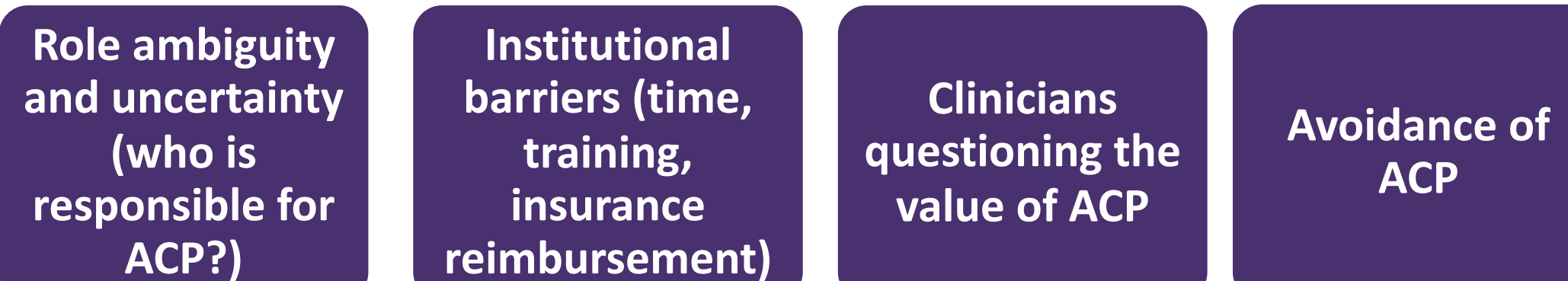


## Introduction

- Chronic kidney disease (CKD) affects **1/3 of adults over the age of 65**<sup>1</sup>.
- Older CKD patients **2x as likely to die in the ICU** as compared to patients with similar conditions<sup>2</sup>.
- Early discussions and/or documentation regarding preferences for future medical planning and late-life care, known as **advance care planning (ACP)**, are critical for this population, yet significant barriers to ACP have been identified<sup>3</sup>:



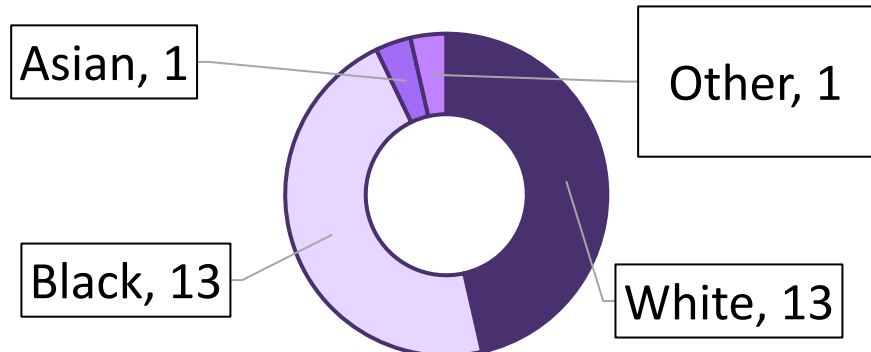
- Decision aids** are digital tools that increase patients' knowledge of their condition, leading to more informed decisions regarding their medical care<sup>4</sup>.
- Based on the **DART clinical trial (Decision Aid for Renal Therapy)** (ClinicalTrials.gov NCT03522740)<sup>5</sup>, **DART-ACP** (Decision Aid for Renal Therapy – Advance Care Planning) was developed with Wolters Kluwer, an information services company, using Emmi, a web-based program that synthesizes complex medical information for patients and their families.
- This study aims to inform changes using perspectives from patients and clinicians to the current Emmi ACP decision aid to assist in increasing ACP completion among patient populations.

