## INQUIRY INTO COAG REFORMS RELATING TO HEALTH AND HOSPITALS

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### **SUBMISSION**

The terms of reference of this enquiry refer to the "...role, structures (and) operations...of any new statutory bodies or organizations needed to establish, oversee (or) monitor the National Health and Hospital Networks (and) Primary Care Organisations...".

This submission proposes the establishment of a national body to co-ordinate public input into health services planning- the Australian Health Committee. This body will take a lead role in public education to increase health literacy and to engage the public in the process of priority setting for health care services.

Background-Defining the purpose of the health care system

In the executive summary of the report of the National Health and Hospital Reform Commission, the vision of a "sustainable, high quality, responsive health system for all Australians, now and into the future" is enunciated. The summary also refers to "access…equity…emerging challenges… (and) a self-improving system" as desirable reform goals. Health is regarded as a universal public good, and through its "nationally unified and locally controlled health system", Australia aims to deliver "world class, universally accessible health care". It is not clear however, exactly what Australians want from their health system, nor is it clear what their priorities and preferences regarding health spending might be.

## The need to prioritise health care planning and spending

The need to establish and define priorities for health care spending is undeniable. The proportion of Australia's wealth devoted to health care spending is high by international standards (9.1% of GDP in 2007-8), and increasing. Demographic change and increasing public expectations converge to create an environment of almost inevitable dissatisfaction with our health care system. Rationing of health services occurs now in Australia, but is largely implicit, hidden from public view and with variable direct input from citizens. Many countries around the world have recognised the need for more explicit rationing of health services. Some countries have established formal arrangements or organisations whereby citizen's input into health policy planning can be utilised productively. There will be a need to create a framework for prioritisation of health care spending in Australia. It will be essential to re-educate and re-engage the

Australian public in the purpose and limitations of our national health care system. In order to create such a framework, it will be essential to distil the "essence" of what Australians require from our health system. With the proposed reforms, there is an opportunity to synchronise education of the public, with wider public consultation in health systems planning and, potentially, prioritisation.

The imperative for community engagement in health care planning. The Alma-Ata declaration of 1978 refers to "the right and duty (of the citizens) to participate individually and collectively in the planning and implementation of their health care". This declaration was unanimously adopted by all World Health Organisations (including Australia). In other countries, community involvement in priority setting has promoted increased trust and confidence in public health services. With the decline of the paternalistic approach to clinical medicine, and the rise of evidence-based treatments, the concept of "shared decision-making" between patients and clinicians is becoming more commonplace at the individual care level. It is also likely that at a health services organisation level increasing citizen involvement in decision-making will legitimise the strategic direction and focus of health services.

History of public involvement in health policy making in Australia There is no significant history in Australia of citizen involvement in health care policy-making at any level. The report of the Australian Institute of Health Policy Studies Research Project (2008) concluded that "there is not a culture of consumer engagement surrounding health policy development" in Australia. There is a paucity of literature examining community engagement at the "broad policy level". This review noted that in general, and in non-health areas in Australia, consumer engagement at a broad policy level is both "feasible and successful". It is noted that this organisation (AIHPS) is funded in part from private sector funding (including from multi-national drug companies), and that the terms "consumer engagement" appear throughout its literature, apparently synonymously with "citizen participation" and "public involvement". I will refer in the following section to the distinction between "consumer engagement" in health care by special interest groups, and the more general notion of public involvement in defining the purpose of health care systems in a less personalised and more dispassionate way.

Contemporary examples of opportunities for public input into health policy development in Australia

There are a number of individual organisations where community input might currently be possible, welcomed or expected (or not). Some examples are given below. There is no over-arching national organisation to harness community input into defining the wider purpose or values of the health care system, nor any national body whose purpose is to educate the public on health care related issues.

Jurisdictional Examples of Community Engagement

Queensland Health established Health Community Councils in 2007. These organisations provide a advisory role, and also have an outreach role to engage and educate their communities, and "provide an opportunity for community members to participate in

decision making about health services". Should other jurisdictions develop community councils or similar bodies, the Australian Health Committee I propose could act as an umbrella organisation for such bodies.

### Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Advisory Committee (PBAC) allows public input into its decision-making process by way of submissions from individuals, or "consumer interest groups". It has been noted that "spending on pharmaceuticals is likely to be the largest single contributor to the increasing cost of our ageing population". It is also worthwhile noting that many "consumer groups" which have been involved in petitioning for individual medications to achieve PBS listing are often funded by large pharmaceutical companies who stand to benefit financially from the activities of their sponsored "consumer groups". This type of lobbying might be perceived as the action of "special interest groups" rather than public input with an impartial view to improving the overall health of the nation.

## Australian Commission on Safety and Quality in Health Care

This body, while having a role in reporting to the public on important matters of healthcare safety and quality, appears not to incorporate any attempt to consult with the public in defining matters of importance (to the public) regarding safety or quality in healthcare. Even on its website, access to lists of members of the various committees of this organisation is restricted to those members.

## Office for Aboriginal and Torres Strait Islander Health-OATSIH

Of all the bodies which make up the Department of Health and Ageing, OATSIH appears to have the most inclusive mission regarding public consultation and input; indeed its strategy is "firmly based on the principle of working in partnership with the Aboriginal and Torres Strait Islander community controlled health sector".

## Cancer Council and other Bodies

The various state-based cancer councils and the national Cancer Council of Australia provide opportunity for community input into fund raising and research activities, but little apparent opportunity for direct community input into policy making or priority setting.

