: 0.9516019

00:04:19.290 --> 00:04:20.890 kind of may focus on  
NOTE Confidence: 0.9516019

00:04:20.890 --> 00:04:22.730 finding a problem, certain actors  
NOTE Confidence: 0.9516019

00:04:22.730 --> 00:04:24.890 are not acting in a  
NOTE Confidence: 0.9516019

00:04:24.890 --> 00:04:27.770 ethical or appropriate way. And,  
NOTE Confidence: 0.9516019

00:04:28.250 --> 00:04:29.514 I think the tendency in  
NOTE Confidence: 0.9516019

00:04:29.514 --> 00:04:30.955 academia is to focus on  
NOTE Confidence: 0.9516019

00:04:30.955 --> 00:04:32.235 publishing the work. Like, Hey,

NOTE Confidence: 0.9516019  
00:04:32.235 --> 00:04:33.354 look what we found. These  
NOTE Confidence: 0.9516019  
00:04:33.354 --> 00:04:34.735 guys aren't doing things right.  
NOTE Confidence: 0.9675455  
00:04:35.275 --> 00:04:36.315 The world should know about  
NOTE Confidence: 0.9675455  
00:04:36.315 --> 00:04:37.354 this and the world should  
NOTE Confidence: 0.9675455  
00:04:37.354 --> 00:04:38.714 just go, go fix it.  
NOTE Confidence: 0.9675455  
00:04:38.714 --> 00:04:40.154 So my job here is  
NOTE Confidence: 0.9675455  
00:04:40.154 --> 00:04:41.610 done. That's not at all  
NOTE Confidence: 0.9675455  
00:04:41.610 --> 00:04:42.890 the approach that Jen takes.  
NOTE Confidence: 0.9675455  
00:04:42.890 --> 00:04:44.810 She really forges partnerships with  
NOTE Confidence: 0.9675455  
00:04:44.810 --> 00:04:46.250 those who are engaging in  
NOTE Confidence: 0.9675455  
00:04:46.250 --> 00:04:47.310 and funding research  
NOTE Confidence: 0.98400456  
00:04:47.610 --> 00:04:48.570 and tries to work with  
NOTE Confidence: 0.98400456  
00:04:48.570 --> 00:04:49.790 them to find solutions  
NOTE Confidence: 0.85850286  
00:04:50.410 --> 00:04:51.290 to try to kind of  
NOTE Confidence: 0.85850286  
00:04:51.290 --> 00:04:52.190 cajole them,  
NOTE Confidence: 0.9539512

00:04:52.755 --> 00:04:54.515 into not only partnering, but  
NOTE Confidence: 0.9539512

00:04:54.515 --> 00:04:55.955 also moving in the right  
NOTE Confidence: 0.9539512

00:04:55.955 --> 00:04:57.415 direction. I think it's really  
NOTE Confidence: 0.9539512

00:04:57.475 --> 00:04:58.675 commendable and I'm really glad  
NOTE Confidence: 0.9539512

00:04:58.675 --> 00:04:59.895 she's here to share,  
NOTE Confidence: 0.96886563

00:05:00.435 --> 00:05:01.555 her prior work and and  
NOTE Confidence: 0.96886563

00:05:01.555 --> 00:05:02.775 next steps. So  
NOTE Confidence: 0.9639637

00:05:03.155 --> 00:05:05.075 without further ado, excited to  
NOTE Confidence: 0.9639637

00:05:05.075 --> 00:05:05.575 introduce,  
NOTE Confidence: 0.9216238

00:05:06.349 --> 00:05:08.110 associate professor Jen Miller to  
NOTE Confidence: 0.9216238

00:05:08.190 --> 00:05:08.910 who is here to talk  
NOTE Confidence: 0.9216238

00:05:08.910 --> 00:05:11.650 about advancing bioethics performance measure-  
ment  
NOTE Confidence: 0.9649146

00:05:12.270 --> 00:05:13.629 and public reporting in the  
NOTE Confidence: 0.9649146

00:05:13.629 --> 00:05:14.129 pharmaceutical  
NOTE Confidence: 0.93400073

00:05:14.509 --> 00:05:16.589 industry, evolving metrics and emerging  
NOTE Confidence: 0.93400073

00:05:16.589 --> 00:05:18.210 trends from the good pharma  
NOTE Confidence: 0.93400073

00:05:18.349 --> 00:05:18.849 scorecard.  
NOTE Confidence: 0.9926587

00:05:19.389 --> 00:05:20.289 Thank you, Jen.  
NOTE Confidence: 0.8118291

00:05:32.005 --> 00:05:32.505 Thanks,  
NOTE Confidence: 0.948285

00:05:33.205 --> 00:05:34.565 doctor Gross, for that great  
NOTE Confidence: 0.948285

00:05:34.565 --> 00:05:36.104 introduction. It's really generous.  
NOTE Confidence: 0.99976015

00:05:37.139 --> 00:05:38.419 And for the opportunity to  
NOTE Confidence: 0.99976015

00:05:38.419 --> 00:05:39.479 present today  
NOTE Confidence: 0.9969947

00:05:39.779 --> 00:05:41.400 on work to advance quality  
NOTE Confidence: 0.9969947

00:05:41.460 --> 00:05:41.960 measures  
NOTE Confidence: 0.9786741

00:05:42.660 --> 00:05:44.279 and benchmarks in the pharmaceutical  
NOTE Confidence: 0.9786741

00:05:44.339 --> 00:05:46.839 industry focusing on their bioethics,  
NOTE Confidence: 0.999928

00:05:47.940 --> 00:05:48.440 performance  
NOTE Confidence: 0.909725

00:05:48.979 --> 00:05:50.100 through an initiative called the  
NOTE Confidence: 0.909725

00:05:50.100 --> 00:05:51.080 good pharma scorecard.  
NOTE Confidence: 0.98443425

00:05:51.425 --> 00:05:52.865 But before I begin talking

NOTE Confidence: 0.98443425

00:05:52.865 --> 00:05:54.305 about the GoodPharma scorecard, I

NOTE Confidence: 0.98443425

00:05:54.305 --> 00:05:55.685 want to begin by acknowledging

NOTE Confidence: 0.9834417

00:05:56.145 --> 00:05:57.904 acknowledging and thanking the people

NOTE Confidence: 0.9834417

00:05:57.904 --> 00:05:59.505 in this room and on

NOTE Confidence: 0.9834417

00:05:59.505 --> 00:06:00.705 Zoom and beyond who have

NOTE Confidence: 0.9834417

00:06:00.705 --> 00:06:02.705 been so incredibly helpful and

NOTE Confidence: 0.9834417

00:06:02.705 --> 00:06:03.904 instrumental in the work that

NOTE Confidence: 0.9834417

00:06:03.904 --> 00:06:04.885 I'm gonna present,

NOTE Confidence: 0.9369234

00:06:05.265 --> 00:06:06.404 particularly Carrie,

NOTE Confidence: 0.7978346

00:06:07.210 --> 00:06:09.290 Gross and Joe Ross and

NOTE Confidence: 0.7978346

00:06:09.290 --> 00:06:09.790 Chris,

NOTE Confidence: 0.95373684

00:06:10.410 --> 00:06:12.410 Lee and Sakina and so

NOTE Confidence: 0.95373684

00:06:12.410 --> 00:06:13.150 many others.

NOTE Confidence: 0.9742562

00:06:13.610 --> 00:06:14.570 Hope you'll see your names

NOTE Confidence: 0.9742562

00:06:14.570 --> 00:06:15.370 on the screens, but I

NOTE Confidence: 0.9742562

00:06:15.370 --> 00:06:16.570 just also wanted to acknowledge  
NOTE Confidence: 0.9742562

00:06:16.570 --> 00:06:17.070 you,  
NOTE Confidence: 0.999872

00:06:17.450 --> 00:06:18.350 before starting.  
NOTE Confidence: 0.99552006

00:06:20.695 --> 00:06:22.475 I have, several disclosures  
NOTE Confidence: 0.8552662

00:06:22.935 --> 00:06:24.235 which are on the slide.  
NOTE Confidence: 0.97882426

00:06:25.815 --> 00:06:27.255 Okay. So for the there's  
NOTE Confidence: 0.97882426

00:06:27.255 --> 00:06:28.055 a lot of new people  
NOTE Confidence: 0.97882426

00:06:28.055 --> 00:06:28.854 in the room, so I'll  
NOTE Confidence: 0.97882426

00:06:28.854 --> 00:06:30.134 begin at the beginning. What  
NOTE Confidence: 0.97882426

00:06:30.134 --> 00:06:31.895 is the GoodPharma scorecard? So  
NOTE Confidence: 0.97882426

00:06:31.895 --> 00:06:33.500 the scorecard is designed to  
NOTE Confidence: 0.97882426

00:06:33.500 --> 00:06:34.940 be an index that rates  
NOTE Confidence: 0.97882426

00:06:34.940 --> 00:06:37.440 and ranks pharmaceutical companies annually  
NOTE Confidence: 0.99865067

00:06:38.140 --> 00:06:39.520 on their bioethics performance.  
NOTE Confidence: 0.9823811

00:06:39.980 --> 00:06:41.820 We started developing the index  
NOTE Confidence: 0.9823811

00:06:41.820 --> 00:06:43.260 in around two thousand five,

NOTE Confidence: 0.9823811

00:06:43.260 --> 00:06:44.779 two thousand six when I

NOTE Confidence: 0.9823811

00:06:44.779 --> 00:06:46.080 was finishing my master's,

NOTE Confidence: 0.969453

00:06:46.460 --> 00:06:47.839 in bioethics and beginning

NOTE Confidence: 0.94902444

00:06:48.265 --> 00:06:49.705 my PhD program. And we

NOTE Confidence: 0.94902444

00:06:49.705 --> 00:06:50.505 did this for a few

NOTE Confidence: 0.94902444

00:06:50.505 --> 00:06:52.105 reasons, but chief of them

NOTE Confidence: 0.94902444

00:06:52.105 --> 00:06:53.464 was at the time the

NOTE Confidence: 0.94902444

00:06:53.464 --> 00:06:54.445 medical literature,

NOTE Confidence: 0.99484736

00:06:54.985 --> 00:06:56.585 the media coverage, and the

NOTE Confidence: 0.99484736

00:06:56.585 --> 00:06:57.404 court cases,

NOTE Confidence: 0.98038006

00:06:58.265 --> 00:06:59.964 covering the industry were incredibly

NOTE Confidence: 0.98038006

00:07:00.105 --> 00:07:01.885 negative, focusing on

NOTE Confidence: 0.9733851

00:07:03.080 --> 00:07:05.560 mostly the ethics challenges, failures,

NOTE Confidence: 0.9733851

00:07:05.560 --> 00:07:07.000 and outright scandals. And so

NOTE Confidence: 0.9733851

00:07:07.000 --> 00:07:08.279 you can think about concerns

NOTE Confidence: 0.9733851



00:07:08.279 --> 00:07:10.539 ranging from worries about companies'

NOTE Confidence: 0.9733851

00:07:10.759 --> 00:07:12.680 honesty and truth telling about

NOTE Confidence: 0.9733851

00:07:12.680 --> 00:07:14.199 the safety and efficacy about

NOTE Confidence: 0.9733851

00:07:14.199 --> 00:07:14.699 products

NOTE Confidence: 0.9994989

00:07:15.405 --> 00:07:17.505 to deceptive marketing practices

NOTE Confidence: 0.89974517

00:07:18.125 --> 00:07:18.705 and then

NOTE Confidence: 0.9981391

00:07:19.245 --> 00:07:20.705 outright price gouging

NOTE Confidence: 0.9949658

00:07:21.245 --> 00:07:22.065 on products.

NOTE Confidence: 0.9950074

00:07:22.605 --> 00:07:23.565 And so in some ways,

NOTE Confidence: 0.9950074

00:07:23.565 --> 00:07:24.605 you can think about all

NOTE Confidence: 0.9950074

00:07:24.605 --> 00:07:26.845 of these concerns as being

NOTE Confidence: 0.9950074

00:07:26.845 --> 00:07:29.105 summarized as worries that companies

NOTE Confidence: 0.9950074

00:07:29.165 --> 00:07:29.665 put

NOTE Confidence: 0.9950436

00:07:30.000 --> 00:07:31.620 profits before people.

NOTE Confidence: 0.9966948

00:07:32.480 --> 00:07:33.760 And so while the literature

NOTE Confidence: 0.9966948

00:07:33.760 --> 00:07:34.880 and the media and the

NOTE Confidence: 0.9966948  
00:07:34.880 --> 00:07:36.640 court cases can be pretty  
NOTE Confidence: 0.9966948  
00:07:36.640 --> 00:07:38.000 good at bringing to light  
NOTE Confidence: 0.9966948  
00:07:38.000 --> 00:07:38.900 certain problems,  
NOTE Confidence: 0.9919923  
00:07:39.360 --> 00:07:41.520 they don't answer necessarily four  
NOTE Confidence: 0.9919923  
00:07:41.520 --> 00:07:42.500 critical questions.  
NOTE Confidence: 0.9988101  
00:07:44.325 --> 00:07:45.765 One, the prevalence of the  
NOTE Confidence: 0.9988101  
00:07:45.765 --> 00:07:46.265 problem.  
NOTE Confidence: 0.9880295  
00:07:46.725 --> 00:07:47.945 Now is the transgression  
NOTE Confidence: 0.9959547  
00:07:48.405 --> 00:07:50.425 the product of an outlier  
NOTE Confidence: 0.96899396  
00:07:51.045 --> 00:07:52.645 company in an otherwise sound  
NOTE Confidence: 0.96899396  
00:07:52.645 --> 00:07:54.245 industry, a rogue employee in  
NOTE Confidence: 0.96899396  
00:07:54.245 --> 00:07:55.545 an otherwise good company?  
NOTE Confidence: 0.9769657  
00:07:56.300 --> 00:07:57.420 Is it a rear view  
NOTE Confidence: 0.9769657  
00:07:57.420 --> 00:07:58.860 mirror problem? I get this  
NOTE Confidence: 0.9769657  
00:07:58.860 --> 00:08:00.160 all the time. You academics,  
NOTE Confidence: 0.9769657

00:08:00.220 --> 00:08:01.900 you use old data. Your  
NOTE Confidence: 0.9769657

00:08:01.900 --> 00:08:03.340 studies are outdated. If only  
NOTE Confidence: 0.9769657

00:08:03.340 --> 00:08:04.220 you were, you know, doing  
NOTE Confidence: 0.9769657

00:08:04.220 --> 00:08:05.260 the most cutting edge data,  
NOTE Confidence: 0.9769657

00:08:05.260 --> 00:08:06.060 you'd see that we had  
NOTE Confidence: 0.9769657

00:08:06.060 --> 00:08:07.040 fixed this problem.  
NOTE Confidence: 0.9526273

00:08:08.284 --> 00:08:09.405 Or is it actually a  
NOTE Confidence: 0.9526273

00:08:09.405 --> 00:08:10.925 rotten barrel? Right? Is the  
NOTE Confidence: 0.9526273

00:08:10.925 --> 00:08:12.944 problem genuine, current, and widespread  
NOTE Confidence: 0.9526273

00:08:13.085 --> 00:08:14.224 and in need of reform?  
NOTE Confidence: 0.95897335

00:08:15.965 --> 00:08:17.645 If there is a rotten  
NOTE Confidence: 0.95897335

00:08:17.645 --> 00:08:19.004 barrel, the question is how  
NOTE Confidence: 0.95897335

00:08:19.004 --> 00:08:20.064 do you fix it?  
NOTE Confidence: 0.98885185

00:08:23.500 --> 00:08:24.539 And then what do good  
NOTE Confidence: 0.98885185

00:08:24.539 --> 00:08:25.979 practices look like? What's the  
NOTE Confidence: 0.98885185

00:08:25.979 --> 00:08:26.880 upward counterfactual?

NOTE Confidence: 0.9962418  
00:08:27.259 --> 00:08:27.740 We  
NOTE Confidence: 0.9905369  
00:08:28.300 --> 00:08:29.979 as Carrie mentioned, we focus  
NOTE Confidence: 0.9905369  
00:08:29.979 --> 00:08:30.860 so much on what the  
NOTE Confidence: 0.9905369  
00:08:30.860 --> 00:08:32.400 bad looks like. We often  
NOTE Confidence: 0.99925905  
00:08:32.754 --> 00:08:34.375 don't focus enough on defining  
NOTE Confidence: 0.99925905  
00:08:34.514 --> 00:08:35.254 and conceptualizing  
NOTE Confidence: 0.9934567  
00:08:35.554 --> 00:08:36.855 what the good best practices,  
NOTE Confidence: 0.96354705  
00:08:37.394 --> 00:08:38.595 can and should look like,  
NOTE Confidence: 0.96354705  
00:08:38.595 --> 00:08:39.875 and then how effective our  
NOTE Confidence: 0.96354705  
00:08:39.875 --> 00:08:41.554 policies or regulations and laws  
NOTE Confidence: 0.96354705  
00:08:41.554 --> 00:08:42.694 have been at curving,  
NOTE Confidence: 0.99820983  
00:08:43.154 --> 00:08:45.235 the ethical lapses. So these  
NOTE Confidence: 0.99820983  
00:08:45.235 --> 00:08:46.134 four questions  
NOTE Confidence: 0.90555143  
00:08:47.230 --> 00:08:48.030 are what,  
NOTE Confidence: 0.9727426  
00:08:49.230 --> 00:08:50.429 inspired the founding of the  
NOTE Confidence: 0.9727426

00:08:50.429 --> 00:08:51.410 GoodPharma scorecard.  
NOTE Confidence: 0.98992395

00:08:53.470 --> 00:08:55.070 So the scorecard aims to  
NOTE Confidence: 0.98992395

00:08:55.070 --> 00:08:56.830 do five things. First, set  
NOTE Confidence: 0.98992395

00:08:56.830 --> 00:08:57.650 and communicate  
NOTE Confidence: 0.97607815

00:08:58.110 --> 00:08:59.790 clear ethics goals for the  
NOTE Confidence: 0.97607815

00:08:59.790 --> 00:09:01.230 sector. So define what good  
NOTE Confidence: 0.97607815

00:09:01.230 --> 00:09:02.975 can look like, and then  
NOTE Confidence: 0.97607815

00:09:02.975 --> 00:09:04.755 translate those goals into  
NOTE Confidence: 0.9817182

00:09:05.295 --> 00:09:06.894 measures and outcomes that are  
NOTE Confidence: 0.9817182

00:09:06.894 --> 00:09:09.315 observable, comparable, and publicly accountable.  
NOTE Confidence: 0.9995487

00:09:10.735 --> 00:09:11.855 And then use them to  
NOTE Confidence: 0.9995487

00:09:11.855 --> 00:09:13.615 evaluate and track progress on  
NOTE Confidence: 0.9995487

00:09:13.615 --> 00:09:14.274 our goals  
NOTE Confidence: 0.9824403

00:09:14.970 --> 00:09:16.190 annually and over time  
NOTE Confidence: 0.7258925

00:09:16.970 --> 00:09:17.949 to recognize  
NOTE Confidence: 0.9483492

00:09:18.250 --> 00:09:19.370 where there are any best

NOTE Confidence: 0.9483492

00:09:19.370 --> 00:09:21.230 practices so we can study

NOTE Confidence: 0.9483492

00:09:21.370 --> 00:09:22.490 and figure out how they

NOTE Confidence: 0.9483492

00:09:22.490 --> 00:09:24.089 were done and replicated across

NOTE Confidence: 0.9483492

00:09:24.089 --> 00:09:26.269 the sector, but importantly and

NOTE Confidence: 0.93842524

00:09:26.730 --> 00:09:28.990 most importantly, to catalyze change,

NOTE Confidence: 0.93842524

00:09:29.245 --> 00:09:30.684 better behaviors were needed for

NOTE Confidence: 0.93842524

00:09:30.684 --> 00:09:31.184 patients.

NOTE Confidence: 0.9659329

00:09:34.125 --> 00:09:35.485 So so far, we have

NOTE Confidence: 0.9659329

00:09:35.485 --> 00:09:36.465 five scorecards,

NOTE Confidence: 0.92612696

00:09:36.845 --> 00:09:39.245 three launched and two under

NOTE Confidence: 0.92612696

00:09:39.245 --> 00:09:39.745 development.

NOTE Confidence: 0.9668491

00:09:41.179 --> 00:09:42.540 The first one is focused

NOTE Confidence: 0.9668491

00:09:42.540 --> 00:09:44.559 on transparency in clinical research,

NOTE Confidence: 0.9668491

00:09:44.620 --> 00:09:45.899 the second one on data

NOTE Confidence: 0.9668491

00:09:45.899 --> 00:09:47.360 sharing practices in research,

NOTE Confidence: 0.9725154

00:09:47.819 --> 00:09:49.500 the third on representation in  
NOTE Confidence: 0.9725154

00:09:49.500 --> 00:09:50.720 clinical trial enrollment,  
NOTE Confidence: 0.9892157

00:09:51.420 --> 00:09:52.620 the fourth one launching this  
NOTE Confidence: 0.9892157

00:09:52.620 --> 00:09:53.660 year is on access to  
NOTE Confidence: 0.9892157

00:09:53.660 --> 00:09:55.019 medicines in low middle income  
NOTE Confidence: 0.9892157

00:09:55.019 --> 00:09:55.519 countries,  
NOTE Confidence: 0.96077293

00:09:55.904 --> 00:09:56.785 And then the fifth one  
NOTE Confidence: 0.96077293

00:09:56.785 --> 00:09:58.464 that's really in the beginnings  
NOTE Confidence: 0.96077293

00:09:58.464 --> 00:09:59.904 of development is on patient  
NOTE Confidence: 0.96077293

00:09:59.904 --> 00:10:01.125 centricity in pharma.  
NOTE Confidence: 0.998092

00:10:01.505 --> 00:10:03.024 So I'll briefly touch on,  
NOTE Confidence: 0.998092

00:10:03.345 --> 00:10:04.725 all five of these today.  
NOTE Confidence: 0.9612578

00:10:06.704 --> 00:10:07.665 But before I begin, I  
NOTE Confidence: 0.9612578

00:10:07.665 --> 00:10:08.790 wanna say, like, is any,  
NOTE Confidence: 0.9612578

00:10:08.790 --> 00:10:10.070 do the pharma companies even  
NOTE Confidence: 0.9612578

00:10:10.070 --> 00:10:11.269 care about this? Because we

NOTE Confidence: 0.9612578  
00:10:11.269 --> 00:10:12.070 we could build this, and  
NOTE Confidence: 0.9612578  
00:10:12.070 --> 00:10:12.730 they may  
NOTE Confidence: 0.9901236  
00:10:13.429 --> 00:10:14.889 never look at it.  
NOTE Confidence: 0.9972711  
00:10:15.269 --> 00:10:16.709 But they actually do pay  
NOTE Confidence: 0.9972711  
00:10:16.709 --> 00:10:18.149 very close attention to their  
NOTE Confidence: 0.9972711  
00:10:18.149 --> 00:10:18.649 scores.  
NOTE Confidence: 0.96346986  
00:10:19.029 --> 00:10:20.070 And so here you can  
NOTE Confidence: 0.96346986  
00:10:20.070 --> 00:10:21.529 see that it's in their  
NOTE Confidence: 0.99889195  
00:10:21.990 --> 00:10:22.889 annual reports,  
NOTE Confidence: 0.9982759  
00:10:24.705 --> 00:10:27.125 their CEO letters, their CSR,  
NOTE Confidence: 0.99889654  
00:10:28.385 --> 00:10:30.625 publications, their impact reporting, their  
NOTE Confidence: 0.99889654  
00:10:30.625 --> 00:10:31.765 ESG efforts,  
NOTE Confidence: 0.94713277  
00:10:32.304 --> 00:10:34.304 their SEC filings, which is  
NOTE Confidence: 0.94713277  
00:10:34.304 --> 00:10:35.045 really interesting,  
NOTE Confidence: 0.87209666  
00:10:38.160 --> 00:10:39.620 when they score well.  
NOTE Confidence: 0.73262334



00:10:41.120 --> 00:10:41.620 And  
NOTE Confidence: 0.95640224

00:10:42.000 --> 00:10:43.120 and importantly, we have been  
NOTE Confidence: 0.95640224

00:10:43.120 --> 00:10:44.559 able to show progress, so  
NOTE Confidence: 0.95640224

00:10:44.559 --> 00:10:46.000 upward movement on some key  
NOTE Confidence: 0.95640224

00:10:46.000 --> 00:10:46.500 measures.  
NOTE Confidence: 0.9860627

00:10:48.959 --> 00:10:50.240 Alright. So I'm gonna begin  
NOTE Confidence: 0.9860627

00:10:50.240 --> 00:10:51.360 by going through the first  
NOTE Confidence: 0.9860627

