

Australian Association of Gerontology

Submission to NH&MRC/ARC

Ageing well, Ageing Productively

Introduction and background

The Australian Association of Gerontology (AAG) has a broad multidisciplinary membership of academics, researchers, government administrators, service providers and others interested in the issues of ageing. Across the spectrum of their interests, there are many areas where research focus could be applied to assist in meeting the needs and concerns of older Australians. AAG therefore welcomes the multidisciplinary focus of the Aging Well, Ageing Productively initiative. There is a major role for the AAG in facilitating multi-factorial research, which requires dynamic linkages between communities and service providers with researchers in multiple disciplines.

Declining fertility rates mean fewer children and older populations. Rapid population ageing is now a worldwide phenomenon. Australia has aged rapidly in the past 30 years with rapid growth in numbers of the “young-old” – those aged 65 to 75 years. However more rapid population ageing in Australia will result from “ageing of the aged”, as our mortality rates decline in the over 70s to 90s. Population ageing will then greatly accelerate from the 2020s, when the baby boomers reach 75 years. Average survival in NSW is now over 80 years (83 years for women and 77 years for men) and human life span will continue to rise relentlessly. Average life span is projected to reach 100 years for women by 2060, with men slowly closing the gap. Absolute numbers of the “oldest-old” (85 years and over) will increase exponentially over the decades to 2051 - by 50% to 2011, by 440% to 2051- while the total Australian population grows by just 30% from 20M to 26M people (ABS).

There remains a brief window of opportunity to prepare for the coming exponential growth in numbers of very old people that will confront health aged care and medical services in coming decades. Population ageing can be dealt with most effectively through policy structures which are designed to engage all concerned parties, and which integrate public policy with public sector, private sector and non-government organisation activities and initiatives. Research and education as well as health, hospitals, housing and aged care are crucial issues for a successful ageing policy

Population based health care for older people, and especially the “old-old” (or people aged 75 to 100 years and over) is currently based on a coordinated “Local Sector Model” of multi-disciplinary medical, social, functional and cognitive assessment and management. This should ideally function across community, hospital care and residential care settings. While challenging existing models Aged Care Services Research and Health Services Research, and resulting translation of research into practice, must respect and understand existing multi-disciplinary teams, service boundaries and appropriate population densities for the coordinated delivery of integrated services.

Research challenges

Demographic transition is generating major research challenges across a wide range of economic, financial and policy areas. With rapidly changing demographics, we are

largely in uncharted territory in terms of our understanding of the many interrelated factors influencing the quality of life for older Australians. This is clearly the case for the older age groups, where multiple health problems may affect wellbeing and where there is an ever-growing need for research and understanding of the causes and treatment of medical conditions. Equally if not more vital, is understanding the social factors influencing well-being of older people, including suitability of care and support models and effective social participation.

Ageing is a major issue for the full range of research supported by the ARC and NH&MRC and there are few aspects of medical, scientific or social research that will not impact upon or be affected by, the ageing pattern of the Australian community.

Unlike much traditional health and scientific research, *Ageing Research* does not apply a single issue, reductionist research model. It recognises the complexity of ageing and the multi-factorial causality of age-related health and decline. It requires cross-disciplinary research, building capacity in medical, psycho-social, nursing and allied health areas. It will include study of multi-factorial preventive and clinical outcomes including social, environmental & biological factors responsible for late life decline. While the outcome of *Ageing Research* is the well being of the general population of older adults, there may also be a need to examine ageing across the whole life span.

Against this broad and varied effort, it is essential that the Ageing Well, Ageing Productively research program be appropriately focused. This will involve targeted medical, health science, social and economic research that examines socio-biological factors promoting successful ageing, including: mental and physical activity, social activity and support, nutritional factors, education and human capital accumulation, the local environment and social capital.

There is an urgent need to build Australia's capacity in ageing research. A strong research and development focus, supporting skill development and career opportunities for researchers will be a national resource in addressing an ageing population over the coming decades. For successful research outcomes it will be necessary to harness all the existing expertise as well as promoting the development of additional expertise. This development of young human capital is an essential output of this kind of initiative, and will stand Australia, and the region, in good stead into the future. It will also be important to tap into existing research programs. Currently substantial support may be available for high profile researchers or those with extensive track records, and support is becoming available to emerging (early career) researchers. However, less attention is given to researchers that are outside these two groups – researchers that with some support could make a more significant contribution to knowledge in Australia. This group could be networked into existing research hubs or developing ageing research collaborations.

