

**Analysing sub-acute and primary health care interfaces – research  
in the elderly**

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# Analysing sub-acute and primary health care interfaces – research in the elderly

## ASPIRE Study

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# Chapter One: Background and Literature Summary

## 1.1 POLICY CONTEXT

### Geriatric Evaluation and Management Services

The National Health and Hospital Reform Commission (NHHRC)<sup>1</sup> recommended major changes to the way services are delivered to ensure people with complex needs get appropriate and timely care in the most appropriate setting. Of particular concern is the increasing number of older people who present to the Emergency Department (ED) with multiple, interrelated medical, functional and psychosocial issues with resulting complex care needs<sup>2</sup>. In the absence of coordinated, comprehensive assessment and planning, these patients have an increased risk of deterioration in function, readmissions and unplanned institutional care<sup>3</sup>. The current system is often confusing to navigate and services are poorly coordinated across the various providers and sectors. Moreover, it is often ill-equipped to provide coordinated and integrated support needed to optimise recovery and outcome and community living. In response, the Commission reinforced the need to expand specialist services in the community, including sub-acute services, to enhance the primary and secondary care interfaces and to optimise the responsiveness of the primary health care sector to address the needs of older people who are at risk of hospital admissions.<sup>1</sup> The rationale was to avoid inappropriate use of hospital and emergency services and to enhance integration and coordination across sectors. Following this, in 2010 the Australian Government announced an investment of \$1.6 billion to deliver 1300 sub-acute beds with the goal of timely care, appropriate use of resources and better health outcomes.<sup>4</sup>

The Geriatric Evaluation and Management (GEM) model of care promotes multidisciplinary, coordinated care of older patients with multiple conditions and complex health care needs who present at the hospital emergency department.<sup>1</sup> This geriatrician led service model aims to plan and provide medical, psychosocial and rehabilitative care tailored to the patient's specific needs and coordinated discharge planning. Evidence indicates that a GEM model of care delivered in a dedicated ward is effective in reducing functional decline, mortality and discharge to residential aged care compared to usual care.<sup>3</sup> However, due to system fragmentation and the complex needs of older patients following discharge, a GEM service is unlikely to significantly impact on avoidable hospital admissions unless issues at the acute, sub-acute and primary care interfaces are also identified and addressed. Patient care can be compromised during transitions between hospital and community based care because of poor integration between sectors, services and providers,<sup>5</sup> consumers being unaware of, or unable to access services, poor communication and service gaps.<sup>6</sup>

## 1.2 LITERATURE SUMMARY

### 1.2.1 Overview of the problem

Older people with complex health needs frequently access care from multiple health professionals in a variety of settings.<sup>7,8</sup> For community living older people, this may include acute, sub-acute, transitional and community services.<sup>9</sup> Care transitions are "periods of time when an individual either moves to a new care setting or changes levels of care within a setting".<sup>8 p.138</sup> These transitions may be precipitated by a change in health status or functional ability that requires a different level or intensity of care<sup>8</sup> and occur in the context of fragmented and unevenly distributed health services for older people.<sup>9</sup> If poorly managed, care transitions can have a detrimental effect on patient safety and the quality of care<sup>10</sup> and lead to further readmissions.<sup>11</sup> Older people with multiple co-morbidities and increased frailty are particularly vulnerable due to the frequency and unpredictability of their care transitions.<sup>8,12</sup> Transition-related health risks for older people include medication errors, falls, errors in diagnosis, infections and confusion.<sup>13,14</sup> In addition, poor preparation for care

transitions and lack of timely follow up can undermine gains in the preceding setting, contribute to patient dissatisfaction and increase carer burden.<sup>14</sup>

Components of quality care transitions which focus on medically relevant issues and the immediate provider to provider transfer have been identified to a limited extent in the literature,<sup>11,13,15,16</sup> but it remains a problematic area of policy and practice.<sup>10,14,17-21</sup> Care transitions take place at the interface between complex interconnecting human and health systems.<sup>21</sup> Studies which examine care transitions from a patient, carer and provider perspective<sup>7,8,12,22-24</sup> contribute to an understanding of the contextual complexity of care transitions by examining the experience of service users and providers to identify how they can be improved.

### 1.2.2 System challenges and patient and carer perspectives

Frequent transfers involving multiple teams can have a detrimental impact on continuity of care<sup>7</sup> and be experienced by patients with mixed feelings and vulnerability that can undermine trust in staff.<sup>25</sup> Toscan<sup>7</sup> reported that as the number of providers involved in care increased, each individual's personal ownership of the outcome was diluted. This can lead to a lack of accountability by providers while patients become disengaged from the management of their care and perceive their role to be passive recipients of care.<sup>7</sup>

Care transitions of older people can involve frequent transfers across different levels and approaches to care and in different settings. Vulnerability to sudden changes in health status often leads older people to present to an ED to access care.<sup>2,8,12</sup> Older people are more likely to arrive at an ED by ambulance, and be more acutely unwell and require admission.<sup>26</sup> The fast-paced, episodic focus of ED models of care is not well suited to the complex care needs of frail older people.<sup>2,22,27</sup> In Australia, the situation is compounded by the national performance benchmark regarding National Emergency Access Target (NEAT) which requires that by December 2015, 90% of all patients presenting to an ED will be discharged home, admitted to hospital, or transferred to another facility within four hours of arrival.<sup>28</sup> Transfers to surgical or other sub-speciality units may be an essential part of care following a sudden health crisis<sup>7,8</sup> but beyond that, the nature of an older person's progression through the hospital system can be uncertain and involve multiple teams.<sup>7</sup> Older people may then require follow-up in home support which is dependent upon a holistic approach to care.<sup>20</sup>

Lack of standardisation in hospital discharge processes can erode the quality of transitions. Dissatisfaction has been reported by primary care providers, such as GP's, about not receiving timely, relevant discharge summaries which can lead to discontinuities in care and a lack of follow up.<sup>7,15,17</sup> Delays in recording information for transfer and different recording practices can also result in duplication of assessments.<sup>7</sup> Studies of patient and carer perceptions of discharge processes have reported complaints about poor communication and consultation by staff, uncertainty about medication, inadequate notice of discharge timing, inadequate assessment of home circumstances, lack of involvement in discharge arrangements and uncertainty about coordination of post discharge services.<sup>15</sup> Rushed or delayed discharges can lead to patient misunderstanding about post discharge arrangements and incomplete information.<sup>24</sup> Specifically, who to call for clarification beyond the immediate post discharge period and difficulty in contacting hospital providers has been found to be problematic.<sup>23</sup>

Numerous studies have reported the value of involving patients and carers in effective care transition processes<sup>7,8,12,29,30</sup> and lack of involvement was a concern to patients and carers.<sup>12,22</sup> Carers are often the only person consistently involved across the continuum of care and provide continuity and support.<sup>30</sup> A systematic review of outcomes of family meetings concluded that pre-discharge family meetings reduce psychological distress of family carers and assist in meeting their information and support needs.<sup>31</sup>

A recent study has highlighted the high expectations of people in caring roles and the need to build the capacity to care.<sup>8</sup> Family caregivers may be overwhelmed by the emotional

aspects surrounding patient admission and transitions.<sup>8</sup> Caregivers often find the hospital setting uninviting and acute care wards can be a missed opportunity to equip carers with practical information and raise awareness of community supports.<sup>8</sup> The transition from hospital to home can be daunting for both patients and carers. Strategies including who to contact for information can build confidence.<sup>8</sup> Other studies have reported the central role of carers in filling gaps in services, advocating for patients, providing support and navigating the system.<sup>22,30,32</sup> Beech<sup>22</sup> found that a network of support, rather than a single carer was helpful to patients once they had returned home.

Lack of effective communication between providers and between providers and patients and carers is detrimental to effective care transitions. Communication issues between providers reported in the literature include illegible information and different record keeping systems, missing parts of patient records and lack of communication between acute and community healthcare professionals.<sup>12</sup> Older people and families can be confused about information provided on therapy equipment,<sup>23</sup> or how to access information<sup>23,32</sup> and may also be reluctant to seek information.<sup>8</sup> Accessibility issues arise when unanticipated needs emerge post discharge or after hours and information needs are not met.<sup>23</sup> Available and acceptable information has a positive impact on service accessibility.<sup>33</sup>

### 1.2.3 System and organisational responses

System and service level strategies including integrated models of care have been implemented to improve care transitions and address service fragmentation.<sup>34-36</sup> At a minimum, integration involves coordinated, interdisciplinary services linked to individual client need across the continuum of care.<sup>34</sup> Important service-level elements of integrated care include a well linked provider network, holistic care assessments, care planning, a single point of entry and care coordination.<sup>37</sup> Several studies have identified the need for improved mutual understanding of worker roles, better working relationships between acute and community settings<sup>12,38</sup> and improved information sharing and communication across organisational boundaries,<sup>22</sup> highlighting the need for education and professional development in the specific skills and work practices required for integrated care.<sup>36</sup> At an organisational level, key worker roles have been devised to ensure safe and effective care transitions for individual service users. The focus of these roles, identified as a system navigator,<sup>39</sup> case manager<sup>40</sup> or transition coach<sup>29</sup> is self-management education, identifying needs and brokering services rather than direct service provision. Evaluations of these roles are promising in terms of reduced hospital use<sup>29,39,40</sup> but shortcomings in terms of missed opportunities for prevention and early intervention by focusing on acute settings<sup>29</sup> have been acknowledged and there is an absence of in-depth patient and carer experience perspectives which can contribute to an understanding of the impact of these roles on the quality of care transitions.

Despite the critical importance of care transitions there is limited empirical research in the Australian health context. Information about care transitions involving sub-acute care, which is a relatively recent policy initiative, is even more limited. In-depth investigation of care transitions is required to obtain a better understanding of issues that arise at system interfaces and how they can be addressed. Moreover patient, carer and provider perspectives will ensure policy and practice solutions are based of comprehensive evidence.

## 1.3 STUDY AIM

The aim of this study is to examine the diverse care transitions of older people who transfer from the community across different locations and levels of care incorporating sub-acute care. This will provide a better understanding of the complexity of factors that influence these experiences and assist in deriving a whole-of-system approach to optimal patient care. The study is timely and critical for building the evidence base about the delivery end of policy initiatives aimed at enhanced integration of sub-acute and primary health care services for older people.

## Chapter 2: Methodology

This chapter details the research questions and provides an overview of the study design. A detailed description of the methods and study procedures is contained in Appendix 1.

### 2.1 RESEARCH QUESTIONS

1. What are the experiences and impacts of the GEM service from the perspective of patients and their carers?
2. What personal, systemic and local community factors influence GEM patients' journeys across acute, sub-acute and primary care settings from the perspective of patients, their carers and service providers?
3. How can local coordination of primary health care and sub-acute services for older people with complex care needs be improved?

### 2.2 RESEARCH DESIGN

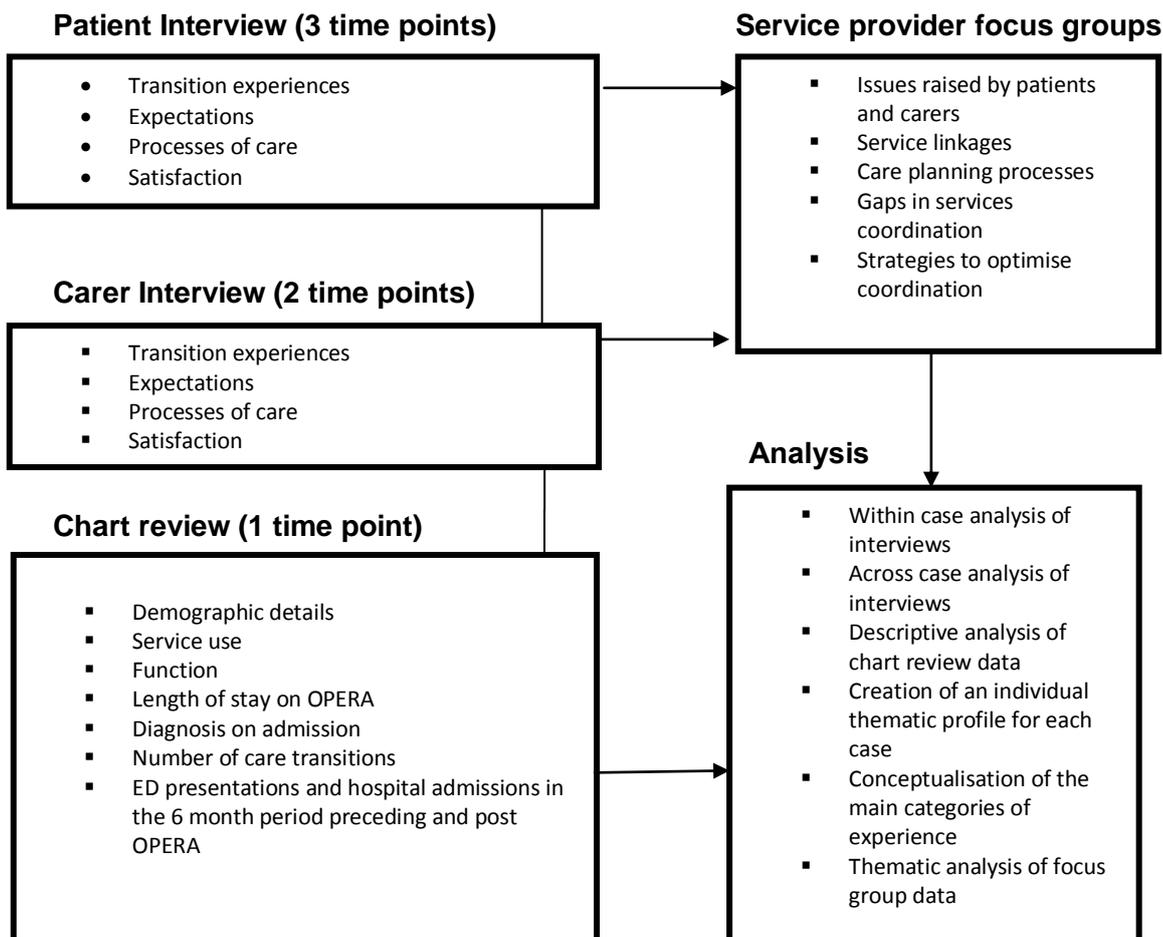
This was an exploratory, longitudinal case study design employing multiple qualitative data collection methods and thematic analyses. An overview of the research design is shown in Figure 2.1. Case study design is ideally suited to in-depth investigation of complex social issues<sup>41</sup> and has been utilised by Beech<sup>22</sup> and Toscan<sup>7</sup> to examine patient journeys across time and along the care continuum by capturing their experiences within service boundaries and during care transitions. Study participants consisted of three groups: OPERA ward patients, their carers and service providers. Data for each "case" included three patient interviews, two carer interviews and chart review data. In addition, three focus groups were conducted with hospital and community service providers to supplement and enhance understanding of patient care transitions.

Site selection and timing are integral to data quality and relevance elements of good design in qualitative research.<sup>42</sup> Cairns and Hinterland Hospital and Health Service (CHHHS) was a highly relevant location for a study on care transitions. The CHHHS is located in far north Queensland and provides public hospital and health services for a population of approximately 283,197. The population is forecast to grow by 9% by 2026, with the highest level of growth occurring within the 65 and over age group. The secondary catchment for the service includes the remote communities of Cape York, Torres Strait and Northern Peninsula area. The Cairns Hospital currently has 450 beds which will increase to 531 upon completion of a major redevelopment in 2015.

In September 2010 there were 586 presentations in the ED for those over 65 years of age, representing 15% of total presentations. Those patients over 65 years of age were more likely to be admitted overall, particularly in triage categories 2 – 5. It was estimated there were up to 20% of patients over 70 years of age admitted for more than 48 hours who would benefit from a sub-acute level of care. In 2010 the CHHHS was successful in obtaining funding to open two Older Persons Evaluation, Rehabilitation and Assessment (OPERA) Units: 12 beds at Gordonvale Memorial Hospital and eight beds at Mareeba Hospital. Further funding was obtained in 2013 enabling the opening of a 27 bed OPERA unit in Cairns Hospital which absorbed the Gordonvale OPERA unit.

Within the OPERA units the GEM service is delivered in a sub-acute setting focusing on optimizing functional independence. Each patient is assessed by a multidisciplinary team and individual care plans developed. For continuity of care, each plan involves discussions with the patient, the patient's family and community agencies that are already involved, or could potentially enable discharge to the community.

Figure 2.1 Overview of research design and methods



## 2.3 ETHICS AND RIGOR

Ethical conduct of research was an integral part of the study design. Protocols for cognitive screening, the option of appointment of a patient proxy for interviews, respectful engagement with Indigenous participants and home visits were developed. The potential for undue influence was managed by including non-clinical investigators in each phase of the research. Ethics approval was obtained from the local health service and university ethics committees. Study rigor was derived according to the criteria of trustworthiness, credibility and auditability developed by Lincoln and Guba.<sup>43</sup> Trustworthiness was demonstrated by the skill and expertise of the research team, credibility by the salience of the research design and methods and auditability by a comprehensive audit trail in conducting and reporting the study.

## 2.4 CONSUMER AND STAKEHOLDER PARTICIPATION

A Project Advisory Committee (PAC) and Consumer and Carer Reference Group (CCRG) comprising key stakeholder groups were established to optimise community participation. Terms of Reference (Appendix 2) were agreed and each group, comprising approximately seven members met three times during the course of the study to provide feedback on the study design and implementation, early results and recommendations and to provide input into the draft report and dissemination plan.

## Chapter 3: Patient and Carer Experiences of Care Transitions in Acute, Sub-acute and Primary care

### 3.1 OVERVIEW

This chapter presents a within and across case analysis of the patient and carer interview data. The within case analysis is presented in 19 individual case studies composed from a thematic analysis of semi-structured interviews and descriptive data from chart reviews. The across case analysis is presented in two parts. First, a descriptive overview of the key features of the cases as a whole using the chronological structure of the case study template as a framework is presented. This is followed by a description of pre and post OPERA presentations and admissions. An across-case comparison is then used to discern the main transition trajectories based on the experiences in the 19 case studies. These categories are conceptualised as *disrupted*, *manageable* and *emergent*. Each category includes a description of the key attributes of the experience followed by a case study example which summarises the experience with reference to personal, systemic and local community factors.

### 3.2 WITHIN CASE ANALYSIS

The case studies are presented in full in Appendix 3. These profiles trace the experiences, influences and determining events from a patient and carer perspective, noting discrepancies and recurring themes which are captured in a thematic storyline. The predominant storyline of each case, influencing factors and illustrative quotes together with pre and post presentation and admission data to contextualise their experience is summarised in Appendix 4. A summary of the storylines and influencing factors is in Table 3.1

Table 3.1 *Thematic Storyline and Major Influencing Factors*

<b>Thematic Storyline</b>	<b>Patient and System Influencing Factors</b>
Battling against despondency	Help seeking, agency, short term planning
Reaching the limits of capabilities	Discontinuities in care, carer fatigue
Reclaiming a productive life	Help seeking, TCP, emergent needs
Adapting to an unfamiliar lifestyle	Positive OPERA experience, TCP
Enduring a precarious recovery	Poor discharge experience, discontinuities
Resuming an independent lifestyle	GP trust, agency, TCP, service links
Holding onto independence	Help seeking, GP trust, TCP, service links
Regaining a manageable routine	Carer agency, positive OPERA experience
Being unprepared for change	Help seeking, short term planning
Balancing family and professional helping	Help seeking, poor discharge experience
Breaking the cycle of falls	Positive OPERA experience, GP trust
Resisting patient trajectory	Help seeking, positive OPERA experience
Withdrawing from system interventions	Agency, TCP, negative appraisal of care
Adapting to changing needs	Agency, forward planning, positive discharge
Battling through disconcerting times	Help seeking, agency, inflexible services
Negotiating complex caring	Carer agency, negative OPERA experience
Languishing in the health system	Agency, service links, service accessibility
Moving into uncharted territory	GP trust, short term planning
Succumbing to dependency	GP trust, agency, positive OPERA

### 3.3 ACROSS CASE ANALYSIS

#### 3.3.1. Overview of key features of cases

##### 3.3.1.1 Pre OPERA Experiences

Although some participants had generally good health prior to this event, many had experienced progressively deteriorating health resulting in a restricted lifestyle and increasing dependency on informal carers and personal support agencies. For a few, managing daily life involved precarious self-reliance with a spouse who also had disabling health issues or family members with other caring responsibilities. Where only one informal caregiver predominantly provided support, the viability of this arrangement was at risk. Most

participants were stoic, self-reliant and valued their independence. They adopted a 'wait and see' approach and delayed seeking help until a perceived crisis which required immediate and specialised medical care (which was identified as the ED) arose:

"I said to myself, I should be ok, it will go away. I'll stay at home. But then it didn't let up ... and I said to my son "call me a doctor". But if I knew it would take two hours for the doctor to arrive I would have said go and ring Cairns Base Hospital now."

