

End of life care decisions

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The information in this resource should not replace a clinician's professional judgement.

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Summary

Introduction

Ensuring that a patient's end of life wishes and goals of care are heard, communicated, documented and actioned is crucial for providing high quality patient-centred end of life care. One important component in the planning for quality end of life care is making and documenting a resuscitation plan.

A resuscitation plan is a medically authorised order to use or withhold resuscitation measures and documents other aspects of treatment relevant at end of life. Within NSW Public Health Organisations, resuscitation planning is guided by the Using Resuscitation Plans in End of Life Decisions: Policy Directive¹ (the Resuscitation Policy).

This evidence report summarises local experience and insights into resuscitation planning in NSW from various perspectives and outlines the international evidence. It integrates various types of evidence and triangulates the perceived barriers and enablers using the Consolidated Framework for Implementation Research (CFIR).²

Structure

The report draws on and triangulates three sources of evidence:

- Empirical evidence: quantitative data drawn from Clinical Excellence Commission (CEC) Death Review Database
- Research evidence: literature identified through PubMed and Google searches
- Experiential insights: collected using a questionnaire from 381 health professionals and 25 consumers, and perspectives gathered through two policy impact labs

Barriers and enablers

The CFIR constructs identified across the multiple evidence sources as both enablers and barriers were culture: recipient-centeredness, culture: deliverer-centeredness, access to knowledge and information, and structural characteristics (work infrastructure).²

Improvements and innovations

Broader system-level improvement or innovation is required to ensure that:

- the end of life wishes and goals of care of patients, families and carers are heard, communicated and documented
- clinicians are equipped with the skills and confidence to have quality goals of care conversations, at the right time and place, using the right tools.

Key findings

Evidence source	Key points
Empirical evidence	<p>In the 2022 calendar year, there were 24,427 in-hospital patient deaths in NSW public hospitals with a death screen completed in the CEC Death Review Database. Of these patients, 15,216 (62.3%) had a resuscitation plan documented:</p> <ul style="list-style-type: none"> • 33.2% (n=5,049) had their resuscitation plan documented less than 48 hours before their death. • 45.0% (n=6,841) had capacity and were involved in the decision-making process related to treatment plans and goals of care.* • 49.9% (n=7,587) did not have capacity and had a substitute decision maker, family or carer involved in the decision-making process related to treatment plans and goals of care.* • 3.3% (n=502) had neither the patient nor a substitute decision maker, family or carer involved in the decision-making process related to treatment plans and goals of care.* <p>* Numbers do not add up to the total number of completed resuscitation plans due to missing data (n=286).</p>
Research evidence	<p>Findings from a narrative review suggest it is not the content or format of the resuscitation plan that is important, but rather the way information is communicated, the transparency of decisions and shared mutual understanding between treating clinicians, patients, families and carers. Four themes were identified for discussing and documenting resuscitation and goals of care decisions at end of life:</p> <ul style="list-style-type: none"> • Ensure a systematic approach is in place to discuss and document resuscitation and goals of care plans. • Use shared decision-making processes and tools (and ensure resuscitation planning decisions are considered in the context of the patients' broader goals of care). • Use standardised documentation that is accessible across care settings. • Revisit decisions to withhold or limit treatment decisions as preferences may change.
Experiential insights (health professionals and consumers)	<p>Health professionals and consumers suggested three key points:</p> <ul style="list-style-type: none"> • Resuscitation planning conversations can be confronting, overwhelming and distressing for health professionals and consumers. • Health professionals as well as consumers can feel reluctant to discuss goals of care and/or resuscitation planning. • Positive experiences occur when conversations are initiated early and there is two-way communication between consumers and healthcare professionals. <p>Perceived barriers to having resuscitation planning conversations included:</p> <ul style="list-style-type: none"> • lack of community awareness and understanding of end of life care • lack of standardised documentation and limited integration and functionality of the plan across care settings • difficulties navigating different cultural, moral, spiritual and ethical preferences. <p>Perceived enablers to having resuscitation planning conversations included:</p> <ul style="list-style-type: none"> • multidisciplinary team collaboration • use of standardised documentation across care settings • access to a role model to coach and mentor staff in having difficult conversations.

Setting the context

What is a resuscitation plan?

End of life care conversations can be complex and difficult to navigate, as they involve discussions around a person's values and goals of care and the appropriate use of life-sustaining interventions.

One important component in planning for quality end of life care is making a resuscitation plan. A resuscitation plan is a medically authorised order to use or withhold resuscitation measures and documents other aspects of treatment relevant at the end of life. An integral part of a resuscitation plan is the documentation of a person's goals of care. This may include cure of their illness, relief of their symptoms, stabilisation of their condition or general improved quality of life.

In NSW, the Resuscitation Policy and associated state forms (adult and paediatric resuscitation plan) describes the standards and principles relating to the appropriate use of resuscitation plans by NSW Public Health Organisations, for patients 29 days and older. For patients under the age of 29 days, the paediatric resuscitation plan may be used to guide discussions. It is mandatory for all NSW Public Health Organisations, including acute and sub-acute facilities, ambulatory and community settings, and NSW Ambulance to use NSW Health resuscitation plans. Resuscitation plans are only valid for NSW Health staff members, which includes general practitioners with public hospital admitting rights.

When are life sustaining treatments withheld?

- Where there is a clearly stated, adequately informed and properly documented or verbally expressed refusal by a person with decision-making capacity. An advance care directive (ACD) and advance care plan (ACP) can inform decisions recorded in the resuscitation plan.

- Where the person has no capacity to make this decision, there is an adequately informed and properly documented decision to withhold resuscitation by the attending medical officer in consultation with the person responsible, family and/or carer.
- Where the attending medical officer judges that resuscitation offers no benefit or where the benefits are small and overwhelmed by the burden to the patient.

Not having a resuscitation plan does not necessarily mean that resuscitation is a default action that must be applied in all situations. A medical officer's clinical judgement should be used where resuscitation is manifestly inappropriate and/or the patient is deceased.

How does a resuscitation plan differ to an advance care directive or advance care plan?

Advance care planning involves individuals thinking about what care they would like should they find themselves in a position where they cannot make or communicate decisions about their treatment or care. It can include the individual talking with family, carers and/or health professionals, developing an ACP, appointing an enduring guardian or making an ACD. An ACP can be made by the individual or together with people that they trust and/or who are important to them. Where the individual is not able to make decisions, the ACP can be made by their family with a health professional. An ACP is not a legal document.

An ACD is a way an individual can document what health care treatments they would like to have or refuse, should they find themselves in a position where they are unable to make or communicate decisions about their treatment and care. An ACD in NSW can be spoken or written, there is not a specific form. An ACD can only be made by an adult with decision-making capacity and if it is valid, it must be followed. Health professionals and persons responsible have no authority to override a valid ACD.

