TOP 5

IMPROVING TRANSITIONS OF CARE FOR
PEOPLE LIVING WITH DEMENTIA: 2014-2015

Research report prepared for the HCF Research Foundation
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FOREWORD

By 2020, the number of people living with dementia in Australia is likely to reach almost 400,000. With dementia affecting more people than ever before, increasing numbers of people with dementia are engaging with health services to receive care. In these interactions with unfamiliar people and environments and in transitions of care, patients with dementia can experience heightened distress and anxiety. New approaches are needed to ensure that we improve the care and outcomes for these vulnerable patients.

Carers of patients with dementia are an invaluable source of ‘tips’ and personal information that can be used by clinicians to improve care and allay distress for the patient with dementia. TOP 5 is an approach to improving clinician and carer communication that was developed by the Central Coast Local Health District in New South Wales (NSW). Information shared by carers with clinical staff is recorded on the TOP 5 form on the bedside chart, actively used in care delivery and conveyed to clinicians at shift handover.

In a previous report, we found that TOP 5 is a low cost, patient based communication strategy for patient care associated with significant improvements in patient outcomes, safety, carer experience and staff satisfaction with the potential to provide cost savings to health services.

In this study, we found significant benefits for staff, patients and carers when using TOP 5 while transferring dementia patients between hospitals, aged care facilities, community services and NSW Ambulances.

The research described in this report was supported by a grant from the HCF Research Foundation.

We believe that the findings of this study provide further evidence of the benefits of engaging family and carers to improve patient care.

Dr Karen Luxford
Principal Investigator, TOP 5 Study
Director, Patient Based Care, Clinical Excellence Commission
“Carers can't believe that something so simple can make such a big difference”.

“The family were very happy that we took the time to understand their mother and individualise her care”.

“I think it is a fantastic contribution to reducing patient distress levels on the ward, and to improving staff satisfaction, coping with difficult behaviours”
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Dr John Dobrohotoff, Maureen Strudwick and Professor Rosalie Viney are acknowledged as co-investigators on the grant and for their contributions and support for the conduct of this study.

The CEC TOP 5 Project Team is acknowledged for its hard work and devotion to this inspiring undertaking. This study would not have been possible without the talents of Virginia Armour (Acting Program Manager), Melissa Tinsley, Erin Gilmore (Project Officer) and Mei Chan (Research Assistant and Data Analyst).

The CEC TOP 5 project team wishes to thank Anne Axam and Theresa Moait for their wisdom and support throughout the study.

ACRONYMS AND ABBREVIATIONS

ACSQHC - Australian Commission on Safety and Quality in Health Care
AIHW - Australian Institute of Health and Welfare
ASET - Aged Care Services Emergency Team
CEC - Clinical Excellence Commission
CHOPs - Confused Hospitalised Older Persons program
ED - Emergency Department
EMR - Electronic Medical Record
GP - General Practitioner
IIMS - Incident Information Management System
LHD - Local Health District
LSL - Local Site Liaisons
MOU - Memorandum of Understanding
PTO - Patient Transport Officer
RACF - Residential Aged Care Facility
RN - Registered Nurse
SPSS - Statistical Package for the Social Sciences
SD - Standard Deviation
1. EXECUTIVE SUMMARY

This research study builds on the results of the TOP 5 Phase 1 study, which concluded that TOP 5 is a low cost, patient based communication strategy that positively impacts care. It is associated with improvements in patient outcomes, safety, carer experience and staff satisfaction when used in a hospital setting for patients with dementia.

TOP 5 involves staff engaging with carers to discover their five most important non-clinical tips (TOP 5 tips). TOP 5 incorporates management strategies to help communication and support personalised care for individuals with cognitive impairment.

This research study examined the use of TOP 5 in transitions of care between hospital, Residential Aged Care Facilities (RACFs) and community services. The results indicate that TOP 5 is a valuable communication strategy that can be used during transitions of care to improve patient safety, staff and carer satisfaction. It also promotes knowledge and overall communication between all parties involved in the care of people living with dementia.

• An estimated 1.2 million Australians are caring for someone with dementia. With an ageing population, increasing levels of dementia will lead to increasing pressures in the health care system.
• People living with dementia are especially vulnerable when placed in unfamiliar environments, such as health care services.
• People living with dementia will receive care from a variety of health services across the continuum of care. These may include primary care physicians, emergency services, allied health services, long-term residential care, in the home, acute and community settings.
• The TOP 5 program uses up to five personal tips (TOP 5 tips) from carers to improve communication and promote personalised care. Tips and strategies from carers are available for all staff to use.
• In this study, TOP 5 was used and evaluated in seven public hospitals and four private hospitals, seven RACFs, six community services and the Ambulance Service of NSW.
• The evaluation investigated process implementation and impact of TOP 5 during transitions of care, use of TOP 5 by staff, acceptability to staff and carers and the impact on patients (including falls and use of anti-psychotic drugs).

In summary:
• Overall, 748 participants including 685 staff members, 41 carers and 22 local site contacts known as Local Site Liaisons (LSL) from five different types of facilities (i.e. Emergency Department (ED), Peri-operative unit, RACF, community service and Ambulance Service of NSW) across NSW took part in the study of TOP 5.
• The total number of TOP 5 forms initiated during the study period was estimated at 831 (average of 44 per site), with the majority (52.1%) occurring in EDs.
• More than 80 per cent of the staff respondents reported that they had implemented the TOP 5 strategies as part of the individual’s care.
• Enablers for the implementation of TOP 5 included leadership, multidisciplinary local implementation teams, a whole-of-health service approach to implementation, incorporating TOP 5 into already established local processes and education.
• Barriers to uptake included high rates of LSL staff turnover, staff resistance to implementation, time constraints, lack of feedback to staff and carer issues.
• TOP 5 was well-received by staff in all participating facilities.
- Up to 90 per cent of staff perceived TOP 5 as an easy process and not time consuming;
- Eighty per cent of staff agreed that patients, residents or clients were less agitated and more cooperative with the use of TOP 5 strategies;
- The majority of staff respondents (100% of ED staff) reported a reduction in the use of chemical restraints;
- Sixty-seven per cent of staff agreed that less patient “specials” (intensive 1:1 nursing) were needed;
- One hundred per cent of staff reported that carers appeared to be more satisfied and the majority of carers had less concern with the care provided to their loved ones.

- Staff confidence in caring for people with dementia was significantly enhanced in EDs, community services and peri-operative units with TOP 5 in place.
- Carers reported high levels of acceptability, with 92 per cent reporting being more engaged with staff and involved in the care. All carers reported significant improvement in their confidence of the staff’s ability to care for their loved one. TOP 5 was perceived by 90 per cent of the carer respondents as beneficial to overall patient care and effective in settling their loved ones.
- There was increasing use of TOP 5 during transition of care throughout the study and carers were satisfied with the overall transfer process. Up to 80 per cent of the LSLs agreed that the use of TOP 5 helped to improve communication between staff within and between facilities.
- Limitations with data collection restricted the ability of results to inform the impact of TOP 5 on falls, incidents of aggressive behaviour and the use of anti-psychotics or physical restraints. However, in one RACF where complete falls data was available before and during the study, a significant downward trend in falls over time was noted after TOP 5 was introduced. An estimated monthly reduction of 8.44 falls in residents with dementia in the facility highlights the potential cost savings for health services.

Future opportunities include the broader application of TOP 5 for all people who experience difficulties with communication, across a range of acute and community health care settings. The use of TOP 5 to focus on personalised care strategies and working with carers as part of the health care team across the patient journey will improve the overall experience of staff, patients and carers.
2. THE CLINICAL EXCELLENCE COMMISSION

The mission of the Clinical Excellence Commission (CEC) is to build confidence in health care in NSW, by making it demonstrably better and safer for patients and a more rewarding workplace. The CEC is a board-governed organisation established in 2004 under the Health Services Act 1997, as a key component of the NSW Patient Safety and Clinical Quality Program. Following the Garling Report in 2008, the CEC has become one of the pillars of NSW Health, with increased responsibility for quality and safety. Some of the key areas of focus include falls, medication safety, sepsis, clinical handover and patient based care.

The CEC’s Partnering with Patients program (established in 2010) fosters the inclusion of patients and family as care team members, to promote safety and quality. It recognises the importance of improving quality of care, by responding to the needs and preferences of patients, while equally engaging staff in creating supportive environments for all.

The CEC’s Patient Based Care model (see Section 3) is a patient centred approach highlighting that everyone working in health services has both the responsibility and the opportunity to improve patient care. Improving patient focused care has a range of benefits for patients, providers and health care services, including improving patient care experience, staff satisfaction, clinical outcomes and operational benefits.

An expert advisory committee helps to inform the Partnering with Patients program. A consumer advisory panel facilitates partnering with patients and families on CEC’s safety and quality initiatives.
3. PATIENT BASED CARE

3.1 Concept

Patient based care refers to a model of care focused on the patient, built on genuine partnerships between providers and patients (Figure 1). Creating such partnerships requires engagement with patients, families and carers on multiple levels: from involvement in their own care team, to consultation at the management and governance level.

Patient centred models have emerged from an extensive scientific literature and exchange of ideas in the health care sector over the past 30 years. Over this time, researchers have employed a range of conceptual frameworks and terminology in reference to the process of shifting focus on to the patient (Australian Commission on Safety and Quality in Health Care, 2011). Key research by the Picker Institute in 1993, crystallised this approach by identifying eight domains of patient centred care: respect for patient preferences and values, emotional support, physical comfort, information, communication and education, continuity and transition, coordination of care, the involvement of family and friends, and access to care (Gerteis et al., 1993). From the 1990s, the patient centred care movement has steadily gained momentum in safety and quality improvements.

Figure 1. The CEC Patient Based Care Model
3.2 Drivers

Delivering patient based care requires change in institutional culture and clinical practice, underpinned by evidence (derived from research). Such approaches have regularly been linked to an improvement in reported patient experience (Charmel and Frampton, 2008, Doyle et al., 2013). Patient based care has also been found to improve objective measures of clinical outcomes, such as increased treatment compliance (Arbuthnott and Sharpe, 2009), reduced length of stay (DiGioia, 2008), and reduced mortality following acute myocardial infarction (Meterko et al., 2010). In summary, research indicates that patient based care initiatives improve both clinical outcomes and the patient and staff experience.

Health care advisory, accreditation and regulatory bodies are now acknowledging this growing evidence base. In the 2011 National Safety and Quality Health Service Standards, the Australian Commission on Safety and Quality introduced Partnering with Consumers as National Accreditation Standard 2 (Australian Commission on Safety and Quality in Health Care., 2012). This standard calls on health services to engage patients in governance, service planning, designing care, and evaluation of service delivery. Such recognition provides an additional driver for change towards a patient based approach, as the standards form the basis of the National Health Service accreditation system.
4. BACKGROUND

4.1 Dementia

Dementia is an umbrella term applicable to a range of diagnoses, characterised by progressive impairments in memory, cognition, language, perception and personality changes (Australian Institute of Health and Welfare (AIHW). 2007). These impairments manifest in a decline in a person's ability to perform activities of daily living. The course of decline in functioning is highly variable between individuals and may differ according to the specific illness causing dementia, of which more than 100 have been identified. Among the most common are Alzheimer’s disease (responsible for approximately 50 per cent of cases), vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Australian Institute of Health and Welfare (AIHW). 2007). While research has identified some pharmacological agents and lifestyle factors that may protect against the development of dementia or slow its progress, there is no known cure (Access Economics., 2009 (a)).

4.2 Dementia in Australia

Australia’s population is ageing. Although dementia is not considered a natural part of the ageing process, the majority of people living with dementia are more than 70 years of age. This has a significant impact on the provision of health services now, and for the future. It is estimated there were 266,574 people living with dementia in Australia in 2011, 91,038 in NSW. For NSW, this is projected to increase to 182,331 people by 2030 and 303,673 people by 2050 (Deloitte Access Economics., 2011).

4.3 Hospitalisation and transitions of care for patients with dementia

Being admitted to hospital is a stressful time for people living with dementia and their carers and this has an impact on the safety and quality of care. Anxiety levels can be high for patients with dementia who are removed from their usual place of residence. They may also be experiencing pain or discomfort and will be cared for by staff that may not be familiar with their individual needs and preferences. All of these factors will increase their distress, worsen cognitive function and increase behavioural and psychological symptoms of dementia. Hospital staff may find it difficult to communicate effectively with the individual and may miss subtle changes demonstrating escalating levels of anxiety.

People living with dementia may suffer from other chronic and complex health conditions associated with older age, as well as acute illness or injury. This can require frequent hospital admissions and transfers between their residence in the community or RACFs and an acute health service. Less than 10 per cent of hospitalisations of persons with dementia in NSW are specifically for dementia or conditions which are often characterised by dementia (such as Alzheimer's or Parkinson's disease). The remaining 90 per cent of hospitalisations are for other unrelated conditions with dementia identified as comorbidity (HealthStats NSW, 2015). In 2013-14, 29,401 (3%) people admitted to hospital in NSW had dementia as a principal diagnosis or comorbidity.

Many patients with dementia continue to live in their own home in the community and receive care from general practitioners (GPs) and Allied Health clinicians in the primary health care setting. Most (nearly 91%) of the 1.1 million hospitalisations in Australia for people aged 65 and over were for people who had come from their home in the community. The remaining 9 per cent of admissions for older persons were for people living in residential aged care (HealthStats NSW, 2015).
Transitions between health services can be difficult and frightening for people with dementia and their carers. Deterioration necessitating transition to other services can sometimes be rapid. An unfamiliar environment and care providers can exaggerate behaviours, anxiety and agitation. The special needs of this vulnerable population need to be considered, especially in transitions to the hospital setting (Cohen and Pushkar, 1999). It is vital for care to be coordinated across settings and that the information about patient needs and preferences is seamlessly communicated, to ensure that care is personalised and safe (CEC, 2014).

### 4.4 Use of anti-psychotic medication and falls

The use of anti-psychotic medication to manage the behaviours of patients with dementia, without a diagnosis of psychosis, is increasing despite the associated risks. A 10-year retrospective case-control study conducted by Donovan et. al., investigated the absolute mortality risk increase associated with anti-psychotic use in 90,786 patients aged 65 years or older, with a diagnosis of dementia (Donovan et al., 2014). The authors concluded that the absolute effect of anti-psychotics on mortality in elderly patients with dementia may be higher than previously reported, and increases with dose. Alternative strategies to the use of chemical restraint are needed to manage aggressive and difficult behaviours in patients with dementia.

A relationship between the use of anti-psychotics for the purpose of managing behaviours and anxiety in patients with dementia, and the number of reported falls involving those patients, was identified in Phase 1 of the TOP 5 study (CEC, 2014). Results of the TOP 5 Phase 1 study found a statistically significant reduction in the use of anti-psychotics following the introduction of TOP 5 at one site, and a statistically significant decrease in the usage of Risperidone quicklets at another hospital.

Falls remain a major cause of harm in health care settings and place a significant financial burden on services. An Australian study of in-hospital falls by Morello et. al. concluded that patients who experience an in-hospital fall have a significantly longer length of stay and higher associated costs (Morello et al., 2015). People with dementia are over represented in injury related hospitalisations. Reducing the number of falls in this high risk population through the implementation of fall related preventative strategies is paramount (Harvey et al., 2015).

### 4.5 Carer engagement

Patient based care is grounded in a genuine partnership between the clinician and patient. While health care providers may initiate this partnership, participating in engagement requires the patient to be able to articulate their needs and preferences in response. Depending on the stage of illness, this can present some practical challenges for many patients living with dementia. The disease course of dementia means that patients develop impairments in both cognition and communication, inevitably creating barriers to engagement.

The value of carer input cannot be underestimated. The carer can provide important information and engagement on behalf of the patient that is essential to achieving patient based care. Carers have extensive knowledge of the patient’s needs and preferences. When engaged with the clinical team, the carer can provide this information to personalise care and improve the overall safety and quality of the care delivered.
5. WHAT IS TOP 5?

5.1 The concept

TOP 5 involves staff engaging with carers to discover their five most important non-clinical tips (TOP 5 tips) and management strategies to aid communication and support personalised care for individuals with cognitive impairment.

When an individual with cognitive impairment is identified, staff member(s) approach the carer and explain the TOP 5 concept. The carer is encouraged to think about what would be important information for the staff to know about the individual.

The TOP 5 tips are not clinical, but contain information to help staff communicate with and understand the person they are caring for. The carer’s tips are discussed and strategies are developed collaboratively between the carer and staff, so the strategies can be utilised within the health care setting.

A standardised form is used to record the strategies. The location of the TOP 5 form is dependent on where the individual is receiving care:

- Hospital – if the individual is in a hospital setting, the TOP 5 form is typically located at the patient’s bedside, or in their medical notes and is accessible to all staff
- RACF – if the individual is in a RACF setting, the TOP 5 form is typically located in a folder kept at the nurse’s station
- Community – if the individual is at home, the TOP 5 form is located inside their home. Community staff locate a TOP 5 tag at the entrance to the home. The location of the TOP 5 form is written on the back of the tag.
- Ambulance – if the individual is being transferred via Ambulance Service of NSW, the paramedic or the patient transport officer (PTO) will locate the TOP 5 form and carry a copy, along with other necessary clinical documentation, to the health service.

Upon discharge or transfer of care, the TOP 5 strategy form will accompany the individual as they move throughout the health care system, or return home. At each subsequent visit to another facility, the original TOP 5 strategies may be amended or updated by staff. See Appendix A for more information.

5.2 The origins of TOP 5

TOP 5 was conceived and implemented in the NSW Central Coast Local Health District (CCLHD) in 2007. The concept was developed from carer feedback. Carers found the information that they contributed about the person they cared for with cognitive impairment was not being communicated to staff on the next shift. The carers wanted the opportunity to write down this information so that all staff would be aware of the non-clinical tips that would assist staff to personalise care. In addition, staff feedback indicated that they were under-equipped to manage the behavioural issues of patients with dementia and wanted to provide better care for their patients. TOP 5 was developed by CCLHD Carer Support Unit as a solution to address these concerns.

The program was initially designed to support patients with cognitive impairment and focused on effective communication between the patient, carers and staff with a personalised approach to care. By mid-2011, the CCLHD TOP 5 pilot had expanded to include RACFs and community services within the Local Health District, to
transfer the TOP 5 form to and from the hospital, with resources and protocols also developed for Ambulance Service of NSW.

In 2011, the CEC made a successful submission to the HCF Research Foundation, who provided funding to support researching the implementation of TOP 5 in 17 public and four private hospitals in NSW in 2012-13. The focus of the implementation and evaluation was on the impact of TOP 5 on hospital staff, on the carers of hospitalised patients with dementia and patient safety outcomes.

The aims of the study were:

• to evaluate the outcomes of patients with dementia, in a variety of lead hospital sites
• to demonstrate the impact of the TOP 5 process on the carers, patients and staff
• to evaluate a range of quantitative indicators, during a specific time frame (implementation phase).

Results of the 2012-13 study indicated that TOP 5 is a low cost, patient based communication strategy for patient care, associated with improvements in patient outcomes, safety, and carer experience and staff satisfaction, while also providing potential cost savings to health services.

The TOP 5 initiative was well received by carers of patients with dementia, and a range of health care providers. The findings of this study indicated that TOP 5 is a simple and useful communication tool to assist staff in formalising personalised care delivery and engaging with carers of patients with dementia. TOP 5 strategies developed for individual patients were easy to use and effective.

Opportunities to improve the care of patients with dementia, through exploring the use of TOP 5 during transitions of care between health care services were identified.
6. THE USE OF TOP 5 IN TRANSITIONS OF CARE – CEC TOP 5 INITIATIVE

In 2014-15 the CEC undertook a study to investigate the use and transfer of TOP 5 information in referral linkages. Participating in this study were hospital sites (primarily in the EDs and pre-admission clinics, focusing on where the patient would enter the hospital), RACFs and community services (focusing on where the patient would likely be transferred to and from the hospital), and the Ambulance Service of NSW (as the likely mode of transfer).

The objectives of the TOP 5 program in 2014-2015 were:
- To evaluate quantitative indicators in hospitals, RACFs, community services and Ambulance Service of NSW
- To demonstrate the impact of the TOP 5 process on carers, staff and individuals with dementia
- To evaluate the transfer of TOP 5 information during the transition between health care services.

6.1 Methodology

6.1.1 Governance

The TOP 5 Steering Committee formed in Phase 1 of the TOP 5 study continued to provide oversight of Phase 2 of TOP 5. The role of the TOP 5 Steering Committee was to oversee the implementation of the TOP 5 program in the acute setting and to support the extended use of TOP 5 for patients with dementia, in transitions of care. Members of the initial Steering Committee were invited to continue their participation during Phase 2 of TOP 5. Three additional members joined the Steering Committee, representing the new stakeholder groups in the study. This included Aged and Community Services, Australia, Ambulance Service of NSW and NSW Medicare Locals (see Appendix B & C). All members had expertise in the field of aged care and dementia. The Committee met on seven occasions during 2014-15.

6.1.2 Ethics approval

Ethics approval was granted by the Northern Sydney Local Health District (NSLHD) Lead Human Research Ethics Committee (HREC) for the original implementation and evaluation of the TOP 5 study (Phase 1), in August 2012. This ethics approval applied to all participating hospitals and was approved as ‘negligible risk’ and valid for five years from approval date.

An amendment to the research protocol was submitted in June 2014, to include the revised evaluation methodology for the TOP 5 Phase 2 study and the new stakeholder groups. The amendment was approved in June 2014. Specific hospital sites were either covered by their original site-specific ethics application, or submitted an extension for a new one.

A separate research proposal and site-specific ethics access request was submitted and accepted by Ambulance Service of NSW.

