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HCCA Submission on The ACT Clinical Services Plan 2012-2017 Draft for Consultation

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

It is with reference to these principles that the HCCA has developed its submission to the Clinical Services Plan 2012-2017.

The HCCA is pleased to have the opportunity to comment on the draft ACT Clinical Services Plan 2012-2017.

HCCA held a consultation workshop on 18 October 2012 at the Pearce Community Centre to discuss the Clinical Services Plan (CSP) with our members. The main aim of the forum was to prioritise challenges and objectives within the Plan and identify

areas not covered in the CSP. Consumers also had the opportunity to share general comments in response to the CSP. We have drawn on this workshop and other consumer input in responding to the draft. A summary of the workshop has also been included in Appendix 1.

Summary

An effective CSP is important to consumers; it should clearly set out the planned structure of public health provision in the ACT over the next five years, encompassing public sector clinical planning and all facets of hospital care. It should predict the needs of the community and ensure adequate services will be provided to meet those needs and help consumers to remain healthy; access safe, quality services; and have an easy and effective journey through the health system.

However, extensive consultation with our members has raised serious concerns regarding many aspects of the draft CSP. These include the clarity and intended audience of the Plan, its overall readability and confusing objectives and strategies.

We have also identified a number of gaps in the Plan, including end of life care, the role of sub-acute care, the social determinants of health, health literacy, stroke care, pain management, complementary medicines and therapies and support of vulnerable people.

In structuring our response, we have first addressed a number of general issues including purpose, audience, readability, layout, planning principles, objectives and strategies, and links to other plans. We have then identified major gaps in the CSP. Following this, the comments are related to specific sections of the CSP, using the headings and numbering provided in the draft. Finally, we have discussed the importance of role delineation and networking, as well as clarifying the meaning of collaboration.

Purpose

We have concerns regarding the clarity of the CSP. The purpose of the document is unclear. Unless this is addressed the CSP may well be relegated to the top shelf to collect dust rather than be used to drive the health services planning for which it is intended.

Audience

The intended audience of the CSP is also unclear. This needs to be stated early on in the introduction, but also consistently reflected throughout the document.

Consumers would like to see a community version of the CSP published, targeted specifically at consumers. This document would need to use clear and simple language to outline the key points of the CSP and the steps that the Health Directorate intends to take to ensure that health services will be able to meet our needs. For example, the West Australian Health Directorate have provided a separate consumer version of their Primary Health Care Strategy, which provides the necessary information in a clear and accessible format.

Readability

We are concerned about the overall readability of the Plan. This is a significant plan, encompassing all areas of our health system and it is vital that it is well written, clear and free from jargon. One of our members sampled pg. 5 of the CSP in an online readability test[1]. The results indicated that the CSP would receive a Gunning Fog Index of 19.61, meaning that a person would require 19.61 years of formal education to be able to 'easily understand the text on first reading'. The test also calculated that the CSP had a Flesch-Kinkaid Grade level of 18, meaning that a two-year Master's degree is required to interpret this document. In concluding, the member stated:

"In summary, this document is not sufficiently readable! It is unsuitable for release beyond academic research."

For instance, the term 'settings' is used frequently in phrases such as 'community settings', and 'across all settings'. This is an ambiguous term, making it hard for consumers to understand what 'community settings' actually encapsulates. We suggest replacing this term with 'facilities' or explaining what is meant by the term 'settings'.

Another issue with readability is the use of program and initiative labels without any accompanying explanation. For instance, what is the 'NSW COMPacks program'. Terms like this need to be included with links to more information, perhaps in a footnote.

[1] http://www.online-utility.org/english/readability_test_and_improve.jsp

Layout

The unanimous opinion among our members is that the layout of the document, and much of the language used throughout, is extremely hard to comprehend. And this view is shared by consumers with a high level of knowledge and experience of the health system. As one of our newer members commented, if it is difficult for us to understand, it is likely to be incomprehensible to less experienced consumers.

The layout of the document could also be significantly improved. Tasmania's Health Plan: Clinical Services Plan: update of May 2008[2] is an example of a planning document with a highly accessible layout. There are a number of aspects of the Tasmanian Health Plan that we would like to see adapted for this CSP. These include:

- Implementation Commitments (pg. 9) – these provide a clear overview of what the CSP is aiming to achieve and within what timeframe.
- Tasmania's Community and its Health Status (pg. 15) – the information included here is much more comprehensive and relevant than what is provided in section 5 of this draft.
- Tasmania's Public Acute Hospital System (pg. 22)

Throughout the Tasmanian document, there is a clear focus on the implementation commitments, which seems to be lacking from this current draft. We also like the 2008 Clinical Services Strategic Plan for Northern Sydney and Central Coast. The heading 'Our Response for the Future' (pg. 13) would be particularly useful for the ACT's CSP in order to clearly articulate the ACT Health Directorate's commitment to meeting service needs in the future. This would be a good section to discuss role delineation and networks between service providers.

The Northern Sydney and Central Coast CSP[3] also covers the need to engage with private services (pg. 15-16) and Medicare Locals, which we would like to see in this CSP.

The ACT Planning Strategy is another example of a document with an excellent layout. We would like to see the ACT CSP presented in a similar way.

Planning Principles

This document needs to articulate the planning principles that have been applied. Planning principles were included in an earlier draft but omitted in the consultation draft. Instead, we note that 'Service Development Criteria' have been used, which are similar to those
Planning principles guide the development of options and strategic directions during a planning process to align with agreed priorities. We propose:

- *Patient Safety will be at the centre of all health service planning.*

[2] http://www.dhhs.tas.gov.au/about_the_department/our_plans_and_strategies/tasmanias_health_plan/clinical_services_plan
[3] http://www.nsccahs.health.nsw.gov.au/clinicalservicesplan/ServicesPlan/Executivesummary/default.shtml

