A model for patient navigation in the ACT for people with chronic and complex conditions

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About the Health Care Consumers' Association

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services
- research into consumer experience of human services.

Acknowledgements

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Executive Summary

Context for this report

In 2017, the ACT Government commissioned the Health Care Consumers' Association (HCCA) Inc. to develop a model of patient care navigation in the ACT. The intent of the model is to improve the health and wellbeing of consumers with chronic and complex conditions. This project sits within the broader context of the work agenda for Policy and Stakeholder Relations, ACT Health, and it constitutes Phase 1 of a three-phase program:

Phase 1. Review current situation and develop model
Phase 2. Trial model
Phase 3. Prepare business model

This report presents the body of work the HCCA has undertaken, collecting examples, thoughts, experiences and stories, and concludes with a model of patient navigation for the ACT.

Objective of the model

As proposed by ACT Health, the objective of this model for patient navigation is to **remove barriers that prevent a smooth transition between hospital and the community for people with chronic and complex conditions.**

Findings

To inform this model HCCA sought to understand the care coordination experiences of both consumers and health professionals. Care coordination is a critical aspect of navigation. The voices of consumers and health professionals in this report reveal that there are varying degrees to which coordinated care is given and received. Health professionals told us that they would like more support to enable them to provide coordinated care. Consumers told us that they would like to be assessed as a whole person, and be provided with information that suits their very specific circumstances. Participants' experiences with care coordination **indicate a need for a patient navigation service in the ACT.**

Both cohorts indicated barriers to providing and receiving good coordinated care. **Importantly, the challenges identified by health professionals directly affect consumer experiences of care coordination.**

Major barriers to providing good care coordination identified by health professionals:

- There is not enough time to provide a comprehensive, holistic assessment of patients, including everyone involved in their care, before they are discharged
- Coordinator roles and responsibilities are not clearly defined

- Processes for coordinating care, including discharge, are not standardised
- Poor flow of patient information generally, but especially among/between treating clinicians when a patient has multiple conditions
- There are not enough dedicated discharge roles such as discharge liaison nurses and social workers
- Added complexity and time delays caused by government systems such as My Aged Care and National Disability Insurance Scheme (NDIS)

Major barriers to receiving good care coordination identified by consumers:

- Significant gaps in information about their conditions, treatment options and staying healthy, and difficulty sharing information between health services and professionals
- Cost barriers
- Time barriers
- Cursory hospital discharge planning

Removing barriers to provide good coordinated care requires a more patient-centred, integrated health system.

There are care coordination programs aimed at providing patient-centred care in areas of need in the ACT, but they are often disease-specific and do not **comprehensively address the needs of patients with chronic and complex conditions**. According to our research, barriers to good coordinated care remain. Done properly, HCCA feels that a patient navigation service would address some of these barriers and meet the priority needs of consumers.

As well as interviewing health professionals and consumers, HCCA visited two navigator services - the Queensland Nurse Navigator Service and the Western Healthlinks Health Navigator Service. These services provided excellent examples to identify challenges and successes of establishing and maintaining an existing navigator service. The services represent two different navigator models, displaying different strengths, which the HCCA has integrated into the model for patient navigation in the ACT.

Finally, in developing a model of patient navigation the HCCA have drawn on the knowledge and experience of stakeholders representing the multicultural community, carers, older people, women's health, maternity, nursing, general practitioners, paediatrics, chronic conditions, medicine, surgery, rehabilitation, human relations, peer support, GP liaison, ambulatory care, allied health and mental health.

Definitions

For the purposes of this report, HCCA uses the following definitions:

Patient Navigator

While there are many definitions of patient navigator, they share a common goal to anticipate and identify barriers to good patient care and help patients to remove them. In doing so they improve patient outcomes and the overall quality of health care delivery.

Chronic Conditions

Chronic conditions are long-term and persistent, often leading to a gradual deterioration of health and loss of independence, not often immediately life threatening.[1]

Chronic conditions

- have complex and multiple causes
- may affect individuals either alone or as comorbidities
- usually have a gradual onset, although they can have sudden onset and acute stages
- occur across the lifecycle, although they become more prevalent with older age
- can compromise quality of life and create limitations and disability
- are long-term and persistent, and often lead to gradual deterioration of health and loss of independence, and
- while not usually immediately life threatening, are the most common and leading cause of premature mortality.[2]

We also include mental illness, trauma, disability and genetic disorders.[3] Chronic conditions can occur across the life cycle, but they become more common with ageing, can result in disabilities, and may compromise one's quality of life.[4] People on low incomes are more likely to be effected by chronic conditions.[5]

The emphasis in this report is on the experience of people with multimorbidity[i] and comorbidity[ii], which are the coexistence, and interaction of multiple chronic conditions.[6]

Complexity

Complexity is a combination of health needs that can include diagnosis, treatment and rehabilitation, and social needs such as housing, social care and independent living.[7]

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[i] Multimorbidity has no single definition. It is also known as multiple morbidity and comorbidity. The Academy of Medical Sciences defines multimorbidity as the coexistence of several conditions, none of which is considered an index condition.

[ii] Comorbidity is the co-existence of other conditions with an index condition that is the specific focus of attention. For both definitions, see Australia's Mental and Physical Health Tracker - background paper. (2018), (06), 60.

The model for patient navigation in the ACT

Using the information collected through interviews, case studies and stakeholder feedback, the HCCA has developed a model for patient navigation in the ACT. **The outcome of the model is to improve the quality of life for consumers and partner with them to achieve the best health and wellbeing possible.**

Underpinning the model are four Key Principles:

Advocacy

- Promote patient centred care
- Provide personalised and holistic assessment and planning
- Be the single point of contact

Linkage

- Provide links to existing services and resources
- Expedite centrally coordinate care
- Create partnerships with everyone involved in the patients' care
- Include carers and families
- Build professional relationships

Education

- Improve health literacy
- Plan and set goals for self-management

Health system improvement

- Assess and monitor systems for improvement
- Enhance existing services
- Ensure succession planning
- Promote research, assessment and development

The model consists of eight criteria for a successful navigation service:

1. Patient need and service response

A navigator service must determine the needs of the patient and respond with the appropriate level of service.

2. Roles and responsibilities

It is essential that the parameters of a navigation service are made clear, and that navigators are enabled to adapt their role to suit a patient's individual needs.

3. Referral and eligibility

A straightforward and open referral system, with simple eligibility criteria is essential to ensure the service reaches the people who most need it.

4. Training

Training navigators in a chronic disease management program can strengthen the service by providing consistency and reassurance for patients and navigators.

5. Evaluation and data collection

Data must be systematically recorded from the beginning of the service to ensure accurate and complete service evaluations, and wider health system assessments.

6. System support

For a navigation service to be successful, it must be implemented with Territory-wide support from consumers, health professionals, and health services as well as ongoing clinical and corporate support.

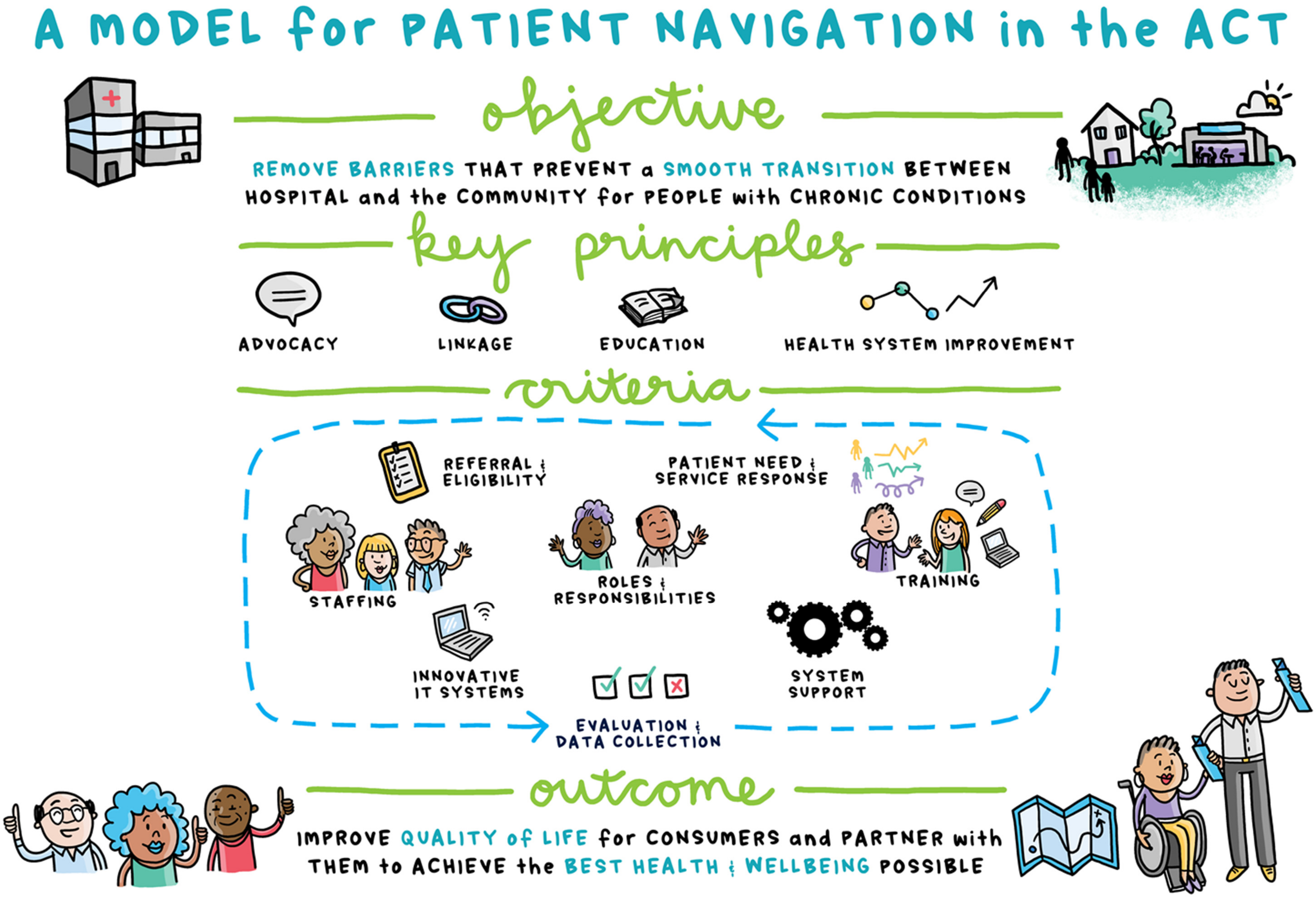
7. Staffing

Whether clinical, non-clinical, or a combination of both, a navigator team needs to be knowledgeable, experienced, highly skilled and excellent communicators.

8. Innovative IT systems

A successful navigator service relies on adequate IT systems to manage aspects of patient coordination including recruitment, referral, monitoring, and accessing and sharing patient records.

This model is the first step in developing a navigation service in the ACT. The HCCA looks forward to ongoing discussions with ACT Health and stakeholders that lead to the implementation of a service that improves the quality of life for consumers with chronic and complex conditions.



A MODEL for PATIENT NAVIGATION in the ACT

objective

REMOVE BARRIERS THAT PREVENT a SMOOTH TRANSITION BETWEEN HOSPITAL and the COMMUNITY for PEOPLE with CHRONIC CONDITIONS

key principles

- ADVOCACY
- LINKAGE
- EDUCATION
- HEALTH SYSTEM IMPROVEMENT

criteria

- REFERRAL & ELIGIBILITY
- PATIENT NEED & SERVICE RESPONSE
- STAFFING
- ROLES & RESPONSIBILITIES
- TRAINING
- INNOVATIVE IT SYSTEMS
- SYSTEM SUPPORT
- EVALUATION & DATA COLLECTION

outcome

IMPROVE QUALITY of LIFE for CONSUMERS and PARTNER with THEM to ACHIEVE the BEST HEALTH & WELLBEING POSSIBLE

Introduction

People with chronic and complex conditions are high users of health services and their needs are rarely met by a single health professional.[8, 9] Indeed, having multiple conditions and high levels of complexity can mean that people need treatment from numerous specialists, administered through separate health care providers and funding entities, in various locations. This fragmented health care does little to support the long-term and multidisciplinary care required for managing chronic and complex conditions (see pp. 9-10 for definitions of chronic and complex).[iii] Considerable focus on coordinating this fragmented system is required if patients with chronic conditions are to receive the best possible care. Engaging patient navigators[iv] can help patients find their way through the health care system and coordinate the fragmented clinical and social services they need to manage their conditions.

The HCCA have developed a model of patient navigation for the ACT (see Section 3). This report presents the body of work the HCCA has undertaken, collecting examples, thoughts, experiences and stories, and concludes with a model of patient navigation for the ACT.

Background of the Patient Navigator

A patient navigator anticipates and identifies barriers to good patient care and helps to remove them.[10] In doing so they improve patient outcomes and the overall quality of health care delivery.[11] These barriers can usefully be broken down into three categories:[12]

Patient barriers

- Lack of awareness of community based resources
- Financial constraints
- Competing priorities
- Personal circumstances
- Language and culture

Provider barriers

- Lack of clinical support
- Lack of time and knowledge

System barriers

- Complexity of the health care system
- Sub-optimal access to primary or specialty care

[iii] Most literature on patient navigation for people with chronic conditions refers to medical and social complexity. In this report, when we refer to chronic conditions we are, by default, including medical and social complexity.

[iv] See p.8 for a definition of patient navigation.

Surgical oncologist Dr. Harold. P. Freeman is generally credited with creating the first patient navigator roles in 1990 at the Harlem Hospital Center, New York City. These original navigators were established to improve the timely diagnosis and treatment of cancer, particularly in poorer communities. Today, the role of the patient navigator remains mostly in the cancer setting. Some studies claim that the benefits of a navigator service are not specific to cancer, and can be generalised across diagnoses.[13] Indeed, the concept of navigation has spread to include a range of conditions and diseases.

According to the American Medical Association,

> *“the primary role of a patient navigator should be to foster patient autonomy and provide patients with information that enhances their ability to make appropriate health care choices and/or receive medical care with an enhanced sense of confidence about risks, benefits and responsibilities”.*[14]

Most importantly, from a consumer perspective, navigators teach patients about steps they can take to successfully navigate the health system. **They help patients gain skills to take ownership of their health**.[15]

Based on over 20 years’ experience designing and implementing patient navigator programs Freeman created the following set of principles of patient navigation:[16]

1. Patient navigation is a patient-centered health care service delivery model. The focus of navigation is to promote timely movement of an individual patient through an often complex health care continuum.
2. The core function of navigation is to eliminate barriers to timely care across all phases of the health care experience.
3. Patient navigation may serve to virtually integrate a fragmented health care system for individual patients.
4. Patient navigation should be defined with a clear scope of practice that distinguishes the role of the navigator from that of other providers.
5. The delivery of patient navigation services should be cost-effective and commensurate with the training and skill necessary to navigate a patient through a particular phase of the care continuum.
6. The determination of who should navigate should be based on the level of skill required at a given phase of navigation.
7. In a given system of care, there is a need to define the point at which navigation begins and the point at which it ends.
8. Patient navigation can serve a process that connects disconnected health care systems, such as primary care and tertiary care.

9. Patient navigation systems require coordination. In larger systems of patient care, this coordination is best carried out by assigning a navigation coordinator who is responsible for overseeing all phases of navigation within a given health care site or system.

