

## Appendix E Patient and carer interview analysis

The table below highlights the main themes regarding access to health care services, which were revealed during consultations and interviews with Aboriginal patients and their carers. Possible improvements have also been identified during the interviews.

Theme	Issues	Quote	Suggested Improvements
Geography	<ul style="list-style-type: none"> <li>Poor access to mainstream services resulting from limited transport, including affordability and availability.</li> <li>Aboriginal people relocating from 'country' to Casino so they can access treatment and specialist services in Lismore.</li> <li>AMSs only provide transport to medical appointments for their clients.</li> </ul>	<ul style="list-style-type: none"> <li>"We need to have more assistance provided to Aboriginal people in the community who struggle to meet the costs of transport to attend treatments and specialist appointments in towns located over 100kms from Condobolin."</li> <li>"We have been going every second day to Dubbo and Orange for three months straight. It is making us tired with all the travel and the treatments. Last week we went to the AMS to seek transport or petrol assistance as we had three appointments we needed to get to. We were told because we were now under Dr. [Name provided] at the Shire that they couldn't provide us with help so we missed the appointments."</li> <li>"We were told by the AMS because we were no longer clients visiting a GP at the AMS we could not have transport from them to attend our appointments."</li> <li>"If we can't arrange transport we just don't go to our appointments out of town. It's as simple as that and our family suffers from it too."</li> <li>"I didn't know that I wouldn't be flown back the same way I came to the Sydney hospital. I needed to come back home because I wanted to be closer to my brother and family."</li> <li>"We have to keep Aboriginal people on country if they are to see a longer life."</li> <li>"We have to realise that people die out of country. Lots of family have to leave their country to come to Casino and Lismore just so they can have dialysis. When we are forced to leave our country and our homes we lose touch with our culture and identity."</li> </ul>	<ul style="list-style-type: none"> <li>To make transport more affordable to encourage Aboriginal clients to attend scheduled medical appointments and treatments for their chronic health conditions.</li> </ul>
Prevention	<ul style="list-style-type: none"> <li>Aboriginal people often do not present to health services until late in their illness.</li> <li>Low participation in preventative health care activities and programs, such as poor diet,</li> </ul>	<ul style="list-style-type: none"> <li>"I wasn't aware I had diabetes and I was sweating a lot and just feeling poorly every day. The first sign for me and acknowledging for myself that I had a serious chronic care condition was when I had to have my toe amputated."</li> <li>"I don't understand what the doctors and nurses are saying to me when</li> </ul>	<ul style="list-style-type: none"> <li>Provide Aboriginal Chronic Health Care Awareness sessions in the Aboriginal community. This will help inform Aboriginal people about prevention and management of chronic conditions, as well as</li> </ul>

Patient and carer interview analysis

Theme	Issues	Quote	Suggested Improvements
	<p>lack of exercise and adult health checks.</p> <ul style="list-style-type: none"> <li>Limited knowledge of the conditions and lifestyle choices that have major impacts on chronic disease eg smoking.</li> </ul>	<p>they explain the operation and tests I need to have and what I need to do.”</p> <ul style="list-style-type: none"> <li>“I was never given any advice on the affects of smoking or provided with anything like nicorette gum or patches to help me quit smoking. I am starting to believe people now and I should have listened more in the early days.”</li> <li>“I know what I have to do <u>now</u> and what foods I should eat and not eat. The biggest problem is keeping to it.”</li> <li>“I have seen too many Aboriginal people with their legs and arms needing to be cut off because they haven’t looked after themselves.”</li> </ul>	<p>providing information on where to go for assistance. Local media could be used to promote these information sessions.</p> <ul style="list-style-type: none"> <li>Additionally, regular and ongoing health promotion positions should be developed with the Aboriginal community and AMSs.</li> </ul>
Affordability	<ul style="list-style-type: none"> <li>High costs for regular and on-going medications.</li> <li>High costs for medication, transport, specialist appointments, air-fares and accommodation.</li> <li>Aboriginal patients needing treatment at Sydney, Dubbo and Brisbane hospitals residing in rural and regional areas do not have access to affordable accommodation or personal effects.</li> <li>Limited Bulk Billing services in the area.</li> <li>Aboriginal patients often do not understand the care packages available to them.</li> </ul>	<ul style="list-style-type: none"> <li>“We struggle to meet the costs of transport to attend treatments and specialist appointments in towns located over 100kms from Condobolin.”</li> <li>If there is no bulk billing services provided, this deters Aboriginal people to attend their medical appointments.”</li> <li>“I don’t just want to go to an appointment to pay \$250 for them to say my heart is ok and it costs me \$250 for that privilege.”</li> <li>“They [Aboriginal patients] don’t have their personal items like soap, shampoo, money, ID, change of clothing, etc. I provide Elders with basic personal items out of my own pocket because I don’t want the Elders to feel shame.”</li> <li>“Where do we go if we need oxygen? Other services get dollars to provide oxygen to their other clients but not for Aboriginal people. We always get told to go to Yarrabah or the AMS.”</li> <li>“If we can’t afford it we don’t go and we don’t buy healthy food or tablets we need.”</li> <li>“I have to get 3 packets of tablets every fortnight for blood pressure. It costs me \$65.00 each time. The chemist use to let me pay it off because he knew I was Aboriginal. Other people in our community just can’t afford it every week so they go without and get sicker.”</li> <li>“I have rung the community health centre in Lismore regarding transport funds for my brother. They helped a bit for us to drive him from Casino to Brisbane and to bring him back home. The problem is that we need to take him there every 3 months for treatment and we are in debt up to our eyeballs.”</li> </ul>	<ul style="list-style-type: none"> <li>Making specialist appointments more affordable to Aboriginal people.</li> <li>Reducing the costs of medications for Aboriginal people needing medications for serious chronic conditions on a regular basis.</li> <li>Personal care packages for Aboriginal clients presenting at Sydney hospitals who have come from regional and rural areas. These packages can include soap, shampoo and conditioner, incontinence pads, health service contact details, affordable short term accommodation, bulk billing services available and healthy food items for day trips.</li> </ul>
Workforce	<ul style="list-style-type: none"> <li>Absence of Aboriginal Male Health Workers in regional and rural Aboriginal communities.</li> </ul>	<ul style="list-style-type: none"> <li>“A lot of our male community members don’t look after their health care as much as the women because we don’t have male Aboriginal health workers.”</li> </ul>	<ul style="list-style-type: none"> <li>Consideration of extending the Aboriginal Employment Strategy in the Health system to include</li> </ul>

Patient and carer interview analysis

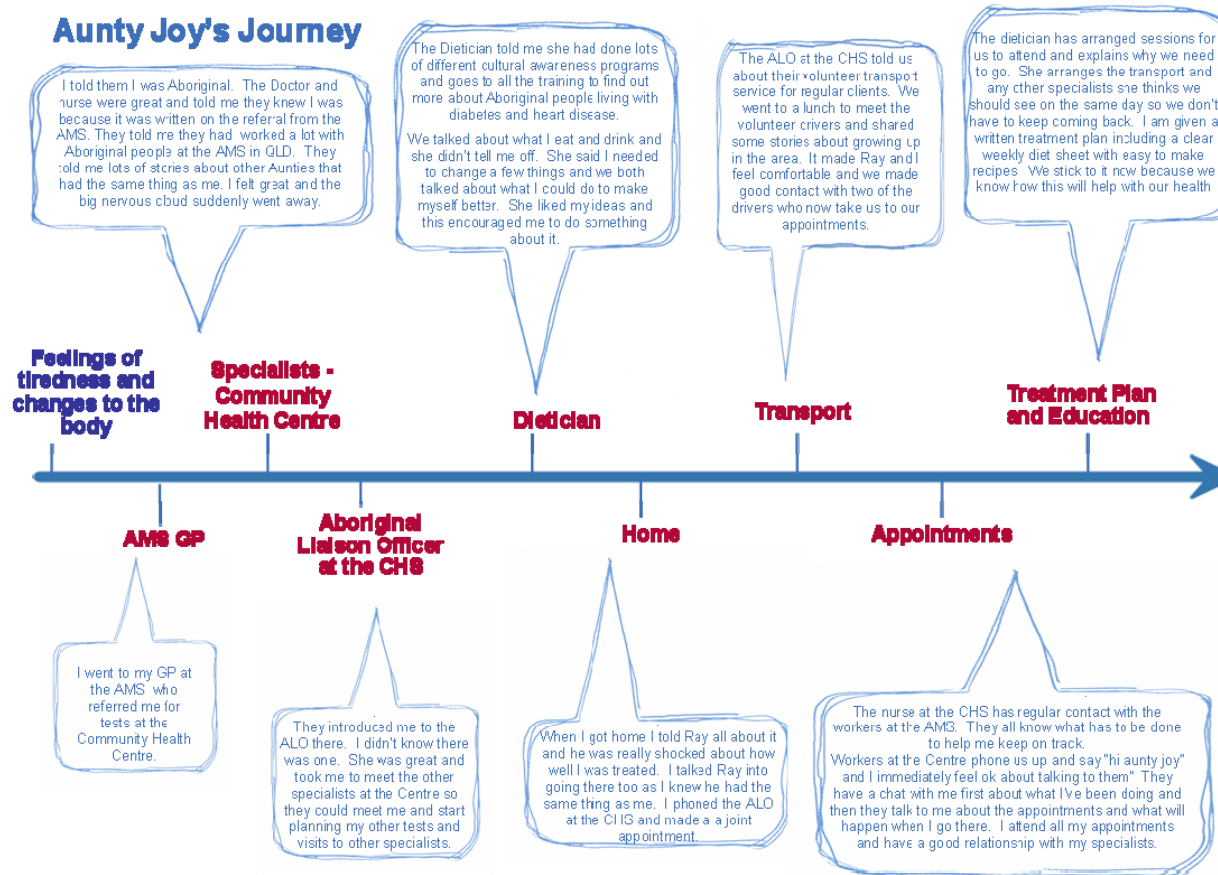
Theme	Issues	Quote	Suggested Improvements
	<ul style="list-style-type: none"> <li>• Not enough flexible Aboriginal employee programs in health.</li> <li>• Limited skills transfer in relation to education and training.</li> </ul>	<ul style="list-style-type: none"> <li>• “The reason why we have such a high quality level of health care at the hospital is due to the high numbers of Aboriginal staff employed who have been trained to deliver cultural awareness to the non-Aboriginal staff at the hospital.”</li> <li>• “We need more funding to be made available to employ more Aboriginal Health Worker positions in the areas of Drug and Alcohol, Mental Health and facilitating client group health Information sessions.”</li> <li>• “There should be more Aboriginal people employed in mainstream health services. There should be more Snicker’s bars and chocolates in the Hospital canteen-why, because they have peanuts in it.”</li> <li>• “Not all Aboriginal Hospital Liaison Officers have all the qualifications or skills required. They are only skilled to a certain level.”</li> <li>• “We don’t have enough funds to employ additional support workers to the ALOs in hospitals to address the back log of work and also to back fill our positions so we can take our leave when we need to. I don’t like to take my leave if I know I have clients in the hospital that need my help.”</li> </ul>	<ul style="list-style-type: none"> <li>• Aboriginal male health worker positions.</li> <li>• More flexible Aboriginal employment programs and initiatives to be introduced into the mainstream health service system.</li> <li>• Regular ongoing Aboriginal health promotion positions be developed in partnership with the Aboriginal community, the AMS and the community health centres.</li> <li>• Hospitals and health service staff be provided with training on identification and recording of Aboriginal status at intake and during all levels of health service provided.</li> </ul>
Cultural Sensitivity	<ul style="list-style-type: none"> <li>• Family priorities are viewed as more important than individual health care.</li> <li>• Fear of hospitals and mainstream health services.</li> <li>• Mistrust in health care professionals.</li> </ul>	<ul style="list-style-type: none"> <li>• “Young nurses need to be more aware of our Aboriginality and culture as they treat you like you’re stupid.”</li> <li>• “One community health centre I attended had staff complaining about Aboriginal families coming and going when one of the male Elders had died. They said things like typical black fellas.”</li> <li>• “Aboriginal people still seem to be waiting longer to be seen by anyone when we go to the Emergency area.”</li> <li>• “I phoned for an ambulance trolley that could take my weight. When I got to the hospital and they wheeled me out all the nurses came out and stood around me, looking at me and laughing.”</li> <li>• “My GP wanted to know why I was going to the Mount Druitt AMS. He laughed when I told him I was a Koori.”</li> <li>• “This one doctor was patronising and discriminating against me as a mother and foster carer. He kept telling me what types of fruits and vegetables were healthy for the kids-as if I didn’t know this. “</li> </ul>	<ul style="list-style-type: none"> <li>• Mandatory Aboriginal Cultural Awareness Training programs need to be developed and delivered to staff in mainstream health services. The programs need to relate to Aboriginal health and chronic care issues.</li> </ul>
Infrastructure/ Accountability	<ul style="list-style-type: none"> <li>• Poor coordination between hospitals, AMSs and health care system for Aboriginal patients.</li> <li>• Treatment Plans not provided to Aboriginal patients and clients.</li> </ul>	<ul style="list-style-type: none"> <li>• “The AMS doesn’t open after hours and I can’t get there during the day because I work. I was a bit frightened to attend a mainstream after hours clinic and didn’t for many years.”</li> <li>• “There is no specific ‘Koori room’ for Aboriginal patients and their families like they have in other hospitals in other states. If there was a family room</li> </ul>	<ul style="list-style-type: none"> <li>• NSW Health Services to consider coordinating Aboriginal Carer Forums, held within close proximity of where the majority of Aboriginal people reside.</li> </ul>

Patient and carer interview analysis

Theme	Issues	Quote	Suggested Improvements
	<ul style="list-style-type: none"> <li>Lack of general practitioners and specialist services available.</li> <li>Limited after hour access to services.</li> <li>Limited Aboriginal family rooms in hospitals.</li> </ul>	<p>for our mob I would also make sure I could go to that hospital so then I don't have to worry about my family when they come to support me."</p> <ul style="list-style-type: none"> <li>"I have all sorts of health issues and have never been provided with a written copy of my treatment plan."</li> </ul>	<ul style="list-style-type: none"> <li>Treatment Plans provided to all Aboriginal patients and carers. Treatment plans need to be clearly written in formats that are easy to understand.</li> </ul>
Communication	<ul style="list-style-type: none"> <li>Lack of knowledge within patient and carer groups about who provides what.</li> <li>The need for more Aboriginal carer forums, education and awareness.</li> </ul>	<ul style="list-style-type: none"> <li>"I would attend the Community activities and programs held at mainstream health if I was informed."</li> <li>"I was told to give up smoking and I have but it is a bit late as I have emphysema and need oxygen to help me breathe. I don't know where to go to get this help or if I do get it how I will be able to afford it."</li> <li>"We need more education and training needed to be provided to Carer's about how to look after their Aboriginal families with chronic health needs."</li> <li>"Some carer's have health issues themselves and are not taking care of their own health needs. How can they be given the role of carer for other Aboriginal people with the same health care needs? If they are eating junk food and have diabetes how can they look after their mother who also has diabetes?"</li> </ul>	<ul style="list-style-type: none"> <li>Provide Aboriginal Chronic Health Care Awareness sessions in the Aboriginal community.</li> </ul>
Provision of Care	<ul style="list-style-type: none"> <li>Hospitals often do not cater for all needs.</li> <li>Long waiting periods for specialist appointments.</li> <li>AMS not informing Aboriginal patients about specialist visits.</li> <li>Hospital staff failing to ask Aboriginal identifier question.</li> <li>Poor referral systems and follow-up.</li> <li>Lack of knowledge within patient and carer groups about who provides what.</li> </ul>	<ul style="list-style-type: none"> <li>"The intake staff assumes Aboriginality of a patient admitted just by looking at the patient when they present at the hospital."</li> <li>"When I tick the box that I am Aboriginal at other services I use I do not get offered an Aboriginal response or any specific Aboriginal information."</li> <li>"I am told I should see dieticians, counsellors and other health workers to assist me but I don't get the referral note."</li> <li>"When I get the courage to actually go to another appointment they tell me the referral hasn't come through and I have to wait another few weeks."</li> <li>"I have not received any follow-up contact to attend future medical appointments or to be told the results of tests."</li> <li>"I had diaticulitis at one stage and was coming into the hospital on a regular basis. I would go home in the afternoon and would return that evening and the hospital staff were not taking my views and symptoms seriously. The doctor at the hospital would say go home because there is nothing wrong with you. I went home and called my GP, he had me sent to Westmead Hospital, and they found I had a hernia."</li> </ul>	<ul style="list-style-type: none"> <li>Specialist treatment services, such as dialysis, oxygen and cancer treatment, should be provided at regional and rural hospitals that have a large population of Aboriginal people.</li> <li>Long waiting times in the Emergency Outpatients area of Hospitals be reduced for Aboriginal people.</li> <li>To improve Aboriginal people's awareness of visiting specialists to the AMS' in rural and regional cities so that they can be available to meet scheduled appointments.</li> </ul>

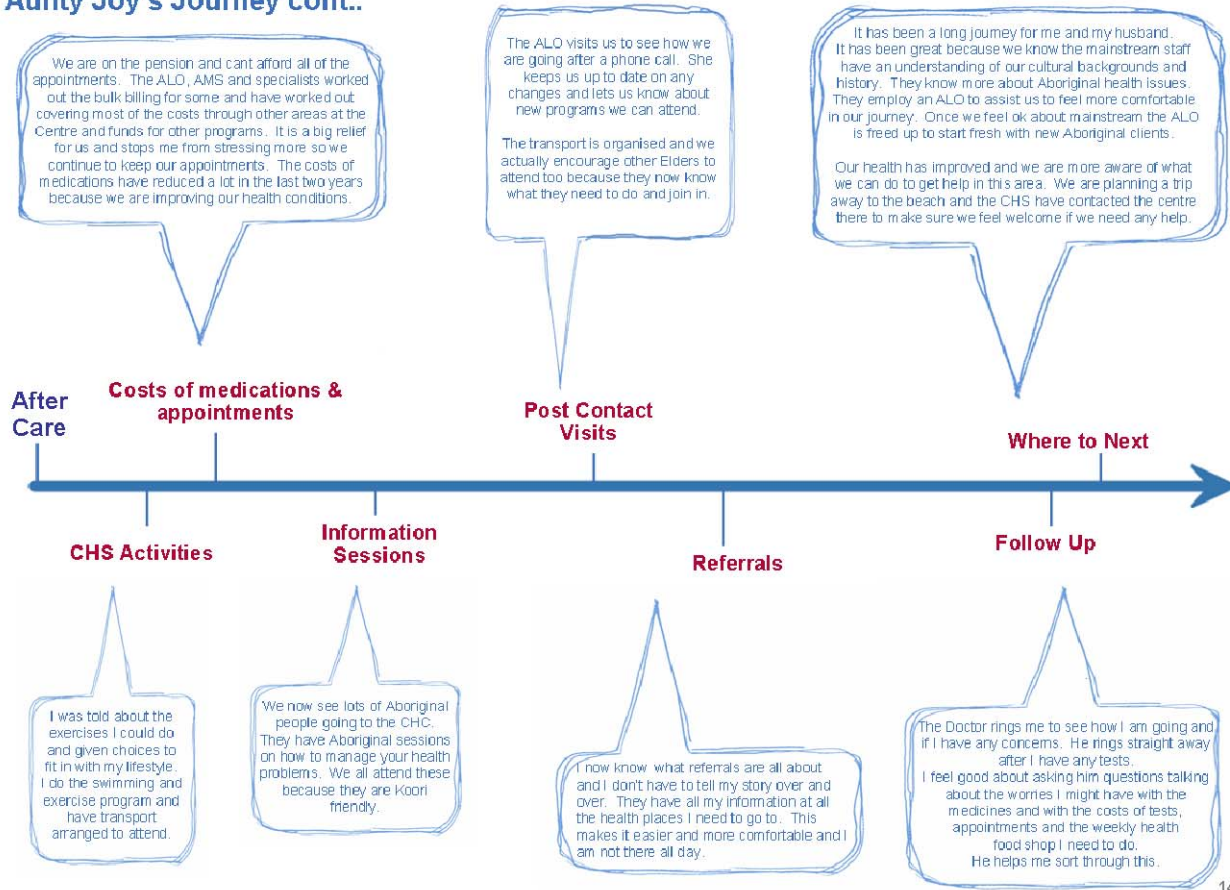
# Appendix F Aunty Joy and Aunty Tilly's journeys

Note: these patient journeys are a compilation of the stories head from patients and their carers and are not one individual's true story.



