

## Supplemental Material

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**Supplemental Table 1. Patient Demographic and Clinical Characteristics (n=1,459)**

<b>Patient Characteristic</b>	<b>n (%)</b>
Sex	
Male	846 (58%)
Female	613 (42%)
Comorbidities at Dialysis Initiation*	
Hypertension	1277 (87.5%)
Diabetes Type 2	642 (44%)
Pulmonary Edema	350 (24%)
Myocardial Infarction	255 (17.5%)
Angina	248 (17%)
Coronary Bypass	211 (14.5%)
Peripheral Vascular Disease	190 (13%)
Smoker	175 (12%)
Cerebrovascular Disease	168 (11.5%)
Malignancy	146 (10%)
Chronic Obstructive Pulmonary Disease	102 (7%)
Diabetes Type 1	58 (4%)
Length of Time on Dialysis	
Less than 1 year	205 (14%)
1 to 5 years	678 (46.5%)
5+ years	576 (39.5%)

\*Patients often have multiple co-morbidities; therefore, total exceeds 100%

**Supplemental Table 2. Profile of Survey Respondents Pre- & Post-Implementation**

<b>Demographic Variable</b>	<b>Pre-Implementation Survey</b>	<b>Post-Implementation Survey</b>
<b>Patient Surveys</b>	<b>n=718</b>	<b>n=569</b>
Site:		
CVH	161 (22%)	141 (25%)
JHH	65 (9%)	89 (14%)
LHS	94 (13%)	39 (7%)
NBH	48 (7%)	47 (8%)
NFS	50 (7%)	51 (9%)
OTM	113 (16%)	82 (14%)
SMH	92 (13%)	20 (4%)
TGH	95 (13%)	100 (18%)
Length of time on dialysis:		
Less than 6 months	79 (11%)	9%
6 months to 1 year	79 (11%)	14%
1 to 3 years	223 (31%)	32%
More than 3 years	330 (46%)	44%
<b>Provider Surveys</b>	<b>n=514</b>	<b>n=319</b>
Site:		
CVH	145 (28%)	49 (15%)
JHH	44 (9%)	45 (14%)
LHS	54 (11%)	41 (13%)
NBH	17 (3%)	22 (7%)
NFS	26 (5%)	16 (5%)
OTM	60 (12%)	30 (9%)
SMH	66 (13%)	6 (2%)
TGH	102 (20%)	110 (34%)
Profession:		
Nephrologist	31 (6%)	16 (5%)
Nurse Practitioner	7 (1%)	6 (2%)
Registered Nurse	381 (74%)	239 (75%)
Registered Practical Nurse	21 (4%)	5 (2%)
Pharmacist	9 (2%)	4 (1%)
Social Worker	10 (2%)	10 (3%)
Dietitian	12 (2%)	11 (3%)
Clerk	26 (5%)	12 (4%)
Other	17 (3%)	16 (5%)
Years in Practice:		
Less than one year	31 (6%)	16 (5%)
1-5 years	129 (25%)	83 (26%)
6-10 years	72 (14%)	38 (12%)
11-20 years	200 (39%)	112 (35%)
21 years or more	82 (16%)	70 (22%)

## Implementation Details for “Your Symptoms Matter” (ESAS-r:Renal) Project

Implementation of the “Your Symptoms Matter” (ESAS-r:Renal) Project was a joint effort between the Ontario Renal Network (ORN) project team and the eight participating sites, specifically 1-2 designated project leads at each site. Project leads were individuals in administrative or managerial roles responsible for overseeing and facilitating implementation at their site, attending bi-weekly teleconferences with the ORN team, and ensuring submission of required deliverables to the ORN. Each site also had multiple designated project champions. Champions were practicing clinicians (one per discipline where possible) and were responsible for promoting the project to their peers. It is important to note that although all eight sites volunteered to participate in the project, data submission associated with the project was included in the funding agreements of the participating sites and was therefore a mandated deliverable with financial implications for non-compliance.

The seven phases of the implementation process are outlined below and were executed over approximately a two-year period from April 2016 to June 2018.

### 1. *Phase 1: Current State Assessment*

In partnership with the sites, the ORN conducted a current state assessment. Each site developed a current state workflow that was validated by the ORN.

