Slide 1: Response to: Web-Based Cancer Communication and Decision-Making Systems

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Slide 2: About NCCS

- Patient-centered voice for providing systematic solutions to improve the quality of cancer care
- About me: 12-year Ewing's Sarcoma survivor working to develop and maintain programs focused on improving shared-decision making across the cancer continuum

Slide 3: Changing the Culture of Oncology

- Resistance from physicians and patients
- Assumption that all patients want to/can be highly involved
- Cancer care as a system including caregivers, oncologists, nurses, social workers, pharmacists, family/friends, support groups, etc.
- Cancer care as a broken system

Slide 4: Self-Advocacy: Reframing the Model

- What is it?
  - Arming yourself with tools and skills to feel comfortable asserting yourself and communicating clearly about your needs
  - Taking responsibility and assuming some control of your life circumstances with cancer
- Evidence-based skills:
  - Communicating
  - Finding Information
  - Solving Problems
  - Making Decisions
  - Negotiating
  - Standing up for Your Rights

Slide 5: Coordination of Care

- Who is responsible?
- Negotiation of roles

- Changes across trajectory of care
- Appropriate time and type of communication
- Psychosocial needs

Slide 6: Skills vs. Decision Aids

- Patients need competencies
- Implementation AND evaluation are not enough
- Map IHCS characteristics to self-advocacy skills
- Skills form foundation for sustainable self-advocacy and shared decision-making

Slide 7: End of Life

- When is the appropriate time for this discussion?
- Death panel versus informed decision-making
  - No one wants to die hooked up to machines in a hospital.
- Setting realistic expectations and communicating prior to a significant event that can lead to bad decisions

Slide 8: Challenges to Active Participation

- Physician motivation and perceptions
- Changing needs across continuum of care
- Integration with other healthcare professionals
- Technology and health literacy
- Culture

Slide 9: Key Factors to Active Participation

- Start from the moment of diagnosis
- Meet patients where they are (in their cancer experience, with their self-advocacy skills, with their decision-making preferences, etc.) and adjust throughout continuum
- Set the foundation of basic skills that enable long-term shared decision-making

Slide 10: Final Thoughts

- "Daunting but not hopeless" – with proper framing, patients are more realistic about options and decisions
- Cancer is a system and interventions need to acknowledge and include different components of that system in development and implementation