Serious Illness Conversation

KCC Lunch and Learn

April 25, 2019

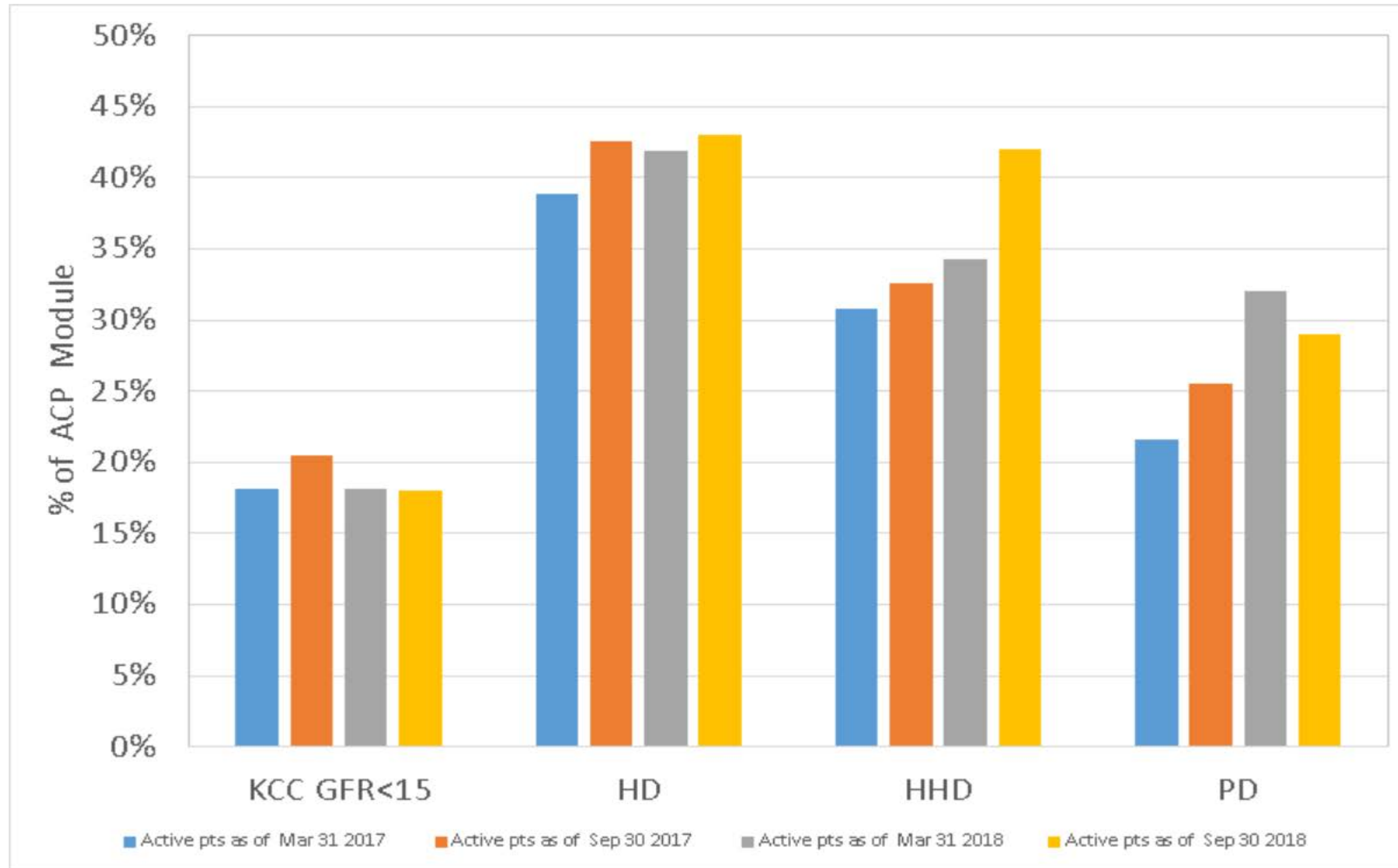
BCRenal

Provincial Health Services Authority

BC Renal Palliative Care Committee Project

To enhance the capacity of renal health care professionals to embed a palliative approach for patients with advanced Chronic Kidney Disease (CKD) by developing toolkits/resources to assist clinicians shift practice to an integrated palliative approach.

