

Supplemental Materials

1. Literature search terms and strategy
2. Pathways Project Change Package – 1-page summary
3. Ask-Tell-Ask card
4. Interview guide for interviews of implementation leaders
5. Questions for the Technical Expert Panel meeting
6. Evaluation data collection and survey instruments
 - a. Chart audit instructions
 - b. Patient survey instrument
 - c. KSC-IQ
 - d. NOMAD adaptation

Supplement 1: Search Terms for focused Literature Review

Search Terms for Focused Literature Review:

active medical management without dialysis

bereavement care

chronic kidney disease

chronic kidney failure

chronic renal failure

CKD

communication

comprehensive conservative care

conservative care

conservative kidney management

conservative management

conservative, non-dialytic management

disease, end stage kidney

disease, end stage renal

emergency care

emotional support

end stage kidney disease

end stage renal disease

end stage renal failure

ER

health resource

healthcare resources

hospice

hospice care

hospice program

hospital mortality

hospital readmission

hospitalization

intensive care

kidney disease, end stage

maximal conservative management

morbidity

mortality

non-dialytic management

outcome and process assessment health care

outcomes

pain management

pre ESRD

prognosis

quality of life

renal disease, end stage

renal failure, end stage

renal palliative care

renal supportive care

spiritual support

symptom assessment

symptom management

Supplement 2: Pathways Project Change Package



Pathways Project CHANGE PACKAGE

Evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.



Supportive Care Capacity

Create the System

1. Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
2. Assess unmet supportive care needs in patient population
3. Provide education to staff on the principles and practices of primary supportive care, including communication skills
4. Collaborate with palliative care/hospice specialists



Values Guide Care

Elicit & Respect Patient Values and Preferences

5. Implement shared decision-making for current and advance care planning for future care options **
6. Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
7. Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings



Just Right Care

The Right Care to the Right Person at the Right Time

8. Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions **
9. Provide medical management without dialysis to patients avoiding or delaying dialysis
10. Screen and manage pain and symptoms
11. Assess psychological and spiritual needs and address needs
12. Proactively identify and manage patients at high-risk for frequent hospital readmission



Throughout the Continuum

Enhanced Support at the End of Life

13. Coordinate care and care transitions with specialty palliative care and hospice
14. Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients **

****Indicates a mandatory practice that project participants are required to test and implement**

Supplement 3: Ask-Tell-Ask card



The Ask-Tell-Ask Approach to Conversations
with Seriously Ill Patients with Kidney Disease*
Alvin H. Moss, MD, FACP, FAAHPM

ASK

- **Build trust and strengthen relationship**
 - “I would like to be able to respect your wishes for future medical care. Would it be ok for us to talk about what you would want?”
 - “How are you doing compared to a year ago?”
- **Assess patient/family understanding of the patient’s medical condition and prognosis**
 - “What have physicians told you about your (the patient’s) condition?”
 - “What is your understanding of your (the patient’s) major medical problem now?”
 - “How serious is it?”
- **Determine patient’s goals for treatment in his/her present condition?**
 - “How much information about what is likely to be ahead with your illness would you like from our team?”
 - “What is most important to you in receiving treatment for your illness? What do you hope for?”
 - “What would you want to avoid in receiving treatment for illness (some patients say they would want to avoid being placed on a breathing machine or in a nursing home)? What do you fear?”
- **What are your most important goals if your health situation worsens?**
 - To the health care proxy, “If your _____ (mother, father, etc) was mentally clear and could see what condition he/she is in what would he tell us to do? Are there things he or she would want us to avoid in his/her treatment?”

MEDICARE BILLING CODES FOR ADVANCE CARE PLANNING

99497 16 minutes or longer of first 30 minutes
99498 add on to 99497-includes 30 minutes from 99497 and at least 16 minutes for 99498 for at least 46 minutes of advance care planning

- **Explore understanding of who the patient wants to be his/her healthcare proxy and what the role of the proxy should be.**
 - “Who would you want to make medical decisions for you if you became too sick to make them yourself?”
 - To the patient’s health care proxy, “What do you understand about your role as the healthcare proxy? How are you to make decisions?” (NB: Proxy is to make decisions based upon the patient’s expressed wishes or, if unknown, the patient’s best interest.)

