# Research Report

## Exploring carer inclusion in delirium prevention and management in the emergency department: an interim report

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### Acknowledgements:

I would like to express my gratitude to the NSW Health Education & Training Institute for granting me this invaluable opportunity to partake in such a transformative program. I am equally grateful to Northern NSW Health LHD and the vital members of the Grafton Base Hospital management team for their support and encouragement as I embarked on this research project, and to the dedicated staff of the Grafton Base Hospital emergency department, who played a key role by identifying potential participants and distributing the PREDICT tool to eligible carers, enabling this crucial research to unfold.

I would also like to extend my sincere thanks to Christina Aggar and Ya-Ling Huang for their continuous support and insightful guidance as I navigate the intricate world of research. Your mentorship has been invaluable.

Last but certainly not least, I wish to express my profound appreciation for David and Kerith. Their steadfast support and unwavering belief in my capabilities have been instrumental in making this journey not just enlightening, but truly inspiring.

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| **Abbreviations** | |
|---|---|
| Carers | Family carers, non-paid carers, informal carers, caregivers |
| CDKQ | Caregiver Delirium Knowledge Questionnaire |
| CPR | Cardio-Pulmonary Resuscitation |
| DEL-B-C | Caregiver Delirium Burden Scale |
| GP | General Practitioner |
| IQR | Inter-Quartile Range |
| K10 | Kessler Psychological Distress Scale |
| PFCC | Patient- and Family-Centred Care |
| PREDICT | Prevention and Early Delirium Identification Carer Toolkit |
| SD | Standard Deviation |
| T1 | Baseline |
| T2 | 4- 6 weeks post baseline |

# Abstract

Delirium is an acute onset condition that can have profound health impacts on older adults, with unrecognised delirium increasing the risk of mortality and morbidity considerably. The cost of delirium to patients, their families, and the healthcare system is significant. The predicted increase in older adult presentations to the emergency department raises the potential for a rise in delirium numbers under current management processes. Care partnerships with informal carers (to be called carers here on in) have been suggested as an addition to current staff-led prevention and detection processes.

The Prevention and Early Delirium Identification Carer Toolkit (PREDICT) has been co-designed to engage carers as partners in the prevention and management of delirium. This online toolkit offers short educational videos designed to increase knowledge of delirium signs and symptoms, approaches to prevention and management, and provides resources to support carer well-being. It also contains a carer-led delirium screening tool to be used by the carer to support the early detection of delirium signs and symptoms.

The aim of this study was to evaluate the impact of a co-designed Prevention & Early Delirium Identification Carer Toolkit (PREDICT) on Carers in the emergency department.

**Methods**:

Underpinned by the philosophy of Patient and Family Centred Care, this pilot study utilised a pre-post implementation design with data collection via questionnaires at baseline and at the 4–6 week follow-up. The study site was the Grafton Base Hospital emergency department, with purposive sampling used to recruit carers of older adults aged 65 years and older, including Aboriginal and Torres Strait Islander people aged 45 years and older. Questionnaires provided with PREDICT to eligible carers measured carer delirium knowledge, carer burden and psychological distress.

**Results**: 83 Carers have been provided with PREDICT to date. At the time of this report, 11 carers had completed a questionnaire at baseline and follow-up, and nine carers had completed the initial questionnaire. Interim results indicate nil statistically significant change in knowledge of delirium or experience of carer distress between the two timepoints in the paired questionnaires (n=11); however, this small sample size does not allow for conclusive results. Thematic analysis of the short-answer questions indicates that inconsistent staff approaches to inclusion and carer burden contribute to the distress experienced by carers.

**Conclusion**: Data collection for this study continues. Early indicators show several improvements could be made to inclusion processes. Implementing a formal approach to address these will help to minimise inconsistencies. Further quantitative analysis will allow a more nuanced understanding of the impact of the toolkit on carer knowledge of delirium and carer distress. Findings from the short-answer questions highlight the need for ongoing carer support and implementation of consistent inclusion processes. Whilst carers wish to be involved in care processes, there is a need for ongoing carer education and increased support to reduce the carer burden.

**Keywords: Delirium, carers, emergency department, care partnerships, education toolkit**

# Executive Summary

The complex healthcare needs of older adults, particularly those with chronic conditions and cognitive impairment, pose a challenge for clinicians to provide timely person-centred care in the emergency department (Burkett et al., 2017; De Brauwer et al., 2021). Older Adults over 65 years of age are at an increased risk of experiencing delirium, a condition that increases the patient's risk of death, length of stay, risk of falls, risk of developing dementia and chance of being discharged to a higher dependency of care (Australian Commission on Safety and Quality in Health Care, 2021). Additionally, delirium costs the Australian healthcare system approximately AUD 8.8 billion each year (Pezzullo, 2019). To enhance a patient-centred care approach, partnerships with carers have been suggested as a way to manage the complex care needs of older adults (Gallagher et al., 2014; Schnitker et al., 2016).

An integrative review exploring primary research reporting the inclusion of informal carers in caring for older people in the emergency department was undertaken to support this study (Nichols et al., 2025). This review emphasises the importance of care partnerships involving informal carers in the emergency department in providing high-quality care to older adults with complex care needs, including evidence on barriers and facilitators of successful carer inclusion (Nichols et al., 2025). The integrative review was important as it provided guidance on key elements to promote partnerships with carers to optimise care delivery to older adult patients, including collaboration, communication, education, and support for the carers (Nichols et al., 2025).

