WEBVTT

NOTE duration:"00:59:49" NOTE recognizability:0.866

NOTE language:en-us

NOTE Confidence: 0.791109643333333

 $00:00:00.000 \longrightarrow 00:00:03.310$ So it's a pleasure to introduce Jeremy

NOTE Confidence: 0.798762552

 $00{:}00{:}03.440 \dashrightarrow 00{:}00{:}05.795$ Warner, who actually I first met

NOTE Confidence: 0.798762552

 $00:00:05.795 \dashrightarrow 00:00:08.348$ this year when when I was chairing

NOTE Confidence: 0.845342642857143

 $00:00:08.360 \longrightarrow 00:00:10.915$ a panel at ESMO and he was

NOTE Confidence: 0.928525481428571

 $00:00:10.930 \longrightarrow 00:00:12.869$ 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

 $00:00:18.216 \longrightarrow 00:00:21.378$ Lifespan Center for Cancer Bioinformatics

NOTE Confidence: 0.857374834

 $00{:}00{:}21.390 \dashrightarrow 00{:}00{:}24.410$ 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

 $00{:}00{:}29.480 \dashrightarrow 00{:}00{:}31.130$ His clinical focus is Morgan

NOTE Confidence: 0.668117082

 $00{:}00{:}31.130 \dashrightarrow 00{:}00{:}34.180$ hematology and he received

NOTE Confidence: 0.97649878

 $00{:}00{:}34.190 \dashrightarrow 00{:}00{:}37.270$ his medical degree from from Boston

NOTE Confidence: 0.97649878

 $00{:}00{:}37.270 \dashrightarrow 00{:}00{:}41.309$ University and also in a Masters in

 $00:00:41.310 \longrightarrow 00:00:43.210$ Photonics and Electrical and Computer

NOTE Confidence: 0.97649878

 $00:00:43.210 \dashrightarrow 00:00:44.990$ Engineering from UC San Diego.

NOTE Confidence: 0.91951521

 $00:00:46.280 \longrightarrow 00:00:48.260$ 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

 $00:00:49.680 \longrightarrow 00:00:51.320$ Warner is a leading expert in

NOTE Confidence: 0.91951521

 $00:00:51.320 \longrightarrow 00:00:52.800$ the clinical and translational

NOTE Confidence: 0.91951521

 $00:00:52.800 \longrightarrow 00:00:53.910$ clinical and translational

NOTE Confidence: 0.91951521

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

NOTE Confidence: 0.908135898

 $00{:}00{:}56.160 \dashrightarrow 00{:}00{:}58.040$ including high dimensional data

NOTE Confidence: 0.908135898

 $00:00:58.040 \longrightarrow 00:00:59.460$ analysis and visualization,

NOTE Confidence: 0.908135898

 $00{:}00{:}59.460 \dashrightarrow 00{:}01{:}01.032$ natural language processing

NOTE Confidence: 0.908135898

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

NOTE Confidence: 0.908135898

 $00:01:02.960 \longrightarrow 00:01:03.828$ and the creation and

NOTE Confidence: 0.958742508

 $00:01:03.840 \longrightarrow 00:01:07.680$ implementation of health data standards.

NOTE Confidence: 0.958742508

 $00:01:07.680 \longrightarrow 00:01:11.840$ Before coming to Brown.

NOTE Confidence: 0.958742508

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

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

NOTE Confidence: 0.93045476

 $00:01:15.516 \longrightarrow 00:01:18.090$ where he was an associate professor of

NOTE Confidence: 0.93045476

 $00:01:18.090 \longrightarrow 00:01:21.730$ medicine and biomedical informatics.

NOTE Confidence: 0.93045476

 $00:01:21.730 \longrightarrow 00:01:24.425$ 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

 $00:01:27.160 \longrightarrow 00:01:28.959$ Clinical Cancer Informatics Journal

NOTE Confidence: 0.93045476

 $00:01:28.959 \longrightarrow 00:01:31.328$ 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

 $00:01:34.870 \longrightarrow 00:01:36.815$ Bioinformatics and Data Science.

NOTE Confidence: 0.93045476

 $00:01:36.815 \longrightarrow 00:01:37.990$ So without further

NOTE Confidence: 0.842243421428572

 $00:01:38.000 \longrightarrow 00:01:40.338$ ado, you're going to speak to us

NOTE Confidence: 0.894348995

 $00:01:40.350 \longrightarrow 00:01:42.258$ about using and improving real world.

NOTE Confidence: 0.894348995

 $00:01:42.260 \longrightarrow 00:01:45.440$ Hey there. Ecosystem in cancer.

NOTE Confidence: 0.894348995

 $00:01:45.440 \longrightarrow 00:01:48.710$ Thanks. Look forward to it.

NOTE Confidence: 0.930034288888889

 $00:01:48.710 \longrightarrow 00:01:51.203$ Thank you. Thank you so much for having me.

 $00:01:51.210 \longrightarrow 00:01:52.230$ 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

 $00:01:57.640 \longrightarrow 00:02:00.460$ Really nice that we're so close here.

NOTE Confidence: 0.930034288888889

 $00:02:00.460 \longrightarrow 00:02:03.187$ In New England, so I just have a few

NOTE Confidence: 0.930034288888889

 $00{:}02{:}03.187 \dashrightarrow 00{:}02{:}05.266$ 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

 $00:02:06.750 \longrightarrow 00:02:07.652$ some consulting.

NOTE Confidence: 0.930034288888889

 $00{:}02{:}07.652 \dashrightarrow 00{:}02{:}10.584$ I do have ownership in hemlock.org LLC,

NOTE Confidence: 0.930034288888889

 $00:02:10.584 \longrightarrow 00:02:12.921$ but has no monetary value unless one

NOTE Confidence: 0.930034288888889

 $00{:}02{:}12.921 \dashrightarrow 00{:}02{:}15.409$ of you wants to be an Angel investor

NOTE Confidence: 0.930034288888889

 $00:02:15.409 \longrightarrow 00:02:18.266$ and we can talk after the presentation.

NOTE Confidence: 0.930034288888889

 $00:02:18.270 \longrightarrow 00:02:20.370$ So what I'm going to talk

NOTE Confidence: 0.930034288888889

 $00:02:20.370 \longrightarrow 00:02:21.978$ about here is you know why,

NOTE Confidence: 0.930034288888889

 $00:02:21.978 \longrightarrow 00:02:24.328$ why do we need real world data and real

NOTE Confidence: 0.930034288888889

 $00:02:24.328 \dashrightarrow 00:02:26.329$ world evidence in oncology and I'm going

 $00:02:26.329 \longrightarrow 00:02:27.847$ to focus on electronic health records.

NOTE Confidence: 0.930034288888889

 $00:02:27.850 \longrightarrow 00:02:29.400$ There are other sources of

NOTE Confidence: 0.930034288888889

 $00:02:29.400 \longrightarrow 00:02:30.950$ 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

 $00:02:34.664 \longrightarrow 00:02:36.880$ I will spend some time on talking about

NOTE Confidence: 0.930034288888889

 $00:02:36.941 \longrightarrow 00:02:39.311$ in particular interest in mine which

NOTE Confidence: 0.930034288888889

 $00{:}02{:}39.311 \dashrightarrow 00{:}02{:}41.364$ is standardizing systemic anti cancer

NOTE Confidence: 0.930034288888889

 $00:02:41.364 \longrightarrow 00:02:43.012$ 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

 $00:02:45.508 \longrightarrow 00:02:48.504$ our COVID and COVID-19 and cancer consor-

tium.

NOTE Confidence: 0.930034288888889

00:02:48.510 --> 00:02:50.148 Which is a bit of a culmination,

NOTE Confidence: 0.930034288888889 $00:02:50.150 \longrightarrow 00:02:50.981$ if you will, NOTE Confidence: 0.930034288888889

 $00:02:50.981 \longrightarrow 00:02:52.366$ of some of these thoughts.

 $00:02:52.370 \longrightarrow 00:02:54.687$ So there are some learning objectives here.

NOTE Confidence: 0.930034288888889

 $00:02:54.690 \longrightarrow 00:02:57.366$ If hopefully this is a CME,

NOTE Confidence: 0.930034288888889

 $00:02:57.370 \longrightarrow 00:02:59.342$ so we'll we'll cover,

NOTE Confidence: 0.930034288888889 00:02:59.342 --> 00:03:00.328 you know, NOTE Confidence: 0.930034288888889

 $00{:}03{:}00.330 \dashrightarrow 00{:}03{:}01.735$ some aspects of natural language

NOTE Confidence: 0.930034288888889

 $00:03:01.735 \longrightarrow 00:03:03.675$ 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

 $00{:}03{:}05.130 \dashrightarrow 00{:}03{:}07.885$ why we need formal representations

NOTE Confidence: 0.930034288888889

 $00:03:07.885 \longrightarrow 00:03:09.538$ for complex concepts.

NOTE Confidence: 0.930034288888889

 $00:03:09.540 \longrightarrow 00:03:11.736$ 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

 $00{:}03{:}16.380 \to 00{:}03{:}19.578$ 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

 $00:03:22.994 \longrightarrow 00:03:24.260$ familiar with these definitions,

NOTE Confidence: 0.930034288888889

 $00{:}03{:}24.260 \dashrightarrow 00{:}03{:}26.204$ 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

 $00:03:27.950 \longrightarrow 00:03:29.620$ what is real world evidence.

NOTE Confidence: 0.930034288888889

 $00:03:29.620 \longrightarrow 00:03:32.217$ 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

 $00:03:34.300 \longrightarrow 00:03:35.684$ you know, the, the resource you look at,

NOTE Confidence: 0.930034288888889

 $00:03:35.690 \longrightarrow 00:03:37.460$ you'll get a different definition.

NOTE Confidence: 0.930034288888889

 $00:03:37.460 \longrightarrow 00:03:38.760$ But this is my definition,

NOTE Confidence: 0.930034288888889

 $00:03:38.760 \longrightarrow 00:03:41.250$ which is really based on something

NOTE Confidence: 0.930034288888889

 $00:03:41.250 \longrightarrow 00:03:43.660$ called the I kW pyramid.

NOTE Confidence: 0.930034288888889

 $00:03:43.660 \longrightarrow 00:03:45.580$ Has anybody heard about this?

NOTE Confidence: 0.930034288888889

 $00:03:45.580 \longrightarrow 00:03:47.056$ Heard of the DKW? OK great.

NOTE Confidence: 0.930034288888889

 $00:03:47.060 \longrightarrow 00:03:48.726$ So teach you a little bit here.

NOTE Confidence: 0.930034288888889

 $00:03:48.730 \longrightarrow 00:03:51.850$ So the idea here is that it's a

NOTE Confidence: 0.930034288888889

 $00:03:51.850 \longrightarrow 00:03:53.975$ pyramid where you're climbing a

 $00:03:53.980 \longrightarrow 00:03:57.179$ levels here from a base of data.

NOTE Confidence: 0.930034288888889

 $00:03:57.180 \longrightarrow 00:03:58.640$ The next step is information.

NOTE Confidence: 0.930034288888889

 $00:03:58.640 \longrightarrow 00:04:00.320$ The next step is knowledge.

NOTE Confidence: 0.930034288888889

 $00:04:00.320 \longrightarrow 00:04:01.360$ The next step is wisdom.

NOTE Confidence: 0.930034288888889

 $00:04:01.360 \longrightarrow 00:04:02.608$ You'll know there's 5 levels here.

NOTE Confidence: 0.930034288888889

 $00:04:02.610 \longrightarrow 00:04:04.938$ 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

 $00{:}04{:}07.540 \dashrightarrow 00{:}04{:}10.242$ But basically the idea is no matter

NOTE Confidence: 0.930034288888889

 $00:04:10.242 \longrightarrow 00:04:12.719$ 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

 $00:04:13.698 \longrightarrow 00:04:15.654$ 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: 0.93003428888888900:04:18.524 --> 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

 $00:04:21.020 \longrightarrow 00:04:22.792$ you're generating real-world evidence,

 $00:04:22.792 \longrightarrow 00:04:26.130$ whereas real world data is really that base.

NOTE Confidence: 0.930034288888889

 $00:04:26.130 \longrightarrow 00:04:28.188$ On the right here you see the

NOTE Confidence: 0.930034288888889

 $00:04:28.188 \longrightarrow 00:04:30.167$ the sort of traditional pyramid

NOTE Confidence: 0.930034288888889

 $00:04:30.167 \longrightarrow 00:04:32.727$ of of evidence based medicine.

NOTE Confidence: 0.930034288888889

 $00:04:32.730 \longrightarrow 00:04:34.522$ 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

 $00{:}04{:}39.070 \dashrightarrow 00{:}04{:}40.904$ 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

 $00:04:42.290 \longrightarrow 00:04:44.312$ there's the genotype, the phenotype and

NOTE Confidence: 0.884899444166667

 $00:04:44.312 \longrightarrow 00:04:46.469$ then the environment and sort of for

NOTE Confidence: 0.884899444166667

 $00:04:46.469 \longrightarrow 00:04:48.233$ each of these you have these layers.

NOTE Confidence: 0.884899444166667

 $00:04:48.240 \longrightarrow 00:04:49.899$ So, so if you think about the

NOTE Confidence: 0.884899444166667

 $00:04:49.899 \longrightarrow 00:04:51.705$ 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

 $00{:}04{:}53.430 \dashrightarrow 00{:}04{:}55.870$ just the somatic tumor sequence.

 $00:04:55.870 \longrightarrow 00:04:56.932$ For phenotype,

NOTE Confidence: 0.884899444166667

 $00:04:56.932 \longrightarrow 00:05:00.649$ it might be just a histologic type,

NOTE Confidence: 0.884899444166667

 $00:05:00.650 \longrightarrow 00:05:03.149$ a cell, you know what, what is that?

NOTE Confidence: 0.884899444166667

 $00:05:03.149 \longrightarrow 00:05:04.148$ And for environment,

NOTE Confidence: 0.884899444166667

 $00:05:04.150 \longrightarrow 00:05:05.070$ it might be pollutant levels.

NOTE Confidence: 0.884899444166667

 $00:05:05.070 \longrightarrow 00:05:06.010$ 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

 $00:05:08.118 \longrightarrow 00:05:10.450$ So we need to kind of walk up this pyramid.

NOTE Confidence: 0.884899444166667

 $00:05:10.450 \longrightarrow 00:05:12.730$ The next level for for these three buckets

NOTE Confidence: 0.884899444166667

 $00:05:12.730 \longrightarrow 00:05:14.978$ would be for genotype and environment.

NOTE Confidence: 0.884899444166667

 $00:05:14.980 \longrightarrow 00:05:16.610$ You might talk about pathogenicity.

NOTE Confidence: 0.884899444166667

 $00{:}05{:}16.610 \dashrightarrow 00{:}05{:}19.790$ What does that change mean in terms of is it,

NOTE Confidence: 0.884899444166667

 $00:05:19.790 \longrightarrow 00:05:21.430$ is it a driver mutation?

NOTE Confidence: 0.884899444166667

 $00:05:21.430 \longrightarrow 00:05:24.202$ That's sort of the next level information

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

NOTE Confidence: 0.884899444166667

 $00:05:26.390 \longrightarrow 00:05:27.766$ Side so is it,

NOTE Confidence: 0.884899444166667

 $00:05:27.766 \longrightarrow 00:05:28.798$ is it aggressive,

NOTE Confidence: 0.884899444166667

 $00:05:28.800 \longrightarrow 00:05:30.696$ is it a high grade malignancy

NOTE Confidence: 0.884899444166667

 $00:05:30.696 \longrightarrow 00:05:32.560$ or is it something indolent

NOTE Confidence: 0.884899444166667

 $00:05:32.560 \longrightarrow 00:05:34.820$ kind of stepping up further?

NOTE Confidence: 0.884899444166667

 $00:05:34.820 \longrightarrow 00:05:36.236$ For genotype knowledge,

NOTE Confidence: 0.884899444166667

 $00:05:36.236 \longrightarrow 00:05:38.596$ the knowledge level is actionability.

NOTE Confidence: 0.884899444166667

 $00:05:38.600 \longrightarrow 00:05:41.260$ What can you do with this information?

NOTE Confidence: 0.884899444166667

 $00:05:41.260 \longrightarrow 00:05:43.619$ 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

 $00:05:46.412 \longrightarrow 00:05:46.674$ same,

NOTE Confidence: 0.884899444166667

 $00:05:46.674 \longrightarrow 00:05:47.198$ you know,

NOTE Confidence: 0.884899444166667

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

NOTE Confidence: 0.884899444166667

 $00{:}05{:}48.508 \dashrightarrow 00{:}05{:}50.301$ the treatment options and then the

 $00:05:50.301 \longrightarrow 00:05:51.781$ environment are there risk modifications

NOTE Confidence: 0.884899444166667

 $00:05:51.825 \longrightarrow 00:05:53.253$ 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

 $00:05:55.055 \longrightarrow 00:05:57.425$ you know this is this is

NOTE Confidence: 0.884899444166667

 $00:05:57.425 \longrightarrow 00:05:59.190$ really complicated now.

NOTE Confidence: 0.884899444166667

 $00:05:59.190 \longrightarrow 00:06:00.972$ So in in phenotype you're thinking

NOTE Confidence: 0.884899444166667

 $00:06:00.972 \longrightarrow 00:06:02.552$ about what are patient values

NOTE Confidence: 0.884899444166667

 $00{:}06{:}02.552 \dashrightarrow 00{:}06{:}04.556$ and preferences and how do those

NOTE Confidence: 0.884899444166667

 $00:06:04.556 \longrightarrow 00:06:05.951$ 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

 $00:06:07.582 \longrightarrow 00:06:09.724$ what's the tumor going to do once

NOTE Confidence: 0.884899444166667

 $00:06:09.724 \longrightarrow 00:06:11.747$ it gets exposed to treatments,

NOTE Confidence: 0.884899444166667

 $00{:}06{:}11.750 \longrightarrow 00{:}06{:}13.311$ how is it going to evolve under

NOTE Confidence: 0.884899444166667

 $00:06:13.311 \longrightarrow 00:06:14.584$ treatment pressure and an environment

NOTE Confidence: 0.884899444166667

 $00:06:14.584 \longrightarrow 00:06:16.258$ you've got issues about social justice.

 $00:06:16.260 \longrightarrow 00:06:16.989$ And structural racism.

NOTE Confidence: 0.884899444166667

 $00:06:16.989 \longrightarrow 00:06:18.690$ 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

 $00:06:21.810 \longrightarrow 00:06:23.285$ the difference between data and

NOTE Confidence: 0.884899444166667

 $00:06:23.285 \longrightarrow 00:06:24.570$ 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

 $00:06:30.120 \longrightarrow 00:06:31.832$ but they're also expensive,

NOTE Confidence: 0.884899444166667

 $00:06:31.832 \longrightarrow 00:06:34.545$ slow to conduct, and they don't

NOTE Confidence: 0.884899444166667

 $00{:}06{:}34.545 \dashrightarrow 00{:}06{:}36.920$ 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

 $00:06:40.960 \longrightarrow 00:06:43.852$ collect some but not all potentially

NOTE Confidence: 0.884899444166667

 $00:06:43.852 \longrightarrow 00:06:44.816$ pertinent information.

