Department of Health Evaluation of the Aged Care System Navigator Measure **Discussion Paper** August 2019



# Australian Healthcare Associates

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# List of abbreviations

Abbreviation	Definition
A&S program	Access and Support program
АНА	Australian Healthcare Associates
ANAO	Australian National Audit Office
CALD	Culturally and Linguistically Diverse
the Commission	The Productivity Commission
the Department	The Australian Government Department of Health
DHS	Department of Human Services
FNP	Family Navigator Project
FIS Officers	Financial Information Service Officers
FTE	Full-time equivalent
GP	General Practitioner
LGBTI	Lesbian, gay, bisexual, transgender or intersex
LLLB	Living Longer Living Better
the Measure	The Aged Care System Navigator measure
NHS	National Health Service
PHN	Primary Health Network
NACA	National Aged Care Alliance
SNAF	Service Navigation Relational Autonomy Framework
SSW	Specialist Support Worker
UK	United Kingdom
USA	United States of America

# **1** Overview

## 1.1 Introduction

In January 2019, the Australian Government Department of Health (the Department) engaged Australian Healthcare Associates (AHA) to undertake an evaluation of the Aged Care System Navigator measure (the Measure). The Measure is being trialled across Australia between October 2018 and June 2020. The **evaluation objectives** are to:

- Assess the implementation, appropriateness, effectiveness and cost-effectiveness of the programs implemented under the Aged Care System Navigator Measure
- Identify and review existing and historical system navigator services, including aged care system navigator services and system navigator services in other sectors in Australia and internationally
- Identify stakeholder views on aged care system navigator models and opportunities for the future
- Identify potential aged care system navigator models to inform future policy considerations, including barriers and enablers to achieving intended outcomes.

AHA has developed this discussion paper as part of the review of existing and historical system navigator models/services. It has been informed by a series of initial research and consultation activities described in *Appendix A*.

### 1.1.1 Purpose

The **purpose of this discussion paper** is to seek feedback from stakeholders who are familiar with, are working with, and/or have views on existing and historical aged care system navigator models and system navigator models in other relevant sectors in Australia and internationally. This feedback will contribute to the development of advice on policy direction for the Department in relation to aged care system navigator models.

### Have your say

Discussion questions are provided in Section 3.

Please respond to the discussion questions using the survey link <u>here</u>.

You may also respond to these questions using the feedback form embedded into this document and submit them to: <a href="mailto:acsn@ahaconsulting.com.au">acsn@ahaconsulting.com.au</a>

The closing date for submissions is 16 September 2019.

Please note: Not all questions will be relevant to all stakeholders.

If you have any questions about the discussion paper or the feedback process, please contact:

Anna Bishop-Bailey or Shae Quirk at AHA on 1300 242 111 or email: <u>acsn@ahaconsulting.com.au</u>.

# **1.2 Background**

### 1.2.1 My Aged Care

In 2011 the Productivity Commission (The Commission) reported that older Australians were faced with a complex and confusing set of entry points into aged care services, creating significant barriers to access for this often-vulnerable group (1). The report highlighted that, given the complexity of the aged care system, wide-scale reform was required in order to make the system fairer, more responsive to the needs of individuals, and more sustainable for an ageing population (1). The Commission recommended establishing a central gateway into, and pathway through, the aged care system, and in 2013 the Australian Government introduced My Aged Care as a single identifiable entry point for accessing aged care services (2). A review of My Aged Care brand awareness, including evaluation of the experiences and perceptions of aged care consumers, carers, assessors and health professionals, was undertaken between 2015 and 2016 (3). Among the key findings reported by consumers was increased awareness of My Aged Care, and positive satisfaction ratings regarding some types of contact centre and assessment experiences (3). However, in 2016, participants in a co-design workshop (involving the aged care sector and stakeholders with diverse needs) identified 'face-to-face community presence for My Aged Care' as a priority (4).

In 2017, the Legislated Review of Aged Care found that the Living Longer Living Better (LLLB) reforms, including the 'significant improvement' represented by My Aged Care, had successfully taken Australian aged care 'further along the road towards a consumer demand-driven and sustainable system' (5:p12). However, it also noted there was still unmet need for certain individuals accessing and navigating aged care services, and further reform was recommended (5).

Further background and policy context is available in the <u>National Aged Care Alliance (NACA) Integrated</u> <u>Consumer Supports position paper(6)</u> and the <u>Royal Commission into Aged Care Quality and Safety</u> (7).

### 1.2.2 The Measure

In response to the recommendations set out in the 2017 Legislated Review of Aged Care, the Australian Government announced the introduction of the Aged Care System Navigator Measure in the 2018/2019 More Choices for a Longer Life budget package (8). The Measure involves the implementation of four programs of trials to test different system navigator models in different circumstances, with the aim of building an evidence base to inform future decision-making. Trials under the Measure are particularly aimed at vulnerable individuals and/or those with complex needs (including those from the groups listed in *Table 1-1*). A consortium of 30 partner organisations led by COTA Australia has been engaged to trial the provision of:

- Aged care Information hubs to provide locally targeted information and build people's capacity to engage with the aged care system
- Community hubs where members support each other in navigating aged care and healthy ageing
- Specialist Support Workers (SSW) in consumer-focused organisations to offer one-on-one support.

### 1. Overview

In addition, as part of the Measure, six Financial Information Service (FIS) Officers in the Department of Human Services (DHS) are providing targeted support to help people understand their options to fund their aged care (9).

### Table 1-1: Population groups facing challenges when accessing and navigating aged care services

Aboriginal and Torres Strait Islander people

Culturally and Linguistically Diverse (CALD) people

People identifying as lesbian, gay, bisexual, transgender or intersex (LGBTI)

People who live in rural or remote areas

People with limited access to technology or people with limited computer literacy

People who have special website accessibility requirements, such as people who are visually impaired

Target populations who are considered vulnerable

People who are financially or socially disadvantaged

People who are socially isolated or at risk of social isolation

People who are homeless or at risk of becoming homeless

Care leavers/people separated from children by forced adoption/removal

People with a disability

People with cognitive impairment, including dementia

People with a mental health problem or illness

Veterans

# 2.1 Introduction

This section presents a summary of the literature that describes system navigator models along with their associated outcomes (where available), both in Australia and internationally. It is informed by a scan of the literature and consultations with experts working in this field. Please note that given the scope and breadth of the literature, this summary is not intended to present a complete, or systematic view of all existing and historical system navigator models. This summary forms part of a larger body of work and is intended to provide background to the discussion questions presented.

