

WHAKARONGO MAI LISTEN TO ME

Adolescent & Young Adult Experiences of Cancer Care and Support in Aotearoa New Zealand

Results and Analysis of the
2018 Patient Experience Survey



FULL REPORT

DEDICATION-TŪTURU

This report is dedicated to all the young people who participated in this survey.

*These are your words,
these are your results,
these are your findings.*

*Through sharing your stories
you enable us to learn, grow and
improve cancer care and services
for adolescents and young adults
in Aotearoa New Zealand.*

Hapaitia te ara tika pūmau ai te
rangtiratanga mo ngā uri whakatipu.

Foster the pathway of knowledge to strength,
independence and growth for future generations.

Whakatauki gifted by Jayden Pattison
(AYA Advisory Group Member)

*"I have a story to tell!
We all have a story to tell!"*

Paul

*"The Network wants to
ensure that they aren't
just assuming what we as
cancer patients are feeling
and needing"*

Jayden

*"We've been given a
platform to have a say,
to let our voices be heard,
not just for ourselves but
for those who are no longer
here. We want to be part of
a generation that is going
to make a change"*

Esther

*"I want my experience to be
more than just me, I want
to change cancer care for
the next generation"*

Jo

*"I hope that the change that
will come from the survey
will make a significant
impact to improving the
experience of young people
facing cancer"*

Paul



Introduction- Whakatūwheratanga

In Aotearoa New Zealand every year approximately 200 individuals aged 12 to 24 years are told that they have cancer. People in this age group are classified as Adolescents and Young Adults (AYAs).

It is widely recognised that the AYA cancer population have distinct and unique developmental needs that can only be met through care that is high quality, multidisciplinary and age appropriate. In New Zealand the expected standard of AYA cancer care is outlined in the AYA Cancer Network Aotearoa *Standards of Care* (2016).

In 2018 two hundred young New Zealanders who have received or are receiving cancer treatment participated in a national survey about their experiences of cancer care and services. This report presents these findings and explores whether the young people's perspectives reflects the level of care described in the 2016 AYA cancer *Standards of Care*.

Whakarongo Mai: Listen to Me reports these findings to help identify strengths in care delivery, areas for improvement and inequities. The results will contribute to and inform the development of a five-year national strategy for AYA cancer care in New Zealand. This strategy will include a proposed model of care that ensures young people diagnosed with cancer have equitable access to high-quality medical and supportive care regardless of their ethnicity, where they live or their age.

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Background to the survey

Aims of the study

To explore through a patient experience survey whether Adolescents and Young Adults (AYAs) with cancer in New Zealand receive the care described in the 2016 AYA Cancer Network Aotearoa *Standards of Care*.

Objectives

- Empower AYAs with cancer to voice their views on the care and services they receive as measured by the Standards of Care.
- Determine whether the standards of care are being met as described in the Standards of Care document.
- Determine whether there are variations by geographical location, age, and/or ethnicity in the cancer care and services experienced by AYAs with cancer.

Methodology

The survey was created with input from two focus groups: one with a mix of 16-32 year olds and one specifically for Māori and Pacific AYAs.

The survey was open to young people over the age of 16 years, who had been diagnosed between the ages of 12 and 30 years and had received care any time since 2015, including those still receiving care. All participants needed to give their consent to participate and all answers were anonymous.

The survey was delivered online and was open for 3 months (August-October 2018).

Promotion and recruitment occurred through social media platforms, consumer-designed

posters, cancer focused Non-Government Organisations and the 7 regional AYA Keyworkers.

Participants

Two hundred young people between the ages of 16 and 32 years participated in the survey. The participants included those diagnosed between 12 and 24 years - AYAs (n=170), and those diagnosed between 25 and 30 years - older young adults (n=30).

The AYA Cancer Network is committed to understanding and addressing existing inequities in health care delivery within the AYA population, including the poorer survival outcomes identified for Pacific and Māori young people. Consequently there was a strong focus on ensuring their voice was well represented – of our 200 participants, 24% identified as Māori and 8.5% identified as Pacific ethnicity.

The young people who participated also represented a diverse population in relation to disease, age and living location

with a population of over 35 cancer diagnoses, living across 40 different locations throughout Aotearoa. Capturing the diverse voice of our young people is essential to understanding how to deliver an equitable health care service that reflects their experiences and knowledge of AYA cancer care.

Report user guide

AYA Voice

All quotes have been left verbatim to ensure the young people's authentic voice remains. The only exception to this is where a person could be identified in a quote, we have removed any identifiers and used [] square brackets to indicate this.

Percentages

Percentages are given in whole numbers and as a result, totals will range from **99-101%**.

Definitions

Refer to pages 57-58 for definitions of the terms used in this report.





BEFORE DIAGNOSIS

- I MUA I TE WHAKATAU I TŌ MATE

Realising something is wrong ... Is it cancer?

Evidence suggests healthy young people have low levels of AYA cancer awareness.

Below is an example of the range of cancer signs and symptoms experienced by the young people that participated in the survey.

51%
extreme
tiredness/
fatigue

39%
lump or
swelling

38%
pain for no
apparent
reason

29%
headaches

24%
sweating at
night

23%
vomiting
and/or nausea

22%
losing weight
without dieting

22%
swollen/
enlarged lymph
nodes

21%
fever

20%
feeling dizzy

13%
limping/
difficulty with
walking

12%
loss of vision

12%
bruising or
bleeding for
no apparent
reason

10%
or less
noted these
symptoms:
persistent
cough/
hoarseness;
rash/itching;
change in
periods; sores
that didn't
heal; repeated
infections;
seizures; or
change in the
size, colour or
appearance of
a mole.

Over half
of young people
experienced
extreme tiredness
or fatigue as a
symptom

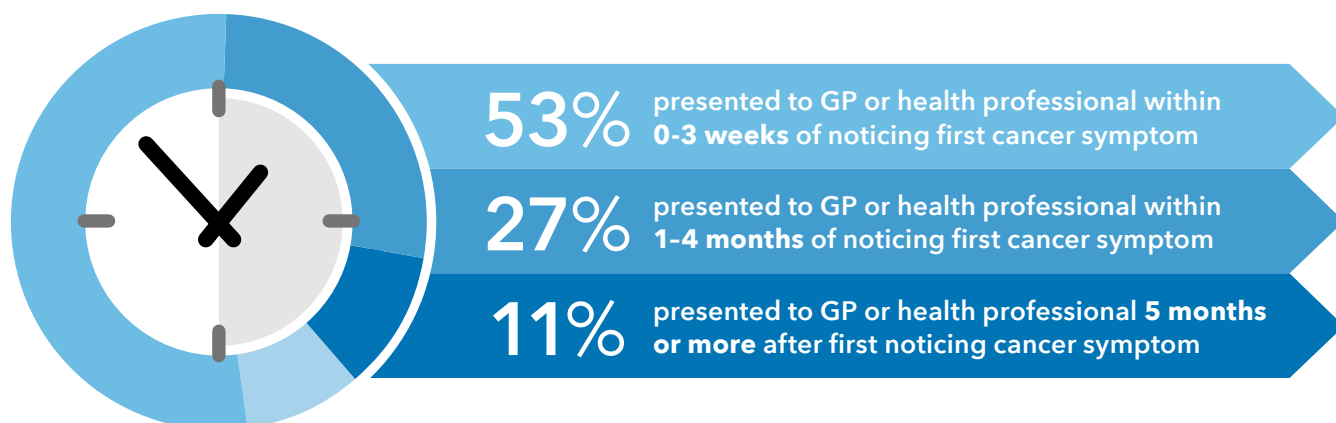
'I was living a normal life, living the same life as my friends. I had a pretty good base line health and had no history of leukaemia in my family so it was very out of the blue.'

Signs and symptoms of AYA cancers can be overlooked as most on their own are non-cancer-specific and can often be attributed to something other than cancer.

Cancer is rare in adolescents and young people: making up less than 1% of all cancers diagnosed in NZ annually. This rarity can mean both young people and health professionals might not initially consider cancer as a possibility. Signs and symptoms of AYA cancers can be overlooked as most on their own are non-cancer-specific and can often be attributed to something other than cancer.

'I was working two jobs, one of which was at a petrol station. Rashes from spilled petrol and fatigue from working two jobs was common and provided cover for the symptoms of my cancer.'

GRAPH 1 | Length of time between noticing a symptom and going to a GP/Health professional

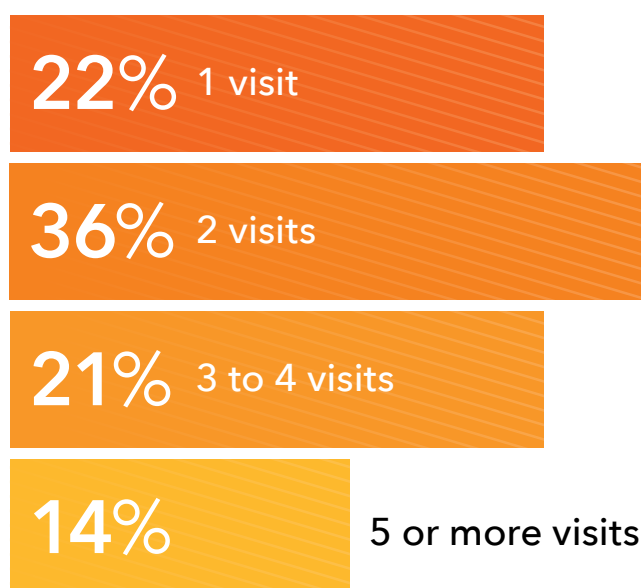


Over half of the young people surveyed presented to their General Practitioner (GP) or to a health professional within 3 weeks of noticing their first cancer symptom, just over a quarter of young people took 1-4 months and **11%** waited more than 5 months to present once a symptom was noticed.

The number of visits an AYA made to a GP/health professional before gaining a referral to a hospital or specialist ranged from 1 visit (22%) to 5 or more visits (14%).

The majority of young people (58%) were referred to a specialist/hospital after 1-2 visits to a GP or health professional.

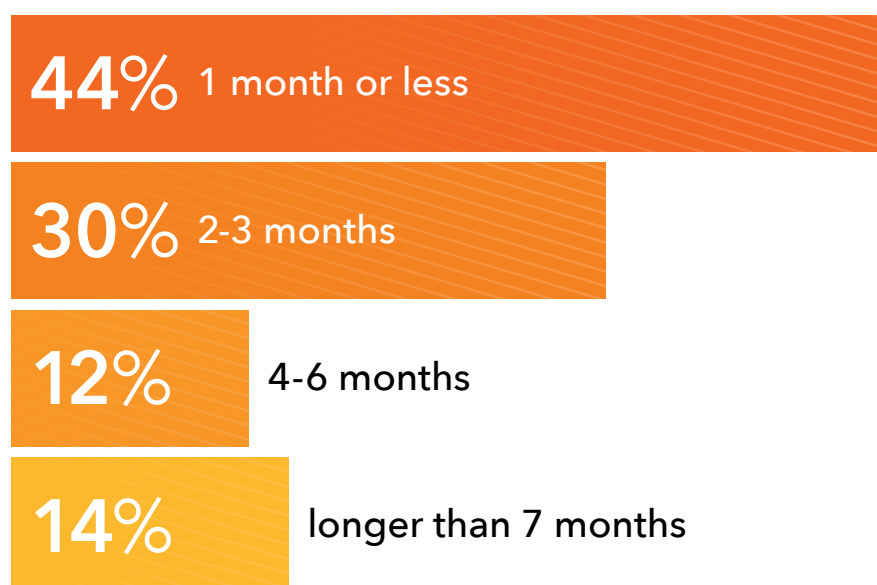
GRAPH 2 | Number of visits to a GP/Health professional before a referral is made



The number of visits to a GP or health professional is one way to illustrate time to referral. Also important is over what time period those visits took place. For those surveyed, **44%** were referred within a month of presenting with a symptom, while **26%** were referred after visits spanning 4 months or more.

'I don't feel that the private paediatrician that I saw took me seriously and I feel that I could have been diagnosed much earlier if he had listened properly.'

GRAPH 3 | Period over which visits to a GP/Health professional occurred before a referral was made



Every young person has their own story about how they found out they might have cancer.

These stories from AYAs, and the findings about the number of visits to a GP or health professional before referral indicate that many young people have had to persevere in order to be listened to, have their symptoms investigated further, and gain a referral for further testing.

'I spent a bit more than six months visiting the GP over a dozen times before I was finally referred for an ultra sound and then diagnosed.'

‘The doctor I originally got assigned was rude & tried to send me away without doing further testing.’

‘The first lump appeared 3 years before diagnosis. Not picked up by fine needle biopsy. Not offered surgery. Told no cancerous cells were found (later told that fine needle would not pick up hodgkin’s). Told not to worry but to keep an eye on it ... two more lumps had popped up next to first lump.’

‘It was picked up by midwife during routine bloods, if she hadn’t been persistent with the GP for a referral to haematology on platelet count rise we may have lost myself and baby...’

‘When I was first sent to the hospital I had blood tests taken and then sent home without any clear details as to when my next appointment was because they were not sure where to place me within the hospital as I had not yet been officially diagnosed with anything. My father went to the hospital every day to try and follow up where my next step would be and we eventually got a next appointment because of this.’



BEFORE STARTING TREATMENT

- I MUA ATU I TE TIMATANGA HEI ŌRANGA MŌU

What's the plan?

All AYA cancer patients should have a documented treatment plan that adheres to best practice recommendations. This includes the most appropriate expertise, the most appropriate treatment environment and the most appropriate psychosocial care.

Before commencing treatment **59%** of young people reported receiving a detailed written treatment plan that included information on the types of treatment they would receive and information for each step of their treatment phase.

Only **59%** reported receiving a detailed written treatment plan before commencing treatment

'The amount of information the staff gave us about my case and the plans was excellent.'

Clinical Trials

Gains in cancer survival rates over the past 20 years have not been as marked in the AYA cancer population as they have been in the paediatric and adult cancer populations. Poor clinical trial enrolment rates are cited as a reason for this.

Twenty-three percent of young people identified that as part of their treatment plan they were **offered enrolment** onto a clinical trial. Only **17%** of young people **enrolled** in a clinical trial, **4%** declined to participate and **2%** withdrew once they had entered the trial.

Only **17%** of young people enrolled in a clinical trial

Eighteen percent of young people reported that they **didn't know or couldn't remember**. It should be noted that these patient reported findings do not correlate with previously published literature which has found only 5% of AYAs in NZ have been enrolled onto trials.

Kids? Me?

Adolescents and young adults place information about their future fertility as a priority, yet they are often dissatisfied with how health providers address the topic.

Reassuringly **90%** of young people in the survey can recall having a conversation with a cancer health professional before starting their first cancer treatment about the possible effects of treatment on their fertility.

However only **59%** were offered the opportunity to see a fertility specialist for a consult prior to starting treatment (57% female and 65% male).

'I had to demand a fertility appointment, I was not offered this. I had to push for it.'

90% of young people recalled having a conversation with a health professional about the possible impacts of treatment on fertility

Only **57%** of females and **65%** of males were offered the opportunity to meet with a fertility specialist prior to starting treatment

Many young people describe the prospect of therapy-related infertility to be as distressing as the cancer diagnosis.

