FTS NHGRI

Moderator: Sarah Harding
September 11, 2008
12:00 pm CT

Alan Guttmacher: Good afternoon or good morning depending on how far west you are. Everyone this is Alan Guttmacher. I'm the Acting Director of the National Human Genome Research Institute here at the NIH.

And I too would like to welcome you to this which is the second session of NIH's new webinar series.

Today we're going to talk about family health history projects and the importance of involving communities as we move forward encouraging the use of family health history as a cornerstone of healthcare.

As many of you know already Thanksgiving has for a number of years now been the Annual National Family History Day by proclamation of the U.S. Surgeon General.

Since Thanksgiving is now less than or a little bit I guess less than three months away, almost two months away we wanted to use this webinar to give folks an overview of what's happening in the world of family history and also to highlight a couple of examples of what we think has been successful

community engagement demonstration projects around family history with the hope that our discussion today might spark ideas of events or projects that you or your organization might want to hold in your own community this coming Thanksgiving.

A few logistic notes before we get started. One is if you're having any technical problems during the call for instance, if you can't access the web portion of the call dial star 0 to talk to the Operator.

We will hear in a moment from several speakers, Greg Feero, Melanie Myers and Mike Murray and that will be the first part of the webinar.

And after that we're going to take questions from you. We're going to take questions over the phone. Any time during the webinar simply dial star 0 to talk to the Operator and she can put you into queue to ask your question.

We ask that you have a BlackBerry, cell phone, PDAs or anything else near your phone that might cause interference that you move it away so everyone can hear things better.

If you have any technical difficulties accessing a portion of the webinar and can't get through to the Operator for some reason you can always as a last resort email Sarah Harding here at NHGRI. Her email address is sharding@mail.nih.gov.

We will be recording these presentations and the question and answer session that follows them and our plan would be to post the call online so others can benefit later from the conversation or you can revisit it yourself if you'd like to.

So now to get us started I'd like to welcome Dr. Greg Feero who's Chief of the Genomics Healthcare branch here at NHRI and also is our Senior Advisor for Genomic Medicine.

Among Greg's many interests are the developments of electronic health record-based tools for genomics use in clinical practice as well as genomics education for health professionals.

Greg will start us off with a broad overview of the upcoming activities related to family history stressing the importance of involving communities before we move onto those examples we mentioned before.

Greg, take it away.

Greg Feero: Well thanks Alan. Good afternoon and good morning to all of you out there on the phone and on the web.

You might wonder a little bit about my choice of titles here and you were wondering if this is going to be more about clothing than family history.

And I really chose this title to point out that though right at this juncture in time the use of genetic markers is sort of in vogue for risk assessment for the genetic underpinnings of common inherited conditions, it's actually the case that family history remains the most accessible and least expensive way to get a rough estimate of genetic component of disease risk for many diseases of great public health importance.

Not only does family history capture a bit of a genetic component of risk but it also captures some of the environmental factors as well. Most on the phone probably are aware of this.

In addition to risk assessment of course family history in the course of providing healthcare has a tradition of other uses. That includes the organization of knowledge of family relationships and structure that has a major impact on most people's existence in their home environment.

You can learn by gathering a family history of patient's concerns. For example it's not uncommon to see a fairly young individual in the office and realize that it's a little unclear exactly why they're seeing you today.

And at the end of this visit they finally come out and say, "You know my aunt just had such and such. Am I going to have a problem with this?"

And by gathering a family history you sometimes get a glimpse into that person's psyche.

You can also use family history to inform differential diagnoses when you're presented with the actual complaint or condition.

And, you know, classic example of this would be a young individual presents with chest pain. If in fact they had a very strong family history of cardiovascular disease that might move coronary heart disease up in your differential diagnosis over things like GERD, etcetera, etcetera, potentially.

You can also use family history in the setting of case finding. For example if you have an individual who has say colorectal cancer at a very early age, gathering family history from that individual may provide very useful information for mitigating risk of family members from that individual.