- *Services will aim to promote health and reduce the need for acute health care*
- *Services will be, where possible, provided in community facilities away from a hospital campus*
- *Services will be integrated across facilities, with a clear role delineation for each service at each facility*
- *Public sector services will operate collaboratively with primary care, non-government and private sector service providers.*
- *Decisions will be taken regarding which highly specialised services are not feasible to provide in the ACT. This includes when services are not safe to provide.*
- *Health Directorate will support ACT residents to access highly specialised services not provided in the ACT.*
- *The Canberra Hospital will continue to provide a tertiary referral service for the surrounding region of New South Wales, and planning will consider regional health planning directions and clinical services plans developed by the Southern NSW Local Health District and Murrumbidgee Local Health District.*
- *Consumers and carers will be actively involved in identifying service needs and opportunity will be provided for consumer participation in strategic direction-setting.*
- *Planning for services will be evidence-based and will take into account current and projected demand for services, service viability, workforce availability and best practice benchmarks.*
- *Planning will take into account National Health Reform and other national agreements and local commitments entered into by the ACT Government.*
- *Consumers will be supported to self-manage their health and be actively involved in decisions about their treatment.*
- *Projections will be readjusted to take into account new information as is arises and services will be amended accordingly.*

Objectives and Strategies

We feel statements claiming to be objectives and strategies are actually merely subject areas and fail to clearly explain how and when the issues mentioned will be

addressed. The plan includes no specific timeframes, nor does it show how the plan integrates with other important, lower level plans and strategies. A good example of clearly written objectives, commitments and timeframes is on pages 9-13 of Tasmania's Health Plan, May 2008.

It is also essential for the CSP to be based on up to date and relevant population health date. We are extremely concerned that the statistics used to calculate projections are from census data collected in 2006. The Health Directorate must update the projections using the ABS data released in 2012 and the recent report from the Australian Institute of Health and Welfare.

Links to Other Plans

Consumers were very clear in their appraisal of the CSP. They found it to be an inward looking document that does not seem to be inclusive of the broader Government directions. References to the ACT Planning and Transport Strategies are lacking yet these will have an impact on the planning of health services in terms of locating services.

The regional demands placed on Canberra for services and the implications for effective delivery must be considered. Canberra is the regional centre for a population estimated to grow to over half a million people in the next ten years. This places continuing and growing demands on the services Canberra provides to the region, particularly its hospitals and schools. Addressing the means of funding and planning for the delivery of these services will require greater quantification and better information about what exists in the region.[4]

The CSP also needs to be linked to the Physical Activity Strategy referred to in the ACT Planning Strategy on pg. 68

Gaps in the CSP

We recognise that the CSP is a broad, high-level document. However, some key areas have been almost completely overlooked, such as dental and oral health, and pain management. People living with disabilities also appear to have been excluded from consideration. This group overlaps significantly with people living with chronic conditions and who need to access health services regularly. All health service planning needs to occur with these consumers in mind.

Clinical services provided by the ACT Government are only one aspect of the health system. The health care continuum ranging from public health to acute hospital services need to be reflected in the CSP. We would like to see more references to preventive health strategies and health promotion.

There are a number of gaps in the CSP our members identified in the draft Plan that we would like to see included. These are:

[4] ACT Planning Strategy 2012: pp 62 - 63

- End of life care
- The role of sub-acute care
- The social determinants of health
- Stroke care
- Pain management
- Complementary medicines and therapies
- Supporting vulnerable people
- Health literacy

End of Life Care

End of life care needs to be added as a main challenge in the CSP. Clinicians and health staff are still failing to recognise consumers' Advanced Care Plans. This was raised at a Clinical Services Plan Steering Committee last April, when HCCA's arguments were supported by clinicians. Older people need to know that they have the right to refuse a service that is not in their Advanced Care Plan. Currently, most are not aware of this and do not know about the different options available for end of life care.

To recognize the importance of improving end of life care, we recommend adding a dot point to the list of focus areas:

- Improving palliative education and end of life care

Under objectives, another two points could be added:

- Improving palliative and advanced care education among clinicians and in the community
- Relieving pressure on Intensive Care services

There also needs to be something in the main body of the document which argues the benefits of this way forward.

Aside from the inherent right of all individuals to die well and with some dignity, palliative care is cheaper and what most people want. Hillman in 2009 argues that intensive care beds cost $3000 per day[5] and later information from NSW indicates that the cost nowadays is "as much as $4000 per day" compared with $200 (in an aged care facility) or $600 in a palliative care unit per day[6].

The Role of Sub-acute Care

The stronger emphasis that needs to be placed on the growing demand for subacute care has been acknowledged by the ACT Government, as consumers are increasingly seeking to receive care away from acute settings. It is also being

[5] Hillman, Ken. 2009. *Vital Signs: Stories from intensive care*. pp. 259
[6] The Voice, 2012. Pp. 9

considered in terms of how best to provide safe, appropriate care in a cost effective way. This is consistent with the Ambulatory Care Framework and planning principles for the Health Infrastructure Program. The Commonwealth Government are also investing in sub-acute care, with a flow of funds to the ACT within the Health Care Partnership Agreements.

Social Determinants of Health

The challenge of inequity in access and outcomes is a critical one. This section needs to explicitly state that the Health Directorate recognises the Social Determinants of Health and is committed to working with other sectors of the ACT Government to identify and address these issues. We would like to see an approach similar to South Australia's 'Health in All Policies' (HiAP)[7], which focuses on improving the connections and interactions between health and other domains such as education, environment, fiscal policies, housing and transport to improve population health.

The ACT Medicare Local has adopted the definition of the social determinants of health as provided by the World Health Organisation:

"The World Health Organization notes that the social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries."[8]

It would be useful to include a similar statement in the CSP.

Stroke Care

Alarmingly, Stroke care is not mentioned once in the entire document. Stroke is currently the second most frequent cause of death for females and third for males in Australia, and represents a significant burden on the health system. Currently there is only one nurse specialising in stroke in the ACT, and any person requiring emergency care would need to be sent to TCH. Yet, the ambulance service will still take the consumer to Calvary if this is the nearest hospital. This disadvantages consumers living in the north of Canberra, as they would then have to wait to be transferred from Calvary to TCH before receiving the proper treatment. Given that there is only and estimated four hour window for a person to receive treatment, these consumers are at risk of suffering severe brain damage and disability or even death.

[7] http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+reform/health+in+all+policies

[8] http://www.actml.com.au/Uploads/Documents/About%20Us/Strategic%20Plan_full.pdf

We are aware that the National Stroke Foundation Guidelines[9] suggest that all hospitals with more than 200 beds need to have a dedicated stroke unit. We cannot determine whether this planning to meet this need is in progress. We consider this to be an example of an implementation goal for the CSP, requiring dates and responsibilities to be assigned.