NOTE Confidence: 0.884899444166667

 $00:06:44.820 \longrightarrow 00:06:46.100$ And our space is huge.

 $00{:}06{:}46.100 \dashrightarrow 00{:}06{:}46.466 \ \mathrm{Oncology},$

NOTE Confidence: 0.884899444166667

 $00:06:46.466 \longrightarrow 00:06:49.028$ the treatment space and oncology is huge.

NOTE Confidence: 0.884899444166667

 $00:06:49.030 \longrightarrow 00:06:49.672$ And then lastly,

NOTE Confidence: 0.884899444166667

 $00:06:49.672 \longrightarrow 00:06:51.492$ I think last but not least is that

NOTE Confidence: 0.884899444166667

 $00:06:51.492 \longrightarrow 00:06:53.124$ we've got this enormous data source,

NOTE Confidence: 0.884899444166667

 $00:06:53.130 \longrightarrow 00:06:55.776$ which is the electronic medical record.

NOTE Confidence: 0.884899444166667

 $00:06:55.780 \longrightarrow 00:06:57.026$ So just a few words about each

NOTE Confidence: 0.884899444166667

 $00:06:57.026 \longrightarrow 00:06:57.560$ of these items.

NOTE Confidence: 0.884899444166667

 $00:06:57.560 \longrightarrow 00:06:58.860$ So when you think about

NOTE Confidence: 0.884899444166667

 $00:06:58.860 \longrightarrow 00:06:59.640$ trials and disparities,

NOTE Confidence: 0.884899444166667

 $00{:}06{:}59.640 \dashrightarrow 00{:}07{:}02.454$ this is a paper we just published

NOTE Confidence: 0.884899444166667

 $00{:}07{:}02.460 \dashrightarrow 00{:}07{:}05.808$ very recently and this one was

NOTE Confidence: 0.884899444166667

 $00{:}07{:}05.808 \dashrightarrow 00{:}07{:}06.864$ earlier this year and we just

NOTE Confidence: 0.884899444166667

 $00:07:06.864 \longrightarrow 00:07:07.904$ published another one in Jim

NOTE Confidence: 0.884899444166667

 $00:07:07.904 \longrightarrow 00:07:08.939$ Oncology looking at prostate cancer.

 $00:07:08.940 \longrightarrow 00:07:10.992$ 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

 $00:07:12.020 \longrightarrow 00:07:14.358$ And basically the take home message here

NOTE Confidence: 0.884899444166667

 $00:07:14.360 \longrightarrow 00:07:16.075$ is that when you look across Childs,

NOTE Confidence: 0.884899444166667

 $00:07:16.080 \longrightarrow 00:07:19.636$ there is really a lot of disparity

NOTE Confidence: 0.884899444166667

 $00:07:19.636 \longrightarrow 00:07:22.299$ 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

 $00:07:24.560 \longrightarrow 00:07:26.940$ but it's pretty consistent across the board.

NOTE Confidence: 0.915224604285714

 $00:07:26.940 \longrightarrow 00:07:28.760$ 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

 $00{:}07{:}29.908 \dashrightarrow 00{:}07{:}32.220$ 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

 $00:07:35.320 \longrightarrow 00:07:40.210$ the yellow circles are intersections of,

NOTE Confidence: 0.915224604285714

 $00{:}07{:}40.210 \dashrightarrow 00{:}07{:}43.600$ in this case, gender, age,

NOTE Confidence: 0.915224604285714

 $00:07:43.600 \longrightarrow 00:07:46.218$ race and ethnicity, and a cancer type

NOTE Confidence: 0.915224604285714

 $00:07:46.218 \longrightarrow 00:07:48.640$ where the enrollment is as you'd expect.

 $00:07:48.640 \longrightarrow 00:07:50.296$ If it's green, it's sort of more than

NOTE Confidence: 0.915224604285714

 $00:07:50.296 \longrightarrow 00:07:52.240$ you'd expect, and if it's red, it's.

NOTE Confidence: 0.915224604285714

 $00:07:52.240 \longrightarrow 00:07:53.360$ It's less than you'd expect.

NOTE Confidence: 0.915224604285714

 $00:07:53.360 \longrightarrow 00:07:55.230$ So. So you know this,

NOTE Confidence: 0.915224604285714

 $00:07:55.230 \longrightarrow 00:07:57.270$ 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

 $00{:}08{:}03.300 \dashrightarrow 00{:}08{:}05.355$ Our knowledge from clinical trials

NOTE Confidence: 0.915224604285714

 $00{:}08{:}05.355 \dashrightarrow 00{:}08{:}08.082$ is primarily coming from younger.

NOTE Confidence: 0.915224604285714

 $00:08:08.082 \longrightarrow 00:08:12.410$ 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

 $00:08:14.390 \longrightarrow 00:08:16.700$ So this is, this was amazing.

NOTE Confidence: 0.915224604285714

 $00{:}08{:}16.700 \dashrightarrow 00{:}08{:}18.674$ 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,

 $00:08:22.870 \longrightarrow 00:08:23.572$ 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

 $00:08:28.743 \longrightarrow 00:08:31.028$ important treatment options for COVID.

NOTE Confidence: 0.915224604285714

 $00:08:31.030 \longrightarrow 00:08:32.278$ This is one of their papers.

NOTE Confidence: 0.915224604285714

 $00{:}08{:}32.280 \dashrightarrow 00{:}08{:}35.388$ This is probably the most impactful look,

NOTE Confidence: 0.915224604285714

 $00:08:35.390 \longrightarrow 00:08:37.554$ showing that dexame thasone could

NOTE Confidence: 0.915224604285714

 $00:08:37.554 \longrightarrow 00:08:40.259$ 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

 $00:08:45.270 \longrightarrow 00:08:46.190$ 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

 $00:08:47.750 \longrightarrow 00:08:49.731$ So this is a table of previous

NOTE Confidence: 0.860007212

 $00:08:49.731 \longrightarrow 00:08:50.933$ coexisting diseases in the

NOTE Confidence: 0.860007212

 $00{:}08{:}50.933 \dashrightarrow 00{:}08{:}52.129$ patients who have COVID.

NOTE Confidence: 0.860007212

 $00:08:52.130 \longrightarrow 00:08:54.658$ Is there something missing?

NOTE Confidence: 0.860007212

 $00:08:54.660 \longrightarrow 00:08:55.659$ From this table.

00:08:58.170 --> 00:09:02.237 Something that's the topic of this talk.

NOTE Confidence: 0.867837141428571

 $00:09:02.240 \longrightarrow 00:09:03.114$ Cancer, right.

NOTE Confidence: 0.867837141428571

 $00:09:03.114 \longrightarrow 00:09:05.736$ There's no cancer in the stable.

NOTE Confidence: 0.867837141428571

 $00:09:05.740 \longrightarrow 00:09:07.426$ They did not collect cancer and

NOTE Confidence: 0.867837141428571

 $00:09:07.426 \longrightarrow 00:09:09.170$ 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

 $00:09:13.720 \longrightarrow 00:09:14.816$ they didn't record cancer.

NOTE Confidence: 0.867837141428571

 $00{:}09{:}14.816 \dashrightarrow 00{:}09{:}16.830$ So here they enrolled 10s of thousands

NOTE Confidence: 0.867837141428571

 $00:09:16.830 \longrightarrow 00:09:18.410$ 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

 $00:09:19.970 \longrightarrow 00:09:21.270$ patients had cancer or not.

NOTE Confidence: 0.867837141428571

 $00{:}09{:}21.270 \longrightarrow 00{:}09{:}23.130$ And so I mean, a mazing work,

NOTE Confidence: 0.867837141428571

 $00:09:23.130 \longrightarrow 00:09:26.834$ but we're missing a key piece of information.

NOTE Confidence: 0.867837141428571

 $00:09:26.840 \longrightarrow 00:09:29.036$ And then sort of the last item you know

 $00:09:29.036 \longrightarrow 00:09:31.141$ that I met that I mentioned before is

NOTE Confidence: 0.867837141428571

 $00{:}09{:}31.141 \dashrightarrow 00{:}09{:}33.890$ that this idea that our treatment space

NOTE Confidence: 0.867837141428571

 $00:09:33.890 \longrightarrow 00:09:36.121$ is huge but head-to-head comparisons

NOTE Confidence: 0.867837141428571

 $00:09:36.121 \longrightarrow 00:09:39.079$ of important drugs are mostly absent.

NOTE Confidence: 0.867837141428571

 $00:09:39.080 \longrightarrow 00:09:41.075$ 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

 $00:09:43.768 \longrightarrow 00:09:46.341$ 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

 $00:09:48.436 \longrightarrow 00:09:50.820$ 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

 $00{:}09{:}54.604 \dashrightarrow 00{:}09{:}57.246$ using 64 different regimens of of various.

NOTE Confidence: 0.867837141428571

 $00:09:57.250 \longrightarrow 00:09:58.064$ 81 inhibitors.

NOTE Confidence: 0.867837141428571

 $00:09:58.064 \longrightarrow 00:10:00.506$ This includes XUS by the way.

NOTE Confidence: 0.867837141428571

 $00:10:00.510 \longrightarrow 00:10:02.182$ If you're like they're not 13 P you

NOTE Confidence: 0.867837141428571

 $00:10:02.182 \longrightarrow 00:10:03.830$ want to have actually there are,

NOTE Confidence: 0.867837141428571

 $00:10:03.830 \longrightarrow 00:10:06.809$ but many of those are only approved in China.

 $00:10:06.810 \dashrightarrow 00:10:10.666$ So 83 of those are phase three trials.

NOTE Confidence: 0.867837141428571

 $00:10:10.670 \longrightarrow 00:10:13.878$ Take home point is one of those 83

NOTE Confidence: 0.867837141428571

 $00:10:13.878 \longrightarrow 00:10:15.825$ actually compared to PD1 inhibitor

NOTE Confidence: 0.867837141428571

 $00:10:15.825 \longrightarrow 00:10:18.879$ to a PDL 1 inhibitor kind of it

NOTE Confidence: 0.867837141428571

 $00:10:18.879 \longrightarrow 00:10:21.417$ actually compared to Kobe matanov and

NOTE Confidence: 0.867837141428571

 $00:10:21.417 \longrightarrow 00:10:23.437$ 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

 $00{:}10{:}26.144 \dashrightarrow 00{:}10{:}28.628$ inhibitor to another PD1 inhibitor so.

NOTE Confidence: 0.867837141428571 00:10:28.630 --> 00:10:29.068 You know,

NOTE Confidence: 0.867837141428571

 $00{:}10{:}29.068 {\:\raisebox{--}{\text{--}}}{\:\raisebox{--}{\text{--}}}{\:\raisebox{--}{\text{--}}} 00{:}10{:}30.601$ 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

 $00:10:34.030 \longrightarrow 00:10:37.225$ we don't have any data at all on whether

NOTE Confidence: 0.867837141428571

 $00:10:37.230 \longrightarrow 00:10:39.702$ 1PD1 inhibitor is better than another

NOTE Confidence: 0.867837141428571

 $00:10:39.702 \longrightarrow 00:10:42.162$ except for indirect treatment comparisons,

 $00:10:42.162 \longrightarrow 00:10:42.706$ so.

NOTE Confidence: 0.867837141428571

 $00:10:42.706 \longrightarrow 00:10:45.426$ Hopefully I've convinced you that.

NOTE Confidence: 0.867837141428571

 $00:10:45.430 \longrightarrow 00:10:47.180$ We should at least think

NOTE Confidence: 0.867837141428571

 $00:10:47.180 \longrightarrow 00:10:48.580$ about using real-world data.

NOTE Confidence: 0.867837141428571

 $00:10:48.580 \longrightarrow 00:10:49.164$ But.

NOTE Confidence: 0.867837141428571

 $00:10:49.164 \longrightarrow 00:10:50.916$ They are messy,

NOTE Confidence: 0.867837141428571

 $00:10:50.916 \longrightarrow 00:10:52.668$ 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

 $00{:}10{:}54.777 \dashrightarrow 00{:}10{:}56.702$ challenges that we have once we

NOTE Confidence: 0.867837141428571

 $00:10:56.702 \longrightarrow 00:10:58.622$ start delving into the real world.

NOTE Confidence: 0.867837141428571

 $00{:}10{:}58.630 \dashrightarrow 00{:}11{:}01.250$ So first of all.

NOTE Confidence: 0.867837141428571

 $00:11:01.250 \longrightarrow 00:11:04.568$ 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

 $00:11:12.283 \longrightarrow 00:11:15.427$ clinical trial institutions in New Haven?

NOTE Confidence: 0.918139125882353

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

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

 $00:11:27.840 \longrightarrow 00:11:30.030$ Yale Cancer Center.

NOTE Confidence: 0.918139125882353

 $00:11:30.030 \longrightarrow 00:11:32.172$ 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

 $00:11:35.838 \longrightarrow 00:11:38.414$ 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

 $00:11:42.479 \longrightarrow 00:11:46.277$ 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?

 $00:11:49.370 \longrightarrow 00:11:51.680$ That is a big part of working

NOTE Confidence: 0.918139125882353

 $00:11:51.680 \longrightarrow 00:11:53.209$ with real world data.

NOTE Confidence: 0.918139125882353

 $00:11:53.210 \longrightarrow 00:11:54.610$ 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

 $00:12:01.920 \longrightarrow 00:12:03.000$ how about treatments,

NOTE Confidence: 0.918139125882353

00:12:03.000 --> 00:12:05.388 how many tyrosine kinase

NOTE Confidence: 0.918139125882353

 $00:12:05.388 \longrightarrow 00:12:07.179$ inhibitors are there?

NOTE Confidence: 0.918139125882353

 $00:12:07.180 \longrightarrow 00:12:10.212$ And so this is a little project that

NOTE Confidence: 0.918139125882353

 $00{:}12{:}10.212 \dashrightarrow 00{:}12{:}13.170$ 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

 $00:12:15.655 \longrightarrow 00:12:18.536$ to switch around or basically misspell.

NOTE Confidence: 0.918139125882353

 $00{:}12{:}18.540 \dashrightarrow 00{:}12{:}21.024$ So that one tyrosine kinase inhibitor

NOTE Confidence: 0.918139125882353

 $00:12:21.024 \longrightarrow 00:12:23.010$ would actually be another one.

NOTE Confidence: 0.918139125882353

 $00:12:23.010 \longrightarrow 00:12:25.440$ And so it's it's fewer letters

 $00:12:25.440 \longrightarrow 00:12:27.085$ than you think and.

NOTE Confidence: 0.918139125882353

 $00{:}12{:}27.085 \dashrightarrow 00{:}12{:}29.635$ You know, these drugs get misspelled

NOTE Confidence: 0.918139125882353

 $00:12:29.635 \longrightarrow 00:12:33.550$ all the time in a pretty amazing ways.

NOTE Confidence: 0.918139125882353

 $00:12:33.550 \longrightarrow 00:12:34.410$ I see that the net,

NOTE Confidence: 0.918139125882353

 $00:12:34.410 \longrightarrow 00:12:35.586$ there's a little bit of formatting

NOTE Confidence: 0.918139125882353

 $00:12:35.586 \longrightarrow 00:12:38.480$ issue with the next slide, but.

NOTE Confidence: 0.918139125882353

 $00:12:38.480 \longrightarrow 00:12:42.968$ 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

 $00:12:45.114 \longrightarrow 00:12:46.186$ Medical Center.

NOTE Confidence: 0.918139125882353

 $00:12:46.190 \longrightarrow 00:12:49.234$ 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

 $00{:}12{:}51.920 \dashrightarrow 00{:}12{:}53.248$ we've got to be able to get these

NOTE Confidence: 0.918139125882353

 $00:12:53.248 \longrightarrow 00:12:54.149$ medications from structured data.

NOTE Confidence: 0.918139125882353

 $00:12:54.150 \longrightarrow 00:12:55.949$ That may or may not be true.

 $00:12:55.950 \longrightarrow 00:12:58.326$ It depends. We can talk more about that.

NOTE Confidence: 0.918139125882353

 $00{:}12{:}58.330 \dashrightarrow 00{:}12{:}59.600$ But these are real misspellings

NOTE Confidence: 0.918139125882353

 $00:12:59.600 \longrightarrow 00:13:01.070$ 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

 $00:13:02.834 \longrightarrow 00:13:04.966$ 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

 $00:13:08.332 \longrightarrow 00:13:12.210$ 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

 $00:13:13.440 \longrightarrow 00:13:14.670$ which patient got what drug.

NOTE Confidence: 0.918139125882353

 $00{:}13{:}14.670 \dashrightarrow 00{:}13{:}15.058$ 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

 $00{:}13{:}17.828 \dashrightarrow 00{:}13{:}20.264$ world issue with real world data.

NOTE Confidence: 0.918139125882353

 $00:13:20.270 \longrightarrow 00:13:21.999$ This is work that we did some

NOTE Confidence: 0.918139125882353

 $00:13:21.999 \longrightarrow 00:13:23.270$ years ago on staging,

NOTE Confidence: 0.918139125882353

 $00:13:23.270 \longrightarrow 00:13:26.438$ so cancer staging.

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

 $00:13:31.530 \longrightarrow 00:13:32.390$ so.

NOTE Confidence: 0.918139125882353

00:13:32.390 --> 00:13:33.824 And again and and maybe you

NOTE Confidence: 0.918139125882353

 $00{:}13{:}33.824 \dashrightarrow 00{:}13{:}35.136$ know during sort of discussion

NOTE Confidence: 0.918139125882353

 $00:13:35.136 \longrightarrow 00:13:37.236$ we can talk about the value of

NOTE Confidence: 0.918139125882353

 $00:13:37.236 \longrightarrow 00:13:38.809$ structured versus unstructured data,

NOTE Confidence: 0.918139125882353

 $00:13:38.810 \longrightarrow 00:13:41.402$ but the idea here is that we would

NOTE Confidence: 0.918139125882353

 $00{:}13{:}41.402 \dashrightarrow 00{:}13{:}43.646$ take data from progress notes from

NOTE Confidence: 0.918139125882353

 $00{:}13{:}43.646 \dashrightarrow 00{:}13{:}46.040$ 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

 $00:13:48.800 \longrightarrow 00:13:51.075$ 123 or four. So just forget ABC.

NOTE Confidence: 0.918139125882353

 $00:13:51.080 \longrightarrow 00:13:55.337$ 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

 $00:13:56.048 \longrightarrow 00:13:57.700$ the problem that we knew ahead of

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

NOTE Confidence: 0.918139125882353

 $00{:}13{:}59.512 \dashrightarrow 00{:}14{:}01.294$ to be recorded variably in different

NOTE Confidence: 0.918139125882353

 $00:14:01.294 \longrightarrow 00:14:03.238$ notes by different types of doctors.

NOTE Confidence: 0.918139125882353

 $00:14:03.240 \longrightarrow 00:14:05.508$ But you know we did a pilot

NOTE Confidence: 0.918139125882353

 $00:14:05.508 \longrightarrow 00:14:07.439$ with about 1000 patients with

NOTE Confidence: 0.918139125882353

 $00:14:07.439 \longrightarrow 00:14:09.652$ 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

 $00:14:14.012 \longrightarrow 00:14:15.188$ 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

 $00:14:17.650 \longrightarrow 00:14:19.748$ 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

 $00:14:21.783 \longrightarrow 00:14:22.950$ 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 do this kind of work at scale.