And finally it can be used as I discussed earlier for the screening purposes.

And unlike currently existing genetic markers coming out of genome-wide association studies there's a fair number of or are a fair number of guidelines for medical care that use or impacted on by family history information.

And this slide lists a number of these. Many of these guidelines are now becoming more and more evidence-based rather than simply based on expert opinion. And we can use these in daily practice to actually save people's lives.

So in recognition of the potential value of family history in healthcare the Surgeon General initiated in 2004 the Surgeon General's Family History Initiative, and as Alan mentioned earlier along that time came the idea that Thanksgiving should be the Annual Family History Day for the nation.

The initiative it included a number of different activities. Probably the most prominent obvious of which is the development of the Surgeon General's family history tool which is a web-based tool now available in both English and Spanish for - which allows patients to gather in the privacy of their own home environment family history information for use in their care.

So what is new in family history currently?

Well coming up soon there will be a wealth of information from the CEC and a large trial that they conducted using their own version of the Surgeon General's family history tool that provides some risk assessment information.

The trial actually looks at whether or not having risk information will change patient's behavior in their care setting.

And the Initial Data Release Meeting for this will be on October the 16th.

And I understand that there are over a half dozen publications in preparation relating the results of this study so we're about to learn quite a bit about the use of family history and behavioral change.

Also upcoming next year, almost exactly a year from now, will be an NIH State-of-the-Science Conference on family history.

And this conference will focus on the evidence-based supporting the use of family history as a screening tool in the primary care setting. I think that will be very informative. It'll tell us a lot about what we know and what we don't know. And hopefully define a research agenda for the future for family history.

As I stated it's next year at about this time, August 24 through 26, 2009. This meeting is actually open to the public and it's sponsored by the Office of Medical Application Research here at the NIH.

So perhaps the most exciting area right now with family history is the idea that we may be able to harness evolving health information technology systems, otherwise known as electronic health records or personalized health records, to more effectively capture and utilize family history information.

One can envision these systems to be designed to help with efficient data capture, help provide expert risk stratification at the point of either the patient's interaction with the system or the provider's interaction with the system, provide point of care education for both physicians and patients, and then improve how this information is utilized with other healthcare information in health information technology systems advanced care.

This area got a major boost out of the activities of the Personalized Healthcare Work Group, the American Health Information Community. Several recommendations were advanced in the middle of 2007 along these lines the first of which was that a core data set for family history for EHRs and THRs should be developed.

And the following to focus on developing federal projects and partnerships outside of the federal government to utilize a core data set and emerging family history tools in pilot projects to demonstrate family history utility.

The core data set has been created and is now accepted for publication in the Journal of the American Medical Informatics Association. It's available through their web site. You'll see on the screen now we have the preprint of the cover.

And these slides presumably will be available in archive form for future use.

So the current activities in the federal spear surround taking the current Surgeon General tool, modifying it to encompass all the data elements mentioned in the core data set document that I just showed you and then taking that and more sort of expanded tools and developing the capability to connect that tool to EHR and THR systems both within the federal government and outside of the federal government.

The timetable for sort of the early demonstration of proof of principle of this is in the next several months actually and software development is already underway.

And I think this is very exciting. I think it'll likely take the Surgeon General's tool to the next level and will probably provide a new generation of public health tools for family history.

Thanks.

Alan Guttmacher: Thank you Greg very much. One logistic note again and that is if you have any questions for Greg please hold them till after all three of our speakers have had a chance to speak and then we'll take all of the questions because we think there'll be some that will probably go across speakers so we'll wait until all of them have spoken before we start taking your questions.

But you can get into queue at any point by calling the Operator.

So next we'd like to feature two of the community-based demonstration projects involving family history that the NIH has funded over the past few years.

We're going to hear from the leaders of two of those efforts. First we'll hear from Dr. Melanie Myers from the University of Cincinnati and then we'll hear from Dr. Mike Murray from Brigham and Women's Hospital in Boston.