Patient navigation services can be provided by clinical or non-clinical personnel, and are usually paid rather than volunteers.[17] In the published literature, most navigator programs are in cancer diagnosis and screening, and the majority of these employ non-clinical navigators.[18] There is little published information on navigation programs in Australia, although health professionals such as nurses and social workers seem to be preferred over non-clinical staff.[v, vi]

Lay navigation programs have proven particularly successful in improving access to health services for lower-socioeconomic groups, and culturally and linguistically diverse communities.[19, 20] For example, a primary care patient navigation service based on the West Coast of New Zealand has had positive results through using lay navigators. A survey of consumers and health professionals revealed high customer satisfaction with the navigators, and an increase in connecting, or reconnecting consumers to primary care services.[21] However, lay navigators can struggle with emotional situations (such as cancer diagnoses) and preventing burnout or overload. For these reasons, one study concludes that a model with both clinically trained and lay navigators is more supportive to lay-navigators and can better meet patients' needs. [22]

Impacts of patient navigation

Effectiveness

Published research on the impacts of patient navigation programs in chronic conditions is scarce. An obvious issue when developing a model of patient navigation is the lack of evidence on successful characteristics of navigation for people with chronic conditions. Some studies cite the importance of adequate assessment of patients' homes and a comprehensive handover processes in avoiding preventable readmissions.[23, 24] Whereas a meta-study on the beneficial characteristics of 67 navigation programs found a positive impact on those programs' primary outcomes. These outcomes focused on processes such as completion of disease screening and adherence to follow-up procedures.[25] This meta-study found no significant positive outcomes in patient experience, clinical outcomes or costs but noted that the variability in navigation programs precluded definitive statements of effectiveness.

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[v] Based on a review of advertised job descriptions on staff for navigator roles.

[vi] There are programs that explicitly use lay-navigators such as the Community Navigators in Logan, Queensland (Henderson and Kendall 2011, 'Community Navigators: making a difference by promoting health in culturally and linguistically diverse (CALD) communities in Logan, Queensland.

Financial incentives

Among other things, poor data quality and short-term programs make it difficult to ascertain how much money a navigator program can potentially save. One hospital in the UK estimates a net gain of over AU$280,000 per year for each whole-time equivalent navigator.[26] Other estimates are less generous, though some organisations claim that their navigator services became cost-neutral mere months after commencement.[27] Many navigator programs attach cost savings directly to the reduction of avoidable hospital readmissions. This method is in line with recent proposals by the Independent Hospital Pricing Authority (IHPA) that aims to incentivise hospitals by linking funding to avoidable readmissions. The IHPA anticipates such a move will improve discharge planning, care co-ordination and the provision of health and other support services in the community.[28] If a simple program such as a phone service for recently discharged patients can reduce the incidence of readmissions by almost a third,[29] then conceivably, a navigator service could be considered as a cost-effective innovation.

Types of models

The current heterogeneity of existing models of patient navigation, and the scarcity of reliable evidence make developing a prescriptive model difficult. The difficulty is exacerbated "because the patient experience is very individual, there's not a template or list that every patient will follow in order".[30] Arguably, the more complex the patient cohort the more complex a model for patient navigation needs to be.[31] Despite the variability, most navigation programs deliver patient-centred care, linking patients and families to primary care, specialists and community-based services.[32] While there is no definitive list of components for a successful navigation program for people with chronic diseases, it could be useful to understand common attributes for a successful model of care for **high-need and high-cost patients**. Based on a synthesis of several studies, researchers at The Commonwealth Fund suggest such a model of care should [33]

- target individuals most likely to benefit
- provide a comprehensive assessment of patients' risks and needs
- use evidence-based care planning and patient monitoring
- promote patient and carer engagement in patients' self-care
- facilitate transitions between hospital and community, and
- provide appropriate care in accordance with patients' goals and priorities

The diverse roles of patient navigation, and broad suite of health care settings where they have been used, suggests that there is no 'one size fits all' model for the health system.[34] However, a rapid analysis of position descriptions for coordinator/navigator roles in Australia revealed common elements as demonstrated below.

An example of coordinator/navigator functions from position descriptions in Australia:

- Provide end-to-end care across the progression of the condition/s
- Provide links to appropriate services
- Provide individually tailored advice and support for patients and families
- Support patient's self-management and improve health literacy
- Work across interagency, multidisciplinary/interdisciplinary teams
- Act as an advocate for patients and family
- Coordinate care with all those involved in the patient's treatment
- Remove barriers in the health system
- Provide single point, ongoing patient contact
- Assist with administration and systems such as My Aged Care and Advanced Care Planning
- Use methods such as care planning, goal-setting, health coaching and motivational interviewing
- Provide after-hours support
- Undertake comprehensive assessment

A key factor in creating a relevant model for the ACT means gaining a clear understanding of patients' needs.[35] In developing a model of patient navigation, the HCCA has explored the needs of both patients and health professionals. **From this, we have developed a model that attempts to balance need with what is practical and achievable.**

Chronic and complex conditions

The aim of HCCA's model is **to remove barriers that prevent a smooth transition between hospital and the community for people with chronic and complex conditions**. There is no single definition for chronic conditions. In this report we define chronic conditions as long-term and persistent, often leading to a gradual deterioration of health and loss of independence, not often immediately life threatening.[36] Examples of chronic conditions include cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma), and diabetes.[37] We also include mental illness, trauma, disability and genetic disorders.[38] People living on low incomes are more likely to be affected by chronic conditions,[39] as are people with poor mental health.[40]

Chronic conditions

- have complex and multiple causes
- may affect individuals either alone or as comorbidities
- usually have a gradual onset, although they can have sudden onset and acute stages
- occur across the lifecycle, although they become more prevalent with older age

- can compromise quality of life and create limitations and disability
- are long-term and persistent, and often lead to gradual deterioration of health and loss of independence, and
- while not usually immediately life threatening, are the most common and leading cause of premature mortality.[41]

The emphasis in this report is on the experience of people with multimorbidity[vii] and comorbidity[viii] which is the coexistence and interaction of multiple chronic conditions.[42]

Chronic conditions account for 87 percent of deaths in Australia and one in four people have two or more chronic illnesses.[43] People with chronic conditions experience a range of disadvantages such as

- fragmented health care system, with providers and services working in isolation from each other rather than as a team,
- uncoordinated care,
- difficulty finding services they need,
- at times, service duplication and at other times, absent or delayed services,
- a low uptake of eHealth and other health technology by providers to overcome these barriers,
- difficulty in accessing services due to lack of mobility, transport, language, financial barriers and remoteness, and
- feelings of disempowerment, frustration and disengagement.[ix]

Complexity, according to the National Complex Needs Alliance, is a combination of health needs that can include diagnosis, treatment and rehabilitation, and social needs such as housing, social care and independent living.[44] By not addressing these social needs consumers may be too stressed and anxious to focus on their health needs. For example, while a consumer may have access to appropriate health care, it may be a lack of access to affordable housing that limits her ability to self-manage.[45]

ACT context

According to the ACT Chief Health Officer's Report 2018 chronic diseases now cause most of the poor health and premature death in the ACT.[46] The ageing of the

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[vii] Multimorbidity has no single definition. It is also known as multiple morbidity and comorbidity. The Academy of Medical Sciences defines multimorbidity as the coexistence of several conditions, none of which is considered an index condition.

[viii] Comorbidity is the co-existence of other conditions with an index condition that is the specific focus of attention. For both definitions see Australia's Mental and Physical Health Tracker - background paper. (2018), (06), 60.

[ix] These experiences were revealed in submissions for the Primary Health Care Advisory Group's (2016) *Better Outcomes for People with Chronic and Complex Health Conditions*. Commonwealth of Australia as represented by the Department of Health.

ACT population, in combination with risk factors such as obesity, smoking and lack of physical activity present a major challenge for ACT Health placing a greater burden on the health care system.[47] **Chronic conditions account for half the total preventable hospital presentations in the ACT.[48]**

The most recent Chief Health Officer's Report (2018) states that

> *"in 2014-2015, more than half of all adults in the ACT had at least one of the following chronic diseases: arthritis, asthma, back problems, cancer, chronic obstructive pulmonary disease, cardiovascular disease, diabetes and mental health conditions. Of all adults, 23.2% had at least two of these chronic diseases. Of those aged 45 years and over, 44.8% had at least two of these conditions.[49]*

ACT health's Chronic Conditions Strategy "sets out a basis for improving the quality of support and management of chronic conditions in the ACT through a person centred approach."[50] The Strategy emphasises the commitment that "every person with a chronic condition receives the right care, in the right place, at the right time from the right team" which is consistent with the principles of patient navigation. On this point, the Strategy stresses the importance of comprehensive patient support through team-based care yet falls short of suggesting who should coordinate such care. A patient navigator service is perfectly placed to fulfil this role.

Study outline

Philosophical approach

HCCA commits to **consumer-centred care**[x] as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.[51]

Research Question

- What model of patient care navigation would meet the needs of consumers with chronic and complex conditions in the ACT
    a) What are the needs of consumers in the ACT?
    b) How does the ACT currently meet that need?
    c) What are the gaps?

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[x] Different people use different words to describe consumer-centred care, including person centred care, patient and family centred care, client centred care, and patient centred care.

Research Project

This project sits within the broader context of the work agenda for Policy and Stakeholder Relations, ACT Health, and it constitutes Phase 1 of a three-phase program.[52] ACT Health's current work program for patient care navigators comprises:

Phase 1) Review current situation and develop model
Phase 2) Trial model
Phase 3) Prepare business case

Aim

Both HCCA and ACT Health would like to improve patient outcomes and the overall quality of health care delivery. Meeting the needs of people with chronic and complex conditions is especially challenging, and it is within this context that the project will be take place. The specific aim of this project is to:

- Produce a model of patient care navigation that meets the needs of patients within the context of the ACT health care system.

Objectives

1) Scope the current approach to care coordination across the ACT including Canberra Hospital and Health Services, Calvary Public Hospital and Capital Health Network.
2) Undertake research into consumer experiences and expectations of
    - care coordination, and
    - the support they need to navigate the system when living with complex and chronic conditions.
3) Develop a model of patient care navigators suited to the ACT context

While not an explicit objective of the project, HCCA explored health professional experiences with care coordination in addition to consumers' experiences.

Report outline

This report has four sections:

- Section 1 discusses some examples of care coordination in the ACT and introduces two case studies of navigation services operating in Queensland and Victoria. These case studies are a statewide nurse navigator service in Queensland and a health navigator program servicing Melbourne's Western suburbs.
- Section 2 contains analyses of health professional and consumer interviews. The section discusses the main observations from the interviews as well as thoughts and opinions on a potential navigation service.

- Section 3 introduces a model for patient navigation in the ACT, which includes Key Principles, and eight criteria for a successful service.
- Section 4 recommends next steps for ACT Health in transitioning the model to a service.

Section 1 – Examples of care coordination

What follows are examples of hospital-based and community-based services in the ACT that coordinate care for patients in hospital and at home. Two programs, the Chronic Care Program and the Transitions of Care Pilot focus on chronic conditions. Other services such as the Geriatric Rapid Acute Care Evaluation (GRACE), Rapid Assessment of the Deteriorating Aged at Risk (RADAR) and rehabilitation, and roles such as nurses and social workers, address chronic conditions as part of a broader service.[xi]

Of all the services, the approach of the Chronic Care Program is most closely aligned to patient navigation. The program has not been formally evaluated, so it is difficult to draw definite conclusions about the efficacy of this service in providing coordinated care to people with chronic and complex conditions. Anecdotally, the service is considered to provide excellent coordination services. At the time of writing, the Transitions of Care Pilot is being formally evaluated. [xii]

To determine the number of coordinator roles in the ACT, HCCA attempted to search job descriptions for corresponding terms. This method proved immediately problematic, as coordinating care for patients was included in the majority of role descriptions. That coordination has become a generic responsibility on health professional duty statements is an issue that requires attention. **Evidence discussed in the following section of this report suggests this 'mainstreaming' of care coordination is ineffective for complex patients.**

The information below is drawn from discussions with key stakeholders, supplemented with available documentation and online material.[xiii] We were able to find more information for some services and less for others and this disparity is reflected in the summaries below.

1. Hospital based services

1.1 Clinical Care Coordinators, Chronic Care Program, Canberra Hospital and Health Services

The Chronic Care Program promotes patient-centred care with an aim to 'assist the client to remain well in the community, navigate and engage with our health system and prevent unnecessary hospital presentations and admissions'.[53]

[xi] Coordinating care, to varying degrees, is an element of all nurses and numerous health professional roles, and due to time constraints, we were not able to investigate them all. However, many of the challenges and benefits of care coordination for health professionals working in these roles are well represented in the health professional interviews in the following section.

[xii] The Transitions of Care program was discontinued in December 2018

[xiii] HCCA met with stakeholders representing the following groups: multicultural, carers, older people, women's health, maternity, nursing, general practitioners, paediatrics, chronic conditions, medicine, surgery, rehabilitation, human relations, peer support, GP liaison, ambulatory care, allied health and mental health.

The Program is based in Chronic Disease Management within the Division of Medicine of Canberra Hospital and Health Services (CHHS). The program targets frequent users of the acute care sector with heart failure, chronic obstructive pulmonary disease, Parkinson's disease and other movement disorders.

The Program currently consists of allied health professionals who work as Clinical Care Coordinators. Additionally, the Program has links to specialty disease nurses within the hospital. The Coordinators provide clinical care coordination services that include comprehensive patient assessment (excluding inpatients) and goal setting with the patient and health professionals involved in the patient's care. With consent, coordinators visit patients in their home.

Coordinators perform the following tasks:

- Arrange support services for the patient in the community to assist with health management
- Provide patient education and strategies to help patients to self-manage their condition
- Provide ongoing patient contact via home visits and phone consultation
- Liaise and advocate with a patient's GP, specialists and other health care professionals/services regarding appointments and care
- Discuss Advanced Care Planning

The program enrolls patients for as long as they need. Some patients are on the program for a number of years, and for patients that are discharged from the program, the Coordinators remain contactable.

1.2 Rehabilitation Care Coordinators, Rehabilitation, Aged and Community Care (RACC), Canberra Hospital and Health Services

The two Rehabilitation Care Coordinators (nurse and occupational therapist) are assigned to patients in RACC to help them adjust to their new surroundings and understand their rehabilitation program.[54]

The Rehabilitation, Aged and Community Care (RACC) Division provides integrated and effective services in rehabilitation, aged care and community care in hospitals, community health centres and the homes of clients.[xiv]

The Coordinators work with patients and families while in hospital and maintain contact by phone or home visits for up to 12 months after discharge. After assessing the patient, Coordinators ascertain the patient's therapy goals and collaboratively plan the appropriate treatment with the patient's medical team. The coordinators are the central point of information for both the patient and their multidisciplinary team. Coordinators plan the patient's discharge from the day of admission and, guided by the patient's treatment plan and goals, determine the date of discharge.

[xiv] This may have changed due to the sub-acute rehabilitation services now provided by the University of Canberra Hospital.

1.3 Discharge Liaison Nurses (DLNs), Canberra Hospital and Health Services

Discharge Liaison Nurses act as the communication link relating to the discharge process between relevant internal and external stakeholders and the patient. In collaboration with the patient's multidisciplinary team, the DLN is responsible for

- the coordination and referral of discharge services for patients with complex needs, and
- ensuring the discharge plan is patient-centred, adheres to best practice and facilitates safe and timely transfer of care between the acute care setting and the discharge destination.[55]

There are currently 11 registered nurses, who work as DLNs on medical and surgical wards and in emergency departments across Canberra Hospital and Health Services. The Ward Clinical Nurse Consultant alerts DLNs to complex patients within 24 hours of patient admission. Complexity is determined by the Early Screen for Discharge Planning Algorithm as stated in the DLN Guidelines. However, the guidelines are used inconsistently across CHHS.

1.4 Hospital-based Social workers, Canberra Hospital and Health Services

Among other responsibilities, hospital social workers help patients coordinate community services as part of their discharge planning.