### 2. *Phase 2: Future State Planning*

Sites developed their future state workflow for screening, assessment, management, and documentation using an ORN-developed workflow guidance document. Future state workflows were reviewed and validated by the ORN. In general, the project was considered a nursing-led initiative in which nurses conduct symptom screening and assessment followed by consultation with and triage to other disciplines, as needed (e.g., nephrologists, social workers, dietitians). Clerks also played a key role in directing patients to complete the questionnaire upon arrival.

### 3. *Phase 3: ORN-Led Education & Training*

Using a “train the trainer” approach, a total of 105 clinical and administrative project leads and champions from across the sites participated in ORN-developed education and training sessions, including 40 allied health professionals, 27 clinical and administrative managers, 15 supportive staff members (clerks, data leads, educators), 12 nurses, and 11 nephrologists. Session attendance was mandatory for project leads and project champions. The sessions were held in person at each site and led by an ORN-affiliated nephrologist and ORN staff members. The sessions covered: (1) rationale for a standardized approach to symptom screening, assessment, and management, (2) description of patient-reported outcomes and associated evidence base, (3) description of ESAS-r:Renal questionnaire and associated evidence base, (4) implementation plan, including provider roles and workflow, (5) evaluation plan, and (6) provider and patient resources to support implementation.

Regarding resources to support implementation, the ORN developed five symptom management guides for providers on anxiety and depression, insomnia, pain, pruritus, and restless legs syndrome. Revised versions of these guides are publicly available at: <https://www.ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/symptom-management>. To view the original versions of the guides used in the study, please contact the authors because these are no longer publicly available. For providers and managers, the ORN also provided scripts and tips for patient interactions, including inviting patients to participate, responding to patients who decline to participate, and communicating about the project with cognitively impaired, non-speaking, non-hearing, and non-English speaking patients. The ORN also requested that sites encourage providers to complete Pallium Canada’s Learning Essential Approaches to Palliative Care (LEAP) Renal course, which covers symptom management in addition to other topics.

#### *4. Phase 4: Site-Led Education & Training*

As per a “train the trainer” approach, after completing their training, project champions then trained members of their care team using the content and materials provided in phase 3. Given contextual differences across sites, local leaders and champions had the autonomy to determine how best to disseminate the necessary information. Sites used a variety of strategies to educate and train providers, such as huddles, presentations, e-mails, and bedside demonstrations. Commonly reported barriers to provider participation in education and training included time constraints, competing priorities, schedule conflicts, and the learning curve associated with changes to documentation.

Care team members educated patients about the project and about ESAS-r:Renal. The following strategies were used to educate and recruit patients: brochures, instruction sheets, posters, newsletters, video via monitors, and discussion at patient and family advisory council meetings. Providers commonly reported the following reasons for patient declines: patient does not feel there is any benefit, is too sick or tired to complete it, has a cognitive impairment, or does not have symptoms to report.

#### *5. Phase 5: Site Readiness and Sustainability Assessment*

Sites completed an ORN-developed readiness assessment to confirm implementation readiness based on completion of key activities in the following areas: training and education, workflow, data submission, and ongoing communication and engagement.

During early and late implementation, sites also completed the National Health Service (NHS) Sustainability Survey to support local change management. The survey entailed participants self-assessing their site’s implementation of the project against ten evidence-based criteria for sustaining change organized into three categories: Staff, Process, and Organization.

#### *6. Phase 6: Implementation*

Sites implemented project tools and processes. Implementation was monitored by the ORN project team (see phase 7 below) to ensure implementation fidelity to the core aspects of the project, recognizing that contextual differences between sites would necessitate some variation in approaches to both training and implementation. A prime example is the use of iPads at one site (TGH). Use of iPads appeared to facilitate implementation and providers at other sites often mentioned that use of technology would streamline workflow and documentation. However, it is important to note the costs of the iPads as well as the logistics of using them, which included challenges like sanitizing, charging, and storing them as well as linking data input to patient charts.

There were no major contextual changes during this period that may have influenced implementation.

