

WEBVTT

NOTE duration:"00:59:49"

NOTE recognizability:0.866

NOTE language:en-us

NOTE Confidence: 0.791109643333333

00:00:00.000 --> 00:00:03.310 So it's a pleasure to introduce Jeremy

NOTE Confidence: 0.798762552

00:00:03.440 --> 00:00:05.795 Warner, who actually I first met

NOTE Confidence: 0.798762552

00:00:05.795 --> 00:00:08.348 this year when when I was chairing

NOTE Confidence: 0.845342642857143

00:00:08.360 --> 00:00:10.915 a panel at ESMO and he was

NOTE Confidence: 0.928525481428571

00:00:10.930 --> 00:00:12.869 one of the speakers who we invited.

NOTE Confidence: 0.7411608

00:00:14.950 --> 00:00:18.216 Jeremy is the director of the Brown

NOTE Confidence: 0.7411608

00:00:18.216 --> 00:00:21.378 Lifespan Center for Cancer Bioinformatics

NOTE Confidence: 0.857374834

00:00:21.390 --> 00:00:24.410 and data science and associate professor

NOTE Confidence: 0.857374834

00:00:24.410 --> 00:00:28.798 technically pending I guess, at Ed Brown.

NOTE Confidence: 0.668117082

00:00:29.480 --> 00:00:31.130 His clinical focus is Morgan

NOTE Confidence: 0.668117082

00:00:31.130 --> 00:00:34.180 hematology and he received

NOTE Confidence: 0.97649878

00:00:34.190 --> 00:00:37.270 his medical degree from from Boston

NOTE Confidence: 0.97649878

00:00:37.270 --> 00:00:41.309 University and also in a Masters in

NOTE Confidence: 0.97649878

00:00:41.310 --> 00:00:43.210 Photonics and Electrical and Computer

NOTE Confidence: 0.97649878

00:00:43.210 --> 00:00:44.990 Engineering from UC San Diego.

NOTE Confidence: 0.91951521

00:00:46.280 --> 00:00:48.260 In addition to his focus on

NOTE Confidence: 0.91951521

00:00:48.260 --> 00:00:49.680 malignant hematology, Dr.

NOTE Confidence: 0.91951521

00:00:49.680 --> 00:00:51.320 Warner is a leading expert in

NOTE Confidence: 0.91951521

00:00:51.320 --> 00:00:52.800 the clinical and translational

NOTE Confidence: 0.91951521

00:00:52.800 --> 00:00:53.910 clinical and translational

NOTE Confidence: 0.91951521

00:00:53.910 --> 00:00:55.570 cancer informatics research,

NOTE Confidence: 0.908135898

00:00:56.160 --> 00:00:58.040 including high dimensional data

NOTE Confidence: 0.908135898

00:00:58.040 --> 00:00:59.460 analysis and visualization,

NOTE Confidence: 0.908135898

00:00:59.460 --> 00:01:01.032 natural language processing

NOTE Confidence: 0.908135898

00:01:01.032 --> 00:01:02.960 of narrative oncology texts,

NOTE Confidence: 0.908135898

00:01:02.960 --> 00:01:03.828 and the creation and

NOTE Confidence: 0.958742508

00:01:03.840 --> 00:01:07.680 implementation of health data standards.

NOTE Confidence: 0.958742508

00:01:07.680 --> 00:01:11.840 Before coming to Brown.

NOTE Confidence: 0.958742508

00:01:11.840 --> 00:01:13.728 Jeremy was at Vanderbilt

NOTE Confidence: 0.93045476

00:01:13.740 --> 00:01:15.516 University Medical Center,

NOTE Confidence: 0.93045476

00:01:15.516 --> 00:01:18.090 where he was an associate professor of

NOTE Confidence: 0.93045476

00:01:18.090 --> 00:01:21.730 medicine and biomedical informatics.

NOTE Confidence: 0.93045476

00:01:21.730 --> 00:01:24.425 And I should also note that he

NOTE Confidence: 0.93045476

00:01:24.425 --> 00:01:27.159 is the deputy director of Escos

NOTE Confidence: 0.93045476

00:01:27.160 --> 00:01:28.959 Clinical Cancer Informatics Journal

NOTE Confidence: 0.93045476

00:01:28.959 --> 00:01:31.328 and a founding director of the New

NOTE Confidence: 0.93045476

00:01:31.328 --> 00:01:34.870 Brown University Center for Cancer

NOTE Confidence: 0.93045476

00:01:34.870 --> 00:01:36.815 Bioinformatics and Data Science.

NOTE Confidence: 0.93045476

00:01:36.815 --> 00:01:37.990 So without further

NOTE Confidence: 0.842243421428572

00:01:38.000 --> 00:01:40.338 ado, you're going to speak to us

NOTE Confidence: 0.894348995

00:01:40.350 --> 00:01:42.258 about using and improving real world.

NOTE Confidence: 0.894348995

00:01:42.260 --> 00:01:45.440 Hey there. Ecosystem in cancer.

NOTE Confidence: 0.894348995

00:01:45.440 --> 00:01:48.710 Thanks. Look forward to it.

NOTE Confidence: 0.930034288888889

00:01:48.710 --> 00:01:51.203 Thank you. Thank you so much for having me.

NOTE Confidence: 0.930034288888889

00:01:51.210 --> 00:01:52.230 And if anybody wants to
NOTE Confidence: 0.930034288888889

00:01:52.230 --> 00:01:53.046 come up to Providence,
NOTE Confidence: 0.930034288888889

00:01:53.050 --> 00:01:57.640 just one stop away on the Acela, so.
NOTE Confidence: 0.930034288888889

00:01:57.640 --> 00:02:00.460 Really nice that we're so close here.
NOTE Confidence: 0.930034288888889

00:02:00.460 --> 00:02:03.187 In New England, so I just have a few
NOTE Confidence: 0.930034288888889

00:02:03.187 --> 00:02:05.266 disclosures first before I get started.
NOTE Confidence: 0.930034288888889

00:02:05.270 --> 00:02:06.746 So I have some grant funding,
NOTE Confidence: 0.930034288888889

00:02:06.750 --> 00:02:07.652 some consulting.
NOTE Confidence: 0.930034288888889

00:02:07.652 --> 00:02:10.584 I do have ownership in hemlock.org LLC,
NOTE Confidence: 0.930034288888889

00:02:10.584 --> 00:02:12.921 but has no monetary value unless one
NOTE Confidence: 0.930034288888889

00:02:12.921 --> 00:02:15.409 of you wants to be an Angel investor
NOTE Confidence: 0.930034288888889

00:02:15.409 --> 00:02:18.266 and we can talk after the presentation.
NOTE Confidence: 0.930034288888889

00:02:18.270 --> 00:02:20.370 So what I'm going to talk
NOTE Confidence: 0.930034288888889

00:02:20.370 --> 00:02:21.978 about here is you know why,
NOTE Confidence: 0.930034288888889

00:02:21.978 --> 00:02:24.328 why do we need real world data and real
NOTE Confidence: 0.930034288888889

00:02:24.328 --> 00:02:26.329 world evidence in oncology and I'm going

NOTE Confidence: 0.930034288888889
00:02:26.329 --> 00:02:27.847 to focus on electronic health records.
NOTE Confidence: 0.930034288888889
00:02:27.850 --> 00:02:29.400 There are other sources of
NOTE Confidence: 0.930034288888889
00:02:29.400 --> 00:02:30.950 real world data of course,
NOTE Confidence: 0.930034288888889
00:02:30.950 --> 00:02:32.749 but you know most of this talk
NOTE Confidence: 0.930034288888889
00:02:32.749 --> 00:02:34.108 will really focus on the ER,
NOTE Confidence: 0.930034288888889
00:02:34.110 --> 00:02:34.664 the HR.
NOTE Confidence: 0.930034288888889
00:02:34.664 --> 00:02:36.880 I will spend some time on talking about
NOTE Confidence: 0.930034288888889
00:02:36.941 --> 00:02:39.311 in particular interest in mine which
NOTE Confidence: 0.930034288888889
00:02:39.311 --> 00:02:41.364 is standardizing systemic anti cancer
NOTE Confidence: 0.930034288888889
00:02:41.364 --> 00:02:43.012 treatment representations and then
NOTE Confidence: 0.930034288888889
00:02:43.012 --> 00:02:45.508 I'll spend some time talking about
NOTE Confidence: 0.930034288888889
00:02:45.508 --> 00:02:48.504 our COVID and COVID-19 and cancer consortium.
NOTE Confidence: 0.930034288888889
00:02:48.510 --> 00:02:50.148 Which is a bit of a culmination,
NOTE Confidence: 0.930034288888889
00:02:50.150 --> 00:02:50.981 if you will,
NOTE Confidence: 0.930034288888889
00:02:50.981 --> 00:02:52.366 of some of these thoughts.

NOTE Confidence: 0.930034288888889
00:02:52.370 --> 00:02:54.687 So there are some learning objectives here.
NOTE Confidence: 0.930034288888889
00:02:54.690 --> 00:02:57.366 If hopefully this is a CME,
NOTE Confidence: 0.930034288888889
00:02:57.370 --> 00:02:59.342 so we'll we'll cover,
NOTE Confidence: 0.930034288888889
00:02:59.342 --> 00:03:00.328 you know,
NOTE Confidence: 0.930034288888889
00:03:00.330 --> 00:03:01.735 some aspects of natural language
NOTE Confidence: 0.930034288888889
00:03:01.735 --> 00:03:03.675 processing and how it can be used
NOTE Confidence: 0.930034288888889
00:03:03.675 --> 00:03:05.127 to get information out of EHR's,
NOTE Confidence: 0.930034288888889
00:03:05.130 --> 00:03:07.885 why we need formal representations
NOTE Confidence: 0.930034288888889
00:03:07.885 --> 00:03:09.538 for complex concepts.
NOTE Confidence: 0.930034288888889
00:03:09.540 --> 00:03:11.736 Such as systemic anti cancer therapy
NOTE Confidence: 0.930034288888889
00:03:11.736 --> 00:03:14.303 and then learning about how these these
NOTE Confidence: 0.930034288888889
00:03:14.303 --> 00:03:16.379 ideas went and propelled the COVID,
NOTE Confidence: 0.930034288888889
00:03:16.380 --> 00:03:19.578 the C19 registry.
NOTE Confidence: 0.930034288888889
00:03:19.580 --> 00:03:21.734 OK, so first of all, you know,
NOTE Confidence: 0.930034288888889
00:03:21.734 --> 00:03:22.994 probably everybody might be already
NOTE Confidence: 0.930034288888889

00:03:22.994 --> 00:03:24.260 familiar with these definitions,
NOTE Confidence: 0.930034288888889

00:03:24.260 --> 00:03:26.204 but I think it's always helpful to go over,
NOTE Confidence: 0.930034288888889

00:03:26.210 --> 00:03:27.946 you know, what is real world data,
NOTE Confidence: 0.930034288888889

00:03:27.950 --> 00:03:29.620 what is real world evidence.
NOTE Confidence: 0.930034288888889

00:03:29.620 --> 00:03:32.217 And you know, it's nebulous a little
NOTE Confidence: 0.930034288888889

00:03:32.217 --> 00:03:34.299 bit and depending on where you,
NOTE Confidence: 0.930034288888889

00:03:34.300 --> 00:03:35.684 you know, the, the resource you look at,
NOTE Confidence: 0.930034288888889

00:03:35.690 --> 00:03:37.460 you'll get a different definition.
NOTE Confidence: 0.930034288888889

00:03:37.460 --> 00:03:38.760 But this is my definition,
NOTE Confidence: 0.930034288888889

00:03:38.760 --> 00:03:41.250 which is really based on something
NOTE Confidence: 0.930034288888889

00:03:41.250 --> 00:03:43.660 called the I kW pyramid.
NOTE Confidence: 0.930034288888889

00:03:43.660 --> 00:03:45.580 Has anybody heard about this?
NOTE Confidence: 0.930034288888889

00:03:45.580 --> 00:03:47.056 Heard of the DKW? OK great.
NOTE Confidence: 0.930034288888889

00:03:47.060 --> 00:03:48.726 So teach you a little bit here.
NOTE Confidence: 0.930034288888889

00:03:48.730 --> 00:03:51.850 So the idea here is that it's a
NOTE Confidence: 0.930034288888889

00:03:51.850 --> 00:03:53.975 pyramid where you're climbing a

NOTE Confidence: 0.930034288888889
00:03:53.980 --> 00:03:57.179 levels here from a base of data.
NOTE Confidence: 0.930034288888889
00:03:57.180 --> 00:03:58.640 The next step is information.
NOTE Confidence: 0.930034288888889
00:03:58.640 --> 00:04:00.320 The next step is knowledge.
NOTE Confidence: 0.930034288888889
00:04:00.320 --> 00:04:01.360 The next step is wisdom.
NOTE Confidence: 0.930034288888889
00:04:01.360 --> 00:04:02.608 You'll know there's 5 levels here.
NOTE Confidence: 0.930034288888889
00:04:02.610 --> 00:04:04.938 There's a little tiny level at the top
NOTE Confidence: 0.930034288888889
00:04:04.938 --> 00:04:07.540 which some people use you for understanding.
NOTE Confidence: 0.930034288888889
00:04:07.540 --> 00:04:10.242 But basically the idea is no matter
NOTE Confidence: 0.930034288888889
00:04:10.242 --> 00:04:12.719 what where the data comes from.
NOTE Confidence: 0.930034288888889
00:04:12.720 --> 00:04:13.698 What it is,
NOTE Confidence: 0.930034288888889
00:04:13.698 --> 00:04:15.654 whether it's from a randomized control
NOTE Confidence: 0.930034288888889
00:04:15.654 --> 00:04:18.524 trial or case control registry,
NOTE Confidence: 0.930034288888889
00:04:18.524 --> 00:04:19.160 etcetera,
NOTE Confidence: 0.930034288888889
00:04:19.160 --> 00:04:21.020 the idea is that as you move up this pyramid,
NOTE Confidence: 0.930034288888889
00:04:21.020 --> 00:04:22.792 you're generating real-world evidence,
NOTE Confidence: 0.930034288888889

00:04:22.792 --> 00:04:26.130 whereas real world data is really that base.

NOTE Confidence: 0.930034288888889

00:04:26.130 --> 00:04:28.188 On the right here you see the

NOTE Confidence: 0.930034288888889

00:04:28.188 --> 00:04:30.167 the sort of traditional pyramid

NOTE Confidence: 0.930034288888889

00:04:30.167 --> 00:04:32.727 of of evidence based medicine.

NOTE Confidence: 0.930034288888889

00:04:32.730 --> 00:04:34.522 So if you look at this from another

NOTE Confidence: 0.930034288888889

00:04:34.522 --> 00:04:36.010 dimension kind of looking from above,

NOTE Confidence: 0.930034288888889

00:04:36.010 --> 00:04:39.069 when we think about cancer in particular,

NOTE Confidence: 0.884899444166667

00:04:39.070 --> 00:04:40.904 you know I think about sort of

NOTE Confidence: 0.884899444166667

00:04:40.904 --> 00:04:42.290 three big aspects of cancer,

NOTE Confidence: 0.884899444166667

00:04:42.290 --> 00:04:44.312 there's the genotype, the phenotype and

NOTE Confidence: 0.884899444166667

00:04:44.312 --> 00:04:46.469 then the environment and sort of for

NOTE Confidence: 0.884899444166667

00:04:46.469 --> 00:04:48.233 each of these you have these layers.

NOTE Confidence: 0.884899444166667

00:04:48.240 --> 00:04:49.899 So, so if you think about the

NOTE Confidence: 0.884899444166667

00:04:49.899 --> 00:04:51.705 data level for genotype that might

NOTE Confidence: 0.884899444166667

00:04:51.705 --> 00:04:53.425 that's just the sequence right,

NOTE Confidence: 0.884899444166667

00:04:53.430 --> 00:04:55.870 just the somatic tumor sequence.

NOTE Confidence: 0.884899444166667
00:04:55.870 --> 00:04:56.932 For phenotype,
NOTE Confidence: 0.884899444166667
00:04:56.932 --> 00:05:00.649 it might be just a histologic type,
NOTE Confidence: 0.884899444166667
00:05:00.650 --> 00:05:03.149 a cell, you know what, what is that?
NOTE Confidence: 0.884899444166667
00:05:03.149 --> 00:05:04.148 And for environment,
NOTE Confidence: 0.884899444166667
00:05:04.150 --> 00:05:05.070 it might be pollutant levels.
NOTE Confidence: 0.884899444166667
00:05:05.070 --> 00:05:06.010 Now this is data,
NOTE Confidence: 0.884899444166667
00:05:06.010 --> 00:05:07.910 but it's not really telling you anything,
NOTE Confidence: 0.884899444166667
00:05:07.910 --> 00:05:08.118 right.
NOTE Confidence: 0.884899444166667
00:05:08.118 --> 00:05:10.450 So we need to kind of walk up this pyramid.
NOTE Confidence: 0.884899444166667
00:05:10.450 --> 00:05:12.730 The next level for for these three buckets
NOTE Confidence: 0.884899444166667
00:05:12.730 --> 00:05:14.978 would be for genotype and environment.
NOTE Confidence: 0.884899444166667
00:05:14.980 --> 00:05:16.610 You might talk about pathogenicity.
NOTE Confidence: 0.884899444166667
00:05:16.610 --> 00:05:19.790 What does that change mean in terms of is it,
NOTE Confidence: 0.884899444166667
00:05:19.790 --> 00:05:21.430 is it a driver mutation?
NOTE Confidence: 0.884899444166667
00:05:21.430 --> 00:05:24.202 That's sort of the next level information
NOTE Confidence: 0.884899444166667

00:05:24.202 --> 00:05:26.390 cancer behavior on the phenotype.
NOTE Confidence: 0.884899444166667

00:05:26.390 --> 00:05:27.766 Side so is it,
NOTE Confidence: 0.884899444166667

00:05:27.766 --> 00:05:28.798 is it aggressive,
NOTE Confidence: 0.884899444166667

00:05:28.800 --> 00:05:30.696 is it a high grade malignancy
NOTE Confidence: 0.884899444166667

00:05:30.696 --> 00:05:32.560 or is it something indolent
NOTE Confidence: 0.884899444166667

00:05:32.560 --> 00:05:34.820 kind of stepping up further?
NOTE Confidence: 0.884899444166667

00:05:34.820 --> 00:05:36.236 For genotype knowledge,
NOTE Confidence: 0.884899444166667

00:05:36.236 --> 00:05:38.596 the knowledge level is actionability.
NOTE Confidence: 0.884899444166667

00:05:38.600 --> 00:05:41.260 What can you do with this information?
NOTE Confidence: 0.884899444166667

00:05:41.260 --> 00:05:43.619 Can can you actually prescribe a medication
NOTE Confidence: 0.884899444166667

00:05:43.619 --> 00:05:46.149 that will change the outcome for a patient?
NOTE Confidence: 0.884899444166667

00:05:46.150 --> 00:05:46.412 Phenotype,
NOTE Confidence: 0.884899444166667

00:05:46.412 --> 00:05:46.674 same,
NOTE Confidence: 0.884899444166667

00:05:46.674 --> 00:05:47.198 you know,
NOTE Confidence: 0.884899444166667

00:05:47.198 --> 00:05:48.508 just generally speaking what are
NOTE Confidence: 0.884899444166667

00:05:48.508 --> 00:05:50.301 the treatment options and then the

NOTE Confidence: 0.884899444166667
00:05:50.301 --> 00:05:51.781 environment are there risk modifications
NOTE Confidence: 0.884899444166667
00:05:51.825 --> 00:05:53.253 that can be taken and then really
NOTE Confidence: 0.884899444166667
00:05:53.253 --> 00:05:55.055 getting to that top level wisdom,
NOTE Confidence: 0.884899444166667
00:05:55.055 --> 00:05:57.425 you know this is this is
NOTE Confidence: 0.884899444166667
00:05:57.425 --> 00:05:59.190 really complicated now.
NOTE Confidence: 0.884899444166667
00:05:59.190 --> 00:06:00.972 So in in phenotype you're thinking
NOTE Confidence: 0.884899444166667
00:06:00.972 --> 00:06:02.552 about what are patient values
NOTE Confidence: 0.884899444166667
00:06:02.552 --> 00:06:04.556 and preferences and how do those
NOTE Confidence: 0.884899444166667
00:06:04.556 --> 00:06:05.951 influence what treatment options
NOTE Confidence: 0.884899444166667
00:06:05.951 --> 00:06:07.582 you might consider for genotype,
NOTE Confidence: 0.884899444166667
00:06:07.582 --> 00:06:09.724 what's the tumor going to do once
NOTE Confidence: 0.884899444166667
00:06:09.724 --> 00:06:11.747 it gets exposed to treatments,
NOTE Confidence: 0.884899444166667
00:06:11.750 --> 00:06:13.311 how is it going to evolve under
NOTE Confidence: 0.884899444166667
00:06:13.311 --> 00:06:14.584 treatment pressure and an environment
NOTE Confidence: 0.884899444166667
00:06:14.584 --> 00:06:16.258 you've got issues about social justice.
NOTE Confidence: 0.884899444166667

00:06:16.260 --> 00:06:16.989 And structural racism.
NOTE Confidence: 0.884899444166667

00:06:16.989 --> 00:06:18.690 So those are all kind of like.
NOTE Confidence: 0.884899444166667

00:06:18.690 --> 00:06:20.629 The ideas of climbing this pyramid alright,
NOTE Confidence: 0.884899444166667

00:06:20.630 --> 00:06:21.810 hopefully I've convinced you
NOTE Confidence: 0.884899444166667

00:06:21.810 --> 00:06:23.285 the difference between data and
NOTE Confidence: 0.884899444166667

00:06:23.285 --> 00:06:24.570 evidence as we kind of step up.
NOTE Confidence: 0.884899444166667

00:06:24.570 --> 00:06:27.634 Now, why do we need this real-world evidence?
NOTE Confidence: 0.884899444166667

00:06:27.640 --> 00:06:30.120 Well, clinical trials are wonderful,
NOTE Confidence: 0.884899444166667

00:06:30.120 --> 00:06:31.832 but they're also expensive,
NOTE Confidence: 0.884899444166667

00:06:31.832 --> 00:06:34.545 slow to conduct, and they don't
NOTE Confidence: 0.884899444166667

00:06:34.545 --> 00:06:36.920 always represent the full population.
NOTE Confidence: 0.884899444166667

00:06:36.920 --> 00:06:39.612 At risk also trials,
NOTE Confidence: 0.884899444166667

00:06:39.612 --> 00:06:40.958 prospective trials,
NOTE Confidence: 0.884899444166667

00:06:40.960 --> 00:06:43.852 collect some but not all potentially
NOTE Confidence: 0.884899444166667

00:06:43.852 --> 00:06:44.816 pertinent information.
NOTE Confidence: 0.884899444166667

00:06:44.820 --> 00:06:46.100 And our space is huge.

