The Centre for Health Services Research
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THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

evaluating Quality of Care (eQC) Project

NHMRC Boosting Dementia Grant 2018-2023

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Acknowledgement

Is it possible to do research when the world is shutting down during a global pandemic? If research occurs, what research is important during a time of global change?

We were awarded a Boosting Dementia research grant from the National Health and Medical Research Centre (NHMRC) to commence in 2018. The project was focused on improving the quality of care delivered to people with cognitive impairment in hospital by implementing an electronic assessment system for all adult patients which improved the effectiveness and efficiency of the admission nursing assessment process in hospital for all patients. The rationale being, that improving process for all patients, would result in screens that picked up the care needs of people with cognitive impairment. No one would be missed. It was an ambitious and exciting project, made even more innovative by the patient and carer focused collaboration which drove all aspects of the research design, implementation, and dissemination partnership.

Progress was slow but steady for this complex research. We were indebted to the incredible Patient and Carer Advisory Board which was the first part of the project that was established. Staff were then appointed to help refine the protocol. Sites were sourced and PhD students recruited with scholarships. An exciting development was the partnership with the State of Tasmania to implement the assessment system (interRAI) across their health service. A strong business model was developed for discussion with all interested parties as this was more than a research project, it was about implementation that would continue to be a part of usual care well after the project was finished.

As COVID struck in early 2020 all government health services and hospitals had to re-think their involvement in such a complex project. Funds and staff needed to be reallocated to respond to the international crisis. We also had to reallocate our staff so that money wasn't wasted.

We would like to acknowledge the incredible support of the NHMRC during the period of the pandemic and afterwards. They remained in contact with the research team, responding to our reports and changes and delays. Disappointments were common during this time. We worked with our Patient and Carer Advisory Board to identify what was important, what could we contribute around our topic of evaluating quality of care for people with cognitive impairment during this time. Despite having to make changes to our primary protocol, we were able to continue to focus on our goal of improving care for people with dementia and cognitive impairment. This enabled us to respond to questions that were a priority during a period of rapid change.

We would like to acknowledge the board, who were tireless in their commitment to provide advice during this time, the staff on this project who worked with great flexibility during periods of uncertainty, and to the public and patients who participated in focus groups, as research participants, and advisors, to support what we did for this body of work on quality of care for people with cognitive impairment.

Throughout this whole COVID pandemic period, during times of uncertainty and research bleakness, the advisory board, investigators, and staff, have always approached their roles with the key question 'How can we help?'. We believe that the work outlined in this report, reflects a contribution to improving the care for people with cognitive impairment in hospital, but also, equally as important, it highlights how we can work together during challenging times, to make a difference. We are better together.

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Health Scientist/Research Fellow

Professor Len Gray
Geriatrician/Professor

Project Team

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eQC Patient and Carer Advisory Board

Current Members:

Dr Jane Thompson, Chairperson, 2020 - current
Dr Leanne Jack, 2020 - current
Karyn Lendich, 2023 - current
Ivy Yuen Yee Webb, 2020 - current
Elizabeth Miller, 2020 - current
Glenys Petrie, 2020 - current
John Quinn, 2020 - current

Retired Members:

Eileen Jones, 2020 - 2021
Marianne Smith, 2020 – 2021
Jennifer Lawson, 2022 - 2023

Meetings attended by:

Dr. Melinda Martin-Khan (Project lead investigator)
Dr. Daniel Bailey (Project Manager)
Paul Prudon (Board Administrator)
Others by invitation

Funding Contributors: NHMRC Boosting Dementia Grant APP1140459

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Foreword

eQC Report Foreword by

Dr Jane Thompson

Chair, eQC Patient and Carer Advisory Board

The valuing of the experiential knowledge of people who draw on health and social care services has become a key feature of contemporary healthcare research practice. It is a valuable source of information which complements that of health professionals and researchers and its inclusion improves the quality and relevance of research. I refer to this practice broadly as public involvement in research, noting there are other terminologies used in different countries and different parts of the research sector, and, that it may take different forms depending on the discipline and nature of the research.

In Australia, in line with international trends, there has been a growing interest in public involvement in research, although dementia/ageing research has lagged behind other disciplines, for example, mental health and cancer research.

Nonetheless, there have been efforts to actively involve people impacted by dementia/ageing across all phases of the research cycle and to ensure researchers approach their studies in this field in line with best practice in public involvement in research. This interest has been at the individual researcher level, the project and program level, as well as at the organisational (universities, medical research institutes) and broader system levels (funding bodies, collaborations).

The Patient and Carer Advisory Board for the Evaluating Quality Care project at the Centre for Health Services Research at the University of Queensland is an excellent example of a formal advisory group associated with a program of research. This program focuses on improving the quality of care for older people, and specifically those with cognitive impairment or dementia drawing on care in the hospital setting. This is an area of general concern and was of personal interest to myself as a former carer of my husband who died of Alzheimer’s disease. We were not alone in experiencing the vagaries of the health system. I was excited to take on the role of Chair of the Board when approached in 2019, in part because I saw the potential for such a group to significantly influence the direction and nature of the body of research that was being planned, but also because the proposed research promised to yield valuable information which would benefit patients and carers in the future.

Importantly, the Chief Investigator and Investigator Team and were clearly committed to the concept of public involvement in research. They demonstrated a genuine commitment to provide the resources and necessary funding to develop and embed public involvement in their research program. They had included in their research budget funds to reimburse the costs associated with public involvement and had budgeted for an honorarium for Board members. Selecting the right people with relevant experiential knowledge to join the Board was important and the inclusion of at least two members living with neurodegenerative diseases causing cognitive impairment or dementia and at least two care partners was a priority. Expressions of interest were sought, and the Board Chair was involved in interviews with applicants. Appointees had clear role descriptions from the outset although also had to adapt to changing circumstances including an unpredicted pandemic.

Over its nearly five-year term, there has been a small turnover of Board members but a stable core demonstrating the commitment of members. The Board has influenced the scope of the research program and influenced the direction and conduct of individual research projects. This has been possible as the research team has created space within the research process for us to have real influence on conception, design, implementation, and outcomes of the research. There has also been time to reflect on the values identified in the literature as essential to good public involvement such as inclusivity, working in partnership, purposefulness, transparency and valuing different kinds of knowledge, and, to jointly reflect and adjust processes and practices where necessary.

Experiential knowledge needs to be valued by organisations and recognised and supported in concrete ways. Establishing advisory groups like the Patient and Carer Advisory Board to work in partnership in research programs is one way of doing this and significantly impacts on the quality and relevance of research.

It has been a positive experience working with the research team and Board members and hopefully there will be ongoing funding to support the continuation of initiatives like this long term.

> John Quinn, Board Member
>
> ‘On diagnosis of dementia you are stripped of your dignity, sense of worth and agency. My appointment as a valued member of the eQC board has provided meaningful, cognitively stimulating interactions thus providing numerous opportunities to reframe my pre-diagnosis role of being an educator’

What the collaborators say

Ivy Yuen Yee Webb, Board Member

‘I was excited to read the research findings that include members' input including mine. The Board created the bridge between the academic’s eyes and the general public’s needs’

Karyn Lendich, Board Member

‘The importance of inclusion brings a feeling of freedom that feels lost soon after diagnosis’

Dr Daniel Bailey, Project Manager / Post Doc

‘I joined the project in late 2022, with the Board and project already well underway. My previous experience with lived experience experts at the Dementia Collaborative Research Centre taught me their unique insights were invaluable. However, I was blown away by the Board's impressive and spot-on insights at my first meeting. Their contributions at all stages—from planning and methodology to highlighting and framing key findings—greatly enriched the eQC project's research’

Muhammad Haroon, PhD student

‘I had never thought that through the session I would be actually able to network with the members and will get to know people who I can include in my studies as participants. The members got me in touch with people living with dementia who are participating in the next study (interviews) of my project’

Ann Lord, Dementia Advocate -Dementia Australia, Reader – COVID project

‘As a carer of a PLWD in a remote regional community during covid, our experiences included: ability to walk out of ward and hospital unobserved and disappearing requiring police involvement; food left out of reach with cutlery wrapped /invisible; bathroom door being repeatedly closed so unable to locate toilet (despite my signage to leave door open) -all resulting in distressing "undignified” incidents. I believe this is partially due to workload and time constraints of nursing staff, yet more particularly with other ward staff (cleaners, food delivery staff, orderlies) who had no understanding of variations in behaviours of unwell PLWD. To have guidelines for PLWD to be clinically treated with dignity and respect during their hospital stay is long overdue’

What the collaborators say

Beibei Xiong, eQC PhD Student

‘Overall, working with the Board was incredibly rewarding. The insights we gained and the improvements we made were beyond what I had hoped for’

Elizabeth Miller, Board Member

‘One of the activities I’ve particularly enjoyed on the eQC Patient and Carer Advisory Board has been the privilege of providing external Researchers with a ‘Consumer Lens’ on the different projects they’ve brought to our attention. It’s very gratifying when they submit regular feedback on how their project is progressing, and again when it’s at the point of being published! The next step in ‘closing the loop’ is to help disseminate the findings to our consumer networks so they become translated into everyday practice – thus improving patient outcomes’

Dr Melinda Martin-Khan, Lead Investigator

‘Working with collaborators that are all experts in their field including people with lived experience, has resulted in one long ‘good day at the office’. It has been a pleasure to work with people who love what they do, who are committed to excellence, and to innovation. Everyone walked into the room and gave their best despite often facing many personal challenges. It was a privilege to work with such inspirational people. I was often amazed at the brilliance that resulted, but I shouldn’t have been surprised’

Executive summary

Older patients admitted to hospital often present with more than one medical or surgical problem. Non-disease specific geriatric syndromes such as delirium and dementia are common, affecting recovery or compliance with treatment and resulting in hospital complications and increased costs. Identification and documentation of dementia is often poor in hospitals. Routine cognitive screening is uncommon - assessment and care is generally focused on managing the immediate problem that triggered hospitalisation. Supporting people with cognitive impairment also requires an individually tailored response in the care plan following communication with the patient and their choice of supporters.

This is a research translation project focused on improving the care of people with cognitive impairment in hospital. You can follow the outcomes of the project on the UQ website here. The initial project had two aims:

- To conduct a large scale implementation of an assessment and care planning system to improve the care and support of people with dementia in hospital
- To implement and evaluate a bench-marking service built on the integrated outcome Quality Indicators (QIs) for care of older people with dementia.

People with cognitive impairment often have complex care needs arising from physical and psychiatric morbidities, behavioural and psychological symptoms (BPS), and a need for functional support which can result in frequent hospitalisations and long hospital stays. During hospitalisation, people with a diagnosis of cognitive impairment are at high risk of adverse outcomes such as falls, delirium, pressure injuries, becoming lost, dehydration, or malnutrition regardless of the reason for admission. These risks are further compounded when BPS are present.

While the protocol was being refined and a plan to recruit sites was being developed, the patient and carer advisory board was established. Section 1 (Patient and Carer Advisory Board) describes the evaluation associated with this process. Later in the report we go into more detail about the activities of the board and their commitment to supporting researchers and capacity building, including what this looks like in practice.

The steps taken to implement the grant in it’s original form are outlined in section 5(a-b). The implementation was based around the use of the interRAI Acute Care system (iAC) in eight acute care settings in participating hospitals. Following challenges during the COVID-10 pandemic, implementation was reduced to one primary hospital. When this hospital withdrew a revised implementation plan for the grant was developed (described in sections 2-4, 5c, 5e).

When the work in our recruited hospitals was put on hold during the COVID lockdown, we gathered together a group of people with lived experience and clinicians to develop a resource for guidance on the care of people with cognitive impairment during the pandemic (Section 2). This work made recommendations around five themes: Goals of care (n=13); patient and care partner/advocate support (n=10); infection control (n=8); identifying triggers for behavioural and psychological symptoms leading to distress in relation to prevention strategies (n=9) and safe clinical environments (n=3); restraint use (n=5) and medication (n=10). A public facing document was published for the purpose of describing in lay terms the decisions clinicians would be making so that patients and their care partners could have informed discussions when they were in hospital by making it possible, in a more overt way, to bring everyone to the table on a more equal footing. Following this work we supported the Australian Commission on Safety and Quality in Health Care (ACSQHC) to develop two resources on safe care for people with cognitive impairment in hospital: a poster, and a fact sheet.

Section 3 involved a literature review to understand how information about cognitive impairment status was managed in hospital. The identification and management of cognitive impairment information is crucial for providing quality care and ensuring positive patient outcomes. Cognitive impairment remains under recognised in hospital, which impacts quality of care resulting in adverse events and longer lengths of stay. The final part of this sub-project is a protocol for managing cognitive impairment status in patient records based on the outcomes from the literature review, interviews, and input from the eQC advisory board.

Section 4 (consideration of the comprehensive care standard in acute care) is work by a PhD student for the eQC program of work. This included a number of literature reviews, surveys and interviews (with staff and patients). Given the recent nature of the comprehensive care standard, this work is important in understanding the implementation process and how this may have impacts on care planning and person centered care for people with cognitive impairment. At this time, it appears that hospitals are under resourced to train and implement the CCS in a way that will enable the desired outcomes to be achieved, particularly for patients with cognitive impairment.

The focus on this grant was on the implementation of an electronic (software based) assessment system in acute care hospitals (Section 5a). Therefore, it was important to understand the change management process during digital transformation. Two literature reviews were undertaken which explore the challenges associated with digital transformation with particular relevance to health care, and provide recommendations that management can follow to maintain trust with employees when implementing change that involves new technology (Section 5c).

The second aspect of this grant was focused on improving the quality of care for patients with dementia in hospital (Section 5b). A study looking at occupational violence in hospital has been undertaken in an effort to understand was risk factors are present for the population of patients involved in reports of episodes of occupational violence in hospital (Section 5e). With this study, the goal is to improve our understanding both of the information collected, and the situations in which violence occurs. In this way, it may be possible to provide better training for staff to avoid violence or de-escalate in certain situations.

This project was funded by the NHMRC in 2018. With both extensions to the time to completion, and adjustments to the primary aims, as a result of the COVID pandemic, the project funding was completed but final aspects of the analysis and publications are being written in 2024. During the anticipated final year, lead investigator Dr. Melinda Martin-Khan, took a position at the University of Exeter and was a resident there from June 2022, though she remained working on this project. Professor Len Gray (originally CIB) was nominated as CIA for the period that Dr. Martin-Khan was not resident in Australia.

Introduction

A whole of hospital assessment system changes the quality of care for people living with dementia by improving the identification of people with cognitive issues in hospital (dementia, delirium, depression, and cognitive impairment); assessing their risk of adverse events; guiding the development of a personalised care plan for maintaining function and cognitive health during the admission; and measuring the quality of care over time to direct quality improvement activities. Integrating the assessment of cognition and risk within an assessment system for all admitted patients, improves familiarity with the system, reduces non-compliance, impacts work efficiency, and identifies people who might be overlooked because of poor training, complex presenting symptoms, or lack of time[1].

Older patients admitted to hospital often present with more than one medical or surgical problem. Non-disease specific geriatric syndromes such as delirium and dementia are common, affecting recovery or compliance with treatment and resulting in hospital complications and increased costs[2]. Identification and documentation of dementia is often poor in hospitals. Routine cognitive screening is uncommon - assessment and care is generally focused on managing the immediate problem that triggered hospitalisation.

The assessment system that was to be implemented as part of this body of work addressed key recommendations from the *Clinical Practice Guidelines and Principles of Care for People with Dementia*[3]*.* Standards and recommendations from other national policy documents relevant to the care of people with cognitive impairment and dementia (such as *Delirium Clinical Care Standard*[4] and the *National Framework for Action on Dementia 2015-2019*[5]. The *Comprehensive Care Standard*[6] is seeking to ensure that patients are integrated into the assessment, planning and delivery of care in hospital. While the initial approach needed to be modified as a result of COVID pandemic lockdown, the work remained focused on understanding how that integrated approach would support people with dementia in hospital.

The role of nurses is critical to the identification of people with cognitive impairment, delivery of best care, and prevention of adverse outcomes. The nurse admission process provides an ideal opportunity to assess and document patient needs, problems, and risks. For people with dementia, early identification of “at risk” patients on the hospital ward decreases the chances of adverse events and improves patient outcomes[7].

It is difficult to build and operate systems of assessment and care planning for sub-groups of patients, particularly when the reason for admission is usually not CI. Therefore, a strategy designed only for patients with CI is likely to add burden and complexity to a workforce that is already unable to fully manage clinical care and documentation.

Standardised assessment and electronic documentation have enormous potential to improve the effectiveness and efficiency of any type of assessment, reduce administration burden and the risk of adverse

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events, and enable quality interdisciplinary care and discharge planning. But implementing these systems bring challenges for organisation and patients.

An electronic nursing assessment system for inpatients which reduces nursing admission documentation time, increases identification of patients with cognitive impairment and risk of delirium on admission, supports care planning and increases time for direct clinical care will improve the quality of care for patients with dementia in hospital[8]. In considering the implementation of these forms of electronic assessment systems, we need to understand how we store and manage patient information, in particular in formation about cognition.

In preparing for this project, a patient and carer Advisory Board was established to ensure that the body of work was participatory research. Participatory research is an approach which encourages ‘inclusivity and recognises the value of including those who are intended beneficiaries, users, and stakeholders of the research[9]. Projects were put forward by research investigators and the board and negotiated from point of protocol through to implementation and decimation, always with a view to how the outputs might support improving the quality of care for patients with cognitive impairment in hospital. The work has been divided into a number of sub-projects (referred to as sections). Investigators, staff, and key contributors have been listed as they have contributed to the sections. A flowchart illustrates how the individual sub-projects work together as a whole (Figure 1) with key messages reflecting highlights from each.

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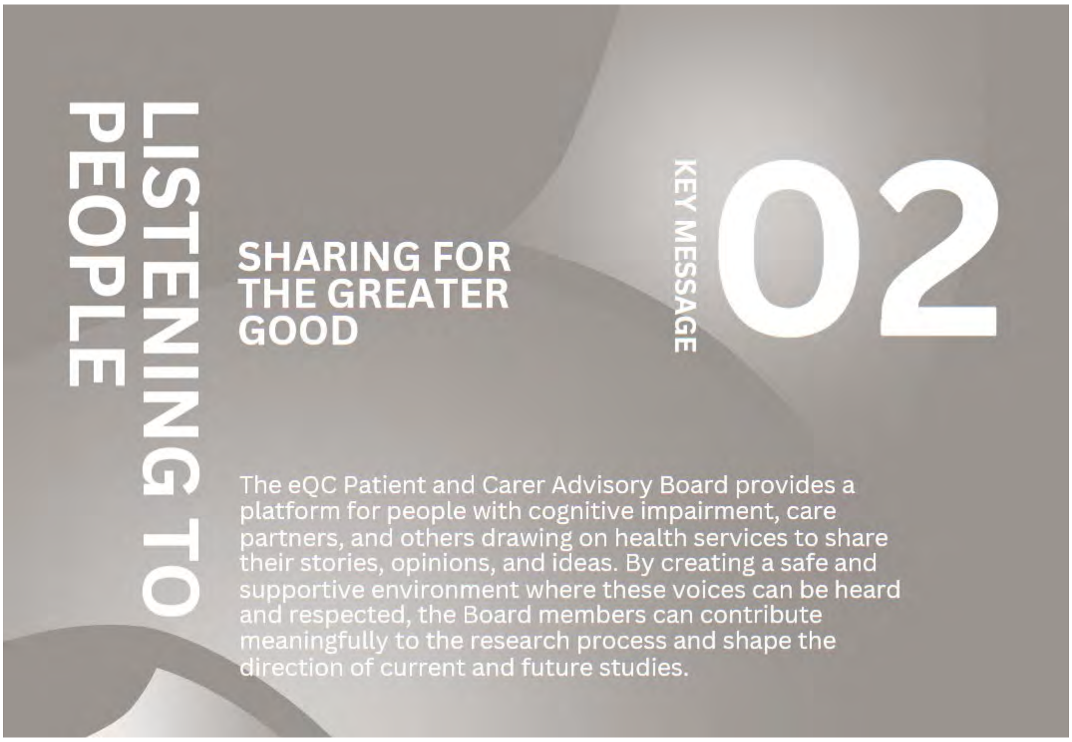
eQC Project Key Messages

RELATIONSHIPS AND TRUST

KEY MESSAGE 01

RELATIONSHIPS WITH EXPERTS FROM EXPERIENCES ARE BUILT ON TRUST

By actively seeking and incorporating the insights of people with firsthand experience of navigating health services, researchers can ensure that their work addresses the most pressing needs and concerns of the communities they aim to serve and results in better outcomes for all. Fundamental to this process is building a foundation of trust and mutual respect where everyone feels valued and heard.