Both are going to give us brief overviews of the project they led and some thoughts about the models that their work has established.

So first Dr. Myers who is a Board Certified Genetic Counselor with interests beyond family history that includes provision of genetics related health services in a variety of forms and very much includes the education genetic counselors.

Melanie it's all yours.

Melanie Myers: Oh, thank you Dr. Guttmacher. And thanks also to the Education and Community Involvement Branch for funding us to develop this project.

So we worked with Urban Appalachian Communities in Southwest Ohio.

And as you know the Surgeon General's Initiative encourages all Americans to collect their family health history and then to share that information with their healthcare providers.

And at the time that we initiated this project there were a fair number of resources about family history for consumers but really none for medically underserved population with low literacy skills such as Urban Appalachian Community in Southwest Ohio.

So we therefore proposed to develop a model program to educate Urban Appalachian women with less than two years of college about the collection and use of their own family health history.

And as part of this program we also created a variety of low literacy family health history resources.

We chose to work with the Urban Appalachian Community because they're a relatively large community here in the greater Cincinnati area.

And the estimates I've seen suggest that about a third of the population has some Appalachian background.

But also because the community as a group experiences higher poverty rates related to a high school dropout rate that approaches 100% at some schools, an elevated unemployment rate, and then increased risk for some chronic diseases particularly those that we see on the Surgeon General's tool.

We specifically focused on engaging women because the available data suggests that females are more likely than males to collect family history information but also because Appalachian women in particular are often likely to play key roles, caregiver and gatekeepers in family health.

So we formed a Family History Working Group to guide the project.

And that group consisted of 11 members including three representatives from community organizations that provide services to Urban Appalachians.

And we had a variety of expertise represented on this working group and you can see them listed here on this slide.

This group helps to develop all the resources and the methods really utilized in this project.

We also partnered with six community organizations that provide services to the Urban Appalachian Community.

And the organizations were selected based on recommendations from our working group but also through the recommendation of some other community organizations.

And in addition to serving on the Family History Working Group and providing guidance to the project overall these community partners provided

insights into cultural aspects that were unique to the Urban Appalachian Community and they also recruited all the participants to the project and provided the facilities where we held education sessions and Focus Groups.

And you can see that two of these community organizations were located in Cincinnati. One was in Newport, Kentucky which if you're not familiar with the geography its right over the river from downtown Cincinnati, and then three were in Dayton, Ohio which is about 50 miles north of Cincinnati.

There were four components overall for this project. I'll touch on each briefly.

But we held Focus Groups. We had to two separate education sessions. And then we contacted participants by phone.

So early on we held two Focus Groups to learn how Urban Appalachian women define family health history, what they perceive the importance of it to be, and also how participants wanted to learn about family health history.

And findings from these Focus Groups then guided the development of our illiteracy resources and also the content and the structure of the education session.

Thirteen groups of about 8 to 12 women participated in two separate education sessions.

And the objectives for both of these education sessions were developed by the Family History Working Group with the help of a professional evaluator.

And you can see the objective for the first education session listed here which were for all participants to be able to record their family health history using

My Family Health Portrait, for participants to be able to identify the importance of family health history, for participants to be able to explain how to access My Family Health Portrait using the Internet, and to be able to identify at least four relevant questions about family health history to ask their relatives.

The second education session was held two weeks after the first.

And objectives of the second education session were for participants to be able to report problems that they encountered when collecting their family health history between the two education sessions, to report how they intended to use the information they had collected, and then to be able to constantly ask questions of healthcare providers about family health history.

Four weeks after the last education session that participants attended we followed up with phone calls.

And objectives of the phone calls were to learn with whom participants had shared their family health history and particularly if they had shared it with the healthcare provider.

So I mentioned that there were several illiteracy resources developed for this project which are listed here. Eleven illiteracy fact sheets, nine of which were disease specific and two which were general fact sheets about family health history were developed.

