**2017 KT Conference:**

**Knowledge Translation Outcome Measurement**

New Patient Centered Approaches for Assessing the Social Integration of Burn Survivors: The LIBRE Project.

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ANN OUTLAW: Today we'll hear from two sets of NIDILRR grantees about how they've implemented KT strategies into their projects. We'll first hear about the LIBRE project out of Boston University and using patient-centered approaches for increasing social interaction among burn survivors and we'll hear from Allen Heinemann and Linda Ehrlich-Jones from the Shirley Ryan AbilityLab-- about the Rehabilitation Measures Database and later this afternoon we'll be joined by Dr. Diane Finegood from the Center for Dialogue at Simon Frazier University who will discuss knowledge translation in the age of complexity. And at the end of the day we’ll have another interactive discussion which will be led by Kathleen Murphy. For additional information about these sessions and presenters take a look at our conference webpage that you can find in the helpful links pod. Let's get started.

We'll first hear about the LIBRE project. Lewis Kazis is a professor of health policy and management, the director of health outcomes unit in the Department of Health, law, policy and management at Boston University School of Public Health. And is the principal investigator for the LIBRE project. Dr. Ryan has led efforts to have patient reported outcome measures to measure outcomes and define the health needs of burn survivors.

Jeffrey Schneider is the medical director of burn, trauma and orthopedic rehabilitation at Spalding rehabilitation hospital, associate chair of physical medicine at rehabilitation at Harvard medical school and director of the rehabilitation outcomes group at Spalding rehabilitation hospital. He is also a PI and project director of the Boston Harvard burn injury model system. We also have Mary Slavin who is the research Assistant Professor and the health law policy and management department at Boston University School of Public Health and Dr. Slavin has been involved in the development of several rehabilitation outcome measures and engaged in knowledge translation measures in clinical settings. Dr. Kazis, are you ready to begin?

LEWIS KAZIS: Whenever you say.

ANN OUTLAW: All right. You're up

LEWIS KAZIS: I'm delighted to be here today. First, I want to thank the KTDRR and AIR for featuring this conference. We're delighted to be part of this. You've already stated our backgrounds. I just want to mention that Dr. Ryan, Dr. Schneider and Dr. Slavin are members of our team and we worked together for a number of years, a very cohesive group and I think you'll agree our project is a contribution to the field. Next slide.

LEWIS KAZIS: So in terms of disclosures, I want to thank the national institute on disability independent living and rehab research for supporting this project. We're now in the fifth year of what's called a drip. And this particular project has given us an opportunity to develop what is the LIBRE profile or cat. I also want to give credit to the Frazier fund of the Massachusetts general hospital who also have been involved in this effort. So as far as staff and investigator we're a multidisciplinary team of people a lot smarter than I am. Literally I become more of a coach in the later years of my career and it has been a pleasure to work with all of these folks. I also want to make special mention of Allan Jedi, a co-PI with me on the project and brought me into the technology and approaches used to develop computer adaptive tests. I also want to make mention of Amy Acton of the Phoenix Society who has been an active participant in this project and really allowed us to enfranchise the burn community nationally in our efforts. Next slide.

LEWIS KAZIS: The LIBRE clinical advisor board is a group of clinicians and others engaged in the work that we're doing for a number of years and play an important role in terms of work in the dissemination activities that are now proceeding with the LIBRE profile and Mary Slavin will be talking about the dissemination efforts later on in this talk. The agenda today is going to be to provide some understanding of the objectives of this project from the first year and I do want to say at the outset in franchising community in the burn unit has been one of our primary goals and been able to achieve and played an important role in the development of the cat. We'll talk about the conception framework. Some of our results rely on the validity of the assessment and we'll turn to the dissemination plans and the important networking of our activities with both Phoenix Society as well as the Boston Harvard burn injury model system and Jeff Schneider will be talking about this. I will now turn to Colleen Ryan who will talk briefly about the clinical implications of the cat and its importance in the burn community. Colleen?

