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Dear Ms Bleeser

The National Stroke Foundation and the National Heart Foundation of Australia welcome the opportunity to provide comment regarding the National Health and Hospitals Network Bill 2010 (the Bill).

We strongly support the decision to establish the Commission at the centre of the National Health and Hospitals Network and provide it with additional funding to support its enhanced role as a driver of quality and safety in healthcare.

## CVD IN CONTEXT

Cardiovascular disease (CVD) remains Australia's largest killer, responsible for more than 48,000 deaths each year, or 34% of all deaths.<sup>1</sup> While mortality rates have been steadily declining since the late 1960s, the prevalence of CVD is predicted to rise as the population ages and some risk factors become more prevalent. CVD takes a particularly high toll on Aboriginal and Torres Strait Islander peoples with death rates three times as high as non-Indigenous Australians between 2002-2005.<sup>2</sup>

CVD is recognised as a National Health Priority Area. Since 2005 CVD care has been guided by the National Service Improvement Framework for Heart, Stroke and Vascular Disease (NSIF). While the NSIF was endorsed by the Australian Health Ministers' Conference in 2005, the Framework has only been partially implemented and – in contrast to other major chronic disease groups – there remains no national action plan for CVD.

## ABOUT THE FOUNDATIONS

The National Stroke Foundation is the peak non-government organisation for stroke and develops strategies and programs to improve stroke identification, treatment and rehabilitation. Programs span prevention and awareness campaigns, promotion of evidence based-care including National Stroke Audits and Clinical Guidelines program, support for survivors, and research.

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<sup>1</sup> Australian Institute of Health and Welfare, 2010. *Australia's Health 2010*.

<sup>2</sup> Australian Institute of Health and Welfare. 2005. *Cardiovascular Disease and its associated risk factors in Aboriginal and Torres Strait Islander Peoples 2004-05*.

The National Heart Foundation of Australia is the peak non-government organisation for cardiovascular disease and undertakes a range of activities to reduce death and suffering from cardiovascular disease including funding medical and scientific research, public education, promoting lifestyles that improve cardiovascular health, and conducting programs that improve heart health.

Both Foundations have significant expertise in the development of clinical guidelines. The National Stroke Foundation recently launched its 2010 Clinical Guidelines for Stroke Management that covers all phases of care, incorporating the previously separate Acute and Rehabilitation and Recovery Guidelines. The 2010 Guideline was developed in accordance with the NHMRC-NICS standards and procedures for externally developed guidelines. The National Stroke Foundation is also leading the development of guidelines for the management of absolute cardiovascular disease risk on behalf of the National Vascular Disease Prevention Alliance (NVDPA). The NVDPA includes both foundations, Diabetes Australia and Kidney Health Australia.

The National Heart Foundation, often working with the Cardiac Society of Australia and New Zealand, develops a range of cardiovascular guidelines, including guidelines for lipids, hypertension, coronary heart disease secondary prevention, heart failure and rheumatic heart disease and acute coronary syndromes.

## **KEY POINTS**

The Foundations believe that while the quality of care provided to patients with heart disease and stroke is generally high, there remain serious barriers to improved quality of care for those suffering from heart, stroke and blood vessel disease.

The Bill before the committee offers an opportunity to address some of these barriers through the new and enhanced role of the Commission.

Four areas where we see a strong role for the Commission are:

1. Providing a national framework for prioritising, funding and implementing clinical guidelines;
2. Identifying and addressing data gaps;
3. Supporting and prioritising clinical registries that drive quality improvement; and
4. Identifying and addressing gaps in current quality/performance indicators and setting clinical standards that are linked to accreditation.

## **1. GUIDELINE DEVELOPMENT**

Clinical guidelines are a critically important tool for driving consistency, quality and safety in health care across Australia. They provide health practitioners with a guide to best practice in an increasingly complex health care sector in which some 2,500 new peer-reviewed research papers are published every day. It is important to note the strong and ongoing role of National Health and Medical Research Council-National Institute of Clinical Studies (NHMRC-NICs) in supporting the development of guidelines in Australia and the significant experience and expertise that many external health stakeholders have due to the predominance of externally developed guidelines in Australia.