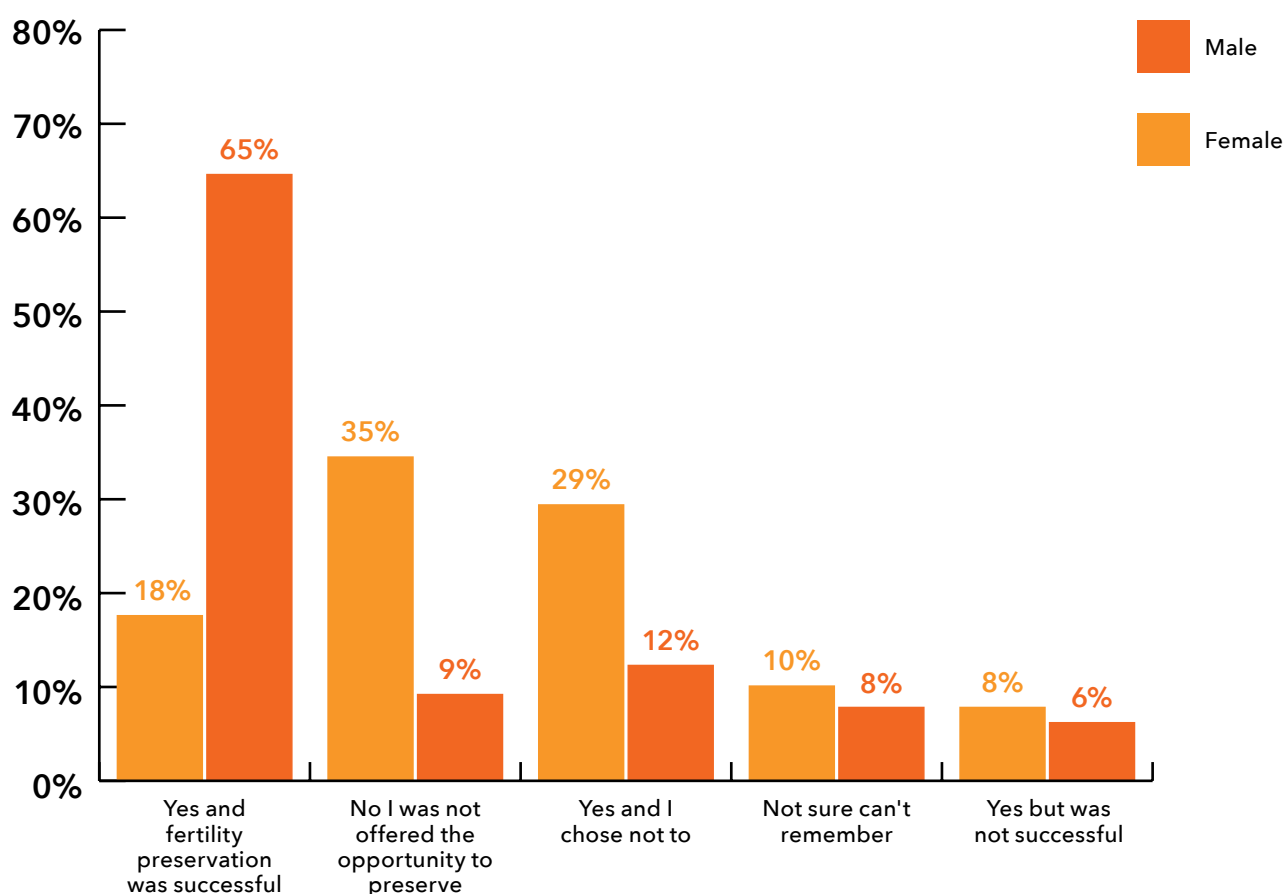
Sixty five percent of young people were offered the opportunity to preserve their fertility by freezing their eggs, embryos, ovarian tissue or sperm. Thirty five percent successfully preserved their fertility, while 22% were offered the opportunity but chose not to and 8% were unsuccessful despite

trying. This differed between males and females as shown in graph 4.

There were a small number of people who identified as gender diverse answering the survey. The numbers are small and therefore have not been graphed but it is important to note that none of the gender diverse young people were offered the opportunity to meet with a fertility specialist prior to starting treatment.

Only 35% of all young people successfully preserved their fertility prior to starting treatment

GRAPH 4 | Fertility preservation opportunity and success (male and female)



Fertility risks and any appropriate options for fertility preservation should be discussed with AYAs and/or whānau regardless of the person's age, prognosis, treatment plan, perceived level of risk to fertility, sexual orientation or relationship status.

'My risk was not high enough for fertility preservation, but that wasn't the point. It was still a risk! that upset me..... THE RISK WAS NOT TRUE.'

'During fertility treatment as a gay person I was denied the opportunity to leave my sperm to my partner as they were not a female.'

Having those difficult or private conversations

Hearing “you have cancer”

Many AYA cancer patients are reliant on their whānau and/or partner during treatment for practical, emotional and financial support.

Two thirds of young people surveyed identified **always** having

their whānau or significant person with them at the time of being delivered important information and a quarter of young people said they were with them **some of the time**. Sadly **6%** said they were **not present** at the time of important information being delivered and had wanted them to be there.

66% of young people always had whānau or a significant person with them when important information was given

‘My family was with me for 6+ hours before they went back to the motel to have a shower and get some food, and it was at that time the doc came in and told me I had cancer.’

‘I was told I had cancer by myself despite all of my family being around the corner, the doctor just walked in closed the curtain and told me even though he knew my entire family was there and had seen them around me constantly.’

Being treated for cancer. Will it work?

Health care providers can feel uncomfortable and under skilled in discussing issues around survival with young people. Evidence suggests that young people are comfortable in talking about these issues and a lack of conversation can in fact create a sense of isolation, fear and anxiety.

Thirty two percent of young people currently undergoing treatment had not discussed what would happen if their treatment was not successful with their health professional. They indicated they would like the opportunity to talk about this and to ask questions. Fifty percent of those who identified that **no more treatment is possible to cure my cancer** reported that they had not had the opportunity to talk about this and would have liked this opportunity.

32% of young people currently undergoing treatment had not been given the opportunity to discuss what would happen if their treatment was unsuccessful and would like this opportunity

‘Sometimes I wouldn’t like my family in the room with me, but can’t ask them to leave as they would get extremely upset with me later on.’

‘When they brought up the fertility thing my parents were there with me. As it’s an awkward topic to talk about in front of your parents I didn’t pursue that conversation much. It hasn’t made a difference to me since I’m not looking to have kids. But it might be better to discuss things of that nature privately if it makes people more comfortable.’

‘No private cubicles in the treatment area, so consultations with Drs are often held in front of other patients. (Not meaning private appointments, but follow ups from the drs whilst getting blood transfusions, etc).’

‘The staff mis-assumed my gender (probably from my out-of-date name stored in the hospital records), and my age in preparation to the meeting and found it quite a surprise (and a bit awkward) when that staff saw me.’

‘Just pronouncing my name correctly, although they meet new people every day it’ll still be nice.’

Need my space and a place to ask

While AYA may appreciate having whānau and support people present when important information is delivered, providers also need to ensure all AYA patients are offered the opportunity to meet with them alone on a regular basis.

Assuring confidentiality and privacy is an important aspect to develop a sense of trust and rapport between young people and health providers.

Reassuringly **81%** of young people were **sometimes** or **often** given the opportunity to speak with their health professionals alone about their cancer experience or treatment without their whānau, partner or support person being in the room.

My identity being respected

There are differences between young people in regards to their identity, including religious beliefs, sexual orientation, culture and ethnicity.

Encouragingly, **94%** of young people felt their identity was respected and taken into consideration in the planning of their care and support. However, some of the comments here provide an indication of where this was not the case.



DURING TREATMENT

- I WAENGANUI I TE TITIRO E PĒHEA ANA TŌU ŌRANGA

Putting me at the centre of my care

Adolescent and young adult cancer patients need to develop knowledge of their disease, and then need to be motivated and encouraged to take greater responsibility for their care.

Age appropriate information and consultations

Seventy three percent of young people felt information and resources provided to them was at an appropriate age and level for their understanding **most** or **all of the time**.

Being involved in care includes young people feeling respected and that their time is valuable. Health providers should work in partnership with AYA patients to arrange flexible treatment and consultation times to prevent disruption of normal activities.

Over half of young people reported being kept waiting for more than 45 minutes for an appointment **some of the time** or **often**.

Involvement in decision-making

Almost half of the young people (47%) felt health professionals **often** involved them in their care through ways such as speaking directly to them rather than someone else in the room, listening to what they had to say and involving them in decisions. An additional third reported that they experienced this **most of the time**. However, around **16%** identified this happened only **sometimes, rarely** or **never**.

Health providers should encourage AYA patients to ask questions, give them time to prepare for conversations and suggest they write questions down prior to discussions. The responsibility of self-management of care may result in increased self-confidence for AYAs, but it should also be recognised that some young people may not have the ability, confidence or desire to undertake this responsibility.

'In the beginning months there were a lot of these situations that led to my family and I feeling like we were left in the dark a bit. Because of that I chose to be more active in asking as many questions as possible, and taking charge of my situation by being one step ahead at all times.'

Certain key factors influence the decision-making process regarding where a patient is treated, including the type of cancer, clinical trial access, school attendance, reliance on parents for decision making, geographical considerations and AYA/whānau preference. AYA Cancer services play a key role in supporting health professionals and AYA/whānau to make this decision.

Determining where an AYA will receive treatment is part of the treatment plan, with AYAs and their whānau involved in this decision.

For those young people who did not have to move from their region to receive treatment the survey asked: 'If you had been told there was another treatment available at a different hospital in New Zealand that doctors thought could improve your survival would you have been willing to move?' Seventy six percent said yes, **17%** said not sure and **7%** said no. The biggest reason cited for not being willing to travel for treatment was not wanting to move away from family.

73% of young people felt information and resources were age appropriate **most** or **all of the time**

81% of young people **often** or **most of the time** felt health professionals involved them in their care

‘Because nothing means more to me than family, if they can’t visit regularly I get really panicked.’

76% of young people would be willing to move for treatment if doctors thought it could improve their survival



The co-ordination of my care

Care co-ordination is essential in the delivery of AYA cancer care.

Positively **97%** of young people were able to identify a doctor that took overall responsibility for their care and **90%** of young people were able to identify a health professional (i.e. AYA key worker, nurse co-ordinator) that was their main point of contact during their treatment, supporting them in all aspects of their care.

‘My young cancer nurse specialist, [], was incredible. If not for her I wouldn’t have known anything or had any support. She still talks and helps me (much less) now two years later. I often got support from her that others should have been providing on many occasions, whether that be appointments, different branches of public health system, treatment information, mental health assistance, etc.’

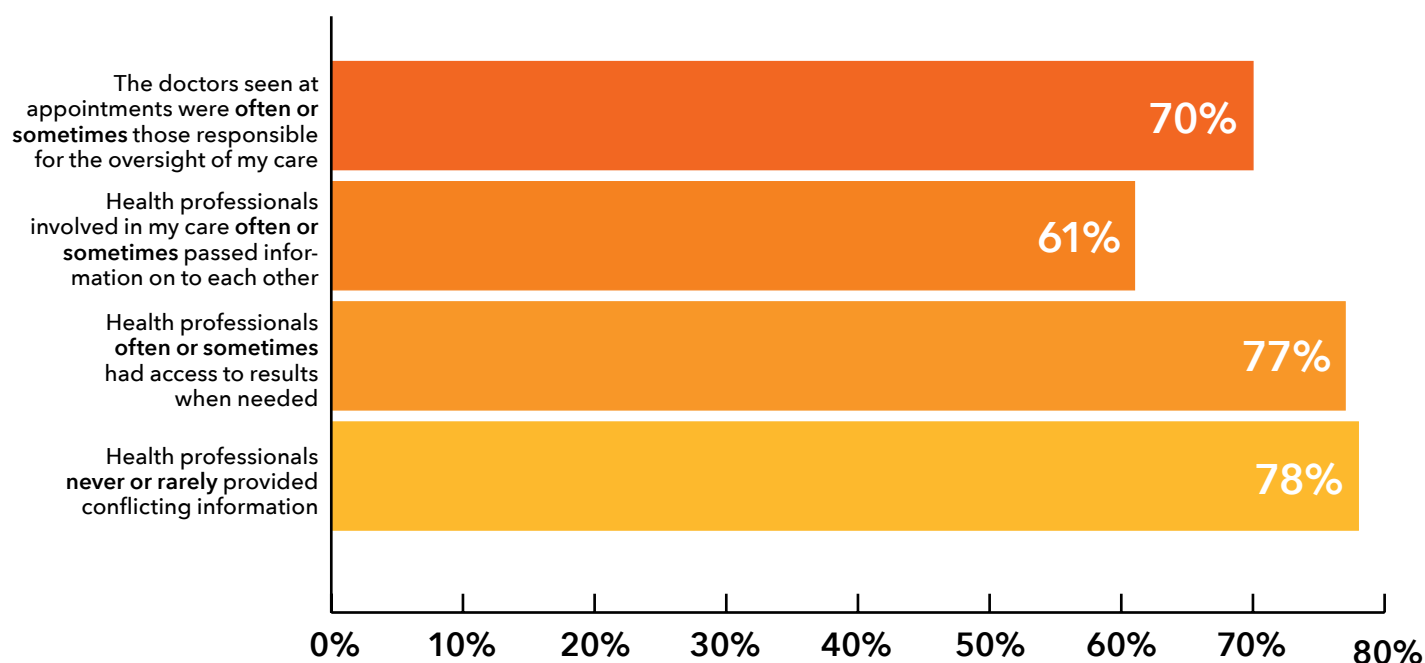
‘AYA Nurse [] from [my centre] is probably the most helpful person for information about my treatment and alongside my treatment. She makes herself available around the clock for contact and has made my treatment many times easier.’

‘Some doctors that I’ve had have been absolutely astounding, have really made me feel really looked after and you could see that they are doing their best to do everything in their power.’

For multidisciplinary/agency supportive care to be effective, providers need to overcome barriers to find innovative ways of working together.

As shown by graph 5, 61%-78% of AYAs identified that health professionals effectively co-ordinated their care during treatment.

GRAPH 5 | Young people's experience with health professionals, consultations and care co-ordination



Many young people will experience a transfer from one service or hospital to another through the course of their treatment or after. This includes from one region to another. Optimal care coordination includes facilitating good handover processes, and creating effective communication networks.

For young people requiring transfer of care from one hospital to another 87% felt their transfer was well organised **always** or **most of the time**.

'Not all hospital data links which means my scans in Christchurch and Wellington are not seen in Starship.'

'My original diagnosis was reviewed and changed and during this time there was a lot of communication problems between the doctors themselves and also informing me what was happening. It took me a lot of following up to get answers.'



A team approach is essential

43% did not have access to complementary therapy but would have liked this

Multidisciplinary/multiagency care for AYA patients and whānau should incorporate access to the following professionals/services: the cancer treatment team, psychology/psychiatry, education, palliative care, spiritual care advisors, youth providers, NGO providers, cultural support, physiotherapy, occupational therapy, social work, dietitians, government agencies, primary care services and community health and social teams.

