



Palliative Approach to CKD Care

Presented by :

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OBJECTIVES



- What is the PCC?
- What is the Integrated Palliative Nephrology (IPN) project?
- Define a palliative approach to care
- Why is it important to renal care?
- How to use the palliative approach in the KCC setting
- Tools available
- Define renal palliative care quality metrics in BC

Goal of the BCPRA Palliative Care Committee (PCC)



- To ensure that all patients with CKD have access to high quality, integrated palliative care
- Works collaboratively and aligns with HA efforts in end of life care
- Close the gap between primary care physicians and nephrologists

Working together

- Provide opportunities that maximize partnerships, networking and information sharing throughout the renal network
- Continue collaboration between KCC and PCC committees

2012-2013			2014-2015		2016-2017		2018+
Publication of protocol and algorithms for symptom management	Launch of online training module for symptom assessment	Initial use of mESAS tool (SPH, VGH, Victoria HD Units / KCC)	Formation of research working group to address knowledge gaps in renal palliative care	Environmental scan to review progress for strategizing improvement in renal palliative care	Formation of Quality Metrics Working Group leading to development of standardized reporting of mESAS for <i>all HA renal programs</i> via PROMIS	Development of ACP Module (PROMIS) with launch of broad implementation plan across all HA renal programs	Environmental scan to understand current knowledge, available resources, gaps, & barriers related to integrative palliative renal care
Conservative Care Pathway Developed							

Integrated Palliative Nephrology Project



- Develop a provincial strategy to effectively integrate a palliative approach for all Chronic Kidney Disease (CKD) patients
- Working group provides input and feedback to support decision making and next steps (monthly meetings)
- WG Membership

What are patients telling us?

- Proactive and empathetic listening
- Health care providers to assess, discuss and listen to their personal goals
- Information about treatment options and progression
- A holistic approach to care
- Good pain and symptom management

