

Dementia Discharge Pathway Report

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Dementia Discharge Pathway Report

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Summary

The aim of this three-phased project was to improve the hospital discharge processes for older people living with dementia. Using an integrated knowledge translation process, which involved collaboration and consultation with end users at each phase, a communication package, called *Partnering for Discharge*, was created. The package has four elements to support family inclusion in discharge planning:

1. A person-centred guide, titled 'My Hospital Guide' which provided information for family and friends of people living with dementia; and
2. A procedure for a family meeting within 72 hours of admission for people who were diagnosed living with dementia (included a meeting procedure document with recommended agenda and meeting summary document);
3. A family-held record of care and discharge information, called 'My Journal'; and
4. 'This is Me' - a document that outlines the background, preferences, and interests of the person living with dementia for people unfamiliar with the person's preferences, such as hospital staff.

The i-PARiHS implementation model was adopted, where onsite staff facilitated the implementation of the intervention in one ward in each of three hospitals. Evaluation focused on the effectiveness of the communication package and the feasibility of the implementation activities.

The patient inclusion criteria for the study were restricted to people diagnosed with dementia, which was problematic as there were many patients who were excluded because their cognitive status was under review for possible dementia and not yet confirmed. This restriction led to lower recruitment than expected, and the subsequent small sample size making it difficult to draw conclusions about intervention effectiveness. However, feasibility was established. Family members valued the consultation prior to discharge and the availability of care information that was developed during the hospitalisation, and there was widespread staff agreement that the communication package was beneficial for families.

The program aligns with the second edition National Safety and Quality Health Service Standards. Partnering for Discharge provides an opportunity for patients and their family carers to partner in their care (*Standard 2*), supports the psycho-emotional care known to reduce harm in people with dementia (*Standard 5*), and provides an evidence-based process for high quality communication at a time critical to patient safety (*Standard 6*), in this case the time of discharge. As such, implementing Partnering for Discharge supports health services to demonstrate achievement in these three standards.

Key recommendations emerging from this study include:

- Statewide policy development towards routine cognitive screening in older patients, would make projects such as this easier to do;
- Consider an early family meeting (within 72 hours) for older people with cognitive impairment as part of the Queensland Health discharge policy framework;
- Make the Partnering for Discharge communication package available to consumers, clinicians, and researchers through the Clinical Excellence Division website;
- Partner with major research funders to test the effectiveness of the Partnering for Discharge communication package in acute care settings; and
- Continue investment into integrated knowledge translation for future innovations in health services.

General

Background

Dementia is internationally recognised as a chronic disease with significant societal impact. Worldwide there are over 46 million people living with dementia with the number expected to increase to 131.5 million by 2050 (ADI, 2015). In Australia, dementia is the second leading cause of death (AIHW, 2015) and the fourth leading cause of overall burden of disease (ADI, 2015). Hospitals can be overwhelming for people living with dementia, challenging long held routines and familiarity (Dewing & Dijk, 2016) and contribute to acceleration in cognitive deterioration and death (Fong et al., 2012). While early discharge is not always practicable, a smooth transition to home requires planning that is inclusive of family members who carry responsibility for care and support in the home environment (Jamieson et al., 2014).

Adults aged 65 years and older, who constitute only 15% of the population, account for 41% of all hospital separations and 48% of bed days in 2015-16 (AIHW, 2017). Identification and reporting of dementia is often poor in hospitals. People living with dementia have a longer length of stay in hospital than other patients, with greater costs to the health system (AIHW 2013). The longer older patients, and particularly older patients living with dementia, remain in hospital, the more likely they will develop debilitating complications such as delirium, pressure injuries, urinary tract infections and pneumonia (Bail et al., 2013). Early discharge planning is an important element in reducing hospital length of stay, and thereby reducing hospital-acquired complications.

An integrative literature review of discharge planning for older adults revealed that the family was acknowledged as the first defense against problems but there was little work undertaken to build partnerships between patients, families and health care providers (Popejoy, Moylan & Galambos, 2009). The consideration of consumer (inclusive of the patient and carer dyad) involvement in care decisions for the patient with cognitive impairment is critical (ACSQHC, 2014). However, inclusion of carers in discharge planning can be challenged by assumptions made in everyday clinical practice. For example, a custodial or paternalistic approach to care (Moyle et al., 2010) or the exclusion of carers in the interests of being person-centred (Jamieson et al., 2014) can reduce opportunities for meaningful engagement. Further, when discharge is targeted at the individual, older people living with dementia are less likely to (a) benefit from discharge education, (b) adhere to instructions or (c) report changes in symptoms (Teodorczuk, 2016). A systematic integrated literature review conducted for this study found common barriers to collaborative discharge processes were associated with distributed responsibility for discharge, risk averse approaches to discharge that led to extended length of stay, limited carer confidence, and limited validation of assumptions about family competency to manage at home (Stockwell-Smith et al., 2017).

The transfer of research findings into practice can be an unpredictable, slow or haphazard process and attention to implementation is recommended (Eccles et al., 2009). As such, further research that focuses on the refinement and testing of implementation strategies is required (Powell et al., 2014). The aim of this study was to improve hospital discharge processes for older people living with dementia through a three-phase implementation project. Phase 1 focused on organisational readiness, phase 2 on developing a discharge intervention, and phase 3 on implementation and evaluation.

Method

Design. As an implementation study, the design was multifaceted. Discharge was conceptualised as a transition from hospital to home, informed by Meleis' middle-range theory of transitions (Meleis et al., 2000). The transition incorporates preparation, the actual discharge moment when short-term outcomes of the preparatory process can be measured and post-discharge when patients' perceptions of their ability to cope could be determined (Meleis et al., 2000; Weiss et al., 2010). An integrated knowledge translation approach was adopted. In this approach, an ongoing relationship between researchers and decision-makers such as clinicians, managers, and consumers exist to engage in a mutually beneficial research project (Gagliardi et al., 2016). The availability of clinician experts through the two Queensland Health Statewide Clinical Networks for Older Person Health and Dementia was considered an important resource in achieving project outcomes and long-term sustainability of the *Partnering for Discharge* communication intervention.