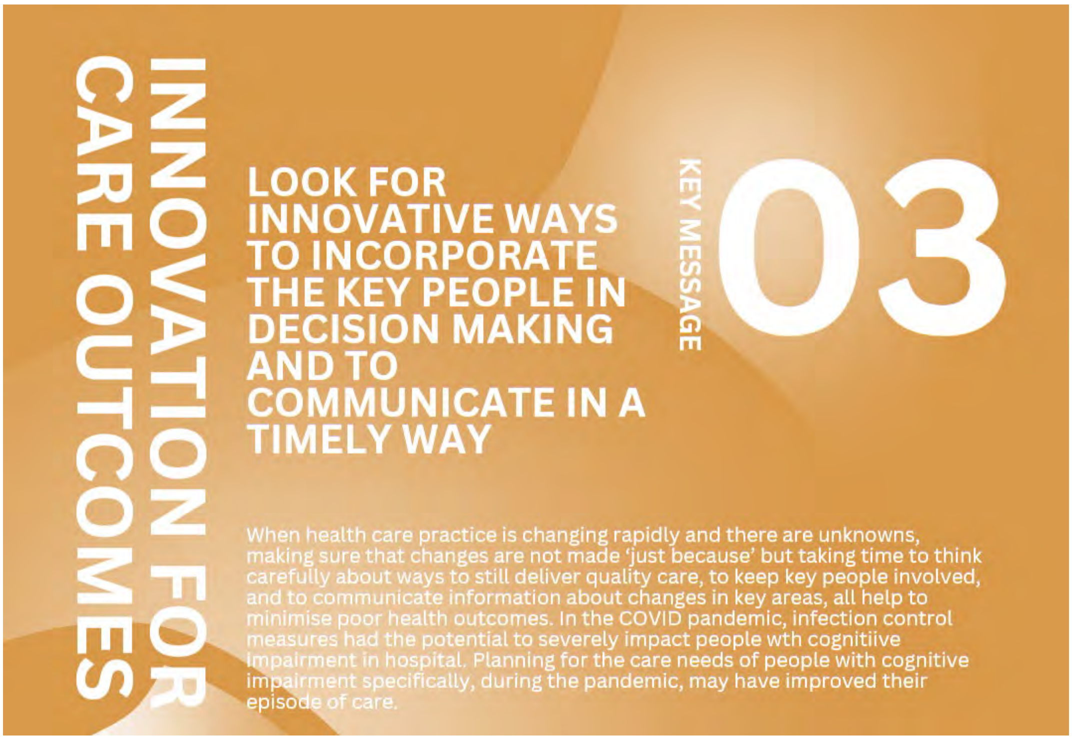


LISTENING TO PEOPLE

KEY MESSAGE 02

SHARING FOR THE GREATER GOOD

The eQC Patient and Carer Advisory Board provides a platform for people with cognitive impairment, care partners, and others drawing on health services to share their stories, opinions, and ideas. By creating a safe and supportive environment where these voices can be heard and respected, the Board members can contribute meaningfully to the research process and shape the direction of current and future studies.



INNOVATION FOR CARE OUTCOMES

KEY MESSAGE 03

LOOK FOR INNOVATIVE WAYS TO INCORPORATE THE KEY PEOPLE IN DECISION MAKING AND TO COMMUNICATE IN A TIMELY WAY

When health care practice is changing rapidly and there are unknowns, making sure that changes are not made 'just because' but taking time to think carefully about ways to still deliver quality care, to keep key people involved, and to communicate information about changes in key areas, all help to minimise poor health outcomes. In the COVID pandemic, infection control measures had the potential to severely impact people wth cognitiive impairment in hospital. Planning for the care needs of people with cognitive impairment specifically, during the pandemic, may have improved their episode of care.

ASSESSMENT AT ADMISSION

KEY MESSAGE 04

TRAINING ALL STAFF AND USING FORMAL COGNITIVE SCREENING TOOLS FOR ASSESSMENT AT ADMISSION SHOULD BE STANDARD PRACTICE

Identification of cognitive impairment at admission remains a concern despite guidelines indicating the importance for improved patient outcomes in hospital. Formal assessment is often overlooked, relying on an informal approach or the knowledge and experience of clincians. This can result in under recognition of cognitive impairment. Incorporating cognitive assessment in an integrated system which uses information technology, as well as providing staff training, can reduce adverse events, and increase compliance with national guidelines and standards.

NURSE-LED IMPLEMENTATION

KEY MESSAGE 05

NURSES ARE AT THE FOREFRONT OF COMPREHENSIVE CARE DELIVERY AND MUST BE RESOURCED APPROPRIATELY FOR EFFECTIVE CHANGE

A qualitative study conducted in Australian healthcare settings revealed that the successful implementation of Comprehensive Care Standard heavily depends on nurse-led process changes. However, the study underscored a consistent lack of essential resources, training, and support, which were identified as critical factors for the effective execution of Comprehensive Care Standard across hospitals.

PERSON-CENTRED APPROACH

KEY MESSAGE 06

IMPLEMENTATION OF THE CCS MUST ADDRESS THE NEEDS OF BOTH CARE PROFESSIONALS, WHO DELIVER THE CARE, AND PATIENTS, WHO RECEIVE IT.

A mixed-method study conducted in Australian hospitals revealed that Comprehensive Care Standard (CCS) implementation consistently lacked essential resources, training, and support. Additionally, patients experienced various gaps in care, including lack of shared decision-making, insufficient information and guidance, and poor care planning and coordination. To effectively execute the CCS, care professionals must be adequately resourced, and patients' needs must be addressed.

MEASURING QUALITY OF CARE

KEY MESSAGE 07

EXISTING QIs MAY NOT MEASURE THE CARE QUALITY THAT YOU ARE AIMING TO MEASURE. CHECK, DON'T ASSUME, WHEN CARING FOR SPECIFIC PATIENT COHORTS

Exising acute care quality indicators and quality indicator time points may not be sensitive enough to the nuances of specific cohorts (for example people with dementia, COVID patients, or surgical patients). Before applying quality indicators, consider whether there is a requirement for adjustment or interpretation because of who the specific data is being applied to.

TRUST & DIGITAL TRANSFORMATION

KEY MESSAGE 08

DIGITAL TRANSFORMATION IS CHANGING THE WAY WE WORK AND INTERACT. THIS CREATES UNCERTAINTY AND VULNERABILITY, CHALLENGING TRUST.

For digitial transformation (like moving to electronic medical records or assessment) to be successful, regardless of the sector or technology, employee trust in management and the technology remains significantly important. The experience of digital transformation itself can be a factor in undermining trust in management. This is important to understand in healthcare organisations when organisational stress is already signficant.

ORGANISATIONAL CHANGE

KEY MESSAGE

09

TRUST IS A CRITICAL FOUNDATION FOR EFFECTIVE ORGANISATIONAL CHANGE

Trust is influenced by a range of factors operating at different levels across different forms of organizational change. Leadership behaviours, including clear communication, transparency, and commitment of appropriate resources, foster trust by reducing uncertainty and demonstrating commitment to change. Empowering employees through participation in decision-making processes enhances trust and acceptance, while comprehensive training and education, positive past experiences with technology, and the perceived usefulness of new technologies increase trust and adoption of new technologies. Additionally, a supportive organizational climate further enhances trust and the success of organizational change. It is particularly important for healthcare leaders to cultivate trust when they are implementing change.

STAFF WELLBEING & QUALITY CARE

KEY MESSAGE

10

PERSON CENTERED CARE, AS A RESULT OF IT'S RELATIONAL FOCUS, IS AFFECTED BY STRESS FOR BOTH STAFF AND PATIENTS WITH COGNITIVE IMPAIRMENT

If staff are impacted by occupational violence they may have heightened levels of stress at work which could impact their ability to deliver higher levels of consistent quality person centered care. Understanding the reasons for occupational violence, training staff to be better equipped to reduce the risk of it's occurance and to manage escalation when it is occuring will also improve the hospital episode for the patient and the staff member.

Sub-Projects

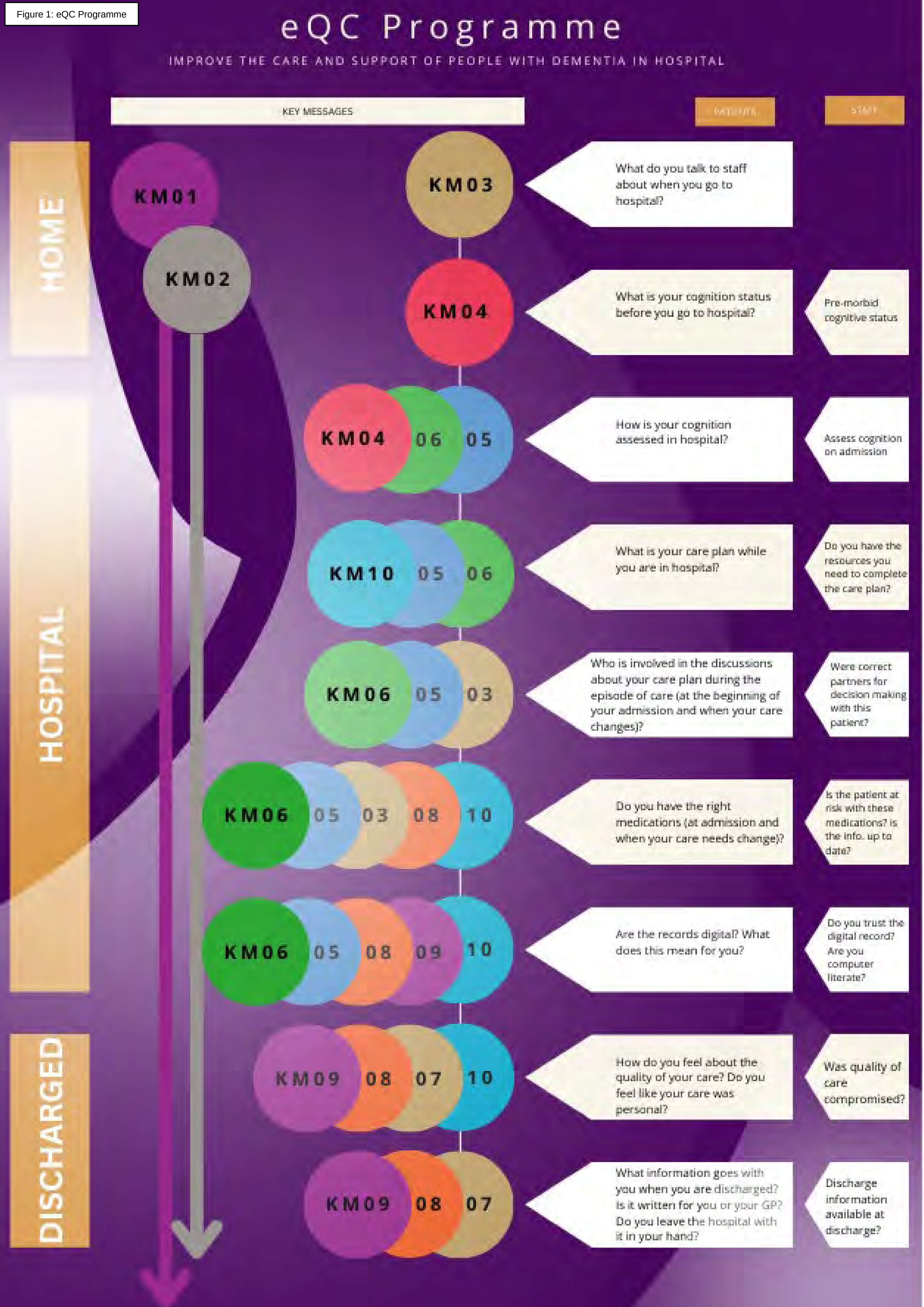
The development of the eQC body of work

A series of sub-projects make up the eQC body of work (Table 1). The grant was awarded, and the eQC Patient and Carer Advisory Board was established as a primary aspect of the research methodology (Section 1). Staff were appointed and sites identified for implementation of the grant protocol (Section 5a and b). PhD students were recruited (Section 4). COVID struck and other interim tasks were undertaken (Section 2). As COVID continued, and the primary project became less tenable, more focused interim projects were undertaken to inform the details associated with the assessment systems driving quality of care in hospital for people with cognitive impairment (Section 3, Section 5c). Finally, connected with data recording, medications, and risk assessment, an outcomes based study was undertaken utilising data from electronic medical records and hospital incident reporting that would inform record keeping in the future. This would provide opportunities to ensure improvements in quality of care for patients with cognitive impairment.

Table 1 Summary of sub-projects completed within the eQC project

#	Key Message	Name	Aim
1	01 02	**eQC Patient and Carer Advisory Board**	Embed patient and public involvement in medical research about cognition and health service utilisation across the research cycle
2	03	**COVID Guidance**	Understand the care and support people with dementia receive in hospital following the implementation of the Comprehensive Care Standard (CCS)
3	04	**Cognitive Impairment (CI) Status in Hospital Records**	Describe the recording of cognitive status in hospital; and the utilisation, sharing and referral of this information
4	05 06	**The Comprehensive Care Standard (CCS) in hospitals**	Examine the implementation challenges and impacts of the introduction of the CCS on episodes of care and patient outcomes in acute care hospitals in Australia
5a and 5b	07	**interRAI Acute Care assessment in hospital**	Implement a comprehensive nursing assessment in Acute Care; and Share data across organisations to identify quality in acute care settings
5c	08 09	**Digital transformation**	Conduct and publish a systematic literature review examining the antecedents and consequences of trust during organisational transformation and change Examine and evaluate the implementation and change process from an organizational and multi-stakeholder perspective using a mixed method approach
5d		**Project concept abandoned**	
5e	10	**Occupational violence (OV) incidence in hospitals**	Examine the distribution of OV reports for older people (>65) and those with cognitive impairment versus other age and patient groups Identify risk factors for OV incidents among and between these patient groups. Qualitatively explore incidents to identify common themes amongst risk factors and precipitating events

Figure 1: eQC Programme



eQC Programme

IMPROVE THE CARE AND SUPPORT OF PEOPLE WITH DEMENTIA IN HOSPITAL

KEY MESSAGES	PATIENTS	STAFF
KM03	What do you talk to staff about when you go to hospital?	
KM04	What is your cognition status before you go to hospital?	Pre-morbid cognitive status
KM04 06 05	How is your cognition assessed in hospital?	Assess cognition on admission
KM10 05 06	What is your care plan while you are in hospital?	Do you have the resources you need to complete the care plan?
KM06 05 03	Who is involved in the discussions about your care plan during the episode of care (at the beginning of your admission and when your care changes)?	Were correct partners for decision making with this patient?
KM06 05 03 08 10	Do you have the right medications (at admission and when your care needs change)?	Is the patient at risk with these medications? Is the info. up to date?
KM06 05 08 09 10	Are the records digital? What does this mean for you?	Do you trust the digital record? Are you computer literate?
KM09 08 07 10	How do you feel about the quality of your care? Do you feel like your care was personal?	Was quality of care compromised?
KM09 08 07	What information goes with you when you are discharged? Is it written for you or your GP? Do you leave the hospital with it in your hand?	Discharge information available at discharge?

Section 1. eQC Patient and Carer Advisory Board

Lay summary

Patient and Public Involvement (PPI) in medical and health service research is becoming an increasingly mandatory component of funding applications around the world. Public involvement is broadly viewed as a net positive, improving the quality, relevance, and impact of recommendations based on research findings. It is therefore important to evaluate research partnership endeavours across metrics which measure outputs alongside costings, and whether the experience of partnership was empowering to members.

Keywords

Patient and public involvement, PPI, public engagement, dementia, patient advisory group, evaluation

Aim

To embed patient and public involvement in medical research about cognition and health service utilisation across the research cycle.

To evaluate the eQC Board across both economic and experience metrics. The economic component aims are to provide a comprehensive understanding of the PPI Board costs and cost drivers, to identify cost-saving opportunities to improve the financial efficiency of the Board, and to serve as a costing tool to be used by other institutions to help them develop an IPP Board.

The experience evaluation component aims to examine members' experience of contributing to the project, what contribution means to them, and identify facilitators and barriers to good research partnership which will inform recommendations on how future researchers can foster productive, respectful public partnerships.

Ethics

This project has been approved by the following ethics committees: The University of Queensland Human Research Ethics Committee A [2018/HE001582]; University of Tasmania Human Research Ethics Committee [H—18049]; Queensland Health Townsville Hospital and Health Service [HREC/2019/QTHS/57317]; Tasmanian Health Service [H0018049].

Method

Members of the eQC project team collaborated to identify broad recruitment references and expressions of interest for board members were distributed.

The Chief Investigator and one other investigator invited a Chair for the Board, and interviewed all other applicants. In collaboration with the chair the final Board members were chosen. Terms of reference were developed at the initial Board meetings (Appendix 1).

All board meetings were held by zoom. Board members were remunerated based on Consumer Queensland rates. Information regarding the board can be found at the website https://chsr.centre.uq.edu.au/improving-quality-of-care-for-people-with-dementia-in-the-acute-care-setting

For the economic component, we are developing a retrospective costings analysis of Board activities and supporting actions incurred during conceptualisation, implementation, and operation. We have included everything relating to running the Board, including staff time for support.

Our planned experiential component will consist of hour-long semi-structured interviews with each individual Board member on the positives and negatives of their experience. Interviews will be conducted by an external researcher for objectivity, external perspective, and confidentiality of responses. Thematic analysis will be used to extract themes.

Interaction with the eQC Board

The goals for the evaluation were derived from discussion with the board. Workshops were held to discuss the protocol and content of the evaluation with the board. Board members co-authored the paper on the evaluation of the board focused on experience.

Development and Implementation

For the economic evaluation we quantified all conceivable actions directly related to Board operation, assigning invested time and hourly rate for each. Staff hours and member remuneration were both included, as maintaining an advisory group requires preparation, planning, and communication in addition to time spent in meetings. Costs have been analysed by activity or action, personnel involved, and process stage to comprehensively investigate where and how costs are incurred for the purposes of reporting and process improvement.

Our experiential evaluation thematic focus has been developed in collaboration with the Board, based on a values and practicalities framework by Liabo and colleagues (2020). An interview plan is under development.

Results

Preliminary cost analysis indicates that by far the largest cost for the Board has been staff hours at 81%. Member remuneration only represented 17% of the total costs. Of the staff, senior academics represented the largest expenditure at 57%; however, we note that many of the actions undertaken by senior staff were later attended by junior staff at a considerable reduction in cost. By stage, conceptualisation, and formation early in the project represented the largest portion of money spent at 61%, whereas day-to-day running costs over approximately three years was only 32%.

We expect to complete the data collection of the experiential evaluation in the second half of 2024.

Translation into Practice or Policy

Our preliminary economic analyses indicate that even when remunerating public partners, the greatest cost incurred is research staff time, which was hidden until directly investigated. Moreover, when viewed stage-wise, design, conceptualization, and formation are considerably more expensive than day-to-day operation, accounting for two-thirds of the total operating cost over three years.

Cost is often cited as a barrier to public involvement; however, the picture is more nuanced. Key points for future partnerships are:

- Time investment of staff should be considered and budgeted for when planning public involvement.
- Over-reliance on high-level academic staff inflates costs. Consider where actions can be performed by junior staff effectively, and without compromising relationships with public partners.
- Day-to-day operation time and money costs once an advisory body is established are significantly lower than during formation. Advisory groups established for the long-term are beneficial in terms of expense and maintain established collaborative relationships.
- Standardized processes and guidelines for forming advisory groups may reduce time and cost when the group is not intended to be long-term.
- Monitor costs incurred throughout operation to seek savings proactively rather than retrospectively.

Impact

This is participatory research with a focus on including members of the public who are frequent users of health services, particularly those who are people with cognitive impairment or are closely connected to people with cognitive impairment (family members or care partners). Expected outcomes included:

- An increase in the involvement of people with lived experience in the full research cycle of studies, particularly higher degree research students
- Grant applications submitted by collaborators to include review by PPI prior to submission
- The eQC project models an evolving strategy which enables the collaborative input of patients and care partners as co-researchers throughout the complete research cycle of the project.

Throughout the remaining sections of this report, it is possible to see the involvement of the Board in a range of projects. The Board has also undertaken internal projects which resulted in specific outputs. For example, the development of guidance to support people with cognitive impairment during zoom meetings (Appendix 2; Appendix 3).

Investigators and Collaborators

Melinda Martin-Khan, Elizabeth Beattie, Jane Thompson, Paul Prudon, Daniel Bailey, Beibei Xiong, Leanne Jack, Jennifer Lawson, Karyn Lendich, Elizabeth Miller, Glenys Petrie, John Quinn, Ivy Yuen Yee Webb, Leonard Gray, Paola Vasquez, Susan Ben-Dekhil, Tracy Comans.

Publications

1. Bailey DX, Vasquez P, Ben-Dekhil S, Prudon P, Gray LC, Martin-Khan MG. (2024). Silver linings playbook: A costing template for the implementation of a patient and public advisory board for health research. **Drafted (2024)**
2. Prudon P, Bailey D X, Xiong B, Thompson J, Jack L, Lawson J, Lendich K, Miller E, Petrie G, Quinn J, Webb IYY, Prudon P, Martin-Khan M. (2025). Experiential evaluation of the facilitators and barriers in the eQC Board experience. **Planned (2025)**
3. Prudon P, et al. Online collaboration Guide. **Drafted (2024)**

Section Editor

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

> Karyn Lendich, Board Member
>
> ‘Being a member of the patient advisory board has been a very rewarding experience for myself and larger, for my family and friends also as the ripple effect of interest carries with it greater understand of what it means to live with a neurodegenerative disease (dementia). Having a voice to help educate and explain the challenges of complex and baffling symptoms to others that have opportunity to effect change in health care systems brings a sense of inclusion. The use of technologies such as virtual meetings, recordings and electronic communications has helped bridge barriers of engagement and an opportunity to establish information sharing pathways with a truly inclusive cohort diverse in practice knowledge, emotional awareness, insights and practical skills across a wide experiential base. New ideas and developing novel solutions to complex problems have been found by meaningful and exploratory discussions with formal and informal carers, researchers, clinicians and non-clinical practitioners’

Section 2. COVID guidance

Lay summary

The COVID-19 pandemic has created unique challenges for the care of people with cognitive impairment such as dementia or delirium, in hospital settings.

