Advanced Cancer Patients' Perspectives on a Video Decision Support Aid used to Enhance Goals of Care Discussions

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Background

- End-of-life (EOL) care discussions
  - associated with less aggressive medical care near death
  - earlier hospice referrals
  - aggressive care at the EOL is associated with a lower quality of life among patients
  - {{13 Wright,A.A. 2008; 84 Hui,D. 2009; 85 Mack,J.W. 2012;}}

Wright, A. A., et al.(2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama, 300*(14), 1665-1673.

Hui, D., et al. (2009). Goals of care and end-of-life decision making for hospitalized patients at a Canadian tertiary care cancer center. *Journal of Pain & Symptom Management, 38*(6), 871-881.

Mack, J. W., et al. (2012). Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology, 30*(35), 4387-4395.

Background

- Results of the first phase of ACCEPT study
  - 76.3% of patients at high risk of dying admitted to acute care hospitals have thought about their care at the EOL.
  - Most of these patients have discussed their wishes with someone (most commonly with their family members)
  - Only about half of the patients had discussed it with any member of their health care team.
  - The level of agreement between patients' expressed EOL preferences and their documentation in the medical records was only 30%.

Heyland, D. K. et al. Canadian Researchers at the End of Life Network (CARENET). (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Internal Medicine, 173*(9), 778-787.

Background

- ACP process – relevant for everyone
- GOC should be addressed primarily with inpatients with high risk of dying - defined as estimated prognosis of 1 year or less.
- Prognostic index developed by Walter - specific clinical and laboratory criteria to calculate the score used to estimate the likelihood of dying within 1 year

Levy, M. H., et al. (2009). NCCN clinical practice guidelines in oncology: Palliative care. *Journal of the National Comprehensive Cancer Network, 7*(4), 436-473.

Walter, L. C., et al. (2001). Development and validation of a prognostic index for 1-year mortality in older adults after hospitalization. *Jama, 285*(23), 2987-2994

You, J. J et al. Canadian Researchers at the End of Life Network (CARENET). (2014). Just ask: Discussing goals of care with patients in hospital with serious illness. *CMAJ : Canadian Medical Association Journal = Journal De l'Association Medicale Canadienne, 186*(6), 425-432.

Background

- Decision Support Aids (Cochrane Systematic Reviews)
  - increased patient knowledge and accurate risk
  - positive effect on the relationship between patients and health care providers (HCP)
  - lower decisional conflict
  - Reduce the proportion of people who remained passive in decision making or undecided post-intervention

  - All reviews excluded DAs related to ACP/GOC (hypothetical decisions)
  - Evidence using the videos to support ACP/GOC in cancer patients – scarce – Volandes et al. from Harvard Medical school

Stacey, D., et al. (2014). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews, 1*,

Background

Study	El Jawahri et al. (2010)	Volandes el al. (2012)	Volandes el al. (2013)	Epstein el al. (2014)
Study type	RCT	Pre-Post Study	RCT	RCT
Type of Cancer	Malignant glioma	Advanced Cancer	Advanced Cancer	Progressive HPB Cancer
Number of participants	50	80	150	56
Results	1. Video group participants more likely to prefer less aggressive care 2. Video group participants more certain of their decision	1. No overall changes in preferences Less preference for CPR and ventilation 2. Increase in knowledge	1. Differences in CPR preferences, less participants wanted CPR in the video group 2. Increase in knowledge	1. Rates of CPR documentation 2. Increase in knowledge 3. Changes in CPR and ventilation preferences in the video group

Background

- What are the factors that make the videos effective compared with written instructions?
- What is the appropriate timing and setting?

Conceptual Framework

Elaboration Likelihood Model (ELM - Petty & Cacioppo, 1986)

- **issue involvement** (a personal relevance of a message to an individual) - mediator to development of lasting knowledge and changes in attitudes
- further extended to study of narrative effects (Slater M. D., & Rouner, D., 2002)
- persuasive effects of narratives occur **through identification with the characters and engagement in stories**

Petty, R.E. &Cacioppo, (1986). The elaboration likelihood model of persuasion. *Advances in experimental social psychology* Orlando, FL: Academic Press.
Slater M. D., &Rouner, D. (2002). Entertainment-education and elaboration likelihood: Understanding the processing of narrative persuasion. *Communication Theory, 12*(2)

Conceptual Framework

- the GCD video - more conventional issue oriented persuasive message
- argument - the extended ELM can be applied
  - scenarios describing the 3 levels of care show people undergoing specific interventions
- **hypothesis** - *identification with these people and engagement with the scenarios will have a significant impact on the attitudes that participants form toward the video*

Study Objectives

- To explore advanced cancer patients' perspectives regarding a video support aid on the GOC decision making process
- To evaluate which aspects of the video affect patient's decision making process

Study Questions

1. What are the participants' responses to the scenarios presented in the video?
2. What aspects of the video influenced participants' knowledge and perceptions about the GOC?
3. What suggestions would participants make for improving the video decision aid?
4. What setting would participants suggest is most appropriate for watching the video?

