Digital Advance Care Planning for dialysis patients

Dr Chetna Malhotra
Associate Professor
Research Director
Lien Centre for Palliative Care
Duke-NUS Medical School
Singapore

What is Advance care planning (ACP)?

ACP is one of the most discussed interventions to promote EOL conversations.

It enables understanding and sharing of values, goals, and preferences regarding current and future medical care.

Goal of ACP is to Educate-Share-Prepare

Objectives for ACP
Educate- Share-Prepare

1) Illness education

- Most patients do not understand enough about their illness and prognosis

2) Elicitation of values and goals to guide current decisions

- This allows them to engage in shared decision making. As goals change, ACP conversations need to be a continuous process

3) Prepare for future end-of-life decisions

‘Preparation’ rather than ‘planning’ is an objective

Public perspective: Uptake of ACP is low

e.g. Singapore: Lack of readiness to engage in ACP among general public.

	Positive attitude (n=262)
Ready to sign official papers putting your wishes in writing about the kind of medical care you would want if you were near the end of life	9.9%
Ready to speak with your Healthcare Professional about the kind of medical care you would want if you were near the end of life	8.8%
Ready to speak with your Nominated Healthcare Spokesperson about the kind of medical care you would want if you were near the end of life	11.1%
Ready to sign official papers naming a person or group of people to be your spokesperson or to make decisions for you	15.3%

Low et al. BMC Palliative Care 2024

Provider perspective: ACP conversations and documentations are time consuming and complex

- Conversations and documentations are time consuming
- Most conversations required multiple sessions, each taking an hour or more
- Procuring multiple signatures time-consuming
- Many ACP conversations are never documented or uploaded on the IT system

ACP is very tedious. I think if it was less tedious more people will come onboard. … And in terms of documentation, if you want to do more in depth documentation it takes also almost an hour. …. So, the whole process is pretty tedious and it puts people off doing ACP. .. FGD10-2

Lack of physician engagement

- Lack of dedicated time for ACP conversations, compounded by length of conversations and documentations
- Not consulting ACP documents when making treatment decisions

In my normal clinic, I won't want to actually bring up ACP, because once you start the conversation, you should continue... and you cannot do it in your ordinary day. You will never be able to wrap up the conversation in a nice way. There is no time. You have so many things to deal with, in your normal clinic, you cannot deal with another factor. It's like you throw another thing in the plate and you don't have the time. It's very difficult. FGD1B-1

Policy perspective: High interest in ACP

- Reduce use of low-value care
- Reduce acute care use at EOL
- Reduce healthcare costs at the EOL
- Support dying at home

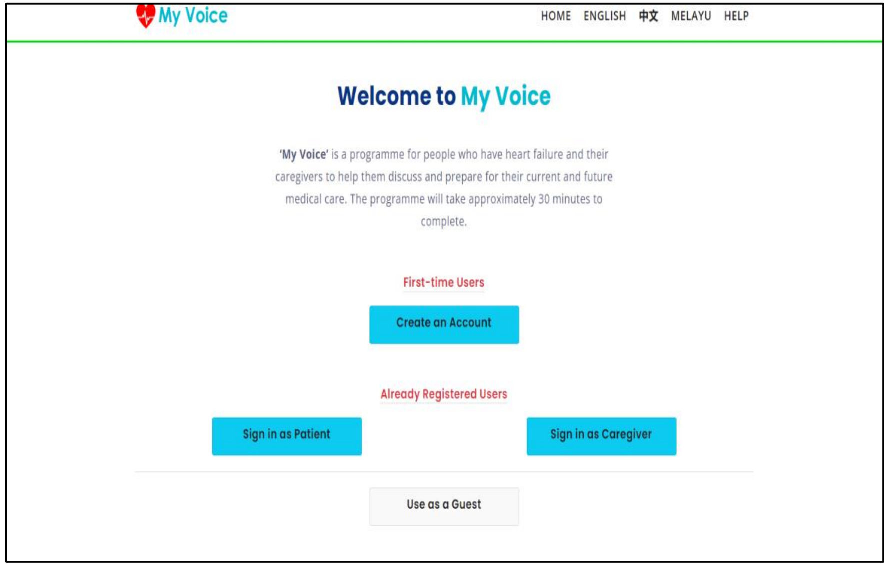
‘My Voice’ – An interactive website for patients and caregivers to do ACP

Shift from

Complex forms and process → Simple interactive website that makes ACP easily accessible and easy to update

Planning → Preparedness for in-the-moment decision making

Goal is to EDUCATE-SHARE-PREPARE



Welcome to My Voice

‘My Voice’ is a programme for people who have heart failure and their caregivers to help them discuss and prepare for their current and future medical care. The programme will take approximately 30 minutes to complete.

