



# **Making Medicines Manageable: A culturally and linguistically diverse perspective**

**June 2011**

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**A research project funded by:  
The Helen Macpherson Smith Trust**

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Published by:

Helen Macpherson Smith Institute of Community Health  
Royal District Nursing Service  
Melbourne, Australia  
ABN 49 052 188 717

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ISBN: 978-0-9806380-6-6

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## Acknowledgements

The authors of this report would like to gratefully acknowledge the contribution from the following:

- The Helen Macpherson Smith Trust for its generous financial support of the study.
- The older people and family carers interviewed for their time and vital contribution to the study.
- Jaklina Michael, Manager – Diversity for her guidance, advice and commitment to this study. Jaklina’s contribution to the design of the study, the translation of documents, and contacts with CALD organisations was integral to the successful completion of this work.
- Tina Douvos, Lydia Chang, Qui Ma, Marina Rozic, Nirmala Abraham, Connie San Jose, Blaga Petrevska and Diana Sterjovska for their assistance with recruiting participants for this study.
- Kim Cross and Elizabeth Gibson for their assistance with the formatting and editing of this report.

## Project team

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## Executive summary

### **Background**

This report describes the thoughts and perceptions of older people and family carers of non-English speaking culturally and linguistically diverse (CALD) backgrounds in relation to managing medicines at home. The findings of this study have informed the development of a tool to assess self-management of medicines.<sup>1</sup>

### **Design**

Using a qualitative method, the research was undertaken using semi-structured interviews with twelve older people and ten family carers who do not speak English and who manage their own or a relative's medicines. Interviews aimed to deepen the understanding of the needs of people in maintaining independence with medicine management from the perspective of non-English speaking CALD older people and family members, and how they perceived current medicine management practices could be improved. This work was complementary to a larger study into medicine use in the community, which involved interviews and focus groups with older people, older people with dementia, family carers, nurses, pharmacists and general practitioners.

### **Results**

Medicine management among older people has been described as a journey with four distinct stages:

- Self-management of medicines.
- Something changes. Identified factors that contribute to the transition from self-management to needing more help.
- Family member advocacy and the carer role in relation to managing medicines.
- Locus of control and the medication team involved in managing medicines (While, Duane, Beanland & Koch, 2011)

### **Recommendations and implications for practice**

The findings of this study complement the journey of medication management described by While et al. (2011), showing that for non-English speaking CALD people this journey is longer and more complex than for the general older population.

Findings from this study include:

- Family members often assist in establishing relationships with a GP who can speak the older person's language.
- Having a GP who can speak an older person's language is the primary way of overcoming language barriers and obtaining medicine-related information.
- The individual's literacy level and their preference regarding the amount and format of information they wish to be given (for example, verbal or written) should be considered.
- There is a need for awareness and access to interpreters; and translated medicines information in a variety of formats.
- There is a need to include the people involved within the 'network' or 'team' supporting non-English speaking older people with their medicines; and promote their role and communication with other people in the support network.

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<sup>1</sup> The use of the terms 'medicine' and 'medication' reflect how these terms have been used in the document *Guiding principles for medication management in the community*, Australian Pharmaceutical Advisory Council (2006).



## Introduction

It has been found that over 80% of people aged over 60 are taking at least one prescribed medicine (Cohen, Rogers, Burke, & Beilin, 1998). Adverse drug events are a growing concern for individuals in the community, with the consequences of poor management of medicines ranging ‘...from feeling unwell, to permanent disability or death...’ (Stephenson & Dobson, 2008, p. 31). The elderly in particular are susceptible to adverse drug events, with this population accounting for more than 30% of hospital admissions (National Prescribing Service, 2009). The cost implications of medicine mismanagement have been estimated to be in excess of \$350 million (Australian Council for Safety and Quality in Healthcare, 2002).

The culturally and linguistically diverse (CALD) population in Australia is particularly vulnerable to medicine-related adverse events for reasons including: having English as a second language; inadequate use of interpreters; lower literacy levels; insufficient cultural competency among service providers; and socio-economic barriers limiting access to the health care system (Webster & Kaplan, 2003, as cited in Federation of Ethnic Communities' Councils of Australia, 2010).

The Royal District Nursing Service (RDNS) has an important role in facilitating medicine management in the community, with up to 58% of RDNS client care involving medicine management support. This equates to approximately one million visits per year. Driving this demand is the increasing number of older people now in RDNS care (almost 75% of clients are aged over 60 years). A recent audit of the RDNS database showed that 19% of clients who receive support with managing medicines speak English as a second language or speak no English at all.

Medication management has been described as a cycle that has several components. These components include: the decision to treat health concerns through prescribed medicine; maintaining a record of prescribed medicines; dispensing the medicine; providing medicine-related information; storage of medicines; medicines administration and monitoring of responses to medicines (Australian Pharmaceutical Advisory Council, 2005).

Community nurses assume a wide range of roles in relation to medicine management, with the key responsibility being assessment of the client's ability to self-medicate. The Australian Pharmaceutical Advisory Council (2006, p. 7) identified that ‘consumers should be encouraged to maintain their independence for as long as possible, including managing their medicine in a safe and effective way’. Where clients have been identified as experiencing problems in this task, the likely outcome for the client is that their medicines will be administered by the community nurse. However, it is unclear what parameters are used by individual nurses when assessing medicine self-management abilities and planning care for their clients.

The major issues from the perspective of providers of home nursing care to members of older people are the inconsistencies in the assessment of an older person's capacity to self-administer their medicines. Anecdotal evidence in this area suggests that assessment of a person's ability to self-administer medicines has focused on deficits and on what health care providers think that person requires. Medicine management interventions based on these assumptions have not been effective in improving client health outcomes. There is a need for a shift in focus to a strength-based and person-centred approach.

Approaches to care for older people and those with dementia in the community are currently undergoing a shift in focus. Nationally, the community health care sector is implementing models of care that are person-centred, goal-orientated and enabling; and involve working with clients to achieve greater independence and wellbeing. In Victoria, this approach is known as the Active Service Model (State of Victoria, 2008). This project has been developed to inform nursing practices that support safe and independent medicine management by non-English speaking CALD older people and carers living in the community.

## **What is medicine management?**

Successful medicine management is a multifaceted task requiring a person to possess both cognitive and physical abilities. For the purposes of this project, the working definition of medicine management that has evolved from the literature is as follows:

Medicine management should involve: safe and rational prescribing practices; communication and understanding of the person's medicine-taking beliefs and behaviours; understanding of their ability to obtain and self-administer the medicine; ensuring the person has sufficient knowledge of their medicine regime; and ensuring that interventions are implemented before the any harm from adverse medicine events or error can occur.

The consequences of poor medicine management include suboptimal symptom management or disease progression, an increase in the need for diagnostic investigations, an escalation of medicines being prescribed that lead to increased risks of adverse drug events, and hospital admission and readmission (Arlt, Lindner, Rosler, & von Renteln-Kruse, 2008).

## **Ageing, medicine and risk**

Research indicates that poor management of medicines occurs across the age span (Arlt, et al., 2008). However, the older adult is more likely to experience difficulties due to the fact that they are more susceptible to intercurrent health problems, are prescribed more medicines and are more at risk of adverse drug events (Arlt, et al., 2008; Marek & Antle, 2006).

The inability to take medicines as prescribed affects 40–45% of older adults (MacLaughlin, et al., 2005). There are numerous risk factors associated with ageing (such as sensory deficit, impairment of dexterity and coordination, cognitive impairment, and dementia, as well as conditions such as incontinence, dizziness, and falls) which occur either singularly, or more particularly, in combination that will influence self-management of medicine (Arlt, et al., 2008).

Unfortunately there is a double jeopardy associated with the presence of chronic illness and ageing. Not only do chronic conditions such as diabetes, heart failure and chronic obstructive airways disease have a negative impact on cognitive function, so do some of the drugs prescribed to treat these conditions. In turn the decreased cognitive functioning impairs the person's ability to self-medicate (Insel, Morrow, Brewer, & Figueredo, 2006).

There is conjecture in the literature about what determines the person's ability to safely self-manage their medicine. It is proposed that psychomotor and cognitive ability are the two key determinants that will affect the person's ability to maintain safety (Maddigan, Farris, Keating, Wiens, & Johnson, 2003). The cognitive capacity more specifically required for medicine management is the executive function that supports planning, organisation, initiation, perseveration, and regulation of a task to its completion. Psychomotor ability includes mobility and functional capacity, both of which can affect the person's access to medicine, and involves the ability to open packaging, administer medicine, use devices such as inhalers and eye droppers, and apply topical preparations correctly (Thwaites, 1999).

The community-dwelling older population face a number of challenges in managing medicines. In a 2002 Australian-based study, only 10.8% of participants were able to undertake all medicine management tasks successfully. Challenges identified by participants included: difficulty reading a dot point matrix label on a box or bottle (25.2%), difficulty hearing medicine-related instructions (3.6%), and difficulty using a dosette (11.7%) or blister pack (13.5%). There were also problems for participants in differentiating between green, lavender and blue colour tablets (28.8%) and swallowing medicine (31.5%) (Johnson, Griffiths, Piper, Langdon, & Stephens, 2002, pp. 54-55). Problems related to swallowing medicines are more likely to be encountered in people with cerebrovascular, motor-neurone or Parkinson's disease (Thwaites, 1999).

Physical problems may also encompass inability to open medicine containers or lids (Vik, Maxwell, & Hogan, 2003) as cited in (University of Queensland, 2004). Eye drop administration has been found to be problematic for people who have hand tremors or difficulty moving their head, raising their arms or squeezing the bottle (Winfield, Jessieman, Williams, & Esakowitz, 1990). The ability to use inhalers may also be difficult for up to 60% of people, particularly those with hemiplegia, rheumatoid arthritis and cognitive impairment (Teale, et al., 1995).

### **Culture, literacy and medicine management**

It is not only current models of care that need consideration when determining how to support people of non-English speaking CALD background in managing their medicine. It is essential that health professionals undertaking this service understand how the client's use of medicines may be affected by their health and cultural beliefs and background (Chia, Schlenk, & Dunbar-Jacob, 2006).

'Cultural variation can be seen in beliefs about disease etiology, appropriate treatments, proper self-care and preventative treatment, human physiology and appropriate doctor and patient conduct' (Shaw, Huebner, Armin, Orzech, & Vivian, 2008, p. 461). Past research has highlighted how cultural beliefs may impact on their medical treatment. In a publication through the Federation of Ethnic Communities' Councils of Australia (FECCA), Stephenson and Dobson reference work regarding Chinese, Vietnamese, Italian and Greek older people's medicine-taking beliefs and perceptions.

They suggested that the participants:

- had limited time to discuss medicine-related questions with their doctor
- did not know what questions to ask with regards to medicines
- believed it would be disrespectful to question their doctor regarding treatment
- did not view questioning their doctor about their medicines as being their responsibility
- stopped taking medicines when they felt their condition had improved, rather than when the course of medicines had been finished.
- shared medicine with family and friends
- doctor shopped
- became confused on occasion when multiple medicines were prescribed
- kept medicines they no longer needed
- did not inform health professionals about traditional medicines they were taking (Stephenson & Dobson, 2008).

While these findings refer to traditional medicines, Stephenson and Dobson do not clarify whether traditional medicines are, or include, complementary medicines.

Perhaps, though, the greatest influence on the CALD population's use of medicine is not culture, but that many may be illiterate. Literacy by definition is 'the ability to read and write' (Delbridge, et al., 1997, p. 1253). An individual who is illiterate may also be health illiterate, which means they may have difficulty in managing medicine for the following reasons: the complex nature of printed information regarding medicine, which requires a high-level reading skill to understand; and the insufficient time or verbal communication provided by health care professionals with regard to medicines (National Quality Forum, 2005, as cited in The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006).

