Session 6 WEBVTT

9
00:17:14.550 --> 00:17:15.390
Kim Kelly: Can you folks hear me?

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00:17:17.520 --> 00:17:26.790
Kim Kelly: Okay sorry for the delay, I wasn't able to get in. I was having a little trouble and calling around so I'm appreciative for the

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00:17:28.290 --> 00:17:34.110
Kim Kelly: folks that are working with us and getting things set up so

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00:17:36.510 --> 00:17:40.140
Kim Kelly: I apologize for the delay, and I thank you for your patience.

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00:17:41.400 --> 00:17:43.560
Kim Kelly: So if we're ready, I believe we're

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00:17:43.560 --> 00:17:44.250
Kim Kelly: recording.

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00:17:45.090 --> 00:17:46.350
Kim Kelly: Are we recording now?

16
00:17:48.210 --> 00:17:50.010
wade bowser: Yes, ma'am.

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00:17:50.940 --> 00:17:51.420
Kim Kelly: Thank you. Alright.

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00:17:52.980 --> 00:17:56.400
Kim Kelly: So I was getting in on two different computers, so that we could

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00:17:58.530 --> 00:18:01.440
Kim Kelly: I can, I can make sure that I was there all right.

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00:18:03.660 --> 00:18:04.470
Kim Kelly: You just leave this

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00:18:07.980 --> 00:18:28.320
Kim Kelly: screen. So welcome everyone to the sixth session of the webinar series on Genetic Services in Appalachia. We ask that you mute your microphone for the talk and place any comments or questions in the chat box, and we should have time to ask some questions towards the end.

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00:18:31.080 --> 00:18:48.000
Kim Kelly: At the end of the session today, we will ask you to complete an assessment to give us feedback. As you know, our aims include to develop a research agenda for genetic services in rural Appalachia. Each month we've been having speakers who are working in genetic service provision

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00:18:48.210 --> 00:19:01.350
Kim Kelly: to the medically underserved populations around our area, with a focus on setting a research agenda in rural Appalachia. I would now like to introduce our speaker.

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00:19:05.550 --> 00:19:12.000
Kim Kelly: And I'll just ask everyone to mute their microphones, please give it a double check.

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00:19:13.260 --> 00:19:24.540
Kim Kelly: Dr. Graves received her PhD in clinical psychology from Virginia Polytechnic Institute and State University and completed postdoctoral training at the University of Kentucky.

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00:19:25.680 --> 00:19:32.310
Kim Kelly: She is a tenured Associate Professor of Oncology in the Cancer Prevention and Control Program.

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00:19:33.060 --> 00:19:42.480
Kim Kelly: In January 2021, Dr. Graves began serving as the Associate Dean for Faculty Development at Georgetown University Medical Center.

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00:19:43.260 --> 00:19:53.220
Kim Kelly: Her research focuses on cancer survivorship and translational genomics with a particular emphasis on community engagement and addressing health disparities.

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00:19:53.610 --> 00:20:03.690
Kim Kelly: Dr. Graves is co-leading an R01 funded project to explore symptoms experienced by patients diagnosed with thyroid cancer, who receive radioactive iodine treatment.

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00:20:04.590 --> 00:20:13.650
Kim Kelly: She is site PI on an R01 to evaluate an expressive helping writing intervention to reduce symptoms among patients treated with stem cell transplant.

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00:20:14.160 --> 00:20:24.360
Kim Kelly: Another area in which Dr. Graves conducts work is raising awareness about genetic counseling and testing and underserved communities, which is what is going to be the focus of her talk today.

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00:20:25.050 --> 00:20:36.630
Kim Kelly: She is a multiple principal investigator on an NCI-R25 award to train Community health educators, patient navigators, and promotoras

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00:20:37.080 --> 00:20:48.240
Kim Kelly: about hereditary breast and ovarian cancer and Latinos. This training project is called ARBOLES Familiares (Family Tree).

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00:20:48.930 --> 00:21:04.530
Kim Kelly: And so I also know that Dr. Grave's has done a fair bit of work with the Appalachian population in Kentucky; so we look forward to hearing her presentation today. Are you ready Dr. Graves to share your screen?

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00:21:05.520 --> 00:21:11.070
Kristi Graves: Thank you so much, Dr. Kelly; I'm really excited to be here. Yes, I can share my screen, thank you.

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00:21:15.510 --> 00:21:17.370
Kristi Graves: Can everyone see that okay?

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00:21:20.010 --> 00:21:28.860
Kristi Graves: Great alright. Well I'm really excited to be with you all today, and we should have plenty of time at the end for questions and answers.

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00:21:30.840 --> 00:21:49.860
Kristi Graves: So no formal disclosures. This was taken when we were at our most recent ARBOLES Familiares training, which was last November. Our first in-person training in two years, and we had a guest who like to watch and learn about genetics standing outside.

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00:21:52.200 --> 00:22:06.030
Kristi Graves: So many of you may be familiar with this translational continuum, but I want to just to set the stage for us today to think about how some of the basic science genetics work and the discovery of the

41
00:22:06.720 --> 00:22:28.410
Kristi Graves: genes related to hereditary cancer is now moving, you know, not only well into practice, but also through ways that we can then bring these discoveries into the community, and ideally, take ideas and lessons from the community to inform the research and how we deliver this care.

