



UNIVERSITY OF
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How do people with disabilities perceive advance care planning?

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for ACP CRIO

Research questions

How do people with disabilities perceive advance care planning?

- What prompts people with disabilities to participate in advance care planning?
- What are the barriers that people with physical and sensory disabilities face in completing the process of advance care planning?
- How is readiness to participate in advance care planning identified in people with disabilities?

Recruitment process

- invitation to Participate letter
- snowball sampling

Interviews

- one-to-one (face-to-face/telephone)
- interviews
 - 30 min – 1hr. 10 min.
 - semi-structured and open ended questions
 - recorded and transcribed verbatim

Demographic information

- 11 participants
 - male, female
 - paralysis, vision loss, hearing loss, diabetes, MS

Data analysis

Charmaz' grounded theory

- initial and focused coding
- constant comparison
- memoing

Trustworthiness

- credibility (verbatim accounts, supervisor review, triangulation)
- dependability (member checking)
- transferability (other health care contexts)

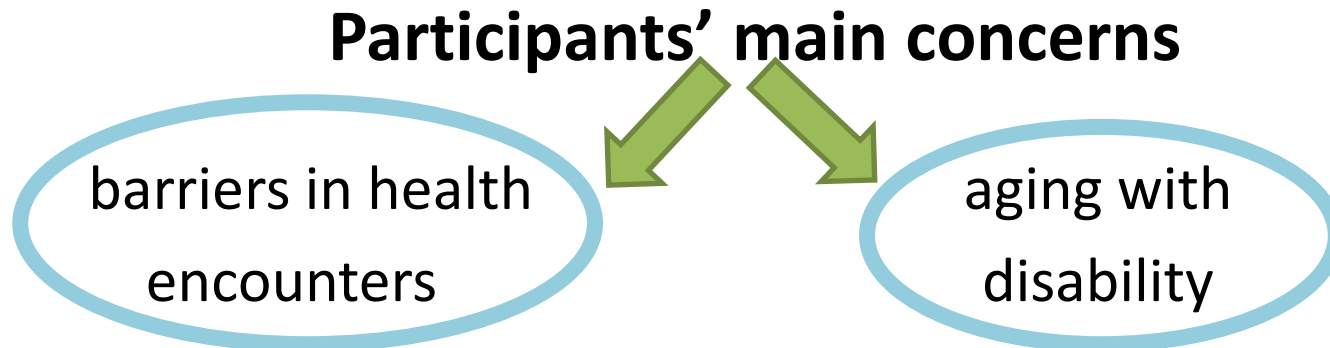
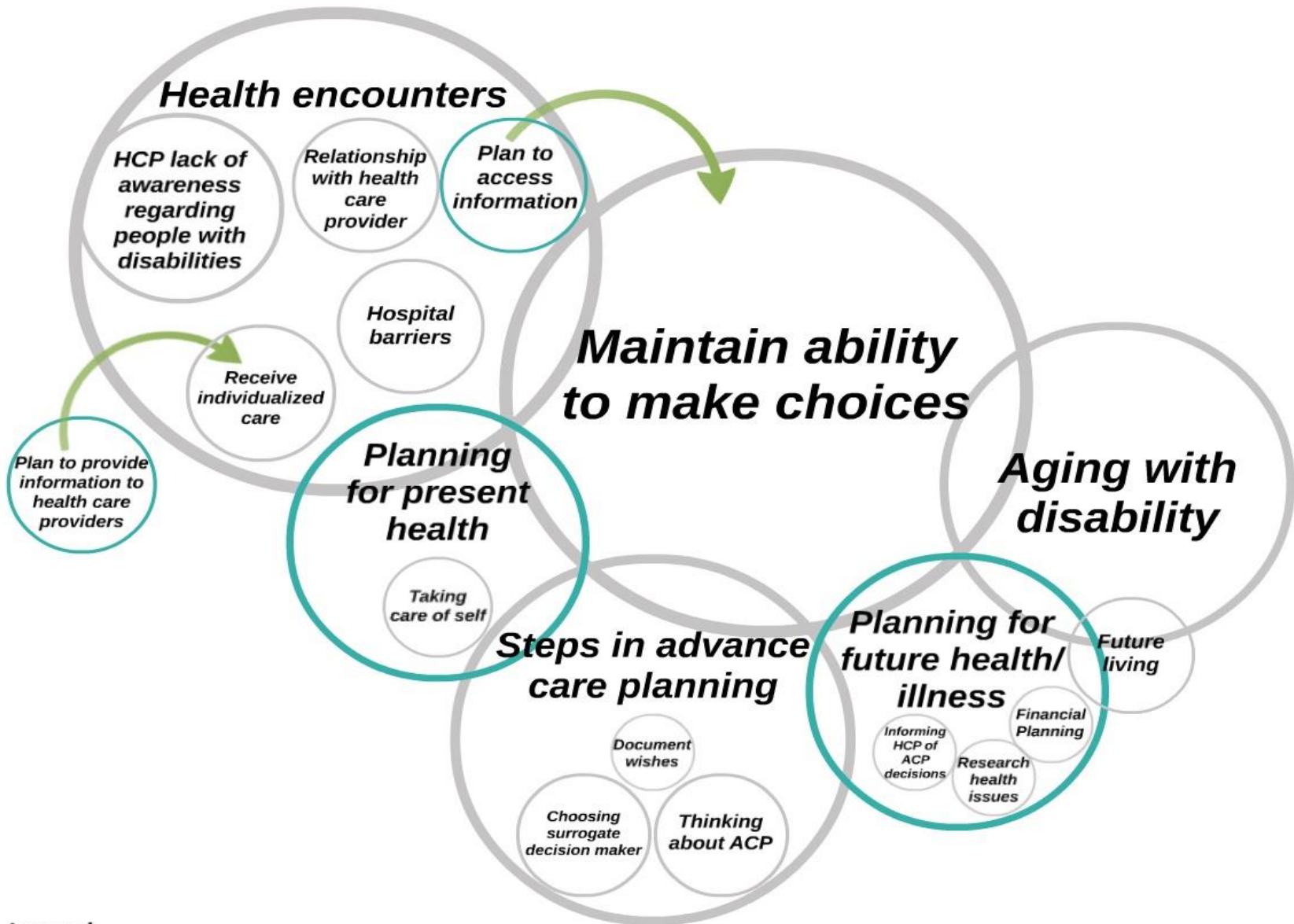


