AAMRI Submission

Health and Hospital Reform Commission 2008

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Summary of recommendations

A culture of research

- Promote and foster a culture of research throughout health and the most effective way to achieve this is making sure more of our discoveries become practice as per a rejuvenated NICS (see next section)
- Evidence-based healthcare is dependent on clinicians having a science base

Knowledge transfer into practice – A rejuvenated National Institute for Clinical Studies (NICS)

- Establish the National Institute of Clinical Studies as the central agency for knowledge transfer from evidence to health practice.
- COAG needs to recognise and adopt the new model of NICS so that it can be embedded throughout the health system
- Include support and mechanisms for implementation of research into practice as per the UK model of NICE
- Set a funding target of 1% of the health budget by 2020 for knowledge transfer from evidence to health practice.

A national approach to funding the indirect costs of research

- COAG should develop a unified national scheme to support the indirect costs of research, linked to competitive funding and provided in the same way to hospitals, universities, medical research institutes and other agencies.

Combining University medical research infrastructure support under health

- The Universities Australia proposal (in their innovation Review 2008 submission) to have all health and medical research funding, the equivalent of their RIGB, RGS and other schemes and support for the indirect costs of research under the health portfolio should be explored.

Equipment and research space

- The culture of research throughout health needs to extend to include the use of specialized equipment and in the planning for new buildings. These new buildings should provide space for health care alongside clinical research and laboratories especially on hospital campuses.

Workforce

- Clinician researchers and scientists should have a key role in teaching the next generation of health professionals
- Career support schemes such as the NHMRC Practitioner Fellowships and Research Fellowship programs are critical to providing a skilled and qualified health and medical research workforce to meet the national health challenges
- Elite schemes such as the Federation Fellowships and Australia Fellowships, must be retained and expanded to attract elite clinician/ scientists
- The proposed development of a national mid-career support scheme (Future Fellowships) to support 1,000 of our nations best and brightest, and accessible to researchers, wherever they are based, is welcomed by AAMRI.

Career structure for translational clinician researchers

- Career support schemes for clinician researchers require development with remuneration commensurate with clinical activities.
- Universities and Specialist Colleges need to collaborate to develop training programs that allow concurrent research and specialist training to shorten the duration for gaining specialist clinician/ scientist credentials.

Health informatics (benchmarking and monitoring)

- Australia requires an electronic health data system, that protects privacy but provides current health information for both treatment and monitoring purposes.
- COAG should examine the model of the WA Data Linkage Unit as a possible starting point for the development of a national system

A streamlined ethics approval system for large multi-centre trials

- Australia requires an integrated national system for ethics approval of multicentre clinical trials (Appendix 2).

Promoting national and international collaborations

- Ensure adequate funding remains available to allow for participation in international research consortia that will be to the national advantage.

One example of putting research into practice is the UK model for cardiovascular disease. Australia needs to develop a program to reduce obesity and improve cardiovascular outcomes

- Initiate a comprehensive Government-led program to promote a 5 kg weight reduction in overweight adult Australians to reduce chronic disease (analogous to the anti-smoking campaign)

Introduction

The Association of Australian Medical Research Institutes (AAMRI) welcomes the opportunity to make a submission to the National Health and Hospitals Reform Commission.

AAMRI represents 36 independent medical research institutes (MRIs) across Australia. The MRIs are independent, not-for-profit organisations, closely affiliated with the health sector and hospitals and higher education and universities. The MRIs employ more that 6000 researchers and support staff, and train more than 1500 post-graduate students each year. They have a combined research income of more than $350 million per annum, winning most of that from competitive grant funding. About half of this is derived from the NHMRC, and a significant amount is awarded by international funding agencies.

AAMRI members carry out much of Australia's most distinguished and world-renowned health and medical research, in almost every aspect of human health and disease and are major partners in commercialisation of Australian biomedical discoveries.