00:10:51.360 --> 00:10:52.100 two scorecards,  
NOTE Confidence: 0.9704822

00:10:52.904 --> 00:10:54.445 the ones focused on transparency  
NOTE Confidence: 0.9704822

00:10:54.505 --> 00:10:55.964 and data sharing in research.  
NOTE Confidence: 0.9726351

00:10:57.304 --> 00:10:58.584 So in this set this  
NOTE Confidence: 0.9726351

00:10:58.584 --> 00:10:59.704 part of the talk, I'll  
NOTE Confidence: 0.9726351

00:10:59.704 --> 00:11:01.225 just go through four things,  
NOTE Confidence: 0.9726351

00:11:01.225 --> 00:11:02.824 why we tackled this issue  
NOTE Confidence: 0.9726351

00:11:02.824 --> 00:11:03.785 with the scorecard. It was  
NOTE Confidence: 0.9726351

00:11:03.785 --> 00:11:05.879 the debut topic. The metrics

NOTE Confidence: 0.9726351  
00:11:05.879 --> 00:11:07.480 we use to benchmark and  
NOTE Confidence: 0.9726351  
00:11:07.480 --> 00:11:09.879 track transparency over time, the  
NOTE Confidence: 0.9726351  
00:11:09.879 --> 00:11:11.240 trends we've been seeing over  
NOTE Confidence: 0.9726351  
00:11:11.240 --> 00:11:12.440 the last ten years in  
NOTE Confidence: 0.9726351  
00:11:12.440 --> 00:11:14.040 transparency, and then I'm gonna  
NOTE Confidence: 0.9726351  
00:11:14.040 --> 00:11:14.540 debut,  
NOTE Confidence: 0.9737478  
00:11:15.000 --> 00:11:16.220 the forthcoming rankings,  
NOTE Confidence: 0.9484027  
00:11:17.000 --> 00:11:18.440 which, I haven't sent to  
NOTE Confidence: 0.9484027  
00:11:18.440 --> 00:11:19.559 any of the coauthors yet.  
NOTE Confidence: 0.9484027  
00:11:19.559 --> 00:11:20.440 So all the errors are  
NOTE Confidence: 0.9484027  
00:11:20.440 --> 00:11:20.940 mine.  
NOTE Confidence: 0.9766777  
00:11:22.175 --> 00:11:23.715 So the reason we prioritized  
NOTE Confidence: 0.9766777  
00:11:23.934 --> 00:11:25.855 clinical trial transparency as the  
NOTE Confidence: 0.9766777  
00:11:25.855 --> 00:11:27.635 debut issue for the scorecard  
NOTE Confidence: 0.9766777  
00:11:27.695 --> 00:11:28.735 was that, at the time,  
NOTE Confidence: 0.9766777

00:11:28.735 --> 00:11:30.975 there was pretty robust substantial  
NOTE Confidence: 0.9766777

00:11:30.975 --> 00:11:31.955 evidence suggesting,  
NOTE Confidence: 0.9994434

00:11:33.054 --> 00:11:33.715 a pervasive  
NOTE Confidence: 0.9719993

00:11:34.095 --> 00:11:35.855 transparency problem. And here's just  
NOTE Confidence: 0.9719993

00:11:35.855 --> 00:11:36.675 one paper,  
NOTE Confidence: 0.9697739

00:11:37.370 --> 00:11:39.210 published by Monique Anderson, and  
NOTE Confidence: 0.9697739

00:11:39.210 --> 00:11:40.570 you've probably all heard of  
NOTE Confidence: 0.9697739

00:11:40.570 --> 00:11:42.010 Rob Califf, a former head  
NOTE Confidence: 0.9697739

00:11:42.010 --> 00:11:43.690 of the FDA, showing that  
NOTE Confidence: 0.9697739

00:11:43.690 --> 00:11:45.529 only twenty percent of clinical  
NOTE Confidence: 0.9697739

00:11:45.529 --> 00:11:47.450 trials registered in clinical trials  
NOTE Confidence: 0.9697739

00:11:47.450 --> 00:11:49.470 dot gov had public results,  
NOTE Confidence: 0.9938729

00:11:49.945 --> 00:11:51.545 a year after their primary  
NOTE Confidence: 0.9938729

00:11:51.545 --> 00:11:52.745 completion date. And even if  
NOTE Confidence: 0.9938729

00:11:52.745 --> 00:11:54.105 you looked at, you know,  
NOTE Confidence: 0.9938729

00:11:54.105 --> 00:11:55.865 sixty months later, years later,

NOTE Confidence: 0.9938729  
00:11:55.865 --> 00:11:57.225 you could only find about  
NOTE Confidence: 0.9938729  
00:11:57.225 --> 00:11:58.684 half of the clinical trials,  
NOTE Confidence: 0.99405587  
00:11:59.144 --> 00:12:01.464 having public results in clinical  
NOTE Confidence: 0.99405587  
00:12:01.464 --> 00:12:02.605 trials dot gov.  
NOTE Confidence: 0.9945783  
00:12:06.080 --> 00:12:06.820 And so  
NOTE Confidence: 0.9358002  
00:12:07.679 --> 00:12:08.720 our group kinda stepped back  
NOTE Confidence: 0.9358002  
00:12:08.720 --> 00:12:09.520 and said, well, is this  
NOTE Confidence: 0.9358002  
00:12:09.520 --> 00:12:10.800 a problem? Well, yes. It's  
NOTE Confidence: 0.9358002  
00:12:10.800 --> 00:12:11.760 a it's a very big  
NOTE Confidence: 0.9358002  
00:12:11.760 --> 00:12:12.260 problem.  
NOTE Confidence: 0.97810704  
00:12:13.520 --> 00:12:15.600 We need that data for  
NOTE Confidence: 0.97810704  
00:12:15.600 --> 00:12:16.640 the quality of our medical  
NOTE Confidence: 0.97810704  
00:12:16.640 --> 00:12:18.240 evidence and patient care for  
NOTE Confidence: 0.97810704  
00:12:18.240 --> 00:12:19.520 innovation so we can learn  
NOTE Confidence: 0.97810704  
00:12:19.520 --> 00:12:20.720 and build upon the lessons  
NOTE Confidence: 0.97810704

00:12:20.720 --> 00:12:22.214 of the scientists that go  
NOTE Confidence: 0.97810704

00:12:22.214 --> 00:12:23.335 before us. But as an  
NOTE Confidence: 0.97810704

00:12:23.335 --> 00:12:23.835 ethicist,  
NOTE Confidence: 0.99268764

00:12:24.855 --> 00:12:26.775 it's also transparency is critical  
NOTE Confidence: 0.99268764

00:12:26.775 --> 00:12:28.375 for honoring and protecting research  
NOTE Confidence: 0.99268764

00:12:28.375 --> 00:12:28.875 participants.  
NOTE Confidence: 0.9998307

00:12:29.335 --> 00:12:30.615 One of the key reasons  
NOTE Confidence: 0.9998307

00:12:30.615 --> 00:12:31.115 that  
NOTE Confidence: 0.933796

00:12:31.975 --> 00:12:32.955 medical experimentation  
NOTE Confidence: 0.9959071

00:12:33.335 --> 00:12:34.955 is justified is the potential  
NOTE Confidence: 0.9959071

00:12:35.015 --> 00:12:36.929 to contribute to generalizable knowledge  
NOTE Confidence: 0.9959071

00:12:37.010 --> 00:12:38.370 that can advance human health.  
NOTE Confidence: 0.9959071

00:12:38.370 --> 00:12:39.250 So if you don't put  
NOTE Confidence: 0.9959071

00:12:39.250 --> 00:12:40.529 the results in the public  
NOTE Confidence: 0.9959071

00:12:40.529 --> 00:12:41.730 space, it's very hard to  
NOTE Confidence: 0.9959071

00:12:41.730 --> 00:12:42.850 do that, and the whole

NOTE Confidence: 0.9959071  
00:12:42.850 --> 00:12:44.290 ethics of the experiment comes  
NOTE Confidence: 0.9959071  
00:12:44.290 --> 00:12:45.029 into question.  
NOTE Confidence: 0.9883694  
00:12:47.890 --> 00:12:49.110 So what are we measuring  
NOTE Confidence: 0.9883694  
00:12:49.250 --> 00:12:50.390 in the transparency,  
NOTE Confidence: 0.99952495  
00:12:51.675 --> 00:12:53.455 scorecard? We're looking at  
NOTE Confidence: 0.9389906  
00:12:54.395 --> 00:12:54.795 five,  
NOTE Confidence: 0.99872315  
00:12:55.515 --> 00:12:57.035 sets of standards. One, we're  
NOTE Confidence: 0.99872315  
00:12:57.035 --> 00:12:58.395 looking to see whether clinical  
NOTE Confidence: 0.99872315  
00:12:58.395 --> 00:12:59.455 trials are registered  
NOTE Confidence: 0.9855568  
00:13:00.315 --> 00:13:02.075 in clinical trials dot gov,  
NOTE Confidence: 0.9938416  
00:13:02.635 --> 00:13:04.075 a registry maintained by the  
NOTE Confidence: 0.9938416  
00:13:04.075 --> 00:13:05.995 National Library of Medicine and  
NOTE Confidence: 0.9938416  
00:13:06.075 --> 00:13:06.895 at the NIH.  
NOTE Confidence: 0.99880993  
00:13:07.460 --> 00:13:08.340 We're looking to see if  
NOTE Confidence: 0.99880993  
00:13:08.340 --> 00:13:10.100 results are also reported in  
NOTE Confidence: 0.99880993

00:13:10.100 --> 00:13:11.080 that same registry.  
NOTE Confidence: 0.9908814

00:13:11.620 --> 00:13:12.580 We're looking to see if  
NOTE Confidence: 0.9908814

00:13:12.580 --> 00:13:13.620 trials are published in the  
NOTE Confidence: 0.9908814

00:13:13.620 --> 00:13:14.520 medical literature,  
NOTE Confidence: 0.9980442

00:13:14.980 --> 00:13:16.100 and we're looking to see  
NOTE Confidence: 0.9980442

00:13:16.100 --> 00:13:18.420 if, clinical trials comply with  
NOTE Confidence: 0.9980442

00:13:18.420 --> 00:13:18.920 baseline  
NOTE Confidence: 0.99747825

00:13:19.540 --> 00:13:21.300 US legal requirements for trial  
NOTE Confidence: 0.99747825

00:13:21.300 --> 00:13:22.840 registration and results reporting.  
NOTE Confidence: 0.94718444

00:13:23.554 --> 00:13:24.934 And then we're also evaluating  
NOTE Confidence: 0.94718444

00:13:25.075 --> 00:13:26.695 companies' data sharing practices.  
NOTE Confidence: 0.9689842

00:13:28.355 --> 00:13:29.635 The sample that we apply  
NOTE Confidence: 0.9689842

00:13:29.635 --> 00:13:31.635 our metrics to are trials  
NOTE Confidence: 0.9689842

00:13:31.635 --> 00:13:33.475 supporting FDA approval of novel  
NOTE Confidence: 0.9689842

00:13:33.475 --> 00:13:35.255 drugs and novel biologics.  
NOTE Confidence: 0.97340816

00:13:36.090 --> 00:13:37.290 And within those trials, we

NOTE Confidence: 0.97340816  
00:13:37.290 --> 00:13:38.570 look at three samples. All  
NOTE Confidence: 0.97340816  
00:13:38.570 --> 00:13:40.010 of the trials supporting a  
NOTE Confidence: 0.97340816  
00:13:40.010 --> 00:13:41.130 product approval, so in an  
NOTE Confidence: 0.97340816  
00:13:41.130 --> 00:13:42.110 NDA or BLA,  
NOTE Confidence: 0.9958664  
00:13:42.970 --> 00:13:44.410 just the trials conducted in  
NOTE Confidence: 0.9958664  
00:13:44.410 --> 00:13:46.030 patients for the approved indication,  
NOTE Confidence: 0.99839497  
00:13:46.809 --> 00:13:48.190 and then a still narrower  
NOTE Confidence: 0.99839497  
00:13:48.250 --> 00:13:49.870 sample of just trials legally  
NOTE Confidence: 0.99839497  
00:13:49.930 --> 00:13:51.495 required to be registered and  
NOTE Confidence: 0.99839497  
00:13:51.495 --> 00:13:52.155 reported under US  
NOTE Confidence: 0.9927706  
00:13:55.335 --> 00:13:57.015 laws. In case anyone wants  
NOTE Confidence: 0.9927706  
00:13:57.015 --> 00:13:57.895 to know how we develop  
NOTE Confidence: 0.9927706  
00:13:57.895 --> 00:13:59.895 our metrics, we generally follow  
NOTE Confidence: 0.9927706  
00:13:59.895 --> 00:14:01.815 a four step process where  
NOTE Confidence: 0.9927706  
00:14:01.815 --> 00:14:02.315 we  
NOTE Confidence: 0.9754309



00:14:03.015 --> 00:14:04.855 review the literature, we review  
NOTE Confidence: 0.9754309

00:14:04.855 --> 00:14:06.375 the relevant guidelines in the  
NOTE Confidence: 0.9754309

00:14:06.375 --> 00:14:06.875 area,  
NOTE Confidence: 0.9850433

00:14:07.200 --> 00:14:09.700 We engage, stakeholders in consultations,  
NOTE Confidence: 0.9850433

00:14:10.000 --> 00:14:11.360 focus groups, and interviews for  
NOTE Confidence: 0.9850433

00:14:11.360 --> 00:14:12.800 their input, and we conduct  
NOTE Confidence: 0.9850433

00:14:12.800 --> 00:14:14.160 bright spot analyses, which I'll  
NOTE Confidence: 0.9850433

00:14:14.160 --> 00:14:15.120 talk about later when we  
NOTE Confidence: 0.9850433

00:14:15.120 --> 00:14:15.620 can.  
NOTE Confidence: 0.88443017

00:14:17.760 --> 00:14:18.260 So  
NOTE Confidence: 0.95300245

00:14:19.120 --> 00:14:20.320 I'll go a bit through  
NOTE Confidence: 0.95300245

00:14:20.320 --> 00:14:21.620 the development of the transparency,  
NOTE Confidence: 0.99208397

00:14:23.015 --> 00:14:23.895 standards just so you can  
NOTE Confidence: 0.99208397

00:14:23.895 --> 00:14:24.615 get a sense of how  
NOTE Confidence: 0.99208397

00:14:24.615 --> 00:14:25.515 things are done.  
NOTE Confidence: 0.96534485

00:14:25.975 --> 00:14:26.935 So in two thousand and

NOTE Confidence: 0.96534485  
00:14:26.935 --> 00:14:28.615 fifteen, we published our first  
NOTE Confidence: 0.96534485  
00:14:28.615 --> 00:14:30.855 GoodPharma scorecard on clinical trial  
NOTE Confidence: 0.96534485  
00:14:30.855 --> 00:14:32.935 transparency, and we focused just  
NOTE Confidence: 0.96534485  
00:14:32.935 --> 00:14:33.435 on,  
NOTE Confidence: 0.9892186  
00:14:33.975 --> 00:14:35.335 novel drugs approved by the  
NOTE Confidence: 0.9892186  
00:14:35.335 --> 00:14:37.015 FDA in twenty twelve. And  
NOTE Confidence: 0.9892186  
00:14:37.015 --> 00:14:38.235 there, we looked at  
NOTE Confidence: 0.94626564  
00:14:40.730 --> 00:14:41.930 just the drugs sponsored by  
NOTE Confidence: 0.94626564  
00:14:41.930 --> 00:14:43.529 the twenty largest companies by  
NOTE Confidence: 0.94626564  
00:14:43.529 --> 00:14:45.290 their market caps. And we  
NOTE Confidence: 0.94626564  
00:14:45.290 --> 00:14:46.970 have only evaluated base looking  
NOTE Confidence: 0.94626564  
00:14:46.970 --> 00:14:48.170 at all the trials supporting  
NOTE Confidence: 0.94626564  
00:14:48.170 --> 00:14:49.769 product approval and just trials  
NOTE Confidence: 0.94626564  
00:14:49.769 --> 00:14:51.209 legally required to be,  
NOTE Confidence: 0.99021024  
00:14:52.010 --> 00:14:53.949 reported under US laws.  
NOTE Confidence: 0.9623416

00:14:54.295 --> 00:14:55.095 And we only,  
NOTE Confidence: 0.99632114

00:14:56.215 --> 00:14:57.735 were evaluating the drug. We  
NOTE Confidence: 0.99632114

00:14:57.735 --> 00:14:58.775 didn't look at the company  
NOTE Confidence: 0.99632114

00:14:58.775 --> 00:14:59.595 level yet.  
NOTE Confidence: 0.98679227

00:15:00.135 --> 00:15:01.575 Then in twenty seventeen, we  
NOTE Confidence: 0.98679227

00:15:01.575 --> 00:15:03.275 looked at twenty fourteen approvals,  
NOTE Confidence: 0.98679227

00:15:03.495 --> 00:15:04.935 and we added a company  
NOTE Confidence: 0.98679227

00:15:04.935 --> 00:15:06.395 ranking for the first time,  
NOTE Confidence: 0.99782705

00:15:07.255 --> 00:15:08.475 mostly because companies  
NOTE Confidence: 0.96159947

00:15:09.430 --> 00:15:10.550 were creating a badge and  
NOTE Confidence: 0.96159947

00:15:10.550 --> 00:15:11.830 calling themselves ethical, and we  
NOTE Confidence: 0.96159947

00:15:11.830 --> 00:15:12.790 never rolled anything up to  
NOTE Confidence: 0.96159947

00:15:12.790 --> 00:15:13.990 the company level. So we  
NOTE Confidence: 0.96159947

00:15:13.990 --> 00:15:14.950 we probably better look at  
NOTE Confidence: 0.96159947

00:15:14.950 --> 00:15:15.450 that.  
NOTE Confidence: 0.9731109

00:15:15.910 --> 00:15:17.190 And we added forty five

NOTE Confidence: 0.9731109  
00:15:17.190 --> 00:15:18.870 different data sources. And this  
NOTE Confidence: 0.9731109  
00:15:18.870 --> 00:15:19.450 is because,  
NOTE Confidence: 0.92188084  
00:15:20.390 --> 00:15:21.735 companies were complaining after  
NOTE Confidence: 0.9353242  
00:15:25.015 --> 00:15:26.295 the entire globe, you would  
NOTE Confidence: 0.9353242  
00:15:26.295 --> 00:15:27.334 find that we scored a  
NOTE Confidence: 0.9353242  
00:15:27.334 --> 00:15:28.154 hundred percent.  
NOTE Confidence: 0.997426  
00:15:28.774 --> 00:15:30.055 So we added forty five  
NOTE Confidence: 0.997426  
00:15:30.055 --> 00:15:31.735 different clinical trial registries, and  
NOTE Confidence: 0.997426  
00:15:31.735 --> 00:15:32.714 it was a complete  
NOTE Confidence: 0.98929685  
00:15:33.015 --> 00:15:34.470 waste of time. We only  
NOTE Confidence: 0.98929685  
00:15:34.470 --> 00:15:36.390 found one trial that was  
NOTE Confidence: 0.98929685  
00:15:36.390 --> 00:15:38.230 registered in a registry other  
NOTE Confidence: 0.98929685  
00:15:38.230 --> 00:15:39.430 than clinicaltrials dot gov, and  
NOTE Confidence: 0.98929685  
00:15:39.430 --> 00:15:40.390 it was one trial in  
NOTE Confidence: 0.98929685  
00:15:40.390 --> 00:15:41.910 a corporate registry. So we  
NOTE Confidence: 0.98929685

00:15:41.910 --> 00:15:42.890 don't do that anymore.  
NOTE Confidence: 0.99856186

00:15:45.350 --> 00:15:46.550 And then we added an  
NOTE Confidence: 0.99856186

00:15:46.550 --> 00:15:48.205 analysis of just the trials  
NOTE Confidence: 0.99856186

00:15:48.205 --> 00:15:49.405 conducted in patients for the  
NOTE Confidence: 0.99856186

00:15:49.405 --> 00:15:50.305 approved indication.  
NOTE Confidence: 0.980151

00:15:51.085 --> 00:15:53.005 Then in twenty nineteen, we,  
NOTE Confidence: 0.980151

00:15:53.325 --> 00:15:55.005 added data sharing measures, and  
NOTE Confidence: 0.980151

00:15:55.005 --> 00:15:56.625 we added an amendment window  
NOTE Confidence: 0.980151

00:15:56.845 --> 00:15:58.685 where we said, look, companies,  
NOTE Confidence: 0.980151

00:15:58.685 --> 00:15:59.645 if you're really interested in  
NOTE Confidence: 0.980151

00:15:59.645 --> 00:16:00.685 changing, we'll give you thirty  
NOTE Confidence: 0.980151

00:16:00.685 --> 00:16:01.690 to sixty days, and you  
NOTE Confidence: 0.980151

00:16:01.690 --> 00:16:03.050 can improve your procedures, and  
NOTE Confidence: 0.980151

00:16:03.050 --> 00:16:04.089 we'll publish a pre and  
NOTE Confidence: 0.980151

00:16:04.089 --> 00:16:05.930 post score. And fifty percent  
NOTE Confidence: 0.980151

00:16:05.930 --> 00:16:07.209 of the low scoring large

NOTE Confidence: 0.980151  
00:16:07.209 --> 00:16:08.089 companies took us up on  
NOTE Confidence: 0.980151  
00:16:08.089 --> 00:16:09.070 the amendment window.  
NOTE Confidence: 0.91351324  
00:16:10.490 --> 00:16:11.370 Jim, can you talk a  
NOTE Confidence: 0.91351324  
00:16:11.370 --> 00:16:12.810 little bit about this your  
NOTE Confidence: 0.91351324  
00:16:12.810 --> 00:16:14.730 communication and interaction with the  
NOTE Confidence: 0.91351324  
00:16:14.730 --> 00:16:15.930 companies? Because you're saying things  
NOTE Confidence: 0.91351324  
00:16:15.930 --> 00:16:17.745 like companies planting. Yeah.  
NOTE Confidence: 0.8935447  
00:16:18.204 --> 00:16:19.245 How did it get started  
NOTE Confidence: 0.8935447  
00:16:19.245 --> 00:16:21.324 that you actually ended up  
NOTE Confidence: 0.8935447  
00:16:21.324 --> 00:16:22.685 having a dialogue? Would you  
NOTE Confidence: 0.8935447  
00:16:22.685 --> 00:16:22.925 think  
NOTE Confidence: 0.96126765  
00:16:29.005 --> 00:16:30.605 Well, one was a, a  
NOTE Confidence: 0.96126765  
00:16:30.605 --> 00:16:31.745 conceptual commitment.  
NOTE Confidence: 0.99853635  
00:16:33.120 --> 00:16:34.720 So before taking the faculty  
NOTE Confidence: 0.99853635  
00:16:34.720 --> 00:16:35.699 position at NYU,  
NOTE Confidence: 0.98435193

00:16:36.079 --> 00:16:37.220 I went down to study,  
NOTE Confidence: 0.9788661

00:16:38.560 --> 00:16:40.319 regulatory governance with Ed Ballison,  
NOTE Confidence: 0.9788661

00:16:40.319 --> 00:16:42.079 a historian at Duke, to  
NOTE Confidence: 0.9788661

00:16:42.079 --> 00:16:43.040 try and see if you're  
NOTE Confidence: 0.9788661

00:16:43.040 --> 00:16:44.660 gonna build a quasi  
NOTE Confidence: 0.98749876

00:16:44.975 --> 00:16:46.895 public, quasi private governance system,  
NOTE Confidence: 0.98749876

00:16:46.895 --> 00:16:48.335 what's the most effective model  
NOTE Confidence: 0.98749876

00:16:48.335 --> 00:16:49.135 to do that? Is it  
NOTE Confidence: 0.98749876

00:16:49.135 --> 00:16:49.795 a technocratic  
NOTE Confidence: 0.9517548

00:16:50.575 --> 00:16:52.095 model, a bunch of experts  
NOTE Confidence: 0.9517548

00:16:52.095 --> 00:16:53.375 in a room who come  
NOTE Confidence: 0.9517548

00:16:53.375 --> 00:16:54.195 up with metrics?  
NOTE Confidence: 0.9790136

00:16:54.655 --> 00:16:56.175 Is it some kind of  
NOTE Confidence: 0.9790136

00:16:56.175 --> 00:16:56.675 multistakeholder  
NOTE Confidence: 0.9600542

00:16:58.440 --> 00:17:00.120 engagement process? And it turns  
NOTE Confidence: 0.9600542

00:17:00.120 --> 00:17:01.160 out, you know, looking through

NOTE Confidence: 0.9600542  
00:17:01.160 --> 00:17:02.840 all these different models, that  
NOTE Confidence: 0.9600542  
00:17:02.840 --> 00:17:04.760 engagement of all affected parties  
NOTE Confidence: 0.9600542  
00:17:04.760 --> 00:17:06.200 is critical. So not just,  
NOTE Confidence: 0.9600542  
00:17:06.200 --> 00:17:07.320 you know, the ultimately, the  
NOTE Confidence: 0.9600542  
00:17:07.320 --> 00:17:09.160 patients, but the entity that  
NOTE Confidence: 0.9600542  
00:17:09.160 --> 00:17:10.520 you are hoping to change  
NOTE Confidence: 0.9600542  
00:17:10.520 --> 00:17:12.380 behavior. And so, conceptually,  
NOTE Confidence: 0.9348341  
00:17:13.555 --> 00:17:14.835 I was I was leaning  
NOTE Confidence: 0.9348341  
00:17:14.835 --> 00:17:15.815 towards engagement,  
NOTE Confidence: 0.9998385  
00:17:16.835 --> 00:17:17.575 and then  
NOTE Confidence: 0.99418014  
00:17:18.035 --> 00:17:19.155 they paid attention when the  
NOTE Confidence: 0.99418014  
00:17:19.155 --> 00:17:20.615 first scorecard came out.  
NOTE Confidence: 0.98135036  
00:17:23.395 --> 00:17:24.515 We started the dialogue. I  
NOTE Confidence: 0.98135036  
00:17:24.515 --> 00:17:25.075 don't know if that's a  
NOTE Confidence: 0.98135036  
00:17:25.075 --> 00:17:26.035 good enough answer. I have  
NOTE Confidence: 0.98135036



00:17:26.035 --> 00:17:26.935 to think it through,  
NOTE Confidence: 0.9871355

00:17:27.475 --> 00:17:28.615 but they're very engaged.  
NOTE Confidence: 0.958316

00:17:33.470 --> 00:17:34.590 I've been so busy bill  
NOTE Confidence: 0.958316

00:17:34.670 --> 00:17:35.710 building it. I haven't really  
NOTE Confidence: 0.958316

00:17:35.710 --> 00:17:36.670 asked, like, how did it  
NOTE Confidence: 0.958316

00:17:36.670 --> 00:17:38.110 get you know, how did  
NOTE Confidence: 0.958316

00:17:38.110 --> 00:17:39.170 it all work out?  
NOTE Confidence: 0.9518298

00:17:40.990 --> 00:17:42.270 Alright. So in twenty twenty  
NOTE Confidence: 0.9518298

00:17:42.270 --> 00:17:44.395 one, we added all sized  
NOTE Confidence: 0.9518298

00:17:44.395 --> 00:17:45.515 companies, so not just the  
NOTE Confidence: 0.9518298

00:17:45.515 --> 00:17:46.955 twenty largest by market cap,  
NOTE Confidence: 0.9518298

00:17:46.955 --> 00:17:47.675 but the small and the  
NOTE Confidence: 0.9518298

00:17:47.675 --> 00:17:49.035 medium sized companies, and we  
NOTE Confidence: 0.9518298

00:17:49.035 --> 00:17:49.855 added biologics.  
NOTE Confidence: 0.97843474

00:17:50.795 --> 00:17:52.555 In twenty twenty three, we  
NOTE Confidence: 0.97843474

00:17:52.555 --> 00:17:53.915 added more metrics looking at

NOTE Confidence: 0.97843474

00:17:53.915 --> 00:17:55.755 representation and research. And then

NOTE Confidence: 0.97843474

00:17:55.755 --> 00:17:57.195 this year, we'll publish, the

NOTE Confidence: 0.97843474

00:17:57.195 --> 00:17:57.935 new scorecard.

