DENISE KENNEDY: Hello, everyone, my name is Denise Kennedy and I'll run through a few reminders before today's Mobile Kidney app. If you're experiencing difficulties, use the chat function available on the right of your screen in the middle. To respect everyone's schedules we'll get this started to make sure the session ends on time.

Today we welcome Dr. Brooks Robey at the VA medical center in Vermont. We're hoping for no technical issues, though they are expecting snow. Dr. Robey is also the business owner for the Mobile Kidney app.

If you have questions, use the chat feature. If we don't get to your question, we'll send out an email with any relevant answers. To download the presentation, click on the file name on the bottom right, below the chat box. With that, I'll turn it over to you, Dr. Robey.

BROOKS ROBEY: Thank you. So, welcome, everybody, I'm going to talk to you today about something the VA Kidney Field Service has been working on for a while: the VA Mobile Kidney app. What I'd like to do before I dive into the app itself, is just to step back for a second and talk about some of the barriers that we are trying to attack, not only with this app, but also with other technological resources that are now becoming available to us throughout the VA.

When you're managing chronic kidney disease – this is a very long term, debilitating illness – the barriers are multi-fold. The barriers that I have listed on the first slide are certainly not all inclusive, but they are representative of the types of barriers that are important to consider when dealing with not only kidney disease, but with anybody that has chronic illnesses of any kind.

Specifically dealing with issues like health literacy and education can be very multifaceted, because for a patient to get education, we need to have resources. We have to be able to provide information to them that cannot only be real-time, such as in the setting of a classroom or in the clinic, but also provide them with access to go back and either look at new material or to reinforce old material. Material that is in a durable format that they can access at their convenience.

Some of the technological approaches we've taken to deal with this have involved creating things like virtual kidney clinics that will reside in the cloud. An outgrowth of that experience is the Mobile Kidney app, where we can provide a resource that can be mobile and accessible 24/7 on the patient's time table.

Obviously this seeds in very neatly with closely related issues of patient engagement and buy-in. As a clinician, I have a limited amount of face time, and it's interspersed with long periods of time when I don't really have contact with, or much feedback, from the patient. Arguably, that time frame between visits is as or more important than what is going on physically during those intermittent visits to the clinic. We are trying to assess not only where they are, but trying to extrapolate where they've come since the last time we saw them. Having a mobile platform that can engage the patient, not only engage the patient on an educational process, but maybe

engage them so they can use it as a resource to then gather information, can help fill in those gaps between the clinic visits, can be very important.

Having a source for codifying information and organizing information, and looking at it, may provide us a little more granularity in the types of things we are looking for when we have patients come in. This syncs into better care coordination because better buy-in, better education leads to better communication and the patients actively participate in their own care. That's a very broad sweeping oversight with what we've been trying to achieve with some of the resources.

What I'd like to do is just show you what I'm talking about in a little bit more specific times. The story really starts with the VAE Mobile Kidney Clinic. This is an existing resource that we started building around 2010. It went live in 2013, and we have several years of experience with this now, but the VAE Kidney Clinic is a virtual kidney clinic.

You can see on the right-hand panel the entryway is depicted here, and the web address is depicted here below. This is publicly accessible. You don't have to be behind the VA firewall. This is a virtual clinic where the patient can get information. This slide has been resized, so you can't read all of the headings, but basically there are opportunities for the patient to come in. This is the home page depicted, but there are numerous other sites that are in here. You can go to a virtual nutritional clinic and talk about dietary issue, go to a virtual laboratory and learn about, not only what kinds of labs are important to kidney patients, but also kinds of care for at home, and at the clinic. You can also go see a social worker, or you can go see a pharmacist. You can get information not only about basic disease, but also approaches to disease.

Many of our patients, because they are chronically ill, and because some of the things we are talking about have very profound, direct health implications. You're telling a patient that you have a very serious disease, that the natural history is chronic inexorable decline, so it's not really a question of if, but when your kidneys will can fail.