A resuscitation plan is made with reference to pre-planning by patients (such as ACPs and ACDs), in consultation with patients and families, and by taking account of the current clinical status, as well as the wishes and goals of the patient. Resuscitation encompasses a spectrum of emergency interventions such as supplemental oxygen, intravenous fluids and non-invasive ventilation. It is not limited to cardiopulmonary resuscitation.

Where can a resuscitation plan be created and accessed?

In NSW resuscitation plans have been included in the statewide ACP solution of the electronic medical record (eMR). This portal is designed to support clinicians through documenting a patient's advance care needs and to facilitate conversations with patients, families and carers. It contains a section where ACDs can be uploaded to the eMR record of the patient. This solution also includes the electronic version of the adult and paediatric resuscitation form.

Policy context

The following policy instruments have been reviewed, to ensure there is alignment:

- End of Life and Palliative Care Framework 2019-2024³ (the Framework) sets out the vision and future direction for palliative and end of life

care for people across NSW. The Resuscitation Policy has direct alignment with priority area 1 (care is person centred) and priority area 4 (care is well-coordinated and integrated).

- National Safety and Quality Health Service Standards⁴, developed by the Australian Commission on Safety and Quality in Health Care, support safe, high-quality end of life care as part of the Comprehensive Care Standard. Comprehensive care is the coordinated delivery of the total health care required or requested by a patient. This care is aligned with the patient's expressed goals of care and healthcare needs, considers the impact of the patient's health issues on their life and wellbeing, and is clinically appropriate.

Aim of this evidence report

The evidence report aims to integrate various types of evidence, perspectives and insights about resuscitation planning at the end of life to inform statewide improvements to the revised Resuscitation Policy in NSW. The evidence inquiry was guided by the following five framing questions:

- Are resuscitation plans being used to inform end of life decisions?
- Does the current policy directive align with evidence-based best practice and other legislative requirements?
- What can be learned from the literature and other jurisdictions about the use of resuscitation plans in end of life care decisions?
- What barriers and enablers exist for health professionals, patients, carers and families?
- What is the experience of health professionals, patients, carers and families?

Methods

Design

A mixed methods approach using quantitative data drawn from NSW Health datasets, research literature, and experiential insights from health professionals and consumers.

Data collection and analysis

Empirical evidence

Quantitative data was drawn from the CEC Death Review Database (including data from the Admitted Patient Death Screening Tool). The CEC Death Review Database includes data on patients who have died in NSW public hospitals and had a death screen completed in the CEC Database. Death screen data for deaths in public hospitals in the 2022 calendar year were used in the analysis. About 96% of deaths in public hospitals in 2022 had a death screen completed in the CEC database. Deaths that were classified as 'dead on arrival' were excluded from the analysis. A small number of death screens for in-hospital deaths in 2022 were entered into the CEC database after data was extracted for this analysis and are missing from this analysis.

Research evidence

PubMed and Google searches were completed on 16 August 2021 using key terms 'resuscit*', 'DNR/Do-Not-Resuscitate', 'NFR/Not-for-resuscitation', 'advance care directive', 'advance care planning' and 'inpatient*', 'system', 'system', 'organisation*', 'polic*', 'pathway*', 'principle*' and 'review', 'systematic review'. A 10-year date limit was applied and the peer-reviewed search was limited to review articles. The search was targeted to include policy documents. One narrative review was found which met the inclusion criteria, so rather than duplicating efforts, results from this review form the basis of the evidence search. It captured a 60-year period to February 2021 which explored the evolution of

hospital patient no-CPR and do not resuscitate decisions.⁵ Peer-reviewed articles and grey literature on guidance from other Australian jurisdictions and peak bodies have been included. One study was included from peer-reviewed literature and seven publications from grey literature. The findings were synthesised into a report (see [Appendix 1: Use of resuscitation plans in decisions at the end of life: Evidence check](#)).

Experiential insights

SAX Institute Policy Impact Lab

A two-day (six hours in total) policy impact lab was conducted on 14 and 16 February 2023 in partnership with the SAX Institute. The framing question for deliberation was: What do we need to learn from stakeholders to improve the current resuscitation policy and its implementation in practice? The Policy Lab members (n=32) were purposively recruited from the ACI End of Life Care Decisions Clinician and Consumer Expert Advisory Group (EAG). The findings from the Lab were synthesised into a report (see [Appendix 2: SAX Policy Impact Lab Summary Report](#)).

Health professional questionnaire

A cross-sectional online questionnaire was used to gather experiences and perspectives from health professionals on resuscitation planning conversations and practice in NSW, including perceived barriers and enablers. The outcome of the Policy Impact Lab informed a bespoke questionnaire. Rapid questionnaire testing was conducted with the Clinician and Consumer EAG, assisting in refining the question set. The final questionnaire included 14 closed – and nine open-ended questions (see [Appendix 3: Health professional and consumer questionnaire report](#)). The questionnaire was disseminated using a convenience and snowball sampling approach. Consent was implied by completion of the questionnaire, which was

voluntary. Data was collected using an online questionnaire from 9 May 2023 and 30 May 2023 through Microsoft Forms, and there were 340 responses. The questionnaire was re-opened from 25 July 2023 to 4 August 2023, and was disseminated using a purposeful approach to reach specific networks of interest, and there were 41 responses. Descriptive statistics were used to analyse the data collected from the closed question sets. Free text was analysed using an inductive content analysis approach. The analysis identified main concepts from the free-text responses based on frequency of mentions. NVivo software and Microsoft Excel was used to support data analysis.

Consumer questionnaire

An online questionnaire was used to gather self-reported experiences of goals of care and/or resuscitation planning conversation experiences from consumers, i.e. patients, families and/or carers, in NSW. Rapid questionnaire testing was conducted with five consumer partners from the Project Steering Committee and Clinician and Consumer EAG. The final questionnaire included seven questions in total, consisting of demographic, open (n=1 with three prompt questions) and closed ended (n=6) questions (see [Appendix 3: Health professional and consumer questionnaire report](#)). The questionnaire was disseminated using a convenience and purposeful sampling approach. Consent was implied by completion of the questionnaire, which was voluntary. Data was collected using an online questionnaire from 21 June 2023 to 17 July 2023 using Microsoft Forms, and there were 21 responses. Descriptive statistics were used to analyse the data collected from the closed question sets. Qualitative data was analysed using an inductive content analysis approach. The analysis identified main concepts from the free-text responses based on frequency of mentions. NVivo software was used to support data analysis.