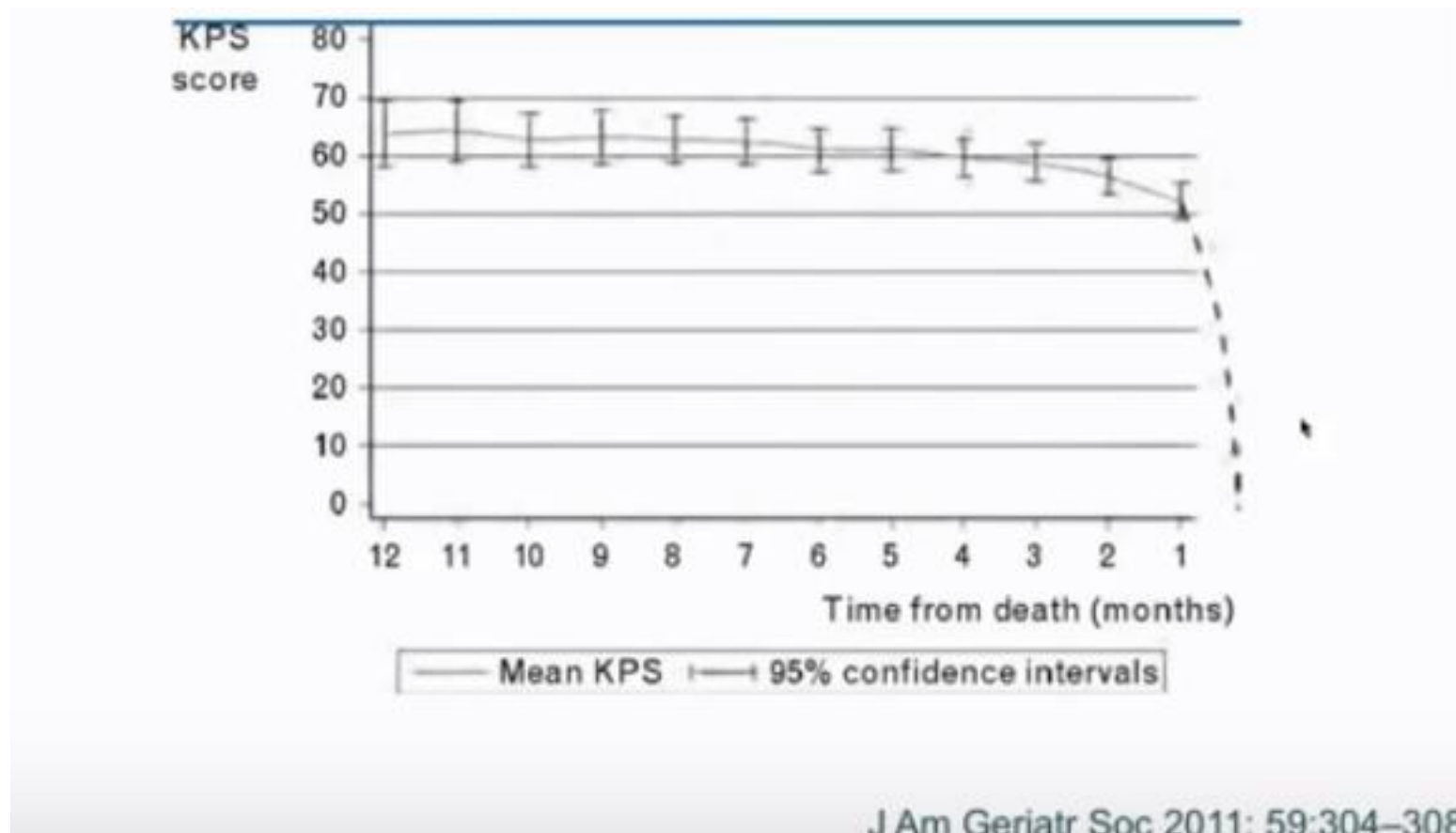


Who are our CKD patients?

- Mostly elderly average >70 years
- Multiple coexisting co-morbidities
- High symptom burden
- Challenging EOL planning and progression
- High mortality rate



The last year of life for patient with CKD-5



KPS = Karnofsky Performance Scale

Palliative approach

- Person centred care guided by the understanding that the person is on a progressive life limiting journey



Palliative approach

- Palliative approach is different from “palliative care” which is traditionally reserved for patients in their final six months of life, when they qualify for registration with the BC Palliative Benefits Program



Palliative approach

- Living well at all stages
- Shared decision making to best suit patient needs
- Focuses on values and wishes, more than prognosis
- Provides vital elements that can inform health care decisions in the future



Importance of a palliative approach

- Improvement of QOL in all stages of care
- ACP and goals in early stages
- May prevent emotional trauma at end of life
- Reinforces patients' right to be involved



Some ways to use a palliative approach in KCC

- Initiating conversations that will identify patient's wishes and values
- Working as a team collaboratively to honour the values and wishes of the patients
- Encouraging patients to reflect on, communicate their values (ethnic, cultural, religious)