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00:22:32.850 --> 00:22:52.650
Kristi Graves: A reminder I'm sure for this group, but just to put the context that again, about 10% of colorectal cancers and breast cancers are considered hereditary with a larger proportion of individuals who are diagnosed with ovarian cancer having hereditary cancer.

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00:22:55.380 --> 00:23:01.380
Kristi Graves: And again likely a review for this group, but just to reinforce some of the potential impacts

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00:23:01.770 --> 00:23:16.170
Kristi Graves: that someone may have, if they do have genetic counseling, opt for genetic testing, and then receive a positive genetic test result, so it could influence someone's patterns of their cancer screening.

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00:23:17.100 --> 00:23:31.410
Kristi Graves: In terms of either frequency or type of screening, for individuals who are found to have positive test results, it might reduce, it might influence uptake of risk reducing surgery, for example, prophylactic oophorectomy.

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00:23:32.700 --> 00:23:40.680
Kristi Graves: It might influence in a small number, and we know that this research is growing, but to think about chemo prevention

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00:23:41.520 --> 00:23:47.940
Kristi Graves: through use of selective estrogen receptor modulators or aromatase inhibitors.

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00:23:48.900 --> 00:23:58.740
Kristi Graves: For some, it might influence how they think about their lifestyle, for example, reducing alcohol intake to also reduce the risk of breast cancer.

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00:23:59.490 --> 00:24:08.970
Kristi Graves: For individuals who have been diagnosed with cancer and then have a positive test result, it could influence the type of chemotherapy that their

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00:24:09.480 --> 00:24:24.330
Kristi Graves: provider team recommends or the again the type of treatment, for example, a woman diagnosed with a unilateral breast cancer, who have who has a positive test result may decide to have contralateral prophylactic mastectomy, on the other, breast

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00:24:25.500 --> 00:24:41.760
Kristi Graves: to reduce risk of cancer and that risk. And then of course implications for family members, the idea that others may carry this gene and may find it useful to have genetic counseling and perhaps genetic testing.

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00:24:45.420 --> 00:24:50.340
Kristi Graves: So I wanted to set the stage for what we're going to talk about with

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00:24:51.360 --> 00:24:58.200
Kristi Graves: genetic services and finding ways to reduce barriers of uptake by reminding us that

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00:24:59.340 --> 00:25:15.720
Kristi Graves: the uptake of genetic testing does remain lower than it could be, both in individuals who are affected with breast cancer and among individuals who are affected with ovarian cancer, and these are some studies from 2019.

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00:25:19.770 --> 00:25:28.020
Kristi Graves: And so soon after I arrived at Georgetown, one of the projects that I had the opportunity to work on, and this is when I was

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00:25:30.300 --> 00:25:39.120
Kristi Graves: project director as an instructor so I was really fortunate to be able to enter into this study, which was a

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00:25:40.200 --> 00:25:57.540
Kristi Graves: non-inferiority study, where two different approaches to genetic counseling were evaluated. And so the overall goal of this project, we called it, the telephone genetic counseling study or TGC,

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00:25:58.860 --> 00:26:10.620
Kristi Graves: was to look at, and this was back in you know early 2009 and 10 when we were looking at this, is there equivalence between

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00:26:11.640 --> 00:26:17.370
Kristi Graves: genetic counseling that's done over the telephone and genetic counseling that's done in-person?

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00:26:18.750 --> 00:26:25.860
Kristi Graves: This question I think has been answered, more recently, as well, but this was one of the first studies to do a full

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00:26:26.580 --> 00:26:37.890
Kristi Graves: equivalence type study of these two approaches. And so the goal, and this work was led by my mentor Mark Schwartz, but at the time it was to compare the safety,

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00:26:38.430 --> 00:26:46.590
Kristi Graves: are we causing any harm, if we're not having a patient sit directly in front of us, the efficacy, does it work as well.

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00:26:47.250 --> 00:26:52.740
Kristi Graves: When genetic counseling is delivered over the telephone in terms of patients understanding.

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00:26:53.490 --> 00:27:10.890

Kristi Graves: If they have any distress, the types of decisions they make about genetic testing, and then another component I won't be presenting today but it's in the paper referred here, is the cost. The take home message, there is that telephone genetic counseling costs less than in person.

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00:27:12.330 --> 00:27:32.790
Kristi Graves: So again, this was a non-inferiority trial we recruited women from four different sites, you can see some of the reasons why people declined or we're not fully enrolled in the study and then randomize to telephone counseling or usual care in person counseling.

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00:27:34.620 --> 00:27:45.990
Kristi Graves: And we compared to the outcomes two weeks after the genetic counseling and then again following receipt of the genetic test for those who are interested in having testing.

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00:27:47.700 --> 00:27:58.260
Kristi Graves: So the take home messages here, we did not see any differences in uptake of genetic counseling when people were offered to do the genetic counseling either in person

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00:27:58.680 --> 00:28:11.490
Kristi Graves: or by telephone. So it was equally accessible and appealing to folks. We did see a slight decrease in the uptake of genetic testing

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00:28:12.150 --> 00:28:27.630
Kristi Graves: for those who were randomized to telephone genetic counseling or telegenetics. So 90% of those who were in person with their genetic counseling had opted for genetic testing versus 84% and

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00:28:28.200 --> 00:28:42.480
Kristi Graves: we can talk about this again at the end. One of the big differences was that when someone's in front of you in in in the center, they can walk immediately to the at that time, the blood draw room

71
00:28:43.710 --> 00:28:47.670
Kristi Graves: to have a sample taken for genetic testing.