Pain Management

There is very little consideration given to pain management services. Chronic pain is highly prevalent in our community and the services available to consumers are limited. Recent statistics have indicated that one in five Australians has experienced chronic pain, and this prevalence increases with age. Given our ageing population, this means that chronic pain will continue to place a significant burden on the ACT health system.

Unfortunately, 79% of people suffering from chronic pain in Australia are not able to gain access to effective pain management.[10] This is particularly the case for children and consumers who are less able to express themselves, such as members of the Culturally and Linguistically Diverse (CALD) community. Chronic pain has a huge impact on the lives of the people living with it, as their mobility, strength, immune system, and basic life capacities are often impaired.

In 2007, an Access Economics[11] report estimated that chronic pain is the third most costly health area in Australia, costing $34 billion annually. The report also indicated that most of these cases could have been treated effectively by pain management services, had they been available.

Chronic pain has been identified as one of the most neglected areas of health in Australia, and the CSP needs to address this issue in the ACT. This is an area of critical importance for consumers and particularly those living with chronic conditions.

Complementary Medicines and Therapies

It is important to acknowledge the value that some consumers place on complementary medicines and therapies, and to consider how these can be incorporated with mainstream treatments. Increased integration and collaboration between health care providers would enable consumers to access these treatments without having to seek them out and coordinate their treatment regime unsupported.

[9] http://www.strokefoundation.com.au/index2.php?option=com_docman&task=doc_view&gid=278&Itemid=39
[10] http://www.painaustralia.org.au/images/pain_australia/NPS/National%20Pain%20Strategy%202011%20Exec%20Summary.pdf
[11] http://www.bupa.com.au/staticfiles/BupaP3/Health%20and%20Wellness/MediaFiles/PDFs/MBF_Foundation_the_price_of_pain.pdf

Supporting vulnerable people

The ACT Planning Strategy (2012) acknowledges that there are minimal concentrations of socially vulnerable people due to Canberra' planned structure. This means that vulnerable people are living throughout our city. Vulnerable people include those people living with chronic conditions especially those who are reliant on our public health services. The location of services is a challenge that needs to be considered in this context. The ACT Government has established the Vulnerable Families Coordinating Committee, which could provide assistance in this regard.

The location of health services also has a significant impact on people with disabilities who need to be able to access services. Often, people living with disabilities rely on public transport to get to their appointments. Health services must be provided in areas located on high frequency public transport routes

Health Literacy

In order to ensure that disadvantaged consumers are able to have enhanced access to health services, the CSP needs to consider adopting an approach such as HiAP and implementing strategies to improve health literacy. Consumers cannot access new services if they do not even know they exist.

Specific Comments Relating to the Draft CSP

The following paragraphs relate to specific issues we have identified throughout the CSP. However, we feel that making small amendments to the document will not be sufficient to address the fundamental weaknesses in the CSP.

1. The Clinical Services Plan

The Local Hospital Network (LHN) will be an important component for improving service delivery; it would be worth mentioning it in the introduction.

This section also fails to mention the use of population profiles in developing the CSP.

It is important to include the private, as well as the public sector. Even though the Health Directorate is not responsible for private services, they are responsible for acting as a safety net when these services fail. Moreover, if the private health care costs become too high, people will default to the public system, creating more demand for already overstretched public health services. There needs to be a clear description of how the public and private sector can work together and areas identified where the private sector could alleviate some of the burden from public health services.

The paragraph beginning *'While public sector health services…'* provides a good summary of the factors outside of health services that influence consumer health outcomes. However, we think it is important to explicitly recognise that these factors are the 'Social Determinants of Health'. The Health Directorate needs to take a leading role in encouraging all sectors of the ACT Government to consider the health

impacts of all of their policies to take a more holistic approach to improving health outcomes.

The CSP needs to consider the more distant future as well as the next five years. It is important to consider the long term consequences of the short term decisions made by the Health Directorate. Consumers at our workshop did not consider this draft to be sufficient in planning for the longer term. There was a strongly held view that it was more a listing of existing services rather than a projection of what was needed. Projections of future service demand will be particularly useless if they are created using out-dated data.

2. Challenges for the public health system

Priorities

We believe it is important for the Health Directorate to analyse the risks inherent in the challenges that have been identified in the CSP. As part of our consultation forum, members were asked to arrange the challenges in order of importance. Consumers perceived that by addressing the more important challenges, there would be a trickle-down effect on other challenges. Some examples of these arrangements are shown below.

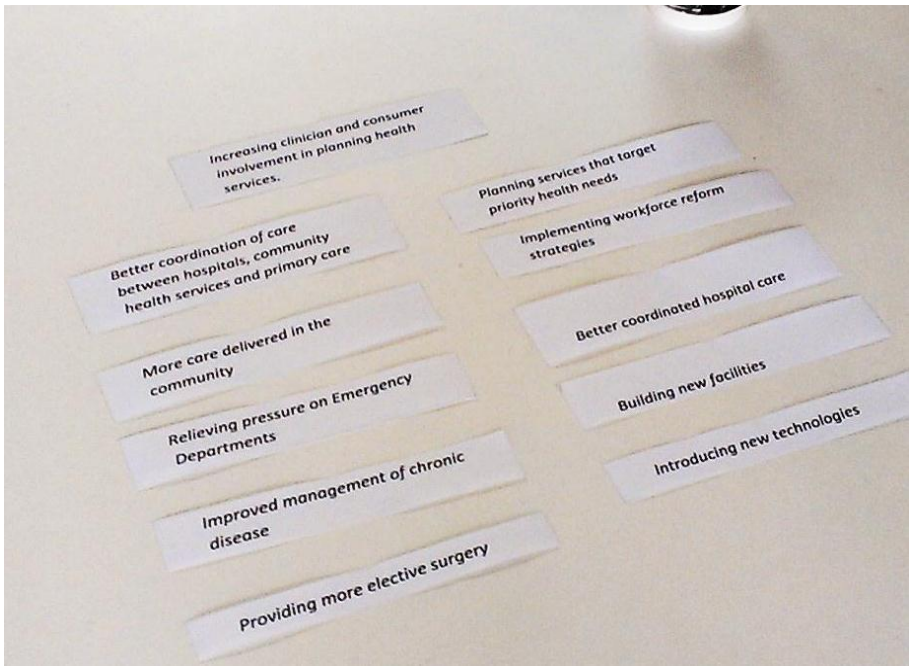

Figure 1 – One group argued that consumer and clinician involvement should be the top priority for the CSP, and that this would assist in meeting all other challenges. The remaining challenges were grouped as either driving community needs or the service requirements to meet those needs.

