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Ms Josephine Smith
Healthcare Improvement Division
ACT Health Directorate
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Dear Ms Smith,

RE: Feedback on the ACT Health Consent and Treatment Policy

HCCA welcomes the opportunity to provide feedback on the Health Consent and Treatment Policy. Attached is our full response to the draft policy and Attachment A, which shows some of our suggested changes to the draft policy based on our consultation with consumers and the community sector. Both documents need to be read together.

Consent to treatment and the principles of informed consent are central to acknowledging that consumers have the right to control their health and health care as acknowledged in the Australian Charter of Healthcare Rights.

We consulted with our members and other community organisations. We received input from Hepatitis ACT, ACT Disability, Aged and Carer Advocacy Service (ADACAS), Advocacy for Inclusion, Mental Health Consumer Network, Mental Health Community Coalition ACT, Partners in Culturally Appropriate Care (PICAC) NSW & ACT and COTA ACT. We also had comments from several of our individual members and consumer representatives.

Overall there is support for the amalgamation of policies relating to informed consent and consent to treatment. There was particularly strong comments around the need to strengthen the consumer focus in the policy. There was concern that the policy did not adequately interpret the changes to legislation.

We also received a number of comments on the timing of the consultation so close to the legislation coming into effect on 1 March 2016. Many of our community partners and members commented that they were disappointed about the lack of dialogue between ACT Health and their organisations in drafting the policy. They felt they were not given adequate opportunity or support to directly provide comment.

We encourage further consultation on future drafts with consumers and community organisations. We look forward to seeing how these changes have been incorporated.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Darlene Cox', is written over a light blue horizontal line.

Darlene Cox
Executive Director

15 February 2016

Feedback on the ACT Health Consent and Treatment Policy

The Health Care Consumers' Association (HCCA) provides a voice for consumers on local health issues and also provides opportunities for 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, community forums, and information sessions about health services and conducts training for consumers in health rights and navigating the health system.

HCCA welcomes the opportunity to provide feedback on the **Health Consent and Treatment Policy**. Overall feedback from our membership and community we consulted is that it is appreciated that the new policies amalgamate the older documents used particularly those around consent. There was particularly strong comments around the need to strengthen and refocus the Consent and Treatment Policy on person centred care, and some concern that the policy did not adequately interpret the changes to legislation coming into play in March. We received input from Hepatitis ACT, ACT. Disability, Aged and Carer Advocacy Service (ADACAS), Advocacy for Inclusion, Mental Health Consumer Network, Mental Health Community Coalition ACT, Partners in Culturally Appropriate Care (PICAC) NSW & ACT and COTA ACT. We also had comments from several of our individual members and consumer representatives. We have included comments from stakeholders throughout our response. Attachment A shows some of our suggested changes to the draft policy based on our consultation with consumers and the community sector. Both documents need to be read together.

Consent to treatment and the principles of informed consent are central to acknowledging that consumers have the right to control their health and health care as acknowledged in the Australian Charter of Healthcare Rights. In particular, the charter rights of safety, respect, communication and participation.

We appreciate that this document amalgamates all of the consent to treatment policies into one place. This appears to be a sensible approach and provides an opportunity to ensure that all ACT Health staff are adequately informed about our rights when we are in the care of ACT Health staff. As one of our members commented:

Overall I applaud the move to incorporate a number of consent and treatment policies in one document, hopefully making it easier for ACT Health staff to access this important information. The document appears to be fairly comprehensive and covers the important aspects of informed consent and, in particular, the importance of being aware of options and requirements for the use of substitute decision makers. The document is generally written in everyday, easy to understand English. The importance of providing comprehensive information, including a discussion of all available options cannot be overstated. This document seems to cover that well. – HCCA Member

There was some concern that the document was too long and complicated to adequately share information around consent, particularly in an emergency if a staff member is unsure about their legal obligations. One HCCA member commented:

'My impression is that the document seems to cover all the necessary scenarios. However I wonder how user friendly it is, particularly if, as the document states the scope of the document is: "This policy document applies to all staff across all Divisions, Branches and Units within the ACT Health Directorate. Compliance with this policy is mandatory." I can't imagine that a busy nurse or junior doctor would have the time or inclination to read this document. In which case the flow charts at the end of the document are excellent. Perhaps a simpler, user friendly, document, building on the flow charts could be produced. – HCCA Member

