Final report (updated)

Consumer experience and expectations of after-hours primary care in the ACT

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Executive Summary

For most of us, good health is not a constant or infallible state of being. Even for those in excellent health, occasional illness and injury are unavoidable and can impact our lives at any time or day of the week. Consequently, after-hours care is an essential component of our health care system. There are several models of after-hours service available in the ACT and this research has sought to gain a better understanding of how and why these services are used and how satisfied people in the ACT are with these important services.

Why do people use after-hours services?

Overwhelmingly, the most common reason for using after-hours services is because the event precipitating care occurs outside standard working hours. This challenges a possible misconception that consumers who use after-hours services are seeking an alternative to general practice, and is consistent with the literature. Instead, most consumers indicated that they are using after-hours services out of necessity and this drives their decision. However, our conversations with stakeholders indicate that what consumers perceive as urgent is not necessarily considered urgent by clinicians. This disconnect suggests that there is room to educate the ACT population about what constitutes an urgent need for treatment and to provide them with the skills and confidence to manage situations that are not "clinically urgent" until the following day when a general practice will be able to address their needs. This report also illustrates that the need for an out-of-pocket payment will always be an issue for some sectors of the community. Convenience is also a factor and is discussed below.

What care is provided?

Prescription of medication is the major kind of care provided at after-hours services with 60 and 80 percent (depending on the service) of consumers stating they were prescribed medicine and 20 and 30 percent stating they were given medicine. Procedures such as stitches, plaster casts and the removal of ticks were far less common and overwhelmingly done at the Walk-in Centres and Emergency Departments. Less than 10 percent of respondents were referred for tests, except for after-hours general practice that referred over 30 percent for tests. Referrals to GPs and other specialists were similarly low (less than 20%) across all groups. One way to reduce the number of ED presentations is to widely advertise what other after-hours services are available and care they can provide.

What do consumers consider important when choosing an after-hours primary care service?

The convenience provided by after-hours services was highly valued by consumers and more than 60 percent of respondents rated a service's opening hours as very important. Proximity to home and ease of parking were also important to between 40 and 60 percent of respondents. Depending on the service they used, waiting times were very important to between 30 and 50 percent of respondents. Those who made an appointment were more likely to perceive waiting times as important, than those who used services that did not require an appointment. This suggests that after-

hours services need to continue to cater both to consumers who prefer appointments as well as those that do not.

The clinical expertise of staff was very important to more than 50% of all respondents and as high as 90% for those using the Emergency Departments. The range of services offered was almost as high for all services (between 50-80% depending on the service). The cleanliness and comfort of the service, and the friendliness and attentiveness of its staff varied in importance but were largely about 50%.

The inability to see a GP during work hours and satisfaction with previous use of the service was important to between 30 and 55% of respondents. The likelihood of not seeing someone you knew was important to the respondents and there is clearly consumer demand for extended hours general practice beyond that currently provided by most practices.

Interview insights

Interviews with consumers about their recent experience of using an after-hours service in the ACT speaks to the diversity of needs and the capacity of services to support those needs. Three main themes emerged from the interviews

- the variety of reasons for using the services
- the variability in perceived care at the Emergency Department, and
- the importance of professional and personal conduct of staff.

Consumers seek after-hours care because the event precipitating care occurs after-hours and because they feel it cannot wait. It is worth noting that the perception of urgency is indistinguishable from actual urgency from a consumer perspective. That is to say, consumers will consider a situation urgent until persuaded otherwise by a health professional, and perceptions of urgency vary among consumers. Reassurance is highly valued but not always guaranteed from after-hours services. This tends to arise because communication between health professionals and consumers is poor. It can also be due to the algorithms that guide some telephone help lines. Convenience was highly valued by consumers, and the desire for it depends upon one's circumstances, such as weather conditions, time of day, and the consequences of one course of action over another.

Regrettably our consumers' experiences of ED were variable. Some had extremely positive experiences and some had the opposite at the very same service. This applies to both public hospitals in the ACT, including the new paediatric emergency service at The Canberra Hospital.

Consumers greatly value professional aptitude and the personal touch. It influences consumers' confidence and overall satisfaction, as well as peace of mind and reassurance. While professional and personal behaviour is arguably attributable to individuals rather than services, the friendliness of Walk-in Centres and the National Home Doctor Service was especially noted in interviews.

Conclusion

ACT consumers value and require the after-hours services available to them and are very satisfied with the care they receive.

> *I feel very blessed that we have got [General Practice, Pharmacies and the Walk-in Centres]. [We had] easy access, and we didn't need to use A&E, as we have had to in the past, knowing that we could go somewhere that we wouldn't need to wait and wait, and also be around much sicker people, risking getting sicker. Participant K*

This report highlights the importance of after-hours services and the value they add to standard-hours practices. Consumers appreciate that these services support the fact that *life happens* outside of standard working hours and that these services are available in the occasional times where good health fails. Also appreciated are the variable ways and means that consumers are supported to seek health care that suits our often chaotic and unpredictable lives when our health takes a turn for the worse. While there is clearly an opportunity to improve health literacy regarding clinically urgent situations the importance of high standards of medical care, reassurance and peace of mind should not be underestimated.

Recommendations

Consumers value and require care after-hours and want that care to be person-centred. They value the skill and expertise of the health professionals providing care. Nevertheless, there is much scope to improve communication between the person seeking care and those providing it.

Recommendation 1) After-hours service providers ensure that professional staff are skilled in taking a person-centred approach, including the provision of reassurance.

Recommendation 2) After-hours professionals are given sufficient time and resources to take a person-centred approach.

Recommendation 3) ACT Health considers an advertising campaign that promotes the wide range of after-hours services and the care they provide to ACT residents.

Recommendation 4) ACT Health develops a comprehensive health literacy strategy that gives consumers the information, skills and confidence to manage situations that are not "clinically urgent."

Recommendation 5) ACT Health supports a mix of after-hours services including services that

- do not require a co-payment, and
- do not require appointments.

Recommendation 6) ACT Health encourages general practices to offer extended hours to their patients.

Recommendation 7) ACT Health supports pharmacies to continue providing valuable health information to the community.

Recommendation 8) ACT Health explore options to identify patients who repeatedly attend ED and then place a flag on their records to indicate the usual care that is required.

Recommendation 9) ACT Health commission research to better understand the impact that after-hours health services have on ED presentations.

Introduction

Aims of the study

In undertaking this study HCCA was interested in

1) why consumers choose to use after-hours services,
2) what care is provided once they attend a service, and
3) what consumers consider important when choosing an after-hours primary care service, including
   - convenience,
   - quality and range of services, and
   - likelihood of seeing people you know, previous experience, and the inability to see a GP during work hours.

Additionally, we wanted to understand

4) how satisfied consumers are with the care provided.

Definition of after-hours primary care

For the purposes of this study we defined after-hours as

- after 6pm on weekdays
- after 12pm on Saturdays
- all day Sunday and public holidays.

This definition is based on the Medicare Benefits Schedule for urgent after-hours primary care (see Appendix I – GP consultation type). However, our definition slightly truncates weekday closing time to reflect the reality of general practice opening hours in the ACT.

"Standard hours" in general practice run between 8am and 8pm on weekdays and between 8am and noon on Saturdays. Consultations outside these hours are considered "after-hours" but include the further sub-category of "unsociable hours", which commence at 11pm on weekdays, Sundays and public holidays, and 11am on Saturday. Based on Capital Health Network 2016 data, only five practices are open standard hours (8am-8pm) and a further three practices are open for longer. However, most practices close their doors at 6pm on weekdays, hence we define weekday after-hours commencing at 6pm.

All accredited general practices[1] – the large majority – are obliged to arrange for their patients to receive care outside normal opening hours.[i] They do not have to provide that care but they must ensure that their patients have access. Some choose to be part of a medical deputising service (discussed below) and far fewer provide it themselves.

[1] An accredited general practice has been assessed to meet the *RACGP standards for general practice,* https://www.racgp.org.au/your-practice/standards/standards4thedition/ (Accessed 19 October 2017).

Background

Illness and injury do not consider the time of day before turning someone's life upside-down. Nevertheless,

> *ACT Health is today urging Canberrans to save our ACT Emergency Departments for genuine medical emergencies following a succession of extremely high numbers of patients presenting to the EDs.*[ii]

What is a medical emergency?

The Canberra and Calvary emergency departments prioritise critically ill patients, especially people who have experienced or are experiencing

- breathing difficulties
- heart attack symptoms
- stroke symptoms
- major accident
- sudden collapse
- uncontrollable bleeding
- injury limiting normal function
- pain that is not relieved by regular, pain relief medications

The emergency departments will also treat acute illnesses and injuries, but everyone is triaged (or prioritised) according the urgency of their need. Part of the problem, from a hospital or clinical perspective, is that many people attend an emergency department (ED) with conditions or injuries that could be seen the next day or addressed by alternate after-hours primary care services. A trend towards increasing ED workloads can be seen both locally[iii] and internationally.[iv,v]

Among the factors believed to contribute to this rise are

- an increasing population, increasing prevalence of non-communicable diseases, and an increase in the relative proportions of older people,
- inconsistent short-term planning for primary care services,
- reduced working hours within the medical profession, and
- lack of patient understanding of what constitutes urgent care and what other services are available.[vi]

Additionally, the lack of available hospital beds can cause delays in ED, which has led the Canberra Hospital to develop a Whole of Hospital Patient Flow Strategy.[2]

What is an urgent GP consultation?

The first step down from a medical emergency is the requirement for an urgent consultation. One could reasonably expect to find a definition of what constituted an "urgent consultation" in the Medical Benefits Schedule (MBS), which specifies the rebates consumers receive if they use the services of registered general practitioners. Unfortunately, the MBS has no clear definition of an 'urgent' consultation. A recent, rapid and significant increase in the rate of urgent after-hour claims has prompted the Medicare Benefits Schedule Review Taskforce to suggest defining urgent after-hours care as that which

[2] Narelle Boyd, Acting Executive Director Clinical Care, Canberra Hospital, 13 September 2107

- cannot be delayed until the time a GP is available during normal work hours; and
- requires the GP to attend the patient at the patient's location or to reopen their practice rooms.[vii]

All accredited general practices[3] – the large majority – are obliged to arrange for their patients to receive care outside normal opening hours.[viii] They do not have to provide that care but they must ensure that their patients have access. Some choose to be part of a medical deputising service (discussed below) and far fewer provide it themselves.

Demand for emergency and after-hours services

EDs are not the only after-hours service in high demand. As mentioned, the federal government is concerned by the increasing growth rate of urgent home visits from a doctor.[ix] For instance, the ACT saw a 1,270% increase in urgent after-hours general practice claims between 2010–11 and 2015–16, which coincided with the introduction of the National Home Doctor Service, a commercial medical deputising service.[x] This same research was unable to find any corresponding decrease in emergency department (ED) presentations in Tasmania where they also had access to ED data from the corresponding period. Nevertheless, some argue that the use of after-hours house call services decreases use of emergency departments.[xi]

Demand for after-hours services can be driven by

- clinical need (i.e. potentially life-threatening illness or injury)
- the patient (e.g. worry, a perceived need, the need for medical information or a second opinion, and not having time to see a GP during the day)[xii,xiii] or
- the health system (e.g. deficiencies in availability and accessibility of a patient's own GP).[xiv]

Models of after-hours primary care

Let's consider the different models available within the ACT and the evidence around their effect on ED presentations. Table 1 summarises the after-hours services available in the ACT.

[3] An accredited general practice has been assessed to meet the *RACGP standards for general practice,* https://www.racgp.org.au/your-practice/standards/standards4thedition/ (Accessed 19 October 2017).

Table 1. Summary of the after-hours services available in the ACT.

Service	Type of service	Location	Opening hours	Restrictions	Co-payment required	Focus
Walk-in Centres	• Walk-in centre	Belconnen Tuggeranong	7.30am-10pm	Non-emergency No children under 2 years	✘	• Minor illness & injury
CALMS	• Not for profit medical deputising organisation • Telephone triage & advice	Belconnen Woden Tuggeranong	6pm-8am	Non-emergency	✓	• After-hours general practice
National Home Doctor Service	• Commercial medical deputising organisation	Across Canberra	6pm-8am	Non-emergency	✘	• After-hours general practice • unsociable hours GP
ED	• Emergency department	Belconnen Woden	24 hrs	Emergency	✘	• Medical emergencies • Minor illness & injury
Extended hours general practice	• General practice	Across Canberra	6-10pm weekdays 12-10 Saturday	Non-emergency	✓	• After-hours GP •
healthdirect	• Telephone triage & advice	All of the ACT	24 hrs	Non-emergency	✘	• Health advice

Commercial medical deputising services are commercial companies that employ doctors to provide an after-hours service. The National Home Doctor Service is the only such service in the ACT. It provides home visits by doctors 6pm-8am during the week, from 12pm Saturday onwards, and all day public holidays. Opinions on the overall effect of such services are mixed. Some Australian research indicates that a national increase in the use of urgent consultations during unsociable hours (11pm-7am) coincided with the arrival of commercial deputising services, while finding no decrease in the use of ED.[xv] Other research believes that the data shows home visits are responsible for a significant decline in ED presentations.[xvi] An international review found that deputising services increase immediate medical workload because consumers are less likely to rely on telephone advice and home visiting increases.[xvii]

Not-for-profit medical deputising services, also known as GP cooperatives, are formed by different general practices to provide care for their own patients after hours. The Canberra After-hours Locum Medical Service (CALMS) is a not-for-profit organisation created by Canberra GPs. CALMS offers a telephone triage service, with up to 40% of phone calls resulting in face-to-face consultations and roughly one home visit a night.[4] Evidence of cooperatives' success in reducing ED presentations comes from the Netherlands where the first point of contact is in person with a nurse, who is under the supervision of a GP. At CALMS the phones are answered by registered nurses and face-to-face services are provided by vocationally registered GPs. Notwithstanding these differences, it suggests that CALMS may be associated with a shift of care away from ED.[xviii]

Walk-in centres provide a service that does not require an appointment for the treatment of minor injury or illness and does not require a co-payment. ACT Health opened its first Walk-in Centre in 2008. The original was located at the Canberra Hospital, but since then it has been replaced by Walk-in Centres in large community health centres, in Belconnen and Tuggeranong. UK experience suggests that walk-in centres have the potential to reduce non-urgent emergency presentations, but the data is weak and mixed.[xix] An evaluation of Canberra's original Walk-in Centre in 2011 found the overall impact was a net increase in ED activity.[xx]

Telephone triage and advice services are telephone consultations for primary care patients seeking medical help after hours. This is provided by CALMS and telephone arm of *healthdirect*. Telephone services appear to reduce immediate medical workload, by reducing the number of face-to-face consultations,[xxi] particularly inappropriate visits to ED.[xxii,xxiii] Unfortunately, research consistently shows that patients are dissatisfied with telephone consultations, in part because they expect a home visit.[xxiv]

Extended hours general practice is offered by 19 ACT general practices on a Saturday.[5] Only two of these are open until 10pm, one is open until 8pm, seven until 6pm, and one until 5pm. The rest close at 1 or 2pm. During the week extended hours are offered by 15 practices. Once again two open until 10pm, one until 9pm. Thirteen practices are open on Sundays and public holidays, and they are open from four to14 hours.

[4] Private correspondence with Graeme Sellar, General Manager, CALMS Ltd, 11 October 2017.
[5] Angelene True, Senior Manager, Service Planning and Design, Capital Health Network, private correspondence, 19 October 2017.

Community pharmacists provide some urgent care and 55 pharmacies based in the ACT are available after-hours at least some of the time.[6] However, the latest any of these are open is until 11pm, so no one provides 24 hours access. Peak after-hours availability occurs on Saturdays, followed by Sundays and public holidays. In addition to their usual dispensing role, community pharmacists can dispense prescriptions, provide primary healthcare advice and support, and educate customers on health promotion, disease prevention and the quality use of medicines.[xxv] Consumers requiring assistance are "often somewhat desperate" because of the limited choices. Pharmacists are often required to problem-solve where the strength of medicine is out of stock or the doctor has not specified the correct dose, for instance.[7]

In summary, there is no definitive research on which after-hours service or combination of services is best placed to reduce pressure on emergency departments. All of them offer a valuable service to the ACT community. In the following section we discuss the approach we took to conducting the study.

[6] Capital Health Network, Private correspondence, 19 October 2017.
[7] Elise Apolloni, Pharmacist and owner, Capital Chemist Waniassa, 19 June 2017.

Approach

Study design

We took a three stage approach.

1) We sought the perspective of service providers and planners on the challenges associated with providing after-hours primary health care.
2) We reviewed and refined two earlier HCCA surveys that gave a snapshot of consumers' experience of general practice in the ACT. An additional section asked questions about consumer use of after-hours services in the ACT.
3) We interviewed 15 consumers[8] about their experience using general practice and after-hours services in the past 12 months.

HCCA submitted the project for review by the ACT Health Human Research Ethics Committee. However, we were advised by the committee that this project meets the definition for quality assurance and, as per the NHMRC Ethical Considerations in Quality Assurance and Evaluation Activities 2014, ethical clearance was not required. Nevertheless, the research was conducted in line with the National Statement on Ethical Conduct in Human Research (2007).

Consumers who were willing to share their stories of after-hours access were recruited through HCCA networks. The interviews were conducted by two HCCA researchers (Kathryn Dwan and Kathryn Briant), recorded and professionally transcribed.

Stage 1

The research team met with representatives of key organisations involved in the planning and provision of after-hours services; CALMS, Canberra Hospital, Calvary Health Care ACT, *healthdirect*, and the Walk-in Centres. A summary of each of the after-hours primary care services in the ACT is discussed under Centre-Specific Information from p30. We also met with a local pharmacist, a general practice open extended hours, an organisation providing services for people in insecure housing, and Capital Health Network, the local primary health network (see Appendix II – Key stakeholders). Three extra questions were added to the survey as a result of these meetings.

Stage 2

The survey ran for four weeks between 7July and 4 August 2017 and was completed by 1035 participants (see Appendix III – Data cleaning). The survey was promoted through email, social media and via other community organisations. Considerable effort was made to solicit input from people who do not normally complete online surveys either because of disabilities, health issues or difficulty using computers. We worked with the community groups and services that support people in these three locations to identify potential participants and ensure that they were appropriately supported to participate. Consequently, we were able to interview two residents of Common Ground[9] and two from Ainslie Village[10], while entering the answers they

[8] One consumer chose to withdraw from the study, so we report on only 14 consumers in this report
[9] Low income housing in Gungahlin https://www.commongroundcanberra.org.au/
[10] Social housing complex in Campbell http://argylehousing.com.au/social/ainslie-village/

provided into the online survey. In addition, we informally interviewed three people who were regular attendees at The Roadhouse[11].

Stage 3

Recruitment for consumer interviews commenced soon after the survey went live and used the same organisational and personal networks. Fifteen participants took part in a semi-structured interview designed to elicit their journey through the health system (see Appendix IV – Interviewee characteristics). We used the applied qualitative research method Real People, Real Data, developed by the Consumers' Health Forum of Australia.[xxvi] In the Real People, Real Data method, participants' key experiences of care are presented as a Health Experience Wheel, a simple visual depiction used the consumers own words to convey what mattered most for each person as they used services. This image is intended to clearly communicate areas for improvement as well as what individuals' value about the services they received.

To create these images, HCCA provided each participant with a transcript of their interview. People were invited to review their transcript and identify their key positive and negative experiences. The key experiences that appear on the Health Experience Wheels were coded according to which of twelve evidence-based domains of person-centred care applied.

Study limitations

The survey respondents were self-selected and thus are not representative of the ACT population. In particular, older, well educated women are over-represented. These biases are common in health surveys and HCCA intends to undertake statistical analysis to control for these variables. Unfortunately, the satisfaction question associated with each of the after-hours services used in the previous 12 months was missing from the first 125 surveys that were completed.

The interview participants were recruited largely through personal networks and are predominantly well-educated women. However, these interviews did not seek to be representative of the population, but were chosen to illustrate experiences of consumers at after-hours services in the ACT.

[11] Free hot meal and information service in Civic
https://www.assistance.act.gov.au/adult/food/freelow_cost_food/room_1_griffin_centre

Participants

The majority of respondents were female, heterosexual, highly educated, and long-term residents of Canberra.

Two thirds reported having one or more chronic conditions.

There was fairly good representation from different geographical areas of the ACT.

Age

The survey sample appreciably under represents people aged less than 24 years, and over-represents people age 35 years and above. Given ageing and child rearing are associated with increasing health issues, it is not surprising that the people most likely to need health care were highly motivated to participate (see Appendix V, Table V-1).

Gender and sexuality

Considerably more women than men answered the survey (♀=80%, ♂=19%, n=906), but this is not surprising as women tend to be more engaged with health issues[xxvii] and more likely to participate in surveys.[xxviii,xxix] The respondents identified overwhelmingly as heterosexual, with 7.6% identifying as Lesbian Gay Bisexual Transgender or Intersex (LGBTI), and 3% preferring not to disclose (n=884). This suggests reasonably good representativeness of the LGBTI community.[xxx]

Socio-economic status

People with higher levels of education, employment and income have higher socio-economic status and tend to enjoy better health.[xxxi] This is because a person's health is influenced by the conditions in which they are born, grow, work, live, and age.[xxxii] While we didn't set out to measure socio-economic status the answers to questions about education and employment suggest our respondents tended to have greater socio-economic resources.

Our sample was well educated with over half completing undergraduate or post-graduate degrees. Nearly a quarter had vocational qualifications or a diploma, and fewer than seven percent of respondents did not complete Year 12 (see Appendix V, Table V-2). Over half of respondents were in full-time or part-time paid employment (see Appendix V, Table V-3), and the vast majority of respondents indicated that they were in secure housing, meaning they owned their home or they were able to meet their rent or mortgage.

Vulnerable groups

Participation from Aboriginal or Torres Strait Islander people living in the ACT (1.5%, n=900) was comparable with 2016 ACT Census data.[xxxiii] However, the proportion of people speaking a language other than English at home was lower in our sample (9%, n=904) than the 2011 ACT Census data (12.5%).[xxxiv]

Knowing that people in insecure housing tend to have poorer health[xxxv] we asked people to describe their housing situation and included the option 'Insecure or unstable (e.g. couch surfing, homeless, difficult environment)'. Twenty-three people indicated that they were in insecure or unstable housing (n=900).

Chronic conditions and caring responsibilities

Over two thirds of our respondents identified as having one or more chronic conditions (69%, n=1035). In this report we define chronic conditions as ones that are generally long-term and persistent, often leading to a gradual deterioration of health and loss of independence, not often immediately life threatening.[xxxvi] There are four main types of chronic conditions, according to the World Health Organization:

- cardiovascular diseases (like heart attacks and stroke),
- cancers
- chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma)
- diabetes.[xxxvii]

The Australian Department of Health also include mental illness, trauma, disability and genetic disorders in the list,[xxxviii] as does HCCA. Chronic conditions can occur across the life cycle, but they become more common with ageing, can result in disabilities, and may compromise one's quality of life.[xxxix]

Almost a fifth of our respondents care for children under five years (18%, n=904) and the same proportion care for others with disabilities or chronic conditions (18%, n=901). Three percent of our respondents (n=26) care for both a young child and someone with disabilities or chronic conditions.

Location and length of residency

The majority of respondents (88%, n=896) have lived in the ACT for 6-10 years or more. Each of the major geographical regions of the ACT areas was well represented compared with the 2016 Census data, our sample does slightly over-represent the Belconnen and Gungahlin areas (see Appendix V, Table V-5).

Self-rated health status

The majority of our respondents enjoy good health (see Appendix VI, Figure VI-1). These data are broadly consistent with 2014-15 National Health Survey. However, more of our respondents rated their health as 'poor' or 'fair', and fewer rated their health as 'very good' or 'excellent' when compared with the National Health Survey.

When we considered groups known to have poorer outcomes overall, we get a different picture. Carers and people with disabilities are more likely to describe their health as 'poor' or 'fair' than the overall sample. Respondents with disabilities are also very unlikely to rate their health as 'very good' or 'excellent' (see Appendix VI, Figure VI-2). However, carers are more likely to rate their health as 'good' than the National Health Survey (see Appendix VI, Figure VI-2). Carers, in theory, must be in reasonably good health to be in a position to help others, but we know that this is not always the case. Interestingly, although over two thirds of our respondents have one or more chronic conditions, they are managing their health well and also report high rates of good and very good health (see Appendix VI, Figure VI-2).

Two other groups worth mentioning are people from the LGBTI community and people in insecure or unstable housing. Gay, lesbian, bisexual, transgender and intersex people are three times more likely to suffer depression.[xl] Happily

respondents identifying as being LGBTI rated their health similarly to those who identified as heterosexual (see Appendix VI, Figure VI-3).

Depression is also common among people who are homeless. These people are also more likely to experience poor nutrition, poor dental health, substance abuse and mental health problems.[xli] Furthermore, homeless people have poorer access to health services than the broader population.[xlii] Unfortunately our homeless respondents did not fare so well. Less than a half of these considered their health to be ‘good’ or better, and nine people considered their health to be ‘poor’ (see Appendix VI, Figure VI-4).

After-hours services

After-hours services

All of the following after-hours services are provided to ACT residents:

- Commercial medical deputising organisation (National Home Doctor Service)
- Not-for-profit medical deputising organisation (CALMS)
- Walk-in Centres (Belconnen and Tuggeranong)
- Telephone triage & advice (*healthdirect*, CALMS)
- Extended hours general practice
- Community pharmacists
- Emergency departments

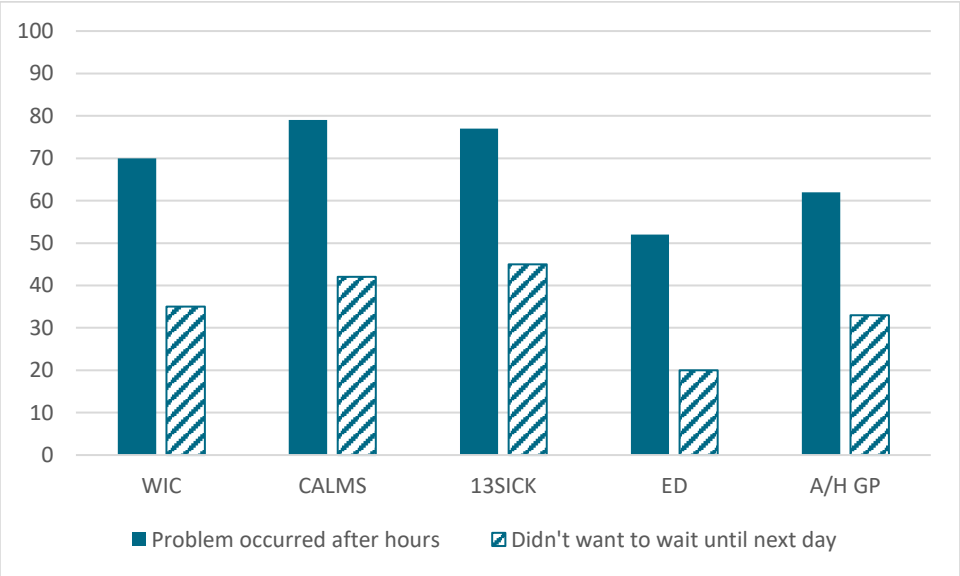
Ideally, medical emergencies are dealt with by the emergency departments in Canberra's two public hospitals. While emergency departments are used for after-hours care (see next section), health issues that require primary care outside of standard hours are addressed to various degrees by the remaining services.

Why do people use after-hours primary care services?

- People chose to attend an after-hours service because the issue occurred outside standard hours.
- Approximately a third did not want to wait until the next day.

Survey respondents who had used an after-hours service in the past 12 months were asked why they chose the particular service they did. Overwhelmingly, the most common reason respondents gave was because the issue occurred outside standard hours (see Figure 1). There is clearly consumer demand for extended hours general practice beyond that currently provided by most practices.

Figure 1. The most common reasons for choosing to use after-hours primary care services (n=908)



The second most common reason for using an after-hours service was because respondents did not want to wait until the next day (see Figure 1). Research into attendances at an Australian GP cooperative found that the majority of patients only attended once, they were more likely to be under 18 years, and the consultations produced a higher rate of antibiotic prescriptions than that normally seen in general practice.[xliii] Taken with our findings, this suggests that consumers are not seeking an alternative to general practice, but use after-hours services only when they judge it necessary. The high prescription rates reflect both the high rates of bacterial infections[xliv] and possibly patient or parental distress.[xlv,xlvi]

Another reason given by survey respondents for using after-hours services included 'Because it wouldn't cost me anything'. Unsurprisingly, this response seemed more important to respondents who had used services that did not require a co-payment; the Walk-In Centre (22%) and the National Home Doctor Service (24%). Only respondents who had used the National Home Doctor Service were asked about the importance of not having to leave their home, but this response was given by a third of respondents (34%). Finally, a quarter of respondents who had used GP after-hours services stated that 'After-hours is my only option due to work or study commitments'.

Our survey did not seek to explore in any detail consumers preferences for appointments. What does seem apparent is that the after-hours services need to cater both to consumers who prefer appointments as well as those that do not. HCCA welcomes further research in this area, but notes that it would require careful research design and sophisticated analyses.

We conclude that respondents use after-hours services out of perceived necessity and not because they are seeking an alternative to general practice. Our conversations with stakeholders indicate that what consumers perceive as urgent is not necessarily considered urgent by clinicians. This suggests that there is room to educate the ACT population about what constitutes an urgent need for treatment and also provide them with the skills and confidence to manage situations that are not "clinically urgent" until the following day when a general practice will be able to address their needs. The need for an out-of-pocket payment will always be an issue for some sectors of the community. For this reason, HCCA supports the continued availability of primary care that does not require a co-payment.

What care is provided?