Study Design

- Pre-post design
- Qualitative approach
- Individual semi-structured interviews
- Outpatient Radiation Oncology Clinic TBCC

  (Fast Track Bone Metastases)
  - Natural environment of GOC conversations
  - No additional time and travel burden

Study design

Inclusion criteria

- Adults patients coming to the clinic able to understand and communicate in English and provide informed consent

Exclusion criteria

- EQ-5D-5L anxiety score ≥ 7
- Additional criteria as established by the clinical team – frailty, too much pain, cognitive impairment, inpatients

Sampling strategy

- Purposeful
- Fast track Bone metastases patients:
  - Incurable phase of their disease
  - Likely die of their cancer
  - All would be appropriate for initiation of GOC as recommended by You et al.
  - Heterogeneous – prognosis, type of cancer, age

Data Collection

- Individual semi-structured face to face interviews
- First part of interview prior watching the video
- Watching the video
  - 3-minute version on youtube – 1st 8 participants
  - 8-minute version on DVD – 2nd 6 participants
- Second part of the interview
- Transcribed verbatim
- Pseudonyms assigned to transcripts

Data analysis

- Thematic content analysis as described by Creswell (2013)
- Data
  - organized into computer files, converted into text units
  - analyzed using reading and memoing
  - initials codes developed using hard copies
  - inductive and deductive methods of coding
  - organized into themes
  - code book developed
  - separate coding by 2 investigators
  - larger meaning of themes interpreted with respect to the research questions

Results

- Overall recruitment period – 6 months
- 80 clinics
- 133 patients
- 121 outpatients – potentially eligible
- Most common reason for not participating:
  - not feeling ready for GOC discussions
  - being in too much pain
  - not being treated

Results

- 19 patients initially agreed to discuss the study
- 4 declined to participate after reviewing the consent form
  - Being in too much pain
  - Not ready to discuss end-of-life topics

“When I die, I die but I don’t want to talk about it.”

- One participant signed the consent form but decided to withdraw the consent prior to seeing the video (questions *“too private”)*

- 14 completed interviews (8 – short version, 6 – long version)

Results

	Short Video	Long Video
Number of participants	8	6
Gender	M – 4, F - 4	M – 2, F - 4
Age	Range 60 – 72 years 60 – 69 years – 7 > 70 years- 1	Range 50 – 84 years 50 – 59 years – 4 70 – 79 years – 1, > 80 years - 1
Ethnic Background	Caucasian – 7 Chinese - 1	Caucasian – 4 Mixed – 1, Middle Eastern - 1
Had seen the video before?	0	0

Results

Factors important in care currently, longer term and at the end of life

- Themes identical for present, near future and end of life
- **Quality of life** (pain control, avoidance of suffering, ability to function, ability to communicate, place of their EOL)
  - *"That's my…. Main concern, getting around…. I spent so much time on the couch that I couldn't do anything with my leg swollen up like balloon that I don't want to go back there"* (Jane, 4)

Results

Factors important in care currently, longer term and at the end of life

- **Family and loved ones** (time with the family and impact on the loved ones)
  - *"I think if I stayed at home (at the end of life) that would put pressure on my husband, he's not really into caring for people"* (Emily, 10)
  - *"It's important that they'd (family members) be there. It's important for you because you feel the support, the love and for them it's a learning process, it… it'll make them better people"* (Anne, 5)
- Other important themes – **closure** (short video), **good quality of health care**

Results

Factors important in care currently, longer term and at the end of life

- Control of cancer, length of life – infrequent

- **After the video:** themes similar
  - Family/loved ones (impact on loved ones)
  - Quality of life (avoidance of states with no quality of life)

Results

Thoughts about GOC and EOL prior watching the video

- Short video group – prognosis awareness
  - *“It’s terminal. What I have is terminal, not getting out of it”.* (John, 1)
- Long video group – unpredictability of EOL
  - *“I remember thinking when I was first diagnosed I was around a campfire and I remember thinking, you know, I was really down and I thought "I'm going to die before all these people here, this is....oh god, this is not fair" you know, and then the next week one of them actually unfortunately got killed in motor vehicle accident and I was thinking "oh, I was wrong.”* (Emily, 10)
- Internal conflict

