Improving End of Life Care in Long Term Care Facilities:
Perspectives of Healthcare Providers

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NELS Work In Progress Presentation

NELS Network for End of Life Studies
ICE Interdisciplinary Capacity Enhancement
Capital Health
DALHOUSIE UNIVERSITY Inspiring Minds
CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Acknowledgments

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Co-investigators

- Dr. Fred Burge
- Dr. Raewyn Bassett, Health Professions
- Dr. Paul McIntyre, Palliative Medicine

Outline

- Background
- Objectives
- Methods
- Participants
- Themes and proposed framework
- Suggestions ???

Background

- NELS Project 6: *"Ensuring Quality End of Life Care for the Vulnerable Elderly"*
- Proportion of elderly in Nova Scotia living in LTC is rising (12% → 20% by 2030)
- Proportion of elderly dying in LTC is rising (25% → 50% 2020)
- Previous studies have described several barriers to optimal EoL care in LTC

Literature Review

- Multiple studies of perspectives of:
  - Perceived aspects of best practice EoL care
  - Perceived deficiencies/barriers

- Little focus on:
  - Canadian context (no Maritime)
  - Strategies for improvement

Research Objectives

1. To deepen understanding of current issues and challenges of providing EoL care for elderly in LTC within CDHA

2. To elicit proposed solutions from healthcare providers on how to overcome these challenges

Objectives (cont.)

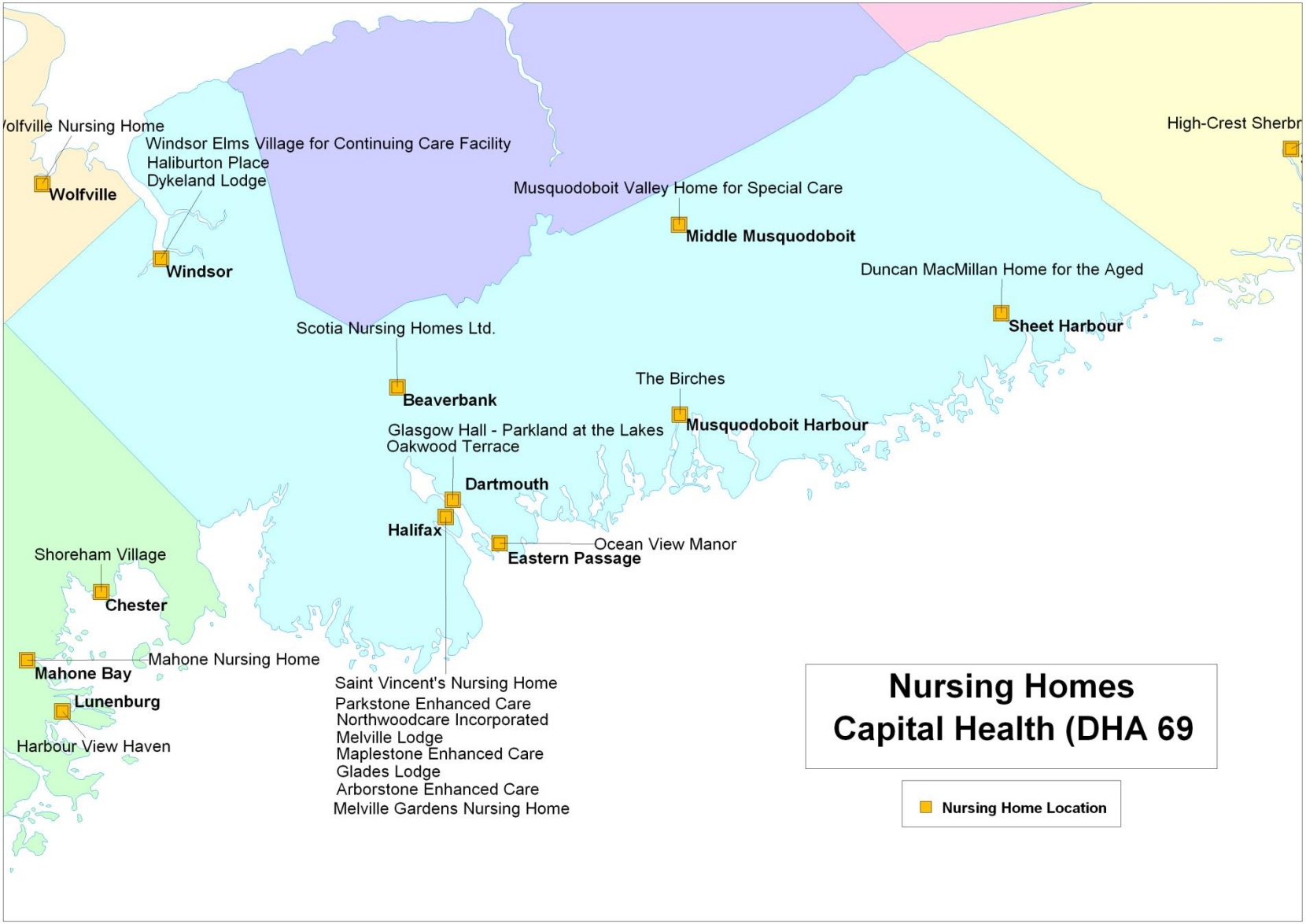
3. Synthesize data on perspectives in order to inform development of a health services intervention for quality improvement