To date, traditional research funding bodies, such as the NH&MRC and ARC, have not funded ageing research in proportion to Australian population ageing and the growth in absolute and proportional numbers of very old people. While existing Research Institutes and Foundations cover heart and lung diseases, arthritis, diabetes, cancer, mental illness and neuroscience, no public or community bodies at a State or Commonwealth level exist with capacity to promote or fund multifactorial

Ageing Research, as a defined research process, aiming at a defined body of knowledge.

New approaches to conducting research are needed that complement traditional investigator-led efforts by individuals and discipline based teams: In particular promotion of collaborations is important. In order for research to have a significant impact on the lives of older people, we need to bring together researchers from multiple areas to work together in addressing issues of ageing. There has been limited incentive or ability for social scientists and medical and health researchers to collaborate on research projects. Barriers to multidisciplinary projects such as single-discipline grant assessing panels could also be addressed.

In order to promote targeted multi-factorial research the AAG supports the concept of ARC Centres of Excellence (CoE) built around the economic social and health implications of ageing. Such a centre could focus on economic, financial, workforce and policy dimensions of ageing and health issues with selected research involvement from epidemiology, gerontology, and community health experts. However, this type of institution should be complementary to the role played by the ARC/NH&MRC in Ageing Well, Ageing Productively.

Key research foci

An initial focus must be on research outcomes for the population whose numbers are increasing most rapidly and who carry the greatest burden of acute illness, chronic disease, disability and social need - the "old-old" or people aged 75 to 100 years and over. For ageing research it is commonly the *status of the old-old* that is the outcome variable of interest, whatever the issue, condition or age-group under study.

For example, the Sydney Older Persons Study (SOPS) shows excessive levels of multiple physical diseases in community living people over 75 years (SOPS: arthritis 70%; heart disease 46%; lung disease 20%; stroke 16%; obesity 14%; PVD 11% etc). Gait, sensory and cognitive (neurodegenerative) disorders are even more prevalent in the old-old and (in contradistinction to the somatic diseases) increase exponentially with age over 75 years (SOPS: gait instability 50%; visual impairment 43%; cognitive impairment 38%; motor slowing 19%; dementia 17%; Parkinson's disease 5%). These disorders cause 70% of all disability and the limited research so far has found few proven protective factors. There can be little doubt that research into the causes, prevention and management of cognitive impairment is a priority area for ageing research focus. This is also true for research into multifactorial movement and gait disorders associated with advanced ageing. However, this needs to be broader than discipline defined research into specific movement disorders (such as Parkinson's disease in the young-old).

In conjunction with a focus on the health status of the old-old, there must be research into the care and support needed for this group. For example, on current figures (SOPS): 80% of the over 85s need assistance in domestic care; 30% require personal care (bathing, dressing, toileting); 70% are mobility impaired (high falls risk) and 80% are cognitively impaired (high delirium risk). They are vulnerable to acute illness, disability & hospitalisation while there has been very limited study or quantification of the impact on carers, who are vulnerable to stress, depression, poor health as well as considerable social & economic loss.

The need for evaluation and monitoring of policies, programs and interventions to provide soundly based information on both beneficial and harmful social and health outcomes must be a foundation of all ageing research.

Aspects of ageing research program

Key aspects of a successful ageing research program should

- Be multi-disciplinary (bio-psycho-social paradigms) to ensure that knowledge gains have value in informing constructive action. For example, the understanding of productivity and independence in later life, must jointly consider health, employment, and family issues. Single discipline research is already catered for in the established ARC and NH&MRC programs.
- Include participation by key stakeholders (older people organizations, NGOs, government agencies, industries and services, etc) in the development, conduct, and application of research.
- Emphasize positive outcomes - how to maximize gains of various kinds – as well as how to prevent or ameliorate negative aspects of ageing.
- Be of sufficient scale, quality, and continuity to bring together collaborative teams and build substantial bodies of knowledge
- Include development of Strategic Research Plans and processes and criteria for research assessment involving key action stakeholders as well as researchers.
- Incorporate mechanisms for dissemination and translation of research findings to increase the uptake and application of knowledge.