COLLEEN RYAN: Thank you, Lewis. Can you hear me?

LEWIS KAZIS: Yes

COLLEEN RYAN: I would like to begin talking about the overall root of this project. When I began as a clinical burn surgeon almost 30 years ago, there was one outcome that people really cared about and that was mortality. And around 1984, it became standard for people with large burns to survive. And in the ensuing years and throughout my career it became evident that we needed to look at outcomes other than simply survival and move towards quality of life in the evaluation of our therapies for patients with massive burns. Now as you can imagine, entering the society with severe scars can have some significant social implications. And there is really little known about that and actually little known about the long-term outcome of burn survivors and how they navigate the rest of their lives following these severe injuries. So, what we were hoping to do is to look at long-term outcomes of burn survivors.

So, the first thing we wanted to do was identify the needs of the population. We wanted to know really what happens to burn survivors physically, mentally, socially, and we could do that by collecting large volumes of data and examining it. We also would like to optimize care. For instance, if we had our long-term outcome measure we would like to compare one treatment against the next and determine which one most efficiently reaches our goals so that we can streamline care and improve recovery. Once we have these large bodies of data, we may also be able to use them at the individual level and provide realtime feedback. For instance, suppose you had a massive burn injury, you came out of the ICU, you went home. You are there with your wife or your significant other and you have to go to the doctor's office. And you know, it's three months after the injury. You are still doing a lot of dressings and you have -- you go in and you have maybe 40 minutes with your doctor in a very extensive long appointment. Well, you go in, the doctor asks how you're doing, and it is very hard in that short amount of time, to explain the magnitude of the disruption of this injury in your life. You really don't even know where to begin. And during that 40 minutes you have to have your dressings done, you have to talk about pain, you have to have your medications reviewed, you need to schedule your next surgery. You need to do consent and there is really a limited amount of time where you can talk to the doctor or the caregiver to explain what is going on with you. And we were looking at the possibility of patient-reported outcome measures done before the visit to help explain to the doctor particularly when they are bench marked against known results how you are actually doing. And also the caregiver can then provide to you, the patient, how you are actually doing by benchmarking your results against those of others with similar injuries.

When we began this project, I think it was important to involve survivors from the very, very beginning. And this was through focus groups, committees, having survivors actually work alongside us on these measures. But we asked them what is the most important outcome to you long term following the burns? And in addition to scarring, it was social participation. So, with that, we went on to look for a measure of social participation and we wanted to make sure that it was relevant, accessible and useful. We did this through an ongoing collaboration with Phoenix society, which is one of the leading burn survivor organizations in the United States and Canada.

So, our objective was to create a social impact of burns in adults. We called it the Life Impact Burn Recovery Evaluation or the LIBRE profile. This is our little trademark here. So, the implications for survivors of such a measure would be --That we would understand what challenges are faced by burn survivors over the course of their recovery. We could be able to define it with numbers in a hard or in a fashion that we could compare one treatment against the next and we can sort out which resources or therapies are most effective in improving the burn survivors' social participation and streamlining their recovery and we could also provide survivors and families and health providers and even administrators with important recovery information. In some of our pilot work, some people say finally it's organized in my mind so I can understand how to approach it. And I have an expectation of how long, for instance, I'm going to be out of work. It helps the survivor explain to their families, it helps the health providers understand the context of their illness, and it also helps administrators and third party payers with resource allocation following a massive injury.

Finally, it enables the survivors to better understand their recovery and also to communicate their needs to doctors and others. Now, for instance, you take a test before you go into the doctor's office. When you go into the doctor's office, there is a complete list of how you are doing in all these areas. And if you are doing well it's perhaps a green. You get a green number on that. And if you are under performing that's indicated. If you are over performing that's doing as well. We've had some success from previous measures doing feedback, for instance, the Shriners hospitals for children, American burn association, burn outcome questionnaires. An example of this clinically would be a mother that comes in with a child very, very upset about how things are going. They take the instrument and then the results are reviewed with the mother and everything is green except for parental worry which was really very low. In a very concrete fashion you can explain to the mother that the problem is her worry and not so much the child, who is doing well.