First-time Users

Already Registered Users

My Voice-Heart

Click here for your spokesperson to receive an invitation to view your ‘My Voice’ document.

PERSONAL DETAILS

Name: Sanam
Phone Number: 91808493

SPOKESPERSON(S): YES [EDIT]

SPOKESPERSON 1

Name: Cookie
Relationship: Friend
Phone Number: 94568833

SUMMARY	
FOLLOWING THINGS ARE IMPORTANT TO ME: [EDIT]	1. Being independent in my daily life 2. Being able to do things I enjoy (eg: hobbies, traveling, working) 3. Making a legacy (something that is passed on, monetary or non-monetary)
DIALYSIS IS HELPING ME: [EDIT]	1. Fulfill duties towards my family 2. Live longer
WHEN I THINK ABOUT MY HEALTH GETTING WORSE, WHAT WORRIES ME MOST ARE: [EDIT]	1. Having symptoms (e.g., breathlessness, swelling, pain, tiredness etc.) 2. Being unable to spend time with my loved onesfamily and friends 3. Having a sense of uncertainty about the future 4. Receiving more treatment
IF MY HEALTH CONDITION WORSENS, WHAT MATTERS MOST TO ME ARE (IN ORDER OF IMPORTANCE WITH 1 BEING THE MOST IMPORTANT) [EDIT]	1. Being able to think and think make decisions myself 2. Doing my daily tasks activities independently (eg bathing, eating, walking) 3. test
IN THE FUTURE, I MAY CONSIDER STOPPING DIALYSIS IF [EDIT]	1. Unable to think and take own decisions 2. Alone with no one to take care 3. Unable to communicate with others

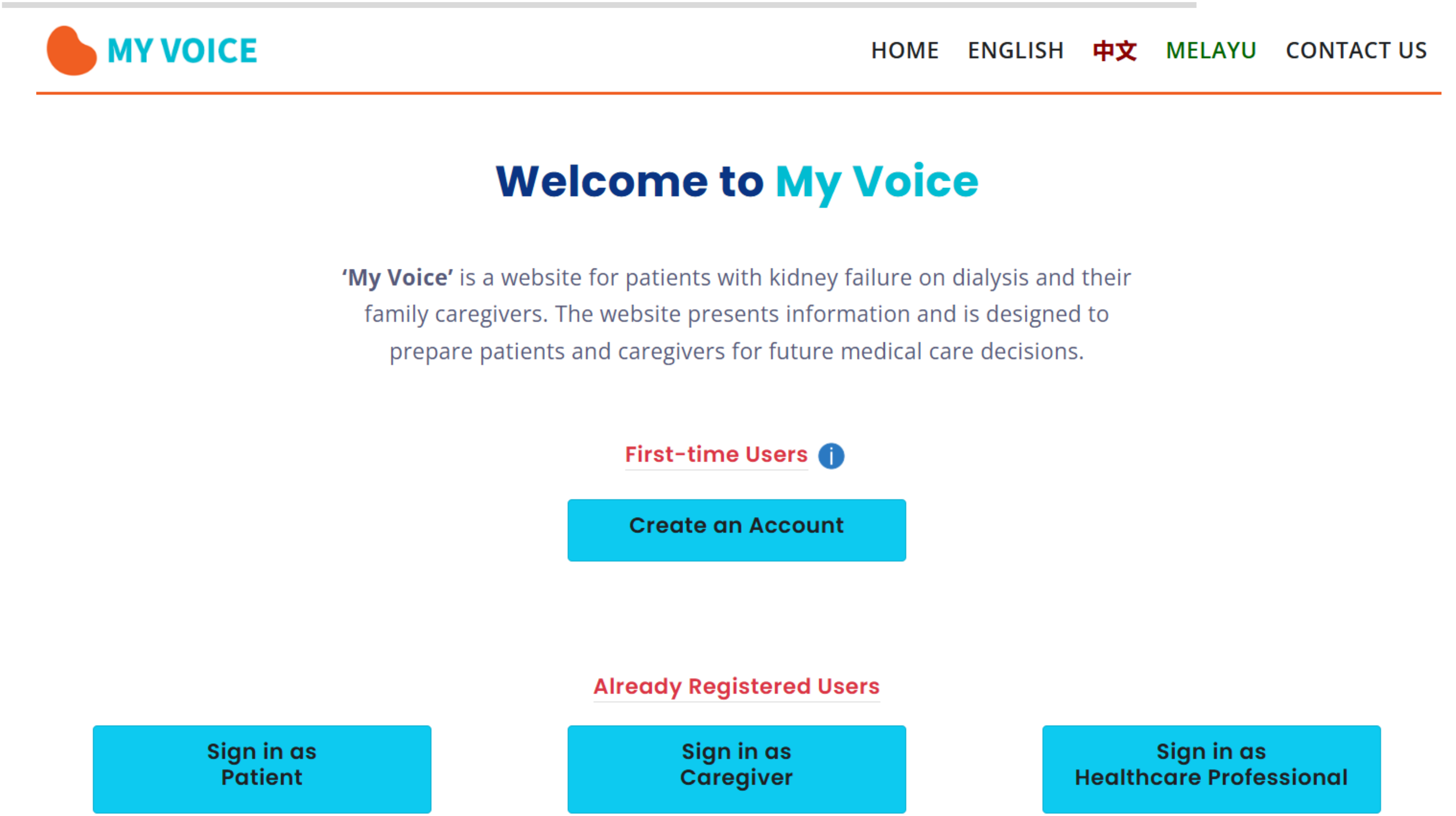
MVPT006-v2 updated at January 31, 2025, 3:52 pm

