CARE FOR THE DYING IN NSW

A review of the data from the
2012 Quality Systems Assessment

Authors and data analysis: Hannah Baird, Bernadette King, Roger Kerr and Dr Amanda Walker.

Clinical Excellence Commission

Contents

1. Executive Summary

Nearly 50% of deaths in NSW occur in the acute care setting, with more than 23,000 deaths occurring in 2010 (see *Appendix 1*) in hospital facilities. Review of the 'Between the Flags' program and Incident Information Management System (IIMS) reporting have highlighted that there is often a delay in identifying patients whose deaths could be anticipated.

Morbidity and mortality reviews highlight issues in care delivered that may have prevented or avoided deaths, but outside of the context of palliative care, there is minimal examination of the quality of care provided to patients dying in acute care facilities.

In 2012, the Quality Systems Assessment (QSA) program of the Clinical Excellence Commission focused its self-assessment on end of life care in NSW public health organisations (PHOs). The QSA program is an annual process involving completion of an online self-assessment, verification site visits, feedback and reporting. Undertaken at three system levels of each PHO, the process allows exploration of gaps in implementation, and differing perceptions of issues, processes and resources. This report provides a summary of the self-assessment results, identifies current perceptions, issues and gaps within current practice and recommends action for improvement.

Key self-assessment findings included:

- 63% (740/1,183) of Local Health Districts (LHD) and Justice Health (JH) clinical units that responded to the self-assessment, indicated that care is provided for people who are dying or approaching the end of their life, their families and carers;

- Ambulance Service of NSW (ASNSW) stations/zones responding to the self-assessment, 92% (114/126) indicated that care is provided for people who are dying or approaching the end of their life, their families and carers;

- 61% of clinical units reported they routinely identified patients who were likely to die in the next 6-12 months;

- 42% of clinical units that responded indicated they followed a standardised approach to treating patients in their last days of life;

- Clinical units indicated the most challenging issues when managing patients at the end of life were incomplete documentation in the medical records (59%), staff members not feeling comfortable initiating the conversation with the patient, their family or carer (53%) and poor communication between staff and family or carers (31%);

- 87% of clinical units responded that education and training is provided to relevant clinicians in relation to end of life management. Areas covered included symptom management (66%), advance care directives (58%), using the principles of a palliative approach (56%) and communication skills (50%);
- 32% of clinical units responding to the self-assessment indicated they did not monitor any performance measures relating to end of life care; and
- Of those that did monitor performance measures, 78% of clinical units reported monitoring complaints and compliments, 40% indicated the involvement of palliative care teams in patient end of life management and 33% reported the number of patients with a documented end of life care plan.

The self-assessment results identified a number of issues and gaps that need to be addressed. These include the early and timely identification of dying patients, communication between health professionals and patients and their families, the human experience of dying, the lack of a standardised approach and the policy environment.

While palliative care services play a critically important role in managing end of life care for patients and their families, including meeting complex patient needs and contributing to the knowledge base, all health professionals have a role to play. This includes not only supporting generalist clinical services to provide excellent patient care, but also policy makers for the development of consistent and standardised state-wide protocols, guidelines, pathways and training. The NSW Palliative Care Role Delineation Framework[i] highlights the need for specialist palliative care, but also identifies a large group of patients whose needs can be met by primary care services, including those in acute hospitals.

The institutionalised way we die seems to be in conflict with the way most people would prefer to die. Without the early identification of dying patients and an understanding and responsiveness to patient preferences, this trend is likely to continue. Early and ongoing communication between health professionals and patients and their families and advance care planning can lead to improvements in the 'quality of death', a therapeutic alliance, fewer stays in hospitals and better psychosocial care enabling patients to find closure and a sense of peace.

Ultimately reform in end of life care in NSW can be developed through a values based approach built on a sound foundation of best clinical practice, towards enabling a 'good death'[ii], with dignity, empowerment, compassion and respect at the core of this experience.[iii] Developing a strategic and long term approach to end of life care will require strong leadership, collaboration across different NSW health organisations, effective clinical champions and a solid understanding of the evidence and best practice including how it can most effectively be applied in the NSW context.

The QSA program is an annual process involving completion of an online self-assessment, verification site visits, feedback and reporting.

2. Recommendations

Recommendations for change by 2017 are:

To develop standardised, evidence-based and consensus focused best practice systems around managing all aspects of end of life care. This will include:

a. The development of a process to identify those at risk of dying in a timely manner in order to initiate advance care planning processes and consider referral to appropriate support services;

b. A state-wide system to identify those patients with advance care planning documents to ensure accessibility to all health professionals including paramedics;

c. Tailored training programs in communication skills and clinical management relating to end of life care;

d. A state-wide end of life care pathway to ensure all dying patients benefit from a consistent approach to individualised end of life care, incorporating excellent symptom control, a prompt for communication to address social, spiritual and cultural needs as well as bereavement support for families and carers;

e. All facilities ensuring that the physical environment supports the need for communication with patients and their families by identifying suitable spaces for this to occur, and consider the need for privacy in bed allocation to dying patients; and

f. Implement a state-wide death review approach, exploring the circumstances of the death, including symptom management in the last 24-48 hours of life.

To develop standardised, evidence-based and consensus focused best practice systems around managing all aspects of end of life care.

3. Introduction

There were 47,945 deaths in NSW in 2010, representing about a third of all Australian deaths[iv]. Almost half of these individuals died in NSW hospitals rather than in their homes or in the community (see *Appendix 1*), emphasizing the importance of this setting for providing effective end of life care.

Recent data indicates that 51% of Australian deaths in people aged over 80, and 88% deaths in those aged 65+ had three or more chronic conditions[v]. These conditions make up more than 70% of Australia's overall burden of disease and are on the rise, expected to increase to 80% by 2020.[vi] By 2056, there is forecast to be a quadrupling of people aged 85 years and over and death rates are predicted to double to 320,000 per year.[vii]

The need for skilled health professionals in dealing with these complex medical conditions, co-morbidities and effective end of life care is rapidly increasing. Effective palliative care becomes important for all clinical units, primary health care environments and aged care services. Dying in effect, becomes everyone's business.