Unfortunately external guideline development has been undertaken in the absence of a nationally coordinated approach for the prioritisation, funding and development and implementation of CVD guidelines in Australia. While NHMRC-NICS provides standardising guidance for those guidelines seeking their endorsement, not all CVD guidelines fall into this category.

Considering the range of guidelines currently available in Australia for the prevention and acute and ongoing management of people with CVD, several critical issues need to be addressed:

- **Prioritisation**

Australia has no systematic approach or framework to prioritise, fund, develop and implement clinical guidelines. Recent developments to create a national portal for the registry of clinical guidelines have made important inroads to addressing the need for a single access point. However, there is still no national mechanism for identifying gaps in guideline availability or to identify those in need of updating. As a result there is a risk of different organisations producing overlapping guidelines that lack consistency or worse contain contradictory advice.

- **Development**

Rigorous guideline development consumes considerable effort for developers and experts. Funding and other support for guideline development and implementation has generally been provided on an ad hoc basis and often from charity dollars. Developers need certainty around funding mechanisms. Support systems should also be in place to support and assist the work of developers.

- **Implementation**

Adoption of clinical guidelines into practice is often slow and dependent of successful implementation strategies. There is currently limited uptake and implementation of clinical guidelines across the acute and primary health care sector due to the volume, length and currency of individual guidelines and the time taken to gain familiarity with multiple guidelines. Clinical guidelines need to be developed within a national framework that facilitates their implementation across a range of primary care, community and acute care settings.

## **2. THE BILL**

The Foundations support the overall intent of the Bill to establish the Australian Commission on Safety and Quality in Health Care as a permanent, independent statutory authority.

### **Section 9 - Functions of the Commission**

We support the expanded role for the Commission in setting national clinical standards and standards under the Performance and Accountability Framework.

The Commission's proposed role to support and monitor the uptake of guidelines and standards including through awareness-raising and education for health professionals and providers is also commended and will be critical to address key guideline implementation issues.

We argue, however, that several aspects of the Commission's proposed role in standards and guidelines development and accreditation are not clearly articulated. Neither the Bill nor its supporting documentation make clear the role and responsibilities that the Commission is to play in regard to clinical standards and guidelines, and how these relate to the roles of other

relevant agencies, including the Department of Health and Ageing and the NHMRC-NICS. There is currently no national framework for the prioritisation, development, funding and implementation of clinical guidelines in Australia. While an online national clinical guidelines portal has recently been established by NHMRC-NICS, Australia remains seriously behind international best practice when it comes to a coordinated, national approach to the development and implementation of clinical guidelines.

Establishment of a national coordinated system for clinical guidelines and their translation into evidence-based care and practice is critical. We believe a National Clinical Guidelines Framework agreed across relevant agencies would assist addressing this issue and ensuring a well-coordinated system with work prioritised on evidence-based need.

Section 9(b) and Section 9(j) provide general provisions for data collection and dissemination of information relating to health care safety and quality and implementation and impact of standards and guidelines. The Foundations would like to see the Bill strengthened to reinforce the role of the Commission in identifying and helping address data gaps that are important to quality and safety improvement, in conjunction with data collection agencies, such as the AIHW. These issues are elaborated on in further detail in the second section of the submission below.

Clarification is also sought regarding the Commission's funding arrangements for guideline development. It should be made clear how and to which the Commission will fund and support prioritised clinical guidelines and standards or all such tools, if indeed this is the case.

Guideline developers, such as the Heart and Stroke Foundations, have a vital interest in the new role the Commission will play and look forward to working with it to improve clinical quality and standards across the country. Ensuring the clarity regarding the roles and responsibilities of government agencies and their relationship with all stakeholders will greatly assist in progressing this work.

### **Section 10(2) - Consultation**

Section 10(2) provides consultation requirements for the new statutory authority. It is noted that under Section 10 (2)(a) and (b) the Commission must consult clinicians and lead clinician groups as established under the national reform agenda. In addition the Commission must also consult under Section 10(2)(d) with any other stakeholders in relation to the development of standards, guidelines or indicators.

Clinician involvement in the development and review of clinical practice guidelines is critical to their successful adoption and implementation. Similarly, as noted above the level of expertise held by a number of key individuals and external organisations (including health NGO's and professional organisations) in standards and guidelines development is significant and must be harnessed as the Commission expands its work.