The process of referring complex patients to hospital social workers varies, but Discharge Liaison Nurses can refer to social workers if the patient lives alone or requires social or domestic supports for their return home. Hospital social workers also help patients apply for the Commonwealth care packages such as My Aged Care[xv] and short-term support programs such as Community Options' Post Hospital Program.[xvi] However, once a patient is discharged from hospital, social workers are unable to follow-up on the progress of these applications.

Hospital social workers prioritise patients according to risk to their safety once discharged. Patients with obvious risk are followed by patients requiring complex planning, then patients with more simple planning requirements.

1.5 Nurse specialists, Canberra Hospital and Health Services

Nurses specialising in chronic diseases often run programs that offer rehabilitation and education to acutely unwell patients. There are some elements of coordination in these programs though they are usually focused on a specific disease. These programs may run for several weeks and, based on a holistic patient assessment,

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[xv] My Aged Care is a Commonwealth Home Support Program for people aged 65 years and over or 50 years and over for Aboriginal and Torres Strait Islander people. The program is designed to provide all older Australians with information and connections with appropriate entry-level home support services to assist with daily living.

[xvi] Community Options is a local ACT not-for-profit community-based organisation providing services to older people, people with disabilities and their families. The Post Hospital Program is eight weeks.

can include a range of assistance with diet, exercise, mental health, pharmacy and peer support. These nurses can help coordinate specialist care and community services. There are approximately 70 specialist nurses across CHHS in specialist areas such as cardiology, diabetes, cancer and urology.

1.6 Clinical Care Coordinators

Clinical Care Coordinators are part of the Ward Leadership Program at the Canberra Hospital. The program consists of 12 ward-based, registered nurses that provide clinical leadership on the wards, and plan and coordinate patient centred care. The program was established to address a lack of coordinated care on the wards, which can potentially lead to increased length of stay and lack of complex discharge planning. The rationale for the program is that Coordinators will take over the bulk of care coordination duties from Clinical Nurse Consultants, allowing them to focus on clinical leadership.[56]

1.7 GRACE (Geriatric Rapid Acute Care Evaluation) program – ACT PHN and Calvary Hospital

The aim of the program is to act as a point of liaison, education and clinical support at the Residential Aged Care Facility/acute care-setting interface, and facilitate clinical care as close to the point of residence as possible for acutely unwell residents.[57]

The GRACE trial program began in October 2017 to improve the health care journey for aged care residents by treating them where they live. The model integrates Residential Aged Care Facilities, GPs and hospital outreach resources for acutely unwell aged care residents. This model is currently being trialed by the ACT Primary Health Network in partnership with Calvary Hospital Bruce and. From the first weeks of implementation, there were decreased transfers to the Emergency Department, reduced acute in-hospital admissions, and where admission was unavoidable, decreases in the average length of stay in hospital for those admissions.[58]

The GRACE clinical team are registered nurses who treat patients in their home. If hospital admission is unavoidable, the clinical team coordinates and case manages the patient's care until they return home.

1.8 Aboriginal and Torres Strait Islander Liaison Officers

There are a number of Health Liaison officers within the ACT such as the Alcohol and Drug Aboriginal and Torres Strait Islander Liaison Officer, Calvary Aboriginal and Torres Strait Islander Officer, Canberra Hospital Aboriginal and Torres Strait Islander Liaison Officers and the Mental Health Aboriginal and Torres Strait Islander Liaison Officer.[xvii]

[xvii] See http://health.act.gov.au/our-services/aboriginal-torres-strait-islander-health/health-liaison-officers for more information about these services.

2. Community-based services

2.1 Transition Coordinators, Capital Health Network Transitions of Care pilot program

The Transitions of Care (ToC) pilot program aims to “improve patient focused transitions of care between hospital and primary health care and community settings”.[59]

The 12-month pilot, delivered by the Capital Health Network, provides service navigation, medication support and health coaching for patients with complex chronic conditions. Patients enrolled in the program are offered support through:

- transitioning from hospital to community with appropriate services and supports
- optimising patient activation and self-management
- reducing adverse events, emergency department presentations and readmissions, and
- enhancing patient satisfaction and continuity of care

The service targets patients with increasingly complex, multiple conditions as determined by the Coordinators. Once patients are enrolled, Transition Coordinators (enrolled nurses) work with other hospital staff to develop a comprehensive discharge plan and then assist the patient and their family in implementing that plan. They also help patients with Care Plans developed by the patient’s GP. With consent, Coordinators visit patients at home.

2.2 RADAR (Rapid Assessment of the Deteriorating Aged at Risk), Canberra Hospital and Health Services

The aim of the RADAR program is to provide an older person with a rapid medical intervention to enable the person remain at home and prevent a subsequent hospital admission.

The RADAR team comprises of a geriatrician, registered nurses, social worker, occupational therapist and dietician. The team works with the patient’s GP and liaises with relevant services including pathology, imaging, Hospital In The Home, domiciliary allied health, community rehabilitation, and the Aged Care Assessment Team (ACAT).[xviii]

2.3 Other providers of care coordination

People with chronic and complex conditions often receive coordinated care outside of specific programs. Examples include

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[xviii] Australian Government Funded Aged Care Assessment Teams (ACAT) conduct comprehensive assessments for people needing Home Care Packages and/or Residential care (both permanent and/or respite).

- community nurses
- general practitioners
- peer-based support
- Community Options,[xix] and
- networks such as the ACT Renal Network

3. Patient navigator case studies

In January and April 2018, HCCA visited the Queensland Department of Health and Silver Chain Group, respectively, to learn about their patient navigator models. These models were chosen largely for practical reasons – both had been operating for over 12 months, both focus on chronic conditions, both explicitly use the term ‘navigator’, and both were able to meet with HCCA within our timeframe. At the time of writing, in Australia, there are many programs that offer care coordination for people with chronic and complex conditions - for example, the Hospital Admission Risk Program (HARP) available in most states, and Transitions of Care program in the ACT. However, to our knowledge, the Queensland and Silver Chain programs are the only current programs for people with chronic and complex conditions that are more or less **based on the principles of patient navigation**. They provide good examples of patient navigation for this report and demonstrate two different navigation services. While Queensland is a government service that employs nurses based primarily in hospitals, the Silver Chain program is not-for-profit, employs allied health professionals, and is based in the community. The HCCA was impressed with both programs, and feel that many of their characteristics can and should be implemented in the ACT.

The two programs are discussed below.

3.1 The Queensland Nurse Navigator Service

Governance

The Nurse Navigator service began in 2016 in four initial pilot sites over 6-12 months with the aim to roll out 400 Nurse Navigator roles over four years. The program is part of a strategy to improve patient outcomes through nurse-led service models. There are currently 240 funded positions across Queensland’s Health and Hospital Services (HHS) with an additional 160 positions planned over the next 12 months (at July 2018).

The program was designed and led by the Queensland Practice Innovation Division and is overseen by a steering group. The program has the advantage of drawing from lessons learned from similar programs, such as the Children’s Health

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[xix] Through a number of ACT Government funded programs, Community Options provides short- to medium- term post-hospital support and case management services to eligible ACT residents including older people, people with complex health conditions, and people with disabilities.

Queensland Connected Care Program. While the program is designed by the Practice Innovation Division, implementing the roles, and ensuring that they adhere to the key principles, is the responsibility of the individual HHS.

The four key principles of the Nurse Navigator Service are

- coordinating patient-centred care
- creating partnerships
- improving patient outcomes, and
- facilitating systems improvement

The role is designed to be appropriate for many areas across Queensland Health with individual HHS having authority over how the role can be best used to benefit their patients.[xx] Some navigators are based in hospitals while others are based in remote and community health centres. To aid consistency across HHSs, a Nurse Navigator Model of Care has been designed and a State-wide Model of Service is under development to improve consistency across service delivery.

Aim

The aim of the service is to assist patients with complex health care needs in navigating to and from their referring primary care provider, through to hospital, community and back home again. Broadly, the service is end-to-end care for those patients with the greatest health care needs. This may include patients with multiple chronic illnesses, those with a high need for health services, or those who have complicated health conditions.

Role

The Queensland Nurse Navigators are a team of senior-level registered nurses that provides a service for patients with complex health conditions and require a high degree of comprehensive, clinical care. The Navigators are highly experienced with an in-depth understanding of the health system, each costing $165,000 at the time of implementation. The reasons for choosing nurses over other health professionals are a combination of pragmatics and historical fit. Queensland Health felt that nurses

- possessed the necessary clinical knowledge and experience,
- were a standardised professional group,
- had the trust of patients and other health professionals, and
- were educated to take a holistic view of patient health.

A Nurse Navigator workload comprises 40 active and 40 inactive patients and they work 9am to 5pm Monday to Friday. However, not all patients represent an equal workload. Nurse Navigators will likely have active patients from each of the five phases (see below) and so caseloads need to be closely monitored to avoid burnout.

[xx] For example, five Nurse Navigators in the Darling Downs Hospital HHS have been implemented as Nurse Practitioners Aged Care Nurse Navigators. https://clinicalexcellence.qld.gov.au/improvement-exchange/nurse-navigator

Patient recruitment

The service has an open referral system. Initial contact with the patient happens within five days of referral, and its purpose is to gain consent and introduce the service. Eligibility for the service is guided by a matrix of chronicity, complexity, fragility, and intensity of care. The service accepts paediatiric, adults, and Medicare eligible and private patients. There is limited eligibility for patients already receiving coordinated care from another service.

Patient management

The Navigator organises a comprehensive face-to-face assessment that establishes the patient's health literacy, gains consents for sharing information, and develops a care plan. The implementation of the service will be unique to each enrolled patient, however, the main aspects of the service include

- advanced hospital discharge,
- patient and caregiver condition specific education,
- provision of Nurse Navigator led clinics in outpatient or Telehealth sites,
- coordinating patient and caregiver care,
- hospital avoidance,
- evaluation and review, and
- discharge or exit from the service.

As part of the Model of Care, the Nurse Navigated Patient Continuum outlines phases of patient-centred care that form the basis of the nurse navigator patient journey. The five phases (Intensive, Managing, Maintaining, Transitioning, Discharge) support Nurse Navigator Role Principles as part of the Model of Care. While some patients may not be able to fully exit the program they may stay on as inactive patients and access the Nurse Navigators in times of need. The majority of patients will exit the service once their goals have been achieved.

Training

Types of training and system access for Nurse Navigators is guided by a document that outlines the required education framework. The Nurse Navigator program does not demand specific training in chronic disease management, preferring instead to promote a 'toolbox approach'.[xxi] However, the Navigators we spoke to had training in motivational interviewing and Flinders Chronic Conditions Management Program. New staff will also partake in annual Nurse Navigator orientation and induction

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[xxi] Navigators are encouraged to use a range of tools to teach patients self-management strategies and improve patient health outcomes. See for example, Hogden, A., Short, A., Phillips, R., Dugdale, P., Nugus, P., & Greenfield, D. (2012). Health coaching and motivational interviewing: Evaluating the chronic disease self-management toolbox as a tool for person-centred healthcare. *Journal of Medicine and the Person*, *2*, 520–530.

workshops as well as have access to a Nurse Navigator Network and monthly education sessions.

IT Systems

An improvement on existing IT systems was considered critical to supporting an effective navigation service. An innovative IT system for patient information, called Compass, is being developed. Compass will provide Navigators with access to all of their patients' necessary information by pulling data from other health applications and presenting it in one spot.

Challenges

Being a new service, there were some misunderstandings by other health practitioners about the scope of the Navigator role. In some HHSs the program drifted away from the key principles when not implemented as a service. The Practice and Innovation Division found that when the program was implemented as a team of navigators with a lead navigator they adhered more firmly to the key principles. Additionally, there were some early incidents of burnout caused by difficulties in establishing parameters for the scope of navigators' responsibilities.

There have been some challenges in the first phase of the service rollout, including confusion around role definition and some resistance from allied health. The key lesson is that Nurse Navigators are more functional and get better support if they are implemented as a service rather than a single role or position.

Review

A review of the service is underway in collaboration with Central Queensland University. However, as part of the services data collection, Nurse Navigators record monthly "case studies". We gained permission to include the following quotes from these case studies to demonstrate the overwhelmingly positive feedback:[60]

> *It is good having someone to help that isn't aligned to any specific field, they don't have a biased opinion. Every specialist thinks their field is the major problem, their main priority, when it's actually all the same. Nothing is worse than anything else. The Nurse navigator changed my relationship with doctors, there is now more communication between them.*

> *The Nurse Navigator can explain what's going on in my body. I now have the confidence in understanding my condition and what I need to do to manage it.*

> *There is not one specific thing the Nurse navigator does – she encompasses all of the activities I am concerned about and can supply knowledge for me so I become better involved.*

> *Due to many health issues I had many healthcare professionals involved in my care but felt I was not treated holistically. The Nurse Navigator has been the best thing that has happened to me. I have learnt so much of how to manage my healthcare issues and now feel more confident and optimistic about my future.*
>
> *I was completely overwhelmed with the ramifications of my daughter's diagnosis. The myriad of appointments necessary meant appointments were being missed. The support the Nurse navigator supplies in a complicated system that carers and patients don't have the energy or time to do… We will be forever grateful.*
>
> *I was no longer able to manage my health… The Nurse Navigator service is the best thing to happen to me. They explain everything to me and talk to all the doctors in the hospital and my doctor. When I was readmitted they led a meeting with other healthcare professionals and a plan was agreed to. I have not been back to the emergency department since.*

3.2 Western Healthlinks Service

Governance

The Western Healthlinks Service is a three-year pilot program funded by the Victorian Department of Health and Human Services. The Service forms part of a broader objective to implement quality care integration. The pilot, which began in November 2016, is jointly managed by Western Health and West Australian based Silver Chain Group (SCG). Western Health provide health services for the western region of Melbourne. Services include three acute public hospitals, and a range of community based services. The SCG is a not-for-profit organisation delivering community health and aged care services across Australia. The Western Healthlinks service is managed from SCG's office in Sunshine, Victoria.

Aim

The aim of the Healthlinks service is to prevent the hospital readmission of people with chronic conditions by bridging the gap between hospital and community care. Healthlinks does this by enrolling patients at risk of readmission into a program that provides 24/7 single point of contact and Health Navigators that coordinate the patient's care both in and out of hospital.

Role

The service currently provides 18 full-time navigators. Health Navigators are either registered nurses or allied health professionals. The Navigators are based in the Sunshine office, except for two who are hospital-based.

The service is available from 7am-11pm, seven days a week. All patients are given access to a 24/7 Priority Response Assessment (PRA) nursing service. The aim of the PRA is to provide a clinical assessment over the phone to avoid emergency department admissions. The PRA triages actions based on a patient's symptoms and will either arrange an appointment with the patient's GP, arrange a specialist appointment through outpatients Registrar, or organise an emergency department (ED) admission. Approximately 70% of patients who call the PRA remain at home.

Patient recruitment

The majority of eligible patients are identified in Emergency Department through an algorithm developed by Western Health that triggers an automated alert sent to navigators based at the hospital. This algorithm targets patients who are high users of the Emergency Department, have frequent inpatient admissions, and have multiple co-morbidities. Once patients are admitted or put into Emergency Observation, they can enrol in the program. Exclusions are catastrophic injury, palliative care and maternity.

The two hospital-based navigators sit within the hospital's ACE (Advise Coordination & Expertise) Emergency Department Care Coordinators. Patients can also be identified by ACE Care Coordinators who then work with the navigators to develop care plans and act as a conduit between the community and acute services for enrolled patients.

Patient management

In consultation with a patient's GP, all Health Navigators use the same process to assess and manage patients including a

- Debility and Psychosocial Risk Score,
- Flinders Partners in Health Scale and Cue and Response,
- Flinders Problem and Goals Assessment, and
- Flinders Chronic Condition Management Care Plan.