LTC Restructuring within CDHA

- Devolution to the district health authorities in Spring 2009
- District Medical Director for LTC
- LTC Medical Advisory Committee
- Pilot projects: nursing home physician and nurse practitioner
- "Doc per floor" Fall 2009

Study Design

- Qualitative methodology
- Focus group method: 4 homogeneous groups of healthcare providers
- Administrators at each of 20 licensed nursing homes in CDHA approached for recruitment (telephone and/or e-mail)
- Other individual contacts through Integrated Palliative Approach for Long Term Care meeting held in Dec 2008



Nova Scotia Department of Health, August 2008

Focus Groups

1. Medical Directors / MDs (n=9)
   - 10 different nursing homes, all urban
   - Median years of work = 12.5

2. Nurse Managers / Directors of Care (n=6)
   - 3 different nursing homes, all urban
   - Median years of work = 8.5

Focus Groups (cont.)

3. Personal Care Workers / Continuing Care Assistants (n=8)
   - 3 different nursing homes, 1 rural
   - Median years of work = 8

4. Registered Nurses / Licensed Practical Nurses (n=11)
   - 6 different nursing homes, 3 rural
   - Median years of work = 15

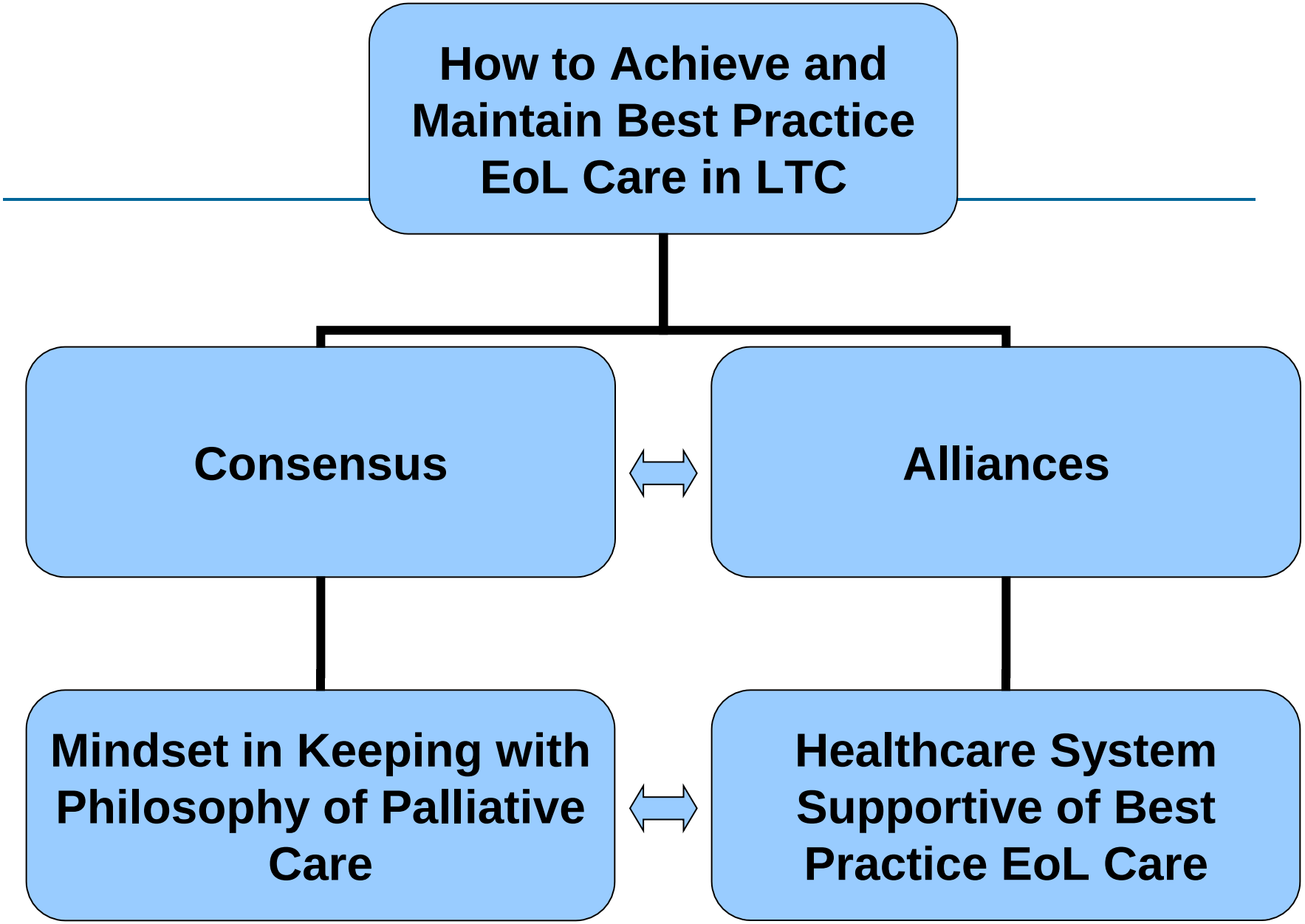
Focus Group Format

A. Presentation
   - Summary of literature review

B. Discussion
   - Why interested in participating?
   - Did issues raised in presentation resonate with your experiences in LTC?
   - What are your ideas re: strategies for improvement?

Inductive Thematic Analysis

1. Familiarize with data
2. Generate initial topical codes
3. Search for themes
4. Review themes – thematic map
5. Defining and naming themes – recursive process
6. Discussion and agreement among investigators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WHO Definition of Palliative Care

- " an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

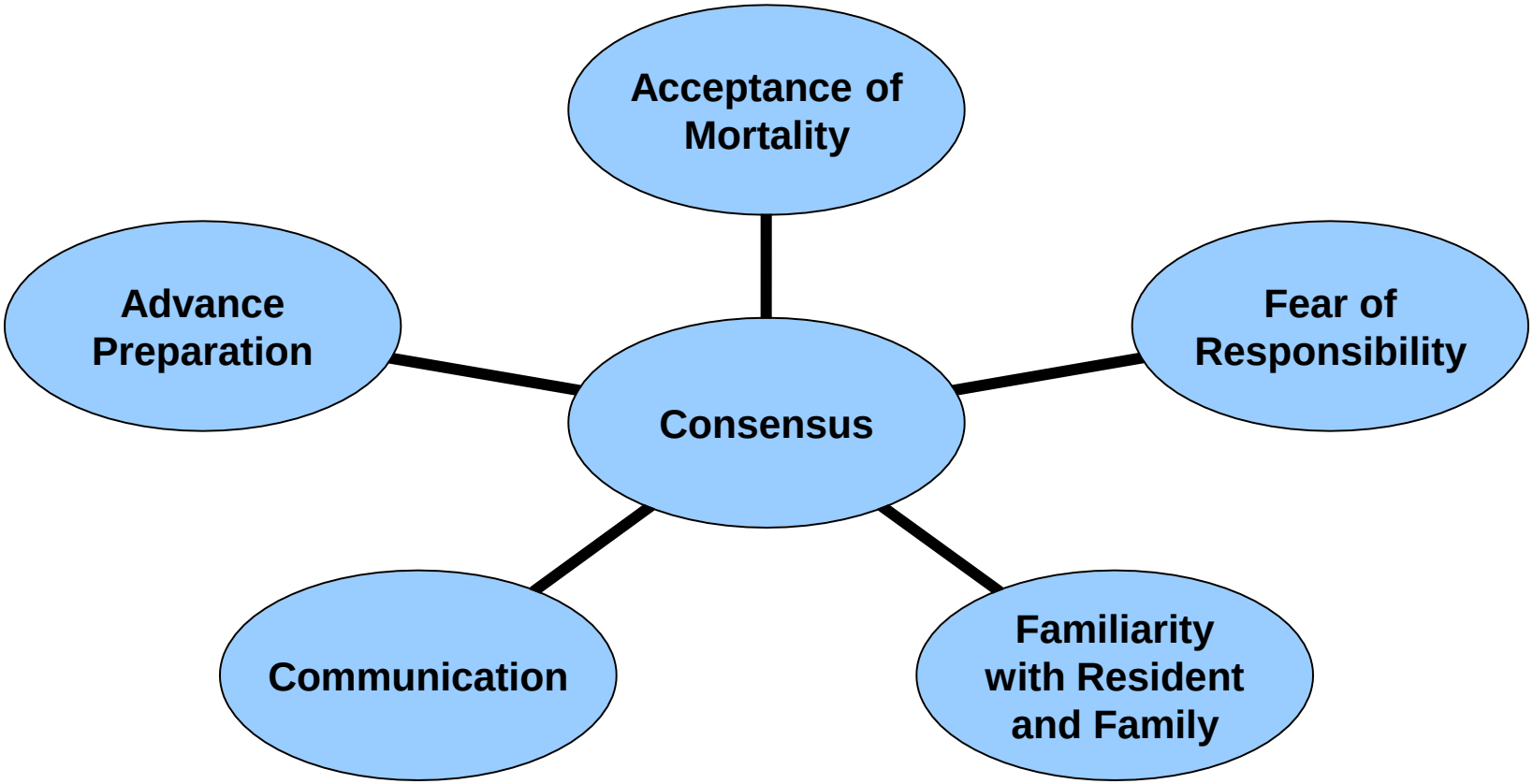
Palliative Care Mindset: Family Caregivers