ACP Discussions in B.C.



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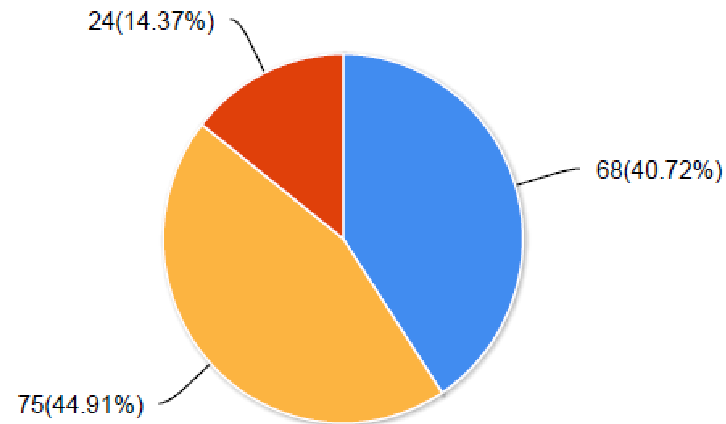
Environmental Scan

14. Do you believe there are barriers for you to have EOL...s?



Yes No Not my role

Answer	Count	Percent
Yes	68	40.72%
No	75	44.91%
Not my role	24	14.37%

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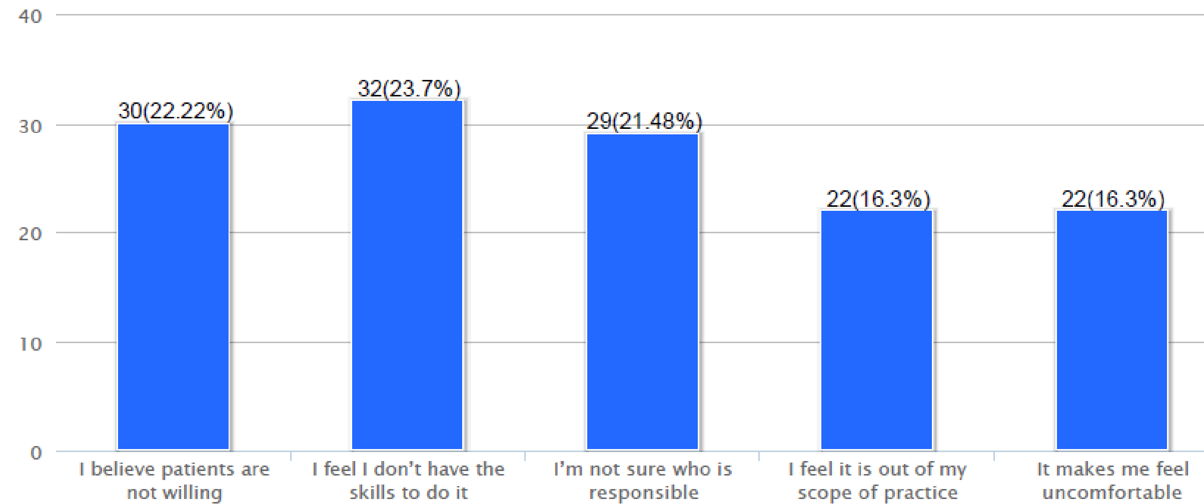
Environmental Scan



Answer	Count	Percent
I believe patients are not willing	30	22.22%
I feel I don't have the skills to do it	32	23.70%
I'm not sure who is responsible	29	21.48%
I feel it is out of my scope of practice	22	16.30%
It makes me feel uncomfortable	22	16.30%

BARRIERS

Hemodialysis unit not private

Can't find the information in the chart

No time to have conversation

No space to document

Lack of confidence to have conversations

"is this my role?"

Patient or family "in denial"

Patient load increasing

Conversations interrupted by 'tasks"

Lack of skill in conversations

Don't know how to "open conversation"

No time to document

Cultural issues

Information buried in other charting

What does patient know?

Don't want to destroy hope

Don't want to step on toes

Family not wanting conversation to happen

How can we assess "readiness" for conversation?