So, with this sort of experience in mind, we went on to develop the LIBRE. Dr. Kazis will talk about the LIBRE project.

LEWIS KAZIS: As Colleen indicated, very early on from the beginning of the project, we began to really enfranchise the burn community and also clinical experts. And in doing so –

ANN OUTLAW: Would you speak up just a tad?

LEWIS KAZIS: Sure, in doing so we created an item pool. The item pool involved qualitative work and also comprehensive LIBRE reviews and consulting with experts. We were interested in developing items that in fact emanated in a number of respects from what the needs of the burn community were and the burn survivor as Colleen indicated. And this became, I think, an important starting point for the project. We clearly communicated to those burn survivors that we worked with that the information that they were providing would ultimately lead to the development of an instrument that would help to understand the outcomes that might be important to the burn survivor.

We then created an item pool on the basis of this. I'll go into some detail about this. And this item pool was, in fact, a fairly lengthy questionnaire that was then administered nationally to over 600 burn survivors. And we were able to do that through the networks that we created or that we tapped into through such organizations as the Phoenix society that were very important in the foundation of this. We then conducted calibration work in the third year. As I indicated this is a five-year study. And validated the assessment tool that was being developed across six domains that I'll detail in the coming slides. We finally conducted in the fourth year a pilot study. The pilot study was to look at the reliability and validity of the community adapted test assessment. We also have created not only a cat, which is computer based, but also a fixed form assessment which can be administered through paper and pencil or on computer and this fixed form assessment provides basically scores that would be on the same metric as the cat. And then finally in the fifth year we're conducting or beginning to conduct alpha testing as part of the dissemination activities of the project and as I indicated, Dr. Slavin will be talking about this later on in the talk, as well as Jeffrey Schneider who, in fact, is the director of the BH program. Next slide.

So in the -- we're now entering the fifth year of the project and have had a number of publications. For those interested in this work they can turn to any of thieves that will provide the details concerning the methodology, as well as the applications of the LIBRE profile, and there are now six of them that have either been published or accepted for publication and we can make all these available to any of you that are listening in on this conference. Next slide.

So the conceptual framework development in the first year included performing a comprehensive lit review and consulting with clinical experts and burn survivors about the social life areas impacted by burn injury. We used the international classification of functioning or the ICF, WHO ICF as the primary grounding of this content model that we developed or that we used in the context of the development of the assessment. And then qualitative results strongly suggested that the conceptual model fitted the constructs for societal role and personal relationships with the respective sub domains and we'll be talking more about that. We also conducted specifically focus groups to validate the framework and revise and augment the initial item pool and then we conducted cognitive interviews with the burn survivors to get consistency in the items developed. The conceptual framework. Many of you are familiar with the classification of functioning includes health conditions, the disorder that in fact in this case we're talking about burns, body functions and structures which lead to activities, and it all sort of focuses for us in terms of participation as far as the social role aspects for the burn survivor. Once they are burned and have a really major impact on their lives, how does that impact on their social participation? So, we also consider the issues of around environmental factors and personal factors that may impact on that participation.

Next slide. So the process for this included sort of initially -- we picked out 19 measures amongst many others we looked at in terms of this comprehensive LIBRE review that included 560 items. We then removed those items in which they were less relevant or, in fact, led to a lot of redundancy. That provided us with 276 items. We then conducted focus groups amongst the burn survivors and also we went to clinical experts as a way of culling the assessments and basically modifying some of the others. That actually increased our item pool to 315 items. We then revised and removed items that tended to be redundant or less relevant that led to 253 items and conducted cognitive testing for further item refinement which then led to a little under 200 items for this battery. We then administered the battery, as I mentioned, to over 600 burn survivors and that provided us then with the database that would be used to do the calibration of the items.