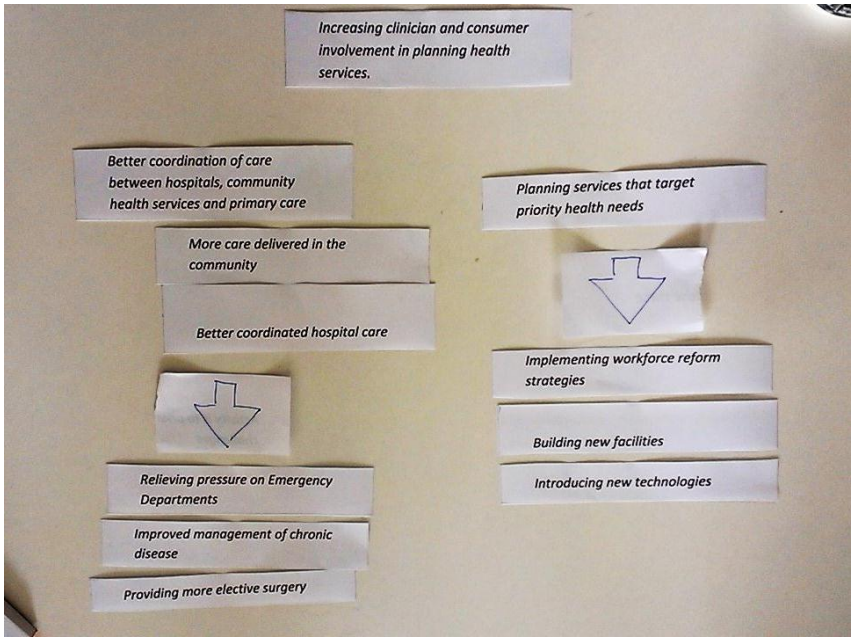

Figure 2 – A second group also placed consumer and clinician involvement at the top of their list. Coordination of care and care delivered in the community would then lead to improved management of chronic disease and reduced pressure on emergency departments and elective surgery waiting lists. Targeting priority health needs would then require new facilities and technology as well as workforce reform.

Service Fragmentation

Service Fragmentation is a serious concern for consumers, because it makes it very difficult to move between different health services. There are a number of other aspects of services fragmentation that also need to be addressed. Firstly, fragmentation occurs between sectors as well as locations and types of service. The ACT Health Directorate can play a role in improving cooperation between public and private services to reduce elective surgery waiting lists.

Consumers commented that better engagement is needed between specialists, the Medicare Local, and general practice to close the gaps between existing services.

The last point claims that service fragmentation leads to an increasing number of emergency presentations and hospital admissions. Evidence needs to be provided to support this statement.

We note that service fragmentation is the only issue that does is not addressed in any specific chapter of the CSP. More detail is needed in the CSP about how to address this challenge.

Changing Disease Profile

The increasing prevalence of chronic disease in the ACT will significantly impact on the resources and finances of the Health Directorate unless more is done to improve access to primary and community health services. Consumers living with chronic conditions want to spend as little time as possible in hospital, yet there are currently significant restrictions on eligibility to access community based services. Without

addressing this barrier to community care, the pressure on acute care facilities will continue to rise.

Workforce/ Service Innovation

Workforce innovation is another important area that is often overlooked. There will be little use in providing new facilities and technology if there are not enough staff to fill the positions required to operate them. The CSP needs to cover the development of new roles in the health sector and consider specific, impending workforce challenges. For instance, the Eye Clinic which opened at The Canberra Hospital (TCH) at the end of 2011 will face difficulty in the near future unless something is done to increase the low number of ophthalmologists currently in training in the ACT.

The CSP also needs to identify opportunities for industrial relations reform, such as improving contracts for ward clerks, nurses and Visiting Medical Officers, as well as clearer role delineation at hospitals. Industrial relations issues have a significant impact on our capacity to innovate and for the resources within the LHN to be used in a coordinated way. There are too many differences between rate of pay and entitlements for staff working across all health services. While we acknowledge that this is not within the remit of the Health Directorate to resolve in the short term, we do see that the ACT Government needs to address this in the medium term.

3. Meeting the Challenges for our Health System

While we generally support the challenges identified in the CSP, we are concerned that the objectives listed here will be insufficient to address each challenge effectively.

We recommend that the objective *'More health care delivered in the community'* be changed to 'More health care delivered off the hospital campus' to mitigate concerns that the Health Directorate will place an excessive burden on community organisations to provide health services.

We are very concerned that the objective '*planning services that target priority health needs'* is not addressed specifically anywhere else in the CSP, aside from a vague brief mention in Section 5. What are the priority health needs? Consumers would like this to be made explicit.

The ACT Hepatitis Resource Centre has also raised concerns that viral hepatitis has not been identified for increased investment or priority focus. Viral hepatitis is a ticking time-bomb for the health system and community. For instance, hepatitis C is chronically undertreated, with only 2 per cent of the infected population treated annually. If capacity is not created within the health system to meet this future demand, the benefits of new treatments will be lost on those who want it but cannot access it. More information on this area and data references have been included in Appendix 2.

The objective 'relieving pressure on Emergency Departments' misses the bigger picture. By providing more effective care in the community, primary health care and

subacute services and management of chronic conditions, admissions to hospital via the ED will inevitably decrease. The role of the ACT Medicare Local and Southern Medicare Local cannot be underplayed here. Often it is the failure of general practice and community services that result in the deterioration of the clinical status of consumers and lead to preventable hospital admissions. With an ageing population, we strongly urge the ACT Health Directorate to work with the two Medicare Locals to prevent this.

A preventive health strategy is another important objective within the CSP. Although the CSP focuses on service delivery for those who already require health services, an effective preventive health strategy will significantly reduce pressure on these services. On page 24, the data provided under Potential Public Health Risks clearly indicates that preventive strategies are needed to reduce the prevalence of unhealthy lifestyle factors contributing to the disease burden. As such, preventive health needs to be included when planning service development and delivery. We note that this has been touched on in the Service Delivery Criteria, but would like to see this addressed in the challenges and objectives as well.

It would be good to explain, in this section, how these objectives relate to either the LHN or Canberra Hospital and Health Services (CHHS).