Language barriers may restrict communication between the CALD client and their health care professional in other ways. Non-English speaking people have an increased likelihood of having difficulty ‘...understanding basic medical instructions, and adhering to medication regimens’ (Scott, 2003, as cited in The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006, p. 18). The non-English speaking population may also feel shame in clarifying concerns or asking for assistance with their medicines (Mayeaux, Murphy, Arnold et al, 1996, as cited in The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006).

Thus, there are multiple ways non-English speaking CALD people may be challenged in the management of their medicines. There is, however, little representation of the older person’s perspective in published research. This study aims to address this need through conducting research to explore further medicine-taking beliefs and behaviours among Australian ethnically diverse samples of older adults and family carers.

This project will explore how medicine is managed by non-English speaking older people and family carers of CALD background living in the community. The findings of this work will be used to inform strategies to support older people living in the community environment, including the assessment of medicine capacity, and to develop a standardised approach to this issue.

### **Research aim**

The aim of this study was to develop an understanding of the experiences of non-English speaking older people and family carers in managing their own or a relative’s medicines.

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## Approach

The primary focus of this study was to explore the perspective of ten older people and ten family carers of non-English speaking CALD people in relation to medicine management in the community. Conducting research with people who do not speak English required the approach of this study to be sensitive and flexible to the participants' needs. Specifically, the study required strategies to identify and recruit potential participants, and methods to enable communication of information pertaining to the study. Recruitment strategies needed to consider how participants were recruited, how the research team approached them, and how the team interacted with them. The communication of information related to the study required the translating of documents by professional translators, and working with professional interpreters during interviews, both of which will be discussed in detail later on.

The study specifically chose to recruit non-English speaking people. To identify the most common non-English speaking CALD populations being serviced by the organisation, an audit of the RDNS client database was completed. This audit identified that Greek, Italian, Chinese, Vietnamese, Macedonian and Croatian communities were among the most common cultural backgrounds of RDNS clients. As such, these nationalities were chosen to be the focus of the study. Before recruitment of participants into the study could occur, discussion with the RDNS Manager – Diversity identified that the documents pertaining to the study needed to be translated into the six languages. This work was undertaken as follows:

- Documents detailing the study were developed in English by the research team. These included: For Your Information (originally known as the Plain Language Statement, retitled at the request of the Manager – Diversity), Invitation to Participate, and Consent forms (see an example of each form in Appendix 5).
- The Manager – Diversity then requested that the documents be translated by ONCALL Interpreters and Translators from English into the targeted languages.
- Once the documents were translated, six ethnic service providers were formally asked to undertake a cultural and linguistic assessment of the translated documents to ensure they were appropriate for the intended audience. These ethno-specific agencies were: Australian Greek Welfare society, CO.AS.IT Italian Assistance Association, Chinese Community Social Services Centre Inc., Australian Vietnamese Women's Welfare Association, Macedonian Community Welfare Association, and the Australian Croatian Community Services. The assessment process was completed using the RDNS Translation Assessment Form.
- Once the assessment was completed, the findings were forwarded by ethnic service providers to the Manager – Diversity. In consultation with the research team, the Manager – Diversity organised for minor corrections to be made by ONCALL Interpreters and Translators based on the community feedback.
- The final documents were returned to the research team for distribution to participants and agencies assisting with recruitment.

## **Design**

### **Ethics**

Ethical approval for the study (project number 117) was provided by the Royal District Nursing Service Human Research Ethics Committee on 8th September 2010.

### **Inclusion criteria**

To be eligible to participate, the person had to be a non-English speaking person of CALD background who managed their own medicine, or a family carer who did not speak English who managed the medicines of another person. Older people had to be aged over 65 years; however, for carers there were no age restrictions.

## **Methods**

### **Recruitment and working with interpreters**

While documents were undergoing translation and checks for cultural appropriateness by ethno-specific agencies, the research team visited the same agencies to begin recruitment by explaining the aim of and inclusion criteria for the study. Once all documents were translated and checked, letters containing the translated information sheets (For Your Information and Invitation To Participate) were sent to the agencies. These letters requested that the translated documents be distributed to those clients who met inclusion criteria for the study.

Phone and email contact were made by the research team with the agencies approximately one month after letters were mailed. The purpose of this contact was to prompt the agencies to supply the name, address and contact details of anyone who met the inclusion criteria and expressed interest in participating. The research team contacted people interested in participating via phone interpreter. As mentioned previously, the study aimed to recruit ten older people and ten carers. An account was arranged for the study with the interpreter service (ONCALL Interpreters and Translators) prior to contacting participants.

Contacting participants through working with an interpreter involved the following process:

- The participant was phoned to check they were home.
- Once it was ascertained they were at home, the participant was advised they would be contacted within five minutes by an interpreter.
- ONCALL Interpreters and Translators agency were then contacted and the study PIN quoted. The participant's details (name, language and phone number) were given to the agency.
- The operator arranged a three-way telephone phone call with the participant, interpreter and researcher. The phone call was used to confirm interest in participating in the study and to arrange a time for the interview to be conducted.
- Another phone call was then made by the research team to ONCALL Interpreters and Translators to book an on-site interpreter for the interview.

This process took approximately half an hour for each participant.

An on-site interpreter was present at each interview. Interpreters were required to sign a Declaration of Confidentiality by Interpreters of Data document (see Appendix 4). At the end of each interview a service confirmation form was completed, with the original of the form given to the researcher, and a carbon copy kept by the interpreter. It should be noted that the researcher undertaking the interviews had been trained in working with interpreters and had several years' experience working with interpreters prior to the study.

### **Data collection**

Interviews were conducted with non-English speaking older people and family carers from CALD backgrounds. Interviews were approximately 45–60 minutes in length and were conducted at the participant's home at a time convenient to them. Time was spent with each participant building rapport, undertaking the consent process and conducting the interview itself. Data were collected using semi-structured interviews as this approach allowed the participant '...to respond in their own words, provide as much detail as they like, and offer illustrations and explanations' (Polit & Tatano Beck, 2008, p. 394). Participants were asked about how they manage medicines, and what helps or challenges this process (see Appendixes 2 and 3). These themes were explored using the approach by Kretzmann and McKnight (1993, p. 6), which focuses on the capacities of a people, particularly those who may be marginalised, rather than focusing on deficits. Participants were given a gift card at the completion of the interview, to thank them for their involvement in the study. Participants were also offered reimbursement for out-of-pocket expenses incurred as a result of their involvement in the study. No participant requested reimbursement for their participation; however, several expressed immense gratitude upon receiving the gift card.

### **Data analysis**

With the participants' consent, interviews were audio recorded and later transcribed for analysis. Only the dialogue in English, that is, the narrative of the researcher and the interpreter, was transcribed. This work was performed by an experienced transcribing company. A constant comparative method of thematic data analysis as described by Guba & Lincoln (1989) was used to explicate issues as it allowed development of theoretical understandings of the participants' views on each topic. To enhance the validity and reliability of the analysis, transcripts were provided to research team members, and critical analysis was undertaken via team discussion. Team meetings were used to validate the themes emerging during data analysis. Data analysis was also supported through the researcher reflecting on participant responses after each interview. These reflections informed subsequent interviews. The QSR NVivo8 computer program was used in the management of data. Transcriptions have been stored in a secure, password-protected Word file.

## Results

This chapter will present the results from interviews with older non-English speaking people who manage their own medicine, and with family carers who do not speak English and manage medicines for another person. Overall, the findings deepened the understandings of the thoughts and perceptions of these people in relation to medicine management in the community.

### Participants

In total, twenty-two people were recruited and interviewed: twelve older non-English speaking people who manage their own medicine, and ten family carers who do not speak English and manage the medicines of another person. A higher than anticipated number of older people expressed an interest in participating and, as a result of this, the projected number of participants was exceeded. The breakdown of participants by cultural background, and for family carers by their care relationship, has been tabulated (see Tables 1 and 2).

*Table 1: Older people who manage their own medicine*

| Older person number | Ethnic background |
|---------------------|-------------------|
| One                 | Croatian          |
| Two                 | Croatian          |
| Three               | Croatian          |
| Four                | Chinese           |
| Five                | Chinese           |
| Six                 | Greek             |
| Seven               | Vietnamese        |
| Eight               | Greek             |
| Nine                | Macedonian        |
| Ten                 | Macedonian        |
| Eleven              | Italian           |
| Twelve              | Italian           |

*Table 2: Carers who manage medicines for another person*

| Carer number | Ethnic background | Care relationship |
|--------------|-------------------|-------------------|
| One          | Chinese           | Daughter          |
| Two          | Vietnamese        | Husband           |
| Three        | Chinese           | Daughter          |
| Four         | Macedonian        | Wife              |
| Five         | Croatian          | Husband           |
| Six          | Croatian          | Wife              |
| Seven        | Italian           | Husband           |
| Eight        | Greek             | Daughter          |
| Nine         | Greek             | Wife              |
| Ten          | Italian           | Wife              |

### ***The CALD journey in managing medicines***

The findings of the data gathered in this study suggest that for the non-English speaking CALD population, the journey of medicine management is a longer and more complex one than that experienced by the general older population. The journey of medicine management for the older population was described by While et al. (2011) as having four distinct stages:

- Self-management of medicines.
- Something changes. Identified factors that contribute to the transition from self-management to needing more help.
- Family member advocacy and the carer role in relation to managing medicines.
- Locus of control and the medication team involved in managing medicines (While, et al., 2011).

There are several challenges that have to be overcome for the non-English speaking CALD population to reach the stage of self-management of medicines. These challenges necessitate the development of systems and networks to allow access to medicine-related information, navigation of the health care system, and understanding of the society in which they live. The self-management of medicines was affected by the same age- and health-related concerns that affect the general older population, with the additional overlay of issues that stem from language and cultural differences. Similar issues and experiences were identified in the narrative of the participants, suggesting that saturation of themes was achieved.

The journey for the non-English speaking CALD population in managing medicines first begins with establishing relationships with their community and health professionals. In all cases it was the family and friends of the participant who assisted them to achieve this through navigating the health care system and identifying health professionals who could communicate in their language. The older person gained trust and confidence in their health professional and in their own ability to manage medicines if their doctor and/or pharmacist was able to communicate with them in their language. These relationships were crucial in the transfer of medicine and health-related information and instruction to the older person.

Within the network of supports for older people, including family carers and professional supports, the quality of each relationship was highlighted. Participants seemed clear about the role each person held in managing medicines. As found by While et al. (2011), trust and confidence in the health professional were paramount. However, the non-English speaking CALD population had a greater dependence on these relationships as they were often the only means of obtaining medicine-related information. Language barriers inhibited the use of information from other sources, such as information sheets provided with medicines, as the information was written in English. Older people also used consultations with their doctor as a time to inform them of any changes in health and/or concerns they had. Relationships with family were also highlighted as pivotal in the medication management process through the advocacy role carers adopted for the older person. The advocacy role of family members involved them in establishing links with health professionals who spoke the older person's language, and attending medical appointments and interpreting concerns as needed. Factors that impact on medication management processes for older people and carers were highlighted. These included the need for improved collaborative and communication processes and easier access to professional support for carers.

Equipped with medicine information and support networks, the older non-English speaking CALD population reached the 'self-management' stage of their journey, similar to that described in While et al. (2011). During this phase, older non-English speaking CALD people used strategies to ease the medication management process. These strategies included having a routine, documenting when medicine had been taken, and using dosette and Webster-paks®.

Family also assisted in providing physical support and transportation. Additional strategies to further enhance medicine management processes for non-English speaking CALD older people living in the community were put forward by participants.

The journey of medicine management as perceived by non-English speaking culturally and linguistically diverse older people is illustrated in the figure:



*Figure 1: The journey of medicine management by non-English speaking culturally and linguistically diverse older people.*

## Major themes

The findings have been discussed using the major themes that emerged from the interviews. These were: giving and receiving information, support networks, and self-management. The findings from the interviews are presented as a narrative. Quotes from participants have also been included to support the themes (with any words added for clarity appearing in square brackets).