NOTE Confidence: 0.884899444166667
00:06:46.100 --> 00:06:46.466 Oncology,
NOTE Confidence: 0.884899444166667
00:06:46.466 --> 00:06:49.028 the treatment space and oncology is huge.
NOTE Confidence: 0.884899444166667
00:06:49.030 --> 00:06:49.672 And then lastly,
NOTE Confidence: 0.884899444166667
00:06:49.672 --> 00:06:51.492 I think last but not least is that
NOTE Confidence: 0.884899444166667
00:06:51.492 --> 00:06:53.124 we've got this enormous data source,
NOTE Confidence: 0.884899444166667
00:06:53.130 --> 00:06:55.776 which is the electronic medical record.
NOTE Confidence: 0.884899444166667
00:06:55.780 --> 00:06:57.026 So just a few words about each
NOTE Confidence: 0.884899444166667
00:06:57.026 --> 00:06:57.560 of these items.
NOTE Confidence: 0.884899444166667
00:06:57.560 --> 00:06:58.860 So when you think about
NOTE Confidence: 0.884899444166667
00:06:58.860 --> 00:06:59.640 trials and disparities,
NOTE Confidence: 0.884899444166667
00:06:59.640 --> 00:07:02.454 this is a paper we just published
NOTE Confidence: 0.884899444166667
00:07:02.460 --> 00:07:05.808 very recently and this one was
NOTE Confidence: 0.884899444166667
00:07:05.808 --> 00:07:06.864 earlier this year and we just
NOTE Confidence: 0.884899444166667
00:07:06.864 --> 00:07:07.904 published another one in Jim
NOTE Confidence: 0.884899444166667
00:07:07.904 --> 00:07:08.939 Oncology looking at prostate cancer.
NOTE Confidence: 0.884899444166667

00:07:08.940 --> 00:07:10.992 This one looks at immune checkpoint
NOTE Confidence: 0.884899444166667

00:07:10.992 --> 00:07:12.018 inhibitors across cancers.
NOTE Confidence: 0.884899444166667

00:07:12.020 --> 00:07:14.358 And basically the take home message here
NOTE Confidence: 0.884899444166667

00:07:14.360 --> 00:07:16.075 is that when you look across Childs,
NOTE Confidence: 0.884899444166667

00:07:16.080 --> 00:07:19.636 there is really a lot of disparity
NOTE Confidence: 0.884899444166667

00:07:19.636 --> 00:07:22.299 in who enrolls in trials.
NOTE Confidence: 0.884899444166667

00:07:22.300 --> 00:07:24.556 And it can be different by cancer type,
NOTE Confidence: 0.915224604285714

00:07:24.560 --> 00:07:26.940 but it's pretty consistent across the board.
NOTE Confidence: 0.915224604285714

00:07:26.940 --> 00:07:28.760 And it's not always underrepresentation.
NOTE Confidence: 0.915224604285714

00:07:28.760 --> 00:07:29.908 Sometimes it's over representation,
NOTE Confidence: 0.915224604285714

00:07:29.908 --> 00:07:32.220 as you can see from the bottom row.
NOTE Confidence: 0.915224604285714

00:07:32.220 --> 00:07:35.314 But you know, essentially the yellow ones,
NOTE Confidence: 0.915224604285714

00:07:35.320 --> 00:07:40.210 the yellow circles are intersections of,
NOTE Confidence: 0.915224604285714

00:07:40.210 --> 00:07:43.600 in this case, gender, age,
NOTE Confidence: 0.915224604285714

00:07:43.600 --> 00:07:46.218 race and ethnicity, and a cancer type
NOTE Confidence: 0.915224604285714

00:07:46.218 --> 00:07:48.640 where the enrollment is as you'd expect.

NOTE Confidence: 0.915224604285714
00:07:48.640 --> 00:07:50.296 If it's green, it's sort of more than
NOTE Confidence: 0.915224604285714
00:07:50.296 --> 00:07:52.240 you'd expect, and if it's red, it's.
NOTE Confidence: 0.915224604285714
00:07:52.240 --> 00:07:53.360 It's less than you'd expect.
NOTE Confidence: 0.915224604285714
00:07:53.360 --> 00:07:55.230 So. So you know this,
NOTE Confidence: 0.915224604285714
00:07:55.230 --> 00:07:57.270 this gets that generalizability and there
NOTE Confidence: 0.915224604285714
00:07:57.270 --> 00:07:59.289 might be statistical ways around this,
NOTE Confidence: 0.915224604285714
00:07:59.290 --> 00:08:03.298 but you know, essentially.
NOTE Confidence: 0.915224604285714
00:08:03.300 --> 00:08:05.355 Our knowledge from clinical trials
NOTE Confidence: 0.915224604285714
00:08:05.355 --> 00:08:08.082 is primarily coming from younger.
NOTE Confidence: 0.915224604285714
00:08:08.082 --> 00:08:12.410 White men, OK, so.
NOTE Confidence: 0.915224604285714
00:08:12.410 --> 00:08:14.386 How about the information that gets left out?
NOTE Confidence: 0.915224604285714
00:08:14.390 --> 00:08:16.700 So this is, this was amazing.
NOTE Confidence: 0.915224604285714
00:08:16.700 --> 00:08:18.674 This is the recovery group that
NOTE Confidence: 0.915224604285714
00:08:18.674 --> 00:08:20.679 really geared up during the early
NOTE Confidence: 0.915224604285714
00:08:20.679 --> 00:08:22.863 days of the COVID pandemic and found,
NOTE Confidence: 0.915224604285714

00:08:22.870 --> 00:08:23.572 you know,
NOTE Confidence: 0.915224604285714

00:08:23.572 --> 00:08:25.678 pragmatic trials that they ran in
NOTE Confidence: 0.915224604285714

00:08:25.678 --> 00:08:28.743 the UK and they found some really
NOTE Confidence: 0.915224604285714

00:08:28.743 --> 00:08:31.028 important treatment options for COVID.
NOTE Confidence: 0.915224604285714

00:08:31.030 --> 00:08:32.278 This is one of their papers.
NOTE Confidence: 0.915224604285714

00:08:32.280 --> 00:08:35.388 This is probably the most impactful look,
NOTE Confidence: 0.915224604285714

00:08:35.390 --> 00:08:37.554 showing that dexamethasone could
NOTE Confidence: 0.915224604285714

00:08:37.554 --> 00:08:40.259 help hospitalize patients with COVID.
NOTE Confidence: 0.915224604285714

00:08:40.260 --> 00:08:43.148 And I've excerpted a table from that paper.
NOTE Confidence: 0.860007212

00:08:45.270 --> 00:08:46.190 Take a minute and let.
NOTE Confidence: 0.860007212

00:08:46.190 --> 00:08:47.750 So what's missing from this table?
NOTE Confidence: 0.860007212

00:08:47.750 --> 00:08:49.731 So this is a table of previous
NOTE Confidence: 0.860007212

00:08:49.731 --> 00:08:50.933 coexisting diseases in the
NOTE Confidence: 0.860007212

00:08:50.933 --> 00:08:52.129 patients who have COVID.
NOTE Confidence: 0.860007212

00:08:52.130 --> 00:08:54.658 Is there something missing?
NOTE Confidence: 0.860007212

00:08:54.660 --> 00:08:55.659 From this table.

NOTE Confidence: 0.867837141428571
00:08:58.170 --> 00:09:02.237 Something that's the topic of this talk.
NOTE Confidence: 0.867837141428571
00:09:02.240 --> 00:09:03.114 Cancer, right.
NOTE Confidence: 0.867837141428571
00:09:03.114 --> 00:09:05.736 There's no cancer in the stable.
NOTE Confidence: 0.867837141428571
00:09:05.740 --> 00:09:07.426 They did not collect cancer and
NOTE Confidence: 0.867837141428571
00:09:07.426 --> 00:09:09.170 and or they didn't report it.
NOTE Confidence: 0.867837141428571
00:09:09.170 --> 00:09:11.319 Well, we actually, we actually went and
NOTE Confidence: 0.867837141428571
00:09:11.319 --> 00:09:13.718 you know got their case report forms,
NOTE Confidence: 0.867837141428571
00:09:13.720 --> 00:09:14.816 they didn't record cancer.
NOTE Confidence: 0.867837141428571
00:09:14.816 --> 00:09:16.830 So here they enrolled 10s of thousands
NOTE Confidence: 0.867837141428571
00:09:16.830 --> 00:09:18.410 of patients in these trials.
NOTE Confidence: 0.867837141428571
00:09:18.410 --> 00:09:19.970 And they don't know if these
NOTE Confidence: 0.867837141428571
00:09:19.970 --> 00:09:21.270 patients had cancer or not.
NOTE Confidence: 0.867837141428571
00:09:21.270 --> 00:09:23.130 And so I mean, amazing work,
NOTE Confidence: 0.867837141428571
00:09:23.130 --> 00:09:26.834 but we're missing a key piece of information.
NOTE Confidence: 0.867837141428571
00:09:26.840 --> 00:09:29.036 And then sort of the last item you know
NOTE Confidence: 0.867837141428571

00:09:29.036 --> 00:09:31.141 that I met that I mentioned before is
NOTE Confidence: 0.867837141428571

00:09:31.141 --> 00:09:33.890 that this idea that our treatment space
NOTE Confidence: 0.867837141428571

00:09:33.890 --> 00:09:36.121 is huge but head-to-head comparisons
NOTE Confidence: 0.867837141428571

00:09:36.121 --> 00:09:39.079 of important drugs are mostly absent.
NOTE Confidence: 0.867837141428571

00:09:39.080 --> 00:09:41.075 And I'll just give you one example.
NOTE Confidence: 0.867837141428571

00:09:41.080 --> 00:09:43.768 So this is the space of PD1 inhibitors
NOTE Confidence: 0.867837141428571

00:09:43.768 --> 00:09:46.341 which have changed our obviously changed
NOTE Confidence: 0.867837141428571

00:09:46.341 --> 00:09:48.436 our fields from our hemac knowledge
NOTE Confidence: 0.867837141428571

00:09:48.436 --> 00:09:50.820 base which I'll talk about a bit later.
NOTE Confidence: 0.867837141428571

00:09:50.820 --> 00:09:54.604 We have 137 trials that have been published
NOTE Confidence: 0.867837141428571

00:09:54.604 --> 00:09:57.246 using 64 different regimens of of various.
NOTE Confidence: 0.867837141428571

00:09:57.250 --> 00:09:58.064 81 inhibitors.
NOTE Confidence: 0.867837141428571

00:09:58.064 --> 00:10:00.506 This includes XUS by the way.
NOTE Confidence: 0.867837141428571

00:10:00.510 --> 00:10:02.182 If you're like they're not 13 P you
NOTE Confidence: 0.867837141428571

00:10:02.182 --> 00:10:03.830 want to have actually there are,
NOTE Confidence: 0.867837141428571

00:10:03.830 --> 00:10:06.809 but many of those are only approved in China.

NOTE Confidence: 0.867837141428571
00:10:06.810 --> 00:10:10.666 So 83 of those are phase three trials.
NOTE Confidence: 0.867837141428571
00:10:10.670 --> 00:10:13.878 Take home point is one of those 83
NOTE Confidence: 0.867837141428571
00:10:13.878 --> 00:10:15.825 actually compared to PD1 inhibitor
NOTE Confidence: 0.867837141428571
00:10:15.825 --> 00:10:18.879 to a PDL 1 inhibitor kind of it
NOTE Confidence: 0.867837141428571
00:10:18.879 --> 00:10:21.417 actually compared to Kobe matanov and
NOTE Confidence: 0.867837141428571
00:10:21.417 --> 00:10:23.437 atezolizumab and that's grand total
NOTE Confidence: 0.867837141428571
00:10:23.437 --> 00:10:26.144 of zero of these trials compared 1PD1
NOTE Confidence: 0.867837141428571
00:10:26.144 --> 00:10:28.628 inhibitor to another PD1 inhibitor so.
NOTE Confidence: 0.867837141428571
00:10:28.630 --> 00:10:29.068 You know,
NOTE Confidence: 0.867837141428571
00:10:29.068 --> 00:10:30.601 maybe I'm missing some trials that are
NOTE Confidence: 0.867837141428571
00:10:30.601 --> 00:10:32.190 ongoing now that have yet to be published.
NOTE Confidence: 0.867837141428571
00:10:32.190 --> 00:10:34.026 But at this point in time,
NOTE Confidence: 0.867837141428571
00:10:34.030 --> 00:10:37.225 we don't have any data at all on whether
NOTE Confidence: 0.867837141428571
00:10:37.230 --> 00:10:39.702 1PD1 inhibitor is better than another
NOTE Confidence: 0.867837141428571
00:10:39.702 --> 00:10:42.162 except for indirect treatment comparisons,
NOTE Confidence: 0.867837141428571

00:10:42.162 --> 00:10:42.706 so.
NOTE Confidence: 0.867837141428571

00:10:42.706 --> 00:10:45.426 Hopefully I've convinced you that.
NOTE Confidence: 0.867837141428571

00:10:45.430 --> 00:10:47.180 We should at least think
NOTE Confidence: 0.867837141428571

00:10:47.180 --> 00:10:48.580 about using real-world data.
NOTE Confidence: 0.867837141428571

00:10:48.580 --> 00:10:49.164 But.
NOTE Confidence: 0.867837141428571

00:10:49.164 --> 00:10:50.916 They are messy,
NOTE Confidence: 0.867837141428571

00:10:50.916 --> 00:10:52.668 ambiguous and unpredictable.
NOTE Confidence: 0.867837141428571

00:10:52.670 --> 00:10:54.777 So let me talk about some some
NOTE Confidence: 0.867837141428571

00:10:54.777 --> 00:10:56.702 challenges that we have once we
NOTE Confidence: 0.867837141428571

00:10:56.702 --> 00:10:58.622 start delving into the real world.
NOTE Confidence: 0.867837141428571

00:10:58.630 --> 00:11:01.250 So first of all.
NOTE Confidence: 0.867837141428571

00:11:01.250 --> 00:11:04.568 This is real-world data from the Medline.
NOTE Confidence: 0.918139125882353

00:11:06.670 --> 00:11:07.670 Institution information.
NOTE Confidence: 0.918139125882353

00:11:07.670 --> 00:11:12.283 OK, so did you know that there were 21
NOTE Confidence: 0.918139125882353

00:11:12.283 --> 00:11:15.427 clinical trial institutions in New Haven?
NOTE Confidence: 0.918139125882353

00:11:15.430 --> 00:11:16.450 Did you know that?

NOTE Confidence: 0.918139125882353
00:11:16.450 --> 00:11:19.368 That's amazing, right? Here they are.
NOTE Confidence: 0.918139125882353
00:11:19.368 --> 00:11:22.860 Smilow Cancer Center, Smilow Cancer Hospital,
NOTE Confidence: 0.918139125882353
00:11:22.860 --> 00:11:25.660 smilow cancer hospital at Yale,
NOTE Confidence: 0.918139125882353
00:11:25.660 --> 00:11:27.838 Smilow Cancer Hospital at Yale University,
NOTE Confidence: 0.918139125882353
00:11:27.840 --> 00:11:30.030 Yale Cancer Center.
NOTE Confidence: 0.918139125882353
00:11:30.030 --> 00:11:32.172 Yale Cancer Center and Smilow Cancer
NOTE Confidence: 0.918139125882353
00:11:32.172 --> 00:11:33.412 Hospital, Yale Medical school.
NOTE Confidence: 0.918139125882353
00:11:33.412 --> 00:11:35.838 Alright, I think you get the idea, right?
NOTE Confidence: 0.918139125882353
00:11:35.838 --> 00:11:38.414 So I mean this is real world.
NOTE Confidence: 0.918139125882353
00:11:38.420 --> 00:11:39.848 I mean you have to do something.
NOTE Confidence: 0.918139125882353
00:11:39.850 --> 00:11:41.479 I mean, a computer is not going to know,
NOTE Confidence: 0.918139125882353
00:11:41.480 --> 00:11:42.479 right? I mean,
NOTE Confidence: 0.918139125882353
00:11:42.479 --> 00:11:46.277 so if you want to use this data in some way,
NOTE Confidence: 0.918139125882353
00:11:46.280 --> 00:11:47.936 someone's got to do some work
NOTE Confidence: 0.918139125882353
00:11:47.936 --> 00:11:49.370 to actually fix this, right?
NOTE Confidence: 0.918139125882353

00:11:49.370 --> 00:11:51.680 That is a big part of working
NOTE Confidence: 0.918139125882353

00:11:51.680 --> 00:11:53.209 with real world data.
NOTE Confidence: 0.918139125882353

00:11:53.210 --> 00:11:54.610 Yale New Haven hospital.
NOTE Confidence: 0.918139125882353

00:11:54.610 --> 00:11:57.840 There's the 21st, OK?
NOTE Confidence: 0.918139125882353

00:11:57.840 --> 00:11:59.600 OK. So how about,
NOTE Confidence: 0.918139125882353

00:11:59.600 --> 00:12:01.920 so that's bibliometrics to some degree,
NOTE Confidence: 0.918139125882353

00:12:01.920 --> 00:12:03.000 how about treatments,
NOTE Confidence: 0.918139125882353

00:12:03.000 --> 00:12:05.388 how many tyrosine kinase
NOTE Confidence: 0.918139125882353

00:12:05.388 --> 00:12:07.179 inhibitors are there?
NOTE Confidence: 0.918139125882353

00:12:07.180 --> 00:12:10.212 And so this is a little project that
NOTE Confidence: 0.918139125882353

00:12:10.212 --> 00:12:13.170 a student of mine undertook where they
NOTE Confidence: 0.918139125882353

00:12:13.170 --> 00:12:15.655 mapped out how many letters you'd have
NOTE Confidence: 0.918139125882353

00:12:15.655 --> 00:12:18.536 to switch around or basically misspell.
NOTE Confidence: 0.918139125882353

00:12:18.540 --> 00:12:21.024 So that one tyrosine kinase inhibitor
NOTE Confidence: 0.918139125882353

00:12:21.024 --> 00:12:23.010 would actually be another one.
NOTE Confidence: 0.918139125882353

00:12:23.010 --> 00:12:25.440 And so it's it's fewer letters

NOTE Confidence: 0.918139125882353
00:12:25.440 --> 00:12:27.085 than you think and.
NOTE Confidence: 0.918139125882353
00:12:27.085 --> 00:12:29.635 You know, these drugs get misspelled
NOTE Confidence: 0.918139125882353
00:12:29.635 --> 00:12:33.550 all the time in a pretty amazing ways.
NOTE Confidence: 0.918139125882353
00:12:33.550 --> 00:12:34.410 I see that the net,
NOTE Confidence: 0.918139125882353
00:12:34.410 --> 00:12:35.586 there's a little bit of formatting
NOTE Confidence: 0.918139125882353
00:12:35.586 --> 00:12:38.480 issue with the next slide, but.
NOTE Confidence: 0.918139125882353
00:12:38.480 --> 00:12:42.968 So this this is real data.
NOTE Confidence: 0.918139125882353
00:12:42.970 --> 00:12:45.114 From the Vanderbilt University
NOTE Confidence: 0.918139125882353
00:12:45.114 --> 00:12:46.186 Medical Center.
NOTE Confidence: 0.918139125882353
00:12:46.190 --> 00:12:49.234 So this is from our text list of medications.
NOTE Confidence: 0.918139125882353
00:12:49.234 --> 00:12:50.824 Now you might say, oh,
NOTE Confidence: 0.918139125882353
00:12:50.824 --> 00:12:51.920 let's just, you know,
NOTE Confidence: 0.918139125882353
00:12:51.920 --> 00:12:53.248 we've got to be able to get these
NOTE Confidence: 0.918139125882353
00:12:53.248 --> 00:12:54.149 medications from structured data.
NOTE Confidence: 0.918139125882353
00:12:54.150 --> 00:12:55.949 That may or may not be true.
NOTE Confidence: 0.918139125882353

00:12:55.950 --> 00:12:58.326 It depends. We can talk more about that.

NOTE Confidence: 0.918139125882353

00:12:58.330 --> 00:12:59.600 But these are real misspellings

NOTE Confidence: 0.918139125882353

00:12:59.600 --> 00:13:01.070 of the drug or Latino BI.

NOTE Confidence: 0.918139125882353

00:13:01.070 --> 00:13:02.834 Think you can tell looking at this

NOTE Confidence: 0.918139125882353

00:13:02.834 --> 00:13:04.966 that all of these are or lot in him.

NOTE Confidence: 0.918139125882353

00:13:04.970 --> 00:13:05.574 But again,

NOTE Confidence: 0.918139125882353

00:13:05.574 --> 00:13:08.332 I mean if you don't have some sort of

NOTE Confidence: 0.918139125882353

00:13:08.332 --> 00:13:12.210 system to harmonize all those misspellings.

NOTE Confidence: 0.918139125882353

00:13:12.210 --> 00:13:13.440 You're not going to know

NOTE Confidence: 0.918139125882353

00:13:13.440 --> 00:13:14.670 which patient got what drug.

NOTE Confidence: 0.918139125882353

00:13:14.670 --> 00:13:15.058 So.

NOTE Confidence: 0.918139125882353

00:13:15.058 --> 00:13:17.828 So that's you know, that's a real

NOTE Confidence: 0.918139125882353

00:13:17.828 --> 00:13:20.264 world issue with real world data.

NOTE Confidence: 0.918139125882353

00:13:20.270 --> 00:13:21.999 This is work that we did some

NOTE Confidence: 0.918139125882353

00:13:21.999 --> 00:13:23.270 years ago on staging,

NOTE Confidence: 0.918139125882353

00:13:23.270 --> 00:13:26.438 so cancer staging.

NOTE Confidence: 0.918139125882353
00:13:26.440 --> 00:13:29.807 Here is what I call manageable ambiguity.
NOTE Confidence: 0.918139125882353
00:13:29.810 --> 00:13:31.530 All right,
NOTE Confidence: 0.918139125882353
00:13:31.530 --> 00:13:32.390 so.
NOTE Confidence: 0.918139125882353
00:13:32.390 --> 00:13:33.824 And again and and maybe you
NOTE Confidence: 0.918139125882353
00:13:33.824 --> 00:13:35.136 know during sort of discussion
NOTE Confidence: 0.918139125882353
00:13:35.136 --> 00:13:37.236 we can talk about the value of
NOTE Confidence: 0.918139125882353
00:13:37.236 --> 00:13:38.809 structured versus unstructured data,
NOTE Confidence: 0.918139125882353
00:13:38.810 --> 00:13:41.402 but the idea here is that we would
NOTE Confidence: 0.918139125882353
00:13:41.402 --> 00:13:43.646 take data from progress notes from
NOTE Confidence: 0.918139125882353
00:13:43.646 --> 00:13:46.040 clinical text to all these notes.
NOTE Confidence: 0.918139125882353
00:13:46.040 --> 00:13:48.800 And figure out if a patient had stage
NOTE Confidence: 0.918139125882353
00:13:48.800 --> 00:13:51.075 123 or four. So just forget ABC.
NOTE Confidence: 0.918139125882353
00:13:51.080 --> 00:13:55.337 We're just trying to go for the big stages.
NOTE Confidence: 0.918139125882353
00:13:55.340 --> 00:13:56.048 And you know,
NOTE Confidence: 0.918139125882353
00:13:56.048 --> 00:13:57.700 the problem that we knew ahead of
NOTE Confidence: 0.918139125882353

00:13:57.755 --> 00:13:59.512 time is that these things are going
NOTE Confidence: 0.918139125882353

00:13:59.512 --> 00:14:01.294 to be recorded variably in different
NOTE Confidence: 0.918139125882353

00:14:01.294 --> 00:14:03.238 notes by different types of doctors.
NOTE Confidence: 0.918139125882353

00:14:03.240 --> 00:14:05.508 But you know we did a pilot
NOTE Confidence: 0.918139125882353

00:14:05.508 --> 00:14:07.439 with about 1000 patients with
NOTE Confidence: 0.918139125882353

00:14:07.439 --> 00:14:09.652 lung cancer with over 460,000
NOTE Confidence: 0.918139125882353

00:14:09.652 --> 00:14:11.460 clinical documents across them.
NOTE Confidence: 0.918139125882353

00:14:11.460 --> 00:14:13.950 Now if you pause for a minute and you think
NOTE Confidence: 0.886603504545454

00:14:14.012 --> 00:14:15.188 about. A chart review.
NOTE Confidence: 0.886603504545454

00:14:15.188 --> 00:14:17.650 Think about how long it would take you to
NOTE Confidence: 0.886603504545454

00:14:17.650 --> 00:14:19.748 go through 460,000 documents, right so.
NOTE Confidence: 0.886603504545454

00:14:19.748 --> 00:14:21.783 Here's my pitch for natural
NOTE Confidence: 0.886603504545454

00:14:21.783 --> 00:14:22.950 language processing.
NOTE Confidence: 0.886603504545454

00:14:22.950 --> 00:14:25.519 You can actually automate this kind of
NOTE Confidence: 0.886603504545454

00:14:25.519 --> 00:14:30.164 thing and and do this kind of work at scale.
NOTE Confidence: 0.886603504545454

00:14:30.170 --> 00:14:34.553 So cutting to the chase a little bit here.