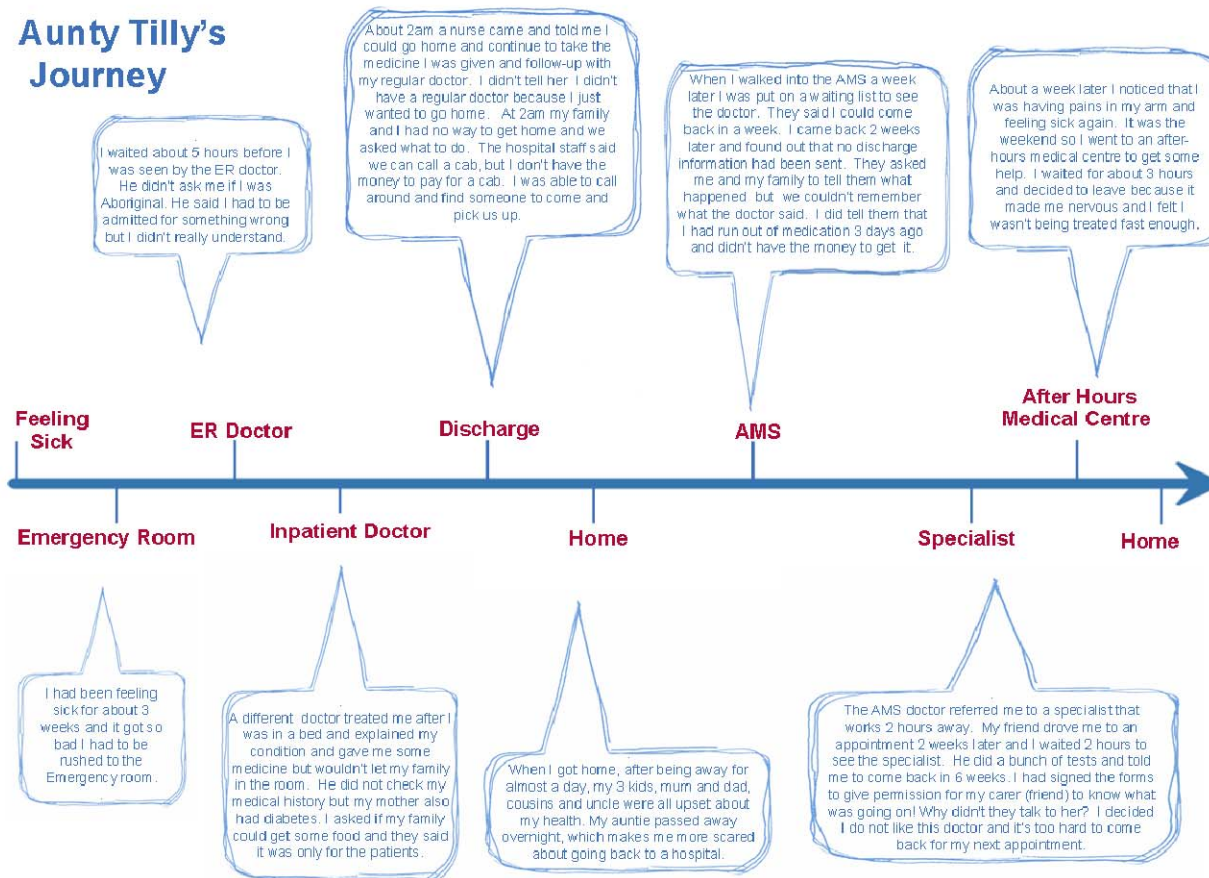
Aunty Joy and Aunty Tilly's journeys

**Aunty Joy's Journey cont..**



Aunty Joy and Aunty Tilly's journeys

### Aunty Tilly's Journey



# Appendix G Patient Assessment of Chronic Illness Care analysis

The Patient Assessment of Chronic Illness Care, (PACIC) is a tool which was developed by an organisation known as Improving Chronic Illness Care (ICIC)<sup>1</sup>. The tool assesses the quality of chronic illness care delivery from the patients' point of view. The PACIC is a brief 20 question survey which the patients self report using a scale rating. The questions measure care in relation to it being patient-centred, proactive, planned and includes collaborative goal setting, problem-solving and follow-up support.

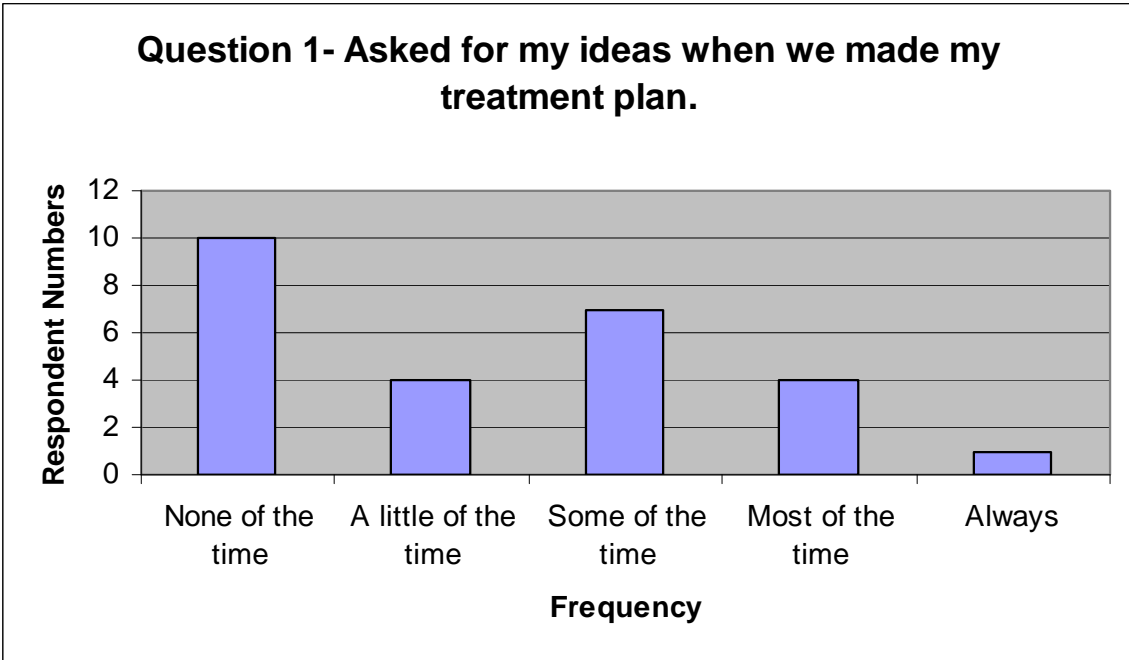
A modified PACIC survey was administered to a number of Aboriginal patients during the diagnostic phase of the Walgan Tilly Project. Twenty- seven responses were collected. Including; twelve responses from the Mini Olympics, two responses from Condobolin, four responses from Casino, six responses from Mt Druitt and three from Justice Health.

The following graphs are the combined results of the responses.

### Question 1

(N=26)

40% of respondents were not involved in making their treatment plans. Only one respondent indicated being always involved.

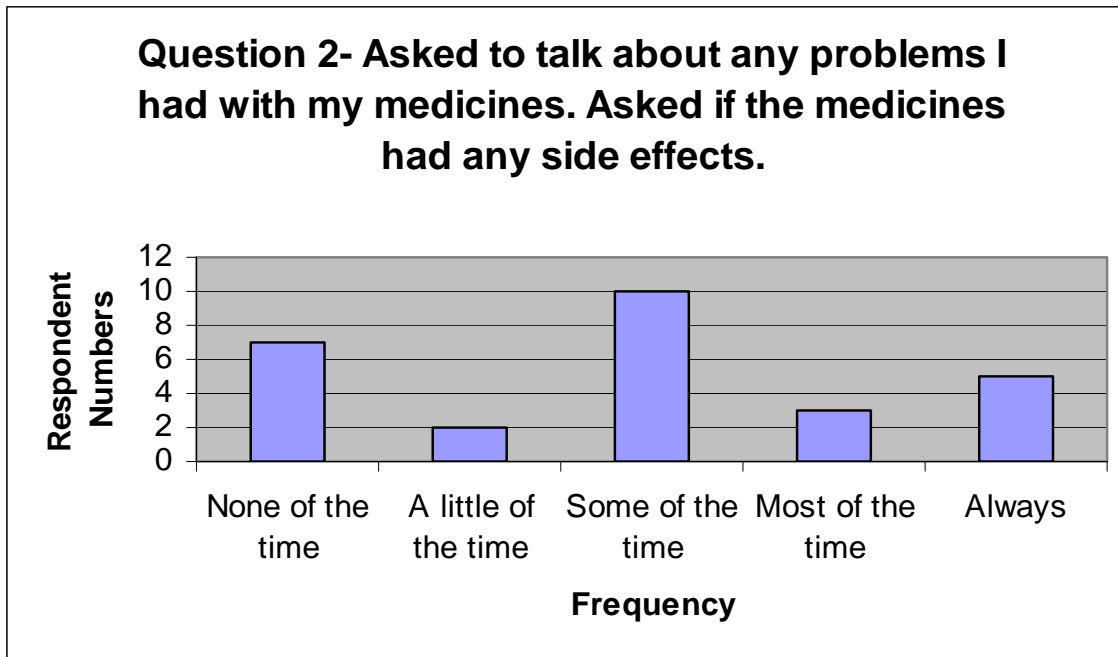


<sup>1</sup> Improving Chronic Illness Care, n.d., <<http://www.improvingchronic care.org>> (8 February 2008)

### Question 2

(N=27)

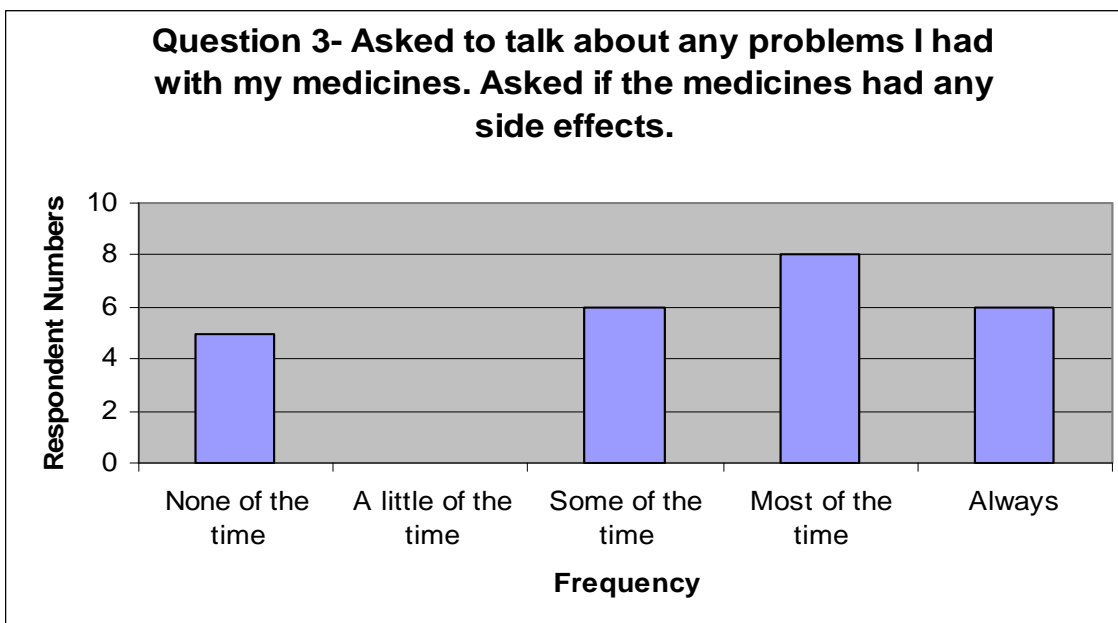
Responses were inconsistent regarding doctors asking about problems with medication, with the most responding some of the time.



### Question 3

(N=25)

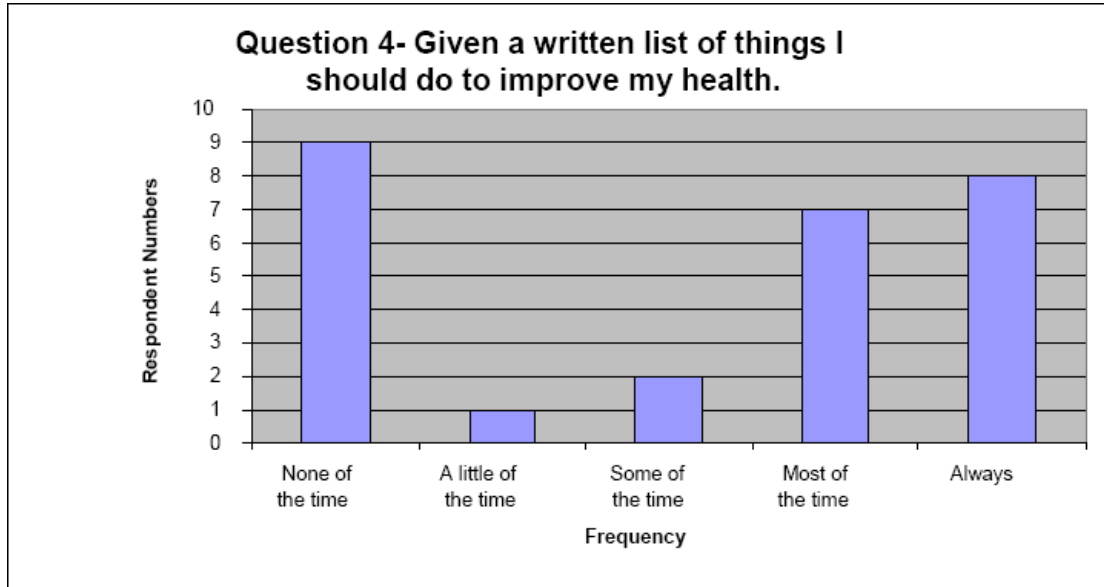
70% of respondents were asked to talk about any problems they had with medicines, including side effects, either some of the time, most of the time or always. 18.5% of respondents were never asked.



**Question 4**

(N=27)

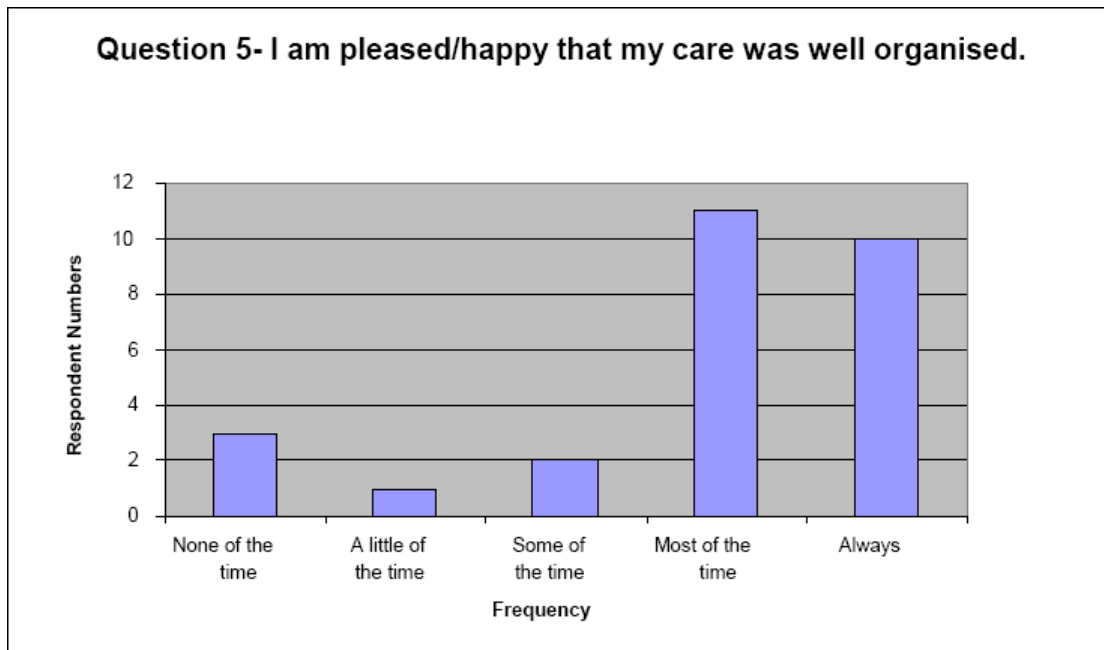
Responses were quite varied regarding patients being given a lists of things to improve their health. Whilst 15 responded most of the time or always, a relatively large number, 9, responded most of the time.