Those are available online or you can contact me and Sarah. We can email those to you.

The disease specific fact sheets cover the six diseases on the Surgeon General's tool but also three additional questions which participants in the Focus Groups told us they were interested in and those include asthma, lung cancer and depression.

We also developed four presentations for the education sessions.

And they covered the importance and use of family health history, an overview of the six common diseases in My Family Health Portrait, how to access My Family Health Portrait, and then how to talk with relatives about family health history.

And finally we developed a handout about how to talk with healthcare providers about family health history.

And that handout was developed based on recommendations from our community partners because they were concerned that the participants wouldn't know what questions to ask providers or wouldn't feel confident talking to healthcare providers.

This is an example of one of our fact sheets. We tried to follow the same structure for all our different fact sheets.

Twenty-four women participated in one of the two Focus Groups.

One hundred women participated in an Education Session-1, and 92 returned two weeks later to an ES-2.

We reached 58 women by phone roughly four weeks after the last education session.

And the women who attended a Focus Group were not eligible to attend an education session so those two groups are mutually exclusive.

Here are some general characteristics of the women who participated in the education session.

And you can see that less than half had a high school diploma or GED and only about 11% had some college.

We also have slightly over 50% age 40 or under and that really reflects the services provided by community organizations.

So for example many of them provided GED training which really targeted younger individuals.

And finally 79% of participants self identified is white, 18% is black and not shown on this slide is that 89% of the participants had children.

So that's the Surgeon General findings and I tried to boil it down but you may have more questions.

But based on evaluations completed by the participants after each education session the learning objectives were met.

Ninety-one percent felt that the first education session was very helpful in teaching the importance of family health history.

Seventy-five percent reported that they shared their family health history with family members or significant others between the two education sessions.

And 40% of the 58 participants reached by phone reported that they had shared their family health history with their healthcare provider.

So next steps ideally if we can get funding would be to develop a multimedia educational program about collection and use of family health history because we think that would create a more sustainable educational program.

And then we'd like to follow-up to see if family health history is getting into medical records and if so, how it's being utilized by providers.

And I know we're taking questions at the end but if you want to email me about the fact sheets or other things I'm providing my contact information.

Alan Guttmacher: Thank you very much Melanie. That was a wonderful presentation.

Now we're going to move and I get the web speed from Appalachian to Boston where we'll hear from Dr. Mike Murray, the Chief of Clinical Genetics at Brigham and Women's Hospital.

Among his many activities Dr. Murray runs the Adult Genetics Clinic at the Brigham as well as the Annual Genetic-Based of Adult Medicine Course at Harvard Medical School.

Mike.

Mike Murray: Thanks Alan and hello from Boston to everyone.

So I'm going to tell you about a project that we did focused on the employees of our hospital.

And this was funded by the NHGRI, and took place from 2005 to 2006.

We chose to engage our employees who number about 13,000 people because they're such a diverse group. While about half of them are healthcare providers the other half are all other folks that go into making a hospital run from environmental services to cafeteria workers to the administrators of the hospital.

So I'm going to tell you a little bit about some of the work that we did there.

So as I said the project ran from Thanksgiving '05 to '06. We encouraged and supported the use of the Surgeon General's family history tool amongst our employees.

And our goals were to understand the obstacles to participation to understand what participants wanted to do with the information and ultimately what providers did with the information when they got it.

And we had great support at the very highest levels of the hospital which made our job easier. The Vice President of the hospital sent out an email telling everyone, all the Managers that employees should be given 20 minutes to either work with our team or to work online on their family history during work time. So that was a great advantage of really moving the project along.

From the beginning we made it clear to participating employees that they completely controlled their own information.

And it was interesting that when this project was first launched there were people that were concerned that somehow I was personally collecting all their

family histories but in fact we encouraged people to go to the Surgeon General's web site to fill out their information and then to keep it to themselves or share it with their families or their providers.

