

Human-centred Design of a Decision Aid for People with Chronic Kidney Disease Facing Coronary Artery Disease Treatment Decisions: Towards Implementation

Julie Babione (1), Pantea Javaheri (1), Denise Kruger (1), Todd Wilson (1), Winnie Pearson (1), Krystina B. Lewis (3), Michelle M. Graham (2), Stephen B. Wilton (1), Matthew T. James (1)
 (1) University of Calgary, (2) University of Alberta, (3) University of Ottawa

Motivation, Background, & Methods

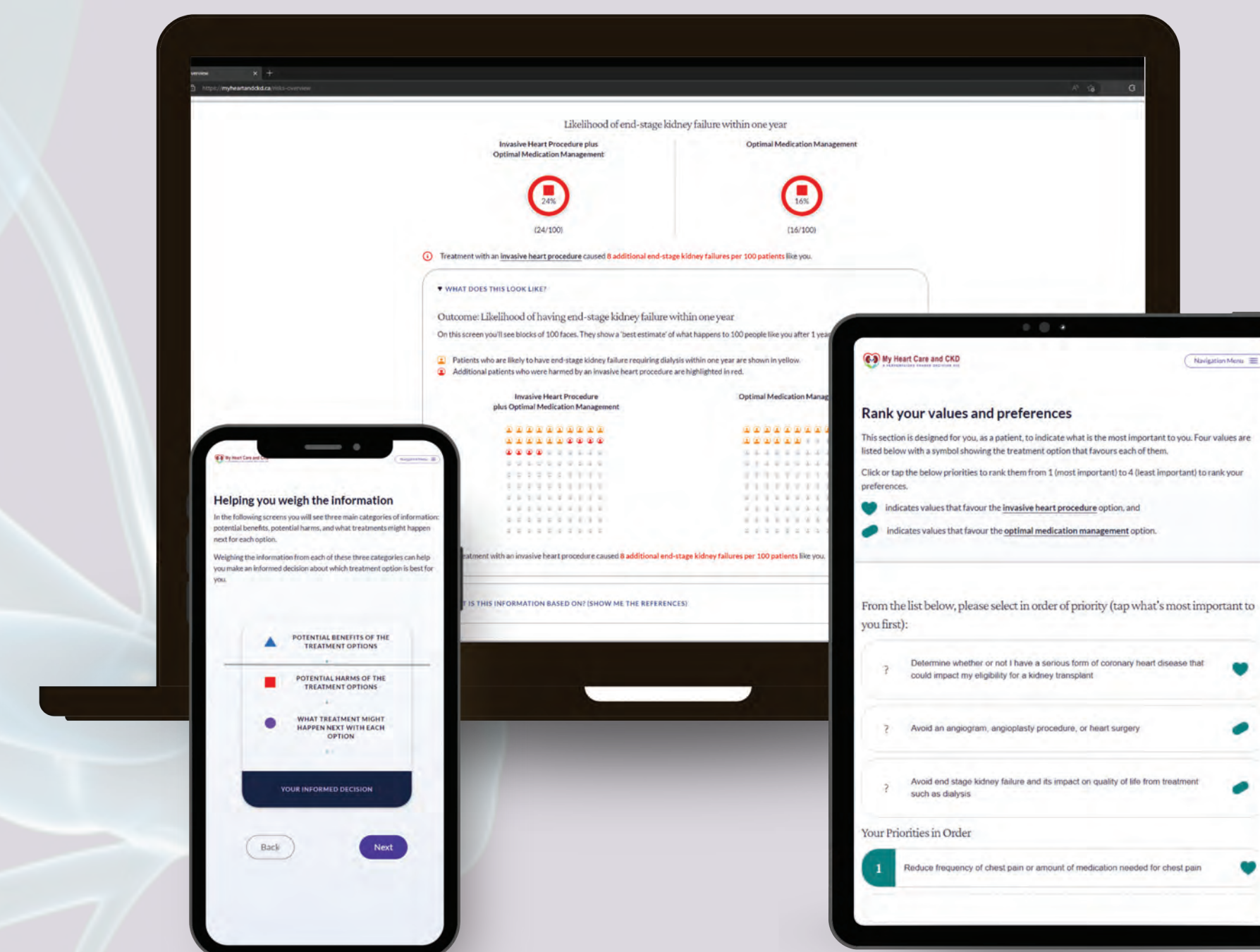
"They gave me the option. It's either your kidneys or your heart. And I said, 'You realize, Doctor, that from the last episode that the dye is what caused the damage to my kidneys.' He said, 'Well, we've got a little bit of an issue here.'"
 - Sam, Patient Partner