Carers possess essential knowledge regarding the baseline cognitive and physical status of older adults, which enables them to identify changes in condition sooner than staff members may detect (Fry et al., 2022). Their desired involvement in decision-making processes and attention to basic care needs make them well-suited to collaborate in the prevention and management of delirium within the emergency department (de Oliveira Assis et al., 2022). While the significance of carers in delirium management is acknowledged, there remains a lack of thorough research and structured programs within emergency departments (Dyer et al., 2016; Fry et al., 2022)

The Prevention and Early Delirium Identification Carer Toolkit (PREDICT) was co-designed to strengthen partnerships with the carers of older adults in the prevention and management of delirium (Aggar et al., 2023b). Following validation, PREDICT was successfully piloted on a medical ward in a regional hospital in Northern NSW (Aggar et al., 2024). PREDICT presented an opportunity to trial a structured carer inclusion program in the emergency department. This study sought to determine the impact of PREDICT on carers' satisfaction with care, knowledge of delirium, and experience of caregiving burden, anxiety, and depression when provided in the emergency department.

| ***PREDICT's relevance to policy:*** | |
|---|---|
| The Delirium Clinical Care Standard (Australian Commission on Safety and Quality in Health Care, 2021 | PREDICT aligns with the Delirium Clinical Care Standard by:<br>• Supporting family carers to be actively part of their relative's care.<br>• Recognising that family carer involvement is integral to patient-centred care.<br>• Allowing carers to be involved in screening for delirium and risks, allowing informed decisions by the patient and carer before admission or discharge from the emergency department.<br>• Providing support for carers through the provision of education and relevant information. |
| NSW Carers Strategy 2020-2030 (Department of Communities and Justice, 2020) | PREDICT:<br>• Provides carers with increased access to information, services, and support (aligning with priority 1).<br>• Enables increased recognition, respect, and empowerment of carers (aligning with priority 2).<br>• Seeks to improve carer well-being (aligning with priority 4). |

## Methodology:

This pilot study utilised a pre-post implementation design with pre- and post-questionnaires completed by eligible carers. This study sought to evaluate the impact of the co-designed Prevention and Early Delirium Identification Carer Toolkit (PREDICT) on Carers in the emergency department.

## Findings:

Interim results indicate nil statistically significant change in knowledge of delirium or experience of carer distress between the two timepoints in the paired questionnaires (n=11); however, this small sample size does not allow for conclusive results. The majority of carers in this sample (n=10) have indicated a desire to be included in delirium prevention and management. Thematic analysis of the short-answer questions indicates that there are inconsistent staff approaches to inclusion, with staff demonstrating a lack of empathy and poor understanding of the patient's presentation. Carer burden was also thought to contribute to the distress experienced by carers, balancing additional worries, such as poor health, work and home duties with the role of carer.

## Conclusion:

Data collection for this study is ongoing, with the current sample size restricting the ability to conduct a robust analysis of PREDICT's effects. Preliminary analysis of the short answer questions, along with the question on carer involvement, indicate that whilst carers wish to be involved, there is a need for a more consistent carer inclusion process and increased carer support of carer wellbeing in the emergency department.

## Recommendations:

Development of formal policies and procedures that:

- promote effective communication and inclusive decision-making processes.
- Minimise carer inclusion inconsistencies between staff
- Enhance staff capacity to include carers
- Allow inclusion without increasing carer burden and distress.

To inform the development of formal processes, further research that incorporates insights and perspectives of key stakeholders is required. This research should actively involve emergency department staff members, caregivers who provide direct support to older adults, and management personnel responsible for overseeing operations. Engaging these groups will ensure that processes developed are not only thorough and practical but also sustainable in the long term. This collaborative approach will help identify the specific needs of the stakeholder groups, potential challenges for implementation, and effective solutions to current inclusion challenges.

# Introduction

## Context

In Australia, older adults, 65 years and older, currently account for 22% of emergency department presentations and have the highest proportional urgency of care and hospital admission rates (Australian Institute of Health and Welfare, 2024b). Rates of delirium for older adults in the emergency department can be as high as 38% (Chen et al., 2022; Filiatreault et al., 2024; Oliveira et al., 2021), and up to 25% of older adults are thought to be discharged home from the emergency department with an unrecognised delirium (Eagles et al., 2022). With the number of adults 65 years and older expected to double globally by 2050 (World Health Organisation, 2022) and a predicted increase in the number of older adults presenting to the emergency department (Burkett et al., 2017), there can be an assumed increase in the number of delirium cases if additional preventative steps are not undertaken.