Specific research themes as suggested by NH&MRC/ARC

The four themes proposed by the Working Group are acceptable as a broad means of organizing topics for research. Care is needed to not artificially categorize topics that benefit from being considered together.

Structural issues –

It is assumed that this broad research theme is focusing principally on gaining understanding of the demographic, cultural, economic and social trends, which underpin the current and projected ageing experience in Australia. Little is understood about the many socioeconomic factors, which will influence the management of ageing in Australia in the coming decades. This essential area can include an explicit focus on the social changes ahead for an ageing society (over the 10 to 20 years of the National Strategy) and projections, scenarios, and knowledge that informs constructive, anticipatory responses. Some key elements of focused research will include

- Societal monitoring of cohort change, social attitudes and values (and how they do and can change and influence behavior), the aspirations and resources of the baby boom cohort,
- Opportunities and barriers in institutional adaptation (e.g. employers and older workers), and relationships between generations and age groups.
- Socio-economic status and ageing;
- Population health research that addresses responses to geographic patterns of ageing in the majority of Australian old-old people who remain community living
- Aboriginal ageing, with particular emphasis on the structural inequities that have resulted in a lack of advanced ageing, in both rural and urban Aboriginal communities, as a paradigm of socioeconomic, education, housing and health factors that lead to “Unsuccessful Ageing” and away from “Ageing Well, Ageing Productively”.

- Special groups in the ageing population, including people with disabilities and those living in isolated communities as well as their ageing carers.
- Population health research that addresses community responses to ageing issues e.g. advanced care directives, very old people living alone, isolation, carer support, access to health and allied services, access to transport and strategies for intervention

Some initial specific tasks, which should be given priority, include

- Funding for new analyses of existing data sets in order to make important findings available more quickly and to make better use of the substantial investment in current data collections. This includes resources to make existing data sets more widely available, to support improved analytical skills and to build emerging researcher capacity in ageing research.
- Funding to support update of existing data collections essential to understanding individual and societal ageing. This includes especially, continuation of existing longitudinal studies as well as new efforts that assemble the best scientific teams focused specifically on topics of national priority.
- Hence further longitudinal studies, analysing existing and future matched data sets to provide information on trends and differences between age cohorts.
- Further, ongoing collection and analysis of national cross-sectional surveys (notably by the ABS and AIHW), which provides 'social monitoring' of change, associated with individual ageing, cohort succession, and social change.
- Linking clinical research to population outcomes e.g. such as SOPS data, which relates what happens to individual older people and can then be extrapolated to the broader demographic trends. The need for more meta-analyses of clinical and non-clinical ageing studies that groups together data sets to maximize value and results for understanding and responding to population ageing
- An emphasis on new and existing neurodegenerative diseases morbidity and mortality data. Based on a review of the limited mortality, life expectancy and survival data available, deaths from many systemic degenerative diseases (heart, lung, cancer) continue to decline and are being replaced by deaths from even later onset neurodegenerative diseases, as part of a new disease transition. While the quality of mortality data for both infectious and systemic degenerative diseases is relatively good, the same is not true for mortality data for the neurodegenerative diseases. Although dementia is the commonest neurodegenerative disease, its prevalence and incidence had not been well defined up until the last decades of the 20th century, particularly in the "old-old".
- The essential issue to address is the current and projected incidence of neurodegenerative diseases. If current incident rates continue then the ageing of the population will create an epidemic of dementia, with the associated demand for care and assistance. The possibility that healthier old age, better education and increased mental and physical activity, will reduce the incidence of such diseases is one positive scenario which needs thorough study: as does the more negative scenario that suggests the age related incidence of neurodegenerative diseases may in fact be increasing. Factors such as changes in the levels and timing of diagnosis and reporting could artificially inflate such incidence figure but research is urgently needed to determine underlying disease incidence and trends.

Since much of the cost of effective management of older people will relate to the patterns of dependence and care, particular attention should be given to morbidity

data. Overall, the quality of data to examine and compare morbidity and disability by disease cause across populations has been less accurate than mortality data, with little reliable data on morbidity available. However it is increasingly important to define and measure morbidity, taking into account the delayed onset, slower course and reduced mortality associated with many important chronic systemic diseases over the past 50 years, the concomitant rise of the age-related neurodegenerative diseases, and the current controversies about compression of morbidity.