The Greater Western Human Research Ethics Committee granted full ethics approval to the project on 15 May 2023: 2023/ETH00721.

Data triangulation using the Consolidated Framework for Implementation Research

The CFIR was used as secondary analysis tool and provides a theoretical framework to triangulate data across the various evidence sources. The CFIR is a well-renowned determinant framework in implementation science. The CFIR includes five domains that can explain barriers and enablers to implementation effectiveness and can be used to inform choice of implementation strategies.⁶ Using the CFIR provided a systematic and theoretical approach to understanding barriers and enablers, and to identifying actionable findings for system-wide innovation or improvement in NSW.

A CFIR template was developed in Microsoft Excel, using the publicly available CFIR domain and construct definitions.⁶ Each domain and construct were clearly defined within the context of this project and data from the various evidence sources were charted and mapped into the template.

A codebook was developed to guide the secondary analysis and includes concise definitions of identified barriers and enablers (see [Appendix 4: Consolidated framework for implementation codebook](#)).

The relevant domains and constructs across all the evidence sources were displayed on a Mural board. This visualisation of enablers and barriers (organised by domains and constructs) may be helpful to identify key areas of focus that may be important for implementation success.

Project governance and consumer involvement

The project governance groups (the Steering Committee and Clinician and Consumer EAG) have been involved throughout the project. These governance groups provided expertise to inform the project scope and direction, guidance on consultation planning, developed and piloted questionnaires, participated in consultation activities and peer reviewed the evidence report.

Consumers have been engaged throughout the project. They provided expertise through representation on project governance groups, informed the project scope and direction, developed and piloted questionnaires, participated in consultation activities and reviewed the evidence report.

those already engaged with ACI in some capacity. The data collection tools were not developed prospectively using CFIR. CFIR was applied as a secondary framework to triangulate the barriers and enablers. The evidence check retrieved very few articles, and the one included paper was a narrative review.

Limitations

The majority of respondents to the health professional questionnaire reported that they felt familiar and comfortable with having resuscitation planning conversations. The skew in responses may limit the generalisation of the results to NSW-wide. The small and self-selected sample size of the consumer questionnaire also limits generalisation of the results to NSW-wide and may have resulted in a bias in reporting practices on the part of the respondents. The low number of respondents identifying from a culturally or linguistically diverse background, and a high proportion with an ACD and ACP is not representative of the population. The design of the questionnaire, recruitment and data collection have likely biased the sample towards those with access to digital communications and

Triangulation with the Consolidated Framework for Implementation Research

Enablers and barriers to the implementation of the Resuscitation Policy were identified across the various evidence sources, and these were mapped to the CFIR. Diagrams showing the mapping can be requested by emailing ACI-PallCare@health.nsw.gov.au

The key enablers and barriers were identified across 67 CFIR constructs, with some factors (depending on context) being both enablers and barriers. Most of the barriers and enablers were mapped to the inner setting domain of CFIR, i.e. within NSW Health public health organisations, as shown in Tables 1-4.

Table 1: Inner Setting - Culture: Recipient-centredness, e.g. there are shared values, beliefs, and norms around caring, supporting, and addressing the needs and welfare of patients

Enablers (C) (S) (H) (R)	Barriers (C) (S) (H) (R)
<ul style="list-style-type: none"> • Shared decision making • Cultural, moral, spiritual and ethical preferences • Review frequency • Patient-centred care • Positively framed language • Interpreters • Timing of conversation • Standardised documentation • Consumer support • Death and dying discussions • Clear communication • Consumer education • Carer involvement in conversations 	<ul style="list-style-type: none"> • Unwanted care • Timing of conversation • Community awareness • Cultural, moral, spiritual and ethical preferences • Consumer education • Death and dying discussions • Clinician awareness • Difficult conversations

Table 2: Inner Setting - Culture: Deliverer-centredness, e.g. there are shared values, beliefs, and norms around caring, supporting and addressing the needs and welfare of health professionals

Enablers (C) (S) (R)	Barriers (C) (S) (H) (R)
<ul style="list-style-type: none"> • Shared decision making • Patient-centred care • Positively framed language • Systematic approach • Time needed for conversations • Cultural, moral, spiritual and ethical preferences • Adherence to plans 	<ul style="list-style-type: none"> • Difficult conversations • Death and dying discussions • Community awareness • Shared decision making • Consumer support • Adherence to plans • Cultural, moral, spiritual and ethical preferences • Conflict arising from difficult conversation

Key: (C) Consumer questionnaire (S) SAX Policy Impact Lab Report (H) Health professionals questionnaire (R) Rapid evidence review

Table 3: Inner Setting – Access to knowledge and information, e.g. guidance and/or training is accessible to implement and deliver the policy directive

Enablers	(S) (H) (R)	Barriers	(C) (S) (H) (R)
<ul style="list-style-type: none"> • Access to clinician training • Existing tools • Existing programs • Skills and confidence • Coach and mentor for conversations • Consumer education 		<ul style="list-style-type: none"> • Difficult conversations • Access to clinician training • Skills and confidence • Review frequency • Prognostic uncertainty • Formal training 	

Table 4: Inner Setting – Structural characteristics: Work infrastructure, e.g. organisation of tasks and responsibilities within and between individuals and teams and general staffing levels, support functional performance of NSW Health

Enablers	(C) (S) (H) (R)	Barriers	(S) (H) (R)
<ul style="list-style-type: none"> • Systematic approach • Shared decision making • Review frequency • Standardised documentation • Timing of conversation • Integration and functionality of plans across settings • Access to clinician training • Existing tools • Access to palliative care service • Team accountability • Mandatory to admission • Clarity of process 		<ul style="list-style-type: none"> • Clarity of process • Timing of conversation • Time needed for conversations • Resource availability • Cultural, moral, spiritual and ethical preferences • Consumer education • Integration and functionality of plans across settings • Initiators • Access to clinician training • Review frequency • Time needed for conversations • Authorisation 	

Key: (C) Consumer questionnaire (S) SAX Policy Impact Lab Report (H) Health professionals questionnaire (R) Rapid evidence review

Findings from the empirical evidence

Based on data extracted from the CEC Death Review Database, in the 2022 calendar year, there were 24,427 in-hospital patient deaths in NSW public hospitals with a death screen completed in the CEC Database. Of these patients:

- 15,216 (62.3%) had a resuscitation plan documented prior to death
- 3,188 (13.1%) had an ACD available prior to death
- 6,037 (24.7%) had an ACP available prior to death

Profile of patients who died with a resuscitation plan

Table 5 shows the percentage of patients with a resuscitation plan documented by age group, including patients aged less than 29 days (who are currently excluded from the resuscitation policy).