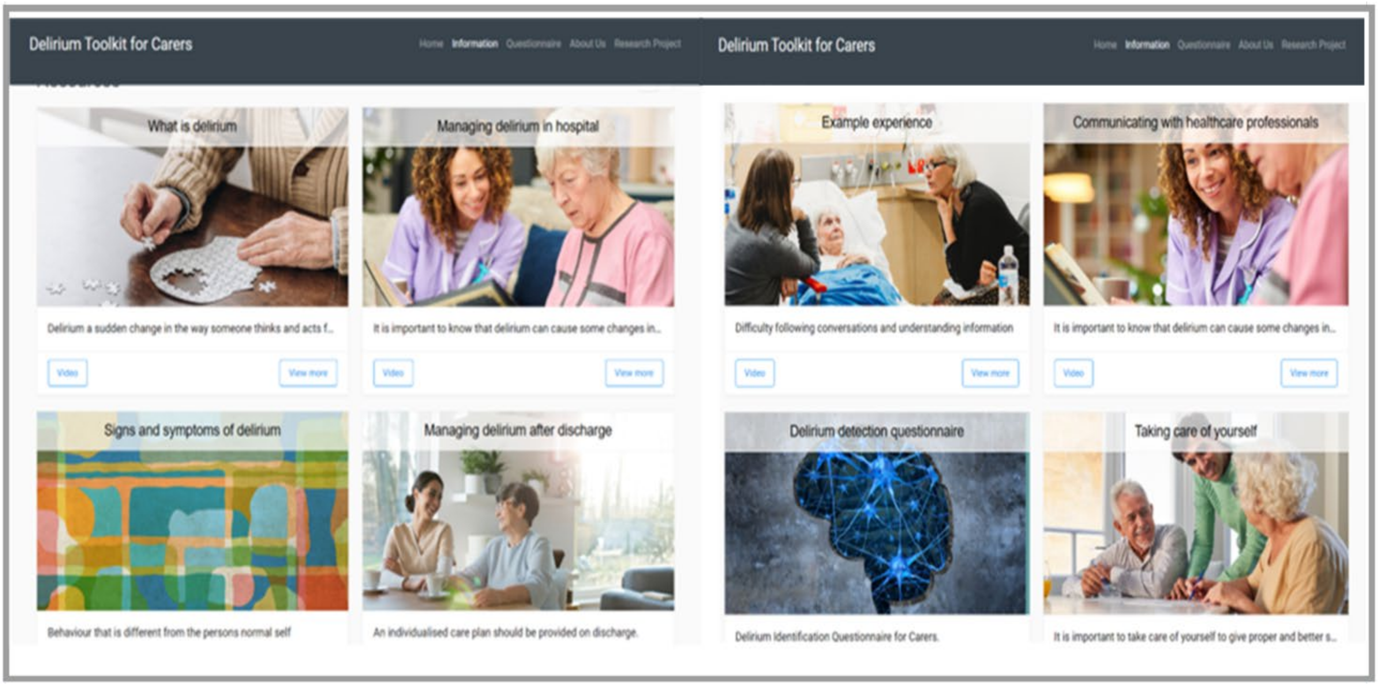
Delirium is a preventable syndrome (León-Salas et al., 2020) and the recognition of delirium risk factors and early disorder manifestations is an essential part of delirium management (Australian Commission on Safety and Quality in Health Care, 2021; Eagles et al., 2022; Lee et al., 2022b; León-Salas et al., 2020). Two barriers to delirium identification include the inability of staff to assess cognitive changes in the older adult properly (Schonnop et al., 2022) and the existence of competing clinical tasks. These barriers can result in a failure to complete screening assessments (Eagles et al., 2022). To manage the complexity of care for older adults, it has been recommended that healthcare professionals actively partner with carers to enhance a patient-centred care approach (Gallagher et al., 2014; Schnitker et al., 2016).

Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged (Carers Australia, 2024). Carers have a greater knowledge of the older adults' cognitive and physical baselines than the emergency department staff (Fry et al., 2022). Their involvement in care partnerships has the potential to ensure safe, high-quality care and increase the well-being of the patient (Fry et al., 2022; Mailhot et al., 2020).

The involvement of carers as partners in the prevention, early identification, and management of delirium in older adults has been successfully demonstrated in admitted patients using the Prevention and Early Delirium Identification Carer Toolkit (PREDICT) (Aggar et al., 2024). This web-based toolkit (a summary of the information and screening tool is available in paper format for caregivers who prefer not to use the online platform) is designed to be provided to caregivers upon admission, with carers encouraged to engage with PREDICT daily. The Prevention and Early Delirium Identification Carer Toolkit (PREDICT), described in Table 1, strengthens nurse-carer partnerships in the prevention and management of delirium by improving delirium knowledge and supporting carer well-being (Aggar et al., 2023b)

Table 1: PREDICT content description

| The Prevention and Early Delirium Identification Carer Toolkit (PREDICT) |
|---|
| • short educational videos of delirium signs and symptoms, approaches to prevention and management, communication with healthcare professionals and self-care. (Figure 1)<br>• 7-item psychometrically tested screening tool designed by Shulman et al. (2016) for non-healthcare professionals to identify delirium risk and implement prevention strategies. Scores of 4 and over indicate a potential delirium. (Figure 2)<br>• Links for counselling and social service programs to provide further support.<br>• Information on the discharge process and managing at home post-discharge. |



Delirium a sudden change in the way someone thinks and acts f...

It is important to know that delirium can cause some changes in...

Behaviour that is different from the persons normal self

An individualised care plan should be provided on discharge.

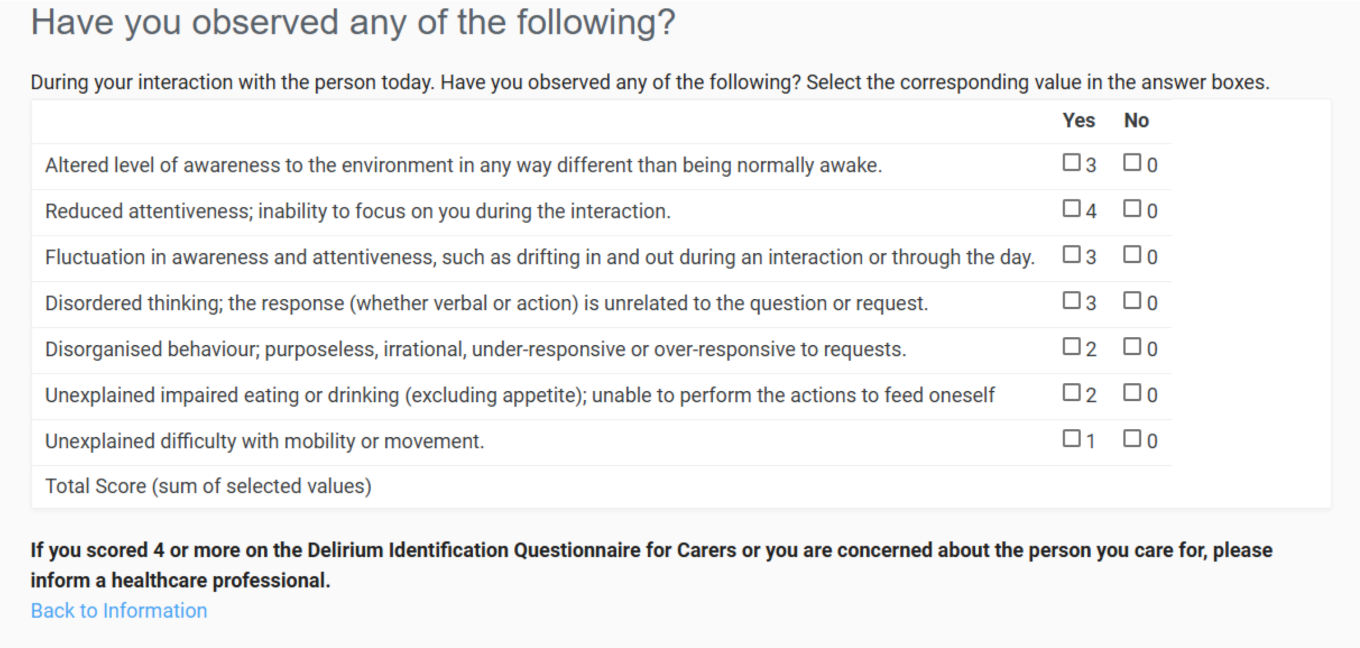
Difficulty following conversations and understanding information

