

# "Too Young": An Exploration of Youth Ageism in the Healthcare System

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## GLOSSARY

AGEISM	Prejudice or discrimination on the grounds of a person's age
ADULTISM	Bias or discrimination adults and social institutions demonstrate against young people on account of their youth
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, plus
NON-BINARY	Denoting or relating to a gender identity that is not defined in terms of traditional binary oppositions, male and female.
ABLEISM	Discrimination and social prejudice against people with disabilities and/or people who are perceived to be disabled

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“Young people are subject to the *legal, social and the institutional norms* and practices that *marginalise them, exclude them, and give adults the power to act on them and for them without their agreement...*”

Dr. Barbara J. Love  
(Companion Websites, 2013, 2:07)

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## ABSTRACT

Young people face a myriad of barriers when it comes to accessing, navigating, and engaging with the healthcare system. The impacts of age on young people's abilities to access services, such as costs, are well understood. However, with regard to settings such as healthcare, there is very little research regarding age discrimination or ageism towards young people and the effects of such on system access and navigation.

The purpose of this research report is to explore, not only the impacts of age, but of ageism, on young people's experiences within the healthcare system.

An online survey was conducted, with 61 young participants, aged 12-24. Survey questions were developed to gain an understanding of general attitudes and opinions of young people with regard to ageism, as well as the frequency of experiences of ageism, both in general society and within the healthcare system. Respondents were also given the opportunity to share further about any experiences of ageism through an open-response question at the end of the survey.

The quantitative findings indicate the significance of ageism in the lives of young people, with an overwhelming majority indicating experiences of ageism, and an overall opinion that ageism towards young people should be taken more seriously. Similarly, the qualitative findings indicate clear and compelling considerations for healthcare practice with young people, particularly those living with chronic conditions and disabilities.

I conclude that ageism towards young people in healthcare is a considerable issue; one that requires far more attention within future research. Recommendations include a focus on intersectionality within future research, future research regarding young people with chronic illness/disability, and collaboration and codesign with young people on any system changes and service design.

## INTRODUCTION

Barriers experienced by young people in accessing and engaging the healthcare system are well documented across disciplines. There exists, however, a significant gap in our understanding of the direct and explicit impacts of age and age discrimination on young people's experiences within healthcare. The vast majority of literature regarding age discrimination in healthcare explores older people's experiences. We therefore understand that age, and the biases, stereotypes and attitudes that come with it, can have massive impacts on one's ability to safely, effectively, and comfortably access and utilise healthcare. Why then, do we not apply this lens to a younger group?

Do we believe that the stereotypes we hold of young people, such as 'naive' and 'risk taker', are justified while those of older people are not? Research regarding structural and attitudinal barriers present for young people is integral and has shaped our understanding of what makes healthcare 'youth-friendly', however by overlooking the essential component of age and the potential for explicit and implicit age discrimination within healthcare, we are doing young people a disservice. Currently, there are more than 4 million young people (aged 12-24) living in Australia, the majority of which are living in New South Wales (Australian Bureau of Statistics, 2020). Thus, the impact of these issues is potentially immense.

The purpose of this research project is to explore young people's experiences of age discrimination, sometimes referred to as ageism or adultism, within the healthcare system. This research and the subsequent findings, discussion and recommendations attempt to capture insight into young people's understanding of age discrimination, their opinions and attitudes towards the ways age impacts on power and social relations, and perceived experiences of age discrimination. It is hoped that through this preliminary research, a foundation for understanding ageism, as it is experienced by young people, can be developed. This research will inform any recommendations formulated with the aim of ultimately improving young people's access, engagement, and navigation of the Australian healthcare system.

## DEFINING AGEISM, ADULTISM & AGE DISCRIMINATION

Throughout this report the terms 'ageism against young people', 'adultism' and 'age discrimination' may be used interchangeably. This is because, while 'adultism' is the most correct term for the ways in which young people are discriminated against and oppressed in an adult-tailored society, its usage is not mainstream and is easily misconstrued. Similarly, while 'ageism' can be understood as a general term for age discrimination, not specific to any age group, it is most commonly used to refer to the experiences of older people and therefore may become confusing if used in isolation. Thus, 'ageism against young people' will be used in order to ensure accuracy.

The term 'adultism', first coined in 1978 by psychologist Jack Flasher, refers to the "oppression experienced by children and young people at the hands of adults and adult-produced/adult-tailored systems" (LeFrancois, 2014, p. 47). Through this, we can begin to conceptualise the ways in which systems and structures tailored for adults may oppress young people. Adultism is systemic, social, and individual. It allows us to examine the socio-political and power disparities between adults and young people through a new lens. We tend to view the adult power over young people as inherent to the adult-child/adult-young person relationship. We must also, then, examine the ways in which this creates adult privilege, policing of young people and unnecessary power differentials, particularly within healthcare settings.