This study focused on the multiple and layered barriers and enablers that can influence the discharge process. The i-PARIHS model is a determinant framework that recognises the process of implementation as a multidimensional phenomenon (Nilsen, 2015) and this framework was selected for the study. In the i-PARIHS framework, active facilitation by individuals who negotiate the fit of the intervention with context through negotiation with recipients (Harvey & Kitson, 2016) is required. Facilitation relies on interpersonal relationships and is a deliberate process of interactive problem solving and support with a shared focus on the need for improvement (Kitson & Harvey, 2016).

Finally, in terms of the overall outcomes of the study, an effectiveness-implementation hybrid design, which blends the design components of intervention effectiveness and implementation, has been adopted for the study. The advantage of the hybrid design was more rapid translational gains, more effective implementation strategies, and more useful information for decision makers (Curran, Bauer, Mittman, Pyne, & Stetler, 2012).

The **intervention effectiveness** of the carer-inclusive discharge process addressed the utility of the discharge process in terms of improving readiness for discharge. Other measures used to evaluate effectiveness included: ongoing coping and use of community-based support and services at home; length of hospital stay; and incidence of hospital-acquired complications.

The **implementation feasibility** of the carer-inclusive discharge process addresses the usefulness and success of the selected implementation framework, i-PARIHS (Harvey & Kitson, 2016). In the i-PARIHS framework, successful implementation (SI) was a product of facilitation (Facn) and the intervention (I), recipients (R), and context (C):

$$SI = Facn (I + R + C)$$

Successful implementation is assumed when the project goals were met in the local contexts (Harvey & Kitson, 2016).

The study was conducted over three phases (Figure 1). Each phase of the study advanced the project towards the implementation and evaluation of a family-inclusive discharge process specifically for older people living with dementia. In phase 1, organisational readiness was assessed, and a project implementation plan was developed. In phase 2, a family inclusive discharge intervention, titled *Partnering for Discharge*, was developed. In phase 3, the *Partnering for Discharge* intervention was implemented, and intervention effectiveness and implementation feasibility were evaluated.



Figure 1. Study phases

The research questions guiding the evaluation (phase 3) included:

1. How did the family-focused discharge intervention, Partnering for Discharge, influence patient and family readiness for hospital discharge?
2. How did the family-focused discharge intervention, Partnering for Discharge, influence patient and family experience of discharge?
3. What was the association between conducting a family focused discharge intervention, Partnering for Discharge, on length of stay and hospital-acquired delirium, pneumonia, pressure injuries and urinary tract infections?
4. Was the implementation of the family-focused discharge intervention, Partnering for Discharge, successful?
5. Was the intervention, Partnering for Discharge, feasible in subacute and acute hospital settings?

Project Engagement and Communication. The project was designed to be collaborative, engaging clinicians and consumers from across Queensland. The cooperation and collaboration of individuals from multiple stakeholder groups was necessary to develop an intervention that met the unique practice contexts in Queensland. The project team produced an engagement and communication plan for the Dementia Discharge Processes Project, following the principles of:

- Transparency
- Clarity
- Mutual respect and goodwill
- Inclusiveness
- Honesty and integrity
- Accountability
- Timely and effective communication
- Representation of key stakeholder groups

To meet these commitments, there were several communication and engagement mechanisms. These are outlined in Table 1. While most engagement activities offered traditional methods such as newsletter and meetings, the workshops for document analysis and implementation were conducted using a world café methodology. This is an established format for hosting large group dialogue that can produce shared understandings derived from different perspectives (The World Café, 2019).

Table 1 Communication and Engagement Mechanisms

Mechanism	Clinicians	Consumers	Network members*	Researchers	Hospital managers
Research team meetings	✓	✓	✓	✓	
Design group meetings	✓	✓	✓	✓	
Project Management team meetings				✓	
Site facilitator meetings	✓		✓		
e-bulletin	✓	✓	✓		✓
Project progress reports			✓		
Briefs to participating hospitals					✓
Discharge process survey			✓		
Document analysis workshop			✓	✓	
Implementation workshop	✓	✓	✓	✓	
Local site meetings	✓	✓		✓	

*Included members of the Older Persons Health and Dementia Clinical Networks

Setting and participants. Three health services were purposefully selected for the study on the grounds of: (1) different hospital ward types and (2) research team member prepared to act as facilitator. The three sites are outlined in Table 2. Note that two months into implementation at the Gold Coast Health, the ward was changed due to changes in the facilitator's work role.

Participants for the study varied across each of the three phases and in some cases extended beyond the clinical sites to include participants from other parts of Queensland Health, Griffith University, and consumers. Study participants are outlined in Table 3.

Data collection. A range of data were collected throughout the study and an overview is provided in Table 4. Multiple data sources were used to increase our understanding of the discharge process from multiple perspectives.

Table 2. Description of Study Sites

Site	Site facilitator	Ward	Classification	Beds
Cairns	Keith Layton	Older Persons' Ward, D Block, 3 rd floor	Subacute	32
Townsville	Riri Santoso	Acute Care of the Elderly, Medical 5	Acute	30
Gold Coast	Elizabeth Soleil-Moudiky-Joh	B5South – general medical	Acute	24
		B1 – acute care of the elderly (ACE) ward	Acute	24

Table 3 Study Participants

P1: Readiness	P2: Design	P3: Implement
Clinical staff working in participating wards	Queensland Health clinical staff, researchers, consumers who met to develop the draft communication package	Clinical staff in the participating wards
Families of patients admitted to participating wards	Members of the Statewide Clinical Networks for Older Persons Health and Dementia	Families of patients admitted to participating wards
	Queensland Health clinical staff, researchers, consumers who met to finalise the communication package	Local hospital staff stakeholders in each hospital.
		All patients aged 65 years* and older admitted to the participating wards over the last two years
		<i>*This age was lowered to 55 years for Aboriginal or Torres Strait Islander peoples</i>

Table 4 Data Collection

Participants	P1: Readiness	P2: Design	P3: Implement
	Queensland Health documents related to the discharge process, included policies, procedures and forms		
Clinical staff working in participating wards	Individual interview		Compliance with intervention Individual interview NoMAD Survey
Families of patients admitted to participating wards	Individual interview		RHDS for older people Individual interview
Members of the Statewide Clinical Networks for Older Persons Health and Dementia		Survey responses to draft intervention	
Queensland Health clinical staff, researchers, consumers	Document analysis workshop (summary)	(Design group) Meeting minutes Workshop summary	(Monitoring group) Meeting minutes
Local hospital staff stakeholders in each hospital.			(Site implementation group) Meeting minutes
All patients aged 55 years and older admitted to the participating wards over the last two years			Administrative data for study period and previous 6 months (included age, sex, DRG, LOS)

NoMAD = Normalisation Measure Development instrument; RHDS = Readiness for Hospital Discharge Scale; DRG = diagnostic related group; LOS = length of stay.

