



Health Care Consumers Association of the ACT INC
100 Maitland Street, Hackett ACT 2602
Phone: 02 6230 7800
Fax: 02 6230 7833
Email: adminofficer@hcca.org.au
ABN: 59698548902

Ross O'Donoghue
Executive Director
Policy Division
ACT Health
GPO Box 825
ACT 2601

2 May 2011

Dear Ross

Re: Primary Health Care Strategy 2011 – 2014 Consultation Draft

The Health Care Consumers' Association of the ACT welcomes the opportunity to continue to assist the development the Primary Health Care Strategy 2011 – 2014 Consultation Draft.

HCCA based its submission on consumer feedback obtained from our community consultation on 12 April. We also advertised for written responses from Consumers and Member Organisations and have incorporated the responses we received. Our submission is based on the outcome of the discussions at our consultation and the written responses we received. HCCA Members also attended the consultation forum at CSIRO Discovery on 24 March.

HCCA commends ACT Health on the visual representation of how the PHC strategy relates to the other frameworks and strategies of ACT Health. It is of critical importance that policies and strategic frameworks are integrated and we see this as a positive. We would also like the objectives mapped to the other frameworks. We are interested to hear more about how the progress against the objectives will be monitored, particularly in relation to the role of the ACT Primary Care and Chronic Disease Strategy Committee.

Our main areas of concerns from the 2010 draft still continue to be of concern in the **Primary Health Care Strategy 2011 – 2014**. We have included a summary of the issues from our previous response because many of the issues HCCA raised were not picked up and our previous feedback is still relevant for further consideration.

If you require any clarification of our response, please do not hesitate to contact me on 02 6230 7800 or via email darlenecox@hcca.org.au.

Yours sincerely



Darlene Cox
Executive Director

HCCA Submission Primary Health Care Strategy 2011 – 2014.

Background

The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

Consumer-Centred Care

We recognised that our health system is under pressure and cannot cope if policies and planning continue to focus on diseases rather than consumers. The key to changing our health system lies in involving individual consumers, to empower us to understand our conditions, treatments and options. It is through understanding that we adhere to treatments, make behavioural changes and self-manage. HCCA considers that consumer-centred health care is the most cost-effective way to improve health

The essence of consumer-centred health care is that the health care system is designed and delivered to address the health care needs and preferences of consumers so that health care is appropriate and cost-effective. By promoting greater consumer responsibility and optimal usage, consumer-centred health care leads to improved health outcomes, quality of life and optimal value for health care investment.

We support the common priorities that the International Association of Patient Organisations have identified as critical to achieve consumer-centred health care at every level in every community.

To achieve consumer-centred health care we believe that health care must be based on the following Five Principles:

1. **Respect**
2. **Choice and empowerment**
3. **Consumer involvement in health policy**
4. **Access and support**
5. **Information**

Part One: Issues carried over from our 2010 submission

Consumer Centred Care: HCCA still has concerns that a commitment to Consumer Centred Care is not at the heart of this strategy in a workable integrated form.

Integrating the Charter of Health Care Rights: We are concerned at omission of the Charter of Health Care Rights and its place within the Primary Health Care Strategy.

Evaluation of Progress: We would like the strategy to include long-term plans to assess progress, measure changes and monitor the development of the strategy? This includes both qualitative and quantitative measurements.

More analysis of need using demographic data: It was good to see more emphasis on providing demographic data but we believe a more detailed analysis is needed to really tease out and identify areas of current and future need, particularly within disadvantaged groups, to address health inequalities.

Addressing Health Inequalities: Fuller discussion and specific strategies developed within the Primary Health Care Strategy need to be included for known areas of concern, such as Mental Health Consumers, Dental Health, Culturally & Linguistically Diverse Communities, Aboriginal & Torres Strait Islanders, People with Disabilities, Consumers living with chronic conditions and other disadvantaged health consumers.

Continued use of Passive Voice: Consumer feedback strongly expressed dismay at the continued use of the passive voice in the strategy.

