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Consolidated framework for implementation codebook

Appendix 4 to End of Life Care Decisions Evidence Report

May 2024

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We also work closely with the Ministry of Health and the four other pillars of NSW Health to pilot, scale and spread solutions to healthcare system-wide challenges. We seek to improve the care and outcomes for patients by re-designing and transforming the NSW public health system.

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This codebook has been developed as Appendix 4 of the **End of Life Decisions: Evidence Report**.

The Consolidated Framework for Implementation Research (CFIR) was used as a systematic and theoretical approach to understand barriers and enablers, and to identify actionable findings, for systemwide innovation and improvement in resuscitation planning in NSW. The CFIR includes five domains that can explain barriers and enablers to implementation effectiveness.

This codebook includes definitions for identified barriers and enablers. These were used to help guide analysis.

Code	Definition	Relevant constructs
Access to clinician training	**Enabler**: Access and provision of training and communication resources for clinical staff having discussions about resuscitation planning and end of life care, to improve their knowledge and comfort with end of life conversations. This includes mention of training programs for healthcare providers, including senior and junior medical staff, related to communication skills and clinical management for end of life care. Any mention of existing tools such as skills training for conversations with families **Barrier:** Difficulties accessing training and deficiency in training. This includes mention of how education on resuscitation planning is currently inconsistent, voluntary and of varying quality	• Capability • Opportunity • Assessing needs: innovation deliverers • Structural characteristics: work infrastructure • Access to knowledge and information
Access to palliative care service	**Enabler:** Increase access to palliative care service	• Structural characteristics: work infrastructure
ACSQHC goals of care	**Enabler:** The Australian Commission on Safety and Quality in Health Care (ACSQHC) has developed a Comprehensive Care Standard including identifying and considering goals of care	• Innovation design • Innovation evidence base
Adherence to plans	**Enabler:** Adhere to what is stated in the resuscitation plan **Barrier:** Not adhering to what is stated in the resuscitation plan	• Culture: deliverer centeredness
ARC guidelines for clinical practice	**Enabler:** Australian Resuscitation Council (ARC) has developed guidelines for clinical practice and education for healthcare providers that are to be used by healthcare services and jurisdictions to	• Policies and laws

Code	Definition	Relevant constructs
	inform the development of local policy and procedures to support resuscitation practices	
Authorisation	**Barrier:** Any mention of uncertainty with who is responsible for authorising and signing resuscitation plans, who is accountable for the decision and ambiguity regarding who can write forms and assume responsibility. This includes mention of how in rural areas, a policy-approved individual may not be available to authorise and sign resuscitation plans	• Policies and laws • High-level leaders • Mid-level leaders • Structural characteristics: work infrastructure • Implementation leads • Innovation deliverers
Awareness of policy	**Enabler:** High awareness of policy. 67% and 73% of respondents, in the primary and secondary analysis of the health professional questionnaire respectively, reported awareness of the NSW Health 'Using Resuscitation Plans in End of Life Decisions' Policy Directive **Barrier:** Low awareness of policy. Percentages as above, which also reflects the low awareness of the policy	• Policies and laws
Carers in conversations	**Enabler:** Family and carer involvement and support in conversations	• Relational connections • Culture: recipient-centeredness
Clarity of guidelines	**Enabler:** Clarity of guidelines	• Communications
Clarity of process	**Enabler:** Clarity of process, e.g. who is responsible for initiating the conversation, documenting and authorising the resuscitation plan **Barrier:** Lack of clarity of process, e.g. who is responsible for initiating the conversation, documenting and authorising the resuscitation plan. This includes mention of the lack of consensus on the process or components that should be contained within any goals of care or resuscitation tool	• Innovation evidence base • Local conditions • Assessing needs: innovation deliverers • Structural characteristics: work infrastructure • Mission alignment
Clear communication	**Enabler:** Open, honest and regular communication between healthcare professionals and the patient and their family. Agreed goals of care should be clearly communicated. This includes mention of using a clear communication framework which increase patient and doctor satisfaction, reduces inpatient costs, minimises	• Communications • Relational connections • Implementation team members

