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Health professional and consumer questionnaire report

Appendix 3 to End of Life Care Decisions Evidence Report

May 2024

NSW GOVERNMENT

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Agency for Clinical Innovation

1 Reserve Road St Leonards NSW 2065 Locked Bag 2030, St Leonards NSW 1590

Phone: +61 2 9464 4666 | Email: **aci-info@health.nsw.gov.au** | Web: **aci.health.nsw.gov.au**

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Contents

Background

The **Using Resuscitation Plans in End of Life Decisions Policy Directive** (the Resuscitation Policy) describes the standards and principles related to appropriate use of resuscitation plans. The Resuscitation Policy was published in 2014. The ACI is responsible for undertaking a review and update of the policy directive and associated forms.

The End of Life and Palliative Care Network is leading the policy review.

An evidence check was completed in September 2021 and the Sax Institute was commissioned to facilitate a series of Policy Impact Labs. The performance agreement deliverable for Quarter 1 2023-24 (September 2023) is an evidence (diagnostic) report.

Clinician and managers experiences and perspectives

Methods

Design
A cross-sectional questionnaire to gather self-reported experiences.

Aim
To gather experiences and perspectives from clinicians and managers (health professionals) on resuscitation conversations and to understand real-world barriers in NSW to inform the policy directive review for NSW.

Participant groups and sampling
Invitations to participate were sent to a convenience sample of members engaged with relevant ACI Networks (including End of Life and Palliative Care Network) and the local health district (LHD) and specialty health network (SHN) Chief Executives. The questionnaire was open to health professionals in NSW Health and across clinical specialities**.** A snowballing approach was used where the questionnaire link could be shared to increase reach and visibility to all audiences. Responses were anonymous. The link to complete the questionnaire was also disseminated through Twitter and LinkedIn to reach audiences not otherwise engaged with the Networks.

Data collection
Data were collected from respondents using an online questionnaire administered through Microsoft Forms from 9 May 2023 to 30 May 2023.

Data collection tool
A bespoke questionnaire was informed by the outcomes of the March 2023 Policy Impact Lab Report. Rapid testing of the questionnaire was conducted with the Project Expert Advisory Group assisting in the refinement of the question set.

Analysis

Descriptive statistics were used to analyse the data collected from the closed question sets. Free text was analysed as a singular narrative 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 were used to support data analysis. A secondary analysis was completed to map the key results to the constructs and domains of the Consolidated Framework for Implementation Research (CFIR). Using the CFIR provided a systematic and theoretical approach to understanding local barriers and enablers and to identifying actionable findings for system-wide innovation or improvement in NSW.[1]

Consumer and family insights

Methods

Design

A qualitative questionnaire to gather self-reported experiences of goals of care and/or resuscitation planning conversation experiences in NSW.

Aim

To understand how consumers and their families have experienced resuscitation conversations near the end of life in NSW to 1) inform the Using Resuscitation Plans in End of Life Decisions Policy Directive review and 2) identify priorities to improve the quantity and quality of resuscitation conversations in the NSW Health system.

Participant groups

Invitations to participate were sent to a convenience sample of members engaged with relevant ACI Networks (including End of Life and Palliative Care) and through Health Consumers NSW. The link to complete the questionnaire was also disseminated through Twitter and LinkedIn to reach broader audiences. Purposeful sampling was used to recruit consumers with direct or indirect experience (e.g. a carer or family member) with goals of care and/or resuscitation planning conversations in NSW and aged 18 and over. The recruitment strategy required participants to opt in and a detailed Participant Information Sheet (PIS) was embedded in the questionnaire. Participants were required to indicate they had read the PIS as part of the consent process, which was then implied by completing the questionnaire. Participation was voluntary and participants were not paid for completing the questionnaire.

Data collection

Data were collected from respondents using an online questionnaire administered through Microsoft Forms from 9 May 2023 to 30 May 2023.

Data collection tool

A recently published systematic review informed that a bespoke questionnaire and rapid testing of the questionnaire was conducted between 23 May 2023 and 31 May 2023 with five consumer partners assisting in refining the questions.[2] The final questionnaire included seven questions in total consisting of demographic, open (n=1 with three prompt questions) and closed-ended (n=6) questions.

Analysis

Descriptive statistics were used to analyse the data collected from the closed question sets. Free text responses were analysed as a singular narrative for each respondent using an inductive content analysis approach. The content analysis approach identified core concepts and then frequencies. NVivo software was used to support data analysis. A secondary analysis was completed to map the key results to the constructs and domains of the CFIR. Using the CFIR provided a systematic and theoretical approach to understanding local barriers and enablers, and to identifying actionable findings for system-wide innovation or improvement in NSW.[1]

Ethics

Approved by the Greater Western Human Research Ethics Committee on 15 May 2023: 2023/ETH00721

Clinician and managers experiences and perspectives: supplementary questionnaire

Methods

Participant groups and sampling

The project team consulted closely with the project clinical leads to review the findings of the initial health professional questionnaire. Following review of the findings, the project clinical leads identified certain clinical specialty groups that were low responders to the questionnaire. These groups were given another chance to participate.

The duplicated questionnaire was disseminated to the following ACI clinical networks via the network managers:

- Blood and Marrow Transplant and Cellular Therapies Network
- Maternity and Neonatal Network
- Paediatric Network
- Chronic Care for Aboriginal People Network
- Respiratory Network

Data collection and analysis

Data collection and analysis were conducted in an identical fashion to the initial questionnaire. Data was collected from respondents through Microsoft Forms from 25 July 2023 to 4 August 2023.

Limitations

The gathering of experiential insights has a few limitations; it is a small, self-selected sample and there may be a bias in reporting practices on the part of respondents. While the sample lacks representativeness, it does provide insights directly from patients and consumers and their carers and families. We cannot, however, generalise from these results and claim that this is an NSW-wide account. The design, recruitment and data collection have likely biased the sample towards those with access to digital communications and those engaged with ACI in some capacity.

Results

Using Resuscitation Plans in End of Life Decisions Policy Review Survey: clinician and managers perspectives

From 9 May 2023 to 30 May 2023, 340 NSW Health staff completed the questionnaire. Responses were received from clinical staff across all seventeen LHD and SHN in NSW as well as from Ambulance NSW. Tables 1 and 2 present the respondent characteristics.

Table 1: Respondent role (N=340)

Role	n	%
Aboriginal health worker	4	1%
Clinical advisor	1	<1%
Dietitian	4	1%
Junior medical officer	17	5%
Multicultural health worker	1	<1%
Nurse (all)	159	47%
Nurse practitioner	8	2%
Occupational therapist	4	1%
Paramedic	16	5%
Patient safety or clinical governance	1	<1%
Physiotherapist	4	1%
Project or program manager	2	1%
Senior medical officer	87	26%
Service manager	4	1%
Social Worker	13	4%
Speech pathologist	5	1%
Support worker	1	<1%
Other	9	3%
Total	340	100%

Table 2: Respondent specialty (N=340)

Specialty	**n**	**%**
Aboriginal health	1	<1%
Anaesthesia	18	5%
Cardiology	4	1%
Cardiothoracic	1	<1%
Clinical education and training	3	1%
Clinical governance or patient safety	2	1%
Critical care	24	7%
Emergency	62	18%
General medicine	12	4%
General surgery	10	3%
Geriatrics	16	5%
Haematology	1	<1%
Intensive care	25	7%
Medical administration	2	1%
Neonatology	3	1%
Neurology	4	1%
Oncology	16	5%
Orthopaedics	1	<1%
Paediatrics	3	1%
Palliative care	56	16%
Rehabilitation	4	1%
Renal	25	7%
Respiratory	4	1%
Other	43	13%
Total	340	100%

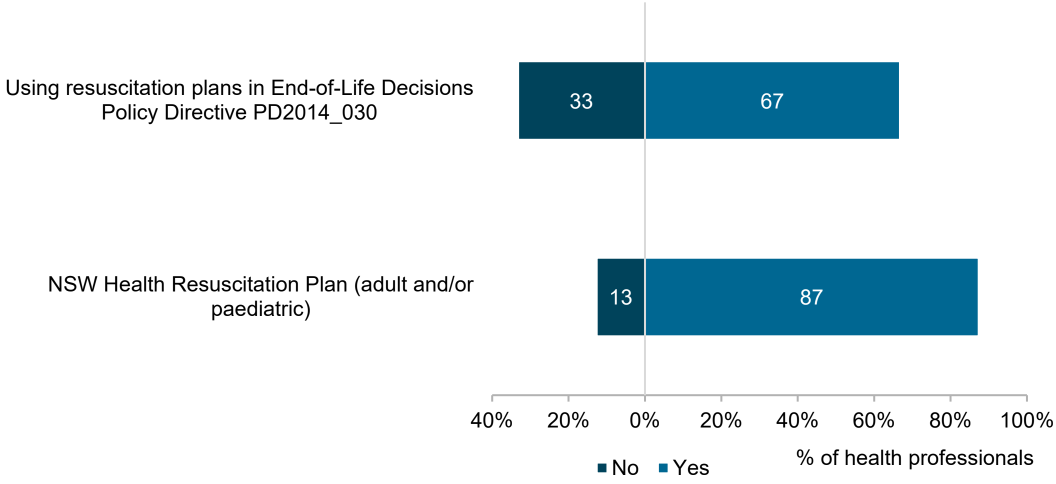
Nearly one half of all respondents to the survey identified as a nurse or a nurse practitioner (47%, n=159 and 2%, n=8 respectively) and more than a quarter of responses being from senior medical officers (26%, n=87). Junior medical officers submitted 5% (n=17) of the responses. Other roles reported included administrative (<1%, n=3), maintenance and trade (<1%, n=2), public health, genetic counsellor, radiation therapist (all <1%, n=1) and unknown (<1%, n=1).