72
00:28:48.750 --> 00:28:50.880
Kristi Graves: But with telegenetics it involved

73
00:28:51.990 --> 00:28:54.750
Kristi Graves: a kit to obtain a sample.

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00:28:56.010 --> 00:28:59.280
Kristi Graves: If everybody could again check their mute that would be great.

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00:29:04.170 --> 00:29:06.630

Kristi Graves: So, then the other piece was the

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00:29:08.310 --> 00:29:16.170
Kristi Graves: efficacy. Do we see the same results across these two modes of delivery of genetic counseling and this

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00:29:16.620 --> 00:29:25.530
Kristi Graves: time point was after genetic, the first genetic counseling session, but before disclosure of the genetic testing results.

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00:29:26.070 --> 00:29:44.160
Kristi Graves: And the yellow framing on the graph to the right indicate the range, at which the scores would be considered non-inferior meaning no differences in this non-inferiority trial. So because the

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00:29:44.820 --> 00:29:58.740
Kristi Graves: confidence limit does not extend past the yellow range, it was found that telephone genetic counseling was not inferior to in person genetic counseling on

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00:29:59.100 --> 00:30:15.630
Kristi Graves: patient satisfaction with the process their knowledge about what it means to have a hereditary cancer syndrome or be at risk for hereditary cancer syndrome, their perceived stress overall kind of global stress, as well as cancer distress.

81
00:30:18.330 --> 00:30:29.700
Kristi Graves: Then we looked at similar outcomes after the disclosure of test results, because you know there potentially could be differences, if someone

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00:30:30.630 --> 00:30:37.380
Kristi Graves: you know, was able to have genetic testing and then how they understood that information or or how it made them feel.

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00:30:37.740 --> 00:30:49.260
Kristi Graves: Once they got their test results so again, it was found that telephone genetic counseling or telegenetic counseling was not inferior to in person genetic counseling on all of the

84
00:30:49.560 --> 00:31:04.200
Kristi Graves: key outcomes that were assessed in terms of physical functioning, mental functioning that was assessed with a kind of global quality of life type index. Perceived stress, cancer distress. and importantly decisional conflict.

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00:31:05.250 --> 00:31:15.600
Kristi Graves: Individuals who had the telephone genetic counseling did not experience more conflict about their decisions to have genetic testing and those who had in-person.

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00:31:18.000 --> 00:31:23.250
Kristi Graves: And so from those results, we were interested in

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00:31:24.300 --> 00:31:34.650
Kristi Graves: you know, as time went on, and we learned more about genetics and genetic risk we were interested in extending some of this work to other types of cancers, as well as

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00:31:35.430 --> 00:31:53.280
Kristi Graves: different levels of risk conveyed, and so I led a pilot study to look at individuals who were identified from primary care clinics for interest and uptake of testing for a single nucleotide polymorphism.

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00:31:54.390 --> 00:32:10.230
Kristi Graves: related to colon cancer risk. And so we wanted to know who might be interested in this type of testing what information is important to make sure that people understand the information and then importantly, how we should communicate this information to diverse audiences.

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00:32:11.430 --> 00:32:16.350
Kristi Graves: And so the the protocol was that we would recruit from primary care.

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00:32:17.400 --> 00:32:36.180
Kristi Graves: And, given the at the time, relative novelty of looking at single nucleotide polymorphism, we thought it was best to stick with the in person genetic counseling for this project but we've since looked at other ways of delivering information,

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00:32:37.230 --> 00:32:46.260
Kristi Graves: by telephone. Individuals could choose whether to have or not a SNP test and then after the test results were returned,

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00:32:48.210 --> 00:32:51.600
Kristi Graves: coming in to discuss the results.

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00:32:54.960 --> 00:32:56.130
Kristi Graves: And so we worked

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00:32:57.540 --> 00:33:14.370
Kristi Graves: hard to find ways to communicate this risk, and now, when I look at this, you know, many years later, it seems even more complicated than it should have been. At the time we were we were working to follow best practices and risk communication and so describing what the SNPs we're

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00:33:15.510 --> 00:33:22.440
Kristi Graves: conveying, the level of increased risk, by showing someone what increased risk look like versus not increased risk.

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00:33:22.710 --> 00:33:35.970
Kristi Graves: Placing that in the context of of the grid, with the number of people highlighted, in terms of estimated lifetime risk of colon cancer, based on the on the genetics, the genomic profile.

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00:33:37.050 --> 00:33:47.520
Kristi Graves: Also at the time, we wanted to make sure that people knew that this was you know not conclusive; it was still in the research phase that it was based on only three specific SNPs.

99
00:33:48.660 --> 00:33:55.050
Kristi Graves: That we didn't know how other types of colon cancer risk factors related with these SNPs as well as

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00:33:55.800 --> 00:34:11.070
Kristi Graves: the limited evidence on this estimates for individuals who are not from predominantly European descent, given how some of the studies and the risk estimates were were concluded at the time.