For participating RACF and community services, a Memorandum of Understanding (MOU) was created and endorsed by the site and the Clinical Excellence Commission (see Appendix D). The MOU outlined the intended cooperative relationship between CEC and participating sites, and described the terms and duration under which the CEC would undertake the TOP 5 Phase 2 study and evaluation.
6.1.3 Development of a toolkit

Separate toolkits for hospital, RACFs and community services were developed to assist staff with the implementation of the program.

- A TOP 5 toolkit that was developed for hospital staff in the previous study, based on CCLHD materials, was revised and provided to hospital staff in July and August 2014.
- Two new toolkits, aimed at RACF and community staff, were developed based on the original TOP 5 hospital toolkit. Resources were amended to reflect the needs of the two different health care settings and were provided to sites in August and September 2014.

All toolkits included details of the TOP 5 program background and processes, as well as resources including: carer brochures, the TOP 5 yellow strategy form, TOP 5 tags and stickers for clinical notes, promotional posters, educational materials, suggested scripts for staff to use when engaging with carers and effective examples of TOP 5 strategies.

Each site was encouraged to tailor implementation to meet local needs and to determine which resources would best assist them with TOP 5 implementation. The toolkits were well-received by all sites.

Custom resources, including posters and information flyers, were developed for Ambulance Service of NSW to promote awareness of TOP 5 among paramedics and PTOs.

Based on feedback from staff, additional resources were developed during the study period to promote awareness of TOP 5 and included TOP 5 badges and fridge magnets. TOP 5 fridge magnets were provided to community services to give to clients to use to record the location of the TOP 5 form inside the home. This enabled the TOP 5 form to be located quickly and easily by paramedics, PTOs and community services staff. Hospitals were also provided with fridge magnets to give to TOP 5 patients on discharge with their TOP 5 strategy forms.

6.1.4 Site selection

Eleven hospitals from the initial 2012-13 study (seven public and four private), were invited to participate in the program. A letter was sent to each chief executive, inviting their hospital to continue their involvement in the TOP 5 initiative (see Appendix E). Once confirmation from each hospital was received, participating hospitals were asked to nominate up to two RACFs and one community service that they had an established relationship with, when caring for individuals with dementia. To determine this, hospital sites were asked to look at where the majority of their patients with dementia were admitted from, and what facility or services were they discharged to. Ten hospitals accepted the invitation to participate.

The nominated referral RACFs and community services were contacted by phone to gauge interest in participating in TOP 5. A letter of offer to participate in the study was sent to all interested sites. A total of 11 RACFs and 10 community sites agreed to participate in the TOP 5 study (see Appendix F & G).

Associated Ambulance Service of NSW sites were selected and invited to participate in the program. As the focus of the study was to look at the transfer of the TOP 5 information between facilities, Ambulance Service of NSW sites were selected according to their proximal location to each lead hospital site.
6.1.5 Identifying the team
At each participating hospital, RACF and community service, sites were asked to identify an implementation team consisting of:

- Executive sponsor – to provide leadership support and receive progress updates
- Local site liaison (LSL) – the main contact for the CEC to provide regular updates, and provide local direction for the initiative
- Clinical champion or other identified person of interest (where available) – usually a member of staff working with individuals with dementia, and/or carers who were likely to be involved with the TOP 5 program

Most participating RACF and community services sites opted to combine the role of the executive sponsor and LSL.

Ambulance Service of NSW was asked to nominate a relationship manager in each of the local areas to act as the LSL for their crews.

6.1.6 Education
TOP 5 education sessions were held at all participating sites. LSLs were asked to invite staff members, who would be likely to initiate a TOP 5, to attend an internal education session. This was presented on-site at participating facilities, by a member of the CEC project team and included an explanation of the TOP 5 resources. Staff also had an opportunity to ask questions about the TOP 5 program and the research study.

At lead hospital sites, a mixture of ED, aged care services emergency team (ASET), pre-admission, peri-operative and day surgery unit staff attended in-house hospital education sessions along with clinical nurse educators (CNEs).

Education sessions at RACFs and community services were attended by general aged care staff, dementia care workers and members of the executive teams. All community services opted to educate all staff members involved in caring for clients with dementia. Additional education sessions were provided by local educators, using CEC resources and materials.

Feedback from the TOP 5 education sessions was positive, with many staff members acknowledging the potential benefits of TOP 5 for their own sites. Many sites were keen to begin implementation as soon as possible following the education sessions.

TOP 5 education sessions for Ambulance Service of NSW staff consisted of a CEC staff member providing a PowerPoint presentation to PTOs during their induction training in 2014. In addition, a TOP 5 article and frequently asked questions document were promoted through the Ambulance Service of NSW’s internal Sirens newsletter and published on their intranet. TOP 5 resources and information were co-branded Ambulance Service of NSW and CEC. These were distributed to each local manager and relationship manager at participating sites for dissemination and promotion to local staff. Additional TOP 5 education sessions have been presented during training to new PTOs, with positive feedback.
6.1.7 Communication

A regular bi-monthly TOP 5 newsletter was developed by the CEC and disseminated to all participating sites who were encouraged to distribute it to their staff, networks and facilities.

Regular monthly teleconferences were held by the CEC with each LSL and their associated RACF, community service, and an Ambulance Service of NSW representative. The teleconferences were held to ensure local TOP 5 processes were running smoothly and to identify and solve any potential barriers faced during implementation. The teleconferences were a good opportunity for referral sites to learn how the TOP 5 process was working across the different health care settings in their area and to discuss the effectiveness of the transfer of the TOP 5 information between these services.

All site representatives were encouraged to share any barriers and solutions, effective examples of strategies or stories where TOP 5 worked particularly well for a carer, staff member or individual with dementia, or any questions they would like to ask other sites regarding how they have successfully implemented TOP 5. The feedback received was used for the evaluation, the content of the newsletter, and for updates from the CEC project team to the Steering Committee.

6.1.8 Scope of implementation

a. Hospitals

The TOP 5 program was implemented in all pre-admission/pero-operative clinics and EDs at participating lead hospital sites, where TOP 5 had been implemented in wards in 2012-13.

Local implementation teams were formed at all participating sites, and were encouraged to develop their own local processes for identifying potential TOP 5 candidates when they presented to ED, or the pre-admission clinic. Once identified, staff initiated developing TOP 5 strategies with the carers. Guidance was provided by the CEC project team when necessary, but this was a local decision to both acknowledge local processes and to ensure adequate resources and staff were available.

A few participating hospitals opted to have the ASET staff complete the TOP 5 form with carers of patients with dementia who presented to the ED. This was optimal for some sites as ASET staff were more likely to engage and spend more time with potential TOP 5 patients and their carers, than general ED staff.

b. Residential Aged Care Facilities (RACFs)

Participating RACFs decided which residents or units in their facility would benefit from the implementation of the TOP 5 program. Some sites targeted specific units within their facility, whereas other sites opted to roll out TOP 5 across the whole facility.

Some RACF sites chose to conduct a staged implementation. For example, a TOP 5 was commenced upon admission for new residents with dementia. Existing residents with dementia had a TOP 5 initiated for them throughout the implementation period.

Some long-term RACF residents had developed a close relationship with staff members, and had minimal to zero interactions with carers. In these cases, staff members completed the TOP 5 form in-lieu of the carer as they had first-hand knowledge of the resident’s unique needs and preferences. Some RACF sites opted to focus on completing one to two strategies per resident during the admission process, due to time and support constraints, and completed the remaining strategies at a later date when more time was available.
All sites elected to keep the TOP 5 forms in a centralised folder within their site. The folder could be accessed by all staff at any time, and enabled staff to retrieve and photocopy the form on request, or when the resident was transferred to another health care setting.

c. Community
All participating community services implemented TOP 5 during the in-home client assessment for clients with dementia. The TOP 5 form was kept in a safe and easily identified place inside the client’s home where all staff members had access to it.

Additionally, two community services implemented TOP 5 in their dementia day care centres. The TOP 5 was initiated at the day care centre and a copy of the form was left at the centre. The carer then took another copy of the form home with them. The carer was advised to take the TOP 5 form with them if their loved one was transferred to hospital from home. The facility copy of the form was kept in a centralised folder, which all staff had access to.

d. Ambulance Service of NSW
Ambulance Service of NSW sites were not expected to initiate TOP 5 for clients. This would not have been feasible because patients were not under the care of paramedics for a long period of time and it was not practical to sit down with carers to develop strategies.

Instead, Ambulance Service of NSW sites were involved at an awareness level. Paramedics and PTOs were educated about the TOP 5 program to support transfers of care and had an awareness of what the TOP 5 form looked like, what to do with the form on transfer to a health care facility, and how to utilise the TOP 5 strategies, if appropriate.

6.1.9 Midway site visits
Midway site visits were conducted at each participating hospital site during March and April 2015. A CEC TOP 5 project team member visited each hospital and invited the RACF, community service and Ambulance Service of NSW representatives to attend. Some referral linkages opted to dial-in to these site visits. The visits were an opportunity for each site to demonstrate their progress with the program and share their achievements and processes with other site representatives. Some sites had previously requested additional TOP 5 staff education sessions, which were conducted during the midway site visit by the CEC project team.

6.1.10 Final site visits
Final site visits by the CEC project team were conducted at selected hospitals and their referral linkages in August 2015 to ensure final data collection was optimal and to highlight local implementation. Sites were selected based on the extent of implementation and data collection achieved.

The hospitals’ associated RACF, community service and Ambulance Service of NSW representatives were invited to attend. Local sustainability and possible future directions of TOP 5 after the study period ended were also discussed.
7. EVALUATION

7.1 Overview

Data collection and analysis were achieved using a mixed method approach involving both qualitative and quantitative data (Appendix H, I & J).

Questionnaire surveys were used to collect qualitative (open-ended) and quantitative (close-ended) data from staff, carers and LSLs.

A minimum of six completed staff surveys were requested from each site at each survey point - baseline, six-months post implementation and 12-months post implementation. One LSL survey was requested from each site at midway and final point. All survey data were collected, in either hard copy or electronic format, and entered into a secure database at the CEC. The tables on the following pages (Table 1, 2, 3 and 4) summarise the total number of participants, number of questions and domains examined in each survey.

Additional quantitative data were obtained from the Incident Information Management System (IIMS) and department data files, and were used for evaluation of TOP 5 implementation. The effectiveness of the TOP 5 program on patient care was measured by several clinical indicators:

- reported falls incidents
- reported behavioural disturbances
- completed behavioural assessments
- use of chemical and mechanical restraints

Department data files and IIMS were used to collect quantitative data on clinical indicators during the pre-implementation period (i.e. from August 2013 to July 2014) and post-implementation period (i.e. from August 2014 to August 2015). Table 5 and 6 outline the inclusion criteria and information collected from department data files and IIMS, respectively. This data was only available from hospital EDs and some RACFs, limiting the analysis of these indicators.

Data entry and analyses were performed by the CEC TOP 5 project team using IBM SPSS Statistics 21.

7.2 Midway report and final survey (Local Site Liaison)

Each LSL was asked to provide information about how the TOP 5 process was implemented in their facility. The first tool used to collect this information was the midway survey, which was distributed via email to each LSL at the midway (6 month mark) of the study period. This midway survey focused on local implementation, processes and barriers, as well as the impact of CEC support on implementation (see Appendix K).

A second LSL survey was emailed to sites at the final point (12 month mark) of the study period. This survey focused on exploring implementation processes further and the potential benefits of implementing TOP 5 experienced by sites (see Appendix L).
Table 1. Local Site Liaison Survey

<table>
<thead>
<tr>
<th>Study Stage</th>
<th>No. of Participants</th>
<th>No. of Questions</th>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midway (6 month)</td>
<td>22</td>
<td>34</td>
<td>Implementation process, Staff awareness, knowledge and attitude, Carer attitude, Enablers of successful implementation, Barriers encountered during implementation, Satisfaction with available resources and support</td>
</tr>
<tr>
<td>Final (12 month)</td>
<td>21</td>
<td>37</td>
<td>In addition to “Midway” local site liaison survey above: Perceived impact on staff, Perceived impact on dementia patients, Perceived impact on transition of care, Potential confounders, Potential benefits</td>
</tr>
</tbody>
</table>

Source: SurveyMonkey online survey

7.3 Staff survey

Staff surveys were completed at all participating sites by pre-admission/peri-operative hospital staff, ED hospital staff, RACF staff, community service staff and Ambulance Service of NSW staff (including paramedics and PTOs). Staff members were required to read the participant information sheet, sign the consent form (see Appendix M) prior to completing the relevant survey.

Staff surveys were conducted at three points and consisted of:

- Baseline survey – surveys were completed by staff members prior to receiving any formal TOP 5 education. This survey focused on staff knowledge and confidence in caring for individuals with dementia. It also focused on work environments and transfer of care between services (see Appendix N).
- 6 months post implementation survey – the midway survey retained the same questions that were asked in the baseline survey. In addition, staff were asked questions regarding their use, acceptability and impact of TOP 5 at their site (see Appendix O).
- 12 months post-implementation survey – baseline and 6 month post-implementation survey questions were retained, with additional open ended questions to allow for more comprehensive staff responses regarding the impact and benefits of TOP 5, when caring for individuals living with dementia (See Appendix P).

The surveys were provided to each LSL who was responsible for ensuring their completion by at least six staff members at their site and returning them to the CEC, via email or post. Due to staff turnover at each site it was not always possible to ensure the same staff members were surveyed at each survey point (baseline, 6 months post implementation and 12 months post implementation).
Table 2. Staff Survey (Intervention sites)

<table>
<thead>
<tr>
<th>Study Stage</th>
<th>No. of Participants</th>
<th>No. of Questions</th>
<th>Domain</th>
</tr>
</thead>
</table>
| Baseline                           | 397                 | 5-8              | Knowledge of dementia  
Confidence in dementia care  
Satisfaction with available resources and supports  
Attitude towards carer involvement  
Transferral of care information |
| 6 months post-implementation       | 142                 | 21-35            | In addition to “baseline” staff survey above:  
Work satisfaction in dementia care  
Awareness and understanding of TOP 5  
Evaluation of implementation process  
Perceived impact on staff  
Perceived impact on dementia patients  
Perceived impact on carers  
Perceived impact on transition of care |
| 12 months post-implementation      | 146                 | 21-42            | Similar as “6 months-post implementation” staff survey above           |

Source: Self-administered questionnaire and collected via email or mail

7.4 Carer survey

Each participating site was provided with carer surveys, to disseminate to the carers they had engaged with when initiating a TOP 5. The carer survey assessed the carer’s satisfaction with the way staff had communicated with them, their satisfaction of the TOP 5 process, and their perceptions of its impact on the care of their loved one. Prior to completing the carer survey, carers were asked to sign a consent form explaining the purpose of the research study and the confidentiality of information collected (see Appendix Q). The carer was also given the opportunity to ask questions about the survey and the research study (see Appendix R).

Each site decided the best time for their staff to give the carer a survey to complete. The surveys were accompanied with a self-addressed, pre-paid envelope addressed to the CEC. This allowed carers to take the survey home to complete, if they preferred and return it on their own time. This meant that staff did not have to chase or follow up the carers for the completed surveys.

Table 3. Carer Survey

<table>
<thead>
<tr>
<th>Study Stage</th>
<th>No. of Participants</th>
<th>No. of Questions</th>
<th>Domain</th>
</tr>
</thead>
</table>
| During implementation period       | 41                  | 10               | Satisfaction with implementation process  
Perceived impact on staff  
Perceived impact on residents/patients  
Perceived impact on carers |

Source: Self-administered questionnaire and collected via email or mail
7.5 Quantitative indicators

Data on clinical indicators were collected using two methods – quantitative data from sites and IIMS data.

a. Quantitative data from sites

Data files were provided by the LSLs from the participating sites on a monthly basis. This method was also used in RACFs and EDs of the private hospitals, to extract data on the number of falls, behavioural disturbances, and mechanical and chemical restraint uses, as these sites did not have IIMS to electronically record these incidents. In addition, the total number of patients/residents, number of patients/residents with dementia and the number of behavioural assessment were obtained directly from all RACFs and EDs.

All data were collected based on the criteria specified by the CEC TOP 5 project team, as shown in Table 4. Copies of the data files were received electronically via emails and securely saved in the HP TRIM Records manager server at the CEC.

<table>
<thead>
<tr>
<th>Clinical Indicator</th>
<th>Measurement</th>
<th>Inclusion Criteria</th>
</tr>
</thead>
</table>
| Total number of patients/residents | • Total number of patients presented to individual ED, each month  
• Total number of residents in individual RACF, each month | • All residents/patients regardless of diagnosis  
• Residents admitted for respite in RACFs |
| Number of patients/residents with dementia | • Total number of patients presented to individual ED with dementia, each month  
• Total number of residents with dementia in individual RACF, each month | • Patients/residents with dementia only  
• All levels of dementia |
| Falls | • Total number of falls from all patients/residents in individual ED/RACF, each month  
• Total number of falls from patients/residents in individual ED/RACF with dementia, each month | • All types of falls |
| Behavioural disturbance | • Total number of incidences of behavioural disturbance from all patients/residents in individual ED/RACF, each month  
• Total number of incidences of behavioural disturbance from patients/residents with dementia in individual ED/RACF, each month | • Aggression, agitation and anxiety |
| Behavioural assessment | • Total number of patients reviewed by aged care service in individual ED, each month  
• Total number of behavioural assessments performed on residents with dementia in individual RACF, each month | • Number of routine assessments and post-incident assessments |
| Mechanical restraint | • Total number of all residents requiring mechanical restraint in individual RACF, each month  
• Total number of residents with dementia requiring mechanical restraint in individual RACF each month | • Environmental confinement, use of bedside rail, body holder and poesy vest |
| Chemical restraint | • Total number of all residents requiring chemical restraint in individual RACF, each month  
• Total number of residents with dementia requiring chemical restraint in individual RACF each month | • Non-regular medication used for the purpose of controlling agitated or aggressive behaviours. |

Source: Local Site Liaisons of RACF and ED
b. Incident Information Management System (IIMS) Data

The IIMS database is a clinical incident reporting system, and is available to all public hospitals and NSW health employees, who are required to report all identified clinical incidents, near misses and complaints at their facility.

IIMS was used to collect data on the number of falls and behavioural disturbances reported in the EDs of the public hospitals in the study. All IIMS data extraction was performed by the TOP 5 project team at the CEC, according to the inclusion criteria listed in Table 5. Incidents of medically-related falls (e.g. seizure and hypotension) and behavioural disturbances due to psychiatric illness, alcohol and substance abuses were excluded from the final analysis. All IIMS data were collated and entered into a secure database at CEC.

<table>
<thead>
<tr>
<th>Clinical Indicator</th>
<th>Measurement</th>
<th>Inclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls</td>
<td>• Total number of falls from all patients in individual ED, each month</td>
<td>• All types of falls</td>
</tr>
<tr>
<td></td>
<td>• Total number of falls from patients in individual ED with dementia, each month</td>
<td>• Aged ≥ 60 years</td>
</tr>
<tr>
<td></td>
<td>• Principal incidence as “Fall”</td>
<td>• Principal incidence as “Fall”</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred between 1/8/2013 and 31/8/2015</td>
<td>• Incidences occurred between 1/8/2013 and 31/8/2015</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred within areas of emergency departments</td>
<td>• Incidences occurred within areas of emergency departments</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred in patients with dementia, cognitive impairment or signs of dementia e.g. confusion</td>
<td>• Incidences occurred in patients with dementia, cognitive impairment or signs of dementia e.g. confusion</td>
</tr>
<tr>
<td>Behavioural disturbance</td>
<td>• Total number of incidences of behavioural disturbance from all patients in individual ED, each month</td>
<td>• Aggression, agitation and anxiety</td>
</tr>
<tr>
<td></td>
<td>• Total number of incidences of behavioural disturbance from patients with dementia in individual ED, each month</td>
<td>• Aged ≥ 60 years</td>
</tr>
<tr>
<td></td>
<td>• Principal incidence as “Aggression”, “Behaviour/ human performance”</td>
<td>• Principal incidence as “Aggression”, “Behaviour/ human performance”</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred between 1/8/2013 and 31/8/2015</td>
<td>• Incidences occurred between 1/8/2013 and 31/8/2015</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred within areas of emergency departments</td>
<td>• Incidences occurred within areas of emergency departments</td>
</tr>
<tr>
<td></td>
<td>• Incidences occurred in patients with dementia, cognitive impairment or signs of dementia e.g. confusion</td>
<td>• Incidences occurred in patients with dementia, cognitive impairment or signs of dementia e.g. confusion</td>
</tr>
</tbody>
</table>

Source: IIMS records for EDs at Public Hospitals

7.6 Analysis methodology

Statistical analyses were conducted using IBM SPSS Statistics 21. Descriptive statistics including mean, standard deviation, median and frequency in percentage, were calculated as appropriate. Differences between groups were analysed using Pearson’s Chi-squared test for binomial data and adjusted for Fisher’s exact test for sample size less than five. In the case of multiple group comparisons, analysis of variance (ANOVA) was performed, followed by post-hoc analysis using Scheffe’ tests, to examine significant differences between groups. Subgroup analyses were based on individual facility type i.e. RACF, ED, peri-operative unit, community service and Ambulance Service of NSW.

Open-ended questions were analysed using thematic analysis according to the guidelines of Braun and Clarke (2006). Each response was read several times to ensure thorough comprehension. Patterns within the data were identified and coded. Data with the same codes were collated and organised into key themes and subthemes (Braun and Clarke, 2006).
Interrupted time series was used to evaluate the impact of TOP 5 on falls, behavioural disturbances among patients/residents with dementia, taking into account background secular trends. Dickey-Fuller test was used to test for trend stationarity and Durbin-Watson test was used to test for autocorrelation. The change in level and trend of these variables after TOP 5 implementation were assessed using the models with and without seasonal adjustment.
8. FINDINGS

8.1 Information on participating sites

8.1.1 Hospitals by peer group

There were seven participating public hospitals across NSW involved in TOP 5 acting as lead sites. Five of these hospitals were located in five different metropolitan local health districts, and two hospitals were located in two different regional/rural local health districts in NSW.

