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**HCCA Submission on  
the Strategy for Improving Care  
and Support for those Living with  
Chronic Conditions  
2012-2017**

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## 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.

HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

HCCA is an organisational member of the *International Alliance of Patient Organisations (IAPO)*. IAPO is a unique, global alliance representing patients of all nationalities across all disease areas and promoting patient centred healthcare around the world. HCCA, like IAPO, supports the view that consumer-centred healthcare is the way to a fair and cost-effective healthcare system. We believe that consumer-centred health care can be successfully achieved through the application of five key principles:

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

It is with reference to these principles that the HCCA has developed its submission to the Chronic Conditions Strategy.

## Introduction

HCCA welcomes the opportunity to provide feedback on the ACT Health Directorate's Strategy for Improving Care and Support for those Living with Chronic Conditions. Overall, we are pleased with the progress that has been made since the last draft version was released.

We have consulted extensively with our membership to develop this submission. Prior to the release of the Draft Chronic Conditions strategy, HCCA hosted a number

of discussion groups and forums with our members and other consumer organisations to develop a deeper understanding of the issues relating to the care of chronic conditions that are high importance to consumers. On October 22<sup>nd</sup>, we held a Health Issues Group with Ms Cathie O'Neill, the consultant engaged by the Health Directorate, to discuss the most recent draft of the Chronic Conditions Strategy with our members. Much of the feedback received during this meeting was documented by Ms O'Neill for consideration, and so has not been reflected in our submission. However, a summary of the discussion has been included as an attachment. Individual consumer feedback has also been collected through email correspondence and conversations.

We would like to acknowledge that many of the recommendations we made during the confidential consultation on the chronic conditions strategy prior to its release have been reflected in this draft version. This demonstrates the commitment of the ACT Health Directorate to working with consumers to deliver more effective consumer centred care. We are greatly encouraged by the progress that has been made in developing this Strategy, and believe that it represents a major step forward for strategic health documents in the ACT. This innovative Strategy will enable the Health Directorate to implement effective and forward thinking health care reform.

There are a number of areas of the Strategy that we believe could be improved.

1. One main overarching issue is the lack of focus on children living with chronic conditions, who are often disadvantaged by eligibility criteria, and the need to improve the transition of consumers from paediatric to adult services.
2. The aspirational nature of this document is also concerning. There is little value in having a Chronic Conditions Strategy that will not lead to any real changes in health services to provide better care for people living with chronic conditions. To demonstrate a more practical approach to health reform, we would like the first sentence on page 3 to read:

*"To provide appropriate, effective and efficient services requires communication, integration, resources, and collaboration."*

Without allocating additional resources to service providers, they will be unable to implement many of the action areas included in the Strategy.

3. We support the increased focus on providing care in sub-acute, primary and community settings. However, it is also important to recognise that there are still serious problems with acute care services that impact on the quality of care provided to people living with chronic conditions. This area needs to be covered in more detail in the strategy.
4. It may also be useful to include a section in the beginning of the strategy covering the lessons learned from the previous Chronic Conditions Strategy and how they can be applied to the implementation of the new Strategy

The rest of our comments relate to specific areas of the strategy and have been addressed under the corresponding headings.

### **Scope / Exclusions**

While we understand that the aim of this Strategy has been to avoid duplication with other strategies and address existing service gaps, we believe that primary health care, palliative care and mental health services are inextricably linked to the care of people living with chronic conditions. Also, the Clinical Services Plan needs to reflect the directions outlined in these documents.

So much of the care of people living with chronic condition occurs in primary health care settings that it would be impossible to develop a chronic conditions strategy without taking these services into account. Although this is acknowledged in the Strategy, we are concerned that without closer linkages to the Primary Health Care Strategy, service provision and reform will continue to occur in silos, which makes it extremely difficult for consumers to access the services we need.

Similarly, mental illness has high comorbidity with many chronic conditions, making it essential for care plans to take mental health services into account.

In the very least, the Chronic Conditions strategy will need to clearly explain the nature of the links with the Primary Health Care Strategy, Palliative Care Services Strategy and Mental Health Strategy.