People are most likely to receive the following care in this order

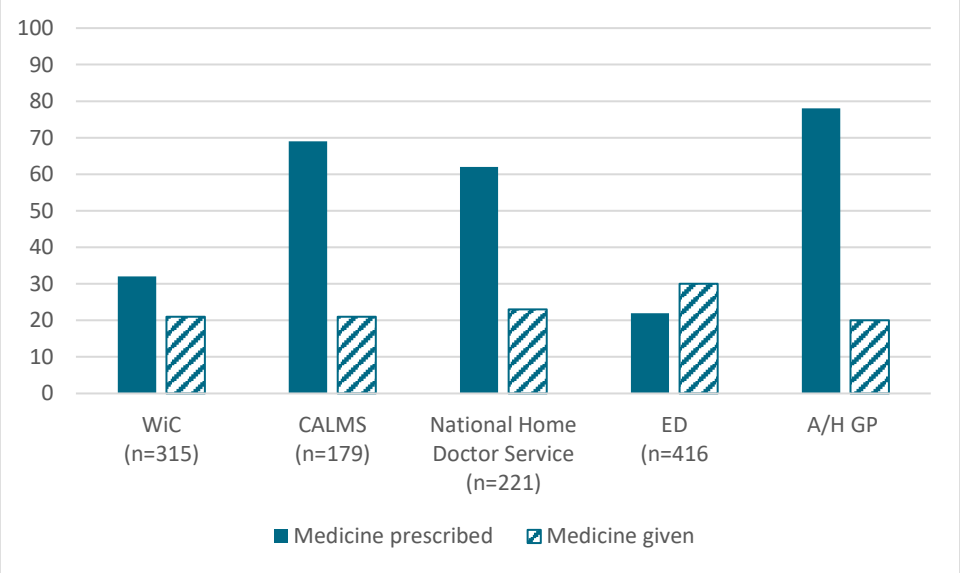
- Medication is given or prescribed
- Procedures are done (e.g. stitches, plaster casts)
- Tests are done or ordered (e.g. blood and urine tests)
- Referrals are made to other health professionals

Survey respondents were asked about the care they received. Options included

- education
- counselling and support
- receiving medicine
- being prescribed medicine
- having procedures done (e.g. stitches, plaster casts)
- having tests done
- referrals for test or to other health practitioners.

Medicine was overwhelmingly the most common care provided, which is consistent with the literature.[xlvii] Medicine was most likely to be prescribed by After-Hours GPs (78%, n=148), CALMS (69%, n=179) and the National Home Doctor Service (62%, n=221). However, respondents were more likely to receive medicine from the Emergency Departments (29%, n=416) than any of the other services (see Figure 2).

Figure 2. The most common care received in after-hours primary care services.

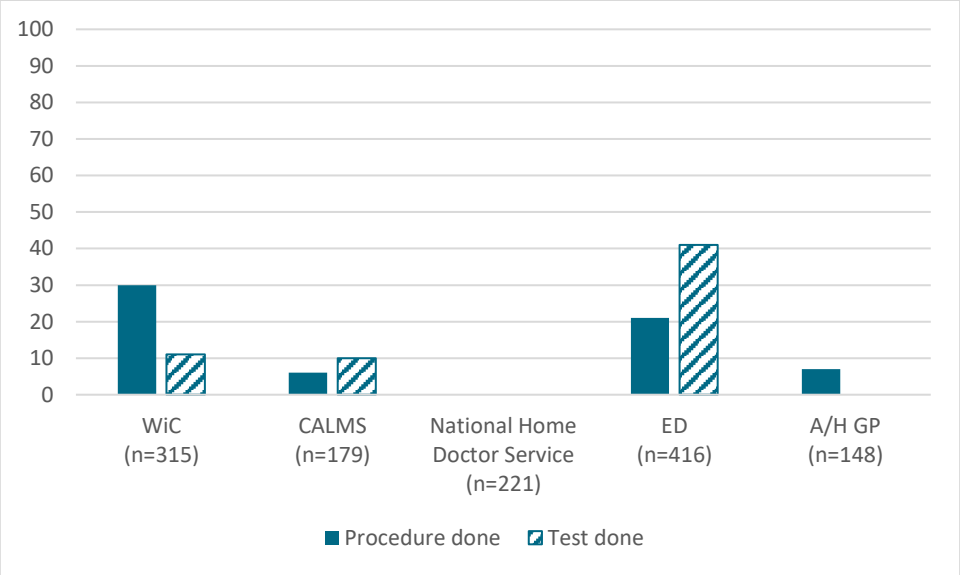


Procedures (e.g. wound care, removal of bee stings) were most likely to be done by the Walk-in Centres (30%) and then the Emergency Departments (21%). After-Hours GPs (7%) and CALMS (6%) did considerably fewer procedures, while the National Home Doctor Service did none. The capacity to do procedures is clearly more limited in the general practice provided services (i.e. CALMS, After-Hours General Practice).

Tests were much less likely after-hours except at ED where roughly 40% of people had them done. In contrast, around 10% of consumers presenting at the Walk-in Centres and CALMS had tests done. After-Hours GPs and the National Home Doctor Service did not do tests (see Figure 3).

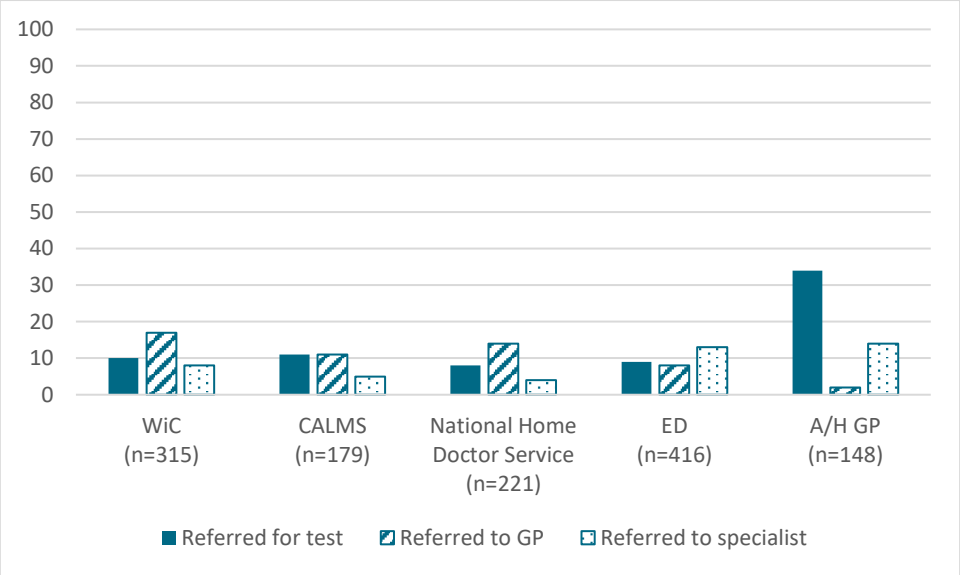
The provision of services – providing medication and doing procedures – was service dependent. Those with the greater capacity for a given care option were more likely to provide that service. Care options may also have been dependent on the information available about the service.

Figure 3. Rates of having procedures and tests done in different after-hours primary care services.



After-Hours GPs referred approximately a third of their patients for tests (32%). In contrast the rates for test referrals from other services varied between eight and twelve percent. The Walk-in Centres were most likely to refer patients to a GP (17%). Specialist referrals were most common among After-Hours GPs (14%) and Emergency Departments (13%), but overall, referral to specialists was not common (see Figure 4).

Figure 4. Rates of referrals done in different after-hours primary care services.



Referrals for tests were not common, except for After-Hours General Practice. Generally, these patients would have been seeing their own GP (or a GP in their practice) and that might have influenced the number of tests ordered. Referrals to GPs and other specialists were similarly low across all groups, never reaching 20%.

What do consumers consider important when choosing an after-hours primary care service?

Convenience

- A service's opening hours was the biggest element driving consumer choice.
- Proximity to home and ease of finding parking are also important.

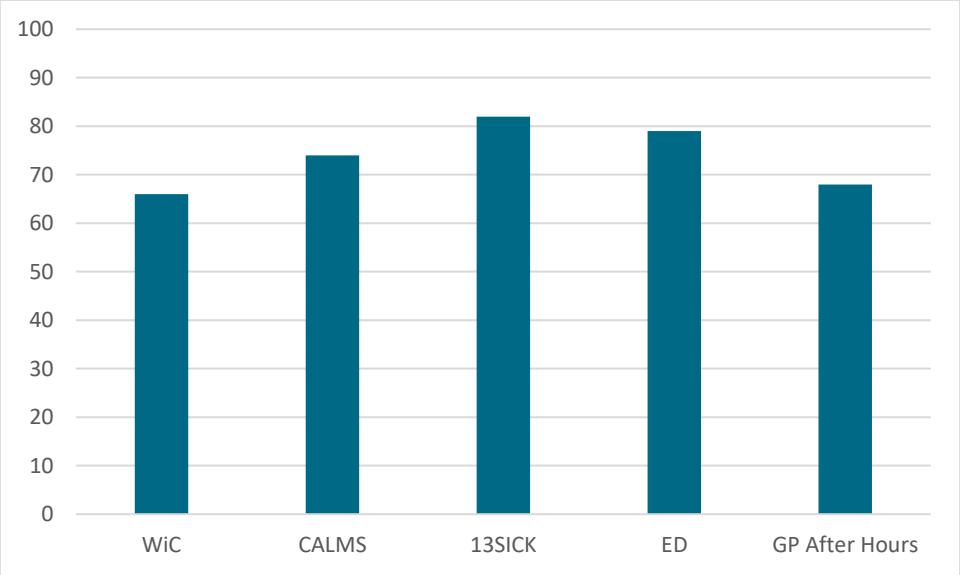
For each after-hours service they used, respondents were asked to rate the importance of a variety of elements associated with convenience, the quality and range of services, and the likelihood of seeing people you know, previous experience, and the inability to see a GP during work hours.

Convenience was assessed by respondents rating the importance of the following elements on a three-point scale from 'very important' to 'not important':

- Close to home
- Close to work education
- Easy to get to
- Easy to find parking
- I can make an appointment / No appointment is needed
- Short waiting time
- Opening hours

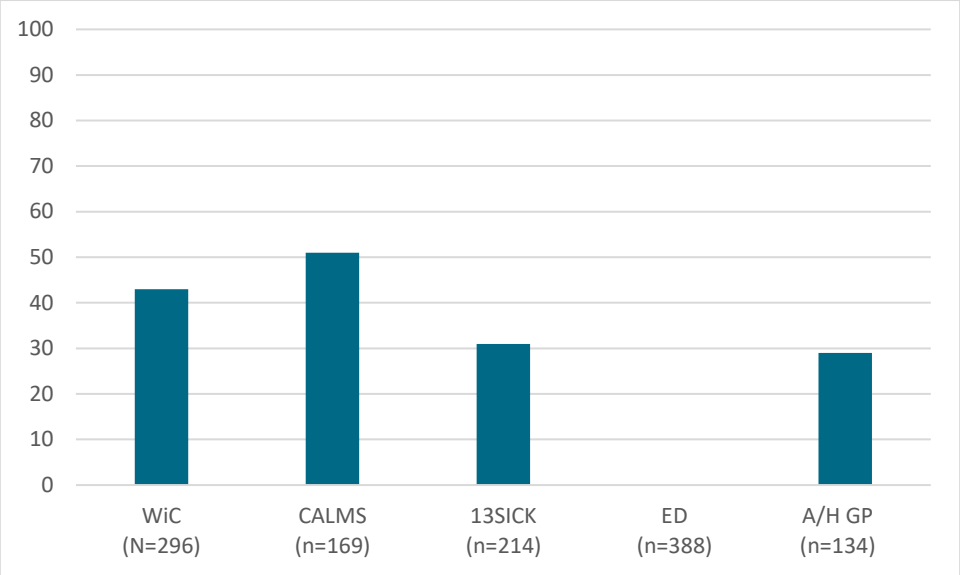
More than 60% of all consumers, across all services, consider opening hours very important (See Figure 5).

Figure 5. The proportion of respondents rating opening hours as 'very important'.



A short waiting time was considered 'very important' to respondents who used CALMS (51%), which has appointments, and the Walk-in Centres (43%), which don't (see Figure 6). So individual consumers may well have a preference for services that offer appointments or those where no appointment is required, but we cannot generalise about whether appointments or their absence suit consumers better. Expectations of short waiting times hovered around 30% for the National Home Doctor Service and After-Hours GPs (see Figure 6). As people are able to wait in the comfort of their own home for the National Home Doctor Service, it seems reasonable that waiting times would not be as important. (**NB** We did not ask the question of ED, because short wait times are generally not expected).

Figure 6. The proportion of respondents rating a short wait time as 'very important'.



The ease of reaching an after-hours service was generally considered very important to 40% or more of respondents, and ease of finding parking was considered slightly more important (see Figure 7).

Figure 7. The proportion of respondents rating ease of location and parking as 'very important'.

Convenience is obviously attractive to the majority of consumers. Proximity to home and ease of finding parking was also very important. The time a consumer could expect to wait was very important to consumers, and depended to some extent on the service they used. So those who made an appointment were more likely to

perceive waiting times as important, than those who used services that did not require an appointment. Respondents who received a home visit from the National Home Doctor Service did not rate waiting time as very important. Our interviews suggest that this is because consumers could avoid travel and could wait in the comfort of their own home.

Quality and range of services

- Respondents primarily valued the clinical expertise of staff
- The importance of other elements varied according to the service

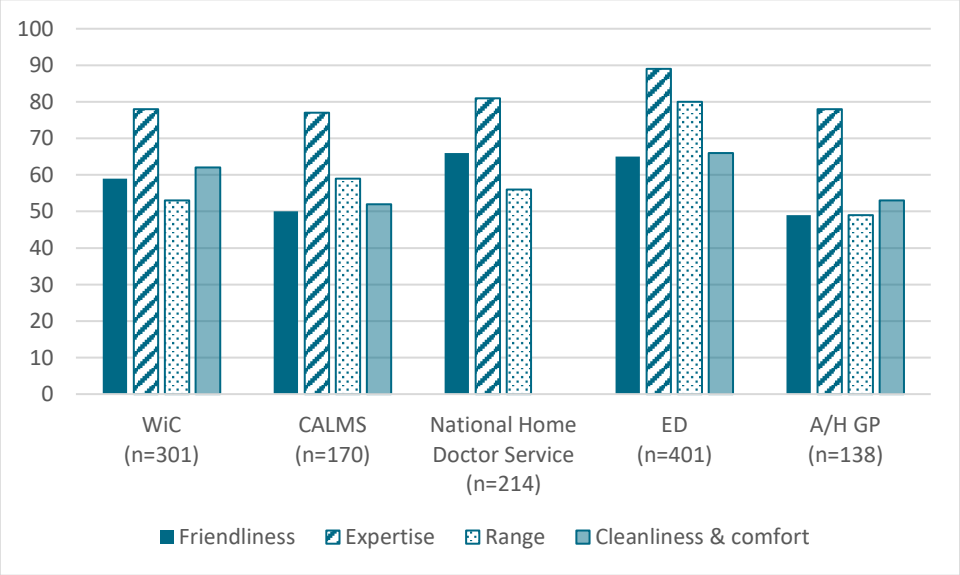
As a measure of a service's quality and range of services, respondents were asked to rate the importance of the following elements on a three-point scale from 'very important' to 'not important':

- Range of services
- Clinical expertise of staff
- Cleanliness and comfort
- Friendliness and attentiveness of staff

Consumers valued clinical expertise very highly across all the services and 89% of consumers who used the Emergency Departments considered the clinical expertise very important. However, more than 50% of respondents who used the Walk-in Centres, CALMS, and the National Home Doctor Service also considered clinical expertise to be 'very important' (see Figure 8).

Almost half of all respondents across all services rated 'cleanliness and comfort' as very important. Respondents who used the National Home Doctor Service were not asked this question, because the cleanliness and comfort would have meant an assessment of the respondent's own home.

Figure 8. The proportion of respondents rating a service's quality and range of services as 'very important'.



The range of services was considered very important to respondents who used the Emergency Departments (80%), followed by CALMS (59%), the National Home Doctor Service (56%), the Walk-in Centres (53%) and After-Hours General Practitioners (49%). Consumers who used the Walk-in Centres and National Home Doctor Service felt that 'friendliness and attentiveness' were more important than the 'range of services' (see Figure 8).

The clinical expertise of staff was very important to more than 50% of all respondents and as high as 90% for those using the Emergency Departments. The range of services offered was almost as high across the board (between 50-80% depending on the service). The cleanliness and comfort of the service, and the friendliness and attentiveness of its staff varied in importance but were largely about 50%.

Likelihood of seeing people you know, previous experience of service and inability to see a GP

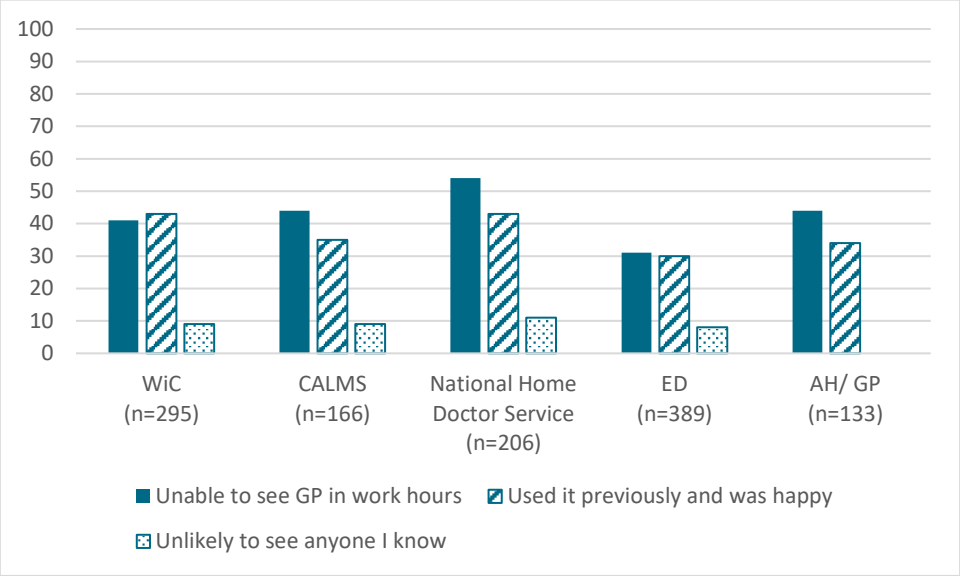
- The inability to see a GP during work hours was of most importance
- A satisfactory previous experience was important to many respondents.
- Privacy was not important to the respondents.

Respondents were asked to rate the importance of the following elements on a three-point scale from 'very important' to 'not important':

- Unlikely to see anyone they knew
- Visited previously and was happy with the service
- Not able to get in to see a GP during work hours

Being unable to see a GP during work hours was very important to over half the respondents who used the National Home Doctor Service (54%). This was much less so the case for those who used the Emergency Departments (see Figure 9). Perhaps those accessing ED had matters that they felt a GP would not be able to handle. Having used the service and being happy with the care provided was important to respondents, with a third or more of respondents across all services stating that it was 'very important' (see Figure 9). The ability to avoid seeing anyone they knew while using a service was not very important to the respondents.

Figure 9. The proportion of respondents rating the likelihood of seeing someone they know, previous experience of the service, and the inability to see a GP during work hours as 'very important'.



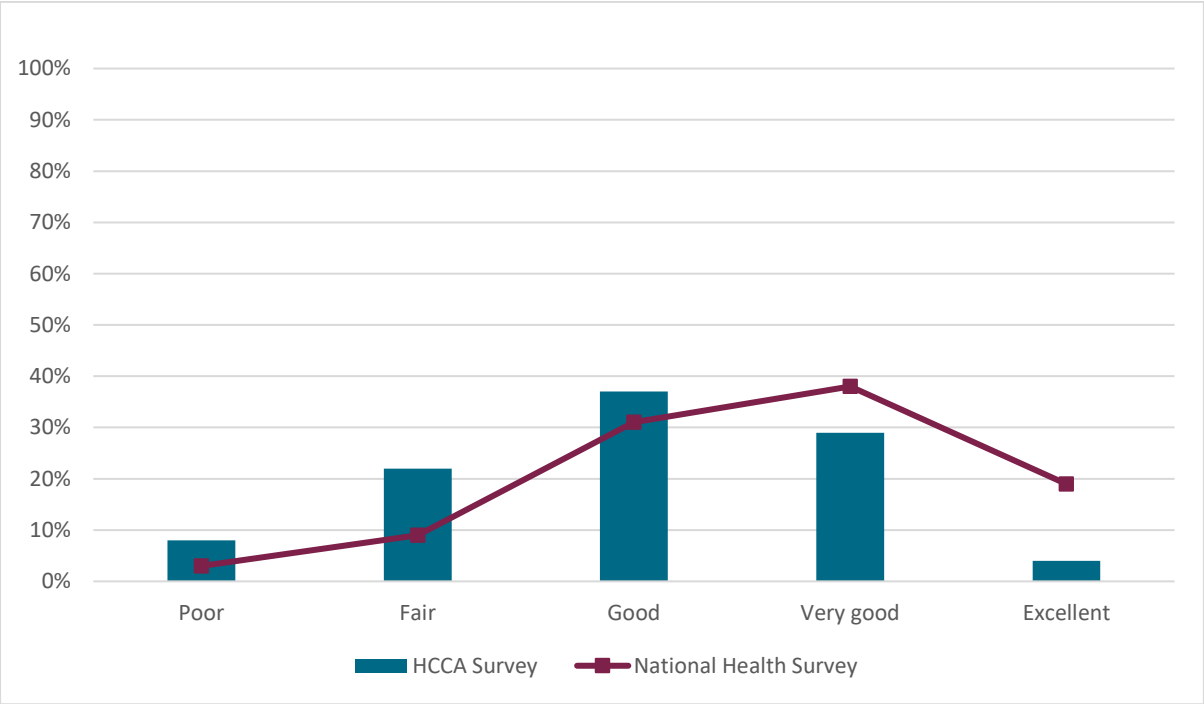
The inability to see a GP during work hours and satisfaction with previous use of the service was important to between 30 and 55% of respondents. The likelihood of not seeing someone they knew was not important to the respondents.

Vulnerable groups

People with chronic conditions

Almost two thirds of survey respondents (62%, n=1035) had one or more chronic conditions. Fewer people with chronic conditions reported their health as 'good' or 'very good' compared with the National Health Survey (see Figure 10). Also, this group of people used ED (48%) more than those without a chronic condition (28%). Nevertheless, the majority (86%) reported that they had a regular GP and that their GP was very likely to support them to manage their conditions (85%). At first glance this seems counter-intuitive that those who have a good relationship with their general practitioner are more likely to use ED. However, a cross-sectional study found that people with chronic conditions comprised a third of requests for after-hours GP calls, and a quarter of these were due to an acute exacerbation of their condition.[xlviii] Therefore, it seems that people with chronic conditions are more likely to experience health issues after-hours, than those without chronic conditions.

Figure 10. The self-rated health status of respondents with one or more chronic conditions (n=636) compared with the National Health Survey 2014-15.



When seeking health information, people with one or more chronic conditions talked to pharmacists (69%) and consulted books (17%) to a greater extent than those without a chronic condition (28% pharmacists, 7% books).

While we haven't undertaken tests of significance it is probable that these differences are statistically significant given the large numbers of people with one or more chronic conditions (n=635).

People in insecure housing

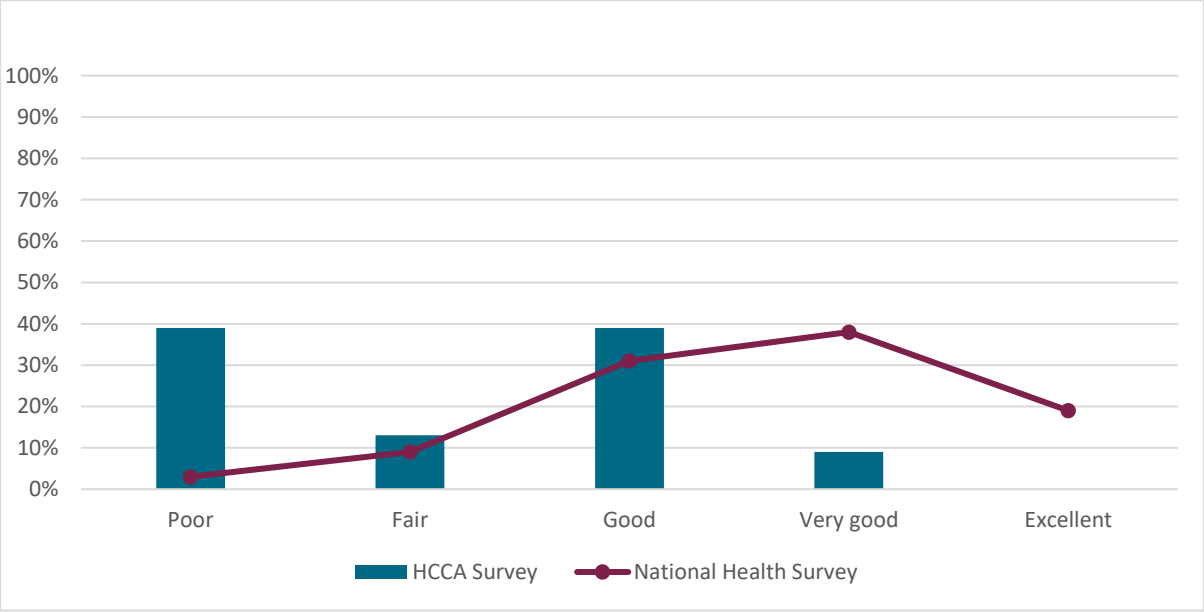
Twenty-three respondents indicated that they were living in insecure housing (e.g. couch surfing, homeless, difficult environment). Among the sample

- 16 were women,
- 6 cared for others,
- 3 identified as bisexual,
- 3 had children under five living with them, and
- 3 spoke a language other than English at home.

The education of this group of people varied greatly and included people who had not completed Year 12 (n=2), those with vocational qualifications (n=8), two with university degrees and five with postgraduate qualifications.

All but two of this group had one or more chronic conditions. The most commonly noted were depression (n=16), chronic pain (n=10), other mental health issues (n=9), and arthritis (n=9). Additionally, five reported that they had disabilities. The high rates of chronic conditions and disabilities would have contributed to their self-rated health. While no conclusions can be drawn from the very small sample, the respondents tended to rate their health as poor relative to the National Health Survey (see Figure 11).

Figure 11. Self-rated health of people in insecure house (n=23) and compared with the National Health Survey 2014-15.



As noted earlier, we assisted four men who were living in supported accommodation to complete the online survey. In addition, we spoke informally with three men at The Roadhouse. All seven indicated that they currently had a regular GP whom they trusted. The Early Morning Centre, Interchange General Practice, and the National Health Cooperative were mentioned by more than one consumer. However, it had not been easy to find a suitable GP and to establish a good relationship. We can illustrate the difficulties disadvantaged people face finding a GP by drawing on an

interview with the relative of one of the men. His story is told in Appendix VII Participant I.

Participant I's nephew was born with a chromosomal disorder, which resulted in a speech impediment, among other things. He contacted his aunt when he had a continual sore throat that he felt wasn't getting any better. Despite returning numerous times to the same general practice with the same complaint, nothing changed. He aunt arranged to accompany him to his next GP appointment, and at that appointment he was given a referral to an ear, nose and throat specialist. His aunt was adamant that …

> *He only got the referral to the specialist because I went with him, absolutely. He has been going to that surgery for some time and he was just constantly having sore throats [and] he was constantly getting a script for antibiotics. Participant I*

The ear, nose and throat specialist immediately diagnosed tonsillitis and his tonsils were out within a week. We asked if she thought the GPs had the skills to identify tonsillitis, but she claimed it was more likely to be a response by the GPs to his disabilities.

> *I think… it was because he is difficult to understand [and] I think that they were not giving him the time and the attention that he needed or the referrals that he needed. I think it was to do with his disability and presentation. Participant I*

She shared her thoughts on bulk-billing practices and they weren't positive.

> *I think [at] the bulk-billing practice some of the effort is minimal. … In medicine there is obviously a lot of discretionary effort … In bulk-billing practice, I think discretionary effort may not be rewarded in any way shape or form, certainly not in their Medicare rebates*.
> *Participant I*

Subsequently *Participant I* arranged for her nephew to become a patient of her own GP and she spoke very highly of that GP and the practice.

> *He goes to my GP now, so he has a regular GP, a family doctor. She's wonderful. She is fabulous with him. As soon as I saw what the [previous] practice was like, he didn't go back there anymore. … His current GP bulk bills him. So that's good [as] he doesn't have to pay extra. They have got a nurse's clinic and pathology there, so he has a full check up with a nurse every year. … His current GP has got all of his immunisation up to date. She makes sure he has his flu injection every year. It's really good. They are very thorough.*
> *Participant I*

Regrettably, very few vulnerable people are fortunate enough to have a relative or friend who can help them navigate their way through the health system and to advocate for them when necessary. All the men spoke highly of the support they received from The Roadhouse, Ainslie Village and community workers. However, more resources are clearly needed for vulnerable people.

Summary

Overwhelmingly, the most common reason for using after-hours services was because the issue occurred outside standard hours. The second most common reason was that consumers did not want to wait until the next day. The third, was that GP after-hours services stated that their 'only option due to work or study commitments'. Notably, cost appears to be more important to those who chose to use services that did not charge a co-payment. Our interviews indicate consumers are pleased that services not requiring co-payments are available to them both during standards hours and after-hours. The most common outcome of consulting an after-hours service was for medication, which was prescribed or given. Procedures were less common, and referrals for tests or to other health professionals was very small. Consumers value convenience, most especially a service's opening hours. They also value the quality and range of services provided.

People with chronic conditions appear more likely to require ED services, despite regular use of general practice. Those in insecure housing face multiple challenges and suffer generally poor health. Finding and establishing a good relationship with a GP appears to be particularly challenging.

Centre-specific information

Walk-in Centres

- Consumers are very happy with the care they receive at the Walk-in Centres.
- The most common tasks are prescribing medicine and doing procedures (e.g. ear wax removal, bandaging sprains).

Summary

Consumers are very happy with the care they receive at the Walk-in Centres (see Figure 12). As with all services most respondents used the service because their problem occurred after-hours and they didn't want to wait until the next day. The absence of a co-payment was important to 20% of respondents (see Figure 13). Prescribing medicine and doing procedures (e.g. removal of ticks) were the most common tasks undertaken by Walk-in Centre nurses (See Figure 14). As discussed elsewhere, respondents value the expertise and friendliness of the staff and the range of services on offer (see Quality and range of services – p23).

Figure 12. Consumer satisfaction with care provided by the Walk-in Centres (n=222).

