



Representing consumers on national health issues

Mr Stephen Palethorpe
Committee Secretary
Senate Select Committee on Health
PO Box 6100
Parliament House
CANBERRA ACT 2600

By email: health.sen@aph.gov.au

Dear Mr Palethorpe

Supplementary Submission to Senate Select Committee on Health

The Consumers Health Forum is pleased to respond to the Select Committee's invitation to provide it with a submission addressing indigenous health issues.

Australia's indigenous community-controlled health sector is unique in our country, and provides many advantages in delivering a culturally appropriate and secure health services to Aboriginal and Torres Strait Islander people. The unique organisational model delivers a structure which involves health consumers more closely in service delivery planning, provision and evaluation, than most other health services.

There remains, however, a significant challenge to be grasped, in engaging Aboriginal and Torres Strait Islander health consumers in the planning, provision and evaluation of health services provided to them, both in mainstream and community-controlled settings. We believe that this is a challenge which must be tackled in a structural way by all government agencies, health services and programs which deliver health services to these communities.

CHF appreciates the opportunity to provide further input to the work of the Committee, and we look forward to the Committee's deliberations on the very important issue.

If you would like to discuss these comments in more detail, please contact CHF Policy Manager Ms Jo Root on

Yours sincerely

Adam Stankevicius
Chief Executive Officer

27 January 2014



Submission to the

**Senate Select Committee on
Health**

**Inquiry into Indigenous
Health**

January 2015

Introduction

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to provide a supplementary submission on Indigenous Health issues to the Senate Select Committee on Health.

CHF is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

As a consumer organisation, we have an interest in ensuring the health system meets the needs of all Australians, including Aboriginal and Torres Strait Islander people. The gap in life expectancy and health outcomes between Indigenous and non-Indigenous people is a matter of concern for all Australians. We have drawn on significant input from the Health Consumers Council of Western Australia and their extensive experience of working with Aboriginal health consumers.

CHF previously provided evidence to the Select Committee on our draft principles of Consumer Centred Healthcare. We argued that consumers want a healthcare system that enables them to make informed decisions about their care options, while empowering them to manage their own health and wellbeing. Consumers want a healthcare system that treats them as a whole person, not simply as an experiment, condition, disease or illness. Such a system would include a consideration of a person's emotional, physical, cultural and social needs, as well as the needs of their carers and support network.

Listening to Indigenous Voices

In relation to Indigenous health, CHF urges the Committee to heed the recommendations and expertise of Aboriginal and Torres Strait Islander people, communities and health organisations, as reflected in the numerous submissions that have been provided to this Inquiry alone, in addition to the many undertaken previously.

The Lowitja Institute argues that the development and implementation of Indigenous health policy must be underpinned by a set of fundamental principles that include acknowledgement of the Aboriginal and Torres Strait Islander definition of health; recognition of the value of Aboriginal and Torres Strait Islander leadership; genuine partnership and engagement with Aboriginal and Torres Strait Islander people, communities and organisations; and respect for the skills and abilities of Aboriginal and Torres Strait Islander people to make decisions about their own lives.¹

There is a plethora of research around health issues of Aboriginal and Torres Strait Islander people but CHF shares the concern of others that Aboriginal and Torres Strait Islander people are not properly engaged in that research; as either participants in the study or in assisting to design and implement the research. We would like to draw the Committee's attention to the ground breaking accord the South Australian Health and Medical Research Institute's Aboriginal Research Unit has struck with the Aboriginal community in the way it conducts its research. This accord is based on the following key principles which we believe should be applied to health research but could also be applied to health service provision.

¹ Lowitja Institute, *Submission to the Senate Select Committee on Health*, October 2014.
<http://www.aph.gov.au/DocumentStore.ashx?id=a4a89daf-a18a-40f1-a843-0a191ae9f7f6&subId=300784> (accessed 8 January 2015)

- **PRIORITIES:** Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance and accountability.
- **INVOLVEMENT:** The involvement of Aboriginal people and organisations is essential in developing, implementing and translating research.
- **PARTNERSHIP:** Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.
- **RESPECT:** Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.
- **COMMUNICATION:** Communication must be culturally and community relevant and involve a willingness to listen and learn.
- **RECIPROCITY:** Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.
- **OWNERSHIP:** Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.
- **CONTROL:** Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.
- **KNOWLEDGE TRANSLATION:** Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.²

The health system is complex and consumers often have difficulty navigating it. CHF believes that there needs to be greater investment in training and supporting consumer advocates to help people find their way through the system.