- "There are an awful lot of people out there who haven't come to terms with mortality of any kind… and they want mum or dad to live on forever, regardless of how much misery they're in. And sometimes they're quite unreasonable."
- "…if in fact we get over that hurdle with families, and they're able to go there…"

Palliative Care Mindset: Healthcare Providers

- "I still find that there are nurses who are afraid to give that last dose of morphine. It's still a mentality that they hold, and it's really hard to get them through to the other side."

Consensus


Acceptance of Mortality
Advance Preparation
Fear of Responsibility
Consensus
Communication
Familiarity with Resident and Family

Consensus

- "It's breaking the gaps between physician, families, nurse, caregiver, and you can really see, as a navigator, as a palliative care nurse, how everybody can be on the same page and ultimately provide that ultimate end-of-life care."
- "But it was getting everyone onboard so that it wasn't just A doing it or B doing it or C doing it or D; everyone felt that same comfort that yes, they made the observations and they talked with family, talked it over with the staff that were there and it was decided that this is time."

Consensus

- "And we've had nurses actually arguing, advocating for the resident, "This person should not go to hospital. Family do not want them to go. In this chart is the directive." And the physician will call the family and the next thing is you get a call from the family saying "I want to send them", when the conversation has already been had "No, keep them there, keep them comfortable". So it's frustrating, it's very frustrating."

Acceptance of Mortality

- "…it comes down to the family's denial of the family member passing away. They don't want to have that conversation because that means I'm admitting that the end is coming."

Acceptance of Mortality

- "You people have years of experience and training, but there's one thing lacking in your --- it's a system of you're not all saving, you have to end, and so many are more important with living, and you don't go to that other end of the spectrum of end of life."

Fear of Responsibility: Family Caregivers

- "…nobody wants to make that decision if Mom and Dad is incapable because they don't want to be held accountable if Mom and Dad die, Mom or Dad die because they didn't get resuscitated."

Fear of Responsibility: Healthcare Providers

- "I'm not going to give that dose of morphine. I don't want them dying on my shift. I don't want to be the last one giving the morphine."
- "I don't want to order this you might use it!"

Familiarity with Residents and Family Caregivers

- "The best results accrue when you get some continuity among your nursing staff, and one of the problems I know for (Facility X) in summers and Christmas and everything like that is you get an awful lot of casual staff who are just popping in. They don't know the residents, they don't have the rapport with the family, and that sometimes seem to be the… when you run into more issues in terms of… (inappropriate emergency room visits)"

Communication

- "I think one of the problems, at least in my long term care facility, we notice that the family, when they sign the care directive, they really aren't explained in detail what it's all about."