Best practice for young people with cancer and their whānau is delivered through a combination of specialised medical management and expert age appropriate psychosocial management.

The below tables highlight the input and range of services and support that young people and their whānau received through their cancer journey. The results presented here are met and unmet health needs as identified by young people.

While some young people identified that these services were not received but not needed there is the possibility that, if they had been offered and received this support as recommended in the Standards of Care, some benefit may have been experienced. This is bolstered by comments from young people at the inaugural AYA Cancer Consumer Group (May 2019) that many people did not know what role many of the allied health professionals could play in their treatment provision.

Allied Health

Of note is that nearly a third of all young people did not have access to allied health services that they felt could have benefited them (see table 1).

Complementary Therapy

A large proportion of young people (43%) wished that they had access to a complementary therapist for information and support around complementary therapy (see table 2).

I think we should be able to openly discuss the benefits of the medicinal use of marijuana. It's not for everyone but I know many including myself that used this as a primary resource for pain relief and appetite. We should be talking about this more and not being afraid of it just because it's illegal.'

TABLE 1 | Met and unmet allied health needs as identified by young people

	Needs met	Support received, and it was helpful	Support not received, but I did not need this	Support received but it was not helpful	Support not received, but I would have liked this	Unmet needs
Dietitian	58%	33%	25%	14%	28%	42%
Occupational Therapist	65%	17%	48%	7%	29%	36%
Physiotherapist	61%	30%	31%	6%	33%	39%

TABLE 2 | Met and unmet complementary therapy needs as identified by young people

Complementary therapy	54%	13%	41%	3%	43%	46%
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Psychosocial Support

The availability and usefulness of psychosocial support for young people varied. However, in all areas the majority of young people

felt their psychosocial needs were met – whether this involved wanting and receiving support, or not wanting those support services (see table 3).

TABLE 3 | **Met and unmet psychosocial needs during treatment as identified by young people**

	Needs met	Support received, and it was helpful	Support not received, but I did not need this	Support received but it was not helpful	Support not received, but I would have liked this	Unmet needs
Psychologist/Counsellor	72%	40%	32%	9%	20%	29%
Spiritual/Religious Counsellor	91%	7%	84%	3%	5%	8%
Social Worker	77%	45%	32%	9%	14%	23%
Youth worker	86%	57%	29%	5%	9%	14%
Hospital School teacher	87%	24%	63%	7%	6%	13%

Non-hospital-based support

Non-hospital support groups were identified by young people to have been a great source of support throughout their cancer journey with **73%** accessing support through these groups and finding them helpful. A further **19%** did not receive support from non-hospital support groups but felt that they did not need this, while **4%** received support they did not find helpful and **5%** did not receive support but would have liked this.

‘Mental health support was frankly underwhelming - It was infrequent, short visits, with a different practitioner each time. Throughout my treatment I spent nearly 8 months straight in Hospital, with 5 of those in an isolation room. I was just lucky my mother could support me when and where needed. If I wouldn't have had her my mental health would have been significantly worse. Both myself and her were incredibly disappointed by the lack of recognition regarding the impacts on mental health that this length of time in hospital can have.’

'I couldn't find a psychologist or a counsellor that's helpful. Probably because my situation was too complicated and one of a kind... Lol.'

'Canteen really helped I think they need more recognition for making young people's lives during cancer journeys a little bit easier.'

'The LBC (Leukaemia and Blood Cancer NZ) service have been the best thing because they have helped me meet others going through the same thing of a similar age, helped me with petrol...supported me through work...'

'Many things that other young people would find extremely helpful were not applicable to me. But it was very nice to meet other young people with cancer and share jokes with someone who understands. Canteen helped me a lot with food as well. Cancer society provided me with counselling services.'

'I was once contacted by [a support group] because my family friend found out about this and made them contact me (she works closely with [the support group]) but they just invited me to one event which I couldn't go to and then no one contacted me ever again.'

Medication and Supportive Techniques for Painful Procedures



Offered **ALWAYS**
49%



Offered **OFTEN**
30%



Offered **SOMETIMES**
17%

Health Care Support

Managing uncomfortable or painful procedures

Just under half (49%) of young people reported **always** being offered enough medication (pain relief, sedation, general anaesthetic) and/or supportive techniques (meditation, hypnosis) to manage any uncomfortable and/or painful procedures such as IV insertion, nasogastric placement and bone marrow aspirates. Thirty percent reported being offered enough medication or supportive techniques **often** being offered enough medication or supportive

‘Age is a big barrier when it comes to not being believed when you had pain issues.’

techniques, **17%** reporting only **sometimes** and, reassuringly only 1.2% reported **never** being offered such assistance.

Pain Management

Young people were also asked whether their needs were met regarding receiving the health care support services of pain management, community nursing and the palliative care and/or hospice team. Of note almost one

quarter of young people felt their pain management needs were not met (see table 4).

One quarter of young people felt their pain management needs were not met

TABLE 4 | Met and unmet health care support needs as identified by young people

	Needs met	Support received, and it was helpful	Support not received, but I did not need this	Support received but it was not helpful	Support not received, but I would have liked this	Unmet needs
Pain management	77%	27%	50%	5%	19%	24%
Community Nurse	91%	48%	43%	2%	7%	9%
Palliative Care/Hospice Team	89%	12%	77%	1%	10%	11%

Maintaining a sense of normality and achieving developmental milestones

Young people need help to maintain a sense of normality and achieve their developmental milestones, with the goal of promoting good self-esteem, effective coping, good emotional health, treatment adherence and reintegration back to healthy functioning after treatment.

Young people were asked to think back to their first month of diagnosis and whether a health professional or support worker talked to them and provided enough information on the topics shown in table 5.

Where support was provided, it was overwhelmingly helpful – with between only **4%** and **8%** across all topics selecting ‘support provided but unhelpful’. When information was provided on the below topics, **82%** of young people reported that these topics were either **often** or **sometimes** revisited during their treatment phase.

While it is a positive finding that most young people are receiving some information and support for meeting their developmental needs, some areas could be improved on. In particular young

people have identified an unmet need in the information and support provided around substance use (38%), relationships/sexuality (44%) and finances (41%).

44% of young people reported they did not receive helpful support and information on relationships and sexuality

TABLE 5 | Met and unmet developmental milestones support as identified by young people

	Needs met	Support received, and it was helpful	Support not received, but I did not need this	Support received but it was not helpful	Support not received, but I would have liked this	Unmet needs
School / Work	82%	52%	30%	4%	14%	18%
Emotional/Mental Health	74%	48%	26%	4%	22%	26%
Physical Changes	86%	54%	32%	5%	10%	15%
Substance Use	63%	40%	23%	5%	33%	38%
Whānau and friends	78%	44%	34%	8%	14%	22%
Relationships and Sexuality	56%	41%	15%	7%	37%	44%
Peer Support	82%	56%	26%	4%	13%	17%
Finances	59%	27%	32%	7%	34%	41%

'I felt like my age was taken into consideration and people were aware I was young and would still want to have the young adult lifestyle I had before. All the doctors said to me "stay healthy and live like you lived before", no one was trying to hold me back it was great.'

'The physical side effects of treatment was manageable, talked about and looked after but the mental health effects of chemotherapy were not discussed enough or considered by any of the doctors.'

'Schooling was quite difficult. [The] School I attended did not want to help at all'.

'The social support received from both CanTeen and my AYA nurse was brilliant. It was incredibly useful having someone other than my family or partner to talk to about what I was going through.'

'It was a very emotionally confusing and frustrating experience and I wish I had more support and relief from that. I used to be very active so some help to keep my body going would have helped me not feel so depressed about losing that aspect of my life. I just felt like I had lost all my abilities. And I was definitely capable of doing things. I often went to the gym in my second week before treatment again because I wanted part of my life back in part.'

'I would have liked my lifestyle to be brought into my treatment more. To make it more personal. I have found tiredness very hard and I have had no one to go about it. I was told I would be tired but not what else I could do to help it.'

Difficulties sticking to my treatment plan

Adherence is an issue during the adolescent years; a number of risk factors are associated with increased non-adherence in the AYA cancer population such as family/parental dysfunction, multiple problems of disadvantage, psychological distress and not being engaged in training/work. Early identification of those at risk of non-adherence and early intervention is likely to be the most effective in supporting adherence and preventing treatment abandonment.

Some international studies report that up to half of AYAs are non-adherent with oral chemotherapy.

The survey findings show that for young people with a diagnosis of Acute Lymphoblastic Leukaemia (ALL) and Chronic Myeloid Leukaemia (CML), requiring long term oral chemotherapy use, adherence was identified as more of a concern: with a quarter of CML young patients missing 10 or more doses and **21%** of ALL young patients missing more than 10 doses (see table 6).

Fever in patients with cancer who are receiving chemotherapy is common and requires urgent assessment to avoid potentially life-threatening consequences.

TABLE 6 | Adherence rates reported by young people

	Never	Once or twice	3-10 times	More than 10 times
Missed a dose of your oral anti-cancer or chemotherapy medicine	66%	22%	8%	5%
Missed a planned hospital admission, clinic appointment or scheduled outpatient treatment visit	71%	23%	4%	1%
Had/have a fever following chemotherapy and not spoken to your health professional about it	70%	23%	6%	1%
Missed other medication prescribed for you such as anti-sickness medicine, antibiotics and anti-viral medicines	35%	39%	19%	7%



Challenges and stressors

There are a number of financial and non-financial factors that can cause additional stress on a young person or their whānau and some can impact a young person's ability to engage in their cancer treatment.

For most young people these factors, listed in table 7 and table 8, were **never** or **rarely** a problem but for about a third they were **sometimes** or **often** an issue.

Certain situations were an additional stressor for young people.

In many cases the issues, outlined in table 7, are financially related – with costs such as parking and petrol adding up. Such stressors

are potentially exacerbated by an inability or reduced ability for the young person or their whānau or partner to earn money while on treatment. Living costs and income over this period can be supplemented by benefits and allowances provided by government or non-government organisations. These require paperwork, appointments and monitoring obligations that can place additional stress on the

young person. Thirty eight percent of young people said these processes **sometimes** or **often** caused them difficulty.

Many AYA cancer patients are reliant on their whānau and/or partner during treatment for practical, emotional and financial support. This can cause a significant economic and emotional burden for whānau.

'While we were never unable to afford parking, the simple lack of parking often meant that I would be dropped off to get to my treatment on time, while my parent had to spend more time circling the block looking for parks. This meant that occasionally I would start the dose alone, which was uncomfortable/mildly distressing.'

'I did ask to speak to a social worker to get help with financial assistance with winz but was told that we were to sort that ourselves.'

'Had ALOT of trouble with WINZ when I first got diagnosed, I didn't have money for about 3 months as the [] branch forgot to process my payment. I ended up going to my local MP office and they helped me so much and got the ball rolling. My friends and family kindly did a gofundme page for me as well as I was struggling to pay for things and had to use all my savings I had saved for many years when I was working before being diagnosed.'

'If it wasn't for the Cancer Society I would not have had any food over the whole treatment as they were giving me food vouchers and help me sometimes get my medication cause I was getting that little and apparently I was maxed out when it couldn't cover rent let alone power and fuel and medication and food.'

38% of young people sometimes or often had difficulty completing forms for benefits, allowances or grants

'Although I have not had my benefit from WINZ cut I did have a battle getting the appropriate one which was embarrassing and demoralising as I had a good career and would prefer to be working if it were possible.'

'Appointments are generally out of town so I need to travel and take time off work. Can't afford to have husband also having time off work.'

TABLE 7 | Experiences of financial stressors

	Never	Rarely	Sometimes	Often
Transport difficulties getting to appointments and/or hospital such as no one to drive them, no access to a vehicle and petrol costs.	48%	21%	17%	14%
Unable to afford parking	59%	10%	21%	11%
Unable to afford prescriptions/medication	69%	14%	15%	3%
No access to a phone or credit to contact their health care team when required	83%	8%	6%	3%
Difficulty completing processes for benefits and allowances (such as the WINZ benefit application process, travel assistance scheme, access to the wig and headwear allowance)	42%	21%	22%	16%
Having a benefit cut off due to an expired/out of date medical certificate	78%	8%	8%	8%

Other Stressors (non-financial)

Non-financial stressors include timing of scheduled appointments and treatments not suiting the young person and their commitments (work, study, family, social commitments), as well as

difficulties arranging childcare in order to attend appointments.

While the timing of appointments is a problem **sometimes** or **often** for **30%** of young people, childcare is only **sometimes** or **often** an issue for 6% of young people.

TABLE 8 | Experiences of non-financial stressors

	Never	Rarely	Sometimes	Often
Timing of scheduled appointments did not suit work, study family or social commitments	43%	28%	21%	9%
Having difficulty finding childcare to attend appointments and treatment	89%	5%	3%	3%

Age appropriate environments

It is essential that we treat AYA patients in environments that provide developmentally appropriate care, and enable access to age appropriate facilities and recreational resources.

65%
of young people
felt the environment
they were treated
in was **always**
or **often** age-
appropriate

Sixty five percent of young people felt the environment in which they were cared for was **always** or **often** suitable for someone of their age with half of young people reporting good access to recreational support and activities while receiving their treatment.

Seventy one percent of young people reported that their whānau was allowed to support and visit them as much as they wanted and **62%** felt their friends were allowed to support and visit as much as they wanted.

'There was no one my age or nothing to entertain me ... I was put amongst much older people which made me feel uncomfortable at times but was fine.'

'[The Ward] at [] hospital was outstanding!!! Beautiful rooms, fantastic staff, privacy, excellent flexibility allowing visitors and family members to stay.'

'I was 16-17 surrounded by children under 10. I felt Alone in my age group as I never saw someone my age and the environment is meant for younger kids but I don't mind :).'

'The waiting room before my follow-ups, at [] hospital, they had a dedicated room for teenagers that was suitable for our age, and would not feel out of place compared to waiting in the children's waiting room.'

'I feel the space can feel quite claustrophobic, everyone is close to each other and we're all kind of facing each other - and as you're going through a tough day of treatment it can feel even worse when you are surrounded by people that are visibly suffering.'



POST TREATMENT

-Ā MURI IHO AKE I TE WHAKATAUTANGA AKE Ā TOU MATE

Finding a new normal

Providers need to recognise and address the medical and psychosocial needs of AYA cancer survivors at the end of treatment and at regular intervals thereafter.

Only **22%** of young people received a detailed written end-of-treatment summary on completion of treatment

A formal end-of-treatment summary or “passport” that survivors and providers can both access facilitates easier transition into life without cancer. Topics in this document can include: the long-term effects of cancer and its treatment; identified psychosocial support resources in the community; guidance on follow-up care; prevention and health maintenance.

At the end of treatment **22%** of young survivors were given a detailed written/taped end of treatment summary that included the treatment they had received, possible future long term effects

of treatment, on-going monitoring required and their follow-up plan, with an additional **36%** being given a written plan with some of the above information included.

Positively **82%** of young people recalled that on finishing treatment a health professional or support worker spoke to them about the medical aspects of their follow-up care which they either found **very helpful** or **helpful**.

Many young people continue to experience physical, emotional and social challenges in the years after their treatment has ended. Successful re-entry into life without cancer improves quality of life, reduces social isolation and increases self-esteem.