The ACT Planning Framework Diagram on page 11 should also include [HIV/AIDS, Hepatitis C and Sexually Transmissible Infections: A Strategic Framework for the ACT 2007–2012](#) and its replacement.

### **How to use the Strategy**

We are concerned that the phrase '*It is suggested that all services and business units consider...*' is too soft to ensure adequate uptake of the Commitment Goals and Key Action Areas. This is an essential strategy and consumers want to see steps being taken to ensure that it will be implemented effectively.

### **The Chronic Disease Context**

Many people living with chronic conditions are also living with one or more disabilities. Often, their disability is a direct result of their chronic condition. Not enough consideration is given to the impact that disability can have on accessing services. We would like to see this recognised in this section and better reflected throughout the rest of the document.

We are aware that there has been much debate with regard to how the 'Chronic Conditions Management Pyramid' should be presented. The main suggestions that we would support include a clearer indication that a person may have multiple chronic conditions, each at different stages of the pyramid, and that a person may have an unstable condition that does not require hospitalisation. It is also important

to note that stable and unstable conditions may be managed in respite care or nursing homes as well as the hospital and in the home.

The list of components of good management of chronic conditions could also include the timely provision of information about management and service options for their particular condition. We would also like the first dot point to read '*Improved early detection and early intervention*'.

### **Commitment**

The phrase 'aspirational commitment' is an oxymoron. If the ACT is expected to commit to achieving these goals, they are more than aspirational. We would like to see stronger wording being used in these sections.

#### **Commitment Goal 1 – Every person at risk of a chronic condition receives appropriate screening and early detection**

We would like to see a clear indication of which service providers would be responsible for the particular components of effective early detection. For instance, general practitioners would play a key role in risk factor screening, as they have access to consumers on a regular basis and can identify risk factors during regular health check-ups. Clear role delineation is needed to give more weight to the Commitment Goals.

The proper term for 'injecting drug users' is 'people who inject drugs'. This needs to be amended in the first dot point .

#### **Commitment Goal 2 – Every person with a chronic condition receives the right care, in the right place, at the right time from the right team**

Ensuring that consumers have access to the right care at the right time requires continuity and coordination of care, which makes it easier for consumers to navigate the complex health system to access the services they need.

One of the difficulties often experienced by consumers is ensuring that the treatment they receive for one chronic condition will not interfere with treatment they are receiving for another condition. This particularly applies to medications. Cross specialty consultation is invaluable to consumers living with multiple chronic conditions but is notoriously difficult to organise. We would like this to be flagged as an area for improvement in order to ensure that consumers receive the right care for their specific combination of conditions. There may also be value in the role of the general physician in this context. This is a decision about clinical resources that we anticipate will emerge in the development of the Clinical Services Plan and models of care.

There is also a need to improve health literacy amongst clinicians regarding pain management and the status of chronic pain as a chronic condition in its own right.

The diagram provided in this section is a good depiction of the multiple components of care of chronic conditions, and we are pleased to see that the person has been placed at the centre of the team. The only addition we suggest is Palliative Care, as this will be relevant for many consumers living with chronic conditions, particularly as they age.

However, this diagram also demonstrates just how complicated it can be for a consumer, who may be quite unwell at different times, to try to coordinate their care between the multiple sources and service providers. An essential component of providing person-centred care is to ensure that they are empowered to control and manage what is going on around them and be involved in decision making. This can be facilitated by a case manager or team leader, who would be responsible for liaising with different members of the consumers care team and assist the consumer with coordinating their care.

Although the role of the care coordinator is relatively new and is currently only applied to acute care, we see that there is great potential for this role to be expanded for sub-acute care. It would be good to explore this possibility as it could provide a valuable source of support for the self-management of chronic conditions.

### **Commitment Goal 3 – Every person with a chronic condition has a plan which supports active participation in their care**

We are unsure why the extent of an individual's plan will be determined by their ability to contribute to their own care. Ideally, all consumers should have a comprehensive care plan to assist with effective management of their chronic conditions. We would expect that the individual's capacity to contribute to their own care would affect the nature but not the extent of their care plan.

