



Government of **Western Australia**
Child and Adolescent Health Service



Developing the Consumer Engagement Strategy 2020-2022

June 2020



Compassion

Accountability

Excellence

Equity

Collaboration

Respect

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Introduction

The Consumer Engagement Strategy will be a three-year plan for Child and Adolescent Health Service (CAHS) aimed at strengthening consumer engagement across all service areas – Neonatology, Community Health (CH), Perth Children’s Hospital (PCH) and Child and Adolescent Mental Health Service (CAMHS). The Strategy is complemented by a Consumer Engagement Framework to support the implementation of the goals and actions defined in the Strategy. The Strategy is divided into the three different ‘relationships’ or ‘engagements’ consumers may have with CAHS services, these are:

1. **direct care and support**¹, which is about partnerships and information exchange between clinicians and consumers in the delivery of and decisions about care and support;
2. **feedback**, which is about consumers giving CAHS positive, negative or neutral feedback by filling in a feedback form, calling, emailing or meeting face to face with the CAHS Client Liaison Officer, as well as posting about their experience on [Care Opinion](#).
3. **consultation**², referring to when CAHS needs to receive information from consumers (existing or potential).

These three different ‘relationships’ or ‘engagements’ were explored across three phases of the developing the Consumer Engagement Strategy. Each of these phases will collect, analyse and refine multiple sources, resulting in a consumer led, staff informed Strategy that is supported by the CAHS Leadership Team and aligned with Standard Two of the National Safety and Quality Health Service Standards (NSQHSS) 2nd Edition.

This document outlines the three phases of development.

Phase One – identified CAHS’s strengths, weaknesses and opportunities in relation to consumer engagement. The goals for the Consumer Engagement Strategy emerged from this phase.

Phase Two - considered the goals and gaps identified in Phase One and detailed actions designed to address these gaps and meet the goals.

Phase Three - brought together staff and consumers to refine the goals and prioritise the actions under each goal.

The surveys and workshop session plans can be made available on request by contacting the **CAHS Consumer Engagement Team** – CAHS.Consumers@health.wa.gov.au

¹ The phrase ‘direct care and support’ used throughout this document was changed to ‘Clinical care, treatment and support’ in the Consumer Engagement Strategy.

² The term ‘consultation’ used throughout this document was changed to ‘participation’ in the Consumer Engagement Strategy.

Phase One – Strengths, weaknesses and opportunities

Purpose

The purpose of Phase One was to identify CAHS's strengths, weaknesses and opportunities in relation to consumer engagement.

Outline of the document

The consultation methodology for Phase One is outlined below, followed by the presentation of demographics of the consumers and organisational positions of the staff involved. The findings of the Phase One are then divided into the three type of consumer engagements outlined above. These are further divided into key components within those engagements and the different sources of data – consumer, staff and organisational priority data. After presenting the complete findings for that 'engagement', a summary of the findings is given, along with possible directions for consumer engagement at CAHS.

Methodology

A range of data was collected during Phase One and is outlined below.

Consumer Consultation

Consumer consultation for this component of the project was conducted through surveys with metropolitan young people aged 12-21 years, metropolitan parents and carers and Western Australian (WA) regional parents and carers. It is important to note that results from WA regional country parents and carers only apply to services provided by CAHS services provided by PCH only.

The surveys were divided into three sections to consider consumer engagement in three different areas:

1. **direct care and support** - which is about partnerships and information exchange between clinicians and consumers in the delivery of and decisions about care and support
2. **feedback** - which includes consumer preferences for access, mechanisms and responses, it also includes opportunities for information related to Healthcare Rights
3. **consultation** - referring to when CAHS needs to receive information from consumers (existing or potential).

The online survey was distributed through:

- posting and sharing on relevant social media pages
- posters and information displayed at CAHS sites
- newsletters of relevant services (e.g. Kalparrin)
- volunteers inviting consumers at PCH to complete the survey using iPads
- a survey link text to recent consumers of CH and PCH services.

Staff Consultation

Staff consultation for the project was conducted through:

Surveys with CAHS staff: The survey focused on questions about staff experiences of consumer engagement at the levels of:

- direct care and support
- feedback
- consultation.

Interviews with CAHS staff and key stakeholders: The interview schedule focused on identifying strengths and weaknesses in consumer engagement across the different CAHS services and also opportunities for the Strategy and Framework.

Organisational Priority Data

Existing organisational priority data from across CAHS was also collected for analysis. This included:

- NSQHSS Standard 2 gap analysis
- CAHS complaint data
- CAHS clinical incident data
- CAMHS Experience of Service Questionnaire (ESQ) analysis.

Analysis

Frequency data from the consumer and staff surveys was analysed using Excel. The findings from these data sources was then triangulated with the analyses from the:

- staff interviews (analysed for themes using NVivo)
- Standard 2 gap analysis
- CAHS complaint data
- ESQ analysis.

Findings from a review of the Consumer Engagement Strategies of other states and territories are also drawn on to support or challenge the findings.

Demographics

This includes information on how the surveys were distributed, as well as demographic information.

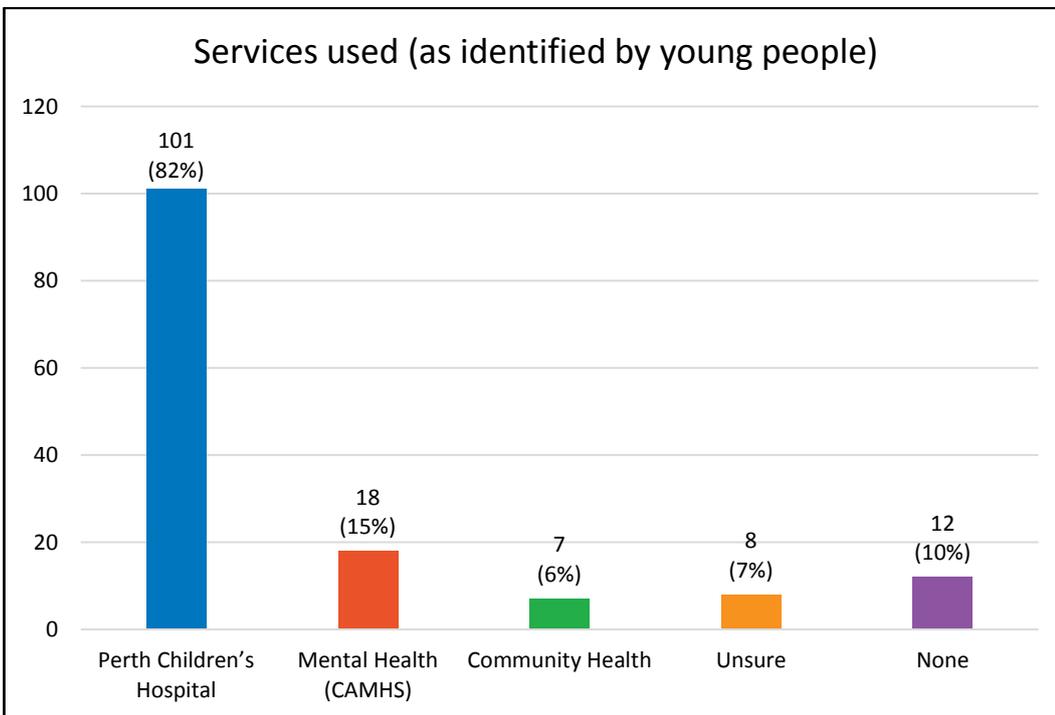
Young people

A total of 123 young people engaged with the survey, however, the number of responses for different question varied due to the respondents exiting the survey before fully completing it. This impacted on the demographic information collection, as demographic questions were positioned at the end of the survey. Of those who responded to the demographic questions (n=69):

- 12% (n=8) identified as Aboriginal or Aboriginal and Torres Strait Islander
- 4% (n=3) mainly spoke a language other than English at home
- 13% (n=9) had a disability.

The most utilised CAHS service of the young people who responded was PCH, with 82% of young people identifying it as a service they have used. However, it is acknowledged that the CH school health nurses role may not be recognised by respondents as being part of CAHS services.

Figure 1: Services used (as identified by young people)



Parents and carers

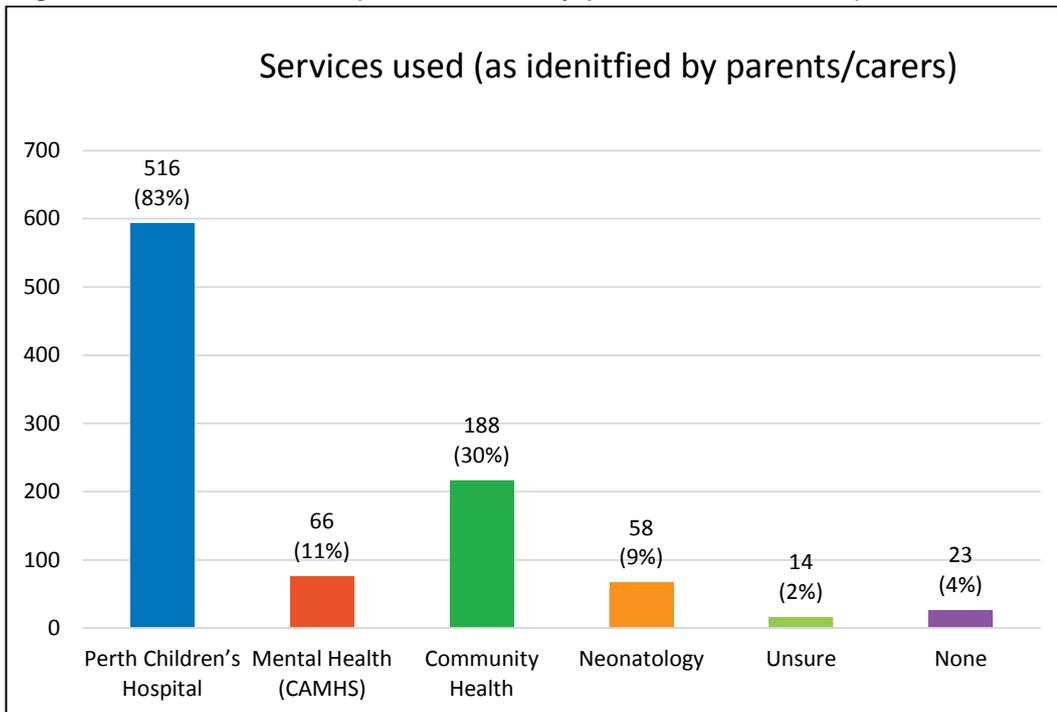
A total of 620 Perth metropolitan parents and carers engaged with the survey, however, the number of responses received for different questions varied due to respondents exiting the

survey before completing all questions. Of those who responded to the demographic questions (n=445):

- 7% (n=29) identified as Aboriginal or Aboriginal and Torres Strait Islander
- 9% (n=38) mainly spoke a language other than English at home
- 29% (n=127) had a child with a disability
- 2% were a parent with a disability.

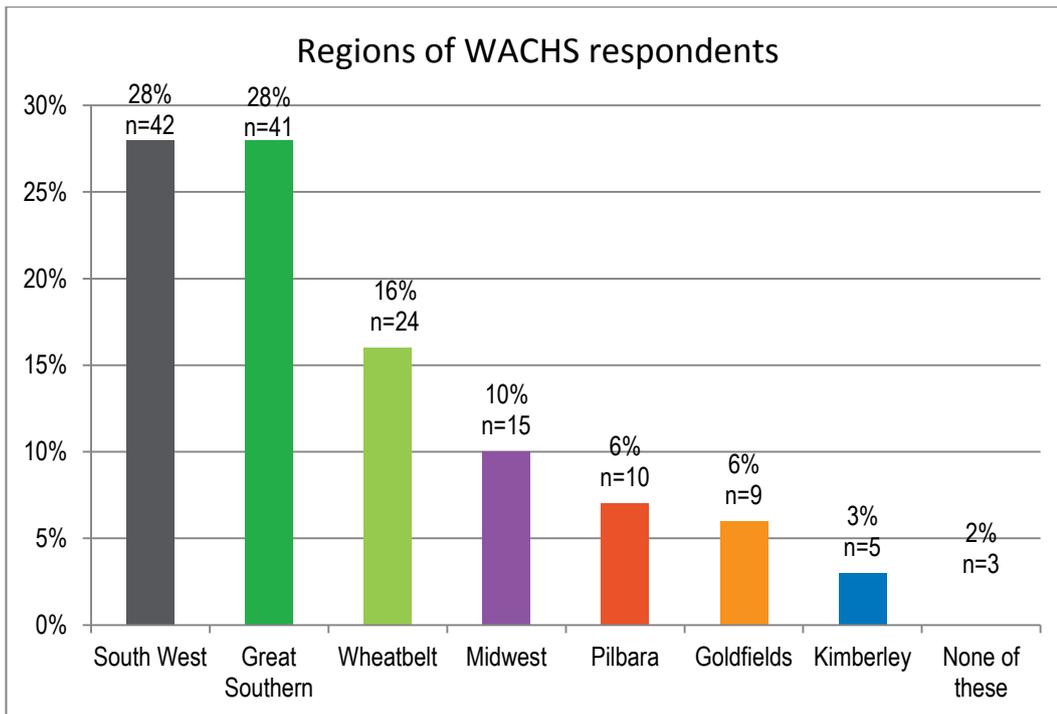
The most utilised CAHS service according to parents and carers was PCH, with 83% of parents and carers identifying it as a service they have used. The low selection of CH services as services used by parents and carers need to be interpreted cautiously given that Community Health services are universal services that are provided to over 90% of babies and children in some instances (e.g. initial child health assessment, School Entry Health Assessment). Parents and carers may not identify or recall these services as being associated with CAHS, but it is likely that a higher proportion of parents and carers have accessed them, than reported in the graph below.

Figure 2: Services used (as identified by parents and carers)



A total of 149 WA regional parents and carers engaged with the survey, with most responses coming from the South West and the Great Southern regions of the WA Country Health Service (WACHS). The Kimberley received the least amount of responses (3%, n=5), so alternate methods for capturing more detailed feedback from this group are required.

Figure 3: Regions of WACHS respondents



Of those who responded to the demographic questions (n=99)

- 3% (n=3) identified as Aboriginal
- all respondents indicated that they speak English at home
- 26% (n=26) had a child with a disability
- 4% (n=4) were a parent with a disability.

Of the 149 WA regional parents and carers who responded to the survey in total, just under half (45%, n=56) of WACHS respondents to this question had used PCH services with their child. Of people whose family had used PCH services, the most common response was outpatients – provided in person (n=39). This was followed by:

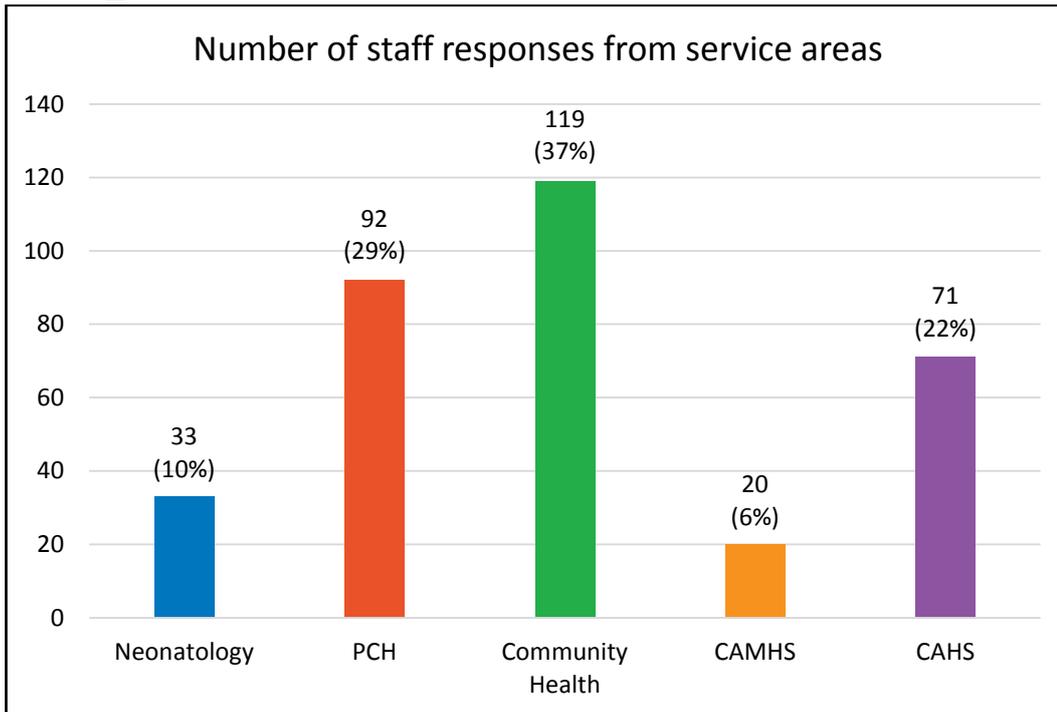
- inpatient services (n=30)
- PCH emergency department (n=21)
- outpatient services provided by a visiting specialist to the WACHS region (n=16)
- outpatient services provided by telehealth (n=14)
- other (n=2).

Staff

Survey

A total of 318 CAHS staff completed a survey to inform the development of the CAHS Consumer Engagement Strategy. A breakdown of the number of staff responses to the survey from different service areas is shown in Figure 4. The overall response rate was 5% of total CAHS staff. In terms of responses from clinical and non-clinical staff, 58% (n=184) of the respondents primarily held clinical roles and 42% (n=134) primarily held non-clinical roles.

Figure 4: Number of staff responses from service areas



Interviews

Interviews were held with 34 staff from across teams and services streams CAHS. Selection ensured that there was representation from:

- different service streams –
 - Medical
 - Surgical
 - Community Health
 - CAMHS
 - Neonates
 - Allied health
 - Nursing
- those working with vulnerable populations –
 - Aboriginal Health Team
 - Cultural Diversity
 - Refugee Health Teams (PCH and CH)
 - Kalparrin

those working in areas directly related to consumer engagement –

- Perth Children's Hospital Foundation (Fun on Four)
- Communications (CAHS) / Publications (CH)
- CaFES
- Starlight Foundation and Radio Lollipop
- Strategy and Development
- Safety and Quality
- Nursing Research

Phase One Findings

In most cases the findings have been divided into the three areas of consumer engagement across CAHS:

- **direct care and support**
- **feedback**
- **consultation.**

Some data, however, is broader and does not fit into these categories. This includes some data collected in the staff survey, regarding consumer engagement at CAHS. From the table below, the overwhelming majority (96%) of staff believe that consumer engagement should be embedded in decision making at CAHS. Seventy percent *agree* or *strongly agree* that the development and direction of CAHS is based on consumer preferences and feedback. Nearly two thirds (65%) of staff believe the leadership and culture of CAHS supports genuine consumer engagement. Over half (55%) *disagree* or *strongly disagree* that CAHS effectively engages vulnerable consumers.

Table 1: Consumer engagement at CAHS

	Strongly agree	Agree	Disagree	Strongly disagree
I believe consumer engagement should be embedded in how CAHS makes decisions.	132 (55%)	97 (41%)	8 (3%)	2 (1%)
The development and direction of CAHS is based on the preferences and feedback of consumers.	47 (20%)	119 (50%)	63 (27%)	7 (3%)
CAHS effectively engages vulnerable consumers.	15 (6%)	91 (39%)	107 (45%)	23 (10%)
The leadership and culture of CAHS supports genuine engagement.	22 (9%)	131 (56%)	71 (30%)	11 (5%)

Direct Care and Support

Direct Care and Support crosses three criteria of Standard 2 – Clinical governance and quality improvement systems to support partnering with consumers, Partnering with patients in their own care and Health Literacy.

Within these criteria there is an expectation that:

- health information and communication mechanisms are appropriate for the diverse range of consumers and easy to understand by all
- systems exist to enable partnerships and processes for ensuring consumers are involved decision-making.

For the purpose of this work, we have divided 'Direct Care and Support' into:

- Making decisions about care and support.
- Information and communication about health.

Making decisions about care and support

This area of Direct Care and Support specifically relate to the following actions and associated intentions:

- Action 2.1. Safety and quality systems support clinicians in partnering with consumers in the delivery of care.
- Action 2.2. Quality improvement systems are used to support processes for partnering with consumers at the level of the organisation.
- Action 2.6. Patients receive safe and high-quality care by being involved in decisions and planning about current and future care.
- Action 2.7. Clinicians work with patients to enable them to be partners in their own care.

Presented below is what consumers said about being involved in making decisions about their or their child/ren's care and support at CAHS.

What did consumers say?

Parents and carers, as well as young people were asked if, when using CAHS services, they had the opportunity to be involved in making decisions about their child or children's or their own care and support. Just over 60% (61%, n=347) of parents and carers replied *always*. While, only 30% (n=31) of young people replied *always*. Details of the responses are presented in Figure 5 and 6 below.

For regional consumers, just over 40% (41%, n=21) parents and carers said they had a lot of involvement in planning their child/ren's care and around a quarter (24%, n=12) had a little involvement. Over a third (35%, n=18) of parents and carers felt that they didn't have much say in planning their child's care. Some comments illustrating this experience were:

"I find that specialist doctors do not respect or listen to a parent's opinion and say on the child's treatment, as the parent is not a doctor".

"We have never really been given the opportunity to have a say in what happens".

"When I have tried, they don't listen".

Figure 4: Young people's involvement in decision making

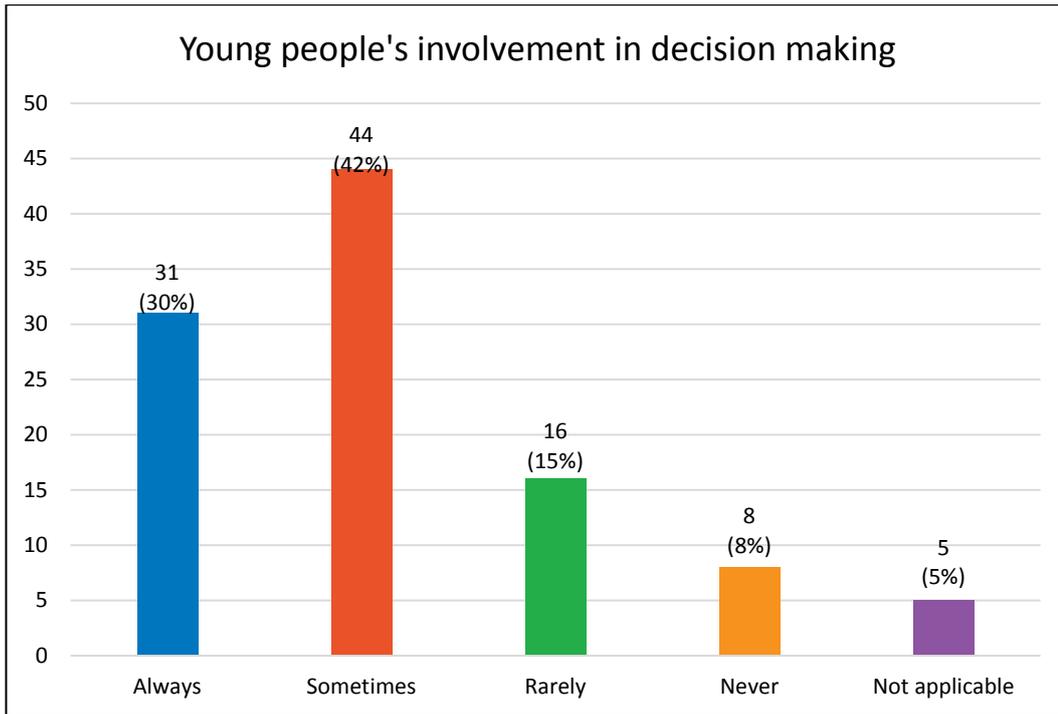
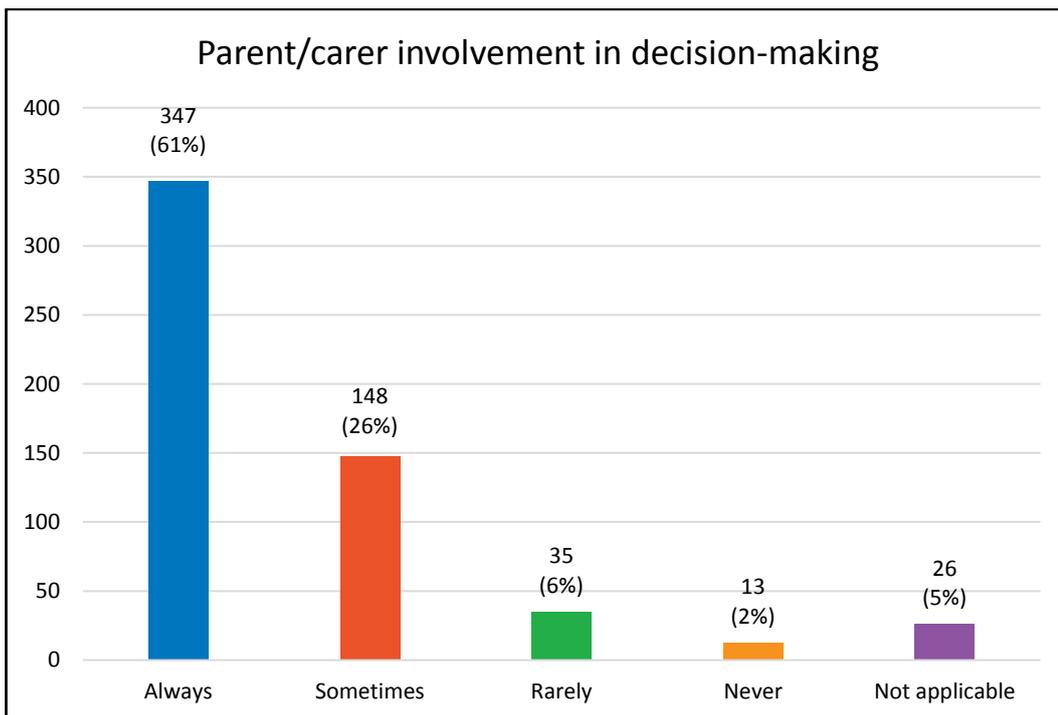


Figure 5: Parent/carer involvement in decision-making



Those who replied *sometimes*, *rarely* or *never* were given the opportunity to respond to the question of how they could be more involved. Thirty two young people and 109 parents and carers responded.

Three main themes emerged for how young people could be more involved in making decisions about direct care and support. These were:

- Given the information to be involved in decision making
- Two-way communication
- Being directly involved.

There was overlap between these themes and as a whole they identify some clear approaches to how young people would like to be involved in decision-making about their care and support.

Another seven comments were made by young people who did not know how they could be involved or were happy with their level of involvement. These were also excluded from the table.

Three main themes emerged from parents and carers as to how they could be more involved. These were:

- Time for two-way communication
- Increase in amount and quality of information
- Incorporating family strengths, experiences and circumstances into decision-making.

There was considerable overlap between these three themes, with many responses sitting across two or more themes. A fourth theme (16 responses) related to changes in treatment to care (e.g. consistency, access). However, the majority of these responses overlapped with one of the three main themes and as such has not been included in the table below. Another 15 comments were made by parents and carers who did not know how they could be involved or were happy with their level of involvement. These were also excluded from the table.

