

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 Pontifical University of Regina
NOTE Confidence: 0.9143204
00:03:45.725 --> 00:03:46.225 Apostolorum,
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.