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# **Decision-Aid for Rental Therapy Trial Stakeholder Advisory Board**

#### 1. Geri Lynn Baumblatt, MA

Chief Engagement Officer, Docola

Co-founder, Difference Collaborative & Difference Collaborative Alliance (NFP)

#### 2. Megan Cheung, MSW LICSW RN

Associate Director/Clinical Director

Greater Boston Chinese Golden Age Center

#### 3. Andrew Chin, MD

Interim Chief of Nephrology

Health Sciences Clinical Professor

Fellowship Training Program Director

Division of Nephrology

Department of Internal Medicine

**UC Davis-Health** 

#### 4. Kelli Collins, MSW

Vice President, Patient Engagement

**National Kidney Foundation** 

#### 5. Renee Dupee, JD

Director, Community Coalitions Quality Improvement Program

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## 6. Catherine Alicia Georges, EdD RN FAAN

Professor and Chairperson, Department of Nursing

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President, National Black Nurses Foundation

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#### 7. Rebecca Hutchinson, MD

**Internal Medicine** 

Hospice and Palliative Medicine

Maine Medical Center

#### 8. Richard Moskow

**Patient Voice** 

#### 9. Beatrice M. Oakley, BA

Care Partner Voice

#### 10. Scott Prushik, MD

Vascular Surgeon

Saint Elizabeth's Medical Center

#### 11. Shennon Wofford, MSW

**CKD Care Coordination Manager** 

Dialysis Clinic, Inc.

#### Selected patient questions

- 1. What have you been doing in terms of your kidney care?
- 2. What has your decision-making process been like? Could you describe your thoughts in coming to a decision?
  - a. Can you tell us about your discussions with your doctor? (feelings, prognosis, enough information, timing)
  - b. Did you consider conservative management? Why or why not?
  - c. What did you wish you knew more about? Do you feel like you were given enough information?
  - d. How did [DART or in-person education] help you make your decision or engage in discussions with your clinicians?
  - e. How does this treatment decision support your values?
  - f. Who do you feel made the final decision?
- 3. How have your goals changed or evolved during this time?
  - a. Lifestyle goals- what is most important
  - b. Treatment goals- key factors
- 4. Do you feel like your decision might change? What about your goals?

## **COVID-19 related questions**

COVID-19 has affected many people, changing what we can do in our daily lives and how we interact with our health care team. This may include telehealth visits and differences in the type of treatment available.

- 5. Tell us more about how you have been communicating with your clinical care team during the COVID-19 outbreak.
  - b. How difficulty or easy was it to get in touch with your care team?
    - a. IF TELEHEALTH:
      - i. How well have you been able to understand and engage with your clinicians during your telehealth visits?
      - ii. How have you been able to "keep up" with information over telehealth?
      - iii. What makes that difficult?
      - iv. Were you comfortable using the phone or video calls as a way to communicate with your doctor?
- 6. Did COVID-19 change your decision-making process?
  - a. If it did, how? Can you tell me more about that?

- b. If you changed your treatment decisions, would you consider going back to your previous form of treatment or stay with your new treatment option after the pandemic comes to an end?
- 7. Did your nephrology team talk to you about the risks and benefits of in-center treatment during the COVID-19 pandemic?
  - a. What did they say?
  - b. How did you feel?
  - c. Did you have any questions that they couldn't answer?
- 8. Sometimes COVID-19 has triggered discussion of multiple health decisions, including advance care planning. Have you discussed advanced care planning with your doctor? (Define: documenting your wishes should there come a time when you can't speak for yourself.)
  - a. Have you completed any documentation for ACP?
  - b. How did that conversation go?

We have reached the end of our interview. Is there anything else you would like to share with us that we haven't asked you about?

#### Selected clinician questions:

- 1. Tell me more about how COVID-19 has affected your practice.
  - a. Timing of pandemic
  - b. Type of visits (telehealth, in-person, hybrid, if a mix- who gets what?)
  - c. Changes to staffing and education options (PA, options classes, dieticians, social work, etc.)
  - d. Changes to patients on in-center HD
- 2. How has COVID-19 changed the way you are approaching discussion of treatment options as a result of COVID-19?
  - a. Changes to education (if not answered above)
  - b. Changes in treatment recommendations (changes in the default)
    - i. Changes in treatment recommendations for specific patient groups- what characteristics/which groups are most likely to experience these changes?
  - c. Changes in discussion of prognosis
  - d. Changes in discussion of Conservative Management
- 3. For patients who are 70 years and older, nearing a point where they may need to decide about dialysis
  - a. What is most important for patients to know?
  - b. What is hardest for you to talk about? What makes it so difficult? What might help make it easier?
  - c. Do you use resources, such as written materials, DART, clinician approach, other providers, internet, support groups?
- 4. The high incidence of mortality among dialysis patients during COVID-19 presents a serious challenge. Has the current situation contributed to conversations about advanced care planning with your patients? In what way?
  - a. Documentation?
  - b. Caregivers?
  - c. Ease of access of ACP?
  - d. Are these conversations something you may integrate into your practice moving forward?
- 5. Telehealth is providing a new platform to patients during these challenging times.
  - a. How regularly do you use telehealth?
    - i. Tell me more about your platform/logistics
  - b. What is working well with telehealth?
  - c. What is challenging about telehealth?
  - d. How well do you think patients are able to engage in the encounter?
  - e. How well are patients able to comprehend what you're telling them?
  - f. How do you deal with emotional conversations over telehealth?