Table 5: Resuscitation plan documented by age group for in-hospital patient deaths, NSW public hospitals, 2022

Age group	Patients	Resuscitation plan documented (%)
0	80	0 (0%)
1-28 days	50	<5
29 days to 4 years	100	<5
5-17 years	73	8 (11.0%)
18-64 years	3,774	1,954 (51.8%)
65-74 years	4,638	2,855 (61.6%)
75-84 years	7,305	4,681 (64.1%)
85+ years	8,407	5,713 (68.0%)
Total	24,427	15,216 (62.3%)

Timing

The timing of when resuscitation plans were documented are described in [Table 6](#) and [Table 7](#). Table 6 shows the time a resuscitation plan was documented relative to the time of the patients' death. Most resuscitation plans were documented within the last week of life (64.8%). [Table 7](#) shows the difference in days between the date the resuscitation plan was completed and the date of admission to hospital. Most resuscitation plans were completed in the days after the day of admission (52.2%).

Table 6: Time from when resuscitation plan was documented to in-hospital death, NSW public hospitals, 2022

Time from resuscitation plan documented to time of death	Patients	Percentage
Less than 48 hours before time of death*	5,049	33.2%
48 hours to 7 days before date of death	4,802	31.6%
8 days to 30 days before date of death	3,701	24.3%
31 days to 1 year before date of death	826	5.4%
Between 1 year to 2 years before date of death	51	0.3%
More than 2 years before date of death	40	0.3%
Missing values (date of resuscitation plan not available)	747	4.9%
Total	15,216	100.0%

*Note. A small proportion of resuscitation plans (n=184) had the date of documentation equal to the date of death, however the time of documentation occurred after the time of death. These were assumed to be due to administration effects (delays in data entry) and included in the analysis.

Table 7: Difference in days between date of resuscitation plan completion and date of admission for in-hospital patient deaths, NSW public hospitals, 2022

Difference in days between date of resuscitation plan completion and date of admission	Patients	Percentage
Resuscitation plan completion before date of admission	803	5.3%
Resuscitation plan completion date same day as date of admission	5,721	37.6%
Resuscitation plan completed after date of admission	7,945	52.2%
Missing values (date of resuscitation plan not available)	747	4.9%
Total	15,216	100.0%

Patient and substitute decision maker involvement in decision-making process

Of the 15,216 patients with a resuscitation plan documented:

- 45.0% (n=6,841) had capacity and were involved in the decision-making process related to treatment plans and goals of care (including but not limited to discussion regarding cardiopulmonary resuscitation (CPR)) (Table 8)
- 49.9% (n=7,587) did not have capacity and had a substitute decision maker, family or carer involved in the decision-making process related to treatment plans and goals of care (Table 8)
- For a small proportion of patients (3.3%, n=502), neither the patient nor the substitute decision maker, family or carer was involved in the decision-making process related to treatment plans and goals of care (Table 8)

Other factors

Of those patients who were seen by the specialist palliative care team, a higher proportion (71.3%) had a resuscitation plan documented compared to those patients who were not seen by the specialist palliative care team (54.8%). Furthermore, of those patients who had a standardised framework, guideline or plan to guide care in the last days of life, a higher proportion (75.1%) had a resuscitation plan documented compared to those patients who did not have a standardised framework, guideline or plan to guide care in the last days of life (54.6%).

Table 8: Patient and family involvement in decision-making process, for in-hospital patient deaths, NSW public hospitals, 2022

Patient and family involvement in decision-making process related to treatment plans and goals of care	Patients	Percentage
Patients (with capacity) were involved in decision-making process	6,841	45.0%
Family (patient without capacity) involved in decision-making process	7,587	49.9%
Neither patient nor family involved in decision-making process	502	3.3%
Missing values	286	1.8%
Total	15,216	100.0%

Findings from the research evidence

Findings from a narrative review suggest it is not the content or format of the resuscitation plan that is important, but rather the way information is communicated, the transparency of decisions and shared mutual understanding between treating clinicians, patients, families and carers. Four themes were identified for discussing and documenting resuscitation and goals of care decisions at the end of life:

- **Adopt a systematic approach:** The discussion and documentation of resuscitation plans should be embedded into the clinical practice of all treating clinicians. Holding discussions about the withholding or limiting of treatment options early in a patient's diagnosis, and revisiting these on a regular basis, will improve the uptake of resuscitation plans and the experience for clinicians, patients and their families.
- **Use shared decision-making processes and tools:** All discussions about resuscitation planning need to be patient-centred and use positively framed language. Positive framing of language makes these conversations more comfortable for both the clinician, the patient, and their family/carer. Where English proficiency is limited (for the patient and/or their family and carer), clinicians should engage the use of medical interpreters as required.
- **Use standardised documentation:** The plan or form that is adopted can be transferrable between different care settings. Standardised resuscitation plans increase the frequency and clarity of resuscitation discussions and decisions.
- **Revisit decisions:** Withholding or limiting treatment decisions may change. All resuscitation planning decisions need to be considered within the context of the patient's broad goals of care, that are informed by the patient's values and treatment preferences.

Use of lead agency and other jurisdictions' guidelines

A review of resuscitation policies and guidelines from lead-agencies and across other Australian jurisdictions was conducted. Common themes include:

- Shared decision making – patient focused discussions to understand their values and care preferences.
- Resuscitation planning conversations should occur earlier in the patient's disease journey and be reviewed regularly as circumstances change or at each hospital admission.
- Processes and documentation should be standardised and clearly documented.

Findings from experiential insights

There are three evidence sources informing the experiential insights. The first is the SAX Institute Policy Impact Lab, which then informed the health professional and consumer questionnaires.

SAX Institute Policy Impact Lab

The framing question for the Policy Impact Lab was: What do we need to learn from stakeholders about the current Resuscitation Policy to improve its implementation in practice? The Policy Impact Lab Report describes and consolidates the discussions from the Lab (see [Appendix 2: SAX Policy Impact Lab Summary Report](#)).

The following were identified as **key enablers** to implementing the policy:

- **Access to clinician training and resources:** Access to training for clinicians, particularly for senior and junior medical staff, was mentioned as an enabler for staff having conversations around resuscitation planning and end of life care, to improve their knowledge and comfort with these conversations. Another key enabler was having a 'site champion' at each hospital, who proactively manages end of life care.
- **Existing tools:** Using existing tools as key markers for initiating resuscitation planning conversations was proposed. One example of such a tool is the AMBER Care Bundle⁷.
- **Existing community awareness resources:** Existing community awareness resources, such as Dying to Know Day⁸, was a resource identified to enable community understanding of resuscitation plans, increase awareness and promote informed conversations around end of life care.
- **Standardised documentation:** Increased adoption of a universal resuscitation plan across all districts and network and increased accessibility of the plan from various care settings via eMR were noted as enablers for better system functionality.