A sample of discoveries from MRIs that have been put into practice:

- Scientists at the Telethon Institute for Child health Research along with collaborators, described the connection between lack of folic acid in the maternal diet and spina bifida. They have driven a campaign to have mandatory fortification of food with folate, which aims to prevent up to 70% of spina bifida cases.
- The Walter and Eliza Hall Institute of Medical Research and Ludwig Institute for Cancer Research discovered Colony Stimulating Factors (CFSs) which control white blood cell formation and are now used worldwide to promote recovery from cancer treatment and severe infections
- The Baker Heart Research Institute has invented the "One Hour" Mitral Annular Constraint device, which will revolutionise heart failure patient care and become as commonplace as pacemakers.
- The Burnet Institute provided the research based evidence upon which needle exchange programs were established in Australia early in the HIV epidemic; this was essential to minimize the spread of HIV at that early and critical time.
- After 18 years of intense research and development, the world's first soft artificial cornea was developed by the Lions Eye Institute. The artificial cornea, AlphaCor is marketed all over the world.

A sample of discoveries from MRIs that have not been put into practice (yet):

- The Burnet Institute has developed designer drugs to treat rheumatoid arthritis and these are awaiting clinical testing.
- The Baker Heart Research Institute has completed an audit of heart attack admissions which shows that outcomes for indigenous and non-indigenous people adjusted for complexity are fairly similar in hospital, but separate widely after discharge as the transition to effective long term care does not occur because of lack of access and /or culturally specific systems.
- Research from Prince of Wales Medical Research Institute has been translated into a simple clinical tool that can be applied to brain images to assist with the differential diagnoses of neurodegenerative dementias. Trials in clinical practice are now necessary.
- The Heart Research Institute has discovered that androgens (male sex hormones) have effects on the artery wall that increase the risk of heart disease. This finding partly explains why men tend to develop heart disease at a younger age than women.
- The Garvan Institute of Medical Research has developed a specific antibody drug to treat autoimmune diseases which will enter clinical trials in June 2008.

1. A Culture of Research

AAMRI believes that a culture of research needs to be embedded throughout health care in Australia. The principles the National Health and Hospitals Reform Commission has proposed to shape Australia's health system includes " a culture of reflective improvement and innovation". We welcome this but feel this principle should be strengthened and given one of the highest priorities. In fact, this needs to become part of the system itself, as we know that research can provide the discoveries for new treatments and monitoring and evaluation to improve existing diagnosis, treatments and health solutions.

We believe that through research Australia can make the most of every dollar spent in health to improve health outcomes and make our systems as effective and as efficient as possible. This will mean in turn that each patient will get the best care they can from an informed and responsive system. Research is the only approach likely to lead to healthcare that is both cheaper and better.

Many of the other principles you have listed will be addressed by embedding a culture of research and continually striving to improve our health system that promotes discoveries and ensures that they become part of health practice. This needs to be adopted by all the players (across all levels and sectors) in health including patients. It is also important that there is feedback from the service/ clinical side to inform research.

We believe research benchmarking, evaluation and monitoring needs to be given a higher priority along with a focus on making sure Australia's medical research discoveries become part of clinical practice. In this submission we propose that the National Institute of Clinical Studies (NICS) which was established to play this role be given a higher priority and increased funding to drive these outcomes.

As part of our submission we will also raise some of the road blocks and suggest that this is an opportunity to look at the way funding drives so much of our health care

system and that there are some unintended consequences of this. We will also propose some key areas to focus on in order to create more of a research culture and describe what is missing in order to achieve this.

From a research point of view we can provide some insights on the need to look at the way our health system focuses (for obvious reasons) on treating the chronically ill and dealing with acute episodes to a far greater degree than it does on prevention and early life intervention.

Quality and safety, taking a long term view and providing for future generations are some of your other principles that we believe research can inform and provide direction for the allocation of resources and funding and planning for the future.

There is much we can do to improve our current health care system if we take this opportunity to ensure that we have good data linkages and benchmarking along with monitoring and evaluation. We also need to ensure that the fruits of our research become part of every day practice.