Sometimes that can be all consuming and the patient may forget a lot of the other details that you're trying to transmit to them. They may remember you telling them "here's certain foods you cannot eat or activities you should avoid or engage in," but they may forget those details. This provides a resource to go back and fill in gaps not covered by the clinic visit. Do additional research if they have interests that weren't discuss. And perhaps, more importantly, to go back and reinforce – "I know I was told not to eat certain foods or there were certain issues with medications and treatments that I'm dealing with, but I can't remember what they said."

The entire website is targeted to a fifth-grade reading level. It's very accessible and provides patients with a 100,000 foot view of information that's very important to their care. For those patients who are interested and want to learn more about their condition, there are also links to other resources so they can get more granular information.

This was a very important resource, that's been used a number of different ways in the clinics, some of which we never really anticipated. For example, I've heard anecdotal accounts from both nurses and dietitians, out in the field, who use this as a teaching resource. When talking with patients, they will use it to pull up a table or a specific section to say “Here, this is to remind you, you should be eating more of these type of foods and less of those. These are the kinds of things you need to anticipate if you elect hemodialysis or transplantation” and walk them through all of the social, clinical and nutritional needs that they have with their disease.

With this resource, which is accessible through any computer anywhere, we realize that not all of our patients can access a computer freely at any time. But mobile devices are becoming more pervasive in all populations, in the general population, and also with Veterans. So, there was an interest in trying to port these resources into a mobile format that would provide access. The ability to put it on a mobile platform means that, if a patient is sitting in the waiting room, they in theory could access the same information that they might not be able get unless they were sitting at home at a designated commuter, they can get all the same information they could get elsewhere.

The idea was, we would try and plant this inside an environment that is a common app environment for all mobile platforms called the VA Launch Pad for Veterans. I have the Launch Pad circled in red. If they would be able to access this and in a secure manner, go into the database, and research a question. I have a mock-up of exactly what that would look like. You see on the left-hand side, a list of resources that someone looking at their computer would be able to see.

On the corresponding screen, I have here what it would look like on a mobile device, so there's one-to-one concordance between the information. What I want to point out, we realized early on when we were trying to develop this, there's room for a lot of additional untapped utility with having a mobile device. For example, on this slide I have listed out the standard management issues we have with patients. They have to keep very good blood sugar control and good blood pressure control because that's optimal to their management. So there's more than just educating the patients about the needs of these kinds of interventions.

Sometimes there's a need to monitor the patient's performance at home. So one of the things that we decided we would incorporate into the Mobile Kidney app, is the capacity for patients to use it as an electronic journal. It's common practice for nephrologists to journal important information because blood pressure control is central to the rate of chronic kidney disease. Patients can enter pulse, blood pressure, blood sugar, if that's applicable and they would be able to use it to keep an electronic journal, which is something we repeatedly do in the clinic.

Patients come in with scrap paper, product boxes, you name it, we've seen it, then there's trying to decipher their handwriting and trying to sort what is important and enter it in the record. We decided to allow the patient to enter that information in the mobile device and the mobile device would then provide a vehicle for not only storing this information but organizing it, both in a tabular fashion and a graphical fashion. It also provides a mechanism for them to

use the journaling functions for explanatory notes and record information that the numeric data gathering capacities don't routinely assess.

We were building flexibility into this to allow the provider and the patient to come to an agreement about the kinds of information they would store there. For example, if you were a patient and I want to give you very specialized instructions, I might instruct you to write in the journal, to make a note to yourself that we want you to do this X number of times a week. The patient has a written record in their phone, it's both durable and accessible and allows them a very high fidelity reminder of the kinds of things we want them to do.

I'm being generic on purpose because we didn't want this to be so constrained that the device determined what the provider and patient could do. We wanted this to be a truly flexible vehicle that would record and organize the kind of information that we're really already routinely gathering out in communities. So, now we have a device that has all of this educational information, but now it is a data gathering tool as well.