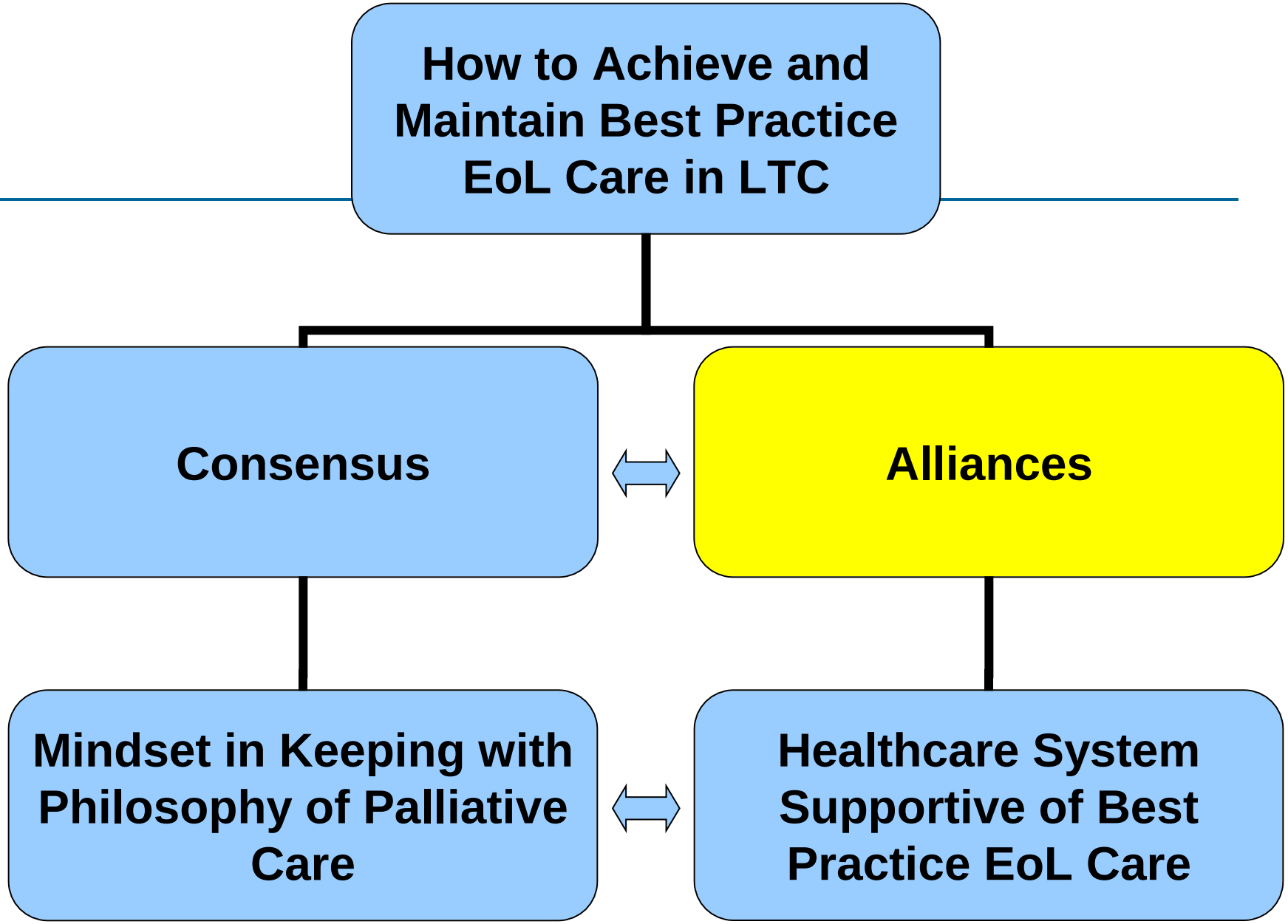
Communication

- "…and sometimes the family members aren't getting that support or explained to them what's going on in the process. They just come in and it's like all of a sudden they're not breathing. Well, why? Why aren't these people breathing? Well they're not explained what apnea is. They're not explained the process of dying, what the breathing sounds like. So when they're walking in, they're getting that, and the next you know they're standing there going "They just died. What happened?""

Advance Preparation

" …it's a very challenging issue to have to be able to resolve these things when that time approaches – I think preparedness is important."

- "And sometimes we see it and sometimes we don't see it, because they never signed. And then it's another case of, if you have to send them to the hospital, what code, what do you do? Is it a full code or just stay at the facility to keep them comfortable? That's where you run into the problems at that time."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Isolation

- "We had no orders for anything and we could not contact the physician."
- And it's the registered staff who have to call the doctors.
- "They have not received the flu vaccine."
- "But they're acute care and their perspective is definitely different than ours."

Isolation (cont.)