So how does the cat work? I think almost everybody on the phone I would assume has taken an SAT or GRE exam. Where there is an extensive item bank behind the scenes and given the technology and science based upon item response theory, only a select number of items have to be asked of that individual. From that item bank. Every response to an item will inform the system as to what that next item to be asked will be. And I'm going to turn to the next slide to provide a little more definition for this.

A cat is called a computer adaptive test. This as the slide reads is an estimation process that begins with a large item bank where the items are ordered according to their difficulty level. The cat then selects an item of medium difficulty to start with. If the person responds positively to that item, then the next item will increase in difficulty. If the -- on the other hand, if the person responds negatively, then the next item will decrease in difficulty. So the test continues to ask these questions until a sufficient level of precision occurs. And that would be a standard error of less than .32 for the methodologists out there or reliable of .9 or higher and include stopping rules within the algorithm so no more than 10 items will be asked and a minimum of 5 and provides us with sufficient reliability based on the work we conducted to give us .9 or higher reliability for the domains. Next slide.

Let me also mention the methodology we used is called the graded response monitor and allows us to establish different slopes for the items. So that does in many ways for those familiar with the promise system out of northwestern, they also use the greater response model approach. In terms of the methods, we then conducted field testing once we collected the data. We also conducted exploratory and confirmatory factor analysis and applied our theory using a greater response model. Next slide. We found there were six domains.

Related to social participation. But what I call social reintegration following a burn injury. These include relationships with family and friends, social interactions, social activities, work and employment, romantic relationships, and sexual relationships. So these are the domains that turned up given our analytic procedures that I just mentioned. Next slide.

So, to explain just a little bit about each of the domains, and again one can turn to any of our -- some of our publications which will detail these quite a bit. The first is relationships with family and friends. This involves the person's ability to interact with and fulfill social obligations and achieve emotional satisfaction with family and friends. So that's relationships with family and friends. Social interactions involve exchanges in contacts that a burn survivor experiences when engaging in various community activities that are important to them and includes several items on relating with strangers. An example might be I don't worry about other people's attitudes towards me. Next slide

For social activities that is burn survivors difficulty in -- maybe I avoid outdoor activities because of my burns. Then there is work and employment. This might be satisfaction with one's ability to complete work and relationships with co-workers and supervisors. Because of my burns I'm unable to finish many work tasks. So work and employment was clearly a domain that really came out of some of our focus groups and was shown to be an important aspect of a burn survivor's social role.

Romantic relationships and sexual relationships made up the fifth and sixth domains and romantic relationships have to do with emotional and physical aspects of those relationships as well as communicating with a partner. An example might be I have a partner who meets many of my emotional needs and finally sexual relationships relate to engagement in and satisfaction with one's current level and quality of sexual activity. An example might be I avoid sexual contact because of my burns. So those were the six domains and they were shown to establish six factors based upon our database.

In the fourth year of the project, we conducted pilot testing using the fixed forms and there were 10 items per domain or 60 items in total for the fixed forms. We conducted test/retest reliability and validity testing of the fixed form cat. I should say the fixed form LIBRE profile. It involved administering the fixed form and then readministering the sixth form seven days later. A lag of 7 to 10 days. The validity testing involved using legacy measures. We correlated those legacy measures with our LIBRE profile of scales and let me mention that there are about 250 subjects that participated in the initial test and where we conducted our validity testing. For the test/retest the numbers were 150 or so that completed both test and retest. Next slide. The results were quite encouraging. And we do have a manuscript that is now under review with a journal. All correlations between the LIBRE profile scales and the legacy measures were shown to be significant at a .05 level and we found that they were in the expected directions when we looked at the issues around convergent and divergent validity. The figure below that is the test/retest reliability and that was shown for in this case an example being social activities where the correlation was a closed .9. For the other five constructs or domains we found that the correlations ranged between .8 and.9. They were all encouraging. The results in the fourth year have been quite encouraging in terms of the -- both the reliability and validity of LIBRE profile assessments. We've now begun to put the LIBRE profile into a cat, computer adaptive test and that is clearly available in a desktop format and we're now moving to a web-based application which will allow it to be administered on any number of elements, including laptop, desktop, and other devices. So we're now in the fifth year of the project. And we're beginning to look to alpha testing across different environments both clinical and in the community.