Phase 1. Readiness. There were four data sources. Firstly, Queensland Health policy and practice documents related to discharge were sourced by a sub-group of the research team, with expertise in discharge within Queensland Health. Secondly, the summary of a document analysis workshop held with stakeholders, including research team members, clinicians, and consumers, was also included as data.

The final two data sources in phase 1 were interviews conducted with staff in each of the three study wards and with carers of people living with dementia who had been admitted to and discharged from the participating wards. Both types of interview focused on individual experience of discharge (for a person living with dementia).

Phase 2. Design. The process of defining the final communication package was iterative, with data collected in three ways.

Firstly, a design group consisting of key stakeholders in the discharge process such as members of the research team, clinical staff and consumers was established, and meeting minutes were collected as a record of areas of contention and negotiation.

The design group met eight times over four months. The Terms of Reference for the design group included:

1. Review and provide advice based on the results of the integrative literature review, document analysis and phase 1 findings;
2. Provide advice on complex intervention bundle design, including the intervention and implementation; and
3. Plan the pilot implementation study (expected to begin in September 2017)

The design group recommended the first draft of the discharge process, which was prepared for review via an online survey.

The second data source was an online survey. Members of the Statewide Clinical Networks for Older Person Health and Dementia were invited to review the draft intervention and provide structured feedback using the online survey. The link to the electronic survey and a copy of the draft intervention document (16 pages) were circulated to all members.

The third source of data in phase 2 was the records of a stakeholder workshop, held with the design group members, invited clinicians from other Queensland Health hospitals, consumers from the Statewide Dementia Network, and researchers who met to finalise the communication package. The summary of the workshop was used as textual data. At this workshop, the details of Partnering for Discharge communication package were finalised.

Phase 3. Implementation. There were eight data sources recording three different stages of the intervention.

In the first stage:

- Compliance with the intervention, including screening for suitability, was monitored.

In the second stage, to determine intervention effectiveness, there were three data sources:

- Readiness for discharge was measured using the Readiness for Hospital Discharge Scale for Older People (short version) (Mabire et al., 2015). The surveys were distributed to older people living with dementia and carer dyads for completion in the pre-intervention phase and to intervention participants in the intervention phase.
- Carer interviews focused on their experience of using the Partnering for Discharge package and their experience of coming home, including support received at home.
- Administrative data for the six-month study period and the same six months in the previous year were collected through the hospital's Data Analytics Unit.

Thirdly, to determine implementation feasibility, there were four data sources:

- The design group continued to meet to monitor and advise on the roll out of the project. The meeting summaries were used as data.
- Local stakeholders, one group at each site, including managers from outside the ward, met regularly to discuss how to implement, and then monitor if implemented, the Partnering for

Discharge communication package. The meeting minutes from their meetings were used as data to determine how barriers were addressed and facilitators leveraged to implement the intervention.

- Clinical staff again participated through interview. The interviews focused on staff experience of working with the Partnering for Discharge package and sought their views on carer engagement.
- Clinical staff were also invited to complete a hard copy survey about the implementation (NoMAD Survey, May et al., 2015). The Normalization MeASURE Development (NoMAD) tool, consists of 23 items: three general questions and 20 that reflect four constructs of coherence (4 items), cognitive participation (4 items), collective action (7 items) and reflexive monitoring (5 items) (Finch et al., 2015).

Data analysis. In **phase 1**, to determine organisational readiness, the hospital documents were submitted to discourse analysis (Perakyla & Ruusuvuori, 2018), where the ways in which texts of different kinds reproduce gaps in the discharge process were studied. The summary of the document analysis workshop was conceptualised by key themes.

Interview data were professionally transcribed, and a member of the research team validated each transcription with the audio (digital) recording. The interview data for the staff and carers were then submitted to content and thematic analysis. Each data set was analysed separately by two team members. The findings from each data set were then triangulated with data from the literature review. Data triangulation provides a more systematic approach for qualitative research (Flick, 2018).

In **phase 2**, the design and feedback data on the draft communication package and process were analysed individually by data set and then triangulated to produce an overarching implementation plan. Meeting minutes were inductively analysed to identify common themes. The survey results were descriptively analysed and open-ended responses were submitted to content analysis. The summary of the final workshop provided an overview of the arguments and negotiations required to settle on a final draft version.

In **phase 3**, descriptive analysis of screening and compliance was conducted. To determine the **intervention effectiveness**, the three data sets were analysed. Firstly, readiness for hospital discharge surveys were submitted to descriptive statistical analysis. Secondly, interviews with carers were submitted to content analysis. Elements related to satisfaction (or not) with the discharge experience were included as effectiveness. The third data set, the hospital administration data was submitted to comparative statistical analysis.

In **phase 3**, to determine **implementation feasibility**, four data sets were analysed. Firstly, NoMAD surveys were submitted to descriptive statistical analysis. Secondly, interviews with staff were submitted to content analysis. Elements related to the ease (or not) of the discharge experience was included as feasibility. The final two data sets, the summaries for the monthly statewide Queensland Health staff and researchers (design group) meeting, which was focused on monitoring the implementation, and meeting summaries for three site implementation committees were submitted to content analysis.

Rigour and ethical considerations. Consistent with National Statement on Ethical Conduct in Human Research 2007 (updated in May 2013), we believe that people with a cognitive impairment, such as dementia, should be able to participate in research. Researchers worked closely with people living with dementia, clinicians and families to determine whether participation in the research would increase their susceptibility to any discomfort or distress. While the opportunity for people living with dementia to participate in the interviews was available, people living with dementia deferred to their carer for participation. People living with dementia participated in the design and implementation of this research.