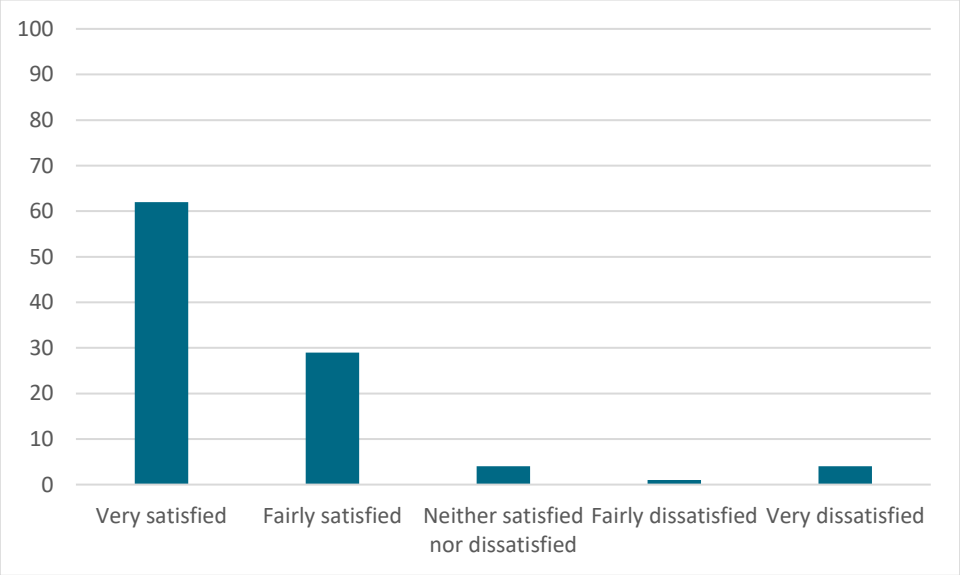


Figure 13. Reasons for choosing to use a Walk-in Centres (n=315).

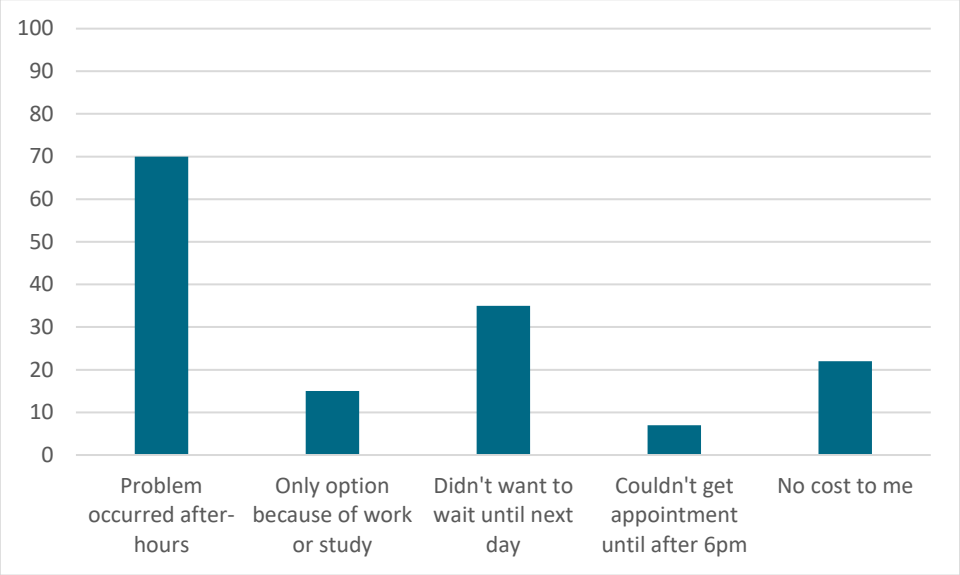
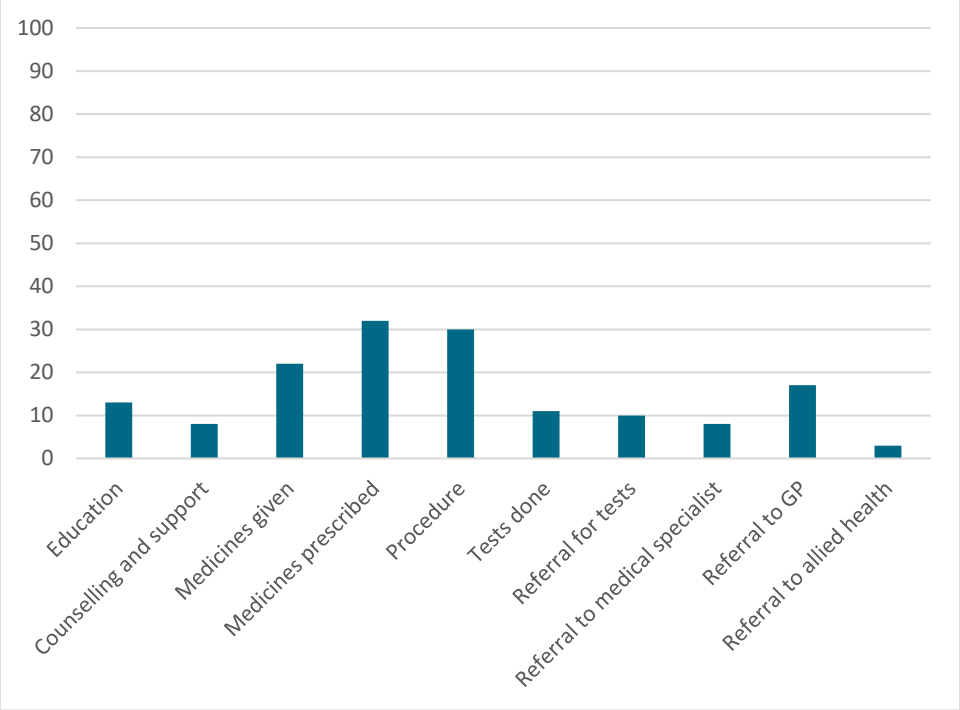


Figure 14. The services provided to respondents by the Walk-in Centres (n=315). Respondents could select all that applied.



CALMS

- Consumers are generally happy with the care they receive at CALMS.
- The most common task is prescribing medicine.

Summary

Respondents who had used CALMS in the past 12 months were very happy with the care they received. (see Figure 15), and used it primarily because the problem occurred after hours and they didn't want to wait (see Figure 16). CALMS prescribed medicine for consumers considerably more often than it provided any other service (see Figure 17).

Figure 15. Consumer satisfaction with care provided by CALMS (n=116).

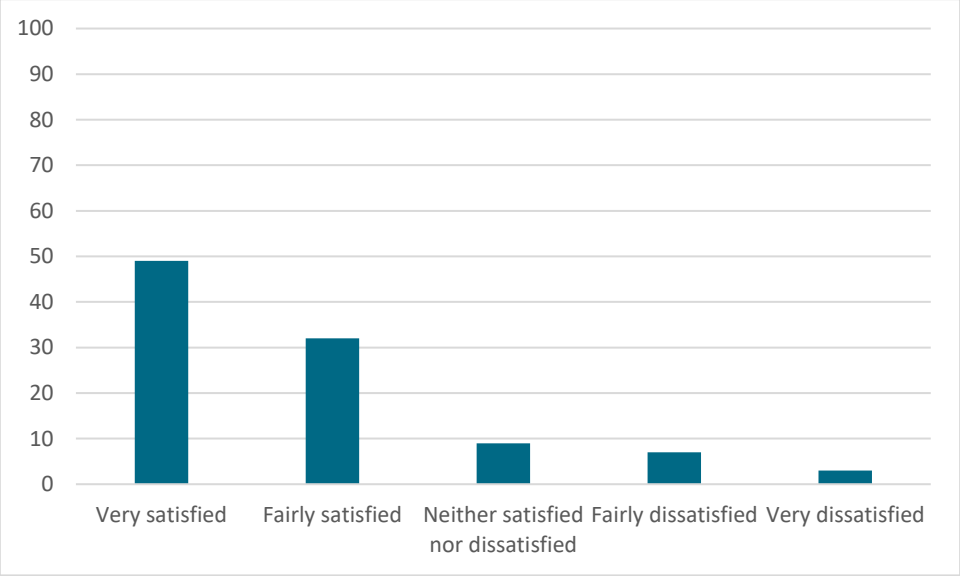


Figure 16. Reason for choosing to use CALMS (n=179).

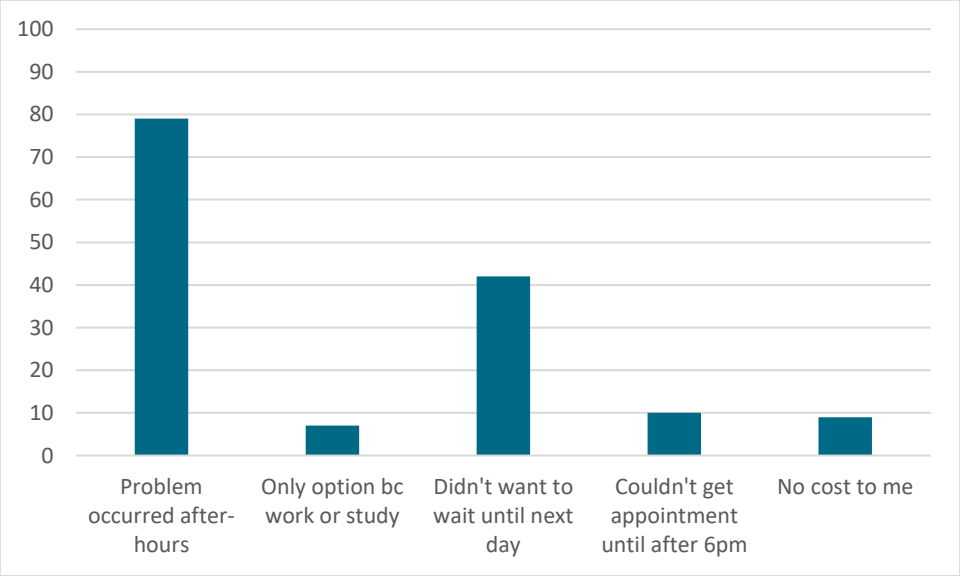
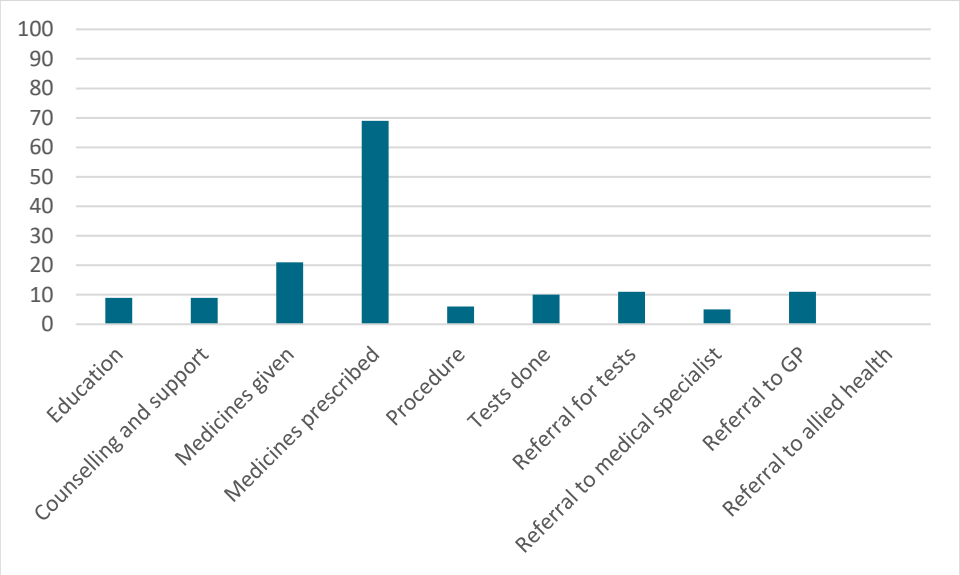


Figure 17. The services provided to respondents by CALMS (n=179). Respondents could select all that applied.



National Home Doctor Service

- Consumers are very happy with the convenience of having a doctor come to their home, particularly the parents of young children.
- The absence of a co-payment was also very appealing to consumers.

Summary

Respondents were very happy with the National Home Doctor Service (see Figure 18). They chose it not only for its opening hours and not wishing to wait, but also because they didn't want to leave their home (34%) and they would not need to provide a co-payment (24%) (see Figure19). Respondents were most likely to receive medication (62%) or be prescribed medication (23%) (see Figure 20).

Figure 18. Consumer satisfaction with care provided by the National Home Doctor Service (n=221).

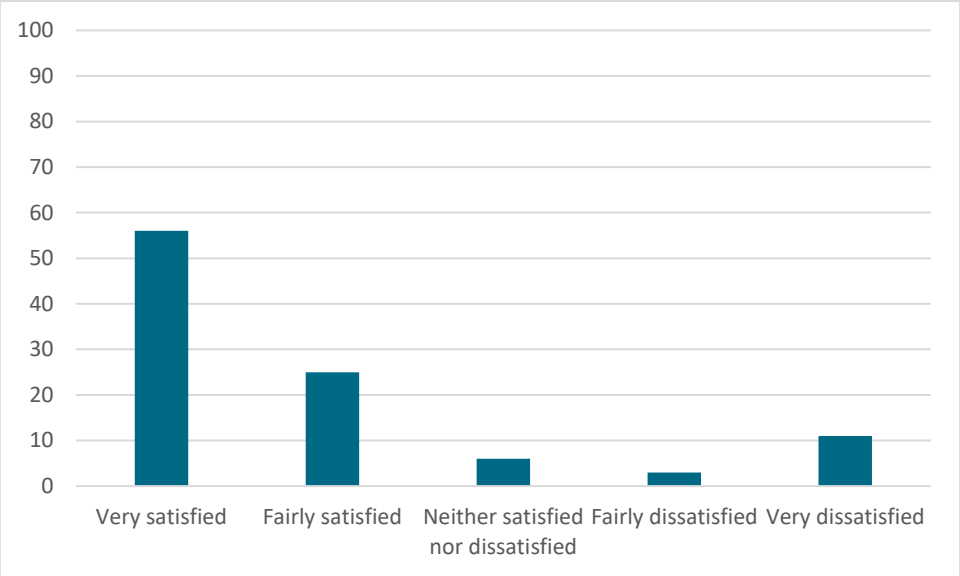


Figure 19. Reason for choosing to use the National Home Doctor Service (n=221)

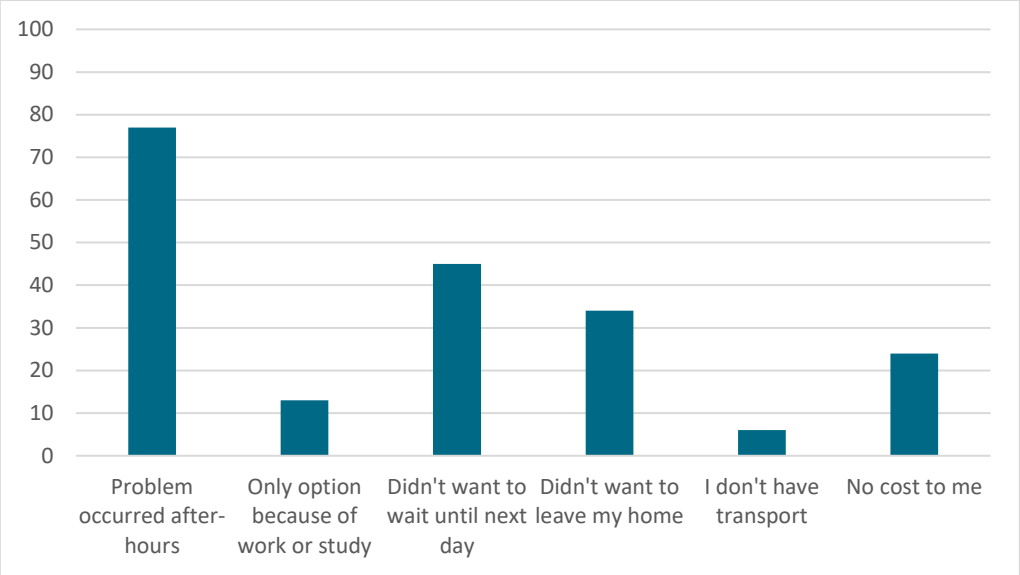
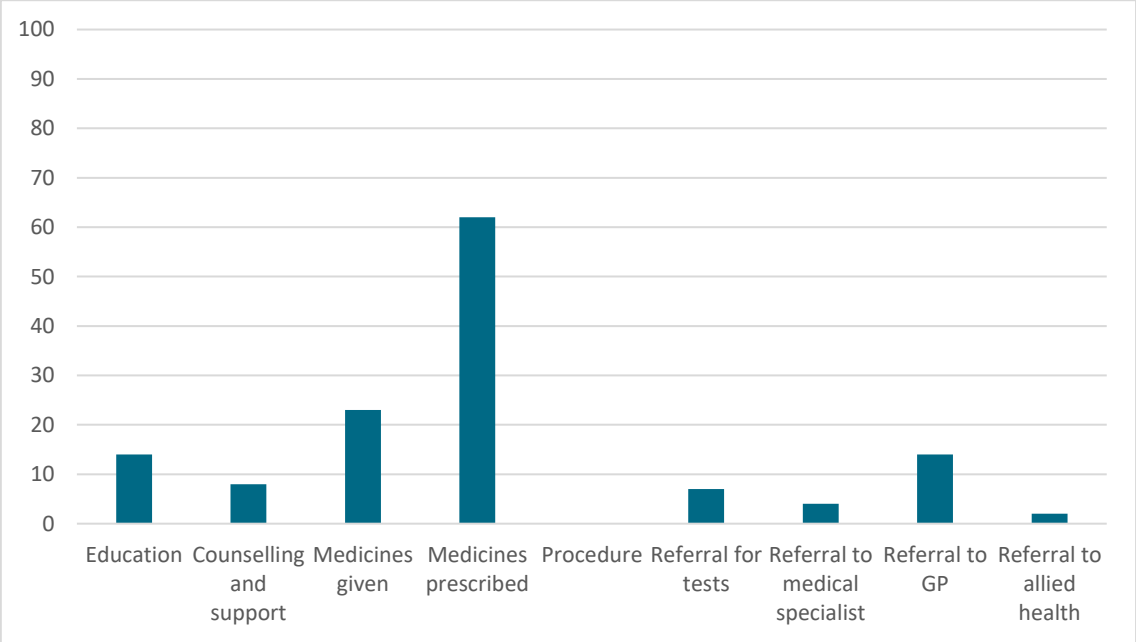


Figure 20. The services provided to respondents by the National Home Doctor Service (n=221). Respondents could select all that applied.



Emergency Departments

- Consumers are generally happy with the care they receive at the Emergency Departments.
- The most common tasks are giving medicine and undertaking procedures.
- Consumer stories pointed to variable quality of treatment.

Summary

In general, respondents were very happy with the care they received at Canberra's Emergency Departments (see Figure 21). The overwhelming reasons for choosing ED was because the problem occurred after-hours and respondents did not want to wait (see Figure 22).

ED provided medication more often and did more tests than all the other after-hours services. (see Figure 23) The clinical expertise of ED staff and the range of services was 'very important' to the respondents who had used ED, more so than those using other services. Respondents who attended ED didn't rate the inability to see a GP during work hours or previous use of ED as very important in their decision to attend ED. The opening hours were considered very important, as was availability of parking.

Figure 21. Consumer satisfaction with care provided by the emergency departments (n=291).

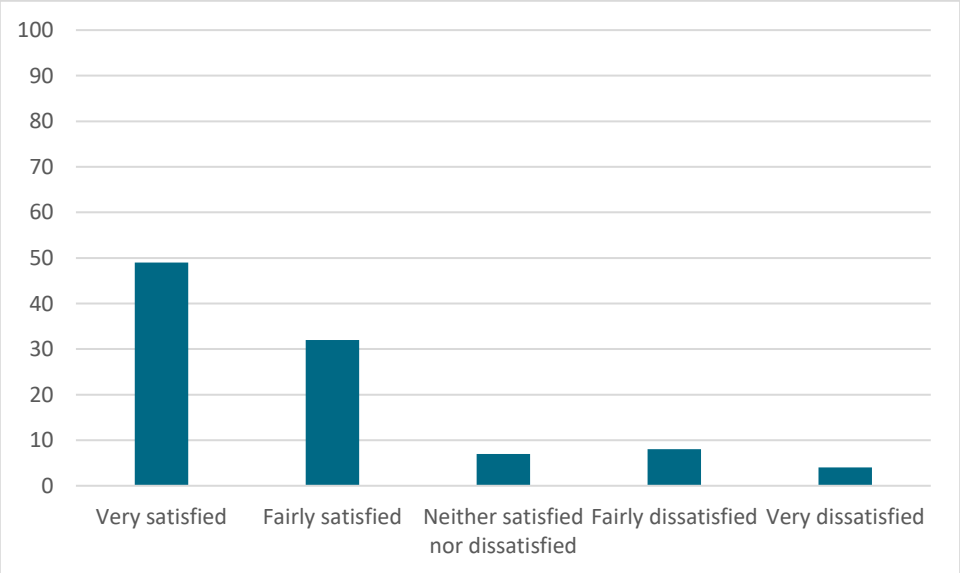


Figure 22. Reasons for choosing to use an emergency department (n=416).

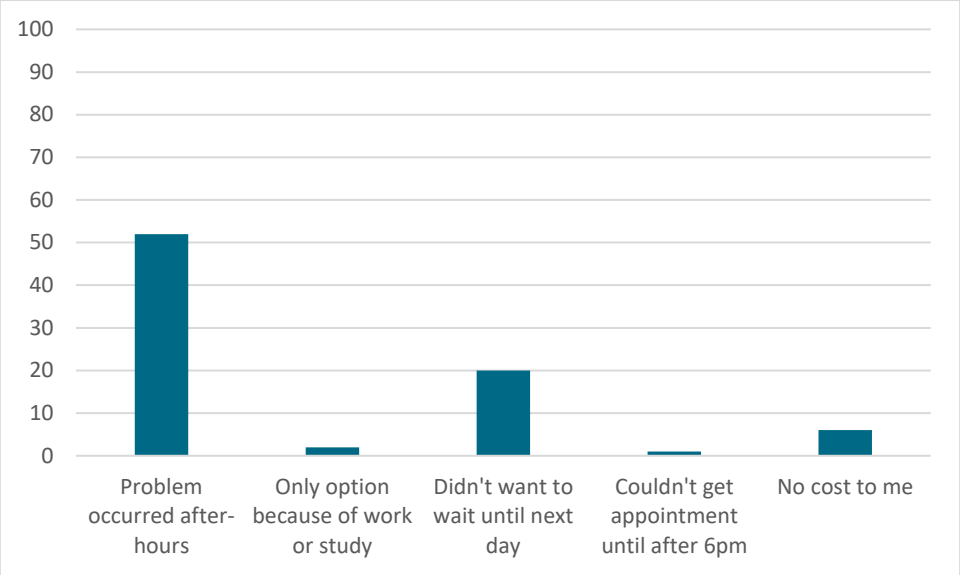
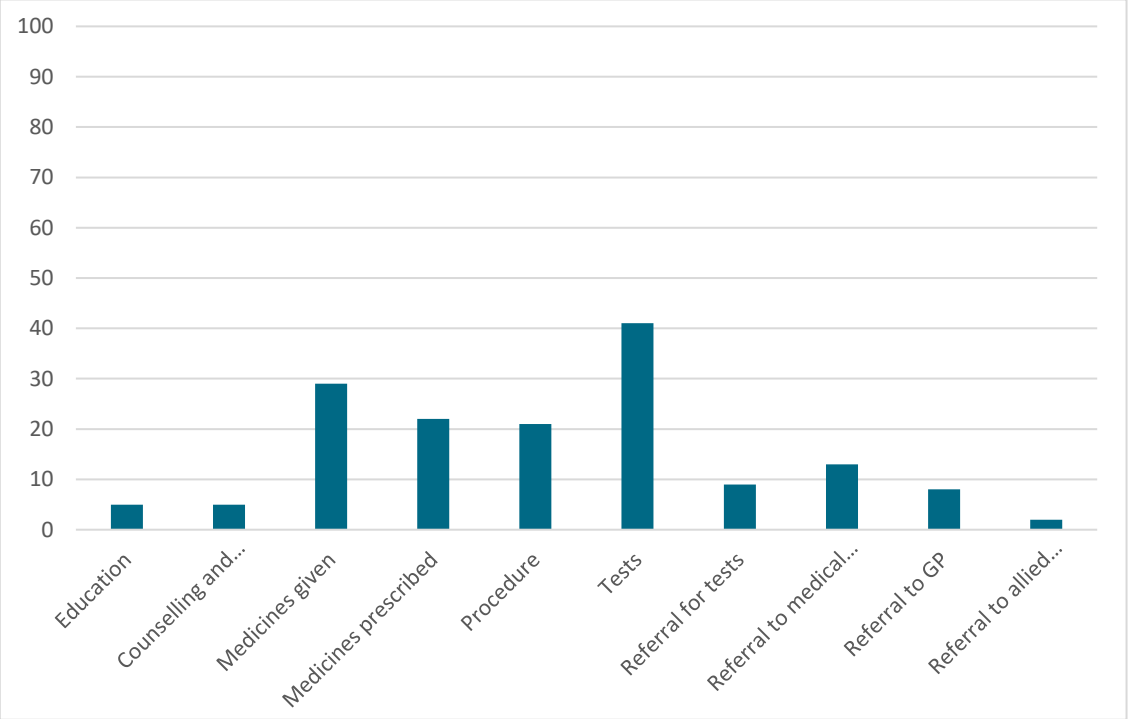


Figure 23. The services provided to respondents by emergency departments (n=221). Respondents could select all that applied.



healthdirect

- Consumers call *healthdirect* when seeking basic information on how to manage a minor injury or illness.
- Consumers seem to use *healthdirect* less often once their children are old enough to attend the Walk-in Centres.
- Experiences of the service were a little mixed, with some feeling it would be better if the service was more personalised.

Experiences with *healthdirect* were explored through interview (see Interview analysis).

Interview analysis

We interviewed 15 consumers about their experience of using after-hours services in the previous 12 months. Overall, consumer comments were positive, indicating a high-level satisfaction with the services. The interviews covered a range of personal and medical situations that speak to the diversity of needs among consumers and the capacity for after-hours services to support those needs.

The three main themes to emerge from the interviews are:

- the variety of reasons for using the services,
- the variability in perceived care at the Emergency Department, and
- the importance of professional and personal conduct of staff.

Why consumers use the services

Urgency

Consumers were asked to indicate how they came to use an after-hours health service and all indicated that the situation, which prompted them to seek care, took place outside of normal hours. This finding is consistent with the survey data. We also sought to understand their initial response to that situation and whether that changed over time. This gave us a sense of how the consumer viewed the urgency of their situation.

Definitional issues plague the term “urgency”. The Medicare Benefits Schedule Review Taskforce has suggested that urgent after-hours primary care should be defined as that which “cannot be delayed until the time a GP is available during normal work hours”. In contrast, emergency departments use the Australasian Triage Scale (ATS) to triage or prioritise the people presenting at ED (see Table 2).

Table 2. Australian Triage Scale[12]

Australasian Triage Scale Category	Maximum waiting time	Description
ATS 1	Immediate	Immediately life-threatening
ATS 2	10 minutes	Imminently life-threatening
ATS 3	30 minutes	Potentially life-threatening
ATS 4	60 minutes	Potentially serious patients
ATS 5	120 minutes	Less urgent

In all cases the consumers we interviewed believed that health care was required before general practice would reopen. Their understanding of urgency, therefore, aligns better with the Medicare Benefits Schedule Review Taskforce, but poorly with that of Emergency Departments.

[12] http://www.health.gov.au/internet/publications/publishing.nsf/Content/triageqrg~triageqrg-ATS

Our interviews with consumers suggest that in some the perception of urgency is linked to an individual's natural inclination, so some people are simply more inclined to seek help sooner than others. *Participant A's* story is told in Appendix VII.

> *To be honest, my husband is a real stressor, especially about health. … so he's more of the "We needed it right now" attitude, whereas I'm a bit more "Oh, we could wait." Participant A*

There are cases however, like the following, where consumers know from experience what is required. Prior experience in ED had taught a young mother that her son's serious asthma attacks required oxygen and steroids. When an attack occurred, she chose to take him to ED immediately. Her story is told in Appendix VII Participant M.

> *So recently my son was having asthma attacks [that required steroids and oxygen]. We went to Emergency … That's one of those situations where you don't think about where you are going, you just go straight to the hospital. Participant M*

The mother was told to give the child Ventolin™ while the staff observed the child's response. Eventually, a doctor was called who decided that oxygen and steroids were required, and the child quickly recovered. The mother was not unreasonably annoyed at the delay in relieving her child's discomfort and also sensed that her knowledge of her son's condition accounted for little. This was not the only case were a consumer's knowledge of their child was disregarded.

It is worth noting that the perception of urgency is indistinguishable from actual urgency from a consumer perspective. That is to say, consumers will consider a situation urgent until persuaded otherwise by a health professional, and perceptions of urgency vary among consumers.

Reassurance

In some cases, the need for urgency is less certain and consumers turn to after-hours services for reassurance that they are providing appropriate care to themselves or others. The next consumer had been diagnosed with a large clot earlier in the day and told to look for particular warning signs. When it seemed to him that he was witnessing those signs, he chose to attend ED. This consumer acknowledged his own anxiety, but in the context of a series of problems emerging within a week of an operation his concern does not appear unreasonable. His story is told in Appendix VII Participant L.

> *I guess for my anxiety levels, if nothing else, it would've been good if I could've been able to get a scan over the course of the weekend … whereas in my case it was quite anxiety inducing thinking that I may potentially have a clot or DVT. Participant L*

About a third of the consumers we interviewed had used *healthdirect* at some time. Some parents spoke of using *healthdirect* for support when dealing with minor issues.

> *We've called healthdirect once before. She [my daughter] fell off a bed and she didn't knock herself out but she gave herself a bit of a bang, so we just called them to see what we should do. Participant A*

> *Yeah, we have called them [healthdirect] maybe more for something like vomiting and just checking when we would need to get help, or maybe about a skin condition or something for the kids. Participant H*

> *There have been a few times where I have been uncertain about whether … temperatures [are] getting too high … I do use that service when I think I'm not sure about something. It's just good to know that you can call someone in the middle of the night without having to take your child somewhere. Participant M*

One consumer relayed that she had called *healthdirect* seeking advice about her medication. Her story is told in Appendix VII Participant B.

> *I've called them because I couldn't remember what the pharmacist told me about medication. I had two different medications and I couldn't remember which one was the antibiotic and so I phoned them up and asked them and they gave guidance for that. … It's good, you know you're talking to nurses. Participant B*

While reassurance is highly valued it is not always guaranteed from after-hours services particularly when the consumer is seeking more nuanced, flexible advice, as in the following example.