Recommendations:

- *Promote and foster a culture of research throughout health and the most effective way to achieve this is making sure more of our discoveries become practice as per a rejuvenated NICS (see next section)*
- *Evidence-based healthcare is dependent on clinicians having a science base*

2. Knowledge transfer into practice – A rejuvenated National Institute for Clinical Studies (NICS)

In Australia it is the remit of the National Institute of Clinical Studies as part of the NHMRC to improve health care by getting the best available evidence from health and medical research into everyday practice (see Appendix 1 for terms of reference). Knowledge transfer is complex and involves activities ranging from mapping of current activities, to systems research, promotion of partnerships and linkages between and within the research and healthcare sectors to evaluation of health outcomes.

NICS has made significant progress in selected disease areas[1] however the very limited funding allocation ($3.8 million in 2008/9 Federal budget) of <0.7% of the funding for biomedical and clinical research through NHMRC, severely restricts Australia's capacity to convert evidence to practice. To fully capitalize on Australia's truly excellent biomedical and health research, NICS requires an expanded funding base to support both the direct and indirect costs of research translating evidence into practice. We need a driver, a source of dedicated funds, a mechanism and agreement and support from across all jurisdictions and sections of the health system to create the impetus to force change and improvements.

To address this issue without eroding the excellence of Australia's fundamental and applied medical research, we propose a significant increase in funding through NICS analogous to the United Kingdom "Best Research for Best Health" strategy[2] established by Professor Sally Davies and administered through the National Health Service (NHS). "The focus of *Best Research for Best Health* is on supporting and funding health-related research, which leads to improved outcomes for people. Evidence from research spanning prevention of ill-health, promotion of health,

disease management, patient care, delivery of healthcare and its organization, as well as public health and social care, is key to improving health." The National Institute for Health and Clinical Excellence (NICE) then develops practice guidelines using evidence garnered from the NHS and the wider healthcare community including healthcare professionals, patients and carers, industry and the academic world.

The U.K. had the advantage that it could pull together existing funding that was already notionally allocated to research in Hospitals, and with added funding there is now over £1 billion pounds allocated for knowledge transfer from evidence to practice within the NHS. This represents approximately 1% of the U.K. health budget. On this basis we propose an analogous allocation through NICS building to a comparable figure in Australia over the next 10 years. The proposed scheme would support the partnerships, the national platforms (eg health informatics, ethics committees), the career structures as well as the direct costs of knowledge transfer to practice.

Recommendations:

- *Establish the National Institute of Clinical Studies as the central agency for knowledge transfer from evidence to health practice.*
- *COAG needs to recognise and adopt the new model of NICS so that it can be embedded throughout the health system*
- *Include support and mechanisms for implementation of research into practice as per the UK model of NICE*
- *Set a funding target of 1% of the health budget by 2020 for knowledge transfer from evidence to health practice.*

3. A national approach to funding the indirect costs of research

The pressure on public hospitals from the growing demand and funding constraints mean that research is not their highest priority. Understandably research money in the past has sometimes been consumed by clinical care. The NICS funding allocation mechanism must be delivered with appropriate funding for indirect research costs. This includes IT infrastructure and licenses, support for participation in international collaborations, technology transfer costs, support systems for very early stage commercialisation and for capturing and maintaining intellectual property. Funding for the indirect costs of research must be separate from hospital funding for the delivery of healthcare. In both the academic and health sectors, Australia risks losing international competitiveness without reform of its research infrastructure provision. Internationally, there is no perfect model for reimbursement of indirect research costs. However, the US system which has evolved over the past half century adopts the principle that indirect research costs are fully reimbursed by the Federal Government through the A-21 Directive process.[3] Funding formulas designed to top up grants to cover the indirect costs are negotiated with federal agencies and are as high as 70% for some institutions. The level of reimbursement in the US is far greater than that currently achieved in Australia, where funding shortfalls inevitably put research programs and partnering capacity at risk. Current systems for funding the indirect costs of knowledge transfer research in hospitals and the community are not appropriately linked to competitive research funding. A national infrastructure system which supports the true indirect costs of research[3] and

linked on a pro-rata basis to competitive funding is fundamental to delivery of translational research outcomes.
Insurance can be a road block when it comes to research. The cost of insurance for any clinical research activity including but not restricted to trials, can be a major impediment to "public good" of industry funded research. It is less of a problem in Victorian public hospitals but in other states, for MRIs and the private sector this is a major issue. This can also be addressed via increased support for the indirect costs of research.