I'm going to turn things now to Mary Slavin, Dr. Slavin, who will talk about the dissemination activities.

MARY SLAVIN: As you've seen from the previous talk from Dr. Ryan demonstrating that we clearly have something that is of value to the burn community and from Dr. Kazis we have something scientifically sound we're at the intersection between having something that is a wonderful research initiative that we now want to make available to the community. From the very beginning we began to think about how we are going to get this tool available to our potential users. We identified three potential audiences, people with burn injury, researchers and clinicians and then we started to think about how to get this computerized adaptive test available to the broad community for use. This is not a very easy process since it requires collaboration between researchers and people involved in developing technology.

So as Dr. Kazis mentioned, we are at the point where we have a measure, the computerized adaptive test that we think works well, that fulfills all our criteria for a good measure. Now we have to make it available. We were fortunate that we were able to find a group at Boston University, the software application and development lab and they worked with us to develop a web-based platform. What you are seeing is a screen shot of the computerized web-based platform that they've developed for us and we have just completed our beta testing of this platform. It works well. We also have a desktop version that we can make available to people interested in using it, sharing that desktop version and we also developed short forms for people who may be interested in using the LIBRE profile but are not able to access computerized -- any computer for administration. So again we've been looking at this online cat.

If you can go to the next slide. An example of the way the items appear as Dr. Kazis mentioned. We have the items specify your level of agreement. Most family members are comfortable being with me and the respondents and what they feel is the most appropriate response. And so the respondent will go through the computer on this adaptive test and the slide that showed you with each new response the computer selects an item that best matches that individual. So with a few well selected items we can get a precise estimate of a person's level of a certain trait that we're assessing. Next slide.

In addition to developing ways to present the LIBRE profile in terms of having access to the computerized adaptive test we're also very interested in score reports. We feel that score reports are very critical to whether or not something is used. If we're just giving a user a response that your score is 45 or 60 it may not have as much meaning as if we can present the score in some context. So we've come up with some ways of presenting the score reports and we just went to world burn conference and administered some of the LIBRE profile assessments and demonstrated some different score reports and we're now looking at data from the respondents to determine what are their preferences for displaying scores and our goal is to have score reports that are deemed valuable and useful by the three different potential users. Next slide.

So in terms of the traditional types of dissemination I feel very fortunate to be working on this project because the dissemination is quite easy because the -- already we have some of the criteria met in that we have a demonstrated need as Dr. Ryan mentioned. As soon as people heard about this project there wasn't a lot of explanation needed in terms of why this would be an important project. So there was an immediate recognition of the value of this LIBRE profile.

We also have the advantage of having key opinion leaders of doctors Ryan and Schneider to help lead the effort. Having leaders in the field was critical to recognize the value of the LIBRE profile. In terms of our dissemination partnersships and collaborations they've been in place since day one and made my job much easier. Partnering with a consumer organization was critical to our success. The Boston Harvard burn model system was an important collaborator. I don't know if you've lost the Adobe presenter. We also have the -- our local burn survivors of New England group who have been incredibly involved with us from the very beginning. They're so excited to work on this project and they are very enthusiastic and Dr. Kazis is on their advisory board. We have a lot of interaction and exchange with them and see them almost every other month and have -- providing regular updates and getting input from them. Also we have a LIBRE clinical advisory group. A group of burn injury experts from across the country who meet with us on a regular basis. And we have the national fire protection association, again another outside group that we work with. You see the college of communication, I'm sure some of you might have noted graphics that Dr. Kazis presented in terms of the -- some of the info graphics and we have been working with the college of communication. They've strengthened some of our ability to create compelling images and to tell our story. Next slide.