3.1 Service Development Criteria

We are unsure of the purpose of the service delivery criteria. Consumers did not understand how the criteria would be used and could not connect them to other areas of the Plan.

The first criterion*, 'provide consistency of access to appropriate services…'*, requires strong relationships between the Health Directorate, Non-Government Organisations (NGOs) and private providers. This is another indication that the CSP needs to broaden its scope to consider these services when developing strategies. The services that will not be provided in the ACT needed to be listed in this section after the last sentence.

We are concerned that the development criteria do not focus enough on patient safety or patient-centred care. These are essential components of quality health care, and it is the responsibility of the Health Directorate to ensure that they are at the centre of service planning. We would like to see these added to the list of criteria.

3.2 Service Delivery Framework

The levels used to categorise the services provided in ACT hospitals need to be clearly explained, otherwise most front line staff and consumers will find this section very difficult to interpret. It needs to provide comprehensive coverage of the health services that exist in the ACT and are planned for 2012-2017.

It would also be helpful to mention the use of some private hospitals and Queanbeyan Hospital for some elective surgery procedures.

There are a number of other gaps, such as rehabilitation services, including equipment loans provided at Village Creek and the Independent Living Centre.

Currently, ACT consumers requiring rehabilitation for spinal cord injury are forced to travel to Sydney to access the treatment. This is a concern not only because of the trauma this causes for SCI Patient, but also the significant disruption to the immediate family who have to coordinate the interstate travel.

The point covering 'population/public health services' needs to be expanded. Public and Population health are broad-ranging and quite distinctive services in their own right. Health Promotion and the role of the Health Protection Service also need to be considered.

Although the new subacute hospital in north Canberra will not be operational until 2017, it is important to consider the demand that its development will place on the Health budget and indicate which services will be relocated as a result of its opening.

3.3 Strategies

In our workshop, consumers worked in groups to prioritise and group strategies. One group found this difficult as the link between strategies and objectives was not clear. Their arrangement of the strategies reflects this:

The strategies listed in the CSP appear to be highly uncoordinated. Some of the items listed as objectives would be better defined as drivers of service planning. At the very least, we urge the Health Directorate to group these objectives in a sequence that provides a logical and clear overall picture. The list of strategies included on pg. 51 is much clearer, and we would like to see these used as the headings in section 3.3. In particular, we are concerned that the following strategies

- *Improve access to health services for vulnerable people; and*
- *Improve general health and health outcomes for:*
    - *Older people*
    - *People with a Mental Illness and/or addictions*
    - *Children with chronic conditions or in vulnerable circumstances*

have all been grouped under *3.3.7 Consumer and Clinician Involvement*. Both of these strategies are very important and need to be covered separately in more detail.

None of the strategies address the specific needs of the multicultural community or people living with disabilities. Removing the barriers preventing these consumer groups from accessing quality health services must be a priority for the Health Directorate.

It would be clearer to use objective headings that convey a specific goal rather than a subject area. Otherwise it is difficult for the reader to extract the essence of the objective from the accompanying paragraphs. For instance, 'Consumer and Clinician Involvement' could be 'Increase effective clinician and consumer involvement in health services', and 'Chronic Conditions' could be 'improved care and management of people living with chronic conditions'.

3.3.1 Clinical Networks

Clinical networks will be important for improving coordinated patient centred care. We suggest that this objective should focus on primary health care providers as well as specialist services, as we anticipate that they will play a leading role in developing coordinated care, particularly for those living with chronic conditions.

3.3.2 A Single Point of Entry for Hospital Services

This objective is beneficial for GPs and specialists as well as consumers. However, it needs to clarify exactly what is meant by 'a single point of entry' and how the Health Directorate plans to implement this objective.

3.3.3 Clarification of the Roles of Health Facilities

While clarification of health facility roles is important for consumers to access the care they need at the right time and place, the paragraph is far too specific and brief and only addresses half of the problem. We recommend that the objective be broadened to consider strategies to improve health literacy in general and for disadvantaged groups in particular.

3.3.4 More Service Delivered in an Ambulatory Care Setting and in the Community

More information is needed on how the Health Directorate intends to facilitate the development of 'community development officers' at Community Health Centres as well as what their roles will be.

3.3.5 An Integrated Cancer Care Centre

This objective is confusing; it is unclear what value it adds to the Plan. It is a specific reference whereas other objectives are more abstract and conceptual.

3.3.6 Chronic Conditions

The nature, severity and range of chronic conditions endured by so many, justify the research and development of new strategies to improve the quality of life of those affected in addition to the strategies that have already been implemented.

3.3.7 Consumer and Clinician Involvement

More could be done in this section to better convey a commitment to consumer-centred care; indeed, the term consumer-centred care is not even mentioned. Moreover, consumers have the right to be involved in all aspects of health services, not just the planning process. It would also be good to acknowledge that services that provide consumer centred care have been shown to produce better health outcomes.

In the second paragraph, it would be more accurate to list CALD consumers in general, including newly arrived refugees, as being amongst the disadvantaged members of the community with regard to accessing health services. Often, CALD consumers have difficulty navigating the health system because of cultural and language barriers. While it is true that part of the solution is to improve health literacy in these disadvantaged groups, the Health Directorate also has the responsibility to adapt services to make them more accessible.

It would be good to outline the role of the Clinical Senate in achieving this objective. This objective also relates to the Consumer and Carer Participation Framework, including the Patient and Family Centred Care model.

We strongly support the need to focus on improving health outcomes for vulnerable children in the care of social services, or those living with chronic conditions. Yet, this is not reflected at all in the new Chronic Conditions Strategy. Many children with chronic conditions are currently managed in general practice and by their parents, who often struggle to get their children access the same level of care as adults living with the same conditions.

It is important to consumers that the ACT Health Directorate is able to attract quality clinicians to work in the region. In order to achieve this, there needs to be more emphasis on conducting research and clinical trials that are initiated by pharmacists rather than the companies producing the medicines.

3.3.10 Meeting Targets for Emergency Access and Elective Surgery

The 4-hour rule is an arbitrary figure and does not accurately capture consumers' experiences of the Emergency Department (ED); it merely indicates the amount of time it takes to see a doctor and does not measure the quality of the system. The first recommendation from the 2012 Auditor General's Report[12] states:

The Health Directorate should review its performance indicators for publicly reporting the performance of Canberra's hospitals' emergency departments to include and give a greater emphasis to qualitative indicators relating to clinical care and patient outcomes. (p.14)

[12] http://www.audit.act.gov.au/auditreports/reports2012/Report%20No.%206%20Emergency_Department_Performance_Information.pdf

We note that the Health Directorate is “currently researching other indicators that would better demonstrate the quality and performance of EDs” (p.14). HCCA is supportive of this and is committed to working with the Health Directorate to further develop these indicators. We would like to see this covered in the CSP.