It is not intended for the patient to communicate back and forth in real-time, but it is a vehicle where the patient can record information that can be helpful to the provider to interpret what the clinical course may have been between the different visits. What I have shown here is a mock-up of what one would see on a computer that would reside, not only on the patient side, but the provider facing interface would have the same information.

What I'm trying to convey is, this information would be automatically organized and shipped behind the VA firewall, and that makes it a bidirectional device. Not synchronous, there's no expectation that a provider would be looking at this in real-time but the patient would be gathering information that would be helpful to the provider at the next regularly scheduled appointment.

Obviously if there's communication between provider and patient, the provider could go back and access this information remotely and use that. The basic intent was to make this a very simple journaling function. What you see here, is the entryway, it is the last recorded blood pressure, weight and blood sugar are depicted here. If there were notifications they would be routinely sent out in a broadcast fashion, then a patient would be able to access that information here.

I saw someone asked about integration with My HealtheVet. It is not integrated. This is not intended to be synchronous, but it would sit on the same platform with My HealtheVet, with the caveat, there's different security characteristics between a lot of the apps that are being developed of which the Mobile Kidney app is one, and the My HealtheVet app. These things have had a great deal of discussion, but in principle, if you are inside the Launch Pad, you can use two apps that effectively could behave similarly. That's a really good question about the integration and it's something that I envision for later.

This is what it would look like on the front end. if you were to take a deeper dive and look at a specific set of criteria, like blood pressure. I put an insert here in the lower right-hand corner of what the tabulated data would be. This is all just made-up data for a fictitious patient and it is graphically depicted here. Systolic and diastolic blood pressures. What's important, is even if the absolute numbers are out of the normal range, or not interpretable, by conventional means on a normal patient. For many of our patients who live in a set of hemodynamic characteristics that lie outside the normal range, a patient can still understand, by trending, whether or not numbers are going up, getting better or staying the same. So, this is the graphical portion, I think it is a really attractive feature, because it's a graphical, visual interface that can be used by the patient not only to interpret information but for us to teach the patient about exactly what it is we want.

The advantage for the tabular data, is that this can actually be looked at, and edited if necessary. It can be selected and then incorporated directly into the electronic medical record. So there are multiple different fashions.

All of this information that would normally be collected by the patient is already pre-organized for everybody to look. For the patient in real-time at home and for the clinician when they come back into the clinic.

Similarly, this is a weight graph and you can see, if I was monitoring a response to a diuretic, you are getting rid of extra fluids because say hypertension or congestive heart failure and cirrhosis are all characterized by fluid retention. Then weight becomes a good proxy by looking at total body water. This is very important because you can deal with it not only in absolute terms by defining targets but you can look at trends over time. If a patient has variations, there's a journaling capacity where they can annotate measurements such as "My blood pressure went up at this point, because I had 50th anniversary and I wasn't compliant on my diet. I had alcohol, some salty foods. Man it was fun. I lost control of my blood pressure but now I'm back on the wagon and now I'm doing OK."

The patient can record granular information that can be helpful when looking at what the expected clinical outcome might be. Same thing here, this is for blood sugars and one of the features is that you can pick out different blood sugar measures.

Basically, anything the patient can measure at home they should be able to enter into the app. The only requirement, there's no pre-selection, no culling of information. If they can read it off the dial, off the scales, off the blood glucose monitor, then they can record it in here. If the information is invalid, we wanted the clinician to be able to make that call. To say, "well, you're using the wrong size cuff. All of these blood pressures look horribly high and you're measuring those high." We didn't want the app doing any selections or modulation of the data.

That brings me to the last point of the features, in the journal, there's the ability to annotate individual numbers within the graphing functions. You can also use the journal independently so the patient would be able to make an entry saying "I was out of the country." "I didn't have

access to my medicine." "My blood sugar was out of control." Or, if the patient had a question come up such as "I had a weird rash come up after I started medication." "It went away after I stopped the medication." "I went to a lower dose. It went away by itself."