One model to assist in navigating the system is currently operating through the Health Consumers' Council WA, which is an independent, community based organisation advocating for the consumer voice in health policy, planning, research and service delivery in Western Australia. Their Aboriginal Advocacy program has employed two Aboriginal staff since 2006 to increase Aboriginal consumer participation in mainstream health service policy, planning and delivery; to promote consumer health rights to Aboriginal consumers across WA; to provide individual advocacy assistance to Aboriginal consumers with a complaint about a health service in WA; and to work in partnership with health services in WA to address systemic issues impacting on Aboriginal consumers.

The WA program has found that many Aboriginal consumers are reluctant to be the only Aboriginal representative on existing mainstream health Community Advisory Councils and groups for a number of reasons. These include the daunting task of representing the disparities impacting health status and life expectancy for Aboriginal and Torres Strait Islander people and the fact that many existing consumer committees are not set up to address such enormous issues.

Other barriers to effective participation can include:

- Language;
- Physical distance and isolation;

² SAHMRI *Wardliparingga: Aboriginal Research in Aboriginal Hands* 2014 South Australian Aboriginal Health Research Accord: Companion Document

- Lack of understanding of Aboriginal cultural beliefs including views on health;
- Lack of awareness of intergenerational impacts of colonisation;
- Discriminatory views about Aboriginal people either from staff or other consumers at a service, and a perception that the service doesn't care;
- High consumer expectation of results and outcomes due to their involvement and investment in consumer representative work, because of involvement in the Aboriginal Community Controlled Health Sector (which obviously has a much higher degree of consumer control).

These barriers highlight the importance of culturally secure Aboriginal consumer engagement and the need for Aboriginal consumer evaluation of programs that are funded to address their needs. They further advocate for Aboriginal consumer groups and forums, which allow consumers to set the agenda and establish a two way ongoing communication process between consumers and services.

Funding for Services

The COAG Closing the Gap National Partnership Agreements and funding was an unprecedented commitment and investment to close gap in health life expectancy between Aboriginal and Torres Strait Islander People and other Australians within a generation. An important element of the Closing the Gap agenda is the attention it gives to the need to address social determinants of health and to have a whole of government approach to addressing inequalities around income, housing, employment and education. CHF believes that there needs to be a continued national effort to address these issues if we are to make any progress towards closing the gap.

The COAG agenda recognised the need for increased investment in both Aboriginal Community Controlled Health Organisations; in Aboriginal Liaison Officers and Outreach Workers both attached to mainstream health services, including hospitals and to co-ordinate between health practitioners and services; including Indigenous Outreach Workers employed by Medicare Locals, linking Aboriginal patients with GP services, allied health professionals, coordinating appointments; and even arranging transport. The commitments also recognised the need for national targets and better coordination between health services, and in WA, for example, doubled the number of Aboriginal Liaison Officers in public hospitals, which is improving communication with, and consideration of, Aboriginal patients' needs and improving co-ordination for patients between services.

It is concerning that a significant amount of the work progressed under Closing the Gap initiatives (particularly for vulnerable consumers and those affected by the Stolen Generations) is being undermined by the substantial funding cuts to Aboriginal Health and the restructuring of broader Aboriginal and Torres Strait Islander funding programs, now within the Department of the Prime Minister and Cabinet.

Whilst new governments will always introduce new and restructured programs, changes to what is funded; how it is administered and what this will mean for both agencies providing the services; their workforce and Aboriginal consumers, there is currently great uncertainty about what programs will continue and what impact the changes will have on consumers and services. The initial funding round was scheduled to be announced in November 2014 and commence in January 2015, but is delayed, which is exacerbating the concern and confusion.

Consumer Experiences

Aboriginal consumer perspectives and mapping of patient journeys and potential gaps for patients should be central to future planning and funding. Currently consumers who are also particularly vulnerable are patients from remote regions that have to travel far away from home to access health services. These patients can be very vulnerable away from family support and everything familiar; sometimes with language barriers and insufficient Interpreter provision. There is also a shortage in affordable and culturally appropriate accommodation available in capital cities and other regional centres, and orienting one's way in an unfamiliar city when one is from a remote and small community that doesn't have public transport, or multistorey buildings with elevators, escalators, can be daunting and frightening.

An important part of any consumer centred model of health care is that people need to understand the care options and treatments and be able to give informed consent. For people for whom English is not their first language this means there should be interpreter services available. However the language needs of Aboriginal and Torres Strait Islander people are often ignored. This means they rely on family /friends or perhaps a staff member who speaks their language for their information about what is happening to them. This is less than ideal as it compromises their privacy and the ad hoc interpreter may not have a good grasp of the medical terminology being used and so cannot relay it correctly. CHF recommends that there needs to be more funding for interpreter services and training for staff in recognising when one might be required.