Some ways to use a palliative approach in KCC

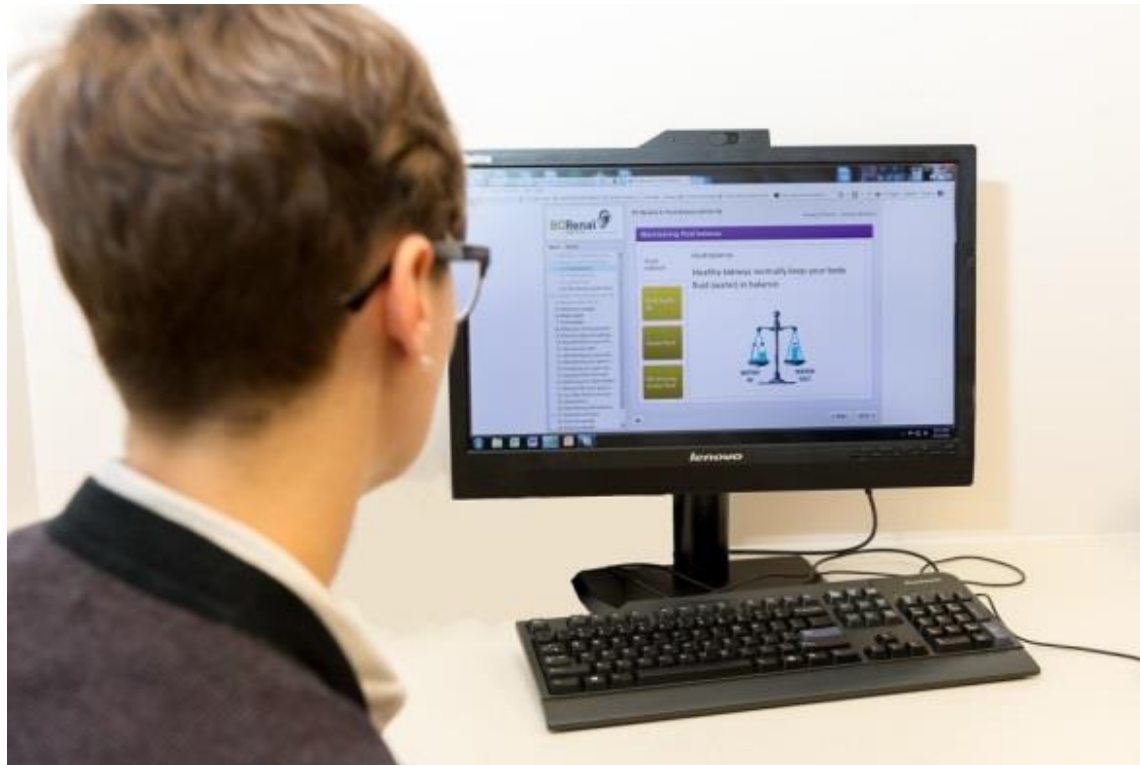
- Why before and throughout journey? To understand values and goals of patient which aligns care based on goals
- Key time to have this type of conversation during modality selection or before

Conversations

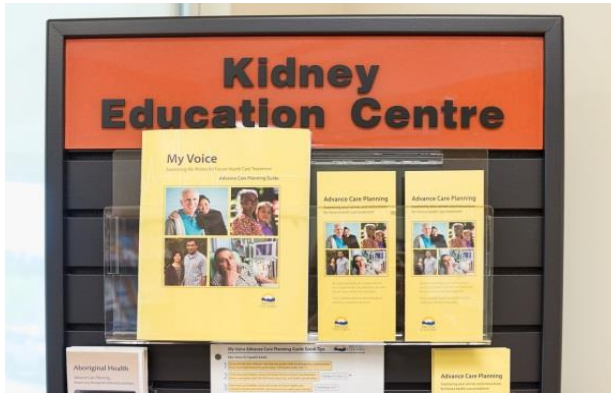


- Having conversations earlier and more frequently throughout KCC journey
- I hope you will start feeling better soon....
- However, I worry that you may not improve....
- I wonder if we should look at a plan that fits with what matters most to you...

Tools to support a palliative approach to care



Health Authority /BC MOH/ National Tools



Speak Up

- My Voice
- Green sleeve
- MOST Form
- Advance Care Planning: Respecting Aboriginal Ceremonies and Rites
- Wallet Cards
- ACP Documents

Label: Renal Program Large Greensleeve Contents
(using Provincial My Voice Workbook)

REQUIRED

- ☐ Advance Care Plan Tracking Record (PH Form #610223)

Preferred but OPTIONAL

- ☐ Advance Care Plan Summary (My Voice, pg. 27)
- ☐ CPR/No CPR Physician Order and/or Provincial "No CPR" Form
- ☐ Advance Directive (pg. 50-51)
- ☐ Temporary Decision Maker List (pg. 28-29)
- ☐ Committee of Person or
- ☐ Representation Agreement 7 (pg. 40-42) or
- ☐ Representation Agreement 9 (pg. 44-45)

*Power of Attorney: is not for Health Care

Aboriginal Health

Advance Care Planning:
Respecting Aboriginal Ceremonies and Rites



Supporting access to appropriate
health care services for First Nations
and Aboriginal peoples



My Symptom Checklist/mESAS

MY SYMPTOM CHECKLIST (MODIFIED ESAS*)

It is important that your care team understand and monitor your symptoms over time. This checklist helps us do this. For more information, please see letter on the other side of this form.