NOTE Confidence: 0.886603504545454

 $00:14:30.170 \longrightarrow 00:14:34.553$ So cutting to the chase a little bit here.

 $00:14:34.560 \longrightarrow 00:14:36.216$ 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

 $00:14:41.307 \longrightarrow 00:14:44.888$ in their note. At least one.

NOTE Confidence: 0.886603504545454

 $00:14:44.890 \longrightarrow 00:14:46.605$ 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

 $00:14:48.490 \longrightarrow 00:14:50.788$ So we were able to compare

NOTE Confidence: 0.886603504545454

 $00:14:50.788 \longrightarrow 00:14:53.390$ 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

 $00{:}14{:}55.550 \rightarrow 00{:}14{:}57.270$ those 964 had tumor registry data,

NOTE Confidence: 0.886603504545454

 $00:14:57.270 \longrightarrow 00:15:00.030$ but we were able to do a comparison and you

NOTE Confidence: 0.886603504545454

 $00:15:00.094 \longrightarrow 00:15:02.789$ 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

 $00:15:03.682 \longrightarrow 00:15:05.320$ basically the matches are in the green,

NOTE Confidence: 0.886603504545454

 $00:15:05.320 \longrightarrow 00:15:07.669$ the big numbers and we got some things wrong,

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

NOTE Confidence: 0.886603504545454

 $00{:}15{:}09.524 \dashrightarrow 00{:}15{:}11.350$ really wrong most of the time.

NOTE Confidence: 0.886603504545454

 $00:15:11.350 \longrightarrow 00:15:12.346$ So if it was stage one,

NOTE Confidence: 0.886603504545454

 $00:15:12.350 \longrightarrow 00:15:13.442$ we called stage four,

NOTE Confidence: 0.886603504545454

 $00:15:13.442 \longrightarrow 00:15:14.807$ that was a big mistake.

NOTE Confidence: 0.886603504545454

 $00:15:14.810 \longrightarrow 00:15:15.830$ Only happened once.

NOTE Confidence: 0.92679775

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

NOTE Confidence: 0.92679775

 $00:15:22.026 \longrightarrow 00:15:23.862$ so again 460,000 documents.

NOTE Confidence: 0.92679775

 $00{:}15{:}23.862 \to 00{:}15{:}26.284$ 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

 $00{:}15{:}28.082 \dashrightarrow 00{:}15{:}30.241$ of those or can you just look

NOTE Confidence: 0.92679775

 $00:15:30.241 \longrightarrow 00:15:31.886$ at notes that were written?

NOTE Confidence: 0.92679775

 $00:15:31.890 \longrightarrow 00:15:33.666$ 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

 $00:15:35.831 \longrightarrow 00:15:37.673$ some of this inspiration for this

NOTE Confidence: 0.92679775

 $00{:}15{:}37.673 \dashrightarrow 00{:}15{:}39.294$ project came from the copi measures.

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

 $00{:}15{:}42.933 \dashrightarrow 00{:}15{:}44.804$ may have changed but at one point

NOTE Confidence: 0.92679775

 $00:15:44.804 \longrightarrow 00:15:46.346$ 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

 $00:15:49.850 \longrightarrow 00:15:51.719$ So it kind of makes sense that

NOTE Confidence: 0.92679775

 $00{:}15{:}51.719 \dashrightarrow 00{:}15{:}53.649$ you would look for stage early on

NOTE Confidence: 0.92679775

 $00{:}15{:}53.650 \dashrightarrow 00{:}15{:}56.114$ but if you look at this black line

NOTE Confidence: 0.92679775

 $00:15:56.114 \longrightarrow 00:15:58.306$ 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

 $00:15:59.240 \longrightarrow 00:16:00.666$ You don't see the arrow, are you?

NOTE Confidence: 0.92679775

 $00{:}16{:}00.666 \dashrightarrow 00{:}16{:}02.705$ I don't think you're seeing the error, OK.

NOTE Confidence: 0.92679775

 $00:16:02.705 \longrightarrow 00:16:04.280$ If you look at the black line

NOTE Confidence: 0.92679775

 $00:16:04.280 \longrightarrow 00:16:05.761$ towards the bottom, you'll see that.

 $00:16:05.761 \longrightarrow 00:16:07.768$ 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

 $00:16:09.050 \longrightarrow 00:16:10.630$ actually there's a pretty high

NOTE Confidence: 0.92679775

 $00:16:10.630 \longrightarrow 00:16:11.894$ 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

 $00:16:17.255 \longrightarrow 00:16:18.995$ mentions of stage that we could

NOTE Confidence: 0.92679775

 $00:16:19.000 \longrightarrow 00:16:21.330$ sort of make that determination.

NOTE Confidence: 0.92679775

 $00:16:21.330 \longrightarrow 00:16:23.090$ So we saw this kind of inflection point.

NOTE Confidence: 0.92679775

 $00{:}16{:}23.090 \dashrightarrow 00{:}16{:}24.740$ And so that's another thing just

NOTE Confidence: 0.92679775

 $00:16:24.740 \longrightarrow 00:16:26.624$ to to note when you're working

NOTE Confidence: 0.92679775

 $00:16:26.624 \longrightarrow 00:16:28.424$ 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

 $00:16:29.682 \longrightarrow 00:16:31.247$ time can matter a lot.

NOTE Confidence: 0.92679775

 $00:16:31.250 \longrightarrow 00:16:32.826$ And the other thing that really matters is,

 $00:16:32.830 \longrightarrow 00:16:33.510$ is ambiguity.

NOTE Confidence: 0.92679775

 $00{:}16{:}33.510 \dashrightarrow 00{:}16{:}35.550$ So I mentioned we found stage

NOTE Confidence: 0.92679775

 $00:16:35.550 \longrightarrow 00:16:37.374$ 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

 $00:16:39.681 \longrightarrow 00:16:42.128$ 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

 $00:16:44.450 \longrightarrow 00:16:47.964$ OK and some some degree of discordance.

NOTE Confidence: 0.92679775

 $00:16:47.970 \longrightarrow 00:16:51.228$ So one note might say they have stage one,

NOTE Confidence: 0.92679775

 $00:16:51.230 \longrightarrow 00:16:54.270$ another note night say they have stage two.

NOTE Confidence: 0.92679775

 $00:16:54.270 \longrightarrow 00:16:56.016$ Actually when we constructed a network

NOTE Confidence: 0.92679775

 $00{:}16{:}56.016 \dashrightarrow 00{:}16{:}58.528$ graph on the right here you see like

NOTE Confidence: 0.92679775

 $00:16:58.528 \longrightarrow 00:17:00.143$ every possible combination was present,

NOTE Confidence: 0.92679775

 $00{:}17{:}00.150 \dashrightarrow 00{:}17{:}02.062$ every possible combination including

NOTE Confidence: 0.92679775

 $00{:}17{:}02.062 \longrightarrow 00{:}17{:}04.930$ you know more terms that are

NOTE Confidence: 0.92679775

00:17:05.011 --> 00:17:07.216 more generic like early stage,

 $00:17:07.220 \longrightarrow 00:17:08.094$ advanced stage.

NOTE Confidence: 0.92679775

 $00:17:08.094 \longrightarrow 00:17:10.716$ Everything you know happens and you

NOTE Confidence: 0.92679775

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

NOTE Confidence: 0.92679775

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

NOTE Confidence: 0.92679775

 $00:17:16.894 \longrightarrow 00:17:19.404$ occurrences of various stage information.

NOTE Confidence: 0.92679775

 $00:17:19.410 \longrightarrow 00:17:22.189$ But I do think that so that

NOTE Confidence: 0.92679775

 $00:17:22.189 \longrightarrow 00:17:23.380$ really potentially ambiguous.

NOTE Confidence: 0.92679775

 $00:17:23.380 \longrightarrow 00:17:24.856$ One take home point from this

NOTE Confidence: 0.92679775

 $00{:}17{:}24.856 \dashrightarrow 00{:}17{:}26.686$ 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

 $00:17:30.400 \longrightarrow 00:17:32.592$ We just chose the phrase that showed up

NOTE Confidence: 0.92679775

 $00{:}17{:}32.592 \dashrightarrow 00{:}17{:}35.200$ the most OK and that and that seems to work.

NOTE Confidence: 0.92679775

 $00:17:35.200 \longrightarrow 00:17:36.520$ So if stage three shows up

NOTE Confidence: 0.92679775

 $00:17:36.520 \longrightarrow 00:17:37.760$ in the notes 100 times,

NOTE Confidence: 0.92679775

 $00:17:37.760 \longrightarrow 00:17:40.160$ in stage one shows up twice.

 $00:17:40.160 \longrightarrow 00:17:41.576$ Chances are at stage three now,

NOTE Confidence: 0.92679775

 $00{:}17{:}41.580 \dashrightarrow 00{:}17{:}45.066$ 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

 $00:17:47.644 \longrightarrow 00:17:48.940$ 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

 $00:17:51.164 \longrightarrow 00:17:52.696$ information and missingness which is

NOTE Confidence: 0.92679775

 $00:17:52.696 \longrightarrow 00:17:54.831$ 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

 $00:17:57.876 \longrightarrow 00:18:00.324$ did looking at colon cancer and

NOTE Confidence: 0.92679775

 $00{:}18{:}00.324 \dashrightarrow 00{:}18{:}02.480$ we wanted to say could you find

NOTE Confidence: 0.866454990625

 $00{:}18{:}02.553 \dashrightarrow 00{:}18{:}04.737$ patients with stage 3 colon cancer

NOTE Confidence: 0.866454990625

 $00:18:04.740 \longrightarrow 00:18:06.560$ and this was for the OCM project,

NOTE Confidence: 0.866454990625

 $00{:}18{:}06.560 \dashrightarrow 00{:}18{:}07.628$ the oncology care model.

NOTE Confidence: 0.866454990625

 $00{:}18{:}07.628 \dashrightarrow 00{:}18{:}09.568$ So you know really important as a

NOTE Confidence: 0.866454990625

 $00:18:09.568 \longrightarrow 00:18:11.284$ metric to know if these patients

00:18:11.284 --> 00:18:12.520 got appropriate treatment within

NOTE Confidence: 0.866454990625

 $00{:}18{:}12.520 \dashrightarrow 00{:}18{:}13.816$ appropriate period of time.

NOTE Confidence: 0.866454990625

 $00:18:13.820 \longrightarrow 00:18:16.268$ But again what we saw here.

NOTE Confidence: 0.866454990625

 $00:18:16.270 \longrightarrow 00:18:18.118$ 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

 $00:18:23.311 \longrightarrow 00:18:25.520$ or it was or is missing in the records

NOTE Confidence: 0.866454990625

 $00:18:25.520 \longrightarrow 00:18:27.319$ and it wasn't until about seven weeks

NOTE Confidence: 0.866454990625

 $00:18:27.319 \longrightarrow 00:18:29.125$ after diagnosis that you get to a

NOTE Confidence: 0.866454990625

 $00:18:29.130 \longrightarrow 00:18:31.153$ kind of steady state where you can

NOTE Confidence: 0.866454990625

 $00{:}18{:}31.153 \longrightarrow 00{:}18{:}32.891$ definitively say a patient has stage

NOTE Confidence: 0.866454990625

 $00:18:32.891 \longrightarrow 00:18:35.020$ 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

 $00:18:43.430 \longrightarrow 00:18:46.280$ where they they actually looked at

 $00:18:46.280 \longrightarrow 00:18:49.182$ missingness as a variable, if you will.

NOTE Confidence: 0.822284337142857

 $00:18:49.182 \longrightarrow 00:18:52.269$ 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

 $00:18:55.692 \longrightarrow 00:18:58.637$ into whether they had complete records or

NOTE Confidence: 0.822284337142857

 $00:18:58.637 \longrightarrow 00:19:01.696$ 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

 $00:19:05.208 \longrightarrow 00:19:07.840$ But it is based on EHR data.

NOTE Confidence: 0.822284337142857

 $00:19:07.840 \longrightarrow 00:19:09.216$ 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

 $00:19:17.080 \longrightarrow 00:19:19.252$ missing this is an independent prognostic

NOTE Confidence: 0.822284337142857

 $00{:}19{:}19.252 \dashrightarrow 00{:}19{:}21.684$ factor for survival which is really an

NOTE Confidence: 0.822284337142857

 $00:19:21.684 \longrightarrow 00:19:23.626$ 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

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

NOTE Confidence: 0.822284337142857

 $00{:}19{:}29.100 \dashrightarrow 00{:}19{:}31.236$ 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

 $00:19:33.390 \longrightarrow 00:19:35.190$ it's the non metastatic patient

NOTE Confidence: 0.822284337142857

 $00{:}19{:}35.190 \dashrightarrow 00{:}19{:}37.773$ 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

 $00:19:39.910 \longrightarrow 00:19:41.933$ 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

 $00:19:43.800 \longrightarrow 00:19:46.495$ 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

 $00:19:47.718 \longrightarrow 00:19:49.038$ minute while I get my water bottle.

NOTE Confidence: 0.822284337142857

 $00:19:49.040 \longrightarrow 00:19:50.480$ It's.

NOTE Confidence: 0.822284337142857

 $00:19:50.480 \longrightarrow 00:19:51.140$ 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

 $00:20:00.980 \longrightarrow 00:20:03.644$ that we conventionally use as a metric.

NOTE Confidence: 0.854016017777778

 $00{:}20{:}03.644 \dashrightarrow 00{:}20{:}05.750$ Certainly not in a clinical trial

 $00{:}20{:}05.828 \dashrightarrow 00{:}20{:}08.683$ 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

 $00:20:11.000 \longrightarrow 00:20:13.364$ but missing this itself can be

NOTE Confidence: 0.854016017777778

 $00:20:13.364 \longrightarrow 00:20:15.839$ informative as in real world data.

NOTE Confidence: 0.854016017777778

 $00{:}20{:}15.840 \rightarrow 00{:}20{:}19.135$ 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

 $00:20:20.850 \longrightarrow 00:20:22.326$ which is a brief diversion into

NOTE Confidence: 0.854016017777778

 $00{:}20{:}22.326 \dashrightarrow 00{:}20{:}23.730$ 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

 $00:20:26.480 \longrightarrow 00:20:30.700$ 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

 $00:20:31.528 \longrightarrow 00:20:33.739$ so it's kind of cool if you never been there.

NOTE Confidence: 0.854016017777778

 $00:20:33.740 \longrightarrow 00:20:35.012$ It's still there.

NOTE Confidence: 0.854016017777778

 $00{:}20{:}35.012 \dashrightarrow 00{:}20{:}37.556$ 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

 $00:20:39.198 \longrightarrow 00:20:43.260$ this in a in a couple slides, so.

NOTE Confidence: 0.854016017777778

 $00:20:43.260 \longrightarrow 00:20:47.196$ 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

 $00:20:50.620 \longrightarrow 00:20:53.918$ 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

 $00:20:55.150 \longrightarrow 00:20:58.006$ I was there for about a decade

NOTE Confidence: 0.854016017777778

 $00:20:58.010 \longrightarrow 00:20:59.179$ and so this is a real vehicle.

NOTE Confidence: 0.854016017777778

 $00:20:59.180 \longrightarrow 00:21:00.605$ There's they actually have a

NOTE Confidence: 0.854016017777778

 $00:21:00.605 \longrightarrow 00:21:02.392$ collection of these and it makes

NOTE Confidence: 0.854016017777778

 $00:21:02.392 \longrightarrow 00:21:03.897$ me think of electronic medical

NOTE Confidence: 0.854016017777778

 $00{:}21{:}03.897 \dashrightarrow 00{:}21{:}05.930$ 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

 $00:21:08.230 \longrightarrow 00:21:10.070$ 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

 $00:21:14.870 \longrightarrow 00:21:17.240$ So our ER, but it works.

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

NOTE Confidence: 0.854016017777778

 $00:21:17.996 \longrightarrow 00:21:19.354$ but are they fit for the purpose

NOTE Confidence: 0.854016017777778

 $00:21:19.354 \longrightarrow 00:21:20.628$ 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

 $00:21:28.370 \longrightarrow 00:21:31.034$ this is obviously a little bit

NOTE Confidence: 0.906796898333333

 $00:21:31.034 \longrightarrow 00:21:33.230$ before the computer, you know,

NOTE Confidence: 0.906796898333333

 $00:21:33.230 \longrightarrow 00:21:35.810$ 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

 $00:21:36.866 \longrightarrow 00:21:39.330$ 3500 years in one form or another.

NOTE Confidence: 0.906796898333333

 $00:21:39.330 \longrightarrow 00:21:41.520$ 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

 $00:21:43.180 \longrightarrow 00:21:44.840$ used for teaching or didactics.

NOTE Confidence: 0.906796898333333

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

 $00:21:46.379 \longrightarrow 00:21:50.375$ that was the only purpose of medical records.

NOTE Confidence: 0.906796898333333

 $00:21:50.375 \longrightarrow 00:21:53.225$ 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

 $00:21:55.754 \longrightarrow 00:21:57.444$ didn't arise until the 1880s.

NOTE Confidence: 0.906796898333333

 $00:21:57.450 \longrightarrow 00:21:59.360$ It's not that long ago if you think about it.

NOTE Confidence: 0.906796898333333

 $00:21:59.360 \longrightarrow 00:22:02.036$ And that was for legal purposes,

NOTE Confidence: 0.906796898333333

 $00:22:02.040 \longrightarrow 00:22:03.076$ legal defense.

NOTE Confidence: 0.906796898333333

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

NOTE Confidence: 0.906796898333333

 $00{:}22{:}04.630 \dashrightarrow 00{:}22{:}06.868$ essentially to have a written record

NOTE Confidence: 0.906796898333333

 $00:22:06.868 \longrightarrow 00:22:10.195$ of what happens in case there was a

NOTE Confidence: 0.906796898333333

 $00{:}22{:}10.195 \dashrightarrow 00{:}22{:}11.959$ lawsuit around medical mal practice.

NOTE Confidence: 0.906796898333333

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

NOTE Confidence: 0.906796898333333

 $00:22:14.234 \longrightarrow 00:22:16.503$ about the there's some Mac to

NOTE Confidence: 0.906796898333333

 $00:22:16.503 \longrightarrow 00:22:18.525$ PC changes here with the font.

NOTE Confidence: 0.906796898333333

 $00:22:18.530 \longrightarrow 00:22:19.784$ So it's a little bit hard

NOTE Confidence: 0.906796898333333

 $00:22:19.784 \longrightarrow 00:22:20.930$ to read some of this,

00:22:20.930 --> 00:22:22.952 but you know how about billing

NOTE Confidence: 0.906796898333333

 $00:22:22.952 \longrightarrow 00:22:24.707$ 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

 $00:22:26.729 \longrightarrow 00:22:28.509$ medical records look like today.