Accuracy of Interpretation of Legislative Requirements

There is concern that there are significant errors in the policy in regards to changes to the Mental Health Act 2015 (ACT), and a lack of clarity in the Treatment in an Emergency, Health Attorney, Advance Care Planning, Health Direction, Substituted Decision Makers, Treatment under the Guardianship ACT – without a guardianship order, Advance Agreement and Advance Consent Directions sections of the document. These concerns are major and come from organisations including Mental Health Consumer Network, and individuals with expertise in guardianship arrangements, supported and substitute decision making, and the changes in the Mental Health Act (ACT). We see that the inaccuracies are such that they warrant review by legal advisors within ACT Health and further community consultation. If the document is implemented as is on 1 March 2016 in its current form we have concerns that it does not provide accurate legal guidance and is not consumer focused.

Attachment A shows some of our suggested changes to the draft policy based on our consultation with consumers and the community sector. Based on the feedback we received we recommend that ACT Health revises the draft policy and sends it out for further consultation to ensure that the issues identified have been addressed satisfactorily and meets consumer needs. We want to have confidence in the policy and implementation plan so that consumers have safe consent processes.

This is demonstrated by the feedback from the Mental Health Community Coalition ACT:

Sections 3 and 4 give an impression of an inaccurate interpretation of the Mental Health Act 2015 (and the earlier amendment acts), including a few examples which I believe are factual errors, and fails to properly reflect the objectives of the Act, including to make supported decision making a core focus and activity of mental health services. It also gives an inadequate reflection of what supported decision making means. The draft policy therefore does not reflect core objectives of enabling consumer consent and respecting decisions by those with decision making capacity.

One HCCA member also questioned the accuracy of the titles of other policies cross referenced in the draft Consent and Treatment Policy:

'I think this NFRP policy has been revised and has a new name as a result of the new policy and procedures around Goal Setting and End of Life (GSEOL) implementation from beginning of February.' - HCCA Member

Implied Consent

We have a number of concerns regarding implied consent which is often subject to interpretation.

On page three of the current draft, dot point two suggests that taking and swallowing medication is implied consent and yet we have heard many anecdotal incidences of consumers not being informed about what they are taking, or being asked to take something they have previously refused to take. We do not think medication, given the safety issues around medication error should be included here.

There is also concern that those with cognitive impairment may be thought to have implied consent when in actual fact they have not been adequately supported to decline treatment if they wish.

We received considerable feedback and as you can see from the comments below there is a degree of unease with the concept of implied consent set out in the draft policy. We are of the view that there needs to be careful consideration of this section in the implementation phase. Consumers, carers, and clinicians need to be aware of the difference between informed and implied consent.

'Section 2 - last para. I would delete "Even though in this circumstance consent is implied by the person's presentation and a formal consent form is not required"...because I don't agree that in all circumstances consent would be implied. As consent has to be obtained anyway, there is no value in mentioning implied consent.' – HCCA Member

'In regards to the last dot point, implied consent makes sense for the other dot points, where the patient is actually doing an action, but a low risk profile doesn't mean that consent can be assumed. Because consent isn't just about risk, it's about bodily autonomy.' –HCCA Member

As a consumer and when and where ever possible, I would wish to be able to give informed consent for any invasive procedure because the administration could add all sorts of procedures to this list and the consumer would have the procedure done to them with administration saying they agreed to it when in fact permission is simply assumed to be given. – HCCA Member

We see that the concept of shared decision making (SDM) needs to be embedded throughout the policy. Consent needs to focus on the information exchange and shared decision making between consumers and their treating clinicians, not on obtaining the consent. This process is important to consumers.

Section 6 Refusal of Information, Treatment or Withdrawal of Consent

The majority of comments from contributors focused on section six of the policy. The below case study indicates the impact of pressure from clinicians to continue treatment, and the difficulties some consumers, carers and families have in declining treatment options.