And we encouraged that but we did not collect the family histories as I said.

So during the project year we had outreach to the employees using the Intranet and the Internet as well as getting out and meeting with small groups of employees during monthly meetings or educational talks. We were essentially pounding the pavements of the hospital for the entire year with a staff of about four people and lots of volunteers.

This is one of the ways that we got information out. If that looks like the writing is all Greek to you, it is. I don't have permission to tell this story outside the hospital.

But this was one of our hospital employees and his family. And we had several employees tell their stories on the Intranet so that other employees could kind of get a sense of what was happening with the project as well as what some of their peers and colleagues found as useful information and outcomes coming out of their participation.

At the end of the project year since we were encouraging people to go to a public web site and then keep the information to their self, we had to try to gauge the overall participation by a survey.

So we sent out a single question survey to every employee via the email system asking them the simple question, have you spent time in the last year gathering and organizing your family health history?

And so people got an email and then clicked on a link that took them to this page.

And as you can see there it's a simple yes, no or I still plan to do it essentially since this was sent out in early November for most people.

And you can see here the overall participation is estimated to be over a third of our 13,000 employees so we sent this all user email to almost 13,000 folks and got responses from 10% and 36% said yes they had engaged in family health history activities during the project year.

And when we did further surveying these are some of the things that we found. We asked folks what was their motivation for participating.

And as you can see there 61% simply thought it would be interesting and then they could check that applied.

So importantly about a half felt that it was - it would be beneficial to their health. About 20% did it for the sake of a family member. And about 20% said that their peers influenced them to participate.

And one of the interesting things is that we really felt like we got people talking beyond the conversations that we had.

So when we asked folks if they learned anything new about their relatives in the process, about a third said that they had.

And then about a third again said that they had shared something with their family that they hadn't shared before that their family may not have known and through this process.

And then fully 94% said that they would encourage others to participate.

And we had encouraged people to discuss this with their primary care providers or other healthcare professionals.

And about at the end of the project year, about 21% already had and many others told us that they plan to at their next visit.

And when we asked what happened in the encounter, as you can see there about 61% said that their primary care provider was very interested.

And then you can see there that many were told to make lifestyle changes and some were referred to other specialists.

And about a third reported quite honestly that they had brought it up with their primary care provider and their provider did not take any specific action based on it.

So overall our estimates are that about 4,500 employees worked on their family health history during this project.

About 20% had done it based on the recommendation of coworkers or supervisors so really we kind of had people throughout the system encouraging others to do it and I think that made a big difference.

Twenty-one percent took their history to their primary care providers.

And we thought it was interesting that only 11% of people who had not participated, so those approximately two-thirds who had not participated in it,

only 11% of those gave a specific reason. Many of them had said we just didn't get around to it or we're still planning on doing it, etcetera.

And if you broke down that 11% some of them had privacy concerns, and many of them had said that their doctors already knew their family history so they didn't feel that they had to participate in this matter.

So I thank to the Educational Community Involvement Branch of the NHGRI. (Vince) and Sarah were the point people for this project.

We also had some internal funding through Brigham and Women's and Harvard Partners.

And then listed there (Ann Cokely), (Karen Holbrook), (Pete Dempsey), and (Phyllis Dean) were the people that were directly involved in the project and then thanks to all 13,000 of our employees.

If you go online to this site you can get a full 70 some page report of the specific activities that we did, the outreach and the ways that we got out to our employees during this year.

And with that I'll end. Thank you very much.

Alan Guttmacher: Thank you very much Mike. That's another excellent brief summary of what's obviously quite a lengthy project for both of you.

So we will now open the lines for questions from everyone that's on the line. Please remember you dial star 0, reach the Operator and you can enter the queue for questions.

So let's hear from all of you any questions you have or discussion you want to raise, if you have other kinds of projects that you want to tell us about briefly, we'd be interested and I'm sure all of us in hearing about those as well.