Reported clinical specialties included emergency (18%, n=62), palliative care (16%, n=56), intensive care (7%, n=25), renal (7%, n=25), critical care (7%, n=24), anaesthesia (5%, n=18), geriatrics (5%, n=16) and oncology (5%, n=16).

Awareness of, and use of NSW Health NSW Health Using resuscitation plans in End of Life Decisions Policy Directive PD2014_030, and the NSW Resuscitation Plan

As a lead-in, respondents were asked to indicate their awareness of the NSW Health Using resuscitation plans in End of Life Decisions Policy Directive PD2014_030 and the NSW Resuscitation Plan (adult and/or paediatric). 67% (n=227) of respondents reported awareness of the policy directive and 87% (n=297) reported awareness of the resuscitation plan (Figure 1). 31 respondents (9%) reported that they were unaware of both.

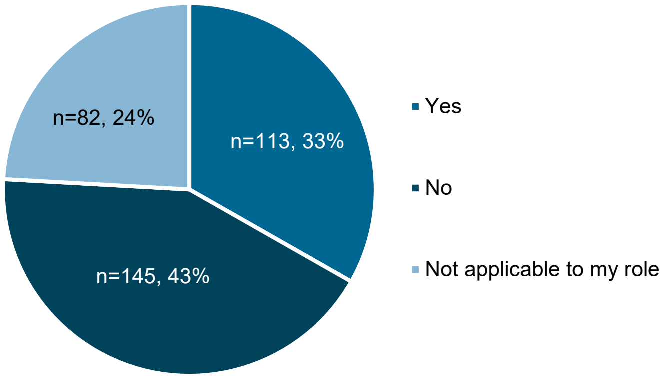
Figure 1: Awareness of the policy and the plan (n=340)



Awareness of the policy directive was greatest among those who identified as nursing staff, including nurse practitioners (37%, n=125) followed by senior medical officers (15%, n=50). Similarly, awareness of resuscitation plans was greatest among nursing staff, including nurse practitioners (44%, n=150) and senior medical officers (23%, n=78), followed by junior medical officers (5%, n=17) and paramedics (4%, n=12).

33% (n=113) of respondents reported that they had previously used the policy and the plan to guide goals of care and resuscitation planning conversation; 16% (n=53) identified themselves as nursing staff (including nurse practitioners), 12% (n=40) were senior medical officers and 2% (n=7) were junior medical officers. Nearly a quarter of respondents (24%, n=82) indicated that the use of resuscitation plans was not applicable to their role (Figure 2).

Figure 2: Use of the policy and the plan (n=340)



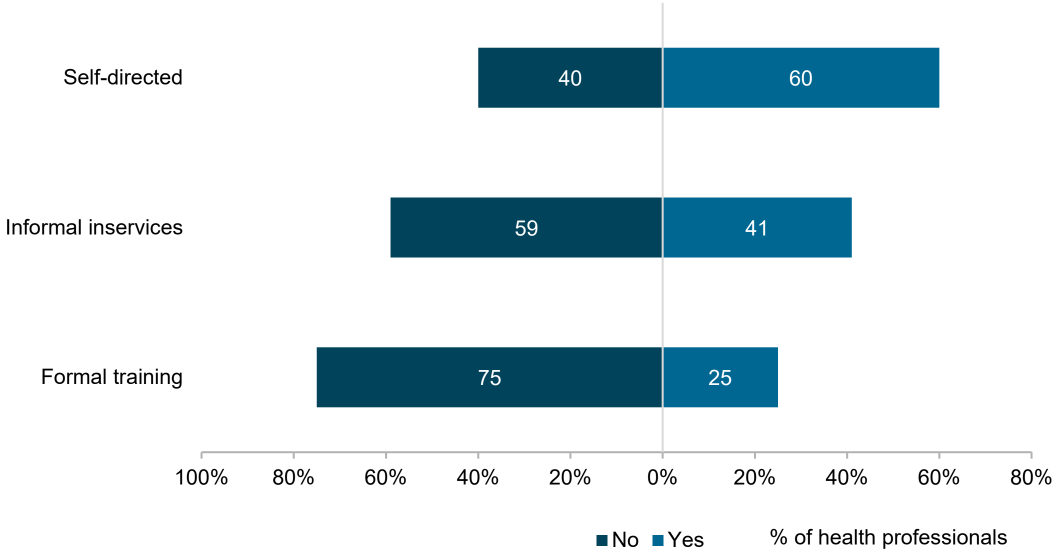
Training

Respondents were questioned of any training they may have received around goals of care and resuscitation planning conversations with patients, family or carers approaching end of life (Figure 3).

Self-directed training was reported by 60% (n=205) of respondents, informal in-services by 41% (n=141) of respondents and only 25% (n=85) respondents reported that they had received formal training. These included 11% of nursing respondents (n=41) and 6% (n=27) of senior medical officer respondents. Formal training for junior medical officers was reported by 1% (n=6) of respondents.

Thirty-one per cent (n=104) of respondents indicated that they did not receive any of the three training options (self-directed, informal in-services or formal); 51 (15%) of nursing staff and 19 (6%) of senior medical officers responded as such.

Figure 3: Training received (N=340)



Respondents who reported receiving formal training mentioned several providers of such training delivered online or face-to-face. The following table presents the number of key formal education providers mentioned by the healthcare practitioner's role.

Table 3: Formal training mentions

Training modality	Senior medical officer (n=27)	Junior medical officer (n=6)	Nurse practitioner (n=3)	Nurse (all) (n=38)	Social worker (n=3)	Other (n=8)
Undergraduate degree	3	0	0	0	0	0
Post-graduate degree	0	0	0	3	0	0
Fellowship training	15	1	0	0	0	0
Continuing education: NSW Health (includes My Health Learning modules, LHD training, simulation training)	4	3	0	11	0	3
Continuing education: Other (includes courses run by peak bodies, scientific meetings, training in other jurisdictions)	4	3	1	10	0	2

Confidence

319 (94%) of the respondents indicated that having goals of care and resuscitation planning conversations with patients, family or carers approaching end of life was applicable to their role. Figure 4 shows their reported levels of confidence in carrying out these conversations.

94 respondents (29%) reported being highly confident in having goals of care and resuscitation planning conversations with patients, family or carers approaching the end of life. Confidence in having these conversations was high among nursing staff, with 19% (n=60) reporting confident and 9% (n=33) highly confident. Among senior medical officers, 10% (n=31) reporting confident and 15% (n=48) highly confident. 3% (n=8) of junior medical officers responded that they felt confident, while 2% (n=5) indicated they felt highly confident. Tables 4-6 outline the reasons for their confidence ratings, which were reported in a free text response.

Figure 4: Reported confidence in carrying out conversations (N=319)

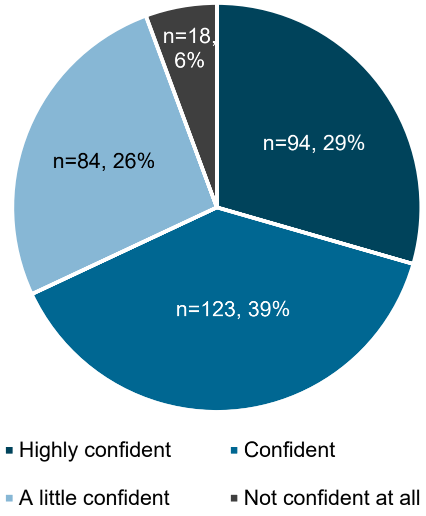


Table 4: Reasons for feeling *highly confident* (N=88)

Reason	Senior medical officer (n=48)	Junior medical officer (n=5)	Nurse practitioner (n=4)	Nurse (all) (n=29)	Social worker (n=2)
Knowledge and training	0	0	1	1	0
Confidence in own communication skills	1	0	0	0	0
Experience and exposure to these conversations	16	3	1	13	0
Work specifically in palliative care	3	1	1	1	0

Table 5: Reasons for feeling *confident* (N=104)