A carer's experience of revoking consent for treatment

My sister, who had been on a trial for a treatment of Multiple Myeloma for seven months became so ill that she could not sit up unaided, feed herself or perform any activities of daily living. She had severe (almost always uncontrolled) pain since her from her skeletal metastases. In addition, the medications she had taken during this period caused bowel necrosis and subsequently, a colostomy.

She was admitted to the TCH from the Hospice because they seemed unable to manage her care. Twenty-four hours after her admission to TCH with her daughters and husband present, she decided to leave the trial and let nature take its course. This was a very distressing time for her and the family as we knew she was very close to death.

When the consultant came to see her and the family he was very abrupt and tried to dissuade my sister from leaving the trial. Amongst other things he said words to the effect that "everyone in Sweden working on the trial are very excited about your results". This was puzzling to us given my sister's results were way outside the wanted parameters.

Family members spent most of the next day with my sister but left late in the afternoon because she was sleeping. When family visited later that day my sister told them that she had agreed not to leave the trial! It transpired that the consultant had just left her bedside and that he had convinced her she should continue the trial for the 'sake of others'.

For most of her care my sister had been a private patient of this consultant. He knew that she had devoted a lot of time and energy during her life to helping others, so appealing to her altruism seemed to be very calculated.

My sister was very distressed about her decision to continue the trial and we agreed to talk about what was best the next morning, when she had had some rest. By the time we gathered in the morning to wait for the consultant my sister was determined to not continue the trial and to go back to the hospice. My sister told the staff that she had changed her mind and wanted to leave the hospital. Several staff members queried her decision (not in a bad way), but the trial team made it very clear that they were displeased with her decision.

I am not sure that she saw the consultant before she went back to the hospice. She died four days later.

Unfortunately this experience is not unusual for consumers and their families and many of those who provided comment on the draft policy talked about the pressure to consent to medical treatment. For example:

In regard to the 'right to refuse treatment section' I would like to see this section include a paragraph that allows the person refusing to continue treatment to have a 'cooling off' period of at least 24 hours. To me the most important component of any such period would be that all health professionals were advised that the cooling off period was in place, and that therefore they were to desist from questioning the consumer about their reasons for the decision. I appreciate that I am probably expecting too much of the health system, but I am quite sure that consumers' who decide to cease treatment will have their decision questioned (probably out of genuine concern) by the majority of health professionals. In my experience this questioning occurs because the health system (medicine especially) is driven to pursue any chance of a cure however remote, even if the quest for the cure fails to recognise the consumer's rights, extends their suffering and ultimately kills the person – HCCA Member

I have talked to a number of consumers in the Cancer area who have encountered problems with being pressured to continue treatment.' - HCCA Member

The document could be stronger from a consumer point of view with an enhanced focus on the importance of ensuring that consumers are fully aware of their rights in decision making about their health care, including the right to elect not to undertake a particular treatment or procedure. Hence I have suggested a slight change in the opening paragraph for consideration and bolding of a sentence about withdrawing consent on P5 of the document. –HCCA Member

Based on this we recommend opening document in the following way:

People have the right to decide whether or not they wish to receive health care and must be actively involved in the decision making process . ACT Health staff must obtain a person's valid informed consent before beginning any clinical activity, treatment or procedure.

This focuses the document on the rights of the consumer rather than the requirements for staff to meet legislation. Bolding the text on page five; **A person should be informed that his or her consent can be withdrawn at any time during a course of treatment** and highlighting this earlier in the document would also emphasise the importance of this.

Many of our members feel that section six and the tone and intent of the document does not adequately state the consumer's absolute right to decline treatment or consent. We recommend that language describing the process of consumers declining consent is revised and strengthened within the document.

One of our member organisations, Hepatitis ACT, raised a specific example to demonstrate the need for clinicians to obtain consent from patients who are not to be treated.