Figure 1 - How people with disabilities perceive advance care planning



Legend

- Size of circles represent importance to participants
- Highlighted bubbles indicate process of planning in areas where participants want to maintain choice
- Arrows represent actions taken to achieve intended consequence
- HCP - health care providers

Steps in advance care planning (ACP)

- previous experience with ACP
- understanding of ACP (complexity, readiness)
- a means to **make choices** and **maintain control over decisions**

Facilitators to ACP

- relieve others from burden of decision making
- illness / greater levels of functional impairment

Barriers to ACP (documenting wishes)

- have not gotten around to it

Readiness

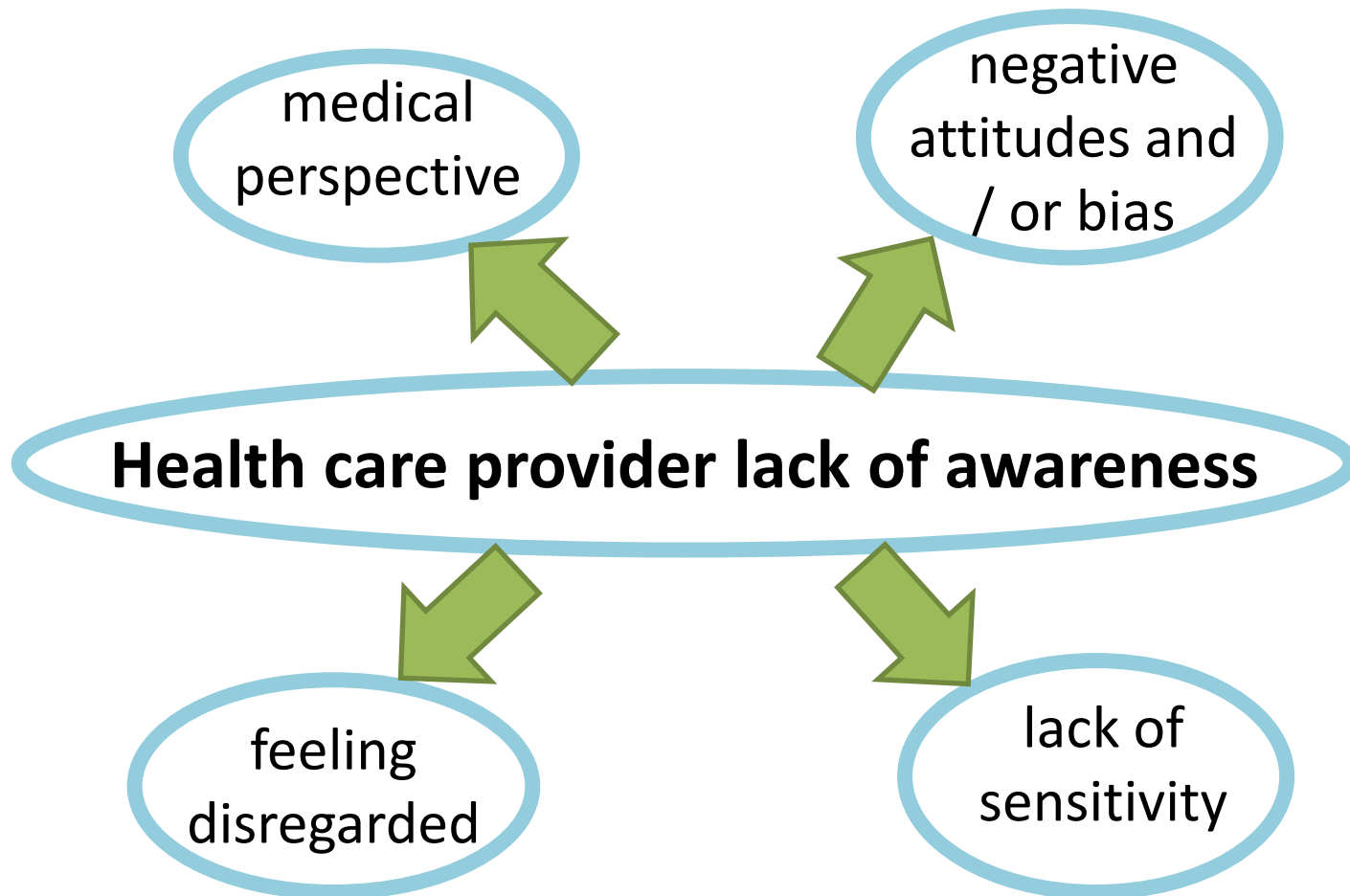
- all participants were **thinking about ACP**
- all but one participant have **had ACP conversations**
- nearly all participants have **chosen a surrogate decision maker**
- few participants have **documented their wishes**

Planning for present health

Taking care of self

- participants were **taking responsibility** for their present health by taking an **active role** in maintaining present health
- making **wise health choices daily** (exercise, healthy eating)
- **attending to medical issues** as they arise
- participants acknowledged that making unwise health choices may change future health and care plans

Health encounters
Health care provider (hcp)
lack of awareness regarding disability



Health encounters (continued)
**Health care provider lack of awareness
regarding disability**

Feeling disregarded

“...doctors don’t seem to understand, if I’m hard of hearing, they need to speak to me. They don’t need to speak to my interpreter – they don’t need to speak to my wife. They need to speak to me. Same with the nurses, same with the reception people. Um... this is one thing that ah, they don’t do well.”