Date: _____ (DD-MON-YYYY)
Time: _____ (HR24:MI)

Please circle the number that best describes how you have been feeling over the PAST WEEK with each symptom.

Scale: 0 = no symptom 10 = the worst possible for the symptom

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired (feeling lack of energy)	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated (feeling like throwing up)	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed (feeling sad)	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious (feeling nervous)	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy (feeling sleepy)	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite (feeling hungry)	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best feeling of wellbeing (overall comfort)	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of wellbeing
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
No itch	0 1 2 3 4 5 6 7 8 9 10	Worst possible itch
No problem sleeping	0 1 2 3 4 5 6 7 8 9 10	Worst possible problem sleeping
No restless legs	0 1 2 3 4 5 6 7 8 9 10	Worst possible restless legs
Any other symptom or concern? Please specify: _____		
No symptom	0 1 2 3 4 5 6 7 8 9 10	Worst possible symptom

This section to be completed by staff.

Scale completed by: (check one)

☐ Patient

☐ Care Team Member Assisted

☐ Family Member

☐ Patient refused (note why if known)

☐ See progress notes for follow up on symptoms

☐ Care plan updated

☐ Results entered in PROMIS

Enter date: _____ Entered by: _____

PATIENT INFORMATION/LABEL

Name: _____

Address: _____

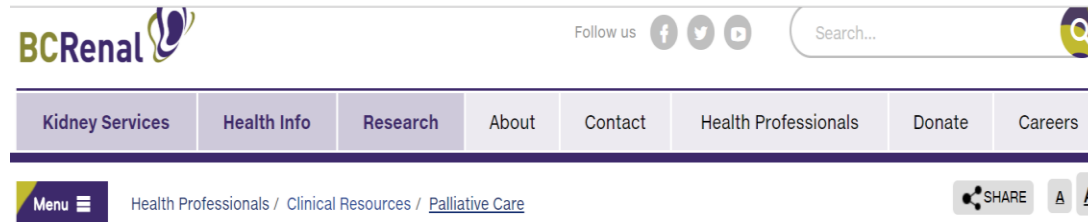
Phone: _____

PHN: _____

- Assessing patients using tool to support their voice and perspective
- Aim to improve symptoms care by reducing overall stress due to symptom burden
- Coming soon...



Symptom Management Guides



Palliative Care

The BC Renal Agency, working with kidney care professionals from across the province, aims to support the delivery of high-quality care for people with kidney disease in the last years, months or days of their lives, regardless of where they live in BC.

[Guidelines & Tools](#)

[Resources](#)

[Symptom Assessment and Management >](#)

Common Symptom Guides

Constipation	+
Depression and Anxiety	+
Fatigue	+
Nausea/Poor Appetite	+
Muscle Cramps	+
Pain Management Resources	+
Pruritus	+
Restless Leg Syndrome	+

Symptom management algorithms with co-related patient resources

Conservative Care Pathway



Conservative Care Pathway

Created November 2016; Updated November 2017
Approved by the BCPRA Kidney Care Committee



Recommendations to Support ESKD Patients in Their Last Days to Hours of Life



- Working with primary care practitioners
- Hospices
- Please share with your patient's primary care provider



Recommendations to Support End-Stage Kidney Disease Patients in Their Last Days to Hours of Life