The preference for presenting to ED was frequently reinforced by recommendations from the ambulance service or their GP. In two cases (R18, M13) it was the GP who called the ambulance. Carers were more willing to act sooner and called an ambulance if they had been advised by the GP to do so, felt out of their depth, were frightened, or unable to physically assist the person. Over half of the pivotal events that led to ED presentations in this study were falls-related. Despite the aversion to hospital admissions, many of these presentations involved falls risk behaviours and in some cases there had been prior admissions for falls.

GPs were a significant but underutilised health resource to participants in the community. All of the patient participants in this study identified a GP as the person who routinely looked after their health. For some, their GP was a trusted health professional. Trust was associated with continuity of GP over a prolonged period, good rapport, and a belief that they had appropriate expertise and accessibility. Despite their reliance on GPs and regular appointments, this was primarily a week-day relationship for non-urgent health issues such as routine health monitoring, chronic disease management (writing scripts, medication review) and minor health concerns (flu injections and in grown toe nails were examples cited). A barrier to accessing GPs was they were not available after hours or on weekends and even during the week there were longer than acceptable wait times for appointments to address issues perceived as urgent such as a fall. In two cases (B02, S19) participants said they were advised by their GP to call an ambulance if they were concerned about their health or if issues escalated on weekends or after hours. Participants who were dissatisfied with GP management were reluctant to change providers because of loyalty and trust in professional expertise:

"I've been with this doctor for twenty years and I don't know whether I should cast aspersions you know or whether he is treating me right or wrong or what. I can't doubt doctors you know. But certainly his treatment hasn't been good for me."

Another participant didn't consult his GP about an issue because he thought he would receive a referral to a private specialist he couldn't afford. Interestingly one participant did instigate a change of GP post discharge but this was unusual.

### **3.3.1.2 Transitions within acute and sub-acute care and preparedness for discharge**

The reluctance of participants to present to ED unless the issue was serious and urgent was matched by a desire to return home as quickly as possible once admitted. Patient participants were generally tolerant of system constraints such as wait times in the ED and ward transfers due to bed shortages except where these transfers were unexpected or unpleasant. Tolerance was underpinned by trust in professional expertise and a belief that their needs would ultimately be met: "Well they're only doing it for my good." One participant did not realise he had been transferred between different wards and thought it was all one place. Similarly, many were unaware of the purpose of these transfers or the names of the different wards. Carers however, were often critical of care transitions perceived to be driven by bed shortages rather than patient care, particularly if they were not kept informed,

excluded from decision making, there was poor communication with staff or it was perceived that patients were not treated with dignity and respect.

For many participants, admission to the OPERA ward was welcome due to the perceived good fit between their objective to return home and the focus on rehabilitation and self-management. Consequently many had high expectations of what could be achieved. All patients were cooperative with this approach but levels of agency varied from passive acceptance to active participation in therapy activities and information seeking. All participants accessed most allied health professions and many expressed surprise and appreciation for the holistic care. One carer commented: “they treated her as a whole person and not just what she went in for.” The value placed on empathic, holistic, goal oriented and inclusive care by both patients and carers is highlighted by the frustration and criticism expressed when patients felt they were not listened to, communication between patients, staff and carers was inadequate or ineffective and carers felt excluded or undervalued.

Discharge preparations were highly anticipated by participants but often marked by confusion and uncertainty due to the perception that arrangements were rushed and frequent changes in time and dates. Patients were rarely able to articulate the plan to support them at home. This may have been because in many cases there was an assumption that their carer was aware of them or because those arrangements had not been communicated at the time the interview was conducted. Confidence on discharge was derived from a home visit and modifications, family meetings, carer involvement and support, improved mobility and functioning and medication reviews. In two cases (B02, K11,) participants said they felt they could have benefited from a longer stay in OPERA, but were nonetheless keen to go home. Some carers were also apprehensive due to their increased responsibilities, a less than expected functional outcome, fear of further falls, fatigue from prolonged caring or not being included in discharge planning processes.

### **3.3.1.3 Transition from sub-acute care to home**

Participants experienced the one month post OPERA period as one of significant readjustment. For patients and carers this was a dynamic period which included changed services and providers, living arrangements, family and carer support, medication or daily routines which could be exacerbated by family tension, fluctuating health and in many cases emerging health issues and needs. This environment exposed instances of inflexibility of service arrangements due to eligibility criteria, operating hours, schedules and methods of delivery, lack of information sharing, knowledge gaps, unresponsive and uncaring attitudes, lack of follow-up and some unexpected delays in service commencement. This environment challenged previous trust and reliance on professional expertise and prompted increased agency by patients and carers. Two participants became frustrated with interviewer references to “the plan” made on discharge because it no longer seemed relevant to their needs: “Everything is up to date. Only the knee is my worry. What can I do?”. Without the knowledge, experience and skills to negotiate the bewildering service landscape, and limited options to pursue, patients and carers floundered or became despondent. Transition Care Program coordination and monitoring, proactive, informed carers and GP links with sub-acute care and other providers were associated with the more successful transitions.

### **3.3.1.4 Patterns of pre and post OPERA presentations and admissions**

Overall, the pattern of admissions and readmissions is a marker of the frailty of the patient group. Eleven participants had either an ED presentation or were admitted in the six months before or after their OPERA experience (Table 3.2). Within cases there is considerable variation in pre and post OPERA presentations and admissions. Of the six participants who presented to ED in the six month period prior to their OPERA experience, four presented at least once post OPERA. The participant with the highest number of pre OPERA

presentations (six) did not present again post OPERA. Of the nine participants that presented to ED post OPERA, five had not presented prior to their OPERA experience. Eight participants neither presented to ED nor were admitted in the six months before or after their OPERA experience.

Table 3.2 *Within-Case Comparison of Pre and Post OPERA Presentations and Admissions*

Participant	Presentations and admissions by study cohort 6 months pre OPERA		Presentations and admissions by study cohort 6 month post OPERA	
	ED presentations	Admissions following ED presentation	ED presentations	Admissions following ED presentation
B	0	0	1	0
D	1	0	2	0
H	0	0	1	1
J	0	0	1	1
K	0	0	3	3
L	6	3	0	0
M	0	0	2	1
N	2	1	0	0
R	5	1	1	1
S	4	2	2	1
T	1	1	3	2

### 3.3.2 Categories of experience

Three categories of experience were identified: disrupted, manageable and emergent. The categories are not mutually exclusive or fixed. Older people can cycle through these experiences in their journey across acute, sub-acute and primary care due to variations in health status, system responses, local care arrangements and temporal factors. Each category comprises notions of care transitions (movements), needs (unmet or otherwise) and access and interactions with services. Case examples have been selected on the basis they provide a good illustration of that category. The attributes of each category are the commonalities of these experiences but are not intended to be an exhaustive list. However, within each category, the combination of the listed attributes for that category was present.

#### 3.3.2.1 Disrupted transition experiences

A disrupted experience involves an *unexpected interruption to care* which *informal system navigators* (patients, family, neighbours) respond to by *embarking on unspecified care pathways* which result in *indeterminate transitions* i.e. links to the next transition are unclear.

The unexpected interruption to care can be precipitated by a health crisis, delays in accessing services or gaps in services resulting in unmet health or social care needs. The carer and the person they care for are unprepared for the change and embark upon a process of finding an appropriate way to have these needs met. Links between service providers and along the continuum of care are not evident and responses, if any, have a short term focus.

#### Case study S19: *Moving into uncharted territory* (Appendix 3.18)

The personal factors which impacted on this participants' disrupted experience were: a single carer; minimal home support; significant carer burden and lack of agency by the carer in relation to the system characterised by a trust in professional expertise and reluctance to

seek information or ask questions of hospital staff; and a rapid decline in health immediately post discharge from OPERA. Local and system factors which impacted this experience were coincidental provision of information about falls prevention, limited options for after-hours health emergencies, repeated presentations to ED, short term, medically focused discharge planning and weak links between acute, sub-acute and primary care providers.

### **3.3.2.2 Manageable transition experiences**

A manageable experience involves the *predictable and timely implementation of care arrangements, positioning of the patient for subsequent transitions and patient and carer agency in relation to system responses* which leads to *continuation of care*.

The predictable and timely implementation of care arrangements in a manageable care transition is underpinned by the positioning which takes place at touch points in the system including with GPs and the OPERA ward, which prepares patients and carers for subsequent transitions. Patient and carer agency is demonstrated by knowledge and skills in interacting with the system and confidence in how to address future needs which contributes to continuity of care.

#### **Case study L12: *Breaking the cycle of falls* (Appendix 3.11)**

For this participant, personal factors which impacted upon a manageable experience were: comprehensive personal and domestic support; a network of family and neighbourhood support; continuous and valued GP monitoring; carer agency in relation to system responses and follow-up of OPERA self-management strategies; and relatively stable post discharge health. Local and system factors which impacted this experience were: repeated pre-OPERA ED presentations; a supportive and inclusive OPERA experience; the timely implementation of health and social care components of the discharge plan including outpatient appointments; and the engagement of a GP in post discharge care.

### **3.3.2.3 Emergent transition experiences**

An emergent experience involves a *patient or carer identified threshold in care, intermittent sign posts of emerging needs, ineffective system responses due to silos of care and consequent unmet patient and carer needs*.

In an emergent transition experience, the patient and /or carer identify arriving at a threshold in terms of future care. The threshold may relate not only to the complexity of the health crisis which led to the presentation, but also personal factors such as the lifestyle impact and the viability of the caring relationship. The threshold is signified by intermittent signposts of change. Emerging needs are unmet due to providers operating independently in silos of care and ineffective system responses.

#### **Case study Q17: *Negotiating complex caring* (Appendix 3.16)**

An emergent experience for this participant is characterised by personal circumstances involving a pivotal health crisis; carer-driven autonomous help seeking behaviours; a single carer; significant public, private, primary and secondary care involvement; minimal domestic and personal support; and carer fatigue. Local and system factors which impacted the experience were carer dissatisfaction with OPERA discharge planning process; lack of timely information provision for emerging needs; and carer navigation and coordination of complex caring arrangements.

# CHAPTER 4: Providers' views on care transitions of community-dwelling older people

## 4.1 OVERVIEW

The analysis of focus groups with hospital and community-based health care professionals and service providers is addressed in this chapter. The aim was to capture a system-level view on the care transitions of community-dwelling older people to supplement and enhance understanding of the patient and carer experiences (Research Question 1). In addressing Research Questions 2 and 3, the key system and community factors shaping care transitions across different levels and locations of care are also discussed in the presentation of themes. Concepts from Transition Theory<sup>21</sup> were applied to develop the thematic analysis.

## 4.2 RESULTS

Details of focus group participants are provided in Appendix 5. The overall story of care transitions was one of indeterminate dynamic transitions in the sense that the care pathway for older people was on the whole unspecified but also unpredictable and constantly evolving by way of the actions of providers at any one transition point. While patient factors were influential, overwhelmingly the contribution of systemic factors was highlighted, including: weak connectivity between providers and services across the system, which undermined continuity; the sheer complexity and changeability of the system which impacted awareness and knowledge among providers; interface blockages due to unique pressures on different locations of care and differential capacities within primary health care and community care. These findings are represented in four main themes produced from the data analysis and discussed below: 1) unpredictable dislocating transitions; 2) weakly connected agents of care; 3) pivotal touch points; and 4) discretionary and emergent care practices. Selected extracts, uniquely coded to represent either hospital (HFG) or community focus group perspectives (CFG1 or CFG2) are included to illustrate these themes.

### 4.2.1 Theme 1: Unpredictable dislocating transitions

The typical form of care transitions of older people from providers' perspectives was unpredictable dislocating transitions. This concept is used here to illustrate the dynamics of care transitions, including the unpredictability of health and care transitions, multiple disconnected providers and unspecified, complex pathways. The hospital and community view was that "it can be very dislocating for people right from the beginning and across the wards" (CFG1) and "the plan changes from ward to ward and it's such a frustrating journey for the patient and the family" (HFG). Location-specific pressures combined with uncertain referral pathways and discharge tensions; multiple changes of providers and communication breaks; and a complex, changeable service system were seen to contribute to the pattern of dislocating transitions. Compounding this was the unpredictable health trajectories and behaviours of older people.

The influence of location-specific targets and pressures on care transitions was a concern across all groups. From the hospital perspective, performance targets for ED and secondary care were areas of tension likely to contribute to dislocating transitions: a "finite period of time to decide to admit or to not" (HFG); while the community view saw patients: "getting discharged too quickly...to get clients out in a timely fashion under the bed days" (CFG2). This together with "not always recognising the specifics that the patient needs and their environment with their care when they get home" (CFG2) was problematic for transition success from hospital to community, and for some participants, "contributes to the preventable admissions" (CFG2).

The “unknown referral pathway for the patient” (HFG) or otherwise location-specific referral processes such as independent assessments, could delay transitions or also cause flow-on effects to other parts of the system: “we’re left hanging sometimes by other people’s operational service delivery” (HFG). Even with the existence of sub-acute services such as OPERA, there remained confusion about referral pathways among providers in the hospital group: “there’s this unknown referral pathway...there’s transition care, rehab and GEMS...that unknown pathway causes a delay in the patient heading in the right direction” (HFG); and among providers in the community groups: “[GPs] don’t know what’s available, they don’t know how to access it and therefore they don’t use it” (CFG1). Furthermore, for community-based participants restrictions on community resources could create “a wait list for services to commence” (CFG2) meaning dislocation occurred because “timely access is just disastrous in a lot of areas” (CFG1).

The sheer complexity of the service landscape and constant change of providers were overwhelming concerns across all focus groups and a challenge for planning care transitions. It was “very confusing for people including GPs and service providers as to where to go to get services” (CFG1); and difficult for providers to establish good relationships: “six months ago, whoever the contact person was or whether that service was needed, it could have quite easily changed” (CFG1). As such, “navigating it is a massive challenge even for people who are experienced” (HFG). Complexity did not equate to availability of services, however, since delayed access was a significant issue impacting the timeliness of transitions: “There’s a lot of time between discharge, too, and the availability of services” (CFG2).

Delayed, sporadic or varying quality of communication and information exchange, particularly around discharge planning, contributed to the dislocating pattern of transition. From the community perspective, “getting information out of the hospital” (CFG1) and “trying to get information back into the hospital about a client” (CFG1) was challenging because “there’s no clear avenue” (CFG1). Some were concerned about “how accurately the information [about a patient] is being transferred from one place to another” (CFG2), while others were concerned about delays in information reaching community providers: “they may be home a week before anyone has actually told us” (CFG2).

Across all focus groups communication and information problems were compounded by the “archaic use of paper systems” (CFG2), which often obstructed quality discharge processes: “most GPs are constantly whinging about discharge summaries” (CFG2). Importantly, for primary health care, concerns were expressed about the relevancy of information: “there isn’t necessary the specifics about what is needed to be discharge” (CFG2); and accuracy of information: “there’s assumptions made about...current medication [on the medication list] and they’re not current” (CFG2).

Unpredictable health transitions or sudden changes in need complicated care transitions. The general experience was that “there isn’t a steady, predictable improvement trajectory...they are up and they’re down” (HFG), which meant it was difficult to detect change early, with some participants reporting not being “aware of the crucial period when actually they are deteriorating” (CFG2). Moreover, “medical instabilities” (HFG) and “escalating care needs” (CFG1), combined with restricted service hours, increased the risk of hospital admission: “and it may be a Saturday night and it’s hard to get the services and then they call the ambulance” (CFG1).

Help-seeking behaviours of older people impacted the timeliness of transitions. According to participants, it is not uncommon for older people and in some cases, their carers, to be “very ambivalent about accepting any services and even seeking help from a GP” (CFG2). Reasons included: “rejected by the carer...it was too invasive” (CFG2); or, “they just want to be independent” (CFG1). On the other hand, providers perceived that seeking help from

specific services such as hospital services could be reassuring for some older people “because there is someone around them 24 hours a day” (HFG), or even preferable for some older people who “wouldn’t tend to bother their GP” (CFG1). However, for one focus group, the hospital was an identifiable contact point, since “people don’t often know that first point of contact” (HFG).

#### 4.3.2 Theme 2: Weakly connected agents of care

Multiple providers dispersed across locations and levels of care were a feature of care transitions based on providers’ discussions. As is typical with complex systems and processes, these are the formal network of agents who organise, enact and shape care transitions.<sup>21</sup> Although reports suggest that interactive patterns between providers occurred around care transitions, it was also clear that providers organised around the transition tasks and procedures of specific locations and were weakly connected across the system. Interactions and information exchange for intra-hospital transitions and discharge planning to some extent followed recognised processes but were commonly usurped by local priorities and demands. Furthermore, the pattern of weak connection was perpetuated by complexity of the service system and unspecified referral pathways, which made it difficult for patients and providers to identify the main network of providers involved in care transitions: “paucity of good quality communication about who the players are from both the patient’s perspective and from the individual provider’s perspective” (CFG2).

Multiple changes involved with intra-hospital transfers were challenging for providers across different locations: “movement from one ward to another and changing teams” (HFG), more so because of system targets and pressures, and unspecified referral pathways. There was some concern that at any one point, these factors encouraged a focus on referral to the next transfer destination, rather than a patient’s coordinated journey through the system: “we often have the patients sitting in the system and a potential discharge planning will be ‘referred to GEMS’, which is not a discharge plan” (HFG). In some instances discretionary blanket referrals were a way to manage pressures and uncertainty about referral pathways: “at the moment you hedge your bets...cast a wide net for all of them which annoys the people on the receiving end of the referrals” (HFG). Confusion and miscommunication about the referral pathway or transfer also reinforced disconnected interactions: “[there] may be 5 patients referred...waiting on GEMS now and there’s the miscommunication, are they in GEMS, are they not, are they going to get accepted...there’s that delay in the triage and how to identify whether they are actually on the GEMS unit and are they not” (HFG).

Community providers were concerned about the difficult information boundaries between hospital and community, which could perpetuate weak connectivity between providers. These could also prevent timely communication around discharge and a break in follow-up: “sometimes they come home and they may be home a week before anyone has actually told us” (CFG2). However, relationships were key: “where we’ve actually developed relationships with units, information is much better and flows a lot easier but where we don’t have...a good working relationship...information is quite hard to get” (CFG 1).

Chance communication and encounters such as “running into someone at the front door” (CFG2) was how community providers described finding out about who comprised the network of providers. With “no kind of official way of... actually knowing” that an existing client was in hospital, this was picked up through chance, for example, “from our inpatient assessor being up there...thinking to check” (CFG1).

