

WEBVTT

NOTE duration:"00:18:40"

NOTE recognizability:0.834

NOTE language:en-us

NOTE Confidence: 0.75432896

00:00:00.000 --> 00:00:02.770 Our last speaker before me

NOTE Confidence: 0.75432896

00:00:02.770 --> 00:00:04.986 is Doctor Cecilia Calhoun,

NOTE Confidence: 0.75432896

00:00:04.990 --> 00:00:07.618 who is assistant professor of internal

NOTE Confidence: 0.75432896

00:00:07.618 --> 00:00:10.370 medicine in the section Pneumatology.

NOTE Confidence: 0.75432896

00:00:10.370 --> 00:00:12.036 We're talking to us about sickle cell.

NOTE Confidence: 0.75432896

00:00:12.040 --> 00:00:15.554 Thanks so much for speaking with us.

NOTE Confidence: 0.75432896

00:00:15.560 --> 00:00:17.653 Fact admit I was kind of nervous

NOTE Confidence: 0.75432896

00:00:17.653 --> 00:00:19.703 to go after Marcella but I

NOTE Confidence: 0.75432896

00:00:19.703 --> 00:00:21.544 remember that one of her titles is

NOTE Confidence: 0.75432896

00:00:21.544 --> 00:00:23.078 guiding light to people like me.

NOTE Confidence: 0.75432896

00:00:23.080 --> 00:00:24.820 She's the reason I'm here and

NOTE Confidence: 0.75432896

00:00:24.820 --> 00:00:26.659 how thankful I am for this

NOTE Confidence: 0.75432896

00:00:26.659 --> 00:00:28.815 opportunity to share my work to her,

NOTE Confidence: 0.75432896

00:00:28.820 --> 00:00:30.828 to Tisha to the YMCA family for giving
NOTE Confidence: 0.75432896

00:00:30.828 --> 00:00:32.897 me the space to talk with you all.
NOTE Confidence: 0.75432896

00:00:32.900 --> 00:00:36.077 A little bit about the work that I do.
NOTE Confidence: 0.75432896

00:00:36.080 --> 00:00:38.760 OK so I wanna just ground us with the case.
NOTE Confidence: 0.75432896

00:00:38.760 --> 00:00:41.532 A patient of mine in the because the work
NOTE Confidence: 0.75432896

00:00:41.532 --> 00:00:44.316 that I do is for my sickle cell patients.
NOTE Confidence: 0.75432896

00:00:44.320 --> 00:00:46.000 So I want to talk to you about an AG
NOTE Confidence: 0.75432896

00:00:46.050 --> 00:00:47.780 so he's a 23 year old man that I met.
NOTE Confidence: 0.75432896

00:00:47.780 --> 00:00:49.748 He has hemoglobin SC disease and I met
NOTE Confidence: 0.75432896

00:00:49.748 --> 00:00:52.215 him as a young adult in Transition clinic.
NOTE Confidence: 0.75432896

00:00:52.220 --> 00:00:53.788 Didn't care for him as a kid.
NOTE Confidence: 0.75432896

00:00:53.790 --> 00:00:55.885 His disease have been complicated
NOTE Confidence: 0.75432896

00:00:55.885 --> 00:00:57.980 by splenic sequestration and pain
NOTE Confidence: 0.75432896

00:00:58.045 --> 00:01:00.145 and also some eye challenges and
NOTE Confidence: 0.75432896

00:01:00.145 --> 00:01:01.925 he was following pretty regularly
NOTE Confidence: 0.75432896

00:01:01.925 --> 00:01:03.485 when he was a child.

NOTE Confidence: 0.75432896

00:01:03.490 --> 00:01:04.960 But as he kind of got older

NOTE Confidence: 0.75432896

00:01:04.960 --> 00:01:06.020 when it's adolescence his care.

NOTE Confidence: 0.75432896

00:01:06.020 --> 00:01:07.270 Became a bit more intermittent.

NOTE Confidence: 0.791284595

00:01:09.650 --> 00:01:11.546 I think I want the same dress when

NOTE Confidence: 0.791284595

00:01:11.546 --> 00:01:14.810 you look at and when you look at AG

NOTE Confidence: 0.791284595

00:01:14.810 --> 00:01:16.812 you know many of the challenges he

NOTE Confidence: 0.791284595

00:01:16.812 --> 00:01:18.962 faced went outside of our clinic and

NOTE Confidence: 0.791284595

00:01:18.962 --> 00:01:20.502 he had academic challenges secondary

NOTE Confidence: 0.791284595

00:01:20.502 --> 00:01:22.646 to his pain and frequent admissions.

NOTE Confidence: 0.791284595

00:01:22.650 --> 00:01:24.156 He had lost his insurance coverage.

NOTE Confidence: 0.791284595

00:01:24.160 --> 00:01:26.183 He wasn't able to take obtained hydroxyurea

NOTE Confidence: 0.791284595

00:01:26.183 --> 00:01:28.402 or is acute pain medications due to

NOTE Confidence: 0.791284595

00:01:28.402 --> 00:01:30.352 insurance issues and it had challenges

NOTE Confidence: 0.791284595

00:01:30.412 --> 00:01:32.740 with the criminal justice system and

NOTE Confidence: 0.791284595

00:01:32.740 --> 00:01:34.292 subsequent challenges with employment

NOTE Confidence: 0.791284595

00:01:34.300 --> 00:01:36.628 because of that and because of its pain.

NOTE Confidence: 0.791284595

00:01:36.630 --> 00:01:38.905 This also precipitated a lot of anxiety.

NOTE Confidence: 0.791284595

00:01:38.910 --> 00:01:40.910 For him.

NOTE Confidence: 0.791284595

00:01:40.910 --> 00:01:42.709 And so the reason I excuse me,

NOTE Confidence: 0.791284595

00:01:42.710 --> 00:01:44.546 the reason I bring up and him as an

NOTE Confidence: 0.791284595

00:01:44.546 --> 00:01:45.794 example is because he represents

NOTE Confidence: 0.791284595

00:01:45.794 --> 00:01:47.730 one of many of the patients that we

NOTE Confidence: 0.791284595

00:01:47.730 --> 00:01:49.330 see who at a very surface level or

NOTE Confidence: 0.791284595

00:01:49.330 --> 00:01:51.166 one on one interaction and clinical

NOTE Confidence: 0.791284595

00:01:51.166 --> 00:01:53.578 setting can seem like a series

NOTE Confidence: 0.791284595

00:01:53.578 --> 00:01:55.066 of pathophysiologic challenges.

NOTE Confidence: 0.791284595

00:01:55.070 --> 00:01:56.636 But the disease that they experience

NOTE Confidence: 0.791284595

00:01:56.636 --> 00:01:58.647 is in the context of so much greater,

NOTE Confidence: 0.791284595

00:01:58.650 --> 00:01:59.654 so much more greater,

NOTE Confidence: 0.791284595

00:01:59.654 --> 00:02:02.321 and my work and my goal is to help to

NOTE Confidence: 0.791284595

00:02:02.321 --> 00:02:03.965 understand the full context of what

NOTE Confidence: 0.791284595

00:02:04.023 --> 00:02:06.435 they are and think about how we can as

NOTE Confidence: 0.791284595

00:02:06.435 --> 00:02:08.048 physician scientists and researchers

NOTE Confidence: 0.791284595

00:02:08.048 --> 00:02:10.278 can improve their care overall.

NOTE Confidence: 0.791284595

00:02:10.280 --> 00:02:10.507 OK,

NOTE Confidence: 0.791284595

00:02:10.507 --> 00:02:12.096 so let's talk a little bit about

NOTE Confidence: 0.791284595

00:02:12.096 --> 00:02:12.980 sickle cell disease.

NOTE Confidence: 0.791284595

00:02:12.980 --> 00:02:15.332 Sickle cell disease is the most

NOTE Confidence: 0.791284595

00:02:15.332 --> 00:02:17.255 common monogenetic disorder in the

NOTE Confidence: 0.791284595

00:02:17.255 --> 00:02:18.638 world with approximately 300,000

NOTE Confidence: 0.791284595

00:02:18.638 --> 00:02:21.200 live births each year in the world.

NOTE Confidence: 0.791284595

00:02:21.200 --> 00:02:23.558 And that's because of its protective

NOTE Confidence: 0.791284595

00:02:23.558 --> 00:02:24.737 Ness against malaria.