Code	Definition	Relevant constructs
	any perceived or actual patient abandonment and improves quality of life **Barrier:** Poor communication between staff and patients and carers	• Culture: recipient centeredness
Clinician awareness	**Barrier:** Lack of awareness and understanding among clinical staff	• Culture: recipient centeredness
Coach and mentor for conversations	**Enabler:** Access to a role model to coach and mentor staff in having difficult conversations. An example is a “site champion” who proactively manages the process of resuscitation planning and end of life care at each hospital	• Opportunity • Assessing needs: innovation deliverers • Implementation facilitators • Access to knowledge and information • Implementation leads • Other implementation support
Communication between teams	**Enabler:** Clear communication and collaboration between teams **Barrier:** Lack of clear communication between teams. This includes mention of lack of communication skills among both junior and senior medical staff	• Relational connections • Communications • Implementation team members
Community awareness	**Enabler:** Greater community awareness and understanding of advance care directives or advance care plans and end of life care. This includes mention of greater community awareness of legal documentation associated with resuscitation plans **Barrier:** Lack of community awareness and understanding of end of life care. This includes mention of a lack of targeted public education campaigns and initiatives to raise awareness about end of life care policies and practices	• Local attitudes • Local conditions • Culture: recipient centeredness • Culture: deliverer centeredness • Innovation recipients • Available resources: materials and equipment • Policies and laws • External pressure: societal pressure
Conflict arising from difficult conversation	**Barrier:** Concerned about conflict arising from the difficult conversation. These conflicts may exist between clinicians, patients and families, or between families, carers and clinicians, which can potentially hinder the initiation of conversations and create complexity in the conversation	• Innovation complexity • Local attitudes • Local conditions • Assessing needs: innovation deliverers

Code	Definition	Relevant constructs
		• Communications • Culture: deliverer centeredness • Innovation complexity
Consumer education	**Enabler:** Education for the patient (understanding of their condition or disease). This includes mention of the importance of initiatives to raise awareness and encourage discussions and planning for end of life **Barrier:** Diverse cultural backgrounds and language barriers within the community can make it challenging for individuals and families to comprehend and navigate the complex end of life care policies and practices. This includes mention of lack of targeted public education campaigns and initiatives to raise awareness and understanding about end of life care policies and practices	• Innovation design • Structural characteristics: work infrastructure • Communications • Culture: Recipient centeredness • Implementation facilitators • Assessing needs: innovation recipients • Other implementation support • Access to knowledge and information • External pressure: societal pressure • Innovation adaptability
Consumer support	**Enabler:** Confer psychological support for patients and their families **Barrier:** Lack of support for patients and families when having the conversation	• Need • Culture: deliverer centeredness • Culture: recipient centeredness
Cultural, moral, spiritual and ethical preferences	**Enabler:** Conducting conversations with sensitivity to cultural and spiritual beliefs and practices. This includes mention of resuscitation planning decisions to be considered within the context of a patient's broad goals of care that are informed by their values and treatment preferences **Barrier:** Difficulties navigating different cultural, moral, spiritual and ethical preferences. This includes mention of how diverse cultural backgrounds and language barriers within the community can make it challenging for individuals and families to comprehend and navigate the complex end of life care policies and practices	• Innovation design • Local attitudes • Structural characteristics: work infrastructure • Communications • Culture: recipient centeredness • Culture: deliverer centeredness • Implementation facilitators • Other implementation support • Culture: human equality centeredness • Innovation adaptability