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“I think I’ve been quite lucky in that I have extremely supportive and understanding family.

If my family were either unwilling or unable to assist me, accessing appropriate health care would be very difficult.

Female Respondent, 21-24

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## PREVIOUS RESEARCH

There exists very little research directly related to the research topic. However, for the purpose of reviewing previous literature, pieces from several different areas of study have been collated to form an understanding of the context in which this research will exist.

## ADULTISM: POWER, PRIVILEGE & POLICING

While adultism is an under recognised concept, it has found some traction in youth advocacy spaces. DeJong and Love (2015) explore adultism as a social justice issue; conceptualising young people as a social identity group subordinated in systems of adult power and privilege. The authors examine relevant literature to construct an understanding of youth as created within a socio-political framework, used to define adulthood as much as it defines youth itself. It is through this that the authors describe the subordination of young people within a hierarchical system in which adults are the dominant group and the only means through which young people can access power. The authors illustrate this by drawing on an example from a study which explored young people's experiences in youth leadership roles within decision making bodies and the ways in which their presence was tokenised and constrained by the system. In this example, a young member of a school committee expresses a differing view from the adult committee members and has no support to effectively contribute to decision making. In this example, the adult members benefit from being able to tokenise a young person without having to relinquish any of their power to the young person. Not only does this scenario do nothing to deconstruct the systems that constrain young people's social political power, but it also actually works to heavily reinforce them. This example illustrates some of the ways in which adultism manifests in our everyday lives. Research on youth healthcare may ask for young people's opinions, but is it enough to simply ask young people what they need but not act on the information and insight provided by them, nor partner with them on design and implementation of services and systems?

While this article successfully exhibits gaps in our consideration, it is important to note that this is written about young people and not with or by young people. The authors do, however, call for the creation of welcoming spaces for young people to reflect and talk about their experiences related to age. This article is significant to the context of this research project, as it assists with conceptualising young people in relation to adults and the systems in which they exist. If we consider the scenario of a young person and an adult healthcare professional, it is integral to explore the potential impact of adultism and the power and socio-political relations that come with it.

Gordon (2007) substantiates this conceptualisation of young people and adultism by DeJong and Love (2015). The author observed two youth movement organisations over a two-year period, studying the presence and impact of adultism and the ways in which the young people involved navigated this issue with their adult counterparts. The author echoes DeJong and Love's (2015) conceptualisation of youth as a socially constructed category used to define and give power to 'adulthood'. The author notes that adolescence and youth "function to maintain adult identity, value systems, and power, and result in young people's actual lived realities of political, economic, and social oppression" (p. 634). Further, in the author's observations and interviews, the theme of tokenisation is present. This is consistent with the suggestion of DeJong and Love (2015) that adults can benefit from youth participation without facilitating genuine participation and inclusion of young people. This is demonstrated by a young person quoted by Gordon (2007); "At adult meetings, they tokenise your ideas... they ask for your input, knowing that they are already going to do what they're going to do... a lot of times it is pointless for you to even be there" (p. 641). The consistency of this theme across literature spanning decades indicates the prevalence and significance of the issue.

While this article is limited in its relevance by its age, its central themes and ideas are echoed by the more current work by DeJong and Love (2015). Further, this article is strengthened by its inclusion of young people's voices. This article aims not to tokenise the experiences of the young activists involved, but to provide a platform to validate their experiences. This article offers significant insight into not only the existence of adultism but the ways in which young people have grown to navigate it.

## POWER: AGE & EXPERTISE

Hickey and Pauli-Myer (2019) view the experience of young personhood as constrained by adult power and adult systems. The authors examined the interactions and experiences of a youth council engaged with a local government in Queensland, Australia. The youth council was composed of 12 specifically selected young people, between the ages of 13 and 24. This initiative was designed with the intent to engage young people in public decision making. Despite assurance that the youth council was a space for the young people to share their thoughts and ideas, the young people's abilities were heavily restricted both covertly by the systems in place, and directly by the participating adults themselves. The authors found that, ironically, the presence of a youth council worked more to reinforce stereotypes of young people as incapable and unwelcome in adult systems than it did to dispel them.

"This interplay of promise and inaction left a confusing array of mixed messages on what was possible, how the young people's views might be enacted in practice, and ultimately, what place these young people held as active citizens" (Hickey & Pauli-Myer, 2019, p. 373).