We strongly support the acknowledgement that the capacity to contribute to our own health care is largely dependent on our health literacy. This is a significant issue, particularly for consumers who are new to the health system. While it will be useful for service providers to work with consumers to improve their health literacy, the ACT Health Directorate also needs to work towards providing and publicising education programs and online information resources that consumers can seek out of their own accord.

Care plans need to be developed by GPs in close consultation with the consumer. Consumer centred care necessitates consumer involvement at all stages of health care, including the planning process.

It is good to see that short and long term goals have been identified as important components of a care plan. We would like this point to acknowledge that these goals should be developed by the consumer and their GP, and that different consumers will have different priorities and goals. For instance, some consumers may be focused on their mobility and daily functioning while others may prefer to focus on effective pain management.

The list of care plan components also needs to include a comprehensive list of the consumer's medications that is easily accessible to members of the consumer's treatment team. This is particularly important when a consumer is prescribed a new medicine, as it would make it easier for the prescribing clinician to check its compatibility with the medications currently being taken. It is also important for clinicians to consider the cumulative impact that taking so many different medications can have on a person's well-being and lifestyle.

We would like to see complementary medicines and therapies being included in the care plan components as well. Consumers often value these therapies and rely on them to improve their quality of life and capacity to self-manage their conditions. It

would be useful for consumers to be able to discuss these with their GP, specialists and other members of the treating team) and find a way to fit these into their care regimen. We note that complementary therapies have been stated to play an important role in promoting the well-being of consumers living with chronic conditions.

#### **Commitment Goal 4 – Every person with a chronic condition is aware of relevant support options and how to access them**

This section is very general and offers little advice regarding how consumers can actually be made increasingly aware of support options. As one of our newer members have commented, if you had not had previous experience moving through the health system, it is nearly impossible to find out where to go for support.

We believe it is important for the ACT Health Directorate to take a more prominent role in providing information about services. Online information services need to be made more accessible and easy to navigate. Currently the Health Directorate's website is unclear and consumers have reported having difficulty locating the services they were looking for.

It is also essential that this section includes reference to financial support options. Although this is beyond the remit of the Health Directorate, it has been acknowledged that this Strategy will involve a range of different services within the ACT and that multiple government sectors will be responsible for its effective implementation. Financial security is an integral component of the social determinants of health and has a significant impact on a person's physical, social and emotional well-being. There is also evidence to suggest that financial constraints can act as a barrier to self-management of a chronic condition<sup>1</sup>.

#### **Commitment Goal 5 – Every person with a chronic condition is provided the necessary information and support to stay healthy and/or minimise the risk of other diseases**

The point listed at the end of this section 'Management of medications in collaboration with medical and pharmacy providers' might be better placed under Commitment Goal 3, as good management of medications has significant quality and safety implications as well as the potential for health promotion.

#### **Commitment Goal 6 – Every person with a chronic condition does not have to repeat their story unnecessarily**

Again, we are concerned that this section is too vague and aspirational to facilitate meaningful reform. It is good to see that eHealth has been identified as a valuable tool for the integration of care; we would like to see more specific recommendations for how new technologies could be utilised for registering care plans for consumers living with chronic conditions.

During the different forums we have held regarding the Chronic Conditions strategy, consumers have raised the need for accurate and updated chronic disease registers at hospitals that can be easily transferred should the consumer need to access

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<sup>1</sup> Bayliss et al, 2003. 'Descriptions of Barriers to Self-Care by Persons with Comorbid Chronic Diseases' in *Annals of Family Medicine*, 1(1): 15-21.

acute care interstate. While chronic disease registers are in use at TCH and Calvary, consumers have found that if they are away from the hospital for a long time, their information is deleted from the system. Ideally, registers for people living with chronic conditions need to be created prior to admission to hospital and maintained unless the consumer indicates that they are no longer living with a chronic condition.

### **Key Action Areas**

For this strategy to have any real weight in the ACT, there needs to be clear requirements and expectations for strategy uptake and implementation. Consumers have expressed strong support for many of the recommendations in this strategy and want to ensure that they will result in tangible change.

We would like to see these action areas being prioritised in terms of what is most essential for consumers and needs to be urgently addressed. It would also be useful to include timeframes for implementation provided for each area based on need as well as feasibility.