This project aimed to develop evidence-based guidance to help healthcare professionals provide safe, high-quality care for this vulnerable population during the pandemic. The interim guidance was developed through a collaborative process involving people with dementia, care partners, clinicians, researchers, and peak bodies.

The project's outputs, including publications, fact sheets, and posters, provide practical recommendations and tools for healthcare professionals to optimise care for people with cognitive impairment in hospitals, reduce the risk of harm, and support patients and their families during this challenging time.

Keywords

Cognitive impairment, dementia, delirium, hospital care, COVID-19, pandemic, patient safety, patient and public involvement, public engagement

Aim

The aim of the interim guidance is to outline the evidence base for care for people with cognitive impairment inclusive of people living with delirium, minor and major neuro-cognitive disorders (Mild Cognitive Impairment and Dementia), or congenital and acquired brain injuries (intellectual disability). The guidance applies to the care of these patients in acute hospital settings in Australia throughout an episode of care, including admission and transitions, during the COVID-19 pandemic, irrespective of their reason for admission (COVID-19 or other). The guidance seeks to maximise the capacity for people with cognitive impairment to be supported to comply with and adjust to the necessary restrictions during the pandemic and continue to contribute to decisions about their care.

Outputs are intended to assist practitioners in optimising care for patients with cognitive impairment in hospital. In addition, a resource was created to provide information for patients who are going to hospital during the pandemic to help establish more open dialogue between staff and patients during the pandemic regarding care options.

Ethics

This project has been approved by the following ethics committees: The University of Queensland Human Research Ethics Committee A [2018/HE001582];

Method

The NHMRC National Institute for Dementia Research (NNIDR) with Melinda Martin-Khan recognised the need for guidance on the care of people with cognitive impairment in hospitals during the COVID-19 pandemic.

Interaction with the eQC Board

The conceptualisation of the COVID-19 Guidance eQC Section was discussed and refined initially with the eQC Patient and Carer Advisory Board which formed only months before the COVID-19 pandemic was declared a public health emergency by the World Health Organization. The Board and researchers reviewed and provided a public perspective on the aims and scope of the project. Members of the board volunteered to join the project, and progress on the project was reported back to the board meeting.

In 2023, the Board and the research team reviewed the impact of the COVID guidance outputs and updated documents which required update for a "post-pandemic” context.

Development and Implementation

When the project was established, a guidance committee and reading group was recruited, which included members of the eQC Advisory Board and members of the Dementia Australia Advisory Committee. Over several months, in a series of meetings, relevant content was identified by the committee and content-specific subgroups. The draft documents were then sent to the reading group for review.

The working protocols were revised several times during the project to ensure they were effective for people with cognitive impairment. The workload was significant due to a desire to have the guidelines available for clinical practice as quickly as possible. It was important that people with cognitive impairment were not sidelined because of the amount of content or the duration of the meetings. The protocols for information sharing and meeting process were guided by participants and resulted in valued in put from all members.

The Australian Commission on Safety and Quality in Health Care (ACSQHC) were consulted in the development of the guidance in relation to links to the National Standards in Quality Health and Safety (NSQHS) Standards and the Delirium Clinical Care Standard. The Dementia Australia Advisory Committee was consulted in the development of the recommendations. The interim guidance was endorsed by NHMRC’s national Institute of Dementia Research (NNIDR) Special Interest Group (SIG), Cognitive Impairment identification and Care in Hospitals, and the Australian and New Zealand Society of Geriatric Medicine (ANZSGM).

The fact sheets and posters developed as part of the project's outputs were based on a synthesis of current evidence and the shared expertise of various stakeholders, including people living with dementia, care partners, clinicians, peak bodies, and researchers.

In June 2020, the Australian Commission on Safety and Quality in Health Care (ACSQHC) published a safety and quality poster and fact sheet for safe care for people with cognitive impairment during COVID-19, developed in collaboration with the project's committee.

Results

A 38-page interim guidance document directed at healthcare professionals for the care of patients with cognitive impairment requiring hospital care during the COVID-19 pandemic in Australia was created.

Development of a fact sheet for clinicians on safe hospital care for people with cognitive impairment during the pandemic. Two posters were also produced, the first providing an overview of the interim guidance with a flowchart of COVID-19 clinical strategies for people with cognitive impairment, and the second providing a basic step-by-step for the provision of safe, high-quality care. (Appendix 4)

Creation of a public-facing document which provides a summary of the staff guidance documents which provide information to the public regarding what they can expect from care and how to discuss aspect of the hospital admission with staff during the COVID-19 pandemic.

The collaboration with ACSQHC and the eQC Board and the publication of the interim guidance in a peer-reviewed journal further validate the project's results and the potential impact on clinical practice.

Translation to Practice or Policy

The interim guidance provides evidence-based recommendations to optimise care for people with cognitive impairment during the pandemic. By implementing these recommendations, hospitals can improve the quality of care, reduce the risk of harm, and better support patients with cognitive impairment and their families.

The fact sheet for clinicians (Appendix 6) and the poster for healthcare professionals and administrators (Appendix 5) provide accessible and practical tools for translating the interim guidance into clinical practice. These resources can be used to educate and train staff, support decision-making, and promote consistent, high-quality care for patients with cognitive impairment.

While the interim guidance was developed in response to the COVID-19 pandemic, many of its recommendations and principles are relevant to the care of people with cognitive impairment in hospitals more broadly. The project's focus on the specific challenges faced by people with cognitive impairment during the COVID-19 pandemic highlights the need for tailored strategies and interventions to support this vulnerable population. The interim guidance can inform the development of longer-term policies and practices to improve the care of people with cognitive impairment in hospitals beyond the pandemic.

Impact

Involving people with dementia and care partners in the development of the interim guidance and associated documents ensures that the recommendations are not only feasible but relevant to patients and families' needs. Further, this project's outputs demonstrate the effectiveness of including a public perspective in the conceptualization, development, and dissemination of health service research.

The interim guidance emphasises the importance of identifying dementia and delirium in patients to prevent adverse events and minimise the use of restrictive practices such as antipsychotics and restraints to prevent patients, staff, and the public from being exposed to contagious illnesses like COVID-19.

This project also highlights the need to involve care partners and family members to support patients with cognitive impairment during hospitalisation even in the context of pandemic visitor restrictions. The guidance provides frameworks for shared decision-making and support in these contexts.

The development of the interim guidance highlights the importance of preparedness and consideration for the care of vulnerable patients during pandemics, social distancing, and lockdowns. The guidance and its collaborative approach can leave Australian health services better prepared to manage such challenges in the future.

Investigators and Collaborators

Melinda Martin-Khan, Kasia Bail, Mark Yates, Elizabeth Beattie, Alyssa Welch, Fred Graham, Linda Schnitker, Jane Thompson, Leanne Jack, Elizabeth Miller, Glenys Petrie, John Quinn, Marianne Smith, Eileen Jones, Ivy Yuen Yee Webb, (Daniel Bailey- version updating).

Committee members (Box 1) and Reading Group members (Box 2) information can be found on pages 25-31 of the Interim Guidance document.

Publications

1. *Martin-Khan M, Bail K, Graham F, Thompson J, Yates MW, Cognitive Impairment and COVID-19 Hospital Care Guidance Committee. (2020). Interim guidance for the care of adult patients with cognitive impairment requiring hospital care during the COVID-19 pandemic in Australia. Brisbane: University of Queensland
2. *Martin-Khan M, Welch A, Bail K, Yates MW, Graham F, Thompson J, Cognitive Impairment & COVID-19 Hospital Care Guidance Committee. 2020. Going to hospital during the COVID-19 pandemic: guidance for adults with dementia or other cognitive impairments, their care partners and families. Brisbane: The University of Queensland.
3. Martin-Khan M, Bail K, Yates MW, Thompson J, Graham F. Cognitive Impairment and COVID-19, Hospital Care Guidance Committee. 2020. *Interim guidance for health-care professionals and administrators providing hospital care to adult patients with cognitive impairment, in the context of*

COVID-19 pandemic. Australas J Ageing. 39: 283–286. Available from: https://onlinelibrary.wiley.com/doi/10.1111/ajag.12831

4. Martin-Khan M, Bail K, Yates MW, Thompson J, Graham F, Cognitive Impairment and COVID-19, Hospital Care Guidance Committee. (2020). Poster - Interim guidance for health care professionals and administrators providing hospital care to adult patients with cognitive impairment, in the context of COVID-19 pandemic. Brisbane: The University of Queensland. Available from: https://chsr.centre.uq.edu.au/files/5024/A4_Poster_HealthProfessional_Interm%20Guidance_COVID19_CI.pdf
5. ACSQHC. (2020). Poster: Safe care for people with cognitive impairment during COVID-19. Canberra: ACSQHC. Available from: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/safe-care-people-cognitive-impairment-during-covid-19-poster
6. ACSQHC. (2020). Fact Sheet: Safe Hospital care for people with cognitive impairment during COVID-19. Canberra: ACSQHC. Available from: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/safe-hospital-care-people-cognitive-impairment-during-covid-19-fact-sheet-clinicians
7. *Martin-Khan M, Bail K, Graham F, Thompson J, Yates MW, Cognitive Impairment and COVID-19 Hospital Care Guidance Committee. (2023). Interim guidance for the care of adult patients with cognitive impairment requiring hospital care during the COVID-19 pandemic in Australia. Brisbane: University of Queensland Available. Available from: https://chsr.centre.uq.edu.au/files/4866/A4-public_facing_v5.pdfhttps://chsr.centre.uq.edu.au/interim-guidance-care-adult-patients-cognitive-impairment-requiring-hospital-care-during-covid-19-pandemic-australia
8. *Martin-Khan, M, Welch A, Bail K, Yates MW, F. Graham, J. Thompson, and Cognitive Impairment & COVID-19 Hospital Care Guidance Committee (2023). Going to hospital during the COVID-19 pandemic: guidance for adults with dementia or other cognitive impairments, their care partners and families. The University of Queensland. Available from: https://chsr.centre.uq.edu.au/files/4866/A4-public_facing_v5.pdf

*An updated version of these outputs [1,2] was released in June 2023 [7, 8] due to substantial changes that had occurred in how acute care treated and managed COVID-19 infections and how hospital visitors were managed.

These updates were drafted by the Research Fellow employed by the project (Dr Bailey) and circulated to the initial authors for confirmation and editing.

Section Editor:

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Dr Daniel Bailey, Project Manager, Post-doctoral researcher, Centre for Health Services Research, UQ.

> Ann Lord, Dementia Advocate -Dementia Australia, Reader – COVID project
>
> ‘As a carer of a PLWD in a remote regional community during covid, including residential care from December 2019- May 2020, we experienced several hospital admissions, including for infections (UTI, pressure sores), one causing a fall resulting in broken femur, all further exacerbated by existing comorbidities (heart failure, type 2 diabetes). Generally, the treatment of medical symptoms was sound. However, managing daily routines in a strange environment for a PLWD was frustrating to see. To have guidelines for PLWD to be clinically treated with dignity and respect during their hospital stay, and to have these available to be implemented for hospitals Australia wide, I believe, was long overdue.… I believe the guidelines should be applicable or transferable for pandemic and "non pandemic” situations’

Section 3. Cognitive Impairment Status in Hospital Records

Lay summary

Cognitive impairment (including dementia, delirium, and mild cognitive impairment) is commonly encountered amongst patients admitted to acute care hospitals. The identification and management of cognitive impairment information is crucial for providing quality care and ensuring positive patient outcomes.

This project examines the current practices instituted in hospitals worldwide for the identification of cognitive impairment in admitted patients and how cognitive information is managed (i.e., recorded, stored, reported, utilised, shared, and referred to) within the hospital.

Keywords

Acute care, cognitive dysfunction, data transparency, delirium, dementia, health information management, patient-centred care

Aim

To report on the current practices in acute care hospitals for the identification of cognitive impairment and the management of cognitive information.

Develop a protocol for the use of cognitive impairment data in hospital and for sharing this data with patients, their care partners, and other health care providers.

Ethics

This project has been approved by the following ethics committee: The University of Queensland Human Research Ethics Committee A [2018/HE001582].

Method

This study was completed in two phases.

Phase 1 was an integrative review. Medline, CINAHL, Scopus databases, and grey literature sources were systematically searched. Articles relevant to programs implemented in acute care hospitals worldwide regarding cognitive impairment identification and cognition information management were included. The Mixed Methods Appraisal Tool and Authority Accuracy Coverage Objectivity Date and Significance (AACODS) Checklist were used for quality assessment, assessed by two members of the research team. Thematic analysis was used to synthesize results.

Phase 2 is the analysis of 13 interviews with the public to confirm literature review results and draw out any additional data. A protocol was then drafted and workshopped with the eQC Patient and Carer Advisory Board during the board meetings (30 minutes allocated to research discussions as part of the meetings) and written feedback either in shared documents or hard copy. The interviews have been completed. The data is being analysed prior to commencing workshopping with the board.

Interaction with the eQC Board

This project was produced in partnership with the eQC Patient and Carer Advisory Board throughout process, who assisted by providing input on the protocol, materials, and manuscript, and providing a public perspective on the key issues impacting patients and carers in the context of cognitive impairment information management.

"The literature review protocol was reviewed by the evaluating Quality of Care (eQC) Patient and Carer Advisory Board (the Board) prior to registration and implementation… The Board's

insights shaped the development of the research objective and the formulation of research questions, aligning both with academic rigor and practical patient and carer concerns. In addition, the Board members were invited to express their opinions on which two issues (among screening, recording, storing, reporting, utilising, sharing, and referring) were likely to have the most impact on patient care in terms of recommendations for resource allocation and use. Six members' responses on nominated priorities and comments were collected via an anonymous questionnaire. This input directly informed recommendations for resource allocation. The Board also reviewed the draft of the manuscript, ensuring the final output reflects a blend of scholarly rigour and real-world applicability. This collaborative effort with the Board underscores the commitment to a patient-centred approach, enriching the literature review with insights that go beyond conventional academic boundaries" (page 124)[1]*.*

Results

Twenty-two peer-reviewed studies and ten industry or government publications were included. Findings revealed gaps between practice and policy in three key areas of current practice:

1. Formal cognitive assessment is frequently overlooked, despite being crucial to patient outcomes.

2. Recording, storing, and transferring of information is inconsistent despite its value in informing quality care.

3. Interaction with patients, carers, and families in regard to cognitive information and its implications is not prioritised, despite being a valuable potential source of cognitive information and patients/carers having the right to be informed and involved in care planning.

Translation to Practice or Policy

Based on the integrative review findings, recommendations include:

- Standardised, reliable, and valid admission assessment for early identification of cognitive impairment and systematic reassessment during patients' stay. Many acute care hospitals use admission assessments, but only in specific circumstances or in unsystematic ways based on clinician or nurse judgement such as patient's behaviour or other clinical indicators.
- Use of integrated information management systems which support information transfer between ward or setting, extending beyond admission to a patient's general practitioner.
- Standard practice in care to include patients and carers in management and treatment plans. Many people with cognitive impairment still have the capacity to make decisions, and relevant laws and regulations should be in place to support their involvement.
- Beyond admission, screening and assessment lies in the purview of clinician and—frequently—nurse decision-making to trigger further cognitive assessment. Training in recognition of the symptoms of cognitive impairment through observation and communication with patients, families, and carers could reduce oversights in treatment.

Impact

This integrative review highlights the varied nature of cognitive impairment information management across acute care hospitals globally. Research on the most effective screening tools and approaches for data management is needed in order to produce an evidence-based model for better screening and care.

This research has significant implications for the identification and management of cognitive impairment in acute care hospitals. By highlighting the gaps between policy and practice, it advocates for the incorporation of standardized cognitive assessments in admission procedures and the development of a system that ensures data transparency across care providers and settings. This approach will support early identification and better management of CI, ultimately enhancing patient safety and care quality.

The findings underscore the need for a national approach to drive these changes, which could lead to the implementation of necessary policies, protocols, and the allocation of resources. Additionally, this research emphasizes the importance of involving patients, families, and carers in the process of identification and management of cognition information, and the need for adequate staff training to use assessment tools effectively and foster better communication. By addressing these critical areas, the research paves the way for a more cohesive and effective healthcare system that can better meet the needs of individuals with cognitive impairment.

Investigators and Collaborators

Melinda Martin-Khan, Beibei Xiong, Daniel Bailey, Paul Prudon, Elaine M. Pascoe, Len C. Gray, Fred Graham, Amanda Henderson, Trinh Ha

Publications

1. Xiong B, Bailey DX, Prudon P, Pascoe EM, Gray LC, Graham F, Henderson A, Martin-Khan M. (2023). *Identification and information management of cognitive impairment of patients in acute care hospitals: An integrative review.* International Journal of Nursing Sciences. 11(1): 120–132. Available at: https://doi.org/10.1016/j.ijnss.2023.11.001
2. Xiong B, Bailey DX, Prudon P, Pascoe EM, Gray LC, Graham F, Henderson A, Quinn J, Miller E, Thompson J, Jack L, Webb IYY, Lendich K, Lawson J, Petrie G, Martin-Khan M. Protocol for the use of cognitive impairment data in hospital and for sharing this data with patients, their care partners, and other health care providers. **Planned 2025.**
3. Xiong, B., Bailey, D. X., Prudon, P., Gray, L. C., ... & Martin-Khan, M. Identification and information management of cognitive impairment of patients in acute care hospitals: An interview study. **Planned 2024.** “

Section Editors:

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Beibei Xiong, Research Nurse, eQC PhD Student, Centre for Health Services Research, UQ.

Dr Daniel Bailey, Project Manager, Post-doctoral researcher, Centre for Health Services Research, UQ.

> Beibei Xiong, Research Nurse and eQC PhD student
>
> ‘The Board was involved in the study protocol development, questionnaire for identifying key issues of recognizing CI, and review of the article draft [*across several different meetings*]…. I found that the 30 minutes allotted during the general Board meetings is not sufficient for explaining the research activity and collecting feedback…. All the feedback we received from the Board was incredibly useful…. Furthermore, the Board has provided us with valuable information on what issues in the management of CI information have the most impact on patient care in terms of recommendations for resource allocation and use….I would like to express our sincere gratitude to the Patient and Carer Advisory Board for their invaluable contributions to our research. We look forward to continuing our collaboration with the Board and are excited to see where this research takes us’ [explanatory italics added]

Section 4. The Comprehensive Care Standard in Hospital

This project forms the basis of the eQC PhD project for Beibei Xiong (which is also reported with this text in the Capacity Building section of this report for completeness).

Lay summary

Comprehensive care (CC) is essential in modern healthcare for improving patient care and clinical outcomes. In 2019, Australia mandated the Comprehensive Care Standard (CCS) in hospitals, but its implementation and impacts were unclear. This study explores how the CCS was implemented, the challenges and facilitators faced, and its impact on hospital, patients, and staff. Key findings showed a lack of resources, training, and support for professionals, and gaps in patient care. Positive changes in care were noted, but improvements are needed. Overall, the study highlights the importance of proper resources and addressing both care professional and consumer needs for effective CCS implementation in hospitals.

Keywords

Policy implementation, Care Standard, Holistic care, Acute care, Influencing factor, Care experience

Aim

This PhD project aims to examine the implementation of the CCS in Australian acute care hospitals.

Specific objectives include identifying organizational policies, procedures, and protocols for implementing the CCS, implementation barriers and enablers, and the perceived effects on health care outcomes.

Ethics

The University of Queensland’s Human Research Ethics Committee (ID: 2022/HE001036 and ID: 2023/HE001179).

Method

This project employs a mixed methods approach consisting of two main phases. The study design was informed by the initial literature review, which identified gaps in knowledge about the implementation and impacts of similar standards in other countries.

Phase 1: Two integrative reviews of the current evidence, synthesizing studies of various methodologies.

Phase 2: Three mixed-methods studies design to examine the implementation challenges of the CCS in Australian acute care hospitals. This phase includes cross-sectional survey and interview studies with care professionals, patients, and carers.

Interaction with the eQC Board

Survey and interview questions for the patient and carer experience studies were developed in collaboration with the eQC Board to enhance relevance and accessibility.

From inception, the eQC Patient and Carer Advisory Board was engaged for a lived experience perspective on research protocol, analysis, and results. The Board also provided feedback on manuscripts for publication. This collaboration helps ensure that the project remains patient-centered and relevant to the needs and concerns of the target population.

Short updates on this project were delivered at each Board meeting, with larger updates and presentations delivered approximately three-to-four times per year.

Overall, the process of engaging the Board was exceptionally successful, with the quality of constructive feedback exceeding expectations.