NOTE Confidence: 0.9982793

00:18:00.940 --> 00:18:02.240 So how are we scoring

NOTE Confidence: 0.9982793

00:18:02.299 --> 00:18:03.359 today on

NOTE Confidence: 0.99857324

00:18:03.820 --> 00:18:05.200 clinical trial transparency?

NOTE Confidence: 0.99720865

00:18:06.780 --> 00:18:08.220 Well, for the first four

NOTE Confidence: 0.99720865

00:18:08.220 --> 00:18:08.720 scorecards

NOTE Confidence: 0.99687654

00:18:09.020 --> 00:18:09.919 that we did,

NOTE Confidence: 0.9550012

00:18:11.020 --> 00:18:12.619 the scores for the large

NOTE Confidence: 0.9550012

00:18:12.619 --> 00:18:14.299 companies were trending in the

NOTE Confidence: 0.9550012

00:18:14.299 --> 00:18:14.865 right direction,

NOTE Confidence: 0.90602136

00:18:15.825 --> 00:18:16.325 upwards.

NOTE Confidence: 0.96347296

00:18:17.905 --> 00:18:17.984 And,

NOTE Confidence: 0.9993784

00:18:18.945 --> 00:18:20.645 that was a statistically significant

NOTE Confidence: 0.9997825

00:18:21.025 --> 00:18:22.325 improvement every year.  
NOTE Confidence: 0.99664944

00:18:24.304 --> 00:18:25.525 So with the new scorecard  
NOTE Confidence: 0.99664944

00:18:25.585 --> 00:18:27.205 coming out, did this trend  
NOTE Confidence: 0.9982437

00:18:27.505 --> 00:18:28.005 continue?  
NOTE Confidence: 0.996846

00:18:28.545 --> 00:18:29.684 So the new scorecard,  
NOTE Confidence: 0.991582

00:18:30.385 --> 00:18:32.359 looks at novel drugs and  
NOTE Confidence: 0.991582

00:18:32.359 --> 00:18:33.799 biologics approved by the FDA  
NOTE Confidence: 0.991582

00:18:33.799 --> 00:18:35.320 between twenty eighteen and twenty  
NOTE Confidence: 0.991582

00:18:35.320 --> 00:18:36.840 twenty one. So it's two  
NOTE Confidence: 0.991582

00:18:36.840 --> 00:18:38.440 hundred and eight drugs sponsored  
NOTE Confidence: 0.991582

00:18:38.440 --> 00:18:39.400 by a hundred and thirty  
NOTE Confidence: 0.991582

00:18:39.400 --> 00:18:41.159 six different organizations, a hundred  
NOTE Confidence: 0.991582

00:18:41.159 --> 00:18:42.039 and thirty five of which  
NOTE Confidence: 0.991582

00:18:42.039 --> 00:18:42.700 are industry,  
NOTE Confidence: 0.9768131

00:18:43.080 --> 00:18:44.200 and sixty percent of which  
NOTE Confidence: 0.9768131

00:18:44.200 --> 00:18:45.080 are based in the United

NOTE Confidence: 0.9768131  
00:18:45.080 --> 00:18:45.580 States.  
NOTE Confidence: 0.8731615  
00:18:49.255 --> 00:18:50.215 For a variety of onco  
NOTE Confidence: 0.8731615  
00:18:50.455 --> 00:18:51.514 a variety of indications,  
NOTE Confidence: 0.99277717  
00:18:51.815 --> 00:18:53.174 the most common one being  
NOTE Confidence: 0.99277717  
00:18:53.174 --> 00:18:53.674 oncology,  
NOTE Confidence: 0.9947545  
00:18:54.934 --> 00:18:55.975 and they were approved based  
NOTE Confidence: 0.9947545  
00:18:55.975 --> 00:18:58.234 on around fourteen hundred trials,  
NOTE Confidence: 0.96649736  
00:18:59.740 --> 00:19:00.859 forty four percent of which  
NOTE Confidence: 0.96649736  
00:19:00.859 --> 00:19:02.220 were in patients for the  
NOTE Confidence: 0.96649736  
00:19:02.220 --> 00:19:03.039 approved indication,  
NOTE Confidence: 0.99261093  
00:19:03.500 --> 00:19:04.779 and thirty three percent are  
NOTE Confidence: 0.99261093  
00:19:04.779 --> 00:19:06.320 legally required to be,  
NOTE Confidence: 0.9787496  
00:19:06.779 --> 00:19:09.200 publicly reported under US laws,  
NOTE Confidence: 0.98786557  
00:19:09.980 --> 00:19:11.260 enrolling about three hundred and  
NOTE Confidence: 0.98786557  
00:19:11.260 --> 00:19:12.080 thirty thousand,  
NOTE Confidence: 0.99979544

00:19:12.460 --> 00:19:13.840 patients around the world.  
NOTE Confidence: 0.99542016

00:19:16.605 --> 00:19:18.125 So for the first time  
NOTE Confidence: 0.99542016

00:19:18.125 --> 00:19:19.905 in the five cohorts  
NOTE Confidence: 0.9924078

00:19:20.285 --> 00:19:21.105 of scorecards,  
NOTE Confidence: 0.999553

00:19:22.205 --> 00:19:23.105 large company  
NOTE Confidence: 0.9929123

00:19:23.565 --> 00:19:25.985 median performance scores went down.  
NOTE Confidence: 0.9998609

00:19:27.005 --> 00:19:27.505 However,  
NOTE Confidence: 0.975181

00:19:27.885 --> 00:19:29.585 it is not statistically significant.  
NOTE Confidence: 0.9995448

00:19:32.800 --> 00:19:33.300 But  
NOTE Confidence: 0.9965687

00:19:34.160 --> 00:19:36.020 if you match the companies  
NOTE Confidence: 0.9965687

00:19:36.080 --> 00:19:37.700 across both the samples  
NOTE Confidence: 0.96427673

00:19:39.040 --> 00:19:40.240 I'm laughing because Carrie asked  
NOTE Confidence: 0.96427673

00:19:40.240 --> 00:19:41.280 if we did this in  
NOTE Confidence: 0.96427673

00:19:41.280 --> 00:19:42.100 another paper.  
NOTE Confidence: 0.97166646

00:19:42.480 --> 00:19:44.240 It is statistically significant, and  
NOTE Confidence: 0.97166646

00:19:44.240 --> 00:19:45.540 you see that eleven

NOTE Confidence: 0.9998747  
00:19:46.435 --> 00:19:47.815 of the large companies  
NOTE Confidence: 0.9936441  
00:19:48.235 --> 00:19:48.735 had,  
NOTE Confidence: 0.9084427  
00:19:49.875 --> 00:19:52.135 declines in scores, some substantial.  
NOTE Confidence: 0.9084427  
00:19:52.355 --> 00:19:53.715 Right there dropped twenty three  
NOTE Confidence: 0.9084427  
00:19:53.715 --> 00:19:55.895 points, Amgen twenty points,  
NOTE Confidence: 0.9802749  
00:19:56.835 --> 00:19:58.515 Novartis nineteen points, and the  
NOTE Confidence: 0.9802749  
00:19:58.515 --> 00:19:59.015 like.  
NOTE Confidence: 0.97283965  
00:20:03.040 --> 00:20:04.080 Now that's just the large  
NOTE Confidence: 0.97283965  
00:20:04.080 --> 00:20:05.040 companies. We actually look at  
NOTE Confidence: 0.97283965  
00:20:05.040 --> 00:20:06.240 two hundred and eight companies,  
NOTE Confidence: 0.97283965  
00:20:06.240 --> 00:20:07.440 and so here's how the  
NOTE Confidence: 0.97283965  
00:20:07.440 --> 00:20:08.800 full sample is scoring. So  
NOTE Confidence: 0.97283965  
00:20:08.800 --> 00:20:10.480 there's some good news. If  
NOTE Confidence: 0.97283965  
00:20:10.480 --> 00:20:11.600 you just look at trials  
NOTE Confidence: 0.97283965  
00:20:11.600 --> 00:20:12.925 conducted in patients for for  
NOTE Confidence: 0.97283965

00:20:12.925 --> 00:20:14.285 the approved indication, you'll see

NOTE Confidence: 0.97283965

00:20:14.285 --> 00:20:15.725 that most trials are registered,

NOTE Confidence: 0.97283965

00:20:15.725 --> 00:20:17.405 ninety five percent, and most

NOTE Confidence: 0.97283965

00:20:17.405 --> 00:20:19.325 have publicly available results, eighty

NOTE Confidence: 0.97283965

00:20:19.325 --> 00:20:21.005 five percent. Seventy percent are

NOTE Confidence: 0.97283965

00:20:21.005 --> 00:20:22.365 reported in the regis in

NOTE Confidence: 0.97283965

00:20:22.365 --> 00:20:23.025 a registry,

NOTE Confidence: 0.9981303

00:20:23.484 --> 00:20:25.005 and sixty percent are published

NOTE Confidence: 0.9981303

00:20:25.005 --> 00:20:25.744 in the literature.

NOTE Confidence: 0.99973136

00:20:26.820 --> 00:20:27.539 But if you look at

NOTE Confidence: 0.99973136

00:20:27.539 --> 00:20:28.840 almost every other standard,

NOTE Confidence: 0.99294114

00:20:29.140 --> 00:20:29.640 there's

NOTE Confidence: 0.9943906

00:20:30.020 --> 00:20:31.480 substantial room for improvement.

NOTE Confidence: 0.9936007

00:20:32.260 --> 00:20:33.460 So only fifty percent of

NOTE Confidence: 0.9936007

00:20:33.460 --> 00:20:34.900 all trials supporting a product

NOTE Confidence: 0.9936007

00:20:34.900 --> 00:20:36.600 approval have public results,

NOTE Confidence: 0.99633104  
00:20:37.380 --> 00:20:38.740 and only sixty two percent  
NOTE Confidence: 0.99633104  
00:20:38.740 --> 00:20:41.000 of applicable trials meet US  
NOTE Confidence: 0.96384263  
00:20:41.914 --> 00:20:43.595 baseline US legal requirements for  
NOTE Confidence: 0.96384263  
00:20:43.595 --> 00:20:44.095 transparency.  
NOTE Confidence: 0.9933733  
00:20:45.275 --> 00:20:45.994 And if you go up  
NOTE Confidence: 0.9933733  
00:20:46.315 --> 00:20:47.275 roll all this up to  
NOTE Confidence: 0.9933733  
00:20:47.275 --> 00:20:48.715 the company level, only twenty  
NOTE Confidence: 0.9933733  
00:20:48.715 --> 00:20:50.234 four percent of companies that  
NOTE Confidence: 0.9933733  
00:20:50.234 --> 00:20:50.975 we evaluated  
NOTE Confidence: 0.99489427  
00:20:51.434 --> 00:20:52.395 share the results of all  
NOTE Confidence: 0.99489427  
00:20:52.395 --> 00:20:53.755 of their clinical trials, and  
NOTE Confidence: 0.99489427  
00:20:53.755 --> 00:20:55.294 we're looking at six months  
NOTE Confidence: 0.9945042  
00:20:55.755 --> 00:20:58.080 post FDA approval of a  
NOTE Confidence: 0.9945042  
00:20:58.080 --> 00:20:58.580 product.  
NOTE Confidence: 0.96088177  
00:21:00.960 --> 00:21:01.760 And then if you look  
NOTE Confidence: 0.96088177



00:21:01.760 --> 00:21:03.679 at Fadal Compliance, only thirty  
NOTE Confidence: 0.96088177

00:21:03.679 --> 00:21:05.679 two percent of evaluated companies  
NOTE Confidence: 0.96088177

00:21:05.679 --> 00:21:07.840 met baseline legal requirements for  
NOTE Confidence: 0.96088177

00:21:07.840 --> 00:21:10.000 trial registration results reporting. So  
NOTE Confidence: 0.96088177

00:21:10.000 --> 00:21:11.380 sixty eight percent of companies  
NOTE Confidence: 0.96088177

00:21:11.440 --> 00:21:12.720 fail to meet baseline legal  
NOTE Confidence: 0.96088177

00:21:12.720 --> 00:21:13.220 requirements.  
NOTE Confidence: 0.9952212

00:21:13.815 --> 00:21:14.934 Just gonna leave that there  
NOTE Confidence: 0.9952212

00:21:14.934 --> 00:21:16.054 for a second. That is  
NOTE Confidence: 0.9952212

00:21:16.054 --> 00:21:17.274 a massive number.  
NOTE Confidence: 0.9596799

00:21:19.734 --> 00:21:20.875 Jen, the  
NOTE Confidence: 0.9326947

00:21:22.534 --> 00:21:23.355 what what changed  
NOTE Confidence: 0.9961401

00:21:23.815 --> 00:21:25.654 between the over that one  
NOTE Confidence: 0.9961401

00:21:25.654 --> 00:21:26.955 year? I mean, these are  
NOTE Confidence: 0.9666121

00:21:27.570 --> 00:21:28.230 these are,  
NOTE Confidence: 0.94331336

00:21:29.090 --> 00:21:30.390 scary numbers. But

NOTE Confidence: 0.99656564

00:21:31.250 --> 00:21:32.529 I don't know. So that's

NOTE Confidence: 0.99656564

00:21:32.529 --> 00:21:33.809 what we're going to start

NOTE Confidence: 0.99656564

00:21:33.809 --> 00:21:35.970 doing the qualitative research to

NOTE Confidence: 0.99656564

00:21:35.970 --> 00:21:37.010 to figure out. I know

NOTE Confidence: 0.99656564

00:21:37.010 --> 00:21:37.750 we stopped

NOTE Confidence: 0.9976989

00:21:38.690 --> 00:21:39.429 our benchmarking

NOTE Confidence: 0.97055066

00:21:40.395 --> 00:21:41.595 for a good five years

NOTE Confidence: 0.97055066

00:21:41.595 --> 00:21:43.035 because of resource constraints, and

NOTE Confidence: 0.97055066

00:21:43.035 --> 00:21:44.335 we were building new scorecards.

NOTE Confidence: 0.98552847

00:21:47.835 --> 00:21:48.715 I don't know. And some

NOTE Confidence: 0.98552847

00:21:48.715 --> 00:21:50.555 companies are voluntarily raising their

NOTE Confidence: 0.98552847

00:21:50.555 --> 00:21:51.295 own bars,

NOTE Confidence: 0.9739018

00:21:51.675 --> 00:21:53.435 returning plain language summaries to

NOTE Confidence: 0.9739018

00:21:53.435 --> 00:21:54.655 to patients, returning

NOTE Confidence: 0.98666

00:21:55.035 --> 00:21:55.535 the

NOTE Confidence: 0.9622665

00:21:55.890 --> 00:21:57.970 data to trial participants so  
NOTE Confidence: 0.9622665

00:21:57.970 --> 00:21:59.010 it can integrate into their  
NOTE Confidence: 0.9622665

00:21:59.010 --> 00:22:00.609 electronic health records. So I'm  
NOTE Confidence: 0.9622665

00:22:00.609 --> 00:22:01.650 not sure. So stay tuned  
NOTE Confidence: 0.9622665

00:22:01.650 --> 00:22:02.550 till next year.  
NOTE Confidence: 0.9969189

00:22:03.650 --> 00:22:05.170 It's a good plug. Thank  
NOTE Confidence: 0.9969189

00:22:05.170 --> 00:22:05.670 you.  
NOTE Confidence: 0.99101996

00:22:07.490 --> 00:22:08.609 And then so when we  
NOTE Confidence: 0.99101996

00:22:08.609 --> 00:22:09.010 got,  
NOTE Confidence: 0.9997405

00:22:09.490 --> 00:22:10.230 the companies  
NOTE Confidence: 0.99832153

00:22:10.530 --> 00:22:11.030 together,  
NOTE Confidence: 0.98626125

00:22:12.554 --> 00:22:13.315 we asked them, what do  
NOTE Confidence: 0.98626125

00:22:13.315 --> 00:22:13.994 you think is going on?  
NOTE Confidence: 0.98626125

00:22:13.994 --> 00:22:14.715 And they said, well, it's  
NOTE Confidence: 0.98626125

00:22:14.715 --> 00:22:16.155 clearly the small companies. It's  
NOTE Confidence: 0.98626125

00:22:16.155 --> 00:22:17.835 not the large companies' fault.

NOTE Confidence: 0.98626125  
00:22:17.835 --> 00:22:18.734 But, really,  
NOTE Confidence: 0.9977968  
00:22:20.155 --> 00:22:21.914 the only the data sharing  
NOTE Confidence: 0.9977968  
00:22:21.914 --> 00:22:23.615 score is statistically different,  
NOTE Confidence: 0.99246293  
00:22:24.075 --> 00:22:25.215 by company size,  
NOTE Confidence: 0.85174876  
00:22:25.755 --> 00:22:27.350 not FEDAW compliance,  
NOTE Confidence: 0.99876815  
00:22:28.210 --> 00:22:29.010 or any of the other  
NOTE Confidence: 0.99876815  
00:22:29.010 --> 00:22:29.510 measures.  
NOTE Confidence: 0.9997888  
00:22:30.930 --> 00:22:31.809 So what do we look  
NOTE Confidence: 0.9997888  
00:22:31.809 --> 00:22:33.030 at for data sharing?  
NOTE Confidence: 0.98737204  
00:22:33.890 --> 00:22:35.570 We're looking at whether first  
NOTE Confidence: 0.98737204  
00:22:35.570 --> 00:22:37.330 companies have a policy committing  
NOTE Confidence: 0.98737204  
00:22:37.330 --> 00:22:39.350 to sharing, patient level data,  
NOTE Confidence: 0.9577272  
00:22:39.815 --> 00:22:41.015 the clinical study report, and  
NOTE Confidence: 0.9577272  
00:22:41.015 --> 00:22:43.015 the analyzable dataset supporting phase  
NOTE Confidence: 0.9577272  
00:22:43.015 --> 00:22:44.135 two and three trials for  
NOTE Confidence: 0.9577272

00:22:44.135 --> 00:22:45.115 their product approvals.  
NOTE Confidence: 0.9978315

00:22:46.054 --> 00:22:47.174 We're looking at whether they  
NOTE Confidence: 0.9978315

00:22:47.174 --> 00:22:48.695 clearly explain how the data  
NOTE Confidence: 0.9978315

00:22:48.695 --> 00:22:49.415 can be,  
NOTE Confidence: 0.9455483

00:22:49.815 --> 00:22:50.315 requested,  
NOTE Confidence: 0.99328333

00:22:50.615 --> 00:22:51.895 that they commit to sharing  
NOTE Confidence: 0.99328333

00:22:51.895 --> 00:22:53.734 by six months after FDA  
NOTE Confidence: 0.99328333

00:22:53.734 --> 00:22:55.200 approval of a product, and  
NOTE Confidence: 0.99328333

00:22:55.200 --> 00:22:56.440 that they report the number  
NOTE Confidence: 0.99328333

00:22:56.440 --> 00:22:57.960 of data requests they receive  
NOTE Confidence: 0.99328333

00:22:57.960 --> 00:22:59.020 and whether they,  
NOTE Confidence: 0.9984411

00:22:59.559 --> 00:23:01.419 approved or rejected the request.  
NOTE Confidence: 0.9614278

00:23:03.559 --> 00:23:04.679 Jen, just real quick. These  
NOTE Confidence: 0.9614278

00:23:04.679 --> 00:23:06.119 are only for FDA approved  
NOTE Confidence: 0.9614278

00:23:06.119 --> 00:23:07.720 products. Isn't part of the  
NOTE Confidence: 0.9614278

00:23:07.720 --> 00:23:09.794 approval also publish that phase

NOTE Confidence: 0.9614278  
00:23:09.794 --> 00:23:11.075 two, phase three trial in  
NOTE Confidence: 0.9614278  
00:23:11.075 --> 00:23:13.395 their right? And it's usually  
NOTE Confidence: 0.9614278  
00:23:13.554 --> 00:23:16.034 The medical review has some  
NOTE Confidence: 0.9614278  
00:23:16.034 --> 00:23:17.895 information about a pivotal trial.  
NOTE Confidence: 0.8228493  
00:23:18.755 --> 00:23:21.075 Just not I. Not Definitely  
NOTE Confidence: 0.8228493  
00:23:21.075 --> 00:23:22.195 not the raw patient level  
NOTE Confidence: 0.8228493  
00:23:22.195 --> 00:23:23.174 data. Yeah.  
NOTE Confidence: 0.948171  
00:23:27.230 --> 00:23:28.030 But I I like that  
NOTE Confidence: 0.948171  
00:23:28.030 --> 00:23:28.830 you're saying, like, why can't  
NOTE Confidence: 0.948171  
00:23:28.830 --> 00:23:29.950 we just ask everybody to  
NOTE Confidence: 0.948171  
00:23:29.950 --> 00:23:31.170 go to the approval packages?  
NOTE Confidence: 0.97695184  
00:23:31.710 --> 00:23:33.150 That doesn't really happen, but  
NOTE Confidence: 0.97695184  
00:23:33.150 --> 00:23:34.270 in theory, some could get  
NOTE Confidence: 0.97695184  
00:23:34.270 --> 00:23:35.630 more information from them. We  
NOTE Confidence: 0.97695184  
00:23:35.630 --> 00:23:36.290 use them.  
NOTE Confidence: 0.9856122