Coronary heart disease often accompanies chronic kidney disease (CKD) and can affect the health of people with CKD including their ability to receive a kidney transplant. Even when contrast dye is carefully managed to protect the kidneys, damage can still occur.

Shared decision-making is a collaborative approach where patients and their care providers work together to make personalized decisions based on a shared understanding of the condition, treatment options, risks and benefits, patient values and preferences, and risk tolerance.

We followed an iterative, three-phase, human-centred design (HCD) process, informed by International Patient Decision Aid Standards (IPDAS) and the Ottawa Decision Support Framework, to create a shared decision aid that provided a personalized patient SDM experience. A concurrent mixed-methods study was conducted using questionnaires and semi-structured interviews with end-users to evaluate content, acceptability, and implementation, as well as guide refinements to the design, throughout development. Transcripts were analyzed using thematic analysis.

My Heart and CKD Shared Decision Aid

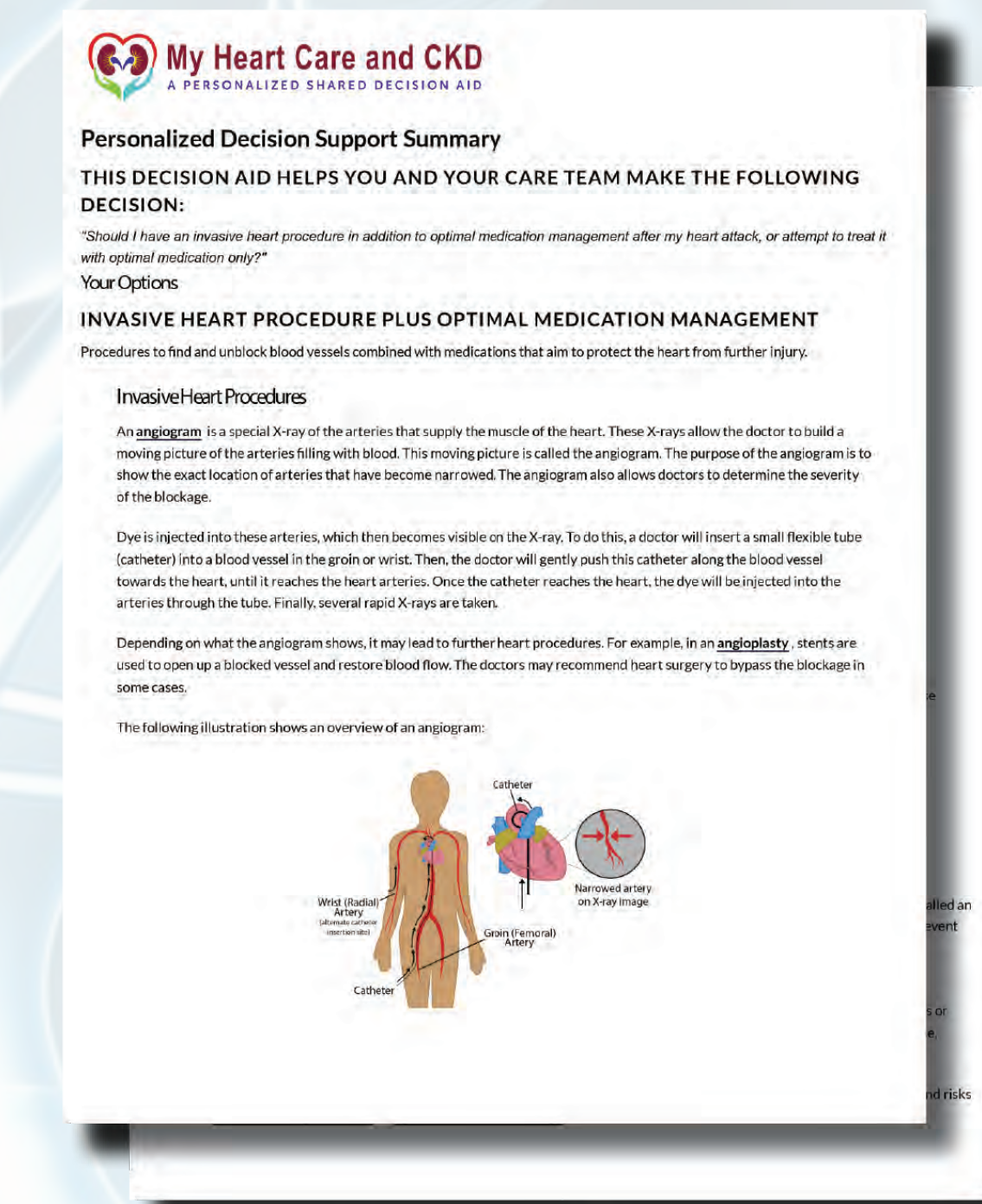


The tool begins with eligibility criteria for doctors, a diagnosis selection screen, and then a patient health factor data entry page to generate personalized risk and benefit profiles. The next screens guide the patient through background information and the decision to be made, the risks and benefits of the two treatment options with layered information presented in different ways. This layering of information as percentages, icon arrays, and references with twirl-down interaction addresses feelings of information overwhelm while providing some interactive control.

The tool then brings the patient and doctor back together for a supported conversation around treatment choice implications, patient values and preferences, and how they relate to the two treatment options. The tool concludes with a check to see if the patient is ready to make a decision or if they need more information, time, or the opportunity to discuss with family.

To accommodate a wider range of workflows and levels of comfort with or access to technology, we also make this complete summary available near the beginning of the tool so that the doctor's office can email the PDF to the patient or print off the document for the patient to take home and consider.

Our hope is that providing these different options will help support more patients in more contexts in making these treatment decisions.



You are Here

We've been working on this project for a few years now, starting with talking to patients and doctors to understand each perspective of the issue, their challenges, and how we might make that experience better for both patients and doctors.