Throughout the report participants have been referred to as the following: ‘older person’, for older people who manage their own medicines; and ‘carer’ for family members who were managing medicines for another person. All participants have been further identified through their study ID number.

### Giving and receiving information

The first major theme that emerged from the data was the giving and receiving of information. For older people, their medication management journey began with establishing relationships with their community and health professionals who could communicate their medicine and health-related needs in their native language. Integral to establishing these relationships was the assistance of family and friends:

*It was really important [establishing relationship with GP] at the beginning because I couldn't speak English. The language was such a big problem for me. However, I went out to get involved in the community, and I participate in the aged/elderly group to make friends. I have made some friends and I can spend time with them. My daughter will just take me to the doctors and tell me what to do step by step. (Older Person 4)*

There was an overwhelming preference of participants to use health professionals who could speak their first language as this relationship allowed them to overcome language barriers:

*The doctor, as well as the chemist, both speak my language. (Older Person 3)*

*I do have that [a Croatian speaking doctor] because I cannot speak English. (Older Person 1)*

*My doctor speaks Greek, and in the hospital they have noted on their form that I need an interpreter so they send one. (Older Person 8)*

*It does help having the doctor speak Italian. (Carer 10)*

Older people gained confidence in their ability to manage a medicine that was packaged in English when their doctor provided an explanation in their own language. As these older people explained:

*If it's not Greek how are we going to communicate, how will I take my tablets? (Older Person 6)*

*For me, the language is not such a big problem because I always go to the doctor who can speak Chinese Mandarin. (Older Person 4)*

All participants obtained information regarding medicines through either their GP or pharmacist:

*I do get the information from the doctor and the pharmacist but I'm forgetful sometimes. (Older Person 6)*

*I speak to the doctor and to the pharmacy as well. (Carer 8)*

*I'll ask the doctor for an explanation [regarding medicines] and he'll say do this, do that. (Carer 10)*

Given the critical nature of information shared between the GP and the older person and/or carer, consultations with the GP carried an expectation of how information was to be presented to the participants. For example, some participants wanted a verbal explanation of medicines provided to be supplemented with written information in their first language:

*Well, he does both. He explains to us and he writes it down. (Carer 5)*

*Every time the doctor prescribes medicine, I will request my doctor to write down a note about how to take the medicine for me. (Older Person 4)*

*They [chemist] know that I don't speak English. They write on the paper if they need to tell me something for my son. This helps. (Older Person 10)*

Carers also spoke of their preference regarding information received at consultations about medicines:

*I am interested in knowing what kind of tablets for what he's taking and all of those things, even like for the blood pressure, if there's a change of blood pressure or anything, I like to know that information regarding the tablets. I want to know those things. (Carer 4)*

*When he gets a new medicine, then I go through first time and then I know if he's allergic to anything or if it's not good for him, what the reaction can be. (Carer 6)*

*I like to know that information regarding the tablets. I have to know how the human body works, how the sickness, is it increasing, it is decreasing, how's it developing. (Carer 14)*

Having the specific information written on the packaging of medicines in their first language was equally important in helping some participants manage their medicine:

*She [chemist] writes it in Chinese. On the packet, on the box. (Carer 3)*

*At the chemist there is a Greek-speaking lady and I ask her to write it down [on the medicine packaging] because there are so many and I don't remember. (Older Person 8)*

*The doctor gave me the prescription and explained what it is, and then when we go to the pharmacist, the label is quite clear. It's in Vietnamese. (Older Person 7)*

The supply of medicine-related information in the English language reinforces the need to obtain information through the GP:

*It says [the instructions] on the package but I can't actually read it (Older Person 3)*

*The information was in English and I did ask the members of my family to go through the information and to explain to me what it was all about, and they were promising that, oh yes one day we'll come and we'll go through it. But unfortunately that never happened. (Older Person 9)*

*Every medicine they do have information leaflet, [however] I couldn't read it so I couldn't understand it and then it ended up in the bin. (Carer 2)*

Preference regarding the method of communication and presentation of information also reflected the level of schooling some of the participants had reached:

*I don't need it written down because if they write it down (in my own language) then I can't read it, that's the hard part. I didn't go to school for very long, that's why it's hard. (Older Person 6)*

Reliance on the GP as the sole source of information was not without risk, with one participant recounting her experience of when she misunderstood the explanation of her prescribed medicines:

*Because I couldn't understand the doctor, for three weeks I was taking the wrong tablets. (Older Person 10)*

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Another older person had different strategies to actively overcome language barriers:

*I'm learning English so I can read bit by bit on the package. Also I have a dictionary and I can check it out as well. Also I know how to make a booking for interpreters. Last time I went to see the dentist and I told the receptionist that I need an interpreter and they arrange for me. (Older Person 5)*

### Summary

The single biggest concern that people who do not speak English have in managing their medicine was overcoming the language barrier. The lack of translated pharmaceutical information necessitated that both older people and carers found other means of gathering information related to medicine.

The single biggest coping strategy in overcoming this barrier in relation to medicines was to see a doctor who spoke their language. Responses showed how highly dependent non-English speaking people were on accessing health professionals who spoke and wrote in their language. Verbal instruction regarding medicines was also the preferred method for obtaining information, given the low level of schooling some of the older people had attained. Both older people and carers were dependent on acquiring medicinal information from their GP. This not only highlighted the critical importance of the GP role, but also that most participants perceived there to be no other means of obtaining this information. The pharmacist was also often chosen because they spoke the older person's language, or because the pharmacy staff did; this again is reflective of the need to overcome the language barrier.

In terms of delivery of information, participants spoke frequently of supplementing verbal explanation with written instructions regarding the purpose and administration of the medicine. Carers in particular were specific about their expectations of consultations and their desire to be informed of how the medicines work, including the side effects or any particular instruction regarding medicines. Some participants made notes during consultation, while others asked for notes to be written for them. In the pharmacy setting, some older people asked for notes to be written on medicine packaging in their language, while others arranged for the pharmacy to have printed labels with this information in their language.

The factors identified in the study that influenced the giving and receiving of information related to medicines have the following implications for an assessment tool:

| <b>Medicines information</b>  |
|---|
| <p>Explore how the person and/or family carer obtains information about their medicines:</p> <ul style="list-style-type: none"> <li>• Identify the person and/or family carer's preferences regarding how information is to be presented</li> <li>• Ascertain literacy levels of the older person and/or family carer in their own language</li> <li>• Ascertain the type and amount of information the person and/or family carer wants and in what format (verbal, written, language needs)</li> <li>• Identify the person and/or family carer's preferred source of information regarding medicines</li> <li>• Identify if the person requires support and education regarding access to interpreter services</li> </ul>   |
| <b>Personal resources for medicine management</b>   |
| <p>Ascertain the person and/or family carer's goals for medicine management:</p> <ul style="list-style-type: none"> <li>• Ascertain the person and/or family carer's expectations of their medicines</li> <li>• Consider the person and/or family carer's experiences of the use of medicines</li> <li>• Look at how the person and/or family carer feels and is responding to their medicines</li> <li>• Explore if the person and/or family carer has any concerns regarding interactions of medicines with prescription, over-the-counter or herbal medicines</li> <li>• Explore beliefs and behaviours around complementary health measures (diet, exercise, physiotherapy) and desire to lessen the need for tablets, if the older person has an interest in this</li> <li>• Explore the person and/or family carer's stance on natural medicines; if yes, have they advised their GP?</li> <li>• Ascertain who the person and/or family carer's chosen health providers are and if they have difficulty accessing them</li> </ul> |

### Support networks

The steps for the non-English speaking CALD population in managing their medicines involved them overcoming the language barrier. Of critical importance to overcoming the language barrier was access to the services of a health professional who spoke the older person's language, so they could understand the medicine-related information and instruction given to them. Support networks were critical for the older person in navigating the health system and establishing these relationships.

The older person often had strong views about the role members of their support network had in relation to medication management processes and the qualities of these relationships they valued.

Family members often took an advocacy role in relation to medicines, initially assisting in establishing relationships with health professionals, then continuing through attending appointments with their relative, taking note of medicine-related information and clarifying concerns the older person may have had:

*The family helps me, especially my daughter. She will take me, say for example if I got an appointment with the family doctor, she will take me to the doctor and if we get prescriptions and we need the medicine she will stop by the pharmacist. If I feel okay, sometimes I come out of the car; otherwise I will just wait in the car until she gets the medicine. (Older Person 9)*

*If I've got a question, say for example I've got a question or I forgot something to ask the doctor prior and I want to ask him to put a question forward, she [daughter] will interpret the question. But if – from her own accord if she's got something that she would like to ask, she does that. (Older Person 9)*

*They put the label on a box of the tablets and they explain to my son. Then my son explains to me how I have to take the tablets. (Older Person 10)*

In some cases family members only assisted until the older person wished to manage alone:

*When I first came all of the things were arranged by my daughter but nowadays I can do things myself. (Older Person 5)*

The relationship with the GP also evolved to cater for the health and information needs of both older people and carers in managing medicines:

*For every visit [to the doctor], normally it lasts about half an hour. He's very thorough. Any question I ask, he will give me the answer. (Older Person 7)*

*Yeah, I can tell her [if I have medicine-related concerns] but then I never get sick off any tablet. (Older Person 2)*

The perceived role of the pharmacist varied; for some, it had evolved to become the primary means of sourcing information regarding medicines:

*I think it is important [the chemist provides explanation of medicines] because there is nobody else who can explain to me (Older Person 3)*

*Normally [the chemist] does explanation with a, like, exact detail ... They would tell me that, because I have high cholesterol and they would tell me that this tablet is good for that and you can take it and how many time – the dosage and they would tell me the dosage. They would also tell me for some specific tablets that I couldn't take. (Older Person 5)*

Other older people limited the role of pharmacists to being the experts on medicines:

*The chemist – they only adjust the medicine. They're not doctors. (Older Person 1)*

*I go to the chemist and give them the prescription. They have a look and they find the medicine and basically, that's it. (Older Person 2)*

Continuity in the relationship with the health professional was fostered through older people attending the same clinic or pharmacy over a long period of time:

*I have had the same doctor for the last 28 years. If anything happens I will phone him and he normally comes to my place. (Older Person 11)*

The trust placed in the GP was so strong that one older person adhered to their medicine, regardless of the outcome:

*Regardless of how sick I feel, I take my medicine regularly. (Older Person 3)*

The trust placed in the GP also reflected the older person's ability to discuss concerns if they arose:

*I might say, look such-and-such is giving a bit of a headache, and he says 'look that is quite normal, do not worry about it'. (Older Person 11)*

*I always take care when, for example, I'm taking this one. It's for pain relief, and when the pain goes away I ring the doctor and say to her it went away, what is your advice? (Older Person 7)*

Some older people reported taking over-the-counter medicines upon recommendation and advice from family member or friends. However, participants reiterated that this was always negotiated with their GP, again highlighting the importance of this relationship in managing medicines:

*My daughter will get calcium and Omega 3, and also some supplements for my joints. For those supplements, my daughter would tell me exactly how to take them, and also she will just write it down, put it in writing, therefore, and I can remember it. I would always tell my doctor about that. (Older Person 4)*

*If someone recommends something I always ask my doctor for advice. (Older Person 7)*

*I would tell my doctor. For example, I have joint pain recently in the last few months and my friends recommended [Mosatil]. I have been taking it and I will go to the doctors and say that I have been taking the Mosatil for a while but it's not – my friends said that it will help my joint pain but it seems that it's not working. I would like tell the situation to my doctor. (Older Person 5)*

*It [fish oil] wasn't suggested by the doctor, and I haven't heard it from anyone else, but I do a lot of reading and I know that fish oil is good for you. My doctor is aware of that. (Older Person 9)*