It is important to know that delirium can cause some changes in...

Delirium Identification Questionnaire for Carers.

It is important to take care of yourself to give proper and better s...

Figure 1: Screenshot of the PREDICT website showing educational videos available for carers.



Have you observed any of the following?

During your interaction with the person today. Have you observed any of the following? Select the corresponding value in the answer boxes.

| | Yes | No |
|---|---|---|
| Altered level of awareness to the environment in any way different than being normally awake. | ☐ 3 | ☐ 0 |
| Reduced attentiveness; inability to focus on you during the interaction. | ☐ 4 | ☐ 0 |
| Fluctuation in awareness and attentiveness, such as drifting in and out during an interaction or through the day. | ☐ 3 | ☐ 0 |
| Disordered thinking; the response (whether verbal or action) is unrelated to the question or request. | ☐ 3 | ☐ 0 |
| Disorganised behaviour; purposeless, irrational, under-responsive or over-responsive to requests. | ☐ 2 | ☐ 0 |
| Unexplained impaired eating or drinking (excluding appetite); unable to perform the actions to feed oneself | ☐ 2 | ☐ 0 |
| Unexplained difficulty with mobility or movement. | ☐ 1 | ☐ 0 |
| Total Score (sum of selected values) | | |

**If you scored 4 or more on the Delirium Identification Questionnaire for Carers or you are concerned about the person you care for, please inform a healthcare professional.**

Back to Information

Figure 2: 7-item psychometrically tested screening tool designed by Shulman et al. (2016) taken from the PREDICT website.

Involvement of carers in the care of older adults in the emergency department is an important aspect of providing high-quality, patient-centred care (Walsh et al., 2022). For delirium, the older adults' critical condition, combined with various comorbidities, may hinder the staff's ability to detect early changes in the patient, resulting in an increased risk in the emergency department (Chen et al., 2022). As carers have a greater knowledge of the older adult’s physical and cognitive baselines, the detection of early cognitive changes can be aided by carer involvement (Fry et al., 2022). However, research exploring the inclusion of carers in the emergency department is limited (Fry et al., 2022; Peguero-Rodriguez et al., 2023) and carer inclusion in delirium prevention and management are underexplored. Expanding the utilisation of PREDICT into the emergency department would provide education on delirium and communication strategies that strengthen care partnerships earlier in the patient’s journey, which may improve patient outcomes and carer burden.

## Background

Delirium is an acute-onset, reversible syndrome that alters an individual's cognitive functioning, producing difficulties in memory, emotions, perceptions, and reasoning (León-Salas et al., 2020; Pezzullo, 2019). Delirium can occur at any age; however, people 65 years and over are more vulnerable (Bugiani, 2021). Delirium can have profound health impacts on the older adult, including increased hospital stays, prolonged or permanent decline in functional and cognitive abilities, repeat emergency presentations, increased risk of hospital-acquired complications such as infections, falls, and pressure sores, and an increased risk of mortality (Martin et al., 2022; Schonnop et al., 2022). Additionally, when delirium goes unrecognised, these health impacts can be worsened by prolonged incidence of delirium (Han et al., 2017).

Carers of older patients experience substantial levels of concern and distress in the event of delirium. Shrestha and Fick (2020) determined that carers struggle with the sudden and unpredictable nature of delirium, citing a lack of understanding regarding the progression of this disorder as a significant contributor to this burden. The carer's well-being is negatively affected by the uncertainty of how to manage a family member with deteriorating cognitive function and fears that they are doing something wrong (Shrestha & Fick, 2020).

In addition to the effects of delirium on the patient and carer, the costs to the healthcare system are significant. Pezzullo and colleagues (2019) estimated that the total cost of delirium to the Australian healthcare system over a year was approximately AUD8.8 billion. This cost was attributed to an increased length of hospital stay for delirium patients (estimated at an extra 2.7 days per patient), greater general practitioner (GP) utilisation following discharge, loss of productivity in working patients and carers, loss of healthy lifestyle due to disability, and funeral costs due to increased morbidity (Pezzullo, 2019). The total cost to hospitals was approximately AUD506.1 million per year (Pezzullo, 2019). In 2022 and 2023, delirium was the second most common hospital-acquired complication in Australia (Australian Institute of Health and Welfare, 2024a) highlighting the ongoing significance of this disorder on the Australian Healthcare system.