The two tables below present the key themes emerging from comments made by parents and carers and young people who responded. Some examples of comments for each theme identified have been included.

Table 2: Young people's responses to how they could be more involved

Theme	Examples of comments
<p>Given the information to be involved in decision making (n=12) Young people wanted more choice regaining care and support and the information required to make those choices.</p>	<p>“Having more say in my treatment plan.”</p> <p>“Being told exactly how the plan would play out and what investigations have been organised.”</p> <p>“More decisions with my mental health and having more information about my condition.”</p> <p>“More knowledge of how certain procedures and medications are used before I agree to undertake them.”</p> <p>“The doctors could have given me a choice in having a surgery when I wanted.”</p>
<p>Two-way communication (n=8) Being able to participate in discussions and feeling:</p> <ul style="list-style-type: none"> • listened to • able to ask more questions 	<p>“Been allowed to communicate my feelings further and concerns, which would allow me understand my care.”</p> <p>“To be listened to and not talked over.”</p> <p>“Been able to ask more questions myself.”</p> <p>“Talking to me instead of my parents, listening to me and what I said.”</p> <p>“Spoken to. When asked questions have them answered instead of answering my parents.”</p>
<p>Being directly involved (n=8) Young people being involved in in discussions, not only parents and carers.</p>	<p>“I could have been more involved by having the medical professionals speak to me as well as my family about my treatment.”</p> <p>“Involved in conversations. Spoken to directly. Not talked down to or over.”</p> <p>“More engaging, and directly telling me what is wrong instead of discussing with parents first. More understanding and caring.”</p>

Table 3: Parent/carer responses to how they could be more involved

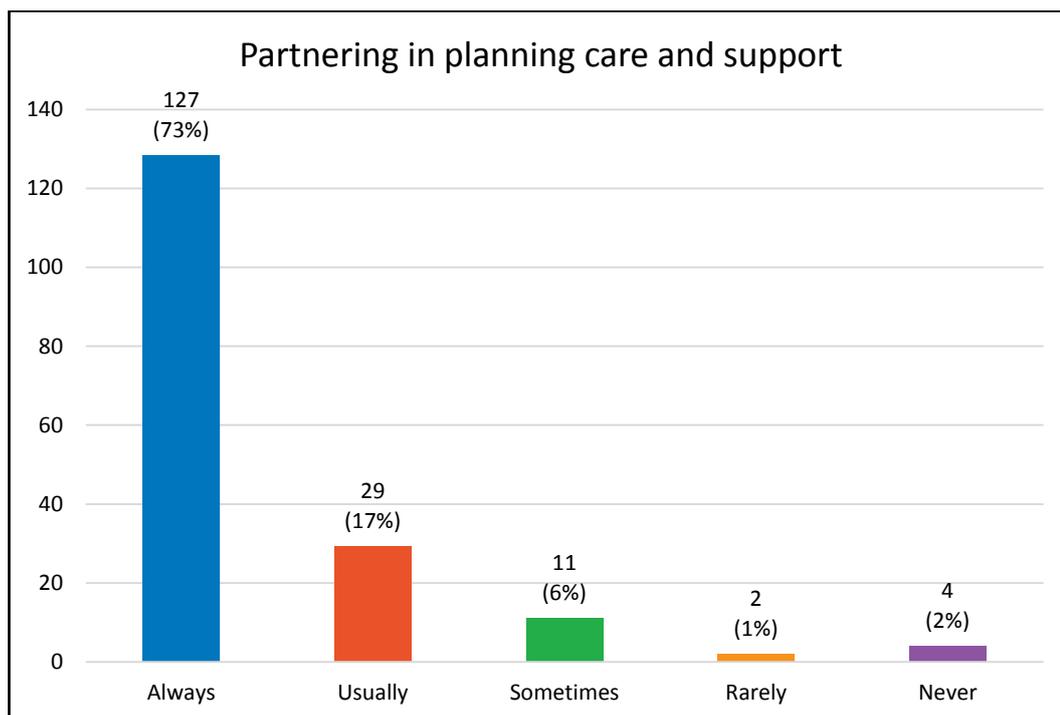
Theme	Examples of comments
<p>Time for two-way communication (n=47) This included:</p> <ul style="list-style-type: none"> • being listened to • being asked more questions • more time and access to communicate with clinicians 	<p>“If the health care professionals actually listened to what we say, we know our child best and know their ‘normal’...”</p> <p>“Staff could take the time to listen. I was completely ignored and made to feel like an inconvenience.”</p> <p>“Conversations around how to speak to my child particularly when asking how the injury happened.”</p> <p>“The counsellor could have asked me for information about my child's condition.”</p> <p>“Speaking to the parents more after each session at CAMHS. Teens generally don't talk to their parents so it's very frustrating and difficult to know what to say and do.”</p> <p>“Further discussion with senior medical staff.”</p> <p>“More informed and more discussions with paediatricians when children in neonates.”</p> <p>“Felt a bit rushed would have liked a bit of time to ask questions.”</p>
<p>Increase in amount and quality of information (n=28) This included receiving:</p> <ul style="list-style-type: none"> • more information • up to date information • consistent information • comprehensive information 	<p>“More complete information shared earlier, rather than only receiving some info later on, after we enquired directly.”</p> <p>“Probably couldn't have been more involved considering most decisions were lifesaving and we trusted Dr's to do that, but it is always appreciated to be kept up to date and up to speed with medical decisions as they are happening. And in layman's terms that parents can understand.”</p> <p>“Whilst in the NICU in PCH, I don't think that all of the options were spelled out. Also, each nurse seemed to have a different opinion which made decision making difficult.”</p> <p>“Child Health nurse didn't offer much advice to help me be involved in overcoming my baby's issues. PCH and Midland paediatrician were excellent.”</p> <p>“Having care/treatment options made aware or more clearer. When there are multiple specialists/departments involved, multidisciplinary team meetings are a must. Parents should not have to demand these. Communication (especially timely communication) between specialities can be very poor</p>

	<p>which can have a negative impact on meeting treatment goals which inevitably leads to more appointments being required, increased hospital admissions and increased length of stay.”</p>
<p>Incorporating family strengths, experiences and circumstances into decision-making (n=26) This included:</p> <ul style="list-style-type: none"> • having parent/carer experience and views incorporated into planning • asking about and considering the limitations and strengths of families in decision-making 	<p>“My insight and input taken on board with a little more weight than it has at times.”</p> <p>“CDS and CAMHS seemed to dismiss my concerns and discharged my son prematurely. Listening and trying to understand my concerns then formulating a plan with me would have been more helpful.”</p> <p>“Discussion with me around care planning rather than being presented with the teams plans that are not practical for our family. Giving advanced notice of meetings to allow me to arrange attendance.”</p> <p>“Most of the time is it great, but some of the time, health professionals do not listen to us, and will not utilise our experience in caring for our child.”</p> <p>“We live remotely and had very little notice on the appointment date and that makes organising time off work, travel & accommodation harder and more expensive.”</p>

What did staff say?

Clinical staff were also asked about how often they partner with consumers in planning their care or support. Nearly three quarters (73%, n=127) replied they *always* partnered with consumers. However, the adequacy of this needs to be considered in relation to clinicians personal view of what it means to genuinely partner with consumers in contemporary health service delivery. Interpretation of the findings also needs to consider that those who completed the voluntary survey may have a higher interest or commitment in consumer engagement than others.

Figure 6: Partnering in planning care and support



The was an open-ended question posed to clinical staff about how CAHS could better partner with consumers, but the responses covered both 'Making decisions about care and support' or 'Information and communication' and as such are presented at the end of the section on 'Direct care and support'.

What did the organisational data say?

Consumer Feedback Data

Consumer Feedback (complaint, compliment and contact) data provided for the three years from January 2017 until December 2019 (inclusive) showed that relevant complaint categories for 'Making decisions about care and support' from Tier 1 – 'Decision making' and 'Rights, respect and dignity', accounted for less than 0.5% and less than 2% respectively.

CAHS Quality Action Plan Data

The table below is drawn from the overview of the CAHS Quality Action Plan (QAP) Progress Overview Tool for NSQHSS Standard 2. The actions relevant to 'Making decisions about care and support' are colour coded red, yellow, green to respectively indicate CAHS's risk rating of currently meeting this action item – high, medium, low.

Table 4: QAP Data on Direct Care and Support

Standard 2 Actions, Intent and Risk Rating	Commentary
Integrating Clinical Governance	
<ul style="list-style-type: none"> Action 2.1. Safety and quality systems support clinicians in partnering with consumers in the delivery of care. 	Consumer Engagement Framework in progress
Applying quality improvement systems	
<ul style="list-style-type: none"> Action 2.2. Quality improvement systems are used to support processes for partnering with consumers at the level of the organisation. 	Standard 2 reporting in progress
Sharing decisions and planning care	
<ul style="list-style-type: none"> Action 2.6. Patients receive safe and high-quality care by being involved in decisions and planning about current and future care. 	Policies require scoping and review
<ul style="list-style-type: none"> Action 2.7. Clinicians work with patients to enable them to be partners in their own care. 	Policies require scoping and review

Information and communication

The 'Information and Communication' area of Direct Care and Support specifically relate to the following actions and associated intentions:

- Action 2.3. Consumers are provided with information about their healthcare rights.
- Action 2.4. The health service organisation ensures that its informed consent processes comply with legislation and best practice.
- Action 2.5. Patients who do not have the capacity to make decisions about their care are identified, and systems are put in place so that the, or agreed substitute decision-makers, are involved in decision-making, including informed consent.
- Action 2.8. Consumers receive the information they need in a way that is appropriate for them.
- Action 2.10. Consumers receive the information they need to get the best health outcomes, and this information is easy to understand and act on.

What did consumers say?

Parent and carers, as well as young people were asked if they were given information about their child/ren's or their own care and support that they could understand. Just over half (53%, n=46) of young people replied *always*, while three quarters (76%, n=403) of parents and carers replied *always*.

Figure 7: Young people given information they could understand

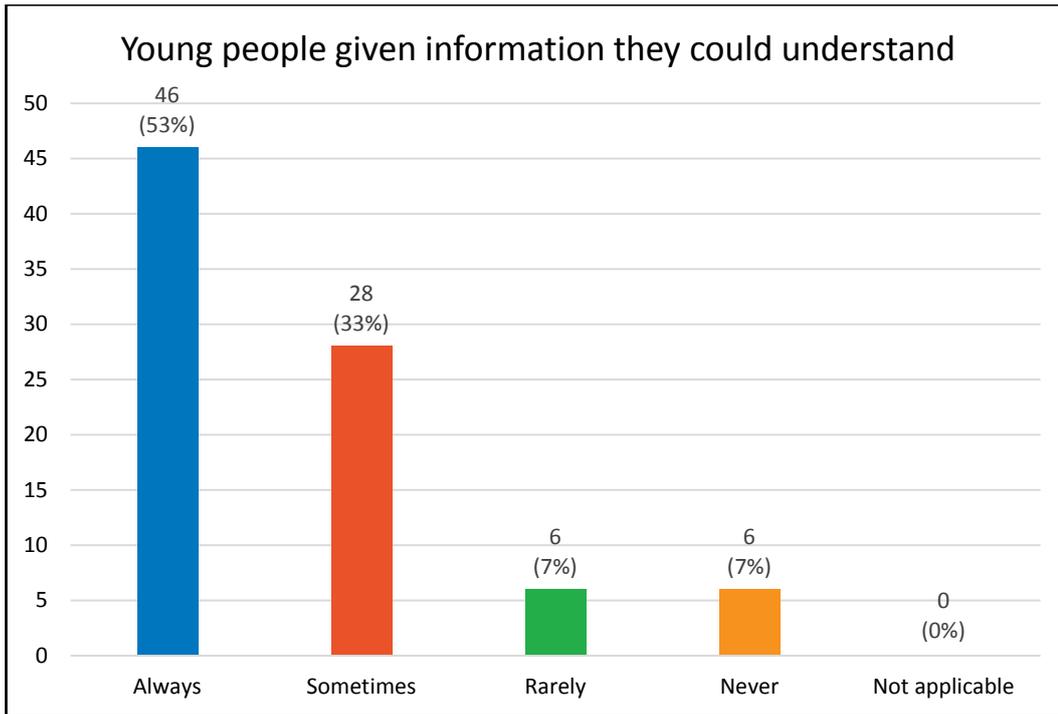
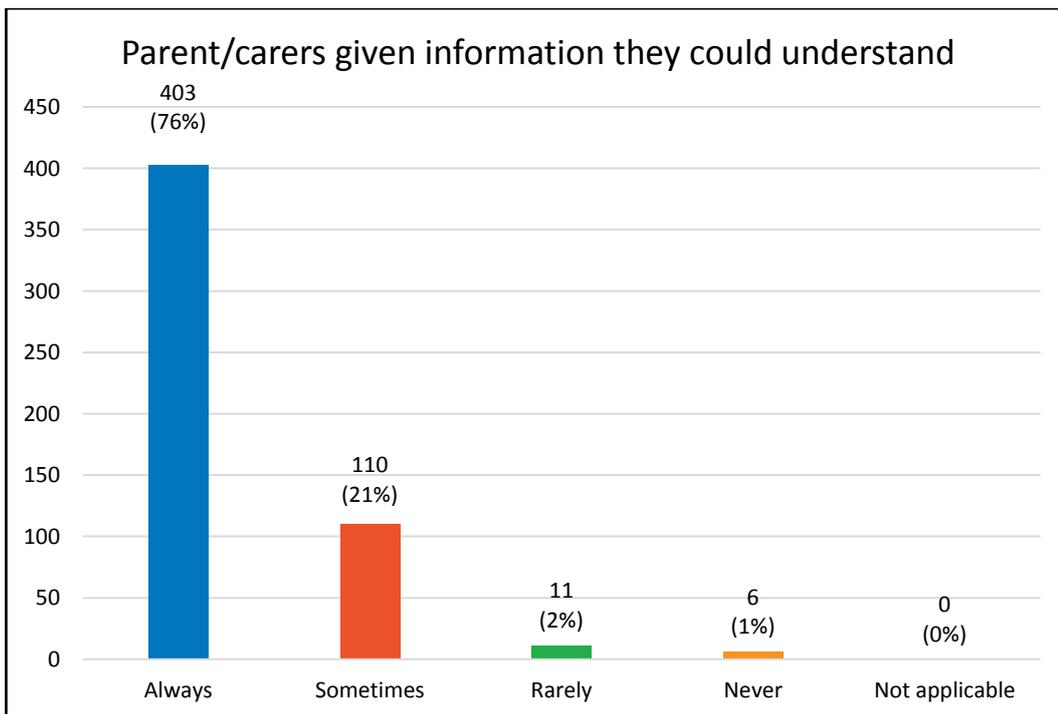


Figure 8: Parents/carers given information they could understand



Those who replied *sometimes*, *rarely* or *never* were asked how the information could be improved. Only 18 young people responded, compared to nearly 80 (n=79) parents and carers. The responses have been themed and key themes emerging from comments made by parents and carers and young people are presented in Tables 5 and 6. Examples of comments for each theme identified have been included.

The three main themes emerging from young peoples' responses included two related to information and one related to communication. Again, there was considerable overlap between the three themes, which included:

- Provide more information
- Communicate for understanding
- Clear, easy and age appropriate information

Three main themes emerged from responses by parents and carers and included:

- Information made available and sources accessible
- Delivery is complete, compassionate and understood by the consumer
- Clear and simple information

Table 5: Young people's responses to how information could be improved

Theme	Examples of comments
<p>Communicate for understanding (n=9) Taking time and using resources to communicate in a way that allows young people to understand.</p>	<p>“Sometimes I found the Drs spoke to my mum more than me and I didn’t understand some words used.”</p> <p>“By talking to explain it to me.”</p> <p>“Time to read and understand before being rushed through appointments.”</p> <p>“Talk to us in more depth. Give the patient a better understanding about the situation at hand.”</p> <p>“Being disseminated in a less rushed manner.”</p> <p>“To be more clear and less dismissive.”</p>
<p>Clear and age appropriate information (n=7) This would help young people understand our service, as well as their own care and support.</p>	<p>“Nothing is provided, information is really unclear and especially on the website doesn't tell you anything about what the service works with so I was turned away unnecessarily!”</p> <p>“Maybe for younger people make it more simple.”</p> <p>“Told to me in a more understandable way.”</p>
<p>Provide more information (n=6) Suggestions of formats for information were included in these responses.</p>	<p>“I was given little information. Doctors could communicate what they are talking about with other teams especially when you have 5 plus teams involved in your care.”</p> <p>“The hospital could have provided a sheet of contacts or places I can go to post surgery for help.”</p> <p>“Websites or booklets.</p>

Table 6: Parent/carer responses to how information could be improved

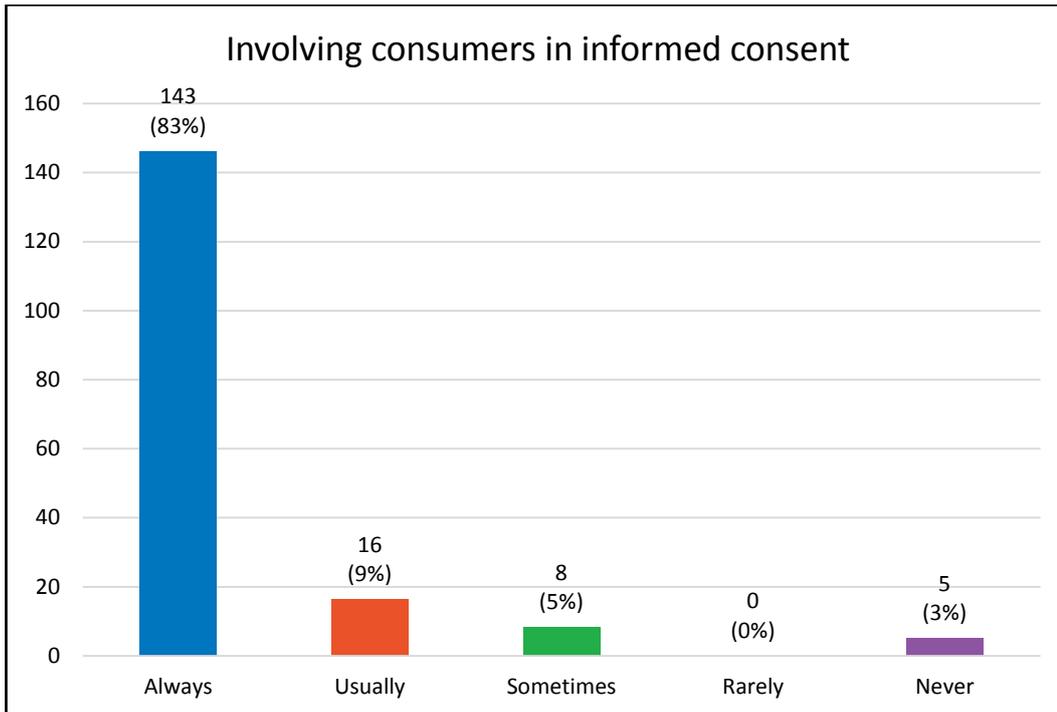
Theme	Examples of comments
<p>Information made available and sources accessible (n=34) This included receiving more information about:</p> <ul style="list-style-type: none"> • services and other sources of support • treatment plans, discharge notes, diagnoses and conditions <p>and being able to access information from appropriate clinical staff.</p>	<p>“I would have loved to have been told more about all the services available, we were never told about local medical kids groups [related to child’s rare condition]...”</p> <p>“Be told what services that my child and I were able to receive.”</p> <p>“Follow up information (so information sent more than just at the time of crisis or appointment when you may not be able to take it in). Multiple formats (paper, links, suggested reading links etc).”</p> <p>“After surgery we were given no aftercare information, literally none. I had to go back and ask about swimming and exercise, there was no patient release procedure or advice at all.”</p> <p>“Easier options to get in touch with the specialists. It’s very hard to get through to them directly or get a call back.”</p> <p>“Take home pamphlets for large topics because I would forget.”</p> <p>“Some information was basic and there were not many links to help you to find out more information that was reliable - only google sources that could be not mainstream practice or researched based therapies (i.e. dangerous and unreliable). If the hospital resources were more thorough people would be satisfied that they were well informed.”</p>
<p>Delivery that is complete, compassionate and understood (n=18) This included:</p> <ul style="list-style-type: none"> • providing all the information slowly • compassion and empathy • checking for understanding or 	<p>“Neonatology was our only negative time. The Drs need to be more compassionate and explain things in a way that scared, sleep deprived, upset parents can understand...”</p> <p>“By asking if I understood or putting it another away.”</p> <p>“Rare diagnoses need more empathetic staff especially at first appointment.”</p> <p>“As a first-time parent, it's always very daunting. So probably some additional time to explain.”</p> <p>“By having someone explain how and why decisions have been made rather than avoiding answering questions like politicians.”</p>

asking for questions	“Tell us everything and don’t keep info hidden in case it might upset us.”
<p>Clear and simple information (n=17) There was a focus on use of non-medical terminology.</p>	<p>“It needs to be explained logically and in language people who are not medically trained can understand.”</p> <p>“Using language that is understandable to those of us who aren’t medically trained. Medical jargon can feel like a foreign language sometimes and it’s hard to always stop to ask questions.”</p> <p>“Test results could have included a fact sheet related to results in non-medical language.”</p> <p>“More information required from start, clear, simple.”</p> <p>“Printouts regarding the condition and clear and deliberate instructions on how to treat it.”</p>

What did staff say?

Clinical staff were also asked about how often they involve consumers in informed consent processes and their provision and ability to provide information about their Healthcare Rights when delivering healthcare. Over 80% (83%, n=143) of responded that they *always* involve consumers in informed consent processes. Again, these results need to be considered in relation to the importance of involving consumers in informed consent and under which circumstances consumers are not involved.

Figure 9: Involving consumers in informed consent



The results presented in the two graphs below relate to providing consumers with information about their healthcare rights. The first relates to whether clinical staff provide consumers with information about their healthcare rights when delivering healthcare, in other words a question about what is done in practice. The second relates to whether clinicians are able to provide information about healthcare rights, in other words a question about knowledge.

Just over half (51%, n=87) of clinical staff responded that they *always* provide information about healthcare rights to consumers when delivering healthcare. However, over 90% (91%, n=159) *agreed* or *strongly agreed* that they are able to provide information about healthcare rights. These findings suggest that clinical staff feel they have the knowledge, but the practice of informing consumers about these rights is not widespread across CAHS.

Figure 10: Providing information to consumers about Healthcare Rights

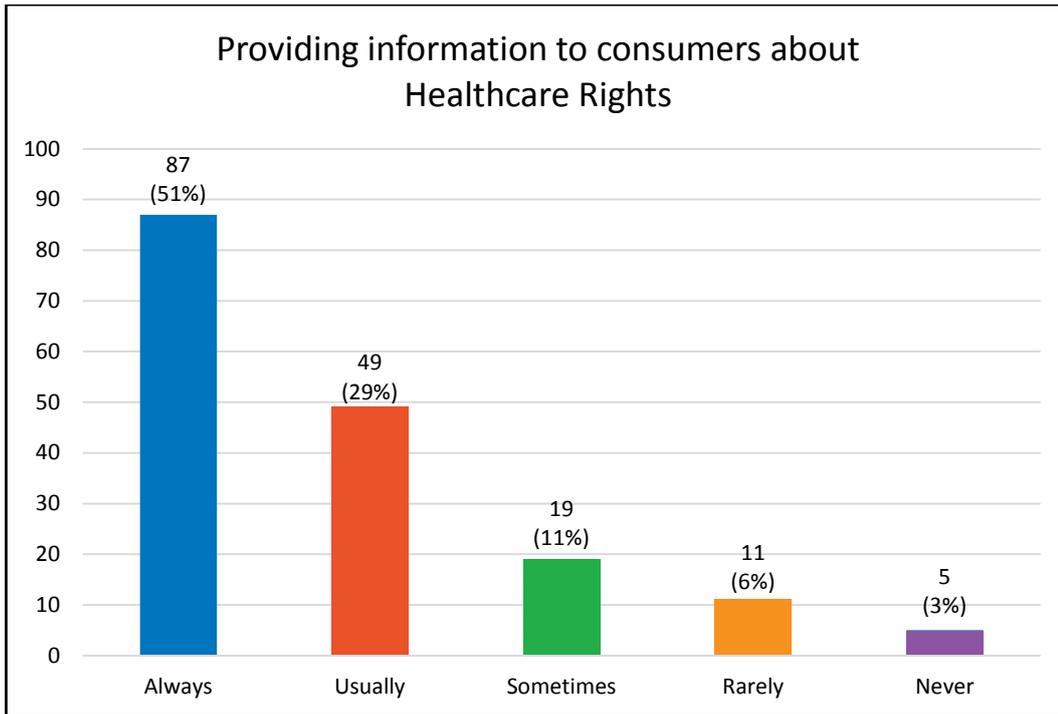
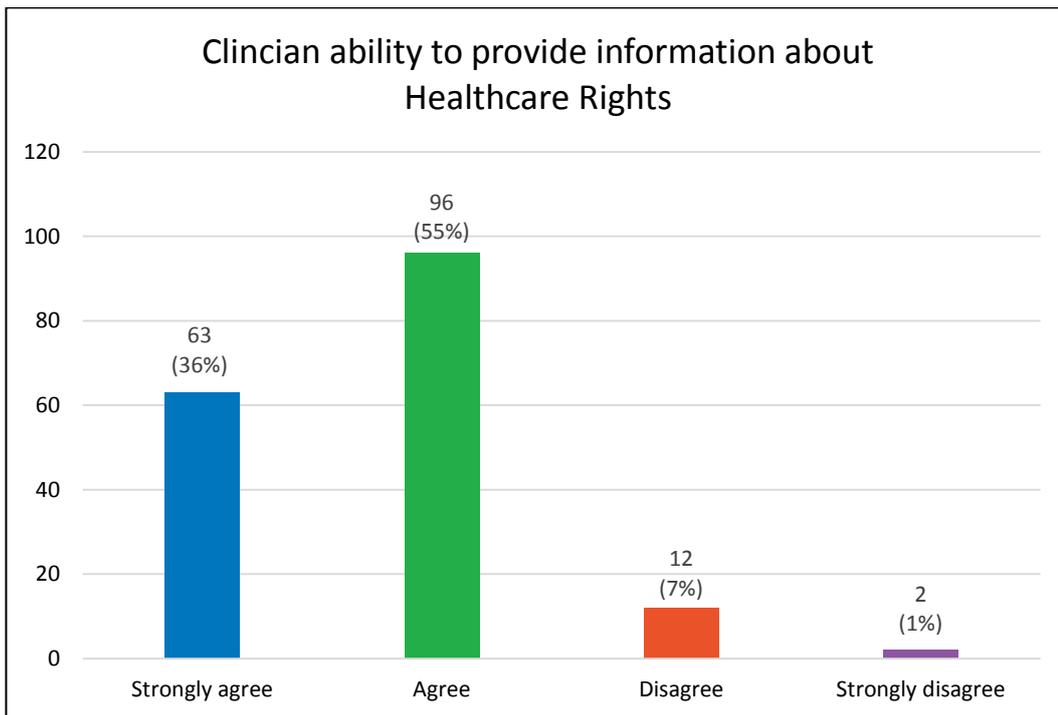


Figure 11: Clinician ability to provide information about Healthcare Rights



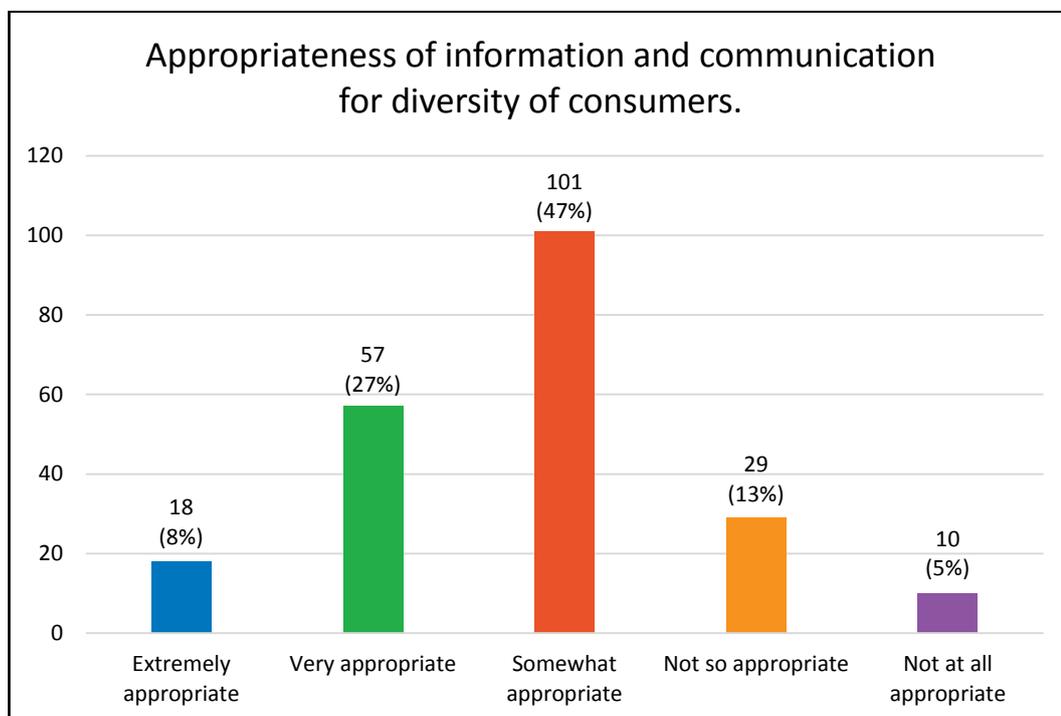
At a broader level, clinical and non-clinical staff were asked how appropriate they felt information and communication was for the diversity of consumers accessing CAHS services. Only 35% (n = 75) of staff members felt the information and communication in their service areas was appropriate. Staff were given the option to present their ideas for making

information and communication more appropriate and 98 staff provided responses. These ideas were analysed and three themes emerged, including:

- Deliver information in inclusive ways
- Increase use of digital communication and social media
- Consulting with consumers

More information regarding these themes is provided in Table 7.