Staff attitudes towards death

Uncertain prognosis

https://www.youtube.com/watch?v=45b2QZxDd_o

Ariadne Labs-Serious Illness Care

- Clinicians were asked to identify patients based on the “Surprise Question”

Results

- People have priorities besides living longer and they change over time
- Anxiety is normal for both patient and clinician during these discussions
- There are straightforward, effective ways to ask about those priorities, and they make a big difference
- Patients want the truth about prognosis
- Talking about end of life goals takes practice
- Patients agreed that this is the way they would like to receive information about EOL

What is a serious illness conversation?

- A Serious Illness Conversation is a clinician-initiated discussion that:
  - Asks patients about values and goals using a structured format
  - Shares prognosis, *when* appropriate
  - De-emphasizes treatments and procedures
  - Occurs early in the course of a serious illness
  - Provides a foundation for making decisions in the future
  - Should be reviewed/revisited over time
  - Is valuable and therapeutic even if medical decisions are not being made

What isn’t a serious illness conversation?

- A Serious Illness Conversation is **not**...
  - A conversation solely focused on medical decisions
  - A MOST conversation
  - A code status conversation

BUT

  - Can be used to inform medical decisions and care planning, *when* appropriate
  - Can and should come before a MOST conversation
  - Can be used even if a patient has a MOST as a way of revisiting values, goals, and decisions

https://www.youtube.com/watch?v=mByh7f7F7a8

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Serious Illness Conversation Guide

Updated – Version 3

Organized as 2 parts: Checklist & Language

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5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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Set up the conversation

Setting up the conversation builds trust-

- Introduce purpose and prepare for future decisions:

  "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want"

- Ask permission:

  "Is this ok?"

- Offer rationale:

  "The goal is to make sure that I have all of the information I need about what matters most to you so I can provide you with the care you want, and so I can best support your family if they ever have to make decisions for you."

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Assess illness understanding and preferences

- *“What is your understanding now of where you are with your illness?”*
- *“How much information about what is likely to be ahead would you like from me?”*
  - Some people want to know about time; others want to know what to expect; others like to know both

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Share Prognosis–Wish/Worry/Wonder Framework

*"I want to share with you **my understanding** of where things are with your illness…*

1. Uncertain:

- *"It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."*

2. Time

- *"I **wish** we were not in this situation, but I'm **worried** that time may be as short as_____ (express as a range, e.g. days to weeks, weeks to months, months to a year."*

3. Function:

- *"I **hope** that this is not the case, but I'm **worried** that this may be as strong as you feel, and things are likely to get more difficult."*

4. Explore previously disclosed prognosis:

- *"Dr. B talked about his worry that you might have weeks to a few months."*

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Explore key topics

- *What are your most important goals if your health situation worsens?"*
- *"What are your biggest fears and worries about the future with your health?"*

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Explore function, tradeoffs and family

- *"What abilities are so critical to your life that you can't imagine living without them?"*
- *"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"*
- *"How much does your family know about your priorities and wishes?"*

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Explore sources of strength

- *What gives you strength as you think about the future with your illness?”*
- For some patients, it is their religious faith, or family and community support

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Close the conversation

- 1. Summarize & Recommend:

  "I've heard you say that____is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you."

- 2. Check in with patient:

  "How does this plan seem to you?"

- 3. Affirm commitment:

  "I will do everything I can to help you through this." Don't make promises you can't keep though

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Document the conversation and communicate with key clinicians

- Document the conversation in the medical record
- Inform members of the team

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1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
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3. ***Share prognosis*** · Share prognosis · Frame as a "wish…worry", "hope…worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness…" *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*." OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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Expect emotion

- Allow silence immediately after giving prognosis
  - It is therapeutic to give a patient time to process emotions after hearing difficult news.

- Respond to emotion by naming it and exploring:
  - *“You seem really upset. Tell me more about what you are feeling.”*
  - *“You seem surprised. Tell me about what you were expecting to hear.”*
  - *“This is really hard to hear. Tell me what you’re thinking about.”*

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Some Specific Communication Tips

3 W' s: Wish, Worry, and Wonder

Patient: *"Will I make it to my granddaughter's graduation in 1 year? "*

Clinician:

- *"I wish that things were different; I worry it is not likely. "*
- *"I hope that you can, but I worry that it may not be possible. "*
- *"I wonder if there are things you can do to prepare in the event you can 't be there. "*

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Resources Available- BC Renal Website

Palliative Care

BC Renal, 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

End-of-life Framework

Serious Illness Conversation Guide

Other Resources

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Resources Available- BC Renal Website

