

TOP 5

IMPROVING THE CARE OF
PATIENTS WITH DEMENTIA:
2012 - 2013



CLINICAL
EXCELLENCE
COMMISSION



Research report prepared for The HCF Research Foundation

© Clinical Excellence Commission 2014

All rights are reserved. In keeping with the NSW Government's commitment to encouraging the availability, dissemination and exchange of information (and subject to the operation of the *Copyright Act 1968*), you are welcome to reproduce the information which appears in this publication, as long as the user of the information agrees to:

- use the document for information only
- save or print a single copy for personal use only and not to reproduce any major extract or the entire document except as permitted under *Copyright Act 1968* (as amended) without the prior written permission of the State of New South Wales
- acknowledge the source of any selected passage, table diagram or other extract reproduced
- not make any charge for providing the Information to another person or organisation without the prior written consent of the State of New South Wales and payment of an agreed copyright fee
- not modify the Information without the express prior written permission of the State of New South Wales include this copyright notice in any copy made:

© - Copyright – Clinical Excellence Commission for and on behalf of the Crown in right of the State of New South Wales.

National Library of Australia Cataloging-in-Publication entry

Title: TOP 5: Improving the care of patients with dementia 2012-2013
ISBN: 9781741871111
SHPN: 140481 (CEC)

Contributing authors:

Luxford, Karen
Axam, Anne
Hasnip, Fiona

Suggested citation

Clinical Excellence Commission, 2014. TOP 5: Improving the care of patients with dementia 2012-2013, Sydney: Clinical Excellence Commission

Clinical Excellence Commission

Board Chair: Associate Professor Brian McCaughan, AM
Chief Executive Officer: Professor Clifford F Hughes, AO

Any enquiries about or comments on this publication should be directed to:

Dr Karen Luxford
Director, Patient Based Care
Clinical Excellence Commission
Locked Bag 8
Haymarket NSW 1240
Phone: (02) 9269 5500
Email: cec-info@health.nsw.gov.au

FOREWORD

By 2050, the number of Australians aged 65 to 84 years is expected to more than double and the number of people 85+ years will more than quadruple. With an ageing population, increasing numbers of people are being diagnosed with dementia. People with dementia who are admitted to hospital can find themselves in environments that result in heightened distress and anxiety for 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.

The TOP 5 approach of key strategies and the personal history for the patient with dementia embodies the heart of patient based approaches to care and, therefore, struck a chord with the Clinical Excellence Commission's Partnering with Patients program.

This research report details the findings of a study aimed at evaluating the implementation and impact of TOP 5 on clinician satisfaction, carer experience, patient safety and cost implications for health services. The research described in this report was supported by a grant from the HCF Health and Medical Research Foundation.

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

Dr Karen Luxford

Principal Investigator, TOP 5 Study

Director, Patient Based Care, Clinical Excellence Commission



ACKNOWLEDGEMENTS

The Clinical Excellence Commission (CEC) acknowledges the support of a grant from the HCF Health and Medical Research Foundation to undertake the TOP 5 study. The CEC acknowledges the permission of the Central Coast Local Health District for the use of the TOP 5 concept and adaptation of materials for this study.

Particular thanks go to the members of the TOP 5 Steering Committee for their guidance and input over the course of the study and support of this patient based initiative.

Maureen Strudwick, Dr John Dobrohotoff 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 Centre for Health Economics Research and Evaluation at the University of Technology Sydney are acknowledged for their conduct of quantitative data analysis and cost analysis.

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 Anne Axaam (Project Coordinator) and Fiona Hasnip (Research Assistant).

Carer's Comment - Engagement in care with TOP 5:

“This initiative makes the carer feel respected as well as involved in the ongoing treatment of their loved one.”

CONTENTS

Acronyms and Abbreviations	8
1. EXECUTIVE SUMMARY	9
2. THE CLINICAL EXCELLENCE COMMISSION	11
3. PATIENT BASED CARE	12
3.1 Concept	12
3.2 Drivers	12
4. BACKGROUND: DEMENTIA AND HOSPITALISATION	14
4.1 Dementia and Patient Based Care	14
4.2 Dementia in Australia	14
4.3 Hospitalisation of patients with dementia	15
4.4 Carers & carer involvement	15
5. TOP 5	17
5.1 Genesis	17
5.2 The concept	17
6. CEC TOP 5 INITIATIVE	19
6.1 Initiation	19
6.2. Implementing TOP 5 (Methodology)	20
7. EVALUATION	24
7.1 Overview	24
7.2 Data Collected	24
7.3 Planning for the Evaluation Components	27
7.4 The Evaluation Process	27
7.4.1 Midway Report and Process Survey	27
7.4.2 Staff Surveys	27
7.4.3 Carer Survey	27
7.4.4 Quantitative Indicators	28
7.5 Control Ward	28

7.6 Analysis Methodology.....	29
8. FINDINGS.....	30
8.1. Information on Participating Hospitals.....	30
8.1.1 <i>Hospitals by Peer Groups</i>	30
8.1.2 <i>TOP 5 Initiations by Hospital</i>	30
8.1.3 <i>Using TOP 5 – Process of Implementation</i>	31
<i>Case Studies</i>	34
8.2 Using TOP 5 – Enablers and Barriers.....	36
8.2.1 <i>Enablers</i>	36
8.2.2 <i>Barriers</i>	37
8.3 Staff Attitudes, Confidence and Knowledge.....	37
8.4 Acceptability.....	41
8.4.1 <i>Staff</i>	41
8.4.2 <i>Carers</i>	41
8.5 Patient-Related Outcomes.....	46
8.5.1 <i>Falls</i>	46
8.5.2 <i>Use of anti-psychotics</i>	46
8.5.3 <i>Use of 1:1 Nursing Care (Specials)</i>	47
8.5.4 <i>Complaints</i>	47
8.5.5 <i>Identification and Coding of Patients with Dementia</i>	47
8.5.6 <i>Average Length of Stay</i>	47
8.6 Cost Outcomes.....	48
8.6.1 <i>Cost</i>	48
8.6.2 <i>Potential cost savings</i>	50
9. CONCLUSIONS.....	52
10. FUTURE OPPORTUNITIES.....	54
11. REFERENCES.....	56
12. APPENDICES.....	61

Acronyms and Abbreviations

ACSQHC	-	Australian Commission on Safety and Quality in Health Care
AIHW	-	Australian Institute of Health and Welfare
ALOS	-	Average length of stay
ANOVA	-	Analysis of variance
CEC	-	Clinical Excellence Commission
CHERE	-	Centre for Health Economics Research and Evaluation
HIE	-	Health Information Exchange
HREC	-	Human Research Ethics Committee
IIMS	-	Incident Information Management System
LHD	-	Local Health District
LSL	-	Local Site Liaison
MPS	-	Multi-purpose Service
SPSS	-	Statistical Package for the Social Sciences
TOR	-	Terms of reference
UTS	-	University of Technology Sydney

1. EXECUTIVE SUMMARY

This TOP 5 research study indicates that the use of a low cost, patient based communication strategy for patient care is associated with significant improvements in patient outcomes, safety, carer experience and staff satisfaction while providing potential cost savings to health services.

- 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.
- 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 17 public hospitals and 4 private hospitals across NSW, focussing on hospitalised patients with dementia. Each site nominated a local site liaison and received toolkit materials and education.
- The evaluation investigated process of implementation, use of TOP 5 by hospital staff, acceptability to staff and carers, impact on patients (including falls and use of anti-psychotic drugs), average length of stay and cost implications.

Results summary:

Data analysis indicated promising findings particularly in the areas of staff confidence in caring for patients with dementia, acceptability to carers, reduced falls, reduced anti-psychotic drug use, impact on staffing levels and associated potential cost savings.

In summary:

- A total of *1277 TOP 5s* were initiated across 21 sites (average six TOP 5s per month, per site).
- *Enablers* for implementation of TOP 5 included leadership, clinical champions, the local site liaison, multidisciplinary involvement and education.
- *Barriers* to uptake included staff resistance to change/time constraints, carer-related issues and staff confidence.
- *Staff reported* that TOP 5 was easy to use (91%), not time consuming (70%), decreased patient agitation and distress (74%), resulted in decreased use of restraint - physical or chemical (61%), increased staff work satisfaction (79%) and sustained increase in staff confidence in caring for patients with dementia. Regarding complaints, 71 per cent of staff responded that less concerns and complaints had been raised by carers of patients following the introduction of TOP 5.
- *Carers reported* high levels of acceptability, high satisfaction with the way staff had used the TOP 5 strategies (97%), agreement that TOP 5 had benefitted the patient (85%) and that the patient was calmer as a result of TOP 5 (82%). Carers who had experience of a previous patient hospitalisation reported higher levels of satisfaction with staff relations when TOP 5 was in place compared to previous admissions without TOP 5.
- A 36.4 per cent *reduction in falls* by patients with dementia by the sixth month of using TOP 5 in hospitals that reported falls involving patients with dementia at the beginning of the initiative.
- An average of 6.85 *fewer falls* per month in the TOP 5 ward than in the control ward in one hospital site where it was possible to obtain data from an 'internal control' (outcome was irrespective of seasonal effects and existing falls prevention activities).
- *Reduction in the use of anti-psychotic drugs* following the introduction of TOP 5 evident in two hospital sites

where long term data collections were available. In one site, there was an overall reduction of 68 per cent in average cost of anti-psychotics per month. In another site, there was a statistically significant decrease of 67mg per month in the use of Risperidone 'quicklets' - used for short-term treatment of persistent aggression in patients with moderate to severe Alzheimer's dementia. Use of anti-psychotics in patients with dementia has been linked to increased mortality and morbidity, especially increased risk of stroke.

- An association between *use of anti-psychotics and increased falls* in patients with dementia – supporting findings of previous research studies.
- *Decreased use of 'specials' staffing* (i.e. 1:1 intensive nursing) following the introduction of TOP 5 at a site where long term specials usage records were available, with an average additional decrease of 0.84 specials each month of the implementation period.
- It was not possible to determine the impact of introducing TOP 5 on *average length of stay* specifically for TOP 5 patients. There was no evidence of a change in ALOS for all patients with dementia, however, this data had a number of limitations including not being specific to 'TOP 5 patients with dementia'.
- Average *cost of conducting a TOP 5 interview with a carer* to elicit strategies was \$20.60. The average time to complete a TOP 5 with a carer was 21 minutes.
- Study findings indicate that TOP 5 can be implemented at minimal cost and without the need for additional staff. Rather, there is the potential for significant *cost savings* to health services after the introduction of TOP 5 in the areas of reduced falls, use of anti-psychotics and 1:1 intensive nursing care ('Specials').

Future opportunities include broader applicability for patients with other types of cognitive impairment as well as linkages to referral services for hospital admissions for patients such as ambulance, residential aged care facilities (RACFs) and home care. Indeed there is potential to use strategies such as TOP 5 on all patients to improve patient focused care delivery.

2. THE CLINICAL EXCELLENCE COMMISSION

The mission of the Clinical Excellence Commission (CEC) is to build confidence in healthcare 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, it 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 focused approach highlighting that everyone working in health services has a responsibility and the opportunity to improve patient care. Improving patient based 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, and 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.

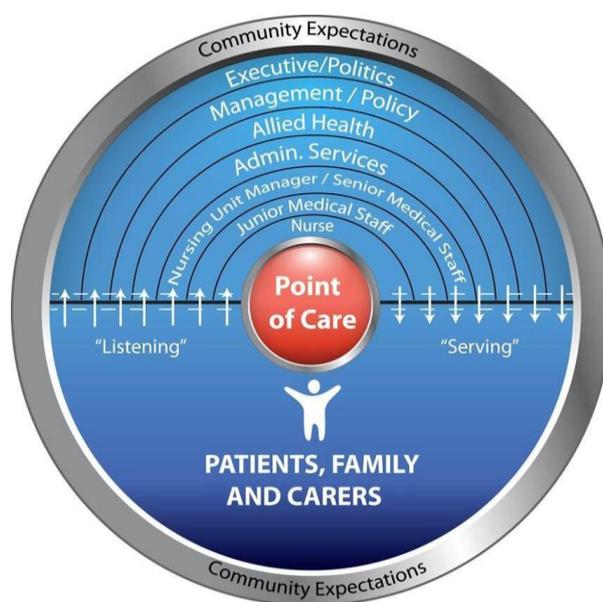


Figure 1: The CEC Patient Based Care Model[©]

Patient focused 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 (ACSQHC, 2011). Key research by the Picker Institute in 1993 crystallised this train of thought 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, co-ordination of care, the involvement of family and friends, and access to care (Gerteis, 1993). From then on, the patient focused care movement has steadily gained momentum.

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, 2008). Patient based care has also been found to improve objective measures of clinical outcomes such as increased treatment compliance (Arbuthnott, 2009), reduced length of stay (DiGioia, 2007) and reduced mortality following acute myocardial infarction (Meterko, 2010). In summary, research indicates that patient based care initiatives improve both clinical outcomes and patient and staff experience.

Health care advisory, accreditation and regulatory bodies are now acknowledging this growing evidence base. In their

National Safety and Quality Health Service Standards, the Australian Commission on Safety and Quality introduced *Partnering with Consumers* as National Accreditation Standard 2 (ACSQHC, 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 new national health service accreditation system.

4. BACKGROUND: DEMENTIA AND HOSPITALISATION

4.1 Dementia and Patient Based Care

Some of the earliest iterations of patient based care models originated in aged care research, particularly regarding patients with dementia (Kitwood, 1992). However, the research literature so far has focused on patient based care in residential aged care, rather than acute care hospitals (Edvarsson, 2010; Sjogren, 2013; van de Ven 2012). Research regarding patient focused models for hospitalised patients with dementia is limited. This paucity of research on vulnerable populations such as patients with dementia provides an opportunity for further research studies about patient focused approaches in hospitals.

Patient based care is grounded in a genuine partnership between 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. Clearly, for patients with dementia this presents some practical challenges. The disease course of dementia means that patients develop impairments in both cognition and communication, potentially creating barriers to engagement.

Therefore, for the care of patients with dementia to be truly patient based, clinician and carer partnership strategies should be encouraged. The carer can provide the important information and engagement that is essential to patient based care.

4.2 Dementia in Australia

Dementia is an umbrella term applicable to a range of diagnoses, characterised by progressive impairments in memory, cognition, language, perception and personality changes (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 (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, 2009a).

With the demographic changes associated with an aging population, dementia is an increasingly common condition in Australia. In 2009, 84,000 people were living with dementia in NSW alone, projected to increase to 341,000 by 2050 (Access Economic, 2009b). While this growth will occur throughout all areas of NSW, both urban and rural, Western Sydney will see the greatest increase in the incidence of dementia (Access Economics, 2009b).

4.3 Hospitalisation of patients with dementia

People living with dementia may also suffer from other chronic health issues associated with older age, as well as acute illness or injury. When any one of these precipitates a hospital admission, their dementia may have an enormous impact upon the safety and quality of care in an acute setting. Our research in this area aimed to identify opportunities to improve care for this patient group because it is known those with dementia tend to have poorer clinical outcomes from their hospitalisation, and are more likely to experience adverse events while hospitalised. Indeed, patients with dementia are more than twice as likely as other patients to die while in hospital (Draper, 2011).

Delirium

Patients with dementia are at increased risk of developing delirium during acute illness. Estimates of the proportion of hospitalised patients with dementia developing delirium during their admission vary from 56 per cent to 76 per cent (Fick, 2002). Delirium is a medical emergency associated with poorer clinical outcomes including functional and cognitive decline and mortality (Inouye, 2014).

Behavioural disturbance

The busy, noisy and unfamiliar environment of an acute care hospital can be very distressing for the patient with cognitive impairment due to dementia. This distress may in turn exacerbate the periodic agitation/aggression that affects about 24 per cent of individuals with dementia (Lyketsos, 2000). Staff who are not trained or experienced in behavioural or environmental approaches to settling a patient with dementia may inappropriately resort to the use of anti-psychotic or other psychotropic medication. The use of anti-psychotics in dementia is associated with significant increases in both mortality (Food and Drug Administration, 2005) and morbidity, especially increased risk of stroke (Committee on Safety of Medicine, 2004).

Falls

Patients with dementia are known to be more likely to fall while hospitalized than other patients (Watkin, 2012). A Victorian study found that dementia was the Diagnosis Related Group (DRG) most commonly associated with a patient falling while in hospital (Hill, 2007). These falls can result in serious injury such as fractures, subdural haematoma and excessive bleeding (Hitcho, 2004) and, therefore, an increased length of stay for that patient while any fall-related injuries are treated. Those deemed to be at high risk of falling are frequently assigned a special (1:1 nursing) (NSW Dept Health, 2010). Additionally, the use of psychotropic medications, including anti-psychotics, is a significant risk factor for falls among older people (Hartikainen, 2007). It should be noted that the current estimate for the cost of hospital care following injury from a fall in Australia is \$18,454 (Watson, 2010).

Length of Stay

Patients with dementia tend to have longer hospital stays. According to recent estimates, patients with dementia had an average length of stay nearly twice that of matched controls without dementia (Draper, 2011). A protracted hospital stay could be considered an adverse event in itself, since these are associated with functional decline in patients with dementia (Mukadam, 2011).

Due to the costs associated with these adverse events (and resources expended toward preventing them) and a longer length of stay, the average cost of a hospital stay for a person with dementia is significantly higher than that of a person of the same age cohort without dementia (\$7,720 compared with \$5,010 per episode, respectively) (AIHW, 2013).