Qualitative researchers were engaged with the research process and participants and as such, needed to recognise their personal bias. Qualitative data analysis was led by experienced and doctorally qualified researchers, Grealish, Marshall, Shaw, Stockwell-Smith, and Teodoczuk and supported by clinician researchers Layton, Santoso, Soleil-Moudiky-Joh. An experienced researcher and clinician reviewed data sets together to increase awareness of possible bias and use clinician understanding to interpret findings. Two researchers conducted the qualitative analyses (content and thematic analysis) independently.

The individual analyses were compared and negotiated to produce a final data set. Differences in findings were discussed with the researchers to achieve a consensus. The findings from the analysis of staff interviews were shared with staff groups in each of the participating wards, confirming that the findings were consistent with their experiences.

The research study received ethical approval from the Gold Coast Human Research Ethics Committee (EC00160) under the code, QGC 2016/218. Site specific approvals for each site was also secured. Approval to access confidential information was provided under the delegation of the Director-General, in accordance with Section 284 of the *Public Health Act 2005* (RD007038).

Outcomes

The specific findings from the research will be disseminated through peer review publications. This section provides an overview of the clinical outcomes of relevance to clinicians and policy makers in Queensland.

Organisational readiness (Phase 1). A total of 131 documents were contributed from seven (from a possible 14) Queensland Hospitals and Health Services (HHS). The process of discharge was consistent across documents: admission to ward for treatment to preparation for discharge. Responsibility for the discharge process appeared to have been shared across doctors, nurses, allied health and administrative staff, with no clear leadership ascribed beyond medical determination of the estimated date of discharge and confirmation of discharge within 24 – 48 hours of date. There appeared to be scope for discussion of the discharge plan with patients and families, with a formal meeting structure and record at two hospital sites. There were no alerts for discharge considerations for people with cognitive impairment within the discharge documents used in the non-mental health areas of the hospital. The absence of follow-up documentation indicates that there may be no follow-up from the hospital to determine whether the person was managing at home or had contacted community-based providers, including the general practitioner.

The primary consideration of consumer (patient/carer dyad) involvement in care decisions found in the national guidelines (ACSQHC, 2014) was not evident in the documents. While people living with dementia are not considered a vulnerable group within the documentation, their need for continuous social and clinical support could be considered similar to people living with mental illness. Therefore, contemporary mental illness models of care and transition across settings may be helpful.

In a workshop held on 21 September 2016, participants contributed their ideas and perspectives on discharge for older people with cognitive impairment. Data from the document analysis, including a poster mapping the patient journey derived from the analysis was used. The poster identified three distinct transition periods: admission/stay, pre-discharge and post-discharge. Participants identified

implementation issues related to identification of the lawful decision-maker, the need for tools to support staff-family engagement, staff skill to conduct a family meeting, and the importance of advising families of the likelihood that the symptoms of dementia may be exacerbated while in hospital and that hospital-acquired delirium may develop. Participants strongly valued the family meeting and advised that it should remain, with resources to facilitate the meeting identified at each site. Workshop feedback from participants revealed that they valued: the collaboration across the state and disciplines, sharing experiences and knowledge, listening to consumer experiences, and the reminder of the importance of partnership with families.

Interviews with clinical staff at the three sites were conducted. Similar to the evidence-based discharge processes recommended in phase one of this project, participants consistently agreed that discharge should begin on admission and that discharge is a multidisciplinary activity. Staff noted that family meetings are usually ad hoc and conducted well into admission and discharge is a process that is negotiated between patients, families and health service stakeholders, from hospital and community, over time and as situation changes.

Eleven carers of people living with dementia were recruited from two of the three sites. The interviews were conducted with the carers after the person living with dementia returned home, following hospital admission. The majority of the carers were adult children of the person living with dementia they supported, three were spousal carers. Carers often expressed surprise that the person living with dementia had deteriorated in hospital. They valued meeting and discussing care with health professionals but many reported feelings of being left out of decisions, such as changes to medications. While carers valued assistance with the transfer home i.e. ambulance, the lack of services when they returned home was distressing for several carers.

In summary, the current discharge documentation does not provide for the specific needs of people living with dementia, particularly the issues arising related to altered cognition. Notably, the consideration of consumer as a patient/carer dyad as recommended in the national guidelines was not evident in the documents reviewed. The need for tools to support the discharge process was raised in the document analysis workshop with stakeholders. Discharge practice was consistent with the documents, whereby clinicians were meeting with families on an ad hoc basis but when held, these meetings were structured and often held several times as the patient's situation changed. Carers confirmed the value of engaging with the clinicians about the person living with dementia, but they continued to report being excluded from many care decisions.

Discharge intervention – Partnering for Discharge (Phase 2). The Partnering for Discharge communication package was developed using three processes. Firstly, a design group was established, with stakeholder representatives from across the state. Secondly, members of the two Queensland Health Clinical Networks for Dementia and Older Person's Health were invited to provide feedback on a draft discharge process using an on-line survey. And thirdly, the design group members met with other consumer and clinician stakeholders and researchers to finalise the package.

The design group identified potential barriers to implementation such as devaluation of the project, structural inhibitors, limited approaches to dementia care, and bringing about change. Enablers included discussion of committee cohesion through shared objectives, and the positive feelings associated with finalising the intervention. During these discussions, an implementation plan was developed collaboratively with the three site facilitators (Layton, Santoso, Soleil-Moudiky-Joh). The implementation plan was shared with key managers at each site for advice and this advice was incorporated into the implementation plan. There were continuous changes over the four-month period of discussion,

consistent with an iterative design process.

To secure feedback on the first version of the intervention, a survey link was distributed through the clinical network membership lists. Around 8% of 493 members responded. Feedback suggested that there were too many proposed steps in the intervention. Various steps, such as holding a family meeting and having an occupational therapist conduct a home visit, were deemed to be less important and could be excluded. Explanatory comments indicated that these opinions were driven by staff concerns over the lack of resources available to them to carry out those steps. The open-ended comments indicated that respondents were concerned about the resources required to hold a family meeting, provide a home assessment, and follow up with a phone call after discharge. The findings from the survey were presented to the design group members and a draft intervention was developed for the June workshop.