Some of this assessment process can occur in the inpatient setting before a patient is discharged. Additionally, the in-hospital service includes a pharmacy review, collaborative care planning, and Rapid Discharge Support Service (RDSS). A questionnaire based on clinical and demographic factors, debility and psychosocial factors is used to assess the patient's risk of readmission. High, medium and low risk patients are allocated a corresponding service response involving a combination of phone calls and in-home visits by Navigators:

- High risk patients receive two visits to establish care plan, a phone call less than 24 hours post discharge and a weekly home visit.
- Medium risk patients receive two visits to establish care plan, a phone call between 24-48 hours post discharge and a combination of one home visit per each month and phone monitoring
- Low risk patients receive a phone call 49 hours post discharge and phone monitoring as per risk score.

This level of service varies as patients move between the three levels of risk. At the time of writing there were 3400 patients enrolled in the service with 250/300 new patients joining every month.

Training

All navigators are accredited by Flinders University in the Flinders Program of Chronic Conditions Management.

IT systems

The service has adopted a sophisticated alert system including a centrally accessed Western Health Community Services e-referral and appointment scheduling system. Once patients are enrolled, their information is kept in the Healthlinks clinical portal for shared patient information.

Challenges

Some challenges in the pilot include difficulty managing workload of the Navigators. Navigators mentioned the danger of “scope creep” resulting in longer hours and more intense case management. The introduction of the Priority Response and Assessment (PRA) service has helped decrease scope creep to some degree. The other challenge has been recruiting qualified staff which may be reflective of the broader national shortage of skilled nurses and health professionals.

Review

Western Health and CSIRO are currently reviewing the service. Though there are no publically available data, the HCCA was told that readmissions in the three hospitals have “significantly” decreased. Health Navigators collect patient stories and the feedback has been positive as the following testimonials demonstrate:[61]

> *After the Healthlinks support I feel so much better. It’s changed my life.*
>
> *I feel like her old self again. The service is great.*

Section 2 – Interviews

Section 2 is divided into two parts. The first part discusses the findings from interviews with **health professionals**. The second part discusses the findings from interviews with **consumers**. The Section concludes with a discussion on the findings of both groups, including how care coordination is delivered and received, the barriers to care coordination shared by both groups, and the unmet needs of consumers.

Health Professionals

Key Findings

- There are many examples in the ACT where patients with chronic conditions get good care coordination
- Coordinating care becomes more difficult if patients deviate from the standard treatment pathway (i.e. have more than one condition or complex non-medical conditions)
- Coordinating care for complex patients takes time
- Current IT systems are not appropriate for the task of coordinating care
- Good discharge is critical to coordinating care
- Current systems and processes do not support self-management of complex chronic conditions

Major barriers to providing good care coordination identified by health professionals

- There is often not enough time to provide a comprehensive, holistic assessment of patients, including everyone involved in their care, before they are discharged
- Coordinator roles and responsibilities are not clearly defined
- Processes for coordinating care, including discharge, are not standardised
- Poor flow of patient information generally, but especially between treating clinicians when a patient has multiple conditions
- There are not enough dedicated discharge roles such as discharge liaison nurses and social workers
- Added complexity and time delays caused by government systems such as My Aged Care and NDIS

Between February-April 2018, the HCCA interviewed a broad range of health professionals who had some involvement with care coordination in the ACT. We conducted 20 interviews (26 people) with nurses, general practitioners, allied health workers and community-based organisations. Interview participants were asked questions regarding the tasks they perform and what they thought were the benefits and challenges of coordinating care for people with chronic and complex conditions. To protect the identity of participants, we have omitted their profession, discipline or any identifying information. Consequently, particular diseases or issues relating to social/cultural groups are not specifically addressed in the discussion below.

What follows is a general discussion of the main themes raised by health professionals, followed by their thoughts and opinions regarding a model for patient navigation. Participants spoke broadly about their jobs, the health profession, health systems and shared their thoughts and ideas. Additionally, health professionals shared their opinions about a model for patient navigation as well as what characteristics they thought made some health professionals particularly good at coordinating care.

This discussion aims to capture the benefits and challenges of existing care coordination in the ACT, and directly inform the model of patient care navigation in the ACT

Main Observations

According to the health professionals[xxii] interviewed, barriers to care coordination for patients with chronic and complex conditions are generally concerned with **information about the patient** and **information for the patient**. Participants told us that **information about the patient** is sometimes recorded inconsistently and rarely flows smoothly through the various systems (such as discharge planning, outpatients, acute and primary care or community and other services like My Aged Care). These barriers to reliable and accessible information make it difficult for health practitioners to form a holistic assessment of the patient and provide integrated care.

Information for the patient about follow-up, services, programs, eligibility for and accessibility to services is also inconsistent. Most participants felt that comprehensive care coordination could be better, but felt that the current environment was not conducive. Participants mentioned that the system's requirements to move patients swiftly along the continuum of care (particularly in hospital) often does not allow the time and support needed to coordinate care for patients with chronic and complex conditions. This expectation is particularly an issue when trying to coordinate care for patients **before they leave hospital**.

Major observations from the health professional interviews were:

- There are many examples in the ACT where patients with chronic conditions get good care coordination
- Coordinating care becomes more difficult if patients deviate from the standard treatment pathway (i.e. have more than one condition or struggle with non-medical conditions).
- IT systems are not appropriate for the task of coordinating care
- Good discharge is critical to coordinating care

[xxii] The terms 'health professionals' and 'participants' are used interchangeably throughout this analysis.

- Current systems and processes do not support self-management of complex chronic conditions
- Coordinating care for complex patients takes time

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1. *There are many examples in the ACT where patients with chronic conditions get good care coordination.*

As discussed in Section 1, there are a number of examples of care coordination across the ACT. But after an analysis of participant interviews we have found that the level of coordination is variable. We have identified four factors that contribute to good care coordination:

- Clinical leadership
- The chronic condition being treated
- Passion and experience of staff
- Home visits

The first factor influencing care coordination is leadership. One health professional expressed this in the following:

> *These nurses probably do more than most other programs because that's the way I've driven it.*

The implication is that such programs require leadership, and that support from the leader also affects the type of complexity a program can or will address. While many programs are designed to assist patients with medical complexity, there are programs that additionally focus on the social aspects of patients' health, but this also varies. There are degrees to which social aspects are addressed, and this may be linked to the type of chronic condition. Programs for patients with conditions considered lifestyle related, such as diabetes, may be more comprehensively assessed to determine the social issues contributing to their poor health.

The condition being treated is the second factor contributing to good coordination, and applies to most patients in this category, to varying degrees, as one health professional commented:

> *Every single patient has some kind of issue. So it'll be mostly psychological, and some of them have infections, severe mental illness, carer situations at home where they've got financial problems, can't drive because they're blind. Just so many aspects of it that it's enormous, so we feel that we do a really good job of care coordination because we don't just look at the patients' disease, we look at them as a whole person.*

Along with a supportive leader and a focus on a particular condition, what sets these more holistic programs apart is the third factor - experience within, and a passion for, a particular discipline. The experience and passion these health professionals bring to their work is a critical aspect of navigation. It enables them to anticipate what a patient needs, when they need it, and know the best ways to access it. These needs invariably include non-medical, including help with depression and anxiety.

It is important to note that social factors are not necessarily at the core of programs for patients with chronic and complex conditions. One exception is the Chronic Care Program (CCP), as part of the Chronic Disease Management Unit, discussed in the previous section. A few participants who referred patients to the CCP did so because the CCP coordinated care that went beyond medical and lifestyle factors. This care might include organising a lawn mowing or housecleaning service, or sourcing a new fridge for a patient.

These are the social issues that can only be assessed with a home visit. A home visit is the third factor, which not all care coordinators can, or are expected to do. Yet, the implications of addressing these more complex social issues are critical to a patient's health, as one participant pointed out, by doing so - *"you may take out the social drivers of their readmissions".* Understandably, a patient's medical issues are the priority for most care coordinators, even if they acknowledge that their patient may be struggling with more complex social issues. The biggest barrier to being able to address those issues is a lack of time and support, leaving some participants feeling powerless to address social complexities for their patients.

2. Coordinating care becomes more difficult if patients deviate from the standard treatment pathway (i.e. have more than one condition or struggle with non-medical conditions).

As mentioned, the degree to which a patient's care is coordinated, **by coordinators**, in the ACT is strikingly variable. This variability is partly explained by the way professional roles have evolved as one participant explained:

> *There are so many different brands of coordinators. … you have different people doing coordinator roles acting in very different levels. You can be an Enrolled Nurse being a coordinator. You can be a level one nurse being a coordinator, a level two nurse being a coordinator, and in our instance, we're level three nurses, with a lot of us with a masters degree, that we're coordinators.*

Unlike the Chronic Care Program, which provides coordinated care for patients with several conditions, most of these roles are, more or less, disease specific. Of these different 'brands' of coordinator some set clearer parameters for their disease specific scope of practice, meaning that patients with comorbidities are not getting all of their needs addressed by one person or program. Some coordinators, particularly those unsure of their boundaries, are careful not to overstep into other health professional domains. For example, rather than link a patient to community based social services some participants preferred to link their patient to a social worker who would then link the patient to a community based service. Because, according to one health professional *"it can easily get messy, these kinds of positions I think, if people don't have a good understanding of where their role starts and stops".*

Avoiding the mess is understandable when coordination is only one of the many demands on a health professional's time. Many participants indicated that they would like to offer better coordination for patients with multiple, complex conditions but feel it is beyond what they can realistically do. For example, one participant mentioned that

> *the whole social side is probably what's lacking, yes. I'd say we're doing it well from a [medical] side, but then you look at ACATs, elderly, home, food, transport, that's probably something that we can try, but we're not going to be able to fulfil all of that. I can't fix all that.*

Patients receiving treatment from a number of medical teams was a commonly reported barrier to more comprehensive coordination, as one health professional explains:

> *I know somebody who's on orthopaedics and under medical oncology and under radiation oncology, and palliative care and nobody's pulling all that together.*

The blame for a patients' information not being 'pulled together' is often leveled at medical specialists who have something of a reputation for not sharing patient information. However, participants identified that the biggest barrier is the way in which patient information is shared. There are often no shared patient records between specialists, so communicating the whole history of the patient relies on one person to coordinate the information manually rather than simply accessing a central point of information.

3. IT systems are not appropriate for the task of coordinating care

Participants mentioned examples of good IT innovations that help patients with chronic and complex conditions access the care they need such as setting up alerts for particular patients presenting to ED. However, for the system to be effective, Admissions needs to read the patient information and contact the person who set up the alert. This places the onus on one staff member to make sure they read the patient's file and send an email to the person who set up the alert. There is no automatic means of identification.

Many participants mentioned that despite the shortcomings of the current system it did perform the important function of protecting patient privacy. However, participants acknowledged the difficulty for patients with multiple chronic conditions. One participant suggested that there needed to be a balance between privacy and convenience:

> *It's getting to the stage that, particularly for the chronic disease patients or people with lots of comorbidities, the amount of*

> *information that you need to juggle and carry with you so that everyone involved in your care, has access to that same information, it's almost impossible.*

The difficulties in coordinating care for complex patients is magnified when patient information systems within the hospital, such as oncology and main hospital, are incompatible. This is particularly problematic when patients have follow-up appointments that cause a cascade of wasted time. One health professional described just such a situation:

> *So you've got an admin area that's in charge of appointments, you've got clinicians making decisions and having absolutely no authority over those wait times and wait lists or knowing when they are. So you get a patient in the middle who is clinically at risk and then what happens is sometimes, of course, they'll either ring the GP or they'll go in to see the GP for follow-up and the GP also doesn't know if the appointment has been made. So then at least for them the GP will ring GP Liaison who can look through the system and spend a lot of their time saying "No, there is no appointment" and "Yes, I can see that referral" or "No, I can't even see that".*

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4. Good discharge is critical to coordinating care

Participants were aware that for patients with chronic and complex conditions, a "*safe and sustainable discharge"* is critical. Many health professionals told us that to ensure a comprehensive discharge the process needs to begin the day the patient is admitted to hospital:

> *It's terribly important that we go to the ward meetings, find out early on what the issues are, get the ball rolling from day one, talk to the family, get the referral in for services pretty much on the day of admission. So that it lines up for when the discharge summary's being typed up by the doctor and the pharmacist is getting the meds into the Webster pack, and then if all the ducks line up, it's magic when it happens. And the few times it does happen I inwardly glow and … I say to others "Isn't it fabulous?"*

That all 'the ducks line up' only rarely is a major issue for health professionals and points to the difficulty in safely discharging a patient with chronic and complex conditions. From a hospital-wide perspective, this difficultly is not helped by the fact that the discharge process is not standardised. Importantly, this comment demonstrates that discharging a patient is never a discrete act performed by one person. It involves the patient, family, services, clinical teams, junior medical officers, and pharmacists. Discharge planning is collaborative, complex and often hectic.

Good social workers were considered crucial in providing a continuity of care post-discharge. However, some participants mentioned that there were not enough social workers and other allied health staff to see all patients before they leave hospital. Similarly, participants commented on the lack of social workers in the community setting, such as general practices.

The accessibility and appropriateness of patient discharge information was raised by a number of health professionals. While most considered the information adequate, there were concerns about the capacity or readiness of patients to absorb it while an in-patient. Capacity and readiness particularly applies to patients who are discharged from hospital after an acute event with no follow-up, as they are more likely to misplace or forget relevant information for linking to community services. For example, patients may be given information up to three times to ensure that they *"actually have the capacity to take it on".* Rarely does a program allow more time for these patients to fully comprehend the information unless it is **built in to the patient pathway**. Rehabilitation pathways, for example, give a patient extra time and continuity with health professionals outside of hospital who (re)provide that information as well as providing the patient with valuable *"inside knowledge"*.

Furthermore, patients with continued support either in or out of hospital get assistance with understanding and simplifying an *"overwhelming pile of paper".* With this assistance, patients are able to plan for services during the course of their illness. As one health professional pointed out, this type of information is not simply *"a health education message. It's a communication. This is what's happening to you message."* Not accessing post-discharge services could mean the difference between readmitting or not.

5. *Current systems and processes do not support self-management.*

Most of the health professionals we interviewed found systems for people who need support to access services unnecessarily complex and time-consuming, as described by one participant:

> *… When people are sick and they haven't already nominated somebody to be their spokesperson with Centrelink and My Aged Care and whoever else, if they haven't done that, nobody can talk on their behalf. [Social workers] were able to do that because, going back again, all those years, the only advocates in the hospital who did this care coordination, care navigation advocacy were social workers. [Social workers] made individual contacts with service agencies, have a chat about the patient and really network and get a really good plan happening before they left hospital.*

My Aged Care website and National Disability Insurance Scheme (NDIS) have added to the complexity facing health professionals and patients. One participant explained that *“we can’t understand it. Imagine how the patient feels?”*

Criticisms of the Commonwealth systems were common with many finding them a barrier to patients self-managing their chronic conditions:

> *The NDIS and My Aged Care are definitely not supporting of a person remaining at home safely, because they're not timely, they're not easy to access and they're very quick to judge that every single person they send a letter to or a phone call to can speak English and read.*

Other aspects of the health care system are confusing to health professionals and this confusion is often compounded by constant change. As one health professional pointed out *“systems are changing all the time”.* These systems include pathways for patients with multiple chronic conditions where even experienced clinicians can get lost. Referrals can be similarly confusing as explained by one participant:

> *I feel like there’s a lot of referrals going back and forth to different people, round in circles, upside down, left to front, you know. Like I’m referring to people who are referring to me and then I’m referring someone else and it’s just going round. Yeah, like do we really need to all be putting in referrals? Why can’t there be one referral which then automatically gets pushed to where it needs to go?*

Many health professionals exhibited a pragmatic acceptance of these kinds of system flaws. It was generally through talking with HCCA about navigation that these flaws became evident, yet remained too hard to address. As one participant remarked, “*And you go, oh, it’s a big hospital, you won’t change it. Just get on and do it.”*

High rotation of staff contributes to confusion and subsequently inconsistent levels of service throughout the hospital. Many participants referred to the ‘culture’ of the system as a barrier to consistently good patient care. The acknowledgement that *“everyone operates in silos”* was common among participants. The implication is that the culture can be unsupportive of many of the aspects necessary for good care coordination such as shared patient records, communication across disciplines and between acute and primary care. Similarly, participants mentioned having to always be aware of the ‘politics’ in the hospital and how, through the fear of ‘stepping on toes’ it compromises their role and, potentially, the quality of care.