Results

A comparison of standards for comprehensive care in Australia, Norway, and the UK have highlighted the challenges and facilitators of implementation. In Australia, the CCS shows some positive effects on patient outcomes, though research is limited.

Various methods have been used by hospitals to implement the CCS, such as implementation teams, staff education, various communication modalities, and new computer information systems.

Care professionals reported moderate overall knowledge of the CCS and identified multiple barriers to implementation; however, they noted a positive influence on patient care.

Patient experiences were largely positive, but areas for improvement were identified, such as staff traits, decision-making processes, addressing patients' needs, information and guidance, and coordination of care.

Caregiver experiences were also positive, but emphasized the importance of shared decision-making, addressing carer needs, and providing comprehensive information to patient and care partners.

Translation into Practice or Policy

We have explored the approaches, barriers, facilitators, and impacts of the CCS implementation. From this we have developed a theoretical case study that illustrates an exemplary implementation, highlighting essential approaches, considerations for overcoming barriers and leveraging facilitators, and addressing gaps in care identified by care professionals, patients, and carers.

Although conducting a real-world case study was not successful, this theoretical case study incorporating our findings can still serve as a valuable reference.

Impact

This research identified various approaches used in the hospitals to implement the CCS. These insights are valuable for Australian hospitals seeking to enhance CCS implementation, as well as hospitals in other countries considering CC implementation.

The findings provide valuable insights into the reality of CCS implementation. These insights have significant political and clinical implications for healthcare practices worldwide, contributing to the continuous refinement of national standards for CC and their effective implementation in acute care hospital settings. Policymakers can draw on these findings to inform policy adjustments and evidence-based decisions.

Furthermore, our research provides valuable feedback to health systems regarding patients' and carers’ care experiences following the implementation of the national CCS roll out, highlighting the gaps between policy and reality.

This information is crucial for policymakers, healthcare providers, and researchers to drive evidence-based improvements in healthcare services, ensuring patients receive quality care as intended. Ultimately, these insights can lead to improved patient outcomes and experiences of care.

Collaborators

Beibei Xiong, Melinda Martin-Khan (Primary Supervisor), Christine Stirling (Supervisor), Daniel Bailey (Supervisor), Paul Prudon, Ziyinyue Zeng, Jane Thompson (eQC Board), Leanne Jack (eQC Board), Elizabeth Miller (eQC Board), Jennifer Lawson (eQC Board), Karyn Lendich (eQC Board), Glenys Petrie (eQC Board), John Quinn (eQC Board), Ivy Yuen Yee Webb (eQC Board), Emmy Trinh

Publications

1. Xiong B, Stirling C, Martin-Khan M. (2023). The implementation and impacts of national standards for comprehensive care in acute care hospitals: An integrative review. International Journal of Nursing Sciences. https://doi.org/10.1016/j.ijnss.2023.09.008
2. Xiong B, Stirling C, Martin-Khan M. The origin, contemporary definition, and evolution of comprehensive care: A narrative review. Australian Journal of Advanced Nursing. **Submitted 2023**
3. Xiong B, Stirling C, Bailey D, Martin-Khan M. (2024). The implementation and impacts of the Comprehensive Care Standard in Australian acute care hospitals: A survey study. (Survey study 1 – quantitative result). BMC Health Services Research. **Revisions Submitted 2024**
4. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. (2024). Identification of Implementation Enhancement Strategies for National Comprehensive Care Standards Using the CFIR-ERIC Approach: A qualitative study. (Survey study 2 – qualitative result). BMC Health Services Research. **Revisions Submitted 2024**
5. Xiong B, Stirling C, Bailey D, Paul Prudon, Martin-Khan M. Implementation approaches of a national standard for comprehensive care in acute care hospitals: A qualitative descriptive study. (Interview study 1) **Submitted 2024**
6. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. Barriers, enablers, and impacts of Implementing national comprehensive care standards: A qualitative descriptive study (Interview study 2) **Submitted 2024**
7. Xiong B, Bailey D, Stirling C, Trinh E, Zeng Z, Martin-Khan M. A mixed method study on experiences of care in hospital: patient perspective. BMC Nursing. **Drafted 2024**
8. Xiong B, Stirling C, Bailey D, Zeng Z, Trinh E, Martin-Khan M. A mixed method study on experiences of care in hospital: carer perspective. BMC Nursing. **Drafted 2024**
9. Xiong B, Stirling C, Bailey D, … Martin-Khan M. Patient and carer perception of comprehensive care: a qualitative study. **Planned 2025**
10. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on factors affecting patient participation in care: a qualitative study. **Planned 2025**
11. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on hospital feedback: a qualitative study. **Planned 2025**

Section Editors:

Beibei Xiong, Research Nurse, eQC PhD Student, Centre for Health Services Research, UQ.

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Section 5a and 5b. interRAI Acute Care assessment in hospital

Lay summary

The eQC project was a translation and implementation research program. The assessment system that was to be implemented as part of the body of work addresses key recommendations from the Clinical Practice Guidelines and Principles of Care for People with Dementia. It sought to ensure that all patients are integrated into the assessment, planning and delivery of care in hospital. The work was focused on understanding how that approach was undertaken for people with dementia in hospital.

This sub-project aimed to support, monitor, and evaluate the implementation of the interRAI Acute Care system (iAC) into eight acute care settings in participating hospitals (5a). Following the implementation, it aimed benchmark the quality of care through monitoring quality indicators to identify if improvements in assessment enabled a change in measures of quality for people with cognitive impairment (5b).

Keywords

Cognitive impairment, dementia, delirium, hospital care, screen, assessment, benchmarking

Aim

To conduct a large-scale implementation of an assessment and care planning system to improve the care and support of people with dementia in hospital.

To implement and evaluate a bench-marking service built on the integrated outcome Quality Indicators (QIs) for care of older people with dementia.

Ethics

This project has been approved by the following ethics committees: The University of Queensland Human Research Ethics Committee A [2018/HE001582]; University of Tasmania Human Research Ethics Committee [H—18049]; Queensland Health Townsville Hospital and Health Service [HREC/2019/QTHS/57317]; Tasmanian Health Service [H0018049].

Method

Each site would make an arrangement with a software provider to ensure they had access to an electronic version of the iAC. Training in the software would be provided by UQ.

Setting: A number of sites were approached for involvement. Contracts were drawn up to partner with the Tasmanian Health Service (THS). They were recruited to implement the iAC at a group of identified hospitals with the intention of embedding the software within their electronic record system. An additional private hospital was recruited from Perth, and a public hospital from Queensland (which would run the software adjacent to their existing system).

Interaction with the eQC Board

The eQC board was established, including a member from Tasmania, to provide oversight of the protocol and guide interactions from implementation to dissemination.

Development and Implementation

Phase 1: Following agreement to participate in the project, during the contract stage, work would begin on mapping the iAC to the current paper assessments that were a part of the nursing admission process. The eQC research team would support the hospital site to remove any duplication when the new iAC system was installed.

Phase 2: When the system was really for use, staff on site would be trained, and a system of ‘train the trainer’ would be commenced. The initial focus would be on implementing the nursing assessment for all adults admitted to the hospital (except specialist wards – maternity, children’s wards).

Phase 3: Benchmarking would commence with comparison of outcomes using quality indicators automatically generated by the iAC. The iAC quality indicators had previously been developed for older adults in acute care and would now be tested in a broader population and in different wards across the hospital with a focus on understanding the extent to which they were amendable to change.

Results

Finalising contracts were not possible when all funding was removed for projects by THS following the introduction of the COVID pandemic lockdown as funds were re-directed to pandemic preparation. Other sites also found it difficult to focus on research projects of this nature given other pressures at that time.

Investigators and Collaborators

Melinda Martin-Khan, Len Gray, John Hirdes, Amanda Henderson, Elaine Pascoe, Nicole Gillespie, Brand Fries, Veronique Boscart, Julia Crilly, Elizabeth Beattie, Fred Graham, Ellen Burkett, Linda Schnitker, Ruth Hubbard, Tracy Comans, Yvonne Hornby, Alyssa Welch, Dianna Ang, Bonnie Pimm, Talitha Khan, Melody Dobrinin, Sifan Cao, Yvonne Hornby-Turner, Donna Maysey, Nancye Peel, Samantha Ward

Publications

1. Martin-Khan M, Welch A, et al. Protocol for the implementation of the interRAI acute care nursing assessment in a hospital setting. **Not published**
2. Welch A, Martin-Khan M, et al. An logic approach to project management for the eQC project. **Not published**
3. Martin-Khan M, Gray LC, Brand C, Wright O, Pachana N, Byrne G, Chatfield M, Jones R, Morris J, Travers T, Tropea J, Xiong B, The Research Collaborative for Quality Care: Acute Care Panel and The Research Collaborative for Quality Care: Dementia Care Panel. (2024). Patient outcome quality indicators for older persons in acute care: original development data using interRAI AC-CGA. BMC Geriatrics. 24(1), 527. Available From: https://link.springer.com/article/10.1186/s12877-024-04980-9
4. Wood T, Chatfield M, Gray LC, Peel N, Freeman S, Martin-Khan M. (2022). Examining the adaptability and validity of interRAI acute care quality indicators in a surgical context. SAGE Open Medicine. 10. Available from: https://doi.org/10.1177/20503121221103221

Section Editor:

Dr Melinda Martin-Khan, Lead investigator, Centre for Health Services Research, UQ.

Section 5c. Digital transformation in the healthcare sector

Lay summary

Australia's healthcare system continues to undergo information management transformation driven by the COVID-19 pandemic and rapid technological advancements. Trust is one of the first casualties in organisational change yet is crucial in facilitating the adoption of new information systems; therefore, this sub-project aims to understand how trust can be built and maintained during digital transformation in healthcare organizations. We are conducting two systematic reviews to identify factors that influence trust during organizational change and digital transformation, with a focus on healthcare settings. The findings will provide actionable recommendations for healthcare leaders to cultivate trust and enable more effective implementation of change.

Keywords

Digital transformation, organizational change, trust, healthcare, systematic review

Aim

To conduct two systematic reviews examining the antecedents and consequences of trust during organizational change and digital transformation, with a specific focus on healthcare contexts.

Method

The sub-project consists of two systematic reviews.

The first review focuses on the antecedents and consequences of employee trust during digital transformation across various sectors and technologies.

The second review concentrates on factors influencing trust during cultural, structural, and technological changes in healthcare organizations.

Interaction with the eQC Board

Professor Nicole Gillespie presented the sub-project's aims, methodology, and impact to the eQC Patient and Carer Advisory Board for discussion in 2022 and will present a final report on the research outcomes to the Board in November 2024.

Development and Implementation

Both reviews followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Relevant databases (e.g., PubMed, CINAHL, Scopus, ISI Web of Science) were searched and articles were screened using Covidence based on predefined inclusion criteria, such as empirical research examining trust in the context of organizational change or digital transformation, inclusion of stakeholder perspectives, and being peer-reviewed and published in English. The reference lists of selected articles were also scanned for additional relevant studies.

Results

These reviews highlight the vital role employee trust plays in the success of digital transformation across a wide range of sectors including health. Trust was found to be positively associated with individual and organisational adoption of new systems. Five key mechanisms supporting trust were identified:

- Employee empowerment and involvement in decision-making

- Perceived management commitment to change in attitudes and resourcing
- Training and education
- Effective and clear communication
- Perception of usefulness of new systems

Translation into Practice or Policy

The findings from these systematic reviews will provide evidence-based recommendations for healthcare leaders and policymakers to preserve and foster trust during digital transformation and organizational change in healthcare settings.

These reviews establish the importance of the previously ambiguous role trust plays in successfully navigating necessary organisational change and outlines why potential impacts on organisational trust must be considered when establishing any policy or standard, or when instituting change directly in a healthcare setting. Further, by demonstrating a commitment to preserving trust during times of change, the outcomes have the potential to be more effective and in turn increase public trust in our health systems.

By understanding the factors that influence trust, healthcare organizations can develop targeted strategies to support effective change implementation and improve patient care.

Impact

Development included the perspectives of patients and carers; those who ultimately stand to benefit recommendations of this research. The impact of patients and carers on research direction differs significantly depending on project and stage, and we acknowledge that in this case public involvement was at a consultation level, this demonstrates a commitment to embedding the public voice in all levels of health service research. Through inclusion—even at early stages—the research community can better align its aims and priorities to focus more on the actual needs of patients who engage with the systems we are working to improve.

The insights gained from these systematic reviews have the potential to improve the success of digital transformation and organizational change initiatives in healthcare by addressing the critical role of trust. Enhancing trust among healthcare professionals can lead to better adoption of new technologies and practices, ultimately resulting in improved patient outcomes and experiences.

Investigators and Collaborators

Professor Nicole Gillespie, Alexandria Macdade, Shannon Colville, Jake Morrill

Publications

1. Macdade A, Morrill J, Colville S, Gillespie N. (2024). Trust during digital transformation: A systematic review. **Planned 2024**
2. Colville S, Macdade A, Gillespie N. (2024). Preserving trust during organizational change: Insights from a systematic review in healthcare. **Planned 2024**

Section Editor:

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Section 5e. Occupational violence

Lay summary

This study investigates occupational violence (OV) incidents involving patients with cognitive impairment relative to other patient groups in five Brisbane Metro South hospitals. By examining the distribution and details of OV reports and identifying risk factors, we intend to make recommendations which could be used to inform targeted interventions which reduce the frequency and impact of these incidents. It may also be possible to identify if the records contain insufficient information to identify risk factors relevant for patients with cognitive impairment which may lead to recommendations for improved investigation during OV incidents and record keeping. A reduction in OV incidents, particularly involving older patients with cognitive impairments will increase patient safety, reduce likelihood of adverse care outcomes, provide a respectful care experience, and create a safer working environment for frontline health staff.

Keywords

Occupational violence, cognitive impairment, dementia, delirium, risk factors, acute care.

Aim

This study has three aims:

1) to examine the distribution of OV reports across all wards and patient groups to determine the scale of OV and characterise the groups involved

2) identify risk factors for OV incidents among i) patients over the age of 65 years, and ii) patients living with cognitive impairment or experiencing delirium, and

3) qualitatively explore incidents to identify common themes amongst risk factors and precipitating events.

Each aim will be explored in a separate academic publication.

Ethics

Metro South Health Human Research Ethics Committee (MSH HREC): HREC/2023/QMS/94861

Method

Incident data collected from OV and behavioural incident reports (sourced from Risk Management systems and iEMR) from five Brisbane Metro South Hospitals between 2018-2022.

The study method has been divided into three phases. In the first phase, descriptive quantitative analysis on OV incidents will be explored first to provide an overall picture of the frequency of incidents by ward and hospital. In the second phase, a quantitative analysis of the risk factors between groups of interest will be performed and examine whether patients with dementia and cognitive impairment are overrepresented. In the last phase, qualitative thematic analysis will be performed to extract themes from the incident descriptions to identify patterns risk and precipitating factors leading to OV incidents in older populations and those with cognitive impairment.

Interaction with the eQC Board

The eQC Board has been involved and providing a public perspective on this project since inception and has been updated on the project at each Board meeting.

As findings emerge at each stage of the study, Board members' perspectives will be used to shape how we approach each phase of data analysis and how to frame and disseminate the findings.

Development and Implementation

Our original analysis plan concerned only examining the details of OV incidents involving patients living with cognitive impairment, as this issue was highlighted to us from an Associate Investigator (Graham) based in a dementia specific ward. After initial presentation of the concept to the Board, the project scope was expanded to include an overview of all OV incidents and comparison with other patient groups, as described in our aims. The Board perspective was that analysing a narrow patient group had the potential to bias findings, inadvertently suggesting that older patients and those with cognitive impairment are the primary cause of occupational violence in hospitals. By expanding our methodology to include quantitative data from all patient groups, this study can now determine if older patients are disproportionately represented in OV incidents. The subsequent qualitative phase examining the reports themselves will provide insights into why older patients and people with cognitive impairment specifically, are involved in incidents by looking at antecedents to provide a more complex understanding.

Data extraction, formatting, and linkage by Metro South Hospitals clinical systems team is underway. Once the format and linkage has been verified this data can anonymised and transferred to the UQ research team for analysis.

Translation into Practice or Policy

As this study's data analysis has not yet been finalised, practice and policy implications listed here are broad and prospective. Many of these tentative recommendations are backed by evidence from our Section 3 study.

The findings from this study should provide further evidence for the adoption of regular, standardised cognitive screening of patients so healthcare staff can engage in more informed risk management and care planning, prioritising patient, staff, and public safety.

The eQC board will engaged in discussions regarding interpretation and translation of the findings into practice with particular emphasis on patient care and the rights of people with cognitive impairment. Once the results are finalised Metro South Health will be approached to us to present the results and for them to hear the options for translation as the beginning of a dialogue on OV.

Our methodology and recommendations may further form the basis of regular review strategies for OV incident reports in order to identify trends and patterns, and use data to address ongoing training, process improvement, and risk management processes.

Impact

Thus far the greatest impact of this project has been on researchers. From our interactions with the eQC Board, significant knowledge gaps, biases, and assumptions were highlighted which without a public perspective would not have been addressed, impacting the quality of the evidence and interpretations produced. This has been an excellent example of the value of public involvement in research.

Potential impacts of this project's evidence and recommendations are reduced numbers and severity of OV incidents in hospitals, and therefore overall improvement of patient, family and staff experience. Improved training and awareness may reduce patient adverse events including over use of medication such as sedatives, reduce staff stress and burnout, improve retention of skilled staff, reduce costs associated with injury, and staff time spent in investigation.

This study will ultimately provide insights into the challenges faced by older populations presenting at acute care hospitals. This research is timely as Australia's aging population means that people aged 65 and older will represent an increasing number of hospital patients.

Investigators and Collaborators

Daniel Bailey, Leonard Gray, Fred Graham, Alan Scanlon, Michelle Lang, Melinda Martin-Khan, Ruth Hubbard, Gillian Stockwell-Smith, Farah Zahir, Jane Thompson (eQC board), Leanne Jack (eQC board), Ivy Yuen Yee Webb (eQC board), Karyn Lendich (eQC board), Glenys Petrie (eQC board), John Quinn (eQC board), Elizabeth Miller (eQC board), Ronald Dendere, Murray Hargrave, Donna Maysey, Charles Okafor

Publications

1. Bailey D, Gray LC, Hubbard R, Martin-Khan K, Lang M, Scanlon A, Graham F. The scale and distribution of occupational violence in acute care hospitals. **Planned 2024**
2. Bailey D, Zahir F, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. Medical and demographic variables which help predict occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**
3. Bailey D, Stockwell-Smith G, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. A qualitative analysis of incidents, risk factors and outcomes of occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**

Section Editor:

Dr Daniel Bailey, Project Manager, Post-doctoral researcher, Centre for Health Services Research, UQ.

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Capacity Building

A primary focus of the eQC project was to overcome knowledge gaps in the quality of care for people with dementia, and to create opportunities for early career researchers to learn about interacting with public and patient researchers as collaborators through the whole research cycle (Table 2). We supported 4 PhD students to get scholarships for this project, but 3 weren't able to either take up the scholarship or continue with it due to COVID lock down. We recruited an early career dementia researcher. And we supported two additional PhD students doing dementia research with access to advice from the eQC Patient and Carer Advisory Board.

Table 2 Summary of early career researchers connected with the eQC project

#	Name	Summary
1	**Name not listed**	eQC PhD. Origin: England. Primary supervisor: CHSR. Successful receipt of a Capacity building grant from The University of Queensland. Had to return to the UK as a result of the COVID pandemic. Withdrew from PhD program after one year during the pandemic.
2	**Name not listed**	eQC PhD. Origin: Australia. Primary Supervisor: UTAS. Successful recipient of scholarship from University of Tasmania. Had to transfer to another program as a result of withdrawal of project partner (Tasmanian Health Service) during COVID pandemic.
3	**Name not listed**	eQC PhD. Origin: Canada. Primary supervisor: CHSR. Application delayed as a result of COVID pandemic. Outcome: Application for PhD scholarship had to be withdrawn.
4	**Beibei Xiong**	eQC PhD. Origin: China. Primary supervisor: CHSR. Successful recipient of a UQ Graduate School Scholarship (UQGSS) – includes Research Training Program (RTP). Had to delay the commence date from April 2020 to April 2021, commenced remotely in China as part-time in April 2021 and transferred to full-time in January 2022.
5	**Muhammad Haroon**	PhD. Not connected to eQC project. Primary supervisor: CHSR. Full-time PhD student CHSR PhD student applied for support and input from the advisory board on his PhD - People living with dementia and care partners
6	**Sandra Smith - Lewis**	PhD. Not connected to eQC project. Primary supervisor: CHSR. Part-time PhD student. Part-time CHSR UQ PhD student applied for support and input from the advisory board for her PhD on the development of person-centred quality indicators for aged care assessment services in Australia.
7	**Daniel Bailey**	eQC Post-Doc. Origin: Australia. Early Career dementia researcher post-doctoral position as project manager with responsibility for protocols, implementing research, and writing papers, as well as supervision of students and staff.