Results

Thoughts about GOC and EOL

- Timing – variable, usually specific trigger

- Post video – similar but more participants recognized that GOC can change over time

- 2 participants – no interest in the concept
  - Too complex, no interest to think ahead
  - Belief system – destiny determined by God
  - Remained after watching the video

Results

Thoughts about GOC and EOL

- Detachment - often using other than first grammatical person narrative when talking about diagnosis, prognosis and end of life,
- second or third person singular or first person plural
- "*When you kind of want to know about the resuscitative care and whether you want to be DNR… because I kind of want to know at what point you can still live, you kind of still want to … there is a fine line in a way*." (Mary, 14)

Results

Discussions about ACP/GOC and EOL

- Recognition of 3 terms:
  - "Life Support Measures" – somewhat familiar
    - (6/8 – 3-minute video; 2/6 – 8-minute video)
    - Opinion – did not want
  - "Being comfortable" – familiar term
  - "Goals of Care" – not familiar
    - (2/8 – 3-minute video; 2/6 – 8-minute video)
    - Palliative care team and booklet

Results

Discussions about ACP/GOC and EOL

- With health care providers (HCP) and loved ones
- Timing variable
  - Long time ago even before sick -> last week
  - Usually specific trigger or impact of personal experience
- Outpatient setting, support groups
- Only one participant mentioned conversation while in hospital

  *"Like, when they put this nephrostomy in, I didn't know what was going on in the world. Seriously, I didn't. She (family physician) might have told me, I remember being in the hospital …. but I remember the first day or so there but after that....for days I .... I don't remember eating, I don't remember things. I slept... you know ... and I would have agreed to have this." (*Jane, 4)
- Initiation of conversations – HCP or participant (waiting for invitation)
- Difficult but necessary topic

Results

Discussions about ACP/GOC and EOL

- 5 participants – Green sleeve
- 4 had not filled it out
- *"… we had some booklets to fill out, keep it on your fridge, or whatever, and you were supposed to fill it with...with, you know, with what you want for resuscitation and that kind of thing, whether it's DNR or whatever…. No (to the question if she filled it out) …I read it ...and I started to fill it out but I got stumped or something, there was something, I forget, what ... I was going to look into getting help to ...you know, filling it out more, 'cause I kind of didn't understand some of that".* (Mary, 14)

Results

Responses to the scenarios presented in the video

- All but one were able to relate their experience to these
- Most related to comfort/EOL care of their loved ones
- Decision making for loved ones
- Generally similar
- Differences
    - Short video – setting – inpatient vs outpatient
    - Long video – realistic portrayal – too technical vs not showing real suffering

Results

Realistic portrayal – quotes

- *"I don't think it shows nearly, what the patient and the family go through, you know, I mean, it's …it's the nighttime, it's, you know, the moaning and pain... they've had medication and …. It's a lot harder in real life than what the video shows. "* (Susan, 13)
- *"I think that looks a little bit more scary maybe, my experience isn't ... oh yeah, that's why I said " I think some people may come a look at it "blah"... yeah, no, my experience ....I think some time it would be better to not show quite as many i.v. stands and bottles and things… I think it made it look more clinical than it needs to look when you're going to medical daycare, that's not the impression that I have there"* (Emily, 10)
- *"It's kind of good that she didn't really, when they're explaining the resuscitative …methods, you know, that she was good that they didn't glance over, they kind of explain what I can do and, you know, that you may not get to the way you were before and just you know, how they try to resuscitate you with the … all the different ways… I do have worry about that, you know, being… I have bone mets, so you know, you think, when they're doing stuff, whether I am going to get all these fractures and different things."* (Mary, 14)

Results

Influence of the video on knowledge and perceptions about the Goals of Care

- not a new concept
- Framework and terms new – 3 approaches to care
- *"… these three stages of the goal of care… I didn't realize it was broken down to three, so … just need to find that out."*(Susan, 13)
- "Comfort care" and "Medical care" terms frequently used
- "Resuscitation", "Three areas/sections/levels" instead "Resuscitative care" and "Goals of Care"

Results

Knowledge

- Not formally tested
- Some misconceptions after watching the video
  - 3-minute video – association of resuscitative care with CPR only
  - 8-minute video – only 1 participants - patients would be resuscitated if being under comfort care, if they wished to do so or if it were appropriate