- **Multidisciplinary team collaboration:** Collaboration among multidisciplinary teams was seen as an enabler for enhancing end of life care decision-making processes. Successful programs operating in similar contexts, such as the Renal Supportive Care (RSC) program for chronic health issues⁹, and DonateLife organ donation courses¹⁰, can be used as references for modelling multidisciplinary collaboration within end of life care.

The following were identified as **key barriers** to implementing the policy:

- **Skills and confidence to have conversations:** There is a deficiency in training and confidence in having conversations. Education around resuscitation planning is currently inconsistent, voluntary and of varying quality, and communication skills among both junior and senior medical officers need improvement.
- **Time-related factors for conversations:** Two time-related factors regarding resuscitation planning conversations were identified. The first relates to the timing of the conversation – conversations are not initiated at the right time, and often occurs late in the disease trajectory. This leads to delayed and hurried conversations which may cause unnecessary stress and suboptimal decisions for patients, families and carers. The second relates to the time needed for conversations. There is insufficient time for conversations due to overloaded clinical schedules.
- **Clarity of process:** There is a lack of clarity among clinicians as to who is responsible for initiating the conversation as well as documenting and authorising the resuscitation plan. In rural settings, there may not be an admitting medical officer available to authorise the plan.

- **Community awareness and understanding:** There is a lack of community awareness and understanding of end of life care policies and practices. The diversity of cultural, spiritual and language backgrounds make it challenging. There is societal stigma around discussing end of life care which limits open conversations. Medical staff who play a crucial role in this process lack the necessary training, resources and time to have conversations with their patients.
- **Integration and functionality of plans across settings:** There is limited integration and functionality (accessibility, sharing, updating) of resuscitation plans across care settings.
- **Standardised documentation and review frequency:** This barrier relates to the lack of standardised documentation and the need for the resuscitation plan to be updated at each admission and reviewed regularly. This can be particularly burdensome for individuals with advanced or complicated illness.
- **Scope of the policy:** The last set of barriers describes how neonates, i.e. patients under 29 days, are not currently reflected in the current policy and state forms. This can result in a lack of clear guidelines for healthcare professionals in managing neonatal end of life care.

The insights from the Lab informed the subsequent questionnaires developed for health professionals and consumers. Specifically, it informed who to distribute the questionnaire to and what key questions to ask them.

Health professional questionnaire

Profile of respondents

From 9 May 2023 to 30 May 2023, 340 NSW Health staff completed the questionnaire, and a further 41 completed the questionnaire between 25 July 2023 and 4 August 2023. Responses were received from clinical staff across all 17 local health districts (LHD) and specialty health networks (SHN) in NSW as well as from Ambulance NSW. [Table 9](#) and [Table 10](#) present the respondent characteristics.

Table 9: Respondent role (N=381)

Role	N	%
Aboriginal health worker	4	1%
Clinical advisor	1	0%
Dietitian	4	1%
Junior medical officer	22	6%
Multicultural health worker	1	0%
Nurse (all)	172	45%
Nurse practitioner	10	3%
Occupational therapist	4	1%
Paramedic	16	4%
Patient safety and clinical governance	2	1%
Physiotherapist	5	1%
Project and program manager	2	1%
Psychologist	1	0%
Senior medical officer	99	26%
Service manager	6	2%
Social worker	15	4%
Speech pathologist	5	1%
Support worker	1	0%
Other	11	3%
Total	381	100%

Table 10: Respondent specialty (N=381)

Specialty	N	%
Aboriginal health	1	0%
Anaesthesia	18	5%
Cardiology	5	1%
Cardiothoracic	1	0%
Clinical education and training	4	1%
Clinical governance and patient safety	2	1%
Critical care	25	7%
Emergency	65	17%
General medicine	15	4%
General surgery	11	3%
Geriatrics	17	4%
Haematology	4	1%
Intensive care	25	7%
Medical administration	2	1%
Neonatology	6	2%
Neurology	4	1%
Oncology	16	4%
Orthopaedics	1	0%
Paediatrics	6	2%
Palliative care	59	15%
Rehabilitation	5	1%
Renal	25	7%
Respiratory	12	3%
Other	52	14%
Total	381	100%

Access to clinician training

Only 26% of respondents received formal training for resuscitation planning conversations (Figure 1). The most frequently reported formal training was through fellowship training for senior medical officers, and continuing education within NSW Health for nursing staff. The majority of respondents (61%) reported that the training they received was self-directed, and 30% of respondents indicated that they did not receive any of the three training options.

Confidence in conversations

Of the respondents who indicated that having goals of care and resuscitation planning conversations with patients, families and carers approaching end of life was applicable to their role, the majority of respondents reported that they were confident (40%) or highly confident (29%) with having these conversations (Figure 2). Most respondents reported that experience and exposure to these conversations were the main reasons for their reported confidence levels, followed by working in palliative care.

Timing of conversation

Ensuring that the resuscitation planning conversation is conducted in a timely manner is essential to ensuring patients, their families and carers have adequate time to consider and understand their condition. Figure 3 shows that the most frequently cited situation when the resuscitation planning conversation should take place is when a patient is considered high risk (92%), followed by at the time of a life limiting diagnosis being communicated (79%), and when recovery is uncertain (78%).

Figure 1: Training received (N=381)