We are glad to see that the Key Priority 'Improve Patient Centeredness' has been linked to each of the Commitment Goals in the Matrix of Goals and Key Priorities. We would also like to see the Key Priority 'Improve Access' linked to Commitment Goal 1- 'Receives appropriate screening and early detection'. Often it is the most disadvantaged and vulnerable in our community that are at risk of developing a chronic condition, and it essential to ensure that they have access to screening and early detection.

The preamble for this section refers to a Chronic Care Steering Committee. We would like to know more about this committee, including who the members will be and who it will report to. We strongly recommend having at least one experienced consumer representative on the Committee. HCCA are keen to work with the Health directorate in assisting with the implementation of this strategy.

### **Key Priority 1 – Optimise existing services through enhanced integration**

Integration is an essential component of effective care of chronic conditions. It is for this reason that we are concerned about the lack of consideration of the Primary Health Care Strategy and mental health services. Without having clear links with and involvement in planning and delivery of primary health care services, integration will remain an impossible goal.

Another important action area to enhance integration would be to improve the transitioning process for adolescents who are no longer eligible for paediatric services. There is an abundance of evidence suggesting that this continuum of care requires urgent attention, as adolescents and their parents find it a real struggle to ensure that they can continue to access the right care<sup>2,3</sup>. This issue has already been flagged in Attachment 2 of the draft Strategy, as it has been in previous drafts, but we are still yet to see evidence that this will be a focus area.

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<sup>2</sup> Tuchmann, Slap, & Britto, 2008. 'Transition to adult care: experiences and expectations of adolescents with a chronic illness' in *Child: Care, Health and Development*, 34(5): 557-563.

<sup>3</sup> Rapley & Davidson, 2010. 'Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness' in *Journal of Clinical Nursing*, 19(3-4): 313-323.



We would like it make clear whether the action area 'improve the sharing of information' could include facilitating cross specialty consultation. As discussed above, this is a difficult process for consumers to organise but is very valuable for the management of multiple chronic conditions.

We see that this priority in particular could benefit from the advances being made in eHealth, it would be good to suggest some areas where this could be applied in the list of action areas.

### **Key Priority 2 – Improve access**

People without transport have been listed as a disadvantaged group, but no action areas have been identified to improve their access to health services. Infrastructure is essential for accessibility; it must be affordable and frequently available. As this strategy is not limited to the Health Directorate, it is within the scope of the document to address infrastructure development.

We welcome the inclusion of improving health literacy as an action area to improve access. Our Health Literacy Project has been aimed at addressing this issue, particularly for disadvantage groups. We are keen to continue working with the Health Directorate in this regard.

Another action area would be to address financial barriers to consumers accessing certain types of treatment. For instance, consumers requiring elective surgery may need assistance to access this via a private hospital in order to avoid unreasonable waiting periods.

We support the initiative to expand the use of telehealth for the management of chronic conditions. Telehealth could be used to provide assistance with chronic pain management, as consumers with chronic pain may have limited mobility. It would also be valuable for consumers with chronic pain to have instant access to support over the phone in times of distress to help protect against anxiety and depression. There could also be a role for telehealth in improving access to services or advice out of hours and for people living in rural areas around the ACT and in NSW.

Interpreting services are also essential to ensure that Culturally and Linguistically Diverse (CALD) consumers have access to the services and health information they need. However, it is important to note that interpreting services are highly limited in the ACT. This issue will need to be addressed before service uptake can be improved.

Finally, consumers must be aware of the services available in order to access them. Services need to be advertised throughout the ACT, with particular consideration given to reaching disadvantaged groups.

### **Key Priority 3 – Better support those in the community**

Research has found that community health organisations are able to support self-management of chronic conditions and that their integration with the health system can facilitate consumers contacting the organisations for support<sup>4</sup>. We would like to

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<sup>4</sup> Boyle et al, 2009. 'Consumer health organisations for people with diabetes and arthritis: who contacts them and why?' in *Health and Social Care in the Community*, 17(6): 628–635

see recommendations that the Health Directorate could work more closely with community support groups to assist consumers accessing these groups.