NOTE Confidence: 0.875576566428572

00:02:27.010 --> 00:02:28.094 In the United States,

NOTE Confidence: 0.875576566428572

00:02:28.094 --> 00:02:29.720 our most recent data says that

NOTE Confidence: 0.875576566428572

00:02:29.776 --> 00:02:31.288 it's about 100,000 Americans,

NOTE Confidence: 0.875576566428572

00:02:31.290 --> 00:02:32.946 mostly of African descent.
NOTE Confidence: 0.875576566428572

00:02:32.946 --> 00:02:34.602 With increasing incidence and
NOTE Confidence: 0.875576566428572

00:02:34.602 --> 00:02:36.570 accounts for about one in every
NOTE Confidence: 0.875576566428572

00:02:36.570 --> 00:02:38.182 365 African American births,
NOTE Confidence: 0.875576566428572

00:02:38.182 --> 00:02:39.391 mostly concentrated in
NOTE Confidence: 0.875576566428572

00:02:39.391 --> 00:02:41.010 the most populous state.
NOTE Confidence: 0.875576566428572

00:02:41.010 --> 00:02:42.960 In fact, 91% of sickle cell
NOTE Confidence: 0.875576566428572

00:02:42.960 --> 00:02:44.999 patients are in about 23 states.
NOTE Confidence: 0.937229555714286

00:02:47.730 --> 00:02:49.767 When we think about sickle cell disease,
NOTE Confidence: 0.937229555714286

00:02:49.770 --> 00:02:51.875 the genetic mutation results in
NOTE Confidence: 0.937229555714286

00:02:51.875 --> 00:02:54.450 abnormal formation of red blood cells,
NOTE Confidence: 0.937229555714286

00:02:54.450 --> 00:02:56.760 which have a negative impact impact
NOTE Confidence: 0.937229555714286

00:02:56.760 --> 00:02:58.300 with the microvascular environment
NOTE Confidence: 0.937229555714286

00:02:58.355 --> 00:03:00.387 causing many clinical manifestations.
NOTE Confidence: 0.937229555714286

00:03:00.390 --> 00:03:02.166 So I know this is a full slide,
NOTE Confidence: 0.937229555714286

00:03:02.170 --> 00:03:05.110 but it can range from acute

NOTE Confidence: 0.937229555714286
00:03:05.110 --> 00:03:06.102 acute complications like pain,
NOTE Confidence: 0.937229555714286
00:03:06.102 --> 00:03:07.886 which I think is most path and
NOTE Confidence: 0.937229555714286
00:03:07.886 --> 00:03:09.146 Monica and what most people
NOTE Confidence: 0.937229555714286
00:03:09.146 --> 00:03:10.550 associate with sickle cell disease.
NOTE Confidence: 0.937229555714286
00:03:10.550 --> 00:03:12.392 But also it's important for us
NOTE Confidence: 0.937229555714286
00:03:12.392 --> 00:03:14.157 to think of other complications
NOTE Confidence: 0.937229555714286
00:03:14.157 --> 00:03:16.750 like stroke that happen long term.
NOTE Confidence: 0.88217897375
00:03:19.790 --> 00:03:22.261 So the life expectancy of patient with
NOTE Confidence: 0.88217897375
00:03:22.261 --> 00:03:24.627 people with sickle cell disease is
NOTE Confidence: 0.88217897375
00:03:24.627 --> 00:03:26.528 significantly lower than their counterparts.
NOTE Confidence: 0.88217897375
00:03:26.528 --> 00:03:28.831 So with this figure shows us is
NOTE Confidence: 0.88217897375
00:03:28.831 --> 00:03:30.474 probability of survival by age and
NOTE Confidence: 0.88217897375
00:03:30.474 --> 00:03:32.091 you can see that patients with
NOTE Confidence: 0.88217897375
00:03:32.091 --> 00:03:33.939 sickle cell have a decreased life
NOTE Confidence: 0.88217897375
00:03:33.939 --> 00:03:37.768 expectancy of really about 20 years.
NOTE Confidence: 0.88217897375

00:03:37.770 --> 00:03:39.966 Even with the advent of hydroxyurea,
NOTE Confidence: 0.88217897375

00:03:39.970 --> 00:03:42.280 which increases fetal hemoglobin and is one
NOTE Confidence: 0.88217897375

00:03:42.280 --> 00:03:45.130 of our only disease modifying medications,
NOTE Confidence: 0.88217897375

00:03:45.130 --> 00:03:46.870 their life expectancy is
NOTE Confidence: 0.88217897375

00:03:46.870 --> 00:03:48.175 still significantly lowered.
NOTE Confidence: 0.859613338

00:03:50.500 --> 00:03:52.230 So again, this point illustrates
NOTE Confidence: 0.859613338

00:03:52.230 --> 00:03:53.960 mortality and sickle cell disease,
NOTE Confidence: 0.859613338

00:03:53.960 --> 00:03:56.011 and what's important to know about this
NOTE Confidence: 0.859613338

00:03:56.011 --> 00:03:57.987 figure with the age of death by age
NOTE Confidence: 0.859613338

00:03:57.987 --> 00:03:59.800 group on the X axis and the percentage
NOTE Confidence: 0.859613338

00:03:59.800 --> 00:04:02.044 of deaths on the Y axis is that in the
NOTE Confidence: 0.859613338

00:04:02.044 --> 00:04:03.660 late 70s there were two peaks of death.
NOTE Confidence: 0.859613338

00:04:03.660 --> 00:04:05.375 There was that infancy and toddler peak,
NOTE Confidence: 0.859613338

00:04:05.380 --> 00:04:07.333 and then it started to rise around
NOTE Confidence: 0.859613338

00:04:07.333 --> 00:04:08.720 adolescence and young adulthood.
NOTE Confidence: 0.859613338

00:04:08.720 --> 00:04:10.735 But because of clinical trials

NOTE Confidence: 0.859613338

00:04:10.735 --> 00:04:13.380 and multi center studies and the

NOTE Confidence: 0.859613338

00:04:13.380 --> 00:04:15.596 implementation of prophylactic penicillin

NOTE Confidence: 0.859613338

00:04:15.596 --> 00:04:18.366 and vaccination and newborn screen,

NOTE Confidence: 0.859613338

00:04:18.370 --> 00:04:19.960 we were really able to decrease.

NOTE Confidence: 0.859613338

00:04:19.960 --> 00:04:22.540 A peak around infancy and toddlerhood,

NOTE Confidence: 0.859613338

00:04:22.540 --> 00:04:24.448 but this piece around adolescence and

NOTE Confidence: 0.859613338

00:04:24.448 --> 00:04:26.240 young adulthood is still persists.

NOTE Confidence: 0.709372502222222

00:04:28.540 --> 00:04:29.688 This data was corroborated

NOTE Confidence: 0.709372502222222

00:04:29.688 --> 00:04:31.123 by the Dallas newborn cohort,

NOTE Confidence: 0.709372502222222

00:04:31.130 --> 00:04:33.643 which was is the largest single center

NOTE Confidence: 0.709372502222222

00:04:33.643 --> 00:04:36.564 cohort today with 940 sickle cell patients.

NOTE Confidence: 0.709372502222222

00:04:36.564 --> 00:04:39.425 What this cohort showed us is that

NOTE Confidence: 0.709372502222222

00:04:39.425 --> 00:04:41.938 the children with sickle cell disease

NOTE Confidence: 0.709372502222222

00:04:41.938 --> 00:04:44.448 are really living until adulthood,

NOTE Confidence: 0.709372502222222

00:04:44.450 --> 00:04:46.842 but it has, so it's shifted from a

NOTE Confidence: 0.709372502222222

00:04:46.842 --> 00:04:48.555 chronic acute disease of childhood
NOTE Confidence: 0.709372502222222

00:04:48.555 --> 00:04:50.998 to a chronic disease and the burden
NOTE Confidence: 0.709372502222222

00:04:51.065 --> 00:04:52.997 of disease is really on adults.
NOTE Confidence: 0.709372502222222

00:04:53.000 --> 00:04:54.230 The interesting thing about this
NOTE Confidence: 0.709372502222222

00:04:54.230 --> 00:04:56.032 cohort is that of the patients who
NOTE Confidence: 0.709372502222222

00:04:56.032 --> 00:04:57.592 reported deaths in the cohort that
NOTE Confidence: 0.709372502222222

00:04:57.592 --> 00:04:59.154 all would die within two years
NOTE Confidence: 0.709372502222222