The Commission's stakeholder consultation strategy must continue to develop as a true partnership with clinicians and external guideline development groups. Strong consultation and collaboration will help to ensure standard and guideline development has the strongest clinical evidence-base and addresses current gaps in standard and guideline development.

### **Section 54 - Work plan**

The Foundations recommend that the Bill specify that the Commission's work-plan be developed on evidence-based need. Section 54(4) requires that the Commission consult across the jurisdictions regarding a draft of its work plan. It is important such deliberations are based on evidence-based identified gaps and highest need.

We believe there are several areas of work that will be critical for the Commission to undertake to address the burden of CVD in Australia. Further details regarding these areas are provided in the following section of the submission.

### **3. IDENTIFYING AND ADDRESSING GAPS IN CVD DATA**

Good data collection and analysis enables problems to be identified and addressed. But this can only be done when the right data is collected in a timely fashion, promptly analysed and fed back to service providers.

Serious gaps in CVD data collections remain. For example, there are no routinely collected national data sets for stroke unit access or times to treatment for people presenting to hospital with heart attack, unstable angina and stroke. Access to specialist care and 'door to needle' or 'door to balloon' times are critical determinants influencing patient recovery and health outcomes. Fast treatment in the case of heart attack and stroke will help minimise the chances of a subsequent event, and will enhance health outcomes. And yet there are no national data sets for 'door to needle' and 'door to balloon' times, let alone a 'call' to treatment time dataset, or stroke unit access as there are in countries like the UK.

Cardiac rehabilitation is a proven strategy for reducing the chances of a subsequent event for people who have had a heart attack. However, it is estimated that only one in three people who have had a heart attack access a cardiac rehabilitation program. For Indigenous Australians, the figure is believed to be much lower, around 5%.

Again, no national data set exists for the number of people who have had a cardiac event accessing and completing a cardiac rehabilitation program.

Stroke unit care is proven to improve patient outcomes and is cost-effective, yet many patients do not access this vital care. Accurate data on access are currently unavailable.

There is also no accurate information on the number of Australians who have heart failure, a serious condition that is responsible for a large percentage of potentially preventable hospitalisations. Estimates based on projections using international data put prevalence at about 300,000 Australians. Similarly there is no accurate information about the stroke in Australia. It is estimated that in 2010 there will be approximately 60,000 new and recurrent strokes in the Australian community – or one stroke every 10 minutes.<sup>3</sup> There is also a need for accurate information regarding CVD risk assessment and management in primary care.

With an ageing population, prevalence of CVD is likely to increase, and national data is therefore critical if we are to improve the quality of care and quality of life for the growing number of Australians with these serious conditions.

The ability to effectively monitor CVD and CVD risk factors is impaired by serious data gaps. For example, as the Australian Institute of Health and Welfare (AIHW) has pointed out, access to clinical records that would provide information on interventions and outcomes such as case fatality, is unavailable at a national level.<sup>4</sup>

Other areas where good quality, recent national data are missing include:

- Prevalence and incidence of some other types of CVD (for example, stroke, transient ischemic attack (TIA), peripheral vascular disease and rheumatic heart disease);

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<sup>3</sup> AG Thrift (personal communication). Estimates obtained using NEMESIS data (assuming no change in incidence), and Australian Bureau of Statistics estimates of a changing population.

<sup>4</sup> Australian Institute of Health and Welfare, 2010. *Women and Heart Disease*, Series 34 (2010)

- The use of some services (for example cardiac rehabilitation); and
- Prevalence of some CVD risk factors, such as blood pressure, blood cholesterol and diabetes prevalence (the data is now 10 years old, though we note that the Australian Health Survey, to be carried out in conjunction with the Heart Foundation, will address some of these biomedical data gaps).

As highlighted above, significant benefits would be achieved if the role of the Commission was further articulated and strengthened to identify and help address data gaps that are important to quality and safety improvement, in coordination with data collection agencies such as the AIHW.

### **3 a. REGISTRIES**

While supporting an expanded role of the Commission as described above, it is also important to note the critical work already identified or underway under its current remit. It is understood that the Commission has had plans to support clinical registries for cardiac procedures and stroke. Both Foundations strongly recommend that this work proceed.