Whole of life care: We believe the strategy needs to incorporate a planned approach to a continuum of care across a lifespan; beginning with pregnancy, birth, critical times such as early childhood, adolescence through to advanced care directives and dying.

Commitment to working partnerships: the emphasis needs to be on teamwork, acknowledging all key players and not just GPs.

Part Two: Key Themes from the HCCA consultations in April 2011

1. Introduction

HCCA agrees that the majority of ACT consumers enjoy living in one of the healthiest communities in the world.

This status should allow us the unique opportunity to have a two-pronged approach whilst maintaining the good health of the majority and offering disadvantaged ACT consumers targeted programs to address social inequality in health care and health outcomes.

Health Inequalities: HCCA believes more strategies could have been included to specifically address the needs of disadvantaged and vulnerable consumers who are not in the long-lived, healthy section of the ACT population.

1.5 Addition of the social determinants of health as a key principle

Role of General Practice within the Primary Health Care Strategy

1.7 Health Stakeholders

General Practice is the key stakeholder in the delivery of services in the primary healthcare sector

Consumers felt strongly that GPs are **one part** of any Primary Health Care Strategy but they felt the strategy should encompass all providers equally, including the roles of allied health and nurse practitioners.

Consumers commented on GPs as gatekeepers to patients' access to referrals, services, advice and support. While some consumers were supportive of, and positive about, the GP's role, others felt GPs were obstructive and unhelpful.

Consumers want to feel confident their GPs are informing them of appropriate programs and allowing the consumer to decide if they want/need to be referred for a particular service, or participate in a program, such as access to Medicare funded dental and podiatry. There was concern that some GPs or their Practices made decisions on behalf of consumers without informing them; and that some GPs had a policy of not participating in certain programs or referring consumers to those programs, despite the fact that they might benefit individual consumers.

Consumers were concerned about disadvantaged and vulnerable consumers who are least likely to have a GP and tend to be in the poorest health. These consumers are often unable to get a GP referral because they do not have access to a regular GP. The reasons for this may include the fact that a GPs books are closed, there is no bulk-billing or the consumer is forced to move away from a GP because of homelessness or insecure housing. The Strategy did not seem to have a plan to address these vulnerable consumer groups.

Concern was expressed about how many GPs will actually participate in, and implement individual parts of, the strategy. We are keen to see what is proposed to involve GPs in the strategy. If GPs are central to the strategy (with little focus on any other health professional) how will the participation, behaviour, referring practise of GPs be monitored against the objectives of the strategy?

(Consumer Case Study Freda Attachment One)

Consumers at the Centre of the Primary Health Care Strategy 2011 – 2014

Consumers felt the overall tone of the strategy needed to be addressed to convey the message that consumers are equal partners in health care. Many felt the wording implied a teacher/pupil relationship, where the consumer was being lectured to, rather than included in an equal partnership.

Access

System navigation is critical to access. We are very keen to see the development of a health service directory for consumers that includes all PHC services, which includes multidisciplinary, integrated care with allied health, rather than focus solely on the medical model. We encourage the ACT Health to work with ACT Medicare Locals to achieve this and to examine the new opportunities available through social media and mobile applications.

Integration with Other Plans

2.1.2 Medicare Locals

If the ACT Division of General Practice (ACTDGP) tender is successful in its bid to form a Medicare Local in the first wave this means that the new entity will be in operation from 1 July 2011. We are disappointed that more consideration of the role of the Medicare Local has not been included. We suggest it would be helpful if the objectives of the Medicare Local were mapped against the objectives of the PHC strategy. This would go some way to demonstrating that the health services will become more integrated and less fragmented.

Consumer need is an important driver of change. The demographic and epidemiological projections are a good start but we want more work to be done with the Medicare Local to identify regional variations and develop strategies to improve health outcomes. We understand the ACTDGP is planning to undertake this work for the ACT Medicare Local.