Participant G works in an allied health field and is comfortable managing her young daughter's health, but she has sought reassurance from *healthdirect*. Unfortunately, she often feels like the response is quite scripted "as opposed to a personal response". Recently her daughter had a bout of vomiting and diarrhoea, so she rang *healthdirect* mainly for a little extra advice and reassurance. Unfortunately, she was quite dissatisfied the service she received. Her story is told in Appendix VII Participant G.

> *I was comfortable with how she was going. She had gastro. She was vomiting. I just wasn't sure what else I could do to lessen the chance of dehydration and those kinds of things. … They [healthdirect] said, "She needs to see a doctor within 2 hours." I actually didn't listen to their advice because I was happy with monitoring her myself. …*

> *Anytime I have called, it's very, "Oh yep, she's under six months, she's got gastric, this is the action," … I said, "I don't want to take her to the hospital, I think she's okay. She's alert, she's not lethargic, she's just vomiting." There was no follow-up of … what to do if I didn't want to take her to the hospital…. I think I would have appreciated that maybe "we can give you a call in an hour and see how she's going" or "this is what we want you to do". There was no flexibility in the treatment. Participant G*

Long waits to be seen, delays in treatment beginning, and formulaic advice over the telephone do not provide reassurance and, in some cases, can increase consumer anxiety. Ideally all after-hours services should provide reassurance to consumers.

Convenience

Some interview participants used after-hours services because of the convenience they provided, both in not disturbing the ill person more than necessary and in allowing them to plan the coming day. Two parents relayed how they value the after-hours services because it allowed them to plan for the following day.

> *[Using an after-hours service means] we can sort out care arrangements for the next day and be ready to roll at 7.30 the next day knowing who is going where rather than waking up, making the GP appointment, then not going to work anyway, but then you might have been able to go to work.* Participant H

> *It was a Saturday. She [young child] had this cough that was persistent and she just started to deteriorate quite quickly, as kids do. So she got a fever, etc. and we were going away the next day. … and I'm glad that I did follow up with it. … [Fortunately], she was fine. [She] just had a virus.* Participant G

Parents certainly appreciated the National Home Doctor Service because they could remain at home thus avoiding harsh weather conditions and places where one risks exposure to illness. A long wait in one's home is eminently more tolerable than one in a medical waiting room (a finding supported by the survey data).

> *The benefits of the home doctor service were that they came to my house […] Trying to take a sick child out in the middle of winter in Canberra is tough.* Participant G

> *Because it wasn't an emergency and we were [able] to wait at home, I was more than happy to wait three hours.* Participant A

Participant L was seeking care for himself when he chose CALMS. This consumer had used a number of services over a week because of an emerging and potentially serious problem. On this occasion he is talking about his interaction with CALMS. It was a weekend and he found it easy to get an appointment.

> *My regular GP was not available at the time, so I rang CALMS and discovered that there was actually a clinic available in Tuggeranong on Saturday afternoons, so I managed to make an appointment and I was actually able to see a doctor within a space of about three quarters of an hour, which was extremely helpful.* Participant L

He had become concerned about a potential blood clot in his leg, which at this stage he didn't see as an emergency.

> *I was concerned of the potential for a clot in my leg, and … if that was the case then that would be potentially serious, and so I decided that I better see a doctor, and I thought it would be appropriate, basically, at that point, and CALMS was basically the best option at the time.* Participant L

Participant L was happy with the service he received and was relieved that he didn't need to go to ED. From his perspective the co-payment was affordable and well worth the price of avoiding a long wait at ED. His story is told in Appendix VII Participant L - CALMS.

> *I have made use of CALMS in the past and I've found that to be a very, very helpful alternative to potentially needing to go to the ED … on a number of occasions. Even if it does cost … I'm much, much happier basically avoiding a gigantic queue.* Participant L

Although this arrangement suited *Participant L,* the definition of convenience is clearly different for parents of young children. *Participant H* who has used CALMS in the past, now choses to use the National Home Doctor Service because she values the convenience of having a doctor come to her home. She explained that she had used CALMS when her new born child needed care. Her story is told in Appendix VII *Participant H.*

> *Well I wouldn't use CALMS now because of the other options. So the time I have used CALMS once was before the Home Doctor Service and it was with a new born, so I couldn't use the walk-in clinic. I actually found it [CALMS] not convenient. Well I took a new born to an 8.00 pm appointment in winter. So nothing was good about that! I had another child who was home with the dad, so it meant I had to go on my own in June in Canberra. If the Home Doctor Service had of existed then, I definitely would have been using them.* Participant H

Convenience depends upon one's circumstances such as weather conditions, time of day, and the consequences of one course of action over another.

Variable ED experiences

We interviewed eight consumers about their experiences of using Canberra's Emergency Departments. Some had extremely positive experiences and some had the opposite at the very same service. For instance, two mothers received extremely good service from the new paediatric emergency service at The Canberra Hospital ED, but another's child was not even assessed in the paediatric area.

Participant D has an accident-prone child and averages two attendances a year at ED. Her son injured his ear on a Saturday morning while she was at work. When she got home and saw the wound for herself she realised it necessitated another visit to ED. She chose to go to The Canberra Hospital because she had heard about the new paediatric emergency service and was very grateful that she did. Her story is told in Appendix VII Participant D.

> *That new paediatric section [at The Canberra Hospital Emergency Department] is fantastic … [The entire experience] was really positive.*
>
> *[My son] had like his own television and his own remote, so he was happy as and it was really nice. … It was great. I had work to do on my computer there and stuff so I was just doing it. Fantastic!* Participant D

That consumer was particularly impressed with the facilities offered by the new paediatric emergency service at The Canberra Hospital. Another parent explained that the new service was valuable, in part, because the age of patients was similar.

She felt more relaxed there because she believed that other parents would be understanding of how children behave.

Participant M's story is told in Appendix VII.

> *I find the new paediatric waiting room is so much better than waiting in the old [one], … because a lot of other people get annoyed with kids being in the wait-room, and … you can relate to other parents in the [paediatric] wait-room. Participant M*

Participant J's experience is in stark contrast to these positive stories. Her son has a chromosome deletion disorder who suffers acute episodes of intense pain. Previous bad experiences had led to the child being given a care plan that allows direct admission to the High Care Paediatric ward. However, on this particular occasion she was told that she would have to present to ED, but not told why. She admitted hoping that the new paediatric service would make the experience less stressful. In the past, she has felt stressed and vulnerable because other adults in the ED waiting area have behaved in unpredictable and aggressive ways.

On this occasion she was made to wait in line to be triaged despite holding a screaming child in her arms who was clearly struggling to breathe. Her story is told in Appendix VII Participant J.

> *They [the paediatric ward] said I had to go to Emergency. I called again and double checked it cos I thought I really don't wanna do it [because of his compromised immune system] and they said, you know "Don't worry, you won't have to queue up. … They know that you're coming, you can just go straight to the desk, and they'll take you straight through. You don't have to sit in the waiting room."*
>
> *I went straight to the fellow at the desk … and I said "Look, we've called ahead, the High Care Ward knows we're coming, the Registrar is gonna come down and meet us." He said, "you still need to join the queue." Participant J*

Once triaged she and the child were taken into the adult assessment area, presumably there were no free beds in the paediatric area. There she was required to relay a complex medical history repeatedly. No one seemed to have access to her son's records. Consequently, she had little positive to say about the experience.

> *First, I dealt with someone who didn't know anything about [my son] … and I had to explain what has happened. … Then I met a doctor in Emergency, who didn't know anything about [my son], and I again just felt this … a sense of frustration well up in me, and having to explain like a very complex medical history [repeatedly is hard].*
>
> *They should get a summary screen that comes up in front of them, that says, you know, gives them like five bullet points on … what this patient's history is … so that you are not relying on the family to give that summary, over and over again, especially when they are stressed, you know, distressed. Participant J*

Had verbal and electronic communication been much better this mother's experience may have been very different. HCCA sought to understand how this situation could be avoided in the future. ACT Health confirmed that patient records were not linked to ED records. However, it is possible for the hospital to add an alert to the ED triage computer system. An alert like this may have also been helpful in the case of Participant M, the mother of a child who suffers serious asthma attacks.

Adult consumers also reported extremely positive and extremely negative experiences from their contact with ED. While many acknowledged that the staff did the best they could under difficult circumstances, they saw a lot of room for improvement.

Participant F's elderly mother had a heart attack and was taken by ambulance to Calvary Emergency Department. Previous experiences had been very good, but on this occasion and after waiting five hours the doctor who saw her mother was very abrupt. Participant F acknowledged that the doctor was clearly stressed and was probably overworked and tired, nevertheless he made some "silly statements". Her story is told in Appendix VII Participant F.

> *[The doctor said] "Oh we're not worrying about your blood pressure till it gets close to 300."… [Where as] we've been told … "If it gets to the 200 mark you really have to bring her [mother] in here." …*
>
> *So that was a little bit disappointing. … [However], I would say that nine out of ten times has been amazing. Participant F*

Participant L underwent major surgery and subsequently suffered several complications, one of which was a large blood clot in his leg. The evening the clot had been diagnosed he started to experience pain in his other leg as well as chest pain. He chose to attend ED because it was the only place likely to have the equipment and expertise needed to investigate the problem. Participant L waited two and half hours after triage, surrounded by people coughing and sneezing, and it was difficult to get information at this time. Ultimately, he was seen by a doctor and certain steps were taken to ensure appropriate follow-up. His story is told in Appendix VII Participant L - Emergency.

> *Without faulting any of the staff or anybody else that were working there, I thought the system looked like it had almost broken down, and I've seen that on a number of other occasions as well. So, I can't say I felt incredibly happy with the experience. Participant L*

The wait was far longer than the benchmarks for the lowest Australasian Triage Scale, communication was very poor, and little reassurance was provided.

One woman initially struggled to get ED staff to focus on the symptom that was giving her the most trouble. This is another case where the consumer's knowledge of their own condition did not appear to be taken into consideration. Her stay continued for three days and she received very little information on what was planned and when plans had changed.

Participant C tripped and cut her foot, severing a nerve, two tendons and an artery. ED was the only option. She was pragmatic about it, but unfortunately this incident coincided with a major, pain event related to another condition. She had great difficulty getting the staff to focus on the pain, which was her priority. She went without food for 36 hours, while never being told when her surgery would take place.

She was never transferred to a ward neither was she told why. She also felt the quality of the food that she was served was enough to make anyone sick. Her story is told in Appendix VII Participant C.

> *The whole hospital experience for me was awful. It was absolutely awful. … Now if I had to go in there for some really serious things … I [would] dread it.*
>
> *36 hours I had to fast before I got to my operation … so I was left in that place to just sit there and wait. And I challenged the nurses. I mean, obviously, it's not the nurses' fault and I always kept that in mind, and I just said, "Look, I need to be informed. It's one thing that you know what's going on but it would really help if I could know." Participant C*

While acknowledging the commitment and clinical expertise of the staff, the variability of experience in ED is worrying. More and better communication, particularly reassurance, is desirable.

Professional and interpersonal behaviour

In addition to urgent situations, needing reassurance and convenience, consumers valued professional aptitude and the personal touch provided by some services. While professional and personal behaviour is arguably attributable to individuals rather than services, the friendliness of Walk-in Centres and the National Home Doctor Service was especially noted in interviews.

> *They [the Walk-in Centre] are really nice ... they try to help … stop you from feeling worried and stressed. Participant K's daughter*
>
> *They [National Home Doctor Service] were both really good [when we used them]. The first time we had a man and the second time was a woman and … they were both really good with [my daughter, which is important] because she doesn't like doctors. Participant A*

The following three examples demonstrate the interpersonal skills of the Walk-in Centre nurses.

Participant K cut her hand while preparing dinner one evening. Initially she assumed it wasn't serious, but the bleeding continued and she realised that she needed to get help. Her partner searched online and located the Walk-in Centres. Prior to that, neither had been aware of the centres' existence. While being driven to a Walk-in Centre she was starting to get anxious because she had to hold the wound together to stop it bleeding.

Once her wound had been dressed, Participant K was fulsome in her praise of the service "They were superb. … I was raving to everyone about it." She appreciated the immediate triage, particularly when she was told what signs would indicate that she would need to attend the Emergency Department. Perhaps even more so she appreciated the skill of the nurse in attending to her wound, while simultaneously engaging with her six-year-old daughter, and stepping Participant K through what the nurse was doing. Her story is told in Appendix VII Participant K.

As a result

> *It was a really, a very positive experience.*

Participant O's eighteen-month-old daughter had cut her eye. This resulted in "quite a bit of blood but not for very long". She took her daughter to a Walk-in Centre, even though she in other circumstances she would have known the Walk-in Centre couldn't see children under two years. Upon reflection, she believes that she must have been in shock, because although her daughter's cut looked bad she kept minimising the situation in her mind. When she presented to the Walk-in Centre she was redirected to an Emergency Department, both because her child was under two but also because of the wound's seriousness. The nurse cannily summed up the situation and double checked with the mother that she was actually safe to drive that far. Participant O was grateful that the nurse considered the state of mind and safety of both mother and child. Her journey is told in Appendix VII Participant O.

Participant L was fixing his child's toy when he took most of the skin off one finger. It was a Sunday afternoon and he bandaged it as best he could, but it wouldn't stop bleeding, so decided to attend a Walk-in Centre close to closing time. No one was waiting so he was treated immediately. While it wasn't a major problem the wound required significant packing. Participant L was impressed with the nurses' clinical skill and found their manner helpful and reassuring. His story is told in Appendix VII Participant L - Walk-in Centre.

Summary

While it is difficult to make comparisons between different consumer experiences of different services the general themes tell us something about how these services are used, and how and why they are valued. The variety of consumer circumstances largely dictate why consumers chose different services and demonstrates that there is no one-size-fits-all model of health care.

People seek after-hours health care because whatever precipitates their need occurs after-hours and they perceive the need for care to be urgent. Consumers are not using after-hours services merely for convenience. Few, if any, of those we interviewed would have been triaged as life-threatening (ATS 1-3). Nevertheless, the perception of urgency is indistinguishable from a clinical emergency from a consumer perspective. Additionally, urgency differs across consumers with some being more inclined to seek help than others. HCCA believes that improving consumer health literacy will help relieve the burden of non-urgent after-hours care.

Many consumers are seeking reassurance when they use an after-hours service. Unfortunately, not all receive it and some we interviewed weren't even given adequate information about what was happening to them.

Consumers do appreciate convenience and the ability to wait with a sick child in one's home is particularly valued. What is considered convenient depends on one's individual circumstances. However, HCCA found no evidence that consumers were using after-hours services in preference to general practice.

The variability of consumer experiences at emergency departments is a concern. HCCA appreciates that emergency departments may lack sufficient resources and staff at times, and that they are affected by system wide issues, such as bed blockages. However, the impact of these systemic issues is amplified when combined with stressful events in an individual's life. It is particularly concerning that consumer's

knowledge based on prior experience is rarely acknowledged, sought or respected. Improving the availability of information and educating staff to respect consumers' knowledge of their own circumstances would significantly enhance consumer experience and may well improve internal processes.

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Appendices

Consumer experience and expectations of after-hours primary care in the ACT

APPENDIX I
GP consultation type

Consultation type	Monday to Friday	Saturday	Sunday/and or public holiday
Standard	8am and 8pm	8am and 12 noon	N/A
Urgent After-hours	7am–8am 6pm–11pm	7am–8am and 12 noon – 11pm	7am – 11pm
Urgent Unsociable hours	11pm – 7am	11am – 7am	11pm – 7am
Non-urgent After-hours	Before 8am or after 8pm	Before 8am or after 1pm	All day

Adapted from the Medicare Benefits Schedule Review Urgent After-hours Primary Care Fact Sheet, http://www.mbsreview.com.au/after-hours.html (Accessed 19 October 2017)

APPENDIX II
Key stakeholders

ACT Shelter Inc	
Travis Gilbert	Executive Officer
CALMS	
Graeme Seller	General Manager
Canberra Hospital	
Narelle Boyd	Acting Executive Director Critical Care
Calvary Health Care ACT	
David Banfield	Acting Medical Director
Capital Health Network	
Angelene True	A/g General Manager Planning and Strategy
Capital Chemist Waniassa	
Elise Apolloni	Pharmacist
healthdirect	
Andrew Byrant	General Manager, Consumer Health Services
Mary Byrnes	Service Director
National Health Cooperative	
Adrian Watts	CEO & Managing Director
Chris Helms	Head of Nursing
Walk-in Centre	
Naree Stanton	Acting Director or Nursing

APPENDIX III
Data cleaning

In total, we analysed the results from 1035 survey respondents. These responses to the survey included both ‘Complete’ and ‘Incomplete or partial’ responses, as defined by the survey host ‘SurveyMonkey’. An ‘incomplete or partial’ response is one where respondents have entered at least one answer and clicked ‘Next’ on at least one survey page, but not clicked ‘Done’ on the last page of the survey. Almost three quarters of our respondents were considered ‘Complete’ by SurveyMonkey, which is an extraordinarily good completion rate. In examining the data, we ascertained that limiting the analysis to only complete responses may have unfairly excluded valuable data so incomplete respondents were analysed as well.

We removed six responses from the data set where it was clear that these were duplicated, with the same IP address and one of the duplicate records unfinished. The unfinished response was removed in each case. Another four responses were removed where they only contained an answer to the very first question and no other information. This may have been where a respondent changed their mind about completing the survey, or where something happened technologically, like the internet connection dropped out and they were not able to complete.

We have indicated the number of missing responses where possible, and identified where this may be due to the skip logic we used in the survey design, to ensure that respondents received questions relevant to them, based on answers to previous survey questions. This design attempts helped to ensure the good survey completion rate.

APPENDIX IV
Interview characteristics

Participant	Interviewee	Walk in Centre	CALMS	National Home Doctor Service	Emergency department	General Practice
A	Mother of 2.5yo girl			✓		
B	Single mother of 2 boys <8yrs, one with autism			✓	✓	
C	Muslim woman				✓	
D	Mother of 8yo boy				✓	
E	Muslim mother of three children under 9yrs					✓
F	Woman who cares for a number of family members	✓			✓	
G	Mother of 2yo girl	✓		✓		
H	Mother of 3 children, 8yrs, 5yrs and 3yrs	✓		✓		
I	Aunt of young adult man with disabilities				✓	✓
J	Mother of disabled 4yo boy				✓	
K	Mother of 6yo girl	✓				
L	Adult man	✓	✓		✓	
M	Young mother 3 children, one with autism			✓	✓	
N	Woman with chronic fatigue syndrome					✓
O	Mother of 1.5yr girl				✓	

APPENDIX V
Survey participant characteristics - Age

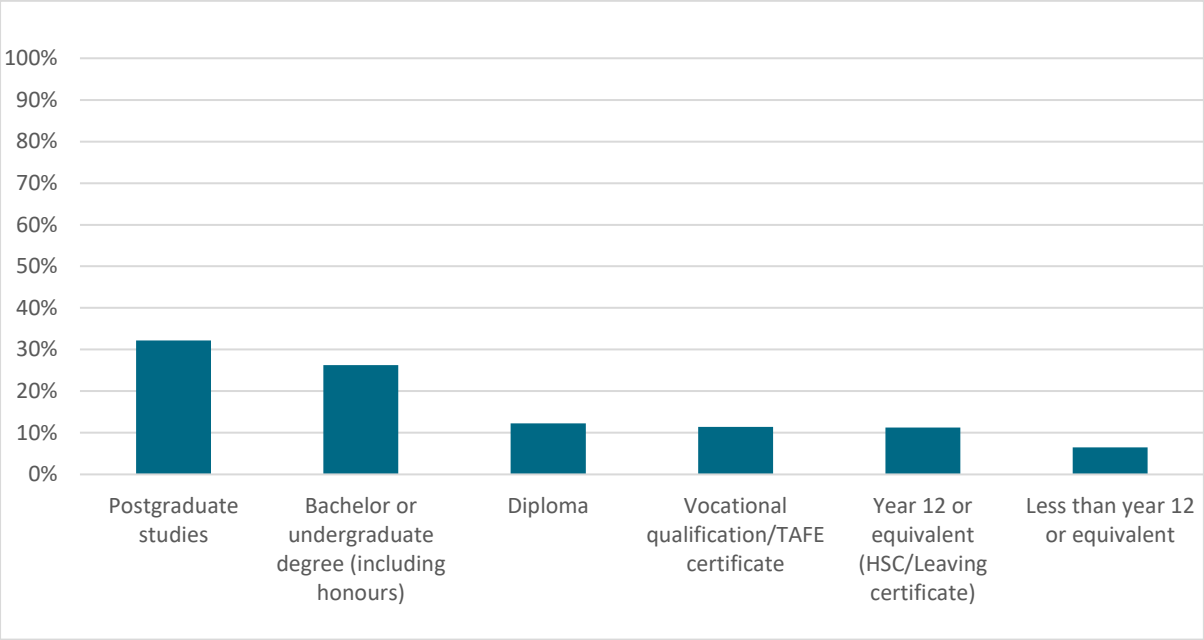
Table V-1. Respondents' age (n=908)1 compared with ACT 2016 Census

Age range (years)	Sample (%)	ACT population (%)
25-34	17	16.7
35-44	22	14.7
45-54	15	12.8
55-64	15	10.4
65-74	20	7.4
75-84	4	2.1
80-84	2	1.5
>85	1	1.5

[1] Four percent of respondents were aged under 24 years. Comparison with census data was not possible because the age range were grouped differently.

APPENDIX V
Survey participant characteristics – Highest education

Table V-2. Respondents' highest education (n=894)



APPENDIX V
Survey participant characteristics – Employment

Table V-3. Respondents' highest education (n=898)

Occupation	Sample (%)
Full-time paid work (35 hrs or more each week)	32
Part-time paid work (34 hrs or less each week)	25
Fully retired from work	24
Caring responsibilities	5
Unable to undertake paid work	3
Volunteer	3
Full-time university student	2
Other (please specify)	2
Unemployed	1
Part-time university student	1
Full-time education at school (high school, primary school, college)	1
Grand Total	**100**

APPENDIX V
Survey participant characteristics – Length of residency

Table V-4. Respondents' highest education

Length of time living in Canberra	Percentage of respondents
More than 10 years	76
6 - 10 years	12
3 - 5 years	7
1 - 2 years	4
Less than 12 months	2

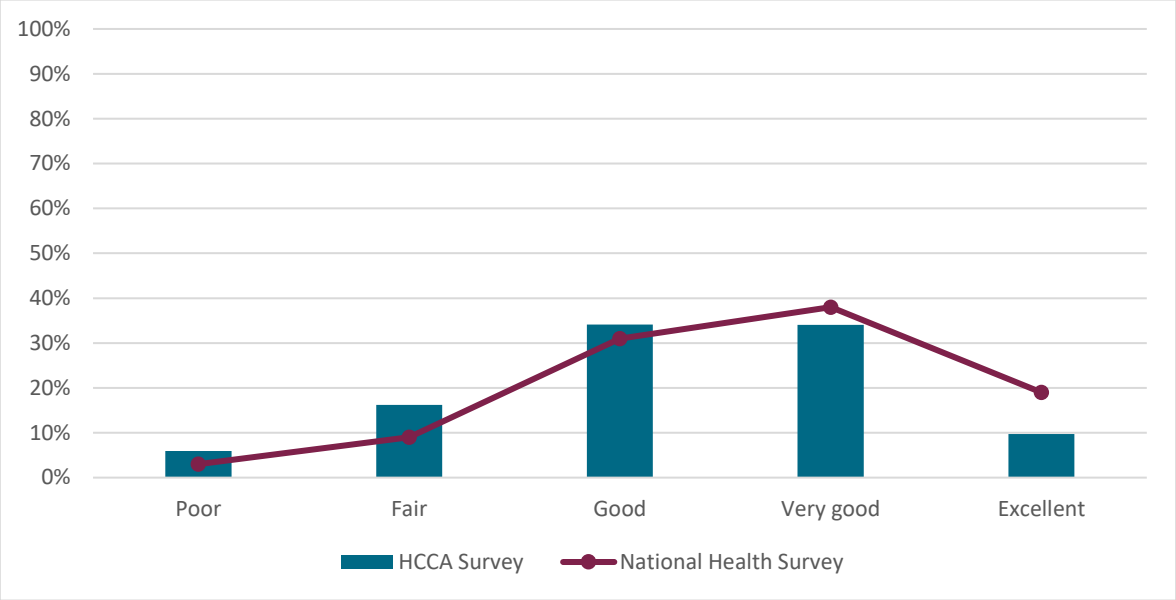
APPENDIX V
Survey participant characteristics – Area of residence

Table V-5. Respondents' place of residence (n=902) compared with ACT 2016 Census

Area of Residence	Sample (%)	ACT Population (%)
Belconnen	31	24.2
Gungahlin	13	17.9
Inner North (including Civic/ Canberra City)	10	13.4
Inner South	5	6.8
Tuggeranong	20	21.4
Weston Creek	9	5.8
Woden	8	8.8
Surrounding area, including NSW	4	N/A

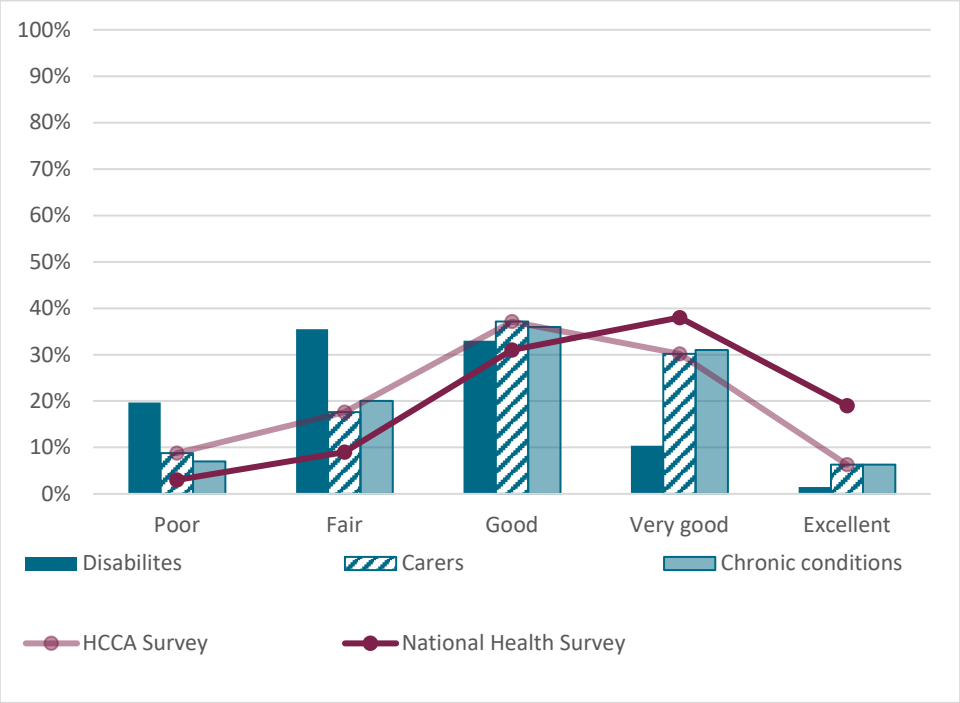
APPENDIX VI
Self-rated health status – Sample

Figure VI-1 . Respondents' self-rated health (n=908) compared with the 2014-15 National Health Survey.



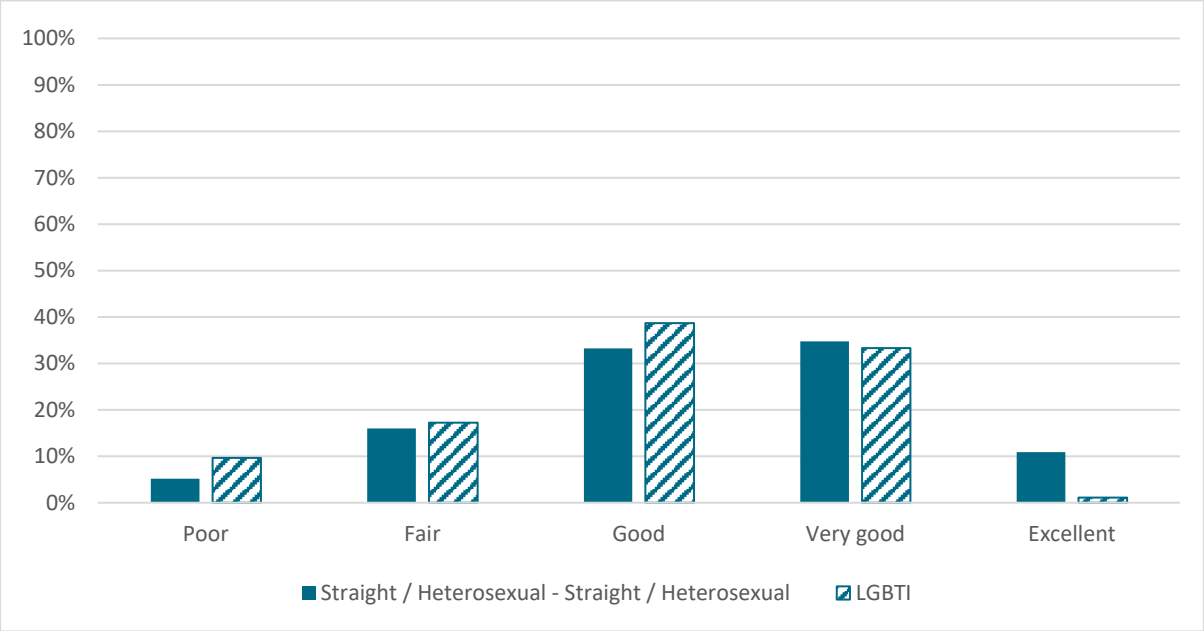
APPENDIX VI
Self-rated health status – Vulnerable groups

Figure VI-2. Respondents' self-rated health in the overall sample (n=715), those with a disability (n=203), carers (n=159) and those with a chronic illness (n=)



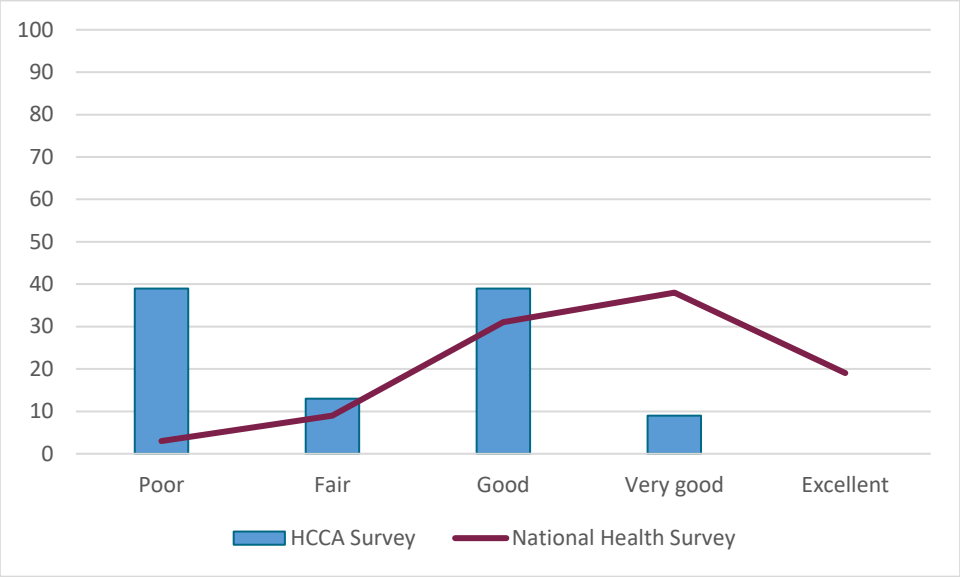
APPENDIX VI
Self-rated health status – Sexuality

Figure VI-3. Respondents' self-rated health status comparing sexuality (n=882).