Nineteen people attended a one-day workshop held on 21 June 2017. During the workshop, participants reviewed several documents:

- Initial (within 72 hours) family meeting protocol
- My hospital patient-mediated decision aid (brochure)
- Patient-held decision tracker
- Example family meeting document in current use (Cairns)
- This is Me (Alzheimer's Society UK & Royal College of Nursing, 2017)
- Focus on the Person (Dementia Centre for Research Collaboration, 2016)

Outcomes of the meeting included agreement to (1) a family meeting within 72 hours of admission, with supporting documents, (2) a decision aid (information brochure) for families about the discharge process, and (3) a patient held diary/tracker to support communication between staff and family members. It was agreed to include the 'This is Me' document as an artefact for supporting partnership between staff and families in the care of the person living with dementia.

The final intervention was a communication bundle titled, "Partnering for Discharge: a communication bundle for people living with dementia and their families", known hereafter as Partnering for Discharge. The intervention aimed to promote family and, when possible, patient engagement in decision-making through formal structures.

The intervention consisted of four elements to support family inclusion and partnership:

1. A person-centred guide, titled 'My Hospital Guide' which provided information for people living with dementia and their family and friends; and
2. A procedure for a family meeting within 72 hours of admission for people who were diagnosed living with dementia (included a meeting procedure document with recommended agenda and meeting summary document);
3. A patient/family-held record of care and discharge information, called My Journal; and
4. 'This is Me' - a document that outlines the background, preferences, and interests of the person living with dementia for people unfamiliar with the person's preferences, such as hospital staff.

Evaluation (Phase 3). The *Partnering for Discharge* intervention was implemented at three sites from 9 October 2017. The three site facilitators underwent an intensive one-day training program, with fortnightly peer support meetings, with an implementation science expert. There were initial delays due to local circumstances at Townsville and Gold Coast, with Gold Coast starting on 23 October and Townsville on 20 November. Enrolment of study participants was slow at Cairns and Gold Coast, which was attributed to the lack of a clear diagnosis of dementia (one of the inclusion criteria). At the Gold Coast, data collection was complicated by a position change for the site investigator and an

alternative ward was approved for the study. However, study participation remained low due to the lack of a clear diagnosis of dementia. Due to low recruitment at Cairns and Gold Coast, data from these sites has been reported carefully or withheld from the report to avoid identification of participants.

Screening. A total of 1103 patients were screened for inclusion across the three study sites, Cairns (260), Gold Coast (589 across two wards) and Townsville (254). Very few patients met the inclusion criteria at each site. The lowest number of people meeting the inclusion criteria were at Cairns (n=15). Gold Coast (n=116), and Townsville's (n=56) inclusion rates were much higher, largely related to higher numbers of patients who had a diagnosis of dementia and were admitted from home. This difference may represent variation of the type of study ward with both being an acute care of the elderly ward and/or variation in local demographic when compared to Cairns.

Not all patients who met the inclusion criteria participated in the study, some carers provided consent but the person living with dementia did not receive the package for undocumented reasons (Cairns n=3, GC=1). Reasons for exclusion of eligible patients are outlined in Table 5.

Table 5 Screening - Exclusion of Eligible Patients

Reason for Exclusion	Cairns (n)	Townsville (n)	Gold Coast (n)
Unable to obtain consent from family members	7	8	5
Short admission period e.g. less than five days	3	6	62
Discharge to a Residential Aged Care Facility (RACF)	2	18	30
Palliation and/or death	0	2	2

Intervention compliance. This section provides detail on compliance. Data completion, including consent to participate, demographics, and data collection is found in *Appendix 1*.

Admission package utilisation compliance. Overall, there was good package utilisation and compliance during the admission period. 'My Journal' (n=31, 91%) and 'My Hospital Guide' (n=29, 85%) were present in the patient's room for most of the time during the patients' admission to the study wards (Appendix 2). 'This is Me' was present in patients' medical charts (n=25, 73%) for most participants, and most patients or carers had completed more than 50 per cent of the 'This is Me' form (n=22, 64%). The number of entries in My Journal were generally low. Only a quarter of participants had more than one entry in (n=6, 25%) 'My Journal' or had completed the discharge checklist (n=7, 29%) on the last page of 'My Journal' during the pre-discharge period. Pre-discharge My Journal entries ranged from 0-10, with an average of two entries per participant. See Appendix 3.

Family meeting compliance. Data were collected to measure compliance with holding a family meeting involving the carer and/or patient and selected health professionals within 72 hours of the patient's admission to the ward. Thirty-two family meetings took place during phase 3 of the project. Family meetings were held in less than 72 hours for just over 40 per cent of participants. A variety of family members and health professionals attended the family meetings. A family member was present at all of the family meetings, while patients participated less than half the time (n=13, 46.6%). A number of different health disciplines were present at the meetings, the most frequent attendees were medical

officers (n=21, 75%) and physiotherapists (n=12, 43%). Social workers attended approximately a third of meetings and nurses attended only two throughout the project. Other staff involved in the family meetings included a discharge planner and community providers. Family meetings occurred with additional doctors (n=5 meetings) and additional family members (n=7 meetings) present. The average time from admission to family meeting was 98.5 hours (range 8 to 504 hours) (Table 6).

Table 6 Time from Ward Admission to Family Meeting in Hours

Site	Number	Range	Mean	Standard deviation
Gold Coast	8	90-504	215.3	156.1
Cairns	1	113	113	n/a
Townsville	20	8-138	51.0	41.5
Total	29	8-504	98.48	113.0

Family meeting documentation compliance. Overall family meeting documentation compliance was good, although compliance was slightly lower for documents accessible to patients and families that were located in the patients' room. The family meeting planning outline had the lowest compliance levels with entries made by less than half of the participants (n=9, 31%) attending family meetings in Townsville, and none in Cairns or Gold Coast.

Following family meetings, compliance was good in completing a family meeting summary (n=20, 69%) and action plan (n=18, 62%) and adding these documents to the patient's chart, indicating high health care professional compliance to these aspects of the intervention. There were similar rates of compliance for having the family meeting summary (n=18, 62%) and action plan (n=17, 59%) present in the patient's room.

More than half the health care professionals (n=19, 65%) had signed the action plan, but fewer than half of family members (n=14, 48%), who participated in a family meeting had signed the family meeting action plan. Refer to Appendix 5.

Compliance summary. Compliance with the use of the discharge package and the family meeting was monitored throughout the study. The results indicated good uptake of the majority of elements of the package, however uptake of the 'My Journal' component was low. Conducting a family meeting within 72 hours (3 days) of admission proved difficult to achieve (with Cairns and Gold Coast low recruitment affected interpretation). Only Townsville was able to achieve this timeframe (70%).