Code	Definition	Relevant constructs
Difficult conversations	**Barrier:** Conversations can be confronting, overwhelming and distressing for the patient and their family or carer. They may also have reluctance to discuss the situation. This includes mention of clinical staff who experience discomfort initiating conversations	• Local attitudes • Culture: recipient centeredness • Culture: deliverer centeredness • Capability • Access to knowledge and information
Discussions about death and dying	**Enabler:** More open discussions about death and dying. This includes mention of normalising discussions around end of life care **Barrier:** Societal stigma around discussing end of life care and planning, which can hinder open conversations to be had	• Local attitudes • Culture: human equality centeredness • Culture: recipient centeredness • Culture: deliverer centeredness • Local conditions • External pressure: societal pressure
Existing programs	**Enabler:** Successful programs operating in similar contexts can be used as models for new approaches, such as the renal supportive care program for chronic health issues and programs within the organ donation field. This includes mention of availability of existing programs such as the SHAPE End of Life Conversations training program available through Health Education and Training (HETI), which focuses on practical, role-playing exercises to facilitate effective communication	• Capability • Compatibility • Adapting • Innovation evidence base • Available resources: Materials and equipment • Access to knowledge and information • Innovation trialability
Existing tools	**Enabler:** Use and availability of existing tools to initiate and guide conversations. Some examples mentioned include the AMBER care bundle which can be used as a trigger to start conversations about resuscitation plans. This tool also emphasises the importance of connecting with general practitioners to close the loop of enquiry, and can also enable a multidisciplinary plan. Another example is the **Dying to Know** resource which can enable greater community understanding of end of life care, and skills training for conversations with families	• Capability • Partnerships and connections • Structural characteristics: work infrastructure • Relational connections • Available resources: materials and equipment • Access to knowledge and information • Innovation design • External pressure: societal pressure

Code	Definition	Relevant constructs
Failure to document	**Barrier:** Clinicians are failing to develop appropriate treatment plan	• Assessing needs: innovation deliverers • Implementation facilitators • Capability
Formal / standardised training	**Barrier:** Lack of standardised and formal training • 31% and 24% of respondents, in the primary and secondary analysis of the health professional questionnaire respectively, indicated that they did not receive any of the three training options (self-directed, informal in-services or formal) • 25% and 34% of respondents, in the primary and secondary analysis of the health professional questionnaire respectively, reported that they received formal training	• Culture: learning centeredness • Access to knowledge and information
Legal responsibility	**Enabler:** Greater awareness of responsibilities of those with authority to carry out people's wishes towards the end of life. These individuals may be the patient's Enduring Guardian or have Power of Attorney	• Policies and laws
Initiators	**Barrier:** Lack of clarity as to who should initiate resuscitation plans, particularly during late-night hours where there is a gap in the system that creates uncertainty as to who should initiate	• Structural characteristics: work infrastructure • Innovation deliverers
Integration and functionality of plans across settings	**Enabler:** Increased adoption of a universal form across local health districts and the electronic capacity for standard documents to be accessed from various locations. This includes mention of resuscitation plans being incorporated into existing systems and processes **Barrier:** Limited integration and functionality of resuscitation plans across all care settings. This includes mention around issues of accessibility, sharing and updating of resuscitation plans across settings due to the range of IT platforms used across NSW Health, which results in challenges to maintain up-to-date plans for patients who are admitted frequently (i.e. haemodialysis patients) and challenges with ensuring relevancy of the plan to the patient's current needs and preferences. This also includes mention around the lack of a	• Innovation design • Structural characteristics: IT infrastructure • Structural characteristics: work infrastructure • Available resources: materials and equipment