Figure 12: Appropriateness of information and communication for diversity of consumers



The was an open-ended question posed to clinical staff about how CAHS could better partner with consumers, but the responses covered both 'Making decisions about care and support' or 'Information and communication' and as such are presented at the end of the section on 'Direct care and support'.

Table 7: Staff ideas for making information and communication more appropriate

Theme	Examples of comments
<p>Deliver information in inclusive ways (n=61) This was about improving access or use of resources and staff available to include consumers from diverse backgrounds.</p> <p>The focus was on the needs of consumers from CALD and NESB, but also the needs of:</p> <ul style="list-style-type: none"> • Aboriginal consumers • children and young people • LGBTQI consumers • those with low literacy levels • consumers with disabilities 	<p>“The provision of resources needs to be available in different language groups e.g. Welcome to your new baby magazine is only available in English, other leaflets are also only in English.”</p> <p>“Bilingual pamphlets, maybe a better welcome to the NICU pamphlets in general with info regarding important info, teaching, workshops, support, staff support etc.”</p> <p>“Have CAHS information printable in other languages, it is embarrassing to hand out pamphlets and brochures from other states because it is not available in all languages.”</p> <p>“Ensure there are no barriers for the non-English speaking families. Resources available in different languages. Easy and dependable access to interpreters.”</p> <p>“We have a lot of good information in English and also have some great resources for Aboriginal families but information in other languages still feels limited and the info I find I'm not always sure if it's endorsed by CAHS.”</p> <p>“Making information more diverse culturally and linguistically, provide information to engage with vulnerable pockets of consumers.”</p> <p>“More information available in multiple languages, for example simple correspondence in commonly used languages. Employment of more Ethnic Health workers who have an understanding of health rather than depending on Interpreters who may not have any health background.”</p> <p>“Communication with AHT consumers, to be genuine in effort, needs to utilise the trusting and understanding relationships that exist between Aboriginal Health Workers and consumers. Keep Aboriginal Health Workers informed, and we can keep Aboriginal consumers informed, with channels to voice their perspectives.”</p>
<p>Increase use of digital communication and social media (n=29) A range of suggestions were made that would</p>	<p>“An intranet which is friendly to negotiate for staff. And an internet site which families can access for resources relevant to their child’s needs to offer sign posting to conditions and services. Most families do not need you to do these things for them, they simply need to know what service and how to contact/engage with them. After looking into the service they may ask for a referral, this may be a good way of ensuring service matches expectation.”</p>

<p>increase the range of options for the delivery of information.</p>	<p>“Information should be presented in AV (e.g. a TV) with different languages and prompts to request from staff if other modalities needed.”</p> <p>“Easy access and availability of all information electronic versions/ web based would allow easier translation, voice overs, change font size.”</p> <p>“Better online resources would be helpful. CAHS also needs to consider the large number of consumers waiting to be seen and try to improve information and communications with them.”</p> <p>“Social media/online portals/chat functions to speak with health professionals for parents.”</p> <p>“Better information access through being able to use smart phones for all information better advertising of information available.”</p>
<p>Consulting with consumers (n=14) Consulting consumers from a range of backgrounds to ensure appropriate delivery and content of information.</p>	<p>“We need to have a better understanding of the diversity of our consumers and then tailor comms from there, in conjunction with asking them how they'd like to receive these comms. We make too many assumptions and excuses as opposed to innovatively trying to reach these audiences.”</p> <p>“Providing resources in various language formats to cater to diversity in areas. A dedicated publications committee with consumer representatives to engage in the ongoing design and development of consumer resources and information.”</p> <p>“Greater use of innovative strategies to deliver information and communicate with consumers under the age of 18. Strategies should be co-designed with young people and evaluated.”</p> <p>“Consult consumers however it cannot be done in a tokenistic manner as it is done now with a few select consumers. To do consumer engagement adequately you need to have dedicated FTE to do it - not add it on to existing workload.”</p> <p>“We prepare information for focus groups based on a particular initiative. We engage consumers to help us understand the service or project from their perspective - their journey.”</p>

What did the organisational data say?

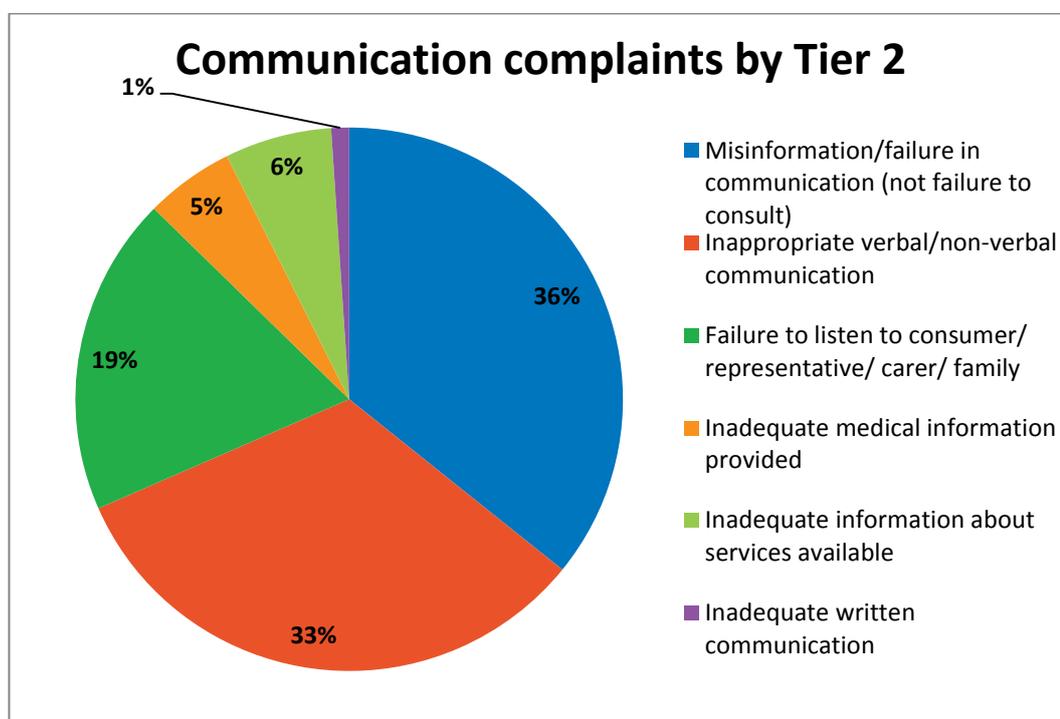
The organisational data includes CAHS consumer feedback data and data from the NSQHSS 2 QAP Progress Overview Tool.

Consumer Feedback Data

Data provided for the three years from January 2017 until December 2019 (inclusive) showed that Tier 1 - 'Communication' (excluding 'B4 -Inadequate/inaccurate personal information in a medical record' (n=7)) related to 16% (n=193) of all the complaints made. As can be seen in the graph below, the three highest Tier 2 categories were:

- Misinformation/failure in communication (not failure to consult) (36%, n = 68)
- Inappropriate verbal/non-verbal communication (33%, n = 62)
- Failure to listen to consumer/representative/carer/family = (19%, n = 36).

Figure 13: Communication complaints by Tier 2



Misinformation/failure in communication (not failure to consult) included the following Tier 3 descriptions:

- delayed information (n=34)
- given confusing/conflicting information (n=20)
- given inaccurate/wrong information (n=14).

Inappropriate verbal/non-verbal communication included the following Tier 3 descriptions:

- careless comments or person speaking beyond their authority (n=48)
- inappropriate demeanour/non-verbal communication (n=14).

QAP Data

The table below is drawn from the overview of the NSQHSS 2 QAP Progress Overview Tool. The actions relevant to 'Information and communication' are colour coded red, yellow, green to respectively indicate CAHS's risk rating of currently meeting this action item – high, medium, low.

Table 8: QAP Data on Information and Communication

Standard 2 Actions, Intent and Risk Rating	QAP Status
Healthcare rights and informed consent	
<ul style="list-style-type: none"> Action 2.3. Consumers are provided with information about their healthcare rights. 	Charter chosen; implementation required
<ul style="list-style-type: none"> Action 2.4. The health service organisation ensures that its informed consent processes comply with legislation and best practice. 	Policies in place; a review would be of benefit
<ul style="list-style-type: none"> Action 2.5. Patients who do not have the capacity to make decisions about their care are identified, and systems are put in place so that they, or agreed substitute decision-makers, are involved in decision-making, including informed consent. 	Policies in place
Communication that supports effective partnerships	
<ul style="list-style-type: none"> Action 2.8. Consumers receive the information they need in a way that is appropriate for them. 	Consumer profile for CAHS in progress
<ul style="list-style-type: none"> Action 2.10. Consumers receive the information they need to get the best health outcomes, and this information is easy to understand and act on. 	Current processes require review

Clinical Incident Data

Since 2014, documentation issues account for 20% of the clinical incidents at CAHS, albeit rated as 3 in the Severity Assessment Code. Documentation refers to various sources of information including medical records, forms, informed consent documentation, patient discharge information/instructions, check lists, policies/procedures/instructions/guidelines, consultation referrals/requests and so on. The incident categories include:

- ambiguous/incorrect/incomplete
- incorrect patient
- temporarily unavailable/delay in accessing
- confidentiality breach
- permanently unavailable.

For the 6 months between November 2019 and April 2020, 52% (n=55) of clinical incidences related to documentation being ambiguous/incorrect/incomplete. Over half (58%, n=61) related to paper medical record or forms.

Staff Perspectives on Direct Care and Support

Responses to the open-ended questions in the interviews with key staff and qualitative comments made by clinical staff were too broad to be placed into 'Making decisions about care and support' or 'Information and communication', so they have been compiled together here.

Staff survey – qualitative comments

The table below details the four main themes identified from the qualitative responses from the question as to how CAHS could better partner with consumers. Thirty-eight percent of clinical staff respondents (n=70) contributed to this question.

Four main themes emerged from staff about how they could better partner with consumers. These were:

- Responsive consultation with consumers
- Accessible information that meets consumer needs and preferences
- Standards and support for staff
- Involvement of consumers in care planning and decision-making

The first of these themes relates to the consultation component of consumer engagement and will be represented in that section. Example quotes are given in Table 9 below.

Table 9: How could CAHS better partner with consumers?

Theme	Examples of comments
<p>Responsive consultation with consumers (n=27) This included:</p> <ul style="list-style-type: none"> • providing more and varied opportunities for consumer consultation • being guided by and more responsive to consumer input 	<p>“Have more time to really listen to consumers. Or making feedback more digital i.e. via surveys on ipads mounted around the hospital.”</p> <p>“More feedback forms from the parents. Every parent should be given one and they can recommend ways to improve our practice.”</p> <p>“Regular ward-based meetings with families of long term pts or frequent flyers to identify ways we could do better. Each ward could / should have a list of parents to liaise with regarding pertinent issues - ie their own consumer liaison group.”</p> <p>“On site parent/caregiver workshops to educate and empower parents. Explore the idea of patient workshops. Create more forums to hear the parents or patients voice. I have previously organised for a parent to speak at the Grand Round and I include parents as presenters at study days - this is well received.”</p> <p>“Make ourselves available to listen to concerns and ideas on how we can improve customer satisfaction.”</p> <p>“Listen to parents regarding their experience in NICU and impact on siblings regarding exclusion of children visiting. A parent led charity has campaigned and fundraised for the use of NICView cameras that are widely used in other NICUs but still not implemented here. This would make a massive difference to our NICU families and our visiting policy an embarrassment when compared to all other NICUs in Australia.”</p> <p>“I'd like to know what specific information consumers would like to receive about their healthcare rights and how I could incorporate this into my clinical practice so that consumers are informed about this.”</p>
<p>Accessible information that meets consumer needs and preferences (n=20) This included providing:</p> <ul style="list-style-type: none"> • translated material • delivery online or through social media • clear information about 	<p>“Education material designed for low literacy in other languages. Phone apps in multiple languages. TV advertising on SBS in multiple languages.”</p> <p>“More use of technology or social media- we will be able to engage with a larger number of consumers by doing so.”</p> <p>“As an organisation I would like us to become more social media friendly.”</p> <p>“Get up to date with technology and use the formats that the younger tech savvy generation use.”</p> <p>“A more clear advertisement of what service delivery is available to support staff when consumers are</p>

<p>services and processes that raises awareness in the community</p>	<p>asking for service that is not offered or available.”</p> <p>“Have an easy to understand and transparent overview of what services can be accessed, the pathways to these services and the wait time for these services. Currently other health professionals, such as GPs, education stakeholders, such as teachers or School Psychologists, and parents have difficulty navigating the service.”</p> <p>“Increase awareness of Community Health Nurse/School Nurse role, so the public are aware of the offer of service to children, young people and families - so they can access us better.”</p>
<p>Standards and support for staff (n=16) This included having:</p> <ul style="list-style-type: none"> • expectations • resources • time • relevant training to better partner with consumers. 	<p>“I believe this begins with the healthcare provider. Healthcare providers should feel clinically supported from management and confident in their role, and have respect for their position and work they provide. All health professionals should be aware and confident of their scope/duties within their role, to ensure all staff are providing the same, safe and effective practice to clients across all catchments. I feel this could be improved in our team. Ensuring that clinical practice is consistent and equal across all catchments is vital. This equality and consistency in caregiving leads to building trust crucial for a professional partnership- allows clients to more clearly understand what to expect from the service. Clinically supported staff, utilising current and evidence-based skills, practicing within their scope is one idea I feel that will lead to staff better partnering with consumers/clients.”</p> <p>“Honestly believe that if the organisation supported staff better there would be direct flow-on effects for patients.”</p> <p>“Our child health nurses require more time & flexibility for the assessments, if they truly are able to work in partnership.”</p> <p>“Having the time to dedicate to this. I often encompass this into another task and wonder if the message is sometimes lost as their focus is elsewhere. However this is sometimes the only way I can deliver this information.”</p> <p>“Access to more cultural diverse education materials for non-English speaking families. Including consumers in the training of clinical workforce - (ie) seminars run by consumers on bedside manner, speaking up for safety, quality improvement, feedback from patients, etc.”</p> <p>“During orientation of workplaces the need for partnering with consumers should be an area highlighted of importance. Also knowing the government and non-government areas of service that can support consumers and empower their health care choices assists in partnering with consumers.”</p>
<p>Involvement of consumers in care</p>	<p>“Stop dictating treatment plans to vulnerable youth.”</p> <p>“-- ask the question about who we can share information with from the beginning (ie other</p>

planning and decision-making (n=10)	<p>departments/health services/ school etc.) - ask how best to contact the families, and who is best to contact (mother/father/ other relative)..."</p> <p>"Requesting doctors should be encouraged to explain procedures to parents/ patients at the time of requesting and not leave it up to the proceduralist to have to fully explain potentially distressing scenarios just prior."</p> <p>"Allowing a wider group within the family to participate."</p> <p>"Open discussion about options for treatment and support. Many clients attend and weren't aware of their options to manage their child's difficulties."</p>
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Staff interviews

Responses from staff who were interviewed were not strongly focused on consumer engagement at the level of ‘Direct care and support’. A reason for this may be that consumer engagement is currently more often understood at the level of consumers providing feedback and/or consulting with consumers. However, there were both strengths and weaknesses identified by staff in relation to consumer engagement at the level of ‘Direct care and support’.

Interestingly, the three broad areas of strength – information, culturally appropriate services and provision of family/patient centre care, were also three of the four broad themes identified as areas of weakness. One interpretation of this is that these aspects are understood as key to delivering quality care and support to consumers and may be areas of strength for some service areas, albeit requiring further improvement elsewhere. Having positive examples in these areas across our service provides a good grounding for this improvement.

Table 10: Strengths and weaknesses of direct care and support at CAHS

Strengths	
Providing information	<p>There were examples across CH, CAMHS and PCH about how they provide accessible information appropriate for consumers. This included:</p> <ul style="list-style-type: none"> • Q&A pamphlets or videos • Message boards from young people previously on the ward • Utilising SMS to provide information in order for Google Translate to be used by consumers • Educational events or activities <p>Fun on Four is also working with PCH to get a welcome script translated into the top five languages other than English spoken by PCH consumers.</p>
Culturally appropriate services	<p>There was an example of how Aboriginal mental health workers at CAMHS help ensure a culturally appropriate service is provided for Aboriginal consumers.</p>
Provision Family/Patient Centred Care	<p>Versions or approaches to family/patient centred care was mentioned across all four service streams. However, CAMHS, Allied Health (including CDS), Neonatology and Community Health appeared to have integrated family/patient centred care more fully into their service delivery.</p>
Weaknesses	
Consistency of Family/Patient Centred Care	<p>The delivery of family/patient centred care was identified as being a quality or skill set some staff and teams had, while it was lacking in others. Challenges to ensuring the approach is more consistent across CAHS included:</p> <ul style="list-style-type: none"> • some staff not identifying it as part of their role and redirecting consumers • how to train and change the behaviours of staff so as to provide family/patient centred care

	<ul style="list-style-type: none"> • shifting away from expert, paternalistic views of delivering health care • setting consumer expectations about what to expect when receiving care and support from our service
Cultural competence (including translation)	A lack of cultural competence amongst staff or delivery of culturally appropriate services was raised by staff, including from two teams dealing directly with consumers from CALD backgrounds. The increased vulnerability of consumers, due this limitation in our services was highlighted by staff. However, barriers were also raised in relation to translating documents and or making them culturally appropriate due to the cost and diversity amongst our consumers.
Capacity to improve partnerships	<p>Staff gave ideas of how partnerships could be improved between consumers and our service including:</p> <ul style="list-style-type: none"> • follow up phone calls • social media • peer support workers <p>However, resourcing these was identified as barrier to implementing these ideas.</p>
Functionality and availability of digital communication and social media	Improving communication for consumers is limited for some service streams or teams by access to social media and digital communication.

Summary of findings – Direct care and support

Making decisions about care and support

61% of parents and carers *a/ways* felt they had the opportunity to be involved in making decisions about their child/ren's care and support, while only 30% of young people felt they had that opportunity. Over a third (35%) of WACHS consumers felt they didn't have a say in their child's care or support at PCH.

Parents and carers who did not *a/ways* feel involved said they wanted:

- more time given to two-way communication between themselves and clinicians
- an increase in the amount of information they were given and the quality of that information
- their family strengths, experiences and circumstances incorporated into decision-making

Similar themes emerged from surveys with young people, although something unique for young people was the request to be directly involved, rather than through their parents. The three themes were:

- given the information to be involved in decision making
- two-way communication that ensures they are listened to and can ask questions
- being directly involved

These themes reflect those raised in staff interviews, through which it was identified that although we have examples of patient/family centred care within our service it is not consistent due to a number of barriers. These barriers include:

- some staff not identifying it as part of their role and redirecting consumers
- how to train and change the behaviours of staff so as to provide family/patient centred care
- some staff having paternalistic views of delivering health care
- setting consumer expectations about what to expect when receiving care and support from our service

The need for a more culturally competent service that extends beyond the specific teams providing this in certain service streams.

73% of staff replied they *a/ways* partnered with consumers and there were only 14% of the qualitative responses to the question of how we could better partner with consumers related directly to the need to involve consumers in care planning and decision-making. Similarly, the organisational priority data from CAHS complaint data and the QAP suggest that sharing decisions, planning care and ensuring the rights, respect and dignity of consumers is maintained, were not major issues at CAHS.

However, according to the QAP data, having the safety and quality systems and processes to support clinicians to partner with consumers is a greater issue. This is supported by 22% of qualitative comments which raised the need for standards and support for clinical staff, including time, resources and training.

How are we going with this at CAHS?

It is assumed CAHS would want consumers to feel more involved in the decisions about their own or their child/ren's care and support, than reported in this survey. More time and support for staff to involve consumers and improvements in how consumers are involved appear to be what the combined data is revealing. This suggests that what may be needed is:

- 1. a shared expectation/standard about partnering with consumers that allows clinicians more time and support, if necessary, to communicate effectively with consumers**
- 2. partnership/family centred care training in clinical care and support, importantly including how to partner with young people and consumers from diverse backgrounds, for staff who require it**
- 3. a culture/philosophy of partnership that is embedded in our service and can be seen in practice by consumers, including young people and regional consumer**

Information and communication

76% of parents and carers, but only 53% of young people, *always* understood information they were given about their own or their child/ren's care and support. The quarter of parents and carers who did not *always* feel they understood said they wanted:

- information made available and easily accessible
- delivery of information that is complete, compassionate and understood by the consumer
- to be given clear and simple information (not medical terminology).

In addition to this 'an increase in the amount of information they were given and the quality of that information' was raised as an issue in the previous section on 'making decisions about care and support'. Again there were similar themes raised by young people wanting:

- more information
- to be communicated with in a way that results in them understanding
- clear, easy and age appropriate information.

Staff views supported those of consumers, with only 35% agreeing that information and communication at CAHS was appropriate for our diversity of consumers. Accessible information that meets consumer needs and preferences was highlighted by staff in qualitative responses to the question of how we could better partner with consumers, accounting for 28% of the responses. This was also raised in the staff interviews in relation to providing translated information and improving information delivery through digital communication and social media.

Based on CAHS complaint data 'Communication' was the most significant area of complaints and accounted for 16% of all complaints made – with main issues being misinformation/failure in communication and inappropriate communication. Ambiguous/incorrect/incomplete documentation accounted for over half of the clinical incidences related to 'Documentation' in the last six months (November 2019-April 2020).

83% of staff replied that they *always* involve consumers in informed consent processes. This is in line with the QAP analysis which identified actions related to informed consent as a medium

risk for CAHS. However, while 51% of staff responded that they *always* provide information about healthcare rights to consumers when delivering healthcare, 91% *agreed* or *strongly agreed* that they are able to do so.

How are we going with this at CAHS?

In regard to effective communication and information provision, again there appears to be a need for improvement in directing consumers to information and delivering information effectively and consistently. This may relate to improvements through:

- 1. resources for consumers that address specific needs and preferences, including those of young people and NESB**
- 2. development and use of digital communication and social media for sharing information**
- 3. communication (for understanding) training and resources for clinical care and support for staff who require it (may be some overlap with partnership/family-centred care training)**

In relation to Healthcare Rights, some actions may be required for:

- 4. raising staff awareness about informing consumers of their Healthcare Rights**
- 5. promotion of Healthcare Rights for staff and consumers throughout the organisation**

Feedback

Feedback crosses two criteria of Standard 2 – Clinical governance and quality improvement and Partnering with consumers in organisational design and governance. Within these criteria there is an expectation that systems are designed and used to support consumers to be partners in planning, designing the service and governing the organisation.

The specific actions and associated intentions for feedback include:

- Action 2.1. - Safety and quality systems support clinicians in partnering with consumers in the delivery of care.
- Action 2.2. - Quality improvement systems are used to support processes for partnering with consumers at the level of the organisation.
- Action 2.11. - Consumers help shape the way the health service organisation operates to achieve mutually beneficial outcomes, and these consumers are reflective of the diversity of the people who use its services or, if relevant, the local community.
- Action 2.14. -The workforce has an understanding of health care from the consumer's perspective, and the value that consumers can bring to organisational design and governance.

What did consumers say?

Parents and carers, as well as young people were asked about their experience of giving feedback, which could include giving a compliment, complaint or suggestion. Just over a third of parents and carers (35%, n=182) and young people (37%, n=30) who responded to this survey question had given feedback.

Those who had previously provided feedback, were given the opportunity to make suggestions of how the experience of could have improved. Only 16 young people and 84 parents and carers provided responses. The responses have been themed and key themes emerging from comments made by parents and carers and young people are presented in Table 11 and 12. Some examples of comments for each theme identified have been included.

The two main themes for the 16 young people who responded to this survey were:

- receiving a response or action to feedback
- accessibility of feedback processes

Another theme was that young people were *satisfied with the service and feedback process* (n=3).

One of the main themes emerging from responses by parents and carers was that they were *satisfied with feedback processes*. The other two key themes were:

- receiving a response to feedback
- accessibility of feedback processes

Table 11: Young people's responses to improving feedback processes

Theme	Examples of comments
	"My experience of giving feedback would have been better if..."
Feedback is responded to or acted upon (n=6) This referred to responses during direct care or support or afterwards.	"I knew something was done with my feedback." "My negative feedback was taken seriously and considered." "I would like to be informed of how my feedback was followed up/if it will be taken into action."
Feedback processes are more accessible (n=4) This incorporated comments in regard to anonymity and access.	"You didn't have to write your name." "Someone contacted me after my appointment so I can give a verbal feedback." "There was a specific place I was instructed to give it to."