So throughout the project we've been able to collaborate with the Phoenix society and we do a lot of cross promotional activities. When we're promoting one of our presentations, we highlight the Phoenix society and vice versa, develop brochures and more traditional promotional materials. We're engaged in social media. We are very present at conferences and when we complete a presentation at a conference we'll upload the presentations to our website. We have an electronic newsletter that we distribute via email marketing campaigns and have seen a continued growth in our -- interest in our newsletter. We also have taken advantage of collaboration with BU film school and BU school of public health to development videos. We'll show you examples of videos we've produced. And the BU college of communication have this wonderful group called ad lab. They have been engaged with the graphic design and graphic development. I think when you first see the LIBRE profile, the image is compelling. Next slide.

You can see us here at the world burn congress. When you see the logo, the LIBRE, I have to give credit to the BU college of communication students for coming up with a compelling image. We've created a brand that I think people recognize. We started from people not knowing what it was to people asking questions about it. So we've become a recognizable group within the burn community and people are aware of what we're doing. So most recently at the world burn congress this year we did a practice improvement study where we demonstrated the LIBRE profile among attendees. They gave a feedback surveil and we're analyzing our results from that now. For participation, we gave a donation to the Phoenix society. We had an exhibit booth, as you can see in the photo, where we have promotional materials and newsletter sign-up and then we were able to get some footage for a consumer-focused video that we're producing. We had interviews with five burn survivors and we filmed at the walk of remembrance. We're capitalizing on these opportunities to engage with the burn community and strengthen our dissemination materials and our presence in the community. Next slide.

So again the throughout project we've been involved with the Phoenix society and burn survivors. We do very little without consultation from our burn survivor community and we're involved with commissions and research partners and we're planning ahead to see how the LIBRE profile will be used in the future. In terms of identifying and engage knowledge our audience we began with the LIBRE profile development. When we first started I can almost remember our first conversation where we said we have something, we don't have anything to disseminate yet. What are we going to do? Where do we start when we don't have a product yet? We began by trying to prepare an audience for our future project. Stories of social participation by burn survivors to promote interest in this as a topic.

Newsletters that emphasized burn survivor stories. We had a public service announcement that was again produced by a student at the BU film school. Next slide. It has had nearly a thousand views on our YouTube video. We have a brochure, nice info graphics developed by the ad lab at the BU school. We want to tell our story simply but in a compelling way. We often have quotes from our burn survivors that are driving a lot of interest and understanding in what we're doing. Next slide. This is just the first scene of a public service announcement video that we did in the very early stages. We were again trying to build our audience and build an understanding for the need for our product. So we created this just smile video.

Worked with our New England burn survivors group and they helped to have roles in the video and we produced a video that basically shows some of the issues around social participation with the message that what people with burn injury want from the public is to treat them normally and just smile and no avoidance behavior. Again, we've had over 1,000 views on our YouTube video where we posted it. Next slide. What we're producing now is a clinician-focused video. That looks very dark, the entrance to the BU school of public health but it will be -- we have a video that was produced with Dr. Kazis and Dr. Ryan and it focuses on why clinicians would want to use the LIBRE profile and about six minutes and we'll use it as part of our promotion to clinicians in developing an interest in using this tool. Next slide

And then for our future work we have again the work that we did at the burn congress this year. Our next video will be the burn survivor focus video. Where we have a video to engage clinicians and their interest in the LIBRE profile. Our next video will develop an interest among burn survivors as to why they might be interested in the LIBRE profile. We continue to update our brochure and promotional materials and finalizing our training materials. When we have our web-based LIBRE profile we'll imbed in the website our training manuals and how-to videos.

Future work will be continued developing testing of our cat at clinical studies. We have a desktop version short form and online cat and we're working with -- in discussion and working with some of our clinical psychologists to do online testing and our goal is to provide the LIBRE profile cat in homes through websites like burn societies where people can go and access the tool.

LEWIS KAZIS: Great. Thank you, Dr. Slavin. So I'm now going to introduce Jeff Schneider, a rehab physician, professor at the Harvard medical school, who will talk about the BH bims project in the context of the LIBRE profile which will be one of the text stages in the dissemination to the burn model system. Jeff?