101
00:34:15.030 --> 00:34:17.070
Kristi Graves: And so we found strong

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00:34:17.100 --> 00:34:28.410
Kristi Graves: interest overall in this type of genomic testing for colorectal cancer risk, and this again, small pilot study, of individuals recruited from primary care so.

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00:34:29.430 --> 00:34:31.530
Kristi Graves: not pre-selected for any

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00:34:31.530 --> 00:34:45.600
Kristi Graves: types of risk factors for colon cancer, although they did have a range of different types of risk factors both familial risk, as well as behavioral risk factors, so we wanted to know you know, do people

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00:34:46.350 --> 00:34:57.690
Kristi Graves: change their behavior based on this risk information, because it was a shorter term follow up with three months, we assessed intentions for colorectal cancer screening.

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00:34:59.190 --> 00:35:08.820
Kristi Graves: And then looked at reports of physical activity and healthy eating. And we did see that there were some changes in terms of

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00:35:10.140 --> 00:35:25.410
Kristi Graves: individuals noting that they were going to communicate with their physician about colon cancer risk factors and colon cancer screening. A quarter of them had made an appointment for colorectal cancer screening and

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00:35:26.670 --> 00:35:38.970
Kristi Graves: again intent, we know intentions, don't always predict behavior, but we were pleased to see that 100% of the individuals who are due for colorectal cancer screening intended to have one.

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00:35:44.130 --> 00:35:51.060
Kristi Graves: So I mentioned earlier, we were interested in and learning about how we communicate this level of of genomic risk

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00:35:51.630 --> 00:36:13.500
Kristi Graves: to patients, and so I was really fortunate to have a number of genetic counselors on the team. And we audio recorded the disclosure sessions that we had with participants, and then we did a discourse analysis of those genetic counseling transcripts and Morgan Butrick

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00:36:14.790 --> 00:36:24.150
Kristi Graves: had had some experience she had worked at the National Cancer Institute as a genetic counseling fellow and she had had some experience with coding

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00:36:24.570 --> 00:36:48.210
Kristi Graves: these transcripts in terms of labeling verbal dominance, as well as turn-taking and used a specific coding program called Reas to do that, and so we did find that genetic counselors demonstrated greater levels of verbal dominance with patients who were

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00:36:50.040 --> 00:36:58.140
Kristi Graves: underrepresented, and a lot of genetic studies so black and African American patients, Latino patients, so I think

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00:36:58.470 --> 00:37:13.680
Kristi Graves: taking something like this could be interesting to look at other types of populations, rural populations and the like, is you know, do we have similar rates of verbal dominance of genetic counselors with different types of patients.

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00:37:14.730 --> 00:37:29.520
Kristi Graves: And we looked as I mentioned before we gave a caveat to our participants about the interpretation of some of the data based on the limited, at the time, the limited findings for risk estimates

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00:37:30.270 --> 00:37:38.220
Kristi Graves: based on the Genome Wide Association Study estimates that we had, whereas most of those estimates were based on European

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00:37:39.300 --> 00:37:48.450
Kristi Graves: descent populations, and so there were some differences in terms of some of the process outcomes again by participant’s race.

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00:37:49.170 --> 00:37:58.260
Kristi Graves: In terms of coverage of the topics that we had in our educational materials, the booklets that you saw a snapshot of previously and then

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00:37:59.160 --> 00:38:11.580
Kristi Graves: the genetic counselors ability to adequately assess participants understanding of the information and in the bubble, there are some quote extracts from our transcripts.

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00:38:12.870 --> 00:38:20.610
Kristi Graves: This was some of the earlier work, there's been some really intriguing work by others in the field, looking at unconscious bias, not only in

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00:38:21.090 --> 00:38:37.800
Kristi Graves: genetic counselors, but this has been applied across a lot of different healthcare professionals and we all carry around these biases and so thinking about ways that we can recognize our patterns of communication with different populations could be, could be important.

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00:38:40.500 --> 00:38:49.080
Kristi Graves: So, given some of that work and some of my survivorship work that had been in Latinx communities and specifically Latina

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00:38:50.010 --> 00:39:04.410
Kristi Graves: women diagnosed with breast cancer, we were interested in taking some of this work and seeing what Latina women knew about hereditary breast and ovarian cancer and

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00:39:05.490 --> 00:39:14.790
Kristi Graves: ways to make connections between genetic services and different types of populations in the community. And you know some of the

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00:39:15.360 --> 00:39:24.720
Kristi Graves: legacy studies, looking at differences and awareness about hereditary breast and ovarian cancer by race and ethnicity.

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00:39:25.680 --> 00:39:35.790
Kristi Graves: But then other work saying that once someone found out about the availability of genetic services, there was high level of interest.

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00:39:36.660 --> 00:39:43.530
Kristi Graves: So we did some background formative work, this was led by a medical student who was interested in

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00:39:44.310 --> 00:40:04.020

Kristi Graves: understanding from the perception of patients and community based members, so we collaborated with a community based organization, here in Washington D.C. and identified women who had had genetic risk factors in terms of strong family history or

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00:40:05.100 --> 00:40:16.440
Kristi Graves: young age, at the time of diagnosis or diagnosis of ovarian cancer, and we found that our participants had a generally low awareness of hereditary breast and ovarian cancer.