Social Capital

This is an expanding area of sociological study. To date, Australian studies have concentrated on measuring and analysing the social capital of whole communities, seeking to understand the relationship between social connectedness and such factors as crime, unemployment, health, family cohesion and domestic violence. There has been little examination of the social capital of older people and the resultant policy implications.

This area can be put more positively to include ways of maintaining and enhancing participation and well being as well as reducing the extent of dependence. Traditionally social issues in relation to ageing seem to take a back seat in relation to funding for ARC and NH&MRC grants. Social issues for older adults are significant as they impact on the quality and quantity of life. If we are to have a well-rounded ageing research agenda, social issues need to be given substantial funding opportunities compared to medical, health and aged care - as most older adults are ageing well.

The key concern is to identify social and physical environmental factors that influence ageing experiences and to inform strategies that improve them. The key themes leading to in-practice solutions include:

- Access to services will always be a high priority for research, and most importantly in practical demonstration projects. Access must incorporate the ease of reaching necessary care or health services, but also those essential aspects of effective social participation, which rely on ability to get out and meet others.
- Issues around family and informal care and the effect of demographic change on the capacity for informal care
- The extent of social connection of older persons relative to the past or to those in countries with a similar level of socio-economic development. Issues such as involvement in civic entitlements and participations in the business of government, need to be examined.
- The extent, availability and importance of social support and social interaction and its relevance to the older community
- Lifestyles – understanding the lifestyles of the elderly and how they are evolving and their evolving needs for support services. This should include the full range of leisure activities with which older people may wish to be involved. One aspect of research, is the extent to which the market will address the needs of older people. It is likely that as the baby boom/60s generation ages, the traditional organised leisure for older persons will need to be expanded and an effective framework will be needed to cater diverse tastes. The capacity of market forces to meet the demands of the ageing population will be an area of social research.
- Work – understanding the role of older individuals in the workplace. This is an area of growing interest and affects mostly those in the young-old category i.e.

those 65-75 years. It will be an essential element in developing models for funding the ageing of the Australian population.

- Financial independence and capacity to pay for a healthy, and satisfying old age as well as to manage the costs of increasing dependence and assistance.
- Education and human capital accumulation – understanding the role of education, in a broad sense, in accumulating human capital across the life span, in preserving brain function, and in producing an educated older group who will have improved capacity to self-manage their own health, to self-manage chronic illness when it occurs, and to use the health and aged care systems effectively.
- Ageing in place is an emerging research theme, which is being put forward as important but with very little work done on the social geography of ageing, i.e. how do older people, including those with cognitive impairment, construct and relate to place versus space, how important is place in successful ageing (eg. own home, local neighbourhood, local communities). How do localized dynamics impact on service providers planning strategies?

Some specific issues to examine include:

- The application of new technologies to population ageing at the clinical through to the social level e.g. using Geographic Information Systems (GIS) and related technologies in enhancing community care interventions, outreach services, community transport and so on. With the growth in the frail aged i.e. 85+, location and localization will grow as important factors in aged care planning. This group is not as mobile as the young old both physically and in terms of access to and use of private and public transport.
- Studies to understand the impacts on older people and other consequences of interventions aimed at individual behaviors, changes to social institutions (e.g. employers) and services and programs.
- Transportation issues: Access will affect all aspects of the ageing experience. Lack of available, affordable and accessible transport reduces social participation and becomes a major cause of social isolation, especially for the increasing numbers of older people without strong family support. This in turn has been shown to increase the demand for and reliance on government support services, including both community-based and residential care. Demographic projections (NATSEM 2004) forecast a decline in the availability of family support, but limited information is as yet available predicting the consequential impact on demand for formal support services. A NSW Division of AAG seminar on the transport needs of older Australians identified key research gaps including the inter-relationship between transport, housing and urban planning and noted that the relationships are not well understood and that little information exists on the economic implications of poor coordination between these sectors. Little is understood about patterns of transport usage amongst older people or current and projected levels of demand.
- Intersectoral (versus silo-based) planning that is centred on older people and their local community.

Models of care

This area could benefit from more focus on care and service delivery (including accommodation), self-care and informal care, and effectiveness and options for improvements including intergovernmental relations and health and welfare integration. The key areas of research include:

- Financing - estimating the resources required by an ageing population and exploring how these resources can be provided. One key issue that must be

addressed is the projected cost of the last years of life. Will a longer life span result in extended periods of care (both acute and residential) or will the costs be compressed into the last year/months of life. The funding implications for extended periods of dependence are significant. Conversely, a very old population may live well, die rapidly and consume fewer resources in the last 2 years of life.