Understandably the draft policy focuses on the provision of treatment. By way of example, typically a patient presents with a condition and the clinician offers a therapeutic intervention. Informed consent is required from the patient before that intervention is provided. If the patient refuses treatment, the treatment is not provided

(or is provided anyway, in certain circumstances). The first paragraph in the draft policy frames this. There are situations however when the patient presents with a condition seeking therapeutic intervention, and the clinician declines to provide it (or postpones it until a later and sometimes undetermined time). Treatment for hepatitis C is a good example of this, whereby people have been seeing specialists and having treatment 'postponed' for years. This backlog of patients is often referred to as 'warehousing'. Understandably, clinicians and patients alike were not in love with interferon based therapies. Some people underwent interferon based therapies because they felt (or were advised) they 'had to' because their stage of liver disease and pace of progression indicated they couldn't wait any longer. Many people were advised (or independently decided) to not undertake interferon based therapies and instead to wait until better medicines were available. Better medicines for hepatitis C get PBS listed on 1 March 2016, and this is the moment that many thousands of Australians have been postponing treatment for. Now that the medicines that everybody wants are becoming available, more people want treatment than specialists clinics can accommodate. In these examples, essentially a patient has 'agreed' to forego an available treatment to instead take up a more appealing treatment some time into the future. In summary, there needs to be some consideration within the Consent and Treatment Policy for situations whereby a patient should be providing informed consent to not be treated. – Hepatitis ACT

Another member also raised the clinician focus of the document.

While the document sometimes mentions a patient's right to choose whether to have treatment or not, the tone of the document is much more about 'how to properly gain consent for what you, the health professional, want to do', rather than 'how to support patients to make their own decisions'. I've addressed this at specific points in the document, but wanted to mention it here as well, because I think the policy could use a lot of work overall to change this tone to be more patient-centred. – HCCA Member

Supported Decision Making Models

Several people suggested that there is a need to further explain and explore the supported decision making model within the policy, stating that it is considerably broader than those being treated under the Mental Health Act and should include all consumers to be supported to make an informed decision about their care. Many commented that the policy does not have a section on people with disabilities and cognitive impairment and seems skewed to cover mental health treatment without considering other instances where supported decision making should be used.

While the document sometimes mentions a patient's right to choose whether to have treatment or not, the tone of the document is much more about 'how to properly gain consent for what you, the health professional, want to do', rather than 'how to support patients to make their own decisions'., because I think the policy could use a lot of work overall to change this tone to be more patient-centred.' – HCCA Member

It is important to recognise that basic decision making support is something that everyone in the community should be able to do. In fact all of us already do it, for example when a friend is stuck between a couple of options and you help them sort it out. Supporting someone who needs significant decision making support is a specific

area of skill and expertise, however, and shouldn't be something that is considered to be done by just anyone, especially if they did a 2 hour workshop once so that's okay then. Just as a police officer would never try to be a paramedic, and vice versa, complex decision making support is a specific expert area that needs to be sourced as required. Usually it's done by people like us (independent advocacy orgs). – Advocacy for Inclusion

There is some good procedural stuff in our [submission](#)¹ to the ALRC national decision making framework (rec 9 for example). Of note is that every decision must be treated differently. What worked last time someone was in the hospital can't become a formula for every time they are there. Each decision needs to be done on a case by case basis otherwise the person is in danger of not being appropriately supported. – Advocacy for Inclusion

This is good policy however the document does not then go on to describe what support might look like we suggest including in the first page the following sentence with an exploration of different ways to support consumers later in the document; 'This presumption of capacity to consent must be applied to all adults. The presence of a disability, frailty due to ageing or a mental health condition does not change the presumption of capacity. Where a person would benefit from support to exercise their capacity to consent, this support should be provided.' – ADACAS, A.C.T. Disability, Aged and Carer Advocacy Service

Capacity and Assessing Capacity

There was concern both about the language used to describe those who may need support to make decisions about their care. Several people commented that the changes to legislation is meant to strengthen the rights of all consumers to make support decisions with the assistance of health care teams or advocates, with the assumption they have capacity even if they have different needs to others. Some felt that the tone of this document implies that ACT Health staff must assess people to see who may lack capacity and find substitute decision makers or situations where consent can be overridden. We are deeply concerned that this document does not fully outline how to provide supported decision making, or the process in which to assess someone's capacity.