APPENDIX VI
Self-rated health status – Homelessness

Figure VI-4. Self-rated health of people in insecure housing (n=23) the National Health Survey data.

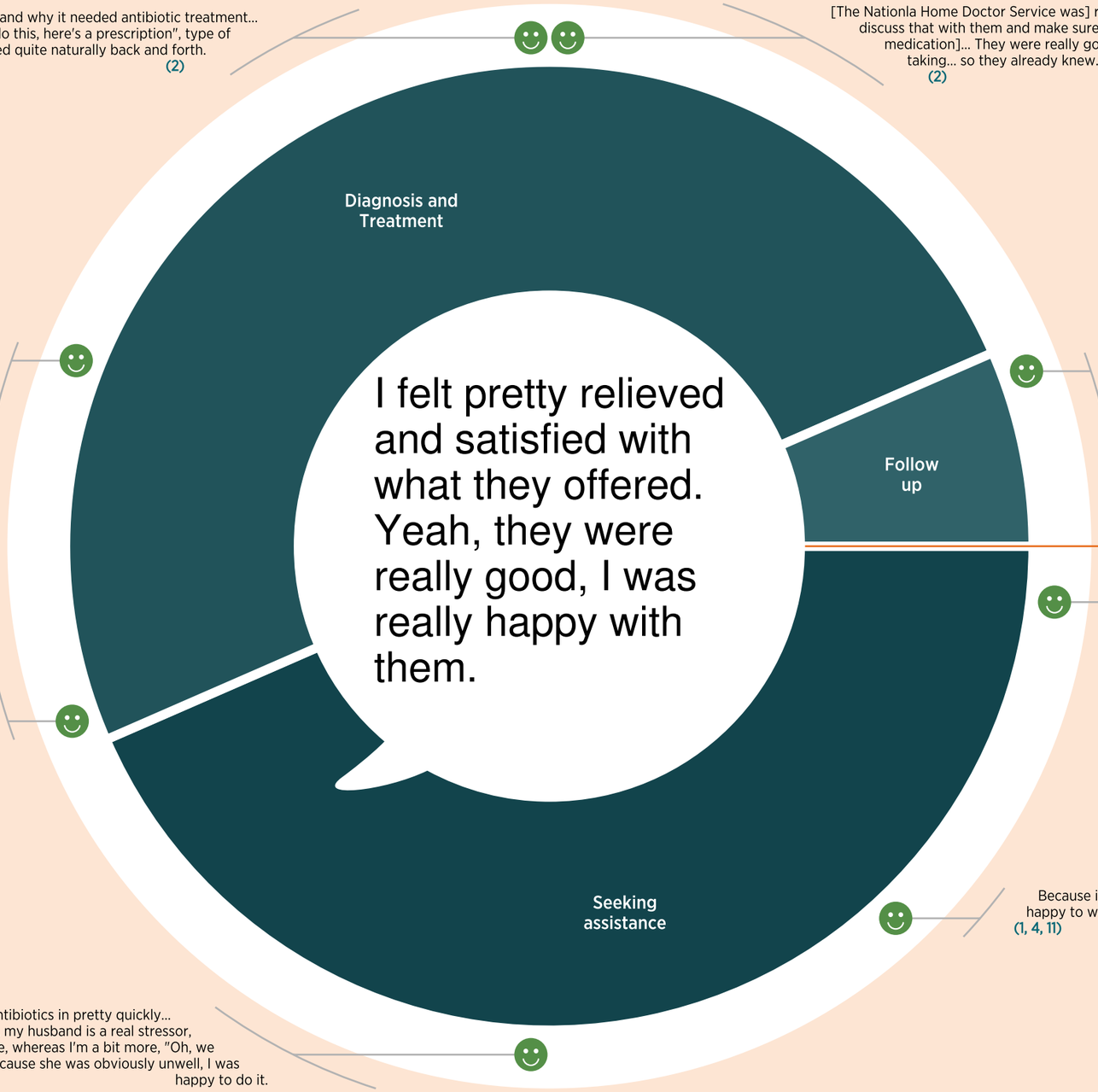


APPENDIX VII
Health Experience Wheels

Participant A - National Home Doctor Service

There was more of a conversation around what was going on inside her ear and why it needed antibiotic treatment... I do ask a lot of questions to doctors... I wouldn't be happy with, "Here, just do this, here's a prescription", type of attitude. [The conversation with the doctor] flowed quite naturally back and forth.
(2)

[The Nationla Home Doctor Service was] really good too because she takes medication for her birthmark, so having to discuss that with them and make sure the things they were offering weren't interfering with [her existing medication]... They were really good.... The next time we used them they'd made a record of... what she was taking... so they already knew.
(2)



[They] gave us prescriptions for antibiotics and ear drops and all that kind of stuff, which was also one of the reasons we used it because she goes to day-care Monday, Tuesday, Wednesday and I wanted to try and get on top of it before Monday so that I could still send her.
(1, 4, 10, 11)

They did say that if it wasn't any better within 48 hours to book in with the GP and just sort of recommended keeping her fluids up and to give her some Paracetamol and all that kind of generic info.
(2, 4)

She was asleep when we decided to call so that was kind of a factor. [We were] thinking, "Can we do this without having to wake her up?" So it was quite a convenient service, they come to your house.
(1, 4, 11)

Both [of the doctors were] really good with my daughter [which was important] because she doesn't like doctors.
(5, 6, 11)

Because it wasn't an emergency and we were able to wait at home I was more than happy to wait three hours.
(1, 4, 11)

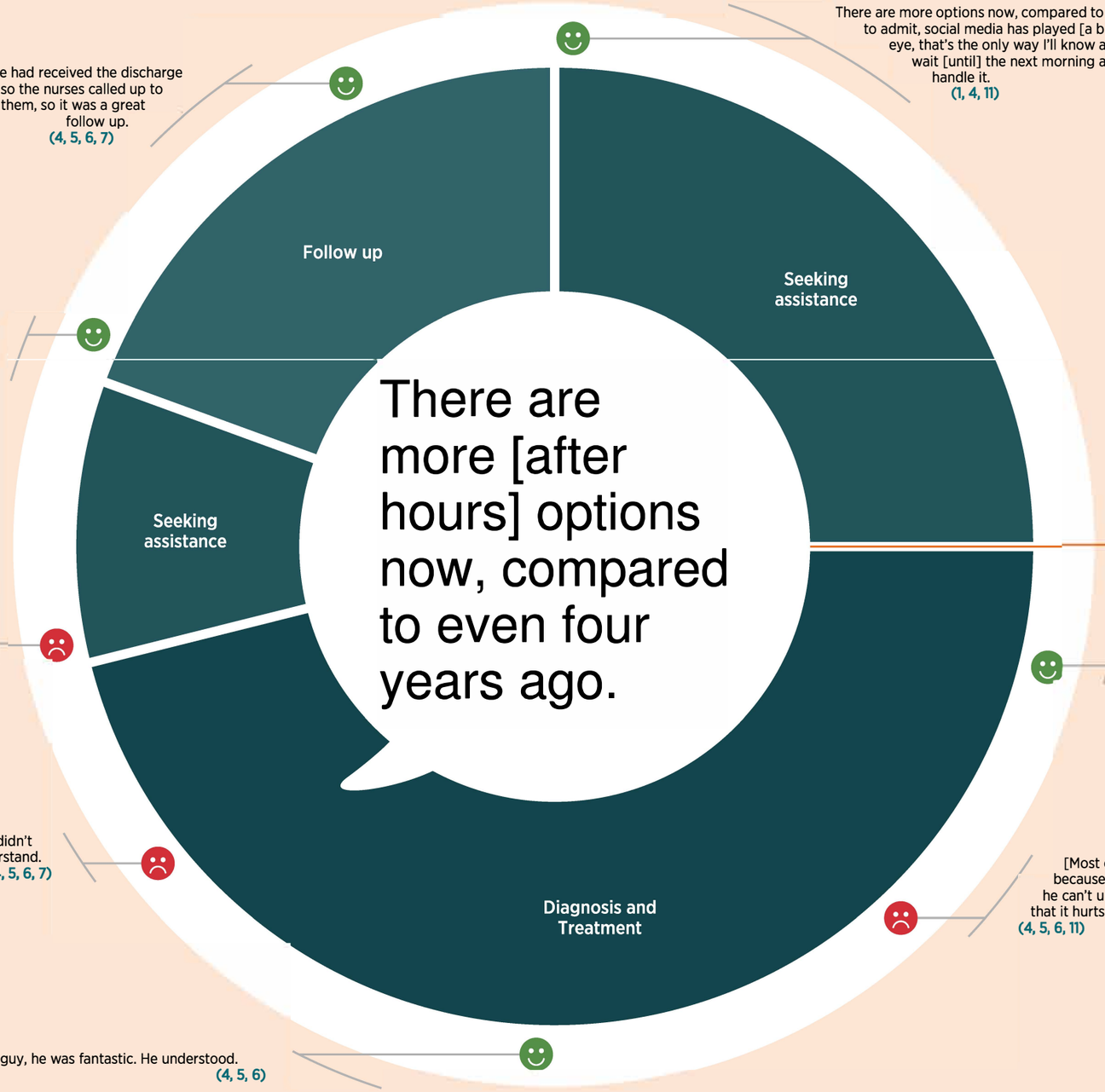
It probably could have [waited]. I think she definitely needed to get some antibiotics in pretty quickly... I was hesitant, I thought it could have maybe waited, but ... to be honest, my husband is a real stressor, especially about health ... He's more of the, "We need it right now" attitude, whereas I'm a bit more, "Oh, we could wait". To make him happy and also to make my daughter happy because she was obviously unwell, I was happy to do it.

Consumer Centred Care

1.	Access, equity and affordability	☺☺☺
2.	Information and understanding	☺☺☺
4.	Appropriate care	☺☺☺☺
5.	Respectful care	☺
6.	Whole of person care	☺

Participant A first used the National Home Doctor Service when her young daughter was unwell, because it meant she and her husband didn't need to wake their sleeping daughter to take her to a health service.

Participant B - Emergency



There are more options now, compared to even four years ago. I didn't know a lot about [the services available]. I have to admit, social media has played [a big part] or if I'm sitting at the doctor's surgery and a pamphlet catches my eye, that's the only way I'll know about it, but now with the kids [there are] a lot more possibilities. Me, I'll just wait [until] the next morning and go to the doctor. I don't want [the participant's sons] to suffer. I can handle it.
(1, 4, 11)

The next morning we got a call from the GP [because the practice had received the discharge summary]... Our family G.P. was away and they were really concerned, so the nurses called up to make sure my son was alright [and to ask] did I need to bring him in to see them, so it was a great follow up.
(4, 5, 6, 7)

They wrote a detailed report of things for us to do and if he didn't pass anything within 48 hours, I had to take him back to them in Emergency and then they'd do the nasty job.
(4, 7)

[On another occasion when the participant's son had a bad stomach ache] I went straight to Emergency and wasn't too happy about the experience. It was at Calvary. We had to wait there for a couple of hours and eventually we got to see someone and they were just like ... they didn't do anything because they couldn't work out what was wrong with him, so they sent us home with some Panadol.
(4)

I've used the Emergency Department with my other son a couple of times. [Once], I could hear him jumping off the couch and [he] landed straight on his arm, screamed the house down, so [we went] straight into Emergency and they were absolutely fantastic. I explained he's autistic [so] he's not going to fully understand what you're talking about, but the nurses and doctors, they were just fantastic with him.
(4, 5, 6, 11)

But [with a] change of shift, [a]new person comes in and he just didn't understand.
(4, 5, 6, 7)

[Most of] the people who did the x-rays ... well, I think we had three lots of x-rays, because they couldn't get a clear picture. They couldn't understand he's autistic [so] he can't understand. He can't hold his arm there, he can't tell you except by screaming that it hurts.
(4, 5, 6, 11)

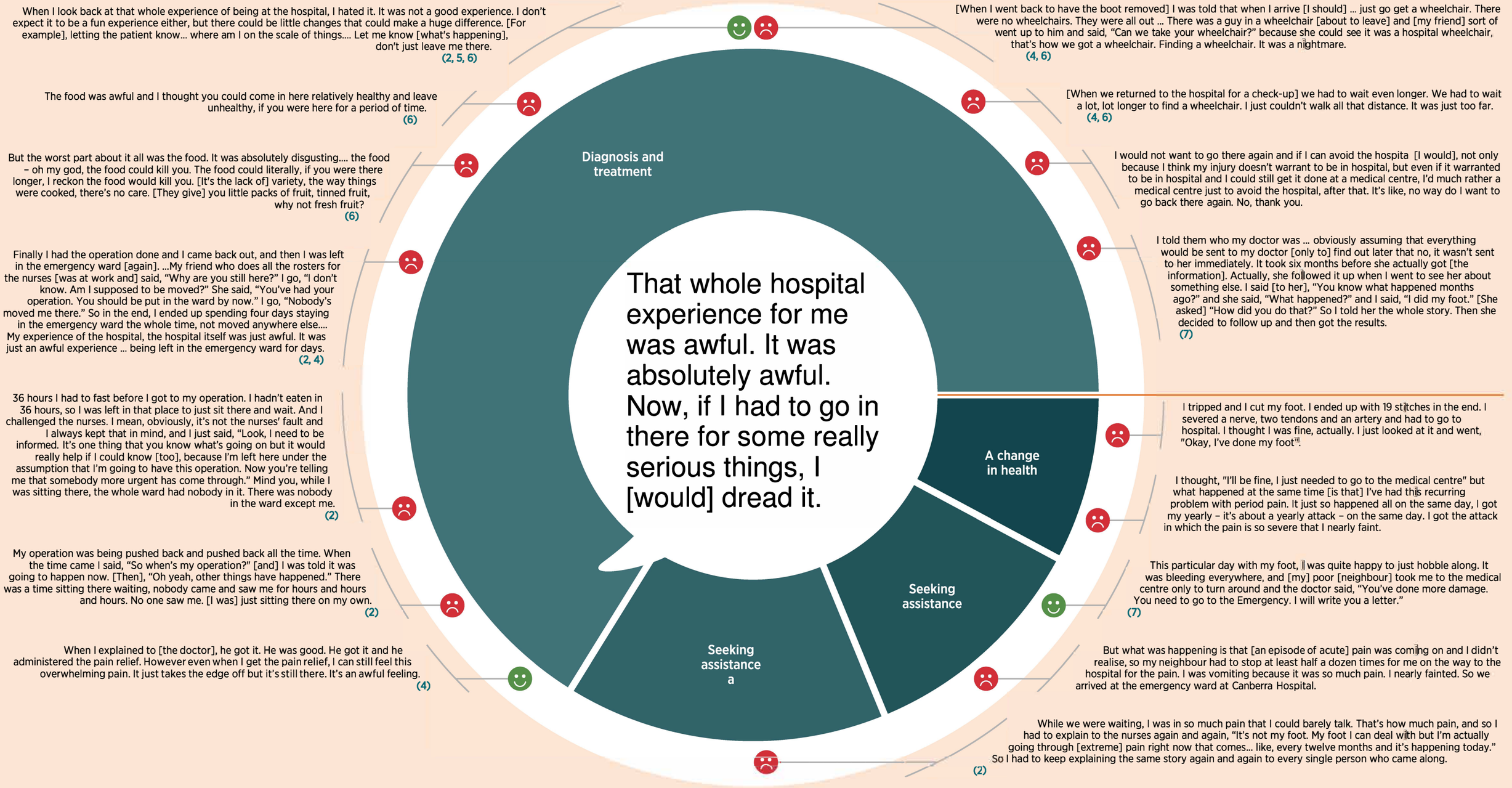
But the first x-ray guy, he was fantastic. He understood.
(4, 5, 6)

Consumer Centred Care

1.	Access, equity and affordability	😊
4.	Appropriate care	😊 × 5 ☹ × 3
5.	Respectful care	😊 ☹ 😊 ☹ 😊
6.	Whole of person care	😊 ☹ 😊 ☹ 😊
7.	Coordinated care and supported transitions	☹ 😊 😊

Participant B has used *healthdirect*, the National Home Doctor Service, Calvary and The Canberra Hospital Emergency Departments, bulk-billing GPs and her own family GP for her for two boys, aged six and eight. One of her children has asthma, the other autism.

Participant C - Emergency department



When I look back at that whole experience of being at the hospital, I hated it. It was not a good experience. I don't expect it to be a fun experience either, but there could be little changes that could make a huge difference. [For example], letting the patient know... where am I on the scale of things.... Let me know [what's happening], don't just leave me there.
(2, 5, 6)

The food was awful and I thought you could come in here relatively healthy and leave unhealthy, if you were here for a period of time.
(6)

But the worst part about it all was the food. It was absolutely disgusting.... the food – oh my god, the food could kill you. The food could literally, if you were there longer, I reckon the food would kill you. [It's the lack of] variety, the way things were cooked, there's no care. [They give] you little packs of fruit, tinned fruit, why not fresh fruit?
(6)

Finally I had the operation done and I came back out, and then I was left in the emergency ward [again]. ...My friend who does all the rosters for the nurses [was at work and] said, "Why are you still here?" I go, "I don't know. Am I supposed to be moved?" She said, "You've had your operation. You should be put in the ward by now." I go, "Nobody's moved me there." So in the end, I ended up spending four days staying in the emergency ward the whole time, not moved anywhere else.... My experience of the hospital, the hospital itself was just awful. It was just an awful experience ... being left in the emergency ward for days.
(2, 4)

36 hours I had to fast before I got to my operation. I hadn't eaten in 36 hours, so I was left in that place to just sit there and wait. And I challenged the nurses. I mean, obviously, it's not the nurses' fault and I always kept that in mind, and I just said, "Look, I need to be informed. It's one thing that you know what's going on but it would really help if I could know [too], because I'm left here under the assumption that I'm going to have this operation. Now you're telling me that somebody more urgent has come through." Mind you, while I was sitting there, the whole ward had nobody in it. There was nobody in the ward except me.
(2)

My operation was being pushed back and pushed back all the time. When the time came I said, "So when's my operation?" [and] I was told it was going to happen now. [Then], "Oh yeah, other things have happened." There was a time sitting there waiting, nobody came and saw me for hours and hours and hours. No one saw me. [I was] just sitting there on my own.
(2)

When I explained to [the doctor], he got it. He was good. He got it and he administered the pain relief. However even when I get the pain relief, I can still feel this overwhelming pain. It just takes the edge off but it's still there. It's an awful feeling.
(4)

[When I went back to have the boot removed] I was told that when I arrive [I should] ... just go get a wheelchair. There were no wheelchairs. They were all out ... There was a guy in a wheelchair [about to leave] and [my friend] sort of went up to him and said, "Can we take your wheelchair?" because she could see it was a hospital wheelchair, that's how we got a wheelchair. Finding a wheelchair. It was a nightmare.
(4, 6)

[When we returned to the hospital for a check-up] we had to wait even longer. We had to wait a lot, lot longer to find a wheelchair. I just couldn't walk all that distance. It was just too far.
(4, 6)

I would not want to go there again and if I can avoid the hospita [I would], not only because I think my injury doesn't warrant to be in hospital, but even if it warranted to be in hospital and I could still get it done at a medical centre, I'd much rather a medical centre just to avoid the hospital, after that. It's like, no way do I want to go back there again. No, thank you.

I told them who my doctor was ... obviously assuming that everything would be sent to my doctor [only to] find out later that no, it wasn't sent to her immediately. It took six months before she actually got [the information]. Actually, she followed it up when I went to see her about something else. I said [to her], "You know what happened months ago?" and she said, "What happened?" and I said, "I did my foot." [She asked] "How did you do that?" So I told her the whole story. Then she decided to follow up and then got the results.
(7)

I tripped and I cut my foot. I ended up with 19 stitches in the end. I severed a nerve, two tendons and an artery and had to go to hospital. I thought I was fine, actually. I just looked at it and went, "Okay, I've done my foot".

I thought, "I'll be fine, I just needed to go to the medical centre" but what happened at the same time [is that] I've had this recurring problem with period pain. It just so happened all on the same day, I got my yearly – it's about a yearly attack – on the same day. I got the attack in which the pain is so severe that I nearly faint.

This particular day with my foot, I was quite happy to just hobble along. It was bleeding everywhere, and [my] poor [neighbour] took me to the medical centre only to turn around and the doctor said, "You've done more damage. You need to go to the Emergency. I will write you a letter."
(7)

But what was happening is that [an episode of acute] pain was coming on and I didn't realise, so my neighbour had to stop at least half a dozen times for me on the way to the hospital for the pain. I was vomiting because it was so much pain. I nearly fainted. So we arrived at the emergency ward at Canberra Hospital.

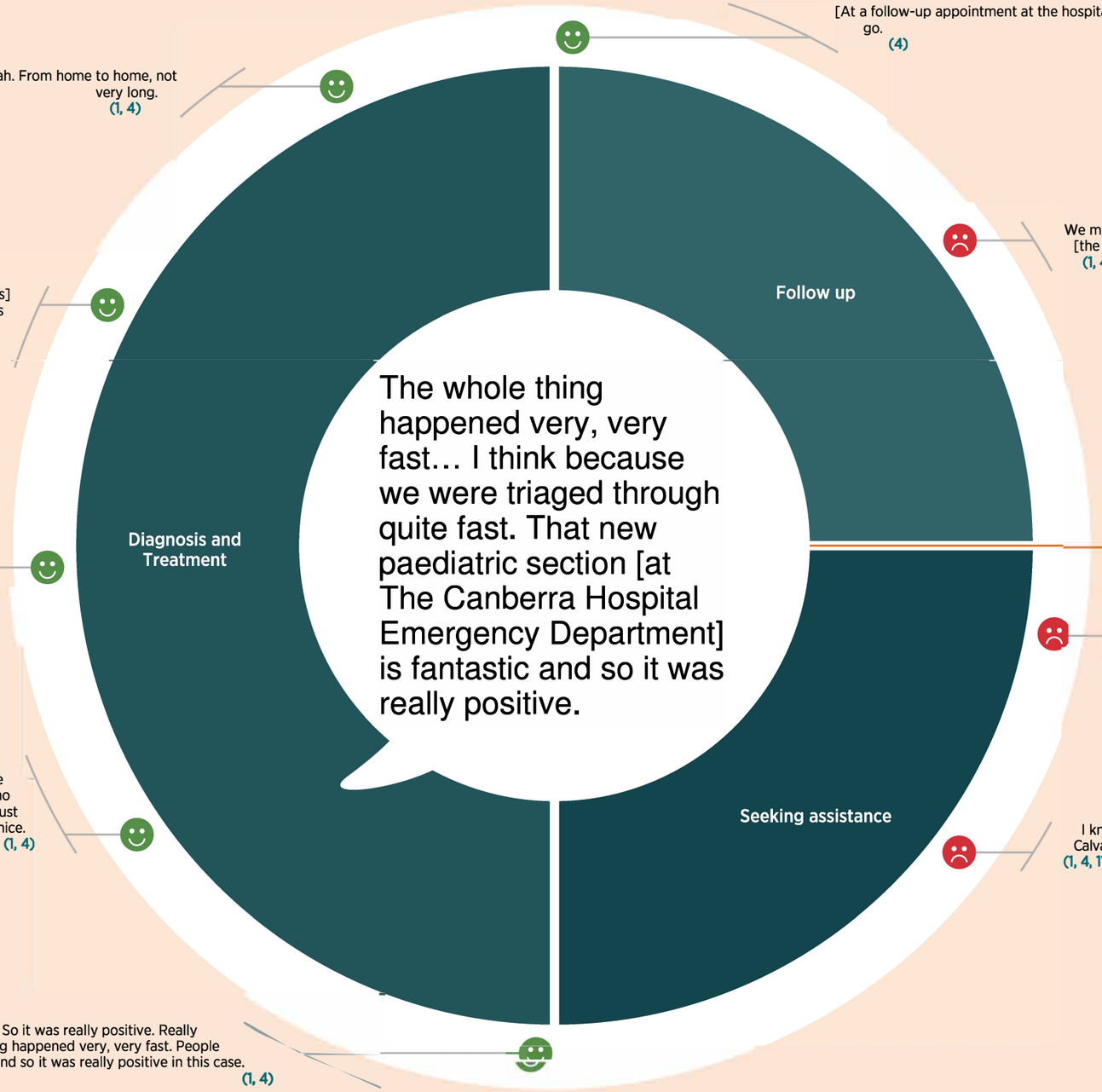
While we were waiting, I was in so much pain that I could barely talk. That's how much pain, and so I had to explain to the nurses again and again, "It's not my foot. My foot I can deal with but I'm actually going through [extreme] pain right now that comes... like, every twelve months and it's happening today." So I had to keep explaining the same story again and again to every single person who came along.
(2)

Consumer Centred Care

2.	Information and understanding	☹☹☹☹☺
4.	Appropriate care	☺☹☹☹
5.	Respectful care	☺
6.	Whole of person care	☹☹☺☹☹
7.	Coordinated care and supported transitions	☺☹

Participant C recently attended a medical centre and the Canberra Hospital Emergency Department after she accidentally cut her foot, and also had severe non-related pain.

Participant D - Emergency Department, Paediatric Ward



[At a follow-up appointment at the hospital the doctor] found that his eardrum was intact and she said he was good to go.
(4)

I reckon, door to door, [the entire experience was] maybe three hours. Yeah. From home to home, not very long.
(1, 4)

We made an appointment for 1 o'clock or whatever it was that particular day for [the follow-up] appointment and waited over an hour, which was so annoying.
(1, 4, 11)

You know, you get recliner chairs [in the paediatric emergency unit which is] awesome. My son had his own television and his own remote so he was happy as and it was really nice. It was very relaxing .... I had work to do on my computer there so I was just doing it. Fantastic.
(4, 6, 11)

I hate going to E.D., but I thought they're going to have everything there for me and I won't get referred on. If it turns out to be something serious, everything will be there. So had I gone to CALMS or something, made an appointment and gone later that afternoon I felt like I might have got moved around and referred [on].
(1, 4)

[In the past] I've spent a long time waiting in Emergency waiting rooms and it's been pretty horrible.
(1, 4, 5, 6, 11)

Once we got into the paediatric section everything became beautiful. The nurses were gorgeous and a doctor came along and he was gorgeous. He couldn't figure out what was going on so he called a specialist in who eventually showed up after a little while and she was gorgeous and it was just all really nice.
(1, 4)

I know Calvary doesn't [have a specialist paediatric unit], otherwise I'd go to Calvary [instead of Canberra Hospital] because it's closer.
(1, 4, 11)

[The new paediatric section in the Emergency Department is] so great. So it was really positive. Really positive, I think because we were triaged through quite fast. The whole thing happened very, very fast. People came very quickly, and that new paediatric section is fantastic and so it was really positive in this case.
(1, 4)

Consumer Centred Care

1.	Access, equity and affordability	× 4 × 3
4.	Appropriate care	× 6 × 3
5.	Respectful care	
6.	Whole of person care	
11.	Carers and support	

Participant D attended the Canberra Hospital Emergency Department Paediatric Ward after her son injured his ear.

