Ask

Early and ongoing conversations

"Conversations are critical, but consider the extra paperwork burden on frontline staff."

"Knowing what my sister wanted was important. As much as we didn't want to talk about it, we needed to."

"We needed information about what to expect, what our choices were and what was available sooner rather than half-way through or at the end."

Opportunities

- Serious Illness Conversation guides and tools
- "Surprise question" trigger
- "Speak Up" Advance Care Planning tools

Gaps

- Not clear who to involve in conversations
- Lack of skills, proficiency and time
- Limited understanding about disease trajectory and end-of-life prognosis

Share

Understand and continually communicate wishes

Opportunities

- Interpreters facilitate culturally sensitive conversations
- Advance Care Planning Framework reinforces ongoing nature of ACP

"They listened to me. They understood–I knew what my husband wanted. If they didn't understand, they asked. We all agreed."

"We knew what we wanted, but we didn't know how to make everyone else know."

"It is so important that staff can differentiate between their beliefs and the client's wishes."

Gaps

- Lack of sharing between care settings and providers
- Varied access and use of tools and documentation
- Changes in patients' wishes not shared

Respond

Decisions are reflected in care plans, documentation and legal papers

"My sister's ACP was simple—she wanted to be at home with her family around her—not in hospital, not in a swirl of chaos in an emergency department."

"The plan was well thought out and in theory was a good plan. The execution and delivery on the plan were what fell short."

"It is not just physical needs. It's also strategies to preserve my dignity, quality of life and a plan to meet my spiritual needs – this is often neglected."

Opportunities

- Communities of practice
- Palliative care teams and networks programs
- Collaborative assess, treat & refer process

Gaps

- Minimal accountability and tracking systems
- Varied understanding of legal and ethical obligations
- Lack of processes and knowledge of how to include decisions into care planning

Advance Care Planning (ACP)

Knowledge · Skills · Processes

INCLUSION OF ADVANCE CARE PLANS INTO CARE DELIVERY

Advance care planning is an ongoing process of making decisions about the care an individual wants to receive if they become unable to speak for themselves.

This Experience Map is a visual representation of opportunities and gaps shared by subject matter experts, patients and caregivers in translating advance care wishes into the planning and delivery of home care. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys. Input was validated through an E-Delphi survey with a panel of experts.

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