TELL

- **Explain the patient’s overall condition emphasizing the patient’s most serious comorbidities**
- **Discuss likely future complications**
- **Assist with informed decision about breathing machine, ICU, and CPR**
 - “Have you been on a breathing machine before? If you got sick, would you want to be on one again if necessary to keep you alive? To proxy, “Has the patient been on a breathing machine before? Has he/she said anything about wanting/not wanting to be on a breathing machine?”
 - “It is helpful to learn what is most important to you. Would you want—to live as long as possible regardless of pain and suffering or to live a shorter period of time to avoid pain and suffering? (75% of dialysis patients want to live a shorter time to avoid pain and suffering)
 - “Under what circumstances if any would you want to stop dialysis?” (Most patients say if they had a large stroke and were unconscious or if they had severe dementia they would not want to be kept on dialysis)
 - CPR is not as successful as most people think. Would you want those treating you to attempt CPR if your heart stopped? If you live through CPR, you will be on a breathing machine. Is that what you would want?

ASK

- **What questions do you have?**
- **What will you tell your family about what we discussed?**
- **In your own words, please tell me what you understand from our conversation.**

*Reference: Mandel EI, et al. Serious Illness Conversations in ESRD. Clin J Am Soc Nephrol 2017;12:854-863.

Supplement 4: Interview guide for interviews of implementation leaders

Interview guide for discussions with model programs or places with innovative practices

Introduction

- Brief overview of Pathways project – looking for tools, practices, examples for any of the pathways
- Consent to record the interview for purposes of transcribing it.
- Consent to share information about program with Pathways TEP. Further dissemination – we would come back to you for further permission.

Description of the program

- What services are provided?
- Who is served? (get actual numbers served if applicable)
- Staffing?
- Funding?

History

- How did it get started?
- What do you consider the successes to date?
- What have been barriers to success or to implementation?
- How did you overcome barriers (if you did)?

Effectiveness

- How are you measuring effectiveness?
- If formal measurement – what measures being used?
- What data is available on effectiveness? Willing to release any internal data to us?
- Are there any formal studies of the program's impact published? Or underway?
- What data do you have on cost, cost effectiveness, cost savings?

Tools to share

- What are the tools, policies/procedures, educational materials being used?
- Will you share samples? If CSCKP likes the material, are you open to dissemination through Pathways project? (Discussion of attribution, licensing, etc would need to follow.)

Lessons learned

- Lessons learned from developing and using these practices?

Snowball

- Snowball – who else do you know of who is doing useful work in this area?

Supplement 5: Questions for the Technical Expert Panel meeting

TEP – What are we hoping to answer?

1. What are the most effective changes* needed to help CKD patients make an informed and supported choice either for dialysis with integrated supportive care or for comprehensive conservative care?
2. What structure, process and resources are needed to effectively provide comprehensive conservative care for patients who choose it?
3. What are the most effective changes needed to help dialysis patients receive supportive care throughout the kidney care continuum?
4. What are the most effective changes needed to help dialysis patients make an informed and supported choice to discontinue dialysis?
5. Are there certain changes that need to be bundled or sequenced in order to maximally effective?
6. What are the most effective measures to help understand whether changes made are improvements?

*Changes might include:

structure of care

care processes

education for providers, patients, family

clinical tools (such as symptom algorithms or trigger lists for PC consultation)

Supplement 6: Evaluation data collection and survey instruments

- a. Chart audit instructions
- b. Patient survey instrument
- c. KSC-IQ
- d. NOMAD adaptation

Supplement 6a: Chart audit instructions

Instructions for Pathways Follow-Up Chart Audit of Advance Care Planning in Records of Seriously Ill Patients

A follow-up audit of the records of patients who have been identified as seriously ill is to be completed once for each patient by October 5, 2020. The goal is to determine the extent to which information about patient advance care planning goals are documented in the medical record.

A HIPAA full waiver of consent has been obtained from your institution, giving us permission to access the medical records for this purpose. **The information gathered must be de-identified before submitting to Pathways.**

Selecting patient records to audit

Your clinic will be developing a list of patients identified as seriously ill at the beginning of each month. Obtain the lists of patients whom your clinic identified as seriously ill at the beginning of July, August, and September 2020. If conducting this audit at a dialysis center, delete new patients. Specifically, delete any patients who had NOT started dialysis by April 1, 2020.