## Participants

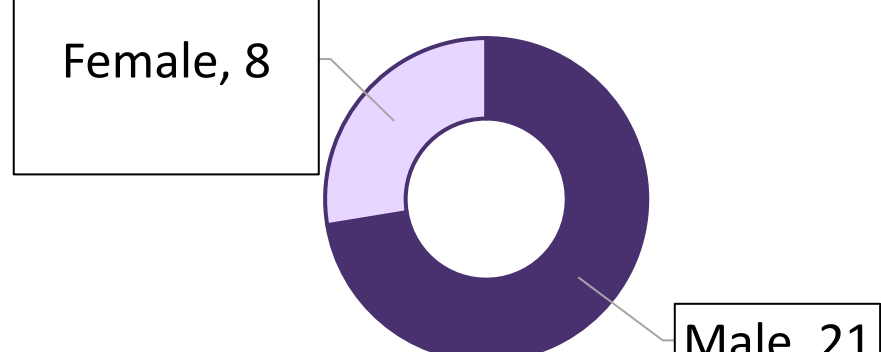
### Patients, n=35

50+ years old      CKD Stage 4 or 5      English-speaking

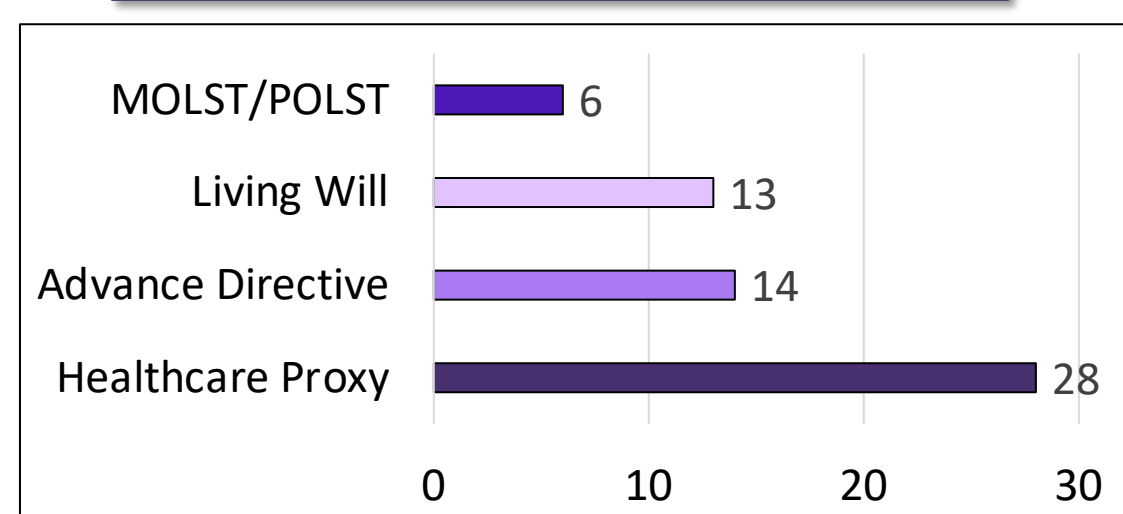
#### Race and Ethnicity



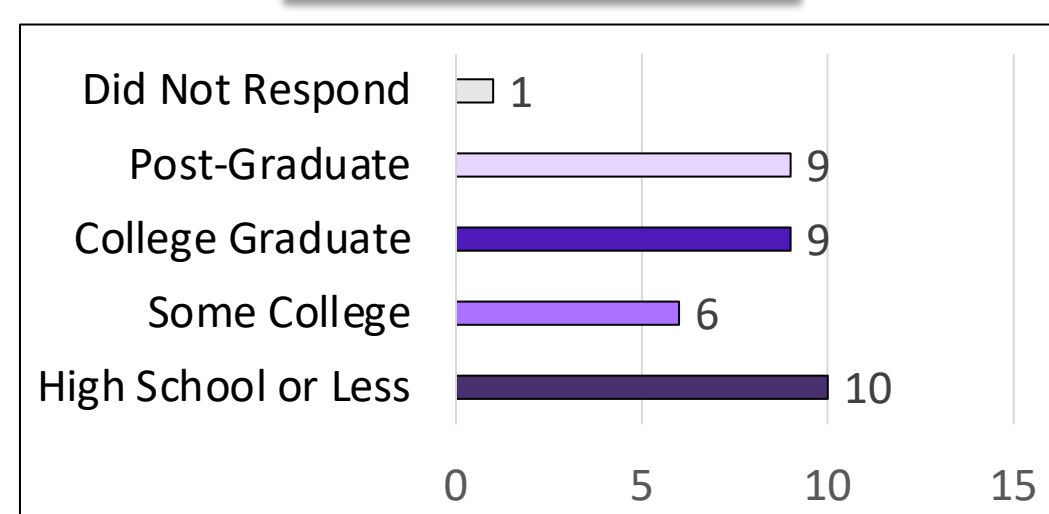
#### Gender



#### Completed ACP Documentation

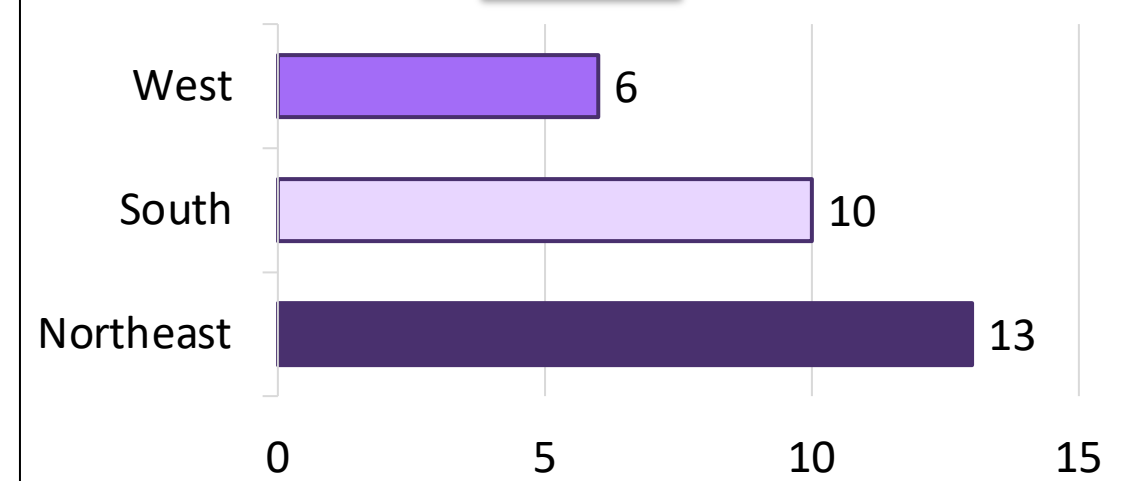


#### Education Level

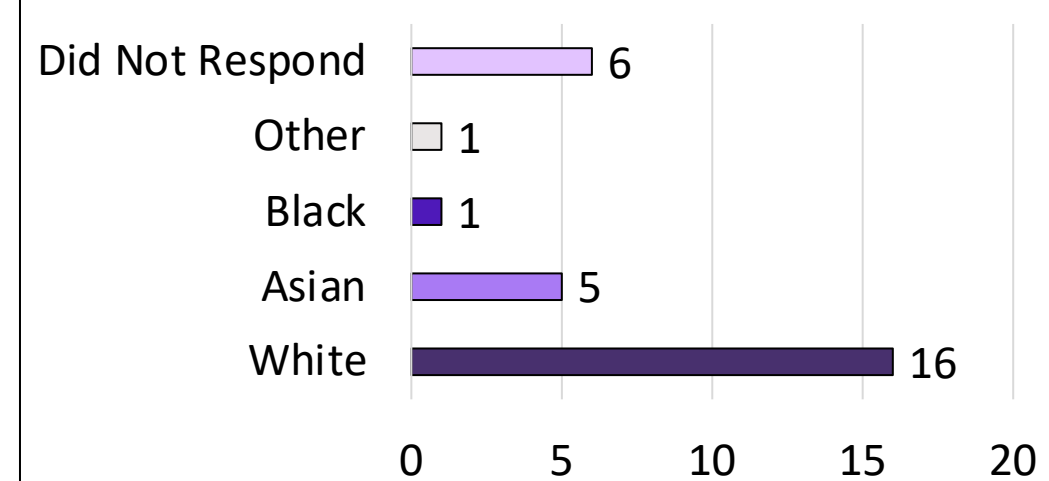


### Clinicians, n=29

#### Region



#### Race



All Nephrologists

38% Female

## Methods

### Development of DART-ACP Modules → Human-Centered Design

#### Discovery Phase

- Medical writer at Emmi was guided through search of relevant literature, including studies and systematic reviews to inform module content

#### Design Phase

- Patient focus groups provided feedback for videos to be revised
- Program was made available to hospitals and clinicians for two weeks for general review and comment