- Targeted health services and workforce research examining health care systems for older people within all settings including the local community, acute hospitals, rehabilitation/functional recovery and residential care. Transitions of care across the four settings, and impacts of change in resources in one setting on activity in the other settings, are of course essential elements of study requiring dynamic systems modelling.
- Models of care and different workforce requirements and associated educational requirements.
- Care generally - there is very little research related to care - as opposed to treatment and cure; with increase in chronic diseases often it is care systems that maximise function.

Determinants of healthy ageing

This area has a strong and valuable focus on the complex interactions and translation. In this area it is especially important to focus on ageing research directly beneficial to older people (e.g. rather than diseases and/or ageing organ systems) and to advance knowledge through multi-disciplinary and multi-method studies, for example, applying genetic and imaging technologies in longitudinal, population studies. The important question for ageing research is not simply “is this degenerative process ageing or disease?” but, more significantly, “can this degenerative process be modified, prevented or delayed, without significant risk, by manipulation of environmental and/or genetic risk factors”. The aim of ageing research remains one of compression of morbidity, towards the end of life and the prolongation of the period of healthy non-disabled life. This aim may, or may not, be consonant with increased longevity. The challenge facing ageing research is to seek new and modifiable risk factors to delay the onset of disorders, which are reducing quality of life in advanced old age.

Prevention of unhealthy ageing

Some key elements of research in the very old group are:

- Modifiable risk factors for decline, to reduce the burden of disease and disability in late old age before we face our demographic explosion (recognising that all previous ABS ageing projections have been under estimates).
- Multi-disciplinary research into the complex causation, prevention and clinical management of the common multifactorial “Geriatric Syndromes” (gait instability and falls, acute confusional state and delirium, cognitive decline and dementia, slowing and reduced mobility, incontinence, depression) that create co-morbidity, prolong length of stay and increase disability following acute systemic illness.
- Recognition of the complexity of diagnosis of neurodegenerative disorders in the old-old. Despite their very high prevalence and incidence these diseases are, in general, poorly defined and diagnosed compared to the common systemic degenerative diseases (such as heart and lung disease and cancer) and there is a high current level of under-ascertainment of neurodegenerative disease mortality. Diagnosis of dementia during life remains difficult in advanced age and a number of studies demonstrate the lack of recognition of dementia in the community. The neurodegenerative disorders outlined, commonly present as the

multifactorial “Geriatric Syndromes”, rather than as specific neurological diseases amenable to specific diagnoses. Age-related prevalence of neurodegenerative diseases is thus not well recorded in mortality data.

- Trials of multiple interventions in these multi-factorial age-related syndromes: combining physical, social and mental activity with medication screening and environmental safety measures
- Preventive research into complex inter-related causes of the cognitive and mobility disorders of old age, where knowledge lags well behind prevention of the systemic diseases (heart, lung, cancer etc) e.g. dementia prevention models combining anti-oxidants, mental stimulation, vascular preventives, physical activity and social involvement in mild cognitive impairment to delay dementia onset. While the study of genetic risk factors has dominated recent research publication in the dementias, there remains good evidence for associated environmental factors, either causal, or as modifiers of timing of disease onset or rate of progression, both of which mechanisms might alter prevalence or morbidity.
- Biological research into the mechanisms causing the common primary neurodegenerative processes affecting cognition and mobility (primary age-related neuronal loss unrelated to known mechanisms - vascular, metabolic, toxic, inflammatory, infective etc)
- Quality of life research focussing on the person not just the disease, with the primary aim being extension of healthy non-disabled life span.

Conclusion

Ageing research must be a major focus of health and social research for the foreseeable future. It is to be expected that the priorities and key tasks will change over time in the light of new data, new technologies, medical advances, changing social trends and improved overall population health. It is important therefore that avenues of research remain flexible and capable of turning attention to new needs and circumstances as they arise.

The Australian Association of Gerontology has a strong focus on ageing research and education across many fields. Its members have considerable expertise in both in-depth medical, scientific and social research, as well as in cross-disciplinary projects. The Association welcomes the opportunity to contribute to further development of the Australian ageing research agenda, both now and in the future.