It would also be good to include the need for increased support for community based service providers, who can enable consumers to manage their condition without needing to go to hospital.

While we welcome the Strategy's support for the principles of self-management, there is a concern that the Health Directorate has made no clear commitment to allocating additional funds to self-management services. Without additional support, these services will not have the capacity to deal with an increase in uptake.

Consumers have also expressed an interest in mentoring programs for self-management of particular chronic conditions. This could be arranged by ACT support groups provided that they were allocated the necessary resources by the Health Directorate.

Self-management also requires readily available technical assistance for medical equipment such as oxygen tanks. If a consumer's equipment is faulty and they cannot get them repaired quickly, they may be forced to go to hospital to receive treatment. This is another issue that was flagged in attachment 2 but has not been addressed.

We would like the Health Directorate to investigate more ways to engage with consumers online and through social media in order to assist with self-management. Consumers want an online one-stop-shop for information regarding their health, and the Health Directorate has yet to provide this.

There are a number of self help groups in the Canberra region that provide significant peer education and support to consumer living with chronic conditions. SHOUT provides a valuable services in supporting the administration and business needs of the groups. We see that there is a need to further support these groups to develop their capacity to network with other groups and to advocate for consumer interests. A network of these groups could work with the Health Directorate to build mutual understanding of consumer needs and how to make changes in the health service to become more consumer centred. This group could provide advice to the proposed Chronic Care Steering Committee. We see that there is a role for HCCA to establish this network and support them to provide a strong, coordinated voice for consumer issues. This is consistent with the work of HCCA and we would like to speak to the Directorate further to advance this idea.

#### **Key Priority 4 – Improve person centeredness**

We believe it is important for staff to be provided with sufficient education in providing patient centred care as well as the necessary report. We would like this to be included in the second paragraph of this section.

Improving person-centeredness would also involve supporting consumer representatives on governance committees and ensuring that the Australian Charter of Health Care Rights is embedded in the organisational culture of all health service.

With the appointment of the Patient Experience Leader as well as the move to the national Health Service Standards we see that there is great potential to undertake projects to advance the implementation of patient centred care.

### **Key Priority 5 – Enhance early detection and illness prevention**

Public awareness campaigns are required to successfully promote early detection and illness prevention. Opportunistic screening by health professionals is only half of the solution. If the Health Directorate can promote a culture of seeking out screening for high risk chronic conditions, people who might not otherwise see a GP may be more likely to seek them out.

Development of guidelines for familial risk identification and genetic counselling needs to occur in consultation with consumers.

### **Key Priority 6 – Enhance governance and system enablers**

It would be essential for the Chronic Care Steering Committee to have close links with primary health care governance committees, as primary health care service planning will need to consider the Commitment Goals and key Action Areas of this Strategy. As mentioned above we see that there is an opportunity to support consumer and self-help organisations to network so that can stronger and more coordinated consumer engagement can be undertaken to complement the existing work of HCCA.

### **Evaluation**

We understand that Cathie O'Neill is currently in the process of developing an evaluation framework to assess the effective implementation of the Strategy. We would like to see the strategy being evaluated against the Australian Charter of Health Care Rights in order to ensure that services are being delivered in accordance with consumer centred care. Feedback from consumers, particularly those living with chronic conditions, also needs to be a key element in the evaluation process.

There also needs to be measurable outcomes and progress indicators throughout the Strategy, otherwise it will be impossible to undertake any meaningful evaluation.

We are happy to discuss our submission further, and look forward to being involved in the implementation, evaluation and monitoring of the Strategy.

## **Attachment 1 – Summary of Discussion from the Consultation Forum on the Chronic Conditions Strategy**



### **Health Issues Group with Cathie O'Neill to discuss *ACT Strategy for Improving Care and Support for those Living with Chronic Conditions***

22 October 2012

**Chair:** Russell McGowan

#### **Attending**

Cathie O'Neill, Terry Swarner, Helen Reynolds, Helen Cotter, Margaret McCulloch, Pat Branford, Anna Saxon Taylor, Denise Mott, Bev McConnell.