The Delirium Clinical Care Standard (Australian Commission on Safety and Quality in Health Care, 2021) prescribes improvements in prevention, early diagnosis and treatment to ensure the quality and safety of care for patients at risk of delirium. Leon-Salas et al. (2020) assert that interventions to prevent delirium should occur before the manifestation of symptoms, claiming that 30% to 40% of delirium could be avoided with preventative strategies. While delirium prevention is considered a central target, if prevention cannot occur, timely recognition of delirium will reduce the negative effects on the patient, family, and healthcare system (Chen et al., 2022; Lee et al., 2022a; Martin et al., 2022; Oliveira et al., 2021; Pezzullo, 2019).

Carer involvement in healthcare settings is recommended in the care of all patients, including those with delirium (Australian Commission on Safety and Quality in Health Care, 2021), and research conducted in the ICU and ward environments has emphasised the importance of carer involvement in prevention and early recognition processes (Aggar et al., 2023a; Aggar et al., 2023b Aggar et al., 2024; Lange et al., 2022; Qin et al., 2022). In the emergency department, research into the implementation of formal carer involvement processes is limited (Peguero-Rodriguez et al., 2023) despite recognition that carer involvement in the care of older adults is an important aspect of providing high-quality, patient-centred care (Walsh et al., 2022). To address this gap, the utilisation of PREDICT in the emergency department was proposed to provide education on delirium and communication strategies to strengthen care partnerships earlier in the patient's journey, aiming to improve patient outcomes and carer burden.

## Research Question

This study aimed to address the following research question:

What is the impact of PREDICT on carers of older people in terms of satisfaction with care, knowledge of delirium, and experience of caregiving burden, anxiety, and depression when provided in the emergency department of a regional Australian hospital?

# AIM

The aim of this study was to evaluate the impact of a co-designed Prevention & Early Delirium Identification Carer Toolkit (PREDICT) on Carers in the emergency department.

# Method

## Study Design

A pre-post implementation design with data collected at baseline and 4-6 weeks follow-up.

### Philosophical context

Patient and Family Centred Care serves as the philosophical underpinning for this research. Anderson and Rose (2019) discuss the importance of a “positive, strength-based and affirming approach” in addressing the needs of older adults in healthcare. The involvement of older adults in their own care processes has been documented by Wolff and Boyd (2015). In implementing PREDICT, the importance of older adults being viewed as active participants in their healthcare journey is recognised. When age-related changes occur in cognitive, physical, or sensory function, family involvement (both related and chosen) is essential for quality care (Wolff & Boyd, 2015). Patient and Family Centred Care involves the partnership of the carer, patient and healthcare professional to plan, deliver, and evaluate the care provided to the older patient (Institute for Patient- and Family-Centered Care, n.d)

The importance of holistic care and the need for the carer’s involvement in patient care to improve care quality are central foundations of this research. Traditional medical models of care focus on processes that exclude the patient and carer from decision-making, expecting compliance to choices made for the patient by the healthcare professional (Kumar & Chattu, 2018). Patient and Family Centred Care approaches acknowledge the importance of the carer and patient in decision-making processes and have been demonstrated to improve care quality (Institute for Patient- and Family-Centered Care, n.d; Kumar & Chattu, 2018; Wolff & Boyd, 2015). A Patient and Family Centred Care philosophy aligns with outcomes of the integrative review Nichols et al. (2025), which found that key elements to promote partnerships with carers to optimise care delivery to older adult patients include collaboration, communication, education, and support for the carers.

### Setting

This study was conducted in the Grafton Base Hospital Emergency Department. Grafton Base Hospital Emergency Department was chosen as the site for this study due to the relatively high number of older adult presentations. Grafton Base Hospital is a level 3 / 4 hospital with an emergency department that had the highest number of patients per 1000 patient days over 70 years of age in Northern NSW Health

District in 2022. Between July 2023 and July 2024, there were 28,426 presentations to Grafton Base Hospital emergency department. Approximately 6253 patients were over 65 years, using the 22% estimation by Australian Institute of Health and Welfare (2024b). Using the delirium prevalence numbers reported by Oliveira  et al. (2021) (7% to 34.7%), delirium occurrence was estimated to range from 437 to 2169 older adults per year. According to  Lee et al. (2022a), a third of patients with delirium were discharged with unrecognised delirium in the early stages. Using this calculation, approximately 145 to 723 older adults could potentially be discharged from the emergency department with an unrecognised delirium (Lee et al., 2022a).

## Participants

Purposive sampling was used to recruit carers of patients aged 65 years and older (Aboriginal and Torres Strait Islander people > 45 years) presenting to the emergency department. Eligibility criteria include carers who: i) are English speaking; ii) accompanied the patient in the emergency department; and iii) have an interest in receiving PREDICT. From this cohort, participants were excluded if: i) the patient has advanced dementia, ii) the patient was significantly unwell requiring intubation, ventilation or CPR, or iii) the patient requires admission for end-of-life care.

Carers who were identified as eligible to participate were provided with access to PREDICT on admission to the emergency department by the researcher and nursing and medical staff familiar with the study requirements. Carers were encouraged to engage with PREDICT and communicate with staff if they had concerns. Instructions and an invitation to participate in the evaluation of PREDICT, along with the Participant Information Statement, were available online or in hard copy.

## Study Size

A statistician was sought to provide advice on the sample size calculation. The estimation of the sample size for this pilot study was based on the work of Birkett and Day (1994). Twenty carers were required to return the questionnaire at baseline (T1) and at 4 – 6 weeks post-intervention (T2). Attrition was expected at a rate of 10% (Egbuchulem, 2023); therefore, the sample size was set at twenty-two.

## Study Measurements

Demographic information obtained included age, gender, whether the carer was of Aboriginal and Torres Strait Islander descent, relationship with the patient, and whether the carer lived with the patient. Two short answer questions also provided the opportunity for carers to provide greater detail on other aspects of care the carers found distressing and factors they felt would facilitate or hinder the inclusion of carers in the identification and management of delirium in hospitalised older adults.