NOTE Confidence: 0.886603504545454

00:14:34.560 --> 00:14:36.216 First of all, we found that

NOTE Confidence: 0.886603504545454

00:14:36.216 --> 00:14:37.996 out of those 964 patients,

NOTE Confidence: 0.886603504545454

00:14:37.996 --> 00:14:41.307 99% had some kind of stage freeze

NOTE Confidence: 0.886603504545454

00:14:41.307 --> 00:14:44.888 in their note. At least one.

NOTE Confidence: 0.886603504545454

00:14:44.890 --> 00:14:46.605 And we also had a gold standard

NOTE Confidence: 0.886603504545454

00:14:46.605 --> 00:14:48.488 which was the tumor registry data.

NOTE Confidence: 0.886603504545454

00:14:48.490 --> 00:14:50.788 So we were able to compare

NOTE Confidence: 0.886603504545454

00:14:50.788 --> 00:14:53.390 our system to to the subset.

NOTE Confidence: 0.886603504545454

00:14:53.390 --> 00:14:55.550 You'll notice only 790 out of

NOTE Confidence: 0.886603504545454

00:14:55.550 --> 00:14:57.270 those 964 had tumor registry data,

NOTE Confidence: 0.886603504545454

00:14:57.270 --> 00:15:00.030 but we were able to do a comparison and you

NOTE Confidence: 0.886603504545454

00:15:00.094 --> 00:15:02.789 know our system worked really pretty well.

NOTE Confidence: 0.886603504545454

00:15:02.790 --> 00:15:03.682 The green, you know,

NOTE Confidence: 0.886603504545454

00:15:03.682 --> 00:15:05.320 basically the matches are in the green,

NOTE Confidence: 0.886603504545454

00:15:05.320 --> 00:15:07.669 the big numbers and we got some things wrong,

NOTE Confidence: 0.886603504545454

00:15:07.670 --> 00:15:09.524 but we didn't usually get things

NOTE Confidence: 0.886603504545454

00:15:09.524 --> 00:15:11.350 really wrong most of the time.

NOTE Confidence: 0.886603504545454

00:15:11.350 --> 00:15:12.346 So if it was stage one,

NOTE Confidence: 0.886603504545454

00:15:12.350 --> 00:15:13.442 we called stage four,

NOTE Confidence: 0.886603504545454

00:15:13.442 --> 00:15:14.807 that was a big mistake.

NOTE Confidence: 0.886603504545454

00:15:14.810 --> 00:15:15.830 Only happened once.

NOTE Confidence: 0.92679775

00:15:18.610 --> 00:15:22.026 This, this shows actually,

NOTE Confidence: 0.92679775

00:15:22.026 --> 00:15:23.862 so again 460,000 documents.

NOTE Confidence: 0.92679775

00:15:23.862 --> 00:15:26.284 So what we wanted to say is.

NOTE Confidence: 0.92679775

00:15:26.290 --> 00:15:28.082 And you have to look at all

NOTE Confidence: 0.92679775

00:15:28.082 --> 00:15:30.241 of those or can you just look

NOTE Confidence: 0.92679775

00:15:30.241 --> 00:15:31.886 at notes that were written?

NOTE Confidence: 0.92679775

00:15:31.890 --> 00:15:33.666 Right after a patient was diagnosed

NOTE Confidence: 0.92679775

00:15:33.666 --> 00:15:35.831 you know with if you think of

NOTE Confidence: 0.92679775

00:15:35.831 --> 00:15:37.673 some of this inspiration for this

NOTE Confidence: 0.92679775

00:15:37.673 --> 00:15:39.294 project came from the copi measures.

NOTE Confidence: 0.92679775

00:15:39.294 --> 00:15:41.310 And if any of you have done that work

NOTE Confidence: 0.92679775

00:15:41.361 --> 00:15:42.933 you'll remember I believe and they

NOTE Confidence: 0.92679775

00:15:42.933 --> 00:15:44.804 may have changed but at one point

NOTE Confidence: 0.92679775

00:15:44.804 --> 00:15:46.346 the coping measure was was stage

NOTE Confidence: 0.92679775

00:15:46.346 --> 00:15:48.212 recorded in one of the first two

NOTE Confidence: 0.92679775

00:15:48.212 --> 00:15:49.850 progress notes written after diagnosis.

NOTE Confidence: 0.92679775

00:15:49.850 --> 00:15:51.719 So it kind of makes sense that

NOTE Confidence: 0.92679775

00:15:51.719 --> 00:15:53.649 you would look for stage early on

NOTE Confidence: 0.92679775

00:15:53.650 --> 00:15:56.114 but if you look at this black line

NOTE Confidence: 0.92679775

00:15:56.114 --> 00:15:58.306 here at the bottom. So does this.

NOTE Confidence: 0.92679775

00:15:58.306 --> 00:15:59.234 Are you seeing my?

NOTE Confidence: 0.92679775

00:15:59.240 --> 00:16:00.666 You don't see the arrow, are you?

NOTE Confidence: 0.92679775

00:16:00.666 --> 00:16:02.705 I don't think you're seeing the error, OK.

NOTE Confidence: 0.92679775

00:16:02.705 --> 00:16:04.280 If you look at the black line

NOTE Confidence: 0.92679775

00:16:04.280 --> 00:16:05.761 towards the bottom, you'll see that.

NOTE Confidence: 0.92679775

00:16:05.761 --> 00:16:07.768 If you look at the the notes in the
NOTE Confidence: 0.92679775

00:16:07.768 --> 00:16:09.048 first five weeks from diagnosis,
NOTE Confidence: 0.92679775

00:16:09.050 --> 00:16:10.630 actually there's a pretty high
NOTE Confidence: 0.92679775

00:16:10.630 --> 00:16:11.894 rate of unknown stage.
NOTE Confidence: 0.92679775

00:16:11.900 --> 00:16:13.480 Like we couldn't determine it.
NOTE Confidence: 0.92679775

00:16:13.480 --> 00:16:15.265 It wasn't until we got to five
NOTE Confidence: 0.92679775

00:16:15.265 --> 00:16:17.255 weeks and out that we had enough
NOTE Confidence: 0.92679775

00:16:17.255 --> 00:16:18.995 mentions of stage that we could
NOTE Confidence: 0.92679775

00:16:19.000 --> 00:16:21.330 sort of make that determination.
NOTE Confidence: 0.92679775

00:16:21.330 --> 00:16:23.090 So we saw this kind of inflection point.
NOTE Confidence: 0.92679775

00:16:23.090 --> 00:16:24.740 And so that's another thing just
NOTE Confidence: 0.92679775

00:16:24.740 --> 00:16:26.624 to to note when you're working
NOTE Confidence: 0.92679775

00:16:26.624 --> 00:16:28.424 with real-world data is that,
NOTE Confidence: 0.92679775

00:16:28.430 --> 00:16:29.682 you know, time matters,
NOTE Confidence: 0.92679775

00:16:29.682 --> 00:16:31.247 time can matter a lot.
NOTE Confidence: 0.92679775

00:16:31.250 --> 00:16:32.826 And the other thing that really matters is,

NOTE Confidence: 0.92679775
00:16:32.830 --> 00:16:33.510 is ambiguity.
NOTE Confidence: 0.92679775
00:16:33.510 --> 00:16:35.550 So I mentioned we found stage
NOTE Confidence: 0.92679775
00:16:35.550 --> 00:16:37.374 in 99% of the records.
NOTE Confidence: 0.92679775
00:16:37.374 --> 00:16:39.600 What I didn't mention is that
NOTE Confidence: 0.92679775
00:16:39.681 --> 00:16:42.128 most of those are 84% had more
NOTE Confidence: 0.92679775
00:16:42.128 --> 00:16:44.444 than one stage in their records,
NOTE Confidence: 0.92679775
00:16:44.450 --> 00:16:47.964 OK and some some degree of discordance.
NOTE Confidence: 0.92679775
00:16:47.970 --> 00:16:51.228 So one note might say they have stage one,
NOTE Confidence: 0.92679775
00:16:51.230 --> 00:16:54.270 another note might say they have stage two.
NOTE Confidence: 0.92679775
00:16:54.270 --> 00:16:56.016 Actually when we constructed a network
NOTE Confidence: 0.92679775
00:16:56.016 --> 00:16:58.528 graph on the right here you see like
NOTE Confidence: 0.92679775
00:16:58.528 --> 00:17:00.143 every possible combination was present,
NOTE Confidence: 0.92679775
00:17:00.150 --> 00:17:02.062 every possible combination including
NOTE Confidence: 0.92679775
00:17:02.062 --> 00:17:04.930 you know more terms that are
NOTE Confidence: 0.92679775
00:17:05.011 --> 00:17:07.216 more generic like early stage,
NOTE Confidence: 0.92679775

00:17:07.220 --> 00:17:08.094 advanced stage.
NOTE Confidence: 0.92679775

00:17:08.094 --> 00:17:10.716 Everything you know happens and you
NOTE Confidence: 0.92679775

00:17:10.716 --> 00:17:13.542 know and and and on the bottom left
NOTE Confidence: 0.92679775

00:17:13.542 --> 00:17:16.894 here you can see a histogram of of Co
NOTE Confidence: 0.92679775

00:17:16.894 --> 00:17:19.404 occurrences of various stage information.
NOTE Confidence: 0.92679775

00:17:19.410 --> 00:17:22.189 But I do think that so that
NOTE Confidence: 0.92679775

00:17:22.189 --> 00:17:23.380 really potentially ambiguous.
NOTE Confidence: 0.92679775

00:17:23.380 --> 00:17:24.856 One take home point from this
NOTE Confidence: 0.92679775

00:17:24.856 --> 00:17:26.686 though is that we we use a
NOTE Confidence: 0.92679775

00:17:26.686 --> 00:17:27.996 really simple decision rule on,
NOTE Confidence: 0.92679775

00:17:28.000 --> 00:17:30.394 you know, what is the actual stage?
NOTE Confidence: 0.92679775

00:17:30.400 --> 00:17:32.592 We just chose the phrase that showed up
NOTE Confidence: 0.92679775

00:17:32.592 --> 00:17:35.200 the most OK and that and that seems to work.
NOTE Confidence: 0.92679775

00:17:35.200 --> 00:17:36.520 So if stage three shows up
NOTE Confidence: 0.92679775

00:17:36.520 --> 00:17:37.760 in the notes 100 times,
NOTE Confidence: 0.92679775

00:17:37.760 --> 00:17:40.160 in stage one shows up twice.

NOTE Confidence: 0.92679775
00:17:40.160 --> 00:17:41.576 Chances are at stage three now,
NOTE Confidence: 0.92679775
00:17:41.580 --> 00:17:45.066 just sort of a practical rule and it worked.
NOTE Confidence: 0.92679775
00:17:45.066 --> 00:17:47.644 Now getting back to that, you know,
NOTE Confidence: 0.92679775
00:17:47.644 --> 00:17:48.940 whole idea of.
NOTE Confidence: 0.92679775
00:17:48.940 --> 00:17:51.164 You know unknown or sort of lack of
NOTE Confidence: 0.92679775
00:17:51.164 --> 00:17:52.696 information and missingness which is
NOTE Confidence: 0.92679775
00:17:52.696 --> 00:17:54.831 a major issue with real world data.
NOTE Confidence: 0.92679775
00:17:54.840 --> 00:17:57.876 This is another mini project we
NOTE Confidence: 0.92679775
00:17:57.876 --> 00:18:00.324 did looking at colon cancer and
NOTE Confidence: 0.92679775
00:18:00.324 --> 00:18:02.480 we wanted to say could you find
NOTE Confidence: 0.866454990625
00:18:02.553 --> 00:18:04.737 patients with stage 3 colon cancer
NOTE Confidence: 0.866454990625
00:18:04.740 --> 00:18:06.560 and this was for the OCM project,
NOTE Confidence: 0.866454990625
00:18:06.560 --> 00:18:07.628 the oncology care model.
NOTE Confidence: 0.866454990625
00:18:07.628 --> 00:18:09.568 So you know really important as a
NOTE Confidence: 0.866454990625
00:18:09.568 --> 00:18:11.284 metric to know if these patients
NOTE Confidence: 0.866454990625

00:18:11.284 --> 00:18:12.520 got appropriate treatment within
NOTE Confidence: 0.866454990625

00:18:12.520 --> 00:18:13.816 appropriate period of time.
NOTE Confidence: 0.866454990625

00:18:13.820 --> 00:18:16.268 But again what we saw here.
NOTE Confidence: 0.866454990625

00:18:16.270 --> 00:18:18.118 Is this sort of crossover at
NOTE Confidence: 0.866454990625

00:18:18.118 --> 00:18:21.678 about seven weeks, at which point?
NOTE Confidence: 0.866454990625

00:18:21.680 --> 00:18:23.311 You know, the the stage was changing
NOTE Confidence: 0.866454990625

00:18:23.311 --> 00:18:25.520 or it was or is missing in the records
NOTE Confidence: 0.866454990625

00:18:25.520 --> 00:18:27.319 and it wasn't until about seven weeks
NOTE Confidence: 0.866454990625

00:18:27.319 --> 00:18:29.125 after diagnosis that you get to a
NOTE Confidence: 0.866454990625

00:18:29.130 --> 00:18:31.153 kind of steady state where you can
NOTE Confidence: 0.866454990625

00:18:31.153 --> 00:18:32.891 definitively say a patient has stage
NOTE Confidence: 0.866454990625

00:18:32.891 --> 00:18:35.020 three or we don't know the stage so.
NOTE Confidence: 0.822284337142857

00:18:37.140 --> 00:18:38.280 Here's some really interesting
NOTE Confidence: 0.822284337142857

00:18:38.280 --> 00:18:41.240 work from here, actually from Yale,
NOTE Confidence: 0.822284337142857

00:18:41.240 --> 00:18:43.430 from the Radiation Oncology department,
NOTE Confidence: 0.822284337142857

00:18:43.430 --> 00:18:46.280 where they they actually looked at

NOTE Confidence: 0.822284337142857
00:18:46.280 --> 00:18:49.182 missingness as a variable, if you will.
NOTE Confidence: 0.822284337142857
00:18:49.182 --> 00:18:52.269 So they took the National Cancer database,
NOTE Confidence: 0.822284337142857
00:18:52.269 --> 00:18:55.692 the NCDB data, and they split patients
NOTE Confidence: 0.822284337142857
00:18:55.692 --> 00:18:58.637 into whether they had complete records or
NOTE Confidence: 0.822284337142857
00:18:58.637 --> 00:19:01.696 had some missing data from their record.
NOTE Confidence: 0.822284337142857
00:19:01.700 --> 00:19:05.208 Now the NCDB is not EHR data, right?
NOTE Confidence: 0.822284337142857
00:19:05.208 --> 00:19:07.840 But it is based on EHR data.
NOTE Confidence: 0.822284337142857
00:19:07.840 --> 00:19:09.216 So it I would call it a real
NOTE Confidence: 0.822284337142857
00:19:09.216 --> 00:19:10.498 world data source because it's,
NOTE Confidence: 0.822284337142857
00:19:10.500 --> 00:19:13.307 you know, curated out of EHR data.
NOTE Confidence: 0.822284337142857
00:19:13.310 --> 00:19:17.072 And you know the punch line here is that
NOTE Confidence: 0.822284337142857
00:19:17.080 --> 00:19:19.252 missing this is an independent prognostic
NOTE Confidence: 0.822284337142857
00:19:19.252 --> 00:19:21.684 factor for survival which is really an
NOTE Confidence: 0.822284337142857
00:19:21.684 --> 00:19:23.626 interesting thing to think about, right.
NOTE Confidence: 0.822284337142857
00:19:23.626 --> 00:19:27.100 And and it kind of depends on what kind
NOTE Confidence: 0.822284337142857

00:19:27.192 --> 00:19:29.096 of what kind of cancer you have as well.

NOTE Confidence: 0.822284337142857

00:19:29.100 --> 00:19:31.236 So they found for instance on the left.

NOTE Confidence: 0.822284337142857

00:19:31.240 --> 00:19:33.384 If you have non small cell lung cancer,

NOTE Confidence: 0.822284337142857

00:19:33.390 --> 00:19:35.190 it's the non metastatic patient

NOTE Confidence: 0.822284337142857

00:19:35.190 --> 00:19:37.773 who had a real difference in their

NOTE Confidence: 0.822284337142857

00:19:37.773 --> 00:19:39.909 prognosis if they were missing data.

NOTE Confidence: 0.822284337142857

00:19:39.910 --> 00:19:41.933 Whereas with prostate cancer it was the

NOTE Confidence: 0.822284337142857

00:19:41.933 --> 00:19:43.799 metastatic group that sort of split apart.

NOTE Confidence: 0.822284337142857

00:19:43.800 --> 00:19:46.495 But either way, I mean this is.

NOTE Confidence: 0.822284337142857

00:19:46.500 --> 00:19:47.718 Yeah, just think about it for a

NOTE Confidence: 0.822284337142857

00:19:47.718 --> 00:19:49.038 minute while I get my water bottle.

NOTE Confidence: 0.822284337142857

00:19:49.040 --> 00:19:50.480 It's.

NOTE Confidence: 0.822284337142857

00:19:50.480 --> 00:19:51.140 Interesting.

NOTE Confidence: 0.854016017777778

00:19:58.460 --> 00:20:00.980 OK. It's it's certainly not something

NOTE Confidence: 0.854016017777778

00:20:00.980 --> 00:20:03.644 that we conventionally use as a metric.

NOTE Confidence: 0.854016017777778

00:20:03.644 --> 00:20:05.750 Certainly not in a clinical trial

NOTE Confidence: 0.854016017777778
00:20:05.828 --> 00:20:08.683 because there's it's not an issue, right?
NOTE Confidence: 0.854016017777778
00:20:08.683 --> 00:20:10.998 Case report forms are complete,
NOTE Confidence: 0.854016017777778
00:20:11.000 --> 00:20:13.364 but missing this itself can be
NOTE Confidence: 0.854016017777778
00:20:13.364 --> 00:20:15.839 informative as in real world data.
NOTE Confidence: 0.854016017777778
00:20:15.840 --> 00:20:19.135 So what I wanted to do now is actually take
NOTE Confidence: 0.854016017777778
00:20:19.135 --> 00:20:20.850 us down a little different path briefly,
NOTE Confidence: 0.854016017777778
00:20:20.850 --> 00:20:22.326 which is a brief diversion into
NOTE Confidence: 0.854016017777778
00:20:22.326 --> 00:20:23.730 the history of medical records.
NOTE Confidence: 0.854016017777778
00:20:23.730 --> 00:20:26.474 Anybody know what the what this is?
NOTE Confidence: 0.854016017777778
00:20:26.480 --> 00:20:30.700 It's a local local.
NOTE Confidence: 0.854016017777778
00:20:30.700 --> 00:20:31.528 Eli Whitney's mill. OK,
NOTE Confidence: 0.854016017777778
00:20:31.528 --> 00:20:33.739 so it's kind of cool if you never been there.
NOTE Confidence: 0.854016017777778
00:20:33.740 --> 00:20:35.012 It's still there.
NOTE Confidence: 0.854016017777778
00:20:35.012 --> 00:20:37.556 Doesn't exactly look like this anymore,
NOTE Confidence: 0.854016017777778
00:20:37.560 --> 00:20:39.198 but you'll see why I'm showing
NOTE Confidence: 0.854016017777778

00:20:39.198 --> 00:20:43.260 this in a in a couple slides, so.
NOTE Confidence: 0.854016017777778

00:20:43.260 --> 00:20:47.196 So this is also this is a real thing.
NOTE Confidence: 0.854016017777778

00:20:47.200 --> 00:20:50.620 OK, so this is one of my favorite vehicles
NOTE Confidence: 0.854016017777778

00:20:50.620 --> 00:20:53.918 from the Lane Motor Museum in Nashville.
NOTE Confidence: 0.854016017777778

00:20:53.920 --> 00:20:55.150 Which is Doctor Weiner mentioned,
NOTE Confidence: 0.854016017777778

00:20:55.150 --> 00:20:58.006 I was there for about a decade
NOTE Confidence: 0.854016017777778

00:20:58.010 --> 00:20:59.179 and so this is a real vehicle.
NOTE Confidence: 0.854016017777778

00:20:59.180 --> 00:21:00.605 There's they actually have a
NOTE Confidence: 0.854016017777778

00:21:00.605 --> 00:21:02.392 collection of these and it makes
NOTE Confidence: 0.854016017777778

00:21:02.392 --> 00:21:03.897 me think of electronic medical
NOTE Confidence: 0.854016017777778

00:21:03.897 --> 00:21:05.930 records because it it works, right?
NOTE Confidence: 0.854016017777778

00:21:05.930 --> 00:21:08.230 It it actually this person's
NOTE Confidence: 0.854016017777778

00:21:08.230 --> 00:21:10.070 actually driving this car.
NOTE Confidence: 0.854016017777778

00:21:10.070 --> 00:21:11.715 But we don't exactly see propeller driven
NOTE Confidence: 0.854016017777778

00:21:11.715 --> 00:21:14.870 cars on the roads these days, right?
NOTE Confidence: 0.854016017777778

00:21:14.870 --> 00:21:17.240 So our ER, but it works.

NOTE Confidence: 0.854016017777778

00:21:17.240 --> 00:21:17.996 So MR's are functional,

NOTE Confidence: 0.854016017777778

00:21:17.996 --> 00:21:19.354 but are they fit for the purpose

NOTE Confidence: 0.854016017777778

00:21:19.354 --> 00:21:20.628 that we want to use them for?

NOTE Confidence: 0.906796898333333

00:21:22.670 --> 00:21:24.642 I think many of us have, you know,

NOTE Confidence: 0.906796898333333

00:21:24.642 --> 00:21:26.810 some ideas about that, but you know,

NOTE Confidence: 0.906796898333333

00:21:26.810 --> 00:21:28.370 when you think about medical records,

NOTE Confidence: 0.906796898333333

00:21:28.370 --> 00:21:31.034 this is obviously a little bit

NOTE Confidence: 0.906796898333333

00:21:31.034 --> 00:21:33.230 before the computer, you know,

NOTE Confidence: 0.906796898333333

00:21:33.230 --> 00:21:35.810 medical records have been around for.

NOTE Confidence: 0.906796898333333

00:21:35.810 --> 00:21:36.866 Almost, you know,

NOTE Confidence: 0.906796898333333

00:21:36.866 --> 00:21:39.330 3500 years in one form or another.

NOTE Confidence: 0.906796898333333

00:21:39.330 --> 00:21:41.520 But what's interesting to me?

NOTE Confidence: 0.906796898333333

00:21:41.520 --> 00:21:43.180 Is that they were primarily

NOTE Confidence: 0.906796898333333

00:21:43.180 --> 00:21:44.840 used for teaching or didactics.

NOTE Confidence: 0.906796898333333

00:21:44.840 --> 00:21:46.379 Until very recently,

NOTE Confidence: 0.906796898333333

00:21:46.379 --> 00:21:50.375 that was the only purpose of medical records.