Searching the EHR

If your clinic has designated a specific place in the chart where advance care planning information is entered, you will search that area first. Record whatever you find in this area as it relates to the data collection items on the spreadsheet. If you do not find the relevant information in that area, you will then search other areas, such as progress notes. Search these areas only back to April 1, 2019. Spend no more than 10 minutes looking up information for each patient. The rationale is that if a provider can't find relevant information about goals of care in 10 minutes, then the information is not in a meaningfully retrievable format. Only information on conversations or documents entered **prior to July 10, 2020** is to be captured.

- First go to area specified for ACP in the chart.
- Then search chart going back no farther than April 1, 2019 and spending no more than 10 minutes per patient, (whichever is less time).
- Only record data for discussions or documents entered into the chart **prior to July 10, 2020**.

Recording the data

- Enter the data into an Excel spreadsheet using the template provided: **"ACP Chart Audit Template.xlsx"**.
- When complete, de-identify the data by removing the MRN and any other identifying information you may have added.
- Save as a de-identified file.

Submitting the data

- Email the spreadsheet using secure email to: pathways_data@gwu.edu OR
- Upload the data to the REDCap project “Pathways”, instrument “Follow-up ACP Chart Audit”.

Definitions

Decision Making Capacity (DMC) Assessed

0=no information recorded about whether DMC assessed

1= clear statement that patient has capacity or not – without any documentation about rationale

2= statement that patient has capacity or not, including documentation of rationale. Expected documentation might include elements such as:

- patient does/does not understand his/her medical condition or
- patient does not remember information provided about his condition earlier in visit or previous visit
- patient is able/not able to weigh the consequences of treatment options
- patient has communicated a choice.

Health care agent/Surrogate named

A surrogate (also called health care proxy, durable power of attorney for health care, medical power of attorney, or health care agent depending on the state) is someone that the patient has named to be able to make medical decisions on the patient’s behalf, if the patient is not able to make decisions for him/herself. For this variable, look for information recorded in the record in an area for surrogate information, on a form for surrogate information used in some states, or in the notes. You do NOT need to look inside an advance care planning form or on POLST/MOLST form.

0=no information recorded whether a surrogate has been named

1= clear statement that patient has declined to name a surrogate

2= statement that patient has named surrogate, but name is not provided (e.g. “sister is surrogate” – but sister’s name not given. The reason this is important is in case where it turns out there are two sisters).

3= Surrogate has been named by patient, name is clearly recorded, but no contact information is recorded.

4 – Name and contact information of surrogate is recorded.

Goals of Care conversation documented

0=no information on goals of care found within 10 minutes of search, or since January 2018.

1= A goals of care conversation is documented, with evidence of the choices selected by patient, but documentation is only from template or checklist.

2= Goals of care conversation is documented, and notes have been personalized to clearly show individual preference. For instance, quotes from patient are included, such as “Patient stated “I’m a fighter, so I would never want to give up.” Or “Patient says “I’ve had a good life, so I’d like to have a gentle end. Just keep me comfortable.”

Date of most recent goals of care conversation or advance care planning conversation

Record month and year of most recent conversation documented. DO NOT RECORD day of the date.

Who conducted most recent GOC or ACP conversation?

Record the person who signed the note of the most recent discussion.

0=unknown

1=nephrologist

2=NP

3=social worker

4=team

5=other

Orders or POLST/MOLST Retrievable in chart

This refers to orders signed by physician or NP, usually using a form for that purpose such as POLST or MOLST. May also include notation of DNR orders or other end of life comfort set orders.

0=absence of any orders such as DNR, POLST, MOLST

1= DNR, POLST, MOLST, LST or other standard end of life order set is in chart

Advance Directive Retrievable in chart

This refers to a form completed by the patient, rather than orders signed by clinician, which is captured above.

0=no evidence patient has completed an advance directive

1= Statement that patient has completed an advance directive, but the document is not accessible in the chart.

2= The advance directive form is retrievable from the chart.

Patient advance directives are in an electronic registry

0= no evidence patient's advance directives or POLST are in a registry accessible to other providers

1= patient's advance directive or POLST has been entered in an electronic registry, such as state registry

Other evidence of ACP

If other evidence of advance care planning found that was not captured by previous questions, record a brief description here.

Optional Notes

Briefly describe any other anomalous or notable information here that was not captured in prior questions.