Inefficiencies were perceived likely due to weak connections such as, “a lot of double handling of the patient” (HFG). There was also a perception that older people were “over-planned” (CFG1) as a result of multiple referrals: “they go to the GP and where a thorough GP management plan has been done...then they go to the Community Health where they’ve

been referred, or the Allied Health provider and they do another plan, and then they go to somewhere else and they do another plan” (CFG1). For these reasons, there was a view that patients “are getting different people telling them different things” (HFG). Keeping up with the constant flux within the service landscape was also time-consuming for community providers and a discretionary activity: “by keeping your ear to the ground and trying to nut out who’s likely to be a key player” (CFG2); “a lot of phone tag” (CFG2); or, “a lot of research” (CFG2).

#### 4.3.3 Theme 3: Pivotal touch points

A key message across the groups concerned the “challenge [of] getting people to the effective touch points so they’re not having to do all the useless ones...” (CFG1). Pivotal touch points were those with potential to generate both transition hitches and solutions: GPs, ED, and sub-acute services, and specifically the OPERA service. However, there were multiple systemic barriers to overcome.

##### (i) GPs a critical touch point for coordination and avoidance of admission

GPs had regular contact and often, long-term knowledge of the patient which facilitated coordination and could avoid admission: “[GP]...knows someone for 30 years...far better that person presents to their GP to have things sorted out than they present to the emergency department” (CFG1). This was refuted by one hospital perspective: “They need to see them a bit more frequently and take a little bit more interest...[for coordination] the best we’ve got is a good local GP” (HFG). However, from the GP perspective, the relationship with secondary care was interdependent and therefore problems at one end could have a flow-on effect: “the hospital whinging about people going to the emergency department but it’s almost a problem of their own making because they don’t have the capacity to support us as GPs when we want someone seen acutely” (CFG1).

There was cautious optimism about financial incentives for GP care coordination: “a lot of money is consumed using Medicare item numbers. It doesn’t necessarily translate into coordinated care of our patients” (CFG2); “A GP management plan doesn’t really fix someone in the community does it? It’s just a summary of health problems” (CFG1); “the GP health coordination plan...often works quite well...but that needs to be used a little bit more frequently” (HFG). Furthermore, it was generally thought that the coordination efforts by GPs were frustrated by lack of knowledge about services and pathways: “[GPs] may not necessarily know what is available...knowing what’s available and how to get your patient to that service” (HFG). The general consensus was that capacity for prevention and intervention relied on effective interactions among providers to make “sure that the service provider and the GP are both aware of the same stories of what’s going on actually in home. I suppose that’s where the three monthly reviews and things like that are good” (CFG2).

##### (ii) ED critical for risk management and early intervention

ED was perceived to have early intervention opportunities due to potential to be “more proactive early in the piece...looking at risk management” (HFG), and providing feedback and education to other parts of the system: “somebody who could contact the GPs and say, I’m...from Base Hospital, could we talk about this patient... just some constant re-education” (CFG1); “look at some of the admissions over the weekend and say, this one’s obviously preventable” (CFG1). The other reason for ED being a pivotal point for some hospital providers was the potential for commencement of discharge planning: “we should be looking at where is the patient sitting in ED, what are their potential risks and what are the potential areas we need to be planning on working with them to safely transition them back into the community. It should start at the first point” (HFG).

However, differences of opinion were expressed based on concerns about the balance between system demands and patient care: “I really don’t like is this EDD stuff that the patient lobs in A&E and already they are saying when is their expected date of discharge. It shouldn’t be that, it should be caring for the client first and foremost” (HFG).

(iii) Sub-acute care critical for responding appropriately and holistically to complex needs

The general perception was that GEMS and OPERA offset a dislocating journey with a more “consistent approach with the processes and the transition... dedicated allied health team” (HFG); and by sorting out a complex case mix and complex needs: “thank God they are referred there now, GEMS or OPERA...and we can concentrate on the other acute patients” (HFG); “it’s just easier to take it to OPERA and sort it out there” (HFG). For some there was a general sense of relief that OPERA will be comprehensive: “but once they get to the specialist service, for example, OPERA, then they can really relax and appreciate the fact then that they’re getting that, it’s actually being properly worked up” (CFG1). For others, the benefit was the preventive and restorative role of OPERA which avoided premature institutional care: “we can pretty confidently say we prevent premature admission to nursing homes” (HFG); “now they are being funneled to OPERA where they should so they are definitely on a better journey...” (HFG).

There was a view that OPERA might address the issue of connectivity of providers by facilitating provider exchange across locations and levels of care: “we have a lot of contact with OPERA too and...find it fantastic, and once someone is on OPERA we take a brief sigh of relief” (CFG1); “A client went into hospital, they were planning her discharge, so I was asked to come in case conference with the family” (CFG1). However, currently there were contrasting experiences about the inclusivity of OPERA and clarity of its care processes, particularly with patients and carers: “there is a confusion on the patients and the relative's part about exactly what is the discharge plan” (CFG2); “doesn't seem to be much discussion at the beginning of the stay about what is hoped for, what is acceptable and what are the goals” (CFG2).

There was some unfamiliarity about OPERA’s role from the community perspective: “I suspect most GPs don’t know enough about [OPERA]...don’t know how to access it” (CFG1). Furthermore, access was an issue across all groups for various reasons such as complex referral processes, dependency on a hospital admission, and waiting lists: “The problem is actually getting them onto OPERA... because there’s a lot of players involved, is difficult” (CFG1); “We need to provide a way for people to access these things that doesn’t require a hospital admission” (CFG1); “they’ve still got 5 patients sitting there waiting for GEMS” (HFG).

The Transition Care Program (TCP) was seen to complement and build on the work of OPERA and bridge secondary/primary care: “we get them to the GP...manage whatever is happening at home and not have them represent back to hospital” (HFG). Likewise, from the GP perspective, “TCP are generally good at keeping me involved when I need to be” (CFG2). Notably, TCP also picked up system failures: “TCP also work well as an advocate on the part of the patient because of the discharge... a couple of people of mine over the years have bounced back from TCP back to hospital” (CFG2).

#### 4.3.4 Theme 4: Discretionary and emergent practices

There were numerous examples of discretionary and emergent practices for dealing with unpredictability, disconnectedness across levels and locations of care and competing demands surrounding care transitions of older people. These tended to be situational rather than structurally transforming, for example:

- > Involvement of allied health was viewed and used positively by hospital providers: “if they came through MAU...we are going to get them very early before any of the other drama of the knock on effects of transitions can occur.” (HFG)
- > GP responses were variable: GPs were “prepared to use...practice nurses a great deal or more than we are and there’s a couple of our nurses who are very keen to go out and do home visits” (CFG1); or set up regular consultations: “over 75 health checks are great...once an issue is identified we’ll say that it’s just standard practice to meet with you once a month” (CFG2).
- > Carers were relied upon to address service gaps and link with GPs post-discharge: “We do expect carers to provide a level of medical service often that we’re struggling with” (HFG); “I’m waiting...assuming...the carer will then look at an appropriate length for appointment for follow up once they’ve come out of hospital” (CFG2)
- > Resource limits meant judicious decisions about how to allocate resources: “We’re a service that go in and see the client and then we discharge them” (CFG2); “CCRT tend to do their assessments quite quickly...I don’t think they keep patients on for a long period of time” (HFG).
- > A contrast was the TCP: “...clients that get onto TCP get a good deal because they get case managed for that period of time” (CFG2), though it was also made clear that TCP was “short-term, goal orientated, client directed care” (CFG1).

There was strong consensus about the need for systemic or structural solutions, including:

- > More scope for early intervention in ED and stronger connections across primary/secondary care with appointment of ‘an expert’ and process of identifying ‘red flags’: “somebody with their own aged care focus to be part of [ED] environment” (CFG2); “...worthwhile for the hospitals or emergency department to fund somebody...[if] you don’t really know where to go to, then phone this person at ED” (CFG1); identify “red flags” and ensure “contact with the general practitioner”(CFG2)
- > More scope in general practice for coordination and prevention with practice nurse capacity: “they target healthy ageing and capture every older person coming through the door”, (HFG) though some reservation expressed: “unless they are specifically funded in some way, to have a person positioned within their service to provide that role they’d be hard pressed to do it well” (CFG2).
- > A single point of contact with system knowledge and expertise to coordinate transitions and pathways was strongly advocated by hospital providers: “would help to at least identify which is the most appropriate pathway for the patient” (HFG); and community providers: “a coordinated service that we could refer...so we can get back to being clinicians” (CFG2); “an intake worker...to...direct the traffic in a way” (CFG1)
- > Enhancement of case management capacity in the community would also provide coordination and a single point of contact for referrals: “I would love there to be more case management happening in the community” (HFG); “A central point where you have some referral pathway coordination” (CFG2).

Older people often experience periods of health instability across the life course, which necessitate a transition point and health professionals are influential in these processes.<sup>32</sup> Unfortunately, consistent with previous research, the analysis suggests that poor coordination among multiple providers and across organizational boundaries,<sup>10,27</sup> and system complexity are barriers, despite emergent ways of improving care transitions.<sup>21</sup>

## CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

In this chapter the key conclusions of the study are discussed in relation to the research questions based on a synthesis of findings from the patient case studies and provider focus groups. First the study sought to explore the transition experiences of patients admitted to GEMS and their carers, across primary, secondary and sub-acute care, and to enhance understanding with an analysis of providers' experiences and perspectives on coordination of care transitions and the linkages and critical interfaces across services and systems. In this study, a care transition is defined as movement to a different location or level of care, and includes both intra-organisational, such as hospital transitions from an acute unit to sub-acute care and inter-organisational transitions such as a transition from sub-acute care to home. Second, drawing on patient, carer and providers' experiences, the study sought to elicit the key patient, system and community factors shaping the care transitions. Three main categories of patient and carer transition experiences and the attributes of each category were identified: disrupted, manageable and emergent. Participant case studies and a descriptive account of issues across cases for transitions from home through acute, sub-acute and primary care explicated the factors which shaped these transitions. From a provider perspective, four main themes characterised care transitions: unpredictable, dislocating transitions; weakly connected agents of care; pivotal touch points and discretionary and emergent practices. The third question concerned ways to enhance integration and coordination across services and system interfaces. This question is addressed following discussion of each key conclusion by way of a description of the main policy and/or practice recommendations.

### 5.1 PERCEPTIONS AND EXPERIENCES OF CARE TRANSITIONS

The first main finding across the analysis as a whole is the likelihood of discernible tipping points associated with patients' transitions and the underutilised opportunities for early intervention across the system. It is noteworthy that in some cases, patients spoke about reaching a threshold, which to them signalled something had to change. Although over half of the patients in this study presented to hospital due to a falls-related event, two more typical health trajectories are apparent across the disrupted, manageable and emergent transitions. Progressive health decline and increasing dependency, in some cases marked by previous acute episodes, followed by the critical event, or conversely, general good health followed by the critical event. These types of health trajectories are consistent with previous research with patients with chronic and complex care needs.<sup>44-48</sup> Providers in the current study also describe a fluctuating profile of need and recovery punctuated at points by an escalation in care needs, which is either undetected until a crisis event, despite in some cases having routine interaction with providers, or the situation exceeds the capacity of services. It is not uncommon for transition points such as deterioration in health to go undetected,<sup>32</sup> particularly as progressive decline can be subtle, even where there are previous critical events.<sup>47</sup>

The critical issue is how to identify, or better predict the crucial moment in the health trajectory if aiming to get the right care, at the right time and in the right location. Trajectories vary significantly<sup>49</sup> and risk factors between progressive and sudden onset situations differ.<sup>46</sup> However, the community setting, and pre-admission point, is an obvious location for development of better indicators for early intervention. Results of an experimental study suggest that early intervention and prevention monitoring of older people in the community can be effective in reducing hospitalisation.<sup>50</sup> Previous research on preventive visits for community-dwelling older people suggests that a focus on frailty and a change or 'tiredness'

in daily activities are useful indicators for early intervention.<sup>47,51</sup> Though there are many standardised ways of monitoring for change, importantly, this requires multidimensional and periodic screening to monitor the range of medical, social and psychological factors intrinsic to predicting decline and more accurately significant change points.<sup>44,46,49</sup> Providers in constant contact with older people in the community also need to have the necessary skills to monitor and distinguish the important tipping points.<sup>35</sup>

Related to the notion of a tipping point, the second main finding is that ED represents a noteworthy systemic tipping point in terms of how care transitions are likely to eventuate. Yet, it is also likely underutilised for early intervention and coordination purposes. Patients and carers identified ED as the key provider of urgent care for serious conditions and an entry point to the hospital system and this perception was reinforced by advice from GPs and other health professionals. Providers, for example, saw ED as a critical turning point, both for timely intra-hospital transitions and ensuring the patient gets to the appropriate touch point, but also for discharge planning. Yet, it is also clear from providers' perspectives, particularly community-based providers, that there is untapped potential within ED to be a feedback mechanism about patient care transitions across the hospital/community boundaries and to be a site to instigate coordinated management of patient risk. The findings of this study indicate that despite previous presentations to ED, or falls, some patients might not be appropriately identified in terms of risk or level of need.

The practice consideration is how to instigate routine risk screening but more so, a coordinated systematic outreach to community providers, specifically GPs when patients are identified for early intervention. This would go some way to addressing the dislocating care transitions perceived by providers. Previous research has shown the benefits of designated navigator roles, that is an appropriately trained worker who facilitates care transitions across boundaries, and specifically, the benefits of involving this worker early in the transition process.<sup>35</sup> Another option that has shown positive impacts on care transitions, namely optimising coordination, is 'floating' geriatric teams which extend elements of specialist geriatric care to other services or units.<sup>52</sup> Although there are variations on models adopted in hospital settings, the aim is to take this expertise to where the patient is admitted and to provide constancy and coordination across the system by engaging multiple providers around a common patient-centred purpose.<sup>52</sup> In the hospital context, these strategies would also reinforce organisational responsibility for older people's care transitions.

A third overall finding is that the OPERA service represented an optimal touch point for patients, carers and providers. For patients and carers this was mainly due to the perceived alignment of the goal to return home, holistic care processes, and expectations of recovery. This is not unlike previous research on critical care patient experiences of intra- and inter-hospital transfer, which found that patients saw transitions equating with recovery.<sup>25</sup> Of note is that patients perceive and appreciate the relational quality of OPERA, which for some was unexpected. This was experienced as multiple providers engaging with them on the basis of their personal goals. However, experiences of care processes were not always positive, specifically around discharge, though this also extended across the hospital to other touch points. Disruptive discharge for many as a whole was due to rushed processes, or information confusion or breakdowns, reinforcing the dislocating experiences that providers highlighted. Notably, as indicated in previous research on intermediate care,<sup>53</sup> the patient, carer and provider perspectives as a whole also highlight OPERA's important role as a buffer that can counteract system pressures for untimely or unplanned discharge and enhance preparedness for discharge. For providers in the current study it not only offered more holistic care but also opportunity to bridge the disconnect between providers and service interfaces.

Noticeable, however, is the sense of frustration and disillusionment that some patients and carers experienced once returning home, despite positive experiences of OPERA. To some

extent, this is not unexpected as patients had high expectations of OPERA. Yet, the transition to community is also often accompanied by changes to services and circumstances,<sup>21</sup> which occurred in these cases by way of inflexible service provision, and which can derail expectations. Moreover, as previous research has indicated, it is also possible there is disconnect between patients' initial expectations about their rehabilitation and how their health and care transitions actually transpired.<sup>54</sup> However, notably, nearly half of the patients represented to ED within six months of discharge from OPERA. This highlights the importance and quality of the provider-patient interactions as part of care transitions to address expectations of recovery but also preparedness for discharge, including follow-up in the community with the GP.

A fourth main finding concerns the somewhat paradoxical role of GP interactions in care transitions. Patients, carers and providers differ in their views of GP interactions in care transitions. All patients identify with a regular GP, in some cases report a highly trusted relationship with their GP, though GP interactions and satisfaction varies. Importantly, there is some evidence to suggest that patients are not seeing their GP as a primary carer, rather having peripheral involvement in their care transitions, particularly hospital transitions. Patients perceived GPs as providing a narrow scope of service, namely episodic monitoring and care for non-urgent or minor health matters that occur during weekdays. The possibility of a minimal or restricted level of patient engagement with GPs combined with a patient mindset about the GP role suggests more work with patients about framing the benefits of GPs and with GPs about older peoples' expectations and complex care needs.

Providers on the other hand, view GPs as central to care coordination and hospital admission avoidance but concede that they are overwhelmed by complex needs and the service density and instability. Specifically, for some community providers, unfamiliarity with services and referral pathways, and the lack of a central reference point for referrals complicated care transitions and continuity. Moreover, despite use of GP Management plans to identify needs, lack of resources to instigate coordinated care were the tipping point for GPs. However, there was discrepancy regarding the tipping point between primary and secondary care. Paradoxically, some hospital providers perceive GPs need to do more to manage patients in the community, yet the community perspective was that GP management is hamstrung by arduous information boundaries and poor quality information exchanges. Moreover, in some cases there were assumptions about GP involvement, particularly post-discharge. Previous research has highlighted the importance of mutual understanding of the roles and tasks of primary health care providers and to facilitate their active involvement in discharge planning.<sup>53</sup>

Collectively, these four main findings highlight a further issue, that of the fluctuating but potentially identifiable risk gradient across the system which warrants practice and policy consideration. Unsurprisingly, there are multiple potential exit points for patients across the system and by consequence multiple turning points in patients' movements across the system, which can either enhance or impede care transitions. Taking into account patients', carers' and providers' views on care transitions as a whole, this brings into focus the challenges of managing both the patient and system level risk gradient. At the patient level, clinical and social risk, including unpredictable health trajectories, fluctuating needs, and help seeking. At the system level, the risks associated with older people presenting to ED from home and surrounding information exchanges, weak provider connectivity across the system, access delays and gaps in follow-up, and the turbulent and complex service system. Inevitably, managing the risk gradient calls for multi-component policy and practice strategies, particularly if readmission is to be avoided.<sup>11</sup>

## 5.2 PATIENT AND SYSTEM FACTORS INFLUENCING CARE TRANSITIONS

The main patient factors distilled from the findings that influence care transitions include help seeking rationalities, personal agency, and trust in professionals and/or care processes. Patients and providers suggested that help seeking and care transitions were connected. However, what is particularly interesting from the case studies is that patients' employ highly personal rationales about the timing and type of service interactions they are prepared to take in relation to different health matters, which in turn has implications for care transitions. In some instances, even those that might be considered urgent such as a fall. In general, providers perceived older people to be ambivalent about, or avoidant of health services and particularly hospitals. Yet, judicious or preferential use of health services was the way patients rationalised their interactions, for example, reliance on GPs for routine care and ED for more urgent, specialist care. Paradoxically, patients in some instances acted in ways that seem risky or illogical, for example, a preference to use ED for crises which require specialist care, but only after a 'wait and see' approach. Similarly, some patients acted in unexpected ways such as continuing to see their GPs despite being dissatisfied. It is not uncommon for older people to delay or avoid seeking help until symptoms are advanced or precipitate a crisis.<sup>55</sup> This can be due to a belief or acceptance that some illnesses or symptoms are a normal part of process of ageing and therefore do not warrant contact with health professionals or services, or a perception that nothing much can be done by seeking help from doctors.<sup>56,57</sup> Enhancing patient and/or carer awareness and knowledge is important, though this alone is likely to be an insufficient response. For example, the uncertainty of health transitions and complexity of the service environment, also indicated in the findings as a whole, suggest a complex interaction of factors.