Hospitals and specialists also featured in the older person's support network, and provided the older person information regarding changes in health and medicines. These changes were also discussed with their doctor, though in addition to this, older people also clarified any such changes, reinforcing the level of trust and reliance on this relationship:

*Sometimes I might see the cardiologist, sometimes the respiratory doctors, and they will tell me what sort of medicine I need and they'll give me – they will give me a prescription but after that I go to my family doctor he explains to me exactly how to take the medicine and I follow that. (Older Person 9)*

*I've got veins there that tend to sort of block a bit and so I had to go to the specialist and the specialist explained. However, I then I go back to my own doctor who explains what's happening. (Older Person 12)*

Carers were generally more assured that they would be informed about medicine-related needs and changes:

*Usually if there is any change in the medicine, the [hospital] pharmacy will tell me about what medicine has been changed. For example, last time when [she got the minor stroke] and changed that to give the aspirin to her. They tell me the details, yes. (Carer 6)*

The desire of older people to discuss all health changes and concerns with their GP also showed the uncertainty older people had about communication between hospitals and GPs regarding medicines:

*I'm not sure but I assume that they have contact. Because when I was admitted in a hospital, they asked me about my GP. (Older Person 3)*

*I don't believe so [the hospital communicates with the local doctor] because the doctor would have told me so. (Older Person 8)*

There was also an example identified of a poor relationship between the older person and their GP:

*Usually she's writing something to herself and then she says, 'we are finished now'. I assume and understand it because she is too busy that she doesn't have enough time for me and to listen to what I have to say but I think that she should. (Older Person 3)*

In one instance a carer who was finding his role stressful had tried to arrange support through service providers. He was seeking respite from some aspects of his role so he could focus on what he considered to be the more important tasks he completed as carer, which included medication management. He explained that he gave up on receiving assistance when his case was not seen as a ‘priority’:

*I tried to get someone ... but they come ... and then they stop. (Carer 7)*

The wishes of the older person could also impact on the carer using support services:

*I did try to get the RNs to come and give the medicine but he [relative] is refusing. He’s depending a lot on us [family]. It’s really hard. (Carer 8)*

Cost may also affect choice and use of services:

*I don’t go to the Chinese traditional doctor. Honestly, the Chinese traditional doctors, they charge a lot so that’s more than we can afford. It’s too expensive. (Older Person 4)*

Another carer described that in the Chinese culture older people were reluctant to seek assistance:

*Older people, they actually don’t like to trouble their children. They know their children are very busy ... they would rather ask friends or other people who could help them first; their circle of friends. (Carer 3)*

Carers also accessed medicine information through other resources:

*I’ll just research it [on the internet], whatever it is. (Carer 8)*

Overall, however, there remains a need to have all the people and resources who contribute to the management of medicines to collaborate for the best outcomes:

*I think everybody must be involved in this, doctor, pharmacy, nurses, everybody, everyone ... And work together. (Carer 3)*

## Summary

Fundamental for most participants in the management of medicines was support. Initially it was the support of the older person’s family that established relationships between the older person and the health professionals, and helped them navigate the health care system in the process. Within the network of supports, the quality of each relationship was highlighted. Participants seemed clear about the role each person had in managing medicines.

Older people used consultations with their doctor as a time to obtain health and medicine information and inform them of any changes in health and/or concerns they had. The trust placed in the doctor was paramount, with both older people and participants reporting they informed their doctor of health advice they had been given, and they clarified and communicated the outcomes of specialist appointments or inpatient stays with them. Family members were pivotal in the advocacy role they adopted for the older person through attending medical appointments with their relative and interpreting concerns as needed. What was less consistent was the information shared between these supports, in particular GPs and hospitals. Discussion highlighted that the relationship between older people and health professionals, and the relationship between different groups of health professionals, may be enhanced through the implementation of collaborative and communications processes, allowing information related to medicine management to be shared in a timely and appropriate manner.

The factors identified in the study that related to the support network for the older person have the following implications for an assessment tool:

|   |
|---|
| <b>Medication team</b>  |
| <ul style="list-style-type: none"> <li>• Identify who is involved in medicine management (ascertain the team members)</li> <li>• Explore the role and responsibilities of each member and check if roles are agreed and understood</li> <li>• Explore if communication between the medication team members has broken down</li> </ul>   |
| <b>Carer role</b>   |
| <ul style="list-style-type: none"> <li>• Explore if the medicine management role is burdensome</li> <li>• If burdensome, identify which components of medicine management cause difficulty and why</li> <li>• Identify which areas the carer might benefit from help in, to relieve or minimise the stress and burden associated with medicine management</li> <li>• Identify the goals for medicine management with the person and/or family carer (ensuring goals are based on their own values and beliefs, or substituted judgements are based on the wishes and beliefs of the person who is being cared for)</li> </ul> |
| <b>Access to medicines</b>  |
| <ul style="list-style-type: none"> <li>• Determine if the person and/or family carer is still able to access health care providers (GP, pharmacist)</li> <li>• Ascertain what help is needed to access to health care providers</li> </ul>  |
| <b>Environmental limitations</b>  |
| <ul style="list-style-type: none"> <li>• Ascertain if the person is a frequent user of hospital or respite services and, if so, if continuity of prescription medicines is a concern</li> <li>• Explore the communication of medicine changes</li> <li>• Explore the multiple sources of prescription and the adequacy of communication between providers</li> </ul>  |

## Self-management

When older people had overcome language barriers to obtain required medicine information and had support networks in place, they reached the self-management stage of their journey. This section describes the subjective experience of managing medicine and the strategies used to overcome changes in health and ability that may affect medicine administration. Strategies used to enhance self-management of medicines included having a routine, documenting when medicine was taken and using dosette and Webster-paks®. Family also assisted in providing physical assistance and transportation. Additional strategies to further enhance medicine management processes for CALD people living in the community were put forward by participants.

The ability to manage medicines varied between all participants, with several experiencing no difficulties in completing this task:

*I do not have those kinds of difficulties. (Older Person 1)*

*I have no problem with medication management. (Older Person 4)*

*It's not stressful at all for me; it's quite easy, quite straightforward. I never make mistakes. (Older Person 7)*

There were numerous factors that may have affected an older person's ability to manage their medicine. The most commonly reported factor was forgetting to take a dose:

*I forget them sometimes because of my memory problems. (Older Person 6)*

*Normally I can manage that independently but just occasionally I will forget that have I taken that tablet or not. (Older Person 5)*

*Sometimes, but not very often forget. (Older Person 2)*

Carers also recounted the cognitive changes in their relative's health that resulted in them undertaking the caring role:

*I've been doing that [administering medicine] because sometimes she forgets. I make it safe. (Carer 7)*

*He's got vascular dementia so he forgets about what time he gets his medicine. (Carer 8)*

For both older people and carers, there were physical reasons that complicated adherence to medicine:

*Opening the bottles sometimes it can be a problem because you have to position the bottle on something that is quite level and you need to press and then to open. There are times when I find that difficult. (Older Person 9)*

*[I have trouble] with those ones [bottles] that you have to push down and open but I'm used to it now. (Carer 10)*

*I'm having a little bit of difficulty now because I'm getting older and my fingers are not as they used to be and I do drop the medicine quite often. (Older Person 12)*

One older person explained that medicines that are only taken as needed (for example, pain relief) or medicine that varies in dose caused confusion as they were not packed into her Webster-pak®, meaning she had to self-administer these:

*When it's something extra it's out of the box and I'm not sure how many tablets to take daily. I have wait for my son to come from work to explain how I have to take the tablets, or maybe even I may have to ring someone else to ask for that. (Older Person 10)*

Both carers and older people developed strategies to overcome changes and safely manage medicine. Having a routine in place was frequently cited as one such strategy:

*If you use them every day, you remember. (Carer 9)*

*There's no problem [giving medicine]. Mostly by memory now, we've been taking so long. (Carer 5)*

*I just memorise all those down, and I know that the high blood pressure tablet is my one tablet after the breakfast. (Older Person 4)*

Older people also made reminders about medicine instructions through making their own notes about the information:

*I would take some notes on the package when they tell me [specific instructions]. (Older Person 5)*

*You can recognise it by having the picture that you've photocopied and then putting your own notes against it. (Carer 2)*

In addition to this some participants kept a written record of when medicines had been taken:

*I write down which tablet I have taken, and when. (Older Person 9)*

*I write it down because if I don't write it down then I'll forget. (Older Person 10)*

*I write it down [instructions] on a piece of paper which is to remind me. (Carer 3)*

One older person had her family prompt her to take her medicine:

*My daughter will call me up sometimes and she'll remind me to take my tablets. (Older Person 6)*

Another family had devised a roster whereby the role of managing medicine was shared:

*So we do have them [medicines] in the Webster-pak, so in the morning someone is there to give the medication, lunchtime, someone is there to give medication and five o'clock medication, we're there to give again. (Carer 8)*

Physical issues that affected ability to take medicine were managed with different strategies, such as transferring newly-opened medicine into old packaging:

*If I've got a bottle that has been used for a long time, it's easier to open and if it is the same medicine I will usually transfer it in the older bottle and then I use that bottle instead of struggling with the new one. (Older Person 9)*

Both older people and carers used dose administration aids<sup>2</sup> such as dosette boxes or Webster-paks<sup>®</sup> to ease administration, with older people often choosing to have the pharmacist fill and deliver them:

*I have a seven day thing, the seven day box. She [chemist] does them every Sunday and puts them all in there. (Older Person 12)*

*It is much easier now with the box than before... But now she [pharmacist] puts it in once and then at the end of the week she just refills it and she knows exactly what to do. (Older Person 11)*

*If something happens [with Webster-pak delivery], I would actually have to stop taking medicine. (Older Person 3)*

*It's safer [using a Webster-pak], and it's a lot easier because I know exactly whether I have taken the medicine or not. (Older Person 9)*

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<sup>2</sup> Dose administration aids are defined as a device or packaging system where doses of one or more solid oral dosage forms of medicines can be organised according to the time of administration (Australian Pharmaceutical Advisory Council, 2006).

*Everything is in here. Whole days – morning, lunch, dinner, before bedtime, so everything is here; I just take them. (Older Person 10)*

The carers also used dosettes and Webster-paks® to ease the administration of medicines:

*That makes a big difference 'cause I suppose you don't have to open bottles. (Carer 6)*

*We decided to put in a Webster-pak to make it easier for everybody. (Carer 8)*

*He said to me, I can put the dates [on the Webster-pak] ... I'll put the sticker on it to see the dates and I don't have any trouble. That's easier; I haven't gotten any problem really. (Carer 9)*

*Because it's Monday, Tuesday, Wednesday, you just take out whatever tablets you have to take out for that particular day. (Carer 10)*

Some carers filled the dosette as it gave them control over medicines given:

*No problem for me. It usually takes me a while, maybe sometimes half an hour to sort them all out for a whole week. (Carer 5)*

*You can make more mistakes if the tablets are just from the package, whereas you can't make as many mistakes as the boxed one. (Carer 4)*

At times, though, Webster-paks® were also problematic as they required a degree of dexterity to open packaging and safely remove tablets:

*Sometimes it happens that some of the tablets fall on the floor because there are so many of them. So sometimes they just fall into my palm, sometimes on the floor. (Older Person 3)*

*We have to be there on time before he actually takes the medicine because he drops them on the floor sometimes. (Carer 8)*

There was also a clear preference among participants to use the same brand of medicine, so as to avoid any confusion that may arise from a change in brands:

*Sometimes they got this cheaper brand or this and that. I say look, give me whatever is on prescription. (Carer 5)*

*They'll ask me do you want the cheaper ones, do you want the more expensive ones, I tell them no, just stick with the ones that I'll always get. The pharmacy, they always recommend a cheaper brand and it's a different name. When I get that cheaper brand, I try to compare it to the original prescribed by the doctor but it's hard to compare because it's a different name. I don't know which one is which. (Carer 2)*

*The chemist tells me, it's the same tablet, but it's a different company. (Carer 4)*

*She [chemist] has asked whether I would like to have another brand but normally I would prefer to have the same company. (Older Person 1)*

*I think sometimes as well it can become difficult because the chemist, sometimes they say do want the brand name or do you want the cheaper brand. One tablet you only need once a day, the other one you need twice a day, even though it's the same medicine. (Older Person 10)*

Medicine administration could also be influenced by other factors, including the notion that some ailments are best addressed through lifestyle changes rather than through medicine administration:

*It's understanding about what could be given ... things that you could do to help you improve your health and wellbeing [apart from taking medicine] ... because of the lack of knowledge and understanding sometimes you can do things that might not be healthy for your body. (Carer 8)*

*There are other things that could help people like exercises or certain things, which we could do to help ourselves. (Carer 6)*

*I think there could be some other supplementary therapy that could be used in conjunction with medicine, because I don't think medicine [alone] is just an answer to everything ... the lack of knowledge and understanding sometimes you can do things that might not be healthy for your body. (Carer 10)*

Suggestions were put forward as how to best to support people from non-English speaking backgrounds in managing medicines. Several involved increased availability of written information:

*What would be a good idea is when a patient is discharged from the hospital it would be a good idea if they've got a list of the medication that they have been prescribed, and that they need to use and the dosage of course, and how many times – the frequency – how many times a day and all that. (Older Person 9)*

*If they got a short sort of explanation about the side effects of that medicine, and maybe the positive effects of the medicine. So that – it's so you are aware exactly what the medicine is for and how it's taken and for what purpose and what could be the consequences if you like, of the medicine. (Older Person 9)*

*I know it could be costly if you asked all the information to be, the leaflet to be translated into different languages and then to give it to the consumers. But if they could even ... compile like a reference book where they would have it – it has to be in the community languages. You can have that book at the pharmacy and people can look and read, or if they need to they can ask for it to be photocopied. (Carer 2)*

Also increased access to interpreter services was highlighted:

*I don't think there's enough service in terms of language because for the elderly or for someone who can't speak English, they've had to go to the pharmacies who find someone who can speak their language to explain to them. (Carer 8)*

*Yeah they're [Cantonese speaking people] not aware that interpreter services are available so what they do is they have to go to the pharmacies who can speak Cantonese. (Carer 3)*

Broader strategies that may enhance medicine management processes were also put forward:

*We have to be able to get the information out to people about support services about people that can take them to appointments if their family can't or information about medicines in Chinese. (Carer 3)*

*Seminars, managing medicine information, things like that. It would help a lot. (Carer 8)*

## Summary

In general, older people were focused on maintaining their independence in all facets of their lives, including management of their medicines. The challenges to the independence of older people in managing their medicines were twofold: first, in the form of memory lapses and second, in the form of physical problems that affected their ability to open packaging and bottles to administer medicines. Additional challenges also came from medicines that were short term or that varied in dose, for example, Warfarin or pain medicine. Both older people and carers reported benefits from using strategies that included having a routine, documenting when medicine had been taken, using dose administration aids, and using the same brand of medicines. Both groups made suggestions around easing medication processes through increased availability of translated information, interpreter and support services.

Factors that result in a change in ability and capacity to manage medicines have the following implications for an assessment tool:

| <b>Personal limitations (functional and cognitive ability)</b>   |
|--|
| <ul style="list-style-type: none"><li>• Ascertain the confidence of the person and/or family carer in administering medicines</li><li>• Observe for physical limitations with taking medicines (difficulty opening lids and packaging, poor vision/trouble reading the label, dexterity, unable to administer inhalers/eye drops, swallowing, cannot hear verbal instruction or cannot understand due to language barrier)</li><li>• Observe organisation and storage of medicines</li><li>• Document experiences of any difficulty with remembering to take medicines</li><li>• Explore whether the person and/or family carer has experienced difficulty in identifying medicines (either by name or appearance)</li><li>• Note changes from pre-morbid behaviour</li><li>• Identify components of the medication management that may be causing difficulty for the person and/or their carer</li><li>• Ascertain the emotional experience of taking medicines</li></ul> |
| <b>Capacity/making medicines manageable</b>  |
| <ul style="list-style-type: none"><li>• Identify what strategies the person and/or family carer has that support medicine management</li><li>• Determine if the person and/or family carer would consider the use of a dose administration aid</li><li>• Explore strategies that may assist administration of medicines</li></ul>  |

## Discussion

The responses of participants highlighted that before a person could self-manage medicines there were challenges to overcome regarding giving and receiving information and developing support networks. The findings will be discussed further through the three themes identified in the data: giving and receiving information; support networks; and self-management.

### ***Giving and receiving information***

The journey for the older non-English speaking CALD population in managing their medicines begins with establishing relationships with health professionals who can communicate in their native language. Language barriers have been linked before to reduced access to service services (Garrett, 2009). For participants, this situation necessitated that they seek the assistance of friends and family to establish relationships with health professionals in order to obtain appropriate health care and information. This was particularly critical as most did not perceive there to be any other way of obtaining this information or feel able to navigate the health care system alone. These findings build on the suggestion of Bastiaens et al. (2007) that ‘...although not all people want to take control over decisions in their medical care, most people want to receive good information on their health and appreciate consideration of their concerns and desires into the care decisions of the GP’ (Bastiaens, Van Royen, Rotar Pavlic, Raposo, & Baker, 2007, p. 41). This is the same for non-English speaking older people and it brings with it the issue of language translation.

Communication of information through the GP was integral for older people and carers in managing medicines. Participants held expectations about what information would be discussed during consultations; this included the dose, administration and side effects of their prescribed medicines. The importance of the consultation in gaining medicines information is not new (Du Pasquier & Aslani, 2008); however, unlike previous research, this study showed that the participants satisfaction with the information they received was quite high. This may reflect that the sharing of a language results in higher levels of satisfaction with health care providers (Carrasquillo, Orav, Brennan, & Burstin, 1999). However, establishing such relationships is not a sustainable way of overcoming language barriers given the ‘...poor match between the languages represented in the bilingual workforce and the workforce and the languages of patients...’ (Garrett, 2009, p. 48).

In overcoming these concerns it has been suggested that use of interpreters be mandated to further reduce the existence of language barriers through allowing consumers to access and use providers who do not speak their language (Federation of Ethnic Communities' Councils of Australia, 2010). However, this suggestion comes with issues attached; interpreters have been found to reduce, omit and revise the content of discussion (Aranguri, Davidson, & Ramirez, 2006). Also, there are concerns regarding interpreter service access and use that need to be addressed, including inefficient booking systems, insufficient interpreter availability, perceptions that interpreters are difficult to book and attain, and the lack of flexibility of the interpreter service (Centre for Multicultural Health, UNSW, 2003, as cited in Garrett, 2009). Pharmacists in particular have reported that they are unable to access interpreter services (While, et al., 2011).

*The review of evidence related to interpreter service effectiveness indicates that systemic changes may be needed at an operational level to maximise the reach and availability of the service. This might include extended usage of technology, selectively changing the mode of communication (e.g. less face-to-face interpreting and more telephone interpreting) or improving interpreter budgets (Garrett, 2009, p. 51)*

Delivery of information is another aspect of communication that requires consideration. The majority of participants in this study preferred verbal instruction with regard to their medicines, which in part reflected the education level they had attained. The research team's findings suggest that a preference to receive information verbally may reflect that an individual has not attained the education level needed to understand written information in English or their first language. This has implications for the transfer of information as it highlights that a variety of modes of communication may be required to communicate with a non-English speaking older person. Communication strategies also need to consider the dialect literacy level of the client as well as the language spoken. This finding also impacted on the consent process where the research team had assumed that using translated documents would overcome language barriers. In these instances, information was read verbatim to some participants by the interpreter.

Other participants made notes, or had notes written for them, as another important way of retaining information gathered at the time of consultation, and as a means of ensuring that medicines were taken as prescribed. One participant used a dictionary and accessed interpreters, though this was an isolated case.

*The readability of medicines is important to patients ... Patients value the idea of information that is tailored, set in the context of the particular illness of the individual patient, and containing a balance of benefit and harm information (Raynor, et al., February 2007, p. x)*

This supports the assertion that 'verbal information should always be followed up by written information, explaining the reasons for and the likely effect of the treatment together with details of the frequency and times of the doses to be taken and any possible side effects' (Nyatanga, 1997, p. 332). As such, the assessment tool to be created acts to identify the amount, type and delivery of medicine-related information the consumer desires.

Additional strategies identified by participants as having potential to further enhance self-management of medicines overwhelmingly involved increased access to and availability of information. This is despite the plethora of resources currently available to non-English speaking CALD communities, including translated health information of medicines, community education sessions, and free interpreting services through the National Prescribing Service. This may reflect that access to these services requires that people are not only literate in English, but also computer literate; given information resources are primarily available online. The research team found that locating online resources could be both a difficult and convoluted process. The need for translated information on medicines, as well as targeted health promotion strategies and a cultural competency framework in primary health care has been recommended in a national submission to improve CALD consumer safety (Federation of Ethnic Communities' Councils of Australia, 2010). '...Australia's age care system needs to consider the diversity of Australia's seniors' population and their requirements for culturally sensitive care, including information about safe and wise use of medicines' (Federation of Ethnic Communities' Councils of Australia, 2010, p. 8).

### **Support networks**

The journey for non-English speaking CALD older people in this study involved creation of a network of people who support their management of medicines; a team that generally consisted of their family, GP and/or pharmacist. Within the network of supports, the quality of each relationship was highlighted. Participants seemed clear about the role each person held in managing medicines. As found by While et al. (2011), trust and confidence in the health professional was particularly important, although the non-English speaking CALD population had an even greater dependence on these relationships given they were often perceived to be the only means of obtaining medicine-related information.

A good doctor–patient relationship has previously been observed in relation to adherence to medicines (Kruger et al., 2003, as cited in The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006, p. 30). Most participants sought continuous support from their health professional over several years, and trusted that consultations with their doctor would allow for discussion regarding any changes in health and/or concerns they had.

The findings of this study also reaffirmed the risk that is created when communication or the relationships between the doctor and client is limited. Poor communication between health professionals and clients has been identified as one of the most common contributing factors to medication incidents (National Prescribing Service, 2009). For one participant in this study, a breakdown in communication was related to them relying on only the one health professional for health information and advice.

There was also uncertainty among participants about how much information is shared between health professionals involved in a client’s care. As the team members who support an individual in the management of their medicines have a shared expertise and responsibility (Australian Pharmaceutical Advisory Council, 2005) it is imperative to identify people involved within this medicine ‘team’, their role and any knowledge or skills that can be shared. Relationships that older people had with their family were also highlighted as being pivotal in the management of medicines. Family members often adopted an advocacy role for their relative. The advocacy role of family members involved establishing links with health professionals who speak the older person’s language, attending medical appointments, and interpreting concerns as needed. Carers valued relationships with health professionals as these relationships enabled them to be informed and supported while managing medicines for another person. Anderson and Kralik (2008) also identified the importance of carer access to support for advice and encouragement. The participants in our study reinforced the value of support, though it also identified the challenge at times in obtaining it. In addition, the amount and type of support that is sufficient for a carer’s needs requires further exploration to ensure prompt further assessment of carer stress levels and appropriate support services if required.

### **Self-management**

Using CALD-specific medicine information and support networks, older people in this study reached the ‘self-management’ stage of their journey, similar to that described by While et al. (2011). During this phase, older CALD people used strategies to ease the medication management process. Inherent in self-management of medicine is self-efficacy, or the belief or confidence that one can successfully perform the action needed to attain the desired outcome (Bandura, 1986). The two main factors that affected self-efficacy in this study were impaired dexterity and impaired cognition. Impaired dexterity ‘...can affect the ability to open product packages or medication containers...’ (The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006, p. 47). Impaired cognition may affect medicine management by causing people to take too much medicine or to miss a dose (The American Society on Aging & American Society of Consultant Pharmacists Foundation, 2006).

Several of the strategies used to assist self-management of medicine have been identified in other studies, including ‘making treatment “part of life”’ (Dowell & Hudson, 1997, p. 373) through incorporation of medicines into daily routine (Metlay, et al., 2005) and use of dose administration devices (Murnane, Kendall, & Gamble, 2009; University of Queensland, 2004) particularly those labelled in the participants’ first language. Some participants also supported their own self-management through keeping a written record of when medicines were administered. Medicine regimens were complicated when doses of medicines varied or were short term, and this necessitated that family or friends assist participants with their medicines, given these medicines were not packed into the dose administration aides they used.

Another important strategy for participants in managing medicine was seeking continuity in the brand of medicine they use. ‘Multiple brand names can cause significant confusion for consumers and/or their carers...’ (Australian Pharmaceutical Advisory Council, 2005, p. 38) Participants relied heavily on taking the same brand of medicine to avoid the confusion that comes from trying to identify and/or administer tablet they do not recognise. It has been suggested that ‘...health professionals should confirm that consumers understand and recognise the active ingredient name of all their medicines’ (Australian Pharmaceutical Advisory Council, 2005, p. 38). However, the means to do this in non-English speaking CALD populations or populations with reduced literacy remain unclear. There was also a clear preference of participants to take medicines they recognised and trusted. It is therefore possible for this population to be penalised through being reliant upon a brand that is not subsidised through medicine benefits schemes, and thus is more expensive.

*Consumers and/or their carers should be given specific information about entitlements and an explanation of the safety net under the Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, together with an indication of costs of any medicines not covered by such schemes (Australian Pharmaceutical Advisory Council, 2005, p. 38).*

### **Contribution to knowledge**

The findings of this study complement the journey of medication management described by While et al. (2011), showing that for non-English speaking CALD people this journey is longer and more complex than for the general older population.

Findings from this study include:

- Family members often assist in establishing relationships with a GP who can speak the older person’s language.
- Having a GP who can speak an older person’s language is the primary way of overcoming language barriers and obtaining medicine-related information.
- The individual’s literacy level and their preference regarding the amount and format of information they wish to be given (for example, verbal or written) should be considered.
- There is a need for awareness and access to interpreters; and translated medicines information in a variety of formats.
- There is a need to include the people involved within the ‘network’ or ‘team’ supporting non-English speaking older people with their medicines; and promote their role and communication with other people in the support network.

### **Future directions**

Exploration of the different non-English speaking CALD populations’ perspectives required use of professional interpreting services. Past research has identified that interpreters have an overall tendency to reduce what was said through omission or revision (Aranguri, et al., 2006). It is possible that this has occurred in this study. As only the narrative of the researcher and interpreter was transcribed, the team suggests that future research should include the transcribing and translating of the narrative of the non-English speaking participants to enhance the reliability and validity of the analysis. Validity would also be enhanced through checking if the findings among the broader population of non-English speaking CALD people and those with limited proficiency in English are similar.

Though time-intensive, this study has paved the way for accessing potentially vulnerable populations through the translations of documents and the use of interpreters to conduct interviews. The Manager – Diversity was integral to the successful completion of the study in that she informed the research team about recruitment strategies and translation standards for documents used in the recruitment process; this allowed ethical requirements to be met and the projected number of participants to be recruited.

The strengths-based approach taken in the design of the study enabled identification of strategies older people use to self-manage their medicine. Future research could benefit from taking a similar approach as it allowed for the journey of how older people use their skills and strength, and how they adapt to change in a positive manner to be identified.

Through integrating the findings of this study with the findings of While et al. 2011, the Medication Management Assessment Tool (see Appendix 1) has been developed. It requires further evaluation through the Delphi technique, using experts and clinicians to increase face validity of the assessment tool. The tool needs testing for validity and reliability in the clinical setting and evaluation of the useability of the tool with other community care organisations within Australia.

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## **Appendixes**

Appendix 1: Medication Management Assessment Tool

Appendix 2: Older Person Interview Questionnaire

Appendix 3: Family Member Interview Questionnaire

Appendix 4: Declaration of Confidentiality by Interpreters of Data

Appendix 5: Translated documents

## **Appendix 1: Medication Management Assessment Tool**

### **Administration instructions:**

It is recommended that the assessment be completed at the time medicines are due to be taken by the client.

Assessment should be conducted in a conversational manner.

The categories listed provide prompts for completing the assessment.

The client and carer columns should be marked to indicate who is responding to the question.

Action column: Actions help to attain the client's goals for self-management. Please indicate the agreed actions that have been identified for each category.

Refer to the accompanying guide for possible interventions (as identified by research participants and evidence-based literature). NB: this is not an exhaustive list.

Review date: Provide a date for reviewing progress.

| Category: Capacity  | Client | Carer | Findings   | Action  | Review date |
|---|--------|-------|--|---|-------------|
| Show me all the medicines you are currently prescribed  |        |       |  |   |             |
| Show me the medicines you are currently taking<br>( <i>explore - prescribed, natural medicines, over the counter, supplements</i> ) |        |       |  |   |             |
| Have you stopped taking any medicines that you were previously happy to take?   |        |       | No<br>Yes ( <i>explore reason</i> )<br>Document response:  | HMR<br>Check for depression, delirium, cognitive change and other physical and mental health conditions.  |             |
| On a scale of 1 – 5: How confident do you feel in how you manage your medicines?  |        |       | 1 = not at all confident<br>2 = not very confident<br>3 = neither confident or not confident<br>4 = reasonably confident<br>5 = very confident |   |             |
| Show me how you store and organise your medicines?  |        |       | Location<br>Satisfactory<br>Unsatisfactory (describe)  | Check medicines are stored as indicated<br>Discard out of date and discontinued medicines<br>DAAs   |             |
| Show me how you take your medicines?  |        |       | Packaging<br>Dispensing<br>Watch administration  | Packaging options<br>Alternative ways routes & preparation of medicine – e.g. Suspension, lozenges, syrups, patches<br>Refer to speech therapist for swallow assessment |             |
| Is this working for you?<br><i>If response is NO: Is any aspect of this difficult or concerning?</i>                                |        |       | Yes/No<br>Document response:   |   |             |

| Category: Capacity   | Client | Carer | Findings                     | Action            | Review date |
|--|--------|-------|------------------------------|-------------------|-------------|
| Is your medicine regimen flexible enough for you?<br><i>(explore timing, frequency of doses)</i> |        |       | Yes/No<br>Document response: | HMR               |             |
| Do changes in name and/or appearance of your medicines cause you concern?                        |        |       | Describe:                    |                   |             |
| Do you have difficulty remembering to take medicines?  |        |       | Yes/No<br>Document response: | Visual aids, DAAs |             |
| Have you tried any DAAs or medication aids to assist with taking your medicines?                 |        |       | Yes/No<br>Document response: | HMR               |             |

| Category: Access  | Client | Carer | Findings   | Action                                    | Review date |
|---|--------|-------|--|---|-------------|
| Who supports you with your medicines?   |        |       | <i>Identify supports/people involved and document what they do:</i><br>GP (regular or variable)<br>Pharmacist (regular or variable)<br>Specialists<br>Community nurse<br>Case manager/ community carers<br>Neighbour friend<br>Family (carer)<br>Other |   |             |
| Who takes overall responsibility for co-ordinating medicines from multiple prescribers? |        |       | Details:   |   |             |
| Are these people your provider of choice?   |        |       | Yes/No<br>Document response:   |   |             |
| Do you have difficulty accessing these supports?  |        |       | Yes/No<br>Document response:   |   |             |
| How do identify which medicines need reordering and when?<br>Is this working for you?   |        |       | Self<br>Other<br>Describe:   |   |             |
| How do you get the repeat prescriptions authorised?<br>Is this working for you?         |        |       | Self<br>Other<br>Describe:   | Organise directly between GP & Pharmacist |             |

|  |  |  |                            |   |  |
|--|--|--|----------------------------|---|--|
| How do you fill a prescription?<br>Is this working for you?  |  |  | Self<br>Other<br>Describe: |   |  |
| How do collect your medicines form the pharmacy?   |  |  | Self<br>Other<br>Describe: | Explore transport and delivery options (half price taxi scheme, community bus, pharmacy delivery, council carers) |  |
| Is cost a barrier in accessing your medicines?<br>Are you aware of the benefits that may be available to you in relation to accessing medicines? |  |  | Describe:                  | Safety net, Health Care Card<br>Use of Generics or branded medicines  |  |

| Category: Attitudes to Medicines   | Client | Carer | Findings                      | Action   | Review date |
|--|--------|-------|-------------------------------|--|-------------|
| What motivates you to take your medicines?   |        |       | Document response:            | Educational, Behavioural, emotional supports   |             |
| What makes it difficult for you to take them?  |        |       | Document response:            |  |             |
| What do you expect from your medicines?  |        |       | Document response:            |  |             |
| Are they meeting your expectations?  |        |       | Yes/No<br>No: describe issues |  |             |
| How do they make you feel? ( <i>explore side effects and adverse drug reactions</i> )      |        |       | Document response:            | HMR  |             |
| Do you have concerns about the interactions or side effects of your medicines?             |        |       | Yes/No<br>Document response:  | HMR  |             |
| Would you prefer a non pharmacological option to the medicines your doctor prescribes you? |        |       | Yes/No<br>Document response:  | Facilitate discussion with doctor;<br>discuss non pharmacological options if appropriate |             |

| Category: Medicines Information   | Client | Carer | Findings  | Action               | Review date |
|---|--------|-------|---|----------------------|-------------|
| How much knowledge do you like to have about your medicines?                |        |       | <i>Tick all that apply</i><br>What to take<br>When to take it<br>Condition it is treating<br>Names<br>Special instructions<br>How it works<br>Side effects<br>Potential interactions with food and other medicines<br>What to do when I miss a dose<br>Long term implications of the medicine<br>Other:<br>.....<br>None of the above | Education<br>Support |             |
| Are you getting the information that you want in the form that you want it? |        |       | Yes/no  |                      |             |
| Where would you prefer to be getting your information from?                 |        |       | <i>Tick all that apply</i><br>Doctor<br>Pharmacist<br>Nurse<br>Internet<br>Mobile phone applications<br>Information leaflets<br>Other: .....  |                      |             |
| In what form do you like your information to be presented?                  |        |       | <i>Tick all that apply</i><br>Language specific<br>Spoken<br>Written<br>Large print/ Braille<br>Audio/ visual<br>Electronic- iPhone, internet   |                      |             |

| <b>Category: Continuity, complexity and change</b>   | <b>Client</b> | <b>Carer</b> | <b>Findings</b>     | <b>Action</b>  | <b>Review date</b> |
|--|---------------|--------------|---------------------|--|--------------------|
| Do you experience frequent medicine changes? <i>(these may result from hospital admissions or specialists visits)</i><br>What are the issues that arise from this? |               |              | Yes/No<br>Describe: | HMR prior to discharge<br>Medicines list<br>Prompt Hospital discharge info to GP   |                    |
| If you have extended hospital or respite stays, how do these affect your ability to resume self-management of medicines on return home?                            |               |              | Describe:           |  |                    |
| <b>Category : Carer</b>  | <b>Client</b> | <b>Carer</b> | <b>Findings</b>     | <b>Action</b>  | <b>Review date</b> |
| What assistance do you need as a carer to safely manage medicines?   |               |              | Describe:           | Support<br>Telephone help lines<br><i>(Commonwealth respite and care link centre 1800 059 059)</i><br>Education<br>Counselling<br>Nurse as monitoring role<br>Complete RDNS carer assessment |                    |
| What are your goals for medicines management for your relative?  |               |              |                     |  |                    |
| <b>Client:</b>   |               |              |                     |  | <b>Review date</b> |
| What are your goals for medicines management?  |               |              |                     |  |                    |

## Appendix 2: Older Person Interview Questionnaire

| Older People Interview                  |   |
|---|---|
| Themes                                  | Questions and prompts   |
| Definition                              | <ul style="list-style-type: none"> <li>What do you think is involved in the management of your medicine?</li> </ul> <p><b>Prompt:</b> Identify the range of people that you see in relation to your medicines and what their role is.</p> <ul style="list-style-type: none"> <li>Does being on medicine result in the belief that you are ill? If so describe this further.</li> </ul>  |
| Barriers to optimal medicine management | <ul style="list-style-type: none"> <li>Can you identify any medicine tasks that are difficult for you?<br/>If Yes, why are they difficult for you?</li> <li>Describe any difficulties that you have experienced in taking your medicine</li> </ul> <p><b>Prompt:</b> Functional ability (mobility, sensory, dexterity)<br/>Health status/condition<br/>Cognitive function/ memory<br/>Access to medicines (getting to the GP or pharmacist, affordability of medicines) and aids<br/>Availability of support</p> <ul style="list-style-type: none"> <li>What strategies have you found help to overcome this problem (with your eye sight, memory, health, language, mobility etc)</li> <li>Do you sometimes forget to take your medicines?<br/>If Yes, describe the circumstances in which this might happen<br/>And: describe any methods you use to help you remember to take your tablets.</li> </ul> |
|   | <ul style="list-style-type: none"> <li>What packaging and medicine administration products cause you difficulty in managing your medicine?</li> </ul> <p><b>Prompt:</b> If you have a health condition that makes it harder to take your medicine please describe why.</p> <ul style="list-style-type: none"> <li>How confident do you feel about how you manage your medicines?</li> </ul>   |
| Safe use of medicine                    | <ul style="list-style-type: none"> <li>Are there any particular medicine characteristics or instructions that cause you difficulty?</li> </ul> <p><b>Prompt:</b> Describe what they are (pulse monitoring, not crushing tablets, measuring fluids)</p> <ul style="list-style-type: none"> <li>Have you found any ways of overcoming these difficulties?</li> <li>What do you do with your unused medicines?</li> <li>Have you ever seen a Chinese herbalist? If so what level of information have you given them about your current health status and treatments?</li> <li>When you think of over the counter medicines or Chinese herbs, do you think of these as medicines like those the DR prescribes?</li> </ul>   |

|                                      |   |
|--------------------------------------|---|
| <b>Assessment</b>                    | <ul style="list-style-type: none"> <li>• Have you ever been asked to demonstrate your ability to take your medicines?</li> </ul> <p><b>Prompt:</b> By whom and describe what you were asked to do</p> <ul style="list-style-type: none"> <li>• Have you ever been asked to demonstrate your knowledge of your medicine?</li> </ul> <p><b>Prompt:</b> If so by whom and describe where it took place and what did they ask you.</p> <ul style="list-style-type: none"> <li>• Does the age or generation of the health professional that is either prescribing or dispensing your medicine make any difference to you? If so describe why.</li> </ul>   |
| <b>Supporting choice (adherence)</b> | <ul style="list-style-type: none"> <li>• Do you take any self purchased/over the counter medicines, vitamins or any other supplements or complementary medicines?</li> </ul> <p><b>Prompt:</b> Would you tell your GP and pharmacist about these?</p> <ul style="list-style-type: none"> <li>• What circumstances would result in a decision to not take your medicine as the doctor has prescribed for you</li> </ul> <p><b>Prompt:</b> Would there be any reason because of your personal or cultural beliefs?</p>  |
| <b>Interventions</b>                 | <ul style="list-style-type: none"> <li>• Describe the strategies you use that help you to take your medicine.</li> </ul> <p><b>Prompt:</b> Ask the participant to describe their medicine routine step by step.</p>   |
| <b>Receiving help</b>                | <ul style="list-style-type: none"> <li>• Who provides support or advice about your medicines and how you take them?</li> <li>• When you go to the Dr for an ailment/illness, who makes sure you know about the medicines given to you? (prompt: GP, practice nurse, pharmacist, other person or the web)</li> </ul> <p><b>Prompt:</b> Is this information easy to understand?</p> <p>Do you find this information useful?</p> <p>When would you make a decision that you were no longer able to manage your own medicines?</p> <p><b>Prompt:</b> What sign would indicate you could no longer manager your medicines?</p> <ul style="list-style-type: none"> <li>• Describe how you think you would feel if this was to happen.</li> <li>• What would you want to see happen if this should ever occur to you?</li> </ul> |

### Appendix 3: Family Member Interview Questionnaire

| Family Member Interview                 |   |
|---|---|
| Themes                                  | Questions and prompts   |
| Definition                              | <ul style="list-style-type: none"> <li>What do you think is involved in managing medicine?</li> </ul>   |
|   | <ul style="list-style-type: none"> <li>What responsibility do you feel you have in giving another person's medicines? Could you give me an example?</li> </ul>  |
| Receiving help                          | <ul style="list-style-type: none"> <li>Who is available to you to provide support or advice about the medicines being taken by the family member?</li> </ul> <p><b>Prompt:</b> How are your GP and pharmacist helping you?<br/>What kind of help did they give you?<br/>Do you feel able or confident to question prescriptions or raise concerns?<br/>Is there anyone else involved that we haven't mentioned?</p>   |
| Barriers to optimal medicine management | <ul style="list-style-type: none"> <li>Describe any difficulties that the family member you care for experiences, in taking their medicine.</li> <li>What is the underlying cause of these difficulties?</li> </ul> <p><b>Prompt:</b> Functional ability (mobility, sensory, dexterity)<br/>Health status/condition<br/>Cognitive function/ memory<br/>Access to medicines (getting to the GP or pharmacist, affordability of medicines), packaging and other medicine aids and equipment<br/>Availability of support</p> <ul style="list-style-type: none"> <li>What strategies have you found help to overcome this problem that you have described (with your eyesight, memory, health, mobility, language etc)</li> </ul> |
|   | <ul style="list-style-type: none"> <li>What packaging and medicine administration products cause you or the person you care for difficulty?</li> </ul> <p><b>Prompt:</b> Identify which products are a problem</p> <ul style="list-style-type: none"> <li>What strategies do you suggest would help overcome the identified problem?</li> <li>The GP, Pharmacist and nurses all have systems and processes by which they manage the prescribing and dispensing of medicines. Have these processes ever caused you difficulty as a carer i.e. when getting the script from the GP or taking the script to the pharmacist or collecting the medicines?</li> </ul>   |

|   |  |
|---|--|
| <p><b>Safe use of medicine</b></p>          | <ul style="list-style-type: none"> <li>• Describe situations in which you have felt concern about your relative's ability to manage their medicine.</li> </ul> <p><b>Prompt:</b> How did you manage this?</p> <ul style="list-style-type: none"> <li>• To your knowledge has any health professional involved with the medicines discussed the management of unused medicine with you or the person taking the medicine?</li> <li>• In your experience have you found any strategies that improve the family member's ability to self-administer their medicine without error?</li> </ul>  |
| <p><b>Supporting choice (adherence)</b></p> | <ul style="list-style-type: none"> <li>• How do you differentiate between the person/family member <b>not wanting</b> to take their medicine to <b>not being able</b> to take their medicine?</li> </ul>   |
| <p><b>Giving help</b></p>                   | <ul style="list-style-type: none"> <li>• What sort of situations would make you feel you have to take over the medicine management of another person</li> </ul> <p><b>Prompt:</b> What were the triggers?</p> <ul style="list-style-type: none"> <li>• What experiences have you had since taking over the management of another person's medicine?</li> </ul> <p><b>Prompt:</b> Would you say that these experiences have caused or decreased feelings of stress or burden?</p> <ul style="list-style-type: none"> <li>• Have you ever experienced a situation where you have not been able to administer the medicines? Could you describe it?</li> <li>• Have you considered if for some reason you are unable to give the medicines, do you have a backup plan?</li> </ul> |

### **Appendix 4: Declaration of Confidentiality by Interpreters of Data**



|  |
|--|
| <h2><b>DECLARATION OF CONFIDENTIALITY BY<br/>INTERPRETERS OF DATA</b></h2> |
|--|

**Research Project Title:**

**Medicine – Improving Management** .....

.....

**Interpreter (please print details below)**

I (full name) .....

Of (address) .....

.....

acknowledge that all information interpreted by me for the research project named above will be treated by me with the strictest confidence.

All material relating to the above project will, while in my possession, be accessible to the researcher(s) only.

**Signature:** .....

**Date:** .....

**Witnessed by: (print name of researcher)**

**Name:** ..... **Signature:** .....

### ***Appendix 5: Translated documents***

Refer to the three translated document on the following pages:

- For Your Information
- Invitation to Participate
- Informed Consent Form

## Για την ενημέρωσή σας

### Τίτλος Προγράμματος: Φαρμακευτική Αγωγή – Βελτίωση Διαχείρισης

#### Για ποιο λόγο γίνεται αυτό το πρόγραμμα;

Η Βασιλική Περιφερειακή Νοσηλευτική Υπηρεσία (Royal District Nursing Service), παρέχει φροντίδα σε πολλά ηλικιωμένα άτομα τα οποία χρειάζονται βοήθεια για να πάρουν τα φάρμακά τους. Θέλουμε να μάθουμε περισσότερα για το πώς τα άτομα αυτά, συμπεριλαμβανόμενα και τα μη αγγλόφωνα ηλικιωμένα άτομα που διαμένουν στην κοινότητα, είναι σε θέση να διατηρήσουν την ανεξαρτησία τους διαχειριζόμενα τα φάρμακά τους και πώς μπορούμε να τα υποστηρίξουμε.

#### Τι περιλαμβάνει η συμμετοχή σας στο έργο;

Έχετε προσκληθεί να λάβετε συμμετοχή σ' αυτό το έργο επειδή οι απόψεις σας είναι σημαντικές για μας. Θέλουμε να σας μιλήσουμε σχετικά με το πώς διαχειρίζεστε τα φάρμακά σας. Αν είστε μέλος της οικογένειας, θέλουμε τις παρατηρήσεις και τις εμπειρίες σας, για το πώς διαχειρίζεται το άτομο την υποχρέωση να παίρνει τα φάρμακά του, και ποια υποστήριξη του παρέχετε εσείς.

Ο υπάλληλος έρευνας θα κανονίσει να σας επισκεφθεί στο σπίτι. Η συνέντευξη θα προγραμματιστεί όταν σας βολεύει και θα διαρκέσει περίπου μία ώρα.

#### Τι θα γίνει με τις πληροφορίες που μας δώσετε;

Θα μαγνητοφωνηθεί η συζήτηση που θα γίνει, έτσι ώστε, να διατηρηθεί ένα αρχείο της συνέντευξης. Οι πληροφορίες που θα μας δώσετε θα συνδιαστούν με τα στοιχεία που συλλέχθηκαν και από άλλες συνεντεύξεις. Τα αποτελέσματα θα μας βοηθήσουν να βελτιώσουμε τον τρόπο με τον οποίο το RDNS, θα παρέχει υποστήριξη σχετικά με τη διαχείριση φαρμάκων μελλοντικά στους πελάτες. Δεν πιστεύουμε ότι η συμμετοχή σας σ' αυτό το πρόγραμμα θα σας προκαλέσει οποιαδήποτε ταλαιπωρία ή ανησυχία.

Εμείς θα γράψουμε μια έκθεση, θα δημοσιεύσουμε άρθρα σε περιοδικά υγείας και θα μιλήσουμε σε συνέδρια σχετικά με τα αποτελέσματα αυτού του προγράμματος. Αυτά που θα ανακαλύψουμε δε θα συμπεριλαμβάνουν το όνομά σας ή οτιδήποτε άλλο που θα επιδεικνύει την ταυτότητά σας.

Όλα τα στοιχεία του προγράμματος θα αποθηκευθούν με ασφάλεια στο Ινστιτούτο Κοινωνικής Υγείας Helen Macpherson Smith (Helen Macpherson Smith Institute of Community Health). Θα διατηρηθούν το λιγότερο για 5 χρόνια, μετά από την ημερομηνία της τελευταίας δημοσίευσης και μετά θα καταστραφούν.

Η ηθική έγκριση για τη διεξαγωγή αυτού του προγράμματος έχει δοθεί από την Επιτροπή Έρευνας Ανθρωπίνων Ηθών του RDNS (RDNS Human Ethics Research Committee) (RDNS HREC Αριθμ. Έργου 117).



## For your information

### Project Title: Medication - Improving Management

#### What is the project about?

Royal District Nursing Service provides care to many older people who require help with taking their medication. We want to learn more about how people, including older people living in the community who do not speak English, maintain their independence with medication management and how we can support them.

#### What does your participation in the project involve?

You have been invited to take part in this project because your views are important to us. We would like to talk to you about how you manage your medication. If you are a family member we would like your observations and experiences of how the person taking medication manages the task and any support that you provide.

The research officer will arrange to visit you at home. The interview will be planned for a time that is convenient to you and will take about an hour.

#### What happens with the information you give us?

The discussion that takes place will be taped so that a record of the interview is kept. The information that you give us will be combined with data collected from other interviews. The results will help us to improve the way in which RDNS provides medication management support to clients in the future. We do not believe that taking part in this project will cause you any discomfort or distress.

We will write a report, publish articles in health journals and talk at conferences about the results of this project. What we find out will not include your name or anything that shows who you are.

All of the project data will be stored securely at the Helen Macpherson Smith Institute of Community Health. It will be kept for a minimum of 5 years after the date of the last publication then destroyed.

Ethical approval for the conduct of this project has been given by the RDNS Human Ethics Research Committee (RDNS HREC Project No.117).



## Tko odlučuje hoćete li sudjelovati u ovom razgovoru?

Molimo pročitajte pažljivo ovu izjavu. Možda ćete o odluci o sudjelovanju željeti porazgovarati s nekim prijateljem ili članom obitelji. Dostavljen vam je također i popis točki o kojima trebate razgovarati. Kada budete znali o čemu se radi u ovom projektu i odlučite na koji način želite da se s vama obavi ovaj razgovor, istraživač će od vas tražiti da potpišete obrazac kojim dajete suglasnost.

Vi niste obvezni sudjelovati u ovom razgovoru pa odluka koju donesete neće ni na koji način utjecati na vaš budući odnos s RDNS-om. Ako se odlučite sudjelovati, a kasnije promijenite odluku, molimo obavijestite o tome nekog iz tima ovog projekta. Sve informacije koje ste dali, a koje nisu podvrgnute analizi, biti će uklonjene.

## Ako imate pitanja o ovom projektu, molimo kontaktirajte:

Fleur Duane  
Research Officer,  
RDNS Helen Macpherson Smith Institute of Community Health  
31 Alma Road, St Kilda, 3182  
Tel: 9536 5232

## Ako imate pritužbu na ponašanje u ovom projektu, molimo kontaktirajte:

Dr Lisa Donohue  
Chair, RDNS Research Ethics Committee  
31 Alma Rd, St Kilda, 3182  
Tel: 9536 5322

Hvala vam što ste razmišljali sudjelovati u ovom važnom projektu.  
Sa štovanjem,

## Fleur Duane

Istraživač  
RDNS Helen Macpherson Smith Institute of Community Health



## Who decides if you take part in the interview?

Please read this statement carefully. You may want to talk about your decision to take part with a friend or family member. A list of discussion points has also been given to you. Once you understand what the project is about and would like to be interviewed, you will be asked to sign a consent form by the research officer.

You are under no obligation to take part in the interview and any decision you make will not affect any current or future relationship with RDNS. If you decide to take part but later change your mind, please notify a member of the project team. Any of your information which has not undergone analysis will be removed.

## If you have any questions about this project, please contact:

Fleur Duane  
Research Officer,  
RDNS Helen Macpherson Smith Institute of Community Health  
31 Alma Road, St Kilda, 3182  
Tel: 9536 5232

## If you have any complaints about the conduct of this project, please contact:

Dr Lisa Donohue  
Chair, RDNS Research Ethics Committee  
31 Alma Rd, St Kilda, 3182  
Tel: 9536 5322

Thank you for thinking about taking part in this important project.  
Yours sincerely,

**Fleur Duane**  
Research Officer  
RDNS Helen Macpherson Smith Institute of Community Health



## Πρόσκληση για Συμμετοχή

Προσκαλούνται μη αγγλόφωνα ηλικιωμένα άτομα και μέλη της οικογένειάς τους να συμμετέχουν σε συνεντεύξεις, για την έρευνα των τρόπων με τους οποίους διαχειρίζονται τα φάρμακά τους.

Το Ινστιτούτο Κοινωνικής Υγείας Helen Macpherson Smith (The Helen Macpherson Smith Institute of Community Health), έχει χρηματοδοτηθεί από την Κτηματική Περιουσία του Εκλιπόντα Glen W Griffiths και το Ίδρυμα της Helen Macpherson Smith (Estate of the Late Glen W Griffiths and the Helen Macpherson Smith Trust), να αναλάβει το πρόγραμμα «Για τη βελτίωση της διαχείρισης των φαρμάκων από τα ηλικιωμένα άτομα, και για τα μη αγγλόφωνα ηλικιωμένα άτομα και για τα ηλικιωμένα άτομα που ζουν με άνοια μέσα στην κοινότητα».

### Στόχοι του Προγράμματος

Αυτό το ερευνητικό πρόγραμμα εκτελείται, έτσι ώστε, οι νοσοκόμες μας να μπορούν να παρέχουν το σωστό επίπεδο υποστήριξης φαρμάκων στους πελάτες τους.

Θα θέλαμε να μας πείτε για τις οποιοσδήποτε δυσκολίες που βιώνετε ή έχετε βιώσει με τη διαχείριση των φαρμάκων σας. Επίσης, θα θέλαμε να μας δώσετε μερικές συμβουλές για τις στρατηγικές που σας βοήθησαν να ξεπεράσετε τις οποιοσδήποτε δραστηριότητες που είχαν σχέση με τα φάρμακά σας. Επίσης, θα θέλαμε να ακούσουμε τις απόψεις των μελών της οικογένειας, σχετικά με το τι είδους υποστήριξη παρέχουν και το πώς μπορούν οι επαγγελματίες υγείας να τους βοηθήσουν σ' αυτό το ρόλο.

Η Επιτροπή μας Έρευνας Ηθών (Committee on Research Ethics), έχει εγκρίνει αυτό το πρόγραμμα στις 20 Απριλίου του 2010 (HREC Αριθ. Έργου 117).

**Οι συνεντεύξεις θα διεξαχθούν μεταξύ Οκτωβρίου και Δεκεμβρίου του 2010.** Κάτω από ιδανικές συνθήκες, οι συνεντεύξεις αυτές θα λάβουν χώρα στην διεύθυνση του σπιτιού σας όποια ώρα σας βολεύει.

Αν νομίζετε, ότι είναι πιθανό να μπείτε σε κάποια έξοδα, για τη συμμετοχή σας σε μια συνέντευξη, παρακαλούμε ενημερώστε τον ερευνητή ο οποίος θα σας βοηθήσει να λάβετε αποζημίωση μέγιστης αξίας έως \$50 δολ.

Αν ενδιαφέρεστε να συμμετέχετε σε μια συνέντευξη παρακαλούμε τηλεφωνήστε στην:

**Κα Φλέαρ Ντουάιν (Fleur Duane) (03) 9536 5243**



## Invitation to Participate

**Non-English speaking older people and their family members are invited to take part in interviews to explore how their medications are managed.**

The Helen Macpherson Smith Institute of Community Health has been funded by the Estate of the Late Glen W Griffiths and the Helen Macpherson Smith Trust to undertake a project to **'Improve medication management for older people, older people who do not speak English and older people living with dementia in the community'**.

### Project Aims

This research project is being carried out so that our nurses can provide the right level of medication support to their clients.

We would like you to tell us about any difficulties you experience or have experienced in managing your medication. We would also like you to provide us with some advice about what strategies help you to overcome any medication related activities. We also want to hear the views of family members about what type of support they provide and how health professionals can assist them with this role.

Our Committee on Research Ethics approved this project 20th April 2010 (HREC Project No.117).

**Interviews will be conducted between October and December 2010.** Ideally these interviews will take place at your home address at a time to suit you.

If you think you are likely to incur any out of pocket expenses as a result of taking part in an interview, please advise the researcher who will be able to assist you to access reimbursement to a maximum value of \$50.

If you are interested in taking part in an interview please phone:

**Fleur Duane (03) 9536 5243**



## Έντυπο Συγκατάθεσης με Επίγνωση

### Πρόγραμμα: Φαρμακευτική αγωγή – Βελτίωση Διαχείρισης

Το Όνομά σας : .....(παρακαλούμε ολογράφως)

Διεύθυνση:.....

Τηλέφωνο: .....

Δια του παρόντος, δίνω την συγκατάθεσή μου για να λάβω συμμετοχή στο παραπάνω πρόγραμμα.

- Οι λεπτομέρειες αυτού του προγράμματος μου έχουν εξηγηθεί προφορικά, και
- Έχω λάβει ένα αντίγραφο Δήλωσης σε Απλή Γλώσσα (Plain Language Statement), και
- Οι οποιοσδήποτε ερωτήσεις που έχω κάνει σχετικά με αυτήν τη μελέτη, έχουν απαντηθεί ικανοποιητικά.

Συμφωνώ να λάβω συμμετοχή σ'αυτό το πρόγραμμα και κατανοώ ότι μπορώ να αποσυρθώ ανά πάσα στιγμή. Αν αποσυρθώ από το πρόγραμμα, τα οποιαδήποτε στοιχεία που προηγουμένως συλλέχθηκαν θα καταστραφούν. Συμφωνώ όπως, οι πληροφορίες που θα παραχθούν από μένα μπορούν να χρησιμοποιηθούν σε εκθέσεις ή να παρουσιαστούν σε συνέδρια, υπό τον όρο, να μην χρησιμοποιηθεί ούτε το όνομά μου, ούτε οι οποιοσδήποτε άλλες πληροφορίες που αποκαλύπτουν την ταυτότητά μου. Κατανοώ ότι, οι οποιοσδήποτε πληροφορίες που παρέχω θα διατηρηθούν απόρρητες.

Η Υπογραφή σας: ..... Ημερομηνία: Όνομα του

Μάρτυρα: ..... (Παρακαλούμε ολογράφως)

Υπογραφή του Μάρτυρα: .....Ημερομηνία:



# Informed Consent Form

## Project: Medication – Improving Management

Your Name: ..... (please print)

Address: .....

Telephone: .....

I hereby consent to participate in the above project.

- The details of this project have been explained to me verbally, and
- I have received a copy of the Plain Language Statement, and
- Any questions I have asked in regard to this study have been answered to my satisfaction.

I agree to participate in this project and understand that I may withdraw at any time. If I withdraw from the project, any data previously collected will be destroyed. I agree that information provided by me may be used in reports or presented at conferences on the condition that neither my name nor any other identifying information is used. I understand that any information I provide will be kept private.

Your Signature: ..... Date: .....

Witness' Name: ..... (please print)

Witness' Signature: ..... Date: .....