This echoes the themes found in the works of DeJong and Love (2015) and Gordon (2007). Young people are constrained by the systems that are built by and for adults. This offers them little to no power to enact any sort of meaningful autonomy, particularly within decision making spaces. When we consider the interplay between adult power and young people as one defined by constraint, we can begin to conceptualise the ways in which power relations and perceived constraint may manifest within healthcare settings.

Gabel (2012) discusses the concept of social power and the ways in which healthcare professionals possess and exert power. The author reviews the six bases of power, as defined by Raven (1959, as cited in Gabel, 2012) and explores the ways in which each may manifest in a healthcare setting. Doctors may possess any of the six primary bases of power, however the most commonly held are expert power, legitimate power, and informational power. These are defined as influence exerted by a person based on the position or authority they hold, on their recognised knowledge and expertise, and on the information they provide, respectively. These types of power and influence can overlap and intertwine throughout the relationships and interactions they exist within. Gabel (2012) provides an example, describing a doctor-patient interaction in which the doctor holds expert power and the patient is left feeling dismissed and unheard. The example exhibits the subtlety of power relations and the ways in which patient care and health outcomes can suffer due to a misuse of power by healthcare professionals.

If we consider the themes and examples provided by Hickey and Pauli-Myer (2019) and Gabel (2012), a picture of the potential interplay between adult power and expert power can be developed.

Consider a young person accessing a healthcare service, seeing an older, experienced doctor. The power relation between these two people is likely to be highly unbalanced. As both articles exhibit, the party holding the power is in control; when used effectively, power can be used to empower the other and balance the interaction. When used ineffectively, however, power can have detrimental effects.

## IMPLICATIONS OF OLDER AGEISM IN HEALTHCARE

The existence of ageism within the healthcare system is a well-documented issue, with significant evidence exhibiting the impacts of ageism on healthcare decisions, patient experiences, and health outcomes. While this evidence is almost all based on older patients, much of our understanding of ageism in healthcare can be used to conceptualise the ways in which adultism, or ageism towards young people, may also manifest in healthcare.

Ouchida and Lachs (2015) explore the presence of ageism in three different spaces: among healthcare providers, among older people, and within the healthcare system. The authors examine the effects of healthcare providers' knowledge and attitudes can have on care they provide, for example dismissing a symptom as an aspect of old age, rather than investigating the symptom and attempting to alleviate it. The authors go on to explain the explicit and implicit ways ageism can manifest within a healthcare provider's practice. Acts such as mocking older patients in front of other staff and disparaging gerontology as a medical speciality are given as examples of explicit ageism. The authors then outline implicit ageism as implicit thoughts, behaviours, and attitudes towards older people. Both types of ageism can be just as harmful as the other and lead to mistreatment, misdiagnosis, under or over treatment, and thus negative health outcomes.

In addition to this, Ouchida and Lachs (2015) exhibit the ways in which older people themselves perpetuate ageist ideas, potentially impacting their healthcare. Negative self-perception and stereotyping are not an uncommon experience and the potential impacts on healthcare are numerous. The attribution of certain issues or symptoms to certain age groups is shown to be a way in which older people exhibit ageist ideas, thus affecting their healthcare. This is an issue that, I predict, can also have an immense impact on young people's healthcare. When we incorrectly attribute illnesses, disabilities, or symptoms to ageing, or to an older age group, it can create a barrier to access for younger people who will thus potentially be dismissed as not possibly experiencing such issues due to their age. This exhibits the ways in which many of the issues explored in ageism research can also translate to the experiences of young people. This article provides a basis for understanding the numerous impacts of ageism and bias on healthcare. Through this basis of understanding, we can then conceptualise the ways in which young people may be experiencing health care and the impacts age and age discrimination may have on a younger cohort.

Wyman, Shiovitz-Ezra and Bengel (2018) mirror the ideas put forth thus far. With discussion of stereotyping, implicit and explicit ageism, and the impacts of such, they, like Ouchida and Lachs (2015), explore ageism within the healthcare system, among older people, and among healthcare providers. Again, this literature only examines the experiences of older people, though many of the concepts explored are applicable to other demographics and help to flesh out the foundation of understanding of ageism in healthcare. According to the authors, there is abundant research noting negative attitudes towards older people among healthcare providers. They note that the attitudes of healthcare providers are obviously highly varied and unique, with some research indicating clear negative attitudes, and some indicating mixed results. The authors do note, however, a clear

association between negative attitudes and practice decision making of healthcare providers. Studies indicate a correlation between implicit bias against different demographics including age may impact clinical practice decision making of healthcare providers, such as the questions they ask patients, the investigations they choose to implement and any screening or testing they choose to perform. The authors provide examples of the ways this may impact older patients, such as doctors being less likely to perform breast cancer screenings on older patients compared to younger patients, despite the likelihood of breast cancer increasing with age (Wyman, Shiovitz-Ezra & Bengel, 2018). This issue of stereotyping and implicit bias is likely to affect young people also, despite the lack of research regarding youth ageism in healthcare.