The patient can store the information but may not have that granular recall when they come in. It provides another mechanism for patients to document information. I've nested in the right-hand corner what the envisioned interface would look like on the mobile device. You can see all of these are concordant with the special constraints that are afforded by the mobile devices, and I've already discussed those issues.

In summary this is our first iteration of the VA Mobile Kidney app which was born from the notion that we developed all of these educational resources and wanted to port it out to a mobile platform so patients would have more continuous access to them and pointers to more granular information. But we also expanded it, so it now provides an electronic journaling capacity, that allows patients to participate in the documentation and effectiveness of their care. Our hope is this will create additional incentive for engagement and participation. So, we have all of these features that are integrated.

I'll re-emphasize again the importance of flexibility. We didn't want this to be constrained. We wanted this to be something that would be very flexible to allow the clinicians to be able to use this in a very broad manner. Although many of us, as nephrologists, use the same tools, we sometimes use them very differently. We didn't want this to be a one trick pony. We wanted it to be a pallet that the clinical artist can use to do what they need to do.

The features like flagging or editing, we intentionally avoided. It's imperative, when the app is distributed, that the patients understand this is not a surrogate for, seeking attention with the normal guidance. If someone has high blood pressure or number that is out of range, they should not expect that just by entering it into the computer or entering it into their phone, that it would automatically be seen by somebody and would trigger a series of actions. That's not what this will do.

We envision a lot of capacities could change from the asynchronous journaling capacity we have now, to a more synchronous mode later. This is not a surrogate to the other real-time functions that would include intermediate functions like My HealtheVet and the fact that this will be shared with mobile apps for other features, I think should enhance the value of this for the Veterans. Hopefully, having multiple mobile apps should make things convenient if they are all housed in the same common platform and the same area.

There are a number of things that we realize that could be incorporated into this. I think I'm running close on time so I'll close here in just a minute. I just want to say, everything from customized data fields and for patients that have the ability to measure clinical variables with automated devices that have the ability to do direct data entry, you can imagine that would be better. You don't have to depend on the patient to enter information. For example, if a blood

pressure cuff, every time you took blood pressure, would enter the reading, that could be quite helpful.

Therapeutic reminders and flagging were not included in the first version because buzzer, whizzers, lights and bells create a lot of fatigue for Veterans. We wanted to see what the simple journaling functions would do first. Because, if your blood pressure, at best, sits higher than what the normal range would be, if the app were constantly dinging saying your blood pressure is abnormal, we have many patients that don't ever achieve fully normal blood pressures, and it may be the normal resting baseline for that patient, so if the patient has to deal with alerts that are inflexionably inserted into there based on demographic data, we were afraid that would create fatigue.

I think these are things that have to be entered into in a later function. I briefly mentioned broadcast capacities and I have listed emergency response activation. I see where this can be a really beautiful boon to emergency management in a future version. Imagine if you were able to send a message to all dialysis patients in the field "Hurricane Karina is about to hit New Orleans. Dialysis units will be closed but here's a number and address where the dialysis resources are available in Baton Rouge," then you have an emergency note that's gone out to all of your population that provides information that might help them and provide them with contact numbers and details.

So I think the capacity for this is really quite endless. Going back to the question about the business for integration with mobile apps, I think that's just a natural consequence. Obviously, the first version won't hold this. I could see that medicine reconciliation, particularly for patients that get medicines at outside facilities, would also be important to integrate into a future version.