00:04:59.154 --> 00:05:00.394 of transition to adult care.
NOTE Confidence: 0.709372502222222

00:05:00.400 --> 00:05:02.290 OK, so what's important to know about
NOTE Confidence: 0.709372502222222

00:05:02.290 --> 00:05:04.435 this is that the transition space is
NOTE Confidence: 0.709372502222222

00:05:04.435 --> 00:05:06.349 a very vulnerable time for patients
NOTE Confidence: 0.709372502222222

00:05:06.405 --> 00:05:08.190 with sickle cell disease persons.
NOTE Confidence: 0.709372502222222

00:05:08.190 --> 00:05:11.452 So it's a further characterize this,
NOTE Confidence: 0.709372502222222

00:05:11.452 --> 00:05:13.462 and in addition to understanding
NOTE Confidence: 0.709372502222222

00:05:13.462 --> 00:05:15.070 the morbidity is high.
NOTE Confidence: 0.709372502222222

00:05:15.070 --> 00:05:16.670 Myself and my colleagues at

NOTE Confidence: 0.709372502222222

00:05:16.670 --> 00:05:18.270 Washington University and the Center

NOTE Confidence: 0.709372502222222

00:05:18.328 --> 00:05:19.608 for Administrative Data Research

NOTE Confidence: 0.709372502222222

00:05:19.608 --> 00:05:21.528 took a look at utilization data

NOTE Confidence: 0.709372502222222

00:05:21.587 --> 00:05:22.787 for sickle cell disease.

NOTE Confidence: 0.709372502222222

00:05:22.790 --> 00:05:24.920 We looked at the healthcare

NOTE Confidence: 0.709372502222222

00:05:24.920 --> 00:05:26.624 cost and utilization project,

NOTE Confidence: 0.709372502222222

00:05:26.630 --> 00:05:28.766 commonly known as H cup data,

NOTE Confidence: 0.709372502222222

00:05:28.770 --> 00:05:31.474 which is a rich source of data for

NOTE Confidence: 0.709372502222222

00:05:31.474 --> 00:05:33.420 inpatient and hospitalizations.

NOTE Confidence: 0.709372502222222

00:05:33.420 --> 00:05:34.760 Admissions and administrative data.

NOTE Confidence: 0.709372502222222

00:05:34.760 --> 00:05:37.703 We looked at the state of New York in 2004,

NOTE Confidence: 0.709372502222222

00:05:37.703 --> 00:05:38.522 five to 14.

NOTE Confidence: 0.709372502222222

00:05:38.522 --> 00:05:40.622 Been used in a crypted identifier to

NOTE Confidence: 0.709372502222222

00:05:40.622 --> 00:05:42.657 understand patient level encounters versus

NOTE Confidence: 0.709372502222222

00:05:42.657 --> 00:05:45.421 single center level encounters to get a

NOTE Confidence: 0.709372502222222

00:05:45.421 --> 00:05:47.226 better understanding of utilization patterns,
NOTE Confidence: 0.7093725022222222

00:05:47.230 --> 00:05:48.150 including hospitalizations.
NOTE Confidence: 0.7093725022222222

00:05:48.150 --> 00:05:49.070 Readmission rates.
NOTE Confidence: 0.7093725022222222

00:05:49.070 --> 00:05:53.270 We were able to look at over 19,000 patients
NOTE Confidence: 0.7093725022222222

00:05:53.270 --> 00:05:57.848 with over 140,000 individual encounters.
NOTE Confidence: 0.7093725022222222

00:05:57.850 --> 00:06:00.230 And what we found corroborated other data.
NOTE Confidence: 0.7093725022222222

00:06:00.230 --> 00:06:00.924 You know,
NOTE Confidence: 0.7093725022222222

00:06:00.924 --> 00:06:02.659 we found that adolescents and
NOTE Confidence: 0.7093725022222222

00:06:02.659 --> 00:06:05.193 adults had the highest rates of
NOTE Confidence: 0.7093725022222222

00:06:05.193 --> 00:06:07.563 hospitalization amongst the entire cohort.
NOTE Confidence: 0.7093725022222222

00:06:07.570 --> 00:06:09.842 So we have the percent of total counters
NOTE Confidence: 0.7093725022222222

00:06:09.842 --> 00:06:11.447 represented by the line in Orange.
NOTE Confidence: 0.7093725022222222

00:06:11.450 --> 00:06:14.180 And then blue represents per
NOTE Confidence: 0.7093725022222222

00:06:14.180 --> 00:06:15.818 ten person years.
NOTE Confidence: 0.7093725022222222

00:06:15.820 --> 00:06:17.876 And then when we looked at readmission rates,
NOTE Confidence: 0.7093725022222222

00:06:17.880 --> 00:06:21.107 they too were highest among adult that

NOTE Confidence: 0.709372502222222

00:06:21.107 --> 00:06:23.820 adolescent and young adult age group.

NOTE Confidence: 0.709372502222222

00:06:23.820 --> 00:06:25.860 So and only do we know that the

NOTE Confidence: 0.709372502222222

00:06:25.860 --> 00:06:27.432 the adolescent and young adult age

NOTE Confidence: 0.709372502222222

00:06:27.432 --> 00:06:29.405 group is a period of high morbidity

NOTE Confidence: 0.709372502222222

00:06:29.405 --> 00:06:31.485 and mortality and high utilization.

NOTE Confidence: 0.709372502222222

00:06:31.490 --> 00:06:32.018 We can.

NOTE Confidence: 0.709372502222222

00:06:32.018 --> 00:06:33.602 We can surmise that young adults

NOTE Confidence: 0.709372502222222

00:06:33.602 --> 00:06:35.531 with sickle cell are the most

NOTE Confidence: 0.709372502222222

00:06:35.531 --> 00:06:36.875 vulnerable during that transition

NOTE Confidence: 0.709372502222222

00:06:36.875 --> 00:06:38.308 from pediatric to adult care.

NOTE Confidence: 0.78750559

00:06:40.660 --> 00:06:42.760 So transition to sickle cell

NOTE Confidence: 0.78750559

00:06:42.760 --> 00:06:44.860 disease is a complicated spot.

NOTE Confidence: 0.78750559

00:06:44.860 --> 00:06:46.960 OK represents this intersection of.

NOTE Confidence: 0.78750559

00:06:46.960 --> 00:06:48.220 I used to say normal adolescent

NOTE Confidence: 0.78750559

00:06:48.220 --> 00:06:49.299 development until I got some

NOTE Confidence: 0.78750559

00:06:49.299 --> 00:06:50.475 pushback like what do you mean?
NOTE Confidence: 0.78750559

00:06:50.480 --> 00:06:51.356 Normal adolescence like?
NOTE Confidence: 0.78750559

00:06:51.356 --> 00:06:53.108 You know my my friends with
NOTE Confidence: 0.78750559

00:06:53.108 --> 00:06:54.540 adolescence tell me it's not normal,
NOTE Confidence: 0.78750559

00:06:54.540 --> 00:06:56.500 but they're the insidious complications
NOTE Confidence: 0.78750559

00:06:56.500 --> 00:06:58.460 of their disease coming together.
NOTE Confidence: 0.78750559

00:06:58.460 --> 00:07:00.290 Changes in resources like our
NOTE Confidence: 0.78750559

00:07:00.290 --> 00:07:02.939 patient AG and then a big changes
NOTE Confidence: 0.78750559

00:07:02.939 --> 00:07:04.810 in that social environment.
NOTE Confidence: 0.801204774166667

00:07:07.310 --> 00:07:08.834 To better characterize this
NOTE Confidence: 0.801204774166667

00:07:08.834 --> 00:07:10.358 specific transition for patients
NOTE Confidence: 0.801204774166667

00:07:10.358 --> 00:07:11.869 with sickle cell disease,
NOTE Confidence: 0.801204774166667

00:07:11.870 --> 00:07:14.030 we conducted a qualitative
NOTE Confidence: 0.801204774166667

00:07:14.030 --> 00:07:16.190 study with 63 participants.
NOTE Confidence: 0.801204774166667

00:07:16.190 --> 00:07:18.302 So key stakeholders,
NOTE Confidence: 0.801204774166667