This is reflected in Fitzgerald and Hurst's (2017) systematic review of literature, which examined evidence of implicit bias among healthcare providers. They identified 42 eligible articles, 35 of which concluded the presence of implicit bias among healthcare providers. Fitzgerald and Hurst (2017) acknowledge the nature of implicit bias; while we can consciously reject stereotypes and biases and aim to treat every person equally, we are so deeply immersed in cultures that enforce such stereotypes, that our view and treatment of certain groups may be subtly and unconsciously influenced by implicit bias. This study indicates a similar degree of implicit bias among healthcare professionals when compared to the general population. This exhibits the pervasive nature of implicit bias, even among professionals whom we assume to be unbiased in their practice. While the strongest and most common biases found were race/ethnicity and gender, age was also a factor found to be subject to implicit bias among healthcare professionals. This lends towards the notion that young people may receive inadequate healthcare because of their age and the assumptions and implicit stereotypes and attitudes that come along with it.

Lastly, Chrisler et al. (2016) discuss ageism within healthcare through an intersectional lens. The authors discuss the impact of sexism in conjunction with ageism and the ways in which both manifest in healthcare settings. This parallels much of the research regarding implicit bias and ageism in healthcare, offering a deeper intersectional lens through which to view patient's engagement with the healthcare system. The authors outline the ways in which "cumulative burden" of intersectional identities can impact heavily on the healthcare received by older women. However, gender bias and sexism do not have an age limit, thus affecting young women and girls too. This understanding put forth by Chrisler et al. (2016) is directly translatable to a younger demographic, however, this requires specific, intersectionality-focused research with young people.

## AGEISM TOWARDS YOUNG PEOPLE

As discussed, ageism is a term most often used to describe age discrimination against older people and there is very little data to indicate the explicit existence of 'ageism' against young people. However, in an analysis of the European Social Survey 2008, Bratt et al. (2018) found significant evidence of ageism experienced by young adults. The authors conducted an analysis of the 2008/2009 European Social Survey, containing data collected from in-depth interviews conducted in 29 countries (n= 56,272) across Europe, in order to explore differences in perceived age discrimination across age groups. The authors assessed the data across countries, ages, and age groups in order to analyse the data effectively. The findings exhibited that young adults showed the highest levels of perceived age discrimination of all the age groups.

Further, the authors note a significant difference in levels of perceived age discrimination across parts of Europe. The data indicates that Northern European countries, noted by the authors as generally perceived to be more "modern and egalitarian" (p.176) than Eastern and Southern

European countries, exhibit low perceived discrimination among older adults and notably high perceived discrimination among young adults. This is potentially due to a focus on older ageism through social campaigns and government assistance, services, and programs. This is an interesting note when considering the Australian context; with an ageing population and several social campaigns focused on reducing ageism against older people, how has this impacted on both older people and younger people?

Bratt et al. (2020) utilise the same data to explore this concept. The authors hypothesise that “older people are less likely, and younger people more likely, to suffer age discrimination if they live in a country with stronger structural support for older people” (p. 1029). Similarly, the authors also hypothesise that strong social norms against age discrimination reduces age discrimination against older people but does not inhibit age discrimination against young people. Again, the authors assessed data from the 2008 European Social Survey to test their hypotheses. The authors identified two age groups to compare: those aged 70-105 (n=8117) and those aged 15-29 (n=11647).

The findings of this analysis support both hypotheses. The authors found that structural support of older people predicted less experiences of age discrimination among older adults and more frequent experiences of age discrimination among young people. Similarly, social norms against ageism were found to be a “substantial and negative predictor of age discrimination experienced by older respondents... [and] a weak and positive association with experiences of age discrimination among younger respondents” (p. 1034).

These findings are significant and note the impact of ageism campaigns and age-based structural support. While the data analysed in both of these studies is aged, the recent nature of the studies indicate the ongoing nature of this issue. The authors also note the limitations of quantifying complex personal experiences and different perspectives. However, this evidence remains significant and lends well to beginning to understand how structures and systems are tailored for adults and actively work to subordinate young people, allowing for discrimination in settings such as healthcare.

## YOUTH & THE HEALTHCARE SYSTEM

There exists considerable research into what makes healthcare more accessible for young people. However, the implementation of the recommendations put forth in such research appears to be lacking within the Australian healthcare system (Kang et al., 2018). Particularly for young people with chronic conditions and disabilities, the transition from the paediatric system into the adult system can be highly fragmented and difficult (Robards et al., 2018; Robards et al., 2019b). Similarly, while there is a specific system for children, and young people aged 18-24 are legally adults, this age group possesses some significantly unique and complex needs and experiences that the adult system does not currently accommodate adequately.