HCCA Staff: Kimberlie Mikulic, Hayley Hoolihan, Alisha Summerton, Karen Jameson, Nicole Moyle, Yelin Hung, Kerry Snell

#### **Welcome to Country**

#### **Introductions**

Members of the group introduced themselves and briefly mentioned any chronic conditions they live with. Some had multiple, entirely unrelated chronic conditions.

Cathie O'Neill provided an overview of progress in the development of the strategy. She was keen to take on board as much consumer feedback as possible. Participants raised issues as Cathie went through the document.

#### **General Comments**

Overall, consumers were happy with the content and layout of the document.

The venue of the public consultation at the Business Event Centre at Regatta Point was very inaccessible for those relying on public transport, therefore some, who would have liked to attend, did not do so.

#### **Scope**

Cathie said the focus was on gap areas. Mental Health, Cancer and Palliative Care all had their own plans/strategies, therefore they were not included in this one. It was felt the last strategy focused too much on health promotion and prevention and not enough on care.

The Strategy is intended to cover all age groups; there will be more focus on paediatrics and young adolescents in the next version.

Eligibility and transition management were important when dealing with children and adolescents, because the regulations are very specific and tight – the Strategy needs to explain the criteria clearly. (The question was asked, Where do you go when you are diagnosed as a teenager?)

### **Multiple chronic conditions**

Is the complexity of multiple chronic conditions sufficiently covered?

There needs to be more focus on silos, because the notion of filling the gaps does not adequately address this issue.

There are more problems in the acute care setting than the primary care setting; these problems need to be addressed.

The introduction of a care navigation role or advocate to help consumers to understand and navigate the health care system is important. (The comment was made “when you do just live with a condition, you’re often stuck when you have a flare up”.)

The care coordination role could be expanded for sub-acute care.

It is important to put the person at the centre of service delivery, as reflected in the flower diagram. Another “petal” should be added representing palliative care.

The pyramid diagram should include:

people with multiple chronic conditions

unstable chronic conditions, that don’t require acute care, which are being managed at home

Good management of chronic conditions list should include

Improved early detection *and intervention* (to put in the economic/psycho/social context and demonstrate a person-centred approach)

A final dot point should be:

early information about medical, community and other options available to the patient

Terminology: COPD could be respiratory conditions/diseases or lung diseases

It would be good to include a glossary - particularly to distinguish condition and disease.

The two most prevalent conditions listed on page 7 are cancer and mental health. It is important to explain in more detail why they have been excluded from the strategy.

One condition may flare up while another is stable. People with few lot of medical resources get very frustrated with this process. This raises the importance of health literacy. Health literacy also applies to professionals who operate in silos.

Comment: "You are not looking at this from the perspective of the people who are sick. Information needs to be tailored to consumer understanding. Doctors are not listening."

Reply: "This is why the walk in centre is so good, there is good, clear communication."

Medication: Doctors need to know what medication patients are taking.

Information about medical and community options/services available for good management of chronic conditions should be included.

There are not nearly enough counsellors available.

Doctors need to consider the effects of multiple medications.

### **Transport**

More references to accessibility and transport are needed; there is only one in the draft.

Good accessibility and transport is vital if people are to stay in the community (rather than hospital). (Comment: "when you're not well, trying to navigate poorly designed transport systems is almost impossible. Poor transport also makes it difficult to obtain medicare rebates etc.)

Many people are unable to attend Lung Life meetings they are not eligible for transport to attend "support" or "social" meetings.

Most "support/social" meetings are held out of normal working hours and are therefore difficult to attend.

There is often a shortage of drivers.

### **Social Inclusion**

Need to look at those living with chronic conditions in a socially inclusive context.

Many services provided aren't known to the patient until the day of a medical procedure. This must have a negative impact on the patient receiving the services and is not patient-centred care.

"If you don't have anyone looking after you, it makes it hard to abide by the rules. You can't plan for anything when the services are so secretive and you don't know what time surgery or discharge will be."

### **Disability**

Disability is often a result of chronic disease, this needs more focus in the strategy.

It is important to look at the person in their social and economic context (social determinants of health); some of the issues they face are outside the remit of the ACT HD.