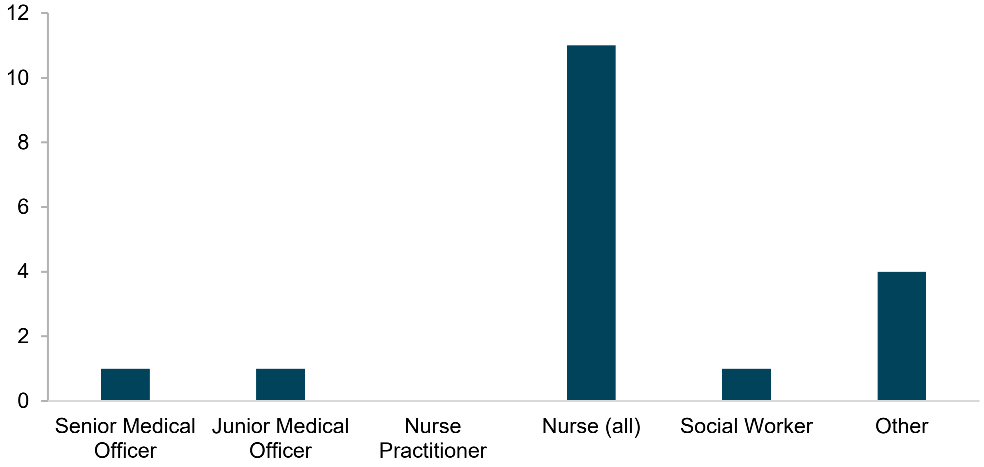
Reason	Senior medical officer (n=31)	Junior medical officer (n=8)	Nurse practitioner (n=1)	Nurse (all) (n=59)	Social worker (n=5)
Knowledge and training	0	0	0	3	0
Confidence in own communication skills	0	0	0	1	0
Experience and exposure to these conversations	4	2	0	9	1
Supportive environment	0	1	0	6	0
Work specifically in palliative care	1	0	0	7	0

Table 6: Reasons for feeling a *little confident* (N=67)

Reason	Senior medical officer (n=7)	Junior medical officer (n=8)	Nurse practitioner (n=3)	Nurse (all) (n=45)	Social worker (n=4)
Minimal knowledge and training	0	0	0	4	1
Difficult conversation	0	0	0	2	0
Minimal experience and exposure to these conversations (e.g. new to the role, not in clinical practice)	0	1	1	15	1
Supportive environment	0	0	0	1	0
Work specifically in palliative care	0	0	0	1	0

Figure 5 presents the role of those who responded as feeling not confident at all.

Figure 5: Role of respondents who were *not confident at all* (N=18)



Of the 18 respondents (6%) who did not feel confident at all, only one offered a reason; it was because they were new in their role.

Barriers to conducting conversations

Figure 6 shows respondents' agreement aligned with 11 pre-defined barriers to conducting goals of care and resuscitation planning conversations with patients, family or carers approaching end of life. The pre-defined barriers were identified from the peer-reviewed literature (see **Appendix 1: Use of resuscitation plans in decisions at the end of life: Evidence check**), findings from the Policy Lab (see **Appendix 2: SAX Policy Impact Lab Summary Report**) and following review by the project Expert Advisory Group and Steering Committee.

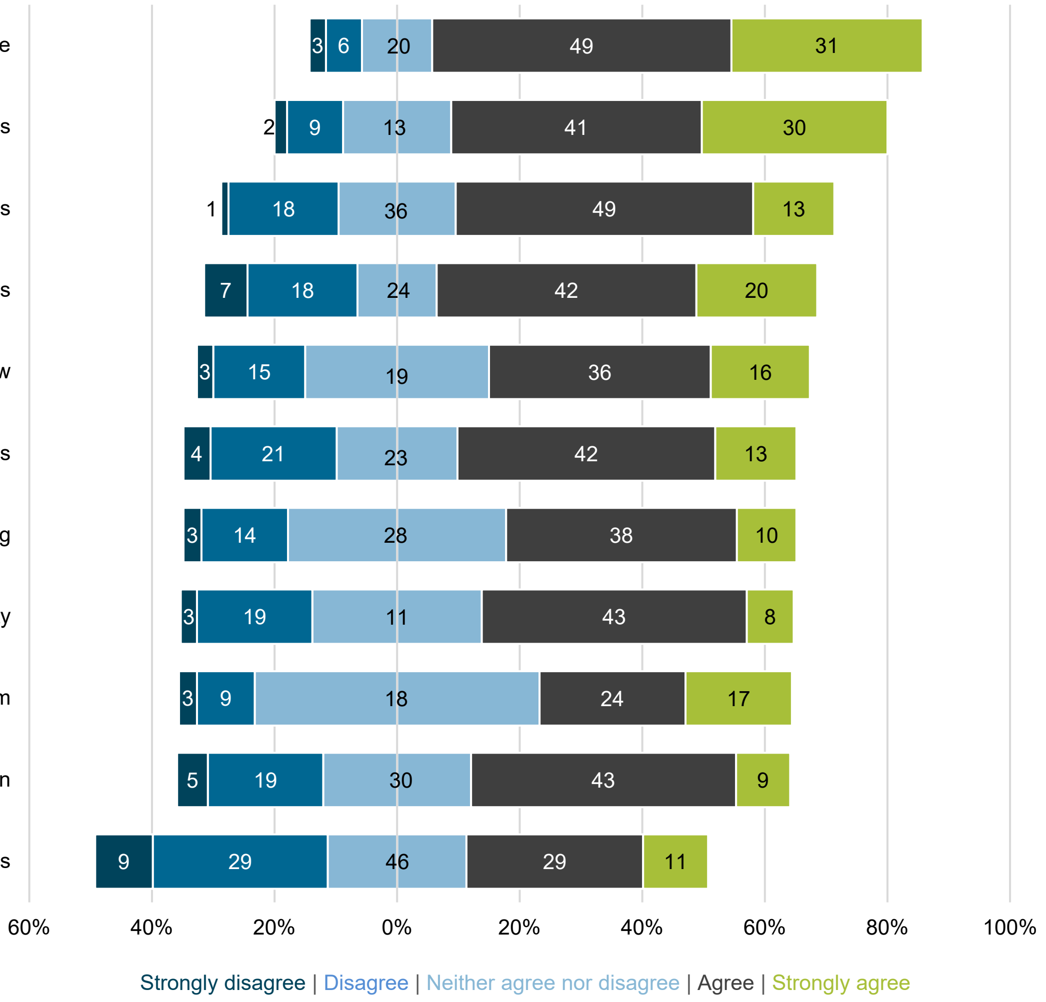
The top three agreed barriers were:

- lack of community awareness and understanding of end of life care (49% agreed, 31% strongly agreed)
- limited integration and functionality of resuscitation plans across all care settings (41% agreed, 30% strongly agreed)
- difficulties navigating different cultural, moral, spiritual and ethical preferences (49% agreed, 13% strongly agreed).

Additional barriers identified by respondents coalesced five themes:

- lack of multidisciplinary collaboration (e.g. poor senior medical officer involvement and conflict and mistrust among treating teams)
- lack of awareness and understanding among clinical staff
- unrealistic expectations of healthcare and outcomes by both clinicians and the community (e.g. the "must do everything" culture)
- delayed timing of the conversation and unsuitable environments to hold conversations
- inappropriate advance care directives.

Figure 6: Perceived barriers to conducting conversations



Enablers to conduct conversations

Figure 7 shows respondents' agreement aligned with six pre-defined enablers to conducting goals of care and resuscitation planning conversations with patients, family and carers approaching end of life. The pre-defined enablers were identified from the peer-reviewed literature (see **Appendix 1: Use of resuscitation plans in decisions at the end of life: Evidence check**), findings from the Policy Lab (see **Appendix 2: SAX Policy Impact Lab Summary Report**) and following review by the project Expert Advisory Group and Steering Committee.