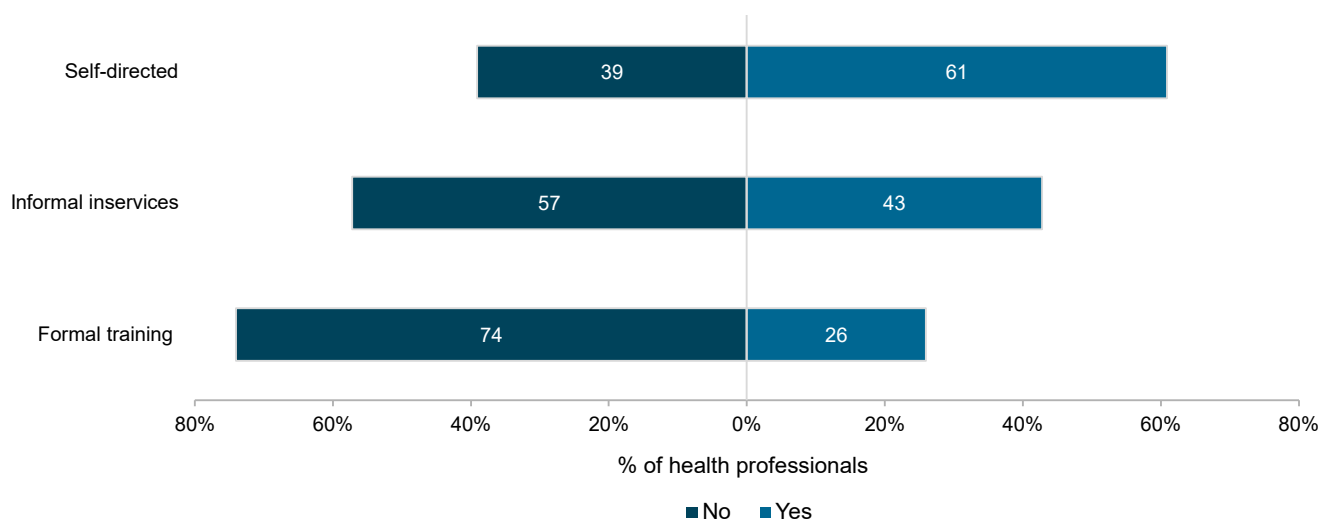


Figure 2: Reported confidence in carrying out conversations (N=357)

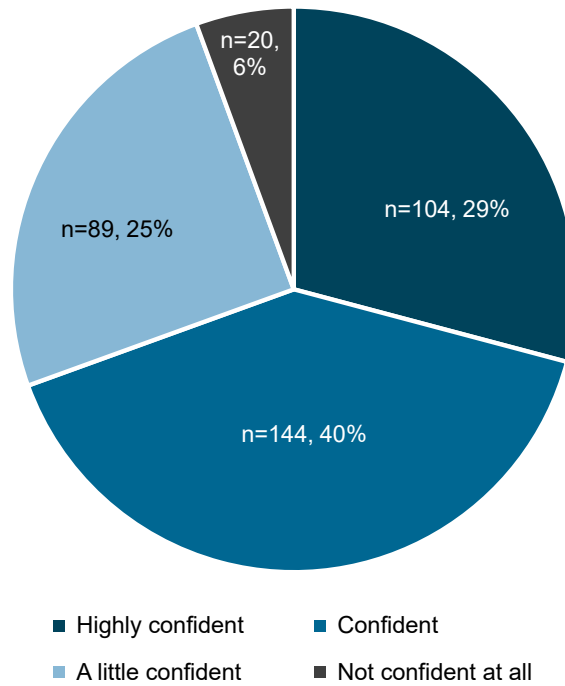
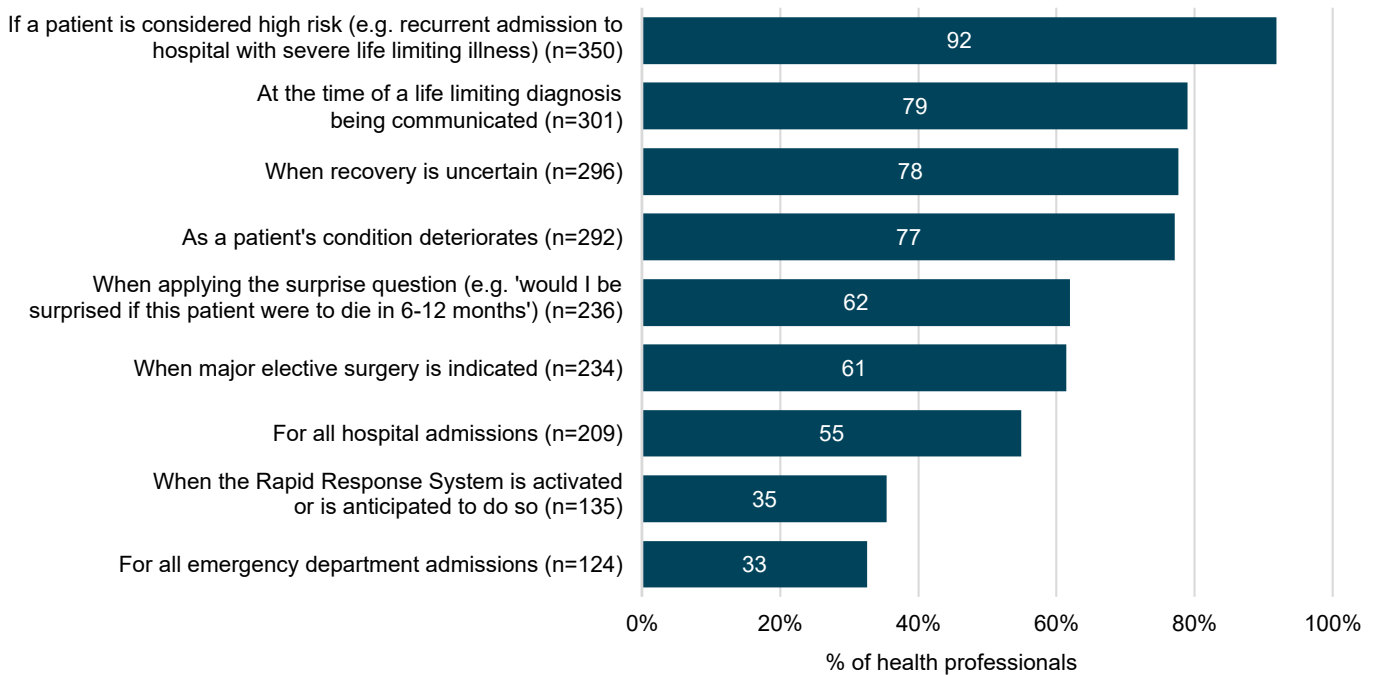


Figure 3: Timing of conversation*



* Percentages will total greater than 100% as respondents could choose multiple events to trigger the resuscitation planning conversation.

Clarity of process

Respondents were asked about who should be responsible for three key components of the resuscitation planning conversation: initiation, documentation and authorisation. Most respondents agreed that senior medical staff should be the initiator of the goals of care and resuscitation planning conversation, and the documenter and authoriser of the conversation and decisions made in the resuscitation plan (Table 11). The main reason for nominating senior medical staff as initiators was due to their expertise and experience in conducting such conversations, as documenters due to the responsibility of the patient held by the medical team, and as authorisers due to their ability to make decisions about and have responsibility for the patient's clinical care.