NOTE Confidence: 0.906796898333333

00:21:50.375 --> 00:21:53.225 And then sort of the second

NOTE Confidence: 0.906796898333333

00:21:53.225 --> 00:21:55.754 purpose that arose, if you will,

NOTE Confidence: 0.906796898333333

00:21:55.754 --> 00:21:57.444 didn't arise until the 1880s.

NOTE Confidence: 0.906796898333333

00:21:57.450 --> 00:21:59.360 It's not that long ago if you think about it.

NOTE Confidence: 0.906796898333333

00:21:59.360 --> 00:22:02.036 And that was for legal purposes,

NOTE Confidence: 0.906796898333333

00:22:02.040 --> 00:22:03.076 legal defense.

NOTE Confidence: 0.906796898333333

00:22:03.076 --> 00:22:04.630 And, you know,

NOTE Confidence: 0.906796898333333

00:22:04.630 --> 00:22:06.868 essentially to have a written record

NOTE Confidence: 0.906796898333333

00:22:06.868 --> 00:22:10.195 of what happens in case there was a

NOTE Confidence: 0.906796898333333

00:22:10.195 --> 00:22:11.959 lawsuit around medical malpractice.

NOTE Confidence: 0.906796898333333

00:22:11.960 --> 00:22:14.234 And we'll skip that and sorry

NOTE Confidence: 0.906796898333333

00:22:14.234 --> 00:22:16.503 about the there's some Mac to

NOTE Confidence: 0.906796898333333

00:22:16.503 --> 00:22:18.525 PC changes here with the font.

NOTE Confidence: 0.906796898333333

00:22:18.530 --> 00:22:19.784 So it's a little bit hard

NOTE Confidence: 0.906796898333333

00:22:19.784 --> 00:22:20.930 to read some of this,

NOTE Confidence: 0.906796898333333
00:22:20.930 --> 00:22:22.952 but you know how about billing
NOTE Confidence: 0.906796898333333
00:22:22.952 --> 00:22:24.707 that that's billing is the
NOTE Confidence: 0.906796898333333
00:22:24.707 --> 00:22:26.729 major driver rate of how our
NOTE Confidence: 0.906796898333333
00:22:26.729 --> 00:22:28.509 medical records look like today.
NOTE Confidence: 0.906796898333333
00:22:28.510 --> 00:22:30.568 But that only really happened in
NOTE Confidence: 0.906796898333333
00:22:30.570 --> 00:22:34.282 1960s is really not long ago and until
NOTE Confidence: 0.906796898333333
00:22:34.282 --> 00:22:37.846 you know not so long ago physicians
NOTE Confidence: 0.906796898333333
00:22:37.846 --> 00:22:41.191 were paid with food and lodging.
NOTE Confidence: 0.906796898333333
00:22:41.191 --> 00:22:43.619 If they were lucky.
NOTE Confidence: 0.906796898333333
00:22:43.620 --> 00:22:46.910 This is a picture from the Confucian
NOTE Confidence: 0.906796898333333
00:22:46.910 --> 00:22:49.084 medical system where there's at
NOTE Confidence: 0.906796898333333
00:22:49.084 --> 00:22:51.758 least some cases where the the court
NOTE Confidence: 0.906796898333333
00:22:51.758 --> 00:22:53.352 physician was basically executed if
NOTE Confidence: 0.906796898333333
00:22:53.352 --> 00:22:55.879 the if the emperor did not get better.
NOTE Confidence: 0.906796898333333
00:22:55.880 --> 00:22:58.706 So that's a pretty harsh payment
NOTE Confidence: 0.906796898333333

00:22:58.706 --> 00:23:00.380 or penalty if you will.
NOTE Confidence: 0.906796898333333

00:23:00.380 --> 00:23:02.180 But you know what really changed
NOTE Confidence: 0.906796898333333

00:23:02.240 --> 00:23:04.673 things was the Medicare Act of 1965,
NOTE Confidence: 0.906796898333333

00:23:04.673 --> 00:23:08.338 which basically established this profile.
NOTE Confidence: 0.906796898333333

00:23:08.340 --> 00:23:09.020 You know,
NOTE Confidence: 0.906796898333333

00:23:09.020 --> 00:23:10.380 quote usual customary and
NOTE Confidence: 0.906796898333333

00:23:10.380 --> 00:23:11.400 reasonable fees which.
NOTE Confidence: 0.906796898333333

00:23:11.400 --> 00:23:13.045 Drive so much of what we do.
NOTE Confidence: 0.906796898333333

00:23:13.050 --> 00:23:14.170 And sorry about the font
NOTE Confidence: 0.906796898333333

00:23:14.170 --> 00:23:15.066 that's messed up here,
NOTE Confidence: 0.906796898333333

00:23:15.070 --> 00:23:18.227 but there's a quote from the AMA,
NOTE Confidence: 0.906796898333333

00:23:18.230 --> 00:23:19.658 the American Medical Association,
NOTE Confidence: 0.906796898333333

00:23:19.658 --> 00:23:22.059 that said that the 1965 Medicare Act
NOTE Confidence: 0.906796898333333

00:23:22.059 --> 00:23:23.997 was the most deadly challenge ever
NOTE Confidence: 0.906796898333333

00:23:23.997 --> 00:23:25.828 faced by the medical profession.
NOTE Confidence: 0.906796898333333

00:23:25.830 --> 00:23:28.530 That's actual quote.

NOTE Confidence: 0.906796898333333
00:23:28.530 --> 00:23:30.240 It certainly changed things a lot.
NOTE Confidence: 0.906796898333333
00:23:30.240 --> 00:23:32.970 And then what I'd argue also changed
NOTE Confidence: 0.906796898333333
00:23:32.970 --> 00:23:34.666 things was really more recent was
NOTE Confidence: 0.906796898333333
00:23:34.666 --> 00:23:36.388 in the 90s when the physician fee
NOTE Confidence: 0.906796898333333
00:23:36.388 --> 00:23:37.888 schedule was introduced and then
NOTE Confidence: 0.906796898333333
00:23:37.888 --> 00:23:39.515 something called the evaluation and
NOTE Confidence: 0.906796898333333
00:23:39.515 --> 00:23:40.976 management guidelines, which I think.
NOTE Confidence: 0.906796898333333
00:23:40.976 --> 00:23:42.600 A lot of us know more than
NOTE Confidence: 0.906796898333333
00:23:42.658 --> 00:23:44.296 we ever wanted to know about,
NOTE Confidence: 0.906796898333333
00:23:44.300 --> 00:23:47.470 but those really changed how
NOTE Confidence: 0.906796898333333
00:23:47.470 --> 00:23:50.640 medical records were were written.
NOTE Confidence: 0.906796898333333
00:23:50.640 --> 00:23:52.230 Noticed that haven't yet used
NOTE Confidence: 0.906796898333333
00:23:52.230 --> 00:23:53.694 the word electronic, right?
NOTE Confidence: 0.906796898333333
00:23:53.694 --> 00:23:56.718 So now what about patient care,
NOTE Confidence: 0.906796898333333
00:23:56.720 --> 00:23:59.060 which I think all of us want that to
NOTE Confidence: 0.906796898333333

00:23:59.060 --> 00:24:01.892 be the primary purpose of medical records.

NOTE Confidence: 0.906796898333333

00:24:01.892 --> 00:24:04.550 This kind of dates back to

NOTE Confidence: 0.906796898333333

00:24:04.640 --> 00:24:06.436 the 1800s in some ways.

NOTE Confidence: 0.906796898333333

00:24:06.436 --> 00:24:08.196 The case records of the

NOTE Confidence: 0.906796898333333

00:24:08.196 --> 00:24:09.500 Massachusetts General Hospital.

NOTE Confidence: 0.906796898333333

00:24:09.500 --> 00:24:11.160 Introduced some ideas like

NOTE Confidence: 0.906796898333333

00:24:11.160 --> 00:24:12.820 history of presenting illness,

NOTE Confidence: 0.906796898333333

00:24:12.820 --> 00:24:15.238 past medical history and so forth,

NOTE Confidence: 0.906796898333333

00:24:15.240 --> 00:24:16.137 medical record numbers.

NOTE Confidence: 0.906796898333333

00:24:16.137 --> 00:24:18.532 The whole idea that you would track a

NOTE Confidence: 0.906796898333333

00:24:18.532 --> 00:24:20.233 patient by a number was introduced at

NOTE Confidence: 0.906796898333333

00:24:20.233 --> 00:24:22.099 the Mayo Clinic in the early 1900s,

NOTE Confidence: 0.906796898333333

00:24:22.100 --> 00:24:24.878 where they also introduced the chief

NOTE Confidence: 0.906796898333333

00:24:24.878 --> 00:24:27.650 complaint and the review of systems.

NOTE Confidence: 0.906796898333333

00:24:27.650 --> 00:24:30.204 And then the American,

NOTE Confidence: 0.906796898333333

00:24:30.204 --> 00:24:32.389 the American College of Surgeons,

NOTE Confidence: 0.764963734545455
00:24:32.390 --> 00:24:33.914 this is amazing bit of history
NOTE Confidence: 0.764963734545455
00:24:33.914 --> 00:24:37.900 if you didn't know in 1918, they.
NOTE Confidence: 0.764963734545455
00:24:37.900 --> 00:24:39.657 There was no federal mandate of any.
NOTE Confidence: 0.764963734545455
00:24:39.660 --> 00:24:41.276 They basically mandated as
NOTE Confidence: 0.764963734545455
00:24:41.276 --> 00:24:42.488 a professional organization.
NOTE Confidence: 0.764963734545455
00:24:42.490 --> 00:24:45.298 They mandated that hospitals had to
NOTE Confidence: 0.764963734545455
00:24:45.298 --> 00:24:47.344 keep records including a discharge
NOTE Confidence: 0.764963734545455
00:24:47.344 --> 00:24:49.552 summary that basically said was the,
NOTE Confidence: 0.764963734545455
00:24:49.560 --> 00:24:50.202 you know, patient,
NOTE Confidence: 0.764963734545455
00:24:50.202 --> 00:24:52.419 you know alive or dead at the time they left.
NOTE Confidence: 0.764963734545455
00:24:52.420 --> 00:24:55.588 And at that time fewer than 20% of
NOTE Confidence: 0.764963734545455
00:24:55.588 --> 00:24:58.260 physicians kept any kind of record at all,
NOTE Confidence: 0.764963734545455
00:24:58.260 --> 00:25:02.830 which is like. Amazing, right?
NOTE Confidence: 0.764963734545455
00:25:02.830 --> 00:25:05.143 Now this is tying back to that Eli Whitney.
NOTE Confidence: 0.764963734545455
00:25:05.150 --> 00:25:06.950 So this is, you know,
NOTE Confidence: 0.764963734545455

00:25:06.950 --> 00:25:09.050 for those that did take records,
NOTE Confidence: 0.764963734545455

00:25:09.050 --> 00:25:10.618 this is kind of what they looked
NOTE Confidence: 0.764963734545455

00:25:10.618 --> 00:25:12.407 like as these are called case books.
NOTE Confidence: 0.764963734545455

00:25:12.410 --> 00:25:13.994 I'm not sure where this one is from,
NOTE Confidence: 0.764963734545455

00:25:14.000 --> 00:25:18.070 but it's basically a handwritten.
NOTE Confidence: 0.764963734545455

00:25:18.070 --> 00:25:19.996 And and what's really interesting about
NOTE Confidence: 0.764963734545455

00:25:19.996 --> 00:25:22.717 this is that it's physician centered, right.
NOTE Confidence: 0.764963734545455

00:25:22.717 --> 00:25:23.638 This is not,
NOTE Confidence: 0.764963734545455

00:25:23.638 --> 00:25:26.348 this is a diary basically it's not you know,
NOTE Confidence: 0.764963734545455

00:25:26.350 --> 00:25:27.630 one patient has one book,
NOTE Confidence: 0.764963734545455

00:25:27.630 --> 00:25:29.750 this was written as.
NOTE Confidence: 0.764963734545455

00:25:29.750 --> 00:25:30.894 The doctor saw patients,
NOTE Confidence: 0.764963734545455

00:25:30.894 --> 00:25:33.788 so if you ever wanted to go back and say OK,
NOTE Confidence: 0.764963734545455

00:25:33.790 --> 00:25:35.422 Mr. Smith or whoever,
NOTE Confidence: 0.764963734545455

00:25:35.422 --> 00:25:37.462 like put their case together,
NOTE Confidence: 0.764963734545455

00:25:37.470 --> 00:25:39.730 good luck.

NOTE Confidence: 0.764963734545455

00:25:39.730 --> 00:25:41.865 So really the the most recent innovation

NOTE Confidence: 0.764963734545455

00:25:41.865 --> 00:25:44.065 if you will in medical records was

NOTE Confidence: 0.764963734545455

00:25:44.065 --> 00:25:46.288 this one and that from Austin from

NOTE Confidence: 0.764963734545455

00:25:46.288 --> 00:25:48.591 the mid 1960s which is the problem

NOTE Confidence: 0.764963734545455

00:25:48.591 --> 00:25:50.501 oriented medical record which which

NOTE Confidence: 0.764963734545455

00:25:50.501 --> 00:25:53.003 was conceived as a quote medical

NOTE Confidence: 0.764963734545455

00:25:53.003 --> 00:25:55.229 record that guides and teaches.

NOTE Confidence: 0.764963734545455

00:25:55.230 --> 00:25:56.974 So kind of back to that idea of

NOTE Confidence: 0.764963734545455

00:25:56.974 --> 00:25:59.074 didactics in a way and and I'm sure

NOTE Confidence: 0.764963734545455

00:25:59.074 --> 00:26:00.146 everybody's familiar with this,

NOTE Confidence: 0.764963734545455

00:26:00.150 --> 00:26:03.800 this idea, this soap notes, right.

NOTE Confidence: 0.764963734545455

00:26:03.800 --> 00:26:06.754 What I like from the paper when

NOTE Confidence: 0.764963734545455

00:26:06.754 --> 00:26:08.880 doctor we'd introduced this idea.

NOTE Confidence: 0.764963734545455

00:26:08.880 --> 00:26:12.324 This is a quote which I think

NOTE Confidence: 0.764963734545455

00:26:12.324 --> 00:26:15.040 actually forecasts the ER right so,

NOTE Confidence: 0.764963734545455

00:26:15.040 --> 00:26:16.040 and it's worth reading it.
NOTE Confidence: 0.764963734545455

00:26:16.040 --> 00:26:17.444 It can be readily,
NOTE Confidence: 0.764963734545455

00:26:17.444 --> 00:26:19.298 readily be seen that all narrative
NOTE Confidence: 0.764963734545455

00:26:19.298 --> 00:26:20.628 data presently in the medical
NOTE Confidence: 0.764963734545455

00:26:20.628 --> 00:26:21.840 record can be structured,
NOTE Confidence: 0.764963734545455

00:26:21.840 --> 00:26:23.618 and in the future all narrative data
NOTE Confidence: 0.764963734545455

00:26:23.618 --> 00:26:25.855 may be entered through a series of
NOTE Confidence: 0.764963734545455

00:26:25.855 --> 00:26:27.275 displays guaranteeing a thoroughness,
NOTE Confidence: 0.764963734545455

00:26:27.280 --> 00:26:27.732 retrievability,
NOTE Confidence: 0.764963734545455

00:26:27.732 --> 00:26:29.540 efficiency and economy important
NOTE Confidence: 0.764963734545455

00:26:29.540 --> 00:26:32.148 to the scientific analysis of a
NOTE Confidence: 0.764963734545455

00:26:32.148 --> 00:26:33.840 type of datum that has hitherto.
NOTE Confidence: 0.764963734545455

00:26:33.840 --> 00:26:36.206 Been handled in a very unrigorous manner.
NOTE Confidence: 0.764963734545455

00:26:36.210 --> 00:26:37.190 It's an amazing quote.
NOTE Confidence: 0.764963734545455

00:26:37.190 --> 00:26:37.680 I mean,
NOTE Confidence: 0.764963734545455

00:26:37.680 --> 00:26:40.710 this is essentially before any

NOTE Confidence: 0.764963734545455

00:26:40.710 --> 00:26:42.102 electronic medical record, right?

NOTE Confidence: 0.764963734545455

00:26:42.102 --> 00:26:44.459 But he basically saw it, saw it coming.

NOTE Confidence: 0.878462154285714

00:26:46.590 --> 00:26:48.956 I think the most important part of

NOTE Confidence: 0.878462154285714

00:26:48.956 --> 00:26:51.528 this quote is this to be concluded.

NOTE Confidence: 0.878462154285714

00:26:51.530 --> 00:26:54.325 We're living through the evolution

NOTE Confidence: 0.878462154285714

00:26:54.325 --> 00:26:57.120 of these electronic medical records.

NOTE Confidence: 0.878462154285714

00:26:57.120 --> 00:26:58.596 This is actually a two-part paper,

NOTE Confidence: 0.878462154285714

00:26:58.600 --> 00:26:59.510 that's why it says this.

NOTE Confidence: 0.878462154285714

00:26:59.510 --> 00:27:00.310 But I think, you know,

NOTE Confidence: 0.878462154285714

00:27:00.310 --> 00:27:02.008 he could have been like OK,

NOTE Confidence: 0.878462154285714

00:27:02.010 --> 00:27:05.174 we don't know what's going to happen.

NOTE Confidence: 0.878462154285714

00:27:05.180 --> 00:27:07.136 It's worth taking a step back

NOTE Confidence: 0.878462154285714

00:27:07.136 --> 00:27:09.068 and saying what you know what.

NOTE Confidence: 0.878462154285714

00:27:09.068 --> 00:27:11.372 So now I'm going to say electron what

NOTE Confidence: 0.878462154285714

00:27:11.372 --> 00:27:13.799 is the electronic health record for?

NOTE Confidence: 0.878462154285714

00:27:13.800 --> 00:27:16.168 And it's got primary uses and secondary uses.

NOTE Confidence: 0.878462154285714

00:27:16.170 --> 00:27:18.501 So the primary uses are are patient

NOTE Confidence: 0.878462154285714

00:27:18.501 --> 00:27:20.472 care and delivery, financial billing.

NOTE Confidence: 0.878462154285714

00:27:20.472 --> 00:27:22.850 But it's this, when you talk about

NOTE Confidence: 0.878462154285714

00:27:22.850 --> 00:27:24.230 real-world data and real world evidence,

NOTE Confidence: 0.878462154285714

00:27:24.230 --> 00:27:25.546 that's a secondary use,

NOTE Confidence: 0.878462154285714

00:27:25.546 --> 00:27:27.950 as it's conceived here in this model,

NOTE Confidence: 0.878462154285714

00:27:27.950 --> 00:27:31.016 which the Institute of Medicine put forward.

NOTE Confidence: 0.878462154285714

00:27:31.020 --> 00:27:31.490 All right.

NOTE Confidence: 0.878462154285714

00:27:31.490 --> 00:27:32.900 So moving ahead a little bit.

NOTE Confidence: 0.878462154285714

00:27:32.900 --> 00:27:35.730 So this is where we were in the mid 2000s

NOTE Confidence: 0.878462154285714

00:27:35.730 --> 00:27:38.295 and this is when I was in medical school.

NOTE Confidence: 0.878462154285714

00:27:38.300 --> 00:27:40.664 At that time there was issues

NOTE Confidence: 0.878462154285714

00:27:40.664 --> 00:27:43.812 around funding to you know roll out

NOTE Confidence: 0.878462154285714

00:27:43.812 --> 00:27:45.800 electronic medical records and.

NOTE Confidence: 0.878462154285714

00:27:45.800 --> 00:27:47.546 What I like on the bottom here is in

NOTE Confidence: 0.878462154285714

00:27:47.550 --> 00:27:49.552 2003 the mass medical society did a

NOTE Confidence: 0.878462154285714

00:27:49.552 --> 00:27:52.302 survey where 89% of physicians wanted

NOTE Confidence: 0.878462154285714

00:27:52.302 --> 00:27:56.064 EHR data, but 48% refused to use an ER.

NOTE Confidence: 0.878462154285714

00:27:56.070 --> 00:27:59.213 So little bit of a disconnect there

NOTE Confidence: 0.878462154285714

00:27:59.213 --> 00:28:01.022 and and by 2004.

NOTE Confidence: 0.878462154285714

00:28:01.022 --> 00:28:03.794 Hardly anybody was using medical records.

NOTE Confidence: 0.878462154285714

00:28:03.800 --> 00:28:05.321 So what changed?

NOTE Confidence: 0.878462154285714

00:28:05.321 --> 00:28:08.166 Arguably this this is, you know,

NOTE Confidence: 0.878462154285714

00:28:08.166 --> 00:28:11.430 one of the events that really changed things.

NOTE Confidence: 0.878462154285714

00:28:11.430 --> 00:28:13.795 Is everybody familiar with Katrina

NOTE Confidence: 0.878462154285714

00:28:13.795 --> 00:28:17.230 and what happened in in New Orleans?

NOTE Confidence: 0.878462154285714

00:28:17.230 --> 00:28:20.100 Does everybody know why the?

NOTE Confidence: 0.878462154285714

00:28:20.100 --> 00:28:21.312 Record so there's a picture there

NOTE Confidence: 0.878462154285714

00:28:21.312 --> 00:28:21.918 on the right.

NOTE Confidence: 0.878462154285714

00:28:21.920 --> 00:28:24.120 It's everybody know why those

NOTE Confidence: 0.878462154285714

00:28:24.120 --> 00:28:25.880 were in the basement.
NOTE Confidence: 0.878462154285714

00:28:25.880 --> 00:28:26.580 That flooded.
NOTE Confidence: 0.878462154285714

00:28:26.580 --> 00:28:29.380 It's the they are so heavy that the
NOTE Confidence: 0.878462154285714

00:28:29.451 --> 00:28:31.701 building literally would have collapsed
NOTE Confidence: 0.878462154285714

00:28:31.701 --> 00:28:34.641 under the weight of the paper if
NOTE Confidence: 0.878462154285714

00:28:34.641 --> 00:28:36.566 they'd been up on higher floors.
NOTE Confidence: 0.878462154285714

00:28:36.566 --> 00:28:38.624 So that's why they have their
NOTE Confidence: 0.878462154285714

00:28:38.624 --> 00:28:40.592 medical records in the basement and
NOTE Confidence: 0.878462154285714

00:28:40.592 --> 00:28:42.320 and they were all destroyed, right?
NOTE Confidence: 0.878462154285714

00:28:42.320 --> 00:28:43.320 They were all just lost.
NOTE Confidence: 0.878462154285714

00:28:43.320 --> 00:28:45.498 So, so fast.
NOTE Confidence: 0.878462154285714

00:28:45.498 --> 00:28:48.078 We're a little bit the High Tech Act in 2009,
NOTE Confidence: 0.878462154285714

00:28:48.078 --> 00:28:51.422 which Obama signed this this is what really.
NOTE Confidence: 0.878462154285714

00:28:51.430 --> 00:28:52.004 You know,
NOTE Confidence: 0.878462154285714

00:28:52.004 --> 00:28:54.013 gave a lot of money for institutions
NOTE Confidence: 0.878462154285714

00:28:54.013 --> 00:28:56.111 to really start putting any Mrs.