The last thing, for those parts of the country where there is a substantial fraction of patients that may use English as a second language, haveing other foreign language capacities, particularly Spanish and French would be helpful as well.
With that, what I'll do, I will close. Again, this is not something I have particular ownership of. I am the business owner, but Susan Crawly, who is in charge of the National Kidney and Dialysis Program has been very generous in supporting these efforts. My co-partner in in crime, Devasmita Choudhury, in Salem Virginia has been very helpful. And obviously, the Office of Connected Care owns this. I don't acknowledge the contracting individuals because there are too many that have been involved. I did want to single out the out the Medical Education Institute in Wisconsin because they were very important in helping us develop the educational materials that are built into the original Virtual Kidney Clinic and were then ported into the mobile device. So, with that, I will stop and I will take questions.

DENISE KENNEDY: Excellent. We do have a few questions. It's a two-parter for you. If you could talk a little about what stage of development this app is in. Has it been nationally released and what is the expected timing on when this will be available?

BROOKS ROBEY: That's a good question. The plan is currently that it should be released sometime this year. We actually started field testing last year, and then through a series of events it went off the radar. It's been resuscitated and we've gone back through internal testing and we are doing final internal testing now. We expect to do field testing as early as April. Sthe release times a bit fluid.

We were initially hoping it would be out in January, before the Kidney Innovation Summit. That didn't come to pass. April was our next target, but I think that might be a bit of wishful thinking. I'm hopeful maybe by the summer it will be out for release. It's ready to go, it's just a matter of making sure it passes muster on the VA Data Protection Standards and it does everything that it's supposed to do. I don't have any indications that that's not the case. It will still be a couple of months before it's finalized so we are in the final stages.

DENISE KENNEDY: Excellent. I know there was an earlier question. I know you addressed one question about secure messaging. We'll come back to that in a second. There's a question about whether any of the resources integrated with the Veterans health library and vice versa from VHL is integrated into this tool at all.

BROOKS ROBEY: We took a broad cross section of resources, both VA and non-VA and inserted them into the app. So, everywhere we found resources that were germane to chronic kidney disease, we tried to provide resources and links to. The answer is, there is integration with VA resources. Some of those may be indirect rather than direct. There may be pointers to VA sites that might have more exhaustive references, and similarly to some of the outside sites like the American Association Of Kidney Patients.

For some of the more mundane items, such as if the patient says “I can't eat this renal diet. It's so bland. You won't let me have any of the following items,” there are resources from other patients affected with similar conditions where recipes are stored online. So it is a very broadly cast net.

We didn't make this specifically geared towards anything that wasn't already incorporated into the Virtual Kidney Clinic. There are a number of resources that we did not include in this. When we go to version 2.0, we're hoping we'll get feedback from other people on resources that we missed. I encourage all of you to visit the Virtual Kidney Clinic and look at it. If you see resources that aren't there, we will add them to our wish list. As much time and effort as we put into this, there are going to be some oversights. The intent was import the finished product on to the platform, we didn’t expand it. We included everything we had at the time of launch in 2013.

DENISE KENNEDY: Excellent. Is this app for Android and iPhone both?

BROOKS ROBEY: It will be, it should work on both. This is supposed to be as universal as possible. I think the idea was we wanted any Veteran with a mobile device to be able to use it.

DENISE KENNEDY: Excellent. And we have a question here. Is this for use to look at for follow-up visits to have a better outcome for data between patient and provider, or is this tool for monitoring a patient, and if so, are the providers expected to monitor this data between visits and contact the patients?

BROOKS ROBEY: I touched on this briefly but I'm glad you asked that because I think this is a really important point to emphasize. One can see that both of those situations represent two ends of a continuum. We're seeing patients intermittently and we are trying to gather information between visits versus we are continually monitoring between visits. The latter scenario might be something that we might try and go to later and there were several people really pushing for us to do that in the first iteration. The problem with that paradigm is, unless you have the resources and somebody standing by to look at information all of the time, that becomes a bit difficult.

The intent is to use this as a tool to extrapolate and to gain insight into what has happened since the last visit. It is not intended to be a real-time or synchronous communication vehicle.