Beibei Xiong

Implementation challenges and impacts of the Comprehensive Care Standard (CCS) in acute care hospitals in Australia

eQC Project. Beibei Xiong received a scholarship and worked as part of the eQC project. Her original research topic was embedded within nursing assessment processes and based in Tasmania. It had to be altered somewhat following the COVID pandemic but it remained focused on nursing practice in acute care as part of the eQC project.

Lay summary

Comprehensive care (CC) is essential in modern healthcare for improving patient care and clinical outcomes. In 2019, Australia mandated the Comprehensive Care Standard (CCS) in hospitals, but its implementation and impacts were unclear. This study explores how the CCS was implemented, the challenges and facilitators faced, and its impact on hospital, patients, and staff. Key findings showed a lack of resources, training, and support for professionals, and gaps in patient care. Positive changes in care were noted, but improvements are needed. Overall, the study highlights the importance of proper resources and addressing both care professional and consumer needs for effective CCS implementation in hospitals.

Keywords

Policy implementation, Care Standard, Holistic care, Acute care, Influencing factor, Care experience

Aim

This PhD project aims to examine the implementation of the CCS in Australian acute care hospitals.

Specific objectives include identifying organizational policies, procedures, and protocols for implementing the CCS, implementation barriers and enablers, and the perceived effects on health care outcomes.

Ethics

The University of Queensland’s Human Research Ethics Committee (ID: 2022/HE001036 and ID: 2023/HE001179).

Method

This project employs a mixed methods approach consisting of two main phases. The study design was informed by the initial literature review, which identified gaps in knowledge about the implementation and impacts of similar standards in other countries.

Phase 1: Two integrative reviews of the current evidence, synthesizing studies of various methodologies.

Phase 2: Three mixed-methods studies design to examine the implementation challenges of the CCS in Australian acute care hospitals. This phase includes cross-sectional survey and interview studies with care professionals, patients, and carers.

Interaction with the eQC Board

Survey and interview questions for the patient and carer experience studies were developed in collaboration with the eQC Board to enhance relevance and accessibility.

From inception, the eQC Patient and Carer Advisory Board was engaged for a lived experience perspective on research protocol, analysis, and results. The Board also provided feedback on manuscripts for publication. This collaboration helps ensure that the project remains patient-centered and relevant to the needs and concerns of the target population.

Short updates on this project were delivered at each Board meeting, with larger updates and presentations delivered approximately three-to-four times per year.

Overall, the process of engaging the Board was exceptionally successful, with the quality of constructive feedback exceeding expectations.

Results

A comparison of standards for comprehensive care in Australia, Norway, and the UK have highlighted the challenges and facilitators of implementation. In Australia, the CCS shows some positive effects on patient outcomes, though research is limited.

Various methods have been used by hospitals to implement the CCS, such as implementation teams, staff education, various communication modalities, and new computer information systems.

Care professionals reported moderate overall knowledge of the CCS and identified multiple barriers to implementation; however, they noted a positive influence on patient care.

Patient experiences were largely positive, but areas for improvement were identified, such as staff traits, decision-making processes, addressing patients' needs, information and guidance, and coordination of care.

Caregiver experiences were also positive, but emphasized the importance of shared decision-making, addressing carer needs, and providing comprehensive information to patient and care partners.

Translation into Practice or Policy

We have explored the approaches, barriers, facilitators, and impacts of the CCS implementation. From this we have developed a theoretical case study that illustrates an exemplary implementation, highlighting essential approaches, considerations for overcoming barriers and leveraging facilitators, and addressing gaps in care identified by care professionals, patients, and carers.

Although conducting a real-world case study was not successful, this theoretical case study incorporating our findings can still serve as a valuable reference.

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This research identified various approaches used in the hospitals to implement the CCS. These insights are valuable for Australian hospitals seeking to enhance CCS implementation, as well as hospitals in other countries considering CC implementation.

The findings provide valuable insights into the reality of CCS implementation. These insights have significant political and clinical implications for healthcare practices worldwide, contributing to the continuous refinement of national standards for CC and their effective implementation in acute care hospital settings. Policymakers can draw on these findings to inform policy adjustments and evidence-based decisions.

Furthermore, our research provides valuable feedback to health systems regarding patients' and carers’ care experiences following the implementation of the national CCS roll out, highlighting the gaps between policy and reality.

This information is crucial for policymakers, healthcare providers, and researchers to drive evidence-based improvements in healthcare services, ensuring patients receive quality care as intended. Ultimately, these insights can lead to improved patient outcomes and experiences of care.

Collaborators

Beibei Xiong, Melinda Martin-Khan (Primary Supervisor), Christine Stirling (Supervisor), Daniel Bailey (Supervisor), Paul Prudon, Ziyinyue Zeng, Jane Thompson (eQC Board), Leanne Jack (eQC Board), Elizabeth Miller (eQC Board), Jennifer Lawson (eQC Board), Karyn Lendich (eQC Board), Glenys Petrie (eQC Board), John Quinn (eQC Board), Ivy Yuen Yee Webb (eQC Board), Emmy Ha Trinh

Publications

1. Xiong B, Stirling C, Martin-Khan M. (2023). The implementation and impacts of national standards for comprehensive care in acute care hospitals: An integrative review. International Journal of Nursing Sciences. Available from: https://doi.org/10.1016/j.ijnss.2023.09.008
2. Xiong B, Stirling C, Martin-Khan M. The origin, contemporary definition, and evolution of comprehensive care: A narrative review. Australian Journal of Advanced Nursing. **Submitted 2023**
3. Xiong B, Stirling C, Bailey D, Martin-Khan M. (2024). The implementation and impacts of the Comprehensive Care Standard in Australian acute care hospitals: A survey study. (Survey study 1 – quantitative result). BMC Health Services Research. **Revisions Submitted 2024**
4. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. (2024). Identification of Implementation Enhancement Strategies for National Comprehensive Care Standards Using the CFIR-ERIC Approach: A qualitative study. (Survey study 2 – qualitative result). BMC Health Services Research. **Revisions Submitted 2024**
5. Xiong B, Stirling C, Bailey D, Paul Prudon, Martin-Khan M. Implementation approaches of a national standard for comprehensive care in acute care hospitals: A qualitative descriptive study. (Interview study 1) **Submitted 2024**
6. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. Barriers, enablers, and impacts of Implementing national comprehensive care standards: A qualitative descriptive study (Interview study 2) **Submitted 2024**
7. Xiong B, Bailey D, Stirling C, Trinh E, Zeng Z, Martin-Khan M. A mixed method study on experiences of care in hospital: patient perspective. BMC Nursing. **Drafted 2024**
8. Xiong B, Stirling C, Bailey D, Zeng Z, Trinh E, Martin-Khan M. A mixed method study on experiences of care in hospital: carer perspective. BMC Nursing. **Drafted 2024**
9. Xiong B, Stirling C, Bailey D, … Martin-Khan M. Patient and carer perception of comprehensive care: a qualitative study. **Planned 2025**
10. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on factors affecting patient participation in care: a qualitative study. **Planned 2025**
11. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on hospital feedback: a qualitative study. **Planned 2025**

Presentations

- Xiong B, Prudon P, Stirling C, Martin-Khan M. (2023). Advancing Comprehensive Care for Older Adults: Insights from a National Survey and Interviews. 56 th Australian Association of Gerontology conference. Gold Coast, Australia. (Oral presentation)
- Xiong B, Stirling C, Bailey D, Prudon P, Martin-Khan M. (2023). Care professionals' insights on the Australian Comprehensive Care Standard: A national survey and interview. Evidence and Implementation Summit 2023. Melbourne, Australia. (Oral presentation)

- Xiong B, Stirling C, Martin-Khan M. (2023). Improve Comprehensive Care: Insights from Care Professionals on the Comprehensive Care Standard via a National Survey. 21th National Conference of Emerging Researchers in Ageing. (Oral presentation)
- Xiong B, Bailey D, Prudon P, Stirling C, Martin-Khan M. (2023). Improving comprehensive care: insights from a mixed method survey following the introduction of Australian Comprehensive Care Standard. 6th UK and Ireland Implementation Science Research Conference 2023. Limerick, Ireland. (Oral presentation)
- Xiong B, Stirling C, Martin-Khan M. (2022). Implementation challenges and impacts of the comprehensive care standard in Australian acute care hospitals: Protocol for a mixed-method study. 20th National Conference of Emerging Researchers in Ageing. (Oral presentation)
- Xiong B, Stirling C, Martin-Khan M. (2022). The implementation and impacts of the standards for comprehensive care: A systematic search and review of Australian and international evidence. The University of Queensland, Faculty of Medicine 2022 HDR Symposium. Brisbane, Australia. (Oral presentation)
- Xiong B, Stirling C, Bailey D, Prudon P, Martin-Khan M. From policy to practice: Unravelling the realities of comprehensive care implementation in acute care hospitals. 35th International Nursing Research Congress, Singapore. (Oral presentation)

Section Editors:

Beibei Xiong, Research Nurse, eQC PhD Student, Centre for Health Services Research, UQ.

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

> Beibei Xiong, Research Nurse and PhD student
> ‘The feedback from the Board was invaluable; their questions and suggestions pushed us to think more critically and thoroughly about our approach’

Muhammad Haroon

Picture-based quality of life (QoL) tool for eliciting information from people living with dementia

eQC adjacent project. Muhammad Haroon is a PhD student from the Centre for Health Services Research Centre (CHSR) with a dementia focused topic. He utilised the eQC Patient and Carer Advisory Board for their advice and input in their role as an advisory board, not because his project was connected with the eQC body of work specifically.

Lay summary

The Alzheimer's Disease Five Dimensions (AD-5D) is a tool used to assess the quality of life of people living with dementia; however, it is text-based and only available in English This can be challenging for people from culturally and linguistically diverse (CALD) backgrounds who may lose their ability to communicate in English even at mild stages of dementia. This research project aims to develop a picture-based version of the AD-5D tool to help people living with dementia express their thoughts and feelings more easily. By involving people living with dementia and their care partners in the design process, we can ensure that the new tool is suitable and well-understood by its intended users.

Keywords

Alzheimer’s Disease Five Dimensions, AD-5D, picture-based assessment, quality of life, patient and public involvement, consumer engagement, dementia, delirium, culturally and linguistically diverse backgrounds.

Aim

To develop and validate a picture-based quality of life assessment tool for people living with dementia based on the AD-5D QoL tool.

We aim to involve stakeholders in the design process to ensure the tool is suitable and understood by people living with dementia.

Method

We first held focus groups consisting of people living with dementia (n = 7) and their care partners (n = 5). In the focus group we had three primary questions for the development of the Picture-based QoL tool:

1. What images do users associate with the five domains of the AD-5D QoL tool, and what images do users associate with the different levels of response options?
2. Which image style or modality (such as photographs vs drawings) do users prefer and why?
3. How many picture-based response options are users comfortable interacting with at one time?

Based on the guidelines developed from the focus group responses, we collected a large pool of images.

The next step will be to survey participants (n = 63) to select the best pictures to represent the AD-5D QoL dimensions and response options. The Picture-based QoL tool will be compared to the AD-5D QoL tool to determine its validity.

Interaction with eQC Board

We presented the progress and future steps for the project to the eQC Patient and Carer Advisory Board in June 2022 to assess the suitability of our methods from a patient and public perspective. Also, we hoped to determine if a stakeholder advisory body like the Board would view such a tool as useful for hospital care for people with dementia.

We found the session was particularly informative for the following reasons:

- Board members asked a surprisingly diverse range of questions about the project, many of which had not been previously considered by the research team.
- The session also highlighted the valuable role carers play in hospital care for a person living with dementia and thus represented an important role in developing the tool. This in particular changed our view of the carer from an ‘external influence on decisions’ to a ‘channel for effective communication.’
- The Board experience was surprisingly collaborative, which was unexpected – instead of a one-way presentation, it was a collaborative consultation.
- The positive community support for this project was overwhelming and reinforced the importance of this work.
- We never expected the networking opportunities that interaction with the eQC Board would present. Board members helped us recruit participants for subsequent focus groups for the study.

We also presented our progress on the QoL tool in October of 2023.

Development and Implementation

Image based depictions of QoL dimensions are subjective and likely to vary between people depending on factors such as age, culture, and linguistic background. Therefore, rather than select images based on our own judgement and interpretations we sought a public perspective from those whom this QoL tool is intended to serve.

The project and its progress has had extensive public input. The eQC Patient and Carer Advisory Board has provided input at various stages of the project, and development of the materials themselves involved people living with dementia and their carers.

Results

We found that the first five AD-5D QoL dimension themes (*mood*, *physical health*, and *memory*) tended to have fairly ‘standard’ images associated with them.

The final two dimensions (*living situation* and *ability to do fun things*) were found to be more subjective to the individual as they tended to reflect heterogeneous age-related challenges with such themes as feelings of vulnerability, social exclusion, isolation, disability, and risk of sedentary life. Compiling these themes allowed us to select a broad array of images which expressed these age-related challenge themes rather than mapping onto the QoL domains themselves.

For image style, seven participants favoured simplified drawing/cartoon style images, one preferred photographs, and the remaining four found both styles equally acceptable. Clear facial expressions and clutter-free depictions of a single activity were favoured overall.

For response options, there was no conclusive preference between seven or three options; however, in general (seven of the twelve participants) we found people preferred fewer options to interact with.

Translation into Practice or Policy

Development of a Picture-based QoL tool can overcome the language barrier limitation of the AD-5D, addressing the needs of culturally and linguistically diverse patients who may lose the ability to communicate in English.

The involvement of persons living with dementia and their care partners in the design process helps ensure this tool is valid, reliable, and understandable by its intended audience.

The Picture-based QoL tool can also complement (rather than replace) text-based tools, providing healthcare professionals with other means to assess patients’ quality of life. This can provide insight into whether more comprehensive assessment of the patient is needed.

Impact

Picture-based tools can help people who have limited language capacity to communicate their thoughts, feelings, and state effectively with healthcare staff without the need for proxies, such as carers or translators to be constantly present. This gives people from cultural and linguistically diverse backgrounds greater autonomy and empowerment over their care.

Australia is a multicultural nation with an aging population. By acknowledging and addressing the linguistic and cultural barriers with innovative assessments such as the Picture-based QoL tool, healthcare providers can deliver more inclusive and equitable care services.

Collaborators

Muhammad Haroon, Tracy Comans (Primary Supervisor), Nadeeka Dissanayaka, Anthony Angwin, Jane Thomspon (eQC Board), Leanne Jack (eQC Board), Jennifer Lawson (eQC Board), Karyn Lendich (eQC Board), Elizabeth Miller (eQC Board), Glenys Petrie (eQC Board), John Quinn (eQC Board), Ivy Yuen Yee Webb (eQC Board).

Publications

1. Haroon M, Dissanayaka NN, Angwin AJ, Comans T. (2022). How Effective are Pictures in Eliciting Information from People Living with Dementia? A Systematic Review. Clinical Gerontologist, 46(4): 511–524. Available from: https://doi.org/10.1080/07317115.2022.2085643

Section Editor:

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

Muhammad Haroon, PhD student

‘A very surprising and refreshing aspect of the session was that I could put my questions before the board members. So it was not a presentation, rather it was a consultation, and I found that very useful’

Sandra Smith - Lewis

Developing a set of quality indicators to measure the quality of the aged care assessment service from a clients' perspective

eQC Adjacent Project. Sandra Smith-Lewis is a part-time PhD student from the Centre for Health Services Research Centre (CHSR) who formerly worked with an aged care assessment team in Queensland. She utilised the eQC Patient and Carer Advisory Board for their advice and input in their role as an advisory board, not because her project was connected with the eQC body of work specifically.

Lay summary

In Australia, older people needing aged care services must undergo an assessment to determine their eligibility and the level of support they require. This study developed a set of 24 person-centered quality indicators (PC-QIs) to evaluate the quality of these assessments from the client's perspective. The PC-QIs were created in collaboration with older adults, aged care assessors, and the eQC Patient and Carer Advisory Board to ensure they capture what matters most to the people receiving these assessments.

Keywords

Aged care assessment, person-centered care, quality indicators, consumer involvement, aged care assessment team (ACAT)

Aim

To develop a set of evidence-based person-centered quality indicators (PC-QIs) for the Aged Care Assessment Team (ACAT) needs assessment component of Australia's aged care system.

Method

The development of the PC-QIs was conducted over three phases using a modified Delphi method approach:

- Phase 1: An international scoping review to identify and develop QIs.
- Phase 2: Collaboration with the eQC Board to refine the developed PC-QIs to ensure person-centeredness.
- Phase 3: A focus group consisting of expert aged-care assessors to determine feasibility of the PC-QIs, followed by individual voting sessions with 25 older persons to achieve consensus on perceived value of the final PC-QIs.

Interaction with the Board

An initial meeting was held with the eQC Board at the preliminary stages of the research during development to enable refinement of the protocol in phase three (engagement with older people living in the community).

Further meetings were held to present the 24 preliminary PC-QIs to the eQC Board to enable further refinement (phase 2). This consultation involved an initial meeting and discussion with the whole group to present the preliminary PC-QIs, followed by individual meetings with two Board members to test the questions posed to clients during phase 3b) consensus voting phase. Additionally, resources used during phase 3b were developed with the Board to ensure their readability was appropriate to the participant group's needs.

Progress updates on the research program were presented in April and October 2023 enabling further feedback.

Three members from the eQC board co-authored the final paper which has been submitted to Research Involvement and Engagement and is currently undergoing peer review.

Development and Implementation

Including the perspectives of primary stakeholders in aged-care assessment was a central part of development. Expert assessors, older Australians, and members of the eQC Board were included throughout the process. Each proposed PC-QI was presented to collaborators with three sub-questions: 1) amenability to change, 2) barriers to incorporation, and 3) changes that could be implemented within the current organizational context.

Results

Twenty-four PC-QIs were developed and refined with the Board, divided into five quality domains. No quality indicators were eliminated throughout the Delphi process by expert assessors, and consensus among older Australian participants was achieved in the first voting round.

Barriers in meeting the intent of proposed PC-QIs were identified across the domains of a) health care staff knowledge, b) clear communication, c) person-centered approach, d) respect for the client, and e) collaborative partnership with the client.

Translation into Practice or Policy

Currently, the PC-QIs are completed and ready to be applied. The next steps involve engaging with stakeholders such as State and Federal Governments to explore implementation and/or piloting testing for further validation.

Importantly, this study's findings provide a more accurate view of what is important to people who receive needs assessments by Aged Care Assessment Teams thanks to the inclusion of a public perspective throughout the research process. These PC-QIs, if incorporated, could provide meaningful information about where aged care assessment processes are lacking from the client perspective and allow informed service improvements to be implemented.

Moreover, considering the upcoming implementation of a single comprehensive assessment process in July 2024, adopting these findings into the reform process could ensure new assessment processes are grounded in the principles of person-centered care.

Impact

Incorporating consistently delivered PC-QIs developed in collaboration with consumers and experts could ensure assessment processes are more responsive to individual client needs. This can ensure care can be more precisely and efficiently tailored to the client, and information collected from PC-QIs can be used to inform more equitable policy decisions around how care is funded and delivered.

By addressing barriers identified in this study such as health care staff knowledge, clear communication, and respect for clients, aged care assessment services can become more accessible and equitable for older Australians from diverse backgrounds, including those with cultural and linguistic differences or cognitive impairments such as dementia.

Collaborators

Sandra Smith, Melinda Martin-Khan (Primary supervisor), Catherine Travers (Supervisor), Natasha Roberts (Primary supervisor final year), Jane Thompson (eQC Board), Leanne Jack (eQC Board), Elizabeth Miller (eQC Board), Jennifer Lawson (eQC Board), Karyn Lendich (eQC Board), Glenys Petrie (eQC Board), John Quinn (eQC Board), Ivy Yuen Yee Webb (eQC Board)

Publications

1. Smith S, Martin-Khan M, Travers C. (2022). What constitutes a quality community aged care service – client perspectives: An international scoping study. Health & Social Care in the Community. 30(6): e3593-e3628. DOI: 10.1111/hsc.13998
2. Smith S, Travers C, Roberts N, Martin-Khan M. (2024). Development of person-centred quality indicators for aged care assessment services in Australia: a mixed methods study. Health Expect. 27: e13958. DOI: 10.1111/hex.13958
3. Smith S, Travers C, Roberts N, Thompson J, Webb IYY, Miller E, Martin-Khan M. Person-Centred Quality Indicators for Australian Aged Care Assessment Services: A mixed methods study. Research Involvement and Engagement. **Submitted 2024.**

Presentations

1. Smith-Lewis, S. (June 2021, November 2021, April 2022, April 2024). eQC Patient and Carer Advisor Board – progress update presentations. [Online].
2. Smith-Lewis, S. (2023). Mens' Shed. Brisbane.
3. Smith-Lewis, S. (2021). Presentation to the State-wide Aged Care Assessment Program conference. Brisbane.

Section Editors:

Sandra Smith-Lewis, PhD Student, Centre for Health Services Research, UQ.

Paul Prudon, Board Support Administrator, Research Assistant, Centre for Health Services Research, UQ.

> Sandra Smith - Lewis, PhD student
>
> 'Collaborating with the board provided me the opportunity to view my research through a different lens, enabling a robust approach to support research findings that have the capacity to bring about positive change for those who are central to aged care assessment processes'

Daniel Bailey

Dementia specific early career post-doctoral researcher

eQC Project. Daniel Bailey was employed as a full-time dementia specific early career researcher (ECR) into a post-doctoral position for the eQC project.