Where relevant, vignettes describing system navigator models are presented, which are intended to provide the reader with real-world examples (i.e. they are not intended to represent 'gold standard' or 'best practice' models).

Note that the aged care system navigator models that are being trialled through the Measure (described in *Section 1.2.2*) are not discussed here because they have only recently been implemented.

# 2.2 Types of system navigator models

'Navigation' through health, social, community and other service systems can be confusing for service users and professionals alike. There is broad agreement in the literature and among stakeholders that while there is no 'one size fits all' approach to system navigation, many people could benefit from system navigation at some point in their life.

**'System navigators are like air-traffic control – they aren't controlling the plane but they have eyes on what's coming in or going out and where things should go' –** *Representative from a community-based organisation in Queensland* 

Numerous system navigator models have emerged both in Australia and internationally, focusing on different target populations, and operating across a range of sectors and settings (10–12). These can be provided in relevant organisational settings, or through outreach activities that bring navigation services to individuals' homes and communities.

The diversity of models in place, and the lack of an agreed definition of a system navigator (and the boundaries with other types of support such as case management or care coordination) make classification and evaluation of the models difficult (10–12).

'Given the range of approaches that characterize navigation programs, there is no commonly accepted definition of system or patient navigation' (11:p2).

Many models have evolved from Harold Freeman's 'patient navigator' model, described in *Section 2.2.1*. While there is significant overlap between them, and little evidence regarding attributable outcomes, this discussion paper goes on to highlight a number of other navigator models classified on the basis of who delivers the service, who the service is provided for, and what services are being navigated:

- Nurse/professional navigators
- Family navigators
- Peer navigators
- Village and hub models
- Financial navigators
- Other aged care system navigator models.

### 2.2.1 Patient navigator models

Model summary	
Target population	Vulnerable populations/people experiencing barriers to health care
Aims	Continuity of care, including prevention, detection, diagnosis, treatment, and survivorship to the end of life
Delivered by	Professionals (e.g. nurses) and 'lay navigators' (depending on type of navigator activity)
Service intensity	Flexible level of service intensity and duration, depending on needs of the patient
Modes of delivery	Ongoing one-on-one, face-to-face, including outreach
Strengths	Accredited training program for 'professional' and 'lay' navigators; evidence base to support practice/implementation
Weaknesses	Little research/evidence available on types of patient-reported experiences and outcomes

The first 'patient navigator' model was developed by Harold Freeman in the early 1990's in the United States of America (USA). The model remains the most widely cited navigator model in the literature. Freeman's model was designed to reduce health disparities among under-served populations as well as people facing substantial barriers to breast cancer care in New York. It has since expanded in scope with the aim to improve access to cancer care across different stages of the healthcare continuum (13).

# 'Patient navigation is a healthcare delivery support system that removes barriers to timely healthcare across the entire healthcare continuum, including prevention, detection, diagnosis, treatment, and survivorship to the end of life' (13:p3540).

Freeman's model aims to remove financial, communication, and psychological barriers as well as structural/system level barriers. The program was successful in reducing cancer-related mortality, and mortality associated with other chronic disease (13). In 2005, the USA government introduced the Patient Navigator Outreach and Chronic Disease Prevention Act, which included \$25 million to implement navigator programs over a five-year period (13).

Since, numerous adaptions of the patient navigator model have emerged in healthcare settings internationally, including in the USA, Canada (14) and to a lesser extent in the United Kingdom (UK) (15). Several review studies have synthesised the evidence on the link between patient navigator models and

patient outcomes, with a focus on different target populations and settings including people with chronic physical health conditions (i.e. different types of cancers, diabetes, HIV/AIDS, cardiovascular disease, chronic kidney disease, dementia, and multimorbidity) (16–18).

The individual studies described in the reviews vary considerably. However, they emphasise that system navigators enable patients to be more engaged in their care by increasing their understanding of their condition and treatment. Studies reported a lack of consistent and/or quality data to assess cost effectiveness but, generally, patient navigator programs tend to yield some financial benefits to healthcare institutions, such as net financial benefits (benefit/cost ratio of the program) and revenue generated from increased screening interventions (19).

The factors linked to the model's success include an accredited training program for 'professional' (i.e. nurses or social workers) and 'lay' navigators (trained 'non-professionals'), implementation resources, and specific legislative and funding support (13,20).

Model summary	
Target population	People with complex physical health conditions, vulnerable populations, and/or people with complex needs
Aims	To assist patients to move more easily through the healthcare system, including between hospital and community settings
Delivered by	Professionals (e.g. nurses/allied health)
Service intensity	Flexible level of service intensity and duration, depending on needs of the patient
Modes of delivery	Ongoing one-on-one, face-to-face, including outreach
Strengths	Robust identification and enrolment processes; intervention component (e.g. enhancing self-management/health literacy); linkages with other health service providers
Weaknesses/ limitations	Relatively resource intensive; paucity of evidence in Australian context

### 2.2.2 Nurse/professional navigator models

Nurse navigators are an adaptation of Freeman's patient navigator model and have emerged in many countries, including Australia (12).

As the name suggests, nurse navigator models use trained nurses to assist patients with complex conditions and needs to move more easily through the healthcare system, and between hospital and community settings (21). Nurse navigator models aim to provide coordination of patient care, create partnerships between hospital and community settings, improve patient outcomes, and integrate siloed systems of care (12,21). This is achieved by:

# 'Linking patients with the right healthcare professional, at the right time and in the right place to ensure they receive safe, quality care that meets users' needs' (21:p104)

Usually, there is also an intervention component that supports patients to self-manage their condition and empowers them to actively participate in decision-making about their care (21). The similarities and differences between comparable roles such as case management, care coordination, and system navigation is summarised in a review by McMurray and Cooper (12). The key point of difference is that

'nurse navigators are specifically appointed with the autonomy to choose how best to help people transition through the system' (12:p209). This enables nurse navigators to provide continuity of care, as well as flexible levels of navigator service intensity and duration of care, depending on the needs of the patient and their goals for care (12).