Disclaimer: This is not a legally binding document

Click here for your spokesperson to receive an invitation to view your ‘My Voice’ document.

My Voice-Renal

‘My Voice’ Renal website



Welcome to My Voice

‘My Voice’ is a website for patients with kidney failure on dialysis and their family caregivers. The website presents information and is designed to prepare patients and caregivers for future medical care decisions.

Development and Evaluation Process

Development Process

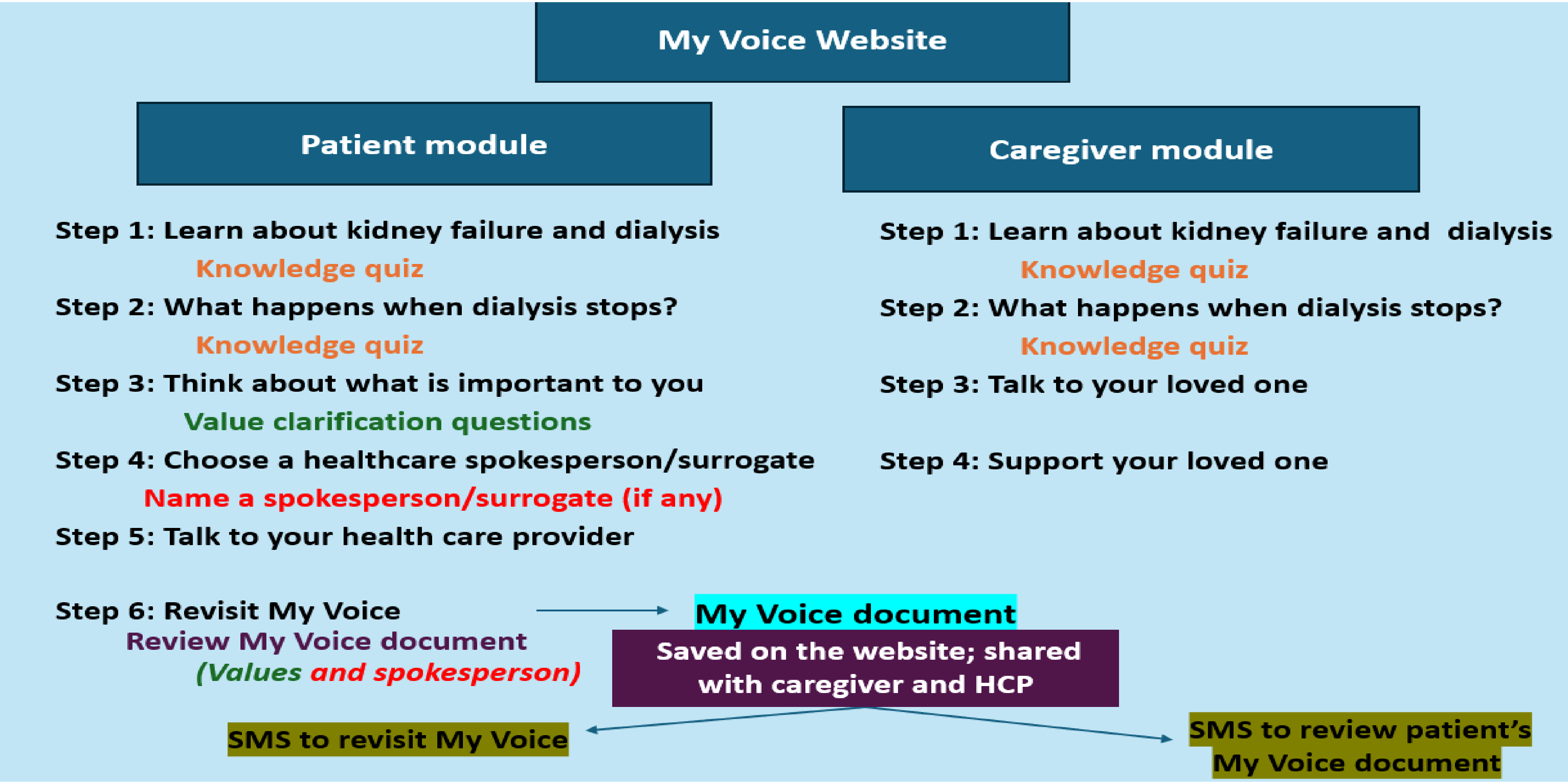
- User centered design principles, COM-B model
- Consists of a series of videos, value-clarification exercise (VCE) and knowledge quizzes
- Initial prototype - Patient and caregiver modules in two languages (English & Mandarin)
- Iterative feedback and suggestions helped refine website