The Quality Systems Assessment program (QSA) is a risk management process involving completion of a multilevel online self-assessment, onsite verification site visits, feedback and reporting, followed by the development of improvement plans to address identified risks. This process is completed at three levels of the system (for example, LHDs, facility and clinical unit), enabling a top down/bottom up comparison and verification of responses within the organisation. The self-assessment themes are chosen annually based on issues that emerge from incident reporting, state-wide policy and national and international quality and safety literature. The specific self-assessment questions for these themes are developed in consultation with expert clinician groups convened for this purpose.

During 2012, as part of the QSA program NSW public health organisations (PHOs) undertook a self-assessment to better understand attitudes and practices in end of life care across the system. Sixty seven percent of respondents indicated they provide care to people who are dying and their families and carers.

The purpose of this report is to:

1. Share the results and insights from this system wide self-assessment of end of life care in NSW PHOs;
2. Identify current NSW practices, training, issues and gaps in end of life care in hospitals; and
3. Provide recommendations on a way forward for NSW Health to continuously improve end of life care for patients, their families and carers and the health system.

The following terms will be used in this Report:

− **Palliative care** – defined as specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life[viii]; and
− **End of life** – referring to the last days of life (e.g. end of life care pathway).

4. Background

End of life care was identified as an important area of need in NSW and chosen as a topic for the 2012 self-assessment process.

The self-assessment was conducted between 27 August and 26 October 2012, with 1,571 participants from clinical units, facilities / stations and LHDs/State levels of LHD's, Justice Health and the Ambulance Service of NSW (see *self-assessment questions in Appendix 2*). Responses to the self-assessment by organisation and level are listed in *Table 1*.

A detailed breakdown of the responses shows:

- Of the 1,513 completed self-assessments, 83.5% were from LHDs (N=1,260), 12.9% from the NSW Ambulance Service (N=198) and 3.6% from Justice Health (N=54);
- LHDs responses were from 1,130 clinical units, 113 facilities and 17 LHDs. Sixty percent were from metropolitan areas and 40% from regional and/ or rural areas; and
- 560 LHD clinical units indicated they dealt with adult patients only, 129 clinical units with children only and 441 clinical units with both adults and children.

The interpretation of the data should be undertaken with some caveats:

- All responses are based on self-assessment;
- Use of terminology such as standardised approach or advance care planning may be open to multiple interpretations; and
- There was no timeframe included in the questions on the elimination of tests and procedures so this could be 48 hours or 3-4 weeks.

The findings from the 2012 NSW self-assessment have been grouped into six main topics, which will be covered in the next section:

1. Identifying patients approaching end of life;
2. Planning and management of treatment – including palliative care;
3. Challenges in end of life patient care;
4. Patient centred approaches;
5. Clinical education and training; and
6. Monitoring performance.

Table 1: Responses to the self-assessment

Organisation	Level of assessment	Sent	Returned	Response rate %
LHDs	District	17	17	**100%**
	Facility	113	113	**100%**
	Clinical Unit	1181	1130	**96%**
Justice Health	State level	1	1	**100%**
	Stream / Op unit	54	54	**100%**
Ambulance Service NSW	State level	1	1	**100%**
	Division	3	3	**100%**
	Station / Zone	137	130	**95%**
	Paramedic	64	64	**100%**
Total		**1571**	**1513**	**96%**

5. Findings

5.1 Identifying patients approaching end of life

Overall 67% of clinical units, station or zone level respondents indicated they (often, sometimes or rarely) provide care for people who are dying or approaching the end of their life with the ASNSW coming into contact with these patients most frequently (see *Figure 1*).

Figure 1: Response to the question "Please indicate the frequency that care is provided for people who are dying or approaching the end of their life, their families and carers?" by Local Health District, Health Network, NSW Ambulance Service and Justice Health
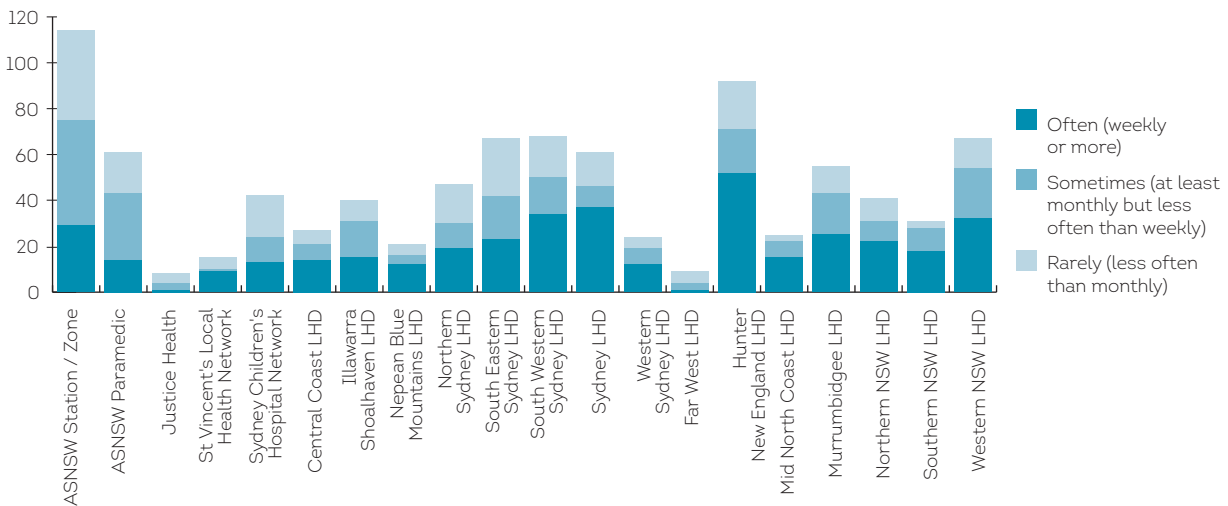
Sixty one percent (451/737) of the LHD and JH departments/clinical units providing care for people who are dying or approaching the end of their life, responded that they routinely identified patients that are likely to die in the next 6-12 months so that end of life planning can begin (*Figure 2*)