There is still a lot of wording around "people who lack capacity" or "Incapacity". This isn't aligned with the United Nations, Convention on the Rights of Persons with Disabilities (CRPD) nor the intentions of the new MH treatment and care Act and its references to SDM. The approach is rather that everyone is presumed to have capacity and it is the responsibility of agencies to determine what level of support a person might then need to make an informed decision. Some people will require significant support to make a complex health treatment decision. Some will also require communications support to indicate their will and preferences. So, it's about identifying that a person requires decision making support NOT whether they lack capacity. The UN has been quite clear about this repeatedly and is clear that substitute decision making is no longer acceptable. Everyone has the right to support, it's simply a matter of how much – Advocacy for Inclusion

¹ Advocacy for Inclusion Submission to ALRC Disability Inquiry July 2014 Accessed 8/ 9 February 2016
http://www.advocacyforinclusion.org/publications/Submission_to_ALRC_Disability_Inquiry_July2014FINAL.pdf

In section two of the policy and in the ACP section it does not state, how does the clinical assessment take place? Who is authorised to undertake it? How is it documented? Is the assessment based on capacity with support or not? Guidance around clinical assessment of capacity should be articulated in this policy or referenced here if it is articulated elsewhere. – ADACAS

Terminology, Language and Context

We note that the definition of terms section seems to be entirely mental health related despite the fact that several of the terms have differing definitions in other areas of the health system. This particularly evident when looking at the definitions of Advance Agreements, Advance Consent Direction, Care Coordinator, Nominated Person and Health Attorney. These terms have broader definitions than the mental health context, such as Advance Care Planning, community care and case management for people with disability, and Powers of Attorney for those with cognitive impairment. It is confusing to include a section on definitions that is solely based mental health, noting that the definitions of some of these terms even in these contexts are wrong.

An example of this is the use of the term 'Health Attorney' in the document which is used within Advance Care Planning, differently to a mental health context and is often poorly understood by clinicians and health staff.

We also were critical of the term Health Attorney, its status in law is unclear and used in different ways. This is when the doctor grabs a relative who does not have PoA and gets them to sign for a procedure. It has no legal status and should be discouraged, as it does not comply with informed consent or safeguard the interests of the patient. There has been a lot of criticism by patients and carers that they are asked to sign multiple documents or consent forms in a hurry or at the last minute, when it is impossible to think through or assess risks & benefits. - COTA ACT Volunteer

Others pointed out that the *Definition of Terms* seems to introduce new terms that are not included or referenced in the document, for instance *experimental healthcare* and *medical research* we understand this has been impacted by recent changes to the Powers of Attorney legislation in the ACT, however these changes are not discussed or explored in the body of the document.

I was intrigued by the fact that, under the Definition of Terms, which commences on Page 19, there is a definition of Experimental healthcare (on page 20) and Medical research and Medical research matter (on page 21). However, I did not find anything in the body of the document about experimental healthcare or medical research. Was there something in a previous draft that has now been deleted? I would have thought it was important to cover these specific areas in this document - or at least to cross-reference to another document that deals with these matters. – HCCA Member

We note a number of consumers felt that the document contains offensive and inappropriate

language in several sections. This was highlighted by several members. On page three many commented that performing a medical procedure without consent should be labelled as *assault* rather than *trespass*, though we understand this may be due to legal terminology. Others commented that the word refusal of treatment should be replaced with decline.

I would like to see the term 'refuse' changed to 'decline' throughout this and every health care policy! 'Refuse' carries strong negative connotations; of a patient being difficult and disagreeable, whereas 'decline' makes a decision not to have treatment sound much more valid. – HCCA Member

On page five under the section about changes in clinical conditions in relation to dot point three, MHCN highlighted;

This should say "illness" and not disease as a mental health condition is not considered a disease but an illness and, likewise, not all physical conditions are diseases – MHCN

The last sentence of the first paragraph on page eight of the document includes the phrase '*people should not be consented...*' several people commented that this does not grammatically make sense as a person cannot be consented. Consent and all of its variations are first person verbs. We suggest: '*... people should not be required/asked to give consent in the holding bay...*' or similar. Otherwise it reads as something that is done to us rather than a process in which we are actively involved. This is core to the notion of partnering with consumers.