6. Coordinating care for complex patients takes time

> *Some people that come in are really complex so it might take you hours and hours to actually focus on one patient before you get to the others.*

Coordinating care for people with chronic and complex conditions is time-consuming. Health professionals told us that they *"try to liaise and coordinate with everybody who's involved with each patient"* including GPs, specialist nurses, specialists, pharmacists and palliative care. Likewise, coordinating care for patients with no pre-existing support also takes time because *"you've got to invent the wheel. You have to sort of juggle what can I get out of the family, what can I get out of short-term services and does a longer term arrangement need to be put down?"* Time becomes an even bigger factor when the patient is in hospital and health professionals have less than a week to put supports in place before they are discharged home. The very serious consequence of these time constraints is that occasionally patients go home with little or no support.

There are few health professional roles in the ACT where time to coordinate care is built in to the role. Not having allocated time does not prevent some health professional from coordinating care but it does increase pressure and often leaves them frustrated and feeling over-burdened as one participant explained:

> *I've got a [non-English] speaking person who needs to have an x-ray, I've got to ring up and make an appointment for them because they can't actually ring up themselves, and often I could describe how to actually get there and a lot of them can't read maps either, and most of the radiology places will not actually organize, will not actually use the translating-interpreting service.*

For comprehensive care coordination patients are physically, medically and psychosocially assessed. Holistic assessments are necessary for determining risk, creating care plans and setting goals for patients to self-manage as much as they can. Participants currently in coordinator roles commented that other health professionals might underestimate, and not always appreciate, the time it takes to provide holistic assessments and coordination of patients. While this pressure is particularly acute for the discharge of patients from hospital, pressure was also experienced by participants who work with clients at home.

Health professionals agreed that while their patient is their priority, most acknowledged the importance of including family and carers in the assessment and planning for the patient. It is not uncommon for health professionals to be coordinating care for multiple people related to one patient. Disentangling these complicated situations demands extra time. One health professional told us the only way to address these situations is to *"wade in, working out how to work it out along* *the way." "I can't look after one person without looking after the other, because the whole system is gonna fall down."*

Advocacy was a common factor in coordinating care for most participants - *"Patient advocacy is my huge thing. So you advocate for them.*" Advocacy requires a high level of familiarity with a patient and personalised coordination to suit a patient's individual requirements. It is time-consuming because it often demands constant communication, interpretation and feedback. For one participant, advocacy means requesting that a deteriorating patient be bumped higher up the waiting list, that an out of town patient has several pathology tests scheduled in the same afternoon, or that a parent of young children sees their specialists during school hours.

For those health professionals with more flexible schedules, advocacy may mean accompanying a patient to a specialist appointment as demonstrated by the following:

> *I go in to meet them here at the hospital and attend the appointment with the gastroenterologist and the patient and their family. Because I've got the rapport with the gastroenterologist and obviously the family's consent. That works really well. I'm hearing all the conversations, I can ask any questions, I know the plan.*

This kind of advocacy offers support for both the patient and the doctor. The rationale is simple, and long maintained by the HCCA, that spending time saves time in the long run.[62] Spending time to teach patients the skills and confidence to self-manage, and lessen their risk of returning to hospital, ultimately saves time.

What do health professionals think about a potential patient navigation service?

During interviews, health professionals were naturally inquisitive about the prospect of a new health professional role. They offered opinions on what navigation might look like and what they considered important for a potential service. These contributions are captured below.

1. Who should be the target group?

Those health professionals with specific experience in care coordination thought there were two main potential groups that would benefit from a navigator service:

- High needs patients with multiple conditions and medical/social complexity needing ongoing help.
- Low needs patients with a single condition and simple barriers like transport or communication between multiple specialists needing short-term help.

Other suggestions included navigation for non-English speaking groups and vulnerable or hard-to-reach groups.

2. What should the service be called?

Participants were generally happy with the phrase Patient Care Navigator. However, there were two comments concerning the term "patient":

- The term 'patient' no longer applies after discharge from hospital.
- The term 'patient' excludes a person's carers or family.

3. Should navigators be professional or lay people?

Opinions were split among health professionals about who should undertake a navigator role but only a few suggested a lay-person (such as peer-support). Some warned against the perils of 'medical models' that might focus overly on tasks or process at the expense of patient-centred care. Most felt that chronically ill people needed a person with clinical experience. While there were a few who stated that the role needed to be a nurse, most were supportive of the role being performed by allied health. One participant explained that *"you don't necessarily have to have the clinical answers, but you do need to know where to find the information".*

4. What should be the navigators' scope of practice?

Some health professionals preferred the idea of case coordination rather than case management because management seemed too intensive. This opinion reflects much of the literature and from our discussions with Queensland Nurse Navigators and Silver Chain Group Health Navigators who, through trial and error, had pared down their scope of practice to avoid being overloaded. Some felt the role should more closely resemble 'traditional social work' practices that employ therapeutic engagement as they saw coordination as little more than making referrals and completing paperwork. One important point made by the Silver Chain Group was that case coordination and navigation are two different things, with coordination being just one of the tasks that a navigator performs.

Some health professionals working with complex patients liked having a flexible role definition. They felt it gave them the necessary independence to make decisions and do what was needed for their patients. This level of flexibility is informally built-in to some roles where, if they are particularly driven, they feel enabled to *"always just go the extra mile"* for their patients.

Other participants also appreciated the freedom to modify their approach to suit individual patients, rather than adhering to one model or program. While there are certain guidelines that must be followed, health professionals enjoyed working beyond program parameters and mixing aspects of good models to suit. For example, one participant said, *"we might actually apply a little bit more of a Flinders model to each individual patient or more of a heart model to another different patient, because it fits with that person"*. Keeping abreast of professional practice and emerging trends was considered critical.

A key aspect of good coordination is establishing trust with patients and families. One of the ways a navigator should do this is to take professional responsibility for the patient. For some participants, a simple and powerful way to demonstrate this responsibility was to give patients their phone numbers. This provides what one nurse described as a “safety net” for patients that there is a person they can contact when things do not go according to plan.

5. What characteristics should a navigator have?

Many health professionals in the hospital mentioned the importance of being able to establish and maintain good external relations. The fact of being known by community service providers and having “personable” relationships expedited coordination for patients. Similarly, “knowing the system” was considered a distinct advantage as one participant commented, *“I know how the system works. I know who to ring. I know who to send that email referral to, to get a quick response, and it works for me”.*

Along with good external relationships comes an understanding of how things work inside and outside the acute setting. Health professionals often lauded the benefits of having worked in both acute and community sectors and often complained when colleagues lacked a similar understanding. The value of a good understanding was particularly expressed through inter-sector communication such as discharge summaries, patient notes and general expectations about roles and capacities.

Some health professionals implied that good coordination is more than simply linking patients with services. It involves identifying the missing pieces in a patients care and then creating a structure around the patient made up of people, services, information, and support. As one health professional stated, the process closely resembles that of a “puzzle master”.[xxiii] The role of puzzle master requires asking questions, repeatedly if necessary, and so a high level of tenacity and a reasonably thick skin are recommended.

While good communication skills are essential for any health professional, the success of patient navigation depends on it. One participant told us *“the whole reason why I think [the program] has been a success, apart from the fact that these guys are clinically very competent, is their ability to communicate.”* Communication in this context requires an almost multi-lingual ability to tailor language and manner to suit the individual – whether they be a patient, carer, GP, specialist or administrator – while having the confidence to advocate for their patient.

[xxiii] ‘Puzzle master’ was a phrase used by one Queensland Nurse Navigator to describe her role as a navigator.

Consumers

Key Findings

- Many people become adept navigators of their own health and care over time, yet value navigation assistance when their circumstances change
- Consumers are more likely to value navigation if they have multiple conditions and complex social circumstances
- Care coordination is currently provided by diverse health professionals and lay people, often on an ad-hoc basis
- Care coordination does not commonly address the needs of people living with multiple conditions
- Information sharing is the most valued aspect of care coordination, particularly during periods of change such as hospital discharge or subsequent diagnoses.

Major barriers to receiving good care coordination identified by consumers

- Significant gaps in information about their conditions, treatment options and staying healthy, and poor flow of information between health services and professionals
- Cost barriers
- Time barriers
- Cursory hospital discharge planning

In February 2018 the HCCA began recruiting consumers who identified as having multiple chronic conditions and had been discharged from and ACT hospital not more than 12 months prior. We conducted 14 interviews between March-May 2018. Interview participants were asked to talk about their experiences managing their conditions as an in-patient and at home. To protect the identity of participants, we have omitted any identifying information. What follows is a general discussion of the main themes raised by consumers which aims to capture the experiences of managing multiple and complex chronic conditions in the ACT, and directly inform the model of patient care navigation in the ACT

After a brief discussion on participant characteristics, this Section discusses four barriers to the best possible coordinated care:

1. Information barriers, unanswered questions, jargon and silos
2. Improving discharge
3. Staying well and avoiding readmission
4. Navigation assistance

The Section concludes with what consumers think about a potential navigation service.

The participants

Interview participants had one or more chronic condition and the median number of chronic conditions per person was three. Out of the 14 participants, 13 had been hospital inpatients in the last 12 months, and one had been in hospital in the last two years. Across the cohort, participants had neurological conditions, conditions of the heart, lungs and kidneys, immune conditions, Type 1 Diabetes, Type 2 Diabetes, and cancer. Four participants were also family carers for a person with a chronic condition or conditions. Most participants were women (10 of 14). Most participants were aged 50 or over. Only four were aged under 40 years. Some participants could be considered to have complex needs (see definition in the Executive Summary, p. 9). In addition to their health conditions, they had social needs such as affordable housing, and assistance to live independently. These participants were receiving assistance from services for these matters.

Most participants were ACT residents, though three lived in regional NSW and received some of their care in the ACT. All had received inpatient and out-patient care at an ACT public hospital. Two had also been inpatients at an ACT private hospital. Two participants received care in NSW public hospitals. All had a regular GP and most saw one or more medical specialists as a private patient. Participants had used other ACT Health services including ACT Health Community Health Centres, Walk-In Centres and ACT Health Community Nursing service.

There are some gaps in the consumer perspectives included in this study. These are:

- There was only one participant from a culturally and linguistically diverse (CALD) background
- There were no Aboriginal and Torres Strait Islander (ATSI) participants,
- There were no participants aged 18-30 years
- There was no participation from parents, kin or carers of children or infants with a chronic condition or conditions

Therefore, the report's findings do not reflect any particular issues that may affect these cohorts.

HCCA also sought feedback from participants in two consumer consultations: one with HCCA members and the other with participants in HCCA Consumer Participation Training. Findings from these consultations and from interviews inform the discussion below.

Main Observations

1. Information barriers: unanswered questions, jargon and silos.

Participants[xxiv] would have better care experiences, and be better able to look after their health, if

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[xxiv] The terms 'participants' and 'consumers' are used interchangeably throughout this analysis.

- their questions about their health, treatment and care were answered,
- health professionals *proactively* provided relevant information about their diagnoses, prognosis, treatment and care, staying healthy *and* the interactions of their multiple conditions,
- they knew what was happening next in their care,
- information was provided in a way that was easy to grasp,
- the roles of their health professionals were clear, and they knew who was accountable for decisions, and
- health services and professionals had reliable processes in place to share information swiftly and seamlessly.

1.1 Please answer my questions

Consumers spoke of having **unanswered questions** about their health and care. Having questions answered was especially important when health circumstances change: for example, when diagnosed with a first or subsequent chronic condition, when contemplating a change in treatment, and during and after an in-patient admission.

Common unanswered questions for participants were

- who is in charge of my care?
- what is going to happen next?
- what is the aim of my treatment?
- what are my options for treatment and care? and
- what is my likely prognosis? What usually happens to people with my condition?

Consumers also had questions about staying healthy after a hospital admission, and accessing the care and assistance they need on an ongoing basis:

- Where can I go for more information?
- What can I do to look after my own health?
- What services can assist me to manage my health at home?
- Where can I access free or less expensive health services?

Additionally, participants had questions about the interactions of their chronic conditions:

- What do I need to know about the interactions of my conditions and my medications?
- How will a change in my medication or treatment affect me? How does this new diagnosis, test, procedure or medication impact on my pre-existing condition/s?
- How do my conditions affect my treatment for an acute health event requiring hospitalisation? How do my health conditions affect the plan for my recovery at home?
- How will my various clinicians share information about my care?

- Who is accountable for decisions about how to treat the complex interactions of my conditions?

Patients who were also carers also wanted to know who would look after the person they care for, while they were unable to do so due to illness or recovery from surgery.

Some participants were unsure what questions they could or should ask health professionals. One participant thought it best to “listen and learn” rather than asking questions in hospital, but consequently felt she was discharged without important information about her prognosis and plan for recovery. Other participants would appreciate **a more proactive approach to information sharing**. This could take the form of a conversation with a health professional, or other person, who can provide answers to common questions about prognosis, treatment options and staying healthy, and who considers the individual’s health and personal circumstances. This conversation would differ from a discussion with a treating clinician by more closely resembling a patient navigation approach where there would be more time to ask questions. There would be a greater focus on imparting knowledge for self-management rather than responding to an immediate medical situation:

> *Everyone’s going to have a different level of awareness of what they need to ask, so I’d be expecting [a Care Navigator] to go, “okay, tell me about your big picture”, spend an hour and a half talking… A good initial getting to know you and your situation, getting to know the context. Then you can ask your questions but then they’ll know the questions that you need to ask.*

1.2 Give me information to inform my decisions

Consumers knew that having multiple chronic conditions increased their risk of medication error, misdiagnosis and inappropriate treatment. This exacerbated their frustration when their questions were not answered, particularly in hospital. One participant was acutely aware of the need to discuss possible medication interactions with an anaesthetist prior to surgery, and felt her requests were brushed off until shortly before the scheduled surgery. At this point, the anaesthetist acknowledged that this conversation was essential to avoid potential serious adverse outcomes. One participant was unable to discuss the benefits and risks that maxillofacial surgery posed for her frail aged mother until surgeons were “gowned” and ready to operate. In both cases, these participants would have valued the opportunity to have earlier discussions in order to give their fully informed consent to these procedures and to minimise the risk of adverse health events.

Many participants felt that they did not have enough information to inform their decisions about care and staying healthy over the longer term. One participant was diagnosed with Type 2 diabetes while pregnant, and would have welcomed impartial advice about her care options and treatment pathways, in both public and private health systems. Another participant would have welcomed an “information service”, either online or at a Community Health Centre, with information about common issues for family carers and people with multiple chronic conditions. Two participants would have appreciated earlier and franker information about palliative care, end of life and bereavement, to inform their expectations and care choices in this area.

1.3 Please tell me what's happening next, in a way I can understand

Some participants described being uncertain about the aims of their treatment, and their care plan. This uncertainty was most pronounced when hospitalised and immediately after discharge. Participants recognised that sometimes the care goals and plan were unclear because clinicians were still forming a view. They also recognised that ill-health may have lessened their ability to understand what had been communicated about these matters. For example, one participant found information

> *hard to retain just because of the state of your health in general.*

However, participants who asked what was happening next in their care often found it difficult to get answers. Nurses advised one participant to ask a doctor, but could not predict when that doctor might be available to speak to. For another, the most difficult aspect of her mother's ill-health was

> *communication with the doctors… updates in terms of where she is at. It was really difficult to get that relayed to me.*

Participants frequently described not knowing what test, treatment, transfer or procedure was going to happen next or when, both in hospital and after discharge. Some processes were complex and unclear. As an in-patient, one participant was surprised to find that he had to leave the hospital to receive an MRI.