Supplement 6b: Patient survey instrument

Patient Survey Instrument - English
Record ID
Unique Patient ID
PATIENT CONSENT: IRB approved consent script to be inserted here.
Introduction letter was read to participant? Yes / No
Did patient agree to participate? Patient agreed to participate / Patient did not agree to participate
If patient provided a reason for declining, please specify:
Interview Start Time:
Patient Pre-and Post-Intervention Questionnaire
Research team to read to participant and administer the test:
Patients with kidney disease sometimes have memory problems. The first set of the questions is to test your memory. It should take 5 minutes or less.
MoCA-5 Minute Test
Memory:
Immediate Recall
Face Velvet Church Daisy Red
No / Yes
Score: _____
(/5, 1 point for each word)
Fluency: _____
Number of animals named in 1 minute
Score: _____
(/9, 0.5 point for each animal named)
Fluency Calculated Score:
Orientation
Date Month Year Day Place City
No / Yes
Score: _____
(/6, 1 point for each)
Memory:
Delayed Recall

<p>Face Velvet Church Daisy Red</p>
<p>No / Yes</p>
<p>Score:</p> <p>_____</p> <p>(/10, 2 points for each word recalled)</p>
<p>Total Score:</p> <p>_____</p> <p>(/30)</p>
<p>Next, we will collect your address to mail your gift card. Once this is completed, that will conclude this interview. Thank you for your time!</p>
<p>Notice: Due to the patient scoring below a 23, their responses may not be fully accurate.</p>
<p>Interview terminated / Interview continued</p>
<p>Research team to read to participant and administer the test:</p>
<p>Now I have a few questions about you.</p>
<p>Demographics</p>
<p>Dialysis Center or CKD Clinic:</p>
<p>Gender:</p> <p>Male Female Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Age: (in years)</p>
<p>Ethnicity:</p> <p>Hispanic or Latino Not Hispanic or Latino</p>
<p>Race:</p> <p>American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Prefer not to say Other</p>
<p>If other, please explain</p>
<p>Primary language spoken by patient:</p> <p>English Spanish Chinese Russian Other</p>
<p>If other, please specify</p>
<p>Education: (in years)</p>

Is patient on Medicaid?
Yes / No / Unknown
Address (this will be used to mail the participants gift card)
Years on Dialysis: (in years)
Number of times hospitalized in the last year:
Karnofsky Performance Status Score categories
Do you live alone?
Yes / No
What are you able to do?
Able to carry on normal activity and work
Unable to work but able to live at home and care for most personal needs
Unable to care for self and need help every day with own needs
Nursing home/assisted living facility resident?
Yes / No
Mobility (from work of Cecile Couchoud, MD, French Renal Epidemiology and Information Network)
I am able to walk without help
I need help to move from a bed to a chair
I am totally unable to get up and move without help
Location of Dialysis Treatment
In-center hemodialysis
Home hemodialysis
Home peritoneal dialysis
Comorbidities
Please say "yes" if you have any of the following illnesses.
Yes / No
Diabetes
Congestive Heart Failure
Heart Attacks or Angina
Peripheral Vascular Disease (problems with circulation in legs)
Stroke
Lung Disease, COPD or Emphysema
Liver Cirrhosis
Cancer
Dementia
Depression
Total Score:
Research team to read to participant and administer the questionnaire:
The next four questions ask about how much anxiety and depression you have. This is a 4-point rating scale with 0 being not at all and 4 being nearly every day.
PHQ-4 Anxiety and Depression
Over the last 2 weeks, how often have you been bothered by the following problems?
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling nervous, anxious, or on edge