Help seeking or help avoidance can also be related to maintaining a sense of independence or equally, a fear of loss of independence such as precipitating residential care,<sup>32</sup> issues also of relevance to the current study participants. Importantly, personal identity issues can rule out certain courses of action.<sup>58</sup> In this case, not wanting to be stigmatised or alternatively, a strong sense of self-reliance help explain some of the resistance or hesitancy of patients to engage with services. Policy and practice interventions that aim to improve care transitions will need to target patient help seeking and preferences. One option is to consider preventive in-home visits which are coordinated from within primary care since this approach may be beneficial for community dwelling older people.<sup>59</sup> These visits could also provide the framework for monitoring for unpredictable or elusive changes in health trajectories. Still, strategies will need to account for possible reluctance to such preventive and health promotion approaches<sup>47</sup> and this heightens the significance and potential of primary health care and specifically, trust relationships with GPs as well as other community-based providers.

As the across case study analysis and three care transition types indicate, patient and/or carer agency is related to help seeking behaviours and consequently, is influential in the timing and nature of care transitions. For example, hesitancy or inability to exercise agency in response to perceived rushed discharge planning or lack of follow-up contributed to a disruptive transition. By contrast, those willing and able to exercise agency about their needs experienced a more manageable transition overall. However, the case studies also reinforce the complex interaction of agency and systemic factors. It is striking that in general patients and carers seemed unprepared and ill-informed as to what to do or who to contact when plans were unclear, went astray or new needs emerged, despite having had on average four transition points, in some cases family meetings and home visits from OPERA and access to Transitional Care Program (TCP), regular GP contact, and pre-existing relationships with services. Moreover, some patients tended to be passive in response to uncertain and

disruptive transitions. For example, patients did not make contact when post-discharge care did not eventuate as anticipated, which meant delays in care. A possible explanation is that patients have difficulties assimilating information at the time of discharge.<sup>11</sup> However, unfamiliarity with a complex system<sup>32</sup> and help seeking behaviours are also likely explanatory factors. In this study, carers often assumed informal system navigator roles by default when there was an unexpected interruption to care but felt ill-equipped to do so and outcomes were suboptimal or indeterminate.

Critical issues from the practice viewpoint to be considered are patient and carer education, in addition to whether OPERA could better prepare and position patients and carers to practically and psychologically manage the transition to home. One strategy is to explicitly address expectations of recovery and care arrangements and also equip patients and carers with the knowledge and skills to self-advocate and navigate the system. This also strengthens the argument for navigator roles across organisations where multiple transitions occur.<sup>35</sup>

The within and across case study analysis also suggest that patients' and carers' experiences relate strongly to their appraisals of the care processes at different touch points and more so, their trust in the professionals and care processes at these locations. This is interesting to contemplate given that providers' view transitions as a dislocating experience. Service interactions and movements across services were viewed in terms of being informed, respected, cared about, valued and included. As such, experiences varied based on these principles, similar to previous research.<sup>25</sup> The findings also suggest that patients and to a lesser extent carers are on the whole accepting or tolerant of system pressures and waiting times across the hospital system. For example, patients expected wait times in ED and were generally tolerant because they anticipated and trusted expert help. Likewise, trust was associated with continuity of GP, even if dissatisfied with other aspects of care such as access. However, there are limits to their tolerance, as patients and carers are negative of care processes if carers are excluded, they are not kept informed, communication is inadequate or if care is compromised. A specific example is that of delayed or changed discharge plans.

Key systemic factors influencing care transitions were the realities of multiple providers across multiple settings, organised around discrete tasks of the settings; a complex and turbulent service landscape; and disconnected information systems. These factors contributed to the dispersal of responsibility for care transitions across system and no central reference point for coordination of care transitions. For patients and carers, multiple providers across multiple locations equated to a bewildering service landscape which could leave them floundering and with unmet needs. Services were perceived to be operating in discrete silos of care with vague or unspecified connections and detached from their emerging or fluctuating needs. This is consistent with previous research that has highlighted the dilution of ownership over care as patients move through the system.<sup>7</sup> It is also not uncommon for providers across primary care and secondary care to view roles and services in isolation from each other,<sup>36</sup> or to function discretely without interaction with, or knowledge of other services when coordinating care for patients with complex needs.<sup>16</sup> However, consistent with previous research, this could lead to disengagement from the management of their own care<sup>7</sup> and distrust in providers.

It is also evident that the siloed nature of provider interactions engendered a view of care transitions as resource relationships, that is, exchanges and interactions with other touch points. As such, care transitions were experienced by providers as boundary work. For hospital providers getting the patient to the next touch point meant negotiating with other units and managing the case mix, while managing the priorities and demands of the specific setting. Consistent with previous research, the dual priorities of timely and appropriate intra-hospital patient transitions, amidst efficiency targets, can generate different priorities and

discretionary practices.<sup>60</sup> Interestingly, while providers differ about where and when to commence discharge planning, referrals and specifically blanket referrals seem to be the default option to optimise patient movement to the next destination but also a way to manage boundary uncertainty, such as service criteria and eligibility.

For community providers boundary work means getting information into and out of secondary care in a timely manner, or trying to identify the network of providers involved in care transitions, though time and resources can be a disincentive. Furthermore, for community providers, the quality, relevancy and timeliness of discharge information, complicated by fragmented information systems, reinforce weak connections and breaks in care transitions across the system.

There are a number of policy and practice considerations, namely, how best to enhance collaboration across the touch points and what incentives are necessary to encourage and sustain collaboration at all levels of the system.<sup>60</sup> Effective policy and practice solutions will also need to address information technology systems that facilitate communication and collaboration across organizational boundaries, with appropriate privacy safeguards.<sup>16</sup> Another overarching consideration is addressing the complexity of the service system as a whole by limiting the number of service and provider interactions for patients and carers.<sup>32</sup>

A further systemic factor for policy consideration is the influence of community based sub-acute resources, such as TCP, and whether these represent missed opportunities for early intervention and prevention. There was some concern among community providers about the bias towards hospital based sub-acute services and hospital as a referral pathway to these services. The inadequate distribution of transitional care has been questioned previously as a policy issue.<sup>9</sup> Patients and carers in the current study, in addition to providers, perceive the TCP role in care transitions positively in general, specifically, in relation to GP liaison and care coordination, which help to bridge the hospital to home interface. Although an Australian study raises questions about the cost-effectiveness of the TCP, it also suggests that in the absence of other viable alternatives and possible positive quality of life benefits, further investigation of the benefits of TCP to patients and the healthcare system is warranted.<sup>61</sup>

The aim of this study was to examine the diverse care transitions of community dwelling older people across acute, sub-acute and primary care in order to better understand the issues that arise at system interfaces and to make recommendations for system-wide approaches for optimizing patient care. Within a fluctuating and emergent health and social profile and a complex and changeable service landscape, hospital EDs, GEM services and GPs are critical touch points for identifying and managing risk and positioning patients and carers for successful subsequent transitions and improved care experiences. Strengthening collaboration between sectors and at all levels of the system and greater flexibility in accessing care is essential to achieve a system-wide response and address the dislocation of multiple services and providers. The importance of patient characteristics and carer roles in determining transition experiences highlights a further opportunity to better manage transitions and support navigation across levels of care and organisations.

## 5.3 RECOMMENDATIONS TO ENHANCE INTEGRATION AND COORDINATION ACROSS THE SYSTEM

### **Embed early intervention and prevention through improved screening, assessment, care coordination and formalised in reach and out-reach linkages**

- > Implement periodic comprehensive assessment and screening for treatable causes of disability in primary and acute care, including ED.
- > Resource Primary Health Networks to administer a program of case management of identified cases in primary care.
- > Implement comprehensive assessment and targeted interventions to prevent premature disability including greater access to GEMS in community and hospital settings.
- > Establish systemised processes for in-reach and out-reach between sub-acute and primary care for coordinated discharge and care planning (increased coordination led by Primary Health Networks).

### **Strengthen system interfaces by building on existing programs**

- > Revise the *Australian Health Minister's Advisory Council Guide to Assessing Older People in Hospitals 2004* to include comprehensive assessment linked to management and intervention plans and create capacity via workforce education in case identification and intervention pathways.
- > Broaden Medicare item numbers 721 and 723 for discharge planning meetings to include public patients including use of telehealth and remote technology.
- > Broaden the scope of the Transition Care Program beyond hospital based discharge planning to extend access in the community via GPs.

### **Enhance care transitions for patients and carers through stronger inclusive practices and educative and self-help initiatives**

- > Support targeted, transparent and meaningful involvement of carers and patients in discharge planning, including Care Transition Coaching in sub-acute care.
- > Establish and evaluate Care Navigator roles in primary, acute and sub-acute settings to assist patients, carers and providers to proactively manage transitions in care and identify referral and access options. These could be new roles or incorporated into existing roles eg Nurse Navigators, General Practice Liaison Officers, Practice Nurses.

### **Build research capacity in the area of care transitions**

- > Design and conduct longitudinal research to accurately identify health transition trigger points, system responsiveness and the factors that improve care transitions and health outcomes for patients and enhance appropriate use of resources across the system.

## List of abbreviations

ACAT	Aged Care Assessment Team
AHMAC	Australian Health Ministers' Advisory Council
CCRC	Cairns Community Rehabilitation Team
CHHHS	Cairns and Hinterland Hospital and Health Service
ED	Emergency Department
FIM	Functional Independence Measure
FNQML	Far North Queensland Medicare Local
GP	General Practitioner
GEM	Geriatric Evaluation and Management
HACC	Home and Community Care
MAU	Medical Assessment Unit
MMSE	Mini Mental State Examination
NEAT	National Emergency Access Target
NHHRC	National Health and Hospital Reform Commission
OPERA	Older Persons Evaluation, Rehabilitation and Assessment
TCP	Transition Care Program

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## Appendix 1: Study Procedures

### 1.1 SEMI-STRUCTURED INTERVIEWS WITH PATIENTS AND CARERS

Semi-structured interviews were conducted with patients at three data points: admission to the GEM service; prior to discharge and one month following discharge; and carers at two data points: prior to and one month following discharge. This design provided the opportunity to capture experiences of transition to the GEM service and processes of care, needs and expectations of care during sub-acute care, and perceptions of the adequacy of services and unmet needs after discharge to the community. Using a combination of convenience, quota and purposive sampling a variant, information rich sample of patients and carers were recruited. Recruitment initially commenced at two sites: Gordonvale Memorial Hospital and Cairns Hospital OPERA wards, with a quota sample of five patients (two from Gordonvale and three from Cairns). Subsequently, patients were purposively sampled from the Cairns Hospital OPERA ward to ensure that study participants included variation in preadmission history, carer circumstances, length of stay and post-acute service eligibility as well as demographic characteristics (age, gender, and ethnicity) and other factors based on the emerging analysis. The research officer met regularly with the Nurse Assessor and Allied Health team leader to identify eligible patients. Sampling ceased when emerging themes were explained by the available data and no new theoretical insights were forthcoming (saturation).

Twenty patients and carers were recruited. One patient withdrew and this data was not included in the study. Eligible patient and carer participants met the following criteria: Patient inclusion criteria: Male and female OPERA ward patients receiving a GEM service, Mini Mental State Examination (MMSE) score of  $\geq 20$ , has an eligible carer. Patient exclusion criteria: Patients with a MMSE score of  $< 20$ , no identified carer. Carer inclusion criteria: Person identified by the patient who provides primary care and support. Carer exclusion criteria: Privately paid carers. The characteristics of the study sample and a profile of recent OPERA patients is contained in the Table below. Overall, the characteristics of the study sample reflect those of OPERA patients generally in the concurrent twelve months.

Comparison of the characteristics of study sample participants with those on the OPERA ward (admitted Nov 2013 – Oct 2014)

Characteristics		ASPIRE study participants (n=19)	OPERA ward (n=329)
Age (yrs)	Range	64-95	50-98
	Mean	83	82
Gender (% of total)	Male	63	45
	Female	37	55
ATSI Status (% of total)	ATSI	10.5	8
Diagnosis	Falls with subsequent fracture	6	The majority of the Top 20 DRG's represented: <ul style="list-style-type: none"> <li>• Rehabilitation post acute illness</li> <li>• Falls and fractures</li> <li>• Dementia</li> <li>• Delirium</li> <li>• Respiratory infections</li> </ul>
	Falls without fracture	4	
	Respiratory (pneumonia, COPD)	4	
	Cardiac (NSTEMI, syncope)	3	
	Urinary Tract Infection	1	
	Back pain	1	
Transition Care Program (% accessing TCP)		26	16.5
Average Length Of Stay on OPERA Ward (days)		14	12

Note: Data for the general OPERA ward for admissions, discharges, LOS, patient demographics and DRG's was obtained from CHHHS Casemix and Clinical Costing Unit and the GEMS database.

A total of 93 semi-structured interviews were conducted, 56 with patients and 37 with carers. Patient and carer interviews were conducted separately. Separate interview guides, based on the literature and study aims were developed for each of the three patient and two carer interviews (Appendix 6). Interviews followed a recursive style with the interview guides used as a prompt and checklist in obtaining data relevant to the research questions. Interviews were between eight and 63 minutes duration and with participant consent, recorded on a

digital recorder. To maintain continuity and build rapport, eligible patients were allocated to two members of the research team on the basis that they conduct all patient and carer interviews for that participant. First patient interviews were conducted outside the ward area (except for one patient who asked to be interviewed at the bedside). Second and third patient interviews were conducted at the hospital or at the patient's home. One patient was not available for interview three because of ill health. Carer interviews were conducted at their home, workplace, or hospital. Four carer interviews were conducted by telephone at their request because it was more convenient. One carer could not be contacted for a second interview during the study period.

Medical chart reviews were conducted after discharge from the GEM service to obtain demographic details, Functional Independence Measures (FIM) scores, length of stay, diagnostic reason for admission, number of transitions, sub-acute service use and Emergency Department presentations and hospital admissions six months prior to and six months following the GEMS admission in order to contextualise the interview data.

Focus groups were conducted with health and community service providers to explore issues derived from patient and carer interviews, service linkages, care planning processes, gaps in services and to generate strategies to optimise coordination of sub-acute and primary care services. Potential participants in acute, sub-acute and nongovernment sectors involved in the provision of clinical care or care and support services to older people were identified by the research team through service and professional networks. Selected participants were sent a letter inviting them to attend and provided with a Service Provider Information Sheet. To encourage participation from general medical practice, ethics approval was obtained to remunerate general practitioners for their time including travel. Those who agreed to participate were asked to sign a consent form.

Three focus groups were conducted: one comprising eight hospital-based providers and two with community-based providers representing government and nongovernment services (seven and eight respectively). Further characteristics of focus group participants are included in Appendix 5. Focus groups were conducted during working hours at the hospital, a community health centre and the Far North Queensland Medicare Local. A focus group guide was developed from a preliminary analysis of interview data and based on the literature on care transitions (Appendix 7). Each focus group was facilitated by the same member of the research team, supported by the research officer. Focus group discussions were recorded on a digital recorder and lasted approximately two hours.

## 1.2 DATA ANALYSIS

Data analysis involved a within and across case analysis of patient and carer interview and chart review data and thematic analysis of focus group data. Following this, a workshop was conducted with the research team to integrate these analyses and produce a synthesis of findings. Qualitative analysis was conducted using constant comparative techniques involving close reading, coding, classifying, sorting and synthesising.<sup>62</sup> Interview recordings were transcribed. NVivo qualitative data analysis software<sup>63</sup> was used to store and manage all interview transcripts and analysis. Two researchers coded the first five complete cases (25 interviews) and three researchers reviewed the codes and developed a coding framework (Appendix 8). All of the interview transcripts were coded according to the coding framework. Where gaps or variations emerged, they were discussed by the researchers and modifications were agreed. By comparing codes and data within transcripts and between patients and carers, a smaller number of codes which crystallised the significance of a group of codes were developed. These codes, the chart review data and analytic memos written by researchers following each interview were used to compose the 19 case studies at Appendix 3. An across case comparison of the case studies was then conducted using grounded theory methods as proposed by Yin<sup>41</sup>. Working inductively, comparisons were made across case studies, noting recurring patterns, connections and variations, to generate useful concepts to delineate patient experiences. Using diagramming and tabulation of concepts

with evidence from case studies, three categories of experience and attributes of each concept were identified. The plausibility of the categories was assessed by one researcher and the research officer who classified case studies using the categories and made adjustments.

All of the focus group transcripts were analysed by close reading, coding, classifying, sorting and synthesising the data by one of the investigators. The integration workshop involving five members of the research team was conducted to review and synthesise the analysis of different data sources and develop preliminary recommendations.

## Appendix 2: Terms of Reference

### Terms of Reference

**Enhancing health system interfaces: a study of experiences of sub-acute care patients, their carers and providers.**

#### Project Advisory Committee

##### **Purpose**

To advise and provide professional and strategic expertise to the operation and progress of the APHCRI funded research project on the experiences of sub-acute care patients, their carers and providers.

##### **Terms of Reference**

The responsibilities of the Project Advisory Committee are to:

- Attend three face-to face meetings of 1-2 hours duration during the course of the research project
- Provide input into the operationalisation of the project
- Contribute strategic knowledge and expertise as the project progresses
- Liaise and assist with interactions with stakeholders important to the progress and outcome of the research project
- Review and comment on data analysis and research findings as the study progresses
- Provide input into the development of policy and practice recommendations
- Review and comment on progress and final research reports
- Assist with dissemination of the research findings where they relate to local policy and practices
- Agree not to disclose any identified information acquired by them as members of the committee.

##### **Membership**

Members:

Dr. Edward Strivens  
Dr. Desley Harvey  
A/Prof Michele Foster  
Dr. Michael Wilson  
Rachel Quigley  
Linda Bailey

**Representatives from:**

- FNQ Medicare Local - GP
- Wuchopperen Health Service
- St. Johns Community Care
- OzCare
- Blue Care
- Commonwealth Carelink and Respite Centre
- Holy Spirit Services
- Cairns and Hinterland Hospital and Health Service – Division of Integrated Medicine

Quorum: 8

**Agenda**

The Agenda will be made available 5 working days before the meeting

**Proceedings**

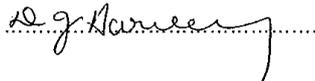
Minutes of the meetings will be recorded

**Meeting dates**

The Advisory committee will meet three times:

1. 10<sup>th</sup> February 2014 10.100
2. August 2014 TBC
3. November 2014 TBC

Endorsed by:



Date: 10 / 2 /14

Approved by:



**Dr. Eddy Strivens**

Clinical Director  
 Older Persons Subacute and Rehab  
 Division 2 Integrated Medicine CHHS  
 Phone: (07) 4226 6197

Date: 10 / 2 /14

Version	Date	Prepared by	Comments
1.0	5.2.14	Rachel Quigley	First ever release of approved document
1.1			First review of the first ever release of approved document
1.2			Second review of the approved document



## Terms of Reference

**Enhancing health system interfaces: a study of experiences of sub-acute care patients, their carers and providers.**

### Consumer and Carer Reference Group

#### Purpose

To contribute consumer and carer perspectives to the operation and progress of the APHCRI funded research project on the experiences of sub-acute care patients, their carers and providers.