End-of-life Framework

Serious Illness Conversation Guide

- Talking with your clinician about the future
- Talking about your illness with loved ones and caregivers
- Serious Illness Care Program *Reference Guide for Interprofessional Clinicians*
- Serious Illness Conversation Guide

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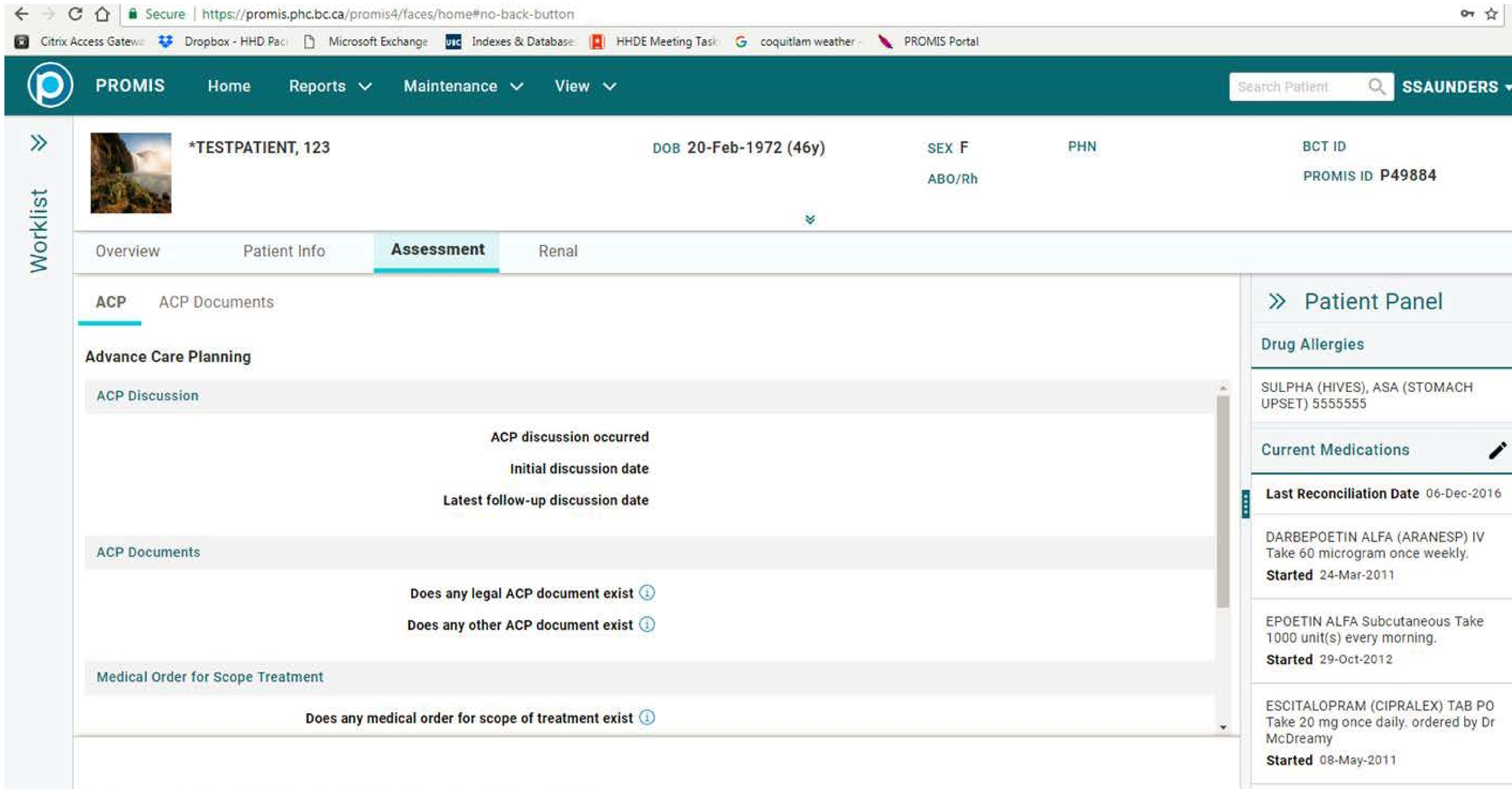
Document Discussions- PROMIS



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Questions?

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