Table 12: Parent/carer responses to improving feedback processes

Theme	Examples of comments
	"My experience of giving feedback would have been better if..."
Receiving a response to feedback (n=28) This included: <ul style="list-style-type: none"> • getting a response • receiving a response that was specific to the feedback given • being listened to • not feeling discriminated against • achieving an outcome from the feedback 	"My suggestions/ feedback was at least acknowledged as to have been received, even if it wasn't implemented." "I received confirmation that my compliment was received? I don't really have a suggestion here... it was fairly easy to give feedback." "They had read my feedback correctly and not given me a standard answer in reply." "Staff listened." "When giving negative feedback, it was addressed without a bias." "They listened more and actually took on board what we were saying and maybe even did a study on them to prove that what we do/did helped, worked in some way." "If you were sure that anyone actually read it and gave a damn. Perhaps a follow up phone call or

	<p>email and acknowledgment that whatever you said had been taken on board.”</p> <p>“Action had been taken. Updates on the action. Always seemed to get to a point but nothing has ever changed. Never passes to decision makers who can drive change.”</p>
<p>Satisfied with feedback processes (n=21)</p>	<p>“I could tell the health professionals knew how much we appreciated them but we could also have an open discussion on the best way to move forward that best works for the specific child.”</p> <p>“Feedback is always greatly taken, I have never had any issues.”</p> <p>“It was addressed to. Satisfactory standard so no comment.”</p>
<p>Accessibility of feedback processes (n=17) This included:</p> <ul style="list-style-type: none"> • having a range of formats • more opportunities • given information about how to give feedback • a focus on digital methods 	<p>“It was easily found on the website. If I was offered a feedback form on discharge.”</p> <p>“It could be given immediately - i.e. forms readily available on the wards (seeing as you can't have a phone or laptop on). I tended to not provide as much feedback as I wanted given the delay in doing it.”</p> <p>“This survey is a great way of giving feedback. Anonymous so you feel comfortable.”</p> <p>“Wasn't sure how to give online feedback. But had opportunity to take cards and gift to clinic and tell in person.”</p> <p>“I have only given verbal feedback at this stage to the treating team. I have not been offered any formal pathways for feedback. As the team are aware of my dissatisfaction they should provide direction on how to feedback.”</p> <p>“It was a digital format which allows a copy to be forwarded to me.”</p>

Young people and parents and carers who had not given feedback were asked the reasons for not giving feedback. There were six fixed response options, as well as an 'other' option, in which respondents were required to provide a description.

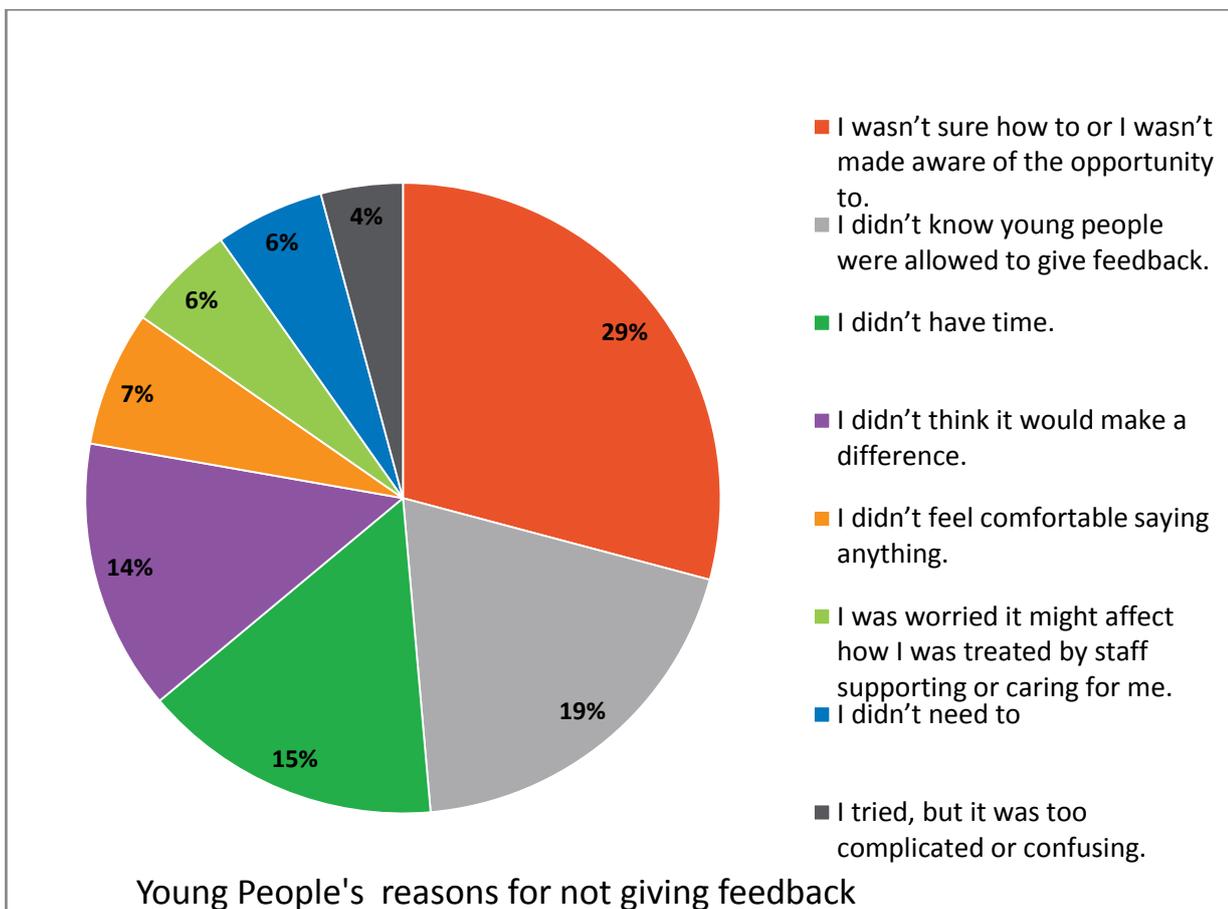
A total of 50 young people responded and the proportion of responses are displayed in Figure 15. The responses in the *other* were analysed in the young people survey, with the result that:

- some responses were included in existing fixed options.
- the fixed category 'I wasn't sure how to' was expanded to 'I wasn't sure how to or I wasn't made aware of the opportunity to'.
- the category of 'I didn't need to' was added.

A total of 333 parent/carers responded and the proportion of responses are displayed in Figure 16. The responses in the *other* were analysed in the parent/carer survey, with the result that:

- some responses were included in existing fixed options,
- the fixed category 'I wasn't sure how to' was expanded to 'I wasn't sure how to or I wasn't made aware of the opportunity to',
- three additional categories add including:
 - I didn't need to.
 - I didn't have capacity to.
 - I gave it directly to the clinicians.

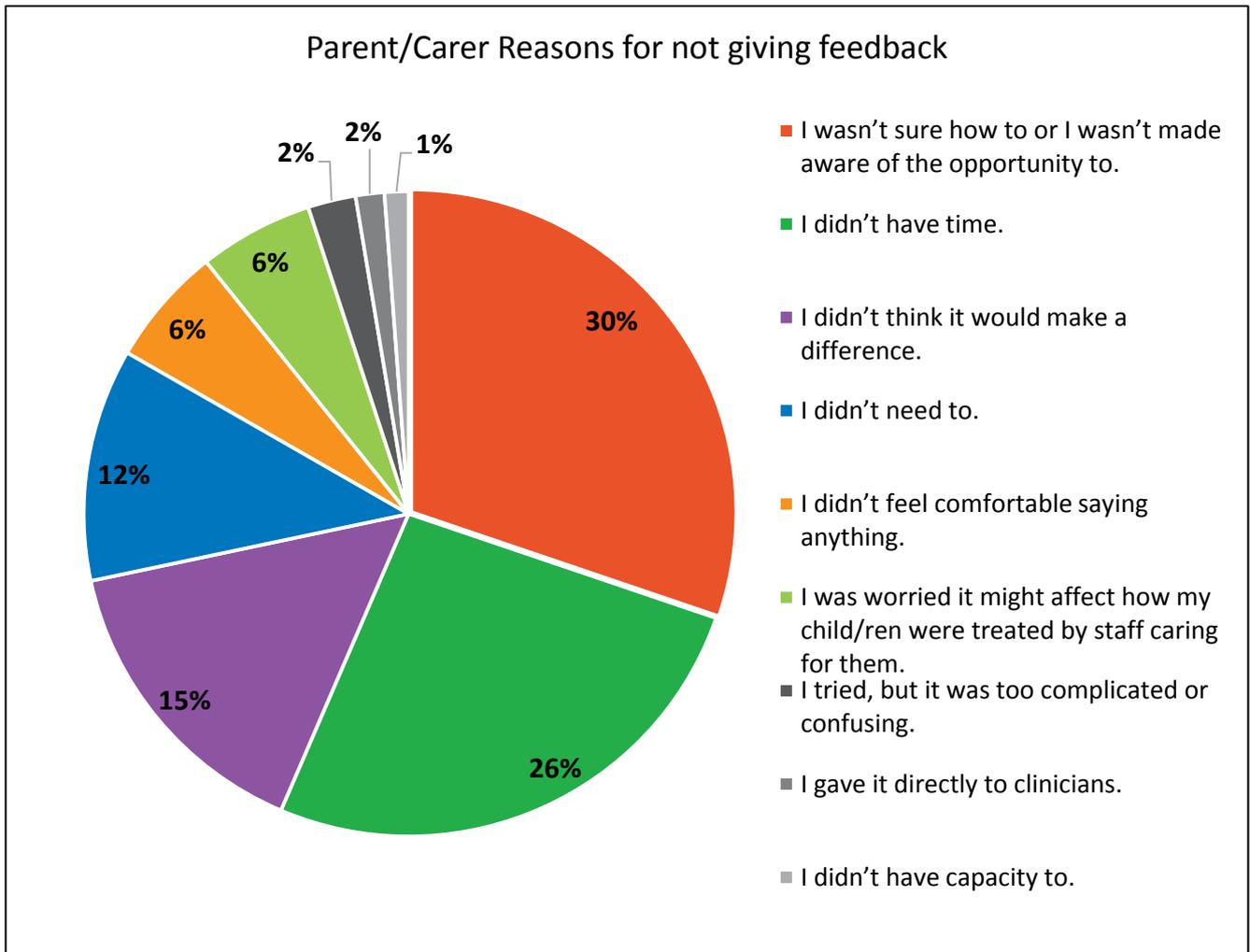
Figure 14: Young people's reasons for not giving feedback



Four key reasons account for over three quarters (77%) of the responses as to why young people don't give feedback. This was made up of young people not:

- being aware of the opportunity or how to make feedback (29%)
- knowing they were allowed to give feedback (19%) (a specific response option for young people)
- having time (15%)
- thinking it would make a difference (14%)

Figure 15: Parent/Carer reasons for not giving feedback



Four key reasons account for 83% of the responses as to why parents and carers don't give feedback. The highest proportion (30%) of responses related to not being aware of the opportunity or how to make feedback. Most of the other response options can be considered either *process* related or *outcome* related.

Process related responses include:

- I didn't have time.
- I didn't feel comfortable saying anything.
- I tried, but it was too complicated or confusing.

- I gave it directly to clinicians (the majority of responses were about positive comments).
 - I didn't have capacity to (this referred to being too exhausted or upset to give feedback).
- When grouped together, 37% of the responses related to the process of giving feedback.

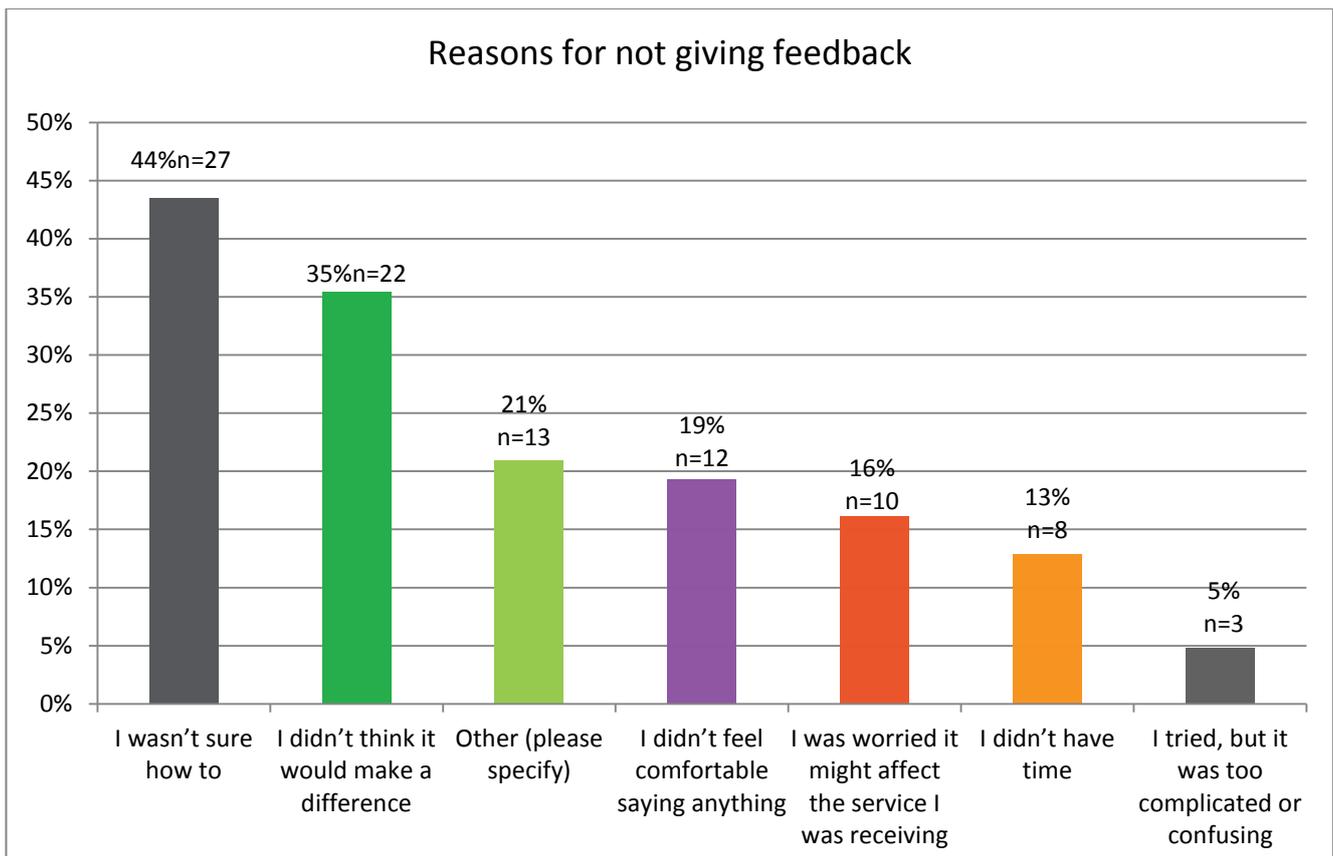
While responses related to the outcome of giving feedback, including:

- I didn't think it would make a difference.
 - I was worried it might affect how my child/ren were treated by staff caring for them.
- accounted for just over 20% of responses.

In regard to those (12%) who stated they didn't need to give feedback, there was possibly an underlying assumption that feedback equated to a complaint. This raises questions of how broadly or narrowly consumers understand feedback at CAHS.

Regional consumers were asked if they had ever given feedback to WACHS or PCH. More than half of people had not given feedback (58%, n=67). The main reasons people had not provided feedback were that they were not sure how to (n=27) or they didn't think it would make a difference (n=22). Further details are in the figure below. For those who had provided feedback, 20 consumers had not received a response, while 18 had received a response.

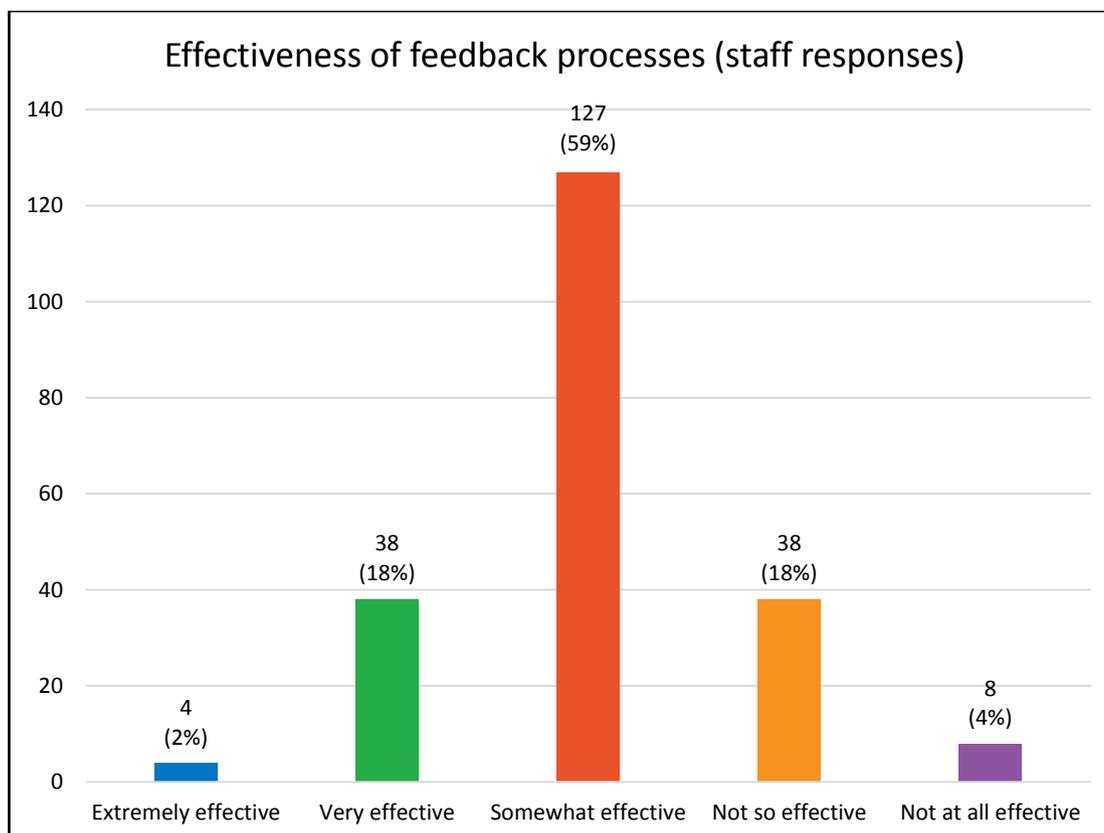
Figure 16: Reasons for not giving feedback (regional consumers)



What did staff say?

Just over half (59%, n=127) of staff indicated that they thought feedback processes for consumers were *somewhat effective*. The numbers of staff who thought they were *extremely effective* or *very effective* (20%, n=42) and those who thought they were *not so effective* or *not at all effective* (22%, n=46) were very similar, as can be seen in Figure 17.

Figure 17: Effectiveness of feedback processes (staff responses)



Staff had the option of providing ideas of how feedback processes could be improved. The 95 responses received were analysed and the top three themes were:

- improved use of digital and online technologies
- raising awareness of feedback opportunities
- using a variety of methods to gain feedback

These are explored in more detail in Table 13. Three other themes included:

- inclusive processes
- easier and more efficient processes
- delivering a response

Table 13: Staff ideas for improving feedback processes

Theme	Examples of comments
<p>Improved use of digital and online technologies (n=38) This included using digital technologies and social media for providing feedback and delivering organisational responses.</p>	<p>“Youth friendly options on Twitter, etc so they can click through and see a proposed leaflet and provide input.”</p> <p>“Apps or a survey monkey sent to mobile/email to get feedback for consumers.”</p> <p>“More opportunities/methods for delivering feedback rather than feedback form i.e. not a lot of people post things these days or go to a post office, but a lot of people have phones. If they had the ability to provide quick and easy feedback online, I think we would get a lot more involvement/feedback from consumers.”</p> <p>“Develop an app that linked them to all their services within CAHS. This way they can easily complete feedback forms following an appointment. This may also help with reducing DNAs and ensuring information is easily accessible to families to feel more connected with the service.”</p> <p>“Make it easier for them to provide feedback, currently there are feedback forms left in the clinics, which they miss. Maybe we should engage every client to do a quick online survey with the use of iPads at the end of appointments. Making sure appointment ample time is given to attend to this.”</p> <p>“Using the CAHS website to display consumer feedback and how it was reviewed and implemented would be a starting point so all consumers could see the value the organisation places in feedback.”</p> <p>“Using Facebook to give back information/ results and what will change due to feedback.”</p>
<p>Raise awareness of feedback processes (n=18) This referred to raising the awareness of consumers about the opportunities, processes and benefits of</p>	<p>“I think that consumers are not aware of how to provide feedback other than going directly to a staff member.”</p> <p>“Requires time to engage with the consumer so that they understand the importance of their feedback.”</p> <p>“Actively encouraging feedback at each appointment, providing parents with the ways in which</p>

<p>providing feedback. In some cases this would require also raising the awareness of staff.</p>	<p>they can provide feedback.”</p> <p>“Providing info on how to provide feedback several times during interaction and afterwards.”</p> <p>“Advertise through media.”</p> <p>“Being able to provide processes to staff so that they can provide the feedback process to consumers.”</p>
<p>Gaining feedback using a variety of methods (n=17) This includes:</p> <ul style="list-style-type: none"> • more efficiently using feedback data we have • consider a range of consumer references 	<p>“Current processes have been used for so long now.. we don't have any culturally secure way of providing feedback for Aboriginal/CalD consumers or for students (hence we get minimal), we overuse surveys and only get responses from the same cohorts, our consumer councils are not diverse enough, our ability to draw analytics from complaints is poor, our forms aren't embedded properly outside of the hospital, we don't properly promote Patient Opinion or analyse the data. Addressing any of these areas would improve feedback processes.”</p> <p>“There is always more we can do. I think there is so much we could be doing with tech. Eg. I pads with the sad, happy and average faces people can click for their experience in an area (eg. wait times in Pharmacy, toilets, etc.). Also we get a lot of honest feedback through patient opinion that we don't get through other avenues. I think we need to give consumers more options to give anonymous feedback, but let them know it will not be able to be investigated.”</p> <p>“Paper forms and a suggestion box to place them in available at clinic waiting rooms?”</p> <p>“Having another way to provide feedback rather than filling in the consumer feedback form.”</p> <p>“I believe face to face is important as it needs to be a conversation - people sometimes need support to unpack what they are unhappy with about a service - they need possible prompts on how we could make our service better.”</p>

In terms of staff interviews, many of the themes, emerging related to both 'Feedback' and 'Consultation', as they both relate to gaining, analysing and acting on consumer input. Those which crossed both forms of consumer engagement are shaded grey.

Table 14: Strengths and weaknesses of feedback

Strengths	
Key mechanism	Complaints and compliments collected through the formal feedback process at CAHS was identified by many staff as the only or main way they gain consumer input.
Limitations	
Incorporating change from feedback	Not having the resources and technology to analyse complaint data and use it to make service wide changes.
Mechanisms to suit all forms of consumer input	Staff spoke a lot about receiving a lot of informal, often verbal feedback. However, it was felt there was a lack of mechanisms to manage and document this feedback. A routine and overarching method for collecting consumer feedback CAHS wide was called for.
Tokenism	There were concerns that consumer input at CAHS was only sought for certain projects; not taken seriously and/or not meaningful. Paternalism and just seeing consumer engagement as a 'tick box' exercise were identified as issues.
Approaches exclude vulnerable communities	Aboriginal people, people from CALD backgrounds and those who did not read, write or speak English were identified as vulnerable groups excluded by existing feedback and consultation approaches used to gather consumer input.
Consumer awareness and preparation	There were concerns that consumers may not be aware of how to provide feedback or be involved in consultation, as well as the processes, protections and limitations around giving feedback and being involved in consultation.

QAP Data

The Table 15 below is drawn from the overview of the NSQHSS 2 QAP Progress Overview Tool. The actions relevant to 'Feedback' are colour coded red, yellow, green to respectively indicate CAHS's risk rating of currently meeting this action item – high, medium, low.

Table 15: QAP Data on Feedback

Standard 2 Actions, Intent and Risk Rating	QAP Status
Integrating clinical governance	
<ul style="list-style-type: none"> Action 2.2. Quality improvement systems are used to support processes for partnering with consumers at the level of the organisation. 	Standard 2 reporting in progress
Applying quality improvement systems	
<ul style="list-style-type: none"> Action 2.11. Consumers help shape the way the health service organisation operates to achieve mutually beneficial outcomes, and these consumers are reflective of the diversity of the 	Number of significant examples available

people who use its services or, if relevant, the local community.	
Partnerships in healthcare governance planning, design, measurement and evaluation	
<ul style="list-style-type: none"> Action 2.14. The workforce has an understanding of health care from the consumer's perspective, and the value that consumers can bring to organisational design and governance. 	Entire education space needs review

Summary of findings – Feedback

35% of parents and carers and 37% of young people had previously given feedback to CAHS, as well as 42% of WACHS consumers. They were asked what could have made it better, while many parents and carers stated that they were satisfied with the feedback process, the two main suggestions from parents and carers and young people were:

- receiving a response or action to feedback
- accessibility of feedback processes

For young people who had not given feedback, the main reasons were due not:

- being aware of the opportunity or how to give feedback
- knowing they were allowed to give feedback
- having time
- thinking it would make a difference

Similar reasons were identified for parents and carers. The four main reasons for parents and carers not giving feedback were due to not:

- being aware of the opportunity or how to give feedback
- having time
- thinking it would make a difference
- needing to

While not being sure how to give feedback and not thinking it would make a difference were issues for WACHS consumers in regard to feedback. They also felt:

- uncomfortable giving feedback
- worried about giving feedback affecting the service they receive

Within these responses we see a focus on feedback processes, but the idea that consumers don't think it would make a difference is about the outcome expectations of feedback. In interviews, staff also raised the issue of needing to take feedback seriously and incorporate feedback into change.

Consumer responses regarding the feedback processes were reflected by staff, the majority (59%, n=127) of whom indicated that they thought feedback processes for consumers were only *somewhat effective* and another 22% (n=46) indicating they were *not so effective* or *not at all effective*. The three main themes for improving feedback processes were:

- improved use of digital and online technologies
- raising awareness of feedback opportunities
- using a variety of methods for gaining feedback

Similarly, interviews with staff raised the need for:

- mechanisms for informal, usually verbal feedback
- effective approaches for vulnerable communities
- increased consumer awareness about the process of giving feedback

The QAP data also identifies that processes for feedback as well as the outcomes of feedback require attention at CAHS.

How are we going with this at CAHS?

Based on all the data analysed there appear to be some clear and consistent results regarding the feedback process at CAHS. For most groups only around a third of people had given feedback and many of the main reasons for not giving it were process related. However, an outcome related response was also key to why consumers did not give feedback and this was because they didn't think it would make a difference.