#### Terms of Reference

The responsibilities of the Consumers and Carers Reference Group are to:

- Attend three face-to-face meetings of 1-2 hours duration during the course of the research project
- Contribute consumer and carer perspectives on the operation and activities of the project as it progresses
- Liaise and assist with interactions with stakeholders and facilitate linkages where necessary for the successful progress of the project
- Review and comment on research findings as the study progresses
- Contribute to and comment on policy and practice recommendations developed from the research findings
- Provide advice on and actively facilitate options for user – friendly dissemination of the research project and findings
- Agree not to disclose any identified information acquired by you as members of the Consumer and Carers Reference Group

#### Membership

**Members:**

Dr. Edward Strivens  
Dr. Desley Harvey  
A/Prof Michele Foster  
Dr. Michael Wilson  
Rachel Quigley  
Linda Bailey

Mark Mappas - Previous GEM Client  
 Paul Gage - Previous GEM client's carer  
 Margaret Stevenson- Retired ACAT nurse & client of Transition Care

**Representatives from:**

RSL Welfare  
 Carers Queensland  
 Positive Ageing Cairns Inc.  
 Younger Onset Dementia Advocacy

Quorum: 7

**Agenda**

The Agenda will be made available 5 working days before the meeting

**Proceedings**

Minutes of the meetings will be recorded

**Proposed Meeting Dates**

The Advisory committee will meet three times:

1. 10<sup>th</sup> February 2014
2. August 2014 - TBC
3. November 2014- TBC

Endorsed by:



Chair of Committee

Date: 10 / 2 /14

Approved by:

  
**Dr Eddy Strivens**  
 Clinical Director  
 Older Persons Subacute and Rehab  
 Division 2 Integrated Medicine CHHS  
 Phone: (07) 4226 6197

Date: 10 / 2 /14

Version	Date	Prepared by	Comments
1.0	5.2.14	Rachel Quigley	First ever release of approved document
1.1			First review of the first ever release of approved document
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## Appendix 3: Case studies

### 3.1 Case study A01

**Key theme:** *Battling against despondency*

#### **Health and social profile prior to acute presentation; transition from community to ED**

This 73 year old man had a history of a progressive neurological condition and increasing mobility and balance problems impacting on independence and leading to a more restricted lifestyle. Despite this, he failed to recognise or minimise the risk when he was left alone for the day with a large dog that unbalanced him causing a fall and fractured femur. He valued his independence and had a stoic, self-reliant attitude to managing his declining health and the escalating pain following the fall. There was a hesitancy to seek help unless absolutely necessary and only after he had done everything possible himself to avoid the situation. This was demonstrated by his approach to his chronic illness which was to do as much as possible himself and not rely on his wife unless absolutely necessary. He adopted a 'wait and see' approach to seeking help after the fall despite serious pain – "I knew I was in bad trouble" although his wife was more reticent about this approach. His ED presentation eight months prior via ambulance was followed by hospitalisation, surgery and an unexpected discharge home after three days with no support. His implicit trust in professional care was demonstrated by his persistence with protracted investigations at outpatient clinics and regular GP consultations over eight months of escalating pain, before being referred by a consultant for further surgery and then accessing GEMS.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

There was acceptance of the shared effort required to regain health capacity while in the OPERA ward. This was exemplified by his willingness to be an active participant in his care "I'm doing what I was asked to do by the doctors and nursing staff, to keep myself motivated and do the things I was told to do, walk and do my exercises." This sense of agency aligns with his personal characteristics and strong evidence of personal agency in relation to service encounters throughout his story. There was appreciation of an inclusive and supportive approach in sub-acute care demonstrated through being listened to and responsiveness of staff other than one experience of asking for help and not receiving it. He accessed all OPERA ward allied health professions except Psychology and there was an improvement in functioning (nine point increase in FIM score) on discharge. For the carer, the inclusive processes of OPERA including feeling staff listened to her concerns and answered questions were especially important to enhance her confidence about preparedness for discharge home. His total length of stay in hospital was 21 days (15 days on OPERA).

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was marked by minimalist, short-term support and a service rather than patient focus suggesting being cut adrift to find ways to manage on their own. The efforts of the carer to engage professional support were confounded by cost concerns, uncaring staff attitudes and inflexibility due to geographical scope, hours of operation and eligibility criteria. The decision to cease physiotherapy follow-up was made by the service provider. Both patient and carer identified "support" as a special person to talk to and check how they are going. Disillusionment with the GP, hospital and lack of social support left them despondent and just "hanging on". Overall he experienced three care transitions and did not present to ED again in the study period.

## 3.2 Case study B02

### **Key theme: *Reaching the limits of capabilities***

#### **Health and social profile prior to acute presentation; transition from community to emergency department**

An 86 year old woman with pre-existing back pain, two chronic diseases and declining eyesight presented to the emergency department on a weekend. She had been resistant to hospital as a care option, preferring the familiarity of her own home where she had strong support from at least one family member (shopping, paying bills, transport, washing), an extensive package of health and social care services (meals, cleaning, ironing, letter writing, nursing) and had confidence in the ongoing care of her general practitioner. The parameters for presentation to the emergency department were arrived at through consultation with her family and GP. The GP recommended that her family call an ambulance if their mother's health got worse over the weekend. Her daughter described her condition that weekend as "the worst we've seen her", declaring that hospital was the "best place" for her at that time. There was acquiescence with this conclusion expressed as "I felt I got to the stage where I felt that I did need help".

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Overall, her experience in the OPERA ward was insightful and supportive. This was expressed through her appreciation of the homely ambience, care displayed by nursing and therapy staff and being included in decisions about admission to the ward and goal setting. The experience was marred by unexpected bed transfers which were a source of frustration as well as a perception that the ward was congested. Interestingly, her OPERA experience had a transformative element, derived from her interactions with other patients, leading to her perception that she had become more tolerant and patient. She accessed all allied health professions of the OPERA ward and there was an improvement in her FIM score (3 points) on discharge. There was a sense that, although medication and mobility issues had been addressed in the OPERA ward, the limits of capability would again be tested on return home. This was demonstrated by the patient's concerns about her carer's health and what would happen if she was no longer able to rely on her care. The carer's declaration of the limits of her capability were exemplified by statements that she was "worn out", and "retiring" from a role for which she had insufficient formal and informal support. Despite this, she acquiesced in discharge planning on the basis of the continuation of her caring role. Her total length of stay in hospital was 21 days, including 12 days on the OPERA ward. There were a total of five care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was marred by a mismatch between needs and some social care arrangements. Follow-up care was unpredictable, delayed or did not eventuate, leading to unmet needs and frustration. Personal agency in addressing gaps and discontinuities was demonstrated by inquiries made by the patient and carer but was thwarted by explanations of staff shortages and waiting lists. There was continued heavy reliance on family and informal networks for social care needs. The limits of capability were again exemplified in the carer's reference to "finishing up at the end of the year" and the cost to her, "I've been here over five years and you do neglect your own kids". This woman presented to the emergency department again post OPERA, but was not admitted.

### **3.3 Case study C03**

#### **Key theme: *Reclaiming a productive life***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 87 year old man experienced a fall while working in the garden resulting in a broken leg. A passer-by noticed him and called an ambulance. Prior to this incident, he led an active and productive lifestyle, focused on manual tasks and contributing to his family. An independent, self-reliant attitude characterised his approach to health “I’m pretty healthy. I look after myself”, and he had minimal contact with a nominated GP for routine monitoring and flu injections. There were no emergency department presentations or hospital admissions in the six months prior to the OPERA ward admission. The incident which resulted in the fall involved a risky manoeuvre in which he fell backwards while shifting a heavy trailer so he could mow the lawn.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

His attitude on the OPERA ward was one of cooperating with care. This was exemplified by his trust in the expertise of care providers, compliance in doing what was asked of him by therapists and passive approach to information about his care. He said “I just left it up to them. They know the rules” and “I just sailed along with it”. This pragmatism was reflected in his expectations of the OPERA ward and optimism about his capacity to manage at home post discharge “Just sort it out and get home so I can do some work you know, it’s building up”. His wife was also trusting in the expertise of medical staff “Well doctor, he is in your hands”. His appreciation of the processes of care was similarly pragmatic and focused on the timeliness of care and the responsiveness of staff to his basic needs. He accessed all allied health professions except Psychology on the OPERA ward. Doubts expressed by this man and his carer about the prospect of a full recovery led to a more active approach to care and a commitment to practice the exercises learned on the ward in order to improve his mobility at home. There was an improvement in functioning (12 point increase in FIM score) while on the OPERA ward. His total length of stay in hospital was 21 days including nine days on OPERA. There were four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute to home was experienced as supportive and well-coordinated. The Transition Care Program case manager was a source of information and reassurance who organised care. Links with sub-acute care were typified by carryover to home of information and advice about dietary requirements and follow-up medical appointments. Despite satisfaction with this care plan, there was increased concern about knee pain post discharge, rather than the broken leg from the accident which resulted in a marked change in attitude and a more proactive approach to care by both this man and his carer. This change involved raising concerns, rejecting medical opinion, seeking alternative care and expressing dissatisfaction with care. A service-driven approach to post discharge care was exemplified by the carer’s comment “Yeah, the plan’s going well and all that. Everything is up to date. Only the knee is my worry, what can I do?” Frustrated attempts by this man to engage both his GP “She don’t even put her hand on it” and a hospital doctor “he sort of pushed it off like ... well they couldn’t do much about it” and cost barriers to accessing a private specialist were indicative of the limited options available to him in primary care, leading this man to contemplate presenting at ED to have the issue resolved although no further presentations occurred in the six months following discharge.

### **3.4 Case study D04**

#### **Key theme: *Adjusting to an unfamiliar lifestyle***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

An 86 year old woman residing in self-contained, shared family accommodation experienced a fall at home which she perceived to be due to her mistake. The circumstances of the incident indicate risk as she recounted being half asleep, wearing loose shoes and standing up abruptly. Good health to this woman involves being able to maintain her independence (cooking, cleaning, shopping, self-care) and contribute to the care and support of her family (cooking, child care, washing). This functional view of health was exemplified by her perception that “I’m very, very healthy” despite deteriorating sight, an ED presentation in the previous six months and later statements that her experience of hospitals was minimal. There was limited pre-injury contact with a regular GP for the purpose of monitoring medication. The strong dissonance between her pre and post injury functioning and self-image and the perception that she has become a burden rather than a help to her family underpinned a period of adjustment to an unfamiliar lifestyle she framed as “frightening”.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

There was acceptance of two intra-hospital ward transfers and wait time in emergency typified by an attitude of waiting your turn (for toilet facilities, staff responses, inter-ward transfers). The experience on the OPERA ward was one of progressive reassurance despite disappointment in functional improvement and hesitancy about the capacity to manage at home. The extent of functional improvement was not recorded. She accessed all allied health professionals other than Psychology while on the OPERA ward. For this woman, reassurance was derived from supportive staff, a home-like atmosphere, information about medication, inclusion in decision making and having concerns about functioning and independence specifically addressed by equipment and home modifications “a lass took me out the other day. They called it a home visit. They have a look to see how everything is”. The carer provided further encouragement by reinforcing her improved capacity on the OPERA ward. Her total length of stay in hospital was 28 days including 25 days on the OPERA ward.

#### **Care transition from sub-acute care to home, system encounters post discharge**

There was a divergence of experience during the transition from the OPERA ward to home. At the personal level, there was a focus on a disrupted life plan due to a loss of independence and family role which resulted in frustration and a resolve to resume valued activities “I like doing things myself. I’ve got to try and do things even if I get frustrated. I burst into tears so many times because I haven’t been able to do something.” The overall post discharge service experience which included the Transition Care Program was positive, although with some notable discontinuities in relation to information and access. Both patient and carer were unclear and unsure about follow up services “The only problem was not knowing what was going to happen, was not being informed well enough in advance” (carer) and the timely availability of a medical alarm. The GP however, was well informed when consulted. The divergence between patient and service goals was revealed by a gap in emotional support and a devaluing of service outcomes. When asked what went well, she replied “I don’t think anything, well, everything’s going alright but nothing’s worked well because I went and did this stupid thing.” She presented to emergency twice post OPERA but was not admitted.

### 3.5 Case study E05

#### **Key theme: *Enduring a precarious recovery***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

In this case, a preventable fall (slipping on a loose mat at a shopping centre), which was diagnosed post discharge as a fracture, compounds a precarious situation where both this 77 year old woman and her carer have been managing numerous musculoskeletal and chronic disease issues with significant primary and secondary care involvement. She did not present to hospital in the six months prior to this admission. Prior to the accident the patient and carer managed domestic tasks and she regularly saw a GP for monitoring and medication review. Despite the complex health issues and consequent lifestyle limitations, this period of adjusting to declining health was characterised by independence, self-reliance and a pragmatic approach to managing at home. For example, she explained “I just try to be careful” when climbing to clean fans. Pragmatism was also expressed by the carer in relation to the emergency presentation following the fall, “You just have to go along with what they found out.”

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Her experience of the OPERA ward was one of positive engagement with health goals tainted by disappointment with a lack of empathy by a staff member and the patients mix which both she and her carer found “depressing”. Overall, there was appreciation of the holistic, timely and goal-orientated approach to care in which she saw herself as an active participant. This was exemplified by her attitude on admission “I have a goal that I want to reach to get me home. If you don’t work hard you will never get anywhere, you will be here for longer still.” She accessed all allied health professions except Speech Pathology while on the OPERA ward and unusually for the study participants, identified staff by their allied health profession when describing specific outcomes that would assist her to manage independently at home. Despite this, there was hesitancy and uncertainty by both patient and carer about the arrangements in place for discharge. Nevertheless, there was a sense of trust in the process “I’ve already had people coming in to ask about that. They do say that they will work out what we need and then organise it.” She was in hospital for 25 days including 19 days on the OPERA ward, experienced four care transitions and there was a small improvement in functioning (a two point increase in FIM score) on discharge.

#### **Care transition from sub-acute care to home, system encounters post discharge**

There was a disorientating transition to home due to unexpected appointments, delays in service commencement, discrepancy in advice, gaps in knowledge about planned services and confusion about home care services being offered. The erosion of confidence in the health system to meet their needs was typified by doubts about medication follow up and scepticism about arrangements for home modifications. Concerns about continuity in medication management were expressed as “They send out how I’ve been discharged, what medication I am on at that present moment. We gave him a list ourselves and I was a bit unsure as to whether things were being worked out.” This was compounded by the perception of a missed diagnosis while in hospital, financial hardship and further deterioration in health. A devaluing of the care plan was exemplified by an emphasis on the loss of independence and a valued lifestyle, “I am definitely not the person I was at all”. She did not present to emergency again and was not admitted to hospital post OPERA.

### **3.6 Case study G07**

#### **Key theme: *Resuming an independent lifestyle***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

A 92 year old woman with pre-existing chronic and degenerative health issues currently being managed by her GP and with strong family support had an unexpected fall at home resulting in an injury which was ultimately diagnosed as a fracture. Prior to the injury, there was pride in her independence and autonomy, yielding only when advised by doctors (to surrender her driver's licence) or when she can no longer physically manage a task, "I used to walk there from where I lived with a big shopping trolley and pull it but I had to give that up towards the end because it pulled on the shoulder with the arthritis." The perception that her GP played a key role in maintaining her health was shaped by her regular and continuous contact with her former GP "I used to go every five weeks. That was because of the diabetes and that. And he says it was his duty to keep me going, and he did." This perception was reinforced post discharge from the OPERA ward by the follow up provided by her new GP and her expressed satisfaction with the care provided.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

There was acceptance of the management of her care prior to the OPERA ward. This was exemplified by her report of the delayed investigation of her injury "and then the next thing I knew I was being whipped down to x-ray". This pragmatic approach was demonstrated again in her expectation of the OPERA ward "I expect to be made as well as possible as soon as possible" and explained her acceptance of some delayed staff responses and disruption which were attributed to the greater needs of other patients. However, there was a sense of agency, shared by the carer in achieving these objectives. This involved utilising opportunities, requesting changes to care arrangements and challenging advice given by a staff member. This was typified by her approach to therapy "as long as you work with all this help that you're getting that really helps even more". She was appreciative of the processes of care, particularly being listened to and treated with care and respect "they treated you as an equal and as a person". Despite expressing some nervousness, there was confidence in her capacity to manage at home derived from a home assessment and modifications, medication review by a pharmacist, comprehensive written information, awareness of Transition Care Program arrangements and the reassurance of family support. She was in hospital for 43 days including 31 days on OPERA and experienced four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

This transition was characterised by timely, coordinated and uninterrupted implementation of the discharge care plan and the involvement of the Transition Care Program. Links with sub-acute care were evident through the transmission of information "I didn't have to arrange it or do anything, it was all there. They just came." In addition, follow up care provided by the GP was proactive, responsive to the patient's concerns and avoided the need for an outpatient appointment. There was agency by her in utilising the available services and a network of family support that aligns with this woman's preference for autonomy and self-reliance. This was exemplified by her approach to proffered services "I said if there's anything I want or need to go anywhere I will ask you, but otherwise I'm ok." She was appreciative of the caring attitude and efforts of the therapists and other providers and gratified about being able to resume enjoyable activities. Post OPERA she did not present to emergency and was not admitted to hospital.

### **3.7 Case study H08**

#### **Key theme: *Holding onto independence***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 95 year old man experienced generally good health with neither hospital presentations nor admissions in the preceding 6 months. He became progressively unwell over a two-week period. This slide into ill health was characterised by his complacency about the situation and indifference to seeking medical advice. This was exemplified by his assessment of how long he had been unwell “Well sometime I suppose it would be that I sort of sat about not doing very much” and rejection of efforts by family members to have him consult a doctor. The GP referred him immediately to the emergency department. This man’s preadmission lifestyle focused on maintaining independence and wellbeing. He managed at home with minimal service and carer giver support, valued his daily domestic routine and enjoyed socialising with his family and listening to music. He demonstrated a sense of agency in relation to his personal care exemplified by making changes if he was not satisfied, “I found that the cooked meals were very poor so I altered that.” Both he and the carer expressed confidence and trust in the GP who he saw regularly and who visited him while in hospital.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

This man’s acceptance of intra hospital transfers aligns with his trust in the expertise of hospital staff and pragmatism about the outcomes of his care, “I am in their hands and in the hands of the gods.” For the carer, the timeliness and satisfaction with care on the acute ward was marred by an experience of exclusion and poor communication, “We would have loved some reassurance, I guess because we were shocked, when we went in and Dad couldn’t talk.” In contrast, the transition to the OPERA ward was experienced as supportive and inclusive. There was appreciation of staff empathy and respect, being offered a choice, self-management support and comprehensive care. He accessed all allied health professions except Speech Pathology and Psychology and there was an improvement in functioning (16 point increase in FIM score). Both the patient and his carer referenced a previous OPERA ward experience at Gordonvale, noting the differences in ambience, patient mix, space, location and facilities. There was confident anticipation by both patient and carer about returning home, derived from an improvement in functioning, continued family support, existing home modifications and awareness of follow-up services and contact information. Although hesitant to criticise, the carer suggested that the experience could have been enhanced by a family meeting to obtain more information. The length of stay in hospital was 33 days, including 19 on OPERA. There were four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was experienced as supportive, coordinated and comprehensive. The close links with sub-acute care were evidenced by two visits to the GP when he was accompanied by a member of the Transition Care Program team in order to explain why there was a change in medication. The transition experience was enhanced by continuity of staff providing care and the sense that his needs were being met. There was ambivalence about costs of care, “a few bob doesn’t hurt anyone” and appreciation for the return to limited autonomy, “I do what I can when I can”. The carer identified someone to check on him regularly as a future support need. Post OPERA there was one emergency department presentation, resulting in an admission.

### **3.8 Case study I09**

#### **Key theme: *Regaining a manageable routine***

#### **Health and social profile prior to acute presentation; transition from community to emergency department**

This 91 year old woman who lives with her carer had an unexpected fall while at home on her own resulting in a fracture. The ambulance was called when she activated a personal medical alarm. She relies almost completely on her carer (a former neighbour) for domestic and personal support, with minimal home care services and limited GP input. There were no emergency department presentations or admissions in the previous six months. Her relationship with her GP was marked by irregular contact and indifference. She recounted that her carer told her she had to have a GP. With limited sight and mobility, she had a restricted lifestyle with a focus on staying safely at home. She believed that a simple change to the location of a wheelie walker contributed to her fall. Her fear of falling and caution was reinforced when she fell again while on the OPERA ward. There was a focus on having her basic needs met and an assumed reliance on her carer exemplified by her proffering "She does all that. I'm not going to change all that."