**Question 5**

(N=27)

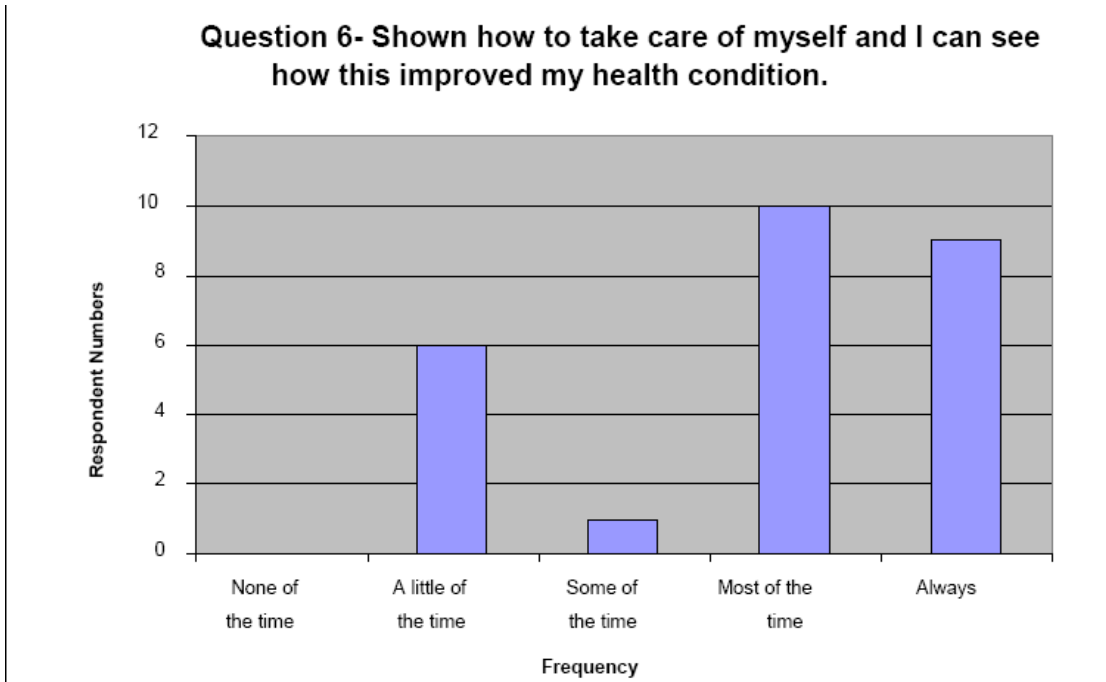
77% of respondents were pleased/ happy that care was well organised always or most of the time.



### Question 6

(N=26)

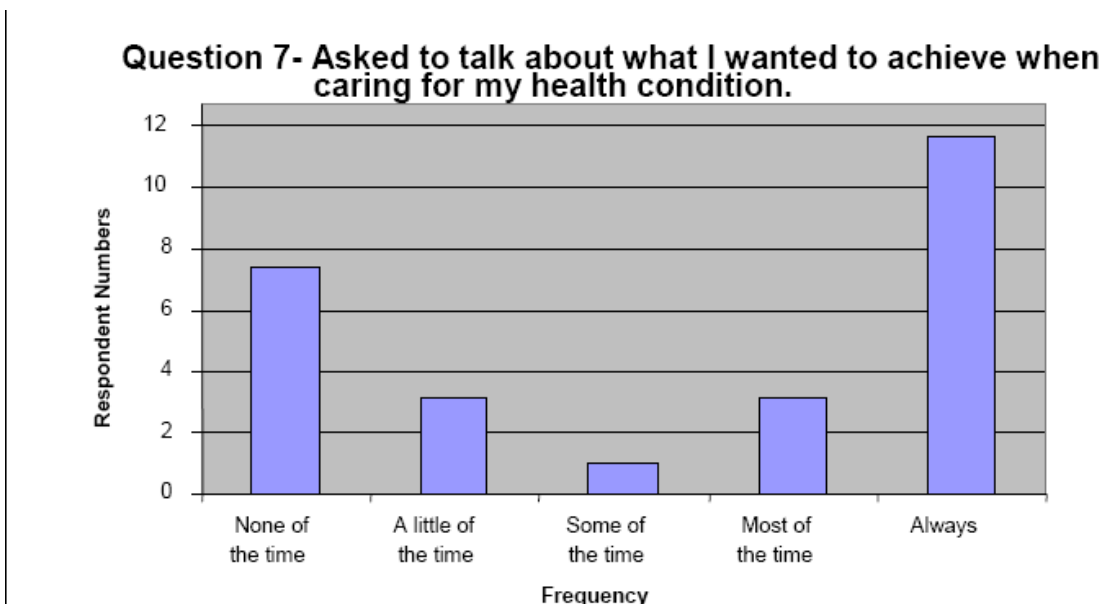
70% of respondents were shown always or most of the time how to take care of themselves and how to improve their health condition.



### Question 7

(N=25)

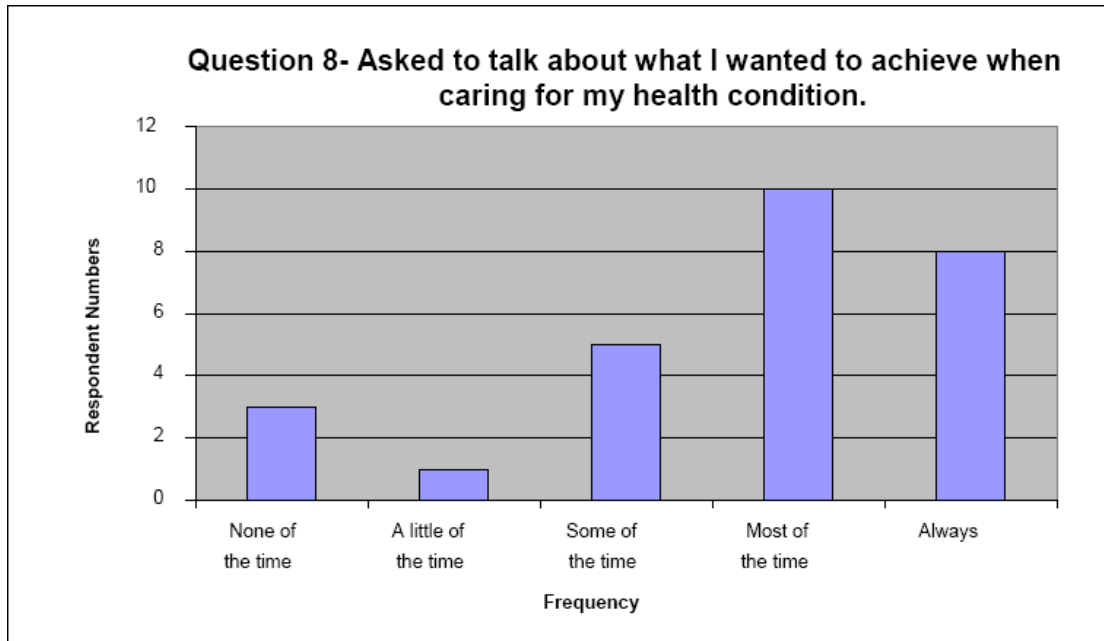
Respondents were split regarding whether they had been asked to talk about what they wanted to achieve when caring for their health situation. 25% of respondents indicated they were never asked, whereas 40% were always asked.



**Question 8**

(N=27)

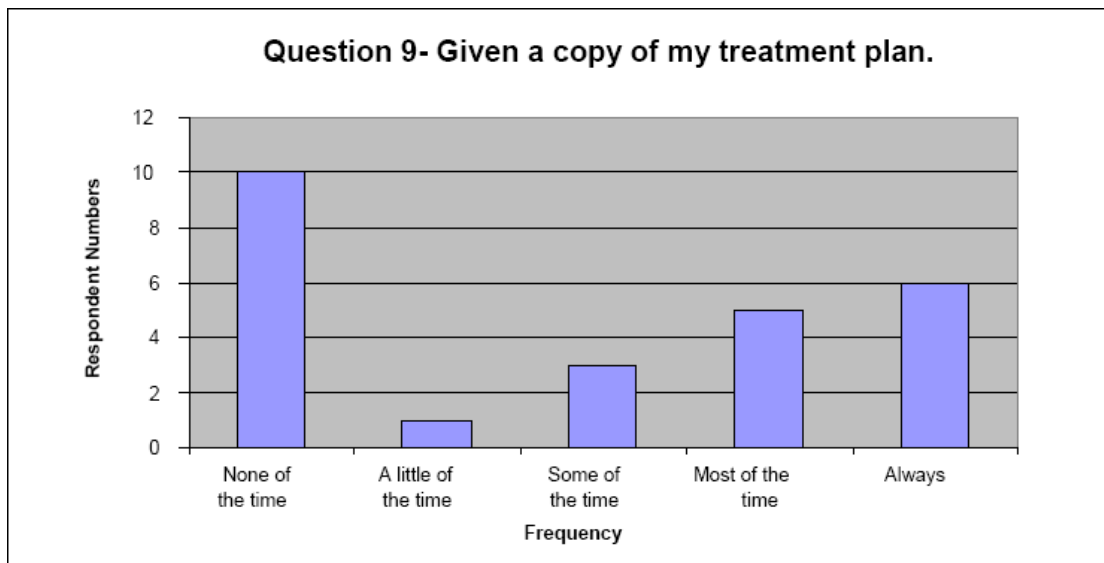
62% of respondents were helped to set specific goals to improve eating or exercise most of the time or always.



**Question 9**

(N=25)

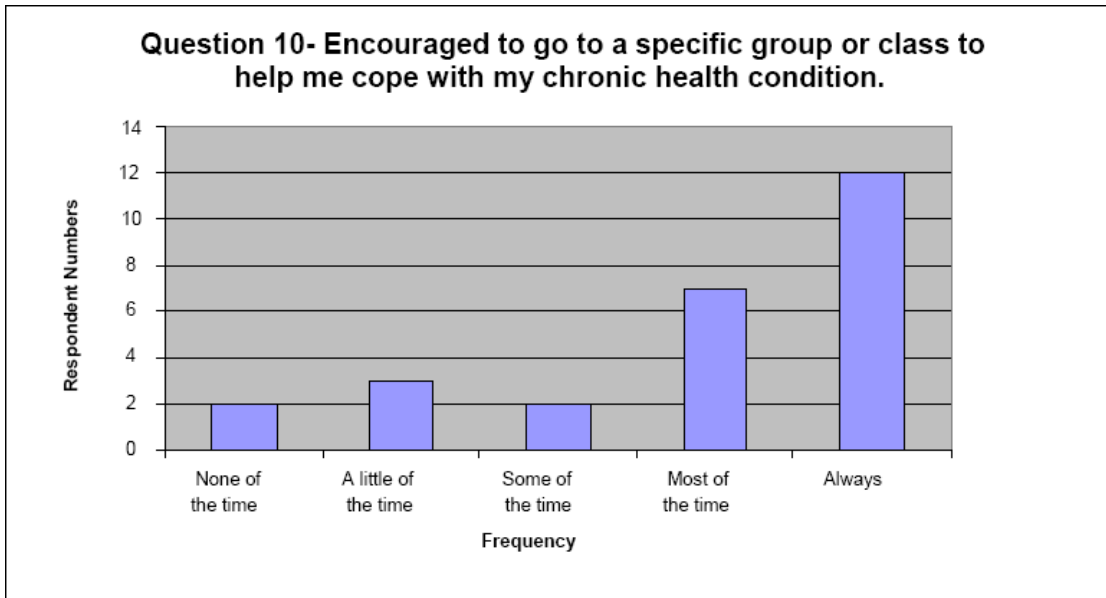
40% of respondents were never provided with a copy of their treatment plan, however 40% of respondents were always or most of the time provided a treatment plan.



### Question 10

(N=26)

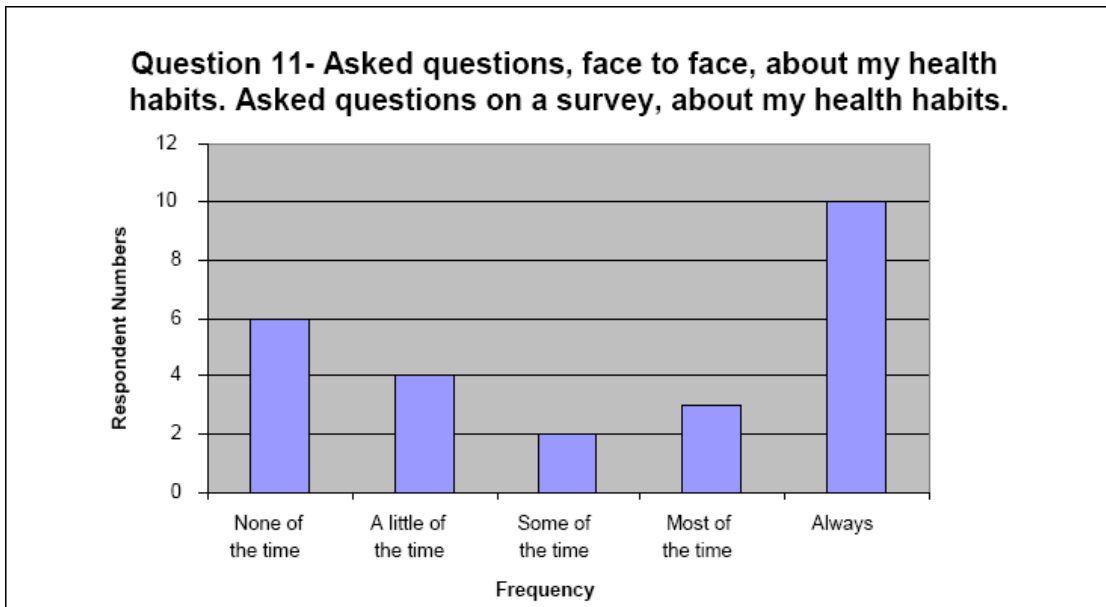
70% of respondents were always or most of the time encouraged to go to a specific group or class to help them cope with their chronic health condition.



### Question 11

(N=25)

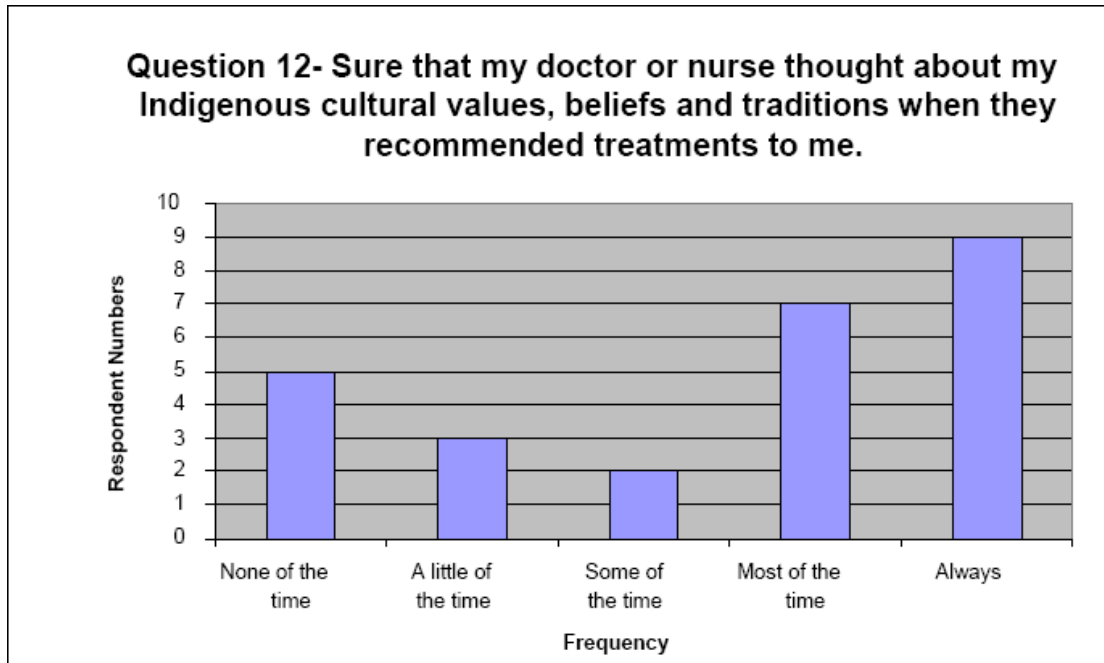
48% of respondents were asked questions face to face regarding health habits and asked questions on a survey regarding their health habits most of the time or always. However 22% of respondents indicated they were never asked.



**Question 12**

(N=26)

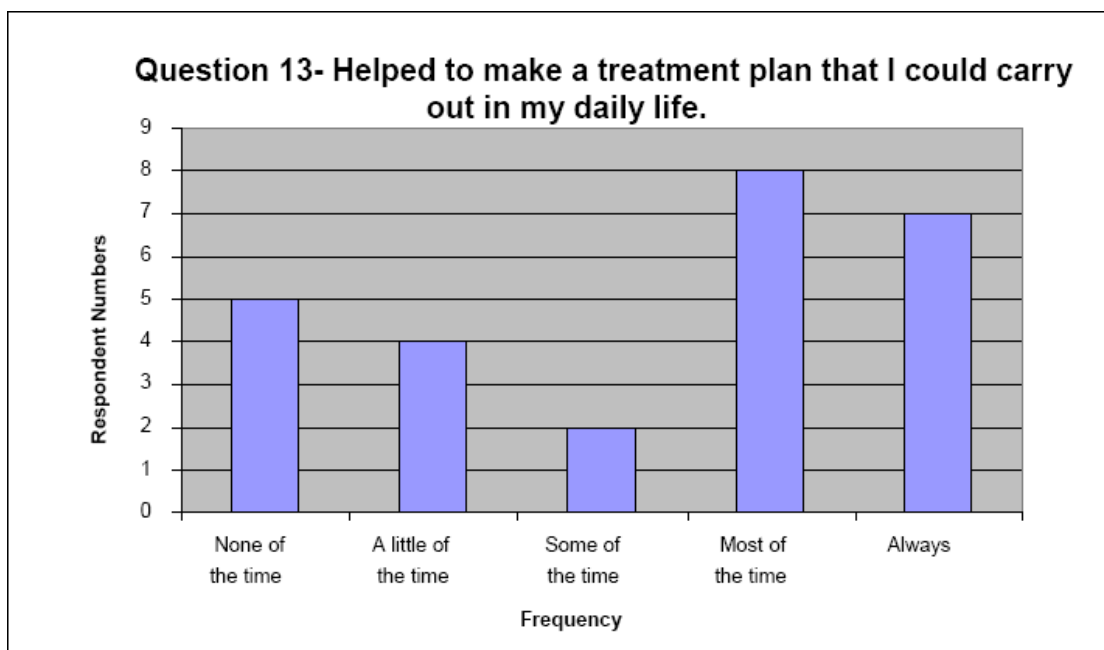
55% of respondents were sure most of the time or always that their doctor or nurse thought about their Aboriginal cultural values, beliefs and traditions when they recommended treatments.