NOTE Confidence: 0.906796898333333

 $00:22:28.510 \longrightarrow 00:22:30.568$ But that only really happened in

NOTE Confidence: 0.906796898333333

 $00:22:30.570 \longrightarrow 00:22:34.282$ 1960s is really not long ago and until

NOTE Confidence: 0.906796898333333

 $00:22:34.282 \longrightarrow 00:22:37.846$ you know not so long ago physicians

NOTE Confidence: 0.906796898333333

 $00:22:37.846 \longrightarrow 00:22:41.191$ were paid with food and lodging.

NOTE Confidence: 0.906796898333333

 $00:22:41.191 \longrightarrow 00:22:43.619$ If they were lucky.

NOTE Confidence: 0.906796898333333

 $00:22:43.620 \longrightarrow 00:22:46.910$ This is a picture from the Confucian

NOTE Confidence: 0.906796898333333

 $00{:}22{:}46.910 \dashrightarrow 00{:}22{:}49.084$ medical system where there's at

NOTE Confidence: 0.906796898333333

 $00{:}22{:}49.084 \dashrightarrow 00{:}22{:}51.758$ least some cases where the the court

NOTE Confidence: 0.906796898333333

 $00{:}22{:}51.758 \dashrightarrow 00{:}22{:}53.352$ physician was basically executed if

NOTE Confidence: 0.906796898333333

 $00:22:53.352 \longrightarrow 00:22:55.879$ 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

 $00:22:58.706 \longrightarrow 00:23:00.380$ or penalty if you will.

NOTE Confidence: 0.906796898333333

 $00{:}23{:}00.380 \dashrightarrow 00{:}23{:}02.180$ 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

 $00:23:04.673 \longrightarrow 00:23:08.338$ which basically established this profile.

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

NOTE Confidence: 0.906796898333333

 $00:23:09.020 \longrightarrow 00:23:10.380$ quote usual customary and

NOTE Confidence: 0.906796898333333

 $00:23:10.380 \longrightarrow 00:23:11.400$ reasonable fees which.

NOTE Confidence: 0.906796898333333

 $00:23:11.400 \longrightarrow 00:23:13.045$ 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

 $00:23:14.170 \longrightarrow 00:23:15.066$ that's messed up here,

NOTE Confidence: 0.906796898333333

 $00:23:15.070 \longrightarrow 00:23:18.227$ 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

 $00{:}23{:}19.658 \dashrightarrow 00{:}23{:}22.059$ 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

 $00:23:23.997 \longrightarrow 00:23:25.828$ faced by the medical profession.

NOTE Confidence: 0.906796898333333

 $00:23:25.830 \longrightarrow 00:23:28.530$ That's actual quote.

 $00:23:28.530 \longrightarrow 00:23:30.240$ It certainly changed things a lot.

NOTE Confidence: 0.906796898333333

 $00:23:30.240 \longrightarrow 00:23:32.970$ And then what I'd argue also changed

NOTE Confidence: 0.906796898333333

 $00{:}23{:}32.970 \dashrightarrow 00{:}23{:}34.666$ things was really more recent was

NOTE Confidence: 0.906796898333333

 $00:23:34.666 \longrightarrow 00:23:36.388$ in the 90s when the physician fee

NOTE Confidence: 0.906796898333333

 $00{:}23{:}36.388 \dashrightarrow 00{:}23{:}37.888$ schedule was introduced and then

NOTE Confidence: 0.906796898333333

 $00:23:37.888 \longrightarrow 00:23:39.515$ 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

 $00:23:40.976 \longrightarrow 00:23:42.600$ A lot of us know more than

NOTE Confidence: 0.906796898333333

 $00:23:42.658 \longrightarrow 00:23:44.296$ we ever wanted to know about,

NOTE Confidence: 0.906796898333333

 $00:23:44.300 \longrightarrow 00:23:47.470$ but those really changed how

NOTE Confidence: 0.906796898333333

 $00:23:47.470 \longrightarrow 00:23:50.640$ 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

 $00:23:56.720 \longrightarrow 00:23:59.060$ which I think all of us want that to

 $00:23:59.060 \longrightarrow 00:24:01.892$ be the primary purpose of medical records.

NOTE Confidence: 0.906796898333333

 $00:24:01.892 \longrightarrow 00:24:04.550$ This kind of dates back to

NOTE Confidence: 0.906796898333333

 $00:24:04.640 \longrightarrow 00:24:06.436$ the 1800s in some ways.

NOTE Confidence: 0.906796898333333

 $00:24:06.436 \longrightarrow 00:24:08.196$ The case records of the

NOTE Confidence: 0.906796898333333

 $00:24:08.196 \longrightarrow 00:24:09.500$ 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

 $00:24:15.240 \longrightarrow 00:24:16.137$ 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

 $00{:}24{:}18.532 \dashrightarrow 00{:}24{:}20.233$ 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

 $00:24:22.100 \longrightarrow 00:24:24.878$ where they also introduced the chief

NOTE Confidence: 0.906796898333333

 $00:24:24.878 \longrightarrow 00:24:27.650$ complaint and the review of systems.

NOTE Confidence: 0.906796898333333

 $00:24:27.650 \longrightarrow 00:24:30.204$ And then the American,

NOTE Confidence: 0.906796898333333

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

 $00:24:32.390 \longrightarrow 00:24:33.914$ 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

 $00:24:37.900 \longrightarrow 00:24:39.657$ There was no federal mandate of any.

NOTE Confidence: 0.764963734545455

 $00:24:39.660 \longrightarrow 00:24:41.276$ They basically mandated as

NOTE Confidence: 0.764963734545455

 $00:24:41.276 \longrightarrow 00:24:42.488$ 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

 $00:24:49.560 \longrightarrow 00:24:50.202$ you know, patient,

NOTE Confidence: 0.764963734545455

 $00:24:50.202 \longrightarrow 00:24:52.419$ you know alive or dead at the time they left.

NOTE Confidence: 0.764963734545455

 $00:24:52.420 \longrightarrow 00:24:55.588$ 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

 $00:24:58.260 \longrightarrow 00:25:02.830$ which is like. Amazing, right?

NOTE Confidence: 0.764963734545455

 $00:25:02.830 \longrightarrow 00:25:05.143$ 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,

 $00:25:06.950 \longrightarrow 00:25:09.050$ for those that did take records,

NOTE Confidence: 0.764963734545455

 $00{:}25{:}09.050 \dashrightarrow 00{:}25{:}10.618$ this is kind of what they looked

NOTE Confidence: 0.764963734545455

 $00:25:10.618 \longrightarrow 00:25:12.407$ like as these are called case books.

NOTE Confidence: 0.764963734545455

 $00:25:12.410 \longrightarrow 00:25:13.994$ I'm not sure where this one is from,

NOTE Confidence: 0.764963734545455

 $00:25:14.000 \longrightarrow 00:25:18.070$ 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

 $00:25:19.996 \longrightarrow 00:25:22.717$ this is that it's physician centered, right.

NOTE Confidence: 0.76496373454545500:25:22.717 --> 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

 $00:25:26.350 \longrightarrow 00:25:27.630$ one patient has one book,

NOTE Confidence: 0.764963734545455

 $00:25:27.630 \longrightarrow 00:25:29.750$ this was written as.

NOTE Confidence: 0.764963734545455

 $00:25:29.750 \longrightarrow 00:25:30.894$ 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

 $00:25:35.422 \longrightarrow 00:25:37.462$ like put their case together,

NOTE Confidence: 0.764963734545455 00:25:37.470 --> 00:25:39.730 good luck.

 $00:25:39.730 \longrightarrow 00:25:41.865$ So really the the most recent innovation

NOTE Confidence: 0.764963734545455

 $00:25:41.865 \longrightarrow 00:25:44.065$ if you will in medical records was

NOTE Confidence: 0.764963734545455

 $00:25:44.065 \longrightarrow 00:25:46.288$ this one and that from Austin from

NOTE Confidence: 0.764963734545455

 $00:25:46.288 \longrightarrow 00:25:48.591$ 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

 $00:25:53.003 \longrightarrow 00:25:55.229$ record that guides and teaches.

NOTE Confidence: 0.764963734545455

 $00:25:55.230 \longrightarrow 00:25:56.974$ So kind of back to that idea of

NOTE Confidence: 0.764963734545455

 $00:25:56.974 \longrightarrow 00:25:59.074$ 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

 $00:26:00.150 \longrightarrow 00:26:03.800$ this idea, this soap notes, right.

NOTE Confidence: 0.764963734545455

 $00:26:03.800 \longrightarrow 00:26:06.754$ What I like from the paper when

NOTE Confidence: 0.764963734545455

 $00{:}26{:}06.754 \dashrightarrow 00{:}26{:}08.880$ doctor we'd introduced this idea.

NOTE Confidence: 0.764963734545455

 $00:26:08.880 \longrightarrow 00:26:12.324$ 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,

 $00:26:15.040 \longrightarrow 00:26:16.040$ and it's worth reading it.

NOTE Confidence: 0.764963734545455

 $00:26:16.040 \longrightarrow 00:26:17.444$ 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

 $00:26:19.298 \longrightarrow 00:26:20.628$ data presently in the medical

NOTE Confidence: 0.764963734545455

 $00:26:20.628 \longrightarrow 00:26:21.840$ record can be structured,

NOTE Confidence: 0.764963734545455

 $00:26:21.840 \longrightarrow 00:26:23.618$ and in the future all narrative data

NOTE Confidence: 0.764963734545455

 $00:26:23.618 \longrightarrow 00:26:25.855$ may be entered through a series of

NOTE Confidence: 0.764963734545455

 $00:26:25.855 \longrightarrow 00:26:27.275$ displays guaranteeing a thoroughness,

NOTE Confidence: 0.764963734545455

 $00:26:27.280 \longrightarrow 00:26:27.732$ retrievability,

NOTE Confidence: 0.764963734545455

00:26:27.732 --> 00:26:29.540 efficiency and economy important

NOTE Confidence: 0.764963734545455

 $00{:}26{:}29.540 \dashrightarrow 00{:}26{:}32.148$ to the scientific analysis of a

NOTE Confidence: 0.764963734545455

 $00:26:32.148 \longrightarrow 00:26:33.840$ type of datum that has hitherto.

NOTE Confidence: 0.764963734545455

 $00:26:33.840 \longrightarrow 00:26:36.206$ Been handled in a very unrigorous manner.

NOTE Confidence: 0.764963734545455

 $00{:}26{:}36.210 \dashrightarrow 00{:}26{:}37.190$ It's an amazing quote.

NOTE Confidence: 0.76496373454545500:26:37.190 --> 00:26:37.680 I mean, NOTE Confidence: 0.764963734545455

 $00:26:37.680 \longrightarrow 00:26:40.710$ this is essentially before any

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

NOTE Confidence: 0.764963734545455

 $00:26:42.102 \longrightarrow 00:26:44.459$ 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

 $00:26:48.956 \longrightarrow 00:26:51.528$ this quote is this to be concluded.

NOTE Confidence: 0.878462154285714

 $00:26:51.530 \longrightarrow 00:26:54.325$ We're living through the evolution

NOTE Confidence: 0.878462154285714

 $00:26:54.325 \longrightarrow 00:26:57.120$ 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

 $00:26:58.600 \longrightarrow 00:26:59.510$ 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

 $00:27:00.310 \longrightarrow 00:27:02.008$ he could have been like OK,

NOTE Confidence: 0.878462154285714

 $00:27:02.010 \longrightarrow 00:27:05.174$ 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

 $00{:}27{:}07.136 \dashrightarrow 00{:}27{:}09.068$ and saying what you know what.

NOTE Confidence: 0.878462154285714

 $00:27:09.068 \longrightarrow 00:27:11.372$ 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?

 $00:27:13.800 \longrightarrow 00:27:16.168$ And it's got primary uses and secondary uses.

NOTE Confidence: 0.878462154285714

 $00{:}27{:}16.170 \dashrightarrow 00{:}27{:}18.501$ So the primary uses are are patient

NOTE Confidence: 0.878462154285714

 $00:27:18.501 \longrightarrow 00:27:20.472$ care and delivery, financial billing.

NOTE Confidence: 0.878462154285714

 $00:27:20.472 \longrightarrow 00:27:22.850$ But it's this, when you talk about

NOTE Confidence: 0.878462154285714

 $00:27:22.850 \longrightarrow 00:27:24.230$ real-world data and real world evidence,

NOTE Confidence: 0.878462154285714

 $00:27:24.230 \longrightarrow 00:27:25.546$ that's a secondary use,

NOTE Confidence: 0.878462154285714

 $00:27:25.546 \longrightarrow 00:27:27.950$ 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

 $00:27:31.490 \longrightarrow 00:27:32.900$ So moving ahead a little bit.

NOTE Confidence: 0.878462154285714

 $00:27:32.900 \longrightarrow 00:27:35.730$ So this is where we were in the mid 2000s

NOTE Confidence: 0.878462154285714

 $00:27:35.730 \longrightarrow 00:27:38.295$ and this is when I was in medical school.

NOTE Confidence: 0.878462154285714

 $00:27:38.300 \longrightarrow 00:27:40.664$ At that time there was issues

NOTE Confidence: 0.878462154285714

 $00{:}27{:}40.664 \dashrightarrow 00{:}27{:}43.812$ 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

 $00:27:45.800 \longrightarrow 00:27:47.546$ What I like on the bottom here is in

 $00:27:47.550 \longrightarrow 00:27:49.552$ 2003 the mass medical society did a

NOTE Confidence: 0.878462154285714

 $00:27:49.552 \longrightarrow 00:27:52.302$ survey where 89% of physicians wanted

NOTE Confidence: 0.878462154285714

 $00:27:52.302 \longrightarrow 00:27:56.064$ EHR data, but 48% refused to use an ER.

NOTE Confidence: 0.878462154285714

 $00:27:56.070 \longrightarrow 00:27:59.213$ So little bit of a disconnect there

NOTE Confidence: 0.878462154285714

 $00:27:59.213 \longrightarrow 00:28:01.022$ and and by 2004.

NOTE Confidence: 0.878462154285714

 $00:28:01.022 \longrightarrow 00:28:03.794$ Hardly anybody was using medical records.

NOTE Confidence: 0.878462154285714

 $00:28:03.800 \longrightarrow 00:28:05.321$ 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

 $00:28:08.166 \longrightarrow 00:28:11.430$ one of the events that really changed things.

NOTE Confidence: 0.878462154285714

 $00:28:11.430 \longrightarrow 00:28:13.795$ Is every body 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

 $00:28:17.230 \longrightarrow 00:28:20.100$ Does everybody know why the?

NOTE Confidence: 0.878462154285714

 $00:28:20.100 \longrightarrow 00:28:21.312$ Record so there's a picture there

NOTE Confidence: 0.878462154285714

 $00:28:21.312 \longrightarrow 00:28:21.918$ on the right.

NOTE Confidence: 0.878462154285714

 $00:28:21.920 \longrightarrow 00:28:24.120$ It's everybody know why those

 $00:28:24.120 \longrightarrow 00:28:25.880$ were in the basement.

NOTE Confidence: 0.878462154285714

 $00:28:25.880 \longrightarrow 00:28:26.580$ That flooded.

NOTE Confidence: 0.878462154285714

 $00:28:26.580 \longrightarrow 00:28:29.380$ It's the they are so heavy that the

NOTE Confidence: 0.878462154285714

 $00:28:29.451 \longrightarrow 00:28:31.701$ building literally would have collapsed

NOTE Confidence: 0.878462154285714

 $00:28:31.701 \longrightarrow 00:28:34.641$ under the weight of the paper if

NOTE Confidence: 0.878462154285714

 $00:28:34.641 \longrightarrow 00:28:36.566$ they'd been up on higher floors.

NOTE Confidence: 0.878462154285714

 $00:28:36.566 \longrightarrow 00:28:38.624$ So that's why they have their

NOTE Confidence: 0.878462154285714

 $00:28:38.624 \longrightarrow 00:28:40.592$ medical records in the basement and

NOTE Confidence: 0.878462154285714

 $00:28:40.592 \longrightarrow 00:28:42.320$ and they were all destroyed, right?

NOTE Confidence: 0.878462154285714

 $00:28:42.320 \longrightarrow 00:28:43.320$ 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

 $00:28:48.078 \longrightarrow 00:28:51.422$ 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

 $00:28:52.004 \longrightarrow 00:28:54.013$ 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.

 $00:28:56.111 \longrightarrow 00:28:58.193$ 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

 $00:29:00.609 \longrightarrow 00:29:02.500$ curve and there's a couple,

NOTE Confidence: 0.878462154285714

 $00:29:02.500 \longrightarrow 00:29:03.648$ I won't get into the details here.

NOTE Confidence: 0.878462154285714

 $00{:}29{:}03.650 \dashrightarrow 00{:}29{:}06.071$ 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

 $00:29:08.550 \longrightarrow 00:29:11.550$ 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

 $00:29:16.010 \longrightarrow 00:29:19.338$ Here's Katrina in 2005.

NOTE Confidence: 0.878462154285714

 $00:29:19.340 \longrightarrow 00:29:20.280$ 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

 $00:29:21.970 \longrightarrow 00:29:24.616$ 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

 $00{:}29{:}27.248 \to 00{:}29{:}30.131$ definitely help things along, but you know,

 $00:29:30.131 \longrightarrow 00:29:32.016$ the process is already starting.

NOTE Confidence: 0.87846215428571400:29:32.020 --> 00:29:32.520 Umm. NOTE Confidence: 0.878462154285714

 $00:29:32.520 \longrightarrow 00:29:35.020$ And then you know where.

NOTE Confidence: 0.878462154285714

 $00:29:35.020 \longrightarrow 00:29:37.078$ 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

 $00:29:41.162 \longrightarrow 00:29:42.352$ can't see the text there.

NOTE Confidence: 0.878462154285714

 $00:29:42.360 \longrightarrow 00:29:44.115$ 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

 $00{:}29{:}48.550 \dashrightarrow 00{:}29{:}51.346$ So, so you know, it's problematic.

NOTE Confidence: 0.881632480833333

 $00:29:51.350 \longrightarrow 00:29:53.426$ But OK, here's a here's a

NOTE Confidence: 0.881632480833333

 $00:29:53.426 \longrightarrow 00:29:54.808$ few other challenges. So.

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

NOTE Confidence: 0.881632480833333

 $00{:}29{:}56.498 \to 00{:}29{:}58.360$ 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

 $00:30:02.162 \longrightarrow 00:30:04.059$ ubiquitous in medical records and

NOTE Confidence: 0.881632480833333

 $00:30:04.059 \longrightarrow 00:30:06.015$ 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

 $00:30:19.760 \longrightarrow 00:30:21.585$ more than half of progress

NOTE Confidence: 0.881632480833333

 $00:30:21.585 \longrightarrow 00:30:23.546$ note material is copy copied

NOTE Confidence: 0.881632480833333

 $00:30:23.546 \longrightarrow 00:30:25.078$ forward from previous notes.

NOTE Confidence: 0.861171268571429

 $00:30:27.270 \longrightarrow 00:30:30.614$ This is a different study looking at you

 $00:30:30.614 \longrightarrow 00:30:32.566$ know how many progress notes have a manually

NOTE Confidence: 0.861171268571429

 $00:30:32.566 \longrightarrow 00:30:34.207$ entered text versus copied in any kind.

