

## Draft

### NACA Working Group

## Strategic Research Directions

### 1 INTRODUCTION

Demographic transition is generating major research challenges across a wide range of economic, financial and policy areas. Ageing is a major issue for research 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. 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 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 the well being of older people, including suitability of care and support models and effective social participation. 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 over the coming half century.

Ageing Research has long recognised the complexity of ageing and the multi-factorial causality of age-related health and decline. It involves cross-disciplinary research, and includes study of multi-factorial preventive and clinical outcomes including social, environmental and biological factors responsible for late life decline. 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.

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 positive 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.

### 2 OBJECTIVES

The Alliance recognises that best practice in providing services to older Australians relies on access to sound evidence based research which focuses on the major issues which affect the health of older people or the quality of care received.

Alliance objectives in developing this paper are to:

- ❖ Assist researchers and research funders to identify the issues, which are of greatest concern to health care and service providers and where targeted reach might yield maximum useable outcomes
- ❖ Assist in identifying research priorities, building on the research priority framework established under the Building Ageing Research Capacity Project and or established under specific programs such as the dementia specific research programs

- ❖ Identify knowledge gaps which could be filled by targeted research i.e. specific reach projects
- ❖ Advocate for a wider, better co-ordinated ageing research funding base.
- ❖ Assist in the dissemination of research outcomes publicly available through websites, publications and public seminars.
- ❖ Assist in the implementation of best practice and in translating evidence based research into practice.
- ❖ Building relationships between researchers, providers and consumers in order to better promote effective multidisciplinary, cooperative ageing research.

### **3 RESEARCH CHALLENGES**

Mechanisms need to be developed for identifying research priorities that ensure that the overall benefit to Australia is optimised. This task cannot be undertaken in isolation and it is essential that as wide a range of researchers, policy makers and those involved in management and care of the elderly and sick in the community are involved in the process of identifying research priorities. Key aspects of a successful 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, leisure activities and family issues.
- ❖ Include participation by key stakeholders (consumer 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
- ❖ Incorporate mechanisms for dissemination and translation of research findings to increase the uptake and application of knowledge

One of the biggest challenges in research is ensuring that outcomes are actually implemented. There are many systematic research reviews undertaken but hardly any study to determine how far recommendations are in fact implemented. Assessing the Impact Factors of research ie how effectively it is translated of research into practice is vital to successful quality care. The Alliance is very well placed to be a partner (or a coordinator of partners) who can participate in this important aspect of clinical research.

### **4 RESEARCH CAPACITY**

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.

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. Barriers to multidisciplinary projects such as single-discipline grant assessing panels could also be addressed.

Research must be directed not just to disease treatment, or to service delivery models but also towards ageing well and the means through which Australians as they age can maximise participation in the community.

The Alliance stresses that both government and the private sector should reaffirm commitment to ageing research, ensuring that research funding levels match those of comparable economies.

The Alliance supports the allocation of substantial research funding to targeted ageing research programs but also recognises the importance of general “for interest” driven research noting that a substantial number of research advances are from serendipitous discoveries.

## **5 KEY RESEARCH PRIORITIES**

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. Identification of agreed research priorities is essential but needs to be handled with some caution. Research priorities are ever changing as a research finding answers one key question but opens up many others. Priorities will change therefore need to be regularly reviewed and updated. The aspects of ageing research particularly relevant to the ongoing interests of the Alliance as on 1 January 2006 are included as Attachment 1.

## **6 RESEARCH FUNDING BASE**

In Australia today the sources of research funds include:

- ❖ Research funded through the traditional sources – ARC/NH&MRC
- ❖ Targeted ageing research programs eg NH&MRC/ARC Ageing Well Network or the Dementia Research fund
- ❖ In house government research through service delivery agencies eg Veterans Affairs or the AIHW
- ❖ Some private sector research funding through foundations and trusts eg the Wicking Trust or the Myer Foundation.
- ❖ A very small level of corporate research

The Alliance potentially has an important role in promoting and expanding the ageing research funding base as the co-operative multifocal interests, connected through NACA provide an excellent basis for approaching potential research funders especially those from the private sector.