Not being able to stop or control worrying
Anxiety Score
Anxiety is defined as a score of ≥ 3 on the first two questions.
Not at All, 0 Several Days, 1 More Than Half of the Days, 2 Nearly Every Day, 3
Feeling down, depressed, or hopeless
Little interest or pleasure in doing things
Depression is defined as a score of ≥ 3 on the second two questions.
Depression Score
Anxiety and Depression Total Score
Scores of ≥ 3 should prompt treatment.
Patient has scored 3 or more; PI must be notified. Record information about notification in the fields below. Research team will email the Principal Investigator within 24 hours for a score of 3 or more.
Was the PI notified? Yes / No
Date PI was notified
Signature of person completing questionnaire
Research team to read to participant:
The next question is about how well you feel the doctors, nurses and those treating you listen to you.
Heard and Understood
Over the last month, how much have you felt, heard, and understood by the doctors, nurses, and staff who care for you at the dialysis center?
Not at all Slightly Moderately Quite a bit Completely
Research team to read to participant and administer the questionnaire:
Quality of Communication Questionnaire
We would like to know, in as much detail as possible, how good the dialysis team taking care of your medical problems is at talking with you about your illness and the types of care that you would want if you became sicker or too sick to speak for yourself. We know that many people think very highly of the people treating them. To help us improve communication between the treatment team and patients, please be critical.
Using the following scale, where "0" is the worst you could imagine, and "10" is the best you could imagine, please tell me the best number for each statement.
Interviewer: use the last two responses when team did not do...
Turn to the response scale card and read response options
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst general communication I could imagine 10 = The very best general communication I could imagine Didn't do Don't know
1. Using words that you can understand. 2. Looking you in the eye. 3. Answering all your questions about your illness and treatment.

4. Listening to what you have to say. 5. Caring about you as a person. 6. Giving you his/her full attention.
Score
When talking with your dialysis team about important issues like becoming very ill, how good are they at:
0 = The very worst communication about End-of-Life Care I could imagine 10 = The very best communication about End-of-Life Care I could imagine Didn't do Don't know
7. Talking with you about your feelings concerning the possibility that you might get sicker. 8. Talking with you about the details concerning the possibility that you might get sicker. 9. Talking to you about how long you might have to live. 10. Talking to you about what dying might be like. 11. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself. 12. Asking about the things in life that are important to you. 13. Asking about your spiritual or religious beliefs.
Score
Total Score
Research team to read to participant and administer the questionnaire:
The next three questions ask how well you feel those taking care of you work with you in making decisions. This is a 5-item scale with 0 being no effort was made up to 4 being every effort was made.
CollaboRATE
Thinking about the discussion you have just had with your kidney care team:
0 = No effort was made 1 = A little effort was made 2 = Some effort was made 3 = A lot of effort was made 4 = Every effort was made
How much effort was made to help you understand your health issues?
How much effort was made to listen to the things that matter most to you about your health issues?
How much effort was made to include what matters most to you in choosing what to do next?
Total Score
Research team to read to participant and administer the questionnaire:
The next few questions ask about how important it is to you to talk with those treating you about medical procedures you would and would not want. This is a 5-item scale with 0 being very unimportant and 5 being very important.
Dialysis Patient Preferences and Experiences with End-of-Life Care Discussions
How important is it to have a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?
Very Unimportant - 0 points Somewhat Important - 1 point Unsure - 2 points Somewhat Important - 3 points Very Important - 4 points

<p>Yes / No</p> <p>Do you know what supportive (palliative) care* is?</p> <p>Have you had a discussion with a member of your dialysis team about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about treatment you do and do not want if you become very ill and cannot speak for yourself?</p> <p>During the past 12 months have you had a discussion with your kidney doctor about your choices for end-of-life care?</p> <p>*Definition of palliative care to read to the patient: Palliative care (pronounced pal-lee-uh-tiv) is special medical care for people who are very ill. This type of care treats pain and symptoms and tries to decrease stress. This care also seeks to find out what matters most to patients to be sure they receive it. The goal is to improve the quality of life for both the patient and the family. Palliative care is provided by specialists who work together with a patient's doctor to provide an extra layer of help. It can be given at any time along with curative treatment.</p>
<p>Research team to read to participant and administer the questionnaire:</p> <p>The next four questions ask about how ready you are to talk to your family and doctor about treatment you would want if you were very sick and if you are ready to fill out papers to put your wishes for treatment in writing. This is a 5-point scale with 1 being I have never thought about it and 5 being I have already done it.</p>
<p>Advance Care Planning Engagement Survey</p>
<p>I have never thought about it - 1 point I have thought about it, but I am not ready to do it - 2 points I am thinking about doing it in the next 6 months – 3 points I am definitely planning to do it in the next 30 days - 4 points I have already done it - 5 points</p> <p>1. How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life? 2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life? 3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? 4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?</p>
<p>Score</p>
<p>Any additional comments or questions:</p>
<p>This concludes the interview. Thank you very much for participating. The \$25 gift card will be mailed to you.</p> <p>**Study team to refer to subject tracker and gift card inventory tracker to complete the process for mailing the gift card. **</p>
<p>Interview End Time:</p>
<p>Interview Length:</p> <p>_____</p> <p>(Time in minutes)</p>