Figure 2: Identification of dying patients, comparing clinical units and facilities: question asked "Are patients that are likely to die in the next 6-12 months routinely identified so that end of life planning can begin?"
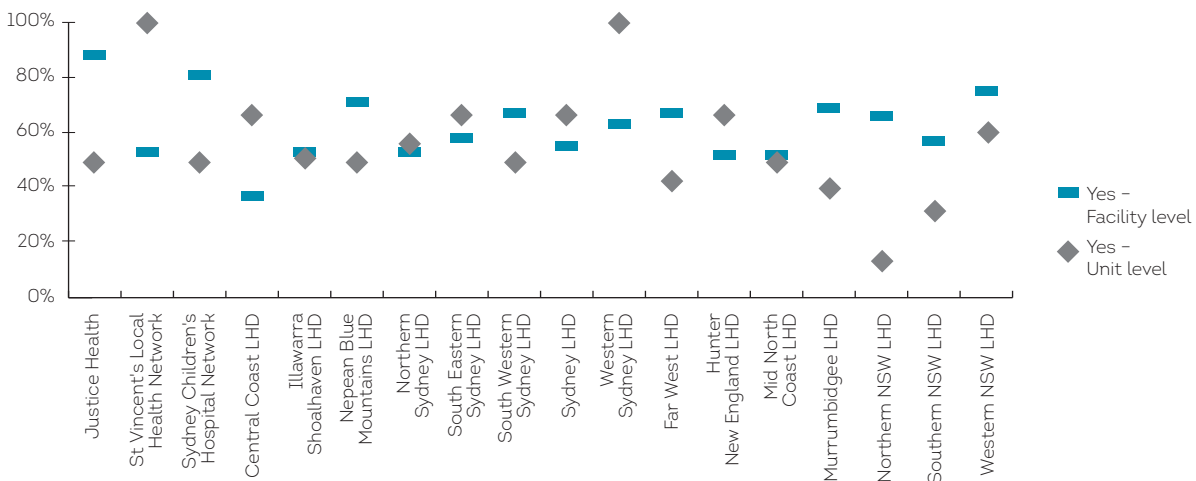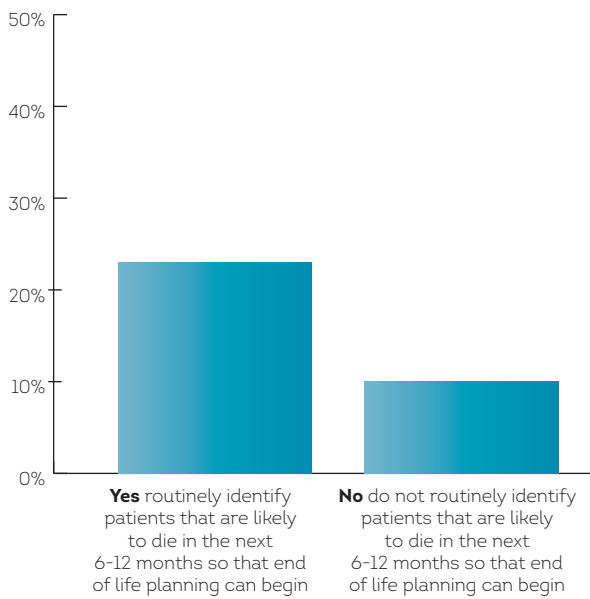
Figure 3: Comparison of clinical units that responded to the question on routinely identifying patients that are likely to die in the next 6–12 months who also indicated that "Nothing" was a challenging issue "when managing patients at the end of life"

5.2 Planning and management of treatment

Overall 42% of self-assessment respondents indicated that they followed a standardised approach in treating patients in the last days of life.

Interestingly, while LHDs consistently reported a standardised approach was undertaken, this was markedly different from the perspective of the facilities and clinical units raising questions about penetration of policy, implementation of process and perception about what represents a standardised approach (see *Figure 4*).

Highlights include:

- 42% (312/737) of LHD and JH departments/clinical units providing care for people who are dying or approaching the end of their life, their families and carers indicated they followed a standardised approach in treating patients in their last days of life;

- There were significant differences between metropolitan (68%) and rural/regional (32%) facilities responding *"Yes"* to the question *"Does the department/clinical unit follow a standardised approach for patients in the last days of life?"* (p=<0.001);

Figure 4: Comparison between LHD, facility and clinical unit responses to the question "Does the organisation/ facility/clinical unit follow a standardised approach for patients in the last days of life?"
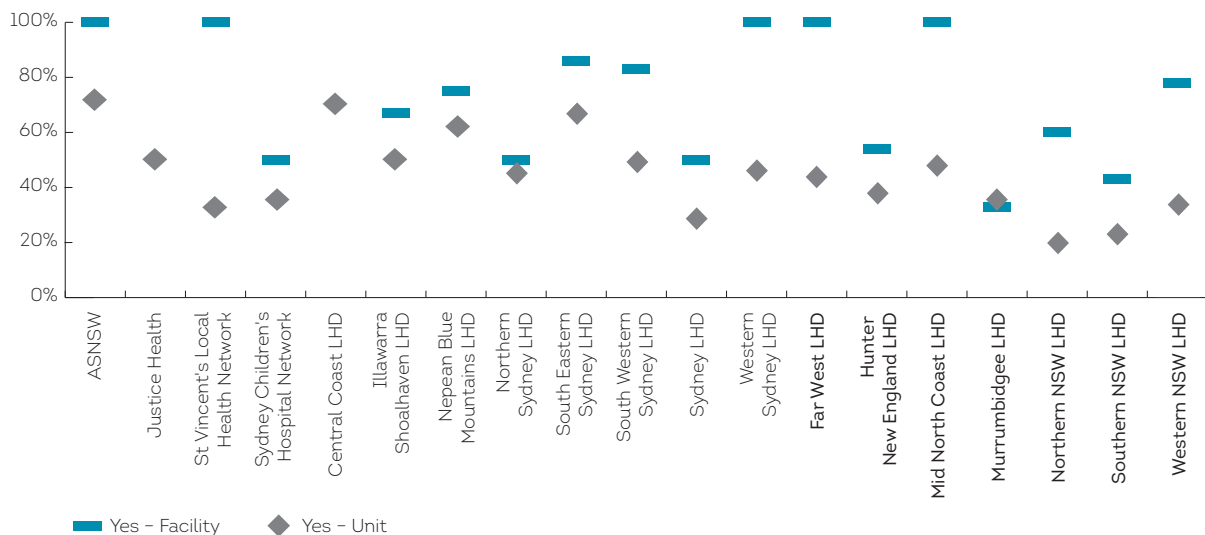
– The differences between facilities in peer groups A (51%), B (25%), C (16%) and D (8%) responding *"Yes"* to the question *"Does the department/clinical unit follow a standardised approach for patients in the last days of life?"* were also significantly different (p=<0.002); and

– 33% (167/500) of LHD and JH departments/clinical units indicated that the number of deceased patients with documented end of life care plans was monitored in relation to end of life care.