00:23:38.684 --> 00:23:39.645 So the takeaway from this  
NOTE Confidence: 0.9856122

00:23:39.645 --> 00:23:41.085 side is that seventy percent  
NOTE Confidence: 0.9856122

00:23:41.085 --> 00:23:42.125 of the companies we looked  
NOTE Confidence: 0.9856122

00:23:42.125 --> 00:23:42.625 at  
NOTE Confidence: 0.9995031

00:23:43.804 --> 00:23:45.085 don't even have a public  
NOTE Confidence: 0.9995031

00:23:45.085 --> 00:23:46.065 policy committing  
NOTE Confidence: 0.98893315

00:23:46.445 --> 00:23:48.205 to data sharing, right, which  
NOTE Confidence: 0.98893315

00:23:48.205 --> 00:23:48.945 makes reproducibility  
NOTE Confidence: 0.9608376

00:23:49.565 --> 00:23:51.244 a challenge or pulling data  
NOTE Confidence: 0.9608376

00:23:51.244 --> 00:23:52.785 across trials for innovation.  
NOTE Confidence: 0.9970436

00:23:53.800 --> 00:23:55.560 However, nineteen percent of companies  
NOTE Confidence: 0.9970436

00:23:55.560 --> 00:23:56.760 were able to score a  
NOTE Confidence: 0.9970436

00:23:56.760 --> 00:23:57.900 hundred percent on  
NOTE Confidence: 0.9714007

00:23:58.280 --> 00:23:59.240 on all of our data  
NOTE Confidence: 0.9714007

00:23:59.240 --> 00:24:00.060 sharing measures.  
NOTE Confidence: 0.99519527

00:24:00.840 --> 00:24:01.160 And,

NOTE Confidence: 0.9990751  
00:24:01.720 --> 00:24:03.260 eight companies scored  
NOTE Confidence: 0.989816  
00:24:03.800 --> 00:24:05.400 a hundred percent across all  
NOTE Confidence: 0.989816  
00:24:05.400 --> 00:24:07.295 of the transparency measures, the  
NOTE Confidence: 0.989816  
00:24:07.295 --> 00:24:09.695 registration, results reporting, publication, legal  
NOTE Confidence: 0.989816  
00:24:09.695 --> 00:24:11.315 compliance, and data sharing measures,  
NOTE Confidence: 0.9988802  
00:24:12.415 --> 00:24:13.855 suggesting it's possible to do  
NOTE Confidence: 0.9988802  
00:24:13.855 --> 00:24:14.755 this right.  
NOTE Confidence: 0.99693406  
00:24:15.215 --> 00:24:16.175 So now we're gonna go  
NOTE Confidence: 0.99693406  
00:24:16.175 --> 00:24:17.075 through and see  
NOTE Confidence: 0.96795195  
00:24:17.455 --> 00:24:18.255 how did they do it,  
NOTE Confidence: 0.96795195  
00:24:18.255 --> 00:24:19.215 especially the ones who have  
NOTE Confidence: 0.96795195  
00:24:19.215 --> 00:24:20.515 been consistent over time,  
NOTE Confidence: 0.98929185  
00:24:20.895 --> 00:24:22.919 why, and then understand why  
NOTE Confidence: 0.98929185  
00:24:22.919 --> 00:24:24.380 the the laggards are  
NOTE Confidence: 0.98563653  
00:24:24.760 --> 00:24:26.039 are either going down or  
NOTE Confidence: 0.98563653



00:24:26.039 --> 00:24:26.279 or,  
NOTE Confidence: 0.99784863  
00:24:27.080 --> 00:24:27.740 not improving.  
NOTE Confidence: 0.9652447  
00:24:31.159 --> 00:24:32.359 So next steps, find out  
NOTE Confidence: 0.9652447  
00:24:32.359 --> 00:24:33.899 why transparency is decreasing.  
NOTE Confidence: 0.91202176  
00:24:36.295 --> 00:24:37.494 How are the bright spots,  
NOTE Confidence: 0.99175715  
00:24:38.295 --> 00:24:39.115 staying bright?  
NOTE Confidence: 0.9820455  
00:24:39.655 --> 00:24:40.775 Should we recalibrate,  
NOTE Confidence: 0.9752401  
00:24:42.295 --> 00:24:43.895 the transparency measures in some  
NOTE Confidence: 0.9752401  
00:24:43.895 --> 00:24:46.475 way? The expectations around transparency  
NOTE Confidence: 0.9752401  
00:24:46.615 --> 00:24:48.375 keep evolving, and we probably  
NOTE Confidence: 0.9752401  
00:24:48.375 --> 00:24:49.435 need to as well.  
NOTE Confidence: 0.98261195  
00:24:50.410 --> 00:24:51.850 Publish the scorecard results I  
NOTE Confidence: 0.98261195  
00:24:51.850 --> 00:24:53.050 just showed you and start  
NOTE Confidence: 0.98261195  
00:24:53.050 --> 00:24:54.090 gathering the data for the  
NOTE Confidence: 0.98261195  
00:24:54.090 --> 00:24:54.590 next,  
NOTE Confidence: 0.99951917  
00:24:55.050 --> 00:24:56.510 the next set of products.

NOTE Confidence: 0.9917455  
00:24:59.930 --> 00:25:00.890 Alright. So now I'm gonna  
NOTE Confidence: 0.9917455  
00:25:00.890 --> 00:25:02.109 move on to the third  
NOTE Confidence: 0.9960485  
00:25:02.505 --> 00:25:04.265 scorecard. This one's focused on  
NOTE Confidence: 0.9960485  
00:25:04.265 --> 00:25:04.765 representation  
NOTE Confidence: 0.99974847  
00:25:05.065 --> 00:25:06.525 in clinical trial enrollment.  
NOTE Confidence: 0.9720302  
00:25:08.825 --> 00:25:10.445 I'll go over why representation  
NOTE Confidence: 0.9720302  
00:25:10.505 --> 00:25:12.345 is so important, what metrics  
NOTE Confidence: 0.9720302  
00:25:12.345 --> 00:25:14.045 we use to benchmark representation,  
NOTE Confidence: 0.9720302  
00:25:14.265 --> 00:25:15.965 the ten year performance trends,  
NOTE Confidence: 0.9720302  
00:25:16.025 --> 00:25:17.225 and then I'll preview the  
NOTE Confidence: 0.9720302  
00:25:17.225 --> 00:25:17.725 forthcoming  
NOTE Confidence: 0.99769974  
00:25:19.750 --> 00:25:20.250 scorecard.  
NOTE Confidence: 0.9409447  
00:25:21.750 --> 00:25:22.890 I think we all  
NOTE Confidence: 0.99954844  
00:25:23.830 --> 00:25:24.970 know that representation  
NOTE Confidence: 0.9949427  
00:25:25.270 --> 00:25:27.109 is a huge challenge in  
NOTE Confidence: 0.9949427

00:25:27.109 --> 00:25:27.609 research,  
NOTE Confidence: 0.98841554

00:25:27.990 --> 00:25:29.109 which is why we're tackling  
NOTE Confidence: 0.98841554

00:25:29.109 --> 00:25:30.950 it. Women, older adults, racial  
NOTE Confidence: 0.98841554

00:25:30.950 --> 00:25:32.355 and ethnic minoritized patients, and  
NOTE Confidence: 0.98841554

00:25:32.355 --> 00:25:33.635 so many other groups are  
NOTE Confidence: 0.98841554

00:25:33.635 --> 00:25:34.695 consistently underrepresented  
NOTE Confidence: 0.9993413

00:25:35.075 --> 00:25:36.195 in research. Right? We tend  
NOTE Confidence: 0.9993413

00:25:36.195 --> 00:25:37.255 to test new medicines  
NOTE Confidence: 0.91209567

00:25:37.795 --> 00:25:39.075 on patient on healthy young  
NOTE Confidence: 0.91209567

00:25:39.075 --> 00:25:40.515 white males that don't represent  
NOTE Confidence: 0.91209567

00:25:40.515 --> 00:25:42.135 the patient population who ultimately,  
NOTE Confidence: 0.9922161

00:25:43.555 --> 00:25:44.615 will use a product.  
NOTE Confidence: 0.9996422

00:25:47.010 --> 00:25:48.369 Many of the foundational studies  
NOTE Confidence: 0.9996422

00:25:48.369 --> 00:25:49.250 in this area have been  
NOTE Confidence: 0.9996422

00:25:49.250 --> 00:25:50.550 done by our own faculty.  
NOTE Confidence: 0.97438824

00:25:51.330 --> 00:25:52.930 In fact, this study dates

NOTE Confidence: 0.97438824

00:25:52.930 --> 00:25:53.890 back all the way to

NOTE Confidence: 0.97438824

00:25:53.890 --> 00:25:55.010 two thousand and four, and

NOTE Confidence: 0.97438824

00:25:55.010 --> 00:25:55.970 it was done by Carrie

NOTE Confidence: 0.97438824

00:25:55.970 --> 00:25:57.170 Gross. So thank you for

NOTE Confidence: 0.97438824

00:25:57.170 --> 00:25:58.630 pioneering in this field.

NOTE Confidence: 0.93008775

00:25:59.090 --> 00:26:00.690 But Joe Ross, Harlan Kremels,

NOTE Confidence: 0.93008775

00:26:00.690 --> 00:26:01.990 and so many others

NOTE Confidence: 0.9988144

00:26:02.554 --> 00:26:03.515 of us in this room

NOTE Confidence: 0.9988144

00:26:03.515 --> 00:26:04.955 have also, worked on this

NOTE Confidence: 0.9988144

00:26:04.955 --> 00:26:05.455 topic.

NOTE Confidence: 0.95809793

00:26:07.035 --> 00:26:08.635 Policy efforts to try and

NOTE Confidence: 0.95809793

00:26:08.635 --> 00:26:10.875 improve representation and research span

NOTE Confidence: 0.95809793

00:26:10.875 --> 00:26:12.234 at least forty years with

NOTE Confidence: 0.95809793

00:26:12.234 --> 00:26:13.135 limited impact

NOTE Confidence: 0.915074

00:26:14.554 --> 00:26:16.155 and now with no to

NOTE Confidence: 0.915074

00:26:16.155 --> 00:26:17.615 possibly even countervailing,  
NOTE Confidence: 0.9964873

00:26:19.210 --> 00:26:20.590 federal support on the issue.  
NOTE Confidence: 0.9849449

00:26:22.970 --> 00:26:24.570 We know why representation is  
NOTE Confidence: 0.9849449

00:26:24.570 --> 00:26:26.029 important for the generalizability  
NOTE Confidence: 0.9841774

00:26:26.330 --> 00:26:27.929 of results for everyone to  
NOTE Confidence: 0.9841774

00:26:27.929 --> 00:26:29.529 have a fair opportunity to  
NOTE Confidence: 0.9841774

00:26:29.529 --> 00:26:31.049 participate in research and for  
NOTE Confidence: 0.9841774

00:26:31.049 --> 00:26:32.555 trust. Studies have shown that  
NOTE Confidence: 0.9841774

00:26:32.555 --> 00:26:34.655 certain racial and ethnic minoritized  
NOTE Confidence: 0.9821862

00:26:35.195 --> 00:26:37.115 patients, groups, and the clinicians  
NOTE Confidence: 0.9821862

00:26:37.115 --> 00:26:38.715 who treat them are less  
NOTE Confidence: 0.9821862

00:26:38.715 --> 00:26:40.655 likely to find trial evidence  
NOTE Confidence: 0.9939248

00:26:41.195 --> 00:26:42.875 relevant for their care, are  
NOTE Confidence: 0.9939248

00:26:42.875 --> 00:26:44.075 less likely to believe a  
NOTE Confidence: 0.9939248

00:26:44.075 --> 00:26:45.195 drug will be effective for  
NOTE Confidence: 0.9939248

00:26:45.195 --> 00:26:46.610 them, and are less likely

NOTE Confidence: 0.9939248  
00:26:46.610 --> 00:26:47.570 to use a medicine when  
NOTE Confidence: 0.9939248  
00:26:47.570 --> 00:26:49.190 they're underrepresented in the dataset.  
NOTE Confidence: 0.9992138  
00:26:49.650 --> 00:26:51.410 Importantly, when the clinical trial  
NOTE Confidence: 0.9992138  
00:26:51.410 --> 00:26:53.330 is representative, the trust gap  
NOTE Confidence: 0.9992138  
00:26:53.330 --> 00:26:53.830 closes.  
NOTE Confidence: 0.9822784  
00:26:57.250 --> 00:26:58.530 So we followed our standard  
NOTE Confidence: 0.9822784  
00:26:58.530 --> 00:27:00.050 process for developing the metrics  
NOTE Confidence: 0.9822784  
00:27:00.050 --> 00:27:00.870 in this space.  
NOTE Confidence: 0.99551064  
00:27:01.545 --> 00:27:02.825 Interestingly, when you review the  
NOTE Confidence: 0.99551064  
00:27:02.825 --> 00:27:04.185 literature at the time and  
NOTE Confidence: 0.99551064  
00:27:04.185 --> 00:27:05.485 you review the guidelines,  
NOTE Confidence: 0.9983108  
00:27:05.945 --> 00:27:07.225 we found a lack of  
NOTE Confidence: 0.9983108  
00:27:07.225 --> 00:27:08.744 consensus on the best way  
NOTE Confidence: 0.9983108  
00:27:08.744 --> 00:27:10.045 to measure representation.  
NOTE Confidence: 0.98261565  
00:27:10.825 --> 00:27:12.665 Two key ways emerged, and  
NOTE Confidence: 0.98261565

00:27:12.665 --> 00:27:13.945 the lack of consensus was  
NOTE Confidence: 0.98261565

00:27:13.945 --> 00:27:15.545 highlighted by a NASEM report  
NOTE Confidence: 0.98261565

00:27:15.545 --> 00:27:16.845 in twenty twenty two.  
NOTE Confidence: 0.99518514

00:27:17.909 --> 00:27:18.409 And,  
NOTE Confidence: 0.95280313

00:27:19.590 --> 00:27:21.049 we wrote in GEM Oncology  
NOTE Confidence: 0.956771

00:27:21.350 --> 00:27:22.630 about these two ways. The  
NOTE Confidence: 0.956771

00:27:22.630 --> 00:27:24.090 first one we called the  
NOTE Confidence: 0.956771

00:27:24.149 --> 00:27:25.850 country population based approach,  
NOTE Confidence: 0.9987331

00:27:26.230 --> 00:27:28.649 which suggests that trial participant  
NOTE Confidence: 0.9987331

00:27:28.869 --> 00:27:29.369 demographics  
NOTE Confidence: 0.98383635

00:27:29.804 --> 00:27:30.924 should mirror the estimates of  
NOTE Confidence: 0.98383635

00:27:30.924 --> 00:27:32.764 a country's population demographics. So  
NOTE Confidence: 0.98383635

00:27:32.764 --> 00:27:33.725 for the US, that would  
NOTE Confidence: 0.98383635

00:27:33.725 --> 00:27:35.804 mean always aiming to enroll  
NOTE Confidence: 0.98383635

00:27:35.804 --> 00:27:37.804 six percent patients identifying as  
NOTE Confidence: 0.98383635

00:27:37.804 --> 00:27:39.484 Asian, fourteen percent identifying as

NOTE Confidence: 0.98383635  
00:27:39.484 --> 00:27:40.544 black, and the like,  
NOTE Confidence: 0.9781784  
00:27:40.845 --> 00:27:42.365 regardless of the condition you're  
NOTE Confidence: 0.9781784  
00:27:42.365 --> 00:27:44.065 studying, so a disease neutral  
NOTE Confidence: 0.9781784  
00:27:44.125 --> 00:27:44.625 approach.  
NOTE Confidence: 0.99981135  
00:27:45.600 --> 00:27:47.700 The other common approach is  
NOTE Confidence: 0.9443921  
00:27:48.320 --> 00:27:49.440 the what we call the  
NOTE Confidence: 0.9443921  
00:27:49.440 --> 00:27:50.580 condition based approach,  
NOTE Confidence: 0.97432756  
00:27:51.440 --> 00:27:53.299 which suggests that trial participant  
NOTE Confidence: 0.97432756  
00:27:53.359 --> 00:27:54.960 demographics should mirror those of  
NOTE Confidence: 0.97432756  
00:27:54.960 --> 00:27:56.320 the patient population with a  
NOTE Confidence: 0.97432756  
00:27:56.320 --> 00:27:57.299 targeted indication.  
NOTE Confidence: 0.99978024  
00:27:58.080 --> 00:27:59.140 These two approaches  
NOTE Confidence: 0.98121196  
00:27:59.765 --> 00:28:01.845 can yield wildly different enrollment  
NOTE Confidence: 0.98121196  
00:28:01.845 --> 00:28:03.045 goals, so it's really important  
NOTE Confidence: 0.98121196  
00:28:03.045 --> 00:28:03.765 for us to think through  
NOTE Confidence: 0.98121196



00:28:03.765 --> 00:28:04.645 which one we were gonna  
NOTE Confidence: 0.98121196  
00:28:04.645 --> 00:28:05.145 use.  
NOTE Confidence: 0.98701394  
00:28:06.405 --> 00:28:08.165 And, ultimately, we settled on  
NOTE Confidence: 0.98701394  
00:28:08.165 --> 00:28:09.465 the condition based approach.  
NOTE Confidence: 0.9962501  
00:28:10.725 --> 00:28:11.785 So we're benchmarking  
NOTE Confidence: 0.9797619  
00:28:12.325 --> 00:28:13.525 three types of,  
NOTE Confidence: 0.99935  
00:28:14.539 --> 00:28:16.220 three groups of measures. First,  
NOTE Confidence: 0.99935  
00:28:16.220 --> 00:28:17.359 we're looking at transparency.  
NOTE Confidence: 0.97290385  
00:28:18.140 --> 00:28:20.059 Can we even tell the  
NOTE Confidence: 0.97290385  
00:28:20.059 --> 00:28:21.980 demographics of trial participants? The  
NOTE Confidence: 0.97290385  
00:28:21.980 --> 00:28:23.520 sex, the age, the race,  
NOTE Confidence: 0.97290385  
00:28:23.820 --> 00:28:24.720 ethnic identity.  
NOTE Confidence: 0.94362736  
00:28:25.419 --> 00:28:26.460 And we're looking in clinical  
NOTE Confidence: 0.94362736  
00:28:26.460 --> 00:28:27.840 trials dot gov and publications.  
NOTE Confidence: 0.98788035  
00:28:28.465 --> 00:28:29.925 Then we're looking at representation.  
NOTE Confidence: 0.98788035  
00:28:30.145 --> 00:28:31.045 Does the population,

NOTE Confidence: 0.9632801

00:28:31.825 --> 00:28:33.765 represent the patient population's demographics

NOTE Confidence: 0.9632801

00:28:33.825 --> 00:28:35.425 with the targeted indication aiming

NOTE Confidence: 0.9632801

00:28:35.425 --> 00:28:36.625 to represent at least eighty

NOTE Confidence: 0.9632801

00:28:36.625 --> 00:28:37.125 percent?

NOTE Confidence: 0.9900682

00:28:37.585 --> 00:28:38.785 And then fair inclusion is

NOTE Confidence: 0.9900682

00:28:38.785 --> 00:28:40.485 both looking at both transparency

NOTE Confidence: 0.9900682

00:28:40.625 --> 00:28:41.365 and representation.

NOTE Confidence: 0.93837327

00:28:42.790 --> 00:28:44.570 Looking at seven measures for

NOTE Confidence: 0.9954604

00:28:44.870 --> 00:28:46.810 transparency and five for representation.

NOTE Confidence: 0.9984903

00:28:49.590 --> 00:28:50.470 And so what did we

NOTE Confidence: 0.9984903

00:28:50.470 --> 00:28:51.530 find? We piloted,

NOTE Confidence: 0.99410504

00:28:52.150 --> 00:28:53.510 the metrics and published them

NOTE Confidence: 0.99410504

00:28:53.510 --> 00:28:55.110 in twenty twenty three in

NOTE Confidence: 0.99410504

00:28:55.110 --> 00:28:56.090 BMJ Medicine.

NOTE Confidence: 0.99252987

00:28:57.015 --> 00:28:57.895 This paper was led by

NOTE Confidence: 0.99252987

00:28:57.895 --> 00:28:58.935 Tanvi Varma. She was a  
NOTE Confidence: 0.99252987

00:28:58.935 --> 00:28:59.975 med student here at the  
NOTE Confidence: 0.99252987

00:28:59.975 --> 00:29:01.755 time, and now she's graduated.  
NOTE Confidence: 0.96675986

00:29:05.815 --> 00:29:07.175 Oh, yes. Anne went on  
NOTE Confidence: 0.96675986

00:29:07.175 --> 00:29:07.975 to make it onto the  
NOTE Confidence: 0.96675986

00:29:07.975 --> 00:29:09.255 Forbes thirty under thirty list  
NOTE Confidence: 0.96675986

00:29:09.255 --> 00:29:09.895 for her work with the  
NOTE Confidence: 0.96675986

00:29:09.895 --> 00:29:11.415 GoodPharma scorecard. I'm really excited  
NOTE Confidence: 0.96675986

00:29:11.415 --> 00:29:12.155 about that.  
NOTE Confidence: 0.9998208

00:29:13.790 --> 00:29:14.610 She's amazing.  
NOTE Confidence: 0.99688154

00:29:15.390 --> 00:29:17.070 So the pilot sample looked  
NOTE Confidence: 0.99688154

00:29:17.070 --> 00:29:18.270 at the products approved by  
NOTE Confidence: 0.99688154

00:29:18.270 --> 00:29:19.890 the FDA for an oncologic  
NOTE Confidence: 0.99688154

00:29:19.950 --> 00:29:21.630 indication between twenty twelve and  
NOTE Confidence: 0.99688154

00:29:21.630 --> 00:29:23.390 twenty seventeen. That was fifty  
NOTE Confidence: 0.99688154

00:29:23.390 --> 00:29:25.090 nine novel cancer therapeutics

NOTE Confidence: 0.9941078

00:29:25.630 --> 00:29:27.230 sponsored by twenty five different

NOTE Confidence: 0.9941078

00:29:27.230 --> 00:29:27.730 companies

NOTE Confidence: 0.97849804

00:29:29.285 --> 00:29:30.505 for a variety of oncological

NOTE Confidence: 0.97849804

00:29:30.645 --> 00:29:32.245 indications based on sixty four

NOTE Confidence: 0.97849804

00:29:32.245 --> 00:29:33.924 pivotal trials enrolling about thirty

NOTE Confidence: 0.97849804

00:29:33.924 --> 00:29:35.365 thousand different patients around the

NOTE Confidence: 0.97849804

00:29:35.365 --> 00:29:36.325 world. It's a median of

NOTE Confidence: 0.97849804

00:29:36.325 --> 00:29:37.445 three hundred and twenty six

NOTE Confidence: 0.97849804

00:29:37.445 --> 00:29:38.585 participants per,

NOTE Confidence: 0.9998061

00:29:38.965 --> 00:29:39.945 pivotal trial.