NOTE Confidence: 0.878462154285714
00:28:56.111 --> 00:28:58.193 but what is interesting is if
NOTE Confidence: 0.878462154285714
00:28:58.193 --> 00:29:00.609 you look at sort of the adoption
NOTE Confidence: 0.878462154285714
00:29:00.609 --> 00:29:02.500 curve and there's a couple,
NOTE Confidence: 0.878462154285714
00:29:02.500 --> 00:29:03.648 I won't get into the details here.
NOTE Confidence: 0.878462154285714
00:29:03.650 --> 00:29:06.071 There's a couple ways of like what is an
NOTE Confidence: 0.878462154285714
00:29:06.071 --> 00:29:08.548 EHR basic versus complete and so forth,
NOTE Confidence: 0.878462154285714
00:29:08.550 --> 00:29:11.550 but you actually see.
NOTE Confidence: 0.878462154285714
00:29:11.550 --> 00:29:12.860 You actually see them starting,
NOTE Confidence: 0.878462154285714
00:29:12.860 --> 00:29:16.010 so here's E&M coming out in the mid
90s.
NOTE Confidence: 0.878462154285714
00:29:16.010 --> 00:29:19.338 Here's Katrina in 2005.
NOTE Confidence: 0.878462154285714
00:29:19.340 --> 00:29:20.280 There's the High Tech act.
NOTE Confidence: 0.878462154285714
00:29:20.280 --> 00:29:21.963 By the time the High Tech Act comes out,
NOTE Confidence: 0.878462154285714
00:29:21.970 --> 00:29:24.616 actually we're like well on the
NOTE Confidence: 0.878462154285714
00:29:24.616 --> 00:29:27.248 adoption curve and so, you know,
NOTE Confidence: 0.878462154285714
00:29:27.248 --> 00:29:30.131 definitely help things along, but you know,

NOTE Confidence: 0.878462154285714
00:29:30.131 --> 00:29:32.016 the process is already starting.
NOTE Confidence: 0.878462154285714
00:29:32.020 --> 00:29:32.520 Umm.
NOTE Confidence: 0.878462154285714
00:29:32.520 --> 00:29:35.020 And then you know where.
NOTE Confidence: 0.878462154285714
00:29:35.020 --> 00:29:37.078 So this is already five years old,
NOTE Confidence: 0.878462154285714
00:29:37.080 --> 00:29:40.209 but I think, you know it's it's.
NOTE Confidence: 0.878462154285714
00:29:40.210 --> 00:29:40.686 And sorry,
NOTE Confidence: 0.878462154285714
00:29:40.686 --> 00:29:41.162 sorry again,
NOTE Confidence: 0.878462154285714
00:29:41.162 --> 00:29:42.352 can't see the text there.
NOTE Confidence: 0.878462154285714
00:29:42.360 --> 00:29:44.115 But you know already by
NOTE Confidence: 0.878462154285714
00:29:44.115 --> 00:29:45.870 five years ago people were
NOTE Confidence: 0.881632480833333
00:29:45.946 --> 00:29:47.392 reporting that EHR's were
NOTE Confidence: 0.881632480833333
00:29:47.392 --> 00:29:48.547 a major driver of burnout.
NOTE Confidence: 0.881632480833333
00:29:48.550 --> 00:29:51.346 So, so you know, it's problematic.
NOTE Confidence: 0.881632480833333
00:29:51.350 --> 00:29:53.426 But OK, here's a here's a
NOTE Confidence: 0.881632480833333
00:29:53.426 --> 00:29:54.808 few other challenges. So.
NOTE Confidence: 0.881632480833333

00:29:54.808 --> 00:29:56.498 And I'm sure everybody who's
NOTE Confidence: 0.881632480833333

00:29:56.498 --> 00:29:58.360 clinical knows these things already.
NOTE Confidence: 0.881632480833333

00:29:58.360 --> 00:30:02.162 But carry forward a copy pasting is
NOTE Confidence: 0.881632480833333

00:30:02.162 --> 00:30:04.059 ubiquitous in medical records and
NOTE Confidence: 0.881632480833333

00:30:04.059 --> 00:30:06.015 there's just a ton of redundancy.
NOTE Confidence: 0.881632480833333

00:30:06.020 --> 00:30:09.310 Here's a paper that basically shows that.
NOTE Confidence: 0.881632480833333

00:30:09.310 --> 00:30:10.922 Umm. You know, large,
NOTE Confidence: 0.881632480833333

00:30:10.922 --> 00:30:13.340 large portions of any note you
NOTE Confidence: 0.881632480833333

00:30:13.418 --> 00:30:15.858 particularly look at have been
NOTE Confidence: 0.881632480833333

00:30:15.858 --> 00:30:18.298 copied forward from other notes.
NOTE Confidence: 0.881632480833333

00:30:18.300 --> 00:30:19.030 Progress notes.
NOTE Confidence: 0.881632480833333

00:30:19.030 --> 00:30:19.760 In particular,
NOTE Confidence: 0.881632480833333

00:30:19.760 --> 00:30:21.585 more than half of progress
NOTE Confidence: 0.881632480833333

00:30:21.585 --> 00:30:23.546 note material is copy copied
NOTE Confidence: 0.881632480833333

00:30:23.546 --> 00:30:25.078 forward from previous notes.
NOTE Confidence: 0.861171268571429

00:30:27.270 --> 00:30:30.614 This is a different study looking at you

NOTE Confidence: 0.861171268571429
00:30:30.614 --> 00:30:32.566 know how many progress notes have a manually
NOTE Confidence: 0.861171268571429
00:30:32.566 --> 00:30:34.207 entered text versus copied in any kind.
NOTE Confidence: 0.861171268571429
00:30:34.210 --> 00:30:37.720 And you can see again like very few progress
NOTE Confidence: 0.861171268571429
00:30:37.720 --> 00:30:40.448 notes have have fully written text.
NOTE Confidence: 0.861171268571429
00:30:40.450 --> 00:30:43.510 Which you would say is fully original, but.
NOTE Confidence: 0.861171268571429
00:30:43.510 --> 00:30:44.973 So I think it's a legitimate question
NOTE Confidence: 0.861171268571429
00:30:44.973 --> 00:30:46.708 to say what are we dealing with here?
NOTE Confidence: 0.861171268571429
00:30:46.710 --> 00:30:47.851 Is it a giant pile of paper
NOTE Confidence: 0.861171268571429
00:30:47.851 --> 00:30:49.099 or is there actually meaning.
NOTE Confidence: 0.861171268571429
00:30:49.100 --> 00:30:51.500 So this is a little little tiny project
NOTE Confidence: 0.861171268571429
00:30:51.500 --> 00:30:54.032 I did and when during fellowship where
NOTE Confidence: 0.861171268571429
00:30:54.032 --> 00:30:56.699 I basically took one of my patients
NOTE Confidence: 0.861171268571429
00:30:56.700 --> 00:30:59.150 charts and I counted up like how
NOTE Confidence: 0.861171268571429
00:30:59.150 --> 00:31:01.569 many data points are in that chart.
NOTE Confidence: 0.861171268571429
00:31:01.570 --> 00:31:04.810 And you can see the blue bars are all the
NOTE Confidence: 0.861171268571429

00:31:04.890 --> 00:31:07.300 structured data elements like billing
NOTE Confidence: 0.861171268571429

00:31:07.300 --> 00:31:10.659 codes or vital signs or lab values.
NOTE Confidence: 0.861171268571429

00:31:10.660 --> 00:31:12.772 And then these red bars are the words
NOTE Confidence: 0.861171268571429

00:31:12.772 --> 00:31:14.716 in the clinical documents and you
NOTE Confidence: 0.861171268571429

00:31:14.716 --> 00:31:17.160 see that that just drowns out right,
NOTE Confidence: 0.861171268571429

00:31:17.160 --> 00:31:18.282 the structured data.
NOTE Confidence: 0.861171268571429

00:31:18.282 --> 00:31:21.270 So there's a lot of data there but.
NOTE Confidence: 0.861171268571429

00:31:21.270 --> 00:31:21.972 It's awesome.
NOTE Confidence: 0.861171268571429

00:31:21.972 --> 00:31:24.238 There's even more than that, right?
NOTE Confidence: 0.861171268571429

00:31:24.238 --> 00:31:26.270 So in this chart.
NOTE Confidence: 0.861171268571429

00:31:26.270 --> 00:31:28.443 And this is small these days, right?
NOTE Confidence: 0.861171268571429

00:31:28.443 --> 00:31:30.787 So this was more than 10 years ago,
NOTE Confidence: 0.861171268571429

00:31:30.790 --> 00:31:34.479 there was another 277 pages of scanned
NOTE Confidence: 0.861171268571429

00:31:34.479 --> 00:31:36.820 documents with 69,000 words in them
NOTE Confidence: 0.861171268571429

00:31:36.820 --> 00:31:38.100 that were basically inaccessible,
NOTE Confidence: 0.861171268571429

00:31:38.100 --> 00:31:41.308 but and and the take home point here.

NOTE Confidence: 0.861171268571429
00:31:41.310 --> 00:31:43.650 Is that this is what it all boils down to,
NOTE Confidence: 0.861171268571429
00:31:43.650 --> 00:31:45.600 OK?
NOTE Confidence: 0.861171268571429
00:31:45.600 --> 00:31:48.106 Patient with diffuse large B cell lymphoma.
NOTE Confidence: 0.861171268571429
00:31:48.110 --> 00:31:50.036 It was a complete remission after
NOTE Confidence: 0.861171268571429
00:31:50.036 --> 00:31:51.930 getting 6 cycles of our chop.
NOTE Confidence: 0.861171268571429
00:31:51.930 --> 00:31:53.806 I think that's enough for most research.
NOTE Confidence: 0.861171268571429
00:31:53.810 --> 00:31:56.990 OK now how can we,
NOTE Confidence: 0.861171268571429
00:31:56.990 --> 00:31:58.698 how can we boil things down like
NOTE Confidence: 0.861171268571429
00:31:58.698 --> 00:32:00.272 that because that's that's kind of
NOTE Confidence: 0.861171268571429
00:32:00.272 --> 00:32:01.862 maybe what we're talking about here.
NOTE Confidence: 0.861171268571429
00:32:01.870 --> 00:32:05.686 So and of course there's more to it right.
NOTE Confidence: 0.861171268571429
00:32:05.690 --> 00:32:08.906 But you know when you think about what's
NOTE Confidence: 0.861171268571429
00:32:08.906 --> 00:32:12.654 in ER's or EHR's and and what is not.
NOTE Confidence: 0.861171268571429
00:32:12.660 --> 00:32:13.007 Umm.
NOTE Confidence: 0.861171268571429
00:32:13.007 --> 00:32:15.089 You have to know what you're,
NOTE Confidence: 0.861171268571429

00:32:15.090 --> 00:32:16.467 you have to know what you're going to find,

NOTE Confidence: 0.861171268571429

00:32:16.470 --> 00:32:16.794 right.

NOTE Confidence: 0.861171268571429

00:32:16.794 --> 00:32:19.062 So, so let's say you know you've

NOTE Confidence: 0.861171268571429

00:32:19.062 --> 00:32:20.689 unlocked this medical record,

NOTE Confidence: 0.861171268571429

00:32:20.690 --> 00:32:21.760 but it's not necessarily going

NOTE Confidence: 0.861171268571429

00:32:21.760 --> 00:32:22.830 to have what you want.

NOTE Confidence: 0.861171268571429

00:32:22.830 --> 00:32:25.050 So here's, here's some, you know,

NOTE Confidence: 0.861171268571429

00:32:25.050 --> 00:32:28.010 basically some big buckets, right.

NOTE Confidence: 0.861171268571429

00:32:28.010 --> 00:32:29.536 So you're going to find the person's

NOTE Confidence: 0.861171268571429

00:32:29.536 --> 00:32:31.003 date of birth, no problem, right.

NOTE Confidence: 0.861171268571429

00:32:31.003 --> 00:32:32.629 But you're not going to find

NOTE Confidence: 0.861171268571429

00:32:32.629 --> 00:32:33.968 probably where they were born,

NOTE Confidence: 0.861171268571429

00:32:33.970 --> 00:32:35.170 the circumstances of their birth,

NOTE Confidence: 0.861171268571429

00:32:35.170 --> 00:32:36.880 where their complications.

NOTE Confidence: 0.861171268571429

00:32:36.880 --> 00:32:39.036 Very unlikely, because they will have.

NOTE Confidence: 0.861171268571429

00:32:39.036 --> 00:32:40.560 You know they won't have lived

NOTE Confidence: 0.861171268571429
00:32:40.614 --> 00:32:42.049 their whole system with their
NOTE Confidence: 0.861171268571429
00:32:42.049 --> 00:32:43.484 life within the electronic air,
NOTE Confidence: 0.861171268571429
00:32:43.490 --> 00:32:45.324 and they won't have all that data.
NOTE Confidence: 0.861171268571429
00:32:45.330 --> 00:32:46.986 You might find their biologic sex,
NOTE Confidence: 0.861171268571429
00:32:46.990 --> 00:32:47.342 no problem,
NOTE Confidence: 0.861171268571429
00:32:47.342 --> 00:32:48.398 but are you going to find
NOTE Confidence: 0.861171268571429
00:32:48.398 --> 00:32:49.210 their gender orientation,
NOTE Confidence: 0.861171268571429
00:32:49.210 --> 00:32:50.215 that sexual identity?
NOTE Confidence: 0.861171268571429
00:32:50.215 --> 00:32:52.225 You'll find race in this city,
NOTE Confidence: 0.861171268571429
00:32:52.230 --> 00:32:54.715 but are you going to find other
NOTE Confidence: 0.861171268571429
00:32:54.715 --> 00:32:56.310 social determinants of health?
NOTE Confidence: 0.861171268571429
00:32:56.310 --> 00:32:57.550 You'll find the medications
NOTE Confidence: 0.861171268571429
00:32:57.550 --> 00:32:58.790 that they are prescribed,
NOTE Confidence: 0.861171268571429
00:32:58.790 --> 00:33:01.446 but will you find what they actually took,
NOTE Confidence: 0.861171268571429
00:33:01.450 --> 00:33:03.529 the medication that they took and the
NOTE Confidence: 0.861171268571429

00:33:03.529 --> 00:33:05.432 regimens and we're going to get into
NOTE Confidence: 0.861171268571429

00:33:05.432 --> 00:33:07.562 that next you'll find laboratory tests,
NOTE Confidence: 0.861171268571429

00:33:07.562 --> 00:33:10.040 but you want necessarily find images.
NOTE Confidence: 0.861171268571429

00:33:10.040 --> 00:33:11.528 And so forth.
NOTE Confidence: 0.861171268571429

00:33:11.528 --> 00:33:15.000 So kind of you know as moving
NOTE Confidence: 0.898628412727273

00:33:15.117 --> 00:33:17.040 forward. Thinking about what you know,
NOTE Confidence: 0.898628412727273

00:33:17.040 --> 00:33:19.760 the low hanging fruit.
NOTE Confidence: 0.898628412727273

00:33:19.760 --> 00:33:21.848 You know it's the cancer type,
NOTE Confidence: 0.898628412727273

00:33:21.850 --> 00:33:23.482 it's easy like we don't need to create
NOTE Confidence: 0.898628412727273

00:33:23.482 --> 00:33:25.147 a new system to get cancer type.
NOTE Confidence: 0.898628412727273

00:33:25.150 --> 00:33:27.376 You can get that from billing codes,
NOTE Confidence: 0.898628412727273

00:33:27.380 --> 00:33:28.426 registry data.
NOTE Confidence: 0.898628412727273

00:33:28.426 --> 00:33:32.087 The treatments are hard like our chop
NOTE Confidence: 0.898628412727273

00:33:32.087 --> 00:33:34.452 times 6, that's hard determining that
NOTE Confidence: 0.898628412727273

00:33:34.452 --> 00:33:36.810 the patients in a complete remission,
NOTE Confidence: 0.898628412727273

00:33:36.810 --> 00:33:37.479 that's really hard.

NOTE Confidence: 0.898628412727273
00:33:37.479 --> 00:33:39.040 So what I go for the middle,
NOTE Confidence: 0.898628412727273
00:33:39.040 --> 00:33:40.325 I don't go for the middle ground, right,
NOTE Confidence: 0.898628412727273
00:33:40.325 --> 00:33:42.620 I'm going to tackle the thing in the middle.
NOTE Confidence: 0.898628412727273
00:33:42.620 --> 00:33:45.124 So now I'm going to switch gears here
NOTE Confidence: 0.898628412727273
00:33:45.124 --> 00:33:48.779 for a bit and talk about our work on
NOTE Confidence: 0.898628412727273
00:33:48.779 --> 00:33:51.360 standardizing systemic anti cancer treatment.
NOTE Confidence: 0.898628412727273
00:33:51.360 --> 00:33:55.188 And before I get into that.
NOTE Confidence: 0.898628412727273
00:33:55.190 --> 00:33:58.025 If you've not seen this XKCD cartoon,
NOTE Confidence: 0.898628412727273
00:33:58.030 --> 00:33:59.155 it's a classic.
NOTE Confidence: 0.898628412727273
00:33:59.155 --> 00:34:01.437 And this is a challenge, right?
NOTE Confidence: 0.898628412727273
00:34:01.437 --> 00:34:04.286 Whenever you decide to create a new
NOTE Confidence: 0.898628412727273
00:34:04.286 --> 00:34:07.210 standard or you actually just you know.
NOTE Confidence: 0.898628412727273
00:34:07.210 --> 00:34:08.650 Just creating more complexity or not.
NOTE Confidence: 0.898628412727273
00:34:08.650 --> 00:34:09.697 Hopefully we're not.
NOTE Confidence: 0.898628412727273
00:34:09.697 --> 00:34:12.140 Well, what we did in this space,
NOTE Confidence: 0.898628412727273

00:34:12.140 --> 00:34:14.108 there really weren't 14 existing standards.

NOTE Confidence: 0.898628412727273

00:34:14.110 --> 00:34:15.094 There were none.

NOTE Confidence: 0.898628412727273

00:34:15.094 --> 00:34:17.062 And so as everybody here knows,

NOTE Confidence: 0.898628412727273

00:34:17.070 --> 00:34:19.128 I could skip past this slide.

NOTE Confidence: 0.898628412727273

00:34:19.130 --> 00:34:22.430 Chemotherapy regimens are complicated and

NOTE Confidence: 0.898628412727273

00:34:22.430 --> 00:34:25.730 given in cyclic fashion combinations.

NOTE Confidence: 0.898628412727273

00:34:25.730 --> 00:34:27.425 This was the standard when

NOTE Confidence: 0.898628412727273

00:34:27.425 --> 00:34:29.550 we got started on our work.

NOTE Confidence: 0.898628412727273

00:34:29.550 --> 00:34:30.602 This is, you know,

NOTE Confidence: 0.898628412727273

00:34:30.602 --> 00:34:32.180 one example of these things called

NOTE Confidence: 0.898628412727273

00:34:32.237 --> 00:34:33.728 cancer chemotherapy handbooks,

NOTE Confidence: 0.898628412727273

00:34:33.730 --> 00:34:37.006 kind of recipe books, physical books,

NOTE Confidence: 0.898628412727273

00:34:37.010 --> 00:34:37.341 right.

NOTE Confidence: 0.898628412727273

00:34:37.341 --> 00:34:38.996 With some some details here,

NOTE Confidence: 0.898628412727273

00:34:39.000 --> 00:34:41.224 but maybe not enough.

NOTE Confidence: 0.898628412727273

00:34:41.224 --> 00:34:45.740 Here's another example from 2005.

NOTE Confidence: 0.898628412727273
00:34:45.740 --> 00:34:48.953 Which if you kind of look in
NOTE Confidence: 0.898628412727273
00:34:48.953 --> 00:34:51.000 detail about what's there.
NOTE Confidence: 0.898628412727273
00:34:51.000 --> 00:34:54.269 There's there's a lot of optionality here,
NOTE Confidence: 0.898628412727273
00:34:54.270 --> 00:34:55.694 some of the references.
NOTE Confidence: 0.898628412727273
00:34:55.694 --> 00:34:58.410 Here's a little excerpt from the Adenoma.
NOTE Confidence: 0.898628412727273
00:34:58.410 --> 00:34:59.690 I don't know carcinoma of
NOTE Confidence: 0.898628412727273
00:34:59.690 --> 00:35:00.458 unknown primary section,
NOTE Confidence: 0.898628412727273
00:35:00.460 --> 00:35:02.532 but the references are to non small
NOTE Confidence: 0.898628412727273
00:35:02.532 --> 00:35:04.931 cell lung cancer so there's sort of a
NOTE Confidence: 0.898628412727273
00:35:04.931 --> 00:35:06.730 mismatch there in the evidence base.
NOTE Confidence: 0.898628412727273
00:35:06.730 --> 00:35:09.250 So what we did is we.
NOTE Confidence: 0.898628412727273
00:35:09.250 --> 00:35:10.570 Really basically tried to collect
NOTE Confidence: 0.898628412727273
00:35:10.570 --> 00:35:11.890 all this information and put
NOTE Confidence: 0.898628412727273
00:35:11.936 --> 00:35:13.126 it into a computable format,
NOTE Confidence: 0.898628412727273
00:35:13.130 --> 00:35:16.130 which is our hemlock.org website and
NOTE Confidence: 0.898628412727273

00:35:16.130 --> 00:35:18.890 the ontology that comes from it.

NOTE Confidence: 0.898628412727273

00:35:18.890 --> 00:35:21.725 So he might.org is a is a website with

NOTE Confidence: 0.898628412727273

00:35:21.725 --> 00:35:24.689 the goal to collect all standard of

NOTE Confidence: 0.898628412727273

00:35:24.689 --> 00:35:27.230 care systemic anti cancer treatment.

NOTE Confidence: 0.898628412727273

00:35:27.230 --> 00:35:28.523 That's the goal.

NOTE Confidence: 0.898628412727273

00:35:28.523 --> 00:35:32.155 It's a big goal and at the website has

NOTE Confidence: 0.898628412727273

00:35:32.155 --> 00:35:35.080 grown over more than a decade now.

NOTE Confidence: 0.898628412727273

00:35:35.080 --> 00:35:37.120 Of almost 1000 primary content pages,

NOTE Confidence: 0.898628412727273

00:35:37.120 --> 00:35:38.656 over 7000 references,

NOTE Confidence: 0.898628412727273

00:35:38.656 --> 00:35:41.216 and a large editorial board,

NOTE Confidence: 0.898628412727273

00:35:41.220 --> 00:35:44.216 actually members of which are from Yale.

NOTE Confidence: 0.898628412727273

00:35:44.220 --> 00:35:46.110 And and many page views,

NOTE Confidence: 0.898628412727273

00:35:46.110 --> 00:35:49.288 so 1.4 million page views last year,

NOTE Confidence: 0.898628412727273

00:35:49.290 --> 00:35:52.300 we do get visitors from all over

NOTE Confidence: 0.898628412727273

00:35:52.300 --> 00:35:55.429 the world were primarily US based.

NOTE Confidence: 0.898628412727273

00:35:55.430 --> 00:35:57.510 I always like to throw in that we've

NOTE Confidence: 0.898628412727273
00:35:57.510 --> 00:35:59.590 had one visitor from North Korea.
NOTE Confidence: 0.898628412727273
00:35:59.590 --> 00:36:00.808 I don't know who it is,
NOTE Confidence: 0.898628412727273
00:36:00.810 --> 00:36:03.426 but I don't think I want to know.
NOTE Confidence: 0.898628412727273
00:36:03.430 --> 00:36:05.806 So what what can we do with this website?
NOTE Confidence: 0.898628412727273
00:36:05.810 --> 00:36:08.330 So what we did over time,
NOTE Confidence: 0.898628412727273
00:36:08.330 --> 00:36:10.360 over the past 11 years is create
NOTE Confidence: 0.898628412727273
00:36:10.360 --> 00:36:12.231 a structure such that we could
NOTE Confidence: 0.898628412727273
00:36:12.231 --> 00:36:13.796 actually take the content and
NOTE Confidence: 0.898628412727273
00:36:13.796 --> 00:36:15.260 develop a formal model.
NOTE Confidence: 0.898628412727273
00:36:15.260 --> 00:36:17.120 And so this is the model?
NOTE Confidence: 0.898628412727273
00:36:17.120 --> 00:36:19.507 Or this is part of the model?
NOTE Confidence: 0.898628412727273
00:36:19.510 --> 00:36:21.070 And I don't have time right
NOTE Confidence: 0.898628412727273
00:36:21.070 --> 00:36:22.110 now obviously to kind
NOTE Confidence: 0.88690812375
00:36:22.169 --> 00:36:23.867 of go through all these details,
NOTE Confidence: 0.88690812375
00:36:23.870 --> 00:36:27.188 but it's somewhat complex and enlarge
NOTE Confidence: 0.88690812375

00:36:27.188 --> 00:36:30.650 we have over 100,000 concepts and

NOTE Confidence: 0.88690812375

00:36:30.650 --> 00:36:33.626 300,000 ways in which those are

NOTE Confidence: 0.88690812375

00:36:33.626 --> 00:36:36.380 interrelated in the latest version.