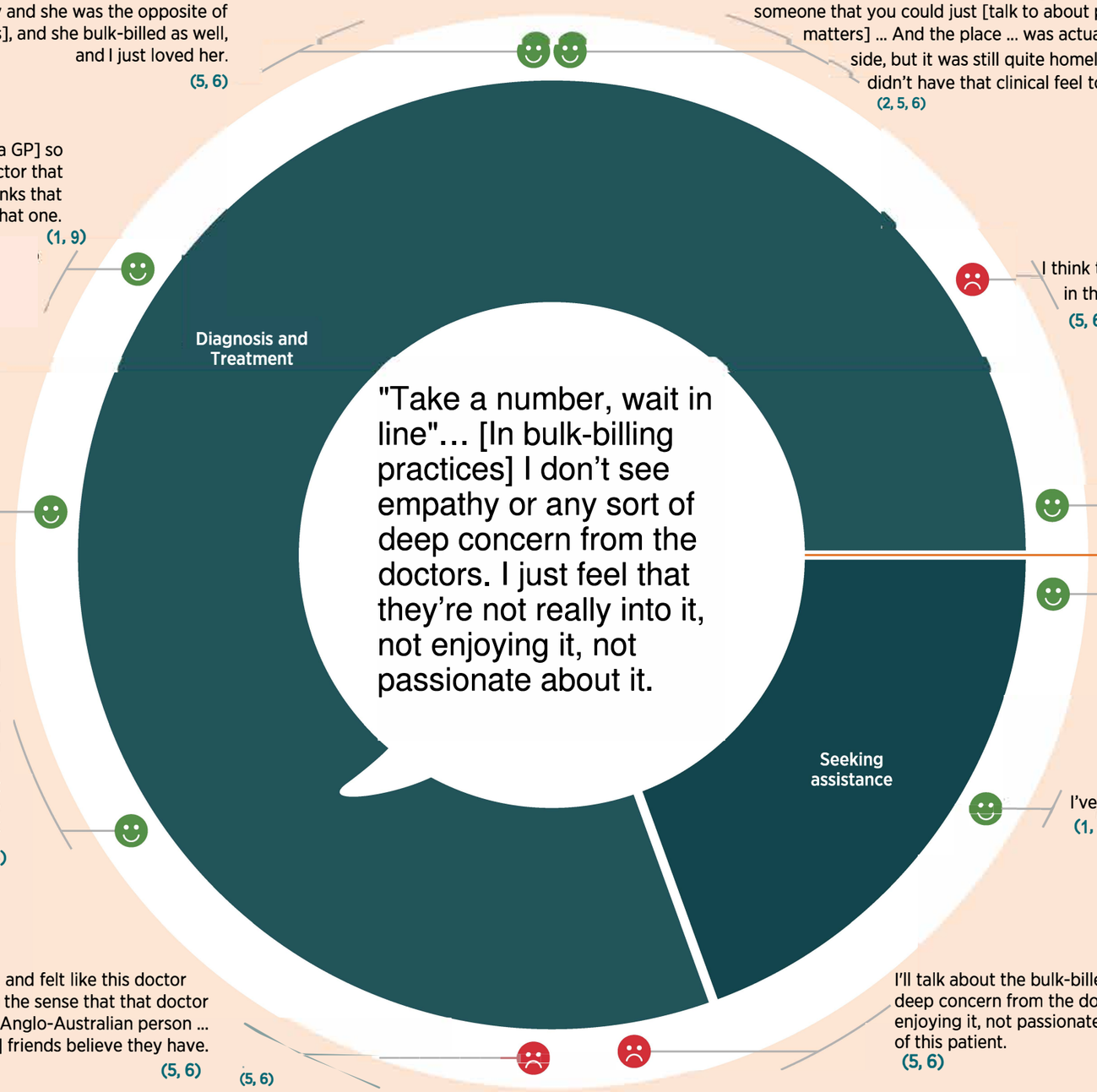
Participant E - GPs

I used to have a GP in Sydney and she was the opposite of [ACT bulk-billing practices], and she bulk-billed as well, and I just loved her.
(5, 6)

She was just someone who was really compassionate, and someone that you could just [talk to about personal matters] ... And the place ... was actually a bit on the shabby side, but it was still quite homely and it definitely didn't have that clinical feel to it.
(2, 5, 6)

[My husband] doesn't care [about the cost of going to a GP] so he'd rather go to a paid one. ... For him, it has to be a doctor that he's comfortable with... [and] he can rely on... [If] he thinks that this doctor knows what he's doing, he'd go to that one.
(1, 9)

I think the doctors and the receptionists ... aren't very different in their [impersonal approach].
(5, 6)



I think [GPs] should be ones that you can just tell your personal things to them, so they should have that skill.
(5, 6)

[To find a GP] I've usually asked a few people. That's what I've usually done. And then also looked [for] some place that was closer. **(1, 4)**

I've taken my children to [non bulk-billing] GPs and I do feel as though they are more confident. You know, they know what they're doing. They seem to be more caring as well. Probably [they show this by] just interacting more, asking more questions, paying more attention, and just showing a bit more... confidence at the same time, a caring attitude... You're letting [GPs]... in on your personal and your secret things, private things, and you just want that sort of attitude from those people, I think
(2, 5, 6)

I've always been seen within about two to three days
(1, 4)

[My friends and I] have visited the same Pakistani doctor, and felt like this doctor wasn't very interested in [us] ... and came away with the sense that that doctor would pay more attention to an Anglo-Australian person ... I haven't seen that but [my] friends believe they have.
(5, 6)

(5, 6)

I'll talk about the bulk-billed experiences first. I don't see empathy or any sort of deep concern from the doctors. I just feel that they're not really into it, not enjoying it, not passionate about it. It's more like [they're] just trying to get rid of this patient.
(5, 6)

Consumer Centred Care

1.	Access, equity and affordability	☺☺
2.	Information and understanding	☺☺☺
4.	Appropriate care	☺☺
5.	Respectful care	☺ × 5 ☹ × 3
6.	Whole of person care	☺ × 5 ☹ × 3

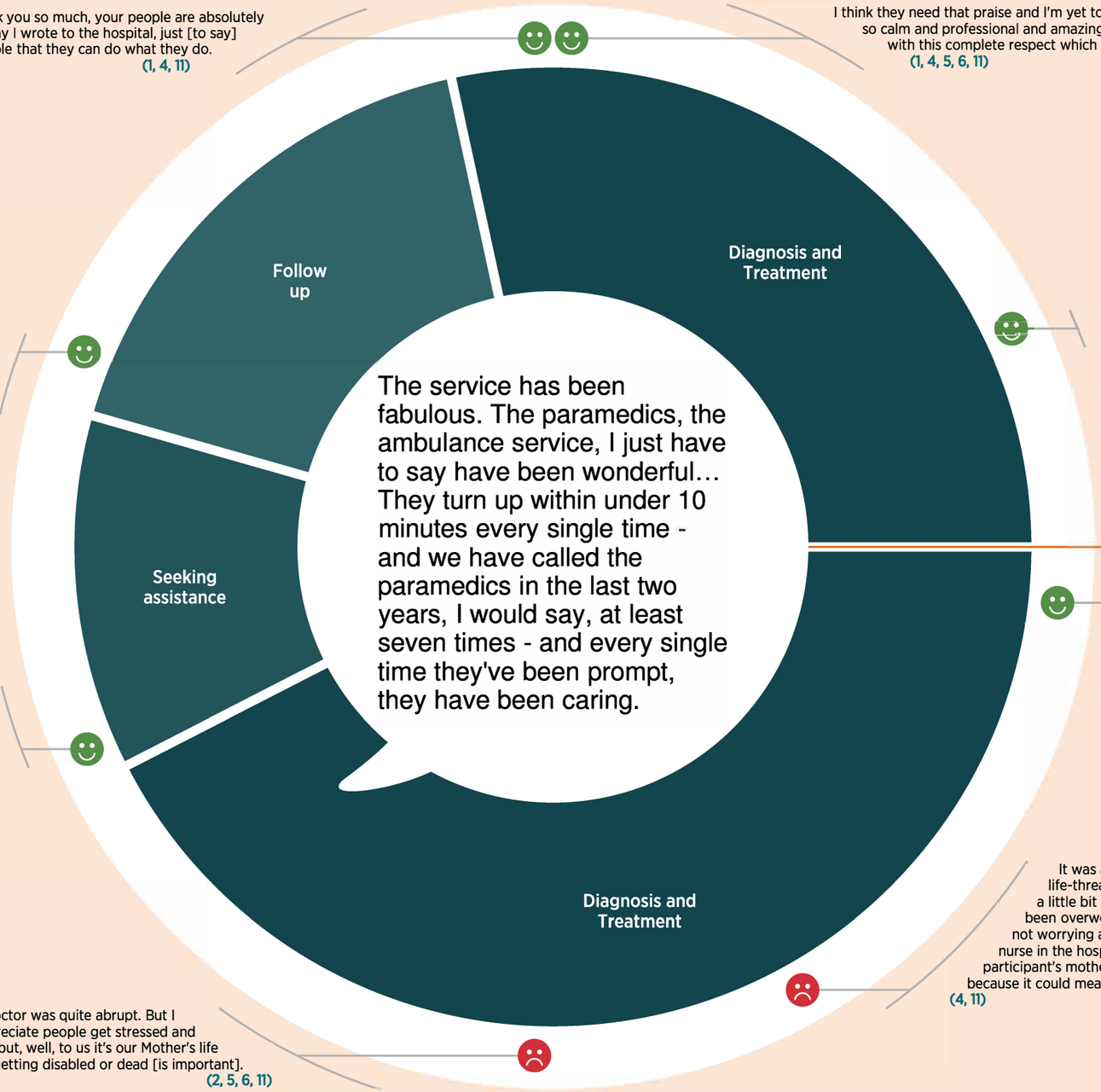
Key issues

Participant E migrated to Australia from Pakistan, and has attended bulk-billed and non-bulk billed General Practitioners both for herself and for her three children.

Participant F - Emergency department

I did write to the hospital, to the paramedics' head and just said, "Thank you so much, your people are absolutely amazing," and brought them chocolates.... I'm very grateful and that's why I wrote to the hospital, just [to say] your people are unbelievable that they can do what they do.
(1, 4, 11)

I think they need that praise and I'm yet to do that for this last stint [when my Mother was in hospital]... They are just so calm and professional and amazing and especially when you're in a panic-stricken state... Mum's just treated with this complete respect which is amazing.
(1, 4, 5, 6, 11)



It was so fabulous, the paramedics had followed up [with them]... [They] actually, went up there [to the ward] to say, "Are you okay, are you alive, are you good?" Wow, wow, you know, [they] stirred him up a little bit, gave him a bit of crap, which was nice.
(6, 7)

Yeah, we're lucky we live in this country and this town.
(1, 4)

With my mother who [was] in hospital [after a] small heart attack, [to have a] stent put in, the service was fabulous. The paramedics, the ambulance service, I just have to say have been wonderful.
(1, 4)

[When phoning healthdirect] you get a nurse on the other end of the phone, yes. I remember [when] my husband was sick we had Hospital in the Home when he came out of intensive care from the hospital and that service is fantastic.
(1, 4, 7, 11)

It was a Friday and they had a lot of accidents and there were a lot of emergency, life-threatening issues ahead of her, but the service [later on] wasn't the best. It was a little bit rushed and one of the doctors obviously had been very stressed and had been overworked and was very tired, but [was] just saying silly things like, "Oh, we're not worrying about your blood pressure till it gets close to 300." ... We've been told by any nurse in the hospital, the heart specialist, the endocrinologist and everyone else that, for [the participant's mother's] <um, if it gets up to that 200 mark you really have to bring her in here because it could mean stroke or heart attack for her history. So that was a little bit disappointing.
(4, 11)

My sister was sat there for five hours at the hospital with Mum and this doctor was quite abrupt. But I suppose having been back and forth to the hospital, we do appreciate people get stressed and overwhelmed and then they may not consider this such an important thing but, well, to us it's our Mother's life and potentially keeping her out of the nursing home or getting disabled or dead [is important].
(2, 5, 6, 11)

Consumer Centred Care

1.	Access, equity and affordability	☺☺☺☺☺
2.	Information and understanding	☹
4.	Appropriate care	☺ × 5 ☹ × 1
5.	Respectful care	☹☺
6.	Whole of person care	☹☺☺

Participant F recently attended the Calvary Public Hospital Emergency Department when her mother was admitted by ambulance after a heart attack.

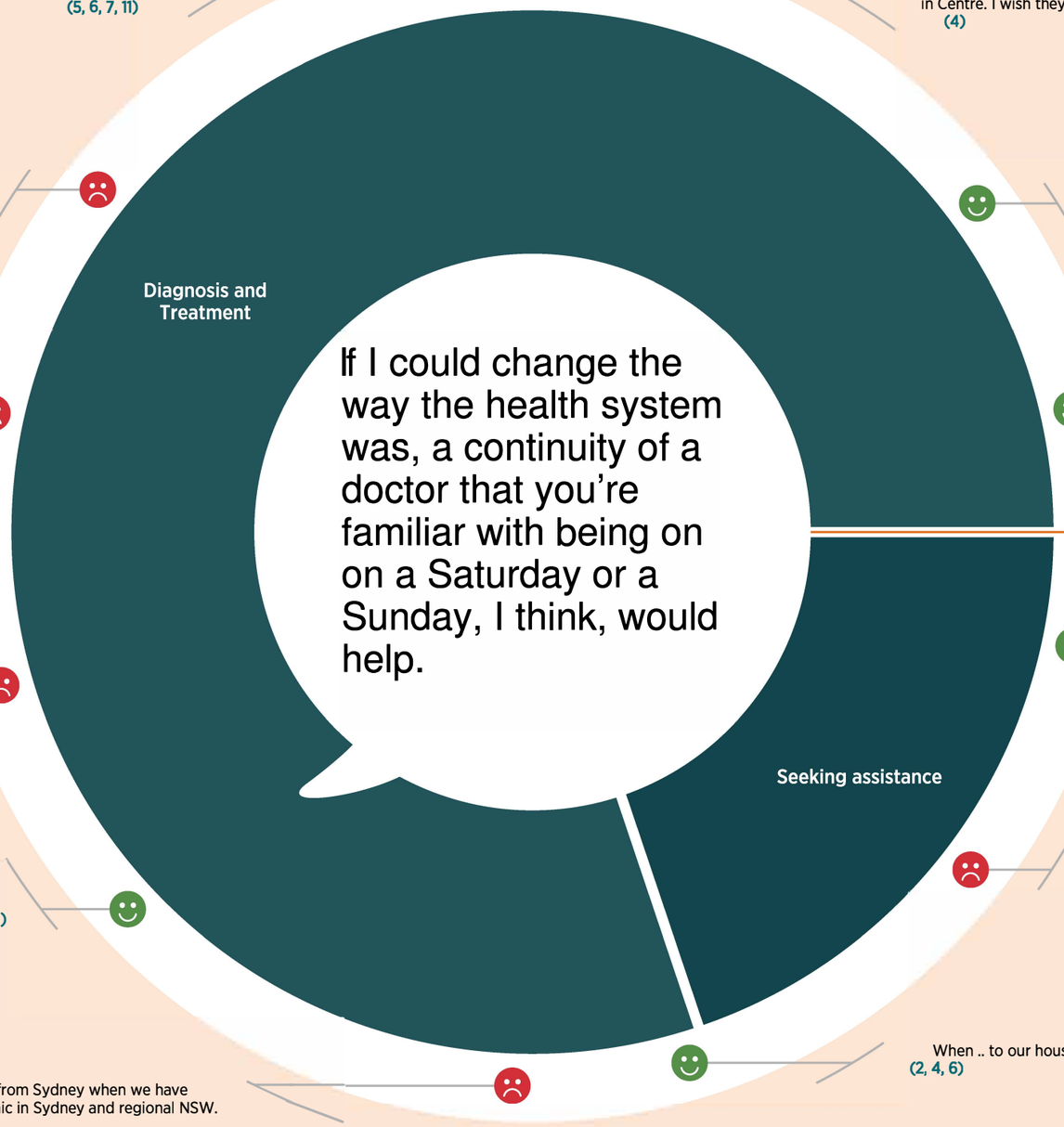
Participant G - National Home Doctor Service

[healthdirect did not] follow-up of me [or give advice about] what to do if I didn't want to take her to the hospital. I think I would have appreciated [if they had said], maybe, "We can give you a call in an hour and see how she's going", or, "This is what we want you to do". There was no flexibility in the treatment.
(5, 6, 7, 11)

I didn't have to wait long [at the Walk-in Centre]. I think I was there 8 o'clock on a Sunday night and I didn't have to wait long. She saw me, couldn't give me antibiotics because it was viral - which she was spot on about because I ended up having the actual flu – she wrote me a certificate [and] offered me support. I'd go back to the Walk-in Centre. I wish they had Walk-in Centres for kids [under two years]. It would help.
(4)

Sometimes healthdirect can exacerbate things as well as undermining things. Because they're on the other end of a phone, they're not seeing, they're not feeling, they're not... Yeah, I found it quite scripted.
(5, 6, 11)

I would hesitate to use healthdirect again. I would use the after-hours medical service again, the Home Doctor Service.
(4)



[When the paricipant's daughter was unwell] I called healthdirect and because she was under six months they said, "You need to take her straight to the hospital."
(11)

I'd probably be more inclined now to try and get [the participant's daughter] seen after hours than I would be to get out of work to get her [to a GP] – you know, if it's just something that I need confirmed. I wouldn't rely on the Home Doctor Service for something that was ongoing, just more of a diagnostic treatment.
(4, 11)

I called [the National Home Doctor Service] to see how long it was going to be and they said they'd come within three hours of making the booking, which they did. I think they were there within two hours, and [the doctor] was great. The guy that came was really good, and I'm glad that I [called]. He was very reassuring that it's better to see a doctor than not, because my daughter was fine [she] just had a virus.
(1, 4)

[When the doctor arrived] I don't think he wrote [the participant's] full name down, so just first initial and last name and then Medicare Card number, but given you've already given it in the [National Home Doctor Service] app, I don't know what the purpose of it is.
(2, 6)

I find healthdirect, to me, [it] feels like they just read off a script, so had I have called and said, "She's got a fever", [and] I feel like it's quite a scripted response as opposed to a personal response.
(4, 6)

So for me, the benefits of the Home Doctor Service were that they came to my house because trying to take a sick child out in the middle of winter in Canberra is tough.
(4, 6, 11)

When .. to our house, I found him quite good, quite personable and very reassuring.
(2, 4, 6)

He was saying he came from Sydney which shocked me. Why are we getting doctors from Sydney when we have doctors in Canberra? He comes down on weekends [and] runs his own clinic in Sydney and regional NSW.

Consumer Centred Care

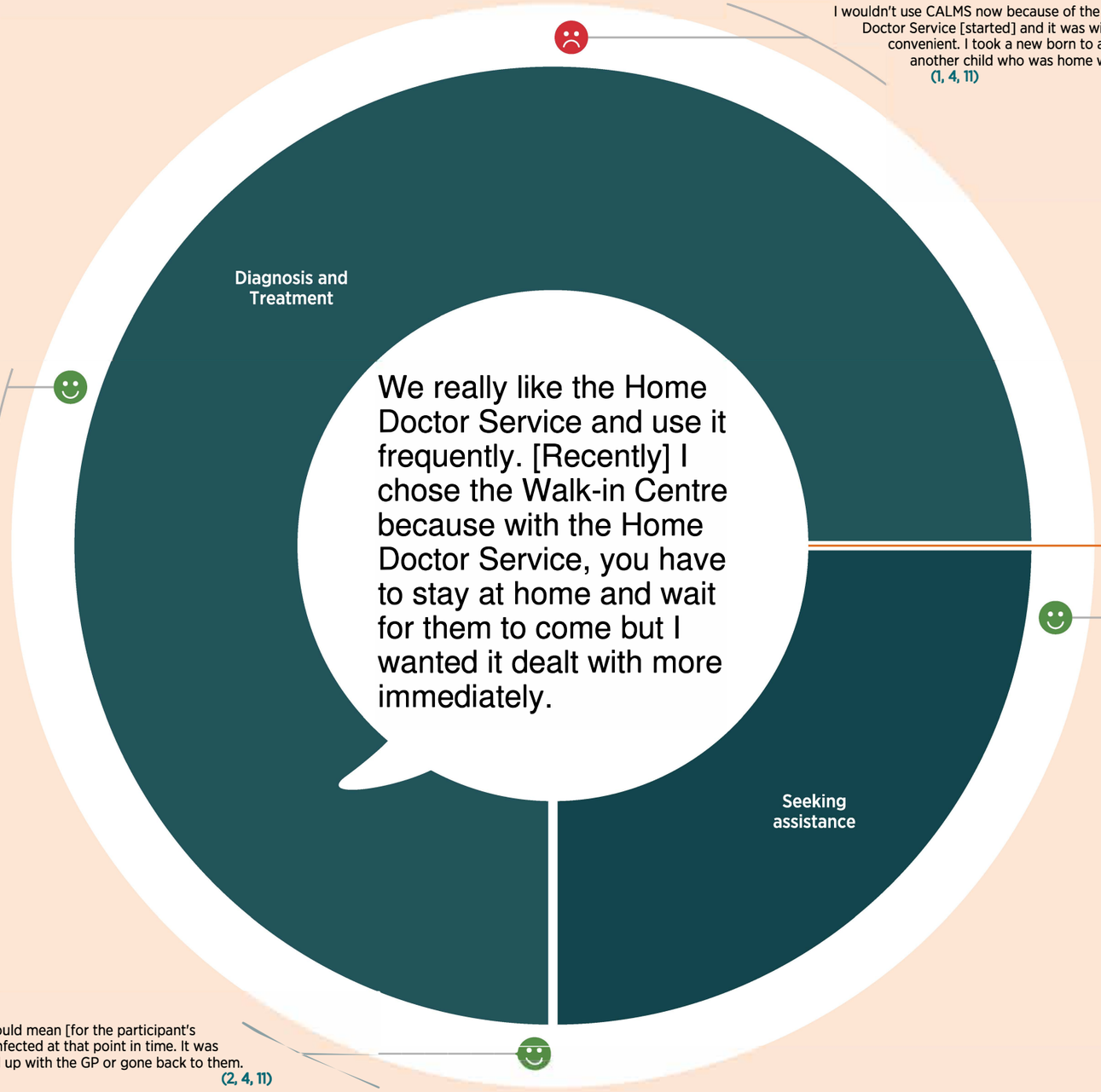
1.	Access, equity and affordability	😊
2.	Information and understanding	😊 ☹
4.	Appropriate care	😊 × 6 ☹ × 1
5.	Respectful care	☹ ☹
6.	Whole of person care	😊 × 2 ☹ × 4

Participant G has used the National Home Doctor Service and *healthdirect* when her young daughter was sick.

Participant H - Walk-in Centre, National Home Doctor Service and CALMS

I wouldn't use CALMS now because of the other options. The time I have used CALMS once was before the Home Doctor Service [started] and it was with a newborn so I couldn't use the Walk-in Centre. I actually found it not convenient. I took a new born to an 8.00 pm appointment in winter. So nothing was good about that. I had another child who was home with the Dad so it meant I had to go on my own in June in Canberra.
(1, 4, 11)

[The National Home Doctor Service] is fantastic. We have had them come in the evening, we can sort out care arrangements for the next day and be ready to roll at 7.30 the next day knowing who is going where rather than waking up, making the GP appointment, then not going to work anyway but then you might have been able to go to work so we really like the Home Doctor Service and use it frequently.
(5, 6, 10, 11)



I chose the Walk-in Centre because if I did the Home Doctor Service, you have to stay at home and you have to wait for them to come but I wanted it dealt with more immediately so we went down to the Tuggeranong Walk-in Centre and we were seen pretty quickly.
(1, 4, 11)

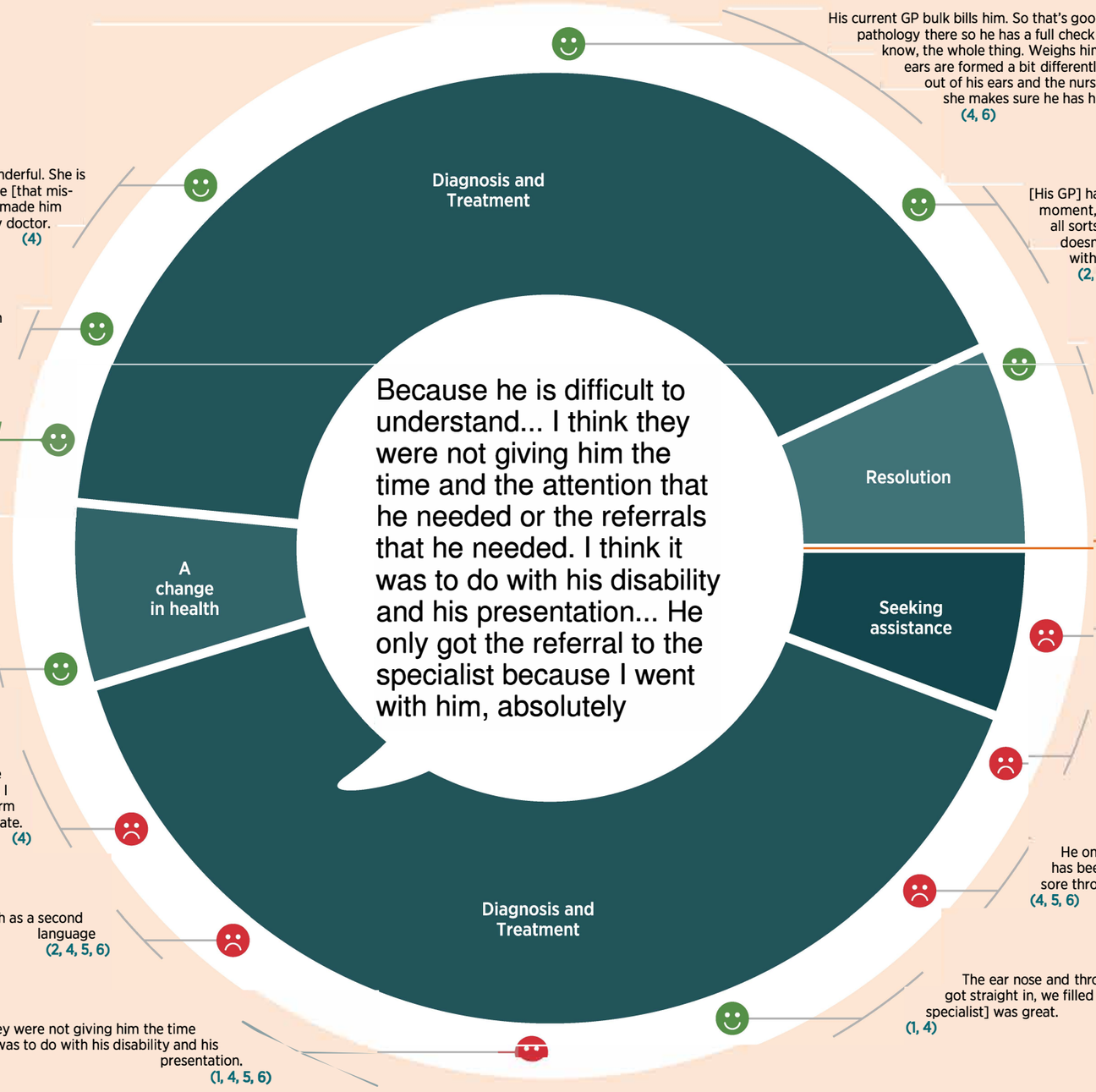
[The nurse in the Walk-in Centre] gave me some education about what it would mean [for the participant's daughter's mosquito bites to be] infected and how she knew it wasn't infected at that point in time. It was wait and see and then I could have followed up with the GP or gone back to them.
(2, 4, 11)

Consumer Centred Care

1.	Access, equity and affordability	☺☹
2.	Information and understanding	☺
4.	Appropriate care	☺☺☹
5.	Respectful care	☺
6.	Whole of person care	☺

Participant H has used the Tuggeranong Walk-in Centre, the National Home Doctor Service and CALMS when her children were unwell.

Participant I - GP, Emergency Department



His current GP bulk bills him. So that's good [as] he doesn't have to pay extra. They have got a nurse's clinic and pathology there so he has a full check up with a nurse every year. She strips him off, looks at his toes and you know, the whole thing. Weighs him and measures him and checks everything and looks in his ears. Because his ears are formed a bit differently the wax doesn't drain out so he ends up needing to have the wax washed out of his ears and the nurse does all that. His current GP has got all of his immunisations up to date, she makes sure he has his flu injection every year. It's really good. They are very thorough.
(4, 6)

He goes to my GP now, so he has a regular GP. A family doctor. She's wonderful. She is fabulous with him ... As soon as I saw what the [bulk-billing] practice [that mis-diagnosed his tonsilitis] was like, he didn't go back there anymore. I made him change and come to my doctor.
(4)

[His GP] has referred him to psychologists and he's on a bit of a health thing at the moment, so she was able to refer him. We have seen specialists and nutritionists and all sorts of things. She has been very thorough and she really listens to him. She doesn't take any "bull" off him but she does listen to him and she is really good with him if he goes there without me.
(2, 4, 5, 6)

I really think emergency [staff] are trained or well equipped to deal with anything. They are used to anything coming their way.
(4)

He has come a long way. He is fantastic, he has put in lots to better himself. There has been a lot of good things like, did he tell you about his flat? ... He has stable housing.

It's usually for an upset stomach. Sometimes he gets cramps and diarrhoea and, stuff like that or vomiting. So if he is frightened or anything like that, he goes to Emergency [and] they have always been great.
(4)

So, [the participant's nephew] had a sore throat. He went to a practice out at Belconnen which was a bulk billing practice. Not one single GP ... would see him. He had been saying for some time that he had a sore throat and they just kept giving him antibiotics and he was saying that they were not listening to him.
(4)

If he is not feeling well during the night he will ring an ambulance [to] go to Emergency or go to Emergency in a taxi himself. So, his after-hours care has always been excellent.
(1)

I went with him to his next appointment and when I went with him the doctor gave him a referral to the ear nose and throat specialist and we got in to see him
(4)

I think [at] the bulk-billing practice, some of the effort is minimal. You know. Discretionary effort is not necessarily better. And look, in medicine there is obviously a lot of discretionary effort ... In a bulk-billing practice, I think discretionary effort may not be rewarded in any way shape or form certainly not in their Medicare rebate.
(4)

He only got the referral to the specialist because I went with him, absolutely. He has been going to that surgery for some time and he was just constantly having sore throats. He was just constantly getting a script for antibiotics
(4, 5, 6)

He has never been difficult but we are talking about doctors with English as a second language
(2, 4, 5, 6)

The ear nose and throat specialist looked at his tonsils and said, "Yes, they should come out" ... He got straight in, we filled out the forms and got in quite quickly to have his tonsils taken out. [The specialist] was great.
(1, 4)

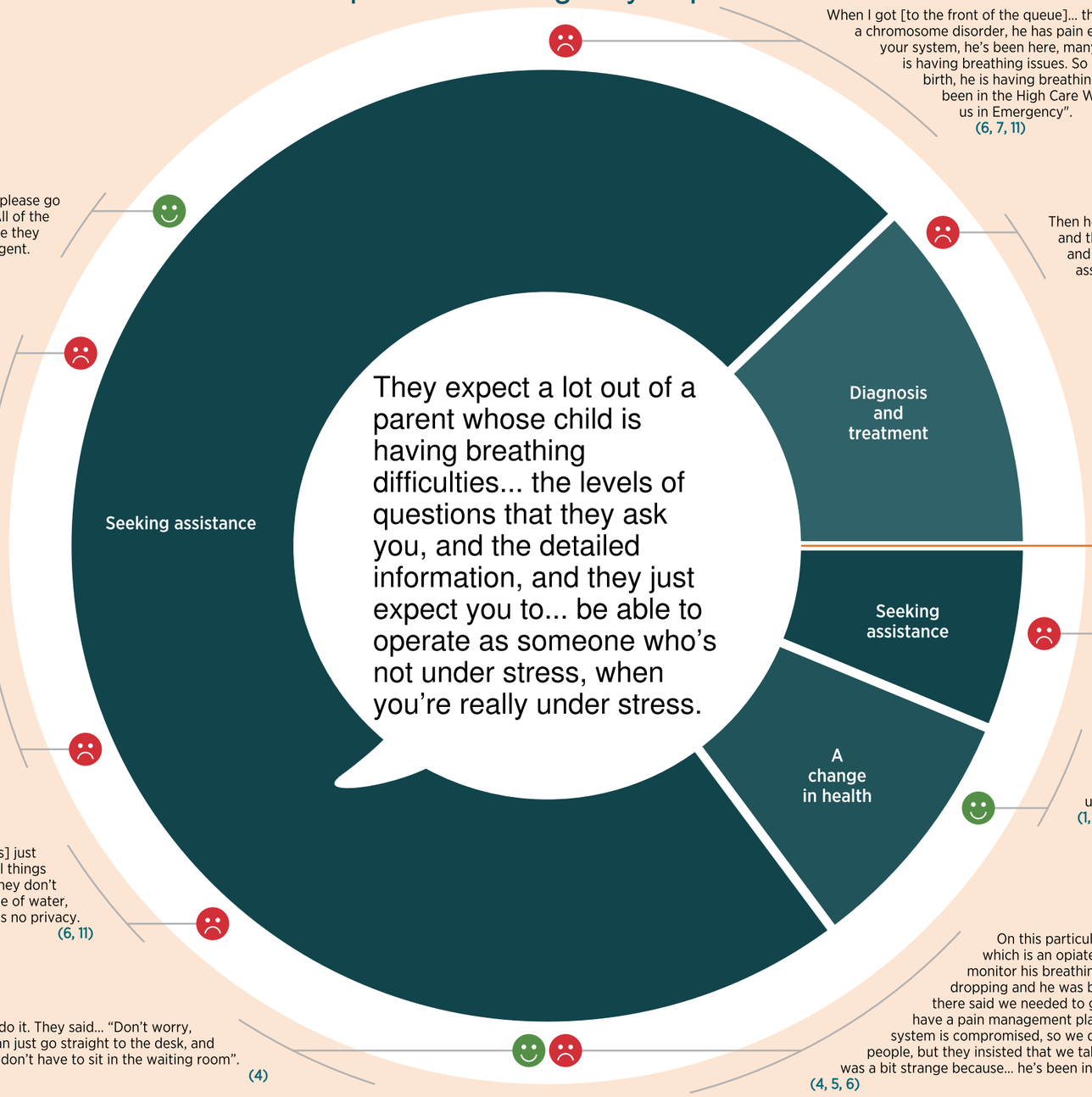
I think that it was because he is difficult to understand [and] I think that they were not giving him the time and the attention that he needed or the referrals that he needed. I think it was to do with his disability and his presentation.
(1, 4, 5, 6)

Consumer Centred Care

1.	Access, equity and affordability	☺☹☺
2.	Information and understanding	☹☺
4.	Appropriate care	☺ × 6 ☹ × 6
5.	Respectful care	☹☹☹☺
6.	Whole of person care	☹☹☹☺☺

Participant I's nephew has a chromosomal disorder. She attended a bulk-billing GP with him when he felt his persistent sore throat was not well-treated. She also recounts some of his experiences of attending a hospital Emergency Department.