00:07:18.302 --> 00:07:20.070 including providers, patients,

NOTE Confidence: 0.801204774166667
00:07:20.070 --> 00:07:21.870 and their caregivers about what
NOTE Confidence: 0.801204774166667
00:07:21.870 --> 00:07:24.019 are the challenges they face when
NOTE Confidence: 0.801204774166667
00:07:24.019 --> 00:07:25.951 they were trying to get essential
NOTE Confidence: 0.801204774166667
00:07:25.951 --> 00:07:27.649 healthcare and educational needs.
NOTE Confidence: 0.801204774166667
00:07:27.650 --> 00:07:29.192 One thing that I enjoy about
NOTE Confidence: 0.801204774166667
00:07:29.192 --> 00:07:30.220 using a qualitative approach
NOTE Confidence: 0.801204774166667
00:07:30.273 --> 00:07:31.628 is that it's not prescriptive,
NOTE Confidence: 0.801204774166667
00:07:31.630 --> 00:07:33.380 but it allows our patients to tell
NOTE Confidence: 0.801204774166667
00:07:33.380 --> 00:07:35.233 us what they need and what's most
NOTE Confidence: 0.801204774166667
00:07:35.233 --> 00:07:37.600 important to them so that we as physicians.
NOTE Confidence: 0.801204774166667
00:07:37.600 --> 00:07:39.325 Scientists can address their needs
NOTE Confidence: 0.801204774166667
00:07:39.325 --> 00:07:41.549 and the way that's important to them,
NOTE Confidence: 0.801204774166667
00:07:41.550 --> 00:07:43.953 so I want to share with you a little
NOTE Confidence: 0.801204774166667
00:07:43.953 --> 00:07:46.305 bit of the themes that emerge and also
NOTE Confidence: 0.801204774166667
00:07:46.305 --> 00:07:49.928 a few of what our participants said.
NOTE Confidence: 0.801204774166667

00:07:49.930 --> 00:07:52.716 So our patients talk to us about
NOTE Confidence: 0.801204774166667

00:07:52.716 --> 00:07:55.020 this change in environment,
NOTE Confidence: 0.801204774166667

00:07:55.020 --> 00:07:56.567 about how when they were kids they
NOTE Confidence: 0.801204774166667

00:07:56.567 --> 00:07:58.167 got treated one way and when they
NOTE Confidence: 0.801204774166667

00:07:58.167 --> 00:07:59.793 went to the healthcare system it was
NOTE Confidence: 0.801204774166667

00:07:59.793 --> 00:08:01.281 different and how lead leaving those
NOTE Confidence: 0.801204774166667

00:08:01.281 --> 00:08:03.122 that have known him their whole lives
NOTE Confidence: 0.801204774166667

00:08:03.122 --> 00:08:04.760 is so intimidating and that they
NOTE Confidence: 0.801204774166667

00:08:04.811 --> 00:08:06.479 can see and feel that difference.
NOTE Confidence: 0.835284696086956

00:08:08.770 --> 00:08:10.126 Our providers individuals committed
NOTE Confidence: 0.835284696086956

00:08:10.126 --> 00:08:12.455 to quality care in these patients told
NOTE Confidence: 0.835284696086956

00:08:12.455 --> 00:08:14.170 us we really need to start talking
NOTE Confidence: 0.835284696086956

00:08:14.170 --> 00:08:15.698 about this with patients young.
NOTE Confidence: 0.835284696086956

00:08:15.700 --> 00:08:16.640 We need to prepare them.
NOTE Confidence: 0.835284696086956

00:08:16.640 --> 00:08:17.996 We want to empower them and
NOTE Confidence: 0.835284696086956

00:08:17.996 --> 00:08:19.549 give them what they need to

NOTE Confidence: 0.835284696086956
00:08:19.549 --> 00:08:20.737 make a successful transition.
NOTE Confidence: 0.892904353333333
00:08:24.130 --> 00:08:26.668 So we use the consolidated framework
NOTE Confidence: 0.892904353333333
00:08:26.668 --> 00:08:27.937 for implementation research,
NOTE Confidence: 0.892904353333333
00:08:27.940 --> 00:08:29.465 which is a commonly used
NOTE Confidence: 0.892904353333333
00:08:29.465 --> 00:08:30.380 implementation science framework,
NOTE Confidence: 0.892904353333333
00:08:30.380 --> 00:08:32.718 which I'll talk a little bit about
NOTE Confidence: 0.892904353333333
00:08:32.718 --> 00:08:34.714 shortly to understand the major themes
NOTE Confidence: 0.892904353333333
00:08:34.714 --> 00:08:36.884 in transition and the way that this
NOTE Confidence: 0.892904353333333
00:08:36.950 --> 00:08:39.070 study expounded upon those previous
NOTE Confidence: 0.892904353333333
00:08:39.070 --> 00:08:41.190 understanding of transition is that
NOTE Confidence: 0.892904353333333
00:08:41.190 --> 00:08:42.636 it really started to include the
NOTE Confidence: 0.892904353333333
00:08:42.636 --> 00:08:44.158 stigma that patients with sickle cell
NOTE Confidence: 0.892904353333333
00:08:44.158 --> 00:08:45.688 disease talked about that they faced.
NOTE Confidence: 0.892904353333333
00:08:45.690 --> 00:08:47.844 We highlighted the systemic issues with
NOTE Confidence: 0.892904353333333
00:08:47.844 --> 00:08:49.583 challenges with hematologic providers that
NOTE Confidence: 0.892904353333333

00:08:49.583 --> 00:08:51.340 want to care for sickle cell patients.
NOTE Confidence: 0.8929043533333333

00:08:51.340 --> 00:08:53.220 It helped us understand the role of health
NOTE Confidence: 0.8929043533333333

00:08:53.220 --> 00:08:54.720 literacy and the need and preparing.
NOTE Confidence: 0.8929043533333333

00:08:54.720 --> 00:08:56.370 Are young adults for transition,
NOTE Confidence: 0.8929043533333333

00:08:56.370 --> 00:08:58.418 in addition to highlighting
NOTE Confidence: 0.8929043533333333

00:08:58.418 --> 00:09:00.466 the disease complications and
NOTE Confidence: 0.8929043533333333

00:09:00.466 --> 00:09:02.439 changing resources that we know.
NOTE Confidence: 0.8929043533333333

00:09:02.440 --> 00:09:05.374 So we know that transition is not only a
NOTE Confidence: 0.8929043533333333

00:09:05.374 --> 00:09:07.806 problem for patients with sickle cell,
NOTE Confidence: 0.8929043533333333

00:09:07.810 --> 00:09:08.754 it's a problem overall.
NOTE Confidence: 0.8929043533333333

00:09:08.754 --> 00:09:10.407 It's full audience and I'm like how
NOTE Confidence: 0.8929043533333333

00:09:10.407 --> 00:09:11.758 many of you all were in college.
NOTE Confidence: 0.8929043533333333

00:09:11.760 --> 00:09:12.753 Seeing your pediatrician.
NOTE Confidence: 0.8929043533333333

00:09:12.753 --> 00:09:15.790 So the question is where do we start like?
NOTE Confidence: 0.8929043533333333

00:09:15.790 --> 00:09:16.510 What do we do?
NOTE Confidence: 0.8929043533333333

00:09:16.510 --> 00:09:17.845 OK, we know that this is a challenge,

NOTE Confidence: 0.8929043533333333
00:09:17.850 --> 00:09:19.215 but we want to be actual oriented.
NOTE Confidence: 0.8929043533333333
00:09:19.220 --> 00:09:21.110 So what do we do?
NOTE Confidence: 0.8929043533333333
00:09:21.110 --> 00:09:22.265 So in 2011,
NOTE Confidence: 0.8929043533333333
00:09:22.265 --> 00:09:24.190 the American Academy of Pediatrics
NOTE Confidence: 0.8929043533333333
00:09:24.190 --> 00:09:26.210 published a report for guidelines
NOTE Confidence: 0.8929043533333333
00:09:26.210 --> 00:09:28.160 for healthcare transition and then
NOTE Confidence: 0.8929043533333333
00:09:28.160 --> 00:09:30.165 in 2018 they actually included an
NOTE Confidence: 0.8929043533333333
00:09:30.165 --> 00:09:32.161 update which was a collaboration with
NOTE Confidence: 0.8929043533333333
00:09:32.161 --> 00:09:33.801 the American Society of Hematology
NOTE Confidence: 0.8929043533333333
00:09:33.801 --> 00:09:35.679 to outline processes for a success.
NOTE Confidence: 0.8929043533333333
00:09:35.680 --> 00:09:37.285 What they proposed as a
NOTE Confidence: 0.8929043533333333
00:09:37.285 --> 00:09:37.927 successful transition,
NOTE Confidence: 0.8929043533333333
00:09:37.930 --> 00:09:40.044 and this was shown to be effective
NOTE Confidence: 0.8929043533333333
00:09:40.044 --> 00:09:42.264 in a primary care clinic and
NOTE Confidence: 0.8929043533333333
00:09:42.264 --> 00:09:43.920 endocrinology clinic as well.
NOTE Confidence: 0.647538321