Information was sometimes relayed in a cursory way or using technical language that was difficult to grasp. One participant was told she would be "going down to rehab":

> *The workers, the professionals, they knew exactly what that meant. [I didn't have]… an immediate full understanding of what people really meant. If anyone had asked me, who do you think works in the rehab ward of a hospital?, it would have been the first time in my life that I'd ever had to consider it. I wouldn't have [known] that you automatically should say, of course, physiotherapists...*
>
> *You're surrounded by professionals. They all know the appropriate language and acronyms. It's almost like you, the breathing body at the centre of it, have been dehumanised while they're magging away about 'TIAs' and all the rest of it… they all make connections and have names for this, that and the other, and you're just lying there.*

Technical language and lack of full explanations compounded this participant's sense of lacking control over her health and care.

1.4 Explain your role, and tell me who is accountable for my care

Participants commonly saw many clinicians across several specialties. In some circumstances, it was difficult to understand what role these different people and areas played in their care, and who was ultimately in charge of decisions. In hospital, one participant found that

> *even in the emergency department one [person] would say, oh we have to get the cardiologist, and another would say, no, it's gastro, and you end up with a neurologist. Who's responsible, who's got the ultimate responsibility for this patient? It was almost impossible to get a straight answer.*

A similar lack of clarity affected people receiving care in the community and as out-patients. One participant was discharged from hospital without an indication of the timeframe in which she would attend any of the three outpatient clinics involved in identifying whether she had a life-limiting condition, and if so how advanced her condition was. She found it very difficult to know which area was responsible for decisions about her care, or how information was shared between the specialities and specialists involved in her care. Uncertainty about such matters was common for participants.

1.5 Make sure the people treating me are sharing information in a timely manner

Participants felt that their clinicians did not always have the information they needed to make timely decisions. One participant's GP did not receive her hospital discharge notes. Another participant was frustrated that hospital clinicians did not regularly share information about her mother's treatment:

> *[We were] dealing with OT, dealing with physio, dealing with cardiology, dealing with maxillofacial, dealing with the orthopaedic, dealing with the aged care clinic, dealing with the geriatrician.*
>
> *And then they said, "Why don't we organise a meeting with everybody?" I turned up that morning and it had been cancelled but I didn't know. No one had told me. There was never a meeting with all the treating people.*

This participant's experience highlights the need for good communication between administrative teams as well as clinicians. When booking a time for investigative surgery in hospital

> *the fact that I would need special care for the anaesthetic, this information came from immunology, but the people in the booking section didn't have access to that information… There wasn't good communication at that point either, at the administrative level, not only the clinical level.*

When information was shared relatively seamlessly among and between services and professionals, participants appreciated this. Some participants appreciated that NSW South Coast residents can receive renal dialysis either at home or at local facilities. When Canberra-based specialists visit, they have access to patients' relevant medical history including pathology and treatments received in both jurisdictions. This gave one participant confidence that his specialist had the information he needed to make the best possible decisions about his care. Consumers welcome processes and collaboration to streamline information sharing between health professionals and services. Two participants suggested the use of telehealth (e.g. Skype consultations) to support patient navigation, especially for people with limited mobility or in regional NSW, where appropriate to the consumer's situation and preferences.

1.6 Tailor information to my circumstances, and my chronic conditions

Consumers with multiple health conditions have a particular requirement for reliable health information that responds to their circumstances. Participants were clear that there is no 'standard' advice or pathway for the management of multiple conditions:

> *I need you to understand my different requirements because I'm different to Joe Bloggs who came in before.*

In some instances, professionals' failure to recognise the interactions of multiple conditions led to poor medical advice and poor health outcomes. A physiotherapist advised one participant to follow a program of pelvic floor exercises to aid her recovery from surgery, but her neurologist advised that this was contra-indicated for her condition. Nurses were reluctant to refer her to a dietician, despite her request for information about possible necessary adjustments to her Type 1 diabetic diet after surgery. When she eventually self-referred to a specialist dietetic service, she was advised to make a number of dietary changes. One participant felt that health professionals were often unable to properly manage her medications for multiple conditions. As an inpatient and in the emergency department, she felt that health professionals had a poor understanding of her requirements and how her different medicines interacted.

Participants recognised that it is not reasonable to expect every clinician to have a detailed understanding of the specific interactions of their conditions. **However, they felt that having access to tailored information about their health was crucial to staying well, avoiding adverse events, and keeping out of hospital.** Personalised information is particularly important when circumstances change, for example when diagnosed with a new condition or when considering a change in treatment.

2. Improving discharge

In participants' experience, having more comprehensive discharge planning would contribute to swifter recovery and reduce the chance of re-admission. The main barriers to good discharge experiences were

- discharge planning not taking full account of personal circumstances,
- not knowing what community services were available, and
- not having an opportunity to actively engage with these services before leaving hospital.

2.1 Personalised advice and warm referral

Most participants experienced cursory discharge planning. One participant was discharged 48 hours after being diagnosed with a rare immune condition. He found this diagnosis "quite a shock" and felt unprepared to return home:

> *You get a doctor to assess vitals and I think they took blood pressure maybe and then you just sign a form and you just - - Away you go. "Oh, your car's here, great, drive".*

This participant would have welcomed **personalised information and options** about his next steps after discharge. While he knew he would need to have pathology tests, he thought that

> *they might be able to tell you, "This [pathology] service is located here and it's 600 metres from here and there's a coffee shop here"… I suppose do warm referral, not just give you the card and go, "You can go to one of these five places".*

Many participants did not know which health and other services they could access after leaving hospital. They would have valued information about available services, eligibility, cost and wait times:

> *People don't know what's available. It's important for [someone] to say, "we can have someone come and help you change your sheets" which is a very hard thing to do [after surgery]. Or "do you want someone to come and take you shopping?".*

Several thought that a home visit is necessary to form an understanding of an individual's situation and the services they will require to recover and stay well at home. For example, it was during an unhurried home visit that an ACT Health community nurse identified one participant's need for carer assistance:

> *She looked at the big picture. I often used to think they must have other patients to see but I never felt rushed.*
>
> *She identified that I had carer stress. She's only the second medical professional, in that sort of more informal way, to not only identify*

> *that, but then to realise what resources I needed to help me with that as a recovering patient.*

Consumers place a high value on recognition of their personal as well as medical circumstances, and information and assistance to access appropriate services.

2.2 Put services in place before discharge

Participants would prefer to have services in place **before** they leave hospital. This is particularly important for people returning home with reduced physical or cognitive capacity. One participant did not want her mother to return home before necessary adjustments were made to her home:

> *She's got really difficult steps to navigate around her house. It's really hard to access her place, and she was wheelchair bound when she got home.… They were telling me that her place was accessible. Two visits with the OT to the house later, [they said] "I see what you're talking about…"*
>
> *Mum got home from hospital and didn't have things put in place for about two weeks. It meant driving back out to the Kambah Equipment Centre, getting chairs, walking aids, all of that, a commode for just in case, all the stuff.*

In this participant's view, her mother's risk of readmission would have been lower if necessary equipment and home modifications were in place before discharge.

Another participant required post-operative care at home in South East NSW after surgery in Canberra. He felt he had to "pre-empt" the discharge process to make sure adequate support was in place:

> *I always remember leaving Canberra Hospital, being discharged with an envelope with just some paper in it. And it kind of was like well, there you go. Unless you could pre-empt it to make sure that you had some sort of contract with the Community Nurses to make sure that you're okay, come and check on whether you had wounds and things like that.*
>
> *Coming home on dialysis, I had a Case Worker from the unit at Canberra Hospital, so I could ring her anytime I liked and have a talk to her about things and that was fine.*

This example illustrates the value consumers place on someone providing **continuity of care,** especially having services in place before leaving hospital.

2.3 Assistance to access services

Some consumers found it time-consuming and tiring to complete unfamiliar administrative processes in order to access community services. After leaving hospital, one participant could not drive to her physical rehabilitation classes, and discovered that to access community transport she would first need to register for an ACAT assessment. Consequently, it took three weeks and interactions with several agencies to complete what initially seemed a simple task. In poor health, another participant struggled to complete the paperwork associated with travelling from regional NSW to receive care in the ACT:

> *I kept saying all the time "I've got a travel form and I wanted the specialist to sign it", and at the end there I was having the surgery and I said, "Have you told the doctor that I need this signed for?" "No"…. This is form after form after form. And you're not even reading them in the end because you can't. There's just so many.*

Occasionally, consumers were ineligible for services that would assist them. Aged under 65 years, one participant was initially advised that she was ineligible for community transport to attend daily radiation therapy, and only accessed this service after spending considerable time herself ringing different services until she found one provider with the flexibility to provide this service to her. These examples illustrate that participants would appreciate more information about what to expect of administrative process when entering new services. In some instances, consumers require practical assistance to complete these processes, and advocacy to access services they need.

2.4 Coordinating family and personal networks

Many consumers appreciated and relied on the care of family members, friends and community networks. One participant's husband negotiated with clinicians on her behalf when she could not. Members of another participant's church had a roster to drive him to and from medical appointments. However, some participants would welcome assistance to negotiate with family, friends and personal networks to get the assistance they would most value, particularly after being discharged from hospital:

> *Getting family and friends on board if you're not lucky enough to have that.*

Some would also appreciate a health professional taking the time to frankly explain their condition, treatment and recovery plan to family members:

> *They're sort of detached from your situation. That's where they might be beneficial, particularly if it's a terminal diagnosis or something.*

3. Staying well and avoiding readmission

Participants saw a need for personalised information over the longer term, to stay well and avoid readmission. In this context, consumers would welcome information about

- relevant health and community services

- consumer organisations and self-help groups,
- less expensive or free services, and
- treatment options.

> *Practical support is the biggest thing you need, knowing where to go for subsidised things. Not being given money but you know, where are the free services?*

Participants felt that this information would support self-management and access to appropriate, affordable and coordinated care.

4. Care navigation assistance

A diverse range of health professionals provided varying degrees of care navigation assistance to participants. These people included

- GPs
- hospital social workers
- Clinical Nurse Coordinators (CNC)
- ACT Health community nurses
- Walk-In Centre nurses
- medical specialists

Other people and organisations also provided care navigation assistance:

- Family carers, family members and friends,
- Community networks,
- Consumer organisations,
- An ACAT assessor, and
- ACT Police Vulnerable Person's Unit.

These people took time to understand participants' individual circumstances, and responded to the complexity of their situations.

In many cases, care navigation was provided in an ad-hoc way rather than as a formal aspect of a model of care. For many participants, the quality of care navigation depended more on the willingness of the individual professional to take the person's concerns seriously and to think creatively about the situation and possible solutions, than it did on the scope and components of their professional role.

Those who had received formal care coordination valued this approach:

> *If I had a nurse coordinator for all the chronic conditions and parts of my life, I'd be able to sit on the deck drinking white wine. Not that I can drink like that. [Care coordination] reduces stress, anxiety, complications, ramifications, and a better health outcome. And that's what all this is about.*

Participants saw a gap in the availability of care navigation that addresses multi-morbidity. For example, one participant received excellent care navigation when receiving treatment for one health condition, but when diagnosed with an additional condition felt that the care coordination service struggled to fully respond to the interactions of his two conditions.

What do consumers think about a potential patient navigator service?

1. *Participants suggested a care navigator could perform the following:*

- Provide personalised information about their chronic conditions and their interactions, prognosis, treatment options, available health and psychosocial services, and low cost or free services as well as clinical trials or opportunities to participate in research (particularly for rare conditions).
- Coordinate discharge planning that considers home and personal circumstances, including visiting their home before or after discharge,
- Ensure various treating clinicians and administrative staff have the information they require to provide coordinated care,
- Involve family and friends in care,
- Assist the person to access services, including providing warm referral and establishing links to services prior to discharge,
- Assist South East NSW residents to access necessary services in the ACT and at home,
- Liaise with clinicians, in particular to ensure that information is shared between different professionals and services,
- Conduct reliable research into the specific interactions of a person's chronic conditions or medications,
- Ensure follow-up tests and medical appointments are booked after hospital discharge,
- Actively manage wait times, e.g. for outpatient appointments and procedures, and
- Work with others to improve inter- and intra-service collaboration and information sharing:

> *I guess they could look into what generally is considered best practice for treatment of this condition. How do I access that? What different departments need to be involved and how frequently? Again, where are the experts in the country and how do I link in with those? And is there any sort of phone line or support network available?*

Importantly the care navigator would provide a consistent point of contact over time:

> *Well I think you should be given one contact number, I agree with that, like "This is Jenny Jones and she's your - ring her".*

> *Maybe, once I was released from ICU or even when I was in ICU, it would have been better if there was a central coordination point advised to me at that point… It would have been good if at least someone would have made an appointment for me to come and talk to somebody. Or someone had given me a ring and said, "The central coordination point is X".*

One participant observed that the Patient Care Navigator should provide consumers with clear information about the scope and limitations of the role, and the length of time over which assistance is provided.

2. Consumers recognised that a care navigator would require

- willingness to listen and understand the individual's situation,
- flexibility to find options that meet the individual's circumstances,
- knowledge of chronic conditions, care pathways and treatment options,
- knowledge of health and psychosocial services, consumer organisations and human service systems including the NDIS and aged care,
- ability to communicate with family members and informal support networks, and involve them in care when appropriate,
- access to clinicians, and confidence to raise questions, issues and concerns for the person with clinicians,
- good knowledge of existing information resources on chronic conditions, and
- support from clinicians and health professionals who recognise the benefits of the role for patient care.

3. Where should navigators work?

Consumers see a role for care navigation for inpatients, after discharge and on an ongoing basis. There is a particular need for care navigation when circumstances change – for example after discharge, when diagnosed with a new condition, when considering a change in treatment or during acute ill-health.

There is no consumer consensus on where a care navigator should be based:

> *I'm thinking hospitals is where they'd be based, but that's not where it's often most confusing, it's the out-patient services… Because [in hospital] you're stuck there in a bed so the services are all delivered to you.*

In consumers' experience it is important that the care navigator be able to work across hospital and community settings, including in their own home. Home visits are important, as participants perceive that this allows a comprehensive understanding of a person's situation and requirements.

4. How could a navigator help the most?

Information sharing is the most important aspect of care navigation. Participants were clear that for them, improvements in what information is shared with them, and how it is shared, would

- assist them to stay as well and healthy as possible,
- improve their understanding of their chronic conditions and the interactions of their different conditions,
- help them to set realistic expectations of their prognosis and experiences of health care services,
- improve the coordination of their care, including with regard to timely information sharing between different treating clinicians,
- improve their access to appropriate care, treatment, support and services,
- respond to their individual situation, both medical and personal, and
- prevent avoidable hospital re-admissions.

Discussion

At the conclusion of this section we have a better understanding of current care coordination in the ACT for people with chronic and complex conditions. In particular, we have a better understanding of what care coordination means to health professionals and consumers, how the delivery of coordinated care affects how it is received, and the gaps remaining in care coordination for people with chronic and complex conditions. These findings are discussed below.

What does care coordination mean to health professionals and consumers?

For the most part, good care coordination means similar things to both health professionals and consumers, including

- personalised care
- comprehensive assessment and planning
- home visits
- sharing information on
    - appropriate community services
    - commonwealth Home Care packages
    - disease management
    - lifestyle changes
    - carer assistance

Experiences of giving and receiving care coordination are intimately connected

In this section, health professionals identified barriers to **providing** good coordinated care. Similarly, consumers identified challenges in **receiving** good coordinated care. There are strong links between these two sets of identified challenges. Most notably, consumers' experiences of receiving care coordination are intimately linked with health professionals' challenges to provide it. These challenges to coordinating care, identified by health professionals, had a direct impact on how consumers experienced care. These connections are illustrated in Table 1.1 below.