Recommendations:

- *COAG should develop a unified national scheme to support the indirect costs of research, linked to competitive funding and provided in the same way to hospitals, universities, medical research institutes and other agencies.*

3a. Combining University medical research infrastructure support under health

Further to the recommendation above. AAMRI believes that the proposal mentioned in the Universities Australia submission to the Innovation Review 2008 warrants further exploration.
On page 11 of their Submission, Universities Australia have written "Given that a significant amount of block funding (to Universities) is allocated to health and medical research projects, in order to better support research in general, one further suggestion is that responsibility for the block funding component of health and medical research be given to the more appropriate health portfolio, leaving the current amount of block funding to support non-health and medical research."
This would mean that universities would then be in the same infrastructure support scheme as institutes and under the same conditions. There would need to be a greater opportunity for funding growth and linking it to a percentage of the health budget could be one way to deal with this.

Recommendations:

- *The Universities Australia proposal (in their innovation Review 2008 submission) to have all health and medical research funding, the equivalent of their RIGB, RGS and other schemes and support for the indirect costs of research under the health portfolio should be explored.*

4. Equipment and research space:

The Rudd Government's announcement of the new $10 billion Health and Hospital Investment Fund for equipment is a far sighted move. This is crucial if Australia is to attempt to keep pace with new technologies and the latest equipment. Research time, however, also needs to be provided wherever possible so that the capabilities and learnings from equipment such as PET and MRI for imaging can be maximized. The funding of this technology and their use often means that research time is limited and sometimes prohibitive due to the costs. Space also needs to be provided for research to occur.

Recommendations:

- *The culture of research throughout health needs to extend to include the use of specialized equipment and in the planning for new buildings. These new*

buildings should provide space for health care alongside clinical research and laboratories especially on hospital campuses.

5. Workforce

One of the greatest limiting aspects to our health system is the workforce constraints. This is an even greater problem in rural and remote areas and in indigenous health. Australia needs to place a higher priority on recognition of our health professionals and provide increased support to them and thus encourage greater numbers of health professionals. We also need to look at the most efficient and creative ways to use our existing health professionals. Research informs education and is the basis for the future practice of medicine. Clinical researchers have a very important role in teaching of the next generation of professionals. Whilst established busy full-time non research clinicians have a very valuable role in education, there is a tendency for them to teach medicine as it is practiced, now or often when they received their training. If the next generation is to be educated in evidence based practice, it needs to be taught by those defining that future, which usually involves those in research. Fundamental to the health service therefore is the need to attract and retain the best and brightest, whether it is locally or overseas. A health sector in which research is respected, valued and facilitated will ensure that happens. It will also substantially counter-balance the attractions of a purely remuneration-driven professional career.

The following is an extract from the AAMRI submission to the Innovation Review 2008 and is focused on researchers and scientists but could just as well include health professionals:

"There must be a focus on positioning Australia as a 'smart country'. This will need a robust and well-supported career path to build research capacity and attract and retain high-calibre researchers and intellectual capital in Australia. AAMRI supports the recommendations in the Walter & Eliza Hall Institute of Medical Research submission to the Innovation Review 2008 on education including initiatives to attract and retain the best possible science teachers at primary and secondary level and to encourage and support women in research careers.
A recent survey by the Australian Society for Medical Research (ASMR) showed significant dissatisfaction among the Australian health and medical research workforce. Of particular concern were employment insecurity and the lack of a career structure. As highlighted by the Telethon Institute for Child Health Research in its submission for the Innovation Review 2008, inadequate salary support has meant that some of their staff are moving into University or private sector positions in Australia or overseas. There is an increasing gap between the salary levels for staff in universities compared to MRIs. Research funding needs to be able to attract and retain the very best people in research and this will pave the way for greater innovation from health and medical research."