You come in, I saw you three months ago, and rather than me generically asking what your blood pressure or weight has been, I can get hard data. It supplants even those patients that would be really good about bringing data. By having it electronically entered and organized, the clinician can spend more time analyzing the data rather than entering the data before trying to analyze it.

It's intended to be intermittent. I think all of us would like to go to the continuous model, but risks are not trivial. There are, I think, additional liabilities and expectations on the part of the patient. At this point in time the patient should see this as journaling. You're storing information to be reviewed by your clinician at the next regularly scheduled visit. The clinician will use that information to understand how you have been doing. If you are not doing well in the interim, you should contact your physician in the normal manner and we would review your information earlier. But just by the virtue of being in there, the data will not be reviewed and acted upon based on entries themselves. I hope that answers the question.

DENISE KENNEDY: I want to be true for anyone not following along. There are a few conversation elements, not necessarily questions, around secure messaging. As it's not synchronous communication, it would be a great convenience to include a link in the app. Putting a link to secure messaging would allow users to send a message to their provider to update them in between visits if they have questions. That's just more of a note. I know you briefly touched on secure messaging, do you have anything else to say on that, Dr. Robey?

BROOKS ROBEY: No. Obviously as this approaches maturity and we get some experience, that would be an aspirational goal. In practical terms, the patient that has the app on their phone will also have access to the My HealtheVet platform. Since it will sit on the same Launch Pad, in theory, once you've lodged into the Launch Pad you don't have to log out and log back in to access a different app. Although this is a promissory note, my understanding is the patient will

be able to log in once and be able to use all of the apps. So you might not be able to send me a message in Mobile Kidney, but all you would have to do is go back to the Launch Pad and send me a message in My HealtheVet, which does come through and has a time stamp ingrained in it. It's an imperfect work-around, but we think it's sufficient for something that need to come through, but is not an emergency, but might have enough urgency that you would want to contact somebody between then and the next visit.

DENISE KENNEDY: Excellent. Thank you for that. It looks like we don't have any more questions right now. I wanted to, Dr. Robey, see if you have any final parting thoughts before you get back to, what we hope is, your final snowstorm.

BROOKS ROBEY: No. I appreciate the opportunity to try and sell this. We are obviously very excited about this, I think the potential is great. It is obviously a work in progress. The present product has been designed and headed towards launch for some time now. We have a lot of really good ideas that we would like to incorporate into the next version, but I think it would be premature to try and reformulate the app until we get experimental data back.

That said, we are always looking for good ideas or additional partners. I'll give you an example, at the VA Kidney Innovation Summit, Dori Schatell of the Medical Education Institute came up to me. And we were talking about a new tool they have where a patient can enter lifestyle questions into a survey and it would give feedback about which type of renal replacement therapy is best suited for them. It immediately occurred to me and to Dori, that would be the ideal kind of thing to work into a future version of the app.

I think the sky's the limit. We have modest goals this first time because this was going to be porting an educational resource to a different platform. Then we started to get ambitious, and it became readily apparent that the level of ambitiousness can be endless. I have a long wish list, and this is the start of it, version 2.0 plus that I listed. I have a growing list that could be 2.1 and beyond and I would love to have additional ideas from people in the audience, feedback good and bad additional ideas. If other people are in the process of developing, or know other people who are developing where the Venn diagrams overlap, maybe we can partner and take two imperfect vehicles and either merge them together or interdigitate with one another, to make a better product. We're all about improving it.

DENISE KENNEDY: Excellent. Well, thank you so much. Thanks for giving us the download on Mobile Kidney. We're getting a lot of positive feedback here on the chat. So thank you so much. Dr. Robey, we appreciate it. I want to thank everyone in attendance for your participation. On the screen, there is a link to tell us how we are doing and if there are any other topics you want us to cover. With that, we will give you a couple minutes back to your Friday. I hope everyone has a great, safe, and fun-fill weekend.