#### Pre-Testing Phase

- Viewing of DART-ACP was followed by a semi-structured interview with patients and clinicians and took place from March 2022-March 2023

### Thematic Analysis

Interviews were transcribed verbatim

Preliminary codebooks (clinicians and patients) were developed by research team

Codebook was refined and interviews were cross-coded and recoded to ensure agreement

Codes were organized into themes and subthemes

## Results

### Theme 1: Content

"Maybe show them the MOLST form, and ask them what we want them to actually decide on..." (Clinician)

- Patients generally viewed videos as **beneficial and relevant** to their current medical care.
- Patients and clinicians felt **palliative care videos were especially useful**.
- Participants felt that **including lived experiences, explanations of life-saving procedures, and examples of documentation** would assist in their ACP decision-making process.

"So more descriptive form of what [palliative care is] about, more descriptive form about **how you would enact it, how you would become part of it, who you would talk to, some type of instructions on how to do all that would be good.**" (Patient)

### Theme 2: Timing and Provision

"If you gave me just a blank sheet, you would never get an answer. Yeah, like, do you want this? Do you believe in that, and if so, what do you want? Stuff like that..." (Patient)

- Clinicians stressed timing restraints in the clinic, citing that there are benefits and drawbacks to viewing the decision aid at home.
- Many patients agreed decision aid was **not appropriate for recently diagnosed CKD patients**.
- Patients agreed that **any professional who works with CKD patients** could distribute the decision aid.
- Patients felt that making the module **interactive** would aid learning.

"If you have some module that you can send them and they can go through it when they have more time that would be a useful thing." (Clinician)

### Theme 3: Format and Accessibility

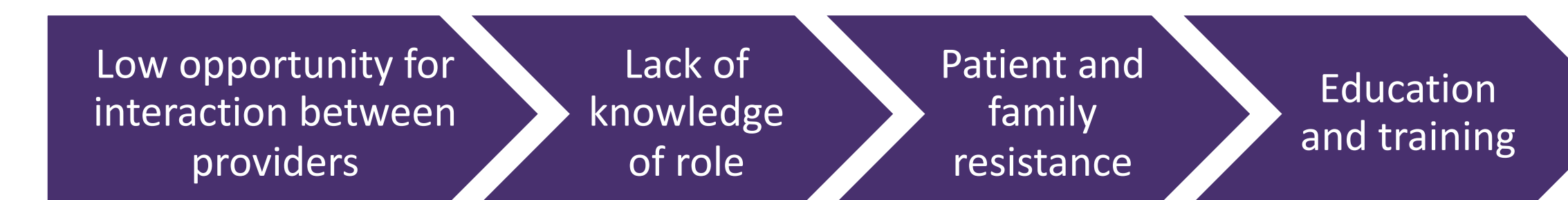
"So maybe some sort of feature where it just rolls straight into the next video just to make it a little more easy." (Patient)

- Participants viewed modules as **clear and easy to understand**.
- Most clinicians felt **language was appropriate** for patients' health literacy.
- Some patients expressed **frustration in website usability**.
- Clinicians expressed **concern for patients with limited access to technology** or technological barriers.

"The amount of patients now who I ask, 'Hey, it's time. Are you up for education? I want to set you up for this.' 'Okay, I don't have a way to do Zoom,' whether they don't have the technology or they don't have the knowledge for it..." (Clinician)

## Discussion

- Overall, clinicians and patients generally viewed the decision aid favorably in areas of content, format, and accessibility.
- Clinicians stressed that patients may be making ACP decisions or conveying preferences without adequate knowledge the impact of life-saving procedures on their quality of life.
- By emphasizing real-world examples and lived experiences within our next iteration of the modules, we can better assist CKD patients in the full understanding and completion of ACP.
- When and where patients should view the modules remains up to discussion when considering time restraints in the clinic.
  - Can patients readily get follow-up questions answered at home?
- Patients questioned how to obtain referrals to palliative care, pointing to barriers to referrals between nephrologists and palliative care physicians.
  - Previous gaps that have been identified include<sup>6</sup>:



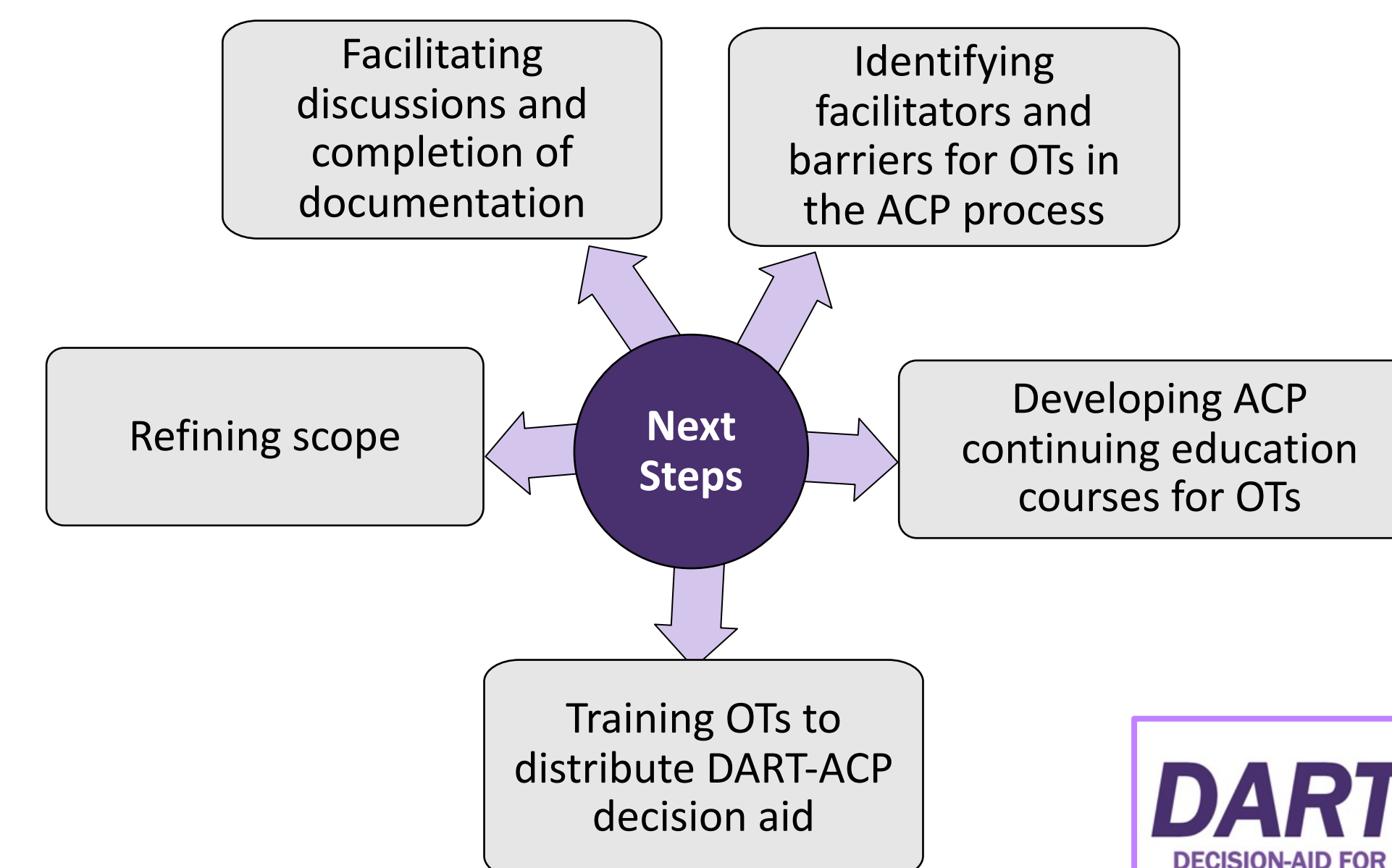
- The emergence of the geriatric nephrology subfield to address specific needs in the older CKD patient population can bridge the gap between CKD patients and palliative care<sup>7,8</sup>.

## Occupational Therapy & ACP

- Occupational therapists' current established role in palliative and end-of-life care<sup>9</sup>:



Although we have a more established role in palliative and hospice care, **there are currently unidentified gaps in facilitating earlier advance care planning discussions with patients for occupational therapists, not limited to**<sup>10</sup>:



### References



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