Appendix 1: Focus Group Questions (Patients & Caregivers):

1. What is it like for you when you go to the CKD clinic?
   Probes: *What stands out the most?*
   What do you like the best?
   What do you like the least?
   What would you like to see done differently?

2. Tell me about the care you have received at the CKD clinic
   Probes: *What is helpful?*
   What is not helpful?
   What would you change?

Introduce the kidney failure risk-based care model

3. How would you feel if you were considered “low-risk”; “intermediate-risk”?
   Probes: *What would be some of the perceived challenges?*
   What would be some of the perceived benefits?
   What would be helpful for you during this care transition?

4. How would you feel if you were considered “high-risk”?
   Probes: *What would be some of the perceived challenges?*
   What would be some of the perceived benefits?

5. Any other suggestions or comments:

Appendix 2: Interview Questions (Healthcare Providers):

1. How long have you worked in this profession?

2. What is your role at the clinic?

3. How long have you been in your current position?

4. How do you feel about the level of care delivered at the clinic?
   Probes: *What issues are most important?*
   What works well?
   What doesn’t work well?
   What would you like to see done differently?

5. Tell me about the care patients receive at the CKD clinic
   Probes: *What is helpful?*
   What is not helpful?
   What would you change?

Introduce the kidney failure risk-based care model

6. What do you think of the proposed risk-based model of care for patients?

Probes: *What are some of the perceived challenges?*
What are some of the perceived benefits?
What barriers/facilitators do you foresee for patients transitioning out of the CKD clinic?
What would do you think would most help patients through the transition?
How do you feel this model may impact your workload?
How do you feel this model may impact patient care?

7. Any other suggestions or comments:

Appendix 3: Open-ended Survey Questions (Healthcare Providers)

1. What do you think will be the greatest potential benefits in implementation of the kidney failure risk prediction tool to stratify only high risk patients to receive multidisciplinary care?

2. What do you think will be the greatest potential risks in implementation of the kidney failure risk prediction tool to stratify only high risk patients to receive multidisciplinary care?

3. Do you have any additional comments?

Appendix 4: Exemplary Quotes (supplementary)

Theme(s)		Patients & Family Members	Healthcare Providers
CHRONIC KIDNEY DISEASE (CKD) MANAGEMENT			
Challenges	Lack of CKD education & capacity outside of the CKD clinic	The family doctor was the one who prescribed the medication [metformin] for diabetes…I was left on those medications and the pharmacist caught it, that I shouldn't be taking it because my kidneys at that time had failed. Personally I want to go to the clinic. If I have a kidney problem, I want to be in a clinic where there are people who are competent to deal with all aspects of the problem. Heaven forbid if I was to turn around and crash, and I had to go to the hospital in <rural town>, what would happen is the ambulance would pick me up, bring me to the hospital, the hospital is supposed to stabilize you, that is what they are supposed to try to do. But because they have no knowledge of kidney failure in any way shape or form, and I mean that sincerely, then they are going to try to stabilize me and that is going to be a problem, because if they try to stabilize me and they can't stabilize me, now they have to transport me from there into here. Now the time lapse that is there, to be straight forward I will be dead before I make it. The only problem that I find is that if you are with the family doctor who doesn't really want to put in the effort with you or who is overburdened with a lot of patients then you don't have the time with them that they need to figure out if you have to go to the next level.	The CKD clinic should not do everything…[the clinic] should build capacity for other providers to provide better care for patients with CKD. I guess the challenges will be, ultimately, the burden on the primary care system right now. Family doctors are busy, they don't have time, let alone to find or follow or reach targets of blood pressure targets, diabetes targets, you know. It is unrealistic…to expect a family doctor to know all of the guidelines and all of the ins and outs of the various diseases that a primary care family physician is expected to attend to. It is just too much information. I do think they are probably going to get maybe not quite as much information as we would give them here…so they wouldn't get their information in a timely dose unless they are doing their own research.
	Lack of patient self-management	99% of us are, we are not advocates. We are not. If you get someone in there who is not an advocate for themselves, and they don't want to say too much they can easily just slip past.	When we started taking a lot of those [multidisciplinary clinic resources], you take away their ownership and they become dependent on the CKD [clinic]. I can't tell you how many times I see a patient not in CKD [clinic], maybe in a hospital or somewhere else, you ask them what medications you are taking or what's going on – [the patient says] oh I don't know just look into the computer. We need to empower patients, they need to know and sometimes by doing everything for them, they become dependent on us…. So we are all here [at the CKD clinic], but then we are all trying to provide care but patient's not really in the driver's seat. They are in the middle by concept but they are not really there, in a way.