NOTE Confidence: 0.97310996

00:29:41.700 --> 00:29:42.820 So what we found is

NOTE Confidence: 0.97310996

00:29:42.820 --> 00:29:44.419 while a hundred percent of

NOTE Confidence: 0.97310996

00:29:44.419 --> 00:29:46.419 trials reported the sex of

NOTE Confidence: 0.97310996

00:29:46.419 --> 00:29:47.780 participants, so we could tell

NOTE Confidence: 0.97310996

00:29:47.780 --> 00:29:48.580 the number of women or

NOTE Confidence: 0.97310996

00:29:48.580 --> 00:29:50.100 older, or men in,  
NOTE Confidence: 0.89122605

00:29:51.220 --> 00:29:51.720 enrolled,  
NOTE Confidence: 0.99819565

00:29:53.540 --> 00:29:54.840 we could not  
NOTE Confidence: 0.99873346

00:29:55.425 --> 00:29:56.545 often tell the age of  
NOTE Confidence: 0.99873346

00:29:56.545 --> 00:29:58.145 trial participants or the racial  
NOTE Confidence: 0.99873346

00:29:58.145 --> 00:29:59.685 and ethnic identity of participants.  
NOTE Confidence: 0.99484825

00:30:01.025 --> 00:30:02.305 Further, not only was it  
NOTE Confidence: 0.99484825

00:30:02.305 --> 00:30:03.905 not transparent, it was not  
NOTE Confidence: 0.99484825

00:30:03.905 --> 00:30:04.405 representative.  
NOTE Confidence: 0.991307

00:30:08.170 --> 00:30:09.690 And to some degree, representation  
NOTE Confidence: 0.991307

00:30:09.690 --> 00:30:10.810 of women also needs to  
NOTE Confidence: 0.991307

00:30:10.810 --> 00:30:11.470 be improved.  
NOTE Confidence: 0.9989764

00:30:14.890 --> 00:30:15.390 Interestingly,  
NOTE Confidence: 0.9966571

00:30:15.690 --> 00:30:17.610 one company did meet all  
NOTE Confidence: 0.9966571

00:30:17.610 --> 00:30:19.310 of our measures, United Therapeutics.  
NOTE Confidence: 0.9988462

00:30:20.010 --> 00:30:21.690 This company is a public

NOTE Confidence: 0.9988462  
00:30:21.690 --> 00:30:22.750 benefit corporation.  
NOTE Confidence: 0.9497861  
00:30:24.305 --> 00:30:25.585 They were started in nineteen  
NOTE Confidence: 0.9497861  
00:30:25.585 --> 00:30:26.465 ninety six, and then in  
NOTE Confidence: 0.9497861  
00:30:26.465 --> 00:30:27.905 twenty twenty one changed their  
NOTE Confidence: 0.9497861  
00:30:27.905 --> 00:30:28.945 legal structure to be a  
NOTE Confidence: 0.9497861  
00:30:28.945 --> 00:30:29.445 PVC.  
NOTE Confidence: 0.9898295  
00:30:32.225 --> 00:30:33.345 So while no other company  
NOTE Confidence: 0.9898295  
00:30:33.345 --> 00:30:34.625 scored a hundred percent, some  
NOTE Confidence: 0.9898295  
00:30:34.625 --> 00:30:35.905 scored a hundred percent on  
NOTE Confidence: 0.9898295  
00:30:35.905 --> 00:30:36.805 different measures,  
NOTE Confidence: 0.96581626  
00:30:38.640 --> 00:30:39.920 and we introduced a rating  
NOTE Confidence: 0.96581626  
00:30:39.920 --> 00:30:40.880 for the first time. So  
NOTE Confidence: 0.96581626  
00:30:40.880 --> 00:30:41.920 there wasn't may not be  
NOTE Confidence: 0.96581626  
00:30:41.920 --> 00:30:43.040 a big difference between number  
NOTE Confidence: 0.96581626  
00:30:43.040 --> 00:30:44.160 one and number two, number  
NOTE Confidence: 0.96581626

00:30:44.160 --> 00:30:45.360 three, number four. So we're  
NOTE Confidence: 0.96581626

00:30:45.360 --> 00:30:47.120 grouping top twenty five percent  
NOTE Confidence: 0.96581626

00:30:47.120 --> 00:30:48.240 above the median and then  
NOTE Confidence: 0.96581626

00:30:48.240 --> 00:30:49.760 unrated as everyone below the  
NOTE Confidence: 0.96581626

00:30:49.760 --> 00:30:50.660 median score.  
NOTE Confidence: 0.96652144

00:30:52.745 --> 00:30:54.505 So we just, finished writing  
NOTE Confidence: 0.96652144

00:30:54.505 --> 00:30:55.325 up the results,  
NOTE Confidence: 0.947753

00:30:55.865 --> 00:30:57.245 the first draft, for the  
NOTE Confidence: 0.947753

00:30:57.385 --> 00:30:58.445 forthcoming scorecard,  
NOTE Confidence: 0.98394114

00:30:59.465 --> 00:31:01.065 and it looks at novel  
NOTE Confidence: 0.98394114

00:31:01.065 --> 00:31:02.505 oncology products approved by the  
NOTE Confidence: 0.98394114

00:31:02.505 --> 00:31:04.105 FDA between twenty eighteen and  
NOTE Confidence: 0.98394114

00:31:04.105 --> 00:31:05.740 twenty twenty three. So it's  
NOTE Confidence: 0.98394114

00:31:05.740 --> 00:31:06.640 seventy five,  
NOTE Confidence: 0.9933869

00:31:07.179 --> 00:31:07.679 products  
NOTE Confidence: 0.9788831

00:31:08.220 --> 00:31:09.500 sponsored by fifty two different

NOTE Confidence: 0.9788831  
00:31:09.500 --> 00:31:10.000 companies  
NOTE Confidence: 0.9719428  
00:31:10.460 --> 00:31:12.000 based on eighty pivotal trials,  
NOTE Confidence: 0.9719428  
00:31:12.140 --> 00:31:13.679 enrolling about twenty thousand  
NOTE Confidence: 0.9767225  
00:31:14.220 --> 00:31:15.740 patients. And what are we  
NOTE Confidence: 0.9767225  
00:31:15.740 --> 00:31:17.659 finding? On the company level,  
NOTE Confidence: 0.9767225  
00:31:17.659 --> 00:31:19.020 you'll see that almost all  
NOTE Confidence: 0.9767225  
00:31:19.020 --> 00:31:20.159 the companies reported  
NOTE Confidence: 0.9387985  
00:31:20.475 --> 00:31:21.755 the sex of,  
NOTE Confidence: 0.99488944  
00:31:23.515 --> 00:31:25.455 all their pivotal trial participants.  
NOTE Confidence: 0.98386925  
00:31:27.275 --> 00:31:28.794 However, only eighty three percent  
NOTE Confidence: 0.98386925  
00:31:28.794 --> 00:31:30.174 reported the age of participants  
NOTE Confidence: 0.98386925  
00:31:30.235 --> 00:31:31.515 and seventy one percent the  
NOTE Confidence: 0.98386925  
00:31:31.515 --> 00:31:32.794 racial and ethnic identity of  
NOTE Confidence: 0.98386925  
00:31:32.794 --> 00:31:34.335 all pivotal trial participants.  
NOTE Confidence: 0.9940102  
00:31:34.860 --> 00:31:35.900 And then in terms of  
NOTE Confidence: 0.9940102



00:31:35.900 --> 00:31:37.580 representation, you'll see that only  
NOTE Confidence: 0.9940102

00:31:37.580 --> 00:31:39.020 seventy one percent of companies  
NOTE Confidence: 0.9940102

00:31:39.020 --> 00:31:40.480 adequately represented women,  
NOTE Confidence: 0.95645285

00:31:41.340 --> 00:31:43.260 forty two percent adequately represented  
NOTE Confidence: 0.95645285

00:31:43.260 --> 00:31:44.620 older adults age sixty five  
NOTE Confidence: 0.95645285

00:31:44.620 --> 00:31:45.280 and older,  
NOTE Confidence: 0.9878857

00:31:45.660 --> 00:31:47.280 and only four percent adequately  
NOTE Confidence: 0.9878857

00:31:47.340 --> 00:31:49.200 represented racial and ethnic minoritized  
NOTE Confidence: 0.9878857

00:31:49.340 --> 00:31:49.840 patients.  
NOTE Confidence: 0.94748825

00:31:52.135 --> 00:31:53.415 And then obviously goes down  
NOTE Confidence: 0.94748825

00:31:53.415 --> 00:31:54.775 for fair inclusion with only  
NOTE Confidence: 0.94748825

00:31:54.775 --> 00:31:56.295 two percent of companies. That's  
NOTE Confidence: 0.94748825

00:31:56.295 --> 00:31:57.035 one company  
NOTE Confidence: 0.80516887

00:31:57.495 --> 00:31:58.395 fairly including,  
NOTE Confidence: 0.96059227

00:31:59.335 --> 00:32:00.615 all analyzed racial and ethnic  
NOTE Confidence: 0.96059227

00:32:00.615 --> 00:32:02.135 minoritized patients, and that one

NOTE Confidence: 0.96059227

00:32:02.135 --> 00:32:03.515 company is Jazz Pharmaceuticals.

NOTE Confidence: 0.9195269

00:32:05.600 --> 00:32:07.040 And quick question. How do

NOTE Confidence: 0.9195269

00:32:07.040 --> 00:32:08.800 you think about international trials?

NOTE Confidence: 0.9195269

00:32:08.800 --> 00:32:09.760 So, like, say there's a

NOTE Confidence: 0.9195269

00:32:09.760 --> 00:32:12.260 pivotal trial and half of

NOTE Confidence: 0.9688396

00:32:12.720 --> 00:32:14.400 the participants were enrolled in

NOTE Confidence: 0.9688396

00:32:14.400 --> 00:32:15.600 the US and half of

NOTE Confidence: 0.9688396

00:32:15.600 --> 00:32:17.620 them were Yeah. Yeah.

NOTE Confidence: 0.9586101

00:32:18.080 --> 00:32:19.200 When you think about, like,

NOTE Confidence: 0.9586101

00:32:19.200 --> 00:32:20.865 the composition of race and

NOTE Confidence: 0.9586101

00:32:20.865 --> 00:32:22.625 ethnicity of people in that

NOTE Confidence: 0.9586101

00:32:22.625 --> 00:32:23.125 trial,

NOTE Confidence: 0.92140275

00:32:24.385 --> 00:32:25.105 how do you

NOTE Confidence: 0.76819

00:32:26.145 --> 00:32:26.885 the US?

NOTE Confidence: 0.980496

00:32:27.905 --> 00:32:29.025 As you know, Carrie, we

NOTE Confidence: 0.980496

00:32:29.025 --> 00:32:30.165 use global enrollment.  
NOTE Confidence: 0.97691196

00:32:31.105 --> 00:32:32.545 Yeah. So this is one  
NOTE Confidence: 0.97691196

00:32:32.545 --> 00:32:33.845 of the pushbacks from  
NOTE Confidence: 0.97669613

00:32:34.679 --> 00:32:35.720 companies. They'll say, well, if  
NOTE Confidence: 0.97669613

00:32:35.720 --> 00:32:36.519 only you had looked at  
NOTE Confidence: 0.97669613

00:32:36.519 --> 00:32:37.879 our US enrollment, you'd see  
NOTE Confidence: 0.97669613

00:32:37.879 --> 00:32:38.700 that we are  
NOTE Confidence: 0.9842901

00:32:39.000 --> 00:32:39.980 perfectly representative.  
NOTE Confidence: 0.9973958

00:32:40.360 --> 00:32:41.960 But the median US enrollment  
NOTE Confidence: 0.9973958

00:32:41.960 --> 00:32:42.860 is around eight  
NOTE Confidence: 0.97719496

00:32:43.399 --> 00:32:44.700 patients per trial.  
NOTE Confidence: 0.9570339

00:32:47.265 --> 00:32:47.925 So that's  
NOTE Confidence: 0.9995063

00:32:48.705 --> 00:32:50.405 not even feasible to really  
NOTE Confidence: 0.9991044

00:32:50.705 --> 00:32:51.205 do.  
NOTE Confidence: 0.99314964

00:32:51.585 --> 00:32:53.125 So we use global enrollment  
NOTE Confidence: 0.99926996

00:32:53.745 --> 00:32:55.285 to benchmark against US

NOTE Confidence: 0.9987628  
00:32:56.145 --> 00:32:56.645 demographics.  
NOTE Confidence: 0.9992516  
00:32:57.905 --> 00:32:58.785 If you have a better  
NOTE Confidence: 0.9992516  
00:32:58.785 --> 00:32:59.925 way of doing this,  
NOTE Confidence: 0.99951  
00:33:00.700 --> 00:33:01.440 let us  
NOTE Confidence: 0.9975441  
00:33:01.860 --> 00:33:02.360 know.  
NOTE Confidence: 0.9507511  
00:33:02.780 --> 00:33:03.760 I'm all ears.  
NOTE Confidence: 0.9931726  
00:33:10.140 --> 00:33:10.640 So  
NOTE Confidence: 0.9936764  
00:33:11.420 --> 00:33:12.700 so what how how do  
NOTE Confidence: 0.9936764  
00:33:12.700 --> 00:33:13.660 we think about those two  
NOTE Confidence: 0.9936764  
00:33:13.660 --> 00:33:14.160 scorecards?  
NOTE Confidence: 0.8962178  
00:33:14.620 --> 00:33:15.520 Are are,  
NOTE Confidence: 0.9945833  
00:33:17.545 --> 00:33:18.605 are things improving?  
NOTE Confidence: 0.97793484  
00:33:19.865 --> 00:33:21.225 And, yes, the good news  
NOTE Confidence: 0.97793484  
00:33:21.225 --> 00:33:22.345 is they are improving for  
NOTE Confidence: 0.97793484  
00:33:22.345 --> 00:33:22.845 transparency.  
NOTE Confidence: 0.97013575

00:33:24.425 --> 00:33:26.425 For both older adults and,  
NOTE Confidence: 0.97013575

00:33:26.665 --> 00:33:28.345 racial and ethnic minoritized patients,  
NOTE Confidence: 0.97013575

00:33:28.345 --> 00:33:31.145 transparency reporting of, demographics has  
NOTE Confidence: 0.97013575

00:33:31.145 --> 00:33:31.645 improved.  
NOTE Confidence: 0.9963589

00:33:33.690 --> 00:33:35.130 However, nothing has improved for  
NOTE Confidence: 0.9963589

00:33:35.130 --> 00:33:36.590 representation or fair inclusion.  
NOTE Confidence: 0.9399939

00:33:38.010 --> 00:33:39.210 And so that's leading me  
NOTE Confidence: 0.9399939

00:33:39.210 --> 00:33:39.950 to ask,  
NOTE Confidence: 0.9980475

00:33:40.490 --> 00:33:41.950 what more can we do  
NOTE Confidence: 0.9980475

00:33:42.170 --> 00:33:43.870 to try and improve representation?  
NOTE Confidence: 0.99647784

00:33:45.055 --> 00:33:47.295 And so one idea, and  
NOTE Confidence: 0.99647784

00:33:47.295 --> 00:33:48.255 I'm curious to hear what  
NOTE Confidence: 0.99647784

00:33:48.255 --> 00:33:48.995 you think,  
NOTE Confidence: 0.9989256

00:33:49.295 --> 00:33:51.315 is to build leading indicators  
NOTE Confidence: 0.9989256

00:33:51.455 --> 00:33:52.355 into the scorecard.  
NOTE Confidence: 0.9885284

00:33:52.735 --> 00:33:54.495 Right? We use what economists

NOTE Confidence: 0.9885284  
00:33:54.495 --> 00:33:55.695 might call a lag indicator,  
NOTE Confidence: 0.9885284  
00:33:55.695 --> 00:33:56.895 an outcome measure. Did you  
NOTE Confidence: 0.9885284  
00:33:56.895 --> 00:33:57.935 or did you not enroll  
NOTE Confidence: 0.9885284  
00:33:57.935 --> 00:33:59.455 a representative sample in your  
NOTE Confidence: 0.9885284  
00:33:59.455 --> 00:34:01.270 clinical trial? But another type  
NOTE Confidence: 0.9885284  
00:34:01.270 --> 00:34:02.630 of measurement is a leading  
NOTE Confidence: 0.9885284  
00:34:02.630 --> 00:34:04.650 indicator that evaluates the steps  
NOTE Confidence: 0.9885284  
00:34:04.650 --> 00:34:06.390 put in place to achieve  
NOTE Confidence: 0.9885284  
00:34:06.390 --> 00:34:07.510 the outcome that we're trying  
NOTE Confidence: 0.9885284  
00:34:07.510 --> 00:34:08.170 to drive.  
NOTE Confidence: 0.9877186  
00:34:09.190 --> 00:34:10.469 So we've been exploring what  
NOTE Confidence: 0.9877186  
00:34:10.469 --> 00:34:11.910 types of leading indicators we  
NOTE Confidence: 0.9877186  
00:34:11.910 --> 00:34:13.190 might want to add to  
NOTE Confidence: 0.9877186  
00:34:13.190 --> 00:34:14.725 the scorecard, and we've been  
NOTE Confidence: 0.9877186  
00:34:14.725 --> 00:34:15.685 doing this by,  
NOTE Confidence: 0.9998486

00:34:17.125 --> 00:34:17.625 conducting  
NOTE Confidence: 0.99983656

00:34:18.244 --> 00:34:20.505 a review of prominent guidelines  
NOTE Confidence: 0.99536324

00:34:21.205 --> 00:34:21.705 and  
NOTE Confidence: 0.92086655

00:34:22.085 --> 00:34:23.385 a bright spot analysis.  
NOTE Confidence: 0.9783242

00:34:24.965 --> 00:34:26.244 I'm gonna briefly go through  
NOTE Confidence: 0.9783242

00:34:26.244 --> 00:34:27.145 what we're finding  
NOTE Confidence: 0.9941803

00:34:27.525 --> 00:34:28.665 in in these analyses.  
NOTE Confidence: 0.9939885

00:34:29.370 --> 00:34:31.310 So we published the the,  
NOTE Confidence: 0.9809162

00:34:31.690 --> 00:34:33.370 guideline review in May of  
NOTE Confidence: 0.9809162

00:34:33.370 --> 00:34:34.750 twenty twenty four in BMJ  
NOTE Confidence: 0.9809162

00:34:34.810 --> 00:34:35.310 Medicine.  
NOTE Confidence: 0.99488944

00:34:37.370 --> 00:34:38.910 We reviewed eight different guidelines,  
NOTE Confidence: 0.99840575

00:34:39.690 --> 00:34:41.210 from the FDA, EMA, World  
NOTE Confidence: 0.99840575

00:34:41.210 --> 00:34:41.950 Health Organization,  
NOTE Confidence: 0.99306

00:34:43.235 --> 00:34:44.435 different groups. And what we  
NOTE Confidence: 0.99306

00:34:44.435 --> 00:34:45.495 found is twelve

NOTE Confidence: 0.9996996

00:34:46.435 --> 00:34:49.255 recommended strategies for advancing representation.

NOTE Confidence: 0.98488975

00:34:50.915 --> 00:34:52.675 I'll just mention three. For

NOTE Confidence: 0.98488975

00:34:52.675 --> 00:34:53.175 example,

NOTE Confidence: 0.99992055

00:34:53.635 --> 00:34:54.695 broadening eligibility

NOTE Confidence: 0.96717274

00:34:54.995 --> 00:34:56.855 criteria. Right? So more trials,

NOTE Confidence: 0.96036595

00:34:57.290 --> 00:34:58.330 more patients can,

NOTE Confidence: 0.95714146

00:34:59.530 --> 00:35:01.290 can qualify for participation when

NOTE Confidence: 0.95714146

00:35:01.290 --> 00:35:01.790 appropriate,

NOTE Confidence: 0.9973885

00:35:02.489 --> 00:35:04.590 expanding site locations beyond

NOTE Confidence: 0.9930154

00:35:05.050 --> 00:35:06.650 the large academic medical centers

NOTE Confidence: 0.9930154

00:35:06.650 --> 00:35:07.849 that we traditionally use that

NOTE Confidence: 0.9930154

00:35:07.849 --> 00:35:08.750 are on the coasts

NOTE Confidence: 0.9677154

00:35:09.130 --> 00:35:09.790 to include

NOTE Confidence: 0.9672007

00:35:10.545 --> 00:35:11.364 community centers,

NOTE Confidence: 0.9982918

00:35:12.145 --> 00:35:13.905 educating communities and patients to



NOTE Confidence: 0.9982918  
00:35:13.905 --> 00:35:15.844 increase awareness about trial opportunities.  
NOTE Confidence: 0.9960577  
00:35:20.785 --> 00:35:22.244 In the bright spot analysis,  
NOTE Confidence: 0.99947065  
00:35:22.785 --> 00:35:23.285 we  
NOTE Confidence: 0.98418736  
00:35:23.680 --> 00:35:25.040 went through our dataset to  
NOTE Confidence: 0.98418736  
00:35:25.040 --> 00:35:26.080 see if there were any  
NOTE Confidence: 0.98418736  
00:35:26.080 --> 00:35:28.000 bright spots. Was anyone getting  
NOTE Confidence: 0.98418736  
00:35:28.000 --> 00:35:29.120 this right? There were a  
NOTE Confidence: 0.98418736  
00:35:29.120 --> 00:35:30.000 few. And then we went  
NOTE Confidence: 0.98418736  
00:35:30.000 --> 00:35:31.520 and interviewed them to see  
NOTE Confidence: 0.98418736  
00:35:31.520 --> 00:35:32.500 how they thought  
NOTE Confidence: 0.90465164  
00:35:32.800 --> 00:35:34.000 but what were the factors  
NOTE Confidence: 0.90465164  
00:35:34.000 --> 00:35:34.980 driving their success.  
NOTE Confidence: 0.97395444  
00:35:36.835 --> 00:35:37.495 And we,  
NOTE Confidence: 0.94354844  
00:35:38.515 --> 00:35:39.815 published aim one,  
NOTE Confidence: 0.98982847  
00:35:40.915 --> 00:35:41.655 in May.  
NOTE Confidence: 0.9989481

00:35:43.315 --> 00:35:44.195 So we looked at a  
NOTE Confidence: 0.9989481

00:35:44.195 --> 00:35:45.735 hundred and eleven products  
NOTE Confidence: 0.9964124

00:35:46.114 --> 00:35:47.575 sponsored by seventy companies  
NOTE Confidence: 0.96118695

00:35:47.955 --> 00:35:48.915 and a hundred and twenty  
NOTE Confidence: 0.96118695

00:35:48.915 --> 00:35:50.559 one pivotal trials, and we  
NOTE Confidence: 0.96118695

00:35:50.559 --> 00:35:52.400 found thirty one bright spot  
NOTE Confidence: 0.96118695

00:35:52.400 --> 00:35:52.900 trials,  
NOTE Confidence: 0.998646

00:35:53.839 --> 00:35:55.119 nineteen of which were sponsored  
NOTE Confidence: 0.998646

00:35:55.119 --> 00:35:56.180 by a large company.  
NOTE Confidence: 0.99827784

00:35:56.640 --> 00:35:58.480 And so we interviewed thirteen  
NOTE Confidence: 0.99827784

00:35:58.480 --> 00:36:00.099 teams from eight large companies.  
NOTE Confidence: 0.9847976

00:36:00.400 --> 00:36:02.000 We hit saturation, so we  
NOTE Confidence: 0.9847976

00:36:02.000 --> 00:36:03.539 stopped at, thirteen.  
NOTE Confidence: 0.99852425

00:36:04.559 --> 00:36:05.059 And  
NOTE Confidence: 0.9868567

00:36:07.025 --> 00:36:08.225 seven of the strategies that  
NOTE Confidence: 0.9868567

00:36:08.225 --> 00:36:09.265 the bright spots are using

NOTE Confidence: 0.9868567

00:36:09.265 --> 00:36:10.705 are in the guidance already,

NOTE Confidence: 0.9868567

00:36:10.705 --> 00:36:11.745 although they added a lot

NOTE Confidence: 0.9868567

00:36:11.745 --> 00:36:13.265 more details to it. So,

NOTE Confidence: 0.9868567

00:36:13.265 --> 00:36:14.705 for example, instead of just

NOTE Confidence: 0.9868567

00:36:14.705 --> 00:36:15.985 saying use more diverse sites,

NOTE Confidence: 0.9868567

00:36:15.985 --> 00:36:17.185 they said exactly how they're

NOTE Confidence: 0.9868567

00:36:17.185 --> 00:36:18.465 doing that. They're leveraging, for

NOTE Confidence: 0.9868567

00:36:18.465 --> 00:36:19.445 example, an NCI

NOTE Confidence: 0.99022

00:36:21.309 --> 00:36:22.510 designated cancer center that they're

NOTE Confidence: 0.99022

00:36:22.510 --> 00:36:23.309 using. So instead of just

NOTE Confidence: 0.99022

00:36:23.309 --> 00:36:24.130 coming to Yale,

NOTE Confidence: 0.9333123

00:36:24.589 --> 00:36:25.869 Smilo every time, they're gonna

NOTE Confidence: 0.9333123

00:36:25.869 --> 00:36:26.910 go to Bridgeport, right, in

NOTE Confidence: 0.9333123

00:36:26.910 --> 00:36:27.890 any of our affiliations.