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00:40:17.370 --> 00:40:23.460
Kristi Graves: Some had never heard of genetic counseling, and many had never heard of genetic testing.

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00:40:24.270 --> 00:40:33.660
Kristi Graves: Once the concepts of genetic counseling and genetic testing were explained, and this mentee created a fantastic short five-minute video in

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00:40:34.470 --> 00:40:44.580
Kristi Graves: Spanish with English subtitles explaining kind of Genetics 101, what is hereditary breast and ovarian cancer, what is genetic counseling, what is genetic testing.

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00:40:45.090 --> 00:40:55.320
Kristi Graves: Our participants indicated they were very interested in learning about this information, not only for themselves, but in particular for their family members.

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00:40:56.640 --> 00:41:13.800
Kristi Graves: And a strong emphasis on value valuing health, although there were conversations about in that there's other competing priorities as well and wanting to take care of people and not always prioritizing making time for their own individual health.

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00:41:14.940 --> 00:41:26.910
Kristi Graves: And then we also talked about and asked about barriers to genetic counseling and testing and the ones that kept surfacing included cost language barriers and insurance barriers.

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00:41:30.480 --> 00:41:33.720
Kristi Graves: And so, based on this information and some others,

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00:41:34.890 --> 00:41:41.850
Kristi Graves: formative work led by my collaborator Susan Vadaparampil, down at Moffitt Cancer Center. We set about

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00:41:43.980 --> 00:42:02.490
Kristi Graves: developing a training program, and this is the one Dr. Kelly referred to that's called Árboles Familiares, or family tree in Spanish, and we wanted to help think through ways we could reduce barriers to accessing genetics professionals and genetic services

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00:42:03.780 --> 00:42:17.790
Kristi Graves: which are often located in a you know, an urban center or in cities or in larger hospitals, when many people may receive their pair out in different community clinics.

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00:42:19.170 --> 00:42:23.550
Kristi Graves: And so, our goal was to create this training program to

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00:42:26.400 --> 00:42:36.840
Kristi Graves: develop a cohort of individuals who had high knowledge about hereditary breast and ovarian cancer confidence about how to explain cancer genetics

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00:42:37.770 --> 00:42:52.380
Kristi Graves: in terms of talking with community members, and identify red flags for hereditary breast and ovarian cancer, so that they could make appropriate referrals and navigate women to fully trained genetics professionals.

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00:42:56.040 --> 00:43:01.860
Kristi Graves: And so, our target training participants which we've abbreviated CORE-P.

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00:43:03.930 --> 00:43:12.360
Kristi Graves: Just something we made up, but community health educators, Promotoras, lay health advisors or patient navigators.

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00:43:13.980 --> 00:43:28.890
Kristi Graves: Sometimes these individuals who are working within the community are also called community health workers. Requirements for our training program or that they are bilingual in English and Spanish and engage with the Latino community.

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00:43:30.000 --> 00:43:40.080
Kristi Graves: And we know from other work that individuals who are community health educators or community health workers have been very effective in improving cancer screening

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00:43:40.590 --> 00:43:49.980
Kristi Graves: in different populations and that again they there was strong interest in building these bridges between genetics professionals and the community.

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00:43:51.420 --> 00:43:57.300
Kristi Graves: And so here the goals of Árboles Familiares to increase trainees knowledge about genetics.

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00:43:57.750 --> 00:44:13.170

Kristi Graves: Again, their understanding of what happens during genetic counseling and information about the genetic testing process and then build that self efficacy or their confidence in identifying individuals who are at high risk, and we have a two two format

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00:44:14.310 --> 00:44:15.540
Kristi Graves: training plan

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00:44:16.560 --> 00:44:23.880
Kristi Graves: that consists of in-person, workshops and online modules, although we during Covid, we had a completely virtual version.

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00:44:27.420 --> 00:44:36.480
Kristi Graves: So individuals who are interested in the training program apply and complete a baseline survey, then we have two introductory modules, a very

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00:44:36.900 --> 00:44:47.760
Kristi Graves: global overview of of Genetics 101 and Introduction to Hereditary Cancer, then we have our in-person workshop.

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00:44:48.300 --> 00:45:00.480
Kristi Graves: And again, we were just able to redo this in November, for the first time in a while, but it's a two and a half day kind of intensive in person workshop that's followed by online learning modules.

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00:45:01.770 --> 00:45:03.810
Kristi Graves: We ask that all of our trainees

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00:45:04.950 --> 00:45:16.350
Kristi Graves: apply what they learn through what we call the action project and so that's application in the community that can be an educational session development of a navigation guide,

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00:45:17.070 --> 00:45:31.320
Kristi Graves: development of a referral list to genetic specialists in their community. And then we've asked them, you know, how are things going, have you been able to educate women or individuals at risk for hereditary breast and ovarian cancer in the community?

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00:45:32.610 --> 00:45:37.260
Kristi Graves: And, have you referred anyone? And we ask that at six months and 12 months.

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00:45:39.540 --> 00:45:42.510
Kristi Graves: And throughout the next few slides there'll be some quotes

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00:45:43.560 --> 00:45:46.200

Kristi Graves: on the slides that come from some of our trainees.