Maybe while we're waiting for the Operator to start with the questions I'll just remind people or let you know that our next webinar will be in about two months on November the 19th at 1:00 pm Eastern Time.

It's going to present information with genome-wide association studies and how information from GWAS as we have learned to know and love them are already starting to dramatically change the field of genetics and even medicine in general.

Sarah Harding will be sending you information about the webinar as the time draws closer for that.

So do we have any questions yet Operator?

Coordinator: At this time if you would like to ask a question please press star 1; one moment.

(William Wu), Chicago State University, you may ask your question.

(William Wu): Okay. Thank you so much for the presentation. The - found it fully interesting to me.

The two questions I have, have to do with the known existence. I did not hear anything about ethical, legal and social implications of these family history resource activities because I realize in 1990 (Winston) Watson played a major role in genomic sequencing.

The very first issue he brought up was the relevance, the importance of ethical, legal and social implications of this project.

Why is that we don't hear this in the presentation?

Then the second aspect is have we done enough job of educating provider regarding use of Medicare and Medicaid to actually meet the needs of patients who's genetic intrafamiliar risk factors had they been pointed from use of family history tree?

Those are the two questions I have.

Greg Feero: So this is Greg Feero. I'm willing to tackle the first one at least from the standpoint of emerging software tools.

Part of the American Health Information Communities activity is in fact a large part of it is deals with confidentiality, privacy and security issues.

(William Wu): Yes.

Greg Feero: Of this type of information in the electronic health record and personalized health record.

And there has been and continues to be many, many discussions around the various issues that arise.

One of the early aspects of the current Surgeon General's tool development was a decision that because of concerns about these types of issues that when

any one individual comes to use the tool at this point in time there is no data stored on any sort of storage media in the federal IT architecture.

So the data only exists as you're interacting with the tool. And in the consideration for the next version of the tool is how can we maintain that sort of pristine non-capture of data by federal systems while at the same time permitting an individual using the tool to send - permitting them to send their data to their healthcare provider system where in fact presumably want to have the information sent and stored.

And so there are many discussions along these lines and I'm sure you'll hear more about that as these types of tools progress.

(William Wu): Are the patients made aware of this? Are your clients, your subjects, your interviewees are they aware of this confidentiality?

Greg Feero: I believe the current Surgeon General's web site does indeed state that there's no information maintained when they're using the tool so.

Alan Guttmacher: I think so. And this is Alan Guttmacher. Mike Murray I might ask you to comment. Obviously there was an interesting issue that I know you dealt with at the Brigham in that you were gathering this or you were providing the service, this information center to folks in fact who of course were employees of the Brigham. And that creates a special kind of relationship.

Do you want to talk a little bit about how you handled that whole issue?

Mike Murray: Sure. We realized from the start that we were going to this group of 13,000 people and saying that it's your government and your employer that are encouraging you to do this but don't be worried.

So we try to get out in front of that right away by ensuring people that the Surgeon General's web site does not capture any information just as Greg just said.

And that we didn't want to collect these family histories because there were people who would do it and then save their file and send it to us.

So we had to keep repeating the fact that this was their private information. They should share it only with those individuals that they feel comfortable with.

And when they asked who would be the people that would make the most sense we encouraged them to do it with family since we certainly found that the data got better when they reviewed it with their family and they realized that they had some of the facts wrong individually but as a group they could really clarify the data.

And for those individuals and there were some who said look, I'm simply not going to trust the computer with this, we had lots of paper versions of the tool that we would get out to anybody who just didn't feel comfortable with that.

(William Wu): Thanks.

Melanie Myers: And this is Melanie Myers. And I'll comment just briefly on your second question about have we done a good enough job of educating providers particularly those who provide services to individuals who are on Medicare or Medicaid.

(William Wu): Yes.

Melanie Myers: And one of the things that we did early on was sent out packets of information to the clinics that would be most likely to provide healthcare services to the Appalachian women who were participating in our project.