JEFF SCHNEIDER: Hi, Lewis, thank you for the introduction. Can you all hear me?

ANN OUTLAW: You might want to speak up just a tad, please.

JEFF SCHNEIDER: The Boston Harvard burn injury model system is really excited to be involved in one of the next major steps with the LIBRE project and the BH bims is one of four burn model systems funded by the National Institute of disability, independent living and rehabilitation research across the country. As part of our grant this cycle that just start evidence a month ago and part of the five-year project our major research project will be developing recovering trajectories with the LIBRE project. When we speak about recovery trajectories, some people might think of a pediatric growth curve. This is using the LIBRE scales as the metrics that will be examining over time to create these trajectories and looking at these different six social constructs or outcomes over time. And so, you know, what are the benefits of developing recovery trajectories for the burn population? I think for one it enables one to enhance our understanding of the social changes that occur over time for burn survivors. Some issues may be more pertinent at certain time points and others may linger and remain issues later and those are things we're still trying to figure out. Another important thing is it will help us identify risk factors associated with the development of specific social recovery trajectories. For example, certain factors like demographics, gender, marital status, different medical factors, maybe ways of stratifying risk for development of different trajectories of recovery in these specific areas of LIBRE scales. Another implication is it will help us evaluate clinical interventions that address social integration outcomes on both an individual and population level. So if we try a new intervention, we can only look at an individual and put them on a scale and this recovery trajectory and see how they respond and compare whole groups of people to that scale.

Another important implication is enable burn survivors to self-assess their own social integration recovery by taking this LIBRE profile either in the home, in their own setting they can benchmark how they're doing and to assess the social recovery and get individualized care plans to guide what their own needs are according to how they're doing in this trajectory and ultimately help guide social integration resources for the burn survivor community as a whole. So in order to do this we'll be looking at the six LIBRE profile scales which include family and friends, romantic relationships, social activities, social interactions, sexual relationships and work and employment. And we'll be administering the LIBRE profile to 600 participants over the span of five years and follow those participants for up to two years time period and they'll receive five administrations of the LIBRE profile over that period. So that gives us repeated measures in order to assess this trajectory of recovery. And people will be administered the LIBRE profile cat either online or by mail short forms or even by phone interviews in order to make this as accessible as possible to the burn survivor community.

The image here on the right is some prior work we've done with a different instrument, the WABOQ, the young adult burn patient questionnaire. A picture of what we hope to develop. These trajectories of recovery. We've done this sort of work before with other instruments but they haven't really been done with the LIBRE profile or other social participation outcome instruments in the burn survivor community. This enables, you can see a trajectory of recovery over time. This is in months and this figure and you can see a curve that is generated over time and an individual can put themselves on the curve. This curve has two different lines which are stratified by the server tee of the size of the burn. This is an example of the type of information we can generate from these recovery curves. Next slide, please.

As we're all speaking about one of the major important aspects is how do we get this information from the research side to the people who need it most and disseminate it? We've thought about the dissemination of this project along different audiences. So when we think about the clinicians and researchers, we'll be presenting our results at the major scientific conferences which include the American burn association, we will be publishing manuscripts in peer review journals and collaborating with the knowledge translation center which performs quick reviews which are basically consolidated information based on peer review manuscripts and puts it into more accessible language for the lay public to interpret scientific literature and produce graphical abstracts. A nice, new visual way of understanding research results and are being widely disseminated in social media as well as in now traditional academic journals. When we think about the burn survivor and family community, you know, we'll be having workshops at the world burn congress, which is a national -- international conference each year dedicated to burn survivors and their families about the use of the recovery trajectories and the LIBRE profile.

We have fact sheets highlighting our social media presence on both Facebook and Twitter and then also having consumer sessions at local support and national support group meetings. When we think about all the stakeholders together, we'll be developing a LIBRE profile toolkit which will really be interfaced that will help both clinicians and researchers as well as burn survivors and their family utilize and help them walk through how to make use of the LIBRE profile and these recovery trajectories. That toolkit will look a little different for a burn survivor and how they would walk through the use of the LIBRE profile recovery trajectories rather than a researcher. We are planning to have a symposium at the end of our project on community participation following burn injury to help tie together the work we do and bring together the different stakeholders who are really invested in this work as well and really helping us disseminate it.