4.4 Carers & carer involvement

A carer is someone who provides regular, ongoing personal care, assistance and support to an individual who requires it due to their illness or disability (Carers Recognition Act, 2010). Most organisations restrict their definition of carer status

to family members or friends of the care recipient, providing care without payment (AIHW, 2007). However, a paid professional care worker may in some cases take on a similar role.

It has long been established that carers experience negative consequences to their physical health and general well-being as a result of providing a carer role (Cummins, 2007). Those caring for individuals with dementia appear to be especially vulnerable, displaying high rates of psychological strain and burnout (Brodaty, 2009).

When a patient has experienced poor health leading to hospitalisation, a carer's anxiety will be heightened. Worry about the health issue itself may be compounded by concerns about whether the care provided will be suitable for the patient with dementia. Where attitudes have been studied, carers of individuals with dementia have expressed low levels of satisfaction with the care received in acute hospitals. Carers expect that there are specialised systems in place for the management of patients with dementia, and are surprised and disappointed to find that in many facilities this is not the case (Jurgens, 2012).

As outlined in Section 3, carer involvement is a key component of patient based care, and in the case of patients with dementia, essential for a productive partnership with clinical staff. However, current research indicates that carers are not always treated with inclusion and respect by hospital staff, and health services more broadly (Jurgens, 2012). New strategies and mechanisms are needed to enable carer engagement in making care for patients with dementia more patient focused, and in so doing improve the safety and quality of their health care.

There is limited published evidence concerning the effectiveness of carer engagement on patient outcomes. In their review of safety and quality issues for patients with dementia and delirium, the Australian Commission on Safety and Quality in Health Care (ACSQHC) recommend further research in this area (ACSQHC, 2013).

5. TOP 5

5.1 Genesis

TOP 5 was developed and implemented in the Central Coast Local Health District (CCLHD) in 2007. The concept came from carers who found the information that they contributed about the person with cognitive impairment that they cared for was not being conveyed to staff on the next shift. They wanted the opportunity to write down their contribution so that all staff would be aware of the things the carers believed staff should know. In addition, staff believed that they were under equipped to deal with the behavioural issues of patients with dementia and wanted to provide better care for their patients. The concept was developed as a solution to address these concerns by the CCLHD Carer Support Unit. 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.

A pilot study using surveys was undertaken in five wards in Central Coast hospitals and reached the following conclusions (Strudwick, 2009):

- Patients were reported as being more compliant with treatment, receiving more effective treatment, being less distressed, having quicker recoveries and shorter length of stays.
- Carers perceived the hospital as providing a better health care service that included more personalised care for the patients.
- Nurses reported being more confident and comfortable in caring for patients.

Subsequently TOP 5 has been implemented across all Central Coast hospitals in medical and surgical wards treating patients with cognitive impairment. (Strudwick, 2010). Additionally, in 2010 a survey of 60 staff was completed involving staff at Gosford and Wyong Hospitals.

5.2 The concept

TOP 5 involves staff engaging with carers through the process of eliciting their five most important tips (TOP 5 tips) and management strategies to aid communication and support personalised care for patients with cognitive impairment.

When a patient with cognitive impairment is identified, the nursing staff approach the carer and explain the TOP 5 concept. They then gently prompt the carer to think about what would be important for the staff on the ward to know about the patient.

The TOP 5 tips are not clinical but contain information to help staff communicate 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 that the resultant strategies can be managed in the hospital setting.

A standardised form is used to record strategies and these are typically located at the patient's bedside available for each member of the care team to use. Upon discharge or transfer of care, the strategy form was returned to the carer to take to another facility or to keep at home. Each subsequent visit to the facility requires a new TOP 5 strategy form to be developed or the original strategies revisited and updated.

Surname..... MRN.....

Given Names.....

Date of Birth..... Sex.....

(Affix Patient Label here)



Strategies to Support Care and Communication

Place this form on top of the patient bed chart notes

- 1.
- 2.
- 3.
- 4.
- 5.

Carer Name: Date:

Staff Member: Date:

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.

2012 Version:2

Figure 2: TOP 5 Strategy Form

6. CEC TOP 5 INITIATIVE

6.1 Initiation

The CEC became aware of the TOP 5 concept in 2011 when the Carers Support Unit, Central Coast Local Health District shared the results from the pilot study and the results collated in the 2010 staff TOP 5 evaluation survey, as well as introducing the extensive resources developed over the previous four years. The overall concept and outcomes demonstrated a patient based approach to care.

The CEC made a successful submission to the HCF Health and Medical Research Foundation who provided funding to support researching the implementation of this initiative in 15 public and five private hospitals in NSW in 2012-2013. The focus of the implementation and subsequent evaluation was on the impact of TOP 5 on staff, on the carers of hospitalised patients with dementia and patient outcomes.

The overall aim of this study was:

- 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).



Figure 3: TOP 5 Card

Site Selection

The process of site selection involved initially sending a letter (Appendix A) from the CEC to most local health districts (LHDs) advising of the initiative and asking for expressions of interest to participate in the study.

LHDs and relevant specialty networks were approached by sending a letter to the chief executive and director of clinical governance. A notification of the initiative was also made to carer support units in each LHD.

For the private sector, the main private health care organisations were identified and a letter was forwarded to each chief executive advising of the opportunity to be part of the TOP 5 initiative and requesting facility nominations.

A total of 17 public facilities were nominated to be a lead site. This included a group (3) of multipurpose service sites. Five private hospitals were also nominated. The nominations were approved by the Chief Executive Officer of the CEC. The sites represented a diverse range of geographical location and peer groups throughout NSW.

Governance

A TOP 5 Steering Committee was formed to oversee the implementation of the initiative. Chaired by the Director of Clinical Governance of the Mid North Coast LHD, the committee consisted of nine members with a range of expertise and knowledge of aged care and dementia. Membership included a consumer advisor who had previously cared for a relative with dementia (Appendix B & C). The Steering Committee met on eight occasions with one of these eight meetings being held at a lead site (November 2012) so members could witness progress and to provide an opportunity to speak to local teams and hear of their experiences.

6.2. Implementing TOP 5 (Methodology)

Identifying the Team

After each Local Health District was notified of the inclusion of their lead site within the CEC initiative, they were asked to identify an implementation team consisting of:

- A Local Site Liaison officer (LSL) who would be the main contact with the CEC as well as providing local direction for the initiative.
- An Executive Sponsor – to provide leadership support and receive progress updates.
- Clinical Champion – usually a member of staff working with patients/carers likely to be involved with TOP 5.
- Carer Support Group contact (where available).

First Site Visits

The TOP 5 Project Coordinator (CEC) contacted each LSL to arrange a site “meet and greet”. The meeting purpose was to engage with the executive and clinical staff at the site to discuss the expectations and timeframes for the implementation and evaluation. The first visits were undertaken during June, July and August of 2012. The CEC TOP 5 Project Team conducted the sessions. Initial discussions with the sites were used to gauge their enthusiasm and commitment to the initiative.

Education

An initial education session was also held and involved a range of clinical staff who cared for patients with dementia as well as staff from other specialties who had less experience with this group of patients.

In the session, an initial overview of the TOP 5 initiative was provided by the CEC Project Team, followed by education provided by clinicians with expertise in dementia and delirium. The depth of education varied from site to site, from a comprehensive education program provided to all members of staff to a more targeted education for staff on the wards where TOP 5 was to be used.

Scope of Implementation

As the implementation teams were formed, sites were encouraged to determine the scope of implementation within their facility and the process to be used for the identification of the patients. Guidance was provided by the CEC project team when necessary but this was a local decision to both acknowledge local culture and to ensure adequate resources were available. Some metropolitan sites were keen to implement TOP 5 throughout the hospital but changed this approach soon after starting when they realised a focused implementation on one or two wards was likely to achieve the best initial

uptake.

The sites used a variety of methods to promote TOP 5 within their organisation and the local community. To promote TOP 5 internally, sites held a variety of events and presentations to clinical leaders to convey the message. Clinical champions also shared the concept with their colleagues in their clinical networks and in the hospital newsletters. To engage the local community carer support groups and community services were invited to attend information sessions or provided with brochures and newsletters. Many sites held a formal launch of TOP 5 involving the local community, hospital staff and media outlets.

Development of a Toolkit

A toolkit, based on CCLHD materials, was provided by the CEC to participating sites in August 2012, to be used for implementation purposes. This included promotional information, carer brochures, evaluation tools and a presentation and outline for education purposes. Templates for letters to media outlets and local stakeholders were also included. Additional materials such as printed carer brochures, TOP 5 Strategy Pads, laminated posters and record labels were also sent during the course of implementation.

Following discussion with the sites and multicultural health services, the carer brochure was produced only in English for this study. The range of sites meant that there was too much variability between sites in the most prominent non-English languages to obtain any commonality for translation. In addition, many sites stated a preference for face to face discussion with the carers and added that literacy was sometimes a problem in older carers from a non-English speaking background.

Gaining Research Ethics Approval

Research ethics approval was gained for the overall evaluation and site specific ethics approval gained for each site. The TOP 5 Project Team submitted a Low Risk/Negligible Risk application for approval to the Northern Sydney Local Health District (NSLHD) Lead Human Research Ethics Committee (HREC) for the public hospitals. Ethics approval for the research was granted in August 2012, including master forms for the evaluation.

For those private facilities without a formal ethics process, NSLHD HREC entered into a Memorandum of Understanding with the site. A part-time Research Assistant commenced in October 2012 and continued with the preparation of documents for ethics and ongoing liaison with site personnel about evaluation data.

For local research governance, each site required a 'Site Specific Approval' that demonstrated the facility was both aware of, and in a position to, undertake the project. This proved something of a challenge as each local health district had a different process in place. Contact was made with each research and ethics governance officer to facilitate this process. Site Specific Approval was gained for most sites before the end of 2012, with all sites approved by March 2013.

Local Site Liaison Forums

The TOP 5 Project Team established forums for the local site liaison officers (LSL) to meet, network and exchange ideas. The inaugural forum was held on 13 December 2012 with subsequent forums in May and November 2013. LSL attendance was high for these forums and the LSLs shared their stories and motivated each other in a structured way. The TOP 5 Project Team were able to answer questions, provide or clarify information and provide encouragement and acknowledgement in relation to the work the sites were undertaking.

Midway Site Visits

Further site visits were conducted between February and April 2013 by the project coordinator. The primary aim of these midway visits was to review how local implementation was progressing, to see how the staff were finding the process

and support evaluation data collection. At the ward level, the project team were welcomed and staff were eager to show what had been accomplished. Carers were also able and willing to share their experiences with the project team. For some sites, this visit was also used to further support the uptake of TOP 5 and to work on strategies to assist the LSL with aspects that needed improvement. Five sites required additional visits to work through issues that were barriers to uptake.

Throughout the initiative, the TOP 5 Project Team maintained regular contact with each site to support and encourage the local staff. Sites were encouraged to contact the project coordinator or research assistant if they required assistance or clarification of the implementation process or evaluation requirements.

Many staff commented that gaining information from carers was not unusual, however what was missing was that the current process was often informal and elements of staff communication had not been optimal nor always shared between staff.

7. EVALUATION

7.1 Overview

A mixed methods approach was used with both quantitative data (clinical indicators) and qualitative data (surveys, narrative text) collected from the participating wards. Variability in existing local data collections presented limitations to the collection and analysis of study data. At one public hospital site, there was the opportunity to collect quantitative data from a matched 'control ward' not implementing TOP 5.

For the data analysis, the 3 multi-purpose services (MPS) were treated as three separate facilities as they provided separate data. One private facility (a rehabilitation hospital) was excluded from the data analysis as they did not manage to implement TOP 5 and collected no data. The final process evaluation, however, includes consideration of barriers identified at this site. Hence the final sample for data analysis was 21 hospitals: 17 public and four private.

The quantitative data was analysed by the research team from the CEC and the UTS Centre for Health Economics Research and Evaluation (CHERE) using a range of statistical methods within the STATA and SPSS programs. Thematic analysis was undertaken for the qualitative data. Health economists at CHERE conducted the cost analyses.

Whenever possible electronic collection was used to obtain the data required. During the implementation period, each site was asked to collect and provide specific data from the wards using Log Sheets to demonstrate more accurately the clinical outcomes for patients with dementia.

Surveys were used to gather additional information from staff about the process and their knowledge and perceptions about TOP 5. Each site was encouraged to share stories relating to the use of TOP 5 and some of the tips and strategies developed. These insights were shared between the sites at local site liaison forums held at regular intervals at the CEC.

Carers were asked to provide feedback on the initiative and many provided comments that were additional to the evaluation surveys completed by carers.

During site visits by members of the TOP 5 Project Team, additional information was obtained through feedback from the staff and observation at the time of the visit and was recorded in the site visit report.

7.2 Data Collected

The following tables outline the indicators used and associated data sources. The data was obtained for the wards or units or services that implemented TOP 5.

Table 1: Midway Report & Process Survey		
Source: LSL required to provide process information via online electronic survey		
Name	Areas	Main Use for Data
Midway Report	Implementation process Local governance Staff knowledge & acceptance Carer knowledge & acceptance Observed benefits Enablers & barriers	To determine how implementation had progressed, who was involved
Process Survey	Classification of staff for LSL and Implementation Team Time spent on TOP 5 activities Education provided Method for obtaining TOP 5 Other strategies implemented that could confound the evaluation of the impact of TOP 5.	Mainly used for economic analysis. Identified barriers to the process.

Table 2: Surveys – Staff*		
Source: On wards/units/services where TOP 5 was implemented		
Name	Period of evaluation	
Staff survey 1 (12 questions)	Pre-education/implementation	> 6 staff
Staff Survey 2 (15 questions)	Midway (after approximately 6 months of implementation)	> 6 staff
Staff Survey 2 (15 Questions)	End of implementation	> 6 staff

*N.B. A sample number of 6 or more of staff were identified to complete the survey. The surveys were used to elicit staff perceptions about TOP 5 and their understanding of dementia care and their skills in aspects of communication.

Table 3: Surveys – Carers**		
Source: Survey provided to carer with envelope (process for provision & return varied across sites)		
Name	Process Provision	Process Return (SAE Provided)
Carer Survey (6 questions)	Provided during stay Provided at discharge Follow up after discharge	Placed in box on ward Returned to LSL Posted directly to CEC

**N.B. Carer surveys were obtained by the local sites in a variety of ways. Not all sites kept records of how many carers had been asked to provide a response so it was not possible to determine the response rate. This resulted in some limitations on the feedback.

Table 4: Ward Log Data - Collected by Staff During Implementation Period		
Source: Collected on each ward using TOP 5 by a member of staff/LSL and collated by LSL		
Indicator	Period and format***	Source
Number of patients with dementia	By month with collection ceasing in August 2013	Staff recording of patients on their ward
Number of TOP 5s initiated		
Number of Patients assessed and identified with dementia after TOP 5		
Number of patients with dementia requiring 1:1 'Specials'		
Number of patients with dementia restrained (mechanical)****		
Number of patients with dementia restrained (chemical)		
Number of patients with dementia who had a fall		

***N.B. The collection start period varied as each site started using TOP 5 at different times (i.e. after local ethics approval, after education etc.)

**** Collection of this indicator ceased after feedback from the sites indicating that mechanical restraint was rarely if ever used.

Table 5: Electronic Data Collection		
Source: Health Information Exchange (HIE), Incident Information Management System (IIMS)*****, Hospital Records		
Indicator	Period and format	Source
Number of patients admitted – any diagnosis	July 2011 to Aug 2013 by month	HIE
Average length of stay – any diagnosis		
Number of patients admitted – 1° or 2° diagnosis of dementia		
Average length of stay – any diagnosis 1° or 2° diagnosis of dementia		
Number of patients assessed for dementia	July 2011 to Aug 2013 by month	Hospital Records
Number of patient falls (NB: ALL PATIENTS)	July 2011 to Aug 2013 by month	IIMS
Number of patient complaints (regarding communication with carers)		
Number of Specials (1:1 care) used	July 2011 to Aug 2013 by month	Hospital Records
Use of non-regular anti-psychotics		

*****N.B. The IIMS system is a self-reported incident management system. Data may, therefore, not be reflective of all incidents.

7.3 Planning for the Evaluation Components

The indicators required for evaluation were presented and discussed with the lead sites on the CEC's initial visit. The aim was to determine indicators that were relevant and not too onerous for staff to collect. All sites expressed a willingness to provide the data. During the first few months of the implementation, the following items were provided to assist the staff with their collection:

- Log Sheet for the recording and collation of the ward level log data. (Appendix D)
- Clarification on the use of anti-psychotics for chemical restraint and identification of commonly used drugs for this. (Appendix E)
- Evaluation Components and Due Dates – to clarify data required and when it was due by each site for submission to CEC. (Appendix F)

7.4 The Evaluation Process

7.4.1 Midway Report and Process Survey

The LSL was asked to provide information that would be used to evaluate the implementation process. Two tools were developed to support this part of the evaluation. The first tool was the Midway Report (Appendix G) which was completed by most sites in January 2013. This information provided understanding of how implementation had progressed and who was involved at the site.

A further collection of information was requested of the LSL in August 2013. The 'Process Survey' information (Appendix H) was used for economic analysis and also identified barriers to the process of evaluation.