Code	Definition	Relevant constructs
	standardised and interoperable format for resuscitation plans across all care settings	
Interpreters	**Enabler:** Involvement of professional medical interpreters is important in conversations about goals of care where there is limited English proficiency	• Engaging: innovation deliverers • Culture: recipient centeredness
Mandatory to admission	**Enabler:** Mandatory part of admission process	• Structural characteristics: work infrastructure
Multidisciplinary team	**Enabler:** Collaboration across the multidisciplinary team. Goals of care conversations should be multidisciplinary in nature. This includes mention of collaboration among healthcare providers, patients, families and general practitioners **Barrier:** Lack of multidisciplinary collaboration. This includes mention of uncertainty on how best to involve multidisciplinary teams	• Teaming • Relational connections • Communications • Implementation team members
palliAGED GoC	**Enabler:** palliAGED (palliative care aged care evidence) has completed an evidence review and developed practice points for clinicians to guide their discussions with patients, families and substitute decision makers around goals of care	• Innovation evidence base • Innovation design
Patient-centred care	**Enabler:** Fostering a patient-centred approach to end of life care planning. This includes mention of flexibility around a patient's documented goals of care as their condition changes or circumstances change and ensuring that all resuscitation planning decisions are considered within the context of a patient's broad goals of care that are informed by their values and treatment preferences. This also includes mention on how the focus on patient experience is critical to the delivery of comprehensive care, and the importance of promoting patient autonomy	• Culture: human equality centeredness • Culture: recipient centeredness • Culture: deliverer centeredness
Positively framed language	**Enabler:** Discussions around resuscitation planning to use positively framed language. This makes the conversations more comfortable for both clinician, patient and their family	• Communications • Culture: human equality centeredness • Culture: recipient centeredness • Culture: deliverer centeredness

Code	Definition	Relevant constructs
Primary care physicians as deliverers	**Enabler:** Primary care physicians as initiators and documenters of the conversation **Barrier:** Although general practitioners play a crucial role in raising and discussing end of life care with their patients, they may lack the necessary training, resources or time	• Partnerships and connections
Prognostic uncertainty	**Barrier:** Prognostic uncertainty	• Access to knowledge and information
Recognise end of life	**Barrier:** Clinicians failing to recognise when patients are at risk of dying	• Assessing needs: Innovation deliverers • Assessing needs: Innovation recipients • Capability
Relevance to role	**Enabler:** High relevance to a clinician's role • 94% and 83% of respondents in the primary and secondary analysis of the health professional questionnaire respectively, indicated relevance of the policy to their role	• Opportunity
Resource availability	**Barrier:** Resource challenges (e.g. competing demands, understaffing, skill mix). This includes mention of scarcity of resources in outpatient settings, which can limit opportunities for conversations. Also mention around overloaded clinical schedules, which can limit time to engage in meaningful conversations with patients and their families	• Innovation cost • Structural characteristics: work infrastructure • Compatibility • Relative priority • Available resources: funding • Available resources: space • Available resources: materials and equipment
Review frequency	**Enabler**: Revisiting resuscitation planning conversations on a regular basis. This includes mention of the importance of renegotiating a patient's goals of care **Barrier:** Frequency the resuscitation plan requires review. This includes mention of needing to revisit the resuscitation plan at every hospital admission and ambulance ride, which can be distressing for the patient, family and carers. The code also relates to the cumbersome process of using a new form for each hospital admission, which can be burdensome for individuals with advanced or complicated illnesses	• Innovation design • Structural characteristics: IT infrastructure • Structural characteristics: work infrastructure • Assessing needs: innovation recipients • Local conditions • Available resources: materials and equipment • Access to knowledge and information