Recommendations:

- *Clinician researchers and scientists should have a key role in teaching the next generation of health professionals*
- *Career support schemes such as the NHMRC Practitioner Fellowship and Research Fellowship programs are critical to providing a skilled and qualified health and medical research workforce to meet the national health challenges*

- *Elite schemes such as the Federation Fellowships and Australia Fellowships, must be retained and expanded to attract elite clinician/ scientists*
- *The proposed development of a national mid-career support scheme (Future Fellowships) to support 1,000 of our nations best and brightest, and accessible to researchers, wherever they are based, is welcomed by AAMRI.*

6. Career structure for translational clinician researchers (scientists)

The small number of clinician researchers are a critical gap in Australia's health research workforce which contributes significantly to the difficulties of research translation. These are clinically trained professionals who work in the health system and who also have a strong research background. Specialist Colleges require many years of full time training from their trainees and there is little incentive for the candidates to add to this load and to take further time out to complete PhDs in research. To add to this, the training times are getting longer and at the same time opportunities to do research is diminishing. Career support schemes which allow clinician researchers to quarantine time from clinical practice for research endeavors are urgently required. While such schemes exist through NHMRC, to be effective, remuneration at rates commensurate with clinical activities are required.

Recommendations:

- *Career support schemes for clinician researchers require development with remuneration commensurate with clinical activities.*
- *Universities and Specialist Colleges need to collaborate to develop training programs that allow concurrent research and specialist training to shorten the duration for gaining specialist clinician/ scientist credentials.*

7. Health informatics (benchmarking and monitoring)

Australia is behind in the electronic health area and this negatively impacts on the health care of patients. One example is that many GPs receive no discharge summaries from hospitals for their patients so they have no idea what medication they have been given, treatment they have had or even that their patient has spent time in hospital. There have been great results from studies that involve careful and planned follow up with individuals after an acute episode in hospital. This can improve patient wellbeing and significantly reduce hospital readmission. The benefits extend beyond the individual patient to the healthcare system. Integration of clinical databases across the nation is critical to tracking patient outcomes and to assess the impact of implementing changes to research practice. Mechanisms are currently available to realize this goal with due consideration of ethics, privacy, security and intellectual property. A universal register-based system of health information is necessary to provide the required healthcare delivery, quality and safety, system performance monitoring, incentive-based remuneration for providers based on outcomes rather than on services, and efficiency and effectiveness monitoring. Linkages should include Medicare, the PBS, mortality and hospital registers.

In the Research Australia submission to this review they discuss how statistics and patient data are a challenge due to the poor standard of data currently collected and the lack of data linkage and IT systems. Research Australia also mentions the efforts being made in Western Australia through the WA Data linkage Unit which allows evaluation of medical care, as well as studies in the epidemiology of a number of

major diseases.[4-6] They go on to say that a nationwide approach to collection and management of patient data will require cooperation between jurisdictions and providers and will need appropriate privacy and security safeguards. AAMRI agrees with Research Australia that this is an essential tool. Australia can no longer afford to ignore the electronic age and the opportunities it provides.

Recommendation:

- *Australia requires an electronic health data system, that protects privacy but provides current health information for both treatment and monitoring purposes.*
- *COAG should examine the model of the WA Data Linkage Unit as a possible starting point for the development of a national system*

8. A streamlined ethics approval system for large multi-centre trials

Participation in large clinical trials will facilitate access to the most current healthcare practice for all Australians. The regulatory environment in Australia is generally highly conducive for the conduct of large scale clinical trials. However, currently ethics approval mechanisms for multi-centre clinical trials are a significant obstacle to translation research. Multi-centre ethics submissions consume a large amount of time for both coordinating investigators and the multiple committees that undertake the reviews. Typically a submission for the same trial to be conducted at 10 sites around Australia would go through 10 ethics committee reviews, each committee would spend time considering the protocol and consent form and other associated documents, each site would probably also make their own minor changes to the consent form. This is a huge workload for the coordinators of the study and a huge waste of ethics review resources. This resource is then further stressed due to the ongoing communication with 10 ethics committees during the trial (protocol amendments, adverse event reporting etc).

Several multi-centre streamlining projects have commenced in Australia. The NSW model is in place, however the approval time benchmark is 60 days which is not internationally competitive and the real time achieved is a lot slower than this due to the local “site assessment” at each hospital. The Victorian project was looking promising, however it failed to get funding in the recent state budget.