Examples of nurse navigator models include a program in Queensland that provides care for people with comorbidities or complex medical concerns (22). A representative of the program described the following components as important to this model, which is consistent with the literature:

- Robust identification and enrolment criteria
- Development of shared care plans
- Seamless and integrated care pathways
- Skills and experiences of the nurses in the navigator role
- Flexible modes of delivery including face-to-face and outreach
- Intervention components (e.g. motivational interviewing/enhancing self-management/health literacy)
- Capacity to support the patient over the longer term (12,21).

The same representative reported many successes, including the creation of meaningful patient-nurse navigator relationships, the relationships developed between nurse navigators and other healthcare providers in the hospital and community, as well as cost savings – noting that the evidence regarding the program's effectiveness is still being collected.

'Delivered by senior nurses, nurse navigators have a key role in developing health literacy and self-management. This adds dimensionality to the care role because they have an understanding of disease processes and how hospitals and the systems work. They aid patients, knock down barriers between primary, secondary and tertiary care. Nurses coordinate care and take care of the patient over the long-term – *Representative* for the Nurse Navigator program

Preliminary research suggests that challenges related to the nurse navigator role include:

- Navigators being called on to carry out additional activities to fulfil service gaps (e.g. other clinical duties)
- Difficulties adhering to program enrolment criteria, which can lead to inappropriate referrals
- Delays in patients being linked to a nurse navigator
- Lack of clear definitions regarding roles and responsibilities of nurse navigators (21,23).

Another example of a nurse/professional navigator pilot program can be found in Victoria, delivered by Western Health Links (Western Health and Silver Chain Group partnership). The aims, key components, successes and weakness/challenges of the model are presented in the box on the next page.

#### Western Health Links – Health Navigator

In 2016, Western Health and the Silver Chain Group were funded by the Victorian Department of Health and Human Services to deliver a three-year partnership pilot program involving the provision of health navigators for patients with chronic diseases and complex comorbidities (commenced 21 November 2016).

The aim of the program is to improve capacity to provide care outside of the hospital setting and reduce hospital admissions and unplanned readmissions. Since its inception, approximately 19 full-time equivalent nurses or allied health workers have been employed to deliver health navigator services in Western Melbourne seven days per week between 7am and 11pm. The health navigator role is supported by a 24-hour contact centre (Western Health Links), which is serviced by a customer service centre and nursing staff.

The model of care is based on the concepts and principles of the Flinders Chronic Condition Management Program, which is a person-centred, problem– and goal–focused approach to assessment and care planning that aims to enhance self-management of chronic diseases.

Patients are invited to enrol in the Western Health Links program, after being 'flagged' in the hospital system as someone who may need extra support due to the complexity of their conditions. These patients are identified from an algorithm that draws on diagnostic information and the number of times the patient may have presented to the emergency department or admitted to hospital. Patients receive an outreach assessment promptly following discharge, and a care plan is developed in partnership between the patient, health navigator, and health professionals such as their GP, based on the client's own goals as well as other interventions that may be needed to support them in the community or hospital setting. Measures are also used to track client progress, goals, and outcomes.

High-intensity outreach, a holistic approach to care, having goal-orientated discussions with clients, and strong linkages and partnerships with other agencies are considered to contribute to the success of the program.

# **'We help people to know what's available and provide the linkage.'** – Organisation representative for the Western Health Links program

Whilst in-house training is provided to experienced nurses or allied health workers, challenges for the program include recruiting health professionals who have the 'soft skills' necessary to effectively and sensitively work with clients.

In Ontario, Canada, the Nurse on Board model is a private, face-to-face nurse navigator model covering physical and mental health needs from the point of diagnosis through acute and chronic care periods, and ultimately end-of-life care. The model addresses several aspects of care including assessments, developing tailored care plans, assistance preparing for and attending medical appointments, advocacy, enhancing confidence to make choices though education, communication with family members, building linkages in the community, and end-of-life care (24). Nurse on Board also provide assistance with access to aged care.

Some nurse navigator models target specific under-served population groups (25,26). For example, in Canada, the First Nations Health Authority, in partnership with Island Health, have established nurse navigators to support First Nations peoples and their communities by providing face-to-face and outreach nurse navigator services (27).

'Vulnerable people need empowering, and the intervention of a nurse navigator can empower these people with access to support, and to improve their knowledge and health literacy' – *Representative from the nurse navigator program in Queensland* 

The nurse navigator model is increasingly recognised by governments as an important element of patient care, particularly for vulnerable populations and/or people with complex needs. For example, the Swedish government has outlined plans for widespread implementation of nurse navigator positions as part of their 'National cancer strategy for the future' (28). Moreover, there are calls in the literature to recognise the potentially important and relevant role of nurse navigators in different sectors including aged care (12,21,23,29).

In Victoria (Australia), the Access & Support (A&S) program and network (described in the box below) combines elements of patient/nurse/professional navigator models. Initial evaluation of the A&S program in 2015 reported that while it was still in its infancy, it demonstrated success in engaging with and linking vulnerable people to aged care services (30).

#### The Access and Support program

The Access and Support (A&S) program is a Victorian state-wide service that provides face-to-face system navigation to people aged 65 years and over (over 50 for Aboriginal and Torres Strait Islander people). It is funded by the Australian Government Department of Health through the Commonwealth Home Support Programme. The program also receives funding from the Victorian Government Department of Health and Human Services to support people under 65 years. The program was established to help link individuals who are experiencing barriers, as a result of their diversity or circumstances, to access the aged care system and other services. There are approximately 80 A&S workers (who have qualifications in aged care/community care/allied health) positioned within auspice organisations covering seven geographic locations in Victoria.

The A&S program is underpinned by principles of independence, impartiality and person-centred service delivery, and aims to overcome the barriers that people face when trying to understand and access aged care and other services. A&S workers provide assertive outreach in the community. While not considered a case management model, A&S workers report spending lengthy or repeated interactions with their clients to build the trust and rapport that they feel is needed in order to link them into the right services at the right time.

# **'An Access and Support worker connects the clients to services through the position of trust'** – A&S worker

Through their assertive outreach approach, A&S workers develop strong local knowledge of, and partnerships with, advocacy and community-based organisations, local councils, and social, health, and aged care service providers. Through these partnerships, the A&S program works closely with Regional Assessment Service and Aged Care Assessment Team assessors, and GPs, to facilitate bidirectional referrals and provide support that covers the whole My Aged Care pathway – from accessing My Aged Care through to screening and assessment, helping clients follow up with referrals, and linking to other appropriate services. A&S workers also feel it is important to use their knowledge to educate and empower clients, and their carers and family members to make their own choices and decisions.

While representatives from the A&S program consider the program to be doing well in 'linking people to information, to services and systems', barriers to the long-term implementation of the program are reported to include an 'explosion of scope' including complexity of cases, lengthy interactions with clients, and a lack of capacity in regional and rural areas.

**'The river causes problems, but there are bridges'** – *A&S Advisory Committee representative* 

### 2.2.3 Family navigators

Model summary	
Target population	Youth/families with developmental/mental health difficulties
Aims	To assist youth/families to navigate the complex youth mental health and addictions system.
Delivered by	Professionals (i.e. psychologists/allied health)
Service intensity	Flexible level of service intensity and duration, depending on needs of the patient
Modes of delivery	Telephone (screening/assessment), ongoing one-on-one, and face-to-face including outreach
Strengths	In depth knowledge of and strong relationships with service providers; relationship- based care
Weaknesses/ limitations	Difficulties tracking youth/family outcomes once linked into care; restricted eligibility for enrolment (i.e. age and catchment boundaries)

Family navigation models have arisen in response to concerns that children, young people and their families face challenging barriers to accessing care, particularly related to developmental and mental health difficulties (31–33). Family navigator models are underpinned by relationship-based approaches, which recognise the importance of the relationships that exist between the service user and others around them (31–33).

Similar to nurse navigators, family navigators typically provide high levels of face-to-face service intensity, including outreach, to help people in the mental health system access timely, appropriate, and specialised care. Family navigators aim to engage the whole family in the system navigation process, and work to provide supports for other family members as well as the individual requiring care.

The Family Navigation Project (FNP) at Sunnybrook Health Science Centre in Canada (described below), is a non-profit program that offers mental health and addictions service navigation for young people and their families through a relationship-centred model (31,32). The literature and project representatives indicate the family navigator model should include:

- An individualised, flexible and family-centred **navigation process** to engage youth/families, which should be underpinned by expert information sharing and provision
- A service 'matching' process, which links youth/families and the most appropriate services for their needs
- A **compassionate** approach to working with youth/families, which builds rapport and solidarity, and ensures there is 'no wrong door' to achieve outcomes that are most important to them (31,32).

Data for the evaluation of the program are not yet available, however weakness/challenges reportedly include:

- Difficulties tracking patient outcomes once youth/families are linked into care
- Restricted target age ranges and geographic catchment areas
- Difficulties securing sustainable funding (31,32).

### The FNP – Sunnybrook Health Sciences Centre, Canada

The FNP was established in 2013 as a non-profit service providing free navigation for families of youth aged 13 to 16 with mental health and/or addiction concerns. The FNP delivers a navigation service that supports families while they are going through the complex youth mental health and addictions system.

The navigators are graduate-level clinicians with expertise in mental health and addiction. Approximately 20% of the navigator's time is devoted to locating resources, visiting service providers to explore their service provision and build relationships, or arranging meetings for service providers to visit FNP. This enhances in-depth knowledge of local services and also develops meaningful relationships with providers, which greatly assists navigators' ability to provide client-tailored navigation and generate bi-directional referral pathways. This has been noted as an important element of the model, in order to ensure services are 'well matched' to the user's needs.

# **'There is a secret language that service providers use and we help families to understand it'** – Organisation representative for the Family Navigation Project

Families contact the FNP via phone or email and are then contacted within one business day for a phone screen by an intake coordinator, who then assigns the family to a navigator. The navigator will proceed to conduct an intake call to learn about the youth social and medical history and the family's goals and provide matching to appropriate services. 'Getting in the boat' with patients and their families refers to the flexibility of the model, which allows family navigators to not only provide the 'matching' and linking in to services, but allows them to follow up with families to ensure services are a 'good fit', and providing 'course-correction' if needed.

Model summary	
Target population	Specific population groups (including but not limited to carers, people with a disability/chronic physical health condition, people from CALD backgrounds)
Aims	To assist people to access information, education, training and/or connect with different types of systems of care or services
Delivered by	'Lay/peer' navigators with lived experience (paid or unpaid)
Service intensity	Once-off or ongoing face-to-face/group interactions
Modes of delivery	One-on-one telephone or face-to-face (including outreach in some cases), hubs (community/online) – or a combination of these
Strengths	May offer some alternative benefits over professional navigators, such as building trust/rapport through shared experiences; 'Gatekeeper' type navigators enhance opportunities to identify and engage at-risk individuals in the community
Weaknesses/ limitations	Limited evidence available regarding key components/effectiveness; need for ongoing training/support of navigators to ensure quality of service/information provided

### 2.2.4 Peer navigators

While there is no universal definition of a peer navigator, the literature suggests they are usually trained lay navigators with relevant 'lived experiences' (34,35). The peer navigator role can include 'peer support', which could range from having informal conversations to formal programs/services delivered by lay people (6,36). Peer navigator models are emerging in Australia, and provide varying combinations of one-on-one, outreach, group, and/or online service delivery modes. Peer navigator models exist across a range of target population groups including carers (37), people living with HIV (38), and people from CALD backgrounds (35,39) – as well as people seeking assistance with aged care (40,41). However, it should be noted that many of these programs are in their infancy, and effectiveness data is not yet available.

Nevertheless, the grey literature suggests that peer navigators may offer different benefits compared with navigation support delivered by professionals. These include:

- Giving individuals a platform to express their experiences and feelings with people who have had similar life experiences
- Instilling a sense of hope for the future and trust through mutual sharing of personal experiences
- Fostering inclusion among people who may be socially isolated (6,42).

Stakeholders representing other system navigator models emphasised the importance of peer navigators being appropriately trained/qualified, and working within the scope of these qualifications, to ensure appropriateness and quality of navigator services being delivered (i.e. this mode may be inappropriate for assisting people with complex needs/high risk).

Internationally, the Gatekeeper Program (funded by the USA government) involves elements of peer navigation. It is an organised outreach effort designed to build the capacity of community members to recognise and reach at-risk older people who may have little contact with others and require assistance (43). Gatekeepers come into contact with older people in their day-to-day work as supermarket workers, librarians, customer service representatives or postal workers. Once the gatekeeper identifies an at-risk person, they are referred to a relevant government agency helpline who, in turn, provides a follow up telephone call, assessment, and linkage into services (43).

Research on previous iterations of the Gatekeeper Program found that people referred to services by the gatekeepers were more frequently socially isolated, economically disadvantaged, and less likely to be linked into a regular healthcare provider and the services they need than others in the community (44). The gatekeeper role has resulted in reduced emergency department and hospital admissions, and savings to healthcare costs (45). Various government departments in the USA provide implementation guides and training materials and resources for the Gatekeeper Program (43).

### 2.2.5 Village and hub models

Model summary	
Target population	General community
Aims	To improve social engagement/connectedness and provide services/supports
Delivered by	Lay/peer navigators (paid or unpaid)
Service intensity	Once-off or ongoing group interactions
Modes of delivery	Community hubs (physical/online)
Strengths	Shown to support social connectedness/ageing in place
Weaknesses/ limitations	Limited evidence available regarding key components/effectiveness; may not reach vulnerable populations/people experiencing barriers to care

The Village Movement is a type of grassroots organisation (self-funded by membership fees), initiated in Beacon Hill in the USA approximately a decade ago, to facilitate social engagement and provide services and supports to improve health and wellbeing for community-dwelling older people. Two 'hubs' have been established in Australia, in Victoria and New South Wales (46). The Village Movement appears to incorporate elements of peer navigation, however there is little research available describing the elements of the model. The available evidence does suggest that while members of the movement may already be socially connected and linked into services, the model may enhance people's confidence to age in place (47).

There are numerous other 'hub' models emerging in Australian communities (46,48). Community hubs are designed as community-based services provided by the community for their members/peers, commonly staffed by volunteers and/or paid staff members. Peer-to-peer support underpins their model as it is seen as the best way to deliver information and create cohesion.

# 'For older people, the personal experiences are really important to them. Hearing other people's personal experiences are more helpful and carries more weight to them than a professional' – Representative from a community hub model

Finally, 'virtual hubs' are emerging in Australia that provide information about or 'directories' of aged care services (49,50). These models appear to primarily focus on information provision, rather than navigation support, and to date, there is little evidence on the effectiveness of such approaches in helping people to engage with aged care.

### **2.2.6 Financial navigators**

Model summary	
Target population	Vulnerable populations/people experiencing financial barriers
Aims	To assist people to understand financial options/impact of financial decisions
Delivered by	Range of qualifications; unclear from the literature
Service intensity	Once-off or ongoing interactions
Modes of delivery	One-on-one, telephone, and face-to-face including some outreach – or a combination of these
Strengths	Reduces financial barriers to healthcare
Weaknesses/ limitations	Limited evidence available regarding key components/effectiveness in non-healthcare sectors

There are calls in Australian literature to understand the 'financial toxicity' that is associated with having a chronic disease, and how financial navigators could assist to alleviate financial barriers for patients (such as out of pocket costs for healthcare) (42,51,52).

Internationally, financial navigators have emerged out of oncology teams in the USA, to help people with cancer understand their eligibility and insurance coverage, provide resources to service users about financial issues, and facilitate communication between service users, caregivers and relevant health professionals to reduce economic barriers to care (53,54).

In the literature, proposed recommendations for financial navigators include the provision of information and education on a range of financial issues. These include budgeting, eligibility of payments/benefits, superannuation, assistance with making financial decisions, completing government forms (e.g. from Centrelink), and debt management as part of multidisciplinary teams. Information and education may also include financial issues related to aged care transitions (42).

An example of a financial navigator service in Australia is the FIS, a freely available education and information service that is delivered by DHS, and covers a broad range of financial topics (55). This service is distinct from the FIS Officer trials as part of the Measure (see *Section 1.2.2*), which provides targeted information related to the aged care system. Intended for the general population, the FIS typically involves one-off, face-to-face appointments that are held at DHS Service Centres in each State/Territory (55). FIS Officers also deliver information seminars to the general public. They also conduct outreach, which involves delivering information in community-based settings in metropolitan and regional areas (e.g. at Community Agencies or libraries).

In 2016, the Australian National Audit Office (ANAO) conducted an audit of the FIS, according to the following high-level criteria:

- Effective arrangements for the promotion and delivery of services
- Effective training and quality assurance mechanisms to support the delivery of FIS in accordance with legal and policy requirements
- Sound monitoring, reporting, and evaluation arrangements to assess the effective delivery of FIS (56:p7).

The ANAO report noted that the FIS had not undergone evaluation since its introduction in 1989, and recommended future review. An additional recommendation was the development and implementation of a national servicing strategy in order to enhance the administrative arrangements of the FIS (56).

### 2.2.7 Other aged care system navigators

Stakeholders noted that there are numerous aged care navigator models/roles emerging within local government and Primary Health Networks (PHN) – but these may not be officially labelled a 'system navigator'. Local government is reported to be well-placed to incorporate aged care system navigation as part of existing local efforts, due to their knowledge of and connection with other agencies in the community, as well as potentially being a trusted source of information for people who are experiencing barriers or who have complex needs, and who otherwise may not present to services.

**'Local councils are connected with their community. They provide all sorts of information and referrals. There's a lot of knowledge here, and you just have to tap into it'** – *Representative from a local council in New South Wales* 

The literature review and stakeholder consultations also uncovered a number of other 'navigator-type' services that are associated with/attached to providers of residential or home-based aged care (including for-profit and not-for-profit providers). These services typically provide telephone information about available services, costs and eligibility criteria, and support people to access My Aged Care to commence the assessment process. While marketed in some instances as 'navigator' services, many of these services appear to be primarily focused on promoting their own aged care service offerings, and as such may not be offering impartial information or support.

### 2.2.8 Summary

The literature review and consultations undertaken to inform this discussion paper found that a range of system navigator models exist. While there is considerable variation between the models, they most commonly involve multiple one-on-one (with individuals and/or carers/families) and face-to-face interactions, and elements of ongoing support and education, rather than one-off provision of information.

It is noted that while the evidence base for the effectiveness of system navigator services across different modes and types of service delivery is still relatively small, it is an area of growing research interest.

### 2.3 Frameworks for practice

Currently, there is little research to guide system navigator practice in the Australian context (10). In response to the current growth of system navigator models in health and human service sectors in Australia, Donovan and colleagues at The University of Melbourne developed the Service Navigation Relational Autonomy Framework (SNAF) as a guide to assist practitioners and managers implementing one-on-one (including activities involving carers/families) and face-to-face system navigation models. The SNAF is intended to be suitable across different sectors (10), however the framework is intended for services delivered by 'professional' (rather than lay) navigators.

#### Service Navigation Relational Automony Framework

The four key domains highlighted in the Service Navigation Relational Autonomy Framework (SNAF) were written to facilitate consistent approaches to navigation service delivery across sectors including disability, social work, mental health and aged care. The SNAF intends to clarify the expectation of navigation roles to ensure the quality and competence of the service.

#### **Fostering self-determination**

Service navigators should consider factors in relation to self-determination, such as autonomous decision making and how the role of family and/or social networks are working within this context. Navigators may step in where family support is not present, but the role of the navigator is to strengthen these supports rather than replace them.

#### Supporting transitions and wellbeing

Understanding the service user, including their context, needs and priorities, is considered essential to providing a personalised navigation service.

#### **Mobilising service systems**

Service navigators require an in-depth understanding of what systems offer, where and to whom, as well as the complexity of how systems interact and intersect. The 'mobilising services' domain also draws attention to risk assessment and risk management. Working within this framework, navigators need to be mindful of the physical, emotional, legal and organisational risks when clients interact with service systems.

#### **Reinforcing ethical practices**

In defining ethical navigation practice, the framework considers clarifying roles and responsibilities, transparency, and efficient and effective use of resources. This domain also focuses on 'relational autonomy' and the importance of power influences.

# **'Information is giving someone the map. Navigators assist with decisions when working through the map'** – Academic in social work and system navigation

Internationally, the National Health Service (NHS) in the UK released 'The Care Navigation: A Competency Framework', which was designed to provide a 'common language' and consistent approach to care navigation, and to ensure relevant staff in navigator roles in healthcare receive appropriate education and training (57). Similarly, in the USA, Willis and colleagues have described the functions of 'patient' and 'nurse' type navigators across several domains including person-centred care, levels of core competencies for different tasks and responsibilities, and building and sustaining professional relationships (58). However, there is limited literature describing frameworks to guide the practice of other (non-face-to-face) system navigator services/models.

## **2.4 Barriers and enablers**

This section presents barriers and enablers to the implementation of system navigator models in aged care and other sectors more broadly. The information presented below is derived from consultations with representatives from system navigator models in aged care and other sectors, and the literature (where available).

### 2.4.1 Capacity

Representatives from system navigator models in aged care and other sectors noted workload pressures faced by those in navigator roles.

These pressures were reported to include the complexity of individuals' needs, lengthy interactions with clients, as well as performing outreach across vast distances – and associated lack of funding and resources.

This is consistent with the literature, particularly in the 'family' (31,32) and 'nurse' navigator literature (21).

Stakeholders suggested that developing a clear scope of practice, roles, responsibilities, and training for aged care navigators may enhance the capacity of aged care system navigators, as well as alleviate burden on other sectors.

The importance of delineating clear roles and responsibilities has also been emphasised in the literature in relation to other navigator types (i.e. patient and nurse navigators) (58).

### 2.4.2 Reaching target populations

Representatives from system navigator models in aged care and other sectors reported that many population groups in Australia are facing significant barriers to accessing and navigating aged care, and the factors that contribute to these barriers may also limit access to aged care system navigation services.

Engaging 'hidden' populations may be difficult due to:

- A mistrust of the aged care system or systems more broadly due to prior life experiences
- Social isolation
- Low levels of awareness of the aged care system, or of health and social systems more broadly
- Language/communication barriers (including low levels of literacy).

This is consistent with the literature, particularly regarding 'patient navigator' models (13).

Representatives from system navigator models in aged care and other sectors proposed different options to meet the diverse needs of those requiring aged care navigator services.

These included:

- Face-to-face and outreach modes of delivery are particularly important for building trust and rapport and reaching individuals experiencing barriers and people with complex service needs
- Telephone/online modes of delivery may enable access to difficult-to-reach populations or geographically isolated regions (noting this mode may be challenging for people with barriers to accessing technology)
  - These modes may also reach a greater number of service users at a lower cost compared with face-to-face modes—although the effectiveness of such approaches is not yet clear
- Peer-to-peer/lay navigators (paid or volunteer) may provide unique benefits to service users such as enhancing knowledge, emotional, social or practical supports because of similar experiences or circumstances in their life (noting this mode may be inappropriate for assisting people with complex needs/high risk).

### 2.4.3 Funding, independence and competition for services

Representatives from system navigator models in aged care and other sectors reported that the 'marketisation' of the aged care system is intended to enable consumer-driven choices. However, stakeholders have suggested this may present some challenges. These include:

- The need (or perceived need) for aged care system navigator services to 'compete' with other services/organisations for service users
- Increased choice and control may only benefit service users who are already 'linked' in to the system, have higher levels of knowledge about services, or more resources to support them in seeking and accessing services
- Some aged care system navigator models come from 'within' organisations that provide aged care services, and thus may not be underpinned by the principle of independence
- Costs associated with fee-for-service/private models may disadvantage people who experience financial barriers
- There is a risk that service users may be recommended a service that is inappropriate for their needs.

Reported enablers included increased and secure (i.e. ongoing) funding to enable established, independent aged care system navigator models to increase their capacity and scale of implementation.

### 2.4.4 Integration

Representatives from system navigator models in aged care and other sectors identified a lack of integration between different sectors as a barrier to the uptake of system navigator services. These issues included:

- Lack of integration or partnership between sectors (e.g. health, social, and aged care)
- Lack of integrated efforts between local government, PHNs, and community-based organisations that could support/build on existing services

• Lack of engagement between primary care professionals with system navigator services (i.e. aged care and other sectors).

This is consistent with the literature concerning system navigator models in the primary care context (11,59).

Several enablers were identified to enhance integration and linkages, which are described as key components of aged care system navigation:

- Increasing partnerships and relationships between aged care system navigators and the aged care assessment workforce (Regional Assessment Services and Aged Care Assessment Teams)
- Building strong relationships between primary care professionals (i.e. GPs) and aged care system navigators to promote shared responsibility and collaborative practices
- Ensuring that aged care system navigators develop and maintain an in-depth understanding of the local service landscape
- Providing dedicated time for aged care system navigators to develop and maintain key linkages.

### 2.4.5 Research/data collection

Representatives from system navigator models in aged care and other sectors raised some barriers related to collecting service user information, including:

- Lack of integrated electronic health/aged care records and platforms for data sharing (due in part to privacy and confidentiality challenges)
- Lack of engagement between navigators and key decision makers who 'hold' health/aged care information on behalf of the service user
- Lack of research and evaluation activities on aged care system navigation that could inform policymakers in challenging fiscal climates
- Lack of patient-reported outcome measures/patient-reported experience measures.

Identified enablers include increased research and evaluation activities that run in parallel to the design and implementation of aged care system navigator models.

# **3** Discussion points

## 3.1 About your organisation

Which of the following best describes your organisation?

Aged Care Assessment Workforce/Provider  $\Box$ 

Aged Care Service Provider  $\Box$ 

Peak Organisation  $\Box$ 

Academic Institution  $\Box$ 

Other : Please specify

What is the postcode of your organisation?

A summary of current and historical system navigator models, derived from the literature and consultations with representatives from system navigator models in aged care and other sectors, was presented in the previous section.

Considering the identified models presented in *Section 2*, please provide responses to the questions below with respect to any or all of the following categories:

- Patient navigator models
- Nurse/professional navigator models
- Family navigator models
- Peer navigator models
- Village and hub models
- Other aged care system navigator models.

Please comment on the strengths and weaknesses of the models.

Please comment on which system navigator models are most relevant to the Australian aged care context.

### 3.3 Design principles

Design principles offer guidelines and a foundation for policy makers/practitioners to integrate and evolve ideas, concepts, and practices consistently and with purpose. Design principles aim to align the development and delivery of services/models by ensuring a shared understanding of their purpose and capabilities (60,61).

The following design principles have been identified through the literature and consultations with representatives from system navigator models in aged care and other sectors as important to future navigator models in the Australian aged care context.

- 1. Clear scope of role and practice. Aged care system navigators should have a defined scope of practice with roles and responsibilities that are transparent and commensurate with the skills and experience of the navigator delivering the service including guidance on management of risk
- **2. Defined target population.** Aged care system navigator models should focus on defined target populations, and prioritise those who are who are vulnerable or are experiencing barriers to accessing information and care
- **3.** Quality workforce. Aged care system navigators should be an appropriately qualified, trained, and supported (e.g. with ongoing training and professional development) workforce
- **4. Implementation resources.** Aged care system navigator programs should include implementation resources/toolkits/guides to support consistent, high quality delivery of navigation services
- **5.** Flexibility and adaptability. Aged care system navigator models should be flexible, adaptable, and responsive to meet the needs of the service user and the required level of service intensity
- **6. Integration.** Aged care system navigator models should aim to integrate fragmented and disconnected systems of care, and draw on existing local efforts/supports/infrastructure
- **7. Relationship-centred services.** Aged care system navigator models should identify the context, needs and priorities of the service user, in order to provide a personalised navigation service. It should also recognise the importance and influence of the relationships that exist between the service user and others, including service providers
- **8.** Active participation. Aged care system navigation should enhance the capacity of service users (including individuals/carers/families) to be actively involved in navigating the aged care system
- **9.** Linkages and partnerships. Aged care system navigators should dedicate time to developing their knowledge of local services, building partnerships with other organisations and sectors, and performing promotional/integration activities
- **10.Evaluation outcomes.** Implementation of aged care navigator programs should include an evaluation framework to monitor outcomes for service users and inform future policy decisions
- **11. Independence.** Aged care system navigators should be independent from service providers, to foster the necessary trust and rapport required to reach people facing challenges when accessing and navigating aged care services

### **3**. **Discussion points**

### 3.3.1 Response

Please rate the importance of each design principle below by typing a number between 0 (Not important) and 100 (Very important) in the box provided.

Principle	Rating
1. Clear scope of role and practice	
2. Defined target population	
3. Quality workforce	
4. Implementation resources	
5. Flexibility and adaptability	
6. Integration	
7. Relationship-centred services	
8. Active participation	
9. Linkages and partnerships	
10.Evaluation outcomes	
11.Independence	

Please expand on your answers above if you wish.

Please list any other design principles you think are important/relevant to system navigator models in the Australian aged care context.

### **3.4 Components of system navigator models**

Components of system navigator models describe what is delivered, how and by whom. The following components have been identified through the literature and consultations with representatives from system navigator models in aged care and other sectors as important to future navigator models in the Australian aged care sector (noting that different combinations of components may be relevant for different target population groups).

#### Providers of system navigator services

- 1. Role 'Professional'. Professional aged care system navigators should hold qualifications in aged care and/or relevant health, behavioural, and/or social sciences
- 2. Role 'Peer/lay'. Peer or lay aged care system navigators should have 'lived experiences' relevant to the target population of the model/service

#### Assessment, planning, and service provision

- **3.** Identification and assessment. Navigator services should have clear referral, intake, and holistic assessment processes to identify service user needs and goals
- **4. Care planning.** Aged care system navigator services should have a clear and consistent approach to developing service user care plans, in consultation with individuals and families (where appropriate)
- **5.** Level of service intensity. Aged care system navigator models should offer a range of service intensities that are appropriate and responsive to changing service user needs
- **6. Financial navigation.** Aged care system navigator models should support individuals to understand the financial implications of decisions related to accessing aged care through the provision of information

#### **Modes of delivery**

- **7.** Face-to-face. Face-to-face navigation services are useful to enhance user-navigator relationships and to build trust and rapport
- **8. Telephone.** Telephone navigation services can improve reach to some population groups as well as those who are geographically isolated
- 9. Online. A virtual/online location can provide a range of information about aged care/services
- **10.Outreach.** Outreach enables face-to-face modes of service delivery to particularly marginalised people that may not otherwise have access to services
- 11. Hubs. A physical or online location where a range of navigator services can be provided

### **3**. **Discussion points**

### 3.4.1 Response

Please rate the importance of each component below by typing a number between 0 (Not important) and 100 (Very important) in the box provided.

Component	Rating
1. Role – 'professional'	
2. Role – 'peer/lay'	
3. Identification and assessment	
4. Care planning	
5. Levels of service intensity	
6. Financial navigation	
7. Mode – Face-to-face	
8. Mode – Telephone	
9. Mode – Online	
10.Mode – Outreach	
11.Mode – Hubs	

Please comment on which mode of delivery you feel is most important (e.g. face-to-face/telephone, online/outreach/hubs), or which combination of the modes of delivery are important.

Please list any other components you believe are important/relevant to system navigator models in the Australian aged care context.

### 3.5 Implementation of system navigator models

Barriers and enablers to implementation of aged care system navigator models (described in *Section2.4*) relate to:

- Capacity
- Reaching target population
- Funding, independence and competition for services
- Integration
- Research/data collection.

### 3.5.1 Response

Noting the **barriers** described in *Section 2.4*, which do you consider to be the most critical to implementation of aged care system navigator models in Australia? Please describe how these could be **overcome.** 

Noting the **enablers** described in *Section 2.4*, which do you consider to be the most critical to implementation of aged care system navigator models in Australia? Please describe how these could be **enacted**.

### **3**. **Discussion points**

What other implementation considerations should be taken into account? Please explain your answer.

For example, you may wish to consider how to build on existing supports/investments and/or the feasibility of widespread implementation.

# 3.6 Other comments

If you wish, please provide additional comments related to this discussion paper.

# 4 Next steps

This discussion paper presents a summary of the evidence related to various system navigator models.

AHA asks stakeholders to read and respond to the discussion points on proposed design principles, components, and implementation considerations.

The feedback garnered from this discussion paper will inform the evaluation of the Aged Care System Navigator Measure, particularly the review on current and historical system navigator models in aged care and other sectors. It could also contribute to the development of advice on policy direction for the Department in relation to aged care system navigation.

#### The closing date for submissions is 16 September 2019.

You may respond to these questions using the survey link here.

You may also wish to complete the feedback form embedded into this document and submit it to: acsn@ahaconsulting.com.au

If you have any questions about the discussion paper or the feedback process, please contact:

Anna Bishop-Bailey or Shae Quirk at AHA on 1300 242 111 or email: acsn@ahaconsulting.com.au.

Thank you for your contribution to the evaluation of the Aged Care System Navigator Measure.

# Appendix A Methodology

# A.1 Methodology

Between January and June 2019, AHA undertook a series of initial research and consultation activities to inform the development of this discussion paper. These are outlined below:

### A.1.1 Research scan

AHA conducted an environmental scan to identify existing and historical system navigator models/services (including aged care system navigator models/services and system navigator models/services in other sectors) in Australia and internationally.

The criteria for inclusion and the search strategy (i.e. Search 1 & 2 and secondary search terms) that was used to identify peer-reviewed and grey literature, and other forms of information/documentation are presented below.

### Scope

Literature/information was deemed in-scope if they described and/or examined **aged care system navigator models/services** or **navigator models/services in other relevant sectors**; and if they:

- Were published in English
- Were published after 1990
- Describe outcomes including measures of satisfaction, confidence, knowledge, skills, health literacy, and other relevant clinical, health and/or social outcomes (where relevant/available).

To note: types of roles, models, individual supports and consumer supports that did not also include components of system navigation were considered out-of-scope. For example:

- Types of Information provision only
- Types of peer support only
- Models of case management only
- Models of care coordination only
- Types of outreach work only.

### Search strategy

Google Scholar and Google were searched as the primary source for peer-reviewed and grey literature/other relevant information, respectively. Academic databases were used to retrieve articles that were not open access publications.

### Screening

Where appropriate, the titles and abstracts of retrieved literature/information were screened for eligibility. Reference lists obtained from eligible records were used to identify additional relevant material.

### Data storage and synthesis

Peer-reviewed literature was stored in a reference management database. Grey literature/other relevant information/documents were filed in labelled folders and tracked in an excel spreadsheet.

Descriptive data derived from consultations, and other documentation was analysed using NVivo 11 Pro software.

### A.1.2 Brief survey

In April 2019, AHA conducted a brief online survey inviting stakeholders and representatives from the aged care and other relevant sectors to register their interest to share information and/or participate in a consultation for the evaluation. The survey generated 297 responses nation-wide.

### A.1.3 Initial consultations

AHA has experienced high levels of engagement and interest in the review of other system navigator models and services, in Australia and internationally.

To date AHA has consulted with n=27 representatives from system navigator models in aged care and other sectors, which has informed the development of this discussion paper.

Consultations with relevant stakeholders will be on-going throughout the evaluation.

### Table A-1:Search terms

Search 1: Aged care system navigator models search	Search terms/key words
"aged care" OR "older" AND navigator OR "system navigation" OR "service navigation" OR access OR guide OR coordinator OR coordination	Aged care Older Navigator System navigation Service navigation Access Guide Coordinate Coordination
Search 2: Other sector system navigator models search	Search terms/key words
service OR system OR patient OR consumer OR customer OR client AND navigator OR "system navigation" OR "service navigation" OR access OR guide OR coordinator OR coordination	Service System Patient Consumer Customer Client Navigator System navigation Service navigation Access Guide Coordinate Coordination
Secondary search	Search terms/key words
Combination	Review patient navigator models International/country terms Navigator Australia Disability Community Health Social services Training and education Veterans' affairs Patient navigator Consumer navigator Healthcare navigation Models of patient navigation Enable Improvement Conceptual Systems wrangler

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