The three private hospitals involved were all located in the Sydney metropolitan area and spanned three different provider groups. All three private hospitals had a pre-admission/peri-op clinic, however only one private hospital had an ED.

All public hospitals involved in the study had an ED and a pre-admission/peri-op clinic targeted for the implementation of TOP 5.

Seven public hospitals and three private hospitals completed the 12 month implementation.

<table>
<thead>
<tr>
<th>Site</th>
<th>Emergency Department</th>
<th>Pre-admission / peri-operative clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital A</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital B</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital C</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital D</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital E</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital F</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital G</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital H (private)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital I (private)</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital J (private)</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Table 6. Participating hospital facilities

Figure 2. TOP 5 hospitals by peer groups

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>Principal referral</td>
</tr>
<tr>
<td>B1</td>
<td>Major hospital group 1</td>
</tr>
<tr>
<td>B2</td>
<td>Major hospital group 2</td>
</tr>
<tr>
<td>C1</td>
<td>District group 1</td>
</tr>
<tr>
<td>PH</td>
<td>Private hospital</td>
</tr>
</tbody>
</table>
An additional private hospital involved in the original TOP 5 study was invited to continue with the TOP 5 Phase 2 study as a lead site. However lengthy ethics processes and approvals, and a lack of time and resources to adequately contribute to the program were given as significant barriers to participation. This private hospital was not included in the study evaluation.

8.1.2 Residential Aged Care Facilities
All participating hospitals nominated RACFs (total of 11) to participate in the study as their main referral linkages in caring for patients with dementia. The RACFs were geographically located in proximity to their associated hospital site.

Seven of the eleven RACFs completed the whole 12 months of implementation. Four RACFs withdrew from the study - either voluntarily, due to not implementing the TOP 5 program at their site; or non-response to follow up by the CEC project team. The sites that withdrew cited competing priorities, renovations to the facility, and improper implementation of TOP 5 at the start of the study by previous staff members who had since left facility as reasons for their withdrawal.

All participating public hospitals had at least one linked RACF complete the 12 month implementation period and one public hospital had two associated RACFs complete the implementation period (RACF B1 and RACF B2).

Seven RACF sites completed the 12 month implementation period

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of beds in facility</th>
<th>Number of secure dementia beds</th>
<th>Number of respite beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF A</td>
<td>61</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>RACF B1</td>
<td>62</td>
<td>16</td>
<td>0</td>
</tr>
<tr>
<td>RACF B2</td>
<td>53</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>RACF D</td>
<td>104</td>
<td>34</td>
<td>1</td>
</tr>
<tr>
<td>RACF F</td>
<td>82</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>RACF G</td>
<td>125</td>
<td>61</td>
<td>0</td>
</tr>
<tr>
<td>RACF I</td>
<td>60</td>
<td>20</td>
<td>0</td>
</tr>
</tbody>
</table>

Two private hospitals opted to nominate hospitals as their referral linkages instead of RACFs, as they did not have a particular RACF that they would transfer their patients to. Two referral hospitals agreed to participate in the TOP 5 program, however one referral hospital withdrew, citing they were not able to identify any potential TOP 5 patients at their site, and they did not have any patients transferred from the lead hospital site with a TOP 5 form in place, as reasons for their withdrawal.

The one referral hospital site that completed the 12 month implementation (RACF H) period was a public hospital specialising in sub-acute aged care rehabilitation.

8.1.3 Community Services
A total of ten community services were identified by lead hospital sites and agreed to participate in the TOP 5 Phase 2 study. Throughout the 12 month implementation period, two community sites withdrew from the study voluntarily and two sites withdrew, due to not implementing the TOP 5 program. The sites that withdrew cited
changes in legislation resulting in losing their contract to care for individuals with dementia, and staff changes throughout the implementation period, as reasons for their withdrawal.

Six community sites completed the 12 month implementation period.

<table>
<thead>
<tr>
<th>Table 8. Participating community services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site</td>
</tr>
<tr>
<td>Community A</td>
</tr>
<tr>
<td>Community B</td>
</tr>
<tr>
<td>Community D</td>
</tr>
<tr>
<td>Community E</td>
</tr>
<tr>
<td>Community G</td>
</tr>
<tr>
<td>Community J</td>
</tr>
</tbody>
</table>

8.1.4 Ambulance Service of NSW
A total of ten Ambulance Service of NSW sectors in NSW aligned with lead hospital locations, were invited, and agreed to participate in the TOP 5 program.

8.2 Using TOP 5

Key strategies used by sites who successfully implemented the TOP 5 program
The following strategies, case studies and quotes have been transcribed directly from staff surveys, LSLs surveys, midway and final site visits and regular teleconferences with participating sites.

**Hospital H**
With executive support and endorsement, Hospital H was able to successfully implement the TOP 5 program hospital-wide and had embedded the program as an ongoing hospital program. Adding to its success, Hospital H was also able to integrate the TOP 5 process in-to their Electronic Medical Record (EMR) system. Hospital staff were able access TOP 5 education and information online at any time, and also were able to access the carer prompts that are required to initiate a TOP 5. Staff were able to type the strategies that were developed with the carer directly into a free-text box on the computer. An online alert was also available to the LSL for quick identification of any TOP 5 patients within that facility at any one time. Staff found this process simple and straightforward and it enabled the LSL to follow up with any TOP 5 patients and carers.

Hospital H had an internal local implementation team who met on a regular basis to discuss the successes and barriers of the TOP 5 program at their site. CEC project team members were also invited to these meetings to receive feedback, provide updates at a project level and provide any assistance required. Communication between all staff involved was optimal and all local TOP 5 implementation team members were providing feedback to their respective teams and NUMs during their own team meetings. TOP 5 was also routinely reported to the hospital’s peak committee, the quality and safety committee and other clinical committees. Awareness of TOP 5 was high, across the whole hospital.

Staff at Hospital H said:

“Identifying and understanding dementia is very important in the area I work in as we have very little time to assess patients before surgery. Carers and relatives have many concerns and are usually very grateful for the recognition and implementation.”
RACF I
RACF I initiated TOP 5 for all of their residents within their high-care unit. The strategies were mainly developed by staff members, after consultation with senior care staff. A review of the residents’ care plans was also carried out while developing the strategies. The LSL was very involved throughout the duration of the study period, providing regular updates to the CEC project team and ensuring staff were aware of the importance of the program. RACF I had a few residents transferred to hospital with the TOP 5 form in place in the implementation period. Key to the success of implementing TOP 5, was the integration of TOP 5 into established processes. For example, during admission and initial assessment processes, and as part of daily care. The TOP 5 form was also standard documentation for transfer to another facility for all patients.

Community D
Community D implemented TOP 5 across a number of their services across the local health district (LHD), including their in-home client services and their dementia day care settings. TOP 5 was integrated and used on all new referrals/assessments of clients with a dementia diagnosis, or those who have been known to have a behavioural disturbance. TOP 5 was also rolled out to all existing clients.

Community D was a LHD-wide service, meaning that the facility was closely linked with Hospital D. This linkage meant the likelihood of a client with dementia coming from the community to hospital with their TOP 5 form was high. Due to this service linkage, staff at both hospital and community sites were able to advocate for permission to incorporate a TOP 5 alert in the EMR, which would benefit both Hospital D and Community D.

Staff at Community D could see the benefit of the program. As a result the implementation ran smoothly and effectively. Often, when the carers could not think of any relevant strategies, staff members were able to pick up simple strategies through general conversation and would advise the carers ‘this is a simple strategy that we can use!’.

TOP 5 was also implemented in the LHD local ‘dementia café’ to promote the program and provide resources. Community D had successful transfer of their clients to Hospital D with their TOP 5 information, during implementation.

Staff at Community D said:

“TOP 5 strategies do not have to be used often, but when they are used, they work a treat. It’s not always the same strategies that are used.”

“Carers can't believe that something so simple can make such a big difference”.

“We need to continue TOP 5 and spread the word, especially to the students, they’re really helpful for them too.”

“TOP 5 is very handy and helpful for everyone - carer and staff and clients. Best practice for the carer and Local Health District”.

“TOP 5 provides valuable information to enable professionals to work effectively with clients with dementia”.

“The TOP 5 program is great and I think it should be carried out in all services in the health system, to ensure a patient centred approach”.

“Spread the word of TOP 5 to the students (e.g. Certificate III and IV to include in the curriculum).”
To illustrate the practical application of TOP 5, a selection of strategies developed for patients, residents and clients, in hospitals, RACFs and community services are detailed below:

### Hospital sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital A</td>
<td>Surgical unit NUM in the hospital described how TOP 5 was effective in helping staff to understand why a patient would be found getting into a cupboard at around 3 o’clock every morning. When questioned why the patient would say he was “at work”, it was established that he had been an elevator repair workman. It helped to formulate a strategy that worked consistently for staff to understand and manage his behaviour.</td>
</tr>
<tr>
<td>Hospital B</td>
<td>A hospital staff member on night duty cared for a patient who became anxious and agitated at the same time every morning at 4am. When this was discussed with the family, staff were informed that the patient used to be a stock transport truck driver who had to have his truck loaded and be on the road by 4am every day. Once staff were made aware of this, when he got up and started pacing the floor at 4:00am staff would tell him that the truck was loaded and the replacement driver had the truck on the road. The patient would then settle with this simple explanation and go back to bed and sleep until daylight.</td>
</tr>
<tr>
<td>Hospital G</td>
<td>Hospital staff noted a patient with dementia would get very agitated very easily. Staff were made aware by the TOP 5 form that the patient loved movies and that the patients son would take her to the movies once a week which was a pleasant experience for her. To calm the patient down the hospital staff would talk about the latest movies and actors involved. The strategy proved to be very successful.</td>
</tr>
</tbody>
</table>

### Residential Aged Care Facility sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF D</td>
<td>RACF staff were aware that a resident was very religious. A strategy was developed to play hymns on a CD player while they attended to her personal needs. After ensuring that the resident had access to a CD player in her room with CDs, the music appeared to make the resident more relaxed and staff were able to attend to the resident’s personal hygiene without being verbally or physically harmed, as had occurred in the past.</td>
</tr>
<tr>
<td>RACF D</td>
<td>A female resident was very resistive to personal hygiene. Staff developed a TOP 5 form that stated that the resident was scared of deodorant, she did not like cream in her face and she did not like to shower (but would accept sponge). Strategies were developed and incorporated successfully. Her behaviours improved and incidents decreased. There were nil reported incidents with that particular resident, who had previously been quite difficult, since TOP 5 implementation 6 months ago.</td>
</tr>
<tr>
<td>RACF G</td>
<td>A TOP 5 strategy for a resident revealed that using the resident’s granddaughter’s name when initialising care delivery was very successful. The strategy was to state: “Ashleigh* has asked me to change you into these clothes”. The resident always complied when the strategy was utilised.</td>
</tr>
</tbody>
</table>

*Name has been changed*
### Community service sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community D</td>
<td>A male client with dementia was known to wander in a community dementia day care centre setting. His wife told staff that she usually offers him a cup of coffee when he starts to become agitated (coffee was one of life’s pleasures for this gentleman). The next time the gentleman tried to leave the day care centre, staff offered the client a cup of coffee and he walked away from the door and sat back down again. The strategy worked effectively.</td>
</tr>
<tr>
<td>Community J</td>
<td>A particular client who lived alone was severely cognitively impaired and worried about going to hospital. This client felt very reassured knowing that she had a TOP 5 in place. One of her TOP 5 strategies was that she didn’t want to be transferred anywhere without knowing her beloved pet cat was being looked after. She was happy to know that in an emergency, even if she is unable to tell anyone, it is on her form for a friend to be notified and to look after her cat. The client was likely to forget and ask if the cat is OK multiple times. With the TOP 5 information the staff were able to reassure her.</td>
</tr>
</tbody>
</table>

### 8.2.1 Case Studies - Transfer of care

#### Hospital G

At Hospital G, all pre-admission staff had been well educated on the TOP 5 program and process, and were implementing TOP 5 on suitable patients as they came through the pre-admission clinic. Pre-admission staff members did note, that although they were able to identify the TOP 5 strategies with the carer, they were not actually the staff who cared or managed the patient with dementia, and were unable to confirm if the TOP 5 strategies were useful in caring for patients with dementia.

Using the CEC education handouts, the LSL at Hospital G was able to hold an internal TOP 5 education session for some of the staff at the receiving ward, within the same hospital. The LSL noted that further TOP 5 education to the whole hospital would ensure the TOP 5 form is not thrown out and is kept with the patient as they move throughout the hospital to ensure continuity of care.

Transfer of care: pre-admission-to-ward

A patient was transferred to a ward from pre-admission with a TOP 5 form in place. The patient was very agitated so staff used her TOP 5 strategy, which was ‘make the patient a cup of tea’ and ‘rub her shoulders’. Feedback was received from the receiving ward to say TOP 5 strategies worked well to calm the patient down and staff were very grateful for the TOP 5.

Staff at Hospital G said:

“I think it is an excellent initiative. It is person-centered, involves the carers and can result in a calmer and more contented patient and it is also simple to develop”.

“[TOP 5] is very good and should be used for all patients with dementia. The carers have a wealth of knowledge and we need to tap into that.”

“The family were very happy that we took the time to understand their mother and individualise her care”.

...
Hospital A

ED staff at Hospital A were all educated on the TOP 5 program, by both the CEC project staff and the LSL at the hospital. The LSL provided numerous TOP 5 in-service sessions to ED with the local ASET nurse also incorporating TOP 5 into her regular in-services. This was a great local success, as the ED environment is very busy and a hard to reach target group for non-clinical education sessions. An ED representative was also selected to participate and attend TOP 5 meetings and site visits by the CEC and provide updates on behalf of the ED. ED staff were provided with a TOP 5 toolkit folder by the LSL, which included all the necessary staff and carer resources to implement a TOP 5. The LSL ensured resources were restocked weekly and that all staff were aware of its location. The persistence and dedication of the LSL ensured TOP 5 was implemented effectively in the ED of the hospital.

Transfer of care: ED-to-ward

An ASET nurse reported to the LSL that she was very familiar with a patient with diagnosis of dementia, who came in yesterday from a local RACF and has had many recent admissions through the ED. The nurse said she was able to complete a TOP 5 strategy form in less than 5 minutes, which assisted management of the patient in ED and during transfer to surgical ward. A visit to the surgical ward by the LSL revealed that not only did that patient have a TOP 5 in place, but all the other patients in the four bed ward had TOP 5s in place. All staff attending clinical handover stated they were aware of, and utilise, the form regularly, to assist with patient management. There are TOP 5 posters on display along the corridor. The Surgical Ward Clinical Nurse Educator reported that she encouraged staff to complete TOP 5 forms for all patients presenting with dementia &/or confusion, often completing them herself.

Transfer of care: Hospital-to-Ambulance-to-RACF

A patient with dementia who was quite strong, was being transported, and managed to unstrap himself and get off of the trolley. The staff members utilised the TOP 5 strategies (talking about his dog and grandkids) and were able to calm the patient down. These TOP 5 strategies were passed on to the receiving nursing home.

Staff at Hospital A said:

“TOP 5 gives an understanding of the patient’s cognitive/behavioural issues. Clinically, we can plan effectively how to manage a client, with a minimum distress to clients /family/carers”.

“Important information, that would previously have been missed, is now passed on”.

“Carers state they like to be involved, and it reassures them about the quality care delivered in hospitals”.

“Carers feel more part of the patient’s hospital journey”.

“TOP 5 gives nursing staff a focus of conversation during handover”.

TOP 5 gives an understanding of the patient’s cognitive/behavioural issues. Clinically, we can plan effectively how to manage a client, with a minimum distress to clients /family/carers”. Important information, that would previously have been missed, is now passed on”. Carers state they like to be involved, and it reassures them about the quality care delivered in hospitals”. Carers feel more part of the patient’s hospital journey”. TOP 5 gives nursing staff a focus of conversation during handover". 
Community G

Community G implemented TOP 5 for clients who visited their dementia day care centre. TOP 5 was always promoted by the LSL at local team meetings, and staff were asked to keep a look out for potential TOP 5 patients. TOP 5 forms would be initiated with carers at the centre and carers were given a copy of the TOP 5 form to take home. Strategies were adapted to suit the day care centre setting.

Transfer of care: Community to RACF
A particular client would become very agitated, anxious and upset if one of the male staff took him to the toilet. At home, his wife assisted with personal care, so it was not an identified issue until he started requiring assistance at the day care centre. The strategy was discussed with the client’s wife, for a female staff member to assist the client. The client did not become distressed or anxious when assisted by a female. This information was transferred to the RACF when the client was permanently placed. This information would have helped alleviate some of the agitation associated with the transition to a RACF, for the client.

Staff at Community G said:

“Carer advised ‘Will be good for others to learn how to deal with certain behaviours without me having to explain all the time’.

“I think it is extremely useful as these strategies can avoid anxiety and challenging behaviours from the client/patient, thus creating a more peaceful and happier environment for others”.

“A great way to formalise the passing of information from one to another carer/community carers to residential carer, so that there is less stress for the client or carer”.

“Good tool to use to discuss care/communication needs of dementia clients with carers. Carers are then more involved in care and leads to more holistic care of the client”.

RACF G

RACF G implemented TOP 5 for both existing and new residents with dementia. TOP 5 was added to admission packs for residents who were being admitted to the facility, with all staff educated on how to complete the form with the carer. Often, as carers were very overwhelmed during the transition, the registered nurse (RN) would make notes on the TOP 5 form as they picked up strategies from conversations with the carer and families. The LSL noted that when a resident came in with a TOP 5 form already in place, it was of great assistance, as the RACF staff were able to quickly adopt the strategies and become familiar with the resident, as well as use the extra time to discuss other important care issues.

Transfer of care: Hospital to RACF
Staff received a patient from the hospital with behaviours that were difficult to manage. The hospital had completed a TOP 5 with the family and this was sent through to the RACF prior to admission. This allowed staff at the facility to prepare the environment for the patient’s arrival and eliminate as many triggers as possible.

Staff at RACF G said:

“It is a case where care can be delivered immediately causing minimum distress. Provides a continuity between different carers and care settings.”
RACF B1
Staff at RACF B1 chose to implement TOP 5 by identifying all existing residents in the facility who would benefit from a TOP 5 and implementing for those residents first. New residents were also identified during the admission process as potential TOP 5 candidates, and staff worked with carers to identify strategies. The original TOP 5 form was kept in a centralised folder and a copy of the form placed in a ready-made transfer pack for each resident in case they were transferred to another health facility. Stickers were used to alert staff, and strategies were imported into the resident’s care plan. Being a rural site, Hospital B and its associated referral linkages were geographically close. Staff members across all participating sites in this area were familiar with each other, and had already established a line of communication between sites prior to the TOP 5 implementation. This RACF also reported that during the study period, at least two residents came into the facility from hospital with a TOP 5 form already in place. This communication between sites was an enabler for this hub to transfer the TOP 5 information between sites.

Transfer of care: RACF to Community
Staff admitted a resident from the community who had been cared for by her daughter for a long time. The daughter had been diagnosed with terminal cancer and had to unwillingly relinquish the responsibility of caring for her mum. It was an emotional time for the whole family, however the community care workers ensured that the transition was stress-free. The resident had TOP 5 strategies implemented by the community staff, in consultation with her daughter. Community staff reassured the daughter that the strategies would continue to be used at the RACF. On admission to the RACF, staff organised a case conference with the family, where staff discussed the TOP 5 strategies and incorporated them into the care plan. The transition of care was smooth and the resident settled in well. The family - especially the daughter - were very relieved and felt reassured that her mum would be well looked after and she could concentrate on her own health.

Staff at RACF B1 said:
“Resident admitted from community care who come in with a TOP 5 strategy form in place is helpful when managing the resident and settling them in a new environment”.

8.2.2 Case Studies - Team work

RACF H
From the start of implementation at RACF H, TOP 5 education was targeted at staff as a multi-disciplinary approach. Throughout the study period, this site was able to involve different teams in the TOP 5 process. The clinical care coordinator would highlight patients admitted who would benefit from a TOP 5, and refer them on to other staff throughout the site to initiate the TOP 5. Social workers, clinicians, nursing staff and Allied Health staff were all encouraged to develop TOP 5 strategies with the carers, ensure the strategies were available and carried out, and the transfer of the TOP 5 information to the receiving health care facility was successful. TOP 5 patients were also identified at case conferences, with all different levels of staff invited to attend and provide feedback on the TOP 5 process and strategies. RACF H also integrated TOP 5 education as part of the orientation to new staff members at the facility and promoted TOP 5 as a team approach, so that TOP 5 was not just left up to nursing staff to complete. As the facility was fairly small, it was easy to keep track of the TOP 5 patients.

Teamwork:
A patient was known to become rapidly distressed daily between 3 and 5pm, when the patient was normally drinking at home. The staff involved in her care were able to share the TOP 5 responsibilities, which included taking her for walks outside, completing puzzles and watching the news, to calm her down.
Staff at RACF H said:

“Family are thankful and agree that their loved one benefits from a TOP 5”.

“[TOP 5 is] easy to use, so there is more of a chance that it will be used, than complicated documentation”.

“Provides ongoing effective strategies for all staff, 24 hours a day”.

“We know things that enable us to provide more person centred care”.

“It has provided personal, directly applicable tips for unique solutions to patients suffering from compromising features of dementia”.

“Enables staff to get to know the patient better, therefore leading to patient satisfaction”.

“I think it is a fantastic contribution to reducing patient distress levels on the ward, and to improving staff satisfaction, coping with difficult behaviours”.

8.3 Implementation process

8.3.1 Staff education

LSLs across all participating health care settings reported that predominantly nursing staff and managers attended the TOP 5 education sessions provided by the CEC at the start of implementation. This finding was supported by information received during site visits and teleconferences, indicating that mainly nursing staff completed the TOP 5 form with the carer at all sites.