7.4.2 Staff Surveys

Staff surveys consisted of:

- Pre-implementation – completed prior to staff education about patients with dementia and the TOP 5 concept (Appendix I)
- Midway Survey – completed at the midway point of the TOP 5 implementation phase (Appendix J)
- Post Implementation – completed at the end of the monitored implementation phase. (Appendix J)
- Staff Consent for providing and using their feedback. (Appendix K)

The LSL was responsible for overseeing the completion of staff surveys at their site. The pre- implementation survey assessed the staff's perceived knowledge of dementia, attitudes towards patients with dementia and their carers and confidence in caring for patients with dementia. The post-implementation version retained these questions and included further material assessing the acceptability of the TOP 5 process and staff impressions of its impact. The surveys were completed by staff in hard copy and returned to the LSL, who delivered them to the CEC in bulk either by post or email. Anonymous survey responses were entered into a secure database and hard copies were stored securely.

Issues: Due to staff turnover and logistical difficulties with follow-up, it was not always possible to retain the same core group of staff to be surveyed at each time point.

7.4.3 Carer Survey

The LSL was also responsible for overseeing the completion of the carer survey. (Appendix L) Carers of patients with dementia were asked to complete one survey each during the acute care admission. They were also asked to provide

consent for the use of their feedback (Appendix M). The carer survey assessed carers' satisfaction with the way staff had communicated with them, their satisfaction with the TOP 5 process and their perceptions of its impact.

One question within the survey identified carers who had had a previous admission experience and this was used to provide a comparison between carer perceptions at these different times. The mode of return/collection varied across the sites. Typically one survey was provided to the carer to complete prior to discharge/transfer. Carers completed the survey in hard copy and either returned it to the LSL, placed it in a designated box on the ward or posted it directly to the CEC. At the CEC, anonymous survey responses were entered into a secure database and hard copies were stored securely.

Issues: Fewer carer surveys were returned than anticipated. Upon inquiry to the sites it was found that a number of carers did not appreciate that the survey was part of the evaluation research. Indeed, many carers expressed that they had already conveyed their satisfaction with the TOP 5 process to the staff and did not feel the need to complete a survey.

7.4.4 Quantitative Indicators

Two separate methods of collection for quantitative data were undertaken:

Ward Log Data

The quantitative indicators making up the ward logs (see Table 4 in Section 7.2) were collected manually by staff on the ward, according to their knowledge of the day-to-day occurrences on the ward. Staff were requested to identify patients with dementia and falls, use of anti-psychotics for chemical restraints and 1:1 nursing (specials). The personnel responsible varied across sites - in many cases the nurse unit manager (NUM) was given this task. The log data was then collated by the LSL and provided to the CEC at monthly intervals, where it was transferred to a secure database.

Issues: This mode of data collection was found to be very time consuming by many staff and was incomplete at several sites. One site chose not to involve ward level clinical staff in this collection and provided a comprehensive monthly report providing the detail requested by the CEC by audit of clinical records.

Electronic Indicator Data Collection

These quantitative indicators were obtained from the Health Information Exchange Data (HIE), the Incident Information Management System (IIMS) and where available from Hospital Records (see Table 5 in Section 7.2). The data was sourced at each site by the LSL, in consultation with their facility's performance or data management unit and according to specifications given by the TOP 5 Project Team. After the CEC received the data, it was transferred into a secure database. The data included all patients that had been admitted to the ward/unit where TOP 5 was implemented.

Issues: a local data person to co-ordinate the collation of this information was not identified at the beginning of the implementation at many sites and hence it became time consuming for the LSL to source the reports. In addition, the coding of medical records occurred after the patient's discharge and this timeframe produced a data availability 'lag' which varied from 4 to 8 weeks.

7.5 Control Ward

At one public, metropolitan principal referral hospital (Hospital 13), the opportunity arose to collect data from a ward not implementing TOP 5, making a 'control ward' possible. At this site, the unit implementing TOP 5 was an acute aged care ward. While the control ward was selected to be the closest possible match to the intervention ward in terms of patient characteristics, there were a number of operational differences between the two wards.

The TOP 5 intervention ward is a locked ward, with patients considered at risk of wandering or falling more likely to be admitted there rather than to the control ward. While the control ward was initially a mixed medical ward, nearly all patients were admitted by a geriatrician and under the care of the aged care department. Six months after the introduction of TOP 5 in the intervention ward, the control ward also became a dedicated acute aged care ward.

HIE and IIMS data (refer to table 5 in Section 7.2) was sourced for both wards. Log data (refer to table 4 in Section 7.2) was collected only for the intervention ward.

7.6 Analysis Methodology

Staff and carer survey data was analysed with basic frequency analysis, supplemented by t-tests and ANOVA with contrasts where responses were to be compared by group or time point. Free-text questions were evaluated using qualitative thematic analysis.

Analysis of quantitative indicators was undertaken by the Centre for Health Economics Research and Evaluation, University of Technology, Sydney (CHERE). HIE and IIMS data (refer to table in Section 7.2) was analysed using a series of regression analyses. Three regression models were formulated. The first contained the overall time trend, shift since the introduction of TOP 5 and change in the time trend since the introduction of TOP 5. The second model added variables controlling for seasonal effects, and the third model also included a variable controlling for any parallel fall-prevention strategies as reported by each site.

For analyses in which data was aggregated across sites, an interrupted time series was conducted. Where sites were analysed individually, an Ordinary Least Squares regression was used.

For all analyses where data was aggregated across sites, only the intervention ward at Hospital 13 was included. For all individual-site analyses, the intervention ward was compared with the control ward over time.

The process survey data was used by the health economists at CHERE to evaluate cost.

8. FINDINGS

Additional information relating to the statistical findings (Notes) can be found in Appendix N.

8.1. Information on Participating Hospitals

8.1.1 Hospitals by Peer Groups

The public hospitals involved ranged in peer group from principal referral to multipurpose service facilities and were located in 10 different NSW Local Health Districts. Services included medical, surgical, aged care, coronary care and emergency departments. The private facilities involved were all metropolitan hospitals, covering three different private provider groups. See Figure 4 for detail.

One hospital (Hospital 22), a private rehabilitation hospital, was nominated as a lead site but did not implement TOP 5, citing the following issues: internal refurbishments reducing the numbers of patients admitted, an overall lack of patients with dementia admitted and a lack of acceptance by staff. Hence this site has not been included in the data analysis but nonetheless provided useful feedback for this report regarding enablers and barriers.

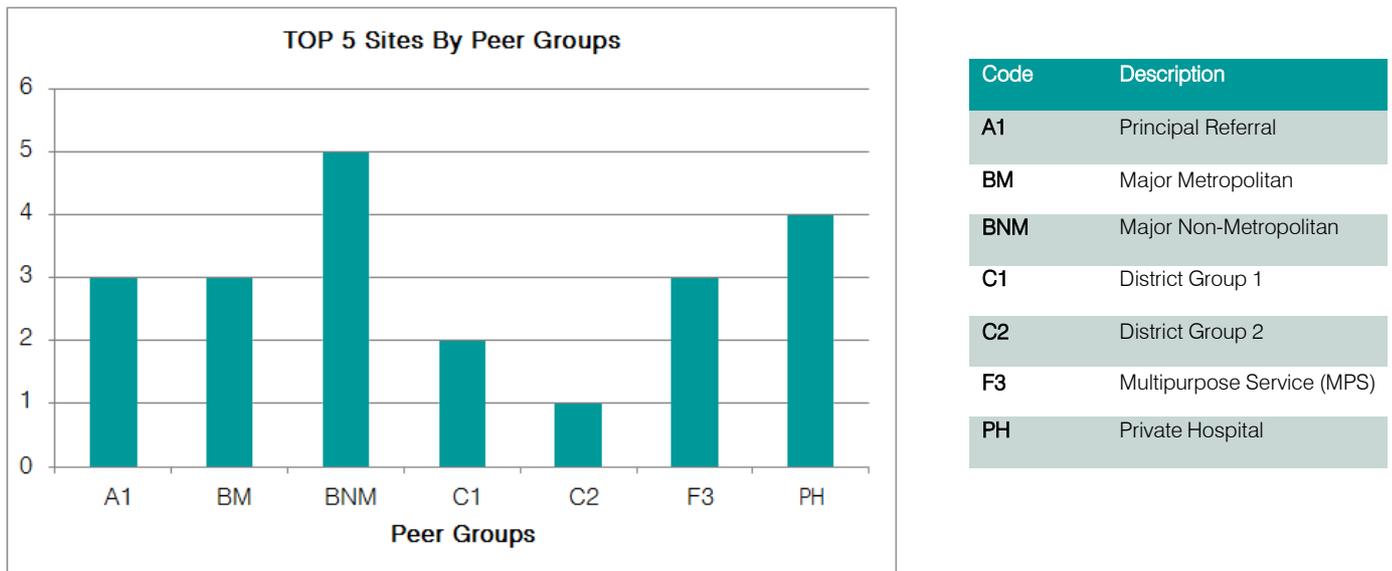


Figure 4: TOP 5 Sites by Peer Group

8.1.2 TOP 5 Initiations by Hospital

A total of 1277 TOP 5s were initiated across 21 sites. Sites initiated an average of 58 TOP 5s each, throughout an implementation period that averaged nine months. This equates to an average of six TOP 5s a month. See Figure 5 for a full breakdown of information by site.

Site	Peer Group	TOP 5s initiated	Av TOP 5s per month
1	C1	157	16
2	BNM	148	13
3	BNM	109	9
4	C2	6	1
5	C1	19	2
6	BNM	24	2
7	A1	191	24
8	MPS	21	3
9	MPS	18	3
10	MPS	6	1
11	BM	115	14
12	BM	59	15
13	A1	102	8
14	A1	114	14
15	BNM	13	3
16	BNM	21	2
17	BM	11	4
18	PH	20	2
19	PH	21	2
20	PH	75	6
21	PH	27	3
PH = Private Hospitals		TOTAL = 1277 AV. = 58.05	AV. = 6

Figure 5: TOP 5s initiated and average TOP 5s per site/month

8.1.3 Using TOP 5 – Process of Implementation

The simplicity of the strategies is key to the success of the program. A selection of strategies developed by sites during the study is included below to illustrate this. The biggest challenge to staff seemed to be translating the carers' tips into a workable strategy for the hospital environment.

Strategy 1 - Major – Non Metropolitan Hospital

Background - One gentleman had been an ambulance officer: all our 'bells and whistles' only escalated his anxiety: with him thinking he needed to jump into action at an 'emergency'. The simple act of discussing all health issues, in a professional exchange, as if we were 'at work' helped a lot. He settled well, and trusted us.

The Strategy – Mr B worked as an ambulance officer and whenever he hears a call bell he becomes very anxious. Speak to him as if he is a member of the team using professional terminology and advise that 'another car is responding'. He will then become settled.

Strategy 2 - Principal Referral Hospital

Background - Mr G was usually a very gentle and proud man but he became very agitated after his shower. Discussion with his wife told us he became very upset if he did not have his watch on his wrist. She always made sure it was replaced as soon as possible.

The Strategy - Mr G is a man who likes to be properly dressed. He always wears a wristwatch and becomes quite agitated if he is not wearing it. During his shower reassure Mr G that you will put his watch back on after he is dry and put his watch back on as soon as possible. Then he will not become agitated

Strategy 3 - Major Metropolitan Hospital

Background - Mrs F came from a Residential Aged Care Facility (RACF). She had limited vision and did not interact well with the staff. At times she became quite verbally aggressive. The RACF was contacted and some tips were provided. Strategies were put into place and the staff saw that Mrs F acknowledged the nurse and was calmer.

The Strategy - Mrs F has a deep faith and likes to read her Bible. Because of her limited vision she can longer do this. If one of the staff is able to read something from the Bible when she becomes restless this will settle her.

Strategy 4 - Major Non – Metropolitan Hospital

Background - An 82 year-old gentleman was admitted from his home where his wife was his carer. The patient had polio as a child and had worn a splint on his left leg when walking.

The Strategy - Mr B had polio as a child and wore a splint on his left leg. The leg gets very cold and painful. When in bed, the left foot should be wrapped up to keep it warm. He will then settle down and sleep.

Strategy 5 - District Group 2 Hospital

Background – Consulting with a distressed patient who didn't want her son to leave her alone at the hospital, a discussion with the son provided a quick overview of what the patient liked to talk about, what provided a pleasant distraction and who to talk about. He also brought some personal things in.

The Strategy – Mrs B gets very anxious when her son is not here. Tell Mrs B her son (Tom) will be back in the morning. Talk to her about her recent holiday and point to the photo on the bed locker. There are also magazines for her to read in her locker draw. Mrs B will quickly settle and will happily read her magazines when you leave.

Strategy 6 – Multipurpose Service

Background – a gentleman (Bob) without a primary carer was admitted to the service. He used to get very agitated each morning at 4.30am and was very difficult to settle. One day a visitor came into the room and recognised Bob. The staff asked the visitor if he knew anything about Bob that might explain his daily agitation. He was able to shed some light on the situation and the staff used the information to develop a TOP 5 strategy

The Strategy – Bob used to manage a delivery yard and part of his job was to get the trucks on the road by 4.30am each day. Just say 'Bob, the trucks are all gone' and he will settle.

Strategy 7 - District Group 1 Hospital

Background - An elderly gentleman was admitted from a RACF. His wife visited him each day but he also had a nurse in the RACF who knew him really well. He had been a prisoner of war in a Japanese POW Camp.

The Strategy - Mr C had been a prisoner of war in a Japanese POW Camp. He will become very distressed if he receives rice to eat or is approached by a Japanese male. If he is distressed please speak quietly to him and talk about his wife. He will then become less distressed and settle.

Strategy 8 - Major Non – Metropolitan Hospital

Background - A male patient was awake about 4am and starting to wander around the ward.

The Strategy - The nurse on duty read the TOP 5 chart and found that the patient liked to watch rugby league, so she turned the TV on to a game and the patient settled in bed in his single room to watch the game.

Strategy 9 - Major Non – Metropolitan Hospital

Background - A male patient was walked by the physiotherapist each day to improve his mobility and improve his safety. After his walk the patient sometimes became agitated and started to walk by himself.

The Strategy – The nurse read the TOP 5 strategies developed for this gentleman and started a conversation about the suburb where he was born and raised. The man sat down in his chair, settled and stopped wandering.

Case Studies

The following site case studies demonstrate the impact that TOP 5 has had in different sites and for a range of staff and carers:

Case Study – Changes to Model of Care

In Hospital 1, TOP 5 was initiated on medical, medical respiratory, surgical wards and the special care nursing unit.

One of the wards, (medical) is a 30 bed unit, has 12 aged care beds and a four-bed behaviour room. This behaviour room is where patients who have dementia and exhibit challenging behaviours are usually cared for. The room is monitored by an assistant in nursing (AIN). This staff member is allocated to this room only.

Upon commencement of the TOP 5 initiative, medical ward staff started to discuss the current model of care that the ward was using. The Ways of Working strategy encourages staff to suggest changes to the manner in which they work and in line with this the staff met with the NUM and discussed the model of care. The possibility of disbanding the four-bed room was discussed given that TOP 5 was now being implemented. From 1 December 2012, the ward decommissioned the room and now dementia patients have the TOP 5 completed and are managed effectively within the main medical ward. The member of staff is now available to all patients in the ward.

The site reported that staff were very positive about TOP 5 and the potential the strategies had to minimise anxiety and stress for patients with dementia admitted to hospital.

Case Study - TOP 5 throughout the Patient Journey

In Hospital 3, TOP 5 was implemented across a network of facilities although the evaluation was confined to the lead site. A large implementation team was identified that met on a regular basis. Minutes of the meetings were distributed widely within the network. A system was developed to register each TOP 5 patient centrally and this was followed up by the LSL. In one year, 109 TOP 5 patients were registered. The TOP 5 patients were identified early in the admission process by either having a diagnosis of dementia or when staff observed some memory problems. This was then clarified with the carer as being a long standing problem or a more recent event. The knowledge gained contributed to better recognition of delirium and the need for specialist input to explore causes. Staff were able to apply the TOP 5 across the continuum of care and information gathered from the carer was communicated to the staff at each point of care.

Patient Story - One patient was admitted from home for an elective procedure. Due to other co- morbidities including vascular dementia, his condition worsened and he moved between several wards. The staff had spoken with his carer when he first came to the hospital and were able to use the information gained to develop TOP 5 strategies to support and calm him (e.g. names of his wife, children and family dog as well as his love of gardening). The patient was unable to return home and required long term placement. The TOP 5 strategies followed this gentleman's journey ensuring that staff had knowledge about his needs and preferences to be used to personalise his care in a changing environment.

Case Study – Impact on Medical Staff

In Hospital 1, TOP 5 was implemented on the surgical and medical wards. The initial meeting at the site involved one or two of the Medical staff but the main enthusiasm came from the nurses and allied health. The Carer Support Group had already recognised the value of the process and were keen to work with the implementation team.

At the midway visit, the TOP 5 Project Team had the opportunity to talk to several registrars. One stated that the best thing about TOP 5 was that it gave the doctors insight into the person and gave them something to talk about. The doctor explained that when covering the hospital after hours they often had to review patients that they had never met. Knowing something about that person was often the key to communicating with the patient, especially those with dementia. The doctor acknowledged that at times anti-psychotics were requested to settle a person whose behaviour was escalating. TOP 5 gave all staff a different option to try first – a communication strategy rather than a drug based approach.