**Question 13**

(N=26)

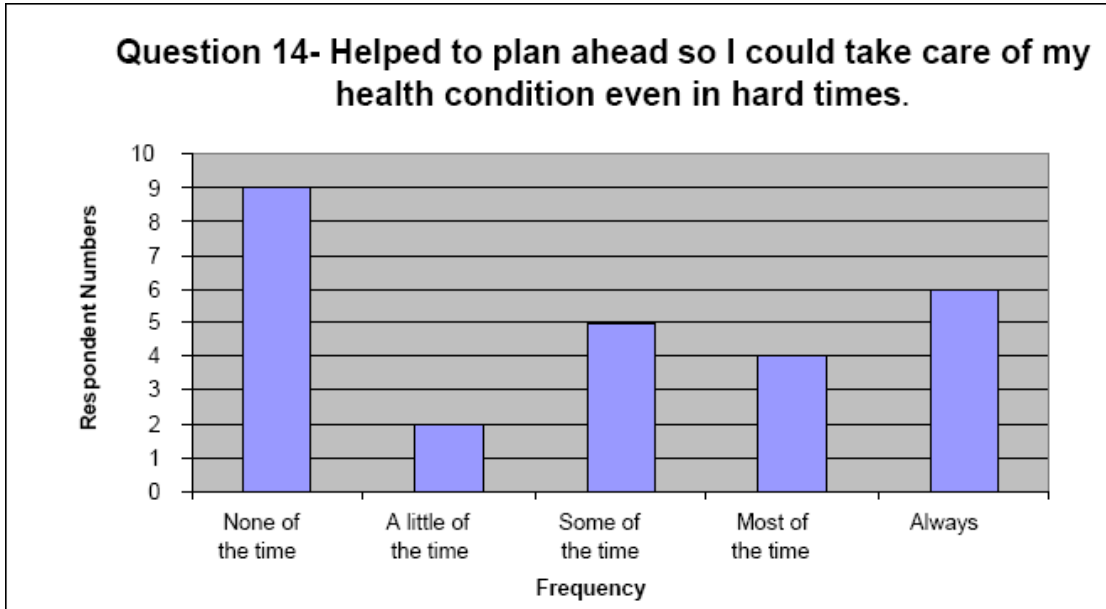
55% of respondents were always or most of the time assisted in making a treatment plan that they could carry out in their daily life.



**Question 14**

(N=26)

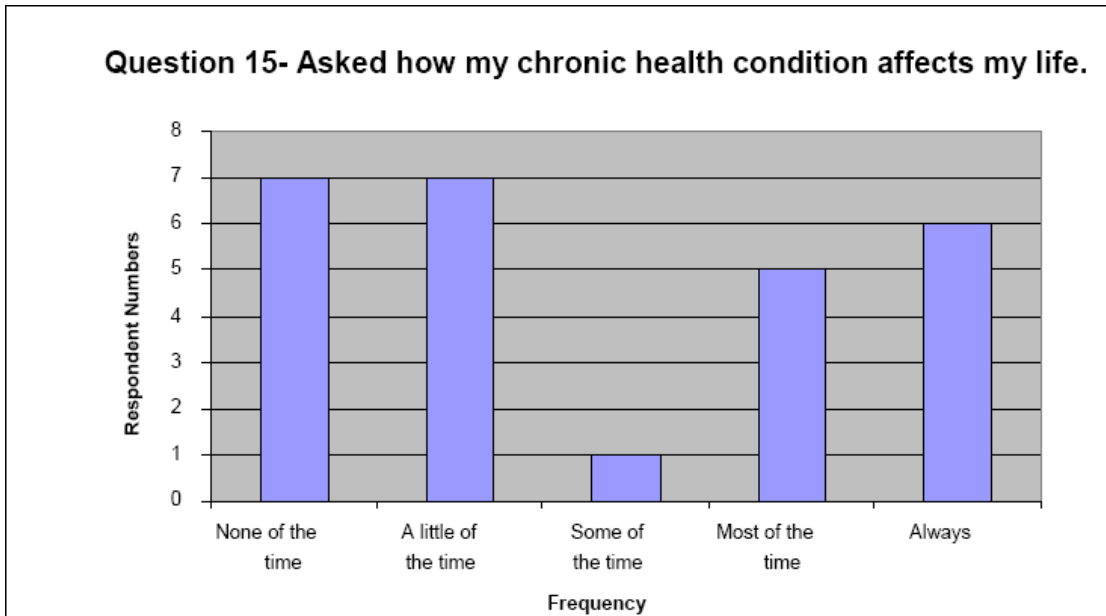
Respondents were split regarding whether they were assisted with planning ahead for difficult times in the future, 33% of respondents were never asked, whereas 37% of respondents were asked most of the time or always.



**Question 15**

(N=26)

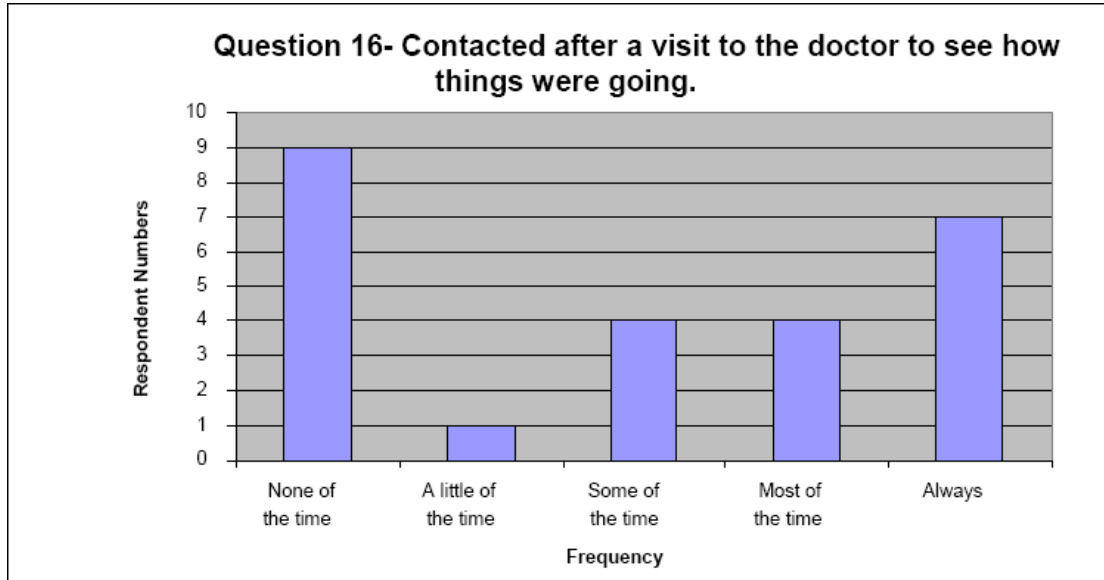
51% of respondents were never or rarely asked how their chronic health conditions impacts on their life.



**Question 16**

(N=25)

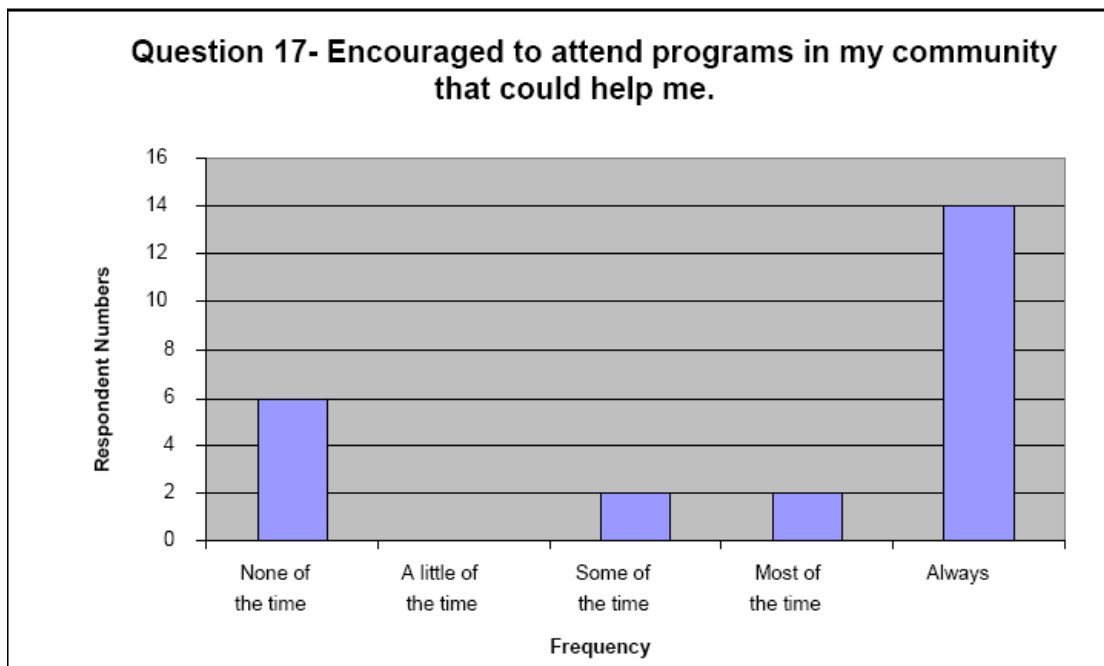
Respondents were split regarding whether their doctor provided follow-up contact after an appointment to check progress. 33% of respondents were never asked, whereas 40% of respondents were asked most of the time or always.



**Question17**

(N=24)

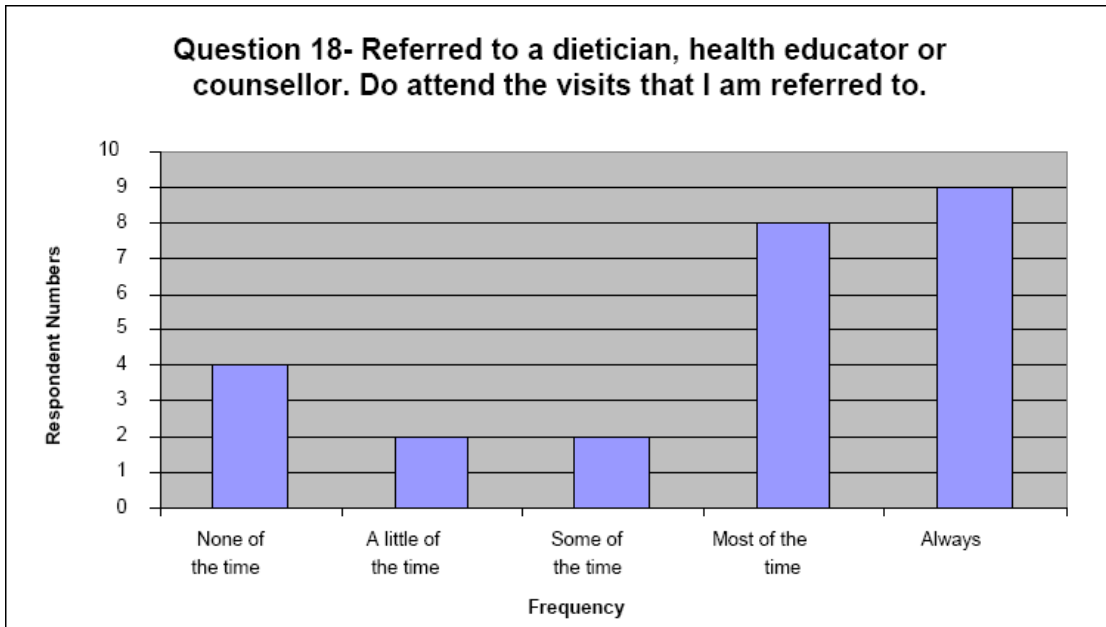
51% of respondents were always encouraged to attend programs in their community.



### Question 18

(N=25)

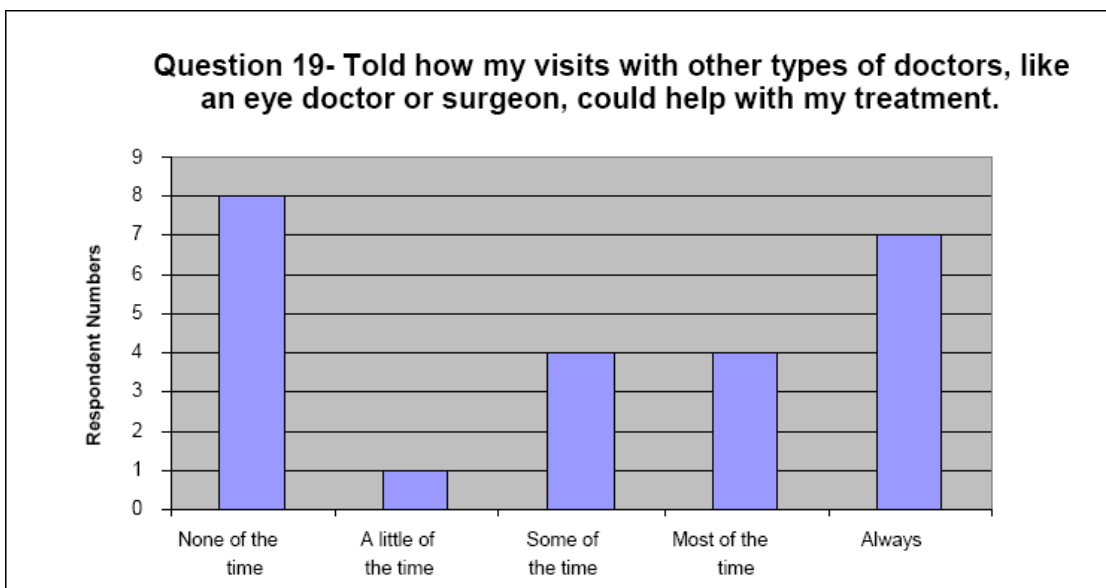
62% of respondents were referred to a dietician, health educator or counsellor attended their visits most of the time or always.



### Question 19

(N=24)

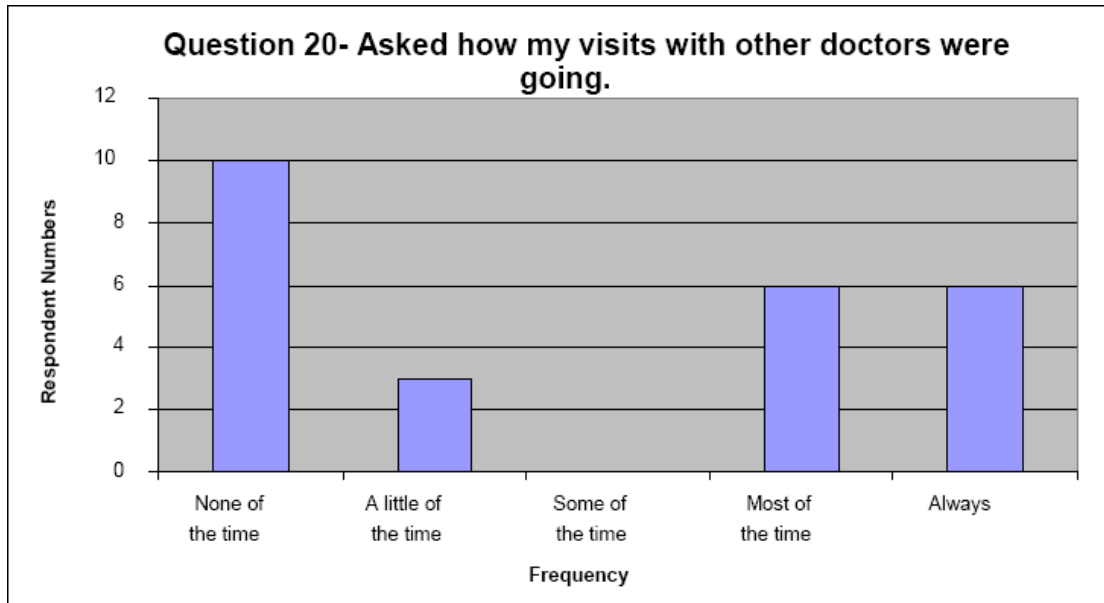
Respondents were split regarding whether their doctor informed them of other specialists who could assist with their treatment, 29% of respondents were asked never, whereas 40% of respondents were asked most of the time or always.



### Question 20

(N=25)

Respondents were split regarding whether their doctor asked how visits to other doctors were going, 37% were asked never, whereas 40% of respondents were asked most of the time or always.