Psychometrically tested tools were used to explore delirium knowledge, caregiving burden and carer distress levels.

**Carer Delirium Knowledge**

- Delirium knowledge was measured using the Caregiver Delirium Knowledge Questionnaire (CDKQ) (Bull et al., 2015). The CDKQ is a 19-item psychometrically tested measure comprising a 10-item risk factor, 5-item symptoms, and a 4-item action scale (Bull et al., 2015). Correct responses to the true and false questions in each section are awarded a score of 1, with higher scores indicating greater knowledge (Bull et al., 2015). Cronbach's alpha of 0.76 (Bull et al., 2015).

**Caregiving Burden**

- Caregiving burden was measured using the 8-item Caregiver Delirium Burden Scale (DEL-B-C) (Racine et al., 2018). This tool provides a rating of caregiver burden between 0 and 40, with 40 representing the highest level of distress (Racine et al., 2018). Cronback's alpha was reported to be 0.82

**Carer Distress**

- Carer distress was measured using the Kessler Psychological Distress scale (K10) (Kessler et al., 2002). The K10 is a 10-item global measure of distress that uses a five-point Likert scale to quantify the degree of anxiety and depression with scores ranging from 10 to 50, with higher scores indicating greater levels of psychological distress (Kessler et al., 2002). Cronback's alpha was reported to be 0.93 (Kessler et al., 2002).

A copy of the questionnaire has been provided in appendix 1.

## Data Analysis

Once data collection is complete IBM SPSS statistics version 28 (IBM Corp, 2021) will be used for statistical analysis.

Collected demographic data will be presented using descriptive statistics. For the complete data set, normally distributed continuous data will be presented using means and standard deviations (SD); non-

normally distributed continuous data will be presented using median and inter-quartile range (IQR). Categorical variables were presented using frequencies and proportions.
Variables of interest surveyed at baseline (T1) and 4 to 6 weeks post-intervention (T2) will be compared to determine the effect of PREDICT. The analysis will be completed in pairs, and the appropriate test will be determined depending on the normality of the data. A paired t-test or non-parametric test will be used for normally distributed data. For data that was non-normally distributed, the Wilcoxon Signed Rank test will be undertaken. Statistical significance will be reported at 95% level.

## Ethics Approval

Ethics approval to undertake this study was obtained from NSW Health REGIS (no: HREA327 2021/ETH11752) and Southern Cross University (SCU HREC) (no.2023/183).

## Ethical Considerations

Consent was assumed following the completion of the initial questionnaire. Participants were informed that they could withdraw from the study at any time without any penalties and that participating in this study was voluntary; that is, participants were made aware that they were not required to participate in the study to access PREDICT if they did not wish to. As the information was deidentified, carers wishing to withdraw were not able to retract survey responses once analysis had commenced.

If the carer disclosed distress or psychological issues, referrals were made to the hospital on-call social worker. They were also provided with information on the Carers NSW website, which provides free and confidential counselling services, Lifeline on 13 11 14, Beyond Blue on 1300 224 636 or the NSW Mental Health Line on 1800 011 511 (24 hours a day) for free confidential counselling or were advised to contact their GP.

De-identified data is stored in the office of the Chief Investigator on a password-protected local area network. The data can only be accessed by research team members. Data will be retained for five years from the date of completion/publication and will be deleted from the password-protected SharePoint and computer. Data to be presented in peer-review journal publications, conference presentations and report format to the Rural Research Capacity building program and in a Thesis to the Southern Cross University examiners will be presented in a deidentified form.

# Results

## Participants

A total of 83 carers have been introduced to PREDICT. Of these, nine carers have completed the first questionnaire only, and 11 have completed both the baseline and second questionnaire. Interim results based on patient demographics, carer knowledge and psychological distress for the 11 paired questionnaires are provided below.

## Carer and Patient Demographics

| CHARACTERISTIC | CATEGORY | N (%) |
|---|---|---|
| **PARTICIPANT GENDER** | Female | 11 (100%) |
| | Male | 0 (0%) |
| **RESIDE WITH THE PATIENT** | Yes | 9 (81.8%) |
| | No | 2 (18.2%) |
| **PATIENT GENDER** | Female | 4 (36.4%) |
| | Male | 7 (63.6%) |
| **PARTICIPANT AGE** | (Range 31–81) | |
| **PATIENT AGE** | (Range 69-86) | |

Table 3. Participant and Patient Demographics (N = 11)

| Question | Pre-Questionnaire | Post-Questionnaire |
|---|---|---|
| Was the patient diagnosed with delirium? | | |
| ***Yes*** | 0 | 1 |
| ***No*** | 9 | 8 |
| ***Uncertain*** | 2 | 2 |
| Do you think that carers should be incorporated into delirium identification and management? | | |
| ***Yes*** | 11 | 10 |

## Variables

A paired samples t-test was conducted on the paired questionnaires received (n=11) to assess whether there were significant differences in participants' delirium knowledge and psychological distress before and after the intervention (table 4). For delirium knowledge, the mean score decreased slightly from 38.45 (SD = 7.10) to 36.18 (SD = 6.46), but this difference was not statistically significant, t(10) = 0.84, p = 0.419. Similarly, the mean psychological distress score (K10) decreased from 16.45 (SD = 4.18) to 16.00 (SD = 4.45), which was also not significant, t(10) = 0.68, p = .510. These findings suggest that there were no significant changes in knowledge or distress following the intervention. One explanation for the insignificant results is the small sample size (n=11), leading to decreased power in statistical findings. Another explanation may be that the t-test is not appropriate for this sample size. For the full data analysis, once collection is completed, the Wilcoxon signed rank test will be utilised.