Language is important and one of our member organisations, Mental Health Consumers Network, raised this in their feedback on the draft policy. Under section two on page eight the word *incompetent* is used. This word is found to be offensive by many people in both the mental health and disability advocacy space. We do not condone the use of this word to discuss people's capacity to consent.

The document does not offer a definition of what it means to be incompetent, we find the term incompetent derogatory in nature. We would recommend referring to lack of capacity in place of referring to in/competence. - MHCN

There is several inappropriate and value loaded terms on page nine of the current draft that were highlighted by MHCN, MHCC, Advocacy for Inclusion and several individual members. This is particularly evident in the dot points describing that a person cannot be assumed to have impaired decision making capacity because. Concerning words are *eccentric*, *unwise decisions* and *immoral conduct*. These words and phrases are judgmental, and subjective and we ask that these phrases are removed.

We note also that references to attached documents are referred to as attachment A and attachment 1 this needs to be consistent throughout the document.

Cogitative impairment and people with intellectual disability, or difficulty communicating.

We recommend including a specific section that relates to cogitative impairment and people with intellectual disability and supported decision making and consent. This policy is meant

to guide ACT Health staff in matters regarding all consent processes. We recommend that a specific section be drafted in consultation with the wide range of disability advocacy groups within the ACT including but not limited to; People with Disability, Women with Disability, Advocacy for Inclusion, ACT. Disability, Aged and Carer Advocacy Service (ADACAS), Carers ACT and Alzheimer's Australia ACT. This section must meet the needs of a wide range of vulnerable consumers and it is important that this is done in consultation with those of whom the policy affects.

I was surprised that the document does not include the term "cognitive impairment" anywhere - when there is currently so much attention to the appropriate treatment of patients with cognitive impairment in the health quality and safety domain. Other words and phrases are used that might be considered to cover cognitive impairment - I just wonder whether this might be a case of unnecessary oversimplification of language leading to possible ambiguity. - HCCA Member

In the Act review process that there was a forgetting of cognitive disability when it's actually heavily impacted by such legislation, and now procedures and policies, we need it included here – Advocacy for Inclusion

Blood and Blood Products

We note that the language in this section suggests that acute patients *must* and *should* consent to transfusions and blood products. This was seen as forceful by some members and inappropriate given that all consumers have a right to decline treatment. We note also that consumers can document decisions around blood products in their Health Directive as well as an Advance Care Plan. One member commented:

*In paragraph three you say patients **should** give consent to blood products, unless they don't want to! Perhaps 'consent should be sought' (sentence will need restructuring so it works grammatically)*

Informed consent for CALD peoples

Several of our members including Partners in Culturally Appropriate Care (PICAC), and our Multicultural Liaison Officer noted that this section is very short and doesn't include support for staff about how to access interpreters and work with those from culturally and linguistically diverse backgrounds. We ask if this document and this section has been reviewed by the ACT Health Multicultural Health Policy Unit? This section is very important given that over 20% of the ACT community is from a multicultural background. We note that this section includes four paragraphs (the last four on page 18) that seem to relate to people with disabilities rather than those from a multicultural background. It would be good to appropriately place these in another section. The section doesn't include how staff can access support to help them work with people from multicultural backgrounds, or reference the multiple documents, resources and training prepared by the Multicultural Health Policy Unit that could aid staff.

The commentary on CALD populations is too brief and needs to contain more culturally specific information. Perhaps targeting the highest CALD groups and their needs. – PICAC

We suggest the following additions to this section;

- *Consulting with ethno-specific organisations which will provide guidance and expertise in matters pertaining to the patient's particular culture.*
- *Staff should consider the following cultural considerations:*
 - *Be aware that the patient is not always the decision maker about his/her future health management.*
 - *Cultural attitudes towards death and dying*
 - *Cultural attitudes around gender*
 - *Cultural attitudes around religion and religious needs*
 - *Complex family and support structures*

-PICAC

It must be made clear to staff that an interpreter MUST be made available if there appears to be any doubt about the person's ability to understand. It is difficult to state generally and succinctly. – HCCA Member