Another doctor stated that patients admitted to hospital were often very scared. Being able to talk about non-clinical things that were relevant to that person was a great 'ice breaker'! Being able to see the TOP 5 strategies by the bedside meant that you could use them immediately.

Case Study – Dying With Dignity

In Hospital 4, TOP 5 was implemented on both the acute and aged care wards. Initially, the uptake was slow and a follow up visit was arranged to work with the local staff to see what could be done to improve uptake.

During the visit, the project coordinator met the carer involved in the first TOP 5 issued at this site. The carer was the wife of the patient and she described some of her husband's issues. His dementia had progressed to a stage where he had behavioural problems that caused distress for both the patient and the people around him. The carer was quite exhausted. When her husband was admitted to hospital, the staff explained TOP 5 and gained some personal information from the carer about the patient which they used when his behaviour became difficult. The carer stated that she believed TOP 5 had provided her husband with a level of dignity she had not previously experienced. Her satisfaction with the process and care provided was significant.

The LSL commented that at first she did not think TOP 5 would be suitable for this patient, as soon after admission the patient progressed into the terminal phase of his illness. Initiating a TOP 5 helped the carer and staff to manage this man's care during the final days of his life.

The patient died soon after the site visit but the patient's wife reiterated her thanks to the LSL who provided feedback to the TOP 5 Project Team.

Case Study – Multicultural

Hospital 17 had the most diverse patient and staff population in the lead sites. TOP 5 was implemented on the transitional care unit and medical ward. The initial engagement with staff was both positive and negative with not all staff seeing the benefits to them and their patients. TOP 5 was promoted around the hospital and implementation started very slowly.

The LSL noticed a patient on one of the wards and asked if the staff had implemented a TOP 5 for the patient. The staff said that had not been done as 'the patient did not speak English'. The patient had an Arabic background. He was known to become very angry at times.

The LSL approached the family and discussed TOP 5. The family had wondered why their father did not have this in place as they had read some information about the process. The family agreed that their father was a little confused but were happy to give the staff some Arabic words to assist their communication with him and also mentioned some things that their father liked to watch on TV or see in books.

After the staff used some Arabic words, the patient responded amazingly. He no longer became angry and when staff observed he was getting agitated the staff directed his attention to a book his family had brought in about his culture.

This case highlighted to staff that TOP 5 can be used for patients from any cultural background.

8.2 Using TOP 5 – Enablers and Barriers

During the course of the implementation, the Project Team and the sites identified 'enablers' and 'barriers'. This information was shared across the sites.

8.2.1 Enablers

Key Learnings – a successful implementation relied on staff acceptability and the existing culture of engagement with carers.

In the Midway Report, LSLs were asked to provide any factors that they felt had particularly enabled the implementation of TOP 5 at their site. From these responses, several main themes emerged:

- Leadership – this was seen to be of great importance during the implementation.
- Executive leadership and support, NUM commitment and medical staff involvement were all in place for the more successful implementations.
- Local Site Liaison – this position was integral to the ongoing implementation and typically acted as a central driver.
- Clinical 'champions' - if the implementation was across several wards it was important to establish clinical champions for each ward/unit to drive the process and maintain the focus of the staff.
- Multidisciplinary involvement - a key component that reinforced the concept of patient based care being everyone's responsibility and developed and supported the team approach to care.
- Education - focused on improving the knowledge and confidence of the acute care staff on aspects of dementia and delirium. Providing the methodology for instigating conversations with carers (as per the TOP 5 supporting information) was also considered important to improve communication skills across the board.

8.2.2 Barriers

Key Learnings - early identification of barriers enabled strategies to be developed and implemented.

In the Midway Report, LSLs were asked to identify any barriers they had faced in implementing TOP 5 at their site and how these were overcome. From these responses, several main themes emerged:

- Staff resistance – despite the simplicity of TOP 5, several staff took some time to embrace the concept. The potential ‘time consuming impact’ of each new undertaking by hospitals was perceived to have often overwhelmed staff. With so many competing priorities, these staff had to visualise the time saving and experience the benefits for themselves and their patients before becoming fully engaged.
- Carers - some sites reported having limited patients that fitted the criteria and in addition many patients without a specific carer being identified. The carers of patients coming from RACFs were often not aware of current patient needs and preferences and the staff within those facilities were not readily identifiable as the main carer.
- Carer reluctance to participate - In the private sector, two hospitals reported that carers were reluctant to identify cognitive impairment in their loved one as they perceived this would impact on the care they received. Some carers did not see the benefits of being part of the TOP 5 process.
- Confidence of staff – some staff were uncomfortable engaging with carers and their communication skills with carers were not always optimal.

8.3 Staff Attitudes, Confidence and Knowledge

The staff surveys contained a series of items intended to gauge staff attitudes toward caring for patients with dementia and engaging with their carers, as well as their self-perceived knowledge of dementia and confidence in caring for dementia patients. These items were common to the surveys conducted prior to implementation, midway through implementation and at the conclusion of the evaluation period, in order to capture any effect the TOP 5 initiative might have had on these variables.

The responses received on surveys submitted prior to the implementation of TOP 5 (N=466) show high levels of staff acceptance of carer input (*Note 1*). These high initial scores produced a ceiling effect, such that no statistically significant change was evident between these and ratings given on surveys submitted after six months of implementation (N=164) and at the end of the evaluation period (N=128). However, there was evidence of a significant increase in the proportion of staff reporting that they obtained key strategies from carers to help manage the patient. This difference was sustained between surveys submitted at six months and those submitted at the end of the evaluation period (*Note 2*). These results imply that while staff already regarded carer input as being positive and valuable, the TOP 5 initiative gave them the tools to actually utilise this input as part of patient care.

A significant increase in staff’s self-reported confidence in caring for patients with dementia was found between surveys completed prior to the introduction of TOP 5 and those completed after six months, see Figure 6. This increase in confidence was sustained between six months and the end of the implementation period (*Note 3*).

Staff Comments - Improved competence and confidence:

"Since TOP 5 arrived I feel more confident in dealing with both patient & carer."

"I think it is excellent - gives you the satisfaction that you are giving competent care."

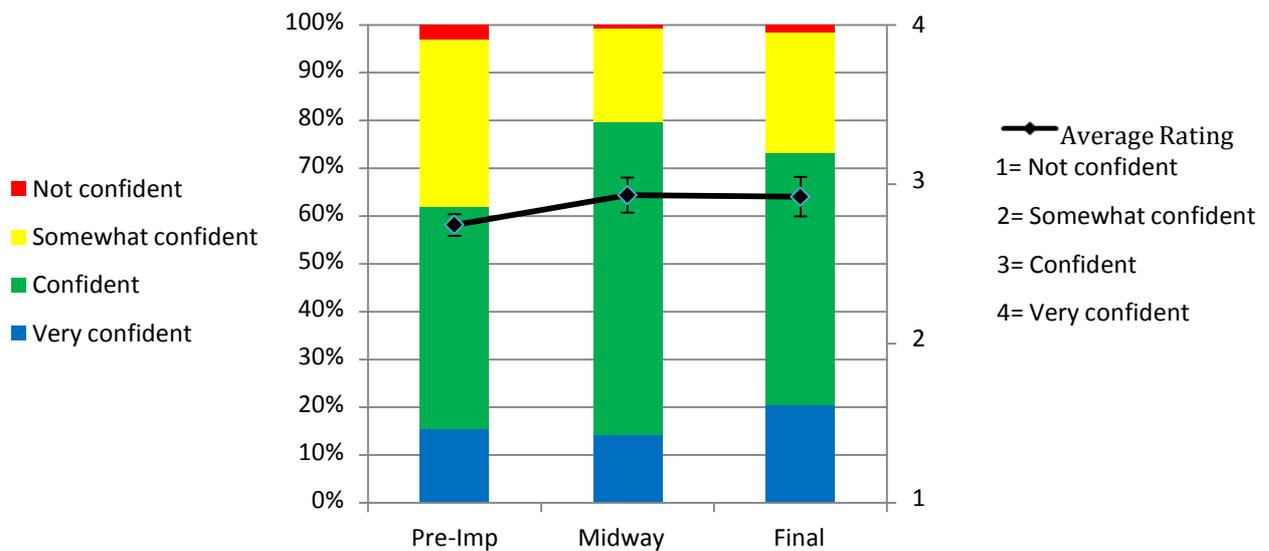


Figure 6: Staff confidence in caring for patients with dementia

These results were echoed in qualitative analysis of staff responses to free-text response questions. One emerging theme from comments by 18 staff was that TOP 5 had had a positive effect on their own experience of caring for patients with dementia. They reported improvement in the quality of care they could provide, increased confidence and improved morale.

A further 22 staff provided responses on the theme of carer and family engagement, making direct reference to TOP 5 as facilitating this engagement and its positive effects.

The findings indicate that TOP 5 has had a positive impact on staff. The initiative has acted as a catalyst in converting positive attitudes toward carer engagement into action. It has brought the unique needs of patients with dementia to the fore, leading to an increase in staff confidence in caring for patients with dementia.

Staff Comments- Facilitating family/carer engagement

"It is basic & easy to understand & it encourages family to participate in their family member's care."

"It's a wonderful tool that assists in 'breaking the ice' between nursing, clinicians and carers."

8.4 Acceptability

8.4.1 Staff

The staff surveys completed midway through implementation (N=164) and at the end of the implementation period (N=128) contained items assessing the acceptability of the TOP 5 process for the staff involved.

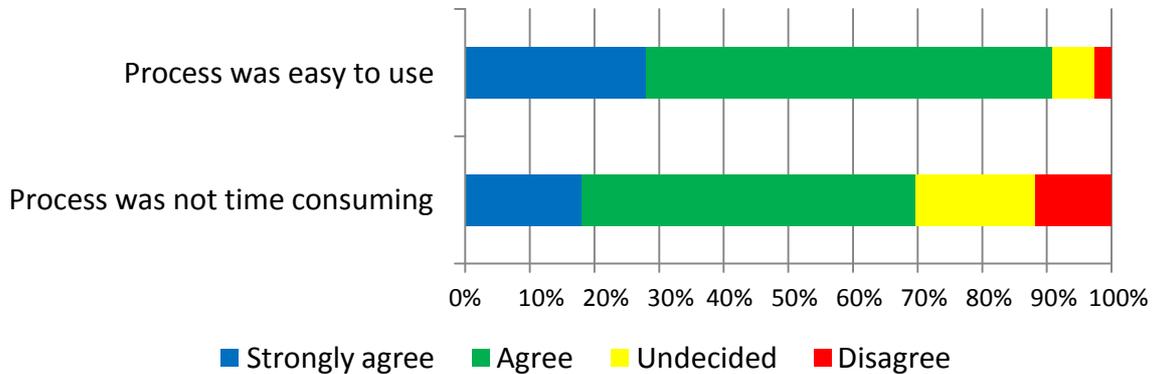


Figure 7: Staff Perception of the acceptability of TOP 5

As seen in Figure 7, the majority of staff perceived the TOP 5 tool to be both easy to use (90.7% agreed) and not unduly time consuming (69.8% agreed). These two key domains of acceptability are crucial to ensuring uptake. Furthermore, staff also perceived TOP 5 to be effective, with 74 per cent agreeing that patients were less agitated and distressed with TOP 5 in place, and 89 per cent agreeing that TOP 5 made it easier to relate to carers. There also appears to have been flow-on effect to staff well-being - 79 per cent reported being more satisfied with their work in caring for patients with dementia.

There were no statistically significant differences in staff ratings of any of these factors between surveys submitted after six months of implementation and those submitted at the end of the evaluation period (*Note 4*). This indicates that these positive staff attitudes towards TOP 5 were sustained over time and further experience with the initiative. Overall, TOP 5 has proved to be acceptable to staff members as a tool to enhance their work in caring for patients with dementia.

Limitations:

Survey results may be subject to response bias - staff who had positive attitudes toward TOP 5 may have been more likely to complete and submit their survey.

Surveys may not have been completed by the same core group of staff at each site over the three time points. Staff changes also made it difficult to ensure the same set of respondents.

8.4.2 Carers

The carer surveys (N=240) contained items assessing the acceptability of the TOP 5 process from the point of view of carers of patients with dementia. 97 per cent of carer respondents reported being satisfied with the information they were given about TOP 5. This reflects the quality of the written materials they received, but also the skill of staff in communicating the aims and process of the initiative in their conversation with carers. Furthermore, 97 per cent were satisfied with the way staff had used the TOP 5 strategies to personalise care, indicating that carers believed the process had been successfully applied. Of the 3 per cent who reported

being unsatisfied, some explained in a free-response question that they admired the TOP 5 concept but had not observed the staff using it for their loved one.

Of the carers completing a survey, 60 per cent reported that their loved one had experienced a previous hospitalisation. Among this group, carers reported significantly higher levels of satisfaction with the relationship with staff for the hospitalisation where TOP 5 was in place compared to the previous hospitalisation, without TOP 5 (Note 5). Figures 8-10 indicate the changes that carers observed in each facet of staff engagement. Note that with TOP 5 in place, no carers indicated being 'Very dissatisfied' with any of these aspects.

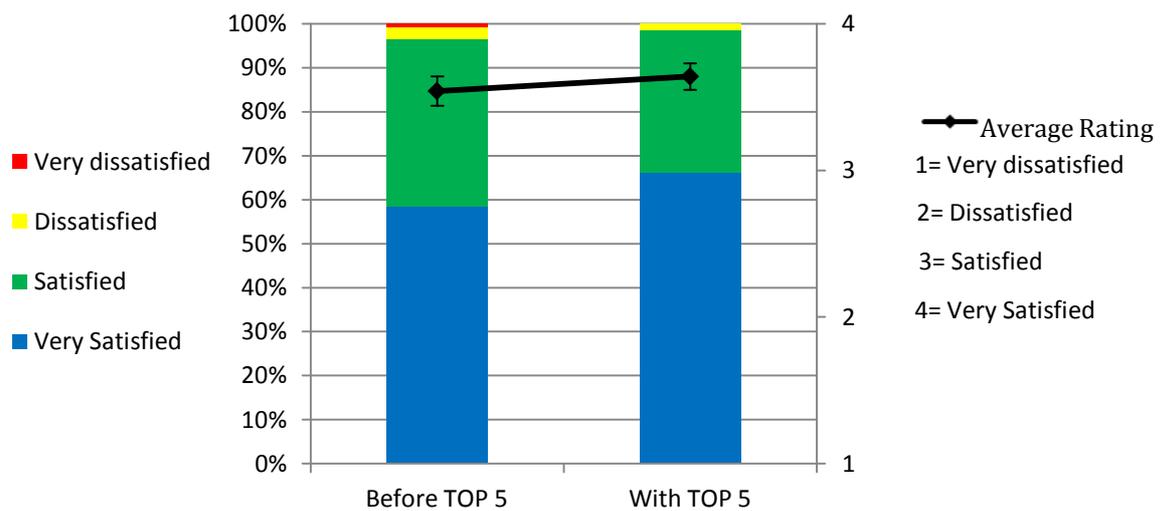


Figure 8: Carer satisfaction with staff awareness of the carer's role

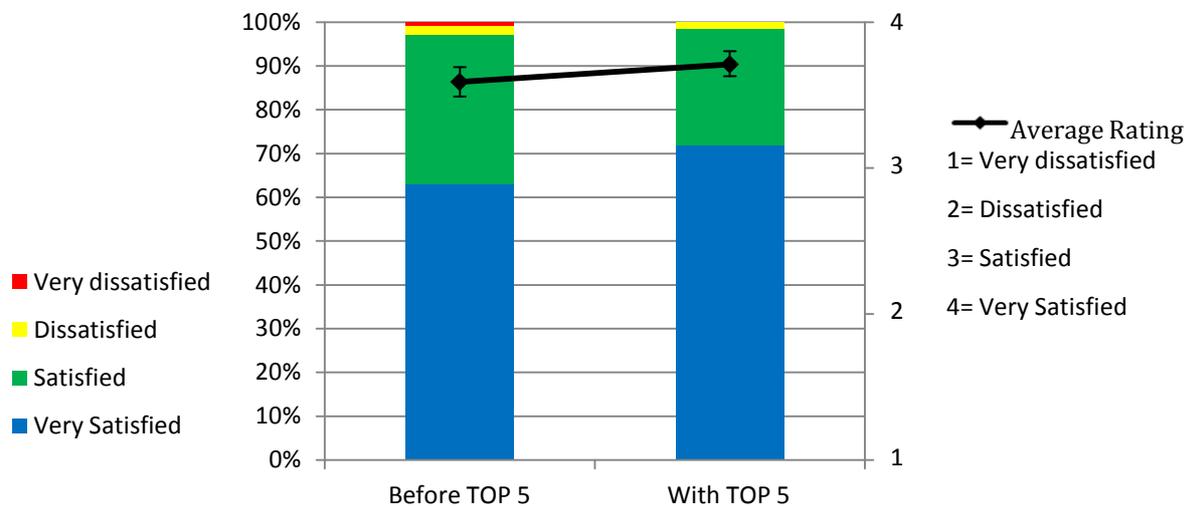


Figure 9: Carer satisfaction that staff made the carer comfortable to provide information

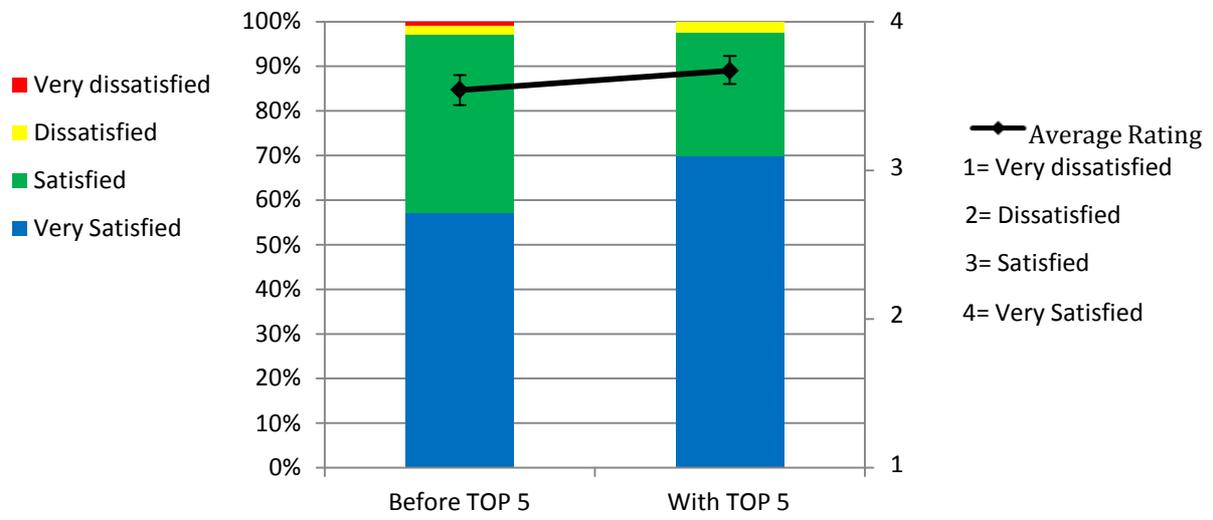


Figure 10: Carer satisfaction that staff listened to and took notice of the information provided.