NOTE Confidence: 0.99957144

00:36:30.030 --> 00:36:31.329 And they had a few

NOTE Confidence: 0.9975626

00:36:31.710 --> 00:36:33.309 other strategies. I'm only gonna  
NOTE Confidence: 0.9975626

00:36:33.309 --> 00:36:34.210 mention three.  
NOTE Confidence: 0.9994193

00:36:36.525 --> 00:36:37.505 These three strategies,  
NOTE Confidence: 0.9958287

00:36:38.204 --> 00:36:39.244 were used by the company  
NOTE Confidence: 0.9958287

00:36:39.244 --> 00:36:40.444 that sponsored the most bright  
NOTE Confidence: 0.9958287

00:36:40.444 --> 00:36:40.944 spots.  
NOTE Confidence: 0.9992378

00:36:41.645 --> 00:36:43.025 One, they had CEO  
NOTE Confidence: 0.96222925

00:36:43.645 --> 00:36:44.785 commitment and involvement,  
NOTE Confidence: 0.99917626

00:36:45.325 --> 00:36:46.704 so top down initiatives.  
NOTE Confidence: 0.99974

00:36:47.085 --> 00:36:48.605 They had a dashboard with  
NOTE Confidence: 0.99974

00:36:48.605 --> 00:36:50.730 real time performance measurements that  
NOTE Confidence: 0.99974

00:36:50.730 --> 00:36:51.230 elevated  
NOTE Confidence: 0.98943615

00:36:51.530 --> 00:36:53.050 representation goals to the same  
NOTE Confidence: 0.98943615

00:36:53.050 --> 00:36:54.330 level of the other corporate  
NOTE Confidence: 0.98943615

00:36:54.330 --> 00:36:55.150 goals, like  
NOTE Confidence: 0.9909457

00:36:55.530 --> 00:36:56.969 first patient enrolled into a

NOTE Confidence: 0.9909457

00:36:56.969 --> 00:36:58.910 trial, time to trial completion,

NOTE Confidence: 0.9909457

00:36:59.050 --> 00:37:00.489 time to regulatory submission of

NOTE Confidence: 0.9909457

00:37:00.489 --> 00:37:01.150 the product.

NOTE Confidence: 0.993797

00:37:02.010 --> 00:37:03.210 And then they had awards

NOTE Confidence: 0.993797

00:37:03.210 --> 00:37:05.550 and recognitions, including financial bonuses

NOTE Confidence: 0.993797

00:37:05.565 --> 00:37:06.625 tied to representation

NOTE Confidence: 0.6832746

00:37:06.925 --> 00:37:07.425 goals.

NOTE Confidence: 0.99712294

00:37:09.805 --> 00:37:11.165 And, of course, visibility for

NOTE Confidence: 0.99712294

00:37:11.165 --> 00:37:12.765 the laggards across the entire

NOTE Confidence: 0.99712294

00:37:12.765 --> 00:37:13.265 company.

NOTE Confidence: 0.972278

00:37:17.244 --> 00:37:18.525 So this the rest, if

NOTE Confidence: 0.972278

00:37:18.525 --> 00:37:19.560 you wanna if you wanna

NOTE Confidence: 0.972278

00:37:19.560 --> 00:37:20.280 see all the other bright

NOTE Confidence: 0.972278

00:37:20.280 --> 00:37:21.000 spots, you have to read

NOTE Confidence: 0.972278

00:37:21.000 --> 00:37:22.200 the paper, which we're submitting

NOTE Confidence: 0.972278

00:37:22.200 --> 00:37:23.180 hopefully this week.  
NOTE Confidence: 0.9537018

00:37:24.600 --> 00:37:25.480 And now I wanna move  
NOTE Confidence: 0.9537018

00:37:25.480 --> 00:37:26.940 on to the fourth scorecard  
NOTE Confidence: 0.9537018

00:37:27.080 --> 00:37:28.440 focused on access to medicines  
NOTE Confidence: 0.9537018

00:37:28.440 --> 00:37:29.820 in low middle income countries.  
NOTE Confidence: 0.9993688

00:37:32.475 --> 00:37:34.235 This scorecard was started based  
NOTE Confidence: 0.9993688

00:37:34.235 --> 00:37:35.055 on an exploratory  
NOTE Confidence: 0.9674978

00:37:35.435 --> 00:37:36.795 study that we published in  
NOTE Confidence: 0.9674978

00:37:36.795 --> 00:37:37.775 twenty twenty one,  
NOTE Confidence: 0.98610675

00:37:38.715 --> 00:37:39.755 where we asked two simple  
NOTE Confidence: 0.98610675

00:37:39.755 --> 00:37:41.995 questions. One, where are drugs  
NOTE Confidence: 0.98610675

00:37:41.995 --> 00:37:43.515 tested for FDA approval on  
NOTE Confidence: 0.98610675

00:37:43.515 --> 00:37:44.980 the country level, And do  
NOTE Confidence: 0.98610675

00:37:44.980 --> 00:37:46.660 those countries who participate in  
NOTE Confidence: 0.98610675

00:37:46.660 --> 00:37:48.840 trials for FDA approvals get  
NOTE Confidence: 0.9903451

00:37:49.460 --> 00:37:51.320 market access to those products?

NOTE Confidence: 0.9903451

00:37:51.380 --> 00:37:52.660 Does the company submit and

NOTE Confidence: 0.9903451

00:37:52.660 --> 00:37:54.580 receive marketing authorization to sell

NOTE Confidence: 0.9903451

00:37:54.580 --> 00:37:56.280 those products in those countries?

NOTE Confidence: 0.96895444

00:37:57.535 --> 00:37:59.855 The sample was products approved

NOTE Confidence: 0.96895444

00:37:59.855 --> 00:38:01.055 by the FDA, novel drugs

NOTE Confidence: 0.96895444

00:38:01.055 --> 00:38:02.175 in twenty twelve and twenty

NOTE Confidence: 0.96895444

00:38:02.175 --> 00:38:03.695 fourteen, just sponsored by large

NOTE Confidence: 0.96895444

00:38:03.695 --> 00:38:04.195 companies.

NOTE Confidence: 0.9528942

00:38:05.135 --> 00:38:06.275 So a small sample.

NOTE Confidence: 0.9977069

00:38:06.735 --> 00:38:07.935 It was thirty four,

NOTE Confidence: 0.99956334

00:38:08.975 --> 00:38:09.875 novel drugs

NOTE Confidence: 0.9611327

00:38:10.690 --> 00:38:11.730 approved based on eight hundred

NOTE Confidence: 0.9611327

00:38:11.730 --> 00:38:12.770 ninety eight trials. We looked

NOTE Confidence: 0.9611327

00:38:12.770 --> 00:38:13.650 at all the trials, not

NOTE Confidence: 0.9611327

00:38:13.650 --> 00:38:14.310 just pivotal.

NOTE Confidence: 0.9498759

00:38:16.130 --> 00:38:17.410 Each drug was tested in  
NOTE Confidence: 0.9498759

00:38:17.410 --> 00:38:18.530 a median of twenty six  
NOTE Confidence: 0.9498759

00:38:18.530 --> 00:38:19.510 different countries,  
NOTE Confidence: 0.93866694

00:38:20.370 --> 00:38:21.890 twenty high income, six upper  
NOTE Confidence: 0.93866694

00:38:21.890 --> 00:38:23.265 middle, and a median of  
NOTE Confidence: 0.93866694

00:38:23.265 --> 00:38:24.645 one low middle income country.  
NOTE Confidence: 0.9725915

00:38:25.184 --> 00:38:26.145 And what we found of  
NOTE Confidence: 0.9725915

00:38:26.145 --> 00:38:28.065 the seventy countries participating in  
NOTE Confidence: 0.9725915

00:38:28.065 --> 00:38:29.905 the clinical trial supporting FDA  
NOTE Confidence: 0.9725915

00:38:29.905 --> 00:38:31.265 approval of those products, only  
NOTE Confidence: 0.9725915

00:38:31.265 --> 00:38:33.424 seven percent got market access  
NOTE Confidence: 0.9725915

00:38:33.424 --> 00:38:34.545 to the products they helped  
NOTE Confidence: 0.9725915

00:38:34.545 --> 00:38:36.140 test within one year of  
NOTE Confidence: 0.9725915

00:38:36.140 --> 00:38:37.420 FDA approval. And even if  
NOTE Confidence: 0.9725915

00:38:37.420 --> 00:38:38.540 you looked at five years,  
NOTE Confidence: 0.9725915

00:38:38.540 --> 00:38:39.820 seven years later, that number



NOTE Confidence: 0.9725915  
00:38:39.820 --> 00:38:40.700 only went up to thirty  
NOTE Confidence: 0.9725915  
00:38:40.700 --> 00:38:41.440 one percent.  
NOTE Confidence: 0.9866452  
00:38:44.300 --> 00:38:46.140 And then, unsurprisingly, approvals were  
NOTE Confidence: 0.9866452  
00:38:46.140 --> 00:38:47.100 higher and faster in high  
NOTE Confidence: 0.9866452  
00:38:47.100 --> 00:38:47.920 income countries.  
NOTE Confidence: 0.9621525  
00:38:51.805 --> 00:38:52.305 Canada,  
NOTE Confidence: 0.99482745  
00:38:52.605 --> 00:38:53.505 most of Europe,  
NOTE Confidence: 0.95744693  
00:38:53.885 --> 00:38:55.724 full access or almost full  
NOTE Confidence: 0.95744693  
00:38:55.724 --> 00:38:57.744 access. In contrast, Africa,  
NOTE Confidence: 0.9993718  
00:38:58.045 --> 00:38:58.545 zero  
NOTE Confidence: 0.94552857  
00:38:59.005 --> 00:39:00.364 access to the products they  
NOTE Confidence: 0.94552857  
00:39:00.364 --> 00:39:01.105 help test.  
NOTE Confidence: 0.997787  
00:39:03.190 --> 00:39:04.730 In ethics, this is arguably  
NOTE Confidence: 0.997787  
00:39:04.950 --> 00:39:05.450 exploitation.  
NOTE Confidence: 0.9166884  
00:39:06.630 --> 00:39:07.130 Right?  
NOTE Confidence: 0.99754727

00:39:08.070 --> 00:39:10.390 Research is not ordinarily supposed

NOTE Confidence: 0.99754727

00:39:10.390 --> 00:39:11.350 to be conducted in a

NOTE Confidence: 0.99754727

00:39:11.350 --> 00:39:12.790 population that doesn't stand to

NOTE Confidence: 0.99754727

00:39:12.790 --> 00:39:13.290 benefit

NOTE Confidence: 0.9996738

00:39:13.590 --> 00:39:14.489 from the intervention

NOTE Confidence: 0.9237281

00:39:15.030 --> 00:39:16.489 with access to the intervention.

NOTE Confidence: 0.95423186

00:39:17.565 --> 00:39:18.525 This is enshrined in the

NOTE Confidence: 0.95423186

00:39:18.525 --> 00:39:19.585 Helsinki declaration,

NOTE Confidence: 0.997232

00:39:19.885 --> 00:39:20.925 in so many of our

NOTE Confidence: 0.997232

00:39:20.925 --> 00:39:21.825 ethical guidelines.

NOTE Confidence: 0.99793273

00:39:23.484 --> 00:39:25.005 So when I presented this

NOTE Confidence: 0.99793273

00:39:25.005 --> 00:39:27.344 data at a very large

NOTE Confidence: 0.99908036

00:39:27.885 --> 00:39:29.825 conference with pharma companies,

NOTE Confidence: 0.94646084

00:39:30.270 --> 00:39:31.390 I was on a panel

NOTE Confidence: 0.94646084

00:39:31.390 --> 00:39:32.670 with a general counsel of

NOTE Confidence: 0.94646084

00:39:32.670 --> 00:39:34.350 major company, and she's she

NOTE Confidence: 0.94646084  
00:39:34.350 --> 00:39:34.850 said,  
NOTE Confidence: 0.9569435  
00:39:36.030 --> 00:39:36.989 to review, we are a  
NOTE Confidence: 0.9569435  
00:39:36.989 --> 00:39:38.590 problem. You old you academics  
NOTE Confidence: 0.9569435  
00:39:38.590 --> 00:39:39.550 use old data. If only  
NOTE Confidence: 0.9569435  
00:39:39.550 --> 00:39:40.270 you looked at the new  
NOTE Confidence: 0.9569435  
00:39:40.270 --> 00:39:41.310 data, you'd see we fixed  
NOTE Confidence: 0.9569435  
00:39:41.310 --> 00:39:42.050 this problem.  
NOTE Confidence: 0.9657561  
00:39:42.670 --> 00:39:43.870 So we updated the study  
NOTE Confidence: 0.9657561  
00:39:43.870 --> 00:39:45.090 to see, is this still  
NOTE Confidence: 0.98482907  
00:39:45.495 --> 00:39:46.235 a problem?  
NOTE Confidence: 0.9994621  
00:39:48.455 --> 00:39:49.675 And the new study  
NOTE Confidence: 0.9813731  
00:39:50.695 --> 00:39:51.575 alright. Let me just take  
NOTE Confidence: 0.9813731  
00:39:51.575 --> 00:39:52.855 a minute and acknowledge Chris  
NOTE Confidence: 0.9813731  
00:39:52.855 --> 00:39:54.375 Lee, who's here, a med  
NOTE Confidence: 0.9813731  
00:39:54.375 --> 00:39:55.575 student who was the first  
NOTE Confidence: 0.9813731

00:39:55.575 --> 00:39:56.615 author on this paper. Thank

NOTE Confidence: 0.9813731

00:39:56.615 --> 00:39:57.575 you, Chris, for all your

NOTE Confidence: 0.9813731

00:39:57.575 --> 00:39:58.235 hard work.

NOTE Confidence: 0.9938421

00:40:00.309 --> 00:40:01.210 So the updated

NOTE Confidence: 0.8581124

00:40:02.790 --> 00:40:04.309 study for this paper, which

NOTE Confidence: 0.8581124

00:40:04.309 --> 00:40:05.270 is Chris is leading, is

NOTE Confidence: 0.8581124

00:40:05.270 --> 00:40:05.989 looking at,

NOTE Confidence: 0.9958844

00:40:06.550 --> 00:40:07.829 novel drugs approved by the

NOTE Confidence: 0.9958844

00:40:07.829 --> 00:40:09.270 FDA between twenty fifteen and

NOTE Confidence: 0.9958844

00:40:09.270 --> 00:40:10.089 twenty eighteen.

NOTE Confidence: 0.99114436

00:40:11.190 --> 00:40:12.550 So it's, a hundred and

NOTE Confidence: 0.99114436

00:40:12.550 --> 00:40:14.925 seventy two drugs sponsored by

NOTE Confidence: 0.99114436

00:40:14.925 --> 00:40:16.445 seventy five different companies based

NOTE Confidence: 0.99114436

00:40:16.445 --> 00:40:17.325 on eight hundred and eighty

NOTE Confidence: 0.99114436

00:40:17.325 --> 00:40:18.065 five trials.

NOTE Confidence: 0.9511833

00:40:20.125 --> 00:40:21.165 So the first thing to

NOTE Confidence: 0.9511833

00:40:21.165 --> 00:40:22.685 see is that these hundred

NOTE Confidence: 0.9511833

00:40:22.685 --> 00:40:24.205 and seventy two products were

NOTE Confidence: 0.9511833

00:40:24.205 --> 00:40:25.485 tested in eighty nine different

NOTE Confidence: 0.9511833

00:40:25.485 --> 00:40:25.985 countries,

NOTE Confidence: 0.9937441

00:40:26.820 --> 00:40:27.960 A median of sixteen

NOTE Confidence: 0.9998573

00:40:28.739 --> 00:40:29.239 countries

NOTE Confidence: 0.98213375

00:40:29.860 --> 00:40:30.600 per drug,

NOTE Confidence: 0.9930946

00:40:30.980 --> 00:40:32.100 fifty five percent of which

NOTE Confidence: 0.9930946

00:40:32.100 --> 00:40:33.700 are high income, twenty six

NOTE Confidence: 0.9930946

00:40:33.700 --> 00:40:35.300 percent upper middle, thirteen percent

NOTE Confidence: 0.9930946

00:40:35.300 --> 00:40:36.500 lower middle, and six percent

NOTE Confidence: 0.9930946

00:40:36.500 --> 00:40:37.540 low income. So this is

NOTE Confidence: 0.9930946

00:40:37.540 --> 00:40:38.360 where trials

NOTE Confidence: 0.9591524

00:40:38.895 --> 00:40:40.495 take place or took place

NOTE Confidence: 0.9591524

00:40:40.495 --> 00:40:42.094 for this sample for FDA

NOTE Confidence: 0.9591524

00:40:42.094 --> 00:40:43.375 approvals. And so now the  
NOTE Confidence: 0.9591524

00:40:43.375 --> 00:40:44.415 question is, do they get  
NOTE Confidence: 0.9591524

00:40:44.415 --> 00:40:46.035 access, physical access?  
NOTE Confidence: 0.98812616

00:40:46.815 --> 00:40:48.175 If you're in Canada or  
NOTE Confidence: 0.98812616

00:40:48.175 --> 00:40:49.935 Western Europe, you're getting pretty  
NOTE Confidence: 0.98812616

00:40:49.935 --> 00:40:51.475 high access, but not perfect.  
NOTE Confidence: 0.98812616

00:40:51.535 --> 00:40:52.895 I didn't I thought I  
NOTE Confidence: 0.98812616

00:40:52.895 --> 00:40:53.715 didn't expect  
NOTE Confidence: 0.97222465

00:40:54.099 --> 00:40:55.140 people from Canada to get  
NOTE Confidence: 0.97222465

00:40:55.140 --> 00:40:56.500 really upset about these numbers.  
NOTE Confidence: 0.97222465

00:40:56.500 --> 00:40:56.980 I got a lot of  
NOTE Confidence: 0.97222465

00:40:56.980 --> 00:40:57.880 interesting emails.  
NOTE Confidence: 0.9851905

00:40:58.339 --> 00:40:59.540 They why isn't it a  
NOTE Confidence: 0.9851905

00:40:59.540 --> 00:41:00.280 hundred percent?  
NOTE Confidence: 0.94844556

00:41:02.099 --> 00:41:02.980 But then if you look,  
NOTE Confidence: 0.94844556

00:41:02.980 --> 00:41:03.859 Africa is still at the

NOTE Confidence: 0.94844556  
00:41:03.859 --> 00:41:04.359 bottom.  
NOTE Confidence: 0.98907423  
00:41:08.684 --> 00:41:10.704 And so is anything improving  
NOTE Confidence: 0.9953091  
00:41:11.005 --> 00:41:11.664 as suggested?  
NOTE Confidence: 0.9490783  
00:41:12.525 --> 00:41:13.025 Yes.  
NOTE Confidence: 0.88879764  
00:41:14.285 --> 00:41:15.505 For high income countries,  
NOTE Confidence: 0.9978515  
00:41:16.765 --> 00:41:17.805 but not for upper middle  
NOTE Confidence: 0.9978515  
00:41:17.805 --> 00:41:18.785 or lower middle.  
NOTE Confidence: 0.97229517  
00:41:19.730 --> 00:41:21.170 And, in fact, access is  
NOTE Confidence: 0.97229517  
00:41:21.170 --> 00:41:23.190 declining in several geographic regions,  
NOTE Confidence: 0.98364544  
00:41:23.809 --> 00:41:25.809 namely Asia and the Middle  
NOTE Confidence: 0.98364544  
00:41:25.809 --> 00:41:26.309 East.  
NOTE Confidence: 0.98292255  
00:41:29.089 --> 00:41:30.789 So now for this scorecard,  
NOTE Confidence: 0.96166503  
00:41:32.465 --> 00:41:33.825 we have a variety of  
NOTE Confidence: 0.96166503  
00:41:33.825 --> 00:41:35.505 step next steps. But one  
NOTE Confidence: 0.96166503  
00:41:35.505 --> 00:41:36.465 of them is that we're  
NOTE Confidence: 0.96166503

00:41:36.465 --> 00:41:37.505 partnering with the Yale and  
NOTE Confidence: 0.96166503  
00:41:37.505 --> 00:41:38.405 the World Fund,  
NOTE Confidence: 0.85037225  
00:41:39.025 --> 00:41:40.465 to start the Yale Medicines  
NOTE Confidence: 0.85037225  
00:41:40.465 --> 00:41:41.905 Access Network, which we're calling  
NOTE Confidence: 0.85037225  
00:41:41.905 --> 00:41:42.645 Y Man.  
NOTE Confidence: 0.97751033  
00:41:43.025 --> 00:41:44.325 And that's with Jeremy,  
NOTE Confidence: 0.9611842  
00:41:44.880 --> 00:41:45.599 here. And I just wanna  
NOTE Confidence: 0.9611842  
00:41:45.599 --> 00:41:46.980 thank Jeremy for your participation.  
NOTE Confidence: 0.9611842  
00:41:47.200 --> 00:41:48.420 So Yale,  
NOTE Confidence: 0.9863715  
00:41:48.799 --> 00:41:49.680 in the world, they they  
NOTE Confidence: 0.9863715  
00:41:49.680 --> 00:41:50.900 called out for an application,  
NOTE Confidence: 0.9962944  
00:41:51.279 --> 00:41:52.339 and they got eighty,  
NOTE Confidence: 0.9790905  
00:41:52.880 --> 00:41:53.920 applicants. And we were one  
NOTE Confidence: 0.9790905  
00:41:53.920 --> 00:41:54.739 of the nine,  
NOTE Confidence: 0.9854128  
00:41:56.000 --> 00:41:57.520 awarded projects. So Jeremy Schwartz  
NOTE Confidence: 0.9854128  
00:41:57.520 --> 00:41:58.319 and I are now building



NOTE Confidence: 0.9854128  
00:41:58.319 --> 00:41:59.539 out this this network,  
NOTE Confidence: 0.99239886  
00:42:01.495 --> 00:42:02.614 which you haven't seen this  
NOTE Confidence: 0.99239886  
00:42:02.614 --> 00:42:03.995 logo, but here you go.  
NOTE Confidence: 0.99930555  
00:42:05.895 --> 00:42:07.035 We can change it.  
NOTE Confidence: 0.9803962  
00:42:07.575 --> 00:42:08.635 Thank you, chat.  
NOTE Confidence: 0.9952154  
00:42:10.215 --> 00:42:10.695 I also  
NOTE Confidence: 0.9959142  
00:42:11.175 --> 00:42:12.935 chat doesn't confirm that this  
NOTE Confidence: 0.9959142  
00:42:12.935 --> 00:42:14.155 isn't somebody else's  
NOTE Confidence: 0.88280314  
00:42:14.535 --> 00:42:16.075 material, so please,  
NOTE Confidence: 0.91152483  
00:42:17.180 --> 00:42:18.400 everyone check the copyrights.  
NOTE Confidence: 0.980435  
00:42:20.299 --> 00:42:21.180 So what are we trying  
NOTE Confidence: 0.980435  
00:42:21.180 --> 00:42:22.880 to do with why, man?  
NOTE Confidence: 0.9770024  
00:42:24.299 --> 00:42:26.539 We're trying to partner the  
NOTE Confidence: 0.9770024  
00:42:26.539 --> 00:42:27.819 the bright spot countries, if  
NOTE Confidence: 0.9770024  
00:42:27.819 --> 00:42:28.779 there are any, with the  
NOTE Confidence: 0.9770024

00:42:28.779 --> 00:42:30.135 low the the dark spots  
NOTE Confidence: 0.9770024

00:42:30.135 --> 00:42:30.855 so that they can learn  
NOTE Confidence: 0.9770024

00:42:30.855 --> 00:42:31.995 from each other and  
NOTE Confidence: 0.91373146

00:42:32.935 --> 00:42:34.535 and maybe even negotiate together,  
NOTE Confidence: 0.91373146

00:42:34.775 --> 00:42:35.915 to fix this problem.  
NOTE Confidence: 0.98842967

00:42:36.295 --> 00:42:37.335 So first step is we  
NOTE Confidence: 0.98842967

00:42:37.335 --> 00:42:38.535 need to identify the bright  
NOTE Confidence: 0.98842967

00:42:38.535 --> 00:42:39.975 spot countries, and we're working  
NOTE Confidence: 0.98842967

00:42:39.975 --> 00:42:40.635 on that,  
NOTE Confidence: 0.9811933

00:42:41.335 --> 00:42:42.695 as well as, the lower  
NOTE Confidence: 0.9811933

00:42:42.695 --> 00:42:43.895 performing ones. And then we're  
NOTE Confidence: 0.9811933

00:42:43.895 --> 00:42:45.599 we're starting to host monthly  
NOTE Confidence: 0.9811933

00:42:45.660 --> 00:42:47.020 meetings with the ministers of  
NOTE Confidence: 0.9811933

00:42:47.020 --> 00:42:48.140 health and the,  
NOTE Confidence: 0.97732574

00:42:49.260 --> 00:42:50.460 clinical trialists and the heads  
NOTE Confidence: 0.97732574