NOTE Confidence: 0.861171268571429

 $00:30:34.210 \longrightarrow 00:30:37.720$ And you can see again like very few progress

NOTE Confidence: 0.861171268571429

 $00:30:37.720 \longrightarrow 00:30:40.448$ notes have have fully written text.

NOTE Confidence: 0.861171268571429

 $00:30:40.450 \dashrightarrow 00:30:43.510$ 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

 $00:30:44.973 \longrightarrow 00:30:46.708$ to say what are we dealing with here?

NOTE Confidence: 0.861171268571429

 $00:30:46.710 \longrightarrow 00:30:47.851$ Is it a giant pile of paper

NOTE Confidence: 0.861171268571429

 $00:30:47.851 \longrightarrow 00:30:49.099$ or is there actually meaning.

NOTE Confidence: 0.861171268571429

 $00:30:49.100 \dashrightarrow 00:30:51.500$ So this is a little little tiny project

NOTE Confidence: 0.861171268571429

 $00:30:51.500 \longrightarrow 00:30:54.032$ I did and when during fellowship where

NOTE Confidence: 0.861171268571429

 $00:30:54.032 \longrightarrow 00:30:56.699$ I basically took one of my patients

NOTE Confidence: 0.861171268571429

 $00{:}30{:}56.700 \dashrightarrow 00{:}30{:}59.150$ charts and I counted up like how

NOTE Confidence: 0.861171268571429

 $00{:}30{:}59.150 \dashrightarrow 00{:}31{:}01.569$ many data points are in that chart.

NOTE Confidence: 0.861171268571429

 $00:31:01.570 \longrightarrow 00:31:04.810$ And you can see the blue bars are all the

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

NOTE Confidence: 0.861171268571429

 $00{:}31{:}07.300 \dashrightarrow 00{:}31{:}10.659$ codes or vital signs or lab values.

NOTE Confidence: 0.861171268571429

 $00:31:10.660 \longrightarrow 00:31:12.772$ 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

 $00:31:18.282 \longrightarrow 00:31:21.270$ So there's a lot of data there but.

NOTE Confidence: 0.861171268571429

 $00:31:21.270 \longrightarrow 00:31:21.972$ It's awesome.

NOTE Confidence: 0.861171268571429

 $00:31:21.972 \longrightarrow 00:31:24.238$ There's even more than that, right?

NOTE Confidence: 0.861171268571429

 $00:31:24.238 \longrightarrow 00:31:26.270$ 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

 $00:31:28.443 \longrightarrow 00:31:30.787$ So this was more than 10 years ago,

NOTE Confidence: 0.861171268571429

 $00:31:30.790 \longrightarrow 00:31:34.479$ there was another 277 pages of scanned

NOTE Confidence: 0.861171268571429

 $00:31:34.479 \longrightarrow 00:31:36.820$ documents with 69,000 words in them

NOTE Confidence: 0.861171268571429

 $00:31:36.820 \longrightarrow 00:31:38.100$ that were basically inaccessible,

NOTE Confidence: 0.861171268571429

 $00:31:38.100 \longrightarrow 00:31:41.308$ but and the take home point here.

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

 $00:31:45.600 \longrightarrow 00:31:48.106$ 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

 $00:31:50.036 \longrightarrow 00:31:51.930$ getting 6 cycles of our chop.

NOTE Confidence: 0.861171268571429

 $00:31:51.930 \longrightarrow 00:31:53.806$ I think that's enough for most research.

NOTE Confidence: 0.861171268571429

 $00:31:53.810 \longrightarrow 00:31:56.990$ OK now how can we,

NOTE Confidence: 0.861171268571429

 $00:31:56.990 \longrightarrow 00:31:58.698$ 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

 $00:32:00.272 \longrightarrow 00:32:01.862$ maybe what we're talking about here.

NOTE Confidence: 0.861171268571429

 $00:32:01.870 \dashrightarrow 00:32:05.686$ So and of course there's more to it right.

NOTE Confidence: 0.861171268571429

 $00:32:05.690 \longrightarrow 00:32:08.906$ But you know when you think about what's

NOTE Confidence: 0.861171268571429

 $00{:}32{:}08.906 \dashrightarrow 00{:}32{:}12.654$ 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,

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

 $00:32:21.760 \longrightarrow 00:32:22.830$ 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

 $00:32:28.010 \longrightarrow 00:32:29.536$ 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

 $00:32:32.629 \longrightarrow 00:32:33.968$ 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

 $00:32:35.170 \longrightarrow 00:32:36.880$ 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

 $00:32:39.036 \longrightarrow 00:32:40.560$ You know they won't have lived

 $00:32:40.614 \longrightarrow 00:32:42.049$ their whole system with their

NOTE Confidence: 0.861171268571429

 $00:32:42.049 \longrightarrow 00:32:43.484$ life within the electronic air,

NOTE Confidence: 0.861171268571429

 $00:32:43.490 \longrightarrow 00:32:45.324$ 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

 $00:32:47.342 \longrightarrow 00:32:48.398$ but are you going to find

NOTE Confidence: 0.861171268571429

 $00:32:48.398 \longrightarrow 00:32:49.210$ their gender orientation,

NOTE Confidence: 0.861171268571429

 $00:32:49.210 \longrightarrow 00:32:50.215$ 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

 $00:32:52.230 \longrightarrow 00:32:54.715$ but are you going to find other

NOTE Confidence: 0.861171268571429

 $00:32:54.715 \longrightarrow 00:32:56.310$ 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

 $00:32:57.550 \longrightarrow 00:32:58.790$ 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

 $00:33:01.450 \longrightarrow 00:33:03.529$ the medication that they took and the

 $00:33:03.529 \longrightarrow 00:33:05.432$ regimens and we're going to get into

NOTE Confidence: 0.861171268571429

 $00:33:05.432 \longrightarrow 00:33:07.562$ that next you'll find laboratory tests,

NOTE Confidence: 0.861171268571429

 $00:33:07.562 \longrightarrow 00:33:10.040$ but you want necessarily find images.

NOTE Confidence: 0.861171268571429

 $00:33:10.040 \longrightarrow 00:33:11.528$ 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

 $00:33:15.117 \longrightarrow 00:33:17.040$ forward. Thinking about what you know,

NOTE Confidence: 0.898628412727273

 $00:33:17.040 \longrightarrow 00:33:19.760$ the low hanging fruit.

NOTE Confidence: 0.898628412727273

 $00:33:19.760 \longrightarrow 00:33:21.848$ You know it's the cancer type,

NOTE Confidence: 0.898628412727273

 $00{:}33{:}21.850 \dashrightarrow 00{:}33{:}23.482$ it's easy like we don't need to create

NOTE Confidence: 0.898628412727273

 $00:33:23.482 \longrightarrow 00:33:25.147$ a new system to get cancer type.

NOTE Confidence: 0.898628412727273

 $00{:}33{:}25.150 \dashrightarrow 00{:}33{:}27.376$ You can get that from billing codes,

NOTE Confidence: 0.898628412727273

 $00:33:27.380 \longrightarrow 00:33:28.426$ registry data.

NOTE Confidence: 0.898628412727273

 $00:33:28.426 \longrightarrow 00:33:32.087$ 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

 $00:33:34.452 \longrightarrow 00:33:36.810$ the patients in a complete remission,

NOTE Confidence: 0.898628412727273

 $00:33:36.810 \longrightarrow 00:33:37.479$ that's really hard.

 $00:33:37.479 \longrightarrow 00:33:39.040$ 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

 $00:33:40.325 \longrightarrow 00:33:42.620$ 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

 $00:33:45.124 \longrightarrow 00:33:48.779$ for a bit and talk about our work on

NOTE Confidence: 0.898628412727273

 $00:33:48.779 \longrightarrow 00:33:51.360$ standardizing systemic anti cancer treatment.

NOTE Confidence: 0.898628412727273

 $00:33:51.360 \longrightarrow 00:33:55.188$ And before I get into that.

NOTE Confidence: 0.898628412727273

 $00:33:55.190 \longrightarrow 00:33:58.025$ If you've not seen this XKCD cartoon,

NOTE Confidence: 0.898628412727273

 $00:33:58.030 \longrightarrow 00:33:59.155$ it's a classic.

NOTE Confidence: 0.898628412727273

 $00:33:59.155 \longrightarrow 00:34:01.437$ 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

 $00:34:04.286 \longrightarrow 00:34:07.210$ standard or you actually just you know.

NOTE Confidence: 0.898628412727273

 $00{:}34{:}07.210 \dashrightarrow 00{:}34{:}08.650$ Just creating more complexity or not.

NOTE Confidence: 0.898628412727273

 $00:34:08.650 \longrightarrow 00:34:09.697$ Hopefully we're not.

NOTE Confidence: 0.898628412727273

 $00:34:09.697 \longrightarrow 00:34:12.140$ Well, what we did in this space,

 $00:34:12.140 \longrightarrow 00:34:14.108$ there really weren't 14 existing standards.

NOTE Confidence: 0.898628412727273

 $00:34:14.110 \longrightarrow 00:34:15.094$ There were none.

NOTE Confidence: 0.898628412727273

 $00:34:15.094 \longrightarrow 00:34:17.062$ And so as everybody here knows,

NOTE Confidence: 0.898628412727273

 $00:34:17.070 \longrightarrow 00:34:19.128$ I could skip past this slide.

NOTE Confidence: 0.898628412727273

 $00:34:19.130 \longrightarrow 00:34:22.430$ Chemotherapy regimens are complicated and

NOTE Confidence: 0.898628412727273

 $00:34:22.430 \longrightarrow 00:34:25.730$ given in cyclic fashion combinations.

NOTE Confidence: 0.898628412727273

 $00:34:25.730 \longrightarrow 00:34:27.425$ This was the standard when

NOTE Confidence: 0.898628412727273

 $00:34:27.425 \longrightarrow 00:34:29.550$ we got started on our work.

NOTE Confidence: 0.898628412727273

 $00:34:29.550 \longrightarrow 00:34:30.602$ This is, you know,

NOTE Confidence: 0.898628412727273

 $00:34:30.602 \longrightarrow 00:34:32.180$ one example of these things called

NOTE Confidence: 0.898628412727273

 $00{:}34{:}32.237 \dashrightarrow 00{:}34{:}33.728$ cancer chemotherapy handbooks,

NOTE Confidence: 0.898628412727273

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

NOTE Confidence: 0.89862841272727300:34:37.010 --> 00:34:37.341 right.

NOTE Confidence: 0.898628412727273

 $00:34:37.341 \longrightarrow 00:34:38.996$ With some some details here,

NOTE Confidence: 0.898628412727273

 $00:34:39.000 \longrightarrow 00:34:41.224$ but maybe not enough.

NOTE Confidence: 0.898628412727273

 $00:34:41.224 \longrightarrow 00:34:45.740$ Here's another example from 2005.

00:34:45.740 --> 00:34:48.953 Which if you kind of look in

NOTE Confidence: 0.898628412727273

 $00:34:48.953 \longrightarrow 00:34:51.000$ 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

 $00:34:54.270 \longrightarrow 00:34:55.694$ some of the references.

NOTE Confidence: 0.898628412727273

 $00:34:55.694 \longrightarrow 00:34:58.410$ Here's a little excerpt from the Adenoma.

NOTE Confidence: 0.898628412727273

 $00:34:58.410 \longrightarrow 00:34:59.690$ 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

 $00:35:00.460 \longrightarrow 00:35:02.532$ but the references are to non small

NOTE Confidence: 0.898628412727273

 $00:35:02.532 \longrightarrow 00:35:04.931$ cell lung cancer so there's sort of a

NOTE Confidence: 0.898628412727273

 $00:35:04.931 \dashrightarrow 00:35:06.730$ mis match there in the evidence base.

NOTE Confidence: 0.898628412727273

 $00:35:06.730 \longrightarrow 00:35:09.250$ So what we did is we.

NOTE Confidence: 0.898628412727273

 $00:35:09.250 \longrightarrow 00:35:10.570$ Really basically tried to collect

NOTE Confidence: 0.898628412727273

 $00{:}35{:}10.570 \dashrightarrow 00{:}35{:}11.890$ all this information and put

NOTE Confidence: 0.898628412727273

 $00:35:11.936 \longrightarrow 00:35:13.126$ it into a computable format,

NOTE Confidence: 0.898628412727273

 $00:35:13.130 \longrightarrow 00:35:16.130$ which is our hemlock.org website and

 $00:35:16.130 \longrightarrow 00:35:18.890$ the ontology that comes from it.

NOTE Confidence: 0.898628412727273

 $00{:}35{:}18.890 \dashrightarrow 00{:}35{:}21.725$ So he might.org is a is a website with

NOTE Confidence: 0.898628412727273

 $00:35:21.725 \longrightarrow 00:35:24.689$ the goal to collect all standard of

NOTE Confidence: 0.898628412727273

 $00:35:24.689 \longrightarrow 00:35:27.230$ care systemic anti cancer treatment.

NOTE Confidence: 0.898628412727273

 $00:35:27.230 \longrightarrow 00:35:28.523$ That's the goal.

NOTE Confidence: 0.898628412727273

 $00:35:28.523 \longrightarrow 00:35:32.155$ It's a big goal and at the website has

NOTE Confidence: 0.898628412727273

 $00:35:32.155 \longrightarrow 00:35:35.080$ 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

 $00:35:37.120 \longrightarrow 00:35:38.656$ over 7000 references,

NOTE Confidence: 0.898628412727273

 $00:35:38.656 \longrightarrow 00:35:41.216$ and a large editorial board,

NOTE Confidence: 0.898628412727273

 $00:35:41.220 \longrightarrow 00:35:44.216$ 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

 $00:35:46.110 \longrightarrow 00:35:49.288$ so 1.4 million page views last year,

NOTE Confidence: 0.898628412727273

 $00:35:49.290 \longrightarrow 00:35:52.300$ we do get visitors from all over

NOTE Confidence: 0.898628412727273

 $00:35:52.300 \longrightarrow 00:35:55.429$ the world were primarily US based.

NOTE Confidence: 0.898628412727273

 $00{:}35{:}55.430 \dashrightarrow 00{:}35{:}57.510$ I always like to throw in that we've

 $00:35:57.510 \longrightarrow 00:35:59.590$ 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

 $00:36:00.810 \longrightarrow 00:36:03.426$ but I don't think I want to know.

NOTE Confidence: 0.898628412727273

 $00:36:03.430 \longrightarrow 00:36:05.806$ So what what can we do with this website?

NOTE Confidence: 0.898628412727273

 $00:36:05.810 \longrightarrow 00:36:08.330$ So what we did over time,

NOTE Confidence: 0.898628412727273

 $00:36:08.330 \longrightarrow 00:36:10.360$ over the past 11 years is create

NOTE Confidence: 0.898628412727273

 $00:36:10.360 \longrightarrow 00:36:12.231$ a structure such that we could

NOTE Confidence: 0.898628412727273

 $00:36:12.231 \longrightarrow 00:36:13.796$ actually take the content and

NOTE Confidence: 0.898628412727273

 $00:36:13.796 \longrightarrow 00:36:15.260$ develop a formal model.

NOTE Confidence: 0.898628412727273

 $00:36:15.260 \longrightarrow 00:36:17.120$ And so this is the model?

NOTE Confidence: 0.898628412727273

 $00:36:17.120 \longrightarrow 00:36:19.507$ 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

 $00:36:23.870 \longrightarrow 00:36:27.188$ but it's somewhat complex and enlarge

 $00:36:27.188 \longrightarrow 00:36:30.650$ we have over 100,000 concepts and

NOTE Confidence: 0.88690812375

 $00{:}36{:}30.650 \dashrightarrow 00{:}36{:}33.626$ $300{,}000$ ways in which those are

NOTE Confidence: 0.88690812375

 $00:36:33.626 \longrightarrow 00:36:36.380$ interrelated in the latest version.

NOTE Confidence: 0.88690812375

 $00:36:36.380 \longrightarrow 00:36:39.290$ 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

 $00:36:42.536 \longrightarrow 00:36:43.094$ 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

 $00{:}36{:}45.302 \dashrightarrow 00{:}36{:}46.770$ website showing basically that

NOTE Confidence: 0.88690812375

 $00:36:46.833 \longrightarrow 00:36:48.729$ each regimen on the website is.

NOTE Confidence: 0.88690812375

 $00:36:48.730 \longrightarrow 00:36:50.490$ In such a way that we can take

NOTE Confidence: 0.88690812375

 $00:36:50.490 \longrightarrow 00:36:52.074$ all those pieces and put them

NOTE Confidence: 0.88690812375

 $00:36:52.074 \longrightarrow 00:36:53.694$ into the into the data model.

NOTE Confidence: 0.88690812375

 $00:36:53.700 \longrightarrow 00:36:55.149$ 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

 $00:36:56.480 \longrightarrow 00:36:59.119$ So here's a project that we did

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

NOTE Confidence: 0.88690812375

 $00:37:01.630 \longrightarrow 00:37:06.600$ Korea who basically had access to.

NOTE Confidence: 0.88690812375

 $00:37:06.600 \longrightarrow 00:37:08.256$ 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

 $00:37:13.330 \longrightarrow 00:37:14.955$ but to actually understand regimens

NOTE Confidence: 0.88690812375

 $00:37:14.955 \longrightarrow 00:37:16.970$ we have to do something extra.

NOTE Confidence: 0.88690812375

 $00:37:16.970 \longrightarrow 00:37:18.909$ And So what they did is they

NOTE Confidence: 0.88690812375

 $00:37:18.909 \longrightarrow 00:37:20.945$ applied our model and they mapped

NOTE Confidence: 0.88690812375

 $00:37:20.945 \longrightarrow 00:37:22.465$ medications through regiments and

NOTE Confidence: 0.88690812375

 $00:37:22.465 \longrightarrow 00:37:24.711$ and they were able to look basically

NOTE Confidence: 0.88690812375

 $00:37:24.711 \longrightarrow 00:37:26.914$ over a decade of time 2008 to 18.

NOTE Confidence: 0.88690812375

 $00:37:26.914 \dashrightarrow 00:37:28.888$ And you can see here that you know the

NOTE Confidence: 0.88690812375

 $00:37:28.888 \longrightarrow 00:37:30.764$ changing pattern of care in that country.

NOTE Confidence: 0.88690812375

 $00:37:30.770 \longrightarrow 00:37:34.885$ So you see that for example of you know

 $00:37:34.885 \longrightarrow 00:37:37.040$ bevacizumab wasn't used really until

NOTE Confidence: 0.88690812375

 $00:37:37.114 \dashrightarrow 00:37:40.054$ 2014 and then it started getting popular.

NOTE Confidence: 0.88690812375

 $00:37:40.060 \longrightarrow 00:37:42.020$ 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

 $00{:}37{:}48.000 \dashrightarrow 00{:}37{:}50.436$ whereas something like fluorouracil

NOTE Confidence: 0.88690812375

 $00:37:50.436 \longrightarrow 00:37:52.263$ 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

 $00:37:55.448 \longrightarrow 00:37:57.362$ by the time you get there.