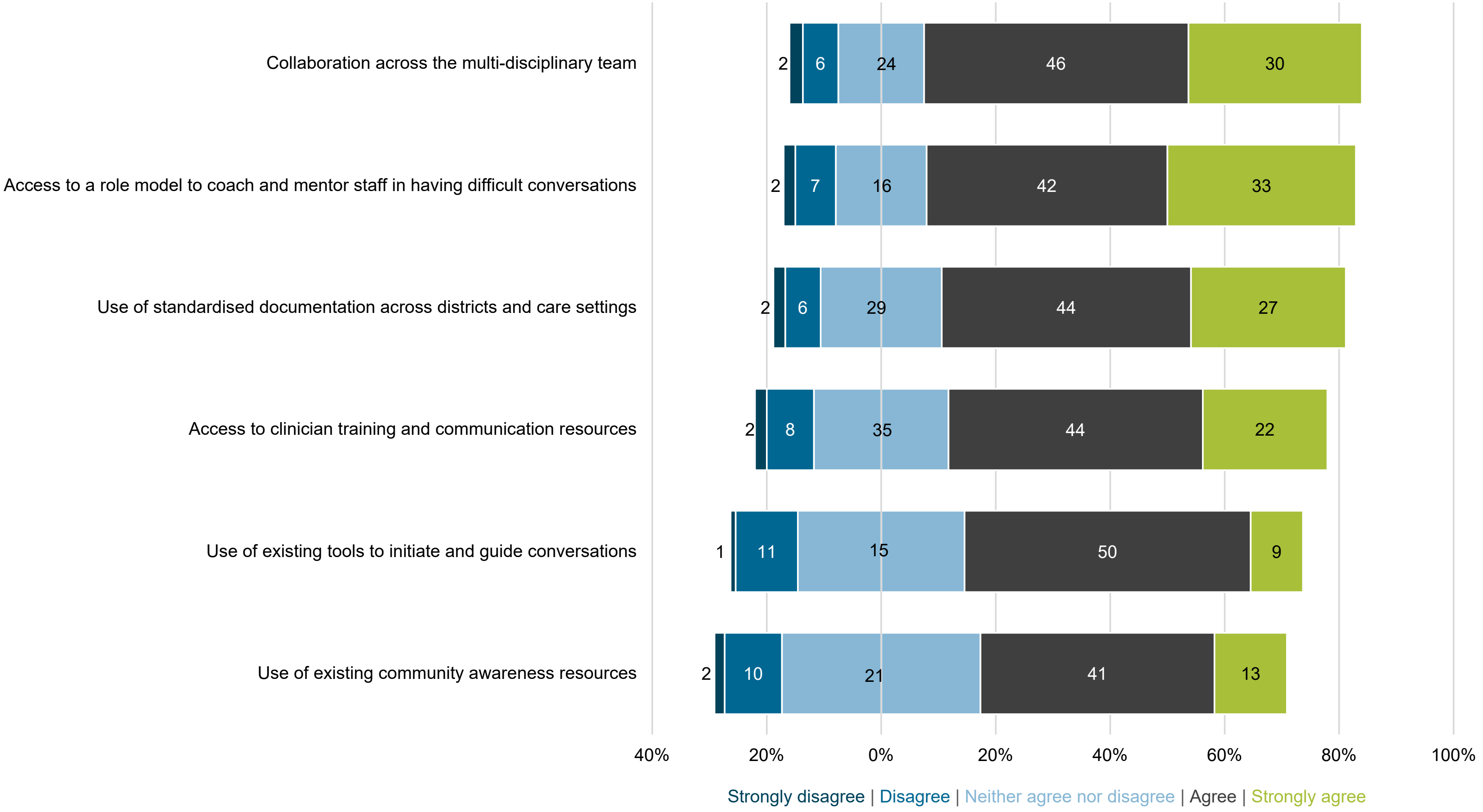
The top three agreed enablers were:

- collaboration across the multi-disciplinary team (46% agreed, 30% strongly agreed)
- access to a role model to coach and mentor staff in having difficult conversations (42% agreed, 33% strongly agreed)
- use of standardised documentation across districts and care settings (44% agreed, 27% strongly agreed).

Additional enablers identified by respondents coalesced six themes:

- greater accountability for clinical teams
- increasing awareness among clinicians
- increased access to palliative care services
- greater clarity of guidelines and policies
- providing a culturally sensitive approach to holding the conversation
- making these a mandatory part of admission to hospital.

Figure 7: Suggested enablers



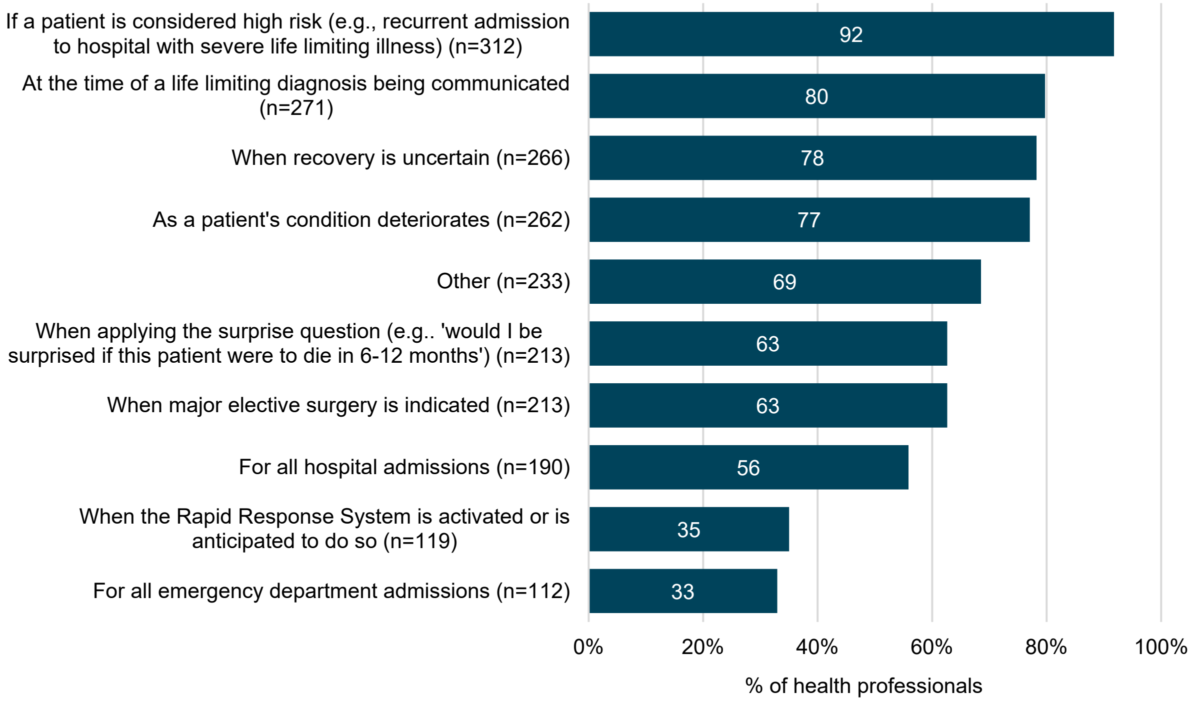
Timing of the conversation

Respondents were asked to indicate when they felt the resuscitation conversation should take place. 92% (n=312) respondents suggested when a patient is considered high risk, followed by at the time of a life-limited diagnosis being communicated (80%, n=271), when recovery is uncertain (78%, n=266) and as the patient's condition deteriorates (77%, n=262) (Figure 8).

Additional times mentioned by respondents included:

- for all patients aged 65 years and older
- for all intensive care unit admissions
- for all patients from a residential aged care facility
- in the community (e.g. when reviewed by their GP).

Figure 8: Timing of the conversation*



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

Conversation process

Respondents were questioned on who should be responsible for three key components of the conversation: initiation, documentation and authorisation. Table 8 shows that most respondents answered that senior medical officers should initiate, document and authorise the conversation. Respondents felt that the conversation could also be initiated by nurse practitioners and junior medical officers. However, one third or less of all respondents felt that nurse practitioners (33%, n=113) or junior medical officers (23%, n=77) could authorise the outcome of the conversation. Nursing (other) and allied health staff were also perceived to be initiators (44% and 31% respectively) and potential documenters (27% and 20% respectively) of the conversation however, very few respondents felt that they should authorise the outcome of the conversation.

Other initiators of the conversation as mentioned by respondents included:

- primary care providers
- the patient
- the patient’s family, carers or enduring guardians
- palliative care staff
- the multidisciplinary team.

Four common reasons for senior medical officers, nurse practitioners and junior medical officers being the required initiator of the conversation is outlined in Table 9.

Respondents also suggested that documentation of the conversation could be done by:

- any staff who initiated or had the conversation
- primary care providers
- the patient or their family.

Common reasons for nominating senior medical officers, nurse practitioners and junior medical officers as documenters of the conversion are in Table 10.

Respondents suggested that authorisation of the conversation could also be done by:

- the patient
- patient family member, guardian
- anyone involved in the conversation.

Common reasons for nominating senior medical officer, nurse practitioners and junior medical officer as the required authorisers of the conversation are outlined in Table 11.

However, across the three process roles (initiator, documenter, authoriser) 55 (17%) respondents emphasised a need for a collaborative and multidisciplinary approach to resuscitation conversations.