2.2 ACT Policy Contexts

The Charter of Healthcare Rights is still missing from the Strategy:

Other Useful ACT Health publications not included or considered in the Strategy

Community Health Centres (Enhanced & General) Part Two Model of Care

The Patient Experience Community Based Services for the Community Health Centre Model of Care Project October 2009

Why does HCCA consider these ACT Health Publications important in the context of the strategy? Both reports are well written. Have excellent research, consultation and implementation strategies

Dr Adele Stevens (HCCA President) described these reports and the process of developing these Models of Care over the last 2 years:

“I was at a consultation in April 2011 with 100 Community Health Staff and they have got it- Consumer Centred Care- that was at the centre of everything that was talked about. The staff all had fantastic ideas about ways to make things better for patients and how it could be made to work. It was very heartening to see. There has to be a way to bring what the practitioners know and are doing day-to-day in to the ACT Health bureaucracy”.

2.3.1 Social Determinants of Health and Health Literacy

It is good to see the Strategy recognising the determinants of health, including housing, education, transport, planning, communication, and access to social and other services. It is important that services are accessible, acceptable and affordable.

Programs like *Get Healthy* and *Chronic Disease Coaching* need to have an equivalent opportunity for the disadvantaged to access similar programs that address the barriers to access identified by the social determinants of health.

We don't want a situation in the ACT where the better off consumers continue to get healthier and live longer while the disadvantaged consumer continues to live in poorer health leading to a shorter unhealthier life.

Health literacy

The Strategy did not set out a plan for increasing the health literacy of the general population and specific strategies for addressing the health literacy of disadvantaged and vulnerable groups.

Continuity of Care – Where is the strategy that promotes continuity of care?

2.3.3

Consumers considered this section insulting and dismissive of older consumers.

Older Consumers were interested in a focus on Positive Ageing and consideration of an increasingly well informed and involved Aging Population that want to keep informed, live healthy live and want a focus on wellness and prevention. Consumers felt a rather dismal hopeless story was told about Ageing in the strategy.

Older consumers commented on the demographic data and modelling as not specific enough to be able to properly plan for the future.

Growth of CALD communities accessing services for older people. Growth of single person households across all age groups with implications for access to carers and in home support.

Some older Consumers saw having a registered Advanced Care Directives as a way to have control of the level of dependence and disability they are prepared to live with. Some Consumer views may be ahead of the planners and demographers who perhaps have underestimated the number of older consumers who if they have a choice do not intend to live with a high level of dependence and disability.

Community Based Self Help Groups

There are many Community Based Self Help Groups in the ACT. Some large and well funded through fund raising and some government funding. Smaller self-help groups often have limited or no funding to operate and use the resources of members to print materials and support their activities. Access to resources may be related to number of people with the issue or condition. E.g. some rare conditions may have small numbers and high levels of need for information and support and limited access to funds.

Community Based Self Help Groups have one mention in the strategy. Consumers had a number of views about the role of self-help groups as part of the strategy.

- Consumers had found access to or membership of support groups helpful and beneficial to their ability to manage and have access to information.
- Consumers had questions about quality control, registration, and recognition of support groups in the ACT.
- Consumers had some concerns about GPs & other health professional's unwillingness to tell consumers about a relevant self help group. Also an unwillingness to display pamphlets and posters. (The clinic having signed a contract with a provider who provided all the material in the clinic and paid a fee to the clinic for the privilege) No community material or posters could be put up.
- Where is the potential for funding the important role of Community Based Self Help Groups (Most do not meet the requirements for Health promotion funding)
- Concern some consumers take a long time to find a self help group and often say- "I wish I had known years ago- it would have helped me a lot to manage my condition".
- Education of health professionals about the role of Community Based Self Help Groups

Freda Consumer. Case Study based on HCCA Consultation

Freda Consumer has been living for 2 years with a long-term chronic condition. Freda has had to give up work and is struggling on a much lower income. Freda really needed access to Podiatry & Dental services and was struggling with the cost of treatment. She had recently asked her long term GP for assistance with her walking and foot problems and her difficulty eating because of dental problems. The GP offered no suggestions. Her friend told her to ask her GP again about a new program- Freda's GP said he did not do referrals for this Medicare funded program because of the paper work. Freda liked her GP but felt she needed to find a GP who would refer her to the services she needed so she could afford the care she needed. Freda found it very difficult to find a GP who would do a proper referral.

