Figure S1. BC Renal network diagram
Item S1. Interim audit survey and interview questions.

**Methods for Survey**

The survey for frontline staff was administered online via FluidSurveys. A copy of the 28-question survey is included in the next section. An e-mail invitation with the URL to the online survey was distributed in May 2014 to nephrologists directly and other frontline renal health professionals (e.g. nurses, allied health professionals, clinical support staff, administrators) via the management of all renal programs across the province. Survey period was five weeks. Overall response rate was 21% (291 responses).

**Online Survey for Frontline Staff**

The BC Provincial Renal Agency (BCPRA) is interested in understanding the effectiveness of end-of-care (EOL) care delivery across the 5 health authority renal programs. This survey will help us assess the level of awareness of different aspects of EOL care by staff who work day in and day out with renal patients. It will take about 15 minutes to complete, and is completely voluntary. All responses will be kept anonymous and confidential with only aggregate results being reported. Should you have any questions, please contact your Health Authority representative on the provincial EOL Steering Committee or the BCPRA directly at bcpra@bcpra.ca.

Your input is very important as it will help shape EOL across BC. Thanks in advance for your participation.

Please identify the Health Authority Renal Program (HARP) you belong to:

- FHA
- NHA
- IHA
- VCH-PHC
- VIHA

Please indicate your role within your HARP?

- Nephrologist
- Nursing staff
- Allied health professionals (e.g. pharmacist, social worker, dietitian, spiritual care, biomedical engineer, renal technician)
- Clinical support staff (e.g. unit clerk, care aid)
- Manager/ Director
- Others

Please indicate where you work (please check all that apply):

- CKD/ pre-dialysis clinic, e.g. KCC
- In-centre dialysis unit
- Community dialysis unit
- Peritoneal dialysis clinic
- Home hemodialysis clinic
- In-patient renal ward
- Others, please specify:
About End-of-life Care in general…
Have you accessed any training relating to EOL care?
   Yes
   No
   Don’t know

If yes, direct respondent to next question. If not or don’t know, skip to “Page 4”.

Do you feel that your training in end-of-life (EOL) care has increased your knowledge in providing care to your patients?
   Strongly agree
   Agree
   Neither agree nor disagree
   Disagree
   Strongly disagree

With your training in EOL care, do you feel confident in addressing EOL issues with your patients and their family caregivers?
   Strongly agree
   Agree
   Neither agree nor disagree
   Disagree
   Strongly disagree

Do you feel you need more multidisciplinary educational opportunities to stay current in the care of patients nearing the end of life?
   Strongly agree
   Agree
   Neither agree nor disagree
   Disagree
   Strongly disagree

About Advance Care Planning…
Do you understand the difference between advance care planning and an advance directive?
   Yes
   No
   Not sure

Are you aware of any advance care planning strategies within your health authority?
   Yes
   No

Are you aware of any specific advance care planning strategies within your renal program?
   Yes
   No
Does your renal program have criteria that trigger conversation of advance care planning with patients?

Yes
No
Don't know

Are you aware of any evaluation plan for the implementation of advance care planning in your renal program?

Yes
No
Don't know

How is the advance care planning discussion documented in your renal program? (please check all that apply):

- Green sleeve
- Blue sleeve
- Chart notes/chart orders
- Electronic medical records, e.g. Sunrise, Meditech, Cerner etc.
- Cardex
- PROMIS
- Others, please specify:
- Not documented at all

In which circumstance would substitute decision-makers usually be identified?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upon registration to renal services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>As deemed necessary by renal staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others, please briefly describe:</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

In your renal program, advance care planning discussion is initiated with patients... (Please check all that apply.)

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others, please briefly describe:</td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

Have you accessed any training relating to advance care planning?

Yes
No
Don’t know

If yes, direct respondent to next page. If not, skip to “Page 6”.
Do you feel that your training has equipped you with the necessary skills to talk about advance care planning with your patients?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

As a result of your training in advance care planning, has your job satisfaction increased?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

As a result of your training in advance care planning, has your confidence to address symptom issues with your patients increased?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please select which, if any, of the following topics would enhance your ability to discuss advance care planning. (Please check all that apply.)