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Care transitions between acute and sub-acute care were expeditious and supportive from the carer perspective. Overall both the patient and the carer expressed a high level of satisfaction with the inclusive, flexible and holistic approach to care, progressive self-management support, timeliness and responsiveness of staff and the outcomes achieved on the OPERA ward. There was a 27 point increase in FIM score on discharge. The carer distinguished their experience on the OPERA ward from previous acute admissions because on the OPERA ward, "they treated her as whole person and not just what she went in for." There was strong evidence of agency on the part of the carer and to a lesser extent the patient which aligns with their desire to be self-determining in relation to care arrangements. This woman appreciated the opportunity afforded by a pre-discharge family meeting to express an opinion and participate in decision-making. The carer welcomed staff updates on daily activities and expressed satisfaction when action taken was consistent with her perception of what should happen. Conversely, delays or a lack of response to expressed needs resulted in frustration. This woman normally sleeps in a chair rather than a bed but was not able to do this on the OPERA ward, "if there is a bed there I've got to stay in the bed but I'll be glad to get home, to get in my own chair." The length of stay was 26 days including 15 days on OPERA and there were 4 care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home involved resuming a support arrangement mutually acceptable to this woman and her carer, with the addition of short term nursing and the offer of respite. The carer was ambivalent about the links between sub-acute and primary care and defined the role of the GP as "Giving her scripts basically" while a further hospital presentation was envisaged for "a major cardiac event, a stroke, pneumonia." The carer's utilitarian approach to services organised on the OPERA ward aligns with her strong sense of agency in relation to care. For example, she stopped the nursing service "because I could do that" and was unconcerned with the lack of contact from a respite service which she was reluctant to use because it had proved unreliable in the past and unnecessary, "she's happy to be on her own and now I know she is so much better it's not a real concern." There were no post OPERA emergency department presentations or hospital admissions.

### **3.9 Case study J10**

#### **Key theme: *Being unprepared for change***

#### **Health and social profile prior to acute presentation; transition from community to emergency department**

This 84 year old man with a progressive neurological condition, chronic back pain and declining mobility toppled backwards while pruning a shrub at his home. In the past he had an active lifestyle focused on work and hobbies and had remained active in retirement with travel, home maintenance and other interests. He valued his independence and was struggling to maintain this active lifestyle while looking after the house and garden and caring for his wife, whose health had begun to decline rapidly. He relied on a network of support from family, neighbours and domestic cleaning services. He had a stoic attitude to managing his own health. This was demonstrated by his 'wait and see' approach to the pain he experienced following the fall. Some hours after the fall, and in severe pain, he called an ambulance after trying unsuccessfully to obtain an immediate GP appointment and discussing it with his daughter. There were no emergency department presentations or hospital admissions in the six months prior to admission to the OPERA ward.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

There were three medical ward transfers prior to OPERA, resulting in a total of six transitions on discharge. He identified clear goals on the OPERA ward. However, his carer was sceptical and believed that he could have been discharged home from the previous ward. There was an attitude of compliance with care while on the OPERA ward based on his trust in the expertise of staff. For example, there was minimal involvement in discharge planning "they just said that they're working on getting me back home and they're trying to get some sort of help to make it easier for me." He accessed all allied health professions except Psychology while on OPERA. Although expressing a desire to go home, there was uncertainty about arrangements and a 'wait and see' approach by this man and his carer to his capacity to manage at home compounded by his wife's move to an aged care facility while he was in hospital. This was exemplified by his belief that "I've always managed before so I can't see any difference. Maybe I will be a bit slower that's all". He expressed confidence that he could rely on family and neighbours if required. This hospital stay was 18 days including 10 days on OPERA.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was marked by a minimalist, family-driven, short-term approach. There was confusion and uncertainty about transmission of information to the GP typified by the carer's comment, "I don't know what's happening or if anything is going to happen or if they're just going to leave it to the GP." This was an unsettling period when this man was adjusting to living alone. There were emerging needs for support where family assistance was no longer available, concerns about the cost of services, frustration with his restricted physical capacity and expressions of loneliness now that his wife was no longer at home. His persistence in trying to meet all of his needs himself was consistent with his stoicism and self-reliance but was also a source of family tension. His struggle to adjust to his changed lifestyle was evidenced by admission of his limitations, "I'm not a bludger, I'm a worker but I can't work. Yeah I would like help." The uncertainty and frustration of this period was also evident in his carer's claim that "We're in a bit of a grey area. We don't know what to do." He presented to the emergency department post OPERA and was admitted to hospital.

### **3.10 Case study K11**

#### **Key theme: *Balancing family and professional helping***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 64 year old man was hospitalised in Cairns three years ago for an acute condition. The event marked a turning point in his approach to his health to a focus on access to care and support. He moved permanently to Cairns where he had the reassurance that hospital care and family support was available if required. He had multiple chronic conditions and declining function which was being managed with the support of his family, regular GP visits for scripts and minor health issues, and a limited home care package. The reassurance he felt about being able to access hospital care contrasts with his avoidance of hospital care unless the issue was serious and urgent. He delayed seeking medical advice for chest pains he had been experiencing for three or four days, hoping it would go away. When it became more acute, he requested a family member to call a 24 hour home visiting medical service. When told they could not respond for two hours, there was a sense of “panic” as related by one family member and an ambulance was called. He had no emergency presentations or hospital admissions in the six months prior to this admission.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

The care provided on acute and sub-acute wards generally met his expectations of expeditious, comprehensive, specialist hospital care, but was marred by instances involving lack of respect, lack of empathy and rudeness by staff on acute wards resulting in anger and frustration. There was resistance to these behaviours which involved discussing the issue with the staff member, but action beyond that was thwarted by lack of information and fear, “I don’t know who to report these things to. And I was afraid that it would come back to me. Because I am a bed patient, I have no strength and I was afraid something would happen to me.” He consequently resolved to “get well quick and get out of here.” He accessed all allied health professions except Psychology and was gratified by the improved functioning achieved on the OPERA ward (supported by a 20 point improvement in FIM score) and friendliness of staff. There was a sense of imperative for the family about discharge planning, exemplified by his daughter being asked to assume the role of carer “We had a family meeting there, and they wanted me to apply to be a carer for him” and his apprehension about the timing, “I was getting better according to them. I felt that I could have stayed a little bit longer because the treatment, the care they were giving me was good ... I wouldn’t be getting that kind of care here [at home].” This hospital stay was 22 days including 10 days on OPERA.

#### **Care transition from sub-acute care to home, system encounters post discharge**

Planned links with sub-acute care including a visiting therapist, home modifications, and someone to check on how he was going had not yet commenced when there was a significant deterioration in his functioning. The carer preferred to seek help from other family members rather than relying on information or services included in the discharge plan. For example, if she required more help at home she would ask her brother’s advice, for assistance in finding out how to apply to be a “proper carer” she would ask her sister. Reverting to the familiar strategy, the carer responded to this man’s declining function by seeking help from her family, “He couldn’t walk much, he just sat in the chair. If he wanted to go to the toilet then my brother had to carry him to the toilet. But then we just rang the ambulance to come.” Post OPERA there were three emergency department presentations all of which resulted in a hospital admission.

### 3.11 Case study L12

#### **Key theme: *Breaking the cycle of falls***

#### **Health and social profile prior to acute presentation; transition from community to emergency department**

This 73 year old man with multiple chronic conditions and complex health issues experienced a recent rapid decline in health leading to six emergency department presentations, three of which resulted in admission to hospital in the six month period prior to the OPERA admission. His declining health resulted in restricted functioning and the relinquishing of valued social activities underpinned by a fear of falling. There was a precarious home care and support arrangement which involved reciprocal caring with his wife for whom he was previously the nominated carer, a suite of domestic and home care services and regular monitoring by a trusted GP. The strain of this arrangement was exemplified by this man's concern that his recurring falls had taken a physical toll on his wife and, "Now she's become my carer but there's no one caring for her." Depending on the circumstances the carer initially responded to recent acute episodes by contacting family, her GP, neighbours or an ambulance. On the occasion that led to this presentation she called an ambulance following her husband's unexpected fall at home because she was unable to lift him up.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Frequent recent presentations resulted in a predictable transition through acute wards and tolerance of delays which were attributed to a shortage of beds rather than the fault of staff; and uncomfortable, noisy surroundings in the emergency department. There was the perception of a good fit between the OPERA ward and his current health goals compared to previous brief admissions which he perceived to be driven by a shortage of hospital beds rather than the management of his health issues. He rejected going to a nursing home as an option and described his goal as "to walk around with a greater degree of safety". He accessed all allied health professions except Psychology. He was cooperative with care and appreciative of the thoroughness of investigations including a medication review. This was echoed by his carer who summed up the experience as "thorough and supportive." Despite satisfaction with care and discharge arrangements, there was a lingering wariness by both this man and his carer about whether he had made sufficient progress to prevent further falls. There was an improvement in functioning (four point increase in FIM score) This hospital stay was 15 days including nine days on OPERA and there were four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was typified by the expected and timely commencement of services and follow up outpatient appointments. Links with sub-acute care were further demonstrated by following advice provided by the OPERA ward dietician, and practising exercises and techniques learned on the ward to prevent falls. The extra financial support of a carer's payment, arranged on the OPERA ward was welcome and there was tolerance again for delays which were perceived to be due to system constraints, "And like anything else you go in a queue, it might be three days or it might be three months." The carer reported feeling more settled and having time to her herself during the social outings that had been arranged. Emerging needs were proactively managed by the carer through involvement of the GP in providing medication advice and she also investigated options for support with gardening and transport. There were no emergency department presentations or hospital admissions post OPERA.

### 3.12 Case summary M13

#### **Key theme: *Resisting patient trajectory***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 87 year old woman with a history of chronic back pain became progressively unwell over a two week period and presented at the emergency department when her daughter activated the medical alarm. Prior to this episode she was generally healthy and was active, resourceful and self-reliant in managing most domestic tasks. She had a supportive family network. She rejected the need identified by her carer for additional support and avoided contact with the health system. Although in the care of her GP, she was indifferent to GP contact, "I don't have much to do with the GP. I go and see her now and again." She was vehemently opposed to presenting at the emergency department. This was exemplified by her strong resistance expressed to ambulance, emergency department and hospital staff and her statement, "If they had any sense they would just leave me where I was and just let me die." This contrasts with her daughter's cautious and vigilant approach to her mother's health care typified by arranging regular GP contact and a preference for calling 000 if concerned. The day prior to this presentation, the carer had also arranged an after-hours appointment with a home visiting medical service but cancelled it when her mother appeared to improve.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Hospital care transitions prior to OPERA were frequent, disruptive, uncomfortable and upsetting for this woman and her carer. Both women perceived these transitions were due to a shortage of beds rather than for patient care. The transition to the OPERA ward was more welcome as it was perceived to be consistent with their goal of improving functioning so that she could return home. Despite the acute ward transitions, described by the carer as "just appalling", this woman was appreciative of nursing and medical care, particularly in the OPERA ward where she described staff as "very, very caring people." Attributes of caring from this women's perspective were: being asked your opinion, being listened to, staff responding to your needs, non-judgmental communication, a kind and understanding approach, providing reassurance, expressing genuine interest and offering a choice. There was a passive attitude towards improving her functioning while on the OPERA ward exemplified by her indifference to participation in therapy and ambivalence about whether being there had made an impact on her readiness to go home. She accessed all allied health professions except Speech Pathology and there was an improvement in functioning (17 point increase in FIM score). The carer reported she did not feel included in discharge planning. The hospital stay was 23 days including 8 days on OPERA and there were seven care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was characterised by a combination of short term live-in family support, follow up therapy by a community rehabilitation service and the transmission of information to the GP upon discharge. There was a predictable divergence in how this woman and her carer perceived this transition at the time of discharge. She was confident of her ability to manage at home without any increased support. Her carer on the other hand perceived that there were gaps with social activities, meal preparation, psychological support, nursing care, taking medication and a need for individual rather than group physiotherapy. There were two emergency department presentations post OPERA and she was admitted on one of those occasions.

### 3.13 Case study N14

#### **Key theme: *Withdrawing from system interventions***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 92 year old man presented at the emergency department with severe back pain. There were two emergency department presentations in the preceding month, one resulting in an admission. There was dissatisfaction with the timing of this discharge exhibited by the carer's perception that it was driven by bed shortages rather than patient care and a warning issued to medical staff that she would call the ambulance again if his health did not improve. Despite his latent dissatisfaction with the GP approach to pain management, there was regular GP contact and this man acquiesced with frequent medication changes. Prior to recent admissions, his restricted health capacity was managed with the support of a comprehensive domestic care package, a network of neighbours and family members and underpinned by a cautious, risk avoidant approach in daily living. While the network of support was reassuring, there was a tendency for him to accept help when offered rather than request it which was a source of frustration for the carer.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Care transitions through acute and sub-acute wards were marked by delayed or unresponsive staff encounters, miscommunication between staff and with family members, and a lack of information about care plans exacerbated by family visits outside the working hours of some staff. Frequent unexplained changes in the discharge date were a source of frustration and anxiety for this man while unexplained changes in medication were disconcerting for family members. This was further demonstrated by confusion about the purpose of the home visit as related by the carer, "It was a bit overwhelming for him because he thought he was going to stay there." He accessed all allied health professions except Psychology. This man's passive acceptance of these encounters and reluctance to complain aligns with his lack of agency in relation to previous unsatisfactory GP and hospital contact. The turning point in relation to the carer's assessment that, "communication has been absolutely shocking" occurred with a teleconference organised by OPERA staff and attended by medical and other staff involved in care which she found informative. There was appreciation of those occasions when empathy was expressed for him personally rather than focusing on his medical condition. This hospital stay was 28 days including 15 days on OPERA.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home involving the Transition Care Program was experienced as disruptive and unsettling by this man. The involvement of multiple service providers was confusing and the lack of consistency and changes in domestic care arrangements was bewildering. Mutual recognition of this outcome by the carer and providers resulted in the termination of this arrangement and a resumption of previous support. Coordination of this (fifth) transition was managed by the carer with assistance from the Transition Care Program staff. The carer perceived domestic care arrangements to be inflexible, inadequate and in some cases of poor quality but nonetheless, she describes it as "better than nothing." This man's rejection of any change in arrangements including a return to hospital or a nursing home was exemplified by his determination to stay at home, "Well they think I'm not able to manage but hand and foot I will contest that because I will not part with my dog for any money, I don't care." Post OPERA there were no emergency department presentations or hospital admissions.

### 3.14 Case summary O15

#### **Key theme: *Adapting to changing needs***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 84 year old man with a history of recent falls experienced a sudden, intense dizzy spell in the early hours of the morning, activated his medical alarm and was attended by paramedics. He activated the alarm again a few hours later and was transported to hospital. He managed the gradual decline in his health with the support of comprehensive domestic and personal care services, a supportive family network and a close neighbour. He had a trusted GP who did regular home visits and he rarely presented to hospital. He had no emergency department presentations or hospital admissions in the six months prior to this admission. He valued his independence and avoided taking risks as he lives alone. His approach to managing his declining health was characterised by a sense of control. Control involved a belief that day to day problems were manageable, agency in ensuring his needs were met, the capacity to adapt to changing health circumstances and an implicit trust in professional health care. This was typified by his confident response when asked if he knew where to go to access extra help if needed. His trust in health professionals was exhibited by his willingness to go to hospital, "I was too sick to be caring, I just wanted to get in there and let them take over".

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

His tolerance of system pressures including delays in the emergency department and multiple ward changes, "Well they're only doing it for my good", and numerous changes in the discharge date from OPERA aligns with his trust in health professionals. His confidence was further exemplified by a cooperative and compliant approach to care on the OPERA ward. For example, he said "They know what they're doing. I just got to lie there and do it". He accessed all allied health professionals except Speech Pathology and Psychology. His appreciation for the responsiveness and respect shown by hospital staff was not shared by his carer who observed a lack of dignity in caring for older patients on acute wards, found it difficult to obtain information when staff were not available at visiting hours and reported an overly rigid interpretation of what is and is not a part of nursing roles. Nonetheless, there was acknowledgement by the carer that this man was treated as a person not just a patient on the OPERA ward and she felt included in discharge planning. This man expressed eagerness and confidence in the timing of the discharge although his carer harboured concerns about further falls. There was an improvement in functioning on OPERA (25 point increase in FIM score). The length of stay in hospital was 24 days including 15 days on OPERA. He experienced four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was characterised by the timely and predictable commencement and resumption of services including therapy and falls prevention activities. His sense of control was exemplified by exercising choice in the way therapy was delivered, participation in optional social outings, confidence in requesting support in daily domestic tasks and capacity to adapt to new services rather than his neighbour's support when that was no longer available. Further, there was acknowledgement of forward planning for residential aged care, "It would take me a few days to get organised ... but no, I've got to the stage now that I know I need it sort of thing." He did not present to the emergency department nor was he admitted to hospital again during the study period.

### **3.15 Case study P16**

#### **Key theme: *Battling through disconcerting times***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

This 86 year old man had a recent history of falls with increasing balance and mobility problems leading to a more restricted lifestyle. He lamented that his health decline had resulted in a significant burden for his carer who also had multiple health issues and restricted mobility. They were both stridently independent and he managed with minimal service support (garden care) and GP monitoring. Although there was continuity of care from the same GP for over a decade and regular contact, this man expressed dissatisfaction with the care provided, which he attributed to the GP's poor communication skills, apathy and lack of follow-up. He was despondent about his declining health and generally pessimistic about the prospect of either GP or hospital care being able to improve it. In contrast, his carer was vigilant in seeking professional help, usually from the GP. This emergency department presentation was instigated by the carer with strong resistance from this man who had fallen approximately one week prior and continued to experience pain.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

The transition from home to sub-acute care was marked by this man's persistent despondency. His characteristic pessimism was exhibited by this description of his day, "I get up in the morning, have a shower, have my breakfast and I sit down and I see somebody and we talk for a few minutes and I'm sitting there for the rest of the day which to me is a waste of time." He expressed frustration with the focus on physical activity rather than his headaches, "Exercises might be good in your legs and arms but not in your brain." His concerns were exacerbated by his assumptions about an x-ray which he saw on a ward monitor, "I don't see how they are going to fix that. I mean I've seen the doctors and I think that if it could be done they would have told me". This perception was challenged by his carer's view that there was a thorough investigation of his condition upon arrival at the emergency department and that care on the OPERA ward resulted in improved function, less pain and reassurance for her. He accessed all allied health professionals except Speech Pathology and had improved functioning on discharge (16 point increase in FIM score). There was appreciation of the friendliness and attentiveness of staff and the reassurance of a home visit. However, both this man and his carer expressed confusion about discharge arrangements which were perceived to be rushed and disappointment that a promised meeting with a doctor prior to discharge did not eventuate. There were four care transitions. The length of stay was 25 days including 15 on OPERA.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home involved minimal uptake of the support arranged in sub-acute care and a reinvigorated sense of agency by this man and his carer. "We are people who don't want help" typified this man's approach to care post discharge. The carer was resolute in her commitment to providing support despite his ongoing concerns about her own health. He refused a referral to a Psychologist but consulted a different GP who he found to be accessible, caring and effective. Respite arrangements were found to be costly and inadequate by the carer, who also declined carer's support because she didn't like groups. An unmet need identified by the carer was "A guy that can every now and then pop up and talk with him and all that because he's got no hobbies, he doesn't mix with people and I think that makes a lot of difference." There were no further presentations or admissions during the study period.