Barriers and enablers to having conversations

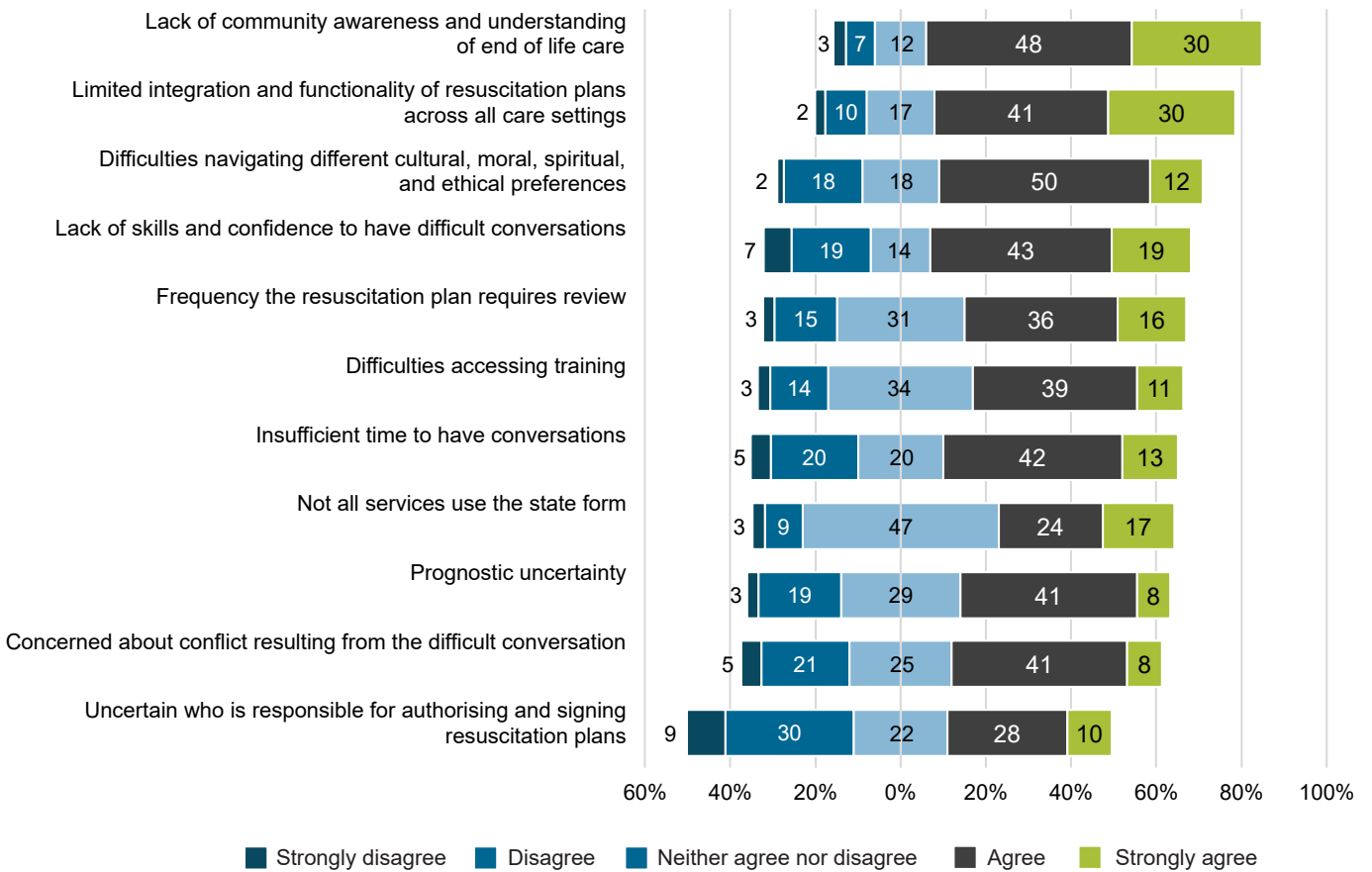
The majority of respondents agreed that the top three barriers to having goals of care and resuscitation planning conversations were (Figure 4):

1. Lack of community awareness and understanding of end of life care.
2. Limited integration and functionality of resuscitation plans across all care settings.
3. Difficulties navigating different cultural, moral, spiritual and ethical preferences.

Table 11: Conversation process (N=381)

Staff	Initiator	Documenter	Authoriser
Senior medical staff	96% (n=366)	95% (n=361)	96% (n=367)
Nurse practitioners	66% (n=252)	58% (n=220)	32% (n=121)
Junior medical staff	57% (n=219)	64% (n=244)	21% (n=81)
Nursing staff (other)	43% (n=164)	27% (n=103)	6% (n=22)
Allied health staff	31% (n=119)	19% (n=74)	4% (n=17)
Other	19% (n=74)	10% (n=38)	8% (n=32)

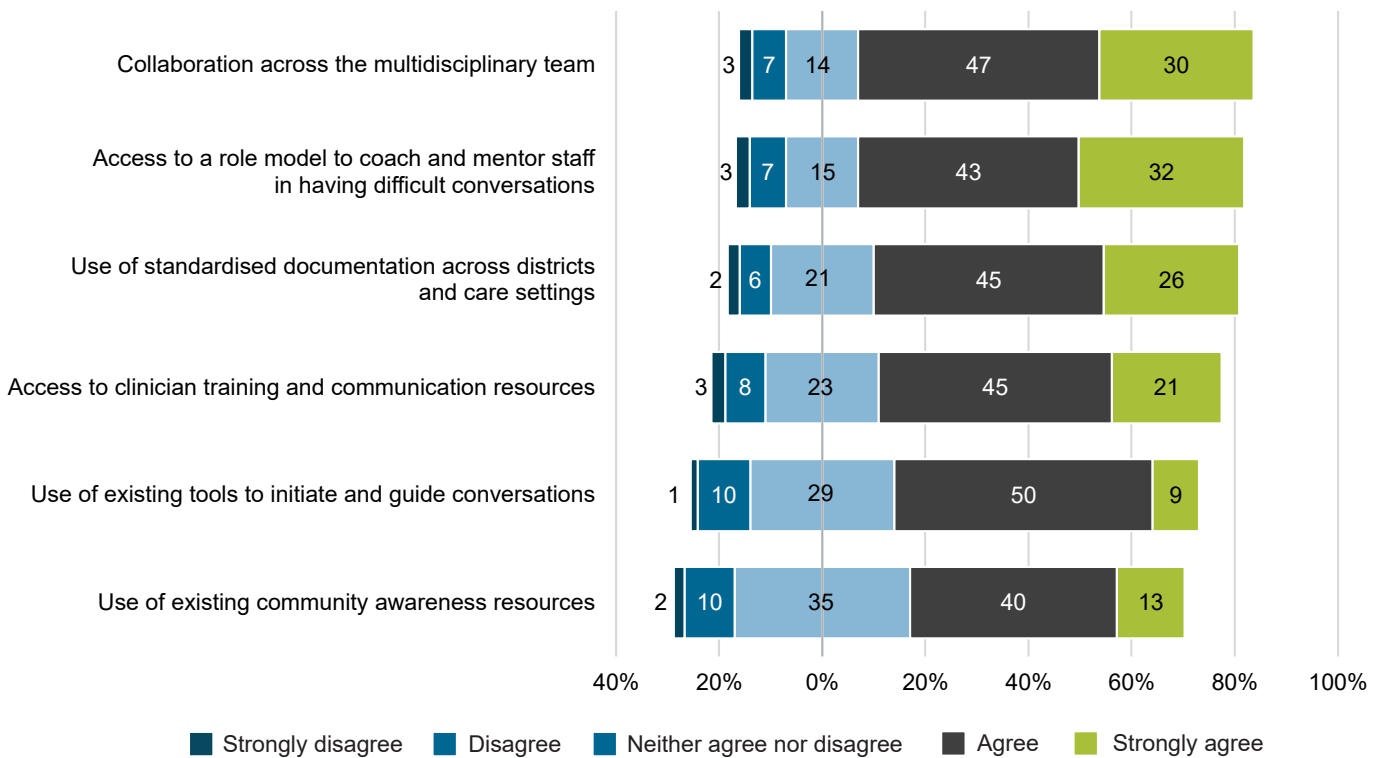
Figure 4: Perceived barriers to conducting conversations