Created 2018

Approved by the BCPRA Palliative Care Committee



Serious Illness Conversation

Serious Illness Conversation Guide

CLINICIAN STEPS

- ☐ **Set up**
 - Thinking in advance
 - Is this okay?
 - Combined approach
 - Benefit for patient/family
 - No decisions today
- ☐ **Guide** (right column)
- ☐ **Summarize and confirm**
- ☐ **Act**
 - Affirm commitment
 - Make recommendations to patient
 - Document conversation
 - Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? <small>FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.</small>
Prognosis	Share prognosis, tailored to information preferences
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes? <small>(Suggest bringing family and/or health care agent to next visit to discuss together)</small>

Draft #4.2 12/10/13
© 2012 Arjanne Laks, A Joint Center for Health Systems Innovation and Dana-Farber Cancer Institute

- Workshop at BCKD
- 10 Renal SIC champions trained
- Educational Outreach visits in your health authority
- Part 2- KCC “Lunch and Learn”

In progress....



BCPRA Palliative care quality metrics report

Why?

- Identified need to develop an evaluation report to show strengths and gaps in renal palliative care

How?

- Consensus-building exercise with a multi-disciplinary team and patients with kidney disease

Quality metrics for renal palliative care

A report designed to inform regional/ provincial quality improvement and strategic planning for end of life renal care



ACP and mESAS Module PROMIS

ACP module tracks *reporting* of:

- ACP discussion
- if patient has any ACP documentation
- If patient has a Medical order for scope of treatment
- Substitute decision maker/agreements

ACP Module - PROMIS

PROMIS Home Reports Maintenance View

Search Patient **SSAUNDERS**

Worklist

***TESTPATIENT, 123** **DOB 20-Feb-1972 (46y)** **SEX F** **PHN** **BCT ID**

ABO/Rh **PROMIS ID P49884**

Overview Patient Info **Assessment** Renal

ACP ACP Documents

Advance Care Planning

ACP Discussion

ACP discussion occurred

Initial discussion date

Latest follow-up discussion date

ACP Documents

Does any legal ACP document exist

Does any other ACP document exist

Medical Order for Scope Treatment

Does any medical order for scope of treatment exist

Patient Panel

Drug Allergies

SULPHA (HIVES), ASA (STOMACH UPSET) 5555555

Current Medications

Last Reconciliation Date 06-Dec-2016

DARBEOETIN ALFA (ARANESP) IV
Take 60 microgram once weekly.
Started 24-Mar-2011


EPOETIN ALFA Subcutaneous Take
1000 unit(s) every morning.
Started 29-Oct-2012

ESCITALOPRAM (CIPRALEX) TAB PO
Take 20 mg once daily. ordered by Dr
McDreamy
Started 08-May-2011

mESAS Module - PROMIS

PROMIS Home Reports Maintenance View

Search Patient **SSAUNDERS**










Worklist >>  ***TESTPATIENT, 123** DOB 20-Feb-1972 (46y) SEX F PHN ABO/Rh BCT ID PROMIS ID P49884

Overview Patient Info **Assessment** Renal

ESAS ESAS Trending

[< ESAS Summary](#)


Assessment Date/Time
02-Feb-2017 15:00

Pain		5
Tiredness		3
Nausea		10
Depression		9
Anxiety		8
Drowsiness		7
Appetite		6
Feeling of well being		5
Shortness of breath		4