Supplement 6c: KSC-IQ

Dialysis Center Where You Work:

KSC-IQ

This Kidney Supportive Care Implementation Quotient (KSC-IQ) helps nephrology practices, clinics, and dialysis centers examine how they are performing in key areas of implementation of supportive care for seriously ill patients with advanced chronic kidney disease (CKD) or end-stage renal disease (ESRD). If you find areas where your practice could improve, the Pathways Project change package provides tools and guidance for change.

What is supportive care?

Supportive care aims to improve quality of life for patients and family members (as defined by the patient). The term supportive care is used rather than palliative care because that term is preferred by patients and physicians. The terms are synonymous. Kidney supportive care can be provided together with therapies intended to prolong life, such as dialysis, and is offered by the kidney care team throughout the course of kidney disease. When more complex or refractory problems arise, the kidney care team partners with specialist palliative care providers to address these issues. If patients' conditions worsen, they often value comfort more highly and wish to avoid hospitalization. Hospice care then provides coordinated services focused on end-of-life needs.

What does this survey cover?

The survey questions are based on the four sections of the Pathways Project change package. The survey questions ask you how well your practice or clinic is currently doing in the specific supportive care practices. Answer choices are:

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

We encourage you to comment in the provided space on anything your practice does particularly well or on any aspect where your practice needs to improve.

The survey takes a 5-10 minutes to complete. It has 20 questions organized into the four main components of the Pathways Project:

- A. Supportive Care Capacity: Create the System
- B. Values Guide Care: Elicit & Respect Patient Values and Preferences
- C. Just Right Care: The Right Care to the Right Person at the Right Time
- D. Throughout the Continuum: Enhanced Support at the End of Life

A. Supportive Care Capacity: Create the System

1. Our practice has an interdisciplinary team responsible for improving supportive care in our practice. It is clear who is the day-to-day leader(s) of the team responsible for implementing supportive care changes. Appropriate champions (professionals who are opinion leaders in your organization, to whom others go to seek advice and who have the capacity to implement change) provide needed support, resources, and visibility. A plan for improvement with specific supportive care goals is supported by leadership.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

2. Our practice regularly re-assesses our supportive care practices and implements quality improvement projects to improve care in this area.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

3. All staff members have received education in supportive care, including communication skills and symptom management approaches.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

4. Our practice has an established relationship with a community palliative care team and at least one community hospice provider to collaborate in care of nephrology patients with supportive care needs. Relationship may include embedding palliative care team member into nephrology clinic, triggers for referrals to specialty palliative care consultation, palliative care back-up for medical management patients, and other proactive co-delivery of supportive care services that go beyond simple referral.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

B. Values Guide Care: Elicit and Respect Patient Values and Preferences

5. Goals of care conversations: We conduct goals of care conversations with almost all of our patients at least at these points of time: shortly after entering the practice; as education about treatment modes is conducted; as there is evidence of decreasing quality of life (such as repeat hospitalizations, increased symptom burden, caregiver burden, dementia). Staff conducting the conversations follow a best practice format such as the Serious Illness Conversation Guide.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Conversations are documented in chart so that goals of care are easily retrievable by all staff and updated as patient condition or goals change (e.g. NOT buried in visit notes. Should have separate area of chart for goals of care and for advance care plans).

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

6. As part of shared decision making, nephrologists routinely and kindly provide patient-specific prognostic information needed for choosing among treatment options. Nephrologist provides patient and family with information from validated prognostic tool and/or practice-specific outcome statistics relevant to their decision options.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

7. When educating patients about their treatment options, our practice uses evidence-based decision aid(s) that include medical management without dialysis in a balanced and informative way.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

8. Our practice encourages patients to develop advance care plans. We have forms available. We have a designated staff person who has been trained to conduct these conversations. We have a designated area of medical record to retain copies of advance directives and/or to record patient preferences regarding future care. Our practice routinely completes POLST/MOLST forms for patients who are seriously ill or who have had an unexpected hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