Participant J - Emergency department 1/2



When I got [to the front of the queue]... they said to me, "Can you tell me what's going on?" I explained, "My son's got a chromosome disorder, he has pain episodes... We have a care plan... We have direct admission". I said, "It's all on your system, he's been here, many, many times." ...They asked me for his medical history, and this is while he is having breathing issues. So I just said, "Look, it's all on your system, this is his name, this is his date of birth, he is having breathing issues, he has a Fentanyl patch on to manage pain".... I said, "Look, we've been in the High Care Ward, [they] know we're coming, and the paediatric registrars are gonna meet us in Emergency".
(6, 7, 11)

Some other parents who were there with children in the line said ,"Please, please go ahead of us" because they could see that the situation [was serious]... All of the people in the queue suddenly pushed us to the front of the queue, because they could recognise that you know, it was quite urgent.

Then he said "I'm just gonna take his oxygen levels"... They went to put on the toe, and they went, "Oh, you've already got one on"... I knew what his heart rate was, and I knew his oxygen levels. Then they took us through to... one of the... assessment bays.

I went straight to the fellow at the desk, and... said, "Look, we've called ahead, the High Care Ward knows we're coming, the Registrar is gonna come down and meet us". He said, "You still need to join the queue". You know, I had an oxygen meter hanging off my son's toe... He wasn't turning blue or anything, but I was really anxious.... I said, "Look, we've called ahead, we've spoken to High Care he had direct admission rights, and they have asked us to come through Emergency because he is having breathing difficulties", and he said, "Yes, you still need to join the queue". And my son was... screaming in pain, and... his breathing was very rapid, and he was working extremely hard to breathe... sucking his chest [was] sucking back in and out. So, I joined the queue, and I almost burst into tears at that point.
(4, 6, 7)

I've had some really bad experiences in emergency, where there has been psychiatric patients in the Emergency area, and I'm there with a... young child, and there's people screaming, and threatening violence, and it's eleven, twelve o'clock at night, and I'm there alone with my child, you know, feeling vulnerable...
(6)

My understanding was they had a new paediatric area, at least a waiting area, and I thought they had a whole other emergency intake for paediatrics... I was really confused as to why... we couldn't just walk into a line, or you know an assessment area, with just children. I would have felt a lot more comfortable if we could have just walked in and been dealt with by a paediatric team immediately, rather than a general team. I think an environment that is set up for children that's a bit more child friendly, would have been more welcoming.
(1, 4, 5, 6)

We have a care plan that allows [my son] direct admission to the Paediatric High Care Ward, because my son has pain episodes... [Previously], we have had some experiences in Emergency where his pain wasn't dealt with quickly, and that led to getting a direct admission plan set up to the High Care Ward.
(1, 4)

Emergency isn't really a great space to be in for a long period of time... [It is] just completely stressful on a sonic level... very bright lights, [there are] stressful things happening around you, as well as dealing with your own situation, and they don't really have any meals or anything to feed you... They might offer you a bottle of water, there is no privacy.
(6, 11)

On this particular occasion, he was having a pain episode ... We have to give him Fentanyl which is an opiate, to be able to manage his pain, and so part of that we actually have to also monitor his breathing with an oximeter at home ... and his heart rate ... His oxygen levels were dropping and he was breathing very rapidly, and so I called the High Care Ward, and ... the registrar there said we needed to go through Emergency, because it was a breathing issue... I said, "No, we have a pain management plan, and we usually bypass Emergency". Part of that is because... his immune system is compromised, so we don't really wanna go and sit in Emergency where there is a lot of sick people, but they insisted that we take him through Emergency because they said it was a breathing issue, which was a bit strange because... he's been in with breathing issues before, related to the Fentanyl patch.
(4, 5, 6)

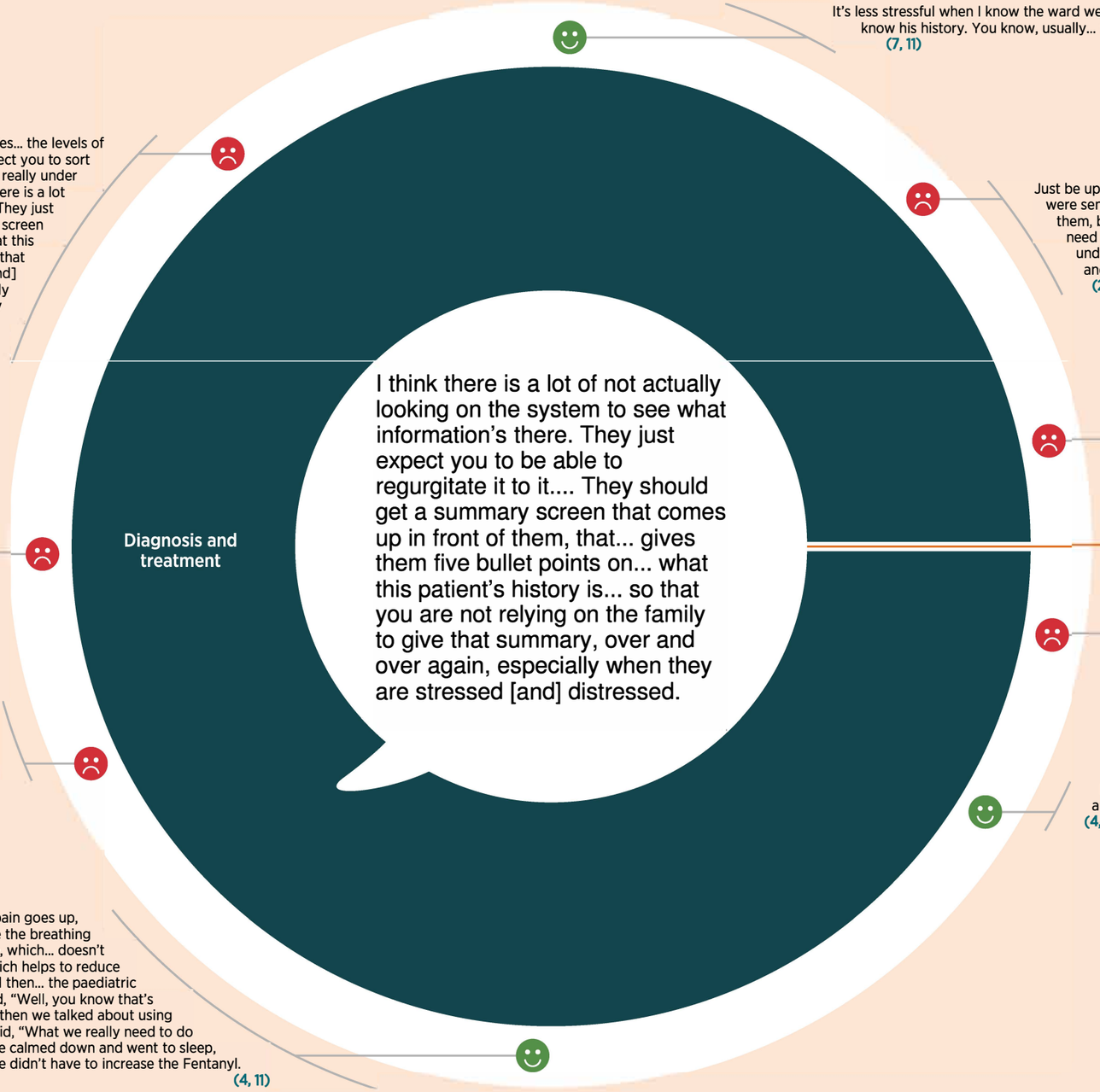
I called again and double checked it, 'cos I thought I really don't wanna do it. They said... "Don't worry, [you] won't have to queue up, ... they know that you're coming. You can just go straight to the desk, and they'll take you straight through, you don't have to sit in the waiting room".
(4)

Consumer Centred Care

1.	Access, equity and affordability	
4.	Appropriate care	
5.	Respectful care	
6.	Whole of person care	× 6
7.	Coordinated care and supported transitions	

Participant J's son has complex health needs including a chronic pain disorder as a consequence of a chromosome deletion. On a recent hospital admission for croup, exacerbated by a pain episode, The Canberra Hospital Emergency Department did not activate his care plan, which allows direct admission to the Paediatric High Care Ward.

Participant J - Emergency department 2/2



It's less stressful when I know the ward we are going into, and I know that at least one of the nurses there is gonna know his history. You know, usually... the head nurses know my son's history and so it's not so stressful.
(7, 11)

They expect a lot out of a parent whose child is having breathing difficulties... the levels of questions that they ask you, and the detailed information, and they just expect you to sort of be able to operate as someone who's not under stress, when you're really under stress. I understand why they need that level of information, but... I think there is a lot of not actually looking on the system to see what information's there. They just expect you to be able to regurgitate it to it.... They should get a summary screen that comes up in front of them, that... gives them five bullet points on... what this patient's history is... so that you are not relying on the family to give that summary, over and over again, especially when they are stressed [and] distressed. I was almost in tears, having to explain, because... I'm already stressed having to take him in there and then you're put on the spot to relay his complex history. I just think, "Why, why don't you have that in front of you?"
(2)

Just be upfront at the beginning, that they didn't have the bed, and that's why they were sending us through Emergency. It took a bit of work for me to get that out of them, because they went, "Ah no, he's got breathing difficulties, that's why you need to go to Emergency, because they've got CPAP machines". I could sort of understand some of that but, you know he's had breathing difficulties before and not had to go to Emergency.
(2)

It felt like there had been a communication breakdown between the ward, the High Care Ward, and Emergency, because this doctor that we first saw didn't know anything about it... Just that frustration, when you are dealing... with a child with special needs and with a very complex medical history, and people ask you to explain [the situation many times], from zero.
(2)

First, I dealt with someone who didn't know anything about my son again, and I had to explain what has happened... And I again felt this... sense of frustration well up in me, [because of] having to explain a very complex medical history, and why he had a Fentanyl patch on, and what his diagnosis was, and what that meant.
(2, 6, 11)

I mean it definitely helped having registrars who'd met my son before, and knew a bit of his background... They did look up his pain management plan... I had a printed-out version, but it was actually an old version.
(2)

We weren't transferred to the ward, and then later I found out, the reason they didn't allow us direct admission to High Care is because they didn't have a bed for us, that's why they bypassed us through Emergency. But they didn't really explain that at the time.
(2)

It just felt quite frustrating, until the registrars came down from paediatrics' and they knew my son.
(4, 7)

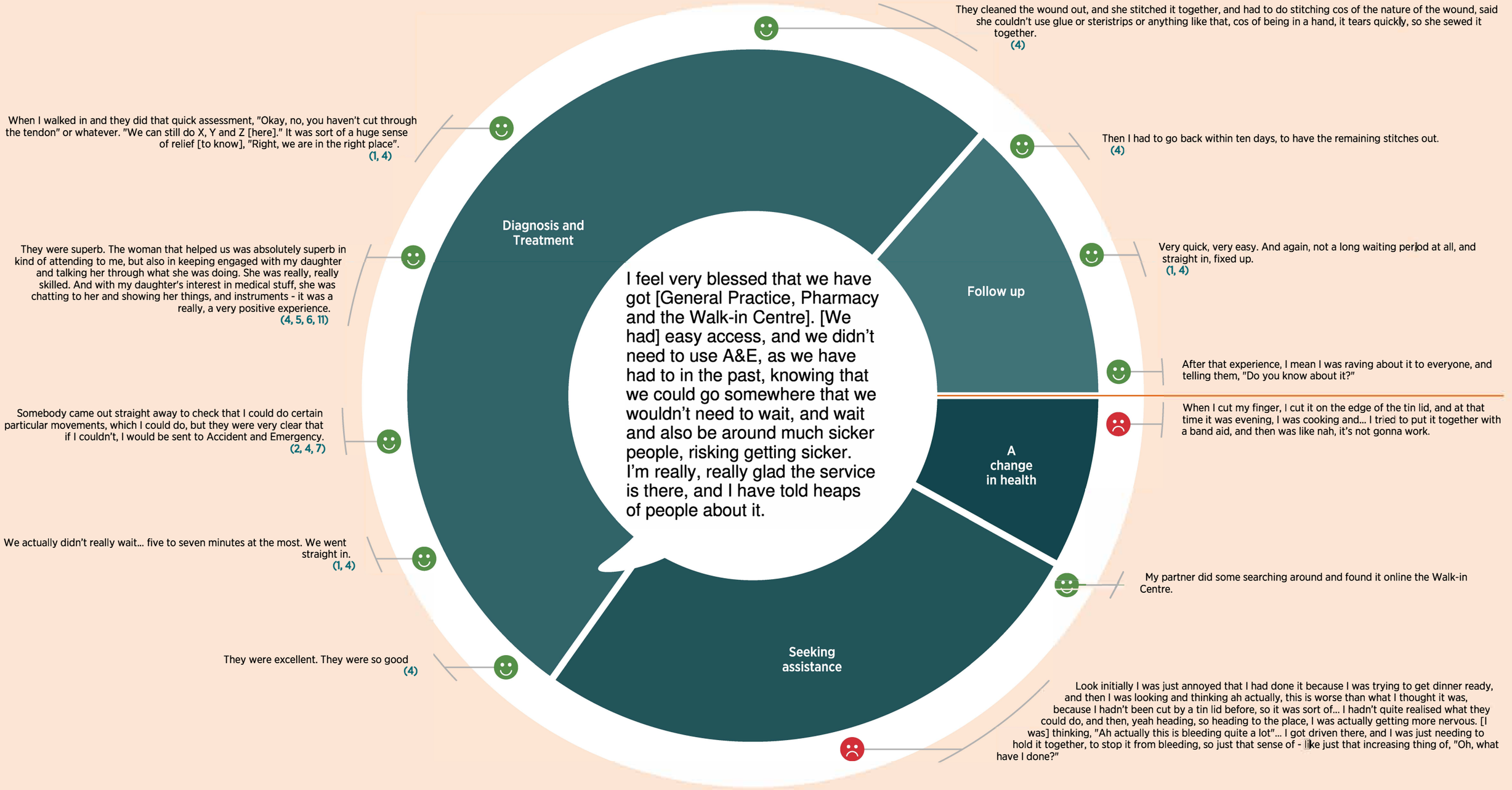
[My son] is sort of in a double bind if you take the Fentanyl patch off. The pain goes up, breathing improves, but... how do you manage the pain, and also manage the breathing issues? ... I remembered that he'd had a sedative before, Chloral Hydrate, which... doesn't affect breathing. What we did is we gave him some more Clonazepam, which helps to reduce muscle stiffening, and it didn't work, it was like a first line of defence... And then... the paediatric registrars... were saying that they could increase Fentanyl patch, and I said, "Well, you know that's going to cause breathing issues, why don't we try sedative first?", and then we talked about using Chloral Hydrate and... we agreed... that that was the best way forward.... I said, "What we really need to do is just try and calm him down", so we gave him the Chloral Hydrate and he calmed down and went to sleep, and we didn't have to increase the Fentanyl.
(4, 11)

Consumer Centred Care

2.	Information and understanding	☹ × 6
4.	Appropriate care	☺☺
6.	Whole of person care	☹
7.	Coordinated care and supported transitions	☺☺
11.	Carers and support	☹☺☺

Participant J's son has complex health needs including a chronic pain disorder as a consequence of a chromosome deletion. On a recent hospital admission for croup, exacerbated by a pain episode, The Canberra Hospital Emergency Department did not activate his care plan, which allows direct admission to the Paediatric High Care Ward.

Participant K - Walk-in Centre

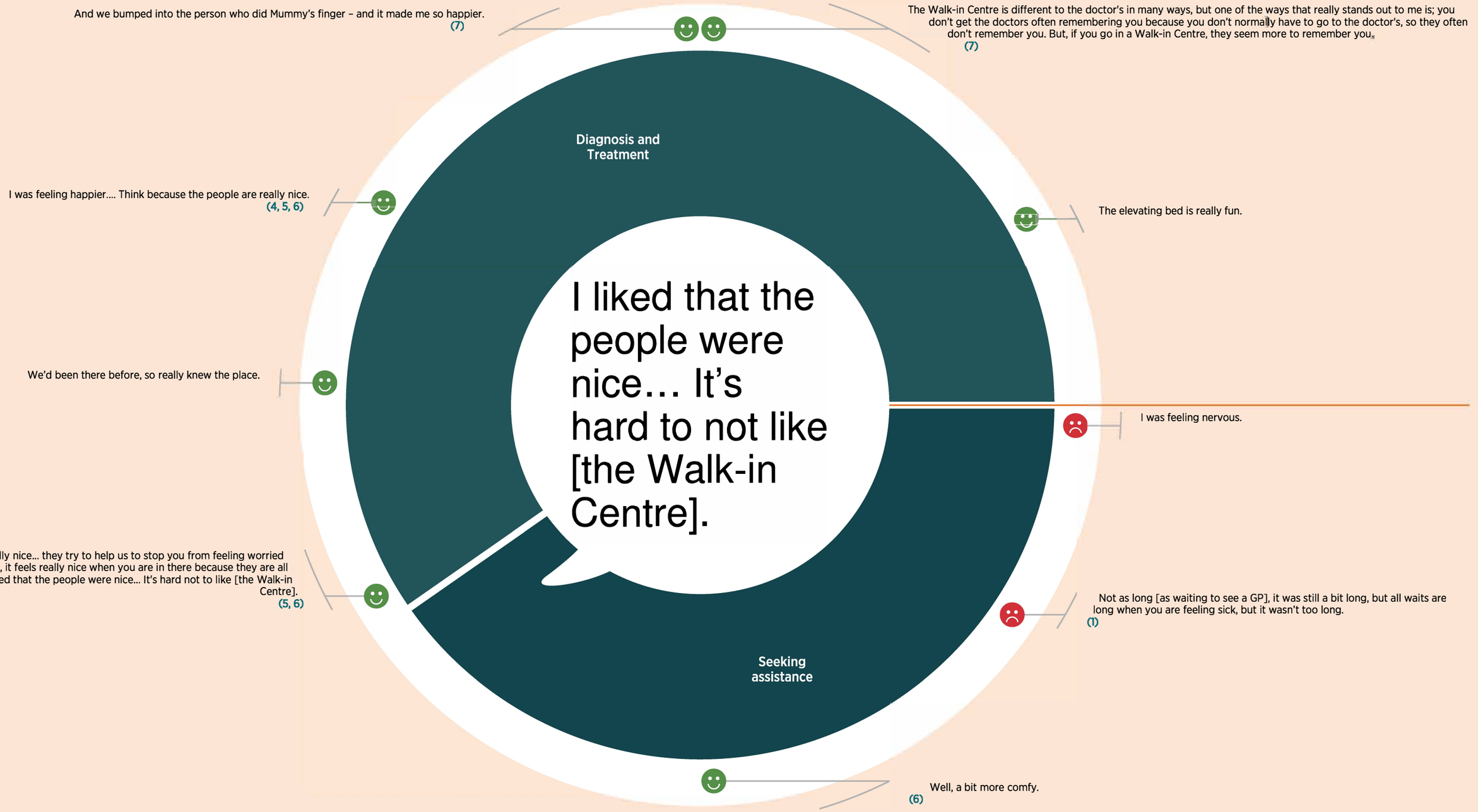


Consumer Centred Care

1.	Access, equity and affordability	😊😊😊
2.	Information and understanding	😊
4.	Appropriate care	😊 × 8
5.	Respectful care	😊
6.	Whole of person care	😊

Participant K attended a Walk-in Centre when she injured her finger, and again with her young daughter who was suffering from a rash.

Participant K's daughter - Walk-in Centre



And we bumped into the person who did Mummy's finger – and it made me so happier. (7)

The Walk-in Centre is different to the doctor's in many ways, but one of the ways that really stands out to me is; you don't get the doctors often remembering you because you don't normally have to go to the doctor's, so they often don't remember you. But, if you go in a Walk-in Centre, they seem more to remember you. (7)

I was feeling happier…. Think because the people are really nice. (4, 5, 6)

The elevating bed is really fun.

We'd been there before, so really knew the place.

I was feeling nervous.

They are really nice… they try to help us to stop you from feeling worried and stressed, it feels really nice when you are in there because they are all nice… I liked that the people were nice… It's hard not to like [the Walk-in Centre]. (5, 6)

Not as long [as waiting to see a GP], it was still a bit long, but all waits are long when you are feeling sick, but it wasn't too long. (1)

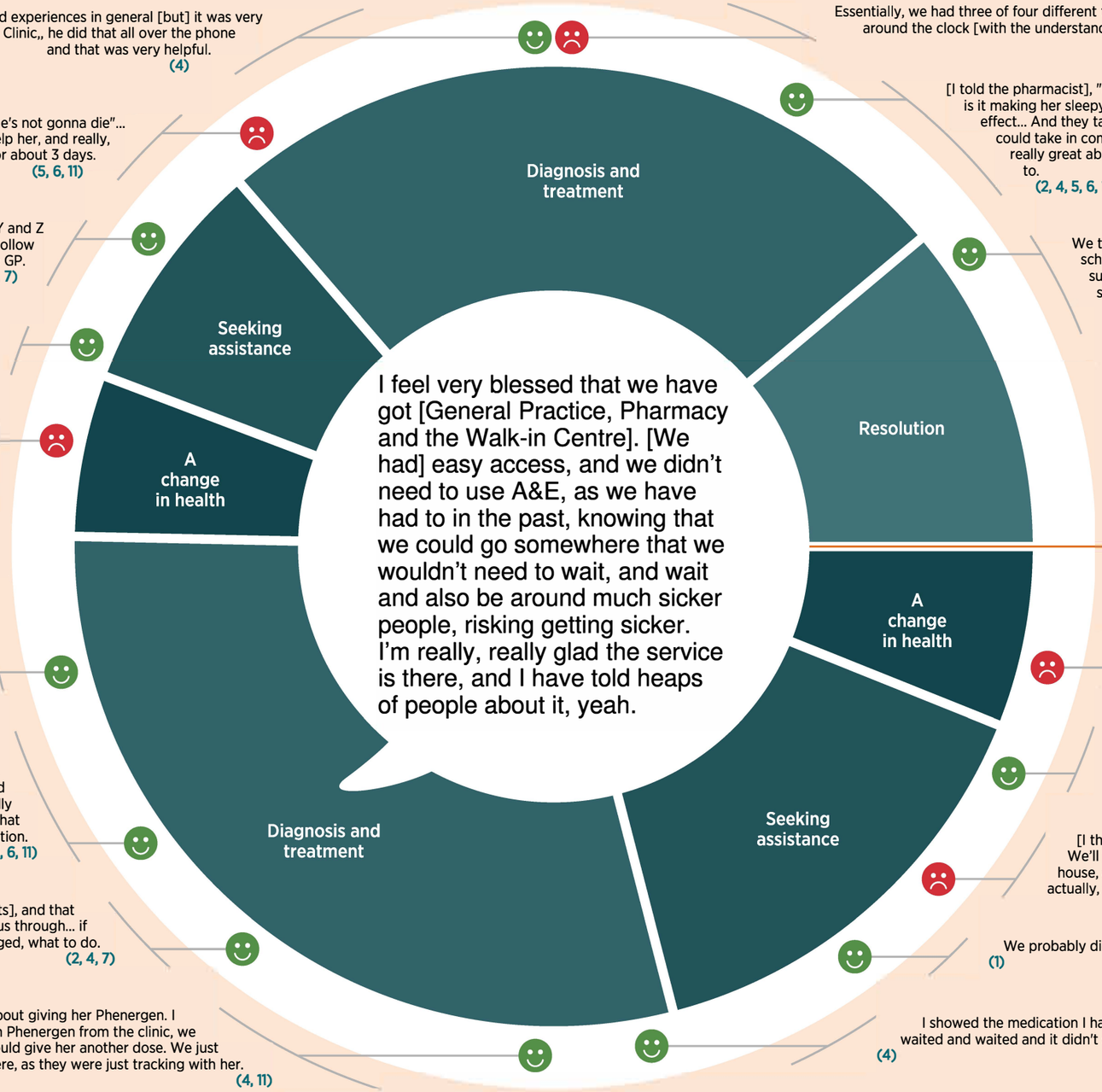
Well, a bit more comfy. (6)

Consumer Centred Care

1.	Access, equity and affordability	☹
4.	Appropriate care	☺
5.	Respectful care	☺☺
6.	Whole of person care	☺☺☺
7.	Coordinated care and supported transitions	☺☺

Participant K's daughter has attended a Walk-in Centre twice: once when her mother cut her finger badly, and more recently when she developed a painful rash.

Participant K - Walk-in Centre 2



In actual fact with the doctor, it isn't that we don't often have good experiences in general [but] it was very unpleasant that time.... When we rang to ask to get a referral to the Allergy Clinic,, he did that all over the phone and that was very helpful.
(4)

To be honest [the GP] was less helpful... He just quote unquote [said], "She's not gonna die"... That's a comfort, but they also didn't give us any instructions on how to help her, and really, [the advice] was, "Just wait for this to go [away]", so I did... for about 3 days.
(5, 6, 11)

They gave us instructions... I can't think exactly what it was, but, "If X, Y and Z happens, take her straight to Accident and Emergency... and..., you know, "Follow up with the GP the next day", which we did. We went to the GP.
(4, 7)

I think we rang Health First... [We thought], "We've just to to ride this out, in a way".
(4)

We actually had a horrible few days. Through the night, she was in heaps of pain, and [we gave] oatmeal baths... [At the Walk-in Centre] I said, "We were thinking, maybe we might [give oatmeal baths], and they said, "Look, we have heard that that can work", but I think... they were cautious about recommending it, if that makes sense. But [they said]... "Yes, we have heard people have done that as well".
(11)

It felt enormously comforting to know that the Walk-in Centre was there, and we didn't have to go to Accident and Emergency... In a funny way, [that] kind of enhances my sense of competence knowing I've got [the option of the Walk-in Centre].... [and that] I had done the right thing [going there]... [It had] a good impact on my sense of confidence.
(1, 4, 11)

At that stage, we were feeling really relieved, someone had seen it, and been calm with us, had helped us dose the medication that, you know, I wasn't sure of, and you know, my daughter has had good experiences there, and it was so sweet, that on the way out the nurse that had attended to me saw her, and chatted to her. She just felt important, so that was a really nice ending to leave... The subsequent few days were very difficult, but at that period she was feeling quite upbeat and you know, dosed up with medication.
(4, 5, 6, 11)

Her breathing wasn't at all problematic during the whole course [of events], and that was one of the other things that the [Walk-In] clinic [did], they had talked us through... if the breathing changed, what to do.
(2, 4, 7)

It was very relieving to be there at that time, cos I wasn't quite sure about giving her Phenergen. I woudn't have felt comfortable making that choice myself. She was given Phenergen from the clinic, we waited some more, it wasn't getting worse, and we were told when we could give her another dose. We just waited quite a while there, as they were just tracking with her.
(4, 11)

Essentially, we had three of four different types of antihistamines including Phenergen and we would both be sitting around the clock [with the understanding] that it would come back, [and we were giving oatmeal baths].

[I told the pharmacist], "Look, this is what's going on, and the Phenergen's not even holding it off, nor is it making her sleepy for periods of time, which we had thought... might be [a] beneficial side effect... And they talked me through two or three different things you could take, and what you could take in combination... And becuase I said I was tired, we wrote it down. They were really great about helping me to write it down, so that I could actually have it to refer back to.
(2, 4, 5, 6, 11)

We thought it was a rash [caused] maybe by a plant that she had touched at school, but we actually still don't know, and never has it happened again. We subsequently found out that that there is a particular type of plan that in sunlight, does a similar thing. So it's possible that it was just this freaky combination of stuff.
(4)

I got a call from my partner saying that [my daughter had] come home from school, and she had a bit of a rash. My partner called me at three, and then at five, it had spread to her torso. She sent a photo to me of her torso... and I grabbed some antihistamines from the Chemist... and came home. By the time I had gotten home, about five thirty, it had also started down her legs. So, I said, "Actually, I'm not giving her antihistamines, let's get her to the Walk-in Centre, I want them to see this". So, we there straight away.