161
00:45:50.670 --> 00:46:00.090
Kristi Graves: So, in terms of the training itself, we have a variety of different learning methods again, the pictures you'll see our pre-covid

162
00:46:01.050 --> 00:46:13.650
Kristi Graves: you'll see some with post-covid with our masks on from November. But we have lectures and videos, a lot of small group discussion, we play games to help apply the information.

163
00:46:14.910 --> 00:46:17.430
Kristi Graves: We have role plays and mock sessions.

164
00:46:18.510 --> 00:46:26.430
Kristi Graves: And then different types of learning sessions, and we have made changes over the delivery of these different cohorts

165
00:46:27.240 --> 00:46:29.010
Kristi Graves: based on our participant and trainee

166
00:46:29.010 --> 00:46:29.700
Kristi Graves: feedback.

167
00:46:33.930 --> 00:46:38.700
Kristi Graves: In terms of the online training, we ask that participants

168
00:46:40.020 --> 00:46:50.160
Kristi Graves: do this every one to two weeks, we have a 30 minute recorded video lecture, they can also download the slides.

169
00:46:50.970 --> 00:47:02.130
Kristi Graves: And we asked them to complete a short evaluation after each one, and these are topics that focus on kind of the application of the information that they learned in the workshop and making it

170
00:47:03.450 --> 00:47:05.190
Kristi Graves: applicable to their community.

171
00:47:07.530 --> 00:47:08.880
Kristi Graves: So these include

172
00:47:10.110 --> 00:47:17.790

Kristi Graves: discussions about how to identify community members who are at risk, so reinforcing the identification of the red flags.

173
00:47:20.160 --> 00:47:28.110
Kristi Graves: As I mentioned, identifying local genetics professionals or services through existing web resources.

174
00:47:29.940 --> 00:47:31.860
Kristi Graves: and local hospitals and clinics.

175
00:47:33.300 --> 00:47:43.650
Kristi Graves: Identifying how they might go about providing referrals and navigation to those genetic services, creating community guides as an example of their training project.

176
00:47:44.430 --> 00:47:53.520
Kristi Graves: And we have both synchronous and asynchronous aspects, so that they could have questions answered or have a conversation with a genetic counselor.

177
00:47:57.690 --> 00:48:03.540
Kristi Graves: So far we have trained 179 individuals from different states.

178
00:48:05.430 --> 00:48:13.620
Kristi Graves: The project is housed in Washington DC, we have a partner site at Icahn School of Medicine in New York and then Moffitt Cancer Center

179
00:48:14.010 --> 00:48:30.090
Kristi Graves: in Florida. When we originally conceived of this idea we were thinking we would cover the East Coast, and you know a bit beyond the region, but we had interest from all over, not quite every state where that's one of our goals.

180
00:48:31.920 --> 00:48:50.460
Kristi Graves: But we did just host that our most recent training in California, because we have a partnership with the Latino Cancer Institute in California. You can see our trainees come from many different countries of origin, although they all are in the US, at the time of the training.

181
00:48:51.690 --> 00:49:02.160
Kristi Graves: And almost half identify as community health educators or patient navigators. We found that many of our trainees identified in in more than one role within their organization.

182
00:49:04.200 --> 00:49:08.550
Kristi Graves: In terms of demographics of our trainees, we most are women.

183

00:49:10.050 --> 00:49:15.330
Kristi Graves: We welcome men or individuals of non-binary gender to apply.

184
00:49:16.680 --> 00:49:17.550
Kristi Graves: In a

185
00:49:18.660 --> 00:49:27.930
Kristi Graves: different reported and identified races, largely our ethnicity is Hispanic given our focus on bilingual.

186
00:49:29.220 --> 00:49:33.930
Kristi Graves: And then differences across our trainees, in terms of language preference.

187
00:49:38.850 --> 00:49:42.630
Kristi Graves: To date, we've been really excited that

188
00:49:43.710 --> 00:49:51.000
Kristi Graves: all of our trainees have indicated that they've educated some community members about hereditary breast and ovarian cancer.

189
00:49:52.470 --> 00:50:00.540
Kristi Graves: Not quite two thirds have reported that they interacted with a healthcare professional about hereditary breast and ovarian cancer, about half

190
00:50:01.140 --> 00:50:08.070
Kristi Graves: thus far, had identified a patient or community member at high risk either one or more, and then

191
00:50:08.760 --> 00:50:27.660
Kristi Graves: 44% indicated that they've navigated at least one person or more to genetic services. We also have seen significant increases in knowledge and self efficacy or self confidence, as well as in genetic literacy between our baseline and the follow-up.

192
00:50:31.980 --> 00:50:50.130
Kristi Graves: And so, some of the lessons learned so far in our work, starting with the telegenetics and telephone genetic counseling, is that it appears to be quite viable option for reducing barriers to access of genetic counseling. I think we saw that,

193
00:50:51.270 --> 00:51:06.330
Kristi Graves: you know, over time, not only during Covid but also before covid I think telephone genetic counseling has been becoming much more common, and if there's any genetic counselors on the line I'd love to hear about their experiences with that.

194
00:51:08.010 --> 00:51:23.160
Kristi Graves: There remain some barriers related to access for genetic testing, and that includes accessing the ability to have the test itself, particularly if genetic counseling was delivered via telegenetics.