Focus

- 3-minute video – Comfort Care
- 8-minute video – GOC framework

Results

GOC concept and framework

- Useful in general
- Personal relevance
- *“Yeah, it is because they broke it down to three areas and then you just sort of say – where am I… where am I on that? And then focus on that… that makes it easier… here is what we have to focus on and look at the steps we have to take at that point.”* (James, 6)
- Only 1 participant – framework not useful nor personally relevant

  “… I can't visualize how somebody would sort through the issues that she described here and say "Okay, that's for me, I guess I better get busy and do something about this or that or the other thing" ...it just doesn't connect with me ... I might as well be truthful and say.... I ...I don't get it.” (Thomas, 11)

Results

Emotional response

- Neutral
- Gentle

  “I think it makes you a little bit more relaxed about what’s coming” (Matthew, 9)

- Potential to scare

  “Like I said to you, like I was okay with you saying “Can you do this?” But I bet some people could be like …”they’re just trying to tell me that maybe they think I am at the end of life?” (Emily, 10)

Results

Identification (spontaneous)

- 9 participants – medical or comfort care
- 4 participants - **intention to make a decision** about their GOC or write their decision into the green sleeve
- 3 participants - **intention to have conversations** about their GOC with their HCP

"…when the nurse gave it to us, she did explain it but it needs, the green paper, needs further discussions and this helps because you see the pictures, it ...it's sort of a continuation of that green paper and it's visual…"

"We haven't written it on the green chart that home care gave us but every time the home care nurse comes, she says we should do it and I will do it today, I'll put the … for the comfort care." (Anne, 5)

Results

Thought and question generating

- General questions - place of EOL, comfort care at home, in hospice and in the hospital, more detail about the actual interventions included in the each approach,
- Specific and personalized - expected course of their disease and their EOL

Results

Suggestions for improvement

- 3 minute video:
  - Positives – information, well presented, value of visual
  - Negatives – length too short, more information
- 8 minute video:
  - Negatives – more detail and depth, too technical (one participant)

Results

"It probably could have been more in depth maybe but… I mean … explained… getting those three levels, kind of showed you a bit, really just kind of small snippets in a way of what... Makes me kind of want to know more about what… when… just more detail, I guess. Like I mean, that's why we come to talk to my own oncologist because he would know my own personal physical, you know what's all happening physically with me, what I would… what would happen, different symptoms that can come up, what can happen to me, my personal body, you know what I mean, like … what I be more likely having a heart attack or stroke or pneumonia or something … just what could happen. I want to kind of discuss that with my own doctor …."