Table 1.1 Links between barriers to delivering and receiving coordinated care

	Barriers to delivering coordinated care	Barriers to receiving coordinated care	Impact on care coordination
Time	Health professionals felt there was not enough time to provide a comprehensive, holistic assessment of patients. Many thought that this time was both underestimated and under-appreciated by other health professionals.	Consumers felt that information provided by health professionals about their conditions or treatment was often rushed and incomplete.	Consumers had to navigate unfamiliar territory in often highly stressful circumstances, such as completing administrative forms, searching for appropriate services, and learning how their multiple conditions interacted.
Flow of information	Health professionals identified poor information flow of patient information, and observed that current IT systems where not up to task.	Consumers identified gaps in information about their conditions and poor information flow between professionals and services.	Consumers felt that poor information flow affected their ability, and their treating clinician's ability, to make fully informed decisions.
Complexity	Coordinating care becomes more difficult if patients have medical and/or social complexity.	Consumers with multiple conditions had particular difficulty getting good coordinated care.	In some instances, a lack of coordination for people with multiple conditions led to poor medical advice and poor health outcomes.
Discharge	Health professionals identified problems with the current discharge process, such as not enough social workers and discharge liaison nurses, and lack of standardised discharge processes.	Consumers experienced cursory discharge planning.	Poor discharge planning meant that consumer's personal circumstances were not addressed. Consumers were not provided with information on what community services were available or given the opportunity to actively engage with those services before leaving hospital.

What gaps remain in the coordination of care for people with chronic and complex conditions?

Clear gaps remain between the current coordination of care and the needs of people living with chronic and complex conditions. According to our analysis of the consumer data, these unmet needs warrant improvements to the current state of care coordination, such as

- better and more personalised information for self-management,
- greater acknowledgement of the interaction of multiple conditions,
- more attention to personal and social issues,
- better knowledge of and linkage to community-based services, and
- more time for comprehensive assessment and planning.

Consumers feel that these gaps make it harder for them to stay well, look after their own health, and stay out of hospital. Rather than coordinated care, consumers with multiple conditions experience a fragmented health care system, often as a series of ad hoc interventions by a diverse range of health professionals and lay people. Consumers want and need individualised care because the number and progression of their conditions, as well as the particular interactions of their conditions, **is individual**. This desire for customised care demands that care coordination be tailored to the individual patient rather than a one-size-fits-all approach to chronic conditions management. Revealingly, consumers felt that better information, tailored to their circumstances could remove a number of barriers. For example, ensuring consumers understand their conditions and are aware of available services and care options potentially reduces costs, time and anxiety as well as aiding self-management. Consumers particularly, need coordinated care at times of change such as hospital discharge and/or a new diagnosis or new medication.

While coordination of clinical and non-clinical care is unquestionably being performed by skilled and dedicated health professionals in the ACT, it is not consistent. Often, the difference between good coordination and great coordination comes down to an individual person (GP, nurse, allied health) who has experience, a supportive team, good networks and takes charge. These health professionals know that medical needs and social needs are inextricable and will go the extra mile to coordinate care for their patients.

Both participant groups highlighted the problems around coordination of services, discharge process and poor follow-up after discharge, which is consistent with findings from other studies.[63, 64, 65] For health professionals, pressures such as time and capacity were the main barriers to providing comprehensive discharge. Patients whose care cuts across disciplines and requires social support present a challenge for health care professionals working in a system with little integration. It is particularly challenging at the point of discharge where several health professionals work separately to ensure a patient has all the information and services they need to go home. For consumers, a lack of information and guidance before and after discharge were the main issues. Specifically, consumers wanted active referral to community services **before discharge**.

Can a patient navigation service help?

Some challenges are systemic and require long-term reform. There are the perennial challenges associated with a poorly integrated system and a culture of silos. There are also ethical challenges regarding a hospital's duty of care regarding patient circumstances at discharge, and political challenges determining at what point ‘health’ care becomes the domain of social or human services. Other challenges, such as comprehensive assessments, providing more tailored information, and ongoing support post-discharge, can be addressed in the short-term. A patient navigation service can meet some of these needs, and most importantly, the priority needs of consumers and health professionals. The clear advantage of a patient navigator is their capacity to provide continuity of care from hospital, community, into the patient’s home, and back to hospital if necessary. Navigators may also circumvent many of the pressures, such as patient flow and limited time felt by many health professionals.

Early in the consultation process, the HCCA was asked a question - “If everyone did their jobs properly, would we really need patient navigators?” It is an important question, and a definitive answer is well beyond the limits of this report. However, considering the complexity of the health care system and the unique challenges of managing multiple chronic and complex conditions we can argue for change based on a different question - **How do we improve coordination for people with complex and chronic conditions without placing an extra burden on existing resources?** In the short-term at least, a patient navigator service is an easily defensible answer. While it was never an objective of this project to establish a need for patient navigation in the ACT, HCCA strongly suggests that health professionals and consumers would benefit from such a service.

The following model for patient navigation describes the criteria needed to implement a service that would meet the needs of health professionals and consumers. The model is firmly grounded in the information collected and discussed in this report. This information has provided rich experiences from which to draw guidelines for an appropriate model for the ACT, however it does have limitations. For example, we were not able to draw on the information to provide details on governance or management structure, costs or physical location. The model focuses on **generic drivers of success** learned through this project. A navigation service with more specific or local needs can adapt these criteria to suit.

Section 3 – A model for patient navigation in the ACT

It is vital that the health system in the ACT is supported and enabled to meet the demands of the growing burden of chronic disease. Extra demands on coordinating and integrating the health care system require health services to rethink how services are accessed and delivered. At the same time, people with chronic and complex conditions need support and confidence to self-manage their conditions. For these reasons, the Health Care Consumers' Association (HCCA) commends ACT Health for commissioning the development of a model for patient navigation in the ACT.

HCCA believes that a navigator service can improve quality of life for consumers and partner with them to achieve the best health and wellbeing possible. A patient navigation service would help meet commitments in the *ACT Chronic Conditions Strategy 2013-2018* (see Appendix A). ACT Health have the opportunity to become a leader in chronic conditions management.

Progressive thinking that drives innovation and development will bring the ACT health care system closer to providing person-centred care. Done properly, innovations such as a patient navigation service can also facilitate better integration of health care services and foster a partnership approach to managing good health. Other advantages include drawing on local strengths such as world class research institutes, and an active consumer population with an engaged and supportive community-based sector.

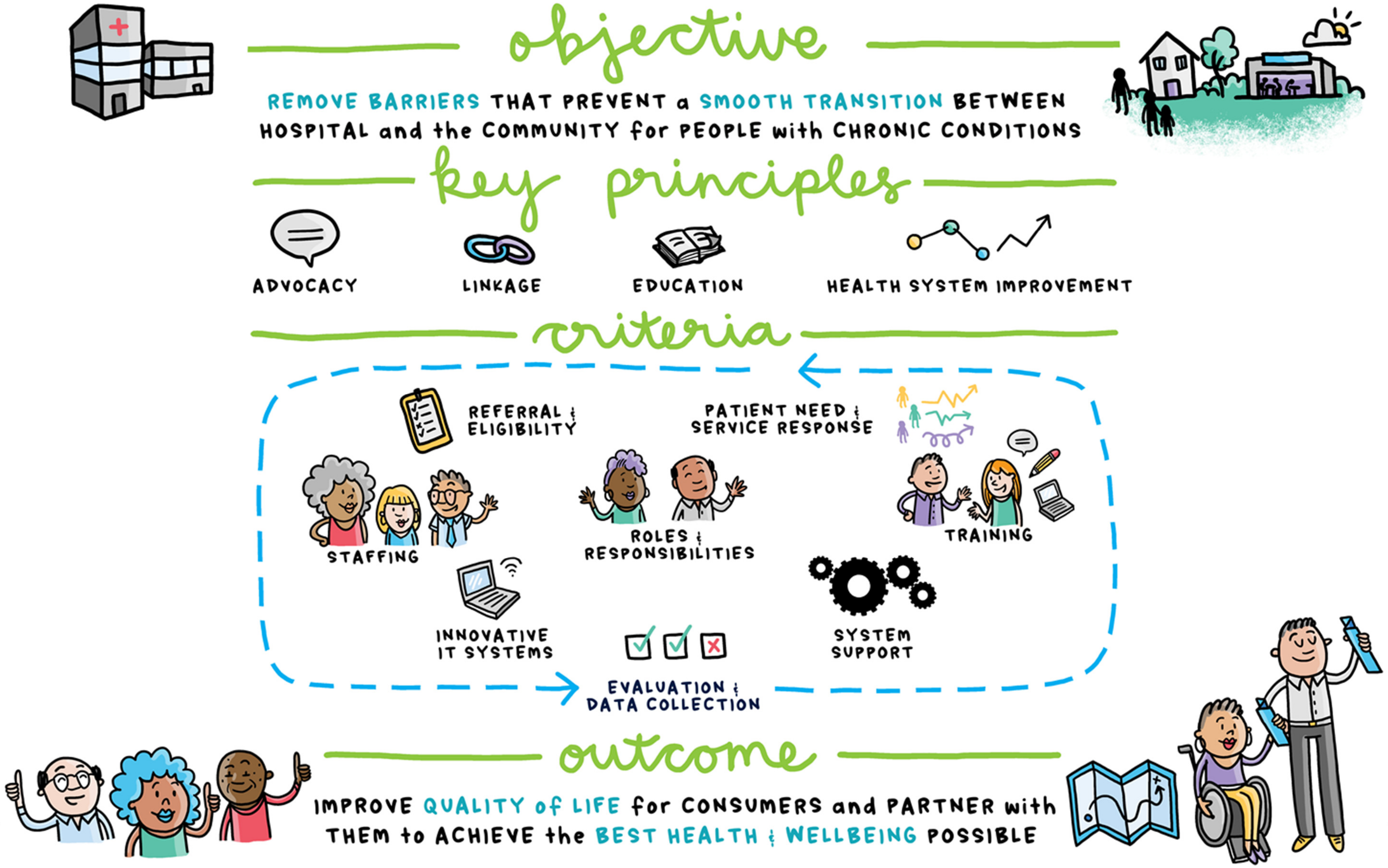
HCCA has drawn on the experiences and knowledge of health professionals and consumers. Information gathered for this project has identified what drives success in coordinating care for patients with chronic and complex conditions. Correspondingly, we have been forewarned of the challenges. From the information presented in this report, we have established that drivers of success depend on decisions about

- key principles,
- roles and responsibilities,
- staffing,
- referral and eligibility,
- patient pathways,
- training,
- evaluation,
- innovative IT, and
- supportive systems.

In providing what we believe is an objective and practical model of patient navigation, we’ve chosen to emphasise these drivers for success, and the pitfalls to avoid, as a model for designing a successful navigation service.

HCCA’s model of patient care navigation comprises four key principles and eight criteria for success. It is informed by two case studies – Queensland and Silver Chain navigator programs – and interviews with ACT health professionals and consumers. The model is intended to preface the development of an operational pilot navigator service, subject to wider consultation, funding, and organisational capacity by ACT Health. The model is illustrated below.

A MODEL for PATIENT NAVIGATION in the ACT



objective

REMOVE BARRIERS THAT PREVENT a SMOOTH TRANSITION BETWEEN HOSPITAL and the COMMUNITY for PEOPLE with CHRONIC CONDITIONS

key principles

- ADVOCACY
- LINKAGE
- EDUCATION
- HEALTH SYSTEM IMPROVEMENT

criteria

- REFERRAL & ELIGIBILITY
- PATIENT NEED & SERVICE RESPONSE
- STAFFING
- ROLES & RESPONSIBILITIES
- TRAINING
- INNOVATIVE IT SYSTEMS
- SYSTEM SUPPORT
- EVALUATION & DATA COLLECTION

outcome

IMPROVE QUALITY of LIFE for CONSUMERS and PARTNER with THEM to ACHIEVE the BEST HEALTH & WELLBEING POSSIBLE

Objective of patient navigation

As proposed by ACT Health, the objective of this model for patient navigation is to **remove barriers that prevent a smooth transition between hospital and the community for people with chronic and complex conditions.**

Typically, navigation services for people with chronic and complex conditions aim to

- improve quality of life of consumers,
- improve patient experience,
- reduce visits to the emergency department,
- reduce unplanned hospital admissions, and
- improve patient self-management.

Components of the model

Key principles

A navigator service should be underpinned by the following principles:

Advocacy

- Promote patient centred care
- Provide personalised and holistic assessment and planning
- Be the single point of contact

Linkage

- Provide links to existing services and resources
- Expedite centrally coordinate care
- Create partnerships with everyone involved in the patients’ care
- Include carers and families
- Build professional relationships

Education

- Improve health literacy
- Plan and set goals for self-management

Health system improvement

- Assess and monitor systems for improvement
- Enhance existing services
- Ensure succession planning
- Promote research, assessment and development

Criteria for a successful patient navigation service

Roles and responsibilities

It is the navigator's role to eliminate barriers to timely care across all phases of the health care experience[66] and help patients meet their personal goals. A patient's goal may be as simple as being able to walk to the mailbox unassisted or a more ambitious wish to self-manage their conditions. Whatever the goal, the navigator's work should adapt to meet that end. Importantly, the care provided is not to be limited by a specific disease or condition.[67]

In addition, to the usual responsibilities expected of ACT Health staff, a navigator will demonstrate the four principles of advocacy, linkage, education and system improvement in all they do. Furthermore, the system in which they work must allow them to transcend clinical and social service silos and span disciplinary boundaries.

While this makes roles and responsibilities difficult to define, our findings strongly suggest that the parameters of a service are well publicised to avoid:

- overlap/duplication of services or tasks,
- navigator burnout through insupportable workload/responsibility,
- confusion or conflict due to misunderstanding the navigator's scope of practice,
- difficulties in recruiting, and
- vague pathways for succession planning and backfill.

These issues can only be addressed through regularly reinforcing the parameters of a navigation service. Reinforcement will be easier if the parameters are clearly defined, well-promoted and widely supported.

Innovative IT systems

Ideally, navigators would have access to an integrated system that provides a single view of patients' complete medical records. Additionally, the success of a navigation service depends on adequate IT systems to receive referrals and patient alerts, manage telehealth services, and monitor, capture, coordinate and communicate patient information.

Examples of navigator IT innovations include:

- Alerting navigators in real time via SMS of eligible patients presenting at emergency departments
- E-referrals
- Algorithms deployed in emergency department and general admission to determine eligibility
- Clinician/patient shared information portals
- COMPASS - A system under development in Queensland that pulls all relevant patient data, from all platforms across the state, into a single application.

There are currently over 200 IT systems across Canberra Health and Hospital Services that capture and store patient information and currently there is no simple or timely way to consolidate that information. This fragmentation of patient information provides barriers to coordinating care that frustrates both health professionals and consumers.