195
00:51:24.210 --> 00:51:33.690
Kristi Graves: We've considered a lot of different options, mailing saliva kits with videos of how to provide a quality saliva sample.

196
00:51:35.220 --> 00:51:52.980
Kristi Graves: In the telephone genetic counseling study kits were mailed to individuals and then they took it to a laboratory in their neighborhood or area in which there was a blood draw, so there was a you know the paperwork associated with how to do that.

197
00:51:54.150 --> 00:52:04.440
Kristi Graves: One thing we've considered and started doing is, for individuals who choose to have genetic testing, to have another appointment by video

198
00:52:05.580 --> 00:52:13.260
Kristi Graves: to then help guide them with the process of providing a sample and then how to get that sample in the mail and return it.

199
00:52:15.420 --> 00:52:26.970
Kristi Graves: And then in our more recent work, you know, a strong level of interest among individuals who are already working out in the community as community health educators or patient navigators.

200
00:52:27.540 --> 00:52:39.210
Kristi Graves: In terms of expanding their knowledge and skill sets to identify individuals who are at high risk for hereditary cancers. I think the model that we have for Árboles Familiares, although focused on

201
00:52:39.750 --> 00:52:45.960
Kristi Graves: hereditary breast and ovarian cancer, could easily be transportable to other hereditary cancer syndromes.

202
00:52:47.370 --> 00:52:55.440
Kristi Graves: And you know, right now, our workshop, we've delivered it virtually. Overall we're still in the process of

203
00:52:56.460 --> 00:53:03.270
Kristi Graves: we're just about to launch our six month follow up of our first virtual cohort so we'll see how they do in terms of their knowledge and

204
00:53:04.200 --> 00:53:20.310

Kristi Graves: improvements in genetic literacy and the like to see if it's comparable to in-person. For our population with individual serving the Latino Community, here does seem to be a interest in having in-person training to be able to connect with one another.

205
00:53:21.540 --> 00:53:26.100
Kristi Graves: And you'll see some of the pictures, here we have one of our case studies, as we have small teams

206
00:53:26.850 --> 00:53:44.790
Kristi Graves: go through a pedigree. So they draw the family, history and then they present a case to the group, we do candy DNA activities where they create double helix is out of candy during the Genetics 101 lecture and then the small group activities.

207
00:53:48.360 --> 00:53:54.960
Kristi Graves: So I'm again really honored to be here today, thank you so much for your time, I think I see something in the

208
00:53:55.350 --> 00:54:03.780
Kristi Graves: chat and very happy to have any questions or hear about your experiences related to telephone genetic counseling or

209
00:54:04.410 --> 00:54:21.210
Kristi Graves: working in the community to help raise awareness of genetic services. So I can and a big thank you, of course, to our team our trainees and then this is the team for Árboles project, so I can stop sharing now.

210
00:54:23.760 --> 00:54:26.490
Kristi Graves: And I do see that there's something in the chat.

211
00:54:29.580 --> 00:54:42.510
Kristi Graves: Oh yes, thank you. This was a question about the background country of origin and acculturation of the Latinx Community. So for our formative work we do have some of that information.

212
00:54:43.530 --> 00:54:50.910
Kristi Graves: I'm happy to share that and follow up and then I presented on some of the countries of origin of our trainees, as well.

213
00:54:52.440 --> 00:54:56.070
Kristi Graves: But happy to talk more about that question if there's more questions.

214
00:54:57.810 --> 00:55:08.040
Kim Kelly: Well, thank you so much, and I have a couple questions here to to kick off and maybe you can give us your impressions.

215
00:55:08.520 --> 00:55:22.110
Kim Kelly: But to begin, of what do you see as the primary challenge for genetic services in rural Appalachia? I know you don't routinely work there now, but maybe you have some ideas, based on your previous work.

216
00:55:22.650 --> 00:55:23.220
Kristi Graves: Sure.

217
00:55:24.300 --> 00:55:26.760
Kristi Graves: I you know I think some of the barriers are

218
00:55:28.020 --> 00:55:32.220
Kristi Graves: exportable to different communities so in rural Appalachia I think

219
00:55:33.990 --> 00:55:46.020
Kristi Graves: the number and location of genetic professionals specifically, genetic counselors, I think we need more genetic counselors overall in this country.

220
00:55:47.160 --> 00:55:52.890
Kristi Graves: And then, making sure that community based clinics

221
00:55:54.570 --> 00:56:03.150
Kristi Graves: have access, if not in house, then access to a genetic counselor ideally by something like telephone.

222
00:56:04.320 --> 00:56:14.880
Kristi Graves: So that individuals who are identified as having you know potential risk for hereditary cancer syndrome can be connected directly, without having to travel.

223
00:56:16.200 --> 00:56:29.580
Kristi Graves: And you know, ideally, from the comfort of their own home or from the clinic itself through telephone or through video, so I think number of genetic counselors is one barrier.

224
00:56:30.990 --> 00:56:39.090
Kristi Graves: And then, access to the testing options, I think that is changing with provision of buckle kits.

225
00:56:41.220 --> 00:56:43.740
Kristi Graves: And the opportunity to mail those in.

226
00:56:45.120 --> 00:56:55.260

Kristi Graves: You know I think a little bit about some of the direct to consumer testing and if people can do this for fun, then we should be able to do this for healthcare.