The majority (>70%) of LSLs rated the TOP 5 education sessions as either “useful” or “very useful”, with approximately 65 per cent of LSLs supplementing these education sessions with their own internal education sessions delivered to staff throughout the implementation period.

The following graphs present the LSL midway survey. Some similar questions were asked at the final LSL survey, however only results that were comparable and useful have been included.
Figure 3. Local Site Liaison survey: Breakdown by profession of staff attending the TOP 5 education sessions provided by CEC across health care settings.

Table 9. Local Site Liaison survey: Additional education sessions for TOP 5.

<table>
<thead>
<tr>
<th>Have you subsequently provided any additional internal education sessions to staff?</th>
<th>Community Service</th>
<th>ED</th>
<th>RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>67%</td>
<td>80%</td>
<td>67%</td>
</tr>
<tr>
<td>No</td>
<td>33%</td>
<td>20%</td>
<td>33%</td>
</tr>
</tbody>
</table>

If yes, how were these education sessions delivered to staff?

<table>
<thead>
<tr>
<th>Delivery Method</th>
<th>Community Service</th>
<th>ED</th>
<th>RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbally</td>
<td>25%</td>
<td>38%</td>
<td>75%</td>
</tr>
<tr>
<td>Printed handout</td>
<td>0%</td>
<td>13%</td>
<td>25%</td>
</tr>
<tr>
<td>TOP 5 Powerpoint</td>
<td>75%</td>
<td>13%</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>25%</td>
<td>0%</td>
</tr>
</tbody>
</table>

8.3.2 TOP 5 local implementation team

The majority of community services and ED sites had their own local implementation team (>60%), compared to 50 per cent of RACF sites. Local implementation teams comprised a diverse mix of staff, across the different participating health care settings. Sites were encouraged to identify local staff to invite to participate in implementation teams.

Hospital local implementation teams typically consisted of: nursing staff, allied health staff, general managers/director of nursing and midwifery and carer support staff.
Community local implementation teams commonly consisted of nursing staff, administration staff and other unspecified health care staff.

RACF local implementation teams commonly consisted of nursing staff, general managers/director of nursing and midwifery, personal care assistants and diversional therapists.

All participating RACFs with a local implementation team reported that they regularly held team meetings for TOP 5, compared to only 35 per cent of hospital teams and 25 per cent of community teams.

This high level of engagement for RACFs may be due to RACF staff being the initiators and developers of TOP 5 for existing residents, and therefore more involved in the TOP 5 programs, than perhaps staff at other settings and were able to directly see the benefits for their residents. RACF sites reported their staff would meet regularly and develop relevant strategies as a team, with everyone having input. RACF staff members get to know the residents quite well, especially for long-term residents and come to know the resident’s behaviours, which can often change over time. They were the ones most knowledgeable and capable to develop the strategies for the residents. Some of the residents did not have a carer or family member to communicate the TOP 5 strategies, so staff members took on this responsibility. Regular meetings were vital for RACFs to ensure the strategies were developed in a timely manner and reviewed regularly.

LSLs at RACF sites that had a local TOP 5 implementation team, confirmed that the local team was extremely involved in promoting TOP 5 within their site. In contrast, LSLs at community sites reported that the internal team’s involvement was average, and LSLs at hospital sites reported that staff in EDs were only somewhat involved in regular team meetings.

Compared to hospital and community sites, RACFs participated in the TOP 5 program more cohesively as a team. Staff actively encouraged and reminded each other of the TOP 5 process, throughout the implementation period. In addition, TOP 5 was integrated into daily resident care and their admission, discharge and transfer processes. The environment of some RACFs also played a part in successful implementation of TOP 5. Enablers included low staff turnover (in general nursing positions), and staff being able to work more closely together on a regular basis and in a smaller physical environment, compared to a community service or hospital environment. The lines of communication between staff members were easier to keep open and the ability to share information between the care team was less complicated.

LSLs from hospital and RACF sites that did not have a local implementation team reported that they did not meet with any other staff members to discuss their progress with TOP 5 (apart from the CEC project team), however community staff generally held regular meetings where local progress on the TOP 5 program was discussed.
Table 10. **Local Site Liaison survey: TOP 5 implementation team.**

<table>
<thead>
<tr>
<th>Do you have a TOP 5 implementation team?</th>
<th>Community Service</th>
<th>ED</th>
<th>RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>67%</td>
<td>60%</td>
<td>50%</td>
</tr>
<tr>
<td>No</td>
<td>33%</td>
<td>40%</td>
<td>50%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If yes, does your TOP 5 implementation team hold regular meetings?</th>
<th>Community Service</th>
<th>ED</th>
<th>RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25%</td>
<td>33%</td>
<td>100%</td>
</tr>
<tr>
<td>No</td>
<td>75%</td>
<td>67%</td>
<td>0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If no, do you and other staff members hold regular meetings to discuss process/progress with TOP 5?</th>
<th>Community Service</th>
<th>ED</th>
<th>RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>67%</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>No</td>
<td>33%</td>
<td>60%</td>
<td>60%</td>
</tr>
</tbody>
</table>

![Figure 4. Local Site Liaison Survey: Delegation of members of TOP 5 implementation team.](image-url)
8.3.3 TOP 5 resources and support
The TOP 5 toolkit, with supporting information and resources, was given to all sites at the beginning of the implementation period. The toolkit was found to be either “useful” or “very useful” by the LSLs across all participating sites.
All of the LSLs rated the CEC’s project support either ‘supportive’ or ‘very supportive’ throughout the implementation period. Project support from CEC was provided via regular teleconferences with sites, midway and final site visits, general enquires and support via phone and email, a quarterly newsletter and assisting with the development of local customised TOP 5 material. More than 70 per cent of LSLs reported that they felt the level of support provided by the CEC was sufficient to successfully implement the TOP 5 program at their site.

Figure 7. Local Site Liason Survey: How would you rate the level of support from CEC in implementing TOP 5?
8.3.4 Surveying carers

At the midway point of the study, 50 per cent of LSLs reported that either they, or their staff, were handing out the TOP 5 carer surveys to carers when initiating the TOP 5. Some sites had only commenced implementation of TOP 5 a few months prior to conducting the LSL midway survey, and staff engagement and awareness may not have been high at this point. This could have influenced the low number of carer surveys received (See section 7.4).

Additional barriers to handing out the carer surveys were identified by the LSLs and the CEC project team during regular teleconferences. Barriers included:

- a lack of time to distribute or follow up with surveys
- that carers were quite distressed or pre-occupied in ED to complete survey
- the physical environment – there was no privacy to complete
- information overload for some carers in pre-admission or peri-op
- lack of understanding amongst staff regarding the need for survey distribution
- staff completing TOP 5 for residents in RACFs, therefore no carers available to complete survey
- staff members in the community only see the client once, and there is no opportunity for follow up
- language barrier with some culturally and linguistic diverse carers
- some carers were cognitively impaired and found surveys difficult to complete even with assistance

The CEC project team and LSLs worked to identify possible solutions and workarounds to the barriers, and monitored and evaluated the site’s progress throughout the implementation period. The number of staff and LSLs reporting distribution of carer surveys increased towards the end of the study period.

LSLs reported that the carers response to the TOP 5 program was either positive or very positive throughout the whole implementation period.
8.3.5 Reporting TOP 5 progress to Executive

All of the community LSLs, and the majority of ED and RACF LSLs reported that they provided updates to their executive regarding the progress of TOP 5. It was important for sites to keep their local executive regularly updated on TOP 5, in order for the executive to become aware of any local issues or barriers as they arose. It also gave the LSLs an opportunity to escalate the risks and issues facing the implementation process.

8.3.6 Barriers and enablers to implementation

Throughout the implementation period, LSLs and staff at participating sites identified many barriers and enablers during implementation of the TOP 5 program. These were communicated via regular teleconferences with the CEC, staff and LSL TOP 5 surveys and site visits.
Enablers
Sites were able to identify enabling factors which helped the success of the implementation of TOP 5 at their sites. Common enablers across all sites included implementing TOP 5 using a team approach, the supply of the TOP 5 resources and project support via CEC, and endorsement/support from internal executives at their site (see Appendix S for more information).

Barriers
Common barriers across all participating sites included a lack of time to initiate/complete the TOP 5 form, staff attitudes, education of staff, and the infrequent need/use for TOP 5 (see Appendix S for more information). Staff were encouraged to share their barriers with the CEC project team and other participating sites, to work through possible solutions, to find out how other sites had overcome similar barriers, and to share learnings. Most sites were able to overcome their identified barriers in some way or develop a solution that worked with their own internal process.

8.4 Staff survey findings

8.4.1 Participants
A total of 685 staff members from 24 participating sites took part in the staff survey of TOP 5 Phase 2 study. Table 11 summarises the number of respondents for baseline, 6-months post implementation and 12-months post-implementation surveys, as stratified by different types of facility.

Table 11. Staff survey: Total number of respondents for each survey by facility types.

<table>
<thead>
<tr>
<th>Facility Type</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Baseline staff survey</strong></td>
<td></td>
</tr>
<tr>
<td>ED</td>
<td>99</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>64</td>
</tr>
<tr>
<td>RACF</td>
<td>136</td>
</tr>
<tr>
<td>Community Service</td>
<td>71</td>
</tr>
<tr>
<td>Ambulance Service of NSW</td>
<td>27</td>
</tr>
<tr>
<td>Subtotal</td>
<td>397</td>
</tr>
<tr>
<td><strong>6-month post-implementation staff survey</strong></td>
<td></td>
</tr>
<tr>
<td>ED</td>
<td>30</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>48</td>
</tr>
<tr>
<td>RACF</td>
<td>31</td>
</tr>
<tr>
<td>Community Service</td>
<td>20</td>
</tr>
<tr>
<td>Ambulance Service of NSW</td>
<td>13</td>
</tr>
<tr>
<td>Subtotal</td>
<td>142</td>
</tr>
<tr>
<td><strong>12-month post-implementation staff survey</strong></td>
<td></td>
</tr>
<tr>
<td>ED</td>
<td>37</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>42</td>
</tr>
<tr>
<td>RACF</td>
<td>32</td>
</tr>
<tr>
<td>Community Service</td>
<td>26</td>
</tr>
<tr>
<td>Ambulance Service of NSW</td>
<td>9</td>
</tr>
<tr>
<td>Subtotal</td>
<td>146</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td>685</td>
</tr>
</tbody>
</table>
As shown in Figure 11, more than 80 per cent of the surveys were completed by nursing staff, with the majority of respondents being registered nurses (38%) and assistant/enrolled nurses (AIN/EN) (24%). Senior nursing and administration staff (i.e. DON/NUM/TL and CNC/CNE/CNS) comprised 19 per cent, and medical officers, Allied Health staff and ambulance officers together accounted for the remaining 20 per cent of the respondents.

8.4.2 Staff attitude, knowledge and confidence

In the staff surveys, a number of questions were included to assess staff attitude, knowledge and confidence in caring for patients/residents with dementia. These questions were repeated at the baseline, 6-month and 12-month post-implementation surveys to evaluate the effect of TOP 5 on such variables over time.

Overall, the self-rated knowledge of dementia among staff was higher after TOP 5 was implemented, regardless of facility type. The improvement in staff knowledge of dementia was particularly pronounced in EDs, where 65 per cent of staff surveyed rated their knowledge of dementia as “good” or “excellent” prior to TOP 5 implementation (mean rating = 2.72, SD=0.59). This figure increased to 83 per cent (mean rating =2.94, SD=0.53; F= 4.13, p<0.05) at the end of the evaluation period (Figure 12).
Another positive effect of TOP 5 was noted in the level of staff confidence while managing patients/residents with dementia. Following the implementation of TOP 5, there were progressive improvements in staff confidence across facilities, particularly in community services, EDs and peri-operative units. Prior to the introduction of TOP 5, on a scale of 1-4, with 1 being “none” and 4 being “excellent”, the average self-rated confidences were 3.21 (SD=0.67) for community services, 2.97 (SD=0.58) for EDs and 2.58 (SD=0.79) for peri-operative units. At 12 months after TOP 5 implementation, the average level of confidence was significantly increased with mean ratings of 3.52 (SD=0.59; $F=4.13$, $p=0.04$), 3.30 (SD=0.52; $F=9.08$, $p=0.003$), 2.85 (SD=0.45; $F=4.01$, $p=0.04$) for community services, EDs and peri-operative units, respectively (Figure 13).
The confidence of staff to engage in discussions with carers about dementia was reported as “high” at the outset in RACFs, community services, EDs and peri-operative units. Although no significant difference was found between mean ratings of surveys submitted before and after TOP 5 implementation in any of the facilities, there was some improvement in the staff confidence in RACFs, EDs and peri-operative units, six months after TOP 5 was introduced (Table 12).

The confidence of staff to engage in discussions with carers about dementia was reported as “high” at the outset in RACFs, community services, EDs and peri-operative units. Although no significant difference was found between mean ratings of surveys submitted before and after TOP 5 implementation in any of the facilities, there was some improvement in the staff confidence in RACFs, EDs and peri-operative units, six months after TOP 5 was introduced (Table 12).
Table 12. **Staff survey**: How confident are you in engaging with carers in discussions about dementia/cognitive impairment?

<table>
<thead>
<tr>
<th></th>
<th>None/Little</th>
<th>Some</th>
<th>Average</th>
<th>Excellent</th>
<th>mean</th>
<th>F</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RACF</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>1%</td>
<td>8%</td>
<td>45%</td>
<td>46%</td>
<td>3.37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-month post-</td>
<td>0%</td>
<td>3%</td>
<td>32%</td>
<td>65%</td>
<td>3.61</td>
<td>1.15</td>
<td>0.33</td>
</tr>
<tr>
<td>implementation survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-month post-</td>
<td>3%</td>
<td>6%</td>
<td>41%</td>
<td>50%</td>
<td>3.38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>implementation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Community Service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>0%</td>
<td>6%</td>
<td>38%</td>
<td>56%</td>
<td>3.51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-month post-</td>
<td>5%</td>
<td>0%</td>
<td>40%</td>
<td>55%</td>
<td>3.45</td>
<td>0.52</td>
<td>0.60</td>
</tr>
<tr>
<td>implementation survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-month post-</td>
<td>0%</td>
<td>4%</td>
<td>56%</td>
<td>40%</td>
<td>3.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>implementation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ED</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>3.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-month post-</td>
<td>0%</td>
<td>3%</td>
<td>23%</td>
<td>73%</td>
<td>3.70</td>
<td>0.001</td>
<td>0.98</td>
</tr>
<tr>
<td>implementation survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-month post-</td>
<td>0%</td>
<td>0%</td>
<td>30%</td>
<td>70%</td>
<td>3.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>implementation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Peri-operative unit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>2%</td>
<td>17%</td>
<td>41%</td>
<td>41%</td>
<td>3.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-month post-</td>
<td>0%</td>
<td>4%</td>
<td>51%</td>
<td>45%</td>
<td>3.40</td>
<td>1.47</td>
<td>0.25</td>
</tr>
<tr>
<td>implementation survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-month post-</td>
<td>0%</td>
<td>7%</td>
<td>48%</td>
<td>45%</td>
<td>3.38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>implementation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In RACFs and community services, most of the staff respondents (up to 98%) were satisfied with the information, support and education provided by their facilities in caring for patients/residents with dementia before commencement of TOP 5, and the level of satisfaction remained equally high after the program was introduced. No statistically significant change was found between the surveys completed before and after TOP 5 was implemented.

In EDs, the proportion of staff who were satisfied with the level of information provided to them was significantly higher at 6-months post implementation (79%) and at 12-months post implementation (86%), compared to pre-implementation (44%). Similar findings were observed in ED staff satisfaction ratings of education offered by their facilities.

In Ambulance Service of NSW, there was a significant decrease in staff satisfaction ratings for information, support and education provided to them after TOP 5 implementation, which was likely due to the small number of participants in the 6-month and 12-month post-implementation surveys (Table 13).

Carer involvement was highly valued by staff in all participating facilities. More than 90 per cent of respondents regarded the involvement of carers as “extremely important” in managing patients/residents with dementia. These
responses were consistent across the three surveys conducted at baseline, 6-month and 12-month post-implementation periods, and no significant difference was found between surveys completed during these time points.

**Table 13. Staff survey**: Are you satisfied with the information, support and education provided to you by your facility in caring for patients/residents with dementia?

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>6-month post-implementation</th>
<th>12-month post-implementation</th>
<th>X²</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RACF</td>
<td>93%</td>
<td>86%</td>
<td>94%</td>
<td>3.89</td>
<td>0.42</td>
</tr>
<tr>
<td>Community Service</td>
<td>93%</td>
<td>95%</td>
<td>96%</td>
<td>0.45</td>
<td>0.79</td>
</tr>
<tr>
<td>ED</td>
<td>44%</td>
<td>79%</td>
<td>86%</td>
<td>25.87</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NSW Ambulance of Service</td>
<td>93%</td>
<td>46%</td>
<td>22%</td>
<td>18.81</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

| **Support**             |          |                            |                            |    |         |
| RACF                    | 92%      | 82%                        | 100%                       | 7.09 | 0.13    |
| Community Service       | 98%      | 95%                        | 100%                       | 1.77 | 0.41    |
| ED                      | 60%      | 70%                        | 72%                        | 4.12 | 0.13    |
| Ambulance Service of NSW| 93%      | 38%                        | 11%                        | 23.97 | <0.001 |

| **Education**           |          |                            |                            |    |         |
| RACF                    | 89%      | 93%                        | 88%                        | 1.28 | 0.86    |
| Community Service       | 84%      | 95%                        | 88%                        | 1.83 | 0.40    |
| ED                      | 42%      | 81%                        | 58%                        | 13.62 | 0.001 |
| Ambulance Service of NSW| 89%      | 23%                        | 11%                        | 25.06 | <0.001 |

Values are the proportion of satisfied respondents unless specified otherwise.
8.5 Staff awareness and attitude towards TOP 5

Apart from Ambulance Service of NSW, the majority of the staff respondents in RACFs, community service, EDs and peri-operative units (81-100%) were aware of the TOP 5 process and had attended education sessions on TOP 5 (60-90%) (Table 14).

Table 14. Staff survey: Staff awareness of TOP 5 program by facilities at 6-month and 12-month post-implementation surveys.

<table>
<thead>
<tr>
<th></th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you aware of TOP 5 process?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RACF</td>
<td>81%</td>
<td>94%</td>
</tr>
<tr>
<td>Community Service</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>ED</td>
<td>83%</td>
<td>86%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>92%</td>
<td>95%</td>
</tr>
<tr>
<td>Ambulance Service of NSW</td>
<td>15%</td>
<td>0%</td>
</tr>
<tr>
<td>Have you attended an education session on TOP 5?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RACF</td>
<td>70%</td>
<td>59%</td>
</tr>
<tr>
<td>Community Service</td>
<td>90%</td>
<td>83%</td>
</tr>
<tr>
<td>ED</td>
<td>67%</td>
<td>63%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>59%</td>
<td>66%</td>
</tr>
<tr>
<td>Ambulance Service of NSW</td>
<td>15%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Results of the LSLs surveys indicated the level of staff knowledge and awareness of TOP 5 ranged from “average” to “high” and was slightly enhanced at the end of the study period. The mean rating on the question increased from 3.09 (SD=0.61) at the 6-month post implementation survey point to 3.29 (SD=0.46) at 12-months post implementation.

A positive attitude by staff toward the TOP 5 program was also indicated in the LSL surveys. Approximately 69 per cent (mean rating =3.73, SD=0.55) of the LSL respondents reported a “good/enthusiastic” attitude of their staff towards TOP 5 at 6 months post implementation. This was increased to 86 per cent (mean rating =3.86, SD=0.57) at the final LSL survey (Figure 14).
Since the introduction of TOP 5, between 70 and 73 per cent of the respondents from community services, 40 to 47 per cent from EDs, 52 to 56 per cent from RACFs and 51 to 67 per cent from peri-operative units had initiated TOP 5 on at least one individual with dementia (Table 15).

Table 15. Staff survey: Proportion of respondents who had initiated a TOP 5 for patients/residents/clients with dementia at 6-month and 12-month post-implementation surveys.

<table>
<thead>
<tr>
<th></th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>52%</td>
<td>56%</td>
</tr>
<tr>
<td>Community Service</td>
<td>70%</td>
<td>73%</td>
</tr>
<tr>
<td>ED</td>
<td>40%</td>
<td>47%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>51%</td>
<td>67%</td>
</tr>
</tbody>
</table>

According to the LSL survey, where LSLs were asked how many TOP 5s had been initiated at their site, an estimated total of 831 TOP 5s had been initiated over the 12 month study period, with an average of 44 per site (range from 1 to 200). Of the 831 TOP 5s, 52.1 per cent (n=433) were initiated in EDs, 23.6 per cent (n=199) in community services and 24.3 per cent (n=202) in RACFs. The breakdown of the number by site is shown in Table 16.
Table 16. Local Site Liaison survey: Estimated number of TOP 5 initiated since implementation

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of TOP 5 initiated</th>
<th>Average number of TOP 5 initiated per month</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community Service</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community A</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Community B</td>
<td>50</td>
<td>4</td>
</tr>
<tr>
<td>Community D</td>
<td>90*</td>
<td>8</td>
</tr>
<tr>
<td>Community E</td>
<td>1</td>
<td>0.1</td>
</tr>
<tr>
<td>Community G</td>
<td>5</td>
<td>0.4</td>
</tr>
<tr>
<td>Community J</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>196</strong></td>
<td><strong>16</strong></td>
</tr>
<tr>
<td><strong>ED/Peri-operative unit</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital A</td>
<td>200</td>
<td>17</td>
</tr>
<tr>
<td>Hospital B</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Hospital C</td>
<td>2</td>
<td>0.2</td>
</tr>
<tr>
<td>Hospital D</td>
<td>90</td>
<td>8</td>
</tr>
<tr>
<td>Hospital F</td>
<td>17*</td>
<td>1</td>
</tr>
<tr>
<td>Hospital H (private)</td>
<td>52</td>
<td>4</td>
</tr>
<tr>
<td>Hospital I (private)</td>
<td>40</td>
<td>3</td>
</tr>
<tr>
<td>Hospital J (private)</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>433</strong></td>
<td><strong>36</strong></td>
</tr>
<tr>
<td><strong>RACF</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RACF B1</td>
<td>52</td>
<td>4</td>
</tr>
<tr>
<td>RACF D</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>RACF G</td>
<td>60</td>
<td>5</td>
</tr>
<tr>
<td>RACF H</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>RACF I</td>
<td>70</td>
<td>6</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>202</strong></td>
<td><strong>17</strong></td>
</tr>
<tr>
<td><strong>Grand total</strong></td>
<td><strong>831</strong></td>
<td><strong>32</strong></td>
</tr>
<tr>
<td><strong>Mean (per site)</strong></td>
<td><strong>44</strong></td>
<td>-</td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td><strong>1 - 200</strong></td>
<td>-</td>
</tr>
</tbody>
</table>

*Estimated median

For staff who had initiated a TOP 5, the majority obtained the information from family members or carers of the patients/residents. In RACFs and community services, staff at other facilities (e.g. hospital) were another important source of information for TOP 5.