Lay summary

Dr Daniel Bailey joined the eQC project as a recent PhD graduate in October 2022 to co-ordinate the different sections of the project. Dr Bailey had more than 10 years' experience in dementia research across academic and hospital settings.

Keywords

Dementia, early career researcher, project manager, postdoctoral, academic.

Capacity Building

Below is a summary of the different aspects of involvement that Dr. Daniel Bailey had within the eQC project which broadened his experience and led to excellent research outputs both personally and for the project.

Project Co-ordination: Dr Bailey gained valuable experience directing larger portfolios of research, directing groups of researchers and Chairing the Investigative Team.

As a Research Officer is his earlier career Dr Bailey had experience working across multiple different projects simultaneously but this was always directed by a senior researcher. As part of eQC Dr Bailey was now co-ordinating five different sections of a $1.8M grant driving the research and supervising research officers. Dr Bailey Chaired the quarterly investigator meetings which determined which CI and Ais would be involved in different sub-projects and sections.

Staff Supervision: summary

As the project co-ordinator of eQC Dr Bailey supervised four research assistants and three external researchers on different sections of the project. These supervision roles have added to Dr Bailey's leadership and supervision capabilities.

Academic Supervision: summary

As a new PhD graduate Dr Bailey had supervised junior staff but had not previously academically supervised students. As Beibei Xiong, in her role as Research Nurse, immediate supervisor across all eQC work, taking on an academic supervision role on her PhD as an Associate Supervisor to give advice and direction to her thesis was a natural progression.

In 2023 Dr Bailey was successful in securing $3,000 in student Enrichment and Employability Development (SEED) funding to employ an undergraduate student to assist the project's PhD student with her qualitative analyses. This student, Ziyinyue Isabella Zeng, was co-supervised by Ms Xiong. The opportunity to work on a research project gave Ms Zeng her first academic publication.

Interaction with the eQC Board

Dr Bailey attended the eQC Board meeting and reported on the activities of the eQC project. He also liaised between the board and the project investigators in discussion regarding any new project ideas.

He worked closely with Paul Prudon to carry out the board evaluation workshops and to write the board feasibility studies papers.

Publications

1. Bailey DX, Vasquez P, Ben-Dekhil S, Prudon P, Gray LC, Martin-Khan M. (2024). Silver linings playbook: A costing template for the implementation of a patient and public advisory board for health research. **Drafted (2024)**
2. Prudon P, Bailey DX, Xiong B, Thompson J, Jack L, Lawson J, Lendich K, Miller E, Petrie G, Quinn J, Webb IYY, Prudon P, Martin-Khan M. (2025). Experiential evaluation of the facilitators and barriers in the eQC Board experience. **Planned (2025)**
3. Prudon P, et al. Online collaboration Guide. **Drafted (2024)**
4. Xiong B, Bailey D , Prudon P, Pascoe EM, Gray LC, Graham F, Henderson A, Martin-Khan M. (2023). Identification and information management of cognitive impairment of patients in acute care hospitals: An integrative review. International Journal of Nursing Sciences. 11(1): 120–132. Available from: https://doi.org/10.1016/j.ijnss.2023.11.001
5. Xiong B, Bailey DX, Prudon P, Pascoe EM, Gray LC, Graham F, Henderson A, Quinn J, Miller E, Thompson J, Jack L, Webb IYY, Lendich K, Lawson J, Petrie G, Martin-Khan M. Protocol for the use of cognitive impairment data in hospital and for sharing this data with patients, their care partners, and other health care providers. **Planned 2025**
6. Xiong B, Stirling C, Bailey D, Martin-Khan M. (2024). The implementation and impacts of the Comprehensive Care Standard in Australian acute care hospitals: A survey study. (Survey study 1 – quantitative result). BMC Health Services Research. **Major Revisions Submitted 2024**
7. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. (2024). Identification of Implementation Enhancement Strategies for National Comprehensive Care Standards Using the CFIR-ERIC Approach: A qualitative study. (Survey study 2 – qualitative result). BMC Health Services Research. **Minor Revisions 2024**
8. Xiong B, Stirling C, Bailey D, Prudon P, Martin-Khan M. Implementation approaches of a national standard for comprehensive care in acute care hospitals: A qualitative descriptive study. (Interview study 1) **Submitted 2024.**
9. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. Barriers, enablers, and impacts of Implementing national comprehensive care standards: A qualitative descriptive study (Interview study 2) **Submitted 2024.**
10. Xiong B, Bailey D, Stirling C, Trinh E, Zeng Z, Martin-Khan M. A mixed method study on experiences of care in hospital: patient perspective. **Drafted 2024.**
11. Xiong B, Stirling C, Bailey D, Zeng Z, Trinh E, Martin-Khan M. A mixed method study on experiences of care in hospital: carer perspective. **Drafted 2024.**
12. Xiong B, Stirling C, Bailey D, … Martin-Khan M. Patient, and carer perception of comprehensive care: a qualitative study. **Planned 2025.**
13. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on factors affecting patient participation in care: a qualitative study. **Planned 2025.**
14. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on hospital feedback: a qualitative study. **Planned 2025.**
15. Bailey D, Gray LC, Hubbard R, Martin-Khan K, Lang M, Scanlon A, Graham F. The scale and distribution of occupational violence in acute care hospitals. **Planned 2024**
16. Bailey D, Zahir F, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. Medical and demographic variables which help predict occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**

17. Bailey D, Stockwell-Smith G, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. A qualitative analysis of incidents, risk factors and outcomes of occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**
18. Xiong, B., Bailey, D. X., Prudon, P., Gray, L. C., ... & Martin-Khan, M. (2023). Identification and information management of cognitive impairment of patients in acute care hospitals: An interview study. **Planned 2024**

Section Editor:

Dr Daniel Bailey, eQC Project Manager, Post-doctoral researcher, Centre for Health Services Research, UQ.

Key Terms

Abbreviation	Definition
CHSR	Centre for Health Service Research
eQC	Evaluating Quality of Care
UQ	The University of Queensland
ACAT	Aged Care assessment team
PC-QIs	Person-centered quality indicators

What the collaborators say

Professor Nicole Gillespie, Investigator

‘We really appreciated hearing the lived experiences shared by members, who were very open and honest. We appreciate their willingness to share their experiences and challenges’

Ivy Yuen Yee Webb, eQC Board Member

‘When the researchers listen and interpret my opinions so well, it gives me confidence that they are approachable. At the same time, I learn from their findings and can see the depth of their work. I think the combination of “listening from them” and the “learning from me” works’

Muhammad Haroon, PhD student

‘I believe a quality-of-life tool like this cannot be realised in isolation. You need community to support it. The support for my project was overwhelming. All the members could relate to what I was proposing and saw it as promising tool for evaluation of quality-of-life’

Elizabeth Miller, Board Member

‘As a Consumer Member of the eQC Patient and Carer Advisory Board, something that has stood out for me has been the respectfulness shown to always accommodate the various needs of the Board Members. This has included posting out hard copies of meeting Agendas, Minutes and other papers a week beforehand; enlarging the font size on printed materials where possible; and labelling the various documents so they are easily identified. This has certainly made it easier to read everything ahead of time and fully participate in meetings’

What the collaborators say

Dr Daniel Bailey, Project Manager / Post-doc

‘Living with dementia or caring for a person living with dementia is challenging when dealing with healthcare, I know that from experiences within my own family… Working with the Board Members was a truly enjoyable and educating experience for me’

Beibei Xiong, eQC PhD Student

‘Collaborating with the Board was an enlightening experience. Their diverse perspectives and expertise greatly enriched the quality of our research’

Professor Nicole Gillespie, Investigator

‘...clinician interactions with patients has flagged a potential antecedent of patient trust that we expect to emerge in the review – effective interpersonal communication during change facilitates patient trust’

Publication Summary

eQC Project

1. Bailey DX, Vasquez P, Ben-Dekhil S, Prudon P, Gray LC, Martin-Khan MG. (2024). Silver linings playbook: A costing template for the implementation of a patient and public advisory board for health research. **Drafted (2024)**
2. Prudon P, Bailey D X, Xiong B, Thompson J, Jack L, Lawson J, Lendich K, Miller E, Petrie G, Quinn J, Webb IYY, Prudon P, Martin-Khan M. (2025). Experiential evaluation of the facilitators and barriers in the eQC Board experience. **Planned (2025)**
3. Prudon P, et al. Online collaboration Guide. **Drafted (2024)**
4. *Martin-Khan M, Bail K, Graham F, Thompson J, Yates MW, Cognitive Impairment and COVID-19 Hospital Care Guidance Committee. (2020). Interim guidance for the care of adult patients with cognitive impairment requiring hospital care during the COVID-19 pandemic in Australia. Brisbane: University of Queensland
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11. *Martin-Khan, M, Welch A, Bail K, Yates MW, F. Graham, J. Thompson, and Cognitive Impairment & COVID-19 Hospital Care Guidance Committee (2023). Going to hospital during the COVID-19 pandemic: guidance for adults with dementia or other cognitive impairments, their care partners and

families. The University of Queensland. Available from: https://chsr.centre.uq.edu.au/files/4866/A4-public_facing_v5.pdf

12. Xiong B, Bailey DX, Prudon P, Pascoe EM, Gray LC, Graham F, Henderson A, Martin-Khan M. (2023). Identification and information management of cognitive impairment of patients in acute care hospitals: An integrative review. International Journal of Nursing Sciences. 11(1): 120–132. Available at: https://doi.org/10.1016/j.ijnss.2023.11.001
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16. Xiong B, Stirling C, Bailey D, Martin-Khan M. (2024). The implementation and impacts of the Comprehensive Care Standard in Australian acute care hospitals: A survey study. (Survey study 1 – quantitative result). BMC Health Services Research. **Revisions Submitted 2024**
17. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. (2024). Identification of Implementation Enhancement Strategies for National Comprehensive Care Standards Using the CFIR-ERIC Approach: A qualitative study. (Survey study 2 – qualitative result). BMC Health Services Research. **Revisions Submitted 2024**
18. Xiong B, Stirling C, Bailey D, Paul Prudon, Martin-Khan M. Implementation approaches of a national standard for comprehensive care in acute care hospitals: A qualitative descriptive study. (Interview study 1) **Submitted 2024**
19. Xiong B, Bailey D, Stirling C, Prudon P, Martin-Khan M. Barriers, enablers, and impacts of Implementing national comprehensive care standards: A qualitative descriptive study (Interview study 2) **Submitted 2024**
20. Xiong B, Bailey D, Stirling C, Trinh E, Zeng Z, Martin-Khan M. A mixed method study on experiences of care in hospital: patient perspective. BMC Nursing. **Drafted 2024**
21. Xiong B, Stirling C, Bailey D, Zeng Z, Trinh E, Martin-Khan M. A mixed method study on experiences of care in hospital: carer perspective. BMC Nursing. **Drafted 2024**
22. Xiong B, Stirling C, Bailey D, … Martin-Khan M. Patient and carer perception of comprehensive care: a qualitative study. **Planned 2025**
23. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on factors affecting patient participation in care: a qualitative study. **Planned 2025**
24. Xiong B, Bailey D, Stirling C, … Martin-Khan M. Care professional, patient, and carer perceptions on hospital feedback: a qualitative study. **Planned 2025**
25. Martin-Khan M, Gray LC, Brand C, Wright O, Pachana N, Byrne G, Chatfield M, Jones R, Morris J, Travers T, Tropea J, Xiong B, The Research Collaborative for Quality Care: Acute Care Panel and The Research Collaborative for Quality Care: Dementia Care Panel. (2024). Patient outcome quality indicators for older persons in acute care: original development data using interRAI AC-CGA. BMC Geriatrics. BMC geriatrics, 24(1), 527. Available from: https://link.springer.com/article/10.1186/s12877-024-04980-9

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27. Macdade A, Morrill J, Colville S, Gillespie N. (2024). Trust during digital transformation: A systematic review. **Planned 2024**
28. Colville S, Macdade A, Gillespie N. (2024). Preserving trust during organizational change: Insights from a systematic review in healthcare. **Planned 2024**
29. Bailey D, Gray LC, Hubbard R, Martin-Khan K, Lang M, Scanlon A, Graham F. The scale and distribution of occupational violence in acute care hospitals. **Planned 2024**
30. Bailey D, Zahir F, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. Medical and demographic variables which help predict occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**
31. Bailey D, Stockwell-Smith G, Gray LC, Hubbard R, Martin-Khan M, Lang M, Scanlon A, Graham F. A qualitative analysis of incidents, risk factors and outcomes of occupational violence involving patients with cognitive impairment in acute care hospitals. **Planned 2024**
32. Xiong, B., Bailey, D. X., Prudon, P., Gray, L. C., ... & Martin-Khan, M. (2023). Identification and information management of cognitive impairment of patients in acute care hospitals: An interview study. **Planned 2024**

**An updated version of these outputs [1,2] was released in June 2023 [7, 8] due to substantial changes that had occurred in how acute care treated and managed COVID-19 infections and how hospital visitors were managed.*

These updates were drafted by the Research Fellow employed by the project (Dr Bailey) and circulated to the initial authors for confirmation and editing.

eQC Adjacent Projects

1. Haroon M, Dissanayaka NN, Angwin AJ, Comans T. (2022). *How Effective are Pictures in Eliciting Information from People Living with Dementia? A Systematic Review.* Clinical Gerontologist. 46(4): 511–524. Available from: https://doi.org/10.1080/07317115.2022.2085643
2. Smith S, Martin-Khan M, Travers C. (2022). *What constitutes a quality community aged care service – client perspectives: An international scoping study.* Health & Social Care in the Community. 30(6): e3593-e3628. DOI: 10.1111/hsc.13998
3. Smith S, Travers C, Roberts N, Martin-Khan M. (2024). *Development of person-centred quality indicators for aged care assessment services in Australia: a mixed methods study.* Health Expect. 27: e13958. DOI: 10.1111/hex.13958
4. Smith S, Travers C, Roberts N, Thompson J, Webb IYY, Miller E, Martin-Khan M. *Person-Centred Quality Indicators for Australian Aged Care Assessment Services: A mixed methods study. Research Involvement and Engagement.* **Submitted 2024**

Appendices

Appendix 1. eQC Patient and Carer Advisory Board Terms of Reference

Version 3: 20220211

The evaluating Quality Care (eQC) project, led by Chief Investigator Dr. Melinda Martin-Khan, sits within the Quality of Care work at the Centre for Health Services Research (CHSR), The University of Queensland (UQ). The eQC Patient and Carer Advisory Board (The Board) was established in 2020 with funding from the eQC project, a National Health and Medical Research Council (NHMRC) Boosting Dementia Research Project Grant (APP1140459).

1. Role/Purpose

The role of The Board is to support engagement of the CHSR with patients and care partners, and to guide opportunities to establish links with the general community.

The purpose of The Board is to inform the embedding of partnerships between lived experience experts and researchers at every level of planning, delivery, monitoring and evaluation of research, translation and policy undertaken by the Quality of Care research group.

The research team, led by Dr. Martin-Khan, values the expert opinions of The Board members, who together will establish strong community collaboration at UQ CHSR for Dr. Martin-Khan’s team, and researchers wishing to work with The Board.

2. Scope

The Board will provide advice and feedback to Dr. Martin-Khan and her research team, and the wider research community as appropriate, in relation to current and future research, and policy work.

It will:

- Advise on opportunities to include lived experience perspectives in CHSR research projects;
- Review CHSR project outcomes and advise on relevance to patients and care partners;
- Review research protocols and research materials for readability and ease of participation (including sensitivity to personal issues) for the public;
- Advise on other (non-CHSR) projects or policy work as requested, if appropriate and available;
- Highlight relevant topics of interest that could be the focus of future CHSR research.

Any Board member may represent The Board in specific research or policy work at different stages and in different ways as part of the wider body of work connected to The Board. This may include:

- Reviewing research materials;
- Participating in focus groups and advising on specific topics where nominated;
- Being a member of a project reference or advisory group;
- Being a research partner and/or named investigator on a project;
- Playing an important ambassadorial role for public involvement in research.

3. Governance Arrangements

Dr. Melinda Martin-Khan is a Senior Research Fellow within the CHSR.

Her research priorities include quality of care and dementia. The Board has been formed as an advisory body to the Quality of Care work carried out by Dr. Martin-Khan and her team. As such, The Board is not a decision-making authority and is not authorised to make decisions on behalf of the eQC project, CHSR or UQ.

The Quality of Care work includes working with a wide range of collaborators and a large number of universities. The Board is currently funded through an NHMRC Boosting Dementia Research Project Grant held at UQ, but this could change as The Board develops over time.

Board meeting procedures:

- Meeting dates are set in advance (preferably by least one month);
- Any member of The Board can nominate agenda items;
- The Board Chair finalises the agenda;
- Matters are discussed amongst the Board members, with due attention to resources and feasibility considerations.

Recommendations from The Board will be forwarded to relevant research teams for implementation decisions by the relevant research team. Research teams will be asked to provide information about project outcomes back to The Board.

4. Membership

The Board membership includes people who have varied experiences of health service utilisation, and who live in different locations across Australia.

The members collectively bring experience that addresses a demographic of health service users with a particular focus on people with dementia, their care partners, and older adults.

The Board membership will collectively have:

- Knowledge and experience of living with dementia or, of supporting and caring for a person living with dementia, in the community and/or in formal care;
- Knowledge and experience of living with a chronic condition resulting in extensive health service use;
- Interest in being involved in dementia research and providing input from a lived experience perspective;
- Knowledge and experience of public involvement in research;
- Knowledge and experience of the delivery of health services, and of how to consider proposals for changes to health services delivery.

Board membership will include approximately 10 members at any one time, including a Chair, and in addition to Dr. Melinda Martin-Khan as Chief Investigator.

- It is preferable that the membership always includes two people with dementia, and two care partners of a person with dementia (not necessarily together);
- The Chair may delegate the role of Chair to an alternative Board member, research investigator or other person with relevant knowledge and experience;
- Observers may be invited by the Chair or Chief Investigator to attend Board meetings for specific agenda items.

Appointment Process:

Vacancies on The Board can be advertised or potential appointees invited personally to apply by the Chief Investigator. All applicants must:

- Complete an application form including the nomination of referees;
- Attend an informal interview either in-person, by video conference or by phone (of 15-30 minutes duration). The interview will be conducted by the Chair, the Chief Investigator and either another Board member or a senior researcher with relevant public involvement in research experience.
- New appointees must be approved by The Board (at a meeting or by email); a quorum of members is required, with a majority in favour for the new Board member to be approved.

5. Appointment term

All members are appointed for an initial term of one (1) year. Reappointment occurs by confirmation of involvement after the first year (by email from the Chair or Chief Investigator). The Chair role is held for a maximum of three (3) consecutive years with a Deputy Chair in the final year to be mentored for the role of Chair the following year. The position of Chair can be held more than once.

Any Board member can request a conclusion of membership from The Board at any time via email request to the Chair, copied to the Chief Investigator, with a nominated time frame in which the action is to come into effect. No minimum time for notice is required.

When more than a quorum of The Board retires at the same time, the possibility of staggering retirement dates will be discussed to ensure a smooth transition and if required, at that time there may be more than 10 Board members while incoming and outgoing Board members cross over.

6. Meeting frequency and location

Members can attend a Board meeting either in-person or by videoconference. There will be at least three Board meetings a year. Each Board meeting may be two to three hours in duration (or 1.5 hours if by video conference). There will be pre-reading for Board meetings (e.g. draft research protocols, data collection forms, video summary texts, policy statements). Reimbursement of Board meeting time will occur (for a set period).

Members may be asked to read a grant for review (usually a lay summary), taking up to two hours. There may be one grant review per member per year. This could be separate from Board meeting paperwork. Reimbursement of grant review time will occur (for a set period).

Frequency of focus groups depends on research activity. Attendance is voluntary. When location and timing permits, Board members may be able to attend one focus group per year if they wish (either in-person or by remote conferencing). Reimbursement for a focus group will occur (for a set period).

Additional opportunities may be offered to The Board which won’t be reimbursed. These are general communications which have come through the University.

7. Quorum

A quorum for each Board meeting will be half the membership plus one (rounded up), not including the Chief Investigator.

A quorum for an extra ordinary meeting will be decided in advance for that meeting and confirmed by the Chair.

8. Decision making

The Board will seek to operate on a consensus basis for decision making. Where a consensus cannot be reached on a specific issue, the different opinions will be recorded and the research team asking the question will make a final decision on how to proceed. Feedback on the outcome will be provided to The Board.

9. Conduct at meetings

Board members are requested to:

- Regularly attend meetings, actively listen, and engage in relevant and respectful discussion and debate;
- Engage in email communication regarding content either before or after the meeting to finalise meeting matters. Preference is for 100% attendance but in some cases absence is unavoidable.

10. Management of conflicts of interest and confidentiality

Members are asked to provide independent and unbiased advice. Declarations of potential conflicts of interest should be shared as they arise.

Members must not share any unpublished material supplied to The Board by the CHSR team, by people requesting assistance from The Board, or by other Board members, without written permission from the authors. Confidentiality is a priority. If authors are unknown, the information should not be shared.