And I'm guessing we sent out about a dozen and a half of those packets.

And as part of that we said, you know, are you interested in an in-service about family health history? If so, please contact us. We'll be happy to come to your organization.

And we didn't get anybody who followed up.

So the short answer is probably no. We're not doing a good enough job.

And, you know, we could probably spend a lot more time talking about what we could do differently.

(William Wu): Thank you so much. I realize that Medicare/Medicaid does not pay for many of these predictive healthcare services, healthcare (programs) that are likely to show up three years, four years from now which we can compute and derive from use of family history tree. You talked about asthma. One of your colleagues spoke about chest pain in the very young individuals. Medicare does not pay.

And with all the sophisticated technology we have in genomics for sequencing (form and pointing) ideals of these monogenetic diseases and polygenic ones Medicare/Medicaid will never pay because we have not done a total job of creating free family history education not only to the public but also to physicians.

Most of our providers who live in places like Midwest -- I'm not speaking of the East Coast or in California area -- are not familiar with this technology at all. I have visited about ten of them. They keep saying we are not there yet. We are not there yet.

The trouble is in the medical school curriculum you don't have genomics on it. You - in public curriculum you do not have professors teaching genomic science to them. Talk less of the applications or the complication with the three (Es). I mean analytical validity, clinical validity, utility computation of specificity and issues of specificity. All those things have not been taken care of.

And our physicians, most of them are not familiar with this technology at all.

Alan Guttmacher: This is Alan Guttmacher. I know we need to move onto some other questions.

But let me, this is a wonderful place for me just to remind people as I probably will do periodically in these series about the National Coalition for Health Professional Education in Genetics which is an umbrella organization that includes dozens of organizations that are really interested and focused on educating health professionals in training and health professionals in practice to answer those very challenges that you've well enunciated because clearly these are challenges.

It doesn't matter where in the U.S. or where in the world for that matter someone's practicing. Clearly we need to do a better job of educating the health professional workforce to be able to use not just family history but some of the other genetics and genome tools that will become available in the next few years, a very good point.

Operator do we have anybody else with questions at the moment?

Coordinator: Once again if you would like to ask a question please press star 1.

One moment please.

Sir at this time I have no further questions.

Alan Guttmacher: Well in that case let me - I might ask both Mike and Melanie a question. This is Alan Guttmacher again.

Now that you've done what you've each done, obviously you learned something from those experiences. In terms of, you know, again the kind of populations that you were targeting and thinking about with your projects, now that you know that you've learned the lessons that the projects themselves taught you what would you do differently if you were, you know, for the first time seeking for instance on the one hand to reach an Urban Appalachian population or the other hand a group of employees at a large urban hospital, how would you set about doing that any differently than you had initially?

Melanie Myers: That's a big question. This is Melanie Myers.

I learned a lot. I'm not quite sure where to start. I think probably one of the biggest challenges for us was logistics. That really took me by surprise the amount of time it took to schedule the education sessions, to set up for the education sessions, the technological issues that we had.

And probably now that I know what I learned thus far I would do some pre-site visits to make sure all the computers were working, to make sure all the printers were working, you know, I would do some things differently with the working group to make sure that we did it as a group, everybody took their family history and not, you know, that they did it on their own.

I would ask some different questions so why did you select the tool that you selected. Some people chose paper, some people chose electronic.

How hard did you think it was to complete it?

How well do you think - how much of your family history do you think you captured?

So a lot of different questions but probably in terms of what I would do differently would focus on logistics, trying to simplify them and, you know, making sure I knew ahead of time because we're going to run smoothly.

Alan Guttmacher: Mike anything you wouldn't do differently.

Mike Murray: Well the thing we're working on now which would have been nice if it had been in place would have been a way to seamlessly transfer the inner data into the electronic medical record.