Table 4: Initial t-test results for the CDKQ and K10

| Sample size n=11 | Baseline (T1) | 4-6 weeks (T2) | T(10) | p |
|---|---|---|---|---|
| Caregiver Delirium Knowledge Questionnaire (CDKQ) | 38.45 (SD = 7.10) | 36.18 (SD = 6.46) | 0.84 | 0.419 |
| Kessler Psychological Distress scale (K10) | 16.45 (SD = 4.18) | 16.00 (SD = 4.45) | 0.68 | 0.510 |

## Further analysis

Two short-answer questions were available for carers to provide additional feedback. A thematic analysis (Braun & Clarke, 2022) was undertaken to explore common themes related to causes of carer distress and the carers' views on facilitators and barriers to carer inclusion. The results of the short-answer question analysis indicate that there are inconsistent staff approaches to inclusion, with staff demonstrating a lack of empathy and poor understanding of the patient's presentation when coupled with conditions associated with cognitive decline, such as dementia. Carer burden was thought to contribute to the distress experienced by carers. Carers indicated that they often balanced additional challenges, such as poor health, work and home duties, with the role of carer.

# Discussion

Data collection for this study is ongoing, with the current sample size limiting the ability to ascertain the effectiveness of PREDICT in alleviating carer distress, reducing carer burden, and enhancing knowledge of delirium. The limited sample size restricts ability to conduct a comprehensive analysis of the data, thereby hindering a deeper understanding of the toolkit's effects. Although the sample size is small (n=11), the majority of carers (n=10) expressed a desire to be involved in delirium care within the emergency department, a result supported by the implementation study by de Oliveira Assis et al. (2022). Interim analysis of the short answer responses indicates that several improvements could be made to the inclusion processes to allow greater carer involvement.

Improvements in staff approaches to inclusion, including consistent approaches and an increase in staff understanding of delirium and conditions that cause cognitive decline, may improve carer inclusion and decrease carer distress. There is a highlighted need to ensure that formalised procedures exist to ensure effective communication and inclusive decision-making processes occur, and that staff are respectful of the carer's knowledge of the patient (Nichols et al., 2025; Peguero-Rodriguez et al., 2023). Inconsistent approaches to inclusions were found by both the short answer questions and the integrative review to hinder carer involvement (Nichols et al., 2025).

Formal processes supporting carers and assessing carers’ capacity for involvement are required to enhance current practice. Carers in the short answer questions indicated that they often balanced their own poor health, work and home duties, with the role of carer increasing the levels of distress they experience. Carer burden is also increased when caring for patients with cognitive impairment (Zaalberg et al., 2023) and when changes in the relationship dynamics occur after a person takes on the carer role (Davidson et al., 2023). Practices supporting carer wellbeing have been shown to increase a carer's motivation to be involved in patient care (Davidson et al., 2023).

A formal approach to minimise inconsistencies in inclusion, enhance staff understanding of the needs of carers and patients, and recognise and manage carer burden will address the findings of the short answer questions and the integrative review (Nichols et al., 2025). To successfully design and implement successful practice changes allowing carer inclusion without increasing carer burden and distress, further research exploring the needs and views of carers, patients and staff is required. Cassarino et al. (2020) found a difference in focus between the service users and staff, and felt that the inclusion of all stakeholders added to the development of a new model of care for the emergency department. To this end, development of these processes should include both staff, carers and patients to ensure sustainability of the approaches.

### Limitations

At this stage, limitations for this study include the small sample size, which limits the significance of the findings, and the prolonged study period due to slow recruitment, leaving the researchers unable to measure the effect on delirium case numbers. Generalizability will be affected by the use of a single centre study.

## Conclusion

Data collection for this study continues. Early indicators show several improvements could be made to inclusion processes. Implementing a formal approach to address these will help to minimise inconsistencies. Further quantitative analysis will allow a more nuanced understanding of the impact of the toolkit on carer knowledge of delirium and carer distress. Findings from the short-answer questions highlight the need for ongoing carer support and implementation of consistent inclusion processes. Whilst carers wish to be involved in care processes, there is a need for ongoing carer education and increased support to reduce carer burden.

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# Appendix 1

## Copy of Questionnaire provided at baseline and 4-6 weeks post-intervention

Health
Northern NSW
Local Health District

Southern Cross University

### Partnering with family carers of hospitalised older adults in delirium identification and management – Carer Questionnaire

Thank you for agreeing to participate in this study investigating delirium identification and management. In order for us to evaluate the effectiveness of the program, we ask you to take the time to complete the following questionnaire. All responses are anonymous and will be used for the purpose of this study only.

To enable us to match your responses pre- and post-program while retaining your anonymity, please provide a **unique identifier** consisting of the last four digits of your phone number and the first initial of your mother's name. For example, if your phone number was 0444 878 989, and your mother's name is Susan, your unique identifier would be **8989 S.** It is important that you provide the **same unique identifier** for all questionnaires that you complete in this study.