Features identified by clinical units undertaken as part of a standardised approach to patient management, include:

1. Resuscitation status discussion (overall 93%);
2. Minimum standards for documentation of decisions and treatment (overall 87%);
3. Identification of the health care proxy and surrogate decision maker (overall 66%);
4. Involvement of guardianship tribunal if necessary (overall 54%);
5. Rapid discharge to the patient's home where the hospital is not the preference (overall 54%); and
6. Conflict / dispute resolution (overall 44%).

Eighty eight percent of LHD clinical units providing care for people who are dying or approaching the end of their life, reported having a symptom management plan. The most widely reported elements were use of equipment to provide care at the end of life (82%), specialist palliative care referrals (82%) and the elimination of unnecessary tests and procedures (80%). Sixty six percent of clinical units indicated they used a symptom assessment process (see *Figure 5*).

These self-assessment results indicate that using a consistent approach is a significant area of need for NSW hospitals and a gap in effective end of life care across the spectrum.

> **There is a lack of understanding of what is deemed 'palliative' care. Documentation and use of advance care directives is poor and end of life pathways are rarely used."**
> **Self-assessment respondent**

Figure 5: Response to the question "Which of the following are included in the patient's symptom management plan?" by LHD, facility and clinical units
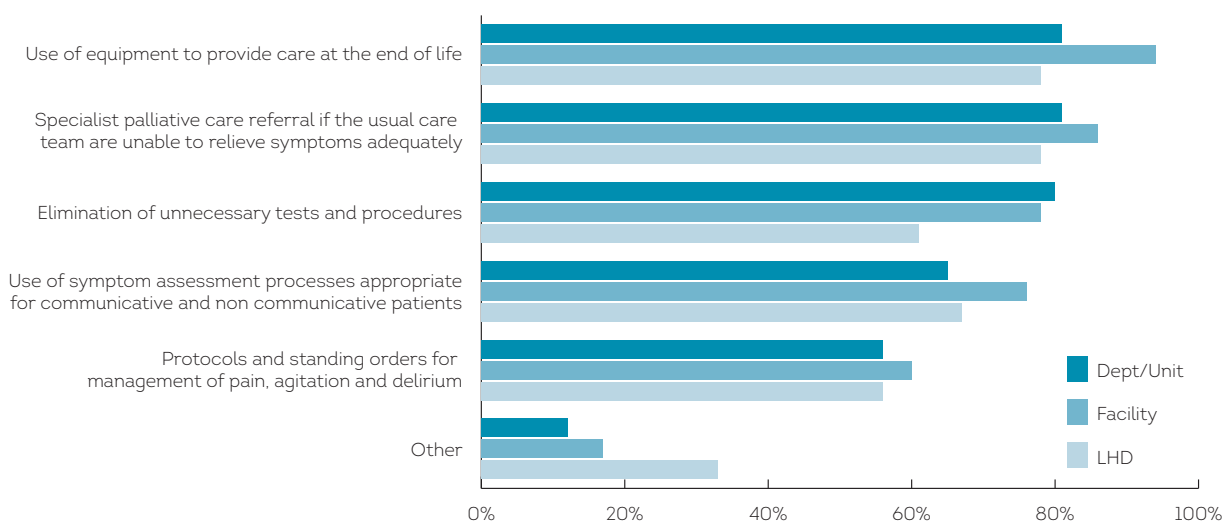
5.2.1 Access to palliative care services

Whilst LHDs reported access to palliative care services, this was not always reflected in the clinical unit level responses and many clinical units commented on the difficulties in accessing palliative care.

At the LHD and JH clinical unit level, 89% (628/703) of those providing care for people who are dying or approaching the end of their life, their families and carers responded they were *"Always"* (100%) or *"Often"* (67%-99%) able to access specialist palliative care services. The results at the facility level were consistent with the clinical unit level results with 89% (89/100) of LHD facilities responding similarly.

Figure 6 indicates the variation across LHDs, facilities and clinical units of referrals to specialist palliative care teams "if the usual care team are unable to relieve symptoms adequately". The results show that clinical units are referring patients less often than facilities believe is happening, Fourteen out of 18 LHD or State level respondents indicate their belief that referrals are happening *Always"* or *"Often"*.

5.2.2 Communication between the Ambulance Service of NSW and NSW hospitals around end of life care

Ninety percent of ASNSW respondents reported that they managed patients who are dying or approaching the end of their life. When asked what links there was for information sharing, less than 50% of paramedics or stations/zones agreed there was a process in place where hospitals or other agencies can alert the call centre and subsequently the paramedic regarding existence of end of life care plans (see *Figure 7*). Other findings included:

− 30% of service respondents reported they had a standardised approach available; and

− 17% of paramedics are *"Always"* or *"Often"* able to access timely clinical advice and decision support 24/7 in relation to end of life issues.

Figure 6: Referral to specialised Palliative Care Units if the usual care team are unable to relieve symptoms adequately "Always" or "Often" by facility and clinical unit
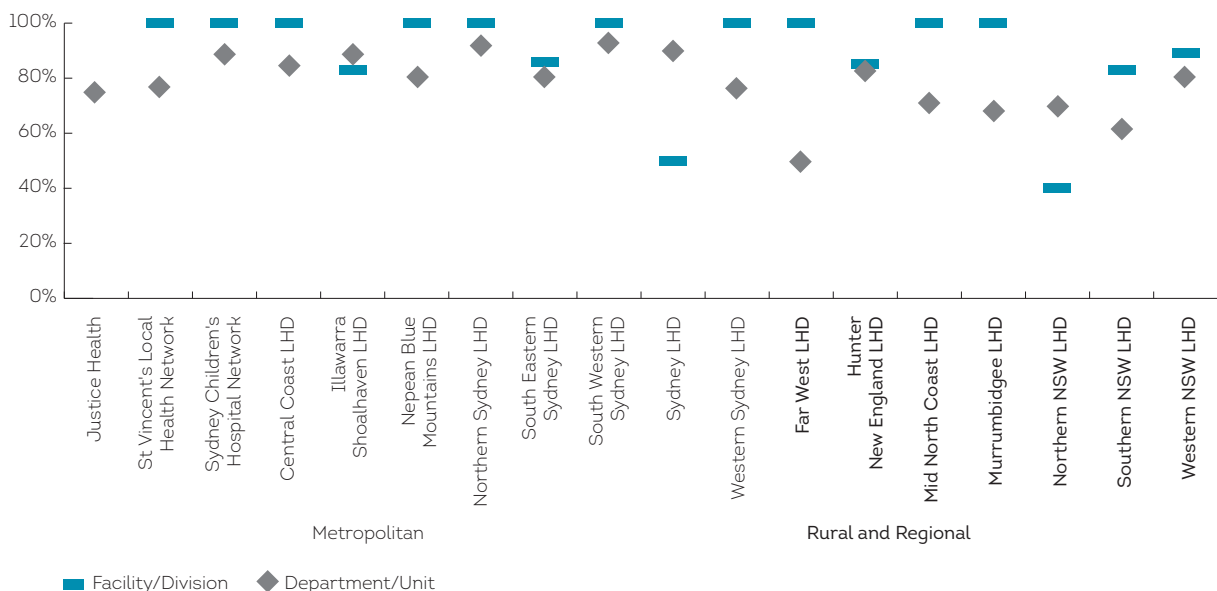
Figure 7: Ambulance Service response to the question "Is there a process in place whereby hospitals/ other agencies can alert the call centre operator and subsequently the paramedic about the existence of end of life care plans (e.g. Allow a Natural Death [AND]/Do Not Resuscitate [DNR] orders)?"