Health encounters (continued)

Hospitals create barriers

Repeating requests for accommodation and participation in medical encounters

“But when I came out of it, you know ... I put my hearing aids back in, I was able to understand that there was some speaking going on. If I don't understand, I will ask, could you speak slower? I am hard of hearing.” If I still have the problem, I'll say thank you. And then I will ask somebody afterwards, “[A]m I okay or not?” And then I will ... if necessary, I'll ask my wife, who comes up afterwards, if she can just find out what it was about. ‘Cause I don't wanna labour the subject. I'm too tired to labour the subject. ... if they don't want to comply with my request, I'll deal with that later.”

Health encounters (continued)

Hospitals create barriers

Transfer of medical information

“...from any health services provider’s perspective, if a patient says they have whatever they have, the patient has met their obligation. It’s now the obligation of the service provider to make sure that that information is passed along [a] continuous trail for that patient. So that if I’m going to hospital, and I’m admitted, and I say I’m hard of hearing, I need support, or whatever, I have met my responsibility by self-identifying. I now depend upon the Alberta Health Services in my case, to make sure that these points are taken and are always, always, always passed along to the next person. Because what I am seeing is that that is not the case. ...people say, “oh, yes, I did – oh, I did see it on your chart.” They need to highlight it. They need to make sure that that is paramount, otherwise the dignity of that patient has been challenged and usurped. And I’m not in favour of that.”