>> Patient Panel

Drug Allergies

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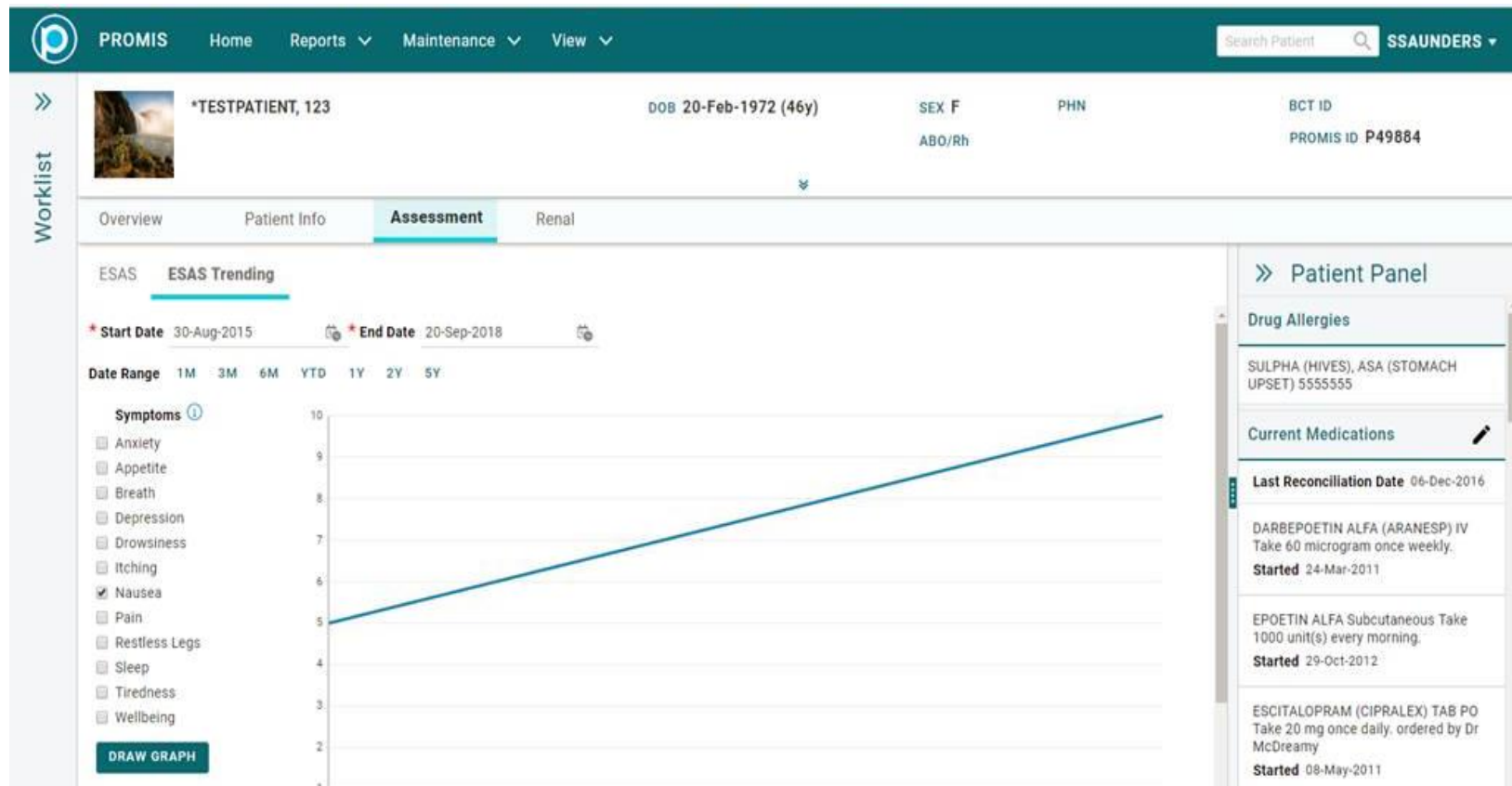
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mESAS Module - PROMIS