C. Just Right Care: The Right Care to the Right Person at the Right Time

9. Our practice routinely screens patients using a standard process such as the "Surprise Question," a frailty score, or another validated prognostic tool to identify appropriate patients for supportive care services.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

10. Our practice has a formal pathway for medical management without dialysis. Our practice has adopted policies, procedures, and standard processes that guide care for patients choosing this pathway. We identify and track patients who have chosen medical management without dialysis. We know the proportion of eligible patients who choose this pathway and the proportion who change their mind and opt for dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

11. We use a validated/standardized symptom assessment tool that is integrated into regular work flow so that symptom data is collected for most outpatient visits, and at least monthly for dialysis patients.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

12. Using validated tools, our practice routinely assesses psychosocial needs, including depression, caregiver burden, and spiritual concerns.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

13. We have social worker and chaplain available on our interdisciplinary team to help address psychosocial and spiritual needs. We also have working referral relationships to help patients access additional community resources.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

14. We proactively assess and develop plans for seriously ill patients at high risk for ED visits or hospitalization.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

D. Throughout the Continuum: Enhanced Support at End of Life

15. We have relationships with palliative care and/or hospice program that enable rapid transition to these services when patient symptoms escalate. In concert with these services, we are effective in helping patients avoid unwanted ED visits, hospitalizations, and ICU stays. We help patients stay at home with support if that is their goal.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in

this area. _____

16. Our practice is able to provide palliative dialysis to meet patient needs and preferences.

Palliative dialysis is a transition from a conventional disease-oriented focus of dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden in patients predicted to have less than one year to live. With a palliative dialysis approach, a dialysis index > 1.2 does not necessarily need to be met if that goal is inconsistent with the patient's preferences. Additionally, dietary restrictions are reduced, management of hyperphosphatemia and hyperparathyroidism is more permissive, laboratory monitoring is decreased to the bare minimum, dyslipidemia is not treated, hypertension may not be as tightly controlled, and a catheter as dialysis access is acceptable.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

17. Our practice follows best practices in responding to patient requests to discontinue dialysis.

- Our practice is doing this well.
- Our practice is doing this, but could do it better.
- Our practice is not doing this.
- I don't know the answer to this question OR this is not applicable

Comment: Please add any further thoughts about what your practice does well or poorly in this area. _____

ABOUT YOU

Thank you for assessing how well your practice provides kidney supportive care. To finish, please answer three questions about your professional role.

18. How many years have you cared for patients with kidney disease, CKD and/or ESRD?

- | | |
|---|---|
| <input type="checkbox"/> Less than one year | <input type="checkbox"/> 6-10 years |
| <input type="checkbox"/> 1-2 years | <input type="checkbox"/> 11-15 years |
| <input type="checkbox"/> 3-5 years | <input type="checkbox"/> More than 15 years |

19. What is your professional job category?

- ☐ Physician
- ☐ Physician Assistant
- ☐ Nurse Practitioner
- ☐ Nurse
- ☐ Dialysis Technician
- ☐ Dietician
- ☐ Social Worker
- ☐ Administrator
- ☐ Other

If other, please explain: _____

20. Where do you work? (check all that apply)

- ☐ Dialysis center(s)
- ☐ Nephrology outpatient practice or clinic
- ☐ Hospital dialysis unit
- ☐ Palliative care team
- ☐ Hospice
- ☐ Other

If other, please explain: _____

Thank you for taking the time to complete this assessment. It is greatly appreciated.

Supplement 6d: NOMAD adaptation

INSTRUCTIONS

Who should complete this survey:

To be completed by all providers and staff involved in implementing the Pathways Project change package for **dialysis patients**.

Purpose:

This survey is designed to help get a better understanding of how to apply and integrate complex interventions in health care. It is a validated tool that has been designed to capture 16 cognitive and behavioral components related to how new practices become a routine part of work. (To learn more about the survey and for references: <http://www.normalizationprocess.org/nomad-study/>).

How to complete this survey:

This survey asks questions about the implementation of the Pathways Project change package. The “change package” refers to the 14 evidence-based recommendations designed to bring about improvements in the supportive care delivery for patients with kidney disease.

This survey is in 3 parts:

Part A asks some brief questions about yourself and your role.

Part B includes general questions about implementing the change package.

Part C contains a set of more detailed questions about your implementation process of 3 components of the change package.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components relate to each of the 3 change package elements separately.