3.3.11 Enabling Technologies

The implementation of enabling technologies will involve both federal and state initiatives. The CSP needs to explain how federal initiatives will impact on, and relate to ACT initiatives, such as increased commonwealth funding for specific technologies.

It is unclear how enabling technologies relate to eHealth. The terms ‘Clinical Decision Support Systems’; and ‘Digital Hospital Infrastructure Project’ need to be defined.

We would also like the Health Directorate to look at enabling technologies that could support the online registry of patient care plans and treatment choices. This would prevent consumers from having to repeat their story unnecessarily when accessing new services, which has been raised as an action area in the Chronic Conditions Strategy.

4. Context

4.2 National Safety and Quality in Health Service Standards

We note that the Health Directorate has included the National Safety and Quality in Health Service Standards as section 4.2 in the CSP. These standards need to be reflected throughout the CSP and not just given a cursory mention. This section does not even mention the relevance of the standards to the CSP.

4.3 Australian Charter of Healthcare Rights

Again, these rights have been given only a cursory mention and need to be explained in more detail. The Australian Charter of Health Care Rights are fundamental to the model of consumer-centred care. The rights need to be listed and explained in this section, along with a paragraph explaining how they relate to health service delivery in the ACT.

5. Population, Demographics and Health Status

We would like this section to be called something more meaningful similar to the Tasmanian CSP. For example, “Our Community Health Needs”.

5.4 Culturally and Linguistically Diverse Population

This section must be updated with 2011 census data. The CALD population is increasing in the ACT and needs strategies in place that accurately reflect their numbers in order to adequately provide for their specific needs.

We would like to see the Health Directorate work with the Medicare Locals to gain a more accurate picture of the needs of the CALD population in Canberra and the Capital Region.

5.5 Health Status of ACT Residents

The information in this section would be much clearer if it was presented using graphs and diagrams, such as those used by the Australian Institute of Health and Welfare in Australia's Health 2012.

We are concerned that people living with disabilities are not mentioned anywhere in this document. This group of people have specific needs and will increase in number as the population continues to age. Health services must be tailored to accommodate this group, which will require collaboration with other government sectors such as Housing and Transport. Statistics about people with disabilities should be included in the section addressing population health status, if not as a new section then as part of section 5.5.

6.3 Walk in Centres

We would like to see more information provided here about the current role of the Walk in Centre and how the Health Directorate is anticipating this role to change and expand over the life of the CSP.

7.1 Models of Care or Service

It is also important that new models of care and services delivery is patient and family centred care, as outlined in the 'Enhancing Patient Experience through the Implementation of a Patient and Family Centred Care Model' Discussion Paper.

8. Addressing Demand for Health Services – Demand Projections

CSP projections are critical in planning appropriate services. This is acknowledged in the plan on pg. 5 where it states:

"It is necessary to have a vision of the more distant horizon."

This is particularly the case for sub-acute care. The University of Canberra Public Hospital will not be open until 2017 and the planning is being undertaken now. This plan needs to extend beyond 2017. Demand projections will inform decisions taking in the HIP and there is only one chance to get them right. Our community cannot afford to have the best guess of demand projections made on out-dated information. Accurate projections inform decisions regarding the types of services and also the staging of development of the supporting infrastructure, including design and

construction of buildings, workforce development and technology. HCCA members at our recent workshop were very concerned about the out-dated data used. How can information about Canberra in 2006 be used to effectively plan for the needs of the Canberra community in 2917.

8.8 Imaging

This section is confusing and vague. The section needs to indicate how existing imaging services are going to be adapted and improved to meet growing demand and implement new technologies.

Role Delineation and Networked Health Service

We are supportive of having clear role delineation and integrated, networked hospital services that has been proposed (p. 47).

However, we have concerns about the efficiency of running two hospitals with different governance structures. We are convinced that a new community hospital would provide a more efficient use of public money, reduce duplication and improve coordination with community based and ambulatory services. But we believe overall improvement in services would be further enhanced by a clarification of the role of the existing Calvary Public Hospital.

We firmly believe the integration of the services across both The Canberra Hospital Calvary and the new University of Canberra Hospital will provide huge benefits, including improved staffing arrangements, integrated health care, clinical information and improved health outcomes.

We support the assertion made by Professor John Dwyer in 2007 when he wrote about role delineation in the Mersey Hospital in Tasmania:

The community must understand that all hospitals cannot provide a full range of services. Their ability to offer services of quality and safety must be the major factors determining role delineation. The distressing level of misadventure in our hospitals is most often related to a mismatch between patient needs and the available skills. It is essential, therefore, that hospital services be networked ... Individual hospitals must no longer act as islands in an ocean of health care but rather be part of a network of hospital services where the role of each hospital is carefully delineated, safety and quality being major determinants.[13]

Role delineation is part of the process which responds to the needs of the population, taking into account clinical needs within the Local Health Network (LHN). We believe this how it is proposed to work in New South Wales where LHNs

[13] John Dwyer, *Splintered healthcare, divided responsibilities*, Online Opinion retrieved on 30 March 2011
http://www.onlineopinion.com.au/view.asp?article=6430&page=0

will have responsibility for determining appropriate role delineation of services for health care facilities within the LHN network.

We believe that delineating the roles of these facilities allows the health system to operate more efficiently, by integrating support services, staff profile, safety standards and requirements, thereby ensuring clinical services are provided safely and with appropriate support.

We share the Government's observations that where a hospital delivers both acute and sub-acute care, the urgency associated with acute care delivery will frequently result in priority given to acute care ahead of sub-acute care; and in resources being diverted from sub-acute care to respond to an increase in demand for acute service. This in turn impacts on the efficiency and effectiveness of sub-acute service delivery[14].

We strongly support a networked hospital system. We encourage Little Company of Mary (LCM) to work constructively with the ACT Government in the best interests of the community to provide integration of the services across both the Canberra and Calvary hospital campuses. We believe this would lead to a significant improvement in health outcomes for our community, through improved staffing arrangements, integrated and consistent policies and sharing of clinical information and better communication.