### 3.16 Case summary Q17

#### **Key theme: *Negotiating complex caring***

#### **Health, social profile prior to acute presentation; transition community to emergency**

This 86 year old woman with an advanced progressive neurological condition and persistent balance and mobility problems led a restricted lifestyle and was heavily dependent on her carer for support. She had regular contact with a GP who also referred her for private specialist medical treatment and therapy. There were public and privately arranged personal and domestic services in place. She had a history of frequent falls (two to three a week) but reported only one previous falls-related admission which was also to OPERA over one year earlier. Her carer was vigilant and astute in managing her care. On this occasion he decided that hospital care was required so he called an ambulance. While acknowledging the demands of caring, this woman was pragmatic about her carer's resistance to further help at home, "I think he could have benefited from more but he says no." The carer was stoic, took pride in his capacity to manage complex caring and valued autonomy and privacy.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Trust in professional care on the OPERA ward was exemplified by passive acceptance of decision making and cooperation with therapy staff apart from irritation with forced help seeking to mobilise. This woman reported that staff listened to her concerns and she was kept informed about her care, "I knew what was happening all the time" including medication changes and the timing of discharge. This experience was not shared by her carer who felt excluded and undervalued. His experience was characterised by the perception that assumptions were made about his needs and those of his wife, the length of stay was unnecessarily long, he was excluded from discharge planning and there was a lack of respect for his knowledge and expertise as a carer. His strongly held view that he should have been included in decision making and discharge planning aligns with his assiduous approach to care giving and preferred autonomy which was demonstrated in this comment about discharge planning, "She told me what I should have and I told her that I thought I could manage all of this myself. Well I tried to be polite but I reckon I knew as much about her than she ever would be able to find out over two weeks." This woman accessed all allied health staff, was in hospital for 16 days, 11 days of which were on OPERA and there were 4 care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

Although the transition from hospital to home involved the timely resumption of existing services, this was a carer-contingent transition that was not viable without sustained carer input, "Without my husband I wouldn't be able to manage of course." Complex care arrangements involving private and public sector providers, a demanding daily routine and newly emerging needs for which there was no pre-planning demonstrated the limits of patient and carer agency in a fragmented and disconnected system, "We seem to go from one health professional to another one who will refer us to another one and we go the rounds and we're sort of going to an OT to a GP to a specialist to a radiographer or radiologist and then back again to a GP." With characteristic stoicism, the carer framed these issues as "time consuming" rather than "difficult" and rejected the need for help. He emphasised the critical importance of "moral" support for carers generally saying, "carers have got to make their own way." Unlike other similarly vigilant carer participants, this man was focused on avoiding future hospital admissions, "I'm going to try and make sure she doesn't go into hospital again." There were no further presentations or admissions in the study period.

### **3.17 Case study R18**

#### **Key theme: *Languishing in the health system***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

With a serious, long term chronic disease, a recent fracture, recurring falls and mental health issues, this 72 year old man had a prolonged period of engagement with the health system. His GP arranged this admission during a routine consultation following a fall the previous day. He leads a restricted lifestyle in supported accommodation with additional personal, domestic and social support, home visiting nursing care, regular GP monitoring and frequent private and public hospital admissions. He presented to ED five times in the preceding six months resulting in one admission into a private hospital after being transferred from ED. He had a supportive family member. He displayed a high level of health literacy. This was demonstrated by his detailed knowledge of his chronic disease medication and dietary requirements and frustration with what he and his carer refer to as “playing the game” with medical staff who did not listen or seek his opinion. He was generally resistant to activating the medical alarm because it led to hospitalisation. However, on this occasion, he admitted that he was struggling with frequent falls and needed more home help.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Care on the OPERA ward held the promise of regaining his independence through improved mobility. This was demonstrated by his high expectations of functional outcomes and frustration with an intervening acute transition where he perceived he was “not achieving much”. He expressed confidence that he would receive help with physical and mental health issues on the OPERA ward and he was eager to participate in therapy, “I’m getting three and five people a day coming in and saying come on, we’re going for a walk ... I’ve never knocked anybody back yet.” He accessed all allied health professions on OPERA. There was predictable anger and frustration with hospital management of his chronic disease and a perceived delay in accessing physiotherapy. However, on discharge he reported feeling stronger physically and mentally and expressed confidence and tenacity about being able to manage at home, “I’m going to be able to manage. I’m going to make a point of it.” There was functional improvement on discharge (28 point increase in FIM score). Despite improved functioning, his carer was cautious about his capacity to manage at home and considered this was contingent upon using a walker, judicious use of the medical alarm, practising exercises and resolution of issues with the GP about pain management medication. There were five care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

The transition from sub-acute care to home was characterised by the timely and coordinated resumption of care arrangements. Links with sub-acute care were evidenced by the transfer of information between the non-government provider, carer, GP, and sub-acute staff. He exhibited a high level of agency in relation to the health system exemplified by identifying needs, requesting new services, negotiating changes in existing services and resourcefulness in utilising his carer. These efforts were facilitated by this man’s eligibility for a wide and flexible range of services without cost and trusting relationships with some providers. Despite this, the carer was despondent, “We are pretty much back to where we started sort of thing and he’s got everyone coming around. He’s not worried about helping himself so he’s never going to get any better.” He was readmitted to hospital and the OPERA ward again within a six month period.

### **3.18 Case study S19**

#### **Key theme: *Uncharted territory***

#### **Health, social profile prior to acute presentation; transition community to emergency**

This 80 year old man with a history of heart problems became progressively unwell over a period of months and presented to the emergency department via ambulance with breathlessness. He had regular contact with a trusted GP. Both he and his carer recounted medical advice to call an ambulance to obtain urgent medical attention, particularly after hours and on weekends if unable to contact their GP. He presented to ED four times in the six months preceding OPERA, resulting in two admissions. His implicit trust in professional health care was demonstrated by his respect for the expertise of his GP and the belief that his medical condition was professionally and successfully managed by hospital staff in the past. For his carer, the emergency department provided the reassurance of immediate, expert care, "I know he is in good hands there." At home, he and his wife provided mutual support and accessed support services for their adult daughter with a disability. He valued his independence and was frustrated by unsuccessful attempts to obtain home oxygen. He was optimistic about returning to good health and being able to travel with his family post OPERA.

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

There was acceptance of system pressures and delays in acute and sub-acute care. His experience of the OPERA ward was supportive and inclusive apart from an incident with a nurse which was resolved when he complained and a "misunderstanding" with a doctor. His confidence in professional care was reinforced by the perception that his medical condition was thoroughly investigated; he was given comprehensive, accurate information about medication and arrangements for an outpatient appointment. He actively engaged in his care by asking questions. He accessed all allied health professions except Speech Pathology and Psychology. In contrast, there was indifference by the carer associated with her trust in professional medical care, typified by the remark, "I had no interest and I was never told what the doctor's reports were. ... I never questioned what they were doing because they know what they do. I have full confidence in them." Falls prevention information that was coincidentally available was, however, welcomed by the carer. He was keen to go home but had a lingering concern about his capacity to manage. However, he was reassured that he could rely on a friend for transport and call the ambulance if "something goes really wrong." His carer adopted a 'wait and see' approach and was uncertain who to contact if problems arose, "I just don't know. I never thought about that ... he gets in touch with his GP and we get in touch with the hospital and that's about it." His hospital stay involved 31 days including nine on OPERA and four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

This transition was minimalist and medically focused. Links with sub-acute care were limited to information provided to the GP and a mobility aid. Unmet needs soon emerged in relation to pain management, transport, social activities and carer support. While she remained stoic, there was a marked change in the carer's approach to help seeking associated with this further unexpected deterioration in health. She was unprepared for caring which involved a greater degree of agency and was uncertain how to access support other than the GP and hospital. For example, she said "I wonder if there is a service that can take him out ... take him out maybe somewhere he can go and relax." but said "I don't know. I haven't got a clue" when asked who she could ask about that. Post OPERA he presented to the emergency department twice, resulting in one admission.

### **3.19 Case study T20**

#### **Key theme: *Succumbing to dependency***

#### **Health and social profile prior to acute presentation; transition from community to emergency**

Rapidly declining health and limited mobility leading to a more restricted lifestyle resulted in this 79 year old man moving in with the family member who coordinated his health and social support arrangements and assisted with daily living. Prior to this emergency department presentation for breathlessness, these arrangements included regular monitoring and pain management by a trusted GP, home visiting nursing care, home modifications, mobility aids and regular respite. For after-hours health issues he relied on a home visiting GP service or called an ambulance. He presented to ED on one occasion in the six months preceding OPERA which resulted in a hospital admission. He valued his independence and expressed frustration with increased dependency, loss of autonomous decision making, limited mobility and side effects of medication. He frequently referred to feeling “mad” about these restrictions on his previously active lifestyle. His carer was vigilant in providing support and astute about help seeking. This was demonstrated by her approach to this emergency department presentation, “I’d done everything possible to keep him healthy before his admission so I knew it was out of my hands.”

#### **Care transitions within acute/sub-acute wards, processes of care, preparedness for discharge**

Admission to the OPERA ward held the promise of improving his mobility, “I want to get rid of this walker if I can.” His sense of agency in achieving this objective was exemplified by being proactive in seeking information and clarification of advice, participation in therapy and engagement with falls prevention information provided as part of discharge planning. He accessed all allied health professions except Psychology. His experience of OPERA was supportive and inclusive. There was disappointment and resistance when expected outcomes were not achieved. Both he and his carer believed he would have benefited from a longer OPERA stay and he contemplated seeking help elsewhere, “And this hip, I might go back down to Brisbane”. For the carer, emergency department and Medical Assessment Unit care was timely, comprehensive and inclusive. This was typified by the provision of an early update on care, “One of the doctors phoned me at 3.30 in the morning just to give me a quick update with what had happened.” There was similar appreciation for medical information proactively provided in the OPERA ward, “He phoned me a couple of days later and updated me with all of the information which was fantastic.” The carer was reluctant to approach OPERA staff for information because, “I don’t want to be a pest”, and relied on information being volunteered by staff or transmitted by her father. His hospital stay was 14 days including 12 days on OPERA. There were four care transitions.

#### **Care transition from sub-acute care to home, system encounters post discharge**

This transition was enhanced by the reassurance of a pre discharge home visit and safety assessment by OPERA staff, outpatient appointments arranged by OPERA staff, fulltime support by his carer who also made an appointment with his GP and a home medication review requested by the GP. Despite this, there was an emergency presentation followed by admission to the cardiac ward within days of discharge from OPERA. Following this admission, there was continued heavy reliance on the carer who displayed confidence in a plan to contact a non-government care provider, GP and the ambulance for ongoing care. There were two further 2 ED presentations resulting in one hospital admission in the six month period following OPERA.

**Appendix 4:** Pre and Post OPERA Emergency Department Presentations, Hospital admissions, Thematic Storyline, Factors Influencing Patient Experience and Care Transitions

<b>Presentations six months Pre OPERA</b>	<b>Thematic Storyline</b>	<b>Major Factors Influencing Patient Experience</b>	<b>Illustrative Quotes</b>	<b>Care Transitions</b>	<b>Presentations Six Months Post OPERA</b>
0	Battling against despondency	'Wait and see' help seeking; active participant in care, unmet needs, minimalist, short-term post discharge care	"I just battled my way through the pain". "I just don't know where to go from here."	3	0
0	Reaching the limits of capabilities	Comprehensive health and social care arrangements, carer fatigue, discontinuities and unmet needs post discharge	"It should have been a bit longer [on OPERA ward], but then I was glad to get home because I was gone three weeks" "It's so hard to get anyone to relieve me" (carer)	5	1 <sup>a</sup>
0	Reclaiming a productive life	Self-reliant and active, preventable fall, supportive and coordinated care, TCP, unmet emergent needs and barriers to care	"I'm pretty healthy, I look after myself" "Just sort it out and get home" "It [accessing private medical specialist] depends on how much it costs"	4	0
1 <sup>a</sup>	Adapting to an unfamiliar lifestyle	Active lifestyle, preventable fall, supportive and inclusive OPERA experience, TCP, unmet emotional needs	"I'm very, very healthy" "When we got there [GP] for her check-up they had been sent all the information" (carer)	4	2 <sup>b</sup>

<b>Presentations six months Pre OPERA</b>	<b>Thematic Storyline</b>	<b>Major Factors Influencing Patient Experience</b>	<b>Illustrative Quotes</b>	<b>Care Transitions</b>	<b>Presentations Six Months Post OPERA</b>
0	Enduring a precarious recovery	Significant primary, and secondary care involvement, preventable fall, lack of confidence on OPERA discharge, financial barriers to care, confusion and discontinuity post discharge	<p>"I have a goal that I want to reach to get me home. If you don't work hard you will never get anywhere, you will be there for longer still".</p> <p>"Because we left on- what you'd call a bad footing because they couldn't understand our meaning of not being able to afford something".</p>	4	0
0	Resuming an independent lifestyle	Close GP and carer involvement, active participation in care by patient and carer, confidence on discharge, TCP, information links between sub-acute and primary care	<p>"I could feel myself getting better. And the physios were excellent."</p> <p>"If I want something, I'll find out what I can do about it".</p>	4	0
0	Holding onto independence	Wait and see help seeking, close GP and carer involvement, prior OPERA and TCP client, confidence on discharge, links between sub-acute and primary care	<p>"We didn't spot this very gradual diminishing of his general health" (carer)</p> <p>"She [TCP] came to two visits with the doctor and explained why the drugs were changed."</p>	4	1 <sup>c</sup>
0	Regaining a manageable routine	Carer dependent for daily living, minimal home care and GP input, cautious attitude, significant improvement in function on OPERA, confident on discharge, strong carer agency in relation to care.	<p>"They said I had to have a GP."</p> <p>"She cooks all the meals for me and she does all my shopping and gives me a shower at night, everything."</p>	4	0

Presentations six months Pre OPERA	Thematic Storyline	Major Factors Influencing Patient Experience	Illustrative Quotes	Care Transitions	Presentations Six Months Post OPERA
			“So they listened and they treated the whole person not just her actual thing that she went in for.” (carer)		
0	Being unprepared for change	Active lifestyle, preventable fall, carer responsibilities, wait and see approach to help seeking, divergent patient and carer goals, minimalist short term family driven post OPERA planning, unmet needs in community	“I’ve always managed before so I can’t see any difference.” “I don’t know what’s happening or if anything is going to happen or if they’re just going to leave it to the GP.” (carer) We’re in a bit of a grey area. We don’t know what to do.” (carer)	6	1 <sup>c</sup>
0	Balancing family and professional helping	Co-located carer and family support, wait and see attitude to help seeking, underutilisation of and restricted access to GP, dissatisfaction with communication on OPERA ward, lack of confidence by patient on discharge, discontinuity and gaps post OPERA	“ I said to myself, I should be ok, it will go away.” “Even though I was getting better according to them, I felt like I [should have] stayed a little bit longer because the care they were giving me was good ... because I wouldn’t be getting that kind of care here [at home].”	5	3 <sup>d</sup>
6 <sup>e</sup>	Breaking the cycle of falls	Multiple prior ED presentations for falls, carer burden, domestic support, supportive and inclusive OPERA experience, links with primary care, confidence in GP	“I’ll be glad when I’ve been home for a week or so and I haven’t fallen over and come back in here.” “Thorough and supportive and you couldn’t ask for better” [OPERA]. (carer)	4	0

<b>Presentations six months Pre OPERA</b>	<b>Thematic Storyline</b>	<b>Major Factors Influencing Patient Experience</b>	<b>Illustrative Quotes</b>	<b>Care Transitions</b>	<b>Presentations Six Months Post OPERA</b>
0	Resisting patient trajectory	Self-reliant, avoids help seeking, regular GP contact, cautious and vigilant carer, disruptive care transitions, supportive OPERA experience, resistance to post discharge planning	“I just decided that she was too ill and needed to be in hospital”. (carer) “There’s some place up at Smithfield that they organise and do exercises up there. And I said oh no, I’m not going with a group of old people.”	7	2 <sup>f</sup>
2 <sup>f</sup>	Withdrawing from system interventions	Comprehensive domestic care package, network of support, lack of agency, carer dissatisfaction with hospital communication and post discharge arrangements, TCP	“I can’t doubt doctors you know. But certainly his [GP] treatment hasn’t been good for me.” “”My father was overwhelmed with so many people coming so I had to stop it.”	5	0
0	Adapting to changing needs	Comprehensive personal and domestic care package, network of support, agency in relation to care, confident on discharge, timely, coordinated post discharge care, forward planning	“I was too sick to care. I just wanted to get in there [hospital] and let them take over.” “I’ve got to the stage now that I know I need it [residential aged care] sort of thing”.	4	0
0	Battling through disconcerting times	Independent, carer burden, avoids help seeking, vigilant carer, despondent about future, inflexibility and cost constraints post discharge	“I think I’m on the way out” “Battling through the best way we can”	4	0

Presentations six months Pre OPERA	Thematic Storyline	Major Factors Influencing Patient Experience	Illustrative Quotes	Care Transitions	Presentations Six Months Post OPERA
0	Negotiating complex caring	Significant primary, secondary, private and public care, complex care arrangements, stoic vigilant carer, carer dissatisfaction on OPERA, carer fatigue	“Without my husband I wouldn’t be able to manage of course” “I’m going to try and make sure she doesn’t go into hospital again.”	4	0
1 <sup>g</sup>	Languishing in the health system	Prolonged engagement with health system, patient agency and health literacy, carer fatigue, links between primary and sub-acute care, extensive service eligibility	“I had an appointment to see the doctor and when I saw him he said I think we better get you into hospital.” “I know I’m going to be able to manage. I’m going to make a point of it.”	5	1 <sup>c</sup>
5 <sup>h</sup>	Moving into uncharted territory	Confidence in GP, optimistic about care, multiple recent ED presentations, short term medically focused discharge planning, unmet needs post discharge, carer burden	“They’ve [OPERA] answered all my questions.” “I never questioned what they were doing because they know what they do.” (carer)	4	2 <sup>f</sup>
3 <sup>c</sup>	Succumbing to dependency	Co-located vigilant carer, close GP connection, patient and carer agency, supportive and inclusive OPERA experience, transmission of information between primary and sub-acute care	“It was out of my hands. I’d done everything possible to keep him healthy before his admission.” (carer) “No, I’m going to be alright, be the same as I was.”	4	1 <sup>i</sup>

*Note.* Care transitions refer to movements between providers and settings for clinical and non-clinical reasons (bed pressures) related to the current OPERA admission. Care transitions included : Home to ED; ED to non-OPERA ward; non-OPERA ward to mobile GEMS (new medical and allied health team but same nursing team and location), Mobile GEMS to OPERA (change of location and nursing staff but same medical and allied health team), non-OPERA to OPERA ward, non-OPERA ward to non-OPERA ward, OPERA to home, home with TCP to home without TCP. Pre and Post OPERA presentations (other than TCP) have not been included in the total number of care transitions. <sup>a</sup>Presented to ED but not admitted; <sup>b</sup>Presented to ED 2 times but not admitted; <sup>c</sup>Presented once to ED and was admitted; <sup>d</sup>Presented to ED 3 times resulting in 3 admissions; <sup>e</sup>Presented to ED 6 times resulting in 3 admissions; <sup>f</sup>Presented to ED 2 times resulting in one admission; <sup>g</sup>Presented to ED 5 times resulting in 1 admission; <sup>h</sup>Presented to ED 4 times resulting in 2 admissions; <sup>i</sup>Presented to ED 3 times resulting in 2 admissions.