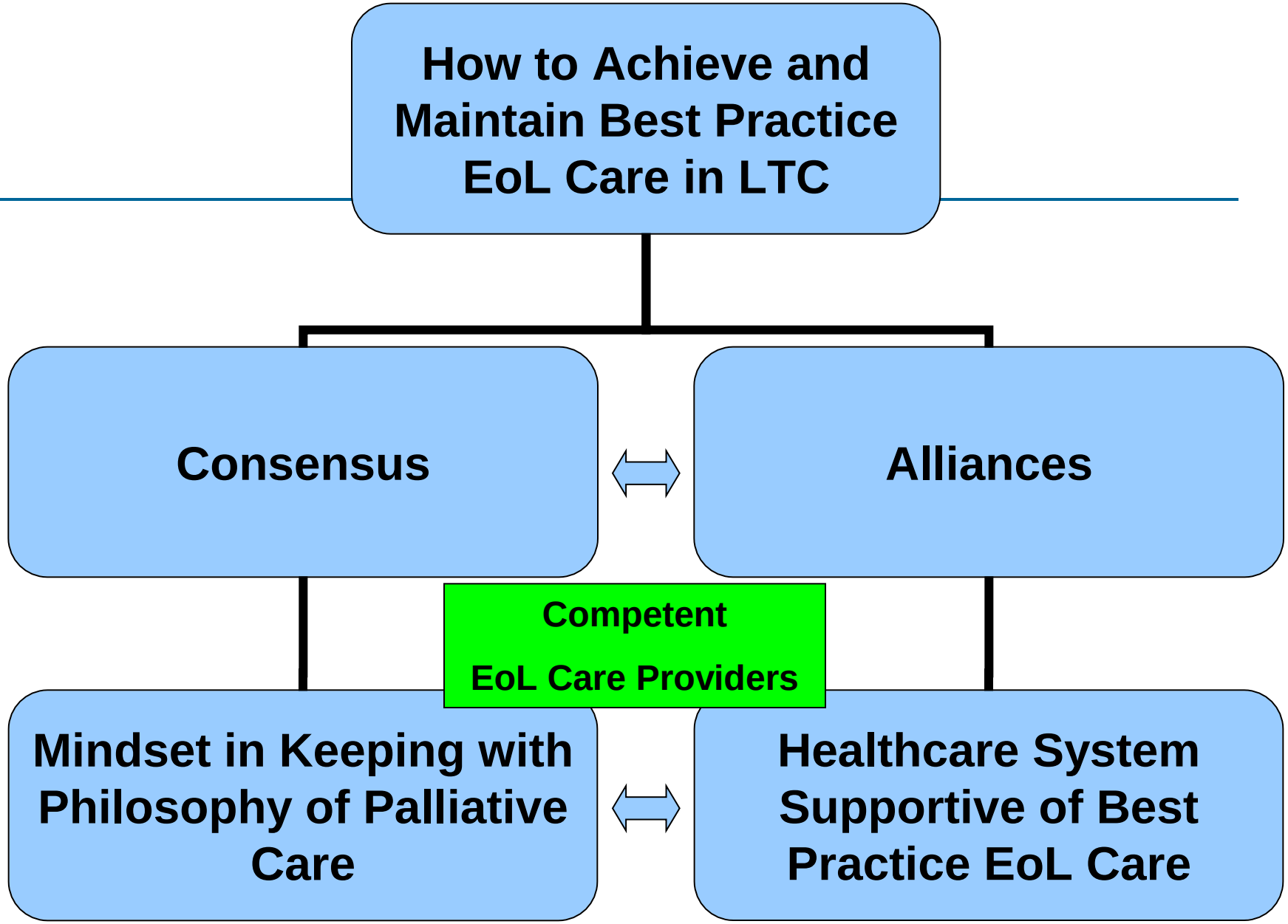
- "we know there's all kinds of research happening in relation to end of life, but we don't have the links, I think. We become very insular in our facilities with what's happening, almost cut off from the rest of the health care system in some regards"
- "we supposedly have a link with palliative care in the district, we supposedly have that. But they're too busy, they can't really respond to us"

Alliances vs. Isolation

- "…what's important, as you said (Person X), it's an alliance between the physician in long-term care. And that should be expanded to a therapeutic alliance in your own facility so that a relationship of the physician with the PCW, LPN, the staff nurse, the social worker, the family and the patient becomes like spokes of a wheel, where we can bring this particular brainstorming here and, you know, responsible caregivers bring to and extend it."