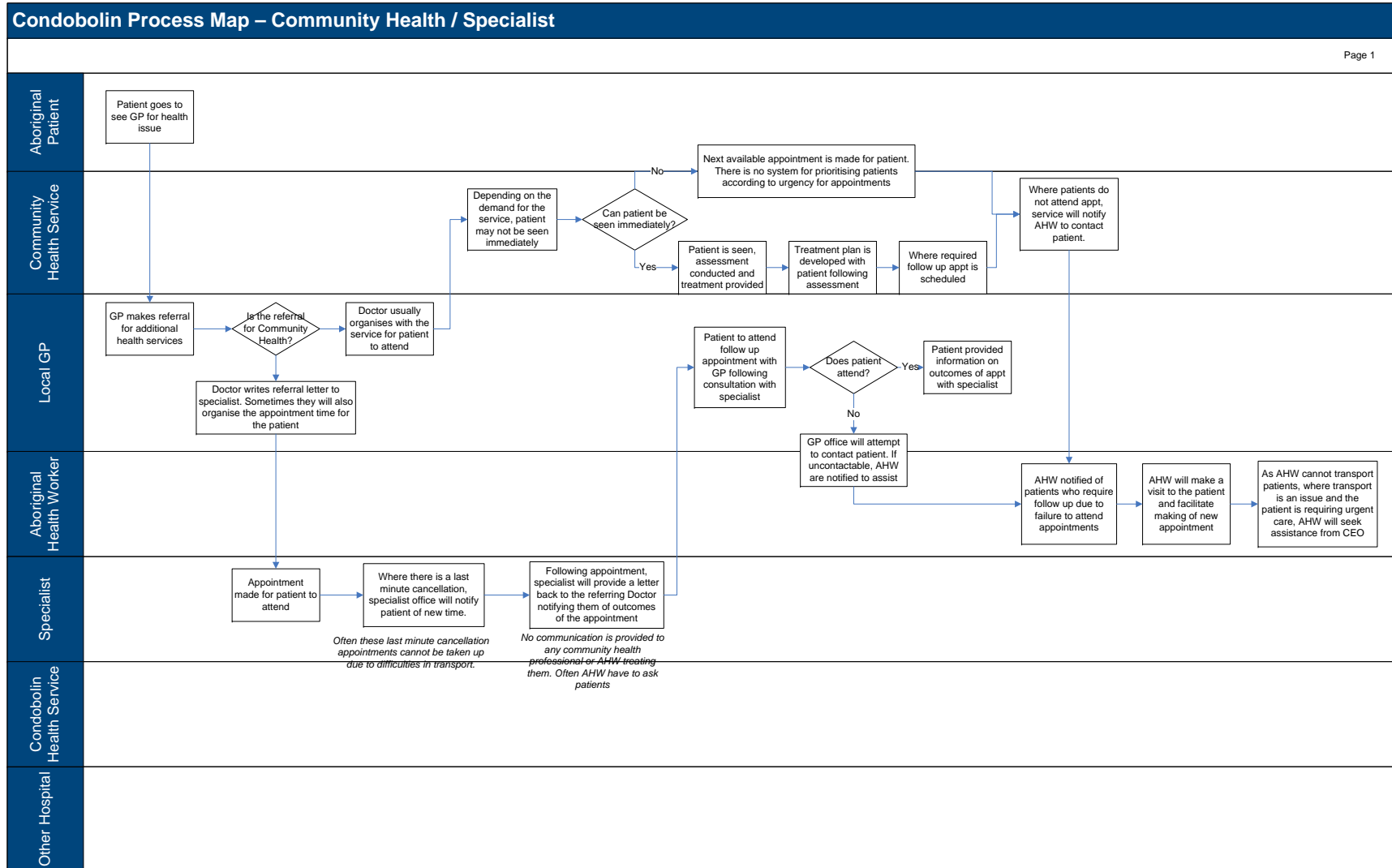


Overall questions where the majority of respondents scored relatively low ie none of the time, a little of the time or some of the time were-

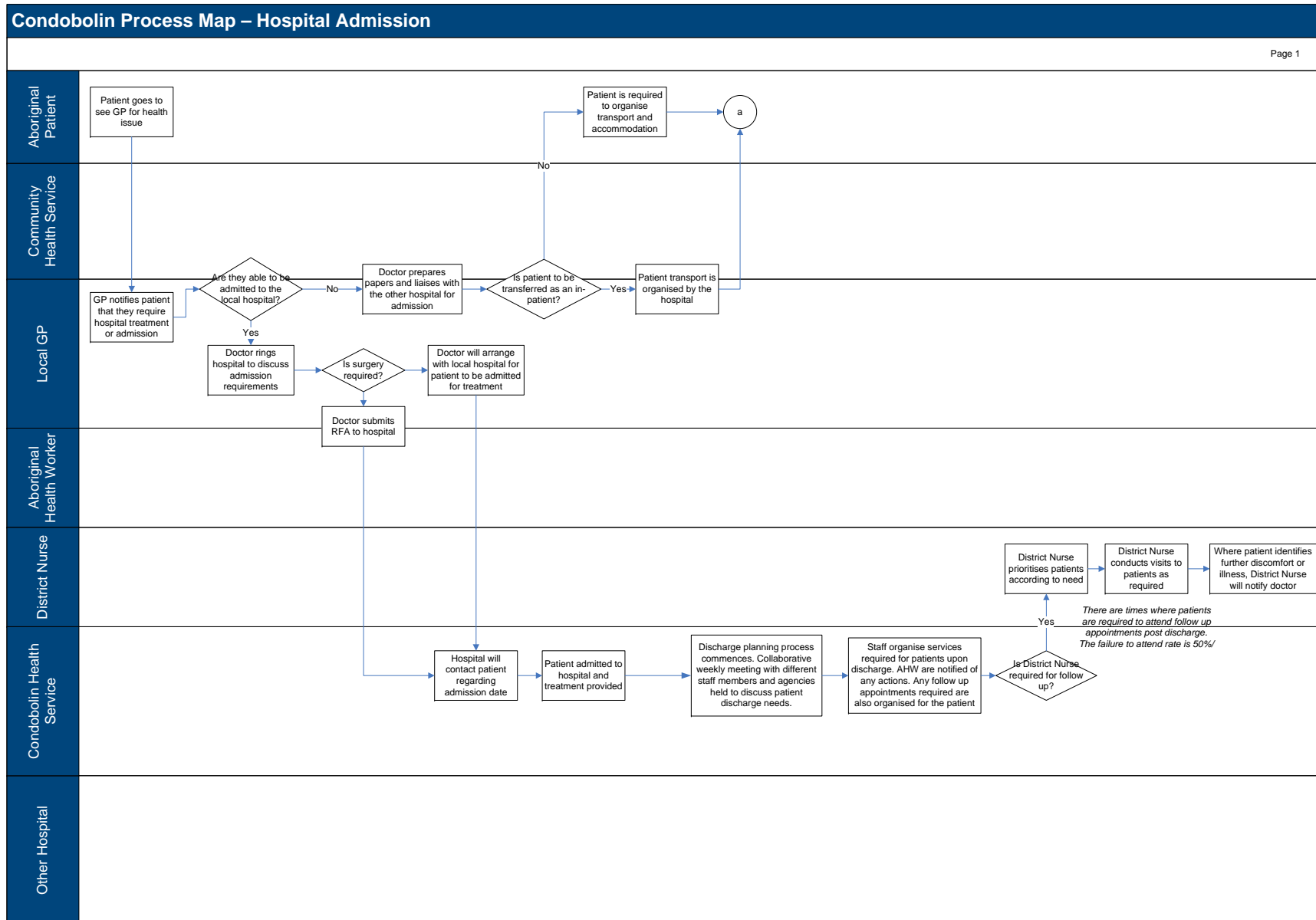
- Question 1- Asked for my ideas when we made my treatment plan.
- Question 2- Given choices about the types of treatment I could think about.
- Question 9- Given a copy of my treatment plan.
- Question 14- Helped to plan ahead so I could take care of my health condition even in hard times.
- Question 15- Asked how my chronic health condition affects my life.
- Question 17- Contacted after a visit to the doctor to see how things were going.