00:42:50.460 --> 00:42:51.980 of the oncology departments in

NOTE Confidence: 0.97732574  
00:42:51.980 --> 00:42:53.200 a selection of countries,  
NOTE Confidence: 0.96683747  
00:42:54.060 --> 00:42:55.820 to figure out what's working,  
NOTE Confidence: 0.96683747  
00:42:55.820 --> 00:42:56.960 but also the barriers.  
NOTE Confidence: 0.99930006  
00:42:59.925 --> 00:43:01.685 And, we're supposed to host  
NOTE Confidence: 0.99930006  
00:43:01.685 --> 00:43:02.965 a big meeting with everyone  
NOTE Confidence: 0.99930006  
00:43:02.965 --> 00:43:03.625 at Yale  
NOTE Confidence: 0.9915705  
00:43:04.405 --> 00:43:05.765 around May, and we're working  
NOTE Confidence: 0.9915705  
00:43:05.765 --> 00:43:06.585 on that too.  
NOTE Confidence: 0.98191535  
00:43:07.045 --> 00:43:08.085 We need help if anyone  
NOTE Confidence: 0.98191535  
00:43:08.085 --> 00:43:09.065 wants to get involved.  
NOTE Confidence: 0.9784475  
00:43:10.405 --> 00:43:11.445 So for year one for  
NOTE Confidence: 0.9784475  
00:43:11.445 --> 00:43:12.570 Y Men, we're gonna focus  
NOTE Confidence: 0.9784475  
00:43:12.570 --> 00:43:13.690 on Africa. And if you  
NOTE Confidence: 0.9784475  
00:43:13.690 --> 00:43:14.969 look at the appendix of  
NOTE Confidence: 0.9784475  
00:43:14.969 --> 00:43:15.710 the paper,  
NOTE Confidence: 0.98789126

00:43:16.010 --> 00:43:17.450 that we just published, you'll  
NOTE Confidence: 0.98789126

00:43:17.450 --> 00:43:18.969 see that we scored the  
NOTE Confidence: 0.98789126

00:43:18.969 --> 00:43:19.469 countries  
NOTE Confidence: 0.9142323

00:43:20.010 --> 00:43:20.510 and  
NOTE Confidence: 0.9487177

00:43:21.850 --> 00:43:23.310 somewhat ranked them, but  
NOTE Confidence: 0.98867667

00:43:25.005 --> 00:43:26.464 but within the regions.  
NOTE Confidence: 0.9961555

00:43:27.005 --> 00:43:27.805 And you'll  
NOTE Confidence: 0.99268967

00:43:28.125 --> 00:43:29.325 there may be some bright  
NOTE Confidence: 0.99268967

00:43:29.325 --> 00:43:30.144 spots emerging,  
NOTE Confidence: 0.9841196

00:43:30.924 --> 00:43:32.605 Ethiopia and Uganda, but the  
NOTE Confidence: 0.9841196

00:43:32.605 --> 00:43:34.625 sample sizes are really small.  
NOTE Confidence: 0.95465314

00:43:35.164 --> 00:43:36.625 So we're expanding our analysis,  
NOTE Confidence: 0.99262756

00:43:37.760 --> 00:43:39.599 to to confirm which groups  
NOTE Confidence: 0.99262756

00:43:39.599 --> 00:43:41.460 will be engaging first.  
NOTE Confidence: 0.99705493

00:43:42.319 --> 00:43:42.980 And then,  
NOTE Confidence: 0.99887335

00:43:43.599 --> 00:43:44.099 secondly,

NOTE Confidence: 0.9998033

00:43:45.599 --> 00:43:46.719 we have a grant to

NOTE Confidence: 0.9998033

00:43:46.719 --> 00:43:47.219 study

NOTE Confidence: 0.9511425

00:43:47.680 --> 00:43:49.200 not just whether countries are

NOTE Confidence: 0.9511425

00:43:49.200 --> 00:43:49.700 getting

NOTE Confidence: 0.971596

00:43:50.555 --> 00:43:52.095 physical access to a product,

NOTE Confidence: 0.971596

00:43:52.315 --> 00:43:53.775 but also affordability,

NOTE Confidence: 0.9824439

00:43:54.555 --> 00:43:55.455 supplies, distribution,

NOTE Confidence: 0.99570715

00:43:55.755 --> 00:43:57.295 you know, broader access issues,

NOTE Confidence: 0.98814106

00:43:58.155 --> 00:43:59.435 in five countries in Africa,

NOTE Confidence: 0.98814106

00:43:59.435 --> 00:44:01.355 Uganda, Zambia, Kenya, Rwanda, and

NOTE Confidence: 0.98814106

00:44:01.355 --> 00:44:01.855 Nigeria.

NOTE Confidence: 0.98979056

00:44:02.410 --> 00:44:04.890 This team includes Thomas Walter,

NOTE Confidence: 0.98979056

00:44:04.890 --> 00:44:05.930 who's also a med student

NOTE Confidence: 0.98979056

00:44:05.930 --> 00:44:06.430 here,

NOTE Confidence: 0.9862722

00:44:06.890 --> 00:44:08.250 at Yale. And for this,

NOTE Confidence: 0.9862722

00:44:08.250 --> 00:44:09.930 we're conducting a systematic review  
NOTE Confidence: 0.9862722

00:44:09.930 --> 00:44:11.050 of the literature to understand  
NOTE Confidence: 0.9862722

00:44:11.050 --> 00:44:12.890 barriers and facilitators for access  
NOTE Confidence: 0.9862722

00:44:12.890 --> 00:44:14.330 to novel oncology products in  
NOTE Confidence: 0.9862722

00:44:14.330 --> 00:44:16.190 these five countries. But, importantly,  
NOTE Confidence: 0.9862722

00:44:16.250 --> 00:44:16.989 we're interviewing,  
NOTE Confidence: 0.9704119

00:44:18.005 --> 00:44:19.705 on the ground, the clinicians,  
NOTE Confidence: 0.9610324

00:44:22.005 --> 00:44:23.525 some patient groups, ministers of  
NOTE Confidence: 0.9610324

00:44:23.525 --> 00:44:24.805 health again, and the heads  
NOTE Confidence: 0.9610324

00:44:24.805 --> 00:44:26.005 of the oncology departments  
NOTE Confidence: 0.9992559

00:44:26.405 --> 00:44:26.905 clinics.  
NOTE Confidence: 0.99971914

00:44:30.565 --> 00:44:32.025 It's too early to share  
NOTE Confidence: 0.9782439

00:44:33.440 --> 00:44:34.880 findings, and we don't have  
NOTE Confidence: 0.9782439

00:44:34.880 --> 00:44:36.180 enough time. So  
NOTE Confidence: 0.9624682

00:44:36.560 --> 00:44:38.160 that'll be next year. And  
NOTE Confidence: 0.9624682

00:44:38.160 --> 00:44:38.900 then talking,

NOTE Confidence: 0.97390294  
00:44:39.440 --> 00:44:40.720 moving off to the last  
NOTE Confidence: 0.97390294  
00:44:40.720 --> 00:44:42.880 scorecard, this one is just  
NOTE Confidence: 0.97390294  
00:44:42.880 --> 00:44:44.240 at the beginning. You see  
NOTE Confidence: 0.97390294  
00:44:44.240 --> 00:44:45.120 how long it takes to  
NOTE Confidence: 0.97390294  
00:44:45.120 --> 00:44:46.640 develop these things. This one  
NOTE Confidence: 0.97390294  
00:44:46.640 --> 00:44:47.140 is  
NOTE Confidence: 0.9989341  
00:44:47.844 --> 00:44:49.685 focused on the concept of  
NOTE Confidence: 0.9989341  
00:44:49.685 --> 00:44:50.505 patient centricity  
NOTE Confidence: 0.9405267  
00:44:52.325 --> 00:44:53.065 and developing  
NOTE Confidence: 0.99890095  
00:44:53.605 --> 00:44:54.885 quality measures that can be  
NOTE Confidence: 0.99890095  
00:44:54.885 --> 00:44:56.344 both implemented and,  
NOTE Confidence: 0.9981322  
00:44:56.805 --> 00:44:57.305 assessed.  
NOTE Confidence: 0.98028076  
00:44:59.125 --> 00:45:00.489 We're using our traditional mixed  
NOTE Confidence: 0.98028076  
00:45:00.489 --> 00:45:01.930 methods, our literature review. We're  
NOTE Confidence: 0.98028076  
00:45:01.930 --> 00:45:03.290 interviewing clinicians. Some of you  
NOTE Confidence: 0.98028076

00:45:03.290 --> 00:45:04.410 in this room have participated  
NOTE Confidence: 0.98028076

00:45:04.410 --> 00:45:05.790 in the interviews. Thank you.  
NOTE Confidence: 0.95408154

00:45:06.410 --> 00:45:08.170 Patient interviews. And we're also  
NOTE Confidence: 0.95408154

00:45:08.170 --> 00:45:09.310 interviewing investors,  
NOTE Confidence: 0.96141756

00:45:09.930 --> 00:45:11.050 to see how they think  
NOTE Confidence: 0.96141756

00:45:11.050 --> 00:45:12.170 about these things in case  
NOTE Confidence: 0.96141756

00:45:12.170 --> 00:45:13.390 they're a lever for change.  
NOTE Confidence: 0.9907998

00:45:14.555 --> 00:45:15.995 And then we're developing a  
NOTE Confidence: 0.9907998

00:45:15.995 --> 00:45:17.535 framework, and then we'll engage,  
NOTE Confidence: 0.9980486

00:45:18.315 --> 00:45:19.995 stakeholders for feedback in in  
NOTE Confidence: 0.9980486

00:45:19.995 --> 00:45:21.135 the refinement process.  
NOTE Confidence: 0.99333

00:45:23.995 --> 00:45:25.755 I just wanna say that  
NOTE Confidence: 0.99333

00:45:25.755 --> 00:45:27.375 patient centricity is  
NOTE Confidence: 0.99441063

00:45:28.320 --> 00:45:28.880 I'm not sure if it's  
NOTE Confidence: 0.99441063

00:45:28.880 --> 00:45:30.080 a well developed construct, but  
NOTE Confidence: 0.99441063

00:45:30.080 --> 00:45:31.860 it is a developed construct



NOTE Confidence: 0.9766667  
00:45:32.480 --> 00:45:33.680 in medicine and in the  
NOTE Confidence: 0.9766667  
00:45:33.680 --> 00:45:35.120 context of the doctor patient  
NOTE Confidence: 0.9766667  
00:45:35.120 --> 00:45:35.620 relationship,  
NOTE Confidence: 0.96286863  
00:45:36.239 --> 00:45:37.460 arguably, right,  
NOTE Confidence: 0.9949175  
00:45:37.840 --> 00:45:38.739 having its  
NOTE Confidence: 0.96935797  
00:45:39.040 --> 00:45:39.520 its,  
NOTE Confidence: 0.95093423  
00:45:40.080 --> 00:45:41.940 roots in the Hippocratic oath.  
NOTE Confidence: 0.95530105  
00:45:42.275 --> 00:45:43.555 But then the term was  
NOTE Confidence: 0.95530105  
00:45:43.555 --> 00:45:45.235 coined in nineteen sixty nine  
NOTE Confidence: 0.95530105  
00:45:45.235 --> 00:45:45.815 by Ina  
NOTE Confidence: 0.9424177  
00:45:46.275 --> 00:45:47.955 Ballant. It, first time it  
NOTE Confidence: 0.9424177  
00:45:47.955 --> 00:45:49.235 appeared in literature, and she  
NOTE Confidence: 0.9424177  
00:45:49.235 --> 00:45:50.295 used the concept  
NOTE Confidence: 0.99156547  
00:45:50.675 --> 00:45:52.275 of patient centricity to call  
NOTE Confidence: 0.99156547  
00:45:52.275 --> 00:45:53.715 for a shift for clinicians  
NOTE Confidence: 0.99156547

00:45:53.715 --> 00:45:55.315 from an illness oriented type  
NOTE Confidence: 0.99156547

00:45:55.315 --> 00:45:56.650 of care to a patient  
NOTE Confidence: 0.99156547

00:45:56.650 --> 00:45:57.930 centered care, which for her  
NOTE Confidence: 0.99156547

00:45:57.930 --> 00:45:59.450 meant seeing the whole person  
NOTE Confidence: 0.99156547

00:45:59.450 --> 00:46:00.350 and not treating  
NOTE Confidence: 0.93195766

00:46:00.810 --> 00:46:02.010 a person as a a  
NOTE Confidence: 0.93195766

00:46:02.010 --> 00:46:02.910 diseased organ.  
NOTE Confidence: 0.9846341

00:46:04.810 --> 00:46:07.050 Then in two thousand, Mead  
NOTE Confidence: 0.9846341

00:46:07.050 --> 00:46:08.350 and Bauer developed  
NOTE Confidence: 0.9994854

00:46:09.085 --> 00:46:09.585 methods  
NOTE Confidence: 0.9559849

00:46:09.965 --> 00:46:11.965 for they defined the concept  
NOTE Confidence: 0.9559849

00:46:11.965 --> 00:46:14.305 and methods for assessing implementation.  
NOTE Confidence: 0.9860731

00:46:14.925 --> 00:46:15.965 And then today, as of  
NOTE Confidence: 0.9860731

00:46:15.965 --> 00:46:17.405 two thousand and one, patient  
NOTE Confidence: 0.9860731

00:46:17.405 --> 00:46:19.165 centricity is considered one of  
NOTE Confidence: 0.9860731

00:46:19.165 --> 00:46:19.905 six dimensions

NOTE Confidence: 0.9754398  
00:46:20.205 --> 00:46:21.585 in health care quality.  
NOTE Confidence: 0.87709916  
00:46:22.619 --> 00:46:23.500 So aiming  
NOTE Confidence: 0.9816306  
00:46:23.980 --> 00:46:24.700 I'm not sure if we're  
NOTE Confidence: 0.9816306  
00:46:24.700 --> 00:46:25.579 aiming to do this, but  
NOTE Confidence: 0.9816306  
00:46:25.579 --> 00:46:26.640 I'm aiming to explore  
NOTE Confidence: 0.99950415  
00:46:27.260 --> 00:46:28.539 whether it's possible to do  
NOTE Confidence: 0.99950415  
00:46:28.539 --> 00:46:30.559 something similar in the pharmaceutical  
NOTE Confidence: 0.99950415  
00:46:30.779 --> 00:46:31.279 context.  
NOTE Confidence: 0.9977673  
00:46:34.380 --> 00:46:35.039 So we've  
NOTE Confidence: 0.98276657  
00:46:35.985 --> 00:46:38.225 finished extracting data from the  
NOTE Confidence: 0.98276657  
00:46:38.225 --> 00:46:38.725 literature,  
NOTE Confidence: 0.98729604  
00:46:39.345 --> 00:46:40.545 and I'm not gonna go  
NOTE Confidence: 0.98729604  
00:46:40.545 --> 00:46:41.585 through. I'm just gonna give  
NOTE Confidence: 0.98729604  
00:46:41.585 --> 00:46:42.625 you just a sense of  
NOTE Confidence: 0.98729604  
00:46:42.625 --> 00:46:43.845 where we are in this  
NOTE Confidence: 0.98729604

00:46:44.145 --> 00:46:44.645 process.  
NOTE Confidence: 0.98812115

00:46:45.105 --> 00:46:46.705 Patient centricity for pharma is  
NOTE Confidence: 0.98812115

00:46:46.705 --> 00:46:47.845 a pretty new concept.  
NOTE Confidence: 0.9994674

00:46:49.000 --> 00:46:50.120 Almost eighty percent of the  
NOTE Confidence: 0.9994674

00:46:50.120 --> 00:46:51.719 articles are published in the  
NOTE Confidence: 0.9994674

00:46:51.719 --> 00:46:53.160 last ten years on patient  
NOTE Confidence: 0.9994674

00:46:53.160 --> 00:46:53.660 centricity.  
NOTE Confidence: 0.9995763

00:46:55.480 --> 00:46:56.219 The term  
NOTE Confidence: 0.9876115

00:46:56.680 --> 00:46:57.560 in the context of the  
NOTE Confidence: 0.9876115

00:46:57.560 --> 00:46:59.239 pharma didn't exist until nineteen  
NOTE Confidence: 0.9876115

00:46:59.239 --> 00:46:59.980 ninety three  
NOTE Confidence: 0.89812756

00:47:00.280 --> 00:47:01.580 when David Forrester,  
NOTE Confidence: 0.999873

00:47:02.775 --> 00:47:03.835 wrote some guidelines  
NOTE Confidence: 0.9647443

00:47:04.295 --> 00:47:06.795 for interactions between medical residents  
NOTE Confidence: 0.9647443

00:47:06.855 --> 00:47:07.355 and  
NOTE Confidence: 0.99688715

00:47:08.135 --> 00:47:09.415 industry. He was worried that

NOTE Confidence: 0.99688715  
00:47:09.415 --> 00:47:11.015 the prescribing practices could be  
NOTE Confidence: 0.99688715  
00:47:11.015 --> 00:47:11.515 corrupted  
NOTE Confidence: 0.97424906  
00:47:11.895 --> 00:47:12.214 with,  
NOTE Confidence: 0.99634963  
00:47:12.934 --> 00:47:14.474 with, industry engagement.  
NOTE Confidence: 0.9998184  
00:47:16.480 --> 00:47:17.940 The literature is  
NOTE Confidence: 0.9720766  
00:47:19.119 --> 00:47:19.619 predominantly  
NOTE Confidence: 0.985674  
00:47:19.920 --> 00:47:20.819 opinion based.  
NOTE Confidence: 0.9997817  
00:47:21.200 --> 00:47:22.019 It's not  
NOTE Confidence: 0.9523107  
00:47:22.480 --> 00:47:23.460 rigorous research,  
NOTE Confidence: 0.99767834  
00:47:24.079 --> 00:47:25.700 and it's driven by industry  
NOTE Confidence: 0.99767834  
00:47:25.759 --> 00:47:27.200 in terms of funding and  
NOTE Confidence: 0.99767834  
00:47:27.200 --> 00:47:27.700 authorship,  
NOTE Confidence: 0.9898212  
00:47:28.079 --> 00:47:28.799 which I found  
NOTE Confidence: 0.97674376  
00:47:30.559 --> 00:47:31.255 I don't know if I  
NOTE Confidence: 0.97674376  
00:47:31.255 --> 00:47:32.215 found it surprising, but it  
NOTE Confidence: 0.97674376

00:47:32.215 --> 00:47:32.955 was interesting.  
NOTE Confidence: 0.9800805

00:47:34.055 --> 00:47:35.335 And there's no agreement on  
NOTE Confidence: 0.9800805

00:47:35.335 --> 00:47:36.695 how to define patient centricity,  
NOTE Confidence: 0.9800805

00:47:36.695 --> 00:47:37.895 but everyone agrees it's really  
NOTE Confidence: 0.9800805

00:47:37.895 --> 00:47:38.955 important to define.  
NOTE Confidence: 0.998827

00:47:40.775 --> 00:47:42.555 And there's only two definitions  
NOTE Confidence: 0.998827

00:47:42.614 --> 00:47:44.315 that surface more than once.  
NOTE Confidence: 0.98529315

00:47:45.260 --> 00:47:46.540 One seems to think patient  
NOTE Confidence: 0.98529315

00:47:46.540 --> 00:47:47.819 centricity in pharma is about  
NOTE Confidence: 0.98529315

00:47:47.819 --> 00:47:49.339 a patient regulating the flow  
NOTE Confidence: 0.98529315

00:47:49.339 --> 00:47:50.540 of information to and from  
NOTE Confidence: 0.98529315

00:47:50.540 --> 00:47:51.500 them and being able to  
NOTE Confidence: 0.98529315

00:47:51.500 --> 00:47:53.520 exercise choice consistent with their  
NOTE Confidence: 0.98529315

00:47:53.660 --> 00:47:55.660 preferences, and another one links  
NOTE Confidence: 0.98529315

00:47:55.660 --> 00:47:57.280 it with engaging patients  
NOTE Confidence: 0.99953717

00:47:59.025 --> 00:48:00.464 to achieve a positive outcome

NOTE Confidence: 0.99953717  
00:48:00.464 --> 00:48:01.045 for them.  
NOTE Confidence: 0.9490048  
00:48:01.984 --> 00:48:03.185 Not gonna dissect those for  
NOTE Confidence: 0.9490048  
00:48:03.185 --> 00:48:05.025 you. But this slide just  
NOTE Confidence: 0.9490048  
00:48:05.025 --> 00:48:06.464 says there's a wide scope  
NOTE Confidence: 0.9490048  
00:48:06.464 --> 00:48:06.964 of  
NOTE Confidence: 0.9769172  
00:48:07.984 --> 00:48:09.265 topics people think you should  
NOTE Confidence: 0.9769172  
00:48:09.265 --> 00:48:10.385 tackle if you're gonna tackle  
NOTE Confidence: 0.9769172  
00:48:10.385 --> 00:48:11.925 patient centricity in pharma.  
NOTE Confidence: 0.94314283  
00:48:14.270 --> 00:48:15.969 So that's a really  
NOTE Confidence: 0.9640855  
00:48:17.070 --> 00:48:18.750 shallow sort of horizontal view  
NOTE Confidence: 0.9640855  
00:48:18.750 --> 00:48:19.570 of the scorecards.  
NOTE Confidence: 0.89017737  
00:48:20.830 --> 00:48:21.730 Three launched,  
NOTE Confidence: 0.9611048  
00:48:22.830 --> 00:48:23.870 one coming out this year,  
NOTE Confidence: 0.9611048  
00:48:23.870 --> 00:48:24.910 and one very much under  
NOTE Confidence: 0.9611048  
00:48:24.910 --> 00:48:25.410 development.  
NOTE Confidence: 0.97145337

00:48:26.155 --> 00:48:26.955 We've come a long way,  
NOTE Confidence: 0.97145337

00:48:26.955 --> 00:48:27.995 yet there's so much more  
NOTE Confidence: 0.97145337

00:48:27.995 --> 00:48:28.655 to do,  
NOTE Confidence: 0.999381

00:48:29.035 --> 00:48:30.875 to translate ethical requirements and  
NOTE Confidence: 0.999381

00:48:30.875 --> 00:48:32.795 commitments into measures and outcomes  
NOTE Confidence: 0.999381

00:48:32.795 --> 00:48:33.615 that are observable,  
NOTE Confidence: 0.9931395

00:48:34.235 --> 00:48:34.735 comparable,  
NOTE Confidence: 0.9518221

00:48:35.355 --> 00:48:36.955 and publicly accountable so we  
NOTE Confidence: 0.9518221

00:48:36.955 --> 00:48:38.315 can improve things for patients.  
NOTE Confidence: 0.9518221

00:48:38.315 --> 00:48:39.055 Thank you.  
NOTE Confidence: 0.9261116

00:48:45.739 --> 00:48:47.520 Hey. Questions from the audience?  
NOTE Confidence: 0.9104794

00:48:50.860 --> 00:48:52.219 Good job, Ken. Thank you,  
NOTE Confidence: 0.9104794

00:48:52.219 --> 00:48:53.915 Adam. Who funds you to  
NOTE Confidence: 0.9104794

00:48:53.915 --> 00:48:54.815 do all of this?  
NOTE Confidence: 0.9983446

00:48:55.355 --> 00:48:56.655 Not enough people.  
NOTE Confidence: 0.97432345

00:48:58.555 --> 00:48:59.515 So we've been doing this



NOTE Confidence: 0.97432345  
00:48:59.515 --> 00:49:00.494 for ten years,  
NOTE Confidence: 0.90532225  
00:49:00.875 --> 00:49:01.855 and, originally,  
NOTE Confidence: 0.97239816  
00:49:02.234 --> 00:49:04.474 it was not funded. Then  
NOTE Confidence: 0.97239816  
00:49:04.474 --> 00:49:05.755 we had some grants from  
NOTE Confidence: 0.97239816  
00:49:05.755 --> 00:49:07.114 the Arnold Foundation for five  
NOTE Confidence: 0.97239816  
00:49:07.114 --> 00:49:07.614 years.  
NOTE Confidence: 0.9630026  
00:49:08.030 --> 00:49:09.469 Then we leveraged grants from  
NOTE Confidence: 0.9630026  
00:49:09.469 --> 00:49:11.390 the FDA, Oncology Center for  
NOTE Confidence: 0.9630026  
00:49:11.390 --> 00:49:11.890 Excellence.  
NOTE Confidence: 0.8046533  
00:49:12.190 --> 00:49:14.050 We've leveraged, like, other grants,  
NOTE Confidence: 0.8046533  
00:49:14.190 --> 00:49:15.170 the spot analyses.  
NOTE Confidence: 0.9982469  
00:49:16.510 --> 00:49:18.109 And we're launching a program  
NOTE Confidence: 0.9982469  
00:49:18.109 --> 00:49:18.930 with a membership  
NOTE Confidence: 0.9957254  
00:49:19.230 --> 00:49:21.089 where pharma companies could participate  
NOTE Confidence: 0.9957254  
00:49:21.150 --> 00:49:22.030 a little bit in some  
NOTE Confidence: 0.9957254

00:49:22.030 --> 00:49:22.690 of this.

NOTE Confidence: 0.9247308

00:49:24.485 --> 00:49:25.385 That's controversial,

NOTE Confidence: 0.9751619

00:49:26.165 --> 00:49:28.165 and we've taken funding very

NOTE Confidence: 0.9751619

00:49:28.165 --> 00:49:29.625 small amounts from five companies.