- How to execute potentially difficult conversations
- How to deal with patients and family members who become emotional
- How to deal with my emotion
- The legal and/or technical aspects of advance care planning
- Others, please specify:
  - I am not interested
  - I don’t know

About Symptom Assessment and Management...

Are all patients at your clinic/unit regularly screened for commonly associated renal symptoms?

- Yes
- No
- Don’t know
How are symptom assessment results documented in your renal program? (Please check all that apply)

- Chart notes/chart orders
- Electronic medical records, e.g. Sunrise, Meditech, Cerner etc.
- Cardex
- PROMIS
- Others, please specify:
- Not documented at all

Are the provincial algorithms created for pain control, insomnia, pruritus, restless leg syndrome used in the care area you work in?

- Yes, always
- Yes, depending on circumstances
- No
- Unaware of these algorithms

Have you accessed any training relating to symptom assessment and management?

- Yes
- No
- Don’t know

*If yes, direct respondent to next page. If not, skip to end of the survey.*

Do you feel that your training has equipped you with the necessary skills to address symptom burden in your patients?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

As a result of your training in providing symptom care, has your job satisfaction increased?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

As a result of your training in providing symptom care, has your confidence to address symptom issues with your patients increased?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
Do you feel that you need more multidisciplinary educational opportunities to improve your knowledge in addressing symptom issues in your patients?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

End of survey

Interviews with Regional Champions

Patient Identification
- What are the common characteristics that would trigger discussion of focused end-of-life care needs and plan?
- Which clinical roles are involved in patient identification? How are they involved?

Advance Care Planning (ACP)
- How does the advance care plan strategy within your renal program align with the strategy within your health authority?
- At what stage do you think would be most appropriate in initiating ACP with individual patients?
- What is the training available for ACP? Do you feel that you are well supported by your health authority with regards to ACP training? If so, do you feel you need more support? How comfortable are you in taking a leadership role with regards to educating staff about ACP?

Symptom Assessment & Management
- What is the process that your program uses for symptom assessment & management and documenting the assessment & management?
- Under what circumstances are the algorithms created for pain control, insomnia, pruritus, restless leg syndrome used in your renal program?

Care of the Dying Patient & Bereavement
- How important it is for you to assess the quality of dying and death of patients in your renal program from the patient perspective? From the family and caregiver perspective? From the health care provider perspective?
- Does your renal program follow up with families and caregivers after the death of patients? If so, how?

End-of-Life Training
- What does EOL training for all (multidisciplinary) staff at your HARP entails?
- Have you developed unique tools for EOL training? If so, what are they? What motivated you to develop those tools?
- Does your HARP assess satisfaction of staff in EOL training and care?
**Table S1. Overview of recommendations and progress in renal palliative care**