Young people were asked whether they received assistance in a number of areas related to after-treatment life, and asked to rank this assistance as **very helpful** or **helpful**, **not received but did not need this**, **received but not helpful**, and **not received but would have liked this**.

These findings show that survivorship and the after-treatment time is the area with the most clearly and consistently unmet needs for AYAs (see table 9).

Young peoples' after-treatment needs for physical, social and emotional support were not met half to one third of the time

'I would have loved follow up plans to be given in written form... Since finishing treatment I have only talked with and seen my surgeon who has been organising when my scans are. I have not heard from the oncology department since finishing treatment.'

TABLE 9 | **Met and unmet after-treatment supportive health needs as identified by young people**

	Needs met	Support received, and it was helpful	Support not received, but I did not need this	Support received but it was not helpful	Support not received, but I would have liked this	Unmet needs
Assistance and help returning to school, study or work	67%	43%	24%	5%	28%	33%
Guidance and assistance in managing my tiredness/fatigue and given a plan to increase physical activity	52%	44%	8%	1%	47%	48%
Information on topics such as living a healthy lifestyle and good nutrition	58%	38%	20%	8%	34%	42%
Information on sexuality and future fertility issues	58%	42%	16%	5%	37%	42%
Information and support on my emotional wellbeing	55%	42%	13%	5%	40%	45%

‘I wanted after treatment support but it wasn’t received’

Sexuality and Future Fertility information

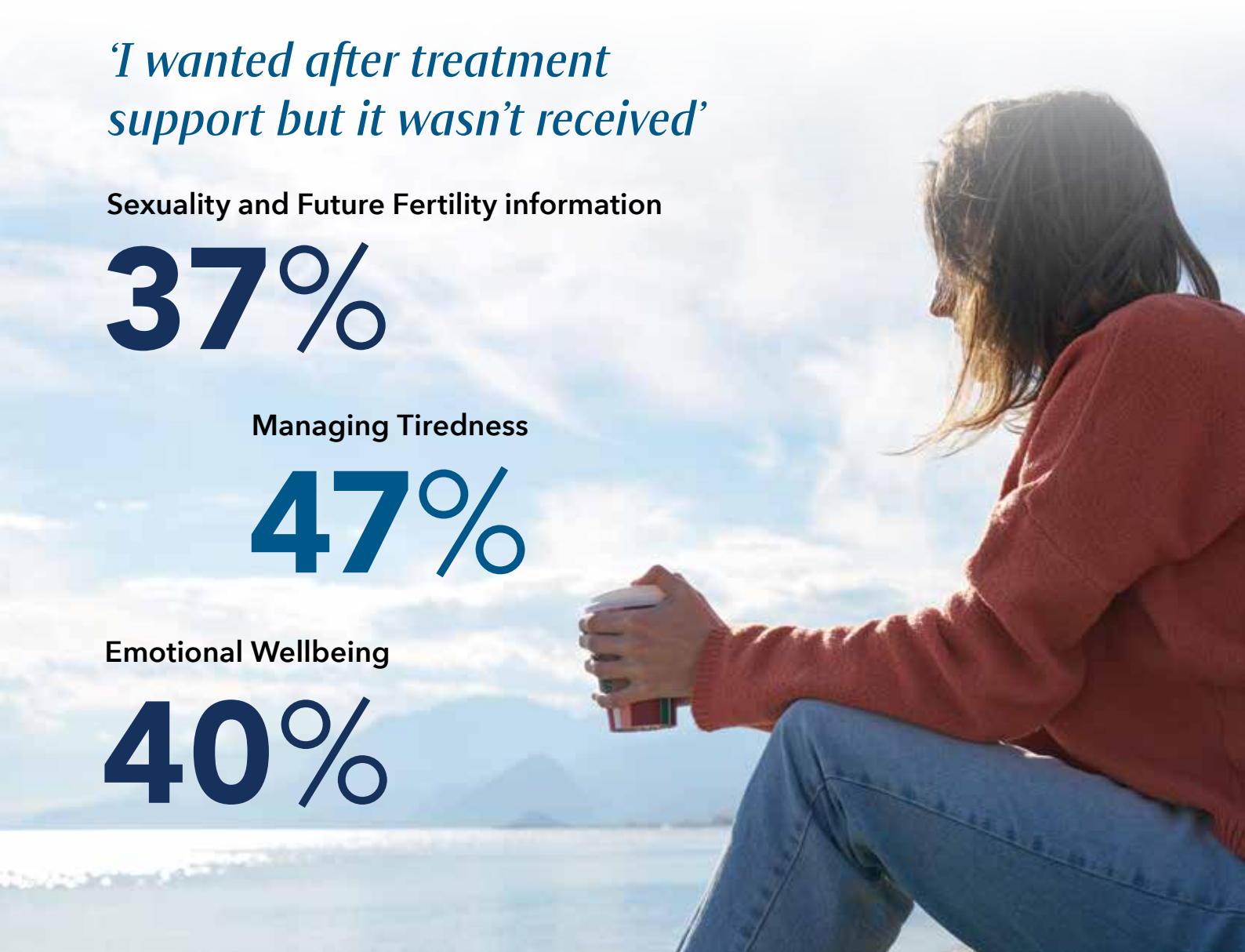
37%

Managing Tiredness

47%

Emotional Wellbeing

40%



'The hospital should be having more things in place to assist us in our recovery such as immediate follow up classes or sessions for diet, fitness, mental health etc because if anything, recovery is the hardest part in this whole journey.'

'I have struggled getting back into fitness as I can't do what I used to be able to do. I wasn't expecting this and it was scary and depressing. It made me feel even weaker and like I would never be the same again.'

So many things were mentioned to me that I could use as support but when I actually showed interest, it never happened or it didn't help. I requested a counsellor on multiple occasions and got given so many references. But I was exhausted and didn't want to have to think about trying to organise it so it just never happened but I wanted it to.

I was also told that the counselling isn't actually available to people who have finished treatment for free. But this is when I felt I really needed it with trying to get back to a normal life and the emotional side of looking different and feeling weaker.'

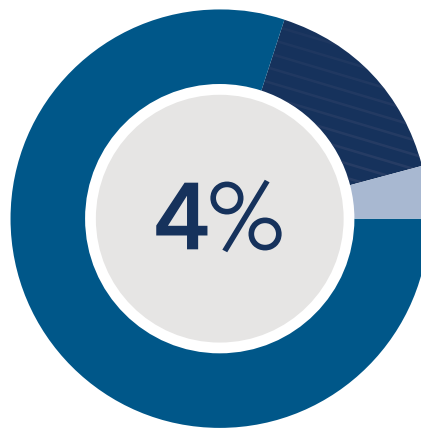
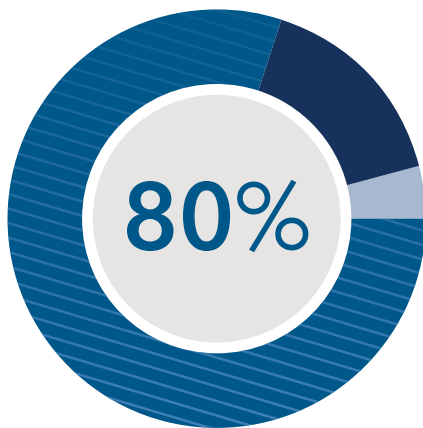
'It would be good to have a group of people who are experiencing complications post the cancer.'

'I was made aware of a counsellor through the Cancer Society, however I did not feel comfortable using this service.'

I would've liked to have received more options after my treatment without having to ask more than once (I asked my oncologist twice and the second time she got my AYA nurse to contact me with a list of people I could contact and ways to get in touch with a psychologist/counsellor).'

'After my treatment, I received no follow up support despite asking the doctors to provide this on many occasions and expressing my need for it.'

Overall Experience



Eighty percent of young people rated their overall cancer experience as **excellent or good**

with four percent rating their experience as **poor or very poor.**



'Overall though the team at [] Hospital and [] Hospital were amazing, including all supporting services as it is difficult to help children who are so sick.'

'Considering how quick my health deteriorated I think the doctors, nurses and youth workers helped me and my family quite a lot / I am very grateful.'

'Despite the cancer diagnosis all my experiences were extremely positive. I have a very supportive family and they were/are with me every step of the way. We were well informed and plans discussed in all treatments.'

'Feeling of Doctors, Nurses, and other carers having a true involvement and dedication into making you feel better is felt in every person working in the medical sector. It's great having a team that you can talk to and get to know with more information conveyed than just treatment. Staff make these places.'



RESULTS BY VARIABLES

-NGĀ MEA I ĀHUA I KITE AI I TŌ MATE

Small/Large Centre, Paediatric/Adult Services and Ethnicity

This section provides results from the survey analysed by different variables to see how these impact on AYAs experience of cancer care and services.

There are three sections: the first looks at the impact of domicile (where someone lives); the second considers the impact of age (younger AYAs and older AYAs); and the third considers the impact

of ethnicity (Māori, Pacific and New Zealand European). Each section only reports on aspects of care and service that showed areas of noteworthy difference based on the variable under consideration.

Impact of Domicile on AYAs' Experience of Cancer Care and Services: Residing in Larger Centres Compared with Smaller Centres

We divided the survey sample into those who received treatment at larger centres or smaller centres.

The following six tertiary centres were classed as 'larger centres' based on the historical definition - Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin. This is to reflect the centres in which an AYA Keyworker is located. AYAs whose residential address is within one of these cities are considered to 'reside' in a larger centre. AYAs whose residential address is outside of these six areas are considered to reside in a smaller centre. The following information uses these definitions, though it is recognised

that AYAs may have received some of their care outside the region in which they live.

An observation from the survey is that young people residing in towns and cities outside of the six tertiary centres with AYA services, appear not to be receiving equitable access to all care and support options as those young people residing in the six tertiary centres.

People residing in smaller centres may have to travel to larger centres to receive treatment or may be treated in adult services within their own region. Where they reside may be a factor in their options for treatment location (adult or paediatric services).

Before Starting Treatment

Young people residing in smaller centres are **1.48** times less likely to be on a clinical trial, **5.85** times less likely to have had a conversation on the impact of treatment on fertility preservation and **6.75** times less likely to have received a detailed treatment plan when compared to those young people residing in a larger centre.

During Treatment

Access to Multidisciplinary Support

Access to the wider multidisciplinary team is similar for young people regardless of whether they reside in a smaller or larger centre. However there are a few exceptions to this.

Graph 6 shows that AYAs residing in larger centres are more likely to have access to helpful multidisciplinary care than AYAs residing in smaller centres.

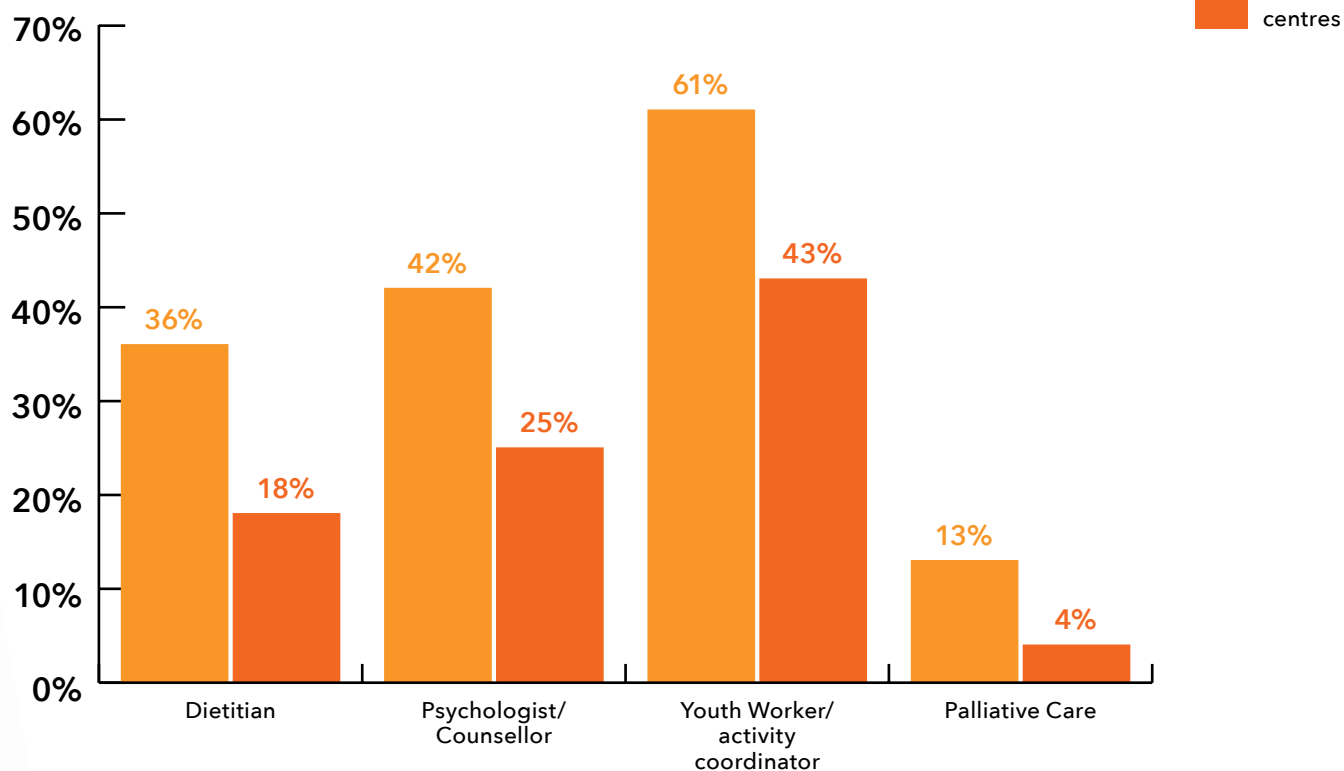
Stressors

The stressors that can impact on a young person and their whānau and for some impact their ability to engage in their cancer treatment were more evident in those living in the smaller centres as shown in graph 7.