Along with this observed improvement in staff engagement, 88.5 per cent of carers agreed that the initiative had facilitated their own engagement in care. This sentiment was echoed in carers' free-text comments, many of which made reference to the positive effect TOP 5 had on their own experience of their loved one's hospitalisation.

These results demonstrate that the TOP 5 initiative and the way staff have used TOP 5 has been generally well-received by carers. Not only is the process itself acceptable to carers, they also perceive it to be effective in enabling engagement and partnership with staff. It is implied that this improvement may translate into an improved experience for the patient. In fact, 85 per cent of carers also agreed that TOP 5 had benefitted the patient with dementia that they cared for and 82 per cent agreed that the patient was calmer as a result of TOP 5.

Limitations:

Survey results may be subject to response bias - staff at many sites reported that carers who said care was good had no further comment and therefore did not feel it necessary to complete a survey.

The true response rate is not known as it is not possible to determine how many surveys were distributed to carers at each site, due to variation in follow-up processes. On average, the carer survey responses represent 26 per cent of TOP 5s initiated at a site, with one site achieving 92 per cent.

Carer's Comment - Engagement in care:

“This initiative makes the carer feel respected as well as involved in the ongoing treatment of their loved one.”

Carer's Comment - Change in staff attitudes:

“TOP 5 is invaluable as it makes staff aware of the patient's humanity & individuality.”

8.5 Patient-Related Outcomes

8.5.1 Falls

Using ward log data, this demonstrated a 36.4 per cent reduction in falls by patients with dementia by the sixth month of using TOP 5 in hospitals that reported falls involving patients with dementia at the beginning of the initiative (Note 6). Due to staggered implementation, overlapping data was only available for the first six months for these five hospitals.

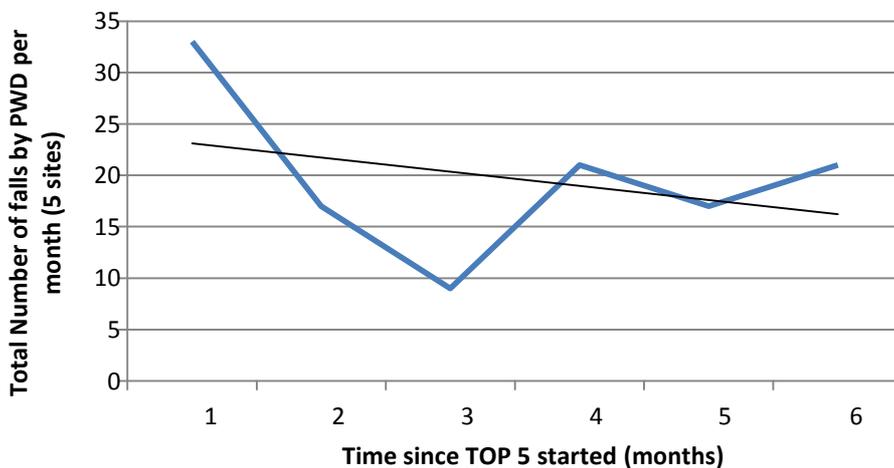


Figure 11: Falls by patient with dementia across five sites that reported falls at the outset.

Analysis of incident reporting (IIMS) for falls among all patients on a unit/ward was conducted for all the public hospitals (NB: it was not possible using this data source to confine the data to falls in patients with dementia). When analysed in aggregate, there was no evidence of a change in the number of IIMS-reported falls across all sites after TOP 5 was put in place. However, when analysed individually, some sites displayed significant change. At hospital 7, an immediate downward shift was detected in the number of falls following the implementation of TOP 5, while at hospital 15 and 16 there was a downward trend in falls over time since TOP 5, when controlling for seasonal effects and existing falls prevention strategies (Note 7).

In the hospital where data from a control ward was available (Hospital 13), there was evidence of a statistically significant decrease in falls in the intervention ward using TOP 5, when compared over time to the control ward. Regression analysis indicated that since the introduction of TOP 5, an average of 6.85 fewer falls per month occurred in the TOP 5 ward than in the matched control ward. This finding held after controlling for seasonal effects and existing falls prevention strategies (Note 8).

8.5.2 Use of anti-psychotics

Data on usage of anti-psychotic medications both before and during the TOP 5 implementation period was available from two sites. One of these sites, Hospital 11, showed a statistically significant reduction in the use of anti-psychotics following the introduction of TOP 5 (Note 9) with an overall reduction of 68 per cent in average cost of anti-psychotics per month. Additionally, at hospital 7 there was evidence of a statistically significant decrease in the usage of Risperidone quicklets (a quickly dissolving oral medication) of 67mg per month following the introduction of TOP 5 (Note 10). Risperidone quicklets are used for short-term treatment of persistent aggression in patients with moderate to severe Alzheimer's dementia.

Staff views reinforce these quantitative findings- 61 per cent of the staff surveyed perceived that there was less need for restraint (physical or chemical) for patients with a TOP 5.

In line with previous scientific literature (Hartikainen, 2007), there appeared to be a robust relationship between use of anti-psychotics for the purpose of restraint in patients with dementia and the number of falls involving these patients, as reported by staff in the ward logs. On average, across all sites in the study each administration of an anti-psychotic for the purpose of restraint to a patient with dementia was associated with an increase in falls by patients with dementia in that same month by a factor of 0.4 (*Note 11*).

8.5.3. Use of 1:1 Nursing Care (Specials)

At one site, longitudinal analysis of specials (1:1 intensive nursing) was possible due to an existing monthly data set kept by the hospital, allowing for a comparison of staffing before and after the introduction of TOP 5. At this facility (Hospital 7), a statistically significant decrease in the trend in use of specials was observed following the introduction of TOP 5. Regression analysis indicates that for each month of the implementation period there was an average additional decrease of 0.84 specials, when controlling for seasonal effects (*Note 12*).

Staff perceptions on the effect on use of specials were equivocal, with 48 per cent agreeing that following the introduction of TOP 5 there was less need to use 1:1 nursing, and a further 35 per cent were undecided.

8.5.4 Complaints

The number of complaints relating to communication issues regarding carers in the units/wards implementing TOP 5 were too few to analyse if any change occurred following the introduction of TOP 5. Despite this lack of data about formal complaints reported, 71 per cent of staff perceived that less concerns and complaints had been raised by carers of patients with a TOP 5 in place.

8.5.5. Identification and Coding of Patients with Dementia

Among the three sites belonging to the major metropolitan peer group, there was weak evidence of a trend towards increasing numbers of patients with a dementia diagnosis following the implementation of TOP 5 (*Note 13*). It is possible that this could reflect an increased awareness of dementia and therefore an increase in formal diagnoses, and correct coding of the medical record. Trends in coding may also have been influenced by the introduction of activity based funding in the same period.

Across all sites there was some degree of disparity between ward-level staff identification of dementia and hospital coding data. On average, for every 100 patients that were identified by staff on ward log sheets as having dementia, only 88 patients had been coded with a dementia diagnosis (*Note 14*).

8.5.6. Average Length of Stay

It was not possible using available datasets to compare the average length of stay (ALOS) of patients with dementia, with and without a TOP 5 in place. An analysis of ALOS for all patients with dementia found no evidence of impact, either across all sites or at each site individually. However, this data had a number of significant limitations. It was not possible to confine the data to ALOS for TOP 5 patients, nor take into account the presenting health problem or destination of transfer.

When analysed in aggregate, there was no evidence of a relationship between the number of IIMS-reported falls incidents and the ALOS of all patients with dementia across all sites. However, when each site was analysed

individually there appeared to be such a relationship at hospital 11. Here falls were associated with a longer ALOS, such that on average each fall was associated with an increase in ALOS of 0.31 days (*Note 15*).

Limitations:

IIMS data relies upon staff self-reporting incidents, and as an adverse event management system it was not intended to be used for data collection. Therefore, it may not be reflective of the true number of falls occurring (particularly less serious falls not resulting in injury). Additionally, it is important to note that the IIMS data is data about patient falls in general and cannot be narrowed down specifically to patients with dementia.

Data on falls, use of anti-psychotics for chemical restraint and specials specific to patients with dementia was only able to be collected during the implementation phase. The unavailability of comparable data for a period of time prior to the introduction of TOP 5, and the relatively short period of evaluation after the introduction of TOP 5, meant that demonstrating statistically significant changes between the pre and post- implementation period in these particular indicators was limited. The inclusion of a control ward in an A1 hospital site enabled the comparison of falls between control and intervention wards. In addition, typically the count of these indicators per month per site was small, making time trends more difficult to detect.

The ALOS data obtained from each site was a monthly numerical average, without case by case information on the presenting health problem or destination of transfer of care. Some sites reported anecdotally that some dementia patients had an extended length of stay while a bed in a residential aged care facility (RACF) was secured for them. It is possible that such outliers obscured any effect TOP 5 might have had on length of stay for patients with dementia.

8.6 Cost Outcomes

The ongoing cost of implementing TOP 5 was estimated from information self-reported by each site, including the position and salary classification of the LSL and other staff members involved, the time they spent on various TOP 5 related activities and the number of education sessions they held. The estimated costs varied considerably between sites, and were influenced by the specific features of the wards/units/specialties where TOP 5 was implemented, as well as the salary classification of staff.

8.6.1 Cost

Four key cost metrics were identified: time taken with the carer and complete a TOP 5, cost associated with staffing to complete a TOP 5, cost of education per month and cost of TOP 5 related admin each month. See Figure 12 for a breakdown of the estimated costs per site.

Site	Peer Group	Time per TOP 5 (minutes)	Est. Cost per TOP 5 (\$)	Est. Cost of education per month (\$)	Est. Cost of admin per month (\$)
1	C1	15	5.90	29	1,073
2	BNM	20	11.00	5	1,017
3	BNM	15	11.00	62	913
4	C2	15	7.00	11	223
5	C1	>40	10.00	20	527
6	BNM	>40	38.40	4	668
7	A1	20	7.00	150	1,115
8	MPS	30	15.00	3	414
9	MPS	30	13.00	2	1,354
10	MPS	30	18.40	2	581
11	BM	15	8.20	10	2,451
12	BM	15	12.00	134	759
13	A1	15	13.00	97	1,145
14	A1	30	15.20	16	1,108
15	BNM	15	13.00	9	1,624
16	BNM	20	14.00	3	2,329
17	BM	30	18.00	83	2,423
18	PH	>40	45.80	55	206
19	PH	30	16.00	5	1,608
20	PH	15	5.90	1	109
21	PH	30	18.00	34	465
	AVERAGE	21	20.60	36	1,053

Figure 12: Time spent and cost associated with TOP 5

Time taken to complete a TOP 5

There was considerable variation between sites in the time reported for a staff member to approach the carer, elicit information, formulate strategies and write them down on the TOP 5 form, ranging from a minimum of 15 minutes to a maximum of more than 40. This variation reflects characteristics of the ward and individualised local processes. Further investigation was undertaken for the three sites reporting times of more than 40 minutes. It was found that two of these sites combined the conversation with the carer with other care tasks, while the third split up the process over two days (with total time taken being over 40 minutes). With these outliers included, the average time taken to complete a TOP 5 was 24 minutes. With these outliers excluded, the average time taken to complete a TOP 5 using the conventional protocol was 21 minutes.

Staffing costs to undertake a TOP 5

The estimated cost of conducting a TOP 5 was calculated from the time taken to do a TOP 5, and the classification of staff reported to be most often completing TOP 5s at that site. On average, this cost was estimated at \$20.60. The estimated cost was also highly variable between sites, ranging from \$5.90 to \$45.80.

Education costs

Sites undertook a program of staff training about the aims and process of TOP 5. Some sites also incorporated general education regarding dementia, delirium and behaviour management. On average, ongoing training costs were estimated at \$36 per month. Again, education costs varied between sites according to the salary classification of the local staff delivering education, ranging from \$1 to \$134 per month.

Administration costs

Administration tasks associated with implementing TOP 5 included attending meetings and general liaison (internal and external). The staffing costs associated with this were estimated from the time taken for each of these tasks and the salary classification of the staff reported to be undertaking them (including the LSL and any other local team members). Administration costs were estimated at an average of \$1053 per month. This includes considerable 'start up' time and as such represents an upper estimate of the likely true cost.

8.6.2. Potential cost savings

While the current evaluation did not have the capacity to measure cost savings directly, a number of inferences can be made as to the potential cost savings that may be associated with TOP 5. In particular, the reduction in certain adverse outcomes as reported in Section 8.4 may be associated with cost savings.

Falls

The average cost of hospital care resulting from a fall with injury has been calculated as \$18,454 (Watson, 2010). Therefore, a reduction in falls represents a considerable cost savings for hospitals. Findings at the site with a control ward, as reported in Section 8.4.1, give an indication of the extent of such potential savings. The 6.85 fewer falls observed each month on average in the TOP 5 intervention ward at Hospital 13 equates to up to \$126,410 saved each month of TOP 5 implementation (*Note 16*).

Anti-psychotic use

Decreasing use of anti-psychotic drugs represents another area for potential cost savings. Findings from a site that had available data on usage of anti-psychotic medications both before and during the TOP 5 implementation period (Hospital 11) indicated a cost reduction for drug usage of 68 per cent in average cost of anti-psychotics per month in the TOP 5 wards. This reduction has wider implications given the link between usage of anti-psychotic drugs and increased patient mortality (Food and Drug Administration, 2005) and morbidity, especially increased risk of stroke (Committee on the Safety of Medicines, 2004)

Staffing

Specials (1:1 nursing) are resource intensive. As such, it would be expected that a reduction in specials would represent a significant cost saving for hospitals. However, this potential saving was difficult to quantify in the current evaluation as each site used a different approach to recording specials and different classifications of staff to fulfil this role. However, it appears that such staff savings are possible, given that at a site where long-term records were available there was an average additional decrease of 0.84 specials for each month of the TOP 5 implementation period, as reported in Section 8.5.3.

Limitations:

Data on time taken for TOP 5-related tasks (including time taken to talk to the carer and complete a TOP 5 strategy form) was self-reported retrospectively by the LSL at each site. As for any data based on recall, it may be subject to error.

9. CONCLUSIONS

This research study indicates that a low cost, patient based communication strategy for patient care was associated with improvements in patient outcomes, safety, carer experience and staff satisfaction while also providing potential cost savings to health services.

The TOP 5 initiative has been well received by carers of patients with dementia and a range of health care providers. The findings of this study indicate 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.

The benefits to staff included an increase in work satisfaction and a sustained increase in confidence in caring for patient with dementia. TOP 5 had a positive effect on their own experience of caring for patients with dementia. Overall TOP 5 has proved to be acceptable to staff members as a tool to enhance their work caring for patients.

The additional engagement and recognition of carer knowledge has increased family and carer confidence in the staff. Confidence was increased when carers saw that staff had used the strategies that were mutually developed, indicating that staff were communicating this knowledge to other staff at handover. Many carers commented on the fact that they did not need to keep reiterating the same information to different staff members, but rather that staff listened to, and took notice of, the information they had provided. For the hospital sites, the TOP 5 tool has become an essential part of the patient journey from admission to leaving the hospital. This ensures that valuable information gained from the carer is not lost when the patient moves through the stages of care and transfers.

When a patient is ready for a transfer of care, sites found that the TOP 5 information could be shared with the receiving service who could then revisit the information with the carer to confirm that the strategy is still relevant. For patients coming from RACFs, their carers are often the staff of that facility. Sites in this study have started to explore the inclusion of their local RACF to gain information to assist during the acute admission.