Yes, routinely

Yes, but dependant on individual hospital/ LHD to develop/implement process
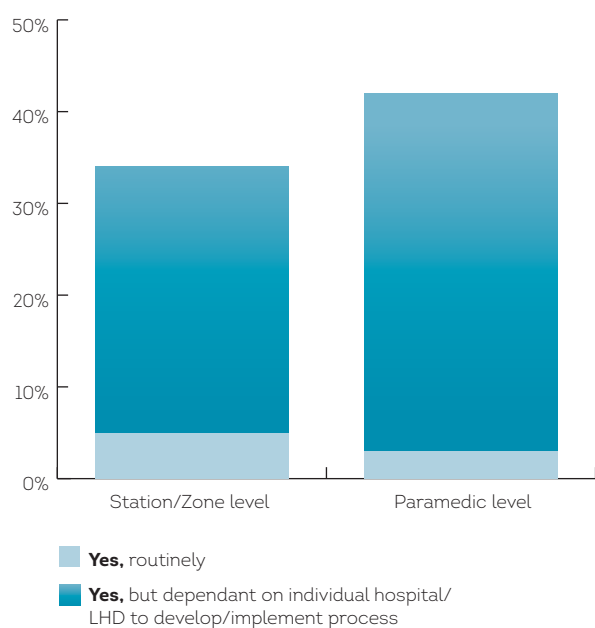
5.3 Challenges in end of life patient care

Mixed results were reported from LHDs and JH units in the challenges they faced in managing patients requiring end of life care (see *Figure 8*). Staff discomfort in having end of life discussions with patients and their families was the primary issue, followed by incomplete documentation and the inability or unwillingness of health professionals to identify patients who are dying. Access to or delays in medications and the inability to give pain medication were the least challenging issues identified by respondents for end of life care.

"

In the future, there is a need to develop protocols and pathways for end of life care."
Self-assessment respondent

Figure 8: Challenges in end of life care management, by all respondents
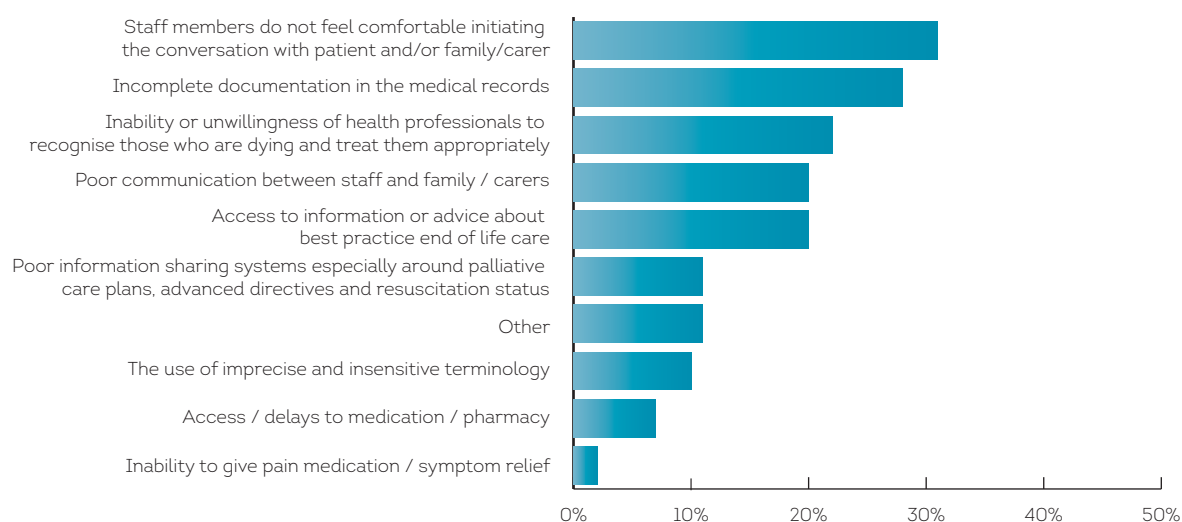
5.4 Patient centred approaches

Clinical units reported where possible that they adopted a patient centred approach to health care for end of life patients, with results demonstrating that:

- About 79% of clinical units *"Always"* or *"Often"* that culturally appropriate palliative care and support are provided including care preferences, spiritual requirements and bereavement expression, with a significant variation across LHDs;

- 82% of clinical units *"Always"* or *"Often"* that patients, families and carers are provided with information about treatment and care options, medication and what to expect at each stage. Clinical units who follow a standardised approach are 10% more likely to provide this information than those that don't (see *Figure 9*);

- 60% of clinical units *"Always"* or *"Often"* had 24 hour access to interpreters trained in end of life care;

- 100% of of units reported that families and carers of patients receive timely verification and certification their death *"Always"* or *"Often"*; and

- 82% of clinical unit level respondents reported that patients are nursed in a single room to ensure privacy and allow uninterrupted access for families/carers *"Always"* or *"Often"*.