This suggests to make feedback processes more effective and encourage more feedback from consumers, we need to:

- 1. broaden opportunities for feedback, with a focus on implementing quick and convenient methods**
- 2. raise consumer awareness of feedback - who can provide feedback, how to provide it and what it involves**
- 3. communication/promotion of how feedback makes a difference**
- 4. have a culture/philosophy that views feedback as an opportunity for the service to improve.**

Consultation

Consultation crosses three criteria of Standard 2 – Clinical governance and quality improvement and Partnering with consumers in organisational design and governance and Health Literacy. Within these criteria there is an expectation that systems are designed and used to support consumers to be partners in planning, designing the service and information about the service and governing the organisation.

There is considerable overlap between the specific actions and associated intentions for feedback and consultation. All those for feedback are relevant for consultation, as well as:

- Action 2.9. - Consumers are involved in the development of information about health and health services, so it easy to understand and act on.
- Action 2.12. - Consumers partnering in organisational design and governance have the skills and knowledge they need to be able to contribute effectively.

Benefits and barriers to consumer consultation

What did consumers say?

When asked if they would want to be involved in making decisions about services provided by CAHS 77% of young people and 68% of parents and carers said they would want to be involved. Those who said they did not want to be consulted were asked why. There were four fixed response options, as well as *other* option, in which respondents were required to provide a description.

None of the 19 young people who responded selected the *other* option and responses from parents and carers in the *other* were analysed and either grouped into one of the four existing response options or placed into two new response options:

- I don't use the service enough.
- I don't have capacity. This related to current health or stress of parents and carers.

As can be seen in the figures below the majority of responses for both young people and parents and carers fell into two categories, either feeling they did not have the skills to be involved in consultation or thinking it would take too much time. In addition this over a quarter (27%) of the responses given by young people related to them thinking it would be too difficult to understand. Only 10% of young people and 7% of parents and carers felt they wouldn't be listened to and therefore did not want to be involved in consultation.

Figure 18: Young people's reasons for not wanting to be involved in consultation

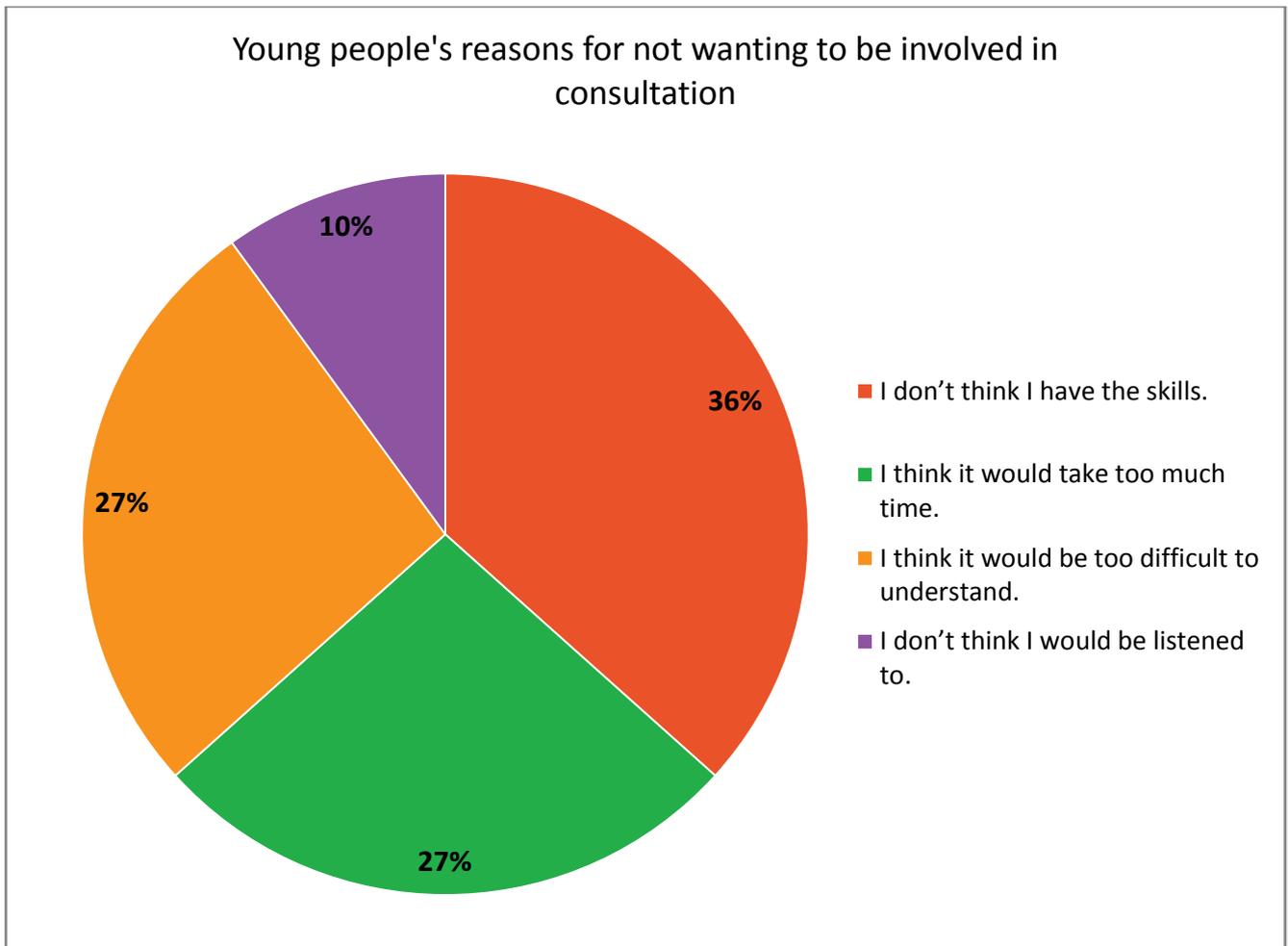
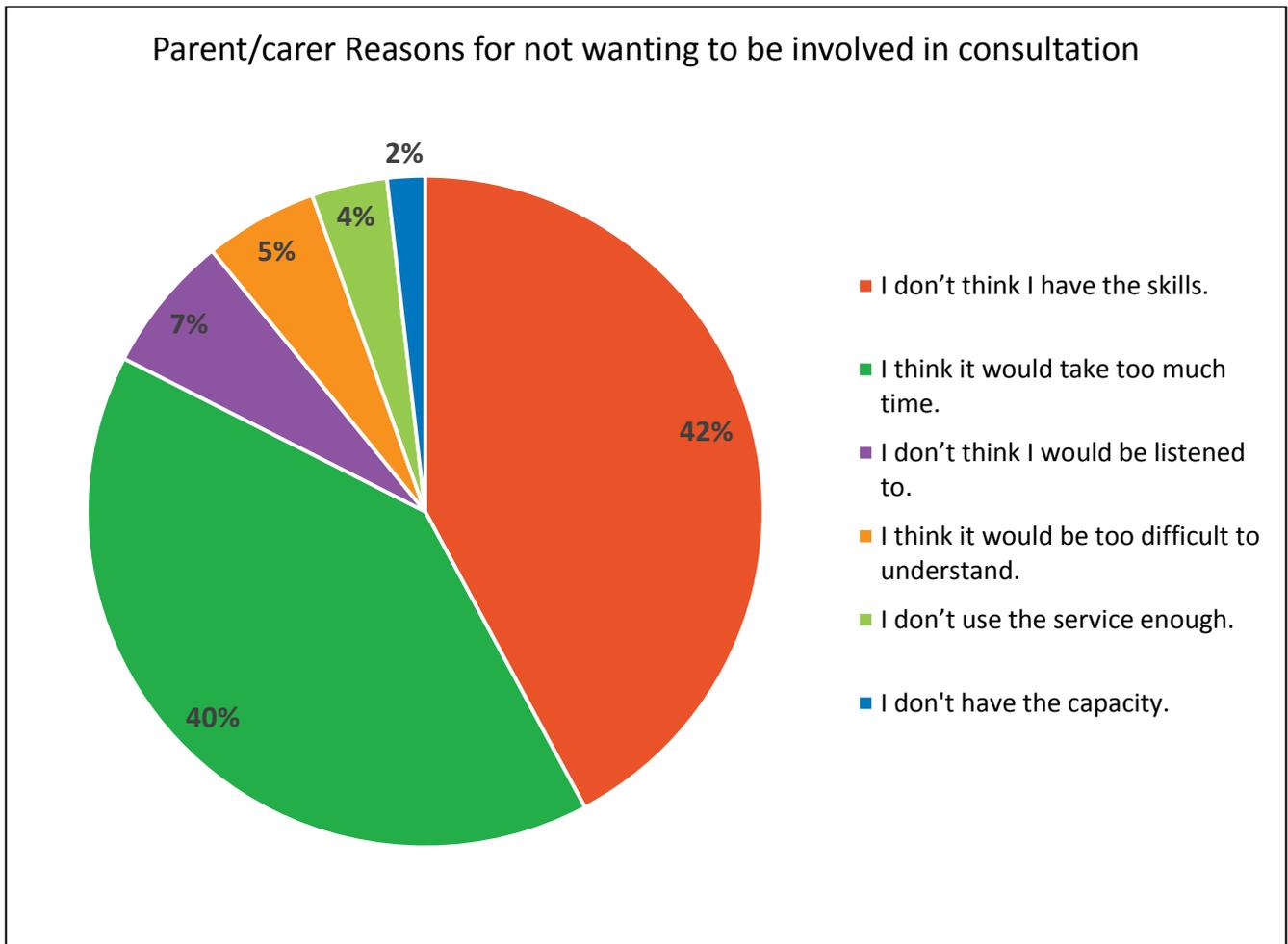
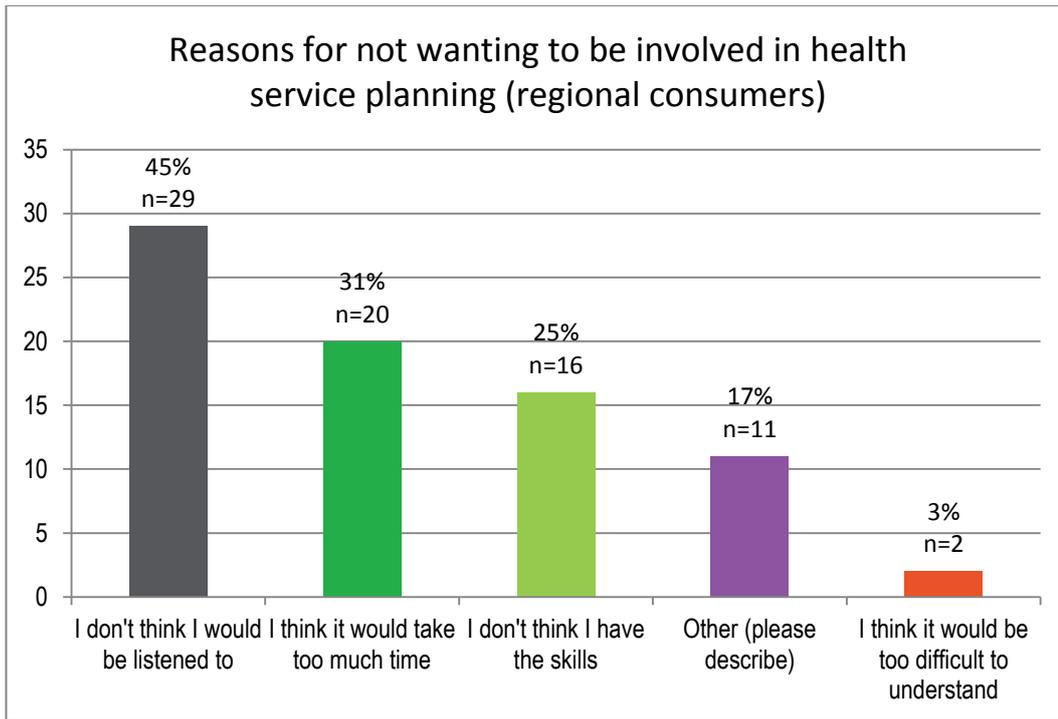


Figure 19: Parent/carer reasons for not wanting to be involved in consultation



While very few (n=5) regional consumers said they had been previously involved in health service planning at PCH. An additional 13 reported being involved in their local health service. Of those that had not been involved, 32 indicated that they would like to in the future, 13 indicated they would not like to be involved in the future and 40 were unsure if they would like to be involved in the future. The main reasons for not wanting to be involved was because they felt like they would not be listened to (n=29) and perceived it would take too much time (n=20).

Figure 20: Reasons for not wanting to be involved in health service planning (regional consumers)



What did staff say?

Over 80% (84%, n=203) of staff *strongly agreed* or *agreed* they had the skills and knowledge to conduct consumer consultation and around 80% (79%, n=192) of staff *strongly agreed* or *agreed* they had the confidence to conduct consumer consultation. However, over 50% (53%, n =129) *disagreed* or *strongly disagreed* they had the resources to conduct consumer consultation and 65% (n=159) *disagreed* or *strongly disagreed* they had the time to conduct consumer consultation.

Table 16: Staff capacity to engage consumers

	Strongly agree	Agree	Disagree	Strongly disagree
I have the skills and knowledge to conduct consumer consultation.	60 (25%)	143 (59%)	38 (16%)	2 (1%)
I feel confident to conduct consumer consultation.	63 (26%)	129 (53%)	51 (21%)	1 (0%)
I have the resources to conduct consumer consultation.	17 (7%)	97 (40%)	107 (44%)	22 (9%)
I have the time to conduct consumer consultation.	9 (4%)	75 (31%)	99 (41%)	60 (25%)

Just over 70% (72%, n=217) of staff replied they had consulted with consumers. Those who had consulted with consumers were asked to describe consultation. Responses to this question related to purpose of consultation and method of consultation. The themes in relation to the purpose of consultation were:

- Review and development of policy, services and resources (35%, n=48)

- Evaluation and feedback (17%, n=24)
- Consumer experience and needs (8%, n=11)

Another two themes related to direct care and support, rather than broader consultation. These included:

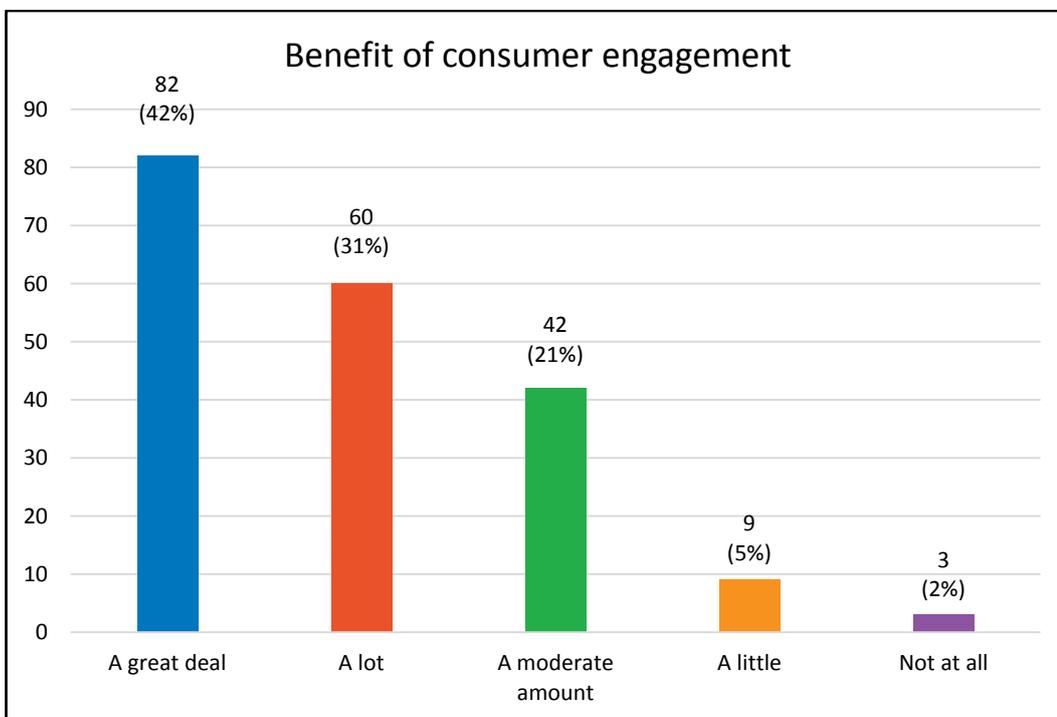
- Provision of information (22%, n=30)
- Involving parents in care and support (18%, n=25)

In regard to the method of consultation, three key methods for consultation were identified:

- Surveys and feedback forms (41%, n=38)
- Discussion groups with consumers (36%, n=33)
- Consumer committees (23%, n=21)

As detailed in Figure 21 below, just over 70% felt that consumer engagement had brought their service or team a *great deal* or a *lot* of benefits.

Figure 21: Benefit of consumer engagement



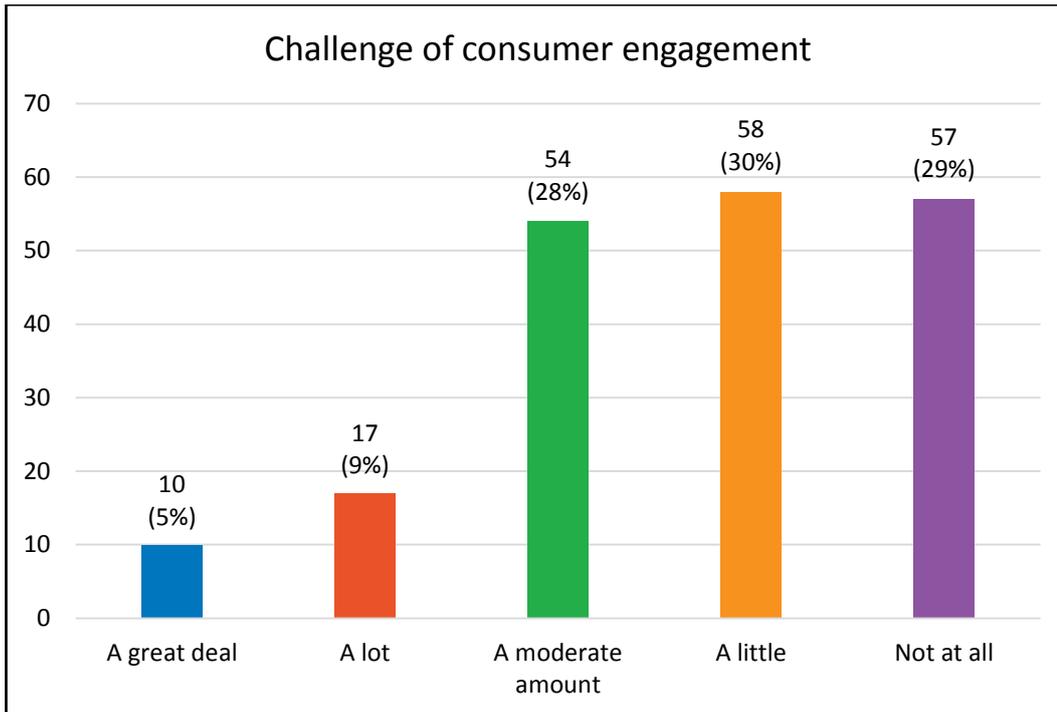
From the staff interviews, there was considerable discussion about being able to respond to consumer input from consultation. The table below illustrate the strengths and weaknesses within CAHS in regard to responding to consumer consultation. While there were many good examples of service areas implementing consumer input, bureaucratic processes and the service areas' scope of influence to implement change were seen as barriers to making changes. Effectively communicating implemented change and those changes not implemented to consumers was a key challenge for CAHS.

Table 17: Strengths and weaknesses of consumer consultation at CAHS

Strengths	
Consumer input part of change	There were examples of how consumer feedback through consultation has resulted in change, including examples from CH, Neonates, research, Starlight Foundation.
Limitations	
Bureaucratic roadblocks	Not being able to implement consumer engagement activities or improvements based on consumer input because of slow processes or policies and practice guidelines that prevent innovation and progress. Examples of barriers included: <ul style="list-style-type: none"> • accessing and using technology • getting approvals • determining ownership
Scope of influence	The challenge of not being able to incorporate input and how this can be managed was raised by a number of staff. The main barrier was financial resources, however, other difficulties to incorporating feedback included: <ul style="list-style-type: none"> • clinical best practice or clinical guidelines • services not well integrated • logistics • conflicting input • too much input • not within the control of the service • individual preferences versus service responsibilities Guidance is required to know how to manage consumer input and expectations.
Communicating change or lack of change	This refers to both communicating change that occurs because of consumer input (feedback and consultation), but also and importantly is communicating reasons why change does not or cannot occur. This is linked to consumers feeling listened to and valued.

In regard to challenges, very few staff (14%, n=17) rated the challenge of consumer engagement as *a great deal* or *a lot*, as shown in Figure 22.

Figure 22: Challenges of consumer engagement



Staff were also asked an open-ended question about what factors prevented them from consulting with consumers. The 208 responses from staff were analysed into four main themes, which reflected responses to other questions. These themes were:

- Time (n=80)
- Consumer related factors (n=55)
- Service or organisational limitations and/or lack of support (n=24)
- Access to tools and resources (n=20)

These are explored further in Table 18.

Minor themes included:

- Consultation is not part of one's role (n=13)
- Clear policies and processes (n=11)
- Resources and awareness to deal with CALD (n=11)
- Staff skills and knowledge (n=10)
- Staffing support (n=10)
- Funding (n=7)

Table 18: Factors that prevent staff from consultation with consumers

Theme	Examples of comments
<p>Time (n=80) This included general statements of time limitations, as well as how it results in incomplete or a lower quality consultation process.</p>	<p>“Time limitations to do meaningful consultation. Suggestions for tokenistic consultation do not interest me as they are just that - tokenistic and I find it insulting to consumers that we would then call that and then claim consultation.”</p> <p>“Sometimes a lack of time to actually collate the feedback, implement change and then evaluate the change.”</p> <p>“Getting consumer feedback when deadlines are tight.”</p> <p>“Often lack of time and ability to get feedback with a short turn around.”</p> <p>“Difficult with a heavy workload to get time to liaise with parents.”</p> <p>“Time to develop appropriate survey and then review the information and provide feedback.”</p>
<p>Consumer related factors (n=54) This included:</p> <ul style="list-style-type: none"> • recruiting and retaining willing and available consumers • contacting or identifying consumers • consumer knowledge and skill • consumer burden or concern 	<p>“Recruiting and retaining consumers is hard. Making sure consumers show up once recruited can also be challenging.”</p> <p>“It can be hard to access mental health consumers as they are often very sick when they are accessing CAMHS teams. We have tried many ways and will keep trying. Sometimes that means accessing consumers/carers once they are well and no longer accessing our services. BUT we still do it and always seek consumer/carer input.”</p> <p>“Accessibility to parent contact details if wanting to consult with frequent flyer / long term families to discuss ward plans that may affect them.”</p> <p>“Working hours make it difficult to partnering as many consumers are not available during school hours or in school health working hours.”</p>

	<p>“Getting consumer feedback from consumers that have a strong understanding of how the health service works. Otherwise, the feedback might not be meaningful/useful.”</p> <p>“Accessing a suitable consumer who is interested in participating and has the knowledge/ experience required.”</p> <p>“My clients can be reluctant to give feedback or information.”</p> <p>“Ready access to consumers. It's especially difficult to gain input from consumers from vulnerable or hard to access groups.”</p> <p>“Awareness that parents get asked to complete surveys/evaluations a lot. Access to consumers - unfair to constantly ask CHNs to get parents to complete them and (potentially) collate and return hard copy forms.”</p> <p>“Availability of consumers to contribute. Feeling as though you don't want to over-burden consumers with requests (especially when unsure how many other departments are also consulting or inviting them to be involved).”</p>
<p>Service or organisational limitations (n=24) This included:</p> <ul style="list-style-type: none"> • not being able to deliver the outcomes of consumer consultation • research protocols and bureaucratic processes • lack of support from leadership 	<p>“Sometimes decisions are out of their control and need to be made regardless.”</p> <p>“Some problems need to be addressed immediately following best practice and growth parameters so there is no provision for consultation.”</p> <p>“The organisation - this issue still hasn't been resolved - engaging families highlights the issues they face but then there is a lack of action to resolve the issues.”</p> <p>“... feelings of frustration when often little positive actions occur after discussions have been undertaken both for myself and the consumer.”</p> <p>“Consulting and partnering with consumers in itself isn't difficult to do, it's very easy. It's what we do with</p>

	<p>that feedback that is the difficult part. For example, I believe more QI activities would occur based on the feedback we receive from consumers that inform service delivery, if there weren't such long and stringent pathways to actually make those changes. We receive the feedback, but then don't have the time to go through all these processes to make the changes that need to occur. That is what needs to be looked at.”</p> <p>“Policies and procedures of the organisation; KPI's and clinical practice guide that informs practice.”</p> <p>“Time pressures of clinical work, little support from above to ease the load.”</p>
<p>Access to tools and resources (n=20) This was mostly a general comment, but there was a number of comments related to social media and digital communication with consumers.</p>	<p>“... lack of resources to encourage consumer consultation.”</p> <p>“Access to varying cohorts within the metropolitan area, lack of availability of social media for this purpose.”</p> <p>“Ability to communicate with consumers, eg on an app, facebook, Instagram.”</p> <p>“IT support - e.g. creations of apps/feedback platforms.”</p> <p>“CALD clients - Not having literature in different languages.”</p> <p>“Loss of local ESQ data which allows timely live feedback.”</p>

A similar set of challenges were identified in staff interviews, as presented in the table below.

Table 19: Challenges to consumer consultation at CAHS

Challenges	
Technology	There are barriers to accessing the technology, including hardware, and connectivity, to consult effectively with consumers and to analyse consumer input data from feedback and consultation. Not having a greater social media presence across all services that could be used for consumer engagement was also raised as a barrier.
Diverse services	It is a challenge to implement consultation processes across the different service areas and incorporate consumer input. There were calls for more integration, which requires a greater understanding and acknowledgement of the diverse roles and responsibilities across and with service areas.
Absence of governance structure and standards	There was a need to have (or to have an awareness of) a governance structure and process to ensure a standard of consumer engagement is met. However, these structures and processes needed to be clear and efficient so as to be supportive, rather than becoming an additional barrier.
Adequate expertise	Increasing the capacity (time, knowledge and skills) of existing staff to be able to complete tasks related to consumer engagement, but also increase dedicated staff with expertise to be able to support clinical staff with consumer feedback and consultation.

Being involved in consultation

What did consumers say?

Those who wanted to be involved in consultation were asked how they would like to receive information about being involved. Email was the preferred method for young people and parents and carers from metropolitan and regional areas. Nearly 50% (48%, n=37) young people said via email. Over quarter of young people also selected:

- Instagram (32%, n=25)
- CAHS website (29%, n=23)
- text message (28%, n=22)

Over 60% of parents and carers from metropolitan areas (61%, n=290) and regional areas (67%, n=67), said via email. The following four communication mechanisms were also preferred methods for around a quarter of the metropolitan parents and carers:

- text message (25%, n=118)
- CAHS website (25%, n=117)
- Facebook (24%, n=115)
- regular newsletter (22%, n=106)

Instagram, posters and an online consumer portal were only preferred by 10% or less of parents and carers.