And we heard a lot of stories from folks that we're very excited about participating and despite the fact that they did it on their computer, they had to print it on a piece of paper and walk into their doctor's office and hand them the piece of paper which either somebody transferred the data back onto a computer or more likely just stuck in a folder somewhere.

So really once somebody spends - invests this 20 minutes it would be nice if it could move right into the electronic medical record.

So we look forward to Greg's work and others to make that happen.

Alan Guttmacher: Yeah, that certainly is a push nationally and both nationally and in lots of specific healthcare networks, providers, etcetera. Those who either have electronic medical records or at least moving in that direction thinking of ways of really integrating this information with the ideal of course that the patient is the one who's the expert about family history.

And if they can put the information in we have reason to believe it will be fairly high quality and certainly save a lot of healthcare professional time in terms of gathering the information and then healthcare providers can spend their time analyzing and using the information. So that certainly does make a lot of sense.

Let me also ask each of you and this is in some ways an impossible question to answer so I realize that in asking it.

But based upon your experience one of the things I know that many people have grappled with is can one use a sort of one size fits all family history in terms of forms and other kinds of things?

So there's sort of some discussion back and forth about gee, well the vast majority of people can utilize the same kind of resource, etcetera, versus others who think that it really needs to be individualized to specific communities and that kind of thing.

Any wisdom from the projects that you've coordinated that you think would be helpful in that discussion?

Melanie Myers: This is Melanie. And issues with us weren't so much the tools. I don't know that the tool needs to change so much as maybe the supporting materials.

We didn't - you know I don't know. I guess I don't the answer because we didn't compare it to a different tool.

But we didn't hear people say - well I guess we did early on. You know, when we held our Focus Groups, one of the things we heard about the paper tool was hey, there's not enough space for all our relatives. My mother has 20 siblings. Obviously the electronic tool can accommodate that a little bit better.

But yeah, you know, I don't know the answer. We didn't have issues with the tool itself aside from space.

But we also developed a lot of supporting materials that were specific to our community group so.

Mike Murray: So this is Mike. And I guess two comments I'd make. One is that the one thing that doesn't fit all is language.

And we generated six paper tools for the employees. We never were - we were requested to create a new language tool.

So they're posted on our web site too if anyone has specific need for a French, Portuguese, Polish, Chinese. I think I'm probably forgetting one or two version of the family history data entry tool.

But I guess as far as the one size fits all for data collected, I think that ultimately this is a reiterative process for everybody.

And just getting people to get down the basic family structure is one of the critical things and then adding data as you acquire it.

So I think that the Surgeon General's tool does a great job of starting the process and then everybody will want different bells and whistles or different focus depending on what their medical questions are or what their community issues are.

But I think you got to start somewhere and it's good just to get the basic information that the Surgeon General asked for.

Alan Guttmacher: Yeah. No, that makes sense.

Operator, I'll - I guess chance for one more question if there is anybody at this point.

Coordinator: I have no questions sir.

Alan Guttmacher: Okay, well in that case I would like to thank all of you for participating in this webinar particularly doctors Myers and Murray. It was I think a quite useful discussion.

And we look forward to having many of you join us again on November the 19th when again we will be talking about genome-wide association studies both for the basics of what they are, what they've shown us. There've been dramatic results as many of you know over the last two years or so where we've known - we've gone from knowing genes involved in only a handful of

common disorders to now having identified through GWAS studies in the last two years or so a couple hundred such genes.

So it'll be an explanation of sort of the signed behind genome-wide association studies and particularly how that's changing the way we approach genetics and through genetics a real understanding. And we hope eventually treatment and prevention of common disease.

So again Sarah Harding will be sending more information about that webinar as we get closer to November 19th. Between now and then don't forget to vote on November the 4th. That may affect the answer to some of the questions about Medicare and Medicaid use of various kinds of things.

And have a good time. Until then we look forward to talking with you again in a couple of months.

Bye-bye.

Mike Murray: Thanks Alan.

Coordinator: Thank you for participating in today's conference.

You may disconnect at this time.

END