5.5 Clinical education and training

Self-assessment results indicated that 82% of respondents receive clinical training and education for managing end of life care patients. The most frequently reported across all LHDs and Networks is training in symptom management (67%) followed by advance care directives (58%) and using the principles of a palliative approach (56%).

However, 18% of clinical units reported not receiving any training or education in relation to end of life care.

Figure 9: Comparison of clinical units that responded they do or do not use a standardised approach for patients in the last days of life with the question "Patients/families/ carers are provided information about care options, medications and what to expect at each stage of the journey towards end of life" "Always" or "Often"
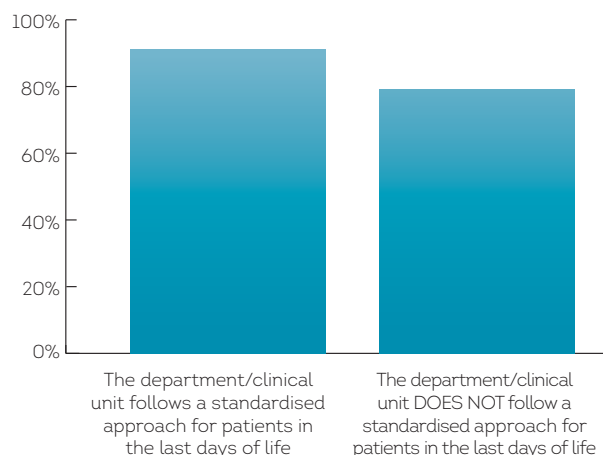
> **,,**
> Although there has not been any education provided, several staff have attended Palliative Care courses in their own time, and share what they have learnt with the staff at this hospital. It would be great to engage education for all the staff so that everyone was well versed in the Palliative Care approach."
>
> **Self-assessment respondent**

5.6 Monitoring performance

Self-assessment results indicated that monitoring performance by health services was largely undertaken through a review of complaints and compliments, with 78% of units reporting this occurred. Of those 40% monitored the involvement of palliative care teams in end of life management (18%), the number of deceased patients with end of life care plans (16%) and the appropriate use of care of dying pathways. Only 12% of respondents report monitoring the number of end of life patients with unrelieved physical symptoms (see *Figure 10*).

"
Palliative end of life care involves a multi disciplinary approach with the pain and palliative care team being one of the most important drivers of the process."
Self-assessment respondent

Figure 10: Response to question "Which of the following performance measures do you monitor relating to end of life care?" by LHD, facility and clinical unit
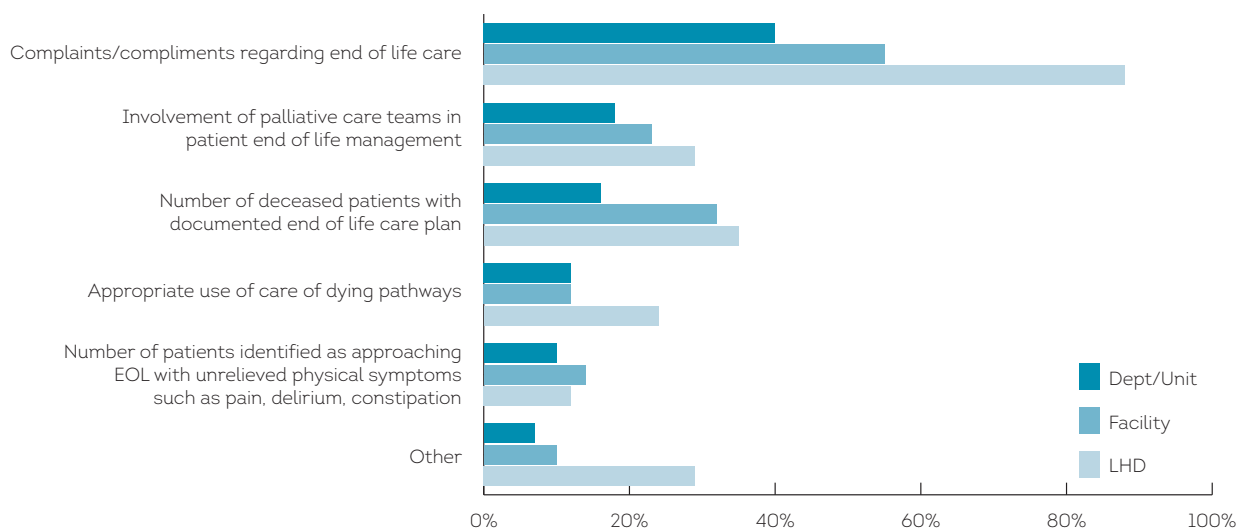
6. Key issues

The key issues for end of life care, in no particular order, are:

6.1 Early and timely identification of patients with a life limiting illness

Approximately one third of respondents indicated patients approaching the end of life are not routinely identified. Thirty eight percent of unit level respondents also indicated this is one of the most challenging issues when managing patients. The implications of this can be delays in advance care planning, informed decision making around treatment and providing adequate time for the patient to get their affairs in order.

Better systems are needed in NSW to support health professionals to more effectively identify patients who need to move into the end of life care stage, as it provides the opportunity to engage the specialist palliative care team, initiate an end of life care pathway and for the patient and their family/carer to consider their preferences for how and where they wish to die in a dignified and supported way.

6.2 Gaps in communication between hospitals and paramedics

Results indicate a significant communication gap between hospitals and paramedics regarding whether patients have an end of life care plan or, if so, how to access this. Less than 6% of station/zones and paramedics responded that a routine process was in place, with over 50% reporting there wasn't a process in place or not knowing.

Implementing a process for hospitals to alert the call centre operator to inform the paramedic about the existence of end of life care plans, would improve the communication and ensure that patients' wishes were followed in emergency treatment and management decisions.

6.3 Communication between health professionals, patients and their families/carers

Effective communication between the patient and health professional enables quality end of life care including appropriate pain management, a therapeutic alliance, fewer stays in hospitals and the Intensive Care Unit, greater responsiveness to patients' needs and psychosocial care that enables patients to find closure and a sense of peace.[ix]

With 20% of unit level respondents indicating there was poor communication between health staff and the family and carers and only 50% of units providing training in communication skills to staff for managing patients requiring end of life care, this is a complex and important issue for NSW.

6.4 Lack of a standardised approach in the last days of life

There is a fragmentation of end of life care across health services with 42% of units using a standardised approach, incomplete documentation (59%) and a lack of important processes such as the identification of surrogate decision makers (65%). This issue has implications including potential duplication, gaps, delays and uncertainty during an already emotional time for patients, their families and carers.