### **Chronic Pain**

Statements about inclusion of all people with chronic conditions is good to see. The draft Strategy is forward thinking and reflects incremental improvement. The acknowledgement of pain as a chronic condition, is a first in Australia.

It would be useful to include chronic pain statistics (see the 2007 National Pain Strategy).

### **Commitments**

Cathie said value based statements that everybody can adhere to were important and also a tool for consumers.

Early feedback – self-management often involves other people, also puts burden and blame on the consumer: hence the term active participation.

There are problems with the term self-management, because there is a need for a carer or another representative to speak for you when you become really unwell. If you are on your own, it is hard to get people to listen to you in the Emergency Department.

If you are not next of kin, staff are likely not to listen to advice offered about the patient.

There needs to be a commitment to team care where the team acknowledges and respects the role of the patient and carer within the team.

It would help to acknowledge that patient and carer-centeredness is at the heart of this document – putting a statement to this effect in the introduction of the strategy would be helpful.

The document needs to explain options available for people who feel they are not receiving the correct care, especially at times such as Christmas.

There should be reference to the Charter of Healthcare Rights .

What about pastoral and palliative care and complementary medicine?

We are moving away from focusing on GPs for maintaining care plans as the PCEHR and the 'medical home' play a greater role. We need a place where we can go to get support for what we want to do. Can we incorporate this technology?

Support groups are most useful in the early stages of diagnosis, but the connection between them and the consumer is often lost. Much is dependent on the nature of the support needed. Often support groups are run by volunteers in their own free time and they need to consider their own health too.

More support is needed for the support groups – funding is very uneven.

A general comment was that wording for the action areas needs to be stronger.

In order to optimise existing services, we need to raise awareness.

### **Priority 1 – Integration**

There is a need to move away from the term 'capture'. Consumers must be free to move around the system.

Transitioning from adolescent and paediatric care needs to be included in the first dot point.

Some services needed to provide coordinated care are completely lacking. It is important not to leave people out. New services need to be provided. The current model might not be the most viable or effective for the future. There is a need to rebalance the deployment of resources.

People are falling through the cracks. For example, someone with a mental illness and profound disability is often unable to access services for either condition. It should not matter which condition is considered to be the most significant; both conditions need to be addressed.

It is important to give due regard to need, rather than labels or age. It is important to build on existing networks.

The term leverage caused some confusion.

Allied health professionals need to be better engaged and connected to GPs.



## **Priority 2 – Improved access**

People with disabilities should be included in the list of disadvantaged groups.

More Aboriginal health workers are needed in the ACT, not just Winnunga. Actual clinicians, not just liaison officers. The model of care needs to change.

Telehealth initiatives were strongly supported, especially those involving cross-specialty consultation.

CALD consumers need access to more than just interpreter services to access quality care.

## **Priority 3 – Better support those in the community**

Not enough people know about self- management courses.

GPs and specialists need to be engaged in self- management initiatives.

Self-management AND active participation have been used as terms.

More support is needed for community groups.

## **Priority 4 – Improve Person Centredness**

Patient stories will be used to highlight system issues.

The new patient centred care officer in the HD will be able to have a role in promoting the use of patient stories.

HCCA is planning to run a workshop on using patient stories to create system change.

The 'empowerment dot point' needs to be made less ambiguous.

## **Priority 5 – Enhance early detection and illness prevention**

Support should be provided to assist people with a disability to cook nutritiously in their own homes.

## **Priority 6 – Enhance governance and system enablers**

Most clinicians and GPs are not available to attend grand rounds.  
'grand rounds' needs to be included in the glossary

Cancer services have innovative, successful care and governance models.

Consumers would like to be able to report areas where care is suboptimal. Informal feedback is desirable and a number to ring would be good.

Opportunity to leverage the NDIS.

Once classified as a diabetic you are labelled. Need to look outside of this scope and check that the person actually has diabetes. Giving GPs control over their own way of treating chronic conditions is problematic.

There is a need to address the stigmatisation of conditions such as chronic pain. People with these conditions are considered to be 'vulnerable groups'. We will also need a change management strategy to get this strategy going, as it is a new approach to care; clinicians need to be engaged.

How do we cater for people who may be ineligible for certain services?