Intervention effectiveness. Drawing conclusions regarding the effectiveness of the Partnering for Discharge intervention was limited by the small sample size. However, the qualitative findings indicated carer satisfaction and that the staff valued the process.

The pre-intervention Readiness for Hospital Discharge Survey (RHDS) distribution was affected by delayed ethical and site-specific approvals processes, with only 11 dyads completing the scale.

Ten carers across two sites were recruited and interviewed. In general, carers valued consultation with the treating team, including learning more about what to do at home, before discharge.

Hospital administration data was collected from the Townsville site only as it was the only site with a reasonable number of participants. The comparison period was 19 November to 11 May in 2016-7 and

2017-18. Data were requested for all patients aged 55 years and older who had a primary or additional diagnosis of dementia. The mean and median length of stay was shorter in the intervention period. The frequency of complications (pneumonia, urinary tract infection, delirium, and pressure injury) during the intervention was slightly higher, but the difference was not found to be statistically, or clinically, significant.

In summary, the challenges of recruitment and the short (six month) pilot period limited the evaluation of intervention effectiveness. Despite qualitative data not being exhaustive, there appeared to be benefits to carer confidence and preparedness for discharge. Future research should consider a comprehensive roll out of the Partnering for Discharge intervention in one ward over a minimum of one year. Analysis of outcome data versus a clinically similar 'control' ward conducting treatment and care as usual would allow more rigorous interpretation of the effectiveness of this intervention. This type of study may require external funding from a nationally competitive grant process.

Implementation feasibility. Implementation feasibility was determined through survey of staff, interviews with staff, and review of site implementation committee meeting summaries.

The NoMAD surveys were distributed to staff at Townsville and Gold Coast, with responses from nurses, medical officers, allied health professionals and ancillary staff. Responses were low (response rate of 62% TSV and 25% GC) but provide an indication of overall adoption of the intervention into practice. In general, staff at both Townsville and Gold Coast found that the intervention still felt relatively new and could become a normal part of their work. As expected, when the intervention made sense (coherence) to the people responsible for implementing it, there was greater success of implementation. At both sites, staff understanding of the purpose of the intervention was mixed, with score averages indicating lower agreement with these items. Staff at Townsville had mixed engagement, with only some staff strongly engaged. At the Gold Coast, there was low levels of engagement reported. Again, responses from both sites indicated ambivalence about the support required to implement the change and the perceptions about limited feedback relating to the effectiveness of the intervention.

Twelve interviews were conducted with nine staff from Townsville and three staff from Gold Coast. The interviews suggest that there was support for the '*This is me*' document and while staff valued the 'My Journal' document for formalising communication, the staff were ambivalent about writing in it as it was owned by the patient. This may be attributed to concerns about the legality of writing in a patient owned record. In relation to the implementation, there was little evidence of interdisciplinary team work and many staff cited workload as the reason for their lack of engagement in the intervention. Rather than see the process of discharge as an opportunity to engage with the patient and family, many staff, particularly nurses, saw the process as a logistic exercise and therefore felt the family meeting was too difficult to organise so early. Promisingly, staff participants who were early adopters valued the change in their relationship with families, and family response to the intervention with greater involvement and learning, noting that families '*had something tangible to walk away with*'.

A site implementation monitoring group provided ongoing feedback regarding implementation at each site. These groups were established before the intervention was implemented to assist with implementation planning, as well as monitoring. While membership varied for each site, the committees carried 14 to 16 members. Key roles on each committee included one Indigenous Health Worker, one consumer representative, at least one representative from the medical and nursing disciplines, and at least one allied health discipline. Meeting attendance was monitored, with most meetings unable to meet a quorum (half membership + 1).

Meeting discussions were the major enabler of the implementation of the project on each site. These discussions helped team building and brought members up to speed on the history of the project, project

phases, steps to be taken in the project phases, timelines, etc. The barriers to implementation related to the research process, individual site challenges, and meeting processes. For example, the Cairns site struggled with patient participant eligibility issues. To address their perceptions of the rigid recruitment criteria, the Townsville site committee undertook a quality improvement project focused on the intervention, as well as participated in the study. While the addition of the quality improvement project provided a local solution to the challenge of insufficient recruitment, it also raised our awareness of the tensions between the integrity of the overall study and the need for further tailoring of the intervention for the local site.

As noted earlier, recruitment of patient participants into the study was limited and therefore the intervention was not widely applied, therefore no staff at Cairns were interviewed. Townsville was stable throughout the intervention and had good engagement from the medical and allied health staff. Although the Gold Coast site was changed, the new ward underwent a reconfiguration half-way through data collection with half of the medical beds replaced by orthogeriatric beds. This required significant staff changes that were disruptive for the study and limited staff recruitment.

The Townsville site fully implemented the project and this implementation appears to be enhanced by the quality improvement project conducted alongside the study. Another enabler for implementation included the presence of the project facilitator (researcher) at each site. A clinical champion who is physically present in the ward and who has expertise in dementia has the potential to enhance implementation.

Challenges to implementation were related to the lack of clarity around accountability for the specific elements of the discharge process and difficulty securing engagement. The low recruitment was attributed to the narrow inclusion criteria, that the patient had an existing diagnosis of dementia and that the discharge destination was returning home rather than to an aged care facility. These challenges were overcome, to some extent, through local discussions and agreements that were held as part of the site implementation committees' work.

Discussion

This three-phase knowledge translation project was conducted over three years. It was established as an integrated knowledge translation project, acknowledging that it arose from clinicians' interest in how to improve discharge for older people with cognitive impairment. The project focused on a topic directly relevant to clinicians' everyday practice, thereby ensuring engagement of the original clinical team over the period of the project.

During the study development phase, a decision was made to limit the inclusion criteria to those people with an existing diagnosis of dementia. While this advice was valuable in clarifying the research population, it highlighted issues around delayed diagnosis for dementia, which had consequences for phase 3 recruitment into the study.