Table 8: Conversation process (N=340)

Staff	Initiator	Documenter	Authoriser
Senior medical staff	96% (n=325)	94% (n=321)	96% (n=327)
Nurse practitioners	66% (n=226)	57% (n=195)	33% (n=113)
Junior medical staff	59% (n=199)	65% (n=220)	23% (n=77)
Nursing staff (other)	44% (n=148)	27% (n=92)	6% (n=21)
Allied health staff	31% (n=104)	20% (n=67)	5% (n=17)
Other	19% (n=66)	10% (n=34)	8% (n=28)

Table 9: Frequency of reasons for nominating specified health professionals as *initiators*

Reason	Senior medical officer	Nurse practitioner	Junior medical officer
Possessing expertise and experience in conducting such conversations	18	15	12
Ability to make decisions about and have responsibility for the clinical care of the patient	16	7	6
Having built trust and rapport with the patient	11	9	8
Having familiarity with the case	10	9	7

Table 10: Frequency of reasons for nominating specified health professionals as *documenters*

Reason	Senior medical officer	Nurse practitioner	Junior medical officer
It is the responsibility of the medical team	7	4	7
Ability to make decisions about and have responsibility for the clinical care of the patient	6	5	4
Having the availability to do so	4	2	5
Possessing expertise and experience	4	2	2
Having trust and rapport with the patient	3	3	2
Having familiarity with the case	2	2	2

Table 11: Frequency of reasons for nominating specified health professionals as *authorisers*

Reason	Senior medical officer	Nurse practitioner	Junior medical officer
Ability to make decisions about and have responsibility for the clinical care of the patient	59	17	3
Possessing expertise, knowledge, and training	13	6	0
To minimise medico-legal risks	8	3	1

Implementation of the Using Resuscitation Plans in End of Life Care Decisions Policy Directive

17 (5%) respondents indicated that they were responsible for monitoring the implementation of the policy in their facility and/or organisation. Predominantly these respondents were from nursing (86%, n=14). The remainder were senior medical officers (13%, n=3).

Local monitoring of the use of resuscitation plans in end of life care decisions was reported to occur in a variety of ways, including:

- documentation review (n=6)
- individual case reviews (n=3)
- discussions in meetings (morbidity and mortality meetings, multidisciplinary team and end of life care committee) (n=3)
- compliance checks (n=3)
- during ward rounds (n=2)
- discussion with the patient (n=2).

Data for such monitoring activities was reported to have obtained through electronic medical record (eMR) documentation and audit (n=5), review of orders in eMR (n=3) and through death review and screening data collections (n=2).

Consumer and family insights: Goals of care and/or resuscitation planning conversation experiences in NSW

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)

Residence	**n**	**%**
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%

Involvement in goals of care and/or resuscitation planning conversations

Respondents were asked whether they had been involved in goals of care and/or resuscitation planning conversations and in what capacity.

Twenty respondents (80%) indicated they had been involved in a goals of care and/or resuscitation planning conversation in the last five years (between 2018-2023), four (12%) indicated being involved in such conversations prior to 2018. One respondent (4%) was unsure.

Respondents reported being involved in the conversation in one or more capacities; this included involvement as:

- a family member (n=16, 64%)
- a carer (n=12, 48%)
- a patient (n=3, 12%)
- a clinician (n=3, 12%).

Ten respondents (40%) indicated they were involved as both a family member and a carer.

Plans in place at the time of the conversation

Respondents were asked whether they were aware of any advance care directives or advance care plans and/or any resuscitation plans in place for the goals of care and/or resuscitation planning conversation. Their responses are listed in Table 13.

Table 13: Plans in place for the goals of care and/or resuscitation planning conversation (N=25)

	Advance care directive or plan in place	
Resuscitation plan in place	**Yes**	**No**
Yes	15 (60%)	2 (8%)
No	1 (4%)	5 (20%)
Unsure	1 (4%)	1 (4%)

17 respondents (68%) reported that advance care directives/advance care plans were in place. A similar number (n=17, 68%) reported that resuscitation plans were in place. 15 respondents (60%) reported that both were in place at the time of the conversation. Five respondents (20%) reported that neither were in place and two respondents (8%) were unsure whether resuscitation plans were in place.

Respondent insights

Respondents were asked to describe the situation leading to the goals of care and/or resuscitation planning conversation, their experience with the process and to suggest any improvements to the process. 24 (96%) respondents shared some aspects of their own personal experience with these conversations.

Respondents identified nine situations that led to their goals of care and/or resuscitation planning conversations:

- admission to a hospital, residential aged care facility or palliative care (n=7, 28%)
- when making wills and discussing end of life wishes (n=5, 20%)
- a diagnosis of a life limiting-illness (n=4, 16%)
- aging or chronic illness (n=4, 16%)
- a family member or friend’s sudden death (n=2, 8%)
- personal decisions not to compromise own quality of life (n=2, 8%)
- witnessing conflict between health care providers regarding goals of care (n=1, 4%)
- a previous experience of not having plans in place (n=1, 4%)

- as a patient being unaware of plans due to the severity of their medical condition (n=1, 4%).

One respondent described a somewhat negative experience of having goals of care and/or resuscitation planning conversations at every admission to the hospital and every ambulance ride.

“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. I would rather he wear a band that alerts staff to look and investigate his plan. It should be simpler and the information readily accessible upon engagement with services. The general practitioner didn’t like engaging in the conversation, she had empathy, but thought it was hard to talk about and could wait. I’m not sure what we would wait for my partner I nearly died a few times, it was hard.” – Carer.

Respondents described a range of negative experiences, in particular, highlighting the confronting, overwhelming and distressing nature of the conversation (n=3, 12%) and indicating a reluctance of some patients to discuss goals of care and/or resuscitation planning (n=3, 12%). Some respondents indicated there was a lack of involvement of the patient (n=2, 8%) and family (n=2, 8%) in discussing goals of care and/or resuscitation planning and overall, a lack of support for patients and families in having these conversations (n=2, 8%).

A smaller number of respondents indicated they felt pressured into making a decision (n=1, 4%) and that it was difficult to navigate their different cultural and spiritual preferences (n=1, 4%). Another respondent said it was a challenging experience, despite having a resuscitation plan in place (n=1, 4%).

“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.” – Family member

However, several respondents identified somewhat positive experiences with their goals of care and/or resuscitation planning conversations. They described having open and two-way communication with healthcare providers (n=9, 36%) and proactively taking the step to hold discussions with loved ones prior (n=4, 16%). One respondent provided the following experience:

“A goals of care and resuscitation planning was discussed when my mother became a resident in an aged care facility late 2019. 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 emergency department (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 ED 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." – Family member

Respondents described what could improve the experience of goals of care and/or resuscitation planning conversation. The main two suggestions coalesced more training for health professionals in conducting these conversations (n=3,12%) and encouraging patients to have these plans in place (n=3, 12%). Other suggestions included the need for more transparent communication between healthcare providers and the patient/family (n=2, 8%), encouraging active participation of the patient in the conversation (n=2, 8%), including preferred support people (n=1, 4%) and allowing time for the patient/family to understand the situation and to express their wishes (n=2, 8%).

Goals of care and/or resuscitation planning conversations need to be conducted with sensitivity to cultural and spiritual beliefs and practices (n=1, 4%) and conducted earlier instead of when a patient is deteriorating (n=1, 4%). Some respondents suggested there needs to be more open communication about death and dying (n=1, 4%) and improved community awareness of advance care directives/advance care plans (n=1, 4%), understanding of legal documentation (e.g. power of attorney, enduring guardianship) and the responsibility of those with given authority (n=1,4 %). Health professionals and facilities must ensure adherence to the plan (n=1, 4%), and one respondent suggested nursing staff could initiate and document the conversation before medical team authorisation (n=1, 4%).

One respondent provided the following recommendation for improvement:

"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 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.

If I'd known that his last four months would be away from home, or if he'd been able to communicate at that time, it's unlikely I would have called the ambulance as his preference was to die at home and he was quite adamant about not going to hospital several weeks before when paramedics helped him

up after a fall at home. We said he wanted to die at home repeatedly in hospital but didn't know how to make it happen." – Carer

Using Resuscitation Plans in End of Life Decisions Policy Review Survey: Clinician and managers experiences and perspectives: supplementary questionnaire

From 25 July 2023 to 4 August 2023, 41 NSW Health staff completed the questionnaire. Responses were received from clinical staff across 13 LHDs in NSW. Tables 14 and 15 present the respondent characteristics.