Usability and acceptability testing

- Iterative feedback through qualitative interviews, audio recorded, transcribed and thematically analyzed in N*Vivo* 11
- Surveys collected System usability score (SUS)[1] and acceptability ratings[2]
- 24 participants (9 patients on dialysis, 5 informal caregivers and 10 renal health care providers (nephrologists, nurses, allied health professionals)

Malhotra, C et al. Digital advance care planning for dialysis patients-usability and acceptability. *Kidney International Reports*.2025

My Voice-Renal



My Voice Website

Patient module

Step 1: Learn about kidney failure and dialysis
Knowledge quiz
Step 2: What happens when dialysis stops?
Knowledge quiz
Step 3: Think about what is important to you
Value clarification questions
Step 4: Choose a healthcare spokesperson/surrogate
Name a spokesperson/surrogate (if any)
Step 5: Talk to your health care provider

Step 6: Revisit My Voice
Review My Voice document
(Values and spokesperson)

Caregiver module

Step 1: Learn about kidney failure and dialysis
Knowledge quiz
Step 2: What happens when dialysis stops?
Knowledge quiz
Step 3: Talk to your loved one

Step 4: Support your loved one

My Voice document

Saved on the website; shared with caregiver and HCP

SMS to revisit My Voice

SMS to review patient's My Voice document

Example Video

- https://www.youtube.com/watch?v=JuN78c_CNWA&list=PLqYLXdZ4Z71G35FgBvV4rtpim179WsGul&index=5

Qualitative feedback– Patients/HCPs/caregivers

Theme 1: Supportive information and reassurance

Very useful. It is something that gives extra knowledge. Even if you go to the doctor, the doctor is unable to explain so much but having this thing (website) and videos, at least you can learn something. PT04

I feel like this website is helpful to patients and family, give the caregiver a lot of help, to understand. Otherwise, they will not understand. …It also gives me more knowledge, so I’m happy I can share what I know with others. CG05

Qualitative feedback– Patients/HCPs/caregivers

Theme 2: Patient-centric tool encouraging ongoing reflection and communication of values and goals of care

Not many people may realise it until answering the questions, "What I want?" …After answering these, you start asking yourself, "Is this what I want?" (then) you somehow have a clearer picture. And it [My Voice document] helps someone to basically understand their issue ... If you see the doctor, it is just like one kind of talk not very valid, consolidated information. PT05

Because normally when that thing happens, people sometimes get confused what to do. So once the patient has already informed their close relatives, brother-sister, then easy for them to execute whatever needed when the worst comes. CG02

Theme 3: User-friendly, interactive

I think it's very good because for people like me, I like to see videos like to do quizzes. I think it's more interactive compared to just like sitting down and just talking to a person for half an hour to an hour HCP08

Theme 4: Perceived implementation challenges

All the videos are clear. If possible, can play to the all the community....Maybe put up mosques, churches, Chinese temple or community centre. So, that more people can see (videos) PT08

Quantitative feedback– Patients/HCPs/caregivers

Usability

- Mean System Usability Scale (SUS) score 75 (SD: 7.5, range 45 to 97.5)
- 66.7% participants report SUS scores of 68 and above indicates good overall usability

Acceptability

- 80% participants rated website ‘good/excellent’
- 92% of participants rated the amount of information ‘just right’
- 91% of participants considered useful tool for making future decisons about dialysis
- 96% would recommend to other patients

Summary

- Structured mechanisms to encourage frequent revisits to ‘My Voice’
  - Education
  - Systematic phone reminders to revisit
- Tailored specifically to patients with renal failure
  - Educates them about their illness and prepares them for dialysis withdrawal discussions
- Seamlessly integrates caregivers
  - Caregiver module
  - Coaching both patients and caregivers to speak to each other
  - Caregivers receive patient’s ‘My voice document’
- Inclusion of content in 3 different languages
  - Improves access
- Involved users in development process
- Theory driven
- RCT ongoing with renal failure patients to assess whether My Voice improves quality of Serious Illness Conversations

thank you

Email: Chetna.malhotra@duke-nus.edu.sg