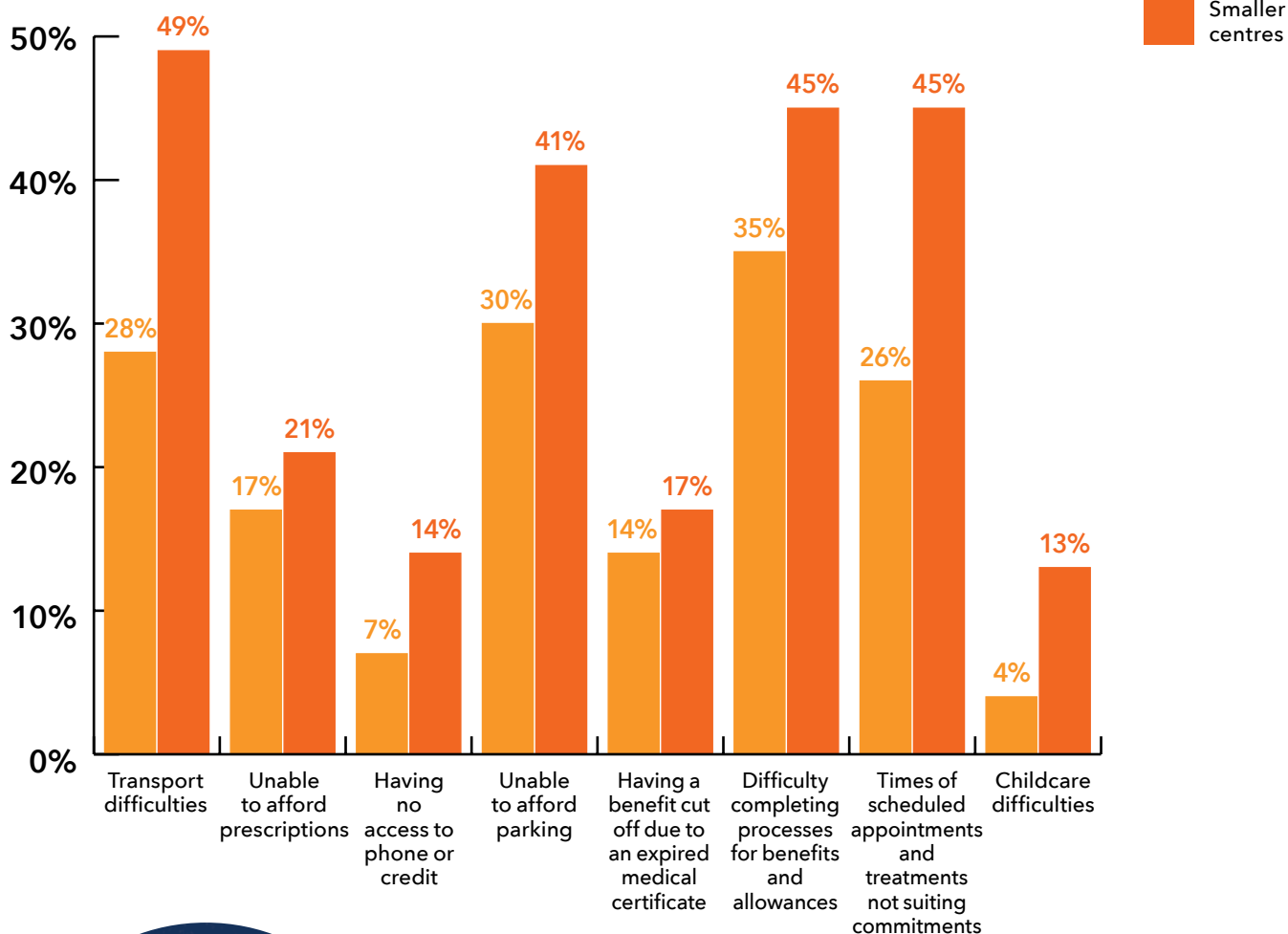
36% of young people in larger centres had access to helpful support from a dietitian compared to **18%** of young people in smaller centres

Young people in smaller centres are 5.85 times less likely to have had a conversation on the impact of treatment on fertility

GRAPH 6 | Access to multidisciplinary support by domicile (smaller and larger centres)



GRAPH 7 | Stressors experienced by domicile (smaller and larger centres)



Young people in smaller centres reported experiencing all stressors more than young people in larger centres

Youth Appropriate Consultations

AYAs were asked 'Have you been given the opportunity to discuss and/or ask questions to a health professional about what would happen if your treatment was not successful?' For those in larger centres, **59%** said **yes they had been given this opportunity**, compared to only **14%** in small centres who had this opportunity. Only **12%** of AYAs in larger centres said they had **not been given the opportunity but would have liked to**, compared to **48%** in smaller centres.

When asked if they had been **seen alone for part of the consultation**, **82%** of AYAs in large centres said yes this had occurred **sometimes, most of the time or all the time**

compared to **62%** of AYAs in smaller centres.

Regarding whether they had felt **involved in their care and treatment**, **95%** of those in large centres and **79%** of those in small centres said this occurred **most of the time or always**.

Twenty three percent of AYAs in larger centres compared to **39%** of AYAs in smaller centres **did not** receive information and support on **relationships/sexuality**.

Thirty two percent of AYAs in larger centres compared to **49%** of AYAs in smaller centres **did not** receive information and support on **substance use**.

Age Appropriate Environments

Regarding the suitability of treatment environments, there is no difference between young people from smaller or larger centres.

There is however difference in access to recreational support, with **72%** of young people in larger centres **always** having access to recreational support and entertainment in comparison to **49%** of those residing in smaller centres.

A difference also exists between young people in larger and smaller centres when it comes to whether they felt their whānau or significant others were welcomed and allowed to support them. In larger centres **72%** of young people reported this happened **all of the time** in comparison to **49%** for smaller centres.

Sixty eight percent of those in larger centres also felt their friends were welcomed and allowed to support them **all of the time** compared to **41%** of young people in smaller centres. In smaller centres, **19%** reported they **never** felt their friends were welcomed, compared to this being reported for only **2%** of those in larger centres.

Care Co-ordination

While place of residence did not impact a young person's ability to identify a lead doctor and keyworker/nurse that co-ordinates their care, those residing in smaller centres fared less favourably in other measures of care coordination. Young people residing in smaller centres were more likely to report health professionals **often/sometimes** not passing information onto one another (52% in smaller centres compared to this happening to 37% of young people in larger centres). In smaller centres **38%** of young people also reported not having access to results when these were needed compared to **21%** of young people in larger centres.

After-treatment

Survivorship

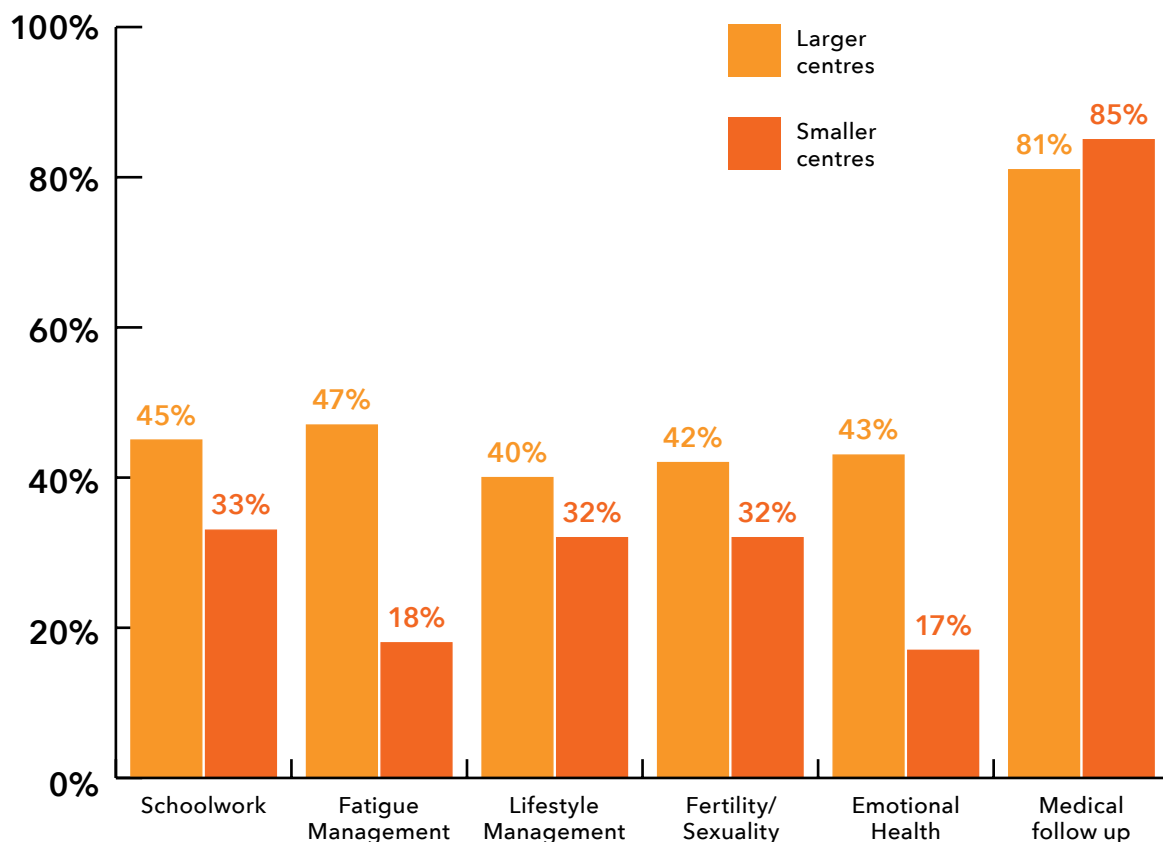
Young people from smaller centres, with the exception of medical follow-up, were less likely to have access to helpful support in trying to reintegrate back into life after treatment (refer to graph 8).

59%
of young people in larger centres were given the opportunity to discuss what would happen if their treatment was not successful. Only 14% of young people in smaller centres had this opportunity

72% of young people in larger centres felt their whānau or significant other was **always** welcomed compared to **49%** of those in smaller centres

43% of young people in larger centres had helpful after-treatment support on emotional health compared to **17%** of those in smaller centres

GRAPH 8 | Access to helpful after-treatment support by domicile (smaller and larger centres)



Impact of Age on AYAs' Experience of Cancer Care and Services: Paediatric and Adult Health Care Environments

We divided the survey sample into those 12-15 years at diagnosis and those 16-24 years at diagnosis.

Those in the younger age group are more likely to be cared for in a paediatric health environment and those in the older age group may have received treatment in an adult environment.

The survey findings reveal inequitable care experienced by

age - with those in the younger (12-15 year) age group reporting better access to age appropriate care and support than those in the older (16-24 year) AYA bracket. This is particularly shown in access to multi-disciplinary support both during and after-treatment.

The comparisons in this section between younger and older AYAs can be taken as indications of likely differences between care received in a paediatric compared

to an adult environment. However, as some of those classified here in the older age group would have actually received their care in a paediatric environment, the differences in care and access to services may in fact be in even greater contrast, in favour of paediatric environments.

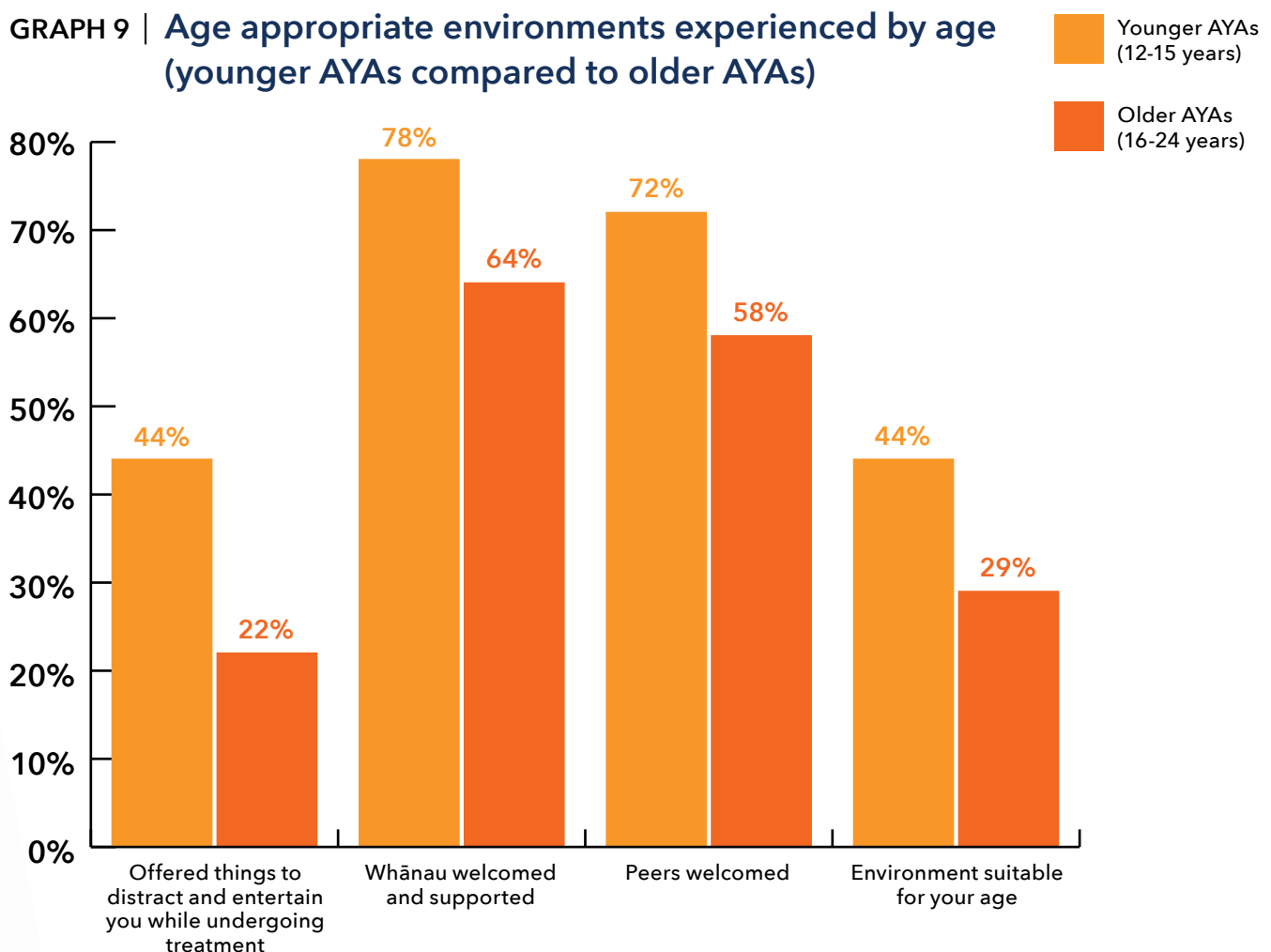
'I was 19 when I got diagnosed with lung cancer, and all I had to compare myself to were 70 year old males. The first thing people asked me was, do you smoke? I haven't smoked a cigarette in my life.'

During Treatment

The two main observations in the data were that those most likely cared for in the child health/ paediatric environment (12-15 year olds) appeared to have better access to an age appropriate environment and input from a wider multidisciplinary team, as highlighted in graphs 9 and 10.