All health professionals, not just palliative care services, have a role to play in managing dying patients, which needs to be recognised and supported with training and advice in appropriate communication, standardised approaches, clinical management and ongoing documentation.

6.5 Context of dying

In addition to the clinical aspects of dying – such as managing the symptoms, the elimination of unnecessary procedures and prescribing the right medication dying is essentially a very human experience. Caring for patients' psychosocial needs and supporting their families and carers through a difficult and traumatic time are important issues in the process of end of life care.

Aspects which support the dying process include appropriate private space in hospitals, access to interpreters and spiritual care. Overall 84% of units responded they were able to care for patients in a single room *"Always"* or *"Often"* and 82% have access to suitable quiet space for family and carer discussion, *"Always"* or *"Often"*. Seventy nine percent of clinical units perceive that they are delivering culturally appropriate care *"Always"* or *"Often"*, with 60% able to access 24 hour interpreter services *"Always"* or *"Often"*.

6.6 Over treatment for dying patients

Once a patient has been placed on the end of life pathway, treatment options can be carefully considered in this context, with the elimination of unnecessary tests and procedures and a focus on the 'quality of dying' and pain management rather than prolonged and avoidable suffering.

Eighty percent of respondents indicated that the elimination of unnecessary tests was happening, however one of the limitations of the data was that there was no time period included in this option meaning it isn't clear whether this occurred 48 hours or 3 – 4 weeks before death. Forty two percent of respondents implement an end of life pathway.

Changing the care goal to focus on delivering comfort and dignity for the patient reduces any false hope when all other treatment options have failed and ensures the appropriate withdrawal of clinical interventions and health system resources for patients where there are limited benefits. This approach is consistent with good medical practice, ethics and NSW law.[x]

6.7 Policy environment

The self-assessment results raised a number of broader safety and quality issues in end of life care. Of particular note is the variance in practice reported between some LHDs on key aspects in the absence of a NSW policy framework such as standardised approaches, the identification of care goals, performance monitoring and clinical training received.

Given this variance, there is a case for more detailed analysis of key indicators towards developing integrated state-wide initiatives to improve end of life care, such as the implementation of a death review approach.

> End of life management needs to encompass principles for culturally appropriate services, and provide space for family/carer/ staff meetings. Specific palliative care rooms should be available, and every effort is made to ensure this but it's not always possible."
>
> **Self-assessment respondent**

7. Conclusion

With chronic conditions and co-morbidities on the rise, an ageing population and death rates expected to double in the next 40 years, there is a growing and urgent need for improvements in effective end of life care and an increase in the skilled health workforce to meet this demand.

The implications are that palliative care services will be increasingly unable to meet this clinical demand and that whilst they will continue to provide services to patients requiring specialist palliative care, generalist services need to increase their role in 'primary palliative care'. All clinicians need to be well trained and skilled in end of life care, so that dying patients in NSW have excellent care to the end.

This first NSW self-assessment into end of life care provides an important snapshot of current clinical care and practice, identifying gaps and perceptions and delivers useful insights for the health system. Its recommendations (see page 4) can be used as a trigger for changes in the State, towards meeting increasingly complex patient needs, supporting dedicated health professionals and contributing to the overall knowledge base in palliative care.

In the hospital setting, improvements are needed in documenting and identifying advance care planning, adopting consistent and systemised approaches, specialised training and support for clinical staff and improved engagement with the patient, family and carers. Changing perceptions for patients with a life limiting illness requires a re-orientation from a focus on 'quality of life' towards 'quality of death'. This re-orientation changes community expectations about 'life at all costs', eliminating unnecessary tests and procedures and ensuring patients die according to their wishes with compassion, respect and comfort.

The next steps in improving the understanding of these results will involve a verification process commencing in the first half of 2013 involving all public health organisations. This will provide an opportunity to investigate some of the self-assessment findings and gain an understanding of the perceptions of health staff. As part of this process an assessment of the current tools used will be undertaken and changes will be identified which could be embedded within practice, systems and training to improve and support hospitals in end of life care.

This self-assessment provides important baseline data on end of life practice in NSW public health organisations. It is envisaged that the QSA self-assessment process will include end of life questions again in approximately five years time, allowing the tracking of key indicators to determine any improvements or changes by 2017.

"

In the hospital setting, improvements are needed in documenting and identifying advance care planning, adopting consistent and systemised approaches, specialised training and support for clinical staff and improved engagement with the patient, family and carers."
Self-assessment respondent

8. Appendices

Appendix 1: Inpatient deaths and average length of stay 2009 – 2012

	2009	2010	2011	2012
Number of patients dying in hospital	23,393	23,287	24,117	24,446
Average number of admissions per patient within 12 months prior to death	3.2	3.2	3.1	3.2
Average number of days patients spent in hospital within 12 months prior to death	34.5	33.5	32.0	32.5
Average LOS per admission within 12 months prior to death	10.9	10.5	10.2	10.3

The above table shows the number of in-patient deaths (excluding Emergency Department) in NSW hospitals from 2009 – 2012 with the average number of days spent in hospital within 12 months of death and average length of stay per admission within 12 months prior to death.

Appendix 2:
Self-assessment questionnaire

Does the district / network have a process in place that assists staff in the early identification of patients whose death may be likely in the next 6-12 months?

Does the district / network have a guideline or follow a standardised approach for patients in the last days of life? If yes, what features does it include?

☐ Minimum standards for documentation of decisions / treatment (e.g. medical facts leading to decision; patient's wishes, persons involved in discussion)

☐ Conflict / dispute resolution (for patient, family and staff)

☐ Identify the health care proxy and surrogate decision maker (i.e. person responsible)

☐ Involvement of guardianship tribunal if necessary (e.g. if patient does not have decision making capacity)

☐ Resuscitation status discussion

☐ Rapid discharge to the patient's home where hospital is not the preferred place of care and dying at home can be supported

☐ Other

From the following list please indicate the most challenging issues when managing patients at end of life?