#### *7. Phase 7: Evaluation & Reporting*

On a bi-weekly basis, the ORN team held teleconferences with project leads to discuss updates and risks and share learnings. On a monthly basis, sites submitted mandatory ESAS-r:Renal data to the ORN, and the ORN provided feedback reports showing screening rates relative to other sites. On a quarterly basis, project leads submitted reports on ongoing education and training efforts, project milestones, and risks. The ORN team conducted site visits on as need basis. Sites also participated in evaluation activities, which included pre- and post-implementation patient and provider surveys, mid-implementation patient and provider interviews, and a chart audit. The evaluation is described in detail in the main manuscript.

**For further details regarding implementation and evaluation, please contact the authors.**

## **Reflections on Provider Education**

A core component of the project was provider education. Based on a separate unpublished evaluation of education, key lessons learned are outlined below.

- The “train the trainer” approach to educating providers appeared effective, allowing for local adaptation of centrally-developed materials and resources. However, it was not possible for the ORN to verify the quality of the training delivered within sites.
- Multiple modes of education maximized reach (e.g., in-person sessions, site visits, emails, posters, printed materials such as symptom management guides).
- Providers need additional education and training in managing psychosocial symptoms.
- Provider symptom management guides were focused on medical and pharmaceutical interventions, and therefore inadvertently targeted nephrologists; the guides should be (and have since been) modified to include non-medical interventions to support other providers in contributing to symptom management.
- In addition to supporting patients, patient self-management guides may serve as educational tools for providers (and have since been developed and disseminated).

## Excerpts from Data Collection Tools: Surveys, Interview Guides, & Chart Audit Template

### Provider Post-Implementation Survey

#### Impact of the ESAS-r:Renal Questionnaire

##### 1. The ESAS-r:Renal Questionnaire:

	Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
a. ensures symptoms are not missed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. serves as a useful starting point to assess patients' symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. helps me prioritize which symptoms to discuss with my patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. improves interdisciplinary communication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. has negatively impacted unit flow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### Teamwork

##### 21. My team communicates and shares information regularly to address patient symptoms and concerns.

Strongly Agree	Agree	Slightly Agree	Slightly Disagree	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

##### 22. Relevant information relating to patient symptoms is reported to the appropriate team member in a timely manner.

Strongly Agree	Agree	Slightly Agree	Slightly Disagree	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

##### 23. The patient chart is used effectively by all team members as a tool for communicating about patient symptoms.

Strongly Agree	Agree	Slightly Agree	Slightly Disagree	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your Symptoms Matter



20. When you have **worries, concerns or feelings of sadness**, does your healthcare team help you with them (listen, provide support, recommend a treatment or medication, refer you to a specialist, etc.)?

Always      Most of the time      Sometimes      Rarely      Never

☐      ☐      ☐      ☐      ☐

21. When you want to be **involved in making decisions** about how to manage your symptoms, does your healthcare team include you?

Always      Most of the time      Sometimes      Rarely      Never

☐      ☐      ☐      ☐      ☐

### Interview Guides

Select questions from the provider interview guide are outlined below (probes not included).

- What value has YSM added, if any, to your clinical practice? Please explain.
- How has YSM detracted from your clinical practice? Please explain.
- It has been about 6 months since go-live of YSM. From your perspective, what has been working well so far in your setting?
- From your perspective, what has not been working well in your setting?
- Has YSM become a routine part of your clinical workflow? Why or why not?
- Has YSM changed the way you communicate with your patients about their symptoms? If yes, in what ways? If no, why not?
- Has YSM changed the way you communicate and interact with other healthcare providers? If yes, in what ways? If no, why not?
- What changes, if any, need to happen to increase the sustainability of YSM in your setting?

Select questions from the patient interview guide are outlined below (probes not included).

- What is your understanding of why “Your Symptoms Matter” was started?
- What do you like about “Your Symptoms Matter”?
- Did you experience any challenges with “Your Symptoms Matter”? Tell me more about that.
- Please think about the times you completed the “Your Symptoms Matter” questionnaire. On average, did someone from your healthcare team talk to you about your results? Overall, do you feel that “Your Symptoms Matter” has benefited you and your care? Why or why not?
- Does it make sense to fill in the “Your Symptoms Matter” questionnaire every 4-6 weeks? Is that too little, too much, or just right? Please explain.



