

## **Navigating the Health System – A Local Perspective**

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### **Executive Summary**

The literature was reviewed to identify factors impacting health service system navigation for consumers such as fragmentation, health service design and health literacy. Aside from those with once off, single health issues, services are often fragmented for those with ongoing complex and chronic conditions. Different funding streams and multiple programs with specific entry criteria can lead to duplication, service gaps and challenges for consumers to navigate through the system.

Governments at all levels are concerned with health system fragmentation and health literacy in the context of an ageing population and rising health care costs and there are numerous programs designed to address this. Broader funding models and structures should be addressed. One of these, the ‘patient centered medical home’ appears to have some support. It is recommended that initiatives be evidence based and localized where possible to ensure they benefit those with the poorest health literacy.

Consumers and health service providers from the G21-Geelong Region Alliance area were surveyed and interviewed. A program, for people over 65 that provides volunteers to assist people in medical consultations was not supported due to concerns with the governance of the program and privacy and confidentiality of patient information. However, people over 50 from both an advantaged and disadvantaged background preferred to have a family member present at medical consultations and were concerned if that was not possible.

Many from a CALD background were overwhelmed by the complexity of the health system and with understanding the role of different medical professionals and what to expect from them. Those with a background of homelessness experienced enormous barriers to navigating the health system and many were reliant on case workers.

Survey results revealed the advantages for older people of having a strong connection to a regular GP to provide care and coordination, as well as a reliable person to accompany and support people in medical consultations, preferably family or friends. Transport to and from medical appointments was an issue for all groups.

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## Introduction

This project was an initiative of the Leaders for Geelong program.



It is supported by the Committee for Geelong; an independent, member based organisation committed to providing strategic leadership.

Most people have experienced, either personally or through someone close to them, difficulty navigating the health system. By navigating the health system we mean accessing, using and understanding the services people require for their individual health needs. We explored some reasons why consumers may have difficulty, such as fragmentation and health system design. These especially impact people with chronic and complex conditions due to the number of funding streams, restrictive eligibility criteria and service gaps. Coordination of care is made more complex by the number of restrictions and boundaries there are around services.

This paper discusses both individual and environmental health literacy and the extent of the problem. A large number of Australians have less than adequate health literacy. An individual's health literacy can fluctuate depending on the context and their individual background and circumstances. We asked representatives from local agencies their views on difficulties that specific groups of people have navigating the health system.

Consumers and health professionals were asked their views on the use of a volunteer to enable, facilitate, encourage and support a patient to ask questions and comprehend the information provided during a health consultation.

Feedback after this survey led to the broadening of questions for consumers to be less specific, therefore a group of disadvantaged and advantaged people were asked their views regarding difficulties navigating the health system and their suggestions for what might help.

Local and national initiatives and plans are discussed along with recommendations for what may help consumers from different backgrounds navigate the health system at a local level.

## Objectives

- Review the literature on factors impacting health service system navigation for consumers
- Obtain views from local consumers and key service providers regarding the concept of consumers having access to a trained volunteer to assist them to navigate the health system
- Obtain information from local consumers and key service providers regarding their experience of navigating the health system
- Explore initiatives designed to address the problems
- Make recommendations based on consumer feedback

## Project Scope

The G21-Geelong Region Alliance is the formal alliance of Local Government business and community organizations working together to improve the lives of people within the Geelong region. Consumer, local service information and recommendations were confined to the G21-Geelong Region Alliance area, which includes the Borough of Queenscliff, City of Greater Geelong, Colac Otway Shire, Golden Plains Shire and Surfcoast Shire.

Consumers from a range of socioeconomic backgrounds were surveyed.

## Methodology

A literature review was conducted via the internet and information was clarified by consulting with key personnel within the Barwon Medicare Local and G21-Geelong Region Alliance.

Retired male and females from a business, professional or otherwise accomplished background were asked their views about potentially being able to access an independent, trained volunteer to help consumers understand and clarify the information they are given at their appointments. Medical Professionals (GPs and Specialists) and stakeholders (senior health service staff) were also asked their views.

It was explained that the volunteer, should they wish to use them would enable, facilitate, encourage and support the individual to ask questions and comprehend the information provided and assist the patient to explore the context.

It would not include:

- Advocacy
- Taking the place of a family member
- Making decisions for the person
- Helping them to complete forms or other functions.

Survey questions included:

1. Would you use the services of a trained, independent volunteer to support you in medical consultations by helping you to understand and clarify what the doctor says?
2. If yes, what types of appointments might you like someone to attend with you – tick all that apply
  - GP
  - Private Specialist
  - Meetings with doctors while in hospital
  - Out-patients appointments
3. Apart from having someone else helping to understand and clarify health information, are there any other ways you would like to be supported in your medical appointments?
4. What sort of person do you think would be best suited for the role of volunteer? Are there any particular personal qualities, skills or training that you think the volunteer should have?
5. What, if any, concerns would you have about this project?

Consumers within the G21-Geelong Region Alliance area, over the age of 50 and from varying socio-economic backgrounds were surveyed or interviewed as a group and the results were uploaded to an electronic survey. Survey questions were:

1. 'Do you find anything difficult about navigating the health system'?
2. 'If you do, what do you think would help'?

Those who required clarity were told that we were interested in how they find accessing, using and understanding of the services they require for their health needs. Survey results were then collated and grouped into themes.

Local information was gathered from key personnel from Diversitat (Geelong Ethnic Communities Council), Wintringham Specialist Aged Care, Glastonbury CALD Counselling and Support service and the Barwon Medicare Local, using the two interview questions:

1. Do you find anything difficult about navigating the health system'?
2. 'If you do, what do you think would help'?

Information about local initiatives were gained using interviews and organization web sites, such as the plans and projects of the Barwon Medicare Local, G21-Geelong Region Alliance, Barwon Health and Deakin University.

## Literature Review

### Fragmentation and Health System Design

According to the Australian Medicare Local Alliance, in Australia, high demand along with rising health care costs has placed pressure on a health system that is already fragmented. They cited an absence of system integration and coordination in both primary care and across the interface between primary and hospital care<sup>1</sup>.

All OECD countries face the challenge of ageing populations and increased chronic disease. While the health service works reasonably well for people with one off single health problems, services are fragmented for those needing ongoing care for complex and chronic conditions. There are a bewildering and confusing number of funding streams and programs with their own eligibility criteria and access barriers and duplication and gaps is the norm. In addition, there are many public, private and non-government health care services providing only some of what a consumer requires and lacking effective linkages to other care options. Transparent referral systems and coordination between government, non- government and private sectors are the exception rather than the norm<sup>2</sup>.

In 2006, a systematic review funded by the Australian Primary Health Care Research Institute focused on coordination of care *within* Primary Health Care and *between* Primary Health Care and other health related services. As the population ages and rates of chronic diseases (and in particular co-morbidities) grow, more and more people receive complex regimes of care from a range of different health service providers, with often intermittent hospital and specialist care along with ongoing care in the community.

Coordination is made more problematic by the boundaries and restrictions that exist within health services. Care is often provided by people with a different professional background who are working in the private or public sectors and are often part of health services that are accountable to different levels of government.

Increasing specialization may bring benefits in the form of more effective care for specific problems, but it creates a matching need for effective coordination so that people with complex care needs receive care that is comprehensive and continuous and allows them to self-manage effectively<sup>3</sup>.

## Health Literacy

Health literacy can be broadly defined as a person's ability to seek, understand and use health information<sup>4</sup>.

The Australian Commission on Safety and Quality in Health Care defines Individual health literacy as *'the knowledge, motivation and competencies of a consumer to access, understand, appraise and apply health information to make effective decisions about health and health care and take appropriate action.'*

**Individual health literacy** covers a range of skills, behaviours and activities such as knowledge of what foods are required for healthy eating, the motivation to participate in a cardiac rehabilitation support group and competency in making an appointment.

Individual health literacy is influenced by personal, social, cultural and environmental context and also by the specific aim or task that the person has within the health system or their everyday life. Individual health literacy is also not static; it can fluctuate depending on situational issues such as illness, stress or where the consumer is in their life course. Low individual health literacy means that people are not able to effectively exercise their choice or voice when making health care decisions.

The **health literacy environment** is defined as: *the infrastructure, policies, processes, materials and relationships that exist within the health system that make it easier or more difficult for consumers to navigate, understand and use health information and services to make effective decisions about health and health care and take appropriate action.*

The health literacy environment includes systems, policies, procedures and protocols at local, regional, jurisdictional and national levels that cover issues such as design and layout of hospitals, support groups and education for consumers. It also includes the communication processes and relationships between consumers and healthcare providers. For example the use of shared decision-making processes, the way in which healthcare providers tailor information they provide during a consultation to the needs of an individual consumer, or check that this information has been understood<sup>5</sup>.

## Levels of health literacy

According to the Australian Bureau of Statistics, in 2006 59% of all Australians had less than adequate health literacy, with levels increasing from 15 up to 39 years then decreasing for those over 40 years. The levels were similar across sexes and broadly throughout Australia. Health Literacy is improved for people from a higher socioeconomic group, those who participated in different types of groups or organisations, employed people, those in cities and where a parent achieved higher levels of educational attainment. People who were born in English speaking countries had similar levels of health literacy as those born in Australia, while those born in a mainly non English speaking country scored much lower <sup>6</sup>.

## Health literacy in the Barwon region

Health literacy was identified as a priority by the Barwon Medicare Local and supported by the Comprehensive Needs Assessment Advisory Group, early year's primary care providers, community service providers and Clinicians Advisory Group. In addition it was identified during community consultations. Both individual health literacy and the health literacy environment were identified as gaps. Service providers generally identified 'Individual Health Literacy', while consumers participating in the community consultations particularly those conducted by the Multiple Sclerosis Society and Diversitat, identified that the 'Health Literacy Environment' was what impacted their access to timely information and services<sup>7</sup>.

### **Health literacy and refugee populations**

Literature consistently recognizes that low health literacy results in significant barriers to better health outcomes, as well as to accessing timely and appropriate services by older people and people from a Culturally and Linguistically Diverse (CALD) backgrounds.

Locating health information in Australia in languages other than English is a challenge. The significant language and health literacy difficulties faced by immigrant populations are further exacerbated by cultural barriers and economic challenges to accessing health services and once accessed, people from CALD backgrounds then need to make sense of relevant health information<sup>8</sup>.

According to a spokesperson from Diversitat (Geelong Ethnic Communities Council) many people from a CALD/refugee background feel overwhelmed by the complexity of the health system particularly the relationship between the GP and the Specialist. Often people are unsure of the process and why they can't directly access the specialist and do not understand why they have to see the GP first. They can be confused by the term Emergency Department. For example, when they arrive and sometimes wait up to several hours, they may be examined and sent home. If an interpreter was not used, they are not clear of the diagnosis and the treatment if any. They describe feeling disempowered and alienated from the system. Some interpret not being seen in order of arrival at the Emergency Department as racist if they are not familiar with the triaging system.

Glastonbury CALD Counselling and Support service pointed out that, although most of their client group are not over 50, in their experience people are completely unfamiliar with the health system, even though most attend information sessions on arrival. Most struggle with understanding the role of different medical professionals and what to expect from them. There is confusion about when they should call an Ambulance and in general how to get to medical sites. Some people (such as asylum seekers) can only access specific clinics and do not have freedom to choose their own GP. Specific approval can be required to access torture and trauma counselling. Use of interpreters can make things even more complicated and there have been instances where a person underwent an operation and did not know the kind of

operation or why it was performed. In addition to access, there are issues of quality care and informed decision making.

## **Homelessness**

Wintringham Aged Care is a not for profit organization which offers a range of services including housing to older people over 50 years of age who are disadvantaged, homeless or threatened with homelessness. A spokesperson identified that many consumers struggled with where to go and to whom, transport and confidence in making appointments. Many did not access health care at all. Many have been homeless for years which has had a detrimental impact on their health. Some have been drug and alcohol users and most have been without any support systems whatsoever.

## **A General Practitioner Perspective**

According to Dr Jane Opie, Medical Advisor at the Barwon Medicare Local, barriers and difficulties that patients experience can include:

- Poor parking
- Poor public transport
- Mental health issues in particular anxiety disorders
- Street safety concerns
- Personal mobility issues
- Financial access barriers (especially dentistry)
- Long waits for lower cost services
- Access to child care when a patient needs a service
- Mal-distribution of healthcare providers e.g. fewer in low socioeconomic and rural and remote areas
- Complicated bureaucratic agencies, processes and red-tape.

Dr Opie states that 'there can be more emphasis on the needs of the service or the healthcare provider compared with the needs of the consumer, for example access to care outside normal business hours.'

Dr Opie points out that low health literacy could also be considered to apply to GPs who are new to a region who themselves have a big learning curve regarding navigating the services available within their local community.

## **G21 - Geelong Region Alliance**

Geelong Region Alliance (G21) is the formal alliance of government, business and community organizations working together to improve the lives of people within the Geelong region. According to the G21 Region Profile, October 2014, 'The socio-economic profile of the G21 region is polarised, with the highest levels of socio-economic disadvantage generally located in Colac Otway and in parts of Greater Geelong while Surf Coast and Queenscliff have very low

levels of socio-economic disadvantage according to a range of indicators such as income, education levels and the SEIFA IRSD scores.’ Within some Local Government Areas the profile can vary and poor health outcomes and behaviors are not limited to those parts that have high levels of socio-economic disadvantage<sup>9</sup>.

## **Survey Results**

### **Proposed Access to an Independent Volunteer**

Consumers, medical professionals and stakeholders were asked about the concept of consumers being able to access an independent, trained volunteer to help them understand and clarify the information they are given at their appointments.

#### **Consumer Survey**

There were 61 respondents, made up of males and females from a business, professional or otherwise accomplished background. While 70% said they would not use a volunteer, many said that they use family and friends to accompany them to appointments and may do so in the future if this was not available.

For those who would use a volunteer, 70% of people would use them for hospital or specialists.

Other ways that they would like assistance included transport and parking (30%), support during appointments and filling out forms, coordination and advocacy.

The type of person they felt would be suited to a role of volunteer included someone with a nursing or medical background (37%) or someone who is caring, understanding, empathic, mature, confident, well dressed and well educated. One respondent suggested that a person, similar to a trained General Practice Nurse would be suited to working across the health system.

Of the concerns about a volunteer in this role, 30% expressed concerns about their privacy and confidentiality, while others felt that the program would be too complex to run and govern. Some felt that it was the responsibility of the hospital to better educate doctors in communication and expand the social welfare team. (Appendix I)

Discussion with this group indicated that most were well connected to a regular GP and many people referred to having private health insurance.

#### **Medical Professional Survey**

Eight medical professionals were asked if they would value an independent volunteer to support people over 65 in consultations by helping them to understand and clarify health information. 87% said yes but they also suggested that support is required for transport, helping to liaise with family and other services, appointment reminders and making up a list of questions ahead of time.

The medical professionals felt that the person best suited to the role would be calm, mature, health literate, compassionate, organized and have common sense and good communication and listening skills.

Their concerns included the difficulties governing a volunteer program, privacy and confidentiality and increased time needed in consultations. (Appendix II)

### **Stakeholder Survey**

Three stakeholders, with extensive health industry experience who occupy senior positions in local health services, were asked if they agree with the volunteer concept and all said yes. They felt that other roles could include transport, communication with family and providing a written record for both clinician and patient. The qualities of the volunteers included being able to maintain boundaries, listening skills, health literacy, confidentiality and flexibility. Concerns about the program included governance, increased time in consultations and confidentiality. (Appendix III)

### **Difficulty Navigating the Health System**

Fourteen people over the age of 50 from a disadvantaged background who had experienced homelessness and isolation were asked: **'Do you find anything difficult about navigating the health system?'**

Two said no. One person commented: 'I went in as an emergency and everyone was waiting for me as the GP had alerted them. My GP explains things very well to me and I have a good relationship with him.'

Twelve people said yes. Some people relied on a support/case worker while others said they felt confused, did not understand the health system and felt that it was uncoordinated, disjointed and hard to navigate.

One person commented, 'For those with family support it is easy, for those without like me, it is hard. I know someone who hasn't seen a doctor for 50 years but has cancer.'

Comments included not knowing what to do if you are unhappy with the treatment, are depressed, cannot read or write, are unable to make appointments and understand medications or explanations/instructions. A man in his nineties experienced language barriers.

The same people were asked **'If you do, what do you think would help?'**

Suggestions included transport, assistance making appointments, help with the cost, advocacy and support, guidance through the services, assistance to interpret care plans and home visiting.

One person commented, 'I think more pension money would help so I could catch a taxi to my appointments. I would also like to see the doctor more regularly so I hope they don't start charging me \$7 every time I want to see him. Some of the folks at the nursing home have access to doctors there, but I am still at home and not many doctors do home visits anymore, so I would like a home visiting service.' (Appendix IV)

Forty people over the age of 50, where were not from a **disadvantaged** background were asked:

**Do you find anything difficult about navigating the health system?’**

Sixty five percent said no, but some said that their family assists them, while one person said they were able to understand as the doctor was great and had known them a long time. Five people said that they were ok at present but might have difficulties in the future while two said they understood as they were from a medical background.

**‘If you do, what do you think would help’?**

Comments included assistance with transport and parking, cost and understanding forms or written information. Some felt there was not enough time in the consultation to consider options while others could not understand the medical terminology. (Appendix V)

## **What is being done?**

### **Integrating Care**

Integrated health care has been a focus of national health reform in Australia and internationally. In Australia, this has culminated in the National Health Reform Agreement (NHR Agreement; August 2011) to deliver reforms to the organization, funding and delivery of health and aged care. Over successive health reform agreements since the National Healthcare Agreement of 2008, there has been a concerted effort to promote integration at the high level between governments. The NHR Agreement sets out the shared intention of Commonwealth, State and Territory governments to work in partnership to improve health outcomes for Australians and ensure the sustainability of the Australian health system. More recently, the Commonwealth has worked closely with states and territories and primary health care (PHC) stakeholders to develop a National Primary Health Care Strategic Framework (Standing Council on Health, 2013)<sup>10</sup>.

### **Care Coordination**

Care coordination solutions should include initiatives at all levels, from the consumer to the health service organization, while the initiatives themselves should be linked to one another. Policy and service development must take account of the realities of service provision which in turn needs appropriate policies and organizational structures to support it. In Australia the

National and State/Territory Governments all have policies relating to integration and coordination of care. In Victoria organizations with a clear aim of improving integration and coordination of care include the former Divisions of General Practice, Medicare Local programs and the Primary Care Partnerships.

Strategies for specific health issues include the National Chronic Disease Strategy and the National Mental Health Strategy. Funding initiatives to support more comprehensive and coordinated care include the Medicare Benefits Schedule items for chronic disease management<sup>11</sup>.

According to Dr Jane Opie, Medical Advisor at the Barwon Medicare Local, single point of entry models can be useful, however they can also present a barrier if the triage person determines that the patient does not fit the criteria. If the decision is made that the patient does not meet the criteria, the GP is faced with having to navigate around a roadblock to get the patient linked with the appropriate service.

Dr Opie believes that one of the best advocates to assist health literacy is a well-informed GP and developing a relationship with a GP who can advocate on a patient's behalf is important. When patients utilize the services of more than one general practice regularly, the medical record becomes fragmented, incomplete and duplication is more likely, for example pathology-testing. This can also mean that the hospital network may forward the appropriate discharge information to the incorrect GP, further impacting good patient care and continuity of care. There may also be the risk of a "dilution of responsibility" if the treating GP knows that they are not responsible for total patient care.

Dr Opie also points out that, 'in addition to the complicating factor of lack of care co-ordination, communication-sharing, duplication and fragmentation is worsened in Australia by the lack of a 'medical home' – i.e. not every consumer is linked in with a specific GP practice. Fee for service funding models are partly to blame for this compared with a focus on outcomes-funding at a local community population health level.'

The Patient Centered 'Medical Home' is a model for health care where people have an ongoing relationship with their GP and their general practice team. Practice nurses work as care managers to help people navigate the health system, and make sure they receive allied health services as required. The medical home coordinates the care delivered by all members of a person's care team, which may sometimes include hospital inpatient care. The medical home ensures that each person experiences integrated (joined-up) health care<sup>12</sup>.

Governments around the world, including Australia are looking at new models of primary care to keep their populations healthy and contain rising health care costs. It is in this context that the Federal Government is exploring the potential of the "patient-centered medical home" model of primary care to strengthen the role of GPs in the health system and deliver better outcomes for patients by encouraging continuous and coordinated care. Governments are consulting with major health groups such as the Australian Medical Association (AMA) and the

Royal Australian College of General Practitioners (RACGP). A survey of AMA members found that nearly three quarters of members supported the 'medical home' provided that linkages are voluntary and reversible and that the doctor maintains a 'fee for service' model. More than half felt that they could better manage patients with chronic and complex illness where there is a defined population, however there was strong opposition to compulsory membership. Other concerns included a lack of financial commitment to general practice and concerns that the 'medical home' may create more bureaucracy and capped funding<sup>13</sup>.

## **Health Literacy**

Health literacy can be addressed at all levels. For example healthcare organizations can work with consumers to make sure that the information they provide is easy to understand. Local health service provider, Barwon Health is committed to consumer participation in the planning, delivery and evaluation of its health services. Consumers can respond to invitations to provide feedback, participate in committees, consultations and focus groups and raise issues from a consumer perspective<sup>14</sup>.

Embedding health literacy into systems at a high level will encourage awareness and action on health literacy in the designing and planning of services. Healthcare providers can also use a range of communication strategies to ensure patients understand their options and share in healthcare decisions. Consumer organizations can support consumers to raise awareness where information or services are hard to understand while consumers themselves can speak up, asking for help and support where needed<sup>15</sup>.

The **Barwon Medicare Local** sought to influence the health literacy environment by developing and promoting a number of initiatives. These include Health Pathways, a central source of information for GPs and other primary health care providers providing specific information on assessment, management and local referral options for clinician use during consultation. Online Navigation Tools were set up to enable consumers and referrers to locate the correct service provider to meet their needs. Referral Net was another initiative to provide a secure audited messaging system between healthcare practitioners, Geelong wide, for the transfer of clinical and patient information. The personally controlled eHealth Record (PCEHR), a secure online summary of an individual's health information was also supported and promoted. The Closing the Gap program will assist in the aim to increase the uptake of mainstream health services for Aboriginal and Torres Strait Islanders by way of Cultural Education to increase cultural safety within these services, to better address health needs<sup>16</sup>.

**The Ophelia project** is a three year Deakin University, Victorian Department of Health and Monash University project that will identify and test new interventions to address health literacy needs in people attending a broad range of Victorian agencies, by improving health outcomes and reducing health inequalities. The Ophelia process will provide organizations with a structured approach to recognize, understand and respond to the health literacy needs of members of their community. They will use a co-creation approach where a wide range of patients, practitioners and policy makers work together to develop health literacy

interventions. Principles include a focus on outcomes, equity, local data and sustainability. The project is now in the second phase where interventions have been co-developed with agencies that will then be evaluated and the results published<sup>17</sup>.

The Geelong Region Alliance (G21) has named addressing disadvantage as a priority project and has engaged local communities in developing plans. Partnerships have been formed and some of the aims include promoting increased physical activity, lifelong learning and social inclusion, linking labor supply and demand and supporting local economic growth. Other projects focus on addressing nutrition, obesity, lack of exercise, smoking and misuse of alcohol and drugs.

The **G21-Geelong Region Alliance Early Intervention and Integrated Care Plan** will seek to enhance early intervention and integrated care and consumer and community empowerment. The planned approach will form a comprehensive strategic regional platform for action across the primary care continuum from prevention to integrated care. During the consultation process, the following issues were identified as key issues and gaps: Access to affordable and culturally sensitive services, transport, IT and tele health, health literacy, access to health and service information, lack of consistent quality of services, early intervention, outreach and flexibility of service models and General Practice knowledge of available services<sup>18</sup>.

## Conclusion and Recommendations

Survey results showed that many people from a skilled and educated background relied on family or friends to assist them to navigate the health system. This group were generally not in favor of having a volunteer to assist them in appointments but some were concerned that, if their health deteriorates, they may not always be able to access family support and therefore may consider using a volunteer if available. Issues of concern included that the service be well governed and their privacy protected. Transport to and from appointments was also a concern for them. It is likely that most of this group were well connected to a regular GP and have private health insurance, which was referred to during discussions and in survey comments.

Most of the medical professionals and senior health service staff were in favor of having a volunteer assist people, but shared concerns about privacy and confidentiality as well as the difficulty of governing the program. They felt that transport was also an issue for patients.

Results suggested that consumers over 50 who were from a disadvantaged background and had experienced homelessness had great difficulty navigating the health system. Many were fully reliant on case workers to assist them with making appointments, transport and providing support during the consultation. Many people did not know when, where or how to access the right care and were also concerned about transport to and from appointments. Most people surveyed had not been well connected to a regular GP, however a partnership arrangement with a local GP has resulted in improved coordination of health services and better health outcomes.

Again, most people who were *not* from a disadvantaged background, when asked if they had difficulty navigating the health system said they did not, but many relied on family to support them and had a range of concerns, including transport to and from appointments.

The service system navigation issues for people from a CALD background centered on a lack of understanding of the health system leading to problems participating in their health decisions and care. Recommendations include greater cultural awareness for all front line health care staff and the consistent and appropriate use of qualified interpreters.

Governments at all levels are concerned with health system fragmentation and health literacy in the context of an ageing population and rising health care costs, and there are numerous programs designed to address this. Transparency and coordination between government, non-government and private sector services is needed. It is recommended that any initiatives be evidence based and localized to ensure they benefit those with the poorest health literacy.

Broader funding models and structures should be addressed. One of these, the 'patient centered medical home' appears to have some support and promotes a strong connection with one general practice. The survey results also emphasized the need for people to have a strong connection with a regular GP to provide care and coordination.

Older people, regardless of their background, were concerned with having support during health consultations, preferably from family or friends. Any scheme that provides support for those who don't have family or friends should be localized, well governed and evaluated.

Transport was a concern for many people, regardless of their background and should be addressed locally to ensure that people can attend appointments. Overall, recommendations for the most disadvantaged include increased access to skilled case workers, assistance with transport and support to form and maintain a strong relationship with a local GP. Case work should include facilitating relationships with care providers while promoting self-reliance where possible.

A respondent captured the importance of good care coordination when he said: *'I went into hospital as an emergency and everyone was waiting for me as the GP had alerted them. My GP explains things very well to me and I have a good relationship with him.'* Another said: *'I do not have an issue with the system, I have doctors that I have been a patient of for a long time who know me well and they are great at explaining things.'*

Thank you to all of the people who provided information for this report.

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## Appendix I - Consumer Survey Results

### Respondent characteristics:

Sixty one retired male and females from a business, professional or accomplished background who were asked their views about potentially being able to access an independent, trained volunteer to help consumers understand and clarify the information they are given at their appointments.

For most questions, respondents were able to select multiple options or use free text.

### 1. 'Would you use the services of a trained, independent volunteer to support you in medical consultations by helping you to understand and clarify what the doctor says?'

Yes – 18

No – 43

Some respondents felt that they didn't need anyone now but may do in the future: 'At the moment I have a spouse. My answers take into account that this could change and I will then be on my own.' 'My attitude may alter if my health failed suddenly.'

### 2. 'If yes, what types of appointments might you like someone to attend with you?'

Meetings with doctors while in hospital - 23

Specialist appointments - 21

Outpatient appointments - 15

GP appointments - 11.

### 3. 'Apart from having someone else helping to understand and clarify health information, are there any other ways you would like to be supported in your medical appointments?'

Transport to and from appointments – 5

Support during the appointment – 3

Discussion after the consultation to give time to consider options - 2

Car Parking – 1

Support filling in forms – 1

A brief written report of the consultation – 1

Coordination of care – 1

Advocacy – 1

Respondents also suggested:

'I think some patients who don't have a support person/carer might need someone who can co-ordinate and perhaps advocate for the patient. I don't feel doctors and health services inform patients of services currently available. One doesn't always know the questions to ask.'

'I feel that it would help to have someone with a patient in hospital while the doctor's visit. The carer is not always there as they visit at all times.'

'As a private patient we choose our doctors because they communicate. In an Emergency Department, this service would be excellent particularly when you don't have private health insurance and have so many long periods without explanations.'

'Sometimes when consulting a doctor you only hear what you want to hear. Another person would certainly help clarify points that were missed. I feel it is a project worth pursuing.'

#### **4. 'What sort of person do you think would be best suited for the role of volunteer? Is there any particular personal qualities, skills or training that you think the volunteer should have?'**

Person with nursing or medical background, or a retired doctor or nurse – 25

Caring/ understanding/ patient/empathy/compassion/common sense – 14

Professional/mature/well educated/confident – 7

Clear thinker – 3

Good communicator – 3

Listening skills – 3

Trained person – 3

Knowledge of the health system – 2

Able to maintain confidentiality – 2

Good hygiene/well dressed - 2

Qualified medical person only – 1

Mature - 1

One respondent suggested: 'A trained person working in a GP surgery, NOT a volunteer, like the nurses now attached to many surgeries'

#### **5. 'What, if any, concerns would you have about this project?'**

Privacy/confidentiality – 9

Concern about the complexity of running and governing a volunteer program – 9

Concern about the competency and reliability of the volunteer – 6

Availability of suitable volunteers – 5

Respondents commented:

'Where do you go to discuss results?'

'How you would make contact with a volunteer?'

'I would like to know if the same person would be able to attend ongoing appointments. The helper needs to meet the patient prior to the appointment in order to establish a rapport otherwise the patient has two strangers to deal with.'

'Adverse reaction from doctors.'

'Conversation between doctor and patient assumes a lot of information already dealt with. Ideally additional help would need to/want to access the patient's history'.

Some respondents felt that it was the responsibility of the hospital and doctors to communicate effectively:

'I wonder if the role is too narrow that it will be difficult to keep within the boundary by the volunteer and the patient. I would prefer to see doctors getting the training they need to be good communicators. There might be a need for a role such as this within hospitals - they can be confusing places. Hospitals should address this.'

'Better to expand social welfare team.'

## Appendix II - Medical Professional Survey Results

### Respondent Characteristics:

**Eight** medical professionals. For most questions, respondents were able to select multiple options or use free text.

### **1. Would you value having a trained, independent volunteer to support people over 65 in consultations with you, by helping them to understand and clarify health information?**

Yes – 7

No – 1

### **2. Apart from helping them to understand and clarify information, are there any other roles you could foresee the trained volunteer carrying out?**

Transport – 3

Helping patient communicate information to family – 2

Appointment reminders/what to bring/where it is – 2

Asking questions on their behalf – 1

Making a list of questions ahead of time – 1

Monitoring adherence to treatment – 1

Helping to chase up test results - 1

Liaising with family and other agencies – 1

### **3. What sort of person do you think would be best suited for the role of volunteer? Is there any particular personal qualities, skills or training that you think the volunteer should have?**

Mature/life experience – 4

Health literacy/understanding of health service models – 4

Communication skills – 3

Calm/patience/empathy – 3

Listening skills – 2

Compassion/common sense/organised - 2

Able to maintain confidentiality – 1

Police check – 1

Understand importance of patients maintaining their own independence – 1

Retired medical professional/case manager - 1

#### **4. What, if any, concerns would you have about the proposed program?**

Concern about boundaries and governing a volunteer program – 5

Privacy/confidentiality - 4

Increased time needed in consultation – 2

May lead to increase in over servicing – 1

Harder for clinicians to confront or deal with difficult issues -1

‘That the volunteer would be influenced by their own values, confidentiality, and there is a fine line between communicating information and being asked for advice which could happen after the consult is finished.’

‘If volunteer starts giving patient advice about management or increases patient anxiety for some reason.’

‘Sometimes well-meaning "advocates" can overstep the role and become demanding’

‘In my experience as a specialist we are good at supporting older people and would always involve family members. In the absence of a family member you need a medical guardian or power of attorney.’

‘An evaluation would be necessary to see if it adds value or if any of risks materialize or compromise utility.’

‘Making sure training includes education about medical culture and support on how to engage constructively with health services and health professionals.’

## Appendix III - Stakeholder Survey Results

### Respondent Characteristics:

Three stakeholders, with extensive health industry experience who occupied **senior** positions in local health services were surveyed. For most questions, respondents were able to select multiple options or use free text.

#### **5. Do you agree with the concept that people over 65 have access to a trained, independent volunteer to help them understand and clarify health information when they attend medical appointments?**

Yes – 3

#### **6. Apart from helping them to understand and clarify information, are there any other roles you could foresee the trained volunteer carrying out?**

Transport – 2

Communication with family members – 1

Supporting staff and patient by making a written record for both - 1

#### **7. What sort of person do you think would be best suited for the role of volunteer? Is there any particular personal qualities, skills or training that you think the volunteer should have?**

Listening skills – 2

Maintain the boundaries/understand of the role – 2

Health literacy/understanding of health service models – 1

Communication skills – 1

Able to maintain confidentiality – 1

Flexible – 1

‘Not be a patient advocate who slows down the consultation but able to interrupt for clarification.’

#### **8. ‘What, if any, concerns would you have about the proposed program?’**

Concern about the complexity of running and governing a program – 2

Increased time needed in consultation – 2

Privacy/confidentiality - 1

Harder for clinicians to confront or deal with difficult issues -1

Concern about the competency and reliability of the volunteer – 1

Concern about boundaries and governing a volunteer program – 1

'Older people may not want a "stranger" volunteer to know about their personal medical history/conditions.'

'A risk that the volunteer may misinterpret what the GP or specialist has said and then pass on that misinterpretation.'

'The volunteer may require additional GP time in order to fully understand what the client's medical condition is and then who pays for the additional GP time with the volunteer?'

'Legal issues such as who is responsible if confusion occurs and connected insurance issues.'

'Monitoring the volunteer's effectiveness and stress levels.'

## **Appendix IV – Disadvantaged Consumer Survey Results**

### **Respondent characteristics:**

**Fourteen** people over the age of 50 from a **disadvantaged** background who had experienced **homelessness and isolation**.

### **1. ‘Do you find anything difficult about navigating the health system?’**

#### **No – 2**

Comments included:

‘I went in as an emergency and everyone was waiting for me as the GP had alerted them. My GP explains things very well to me and I have a good relationship with him.’

‘I am ok with sorting things out for myself.’

#### **Yes – 12**

Comments included:

‘Sometimes. I like to do things on my own but sometimes I need help’.

‘I wouldn’t know where to start I rely on my support people.’

‘I have a worker that sorts out all my appointments for me without her I would be completely confused.’

‘I have been very isolated from health services which was a huge problem. Understanding Medicare and private health care is confusing.’

‘For those with family support it is easy, for those without like me, it is hard. I know someone who hasn’t seen a doctor for 50 years but has cancer.’

‘Coordination of different health services doesn’t always make sense, it is disjointed. The individual needs skills and or support to help navigate the system. Just getting to appointments can be difficult and expensive. Making sense of what the appointment is about, understanding treatments care plans and medications is difficult for the disadvantaged.’

‘I find the health system difficult to navigate. I wish that my Apia insurance would provide guidance to an oldie like myself, but unfortunately they don’t.’

### **2. ‘If you do, what do you think would help?’**

Comments included:

‘Language is a barrier for me, I am from Sri Lanka & I am in my 90's, English is my 2nd language I haven’t got any family support and I couldn’t manage on my own. My support person helps me.’

'My support worker helped me when I needed help with a particular health issue recently. There was a barrier for me in understanding and accessing the services and where to go from here. I wasn't happy with the treatment I was receiving and I didn't know what to do.'

'It would be nice to have help, I didn't know where to go when I was depressed and someone helped me with a counselling service which was great for me, but I wouldn't have known how to find this on my own.'

'What does help is someone there for me, I can't read or write so someone fills in the forms for me and makes appointments and takes me there.'

'My support worker helps me, she does everything for me, makes appointments, sorts out medication.'

'I would like help with transport as getting to the GP is expensive and difficult.'

'Somebody to help interpret my care plan would be good as doctors don't have long enough to do this.'

'Someone to guide you through the services would be great so that everyone is working to the same work plan.'

'Transport, advocacy support and guidance to help make appointments.'

'I think more pension money would help so I could catch a taxi to my appointments. I would also like to see the doctor more regularly so I hope they don't start charging me \$7 every time I want to see him. Some of the folks at the nursing home have access to doctors there, but I am still at home and not many doctors do home visits anymore, so I would like a home visiting service.'

## Appendix V – Advantaged Consumer Survey Results

### Respondent Characteristics:

Forty people over the age of 50 **NOT** from a **disadvantaged** background.

### 1. Do you find anything difficult about navigating the health system?'

#### No – 26

Comments included:

'I do not have an issue with the system, I have doctors that I have been a patient of for a long time who know me well and they are great at explaining things.'

'No, my wife does the navigating.'

'I have family that helps me with this.'

'Luckily I am in good health and do not have to try to navigate the system.'

'Mostly OK, as I get older maybe I will require assistance.'

'No problems yet.'

'No not at this stage'.

'No worries at this stage.'

'I have a medical background so I understand the system.'

'No, my background is nursing, therefore I am at ease with doctors.'

'It can be confusing but I can manage.'

'No I don't really understand the health system as I haven't had to bother with it'.

#### Yes – 14

Transport – 4

Parking – 2

Comments included:

'Difficulty understanding forms.'

'Unable to understand all of the information.'

'Meet and pick up from residence and return home, enable more discussion, follow up AFTER time to consider.'

'Transport to and support in facility.'

'A handout re the illness and a brief written report of matter discussed.'

'Only getting a park that is for enough time.'

'Sometimes, with specialist.'

'Yes, at an advanced age in later years.'

### 2. 'If you do, what do you think would help'?

Transport – 4

Comments included:

'Someone to assist with transport as I cannot rely on taxis'

Parking – 2

Comments included:

Freer and cheaper parking in hospital precincts. As a patient attending for appointments doctors and specialists are often running late. Meters in restricted time zones is an additional concern. Furthermore, for most in patient visitors are a part of the recovery process, but from a visitors point of view finding parking, the potential visitor fines can affect the potential visitors decision on whether to visit or not.'

'More time in the consultation to discuss results etc.'

'Have the opportunity for follow up questions.'

'Easy to read written material.'

'For specialist to speak in 'normal' terms not high level medical jargon.'

'Don't always understand what the doctor says.'

'Helping me fill out forms.'

'I did, a few years ago take my mother in law to medical appointments as she had dementia, she really needed assistance.'