## **7 DISSEMINATING RESEARCH RESULTS**

Disseminating research is a two way street. Researchers need guidance on the important issues facing consumers, policy makers, clinicians and service providers while consumers, policy makers, clinicians and service providers need access to research finding in a manner that allows effective implementation

The use of terms such as “evidence based practice” are often used to describe the important need to ensure that clinical and other practices are based on sound research findings. However access to research must be wider than this simple concept allows

Most research findings are published in academic research journals, which while prestigious, are not generally available (or comprehensible) to those outside the academic discipline. Strong support is given to cross-disciplinary academic journals (such as the Australasian Journal on Ageing), which encourage interdisciplinary research, and publication that greatly extends the available audience for research. Nevertheless these are not generally accessible to consumers, policy makers, clinicians and service providers

Academic research conferences are also important but the proliferation of conferences in recent years and the tendency to have very topic specific conferences limits the scope for wide dissemination of research results.

However growing use of the Internet has meant that most research findings will be traceable through Internet search engines. A valuable and useful role for organisations such as NACA and its member organisations is to encourage and promote research network cross linkages to maximise the opportunity for those seeking research outcomes to trace relevant research reports or in the case of on-going research to contact the project leaders and researchers directly. The role of the Australian Research Online Directory is strongly supported in this context as it provides an accessible online site for Australian ageing research.

However while finding research reports is a major step forward also essential is the task of translating research outcomes into useable documents. Professional associations play an essential role in this task by developing Guidelines etc, which distil research findings into useable practices. Unfortunately often guidelines are still too large and difficult to follow to be readily accessible sometimes being seen as nothing more than door stops or shelf fillers. Effective translation of research into practice requires information to be packaged in easy to read, easy to find and easy to handle documents. The combined experience of the Alliance through its members can play a valuable role in assisting the development of practice guidelines, fact sheets etc and assisting them to be user friendly.

## RESEARCH PRIORITIES

### ***Prevention, treatment and cure of age associated illnesses.***

Priority should be given to 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. 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. Priority research should focus on:

- ❖ Dementia: The size of the projected dementia affected population in 50 years is so large that prevention or amelioration of dementia must be a priority for any research program. This focus on dementia however, should not allow research into the complex causation, and prevention of other aspects of the common multifactorial “Geriatric Syndromes” (gait instability and falls, slowing and reduced mobility, visual or hearing impairment, incontinence or depression) to be overlooked.
- ❖ Gait, sensory and cognitive (neurodegenerative) disorders. Knowledge of the causes and prevention of neuro-degeneration lags which well behind understanding of the prevention of the systemic diseases (heart, lung, cancer etc). However, this needs to be broader than discipline defined research into specific movement disorders (such as Parkinson’s disease in the young-old).
- ❖ Research into modifiable risk factors to reduce the burden of neurodegenerative disease and disability in late old age must be initiated given demographic projections of rapid growth in the numbers of very old people. The essential areas for research involve the search for new risk factors (eg nutrition or education) in delaying the onset of disease or ameliorating disease severity.
- ❖ Cardio-vascular health in particular with reference to stroke prevention and preventing vascular dementia. The essential research area is in the field of health promotion, involving implementation of known protective factors. The primary risk factors for poor cardiovascular health, eg diet, exercise and smoking are well understood (at least relative to the neurodegenerative disorders). They are principally risk factors modifiable by lifestyle changes. The focus of research should be on effective health promotion and health education measures, which encourage and support adoption of lifestyles, which reduce the risk of disease.
- ❖ Nutrition and the role of specific dietary factors in healthy ageing including the prevention or delay of dementia, especially Alzheimer’s disease (AD): and other neurodegenerative diseases such as gait disorders (especially Parkinson’s disease) and the debilitating problems of macular and auditory degeneration. There is some evidence suggesting that anti-oxidants in fruit and vegetables may be protective factors against forms of neurodegenerative decline. Nutrition is also critical in other diseases of old age including diabetes and osteoporosis.