NOTE Confidence: 0.88690812375

00:36:36.380 --> 00:36:39.290 This is yeah, this is basically,

NOTE Confidence: 0.88690812375

00:36:39.290 --> 00:36:41.420 this is showing, you know,

NOTE Confidence: 0.88690812375

00:36:41.420 --> 00:36:42.536 I don't have time to actually

NOTE Confidence: 0.88690812375

00:36:42.536 --> 00:36:43.094 show the website.

NOTE Confidence: 0.88690812375

00:36:43.100 --> 00:36:45.302 This is a screenshot from the

NOTE Confidence: 0.88690812375

00:36:45.302 --> 00:36:46.770 website showing basically that

NOTE Confidence: 0.88690812375

00:36:46.833 --> 00:36:48.729 each regimen on the website is.

NOTE Confidence: 0.88690812375

00:36:48.730 --> 00:36:50.490 In such a way that we can take

NOTE Confidence: 0.88690812375

00:36:50.490 --> 00:36:52.074 all those pieces and put them

NOTE Confidence: 0.88690812375

00:36:52.074 --> 00:36:53.694 into the into the data model.

NOTE Confidence: 0.88690812375

00:36:53.700 --> 00:36:55.149 And and and then we can start to do

NOTE Confidence: 0.88690812375

00:36:55.149 --> 00:36:56.477 cool things with real world data.

NOTE Confidence: 0.88690812375

00:36:56.480 --> 00:36:59.119 So here's a project that we did

NOTE Confidence: 0.88690812375

00:36:59.119 --> 00:37:01.630 with with some folks in South

NOTE Confidence: 0.88690812375

00:37:01.630 --> 00:37:06.600 Korea who basically had access to.

NOTE Confidence: 0.88690812375

00:37:06.600 --> 00:37:08.256 Essentially medication level database.

NOTE Confidence: 0.88690812375

00:37:08.256 --> 00:37:11.115 And remember I mentioned you know way

NOTE Confidence: 0.88690812375

00:37:11.115 --> 00:37:13.327 back when that we might get medications,

NOTE Confidence: 0.88690812375

00:37:13.330 --> 00:37:14.955 but to actually understand regimens

NOTE Confidence: 0.88690812375

00:37:14.955 --> 00:37:16.970 we have to do something extra.

NOTE Confidence: 0.88690812375

00:37:16.970 --> 00:37:18.909 And So what they did is they

NOTE Confidence: 0.88690812375

00:37:18.909 --> 00:37:20.945 applied our model and they mapped

NOTE Confidence: 0.88690812375

00:37:20.945 --> 00:37:22.465 medications through regiments and

NOTE Confidence: 0.88690812375

00:37:22.465 --> 00:37:24.711 and they were able to look basically

NOTE Confidence: 0.88690812375

00:37:24.711 --> 00:37:26.914 over a decade of time 2008 to 18.

NOTE Confidence: 0.88690812375

00:37:26.914 --> 00:37:28.888 And you can see here that you know the

NOTE Confidence: 0.88690812375

00:37:28.888 --> 00:37:30.764 changing pattern of care in that country.

NOTE Confidence: 0.88690812375

00:37:30.770 --> 00:37:34.885 So you see that for example of you know

NOTE Confidence: 0.88690812375

00:37:34.885 --> 00:37:37.040 bevacizumab wasn't used really until
NOTE Confidence: 0.88690812375

00:37:37.114 --> 00:37:40.054 2014 and then it started getting popular.
NOTE Confidence: 0.88690812375

00:37:40.060 --> 00:37:42.020 And by the year 2018,
NOTE Confidence: 0.88690812375

00:37:42.020 --> 00:37:42.926 it's, you know,
NOTE Confidence: 0.88690812375

00:37:42.926 --> 00:37:44.436 full Fox and Bevacizumab Kappa,
NOTE Confidence: 0.88690812375

00:37:44.440 --> 00:37:48.000 a good chunk of of the treatment regimens,
NOTE Confidence: 0.88690812375

00:37:48.000 --> 00:37:50.436 whereas something like fluorouracil
NOTE Confidence: 0.88690812375

00:37:50.436 --> 00:37:52.263 monotherapy essentially disappears
NOTE Confidence: 0.88690812375

00:37:52.263 --> 00:37:55.448 off the off the scene by the
NOTE Confidence: 0.88690812375

00:37:55.448 --> 00:37:57.362 by the time you get there.
NOTE Confidence: 0.88690812375

00:37:57.370 --> 00:37:59.064 This is much more recent so that
NOTE Confidence: 0.88690812375

00:37:59.064 --> 00:38:00.964 that's from a couple of years ago
NOTE Confidence: 0.88690812375

00:38:00.964 --> 00:38:03.150 now we're working with folks at the.
NOTE Confidence: 0.8194428005

00:38:05.210 --> 00:38:07.736 University of California System have a
NOTE Confidence: 0.8194428005

00:38:07.736 --> 00:38:10.080 really cool combined database across all
NOTE Confidence: 0.8194428005

00:38:10.080 --> 00:38:12.456 the UC's and California is kind of a.

NOTE Confidence: 0.8194428005

00:38:12.460 --> 00:38:14.364 You know, country unto itself, once you

NOTE Confidence: 0.8194428005

00:38:14.364 --> 00:38:16.416 start putting all this data together,

NOTE Confidence: 0.8194428005

00:38:16.420 --> 00:38:20.022 this is just from UCSF and again

NOTE Confidence: 0.8194428005

00:38:20.022 --> 00:38:22.777 we're taking, we're taking medication

NOTE Confidence: 0.8194428005

00:38:22.777 --> 00:38:25.324 exposure data including time stamps

NOTE Confidence: 0.8194428005

00:38:25.324 --> 00:38:28.604 and we're mapping that to regimens.

NOTE Confidence: 0.8194428005

00:38:28.604 --> 00:38:31.684 And and you see that.

NOTE Confidence: 0.8194428005

00:38:31.690 --> 00:38:35.638 At least nowadays, full ferox is

NOTE Confidence: 0.8194428005

00:38:35.638 --> 00:38:39.070 the most popular regimen there.

NOTE Confidence: 0.8194428005

00:38:39.070 --> 00:38:40.426 And so that's that alone is

NOTE Confidence: 0.8194428005

00:38:40.426 --> 00:38:43.020 an interesting thing, right?

NOTE Confidence: 0.8194428005

00:38:43.020 --> 00:38:44.782 You also see some funny things, right?

NOTE Confidence: 0.8194428005

00:38:44.782 --> 00:38:47.038 Like so I didn't know Leuprolide was a

NOTE Confidence: 0.8194428005

00:38:47.038 --> 00:38:50.260 treatment for pancreatic cancer, did you?

NOTE Confidence: 0.8194428005

00:38:50.260 --> 00:38:53.842 Is it? Not no, right. No.

NOTE Confidence: 0.8194428005

00:38:53.842 --> 00:38:55.860 But these are real patients, right.
NOTE Confidence: 0.8194428005

00:38:55.860 --> 00:38:57.360 And they actually have second malignancies.
NOTE Confidence: 0.8194428005

00:38:57.360 --> 00:38:58.944 So these are people who have
NOTE Confidence: 0.8194428005

00:38:58.944 --> 00:39:00.402 also have prostate cancer and
NOTE Confidence: 0.8194428005

00:39:00.402 --> 00:39:01.810 they're also getting leuprolide.
NOTE Confidence: 0.8194428005

00:39:01.810 --> 00:39:04.450 So you, you, you kind of have to you know,
NOTE Confidence: 0.8194428005

00:39:04.450 --> 00:39:06.450 it's not enough to get that data out.
NOTE Confidence: 0.8194428005

00:39:06.450 --> 00:39:07.284 You've got to,
NOTE Confidence: 0.8194428005

00:39:07.284 --> 00:39:08.873 you got to apply knowledge, right.
NOTE Confidence: 0.8194428005

00:39:08.873 --> 00:39:10.224 You've got to, you've got to determine,
NOTE Confidence: 0.8194428005

00:39:10.230 --> 00:39:11.787 you know, am I, what am I looking at?
NOTE Confidence: 0.8194428005

00:39:11.790 --> 00:39:13.926 Does it make sense, is it?
NOTE Confidence: 0.8194428005

00:39:13.930 --> 00:39:17.180 Is it relevant and and?
NOTE Confidence: 0.8194428005

00:39:17.180 --> 00:39:19.217 And so that that that's why we're
NOTE Confidence: 0.8194428005

00:39:19.217 --> 00:39:20.599 seeing things like that so.
NOTE Confidence: 0.8194428005

00:39:20.600 --> 00:39:23.522 Umm. Here's another kind of.

NOTE Confidence: 0.8194428005

00:39:23.522 --> 00:39:24.048 Here's another.

NOTE Confidence: 0.8194428005

00:39:24.050 --> 00:39:25.570 Gives you a taste of what we can look at.

NOTE Confidence: 0.8194428005

00:39:25.570 --> 00:39:28.972 So that this is this is looking at folfirinox

NOTE Confidence: 0.8194428005

00:39:28.972 --> 00:39:32.137 and and then looking at cycle by cycle.

NOTE Confidence: 0.8194428005

00:39:32.140 --> 00:39:32.914 What's happening?

NOTE Confidence: 0.8194428005

00:39:32.914 --> 00:39:35.236 So one of my long-term interests,

NOTE Confidence: 0.8194428005

00:39:35.240 --> 00:39:37.400 as well as Doctor Zach here,

NOTE Confidence: 0.8194428005

00:39:37.400 --> 00:39:39.890 is to understand treatment delays,

NOTE Confidence: 0.8194428005

00:39:39.890 --> 00:39:42.080 dose reductions.

NOTE Confidence: 0.8194428005

00:39:42.080 --> 00:39:44.887 Removals of medications from a regimen drop,

NOTE Confidence: 0.8194428005

00:39:44.890 --> 00:39:47.098 you know, dropping a drug and this starts

NOTE Confidence: 0.8194428005

00:39:47.098 --> 00:39:49.555 to get at that and you can kind of see,

NOTE Confidence: 0.8194428005

00:39:49.560 --> 00:39:50.104 you know,

NOTE Confidence: 0.8194428005

00:39:50.104 --> 00:39:52.280 each of those bars represents cycle to cycle,

NOTE Confidence: 0.8194428005

00:39:52.280 --> 00:39:54.200 the cycle you see.

NOTE Confidence: 0.8194428005

00:39:54.200 --> 00:39:54.680 People.
NOTE Confidence: 0.8194428005

00:39:54.680 --> 00:39:56.032 People dropping out, right.
NOTE Confidence: 0.8194428005

00:39:56.032 --> 00:39:58.982 And and so and then you can actually see
NOTE Confidence: 0.8194428005

00:39:58.982 --> 00:40:01.639 why and you can see on the top here.
NOTE Confidence: 0.8194428005

00:40:01.640 --> 00:40:03.536 These, these bands at the top are showing.
NOTE Confidence: 0.8194428005

00:40:03.540 --> 00:40:05.220 You know, these these are folks.
NOTE Confidence: 0.8194428005

00:40:05.220 --> 00:40:06.318 You don't think that you have
NOTE Confidence: 0.8194428005

00:40:06.318 --> 00:40:07.050 a pointer or something.
NOTE Confidence: 0.8194428005

00:40:07.050 --> 00:40:10.235 Oh, actually, let's see if this will.
NOTE Confidence: 0.8194428005

00:40:10.240 --> 00:40:10.510 Yeah.
NOTE Confidence: 0.8194428005

00:40:10.510 --> 00:40:10.780 So,
NOTE Confidence: 0.8194428005

00:40:10.780 --> 00:40:12.670 so you see these bands coming across,
NOTE Confidence: 0.8194428005

00:40:12.670 --> 00:40:14.662 those are basically patients that are
NOTE Confidence: 0.8194428005

00:40:14.662 --> 00:40:16.927 progressing and going on to a second
NOTE Confidence: 0.8194428005

00:40:16.927 --> 00:40:18.679 line treatment what's not shown here.
NOTE Confidence: 0.8194428005

00:40:18.680 --> 00:40:20.198 Just to spare you a little

NOTE Confidence: 0.8194428005

00:40:20.198 --> 00:40:21.560 bit on the visual side,

NOTE Confidence: 0.8194428005

00:40:21.560 --> 00:40:24.458 our patients who are or stopping therapy

NOTE Confidence: 0.8194428005

00:40:24.458 --> 00:40:26.490 and and essentially transitioning to

NOTE Confidence: 0.8194428005

00:40:26.490 --> 00:40:29.362 Hospice or some sort of end of life

NOTE Confidence: 0.8194428005

00:40:29.432 --> 00:40:31.777 care and that's this big bar here.

NOTE Confidence: 0.8194428005

00:40:31.780 --> 00:40:34.090 And then some patients these

NOTE Confidence: 0.8194428005

00:40:34.090 --> 00:40:36.350 little these little ones they're

NOTE Confidence: 0.8194428005

00:40:36.350 --> 00:40:38.400 going to a deescalated regimen.

NOTE Confidence: 0.8194428005

00:40:38.400 --> 00:40:40.056 So they're dropping the.

NOTE Confidence: 0.8194428005

00:40:40.056 --> 00:40:42.540 Arena taken or the oxaliplatin and

NOTE Confidence: 0.8194428005

00:40:42.611 --> 00:40:45.299 so you can really start to see these

NOTE Confidence: 0.8194428005

00:40:45.299 --> 00:40:48.535 patterns of care in the real world data so.

NOTE Confidence: 0.8194428005

00:40:48.540 --> 00:40:49.143 OK,

NOTE Confidence: 0.8194428005

00:40:49.143 --> 00:40:49.746 so.

NOTE Confidence: 0.8194428005

00:40:49.746 --> 00:40:53.967 This is my little advertisement for Humalog.

NOTE Confidence: 0.8194428005

00:40:53.970 --> 00:40:56.194 It's available to you.
NOTE Confidence: 0.8194428005

00:40:56.194 --> 00:40:58.985 You can you can download the whole
NOTE Confidence: 0.8194428005

00:40:58.985 --> 00:41:01.472 thing and and and mess around with
NOTE Confidence: 0.8194428005

00:41:01.472 --> 00:41:04.055 it if you're an academic or non
NOTE Confidence: 0.8194428005

00:41:04.055 --> 00:41:05.887 commercial user and just Google
NOTE Confidence: 0.8194428005

00:41:05.887 --> 00:41:08.869 Hemac dataverse and you'll find it.
NOTE Confidence: 0.91100581

00:41:08.870 --> 00:41:11.310 Or you can you can use these links.
NOTE Confidence: 0.91100581

00:41:11.310 --> 00:41:13.975 It's also available through something
NOTE Confidence: 0.91100581

00:41:13.975 --> 00:41:16.640 called the Odyssey Athena vocabulary.
NOTE Confidence: 0.91100581

00:41:16.640 --> 00:41:19.980 And and yeah, I mean, we want more users.
NOTE Confidence: 0.91100581

00:41:19.980 --> 00:41:21.510 There's I think a lot more
NOTE Confidence: 0.91100581

00:41:21.571 --> 00:41:22.957 that can be done with it.
NOTE Confidence: 0.91100581

00:41:22.960 --> 00:41:25.940 So along comes a pandemic.
NOTE Confidence: 0.91100581

00:41:25.940 --> 00:41:28.793 So, so now I want to spend the last
NOTE Confidence: 0.91100581

00:41:28.793 --> 00:41:31.618 little bit here talking about the
NOTE Confidence: 0.91100581

00:41:31.618 --> 00:41:33.562 COVID-19 and cancer consortium.

NOTE Confidence: 0.91100581

00:41:33.570 --> 00:41:36.330 Which yells a member and this

NOTE Confidence: 0.91100581

00:41:36.330 --> 00:41:38.170 is our mission statement,

NOTE Confidence: 0.91100581

00:41:38.170 --> 00:41:40.270 which has been the same since

NOTE Confidence: 0.91100581

00:41:40.270 --> 00:41:42.549 we were created in March 2020,

NOTE Confidence: 0.91100581

00:41:42.550 --> 00:41:44.230 which is our goal is to collect

NOTE Confidence: 0.91100581

00:41:44.230 --> 00:41:44.950 and disseminate prospective,

NOTE Confidence: 0.91100581

00:41:44.950 --> 00:41:46.087 granular, uniformly organized

NOTE Confidence: 0.91100581

00:41:46.087 --> 00:41:47.982 information on people with cancer

NOTE Confidence: 0.91100581

00:41:47.982 --> 00:41:50.075 who are diagnosed with COVID-19 at

NOTE Confidence: 0.91100581

00:41:50.075 --> 00:41:51.995 scale and as rapidly as possible.

NOTE Confidence: 0.91100581

00:41:52.000 --> 00:41:53.337 But what I want to talk about

NOTE Confidence: 0.91100581

00:41:53.337 --> 00:41:55.127 here for a minute is sort of what

NOTE Confidence: 0.91100581

00:41:55.127 --> 00:41:56.440 I call the ancillary goals of

NOTE Confidence: 0.91100581

00:41:56.440 --> 00:41:58.630 C19 or the unwritten goals.

NOTE Confidence: 0.91100581

00:41:58.630 --> 00:42:00.414 So one of those was, you know,

NOTE Confidence: 0.91100581

00:42:00.414 --> 00:42:01.974 can we build a consortium,
NOTE Confidence: 0.91100581

00:42:01.980 --> 00:42:04.636 can we build an airplane while also flying?
NOTE Confidence: 0.91100581

00:42:04.640 --> 00:42:05.844 Just, you know, can we do it?
NOTE Confidence: 0.91100581

00:42:05.850 --> 00:42:07.202 That was the question.
NOTE Confidence: 0.91100581

00:42:07.202 --> 00:42:08.892 Convening a group of stakeholders
NOTE Confidence: 0.91100581

00:42:08.892 --> 00:42:10.560 was really in, you know,
NOTE Confidence: 0.91100581

00:42:10.560 --> 00:42:11.960 a goal including patients,
NOTE Confidence: 0.91100581

00:42:11.960 --> 00:42:15.260 really engaging patients and then.
NOTE Confidence: 0.91100581

00:42:15.260 --> 00:42:16.900 Pertinent to the talk today,
NOTE Confidence: 0.91100581

00:42:16.900 --> 00:42:18.664 can we demonstrate the additive value of
NOTE Confidence: 0.91100581

00:42:18.664 --> 00:42:20.611 real world data elements that are not
NOTE Confidence: 0.91100581

00:42:20.611 --> 00:42:22.315 easily obtained from structured EMR data?
NOTE Confidence: 0.91100581

00:42:22.320 --> 00:42:24.070 We knew that there were other efforts
NOTE Confidence: 0.91100581

00:42:24.070 --> 00:42:25.884 kind of getting rolling that were based
NOTE Confidence: 0.91100581

00:42:25.884 --> 00:42:27.700 on what was in that structured data.
NOTE Confidence: 0.91100581

00:42:27.700 --> 00:42:31.000 If you remember that's the.

NOTE Confidence: 0.91100581
00:42:31.000 --> 00:42:33.874 The tiny little blue bars right
NOTE Confidence: 0.91100581
00:42:33.874 --> 00:42:37.049 on the graph I showed you.
NOTE Confidence: 0.91100581
00:42:37.050 --> 00:42:38.346 So we wanted to, you know,
NOTE Confidence: 0.91100581
00:42:38.350 --> 00:42:43.400 get more than that. So this is.
NOTE Confidence: 0.91100581
00:42:43.400 --> 00:42:46.128 This is back in back in Rhode Island.
NOTE Confidence: 0.91100581
00:42:46.130 --> 00:42:46.361 Alright.
NOTE Confidence: 0.91100581
00:42:46.361 --> 00:42:47.516 Showed you Eli Whitney earlier.
NOTE Confidence: 0.91100581
00:42:47.520 --> 00:42:50.362 This is the this is Slater Mill
NOTE Confidence: 0.91100581
00:42:50.362 --> 00:42:52.954 in Pawtucket which I think I
NOTE Confidence: 0.91100581
00:42:52.954 --> 00:42:54.674 pronounced correctly but I'm
NOTE Confidence: 0.91100581
00:42:54.674 --> 00:42:57.190 getting my New England shops.
NOTE Confidence: 0.91100581
00:42:57.190 --> 00:42:59.668 And and what's interesting to me about
NOTE Confidence: 0.91100581
00:42:59.668 --> 00:43:02.180 this story is that he earned this name,
NOTE Confidence: 0.91100581
00:43:02.180 --> 00:43:05.030 Samuel Shredder Slater and and the
NOTE Confidence: 0.91100581
00:43:05.030 --> 00:43:08.220 reason he was branded as a traitor
NOTE Confidence: 0.91100581

00:43:08.220 --> 00:43:11.013 is that he was accused of stealing
NOTE Confidence: 0.91100581

00:43:11.101 --> 00:43:13.817 the ideas for industrialization.
NOTE Confidence: 0.91100581

00:43:13.820 --> 00:43:16.150 From from the from the,
NOTE Confidence: 0.91100581

00:43:16.150 --> 00:43:19.975 from England where he was born and grew up,
NOTE Confidence: 0.91100581

00:43:19.980 --> 00:43:22.470 and then replicating it in America.
NOTE Confidence: 0.91100581

00:43:22.470 --> 00:43:25.200 So this is really the beginning of
NOTE Confidence: 0.91100581

00:43:25.200 --> 00:43:27.180 the American Industrial Revolution.
NOTE Confidence: 0.91100581

00:43:27.180 --> 00:43:29.262 But what's interesting about that is
NOTE Confidence: 0.91100581

00:43:29.262 --> 00:43:31.648 that he didn't exactly steal the ideas.
NOTE Confidence: 0.91100581

00:43:31.650 --> 00:43:33.060 Like he didn't steal blueprints
NOTE Confidence: 0.91100581

00:43:33.060 --> 00:43:34.188 or things like that.
NOTE Confidence: 0.91100581

00:43:34.190 --> 00:43:36.914 He just like memorized them and
NOTE Confidence: 0.91100581

00:43:36.914 --> 00:43:39.130 brought the knowledge with him.
NOTE Confidence: 0.91100581

00:43:39.130 --> 00:43:42.064 So it's, you know, that's that's what he did.
NOTE Confidence: 0.91100581

00:43:42.070 --> 00:43:46.198 So. I think that that's great actually.
NOTE Confidence: 0.91100581

00:43:46.200 --> 00:43:47.719 And so you know when we think

NOTE Confidence: 0.91100581

00:43:47.719 --> 00:43:49.493 about C 19 and I certainly don't

NOTE Confidence: 0.91100581

00:43:49.493 --> 00:43:51.420 have time to go through all this,

NOTE Confidence: 0.91100581

00:43:51.420 --> 00:43:55.158 but we have many inspirations he,

NOTE Confidence: 0.91100581

00:43:55.160 --> 00:43:55.672 the hemlock,

NOTE Confidence: 0.91100581

00:43:55.672 --> 00:43:58.060 what I just spoke about is one of them.