The majority of respondents agreed that the top three enablers to having goals of care and resuscitation planning conversations were (Figure 5):

1. Collaboration across the multidisciplinary team.
2. Access to a role model to coach and mentor staff in having difficult conversations.
3. Use of standardised documentation across districts and care settings.

Figure 5: Perceived enablers to conducting conversations



Consumer questionnaire

Profile of respondents

A total of 25 respondents completed the questionnaire between 22 June 2023 and 23 July 2023.

The respondent characteristics are presented in Table 12.

Table 12: Respondent characteristics (N=25)

Respondent characteristics	n	%
Residence		
Metropolitan NSW	12	51%
Regional NSW	8	33%
Rural NSW	4	12%
Outside NSW	1	4%
Gender		
Female	20	80%
Male	5	20%
Age group		
30-44 years	6	22%
45-54 years	5	29%
55-64 years	7	17%
65-74 years	5	24%
75+ years	2	7%
Culturally and linguistically diverse (CALD)		
Yes	3	12%
No	22	88%

Experiences

Capturing patient, family and carer experiences with goals of care and/or resuscitation planning conversations are essential to understand what is working well within current delivery of end of life care and if there are gaps in meeting their physical, mental and social needs.

A representative sample of 25 individuals, who have been involved in goals of care and/or resuscitation planning conversations in NSW, as a patient, family member or carer, were invited to contribute stories about their experiences with these conversations, via an online questionnaire.

Most respondents reported that in their experience, an advance care directive and/or advance care plan was in place for the conversation (n=17 of 25), and that a resuscitation plan was in place for the conversation (n=17).

The online questionnaire included three free-text questions:

- Can you start by telling us about the situation that led to the goals of care and/or resuscitation planning conversations?
- Can you tell us more about the experience of the goals of care and/or resuscitation planning conversation?
- Can you think of at least one thing that would have improved the experience, and explain why?

The most frequently reported situation that led to the goals of care and/or resuscitation planning conversation was on admission to a hospital, residential aged care facility or palliative care (n=7).

One respondent shared a particularly negative experience:

“I found the discussion gruelling. At every admission to hospital and every ambulance ride, the information needed to be reinstated, I hate doing this if my partner is unable. I feel like I’m pushing no resuscitation...I don’t want to feel that responsible... It should be simpler and the information readily accessible upon engagement with services.”

Other respondents also highlighted the confronting, overwhelming and distressing nature of the conversation (n=3). Other frequently cited negative experiences included:

- clinicians were reluctant to hold conversations and that it ‘could wait’
- there was reluctance on the patient’s behalf to discuss goals of care and/or resuscitation planning
- lack of involvement of the patient and family in these conversations.

Despite having a resuscitation plan in place, one respondent reported that it was still a challenging experience:

“I don’t know that they were helpful. Despite having a plan, once he entered hospital, he was asked to complete a health plan and then Dad ended up revoking everything at the last minute because the doctors had confused/frightened him while he was in an acute phase. It was redone with him by the family prior to his final admission.”

Respondents also reported positive experiences with these conversations. Having open and two-way communication between patients, families and carers and the healthcare professionals was the most frequently mentioned positive experience (n=9) followed by conversations initiated earlier in the disease trajectory (n=4).

One respondent reported that the conversation was overall positive and that she felt appropriately included in the conversations:

“A goals of care and resuscitation planning was discussed when my mother became a resident in an aged care facility late 202X. Goals of care and resuscitation planning was agreed on with my mother, myself and the aged care facility staff. This plan was updated yearly. This agreed plan was discussed in May 2022 when my mother became very unwell, was taken to the ED of a major hospital and then transferred back to the facility. The staff at the facility appeared to want to ensure that the plan was reviewed and updated, if necessary, in response to the changed clinical condition of my mother. I thought this was entirely appropriate. The staff at the emergency department referred to my mother’s goals of care and resuscitation planning and suggested that we consider not actively treating my mother’s third episode of pneumonia and that she return to the facility. This also was very appropriate and reassuring.”

Respondents were also asked what could have improved their experience with the conversations. Suggestions included:

- more training for health professionals in conducting these conversations
- encouraging patients to have plans in place
- more transparent communication between the patient, family and carer, and health professional
- encouraging patients to actively participate in the conversation
- allowing time for the patient, family and carer to understand the situation.

The importance of open and transparent conversations was highlighted by one respondent:

“More open conversations about death and dying. I see this as a joint responsibility of patients, their families and health professionals and appreciate that it can be difficult for everyone. But it’s better to be forewarned than focused unrealistically on futile hope or have no prior knowledge about potential end of life care trajectories and experiences. The main lessons I learnt from my partner’s experience are that (1) we were prepared for death but not in any way prepared for dying and (2) we need to plan for dying long before the terminal diagnosis and the end of life.”

Conclusion

The evidence report provides valuable insights into resuscitation planning at end of life in NSW and will inform statewide improvements to the revised policy directive and associated forms. Broader system-level improvement or innovation is required to ensure that:

- patients, families, and carers end of life wishes and goals of care are heard, communicated and documented
- clinicians are equipped with the skills and confidence to have quality goals of care conversations, at the right time and place, using the right tools.

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Glossary

ACD	Advance care directive
ACP	Advance care plan
CEC	Clinical Excellence Commission
CFIR	Consolidated Framework for Implementation Research ²
EAG	Expert advisory group
eMR	Electronic medical record
LHD	Local health district
SHN	Specialty health network

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