Health encounters (continued)

Hospitals create barriers unacknowledged / unaccommodated disability

- can limit **access to information**
- can limit one in providing **informed consent**
- can necessitate **repeating requests** for accommodation
- can limit **participation in medical encounters**
- preclude one from receiving **individualized care**
- can impede **transfer of medical and disability information**
- can **limit access to medical care**



unrealistic expectations of people with disabilities

Health encounters (continued)

Relationship with primary hcp (p-hcp)

- **relationship** with a p-hcp **can remove barriers**
(communication, access to information, participation in m/e)
- half of participants have a **trusting relationship** with their p-hcp

Trusting relationship between patient - hcp

- relationship developed **over time**
- hcp provides **consistent care**
- hcp **gains knowledge** re disability / longitudinal effects of disability
- hcp learns to **accommodate disability** → **provide individualized care**
- hcp learns to **value the knowledge** that the person with a disability has about his/her body/health gained from lived experience that s/he brings to the medical encounter

Health encounters (continued)

Planning to maintain choice in health encounters

planning to access information

- plan for an **advocate**
- plan to obtain information in **electronic format**
- **self advocacy**
- **request information** to access medical care

Health encounters (continued)

Planning to maintain choice in health encounters

plan for an advocate

“...so needless to say, you go in and they ah, give you all kinds of ... risk and liability forms to sign. And... being visually impaired, I always make sure that my wife’s there, and I’ll say to them, “okay, are there any more forms that we have to sign, blah, blah, blah, blah, blah, blah...?” No, we’re fine. And so, my wife leaves. Ah, this one time, my wife left. And just before they were about to start, the anesthesiologist is there, and some tech puts another clip board and form in front of me to sign for consent for something else. And I said, “well, unless you sit here and read the entire form to me, what I’m signing is not gonna be valid, ah, because I’m visually impaired. So I’m giving you ill-gotten consent. So it’s not worth the paper that it’s written on.” And then, the anesthesiologist piped up and said, “what’s the problem?” And... she – the lady said – the tech or whatever said, “the person doesn’t wanna sign the consent form because they’re blind.” The doctor says, in all his wisdom, “oh, you don’t look blind.” So I said, “how is blind supposed to look?” So ah, with the visual disability, um, hospitals can be very challenging. ‘Cause ... they’re ill-prepared for dealing with people that can’t see.”