NOTE Confidence: 0.88690812375

 $00:37:57.370 \longrightarrow 00:37:59.064$ This is much more recent so that

NOTE Confidence: 0.88690812375

 $00:37:59.064 \longrightarrow 00:38:00.964$ that's from a couple of years ago

NOTE Confidence: 0.88690812375

 $00:38:00.964 \longrightarrow 00:38:03.150$ now we're working with folks at the.

NOTE Confidence: 0.8194428005

 $00:38:05.210 \longrightarrow 00:38:07.736$ University of California System have a

NOTE Confidence: 0.8194428005

 $00:38:07.736 \longrightarrow 00:38:10.080$ really cool combined database across all

NOTE Confidence: 0.8194428005

 $00:38:10.080 \longrightarrow 00:38:12.456$ the UC's and California is kind of a.

 $00{:}38{:}12.460 \dashrightarrow 00{:}38{:}14.364$ 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

 $00{:}38{:}16.420 \dashrightarrow 00{:}38{:}20.022$ 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

 $00:38:22.777 \longrightarrow 00:38:25.324$ exposure data including time stamps

NOTE Confidence: 0.8194428005

 $00:38:25.324 \longrightarrow 00:38:28.604$ and we're mapping that to regimens.

NOTE Confidence: 0.8194428005

 $00:38:28.604 \longrightarrow 00:38:31.684$ And and you see that.

NOTE Confidence: 0.8194428005

 $00:38:31.690 \longrightarrow 00:38:35.638$ At least nowadays, full fernox is

NOTE Confidence: 0.8194428005

 $00:38:35.638 \dashrightarrow 00:38:39.070$ the most popular regimen there.

NOTE Confidence: 0.8194428005

 $00:38:39.070 \longrightarrow 00:38:40.426$ 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

 $00:38:43.020 \longrightarrow 00:38:44.782$ You also see some funny things, right?

NOTE Confidence: 0.8194428005

 $00:38:44.782 \longrightarrow 00:38:47.038$ Like so I didn't know Leuprolide was a

NOTE Confidence: 0.8194428005

 $00:38:47.038 \longrightarrow 00:38:50.260$ treatment for pancreatic cancer, did you?

NOTE Confidence: 0.8194428005

 $00:38:50.260 \longrightarrow 00:38:53.842$ Is it? Not no, right. No.

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

NOTE Confidence: 0.8194428005

 $00:38:55.860 \longrightarrow 00:38:57.360$ And they actually have second malignancies.

NOTE Confidence: 0.8194428005

 $00:38:57.360 \longrightarrow 00:38:58.944$ So these are people who have

NOTE Confidence: 0.8194428005

 $00:38:58.944 \longrightarrow 00:39:00.402$ also have prostate cancer and

NOTE Confidence: 0.8194428005

 $00:39:00.402 \longrightarrow 00:39:01.810$ they're also getting leuprolide.

NOTE Confidence: 0.8194428005

 $00:39:01.810 \longrightarrow 00:39:04.450$ So you, you, you kind of have to you know,

NOTE Confidence: 0.8194428005

 $00:39:04.450 \longrightarrow 00:39:06.450$ 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

 $00:39:11.790 \longrightarrow 00:39:13.926$ Does it make sense, is it?

NOTE Confidence: 0.8194428005

 $00:39:13.930 \longrightarrow 00:39:17.180$ 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

 $00:39:19.217 \longrightarrow 00:39:20.599$ seeing things like that so.

NOTE Confidence: 0.8194428005

 $00:39:20.600 \longrightarrow 00:39:23.522$ Umm. Here's another kind of.

 $00:39:23.522 \longrightarrow 00:39:24.048$ Here's another.

NOTE Confidence: 0.8194428005

 $00:39:24.050 \dashrightarrow 00:39:25.570$ Gives you a taste of what we can look at.

NOTE Confidence: 0.8194428005

 $00:39:25.570 \longrightarrow 00:39:28.972$ So that this is this is looking at folfirinox

NOTE Confidence: 0.8194428005

 $00:39:28.972 \longrightarrow 00:39:32.137$ and and then looking at cycle by cycle.

NOTE Confidence: 0.8194428005

 $00:39:32.140 \longrightarrow 00:39:32.914$ What's happening?

NOTE Confidence: 0.8194428005

 $00:39:32.914 \longrightarrow 00:39:35.236$ So one of my long-term interests,

NOTE Confidence: 0.8194428005

 $00:39:35.240 \longrightarrow 00:39:37.400$ as well as Doctor Zach here,

NOTE Confidence: 0.8194428005

 $00:39:37.400 \longrightarrow 00:39:39.890$ is to understand treatment delays,

NOTE Confidence: 0.8194428005

 $00:39:39.890 \longrightarrow 00:39:42.080$ dose reductions.

NOTE Confidence: 0.8194428005

 $00:39:42.080 \longrightarrow 00:39:44.887$ Removals of medications from a regimen drop,

NOTE Confidence: 0.8194428005

 $00{:}39{:}44.890 \dashrightarrow 00{:}39{:}47.098$ you know, dropping a drug and this starts

NOTE Confidence: 0.8194428005

 $00:39:47.098 \longrightarrow 00:39:49.555$ to get at that and you can kind of see,

NOTE Confidence: 0.8194428005

 $00{:}39{:}49.560 --> 00{:}39{:}50.104 \ \mathrm{you} \ \mathrm{know},$

NOTE Confidence: 0.8194428005

 $00:39:50.104 \longrightarrow 00:39:52.280$ each of those bars represents cycle to cycle,

NOTE Confidence: 0.8194428005

 $00:39:52.280 \longrightarrow 00:39:54.200$ the cycle you see.

 $00:39:54.200 \longrightarrow 00:39:54.680$ People.

NOTE Confidence: 0.8194428005

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

NOTE Confidence: 0.8194428005

 $00:39:56.032 \longrightarrow 00:39:58.982$ And and so and then you can actually see

NOTE Confidence: 0.8194428005

 $00:39:58.982 \longrightarrow 00:40:01.639$ why and you can see on the top here.

NOTE Confidence: 0.8194428005

 $00:40:01.640 \longrightarrow 00:40:03.536$ These, these bands at the top are showing.

NOTE Confidence: 0.8194428005

 $00:40:03.540 \longrightarrow 00:40:05.220$ You know, these these are folks.

NOTE Confidence: 0.8194428005

 $00:40:05.220 \longrightarrow 00:40:06.318$ You don't think that you have

NOTE Confidence: 0.8194428005

 $00:40:06.318 \longrightarrow 00:40:07.050$ a pointer or something.

NOTE Confidence: 0.8194428005

 $00{:}40{:}07.050 \dashrightarrow 00{:}40{:}10.235$ 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

 $00:40:10.780 \longrightarrow 00:40:12.670$ so you see these bands coming across,

NOTE Confidence: 0.8194428005

 $00:40:12.670 \longrightarrow 00:40:14.662$ those are basically patients that are

NOTE Confidence: 0.8194428005

 $00{:}40{:}14.662 \longrightarrow 00{:}40{:}16.927$ progressing and going on to a second

NOTE Confidence: 0.8194428005

 $00:40:16.927 \longrightarrow 00:40:18.679$ 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

 $00:40:20.198 \longrightarrow 00:40:21.560$ bit on the visual side,

NOTE Confidence: 0.8194428005

 $00{:}40{:}21.560 \dashrightarrow 00{:}40{:}24.458$ our patients who are or stopping the rapy

NOTE Confidence: 0.8194428005

 $00:40:24.458 \longrightarrow 00:40:26.490$ and and essentially transitioning to

NOTE Confidence: 0.8194428005

 $00:40:26.490 \longrightarrow 00:40:29.362$ Hospice or some sort of end of life

NOTE Confidence: 0.8194428005

 $00:40:29.432 \longrightarrow 00:40:31.777$ care and that's this big bar here.

NOTE Confidence: 0.8194428005

 $00:40:31.780 \longrightarrow 00:40:34.090$ And then some patients these

NOTE Confidence: 0.8194428005

 $00:40:34.090 \longrightarrow 00:40:36.350$ little these little ones they're

NOTE Confidence: 0.8194428005

 $00:40:36.350 \longrightarrow 00:40:38.400$ going to a deescalated regimen.

NOTE Confidence: 0.8194428005

 $00:40:38.400 \longrightarrow 00:40:40.056$ So they're dropping the.

NOTE Confidence: 0.8194428005

 $00{:}40{:}40{:}056 \longrightarrow 00{:}40{:}42.540$ Arena taken or the oxaliplatin and

NOTE Confidence: 0.8194428005

 $00:40:42.611 \longrightarrow 00:40:45.299$ so you can really start to see these

NOTE Confidence: 0.8194428005

 $00:40:45.299 \longrightarrow 00:40:48.535$ patterns of care in the real world data so.

NOTE Confidence: 0.8194428005 00:40:48.540 --> 00:40:49.143 OK,

00:40:49.143 --> 00:40:49.746 so. NOTE Confidence: 0.8194428005

NOTE Confidence: 0.8194428005

 $00:40:49.746 \longrightarrow 00:40:53.967$ This is my little advertisement for Humalog.

 $00:40:53.970 \longrightarrow 00:40:56.194$ It's available to you.

NOTE Confidence: 0.8194428005

 $00{:}40{:}56.194 \dashrightarrow 00{:}40{:}58.985$ You can you can download the whole

NOTE Confidence: 0.8194428005

 $00{:}40{:}58.985 \dashrightarrow 00{:}41{:}01.472$ thing and and mess around with

NOTE Confidence: 0.8194428005

 $00:41:01.472 \longrightarrow 00:41:04.055$ it if you're an academic or non

NOTE Confidence: 0.8194428005

 $00{:}41{:}04.055 \dashrightarrow 00{:}41{:}05.887$ 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

 $00:41:08.870 \longrightarrow 00:41:11.310$ 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

 $00:41:19.980 \longrightarrow 00:41:21.510$ There's I think a lot more

NOTE Confidence: 0.91100581

 $00:41:21.571 \longrightarrow 00:41:22.957$ that can be done with it.

NOTE Confidence: 0.91100581

 $00:41:22.960 \longrightarrow 00:41:25.940$ So along comes a pandemic.

NOTE Confidence: 0.91100581

 $00:41:25.940 \longrightarrow 00:41:28.793$ So, so now I want to spend the last

NOTE Confidence: 0.91100581

 $00:41:28.793 \longrightarrow 00:41:31.618$ little bit here talking about the

NOTE Confidence: 0.91100581

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

 $00:41:33.570 \longrightarrow 00:41:36.330$ Which yells a member and this

NOTE Confidence: 0.91100581

 $00:41:36.330 \longrightarrow 00:41:38.170$ is our mission statement,

NOTE Confidence: 0.91100581

 $00:41:38.170 \longrightarrow 00:41:40.270$ which has been the same since

NOTE Confidence: 0.91100581

 $00:41:40.270 \longrightarrow 00:41:42.549$ we were created in March 2020,

NOTE Confidence: 0.91100581

 $00:41:42.550 \longrightarrow 00:41:44.230$ 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

 $00{:}41{:}47.982 \dashrightarrow 00{:}41{:}50.075$ who are diagnosed with COVID-19 at

NOTE Confidence: 0.91100581

 $00{:}41{:}50.075 \dashrightarrow 00{:}41{:}51.995$ scale and as rapidly as possible.

NOTE Confidence: 0.91100581

 $00:41:52.000 \longrightarrow 00:41:53.337$ But what I want to talk about

NOTE Confidence: 0.91100581

 $00:41:53.337 \longrightarrow 00:41:55.127$ here for a minute is sort of what

NOTE Confidence: 0.91100581

 $00{:}41{:}55.127 \dashrightarrow 00{:}41{:}56.440$ I call the ancillary goals of

NOTE Confidence: 0.91100581

 $00:41:56.440 \longrightarrow 00:41:58.630$ C19 or the unwritten goals.

NOTE Confidence: 0.91100581

 $00:41:58.630 \longrightarrow 00:42:00.414$ So one of those was, you know,

 $00:42:00.414 \longrightarrow 00:42:01.974$ can we build a consortium,

NOTE Confidence: 0.91100581

 $00:42:01.980 \longrightarrow 00:42:04.636$ can we build an airplane while also flying?

NOTE Confidence: 0.91100581

 $00:42:04.640 \longrightarrow 00:42:05.844$ Just, you know, can we do it?

NOTE Confidence: 0.91100581

 $00:42:05.850 \longrightarrow 00:42:07.202$ That was the question.

NOTE Confidence: 0.91100581

 $00:42:07.202 \longrightarrow 00:42:08.892$ Convening a group of stakeholders

NOTE Confidence: 0.91100581

 $00:42:08.892 \longrightarrow 00:42:10.560$ 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

 $00:42:11.960 \longrightarrow 00:42:15.260$ 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

 $00:42:16.900 \longrightarrow 00:42:18.664$ can we demonstrate the additive value of

NOTE Confidence: 0.91100581

 $00{:}42{:}18.664 \dashrightarrow 00{:}42{:}20.611$ 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

 $00{:}42{:}22.320 \dashrightarrow 00{:}42{:}24.070$ We knew that there were other efforts

NOTE Confidence: 0.91100581

 $00:42:24.070 \longrightarrow 00:42:25.884$ kind of getting rolling that were based

NOTE Confidence: 0.91100581

 $00{:}42{:}25.884 \rightarrow 00{:}42{:}27.700$ on what was in that structured data.

NOTE Confidence: 0.91100581

 $00:42:27.700 \longrightarrow 00:42:31.000$ If you remember that's the.

 $00:42:31.000 \longrightarrow 00:42:33.874$ The tiny little blue bars right

NOTE Confidence: 0.91100581

 $00:42:33.874 \longrightarrow 00:42:37.049$ on the graph I showed you.

NOTE Confidence: 0.91100581

 $00:42:37.050 \longrightarrow 00:42:38.346$ So we wanted to, you know,

NOTE Confidence: 0.91100581

 $00:42:38.350 \longrightarrow 00:42:43.400$ get more than that. So this is.

NOTE Confidence: 0.91100581

 $00{:}42{:}43.400 \dashrightarrow 00{:}42{:}46.128$ This is back in back in Rhode Island.

NOTE Confidence: 0.91100581

 $00:42:46.130 \longrightarrow 00:42:46.361$ Alright.

NOTE Confidence: 0.91100581

00:42:46.361 --> 00:42:47.516 Showed you Eli Whitney earlier.

NOTE Confidence: 0.91100581

 $00:42:47.520 \longrightarrow 00:42:50.362$ 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

 $00:42:52.954 \longrightarrow 00:42:54.674$ pronounced correctly but I'm

NOTE Confidence: 0.91100581

 $00{:}42{:}54.674 \dashrightarrow 00{:}42{:}57.190$ getting my New England shops.

NOTE Confidence: 0.91100581

 $00:42:57.190 \longrightarrow 00:42:59.668$ And and what's interesting to me about

NOTE Confidence: 0.91100581

 $00{:}42{:}59.668 \dashrightarrow 00{:}43{:}02.180$ this story is that he earned this name,

NOTE Confidence: 0.91100581

 $00:43:02.180 \longrightarrow 00:43:05.030$ 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

 $00:43:08.220 \longrightarrow 00:43:11.013$ is that he was accused of stealing

NOTE Confidence: 0.91100581

 $00{:}43{:}11.101 \dashrightarrow 00{:}43{:}13.817$ the ideas for industrialization.

NOTE Confidence: 0.91100581

 $00:43:13.820 \longrightarrow 00:43:16.150$ 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

 $00:43:19.980 \longrightarrow 00:43:22.470$ and then replicating it in America.

NOTE Confidence: 0.91100581

 $00:43:22.470 \longrightarrow 00:43:25.200$ So this is really the beginning of

NOTE Confidence: 0.91100581

 $00:43:25.200 \longrightarrow 00:43:27.180$ 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

 $00{:}43{:}29.262 \dashrightarrow 00{:}43{:}31.648$ that he didn't exactly steal the ideas.

NOTE Confidence: 0.91100581

 $00:43:31.650 \longrightarrow 00:43:33.060$ Like he didn't steal blueprints

NOTE Confidence: 0.91100581

 $00:43:33.060 \longrightarrow 00:43:34.188$ 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

 $00:43:36.914 \longrightarrow 00:43:39.130$ brought the knowledge with him.

NOTE Confidence: 0.91100581

 $00:43:39.130 \longrightarrow 00:43:42.064$ 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

 $00:43:46.200 \longrightarrow 00:43:47.719$ And so you know when we think

00:43:47.719 --> 00:43:49.493 about C 19 and I certainly don't

NOTE Confidence: 0.91100581

 $00:43:49.493 \longrightarrow 00:43:51.420$ 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

 $00:43:55.160 \longrightarrow 00:43:55.672$ the hemlock,

NOTE Confidence: 0.91100581

 $00:43:55.672 \longrightarrow 00:43:58.060$ 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

 $00:44:01.300 \longrightarrow 00:44:04.000$ we are borrowing best ideas,

NOTE Confidence: 0.91100581

 $00:44:04.000 \longrightarrow 00:44:06.536$ modifying sometimes and putting

NOTE Confidence: 0.91100581

 $00:44:06.536 \longrightarrow 00:44:09.012$ together this consortium and and

NOTE Confidence: 0.91100581

 $00:44:09.012 \longrightarrow 00:44:11.760$ 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

 $00:44:17.501 \longrightarrow 00:44:19.886$ is that sponsors are critical.

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

 $00:44:23.260 \longrightarrow 00:44:24.638$ Brown who basically fronted him

NOTE Confidence: 0.777663597692308

 $00:44:24.638 \longrightarrow 00:44:26.084$ the money to build those mills.

NOTE Confidence: 0.777663597692308

 $00:44:26.090 \longrightarrow 00:44:28.922$ And our sponsor is Julie Klem at the

NOTE Confidence: 0.777663597692308

 $00:44:28.922 \longrightarrow 00:44:32.004$ 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

 $00:44:38.770 \longrightarrow 00:44:40.442$ So this is our.

NOTE Confidence: 0.777663597692308

 $00:44:40.442 \longrightarrow 00:44:42.532$ This is our data schema,

NOTE Confidence: 0.777663597692308

 $00:44:42.540 \longrightarrow 00:44:44.924$ and what I want to emphasize here related

NOTE Confidence: 0.777663597692308

 $00:44:44.924 \longrightarrow 00:44:47.467$ 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

 $00:44:49.890 \longrightarrow 00:44:52.530$ so as we sort of built this up.

NOTE Confidence: 0.777663597692308 $00:44:52.530 \longrightarrow 00:44:53.066$ You know, NOTE Confidence: 0.777663597692308

 $00:44:53.066 \longrightarrow 00:44:54.942$ some of these things you can collect,

00:44:54.950 --> 00:44:56.408 you know, in many different ways.

NOTE Confidence: 0.777663597692308

 $00:44:56.410 \longrightarrow 00:44:57.266$ But the red items.

NOTE Confidence: 0.777663597692308

 $00:44:57.266 \longrightarrow 00:44:58.873$ And you'll see in a few slides

NOTE Confidence: 0.777663597692308

 $00:44:58.873 \longrightarrow 00:45:00.763$ that those turn out to be critical

NOTE Confidence: 0.777663597692308

 $00:45:00.763 \longrightarrow 00:45:02.580$ things like ECOG performance status,

NOTE Confidence: 0.777663597692308

 $00:45:02.580 \longrightarrow 00:45:05.800$ things like toxicity of

NOTE Confidence: 0.777663597692308

 $00:45:05.800 \longrightarrow 00:45:08.215$ cancer treatment pneumonitis.