The final package was developed based upon an integrated review of the literature, document analysis and multiple consultations with stakeholders. The documentation and processes were complementary to what teams were already doing such as, preparing a discharge plan, developing a contingency plan, as well as including the discharge planner and external service providers at the family meeting when necessary. The inclusion of a family member or carer, who was the lawful decision-maker for the person living with dementia, was considered important. The introduction of integrated electronic medical record

(ieMR) raises issues for some of the documentation used in the project, namely the 'This is Me' document. Concerns continued about how the information included in the patient's 'My Journal' could be recorded as part of hospital records as well.

Any final package will need standardisation but the ability to adapt to local needs is highly valued. In particular, the high level of acceptance at Townsville appeared to be related to the additional quality improvement work conducted in parallel to the project. The process of discharge for people living with dementia was implemented within already established discharge processes at each health service. The inclusion of end users/ stakeholders in the implementation enabled early identification of implementation barriers and collaborative negotiation of solutions. The disconnect between the hospital and community was exacerbated by the lack of follow-up with people once they were discharged and discharge planners were not consistently engaged in the project at all sites. The role of the Nurse Navigator was suggested as a bridge between hospital and home but was outside the scope of this project.

Securing buy-in among the stakeholders was challenging. Within the current project, doctors and physiotherapists were actively engaged. The pharmacist, discharge planners, social worker and nurses should be encouraged to engage in future implementation. Overcoming disciplinary silos remained a challenge in terms of communication. The importance of management buy-in was emphasised to ensure the resources required for successful implementation were provided.

Future opportunities include how to adapt the materials for use with Aboriginal and Torres Strait Islander peoples and people with cognitive impairment, with or without a diagnosis of dementia.

Intervention Design. The integrated knowledge translation approach constituted a large part of the project timeline and resources. The widespread agreement that the Partnering for Discharge intervention has value is attributed to the inclusion of end users, clinicians, managers, and consumers during the design process. Consumer participation in the design stages for the Partnering for Discharge communication package is an example of how the Queensland Health services can position patients and their families as partners in the planning and design of health care services, consistent with Standard 2 of the National Safety and Quality Health Service Standards (2nd edition) (ACSQHC, 2017). The Partnering for Discharge is an evidence-based communication package and is recommended for further investigation in other Queensland Health contexts.

Intervention Effectiveness. The limited numbers of patient participants reduced our ability to draw conclusions about intervention effectiveness specifically in relation to readiness for hospital discharge, length of stay and hospital-acquired complications. However, the wide agreement about the value of the *Partnering for Discharge* intervention among clinicians and consumers leads us to recommend further studies of the intervention in other settings and with other populations such as frail older people. Such studies should include a prospective comparison arm to evaluate effectiveness, including readiness for hospital discharge and length of stay. We would also suggest monitoring outcomes such as: re-presentations to the emergency department and carer confidence in caring for the person living with dementia.

The *Partnering for Discharge* intervention was acceptable to staff and families of people living with dementia, with families expressing satisfaction with the information and support. Further, the *Partnering for Discharge* communication package aligns with the National Safety and Quality Health Service Standards (2nd edition) (ACSQHC, 2017). The communication package is person-centred and supports Queensland Health services to position patients and their families as partners in the delivery of health care services, consistent with Standard 2 of the second edition national standards (ACSQHC, 2017). The 'This is Me' element of the package provides important information about the person living

with dementia to assist nursing and other staff to plan psycho-emotional aspects of care that can reduce harm, consistent with Standard 5. Finally, the *Partnering for Discharge* package provides a process for communication at discharge, a time in the patient journey that is critical to patient safety, consistent with Standard 6.

Implementation Feasibility. This project was informed by the i-PARiHS model of implementation, where successful implementation was a product of facilitation, the intervention, recipients and context. The goals for this project were to improve the discharge process for older people living with dementia. It would appear that the goal was met at the Townsville site but not at the Cairns or Gold Coast sites. The three facilitators received extensive training in knowledge translation and met monthly, and sometimes fortnightly, for peer support throughout the process. The facilitators were not provided with time release from their substantive position for facilitation, but they were supported with research assistants for monitoring compliance. Having a dedicated facilitator for the implementation of the Partnering for Discharge package was considered critical to the success of the project at Townsville and is recommended for future rollout.

There was high engagement in the project at Townsville and this may be attributed to the local investment in a parallel quality improvement study. The local site committees provided good insights into the implementation of the Partnering for Discharge package and assisted with implementation from their various roles between meetings. The value of local tailoring is an important consideration in future study designs. However, inclusion of all stakeholders was challenging, and often people were unable to attend local site implementation meetings. To enable full interdisciplinary practice, identification of the key health disciplines required in the discharge process should lead to inclusion of all interests on the local implementation committee.

Conclusions and Recommendations. This project emerged from discussions among allied health and nursing members of the Statewide Older Persons Health Clinical Network. The value of this and the other statewide networks for clinician engagement in innovation and research is significant. The Partnering for Discharge package was developed using an integrated knowledge translation approach, which was resource intensive but ensured a high-quality output that can be used in future studies. Adopting a recognised implementation framework ensured that the rollout was consistent across sites and provided clarity for the implementation process, which was valued by the site facilitators and project team. The inclusion criterion that limited participation in the discharge process to people with a diagnosis of dementia and discharging to their own home reduced the opportunities to enrol participants. Adopting routine cognitive screening in older patients, consistent with the national Delirium Clinical Care Standard (ACSQHC, 2016), may increase clinician awareness of cognitive impairment and dementia.

The program aligns with the National Safety and Quality Health Service Standards (2nd edition) (ACSQHC, 2017). Partnering for Discharge provides an opportunity for patients and their family carers to partner in their care (Standard 2), supports the psycho-emotional care known to reduce harm in people with dementia (Standard 5), and provides an evidence-based process for high quality communication at a time critical to patient safety (Standard 6), in this case the time of discharge. As such, implementing Partnering for Discharge supports health services to demonstrate achievement in these three standards.

Key recommendations emerging from this study include:

- Statewide policy development towards routine cognitive screening in older patients would make projects such as this easier to do;
- Consider an early family meeting within 72 hours of admission for older people with cognitive impairment as part of the Queensland Health discharge policy framework;

- Make the Partnering for Discharge communication package available to consumers, clinicians and researchers through the Clinical Excellence Division website;
- Partner with major research funders to test the effectiveness of the Partnering for Discharge communication package in acute care settings; and
- Continue investment into integrated knowledge translation for future innovations in health services.