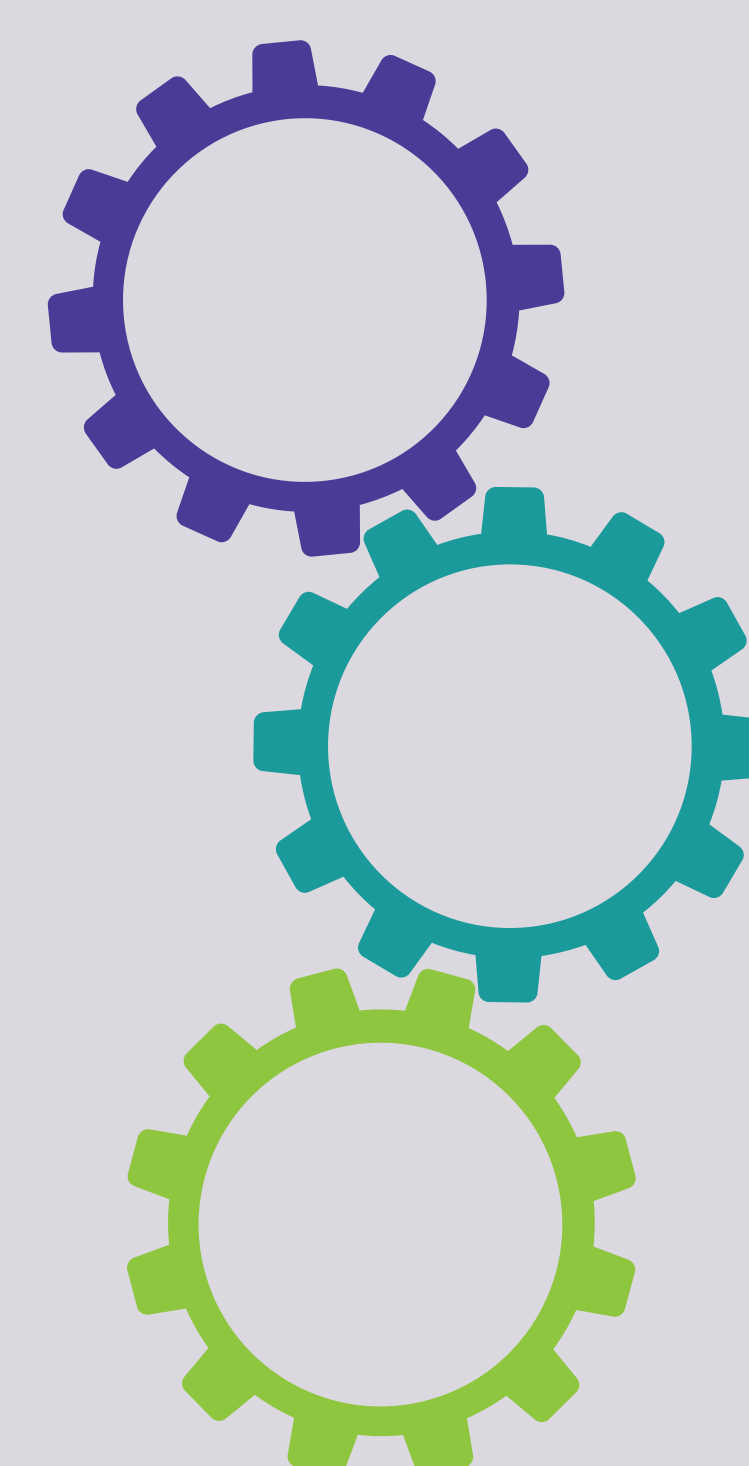
We've gone back and forth with patients, doctors, app/web and experience designers, statisticians, and those who have expertise in shared decision-making to create this personalized tool to help patients (and their doctors) make this decision together.



myheartandckd.ca

Rather than show you screenshots of the tool with random health data, we invite you to try out the tool for yourself on your own mobile phone, tablet, or computer. You can find the tool online at myheartandckd.ca (or scan the QR code to the right with your phone's camera).