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			It's astonishing what people don't know about their medications and I understand you don't have to know exactly what they are for but then bring me your bottle or bring in your blister pack rather than say look it up on the computer. If you don't have that basic health literacy you don't make full use of the clinic, or don't understand even your health situation to a degree.
	Distrust of KFRE	I am no great fan of medical prediction accuracy to put it mildly. I think only too often it is educated guess work at best. Are they going to be able to identify the people properly? That is, what you are saying is good, what you are saying is good, but are they indeed going to be able to identify us.	One of the limitations is that trying to predict for any given individual based upon their GFR what their true healthcare needs are in the present and also in the future and boiling it down to a four variable model is a little oversimplification. It creates the illusion of objectivity, but you cannot take something as complex and expect it to be right all the time. Placing too much trust in the tool that tries to predict something that is inherently difficult to predict.
	Insufficient disease monitoring; insufficient access to preventive education	If somebody is in stage 1 and yeah they could see their family doctor providing the family doctor gets the proper information on what is involved. But if they are in stage 1 and oh well I don't have anything to worry about I am fine everything else, they are going to eat the wrong foods, they are going to do the wrong things, so they have to depend on that doctor or that family doctor, if they don't. Who is going to give you the information that you need to determine how you should structure your lifestyle? For my mom it was only days that her kidneys dropped by 10%. So if you are looking at a timeline in order to get the, like the bloodwork done, everything set up for it, then people can so easily slip through the cracks in this. [The] dietitian is very, very important, and if you don't have that dietitian to assist you and tell you on certain types of foods that you should have you are going to lose.	I think the challenge will be making sure that the patients that are moved out of the clinic do not feel like they are being abandoned, and making sure that no matter, whether they are going straight back to the nephrologist or to their family physician that their care providers have sufficient access to the resources they need. Whether it is being able to consult with a renal dietitian in comparison to a regular dietitian that doesn't have that renal knowledge, or making sure that they have access to social work services so that they can afford the medications that they are prescribed and stuff to make it. Prevention and education is missed out on for a huge portion of the CKD population. This may impact percentage of patients who decline faster thereby placing more strain on treatment side over time. May miss opportunities to prevent lower risk people with late stage 3 to earlier stage 4 CKD from becoming higher risk. May also miss detecting acute changes in GFR. Many acute changes are precipitated by a sudden change in renal blood flow for multiple reasons. Not a challenge but a risk: The inability to intervene and prevent complications from comorbidities due to the lack of contact with the "lower risk" patients. Laying eyes and hands on low or moderate risk patients can prevent them from becoming high risk patients and as much as we would like to think these patients are being managed in primary care, they are not.
Benefits	Multidisciplinary approach; proactive education; targeted care	What has made it good for me is that it is the people. I don't care what they do to the clinic, but if they lose that interrelationship with the people, if they lose that human touch, they will destroy everything.	This is targeted care…you provide the resources where they're most required…It allows us to flag patients that we know are at high risk of progressing so we know that we need to intervene