Hepatitis ACT provided commentary on this section that needs consideration in the revision of the draft policy:

This section should be strengthened. It is good that the draft text directs the reader to "the Language Services Policy and Language Services Interpreters Procedure for more information regarding the use of interpreters", but I wonder how many readers are going to reach for those other documents to complete their understanding. Instead, there is some well-written and compelling direction provided in the Language Services Interpreters Procedure that would strengthen the draft Consent and Treatment Policy if it were included. At a minimum I recommend the following sentences from the Procedure be included prominently in this section of the Draft Consent and Treatment Policy:

- *An interpreter is needed if there is any chance of misunderstanding due to language differences. Some consumers' English skills may be reduced in traumatic or emotional situations.*
- *Multilingual staff and relatives/friends can help to communicate with consumers with limited English proficiency, but they must not replace professional, accredited interpreters, particularly in situations which may be a risk for consumers and/or ACT Health. Professional, accredited interpreters must be used wherever possible, due to the risks involved in using non-professional interpreters. Interpreting is a professional skill and professional interpreters are trained, insured, and bound by a code of ethics.*

Aboriginal and/ or Torres Strait Islander Peoples

We would like to know if this language has been cleared with the Aboriginal and Torres Strait Islander Policy Unit and the Aboriginal Liaison Unit. Some of members expressed concern that the language is patronising, particularly around Men's and Women's Business.

Related legislation, policies and standards

The Language Services Policy and Language Services Interpreters Procedure should be listed under 'policies and procedures'. The National Safety and Quality Health Service Standards are also not referenced.

Flow Charts and attachments.

There were a few minor suggestions for changes to the flow charts.

On page 23, the meaning of the Note under the flowchart is not entirely clear - I suggest delete the semi-colon and start a new sentence, eg. "In such circumstances, the Health Directive is revoked. – HCCA Member

I could not see the point of including the information in the box under the Process Map on page 24 - the content seems to be already covered adequately in the Process Map itself. – HCCA Member

Accessibility of the Documents and Consumer Information

There is some concern that the policy document does not include information about the requirement of ACT Health to provide information in a range of formats and languages as specified as part of the ACT Health Multicultural Coordinating Framework as a key action area to increase health literacy. 'Establish and maintain a register of materials available in languages other than English.'² and the Disability ACT Policy Management Framework³

The only comment I have is that the Policy Statement appears to make no reference to the need to provide people with information in their preferred accessible format. The Policy should include this requirement. Alternative formats include: braille, large print, audio and plain English. A person who is deaf should also be able to communicate through an Auslan interpreter – People with Disabilities

Consumer and Staff education on rights, supported decision making and consent

Changes in the Mental Health Act (ACT, 2015) have been discussed for over a year, these changes dramatically reframe consent procedures to ensure that consumers are supported to make decisions with the assumption we are competent to make these decisions, rather than forced to prove we are able to participate in decision making. We would like to know

² Key Action Areas (Section 6.42) Internal Draft of ACT Health Multicultural Coordinating Framework 2014

³ACT Disability Policy management framework 2012 accessed 10/2/2016 http://www.communityservices.act.gov.au/__data/assets/pdf_file/0020/423290/Disability_ACT_Policy_Management_Framework_Web.pdf

what training ACT Health staff have had to ensure they understand this paradigm shift in the legislation and are well placed to follow appropriate consent processes? We would also like know how compliance with this policy will be measured? We encourage ACT Health to work with community organisations and the Human Rights Commission to develop information for the community about their rights to be actively supported to make informed decisions about our care. We are aware that ADACAS is doing significant work in this area, particularly with people with cognitive impairment.

Additional points requiring clarification

We would like to know if the scope of the document covers the work of VMO's as this is not made explicit and it was raised specifically by our members.

We are interested in how this policy relates to consent processes in other ACT public health systems, such as Calvary Public Hospital.

Also, given that the ACT Government is outsourcing surgery and dental work to private providers we are seeking assurance that due diligence has been taken to determine that all these providers have consent policies consistent with legislation and standards.

Darlene Cox
Executive Director

15 February 2016