Edwards (2016) partnered with young people, gathering their collective experiences to identify areas of consideration for health care professionals, and to design a framework to aid healthcare professionals in working effectively and respectfully with young people. 12 young people were selected, aged 17-25, who are ‘experts by experience’ through regular contact with the healthcare system due to chronic illness and/or disability. The author not only collaborated with the young people involved but co-authored alongside the young people in order to ensure that their experiences and

voices were front and centre. The main themes identified throughout the young people's experiences were communication, relationship and respect, privacy and confidentiality, environment, family and friends, involvement, information, and preparation, and feeling connected. It is clear throughout the article that the young people possessed clear ideas of the gaps within the healthcare system and the ways in which their unique and complex experiences were not catered to adequately by the adult system.

Similarly, Turner et al. (2017) identified several barriers to young people seeking and receiving healthcare in Australia. The authors conducted a survey at a single high school in Tasmania, receiving 155 responses from students aged 16-18. The aim of the survey was to identify what young people value when engaging with general practice healthcare. Results from both Edwards (2016) and Turner et al. (2017) indicate a clear need for improved communication between healthcare professionals and young people. Both studies indicate that young people value effective communication very highly and these needs are not currently being met to an adequate degree. The concepts discussed thus far including power relations and adultism may contribute to the lack of effective, age appropriate and respectful communication between young people and healthcare professionals. Turner et al. (2017) also identified accessibility barriers such as cost, transport, opening hours of services and confidentiality concerns to be among the most prevalent among the students surveyed.

This is echoed by Robards et al. (2019b) who identified barriers to healthcare for young people in three main categories; structural barriers, attitudinal barriers, and barriers associated with emerging autonomy. 1416 young New South Wales residents, with an oversampling of marginalised groups, participated in a cross-sectional survey. As this study is New South Wales based, the data collected is extremely valuable to this research report.

As stated, Robards et al. (2019b) identified several barriers to healthcare present for the young people surveyed. The findings indicate a parallel with other research such as Edwards (2016) and Turner (2017); barriers such as cost, transport, opening hours, confidentiality concerns, fear of embarrassment, parental presence, and a lack of understanding of systems and services such as Medicare. The consistency of these cited barriers across the research indicates the pervasive and continuous lack of support for young people in accessing healthcare, despite the identification of barriers. Robards et al. (2019b) also discuss the impact of marginalisation on healthcare access for young Australians. The findings indicate that respondents with chronic health conditions, disability and/or mental health conditions were more likely to report *all* barriers. This is perhaps due to a higher engagement with the healthcare system, thus higher opportunity to encounter barriers, as well as other factors associated with chronic illness and disability such as financial stress and accessibility concerns.

Echoing this, a report by the Australian Institute of Health and Welfare (2020), focused on the experiences of patients with chronic conditions, found that experiences of young patients and older patients differed significantly. This report was based on data from the Patient Experience Survey from 2017-18, totalling 28,243 complete responses. The survey is open to those over 15 years of age. The report found that younger people, regardless of health status, were more likely to report that healthcare professionals did not listen carefully to them, spend adequate time with them, or show respect for their opinions and experiences. This speaks to the issue present for young people engaging with the healthcare system, beyond structural barriers like cost. This report notes the impact of a significant lack in healthcare professionals' interpersonal interactions with many young patients, including negative perceptions of healthcare professionals and the healthcare system, forgone

healthcare, and negative long term health outcomes. These findings are hugely significant to the current study and indicate the need for research such as this.

## THE IMPACTS OF MARGINALISATION: INTERSECTING ISSUES

Lastly, Robards et al (2019a) look deeper into the impact of marginalisation on healthcare access among young Australians. Through a longitudinal study involving 2-4 interviews with 41 young people (aged 12-24) over a 6–12-month period, the authors capture a picture of healthcare navigation as it exists for marginalised young people in New South Wales. The groups identified for this study were those living in rural and remote areas, sexuality and/or gender diverse people, those experiencing homelessness, refugees and asylum seekers, and/or Aboriginal and Torres Strait Islanders young people.