The use of TOP 5 was evident across facilities in 6-month and 12-month post-implementation staff surveys. More than 80 per cent of the respondents indicated that they had implemented the TOP 5 strategies as part of the patients’/residents’ care (Table 17).
Table 17. Staff survey: Proportion of respondents who had implemented TOP 5 strategies as part of the patients’/resident’s care plan.

<table>
<thead>
<tr>
<th></th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>93%</td>
<td>89%</td>
</tr>
<tr>
<td>Community Service</td>
<td>86%</td>
<td>95%</td>
</tr>
<tr>
<td>ED</td>
<td>92%</td>
<td>81%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>100%</td>
<td>73%</td>
</tr>
</tbody>
</table>

8.6 Acceptability

The acceptability of TOP 5 by staff members in RACFs, community services, EDs and peri-operative units was evaluated in both 6-month and 12 month post-implementation staff surveys. In RACFs, community services and EDs, the majority of the staff who responded perceived the TOP 5 process as “easy” to “very easy”. In community services, although 50 per cent of the respondents reported some degree of difficulty in using TOP 5 at the 6-month surveys (mean rating=2.64, SD=0.74), this figure had significantly reduced to 5 per cent by the end of the study period (mean rating=3.05, SD=0.40; F=4.13, p<0.05). Similar results were observed in staff responses to the process of identifying patients/residents who could potentially benefit from TOP 5 (Figure 15).

Figure 15. Staff survey: Staff perception of TOP 5 process by facilities at 6-month and 12-month post-implementation surveys.
When asked about the time spent on TOP 5, the majority of staff respondents (up to 88%) agreed that it was not a time consuming process. With the exception of EDs, the proportion of staff who responded that the TOP 5 was “not time consuming” increased by 31 per cent in RACFs, 15 per cent in community services and 7 per cent in peri-operative units (Figure 16) 12 months after TOP 5 was implemented. This suggests that TOP 5 was well-received by the staff in these facilities.

Based on the information provided by the LSLs, the range of time it took to complete a TOP 5 form was 10 to 60 minutes, with an estimated average of 21 minutes. The results were in line with the study findings in Phase I (i.e. average of 24 minutes and actual times ranged between 15 and 40 minutes). When comparing all facility types, RACFs required the longest time to complete a TOP 5 form (i.e. estimated average of 32 minutes), while both EDs peri-operative units and community services spent an average of 18 minutes on each case. The variation observed between facilities could be explained by the differences in their care priorities and clinical settings, which determine the time available to spend on individual patient/resident/client communication.

8.7 Perceived impact of TOP 5

The perceived impact of TOP 5 on patients/residents, staff and carers was assessed in RACFs, EDs and peri-operative units at 6 months and 12 months after implementation. Overall, TOP 5 was considered an effective tool in managing patients/residents with dementia, by all staff respondents across facilities. As shown in Table 18, more than 80 per cent of the staff agreed that patients/residents were less agitated and more cooperative when
the TOP 5 strategies were used. 100 per cent of ED staff and the majority of RACF staff reported that they perceived a reduction in the use of chemical restraints since TOP 5 was introduced. No statistically significant difference was noted between responses obtained at 6 months and 12 months post implementation, suggesting that the positive effects of TOP 5 were sustained during the study period.

The majority of respondents agreed that carers appeared to be more satisfied with the care provided to their loved ones and fewer concerns had been raised by the family or carers since TOP 5 was initiated. An improvement in the carers’ attitude was evident in the peri-operative units, wherein the proportion of staff who reported that were “less concerns from the family” after TOP 5 implementation, had increased by 25 per cent at the end of the 12 month period. In addition, over 95 per cent of the staff perceived that TOP 5 made it easier for them to care for patients/residents with dementia.

Table 18. Staff survey: Proportion of respondents who agreed with the statements.

<table>
<thead>
<tr>
<th>(For patient/resident with TOP 5 implemented, did you feel the patient/resident became less agitated and distressed?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>89%</td>
<td>89%</td>
</tr>
<tr>
<td>ED</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>80%</td>
<td>94%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(For patient/resident with TOP 5 implemented, did you feel the patient/resident was more cooperative?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>90%</td>
<td>94%</td>
</tr>
<tr>
<td>ED</td>
<td>89%</td>
<td>95%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>86%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(For patient/resident with TOP 5 implemented, did you feel that less restraint (chemical) was required for the patient/resident?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>76%</td>
<td>80%</td>
</tr>
<tr>
<td>ED</td>
<td>100%</td>
<td>89%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(For patient/resident with TOP 5 implemented, did you feel that carers appeared confident/satisfied with the care provided?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>ED</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>91%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(For patient/resident with TOP 5 implemented, did you feel that less concern was raised by family?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>95%</td>
<td>88%</td>
</tr>
<tr>
<td>ED</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>75%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(For patients/residents with a TOP 5 implemented, were you better able to manage the patients/residents in their environment?)</th>
<th>6-months post implementation</th>
<th>12-months post-implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>95%</td>
<td>95%</td>
</tr>
<tr>
<td>ED</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Peri-operative unit</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
The reported impact of TOP 5 in EDs was particularly prominent. At 12 months post implementation, there was a significant increase in the proportion of staff (i.e. 47% increase, $X^2 = 5.60, p=0.02$) who agreed that there was less need for patient specials (an extra staff member needed to be with the patient constantly to ensure the patient’s safety) due to the TOP 5 (Figure 17). Furthermore, approximately 80 per cent of the LSLs from ED and peri-operative units, 60 per cent from RACFs and 50 per cent from community services reported that the use of TOP 5 helped to improve the communications between staff within the facilities, as well as strengthen their relationships with the other services or facilities.

8.8 Potential confounders

According to the information provided by the LSLs, there were no additional intervention programs for dementia care being concurrently initiated with TOP 5 in any of the participating sites, except for Hospital A and E. In these two hospitals, the Confused Hospitalised Older Persons (CHOPs) program was introduced near the end of the TOP 5 study, in July 2015. However, findings with adjustment for this factor yielded little difference from those without adjustment.

8.9 Carers

The response rate of the carer survey was relatively low (see Section 8.3 for issues cited by sites). Overall, a total of 41 carers of patients/residents with dementia responded to the carer survey, of which 43 per cent were recruited in EDs, 42 per cent in community services and 15 per cent in RACFs. In general, the majority of carers were “satisfied” to “very satisfied” with the TOP 5 information provided to them by staff (mean rating=4.25, SD=1.24). When satisfaction rates were compared across facility types, the satisfaction rating was much higher among carers of residents in RACFs (mean rating=4.83, SD=1.30) (Figure 18).
More than 80 per cent of the carer respondents agreed that their suggestions were well acknowledged and used by the staff in caring for their loved ones. The overall mean rating on a 4-point Likert scale was 3.23 (SD=0.78).

Approximately 92 per cent of the carer respondents felt more engaged with staff and involved in the care, as staff recognised the importance of their role in patient care (mean rating=3.39, SD=0.72). All carers of residents with dementia in RACFs (mean rating =3.50, SD=0.55) and community services (mean rating=3.56, SD=0.51) reported that their confidence in staff improved (Figure 19) and that the staff had communicated well with their loved ones, since the implementation of TOP 5 program (Figure 20).

In EDs, a small proportion of the respondents (23%) were either "unsure" or "disagreed" that the use of TOP 5 had increased their confidence in the staff, and 11 per cent were "unsure" the program had improved the communication between staff and patients. This could be partly explained by the short period of time patients usually spend in EDs, which resulted in lower level of interaction between staff and carers or patients. The short time period may not have been sufficient for carers to see the full effects of the TOP 5 strategies on managing their loved ones' behaviours.
Figure 19. Carer survey: carers’ perception on whether the use of TOP 5 has increased their confidence in the staff.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Mean rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>50%</td>
<td></td>
<td>50%</td>
<td></td>
<td>3.50</td>
</tr>
<tr>
<td>ED</td>
<td>33%</td>
<td>44%</td>
<td>17%</td>
<td>6%</td>
<td>3.06</td>
</tr>
<tr>
<td>Community Service</td>
<td>50%</td>
<td>44%</td>
<td></td>
<td></td>
<td>3.56</td>
</tr>
</tbody>
</table>

Rating scores: Disagree = 1, Unsure = 2, Agree = 3, Strongly agree = 4

Figure 20. Carer survey: carers’ perception on whether the staff had communicated well with their loved ones.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Mean rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>50%</td>
<td></td>
<td>50%</td>
<td></td>
<td>3.50</td>
</tr>
<tr>
<td>ED</td>
<td>28%</td>
<td>61%</td>
<td></td>
<td>11%</td>
<td>3.17</td>
</tr>
<tr>
<td>Community Service</td>
<td>44%</td>
<td>56%</td>
<td></td>
<td></td>
<td>3.44</td>
</tr>
</tbody>
</table>

Rating scores: Disagree = 1, Unsure = 2, Agree = 3, Strongly agree = 4
Approximately 90 per cent of carers of patients/residents with dementia agreed that TOP 5 was effectively implemented and beneficial to overall patient care, particularly in RACFs (mean rating= 3.67, SD=0.52) (Figure 21).

Overall, 66 per cent of the carers either “agreed” or “strongly agreed” that TOP 5 was effective in settling patients/residents with dementia. Approximately 63 per cent of the carers from community services (mean rating=3.00, SD=0.89), 67% from EDs (mean rating=2.89, SD=0.90) and 66 per cent from RACFs (mean rating=2.83, SD=1.17) perceived that their loved ones were less anxious, since TOP 5 was implemented (Figure 22).
In EDs, carers’ perceptions of TOP 5 use during the transition of care were also evaluated. Over the study period, 56 per cent (n=10) of carer respondents from EDs stated their loved ones were transferred to RACFs. Sixty per cent of the respondents were “satisfied” and the remaining 40% were “very satisfied” with the overall transfer process.

8.10 Transfer of care with TOP 5

People with dementia routinely transfer between health care settings (hospital, RACF and community). In this study, it was intended that the TOP 5 strategies accompany the patient on this journey, to ensure personalised care is seamlessly communicated. There was a statistically significant increase between the 6-month and 12-month staff survey ($X^2 = 6.01, p< 0.05$) for RACFs reporting that a resident returned from hospital or other service with a TOP 5 form (Figure 23).

Figure 23. Staff survey: For RACF, did your facility ever receive a resident back from a hospital or other service, accompanied by a TOP 5 form to provide personalised tips for care?

Fifty per cent of patients who were transferred with a TOP 5 form in place were transferred from hospital to a RACF. All health care settings reported that TOP 5 information accompanied the resident/patient with dementia, when they were transferred to another facility ensuring continuous personalised care. A small improvement in the frequency of community services receiving (care of) clients with a TOP 5 form in place was noted, supporting the increased use of TOP 5 during transitions of care; however this was not statistically significant. The number of community service clients transferred from the hospital and RACFs were equal.

Findings indicate that the use of TOP 5 strategies increased during the study period, particularly in the hospital setting. The TOP 5 forms were widely used by all health care settings as the tool to communicate this information during transitions of care between the hospital and RACF and community services (Figure 24).
TOP 5 information was more likely to be passed on to paramedics or PTOs if the patient was being transferred from a RACF or community service to the hospital. However, 100 per cent of paramedics/PTOs surveyed at the end of the implementation period indicated they had not received education and were not aware of TOP 5. These results are likely due to the small sample size (n=9) and the fact that the paramedics/PTOs who completed the 6-month post-implementation staff survey were different to those that completed the 12-month post implementation staff survey and may have been different to the original group receiving education (Figure 25).
8.11 Data Limitations

Survey results are subjected to inherent biases in the self-reporting approach e.g. social desirability bias, over- or under-estimation depending on the perceived feeling of the respondents at the time, and variation in interpretation of the question.

Staff surveys conducted at baseline, 6-month and 12-month post-implementation period may not have been completed by the same respondents.

The number of respondents for the Ambulance Service of NSW was relatively low and only a fraction of the respondents had attended TOP 5 education. Caution is required when interpreting the results from this group.

The number of behavioural assessments carried out on residents may not have been a good indicator of the impact of TOP 5 on care in certain RACFs, as it was routinely collected, regardless of the resident’s mental status.
8.12. Quantitative findings

8.12.1 Falls

In RACFs, most of the sites reported difficulties in retrieving data on the number of falls that occurred in their facilities. As a result, only one RACF (i.e. RACF I) provided a complete set of data for the whole evaluation period 12 months prior to the study and 12 months during the study (from August 2013 to August 2015). In this RACF, a total of 614 falls by residents with dementia were reported, over the 24-months evaluation period. Prior to the implementation of TOP 5, there was an average of 28 falls reported for residents with dementia each month. After TOP 5 was implemented, the average number of reported falls by residents with dementia dropped to 20 per month. Figure 26 shows the numbers and trends of falls in RACF I before and after TOP 5 was introduced. Results from the interrupted time series analysis revealed a statistically significant downward trend in falls, since TOP 5 was implemented (p<0.001). After controlling for seasonal effects, there was an estimated reduction of 8.44 falls reported per month for residents with dementia with TOP 5 in place (Table 19).

The number of falls by patients with dementia reported in EDs was low, with a total of 68 incidents recorded across 8 sites over the entire study period (range from zero to three falls per month, for each site). This low rate of reported falls was not surprising, as patients often spend only short period of time (< 4 hours) in ED, before being discharged or admitted to wards. It was not possible to make a reliable statistical inference due to the low number of reported falls, and the impact of TOP 5 on falls was not analysed in participating EDs.

Figure 26. Falls by patients with dementia in RACF before and after TOP 5 implementation.
### Table 19 Estimated time series effects of TOP 5 on the number of falls in RACF I with and without seasonal adjustment.

<table>
<thead>
<tr>
<th></th>
<th>Coefficients of model I (without seasonal adjustment)</th>
<th>Coefficients of model II (with seasonal adjustment)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>28.3***</td>
<td>28.3***</td>
</tr>
<tr>
<td>TOP 5 intervention</td>
<td>-8.60***</td>
<td>-8.44***</td>
</tr>
<tr>
<td>Time trend</td>
<td>-0.08</td>
<td>-0.10</td>
</tr>
<tr>
<td>Seasonal effect</td>
<td>-</td>
<td>-0.05</td>
</tr>
</tbody>
</table>

***p < 0.001

#### 8.12.2 Behavioural disturbances

Incidences of behavioural disturbances in patients with dementia were rarely reported in EDs. Throughout the evaluation period, only 27 incidents of behavioural disturbances were recorded in IIMS across the eight participating EDs for patients with dementia (ranged from zero to three incidences per month), and therefore statistical inferences were not possible.

In RACFs, data on behavioural disturbances was either incomplete, or unavailable, for all sites, except RACF I. However, the number of behavioural disturbances reported for residents with dementia in RACF I was relatively low, with an average of six incidents of behavioural disturbance reported each month (ranged from 0 to 16 per month). Further analysis found no statistically significant difference in the rate of reported behavioural disturbance among residents with dementia, before and after TOP 5 implementation.

#### 8.12.3 Behavioural assessments

Data on the number of behavioural assessments performed on patients/residents with dementia were largely unavailable due to difficulties in data extraction and tracking. Although two RACFs managed to provide incomplete data on this item, most of the assessments were performed as routine practices to meet funding or regulatory requirements, and therefore, were not reflective of the effect of TOP 5.

#### 8.12.4 Use of chemical and mechanical restraints

Data on the use of chemical and mechanical restraints were unavailable from all participating sites and these items were not included in the final analysis.

#### 8.12.5 Limitations

A number of barriers were encountered during quantitative data collection. Data collection using this process of direct recording and collection was found to be time consuming by many staff and was incomplete for clinical indicators at several sites.

Many local site liaisons from the RACFs found it time consuming and difficult to retrieve data on reported falls and behavioural disturbances, especially during the baseline evaluation period before the TOP 5 program was implemented (August 2013-July 2014). High staff turnover among RACF LSLs resulted in a disjointed implementation of TOP 5 at some RACFs, which also limited the data collection.
In many RACFs, data was recorded and stored as hard copies and data retrieval would have had to have been carried out manually, which became a laborious task for the staff involved. The problem was compounded by heavy workload in some RACF sites, making it difficult to achieve the data requirements for the study.

A National Emergency Access Target (NEAT) in NSW is that 90 per cent of all patients in ED must be discharged or admitted to hospital within 4 hours of their admission. The likely reason that the number of falls or behavioural disturbances that were reported in EDs was low across all participating hospitals, is patients usually do not stay long in the ED environment. In several sites, there was no incidence of falls or behavioural disturbances reported throughout the entire study period.

The number of behavioural assessments completed in RACFs was found to be a poor indicator to measure the effect of TOP 5, as they were routinely completed for most residents, regardless of the residents’ mental status. A common indication for the use of anti-psychotics in patients with dementia is to reduce agitation and aggressive behaviour. In RACFs, anti-psychotic medications were often prescribed as a regular medication for residents with dementia. It was not possible to collect data on the use of anti-psychotics for controlling periods of escalated agitation or aggressive behaviour (chemical restraint) in residents with dementia.

In EDs, insufficient time due to patient care and other priorities were also major issues. As a result, data on both chemical and mechanical restraints was not collected.

The low number of reported falls and behavioural disturbances extracted from the IIMS database are likely an under-representation, as the data was self-reported by staff. This may have resulted in unreliable data due to the exclusion of incidents that occurred without their knowledge, or minor incidents with no adverse outcome not being reported.
9. CONCLUSION

This research study builds on the results of the TOP 5 Phase 1 study, which concluded that TOP 5 is a low cost, patient based communication strategy for patient care. It is associated with improvements in patient outcomes, safety, carer experience and staff satisfaction when used in a hospital setting for patients with dementia.

In this study, the benefits of TOP 5 for staff, carers and patients within the specific health care setting (hospital, RACF and community services), and during transfer of care between health care settings, were found to be significant.

The implementation of TOP 5 was supported by a robust education program, which likely contributed to the improved staff knowledge and confidence when caring for people with dementia, particularly with RACFs, community services and EDs. Staff confidence, their self-reported knowledge of dementia, and satisfaction with the information provided to them during the study were high and significantly increased over time. TOP 5 promoted collaboration between staff and carers as valued members of the health care team. This is fundamental to supporting a patient based model of care and including carers as valued members of the health care team. Through engaging with carers to better understand the patient with dementia, staff were able to use this unique information to personalise care. Both carers and staff felt that the use of TOP 5 strategies contributed to a reduction in anxiety and behavioural disturbances for individuals with dementia, resulting in an overall perception of being more 'settled' and co-operative.

The negative risks associated with the use of anti-psychotics to manage behaviour in the elderly, particularly those with dementia, are becoming more apparent in research evidence, including higher mortality rates and increased risk of stroke. Importantly, a perceived reduction in the use of chemical restraints (anti-psychotic use) to manage acute behavioural disturbances in patients with dementia, was noted by staff during our study, most significantly in RACFs. The success of the TOP 5 strategies in managing behaviours supports the use of TOP 5 as an alternative to pharmacological management and a key to the provision of safer care. In addition, a reduction in the use of anti-psychotics represents an opportunity for potential cost savings.

Falls in hospital are a significant risk for patients with dementia and are a financial burden to services due to increases in length of stay and care required. A link between the implementation of TOP 5 and a statistically significant reduction in the number of reported falls was found at one RACF. The roll out of TOP 5 at this RACF was considered to be exemplary by the project team. Key to the success of implementing TOP 5 was the integration of TOP 5 into established processes and the championing of TOP 5 by the LSL. For example, TOP 5 was incorporated into admission and initial assessment processes and as part of daily care planning. The TOP 5 form was also standard documentation for transfer to another facility, for all patients from this particular RACF.

The uptake of TOP 5 across all facilities was widespread. An estimated 44 TOP 5s per site were initiated during the study period, with the majority occurring in EDs. A high proportion of staff (80%) self-reported they had implemented a TOP 5 as part of patient/resident/client care. TOP 5 was acknowledged as an easy process to implement, and both staff and carers considered it to be beneficial for the person with dementia. Developing a TOP 5 was found to be a quick process with an average of 21 minutes required for completion of a TOP 5 form. This is comparable to the results from the first TOP 5 study in the inpatients setting which found an average of 24 minutes was required to complete the TOP 5 form.
The extension of the use of TOP 5 in transfers of care between hospitals, RACFs and community services highlighted its benefits in improved communication, seamless personalised care and reduced patient anxiety. The findings indicate that the use of TOP 5 strategies increased during the study period, particularly in the hospital setting, and the TOP 5 forms were widely used by all health care settings as the tool to communicate this information during transfer of care between hospitals, RACFs and community services. Staff also found that the use of TOP 5 in transfers of care resulted in improved communication between staff within facilities and strengthened relationships with other services. These benefits highlight the effectiveness of TOP 5 as a useful tool for communicating this information between health care settings.