NOTE Confidence: 0.91100581

00:43:58.060 --> 00:44:01.300 But in all the domains of C19,

NOTE Confidence: 0.91100581

00:44:01.300 --> 00:44:04.000 we are borrowing best ideas,

NOTE Confidence: 0.91100581

00:44:04.000 --> 00:44:06.536 modifying sometimes and putting

NOTE Confidence: 0.91100581

00:44:06.536 --> 00:44:09.012 together this consortium and and

NOTE Confidence: 0.91100581

00:44:09.012 --> 00:44:11.760 this is just sort of a list of that.

NOTE Confidence: 0.91100581

00:44:11.760 --> 00:44:13.140 The other thing I wanted to

NOTE Confidence: 0.91100581

00:44:13.140 --> 00:44:14.060 say about you know

NOTE Confidence: 0.777663597692308

00:44:14.110 --> 00:44:15.466 the C 19. Work and just,

NOTE Confidence: 0.777663597692308

00:44:15.466 --> 00:44:17.501 you know, research in general

NOTE Confidence: 0.777663597692308

00:44:17.501 --> 00:44:19.886 is that sponsors are critical.

NOTE Confidence: 0.777663597692308

00:44:19.890 --> 00:44:21.640 In a Samuel Slater's case,
NOTE Confidence: 0.777663597692308

00:44:21.640 --> 00:44:23.260 he had a sponsor named Moses
NOTE Confidence: 0.777663597692308

00:44:23.260 --> 00:44:24.638 Brown who basically fronted him
NOTE Confidence: 0.777663597692308

00:44:24.638 --> 00:44:26.084 the money to build those mills.
NOTE Confidence: 0.777663597692308

00:44:26.090 --> 00:44:28.922 And our sponsor is Julie Klem at the
NOTE Confidence: 0.777663597692308

00:44:28.922 --> 00:44:32.004 NCI who didn't front us any money but
NOTE Confidence: 0.777663597692308

00:44:32.004 --> 00:44:35.530 was very supportive and helped us kind of,
NOTE Confidence: 0.777663597692308

00:44:35.530 --> 00:44:38.764 you know, surface and socialize our ideas.
NOTE Confidence: 0.777663597692308

00:44:38.770 --> 00:44:40.442 So this is our.
NOTE Confidence: 0.777663597692308

00:44:40.442 --> 00:44:42.532 This is our data schema,
NOTE Confidence: 0.777663597692308

00:44:42.540 --> 00:44:44.924 and what I want to emphasize here related
NOTE Confidence: 0.777663597692308

00:44:44.924 --> 00:44:47.467 to this talk is that everything in red.
NOTE Confidence: 0.777663597692308

00:44:47.470 --> 00:44:49.888 Is not available in structured data,
NOTE Confidence: 0.777663597692308

00:44:49.890 --> 00:44:52.530 so as we sort of built this up.
NOTE Confidence: 0.777663597692308

00:44:52.530 --> 00:44:53.066 You know,
NOTE Confidence: 0.777663597692308

00:44:53.066 --> 00:44:54.942 some of these things you can collect,

NOTE Confidence: 0.777663597692308
00:44:54.950 --> 00:44:56.408 you know, in many different ways.
NOTE Confidence: 0.777663597692308
00:44:56.410 --> 00:44:57.266 But the red items.
NOTE Confidence: 0.777663597692308
00:44:57.266 --> 00:44:58.873 And you'll see in a few slides
NOTE Confidence: 0.777663597692308
00:44:58.873 --> 00:45:00.763 that those turn out to be critical
NOTE Confidence: 0.777663597692308
00:45:00.763 --> 00:45:02.580 things like ECOG performance status,
NOTE Confidence: 0.777663597692308
00:45:02.580 --> 00:45:05.800 things like toxicity of
NOTE Confidence: 0.777663597692308
00:45:05.800 --> 00:45:08.215 cancer treatment pneumonitis.
NOTE Confidence: 0.777663597692308
00:45:08.220 --> 00:45:09.129 Items like that,
NOTE Confidence: 0.777663597692308
00:45:09.129 --> 00:45:11.500 that we really wanted to zero in on.
NOTE Confidence: 0.777663597692308
00:45:11.500 --> 00:45:12.466 I'm going to skip this slide.
NOTE Confidence: 0.777663597692308
00:45:12.470 --> 00:45:14.714 I'm going to skip this and
NOTE Confidence: 0.777663597692308
00:45:14.714 --> 00:45:17.069 I'm going to just say that.
NOTE Confidence: 0.777663597692308
00:45:17.070 --> 00:45:19.023 We've done really pretty well on capturing
NOTE Confidence: 0.777663597692308
00:45:19.023 --> 00:45:21.090 what I would call elusive variables.
NOTE Confidence: 0.777663597692308
00:45:21.090 --> 00:45:22.842 So these are kind of the
NOTE Confidence: 0.777663597692308

00:45:22.842 --> 00:45:25.166 things that they're in the ER,
NOTE Confidence: 0.777663597692308

00:45:25.166 --> 00:45:27.336 but they're in that unstructured.
NOTE Confidence: 0.777663597692308

00:45:27.340 --> 00:45:28.276 Leak of data,
NOTE Confidence: 0.777663597692308

00:45:28.276 --> 00:45:30.980 but we we got a lot of them.
NOTE Confidence: 0.777663597692308

00:45:30.980 --> 00:45:34.070 So cancer status is the patient.
NOTE Confidence: 0.777663597692308

00:45:34.070 --> 00:45:34.780 Getting better,
NOTE Confidence: 0.777663597692308

00:45:34.780 --> 00:45:36.555 getting worse or staying this,
NOTE Confidence: 0.777663597692308

00:45:36.560 --> 00:45:37.688 you know the same as before,
NOTE Confidence: 0.777663597692308

00:45:37.690 --> 00:45:38.599 a stable disease.
NOTE Confidence: 0.777663597692308

00:45:38.599 --> 00:45:41.372 We have that in over 95% of the patients.
NOTE Confidence: 0.777663597692308

00:45:41.372 --> 00:45:43.929 Even smoking status is hard to get right.
NOTE Confidence: 0.777663597692308

00:45:43.930 --> 00:45:45.778 We have that.
NOTE Confidence: 0.777663597692308

00:45:45.780 --> 00:45:48.080 Did COVID affects the patients
NOTE Confidence: 0.777663597692308

00:45:48.080 --> 00:45:50.488 treatment plants that's not going to
NOTE Confidence: 0.777663597692308

00:45:50.488 --> 00:45:51.976 be unstructured data necessarily.
NOTE Confidence: 0.777663597692308

00:45:51.980 --> 00:45:55.418 We have over 90% on that on the ECOG

NOTE Confidence: 0.777663597692308

00:45:55.418 --> 00:45:57.463 which is a notorious notoriously

NOTE Confidence: 0.777663597692308

00:45:57.463 --> 00:45:59.514 difficult thing to get and and all

NOTE Confidence: 0.777663597692308

00:45:59.514 --> 00:46:01.111 the various efforts such as flat

NOTE Confidence: 0.777663597692308

00:46:01.111 --> 00:46:02.894 iron and and so forth have had

NOTE Confidence: 0.777663597692308

00:46:02.894 --> 00:46:04.414 had challenging and cancer link

NOTE Confidence: 0.777663597692308

00:46:04.414 --> 00:46:05.963 have had challenges with this.

NOTE Confidence: 0.777663597692308

00:46:05.963 --> 00:46:08.626 We have we have ECOG data on 88%

NOTE Confidence: 0.777663597692308

00:46:08.626 --> 00:46:10.256 although that does that includes

NOTE Confidence: 0.777663597692308

00:46:10.256 --> 00:46:11.882 patients who just didn't have

NOTE Confidence: 0.777663597692308

00:46:11.882 --> 00:46:13.484 any ECOG recorded but we that

NOTE Confidence: 0.777663597692308

00:46:13.484 --> 00:46:15.088 knowledge of no ECOG is still.

NOTE Confidence: 0.777663597692308

00:46:15.090 --> 00:46:16.350 Knowledge,

NOTE Confidence: 0.777663597692308

00:46:16.350 --> 00:46:17.610 right?

NOTE Confidence: 0.777663597692308

00:46:17.610 --> 00:46:19.920 And you know getting to our

NOTE Confidence: 0.777663597692308

00:46:19.920 --> 00:46:22.199 getting to our results again in

NOTE Confidence: 0.777663597692308

00:46:22.199 --> 00:46:24.284 just focus on the red and what
NOTE Confidence: 0.777663597692308

00:46:24.284 --> 00:46:25.586 we found is that these factors,
NOTE Confidence: 0.777663597692308

00:46:25.590 --> 00:46:28.446 these elusive factors are really important.
NOTE Confidence: 0.777663597692308

00:46:28.450 --> 00:46:30.680 And so this is unadjusted
NOTE Confidence: 0.777663597692308

00:46:30.680 --> 00:46:32.464 just kind of descriptive.
NOTE Confidence: 0.777663597692308

00:46:32.470 --> 00:46:34.582 If you had progressing cancer at
NOTE Confidence: 0.777663597692308

00:46:34.582 --> 00:46:36.668 baseline you get COVID your 30
NOTE Confidence: 0.777663597692308

00:46:36.668 --> 00:46:38.746 day mortality is 26% and if you
NOTE Confidence: 0.777663597692308

00:46:38.746 --> 00:46:41.390 had an ECOG of two or higher your
NOTE Confidence: 0.777663597692308

00:46:41.390 --> 00:46:43.090 your mortality is extremely high.
NOTE Confidence: 0.906268886

00:46:45.190 --> 00:46:48.440 And we also found that immunosuppression
NOTE Confidence: 0.906268886

00:46:48.440 --> 00:46:52.240 which is a somewhat nebulous
NOTE Confidence: 0.906268886

00:46:52.240 --> 00:46:54.160 definition and we have our
NOTE Confidence: 0.906268886

00:46:54.160 --> 00:46:56.080 definition here which is complex,
NOTE Confidence: 0.906268886

00:46:56.080 --> 00:46:58.369 which includes a lot of things you
NOTE Confidence: 0.906268886

00:46:58.369 --> 00:47:00.140 can't easily get out of structured data.

NOTE Confidence: 0.906268886

00:47:00.140 --> 00:47:02.415 So this is sort of the real

NOTE Confidence: 0.906268886

00:47:02.415 --> 00:47:04.417 world data is a is a huge,

NOTE Confidence: 0.906268886

00:47:04.420 --> 00:47:07.778 is a huge driver of of mortality.

NOTE Confidence: 0.906268886

00:47:07.778 --> 00:47:10.699 And if you look at the right on the right,

NOTE Confidence: 0.906268886

00:47:10.700 --> 00:47:12.245 the, the yellow table basically

NOTE Confidence: 0.906268886

00:47:12.245 --> 00:47:14.289 those are the patients who are

NOTE Confidence: 0.906268886

00:47:14.289 --> 00:47:15.609 immunosuppressed at baseline.

NOTE Confidence: 0.906268886

00:47:15.610 --> 00:47:17.282 And across the board,

NOTE Confidence: 0.906268886

00:47:17.282 --> 00:47:18.954 even younger patients have

NOTE Confidence: 0.906268886

00:47:18.954 --> 00:47:20.810 substantial mortality in our data set.

NOTE Confidence: 0.862009429

00:47:23.530 --> 00:47:25.600 Furthermore, if you add on

NOTE Confidence: 0.862009429

00:47:25.600 --> 00:47:27.670 top of that active cancer.

NOTE Confidence: 0.862009429

00:47:27.670 --> 00:47:28.886 So are they immunosuppressed

NOTE Confidence: 0.862009429

00:47:28.886 --> 00:47:30.406 and they have active cancer.

NOTE Confidence: 0.862009429

00:47:30.410 --> 00:47:34.120 Again, we have our definition for that.

NOTE Confidence: 0.862009429

00:47:34.120 --> 00:47:35.570 Because if you're not immunosuppressed
NOTE Confidence: 0.862009429

00:47:35.570 --> 00:47:37.020 and you have inactive cancer,
NOTE Confidence: 0.862009429

00:47:37.020 --> 00:47:39.100 in our data, at least you have a
NOTE Confidence: 0.862009429

00:47:39.100 --> 00:47:41.552 zero chance of dying in the 30 days,
NOTE Confidence: 0.862009429

00:47:41.552 --> 00:47:43.292 whereas if you're older immunosuppressed,
NOTE Confidence: 0.862009429

00:47:43.300 --> 00:47:44.956 your chance goes all the way up to 30%.
NOTE Confidence: 0.862009429

00:47:44.960 --> 00:47:47.384 So really a huge spread here
NOTE Confidence: 0.862009429

00:47:47.384 --> 00:47:49.500 based on these these data.
NOTE Confidence: 0.862009429

00:47:49.500 --> 00:47:52.676 And then if we start to look at.
NOTE Confidence: 0.862009429

00:47:52.680 --> 00:47:54.309 Multivariable adjusted analysis.
NOTE Confidence: 0.862009429

00:47:54.309 --> 00:47:57.567 Again, we see that these factors
NOTE Confidence: 0.862009429

00:47:57.567 --> 00:48:01.031 like ECOG or cancer status are are
NOTE Confidence: 0.862009429

00:48:01.031 --> 00:48:02.923 highly associated with outcome,
NOTE Confidence: 0.862009429

00:48:02.930 --> 00:48:04.790 both mortality as well as severity,
NOTE Confidence: 0.862009429

00:48:04.790 --> 00:48:06.764 which means hospitalization,
NOTE Confidence: 0.862009429

00:48:06.764 --> 00:48:09.396 intubation and so forth.

NOTE Confidence: 0.862009429

00:48:09.400 --> 00:48:11.144 We saw this as well more recently when

NOTE Confidence: 0.862009429

00:48:11.144 --> 00:48:12.679 we looked at vaccinated patients.

NOTE Confidence: 0.862009429

00:48:12.680 --> 00:48:14.765 So patients who are getting

NOTE Confidence: 0.862009429

00:48:14.765 --> 00:48:16.433 breakthrough COVID-19 after vaccine

NOTE Confidence: 0.862009429

00:48:16.433 --> 00:48:18.543 again we saw things like cancer

NOTE Confidence: 0.862009429

00:48:18.543 --> 00:48:20.360 status really you know being a,

NOTE Confidence: 0.862009429

00:48:20.360 --> 00:48:22.508 you know huge adjusted odds ratio

NOTE Confidence: 0.862009429

00:48:22.508 --> 00:48:26.101 there of six if you had an active and

NOTE Confidence: 0.862009429

00:48:26.101 --> 00:48:28.578 progressing cancer of of dying in 30 days.

NOTE Confidence: 0.728421021666667

00:48:31.380 --> 00:48:33.480 So I could talk about COVID

NOTE Confidence: 0.728421021666667

00:48:33.480 --> 00:48:34.660 C19 itself for an hour,

NOTE Confidence: 0.728421021666667

00:48:34.660 --> 00:48:37.540 but I'm going to pause and so I just

NOTE Confidence: 0.728421021666667

00:48:37.540 --> 00:48:40.359 want to share some parting thoughts.

NOTE Confidence: 0.728421021666667

00:48:40.360 --> 00:48:42.558 So, first of all, I think I'm,

NOTE Confidence: 0.728421021666667

00:48:42.560 --> 00:48:43.964 I'm a, you know, I'm, I'm,

NOTE Confidence: 0.728421021666667

00:48:43.964 --> 00:48:45.728 I'm a believer here that real
NOTE Confidence: 0.728421021666667

00:48:45.728 --> 00:48:47.795 world data has a great potential
NOTE Confidence: 0.728421021666667

00:48:47.795 --> 00:48:49.670 to yield real-world evidence if.
NOTE Confidence: 0.728421021666667

00:48:49.670 --> 00:48:51.362 We approach it with an understanding
NOTE Confidence: 0.728421021666667

00:48:51.362 --> 00:48:52.490 about the completeness issues,
NOTE Confidence: 0.728421021666667

00:48:52.490 --> 00:48:53.591 the accuracy issues,
NOTE Confidence: 0.728421021666667

00:48:53.591 --> 00:48:56.160 and we anticipate them and we come
NOTE Confidence: 0.728421021666667

00:48:56.231 --> 00:48:58.359 up with either ways to adjust for
NOTE Confidence: 0.728421021666667

00:48:58.359 --> 00:49:01.870 them or or avoid certain data,
NOTE Confidence: 0.728421021666667

00:49:01.870 --> 00:49:04.846 certain variables in the first place.
NOTE Confidence: 0.728421021666667

00:49:04.850 --> 00:49:07.130 We need a so.
NOTE Confidence: 0.728421021666667

00:49:07.130 --> 00:49:09.160 Yes, we need automated methods, right?
NOTE Confidence: 0.728421021666667

00:49:09.160 --> 00:49:10.700 Like, it wouldn't be great if NLP
NOTE Confidence: 0.728421021666667

00:49:10.700 --> 00:49:12.329 and a computer could do everything,
NOTE Confidence: 0.728421021666667

00:49:12.330 --> 00:49:14.330 but in reality a lot of real world
NOTE Confidence: 0.728421021666667

00:49:14.330 --> 00:49:15.977 data and real world evidence

NOTE Confidence: 0.728421021666667
00:49:15.977 --> 00:49:17.787 depends on human curators going
NOTE Confidence: 0.728421021666667
00:49:17.787 --> 00:49:20.050 into EHR's pulling out that data.
NOTE Confidence: 0.728421021666667
00:49:20.050 --> 00:49:22.874 And to do that we need rigorous approaches.
NOTE Confidence: 0.728421021666667
00:49:22.880 --> 00:49:24.650 We have a paper published earlier
NOTE Confidence: 0.728421021666667
00:49:24.650 --> 00:49:26.145 this year describing the approach
NOTE Confidence: 0.728421021666667
00:49:26.145 --> 00:49:27.420 we used in ACR Genie.
NOTE Confidence: 0.728421021666667
00:49:27.420 --> 00:49:28.736 I encourage you to check that out.
NOTE Confidence: 0.728421021666667
00:49:28.740 --> 00:49:30.604 It basically gets into.
NOTE Confidence: 0.728421021666667
00:49:30.604 --> 00:49:32.934 You know you need directives.
NOTE Confidence: 0.728421021666667
00:49:32.940 --> 00:49:35.370 You need you need two people
NOTE Confidence: 0.728421021666667
00:49:35.370 --> 00:49:37.396 to to independently curate the
NOTE Confidence: 0.728421021666667
00:49:37.396 --> 00:49:39.664 same record at a certain rate so
NOTE Confidence: 0.728421021666667
00:49:39.664 --> 00:49:42.848 you can see if you know there's
NOTE Confidence: 0.728421021666667
00:49:42.848 --> 00:49:44.812 comparability between their results.
NOTE Confidence: 0.728421021666667
00:49:44.820 --> 00:49:46.119 And so forth.
NOTE Confidence: 0.728421021666667

00:49:46.119 --> 00:49:48.284 If if there's widespread adoption
NOTE Confidence: 0.728421021666667

00:49:48.284 --> 00:49:50.310 of standards such as M code,
NOTE Confidence: 0.728421021666667

00:49:50.310 --> 00:49:51.770 hemac, omop and so forth,
NOTE Confidence: 0.728421021666667

00:49:51.770 --> 00:49:54.194 that that will increase the usefulness
NOTE Confidence: 0.728421021666667

00:49:54.194 --> 00:49:56.556 of structured data margin markedly.
NOTE Confidence: 0.728421021666667

00:49:56.556 --> 00:50:00.567 I think NLP is having a moment.
NOTE Confidence: 0.728421021666667

00:50:00.570 --> 00:50:03.370 If you pick up the newspaper nowadays,
NOTE Confidence: 0.728421021666667

00:50:03.370 --> 00:50:05.404 like you're going to see our other paper on,
NOTE Confidence: 0.728421021666667

00:50:05.410 --> 00:50:06.674 you're going to see an article on chat,
NOTE Confidence: 0.728421021666667

00:50:06.680 --> 00:50:08.048 GPT, for example,
NOTE Confidence: 0.728421021666667

00:50:08.048 --> 00:50:11.240 which is generative NLP but sort of
NOTE Confidence: 0.728421021666667

00:50:11.327 --> 00:50:16.409 the other side of NLP, and then Umm.
NOTE Confidence: 0.728421021666667

00:50:16.410 --> 00:50:17.730 You know, really important though,
NOTE Confidence: 0.728421021666667

00:50:17.730 --> 00:50:19.584 and I didn't get to touch on this at
NOTE Confidence: 0.728421021666667

00:50:19.584 --> 00:50:21.681 all except for the very beginning when
NOTE Confidence: 0.728421021666667

00:50:21.681 --> 00:50:23.420 I alluded to disparities and bias.