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		I ask, the assistant nurse answers everything, I can call her at any time and she will respond, if she is busy she will give me a call. I feel very comfortable with them because I can ask anything I want. I think all the people are really great, but <nurse clinician> stands out because it's like talking to my sister... I never had a problem relating to them.	I think this is great because I think a lot of patients that are now being seen by the clinic don't need to be seen by the clinic. They gain the confidence and I think it's the confidence factor that they have multiple specialties of interest approaching their unique problem. The [dialysis] modality discussion may not be relevant if they are at low risk. I think there are also people have concerns that it predicts kidney risk and it doesn't predict risk for other bad things happening. Again they are not being kicked out of the clinic, they are being kicked out of having a nurse and dietitian co-manage them, they can still access those resources on a one off.
	Build other healthcare provider capacity	They are [family physicians], to some degree, effective quarterbacks. They are not effective wide receivers or blockers. They cannot do a lot of things. Their training is not going to equip them to do those things. I would have more faith in the world of the family doctor in this context if we changed the system by which family doctors operate. I'm a great fan of family doctor clinics where they may well be, should be, associated personnel other than doctors. If some of the services that we are talking about were available within the framework of the family doctor clinic, I might be a fraction less skeptical, I would still be skeptical but perhaps not to the degree I am now. There can be change. I think there is a difference between the services that are being delivered and the mode by which those services are delivered. I do not want to see a reduction in the services. I agree the mode has to change.	There are some family doctors who…would be very reassured and appreciative of knowing that [their patient's] kidney failure risk is only 2%... That would be very reassuring and give them confidence that it's appropriate for them to keep managing them in primary care. That they don't have any need to see a nephrologist. I think that they're [family doctors] not comfortable treating…level of discomfort with managing anybody with mild CKD I think. That's the really big concern. And I think that the CKD pathway has actually, at least as far as I know, the family doctors I've talked to…it does seem to make a difference in terms of their management and their comfort level because they're saying, "ok, you know what, the recommendation is that they don't need to see nephrology, they can manage them accordingly." And I think it's just a comfort level. The family physician as they are trying to manage this community, I think CKD pathway has helped a lot of family doctors, there's been a lot of uptake with it and so that's helped them quite a bit. They will say that they are busy and it will be complicated, but it depends a lot on how we communicate to them. So I think the family doctor, once there is a clear documentation in the chart of what is going on, I think it is fine. Most patients like to see the specialist or even the N[urse] P[ractitioner] for education around their health/co-morbidities; effective education is often done during these visits, but I think with time, GPs and primary care physicians can be educated.
	Encourage patient self-management		Patients will have a better understanding of their individual risk to progress to end-stage renal disease, and those resistant to engage in education/discussions may be more inclined to do so with this information. Need to have more resources "upstream" to support and educate patients before they decline and need to attend our clinic.

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			They might go from their nephrologist back to their family doctor mostly and see the nephrologist every once or every two years…If you say that I am going to see them in two years it gives them some comfort that there is still a lifeline there. So I think who they contact, and presumably some resources to help them self-manage and remind them about the importance of blood pressure or their ACE inhibitor, whatever we deem the four or five most important things that we want them to focus on, so that it is also seen as a positive thing. They are graduating, they don't need this resource. One thing I notice is that patients do like handouts…so I think it would be nice to have little hand out and say, "Ok, you are considered low-risk, here are some things that you should do." And the big things that they always ask about is, aside of blood pressure and diabetes and cholesterol management, they always ask about what can I eat? …it would be nice if we just had something general to say, "ok, your kidneys aren't really that bad. You are considered low-risk because of these reasons"…Just simple handouts… and a follow-up plan. So you still need your family doctor for your annual physical etc. and if you have any pre-existing conditions you still need to be followed for those things and I think that would be good. It kind of closes the gap for the patient.
SYSTEM LEVEL FACTORS			
Challenges	Communication	There is so much information that it just goes, pop over the top of your head, you can't remember what the doctor said If the family doctor talks to the specialist that is the half the battle right there, if you cannot get that doctor to talk to the family, or as far as that goes the family doctor or the ER, either one of them talk directly. The terminology of what a doctor says, they have got to turn around and put it in plain English to start with. But, they should put it in stages, they shouldn't turn around and bombard you all at one time… when you first get diagnosed all hell lets loose, and you don't know what to think. We are all flabbergasted. On the information overload, yeah it hits you pretty hard. Too much information. The written material is fine, the written material is great, but that is not what we need, we need face to face and time spent with us.	I don't know how big a difference would it make from their [the family physician's] perspective because to them they still get, they still get the letter from the nephrologist on a regular basis and I think it will be ok as long as we make sure that we communicate clearly, either in a form of dictation or a discharge letter from the CKD clinic. I'm not sure if there is always a consistent system in a way of transferring that information to the primary care and any other specialist was involved in the care. …communication between those clinics. I have heard some patients saying that it is hard for them to follow because the nephrologists will say one thing, the family doctor will say another thing and the cardiologist will come in with another medication. So for them it's really hard to follow all those recommendations and make a decision about it and to know where they are at. Well I think we are constantly working to try and keep family practitioners involved in care, because I think a lot of patients get so much help from this clinic they divorce their family practitioners. Yet we are not doing their annual pap smears or if they have a funny cough for two months we are not sending them usually for a chest x-ray. So trying to really say, we are here to partner with your family practitioner.