System support

Supportive people, processes and resources are needed to ensure that a patient navigation is service implemented and is adequately integrated into the broader health care system. Examples of system support include:

- Establishment of an implementation group to ensure a broad representation of all the areas a navigator is likely to work across including hospital, consumer and community services
- Endorsement from leaders and stakeholders in primary care, hospitals, community based services and policy
- High-quality and accessible interpreter services for non-English speakers
- Adequate mental health support through existing services
- Pharmacy services
- Self-management courses that navigators can refer to
- Adequate supervision, mentoring and succession management plans
- Adequate resources to cover transport and private, adequately equipped offices
- Appropriate documentation, including health summaries and care plans, referral guidelines, enrolment assessment and criteria, service directory, consent forms and discharge summary
- Resourcing for a 24/7 service or providing after-hours access to a program such as the Silver Chain's Priority Response Assessment
- Financial security through ongoing funding
- Adequate community services to avoid 'navigation to nowhere' when community services are inadequate or non-existent to support the particular cohort.[68]

Staffing

Navigator services use both clinical and non-clinical navigators depending on the needs of the patient cohort. For patients with chronic and complex conditions, the Queensland and Silver Chain navigator services use highly experienced nurses and allied health professionals. A clinical background appears to be an advantage for reasons discussed in previous sections of this report. In light of current practices in other States, recruiting clinical staff for the ACT navigator service seems both sensible and appropriate.

However, contingent on funding and capacity, there is potential for a stepped or hybrid service that combines both clinical and non-clinical navigators. Non-clinical navigators may improve outcomes (especially access and equity) if they have personal experience with chronic illness, existing relationships with particular communities, bilingualism, or have a knowledge of cultural values and beliefs.[69]The roles non-clinical navigators perform should be based on their skills and experience; however, workplace and course learning should be encouraged. Mentoring, career progression or academic pathways should also be supported.[70]

The Queensland and Silver Chain examples cited in this report employ navigators who are skilled and experienced clinical professionals. We know that at a minimum these navigators must have a thorough knowledge of the health system and be skilled in:

- Organisation
- Problem anticipation
- Holistic thinking
- Facilitation
- Care planning
- Communication
- Problem solving
- Cultural sensitivity
- Advocacy
- Goal setting
- Education and

From our participant interviews, we know that some navigators exhibit characteristics that lead to greater success. These characteristics can be described as:

- Determined
- Fearless
- Adaptive
- Empathetic and thoughtful
- Passionate
- Flexible
- Collaborative
- Innovative

Referral and eligibility

Our consumer interviews suggest an existing demand for a navigation service in the ACT. Similarly, the ageing population and rising burden of chronic conditions suggest demand will grow. However, given the ACT's population, the potential patient cohort is relatively small. Therefore, eligible patients could be actively recruited with minimal risk of overburdening the service. The referral process should be open and straightforward to further ensure that the service reaches the people who most need it. We recommend that a navigation service address the following items as part of its referral process.

- Patient consent
- An open referral system including general practitioners, allied health workers and community services. Self-referrals should also be considered an option
- Active recruitment of eligible patients
- Alerts that trigger when a patient is seen in emergency department or admitted to hospital[xxv]

[xxv] Ideally, an algorithm is used to capture eligible patients.

- Liaison with the patient's GP prior and subsequent to enrollment

We recommend that a navigation service use the following eligibility criteria for patient recruitment:

- Eligibility criteria
    - High users of emergency department
    - Frequent inpatient admissions
    - Multiple comorbidities
    - Two or more social complexities
    - Two or more psychological complexities
- Single exclusion criterion for patients enrolled in a similar program

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Patient need and service response

The HCCA recommends that a navigator service implement evidence-based processes for determining the needs of the patient and responding with the appropriate level of service. The Queensland and Silver Chain programs offer two similar options for determining needs through risk stratification and offering a response through corresponding patient pathways.

The Queensland Nurse Navigator model operates using a Nurse Navigated Patient Continuum with five phases:

Intensive	weekly contact for patients at high risk of admission
Managing	fortnightly contact for patients who are clinically stable
Maintaining	monthly to three-monthly contact for patients requiring minimal intervention
Transitioning	three to six-monthly contact for patients able to self-manage
Discharge	for patients who are considered independent

The Silver Chain Navigator model determines a patient's risk of admission using a Debility, Psychosocial Risk Score, but narrows the intensity of care to three possible options – High, Medium and Low:

High	weekly home visit for patients at high risk of readmission
Medium	combination of one home visit per month and phone monitoring for patients at medium risk of readmission
Low	monitoring only for patients at low risk of readmission.

Using a standardised stratification system provides consistency for the program and navigators and provides reliable and comparable data for assessment and research. A clear patient pathway with varying levels of intensity helps navigators to manage their work-flow and helps transition some patients towards discharge.

The HCCA also recommends that the service adopt a system that allows patients to be active or non-active. Being non-active, without being fully discharged from the service, can provide security for patients who no longer need regular interventions.

Training

Training navigators in a chronic care program can be beneficial.

For example, the Flinders Program uses cognitive behaviour therapy, problem solving and motivational interviewing techniques (see Appendix B for more information). Adopting an internationally known and evidence-based program can lend integrity to a service, as well as increase the potential for scaling-up or reproducing the service. Training all staff in such a program can help unify navigator teams and provide consistency for processes like assessing, monitoring and creating care plans for patients. Using such a program allows patients and navigators to record changes over time. This consistency makes it particularly useful for monitoring patient goals and program targets, such as improved health literacy.

Additionally, navigators may need internal training to gain a thorough understanding of:

- The health information systems that they will be using
- Reporting responsibilities and processes
- Patient forms and documentation

Evaluation and data collection

A key component of any service is ongoing monitoring and evaluation. Meaningful evaluation is planned alongside the design of the program. It is highly recommended that data be systematically collected and recorded from the beginning to inform internal monitoring and review, as well as the broader health care and research communities. Evaluations should take place regularly and be built into the framework for service delivery. For example, for a three-year pilot program, a review would be appropriate after the first 12 months and then again at conclusion. Money, time and other resources must be allocated to the evaluation from the beginning of the program.

A patient navigator service could be evaluated across several different domains, including:

- Clinical outcomes
- Patient reported outcomes
- Case studies
- Financial impact

Section 4 - Next steps

HCCA recommends that this model be transitioned into a three-year pilot service. Based on discussions with senior staff at ACT Health about governance, IT, and workforce, HCCA suggests the following next steps:

Ensure navigation is implemented as a service

How navigation is defined will have an impact on how the service is understood and used. The Queensland Nurse Navigator program found that the core principles of navigation were more likely to be supported when **navigation was implemented as a service**. They found that the implementation of a single navigator role was more vulnerable to economic or political agendas once recruited by a hospital. The result was that some nurse navigator roles were being used not as intended but rather to fill gaps in an under-resourced workforce. To avoid assumptions that navigation is simply a role or a job, patient navigation is better defined as a *process* or *intervention*[71]. We feel that this description better reflects both the individual and system-wide effects of navigation and mitigates the risks of a single role being appropriated to fill gaps in the workforce.

Promoting navigation as a service rather than a role helps safeguard the Key Principles and anchors the work in the broader health care system. Consequently, we stress the importance of placing such a service within a supportive, high-performing, well-established system that **advocates the service as being beneficial to both consumers and health professionals**.

Provide corporate governance

A patient navigation service would need to be well-resourced, with access to patient records and established links to hospitals and community. Some possibilities for corporate governance of a three-year pilot program are:

- External provider
    - For example, the Silver Chain Health Navigators Program, used as a case study in this report, provides an excellent model of outsourcing a patient navigator service.
- ACT Health
    - For example, an expansion and enhancement of the current Chronic Conditions Program at Canberra Hospital and Health Services.

Additionally, ACT Health need to consider how a service meets the requirements of workforce planning, the Digital Health Strategy, Territory-wide Services Framework, HealthPathways, My Health Record and the Quality and Safety Strategy.

Clearly, there is potential for this model to be advanced in the context of the Specialty Service Plans and developments of models of care. Territory-wide

Services Division has the in-house skills to work collaboratively with clinicians, administrators and consumers to develop the model of care for a navigator service.

Provide clinical governance

A priority to advance the development of a navigation service is to have structures that sustain the model's key principles and criteria. Senior management within CHHS has been clear that a formal structure needs to be established for this purpose, such as a management or steering committee. A committee provides an opportunity to involve clinical and consumer input into the implementation of the service and any further developments such as a service framework.

Recruit staff

Further work needs to be completed to determine staffing levels. Establishing the workforce for a three-year pilot of the navigator service could be determined either by:

- Estimating the number of admissions who meet the model's eligibility criteria
- Estimating the number of readmission who meet the model's eligibility criteria
- Determining what proportion of the hospital's growth should be spent on reorienting the system towards a more integrated, better-coordinated system.

ACT Health may wish to place the pilot service under the management of an existing section of the hospital. However, it is recommended that the service have some structure that allows for a relatively autonomous operation.

Based on discussions with ACT Health People and Culture the following structure is recommended:

- Senior manager (RN5 or HP6) to oversee clinical management for service and service relations within the hospital
- Senior navigator (RN4 or HP4) to supervise navigators, oversee service operations, and take on particularly complex cases
- Office manager (ASO6) to oversee all ACT Health compliance requirements for the service and staff, provide navigators with up-to-date information on community and commonwealth information and services.
- Administration assistance (ASO3) to maintain patient information, and communications
- Navigators (RN2 or HP2) for care coordination and case management

Recruitment of the right staff is critical to the success of the program. ACT Health may wish to transfer existing staff into a pilot navigator service; however, every effort should be made to ensure navigators meet the skills and characteristics required in the model. Testing skills through scenarios is one way to assess candidates' suitability for the role. Having applicants perform the steps critical to the navigation process such as patient assessment, care planning and goal setting would enable the selection panel to assess applicants based on demonstrable skills needed to undertake the job. Additionally, the classification of navigators should be determined prior to recruitment to ensure all navigators receive equivalent entitlements.

Though recommended in the model, backfilling for staff leave and succession planning for a small service can be difficult. One solution is to maintain a 'recruitment bank' of staff who demonstrate the appropriate level of skill and experience.

Provide IT support

A navigator service will fail without appropriate IT support. HCCA recommend that ACT Health:

- Integrate patient navigation information into existing hospital records management system - ACTPAS.
- Implement a Customer Relations Management system (CRM) to manage all interactions with enrolled patients. This system would preferably be cloud based to enable mobile technology such as phones and tablets.
- Develop a secure online portal for patients, families, GPs and other patient nominated services.
- Develop an algorithm to identify eligible patients at emergency departments and inpatient admissions linked to Clinical Communications system for messaging and alerting navigators.

Develop a communications strategy

It will be necessary for ACT Health to develop a communications strategy to facilitate the smooth implementation of the pilot. Marketing the benefits of the service to both consumers and health professionals is critical to generating consumer interest and allowing any questions and concerns to be addressed before implementation. Health professionals should be given every opportunity to raise issues or concerns regarding the service. **A Territory-wide engagement in the service is needed to integrate the service into the existing health systems and ensure that providers are fully informed of the service referral process.** To raise the profile of the service, the strategy should include ‘navigation champions’, such as consumers, clinicians, spokespersons from existing navigator programs, and politicians.

Appendix A: ACT Health Chronic Conditions Strategy: Improving Care and Support 2013-2018

Commitment

For many people with a chronic condition, living with their condition is a part of their life, for the rest of their life. The health system must be responsive to the needs of these people in such a way that empowers them to live their lives to their fullest potential and with a focus on living well. As such, this Strategy is based on the following commitment.

In the ACT we are all working together to ensure our health system is patient and carer centred, evidence informed, and that any person living with a chronic condition:

- Receives appropriate screening and early detection.
- Receives the right care, in the right place, at the right time from the right team.
- Has a plan which supports active participation in their care.
- Is aware of relevant support options and how to access them.
- Is provided with the information and support to stay healthy and/or minimise the risk of other conditions.
- Does not have to repeat their story unnecessarily.

This Commitment is applicable to all people with chronic conditions regardless of age, severity, stage of condition or their treating team.

https://health.act.gov.au/sites/default/files/Policy_and_Plan/Chronic%20Conditions%20Strategy%202013%20-%202018.pdf

Appendix B: The Flinders Program Tools

Adapted from https://www.flindersprogram.com.au/about/information-paper/the-flinders-program-tools/

The Flinders Program care planning tools include both tools used to assess self-management capacity and a care planning tool.

Tools used to assess self-management capacity are:

- Partners in Health Scale
- Cue and Response interview
- Problem and Goals Statement

The care planning tool is the:

- Chronic Condition Management Care Plan.

Use of these tools enables the health professional and the client to identify issues, form an individualised Care Plan and provide a system for monitoring and reviewing progress.

Partners in Health Scale

The Partners in Health Scale is a validated questionnaire based on the principles of self- management. The client completes the questionnaire by scoring their response to each of the twelve questions on a nine-point scale (zero being the lowest response, reflecting low self- management capacity, and eight being the highest, reflecting good self-management capacity).

The questionnaire takes 5-10 minutes to complete and can be used to record change over time.

Cue and Response Interview

The Cue and Response interview is an adjunct to the Partners in Health scale. The Cue and Response process uses a series of open-ended questions (cues) to explore the client's responses to the Partners in Health Scale in more depth. It enables the barriers to self- management to be explored, and it checks the assumptions that either the health professional or the client may have.

The health professional can score the responses and compare their score with the client's scores. While originally developed to enable the client's perception of their self-management (as recorded on the Partners in Health scale) to be 'validated' by the health professional, it has proved to be a useful clinical tool in its own right to explore self-management.

The Partners in Health scale and Cue and Response interview tools can be used together or individually.

The Cue and Response interview is a motivational process for the client and a prompt for behaviour change. It allows the individual the opportunity to look at the effect of their condition on their life.

Scores rated on the lower end of the scale by the client, the health professional or both, flag issues for further discussion. Scores rated on the higher end of the scale allow the health professional to acknowledge areas where the client is managing well. Discussion of lower scores, or scores where there is a discrepancy in rating between client and health professional, allows for clarification of issues and identification of a common set of problems. Collaborative problem identification is a key indicator in successful self-management programs (Wagner et al., 1996). Identification of issues allows relevant strategies and interventions to be discussed and agreed on.

Problem and Goals Assessment

The Problems and Goals assessment is another tool that can be used as an adjunct to the Partners in Health and Cue and Response or as a stand-alone assessment. The Partners in Health and Cue and Response enable the health professional and the client to identify a range of issues or problems that are affecting the client. The health professional may well see one of these issues as the main or biggest problem for the client. The client may see the same thing as their biggest problem, but they may see something else as having a far greater impact.

For example, the health professional might think that the way the client uses their medication is the biggest problem, however the client may think their biggest problem is the demands the family places on them - perhaps they are caring for grandchildren every day and have little time for themselves.

As well as defining the problem from the client’s perspective, this assessment also clearly identifies a goal or goals that the client can work towards.

Problem Statement

The client’s problem statement is based on three open-ended questions:

1. What do you see as your main problem?
2. What happens because of the problem?
3. How does this problem make you feel?

The problem statement should include the Problem, Impact and Feelings and can be clearly and simply evaluated using a scale from 0 (not at all) to 8 (a lot) measuring ‘How much of a problem is this for me?’

Example: ‘Lack of support from my family means I am overwhelmed by the household jobs and I don’t go out and feel depressed’.

Goal Statement

The Goal Statement is the client’s goal and should be written positively and be a personal reward. Goals should be long/medium term and involve a degree of challenge (Locke & Latham 2006), and can be clearly and simply evaluated using a 0 (no success) to 8 (complete success) measuring ‘My progress towards achieving this goal’.

The goal should be a SMART goal:

S – Specific (clearly defined)

M – Measurable (observable)

A – Action based (behavioural)

R – Realistic (not too reliant on others)

T – Timely (how long/how often?)

Example: ‘I will go out to the community club one afternoon a week for 2 hours’.

Chronic Condition Management Care Plan

The information gained from the Partners in Health, Cue and Response (interview and discussion) and Problem and Goals assessments can be summarised on the care plan. The care plan documents the medical investigations, self-management tasks, self-management education and allied health and community services the person will access over the following twelve months.

- The information on a Care Plan should include:
- The identified issues / including the main problem
- Agreed goals – What I want to achieve
- Agreed interventions – Steps to get there
- A sign off by both the patient and health professional
- Review dates.

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