## Appendix 5: Focus Group participants

### Hospital Focus Group (HFG) Participants' Profile

Participants	Profession	Position title	Area of current practice	Years in current position	Gender
1.	Nurse	Bed Manager	Acute care	1-5	Male
2.	Occupational Therapist	Allied Health Team Leader	Sub-acute within an acute facility	1-5	Female
3.	Social worker	OPERA Social Worker	Sub-acute within an acute facility	1-5	Male
4.	Nurse	Nurse Unit Manager	Acute care	<12 months	Male
5.	Physiotherapist	TCP intake officer	Sub-acute within an acute facility and within the community	1-5	Female
6.	Physiotherapist	Clinical Educator	Acute care	1-5	Female
7.	Nurse	Nurse Unit Manager	Sub-acute within an acute facility	<12 months	Female
8.	Doctor	Registrar Sub-acute	Sub-acute within an acute facility	<12 months	Male

Community Focus Group 1 (CFG1) Participants' Profile

<b>Participants</b>	<b>Profession</b>	<b>Position title</b>	<b>Area of current practice</b>	<b>Years in current position</b>	<b>Gender</b>
1.	Doctor	General Practitioner	Primary Health	>5	Male
2.	Doctor	General Practitioner	Primary Health	>5	Male
3.	Nurse	Co-ordinator Support	Non-Government Organisation	<12 months	Female
4.	Nurse	CNC Transition Care Program	Sub-acute in Community Health	<12 months	Male
5.	Social Worker	FNQ ACAT & Memory Service Team Leader	Acute Care & Community Health	>5	Female
6.	Co-ordinator	HACC co-ordinator	Non-Government Organisation	1-5	Female
7.	Nurse	Primary Health Project Officer	Primary Health	<12 months	Female

Community Focus Group 2 (CFG2) Participants' Profile

<b>Participants</b>	<b>Profession</b>	<b>Position title</b>	<b>Area of current practice</b>	<b>Years in current position</b>	<b>Gender</b>
1.	Doctor	General Practitioner	Primary Health	>5	Male
2.	Doctor	General Practitioner	Primary Health	1-5	Female
3.	Nurse	HACC Clinical Nurse	Community Health	1-5	Female
4.	Nurse	ACAT Clinical Nurse	Community Health	1-5	Female
5.	Care Co-ordinator	Community Care Co-ordinator	Non-Government Organisation	1-5	Female
6.	Physiotherapist	Community Rehab Team Leader	Community Health	1-5	Female
7.	Nurse	National Care Manager	Non-Government Organisation	1-5	Female
8.	Care Co-ordinator	Aged Care Co-ordinator	Non-Government Organisation	1-5	Female

# Appendix 6: Interview Guides for patient and carer interviews

## Interview Guide for Patient Interview 1

(30 mins approx)

### Purpose of interview

Understand the events that lead to hospital visit, including behaviours about health use that might lead to use of hospital/ED  
Expectations of what is going to happen

### Introductory comments

- *We are grateful that you have agreed to talk with us about your health care. Please be as honest and as constructively critical as you can because that will really help us.*
- *We are taking steps to protect your privacy. When we talk or write about your experiences, we won't use your name nor where you come from.*
- *Would you like to ask any questions before we get started?*

### Events leading to hospital

#### **1. Tell me about the events that led you to be here at hospital/your presentation at ED?**

Prompt:

*Can you tell me what happened?*

*Who did you talk to about coming to hospital/ED?*

*Can you tell me what your problems were at that time?*

*How did you see the visit to the hospital/ED resolving these problems?*

*Were you aware of any other ways of resolving your problems?*

### Preadmission management

#### **2. How do you think you have been managing at home before you came to hospital?**

Prompt:

*Who typically helps you manage at home?*

*Do you receive any formal services?*

*Why do you think it wasn't enough this time and you had to come to hospital?*

*Who normally looks after your health or medical care when you are living at home?*

*Do you normally have much contact with your GP?*

*Have you had any other admissions to hospital recently?*

*When you have been managing at home has there been anything else that you needed and you weren't able to get?*

**OPERA Unit admission and expectations**

- 3. *What has it been like going from ED to the ward and then onto this OPERA unit?***
- 4. *Now that you have been admitted onto the OPERA Unit what do you hope to get out of being here?***
- 5. *Do you have any concerns or worries about being in hospital?***

## **Interview Guide for Patient Interview 2**

**(Approx 45 mins)**

### **Purpose of interview**

Expressions of processes of care

Preparedness for discharge

Introductory comments

- *We are grateful that you have agreed to talk with us about your health care. Please be as honest and as constructively critical as you can because that will really help us.*
- *We are taking steps to protect your privacy. When we talk or write about your experiences, we won't use your name nor where you come from.*
- *Would you like to ask any questions before we get started?*

### **Experience of GEMS**

#### **1. Tell me what it has been like being on the OPERA Unit?**

Prompt:

*What did you like about being on OPERA?*

*Was there anything that you didn't like about being on OPERA?*

### **Processes of care**

#### **2. What has been important to you in the care that you have received here?**

Prompt:

*What did you find valuable about your care?*

*How did you find the communication with the staff here?*

*Have you always felt you had information about what was happening in terms of your care?*

*Have you felt included in terms of the decisions about your care?*

### **Expectations of care**

#### **3. Tell me how being on OPERA has addressed your problems**

Prompt:

*How has being on OPERA helped you?*

*Have you other needs that you are concerned about at this time?*

### **Preparedness for discharge**

#### **4. Was there anything that you were expecting that did not happen?**

Prompt:

*Can you give me an example?*

*Have your problems been addressed?*

What have you been doing on OPERA with the therapists to get you ready for discharge and being able to manage at home?

**5. Tell me about the preparations for your discharge.**

Prompt

*What do you think you will need help with when you get home?  
Have arrangements been made for someone to come and help you with that?  
What are the arrangements?  
Have any other services been arranged for you (either new or existing)?  
What are they?  
Why have they been arranged?  
Do you foresee any problems in accessing the services?  
Who and how will you contact once you are home if the help isn't enough or doesn't start up?  
How will that work?*

**6. How do you think being on OPERA has helped you be able to return home?**

Prompt:

*How do you feel about going home (or alternative)?  
Do you feel ready to go home?  
Do you have any other concerns about leaving?*

## **Interview Guide for Patient Interview 3**

**(Approx 45 mins)**

### **Purpose of interview**

Implementation of discharge plan

Adequacy, appropriateness and timeliness of services after discharge

### **Introductory comments**

- *We are grateful that you have agreed to talk with us about your health care. Please be as honest and as constructively critical as you can because that will really help us.*
- *We are taking steps to protect your privacy. When we talk or write about your experiences, we won't use your name nor where you come from.*
- *Would you like to ask any questions before we get started?*

### **Experience after discharge**

#### **1. Tell me about how have you been managing since you returned home**

Prompt:

*What was your experience of the transition from hospital to home?*

*What has worked well?*

*Since you have been at home have there been any events or unexpected issues with your services/care that have concerned you?*

*How did that come about?*

### **Implementation of discharge plan**

#### **2. When you left hospital there was a plan for your care at home. How did that go?**

Prompt:

*Have you had any concerns about accessing services?*

*Waiting time, cost, coordination, information?*

*Any other worries or concerns?*

#### **3. How are the services and follow-up therapy planned for you by OPERA been meeting your needs? I am talking about the domestic and personal care services and therapies.**

Prompt:

*Have there been any changes to the plan that you are aware of?*

*Have you been to hospital again?*

*How did that come about? What was the reason for presenting to hospital?*

*Are there any areas where you need additional help?*

*Under what circumstances do you think you would have to come back to hospital/ED?*

## **Engagement with primary health services since discharge**

**4. How reassured are you that you have the level of support you need now to manage at home?**

Prompt:

*Who is the key person or service to help you manage at home now?*

*What role do you see your GP has in helping you manage at home now?*

*Are there other health professionals you think have an important role?*

**5. After your experience, what would you like to change to improve things for the next older person who comes into hospital? What is important to keep?**

## Interview Guide for Carer Interview 1

(Approx 45 mins)

### **Purpose of interview**

Insight into processes of care  
Preparedness for discharge

### **Introductory comments**

- *We are grateful that you have agreed to talk with us about your family member's health care. Please be as honest and as constructively critical as you can because that will really help us.*
- *We are taking steps to protect your privacy. When we talk or write about you and your family member's experiences, we won't use your names nor where you come from.*
- *Would you like to ask any questions before we get started?*

### **Events leading to hospital**

#### **1. Tell me about the events that led your family member presenting at ED?**

Prompt:

*Who normally looks after their health or medical care when they are living at home?  
Do they normally have much contact with their GP?  
Who did you talk to about your family member coming to hospital/ED?  
Have they had many recent hospital admissions?  
Do they receive any formal services?*

#### **2. What did you think was going to happen when they got to hospital?**

Prompt:

*How did you think coming to ED would help?  
Were there any other ways you could have helped your family member at that time?*

### **GEMS admission and expectations**

#### **3. What has it been like for you and your family member having to go through ED, onto another ward and then onto OPERA?**

#### **4. Did the GEMS program meet your expectations?**

Prompt:

*In what ways?  
Was there anything that didn't meet your expectations?*

## Processes of care

**5. What has been important to you in the care that your family member has received here?**

Prompt:

What did you find valuable in the way they were treated?  
How did you find the communication with the staff here?  
Have you known what was going on for your family member?  
Have you felt included in terms of what is happening with your family member?

## Preparedness for discharge

**6. Was there anything that you were expecting that did not happen?**

Prompt:

Can you give me an example?  
Have their problems been addressed?  
Do you feel they are ready to come home?  
Do you feel ready and prepared for them coming home?

**7. Tell me about the preparations here for the discharge of your family member.**

Prompt:

What do you think they will need help with when they get home?  
Have arrangements been made for someone to come and help them with that?  
Are you having to do more to help your family member?  
Has that been discussed with you?  
Have any other services been arranged?  
What are they?  
Why have they been arranged?  
Do you foresee any problems in accessing the services?  
How and who will you contact once you are home if things aren't going to plan?  
Do you have any other concerns?

**8. How do you think being on OPERA has helped you and your family member be able to return home?**

Prompt:

How do you feel about your family member going home (or alternative)?

**9. Overall is there anything that could have been done differently or better?**

## **Interview Guide for Carer Interview 2**

**(Approx 45 mins)**

### **Purpose of interview**

Implementation of discharge plan  
Adequacy, appropriateness and timeliness of services after discharge

### **Introductory comments**

- *We are grateful that you have agreed to talk with us about your family member's health care. Please be as honest and as constructively critical as you can because that will really help us.*
- *We are taking steps to protect your privacy. When we talk or write about you and your family member's experiences, we won't use your names nor where you come from.*
- *Would you like to ask any questions before we get started?*

### **Experience after discharge**

**1. Tell me about how have you and your family member been managing since they returned home.**

Prompt:

*What was your experience of the transition from hospital to home?  
What has worked well?  
Since they have been at home have there been any events or unexpected issues with their care or services that have concerned you?  
How did that come about?*

### **Implementation of discharge plan**

**2. When your family member left hospital there was a plan for their care at home. How did that go?**

Prompt:

*Have you had any concerns about accessing services?  
Waiting time, cost, coordination, information?  
Any other worries or concerns?*

**3. How are the services and follow-up therapy planned for your family member by OPERA been working? I am talking here about the domestic and personal care services and therapies.**

Prompt:

*Are they meeting their needs?  
Have there been any changes to the plan that you are aware of?  
Have they been to hospital again?  
How did that come about?  
Are there still any areas where you or your family member need additional help?*

## **Engagement with primary health services**

**4. How reassured are you that you and your family member have the level of support you both need now to manage at home?**

Prompt:

*What role do you see the GP playing in helping them manage at home now? Are there other health professionals who have an important role?  
Who is the key person to help you manage at home?*

**5. After you and your family member's experiences, what would you like to change to improve things for the next older person who comes into hospital? What is important to keep?**

# Appendix 7: Focus Group Interview Guides

## Internal Focus Group Understanding System Challenges and Local Solutions

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### 1. Context: Overview of study population

- Av 82 (2 participants are under 70 - 64 and 69 both Indigenous)
- 50% approx fractures
- 50% medical complications
- Variation in service access/use prior to admissions
- All nominated a GP – variation in regularity/frequency
- All nominated a carer/family member
- General: don't want to come to hospital; want to get home as soon as possible

### 2. Experiences with study population

- General impressions: what are the challenges in managing the needs of this group of patients in the current health care system?

Prompt: Complexity needs; demands; coordination issues; gaps; access; preventing readmission

Prompt: Challenges unique to this local context?

### 3. Coordination of patient transitions (different locations & levels of care)

- For this population, there are many 'touch' points with the health care system – what kinds of problems occur during transitions from one care setting to the next e.g. in-hospital care (ED through the system to OPERA)?

**Add:** How is patient flow & demand managed here?

**Add:** How is care coordination and communication managed?

- Hospital/primary-community transition is an important phase to ensure continuity and avoid early readmission. What are the specific challenges & problems associated with this transition point?

Prompts: Expectations, referral problems; community linkages; patient/carers issues or preferences

**Add:** How do you interface with primary/community services?

**Add:** What's likely to contribute to an early readmission?

- Overall, where are the main 'trouble' points in the system (possible breakdowns) and what are the risks with this group in terms of care transitions (in-hospital and hospital to community)?

Prompts: Completeness of communication/information; timing/preparation of discharge; adverse events;

**Add:** What makes for a 'successful' care transition?

#### **4. Specialist services to bridge and support primary, community, hospital interface**

The 2009 Report of the National Health & Hospital Reform Commission highlighted the importance of specialist services and programs to bridge and support the primary/community/hospital interfaces for older people - with the aim of returning people to active life, but also to help avoid unnecessary hospital visits. Sub-acute services, including OPERA, are examples (also falls prevention, community programs to assist management at home)

##### **Sub-acute services:**

- What's your impression of the role and capacity of sub-acute services (inc. OPERA) operating here presently to achieve this objective?
- What are the particular constraints and challenges around sub-acute services in this context?
- What more needs to be done around sub-acute services in this context to bridge the community/primary/hospital interface and support older people in the community?
  - How might this be achieved?

##### **Primary/community capacity and service integration**

- What's the role capacity of primary care (GPs and other HPs) to bridge hospital/community interface and enhance coordination of care for older people?
  - Where are the challenges?
- What other specialist services and programs in the primary/community sector are you aware of that help bridge the hospital/community interface and enhance coordination for older people?
  - How do you interface with these?
  - How well are health and aged care services integrated around the needs of older people?
- What more needs to be done in this context to bridge the hospital/primary-community interface and to support older people in the community (and avoid unnecessary admissions)?
  - How might this be achieved?

##### **Other comments?**

**THANK YOU**

**External Focus Group**  
**Understanding of System Challenges and Local Solutions**

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**5. Context: Overview of study population**

- Av 82 (2 participants are under 70 - 64 and 69 both Indigenous)
- 50% approx fractures
- 50% medical complications
- Variation in service access/use prior to admissions
- All nominated a GP – variation in regularity/frequency
- All nominated a carer/family member
- General themes: don't want to come to hospital and want to get home as soon as possible

**6. Experiences with study population**

- What are the challenges in managing the needs of this population in our current health care system?

Prompts: Complexity needs; demands; coordination issues; gaps; access; preventing readmission

Clarify: Challenges unique to this local context?

**7. Coordination of patient transitions (different locations & levels of care)**

- For this population, there are many 'touch' points with the health care system – what kinds of problems occur during transitions from one care setting to the next e.g. hospital to community; service to service?

**Add:** How is care coordination and communication managed across services; for care transitions to different locations?

**Add:** What are the specific challenges?

- Hospital/primary-community transition is an important phase to ensure continuity and avoid early readmission. What are the specific challenges & problems associated with this transition point?

**Add:** How do you interface with primary/community services?

**Add:** Most of our study group don't want to come to hospital if the illness is not serious/surgery, what do you think contributes to their presentations at ED?

**Add:** What's likely to contribute to an early readmission?

- Overall, where are the main 'trouble' points in the system (possible breakdowns) and what are the risks with this group in terms of care transitions (in-hospital and hospital to community)?

Prompts: Completeness of communication/information; timing/preparation of discharge; adverse events;

**Add:** What makes for a 'successful' care transition?

**8. Specialist services to bridge and support primary, community, hospital interface**

The 2009 Report of the National Health & Hospital Reform Commission highlighted the importance of specialist services and programs to bridge and support the

primary/community/hospital interfaces for older people - with the aim of returning people to active life, but also to help avoid unnecessary hospital visits. Sub-acute services, including OPERA, are examples (also falls prevention, community programs to assist management at home)

### **Sub-acute services:**

- What's your impression of the role and capacity of sub-acute services (inc. OPERA and in community) operating here presently to achieve this objective?
- What are the particular constraints and challenges around sub-acute services in this context?
- What more needs to be done around sub-acute services in this context to bridge the community/primary/hospital interface and support older people in the community?
  - How might this be achieved?

### **Primary/community capacity and integration of health and aged care services**

- What's the role and capacity of primary care (GPs and other HPs) to bridge hospital/community interface and enhance coordination of care for older people?
  - Where are the challenges?
- What other specialist services and programs in the primary/community sector are you aware of that help bridge the hospital/community interface and enhance coordination for older people?
  - How do you interface with these?
- How well are health and aged care services integrated around the needs of older people?
  - Are there any formal/joint agreements or care processes in place?
- What more needs to be done in this context to bridge the hospital/primary-community interface and to support older people in the community (and avoid unnecessary admissions)?
  - How might this be achieved?

### **Other comments?**

**THANK YOU**

## Appendix 8: Coding Framework

1. Health profile
  - 1.1 pivotal event – trigger
  - 1.2 medical conditions – diagnosis
  - 1.3 health status – self assessed wellbeing (Before & After)
  - 1.4 help seeking behaviour – attitude to solving health issues
  - 1.5 personal health values e.g. self reliance
  - 1.6 admissions history – experiences and what happened
2. Managing at home all Before & After
  - 2.1 perceptions of coping
  - 2.2 formal support – services
  - 2.3 informal supports – carers, extended family, neighbours
  - 2.4 social networks
  - 2.5 activity level & participation
  - 2.6 living arrangements
3. Relationship with GP
  - 3.1 frequency of visits
  - 3.2 communication
  - 3.3 appraisal – confidence, trust, expertise
  - 3.4 awareness
  - 3.5 perception of GP role
  - 3.6 accessibility (time geography, cost)
4. OPERA experience
  - 4.1 expectations and goals
  - 4.2 ward ambience (physical, feelings, smell, sounds)
  - 4.3 patient mix
  - 4.4 processes of care:
    - a. staff – attitudes, respect, communication, empathy
    - b. decision – making
    - c. information, communication
    - d. engagement with staff (who they saw what they did)
    - e. self management support
  - 4.5 satisfaction overall
  - 4.6 Patient agency – capacity to make a change / how patients acts or behaves in relation to the system.
  - 4.7 Preparedness for discharge
    - a. information
    - b. making home safe
    - c. understanding of process
    - d. help managing at home – services
    - e. confidence in preparedness
    - f. timing
    - g. family role
5. System encounters
  - 5.1 timelessness / delays
  - 5.2 experiences with staff
  - 5.3 accessibility (cost, timeliness, geography, hours, eligibility, cultural)
  - 5.4 unmet needs / gaps (discharge plan & new needs)

- 5.5 satisfaction overall (appropriateness)
- 5.6 continuity of care
- 5.7 system capacity & resources
- 5.8 GP interface with system / community / hospital
- 5.9 Strategies to resolve system problems
- 5.10 Carer issues – respite, stress, payments, expectations
- 5.11 Care co-ordination (negative / positive)