- 6. How do you think telehealth, and/or the COVID-19 pandemic have affected shared decision-making?
- 7. We have reached the end of our interview. Is there anything else you would like to share with us that we haven't asked you about?

Thanks for sharing your thoughts with us. It is really helpful and your opinions are important! Thanks again.

### APPENDIX 3: Methodology Supplement

\*\* We provide additional details to the in-text manuscript which are in line with adapted COREQ checklist for qualitative studies. Additional text is bolded.

#### Design, Setting and Participants

This report is part of the multi-site, mixed-methods Decision Aid for Renal Therapy (DART) trial (clinicaltrials.gov NCT03522740). From 2018-2019 the DART Trial recruited 400 English-fluent patients age 70+ years with non-dialysis CKD and estimated glomerular filtration rate less than 30 mL/min/1.73m2 receiving care at nephrology clinics in Greater Boston, Portland (Maine), San Diego, and Chicago. (17) In 2020, a subset of patients, carepartners, and nephrology clinicians was recruited for a qualitative study using purposive sampling to assure balance representation of age, gender, region, education, race, treatment preference, and education, and years in practice (clinicians). Nephrologists were recruited via letters and confirmed eligibility; participants were identified using electronic health record queries. Carepartners, defined as non-clinical persons identified by patients who they involve when making healthcare decisions, were recruited and provided consent independently. As part of the consenting process, participants were informed about the reasons, goals, risks and benefits of participating in the study. Because this was a subset of an active trial population and because we sampled purposively until saturation, very few people declined and we did not calculate a specific response rate for this. The Tufts Health Sciences Institutional Review Board approved this study.

#### Interview guide and data collection

Based on a literature review and clinical experience, a social scientist with expertise in qualitative methods and kidney disease (KL) and the research team designed three semi-structured interview guides (patients, carepartners, clinicians) that were refined further with the DART Stakeholder Advisory Board (Appendix 1). The interviewers did not have preestablished relationships with the interviewee. However, the DART research coordinators who oversee the DART clinical trial, were familiar and built rapport with the interviewees. Coordinators enrolled the patients and discussed the study with them. Interviewers then followed up for the interview, indicating a smooth transition. No one else was present in the interviews aside from the researchers and participants. Following verbal informed consent, where study related goals, risks and benefits were shared, trained interviewers (KG, TP) conducted and recorded semi-structured interviews from August through December 2020 by

phone. Open-ended questions were used to examine patient, caregiver, and clinician perspectives about treatment decision-making during the COVID-19 pandemic (Appendix 2). Interview questions examined treatment preferences, quality of shared decision-making discussions, satisfaction with treatment choices, the impact of COVID-19 pandemic and their effect on treatment choices. Interviewers took fieldnotes during interviews. The interview guide also included questions specifically about the DART intervention to be presented in a forthcoming paper. Although transcripts were not returned to participants for feedback, we sought input on our findings and implications from our multidisciplinary stakeholder advisory board which includes patients, caregivers, patient advocates, and clinicians (Appendix 2). There were no interviewer biases to report. Study reporting reflects Consolidated Criteria for Reporting Qualitative Health Research (COREQ).(33)

#### **Analysis**

We conducted a thematic and narrative analysis with audio recorded interviews that were transcribed verabtim. Sampling continued until thematic saturation was achieved and confirmed through deliberation by the research team on all COVID-19 related topics. (34) There was no reason to carry out repeat interviews. No one else except the interviewers and **interviewees were present in the interviews.** Subsequently, the team developed two preliminary codebooks (patients/carepartners and clinicians) deductively following the interview guide and inductively based on emergent findings. At least three researchers (TP, KG, KA) independently coded 10 interviews line by line, allowing for new codes to emerge inductively. (36) The qualitative team revised the codebook and independently recoded the initial interviews and six additional transcripts using NVivo (version 11; QSR Int). Iterative deliberation yielded team consensus about coding discrepancies and emergent codes. The process was repeated for the remaining sixty interviews. Codes were then amended and organized into categories through a consensus process to reflect the range and variability of subthemes, and to characterize both confirmatory and contradictory narratives. The code book for the patient carepartner codebook included the following categories, each with corresponding codes: disease progression; caregiving; treatment discussions with CKD team; treatment discussions with loved one; COVID-19; conservative management; COVID-19 ACP triggers. The codebook for the clinicians included the following categories, each with corresponding codes: treatment option approach; disparities; conservative management; shared decision-making; patient education; patient preferences; COVID-19; ACP. Emerging themes were then discussed by the research team. (35) Our diverse, purposively sample had a significant participation from persons identifying as Black or Latinx, which allowed us to explore racial disparities qualitatively. As such, we stratified all thematic responses by race and ethnicity after our initial thematic analysis for all participants.