# International Examples of Successful Community Input into Health Services Planning USA-Oregon state

The most famous example is the Oregon Medicaid experiment of the early 1990's. This was an attempt to rank (by cost-effectiveness) all available medical interventions, in order to define a basic "bundle of services" which could be provided within the available Medicaid budget. Despite the attempt at inclusiveness, the initial results were so poorly received in the community that a method of prioritisation based more on expert input and Commission consensus (albeit with community representation) ensued. The imperative continues in Oregon to maintain or increase community participation in health care planning. With time, and increased public education, it appears that the process of public

engagement in health systems planning is increasingly acceptable.

More recently, the state of Oregon has determined that a Citizen Board be established, which, although advised by technical experts, will consolidate the "decision-making power (regarding health policies, programmes and health services funding allocation)...in the hands of citizens whose livelihoods are not tied to the health care system". The keystone to the current reforms to health care in Oregon has been the establishment of the Oregon Health Authority- a "robust, independent citizen Health Authority with non-political leadership to integrate and oversee all aspects of health reform over the long term".

### New Zealand

In New Zealand the National Advisory Committee on Core Health and Disability Support Services was established in 1993. This committee investigated the possibility of developing an "Oregon" type list of services which would be specifically included or excluded. However, the focus of the work of the committee soon shifted. It accepted that the status quo activity represented an acceptable list of included services, and then attempted to develop eligibility criteria for patients for potential future services. It developed 4 priority-setting principles to guide decisions-making: efficacy, efficiency (cost-effectiveness), equity (to the extent that particular services reduced health disparities), and acceptability/congruity with community expectations. Information was collected from public meetings to provide community input and information around public expectations. The local disbursement of health care funds and the responsibility for planning health services in NZ lies with the District Health Boards. The majority membership of the District Health Boards is publically elected, although it is acknowledged in the New Zealand National Health Strategy that this public involvement is "not a substitute for community, consumer and provider involvement and participation in decision-making".

Since 1996, the renamed National Health Committee has met yearly to re-evaluate decisions and make recommendations on "the kinds, and relative priorities, of public health services, personal health services, and disability support services, that should, in the Committee's opinion, be publically funded". This committee has developed nationally consistent evidence-based guidelines for prioritisation for elective surgery, some medical treatments such as renal dialysis, and also the level of public funding of pharmaceuticals.

## United Kingdom

In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE) advises and makes recommendations on new technologies and interventions, and the development of clinical guidelines. In 2002, NICE established a Citizen's Council, a board of 30 members of the public, which meets regularly to "evaluate social and moral issues", and report to NICE so that "the views of the public underpin the thoughts and processes of NICE". A document has been developed by this council termed "Social Value Judgements", which summarises the recommendations of the council so that NICE can refer when making clinical and cost-effectiveness recommendations.

Israel

A National Advisory Committee (NAC), which includes members of the public, in addition to Health Ministry representatives, and input from private health insurers, considers advice from the Medical Technology Forum regarding cost-effectiveness analysis of new health technologies. The Advisory Committee then makes recommendations regarding the inclusion of new technologies in the basic "basket of services" offered to all citizens. In this way, the NAC allows direct public involvement in priority setting for health care.

## Education and Public input-Synchronicity

It appears to be generally accepted that the public requires education regarding priority setting, and should be involved in such decisions. Health Canada has described a continuum of public involvement in the planning and delivery of health services. This continuum covers education, information gathering and discussion, through to engagement and partnership. The Queensland Health Handbook also refers to the role of effective engagement "to inform and explain to the community what services can realistically be provided".

## Different models of public engagement

Public input can be accessed by a range of methods, from seeking general views and opinions, and then attempting to incorporate these views and opinions into decision-making processes, to having public input into specific choices and decisions. The most successful examples (as judged by impact on policy decisions) appear to come from countries (U.K., Israel, and New Zealand) where public involvement occurs subsequent to high level technical advice, normally from a separate committee. These examples have demonstrated considerable impact on health policy development.

## Local Priority Setting by Networks

As in New Zealand, it is likely that an Australian federal governments of any political persuasion will continue to encourage a more decentralised model of purchasing of health services- and with the proposed establishment of local health networks, purchasing of hospital-based activity (by the states) will be increasingly "split" from provision of these services by the networks. As in New Zealand, it is also likely that explicit priority setting will be viewed as (and is) a complex task which is beyond the expertise of a local health board, no matter how well intentioned. While nationally agreed health programmes will exist, it will be enormously helpful and efficient to have a national body to define priorities and guidance as regards appropriate resource allocation at a local level, so as to avoid spending based on historical activity, and also to avoid regional disparities in health spending which are widely viewed as a marker of poorer quality health service. In NZ, the National Health Committee has provided a common forum for District Health Boards to communicate and collaborate regarding high cost interventions and complex decisions.

## Conclusion

The creation of a national system for health provision involving primary care

organisations and local hospital networks in Australia provides a unique opportunity to increase public input into, and responsiveness of, the entire health system. Within the funding constraints, and with the development of the local network model, and the potential split between purchaser and providers of hospital-based health services, there is a need to ensure equitable access to all health services within a nationally agreed framework.

I submit that COAG establish an Australian Health Committee, with broad community representation, and with both a consultative and educational focus, in order to provide guidance and focus to states, local health networks and primary care organisations, so that each body can function optimally under the reformed national health system, and deliver sustainable, improved health outcomes for all Australians.