00:09:46.360 --> 00:09:48.000 This this guideline centers on
NOTE Confidence: 0.647538321

00:09:48.000 --> 00:09:49.640 6 core elements of transition,
NOTE Confidence: 0.647538321

00:09:49.640 --> 00:09:52.358 so this includes having a clear
NOTE Confidence: 0.647538321

00:09:52.358 --> 00:09:53.717 policy tracking appropriately
NOTE Confidence: 0.647538321

00:09:53.717 --> 00:09:55.658 preparation and readiness planning.
NOTE Confidence: 0.647538321

00:09:55.660 --> 00:09:57.264 Integrating into adult care,
NOTE Confidence: 0.647538321

00:09:57.264 --> 00:09:59.670 and then doing iterative feedback to
NOTE Confidence: 0.647538321

00:09:59.733 --> 00:10:02.134 make sure that this space is completed.
NOTE Confidence: 0.647538321

00:10:02.140 --> 00:10:04.219 So my question was if we know
NOTE Confidence: 0.647538321

00:10:04.219 --> 00:10:06.691 that this is a problem and we
NOTE Confidence: 0.647538321

00:10:06.691 --> 00:10:08.576 have a evidence based solution,
NOTE Confidence: 0.647538321

00:10:08.580 --> 00:10:11.373 why do we not have structured transition
NOTE Confidence: 0.647538321

00:10:11.373 --> 00:10:13.806 programs for sickle cell disease and
NOTE Confidence: 0.647538321

00:10:13.806 --> 00:10:16.368 that is the work that we're doing?
NOTE Confidence: 0.647538321

00:10:16.370 --> 00:10:18.169 So the way that I do that,
NOTE Confidence: 0.647538321

00:10:18.170 --> 00:10:20.214 and I believe the first step in

NOTE Confidence: 0.647538321
00:10:20.214 --> 00:10:21.421 approaching and helping sickle
NOTE Confidence: 0.647538321
00:10:21.421 --> 00:10:23.325 cell patients to use what we have,
NOTE Confidence: 0.647538321
00:10:23.330 --> 00:10:25.290 let's apply what we have to a population
NOTE Confidence: 0.647538321
00:10:25.290 --> 00:10:27.040 that needs it to bring about change.
NOTE Confidence: 0.647538321
00:10:27.040 --> 00:10:28.570 And so I do this through
NOTE Confidence: 0.647538321
00:10:28.570 --> 00:10:29.080 implementation science.
NOTE Confidence: 0.647538321
00:10:29.080 --> 00:10:30.552 So what's implementation science?
NOTE Confidence: 0.647538321
00:10:30.552 --> 00:10:32.024 It says that exactly,
NOTE Confidence: 0.647538321
00:10:32.030 --> 00:10:34.086 that it is the study of methods to
NOTE Confidence: 0.647538321
00:10:34.086 --> 00:10:35.736 promote the increase of evidence
NOTE Confidence: 0.647538321
00:10:35.736 --> 00:10:37.526 based interventions and to usual
NOTE Confidence: 0.647538321
00:10:37.526 --> 00:10:39.922 care gives us the space to rigorously
NOTE Confidence: 0.647538321
00:10:39.922 --> 00:10:41.982 understand what are the context in
NOTE Confidence: 0.647538321
00:10:41.982 --> 00:10:44.142 which we're applying these evidence
NOTE Confidence: 0.647538321
00:10:44.142 --> 00:10:47.490 based interventions to change make change.
NOTE Confidence: 0.647538321

00:10:47.490 --> 00:10:48.915 When we think about the
NOTE Confidence: 0.647538321

00:10:48.915 --> 00:10:49.485 translational pipeline,
NOTE Confidence: 0.647538321

00:10:49.490 --> 00:10:51.492 we know that it spans from our
NOTE Confidence: 0.647538321

00:10:51.492 --> 00:10:52.722 basic scientist colleagues who
NOTE Confidence: 0.647538321

00:10:52.722 --> 00:10:54.327 are making clinical excuse me
NOTE Confidence: 0.647538321

00:10:54.327 --> 00:10:56.005 laboratory discoveries all the way
NOTE Confidence: 0.647538321

00:10:56.005 --> 00:10:57.369 to translation into community,
NOTE Confidence: 0.647538321

00:10:57.370 --> 00:10:59.594 much like our CSA
NOTE Confidence: 0.647538321

00:10:59.594 --> 00:11:00.706 dissemination implementation,
NOTE Confidence: 0.647538321

00:11:00.710 --> 00:11:02.742 science really centers around
NOTE Confidence: 0.647538321

00:11:02.742 --> 00:11:03.936 that T3T4 pathway,
NOTE Confidence: 0.647538321

00:11:03.936 --> 00:11:05.994 bringing this knowledge to the community.
NOTE Confidence: 0.93320974

00:11:08.380 --> 00:11:10.000 Particularly in sickle cell disease,
NOTE Confidence: 0.93320974

00:11:10.000 --> 00:11:11.204 this is really important,
NOTE Confidence: 0.93320974

00:11:11.204 --> 00:11:13.427 and So what this slide is showing
NOTE Confidence: 0.93320974

00:11:13.427 --> 00:11:15.172 is the timeline from understanding

NOTE Confidence: 0.93320974

00:11:15.172 --> 00:11:17.740 and results in a clinical trial to

NOTE Confidence: 0.93320974

00:11:17.740 --> 00:11:19.590 stop trial to clinical practice,

NOTE Confidence: 0.93320974

00:11:19.590 --> 00:11:21.444 and so in 1998 the STOP trial is the

NOTE Confidence: 0.93320974

00:11:21.444 --> 00:11:23.062 trial that showed us if we're able

NOTE Confidence: 0.93320974

00:11:23.062 --> 00:11:24.736 in sickle cell to screen patients

NOTE Confidence: 0.93320974

00:11:24.736 --> 00:11:26.531 using a transcranial Doppler for

NOTE Confidence: 0.93320974

00:11:26.531 --> 00:11:28.326 abnormal vasculature and we start

NOTE Confidence: 0.93320974

00:11:28.326 --> 00:11:29.758 them on prophylactic transfusions.

NOTE Confidence: 0.93320974

00:11:29.760 --> 00:11:31.398 We can stop them from having strokes.

NOTE Confidence: 0.93320974

00:11:31.400 --> 00:11:33.920 OK, so this is an evidence based practice.

NOTE Confidence: 0.93320974

00:11:33.920 --> 00:11:36.580 This is a multi center institutional study.

NOTE Confidence: 0.93320974

00:11:36.580 --> 00:11:38.504 OK, but in 2015.

NOTE Confidence: 0.93320974

00:11:38.504 --> 00:11:40.342 Only 40% of patients were still

NOTE Confidence: 0.93320974

00:11:40.342 --> 00:11:42.043 getting screened. That's 17 years.

NOTE Confidence: 0.93320974

00:11:42.043 --> 00:11:43.727 That's a whole lifespan,

NOTE Confidence: 0.93320974

00:11:43.730 --> 00:11:45.418 and so for those of you all in
NOTE Confidence: 0.93320974

00:11:45.418 --> 00:11:46.679 the audience who are parents.
NOTE Confidence: 0.93320974

00:11:46.680 --> 00:11:48.066 If your child had asthma or
NOTE Confidence: 0.93320974

00:11:48.066 --> 00:11:48.990 a life threatening disease,
NOTE Confidence: 0.93320974

00:11:48.990 --> 00:11:50.796 how long would you be willing to
NOTE Confidence: 0.93320974

00:11:50.796 --> 00:11:52.228 wait to understand like a life,
NOTE Confidence: 0.93320974

00:11:52.230 --> 00:11:53.964 a life saving intervention or a
NOTE Confidence: 0.93320974

00:11:53.964 --> 00:11:55.461 therapy that could change the
NOTE Confidence: 0.93320974

00:11:55.461 --> 00:11:56.597 course of their disease.
NOTE Confidence: 0.93320974

00:11:56.600 --> 00:11:59.050 So for patients with sickle cell disease
NOTE Confidence: 0.93320974

00:11:59.050 --> 00:12:01.209 who already have a short lifespan,
NOTE Confidence: 0.93320974

00:12:01.210 --> 00:12:03.130 time is of the absolute essence
NOTE Confidence: 0.93320974

00:12:03.130 --> 00:12:05.010 and decreasing in this timeline,
NOTE Confidence: 0.93320974

00:12:05.010 --> 00:12:06.828 that's the role of implementation science.
NOTE Confidence: 0.93320974

00:12:06.830 --> 00:12:07.970 So that's why it's important
NOTE Confidence: 0.93320974

00:12:07.970 --> 00:12:09.310 in the work that I do.

NOTE Confidence: 0.93320974

00:12:09.310 --> 00:12:11.571 Because when we have a population with

NOTE Confidence: 0.93320974

00:12:11.571 --> 00:12:13.559 limited interventions and a sense of urgency,

NOTE Confidence: 0.93320974

00:12:13.560 --> 00:12:15.595 having the tools and methodologic

NOTE Confidence: 0.93320974

00:12:15.595 --> 00:12:17.630 rigor to decrease that timeline

NOTE Confidence: 0.93320974

00:12:17.696 --> 00:12:19.199 is critically important.

NOTE Confidence: 0.93320974

00:12:19.200 --> 00:12:21.696 We also know that our CSA works and

NOTE Confidence: 0.93320974

00:12:21.696 --> 00:12:23.419 collaborates with implementation of

NOTE Confidence: 0.93320974

00:12:23.419 --> 00:12:25.499 scientists to promote HealthEquity,

NOTE Confidence: 0.93320974

00:12:25.500 --> 00:12:27.500 so I think it's been a constant theme

NOTE Confidence: 0.93320974

00:12:27.500 --> 00:12:28.858 running throughout the program today.

NOTE Confidence: 0.93320974

00:12:28.860 --> 00:12:30.956 But three main ways that they do that

NOTE Confidence: 0.93320974

00:12:30.956 --> 00:12:33.008 is through community engagement and

NOTE Confidence: 0.93320974

00:12:33.008 --> 00:12:34.576 partnership through it that workforce

NOTE Confidence: 0.93320974

00:12:34.576 --> 00:12:36.650 not just myself as a junior faculty,

NOTE Confidence: 0.93320974

00:12:36.650 --> 00:12:38.232 but we learned a lot about interns

NOTE Confidence: 0.93320974

00:12:38.232 --> 00:12:40.031 who are being trained up in this
NOTE Confidence: 0.93320974

00:12:40.031 --> 00:12:41.366 work and then financial support,
NOTE Confidence: 0.93320974

00:12:41.370 --> 00:12:43.053 which I think we all kind of talked about.
NOTE Confidence: 0.93320974

00:12:43.060 --> 00:12:46.329 The scientists who are presenting our work.
NOTE Confidence: 0.93320974

00:12:46.330 --> 00:12:48.350 So implementation science a lot
NOTE Confidence: 0.93320974

00:12:48.350 --> 00:12:50.825 is executed through the use of
NOTE Confidence: 0.93320974

00:12:50.825 --> 00:12:52.740 frameworks and models which help
NOTE Confidence: 0.93320974

00:12:52.740 --> 00:12:55.170 to give structure to to our work.
NOTE Confidence: 0.93320974

00:12:55.170 --> 00:12:56.146 So for my project,
NOTE Confidence: 0.93320974

00:12:56.146 --> 00:12:58.169 which I'm going to talk about a bit now,
NOTE Confidence: 0.93320974

00:12:58.170 --> 00:13:00.498 I used to integrate it promoting
NOTE Confidence: 0.93320974

00:13:00.498 --> 00:13:02.050 action on healthcare research,
NOTE Confidence: 0.93320974

00:13:02.050 --> 00:13:03.232 implementation and healthcare
NOTE Confidence: 0.93320974

00:13:03.232 --> 00:13:04.808 sciences or IPAROS framework.
NOTE Confidence: 0.93320974

00:13:04.810 --> 00:13:06.574 And So what this framework does is
NOTE Confidence: 0.93320974

00:13:06.574 --> 00:13:08.679 it looks at the innovation of the

NOTE Confidence: 0.93320974

00:13:08.679 --> 00:13:10.294 the intervention of the recipients

NOTE Confidence: 0.93320974

00:13:10.294 --> 00:13:12.012 of the intervention and context

NOTE Confidence: 0.93320974

00:13:12.012 --> 00:13:14.016 and the role of facilitation and

NOTE Confidence: 0.93320974

00:13:14.020 --> 00:13:15.630 successful implementation of this work.

NOTE Confidence: 0.93320974

00:13:15.630 --> 00:13:16.920 So I'm looking at these.

NOTE Confidence: 0.93320974

00:13:16.920 --> 00:13:18.072 When it's based guidelines,

NOTE Confidence: 0.93320974

00:13:18.072 --> 00:13:20.186 I want to understand all of these

NOTE Confidence: 0.93320974

00:13:20.186 --> 00:13:22.166 things and how to implement them

NOTE Confidence: 0.93320974

00:13:22.166 --> 00:13:23.156 more more expeditiously.

NOTE Confidence: 0.93320974

00:13:23.160 --> 00:13:24.792 So at first did this by taking a

NOTE Confidence: 0.93320974

00:13:24.792 --> 00:13:26.325 look at our current transition

NOTE Confidence: 0.93320974

00:13:26.325 --> 00:13:28.110 processes and understanding of the

NOTE Confidence: 0.93320974

00:13:28.110 --> 00:13:30.255 guideline So what I did was I did

NOTE Confidence: 0.93320974

00:13:30.255 --> 00:13:31.720 a qualitative study with pediatric

NOTE Confidence: 0.93320974

00:13:31.720 --> 00:13:33.880 hematology and adult hematology

NOTE Confidence: 0.93320974

00:13:33.880 --> 00:13:36.580 providers to get their knowledge
NOTE Confidence: 0.93320974

00:13:36.655 --> 00:13:38.275 about these AP guidelines had you
NOTE Confidence: 0.93320974

00:13:38.275 --> 00:13:40.131 heard of them are you using them
NOTE Confidence: 0.93320974

00:13:40.131 --> 00:13:41.763 what strategies helped you to use
NOTE Confidence: 0.93320974

00:13:41.763 --> 00:13:43.444 them are they effective do you
NOTE Confidence: 0.93320974

00:13:43.444 --> 00:13:45.152 agree with them and then we use
NOTE Confidence: 0.93320974

00:13:45.152 --> 00:13:46.490 the I Paris framework to frame
NOTE Confidence: 0.777398986153846

00:13:46.538 --> 00:13:47.933 the role of? What is facilitation
NOTE Confidence: 0.777398986153846

00:13:47.933 --> 00:13:49.830 in terms of how we can implement
NOTE Confidence: 0.777398986153846

00:13:49.882 --> 00:13:51.109 this more expeditiously.
NOTE Confidence: 0.90967003368421

00:13:53.750 --> 00:13:55.773 So what we found are three major
NOTE Confidence: 0.90967003368421

00:13:55.773 --> 00:13:58.354 areas in which our guidelines were not
NOTE Confidence: 0.90967003368421

00:13:58.354 --> 00:14:00.409 able to be successfully implemented.
NOTE Confidence: 0.90967003368421

00:14:00.410 --> 00:14:03.198 So a lot of it had to do with lack of
NOTE Confidence: 0.90967003368421

00:14:03.198 --> 00:14:05.529 buy in support and location and Co.
NOTE Confidence: 0.90967003368421

00:14:05.530 --> 00:14:07.014 Location of these clinics.

NOTE Confidence: 0.90967003368421

00:14:07.014 --> 00:14:09.075 But we also asked them, hey,

NOTE Confidence: 0.90967003368421

00:14:09.075 --> 00:14:10.715 what was working well for you and so

NOTE Confidence: 0.90967003368421

00:14:10.715 --> 00:14:12.237 that was these readiness assessments

NOTE Confidence: 0.90967003368421

00:14:12.237 --> 00:14:13.822 and having these integrated clinics

NOTE Confidence: 0.90967003368421

00:14:13.822 --> 00:14:15.817 and ways in which we can improve

NOTE Confidence: 0.90967003368421

00:14:15.817 --> 00:14:16.905 like our process standardization

NOTE Confidence: 0.90967003368421

00:14:16.910 --> 00:14:18.710 and then identifying, again,

NOTE Confidence: 0.90967003368421

00:14:18.710 --> 00:14:20.510 facilitation key personnel involved

NOTE Confidence: 0.90967003368421

00:14:20.510 --> 00:14:23.198 in this work that could help on

NOTE Confidence: 0.90967003368421

00:14:23.198 --> 00:14:24.918 the uptake of these guidelines.

NOTE Confidence: 0.90967003368421

00:14:24.920 --> 00:14:25.848 Interestingly enough,

NOTE Confidence: 0.90967003368421

00:14:25.848 --> 00:14:27.240 but not surprisingly,

NOTE Confidence: 0.90967003368421

00:14:27.240 --> 00:14:29.144 we also found factors that we weren't

NOTE Confidence: 0.90967003368421

00:14:29.144 --> 00:14:31.166 looking for that were relevant to

NOTE Confidence: 0.90967003368421

00:14:31.166 --> 00:14:32.698 these guideline implemented guideline

NOTE Confidence: 0.90967003368421

00:14:32.698 --> 00:14:34.558 implementation and so now we would.

NOTE Confidence: 0.90967003368421

00:14:34.560 --> 00:14:36.414 We would categorize these as a

NOTE Confidence: 0.90967003368421

00:14:36.414 --> 00:14:37.650 social determinants of health.

NOTE Confidence: 0.90967003368421

00:14:37.650 --> 00:14:39.138 But there are so many factors

NOTE Confidence: 0.90967003368421

00:14:39.138 --> 00:14:40.737 outside of our hospital outside of

NOTE Confidence: 0.90967003368421

00:14:40.737 --> 00:14:42.137 our clinic where these guidelines

NOTE Confidence: 0.90967003368421

00:14:42.137 --> 00:14:43.830 are supposed to be implemented that

NOTE Confidence: 0.90967003368421

00:14:43.830 --> 00:14:45.426 really impact the way that we're

NOTE Confidence: 0.90967003368421

00:14:45.426 --> 00:14:47.215 able to successfully care for our

NOTE Confidence: 0.90967003368421

00:14:47.215 --> 00:14:48.730 patients in the clinic setting.

NOTE Confidence: 0.851898085625

00:14:53.710 --> 00:14:55.758 So now what I'm doing is trying to

NOTE Confidence: 0.851898085625

00:14:55.758 --> 00:14:57.377 figure out optimal implementation

NOTE Confidence: 0.851898085625

00:14:57.377 --> 00:14:59.465 strategies for these guidelines,

NOTE Confidence: 0.851898085625

00:14:59.470 --> 00:15:00.962 so implementation strategies that

NOTE Confidence: 0.851898085625

00:15:00.962 --> 00:15:03.200 are methods and tools with which

NOTE Confidence: 0.851898085625

00:15:03.265 --> 00:15:05.095 we use to increase these guideline

NOTE Confidence: 0.851898085625

00:15:05.095 --> 00:15:07.837 uptake and so there is a cadra of

NOTE Confidence: 0.851898085625

00:15:07.837 --> 00:15:08.929 evidence based recommendations,

NOTE Confidence: 0.851898085625

00:15:08.930 --> 00:15:10.792 but maybe all of them aren't applicable

NOTE Confidence: 0.851898085625

00:15:10.792 --> 00:15:13.023 to this and we use what we found

NOTE Confidence: 0.851898085625

00:15:13.023 --> 00:15:14.403 the determinants of barriers and

NOTE Confidence: 0.851898085625

00:15:14.460 --> 00:15:16.338 facilitators from that prior work to

NOTE Confidence: 0.851898085625

00:15:16.338 --> 00:15:18.152 identify which ones are most important

NOTE Confidence: 0.851898085625

00:15:18.152 --> 00:15:20.119 and that and that the initial pass.

NOTE Confidence: 0.851898085625

00:15:20.120 --> 00:15:21.744 We identified 52 right?

NOTE Confidence: 0.851898085625

00:15:21.744 --> 00:15:23.774 So the work I'm doing?

NOTE Confidence: 0.851898085625

00:15:23.780 --> 00:15:25.628 Now is to narrow it down amongst

NOTE Confidence: 0.851898085625

00:15:25.628 --> 00:15:27.190 pediatric and adult hematologists.

NOTE Confidence: 0.851898085625

00:15:27.190 --> 00:15:28.462 Which one of these have which

NOTE Confidence: 0.851898085625

00:15:28.462 --> 00:15:29.889 of these have been most useful?

NOTE Confidence: 0.851898085625

00:15:29.890 --> 00:15:31.465 Which one of these have you tried?

NOTE Confidence: 0.851898085625

00:15:31.470 --> 00:15:33.220 Which ones have you not tried at
NOTE Confidence: 0.851898085625

00:15:33.220 --> 00:15:34.950 all and the goal of the next step in
NOTE Confidence: 0.851898085625

00:15:34.950 --> 00:15:36.595 this work is to put those together
NOTE Confidence: 0.851898085625

00:15:36.595 --> 00:15:37.825 with these guidelines to create
NOTE Confidence: 0.851898085625

00:15:37.877 --> 00:15:38.786 an implementation facilitation
NOTE Confidence: 0.851898085625

00:15:38.786 --> 00:15:40.604 guide which I plan on planning,
NOTE Confidence: 0.851898085625

00:15:40.610 --> 00:15:41.742 piloting here at Yale.
NOTE Confidence: 0.851898085625

00:15:41.742 --> 00:15:44.586 So the idea is to say what are your
NOTE Confidence: 0.851898085625

00:15:44.586 --> 00:15:47.106 specific needs as a sickle cell community?
NOTE Confidence: 0.851898085625

00:15:47.110 --> 00:15:49.308 How do your guidelines fit with these?
NOTE Confidence: 0.851898085625

00:15:49.310 --> 00:15:50.650 What are the strategies we
NOTE Confidence: 0.851898085625

00:15:50.650 --> 00:15:51.990 can use to optimize success?
NOTE Confidence: 0.883319244166667

00:15:54.220 --> 00:15:57.308 My work now works on developing the processes
NOTE Confidence: 0.883319244166667

00:15:57.308 --> 00:15:59.880 to improve guideline implementation,
NOTE Confidence: 0.883319244166667

00:15:59.880 --> 00:16:02.568 but the goal is to develop structure
NOTE Confidence: 0.883319244166667

00:16:02.568 --> 00:16:04.607 transition programs that will overall

NOTE Confidence: 0.883319244166667
00:16:04.607 --> 00:16:06.652 ultimately improve outcomes in our
NOTE Confidence: 0.883319244166667
00:16:06.652 --> 00:16:09.209 young adults with sickle cell disease.
NOTE Confidence: 0.883319244166667
00:16:09.210 --> 00:16:11.149 And we know, and I'm I'm biased.
NOTE Confidence: 0.883319244166667
00:16:11.150 --> 00:16:12.705 I know that that truly
NOTE Confidence: 0.883319244166667
00:16:12.705 --> 00:16:13.949 adolescents and young adults.
NOTE Confidence: 0.883319244166667
00:16:13.950 --> 00:16:15.658 I believe they're at a critical juncture
NOTE Confidence: 0.883319244166667
00:16:15.658 --> 00:16:17.505 in which we can optimize equity and
NOTE Confidence: 0.883319244166667
00:16:17.505 --> 00:16:19.107 support them and the decisions we
NOTE Confidence: 0.883319244166667
00:16:19.158 --> 00:16:20.846 make and how the support that we show
NOTE Confidence: 0.883319244166667
00:16:20.846 --> 00:16:22.830 them at this very pivotal time in
NOTE Confidence: 0.883319244166667
00:16:22.830 --> 00:16:25.265 their life can have long term positive
NOTE Confidence: 0.883319244166667
00:16:25.265 --> 00:16:28.580 implications for how they move forward.
NOTE Confidence: 0.883319244166667
00:16:28.580 --> 00:16:30.155 And so with the hindsight of knowledge,
NOTE Confidence: 0.883319244166667
00:16:30.160 --> 00:16:31.336 when you think about a patient
NOTE Confidence: 0.883319244166667
00:16:31.336 --> 00:16:32.590 that I mentioned earlier, like AG,
NOTE Confidence: 0.883319244166667

00:16:32.590 --> 00:16:34.235 how would you treat him if you
NOTE Confidence: 0.883319244166667

00:16:34.235 --> 00:16:35.280 were his clinician,
NOTE Confidence: 0.883319244166667

00:16:35.280 --> 00:16:36.198 how would you work with him?
NOTE Confidence: 0.883319244166667

00:16:36.200 --> 00:16:38.300 Because despite all of those challenges,
NOTE Confidence: 0.883319244166667

00:16:38.300 --> 00:16:40.286 I'm that I described he managed
NOTE Confidence: 0.883319244166667

00:16:40.286 --> 00:16:42.028 to establish a regular healthcare
NOTE Confidence: 0.883319244166667

00:16:42.028 --> 00:16:43.768 with our clinic he got.
NOTE Confidence: 0.883319244166667

00:16:43.770 --> 00:16:45.597 He was in a behavioral health care
NOTE Confidence: 0.883319244166667

00:16:45.597 --> 00:16:47.160 program to navigate his own trauma.
NOTE Confidence: 0.883319244166667

00:16:47.160 --> 00:16:47.650 We worked,
NOTE Confidence: 0.883319244166667

00:16:47.650 --> 00:16:49.610 he worked with our social worker to find
NOTE Confidence: 0.883319244166667

00:16:49.662 --> 00:16:51.480 stable housing and employment and before
NOTE Confidence: 0.883319244166667

00:16:51.480 --> 00:16:53.508 his untimely death due to gun violence,
NOTE Confidence: 0.883319244166667

00:16:53.510 --> 00:16:55.218 he was on a pathway to success.
NOTE Confidence: 0.883319244166667

00:16:55.220 --> 00:16:56.920 So he's very, very important.
NOTE Confidence: 0.883319244166667

00:16:56.920 --> 00:16:58.670 He's a great example for me because.

NOTE Confidence: 0.883319244166667

00:16:58.670 --> 00:17:00.322 Shows us if we really wrap around

NOTE Confidence: 0.883319244166667

00:17:00.322 --> 00:17:02.140 in a rigorous way our young people,

NOTE Confidence: 0.883319244166667

00:17:02.140 --> 00:17:04.960 they can really achieve success.

NOTE Confidence: 0.883319244166667

00:17:04.960 --> 00:17:06.472 And I asked that because I truly

NOTE Confidence: 0.883319244166667

00:17:06.472 --> 00:17:07.691 believe that our adolescents and

NOTE Confidence: 0.883319244166667

00:17:07.691 --> 00:17:09.251 young adults with sickle cell disease

NOTE Confidence: 0.883319244166667

00:17:09.251 --> 00:17:10.950 are a microcosm of how we treat

NOTE Confidence: 0.883319244166667

00:17:10.950 --> 00:17:12.468 sickle cell patients as a whole,

NOTE Confidence: 0.883319244166667

00:17:12.468 --> 00:17:14.408 but also the most vulnerable

NOTE Confidence: 0.883319244166667

00:17:14.408 --> 00:17:15.572 populations among us.

NOTE Confidence: 0.883319244166667

00:17:15.580 --> 00:17:17.533 And so the strides that we make with them,

NOTE Confidence: 0.883319244166667

00:17:17.540 --> 00:17:19.640 the care and investment to rigorous

NOTE Confidence: 0.883319244166667

00:17:19.640 --> 00:17:21.911 research that we that we make

NOTE Confidence: 0.883319244166667

00:17:21.911 --> 00:17:23.511 regarding this population has

NOTE Confidence: 0.883319244166667

00:17:23.511 --> 00:17:25.420 greater implications for us all.

NOTE Confidence: 0.883319244166667

00:17:25.420 --> 00:17:28.388 And I'll end with this slide because.
NOTE Confidence: 0.883319244166667

00:17:28.390 --> 00:17:30.470 One of the things about the work that
NOTE Confidence: 0.883319244166667

00:17:30.470 --> 00:17:33.091 I do helps me to understand a bit more
NOTE Confidence: 0.883319244166667

00:17:33.091 --> 00:17:35.678 about how and and the patient that I
NOTE Confidence: 0.883319244166667

00:17:35.678 --> 00:17:37.100 mentioned help me to understand how
NOTE Confidence: 0.883319244166667

00:17:37.100 --> 00:17:39.171 the work that I do in treatment with
NOTE Confidence: 0.883319244166667

00:17:39.171 --> 00:17:41.327 patients really fits into a greater context.
NOTE Confidence: 0.883319244166667

00:17:41.330 --> 00:17:42.818 We know that no matter where
NOTE Confidence: 0.883319244166667

00:17:42.818 --> 00:17:44.601 we are along this pipeline, OK,
NOTE Confidence: 0.883319244166667

00:17:44.601 --> 00:17:46.107 whether we are creating the laws,
NOTE Confidence: 0.883319244166667

00:17:46.110 --> 00:17:46.538 regulations,
NOTE Confidence: 0.883319244166667

00:17:46.538 --> 00:17:47.394 and policies,
NOTE Confidence: 0.883319244166667

00:17:47.394 --> 00:17:49.962 whether we are affecting the living
NOTE Confidence: 0.883319244166667

00:17:49.962 --> 00:17:51.890 environment or whether we are
NOTE Confidence: 0.883319244166667

00:17:51.890 --> 00:17:53.685 understanding the risk factors and
NOTE Confidence: 0.883319244166667

00:17:53.685 --> 00:17:55.275 diagnosis and treatment ultimate

NOTE Confidence: 0.883319244166667
00:17:55.275 --> 00:17:57.230 outcomes in a specific disease.
NOTE Confidence: 0.883319244166667
00:17:57.230 --> 00:17:58.886 Equity is along that whole piece.
NOTE Confidence: 0.883319244166667
00:17:58.890 --> 00:18:00.658 So I wanted to end with this just
NOTE Confidence: 0.883319244166667
00:18:00.658 --> 00:18:02.457 to implore you all in the audience
NOTE Confidence: 0.883319244166667
00:18:02.457 --> 00:18:04.077 to think carefully about the work
NOTE Confidence: 0.883319244166667
00:18:04.077 --> 00:18:05.904 you do and where that fits on
NOTE Confidence: 0.883319244166667
00:18:05.904 --> 00:18:06.737 this HealthEquity pipeline.
NOTE Confidence: 0.883319244166667
00:18:06.737 --> 00:18:08.886 I think we want to be intentional
NOTE Confidence: 0.883319244166667
00:18:08.886 --> 00:18:10.550 on the work that we do,
NOTE Confidence: 0.883319244166667
00:18:10.550 --> 00:18:12.135 because if we're not making
NOTE Confidence: 0.883319244166667
00:18:12.135 --> 00:18:13.086 a conscious investment,
NOTE Confidence: 0.883319244166667
00:18:13.090 --> 00:18:14.098 we're choosing to divest.
NOTE Confidence: 0.883319244166667
00:18:14.098 --> 00:18:16.411 And so I just wanted to take a moment
NOTE Confidence: 0.883319244166667
00:18:16.411 --> 00:18:18.140 to end with that and encourage you
NOTE Confidence: 0.883319244166667
00:18:18.198 --> 00:18:20.039 all wherever you are to leverage the
NOTE Confidence: 0.883319244166667

00:18:20.039 --> 00:18:22.510 power you have for the importance of equity,

NOTE Confidence: 0.883319244166667

00:18:22.510 --> 00:18:24.268 and so that's all I have.

NOTE Confidence: 0.883319244166667

00:18:24.270 --> 00:18:25.730 I want to thank Marcella,

NOTE Confidence: 0.871419336666667

00:18:25.730 --> 00:18:27.424 but I'm very much for this opportunity

NOTE Confidence: 0.871419336666667

00:18:27.424 --> 00:18:29.269 and for her continuous mentorship.

NOTE Confidence: 0.871419336666667

00:18:29.270 --> 00:18:31.020 Mentor Allison Kinga watched you,

NOTE Confidence: 0.871419336666667

00:18:31.020 --> 00:18:32.240 my peers, and adult college.

NOTE Confidence: 0.871419336666667

00:18:32.240 --> 00:18:33.690 Obviously the Yale Center for

NOTE Confidence: 0.871419336666667

00:18:33.690 --> 00:18:34.560 Clinical Investigation was

NOTE Confidence: 0.871419336666667

00:18:34.560 --> 00:18:36.017 supporting me and doing this work,

NOTE Confidence: 0.871419336666667

00:18:36.020 --> 00:18:38.230 and more than anybody in

NOTE Confidence: 0.871419336666667

00:18:38.230 --> 00:18:39.998 my patients and families.