Freda thought she would try another GP. She would ask at Reception if the GP did the referrals and was told she would need to discuss it with the GP during the appointment. Freda went to two other GPs before she found a GP who would make a referral through a Medicare funded program.

Freda has had 2 Podiatry appointment and her feet have improved and are not so painful. She has also been able have dental treatment that has helped her eat without pain from broken and decayed teeth.

The third GP she tried was really well organised and Freda spent 30 minutes with the Practise Nurse filling out the forms and discussing her condition. Freda felt very cared for and it helped her understand her condition much better. Freda feels her health and her chronic condition is much better managed and has improved.

Freda felt like her long term GP should have told her about the new program she was eligible for and the other GPs she tried should have been honest and had a sign up that said- This practise will not refer to these programs. Freda said they all had other signs in the waiting room. "We do not prescribe drugs of addiction" and "Payment in full must be made at time of appointment". Freda also thought Reception staff should have been able to tell her so she did not waste her time and have two unnecessary appointments.

Freda's experience is consistent with experiences of consumers who participated in consultations with HCCA. Other Consumers at the Consultation from their own recent experience raised a number of reasons GP gave for not responding to requests and/or not telling Consumers about services they may be eligible for and desperately need.

- GP does not do anything new
- GP does not have time for the paperwork & it is not worth it financially
- GP is thinking about whether it is worth trying

Consumer 2 & 3 were concerned their GP was unwilling to do a care plan. Other Consumers were surprised their GPs had not told them about the new services available under Medicare particularly for Consumers with Chronic Conditions.

Part 3 Community Consultation Raw Consumer Comments HCCA April 2011

When I read the strategy it felt like the strategy was being “done” to consumers rather than in partnership with consumers as equals.

Lack of focus on wellness, no support for positive healthy living

Lack of strategies for continuous assessment and lack of identified outcomes or benchmarks to be able to monitor progress

Need for transparent evaluation and reporting strategies

Where is the commitment to partnership between consumer and provider?

Access to QUIT programs, and NRT products

Comment on sections of the report

1.4 Focus on wellness

Education of health professionals to be able to work cooperatively with other health professionals and with consumers

2.3 Surprised about the lack of ABS statistics which will influence provision of Primary Health Care

E Health integration

Allied Health integrated into strategy

Section on how the *Charter of Health Care Rights* will work with or influence the ACT Primary Health Care Strategy

Limited evaluation options presented to be used to evaluate the strategy over time for improvements, changes, failures, successes,

Use of terminology preferred by consumers *Chronic Conditions* (rather than Disease)

PCC Lack of commitment to PCC within document

It was noted this version is much better written than the first draft.

Lack of emphasis on Partnership and mutual respect

Emphasis on changing consumer behaviour rather than any acknowledgement of change needed within ACT Health

Disconnect between ACT Health administrative arm understanding of and implementation of PCC and the excellent practise of Community/ Palliative Nurses as an example

We would analyse the strategy as uneven- some sections with acceptable strategies – others with not

Where is the strategy that integrates services around the needs of the consumer?

Eg Referral – to another area of ACT Health – the referral itself is seen as the end of responsibility- What if the person the consumer is referred to is on leave, - there is no attempt to check the availability of the referral

Silos- still apparent in document

GP discussion ACT Primary Health Care Strategy was seen to be focused on GPs with not enough mention or emphasis on any other health professional such as the Pharmacist, Allied Health, Nurses, Nurse Practitioner s, Practise Nurses

Missing strategy of how the ACT government is going to get the majority of GPs in Canberra to pay any attention to the ACT Primary Health Care Strategy.

Consumers commented their experience is their GPs do exactly as they like no matter what the “policy” is.

Consumers raised the issue of lack of meld between private providers v/s public or a combination where the providers refuse to communicate or cooperate with each other.

Consumers report having tests repeated because the provider says – Oh no- not that lab/clinic/xray- we will have to do them again with this lab/clinic/xray.