Both staff and carers reported that following TOP 5 implementation, the patients were less agitated and appeared more settled. This also provided indirect support for an improved patient experience of care. Staff using the TOP 5 tips to deal with behaviour or agitation in hospitalized patients with dementia noted that this approach lessened the need for restraints.

In parallel, there is evidence of a lower rate of anti-psychotics usage following the introduction of TOP 5 at sites with long-term drug utilisation records. Given evidence to date of a link between the use of anti-psychotics and the incidence of falls (confirmed by the present study), a decreased use of these drugs would have a significant impact on the safety and quality of care, including the patient experience of care. Decreased usage of anti- psychotics has significant implications for patient outcomes, particularly in the light of evidence linking usage of anti-psychotic drugs to increased patient mortality (Food and Drug Administration, 2005) and morbidity, especially increased risk of stroke (Committee on Safety of Medicines, 2004).

The research findings highlight potential cost savings in the areas of reduced falls, decreased use of anti-psychotic drugs and staff resource implications. Reducing patient falls has significant prospects, as indicated by the 6.85 fewer falls at the hospital with an intervention and control ward comparison. Decreased falls result in lower average lengths of stay and present significant cost savings to health services.

A number of limitations of this study were highlighted throughout this final report. A key limitation was the lack of available ward level data for specific indicators of interest both during the period prior to the study and during the study. The inclusion of additional control sites in future studies is likely to help address further research in this area.

TOP 5 demonstrates that the use of a low cost, communication-based strategy for patient care is associated with improvements in patient outcomes, safety, carer experience and staff satisfaction whilst additionally providing potential cost savings to health services.

Effective strategies such as TOP 5 have the potential for broader application to all patients to embrace a patient focused approach to care delivery.



The logo for TOP 5 symbolizes a lifesaving ring to represent the 'lifeline' it provides to carers, patients and staff.

10. FUTURE OPPORTUNITIES

The research of the impact of TOP 5 in a number of public and private hospitals in NSW has focused on improving care for hospitalised patients with dementia by engaging with carers.

In addition to benefits for patients with dementia, participating sites have noted broader applicability for patients with other types of cognitive impairment. This parallels the use of TOP 5 in the Central Coast of NSW where the program was developed originally and implemented.

A second study has been granted support by the HCF Research Foundation for 2014/2015. The study will enable the investigation of referral services for hospital admissions for patients with dementia: ambulance, residential aged care facilities (RACFs) and home care. Sites in the present study noted the benefit of TOP 5 being used across health services for patients with dementia. Once more, work from the Central Coast of NSW provides a potential model.

In 2012, Australian health ministers recognised dementia as the ninth National Health Priority Area. During the present TOP 5 project, interest has been expressed by Alzheimer's Australia, the NSW Ministerial Carers Advisory Council and the NSW Dementia Implementation Advisory Committee. Close alignment with the NSW Health Carers (Recognition) Act has been noted. Recently, new national and state policy initiatives and care pathways have been released that will help to ensure the longer term sustainability of use of TOP 5.

A range of opportunities for promoting TOP 5 uptake exist and are being investigated including:

- The National Quality Dementia Care Initiative (auspiced by Alzheimer's Australia) - which provides an avenue to fast-track research findings into improved care practice throughout Australia.
- Integration into Alzheimer's Australia national initiatives to promote broader application. Significant interest has been expressed by the National Policy Manager and members of the Alzheimer's Australia Consumer Dementia Research Network.
- Professional clinical colleges being approached to endorse TOP 5 as a supporting strategy for professional compliance with new care pathways - such as the recently released *Handbook for NSW Health Clinicians – Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia* (May 2013).
- Alignment with the Federal Senate Standing Committee on Community Affairs established in May 2013 to consider the 'Care and management of Australians living with dementia'. Key challenge areas identified included: improving acute care services for people with dementia and reducing use of restraint & improving medication.
- Integration into national standards for health service accreditation. The Australian Commission on Safety & Quality in Health Care (ACSQHC) has commenced reviewing strategies to improve the management of cognitive impairment in hospitals. This new work is aligned to the National Safety & Quality Health Service Standards - mandatory for health service accreditation from January 2013.
- Integration into CEC's *Partnering With Patients* program - a wider strategy for promoting engagement of patients, families and carers to improve care - to promote implementation. The CEC has extensive experience with managing state wide program implementation.

Based on the findings to date, the anticipated cost savings from the broader application of the TOP 5 program would include reduced length of stay, reduced use of specials (staffing costs), reduced pharmaceutical use,

reduced falls, decreased complaints and increased staff retention. Indeed the findings support the broader application for all patients in an acute care setting who are experiencing difficulty with communication.

11. REFERENCES

Access Economics Pty Limited. Keeping dementia front of mind: incidence and prevalence 2009-2050. Alzheimers Australia; 2009. Available from: <http://www.fightdementia.org.au/new-south-wales/access-economics-reports-nsw.aspx>

Access Economics Pty Limited. Projection of dementia prevalence and incidence in NSW: 2009 -2050. NSW Dept of Health and NSW Dept of Human Services; 2009. Available from: http://www0.health.nsw.gov.au/pubs/2009/adhc_dementia.html

Arbuthnott A, Sharpe, D. The effect of physician-patient collaboration on patient adherence in non-psychiatric medicine. *Patient Education and Counseling*. 2009;77(1):60-67.

Australian Commission on Safety and Quality in Health Care. Patient-centred care: Improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC; 2011. Available from : <http://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/patient-and-consumer-centred-care-discussion-paper/>

Australian Commission on Safety and Quality in Health Care. Safety and Quality Improvement Guide Standard 2: Partnering with Consumers. Sydney: ACSQHC; 2012. Available from: <http://www.safetyandquality.gov.au/our-work/accreditation/nsqhss/safety-and-quality-improvement-guides-and-accreditation-workbooks/>

Australian Commission on Safety and Quality in Health Care. Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review. Sydney: ACSQHC; 2013. Available from: <http://www.safetyandquality.gov.au/our-work/cognitive-impairment/consultation-draft-handbook/>

Australian Institute of Health and Welfare. Dementia in Australia: National data analysis and development. Canberra: AIHW; 2007. Available from: <http://www.aihw.gov.au/publication-detail?id=6442467941>

Australian Institute of Health and Welfare. Dementia care in hospitals: costs and strategies. Canberra: AIHW; 2013. Available from: <http://www.aihw.gov.au/publication-detail?id=60129542746>

Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2009;11(2):217-228.

Carer Recognition Act: An Act to provide for the recognition of carers, and for related purposes. 2010. Available from: <http://www.comlaw.gov.au/Details/C2010A00123>

Charmel P, Frampton S. Building the business case for patient-centred care. *Healthcare Financial Management*. 2008;62(3):84-92.

Committee on Safety of Medicines (UK). Atypical anti-psychotic drugs and stroke. Department of Health (UK). 2004. Available from: <http://www.mhra.gov.uk/home/groups/pl-p/documents/websiteresources/con019488.pdf>

Cummins R, Hughes J. Wellbeing of Australians, Carer Health and Wellbeing. Australian Unity Wellbeing Index Survey. Geelong: Deakin University and Australian Unity; 2007. Available from: <https://www.deakin.edu.au/research/acqol/auwbi/survey-reports/>

DiGioia A, Greenhouse P, Levison T. Patient and family-centred care collaborative care: an orthopaedic model. *Clinical Orthopaedics and Related Research*. 2007; 463:13-19.

Draper B, Karmel R, Gibson D, Peut A, Anderson P. The Hospital Dementia Services Project: age differences in hospital stays for older people with and without dementia. *Int Psychogeriatr*. 2011;23(10):1649-1658.

Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs*. 2010;19(17-18):2611-2618.

Fick D, Agostini V, Inouye S. Delirium superimposed on dementia: a systematic review. *J Am Geriatr Soc*. 2002;50(10):1723-1732.

Food and Drug Administration (US). Public Health Advisory: Deaths with anti-psychotics in elderly patients with behavioural disturbances. US Department of Health and Human Services. 2005. Available from: <http://www.fda.gov/drugs/drugsafety/postmarketdrugsafetyinformationforpatientsandproviders/drugsafetyinformationforhealthcareprofessionals/publichealthadvisories/ucm053171.htm>

Gerteis M, Edgman-Levitan S, Daley J, Delbanco T. *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care*. San Francisco: Jossey-Bass; 1993.

Hartikainen S, Lonnroos E, Louhivuori K. Medication as a risk factor for falls: critical systematic review. *J Gerontol A Biol Sci Med Sci*. 2007;62(10):1172-1181.

Hill K, Vu M, Walsh W. Falls in the acute hospital setting--impact on resource utilisation. *Aust Health Rev*. 2007;31(3):471-477.

Hitcho E, Krauss M, Birge S, Claiborne-Dunagan W, Fischer I, Johnson S, et al. Characteristics and circumstances of falls in a hospital setting: a prospective analysis. *J Gen Intern Med*. 2004;19(7):732-739.

Inouye S, Westendorp R, Saczynski J. Delirium in elderly people. *The Lancet*. Forthcoming 2014. doi:10.1016/S0140-6736(13)60688-1.

Jurgens F, Clissett P, Gladman J, Harwood R. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatr*. 2012;12(1):57.

Kitwood T, Bredin K. Towards a theory of dementia care: personhood and well-being. *Ageing & Society*. 1992;12:269-287.

Lyketsos C, Steinberg M, Tschanz J, Norton M, Steffens D, Breitner J. (2000). Mental and behavioral disturbances in dementia: findings from the Cache County Study on Memory in Aging. *Am J Psychiatry*. 2000;157(5):708-714.

Meterko M, Wright S, Lin H, Lowy E, Cleary P. Mortality among patients with acute myocardial infarction: the influences of patient-centred care and evidence-based medicine. *Health Services Research*. 2010;45(5p1):1188-

1204.

Mukadam, N., Sampson, E. A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *Int Psychogeriatr.* 2011;23(3):344-355.

NSW Department of Health. The NSW Dementia Services Framework 2010 - 2015. Sydney: NSW Dept of Health; 2010. Available from: http://www0.health.nsw.gov.au/policies/gl/2011/GL2011_004.html

Sjogren K, Lindkvist M, Sandman P, Zingmark K, Edvardsson D. Person-centredness and its association with resident well-being in dementia care units. *J Adv Nurs.* 2013;69(10):2196-2205.

Strudwick M. A win-win partnership for carers and staff in an acute hospital setting. Paper presented at the HammondCare Biennial Conference of Carers NSW; June 2009; Sydney, Australia. 2009.

Strudwick M. Top 5 – Translating a carer’s knowledge into staff action for responsive care across dementia service settings. Paper presented at the conference “Dementia: Do we need a different point of view?”; June 2010; Sydney, Australia. 2010.

van de Ven G, Draskovic I, Adang E, Donders R, Post A, Zuidema S, et al. Improving person-centred care in nursing homes through dementia-care mapping: design of a cluster-randomised controlled trial. *BMC Geriatr.* 2012;12(1):1-9.

Watkin L, Blanchard M, Tookman A, Sampson E. Prospective cohort study of adverse events in older people admitted to the acute general hospital: risk factors and the impact of dementia. *Int J Geriatr Psychiatry.* 2012;27(1):76-82.

Watson W, Clapperton A, Mitchell R. The Incidence and Cost of Falls Injury Among Older People in New South Wales 2006/07. Sydney: NSW Dept of Health: Sydney; 2010. Available from: <http://www0.health.nsw.gov.au/pubs/2010/costoffall.html>

Locked Bag 8
Haymarket NSW 1240
Tel 61 2 9269 5500
Fax 61 2 9269 5599
www.cec.health.nsw.gov.au



CLINICAL
EXCELLENCE
COMMISSION

12. APPENDICES

- A Letter to Local Health District Inviting Expression of Interest
- B TOP 5 Steering Committee Membership
- C TOP 5 Steering Committee Terms of Reference
- D TOP 5 Activity Ward Log
- E Clarification for the Collection of Data for Indicator 5
- F Example of a TOP 5 Evaluation Components and Due Dates
- G TOP 5 Midway Report Survey Questions
- H TOP 5 Process Evaluation Questions
- I TOP 5 Staff Survey – Pre-Implementation (Master)
- J TOP 5 Staff Survey – Midway and Post Implementation (Master)
- K TOP 5 Staff Information and Consent (Master)
- L TOP 5 Carer Survey (Master)
- M TOP 5 Carer Information and Consent Form (Master)
- N Statistical Notes

- This page is intentionally blank -

APPENDIX A

- This page is intentionally blank -

[REDACTED]



CLINICAL
EXCELLENCE
COMMISSION

23 March 2012

[REDACTED]

The Directorate of Patient Based Care is seeking expressions of interest from hospitals to participate in a new initiative that will focus on improving the care of patients with dementia when admitted to an acute care setting. For these patients in particular, knowledge possessed by the carer and family is even more crucial to promote positive outcomes for both the patient and for the staff providing care.

The Clinical Excellence Commission (CEC) '*Partnering with Patients*' Program supports the inclusion of patients, families and carers as care team members to promote health care safety and quality. The CEC is looking to collaborate with hospitals who want to improve integration of carer knowledge for patients with dementia based on an existing model (TOP5) that has been devised and successfully implemented in the Central Coast Local Health District. The results have shown evidence of benefit for patients, carers and staff.

This is an opportunity for your Local Health District to improve patient based care for hospitalised patients with dementia as well as enhance your staff work environment using a simple strategy to integrate carer knowledge about patients. A summary of the program is attached.

We are seeking the involvement of 15 public hospital sites across New South Wales and look forward to your response. If you are interested in nominating one of your facilities to become a lead site, please send your expression of interest to Anne Axam at anne.axam@cec.health.nsw.gov.au by **2 April 2012**.

Please feel free to contact me on 92695515 or Karen.luxford@cec.health.nsw.gov.au.

Yours sincerely,

Dr Karen Luxford
Director, Patient Based Care

Cc: Director of Clinical Governance

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
ABN 79 172 068 820

- This page is intentionally blank -

APPENDIX B

- This page is intentionally blank -



TOP 5 Program Steering Committee Clinical Excellence Commission



Membership List

Current Member	Position
Kathleen Ryan (Chair)	Director of Clinical Governance Mid North Coast Local Health District (LHD)
Maureen Strudwick	Carer Support Unit, Facilitator TOP 5 Central Coast LHD
Dr John Dobrohotoff	Clinical Director and Senior Staff Specialist Old Age Psychiatrist Specialist, Mental Health Service for Older People, Central Coast LHD
A/Professor Rosalie Viney	Health Economics and Director, Centre for Health Economics Research and Evaluation, University of Technology, Sydney
Dr Karen Luxford	Director Patient Based Care Clinical Excellence Commission
Anne Cumming	Principal Policy Officer NSW Dementia Policy Team South Eastern Sydney LHD (Moved to New Position in the ACSQHC in June 2013 - Project Manager Cognitive Impairment Project)
Anthea Temple	ACI Aged Health Network Clinician
Ken Lee	Carer Support Program – Area Coordinator, North Coast, Ballina, Northern NSW LHD
Private Sector	Co-opted when required
Mary Borg	CEC Consumer Advisor
Anne Sammut (Resigned Feb 2013)	Full Time Carer Experience Dementia Educator & Social Worker
Anne Axam	TOP 5 Project Coordinator Clinical Excellence Commission

- This page is intentionally blank -

APPENDIX C

- This page is intentionally blank -

Primary Purpose

The purpose of the TOP 5 Steering Committee is to oversee the implementation of a 2 year program to support integration of carer knowledge about hospitalized patients with dementia.

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 4 times per year.

Reporting Structure

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

Chair

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, 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.

- This page is intentionally blank -

APPENDIX D

- This page is intentionally blank -

REQUEST FOR BASELINE DATA

The **TOP 5** initiative is to be implemented in your hospital (s) starting in August 2012. To evaluate the effectiveness of the initiative we will be asking for data to be collected from each hospital and forwarded to the Clinical Excellence Commission for use in the evaluation. We aim to keep this to a minimum and are looking for a high level overview of de-identified data to consider the impact of TOP 5.

A variety of measures have been chosen to help assess trends over time and compare pre- and post-implementation. For the purposes of this initiative we propose to collect and analyse the following:

(A) Data Collection

		Due August 2012		Due 14 September 2013
	Indicator	Pre- Implementation	During Implementation Aug 2012 – July 2013	Post Implementation
1	Total Number of Patients with Dementia Admitted	Provided by hospital. Period July 2011 to June 2012	–	Provided by hospital. Period Aug 2012 to July 2013
2	Average Length of Stay of Patients with Dementia	Provided by hospital. Period July 2011 to June 2012	–	Provided by hospital. Period Aug 2012 to July 2013
3	Number of Patients Assessed for Dementia	Provided by hospital. Period July 2011 to June 2012	–	Provided by hospital. Period Aug 2012 to July 2013
4	Number of TOP 5 initiated		To be provided by logging each occasion	LOG provided
5	No of Patients with Dementia Requiring Restraint (Physical or Chemical)	If records kept provided by hospital. Period July 2011 to June 2012	To be provided by logging each occasion restraint is required	LOG provided
6	Use of Specials for Patients with Dementia	If records kept provided by hospital. Period July 2011 to June 2012	To be provided by logging each occasion a special is required or through local records	LOG provided
7	Falls	Provided by hospital. Period July 2011 to June 2012	-	Provided by hospital. Period Aug 2012 to July 2013
8	Complaints by Carers citing communication difficulties	Provided by hospital. Period July 2011 to June 2012	-	Provided by hospital. Period Aug 2012 to July 2013

The measures (A Data Collection) would make up the quantitative measures to be collected before, during and after implementation.