We would anticipate significant cost savings with more efficient use of public money, reduction in duplication and improved coordination with community-based and ambulatory services.

Other Issues for Consideration

A Note on Collaboration

There are a number of references to collaboration in the CSP, for instance;

- Health Directorate collaboration with the Medicare Local re. Closing the Gap (pg. 13)
- Cross Border Collaboration (pg. 17)
- Collaboration between tertiary education, vocational education and training sectors (pg. 6)
- CHHS collaboration with public health resources (pg. 78)

Collaboration has many different applications and means different things to different groups and individuals. What does the ACT Health Directorate mean by collaboration? There needs to be 'collaboration' between all areas of the ACT

[14] ACT Health, Expanding hospital services in the ACT: an additional 400 Hospital Beds Health Service
Delivery Public Consultation & Discussion Paper, February 2011, p 6

Government so that an approach similar to HiAP can be taken to address the social determinants of health.

Also, we are concerned that there are so few references to other government directorates and the role they play in planning health services. There is a passing mention of them as ‘partners’ on pg.5, but this is the only reference. Health services cannot be planned effectively in isolation. We need a more coordinated approach.

We are happy to discuss our submission further.

Appendix 1

Consultation Forum for the Draft Clinical Services Plan – 18 October 2012

Darlene Cox facilitated the discussion and began by acknowledging the traditional owners of the land and welcoming participants to the forum.

Attending

Terry Swarner, Adele Stevens, Bill Heins, Roger Killeen, Anna Saxon-Taylor, Cynthia Matheson, Denise Mott, Denis Strangman, Pam Graudenz, Sue Andrews, Margaret McCulloch, and Bev McConnell.

HCCA Staff: Darlene Cox, Karen Jameson, Nicole Moyle, Yelin Hung, Heather McGowan and Alisha Summerton.

Introduction

The purpose of this forum was to discuss the main challenges listed in the Clinical Services Plan (CSP) and identify any other important challenges that are not listed. We discussed whether the strategies listed would be effective and whether they made sense. Finally, there was some general discussion of what consumers thought was missing in the overall plan.

Darlene then provided a brief summary of the background of the draft CSP and its overall purpose.

The CSP is supposed to identify projected community health needs and the services required to meet those needs. The CSP does not focus on private services, although they have significant impact on public service delivery. Moreover, if the private sector fails, responsibility to resolve problems and address failings rests with the government.

This is a high level document that will be linked to more specific strategies such as the Diabetes Services Plan, Primary Health Care Strategy and the Chronic Conditions Strategy. The strategies in the CSP are supposedly then linked to existing services.

Even though this is a general, overarching plan, we still need to be able to locate where important issues would be covered. For instance, there is insufficient reference to the Local Hospital Network (LHN). Participants also commented that more explanation needs to be given as to how these fit into the CSP, and how the CSP connects with existing health services

General Comments:

People with disabilities not listed as a target group. They need to be considered for service development.

It is hard to determine the purpose of the document and intended audience. The language is repetitive and aspirational, rather than practical. Technically, the document is designed for everybody, but it reads as an internal document.

There needs to be clear articulation for consumers of what the ACT Government plans to do for the community and what service will be provided.

The CSP almost reads like a ‘descriptive painting’ of what services already exist. It is important to look at the additional services that are required to meet community needs into the future. Participants did not see this as a document that identifies projected need.

Even if some of our concerns do not fit into the CSP as it is such a broad document, there need to be clear linkages to other documents and strategies that will address our issues.

If the language in the current document can’t be made more accessible, it would be useful for a second document to be developed for consumers so that they can distil the important and relevant information from the CSP and understand it properly. It was agreed that there should be two documents, one for the health sector and one for the community. However, the full document still needs to be publicly available, as many of the issues can only be observed in the details.

The Western Australian Health department has been very good at providing consumer friendly versions of their strategies and plans.

The authors appear to have a lack of forward innovation skills, as the CSP does not really highlight any new strategies to provide more effective services.

Throughout the document, there are terms that are difficult for consumers to understand. For instance, what are “unqualified babies”.

We understand that this is a *clinical* services plan, but clinical services do not exist in isolation from primary and community care. Without a statement of intent regarding this relationship, there will be confusion. For instance, good primary health care services will relieve some of the pressure from clinical services. For a big picture documents, there are very few big picture statements.

We need to look at previous versions of the CSP and include some of these things.

It is important for the CSP to clearly identify where it sits in the continuum of services, including health promotion and population health.

The CSP does not adequately address the Australian Charter of Healthcare Rights. Participants agreed that the acknowledgement of the Charter is very much and add-on. In the very least, the rights needs to be listed in the document. It would also be good to explain what these rights mean and how they will be applied to the CSP.

Role delineation needs to be included as a concept.

Currently the CSP looks like a wish list of services that would require a massive increase of finances and human resources. The CSP needs to clearly identify how the Health Directorate is going to rationalise service design so that it falls within the constraints of the health budget.

Prioritising challenges

For this activity, participants worked in small groups to arrange the challenges proposed by the CSP in order of importance. The whole group then discussed the reasons for their different arrangements.

Some of the challenges listed in the CSP would be substantially addressed by focusing on the higher priority challenges. For instance, with better care of chronic conditions and increased services being provided in the community, pressure on Emergency Departments and Elective Surgery Waiting lists would be relieved.

Better coordination of care and involvement of consumers and clinicians in health service planning were ranked highly by all groups.

Consumer and clinician involvement was seen as integral to addressing each of the other challenges.

There could be a distinction between the challenges relating to service needs and those relating to the clinical resources required to deliver those services.

Increasing new technology needs to be aimed at improving coordination of care.

More General Comments

Where does preventive health care come in to all this?

There was some concern raised about placing too much burden on the community sector to deliver health services. It is also important to focus on better coordinated hospital care.

The CSP needs to address research. Research is an essential component of providing effective health services. It needs to be made clear where research will fit into the bigger picture of clinical service delivery.

It is important to state exactly how priority health areas are going to be identified. What will then happen to the people affected by low-priority health issues? This is where consideration of private services would come into play, as people who can afford to would be likely to turn to private services to avoid long waiting times or access services they are not eligible for in the public sector.

What is Missing?

Alternative or complementary health services are not considered in the CSP.