We understand that some people in their roles may work across organizations and with different patient populations; please answer all questions in relation to the **dialysis patient population ONLY for the organization you mark below**.

Please take the time to decide which answer **best suits your experience for each statement and mark the appropriate box**.

PART A: About yourself

1. For which dialysis center do you work?

2. How many years have you worked for that dialysis center?

☐ Less than one year

☐ 1-2 years

☐ 3-5 years

☐ 6-10 years

☐ 11-15 years

☐ More than 15 years

3. What is your profession?

☐ Nurse

☐ Nurse practitioner / physician assistant

☐ Nephrologist

☐ Social worker

☐ Other: _____

PART B: General questions about implementing the change package

4. Please select which of the 14 elements of the change package you personally have been working to implement so far.

- ☐ Assemble an interdisciplinary team for your setting with a day-to-day leader and champion(s)
- ☐ Assess unmet supportive care needs in patient population
- ☐ Provide education to staff on the principles and practices of primary supportive care, including communication skills
- ☐ Collaborate with palliative care/hospice specialists
- ☐ Implement shared decision-making for current and advance care planning for future care options*
- ☐ Welcome, support and involve family (defined by patient) in the care process to the extent desired by patient
- ☐ Create structures (EMR, registries) to make proxies, advance directives and portable medical orders available and actionable across care settings
- ☐ Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions*
- ☐ Provide medical management without dialysis to patients avoiding or delaying dialysis
- ☐ Screen and manage pain and symptoms
- ☐ Assess psychological and spiritual needs and address needs
- ☐ Proactively identify and manage patients at high-risk for frequent hospital readmission
- ☐ Coordinate care and care transitions with specialty palliative care and hospice
- ☐ Offer palliative dialysis and systematic dialysis withdrawal process for appropriate patients*

**indicates core component*

[illegible]

7. Do you feel advance care planning <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
8. Do you feel advance care planning <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
9. Do you feel palliative dialysis <u>is currently</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10
10. Do you feel palliative dialysis <u>will become or remain</u> a normal part of your work?	0	1	2	3	4	5	6	7	8	9	10

PART C: Specific questions about change package implementation

The next three sections present detailed statements about the three core components of the change package:

1. identifying and prioritizing seriously ill patients;
2. implementing shared decision making and advance care planning; and
3. palliative dialysis.

Rate how much you agree or disagree with each statement for the component of the change package for that section, or state if it is not relevant.

The set of questions in this section are repeated three times because we want to understand how all 16 of the cognitive and behavioral components of how work becomes normalized relate to each of the 3 change package elements separately.

If you have not yet implemented the element of the change package, skip that set of questions.

Section C1. Please think about your practice of **identifying and prioritizing seriously ill dialysis patients** for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how identifying seriously ill patients differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how identifying seriously ill patients affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of identifying seriously ill patients for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive identifying seriously ill patients forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in identifying seriously ill patients is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate identifying seriously ill patients into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to identify seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of identifying seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that identifying seriously ill patients is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that identifying seriously ill patients has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work with identifying and prioritizing seriously ill patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C2. Please think about your practice of **shared decision making and advance care planning (ACP)** with dialysis patients for this section.

If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how shared decision making and ACP differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how shared decision making and ACP affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of shared decision making and ACP for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive shared decision making and ACP forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in shared decision making and ACP is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate shared decision making and ACP into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to implement shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that shared decision making and ACP is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that shared decision making and ACP has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to do shared decision making and ACP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C3. Please think about your practice of **palliative dialysis** for this section.
If you have not yet implemented this component, check the box and skip this section. ☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not relevant
I can see how palliative dialysis differs from usual ways of working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff in this organization have a shared understanding of the purpose of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how palliative dialysis affects the nature of my own work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can see the potential value of palliative dialysis for my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are key people who drive offering palliative dialysis forward and get others involved.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that participating in palliative dialysis is a legitimate part of my role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm open to working with colleagues in new ways to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will continue to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can easily integrate palliative dialysis into my existing work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in other people's ability to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient training is provided to enable staff to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sufficient resources are available to support palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of reports about the effects of palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The staff agree that palliative dialysis is worthwhile.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I value the effects that palliative dialysis has had on my work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can modify how I work to offer palliative dialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the survey!