## Appendix H Process maps and issues identified

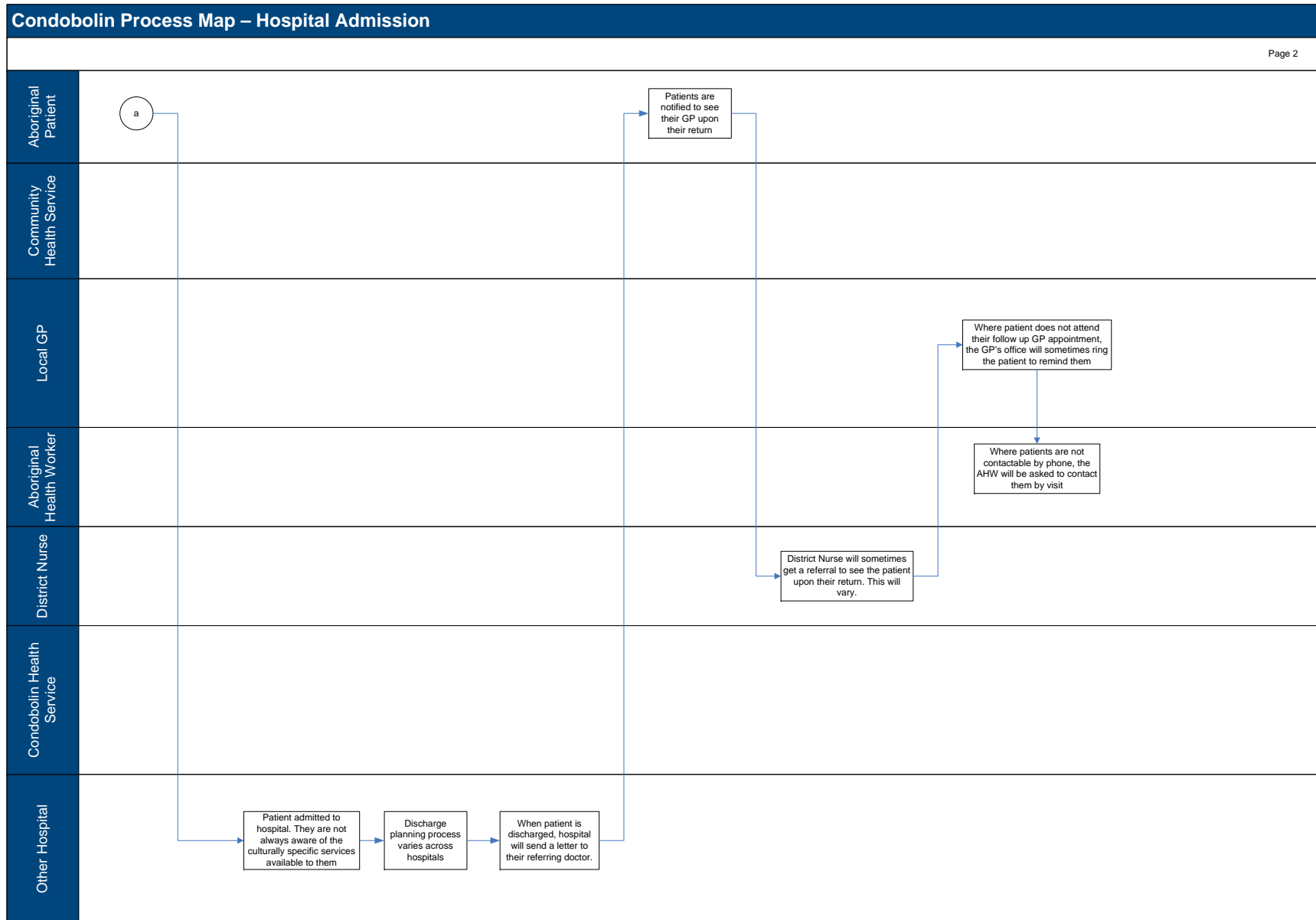
**GWAHS**



Process maps and issues identified

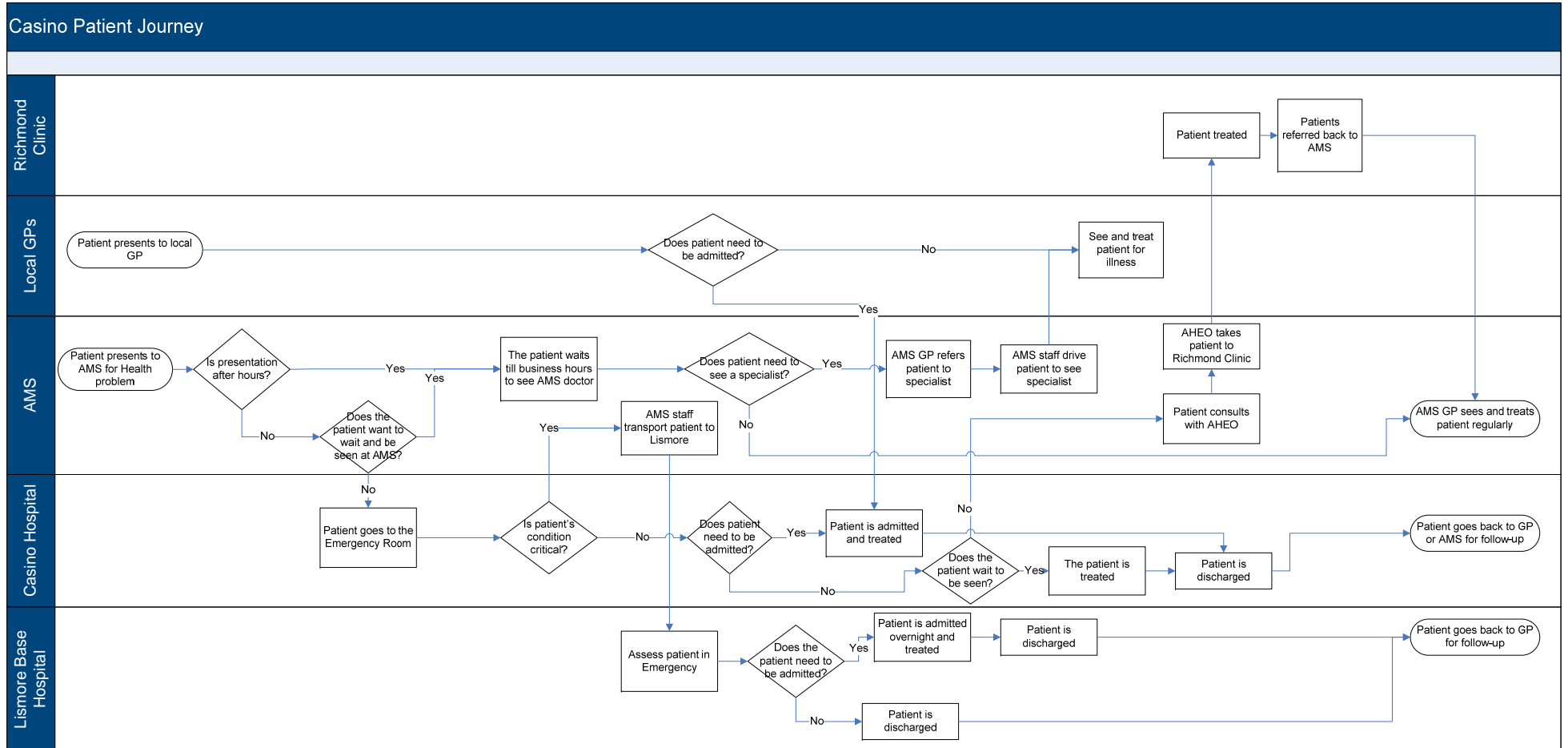


Process maps and issues identified

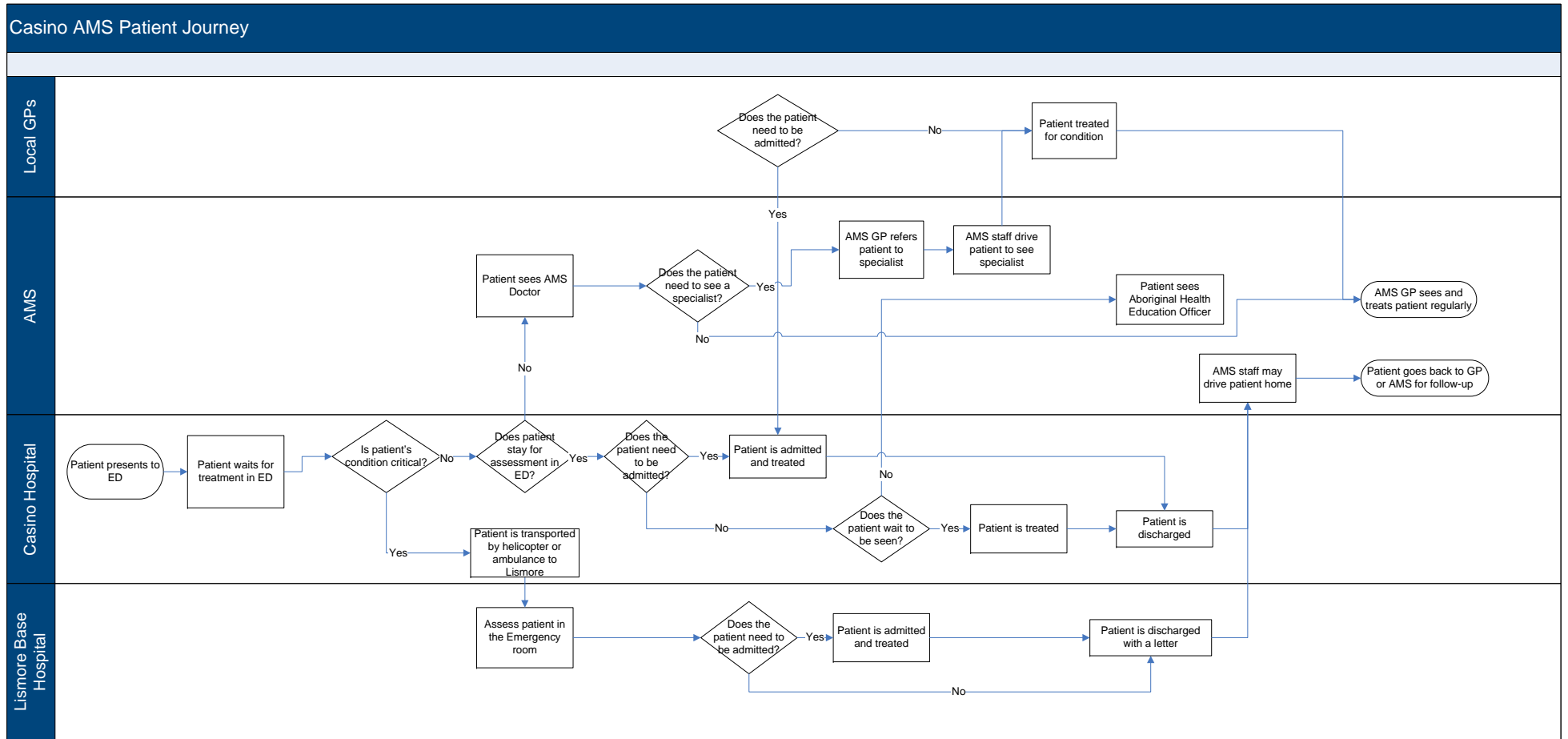


Process maps and issues identified

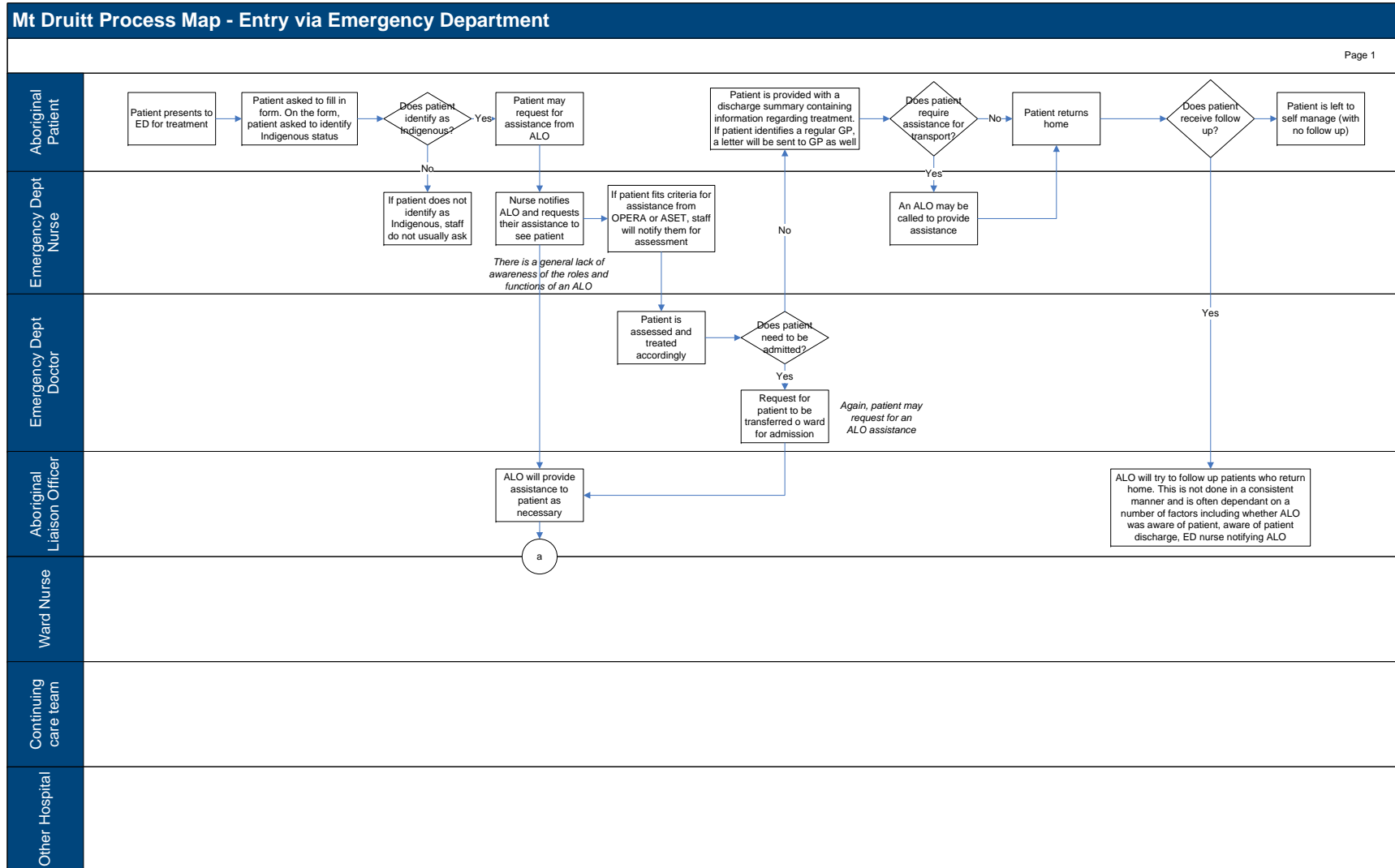
NCAHS



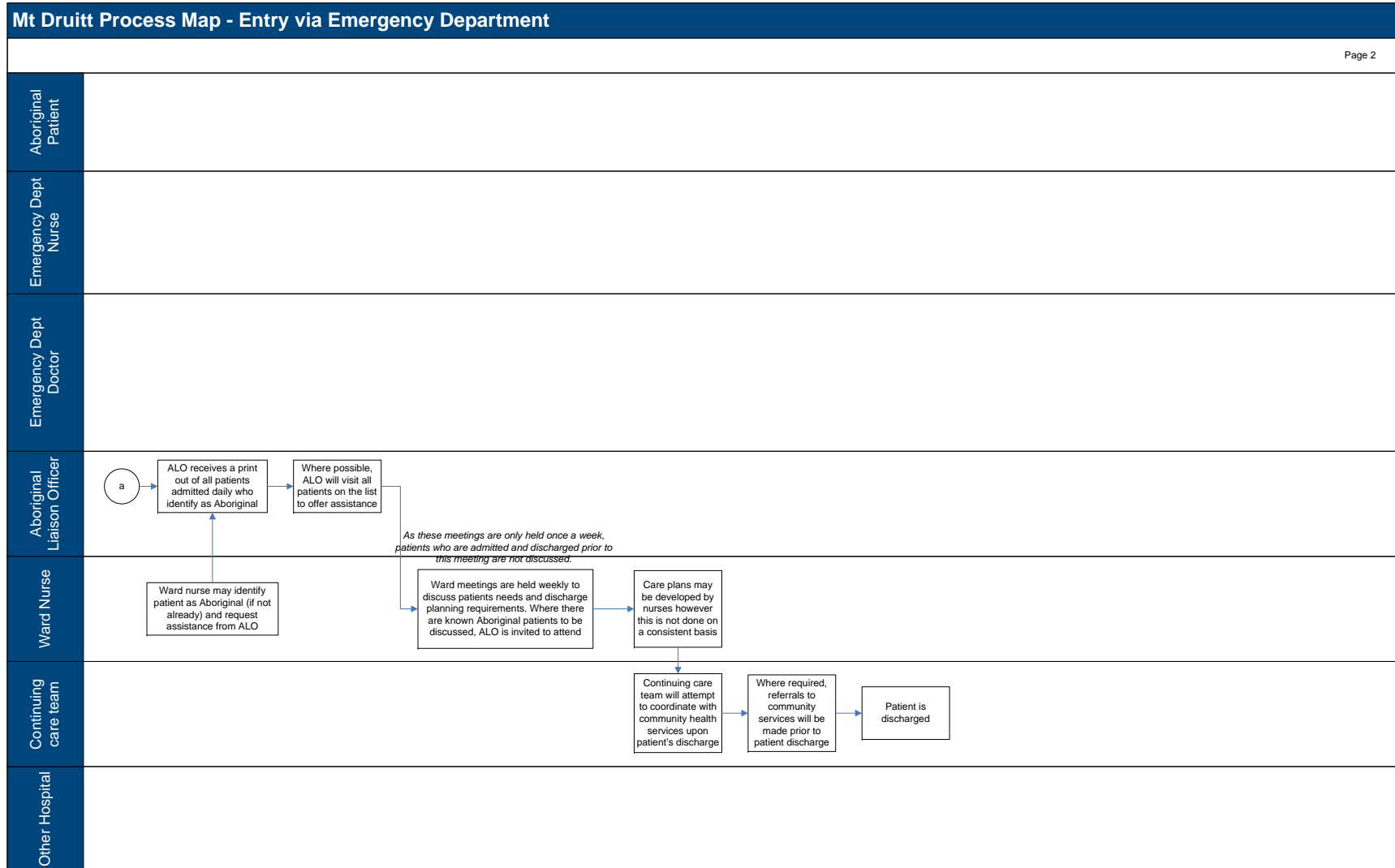
Process maps and issues identified



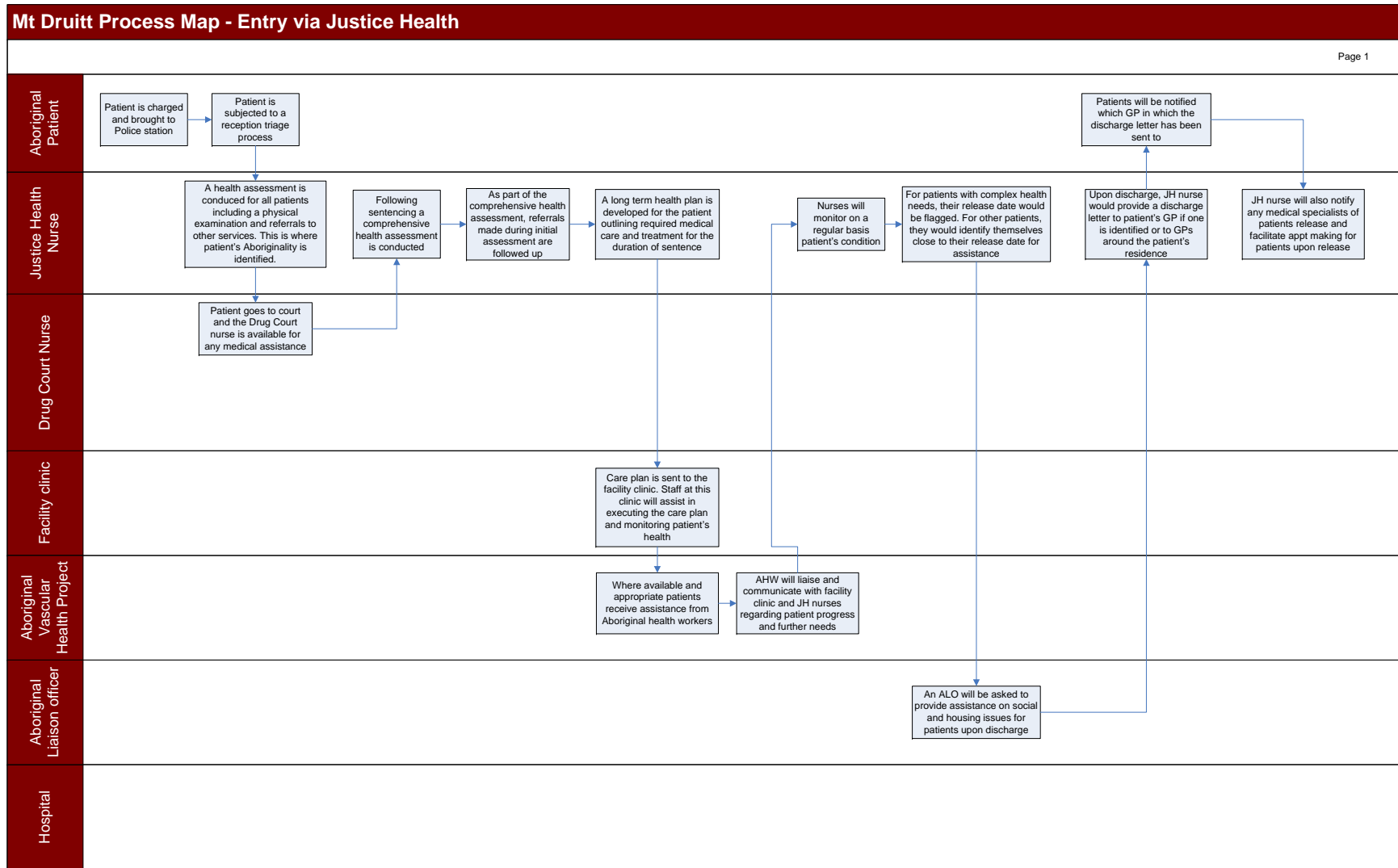
SWAHS



Process maps and issues identified



Process maps and issues identified



**Key issues raised during Process Mapping Sessions**

Key Issues	Issue details
Insufficient information provision	<p>There is insufficient information available to the health service staff and community members on the different types of programs and services available, including Aboriginal specific programs and services.</p> <p>There is also insufficient information available on program eligibility and assessment criteria along with application processes for entry into services.</p> <p>There is insufficient information and education available for patients on the various diseases, risks and disease progression. This has an impact on the patient's awareness of their own condition and serves as a barrier for them to effectively manage their condition when they don't have sufficient information.</p>
Aboriginality of patients often not recorded or identified	<p>Health Service staff often do not ask patients if they are Aboriginal.</p> <p>Even where Aboriginality is known, this is often not recorded in patient records</p>
Lack of standard follow-up procedures following discharge from hospital	<p>There are no standard procedures in place which enable follow-up of patients following discharge from hospital which has an impact on the patient's continuity of care.</p>
Poor communication and handover between Aboriginal Health Staff and other health staff	<p>Often when a patient is identified as Aboriginal, they receive services from an Aboriginal Health Worker. In these cases, there is often poor handover and communication of patient information from the health service to the Aboriginal Health Worker, which impacts on patient care and continuity of care.</p>
Insufficient Aboriginal Health Workers to meet demand	<p>There is currently insufficient numbers of Aboriginal Health Workers available in hospitals and the community to meet demand. As a result, Aboriginal patients may miss out on the services of an Aboriginal Health Worker which has an impact on their health care. In addition, existing Aboriginal Health Workers are often over worked and are likely to suffer high rates of burn out, resulting in high turnover.</p>
Lack of cultural awareness by non-Aboriginal health service staff	<p>There is a general lack of cultural awareness of the Aboriginal culture along with their beliefs and attitudes towards health care by non-Aboriginal staff. This is sometimes due to the lack of education programs available to staff and that these programs when conducted are often tokenistic or not mandatory.</p>
Poor communication across various health services (hospitals/ community/ General Practitioners)	<p>Poor communication across the different types of health services and health professionals has been identified as an issue as it impacts on patient's continuity of care, particularly when they have multiple co-morbidities that require careful management and coordination</p>
General Practitioners	<p>Not all patients have General Practitioners to assist in managing their conditions. This impacts on their continuity of care, particularly following an acute episode and may result in further deterioration of the condition.</p>

Key Issues	Issue details
Geographical issues	Often those living in rural and remote areas do not have sufficient access to specialist medical services. Transport is often a barrier for those wanting to access services in other areas. This impacts on patients who as a result, often do not attend medical appointments or other programs
Insufficient services available after hours and in the community	There are insufficient services available to patients after hours for support and crisis situations. In addition, there are insufficient health staff available to conduct health services in the community. These services are particularly valuable for patients who often do not attend appointments in hospitals or for those who are unable to travel
Transport	Transport is a significant issue and a barrier for those living in rural and remote communities. Patients are often unable to attend appointments or services due to transport barriers. This particularly affects patients who are required to travel to other towns or cities for surgery or specialist appointments
Financial issues	Along with transport issues, affordability of medical services is also a major issue and barrier of access. This impacts on patients who are unable to financially afford specialist care (where they do not bulk bill), cost of accommodation and travel (where they are required to travel to another town for care) or in some cases, even medications required for their conditions.
Long service waiting lists	Long service waiting lists are common, particularly for more specialised medical services. This means that patients' conditions may deteriorate in the interim and reduce attendance rates at appointments if it scheduled too far in advance.

## Appendix I Stakeholder interview analysis

Theme	Issues	Quote
1. Care Provision: a) Referral	<ul style="list-style-type: none"> <li>Aboriginal people not being provided referrals.</li> <li>Hospitals not effectively referring Aboriginal people to community care. This was demonstrated by community health services often not knowing if people had been discharged from hospital.</li> </ul>	“Elder went through program and then became a referral source to the program”.
1. Care Provision: b) Identification of Aboriginality	<ul style="list-style-type: none"> <li>Inconsistent approach to identifying Aboriginality.</li> <li>General Practitioners assuming identification of Aboriginality.</li> <li>General Practitioners not understanding the importance of identifying Aboriginality in the patient journey.</li> <li>General Practitioners believing identifying Aboriginality is a bureaucratic necessity rather than patient care related.</li> <li>Perception that it is racist to ask people to identify Aboriginality.</li> </ul>	<p>“A major issue is the recording of Aboriginal status, some health workers do not feel comfortable asking, and therefore data is variable”.</p> <p>“We do have the younger generation marrying in with South Sea Islanders. We also have Aboriginal patient lists that have names listed that are obviously people from other cultural backgrounds but we have to visit all names on the list just to confirm. It can be very embarrassing if we meet the patient and they are not Aboriginal and then we have to explain why we are there and then apologise for the mistake made”.</p>
1. Care Provision: c) Screening/Discharge planning/Clinical pathways	<ul style="list-style-type: none"> <li>Lack of follow-up after hospital discharge for Aboriginal patients. It was mentioned that discharge planning was “often talked about” however issues around continuity of care due to nurses rosters meant this often did not happen.</li> <li>Aboriginal health workers not being informed about Aboriginal people being discharged.</li> <li>In some area health services ALO’s have indicated that they would like more involvement in the hospital discharge process for Aboriginal patients, to ensure Aboriginal patients understand their care plans and how to manage their conditions outside hospital.</li> <li>Discharge information not being documented and effectively disseminated.</li> <li>A lack of effective and efficient call back systems was noted. Focus on the hospitalisation period and not on discharge.</li> <li>Aboriginal people can be hard to follow-up as they don’t keep appointments.</li> <li>Even if Aboriginal people are provided a follow-up call, this is not always effective because they might not be at home.</li> <li>Aboriginal patients don’t modify risk factors or comply with medication</li> </ul>	<p>“People are discharged without understanding what to do”.</p> <p>“People present too late to Emergency Department”.</p> <p>“Discharge planning and coordination of care is not well organised or undertaken for ease of patient understanding”.</p> <p>“Whilst it would help if community health supported GPs and undertook assessments and care plans. This would effectively be cost shifting-ie, the state is paying for the community health staff who are doing the primary care delivery. Suggested that for the area health service to expand community health could be fiscally suicidal. Suggested needed to develop a network of GPs”.</p> <p>“Specific Aboriginal programs have better attendance however it is difficult to get Aboriginal people to comply with self management and longer term health planning”.</p> <p>“Compliance with health requirements is also difficult. For example, compliance with medication, services and even with things learned at education programs eg healthy eating and cooking. It is difficult to get the message across and many people may attend programs but do not put what they learn into practice”.</p>