Personal information that may be shared either during meeting discussions, or via email, verbally or written as a part of Board meetings is also to be treated with confidentiality.

11. Secretariat

The team of the connected funded project will provide secretariat support for The Board meetings including:

- Coordinating meeting times and logistics;
- Developing meeting papers;
- Documenting and circulating the outcomes and decisions of meetings.

12. Resources and support

The eQC project will provide The Board member(s) with an honorarium payment (based on Health Consumers Queensland rates) for attendance at Board meetings This is intended to cover incidental expenses such as internet and printing costs as well as payment for time and expertise. Other relevant activities will be similarly remunerated.

The eQC project does not cover work on other external projects. When members are involved on such projects, the relevant project will fund their involvement.

13. Contact details

For any questions regarding The Board or an EOI please email chsr@uq.edu.au.

14. Review of Terms of Reference

These Terms of Reference will be reviewed annually or as required.

Terms of Reference Record

Date	Action
August 2020	Terms of Reference drafted
February 11, 2022	Terms of Reference Updated

Appendix 2: Section 1 – A4 eQC Online Collaboration guide

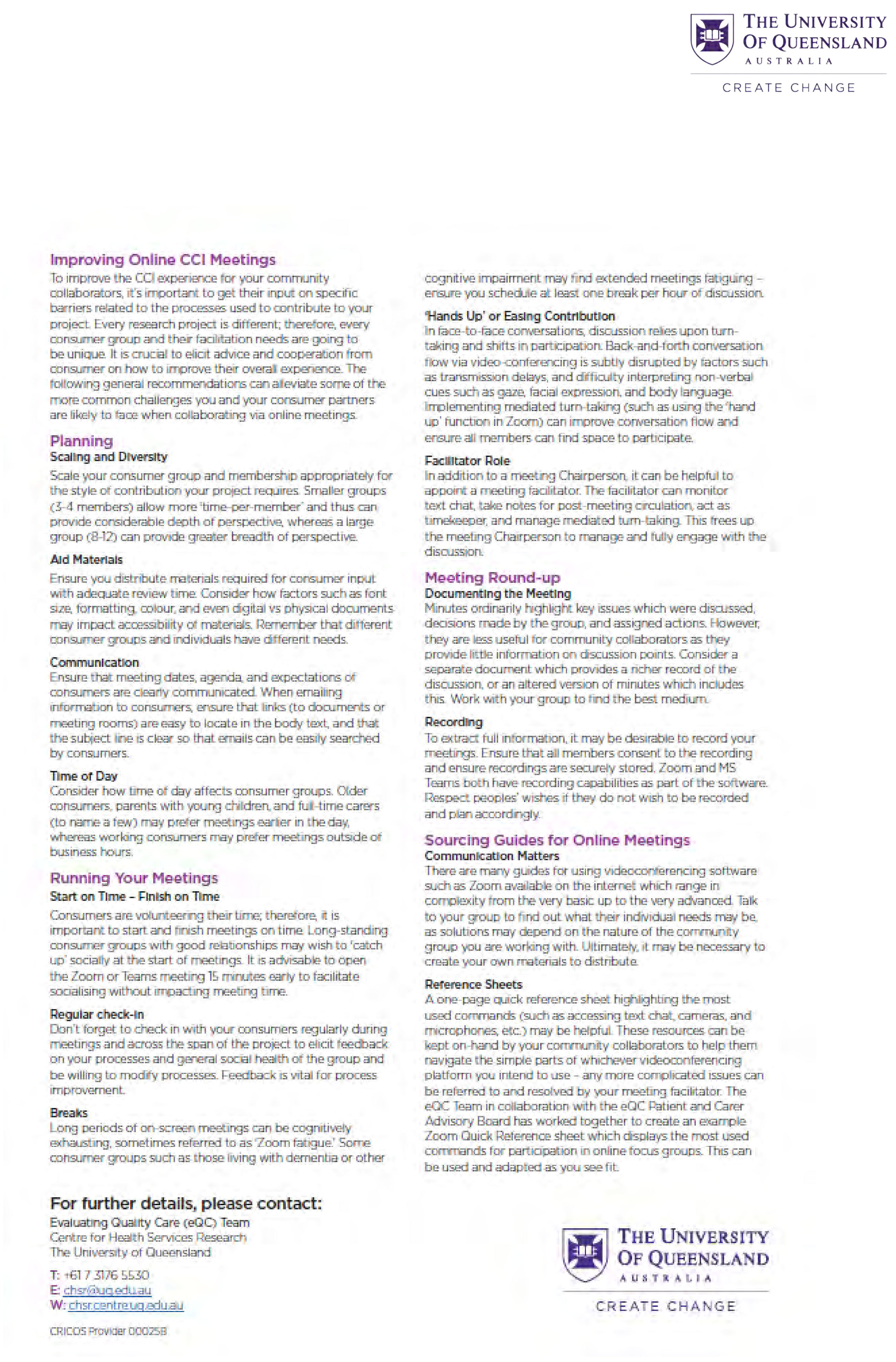
THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

Online Collaboration with Consumers in Research

Consumer and Community Involvement Online
Consumer and Community Involvement (CCI) in research is a collaborative effort between researchers, consumers, and community members who may benefit directly or indirectly from the outcomes of the research efforts. CCI benefits researchers by enhancing study design, improving the validity of findings, increasing community awareness, and highlighting ethical concerns which may not be considered by researchers alone. Consumers benefit from greater alignment of research efforts with community issues, improved translation of evidence into practice, and increased agency in promoting community well-being.

Online meetings using videoconferencing tools such as MS Teams or Zoom are increasingly common tools researchers can use to facilitate wider consumer involvement. Videoconferencing allows participation to be more accessible and convenient than face-to-face meetings by eliminating travel requirements and venue costs. Consumer experts can be gathered from wider geographic locations and can participate from homes or workplaces.

Online meetings introduce complications of their own, however. Barriers include more obvious issues such as consumer computer literacy, disruptions in internet connections, or managing time zone differences. Complications such as 'Zoom fatigue' and difficulties in building group rapport over online platforms can also limit the ability of consumers to contribute as fully as they may in face-to-face meetings.



Improving Online CCI Meetings

To improve the CCI experience for your community collaborators, it's important to get their input on specific barriers related to the processes used to contribute to your project. Every research project is different; therefore, every consumer group and their facilitation needs are going to be unique. It is crucial to elicit advice and cooperation from consumer on how to improve their overall experience. The following general recommendations can alleviate some of the more common challenges you and your consumer partners are likely to face when collaborating via online meetings.

Planning

Scaling and Diversity

Scale your consumer group and membership appropriately for the style of contribution your project requires. Smaller groups (3-4 members) allow more 'time-per-member' and thus can provide considerable depth of perspective, whereas a large group (8-12) can provide greater breadth of perspective.

Aid Materials

Ensure you distribute materials required for consumer input with adequate review time. Consider how factors such as font size, formatting, colour, and even digital vs physical documents may impact accessibility of materials. Remember that different consumer groups and individuals have different needs.

Communication

Ensure that meeting dates, agenda, and expectations of consumers are clearly communicated. When emailing information to consumers, ensure that links (to documents or meeting rooms) are easy to locate in the body text, and that the subject line is clear so that emails can be easily searched by consumers.

Time of Day

Consider how time of day affects consumer groups. Older consumers, parents with young children, and full-time carers (to name a few) may prefer meetings earlier in the day, whereas working consumers may prefer meetings outside of business hours.

Running Your Meetings

Start on Time – Finish on Time

Consumers are volunteering their time; therefore, it is important to start and finish meetings on time. Long-standing consumer groups with good relationships may wish to 'catch up' socially at the start of meetings. It is advisable to open the Zoom or Teams meeting 15 minutes early to facilitate socialising without impacting meeting time.

Regular check-in

Don't forget to check in with your consumers regularly during meetings and across the span of the project to elicit feedback on your processes and general social health of the group and be willing to modify processes. Feedback is vital for process improvement.

Breaks

Long periods of on-screen meetings can be cognitively exhausting, sometimes referred to as 'Zoom fatigue.' Some consumer groups such as those living with dementia or other cognitive impairment may find extended meetings fatiguing – ensure you schedule at least one break per hour of discussion.

'Hands Up' or Easing Contribution

In face-to-face conversations, discussion relies upon turn-taking and shifts in participation. Back-and-forth conversation flow via video-conferencing is subtly disrupted by factors such as transmission delays, and difficulty interpreting non-verbal cues such as gaze, facial expression, and body language. Implementing mediated turn-taking (such as using the 'hand up' function in Zoom) can improve conversation flow and ensure all members can find space to participate.

Facilitator Role

In addition to a meeting Chairperson, it can be helpful to appoint a meeting facilitator. The facilitator can monitor text chat, take notes for post-meeting circulation, act as timekeeper, and manage mediated turn-taking. This frees up the meeting Chairperson to manage and fully engage with the discussion.

Meeting Round-up

Documenting the Meeting

Minutes ordinarily highlight key issues which were discussed, decisions made by the group, and assigned actions. However, they are less useful for community collaborators as they provide little information on discussion points. Consider a separate document which provides a richer record of the discussion, or an altered version of minutes which includes this. Work with your group to find the best medium.

Recording

To extract full information, it may be desirable to record your meetings. Ensure that all members consent to the recording and ensure recordings are securely stored. Zoom and MS Teams both have recording capabilities as part of the software. Respect peoples' wishes if they do not wish to be recorded and plan accordingly.

Sourcing Guides for Online Meetings

Communication Matters

There are many guides for using videoconferencing software such as Zoom available on the internet which range in complexity from the very basic up to the very advanced. Talk to your group to find out what their individual needs may be, as solutions may depend on the nature of the community group you are working with. Ultimately, it may be necessary to create your own materials to distribute.

Reference Sheets

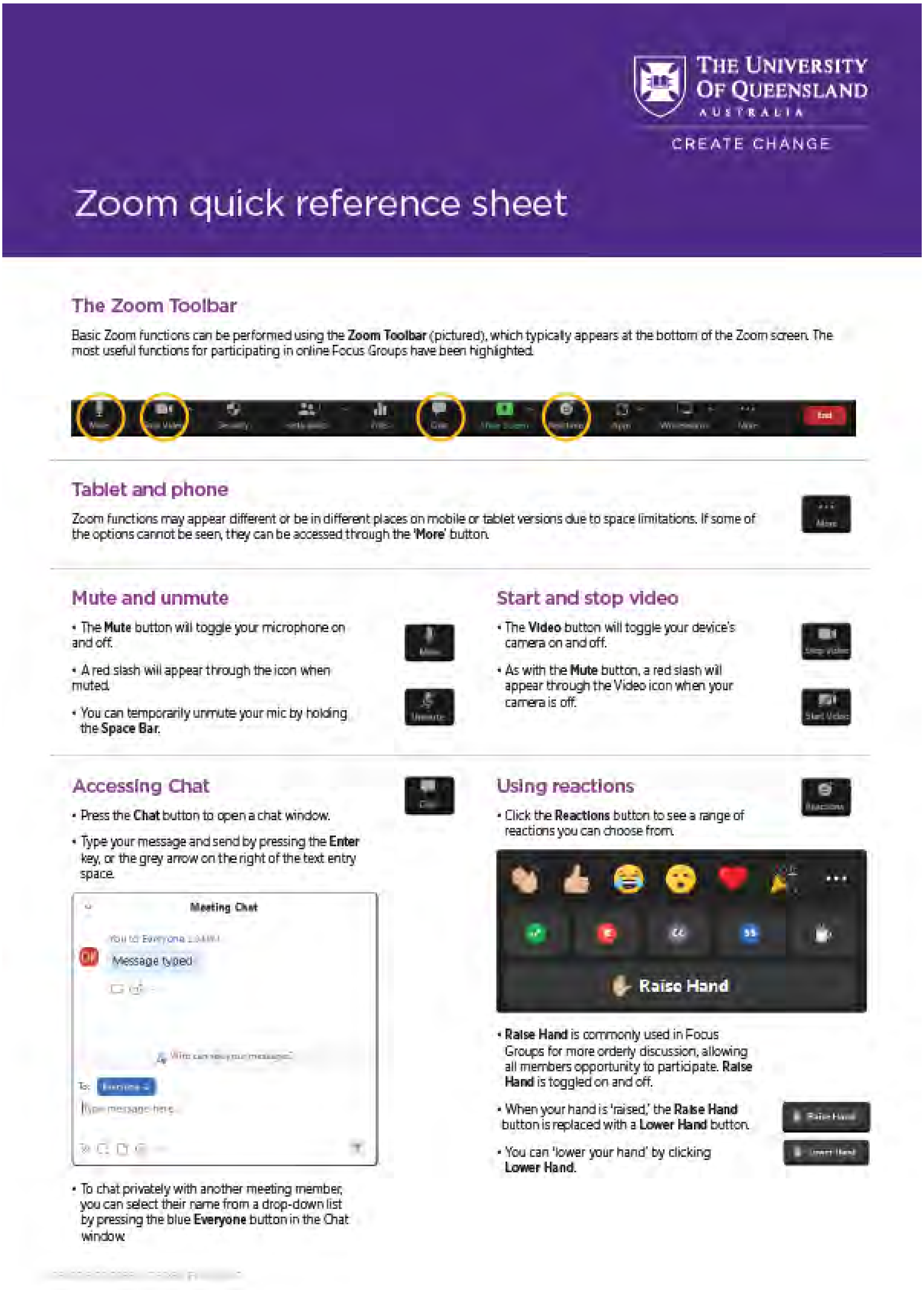
A one-page quick reference sheet highlighting the most used commands (such as accessing text chat, cameras, and microphones, etc.) may be helpful. These resources can be kept on-hand by your community collaborators to help them navigate the simple parts of whichever videoconferencing platform you intend to use – any more complicated issues can be referred to and resolved by your meeting facilitator. The eQC Team in collaboration with the eQC Patient and Carer Advisory Board has worked together to create an example Zoom Quick Reference sheet which displays the most used commands for participation in online focus groups. This can be used and adapted as you see fit.

For further details, please contact:

Evaluating Quality Care (eQC) Team
Centre for Health Services Research
The University of Queensland

T: +61 7 3176 5530
E: chsr@uq.edu.au
W: chsr.centre.uq.edu.au

Appendix 3: Section 1 A4 eQC Zoom Quick Reference Sheet



Zoom quick reference sheet

The Zoom Toolbar

Basic Zoom functions can be performed using the **Zoom Toolbar** (pictured), which typically appears at the bottom of the Zoom screen. The most useful functions for participating in online Focus Groups have been highlighted.

Tablet and phone

Zoom functions may appear different or be in different places on mobile or tablet versions due to space limitations. If some of the options cannot be seen, they can be accessed through the **'More'** button.

Mute and unmute

- The **Mute** button will toggle your microphone on and off.
- A red slash will appear through the icon when muted.
- You can temporarily unmute your mic by holding the **Space Bar**.

Start and stop video

- The **Video** button will toggle your device's camera on and off.
- As with the **Mute** button, a red slash will appear through the Video icon when your camera is off.

Accessing Chat

- Press the **Chat** button to open a chat window.
- Type your message and send by pressing the **Enter** key, or the grey arrow on the right of the text entry space.

Meeting Chat

Message typed

To: Everyone

Type message here...

- To chat privately with another meeting member, you can select their name from a drop-down list by pressing the blue **Everyone** button in the Chat window.

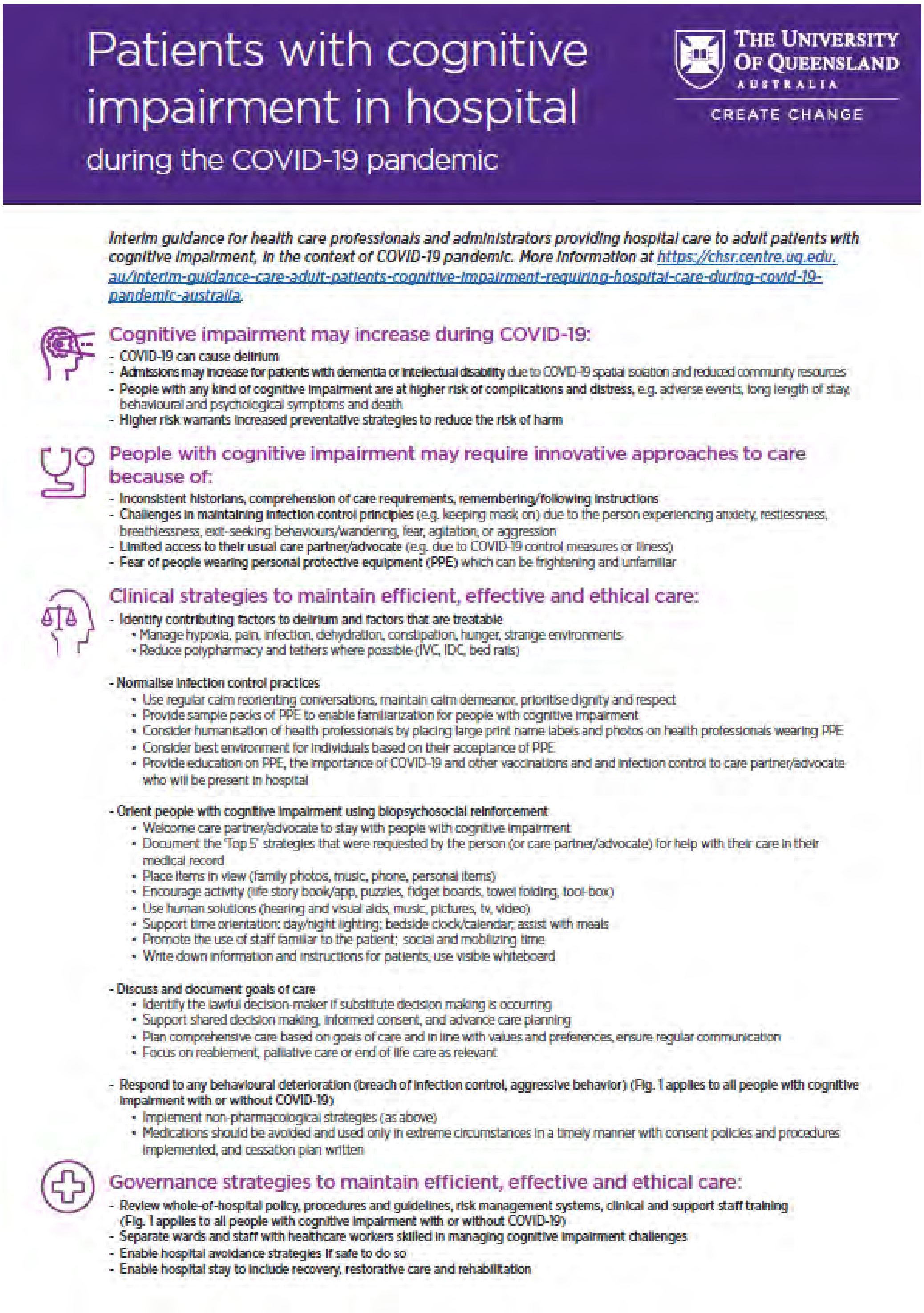
Using reactions

- Click the **Reactions** button to see a range of reactions you can choose from.

- **Raise Hand** is commonly used in Focus Groups for more orderly discussion, allowing all members opportunity to participate. **Raise Hand** is toggled on and off.
- When your hand is 'raised,' the **Raise Hand** button is replaced with a **Lower Hand** button.
- You can 'lower your hand' by clicking **Lower Hand**.

Appendix 4: COVID guidance

https://chsr.centre.uq.edu.au/interim-guidance-care-adult-patients-cognitive-impairment-requiring-hospital-care-during-covid-19-pandemic-australia



Patients with cognitive impairment in hospital

during the COVID-19 pandemic

Interim guidance for health care professionals and administrators providing hospital care to adult patients with cognitive impairment, in the context of COVID-19 pandemic. More information at https://chsr.centre.uq.edu.au/interim-guidance-care-adult-patients-cognitive-impairment-requiring-hospital-care-during-covid-19-pandemic-australia.