Methods for Collection of Data

It is acknowledged that each hospital will have different indicators that they would normally collect. Some of the indicators can be accessed from existing data patient management systems Indicator **(A) 1 & 2**.

Indicator **(A) 3, 5 & 6** may not be routinely collected in all facilities. Please advise how this information may be accessed.

Indicators **(A) 7 & 8** can be obtained from the Incident Information Management System (IIMS). The CEC can run a query to extract this information in each public hospital but if your hospital obtains this information for internal use routinely please advise the project coordinator.

If you need clarification please contact the Project Coordinator on 02 9269 5521 or anne.axam@cec.health.nsw.gov.au to discuss further.

(B) Survey Data

For the surveys the CEC will work with the local site to manage the collection of surveys **((B) a, and b)**. For carers this would involve the carers who engaged in using the TOP 5 initiative. We would like staff to provide the carer information and consent form and the survey document. Assistance with the completion (clarification of language or understanding) of the survey should also be provided if required. The completed surveys would then be forwarded to the CEC.

The collection of the staff survey would involve the participation of the staff who would be involved with the TOP 5 initiative to complete an anonymous survey and then for the staff member to place the completed survey into an envelope which would be sealed and returned to the CEC.

The following table indicates the proposed time frames for the carer and staff surveys.

	Indicator	Baseline	At 6 months	After 12 months
a	Staff Survey # of staff - Clinical - Management	Local liaison to inform CEC of six (6) relevant staff and help liaise with staff engagement	CEC to work with local liaison to identify staff	CEC to work with local liaison to identify staff
b	Carers Survey Carers of patients with a TOP 5 initiated		Survey provided to relevant carers by local staff and then returned separately to CEC	

The Project Coordinator, Anne Axam on anne.axam@cec.health.nsw.gov.au will liaise with each site about sending data to the CEC.



TOP 5 Activity Log

_____ **Hospital**



2012	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
Total Number of Patients with Dementia admitted								0	0	0	0	0	0
Number of TOP 5's Initiated								0	0	0	0	0	0
Number of Patients assessed and identified with dementia after TOP 5													0
Number of Pts with Dementia requiring 1:1 Specials													0
Number of Pts with Dementia Restrained (Physical)													0
Number of Pts with Dementia Restrained (Chemical)													0
Number of Falls													0
Education Sessions													0
Carer Surveys													0

TOP 5 FINAL REPORT

Please provide an update to the TOP 5 Project Coordinator (CEC) each month

2013	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
Total Number of Patients with Dementia admitted													0
Number of TOP 5's Initiated													0
Number of Patients assessed and identified with dementia after TOP 5													0
Number of Pts with Dementia requiring 1:1 Specials													0
Number of Pts with Dementia Restrained (Physical)													0
Number of Pts with Dementia Restrained (Chemical)													0
Number of Falls													0
Education Sessions													0
Carer Surveys													0

TOP 5 FINAL REPORT

Please provide an update to the TOP 5 Project Coordinator (CEC) each month

APPENDIX E

- This page is intentionally blank -



Clarification for the Collection of Data for Indicator 5

TRIM No: D12/15374-1

After discussion with most sites it has been decided that **Physical Restraint** will not be included in this evaluation, as none of the participating sites used physical restraint.

Chemical Restraint - *“Chemical restraint is a term used to describe a pharmacological method used solely to restrict the movement or freedom of a consumer”*. NSW Health (2012). GL2012_005.

Discussion with several Site Liaison Officers has indicated that **Haloperidol** is most likely to be given as a chemical restraint (see definition) followed by Zyprexa (Olanzapine) and Risperdal.

The majority of sites have determined Haloperidol is the most usual drug used for chemical restraint and would be provided PRN. The drug is usually held as an Imprest stock item on most of the TOP 5 wards and the usage could be determined. We will therefore request that information about Haloperidol usage should be collected.

The following methodology would be used to evaluate the use of Haloperidol as a baseline indicator, as well as the use during the implementation stage – from when TOP 5 was started to one year on from the start date (ongoing by the ward/unit and a final use through Pharmacy records for the wards where TOP 5 is initiated).

- **Baseline** - Establish the amount of the drug that was used for the past year -July 2011 to June 2012. (It is understood that this measure will just indicate how much of the drug was used and will not determine what patients it was used on, neither would it be restricted to PRN usage).
- **Use during Implementation of TOP5** - Record how it is used as a chemical restraint (PRN) on the wards, where TOP5 is initiated, for patients with dementia (recorded **each month** by staff on the on the activity log). **(N.B. we will not be collecting information on this drug during implementation if it is used as part of an ongoing treatment regime to lessen behavioural issues)**
- **Use determined by Pharmacy Records for the implementation period** - Record the use once again (Aug 2012 to July 2013) to determine if there is a change in the overall use on the wards where TOP 5 has been initiated

If Haloperidol is not held as an imprest stock item in the ward and your pharmacy is unable to determine the retrospective usage then we will commence collecting this information **each month** during the implementation phase. The monthly report would provide finer detail of the use in patients with dementia.

TOP 5 Project Co-ordinator

November 2012

- This page is intentionally blank -

APPENDIX F

- This page is intentionally blank -



** LHD

TOP 5 Evaluation Components and Due Dates

Time period	Evaluation Component	Due Date
Pre-Implementation	1. Pre-Implementation Staff Surveys <ul style="list-style-type: none"> Consent form and survey to be completed by at least 6 staff members 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). 	<input checked="" type="checkbox"/> Received
	2. Baseline quantitative data (for period July 2011 to June 2012). <ul style="list-style-type: none"> Refer to "Request for Baseline Data" document for details. 	<input checked="" type="checkbox"/> Received
Throughout Implementation	3. Ward/Unit log <ul style="list-style-type: none"> Information to be collected by logging each incidence as it occurs: <ul style="list-style-type: none"> Indicator 3: Patient assessed for dementia after a TOP 5 is instituted. Indicator 4: TOP 5 patients initiated. Indicator 5: Incidences of chemical restraint for patients with dementia. Indicator 6: Specials ordered for patients with dementia. Refer to "Request for Baseline Data" document for further details. Please forward log spreadsheet for the previous month to the CEC on or before the given dates (4 working days following the end of each calendar month). 	<input checked="" type="checkbox"/> Sept 2012 - Received <input checked="" type="checkbox"/> Oct 2012 - Received <input checked="" type="checkbox"/> Nov 2012 - Received <input checked="" type="checkbox"/> Dec 2012 - Received <input checked="" type="checkbox"/> Jan 2013 - Received <input checked="" type="checkbox"/> Feb 2013 - Received <input checked="" type="checkbox"/> Mar 2013 - Received <input checked="" type="checkbox"/> 6 May 2013 <input type="checkbox"/> 6 Jun 2013 <input type="checkbox"/> 4 Jul 2013 <input type="checkbox"/> 7 Aug 2013
	4. Post-Implementation Staff Surveys <ul style="list-style-type: none"> Consent form and survey to be completed on or before the given dates, by at least 6 staff members who have received TOP 5 education and have been involved in the care of TOP 5 patients. If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). 	<input checked="" type="checkbox"/> 15 March 2013 (Midway) <input type="checkbox"/> 13 September 2013
	5. Carer surveys <ul style="list-style-type: none"> Consent form and survey to be completed during the TOP 5 patient's admission, set aside and forwarded in bulk to the CEC on the given dates. If posting surveys, please ensure the name of your facility is clear (on the surveys themselves or on the envelope). 	<input checked="" type="checkbox"/> 8 March 2013 - Received <input type="checkbox"/> 14 June 2013 <input type="checkbox"/> 27 September 2013
At Completion	6. Quantitative data (for period July 2012 – August 2013). <ul style="list-style-type: none"> Please provide this data broken down by month. Refer to "Request for Baseline Data" document for details. 	<input type="checkbox"/> 27 September 2013

- This page is intentionally blank -

APPENDIX G

- This page is intentionally blank -

TOP 5 Site Mid-Way Report

Note that your responses will be kept confidential.

*1. Your name

2. Your Position Title

*3. Name of your hospital

4. Have you had a TOP 5 launch?

Yes

No

5. Have you undertaken staff education session/s at your hospital?

Yes

No

If yes, how many?

6. Who attended the education sessions?

Nurses

Doctors

Allied Health

Executives

Managers

Administrative staff

Other (please specify)

7. Do you have a local TOP 5 implementation team?

Yes

No

TOP 5 Site Midway Report

8. Who is involved in the team?

- Clinicians
- Management
- Consumers

Other (please specify)

9. Does your local TOP 5 implementation team have regular meetings?

- Yes
- No

If yes, how often?

10. To what extent are your implementation team members involved in 'making TOP 5 happen'?

Not at all Sparse involvement Some involvement Gaining momentum Highly involved

<input type="checkbox"/>				
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

11. Are TOP 5 resources (eg. posters) on display in the wards where it is being implemented?

- Yes
- No

12. Do you (as Local Site Liaison) provide updates to your hospital's executive regarding your progress with TOP 5?

- Yes
- No

13. Is the hospital executive supportive of TOP 5?

- Yes
- No

*14. How many patients have been identified as TOP 5, with strategies completed, to date?

15. How would you rate the level of staff knowledge about TOP 5 on the wards where it is being implemented?

Poor So-So Sufficient Good Excellent

<input type="checkbox"/>				
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

16. How would you rate the attitude of your fellow staff members towards TOP 5?

Very Disinterested Disinterested Neutral Good Enthusiastic

<input type="checkbox"/>				
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

TOP 5 Site Midway Report

17. How would you rate the level of uptake of TOP 5 amongst your fellow staff members?

No uptake

Sparse

Some participation

Gaining momentum

Widespread



18. Who is involved in applying the TOP 5 process at your hospital (including: flagging potential participants, speaking with carers about participation, obtaining the TOP 5 tips)? Tick all that apply.

- Nurses
- Doctors
- Allied Health
- Carer Support
- Administrative Staff
- Volunteer

Other (please specify)

19. Who undertakes ongoing data collection at your hospital? Tick all that apply.

- Local Site Liasion (yourself)
- Nurses
- Nurse Unit Managers
- Data Manager

Other (please specify)

20. Do you have any further comments about staff reactions to and participation in TOP 5 at your hospital?

21. Have there been any 'unexplained benefits' from using TOP 5 at your hospital?

22. Please estimate the proportion of carers approached so far about TOP 5 who give consent to participate.

0%

25%

50%

75%

100%



Give a precise percentage if you record the total number of carers approached.

TOP 5 Site Midway Report

23. On average, how would you rate the reaction of carers when informed about TOP 5?

Very negative

Negative

Neutral

Positive

Very positive



24. Do you have any further comment about carers' responses to TOP 5?

25. How would you rate the level of support you have received from the CEC in implementing TOP 5?

Not adequate

So-So

Sufficient

Good

Excellent



26. Is there any other support, from the CEC, that may be helpful for the successful implementation of TOP 5 at your hospital?

27. Can you identify any particular factors or strategies that have been supportive or enabled the implementation of TOP 5 at your hospital?

28. Can you identify any barriers you have faced in implementing TOP 5? If so, how were these overcome?

29. Please share a short story about a TOP 5 patient at your hospital. For example, it may be your first TOP 5. Take care to omit identifying information.

Thank you for taking the time to complete the TOP 5 Mid-way Report. Your information will assist us in supporting you and your site.

APPENDIX H

- This page is intentionally blank -

TOP 5 Process Survey

The purpose of this survey is to gather information about how the TOP 5 process has been operating at your hospital. There are no right or wrong answers, simply respond according to the best of your knowledge. If you have kept records on education session attendance, local TOP 5 team meetings or any other records relating to the implementation process, please have them on hand as they may be useful in answering some questions.

The survey will take approximately 15 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. If you require any clarification or assistance while completing the survey please call Anne Axam on 9269 5521 or Fiona Hasnip on 9269 5588 (Wednesday-Fridays only).

This feedback will form part of the evaluation. Please be assured that neither you nor your hospital will be identified in connection with the information given here.

TOP 5 Process Survey

1. Your name:

2. Your hospital:

3. What is your job title?

4. What is your classification (eg. NUM 2, RN 6 yr)?

TOP 5 Process Survey

5. Are you the only person that has held the role of TOP 5 Local Site Liaison officer since the initiative began?

Yes - Skip to Q7

No

6. If no, when did you start as TOP 5 Local Site Liaison officer?

7. Have you had any significant time off during the period June 2012 to August 2013?

Yes

No - Skip to Q9

8. If yes to Q7, how long were you on leave?

9. Aside from TOP 5, have you undertaken any additional roles (on top of your usual job duties) in the period June 2012 to August 2013?

Yes

No - Skip to Q16 on next page

10. If yes to Q9, what was that additional role?

11. If yes to Q9, did anyone relieve your usual position while you had that additional role?

Yes

No

12. If yes to Q9, did you continue to undertake the role of TOP 5 Local Site Liaison while also undertaking that additional role?

Yes

No

13. If yes to Q9, did another staff member take over the role of TOP 5 Local Site Liaison?

Yes

No - Skip to Q16 on next page

14. If yes to Q13, what was that person's usual position?

15. If yes to Q13, what was their classification (eg. NUM 2, RN 6 yr)?

TOP 5 Process Survey

16. Please estimate how much time, on average, you and your local implementation team spend each week on the following activities related to TOP 5:

	Local Site Liaison	Local implementation team
Administration	<input type="text" value="6"/>	<input type="text" value="6"/>
Data Collection	<input type="text" value="6"/>	<input type="text" value="6"/>
Liasing with other staff members - not including training (eg. talking to NUMs about progress with TOP 5, reminding other staff members to initiate TOP 5s)	<input type="text" value="6"/>	<input type="text" value="6"/>
Liasing with external groups (eg. Carer Support organisations, RACFs, the CEC)	<input type="text" value="6"/>	<input type="text" value="6"/>

17. If your Local Implementation Team undertook any activities named in the question above, what are their job title/s and classification/s (eg. NUM 2, RN 6 yr)?

18. Did you have enough information or understanding at the beginning of the project to determine how much time you would need to implement TOP 5?

Yes

No

19. What kind of staff member most often fills out the TOP 5 strategy form with the carer?

20. On average, what would their classification be (eg. NUM 2, RN 6 yr)?

21. Please estimate how long it takes to talk with the carer and complete the TOP 5 strategy form, on average.

22. How is information for TOP 5 typically obtained from the carer?

TOP 5 Process Survey

23. Do you believe that TOP 5 has improved communication between clinical staff?

Yes

No

24. Has info on TOP 5 been integrated into routine staff training (eg. orientation sessions)?

Yes

No

25. To the best of your knowledge, did all relevant staff make use of the TOP 5 strategies?

Always

Often

Sometimes

Never

Not known

TOP 5 Process Survey

26. In the past year, how many specific TOP 5 training sessions have been provided in your facility?

27. What disciplines have attended the TOP 5 training?

If attendance records are available- please give the total number of staff from each discipline who have attended education sessions since the initiative began.

If attendance records are not available- please estimate.

Medical

Nursing

Allied Health

Ward Clerks

Non-Clinical

28. Who has provided the TOP 5 training?

Select all that apply.

- Local Site Liaison officer (myself)
- Staff from Clinical Excellence Commission
- CNE
- CNC
- Other (please specify)

29. How long would a TOP 5 training session run for, on average?

30. How long would you spend preparing for an education session, on average?

TOP 5 Process Survey

31. Do you recall whether your hospital implemented any significant new strategies or interventions targeting inpatient falls:

	Yes	No
In July 2011 - June 2012?	<input type="checkbox"/>	<input type="checkbox"/>
In July 2012 - present?	<input type="checkbox"/>	<input type="checkbox"/>

32. If yes, please briefly describe. Give approximate date/s if known.

33. Do you recall whether your hospital implemented any new strategies or interventions targeting the use of PRN antipsychotic medications among inpatients:

	Yes	No
In July 2011 - June 2012?	<input type="checkbox"/>	<input type="checkbox"/>
In July 2012 - present?	<input type="checkbox"/>	<input type="checkbox"/>

34. If yes, please briefly describe. Give approximate date/s if known.

35. Do you recall whether your hospital provided any other education or interventions regarding dementia (apart from TOP 5):

	Yes	No
In July 2011 - June 2012?	<input type="checkbox"/>	<input type="checkbox"/>
In July 2012 - present?	<input type="checkbox"/>	<input type="checkbox"/>

36. If yes, please briefly describe. Give approximate date/s if known.

37. Since the introduction of TOP 5, has this strategy been integrated into any pathways or checklists used at your hospital?

Yes

No

38. If yes, please briefly describe. Give approximate date/s if known.

TOP 5 Process Survey

39. How would you rate the support you received from the CEC?

Excellent

Sufficient

Insufficient

40. What additional support would have been helpful?

	5
	6

41. What worked well for you during the implementation of TOP 5 at your hospital?

	5
	6

42. Could anything have been improved about the way TOP 5 was implemented at your hospital?

	5
	6

43. What is your overall impression of the TOP 5 concept?

	5
	6

44. Do you have any further comment?

	5
	6

TOP 5 Process Survey

Thank you for taking the time to complete the TOP 5 process survey! Your feedback is invaluable.