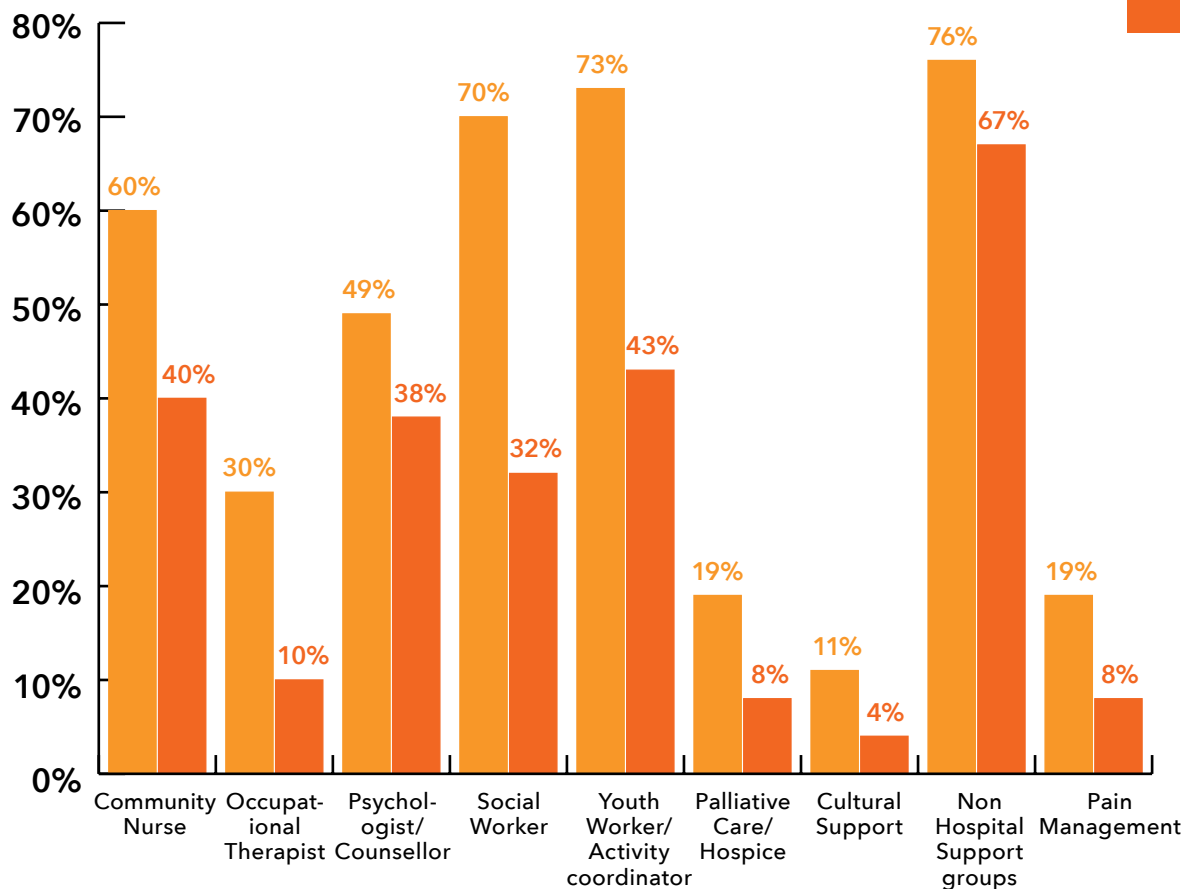
'As I was 17 I decided to be treated in the adult ward, as being treated with children would have been quite distressing. While this was ultimately the better decision, it was still quite lonely and uncomfortable sitting with much older people as well. There was maybe one other patient I encountered at the time who was in my age group, but even then I didn't have the chance to really engage with them.'

GRAPH 9 | Age appropriate environments experienced by age (younger AYAs compared to older AYAs)



GRAPH 10 | Access to helpful multidisciplinary support by age (younger AYAs compared to older AYAs)

Younger AYAs (12-15 years)
Older AYAs (16-24 years)



Access to wider Multidisciplinary Team

The above graph shows those who received care from these providers and **found it helpful**. In all areas of multidisciplinary care, those in the younger age group, and most likely a paediatric environment, were more likely to have received helpful care from these providers than those older AYAs. The biggest difference is with help from a social worker, where **70%** of those in a paediatric environment received this, while only **32%** of those in the older age group and more likely treated in an adult environment received this help.

Pain relief

Young people in child health environments were 2.48 times more likely to report **always** receiving enough pain relief and/or support for uncomfortable and painful procedures (that is **always receiving this** for 67% of those aged 12-15 compared to 45% for those aged 16-24).

70% of younger AYAs (12-15yrs) received helpful support from a social worker compared to 32% of older AYAs (16-24yrs)

Young people in paediatric environments were 2.48 times more likely to report **always** receiving enough pain relief and/or support for uncomfortable and painful procedures than those in adult environments

After-treatment

Survivorship

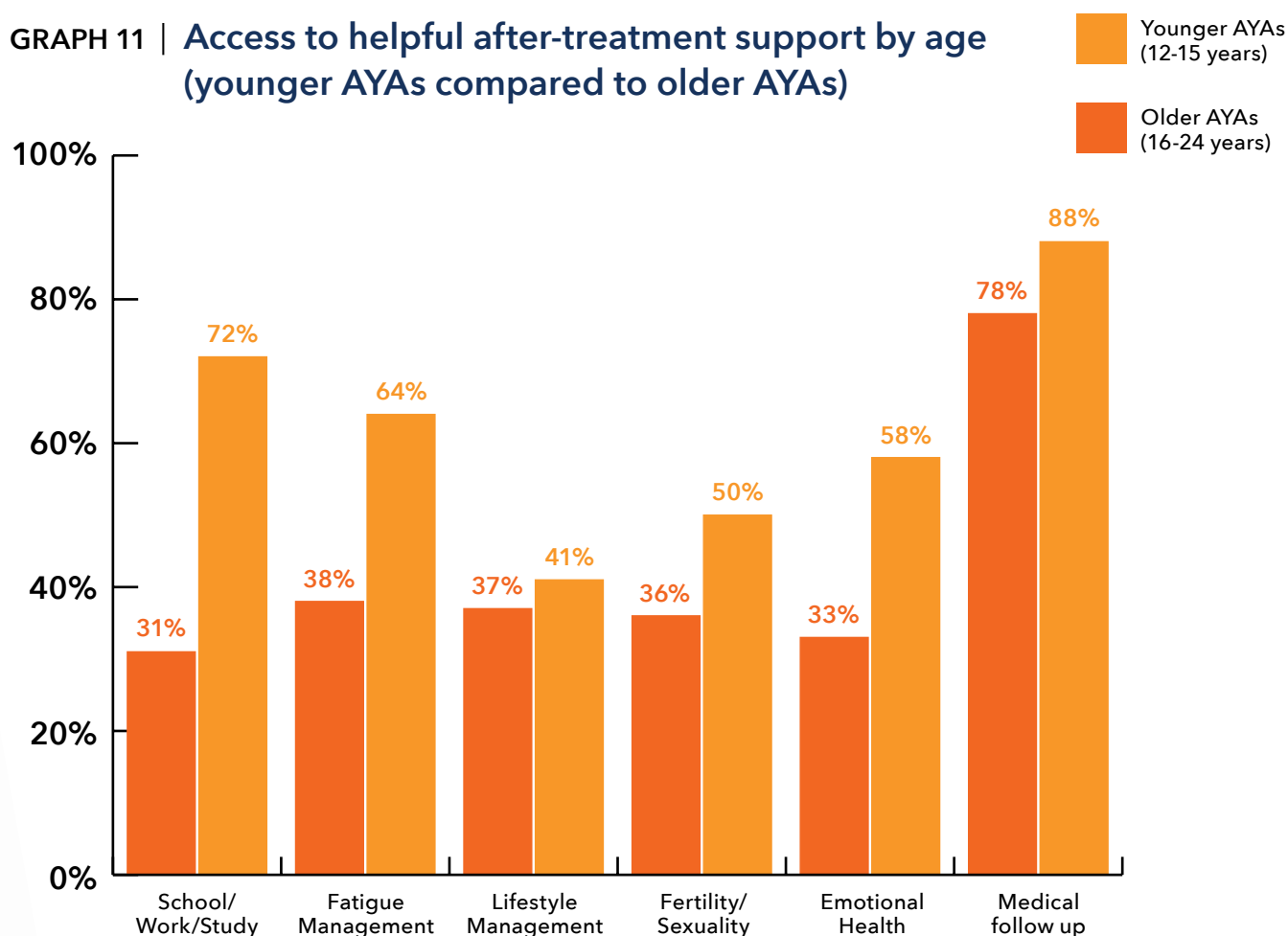
The survey also revealed a difference in access to helpful after-treatment support between the younger and older age group when trying to integrate back into life after treatment. Young people were asked if they received this support and whether it was helpful. If they did not receive this support they were asked if they would have liked to receive support. The below results also indicate that regardless of age, AYAs have an unmet need in most areas of survivorship support.

The area where older and younger AYAs received the highest as well as the most similar levels of helpful support was with medical follow-up care.

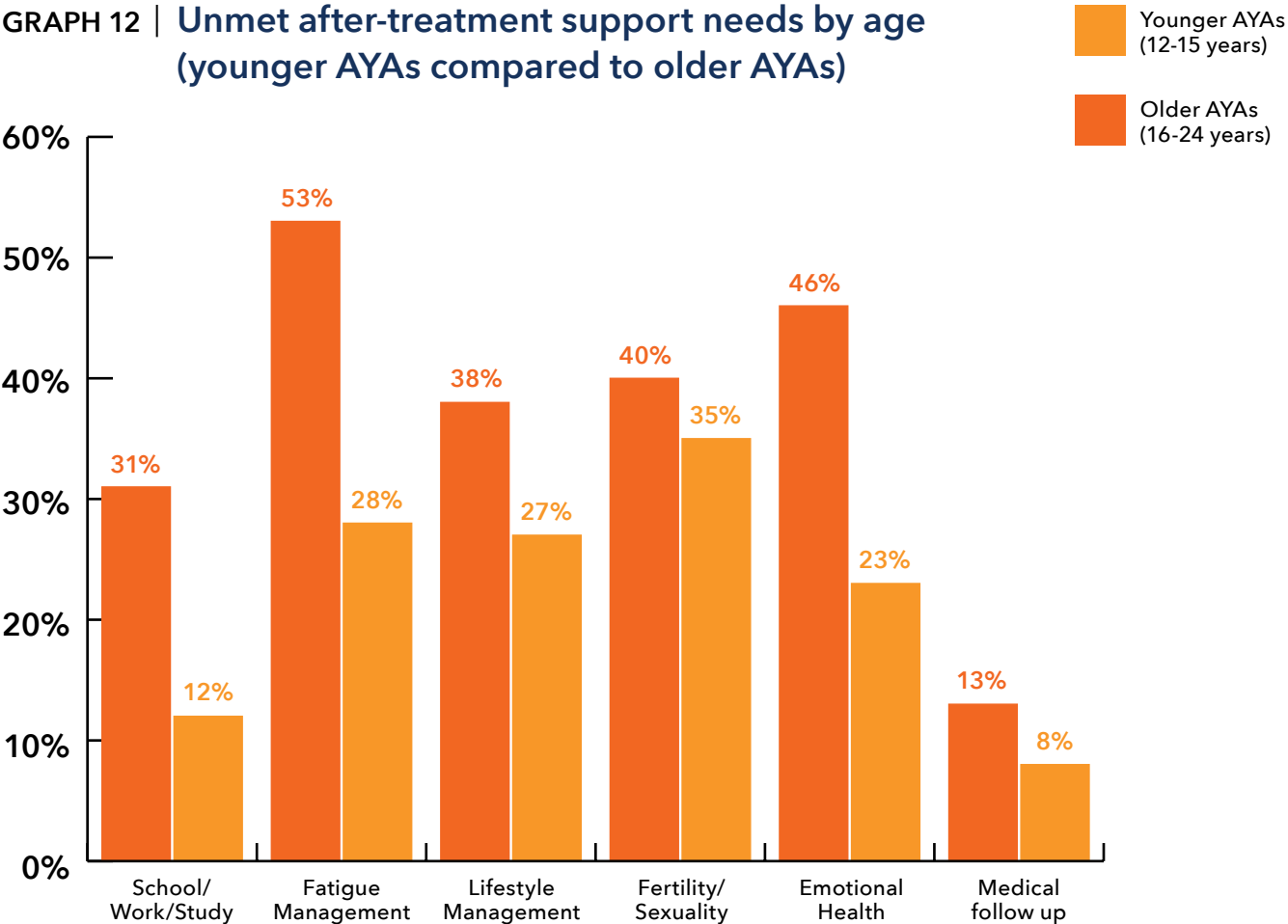
'I have experienced cancer many times and have on going complicated health issues; I have had trouble finding a support group that fits what I'm going through. [NGO] was good for when i was younger, but now i don't find it helpful.'

After-treatment support needs were met for younger AYAs more often than for older AYAs

GRAPH 11 | Access to helpful after-treatment support by age (younger AYAs compared to older AYAs)



GRAPH 12 | Unmet after-treatment support needs by age (younger AYAs compared to older AYAs)



Impact of Ethnicity on AYAs Experience of Cancer Care and Services

We divided the survey sample into ethnicity groupings based on a system of prioritised ethnicity.

This means for those who indicate identification with more than one ethnic group, they are categorised to one ethnic group by a system of pre-determined prioritisation: Māori, Pacific, Asian, other, New Zealand European. This has been done for the purpose of enabling analysis by ethnicity for a small data set.

While respondents were classified into five groups (Māori, Pacific, Asian, New Zealand European and 'other'), the numbers of those categorised as 'Asian' or 'other' are too small here to report on. This means the groups reported on in this section are New Zealand European (Pākehā), Māori, and Pacific Peoples.

The survey findings show inequities by ethnicity, with New Zealand European AYAs experiencing a better level of care and support in some measures than Māori,

and to a lesser extent, than Pacific AYAs. The differences are evident in higher Māori and Pacific AYAs withdrawing or declining clinical trials, experiencing cultural support and respect, treatment non-adherence, and experience of stressors.

Even for these three ethnic categories, the numbers for some answers are small and therefore the following results need to be interpreted with caution.

Before Starting Treatment

Clinical Trial Access

There is a statistically significant difference based on ethnicity for those AYAs who were not on a clinical trial, because they enrolled in a clinical trial and then **withdrew** OR they **declined** enrolment in a clinical trial. Māori AYAs were 4.75 times more likely to withdraw or decline than New Zealand European AYAs. Pacific AYAs were 3.8 times more likely than New Zealand European AYAs to withdraw or decline a clinical trial.

Fertility Preservation

Māori were the group most likely to choose not to pursue fertility preservation despite being offered. Compared to New Zealand Europeans, Māori AYAs were 3.14 times more likely to be offered fertility preservation but not undertake it, while Pacific AYAs were 2.92 times less likely to undertake fertility preservation compared to New Zealand European AYAs.

During Treatment

Cultural Support

When asked if they had been offered cultural support, **46%** of Pacific AYAs said **yes and it was helpful** while **31%** said **no but it was not needed**. No Pacific AYAs indicated that they **did not receive cultural support but would have liked it**.

18% of Māori AYAs did not receive cultural support but would have liked this

When asked if they had been offered cultural support, **21%** of Māori AYAs said yes and it was helpful while **29%** said no but it was not needed. However, **18%** of Māori AYAs indicated that they did not receive cultural support but would have liked it.

Cultural Respect

The survey asked AYAs if they felt that health professionals respected and engaged with their and their family's culture.

For Māori AYAs, **42%** reported this happened **often** or **sometimes**, **37%** reported this **did not happen, but it did not bother them**, and **8%** **could not remember**. However, **13%** of Māori AYAs reported that this **did not happen but they would have liked it to**. No AYAs from any other ethnic groups answered that their culture had not been respected or engaged with but they would have liked it to.

46% of Pacific AYAs received cultural support that was helpful

13% of Māori AYAs felt health professionals **did not respect or engage with their culture** and would have liked them to

For Pacific AYAs, **54%** said health professionals engaged with and respected their culture **often** or **sometimes**, **39%** said this did not happen but it **did not bother them**, and **8%** said they **could not remember**.