Paramedics and PTOs need to be educated about the TOP 5 program to ensure the TOP 5 strategies are handed over to the receiving facility. Findings from this study highlight the need to raise awareness of TOP 5 among paramedics/PTOs, as they are a critical factor in the successful transfer of TOP 5 information between health care settings.

A number of issues with data collection were encountered during the study and may have prevented a complete understanding of the benefits and impact of TOP 5 across the continuum of care. Quantitative data (reported incidents of falls and behaviour disturbances) were extracted from IIMS for hospitals. Unfortunately, an electronic system was not available at most RACFs and community services where data was directly recorded in paper-based a database and collected via retrospective audits. Both methods are resource intensive and facilities were unable to collect this data in a reliable or regular way, resulting in incomplete data that was excluded from the analysis.

The results of the study support the use of TOP 5 as a valuable communication tool to be used when caring for individuals living with dementia, across the continuum of care, and reflect similar results found in the first study. TOP 5 engages staff, carers and individuals with dementia in a collaborative relationship that improves the safety of care, the quality of the individual and carer experience, is easy to use and is associated with potential reduction in costs.
10. FUTURE OPPORTUNITIES

This study focused on the impact and communication of TOP 5 strategies during transitions of care for individuals with dementia, between health services: hospital, RACF, community and ambulance. The results highlight the benefits of using TOP 5 to communicate patient information across various health service settings. Clinical teams noted improved communication between team members and with carers. Clinicians also noted improved communication between clinical teams from referral sites. Carers felt more confident to share vital information with clinicians and also felt valued as part of the health care team. Clinical staff indicated TOP 5 improved their knowledge and understanding of dementia and caring for older persons while in hospital. Carers and staff perceived reduced anxiety and behavioural issues, when using TOP 5 to care for patients with dementia.

These benefits present opportunities for a broader application of the TOP 5 program. A number of sites in the study have indicated that they will expand the roll out of TOP 5 across the whole facility, with 75 per cent including TOP 5 in routine staff training. At the final site visit, two sites detailed plans to develop packages focusing on the care of the older person with dementia and delirium, highlighting TOP 5 as a key communication tool. Similarly, the synergy of TOP 5 with other programs, such as Care of the Hospitalised Older Person (CHOPS) and falls prevention initiatives, provides an opportunity to deliver a more cohesive approach to the implementation of these programs. RACFs noted the value of including the TOP 5 in the admission process and have commenced this initiative.

The findings support the broader application of TOP 5 for all people who experience difficulties with communication, across a range of health care settings. This could include children and adults with intellectual disability, people recovering from stroke or traumatic brain injuries, and people with generalised language or speech difficulties. TOP 5 could also be applied to people living with Huntington’s disease (which may or may not include some participants in this current study, but could be a focus area for future research).

A number of opportunities for collaboration with other agencies to promote the uptake of TOP 5 exist, and include:

- Integration into the National Standards for health service accreditation. The Australian Commission on Safety and Quality in Health Care (ACSQHC) has released an draft version of the revised national standards for comment. The draft 2nd edition national standards include strategies required to recognise and prevent delirium and to manage risks of harm from cognitive impairment. The personalisation of care is emphasised as a key priority throughout the draft standards, along with care coordination.
- Integration into Alzheimer’s Australia national initiatives, to promote boarder application.
- Collaboration with the Integrated Care Branch at the NSW Ministry of Health, to explore the further expansion of the implementation of TOP 5 across health facilities in NSW.
- Collaboration with eHealth NSW, to include the TOP 5 form and alerts in the electronic medical record (eMR).
- Engage with the NSW Multicultural Health Communication Service to develop TOP 5 resources in other languages.
- Link with universities providing courses for aged care to embed TOP 5 in the undergraduate curriculum.
- Further integration into CEC’s Partnering with Patients program to link with a wider strategy for promoting the engagement of patients, carers and families to improve the safety and quality of care. The CEC has extensive experience with managing State program implementation.
11. APPENDICES

A  -  TOP 5 process chart
B  -  TOP 5 Steering Committee membership
C  -  TOP 5 Steering Committee terms of reference
D  -  TOP 5 cover letter and Memorandum of Understanding (MoU)
E  -  TOP 5 Letter of invitation to selected hospital sites
F  -  Letter of invitation to selected residential aged care facilities
G  -  Letter of invitation to selected community sites
H  -  Example of TOP 5 evaluation components and due dates hospital
I  -  Example of TOP 5 evaluation components and due dates RACF
J  -  Example of TOP 5 evaluation components and due dates community
K  -  TOP 5 LSL midway survey
L  -  TOP 5 final survey
M  -  TOP 5 information and consent for staff member
N  -  TOP 5 RACF staff baseline survey (sample)
O  -  TOP 5 RACF staff 6-month survey (sample)
P  -  TOP 5 RACF staff 12-month survey (sample)
Q  -  TOP 5 information and consent for carer
R  -  TOP 5 carer survey
S  -  TOP 5 identified enablers and barriers
A person with dementia could be:
- Home alone with assistance from community services
- Home with a carer and assisted with community services

To assist community services staff
- Personalised strategies are developed to support care and communication with the client
- A TOP 5 identification tag is placed at the front of the home or in the entry way
- This identification tag informs community services where the TOP 5 strategies form is located in that person’s home
- All community service staff have the same information to support the client’s care
- TOP 5 is part of the care plan for individuals who are provided with supportive care while they are living in their own home

TOP 5 in the Home

A person with dementia could be:
- An Emergency admission – for an acute episode for something other than dementia
- Planned admission – for surgery/procedure or appointment

To assist staff in the emergency department or the pre-admission clinic
- Patients with dementia who present to ED or pre-admission clinic with a TOP 5 strategy form
- TOP 5 strategy form is placed in the patients clinical notes and an identification tag placed on top of the patient’s bedside or clinical notes to alert clinical staff of strategies
- For patients with dementia, a TOP 5 can be initiated by an ASET or Aged Care nurse (if appropriate)
- If the patient is transferred to another ward or discharged to another facility, the TOP 5 information should go with the patient

TOP 5 in Hospital

A person with dementia could be:
- In a residential care facility permanently as they can no longer live in their own home
- In respite accommodation for a short term

To assist staff in the residential facilities
- TOP 5 strategies are developed by staff talking with the carer/family. An information brochure is provided to the family
- Strategies are reviewed regularly and changed when required
- Strategies can be incorporated into the resident’s care plan
- The TOP 5 strategy forms are to be kept in a central place where all staff can access them
- If the resident is a new admission and comes from a hospital with a TOP 5 strategy form, the form is forwarded for staff to discuss strategies with the carer/family

TOP 5 in Residential Facilities
### TOP 5 PHASE 2 Program Steering Committee

**Clinical Excellence Commission**

**Membership List**

<table>
<thead>
<tr>
<th>Current Member</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kathleen Ryan (Chair)</td>
<td>Director of Clinical Governance</td>
</tr>
<tr>
<td></td>
<td>Mid North Coast Local Health District (LHD)</td>
</tr>
<tr>
<td>Maureen Strudwick</td>
<td>Carer Support Unit, Facilitator TOP 5</td>
</tr>
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<td></td>
<td>Central Coast LHD</td>
</tr>
<tr>
<td>Dr John Dobrohotoff</td>
<td>Clinical Director and Senior Staff Specialist Old Age Psychiatrist Specialist, Mental Health Service for Older People, Central Coast LHD</td>
</tr>
<tr>
<td>Professor Rosalie Viney</td>
<td>Health Economics and Director, Centre for Health Economics Research and Evaluation</td>
</tr>
<tr>
<td></td>
<td>University of Technology, Sydney</td>
</tr>
<tr>
<td>Dr Karen Luxford</td>
<td>Director Patient Based Care</td>
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<td></td>
<td>Clinical Excellence Commission</td>
</tr>
<tr>
<td>Anne Cumming</td>
<td>Project Manager, Cognitive Impairment Project, Australian Commission Safety &amp; Quality Healthcare Commission</td>
</tr>
<tr>
<td>Anthea Temple</td>
<td>ACI Aged Health Network Clinician</td>
</tr>
<tr>
<td>Janice Oliver</td>
<td>Manager Carer Program – Ambulatory and Primary Health Care, South Eastern Sydney Local Health District (SESLHD)</td>
</tr>
<tr>
<td>Mary Borg</td>
<td>CEC Consumer Advisor</td>
</tr>
<tr>
<td>Colleen Rivers</td>
<td>Policy &amp; Consultancy Manager</td>
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<td></td>
<td>Aged &amp; Community Services Australia</td>
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<tr>
<td>Michelle Shiel</td>
<td>Manager, Low Acuity Care</td>
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<td></td>
<td>Ambulance Service of NSW</td>
</tr>
<tr>
<td>Natalie Cook</td>
<td>State Coordinator &amp; Senior Policy Advisor</td>
</tr>
<tr>
<td></td>
<td>NSW Medicare Locals</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
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</tr>
<tr>
<td>Anne Axam</td>
<td>Project Coordinator, Patient Based Care</td>
</tr>
<tr>
<td>Erin Gilmore</td>
<td>TOP 5 Project Officer</td>
</tr>
<tr>
<td>Virginia Armour</td>
<td>TOP 5 Acting Program Manager, Patient Based Care</td>
</tr>
</tbody>
</table>
Appendix C

TOP 5 Phase 2 Steering Committee
Terms of Reference

Primary Purpose
The purpose of the TOP 5 Steering Committee is to oversee the implementation of a 20 month program to support the extended use of TOP 5 for Patients with dementia in referral services associated with hospitals including community services, residential aged care facilities and the Ambulance Service of NSW.

Role of the TOP 5 Steering Committee
To advise the Clinical Excellence Commission (CEC), Directorate of Patient Based Care by:

• providing guidance regarding implementation, including site engagement and material development;
• overseeing achievement of program objectives;
• providing input into program evaluation;
• advising on program risks as they arise;
• advising and participating when required, on dissemination and promotion of program outcomes.

Meeting Schedule
Meetings will be held at least four times per year. (20 month program)

Reporting Structure
The TOP 5 minutes will be provided to the Partnering With Patients Advisory Committee (PWPAC) and other CEC committees as appropriate.

Chair
Ms Kathleen Ryan (Executive Director of Clinical Governance, Mid North Coast Local Health District)

Quorum
Half of the membership plus one in attendance.

Committee Membership
• Chair and appointed individuals with expertise in clinical governance, service delivery, dementia care, carer support programs, clinical expertise (acute & community), health economics and patient/family experience.
• Other expertise can be co-opted on a short-term or ad hoc basis depending on the subject matter or requirements.
• The CEC will provide secretariat support.
• Membership will be reviewed by the CEC on an annual basis.
Appendix D

25 July 2014

Dear

TOP 5 Program – Memorandum of Understanding

Following initial conversations with XX from your facility, we are pleased to hear that XXXX have agreed to participate in the Clinical Excellence Commission’s (CEC) TOP 5 program.

As you may be aware, the TOP 5 program was granted ethics approval from a lead Committee, the Northern Sydney Local Health District Human Research Ethics Committee (NSLHD HREC) in June 2014. The program has been deemed ‘negligible risk’, meaning there are no foreseeable risks of harm or discomfort to any participant who will be involved in the TOP 5 program. A copy of this ethics approval is attached for your information.

The CEC would like to offer your site a Memorandum of Understanding (MOU) in place of Site Specific Ethics Application (SSA). The attached MOU describes the expected cooperative relationship between CEC and XXXX and outlines the terms and duration under which the CEC will conduct the TOP 5 program and evaluation.

Could you please review and sign the MOU if you agree to these terms. Once signed, the MOU can be returned via email and will be signed by a representative from the CEC. A final copy with signatures from both parties will then be sent to you for your records.

The project team at the CEC is committed to working collaboratively with your facility and staff in the implementation and evaluation of this program.

For further information on TOP 5, please contact Program Manager, [email protected], on [9269 5517].

Yours sincerely,

Dr Karen Luxford
Director, Patient Based Care
Memorandum of Understanding

Between:
The Clinical Excellence Commission
ABN: 96874573624

AND

XXXXXXXXXXXXXXXXXXXXXXXX
ABN: XXXXXXXXXXXX

IN RELATION TO:
TOP 5 Program

July 2014 to August 2015
MOU number: 1
MEMORANDUM OF UNDERSTANDING

PART 1: PARTIES

This Memorandum is between:

1.1 The **NSW CLINICAL EXCELLENCE COMMISSION** (“the CEC”), being a statutory health corporation established in accordance with section 41 of the Health Services Act 1997

AND

1.2 The **XX** (“XX”)

PART 2: LEAD HUMAN RESEARCH ETHICS COMMITTEE APPROVAL

2.1.1 The CEC has ethics approval from the Northern Sydney Local health District (NSLHD) Human Research Ethics Committee (HREC). **NSLHD reference: 1209-270M**

2.1.2 Title: Evaluation of the integration of carer knowledge to improve inpatient care for dementia patients.

2.1.3 **HREC reference: LNR/12/HAWKE/259 (approval rate ‘negligible risk’)**

PART 3: AGREEMENT

3.1 The parties will cooperate with each other to achieve the objectives of the **“Evaluation of the integration of carer knowledge to improve inpatient care for dementia patients”** for the TOP 5 program.

3.2 As signatory to this memorandum the party (stated at 1.2) agrees to provide timely data as requested, to the best of its ability, and contribute to the evaluation process for the duration of the agreement.

3.3 The party (as stated in 1.2) agrees to nominate a local site liaison officer as a person for contact and liaison with the CEC regarding project and data collection.

3.4 The CEC agrees to provide the relevant education, training, material resources and contact details for a project officer who will act as a key liaison for the project and discussions about provision of evaluation data, for the duration of the agreement.
3.5 CEC agrees to keep data confidential and private. Only de-identified, anonymous data will be included in the final report.

3.6 The CEC agrees to provide a copy of the final report regarding study findings to the party stated at 1.2.

PART 4: VERIFICATION

The terms in this Memorandum of Understanding are agreed to by:

................................................................. Date: ........................................

Professor Clifford Hughes (or designee)

Chief Executive Officer

CLINICAL EXCELLENCE COMMISSION

AND

................................................................. Date: ........................................

Chief Executive or General Manager (or designee)
Dear [Name]

The Directorate of Patient Based Care would like to invite your Local Health District to continue your involvement with the in the TOP 5 initiative. Your involvement to date has contributed to the successful outcomes of the first phase of this initiative, as highlighted by the recent confidential draft document sent to you which summarised the evaluation outcomes.

As you are aware, in 2012 the Clinical Excellence Commission (CEC) was granted funding from the HCF Health and Medical Research Foundation to investigate the use of TOP 5 in a number of public and private hospitals in NSW. The study investigated the integration of carer knowledge by staff into the care of hospitalised patients with dementia, using a model developed by the Central Coast Local Health District (TOP 5). The CEC has recently submitted the final report of the evaluation of the TOP 5 initiative to the funder.

Additional funding for a Phase 2 has now been granted by the HCF Research Foundation to the CEC to examine the use of TOP 5 in ‘referral’ linkages between hospitals, residential aged care facilities, NSW Ambulance services and home care for a period of 20 months.

For Phase 2, we are inviting the involvement of a select number of the previous lead sites. Shellharbour Hospital participated as a lead site in the TOP 5 Phase 1 initiative and embraced the concept to demonstrate good outcomes for hospitalised patients with dementia.

We would now like to invite [Name] Hospital to participate in Phase 2 which would involve the hospital forming a “hub” conduit to your local community for the extension of TOP 5 into associated services (e.g. residential aged care facilities; NSW Ambulance; home care). We believe that this approach will assist transitions of care, strengthening the use of TOP 5 in your LHD and building on the good work your health service has already undertaken in the inpatient setting. The evaluation of this new Phase will focus on the use and impact of TOP 5 in the associated services as well as the communication of carer’s information between these facilities and your hospital. Preliminary conversations with site liaison staff involved in Phase 1 indicate support and a willingness to be involved.

We look forward to receiving your response by 30 April 2014 as an indication of your ongoing support for patient based care. Please send responses to [Name] at [Email Address].

Level 13, 227 Elizabeth St, Sydney NSW 2000
Locked Bag A4062, Sydney South NSW 1235
Tel 61 2 9269 5500
Fax 61 2 9269 5599
www.cec.health.nsw.gov.au
Please feel free to contact me on [redacted] or [redacted].

Yours sincerely,

[redacted] Director,

Patient Based Care

Cc:  Director of Clinical Governance - [redacted]
     Local Site Liaison Contact - [redacted]
Dear

TOP 5 – ‘Supporting people with dementia in transitions of care’, Letter of Invitation

TOP 5 is an initiative that was developed in the Central Coast Local Health District to support patients with cognitive impairment and focuses on effective communication between patient, carers and staff with a personalised approach to care.

In 2012 the Clinical Excellence Commission (CEC) was granted funding from the HCF Health and Medical Research Foundation to investigate the use of TOP 5 in a number of public and private hospitals in NSW. The study investigated the integration of carer knowledge by staff into the care of hospitalised patients with dementia. The results have shown positive evidence of benefit for patients, carers and staff and for health services.

The CEC has been granted further funds for a second phase by the HCF Research Foundation. Phase 2 intends to investigate the use of TOP 5 in ‘referral’ linkages between hospital services, Residential Aged Care Facilities, NSW Ambulance services and community services for a period of 12 months. Hospitals in the initial study indicated that transition of information between the hospital and linkages such as NSW Ambulance, Community services and Residential Aged Care facilities could be beneficial for people with dementia.

A subset of 10 of the original hospitals have indicated an interest in participating in Phase 2 which will involve the hospitals forming a ‘hub’ conduit for the extension of TOP 5 into associated services. We believe that this approach will assist transitions of care, and improve communication between services.

The Directorate of Patient Based Care would like to invite your Residential Aged Care Facility (RACF) to participate in Phase 2 of the TOP 5 initiative. An outline of the evaluation methodology is attached to this letter. Preliminary conversations have taken place with XXXX in your area who have indicated patient transfer linkages with your RACF.
The project team at the CEC is committed to working collaboratively with your facility and staff in the
implementation and evaluation of this phase. CEC will work closely with a nominated local site liaison
person to consider appropriate education and supporting materials and relevant evaluation
components.

Based on Phase 1, we believe that this approach to personalised communication will enhance your
staff work environment using a simple strategy to integrate carer knowledge about patients.
We look forward to your response and nomination of a local site liaison contact.

Please feel free to contact me on [contact information] or [contact information].

For further information on TOP 5, please contact Program Manager, [contact information], on [contact information].

Yours sincerely,

Dr [Name]

Patient Based Care
TOP 5 – ‘Supporting people with dementia in transitions of care’, Letter of Invitation

TOP 5 is an initiative that was developed in the Central Coast Local Health District to support patients with cognitive impairment and focuses on effective communication between patient, carers and staff with a personalised approach to care.

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A subset of 10 of the original hospitals have indicated an interest in participating in Phase 2 which will involve the hospitals forming a ‘hub’ conduit for the extension of TOP 5 into associated services. We believe that this approach will assist transitions of care, and improve communication between services.
The Directorate of Patient Based Care would like to invite your community service to participate in Phase 2 of the TOP 5 initiative. An outline of the evaluation methodology is attached to this letter. Preliminary conversations have taken place with XXXX in your area who have indicated patient transfer linkages with your community service.

The project team at the CEC is committed to working collaboratively with your facility and staff in the implementation and evaluation of this phase. CEC will work closely with a nominated local site liaison person to consider appropriate education and supporting materials and relevant evaluation components.

Based on Phase 1, we believe that this approach to personalised communication will enhance your staff work environment using a simple strategy to integrate carer knowledge about patients.

We look forward to your response and nomination of a local site liaison contact.

Please feel free to contact me on [redacted] or [redacted].

For further information on TOP 5, please contact Program Manager, [redacted], on [redacted].