[I said to the pharmacist], "Look, this is what's going on, what do you think would be best?" ...I can't even think what it was, but it was like Clarantyne or something like that.
(4)

[I thought], you know, "I'll go home and give her this and things will calm down. We'll probably watch a movie and just chill". But then when I walked into the house, and had seen how much further it had spread over her body, it was just like, actually, this is not – something's not right here.

We probably did wait a little bit longer [to be seen] that time, but less than fifteen minutes
(1)

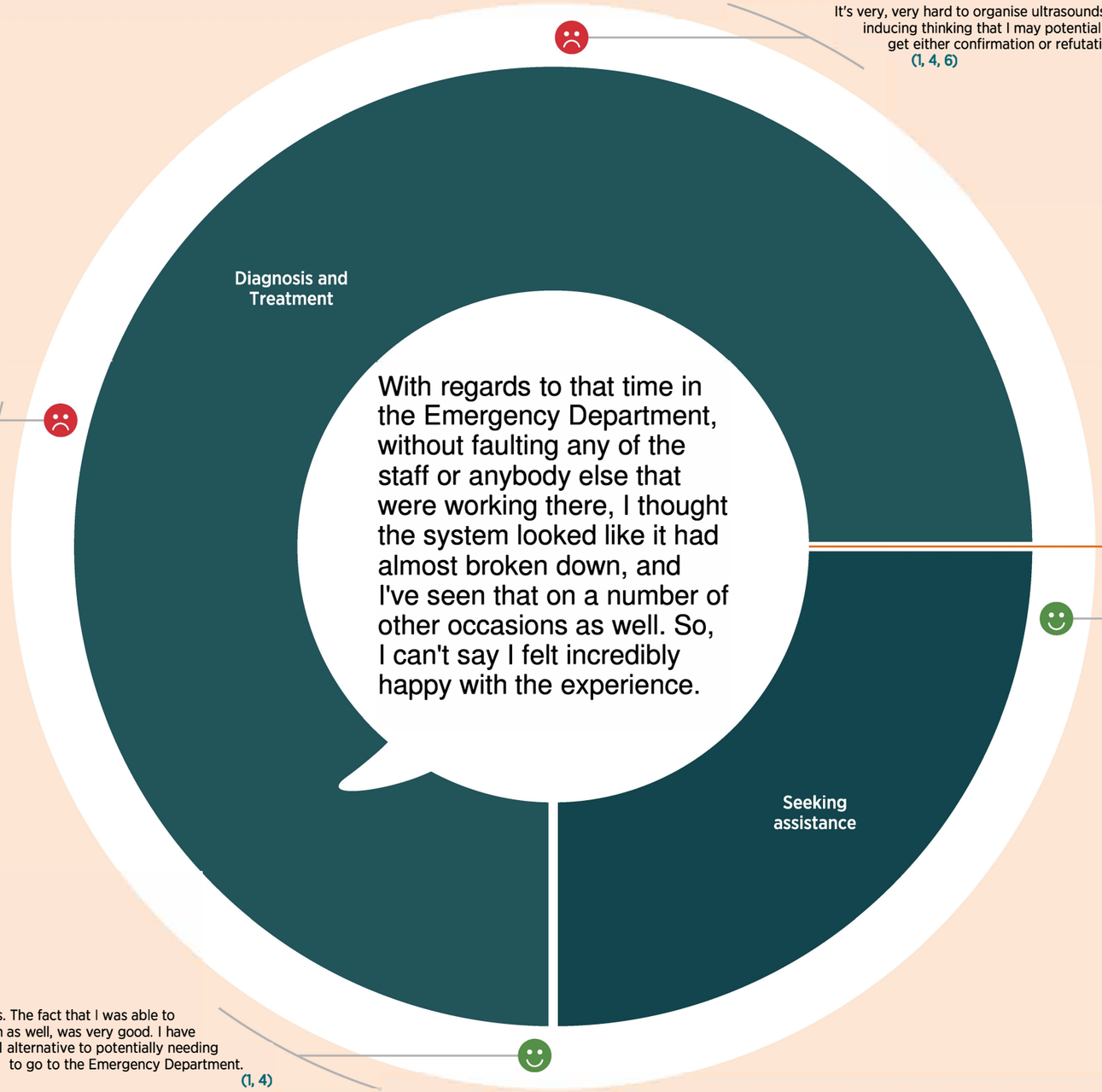
I showed the medication I had bought, and they said, "Okay, yep, let's give her a dose". After that, we waited and waited and it didn't seem to have an impact, and so she was given some Phenergen.
(4)

Consumer Centred Care

1.	Access, equity and affordability	☺☺
2.	Information and understanding	☺☺
4.	Appropriate care	☺ × 11
5.	Respectful care	☺☹☺
6.	Whole of person care	☺☹☺

Participant K's young daughter developed a rash while at school. Her parents used the Walk-in Centre, a pharmacy and a GP.

Participant L - CALMS



It's very, very hard to organise ultrasounds unless it's during a particular set of hours. In my case it was quite anxiety inducing thinking that I may potentially have a clot or DVT but not be able to do anything about that, and actually get either confirmation or refutation of that until working hours on Monday, at the earliest.
(1, 4, 6)

One frustration was, that it would've been, I guess for my anxiety levels if nothing else, it would've been good if I could've been able to get a scan over the course of the weekend.
(1, 4, 6)

I rang CALMS and discovered that there was actually a clinic available in Tuggeranong on Saturday afternoons, so I managed to make an appointment and I was actually able to see a doctor within a space of about three quarters of an hour, which was extremely helpful.
(1, 4)

I thought the care that I received was reasonable under the circumstances. The fact that I was able to be seen fairly promptly in a convenient manner, and in a convenient location as well, was very good. I have made use of CALMS in the past and I've found that to be a very, very helpful alternative to potentially needing to go to the Emergency Department.
(1, 4)

Consumer Centred Care

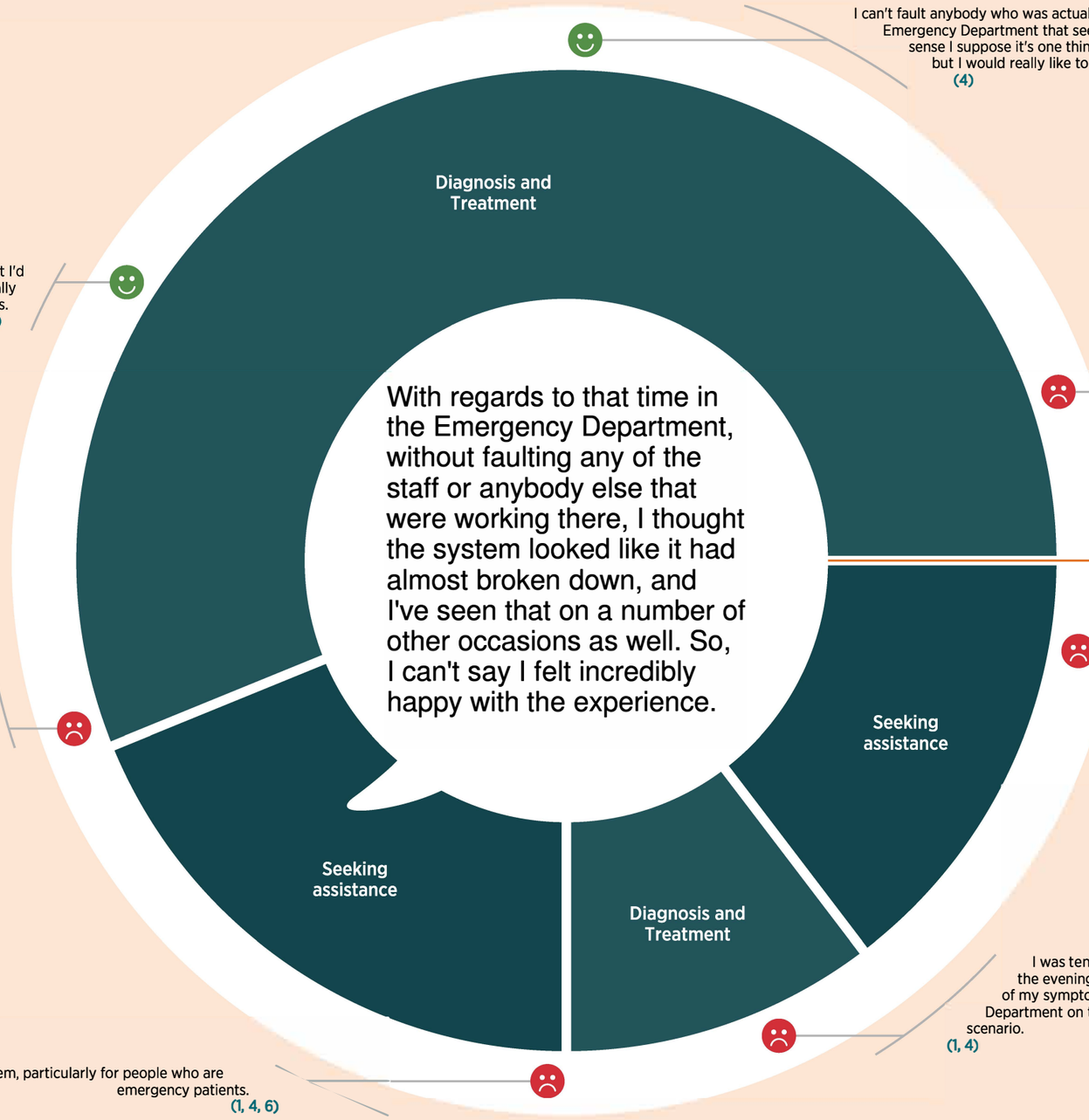
1.	Access, equity and affordability	☺☺☹☹
4.	Appropriate care	☺☺☹☹
6.	Whole of person care	☹☹

Participant L recently attended both CALMS and the Canberra Hospital Emergency Department to diagnose and treat a blood clot in his leg which occurred after surgery.

Participant L - Emergency department

I can't fault anybody who was actually working in the Department at the time, but I get the strong sense of an Emergency Department that seems to be poorly funded and certainly chronically understaffed, and so in that sense I suppose it's one thing to say, well, the Department does its job, it stops people from necessarily dying, but I would really like to see more thought to be given to the quality of the user experience as well.
(4)

[The doctor] made arrangements such that I was able to get a scan that I'd actually already arranged for the following day, he was able to basically organise for me to have a scan done on both legs.
(1, 4)



With regards to that time in the Emergency Department, without faulting any of the staff or anybody else that were working there, I thought the system looked like it had almost broken down, and I've seen that on a number of other occasions as well. So, I can't say I felt incredibly happy with the experience.
(4)

It was a bit of a disaster when I was there, in that it was almost two and a half hours before I was seen in spite of the fact that I had mentioned that I did have some chest pain and the fact that I'd also said that I'd been diagnosed with a very large clot in my leg just earlier in the day.
(1, 4)

It was hard to get information about where I was, and I understand that in the end it's not a hotel. They are there to try and treat people who are sick in some order of precedence and priority, but having said that I spent most of the time there feeling quite anxious that I was going to get a bug that might make things worse, and so in the end I ended up putting a mask on that was provided there not to protect anybody else, but in an attempt to try and protect myself.
(2, 6)

I was tended to by nurses who took observations and the like, but I got in at around 7.30 in the evening and it was actually around 2.00am before I was actually seen by a doctor, in spite of my symptoms, and again I just got the sense that it was quite out of control in the Emergency Department on that evening, as it often is when I've been in there, but that was a particularly bad scenario.
(1, 4)

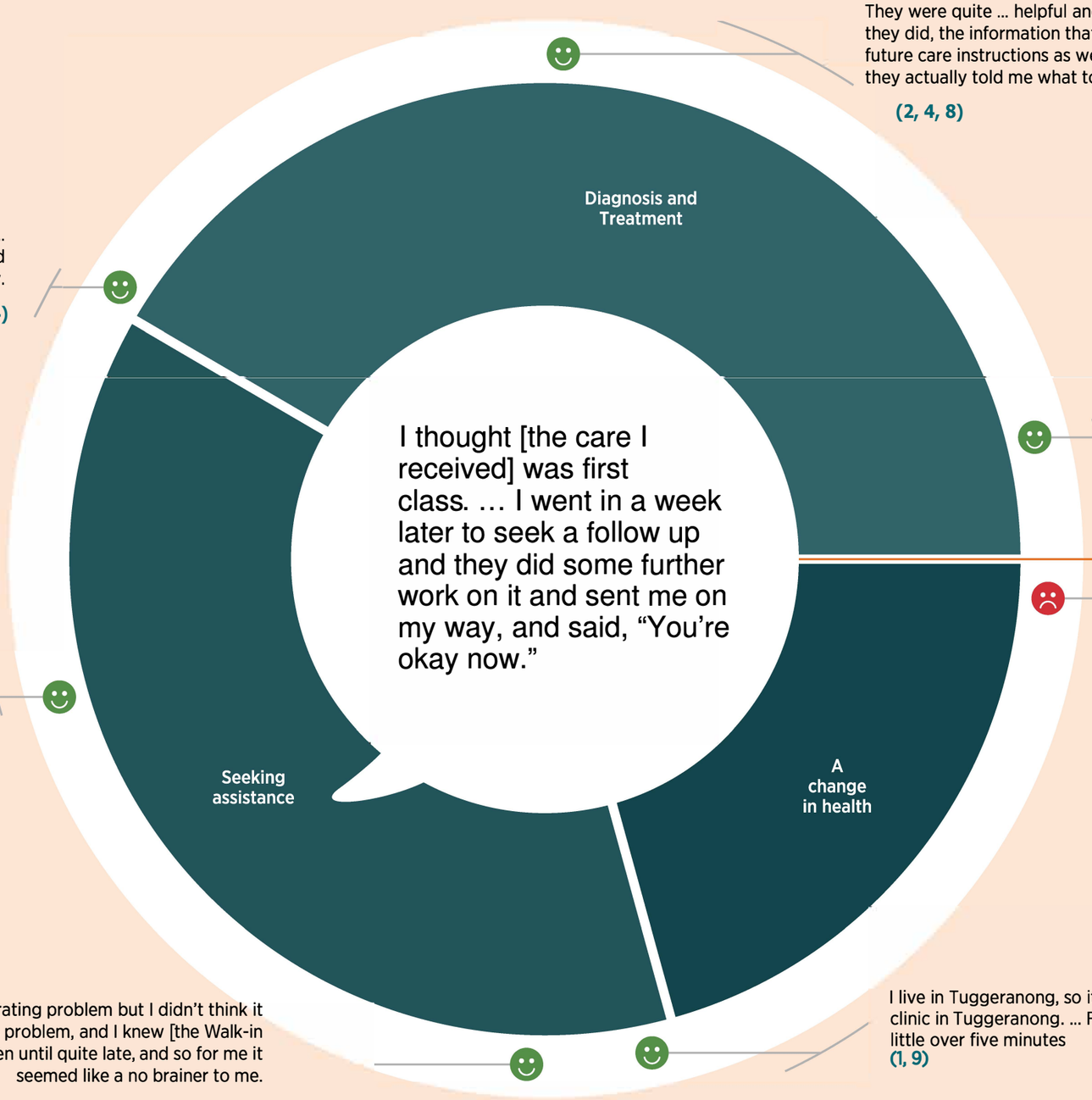
Parking was a problem. Parking at Canberra Hospital is a very major problem, particularly for people who are emergency patients.
(1, 4, 6)

Consumer Centred Care

1.	Access, equity and affordability	☹ ☹ ☹ ☺
2.	Information and understanding	☹
4.	Appropriate care	☺ × 2 ☹ × 4
6.	Whole of person care	☹ ☹

Participant L underwent a scan that suggested a large clot was present in his leg. After suffering leg and chest pain that evening, he attended the Canberra Hospital Emergency Department, where he waited more than two hours to be seen

Participant L - Walk-in Centre



They were quite … helpful and quite reassuring in terms of … what they did, the information that they provided. And, what’s more, future care instructions as well. So, they didn’t just leave me there, they actually told me what to do going further forward.

(2, 4, 8)

It was actually terrific to have two nurses there … and they both worked together as a team, and they got me fixed up quite quickly.

(4)

They reassured me that there wasn’t a major problem but they basically disinfected the wound, gave me a tetanus shot because I’d been exposed to some yucky stuff when I’d taken the skin off … and then carefully wrapped my finger in some packing.

(2, 4, 8)

I was fixing one of my children’s toys when … I accidentally took most of the skin off my finger. It was a frustrating problem but I didn’t think it was a terribly serious problem.

It was actually good to have that option rather than incur … the time and the cost … of potentially having to go and see a doctor to get it looked at.

(1, 9)

In the end, it was a frustrating problem but I didn’t think it was a terribly serious problem, and I knew [the Walk-in Centre] would still be open until quite late, and so for me it seemed like a no brainer to me.

(1, 4, 9)

I live in Tuggeranong, so it was convenient to get to the walk-in clinic in Tuggeranong. … From leaving home, I was there in a little over five minutes

(1, 9)

Consumer Centred Care

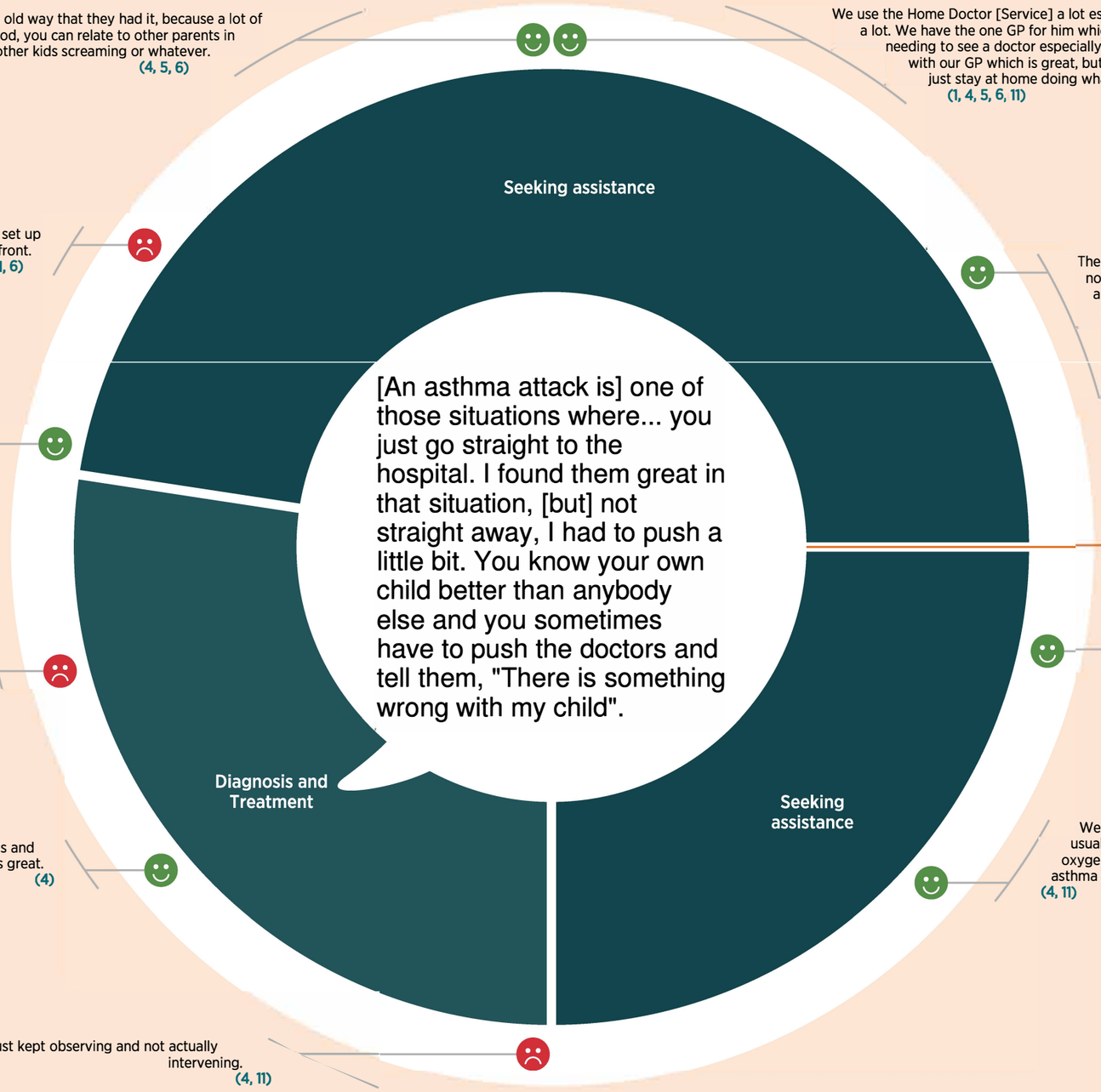
1.	Access, equity and affordability	☺☺☺
2.	Information and understanding	☺
4.	Appropriate care	☺☺
8.	Safety and quality	☺
9.	Control and choice	☺☺☺

Participant L needed a wound dressed on a Sunday evening and went to a Walk-in Centre.

Participant M - Emergency department

I find the new paediatric waiting room is so much better than waiting in the old way that they had it, because a lot of other people get annoyed with kids being in the wait-room and it's just good, you can relate to other parents in the wait-room who aren't getting annoyed at other kids screaming or whatever.
(4, 5, 6)

We use the Home Doctor [Service] a lot especially with one of our sons with autism. He doesn't like to leave the house a lot. We have the one GP for him which he loves but when we can't get into see his GP, it makes it difficult when needing to see a doctor especially when he is reluctant to see anybody else when he such a good relationship with our GP which is great, but when you need to see a doctor, we call the Home Doctor because he can just stay at home doing whatever, playing the iPad or whatever and then the doctor comes.
(1, 4, 5, 6, 11)



I think it is quite difficult for anybody with the way Canberra Hospital is set up having to walk so far from the multi-storey car park down the front.
(1, 6)

There is no interruption to the routine. It's just a quick ten, fifteen minutes like a normal consult but you're at home. [I can say to my son], "It's okay, sit here for a minute, let the doctor check you, okay no worries go back to what you are doing", and then I can just chat to the doctor about what's going on which is great for parents of kids with autism because they can just keep doing what they are doing and not having melt downs at a new doctor that they have never met before or new doctors not understanding all their sensory needs and everything like that. It's just so much easier to do it that way.
(1, 4, 5, 6, 11)

I have a disability parking permit so that makes things a lot easier when you are going to Emergency. So, I can park right out the front.
(1, 4, 5, 6)

We went to Emergency and that's one of those situations where you don't think about where you are going, you just go straight to the hospital. I found them great in that situation, [but] not straight away, I had to push a little bit but, you know, your own child better than anybody else and you sometimes have to push the doctors and tell them, "There is something wrong with my child."
(1, 4)

But before [the steroids were administered], it was just me having to basically treat my own child like I should have just stayed at home. Like obviously I wouldn't have, but it just kind of feels like that.
(4, 11)

Finally they called another doctor and came over and gave him the steroids and then everything was fine. The next doctor was great.
(4)

We have been [to the Emergency Department] a couple of times [before] and usually they have been a lot better. A lot more proactive. Obviously giving him oxygen or steroids and everything straight away. We always go to Emergency for asthma though.
(4, 11)

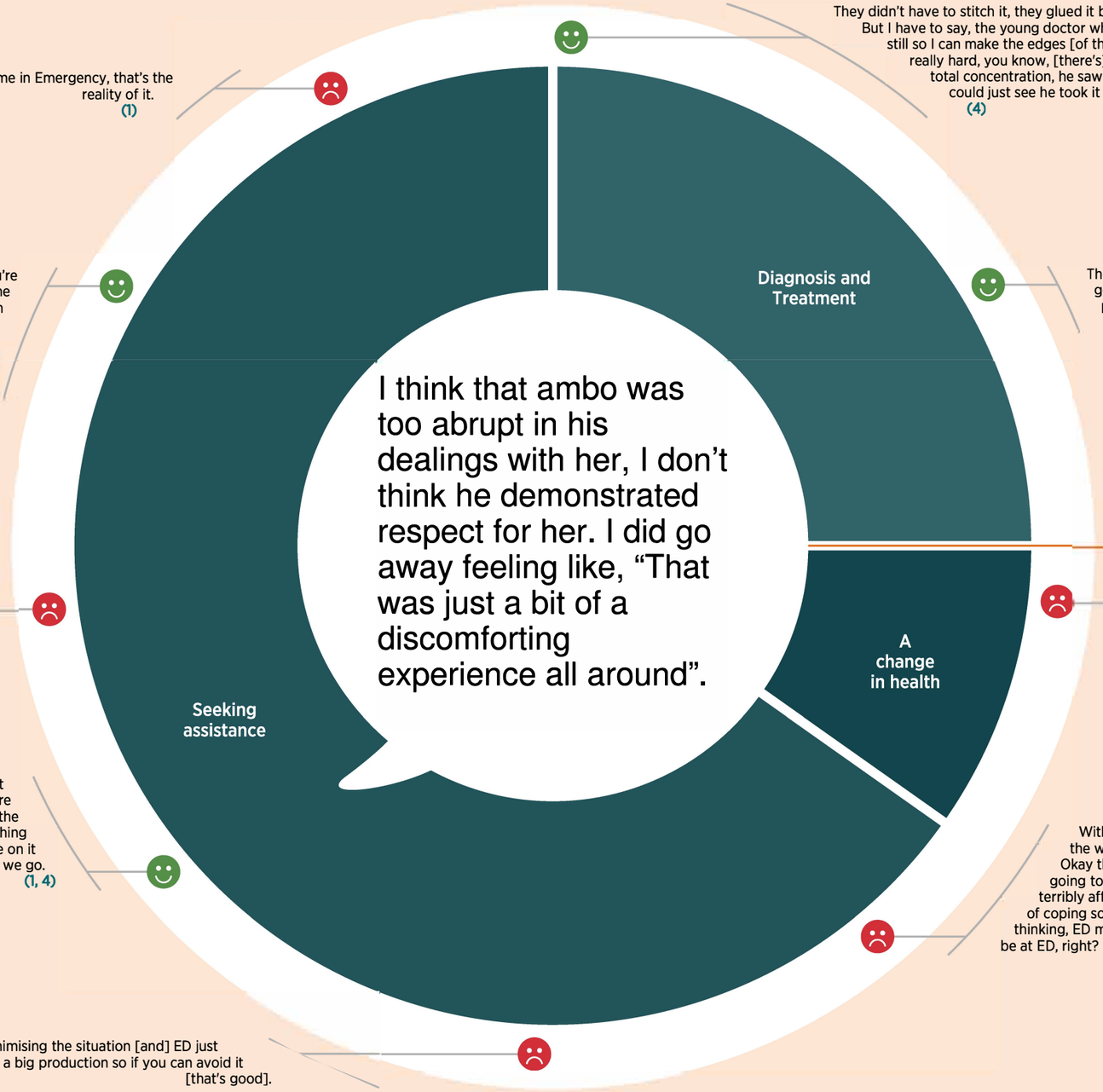
I was a bit annoyed because I kept giving him the Ventolin and they just kept observing and not actually intervening.
(4, 11)

Consumer Centred Care

1.	Access, equity and affordability	😊😊☹😊😊
4.	Appropriate care	😊 × 7 ☹ × 2
5.	Respectful care	😊😊😊😊
6.	Whole of person care	😊☹😊😊😊
11.	Carers and support	😊☹☹😊😊

Participant M is in her 20s and her husband is her full-time carer as she has fibromyalgia. They have two sons, the youngest son is on the autism spectrum and the older one suffers from asthma. On this occasion she is talking about an asthma attack that required them to attend the Canberra Hospital Emergency Department.

Participant O - Walk-in Centre and emergency department



We waited for a very, very, very, very long time, it's just you wait a long time in Emergency, that's the reality of it.
(1)

They didn't have to stitch it, they glued it but even the glue, oh it was really hard for her. Oh yeah, it wasn't nice at all. But I have to say, the young doctor who saw her was absolutely brilliant. [He said], "You have to hold her perfectly still so I can make the edges [of the cut] meet exactly right, so she cannot move a millimetre". [That's] actually really hard, you know, [there's] the poor wailing, hyperventilating child, you know. [He did his job with] total concentration, he saw nothing in the whole universe except that cut that he had to fix and you could just see he took it so seriously.
(4)

But also, the nurse kind of took one look at the two of us and was like, "You're going to Emergency". She knew and I kind of didn't until... I went through the doors, [then] I kind of could see myself through the eyes of a health professional, I was like, "Oh yeah, there actually, there is a bit of blood on the two of us, we look like we're in a bit of a state really don't we?" ...This nurse kind of really sized me up and was like, "Okay, you need to go to Emergency, can you do that?" and I was like, "Yes, I can, I can do that".
(2, 4)

There's never a good experience when you have to go to Emergency but she got the care she needed... They were perfectly well-equipped to handle the problem that I took in for them to solve.
(4)

What I had forgotten actually [was she was under two]... and I did know from past experience that they won't see kids under two and the nurse who was on was like, "No we can't, no, if she's not two, we can't see her".
(1)

[My daughter] was 18 months, a bit older maybe. We were at a friend's house and she tumbled forward and hit the sharp corner of a glass coffee table just above her eyebrow and there was quite a bit of blood but not for very long.

I thought, "Okay, well we'll go to the Walk-in Centre, we'll go to that because if it's got to be ED, they'll say go to ED and then you know you're going where you need to go and hopefully they can do something [at the Walk-in Centre". I really kind of was hoping that they could do something there... I thought that might be possible, like, maybe they can put some tape on it at the Walk-in Centre, and away we go.
(1, 4)

With hindsight I like went pretty much directly into a state of shock and I think the way I coped was to be, "Okay, I think she's alright. Okay, stop the bleeding. Okay the bleeding has stopped, the wound is pretty clean. Okay, she's just now going to sit on my lap". Then she sat on my lap then and ate a potato so she wasn't terribly affected by it, it just kind of looked a bit nasty and just because she was kind of coping so well I thought, "Oh well, maybe ED would be overkill". That was my thinking, ED might be overkill and you don't want to turn up at ED when you don't need to be at ED, right?

I don't know quite what the logic in my mind was, maybe I was sort of minimising the situation [and] ED just felt like a big palaver too, hours of waiting and then doctors and it's just a big production so if you can avoid it [that's good].

Consumer Centred Care

1.	Access, equity and affordability	☺☹☹
2.	Information and understanding	☺
4.	Appropriate care	☺☺☺☺

Participant O has recently gone to both the Belconnen Walk-in Centre and the Calvary Public Hospital Emergency Department after her daughter had a cut on her head.