Table 14: Respondent role (N=41)

Role	**n**	**%**
Junior medical officer	5	12%
Nurse (all)	13	32%
Nurse practitioner	2	5%
Patient safety or clinical governance	1	2%
Physiotherapist	1	2%
Psychologist	1	2%
Senior medical officer	12	29%
Service manager	2	5%
Social worker	2	5%
Other	2	5%
Total	**41**	**100%**

Table 15: Respondent specialty (N=41)

Specialty	n	%
Cardiology	1	2%
Clinical education and training	1	2%
Critical care	1	2%
Emergency	3	7%
General medicine	3	7%
General surgery	1	2%
Geriatrics	1	2%
Haematology	3	7%
Neonatology	3	7%
Paediatrics	3	7%

Palliative care	3	7%
Rehabilitation	1	2%
Respiratory	8	20%
Other	9	22%
Total	**41**	**100%**

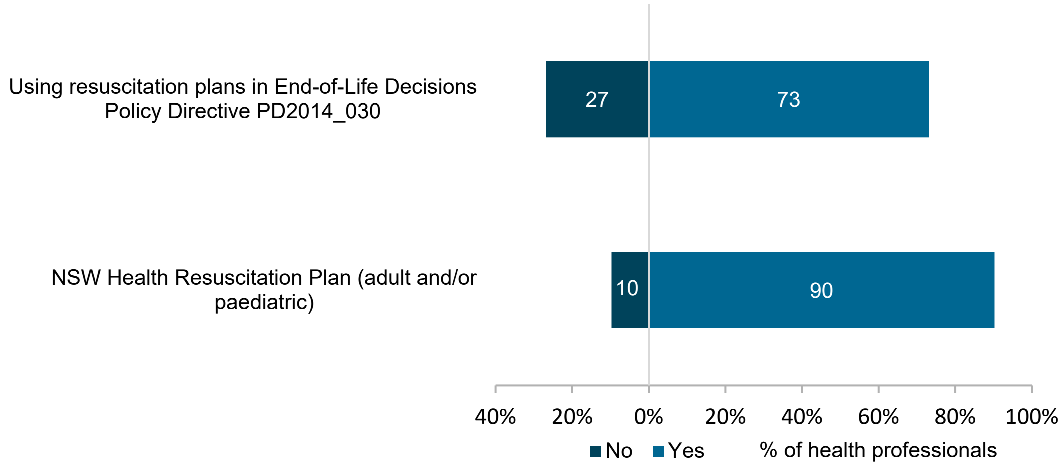
Just over one third of all respondents to the survey identified as a nurse or nurse practitioner (32%, n=13 and 5%, n=2 respectively), and more than a quarter of responses being from senior medical officers (29%, n=12). Junior medical officers submitted 12% (n=5) of the responses. The two other roles reported were both midwives (5%, n=2).

Reported clinical specialties included respiratory (20%, n=8), Palliative Care (7%, n=3), Paediatrics (7%, n=3), Neonatology (7%, n=3), Haematology (7%, n=3), General medicine (7%, n=3), Emergency (7%, n=3).

Awareness of, and use of NSW Health Using Resuscitation Plans in End of Life Decisions Policy Directive PD2014_030 and the NSW Resuscitation Plan

As a lead in, respondents were asked to indicate their awareness of the policy directive and the resuscitation plan (adult and/or paediatric). 73% (n=30) of respondents reported awareness of the policy directive, and 90% (n=37) reported awareness of the resuscitation plan (Figure 9). Three respondents (7%) reported that they were unaware of both.

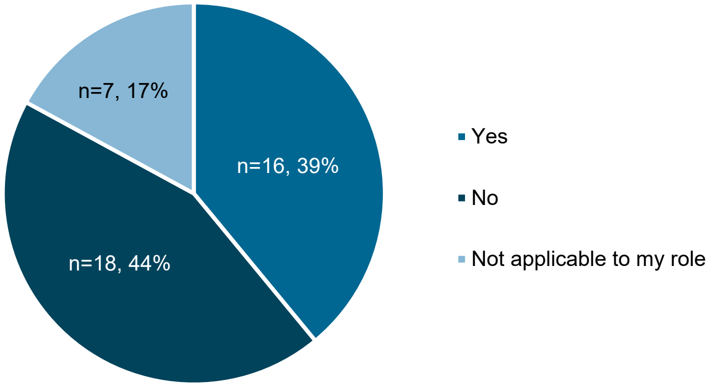
Figure 9: Awareness of the policy and the plan (N=41)



Awareness of the policy directive was greatest among those who identified as nursing staff, including nurse practitioners (27%, n=11), followed by senior medical officers (22%, n=9) and junior medical officers (7%, n=3). Similarly, awareness of resuscitation plans was greatest among nursing staff, including nurse practitioners (34%, n=14) followed by senior medical officers (24%, n=10) and junior medical officers (12%, n=5).

39% (n=16) of respondents reported that they had previously used the policy and the plan to guide goals of care and resuscitation planning conversations; 20% (n=8) identified themselves as nursing staff (including nurse practitioners), 15% (n=6) identified themselves as senior medical officer. 17% (n=7) indicated that the use of resuscitation plans was not applicable to their role (Figure 10).

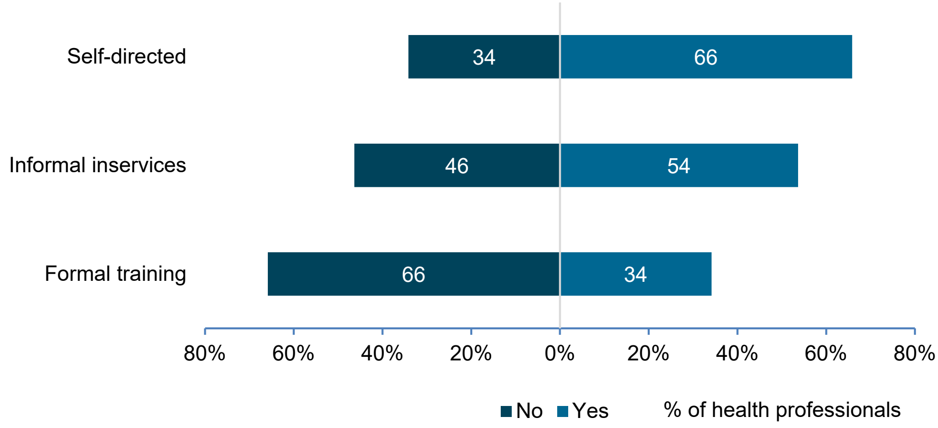
Figure 10: Use of the policy and the plan (N=41)



Training

Respondents were questioned of any training that they may have received around goals of care and resuscitation planning conversations with patients, family or carers approaching end of life (Figure 11). Self-directed training was reported by 66% (n=27) of respondents, informal in-services by 54% (n=22) of respondents, and only 34% (n=14) respondents reported that they had received formal training. These included 12% of nursing respondents (n=5), 7% (n=3) of senior medical officer respondents and 7% (n=3) of junior medical officer respondents. 24% (n=10) of respondents indicated that they did not receive any of the three training options; 4 (10%) of nursing staff, 2 (5%) of junior medical officers and 1 (2%) senior medical officer responded as such.

Figure 11: Training received (N=41)



Respondents who reported receiving formal training mentioned several providers of such training delivered online or face-to-face. The following table presents the number of key formal education providers mentioned by the healthcare practitioner's role. Three respondents reported that they had received formal training. However, they did not mention the specifics of the training.

Table 16: Formal training mentions

Training modality	Senior medical officer (n=3)	Junior medical officer (n=3)	Nurse practitioner (n=1)	Nurse (all) (n=4)	Social Worker (n=2)	Other (n=1)
Undergraduate degree	1	0	0	0	0	0
Fellowship training	1	0	0	0	0	0
Continuing education: NSW Health (includes My Health Learning modules, LHD training)	0	1	1	3	1	1
Continuing education: Other (includes seminars, role play)	0	1	1	1	0	0

Confidence

38 (93%) respondents indicated that having goals of care and resuscitation planning conversations with patients, family or carers approaching end of life was applicable to their role. Figure 12 shows their reported levels of confidence in carrying out these conversations. Ten respondents (24%) reported being highly confident in having conversations with patients, family or carers approaching the end of life. Confidence in having these conversations were high among nursing staff, with 13% (n=5) reporting confident and 11% (n=4) reporting highly confident, and among senior medical officers, 16% (n=6) reporting confident and 13% (n=5) reporting highly confident. 11% (n=4) of junior medical officers responded that they felt confident, with none reporting that they felt highly confident. Tables 17-19 outline the reasons for their confidence ratings, which were reported in a free text response.

Figure 12: Reported confidence in carrying out conversations (N=38)

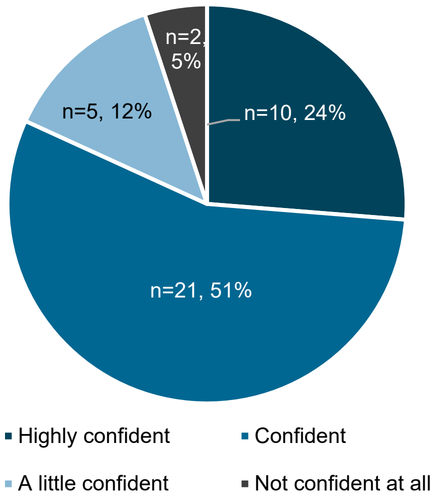


Table 17: Reasons for feeling highly confident (N=10)

Reason	Senior medical officer (n=5)	Nurse (all) (n=4)	Service manager (n=1)
Knowledge and training	1	1	0
Experience and exposure to these conversations	2	4	0
Confidence in own communication skills	0	0	1

Table 18: Reasons for feeling confident (N=21)

Reason	Senior medical officer (n=6)	Junior medical officer (n=4)	Nurse practitioner (n=2)	Nurse (all) (n=5)	Social worker (n=2)
Knowledge and training	2	0	0	0	0
Experience and exposure to these conversations	3	1	2	3	0
Supportive environment	0	0	1	1	0
Work specifically in palliative care	0	0	0	1	1

Table 19: Reasons for feeling a little confident (N=5)

Reason	Senior medical officer (n=1)	Junior medical officer (n=1)	Nurse (all) (n=2)	Patient safety or clinical governance (n=1)
Minimal knowledge and training	0	0	0	1
Minimal experience and exposure to these conversations	1	1	0	0

Two respondents (5%) reported that they did not feel confident at all, the reasons being that they had no training and that it was outside of their scope of practice.