☐ Nothing

☐ Staff members do not feel comfortable initiating the conversation with patient and/or family/carer

☐ Inability or unwillingness of health professionals to recognise those who are dying and treat them appropriately

☐ Poor communication between staff and family/carers

☐ The use of imprecise and insensitive terminology

☐ Incomplete documentation in the medical records (around treatment options / resuscitation status)

☐ Access / delays to medication / pharmacy

☐ Access to information or advice about best practice end of life care

☐ Other

Please indicate how regularly the following activities occur in relation to palliative care services: *(Always, Often, Sometimes, Rarely, Not applicable)*

ALWAYS   OFTEN   SOMETIMES   RARELY   N/A

There is access to specialist palliative care services for patients who are approaching the end of their life (Palliative Care services can include Palliative Care consultant, Clinical Nurse consultant, Allied health)

ALWAYS   OFTEN   SOMETIMES   RARELY   N/A

In rural and remote areas emerging technologies are utilised to enhance communication and support for clinicians, patients and families (e.g.Telehealth networks)

What process does the district / network have in place that ensures other agencies can be supported around the decision not to admit patients for end of life care?

Which of the following are included in the patient's symptom management plan?
(tick all that apply)

- [ ] There is no formalised / individualised plan developed for symptom management
- [ ] Use of symptom assessment processes appropriate for communicative and non communicative patients (for pain, delirium, agitation)
- [ ] Protocols and standing orders for management of pain, agitation and delirium
- [ ] Specialist palliative care referral if the usual care team are unable to relieve symptoms adequately
- [ ] Elimination of unnecessary tests and procedures (e.g. routine vital signs, weights, blood tests)
- [ ] Use of equipment to provide care at the end of life (e.g. pressure relieving mattress)
- [ ] Other

What type of education is provided to relevant clinicians in relation to management of the dying patient / end of life management?
(tick all that apply)

- [ ] No education provided
- [ ] The identification of patients approaching the end of life
- [ ] Assessment and care planning
- [ ] Communication skills
- [ ] Correct use / implementation of end of life pathways
- [ ] Advance care directives (legal issues and documentation)
- [ ] Symptom management
- [ ] Principles of a palliative approach
- [ ] Other

Which of the following performance measures do you monitor relating to end of life care?
(tick all that apply)

- [ ] Nothing
- [ ] Complaints / compliments regarding end of life care
- [ ] Number of deceased patients with documented end of life care plan
- [ ] Involvement of palliative care teams in patient end of life management
- [ ] Number of patients identified as approaching EOL with unrelieved physical symptoms such as pain, delirium, constipation
- [ ] Appropriate use of care of dying pathways
- [ ] Other

Please indicate how regularly the following activities occur:
(Always (100%), Often (67%–99%), Sometimes (34%–66%), Rarely (1%–33%), N/A (0%))

ALWAYS	OFTEN	SOMETIMES	RARELY	N/A

Patients/family/carers are provided information about treatment and care options, medications and what to expect at each stage of the journey towards the end of life

ALWAYS	OFTEN	SOMETIMES	RARELY	N/A

Culturally appropriate palliative care and end of life support is provided which includes care preferences, spiritual requirements and bereavement expression (e.g. Mechanism in place to support 'return to country' for Aboriginal communities who are approaching the end of their life)

ALWAYS	OFTEN	SOMETIMES	RARELY	N/A

There is 24 hour access to interpreters trained to address end of life concerns

ALWAYS	OFTEN	SOMETIMES	RARELY	N/A

There is access to a suitable quiet space in which to initiate end of life discussion and family/carers to be seen post bereavement

ALWAYS	OFTEN	SOMETIMES	RARELY	N/A

Families and carers of patients who have died receive timely verification and certification of death

References

i   Palliative Care Role Delineation Framework, NSW Health, 2007.

ii   Smith RA 2000 'A Good Death' BMJ, vol 320, pp129-130.

iii   Palliative Care Australia 1999, *Palliative Care Standards* (3rd edition), Canberra and CPCRE 2005, *op cit*.

iv   Australian Bureau of Statistics, *Causes of Death Australia 2010*, Canberra. 2012.

v   Australian Bureau of Statistics. *Causes of Death Australia 2009*. Canberra. 2011.

vi   Vos, Tet al. 2005, *Australian burden of disease and injury study: projected health care costs report*, University of Queensland and AIHW Brisbane.

vii   Australian Bureau of Statistics, *Causes of Death Australia 2009*. Canberra. 2011.

viii   Palliative Care Australia. *Palliative and End of Life care glossary of terms*. 2008.

ix   Zhang B, Nilsson M and Prigerson H. *Factors important to patients' quality of life at the end of life*. Arch Intern Med, Published online July 2012 at www.archinternmed.com.

x   NSW Health. draft *Advance Planning for Quality Care at End of Life: Strategic and implementation Framework 2011*

Clinical Excellence Commission programs / projects

Between the Flags

The Between the Flags Program aims to reduce the risk of hospital patients deteriorating unnoticed and ensure they receive appropriate care in response if they do.

BloodWatch

The CEC Blood Watch Program co-ordinates the implementation of improvements in transfusion practices across NSW.

Chartbook

As part of its goal to provide assurance through credible public reporting, the CEC publishes an annual chartbook of health system indicators.

Clinical Leadership

The CEC Clinical Leadership Program has a focus on improving patient safety and clinical quality by supporting and developing clinical leaders in the workplace.

Collaborating Hospitals' Audit of Surgical Mortality (CHASM)

CHASM is systematic peer review audit of patients deaths who were under the care of a surgeon at some time during their hospital stay in NSW.

Falls prevention

The NSW Falls Prevention Program extends Statewide across hospitals, community and residential aged care.

Hand Hygiene

The CEC leads the National Hand Hygiene Initiative based on the "5 Moments for Hand Hygiene" promoted by the World Health Organisation (WHO) – World Alliance for Patient Safety.

In Safe Hands

In Safe Hands is based on the simple premise that clinical teams are the units that deliver care, so the health system must be oriented towards understanding their needs and supporting them in performing to the best of their ability.

Medication Safety

The medication safety/quality use of medicines program focuses around the provision of tools and resources which enable hospitals to analyse and improve their medication management systems.

Partnering with patients

The Partnering with Patients program fosters the inclusion of patients and family as care team members to promote safety and quality.

Patient Safety and incident management

The patient safety program utilises Incident Information Management System (IIMS) and Root Cause Analysis (RCA) reports, to identify opportunities for improvements in the safety and quality of clinical care.

QUAH

The Quality Use of Antimicrobials in healthcare.

Sepsis

This project aims to reduce preventable harm to patients with severe infection and sepsis through early recognition and prompt treatment.