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			…communication between the [CKD clinic] team members as we still really need to address this. I think we all have the right intention and it works very well many times. But, I think we can improve there.
	Inefficiencies in clinic flow	So, to me the idea would be to maintain the clinic, have every patient in the clinic, but to recognize that within the framework of the clinic itself, we don't all need to see everyone on the same timelines. We don't all need to have the same timelines to go back to the clinic. Well I think what you got to change is a rating system as to who comes in. There has to be a set of rules that says if you are this and this and this and this I will see you every six months. If you are this and this I got to see you every month. There has to be a rating system on, I don't know what, I'm not going to say what, it's not GFR, it is going to be something else.	I find that there certainly is some duplication of work because one person would do this, another person would do that and you know, at the end of it when you look at the notes it sounds like everyone is trying to attain the same thing. In terms of clinic flow, in terms of having all the players [at the CKD clinic] see the people… I think that is still bit of a challenge because there's so many players and you have such a short amount of time to really capture that and I think from a physician point-of-view…I felt there was a lot of barging in you know because other people [staff] were already with the patient and what not. I would say wait times, you know the doctors can get hung up in a room or social worker can get hung up in a room and then that patient is waiting, you know they tend to get a little bit frustrated.
	Lost access to nurse case manager; more appointments; shorter duration	A nurse gives you information that the doctor doesn't give you. The nurse actually turns around and mediates between the doctor and the patient, and if you take that nurse away from there, you are asking for trouble because the patients aren't going to get anything. So what is happening, if you take those [allied health providers], like she says, and we are all saying the same thing, if you take that away, take that equation away from the nephrologist by himself. You take that away you are basically asking for an atom bomb to go off that is what it is. More appointments for the people, because then they have to go and make more appointments to see the nurse, dietitian. There is a good example: Your car wouldn't start. So now you have to get onto a bus, transit, you have to go transit to here and over to here and over to here for these people, or I have to travel from <rural town> into here for three or four different appointments, this way [the current CKD clinic] it is all in one.	For some patients they think it is very convenient to be able to contact the nurse between visits and they really like that and they like being able to have that almost hand holding that the nurse does. Some patients don't like it because it makes the clinic visit so much longer, but a lot of patients like that personal interaction, so they are going to not be happy that they are being kicked out so to speak. The patients who are really complicated, like many of these people have long standing relationships with their nurses and so I can see that being the barrier for them being sent out of the clinic. You know, they might feel abandoned or not supported.
	Change Process	The process of reassessment doesn't appeal to me. I have seen it operate in a number of settings where it's not taken very seriously and doesn't happen as a practical matter. Once you are siphoned off into a particular segment of the system,	I think there has to be good knowledge that, how does that process look. There has to be somewhere in the system, either re-triage to nephrology or the nephrologist as the trigger to send them to CKD. I think the family doctor needs to have that good understanding as to how do I get them back into the system… because I think that will give you better buy in to shunting those patients back to the GP if they feel