When asked about their most preferred way of being involved in helping make decisions through consultation around 60% of young people (59%, n=46) and parents and carers (62%, n=299) selected surveys. Similarly, 68% (n=73) of regional consumers selected surveys. However, given these questions were answered via survey, there may have been bias towards surveys in these responses. Again, when asked how they would prefer to receive these surveys nearly half of young people said via email (43%, n=20) and over half of parents and carers said via email (56%, n=166). The next preferred option for young people was the CAHS website (30%, n=14) and Facebook/Instagram (17%, n=8). The next preferred option for parents and carers was the CAHS website (19%, n=57) and text message (18%, n=52).

In regard to consultation methods other than surveys, 18% selected joining a committee or working group and 14% selected online discussions. For parents and carers between 10% and 15% selected online discussions (14%) and joining a committee or working group (11%). Less than 10% (8%) of parents and carers selected coming to a one-off group discussion.

An optional open-ended question about how CAHS can make sure consumers can have their say was asked towards the end of the survey. Over 200 parents and carers (n=229) and 39 young people responded. Table 20 and 21 present the key themes emerging from comments made by parents and carers and young people who responded. Some examples of comments for each theme identified have been included.

Two key themes emerged from responses by young people about how CAHS could make sure young people were heard. This included:

- Providing opportunities to have a say through surveys and feedback forms.

- Ensuring safe, accessible and responsive feedback and consultative mechanisms.

What emerged for parents and carers from this open-ended question was that CAHS could make sure parents and carers were heard by:

- Providing regular, prompted opportunities to have a say through survey/feedback forms.
- Communicating with consumers.
- Hosting consumer discussions.

The theme *communicating with consumers* was multifaceted and included both the service and staff at CAHS connecting with consumers to ask for their input, letting them know about opportunities, but also listening to what consumers are saying, whether prompted or not. Running across each of these theme areas was ensuring that methods used were accessible and convenient to those in a range of different circumstances and increased use of social media and online technologies.

Table 20: Young people's responses to how CAHS can ensure they hear from young people

Theme	Examples of comments
<p>Providing opportunities to have a say through surveys and feedback forms (n=20) There was a focus on asking young people and also delivering through online/social media communication methods.</p>	<p>“Child and Adolescent Health Service wants to make sure we hear what young people have to say about our services. What could help make this happen?”</p> <p>“Have a feedback button machine in all clinics and waiting areas in the hospital.”</p> <p>“A survey after final appointment.”</p> <p>“Ready access to online exit surveys.”</p> <p>“Asking them about the trip/having them do a short questionnaire at the end of the visit/stay.”</p> <p>“By directly asking children face to face or asking them to do surveys like this.”</p> <p>“Maybe put some links on Instagram to ask people for their opinions, like this survey. I think it is quite convenient but it doesn't take too much time 😊.”</p>
<p>Safe, inclusive, responsive feedback/consultation mechanisms n=14) It was acknowledged that safety, being inclusive and responsive was required to encourage young people to have a say.</p>	<p>“Creating surveys for people who use the health system, encouraging young people to speak up/leave suggestions, organising discussions or forums for people who use CAHS.”</p> <p>“Having a group of young advocates that discuss the issues they have found in the services and work together to come up with a solution to the problem.”</p> <p>“Make sure you go through all the feedback.”</p> <p>“Ask them in a safe environment.”</p> <p>“To give everyone a chance to say their opinion.”</p> <p>“Creation of working and consumer groups, and reaching out to children and young people in the community.”</p>

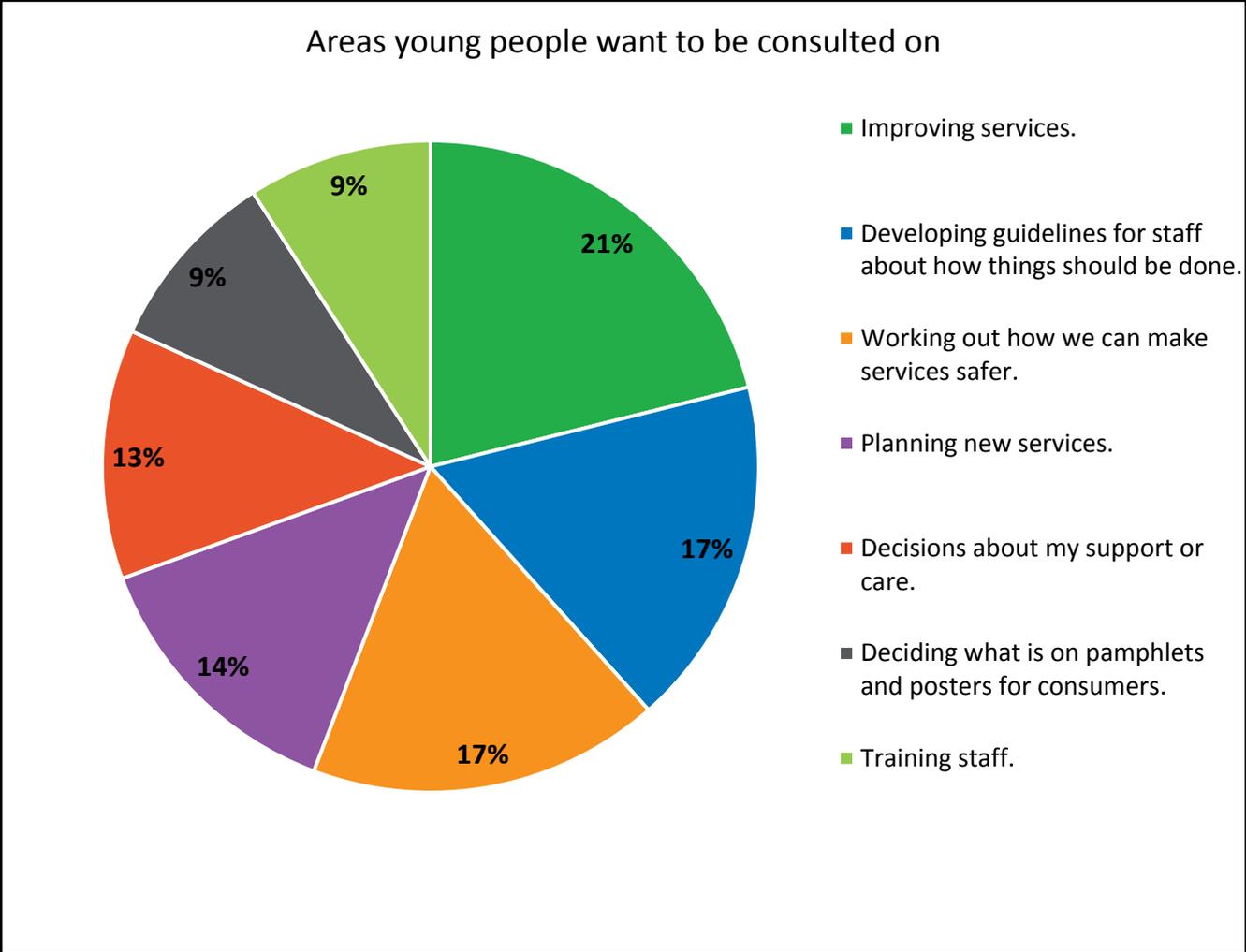
Table 21: Parent/carer responses to how CAHS can ensure they hear from parents and carers

Theme	Examples of comments
<p>Providing regular, prompted opportunities to have a say through survey/feedback forms (n=103) A variety of suggestions were made in regard to format:</p> <ul style="list-style-type: none"> • hardcopy • digital <p>and location/delivery:</p> <ul style="list-style-type: none"> • suggestion boxes • online • social media • post-appointment email or text • at the service 	<p>“Child and Adolescent Health Service wants to make sure we hear what parents and carers have to say about our services. What could help make this happen?”</p> <p>“Sending a feedback survey to parents and carers by email, linking to a survey via text link, and/or providing a hard copy info pamphlet that includes a feedback survey link. This would allow for different preferences in accessing the survey. In addition, staff could direct attention to the survey in the first meeting, to be done after the first appointment, or after a series of appointments.”</p> <p>“Touching base more often whether that be via email, letters, surveys, etc.”</p> <p>“Keep asking! Like this survey.”</p> <p>“Surveys like this given out at hospital.”</p> <p>“Having paper forms and suggestion boxes easily accessible on the wards, clinics and other spaces.”</p> <p>“Anonymous feedback point on website, paper based feedback forms at PCH, an address to send feedback to either post or email.”</p> <p>“An app that makes submitting feedback quick and user friendly.”</p> <p>“Short surveys or open-ended questions about experiences - one at the beginning and one at the end of the time. Maybe even an electronic kiosk on each ward where immediate feedback could be provided. You could also use this as an information portal and extract the data to find out what people are needing/wanting most at each location.”</p> <p>“Online feedback/survey system for post/pre visit feedback. Giving feedback whilst at hospital can feel pressurised as your mind is on your child’s emotions etc on the day.”</p> <p>“Continue doing what you're doing - perhaps amend the sign in computers at PCH so that parents or carer's could provide feedback on their experience with PCH.”</p> <p>“Make it quick and easy. SMS a survey link after appointment. Provide touch screens with happy / neutral / sad face. Acknowledge parents don't have time to do long surveys.”</p>
<p>Communicating with consumers (n=74) This included:</p> <ul style="list-style-type: none"> • staff and service 	<p>“Get all staff to ask people as a matter of course. Make it clear that all feedback is helpful and how it will make a difference. Help staff not to be defensive if they hear some feedback that is negative.”</p> <p>“Ask those directly involved in services. Especially ongoing care like CAHMS versus ED experience.”</p>

<p>making (or enabling) contact with consumers</p> <ul style="list-style-type: none"> • informing consumers about consultation opportunities • listening to what is being said by consumers (prompted or not) 	<p>“Have a direct contact other than complaints, to send emails to rather than the company in general.”</p> <p>“Regular updates and request for involvement.”</p> <p>“Posters and advertising how parents can get involved.”</p> <p>“Higher profile in local newspapers, asking for responses, same on internet.”</p> <p>“When given suggestions please relay back to parents that it has been heard so we know we are being listened to.”</p> <p>“Staff are taught to listen to parents not ignore them.”</p> <p>“Ask us, then actually listen, and implement change in an effective and timely manner.”</p>
<p>Hosting consumer discussions (n=34) This included having discussions with specific groups and the broader community through:</p> <ul style="list-style-type: none"> • social media • online platforms • regular forums 	<p>“A monthly forum that parents/caters could attend where they can voice their concerns.”</p> <p>“Regular meetings to inform of updates that a discussion can be had to input into decision.”</p> <p>“Facebook or online discussions. Emailing people involved or putting it out to parent groups and family support groups etc. Influential groups.”</p> <p>“Advertise social media platforms and encourage interaction on them.”</p> <p>“Focus groups leading to discussions that facilitate real world changes to patient care.”</p> <p>“Hold forums/codesign/workshops etc and actually implement suggestions made.”</p> <p>“All of my friends use Facebook I will see an ad on Facebook much quicker than I would checking emails. I believe also a Facebook Group for Medical Families in each region would be advantageous. You could have a YouTube Channel [and] we could make mock videos of what a committee or consumers meeting is like and what is involved. Regional Facebook Groups would mean everyone could have a say and when a committee member is unavailable someone could sub for them. I am on the Bunbury Emergency Department Consumers Committee and find the volunteer position quite rewarding. I feel like I’m given a fair say and are proud to see some of my suggestions have been implemented.”</p>

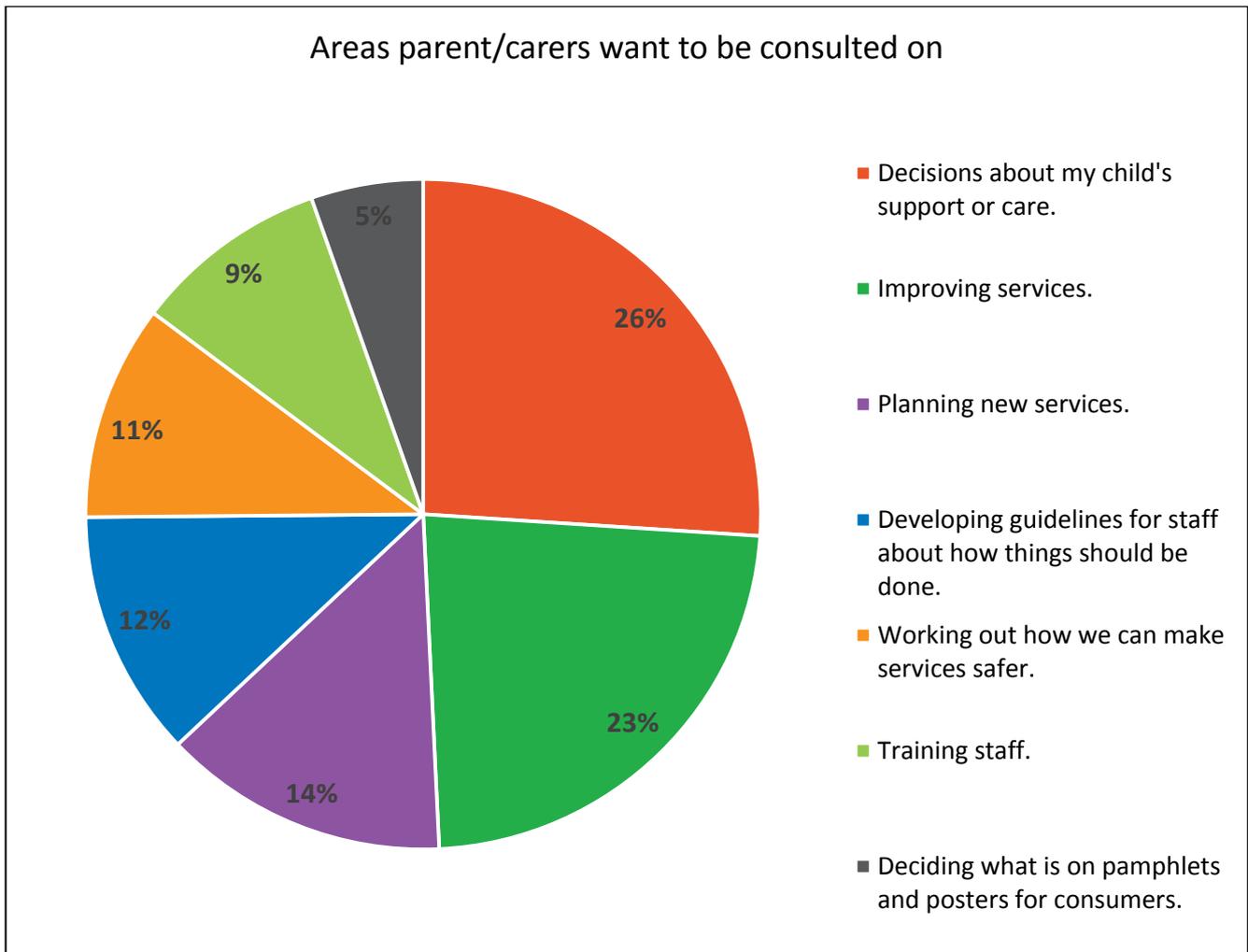
Consumers were also asked what areas of CAHS service provision they felt was important for consumers to have a say about. Just over 80 (n=82) young people and over 480 (n=488) parents and carers selected the top three areas of importance. The question included *other* as a response option, however, through data cleaning it was identified that responses in the other option could be allocated to one of the fixed response options.

Figure 23: Areas young people want to be consulted on



Young people showed a strong interest in being involved in broad service-related areas with only 13% saying they wanted to be consulted on decisions made about their support or care. This is in contrast to the responses made in relation to direct care and support. However, it indicates a wider concern young people may have about the services they are provided and the staff delivering them.

Figure 24: Areas parents and carers want to be consulted on

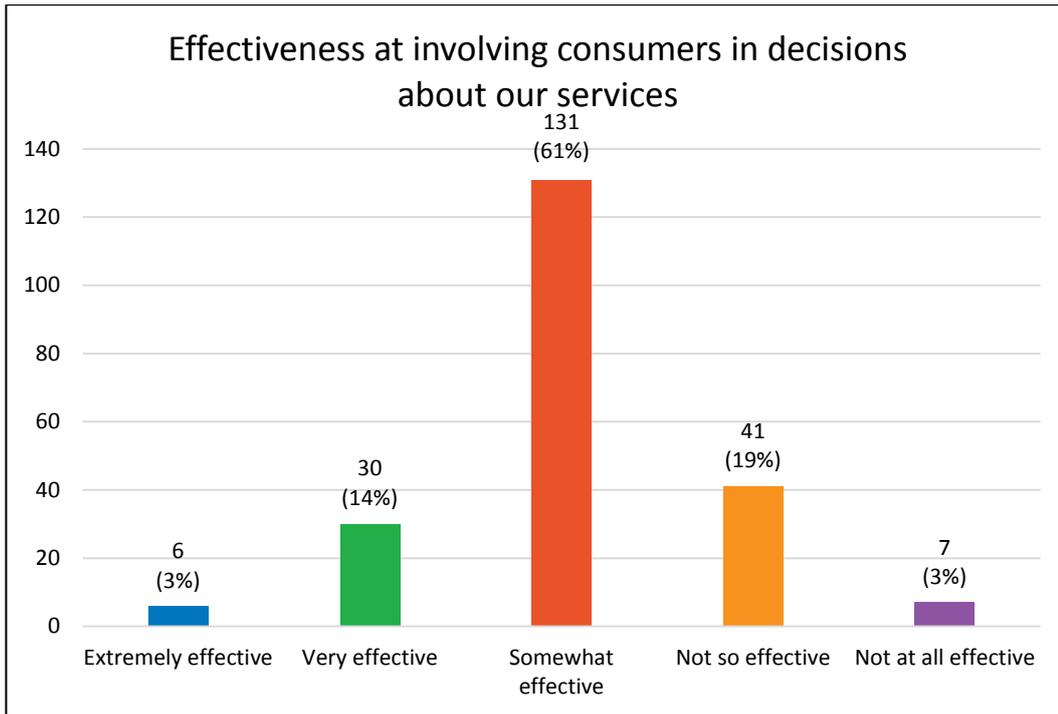


Unlike responses from young people, just over a quarter (26%) of the responses were about parents and carers being involved in their child/ren’s care or support. For broader service-related areas, planning new service or improving services accounted for 37% of the responses. After this, developing guidelines for staff or being involved in staff training combined to account for about a fifth (21%) of the responses. The top three areas regional consumers wanted to be consulted on were improving services (n=86); planning new services (n=58); and decisions about their child’s support or care (n=54).

What did staff say?

In regard to the effectiveness of CAHS at involving consumers in decisions about services, just over 60% (61%, n=131) responded that they were *somewhat effective*, while over 20% (22%, n=48) said they *not so effective* or *not at all effective* and less than 20% said they were *very effective* or *extremely effective*.

Figure 25: Effectiveness at involving consumers in decisions about CAHS services



Staff were asked their ideas for how consumers could be more involved in making decisions about CAHS services. The top three responses from 67 staff were:

- Set standards and expectations for consumer consultation
- Provide varied opportunities for consultation
- Broaden representation

These are detailed in Table 22. Other themes by staff received less than 10 responses.

Table 22: Involving consumers in decisions about services (staff responses)

Theme	Examples of comments
<p>Set standards and expectations for consumer consultation (n=33) This included both a call for a standard across CAHS, as well as components that may need to be incorporated into those standards or expectations, such as:</p> <ul style="list-style-type: none"> • consumer representation • staff involvement • support, time and resources available for consultation 	<p>“This needs stronger governance. Community Health/CAMHS has made a concerted effort to do this but haven't seen this from PCH/CAHS. This should be standard practice and incorporated at the start of decision making processes.”</p> <p>“Standardise our processes across all disciplines to ensure that we all take responsibility for involving consumers in making decisions about our services.”</p> <p>“Representation at executive and board level all the way down to the frontline. Providing staff training on effective, proactive engagement with consumers. Executive support for more face to face interaction between clinical / non-clinical staff and patients/families.”</p> <p>“I think that we have good consumer representation across appropriate committees but we need to send time reinforcing the message that all CAHS staff should take time to A) put your self in the consumers shoes and or B) think about the effects on the consumer as a result of the decisions we make. This could be achieved by creating a consumer focus initiative where before making a endorsement at a meeting the committee is asked to take time before to reflect and comment amongst each other on the potential impact on consumers/ try our best to employ compassion to put ourselves in the consumers shoes.”</p> <p>“Multiple methodologies based on best practice.”</p> <p>“Carer and Consumer Rep on all committees involved in making decisions.”</p> <p>“Listen to them without the opinion that they are 'in charge' and we can't be seen to be told what to do by a charity or group of parents.”</p> <p>“Set realistic project timeframes so that genuine consumer involvement can occur.”</p>
<p>Provide varied opportunities for consultation (n=24) This includes:</p> <ul style="list-style-type: none"> • face to face • paper and pencil • use of existing data 	<p>“Walk around schools and engage with parents that way rather than relying on focus groups of motivated people.”</p> <p>“Have local consumer groups, electronic feedback systems, simple template to provide information back, when we do something that has changed as a direct result of feedback then promote that to raise more community awareness.”</p> <p>“Consumer and carer representatives at all levels of service improvement. Focus groups. More</p>

<ul style="list-style-type: none"> • social media and digital technologies • consumer groups 	<p>involvement at the ground floor in clinical care decision making.”</p> <p>“Occasional(ly) asked to get consumer feedback through surveys- what about competitions, family days that aren't just at the hospital but community settings where people can actually get with minimal/ no cost.”</p> <p>“Rather than a token person sitting around the table, increase volume of feedback & analyse problems according to demographic profile, etc. to better determine service modification according to differing needs.”</p> <p>“Consumer engagement through focus groups, ongoing consultation via surveys, engagement of consumers whilst their baby is an inpatient. Part of follow up post discharge.”</p>
<p>Broaden representation (n=12)</p> <p>There was concern that those consulted are not representative of the diversity of consumers, particularly and many may be excluded, particularly vulnerable populations. Various solutions were proposed.</p>	<p>“My concern is that the consumer groups do not adequately reflect the diversity of our clients especially the most vulnerable hard to engage clients. These clients are unlikely to attend groups for a number of reasons and may be reluctant or unable to commit to regular involvement. Our service needs to engage them where they are , possibly in one on one conversations and be attentive to what they raise rather than asking set questions.”</p> <p>“For Aboriginal consumers, especially most vulnerable - involve Aboriginal Health Workers. Aboriginal consumers will not be too shy or shame to become involved in decision making if it was via Aboriginal Health Workers. However, in suggesting that, Aboriginal Health Workers likewise require a safe avenue for them to be heard in decision making as well.”</p> <p>“Run focus groups within different areas and populations to gain a better understanding of what the unique needs are in each area. I.e. Fremantle vs Armadale. Indigenous vs CALD.”</p> <p>“Being able to have a say despite cultural language differences.”</p> <p>“Each community to have a consumer group, with varied representation of the population, ages, and vulnerabilities.”</p> <p>“Some resources such as PHR appear to have been simplified (verging on 'dumbing down'). This supposedly happened in response to feedback from consumers, but which consumers were targeted? Many of my clients express disappointment at the simplification and minimisation of content of printed information.”</p>

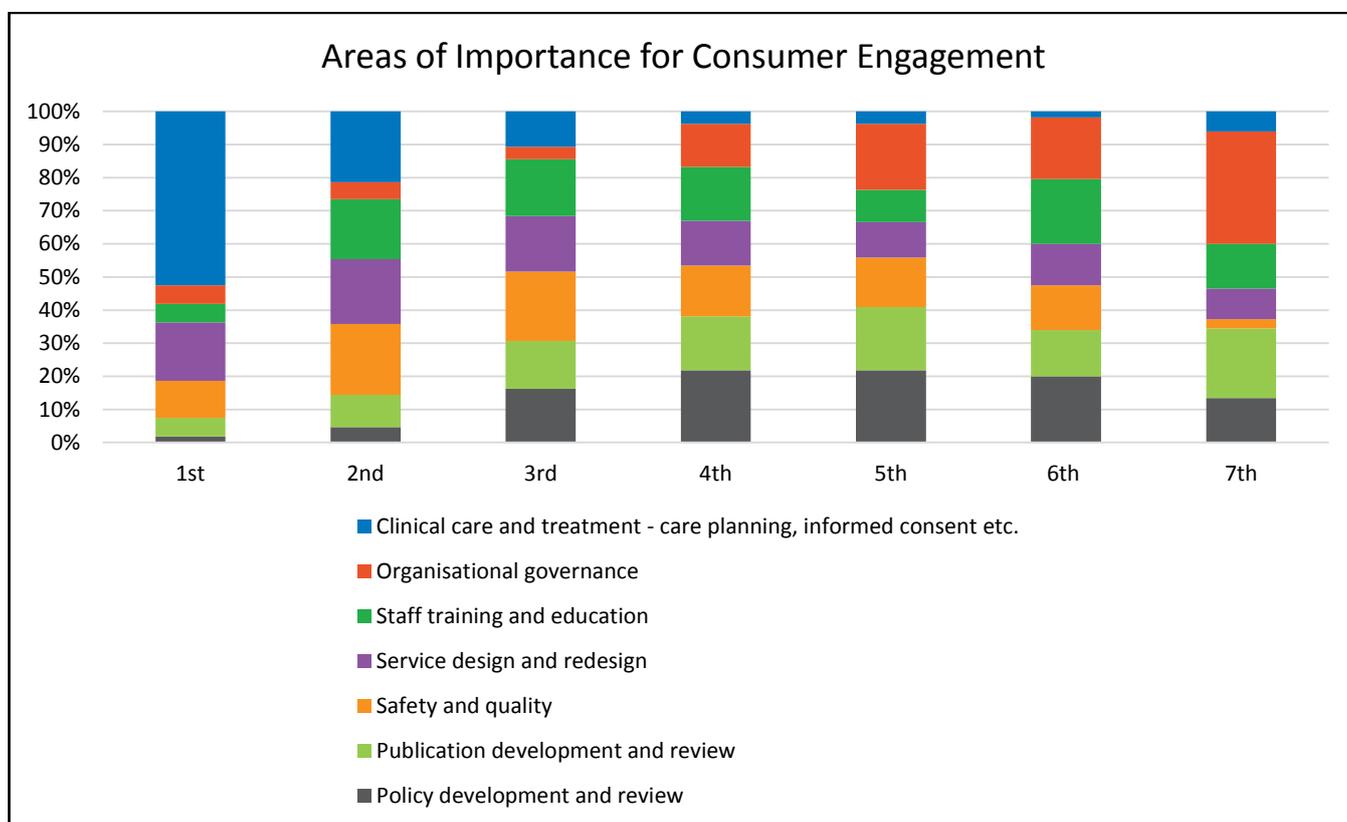
In the staff interviews it was recognised that for many service areas consumer engagement was part of normal business and that CAHS has access to a diverse range of consumers. However, there were concerns about the representativeness of consumers involved, the motivation of consumers and the expectations of the consumers and staff.