The findings of this study showed clear and distinct impacts of marginalisation on healthcare access and navigation. However, the main theme that emerged from the young people's stories was one of ambivalence. Several participants indicated having to weigh up their options of healthcare for financial, health, convenience, and effectiveness, with navigation of the system "becoming a trade-off" (p. 6). This led to many young people going without the healthcare they needed. The authors note the overarching notion of "uncertain movements through a complex, fragmented system over time" and the impact of such on young people's health, wellbeing, and view of the healthcare system (p. 5). Further, the authors found a distinct link between multiple marginalisation (i.e., belonging to more than one marginalised group) and compounding barriers and difficulty in access and navigation. These findings indicate a clear need for an understanding and utilisation of an intersectional lens among healthcare professionals, policy makers, systems, and services.

As DeJong and Love (2015), Gordon (2007) and LeFrançois, (2014) conceptualise youth as an oppressed group subject to adult-created and adult-tailored systems such as the adult healthcare system, the compounding effect of multiple marginalisations may be increased for young people due to their age. Through the research outlined in this section, it is hoped that an understanding of the function, systemic place, and powerlessness of youth within society has been established. By beginning to understand and conceptualise the ways in which young people may be marginalised due to their age within the systems and structures of society, a deeper and more effective understanding of healthcare access and navigation can be developed in order to address the plethora of barriers faced by young people in Australia.



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“Young people may be appreciated for their vigour, their energy, and their enthusiasm, but their participation is nevertheless restricted.”

Dr. Barbara J. Love  
(Companion Websites, 2013, 2:07)

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## AIM

The aim of this study was to explore young people's opinions regarding various aspects of ageism, their experiences of ageism within various settings, and their specific experiences with the healthcare system.

## METHODOLOGY

This study used mixed methods research, using an online survey (see Appendix B) containing questions designed to collect both quantitative and qualitative data. The survey consisted of three sections: demographic questions, opinions and experiences of ageism in general, and opinions and experiences of ageism in the healthcare system. Demographics questions asked included age, gender, and geographic location. From here, Likert Scale questions were utilised in order to gain an understanding of respondents' levels of agreement with particular statements and frequency of particular experiences outlined in the questions. An optional open-ended question was utilised at the end of the survey to gather any further experiences respondents chose to share.

Additionally, an email address was provided in the survey preamble should respondents choose to elaborate on their experiences, or if they would like to receive the final report based on the survey. The online survey could be accessed through a link and was completely anonymous. Responses were entirely voluntary, and respondents were assured of their right to anonymity and confidentiality should they wish to further contact the email address provided in the survey preamble.

The survey was distributed through social media (Facebook, Instagram, Twitter) and well as directly to young people, and was featured in the December 2020 edition of Health Consumers NSW newsletter, the WRAP. Social media was utilised to disseminate the survey, allowing respondents to access the link easily. The posts created for the survey were shared by multiple individuals over the course of the period that the survey was open.

## DATA ANALYSIS

Quantitative analysis of the survey results was conducted using descriptive statistics. Raw data was analysed and summarised into tables and graphs, with the mode of responses being used to infer the prevalence of particular attitudes, opinions, and experiences.

The ordinal data was analysed with descriptive statistics including the frequency distribution and measures of central tendency such as the mean. Demographics were used to compare data where relevant.

A thematic analysis of the qualitative data collected through the survey was also undertaken. Several themes were identified through the coding of 26 long-response answers provided by respondents.

## KEY FINDINGS

The online survey explored young people's (aged 12-24) attitudes, opinions, and experiences of ageism, both in general and within the healthcare system. Key findings from this survey are as follows.

It was found that 52 respondents (85.25%) indicated having experienced ageism, with 6 (9.84%) respondents indicating 'maybe', and only 3 (4.92%) respondents indicating not having experienced ageism at all (see Figure 1). Of those who indicated having, or potentially having, experienced ageism, it was found that the majority of these experiences occurred within a healthcare setting (73.68%), followed by a school setting (63.16%) and in a public setting such as public transport (57.98%) (see Figure 2).

Consistency in opinions was found among respondents in several areas (see Figure 3). The findings show that 91.81% of respondents agreed or strongly agreed with the statement "ageism towards young people is an issue that needs more attention within systems and services such as healthcare" (see Figure A1). No respondents disagreed with this statement. Similarly, 100% of respondents either agreed or strongly agreed with the statement "young people have unique needs and experiences, just like any other age group" (see Figure A2). Lastly, in response to the statement "young people are often overlooked as a group with unique needs, experiences and voices", 91.81% of respondents either agreed or strongly agreed (see Figure A3). Respondents were also asked how frequently, if at all, they had experienced various situations, such as being dismissed or being left out of important decisions because of their age. Perceived experiences of condescension and dismissal were prominent and consistent (see Figure 4).