The key criteria for a successful multi-centre ethics approval are detailed in Appendix 2.

Recommendation:

- *Australia requires an integrated national system for ethics approval of multicentre clinical trials (Appendix 2).*

9. Promoting national and international collaborations:

Medical Science is increasingly conducted on a world stage as the scale of investigation has expanded. For Australia to remain competitive we need to contribute to key international collaborations such as the International Cancer Genome Consortium. Increasing funding for medical research to cover the full costs of research and to cover the indirect costs of research will encourage greater collaboration. This will remove the current disincentives for large collaboration and

allow greater scope for national and international collaboration and for this to occur across disciplines.

An example of the benefits of collaboration between an MRI and a clinical service is:

The Endocrinology Unit at Prince Henry's Hospital/ Monash Medical Centre/ Southern Health which has been intertwined with Prince Henry's Institute of Medical Research has as a consequence of its research commitment, initiated:

- arguably the world's first menopause clinic, which has lead to a series of research programs including very early recognition of the importance of postmenopausal osteoporosis and its treatment
- an infertility service which treated couples, not individuals and was a magnet for trainees and the development of similar clinics around the world as well as a platform for landmark contributions to research
- integration of psychiatric/psychological care into endocrinology clinics and the research training of psychiatrists
- institutional guidelines for the management of thyroid cancer and a series of clinical research projects thereafter
- a dedicated androgen replacement clinic with a parallel research program
- a dedicated clinic for girls with Turners syndrome
- a clinical and research program exploring the management of the menopausal consequences of breast cancer treatment

In terms of international collaborations, "Australia officially became the first associate member of the European Molecular Biology Laboratory (EMBL), the leading European life sciences research organization in March 2008

EMBL is supported by 20 member states, has laboratories in Germany, France, Italy and the UK, and a staff of more than 1,400 researchers from 60 nations.

Australia's membership has been made possible by funding through the National Collaborative Research Infrastructure Strategy and financial commitments from the NHMRC, CSIRO, Monash University, The University of Sydney, The University of Queensland and The University of Western Australia".[7]

While this initiative is to be applauded, a previous opportunity to become a partner in the Human Frontiers Research Organisation took many years before Australia become a partner, thereby significantly limiting the ability of Australian's to contribute to, and more importantly to lead, international research consortia.

Australian medical research institutes have become global leaders in international collaborative clinical research, particularly in the area of cardiovascular disease, neurology and critical care medicine. However, institutes such as The George Institute, have only been able to achieve this by seeking funding offshore. There has little domestic support of these global efforts.

Recommendation:

- *Ensure adequate funding remains available to allow for participation in international research consortia that will be to the national advantage.*

10. Putting research into practice – a program to reduce obesity and improve cardiovascular outcomes

Recent UK experience offers a good example of successful research translation in cardiovascular disease. By more effective transfer of research-based evidence to best practice treatments, the English NHS has dramatically improved cardiovascular disease outcomes, with a 40% reduction in deaths from circulatory diseases between 1995 and 2005 (Appendix 3).[8] This was a wide ranging multi-faceted approach which tackled different parts of the health system simultaneously. It was successful because it was coordinated and well resourced, it was also outcomes focused and provided both carrots and sticks.

A similar approach in Australia in combination with novel obesity prevention strategies tailored to our context, would help to defuse the Australian 'fat bomb'.[9] Among middle-aged Australian men and women (45-64 years old) some 7 out of 10 men and 6 out of 10 women are overweight or obese.[10] Over the next 20 years, this will result in markedly higher rates of cardiovascular disease, Type 2 diabetes and various forms of cancer.

Due to cardiovascular disease alone, this group of Australians will face:
- an extra 700,000 hospital admissions costing at least $2.93 billion,[10] and
- an extra 122,500 deaths.[10]

This looming 'fat bomb' scenario is alarming, but preventable. The challenge is to develop a coherent set of interventions to modify the eating and exercise habits of middle-aged Australians, particularly those at risk, and combine these with new drug therapies and early detection methods.