Stakeholder interview analysis

Theme	Issues	Quote
	<p>regimes. This leads to much higher rates of re-presentation for Aboriginal people in hospitals.</p> <ul style="list-style-type: none"> <li>• It is unclear whether Aboriginal people understand the consequence of failing to follow-up. It leads to huge responsibilities for families, as family responsibilities take precedence over own health.</li> <li>• Aboriginal people don't feel comfortable unless there is an Aboriginal person involved-they don't understand the medical jargon. Therefore Aboriginal people don't get the key messages and information that they need to manage their conditions.</li> </ul>	
<p>Care Provision: d)Justice Health</p>	<ul style="list-style-type: none"> <li>• Staff shortages.</li> <li>• Aboriginal people require escorts to accompany them when they attend medical appointments.</li> <li>• Cultural issues- Aboriginal people are shy and private in regards to their health.</li> <li>• Aboriginal prisoners were not provided education regarding chronic care, and chronic care initiatives.</li> <li>• Poor relationships with AMSs and the need to increase engagement with AMSs.</li> <li>• It was mentioned that staff culture needed to shift to become more proactive in the care of clients, to liaise better with the Aboriginal workers, and to instil a culture where everyone is responsible for the care of the clients.</li> <li>• Discharge letters are often produced after the client has left jail due to internal communication and short incarceration periods.</li> </ul>	<p>"The prisons don't have enough doctors and there isn't a specific doctor for Aboriginal prisoners. Many Aboriginal women in prisons will not openly discuss their health problems to a prison doctor or nurse as they don't think this is culturally appropriate and are often embarrassed".</p> <p>"Women's health is particularly difficult as the women are very suspicious of the care providers and often have a "don't care" attitude".</p> <p>"Aboriginal health workers can not be expected to be o top of all health conditions, and require clinical support".</p> <p>"Services provided must be culturally appropriate".</p>
<p>2. Cultural Awareness a) Aboriginal culture</p>	<ul style="list-style-type: none"> <li>• Fear associated with accessing mainstream services due to historical issues, lack of respect and racism.</li> <li>• Aboriginal people live in many communities' and what works for one community won't necessarily work for other communities'.</li> <li>• Perceived racism and prejudice. This is not overt and usually confined to the older generations.</li> <li>• Aboriginal people are private. particularly the women who may not want to disclose.</li> <li>• Spirituality is not respected in the provision of care.</li> <li>• Hospitals are not culturally appropriate and welcoming for Aboriginal people.</li> </ul>	<p>"The AMS advises many of its Aboriginal clients if they need to be referred to a health specialist that they sometimes have to wait up to 2 months for an appointment. Many Aboriginal clients don't wait and move on with their lives and their health continues to deteriorate".</p> <p>"A lot of Aboriginal people think it's the end of the road if they are told they have to go on dialysis. We also encourage them to get to their medical specialist appointments so that their health conditions can be explained to them in more detail".</p> <p>"The older Aboriginal generation has often left their chronic health care last and will often miss scheduled appointments, not take their pills or have health checks because they are meeting the needs of their grand children</p>

Stakeholder interview analysis

Theme	Issues	Quote
	<ul style="list-style-type: none"> <li>• There is a perception amongst Aboriginal people that you only come to hospital to die and Aboriginal people often have fear related to dying.</li> <li>• The “grapevine” and confidentiality is a problem. Sometimes people at the AMS know the patients family which creates concerns for the patient around confidentiality.</li> <li>• Aboriginal people often do not attend if appointments are organised, this can be because their priorities change over the time period while they are meeting for their appointment.</li> <li>• A lack of participation in rehabilitation programs.</li> </ul>	<p>and other family members”.</p> <p>“Our people’s fear and perception has come from people not coming home when they go into a hospital-they come out in a box. This is so strong because Aboriginal services didn’t eventuate until the 1970’s. There is a big reluctance to go back into the system again because of the past effects of removal and negative health system experiences”.</p> <p>“Aboriginal people have perceptions of- “having lived a good innings” when compared to non- Aboriginal patients are still quite young”.</p> <p>“Older generation don’t speak about their health problems”.</p> <p>“Culturally appropriate resources also need to be more accessible and available”.</p> <p>“Aboriginal people need more time- don’t push them through the system”.</p> <p>“Building trust with Aboriginal people is often difficult and slow”.</p> <p>“We have really sick Aboriginal people rock up at the AMS who have been sick all weekend but they wait until the AMS is open on the Monday and the should have taken themselves to the hospital over the weekend”.</p> <p>“There are some surgeries where no Aboriginal people go- others where lots went- had a look at why that was the case and found that it really depended on family and friends- Aboriginal people tended to go as a group outing and word of mouth important- no differences in way practices operated eg all bulk billing- and similar load on doctors so no differences in waiting lists”.</p> <p>“Aboriginal people do not like to, and will not wait”.</p> <p>“Participation in programs is always better on off pension week”.</p>
<p>2. Cultural Awareness</p> <p>b) mainstream providers</p>	<ul style="list-style-type: none"> <li>• Mainstream health workers need cultural awareness training.</li> <li>• Mainstream service providers need to become culturally appropriate and welcoming. Services need to build trust and rapport with Aboriginal people.</li> <li>• Cultural awareness needs to be built up so that every policy and procedure embraces and integrates culturally sensitive practices. This needs to come from the top down.</li> <li>• Aboriginal people are often labelled ‘non-compliant’ this is due to a lack of engagement and follow-up because services are not culturally appropriate.</li> </ul>	<p>“The AMS has provided opportunities for non-Aboriginal people to come and work at the AMS to gain knowledge and understanding about Aboriginal culture, families and health issues. Some workers attitudes have changed completely due to this work experience. Lots of registrars, GP’s and medical students come into the AMS and are very fearful at first. The key is to work in partnership to break down the barriers”.</p>

## Stakeholder interview analysis

Theme	Issues	Quote
	<ul style="list-style-type: none"> <li>Aboriginal people have fears around racism when accessing mainstream services.</li> <li>Aboriginal health is not just the responsibility of AMSs, it should be a concern of all service providers.</li> <li>University curriculums (health courses) should have more focus on Aboriginal health.</li> <li>Aboriginal people fear accessing mainstream services because it may lead to the potential death of AMS.</li> <li>It is not always easy to engage Aboriginal services to build links due to enormous protocols, bureaucracy and cultural sensitivities.</li> </ul>	
3. Communication  a) Communication with patient community	<ul style="list-style-type: none"> <li>Aboriginal people don't understand why they should be involved in programs, as a lack of clear and appropriate information is provided to Aboriginal people.</li> </ul>	<p>"Aboriginal people often have no idea that they will end up as sick as they do-even if they have been told by the doctor. Need culturally appropriate education packages".</p> <p>"Often mainstream staff are unaware that their language is perceived by Aboriginal people as inappropriate".</p>
b) Communication with services/ providers	<ul style="list-style-type: none"> <li>Alack of awareness about the various health services that are available. This was seen as problematic not only for Aboriginal people but also for health workers.</li> <li>Chronic disease is everyone's issue but people think it's an Aboriginal health issue.</li> </ul>	<p>"Collaboration across services is sometimes disjointed and can be improved".</p> <p>"There are good services, but interactions between the services are poor and can be improved".</p>
4. Geography	<ul style="list-style-type: none"> <li>Transport is a major barrier for Aboriginal people to access chronic care services, including their specialist appointments.</li> <li>The cost of transport is a significant barrier, especially for Aboriginal people living in remote areas.</li> <li>While there are some options for community transport, these are often infrequent and leave Aboriginal people concerned about how they can return home after visiting a health service.</li> <li>Aboriginal people do not travel alone, they bring their families.</li> <li>One area health service mentioned that if they didn't provide transport for Aboriginal clients, "about 50% of clients would not turn up". However, due to budget restraints some AHSs were unable to provide transport. In some circumstances Aboriginal Health Workers provided transport to Aboriginal people, despite it being out of the scope of their role and raising risks around confidentiality.</li> <li>The issue of funding- federal v state, who takes responsibility for transport?</li> </ul>	<p>"Transportation is an issue due to remote and isolated living areas and shortage of vehicles and bus services".</p> <p>"Hospital Transport is time consuming, by the time you book it, go and get the keys, go and get the car, go and get the patient and then back to the car and take a patient to dialysis and then back to the hospital and drop the car back most of the day has been spent on one patient".</p> <p>"We need more transport provided for Aboriginal clients to attend mainstream services as it has major impacts on the staff time at the AMS".</p>

## Stakeholder interview analysis

Theme	Issues	Quote
5 Affordability of care a) Cost to patient	<ul style="list-style-type: none"> <li>• AMSs bulk bill, however in other communities Aboriginal patients go to the ED so they don't have to pay.</li> <li>• General Practitioners run their surgeries are business and they aren't as profitable when they bulk bill.</li> <li>• General Practitioners will bulk bill if it is necessary however Aboriginal people need to ask for this and often they wont ask.</li> <li>• Aboriginal people spend a lot of time searching for bulk billing doctors.</li> </ul>	<p>"The AMS is lucky that the drug representatives leave many samples which are often given to Aboriginal Elder clients as they are aware they need to constantly support their medication needs as a priority".</p> <p>"If there is no bulk billing services provided this deters Aboriginal people to attend their medical appointments".</p> <p>"The ALO's advised that there is no suitable or affordable accommodation for Aboriginal families to stay who come from the regional and remote areas to Sydney's hospitals. Families are often placed in a position where they are unable to stay in accommodation together as one family as there is not enough available accommodation in the area. Families are therefore often forced to split up, women to women's refuges".</p>
5 Affordability of care b) Medicare/ PBS/HACC	<ul style="list-style-type: none"> <li>• HACC is not aware of elderly Aboriginal problems. Elderly Aboriginal people are not accessing packages such as HAC and COMPAKs. This needs to happen at the state level.</li> <li>• Low uptake of Aboriginal people specific MBS items There is a stretch target-aiming for 80% uptake-in 3 years-will be very challenging.</li> <li>• A partnership model with the GPs along the lines of Healthone that can maximise access to MBS items was suggested.</li> </ul>	
6. Prevention	<ul style="list-style-type: none"> <li>• In Mt Druitt the major shopping centre has poor quality fruit and veggies.</li> <li>• It is cheaper to eat take away food than purchase health food.</li> </ul>	
7. Workforce	<ul style="list-style-type: none"> <li>• Mainstream staff need cultural sensitivity training.</li> <li>• Mainstream staff need more training in chronic care.</li> <li>• Need more skilled Aboriginal health workers.</li> <li>• Aboriginal and non Aboriginal health workers suffer burnout quickly. After hours the Aboriginal community still expect AHW to be available. This can be a real burden for Aboriginal staff.</li> <li>• More Aboriginal health workers need to be employed as there currently are not enough.</li> <li>• Make salary packages more attractive to staff.</li> <li>• Aboriginal health workers have a perceived lack of respect by mainstream staff.</li> <li>• Very high staff turnover which results in loss of knowledge and loss of impact of training, especially when this knowledge is not documented.</li> </ul>	<p>"People are always looking for a quick fix but the Aboriginal health workforce will take a long time to build. In the meantime, need appropriately trained Aboriginal people and non-Aboriginal people with appropriate cultural skills and understanding".</p> <p>"High turnover of staff as many allied health staff commence and don't stay as leave for positions on coast (Ballina, Lismore etc)".</p> <p>"Biggest issue is recruiting and retaining Aboriginal male workers, which results in a big service gap".</p> <p>"High turn over of general practitioner's within the AMS at Condobolin. As a result there is no continuity of care and very little patient follow-up. The lack of follow-up leads to an exacerbation of the difficulty of chronic care management".</p>

Stakeholder interview analysis

Theme	Issues	Quote
	<ul style="list-style-type: none"> <li>• Recruiting staff can be a slow process which is very disheartening.</li> <li>• Poor uptake of cultural training programs and limited opportunities for cultural awareness training.</li> <li>• Limited allied health staff.</li> <li>• High turnover of staff which creates issues for Aboriginal people as they need time to build rapport and trust.</li> <li>• Emphasis on men’s health is required, including services tailored to men’s needs.</li> <li>• Aboriginal health workers are often under skilled.</li> <li>• AHEO’s and AHW positions need to have competencies, skills and expectations clearly defined.</li> <li>• The potential to broaden the role of AHW’s is not being recognised. They currently have health promotion roles however this could become a clinical role.</li> </ul>	
<p>8) Infrastructure/ Accountability</p> <p>Funding models</p> <p>Accountability</p> <p>Service infrastructure</p>	<ul style="list-style-type: none"> <li>• Mainstream services need to be more flexible in methods of delivery. There needs to be flexibility in where patients are seen. For example, Aboriginal people need to have services delivered in their homes, particularly around the initial stages. They will not come to the hospital, therefore health workers need to go out to them and build the trust.</li> <li>• The AMS traditionally receives the most funding for specific and additional positions rather than the hospitals or mainstream services.</li> <li>• Vascular risk funding has been stipulated from NSW Health that it had to come via AHS to AMS.</li> <li>• Lots of two year non- recurrent funding programs by State or Commonwealth which leads to lots of scepticism amongst staff and community and associated problem with recruiting to positions.</li> <li>• AMS offer services but Aboriginal people must use the AMS exclusively.</li> </ul>	<p>“Mainstream services need to change and need to be more flexible in methods of delivery. For example, there needs to be flexibility in where patients are seen. For example, Aboriginal people need to have services delivered in their homes, particularly around the initial stages. They will not come to the hospital, therefore health workers need to go out to them and build the trust”.</p> <p>“I am really worried about Aboriginal people who come from the bush and present at the hospital in emergency situations. They don’t have their personal items like soap, shampoo, money, ID, change of clothing, etc. I provide Elders with basic personal items out of my own pocket because I don’t want the Elders to feel shame”.</p>

### Survey background

General Practitioners were invited to participate in the survey through the “10 Minute Update” newsletter which is distributed by the GP Alliance. The survey was mentioned in three editions of the newsletter. In addition, an email was sent to the Division of General Practice which included a link to the survey. The General Practitioner Survey was a 13 question online survey for General Practitioners.

There were six responses in total, of which there were three responses from NCAHS, two responses from NSCCAHS, one response from SESIAHS and one response from SSWAHS.

### Identifying Aboriginality

- Half of the general practitioners responded that they routinely ask new patients if they are of Aboriginal or Torres Strait Islander background.
- Two thirds of the general practitioners indicated Aboriginal or Torres Strait Islander background is clearly marked on their records

### Medicare usage

- All general practitioners use the Aboriginal or Torres Strait Islander Adult Health Check (Medicare Item No.710)
- Half of the general practitioners use the Aboriginal or Torres Strait Island Child Health Check (Medicare Item No.708)
- Two of general practitioners did not use any other MBS items for managing chronic disease for Aboriginal and Torres Strait Islander patients. Of the general practitioners that used other MBS items, they indicated using EPC allied health referrals, mental health referral, mental health plan, review and consult, care plans, team care arrangements, mental health care plans and general practitioner management plans.

### Support from Area Health Service

- In relation to feeling supported by their Area Health Service in their role in the prevention of chronic disease, half of the general practitioners responded that felt they were provided limited support, two thirds were indicated that they were provided basic support and one respondent was provided with good support.
- Five of the six (83.3%) general practitioners surveyed were in between 10-30 minutes proximity of Area Health care. One general practitioner was located approximately 2 hours away from their Area Health Service

### Hospital discharge

- Half of the general practitioners rated the coordination of care related to an Aboriginal patient's discharge from hospital as very frustrating, no communication from hospital and very unhelpful. The other half of the respondents rated the coordination of care as frustrating, limited communication from hospital and unhelpful.

## Area Health Services

- One general practitioner was not satisfied with the availability of Area Health services for patients with chronic illness. Half of the general practitioners were somewhat satisfied, however felt things could be better. One general practitioner was satisfied.

## Communication

- The quality of communication between the above mentioned health services and general practitioners was rated as not useful, poor quality, infrequent and inappropriate in volume of material (both too much and too little) by half of general practitioners. The other half of the respondents indicated that communication is of limited use and minimal information.

## Hospital discharge

- Five of the general practitioners felt that there was some education and they aware of some available services available to them related to chronic illness services. One of the general practitioners felt that there was adequate education and they were aware of available services to them related to chronic illness services.

## Usage

The general practitioners surveyed indicated using the following services:

- Adult Post Acute Care Service (APAC) (1 respondent)
- Asthma Services (2 respondents)
- Cardiac Rehabilitation Services (2 respondents)
- Community Nursing Service (5 respondents)
- Diabetes Service (6 respondents)
- Heart Failure Service (3 respondents)
- Home Education Respiratory Rehabilitation Service (HERRS) (2 respondents)
- Pulmonary Rehabilitation Service (4 respondents)

The general practitioners surveyed indicated not using the following services:

- Aboriginal CVD Program (5 respondents)
- Adult Post Acute Care Service (APAC) (4 respondents)
- Asthma Services (3 respondents)
- Cardiac Rehabilitation Services (2 respondents)
- Community Stroke Support Service (5 respondents)
- Heart Failure Service (2 respondents)
- Home Education Respiratory Rehabilitation Service (HERRS) (2 respondents)
- Pulmonary Rehabilitation Service (1 respondents)
- Renal Services (5 respondents)

- The General Practitioners indicated that the community nursing services and diabetes services provided the most benefit to patients.

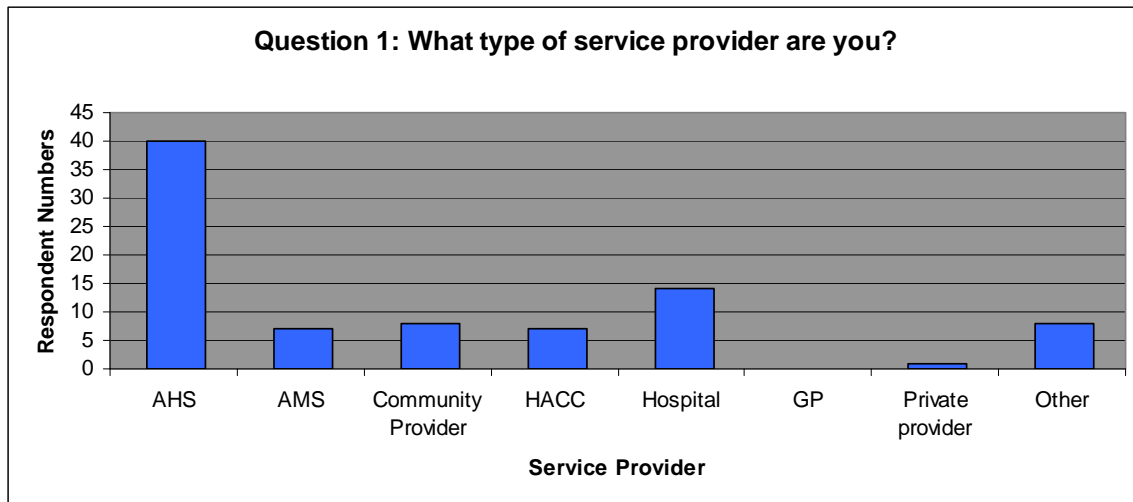
## Communication

- One respondent reported not having good two-way communication with an Aboriginal CVD Program.
- One respondent reported having good two-way communication with an Adult Post Acute Care Service, however another respondent reported not having good two- way communication
- One respondent reported having good two-way communication with asthma services, however another respondent reported not having good two- way communication
- One respondent reported having good two-way communication with Cardiac Rehabilitation Services
- Three respondents reported having good two-way communication with Community Nursing Service, however another respondent reported not having good two- way communication
- One respondent reported not having good two-way communication with Community Stroke Support Service
- Three respondents reported having good two-way communication with Diabetes Service, however another respondent reported not having good two- way communication
- One respondent reported having good two-way communication with Heart Failure Service, however another respondent reported not having good two- way communication
- One respondent reported having good two-way communication with Home Education Respiratory Rehabilitation Service (HERRS), however another respondent reported not having good two- way communication
- Three respondents reported having good two-way communication with Pulmonary Rehabilitation Service, however another respondent reported not having good two- way communication
- One respondent reported not having good two-way communication with Renal Service

## Appendix K Service provider online survey analysis

Seventy eight responses were collected and the following graphs are the results of these responses.