NOTE Confidence: 0.99896604

00:49:30.485 --> 00:49:31.765 But it's less than ten

NOTE Confidence: 0.99896604

00:49:31.765 --> 00:49:33.145 percent of the overall funding

NOTE Confidence: 0.90172625

00:49:34.165 --> 00:49:35.625 and two individual donors.

NOTE Confidence: 0.9174301

00:49:38.200 --> 00:49:38.940 Good question.

NOTE Confidence: 0.89116305

00:49:39.560 --> 00:49:40.840 Yeah. Do you have you

NOTE Confidence: 0.89116305

00:49:40.840 --> 00:49:42.780 considered with your YMed approach

NOTE Confidence: 0.89116305

00:49:42.920 --> 00:49:44.620 expanding it beyond the oncology

NOTE Confidence: 0.89116305

00:49:44.680 --> 00:49:46.220 maps? Because I feel like

NOTE Confidence: 0.89116305

00:49:46.520 --> 00:49:47.960 a town founder is gonna

NOTE Confidence: 0.89116305

00:49:47.960 --> 00:49:49.020 be the resources

NOTE Confidence: 0.9914788

00:49:49.320 --> 00:49:50.360 to do that in the

NOTE Confidence: 0.9914788

00:49:50.360 --> 00:49:52.005 country. So some people

NOTE Confidence: 0.9449102  
00:49:52.724 --> 00:49:55.125 like, other med medical devices  
NOTE Confidence: 0.9449102  
00:49:55.125 --> 00:49:56.825 that have been tested, like,  
NOTE Confidence: 0.8619874  
00:49:57.125 --> 00:49:58.164 vaccines, I think we talked  
NOTE Confidence: 0.8619874  
00:49:58.164 --> 00:49:58.904 about prep.  
NOTE Confidence: 0.9978112  
00:49:59.285 --> 00:50:00.744 Have you thought about expanding  
NOTE Confidence: 0.9978112  
00:50:00.805 --> 00:50:02.424 beyond the oncology formulary?  
NOTE Confidence: 0.98502594  
00:50:03.605 --> 00:50:05.444 Ideally, yes. But we're so  
NOTE Confidence: 0.98502594  
00:50:05.444 --> 00:50:06.565 in the beginning of the  
NOTE Confidence: 0.98502594  
00:50:06.565 --> 00:50:07.065 oncology.  
NOTE Confidence: 0.99865705  
00:50:07.710 --> 00:50:08.930 Jeremy, what do you think?  
NOTE Confidence: 0.8974407  
00:50:09.869 --> 00:50:11.090 Yeah. I mean, we  
NOTE Confidence: 0.95648396  
00:50:12.030 --> 00:50:13.170 oncology is a very,  
NOTE Confidence: 0.938216  
00:50:13.630 --> 00:50:14.750 yeah, I think as Sarah's  
NOTE Confidence: 0.938216  
00:50:14.750 --> 00:50:16.030 suggesting, it's a it's a  
NOTE Confidence: 0.938216  
00:50:16.030 --> 00:50:17.810 challenging one to tackle because  
NOTE Confidence: 0.9996671

00:50:18.270 --> 00:50:19.010 the resources  
NOTE Confidence: 0.9998369  
00:50:19.310 --> 00:50:19.810 surrounding  
NOTE Confidence: 0.9983301  
00:50:20.190 --> 00:50:21.890 the medicines themselves are so  
NOTE Confidence: 0.98927104  
00:50:22.425 --> 00:50:24.105 sparse and complicated. Mhmm. The  
NOTE Confidence: 0.98927104  
00:50:24.105 --> 00:50:25.405 testing and everything. Yeah.  
NOTE Confidence: 0.87942487  
00:50:29.305 --> 00:50:30.665 It's it's too late to  
NOTE Confidence: 0.87942487  
00:50:30.665 --> 00:50:31.165 pivot,  
NOTE Confidence: 0.98850375  
00:50:32.344 --> 00:50:33.565 but we can add.  
NOTE Confidence: 0.9621385  
00:50:34.585 --> 00:50:35.465 So maybe we can talk  
NOTE Confidence: 0.9621385  
00:50:35.465 --> 00:50:36.205 about that  
NOTE Confidence: 0.9979267  
00:50:36.585 --> 00:50:37.085 later.  
NOTE Confidence: 0.77479804  
00:50:39.119 --> 00:50:40.020 Yes. Yeah.  
NOTE Confidence: 0.94345385  
00:50:40.640 --> 00:50:41.920 What would you what in  
NOTE Confidence: 0.94345385  
00:50:41.920 --> 00:50:43.680 your mind would could or  
NOTE Confidence: 0.94345385  
00:50:43.680 --> 00:50:45.440 should pharma companies do to  
NOTE Confidence: 0.94345385  
00:50:45.440 --> 00:50:46.660 expand availability

NOTE Confidence: 0.9118513

00:50:47.039 --> 00:50:49.059 of treatments across the globe?

NOTE Confidence: 0.9892263

00:50:49.520 --> 00:50:51.599 Well, we're starting so humbly,

NOTE Confidence: 0.9892263

00:50:51.599 --> 00:50:53.425 right, with the most basic

NOTE Confidence: 0.9892263

00:50:53.425 --> 00:50:54.545 thing, which is if you're

NOTE Confidence: 0.9892263

00:50:54.545 --> 00:50:55.045 testing

NOTE Confidence: 0.9770112

00:50:55.425 --> 00:50:56.305 a first of all, you

NOTE Confidence: 0.9770112

00:50:56.305 --> 00:50:58.005 should be testing your products

NOTE Confidence: 0.9770112

00:50:58.224 --> 00:50:59.505 in hot spots, right, where

NOTE Confidence: 0.9770112

00:50:59.505 --> 00:51:00.625 the disease burden is high.

NOTE Confidence: 0.9770112

00:51:00.625 --> 00:51:01.844 And then you should absolutely,

NOTE Confidence: 0.9770112

00:51:01.905 --> 00:51:03.265 at a minimum, be submitting

NOTE Confidence: 0.9770112

00:51:03.265 --> 00:51:05.425 products for regulatory approval in

NOTE Confidence: 0.9770112

00:51:05.425 --> 00:51:06.464 those countries so that there's

NOTE Confidence: 0.9770112

00:51:06.464 --> 00:51:08.410 physical access. And that's the

NOTE Confidence: 0.9770112

00:51:08.410 --> 00:51:09.610 first problem we're starting we're

NOTE Confidence: 0.9770112

00:51:09.610 --> 00:51:10.650 trying to tackle. And then  
NOTE Confidence: 0.9770112

00:51:10.650 --> 00:51:11.710 we're gonna tackle  
NOTE Confidence: 0.9968566

00:51:12.170 --> 00:51:12.670 affordability,  
NOTE Confidence: 0.96860796

00:51:14.330 --> 00:51:16.410 adequate supplies, and distribution from  
NOTE Confidence: 0.96860796

00:51:16.410 --> 00:51:16.910 there.  
NOTE Confidence: 0.99576473

00:51:17.290 --> 00:51:18.410 But we can't even tackle  
NOTE Confidence: 0.99576473

00:51:18.410 --> 00:51:19.070 that given  
NOTE Confidence: 0.99921864

00:51:20.655 --> 00:51:21.315 the challenges with the  
NOTE Confidence: 0.9998813

00:51:21.614 --> 00:51:22.435 first problem.  
NOTE Confidence: 0.98946744

00:51:24.415 --> 00:51:25.535 Yeah. I think with the  
NOTE Confidence: 0.98946744

00:51:25.535 --> 00:51:26.355 low income,  
NOTE Confidence: 0.9637948

00:51:27.614 --> 00:51:28.114 countries,  
NOTE Confidence: 0.99396247

00:51:28.975 --> 00:51:30.094 have you looked at the  
NOTE Confidence: 0.99396247

00:51:30.094 --> 00:51:32.175 issue of profit? Because Of  
NOTE Confidence: 0.99396247

00:51:32.175 --> 00:51:32.675 what?  
NOTE Confidence: 0.94770694

00:51:32.975 --> 00:51:33.475 Profit.

NOTE Confidence: 0.996914  
00:51:34.530 --> 00:51:36.130 Because in those countries, a  
NOTE Confidence: 0.996914  
00:51:36.130 --> 00:51:37.410 lot of people can't afford  
NOTE Confidence: 0.996914  
00:51:37.410 --> 00:51:39.030 the drugs at the  
NOTE Confidence: 0.9914585  
00:51:39.489 --> 00:51:40.930 going market rate, and they  
NOTE Confidence: 0.9914585  
00:51:40.930 --> 00:51:42.150 have to be significantly  
NOTE Confidence: 0.9998  
00:51:42.530 --> 00:51:43.030 subsidized  
NOTE Confidence: 0.8854424  
00:51:43.330 --> 00:51:44.630 by either by the government.  
NOTE Confidence: 0.96893543  
00:51:45.250 --> 00:51:47.250 And health insurance is not  
NOTE Confidence: 0.96893543  
00:51:47.250 --> 00:51:48.710 as robust as in  
NOTE Confidence: 0.9748536  
00:51:49.164 --> 00:51:50.924 the high income countries. So  
NOTE Confidence: 0.9748536  
00:51:50.924 --> 00:51:53.164 maybe Yeah. That's exactly yeah.  
NOTE Confidence: 0.9748536  
00:51:53.164 --> 00:51:53.664 Exactly.  
NOTE Confidence: 0.97381866  
00:51:54.125 --> 00:51:55.244 That's the that's one of  
NOTE Confidence: 0.97381866  
00:51:55.244 --> 00:51:57.085 the exact questions on the  
NOTE Confidence: 0.97381866  
00:51:57.085 --> 00:51:58.844 interview guide and then trying  
NOTE Confidence: 0.97381866

00:51:58.844 --> 00:52:00.224 to tease out if there's  
NOTE Confidence: 0.97381866

00:52:00.285 --> 00:52:01.884 a subsidy needed exact you  
NOTE Confidence: 0.97381866

00:52:01.884 --> 00:52:03.150 know, by who should be  
NOTE Confidence: 0.97381866

00:52:03.150 --> 00:52:04.109 paying for it, how much  
NOTE Confidence: 0.97381866

00:52:04.109 --> 00:52:04.910 does it need to be,  
NOTE Confidence: 0.97381866

00:52:04.910 --> 00:52:05.950 is it a proportion, is  
NOTE Confidence: 0.97381866

00:52:05.950 --> 00:52:06.450 it  
NOTE Confidence: 0.9848449

00:52:08.030 --> 00:52:08.829 so if you want, I  
NOTE Confidence: 0.9848449

00:52:08.829 --> 00:52:09.869 can show you what we're  
NOTE Confidence: 0.9848449

00:52:09.869 --> 00:52:10.369 finding  
NOTE Confidence: 0.8681043

00:52:10.670 --> 00:52:11.170 afterwards.  
NOTE Confidence: 0.9773588

00:52:13.950 --> 00:52:15.069 But we're still awash in  
NOTE Confidence: 0.9773588

00:52:15.069 --> 00:52:16.210 data. We haven't,  
NOTE Confidence: 0.9953026

00:52:16.955 --> 00:52:17.915 you know, wrapped our heads  
NOTE Confidence: 0.9953026

00:52:17.915 --> 00:52:19.135 around the next steps.  
NOTE Confidence: 0.8060132

00:52:19.594 --> 00:52:20.094 Steve.



NOTE Confidence: 0.9899515  
00:52:21.594 --> 00:52:22.975 Just thinking about transparency  
NOTE Confidence: 0.97391677  
00:52:24.475 --> 00:52:25.295 and representativeness.  
NOTE Confidence: 0.94491684  
00:52:29.580 --> 00:52:31.260 If the companies change their  
NOTE Confidence: 0.94491684  
00:52:31.260 --> 00:52:32.940 practices so that they all  
NOTE Confidence: 0.94491684  
00:52:32.940 --> 00:52:35.420 got really good scores around  
NOTE Confidence: 0.94491684  
00:52:35.420 --> 00:52:36.940 transparency and represent  
NOTE Confidence: 0.8084552  
00:52:39.020 --> 00:52:39.920 would you expect  
NOTE Confidence: 0.9993918  
00:52:41.260 --> 00:52:41.760 different  
NOTE Confidence: 0.9994924  
00:52:42.060 --> 00:52:42.800 or better  
NOTE Confidence: 0.47134054  
00:52:43.500 --> 00:52:44.000 jobs  
NOTE Confidence: 0.76221573  
00:52:44.885 --> 00:52:45.545 to be  
NOTE Confidence: 0.71577436  
00:52:45.924 --> 00:52:46.424 improved,  
NOTE Confidence: 0.9867191  
00:52:46.805 --> 00:52:48.165 and what's the grounds for  
NOTE Confidence: 0.9867191  
00:52:48.165 --> 00:52:49.065 that expectation?  
NOTE Confidence: 0.99974155  
00:52:50.085 --> 00:52:51.704 How do you define better?  
NOTE Confidence: 0.9769582

00:52:53.285 --> 00:52:54.484 Well, one way to think  
NOTE Confidence: 0.9769582

00:52:54.484 --> 00:52:55.444 about it might be better  
NOTE Confidence: 0.9769582

00:52:55.444 --> 00:52:55.944 targeted,  
NOTE Confidence: 0.93940353

00:52:58.450 --> 00:52:58.950 But,  
NOTE Confidence: 0.9370556

00:53:00.050 --> 00:53:01.110 I'm I'm just wondering,  
NOTE Confidence: 0.93229026

00:53:02.450 --> 00:53:03.650 I I I guess the  
NOTE Confidence: 0.93229026

00:53:03.650 --> 00:53:05.190 the wonderment is most easy  
NOTE Confidence: 0.93229026

00:53:05.330 --> 00:53:06.530 to express in terms of  
NOTE Confidence: 0.93229026

00:53:06.530 --> 00:53:07.030 transparency.  
NOTE Confidence: 0.96118075

00:53:08.610 --> 00:53:09.810 If all that stuff is  
NOTE Confidence: 0.96118075

00:53:09.810 --> 00:53:11.570 not getting published or published  
NOTE Confidence: 0.96118075

00:53:11.810 --> 00:53:13.815 Mhmm. Would that change what's  
NOTE Confidence: 0.96118075

00:53:13.815 --> 00:53:15.575 getting approved? Mhmm. Would that  
NOTE Confidence: 0.96118075

00:53:15.575 --> 00:53:17.094 change the warning labels? Would  
NOTE Confidence: 0.96118075

00:53:17.094 --> 00:53:18.455 that result in drugs being  
NOTE Confidence: 0.96118075

00:53:18.455 --> 00:53:20.555 better targeted or better marketed?

NOTE Confidence: 0.96051586

00:53:22.055 --> 00:53:23.094 In other words, you you

NOTE Confidence: 0.96051586

00:53:23.094 --> 00:53:25.255 want the transparency is wonderful

NOTE Confidence: 0.96051586

00:53:25.255 --> 00:53:26.135 from an ethical point of

NOTE Confidence: 0.96051586

00:53:26.135 --> 00:53:26.935 view, sort of on its

NOTE Confidence: 0.96051586

00:53:26.935 --> 00:53:27.750 own. It's a good in

NOTE Confidence: 0.96051586

00:53:27.750 --> 00:53:29.130 itself in some way. Mhmm.

NOTE Confidence: 0.96051586

00:53:29.350 --> 00:53:30.469 Like there to be payoff

NOTE Confidence: 0.96051586

00:53:30.469 --> 00:53:31.590 for patients at the end.

NOTE Confidence: 0.96051586

00:53:31.590 --> 00:53:33.190 You you'd like to think

NOTE Confidence: 0.96051586

00:53:33.190 --> 00:53:34.090 that with

NOTE Confidence: 0.97392756

00:53:34.469 --> 00:53:35.290 full information,

NOTE Confidence: 0.9990577

00:53:35.830 --> 00:53:37.210 it would inform

NOTE Confidence: 0.9446825

00:53:37.910 --> 00:53:39.670 prescribing practices. Right? And so

NOTE Confidence: 0.9446825

00:53:39.670 --> 00:53:40.630 you would think that if

NOTE Confidence: 0.9446825

00:53:40.630 --> 00:53:41.130 information

NOTE Confidence: 0.97301966

00:53:42.635 --> 00:53:44.075 that was negative, right, came  
NOTE Confidence: 0.97301966

00:53:44.075 --> 00:53:44.734 to light,  
NOTE Confidence: 0.9673109

00:53:45.195 --> 00:53:46.474 that that would inform I  
NOTE Confidence: 0.9673109

00:53:46.474 --> 00:53:47.755 I I I would I'm  
NOTE Confidence: 0.9673109

00:53:47.755 --> 00:53:48.795 an empiricist. I need to  
NOTE Confidence: 0.9673109

00:53:48.795 --> 00:53:50.075 see I need to measure,  
NOTE Confidence: 0.9673109

00:53:50.075 --> 00:53:51.614 right, the the the counterfactual.  
NOTE Confidence: 0.9673109

00:53:51.755 --> 00:53:52.714 Like, if things were better,  
NOTE Confidence: 0.9673109

00:53:52.714 --> 00:53:53.675 what would it look like?  
NOTE Confidence: 0.9673109

00:53:53.915 --> 00:53:55.500 But I would suspect strongly  
NOTE Confidence: 0.9673109

00:53:55.500 --> 00:53:56.860 that it would change practice.  
NOTE Confidence: 0.9673109

00:53:56.860 --> 00:53:58.080 Right? And there are cases,  
NOTE Confidence: 0.9673109

00:53:58.140 --> 00:53:59.260 and we're having that guest  
NOTE Confidence: 0.9673109

00:53:59.260 --> 00:53:59.760 speaker,  
NOTE Confidence: 0.89352375

00:54:00.540 --> 00:54:01.340 who wrote the book no  
NOTE Confidence: 0.89352375

00:54:01.340 --> 00:54:02.560 more tears come,

NOTE Confidence: 0.9839314  
00:54:02.860 --> 00:54:03.900 yes, come to the talk  
NOTE Confidence: 0.9839314  
00:54:03.900 --> 00:54:05.280 that the program for biomedical  
NOTE Confidence: 0.9839314  
00:54:05.340 --> 00:54:06.960 ethics is hosting in February.  
NOTE Confidence: 0.9839314  
00:54:07.100 --> 00:54:08.219 What's the date, Sarah? Are  
NOTE Confidence: 0.9839314  
00:54:08.219 --> 00:54:08.380 you  
NOTE Confidence: 0.6782861  
00:54:09.100 --> 00:54:10.480 The eighteenth, I believe?  
NOTE Confidence: 0.8706667  
00:54:11.555 --> 00:54:12.455 Thank you. Sarah's,  
NOTE Confidence: 0.8878041  
00:54:13.235 --> 00:54:14.695 also director of the program,  
NOTE Confidence: 0.8878041  
00:54:14.835 --> 00:54:15.235 and,  
NOTE Confidence: 0.941349  
00:54:17.235 --> 00:54:19.155 there's an author. Gardner Harris  
NOTE Confidence: 0.941349  
00:54:19.155 --> 00:54:19.955 wrote a book called No  
NOTE Confidence: 0.941349  
00:54:19.955 --> 00:54:21.635 Martyrs, a big expose on  
NOTE Confidence: 0.941349  
00:54:21.635 --> 00:54:22.915 j and j, and it's  
NOTE Confidence: 0.941349  
00:54:22.915 --> 00:54:24.275 case after case after case  
NOTE Confidence: 0.941349  
00:54:24.275 --> 00:54:26.135 of studies not being published,  
NOTE Confidence: 0.9763363

00:54:26.969 --> 00:54:29.469 that showed ethic, safety challenges,

NOTE Confidence: 0.95246685

00:54:30.010 --> 00:54:31.850 for drugs. And after those

NOTE Confidence: 0.95246685

00:54:31.850 --> 00:54:33.310 studies came to light, practices

NOTE Confidence: 0.95246685

00:54:33.369 --> 00:54:34.330 did change. But those are

NOTE Confidence: 0.95246685

00:54:34.330 --> 00:54:35.550 an you know, those are

NOTE Confidence: 0.82196766

00:54:36.090 --> 00:54:37.469 multiple ends of ones.

NOTE Confidence: 0.99760175

00:54:38.010 --> 00:54:39.210 But I would suspect but

NOTE Confidence: 0.99760175

00:54:39.210 --> 00:54:40.890 I don't know. Right? What

NOTE Confidence: 0.99760175

00:54:40.890 --> 00:54:41.710 do you think?

NOTE Confidence: 0.951248

00:54:42.625 --> 00:54:43.745 I I would suspect that

NOTE Confidence: 0.951248

00:54:43.745 --> 00:54:45.265 it would change prescribing pracs.

NOTE Confidence: 0.951248

00:54:45.265 --> 00:54:46.405 Yeah. Negative,

NOTE Confidence: 0.91654915

00:54:46.945 --> 00:54:48.485 or or Or full information.

NOTE Confidence: 0.91654915

00:54:48.705 --> 00:54:49.205 Yeah.

NOTE Confidence: 0.88391685

00:54:50.065 --> 00:54:51.344 Published just there are lots

NOTE Confidence: 0.88391685

00:54:51.344 --> 00:54:52.385 of studies that weren't published

NOTE Confidence: 0.88391685  
00:54:52.385 --> 00:54:53.765 because they showed no  
NOTE Confidence: 0.96629715  
00:54:54.465 --> 00:54:55.665 result from the drug and  
NOTE Confidence: 0.96629715  
00:54:55.665 --> 00:54:56.360 so on. And if it  
NOTE Confidence: 0.96629715  
00:54:56.360 --> 00:54:57.320 turned out that they're cherry  
NOTE Confidence: 0.96629715  
00:54:57.320 --> 00:54:58.600 picking studies that have best  
NOTE Confidence: 0.96629715  
00:54:58.600 --> 00:54:59.880 results for their Mhmm.  
NOTE Confidence: 0.8952927  
00:55:00.360 --> 00:55:01.719 Some Mhmm. All that stuff  
NOTE Confidence: 0.8952927  
00:55:01.719 --> 00:55:02.840 came out, I would expect  
NOTE Confidence: 0.8952927  
00:55:02.840 --> 00:55:04.300 that to affect. Right.  
NOTE Confidence: 0.9997718  
00:55:04.840 --> 00:55:06.280 I was very surprised to  
NOTE Confidence: 0.9997718  
00:55:06.280 --> 00:55:07.100 hear that  
NOTE Confidence: 0.98518395  
00:55:07.400 --> 00:55:08.140 from you,  
NOTE Confidence: 0.9986813  
00:55:08.680 --> 00:55:09.580 that that  
NOTE Confidence: 0.9993637  
00:55:10.715 --> 00:55:11.855 lack of representativeness  
NOTE Confidence: 0.8437635  
00:55:12.235 --> 00:55:12.735 had,  
NOTE Confidence: 0.95499545

00:55:14.155 --> 00:55:15.515 sort of payoff in trust  
NOTE Confidence: 0.95499545

00:55:15.515 --> 00:55:16.395 at the level of the  
NOTE Confidence: 0.95499545

00:55:16.395 --> 00:55:19.035 doctor patient. Mhmm. Mhmm. How  
NOTE Confidence: 0.95499545

00:55:19.035 --> 00:55:20.415 how do they even know?  
NOTE Confidence: 0.9997492

00:55:21.035 --> 00:55:21.835 I think that was a  
NOTE Confidence: 0.9997492

00:55:21.835 --> 00:55:23.535 controlled experiment. Yeah.  
NOTE Confidence: 0.99777853

00:55:24.075 --> 00:55:24.575 Yeah.  
NOTE Confidence: 0.9616604

00:55:26.530 --> 00:55:28.130 Our hour is up. Thank  
NOTE Confidence: 0.9616604

00:55:28.130 --> 00:55:29.890 you for, your questions. So  
NOTE Confidence: 0.9616604

00:55:29.890 --> 00:55:30.770 there's a couple of questions  
NOTE Confidence: 0.9616604

00:55:30.770 --> 00:55:31.650 in the chat, and I'll  
NOTE Confidence: 0.9616604

00:55:31.650 --> 00:55:32.630 just encourage  
NOTE Confidence: 0.8797138

00:55:33.248 --> 00:55:33.748 those,  
NOTE Confidence: 0.82787514

00:55:34.529 --> 00:55:35.889 email you directly to those  
NOTE Confidence: 0.82787514

00:55:35.889 --> 00:55:37.589 questions if that's okay. Great.  
NOTE Confidence: 0.82787514

00:55:37.649 --> 00:55:38.929 Yes. That's okay. So we



NOTE Confidence: 0.82787514

00:55:38.929 --> 00:55:39.909 can do that. Thank

NOTE Confidence: 0.9244851

00:55:41.969 --> 00:55:42.469 you.