For cardiovascular disease alone, programs that enabled this group of Australians to lose just 5kg in weight could cut the projected extra hospital admissions by 27% and the extra deaths by 34%, over the next 20 years.[9] This would also impact on rates of cancer and other chronic diseases such as arthritis.

The UK experience highlights three points of relevance to the current Review:
- maintaining the current linkage between medical research and health services under the health portfolio is vital for effectively translating basic research findings to hospital and community practice,
- well-targeted public investment in creative innovation pays; and
- research to evaluate programs and outcomes is a vital part of any health intervention

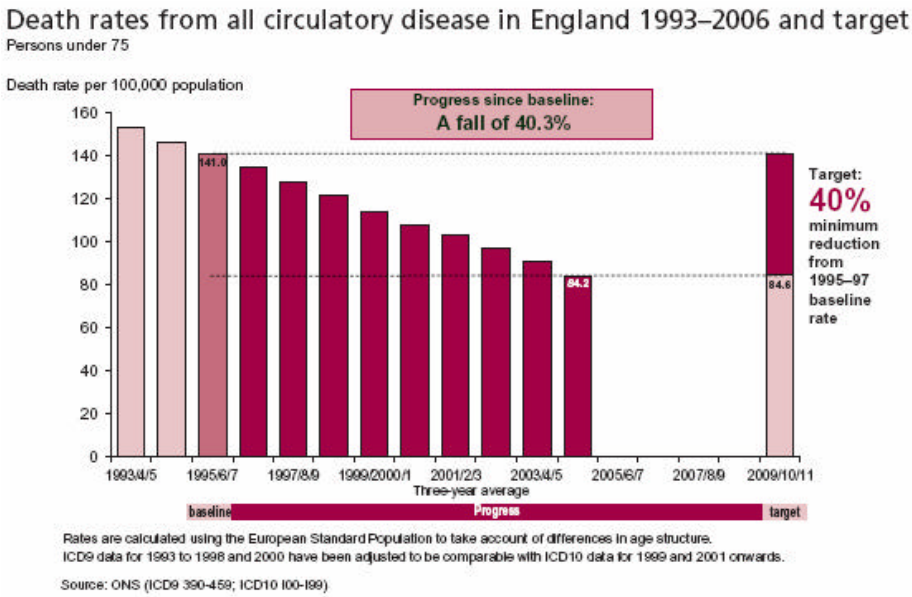

Figure 1 English NHS: the target of reducing deaths from CVD for people under 75 by at least 40% by the year 2010 has been met five years early.

Recommendations:

- *Initiate a comprehensive Government-led program to promote a 5 kg weight reduction in overweight adult Australians to reduce chronic disease (analogous to the anti-smoking campaign)*

Conclusions:

The Health and Hospitals Reform Commission has a unique opportunity to look broadly at Australia's health systems and make recommendations to government. AAMRI recognizes the enormous challenge of this task. We recommend that embedding a research culture throughout health provides the best opportunity to improve and build on our current systems and work towards a more efficient system. In looking to the future, all sectors of our health system need to work more effectively together and we need to make the most of new discoveries, treatments, technologies and equipment. This requires a real commitment across all sectors of the health system and needs the leadership to drive the best health outcomes for Australians.

Appendix 1

The National Institute of Clinical Studies (NICS) was established by the Australian Government in December 2000.

The initial terms of reference for NICS were to:

- Map current activity around improving quality and clinical care, and provide a focus for the consolidation and dissemination of that work;
- Support research to assess and evaluate aspects of the system within which care is provided — including the processes, interactions and relationships — to identify mechanisms to improve care delivery and the most effective means to influence their implementation;
- Identify the best mechanisms to influence and improve clinical practice, in concert with the profession;
- Establish working groups and advisory structures to report and advise on a wide range of matters relating to clinical improvement in the Australian healthcare system;
- Champion best practice within the healthcare system through education and training;
- Build links between professionals, consumers and other stakeholders to improve exchange of information and experience about the operation of the healthcare system and minimise duplication of effort;
- In collaboration with the relevant agencies and bodies, promote the collection and analysis of data and the development of effective data systems;
- Build links both nationally and internationally with organisations with similar objectives, and identify and assess relevant overseas approaches to clinical practice improvement.