Yours sincerely,

Dr [redacted]

Patient Based Care
### TOP 5 Evaluation Components and Due Dates - Hospitals

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Evaluation Components</th>
<th>Due Date</th>
</tr>
</thead>
</table>
| **Pre-Implementation** | 1. Baseline Staff Surveys  
• Consent form and survey to be completed by at least 6 staff member prior to receiving TOP 5 education.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). | □ 31 July 2014         |
|                      | 2. Baseline Quantitative Data (for period between August 2013 – July 2014)  
• Refer to “Request for Baseline Data” document for details.  
• Please provide data broken down by month | □ 31 July 2014         |
| **During Implementation** | 3. Staff Surveys (at 6 months)  
• Consent form and survey to be completed by at least 6 staff member in late January 2015.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope) | □ 31 January 2015      |
|                      | 4. Midway Report Survey  
• Online process survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 January 2015      |
| **At Completion**    | 5. Quantitative Data (for period between August 2014 – July 2015)  
• Please provide data broken down by month.  
• Refer to “Request for Baseline Data” document for details | □ 31 July 2015         |
|                      | 6. Staff Surveys (at 12 months)  
• Consent form and survey to be completed by at least 6 staff member in July 2015.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). | □ 31 July 2015         |
|                      | 7. Final Report Survey  
• Online process survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 July 2015         |
### TOP 5 Evaluation Components and Due Dates - Residential Aged Care Facilities

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Evaluation Components</th>
<th>Due Date</th>
</tr>
</thead>
</table>
| **Pre-Implementation** | 1. Baseline Staff Surveys  
  - Consent form and survey to be completed by at least 6 staff member prior to receiving TOP 5 education.  
  - If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). | □ 31 July 2014 |
|                     | 2. Baseline Quantitative Data (for period between August 2013 – July 2014)  
  - Refer to “Request for Baseline Data” document for details.  
  - Please provide data broken down by month | □ 31 July 2014 |
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  - If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope) | □ 31 January 2015 |
|                     | 4. Midway Report Survey  
  - Online process survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 January 2015 |
| **At Completion**   | 5. Quantitative Data (for period between August 2014 – July 2015)  
  - Please provide data broken down by month.  
  - Refer to "Request for Baseline Data" document for details | □ 31 July 2015 |
|                     | 6. Staff Surveys (at 12 months)  
  - Consent form and survey to be completed by at least 6 staff member in July 2015.  
  - If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope) | □ 31 July 2015 |
|                     | 7. Final Report Survey  
  - Online process survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 July 2015 |
## TOP 5 Evaluation Components and Due Dates
### Community Services

<table>
<thead>
<tr>
<th>Time period</th>
<th>Evaluation Components</th>
<th>Due Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-Implementation</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 1. Baseline Staff Surveys | • Consent form and survey to be completed by at least 6 staff member prior to receiving TOP 5 education.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). | □ 31 July 2014 |
| **During Implementation** |                                                                                       |                |
| 2. Staff Surveys (at 6 months) | • Consent form and survey to be completed by at least 6 staff member prior to receiving TOP 5 education.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope) | □ 31 January 2015 |
| 3. Midway Report Survey | • Online survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 January 2015 |
| **At Completion** |                                                                                       |                |
| 4. Staff Surveys (at 12 months) | • Consent form and survey to be completed by at least 6 staff member prior to receiving TOP 5 education.  
• If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope) | □ 31 July 2015 |
| 5. Final Report Survey | • Online survey to be completed by the nominated Local Site Liaison. Survey link will be emailed three weeks prior to due date. | □ 31 July 2015 |
TOP 5 Phase 2- Local Site Liaison Midway Survey

The purpose of this survey is to gather information about how the ‘TOP 5’ process has been operating at your facility. There are no right or wrong answers, please respond according to the best of your knowledge. This survey can only be completed by one designated staff member at each facility.

This survey will take approximately 10 minutes to complete. You may click the 'back' button to revise previous answers, but if you close the survey before submitting it your answers will not be saved. Once you submit your survey, you cannot go back and redo.

If you have any questions or require any assistance in completing the survey please contact [redacted] TOP 5 Project Support Officer, on [redacted] or [redacted]

This feedback will form part of the ‘TOP 5’ evaluation. All information is kept confidential and your name or hospital will not be identified in anyway.

1. Name

2. Position title

3. Facility

4. The Clinical Excellence Commission (CEC) provided education about ‘TOP 5’ to your staff at your facility. Who attended these education sessions? Please select all relevant options.

- Doctors
- Nurses
- Allied Health
- Executives
- Managers
- Administration staff
- Carers
- Unknown
### TOP 5 Phase 2- Local Site Liaison Midway Survey

#### 5. In your opinion how useful were these education sessions?
- [ ] Not at all/ Very little
- [ ] Fairly useful
- [ ] Useful
- [ ] Very useful

#### 6. Have you subsequently provided any additional internal education sessions to staff?
- [ ] Yes
- [ ] No

#### 7. How were these education sessions delivered to staff? Please select all relevant options.
- [ ] Verbally
- [ ] Printed handout
- [ ] TOP 5 PowerPoint presentation
- [ ] Other (please specify)

#### 8. Do you have a local ‘TOP 5’ implementation team?
- [ ] Yes
- [ ] No
Appendix K

TOP 5 Phase 2 - Local Site Liaison Midway Survey

9. Please list type of staff involved in your 'TOP 5' implementation team. Please select all relevant options.

- Doctor
- Nurse
- Allied Health
- General Manager/Director of Nursing
- Carer support
- Administrative staff
- Personal care assistant
- Diversional therapist

Other (please specify)

10. Does your 'TOP 5' implementation team hold regular meetings?

- Yes
- No

11. How involved is the implementation team in promoting the 'TOP 5' uptake?

- None/ Very little
- Some
- Average
- Extremely

12. Do you and other staff members hold regular team meetings to discuss process/progress with 'TOP 5'?

- Yes
- No

13. Do you have a copy of the 'TOP 5' toolkit?

- Yes
- No
TOP 5 Phase 2- Local Site Liaison Midway Survey

14. How useful do you find the ‘TOP 5’ resources provided by the CEC?
   - Very useful
   - Useful
   - Fairly useful
   - Not at all/ Very little

15. Are there any other resources that could have been useful for your site to implement ‘TOP 5’?
   - Yes
   - No

16. What are the other resources that might be useful for your site to implement ‘TOP 5’?

17. How would you rate the level of staff knowledge and awareness about ‘TOP 5’?
   - Nil
   - Low
   - Average
   - High
   - Very high
TOP 5 Phase 2- Local Site Liaison Midway Survey

18. How would you rate the staff's attitudes towards the ‘TOP 5’ program?
   - Enthusiastic
   - Good
   - Neutral
   - Disinterested
   - Very disinterested

19. (For Residential Aged Care Facilities) In the last 6 months, have any residents with dementia/memory issues, been transferred/sent to other health care facilities (e.g. hospitals)?
   - Yes
   - No
   - N/A

20. Have you or your staff been providing carers with the carers survey to seek feedback about ‘TOP 5’?
   - Yes
   - No

21. What barriers have you encountered in providing carers with surveys?
## TOP 5 Phase 2- Local Site Liaison Midway Survey

### 22. How would you rate the reaction/response from carers when informed about ‘TOP 5’?
- Negative
- Somewhat negative
- Neutral
- Positive
- Very positive

### 23. Please estimate how many TOP 5’s have been initiated at your facility since starting use:

### 24. Please estimate the time (in minutes) it takes to complete a ‘TOP 5’ form:

### 25. Which type of staff member typically completes a ‘TOP 5’ form with the carer?
**Please select only one option.**
- Doctor
- Nurse
- Allied Health
- General Manager/Director of Nursing
- Carer support
- Administration staff
- Personal care assistant
- Diversional therapist
- Other (please specify)
TOP 5 Phase 2- Local Site Liaison Midway Survey

26. Do you (as local site liaison) provide updates to your executive regarding your progress with ‘TOP 5’?
   
   
   Yes
   
   No
   
   N/A

27. How do you provide these updates?

28. How would you rate the level of support from the Clinical Excellence Commission in implementing ‘TOP 5’?

   
   Very supportive
   
   Supportive
   
   Somewhat supportive
   
   Not at all/ Very little

29. Is there any other support from the CEC that may be helpful for the successful implementation of ‘TOP 5’ at your facility/service?

   
   Yes
   
   No

30. What other support from the CEC would be helpful for the successful implementation of 'TOP 5' at your facility/service?
31. Can you identify particular factors that have helped enable the successful implementation of ‘TOP 5’ in your facility/service?

[Blank space]

32. Can you identify any barriers you have faced in implementing ‘TOP 5’?

- Yes
- No

33. Can you briefly describe these barriers?

[Blank space]

34. Were you able to overcome these barriers?

- Yes
- No

35. How were these barriers addressed?

[Blank space]

36. Please share a short story/example (e.g. 1-2 paragraphs) of use and benefit of ‘TOP 5’, for a patient/resident/client at your facility, or one who was involved in a transfer of care. These stories are important and help to illustrate these benefit of ‘TOP 5’ in a practical way.

[Blank space]

Thank you for completing the TOP 5 Local Site Liaison Midway report. Your feedback is greatly appreciated.
The purpose of this survey is to gather information about how the TOP 5 process has been operating at your facility for the last 12 months. You may have completed a similar online survey for the TOP 5 program at the 6-month mark, back in February 2015.

There are no right or wrong answers, please respond according to the best of your knowledge. This survey can only be completed by one designated staff member at each facility.

This survey will take approximately 10 minutes to complete. You may click the ‘back’ button to revise previous answers, but if you close the survey before submitting it, your answers will not be saved. Once you submit your survey, you cannot go back and redo.

If you have any questions or require any assistance in completing the survey please contact [top 5 project support officer], TOP 5 Project Support Officer, on [top 5 email address].

This feedback will form part of the ‘TOP 5’ evaluation. All information is kept confidential and your name or hospital will not be identified in any way.

1. Name

2. Position title

3. Facility

4. Other than what was provided in the CEC's TOP 5 toolkit, are there any other resources that could have been useful for your facility to implement TOP 5?
   - Yes
   - No

5. What are the other resources that could have been useful for your facility to implement TOP 5?
6. How would you rate the level of staff knowledge and awareness about TOP 5?

- Nil
- Low
- Average
- High
- Very high

7. How would you rate the staff attitudes towards the TOP 5 program?

- Enthusiastic
- Good
- Neutral
- Disinterested
- Very disinterested

8. In the last 12 months, have any individuals with dementia/memory issues been transferred or sent from your service to other health care facilities with a TOP 5 in place (e.g. from hospital to RACF)?

- Yes
- No
- Don't know

9. Was the TOP 5 information successfully transferred with the individual?

- Yes
- No
- Don't know
### TOP 5 Phase 2 - Local Site Liaison Final Survey

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Why not?</td>
<td>[Blank]</td>
</tr>
</tbody>
</table>

11. Have you or your staff been providing carers with the carers survey to seek feedback about TOP 5?
- Yes
- No
- Don't know

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. What barriers have you encountered in providing carers with surveys?</td>
<td>[Blank]</td>
</tr>
</tbody>
</table>

13. How would you rate the reaction/response from carers when informed about TOP 5?
- Negative
- Somewhat negative
- Neutral
- Positive
- Very positive

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Please estimate how many TOP 5’s have been initiated at your facility over the last 12 months?</td>
<td>[Blank]</td>
</tr>
</tbody>
</table>
15. Please estimate the time it takes to complete a TOP 5 form (i.e. talking to the carers about the TOP 5 program and developing strategies)?

- 5 minutes
- 10 minutes
- 15 minutes
- 20 minutes
- 25+ minutes

16. Which type of staff member typically completes a TOP 5 form with the carer? Please select only one option.

- Doctor
- Nurse
- Allied Health
- General Manager/Director of Nursing
- Carer support
- Administration staff
- Personal care assistant
- Diversional therapist
- Other (please specify)

17. What would facilitate the continued use of the TOP 5 program at your facility/service?


18. Can you identify particular factors that have helped to implement TOP 5 in your facility/service?

- Yes
- No
### TOP 5 Phase 2- Local Site Liaison Final Survey

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Can you briefly describe those factors?</td>
<td></td>
</tr>
<tr>
<td>20. Can you identify any barriers you have faced in implementing TOP 5?</td>
<td>Yes</td>
</tr>
<tr>
<td>21. Can you briefly describe these barriers?</td>
<td></td>
</tr>
<tr>
<td>22. Were you able to overcome these barriers?</td>
<td>Yes</td>
</tr>
<tr>
<td>23. How were these barriers addressed?</td>
<td></td>
</tr>
<tr>
<td>24. Have there been any unforeseen benefits that the TOP 5 implementation has brought to your facility?</td>
<td>Yes</td>
</tr>
<tr>
<td>25. Please describe these benefits.</td>
<td></td>
</tr>
</tbody>
</table>
TOP 5 Phase 2- Local Site Liaison Final Survey

26. Since the implementation of TOP 5, have staff noticed improvements in anxiety, agitation and distress for individuals with a TOP 5?

- Yes
- No

27. Do you believe that TOP 5 has improved communication between clinical staff at your facility/service?

- Yes
- No

28. Do you believe that the use of TOP 5 strengthened your communication and relationships with other services to improve transitions of care in your area?

- Yes
- No

29. Please describe how.

30. Will you be planning to integrate TOP 5 into routine staff training (e.g. orientation sessions)?

- Yes
- No
TOP 5 Phase 2- Local Site Liaison Final Survey

31. To the best of your knowledge, did all relevant staff make use of the TOP 5 strategies in caring for individuals?

- Always
- Often
- Sometimes
- Never
- Unknown

32. Do you recall whether in the past 12 months if your site/service/ward implemented any significant new strategies or interventions targeting falls?

- Yes
- No

33. Please briefly describe and give approximate dates if known.


34. Do you recall whether in the past 12 months your site/service/ward implemented any significant new strategies or interventions targeting individuals with dementia (apart from TOP 5)?

- Yes
- No

35. Please briefly describe and give approximate dates if known.


TOP 5 Phase 2- Local Site Liaison Final Survey

36. Do you recall whether in the past 12 months your site/service/ward implemented any significant new strategies or interventions targeting individuals with aggressive behaviours?

☐ Yes
☐ No

37. Please briefly describe and give approximate dates if known

☐

38. Do you recall whether in the past 12 months your site/service/ward implemented any significant new strategies or interventions targeting transitions of care?

☐ Yes
☐ No

39. Please briefly describe and give approximation dates if known.

☐

40. Please share a short story/example (e.g. 1-2 paragraphs) of where a TOP 5 was beneficial for either a patient, resident, client or staff member at your facility e.g. who was the person, what was the strategy, how was it successful? These stories are important and help to illustrate the benefit of TOP 5 in a practical way.

☐

Thank you for completing the TOP 5 Local Site Liaison Final report. Your feedback is greatly appreciated.
Information and Consent Form for Staff Feedback

The Clinical Excellence Commission (CEC) is collaborating with several NSW public and private hospitals, residential aged care facilities (RACFs), community services and NSW Ambulance Service to improve the use of carer knowledge in the care of individuals with cognitive impairment (mainly individuals with dementia).

The TOP 5 initiative encourages staff to seek information from an individual’s carer in order to identify some helpful hints & strategies that can be used to lessen the anxiety and gain a better understanding of how the patient/resident/client usually reacts and communicates in their environment.

We are seeking your assistance to find out if the “TOP 5” initiative will have an impact on participating carers and staff by providing a tool that meets the individual needs and preferences of the individuals in these facilities. As part of the evaluation there will be a survey that will look at the impact and effectiveness of sharing this TOP 5 information between services.

What are you asking me to do?

Using two short de-identified and anonymous surveys (pre and post implementation) we would like to ask a few questions about how you care for patients/residents /clients with dementia. You will be asked to sign a consent form to allow your information to be shared with the Clinical Excellence Commission for the purpose of further analysis and evaluation.

Should you wish to have further assistance in completing the survey, please ask the person who provided you with the survey form.

What happens to the information I provide?

The completed surveys will be placed in a sealed envelope and forwarded to the Clinical Excellence Commission for analysis. Your information will be kept completely confidential and the content will not identify you in any way.

What should I do if I would like further information regarding this survey before I decide to participate?

The name of the site/ facility contact is contained on this form. Should you have any questions after reading this information, or require any further additional information, please contact this person in the first instance.

If you:

- Have questions which were not resolved to your satisfaction by the staff;
- Require broader information regarding the initiative; or
- Wish to make a complaint about the survey;

You can contact the Project Support Officer from the Clinical Excellence Commission.

All contact details are provided on the attached Participant Consent Form.

Thank you for taking the time to consider sharing your experience within the NSW health system.

<table>
<thead>
<tr>
<th>Contacts</th>
<th>Project Support Officer (Clinical Excellence Commission)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site Liaison</td>
<td>Name: [redacted]</td>
</tr>
<tr>
<td>Name: [redacted]</td>
<td>Contact No: [redacted]</td>
</tr>
</tbody>
</table>

Thank you for taking the time to consider sharing your experience within the NSW health system.
Appendix M

Consent Section
Staff Member

NOTE: This form will be placed in the envelope provided, sealed and collected by the TOP 5 Site Liaison Person. The form will remain with the Clinical Excellence Commission for their records.

I agree to take part in the research study as specified. I have had the initiative explained to me, and I have read the Participant Information Sheet. I understand that agreeing to take part means that:

I agree to complete the survey with the questions being clarified if required by the TOP 5 Site Liaison Person

☐ Yes ☐ No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the study without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the questionnaire for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide in this questionnaire is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the study, or to any other party.

I understand that data from the questionnaire will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a five (5) year period unless I consent to it being used in future research.

Participant’s name:______________________________________________

Signature:_______________________________________________________

Date:_______________________
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Date .................................................

Position Title .................................................................................................................................

Doctor ☐ Nurse ☐ Allied health professionals ☐ Other.................................

1. How would you describe your overall knowledge of dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

2. How confident are you in managing a resident with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

3. Are you satisfied that your facility provides you with the following?

a. Information to care for a resident with dementia Yes ☐ No ☐

b. Support to care for a resident with dementia Yes ☐ No ☐

c. Education tools to care for a resident with dementia Yes ☐ No ☐

4. If a carer provided information about personalising care for an individual how would you transfer this information? (e.g. to a team member/hospital/ambulance)?

Verbal ☐ Written ☐ None ☐

5. How important do you think it is to involve a carer in managing a patient with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

6. How confident are you in engaging with carers in discussions about dementia?

None/little ☐ Some ☐ Average ☐ Extremely ☐

Thank you for your time in completing this survey. Please place your completed response in the envelope provided. If you have any questions, please contact the TOP 5 Liaison Person.

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF health and Medical Research Foundation.
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix O

TOP 5
STAFF SURVEY
Conducted at 6 months
(Residential Aged Care Facilities)

Date ............................................

Position Title ..................................................................................................................

Doctor □  Nurse □  Allied health professionals □  Other.................................

1. How would you describe your overall knowledge of dementia?
   None/Little □   Some □   Good □   Excellent □

2. How confident are you in managing a resident with dementia/cognitive impairment?
   None/Little □   Some □   Average □   Excellent □

3. Are you satisfied that your facility provides you with the following?
   a. Information to care for a resident with dementia?  Yes □  No □
   b. Support to care for a resident with dementia?  Yes □  No □
   c. Education tools to care for a resident with dementia?  Yes □  No □

4. Whilst caring for a resident with dementia, how would you rate your work satisfaction level?
   Not at all satisfied □  Slightly satisfied □  Moderately satisfied □  Extremely satisfied □

5. If a carer provided information about personalising care for an individual, how would you transfer this information? (e.g. to a team member/hospital)?
   TOP 5 form □  Verbal □  ‘Other’ written □  None □

6. How important do you think it is to involve a carer in managing a resident with dementia?
   None/Little □  Some □  Average □  Extremely □

7. How confident are you in engaging with carers in discussions about dementia/cognitive impairment?
   None/Little □  Some □  Average □  Extremely □
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix O

8. Are you aware of the ‘TOP 5’ process?  
   Yes ☐  No ☐

9. Have you attended an education session on ‘TOP 5’?  
   Yes ☐  No ☐

10. Could you please explain in your own words your understanding of ‘TOP 5’?  
    ____________________________________________________________
    ____________________________________________________________

11. Have you initiated a TOP 5 for resident/s?  
    Yes ☐  No ☐ → go to Question 17

12. How easy did you find it to identify residents who could potentially benefit from having a ‘TOP 5’?  
    Very difficult ☐  Some difficulty ☐  Easy ☐  Very easy ☐

13. Who was the ‘TOP 5’ information obtained from?  
    Staff ☐  Resident ☐  Family/Carer ☐  
    Other ______________________________________________________

14. How easy was the ‘TOP 5’ process to implement and/or use?  
    Very difficult ☐  Some difficulty ☐  Easy ☐  Very easy ☐

15. Was the ‘TOP 5’ process time consuming?  
    Yes ☐  No ☐

16. Did you use any of the TOP 5 strategies or implement the ‘TOP 5’ strategies as part of the resident’s care plan?  
    Yes ☐  No ☐

17. Have you received, cared for, or know of a resident with dementia/cognitive impairment that already had TOP 5 strategies in place?  
    Yes ☐  No ☐ → (If you answered yes to Question 11 → go to Question 19)

   (If you answered no to Question 11 → end of survey)

18. Did you use any of the TOP 5 strategies or implement the ‘TOP 5’ strategies as part of the resident’s care plan?  
    Yes ☐  No ☐
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix O

19. For residents with a ‘TOP 5’ implemented, did you feel:
   a. The resident became less agitated and distressed? Yes □ No □
   b. The resident was more cooperative? Yes □ No □
   c. Less restraint (chemical) was required for the resident Yes □ No □
   d. Carers appeared confident/satisfied with the care provided? Yes □ No □
   e. Less concerns were raised by family? Yes □ No □

20. For residents with a ‘TOP 5’, were you better able to manage the resident in their environment? Yes □ No □

21. Are you aware if any of your residents with a ‘TOP 5’ in place have been transferred to another facility (e.g. hospital)? Yes □ No □ → go to Question 26

22. When the resident was transferred to other health services/facilities (e.g. hospital/ambulance) was the ‘TOP 5’ information passed on/shared? Yes □ No □ → go to Question 26 Don’t know □ → go to Question 26

23. How was the ‘TOP 5’ information communicated/passed on/shared?
   TOP 5 form □ ‘Other’ Written □ Verbal □ Don’t know □
   Other __________________________________________________________

24. Who was the ‘TOP 5’ information passed on to?
   Doctor □ Nurse □ Allied health professionals □
   Paramedic □ Carer □ Don’t know □ Other _______________________

25. How successful do you think the transfer of this ‘TOP 5’ information was to the external facility/service? Poor □ Fair □ Good □ Very Good □

26. Did your facility ever receive a resident back from a hospital or other service, accompanied form to provide personalised ‘tips’ for care? Yes □ No □ → go to Question 29 Don’t know □ → go to Question 29
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix O

27. Where was this resident transferred from?
   Hospital □ Residential Aged Care Facility □ Community service □ Their home □
   Other □ Unknown □

28. How was this information typically received?
   TOP 5 form □ Written □ Verbal □ Other ____________________________

29. Overall would you say ‘TOP 5’ is an effective strategy in managing residents with dementia?
   Yes □ No □

Please comment:
_______________________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________

Thank you for your time in completing this survey. Please place your completed response in the envelope provided. If you have any questions, please contact the TOP 5 Liaison Person.