Table 23: Strengths and limitations to consumer engagement at CAHS

Strengths	
Consumer engagement is a normal part of business	Some service areas felt they had well established consumer engagement processes and that there was trust and expectations amongst their consumers to do this. CH, CAMHS, Allied Health and Starlight all identified good examples within their service.
Access to consumers	CAHS has a wide reach to a diverse group of consumers across the services and a number of actively engaged consumers. Examples include Heart Kids, Diabetes, Endocrinology.
Limitations	
Getting a representative consumer voice	There was a concern that the consumers CAHS hears from are not representative of the broader consumer population. This is in part because often the same consumers volunteer or already engaged consumers are accessed by staff. However, it was acknowledged that many consumers may not have the time or capacity to be involved, while those who do may get consultation fatigue. There was a link here to a lack of branding that may attract more consumers to be involved.
Tokenism	There were concerns that consumer input at CAHS was only sought for certain projects; not taken seriously and/or not meaningful. Paternalism and just seeing consumer engagement as a 'tick box' exercise were identified as issues.
Approaches exclude vulnerable communities	Aboriginal people, people from CALD backgrounds and those who did not read, write or speak English were identified as vulnerable groups excluded by existing feedback and consultation approaches used to gather consumer input.
Consumer buy-in	There were a lot of factors that staff felt might relevant consumers being motivated to be involved in consultation. These included: <ul style="list-style-type: none"> • payment • food • location and time • online opportunities • transport Additional financial resources would be required to meet these preferences or provide these incentives.
Consumer awareness and preparation	There were concerns that consumers may not be aware of how to provide feedback or be involved in consultation, as well as the processes, protections and limitations around giving feedback and being involved in consultation.

Similar to parents and carers, staff identified *clinical care and treatment* at the top priority in terms of areas of consumer engagement for parents and carers, with over half ranking it as the top priority. The area with the second greatest proportion was *service design and redesign*. *Organisational governance* was ranked the lowest (7th) priority by the majority of staff, followed by *publication development and review*. More trends can be viewed in Figure 24.

Figure 26: Areas of importance for consumer engagement (staff responses)



QAP Data

The table below is drawn from the overview of the NSQHSS 2 QAP Progress Overview Tool. The additional actions relevant to 'Consultation' (other previously presented in 'Feedback') are colour coded red, yellow, green to respectively indicate CAHS's risk rating of currently meeting this action item – high, medium, low.

Table 24: QAP Data on Consultation

Standard 2 Actions, Intent and Risk Rating	QAP Status
Communication that supports effective partnerships	
<ul style="list-style-type: none"> Action 2.9. Consumers are involved in the development of information about health and health services, so it easy to understand and act on. 	Current processes require review
Partnerships in healthcare governance planning, design, measurement and evaluation	
<ul style="list-style-type: none"> Action 2.12. Consumers partnering in organisational design and governance have the skills and knowledge they need to be able to contribute effectively. 	Consumer rep guideline completed.

Summary of findings – Consultation

Benefits and barriers to consumer consultation

77% of young people and 68% of parents and carers said they would want to be involved in making decisions about services. Having access to a diverse range of consumers was also identified as a strength by CAHS staff. A considerable number of WACHS consumers also expressed an interest to be involved. The main reasons for not wanting to be involved were consumers:

- not feeling they did not have the skills to be involved in consultation
- thinking it would take too much time

In addition this over a quarter (27%) of the responses given by young people related to them thinking it would be too difficult to understand. While WACHS consumers shared similar concerns, their key concern was *feeling like they would not be listened to*. QAP data rated consumers having the skills and knowledge they need to be able to contribute effectively as low, based on the development of a CAHS Consumer Representative Guideline.

One of the key themes identified from staff responses to how CAHS could better partner with consumers, was the to conduct *responsive consultation with consumers*. The majority (84%) of staff felt they had the skills and knowledge to conduct consumer consultation and 70% of staff said they had consulted with consumers and the staff interviews detailed some examples across CAHS. The main purpose of this was to review and develop policy, services and resources and the main method was through surveys and feedback forms. Over 70% (73%) of staff felt consumer consultation benefitted their service or team. One concern for staff in the interviews and surveys was the barriers to implementing consumer input. These barriers included:

- bureaucratic processes slowing down or preventing implementation
- suggestions from consumer input being out of scope for the service area
- effectively communicating to consumers about implemented change and those changes not implemented to consumers

The QAP data also identifies that the outcomes of feedback require attention at CAHS.

Only 14% of staff found consumer consultation challenging. Key factors that do prevent consumer consultation identified in the staff survey and interviews were:

- time
- access to tools or resources, particularly technology
- lack of integration between services
- access to adequate expertise

How are we going with this at CAHS?

It would appear that CAHS has both an engaged consumer body and staff who feel they have the knowledge, skills and confidence to consult with consumers. However, while consumers were concerned about not having the skills and consultation taking too long; staff were

concerned about barriers to implementing consumer input, communicating consultation outcomes; and not having the time or resources(technological and personnel) to conduct consultation.

This suggests that what may be needed is:

- 1. strategies and resources to equip and support consumers to be involved in consultation**
- 2. improving resources and support for staff, particularly in relation to technology**
- 3. developing communication processes for reporting consultation outcomes to consumers**
- 4. remove or streamline processes that unnecessarily slow down or complicate consultation with consumers**

Being involved in consultation

Email was the preferred by consumers as the method by which they would like to be informed of opportunities to be involved in consultation and surveys were the preferred way of being consulted. To ensure consumers got to have their say, young people felt CAHS needed to: provide opportunities to have a say through surveys and feedback forms

ensure safe, accessible and responsive feedback and consultative mechanisms

Parents and carers felt CAHS needed to:

- provide regular, prompted opportunities to have a say through survey/ feedback forms
- communicating with consumers.
- hosting consumer discussions

Across these themes was the need for accessible and convenient methods suitable for a range of different circumstances and increased use of social media and online technologies.

Only 17% of staff felt CAHS were effective in involving consumers in decisions about CAHS services. The QAP also identified processes for feedback needing attention. Ideas that emerged from the staff survey and interviews for improving consumer involvement included:

- setting standards and expectations for consumer consultation, moving away from tokenism
- providing varied opportunities for consultation, including approaches suitable for vulnerable communities
- broadening representation
- accommodating consumer preferences and providing incentives
- increasing consumer awareness of consultation

In terms of what consumers wanted to have a say in young people wanted to be involved in service-related areas, including *service improvement, developing guidelines and making services safer*. While parents and carers wanted to be involved in *improving services*, the main concern for metropolitan parents/cares was being involved in *decisions about their child's care or support*. Similar parents and carers, staff identified *clinical care and treatment* as the top priority in terms of areas of consumer engagement for parents and carers.

How are we going with this at CAHS?

While there continues to be a focus and comfort with surveys by staff and consumers, both also called for regular, prompted opportunities for consultation and feedback, which was safe and accessible and provided through various methods and formats, including online technologies and social media. For staff there was a call for a stronger focus on the needs and preferences of vulnerable communities and broadening representation. For consumers and staff there was an emphasis on meeting standards and expectations for consultation that was not tokenistic and was responsive.

This suggests that what may be needed is:

1. **increase CAHS capacity to deliver a range of consultation methods, including the use of online technologies and social media**
2. **develop and/or adopt consultation approaches that engage vulnerable communities and attract broader representation**
3. **more attention to developing a culture where consumer input is considered central and important to the success of CAHS**

Strategy Goals

The key findings from Phase One were considered by the Consumer Engagement Team and initially five goals were emerged. These included:

1. A **culture** where consumer engagement is embedded and prioritised.
2. **Technology** that allows opportunities for partnerships, communication and consultation.
3. **Staff with expertise and dedicated resources** to support consumer engagement.
4. Skilled, confident, representative **consumer base who have opportunities to have a voice**.
5. Clear, consistent and coordinated **governance** of consumer engagement.

However, further analysis of the data led to Goal 1 and Goal 5 remaining and Goals 2, 3, and 4 merging to refer to both consumers and staff, with a separate focus on opportunities and communication. These are listed in the table below with a description of the strategies components underlying the goal and according to the different types of 'relationships' or 'engagement' at CAHS. These goals formed the basis of Phase Two and workshops conducted to identify the actions.

Table 25: Goals and Strategic Components

Goal	Strategic components
A strong culture of partnership that is embedded in practices and expectations and is well supported and resourced.	Direct care and support <ul style="list-style-type: none"> • Embed consumer partnership in our service and practice in ways that are clear to all consumers. • Establish a shared expectation about partnering between consumers and staff that allows clinicians more time and support, if necessary, to partner effectively with consumers • Raise consumer awareness of the partnership standards they should expect from CAHS. • Provide partnership training and support staff, who require it, with a focus on partnering with young people and the diverse range of consumers access CAHS.
	Feedback <ul style="list-style-type: none"> • Utilise consumer feedback in in a structured and strategic way, leading to ongoing learning and service improvement.
	Consultation <ul style="list-style-type: none"> • Develop a culture where consumer partnership and input is considered central and important to the success of CAHS.

<p>Opportunities for consumers and staff to partner together in innovative and contemporary ways, including the improved use of technology and online communication.</p>	<p>Direct care and support</p> <ul style="list-style-type: none"> • Develop and implement online communication for sharing information. <p>Feedback</p> <ul style="list-style-type: none"> • Broaden opportunities for consumer feedback, with a focus on implementing timely and convenient methods. <p>Consultation</p> <ul style="list-style-type: none"> • Develop and/or adopt strategies and resources to equip consumers to be involved in consultation. • Improve resources and support for staff, particularly in relation to usage of technology for consultation. • Increase CAHS capacity to deliver a range of consultation methods, including the use of online technologies and social media. • Develop and/or adopt consultation approaches that engage a broad representation from across CAHS's diverse consumers.
<p>Consumers are communicated with effectively, no matter what their needs or preferences are for communication.</p>	<p>Direct care and support</p> <ul style="list-style-type: none"> • Develop and/or adopt resources for consumers that address specific needs and preferences, including those of young people, different literacy requirements and those who speak a language other than English. • Provide training and resources for clinical staff, who require it, to enable them to communicate for understanding. <p>Feedback</p> <ul style="list-style-type: none"> • Promote to consumers and staff how feedback makes a difference. <p>Consultation</p> <ul style="list-style-type: none"> • Develop communication processes for consulting consumers, including preparing consumers and reporting consultation outcomes to consumers.
<p>Clear, consistent and coordinated processes and governance of consumer engagement.</p>	<p>Direct care and support</p> <ul style="list-style-type: none"> • Establish standards for staff in relation to the partnering and communicating with consumers, including providing information about their healthcare rights. <p>Feedback</p> <ul style="list-style-type: none"> • Raise consumer awareness of feedback mechanisms (e.g. who can provide feedback, how to provide it and what it involves). <p>Consultation</p> <ul style="list-style-type: none"> • Develop and embed governance processes and minimum expectations for consumer engagement across CAHS. • Simplify internal processes for consumer engagement.

Phase Two – Identifying actions

Purpose

Phase Two built on the information gained in Phase One in regards to goals and gaps and identified and detailed actions to address these gaps and meet the goals.

Outline of the document

The consultation methodology for Phase Two is outlined, followed by the presentation of demographics of the consumers and organisational positions of the staff involved. The findings of the Phase Two are presented under each goal, specifying which of the three types of engagement they refer to:

1. direct care and support consumers receive
2. feedback consumers may wish to provide about CAHS
3. when CAHS wishes to actively consult with consumers to develop or improve services.

Who or from where these actions have been defined by will also be presented.

Methodology

A range of data was collected for Phase Two and is outlined below.

Consumer Consultation

Consumer consultation for this phase of developing the Strategy was conducted through a series of community workshops with young people aged 12-21 years (1 workshop) and parents and carers (5 workshops) from the metropolitan area. Two of these workshops were conducted online due to COVID-19 restrictions. Planning delays due to COVID-19 restrictions meant that workshops planned for a regional area and further workshops with young people were not conducted. The workshop with young people was conducted by the Youth Affairs Council of WA (YACWA) and staff from the CAHS Consumer Engagement Team conducted the parent/carer workshops. The parent/carer workshop was divided into three activities based around the 'engagements' discussed above.

Activity One

Four scenarios (one for each service) depicting possible interactions that may occur at a clinical level and based on findings from Phase One. In small groups participants were asked to consider the scenario and discuss in relation to:

1. What would have made this situation better?
2. What information could have helped have a say/make a stand?
3. Where would be good places to have this information? What formats would want this information in?
4. How could the staff member done better?

5. What could our service do to improve situations like this?

Activity Two

A map outlining how a consumer might go through any of CAHS services was shown to participants (e.g., receiving an appointment letter, coming into our service, waiting in waiting areas, being seen in a consult room, virtual spaces etc). Common issues faced by consumers, as identified in Phase One were shared with participants. In small groups participants were asked to think about how the feedback process could be redesigned so that it could be easier, clearer, quicker, less threatening to give feedback. Participants were asked to identify:

1. Where do you want to see or find feedback opportunities?
2. What other opportunities for feedback do you want?
3. What would help make giving feedback – safer, more comfortable, more accessible, easier?
4. What would tell young people that we want to hear their feedback?
5. What do you want to happen after giving feedback? How do you know you have been listened to?

Activity Three

Concerns emerging from Phase One about participating in consultation were presented to participants. Following this participants were divided into small groups and given a different format of consultation (e.g., being part of a working group, being in an online network, attending a one-off workshop). Four questions were asked on different postcards and participants were asked to share their ideas on the back. The postcard questions were:

1. Connect – how to find the consumers who can provide the most relevant information (e.g. parents of premature babies, Aboriginal specific groups)
2. Attract – how to make consumers want to come
3. Keep – what motivates and makes consumers feel valued to keep coming
4. Equip – what do consumers need to be involved

Staff Consultation

Staff consultation for Phase Two was through interviews with key staff stakeholders at CAHS. The interview schedule focused in identifying strengths and weaknesses in consumer engagement across the different CAHS services and also opportunities for the Strategy and Framework, responses to questions about opportunities is the focus of this report.

Meetings were also offered and held with Directors and Co-Directors of all service streams to seek feedback on the goals emerging from Phase One and review the actions at the end of Phase Two.

Organisational Priorities

Recommendations for action from the NSQHSS Standard 2 gap analysis were also incorporated into this report.

Analysis

The findings from all these sources were themed according to goals and presented in table form.

Board and Executive Consultation

A survey was developed for the Board and Executive to provide them an opportunity to reflect on:

- how their views of CAHS aligns with the goals and gaps identified from Phase One; and
- their level of commitment to goals in terms of financial resources, leadership and technological change.

Results of this survey were analysed in Excel.

Demographics

The demographics of the consumers involved in Phase Two workshops is presented below.

Young people

A total of 23 young people attended the YACWA workshop. Their ages ranged from 13 to 20 years, with a mean age of 17 years.

- 21% (n=5) identified as LGBTIQA+
- 17% (n=4) identified as having a disability
- 9% (n=2) identified being from refugee or migrant backgrounds

None of the young people who attended told us that they were Aboriginal or Torres Strait Islander. Young people were from a spread of suburbs³ in the Perth metropolitan area.

Parents and Carers

Five workshops were held across the metropolitan area. Two of these were virtual workshops due to COVID-19 restrictions. The workshops were held in:

- Swan
- Banksia Grove
- Langford
- Mirrabooka x 2 virtual workshops

A total of 83 parents and carers attended five workshops.

- 18% (n=15) identified as Aboriginal or Aboriginal and Torres Strait Islander
- 22% (n=19) mainly spoke a language other than English at home

Staff, Board and Leadership

Interviews conducted in Phase One with 34 staff from across teams and services streams CAHS were also included in the analysis of Phase Two. Demographic information for these interviews can be found in Phase One report (p.10). Eleven members of the Board and Executive completed a reflective survey of the findings from Phase One.

³ Not all young people chose to report their suburb. Of those that did, they came from Ardross, Ballajura, Bentley, Claremont (3), Cloverdale, East Perth, Glendalough, Harrisdale, Kalamunda, Kensington, Kingsley, Lockridge, Pickering Brook, Shenton Park, Shoalwater, Stirling and Wanneroo.

Phase Two Findings

The findings from the workshops are presented below followed by the findings from the consultation with the Board and Executive.

Identifying actions

Actions identified from the workshops have been organised according to the:

- broad strategies presented in the Summary Table 17 from Phase One;
- the goal it is associated with;
- the type of 'relationship' or 'engagement' the action relates to (see icons below);
- where the action came from – consumers, staff interviews or organisational priority (see icons below).

Icon	Where the action came from
	Workshops with parents and carers
	Workshop with young people
	Staff interviews
	Organisational Priority
Icon	The type of engagement this action relates to
	Direct care and support
	Feedback
	Consultation

Table 26: Identified Actions

	Strategic Components	Actions	Type of engagement	Where the action came from?
GOAL 1: A strong culture of partnership that is embedded in practices and expectations and is well supported and resourced.	Embed consumer partnership in our service and practice in ways that are clear to all consumers.	No specific actions identified.		
	Establish a shared expectation about partnering between consumers and staff that allows clinicians more time and support, if necessary, to partner effectively with consumers.	Link a set of principles with CAHS values.		
		Staff commit to, and have a shared understanding of, consumer engagement.		
	Raise consumer awareness of the partnership standards they should expect from CAHS.	Equip consumers in regards to consent and decision-making in direct care and support.		
		Provide education on health care rights.		
	Provide partnership training and support staff, who require it, with a focus on partnering with young people and the diverse range of consumers access CAHS.	Provide guidelines to staff about partnering with consumers.		
		Provide training to staff about relationship building.		
		Cultural competency training for staff.		
		Gender competency training for staff.		

		Establish and introduction process between child health nurses and consumers before their first child health check.		
		Offer a follow up service with clinicians when consumers have questions or need information.		  
	Utilise consumer feedback in in a structured and strategic way, leading to ongoing learning and service improvement.	Act on feedback and communicate changes based on feedback to the public.		  
	Develop a culture where consumer partnership and input is considered central and important to the success of CAHS.	Consumers and staff hear the importance of consumer engagement.		 
		Consumer input is visible		
		There is a clear and specific goal and purpose to consultation with consumers.		 
		Payment, incentives and resources are linked to consumer consultation.		  
Develop and implement online communication for sharing information.	Develop a consumer app to provide information about CAHS services and store and record consumer information.			

GOAL 2 – Opportunities for consumers and staff to partner together in innovative and contemporary ways, including the improved use of technology and online communication.

	Information portal to provide health and medical information, as well as practical information about accessing CAHS services.		
Broaden opportunities for consumer feedback, with a focus on implementing timely and convenient methods.	Digital opportunities through electronic feedback stations, SMS, email, an app or through social media. Ask all consumers on discharge.		
	Face to face opportunities through general staff, drop-in feedback sessions, feedback 'champions', feedback officer.		
	Follow up phone call to ask consumers feedback.		
	Provide feedback formats and processes accessible for people with a disability.		
	Provide feedback formats and processes accessible for people who speak languages other than English.		
	Provide child and youth friendly formats and processes for giving feedback.		
	Update existing feedback form.		
	Establish a process for giving anonymous feedback.		
	Develop communications aimed at reducing the fear of giving feedback.		

GOAL 2 – Opportunities for consumers and staff to partner together in innovative and contemporary ways, including the improved use of technology and online communication.

	Establish a process for having informal feedback registered.		
Develop and/or adopt strategies and resources to equip consumers to be involved in consultation.	Consider practicalities and cater for consumer needs - catering, location, venue, timing, transport, child minding, parking.		
	Provide detailed information about location, time and accessibility, but also about the topic, questions, commitment and skills required and facilitator profiles.		
	Describe what participating in consultation activities involves. Provide stories and experiences from other consumers who were involved in consultation. Include FAQs and a contact number for people to ask questions.		
	Have sessions in other languages.		
	Allow time for consumers to make connections with each other.		
	Create relaxed, comfortable and respectful relationships between staff and consumers.		
	Provide consumers training to give them the skills, knowledge and confidence to participate in consultation activities.		
	Ensure confidentiality.		

GOAL 2 – Opportunities for consumers and staff to partner together in innovative and contemporary ways, including the improved use of technology and online communication.

<p>Improve resources and support for staff, particularly in relation to usage of technology for consultation.</p>	<p>Provide staff training on engaging consumers in service development and improvement.</p>		
	<p>Provide staff resources about conducting consumer consultation activities.</p>		
	<p>Increase expertise amongst staff to engage consumers in consultation activities.</p>		
	<p>Provide funding for staff for short, innovative consumer engagement projects.</p>		
<p>Increase CAHS capacity to deliver a range of consultation methods, including the use of online technologies and social media.</p>	<p>Establish online advertising and registration to participate in consultation activities.</p>		
	<p>Develop online strategies to conduct online consultations.</p>		
	<p>Provide information sheets or sessions about how to participate in online consultations.</p>		
<p>Develop and/or adopt consultation approaches that engage a broad representation from across CAHS's diverse consumers.</p>	<p>Provide opportunities for regional consumers.</p>		
	<p>Advertise in a range of public and commercial spaces, including schools.</p>		
	<p>Establish a network of non-government organisations through which consultation activities can be shared.</p>		
	<p>Establish a consumer network to advertise consultation activities through.</p>		
	<p>Invite people to participate via text or email after appointments or through the Purple Book.</p>		

		Information sessions and stalls about participating in consultation activities.		
		Establish a CAHS brand that is beyond PCH and that people recognise and want to partner with.		
		Make it an enjoyable experience for consumers.		
		Target consumers who may otherwise be excluded.		
GOAL 3 – Consumers are communicated with effectively, no matter what their needs or preferences are for communication.	Develop and/or adopt resources for consumers that address specific needs and preferences, including those of young people, different literacy requirements and those who speak a language other than English.	Develop resources for consumers about what to expect and things you might want to ask when accessing CAHS services.		
		Provide interpreters.		
		Provide translated resources on health care rights and information about accessing CAHS services.		
		Develop and provide resources suitable for children and young people about accessing CAHS services and asking questions.		
		Distribute resources widely within and external to services.		
		Establish a consumer review process of the resources provided.		
		Establish parent/carer and peer groups to enable consumers to share experiences.		

GOAL 3 – Consumers are communicated with effectively, no matter what their needs or preferences are for communication.

Provide training and resources for clinical staff, who require it, to enable them to communicate for understanding.	Develop guidelines for staff about encouraging questions, checking consumer understand information and creating safe spaces for consumers to discuss concerns.		
	Provide communication support and aids for people with a disability.		
	Employ a plain language expert to translate medical terminology into to plain language.		
	Have consumer advocates available to support consumers understand information provided and ask questions.		
	Liaison service that consumers can call to ask questions after an appointment.		
	Have training for staff, including frontline administrative staff, to be able to support consumers who are not satisfied with CAHS services.		
Promote to consumers and staff how feedback makes a difference.	Establish guidelines to ensure an appropriate and acceptable response is provided when feedback is given.		
	Publicise feedback in a 'you said, we did' format through on-hold messages, social media and electronic posters.		
Develop communication processes for consulting consumers, including preparing consumers and	Follow up with consumers about the outcomes (positive and negative) from consultation activities they have participated in.		

	reporting consultation outcomes to consumers.	Register outcomes established from consumer input		
		Communicate outcomes from consumer participation in consultation activities through non-government organisations.		
GOAL 4 – Clear, consistent and coordinated processes and governance of consumer engagement	Establish standards for staff in relation to the partnering and communicating with consumers, including providing information about their healthcare rights.	Set minimum expectations around communication with consumers at appointments.		
		Establish a policy around what is and is not consumer engagement.		
	Raise consumer awareness of feedback mechanisms (e.g. who can provide feedback, how to provide it and what it involves).	Provide information about feedback processes when consumers first access CAHS service and continually ask for feedback.		
		Educate young people about giving people.		
		Provide an outline of the feedback process.		
		Promote the feedback process through websites, posters, social media and staff encouragement.		
	Standardise feedback processes across CAHS services.			
	Develop and embed governance processes	Formalise consumer engagement through a reporting system.		

GOAL 4 – Clear, consistent and coordinated processes and governance of consumer engagement	and minimum expectations for consumer engagement across CAHS.	Establish timeframes for reporting back to consumers.		
		Report on the numbers of consumers involved in decisions made about services.		
		Guidelines about consumer participation in service decisions (e.g., how many, in what roles).		
		Define what is meant by consumer.		
		Maintain the effective consumer engagement processes already adopted by CAHS service streams.		
	Simplify internal processes for consumer engagement.	Develop a stance and process for involving young people under 14 in consumer engagement.		
		Monitor consumer consultation activities across CAHS.		

Board and Executive Consultation

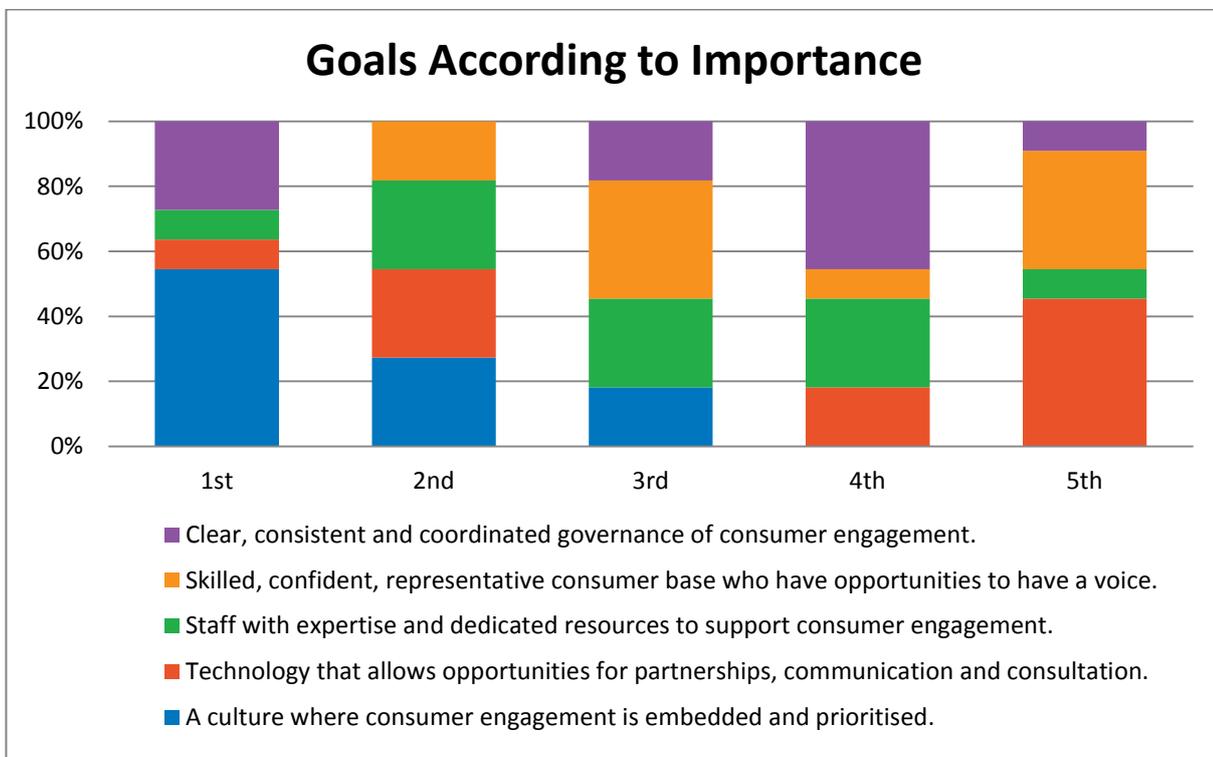
The Board and Executive were provided a summary of findings from Phase One and asked to reflect on whether:

- the findings aligned with their view of consumer engagement at CAHS currently
- how supportive they were of emerging goals for consumer engagement at CAHS.