Please click 'done' to submit your responses.

- This page is intentionally blank -

APPENDIX I

- This page is intentionally blank -



**TOP 5
STAFF PRE-IMPLEMENTATION SURVEY**



To be completed – by staff involved in the care of patients with dementia

1. Date.....
2. Position Title.....
3. Doctor Nurse Allied health professional Other.....

4. Please provide your opinion for each statement. Please tick one box for each question.

		Disagree	Undecided	Agree	Strongly Agree
a	More can be done to manage people with dementia				
b	Managing people with dementia is part of my role				
c	In most cases there is not much that can be done to manage people with dementia				
d	The carer of a patient with dementia can provide valuable information about the patient’s routine, likes and dislikes				
e	I value the input a carer can provide in helping a patient with dementia				
f	Involving the carer enables faster recovery of the patients with dementia				
g	The more information available about the patient’s usual routine, likes and dislikes the easier it is to manage their care in hospital				
h	I always obtain key strategies from carers to help manage the care of patients with dementia				

5. Please list 3 actions that you think are important when communicating effectively with patients with dementia?

6. Please list 3 actions that help you to manage care effectively with patients with dementia?

7. How would you describe your overall knowledge of dementia? Please tick one of the following statements that best describes your overall knowledge

Little or no experience <input type="checkbox"/> working with and knowledge of patients with dementia and their carers	Some experience <input type="checkbox"/> working with and knowledge of patients with dementia and their carers	Regularly worked with <input type="checkbox"/> and undertaken training about patients with dementia and their carers
--	--	---

8. How would you rate your level of confidence in caring for patients with dementia?

Not confident Somewhat confident Confident Very confident

9. My level of comfort in engaging with carers is:

Not comfortable Somewhat comfortable Comfortable Very comfortable

10. Are you aware of the 'TOP 5' process?

Yes No

11. Have you attended an education session on TOP 5?

Yes No

12. Did you receive any written information about TOP 5?

Yes No

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

The CEC would like to thank the Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The CEC would also like to acknowledge the support of the HCF Health and Medical Research Foundation.

APPENDIX J

- This page is intentionally blank -



**TOP 5
STAFF POST-IMPLEMENTATION SURVEY**

LHD
FACILITY

To be completed – by staff involved in the care of patients with dementia

1. Date.....
2. Position Title.....
3. Doctor Nurse Allied health professional Other.....
4. Please provide your opinion for each statement. Please tick one box for each question.

		Disagree	Undecided	Agree	Strongly Agree
a	More can be done to manage people with dementia				
b	Managing people with dementia is part of my role				
c	In most cases there is not much that can be done to manage people with dementia				
d	The carer of a patient with dementia can provide valuable information about the patient’s routine, likes and dislikes				
e	I value the input a carer can provide in helping a patient with dementia				
f	Involving the carer enables faster recovery of the patients with dementia				
g	The more information available about the patient’s usual routine, likes and dislikes the easier it is to manage their care in hospital				
h	I always obtain key strategies from carers to help manage the care of patients with dementia				

5. Please list 3 actions that you think are important in communicating effectively with patients with dementia?

6. Please list 3 actions that help you manage care effectively with patients with dementia?

7. How would you describe your overall knowledge of dementia? Please tick one of the following that best describes your overall knowledge

Little or no experience <input type="checkbox"/> working with and knowledge of patients with dementia and their carers	Some experience <input type="checkbox"/> working with and knowledge of patients with dementia and their carers	Regularly worked with <input type="checkbox"/> and undertaken training about patients with dementia and their carers
--	--	---

8. How would you rate your level of confidence in caring for patients with dementia?

Not confident Somewhat confident Confident Very confident

9. My level of comfort in engaging with carers is:

Not comfortable Somewhat comfortable Comfortable Very comfortable

10. Have you attended an education session on TOP 5?

Yes No

11. Did you receive any written information about TOP 5?

Yes No

12. How did you find TOP 5?

Please let us know how you feel about the following statements by ticking one box.

		Disagree	Undecided	Agree	Strongly Agree
a	The process was easy to use				
b	The process was not time consuming				
c	Improved my time management				
d	Improved my discharge planning				
e	We had less need to 'special' patients				
f	I felt the working environment was safer				
g	I had more work satisfaction when caring for patients with dementia				
h	It was easier to relate to the carers				

13. Did you observe any changes in the patients or carers who had TOP 5 in place? Please let us know how you feel about the following statements by ticking one response per question.

		Disagree	Undecided	Agree	Strongly Agree
a	The patients were less agitated and distressed				
b	Less restraint was required for the patient's (e.g. Physical or chemical)				
c	Patient's recovered more quickly				
d	Carers appeared more confident with the care being provided				
e	Carers were a partner in care				
f	There were less concerns raised by the family/carer				

14. Do you have any general comments about TOP 5?

15. Do you have any suggestions for how TOP 5 should be used in the future?

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 Site Liaison Person

The CEC would like to thank the Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The CEC would also like to acknowledge the support of the HCF Health and Medical Research Foundation.



- This page is intentionally blank -

APPENDIX K

- This page is intentionally blank -



Information and Consent Form for Staff Feedback

The Clinical Excellence Commission (CEC) is collaborating with several hospitals in NSW to improve the use of carer knowledge in the care of patients with cognitive impairment (mainly patients with dementia) when they are admitted to hospital.

When a patient with cognitive impairment is admitted to a hospital environment they are placed in a unknown environment and their daily routine is disrupted. Add to this the reason for their admission - which may involve pain and discomfort - the individual would likely be very anxious and scared and looking for something familiar. Being unable to communicate adequately with patient's is difficult for staff and can lead to situations that cause further anxiety for all concerned.

This initiative encourages staff to seek information from a patient's carer in order to identify some tips & strategies that can be used to lessen the anxiety and gain an better understanding of how the patient reacts and communicates.

We are seeking your assistance to find out if this "TOP 5" initiative will make a difference to carers and staff and subsequently the patient in this facility.

What are you asking me to do?

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

Should you wish to have further assistance in completing the survey, please ask the person who provides 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, please contact this person in the first instance. Similarly, if you would like any further information, please do not hesitate to contact this person.

You can contact the Project Coordinator from the Clinical Excellence Commission. Their details appear below the contact details for your facility liaison contact on the attached Participant Consent Form.

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

Contacts			
Site Liaison		Project Coordinator (Clinical Excellence Commission)	
Name:		Name:	Anne Axam
Contact No:		Contact No:	92695521

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: _____

APPENDIX L

- This page is intentionally blank -



TOP 5 CARER SURVEY

LHD

To be completed – by carers involved in the TOP 5 initiate

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. 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**.

1. Has the patient been admitted previously? Yes No

If yes, please read the following questions and tick one box for each question:

		Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
a	How satisfied are you that the staff are aware of your caring role?				
b	How satisfied are you that the staff made you feel comfortable to provide information about the person you care for?				
c	When you offered information regarding the person you care for, how satisfied are you the staff listened to you and took notice of the information?				

2. Thinking about this admission can you tick one of the following boxes that best describes your experience. Tick one box for each question:

		Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
a	How satisfied are you that the staff are aware of your caring role?				
b	How satisfied are you that the staff made you feel comfortable to provide information about the person you care for?				
c	When you offered information regarding the person you care for, how satisfied are you the staff listened to you and took notice of the information?				

3. How satisfied are you with the information you were given about the TOP 5 initiative?

- Very satisfied Satisfied Dissatisfied Very dissatisfied

4. How satisfied are you the staff acknowledged and used the TOP 5 suggestions you made in the provision of care?

- Very satisfied Satisfied Dissatisfied Very dissatisfied

5. Please provide your opinion for each statement. Tick one box for each question:

		Disagree	Undecided	Agree	Strongly Agree
a	The staff acknowledged and used the TOP 5 suggestions you made in the provision of care.				
b	The TOP 5 initiative has had a positive impact on involving you in patient care.				
c	Your loved one/the patient has benefited from the TOP 5 initiative.				
d	Your loved one/the patient has been calmer and less anxious with the integration of your knowledge into his/her care.				
e	My loved one/the patient has recovered quicker than other admissions.				
f	The staff have communicated well with my loved one/the patient.				

6. Do you have any other comments about TOP 5?

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 Site Liaison Person

The CEC would like to thank the Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The CEC would also like to acknowledge the support of the HCF Health and Medical Research Foundation.

APPENDIX M

- This page is intentionally blank -

Information and Consent Form for Carer Feedback

The Clinical Excellence Commission (CEC) is collaborating with several hospitals in NSW to improve the use of carer knowledge in the care of patients with memory problems when they are admitted to hospital.

When a patient with memory problems is admitted to a hospital environment they are placed in a unknown environment and their daily routine is disrupted. Add to this the reason for their admission - which may involve pain and discomfort - the individual would likely be very anxious and scared and looking for something familiar.

The hospital staff have asked you for your ‘TOP 5’ tips as a carer to lessen the anxiety and gain an understanding of how the patient reacts and communicates.

We are seeking your assistance to find out if this ‘‘TOP 5’’ initiative will make a difference to carers and staff and subsequently the patient in this facility.

What are you asking me to do?

Using a short survey we would like to ask a few questions of you as a carer for a patient with memory problems. You will be asked to sign a consent to allow your information to be shared with the Clinical Excellence Commission for the purpose of further analysis.

Should you wish to have further assistance in completing the survey, please ask the staff member who provides 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 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, please contact this person in the first instance. Similarly, if you would like any further information, please do not hesitate to contact this person.

If you:

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

You can contact the Project Coordinator from the Clinical Excellence Commission. Their details appear below the contact details for your facility liaison contact on the attached Participant Consent Form.

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

Contacts			
Site Liaison		Project Coordinator (Clinical Excellence Commission)	
Name:		Name:	Anne Aham
Contact No:		Contact No:	92695521

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.

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: _____

APPENDIX N

- This page is intentionally blank -

Note 1- Staff Surveys: Acceptance of Carer input

Staff Pre-Implementation Surveys Q4d-g

	Q4d	Q4e	Q4f	Q4g
Strongly Agree	72.0%	70.3%	56.0%	65.5%
Agree	27.5%	28.6%	36.8%	32.6%
Undecided	0.4%	0.9%	6.1%	1.3%
Disagree	0.0%	0.2%	1.1%	0.6%

Q4d) "The carer of a person with dementia can provide valuable information about the person's routine, likes and dislikes": no significant difference in ratings between time points, $F(2,754)=1.05$, $p>.05$.

Q4e) "I value the input carer can provide in helping a patient with dementia": no significant difference in ratings between time points, $F(3,754)=0.42$, $p>.05$.

Q4f) "Involving the carer enables faster recovery of the patient with dementia ": no significant difference in ratings between time points, $F(2,753)=0.12$, $p>.05$.

Q4g) "The more information available about the patient's usual routine, likes and dislikes the easier it is to manage their care in hospital": no significant difference in ratings between time points, $F(2,755)=1.52$, $p>.05$.

Note 2- Staff Surveys: Obtaining key strategies from carers

The proportion of staff reporting that they "always obtain key strategies from carers to manage the care of patients with dementia" was significantly higher among surveys collected after the introduction of TOP 5 ($M=3.22$, $SD=0.66$) than among those collected prior ($M=3.10$, $SD=0.73$); $F(1,712)=5.65$, $p<.05$.

Note 3- Staff Surveys: Confidence in caring for patients with dementia

Staff rated their own levels of confidence in caring for patients with dementia as being significantly higher on surveys completed after the introduction of TOP 5, ($M=2.93$, $SD=0.65$), than those completed prior to TOP 5 ($M=2.74$, $SD=0.75$); $F(1,712) = 11.21$, $p<.05$. This increased confidence was sustained as there was no significant difference in self-reported levels of confidence between those surveys submitted after 6 months and those submitted at the end of the evaluation period, $F(1,712)=0.02$, $p>.05$.

Note 4- Staff Surveys: attitudes towards TOP 5. Comparing responses at 6 months and at end of evaluation period.

Q12a) "The process was easy to use": no significant difference in ratings between time points, $F(1,269)=0.83$, $p>.05$.

Q12b) "The process was not time consuming": no significant difference in ratings between time points, $F(1,269)=0.23$, $p>.05$.

Q12g) "I had more work satisfaction caring for patients with dementia": no significant difference in ratings between time points, $F(1,269)=0.07$, $p>.05$.

Q12h) "It was easier to relate to carers": no significant difference in ratings between time points, $F(1,269)=0.01, p>.05$.

Q13a) "The patients were less agitated": no significant difference between in ratings between time points, $F(1,269)=0.72, p>.05$.

Note 5- Carer Surveys

a) Staff aware of caring role: Satisfaction ratings were significantly higher for the current hospitalisation with TOP 5 (M=3.64, SD=0.63), than for the previous hospitalisation (M=3.55, SD=0.55); $t(135)=-2.30 p<.05$.

b) Staff made you feel comfortable to provide info about the patient: Satisfaction ratings were significantly higher for the current hospitalisation with TOP 5 (M=3.68, SD=0.60) than for the previous hospitalisation (M=3.61, SD=0.54); $t(134)=-2.36 p<.05$.

c) Staff listened to and took notice of that information: Satisfaction ratings were significantly higher for the current hospitalisation with TOP 5 (M=3.66, SD=0.56), than for the previous hospitalisation (M=3.55, SD=0.62); $t(132)=-3.592 p<.05$.

Note 6- Falls involving patients with dementia

Five sites recorded at least one fall involving a patient with dementia (PWD) in the first two months of their TOP 5 implementation period- Hospital 1, 6, 11, 20 and 21. Among these, there was an average decrease of 36.4% in the number of falls involving patients with dementia between the first and sixth month of TOP 5 implementation.

Note 7- Falls before and after TOP 5

An Ordinary Least Squares regression, controlling for seasonal effects and existing falls prevention strategies, found there was a statistically significant decrease in the numbers of falls following the introduction of TOP 5 at Hospital 7, $B=-7.45, p<.10$; and a statistically significant downward change in the time trend in falls at Hospital 15, $B=-3.97, p<.05$; and Hospital 16, $B=-0.67, p<.05$.

Note 8- Hospital 13 - with control ward: Falls

An Ordinary Least Squares regression, controlling for seasonal effects and existing falls-prevention strategies, found that following the implementation of TOP 5 there was a statistically significant decrease in the number of falls reported through the Incident Management System for all patients on the TOP 5 ward when compared to the 'control ward', $B=-6.85, p<.05$. This equates to an average of 6.85 fewer falls per month than the control ward.

Note 9- Hospital 11: Anti-psychotic usage

The total pharmacy stock usage of selected anti-psychotic medications for the participating site wards was obtained for the TOP 5 implementation period, and for the same time period of the previous year (prior to the implementation of TOP 5). Estimated monthly usage for the two time periods was compared and found to be lower in the time period where TOP 5 was in place.

Note 10- Hospital 7: Risperidone quicklet usage

Monthly stock usage of selected anti-psychotic medications for the participating wards was obtained for

18 months prior to and 7 months following the introduction of TOP 5. An interrupted time series regression analysis, controlling for seasonal effects, found that there was a statistically significant decrease in the stock usage of Risperidone quicklets since the introduction of TOP 5, $B=-67.17$, $p<.10$.

Note 11- Falls and use of anti-psychotics for chemical restraint

An Ordinary Least Squares regression of log site data found that across all sites there was a robust relationship between the number of administrations of anti-psychotics for chemical restraint to patients with dementia and the numbers of falls among this same population, $B=0.4$, $p<.01$. For each additional use of anti-psychotics for chemical restraint there was an associated increase of 0.4 falls on average.

Note 12- Hospital 10: 'Specials' staffing

An Ordinary Least Squares regression analysis found that there was a statistically significant decrease in the time trend for the use of specials since the introduction of TOP 5, $B=-0.84$, $p<.05$. Since Top 5 was implemented, each month there was an additional decrease of 0.84 specials, controlling for seasonal effects.

Note 13- Major Metropolitan Peer Group Hospitals: Dementia patients admitted

An interrupted time series regression found that there was a statistically significant increase in the time trend in patients admitted with a dementia diagnosis following the introduction of TOP 5, such that for each month following TOP 5 there was an additional increase of 3.48 patients, $B=3.48$, $p<.10$.

Note 14- Association between HIE data and log data on patients with dementia

An Ordinary Least Squares regression analysis found a statistically significant correlation between the number of patients with a recorded diagnosis of dementia and the number of patients identified by ward staff as likely having dementia, $B=0.88$, $p<.01$.

Note 15- Hospital 11: Falls and ALOS

An Ordinary Least Squares regression analysis found that there was a statistically significant relationship between IIMS-notified falls and a longer ALOS for all patients with dementia at Hospital 11, $B=0.31$, $p<.05$.

Note 16- Hospital 13: Estimate of cost savings from falls prevented

Given the most current Australian estimate for the cost of hospital care following a fall of \$18,454 (Watson, 2010), 6.85 falls prevented per month equates to up to \$126,410 saved each month that this decrease in falls is sustained. This figure represents an upper bound estimate as there is currently no available data specifically costing falls that occur whilst in hospital, although the cost of subsequent care is likely to be similar to that of a fall occurring in the community.

END OF APPENDICES