Difficulties sticking to treatment plan

The survey indicates that Māori and Pacific AYAs have greater representation in certain measures of treatment non-adherence than New Zealand European AYAs. For example, **79%** of New Zealand European AYAs and **75%** of Pacific AYAs said they never failed to report a fever. However, on this same measure **58%** of Māori AYAs had never failed to report a fever. For another indicator of non-adherence, missing medication, **33%** of Pacific AYAs said they had missed medication 3-10 times compared to **23%** of Māori and **17%** of New Zealand European AYAs.

'I feel like I'm always judged being Māori'

'I identify as Māori and this was never considered in my treatment'

Stressors

The survey asked AYAs to rate their difficulties on a range of additional stressors (shown in graph 13) and in all cases except for the benefit and allowance process, these stressors were experienced **sometimes** or **often** more by Māori AYAs.

Some stressors were similar across all three ethnic groups. In the case of the benefit and allowance process, all ethnic groups reported high levels of this causing difficulty **sometimes** or **often**: 37% for New Zealand European AYAs, 38% for Māori AYAs and 46% for Pacific AYAs. High levels of parking unaffordability were also similar across all ethnic groups, with

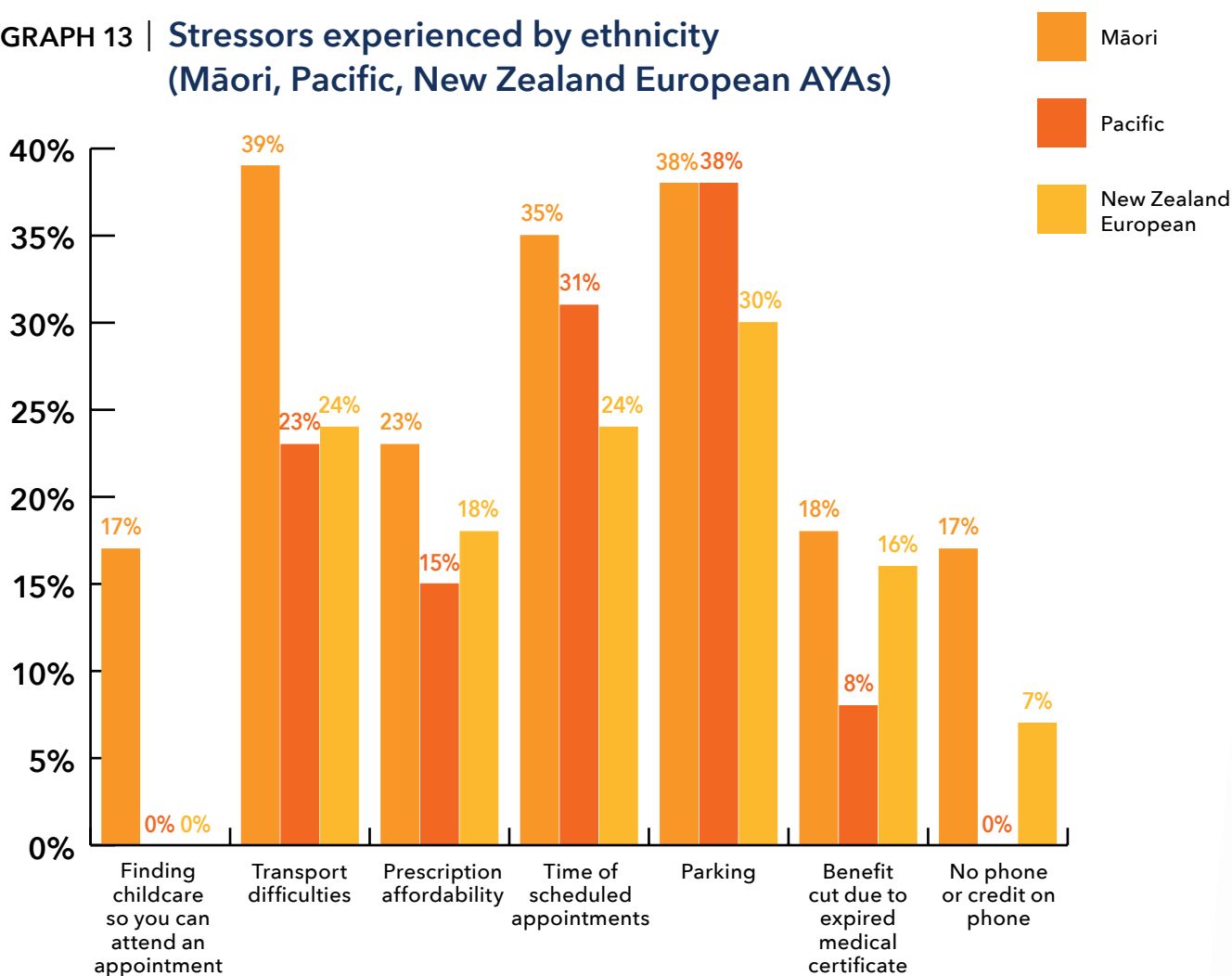
Māori AYAs experienced all but one of the financial stressors more than non-Māori AYAs

parking **sometimes** or **often** being unaffordable for 38% of Māori and Pacific AYAs and 30% of New Zealand European AYAs.

The only AYAs to indicate that finding childcare in order to attend an appointment was **sometimes** or **often** a problem were Māori (17%).

'I don't like doing my treatment I hate it. it takes me away from my kids'

GRAPH 13 | Stressors experienced by ethnicity (Māori, Pacific, New Zealand European AYAs)



Care Coordination

AYAs were asked whether health professionals gave them conflicting information **never**, **rarely**, **sometimes** or **often**. Māori and New Zealand European AYAs indicated this **never** happened **56%** and **41%** respectively, while only **25%** of Pacific AYAs said this **never** happened. Further, **42%** of Pacific AYAs said they were given conflicting information **often** or **sometimes**, compared to **16%** of Māori and **28%** of New Zealand European AYAs reporting this.

42% of Pacific AYAs said health professionals often or sometimes gave conflicting advice. Compared with 16% of Māori and 28% of New Zealand European AYAs who experienced this

'I am lucky to have great family support and to be coping well with chemo and having past experience with chemo I had a fair idea of what I had access to and therefore what questions to ask. But for those who are not so fortunate, who may be tired, and do not have the confidence to speak up or ask questions - I imagine that these seemingly small issues could be major barriers when going through chemo which is hard enough on its own...'



Under 25s/Over 25s:

Age differential experience of cancer care

This section of the report compares the experiences of cancer care in New Zealand between those currently classified as AYAs (12-24 years) and older young adults (25-30 years).

The AYA Cancer Network defined AYA age range in New Zealand is 12-24 years. However, stakeholders have questioned whether this should be extended to include the 25-30 year old age group, as they are thought to face many similar challenges as AYAs with regards to outcomes, developmental needs, treatment effectiveness and tolerance, adherence, and early death. Opening the survey up to those diagnosed up to the age of 30 years allows the Network to hear their experiences of care and assess whether these differ to the age group. These findings may inform a decision on whether the current age limit for accessing AYA services in New Zealand should be extended to include the 25-30 year old age group.

Comparing the experiences of under 25s and the over 25s indicates that age is a factor in how young people with cancer in New Zealand experience cancer care. Overall the findings indicate that older young adults diagnosed with cancer are not experiencing the level of cancer care that AYAs are.

Before Starting Treatment

Clinical Trials

Research indicates that enrolment on a clinical trial is associated with improved outcomes. Enrolment on a clinical trial is lower in AYAs with cancer than in paediatric cancer. And for those over 25 at diagnosis, enrolment is even lower again.

From our survey participants, **17%** of those aged 12-24 at diagnosis were enrolled in a clinical trial compared to **11%** of those over 25 years.

Fertility

Research and expert opinion suggest that issues related to fertility and sexuality are of a high level of concern for many people diagnosed with cancer, and that this translates into a need for timely, accessible, appropriate and current information.

Fertility is the only area where over 25s received a higher level of care than under 25s. Only **59%** of those under 25 years were offered to see a fertility specialist compared to **73%** of those over 25 years.

During Treatment

Treatment Plan

All AYAs should have a documented treatment plan. A treatment plan gives details about the type of cancer treatment/s a person will receive, information about each step of the treatment phase and information about when and how long each phase should take.

For those over 25 years old, **11%** received no written or verbal treatment plan compared to only **1%** of under 25s who received no written or verbal treatment plan.

Age Appropriate Environments

It is essential that AYA patients be treated in environments that provide developmentally appropriate care, and facilitate access to age-appropriate facilities and recreational resources.

Sixty three percent of AYAs felt that they were treated in an age appropriate environment **most or all of the time** compared to only **31%** of older young adults feeling like they were.

Multidisciplinary and multiagency care

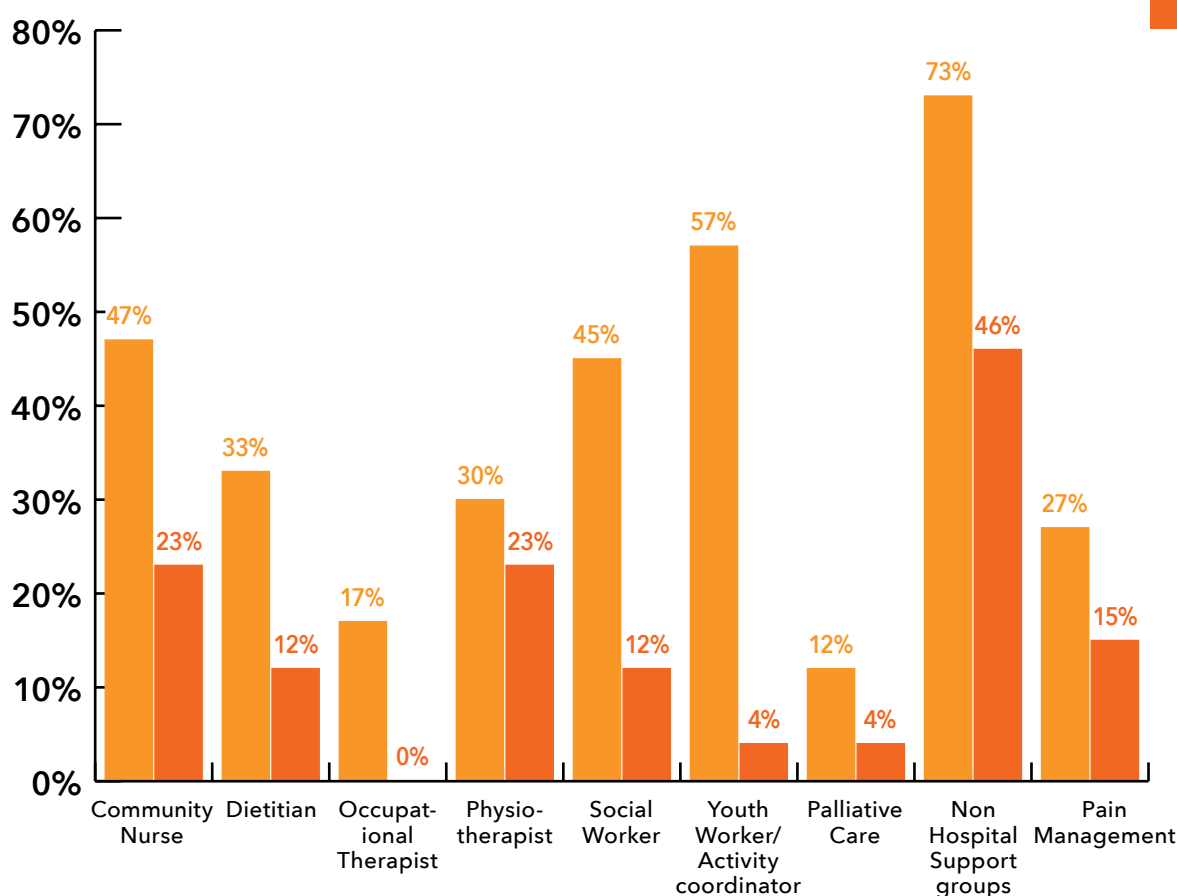
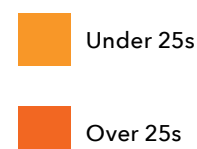
Best practice for young people with cancer and their whānau is delivered through a combination of specialised medical management and expert age appropriate psychosocial management.

As part of a comprehensive treatment perspective, young people should have access to a multidisciplinary team.

Graph 14 shows when young people received multidisciplinary support and found it helpful.

In response to the question on receiving help from a Youth worker/Activity coordinator only 4% of 25–30 year olds said they received this, but 77% said they did not need this, compared to 29% of AYAs who said they did not (see graph 14).

GRAPH 14 | Access to multidisciplinary support that was helpful (by AYA compared to older young adults)



'I think there needs to be more support networking for young people, I was never offered an opportunity to meet other young people or have support groups that were under the age of 30. Most of the support offered did not apply to my situation and were generic support groups full of older people. After my treatment, I received no follow up support despite asking the doctors to provide this on many occasions and expressing my need for it.'

'Canteen has been the biggest support and I'm going to miss them and their support when I age out.'

Developmental Milestones

Following treatment, cancer patients need support to maintain a sense of normality and to achieve their developmental milestones, with the goal of promoting good self-esteem, effective

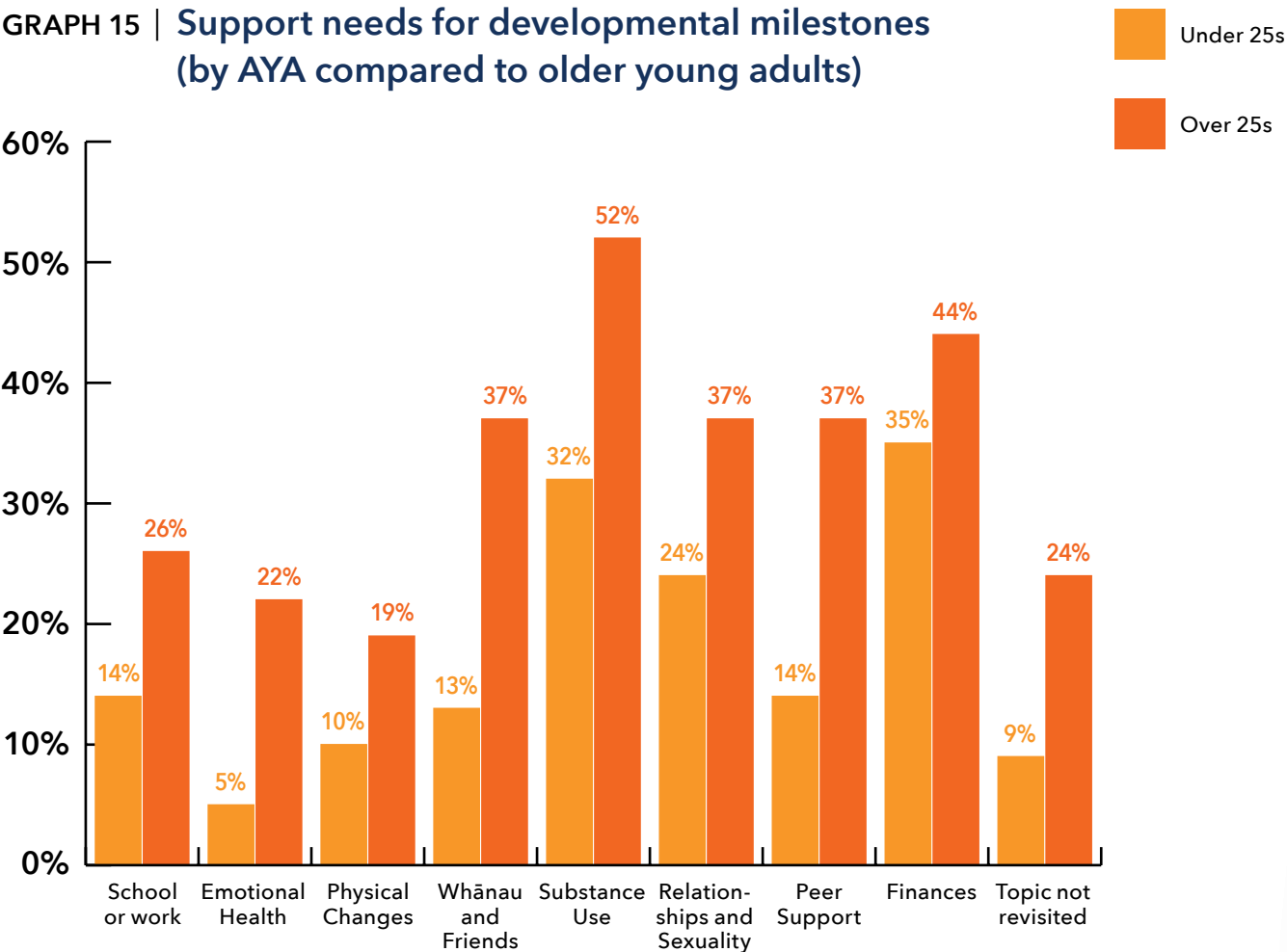
coping, good emotional health, adherence and reintegration back to healthy functioning after treatment.