Alliances

- "… you could have all of us caring physicians but if they don't have – if we don't have access to that environment, the environment doesn't have access to us, that environment doesn't have access to those resources for those areas as you said, then we could be as caring as we want but we're not there."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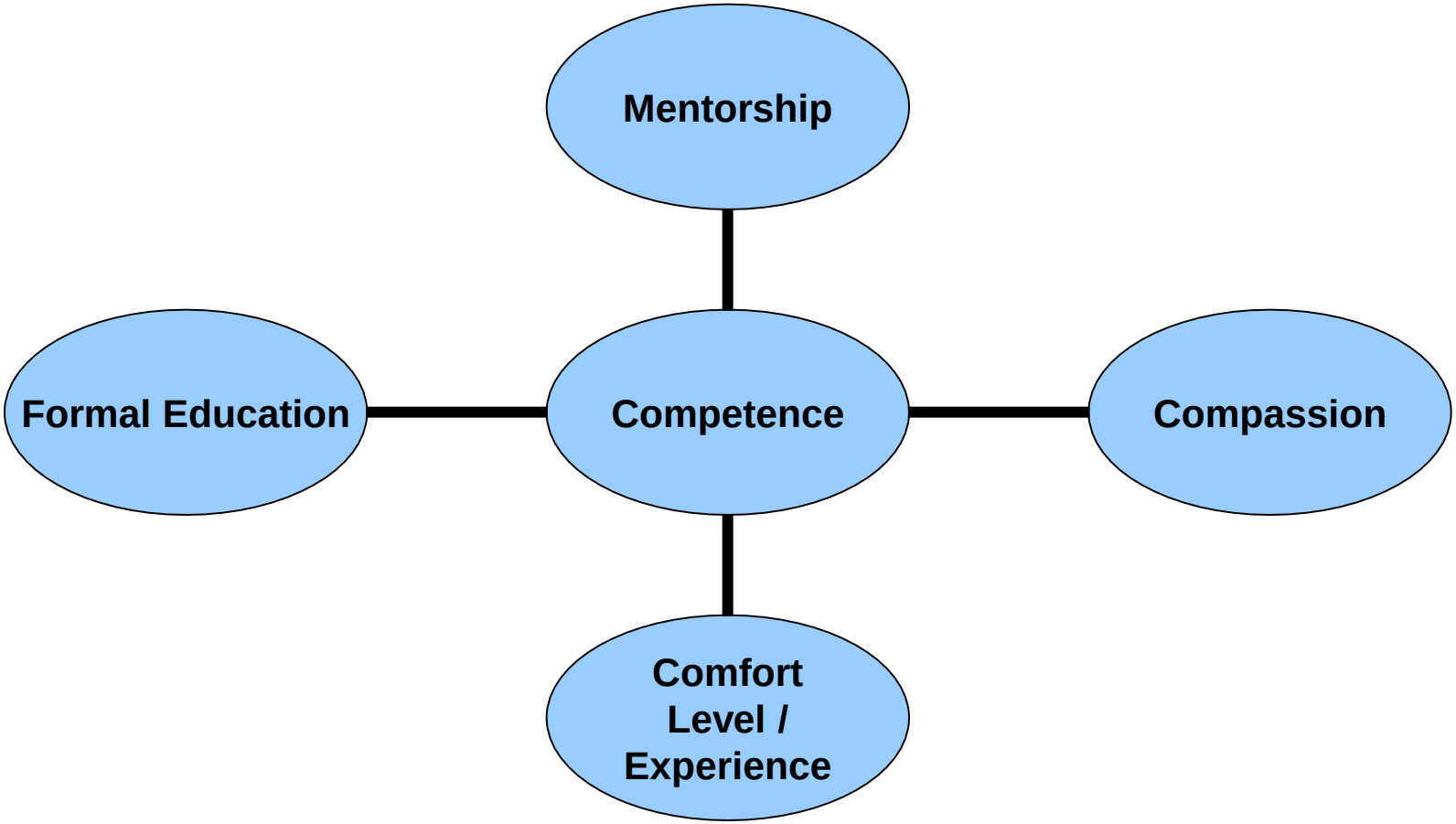
Healthcare Provider Competence



Comfort Level / Experience

- "… my observation has been the more experienced staff members who've been there the longest usually are dead-on or quite comfortable starting the standing orders for palliative care, they're quite comfortable giving the prns."