Code	Definition	Relevant constructs
		• Communications • Culture: human equality centeredness • Culture: recipient centeredness
Scope of policy	**Barrier:** Not all patients are currently included in the policy (i.e. those under the age of 29 days)	• Innovation design • Policies and laws
Shared decision making	**Enabler:** Active participation of the patient and their preferred support individuals in the conversation. This includes mention of discussions being embedded in a hospital culture of shared decision making, and there to be a shared purpose and understanding of the resuscitation planning process. All resuscitation planning decisions to be considered within the context of a patient's broad goals of care, which are informed by their values and treatment preferences. Other mentions include the importance of connecting with general practitioners (via use of an AMBER care bundle) to close the loop of enquiry **Barrier:** Complexities of decision making (e.g. different views between clinical teams, as well as different views and expectations between clinician and patient on how the patient's condition should be managed). This includes mention of pressuring the patient and family into making a decision. This also includes mention of differing views between clinicians on when and how to discuss resuscitation plans	• Relational connections • Communications • Culture: deliverer centeredness • Mission alignment • Partnerships and connections • Structural characteristics: work infrastructure • Relational connections • Culture: human equality centeredness • Culture: recipient centeredness
Skills and confidence in conversations	**Enabler:** Building confidence among healthcare professionals in conducting these discussions **Barrier:** Lack of skills and confidence to have difficult conversations • 29% and 24% of respondents, in the primary and secondary analysis of the health professional questionnaire respectively, reported that they were highly confident in having goals of care and resuscitation planning conversations at the approach of end of life with patients, family members and carers.	• Culture: learning centeredness • Capability • Assessing needs: innovation deliverers • Access to knowledge and information

Code	Definition	Relevant constructs
Standardised documentation	**Enabler:** Goals of care should be documented. This includes mention of the use of standardised documentation (plan or form) across different local health districts and care settings, and its transferability across the settings. This also includes mention of the policy being available to all clinical and managerial staff at all times **Barrier:** Not all services use the state form	• Partnerships and connections • Structural characteristics: IT infrastructure • Communications • Innovation adaptability • Local conditions • Structural characteristics: work infrastructure • Innovation design • Culture: recipient centeredness
Systematic approach	**Enabler:** Discussion and documentation of resuscitation plans should be embedded into clinical practice of all treating clinicians	• Structural characteristics: IT infrastructure • Structural characteristics: work infrastructure • Culture: deliverer centeredness
Team accountability	**Enabler:** Accountability of clinical teams	• Structural characteristics: work infrastructure
Terminology	**Barrier:** Ambiguity of the phrase ‘goals of care’ despite its ubiquitous use in clinician notes and healthcare literature	• Local attitudes • Communications
Time needed for conversations	**Enabler:** Allowing time for the patient and their family to understand and to express their wishes **Barrier:** Insufficient time to have conversations. This includes mention of specific clinical settings, such as emergency department settings where time-sensitive decisions and acute care priorities can hinder the ability and time to have comprehensive and thoughtful conversations, and outpatient settings where the scarcity of resources and time can limit the opportunities for conversations. Overloaded clinical schedules can result in limited time to engage in meaningful conversations with patients and their families	• Innovation cost • Structural characteristics: physical infrastructure • Assessing needs: innovation deliverers • Structural characteristics: work infrastructure • Compatibility • Relative priority • Mission alignment • Opportunity • Available resources: funding • Available resources: materials and equipment • Culture: deliverer centeredness • Innovation adaptability

Code	Definition	Relevant constructs
Timing of conversation	**Enabler:** Initiating and encouraging conversations earlier in the disease course. This includes mention of how identification of goals of care is particularly important for patients with serious illness and acknowledging that goals of care may shift during the disease course **Barrier:** Conversations often occur too late in the process, particularly with elderly or terminally ill patients. This includes mention of the importance of initiating conversations at the right moment, and a common misconception that end of life planning should occur only at the final moments of a patient's life. This also includes mention of differing views between clinicians on when to discuss resuscitation plans	• Innovation evidence base • Local attitudes • Assessing needs: innovation deliverers • Assessing needs: innovation recipients • Structural characteristics: work infrastructure • Culture: recipient centeredness • Mission alignment • Local conditions • Communications
Unsuitable environment	**Barrier:** Unsuitable environment to hold conversations. This includes mention of emergency department settings where time-sensitive decisions and acute care priorities can hinder the ability and time to have comprehensive and thoughtful conversations. This also includes mention of acute hospital inpatient settings, which are unsuitable environments to have sensitive conversations	• Structural characteristics: physical infrastructure • Compatibility • Relative priority • Available resources: space • Innovation adaptability
Unwanted care	**Barrier:** Unwanted care for patients at end of life	• Culture: recipient centeredness