Registries contribute to the evidence base for better practice through the collection and review of data relating to processes of care, use of devices and procedures as well as health outcomes. This work must continue as a priority under the permanent Commission. It will provide strong data to underpin its expanded role in standards development and in implementation.

The National Stroke Foundation is a partner in the Australian Stroke Clinical Registry and independently funds the national audit of stroke services for both acute and rehabilitation inpatient care. These two important yet quite different data collection systems capture self-reported data regarding the services and resources available in hospitals and rehabilitation service to determine whether stroke care is consistent with evidence based recommendations outlined in the clinical guidelines. The registry collects a small amount of data on every stroke patient and can flag areas of concern for further investigation. However the national audit collects far more detailed information on a selected group of patients, which gives a better overall picture of the care provided which is necessary for stroke patients whose care involves a multidisciplinary team. Currently these two data sets run independently of each other and there is a clear need for an integrated approach for stroke data collection and for system that incorporates existing data and the results of stroke audits undertaken by the National Stroke Foundation.

The cardiac registry requires merging two existing clinical registries in cardiac surgery and percutaneous cardiac intervention (PCI) into a national cardiac procedures registry, with the inclusion of implantable devices such as pacemakers and implanted defibrillators.

Significant benefits would be derived from the establishment of a national cardiac procedures registry and a national stroke registry. These include supporting the implementation of clinical guidelines, development of quality indicators and clinical standards and implementation of quality improvement initiatives for practitioners and health services linked to data collection. Importantly in a time of rapid technological change in healthcare, a procedures register will also provide the capability of being able to identify any adverse outcomes that may become associated with their use. Registries will also be able to assist in patient's decisions about treatment options through the provision of better information.

Research indicates clinical registries have the highest degree of compliance and use when they are perceived to be owned by the relevant clinicians.<sup>5</sup> Therefore, like in the other areas of the Commission's work highlighted above, it will be important to ensure clinician engagement in the development of registries.

### 3 b. QUALITY/PERFORMANCE INDICATORS AND STANDARDS

There is a clear need for the Commission to work with the broader health community to identify, prioritise and implement key quality/performance indicators and standards that will drive improvements in quality and safety.

To date, the Foundations have been disappointed that various sets of quality/performance indicators have tended to ignore CVD. This is disturbing, in that CVD is highly prevalent (3.5 million Australians are estimated to have some form of CVD), highly costly (it is the most expensive disease group, at 11% of direct healthcare expenditure) and is responsible for 34% of all deaths.

We support the recommendations of the recommendations of the 2009 AIHW report 'Towards national indicators of safety and quality in health care', which identified a range – though not a comprehensive set – of CVD indicators.

#### **Missing Indicators: CVD Quality/Performance Indicators**

A robust set of CVD performance indicators is required across all jurisdictions, including:

- time from first medical contact to (a) thrombolysis for both stroke and heart attack, and (b) angioplasty/stent implantation for heart attack;
- proportion of stroke patients admitted to a stroke unit;
- proportion of patients admitted to hospital with coronary heart disease (CHD) who, on discharge, receive (a) appropriate medications, and (b) are referred to a cardiac rehabilitation/secondary prevention program;
- proportion of general practices using electronic register recall systems for people with a history of CHD and/or stroke/TIA; and
- proportion of people without CVD aged 45–74 who have had a CVD absolute risk assessment within the past five years.

We believe the role of the Commission in setting key quality/performance indicators should be strengthened in the Bill and combined with appropriate consultation mechanisms.

We thank you for the opportunity to provide input to this inquiry and welcome the opportunity to contribute to further deliberations of the Committee should this be required.

Yours sincerely

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<sup>5</sup> Chong E; Shen L; Soon C; Ong H; Poh K; Teo S; Lee R; Teo S; Lee R; Low A; Tan H, *Two Years Clinical Registry Follow Up of Endothelial Progenitor Cell Capture Stent versus Sirolimus-Eluting Bioabsorbable Polymer-Coated Stent versus Bare Metal Stents in Patients Undergoing Primary Percutaneous Coronary Intervention for ST Elevation Myocardial Infarction*, **Circulation**. 2008;118;S\_1043