Mentorship

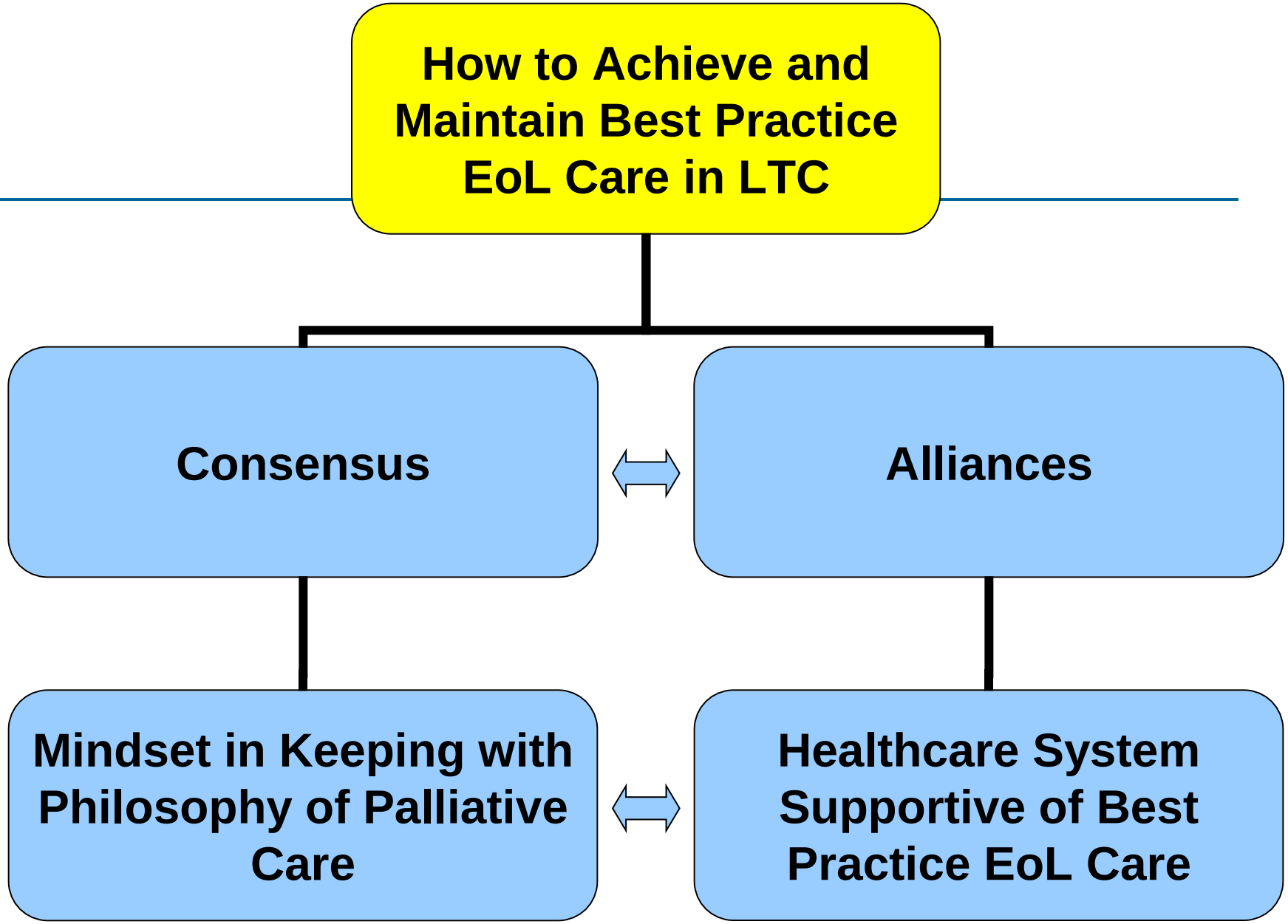
- "But it's the ongoing education, especially for new people coming onboard. For the people who have never witnessed a death, have never witnessed a dying, either personal or professional, there's a lot of growth and a lot of education has to occur."

Compassion

- "You know our last lady there was there for 13 hours, because she died at night time and he didn't get in till after lunch the next day, because he said "Do not call". You know, where's your compassion?"
- "They just got to learn to show a little bit more of compassion."

Formal Education

- 3-day Cancer Care NS course
- Within facility in-service
- Speakers: e.g. palliative care physicians
- University diploma courses
- 1 month core rotation in family medicine residency curriculum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Strategies for Improvement

- "I know myself, when I go back tomorrow – well, not tomorrow I'm off, but when I go back Friday I'm going to go talk to my palliative care director that we have there and discuss like about the heart. And the little care packages. And really, you know, if you think about it, the government, all for the money, they should have little care packages you can order, have like a dozen in your building."

Strategies for Improvement

- "But there is a lot of resources within the district; I think it's how we bring it together."

Thank You!

"… there's speed bumps along the way for sure. But we are, we're getting there, slowly but surely."