### ***Physical, Mental and emotional wellbeing of older people.***

Research should focus on the person not just the disease, with the primary aim being extension of healthy, happy, non-disabled life span. The principle health outcomes from getting this research right will relate to the emotional and mental health of older Australians. By remaining connected, feeling needed and part of wider community it is anticipated that depressive illnesses resulting from loneliness or lack of a defined role will be greatly reduced. Reduced depression will lead to less medication and higher levels of activity with consequent improvement in cardiovascular health and mobility, which will lead to reduced levels of dependency and a longer time residing in community settings. This is intrinsically linked with the degree of social involvement and the interrelationship of such involvement with the overall social fabric. However, it also has strong associations with levels of disability and with early neurodegenerative disease. Priority research areas are:

- ❖ The interaction of on-going mental stimulation and rates of cognitive decline.
- ❖ Education: The role of education and lifetime learning as a possible protective measure in its own right warrants research. 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 and engage with the health and aged care systems effectively.
- ❖ Research into the types of physical activity, which have preventative health benefit for people as they age. The focus for such study should include those who are already showing some signs of physical decline and should extend to therapies of benefit to those already requiring some degree of assistance.
- ❖ Participation by older Australians in the community whether in the workforce, as volunteers or in leisure activities: Participation promotes social contacts, which in turn promotes good health and happiness. Essential research is identifying forms of social interaction that are accessible and affordable. Study is needed as to what older people currently do, what they would like to do and what prevents them from participating to the extent that they would like. Particular study should be made of the financial affordability of leisure activities and into affordable options.
- ❖ Volunteering: The role of volunteering as a means of maintaining the social connections of older people especially those facing socio-economic disadvantage needs further research. Volunteering is a valuable means of helping define identity and will be particularly important as the population ages.
- ❖ Communication: The importance of effective communication for older people is a major aspect of health and well-being. As sight and hearing deteriorates along with mobility access to the usual communication channels becomes increasingly restricted, influencing awareness and decision making capacity. Research is needed into the causes and treatment of sensory decline but also into developing alternative communication strategies to assist those with declining hearing or sight.

### ***Urban development***

Understanding how the urban framework impacts on healthy ageing is a very broad area of research but some important areas of focus are:

- ❖ **Access to services:** This is a key aspect of healthy ageing and particularly continued community living. Urban design, planning and the location of government services will be elements of effective planning for health ageing. Access must incorporate the ease of reaching necessary care or health services.
- ❖ **Access to leisure activities:** Effective social participation relies on the ability to get out and meet others and to have meaningful leisure activities. Study of methods of ensuring there is adequate access including funding demonstration or pilot projects will be needed. Diversity will be very important in this context and an essential element of a healthy ageing population will be ensuring that there is a good mix of social activities for the healthy ageing and also for the partially disabled. Research into cost-effective means of providing a diversity of services/activities will be essential.
- ❖ **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. 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. This in turn has been shown to increase the demand for and reliance on government support services, including both community-based and residential care.
- ❖ **Living environments:** Accommodation type, whether community living or residential care will influence the extent to which older people can adopt healthy lifestyles, involving physical and mental activity with appropriate social interaction and community participation. For those who continue to live in the community in their own home issues of home maintenance and modification need to be considered in the context of effective urban planning and service delivery.
- ❖ **Ageing in place:** This 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?

### ***Research into care and support models***

Research into models of care is strongly supported but care should be taken to avoid the trap of “research” programs that have just a short-term life. Too often there are programs, which obtain funding, support for the trial or demonstration phase, but once the trial period finishes there is no ongoing support, even if the trial is effective. There needs to be integration of funding for “research” with funding for programs or this discontinuity will continue.