Attitudes and experiences with ageism in healthcare settings were varied, with responses spread more across the spectrum provided. However, there was generally a clear attitude across respondents regarding areas such as ease of navigation of the healthcare system, healthcare professionals understanding of young people's needs, and difficulties regarding self-advocacy and 'speaking up' within healthcare settings. Respondents were asked to rate their overall experiences with the healthcare system on a scale of 1 to 10 (1 being the worst, 10 being the best). The mean response was a rating of 5 out of ten (see Figure 5). Further, 45 (73.77%) respondents indicated having experienced ageism in the healthcare system, with 12 (19.67%) respondents indicating 'maybe' and only 4 (6.56%) respondents indicating not having experienced ageism within the healthcare system at all (see Figure 6). The most commonly reported settings of healthcare ageism were general practice, specialists, and mental health settings (see Figure 7).

Key comparisons in data reveal a potential for compelling findings regarding the intersectionality of healthcare experiences and marginalisation. Respondents who identified themselves as non-binary or another variation from the binary male/female genders, were more likely to give lower ratings of their overall experience with the healthcare system (see Figure A6), and higher rates of having experienced ageism, than those who identified as 'male' or 'female' (see Figures A4 & A5).

Lastly, over a third of respondents chose to share their experiences in more detail through the open-ended response question at the end of the survey. This offered great insight into the experiences of young people, as well as speaking to the importance of the issue to many and the eagerness to discuss this issue. Many of the responses indicated that the respondent had a chronic condition or disability. This is unsurprising as these young people are more likely to have had regular contact with the healthcare system, as well as more complex healthcare journeys.

## MAIN FINDINGS

61 young people (12-24) completed the online survey for this research project. The full set of results can be found in Appendix C.

### DEMOGRAPHICS

- 10 (16.4%) respondents were aged 12-14, 4 (6.6%) were 15-17, 10 (16.4%) were 18-20, and 37 (60.7%) were aged 21-24 (see Table C1)
- 9 (14.75%) respondents were male (with 1 of these 9 respondents also selecting to self-describe as a trans man), 45 (73.77%) were female, 4 (6.56%) non-binary, 2 (3.28%) preferred not to say, and 1 (1.64%) self-described as gender fluid (See Table C2)
- 37 (60.66%) of respondents lived in a large city, 11 (18.03%) respondents lived on the edge of a large city, 8 (13.11%) respondents lived in a regional town and 5 (8.2%) respondents in a rural area. No respondents indicated residing in a remote area (see Table C3)
- 33 (54.1%) respondents were from New South Wales, 9 (14.75%) were from Victoria, 4 (6.56%) from the Australian Capital Territory, 3 (4.92%) from Western Australia, 1 (1.64%) from Queensland, 1 from Tasmania, and 1 from the Northern Territory. 9 (14.75%) respondents were from another country including the United States, the United Kingdom, New Zealand, and Finland (see Tables C4 & C5)

### AGEISM IN GENERAL SOCIETY

Respondents were provided with a brief description and example of ageism and were then asked if they believed they had experienced ageism as a young person (see Table C6). In response:

- 52 (85.25%) respondents selected 'yes'
- 6 (9.84%) selected 'maybe'
- 3 (4.92%) selected 'no'

Question: Do you believe you have experienced ageism as a young person?