Dental services are not given enough consideration in the CSP. This is an important area of health that relates to many different chronic conditions.

Given the recent investment by the federal government in oral health, we would like to see the development of a Dental Services Plan for the ACT to utilise this increased funding.

End of life care needs to be added as a main challenge in the CSP. Clinicians and health staff are still failing to recognise consumers' Advanced Care Plans. One participant recounted a story of a family in her network. A woman recently expressed a wish to die in her own home, but staff did not want to respect these wishes, telling her family "just call an ambulance". If the family had not been fully aware of their rights as consumers, they would not have been able to convince the staff that the care needed to be provided in the woman's home. Older people need to know that they have the right to refuse a service that is not in their Advanced Care Plan. Currently, most are not aware of this and do not know about the different options available for end of life care.

Communication and education is another part of health service delivery that needs to be addressed. Consumers cannot access services if they do not know they exist. Health Literacy needs to be improved.

There is also insufficient consideration of access. This needs to be a challenge listed in the CSP. The Health Directorate often relies on the assumption that everybody has internet access, yet many disadvantaged consumers would not be able to access information in this way.

Unless you already have extensive experience of moving through the health system, it is impossible to understand where to go or what to do to access the services you need. Health literacy is a real issue for people that don't 'live' in the system, they need to have sufficient knowledge to be able to access services when they need them.

Psychosocial services also need more attention. There is little mention of psychosocial services in the CSP, yet these services are relevant to a range of different areas that are covered.

It is important to look outside of the bubble of public health care and utilise existing services where partnerships have already been made. For instance, there are external organisations that can assist consumers with developing Advanced Care Directives and providing them with information about the options available to them.

There is also a pre-existing partnership with private hospitals to reduce elective surgery waiting lists. This has been an effective strategy and needs to be considered as part of the CSP.

Clinical Trials need to be increased and initiated by pharmacists. Research like this is too easily disregarded in times of economic stress and because of the small size of the ACT. The Health Directorate needs to improve research standards if it is going to attract good clinicians.

It would also be good to provide some link with the new National Quality and Safety Service Standards and explain how they will be adopted by the Health Directorate

Strategies

On the whole, the strategies are unhelpful and a struggle to make sense of. They often do not read as strategies so much as topics. Some clearly represent corporate responsibility while other relate to service needs.

There is an obvious disconnect between the strategies and objectives (see pg 50-51). Strategies are meant to achieve objectives, and so need to be written using active language.

Better coordination of health care could be an additional strategy.

It is not just a matter of developing technology, but ensuring that health services have access to this technology.

There needs to be another strategy to support social services and volunteers. Volunteers are a significant part of the health workforce and strategies need to be put in place to help retain them.

With regard to emergency departments, it is important that the model of care drives the process, not the other way around. This is a corporate responsibility.

There is an issue of accountability with regard to technology investment and disinvestment. It needs to be clear who is responsible for ensuring that all services and technologies will be cost effective.

Appendix 2

ACT Hepatitis Resource Centre
Feedback on the ACT Clinical Services Plan 2012-2017
It is hard to identify an increased investment or priority focus on viral hepatitis - a ticking timebomb for the health system and community.

Take hepatitis C: chronically under-treated. Under current resourcing, we treat fewer than 2% of the infected population annually. Nationally the total receiving treatment is fewer than 4000 annually whilst there are more than 10000 new infections annually.
http://www.hepatitisaustralia.com/__data/assets/pdf_file/0003/3945/the-economic-impact-of-hepatitis-c-in-australia_final-3.pdf

As the infected population ages, the seriousness of the situation increases. Age-standardised rates of liver cancer are projected by the AIHW to rise by 38% in men and 78% in women from 2007 to 2020.
http://www.aihw.gov.au/publication-detail/?id=6442467752

New treatments will soon offer a better chance of cure and fewer side-effects. Undergoing treatment for hepatitis C will therefore soon become significantly more appealing. In fact, there are thousands and thousands of people nationally who have delayed treatment uptake (or had it delayed for them) on the promise of better outcomes with new treatments. However if capacity is not created within the health system to meet this future demand, the benefits of new treatments will be lost on those who want it but cannot access it. The Auckland Statement calls for governments to guarantee that 5% of people living with hepatitis C receive anti-viral treatment each year.
http://www.aucklandstatement.com/

The system should increase access to hepatitis C treatment for people who inject drugs ("treatment as prevention"). Currently very few PWID are able to access treatment, yet 90% of new infections are transmitted amongst this population group. Recent studies have shown that:
- if offered treatment, PWID have good take up rates
- PWID are treatment compliant and have good completion rates
- treatment is effective; PWID have good SVR rates (cure)
- there are low rates of re-infection
- modeling in Canada and by the Burnet Institute in Melbourne shows that modest increases in access to treatment or PWID has the potential to reduce the prevalence in the population group most likely to transmit new infections.

- Grebely, J & Dore, GJ, 2011, 'An expanding role for primary care providers in the treatment of hepatitis C virus infection in the community', Hepatology, vol. 54, pp. 2259 – 2261
- Rance, J., Newland, J., Hopwood, M., & Treloar, C. (2012). The politics of place(ment): providing hepatitis C treatment within opiate substitution. Social Science & Medicine, 74(2), 245–253. doi: 10.1016/j.socscimed.2011.10.003
- Rance, J., & Treloar, C. (2012). Integrating treatment: key findings from a qualitative evaluation of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) study (Monograph 1/2012). Sydney: National

Centre in HIV Social Research, The University of New South Wales. Available: http://nchsr.arts.unsw.edu.au/media/File/Integrating_treatment.pdf

- http://www.ncbi.nlm.nih.gov/pubmed/22676879
- http://onlinelibrary.wiley.com/doi/10.1002/hep.24656/pdf
- http://www.natap.org/2011/HCV/PIIS0168827.pdf

Hepatitis B and hepatitis C are the reasons why the liver cancer projections by 2020 are dire. Compared to hepatitis C, hepatitis B is under-diagnosed and is also under-treated. The Auckland Statement calls for governments to guarantee that 10% of people living with hepatitis B receive anti-viral treatment.
http://www.aucklandstatement.com/
These (5% and 10%) targets are modest. Imagine if Australian governments were treating fewer than 5% of people living with HIV/AIDS, or asthma, or diabetes.

John Didlick
Executive Officer
ACT Hepatitis Resource Centre