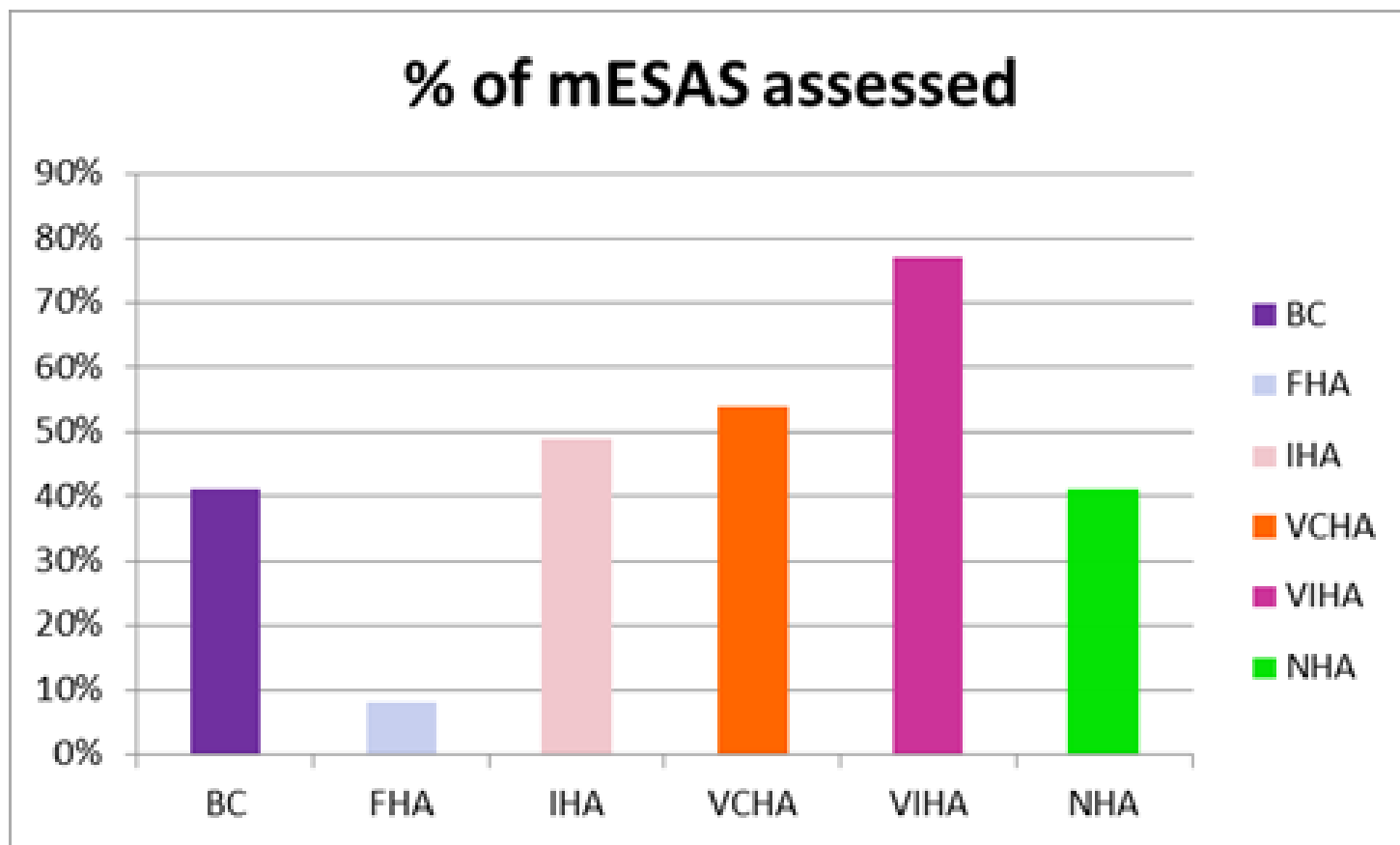


BC results – Modified ESAS assessments KCC GFR <15

Modality	KCC GFR <15					
	BC	FHA	IHA	VCHA	VICHA	NHA
% of mESAS assessed	41%	8%	49%	54%	77%	41%