<table>
<thead>
<tr>
<th>Components</th>
<th>Framework Recommendations (December 2009)</th>
<th>Progress (as of Fall 2018)</th>
</tr>
</thead>
</table>
| Patient Identification               | Use of prognostication strategies (i.e. serum albumin, the surprise question, comorbid conditions and others) to identify patients at risk of death | • Commonly used prognostic parameters include the surprise question, serum albumin and sentinel events.  
• Research working group surveyed Canadian nephrologists and found that similar parameters are used for assessing prognostication in ESKD.  
• In a validation study, the research working group found that a well-received six-month mortality prediction model has limited clinical utility despite reasonable performance in BC cohort. |
| Advance Care Planning (ACP)         | Discussion of goals of ACP, identification of patients who could benefit most from ACP, initiation and structuring ACP conversations, and integrating it into patient care | • In the 2014 survey, 83% of kidney care professional respondents were aware of the ACP strategies in their programs; 57% had received ACP training and the majority thought that their training has equipped them for the ACP conversations with patients  
• A PROMIS module was developed to monitor ACP activities; gradual uptake of the module is observed.  
• ACP is incorporated in all renal programs to various extent, e.g. one renal program has formally integrated a structured process. |
| Symptom Assessment & Management     | Use of symptom assessment tools (i.e. ESAS-revised: Renal and Modified Patient Outcome Scale) and management strategies to enhance patients’ quality of life | • *My Symptom Checklist* (adapted ESAS-revised: Renal) in multiple translations, information sheet and online training were developed and available on website.  
• A PROMIS module was developed to monitor symptom assessment & management using *My Symptom Checklist*; a trending function for scores of individual symptoms was recently added.  
• Algorithms and other resources for common symptoms were developed and periodically updated.  
• Routine symptom assessment using *My Symptom Checklist* and management take place in all renal programs in different forms.  
• Both uptake of *My Symptom Checklist* and scores of common symptoms are reported provincially and regionally every 6 months.  
• Increasing uptake of *My Symptom Checklist* in all kidney care settings is observed over the years. |
| Care of the Dying Patient & Bereavement | High quality care nearing the end of life with agreed-upon care plan, symptom management with support of palliative care specialists as needed, an integrated, culturally appropriate approach followed with bereavement after death for surviving family/ friends as well as staff | • Strengthened relationships with hospice palliative care services and primary care enable collaborations in individual patient care.  
• *Recommendations to Support ESKD Patients in their Last Days to Hours of Life* was developed and disseminated.  
• Various practices in follow up of deaths and bereavement for family/ friends and staff are observed in renal programs, e.g. mailing a personalized condolence card and hosting a bereavement tea for staff and families. |
| Education                           | Education strategy that includes training of champions by palliative and renal experts, ongoing core training in key concepts to renal programs, making available updated tools and resources, advocating for professional educational opportunities, and demonstrating benefit of training and use of guidelines | • Over 33 provincial multi-disciplinary educational sessions via featured provincial rounds and BC Kidney Days were delivered.  
• Funding for continual education and training in HARPs sustains capacity building in palliative and EOL care.  
• Mutual learning is fostered among nearly a hundred champions from all HARPs with both palliative and renal experts via BC Renal Palliative Care Committee.  
• >53 updated tools and resources are made available online. |
### Table S2. Kidney care professionals and their content expertise in renal palliative care

<table>
<thead>
<tr>
<th>Role</th>
<th>Content Expertise in Renal Palliative Care</th>
</tr>
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</table>
| Nephrologist                       | • Prognostication  
• Symptom management  
• Direct communication and collaboration with palliative care specialists (e.g. referral to palliative services)  
• Medical Order of Scope of Treatment                                                                                                                                 |
| Nurse                              | • Symptom assessment  
• Navigation of care and support, e.g. alerting team to patient's sentinel event and/or need to review advance care plan                                                                                                                                 |
| Social worker                      | • Advance care planning, e.g. specifics regarding representation agreement  
• Psychosocial support  
• Liaise with hospice palliative care  
• Bereavement follow up for staff and patient's family                                                                                                                                 |
| Pharmacist                         | • Symptom management: pharmacological and non-pharmacological interventions  
• Medication reconciliation                                                                                                                                 |
| Spiritual health practitioner      | • Spiritual care needs  
• Bereavement                                                                                                                                 |

### Table S3. Symptom assessment practices in health authority renal programs

<table>
<thead>
<tr>
<th>Health Authority Renal Program</th>
<th>Targeted populations</th>
<th>Frequency</th>
<th>Trigger for review</th>
<th>Symptom screening tool presented to patient by</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Non-dialysis, HD, PD</td>
<td>every 6 months and post-hospitalization</td>
<td>medical reconciliation</td>
<td>Pharmacy Technician</td>
</tr>
<tr>
<td>B</td>
<td>Non-dialysis, HD, PD</td>
<td>every 3 months or as needed</td>
<td>as deemed necessary</td>
<td>Nurse</td>
</tr>
<tr>
<td>C</td>
<td>Non-dialysis, HD, PD</td>
<td>every 6 months</td>
<td>medical reconciliation or clinic visit</td>
<td>Pharmacy Technician, Nurse or Unit Coordinator</td>
</tr>
<tr>
<td>D</td>
<td>Non-dialysis, HD, PD</td>
<td>at entry, post-hospitalization, and as needed thereafter</td>
<td>as deemed necessary</td>
<td>Social Worker</td>
</tr>
<tr>
<td>E</td>
<td>Non-dialysis, HD, PD</td>
<td>every 3 or 6 months</td>
<td>designated rotation cycles or clinic visit</td>
<td>Nurse</td>
</tr>
</tbody>
</table>