Appendices

Appendix 1 Data completion compliance

Audit component		Gold Coast n	Gold Coast %	Cairns n	Cairns %	Townsville n	Townsville %	Total sample n	Total sample %
Admission	Patient completed consent	2	16.7	3	100.0	1	5.0	6	17.1
	Family completed consent	12	100.0	3	100.0	20	100.0	35	100.0
	Patient completed demographics	2	16.7	3	100.0	8	40.0	13	37.1
	Family completed demographics	12	100.0	3	100.0	20	100.0	35	100.0
Pre-discharge	RHDS given	4	33.3	1	33.3	13	65.0	18	75.0
	Pre-discharge audit completed								
	• Yes – discharge audit was completed	5	41.7	3	100.0	13	65.0	21	67.7
	• No								
	○ Patient discharged prior to audit	1	8.3	0	0	4	20.0	5	16.1
	○ Excluded – RACF d/c	4	33.3	0	0	0	0	4	12.9
	○ Excluded – Patient deceased	0	0	0	0	1	5.0	1	3.2
	○ Excluded – Patient palliative	0	0	1	33.3	0	0	1	3.2
○ No staff time to fully complete audit	1	8.3	0	0	0	0	1	3.2	
Post discharge	Complete dataset	6	50.0	2	66.7	13	65.0	21	60.0
	Reasons for incomplete dataset								
	• Patient became palliative	1	8.3	1	33.3	0	0	2	5.7
	• Patient deceased	0	0	0	0	3	15.0	3	8.6
	• Discharged to RACF	4	33.3	0	0	3	15.0	7	20.0
	• Permanent transfer off ward	0	0	0	0	1	5.0	1	2.9
	• Patient discharged before package delivered	1	8.3	0	0	0	0	1	2.9

Appendix 2. Partnering for discharge package utilisation

	Package component	Gold Coast		Cairns		Townsville		Total	
		n	%	n	%	n	%	n	%
Admission	My Hospital Guide present in patient's room	11	91.7	2	66.7	16	80.0	29	85.3
	My Journal present in patient's room	11	91.7	3	100.0	17	85.0	31	91.2
	My Journal entries within 72 hours	3	25.0	1	33.3	8	40.0	12	36.4
	This is Me present in patient chart	9	75.0	3	100.0	13	65.0	25	73.5
	This is Me at least 50% completed	9	75.0	3	100.0	10	50.0	22	64.7
Pre-discharge	More than one My Journal entry last 48 hours	1	8.3	1	33.3	4	20.0	6	25.0
	Discharge checklist in My Journal completed	2	16.7	0	0	5	25.0	7	29.2

Appendix 3 My Journal utilisation prior to discharge, number of entries

Site	Number	Range	Mean	Standard deviation
Gold Coast	12	1-3	0.20	1.225
Cairns	3	0-5	3.3	2.887
Townsville	20	0-10	2.0	3.296
Total	35	0-10	2.0	2.919

Appendix 4 Family meeting compliance

	Gold Coast		Cairns		Townsville		Total	
	n	%	n	%	n	%	n	%
Family meeting <72 hours	0	0	0	0	14	70.0	14	41.2
Family meeting >72 hours	9	75.0	3	100.0	6	30.0	18	52.9
Who was present at the family meeting								
Patient	0	0	1	33.3	12	60.0	13	46.4
Family member	7	58.3	1	33.3	20	100.0	28	100.0
Medical officer	1	8.3	1	33.3	19	95.0	21	75.0
Nurse	0	0	0	0	2	10.0	2	7.1
Physiotherapist	1	8.3	1	33.3	10	50.0	12	42.9
Occupational therapist	2	16.7	1	100.0	2	10.0	5	17.9
Speech pathologist	0	0	0	0	0	0	0	0
Dietician	0	0	0	0	0	0	0	0
Social worker	7	58.3	0	0	2	10.0	9	32.1
Pharmacist	0	0	0	0	0	0	0	0
Aboriginal/Torres Strait Islander	0	0	0	0	1	5.0	1	3.6
Other	1	8.3	0	0	14	70.0	15	53.6
Other, please list role								
Community Provider	1	8.3	0	0	1	5.0	2	7.1
Additional family members	0	0	0	0	3	15.0	3	10.7
Additional family members and additional doctors	0	0	0	0	1	5.0	1	3.6
Additional doctors	0	0	0	0	6	30.0	6	21.4
Discharge planner and additional family members	0	0	0	0	3	15.0	3	10.7

Appendix 5 Family meeting documentation compliance

	Gold Coast		Cairns		Townsville		Total	
	n	%	n	%	n	%	n	%
Completed family meeting planning outline entry	0	0	0	0	9	45.0	9	31.0
Completed family meeting summary in patients room	4	33.3	0	0	14	70.0	18	62.1
Completed family meeting summary in medical record	1	8.3	1	33.3	18	90.0	20	69.0
Completed family meeting action plan in patients room	3	25.0	0	0	14	70.0	17	58.6
Completed family meeting action plan in medical record	0	0	1	33.3	17	85.0	18	62.1
Family meeting action plan signed by family	0	0	0	0	14	70.0	14	48.3
Family meeting action plan signed by staff member	2	16.7	1	33.3	16	80.0	19	65.5

Glossary

ACSQHC	Australian Commission for Safety and Quality in Health Care
ADI	Alzheimer’s Disease International
AIHW	Australian Institute of Health and Welfare
Carer	A person such as a family member, friend or neighbour, who provide regular and sustained care and assistance to another person without payment other than a pension or benefit (Australian Government, 2006)
DRG	Diagnosis related group - used to classify care types as part of organisational governance
GC	Gold Coast
i-PARiHS	Integrated Promoting Action on Research Implementation in Health Services – a conceptual framework that is used to implement evidence-based practice
LOS	Length of stay – number of days the patient occupies a bed within a hospital ward
NHMRC	National Health and Medical Research Council
NoMAD	Normalisation MeASURE Development instrument designed to measure implementation processes from the perspective of professionals directly involved in the work of implementing complex interventions in healthcare.
Patient/carer dyad	A relationship between the hospitalised person living with dementia and their identified carer
RHDS	Readiness for Hospital Discharge Scale
TSV	Townsville

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