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		that's where you end up staying until you have to access another part of it through emergency.	– and we do have tools for that, but I think they have to feel – ok let's take another quick look at this, what's changed, what's not changing. Because I think they need the constant reassurance because they do deal with so many and every program is trying to shunt back to them, their case load goes up. So they need to understand. The biggest challenges will be that having a bigger % of patients with lower GFR will make the caseload heavier. Patients with Stage 4-5 require closer monitoring, I am worried with the same number of patients in our caseload (ideal caseload 140) will be heavier to manage. I mean if we do it right, if we reassure them that just because they are not followed by a nurse clinician doesn't mean they are abandoned by the CKD program altogether, right? We need to make sure they understand that piece and we try to spin it in a positive way – the reason you don't need the nurse clinician is because you are doing well, very unlikely to progress. I think the one thing that will make the doctors nervous and the patients nervous is that some faceless tool is going to make a decision, that then commits the patient to going back to their family doctor, never being seen again. And I think that would never be the case, this would be a recommendation and then the nephrologist would talk to the patient and say, actually you are really stable, you are on all the right medications, your blood pressure looks fantastic, I am going to start seeing you once a year or once every two years, and if you have problems then I will see you back in the interim.

Benefits	Focused resources; sustainability; reduce patient stress	The thing is, like you said, for the ones coming in they are not used to the clinic as soon as you come in, not like us. We've been coming to the clinic so we know what it's all about. But for them, if they can just see the nephrologist and keep that, well that's fine because they don't know what it's like to have benefit of the nurse and the dietitian and all of that. So, for them it might work out fine. So the new system would be to be referred to the nephrologist before things are too serious.	This will allow for more time to be spent on the patients at the highest risk. Better quality in care if staff are able to spend more time in clinic and on telephone assessments instead of seeing more patients but [providing] less care, or rushed care. I think that for these low risk patients who aren't necessarily mulitmorbid, its cutting down on the appointments, letting them live more life outside of clinics and doctor's appointments, certainly would cut way down on lab work for a lot of patients. Job satisfaction, better utilization of their skill set, improved patient flow, and staff [will be] better able to meet the needs of this patient population. Then I think it makes sense, to me when you look at the long term metrics of baby boomers and disease trajectories and the rising incidence it only makes sense that we have to utilize our resources in the best way possible, so and the numbers are always growing. So I think the strengths are if you see there really are low risk patients that the vast majority of who, more than 97% of whom are not going to progress, we don't have enough resources to have all these patients followed by a nephrologist. So I think that is very helpful, and then if you are wrong the family doctor can refer back. I am very comfortable with that end of the spectrum. I think that it would help make the CKD clinic sustainable in the long run. I think it would be better for patients honestly. Because I don't think the patients are going to be so overwhelmed...if you are Joe Blow walking off the street and suddenly by the way you are seeing a nephrologist and you see that nephrologist once, the next thing you know you have an entire team of people who say, "you need to go for bloodwork every three months, you need to give us a list of everything you take, and we want you to call us about this that and the other", I think that can be pretty scary. You know, and when we are calling them to book these appointments you can hear fear. You know, like "what is going on, why I am being referred". The thing that I've noticed is the patients are usually very appreciative, the ones that you can, that go back to the family doctor, they're usually really appreciative…I plug the numbers in front [using the online KFRE calculator]…we plug the numbers in and your risk of dialysis in the next 5 years is like 0.1% …well this actually means that you have over 99% of not needing dialysis and they're usually, we see this sign of relief on their face, and they're really thankful.

Theme(s)		Patients & Family Members	Healthcare Providers
			This helps avoiding duplication or roles and care from other specialties. This also supports proper utilization of resources to appropriate patients.