HA results- mESAS assessment

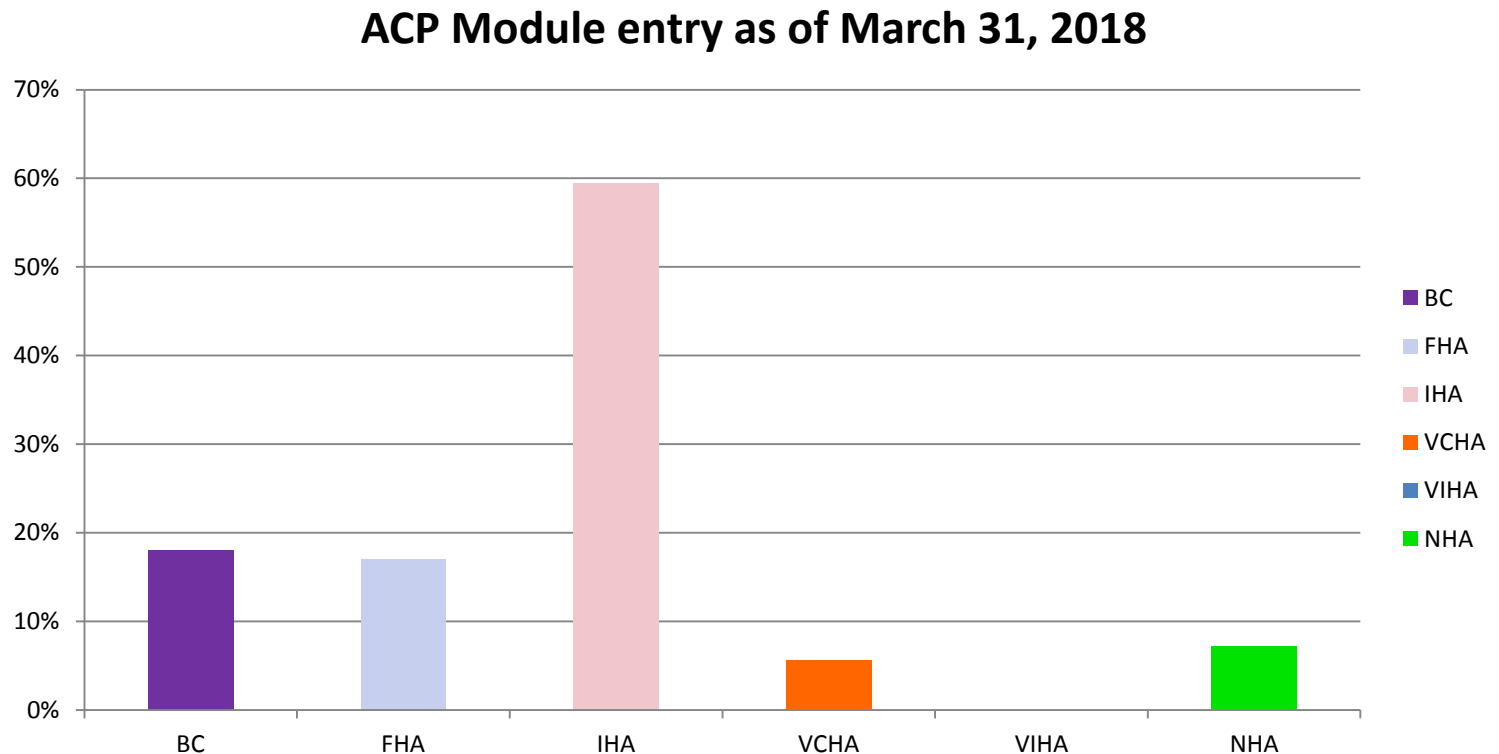
KCC GFR <15



BC results- % patient with any entry in ACP module

Modality	KCC GFR <15					
	BC	FHA	IHA	VCHA	VIHA	NHA
HA						
ACP Module	18%	17%	59%	6%	0%	7%

ACP module data entry for KCC patient <15 GFR



Conclusion



- Think about how to use a palliative approach to care in KCC
- When is best time to have a conversation about values and goals?
- Do the goals align with the patient's modality choice?
- Use tools available to support this approach

Conclusion



- Seek out training opportunities to assist in having discussions about values and goals
- Update data in PROMIS ACP module regularly
- Review quality metrics to keep track of ESAS and ACP activities in your program/region

Thank you for listening

Questions??