227
00:56:56.940 --> 00:57:01.350
Kristi Graves: So those are some of the barriers that I see. The other piece is

228
00:57:03.030 --> 00:57:21.000
Kristi Graves: you know conversations about cancer and conversations about risk factors and conversations about cancer in the family, and in some communities there may be taboos about talking about specific types of cancer or a strong family history.

229
00:57:22.440 --> 00:57:27.750
Kristi Graves: There could be also sense of well that's just how it is in our family without

230
00:57:29.400 --> 00:57:37.800
Kristi Graves: knowing that there could be information that might be of interest to some family members to indicate if they carry these genes that might be

231
00:57:38.220 --> 00:57:56.610
Kristi Graves: putting them at greater risk for having a hereditary cancer. So I think those are some of the pieces, awareness in the community, discussion of cancer in the family, lack of genetic counselors, and then logistic barriers to genetic testing, which includes costs or insurance as well.

232
00:57:58.950 --> 00:58:09.090
Kim Kelly: So, by the same token, what do you see as some potential opportunities, I mean you've talked a little bit about some of your work and maybe there will be some relation to that.

233
00:58:09.600 --> 00:58:11.670
Kristi Graves: Mhmm sure, so I think

234
00:58:12.780 --> 00:58:19.440
Kristi Graves: in rural communities, building on some of those community ties in the

235
00:58:19.470 --> 00:58:39.090
Kristi Graves: settings in which people are receiving some sort of healthcare, so that you know if there are individuals who could have start to have those conversations about cancer in the family or age at diagnosis, so those could be individuals at community clinics.

236
00:58:40.650 --> 00:58:43.320
Kristi Graves: Implementation of some

237
00:58:45.330 --> 00:59:02.310

Kristi Graves: family history taking in a systematic way and some of the clinics we've worked in, they do do that, but then there's sometimes a disconnect between what happens in terms of people are checking you know, I have a mother and a sister with cancer.

238
00:59:03.330 --> 00:59:25.560
Kristi Graves: It doesn't always then result in a referral to a genetic counselor, so I think that's starting to change but implementing some of the workflow systems to translate identification of red flags into a referral, I think, is one of the barriers that we need to overcome.

239
00:59:27.750 --> 00:59:31.140
Kim Kelly: Great. Thank you. Any other questions?

240
00:59:42.300 --> 00:59:53.340
Kim Kelly: So I think Marina was quite interested, but she had to leave, so I understand that this is lunch hour for some folks so

241
00:59:54.420 --> 01:00:12.210
Kim Kelly: appreciate that. Well, thank you for a wonderful talk Dr. Graves, and I enjoyed it learned, even though I'm familiar with your work, I learned a little bit more today, and it's got me thinking about some of the opportunities there, and certainly

242
01:00:14.070 --> 01:00:28.200
Kim Kelly: previously, in our sessions, the idea of kind of information leads and that decision aids has been discussed, so I think there is a fair bit of interest in that among the group and

243
01:00:28.920 --> 01:00:34.560
Kim Kelly: you know some of the folks that had mentioned some interest haven't been here, but hopefully they'll hear this.

244
01:00:36.570 --> 01:00:39.390
Kim Kelly: They'll hear this on the recording.

245
01:00:41.100 --> 01:00:48.990
Kim Kelly: And there's a follow up from Dr. Galves, so and she is interested in pharmacogenomics.

246
01:00:49.290 --> 01:00:49.920
Kristi Graves: Oh great.

247
01:00:50.580 --> 01:00:51.030
Kim Kelly: Um

248
01:00:51.420 --> 01:00:57.870

Kristi Graves: I'll put my email in the chat and if anyone has thinks of other questions later, you know, please feel free to reach out to me and

249
01:01:00.150 --> 01:01:13.830
Kristi Graves: you know I think there's a lot that we can do out in our communities to raise awareness about hereditary cancer and genetic services, so I applaud each of you for doing the work that you're doing and for your interest.

250
01:01:14.850 --> 01:01:28.620
Kim Kelly: Well, thanks so much for your talk today, and we have our evaluation survey link posted in the chat and we appreciate folks giving us feedback and

251
01:01:29.220 --> 01:01:37.800
Kim Kelly: that certainly helps with our funder and to let them know if this is the kind of thing that we need to work on and I

252
01:01:38.220 --> 01:01:50.160
Kim Kelly: am hearing a lot of discussion in different groups about trying to address this issue. So next month, I will be presenting on some of the data

253
01:01:50.790 --> 01:02:00.630
Kim Kelly: from our session, kind of as a wrap-up and appreciate anyone that can come and contribute and discuss how

254
01:02:01.080 --> 01:02:09.480
Kim Kelly: we might plan to move forward, but we've got a lot of great ideas, both from the initial intake whenever people registered

255
01:02:09.900 --> 01:02:24.060
Kim Kelly: for the sessions, as well as during each of our speakers and ways that we might approach, so again, thank you all so much, and if there are no questions, then I'll just thank you again, Dr. Graves and look forward to seeing you next month.

256
01:02:25.590 --> 01:02:30.480
Kristi Graves: Thank you so much for having me and thanks for organizing this great series.

257
01:02:34.320 --> 01:02:35.610
Kristi Graves: Hope everybody has a good day.