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF Health and Medical Research Foundation.
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

**TOP 5 STAFF SURVEY**
*Conducted at 12 months*
*(Residential Aged Care Facilities)*

<table>
<thead>
<tr>
<th>Date</th>
<th>Position Title</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Doctor</td>
</tr>
</tbody>
</table>

1. How would you describe your overall knowledge of dementia?
   - None/Little
   - Some
   - Good
   - Excellent

2. How confident are you in managing a resident with dementia/cognitive impairment?
   - None/Little
   - Some
   - Average
   - Excellent

3. Are you satisfied that your facility provides you with the following?
   a. Information to care for a resident with dementia?  
      - Yes
      - No
   b. Support to care for a resident with dementia?  
      - Yes
      - No
   c. Education tools to care for a resident with dementia?  
      - Yes
      - No

4. Whilst caring for a resident with dementia, how would you rate your work satisfaction level?
   - Not at all satisfied
   - Slightly satisfied
   - Moderately satisfied
   - Extremely satisfied

5. If a carer provided information about personalising care for an individual, how would you transfer this information? (e.g. to a team member/hospital)?
   - TOP 5 form
   - Verbal
   - ‘Other’ written
   - None

6. How important do you think it is to involve a carer in managing a resident with dementia?
   - None/Little
   - Some
   - Average
   - Extremely

7. How confident are you in engaging with carers in discussions about dementia/cognitive impairment?
   - None/Little
   - Some
   - Average
   - Extremely
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix P

8. Are you aware of the ‘TOP 5’ process?  Yes ☐ No ☐

9. Have you attended an education session on ‘TOP 5’? Yes ☐ No ☐

10. Could you please explain in your own words your understanding of ‘TOP 5’?  

_______________________________________________________________________
_______________________________________________________________________

11. Have you initiated a TOP 5 for resident/s?  Yes ☐ No ☐ → go to Question 17

12. How easy did you find it to identify residents who could potentially benefit from having a ‘TOP 5’?  

Very difficult ☐ Some difficulty ☐ Easy ☐ Very easy ☐

13. Who was the ‘TOP 5’ information obtained from?  

Staff ☐ Resident ☐ Family/Carer ☐

Other _____________________________________________________________

14. How easy was the ‘TOP 5’ process to implement and/or use?  

Very difficult ☐ Some difficulty ☐ Easy ☐ Very easy ☐

15. Was the ‘TOP 5’ process time consuming?  

Yes ☐ No ☐

16. Did you use any of the TOP 5 strategies or implement the ‘TOP 5’ strategies as part of the resident’s care plan?  

Yes ☐ No ☐

17. Have you received, cared for, or know of a resident with dementia/cognitive impairment that already had TOP 5 strategies in place?  

Yes ☐ No ☐ (If you answered yes to Question 11 → go to Question 18)  
(If you answered no to Question 11 → end of survey)

18. Please share an example of a ‘successful TOP 5 strategy’ that worked well for a resident with dementia. E.g. What was the strategy? How did it work?  

_______________________________________________________________________
_______________________________________________________________________

___________________________________________________
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix P

19. For residents with a ‘TOP 5’ implemented, did you feel:
   
a. The resident became less agitated and distressed?   Yes ☐    No ☐
   
b. The resident was more cooperative?                 Yes ☐    No ☐
   
c. Less restraint (chemical) was required for the resident Yes ☐    No ☐
   
d. Carers appeared confident/satisfied with the care provided?  Yes ☐    No ☐
   
e. Less concerns were raised by family?                Yes ☐    No ☐
   
f. TOP 5 was a useful tool to use for residents who do not have a carer available    Yes ☐    No ☐

20. How has TOP 5 helped you or the people you work with in managing residents with dementia?
   
_______________________________________________________________________________________
   
_______________________________________________________________________________________
   
_______________________________________________________________________________________

21. For residents with a ‘TOP 5’, were you better able to manage the resident in their environment? Yes ☐    No ☐

22. Are you aware if any of your residents with a ‘TOP 5’ in place have been transferred to another facility (e.g. hospital)?
   
Yes ☐    No ☐  → go to Question 27

23. When the resident was transferred to other health services/facilities (e.g. hospital/ambulance) was the ‘TOP 5’ information passed on/shared?
   
Yes ☐    No ☐  → go to Question 26    Don’t know ☐  → go to Question 26

24. How was the ‘TOP 5’ information communicated/passed on/shared?
   
TOP 5 form ☐  ‘Other’ Written ☐  Verbal ☐  Don’t know ☐

   Other _____________________________________________________________________________

25. Who was the ‘TOP 5’ information passed on to?
   
Doctor ☐  Nurse ☐  Allied health professionals ☐

Paramedic ☐  Carer ☐  Don’t know ☐  Other ____________________________
The following survey is a sample baseline Residential Aged Care staff survey. Similar baseline surveys were sent to participating hospital and community services.

Appendix P

26. How successful do you think the transfer of this ‘TOP 5’ information was to the external facility/service?
   Poor □       Fair □       Good □       Very Good □

27. Did your facility ever receive a resident back from a hospital or other service, accompanied by a TOP 5 form to provide personalised ‘tips’ for care?
   Yes □       No □ → go to Question 30       Don’t know □ → go to Question 30

28. Where was this resident transferred from?
   Hospital □   Residential Aged Care Facility □   Community service □   Their home □
   Other □   Unknown □

29. How was this information typically received?
   TOP 5 form □   Written □   Verbal □   Other ____________________________

30. What do you think of the TOP 5 program?
   ______________________________________________________________________________________
   ______________________________________________________________________________________
   ______________________________________________________________________________________

31. Overall would you say ‘TOP 5’ is an effective strategy in managing residents with dementia?
   Yes □       No □

32. Do you have any further comments?
   ______________________________________________________________________________________
   ______________________________________________________________________________________
   ______________________________________________________________________________________

Thank you for your time in completing this survey.
Please place your completed response in the envelope provided.
If you have any questions, please contact the TOP 5 Liaison Person

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF health and Medical Research Foundation.
Appendix Q

Information and Consent Form for Carer Feedback

The Clinical Excellence Commission (CEC) is collaborating with several NSW public and private hospitals, residential aged care facilities (RACFs), community services and NSW Ambulance Service to improve the use of carer knowledge in the care of patients with cognitive impairment (mainly patients with dementia). The TOP 5 initiative encourages staff to seek information from a patient’s carer in order to identify helpful hints & strategies that can be used to lessen the anxiety of patients/residents and carers and gain a better understanding of how the patient/resident would typically react and communicate in their environment.

We are seeking your assistance to find out if the “TOP 5” initiative will have an impact on participating carers and staff by providing a tool that meets the individual needs and preferences of the patients or residents in these facilities. Part of the evaluation will include a brief survey, this aims to identify the impact and effectiveness of sharing this TOP 5 information between services.

What are you asking me to do?

Using a short, anonymous and de-identified survey we would like to ask a few questions of you as a carer for a person with dementia. You will be asked to sign a consent form to allow your information to be shared confidentially with the Clinical Excellence Commission (CEC) for the purpose of further analysis.

Should you wish to have further assistance in completing the survey, please ask the staff member who provided you with the survey form.

What happens to the information I provide?

The completed surveys will be placed in a sealed envelope and forwarded to the Clinical Excellence Commission (CEC) for analysis. Your information will be kept completely confidential and the content will not identify you or your loved one in any way.

What should I do if I would like further information regarding this survey before I decide to participate?

The name of the site/facility contact is contained on this form. Should you have any questions after reading this information, or require any further additional information please contact this person in the first instance.

If you:

- Have questions which were not resolved to your satisfaction by the staff;
- Require broader information regarding the initiative; or
- Wish to make a complaint about the survey;
You can contact the Project Support Officer from the Clinical Excellence Commission.

All contact details are provided on the attached Participant Consent Form.

Thank you for taking the time to consider sharing your experience within the NSW health system.
Appendix R

<table>
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<tr>
<th>Contacts</th>
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<tr>
<td><strong>Site Liaison</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Contact No:</td>
</tr>
</tbody>
</table>

**Consent Section**

**Primary Carer**

NOTE: This form will be collected by the TOP 5 Site Liaison Person and will remain with the Clinical Excellence Commission for their records

I agree to take part in the research study as specified. I have had the initiative explained to me, and I have read the Participant Information Sheet. I understand that agreeing to take part means that:

I agree to complete the survey with the questions being clarified if required by the TOP 5 Site Liaison Person

[ ] Yes  [ ] No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the study without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the questionnaire for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide in this questionnaire is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the study, or to any other party.

[Partnersing with Patients Logo]

[Clinical Excellence Commission Logo]
You have been asked to provide feedback about the TOP 5 initiative. Our staff will have approached you shortly after admission to gain valuable information from the knowledge and expertise you have in caring for the person who has become our patient/resident/client. We are interested to know how you feel about this hospital stay for both you and the patient and ask that you please think about this when completing the following information. Be assured that your comments will be kept confidential.

Name of Facility (if applicable) ______________________________________________________

1. Were you approached by a member of staff in regards to the TOP 5 process for gaining personalised ‘tips’ from carers about caring for a patient/resident/client?
   Yes ☐ No ☐

2. How satisfied were you with the information you were given about ‘TOP 5’?
   Very dissatisfied ☐ Dissatisfied ☐ Unsure ☐ Satisfied ☐ Very satisfied ☐

3. Did you provide ‘tips’ for staff to use when caring for the patient/resident/client?
   Yes ☐ No ☐

Please provide your opinion for each statement:

4. Staff acknowledged and used the ‘TOP 5’ suggestions you made when providing care.
   Disagree ☐ Unsure ☐ Agree ☐ Strongly agree ☐

5. In your opinion, your loved one/the patient has been calmer and less anxious as a result of the implemented ‘TOP 5’ strategies.
   Disagree ☐ Unsure ☐ Agree ☐ Strongly agree ☐

6. The staff have communicated well with my loved one/the patient/resident.
   Disagree ☐ Unsure ☐ Agree ☐ Strongly agree ☐

7. The use of ‘TOP 5’ by staff has increased my confidence in the staff who are looking after my loved one/the patient/resident.
   Disagree ☐ Unsure ☐ Agree ☐ Strongly agree ☐

TOP 5 CARER SURVEY
To be completed – by carers involved in the TOP 5 initiative
Appendix R

8. I feel more engaged with staff and involved in the care as staff are aware of the importance of my role in caring for the patient. □ □ □ □

9. To the best of my knowledge, I believe my suggested TOP 5 strategies were implemented effectively, and my loved one/the patient/resident benefited as a result. □ □ □ □

Thank you for your time in completing this survey. Please place your completed response in the envelope provided. If you have any questions, please contact the TOP 5 Liaison Person.

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF health and Medical Research Foundation.
### Using TOP 5 – Enablers and Barriers

#### Enablers

**Hospital**

<table>
<thead>
<tr>
<th>Enabler</th>
<th>Context</th>
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</table>
| Team approach | • Staff noted that by encouraging the use of TOP 5 as a team approach and including all staff members including allied health, social workers and doctors as part of the process it ensured the process was conducted for all potential TOP 5 patients  
• Effective communication between staff members ensured TOP 5 process was followed through properly  
• By having a local implementation team it allowed for staff reminders that TOP 5 needs to be done for particular patients  
• Staff were able to promote TOP 5 at different internal team meetings |

| AgedCare Services Emergency Team (ASET) staff assisting with TOP 5 in ED | • Hospital sites with ASET staff who were willing to be involved in the TOP 5 process found more potential patients were identified and captured for TOP 5, as ASET routinely provide specialised care to older persons presenting to the ED. |

| Endorsement/support from executives | • Some hospital sites found it beneficial to have endorsement from senior staff and executives within their site. This allowed for clear local direction and direct support and ensured all staff were aware of expectations and outcomes from senior management. |

| Staff who saw benefits | • Staff who are focussed on the individual and the carers needs willing to assist in completing the forms |

**RACF**

<table>
<thead>
<tr>
<th>Enabler</th>
<th>Context</th>
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<tbody>
<tr>
<td>Team work</td>
<td>• Staff had great knowledge/background of resident’s behaviours. By working together as a team and in groups they were able to successfully develop TOP 5 strategies for residents with dementia</td>
</tr>
</tbody>
</table>

| Turnover of staff | • Some RACFs had little to no turnover of staff, making the TOP 5 process easy to manage |

| TOP 5 orientation for new staff members | • By including TOP 5 as part of orientation for new staff members it ensured the TOP 5 process ran effectively, and allowed new staff members to get to know the residents’ history, background and behaviours easily |

| Good advanced care directives in place for residents | • |
**Appendix S**

| Similar programs already in place | • Staff members who found the process easy to implement due to other projects implemented at the RACF e.g. personalised charts, ‘who am I? programs’ etc. |

**Community**

<table>
<thead>
<tr>
<th>Enabler</th>
<th>Context</th>
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<tbody>
<tr>
<td>Existing relationship with clients</td>
<td>• Community staff members found the process of developing TOP 5 strategies easy with clients and/or carers that they already had a good relationship with</td>
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**All sites**

<table>
<thead>
<tr>
<th>Enabler</th>
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<tbody>
<tr>
<td>Toolkit/resources</td>
<td>• All sites mentioned that the toolkit provided by the CEC containing resources was quite useful in assisting with the TOP 5 implementation at their site. In particular the educational PowerPoint slides, the suggested script to prompt carers and the carer brochures were well received</td>
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<tr>
<td>Regular meetings and contact with CEC</td>
<td>• Representatives from participating sites who participated in regular teleconferences with the CEC felt that regular ongoing support, encouragement and advice from the CEC was a huge enabler that allowed them to implement the program successfully at their site.</td>
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<td>TOP 5 newsletters</td>
<td>• The bi-monthly TOP 5 newsletters developed by the CEC with input from participating sites provided sites with successes, milestones achieved, barriers or issues experienced, real life examples and shared learnings and were printed and left around workplace for staff to read</td>
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## Barriers

### Hospital

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<tr>
<th>Barrier</th>
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<th>Solution/work-around</th>
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| Lack of time in ED            | • ED staff are already quite busy with clinical requirements and do not always have time to sit down with the carer and develop TOP 5 strategies  
   • The introduction of the 4-hour rule in ED in public hospitals means patients have to be either admitted or discharged from ED within 4-hours reducing the amount of time staff have to achieve their clinical tasks for a patient | • Engaging with the hospital’s ASET team to develop/initiate the TOP 5 for patients with dementia who they assess  
   • Educating ED staff to at least identify potential TOP 5 patients as they come through ED during their clinical duties and place a TOP 5 form in their notes to allow nursing staff on receiving ward complete the TOP 5 form  
   • Encouraging staff members to complete form in conjunction with other duties during admission |
| Lack of physical space to complete TOP 5 | • Staff noted that it could be difficult when developing the strategies with the carer if the patient is present and did not have an insight into their condition or dementia diagnosis. | Staff were encouraged to:  
   • if possible, pull the carer aside to another room/different location and talk about TOP 5 in private  
   • Identify potential TOP 5 patients before their appointment and place a TOP 5 form with the patient’s paperwork for the carer to review and complete whilst waiting for appointment  
   • Use clinical judgement/sensitivities when discussing TOP 5. |
| No carer available           | • Staff noted that carer/family was not always present when the patient was admitted to hospital, or often did not stay in the hospital long enough for staff to engage with them – this made it difficult for staff to develop strategies | • One hospital site developed a big poster for the front of the hospital targeting carers to ensure they know they can speak to staff before they leave the hospital to provide sufficient information. |
| Staff attitude                | • At some participating hospitals, some staff members had the attitude of ‘not my job’ or ‘not another form to complete’ when conducting a TOP 5 for a patient. Therefore initiating TOP 5 was usually left for key staff | • Consistent internal and CEC promotion of TOP 5 as a team approach to staff at participating sites  
   • Include TOP 5 education in other internal workshops/education sessions to ensure staff |
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<tr>
<th>Appendix S</th>
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<tbody>
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<td><strong>to complete</strong></td>
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<tr>
<td>• It was noted at one site that some staff members have developed a habit to leave TOP 5 up to the family to complete with all of the paperwork.</td>
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<td>• Some staff members believe that in the ED environment it is not the focus to have these types of conversations with a carer</td>
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<td>• At one site staff mentioned that unfortunately some staff members do not check the patient’s history properly, therefore the flagging of potential TOP 5 patients is sometimes missed</td>
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<tr>
<td><strong>understand the importance and value of the program</strong></td>
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<tr>
<td><strong>Education</strong></td>
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<tr>
<td>• All hospital sites employ a high number of nursing staff in ED, therefore making it very difficult to educate all staff on the TOP 5 program</td>
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<td>• One site mentioned it is quite difficult getting on/staying on in-service calendars to provide internal TOP 5 education to staff</td>
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<td>• Not all wards in the participating hospital were aware of the TOP 5 program – therefore when a patient was transferred from ED/pre-admission to another ward in the hospital with their TOP 5 form, it was sometimes ignored or thrown away by staff on these non-participating wards</td>
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<tr>
<td>• Staff at some sites forgot to take TOP 5 form out of patient notes when patient is discharged, therefore transfer with the TOP 5 form did not always occur</td>
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<td>• The TOP 5 form sometimes went in the back of patient notes where it was not easily identifiable/noticeable to staff members</td>
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<tr>
<td>• Ensuring as many staff as possible were at least aware, if not educated on TOP 5 program through multiple CEC education visits, LSL internal education sessions and internal promotion of TOP 5 resources by LSL and clinical champions on participating wards</td>
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<tr>
<td>• Encouraging a two-way communication channel between NUMS on receiving wards, and the ASET team/ED staff, and pre-admission staff by inviting NUMS to regular TOP 5 teleconferences to ensure feedback is provided on TOP 5 strategies</td>
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<td>• Some sites applied (or are in the process of applying) for the TOP 5 form to be a state-wide form, therefore ensuring the form was not thrown away after discharge</td>
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<td><strong>Competing priorities</strong></td>
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<td>• During the TOP 5 study period other issues arose that took priority over TOP 5 for staff e.g. Ebola crisis, hospital re-accreditation etc.</td>
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<td><strong>Requirement for TOP 5 infrequent</strong></td>
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<td>• Some participating sites advised that they did not have many patients who fit the TOP 5 criteria, and therefore</td>
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<tr>
<td>Barrier</td>
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<tr>
<td>Lack of carer</td>
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| Lack of time    | Staff reported that initiating a TOP 5 during a resident’s admission process was difficult as the process was already intensive and time consuming.  
• To update/add TOP 5 information was difficult as residents already have care plans and progress notes that also have to be updated and as everything done manually (not on a computer) this was quite time consuming | • A schedule developed for staff to take the time to develop strategies  
• Focusing on completing 1-2 strategies at first during the resident’s admission and allowing other members of staff to complete in the following weeks |
| Lack of transfers | Minimal transfers of residents to hospitals in some participating sites who rely on ‘geriatric flying squad’ in RACFs for in house assessment and management of acute conditions which resulted in decreased hospital transfers |  |
| Education       | Staff forgetting to transfer TOP 5 form with resident (night staff)     | • Further internal TOP 5 education sessions to staff  
• Ensuring a central folder for TOP 5 forms are kept in a |
Appendix S

| High turnover of staff | Multiple LSLs during TOP 5 implementation | Regular contact and communication between CEC and participating sites to ensure implementation continues during staff changes | Re-education of new LSLs as soon as possible |

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<td>Limited number of suitable TOP 5 candidates</td>
<td>Some community services advised that due to changes in legislation their clientele changed over the TOP 5 study period and they no longer cared for ‘high-care’ clients, and therefore saw a drop in the number of individuals with dementia that were referred to their services. Clients stage of acceptance/change in condition difficult to capture in a community setting.</td>
<td>Staff discuss TOP 5 with all new carers and clients on assessment visit to keep the TOP 5 profile on assessment check lists. Remind all relevant staff at team meetings to keep looking for potential TOP 5 clients.</td>
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<td>Carers not willing/not enthusiastic in completing forms</td>
<td>At times carers are unable to think of any strategies during assessment. Some carers felt that they would be there for the client’s admission to hospital, and therefore TOP 5 form was no required.</td>
<td>Provide carers with staff contact details to follow up if they think of strategies after client visit. More in-depth discussion between staff and carers.</td>
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<td>Clients not understanding the benefits of TOP 5</td>
<td>Some clients have an insight into their condition and therefore believe they have no need for a TOP 5, however these clients did display signs of anxiety and depression. Carers do not understand importance of program and stated ‘they will be there at hospital to provide strategies if required’.</td>
<td>Staff rephrased the TOP 5 process to carers so the focus is not on challenging behaviours/dementia, but more on what they would like to happen to make the patient feel more comfortable if they have to go to hospital. This approach ensured carers were more willing to engage and share information as the focus was shifted away from ‘dementia’.</td>
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<tr>
<td>TOP 5 form location</td>
<td>Some clients not comfortable with TOP 5 tag (which identified them as a TOP 5 client) visible in their home. Clients would become distressed if TOP 5 tag.</td>
<td>The development of the TOP 5 fridge magnet by CEC ensured that staff could find location of TOP 5 form quickly by looking on client’s fridge, the magnet was</td>
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kept in a visible place inside their home (due to stigma), however would have been thrown it away if they found it hidden somewhere in their home

inconspicuous and had no mention of ‘dementia’ written on it.

- Use of TOP 5 stickers on staff folders to identify TOP 5 clients

| No carer available | There were a high number of clients with dementia who lived alone without a carer. Some clients, did have carers however often their carers also had a mental illness | Staff members tried to pick up on possible TOP 5 strategies during conversations with the client and used them for the TOP 5 form |

Ambulance Service of NSW

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<td>Lack of transfers between services</td>
<td>Overall there were a minimal number of individuals with dementia who were transferred between health care services</td>
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References


AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE. 2011. Patient centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC.

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE. 2012. National safety and quality health service standards (September 2012). Sydney: ACSQHC.