Implementation Planning



Human-Centred Design already has many opportunities to gather insight for implementation planning within it's approach, and so our implementation planning really started at the outset of this project.

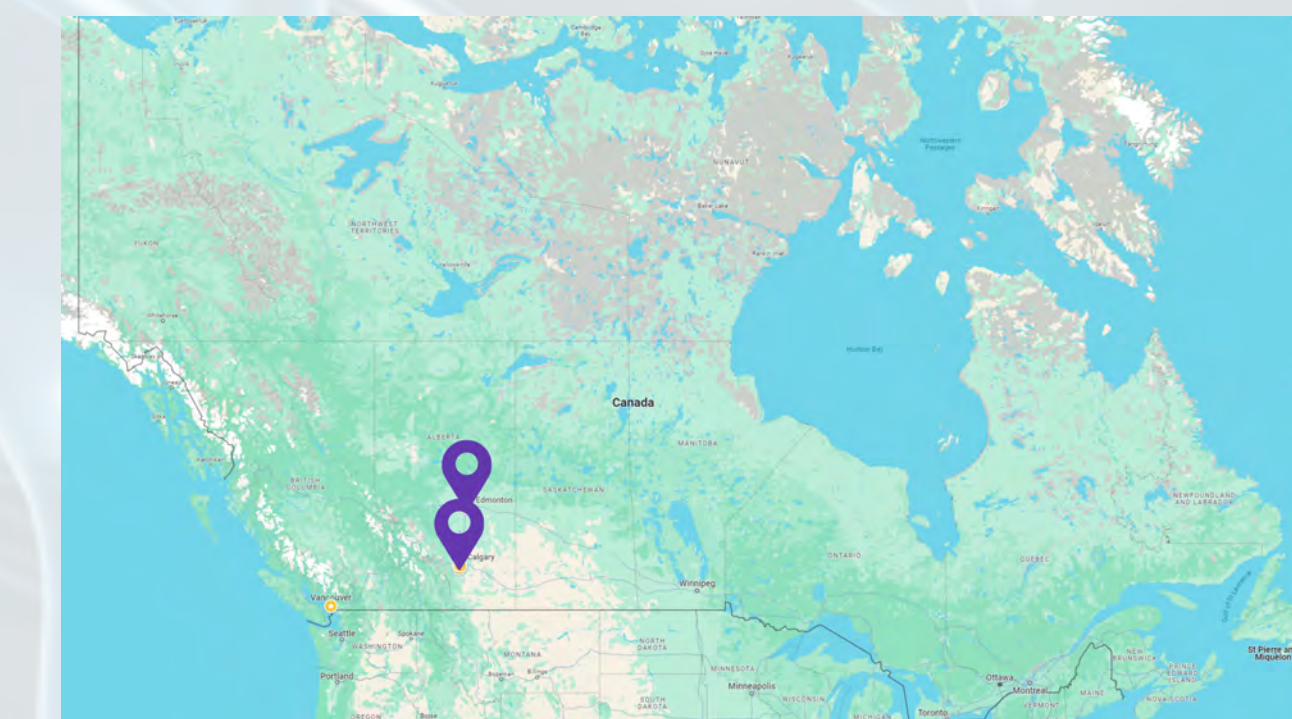
A key element of early planning involved understanding the diverse needs of the environments where we plan to implement the tool, and even including design elements (such as the flexibility to use the tool together or independently, and on screen or on paper).