NOTE Confidence: 0.777663597692308

 $00:45:08.220 \longrightarrow 00:45:09.129$ Items like that,

NOTE Confidence: 0.777663597692308

 $00:45:09.129 \longrightarrow 00:45:11.500$ that we really wanted to zero in on.

NOTE Confidence: 0.777663597692308

 $00:45:11.500 \longrightarrow 00:45:12.466$ I'm going to skip this slide.

NOTE Confidence: 0.777663597692308

 $00:45:12.470 \longrightarrow 00:45:14.714$ I'm going to skip this and

NOTE Confidence: 0.777663597692308

 $00:45:14.714 \longrightarrow 00:45:17.069$ I'm going to just say that.

NOTE Confidence: 0.777663597692308

 $00{:}45{:}17.070 \dashrightarrow 00{:}45{:}19.023$ We've done really pretty well on capturing

NOTE Confidence: 0.777663597692308

 $00:45:19.023 \longrightarrow 00:45:21.090$ what I would call elusive variables.

NOTE Confidence: 0.777663597692308

 $00:45:21.090 \longrightarrow 00:45:22.842$ So these are kind of the

 $00:45:22.842 \longrightarrow 00:45:25.166$ things that they're in the ER,

NOTE Confidence: 0.777663597692308

 $00{:}45{:}25.166 {\:\dashrightarrow\:} 00{:}45{:}27.336$ 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

 $00:45:28.276 \longrightarrow 00:45:30.980$ but we we got a lot of them.

NOTE Confidence: 0.777663597692308

 $00:45:30.980 \longrightarrow 00:45:34.070$ So cancer status is the patient.

NOTE Confidence: 0.777663597692308

00:45:34.070 --> 00:45:34.780 Getting better,

NOTE Confidence: 0.777663597692308

 $00:45:34.780 \longrightarrow 00:45:36.555$ getting worse or staying this,

NOTE Confidence: 0.777663597692308

 $00:45:36.560 \longrightarrow 00:45:37.688$ you know the same as before,

NOTE Confidence: 0.777663597692308

 $00:45:37.690 \longrightarrow 00:45:38.599$ a stable disease.

NOTE Confidence: 0.777663597692308

 $00:45:38.599 \longrightarrow 00:45:41.372$ We have that in over 95% of the patients.

NOTE Confidence: 0.777663597692308

 $00{:}45{:}41.372 \dashrightarrow 00{:}45{:}43.929$ Even smoking status is hard to get right.

NOTE Confidence: 0.777663597692308

 $00:45:43.930 \longrightarrow 00:45:45.778$ We have that.

NOTE Confidence: 0.777663597692308

 $00{:}45{:}45.780 \dashrightarrow 00{:}45{:}48.080$ Did COVID affects the patients

NOTE Confidence: 0.777663597692308

 $00{:}45{:}48.080 \dashrightarrow 00{:}45{:}50.488$ 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

 $00:45:51.980 \longrightarrow 00:45:55.418$ We have over 90% on that on the ECOG

 $00:45:55.418 \longrightarrow 00:45:57.463$ which is a notorious notoriously

NOTE Confidence: 0.777663597692308

 $00:45:57.463 \longrightarrow 00:45:59.514$ difficult thing to get and and all

NOTE Confidence: 0.777663597692308

 $00:45:59.514 \longrightarrow 00:46:01.111$ the various efforts such as flat

NOTE Confidence: 0.777663597692308

 $00:46:01.111 \longrightarrow 00:46:02.894$ 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

 $00:46:04.414 \longrightarrow 00:46:05.963$ have had challenges with this.

NOTE Confidence: 0.777663597692308

 $00:46:05.963 \longrightarrow 00:46:08.626$ We have we have ECOG data on 88%

NOTE Confidence: 0.777663597692308

 $00:46:08.626 \longrightarrow 00:46:10.256$ although that does that includes

NOTE Confidence: 0.777663597692308

 $00{:}46{:}10.256 \dashrightarrow 00{:}46{:}11.882$ 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

 $00:46:13.484 \longrightarrow 00:46:15.088$ knowledge of no ECOG is still.

NOTE Confidence: 0.777663597692308

00:46:15.090 --> 00:46:16.350 Knowledge,

NOTE Confidence: 0.777663597692308

 $00:46:16.350 \longrightarrow 00:46:17.610$ right?

NOTE Confidence: 0.777663597692308

00:46:17.610 --> 00:46:19.920 And you know getting to our

NOTE Confidence: 0.777663597692308

 $00:46:19.920 \longrightarrow 00:46:22.199$ getting to our results again in

 $00:46:22.199 \longrightarrow 00:46:24.284$ just focus on the red and what

NOTE Confidence: 0.777663597692308

 $00:46:24.284 \longrightarrow 00:46:25.586$ we found is that these factors,

NOTE Confidence: 0.777663597692308

 $00:46:25.590 \longrightarrow 00:46:28.446$ these elusive factors are really important.

NOTE Confidence: 0.777663597692308

 $00:46:28.450 \longrightarrow 00:46:30.680$ And so this is unadjusted

NOTE Confidence: 0.777663597692308

 $00:46:30.680 \longrightarrow 00:46:32.464$ 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

 $00{:}46{:}36.668 \operatorname{{\text{--}}}{>} 00{:}46{:}38.746$ day mortality is 26% and if you

NOTE Confidence: 0.777663597692308

 $00:46:38.746 \longrightarrow 00:46:41.390$ 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

 $00:46:45.190 \longrightarrow 00:46:48.440$ And we also found that immunosuppression

NOTE Confidence: 0.906268886

 $00:46:48.440 \longrightarrow 00:46:52.240$ which is a somewhat nebulous

NOTE Confidence: 0.906268886

 $00:46:52.240 \longrightarrow 00:46:54.160$ definition and we have our

NOTE Confidence: 0.906268886

 $00{:}46{:}54.160 \dashrightarrow 00{:}46{:}56.080$ definition here which is complex,

NOTE Confidence: 0.906268886

 $00:46:56.080 \longrightarrow 00:46:58.369$ which includes a lot of things you

NOTE Confidence: 0.906268886

 $00:46:58.369 \longrightarrow 00:47:00.140$ can't easily get out of structured data.

 $00:47:00.140 \longrightarrow 00:47:02.415$ 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

 $00:47:04.420 \longrightarrow 00:47:07.778$ 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

 $00:47:10.700 \longrightarrow 00:47:12.245$ the, the yellow table basically

NOTE Confidence: 0.906268886

 $00:47:12.245 \longrightarrow 00:47:14.289$ those are the patients who are

NOTE Confidence: 0.906268886

 $00:47:14.289 \longrightarrow 00:47:15.609$ immunosuppressed at baseline.

NOTE Confidence: 0.906268886

 $00:47:15.610 \longrightarrow 00:47:17.282$ And across the board,

NOTE Confidence: 0.906268886

 $00{:}47{:}17.282 \dashrightarrow 00{:}47{:}18.954$ even younger patients have

NOTE Confidence: 0.906268886

 $00{:}47{:}18.954 \dashrightarrow 00{:}47{:}20.810$ substantial mortality in our data set.

NOTE Confidence: 0.862009429

 $00:47:23.530 \longrightarrow 00:47:25.600$ Furthermore, if you add on

NOTE Confidence: 0.862009429

 $00:47:25.600 \longrightarrow 00:47:27.670$ top of that active cancer.

NOTE Confidence: 0.862009429

 $00{:}47{:}27.670 \dashrightarrow 00{:}47{:}28.886$ So are they immuno suppressed

NOTE Confidence: 0.862009429

 $00:47:28.886 \longrightarrow 00:47:30.406$ and they have active cancer.

NOTE Confidence: 0.862009429

 $00:47:30.410 \longrightarrow 00:47:34.120$ Again, we have our definition for that.

 $00:47:34.120 \longrightarrow 00:47:35.570$ Because if you're not immunosuppressed

NOTE Confidence: 0.862009429

 $00:47:35.570 \longrightarrow 00:47:37.020$ 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

 $00:47:39.100 \longrightarrow 00:47:41.552$ 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

 $00:47:43.300 \longrightarrow 00:47:44.956$ your chance goes all the way up to 30%.

NOTE Confidence: 0.862009429

 $00:47:44.960 \longrightarrow 00:47:47.384$ So really a huge spread here

NOTE Confidence: 0.862009429

 $00:47:47.384 \longrightarrow 00:47:49.500$ based on these these data.

NOTE Confidence: 0.862009429

 $00:47:49.500 \longrightarrow 00:47:52.676$ And then if we start to look at.

NOTE Confidence: 0.862009429

 $00:47:52.680 \longrightarrow 00:47:54.309$ Multivariable adjusted analysis.

NOTE Confidence: 0.862009429

 $00{:}47{:}54.309 \dashrightarrow 00{:}47{:}57.567$ Again, we see that these factors

NOTE Confidence: 0.862009429

 $00:47:57.567 \longrightarrow 00:48:01.031$ 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

 $00:48:02.930 \longrightarrow 00:48:04.790$ both mortality as well as severity,

NOTE Confidence: 0.862009429

 $00:48:04.790 \longrightarrow 00:48:06.764$ which means hospitalization,

NOTE Confidence: 0.862009429

 $00:48:06.764 \longrightarrow 00:48:09.396$ intubation and so forth.

 $00:48:09.400 \longrightarrow 00:48:11.144$ We saw this as well more recently when

NOTE Confidence: 0.862009429

 $00:48:11.144 \longrightarrow 00:48:12.679$ we looked at vaccinated patients.

NOTE Confidence: 0.862009429

 $00:48:12.680 \longrightarrow 00:48:14.765$ 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

 $00{:}48{:}18.543 \longrightarrow 00{:}48{:}20.360$ 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

 $00:48:22.508 \longrightarrow 00:48:26.101$ 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

 $00{:}48{:}31.380 \dashrightarrow 00{:}48{:}33.480$ 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

 $00:48:34.660 \longrightarrow 00:48:37.540$ but I'm going to pause and so I just

NOTE Confidence: 0.728421021666667

 $00{:}48{:}37.540 {\:{\circ}{\circ}{\circ}}>00{:}48{:}40.359$ want to share some parting thoughts.

NOTE Confidence: 0.728421021666667

 $00:48:40.360 \longrightarrow 00:48:42.558$ 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,

 $00:48:43.964 \longrightarrow 00:48:45.728$ 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

 $00:48:47.795 \longrightarrow 00:48:49.670$ to yield real-world evidence if.

NOTE Confidence: 0.728421021666667

 $00:48:49.670 \longrightarrow 00:48:51.362$ We approach it with an understanding

NOTE Confidence: 0.728421021666667

 $00:48:51.362 \longrightarrow 00:48:52.490$ about the completeness issues,

NOTE Confidence: 0.728421021666667

 $00:48:52.490 \longrightarrow 00:48:53.591$ the accuracy issues,

NOTE Confidence: 0.728421021666667

 $00{:}48{:}53.591 \dashrightarrow 00{:}48{:}56.160$ and we anticipate them and we come

NOTE Confidence: 0.728421021666667

 $00:48:56.231 \longrightarrow 00:48:58.359$ up with either ways to adjust for

NOTE Confidence: 0.728421021666667

 $00:48:58.359 \longrightarrow 00:49:01.870$ them or or avoid certain data,

NOTE Confidence: 0.728421021666667

 $00:49:01.870 \longrightarrow 00:49:04.846$ certain variables in the first place.

NOTE Confidence: 0.728421021666667

 $00:49:04.850 \longrightarrow 00:49:07.130$ 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

 $00{:}49{:}10.700 \dashrightarrow 00{:}49{:}12.329$ and a computer could do everything,

NOTE Confidence: 0.728421021666667

 $00:49:12.330 \longrightarrow 00:49:14.330$ but in reality a lot of real world

NOTE Confidence: 0.728421021666667

 $00:49:14.330 \longrightarrow 00:49:15.977$ data and real world evidence

00:49:15.977 --> 00:49:17.787 depends on human curators going

NOTE Confidence: 0.728421021666667

 $00{:}49{:}17.787 \dashrightarrow 00{:}49{:}20.050$ into EHR's pulling out that data.

NOTE Confidence: 0.728421021666667

 $00{:}49{:}20.050 \longrightarrow 00{:}49{:}22.874$ And to do that we need rigorous approaches.

NOTE Confidence: 0.728421021666667

 $00:49:22.880 \longrightarrow 00:49:24.650$ We have a paper published earlier

NOTE Confidence: 0.728421021666667

 $00:49:24.650 \longrightarrow 00:49:26.145$ this year describing the approach

NOTE Confidence: 0.728421021666667

 $00:49:26.145 \longrightarrow 00:49:27.420$ we used in ACR Genie.

NOTE Confidence: 0.728421021666667

 $00:49:27.420 \longrightarrow 00:49:28.736$ I encourage you to check that out.

NOTE Confidence: 0.728421021666667

 $00:49:28.740 \longrightarrow 00:49:30.604$ It basically gets into.

NOTE Confidence: 0.728421021666667

 $00{:}49{:}30.604 \dashrightarrow 00{:}49{:}32.934$ You know you need directives.

NOTE Confidence: 0.728421021666667

 $00{:}49{:}32.940 \dashrightarrow 00{:}49{:}35.370$ You need you need two people

NOTE Confidence: 0.728421021666667

 $00:49:35.370 \longrightarrow 00:49:37.396$ to to independently curate the

NOTE Confidence: 0.728421021666667

 $00{:}49{:}37.396 \dashrightarrow 00{:}49{:}39.664$ same record at a certain rate so

NOTE Confidence: 0.728421021666667

 $00{:}49{:}39.664 \dashrightarrow 00{:}49{:}42.848$ you can see if you know there's

NOTE Confidence: 0.728421021666667

 $00:49:42.848 \longrightarrow 00:49:44.812$ comparability between their results.

NOTE Confidence: 0.728421021666667 $00:49:44.820 \longrightarrow 00:49:46.119$ And so forth.

00:49:46.119 --> 00:49:48.284 If if there's widespread adoption

NOTE Confidence: 0.728421021666667

 $00:49:48.284 \longrightarrow 00:49:50.310$ of standards such as M code,

NOTE Confidence: 0.728421021666667

 $00:49:50.310 \longrightarrow 00:49:51.770$ hemac, omop and so forth,

NOTE Confidence: 0.728421021666667

 $00:49:51.770 \longrightarrow 00:49:54.194$ that that will increase the usefulness

NOTE Confidence: 0.728421021666667

 $00:49:54.194 \longrightarrow 00:49:56.556$ 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

 $00:50:00.570 \longrightarrow 00:50:03.370$ If you pick up the newspaper nowadays,

NOTE Confidence: 0.728421021666667

 $00:50:03.370 \longrightarrow 00:50:05.404$ like you're going to see our other paper on,

NOTE Confidence: 0.728421021666667

 $00{:}50{:}05.410 \to 00{:}50{:}06.674$ you're going to see an article on chat,

NOTE Confidence: 0.728421021666667

 $00:50:06.680 \longrightarrow 00:50:08.048$ 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

 $00:50:17.730 \longrightarrow 00:50:19.584$ 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

 $00{:}50{:}21.681 \dashrightarrow 00{:}50{:}23.420$ I alluded to disparities and bias.

 $00:50:23.420 \longrightarrow 00:50:25.928$ There's a lot of concern that.

NOTE Confidence: 0.72842102166666700:50:25.930 --> 00:50:26.343 That,

NOTE Confidence: 0.728421021666667 00:50:26.343 --> 00:50:27.169 you know, NOTE Confidence: 0.728421021666667

 $00:50:27.169 \longrightarrow 00:50:29.234$ working with real-world data might

NOTE Confidence: 0.728421021666667

 $00:50:29.234 \longrightarrow 00:50:31.552$ might actually make biases worse that

NOTE Confidence: 0.728421021666667

 $00{:}50{:}31.552 \dashrightarrow 00{:}50{:}33.688$ are already present in that data.

NOTE Confidence: 0.728421021666667

 $00:50:33.690 \longrightarrow 00:50:37.554$ So we need new approaches to to to.

NOTE Confidence: 0.728421021666667

 $00{:}50{:}37.560 \dashrightarrow 00{:}50{:}40.899$ New approaches to deal with that issue.

NOTE Confidence: 0.728421021666667

 $00:50:40.900 \dashrightarrow 00:50:42.220$ Just have some acknowledgements here.

NOTE Confidence: 0.728421021666667

 $00:50:42.220 \longrightarrow 00:50:43.400$ So there's two slides here.

NOTE Confidence: 0.728421021666667

 $00:50:43.400 \longrightarrow 00:50:44.877$ So this is my first acknowledgement slide.

NOTE Confidence: 0.728421021666667

 $00:50:44.880 \longrightarrow 00:50:47.400$ I acknowledge the himanka.org

NOTE Confidence: 0.728421021666667

 $00{:}50{:}47.400 \dashrightarrow 00{:}50{:}48.660 \ {\rm editorial \ board}.$

NOTE Confidence: 0.728421021666667

 $00:50:48.660 \longrightarrow 00:50:50.310$ Others that have worked on

NOTE Confidence: 0.728421021666667

 $00:50:50.310 \longrightarrow 00:50:52.440$ it are funding and and Dolly,

 $00:50:52.440 \longrightarrow 00:50:54.126$ which is the creator of some

NOTE Confidence: 0.728421021666667

 $00:50:54.126 \longrightarrow 00:50:55.540$ 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

 $00:50:58.123 \longrightarrow 00:51:02.482$ which is a huge endeavor that has more

NOTE Confidence: 0.728421021666667

 $00:51:02.482 \longrightarrow 00:51:06.080$ 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

 $00:51:07.124 \longrightarrow 00:51:08.864$ I will pause for questions.

NOTE Confidence: 0.7881931

 $00:51:16.340 \longrightarrow 00:51:21.158$ So I'll I'll start. And can you see

NOTE Confidence: 0.7881931

 $00:51:21.158 \longrightarrow 00:51:22.500$ 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

 $00{:}51{:}27.300 \dashrightarrow 00{:}51{:}29.964$ So I I, I don't for a second dispute

NOTE Confidence: 0.785123106956522

 $00:51:29.964 \longrightarrow 00:51:32.779$ the value of real world data in terms

NOTE Confidence: 0.785123106956522

 $00:51:32.779 \longrightarrow 00:51:35.388$ of being able to answer questions,

NOTE Confidence: 0.785123106956522

 $00:51:35.390 \longrightarrow 00:51:38.510$ but I'm struck by the fact that we

NOTE Confidence: 0.785123106956522

 $00:51:38.510 \longrightarrow 00:51:41.199$ have these two extremes we have.