- Mary, 14

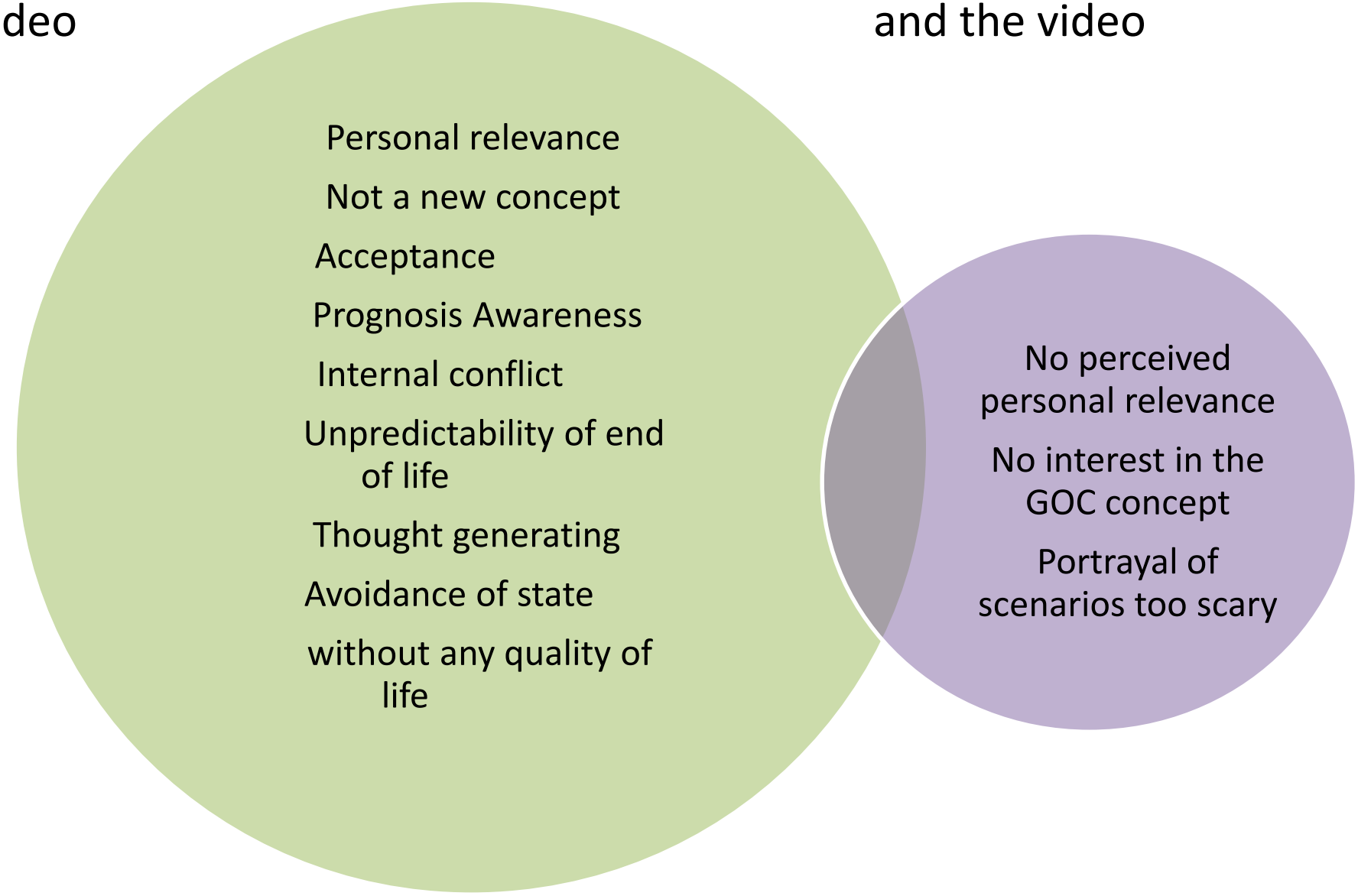
Results

Preferred setting for the video

- Timing – appropriate – incurable disease but still relatively well
- Assess for readiness before the discussions and watching the video
- NOT during high stress situations
- *"I would think that any time it's good to see. But not when you're sick. Never when you're sick because… it just doesn't go in."* (Anne, 5)
- Professional clinic setting
- Not a stand-alone tool
- With family/loved ones

Facilitating factors - Connection with the GOC concept and the video

Barriers - No connection with the GOC concept and the video



Conclusions

- Not a new concept but framework and 3 categories were new despite prior exposure of discussions about this topic within the Calgary zone health care environment
- Division into 3 categories - very useful
  - Simplifies this broad and complex concept

- Personal relevance – very important factor in connection with the concept and the video
  - Shinkendanz et al. identified inability to relate to the concept one of the most important barriers to ACP
  - Emerged as the most important factor in this study
  - Majority of participants found this concept relevant

Schickedanz et al (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. *Journal of the American Geriatrics Society, 57*(1), 31-39.

Conclusions

- Participants were able to relate their values and wishes about their care, to what they saw and heard in the video and identify the approach to care that reflected these values
- Ability to relate the scenarios shown in the video to past and present experience with GOC influenced effectiveness of the video

Conclusions

- Video - useful tool to initiate GOC discussions
- Video made the GOC concept and framework “real” and helped participants to articulate personalized questions for their health care providers
- Watching the video should be followed by discussions with health care providers shortly after

Conclusions

- Outpatient oncology clinic appears to be a suitable place for watching the video and for GOC discussions
- Patients should be individually assessed for their readiness to discuss their GOC
- High stress situations not appropriate for watching the video and initiating the GOC discussion

Discussion

- Are advanced cancer patients ready for the discussions?
  - Poorer accrual than anticipated - main reason: not willing to talk about EOL
- Is it too late?
  - Advanced cancer – “death sentence”, participants might feel too threatened and stressed
- How are the responses to the video going to vary in different populations?
- Should there be a specific video (focus on comfort care) for advanced cancer population?

Limitations

- The findings not transferable to other patient populations, such as general population, patients with non-life threatening illnesses
- No follow up

Further steps

- Thesis defence – spring 2015
- Presentation at local, national and international conferences and publication of results in a peer reviewed journal
- Informing other projects (ACP CRIO)
- Presentations for AHS stakeholders, health care providers and patient support groups
- Further studies?
- Suggestions?


Thank You