In all measures related to developmental milestones and receiving help (discussion, support and/or assistance) over

25s received less help than those under 25 years. Graph 15 shows where the young person **did not receive help** regarding developmental milestones.

‘what support is there for people over 24 years old?’

GRAPH 15 | Support needs for developmental milestones (by AYA compared to older young adults)



After-Treatment

Survivorship and End of Treatment care

Providers need to recognise and address the medical and psychosocial needs of cancer survivors at the end of treatment and at regular intervals thereafter. This includes the use of a formal end of treatment summary covering the long-term effects of cancer and its treatment; identified psychosocial support resources in the community; guidance on follow-up care; prevention and health maintenance.

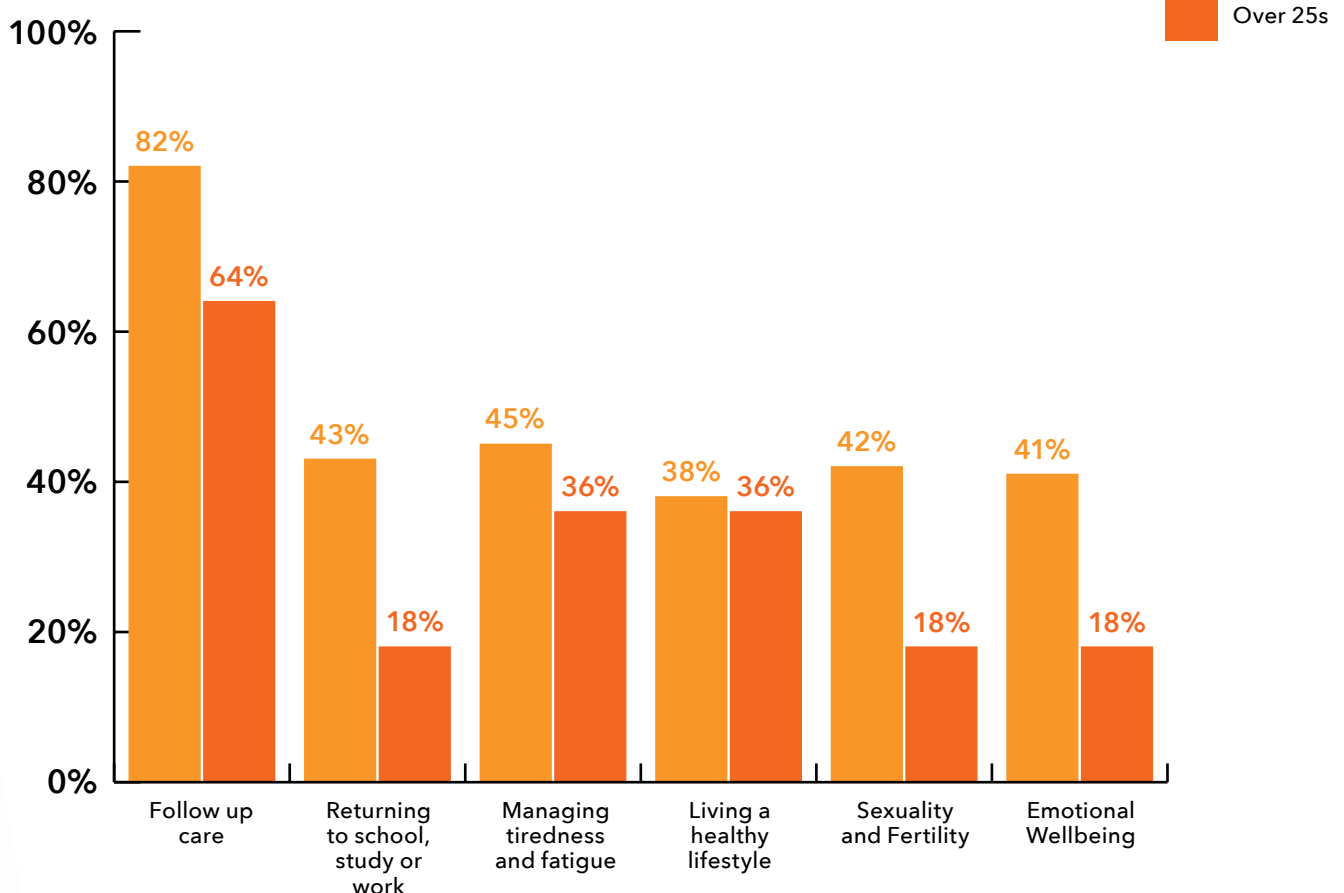
Across all areas of end of treatment and follow-up care, those over 25 fared less well than those under 25. For those over 25 years, **40%** received a written end of treatment plan compared to **57%** of under 25s.

The below graph (graph 16) gives the percentage of under 25s and over 25s who answered that they had **received support, discussion or assistance** in areas and **it was helpful**.

Under 25s/Over 25s Conclusion

Ideal AYA models of care stress the importance of care that is high quality, age-appropriate, multidisciplinary and patient-centred. The findings show disparity across all service delivery measures for the 25–30 age group in comparison to the New Zealand-defined AYA cohort. These findings indicate support for the argument for extending New Zealand's AYA upper age range to 30 years. However, more scoping and investigations would be required to inform the feasibility and appropriateness of such a change.

GRAPH 16 | Access to after-treatment support that was helpful (by AYA compared to older young adults)





Concluding Remarks -Ngā korero kua tau mai i tō mate

Whakarongo Mai: Listen to Me
provides a snapshot of the care and
support experienced by young people
diagnosed with cancer in NZ.

This report is dedicated to the young people who participated in the survey. Young people are at the heart of the AYA Cancer Network Aotearoa. The Network's kaupapa is patient centred, following the healthcare maxim "nothing about me without me".

The dedication at the beginning of this report acknowledges that through sharing your stories you enable us to learn, grow and improve cancer care and services for adolescents and young adults in Aotearoa New Zealand.

Encouragingly the stories reported through the survey illustrate that for many young people the majority of care and services they are receiving are of a high quality and are age appropriate - with psychosocial needs being met, and young people feeling involved and respected through their care.

However, this high quality care is not experienced across the whole pathway of care (before, during and after treatment) or across our AYA whānau (by domicile, age or ethnicity).

The findings show that, for the most part, the care young people experience during treatment is better than that in the before treatment and after treatment periods. Regarding inequity across our AYA whānau, the findings indicate that the care experienced by those in smaller centres, those in the older AYA age group (16-24 years) and Māori AYAs is not equitable to those in larger centres, in the younger age group (12-15 years) and AYAs who are non-Māori. This is unacceptable.

The AYA Cancer Network Aotearoa has a commitment to ensuring that high quality medical and supportive services are delivered to all. Addressing the inequities and gaps in provision of care highlighted in this report will be prioritised within our five-year national strategy for AYA cancer care in New Zealand.

We must honour the stories young people have shared. We must continue to ask ourselves "how can we do better?" We do this by listening and then acting - so we learn, grow and improve the cancer care experiences of adolescents and young adults in Aotearoa New Zealand.

Definitions

-He aha ai i penei ai te pa ō tenei mate kia koe

Clinical trials are studies with patients that test new treatments and medicines to make sure they are safe and effective.

Community Nurse: a nurse that comes to your home for help with medications, changing dressings etc.

Complementary Therapists: someone that provides therapies that complement or assist with recommended medical treatment e.g. yoga, acupuncture, massage, relaxation meditation.

Cultural Specific Support: i.e. Kaiaatawhai, Pacific support, Asian support.

Cultural Support: support that assists families and whānau to access services and ensures cultural needs are both recognised and met.

Dietitian: someone that helps you with your nutrition and assist in planning a diet that meets your unique health needs.

Things to **distract and entertain** you while undergoing treatment: e.g. art/music activities, laptop/ipad, internet access, Wii/playstation.

End of treatment summary/plan: written/typed summary or plan that includes: the treatment you received; Possible future/long term effects from your treatment; Monitoring and tests that are needed to check for new or

recurring/returning cancers; Follow up plan; Healthy behaviours and actions that could reduce your chance of cancer returning.

Fertility is defined as the ability to have your own or further children in the future.

Fertility specialist is a doctor that specialises in fertility likely working at one of the following clinics - Fertility Associates, Fertility Plus, Repromed, Genea Oxford Fertility.

Friends were allowed to support and visit you as much as you wanted: e.g. flexible visiting hours, space to talk.

A **health professional** is a doctor, nurse, social worker, physiotherapist, occupational therapist, dietitian, psychologist, or any other health provider that you may have had contact with.

Hospital School Teacher: a teacher that helps coordinate your schooling and provides extra help to keep up with studies when unwell – either at home or in hospital.

Information appropriate for your age and level of understanding: i.e. not too young, not too old, presented in a way that you can understand, written material uses images and stories that are of people of a similar age to you, offered in your preferred language.

Information on Emotional/mental health: How to manage your worries, fears and emotional issues. This may include access to psychologists, counsellor and support groups.

Information on Finances: How to manage your finances/income in connection with your cancer and treatment demands.

Information on Peer Support: Benefits of peer support i.e. meeting other young people with cancer.

Information on Physical Changes: Possible changes to your appearance and how these could be managed (e.g. obtaining a wig, Look Good Feel Better programme).

Information on Relationships/Sexuality: The impact your cancer treatment may have on your sexuality. This may cover intimacy, relationships, practicing safe sex, contraception, side effects on sexual functioning.

Information on School/Work: How your treatment may impact on your everyday life such as school, study and work. This may include offering advice and support to make sure you can continue or return later to it.

Information on Substance Use: The use of substances including tobacco, alcohol, and marijuana while undergoing treatment.

Information on Whānau and Friends: Possible changes to friendships and relationships and balancing treatment requirements with family responsibilities.

Involve you in your care and treatment: i.e. speak to you directly rather than someone else in the room, listen to what you have to say, involve you in decisions.

Non-hospital support groups e.g. Canteen, LBC, Whole Lotta Life Foundation (support groups that provide opportunities to meet other people with cancer and opportunities to take part in activities and social events).

Occupational therapist: someone that provides you with ways to make life and work more manageable with a focus on meaningful activity and function.

Pain Management Team: a team that provides knowledge in pain control methods, pain management strategies and programmes.

Palliative Care / Hospice Team: a team that focuses on relieving/helping your symptoms such as pain and/or can provide you with care and support if there is uncertainty around your survival from your cancer.

Physiotherapist: someone that helps you with your physical mobility and keeping your body fit and strong.

Procedural medication (pain relief, sedation, general anaesthetic).

Procedural supportive techniques (meditation, hypnosis).

Psychologist/Counsellor: someone that helps you with your feelings and worries. They can help you to come to terms with your situation and help you work out coping strategies.

Respecting and engaging with you and your whānau/family's culture: e.g. asking about your cultural needs, offering a translator/interpreter, correct pronunciation of your name, offering an opportunity for karakia and prayer, using appropriate greetings such as Kia ora, Talofa, Nǎi hǎo.

Social Worker: someone that supports you with financial, work or social issues and can link you in with the right services and supports.

Spiritual/Religious Counsellor: such as a Chaplain, minister, priest, spiritual therapist.

Support and assistance for Emotional Health: you were offered information and support on emotional wellbeing - how to manage fear, worry and anxiety after cancer treatment.

Support and assistance for Fertility/Sexuality: you were provided with information on sexuality and future fertility issues i.e. sexual functioning, regaining intimacy, how to go about assessing your fertility status or accessing fertility services in the future.

Support and assistance for Follow up care: you were provided with information about your follow-up care i.e. tests and check-ups you would need including late effects surveillance.

Support and assistance for Lifestyle: you were provided with information on topics such as living a healthy life style and good nutrition.

Support and assistance for School/work/study: you were provided with assistance and support to help return to school, study or work.

Support and assistance for Tiredness: you were provided with guidance and assistance in managing tiredness/fatigue and given a plan to increase your physical fitness.

Treatment areas either in hospital or outpatient areas **were suitable for people your age** e.g. privacy, space, opportunity to sit or room near others of a similar age and gender, décor etc.

Treatment environments: The term 'environments' here refers to the physical spaces you were treated in and includes everything around you - lighting, furniture, entertainment and activities, rules and regulations - and whether you feel comfortable in those spaces.

A **treatment plan** gives details regarding what types of treatment you will receive for your cancer (e.g. surgery, chemotherapy, radiation therapy) information for each step of your treatment phase information about when and how long each treatment phase will likely take.

Uncomfortable or painful procedures (e.g. IV insertion, nasogastric placement, bone marrow aspirate).

Whānau/family: any of the people who are part of your support team - family, whānau, partners and loved ones.

Whānau and/or partner were welcomed and allowed to support: e.g. flexible visiting hours, welcomed to stay with you overnight, cooking facilities.

Youth Worker/Activity Coordinator: someone that offers you activities in the hospital and provides opportunities to keep you linked in with your friends and other social activities.

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- Our survey was developed after looking at four international patient experience surveys of AYAs with cancer: BRIGHTLIGHT Survey (National Institute for Health Research, Britain); Adolescent and Young Adult Health Outcomes and Patient Experiences (AYAHOPE) (National Cancer Institute, USA);

A questionnaire about your needs and experiences during and after treatment, (Danish Cancer Society, Denmark); and Experiences of care a survey for adolescent and young adults diagnosed with Cancer (Cancer Council Victoria, Australia).

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