CHF supports the model of care provided by Aboriginal Community Controlled Health Services (ACCHS) as an appropriate and effective way to provide health services to Indigenous families and communities and improve Indigenous health outcomes.³ However, not all Aboriginal and Torres Strait Islander people are able to access these services and many continue to use mainstream health services, either through choice or necessity. Accordingly, barriers to healthcare access, particularly those relating to the appropriateness, and the acceptability, of health services to Aboriginal and Torres Strait Islander people, must be addressed.⁴

Where mainstream services have made the effort to provide culturally appropriate health services they have been able to engage Aboriginal and Torres Strait Islander communities and have seen improvements in health outcomes. An example of this is the Inala Indigenous Health Service, a Queensland Government funded primary care services in Brisbane which has adopted the key principles underpinning the ACCHS models of care. It has seen a dramatic increase in the number of their patients from 12 to 3,000 in less than 15 years which suggests that Aboriginal and Torres Strait Islanders feel the service meets their needs.⁵

CHF strongly supports the need to build the consumer voice in Indigenous healthcare to ensure that the perspectives of those using both community-controlled and mainstream services is heard, and that health system improvements are made based on consumer perspectives about their

³ Panaretto K, Wenitong M, Button S, Ring I. Aboriginal community controlled health services: leading the way in primary care. *Med J Aust* 2014; 200 (11): 649 – 652 <https://www.mja.com.au/journal/2014/200/11/aboriginal-community-controlled-health-services-leading-way-primary-care> (accessed 8 January 2015)

⁴ Scrimgeour D, Scrimgeour M. *Health care access for Aboriginal and Torres Strait Islander people living in urban areas, and related research issues: a review of the literature*. Cooperative Research Centre for Aboriginal Health. Darwin: Cooperative Research Centre for Aboriginal Health, 2008. https://www.lowitja.org.au/sites/default/files/docs/DP5_final-pdf.pdf (accessed 8 January 2015)

⁵ Hayman NE, White NE, Spurling GK. Improving Indigenous patients' access to mainstream health services: the Inala experience. *Med J Aust* 2009; 190: 604-606 <https://www.mja.com.au/journal/2009/190/10/improving-indigenous-patients-access-mainstream-health-services-inala-experience> (accessed 9 January 2015)

health experiences. The newly-formed Primary Health Networks (PHN) will have a crucial role to play in order to promote genuine consumer and community engagement and these needs to include engaging with the Aboriginal and Torres Strait Islander communities within their region. However there is insufficient information on the desired objectives, performance measures and composition of Community Advisory Committees in the guidance materials for the PHN tender applications to see if there will be such engagement. CHF is concerned that the set of KPIs against which PHN performance will be measured has not yet been released, so it is not clear if future PHN's will have the necessary incentive to achieve a consumer and community engagement agenda that is inclusive, recognises diversity, and promotes interaction with local health organisations such as ACCHOs.

CHF notes that many submissions to this Inquiry have highlighted the proposed GP co-payment as a matter of significant concern. The National Aboriginal Community Controlled Health Organisation (NACCHO) argued that the proposed co-payment would likely create additional barriers for Aboriginal and Torres Strait Islander people in accessing healthcare services and increase costly hospital admission rates. NACCHO predicted that ACCHS would forego charging the co-payment to patients at an estimated cost of \$10.9 million to the sector.⁶ The revised proposal to reduce Medicare rebates would have a significant impact on the revenues going to ACCHOs which predominantly bulkbill. They would receive lower rebates and are unlikely to be able to pass this cost onto their clients.

CHF does not support the revised GP co-payment proposal as it undermines the principles of fairness and universality enshrined in Medicare, shifts the burden of deciding whether to charge the co-payment onto doctors, and will disproportionately impact the chronically ill, low-income families and the elderly who are not covered by existing concession arrangements.⁷ CHF supports calls for the Government to consult further with Aboriginal and Torres Strait Islander healthcare providers and the ACCHS sector to ensure that Aboriginal and Torres Strait Islander people are not negatively impacted by the revised proposal.⁸

⁶ National Aboriginal Community Controlled Health Organisation, *NACCHO Submission: Senate Select Committee on Health*, October 2014 <http://www.aph.gov.au/DocumentStore.ashx?id=b4ef6202-570d-4d5c-8b58-007c8bf233a6&subId=300662> (accessed 9 January 2015)

⁷ Consumers Health Forum of Australia (2014) *\$5 cut to doctor equals co-payment by default* (media release) <https://www.chf.org.au/pdfs/chf/20141209-%245-GP-Medicare-cut-hits-consumers.pdf> (accessed 9 January 2015)

⁸ Close the Gap campaign (2014) *Consultation needed on GP co-payment changes* (media release) <https://www.humanrights.gov.au/news/media-releases/consultation-needed-gp-co-payment-changes> (accessed 9 January 2015)