Unique identifier:

| | |
|---|---|
| -------------- | ------- |
| Last 4 digits<br>Personal<br>phone number | First initial of Mother's name |

Please indicate the timeframe that you are completing this questionnaire:

- ○ During the patient's admission to the ward
- ○ During the patient's admission to the Emergency Department
- ○ 4-6 weeks after the patient was discharged from the hospital
- ○ Other e.g. representation to the Emergency Department

Please indicate if your relative was:
- ○ Admitted to the hospital from the Emergency Department
- ○ Discharged from the Emergency Department
- ○ Neither

**Demographics**
What is your gender? __________
What is your age? ____________
Do you identify as Aboriginal or Torres Strait islander? ______
How long have you been in a caregiving role? Months___________ Years ____________
What is your relationship to the patient?
- ○ Spouse/partner
- ○ Child
- ○ Friend
- ○ Other __________

Do you reside with the patient?
- ○ Yes
- ○ No

How often do you/ do you intend to, use the Delirium Toolkit?
More than once a day___ Daily____ Several times a week ____ Weekly_____
Occasionally____ Never_____
How often do you intend to/ did you use the Delirium Screening Tool?
More than once a day___ Daily____ Several times a week ____ Weekly_____
Occasionally____ Never_____

**Patient Demographics**
What is the patient's age? __________
What is the patient's gender? __________
**Was the patient diagnosed with a delirium Yes__ No__ Unsure___**

**Family Delirium Knowledge Questionnaire (Bull et al., 2015)**
For each of the following statements regarding risk factors for delirium, symptoms of delirium and caregiver actions once delirium is identified. Please select whether each statement is **True** or **False,** or that you **don't know**.

| | | | |
|---|---|---|---|
| Do you think any of the patients below might be at risk for delirium? | | | |
| 1. Adults older than 70. | True | False | Don't know |
| 2. Adults who are married. | True | False | Don't know |
| 3. Older adults with dementia. | True | False | Don't know |
| 4. Older adults with an infection. | True | False | Don't know |
| 5. Older adults with more than high school education. | True | False | Don't know |
| 6. Older adults who have had surgery. | True | False | Don't know |
| 7. Older adults not drinking enough liquid (dehydrated). | True | False | Don't know |
| 8. Older adults experiencing change in surroundings, such as a move to a new home or hospital. | True | False | Don't know |
| 9. Older adults who are members of minority groups. | True | False | Don't know |
| 10. Older adults started on a new medication. | True | False | Don't know |
| If your family member had signs of sudden confusion, would you | | | |
| 11. Call their doctor right away. | True | False | Don't know |
| 12. Wait a week to see if the person got better. | True | False | Don't know |
| 13. Give the person herbal tea or warm milk to drink. | True | False | Don't know |
| 14. Do nothing. | True | False | Don't know |
| Do you think any of the patients described below might have delirium? | | | |
| 15. Older adult slowly becomes more confused over a few months, is forgetful, has trouble paying attention, and is more confused later in the day. | True | False | Don't know |
| 16. Older adult slowly becomes more confused over a few months, is forgetful, has trouble paying attention, and later in the day sees things that are not there. | True | False | Don't know |
| 17. Older adult suddenly becomes confused over a few days or hours, floats in and out of confusion during the day, has trouble paying attention, sees things that are not there. | True | False | Don't know |
| 18. Older adult suddenly becomes confused over a few days or hours, has trouble paying attention, and sleeps more during the day. | True | False | Don't know |
| 19. Older adult becomes more confused over a few days and suddenly has trouble getting to the bathroom on time. | True | False | Don't know |

## Kessler Psychological Distress Scale (K10; Kessler et al., 2002)

These questions concern how you have been feeling over the past 30 days. Select the option below each question that best represents how you have been feeling.

**1. During the last 30 days, about how often did you feel tired out for no good reason?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**2. During the last 30 days, about how often did you feel nervous?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**3. During the last 30 days, about how often did you feel so nervous that nothing could calm you down?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**4. During the last 30 days, about how often did you feel hopeless?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**5. During the last 30 days, about how often did you feel restless or fidgety?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**6. During the last 30 days, about how often did you feel so restless you could not sit still?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**7. During the last 30 days, about how often did you feel depressed?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**8. During the last 30 days, about how often did you feel that everything was an effort?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**9. During the last 30 days, about how often did you feel so sad that nothing could cheer you up?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

**10. During the last 30 days, about how often did you feel worthless?**

| | | | | |
|---|---|---|---|---|
| None of the time | A little of the time | Some of the time | Most of the time | All of the time |

## Caregiver Delirium Burden (DEL-B-C; Racine et al., 2019)

**Q1a. Was there any time when your loved one experienced changes in memory and thinking in the hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q1b. If you answered "yes" to Q1a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q2a. Was there any time your loved one showed unsafe behaviours (such as pulling tubes, getting out of bed) in the hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q2b. If you answered "yes" Q2a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q3a. Was there any time your loved one became irritable or angry in the hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q3b. If you answered "yes" to Q3a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q4a. Did your loved one see or hear things that were not really there in hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q4b. If you answered "yes" to Q4a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q5a. Was there any time that your loved one did not recognise you in the hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q5b. If you answered "yes" Q5a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q6a. Did you ever feel helpless as a carer while your loved one was in the hospital?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q6b. If you answered "yes" Q6a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q7a. Were you ever concerned that your loved one would never be back to his/her usual self?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q7b. If you answered "yes" Q7a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q8a. Were you ever concerned about increased responsibilities as a carer?**

- ○ Yes
- ○ No
- ○ Uncertain

**Q8b. If you answered "yes" Q8a, how distressing was that for you?**

| | | | |
|---|---|---|---|
| Not at all distressing | A little bit distressing | Somewhat distressing | Extremely distressing |

**Q9. Was there anything else you found distressing while your loved one was in the hospital?**

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

**How satisfied are you with the current care your family member/friend is receiving?**

- ○ Very dissatisfied
- ○ Dissatisfied
- ○ Neutral
- ○ Satisfied
- ○ Very satisfied

**Do you think that carers should be incorporated into delirium identification and management?**

- ○ Yes
- ○ No

**Are there any factors that you think facilitate or hinder the integration of carers in the identification and management of delirium in the hospitalised older patient?**

**We would like to follow-up with you approximately 4-6 weeks after discharge to invite you to complete a final questionnaire and further discuss with the research investigator your experience of the *Toolkit*. If you agree, please provide your contact details:**

**Email:**

**Mobile:**

**Postal Address:**

**THANKYOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE**