“What Older People Want?”

Outcomes from a consultation with older consumers about their priorities for research in ageing.

2012-2013

Study undertaken by the National Ageing Research Institute (NARI) and La Trobe University

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Project Team and Acknowledgements

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1. Introduction

1.1) Background
In 2012 the National Ageing Research Institute (NARI) and La Trobe University Australian Institute for Primary Care and Ageing (AIPCA) received funding from the Victorian Department of Health to conduct a consumer consultation to determine what research in ageing older people perceive to be most important to their needs. NARI agreed to lead the project and NARI volunteers, as well as members of Council on the Ageing, Alzheimer’s Australia Victoria and University of the Third Age were invited to attend the consultation in December 2012. The findings were documented into a report as requested by the Department of Health in order to capture the themes arising from the consultation. This consultation (hereafter referred to as ‘the December 2012 group’) was also seen by both organisations as a fundamental project to guide a potential longer term partnership or collaboration around ageing research and build on individual strengths to achieve better outcomes in research and research translation in Australia. Under Professor Rhonda Nay, AIPCA and NARI discussed the potential establishment of an Academy of Ageing Research, however with the retirement of Professor Nay and restructuring at La Trobe University this proposal is currently dormant.

Following the initial consumer consultation, the Department requested further consultations be undertaken with a broader sample of older people. Subsequently two focus groups were conducted in rural areas and two in metropolitan areas. NARI received further funding from the Victorian Department of Health in mid-2013 to combine the findings of all consultations into one report. This report outlines the findings of all the consultations, capturing the key themes arising.

1.2) Aim
The aim of the consumer consultations was:
• To identify issues of concern to older people, and establish what older people consider to be priorities for future research directions.

1.3) Report structure
The report begins with a brief review of the literature regarding the involvement of older people in establishing research directions, and goes on to outline the methodology, themes and issues raised in relation to each of the consultation questions, and concludes with a discussion and summary.
2. Involving older people in research - Literature review

There has been a gradual shift toward increased involvement of older people in the establishment of research directions (Fudge 2007), with advocates suggesting that when older people and health consumers have input into research priorities, this produces clearer directions for research, and better quality information (Doyle 2009). The current literature suggests that involving older people in research agenda setting can indeed be beneficial for both the research itself, and for the older people who take part (Parent 2012), but this involvement requires a considered approach.

In 2004 in the UK, the James Lind Alliance (JLA) was formed to bring together health consumers, carers and health professionals, in order to better identify and prioritise unanswered research questions (James Lind Alliance 2013). The JLA establishes priority-setting partnerships made up of relevant stakeholders such as patient organisations, medical research charities, professional organisations or research networks, with the goal of finding out what questions health consumers and clinicians have about treatments that remain unanswered (Crowe 2005).

The JLA seeks to address the divide between what the research community may wish to prioritise, and what health consumers and health professionals would like researched (Cowan 2012). The approach they use is based on principles of transparency (regarding any conflicts of interest, and regarding the research process); inclusiveness - through engaging as many representative groups or interested individuals as possible; and evidence base – prioritising what is not already known (Cowan 2012). The JLA also publish a free guidebook for others who may wish to follow this template when conducting consumer driven research.

In Australia, Warburton et. al. (2009) sought to develop a framework of guidelines for successfully involving older people in community-based research. After conducting consultations and workshops with a range of stakeholders, their framework recommends the following steps or guidelines:

- Acknowledge research as a process
- Clarify roles and determine levels of involvement
- Communicate effectively
- Recognise different expectations
- Recognise difference
- Ensure representativeness and diversity.

The first step identified by Warburton et. al is also emphasised in the literature by Doyle (2009) who suggests that whilst researchers can support older people to participate across different parts of the
research process, their cues should be taken from older people regarding how much, and what kind of tasks older people would like to participate in. Warburton et.al (2009) and Mountain (2003) recommend that researchers provide training to older people as required to enable their participation in different parts of the process, as lived experience alone may not always be enough to facilitate successful participation in research.

Parent (2012) concurs with the second guideline regarding the establishment of roles and levels of involvement, suggesting that levels of participation need to be planned, and roles must be clarified if researchers are to avoid tokenistic involvement of older people. Doyle (2009) also acknowledges that although participatory researchers might wish to have older people involved in all parts of the research process, older peoples’ wishes must be the deciding factor when it comes to their participation.

The point raised by Warburton et. al (2009), “communicate effectively”, refers to the importance of clear communication, which they identify as using language that is respectful to older people, free from jargon and easily understood by participants and community members. Robertson (2011) also highlights the need for researchers to listen to peoples’ stories, and understand that research is not just a process of gathering data, but also a vital component of developing trust and rapport within research relationships with older people.

Warburton et. al identify “managing expectations” as another aspect of the research process that requires consideration. Specifically, their paper refers to the often lengthy process from securing funding to publishing results, which may frustrate community members or other stakeholders who are eagerly awaiting research outcomes (Warburton et. al. 2009). Consideration must also be given to partnerships with service providers, who often have their own expectations or user needs to prioritise, and must be clear on what the research may or may not be able to deliver (Warburton et. al 2009).

The framework proposed by Warburton et. al. also emphasises “recognising difference” as an important element of successfully involving older people in research. Warburton et. al. (2009) note differences in agendas and levels of power between stakeholder groups such as researchers, policy makers, service providers and participants. Differences also exist within groups such as older people participating in research. An example of this is highlighted by Parent (2012) who states that age is not a homogenous condition, and notes that the experiences of a 60-year-old and a 90-year-old may indeed be very different.
Recognising difference provides a foundation for the final guideline suggested by Warburton et. al. (2009) – “ensuring representativeness and diversity”. A study by Fudge (2007) provides evidence that age itself is not a barrier to participating in research, but involvement may be rendered inaccessible to some older people due to cultural divisions, language barriers, research skills capacity, ill health, or limited time and resources (Fudge 2007). In order to reduce the impact of these barriers, Parent (2012) and Warburton et. al. (2009) note that researchers must work to ensure accessibility of participation across gender, culture, socioeconomic, health or disability status.

The phenomenon of ageing has changed across time – older people in developed countries now have an increased life expectancy, and although diseases associated with ageing such as cardiovascular disease, cancer, diabetes and dementia are still present, improved treatments for most of these conditions has reduced the number of healthy years of life lost (Everitt & Le Couteur, 2011). Tanner (2012) suggests that despite possibly experiencing deteriorating health or limiting of some abilities, older people still have contributions to make and their input should not be discounted simply because it may be more difficult to obtain. Further emphasis is placed on continuing ageing research by McMurdo (2005), who states that since older people carry the greatest burden of disease, research priorities should better reflect the needs of older people, and Parent (2012) suggests that research on ageing will be limited in its impact and value if the involvement of older people is not taken into consideration.

Parent (2012) describes genuine involvement as being meaningful and productive, and operating with, not for or about seniors. Parent (2012) and Mountain (2003) comment that the experiences of older people can complement the expertise of researchers, and enhance the quality of research. Without effective participation from older people, expert-led studies may conform to pre-set research agendas or continue research in directions that older people do not view as relevant. For this reason, Parent (2012) suggests that a range of research methods should be used, and research participants should be given the opportunity to raise topics that were not originally defined by the researchers.

2.1) **Summary of the literature**

Most of the literature reviewed here suggests that older people should be involved in research to whatever extent is possible, with consideration given to their preferences for level of involvement. Researchers should make efforts to be inclusive of different groups such as those from Culturally and
Linguistically Diverse (CALD) backgrounds, people in rural areas, and other diverse groups and should also work to ensure that different views are represented in research. Communication about the research should be clear, and define the roles and expectations of participants from the outset.
3. Methodology
An interview guide was used by facilitators to guide group discussion, and a scribe took notes at each session. The questions asked of participants were:

1. What issues concern you about growing older: for yourself/family members?
2. What are the major issues for older people in relation to their health?
3. How do you think the health care system could better meet your/your family needs?
4. How do you think health professionals could improve our care of older people?
5. What do you see as the gaps in knowledge: by whom (e.g. older people, families, GPs, acute care, residential care…) and what ideas do you have in terms of making knowledge more available?
6. What specific health topics would like research to focus on? What should be the priorities?
7. How would you like to see yourselves/other consumers more involved in research?
8. What differences, if any, exist between medical research and ageing medical research?

The questions were designed to elicit views and as much information from participants about personal perspectives, experiences with the health system, topics for research and how they would like to be involved in research.

3.1) The December 2012 consultations
The first consultation took place on the 5th of December 2012 at the Moonee Valley Racecourse convention room. Older people who volunteer with NARI, as well as staff from La Trobe University, the Royal District Nursing Service, Council Of The Ageing, Alzheimer’s Australia, the Association of Independent Retirees and the Victorian Department of Health were invited to attend the session. The consultation session was chaired by Professor Rhonda Nay of the Australian Institute for Primary Care and Ageing (AIPCA) at La Trobe University, and Ms Debra O’Connor, Deputy Director of Operations at NARI.

The consultation was primarily conducted via smaller focus groups, with staff from NARI and AIPCA facilitating and scribing for each group of 6-10 participants. A total of 52 participants were consulted. Follow up demographic data was obtained from participants (see Attachment 1 for the demographic survey). One participant was not able to attend but provided feedback via email. This person’s comments are incorporated throughout the report.

An interview outline was used by facilitators to guide group discussion, and scribes took notes at each small group. Once discussion time had finished, each individual group reported back to the group as a whole to summarise their main points of discussion, and these summaries were also
captured in written notes and a brief plenary and discussion took place at the end of the session with the larger group. The questions asked of participants were the eight outlined above.

Notes from each group were sent to the facilitators and scribes within a fortnight of the consultation in order to check they were captured accurately, and that all key points had been captured in the written notes. Following feedback from facilitators and scribes, all notes were compiled into a master document reflecting participants’ responses to the set questions, and the issues they raised.

3.2) Focus group consultations (rural and metropolitan)
Focus group participants were recruited via Planned Activity Groups (PAGs). PAG groups meet on a regular basis and clients were informed of the consultations in advance by PAG staff and provided with the research information sheet (refer Attachment 2). Any interested participants were invited to the consultations which were held either during the time of the normal PAG session (for the metropolitan groups) or at the conclusion of the PAG sessions (for the rural groups), at the same venue. Members of the Planned Activity Groups registered their interest (refer attached Expression of Interest flyer – Attachment 2). Participation was voluntary and participants were informed of this.

Focus groups were recorded and notes were taken (as backup). Recordings were transcribed and then thematically analysed and organised. The sections to follow detail the key issues and topics raised in the group discussions at the consultation.

Each participant was asked to complete a survey which included basic demographic data. This provided the team with a profile of participants. Details are presented in the next section and the survey is included as Attachment 1.

Ethics approval for the focus group component of the consultations was obtained from the Health Sciences Human Ethics Committee (FHEC), La Trobe University as a low risk application. Ethics approval was not obtained for the December 2012 consultations as the session was an extension of an existing annual volunteer thank you day and, therefore consent was implied.

3.3) Demographic profile of participants
3.3.1) The December 2012 consultation participants
Surveys were sent to all participants; 36 (60%) responded. Of these respondents, 30 were volunteers, five were service providers or from other agencies and one was a government department staff member. Twenty-six participants were female and ten were male. Thirty-five (97%)
respondents were born in English-speaking countries, with 30 (83%) born in Australia. Of those six participants born outside Australia, four were born in the United Kingdom/England, one born in Northern Ireland and one born in the Netherlands. The preferred language for all respondents was English, and five also spoke an additional language (three spoke French, one Italian and one Dutch).

Eighteen respondents listed University or other tertiary education such as Teacher’s College as their highest level of education. Seventeen respondents listed their highest level of education as Secondary schooling or TAFE: two respondents completed year 8, four completed year 9, five completed year 10 and four graduated from year 12/High School Certificate. An additional two respondents did not specify their highest Secondary year level completed. Only one respondent ended their formal education at Primary level.

3.3.2) Focus group participants (metropolitan)
Findings of the demographics surveys of both metropolitan focus groups are outlined below (see Attachment 1 for a copy of the survey).

Group 1
Of all 13 participants involved in this focus group, 10 were public housing tenants and the remaining three resided in private residences.

Participants were asked to identify their postcode. In this group, all 13 participants were from postcode 3025. Hence, all resided in the same municipality and the same locality.

Most participants (n=9) were female, and four were male. Dates of birth ranged from 1964-1925 (i.e. approx. 49 years to 88 years). Most participants were born overseas (n=10) and of these ten, nine were born in non-English speaking countries. Years of arrival in Australia ranged from 1953-2003.

Education levels of participants varied, ranging from three years of primary schooling to 12 years of secondary schooling. One participant did not stipulate how many years of schooling they had in secondary school.

Group 2
Of all participants involved in this focus group, all resided in private residences.
Participants were asked to identify their postcode. In this group, three participants were from postcode 3018, three participants’ from postcode 3025, and two from 3028. All resided in the municipality but from a range of locations. Two additional participants were present as observers, one male and one female (one was a visitor from Interstate who occasionally made brief comments).

Most participants were female, with only one male. Dates of birth ranged from 1940-1919 (i.e. approx. 73 years to 94 years). Most participants were born in English speaking countries (n=6); those born in non-English speaking countries were from Ukraine and Italy. Years of arrival were 1949 and 1971 respectively.

Education levels of participants varied, ranging from six years of primary schooling to 12 years of secondary schooling. Two participants did not stipulate how many years of schooling they had (one referring to primary and the other referring to secondary schooling).

3.3.3) **Focus group participants (rural)**
Findings of the demographics surveys of both rural focus groups are outlined below.

**Group 1 (M)**
Participants in rural locations were not asked whether they lived in private or public accommodation (this was not one of the survey questions).

Participants were asked to identify their postcode. In this group, half the participants were from postcode 3677, three participants’ from postcode 3678, and one from 3737. One participant did not state their postcode.

Most participants were female (70%). Dates of birth ranged from 1938-1925 (i.e. approx. 75 years to 88 years). Only one participant was born overseas, all others were born in Australia. The person born overseas was born in England and arrived in Australia in 1950. One participant, born in Australia, also spoke German at home.

Education levels of participants varied; half the participants had gone to secondary school and the remainder had completed 5-8 years of primary schooling.
Group 2 (T)

As mentioned previously, participants in rural locations were not asked whether they lived in private or public accommodation (this was not one of the survey questions).

Participants were asked to identify their postcode. In this group, all 11 participants were from postcode 3700. Hence, all resided in the same municipality and the same locality.

Most participants were female; only one was male in this group. Dates of birth ranged from 1947-1916 (i.e. approx. 66 years to 97 years). All participants in this group were born in Australia and did not speak any other languages.

Education levels of participants varied, ranging from seven years of primary schooling to seven years of secondary schooling.

3.3.4) Summary of all participants

Across all groups, most participants were female which is consistent with the overall older people. Participants’ ages varied with rural groups and the second metropolitan group being an older age group.

Table 1: Age of participants and education

<table>
<thead>
<tr>
<th>Average age of participants</th>
<th>Group</th>
<th>December 2012</th>
<th>Metro group 1</th>
<th>Metro group 2</th>
<th>Rural group 1</th>
<th>Rural group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>74</td>
<td>74</td>
<td>86</td>
<td>82</td>
<td>85</td>
</tr>
<tr>
<td>Highest level education</td>
<td></td>
<td>74</td>
<td>86</td>
<td>82</td>
<td>85</td>
<td>85</td>
</tr>
<tr>
<td>December 2012</td>
<td></td>
<td>38% primary; 25% primary; 50% primary;</td>
<td>62% secondary</td>
<td>75% secondary</td>
<td>50% secondary</td>
<td>44% primary; 56% secondary</td>
</tr>
</tbody>
</table>

Participants born in non-English speaking countries resided mainly in areas of low socio economic status. The December 2012 group appeared to have a higher level of education than the other groups. Of the four focus groups, rural focus group number 1 had the lowest level of education.

The next section of the report provides an overview of participant responses to each of the discussion questions.
4. Summary of participant responses to each discussion question

This section reports the results of all the consultations. The information is presented in order of questions asked of participants and key themes emerging are reported under each question.

1) What issues concern you about growing older: for yourself/family members?

Across all groups, a range of common themes were identified that were of concern to participants about growing older.

| Common themes included: concerns about losing **independence**, moving from one’s own home and needing to move to **residential care**, increased **loneliness and isolation**, remaining **socially connected**, and limited **transport access**. |

Participants in metropolitan areas did not necessarily distinguish the issues for themselves or their families but for rural participants this was emphasised. This is further elaborated below.

In **December 2012** consultation, the issues raised can be grouped under three key areas:

- maintaining independence, mobility and choice;
- isolation, loneliness and connectedness; and
- recognition of diversity in experiences of ageing.

A range of issues were raised in relation to maintaining independence and choice. Issues associated with this included:

- The need for appropriate services including accommodation, housing and transport. Also the need for clear information about services and how to navigate them. It was stated that confusion is sometimes caused by too little or too much choice about services. More equitable funding arrangements will help to avoid a “lottery” of care or services depending on a person’s health condition or location.
- Anxiety about the future; for example becoming ill, getting dementia, going into care. Also, planning ahead for life changes (such as retirement, accommodation, legal issues such as Power of Attorney).
- Concerns were also raised about financial stress, safety, and quality of life. Maintaining health and optimal functioning through physical and mental exercise, nutrition and social activities was mentioned. The need for government to support and fund health promoting activities was stated.
In terms of isolation, loneliness and connectedness, participants talked about:

- Loss, grief and adjustment following the loss of a loved one.
- Health and lifestyle.
- Elder abuse.
- Technology, including connectedness or disconnectedness if one does not have skills to use technology.

Only in this group, was strong emphasis placed on the theme of recognition of diversity in experiences of ageing.

In terms of diversity, participants in this group mentioned:

- The differences in experiences of ageing from the perspective of gender, geographical location, and specific age range (e.g. 50s, 60s, 70s, 80s and beyond).
- Ageism from younger people, medical professionals and the assumptions that older people are lower functioning or have nothing to contribute.
- The desire for people to contribute.
- The need for improved communication between people and services in all directions, and a greater emphasis on getting more accessible information to CALD communities.

In metropolitan focus groups, losing independence, loneliness, memory loss, mobility and needing to move to residential care were raised across both groups as concerns. Across both metropolitan focus groups, environmental issues were raised as well as issues to do with the service system or access to services.

“I don’t want to go [to residential care].” (metropolitan focus group 1)

“My family wouldn’t let me go [to residential care].” (metropolitan focus group 1)

It was only in the metropolitan focus groups that issues regarding the environment were raised. Concerns by participants focused on the impact of industrial pollution on their health (group 1).

In terms of access to services, participants stated that there was limited availability of public transport for people with disabilities. Another participant (in group 2) stated that the convenience to
services depended on where people lived, alluding to the fact that areas of low socio-economic status had limited services. Also, almost all the public housing residents in attendance at focus group 1 commented and agreed on the need for air conditioning to be installed to manage the heat in summer.

For rural participants, mobility and maintaining independence (including relinquishing drivers licence), staying in one’s own home, staying active and healthy (including sufficient sleep), and socially connected were raised as issues of concern. Also, concerns with keeping updated with technology, not having sufficient knowledge to plan for the future, availability and reliance on carers (family members), ageism and appropriate communication with older people, being more prone to illness, staying motivated and limited transport options/general service access in rural areas were reported. For people in rural areas only, maintaining connections to and communication with family were identified as a concern.

Relying on, having access to and being a burden on family members/carers were of concern to people in rural areas.

In terms of carers/family members, participants said that they were concerned to see carers become exhausted when looking after them. They mentioned guilt of “continually having to ask for family assistance or care” (group 1). Across both groups the difficulties of having to become reliant on families and others and the challenges of accepting and asking for help were reported. Family can often live long distances from older relatives and this can impact on relationships as well as support. Others questioned supports available for carers, and challenges of using and accessing technology to communicate with and keep in touch with friends and family (group 1).

A range of comments were made about mobility and physical activity. In terms of mobility, participants talked about the focus on strength and falls prevention. Participants also talked about the difficulty of accepting declining physical ability and limitations (focus group 2). Others emphasised the importance of being actively engaged in activities, including hobbies, garden, dogs, friends and company, social activities, radio, puzzles, reading and CWA (focus group 1). Another mentioned that keeping busy and being active on the farm offers physical exercise and meaningful occupation (focus group 1).

Participants were concerned about being housebound into the future as this could lead to isolation from social activities, being excluded from activities, they could become more prone to illness and
they voiced concerns about losing the capacity to drive (focus group 1). Limited knowledge of what to do in the future such as care needs, medical and financial decisions was raised as a concern (focus group 1). For another participant, it was stressed that it is difficult to sustain effort and motivation to remain socially active when health declines (focus group 2).

Further to the theme of social connectedness, it was reported that “staying in touch” is also matched by “offering and accepting help”. The clear benefits of good community relations (family/neighbours/businesses/peers) were discussed (focus group 2). The experience of these members is that close others and the wider community consistently monitor older people. People check in regularly and proactively (i.e. assist with daily needs in home, and give practical help). They are particularly vigilant of those living on their own (focus group 2).

In terms of ageism, participants cited examples where carers were being addressed on behalf of the older person (an assumption of lowered capacity in older people) (focus group 2). Other comments were that older people are treated as “second class citizens”, that because “people are older there is an assumption they can’t do anything”, “taken our dignity”, and that older people are “made to be invisible, but I have a lot to contribute” (focus group 2).

2) What are the major issues for older people in relation to their health?
Across the various groups, participants identified major issues for older people in relation to their health. All participants across all groups focused on deterioration in health as a major issue for older people. In the December 2012 consultation, management and planning for the future were identified as important. In the metropolitan and rural focus groups, access to services was identified as an important issue for older people in relation to their health.

Management and planning into the future as well as deterioration of health were identified as major issues for older people in the December 2012 consultations.

In terms of management and planning of health, participants raised a range of issues. They discussed illness prevention, nutrition, medication and appropriate treatment of older people. Participants stated that there was a need for illness-prevention and they stressed the benefits of health promoting lifestyle behaviours or early/rehab intervention (e.g. hydrotherapy). Nutrition and how it impacts on health, such as looking at the relationship between diet, vitamins and health was emphasised. Overmedication and poly-pharmacy and the need for more access to medication
information was stated. Participants also believed there was under-treatment of older people for “age-related health issues” such as arthritis, pain, etc.

- In terms of planning, participants stressed the need for Advanced Care Planning. They also talked about euthanasia and choice around end of life circumstances (this also included palliative care and pain relief, and the idea of “the good death”).

When discussing deteriioration in health, participants identified a range of health issues that concerned them. These included issues that focused on cognitive, physical and mental wellbeing; as well as issues regarding pain in older people.

- Dementia and Alzheimer’s, decline of cognitive capacity, stroke, Parkinson’s disease.
- Balance and falls prevention, physical disability or limitations, arthritis.
- Heart attack, high blood pressure, overweight and obesity.
- Cancer (particularly less well-known diagnoses such as male breast cancer).
- Dental health (e.g. gum disease) and impacts of dental problems on eating/life quality.
- Mental health, including depression, stress, anxiety, post-traumatic stress disorder, grief, isolation and suicide.
- Sensory deterioration, including vision (e.g. macular degeneration), hearing, smell, taste and life quality.
- Pain (particularly unrecognised or “taken for granted” pain).

Other areas included: food allergies, incontinence, and insomnia.

In metropolitan focus groups, issues that were raised focused on both physical wellbeing as well as social and mental wellbeing. However, issues were also raised about the service system and service access, including access to adequate transport and health/medical services. Two participants (in group two) commented that services should focus on the individual’s needs.

Specific issues raised about physical, social and mental wellbeing included concerns about overall deterioration and needing to leave one’s own home.

“The most frightening part of getting old is going into a nursing home”. (metropolitan focus group 1)

“I don’t want to grow old!” (metropolitan focus group 1)
“Personal worries are a big issue, e.g. stress / anxiety about the future”. (metropolitan focus group 2)

For others, major issues for older people in relation to their physical, social and mental health were about having family support, having support of friends or neighbours and keeping active.

“We are happy (in the local public housing community) because we know one another here”. (metropolitan focus group 1)

“Keeping active and walking helps me”. (metropolitan focus group 1)

“I’m living with family (daughter and son-in-law) and that helps make it easier”. (metropolitan focus group 2)

“Family support makes a big difference for things like transport to appointments”. (metropolitan focus group 2)

Issues for older people’s health in terms of services and the service system included: long waiting lists for community health services; difficult to travel to services and limited transport; and limited services in the west.

“I can only get transport from the council to go to the doctor on a Wednesday afternoon – what if I get sick on another day?” (metropolitan focus group 2)

“There are transport difficulties; for example the dentist is too far to walk to, but not far enough for a taxi”. (metropolitan focus group 2)

“Need services to be available when you need them”. (metropolitan focus group 2)

“Need appropriate local services such as podiatrist; it’s helpful when health services can come to you”. (metropolitan focus group 2)

Rural participants said that major issues for older people in relation to their health were: maintaining a healthy diet; accessing doctors, hospitals and health services; functional decline and maintaining independence; confidence to get assistance and social wellbeing.
Participants in rural group 1 (group M) talked about the importance of having opportunities to maintain a healthy diet. They suggested that it would be good to go shopping in a group and for organised shopping outings of PAGs. They said that ensuring people eat fresh fruit and vegetables were important as well as access and affordability. The importance of growing one’s own vegetables was also mentioned.

Across both rural groups, access to services such as access to doctors and access to rural hospitals were identified as issues for older people in relation to their health.

- In terms of access to doctors, participants talked about limited access to specialist care in rural areas, and needing to travel to cities. They said that GP involvement is critical to both approval and guidance in care. Monitoring of, relationship with, importance of level of trust of doctors was stressed.
- In terms of access to rural hospitals, participants talked about waiting times and time delays, temporary GPs can impact on trust and relationships, and that this can mean the patient needs to retell their history. They also mentioned having access to rural hospital locums but some said that they need to travel into a regional city (e.g. 50kms) for GPs.

Functional decline and maintaining independence were also raised across both groups as major issues for older people in relation to their health. Participants talked about being vulnerable to multiple illnesses and rapid decline in health. They said that functional decline impacts all areas of wellbeing; for example, hearing loss, memory loss (dementia), pulmonary health, cardiac health, falls and mobility. They also mentioned seasonal illnesses such as influenza being an issue for older people. In terms of staying independent, participants said they fear staying independent in the event of poor health and emphasised the importance of understanding available service supports and aides to remain in their own home. They identified the following focus areas that impact on health of older people: hearing and sight loss, incontinence, arthritis, diabetes, pulmonary health, cardiac health, falls/mobility and exercise.

A lack of confidence to seek assistance and differing levels of health literacy were also reported as issues for older people in relation to their health. Social health and issues of remaining connected and appropriately stimulated were also reported.
3) How do you think the health care system could better meet your/your family needs?

Participants in the metropolitan and rural focus groups responded to this question. Participants in the December 2012 consultations combined their response to this question with their response to question four.

Participants across all focus groups suggested the health system could better meet their needs if services were more accessible and localised. They also talked about needing to feel safe. In metropolitan areas, participants stated that services could be more client focused and health professionals more informed about specific conditions. In the rural focus groups, participants talked about the need for improved referral pathways and transition; and recognition of informal support.

In terms of client focused services, participants in metropolitan areas outlined the assistance they would like to receive from services, in particular from doctors. They mentioned a preference for more home visits, and needing help to get to services. They also mentioned instances when they often get sent around to multiple places for tests. Some participants expressed that they were not getting the help they need; others said they were fine and didn’t really need more help at the moment. In terms of knowledge about specific health conditions, it was stated that “doctors don’t have enough time to help with special conditions or deal with multiple health conditions.”

For the participants of metropolitan focus group 2, safety was a key issue. Participants in this group were oldest of all groups. Key issues raised included the importance of access to after-hours services to alleviate fears and the importance of a personal alert.

“After hours services are important – like someone to talk to if you wake up frightened.” (metropolitan focus group 2)

“Having a personal alert helps for people who are living alone for example if they have a fall.” (metropolitan focus group 2)

In rural areas, service access was a key issue; safety was identified as a concern; improved referral pathways and transition; and recognition of informal support, i.e. carers were also mentioned as ways of improving services.
Improved access to hospital care when living in rural areas (including waitlists) was raised as an issue by rural participants in group 1 (group M). Also, limited access to essential service (such as the decline of rural ambulance service) and the need for more certainty around the availability of ambulance in rural areas was mentioned as an area for improvement for meeting people’s needs.

Feeling safe in one’s own home was also mentioned in this group. Participants stated that “supports are needed to assist older people to remain safe in their home”, therefore the need to build better systems surrounding informal supports (including better help for carers). Being attentive to carer burden and increasing the involvement of the wider family was mentioned (the wider family is often scattered geographically). Recognition and supports of volunteers who “fill in the gaps” was also identified.

Better pathways of care, building capacity of services to actively make referrals, and ensure appropriate referrals was identified in rural group 1. Greater options, or more visible options for respite was also mentioned. Also, greater assistance when in transition between home and permanent care is required.

A key issue raised in focus group 2 (group T) was the need to address the rapid changeover of GPs, including the need for continuity, relationship development, adequate provision of GPs to rural areas (will assist with reduced waitlists), and suitable funding to retain health workforce. It was also stated that more outreach health services were needed e.g. podiatry, dentistry and optometry.

In group 2, it was also stated that close proximity to a regional centre offers advantages that other rural areas don’t necessarily experience (i.e. greater access and options). Greater recognition and supports of volunteers was mentioned as well as recognising carer burden and increase funding is needed to decrease the expectation upon informal supports.

4) How do you think health professionals could improve our care of older people?
A range of suggestions were made about how health professionals could improve care of older people. Similar themes were raised where most suggestions focused on improving services, including the provision of appropriate and relevant services. However, comments within each group were specific to the population and demographic characteristics of the area.
In the December 2012 group, comments included: the need for a more consumer focused approach, more and adequate training, and better coordination of care. In the metropolitan focus groups, participants focused on the environment and raised systemic concerns with services. In rural focus groups, participants focused on: improving communication, and provision of sufficient and appropriate services. This group also highlighted the positive aspects of services.

Participants in the December 2012 consultations stated that more consumer focused care was needed. They said that there was a need for person-centred care, advanced care planning, and improvements to quality of care from the health care field (as care is often rushed and environments such as hospital settings are not always conducive to healing). They also said that there was a need for increased quantity of care and support available, particularly post-hospital discharge. Participants in this group also suggested the need to improve levels of care as people do not always fit into high-care/low care categories.

In terms of training, the December 2012 participants said that more health care and aged care staff with better training is needed. They also said that health professionals need to maintain up to date knowledge about health conditions.

The focus of these participants was on improving the quality of care, providing a more consumer focused approach, better coordination of care and improving communication between patients, health professionals and nominated family or carers. Participants in this group also focused on the need for better coordination of care in services. They reported that the health care system is currently too fragmented and overly specialised. It was stated that the waiting times and costs for health care are too great, and the division between public and private health care is wide. They also spoke about specific areas for improvement, as follows:

- Developing more accurate record-keeping systems, e.g. ehealth records that can be accessed by all health professionals involved with a person’s care.
- Need for better access to evidence-based dental care.
- Streamlined rebates are good (for example, the automatic payment of Medicare rebates).
- Automatic recall for GP appointments might help with more proactive primary patient care.

There appeared to be different comments across both metropolitan groups; group two being a frailer group. However, the focus of both groups was on systemic issues. In group one, the focus was
on both environmental issues (e.g. local industry and pollution; and concern regarding health issues arising from local industry and pollution in the west) and systemic issues.

Systemic issues that were raised included: long waiting lists, limited access to services, attitudes to older people, research gaps, and knowledge by medical staff of patients’ history. Participants expressed frustrations regarding deteriorating health whilst waiting for specialists such as eye and ear, or waiting to get in to see the dentist. They also said that sometimes older people have complex medical histories and new doctors/hospital staff may not know the persons history, causing multiple concerns in terms of care. Another person wanted access to physiotherapy services at her local swimming pool so she could be assisted whilst using it. One participant expressed issues with a specific health service, saying that when she was breathless and had to go to the emergency department, she did not get seen for 7-8 hours, whereas another hospital (Royal Melbourne Hospital) seemed to be able to help her sooner.

For group two, as well as having trust in their health professionals, issues such as difficulties in getting to health services and health professionals as well as the importance and preference of having services come to their homes was highly emphasised. Systemic issues associated with service access were key factors for this group.

“It would be better if doctors made house calls”. (metropolitan focus group 2)

“I can’t get to the dentist – transport / parking is difficult”. (metropolitan focus group 2)

“I can get to specialists in the western suburbs, but it still costs a lot in a taxi regardless of the half-price taxi card”. (metropolitan focus group 2)

In rural areas, participants said that health professionals could improve care of older people by improving communication (e.g. listening to consumers). Participants stressed the importance of active listening and said that this was particularly so for people with complex needs. Also, they emphasised that the manner of professionals is critical to develop trust, relationship and engagement.

In terms of providing sufficient and appropriate services, participants mentioned: coordinating care better (stating that “too many people and too many services” can cause confusion), providing more case managers to meet complex needs effectively, providing holistic care and understanding that not
all people are competent with technology. More specifically, in terms of technology, it was reported that some surgeries in a regional city are trialling a new access system (online where a person selects their own appointment time) but there was concern that not all older people can use technology (this can exclude some older people from health options). Participants emphasised the need for more transport services, and the need to recognise the extra burden of transport (i.e. there is no budget for services to cover travel costs, or in packages to help consumer in travel costs).

Participants also recognised positive aspects of care. In particular, they acknowledged the caring and respectful staff.

“They are trying their hardest”. (rural focus group 1)

“All just lovely”. (rural focus group 1)

“Feel well cared for”. (rural focus group 1)

“They are respectful in treatment”. (rural focus group 1)

“We are so lucky and well serviced here”. (rural focus group 2)

“Most are very caring people”. (rural focus group 2)

5) What do you see as the gaps in knowledge: by whom (e.g. older people; families; GPs, acute care, residential care...) and what ideas do you have in terms of making knowledge more available?

A range of gaps in knowledge were identified by participants. Participants predominantly focused on gaps in knowledge by older people. In metropolitan focus groups, participants also provided ideas about how to make knowledge more available.

Table 2 outlines the common gaps in knowledge identified by participants across all groups.

Table 2: Common gaps in knowledge identified across all groups

<table>
<thead>
<tr>
<th>Gaps identified in response to this question</th>
<th>Group</th>
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<tbody>
<tr>
<td></td>
<td>Older people</td>
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<tr>
<td>Gaps identified in response to this question</td>
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<tr>
<td></td>
<td>Older people</td>
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<tr>
<td>Understanding and navigating the health system.</td>
<td>✓</td>
</tr>
<tr>
<td>Knowledge of health conditions and medications.</td>
<td>✓</td>
</tr>
<tr>
<td>Knowledge of healthy lifestyles.</td>
<td>✓</td>
</tr>
<tr>
<td>Gaps in knowledge about services.</td>
<td>✓</td>
</tr>
<tr>
<td>Gaps in coordination of services.</td>
<td>✓</td>
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<tr>
<td>Gaps in professional development.</td>
<td></td>
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<tr>
<td>Gaps in knowledge and support to access technology.</td>
<td></td>
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<tr>
<td>Information required about planning for the future.</td>
<td></td>
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<tr>
<td>Gaps in how people receive information.</td>
<td>✓</td>
</tr>
<tr>
<td>Gaps in communication between older people and health professionals.</td>
<td>✓</td>
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</tbody>
</table>

In the **December 2012** consultations, gaps in knowledge focused on most of these areas.

The **December 2012** participants identified: navigation of the health system; health promoting lifestyle; knowledge of health conditions and behaviours; and support for older people to stay connected.

In terms of navigation of the health system, participants stated that: communication of funding and services available is too dense and unclear, there are gaps in residential care, and people from a non-English-speaking background are lacking information in general. They also questioned “why is it so difficult to find out about the support that is available?” For example, many people have no knowledge of programs that might assist them such as aids and equipment, funding for oxygen, etc.” They also said it is important to involve families and all family members in the care of older people.

Discussions about health promoting lifestyle behaviours focused on the need to stay active and occupied, including socially active. It was stated that there needs to be more understanding in the community regarding the range of exercises and lifestyle changes that can help promote health and prevent decline more holistically. They talked about not wanting to be a burden and loss of independence. Also, older people need education about different issues. The discussion focused on needing to work out how to get people interested in their health. Questions raised include:
• How do you get them motivated to find out more?
• How do you get people engaged?

Participants said more knowledge of health conditions and medications was required. Participants raised a range of health conditions that they believed there were gaps in knowledge. These included:

• Dementia.
• Vision loss.
• Falls, mobility, strength and balance.
• Blood pressure and exercise to prevent stroke.

In terms of more knowledge about medication, participants said information about medications and their possible interactions is an issue. They stipulated Voltaren/osteopanadol and its effects on kidney/liver failure. They mentioned that leaflets inside prescription and all medicines are required to describe the efficacy and provide warnings. This information should also to be put on the internet.

Participants said that more training is needed (but did not state for whom, however said that current undergraduate training is broad). They said that maintaining current knowledge is an issue and updating knowledge as a professional is important; for example, about dementia. Maintaining knowledge is hard for GPs as “they especially have to have a wide knowledge about everything”. It was mentioned that professional development is expensive.

A general comment about early planning for future was made; for example, Power of Attorney (POA), financial and MEPOA medical. Participants said that people need to be encouraged to appoint a Power of Attorney and do an Advanced Care Plan. They also said that public campaigns are needed to raise awareness of the importance of this.

In terms of support for older people to stay connected and using technology, participants stated that there is a need for funding and assistance for older people to get started with technology. They emphasised the need to ensure that older people are included and supported with newer technologies; for example, internet banking. They said that being connected with others via technology will help to improve social connectivity and decrease depression and isolation. They then talked about knowledge of depression and said that older people can improve their own knowledge about depression and seek help. They talked about elder abuse; that it can be subtle, very difficult, and includes financial abuse.
Participants in the metropolitan focus groups responded to the two components of this question but some participants also used it as an opportunity to raise concerns about gaps in services as well as gaps in knowledge. Gaps in knowledge focused on gaps in services. Participants provided strategies of how to make knowledge more available.

**Gaps in services**

Participants commented on gaps in services such as the local built environment, limited services and how traffic affects safety. Others mentioned that gaps in knowledge included: lack of access to a computer impacting on accessing information, information from different sources can be conflicting, and that there are issues regarding knowing what a person needs.

In focus group one, participants stated that not having local services available makes things more disjointed and fragmented. They said that there are issues with the local built environment such as uneven paths, preventing people from being able to walk and get some sunshine and increasing the incidence of falls. Others commented that the local traffic is going too fast and they feel unsafe with cars travelling fast around the courts (of the local public housing estate). Another comment was that there’s an issue regarding knowing what you need and what’s available; hence it was suggested that there’s a need for a health advocate such as a family member or someone who can “help you absorb information and ask questions at times when you’re not feeling well”.

In focus group 2, the emphasis was on information about services and how people get this information.

“I haven’t got a computer, just a TV and radio.” (metropolitan focus group 2)

“There’s an issue getting information if you don’t have a computer.” (metropolitan focus group 2)

“Sometimes there’s conflicting information from the doctor and what’s available online.”  
(metropolitan focus group 2)

**Making knowledge more available**

Participants in group one talked about how they currently receive information. They basically said they receive information from the radio and TV. In group two, they provided strategies of how
knowledge could be improved and also mentioned barriers in obtaining knowledge. Barriers included: limited capacity to ask questions, knowing questions to ask and doctors being seen as experts.

These barriers prevented participants from knowing what questions to ask and confidence in seeking answers and therefore having to rely on the doctor as expert and sole source of knowledge.

“If you have the capacity to think and ask questions its ok, but if you don’t ask you don’t always get the information.” (metropolitan focus group 2)

“I’m on 21 tablets a day. I asked my GP if I could do without any of them but she says I need them all.” (metropolitan focus group 2)

“If you don’t ask for information medical professionals don’t often offer it. You can often find information on the computer.” (metropolitan focus group 2)

“Even if you have the information you still need to interpret / understand it.” (metropolitan focus group 2)

Strategies for making knowledge more available included: asking questions, interpreting information, getting written information from doctors, having local support.

“You need to know which question to ask to get the information you need.” (metropolitan focus group 2)

“You could try getting the doctor to write down information if you don’t understand it at the time.” (metropolitan focus group 2)

“It might be good to have a printout from the doctor regarding symptoms/treatment/what to expect and when to seek help, so that older people can read through the information and/or give it to family members / friends or neighbours.” (metropolitan focus group 2)

“It helps to have someone nearby such as a neighbour who can check how you are.” (metropolitan focus group 2)
In terms of gaps in knowledge, the rural focus group participants focused on gaps in knowledge about services. Knowledge about services available was emphasised. It was mentioned that the level of consumer motivation can be influenced by the lack of knowledge of what is available, and where to look for it.

“It’s [service system] confusing, and needs to be more understandable to make it easier for everyone”. (rural focus group 1)

“Need better marketing, make them [services] visible, and more services; need to know who’s out there to hand us on to”. (rural focus group 1)

These participants also used it as an opportunity to talk about access issues; in particular, access to doctors. In terms of access to doctors, participants said there was a need to ensure access to regular doctors (which is helpful to patient trust and relationship), and doctors must be skilled and trustworthy. They mentioned the turnover of GPs in rural areas high.

Participants in rural group 1 also talked about gaps in knowledge by doctors and professionals generally. They said that GPs are highly esteemed by older people. Hence, they need to also look beyond physical needs of the patient and consider the services essential to overall care. It was stated that they are a key advocate for improved care. They also said it was important to ensure professionals have “refreshers” (professional development) in knowledge creation of the wider service system.

6) What specific health topics would you like research to focus on? What should be the priorities?
Participants identified health topics and subtopics they would like research to focus on.

Across all groups, Alzheimer’s disease, dementia, memory loss and arthritis, were identified. Also, across all groups, depression, anxiety, loneliness and mental illness were listed as well as social inclusion and social connectedness. More information from each group is presented below, in particular differences across groups.

In addition to the topics identified above, participants in the December 2012 group identified other general medical conditions, preventative health; and service quality and coordination.
In terms of the common topics, participants in this group talked in detail about dementia and about social inclusion and mental wellbeing. In terms of dementia, they said they would like to see more research about: how to better understand dementia and Alzheimer’s; younger onset dementia; non pharmacological approaches to behavioural changes; palliative care (pain relief) for people with dementia; whether there is a link between falls (a person hitting their head) and its effect on the development of Alzheimer’s disease; and the effect of aluminium, copper, chemicals, other elements (in foods), that might play a role on Alzheimer’s. It was also stated that a better understanding of links between modern technology and memory is required:

“I would like to see some research on the cognitive demands of remembering multiple passwords and PIN numbers when using modern technology in the context of maintaining independence, privacy and identity security”.

In terms of social connectedness and mental wellbeing, participants emphasised: the importance of social networks; the links between social networks and technology (for example, they said that not enough work has been done to understand the benefits of technology for older people, such as using Skype to stay connected to family); that there is a greater emphasis on mental health over social health; and they stressed the link between social connection and depression.

[Social connectedness is] “the most important thing of all.”

They said that depression can be invisible even to families, and the loss of social connection can have a huge impact. It was stated that when services break over holidays it can increase isolation for older people.

In terms of general medical conditions, the December 2012 participants stated that medical research should focus on the whole body and not be disease specific. They also listed a range of areas that they believe they would like research to focus on:

- Poly-pharmacy.
- Metabolism.
- Incontinence.
- Stroke studies.
- Parkinson’s disease.
- Research on dental care (as well as concerns raised about design of dental chairs).
They also mentioned vision and sensory loss, including hearing, smell, taste and any genetic links between losing sense of taste and smell.

Participants said they would like more research on preventative health, including lifestyle, nutrition, supplements, balance and falls prevention. Nutrition questions included information about cutting out unnecessary processed foods; diet; how to maintain and improve individual wellbeing, the role of vitamins in diet. When discussing supplements, participants said they would like further research about supplementary medication such as glucosamine, fish oil, magnesium and zinc. They emphasised prevention, treatment and education as well as quality of life:

“I do not care for the way we humans are heading, demanding that everything be delivered faster and faster and cheaper and cheaper. Whatever happened to sitting under a palm tree for enjoyment? What happened to quality? Is my attitude just an “age thing”?”

More research on improving service coordination and quality of care was suggested. This included the need for better coordination of services and continuity of services. Person centred care was mentioned as a means of providing quality service. The discussion also focused on specific services that needed improvement and specific gaps that need addressing:

- Support for carers.
- Palliative care – particularly for people with dementia.
- Advanced Care Planning.
- Timely diagnosis.
- Focus on people who fall through the gaps in systems.
- Better access to public health for people without private health insurance.

Participants in the metropolitan focus groups also identified additional health topics for further research. These topics included falls (including falls prevention, fear of being hurt and fear of falling), ME/CFS, stroke, heart disease. Another participant stated that support is required for those with alcohol addiction and another mentioned being frightened about going into a nursing home.

“People are worried about falls but I recently had a poor experience with a falls clinic – we need more practical advice about preventing falls and what to do if you do have a fall. The only place I got this information was from the paramedics who told me to curl into a ball.”

(metropolitan focus group 2)
“The major thing is to notify someone if you fall!” (metropolitan focus group 2)

In terms of the common topics raised across all groups, participants in the metropolitan groups talked in detail about depression, loneliness and memory loss. Some in group 2 also talked about fear of going into a nursing home.

“The most important thing to me is keeping your marbles.” (metropolitan focus group 2)

“You get frightened when you get older about all sorts of things”. (metropolitan focus group 2)

“I’m frightened of going into a nursing home.” (metropolitan focus group 2)

Participants in metropolitan group 1 expressed different opinions regarding depression e.g. “it’s in your control”; “It’s a health condition”; “medication is not always the answer for things like depression”; and “talking can be important”. One participant stated that physical activity helped them when they were depressed:

“When I’m depressed I feel like withdrawing and not seeing anyone, but I find going for walks helpful.” (metropolitan focus group 1)

Rural participants also identified a range of additional health topics for further research; topics focusing on cancer in older people, continence, eye care, sinus/allergies and hereditary diseases. Another participant stated that further work be undertaken to explore service improvements such as packaged care services and respite. In terms of continence, the concern was on the impact of overall functioning. Comments made about service improvements included exploration of how to make respite work better and better for carers; and exploring self-directed packages, brokerage, increasing options for users and increasing available monies.

Priorities (metropolitan participants)

In terms of priorities, participants in the metropolitan groups gave this a greater focus than other groups. The key areas and how the areas should be prioritised include:

- Alzheimer’s disease/memory loss.
• Falls.
• Depression/loneliness.
• Participants also talked about:
  • needing knowledge and information of each of these areas; and
  • needing strategies to help deal with these conditions and other health conditions including prevention strategies.

7) What differences, if any, exist between medical research and ageing medical research?

The December 2012 group and rural participants raised a range of issues regarding this question; issues varied according to the groups. However, there were also similarities, in particular, the need for an integrated and holistic approach to research. Participants in the metropolitan focus groups did not respond to this question; the discussion focused more on consumer involvement in research (see question 8).

In the December 2012 group, the focus was on: the broader, more holistic approach of ageing research, as compared to the disease focused approach of medical research.

In terms of ageing research, participants said that “a holistic approach over the life span” was required as well as the inclusion of research that focused on the “health system”. It was also stated that ageing research tends to be seen as “softer research”. Participants also identified gaps in ageing research, including the need for research on:

• The Quality of Life in older people.
• Community care > workforce > levels of care required.
• Ageing and multiple problems associated with ageing.

In terms of medical research, participants stated that the focus tends to be on “one thing at a time”, on “single health problems”; and that ageing research should be normalised where a participant stated “put [research] into ‘medical’ terms rather than normalising disease process versus ageing process”. Participants stated that ageing medical research should focus on poly-pharmacy.

In the rural focus groups, the emphasis was on the need for more ageing research as well as the need for an integrated approach to research.
In the first focus group (group M), participants generally felt that there appeared to be less research on ageing and they stated that there is a need for greater knowledge around how physical health impacts on psychosocial health.

In the second rural focus group (group T), participants suggested greater emphasis be given to differences of lifestyle and family connectedness, i.e. quality of life. Members suggested that independence is experienced longer in rural areas (where there is greater opportunity for people to remain active and stimulated) due to country lifestyle. They also said that there appears to be a strong focus on the factors that contribute to longevity, and research on what reduces risk of premature death.

8) How would you like to see yourselves or other consumers involved in research?

Participants across the various groups raised similar issues in relation to how they would like to see themselves or others involved in research. Issues included a recognition that more involvement of older people in research was required, the value of involvement was emphasised, more research was required, research needed to be more inclusive and strategies to improve involvement were suggested.

In the December 2012 group, the focus was on ways of improving engagement, the need for more funding for research and ensuring research was inclusive across all groups of older people (regardless of age, gender, cultural background or socio-economic status).

Participants recognised that it is difficult to engage people to participate in research and that researchers need to improve engagement with consumers. Need for more exposure for research projects in the public sphere was mentioned – for example through media, or visiting groups such as community health, councils, U3A or veterans groups were some strategies suggested that may enhance this process. They also suggested involving consumers in the design and review processes of research.

It was stated that more funding and opportunities for participation are needed. This included the need for more funding overall for research. A question was posed whether more research could be conducted online.
Participants stated that research needs to be inclusive. They felt that there appears to be a gender imbalance, with more women than men participating in research. Other comments focused on the need for inclusion of people from diverse socio-economic and cultural backgrounds and that these groups should be targeted for involvement in research. It was also suggested that the upper age limit for involvement in research studies should be removed and research involving intergenerational contact may help challenge ageism.

Participants in metropolitan areas focused on the benefits for them in being involved in research and cited focus groups and consultation as a good way of being involved in research. Some saw it as important as they are able to share experiences. One participant stated that involvement helped with loneliness.

“Focus groups are good – we need more opportunities to give opinions.” (metropolitan focus group 1)

“I don’t mind talking about the issues like in this group.” (metropolitan focus group 2)

“Being involved is important.” (metropolitan focus group 2)

“Involvement depends on what’s required – for example, if someone comes to you or if you have to travel.” (metropolitan focus group 2)

“Being involved in research might also help with loneliness.” (metropolitan focus group 2)

“It’s important to offer your experience.” (metropolitan focus group 2)

Two participants commented that they’d had a positive experience previously with a research institute and enjoyed being kept up to date with their research. Other participants expressed stories of varied experiences (via friends for example) of being involved in research trials, noting that sometimes there were medical/health effects. For others, it depended on the extent and type of involvement.

“It depends what capacity we’d be involved in – research trials? Focus groups?” (metropolitan focus group 1)
Another participant stated they would like to see research go in identified directions (for example, a stronger focus on specific diseases).

For those living in public housing, the following was raised:

“I think that they put public housing in the lower socioeconomic suburbs where there are other issues like pollution – therefore we need more support/help.” (metropolitan focus group 1)

Participants in the rural focus groups emphasised wanting to be involved in research, and outlined how. They suggested dissemination strategies (including clearly articulated information); the ABS census be enhanced; existing data be used and analysed; intergenerational interactions be encouraged; community grants be provided to undertake research; and face to face interactions was preferred.

Members in group 1 (group M) each held a strong desire to “have a say” and would do so again. They expressed opportunities to be able to give their health and community services feedback of their experience that then can be used in research and continual improvement.

In terms of how to involve participants, it was suggested approaching and targeting existing groups, providing them opportunity to be involved (with invitation/written letters). It was suggested that the ABS Census include a section for older people to complete regarding experiences and needs. It was emphasised that people who have parents in aged care facilities should be targeted for their say, as “the elderly in this situation are excluded from the census”.

Intergenerational involvement in focus groups was also suggested as this may assist, to hear diverse responses, and generate joint understanding of the issues (dispel ageism).

Participants in group 1 (group M) stated that researchers may want to consider using existing data for research purposes. They stated that “much information if given to visiting nurses and other screening assessment– used in databases- can this be translated for use in research”.

Participants in focus group 2 (group T) also mentioned a strong desire to be involved and have a say in research. They talked about how they would like this to occur. Comments included the provision of grants to communities to explore ageing; much wider dissemination to give a greater number of people opportunity to participate; and more face-to-face involvement (the group shared reluctance
to undertake phone surveys). They also mentioned approaching and targeting existing groups, providing them opportunity to be involved (with clear invitation/written letters) as did participants in rural group 1. They said that communication of purpose and aims need to be simple and clear (with opportunity for feedback).

The following section summarises the key findings and issues raised in these consultations.
5. Discussion of findings and concluding comments
The following section discusses the key themes that consultation participants identified as being important to them.

1) Issues of concern about growing older
One of the major themes arising from this topic was the wish to maintain independence and choice across the lifespan. A number of participants commented on their concerns about lack of choice around housing in later life. Participants commented in particular on concerns about decisions being made on their behalf (by aged or healthcare services, or by family) to enter residential care. Questions arose around the reasoning behind decisions about accommodation for older people, specifically the idea that a heavily risk-adverse approach to decision-making from health and community services might mean that independence is compromised in the pursuit of risk-minimisation.

Mobility and transport were also identified as significant issues in terms of maintaining independence, and enabling people to continue their social interactions and community activities. Social connection was discussed as an important factor in overall health and quality of life, and participants commented on how much isolation and loneliness had affected people they knew. Technology was suggested as one medium through which to increase social connection amongst people who may face barriers in terms of mobility or transport.

In summary, the similarities across all groups were:
- Concerns about losing independence.
- Concerns about needing to leave one’s own home.
- Increased loneliness and isolation.
- Not being able to remain socially connected.
- Limited transport access.

Issues specific to certain groups included:
- A strong emphasis placed on the theme of recognition of diversity in experiences of ageing in the December 2012 group.
- Issues regarding the environment (and industrial pollution) in metropolitan focus groups.
- Relying on, having access to and being a burden on family members/carers were of concern to people in rural areas.
2) What are the major issues for older people in relation to their health?

Major issues for older people in relation to their health focused on deterioration in health. In the December 2012 consultations, management and planning for the future were identified as important. In the focus groups, access to services was identified as important for older people’s health.

In summary, the similarities across all groups were:
- Concerns about deterioration in health.
- Management and planning.
- Increased loneliness and isolation.
- Service access.

Issues specific to certain groups included:
- The December 2012 group focused on management and planning into the future as well as deterioration of health.
- In metropolitan focus groups, physical wellbeing as well as social and mental wellbeing, issues about the service system and service access, including access to adequate transport and health/medical services were important to people’s health.
- For rural participants, maintaining a healthy diet; accessing services; functional decline and maintaining independence; confidence to get assistance and social wellbeing were major issues for their health.

3) How do you think the health care system could better meet your/your family needs?

Focus group participants talked about how the health care system could better meet their needs. Accessible and localised services as well as the need to feel safe were common across all groups.

In summary, the similarities across all groups were:
- Accessible and localised services.
- Needing to feel safe.

Issues specific to certain groups included:
- Services could be more client focused and health professionals more informed about specific conditions for metropolitan participants.
- Improved referral pathways and transition; and recognition of informal support for rural participants.
4) How do you think health professionals could improve our care of older people?

Participants mentioned that there was a need to improve both the quantity and quality of healthcare services available. A number of comments were made about healthcare staff often being rushed, and environments such as the hospital setting not always being conducive to healing. Participants also identified a need for person-centred care and advanced care planning. Many participants stated that more support and care should be available to people. Participants also suggested that more health care and aged care staff with better training are needed.

Other issues that were identified with the current healthcare and aged care system included levels of care, and better coordination of care. A number of people also commented on the need for improved communication and coordination of care – suggesting that hospitals and aged care services, community health and welfare services, primary care providers and specialists, and patients and family/friends all need to communicate better with each other, and work together to achieve the best outcome possible.

Many participants noted that they felt the healthcare system was too fragmented and overly specialised, with people detailing experiences of being bounced from one specialist to another multiple times. Participants thought that waiting times and costs for health care were too great. Participants also commented on the importance of health professionals maintaining up to date knowledge about different health conditions in order to best serve their patients.

In summary, the similarities across all groups were:
- The need for improved services.

Issues specific to certain groups included:
- A consumer focused approach, more and adequate training, and better coordination of care for the December 2012 group.
- A focus on the environment and systemic concerns with services for metropolitan focus group participants.
- Improved communication and sufficient and appropriate services was the emphasis for rural focus group participants.
5) What do you see as the gaps in knowledge: by whom (e.g. older people; families; GPs, acute care, residential care...) and what ideas do you have in terms of making knowledge more available?

Participants identified a number of domains in which they saw gaps in knowledge for themselves, as well as for health professionals and services. These domains included: understanding and navigating the health system; health-promoting lifestyle behaviours; knowledge of health conditions and medications; support for older people to stay connected via technology; gaps in knowledge about services; gaps in coordination of services; gaps in professional development; planning for the future; gaps in how people receive information; and gaps in communication.

Many people described having difficulties understanding and navigating the service system and health system, commenting on the fragmentation of services and lack of public communication about what support is available. Participants commented that communication needs to be improved in all directions – between health and aged care services, other community services, older people, family and friends, and government and policy makers. It was suggested that communication between different services is not always good, and similarly participants mentioned experiences of poor communication between themselves or loved ones and their healthcare professionals. Figure 1 below was created after the December 2012 consultations in an attempt to reflect these comments.

Figure 1: Communication flow
Participants expressed that **early planning** was very important for transitional times in life such as retirement, advanced care planning, or transferring power of attorney to another person. Information about **health-promoting lifestyle behaviours** was also identified as important, with participants mentioning aspects such as maintaining social engagement and stimulating activities, exercising and getting good nutrition.

**Knowledge of health conditions** and medications was another broad area where participants experienced gaps in information, both in terms of the information they had access to, and also the level of knowledge of health professionals about specific health conditions, particularly dementia.

In summary, the similarities about gaps across all groups were:

- Understanding the health system.
- Knowledge of health conditions and medications.
- Knowledge of healthy lifestyles.
- Gaps in knowledge about services.
- Gaps in coordination of services.
- Gaps in professional development.
- Gaps in knowledge and support to access technology.
- Information required about planning for the future.
- Gaps in how people receive information.
- Gaps in communication between older people and health professionals.

Issues specific to certain groups included:

- For the December 2012 group, **navigating the health system, health promoting lifestyle, knowledge of health conditions and behaviours, and support for older people to stay socially connected.**
- For metropolitan groups, the focus was on **gaps in services.**
- For rural participants, the focus was overall gaps in **knowledge about services** available; **gaps in knowledge of health professionals,** the need for professionals to consider the **overall care** of the patient, and knowledge about the **wider service system via professional development.**

In terms of how to make knowledge more available, the following was said:
For metropolitan participants, asking questions, interpreting information, getting written information from doctors, having local support.

6) What specific health topics would you like research to focus on? What should be the priorities?
This discussion covered a range of health topics including dementia, Alzheimer’s disease, arthritis, as well as broader topics of social connectedness and mental health.

Dementia typically arose in the discussions as a major health issue that participants thought research should focus on. Comments ranged from a need to better understand and identify Alzheimer’s/dementia early on, to questions over what participants saw as potential causes of dementia, to non-pharmacological approaches to behaviour management. Questions were also raised around the causal factors in dementia, such as the effect of elements like aluminium or other foods or chemicals in the environment, or the effect of head injuries on the development of Alzheimer’s disease. Participants also thought research should focus on younger onset dementia, palliative care and pain relief for people with dementia, and practical issues such as the modern need to remember PINs and passwords for technology use and the impacts of memory loss.

Arthritis was also identified by participants as a health issue requiring further research, with participants commenting that it was often “taken for granted as a condition of ageing” rather than being viewed as a disease and not an inevitable part of getting older. Similarly concerns were expressed about falls in older people and personal experiences with falls clinics were reported.

Participants made links in terms of social connectedness and mental health. They commented on the connections between good social networks and mental health, particularly in relation to depression. One participant discussed her own experience with her father who became very isolated after the death of his wife, and relied on the social contact he received from services such as planned activity groups, but experienced depression when those services had long breaks over the holidays.

In summary, the similarities across all groups were:

- Alzheimer’s disease, dementia, memory loss.
- Arthritis.
- Depression, anxiety, loneliness and mental illness.
- Social connectedness.
Issues specific to certain groups included:

- In the December 2012 group, an emphasis on medical conditions such as sensory loss, preventive health, and service quality and coordination (including the provision of person-centred care and advanced care planning, as well as more support for carers).
- In the metropolitan groups strong emphasis was placed on falls and cardiovascular conditions.
- For rural participants, more research was suggested in a range of areas including cancers, continence, eye care, respiratory health, hereditary diseases and service improvements.

In terms of priorities, the following was said:

- Alzheimer’s disease/memory loss.
- Depression/loneliness.
- Social connectedness.
- Falls.
- Knowledge and information about health conditions.
- Strategies to help deal with these conditions and other health conditions including prevention strategies.

7) What differences, if any, exist between medical research and ageing medical research?

Participants overall did not have as much to say on this topic as compared to other areas. Comments were provided from the December 2012 participants and from rural focus group participants. All groups emphasised that ageing research took a more integrated and holistic approach. Figure 2 below summarises how the December 2012 group perceived the differences:

**Figure 2: The perceived difference in ageing and medical research**

**Ageing Research** was seen as focusing more on the whole person and their experience of ageing - exploring multiple issues, and considering overall quality of life

**Medical Research** was seen as focusing more on specific health conditions or disease, and it was suggested that more needs to be done regarding poly-pharmacy
In summary, the similarity across the two groups was:

- The integrated and holistic approach of ageing research.

Issues specific to certain groups included:

- In the December 2012 group, a focus on the health system was stressed.
- The need for more ageing research, overall, was emphasised by rural participants.

8) How would you like to see yourself or others involved in research?

Many participant responses to this question reflect what is suggested in the literature. Some participants commented that they would like to see consumers become more involved in different parts of the research process, including the design and review of new research. Some participants indicated that they would also like to have input into future areas of research, suggesting for example that research involving intergenerational contact may help to challenge ageism.

Participants also affirmed the importance of recognising difference, commenting that many differences in experiences of ageing exist - from the perspective of gender, geographical location, and specific age range. Participants agreed that researchers need to ensure representative diversity by targeting a balance of participants of different genders, socio-economic and cultural backgrounds.

There was an expectation amongst some participants that increasing community awareness of ageing research findings may also help to challenge ageist assumptions. Some participants in the consultations commented on their experiences of ageism, often involving younger people or medical professionals assuming that older people are lower functioning or have nothing to contribute. Participants did acknowledge that engaging older people in research could sometimes be difficult, and recommended that researchers try to obtain more exposure for research projects in the public sphere.

The similarities across all groups were: acknowledging the importance and benefits of involvement.

Differences across groups regarding strategies for involvement included:

- Engaging people, funding participants, and making research inclusive (December 2012 group).
- Participants would like to see themselves or others involved in research via consultations and focus groups (metropolitan groups).
Targeting existing groups, face to face interactions, providing community grants to groups and clearly communicating aims of requirements (rural groups).

5.1) Concluding comments
The issues identified by participants in the consultations reflect the continued desire for quality of life in older age, with aspects such as independence and choice, maintaining physical and mental health, staying socially connected, and the need for well-coordinated, person-centred care and services emerging as key themes from the consultations. Equity of access to information and services for people from diverse socioeconomic and cultural backgrounds were also identified as areas for improvement.

The key health topics participants saw as research priorities included health conditions such as dementia, arthritis, mental health issues (depression and anxiety as well as social connection.) Social connectedness and technology were seen as important topics for continued research, particularly in terms of how to cultivate connected communities and ensure older people are supported to use newer technologies. Others suggested cancer, neurological problems and sensory deterioration. Participants also suggested that research should focus more on preventative health and factors such as diet, exercise, falls and balance and the efficacy of vitamins and supplements in maintaining health.

Finally, participants highlighted the need for continued research into improving the quality and quantity of healthcare and other services available, with a focus on person-centred care and ensuring healthcare professionals receive adequate continuing education to keep them informed of current developments in major health issues. Keeping older people involved in the process was of major importance. The issue of service coordination and streamlining processes to keep people at the centre of care surfaced as a research priority, with a need to consider the impact of environments such as hospitals. Accessible, localised and well planned services were suggested as areas for improvement. Strategies to providing information to consumers were raised as critical in improving care of older people and increasing their knowledge of health literacy.

Overall, the focus of the many topics covered in this report as well as the research priority recommendations focus on living a good life for as long as possible - maintaining physical and mental health, sense of identity and social connections, and ensuring that when health or other services are required, they too keep the person and their idea of a good life at the centre of their attention.
Where to from here
In summary, this process has highlighted that:

- Older people clearly like to be consulted and contribute valuable insight into their preferred research priorities.
- A number of themes emerged as topics for future research – dementia, mental health issues (depression and anxiety), arthritis, medication, polypharmacy, social connectedness and ageism.
- Barriers to undertaking research focused on ageing – including the lack of inclusion of older people in research agenda setting.
- Strategies to address these barriers were provided – strategies for dealing with one’s health as well as strategies for improving knowledge translation.

It is suggested these findings be considered and disseminated amongst key stakeholders. Funders, researchers and policy makers could consider involving older people in all stages of research agenda setting. In this process of agenda setting, the themes identified be considered as areas for further investigation. Older people perceive a lack of equity in allocation of research funding to address their identified needs. A regular process of engaging older people in the form of a research agenda symposium could be established as a way of reviewing these findings.
6. References


7. Attachments

Attachment 1: Participant Demographic Survey

Consumer consultation about research priorities for older people

DEMOGRAPHIC INFORMATION

Please fill in the details beside each question.

1. What is your postcode? ______________________________

2. What is your gender? □ Male □ Female

3. When were you born (year)? ______________________________

4. What is your country of birth? ______________________________

5. Which year did you arrive in Australia (if born overseas)? ________

6. What is your preferred language/s at home? _____________________

7. Do you speak any other languages? (please list)

_________________________________________________________________

8. Please describe your highest level of education:
   □ No schooling______________________________________________
   □ Number of years in primary school___________________________
   □ Number of years in secondary school_________________________
   □ Completed university_______________________________________

9. Did you attend this session as:
   □ Volunteer ______________________
   □ Service provider ______________________
Invitation to take part in a research project:
Consumer consultation about research priorities for older people

The Australian Institute for Primary Care & Ageing (AIPCA) at La Trobe University and the National Ageing Research Institute (NARI) have received funding from the Victorian Department of Health to conduct consumer consultations. The aim of the consumer consultations is:

• To identify issues of concern to older people, and establish what older people consider to be priorities for future research directions.

We would like to invite you to help us with our research by taking part in a focus group to talk about your experiences and what you think are priorities for future research directions. Before the focus group, you will be asked to complete a brief survey including questions about your age, gender and education levels. The survey and the interview will take about one hour in total. Participation in this project is voluntary. The focus group will be conducted during the normal PAG session/at the completion of the normal PAG session (with refreshments for those who want to stay).

If you would like to be involved in this project, please fill out the form enclosed and return it to your PAG staff member. A researcher will attend your PAG session to run the focus group. You will be notified in advance by your PAG staff members.

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Secretary, Health Sciences Human Ethics Committee (FHEC), La Trobe University, Victoria, 3086, (P: 03 9479 3583, E: fhechealth@latrobe.edu.au). Please quote FHEC application reference number FHEC 13/093.

Thank you for considering participation in this project. We really appreciate your assistance.

Yours sincerely,
Dr Deirdre Fetherstonhaugh 9479 6002 d.fetherstonhaugh@latrobe.edu.au
Professor Jeni Warburton 02 6024 9718 j.warburton@latrobe.edu.au
Betty Haralambous 8387 2331 b.haralambous@nari.unimelb.edu.au
PARTICIPANT EXPRESSION OF INTEREST

The information on this form will be treated as confidential and will only be used for the purposes of this project.

Name: __________________________________________________
Address: _________________________________________________
Suburb and Postcode: _______________________________________
Phone or mobile phone number: ______________________________

I wish to register my interest to take part in the research project, ‘Consumer consultation about research priorities for older people’.

Signature: _____________________ Date ____ / ___ / 2013

Please return this form to the Planned Activity Group staff member.

If you wish to discuss the project before registering your interest, please phone

Melbourne 8387 2305
Albury Wodonga region 02 6024 9718