NOTE Confidence: 0.785123106956522

 $00:51:41.200 \longrightarrow 00:51:43.412$ Randomized controlled trials where

 $00:51:43.412 \longrightarrow 00:51:47.198$ we spend a fortune to collect every

NOTE Confidence: 0.785123106956522

 $00{:}51{:}47.198 \dashrightarrow 00{:}51{:}51.808$ last bit of data and you know they

NOTE Confidence: 0.785123106956522

 $00:51:51.808 \longrightarrow 00:51:56.490$ cost \$15,000 per patient or more.

NOTE Confidence: 0.785123106956522

 $00:51:56.490 \longrightarrow 00:51:59.058$ And we get lots of useless data as

NOTE Confidence: 0.785123106956522

 $00:51:59.058 \longrightarrow 00:52:01.830$ 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

 $00:52:04.494 \longrightarrow 00:52:06.270$ from randomized controlled trials.

NOTE Confidence: 0.785123106956522

 $00:52:06.270 \longrightarrow 00:52:08.566$ So then we go to real world data

NOTE Confidence: 0.785123106956522

 $00{:}52{:}08.566 \rightarrow 00{:}52{:}09.856$ where everything's pretty messy

NOTE Confidence: 0.785123106956522

 $00:52:09.856 \longrightarrow 00:52:12.180$ and you have to make all these

NOTE Confidence: 0.785123106956522

 $00:52:12.249 \longrightarrow 00:52:14.265$ assumptions and clean up the data.

NOTE Confidence: 0.785123106956522

 $00:52:14.270 \longrightarrow 00:52:16.710$ And the question is,

NOTE Confidence: 0.785123106956522

 $00{:}52{:}16.710 \dashrightarrow 00{:}52{:}21.603$ 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 $00:52:28.940 \longrightarrow 00:52:30.000$ I mean sure, yeah,

NOTE Confidence: 0.839671244545455

 $00{:}52{:}30.000 \dashrightarrow 00{:}52{:}32.000$ I mean I think the recovery trial,

NOTE Confidence: 0.839671244545455

 $00:52:32.000 \longrightarrow 00:52:34.440$ I mean that they they showed that you

NOTE Confidence: 0.839671244545455

 $00:52:34.440 \longrightarrow 00:52:36.784$ can do these huge pragmatic trials

NOTE Confidence: 0.839671244545455

 $00:52:36.784 \longrightarrow 00:52:39.678$ in 10s of thousands of patients with

NOTE Confidence: 0.839671244545455

 $00:52:39.680 \longrightarrow 00:52:40.919$ they didn't spend a lot of money.

NOTE Confidence: 0.839671244545455

 $00:52:40.920 \longrightarrow 00:52:42.696$ I mean they used off the shelf drugs,

NOTE Confidence: 0.839671244545455

 $00:52:42.700 \longrightarrow 00:52:45.780$ 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

 $00:52:46.820 \longrightarrow 00:52:48.472$ we won't say the words but you

NOTE Confidence: 0.839671244545455

 $00{:}52{:}48.472 \dashrightarrow 00{:}52{:}50.159$ know and things like oxygen right.

NOTE Confidence: 0.839671244545455

 $00:52:50.160 \longrightarrow 00:52:51.707$ But when you get into the you

NOTE Confidence: 0.839671244545455

 $00:52:51.707 \longrightarrow 00:52:52.894$ know the expensive drugs that

NOTE Confidence: 0.839671244545455

 $00:52:52.894 \longrightarrow 00:52:54.079$ are not yet FDA approved,

NOTE Confidence: 0.839671244545455

 $00:52:54.080 \longrightarrow 00:52:57.480$ I think that's a whole other area but.

NOTE Confidence: 0.839671244545455

 $00{:}52{:}57.480 \dashrightarrow 00{:}52{:}59.730$ I I think that FDA has got to lead

00:52:59.730 --> 00:53:02.224 the way in some ways here because they

NOTE Confidence: 0.839671244545455

 $00:53:02.224 \longrightarrow 00:53:04.737$ 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

 $00:53:05.808 \longrightarrow 00:53:07.588$ there's a high profile rejection

NOTE Confidence: 0.839671244545455

 $00:53:07.588 \longrightarrow 00:53:09.230$ of real-world data within the

NOTE Confidence: 0.839671244545455

 $00:53:09.230 \longrightarrow 00:53:10.675$ last month or two that.

NOTE Confidence: 0.83967124454545500:53:10.680 --> 00:53:11.062 You know,

00:53:11.062 --> 00:53:12.399 there was an attempt to get something

NOTE Confidence: 0.839671244545455

NOTE Confidence: 0.839671244545455

 $00:53:12.399 \longrightarrow 00:53:13.657$ approved based on some real-world data.

NOTE Confidence: 0.839671244545455

 $00:53:13.660 \longrightarrow 00:53:15.196$ And I think they rightly looked at that

NOTE Confidence: 0.839671244545455

 $00:53:15.196 \longrightarrow 00:53:16.523$ 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

 $00{:}53{:}17.915 \dashrightarrow 00{:}53{:}19.235$ 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

 $00:53:21.095 \longrightarrow 00:53:22.780$ shut down the whole endeavor.

 $00:53:22.780 \longrightarrow 00:53:23.840$ I think that they need,

NOTE Confidence: 0.839671244545455 00:53:23.840 --> 00:53:24.482 they need, NOTE Confidence: 0.839671244545455

 $00:53:24.482 \longrightarrow 00:53:26.408$ 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

 $00:53:32.016 \longrightarrow 00:53:34.169$ I think that might simplify things a lot.

NOTE Confidence: 0.746431946928571

 $00:53:35.570 \longrightarrow 00:53:38.270$ Attempt to put together criteria that

NOTE Confidence: 0.746431946928571

 $00:53:38.270 \longrightarrow 00:53:41.470$ that would allow you to say that this.

NOTE Confidence: 0.746431946928571

 $00:53:41.470 \longrightarrow 00:53:44.078$ 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

 $00:53:46.510 \longrightarrow 00:53:49.350$ in terms of how much it has to be cleaned up,

NOTE Confidence: 0.746431946928571

 $00:53:49.350 \longrightarrow 00:53:51.710$ how large the sample size has to be.

NOTE Confidence: 0.90763503

 $00{:}53{:}53.730 \dashrightarrow 00{:}53{:}57.960$ I think. It it's such an interesting

NOTE Confidence: 0.90763503

 $00:53:57.960 \longrightarrow 00:54:00.561$ question and I'm I'm not aware of of

NOTE Confidence: 0.90763503

 $00{:}54{:}00.561 \dashrightarrow 00{:}54{:}02.934$ anything at this moment but I do you

 $00:54:02.934 \longrightarrow 00:54:05.178$ know we are there's this great bias

NOTE Confidence: 0.90763503

 $00{:}54{:}05.178 \dashrightarrow 00{:}54{:}07.684$ that I just learned about called the

NOTE Confidence: 0.90763503

 $00:54:07.684 \longrightarrow 00:54:09.654$ informed presence bias which I kind of

NOTE Confidence: 0.90763503

 $00:54:09.654 \longrightarrow 00:54:12.197$ knew I knew it but not by those words

NOTE Confidence: 0.90763503

 $00:54:12.197 \longrightarrow 00:54:14.108$ 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

 $00{:}54{:}19.362 \dashrightarrow 00{:}54{:}21.319$ right whereas those that don't don't

NOTE Confidence: 0.90763503

00:54:21.319 --> 00:54:23.940 and and it's and and it's actually

NOTE Confidence: 0.90763503

 $00:54:23.940 \longrightarrow 00:54:25.640$ an incredibly important source of.

NOTE Confidence: 0.90763503

 $00:54:25.640 \longrightarrow 00:54:30.050$ The bias? That. That.

NOTE Confidence: 0.90763503

 $00:54:30.050 \longrightarrow 00:54:31.162$ You know, can you?

NOTE Confidence: 0.90763503

 $00:54:31.162 \longrightarrow 00:54:33.231$ 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

 $00:54:35.270 \longrightarrow 00:54:36.600$ that's something we should know.

 $00:54:36.600 \longrightarrow 00:54:37.895$ 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

 $00:54:40.030 \longrightarrow 00:54:41.515$ 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

 $00:54:43.630 \longrightarrow 00:54:45.320$ data study to my knowledge, so.

NOTE Confidence: 0.394810793333333

 $00:54:46.840 \longrightarrow 00:54:47.779$ The online version.

NOTE Confidence: 0.9350764

 $00{:}54{:}52.750 --> 00{:}54{:}53.000 \ {\rm Yeah}.$

NOTE Confidence: 0.031019479

 $00:55:06.820 \longrightarrow 00:55:07.450$ Schedule.

NOTE Confidence: 0.82457125

 $00:55:10.680 \longrightarrow 00:55:11.160$ What is?

NOTE Confidence: 0.839222

 $00:55:16.020 \longrightarrow 00:55:16.430$ COVID-19.

NOTE Confidence: 0.84858656

 $00:55:28.240 \longrightarrow 00:55:31.640$ Yeah. Yeah. So the question is,

NOTE Confidence: 0.84858656

 $00:55:31.640 \longrightarrow 00:55:34.400$ it seems to be the case that the

NOTE Confidence: 0.84858656

 $00:55:34.400 \longrightarrow 00:55:36.650$ patients with the pre-existing cancer

NOTE Confidence: 0.84858656

 $00:55:36.650 \longrightarrow 00:55:39.620$ 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

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

 $00:55:47.440 \longrightarrow 00:55:48.640$ Well, as time goes on,

NOTE Confidence: 0.84858656

 $00:55:48.640 \longrightarrow 00:55:50.176$ it's going to be everybody maybe.

NOTE Confidence: 0.84858656

 $00:55:50.180 \longrightarrow 00:55:52.740$ 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

 $00:55:57.174 \longrightarrow 00:55:59.958$ some way and usually that's a delay.

NOTE Confidence: 0.84858656

 $00{:}55{:}59.960 \dashrightarrow 00{:}56{:}02.012$ But sometimes they can't get the

NOTE Confidence: 0.84858656

 $00:56:02.012 \longrightarrow 00:56:04.210$ same treatment that they were getting

NOTE Confidence: 0.84858656

 $00{:}56{:}04.210 \dashrightarrow 00{:}56{:}06.135$ before a surgery gets cancelled,

NOTE Confidence: 0.84858656

 $00{:}56{:}06.140 \dashrightarrow 00{:}56{:}07.528$ 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

 $00:56:10.920 \longrightarrow 00:56:12.870$ obviously the treatment delays don't

NOTE Confidence: 0.84858656

00:56:12.870 --> 00:56:15.318 usually ever. Work out very well.

00:56:15.318 --> 00:56:17.403 So we haven't yet systematically

NOTE Confidence: 0.84858656

 $00:56:17.403 \longrightarrow 00:56:18.230$ 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

 $00:56:20.036 \longrightarrow 00:56:21.320$ thousands of those patients.

NOTE Confidence: 0.84858656

 $00:56:21.320 \longrightarrow 00:56:22.874$ 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

 $00:56:24.430 \longrightarrow 00:56:27.490$ As far as other patients, well,

NOTE Confidence: 0.84858656

 $00{:}56{:}27.490 \dashrightarrow 00{:}56{:}29.830$ I mean and there were a lot of practice

NOTE Confidence: 0.84858656

 $00{:}56{:}29.888 \to 00{:}56{:}33.809$ 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

 $00{:}56{:}35.110 \dashrightarrow 00{:}56{:}37.918$ but also with sort of substituting

NOTE Confidence: 0.84858656

 $00:56:37.918 \longrightarrow 00:56:39.790$ 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

 $00:56:44.056 \longrightarrow 00:56:45.722$ not quite as good so that patients

NOTE Confidence: 0.84858656

 $00:56:45.722 \longrightarrow 00:56:47.036$ didn't have to come into the.

 $00:56:47.040 \longrightarrow 00:56:48.060$ To the clinic.

NOTE Confidence: 0.84858656

 $00:56:48.060 \longrightarrow 00:56:50.100$ So that's been presented on in

NOTE Confidence: 0.84858656

 $00:56:50.100 \longrightarrow 00:56:51.718$ 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

 $00:56:53.943 \longrightarrow 00:56:56.178$ those substitutions are are generally OK,

NOTE Confidence: 0.84858656

 $00:56:56.180 \longrightarrow 00:56:58.310 \text{ I know that.}$

NOTE Confidence: 0.84858656

 $00:56:58.310 \longrightarrow 00:57:00.902$ You know a lot of people went on

NOTE Confidence: 0.84858656

 $00:57:00.902 \longrightarrow 00:57:02.202$ 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

 $00{:}57{:}04.146 \to 00{:}57{:}05.956$ for early stage breast cancer and

NOTE Confidence: 0.84858656

 $00:57:05.956 \longrightarrow 00:57:08.021$ you know so that they could push

NOTE Confidence: 0.84858656

 $00:57:08.021 \longrightarrow 00:57:10.051$ this you know during periods of time

NOTE Confidence: 0.84858656

 $00{:}57{:}10.051 \dashrightarrow 00{:}57{:}11.970$ when when elective quote UN quote

NOTE Confidence: 0.84858656

 $00:57:11.970 \longrightarrow 00:57:13.590$ elective surgeries were shut down.

NOTE Confidence: 0.84858656

 $00:57:13.590 \longrightarrow 00:57:17.070$ So all those things probably add up right.

 $00:57:17.070 \longrightarrow 00:57:19.180$ But there's but there's absolutely

NOTE Confidence: 0.84858656

 $00:57:19.180 \longrightarrow 00:57:21.713$ a factor of psychology and patients

NOTE Confidence: 0.84858656

00:57:21.713 --> 00:57:24.239 being a fraid 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

 $00:57:29.404 \longrightarrow 00:57:30.316$ 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

 $00{:}57{:}32.602 \to 00{:}57{:}35.336$ quite complex but I think we need to

NOTE Confidence: 0.84858656

 $00:57:35.336 \longrightarrow 00:57:37.504$ 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

 $00:57:39.874 \longrightarrow 00:57:42.200$ starting to get that information.

NOTE Confidence: 0.84858656

 $00:57:42.200 \longrightarrow 00:57:44.027$ There's clearly a stage migration and and

NOTE Confidence: 0.84858656

 $00{:}57{:}44.027 \dashrightarrow 00{:}57{:}46.398$ 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

 $00:57:47.534 \longrightarrow 00:57:50.610$ Because of delays in screening and so forth.

 $00:57:50.610 \longrightarrow 00:57:50.867$ So.

NOTE Confidence: 0.84858656

 $00{:}57{:}50.867 \dashrightarrow 00{:}57{:}52.923$ So I think we're going to face a

NOTE Confidence: 0.84858656

 $00:57:52.930 \longrightarrow 00:57:54.052$ we're going to face a challenging

NOTE Confidence: 0.84858656

 $00:57:54.052 \longrightarrow 00:57:55.624$ decade and I you know I think Ned

NOTE Confidence: 0.84858656

 $00{:}57{:}55.624 \dashrightarrow 00{:}57{:}56.599$ 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

 $00{:}57{:}59.853 \dashrightarrow 00{:}58{:}01.471$ 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

 $00:58:03.250 \longrightarrow 00:58:04.776$ what that might look like and and

NOTE Confidence: 0.84858656

 $00:58:04.776 \longrightarrow 00:58:06.605$ and you know that's probably going to

NOTE Confidence: 0.84858656

 $00:58:06.605 \longrightarrow 00:58:10.450$ that's probably going to come true but.

NOTE Confidence: 0.84858656

 $00{:}58{:}10.450 \dashrightarrow 00{:}58{:}12.630$ Hopefully COVID ends really soon.

NOTE Confidence: 0.84858656

 $00:58:12.630 \longrightarrow 00:58:15.500$ So. Um, yeah.

NOTE Confidence: 0.63317087

 $00:58:20.460 \longrightarrow 00:58:20.910$ Seems like.

 $00:58:30.980 \longrightarrow 00:58:32.892$ 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

 $00:58:35.066 \longrightarrow 00:58:37.090$ 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

 $00{:}58{:}40.695 \to 00{:}58{:}42.721$ can try to mitigate it there's you

NOTE Confidence: 0.880159951333333

 $00:58:42.721 \longrightarrow 00:58:44.341$ 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

 $00:58:46.482 \longrightarrow 00:58:48.041$ case and control style approach where

NOTE Confidence: 0.880159951333333

 $00:58:48.041 \longrightarrow 00:58:50.226$ you you try to make the controls as

NOTE Confidence: 0.880159951333333

 $00{:}58{:}50.226 \to 00{:}58{:}52.025$ 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 some of those are,

NOTE Confidence: 0.880159951333333

 $00:58:56.320 \longrightarrow 00:58:57.545$ some of those been around for decades,

NOTE Confidence: 0.880159951333333

 $00:58:57.550 \longrightarrow 00:58:59.890$ some of those are kind of

NOTE Confidence: 0.880159951333333

 $00:58:59.890 \longrightarrow 00:59:01.450$ emerging at this point.

 $00:59:01.450 \longrightarrow 00:59:04.276$ But I don't think we can forget that there's

NOTE Confidence: 0.880159951333333

 $00:59:04.276 \longrightarrow 00:59:07.858$ bias in in perspective trials as well, right.

NOTE Confidence: 0.880159951333333

 $00{:}59{:}07.858 \dashrightarrow 00{:}59{:}09.594$ So I mean I think either side

NOTE Confidence: 0.880159951333333

 $00:59:09.594 \longrightarrow 00:59:10.838$ 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

 $00:59:14.100 \longrightarrow 00:59:15.444$ it's just one more thing and it's

NOTE Confidence: 0.910771256

 $00:59:15.444 \longrightarrow 00:59:17.332$ not the only, I mean it's there's

NOTE Confidence: 0.910771256

 $00:59:17.332 \longrightarrow 00:59:18.316$ also there's ascertainment,

NOTE Confidence: 0.910771256

 $00:59:18.320 \longrightarrow 00:59:19.856$ but I mean there's a lot of biases,

NOTE Confidence: 0.910771256

 $00:59:19.860 \longrightarrow 00:59:22.072$ right and. You know, one thing we've

NOTE Confidence: 0.910771256

 $00:59:22.072 \longrightarrow 00:59:25.255$ worked on with our consortium is developing

NOTE Confidence: 0.910771256

 $00:59:25.255 \longrightarrow 00:59:27.423$ standardized language around limitations,

NOTE Confidence: 0.910771256

 $00{:}59{:}27.430 \dashrightarrow 00{:}59{:}31.316$ which I think is critical because you know.

NOTE Confidence: 0.910771256

 $00{:}59{:}31.316 \dashrightarrow 00{:}59{:}34.180$ I mean, the data is the data are

NOTE Confidence: 0.910771256

 $00:59:34.180 \longrightarrow 00:59:36.986$ the data use the plural, right? But.

 $00:59:36.986 \longrightarrow 00:59:40.284$ But the way it's presented really

NOTE Confidence: 0.910771256

 $00:59:40.284 \longrightarrow 00:59:41.815$ 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

 $00:59:43.390 \longrightarrow 00:59:45.219$ thinking about and might have some.

NOTE Confidence: 0.910771256

 $00{:}59{:}45.220 \dashrightarrow 00{:}59{:}46.918$ You know, thought pieces or something

NOTE Confidence: 0.910771256

 $00:59:46.918 \longrightarrow 00:59:48.998$ coming out about about how to handle that.