Barriers to conducting conversations

Figure 13 shows respondents' agreement aligned with 11 pre-defined barriers to conducting goals of care and resuscitation planning conversations with patients, family or carers approaching end of life. The pre-defined barriers were identified from the peer-reviewed literature (see **Appendix 1: Use of resuscitation plans in decisions at the end of life: Evidence check**), findings from the Policy Lab (see **Appendix 2: SAX Policy Impact Lab Summary Report**) and following review by the project Expert Advisory Group and Steering Committee.

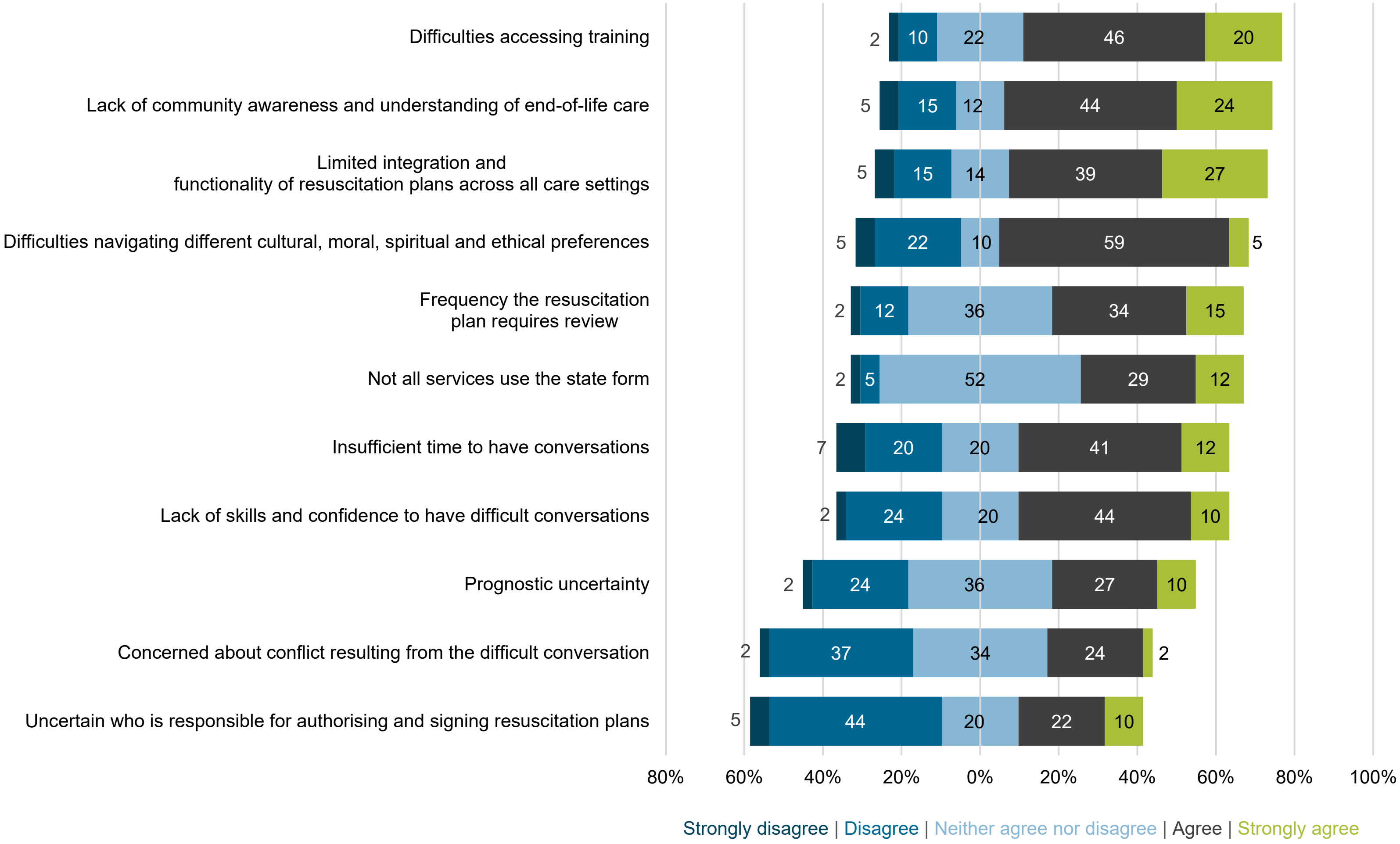
The top three agreed barriers were:

- difficulties accessing training (46% agreed, 20% strongly agreed)
- lack of community awareness and understanding of end of life care (44% agreed, 24% strongly agreed)
- limited integration and functionality of resuscitation plans across all care settings (39% agreed, 27% strongly agreed).

Additional barriers identified by respondents coalesced the following themes:

- resource challenges (e.g. competing demands, understaffing and skill mix)
- complexities of decision making (e.g. differing views between clinical teams and between clinician and patients)
- lack of clear communication between teams
- lack of confidence from clinician and nursing staff
- lack of multidisciplinary collaboration (e.g. not seen as part of everyone's role).

Figure 13: Perceived barriers to conducting conversations



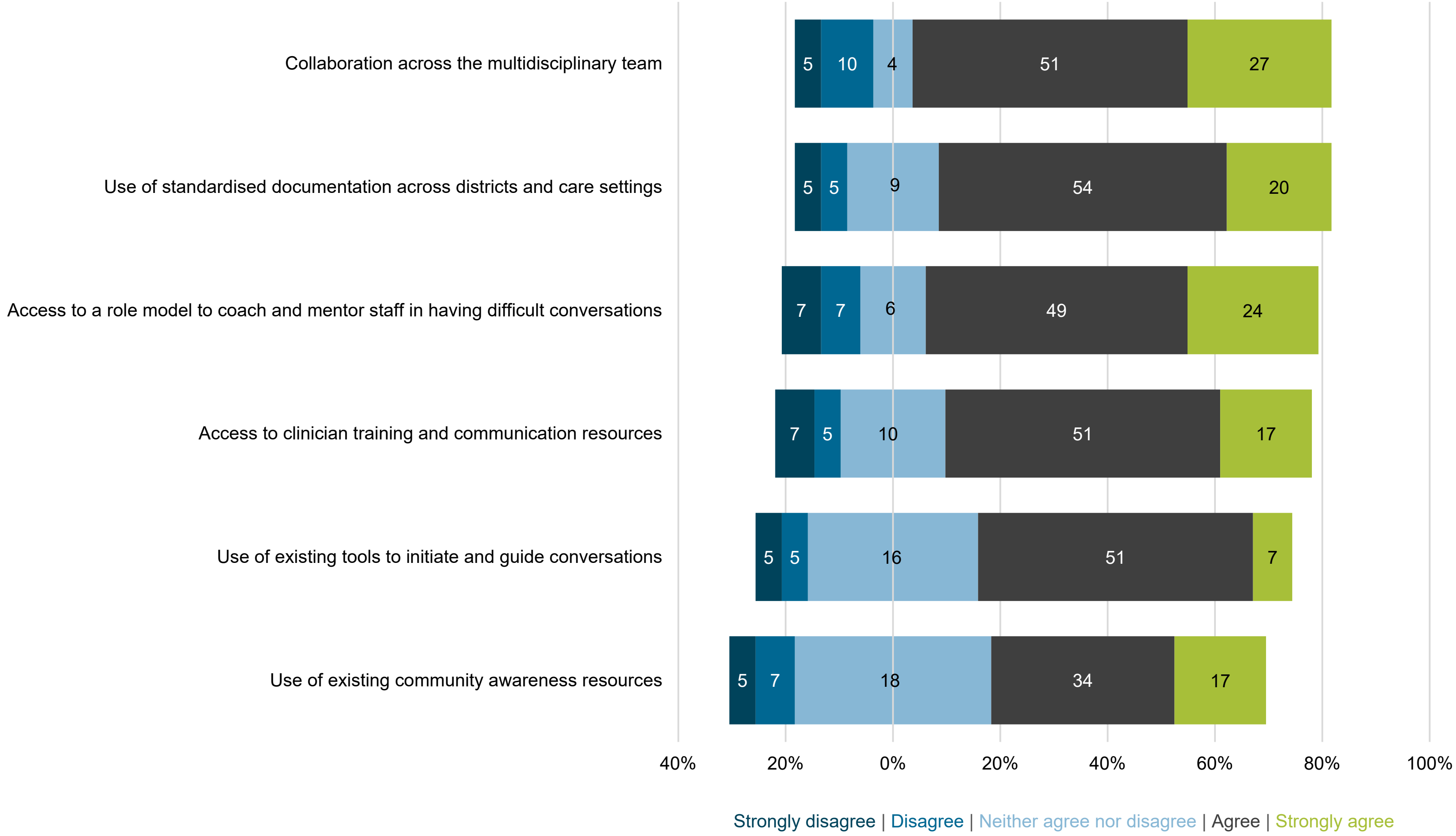
Enablers to conducting conversations

Figure 14 shows respondents' agreement aligned with six pre-defined enablers to conducting goals of care and resuscitation planning conversations with patients, family or carers approaching end of life. The pre-defined barriers were identified from the peer-reviewed literature (see **Appendix 1: Use of resuscitation plans in decisions at the end of life: Evidence check**), findings from the Policy Lab (see **Appendix 2: SAX Policy Impact Lab Summary Report**) and following review by the project Expert Advisory Group and Steering Committee.