We are initially implementing our shared decision aid in a subset of clinics in both Edmonton and Calgary where we have project champions.

We are working with those clinics to identify what supports they need to successfully implement the tool. This may come in the form of educational materials, rounds, on-site support during the implementation, or whatever they need.

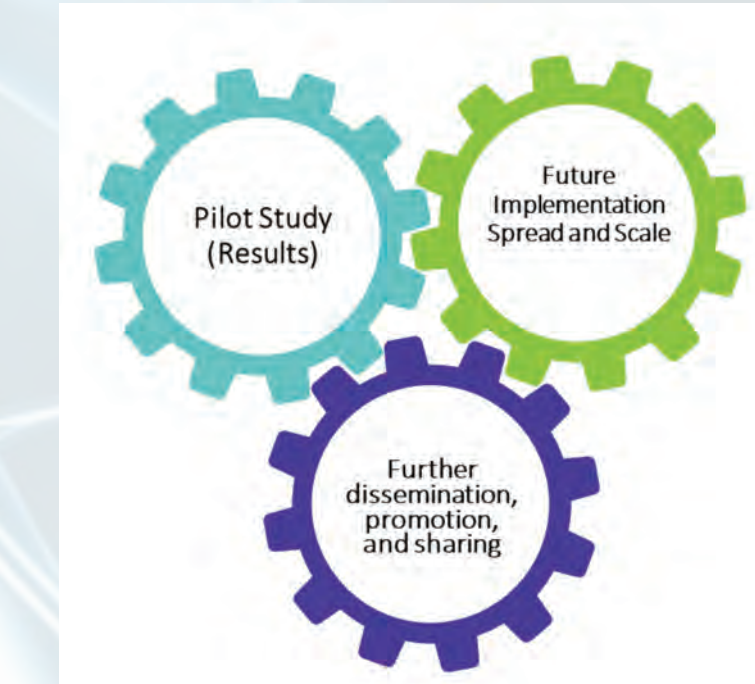
Pilot Study

We are also conducting a stepped wedge design pilot study in these clinics that will look at the tools impact on patient decision making, as well as their experience of shared decision-making and treatment selection both with and without the tool.



We have decided to focus on differences in sex and gender and decision-making experiences in our implementation. This information will be analyzed both qualitatively and quantitatively to explore this aspect of Equity, Diversity, Inclusion, and Accessibility (EDIA).

CanSOLVE CKD Phase 2 pilot study results will inform how we might best implement the tool at other sites in Canada.



My Heart Care and CKD
 A PERSONALIZED SHARED DECISION AID

We thank the patients and health care providers who provided input on the decision aid during the design and development processes. The project was funded by the Can-SOLVE CKD Network.