Focus on care and service delivery (including accommodation), self-care and informal care, and effectiveness is needed. This should include 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.
- ❖ 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. This will include transitions across care settings, and impacts of change in resources in one setting on activity in the other settings.
- ❖ Workforce requirements and associated educational requirements.
- ❖ Care and support for older people. 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 70% 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 role of accreditation standards & auditing processes in providing meaningful information on which to improve Quality Of Life for RACF residents.
- ❖ Systems that encourages GPs, Geriatricians, Palliative Care Physicians, Nurses and Specialist Nurses & Allied Health to be more involved in care of older people (including residents at RACFs), how do we develop clinical networks and work practices that involve a full interdisciplinary team involvement?
- ❖ How do we introduce a culture of evidence-based medicine amongst the clinical staff at RACFs, and searching for the evidence or deriving it when it is not available?

### ***Income and financial support***

This is another broad area of research but some important areas of focus are:

- ❖ **Retirement incomes:** Incomes for older Australians must be sufficient to allow them to live with dignity and maintain functionality. Full participation in society takes money and resources. This requires 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. Financial obstacles may prevent many disadvantaged older people from taking up physical leisure activities such as golf, tennis, aerobics, yoga or even the traditional lawn bowls, which may require club membership fees, expensive equipment or high session fees. Ensuring that older people have financial means to participate in leisure activities must form part of the research and discussion on tax and transfer issues.
- ❖ **Employment:** Given the relationship between employment and good health, getting people into the workforce is a desirable objective. Understanding the role of older individuals in the workplace will be an essential element in developing models for funding the ageing of the Australian population. The AAG stresses that this effort should include older people particularly those in the 65 –75 age group who although officially retired may wish to continue with a role in the workforce although possibly with reduced hours. Research into developing workforce options which suit older workers is essential, not just to meet workforce demands as the population ages but also to ensure many people have financial

incomes needed to support good health and also have an on-going role in the community.

### ***Community resilience or social capital***

This once again is a very broad area of research. Priority ageing research areas include:

- ❖ **The role of community support structures:** For older people most community involvement is structured to some degree with activities centred round a specific purpose. Religious or community groups, charities, sports clubs, service clubs and cultural groups each have roles but there is a tendency for these groups to have a focus in relatively affluent areas and to be poorly provided in areas of social disadvantage.
- ❖ **The role of families and carers in maintaining the emotional health of ageing people:** There are a multitude of issues which will affect the way carers interact with ageing dependents and the mental health implications are significant both for the older people and for their long suffering carers. These issues must be a focus of research and in particular there must be emphasis on the impact of social disadvantage on the role of carers, who themselves may be faced with deteriorating health. Demographic projections 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.
- ❖ **The extent of social connection of older persons:** Issues such as involvement in civic entitlements and participations in the business of government, need to be examined.
- ❖ **Social environment:** This should include understanding the lifestyles of the elderly and their evolving needs for support services. It should also 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 to diverse interests and preferences. The capacity of market forces to meet the demands of the ageing population needs research.
- ❖ **Population health research** that addresses responses to geographic patterns of ageing in the majority of Australian old-old people who remain community living. The patterns of ageing must be considered in context with the socio-economic indicators of the geographic region.
- ❖ **Special groups in the ageing population**, including people with disabilities and those living in isolated communities as well as their ageing carers, will have different outcomes and different needs and the relevance of research findings to special groups needs to be established. A significant group where health problems are severe and where social disadvantages leads to poor health are the mentally ill. The special need of indigenous people as they age and the major discrepancy in life expectancy is clearly a priority area of research.
- ❖ **Carers:** Research into the health and welfare of carers is needed including study of the impact of the caring role on social connections, on mental health on financial status and on health outcomes.