All of those who completed the survey were in strong agreement with the findings and goals that had emerged from Phase One. Additional comments made about the findings and support were that consumer engagement varies across CAHS with positive examples as well as gaps. The Board and Executive also expressed concern about the findings from young people in Phase One and the need for this to be a focus at CAHS.

The survey was designed prior to the number of goals changing from five to four, so the Board and Executive commented were asked to prioritise the five goals. In regards to the importance of the goals presented, over 50% of the Board and Executive placed the goal relating to a culture of consumer engagement as the first priority, followed by the goal for clear, consistent and coordinated governance. Over 40% of the Board and Executive ranked technology as the least important goal, followed by the need for a skilled, confident and representative consumer base.

Figure 27: Goals according to importance

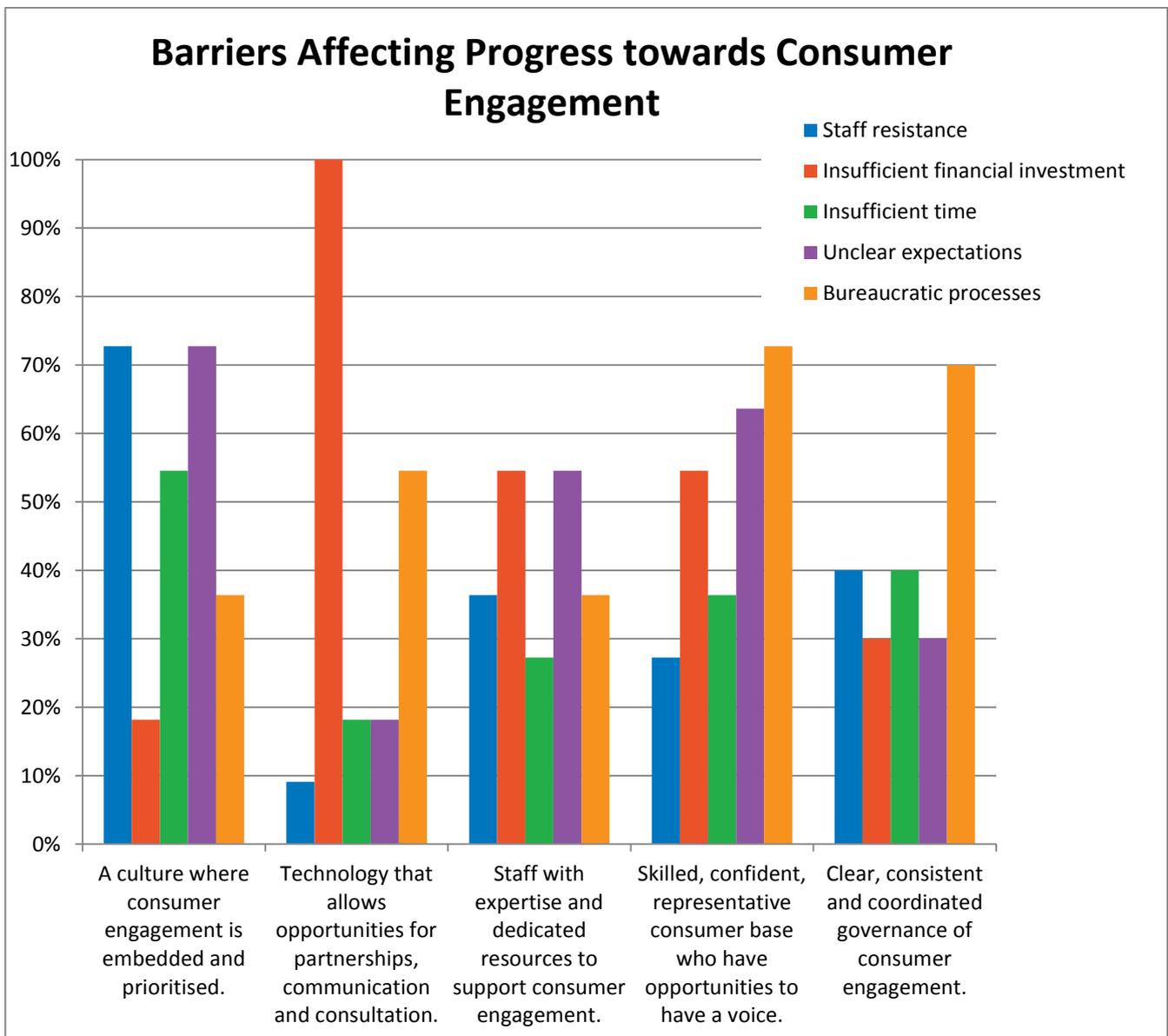


When asked about what barriers they could foresee to each of the goals, the notable findings were:

- staff resistance and unclear expectations affecting a change in a culture of consumer engagement;
- insufficient financial investment limiting a shift to better uses of technology in partnering, communicating and consulting with consumers;
- bureaucratic processes were considered the main barriers in terms of having a skilled, confident and representative consumer base and clear, consistent and coordinated governance.

Overall, bureaucratic processes and in insufficient financial investment, closely followed by unclear expectations were the key barriers to progress in consumer engagement at CAHS.

Figure 28: Barriers affecting progress towards consumer engagement



Additional barriers highlighted by the Board and Executive included:

- expanding consumer engagement beyond PCH
- giving consumer engagement equal priority and sustained focus against other more visible priorities
- communicating to and involving consumers.

Refinement of Phase Two Findings

Prior to embarking on Phase Three, the information gained from Phase Two was refined. The list of actions in Table 26 was reviewed by the Co-Directors of the service streams at CAHS and the Consumer Engagement Team. A number of changes were made including:

- merging some overlapping actions
- adding further actions required to meet Standard Two
- removing actions already in place at CAHS
- removing actions outside the scope of consumer engagement.

The final list of actions is presented in Phase Three of this document and formed the basis of the consensus building workshops.

Similarly the wording of goals was modified based on the review by the Co-Directors of the service streams at CAHS, as well as findings from the Board and Executive reflective survey. Information gained from the Board and Executive reflective survey was also used to place these goals in the current organisational challenges in terms of challenges and enablers.

Phase Three – Consensus building

Purpose

Phase Three, the final phase of the development of the Strategy brought together staff and consumers to refine the goals and prioritise the actions under each goal.

Outline of the document

The consultation methodology for Phase Three is outlined, followed by the findings of Phase Three presented under each goal.

Methodology

Four virtual workshops were conducted with staff and consumers. Each focused on one of the four goals identified in Phase One and the actions identified and modified in Phase Two.

Consumers, previously involved through the steering group, advisory committees or in the workshops were invited to be involved and Executive Directors and Co-Directors were asked to nominate or invite staff. Six consumers (2 young people and 4 parents and carers) and six staff (representing the different service streams) were selected to attend.

A week before the workshops, background material was sent to those selected to participate to help prepare for the workshops. The workshops consisted of two key activities.

Activity One – Prioritise actions

The first component of the workshop involved the staff group and consumer group working separately to prioritise the modified actions from Phase Two (see Table 27 and 28). The consumer group was asked to prioritise according to what they felt was most needed or desirable. The staff group were asked to prioritise according to what they felt was most possible or doable within the constraints of CAHS.

The lists of priorities from both groups were then calculated a final list presented to the group at the end of the workshop. Participants then had an opportunity to challenge and change the order of priorities.

Activity Two – Wording of the goal

Two mixed groups of staff and consumers were given the existing goal wording from Phase One (modified in Phase Two) of the goals and asked to change the wording according to their preferences and to add anything they felt was missing or remove unnecessary aspects of the goal wording. Both sets of wording were presented to the whole group, voted on and changed accordingly.

Phase Three Findings

The findings from the workshops are presented under each goal.

Goal One – Culture of engagement

Prioritise actions

The order of priority given to each of the actions by staff and consumers is presented below in Table 27, along with the total score. The final order of actions is presented in Table 28.

Table 27: Staff and consumer priorities for Goal 1- Culture of engagement

Actions	Staff	Cons.	Total
<p>ACTION 1 Develop educational resources (e.g. factsheets, apps and posters) for consumers that raise awareness about their:</p> <ul style="list-style-type: none"> • healthcare rights and consent • how CAHS partner with consumers • processes for making decisions. <p>This includes developing resources that particularly address young people, Aboriginal people, refugees and people from culturally and linguistically diverse backgrounds.</p>	5	6	11
<p>ACTION 2 Review the training, resources and support provided to staff to partner with children, young people and parents and carers in clinical care and consumer consultation. Develop and implement training, for staff who require it, that focuses on active listening and providing collaborative and non-judgemental care and support. Include the experiences of clinical staff and consumer stories in the development of the training.</p>	1	1	2
<p>ACTION 3 Review the training, resources and support provided to staff regarding healthcare rights of, and consent processes with, children, young people and parents and carers in clinical care.</p>	2	7	9
<p>ACTION 4 Incorporate a process within CAHS policy that requires staff to discuss healthcare rights with consumers at initial appointments and support consumers to use the healthcare charter throughout their healthcare journey.</p>	3	4	7

ACTION 5 Develop and implement diversity and inclusion training for staff which addresses differences in gender, culture and ability. Include consumer stories in this training.	4	2	6
ACTION 6 Demonstrate to consumers that consumer feedback is valued at CAHS. Including that feedback is taken seriously, can be given safely, is listened to and can be positive, negative or neutral.	7	5	12
ACTION 7 Regularly review and incorporate consumer feedback into team and service planning and improvement.	6	9	15
ACTION 8 Update the CAHS Complaints Management Policy to incorporate a process for staff to encourage feedback from consumers and telling them how to do so.	10	10	20
ACTION 9 Demonstrate to staff and consumers the value of consumer contributions and how they result in change at CAHS.	8	11	19
ACTION 10 Provide funding for CAHS service areas and teams consult with consumers, including remuneration for consumers, funding for interpreters and to enable participation of regional consumers.	11	3	14
ACTION 11 Review the policy for payments and incentives provided to support and encourage consumer involvement in consultation to include consumer remuneration and incentives for children, young people and parent/carers, including donated items, events and activities and certificates.	12	12	24
ACTION 12 Increase consumer recognition of CAHS and all the services it represents and establish it as a brand that consumers want to partner with.	9	8	17

Table 28: Final order of actions for Goal 1- Culture of engagement

ACTION 2: Review the training, resources and support provided to staff to partner with children, young people and parents/carers in clinical care and consumer consultation. Develop and implement training, for staff who require it, that focuses on active listening and providing collaborative and non-judgemental care and support. Include the experiences of clinical staff and consumer stories in the development of the training.

ACTION 5: Develop and implement **diversity and inclusion training for staff** which addresses differences in gender, culture and ability. Include consumer stories in this training.

ACTION 4: Incorporate a **process within CAHS policy** that requires **staff to discuss healthcare rights with consumers at initial appointments and support consumers to use the healthcare charter** throughout their healthcare journey.

ACTION 3: Review the training, resources and support provided to staff regarding healthcare rights of, and consent processes with, children, young people and parents/carers in clinical care.

ACTION 1: Develop educational resources (e.g. factsheets, apps and posters) for consumers that raise awareness about their:

- healthcare rights and consent
- how CAHS partner with consumers
- processes for making decisions.

This includes developing resources that particularly address young people, Aboriginal people, refugees and people from culturally and linguistically diverse backgrounds.

ACTION 6: Demonstrate to consumers that consumer feedback is valued at CAHS. Including that feedback is taken seriously, can be given safely, is listened to and can be positive, negative or neutral.

ACTION 10: Provide **funding for CAHS service areas and teams to consult with consumers**, including remuneration for consumers, funding for interpreters and to enable participation of regional consumers.

ACTION 7: Regularly review and incorporate **consumer feedback into team and service planning and improvement.**

ACTION 12: Increase **consumer recognition of CAHS and all the services it represents** and establish it as a brand that consumers want to partner with.

ACTION 9: Demonstrate to staff and consumers the **value of consumer contributions and how they result in change at CAHS.**

ACTION 8: Update the CAHS Complaints Management Policy to incorporate a **process for staff to encourage feedback from consumers and telling them how to do so.**

ACTION 11: Review the policy for payments and incentives provided to support and encourage consumer involvement in consultation. This is to include consumer remuneration and incentives for children, young people and parent/carers, including donated items, events and activities and certificates.

Rewording of Goal 1

The original wording of the goal was “A strong culture of partnership that is embedded in practices and expectations and is well supported and resourced.”

These were rephrased by the two groups and resulted in:

1. Working together in an inclusive, caring way that matters and makes a difference.
2. We will partner with children, teenagers and families in the care we deliver.

The group worked together to combine these to:

Working together with children, teenagers and families in the care we deliver.

Goal Two – Opportunities for partnership

Prioritise actions

The order of priority given to each of the actions by staff and consumers is presented below in Table 29, along with the total score. The final order of actions is presented in Table 30.

Table 29: Staff and consumer priorities for Goal 2 – Opportunities for partnership

Actions	Staff	Cons.	Total
ACTION 1 Develop an information portal or app where consumers can access or be directed to reliable health and medical information and practical information to support the consumer journey through CAHS. Make available in different formats to suit literacy requirements (e.g. pictorials), languages and preferences (e.g. videos, blogs) of CAHS' diverse profile of consumers. Allow the storage and sharing of consumer information, needs and preferences and feedback.	4	4	8
ACTION 2 Review the introduction process between child health nurses and new parents to make the best use of what is often a family's first entry point into CAHS.	10	5	15
ACTION 3 Improve access to clinicians after appointments. This could include follow up phone calls by clinicians, contact details provided to families or a liaison officer to answer questions and ask for feedback.	9	6	15
ACTION 4 Revise the CAHS Feedback Form and process to: <ul style="list-style-type: none"> • broaden the opportunities for consumers to provide feedback (e.g. electronic formats, through online communication and social media, staff 'feedback' champions) • include methods and language that is accessible and appropriate for people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile) • improve the feedback form by reducing the number of words, increasing space for consumer feedback and broaden to include compliments and complaints • develop a mechanism to enable anonymous and informal feedback. 	8	3	11
ACTION 5 Broaden the opportunities for consumer consultation to include: <ul style="list-style-type: none"> • online opportunities and electronic tools 	1	1	2

<ul style="list-style-type: none"> • methods that are inclusive of people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile) Provide staff training and resources in a range of consumer consultation methods and tools. 			
ACTION 6 Develop a staff toolkit for developing and implementing consumer consultation. Include guidelines for conducting online consultation, as well as online promotion and registration of consultation.	2	9	11
ACTION 7 Create education resources to guide and inform consumers considering being involved in consultation at CAHS. Provide it in different formats to accommodate language and literacy requirements (e.g. videos and face to face sessions).	5	8	13
ACTION 8 Develop a consumer network through which staff can tailor invitations to consumers to participate in consultation. As part of this network establish links with non-government organisations representing children, young people and parents and carers accessing our services.	6	1	7
ACTION 9 Increase the number of skilled staff available to support consultation activities.	3	10	13
ACTION 10 Develop a distribution approach to advertise and attract a diverse range of consumers to participate in consultation activities.	11	11	22
ACTION 11 Establish an agreement with schools and educational centres to promote consultation opportunities aimed at young people.	7	7	14

Table 30: Final order of actions for Goal 2 – Opportunities for partnership

ACTION 5: Broaden the opportunities for consumer consultation to include:

- online opportunities and electronic tools
- methods that are inclusive of people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile)

Provide staff training and resources in a range of consumer consultation methods and tools.

ACTION 8: Develop a consumer network through which staff can tailor invitations to consumers to participate in consultation. As part of this network, establish links with non-government organisations representing children, young people and parents/carers accessing our services.

ACTION 1: Develop an information portal or app where consumers can access or be directed to reliable health and medical information and practical information to support the consumer journey through CAHS. Make available in different formats to suit literacy requirements (e.g. pictorials), languages and preferences (e.g. videos, blogs) of CAHS's diverse profile of consumers. Allow the storage and sharing of consumer information, needs and preferences and feedback.

ACTION 4: Revise the CAHS Feedback Form and process to:

- broaden the opportunities for consumers to provide feedback (e.g. electronic formats, through online communication and social media, staff 'feedback' champions)
- include methods and language that is accessible and appropriate for people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile)
- improve the feedback form by reducing the number of words and increasing space for consumer feedback and broaden to include compliments and complaints
- develop a mechanism to enable anonymous and informal feedback.

ACTION 6: Develop a staff toolkit for developing and implementing consumer consultation. Include guidelines for conducting online consultation, as well as online promotion and registration of consultation.

ACTION 7: Create education resources to guide and inform consumers considering being involved in consultation at CAHS. Provide it in different formats to accommodate language and literacy requirements (e.g. videos and face to face sessions).

ACTION 9: Increase the number of skilled staff available to support consultation activities.

ACTION 11: Establish an agreement with schools and educational centres to promote consultation opportunities aimed at young people.

ACTION 2: Review the introduction process between child health nurses and new parents to make the best use of what is often a family's first entry point into CAHS.

ACTION 3: Improve access to clinicians after appointments. This could include follow up phone calls by clinicians, contact details provided to families or a liaison officer to answer questions and ask for feedback.

ACTION 10: Develop a distribution approach to advertise and attract a diverse range of consumers to participate in consultation activities.

Rewording of Goal 2

The original wording of the goal was “Consumers and staff are provided opportunities to partner together in ways that are accessible, contemporary and convenient.” This had been reworded slightly after the refinement process in Phase Two.

These were rephrased by the two groups and resulted in:

1. Staff will partner with consumers in whatever ways work best for consumers.
2. I access what I need, when I need it in a way that works best for me and the people who support me.

Consensus was not reached by the group on the wording of Goal 2 – Opportunities for partnership. The Consumer Engagement Team combined the two:

Partner with children, young people and families in ways that work best for them.

Goal Three – Communicating effectively

Prioritise actions

The order of priority given to each of the actions by staff and consumers is presented below in Table 31, along with the total score. The final order of actions is presented in Table 32.

Table 31: Staff and consumer priorities for Goal 3 – Communicating effectively

Actions	Staff	Cons.	Total
Action 1 Develop materials for consumers about what can be expected when using CAHS services and common questions they could ask. Base this on what other parents and carers have wanted to know. Consider the establishment of consumer liaison positions within services and online options to provide consumers with this information.	7	6	13
Action 2 Improve consumer and staff awareness of the availability of interpreters, including translated written information and confirmation before appointments.	3	8	11
Action 3 Make publications accessible for consumers who speak languages other than English or who require formats to meet different literacy and ability requirements.	2	7	9
Action 4 Provide communication support and aids for consumers requiring assistance with communication due to a disability or literacy requirements.	6	3	9
Action 5 Develop resources for children and young people about what can be expected at our services and how they can ask questions. This could include storybooks, animated videos, games, apps and diagrams.	5	1	6
Action 6 Establish a panel of consumers to review consumer resources and publications. This would include a youth review panel for youth-specific resources and publications. Consider supporting this with the employment of a plain language expert.	8	2	10
Action 7 Incorporate a consistent process within CAHS policy that requires clinical staff to: <ul style="list-style-type: none"> • check with consumers that they have understood the verbal information provided at appointments • use techniques to gain well-informed consent 	1	4	5

<ul style="list-style-type: none"> allow time for questions about clinical care in a safe space. <p>Ensure appropriate processes and styles of communication are used for people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile).</p>			
<p>Action 8 Train staff how to respond appropriately and constructively to consumers who are not satisfied with a service. This may involve managing difficult behaviours, preventing escalation to a complaint or explaining the feedback process to consumers.</p>	4	5	9
<p>Action 9 Review the process of responding to consumers about what action has been taken to address their feedback.</p>	9	10	19
<p>Action 10 Develop a process and resources for staff to provide outcomes to consumers who were directly involved in consultation activities. This must include resources to support staff explaining why consumer contributions could not be acted upon or incorporated.</p>	10	11	21
<p>Action 11 Implement a consistent communication process for sharing outcomes with the organisation and the wider community from consumer consultations, feedback and statistics related to consumer engagement (e.g., social media updates, electronic and hard copy posters).</p>	11	9	20

Table 32: Final order of actions for Goal 3 – Communicating effectively

ACTION 7: Incorporate a consistent process within CAHS policy that requires clinical staff to:

- check with consumers that they have understood the verbal information provided at appointments
- use techniques to gain well-informed consent
- allow time for questions about clinical care in a safe space.

Ensure appropriate processes and styles of communication are used for people with disability, people for whom English is not their first language, Aboriginal people and children and young people (as aligned with the CAHS Consumer Profile).

ACTION 5: Develop resources for children and young people about what can be expected at our services and how they can ask questions. This could include storybooks, animated videos, games, apps and diagrams.

ACTION 4: Provide communication support and aids for consumers requiring assistance with communication due to a disability or literacy requirements

ACTION 2: Improve consumer and staff awareness of the availability of interpreters, including translated written information and confirmation before appointments.

ACTION 3: Make publications accessible for consumers who speak languages other than English or who require formats to meet different literacy and ability requirements.

ACTION 8: Train staff, who require it, how to respond appropriately and constructively to consumers who are not satisfied with a service. This may involve managing difficult behaviours, preventing escalation to a complaint or explaining the feedback process to consumers.

ACTION 6: Establish a panel of consumers to review consumer resources and publications. This would include a youth review panel for youth-specific resources and publications. Consider supporting this with the employment of a plain language expert.

ACTION 1: Develop materials for consumers about what can be expected when using CAHS services and common questions they could ask. Base this on what other parents/carers have wanted to know. Consider the establishment of consumer liaison positions within services and online options to provide consumers with this information.

ACTION 9: Review the process of responding to consumers about what action has been taken to address their feedback.

ACTION 11: Implement a consistent communication process for sharing outcomes with the organisation and the wider community from consumer consultations, feedback and statistics related to consumer engagement (e.g., social media updates, electronic and hard copy posters).

ACTION 10: Develop a process and resources for staff to provide outcomes to consumers who were directly involved in consultation activities. This must include resources to support staff explaining why consumer contributions could not be acted upon or incorporated.

Rewording of Goal 3

The original wording of the goal was “Consumers are communicated with effectively, no matter what their needs or preferences are for communication.”

These were rephrased by the two groups and resulted in:

1. We will connected with children, young people and families taking not consideration their unique needs and preferences.
2. We communicate with all children, teenagers and families effectively, compassionately, according to their needs.

The group worked together to combine these to:

We will connected and communicate compassionately with children, young people and families, according to their unique needs.

Goal Four – Consistent governance

Prioritise actions

The order of priority given to each of the actions by staff and consumers is presented below in Table 33, along with the total score. The final order of actions is presented in Table 34.

Table 33: Staff and consumer priorities for Goal 4 – Consistent governance

Actions	Staff	Cons.	Total
ACTION 1 Develop and implement audits of policies related to consumer engagement (e.g. auditing of care plans).	10	6	16
ACTION 2 Set expectations for consumer consultation, including: <ul style="list-style-type: none"> • consultation involving young people • nature or level of involvement and • outcomes of consumer consultation. 	1	3	4
ACTION 3 Develop a policy for involving children under the age of 14 in consumer feedback and consultation.	2	2	4
ACTION 4 Update CAHS Complaints Management Policy and clarify process, response time and action and storage of information and consider the risks associated with the postage of feedback forms.	9	4	13
ACTION 5 Create a CAHS-wide reporting register for consumer engagement activities undertaken across all CAHS services and establish a monitoring mechanism.	4	7	11
ACTION 6 Implement a mechanism within committee governance processes that require consumer data and input to be considered before approving projects, policies and publications where relevant.	3	1	4
ACTION 7 Introduce mechanisms for monitoring consumer consultation being conducted across the service to consolidate information and use it strategically.	5	7	12
ACTION 8 Implement a consistent mechanism for reporting and identifying risks associated with partnering with consumers.	8	10	18

ACTION 9 Ensure safety and quality performance data and feedback is shared with consumers.	7	5	12
ACTION 10 Incorporate reviews of clinical incidents and consumer feedback to identify areas of concern and guide service improvement and consumer partnerships.	6	9	15

Table 34: Final order of actions for Goal 4 – Consistent governance

ACTION 2: Set expectations for consumer consultation, including:
consultation involving young people
nature or level of involvement and
outcomes of consumer consultation.

ACTION 6: Implement a mechanism within committee governance processes that require consumer data and input to be considered before approving projects, policies and publications where relevant.

ACTION 3: Develop a policy for involving children under the age of 14 in consumer feedback and consultation.

ACTION 5: Create a CAHS-wide reporting register for consumer engagement activities undertaken across all CAHS services and establish a monitoring mechanism.

ACTION 9: Ensure safety and quality performance data and feedback is shared with consumers.

ACTION 7: Introduce mechanisms for monitoring consumer consultation being conducted across the service to consolidate information and use it strategically.

ACTION 4: Update CAHS Complaints Management Policy and clarify process, response time and action and storage of information and consider the risks associated with the postage of feedback forms.

ACTION 10: Incorporate reviews of clinical incidents and consumer feedback to identify areas of concern and guide service improvement and consumer partnerships.

ACTION 1: Develop and implement audits of policies related to consumer engagement (e.g. auditing of care plans).

ACTION 8: Implement a consistent mechanism for reporting and identifying risks associated with partnering with consumers.

Rewording of Goal 4

The original wording of the goal was “Clear, consistent and coordinated and governance of consumer engagement.”

These were rephrased by the two groups and resulted in:

1. Clear guidance for working together consistently with the community.
2. Systems and processes to engage with children, young people and families to meet their needs.

The group decided on the first wording above for goal 4.

Clear guidance for working together consistently with the community.

Refinement of Phase Three Findings

Following the consensus building workshops of Phase Three the actions were further reviewed by the Consumer Engagement Team and the CAHS Executive Committee.

Based on these review process further changes including:

- merging some overlapping actions
- adding further actions required to meet Standard Two
- removing actions outside the scope of consumer engagement.

There were also some minor changes made to the wording of the goals by the Consumer Engagement Team to ensure they were consistently phrased.

The final goals and actions can be found in the Consumer Engagement Strategy.

Limitations

There were some limitations to developing the Strategy, many of which have been addressed in the actions identified for the Strategy. However, it is important to note them and take them on for consideration of future strategies or continuing or related work related to this Strategy. There were originally plans to involve children in the development of the Strategy, as well as more workshops with young people and a workshop with regional consumers. However, restrictions and delays due to COVID- 19 prevented this.

Another limitation was the broad distribution to, and participation of, young people in the survey in Phase One. There was also no interpreter service available for people who spoke a language other than English to complete the surveys in Phase One. Although Aboriginal people completed surveys and were involved in the workshops, it is recognised that these were not necessarily in formats where Aboriginal people could fully express their needs, concerns and preferences in relation to consumer engagement.