The top three agreed enablers were:
- collaboration across the multidisciplinary team (51% agreed, 27% strongly agreed)
- use of standardised documentation across districts and care settings (54% agreed, 20% strongly agreed)
- access to a role model to coach and mentor staff in having difficult conversations (49% agreed, 24% strongly agreed).

Additional enablers identified by respondents coalesced the following themes:
- open, honest, and regular communication with patient and family
- education for staff and for the patient
- family involvement and support in conversations
- conversations happening earlier.

Figure 14: Perceived enablers to conducting conversations

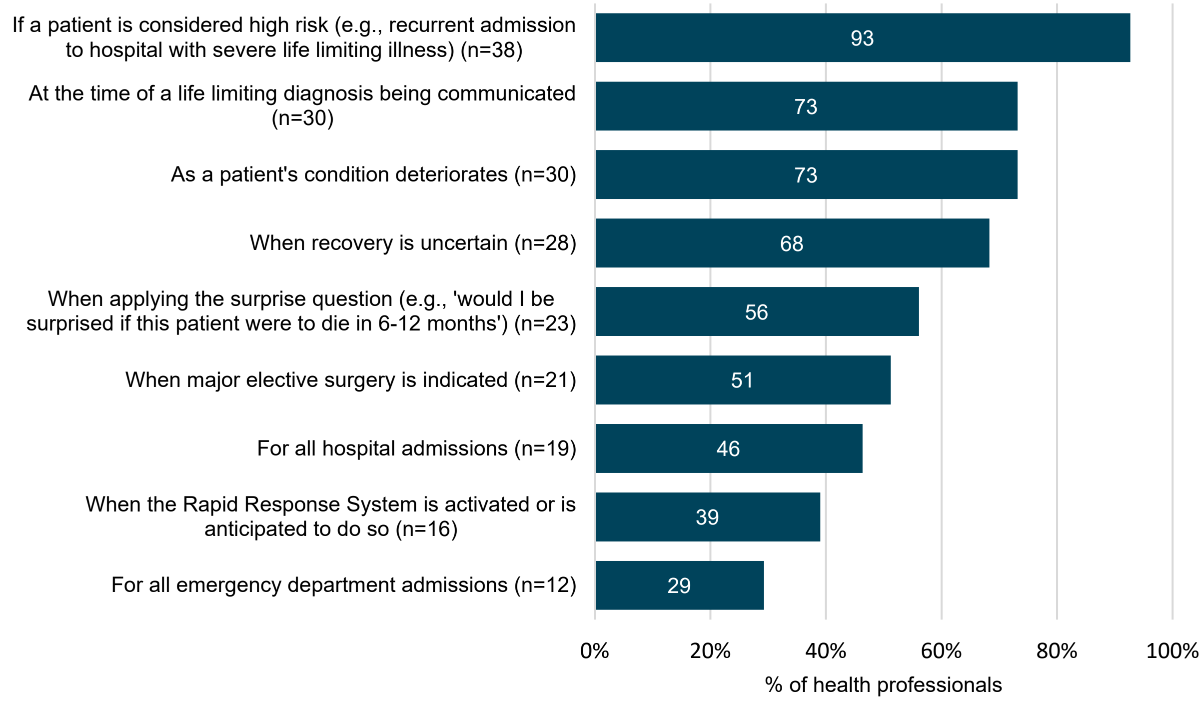


Timing of the conversation

Respondents were asked to indicate when they felt the resuscitation planning conversation should take place. 93% (n=38) respondents suggested when a patient is considered high risk, followed by at the time of a life-limited diagnosis being communicated (73%, n=30), as a patient's condition deteriorates (73%, n=30) and when recovery is uncertain (68%, n=28) (Figure 15). Additional times mentioned by respondents included:

- for all outpatient appointments with case managers
- for all appointments (normalise conversations).

Figure 15: Timing of the conversation*



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

Conversation process

Respondents were questioned on who should be responsible for three key components of the conversation: initiation, documentation, and authorisation. Table 20 shows that most respondents answered that senior medical officers should initiate, document, and authorise the conversation. Respondents felt that the conversation could also be initiated by nurse practitioners and junior medical officers. However, one quarter or less of all respondents felt that nurse practitioners (20%, n=8) or junior medical officers (10%, n=4) could authorise the outcome of the conversation. Nursing staff (other) and allied health staff were also perceived to be initiators (39% and 37% respectively) and potential documenters (27% and 17% respectively) of the conversation however, only one respondent felt that they should authorise the outcome of the conversation.

Other initiators of the conversation as mentioned by respondents included:

- the patient's family or advocate

- other senior nurses (e.g. clinical nurse consultant), particularly in chronic care settings
- anyone whom the patient trusts and has established good rapport with
- staff who have attended specialist training
- all staff members.

Four common reasons for senior medical officers, nurse practitioners and junior medical officers being the required initiator of the conversation are outlined in Table 21.

Respondents also suggested that documentation of the conversation could be done by:

- primary care providers
- case managers
- all staff members.

Common reasons for nominating senior medical officers, nurse practitioners and junior medical officers as documenters of the conversation are in Table 22.

Respondents suggested that authorisation of the conversation could also be done by:

- any clinician with a lead or longstanding role in the patient's care
- the patient.

Common reasons for nominating senior medical officers, nurse practitioners and junior medical officers as required authorisers of the conversation are outlined in Table 23.

Table 20: Conversation process (n=41)

Staff	Initiator	Documenter	Authoriser
Senior medical staff	100% (n=41)	98% (n=40)	98% (n=40)
Nurse practitioners	49% (n=20)	59% (n=24)	10% (n=4)
Junior medical staff	63% (n=26)	61% (n=25)	20% (n=8)
Nursing staff (other)	39% (n=16)	27% (n=11)	2% (n=1)
Allied health staff	37% (n=15)	17% (n=7)	0%
Other	20% (n=8)	10% (n=4)	10% (n=4)

Table 21: Frequency of reasons for nominating specified health professionals as *initiators*

Reason	**Senior medical officer**	**Nurse practitioner**	**Junior medical officer**
Shared responsibility among all staff	7	7	7
Ability to make decisions about and have responsibility for the clinical care of the patient	5	3	2
Possessing expertise and experience in conducting such conversations	5	4	1
Having trust and rapport with the patient	3	3	3
It is the responsibility of the medical team	2	1	1
To minimise medico-legal risks	1	1	0

Table 22: Frequency of reasons for nominating specified health professionals as *documenters*

Reason	**Senior medical officer**	**Nurse practitioner**	**Junior medical officer**
It is the responsibility of the medical team	4	2	4
Ability to make decisions about and have responsibility for the clinical care of the patient	3	2	1
Possessing expertise and experience	2	2	1
Contributed to the conversation	3	2	2
To minimise medico-legal risks	1	1	0

Table 23: Frequency of reasons for nominating specified health professionals as *authorisers*

Reason	Senior medical officer	Nurse practitioner
Ability to make decisions about and have responsibility for the clinical care of the patient	8	1
Possessing expertise, knowledge and experience	6	1
To minimise medico-legal risks	2	1

Implementation of the Using Resuscitation Plans in End of Life Care Decisions Policy Directive

Four (10%) respondents indicated that they were responsible for the monitoring of the implementation of the policy in their facility and/or organisation. Predominantly these respondents were from nursing, including nurse practitioners (75%, n=3) and the remainder was a senior medical officer (25%, n=1).

Only three respondents provided information on how the use of resuscitation plans in end of life care decisions was monitored. This included discussions in meetings (e.g. morning huddles), for the birth of the baby in a neonatal unit and through audits. No respondents provided information on the data that is collected and used to monitor the use of resuscitation plans in their local setting.

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2. Hartanto M, Moore G, Robbins T, et al. The experiences of adult patients, families, and healthcare professionals of CPR decision-making conversations in the United Kingdom: A qualitative systematic review. Resuscitation Plus. 2023/03/01/ 2023;13:100351. DOI: **https://doi.org/10.1016/j.resplu.2022.100351**