## Chart Audit Template

Below is a screenshot of a portion of the chart audit template. Almost all cells had pre-determined drop-down menus. For example, under “What management approach was decided?”, options included: no intervention, patient declined intervention(s) offered, admission to hospital, medication/prescription, patient education, referral, and test (e.g., blood test, imaging), among others. Space for comments was also provided for each patient chart.

[illegible]

**To access complete versions of the patient and provider pre- and post-implementation surveys, interview guides for providers, leaders, and patients, and chart audit template, please contact the authors.**

## Qualitative Coding Trees for Patient and Provider Interviews

### *Patient Interviews Coding Tree*

- Perceived purpose of ESAS-r:Renal
  - Identify symptoms
  - Monitor symptoms over time
  - Hear patient voice/Encourage patients
  - Other
- Completing ESAS-r:Renal
  - Preferred mode of completion (i.e., tablet versus paper)
  - Barriers to completing
    - Time (e.g., called into clinic before completing)
    - Comprehension (e.g., wording, visual analog scale, English as a second language)
    - Require help to complete (e.g., due to disability, cognitive impairment, language)
    - Frequency of screening/Survey fatigue
- Value of ESAS-r:Renal
  - Advantages
    - Feel heard
    - Personal awareness of symptoms
    - Disclose more symptoms to team
    - New symptom management strategies
  - Disadvantages
    - No follow-up action
    - Symptoms already discussed and addressed by team
    - Questionnaire wording (e.g., asks about how feeling “now”)
- Impact on patient-provider communication
  - No impact
  - Positive impact
  - Negative impact
- Self-Management
  - Relative interest in symptom self-management guides
- Sustainability
  - Continuing ESAS-r:Renal
  - Frequency of ESAS-r:Renal
- Miscellaneous Commentary

### *Provider Interviews Coding Tree*

- Value of ESAS-r:Renal
  - Advantages
    - Awareness of symptoms
    - Identifies new symptoms
    - Standardizes processes
    - Relationship-building with patients
    - Symptom trending
  - Disadvantages
    - Diminished returns
    - Chronic symptoms hard to address
    - Competing priorities
- ESAS-r:Renal Questionnaire Itself (e.g., wording, visual analog scale, symptoms included)
- Education and Training
  - ORN-developed resources
    - Enable systematic approach
    - Guide provider decision-making
    - Too physician-oriented (medical/pharmacological, not useful to other staff)
    - Interest in patient self-management guides
  - ORN-led education and training sessions
    - Positive
    - Negative
- Screening & Management Process
  - Lack of confidence managing psychosocial symptoms
  - Inability to manage symptoms
    - Internal factors (e.g., lack of education/training, confidence)
    - External factors (e.g., lack of appropriate resources, referral time)
    - Feelings of 'failure'
  - Extent to which routine part of workflow
  - Documentation/Charting
- Inter-disciplinary Communication
  - Better charting
  - Already had good communication/collaboration
- Patient-Provider Communication
  - Already had good communication re: symptoms
  - More likely to discuss psychosocial symptoms
- Barriers to Implementation
  - Provider Buy-In, Engagement, and Accountability
    - Know patients well
    - Already discuss symptoms with patients
    - Need for supporting evidence
    - Lack of training in psychosocial symptoms
    - Lack of accountability to discuss or act on scores

- Patient Characteristics, Buy-In, and Engagement
  - Patient demographic and clinical characteristics
  - Patients' reasons for declining
  - Survey fatigue
  - Time to complete
  - Require help (e.g., due to language barrier, literacy, vision problems)
- Resourcing and Workload
  - Provider fatigue
  - Time (to consult with patients, to round on patients, etc.)
  - Documentation/Charting
  - Human resources
  - Distribution of workload (by profession)
  - ORN data collection
- Enablers to Implementation
  - ORN support
  - Provider buy-in and engagement
  - Project leads and champions
  - Clerical staff
  - Senior leadership support
  - Technology
  - Extra resources
  - Teamwork and communication
  - Questionnaire in multiple languages
  - Process/workflow clarity
- Sustainability
  - Continuing ESAS-r:Renal
  - Frequency of ESAS-r:Renal
  - Unintended consequences