NOTE Confidence: 0.728421021666667
00:50:23.420 --> 00:50:25.928 There's a lot of concern that.
NOTE Confidence: 0.728421021666667
00:50:25.930 --> 00:50:26.343 That,
NOTE Confidence: 0.728421021666667
00:50:26.343 --> 00:50:27.169 you know,
NOTE Confidence: 0.728421021666667
00:50:27.169 --> 00:50:29.234 working with real-world data might
NOTE Confidence: 0.728421021666667
00:50:29.234 --> 00:50:31.552 might actually make biases worse that
NOTE Confidence: 0.728421021666667
00:50:31.552 --> 00:50:33.688 are already present in that data.
NOTE Confidence: 0.728421021666667
00:50:33.690 --> 00:50:37.554 So we need new approaches to to to.
NOTE Confidence: 0.728421021666667
00:50:37.560 --> 00:50:40.899 New approaches to deal with that issue.
NOTE Confidence: 0.728421021666667
00:50:40.900 --> 00:50:42.220 Just have some acknowledgements here.
NOTE Confidence: 0.728421021666667
00:50:42.220 --> 00:50:43.400 So there's two slides here.
NOTE Confidence: 0.728421021666667
00:50:43.400 --> 00:50:44.877 So this is my first acknowledgement slide.
NOTE Confidence: 0.728421021666667
00:50:44.880 --> 00:50:47.400 I acknowledge the himanka.org
NOTE Confidence: 0.728421021666667
00:50:47.400 --> 00:50:48.660 editorial board.
NOTE Confidence: 0.728421021666667
00:50:48.660 --> 00:50:50.310 Others that have worked on
NOTE Confidence: 0.728421021666667
00:50:50.310 --> 00:50:52.440 it are funding and and Dolly,
NOTE Confidence: 0.728421021666667

00:50:52.440 --> 00:50:54.126 which is the creator of some
NOTE Confidence: 0.728421021666667

00:50:54.126 --> 00:50:55.540 of those graphics you saw.
NOTE Confidence: 0.728421021666667

00:50:55.540 --> 00:50:58.123 And here's our acknowledgement for the C19,
NOTE Confidence: 0.728421021666667

00:50:58.123 --> 00:51:02.482 which is a huge endeavor that has more
NOTE Confidence: 0.728421021666667

00:51:02.482 --> 00:51:06.080 than 600 active investigators at this point.
NOTE Confidence: 0.728421021666667

00:51:06.080 --> 00:51:07.124 And with that,
NOTE Confidence: 0.728421021666667

00:51:07.124 --> 00:51:08.864 I will pause for questions.
NOTE Confidence: 0.7881931

00:51:16.340 --> 00:51:21.158 So I'll I'll start. And can you see
NOTE Confidence: 0.7881931

00:51:21.158 --> 00:51:22.500 the ones that are online or not?
NOTE Confidence: 0.635115704

00:51:22.770 --> 00:51:27.300 I do see, yes, yes, I see.
NOTE Confidence: 0.785123106956522

00:51:27.300 --> 00:51:29.964 So I I, I don't for a second dispute
NOTE Confidence: 0.785123106956522

00:51:29.964 --> 00:51:32.779 the value of real world data in terms
NOTE Confidence: 0.785123106956522

00:51:32.779 --> 00:51:35.388 of being able to answer questions,
NOTE Confidence: 0.785123106956522

00:51:35.390 --> 00:51:38.510 but I'm struck by the fact that we
NOTE Confidence: 0.785123106956522

00:51:38.510 --> 00:51:41.199 have these two extremes we have.
NOTE Confidence: 0.785123106956522

00:51:41.200 --> 00:51:43.412 Randomized controlled trials where

NOTE Confidence: 0.785123106956522
00:51:43.412 --> 00:51:47.198 we spend a fortune to collect every
NOTE Confidence: 0.785123106956522
00:51:47.198 --> 00:51:51.808 last bit of data and you know they
NOTE Confidence: 0.785123106956522
00:51:51.808 --> 00:51:56.490 cost \$15,000 per patient or more.
NOTE Confidence: 0.785123106956522
00:51:56.490 --> 00:51:59.058 And we get lots of useless data as
NOTE Confidence: 0.785123106956522
00:51:59.058 --> 00:52:01.830 part of it. And then we then say,
NOTE Confidence: 0.785123106956522
00:52:01.830 --> 00:52:04.494 well, we can't do get everything
NOTE Confidence: 0.785123106956522
00:52:04.494 --> 00:52:06.270 from randomized controlled trials.
NOTE Confidence: 0.785123106956522
00:52:06.270 --> 00:52:08.566 So then we go to real world data
NOTE Confidence: 0.785123106956522
00:52:08.566 --> 00:52:09.856 where everything's pretty messy
NOTE Confidence: 0.785123106956522
00:52:09.856 --> 00:52:12.180 and you have to make all these
NOTE Confidence: 0.785123106956522
00:52:12.249 --> 00:52:14.265 assumptions and clean up the data.
NOTE Confidence: 0.785123106956522
00:52:14.270 --> 00:52:16.710 And the the question is,
NOTE Confidence: 0.785123106956522
00:52:16.710 --> 00:52:21.603 is there a role for much simpler randomized
NOTE Confidence: 0.785123106956522
00:52:21.603 --> 00:52:25.880 trials done as part of standard?
NOTE Confidence: 0.785123106956522
00:52:25.880 --> 00:52:26.790 Practice.
NOTE Confidence: 0.839671244545455

00:52:28.940 --> 00:52:30.000 I mean sure, yeah,
NOTE Confidence: 0.839671244545455

00:52:30.000 --> 00:52:32.000 I mean I think the recovery trial,
NOTE Confidence: 0.839671244545455

00:52:32.000 --> 00:52:34.440 I mean that they they showed that you
NOTE Confidence: 0.839671244545455

00:52:34.440 --> 00:52:36.784 can do these huge pragmatic trials
NOTE Confidence: 0.839671244545455

00:52:36.784 --> 00:52:39.678 in 10s of thousands of patients with
NOTE Confidence: 0.839671244545455

00:52:39.680 --> 00:52:40.919 they didn't spend a lot of money.
NOTE Confidence: 0.839671244545455

00:52:40.920 --> 00:52:42.696 I mean they used off the shelf drugs,
NOTE Confidence: 0.839671244545455

00:52:42.700 --> 00:52:45.780 right, dexamethason you know things.
NOTE Confidence: 0.839671244545455

00:52:45.780 --> 00:52:46.818 Some of the drugs we won't,
NOTE Confidence: 0.839671244545455

00:52:46.820 --> 00:52:48.472 we won't say the words but you
NOTE Confidence: 0.839671244545455

00:52:48.472 --> 00:52:50.159 know and things like oxygen right.
NOTE Confidence: 0.839671244545455

00:52:50.160 --> 00:52:51.707 But when you get into the you
NOTE Confidence: 0.839671244545455

00:52:51.707 --> 00:52:52.894 know the expensive drugs that
NOTE Confidence: 0.839671244545455

00:52:52.894 --> 00:52:54.079 are not yet FDA approved,
NOTE Confidence: 0.839671244545455

00:52:54.080 --> 00:52:57.480 I think that's a whole other area but.
NOTE Confidence: 0.839671244545455

00:52:57.480 --> 00:52:59.730 I I think that FDA has got to lead

NOTE Confidence: 0.839671244545455
00:52:59.730 --> 00:53:02.224 the way in some ways here because they
NOTE Confidence: 0.839671244545455
00:53:02.224 --> 00:53:04.737 and I didn't get to talk about this,
NOTE Confidence: 0.839671244545455
00:53:04.740 --> 00:53:05.808 but you know,
NOTE Confidence: 0.839671244545455
00:53:05.808 --> 00:53:07.588 there's a high profile rejection
NOTE Confidence: 0.839671244545455
00:53:07.588 --> 00:53:09.230 of real-world data within the
NOTE Confidence: 0.839671244545455
00:53:09.230 --> 00:53:10.675 last month or two that.
NOTE Confidence: 0.839671244545455
00:53:10.680 --> 00:53:11.062 You know,
NOTE Confidence: 0.839671244545455
00:53:11.062 --> 00:53:12.399 there was an attempt to get something
NOTE Confidence: 0.839671244545455
00:53:12.399 --> 00:53:13.657 approved based on some real-world data.
NOTE Confidence: 0.839671244545455
00:53:13.660 --> 00:53:15.196 And I think they rightly looked at that
NOTE Confidence: 0.839671244545455
00:53:15.196 --> 00:53:16.523 and they said that this particular
NOTE Confidence: 0.839671244545455
00:53:16.523 --> 00:53:17.867 set of data is not trustworthy
NOTE Confidence: 0.839671244545455
00:53:17.915 --> 00:53:19.235 and we're not going to go for it.
NOTE Confidence: 0.839671244545455
00:53:19.240 --> 00:53:21.095 But I don't think that that should
NOTE Confidence: 0.839671244545455
00:53:21.095 --> 00:53:22.780 shut down the whole endeavor.
NOTE Confidence: 0.839671244545455

00:53:22.780 --> 00:53:23.840 I think that they need,
NOTE Confidence: 0.839671244545455

00:53:23.840 --> 00:53:24.482 they need,
NOTE Confidence: 0.839671244545455

00:53:24.482 --> 00:53:26.408 we need guidance from them and
NOTE Confidence: 0.839671244545455

00:53:26.408 --> 00:53:28.591 and and you know about what
NOTE Confidence: 0.839671244545455

00:53:28.591 --> 00:53:30.793 components should and should not be,
NOTE Confidence: 0.839671244545455

00:53:30.800 --> 00:53:32.016 you know, collected routinely.
NOTE Confidence: 0.839671244545455

00:53:32.016 --> 00:53:34.169 I think that might simplify things a lot.
NOTE Confidence: 0.746431946928571

00:53:35.570 --> 00:53:38.270 Attempt to put together criteria that
NOTE Confidence: 0.746431946928571

00:53:38.270 --> 00:53:41.470 that would allow you to say that this.
NOTE Confidence: 0.746431946928571

00:53:41.470 --> 00:53:44.078 This set of real world data is adequate
NOTE Confidence: 0.746431946928571

00:53:44.078 --> 00:53:46.507 to Brock inclusions from you know,
NOTE Confidence: 0.746431946928571

00:53:46.510 --> 00:53:49.350 in terms of how much it has to be cleaned up,
NOTE Confidence: 0.746431946928571

00:53:49.350 --> 00:53:51.710 how large the sample size has to be.
NOTE Confidence: 0.90763503

00:53:53.730 --> 00:53:57.960 I think. It it's such an interesting
NOTE Confidence: 0.90763503

00:53:57.960 --> 00:54:00.561 question and I'm I'm not aware of of
NOTE Confidence: 0.90763503

00:54:00.561 --> 00:54:02.934 anything at this moment but I do you

NOTE Confidence: 0.90763503

00:54:02.934 --> 00:54:05.178 know we are there's this great bias

NOTE Confidence: 0.90763503

00:54:05.178 --> 00:54:07.684 that I just learned about called the

NOTE Confidence: 0.90763503

00:54:07.684 --> 00:54:09.654 informed presence bias which I kind of

NOTE Confidence: 0.90763503

00:54:09.654 --> 00:54:12.197 knew I knew it but not by those words

NOTE Confidence: 0.90763503

00:54:12.197 --> 00:54:14.108 but that basically means that patients

NOTE Confidence: 0.90763503

00:54:14.108 --> 00:54:16.700 who spend a lot of time in the clinic

NOTE Confidence: 0.90763503

00:54:16.770 --> 00:54:19.362 or the medical system have a lot of data

NOTE Confidence: 0.90763503

00:54:19.362 --> 00:54:21.319 right whereas those that don't don't

NOTE Confidence: 0.90763503

00:54:21.319 --> 00:54:23.940 and and and it's and and it's actually

NOTE Confidence: 0.90763503

00:54:23.940 --> 00:54:25.640 an incredibly important source of.

NOTE Confidence: 0.90763503

00:54:25.640 --> 00:54:30.050 The bias? That. That.

NOTE Confidence: 0.90763503

00:54:30.050 --> 00:54:31.162 You know, can you?

NOTE Confidence: 0.90763503

00:54:31.162 --> 00:54:33.231 So if a patient doesn't spend enough

NOTE Confidence: 0.90763503

00:54:33.231 --> 00:54:35.265 time to get enough data generated,

NOTE Confidence: 0.90763503

00:54:35.270 --> 00:54:36.600 that's something we should know.

NOTE Confidence: 0.90763503

00:54:36.600 --> 00:54:37.895 That's something we need to know, right?

NOTE Confidence: 0.90763503

00:54:37.895 --> 00:54:40.025 But that's almost that kind of,

NOTE Confidence: 0.90763503

00:54:40.030 --> 00:54:41.515 you know, descriptor is almost

NOTE Confidence: 0.90763503

00:54:41.515 --> 00:54:43.630 never available in in any real world

NOTE Confidence: 0.90763503

00:54:43.630 --> 00:54:45.320 data study to my knowledge, so.

NOTE Confidence: 0.394810793333333

00:54:46.840 --> 00:54:47.779 The online version.

NOTE Confidence: 0.9350764

00:54:52.750 --> 00:54:53.000 Yeah.

NOTE Confidence: 0.031019479

00:55:06.820 --> 00:55:07.450 Schedule.

NOTE Confidence: 0.82457125

00:55:10.680 --> 00:55:11.160 What is?

NOTE Confidence: 0.839222

00:55:16.020 --> 00:55:16.430 COVID-19.

NOTE Confidence: 0.84858656

00:55:28.240 --> 00:55:31.640 Yeah. Yeah. So the question is,

NOTE Confidence: 0.84858656

00:55:31.640 --> 00:55:34.400 it seems to be the case that the

NOTE Confidence: 0.84858656

00:55:34.400 --> 00:55:36.650 patients with the pre-existing cancer

NOTE Confidence: 0.84858656

00:55:36.650 --> 00:55:39.620 having worse outcomes during the COVID

NOTE Confidence: 0.84858656

00:55:39.620 --> 00:55:42.738 era than before and why might that be?

NOTE Confidence: 0.84858656

00:55:42.740 --> 00:55:44.444 I can say from our consortium now we

NOTE Confidence: 0.84858656

00:55:44.444 --> 00:55:46.116 only look at patients who had COVID.

NOTE Confidence: 0.84858656

00:55:46.120 --> 00:55:47.440 So that's a subset, right?

NOTE Confidence: 0.84858656

00:55:47.440 --> 00:55:48.640 Well, as time goes on,

NOTE Confidence: 0.84858656

00:55:48.640 --> 00:55:50.176 it's going to be everybody maybe.

NOTE Confidence: 0.84858656

00:55:50.180 --> 00:55:52.740 But what we do see is that you know at

NOTE Confidence: 0.84858656

00:55:52.813 --> 00:55:55.264 least in our registry 40% of patients

NOTE Confidence: 0.84858656

00:55:55.264 --> 00:55:57.174 have their treatment altered in

NOTE Confidence: 0.84858656

00:55:57.174 --> 00:55:59.958 some way and usually that's a delay.

NOTE Confidence: 0.84858656

00:55:59.960 --> 00:56:02.012 But sometimes they can't get the

NOTE Confidence: 0.84858656

00:56:02.012 --> 00:56:04.210 same treatment that they were getting

NOTE Confidence: 0.84858656

00:56:04.210 --> 00:56:06.135 before a surgery gets cancelled,

NOTE Confidence: 0.84858656

00:56:06.140 --> 00:56:07.528 you know etcetera, etcetera.

NOTE Confidence: 0.84858656

00:56:07.528 --> 00:56:10.918 And and we know from you know previous work,

NOTE Confidence: 0.84858656

00:56:10.920 --> 00:56:12.870 obviously the treatment delays don't

NOTE Confidence: 0.84858656

00:56:12.870 --> 00:56:15.318 usually ever. Work out very well.

NOTE Confidence: 0.84858656

00:56:15.318 --> 00:56:17.403 So we haven't yet systematically
NOTE Confidence: 0.84858656

00:56:17.403 --> 00:56:18.230 evaluated that,
NOTE Confidence: 0.84858656

00:56:18.230 --> 00:56:20.036 but we have you know now several
NOTE Confidence: 0.84858656

00:56:20.036 --> 00:56:21.320 thousands of those patients.
NOTE Confidence: 0.84858656

00:56:21.320 --> 00:56:22.874 So we're going to be looking at
NOTE Confidence: 0.84858656

00:56:22.874 --> 00:56:24.428 that probably in the upcoming year.
NOTE Confidence: 0.84858656

00:56:24.430 --> 00:56:27.490 As far as other patients, well,
NOTE Confidence: 0.84858656

00:56:27.490 --> 00:56:29.830 I mean and there were a lot of practice
NOTE Confidence: 0.84858656

00:56:29.888 --> 00:56:33.809 changes, right, especially in.
NOTE Confidence: 0.84858656

00:56:33.810 --> 00:56:35.110 Especially in China, I think,
NOTE Confidence: 0.84858656

00:56:35.110 --> 00:56:37.918 but also with sort of substituting
NOTE Confidence: 0.84858656

00:56:37.918 --> 00:56:39.790 oral medications whenever possible,
NOTE Confidence: 0.84858656

00:56:39.790 --> 00:56:41.755 even if they were sort of known
NOTE Confidence: 0.84858656

00:56:41.755 --> 00:56:44.056 to be inferior or not, you know,
NOTE Confidence: 0.84858656

00:56:44.056 --> 00:56:45.722 not quite as good so that patients
NOTE Confidence: 0.84858656

00:56:45.722 --> 00:56:47.036 didn't have to come into the.

NOTE Confidence: 0.84858656

00:56:47.040 --> 00:56:48.060 To the clinic.

NOTE Confidence: 0.84858656

00:56:48.060 --> 00:56:50.100 So that's been presented on in

NOTE Confidence: 0.84858656

00:56:50.100 --> 00:56:51.718 in in some settings,

NOTE Confidence: 0.84858656

00:56:51.720 --> 00:56:53.943 but you know I think what we think that

NOTE Confidence: 0.84858656

00:56:53.943 --> 00:56:56.178 those substitutions are are generally OK,

NOTE Confidence: 0.84858656

00:56:56.180 --> 00:56:58.310 I know that.

NOTE Confidence: 0.84858656

00:56:58.310 --> 00:57:00.902 You know a lot of people went on

NOTE Confidence: 0.84858656

00:57:00.902 --> 00:57:02.202 neoadjuvant hormone therapy and

NOTE Confidence: 0.84858656

00:57:02.202 --> 00:57:04.146 instead of going direct to surgery

NOTE Confidence: 0.84858656

00:57:04.146 --> 00:57:05.956 for early stage breast cancer and

NOTE Confidence: 0.84858656

00:57:05.956 --> 00:57:08.021 you know so that they could push

NOTE Confidence: 0.84858656

00:57:08.021 --> 00:57:10.051 this you know during periods of time

NOTE Confidence: 0.84858656

00:57:10.051 --> 00:57:11.970 when when elective quote UN quote

NOTE Confidence: 0.84858656

00:57:11.970 --> 00:57:13.590 elective surgeries were shut down.

NOTE Confidence: 0.84858656

00:57:13.590 --> 00:57:17.070 So all those things probably add up right.

NOTE Confidence: 0.84858656

00:57:17.070 --> 00:57:19.180 But there's but there's absolutely
NOTE Confidence: 0.84858656

00:57:19.180 --> 00:57:21.713 a factor of psychology and patients
NOTE Confidence: 0.84858656

00:57:21.713 --> 00:57:24.239 being afraid to come into the
NOTE Confidence: 0.84858656

00:57:24.239 --> 00:57:26.333 clinic and you know potentially
NOTE Confidence: 0.84858656

00:57:26.333 --> 00:57:29.099 again skipping a a treatment or.
NOTE Confidence: 0.84858656

00:57:29.100 --> 00:57:29.404 So,
NOTE Confidence: 0.84858656

00:57:29.404 --> 00:57:30.316 so I think.
NOTE Confidence: 0.84858656

00:57:30.316 --> 00:57:32.602 To answer your question is that it's
NOTE Confidence: 0.84858656

00:57:32.602 --> 00:57:35.336 quite complex but I think we need to
NOTE Confidence: 0.84858656

00:57:35.336 --> 00:57:37.504 understand it better and of course
NOTE Confidence: 0.84858656

00:57:37.504 --> 00:57:39.874 new diagnosis coming in which we're
NOTE Confidence: 0.84858656

00:57:39.874 --> 00:57:42.200 starting to get that information.
NOTE Confidence: 0.84858656

00:57:42.200 --> 00:57:44.027 There's clearly a stage migration and and
NOTE Confidence: 0.84858656

00:57:44.027 --> 00:57:46.398 you know to later stage more more advanced,
NOTE Confidence: 0.84858656

00:57:46.400 --> 00:57:47.534 more metastatic disease.
NOTE Confidence: 0.84858656

00:57:47.534 --> 00:57:50.610 Because of delays in screening and so forth.

NOTE Confidence: 0.84858656

00:57:50.610 --> 00:57:50.867 So.

NOTE Confidence: 0.84858656

00:57:50.867 --> 00:57:52.923 So I think we're going to face a

NOTE Confidence: 0.84858656

00:57:52.930 --> 00:57:54.052 we're going to face a challenging

NOTE Confidence: 0.84858656

00:57:54.052 --> 00:57:55.624 decade and I you know I think Ned

NOTE Confidence: 0.84858656

00:57:55.624 --> 00:57:56.599 Sharpless forecast that at the

NOTE Confidence: 0.84858656

00:57:56.599 --> 00:57:57.810 very beginning of the pandemic.

NOTE Confidence: 0.84858656

00:57:57.810 --> 00:57:59.853 I think in the first month or two he

NOTE Confidence: 0.84858656

00:57:59.853 --> 00:58:01.471 wrote a paper and nature of science

NOTE Confidence: 0.84858656

00:58:01.471 --> 00:58:03.200 I think you know modeling out what

NOTE Confidence: 0.84858656

00:58:03.250 --> 00:58:04.776 what that might look like and and

NOTE Confidence: 0.84858656

00:58:04.776 --> 00:58:06.605 and you know that's probably going to

NOTE Confidence: 0.84858656

00:58:06.605 --> 00:58:10.450 that's probably going to come true but.

NOTE Confidence: 0.84858656

00:58:10.450 --> 00:58:12.630 Hopefully COVID ends really soon.

NOTE Confidence: 0.84858656

00:58:12.630 --> 00:58:15.500 So. Um, yeah.

NOTE Confidence: 0.63317087

00:58:20.460 --> 00:58:20.910 Seems like.

NOTE Confidence: 0.880159951333333

00:58:30.980 --> 00:58:32.892 Yeah so we're so we're overtime and and
NOTE Confidence: 0.880159951333333

00:58:32.892 --> 00:58:35.066 I think you know I mean there's there's
NOTE Confidence: 0.880159951333333

00:58:35.066 --> 00:58:37.090 many strategies to try to mitigate but
NOTE Confidence: 0.880159951333333

00:58:37.090 --> 00:58:39.120 you can't you can't eliminate bias right.
NOTE Confidence: 0.880159951333333

00:58:39.120 --> 00:58:40.695 So you you can understand it you
NOTE Confidence: 0.880159951333333

00:58:40.695 --> 00:58:42.721 can try to mitigate it there's you
NOTE Confidence: 0.880159951333333

00:58:42.721 --> 00:58:44.341 know there's matching strategies to
NOTE Confidence: 0.880159951333333

00:58:44.341 --> 00:58:46.482 if you're doing sort of a you know
NOTE Confidence: 0.880159951333333

00:58:46.482 --> 00:58:48.041 case and control style approach where
NOTE Confidence: 0.880159951333333

00:58:48.041 --> 00:58:50.226 you you try to make the controls as
NOTE Confidence: 0.880159951333333

00:58:50.226 --> 00:58:52.025 similar to the cases you know and
NOTE Confidence: 0.880159951333333

00:58:52.025 --> 00:58:53.785 everything but the. Closure.
NOTE Confidence: 0.880159951333333

00:58:53.785 --> 00:58:56.318 So you know and and and some of those are,
NOTE Confidence: 0.880159951333333

00:58:56.320 --> 00:58:57.545 some of those been around for decades,
NOTE Confidence: 0.880159951333333

00:58:57.550 --> 00:58:59.890 some of those are kind of
NOTE Confidence: 0.880159951333333

00:58:59.890 --> 00:59:01.450 emerging at this point.

NOTE Confidence: 0.880159951333333
00:59:01.450 --> 00:59:04.276 But I don't think we can forget that there's
NOTE Confidence: 0.880159951333333
00:59:04.276 --> 00:59:07.858 bias in in perspective trials as well, right.
NOTE Confidence: 0.880159951333333
00:59:07.858 --> 00:59:09.594 So I mean I think either side
NOTE Confidence: 0.880159951333333
00:59:09.594 --> 00:59:10.838 of the of the coin.
NOTE Confidence: 0.910771256
00:59:12.980 --> 00:59:14.100 Yeah, it's just, it's just,
NOTE Confidence: 0.910771256
00:59:14.100 --> 00:59:15.444 it's just one more thing and it's
NOTE Confidence: 0.910771256
00:59:15.444 --> 00:59:17.332 not the only, I mean it's there's
NOTE Confidence: 0.910771256
00:59:17.332 --> 00:59:18.316 also there's ascertainment,
NOTE Confidence: 0.910771256
00:59:18.320 --> 00:59:19.856 but I mean there's a lot of biases,
NOTE Confidence: 0.910771256
00:59:19.860 --> 00:59:22.072 right and. You know, one thing we've
NOTE Confidence: 0.910771256
00:59:22.072 --> 00:59:25.255 worked on with our consortium is developing
NOTE Confidence: 0.910771256
00:59:25.255 --> 00:59:27.423 standardized language around limitations,
NOTE Confidence: 0.910771256
00:59:27.430 --> 00:59:31.316 which I think is critical because you know.
NOTE Confidence: 0.910771256
00:59:31.316 --> 00:59:34.180 I mean, the data is the data are
NOTE Confidence: 0.910771256
00:59:34.180 --> 00:59:36.986 the data use the plural, right? But.
NOTE Confidence: 0.910771256

00:59:36.986 --> 00:59:40.284 But the way it's presented really

NOTE Confidence: 0.910771256

00:59:40.284 --> 00:59:41.815 does influence the reader, right?

NOTE Confidence: 0.910771256

00:59:41.815 --> 00:59:43.390 So. So that's something we're

NOTE Confidence: 0.910771256

00:59:43.390 --> 00:59:45.219 thinking about and might have some.

NOTE Confidence: 0.910771256

00:59:45.220 --> 00:59:46.918 You know, thought pieces or something

NOTE Confidence: 0.910771256

00:59:46.918 --> 00:59:48.998 coming out about about how to handle that.