Cognitive impairment may increase during COVID-19:

- **COVID-19 can cause delirium**
- **Admissions may increase for patients with dementia or intellectual disability** due to COVID-19 spatial isolation and reduced community resources
- **People with any kind of cognitive impairment are at higher risk of complications and distress,** e.g. adverse events, long length of stay, behavioural and psychological symptoms and death
- **Higher risk warrants increased preventative strategies to reduce the risk of harm**

People with cognitive impairment may require innovative approaches to care because of:

- **Inconsistent historians, comprehension of care requirements, remembering/following instructions**
- **Challenges in maintaining infection control principles** (e.g. keeping mask on) due to the person experiencing anxiety, restlessness, breathlessness, exit-seeking behaviours/wandering, fear, agitation, or aggression
- **Limited access to their usual care partner/advocate** (e.g. due to COVID-19 control measures or illness)
- **Fear of people wearing personal protective equipment (PPE)** which can be frightening and unfamiliar

Clinical strategies to maintain efficient, effective and ethical care:

- **Identify contributing factors to delirium and factors that are treatable**
  - Manage hypoxia, pain, infection, dehydration, constipation, hunger, strange environments
  - Reduce polypharmacy and tethers where possible (IVC, IDC, bed rails)

- **Normalise infection control practices**
  - Use regular calm reorienting conversations, maintain calm demeanor, prioritise dignity and respect
  - Provide sample packs of PPE to enable familiarization for people with cognitive impairment
  - Consider humanisation of health professionals by placing large print name labels and photos on health professionals wearing PPE
  - Consider best environment for individuals based on their acceptance of PPE
  - Provide education on PPE, the importance of COVID-19 and other vaccinations and and infection control to care partner/advocate who will be present in hospital

- **Orient people with cognitive impairment using biopsychosocial reinforcement**
  - Welcome care partner/advocate to stay with people with cognitive impairment
  - Document the 'Top 5' strategies that were requested by the person (or care partner/advocate) for help with their care in their medical record
  - Place items in view (family photos, music, phone, personal items)
  - Encourage activity (life story book/app, puzzles, fidget boards, towel folding, tool-box)
  - Use human solutions (hearing and visual aids, music, pictures, tv, video)
  - Support time orientation: day/night lighting; bedside clock/calendar; assist with meals
  - Promote the use of staff familiar to the patient; social and mobilizing time
  - Write down information and instructions for patients, use visible whiteboard

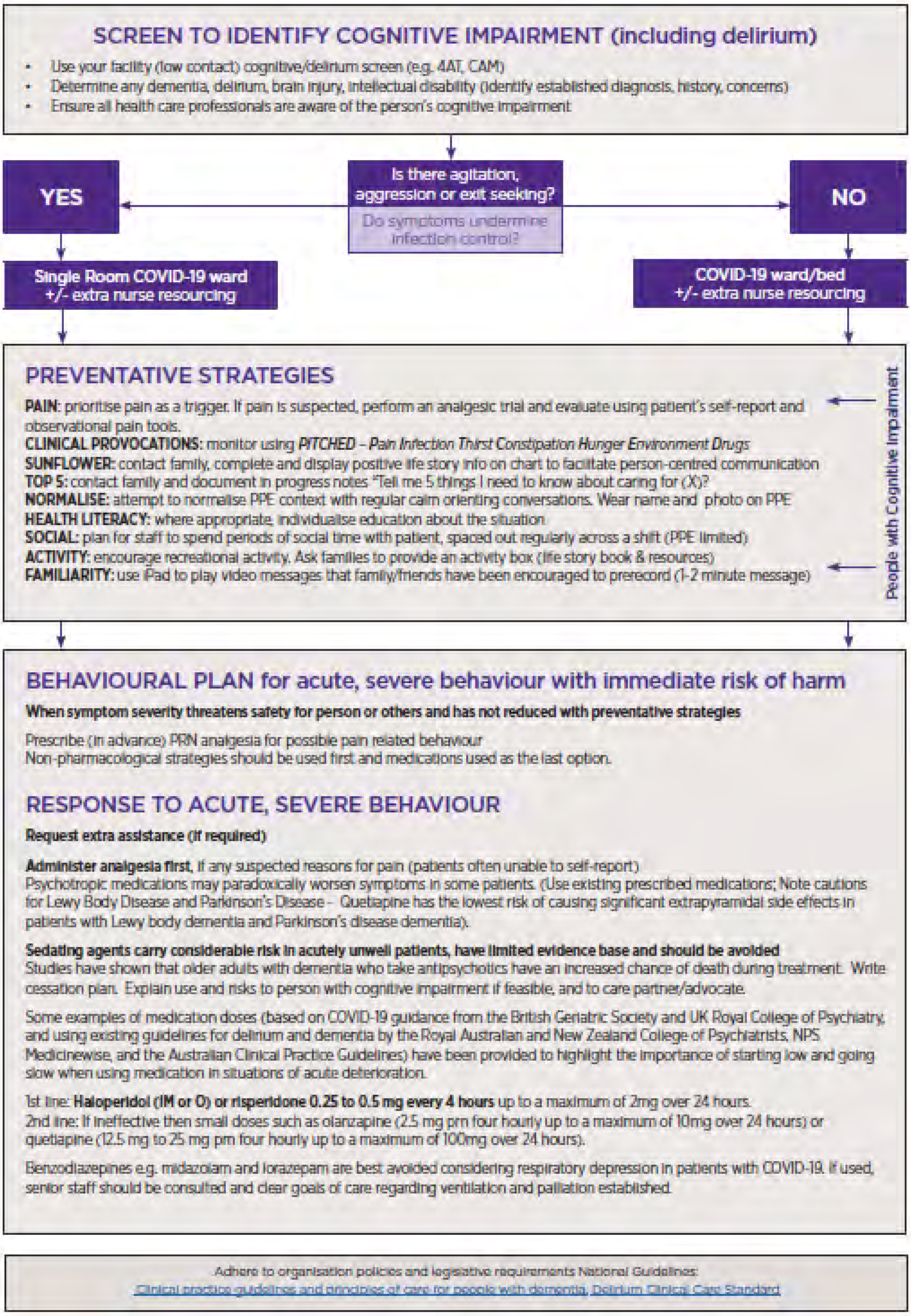
- **Discuss and document goals of care**
  - Identify the lawful decision-maker if substitute decision making is occurring
  - Support shared decision making, informed consent, and advance care planning
  - Plan comprehensive care based on goals of care and in line with values and preferences, ensure regular communication
  - Focus on reablement, palliative care or end of life care as relevant

- **Respond to any behavioural deterioration (breach of infection control, aggressive behavior) (Fig. 1 applies to all people with cognitive impairment with or without COVID-19)**
  - Implement non-pharmacological strategies (as above)
  - Medications should be avoided and used only in extreme circumstances in a timely manner with consent policies and procedures implemented, and cessation plan written

Governance strategies to maintain efficient, effective and ethical care:

- **Review whole-of-hospital policy, procedures and guidelines, risk management systems, clinical and support staff training (Fig. 1 applies to all people with cognitive impairment with or without COVID-19)**
- **Separate wards and staff with healthcare workers skilled in managing cognitive impairment challenges**
- **Enable hospital avoidance strategies if safe to do so**
- **Enable hospital stay to include recovery, restorative care and rehabilitation**

Figure 1: Flowchart of COVID-19 clinical strategies for people with cognitive impairment



SCREEN TO IDENTIFY COGNITIVE IMPAIRMENT (including delirium)

- Use your facility (low contact) cognitive/delirium screen (e.g. 4AT, CAM)
- Determine any dementia, delirium, brain injury, intellectual disability (identify established diagnosis, history, concerns)
- Ensure all health care professionals are aware of the person's cognitive impairment

Is there agitation, aggression or exit seeking?

Do symptoms undermine infection control?

YES

Single Room COVID-19 ward
+/- extra nurse resourcing

NO

COVID-19 ward/bed
+/- extra nurse resourcing

PREVENTATIVE STRATEGIES

PAIN: prioritise pain as a trigger. If pain is suspected, perform an analgesic trial and evaluate using patient's self-report and observational pain tools.
CLINICAL PROVOCATIONS: monitor using *PITCHED – Pain Infection Thirst Constipation Hunger Environment Drugs*
SUNFLOWER: contact family, complete and display positive life story info on chart to facilitate person-centred communication
TOP 5: contact family and document in progress notes "Tell me 5 things I need to know about caring for (X)?
NORMALISE: attempt to normalise PPE context with regular calm orienting conversations. Wear name and photo on PPE
HEALTH LITERACY: where appropriate, individualise education about the situation
SOCIAL: plan for staff to spend periods of social time with patient, spaced out regularly across a shift (PPE limited)
ACTIVITY: encourage recreational activity. Ask families to provide an activity box (life story book & resources)
FAMILIARITY: use iPad to play video messages that family/friends have been encouraged to prerecord (1-2 minute message)

People with Cognitive Impairment

BEHAVIOURAL PLAN for acute, severe behaviour with immediate risk of harm

When symptom severity threatens safety for person or others and has not reduced with preventative strategies

Prescribe (in advance) PRN analgesia for possible pain related behaviour
Non-pharmacological strategies should be used first and medications used as the last option.

RESPONSE TO ACUTE, SEVERE BEHAVIOUR

Request extra assistance (if required)

Administer analgesia first, if any suspected reasons for pain (patients often unable to self-report)
Psychotropic medications may paradoxically worsen symptoms in some patients. (Use existing prescribed medications; Note cautions for Lewy Body Disease and Parkinson's Disease – Quetiapine has the lowest risk of causing significant extrapyramidal side effects in patients with Lewy body dementia and Parkinson's disease dementia).

Sedating agents carry considerable risk in acutely unwell patients, have limited evidence base and should be avoided
Studies have shown that older adults with dementia who take antipsychotics have an increased chance of death during treatment. Write cessation plan. Explain use and risks to person with cognitive impairment if feasible, and to care partner/advocate.

Some examples of medication doses (based on COVID-19 guidance from the British Geriatric Society and UK Royal College of Psychiatry, and using existing guidelines for delirium and dementia by the Royal Australian and New Zealand College of Psychiatrists, NPS Medicinewise, and the Australian Clinical Practice Guidelines) have been provided to highlight the importance of starting low and going slow when using medication in situations of acute deterioration.

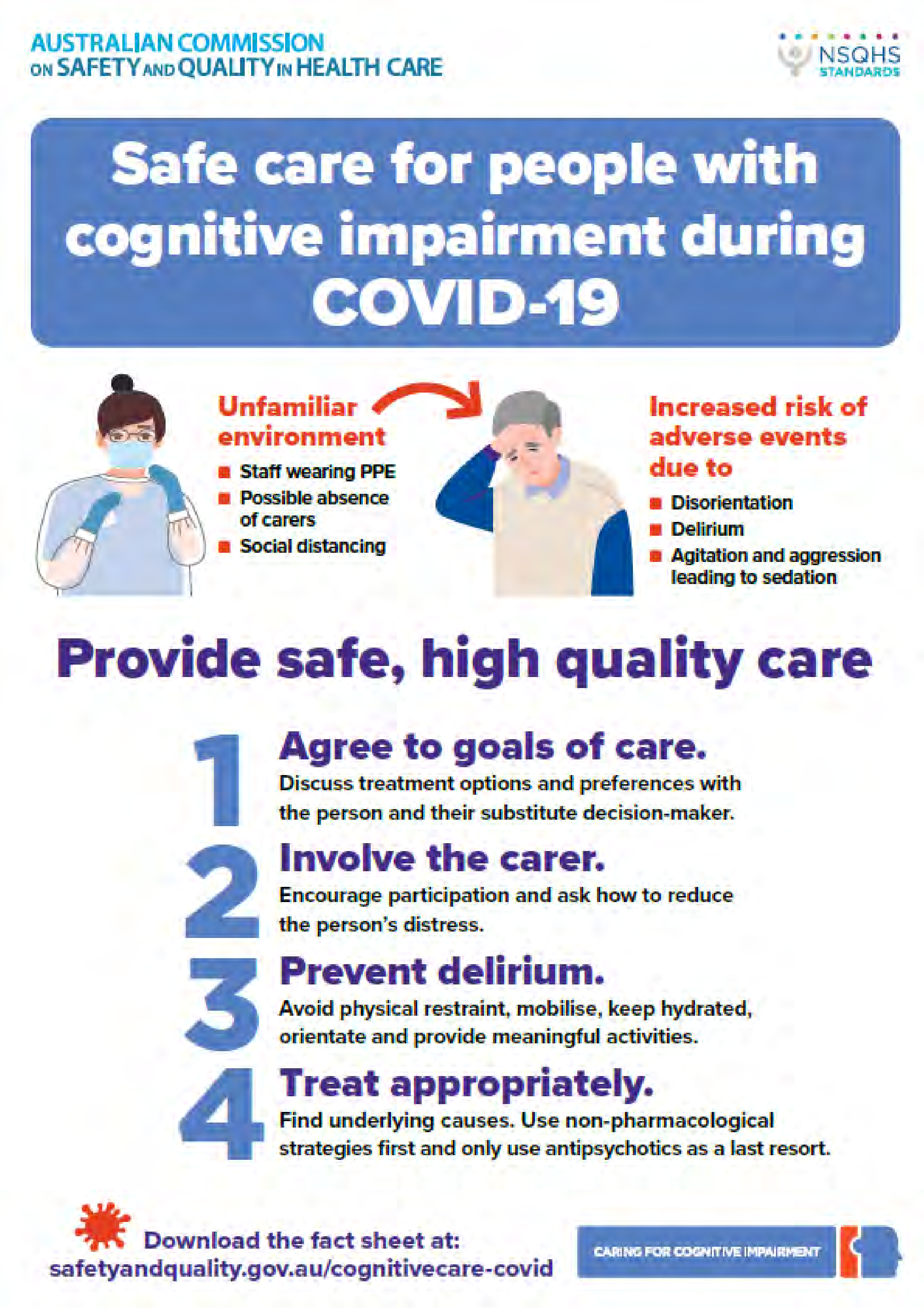
1st line: **Haloperidol (IM or O) or risperidone 0.25 to 0.5 mg every 4 hours** up to a maximum of 2mg over 24 hours.
2nd line: If ineffective then small doses such as olanzapine (2.5 mg prn four hourly up to a maximum of 10mg over 24 hours) or quetiapine (12.5 mg to 25 mg prn four hourly up to a maximum of 100mg over 24 hours).

Benzodiazepines e.g. midazolam and lorazepam are best avoided considering respiratory depression in patients with COVID-19. If used, senior staff should be consulted and clear goals of care regarding ventilation and palliation established.

Adhere to organisation policies and legislative requirements National Guidelines:
Clinical practice guidelines and principles of care for people with dementia, Delirium Clinical Care Standard

Appendix 5: ACSQHC COVID Poster

https://www.safetyandquality.gov.au/publications-and-resources/resource-library/safe-care-people-cognitive-impairment-during-covid-19-poster



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

NSQHS STANDARDS

Safe care for people with cognitive impairment during COVID-19

Unfamiliar environment

- Staff wearing PPE
- Possible absence of carers
- Social distancing

Increased risk of adverse events due to

- Disorientation
- Delirium
- Agitation and aggression leading to sedation

Provide safe, high quality care

1 **Agree to goals of care.**
Discuss treatment options and preferences with the person and their substitute decision-maker.

2 **Involve the carer.**
Encourage participation and ask how to reduce the person's distress.

3 **Prevent delirium.**
Avoid physical restraint, mobilise, keep hydrated, orientate and provide meaningful activities.

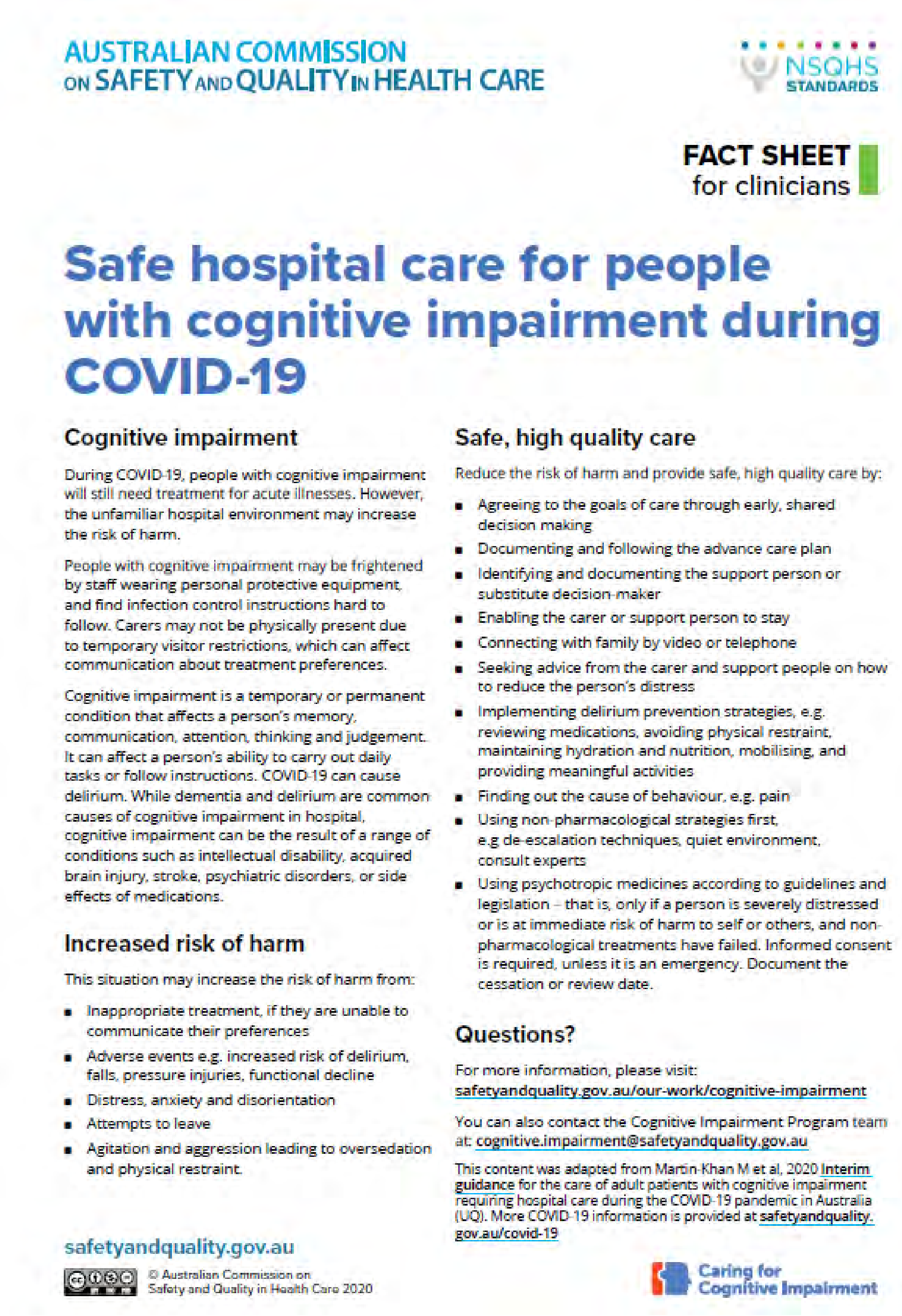
4 **Treat appropriately.**
Find underlying causes. Use non-pharmacological strategies first and only use antipsychotics as a last resort.

Download the fact sheet at:
safetyandquality.gov.au/cognitivecare-covid

CARING FOR COGNITIVE IMPAIRMENT

Appendix 6: ACSQHC COVID Fact Sheet

https://www.safetyandquality.gov.au/publications-and-resources/resource-library/safe-hospital-care-people-cognitive-impairment-during-covid-19-fact-sheet-clinicians



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

NSQHS STANDARDS

FACT SHEET
for clinicians

Safe hospital care for people with cognitive impairment during COVID-19

Cognitive impairment

During COVID-19, people with cognitive impairment will still need treatment for acute illnesses. However, the unfamiliar hospital environment may increase the risk of harm.

People with cognitive impairment may be frightened by staff wearing personal protective equipment, and find infection control instructions hard to follow. Carers may not be physically present due to temporary visitor restrictions, which can affect communication about treatment preferences.

Cognitive impairment is a temporary or permanent condition that affects a person's memory, communication, attention, thinking and judgement. It can affect a person's ability to carry out daily tasks or follow instructions. COVID-19 can cause delirium. While dementia and delirium are common causes of cognitive impairment in hospital, cognitive impairment can be the result of a range of conditions such as intellectual disability, acquired brain injury, stroke, psychiatric disorders, or side effects of medications.

Increased risk of harm

This situation may increase the risk of harm from:

- Inappropriate treatment, if they are unable to communicate their preferences
- Adverse events e.g. increased risk of delirium, falls, pressure injuries, functional decline
- Distress, anxiety and disorientation
- Attempts to leave
- Agitation and aggression leading to oversedation and physical restraint.

Safe, high quality care

Reduce the risk of harm and provide safe, high quality care by:

- Agreeing to the goals of care through early, shared decision making
- Documenting and following the advance care plan
- Identifying and documenting the support person or substitute decision-maker
- Enabling the carer or support person to stay
- Connecting with family by video or telephone
- Seeking advice from the carer and support people on how to reduce the person's distress
- Implementing delirium prevention strategies, e.g. reviewing medications, avoiding physical restraint, maintaining hydration and nutrition, mobilising, and providing meaningful activities
- Finding out the cause of behaviour, e.g. pain
- Using non-pharmacological strategies first, e.g de-escalation techniques, quiet environment, consult experts
- Using psychotropic medicines according to guidelines and legislation – that is, only if a person is severely distressed or is at immediate risk of harm to self or others, and non-pharmacological treatments have failed. Informed consent is required, unless it is an emergency. Document the cessation or review date.

Questions?

For more information, please visit:
safetyandquality.gov.au/our-work/cognitive-impairment

You can also contact the Cognitive Impairment Program team at: cognitive.impairment@safetyandquality.gov.au

This content was adapted from Martin-Khan M et al, 2020 Interim guidance for the care of adult patients with cognitive impairment requiring hospital care during the COVID-19 pandemic in Australia (UQ). More COVID-19 information is provided at safetyandquality.gov.au/covid-19

safetyandquality.gov.au

Caring for Cognitive Impairment

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