Next slide, please. I don't know, Lewis, do you want to talk about the slide here?

LEWIS KAZIS: Thanks, Jeff. Let me just mention in terms of connecting with us, we have a website, I also want to mention there is a website for the BH bims and we're on that website as well as we work closely together with Dr. Schneider and Dr. Ryan. And we also have locations on Facebook, Twitter, although I encourage you not to Twitter the White House these days. And then we have an info graphic. We have a PSA as well and you can contact us directly and we will be glad to answer any questions that you have. So I want to thank all of you and I also want to thank my colleagues who presented. I guess we can start now with questions. And do I take the lead on this? I guess I do take the lead on this. So I'm going to respond first of all to the technical questions that were asked. The cat info graphic was developed by one of our student organizations, let me mention that. And they've literally spent this semester developing that. It was actually at the time and request of Dr. Jedi who wanted a slide and it has become very helpful to us in explaining what the cat is about. The next question by Dr. Chang, are all LIBRE items co-calibrated together? The answer is no. They're treated on a domain basis. That answers that question. One thing I didn't mention is we conducted an Internet-based survey of those without burns representing a national -- it was a sample of the U.S., let me put it that way.

I have to be careful these days when you deal with Internet-based surveys as to whether they're nationally representative. This was non-burned and it does provide us with an ability to norm our scores using a T-scores transformation. So the 50 in our metric represents those without burn injuries. So that's what the 50 represent. It's on the basis of this Internet-based survey. The other question I guess had to do with differential in functioning. There was a difference between males and females and we did separate calibrations for the two. But the other assessments that were done for dip did not present a problem. I think that answers those questions.

The question at the top involving the national quality forum I've been part of some of their efforts. They're very -- it does require a lot of labor, the applications for endorsement are very extensive and require a lot of time invested. So with appropriate resources I think it's a good idea but it would require a lot to be able to do -- basically put the application together for consideration by NQF.

ANN OUTLAW: Would you mind reading the questions you're answering from the chat box so we have a good reference point?

LEWIS KAZIS: Are you seeking national quality form endorsement. Your process is rigorous. Thank you, Elizabeth for that comment. If we were able to have the resources available to do that, I think that's something that we would certainly consider. And then did you conduct the literature review at the side of the five year DRPP project or had you identified that? The answer is no. We began with a comprehensive lit review once the drip was supported and we -- all of that work or most of that work occurred in the first year, first year of the project.

I am going to let Mary respond to that. That's more of a dissemination.

MARY SLAVIN: Kathleen Murphy, had you worked with your partners and collaborators on past projects or was this a new constellation of entities? I think Dr. Kazis has been working with Dr. Ryan and Dr. Schneider on burn assessments and some collaboration with the Phoenix society but bringing this effort under a drip really formalized the relationships and it brought in the dissemination piece which I don't think was often a big feature of this kind of work. And I do think we've learned through the project that some of the big barriers to using the instrument is significant in terms of the technology needed to support the platforms that have to be developed for these instruments. The score reports, the training and that sort of thing. So I think the DRPP really brought us together into a new constellation of entities that had a broader vision of producing a product and result that will be used.

ANN OUTLAW: Thanks, Mary. So the last has to do with did you analyze results for differences with gender location and burn and severity of burn and yes, we did. A good part is documented in some of our publications which I will be glad to send on to those and perhaps to Margaret who has asked the question.

ANN OUTLAW: Thank you very much. We really appreciate your presentation this afternoon. I know there are more questions coming in but perhaps Mary, you will be in the interactive session this afternoon so you can answer the remaining questions then. Thank you all.

LEWIS KAZIS: Thank you.

MARY SLAVIN: Thank you very much.