For more background on the establishment of NICS see this Medical Journal of Australia editorial written by the Institute's inaugural Chair, the late Professor Chris Silagy AO.[11]

In April 2007, NICS became an institute of the National Health and Medical Research Council.

Appendix 2

The key criteria for a successful multi-centre ethics approval system:

- Resourced ethics committee(s) that provided a 'triage service' at the front end to assist investigators to put in 'approvable submissions'
- No greater than 30 days cycle time from submission to ethics committee decision (assuming documentation was complete)
- Parallel site assessment that was done against a standardised set of criteria, utilising a dedicated research governance review group at each hospital – again fixed timelines of no greater than 30 days
- A panel of experts that the committee could draw on to provide review in special areas such as toxicology, immunology etc. – again these experts should be required to meet a timeline that was parallel to the Ethics review Committee (ERC) process (and they should be paid to achieve this)
- Amendments and minor changes to be dealt with "out of session" by research governance office to avoid unnecessary load on the ERC.
- The Victorian model where 4 ethics committees, each working on a monthly cycle, were created so that there was in fact a committee available to accept submissions each week.
- Sufficient committees available such that the workload on each committee was manageable
- Training of committee members (induction, clinical research overview, Good Clinical Practise (GCP), drug development, ethical thinking, understanding of competitiveness of research funding – timeliness and reduced administration allows researchers to spend their grant money on research rather than administration, and for commercial studies, decreased timelines will attract more international work that will provide new treatment options to Australian patients)
- Payment of committee members – sitting fees, to improve professionalism and to recognise the importance of the work done.
- Ethics committees to liaise with patient interest groups.
- All of this is achievable – there are very good models such as the Alfred Hospital ERC in Melbourne that conducts its business within a 30 day period and utilises external experts and drug sub-committees in parallel to the ERC process. Another model that operates successfully is BellBerry, a private , not-for-profit ethics committee in Adelaide.

Appendix 3

Substantial progress is possible in less than 10 years: a dramatic (2008) example of successful action on CVD in the English National Health Service

CVD DEATHS REDUCED BY 40% - TARGET MET 5 YEARS EARLY

The English National Health Service (NHS) has made outstanding progress in the management of cardiovascular disease (CVD) within the last 10 years.

- In 2000 the National Service Framework for CHD set out a ten year framework for action to prevent disease, tackle inequalities, save more lives, and improve the quality of life for people with heart disease. The NHS is now saving more than 22,000 lives per year in this regard.
- The target of reducing deaths from CVD for people under 75 by at least 40% by the year 2010 has been met five years early.
- The prescription rate for cholesterol-reducing statins has more than doubled over the last three years, cutting mortality from CHD and the number of heart attacks each year.
- The prevalence of smoking among adults dropped from 24% in 2005 to 22% in 2006.
- Thrombolysis is now delivered within the NSF standard of 60 minutes in 68% of individuals, up from 64% in 2006/07, and up from just 24% in spring 2001.
- A £735 million investment (Capital Programme) has succeeded in providing world-class facilities for treating patients with CHD, by:

- *improving and increasing local access for appropriate interventions;*
- *providing modern state of the art facilities and equipment for patients and clinicians & replacing old and out of date equipment;*
- *supporting the transfer of appropriate services from tertiary to secondary settings; and*
- *providing more catheter laboratory facilities in District General Hospitals*

- Waiting times for heart surgery have dropped dramatically since the inception of the NSF - no patients are waiting over three months for heart surgery compared with over 5,500 in 200.
- New and refurbished buildings, equipment and technology, including cardiothoracic centres. Have been provided; an additional 72 additional catheter laboratories have been established and 18 others have been replaced.
- Better Cardiac Rehabilitation: good quality rehabilitation reduces mortality and morbidity. A new National Audit of Cardiac Rehabilitation (NACR) has been established to identify areas of challenge and support local areas in adopting models of best practice.
- Better Guideline Dissemination to support service improvement: new National Institute for Health and Clinical Excellence (NICE) guidance on secondary prevention and information on CHD is being disseminated through web based disease prevention toolkit.

References

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