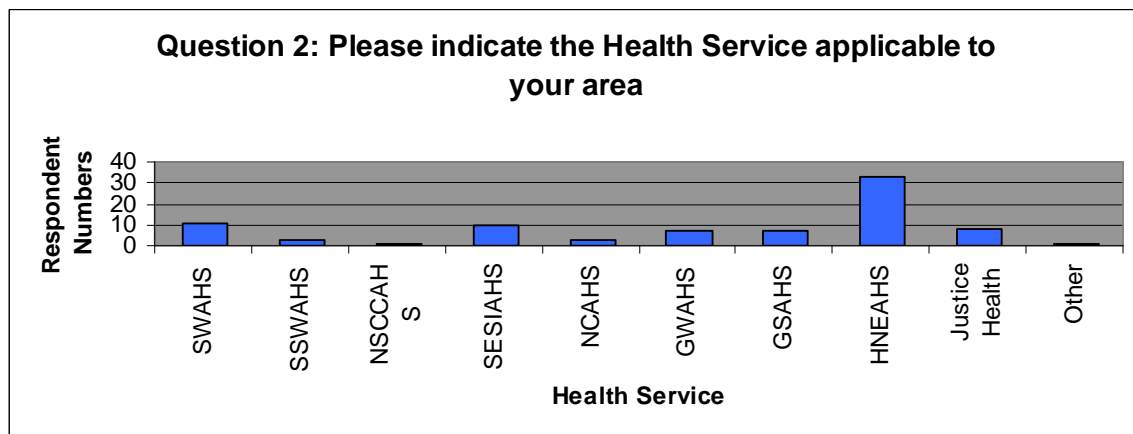
### Question 1-What type of service provider are you?



(N=78)

42% of respondents were classified as Area Health Service providers. Other service providers included AMSs, community providers and HACCs.

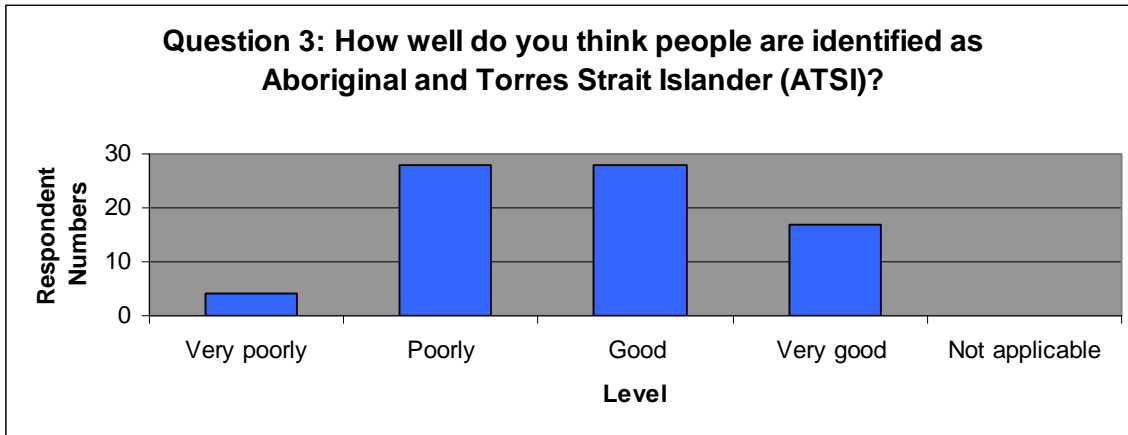
### Question 2-Please indicate the health service applicable to your area?



(N=84)

All nine Area Health Services, including Justice Health, were represented in the survey.

**Question 3-How well do you think people are identified as Aboriginal and Torres Strait Islander (ATSI)?**



(N=77)

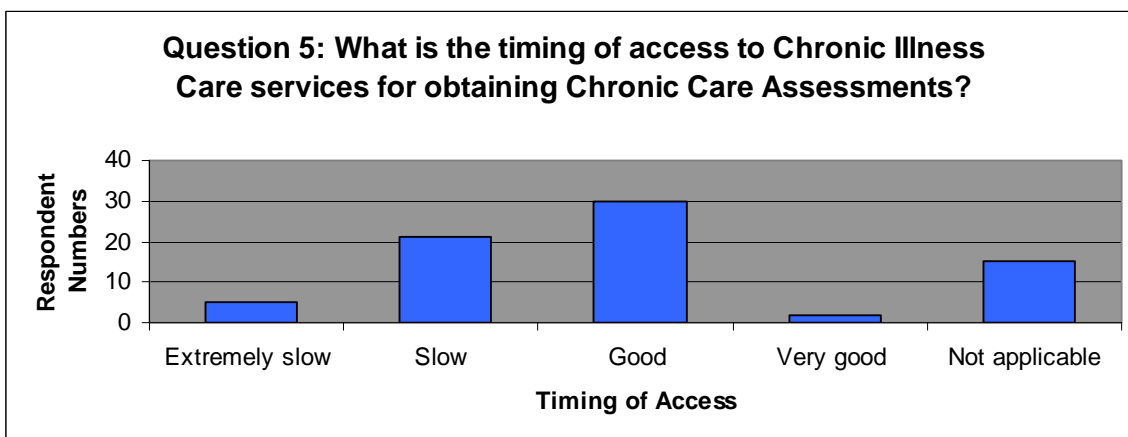
Responses were quite varied regarding how well Aboriginal and Torres Strait Islander people are identified, with most (58%) responding good or very good. 42% of respondents reported that Aboriginal people are poorly identified.

**Question 4-What systems do you have to ensure that staff are able to identify ATSI clients well?**

(N=66)

There was a range of systems identified by respondents which ensure Aboriginal and Torres Strait Islander clients are well identified. These included the PAS system, CHIME, iPM, CIARR and ONI. Several respondents also stated that Aboriginal and Torres Strait Islander clients were identified by asking questions during intake and admission.

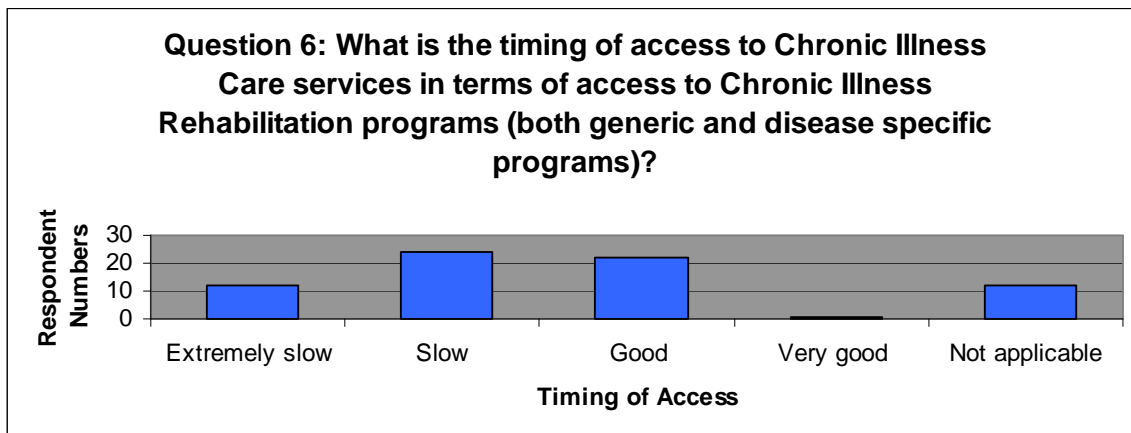
**Question 5-What is the timing of access to Chronic Illness Care services for obtaining Chronic Care Assessments?**



(N=73)

The responses were quite varied regarding timing of access to Chronic Illness Care services, with 41% of respondents felt that the timing of access was good. Several respondents (36%) indicated that the timing of access was slow.

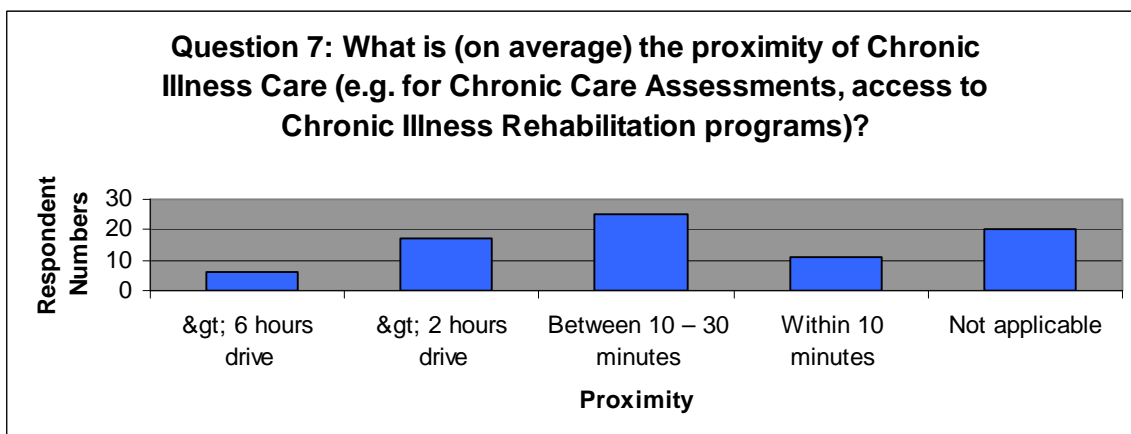
**Question 6-What is the timing of access to Chronic Illness Care services in terms of access to Chronic Illness Rehabilitation programs (both generic and disease specific programs)?**



(N=71)

Responses were inconsistent regarding the timing of access to Chronic Illness Care services in terms of access to Chronic Illness Rehabilitation programs, with the most reporting slow to good (65%).

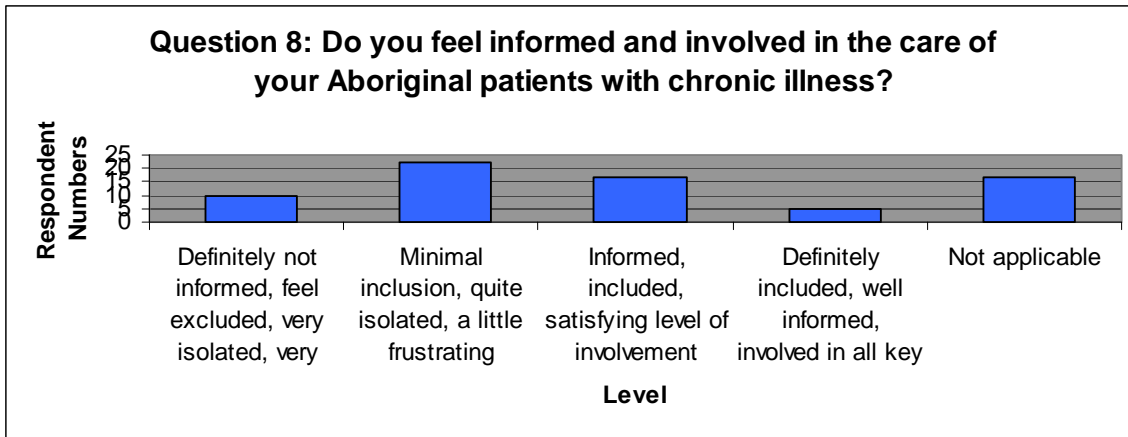
**Question 7-What is (on average) the proximity of Chronic Illness Care (eg for Chronic Care Assessments, access to Chronic Illness Rehabilitation programs)?**



(N=79)

Proximity to Chronic Illness Care ranged from less than 10 minutes to 6 hours and over. 29% of respondents indicated that Chronic Illness Care was a 2 hour and greater drive. Only 14% of respondents indicated that they were within 10 minutes.

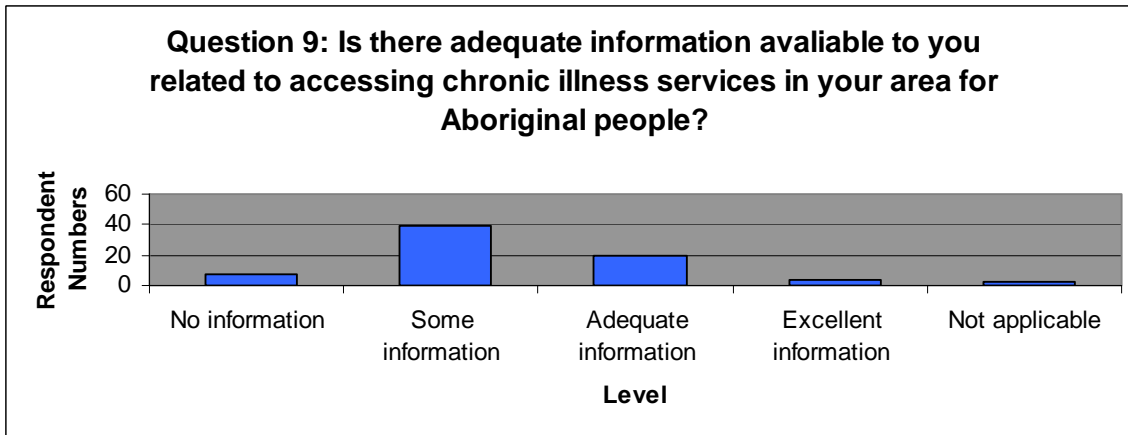
**Question 8-Do you feel informed and involved in the care of your Aboriginal patients with chronic illness?**



(N=71)

Most respondents (45%) indicated that they felt minimal to no inclusion in the care of their Aboriginal patients with chronic illness. Only 7% felt that they were well informed and involved in all key areas.

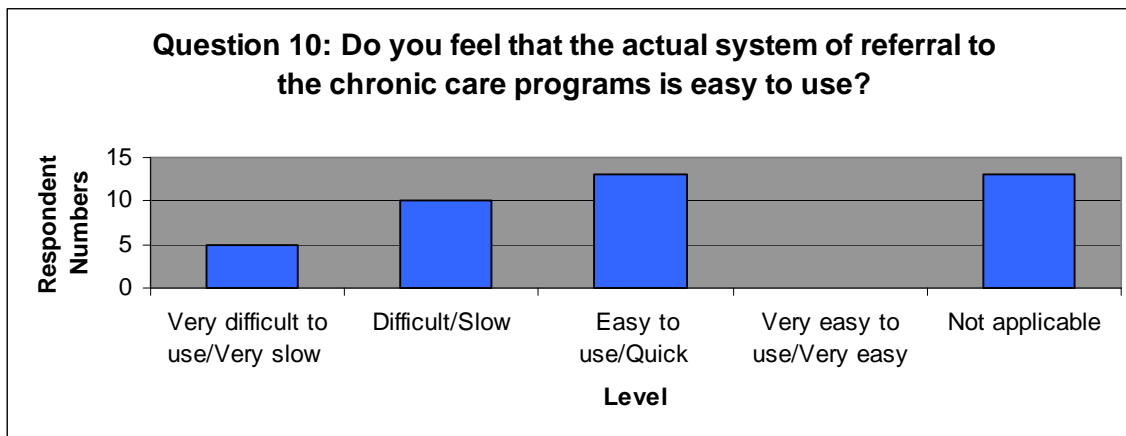
**Question 9-Is there adequate information available to you related to accessing chronic illness services in your area for Aboriginal people?**



(N=72)

The majority of respondents (55%) felt that there was not adequate information available related to accessing chronic illness services in their area. Only 31% of the respondents reported adequate to excellent available information.

**Question 10-Do you feel that the actual system of referral to the chronic care programs is easy to use?**



(N=41)

The responses regarding ease of use of referral systems to the chronic care program were varied. 37% of respondents indicated that they felt the referral systems were difficult to very difficult to use. Only 32% reported that the referral systems were easy to use.

**Question 11-How do you think access can appropriately be improved for Aboriginal people to mainstream chronic care services (eg self management programs, rehabilitation services)?**

(N=55)

Respondents identified a range of different strategies for improving Aboriginal people’s access to mainstream chronic care services, such as improved referral systems and linkages, improved transport, outreach programs, self management programs, Aboriginal Health Workers, and more culturally appropriate services.

**Question 12-Are you aware of any strategies currently in place to improve access for Aboriginal people to mainstream chronic care services?**

(N= 69)

The majority of respondents (67%) stated that they were unaware of any strategies currently in place to improve access for Aboriginal people to mainstream chronic care services. The respondents who were aware of strategies in place (33%) identified the Healthy for Life program, Aboriginal Health Strategic Plan and ACCAHSS programs.

**Question 13-Have you experienced any examples of good engagement with Aboriginal people?**

(N=66)

The majority of respondents (68%) reported that they have experienced examples of good engagement with Aboriginal people. Good engagement examples that were reported include Pit Stop programs, Health for Life programs, partnership meetings with community organisations and Elders and awareness sessions.

**Question 14-Are you aware of any additional chronic illness services that are required by Aboriginal people that are not currently being provided?**

(N=66)

41% of respondents reported that there were additional chronic illness services that are required by Aboriginal people that are not currently being provided. Examples reported include transport services, and screening and self-management services for diabetes, cardiac, renal, and respiratory disease.