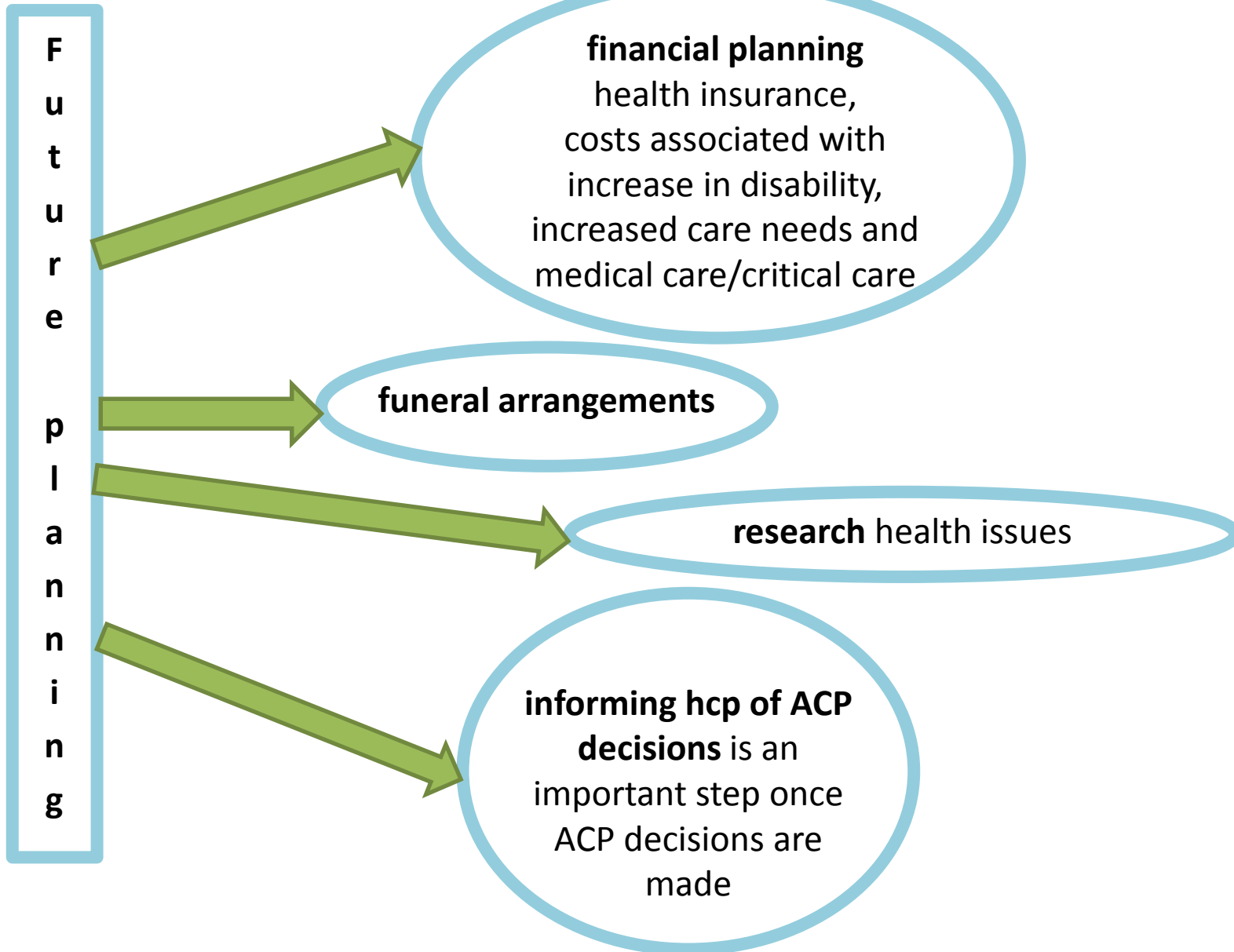
Health encounters (continued)

Planning to maintain choice in health encounters

Planning to **provide information**  **receive individualized care**

- time of **medical crisis**
- **every day** interactions
- **treatment decisions**
- hcp **in-service** training
- **sensitivity** training
- **electronic medical record**

Planning for future health / illness



Aging with disability

Participants are **concerned about aging with disability:**

- ongoing assessment of **abilities and limitations**
- balancing desire for **independence** with **present support**
- anticipating **change in support** due to health decline and / or increase in disability
- **difficulty in planning** – trajectory of disability is unknown
- participants are concerned about **future living**
- **concern over losing choice** in future care and/or support and future living
- considering **alternatives** in future living

Literature Review

Research and policy directions

Hcp lack of awareness re disability

→ disability education in nursing and medical education

- **direct involvement** by people with disabilities
 - informing curriculum
 - interaction with students
- **in-service training to hcp**
 - involve hcp at all levels of health care, hospital administration
 - training needs to be ongoing

Aging with disability

- **aging with disability** – aging into disability
- local / global efforts to **bridge aging and disability services**
- **alternatives to LTC** (age in place, co-operative living)

Research questions reviewed

Facilitators to ACP

- **maintain the ability to make choices** re their present health, in health encounters, in future health, living and care

Barriers to ACP

- health care provider **lack of awareness** re disability
- patient **access to medical information**
- disability and accommodation required is not consistently being **documented, transferred, or accessed** by health care providers

Readiness to participate in ACP

- participants from this study were **engaged in ACP**
- participants are open to **hcp initiating ACP conversations**
- readiness is evidenced by individual efforts in **planning to address experienced and anticipated barriers** in health encounters

Recommendations

- Health care providers should **initiate advance care planning conversations** with people with physical and/or sensory disabilities so that their wishes for care can be known and documented on their health record.
- Alberta Health Services should provide **ongoing sensitivity training** to educate health care providers throughout **all levels of health care** in Alberta Health Services in how to interact with people with physical and/or sensory disabilities.
- Disability information and accommodation required should be **consistently documented** on patient medical records including Goals of Care Designation orders. This information should be **easily accessible** to all relevant medical professionals.
- Alberta Health Services should make advance care planning documents, medical documents, and consent forms available in **electronic format** on the public website so all patients including patients with disabilities can access this material in hospital, on their own time and/or in **preparation** for a medical encounter.