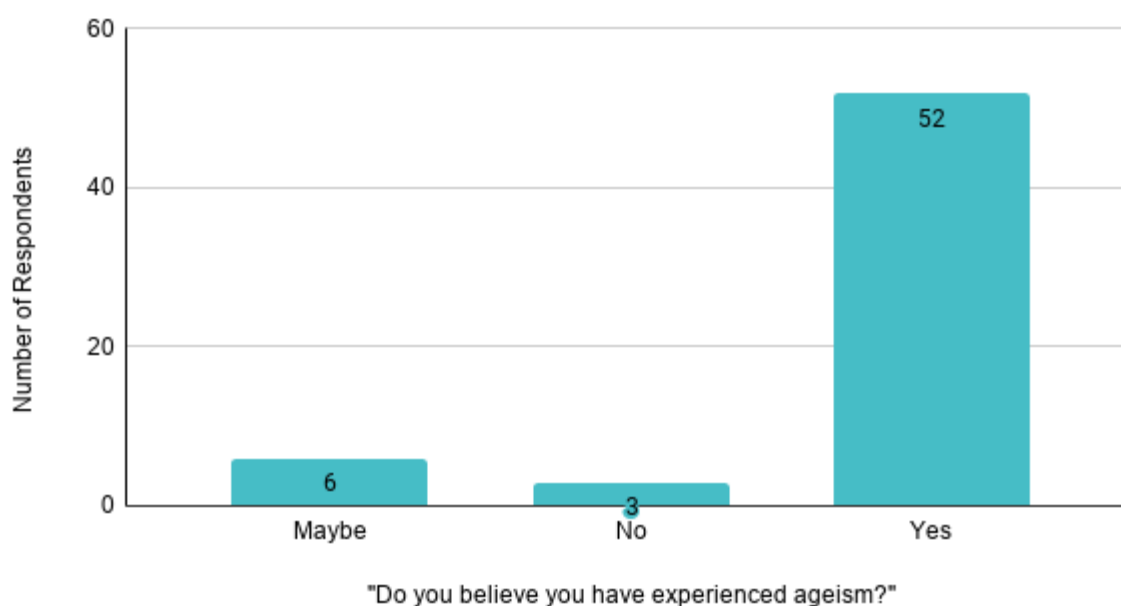


Figure 1

### Where does ageism occur?

Of those who responded 'yes' or 'maybe', the most frequent settings in which ageism occurred were:

- in a healthcare setting (indicated by 73.68% of respondents)
- in a school setting (indicated by 63.13% of respondents)
- in a public setting (indicated by 57.89% of respondents)

Question: Where has this happened to you (you can select more than one option)?

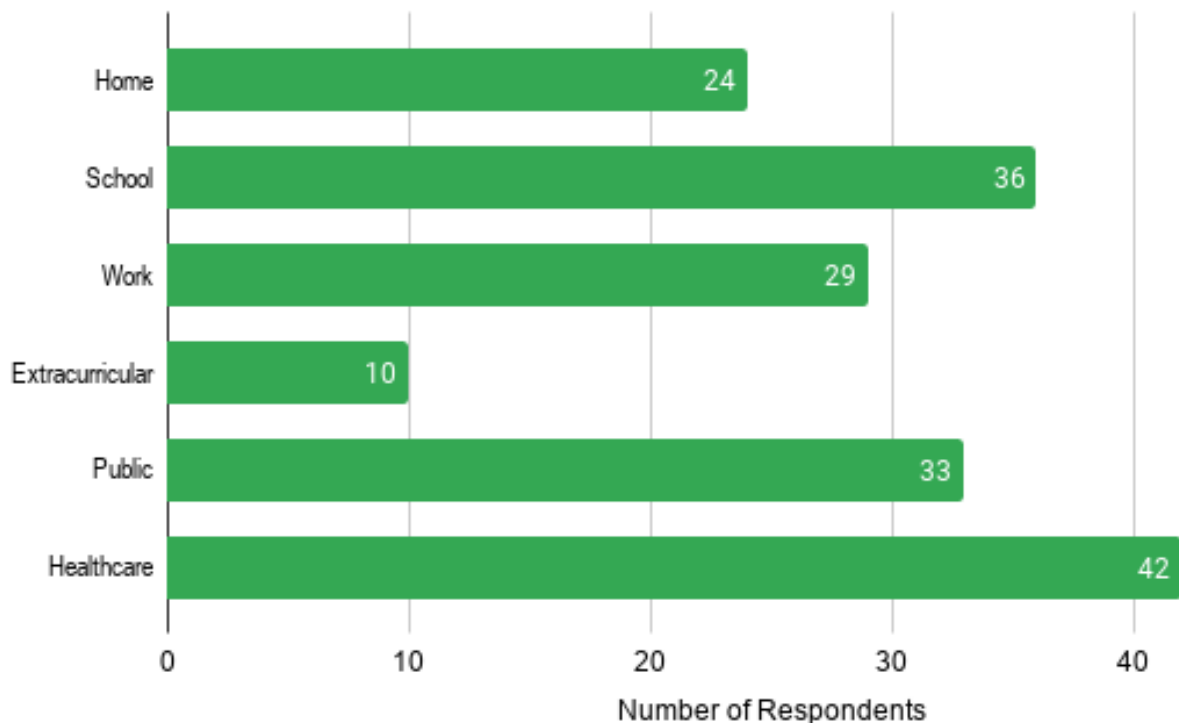


Figure 2

See Table C7 for detailed results.

### Opinions and Experiences of Ageism

Four Likert Scale questions were utilised in the survey. These were questions 7, 8, 12, and 13. Questions 7 and 12 use a scale from 'Strongly Disagree' to 'Strongly Agree', and questions 8 and 13 use a scale from 'Never' to 'Usually'. These questions were utilised to capture respondent's attitudes towards ageism, as well as the frequency of certain experiences relating to ageism, both in general and within the healthcare system.

Significant agreement was found in several areas including stereotyping of young people, ageism as an important social issue, and the unique nature of young people's needs and experiences. The following figure (Figure 3) exhibits this.

Question: Please tell us how much you agree with the following statements...

See Table C8 for detailed results.

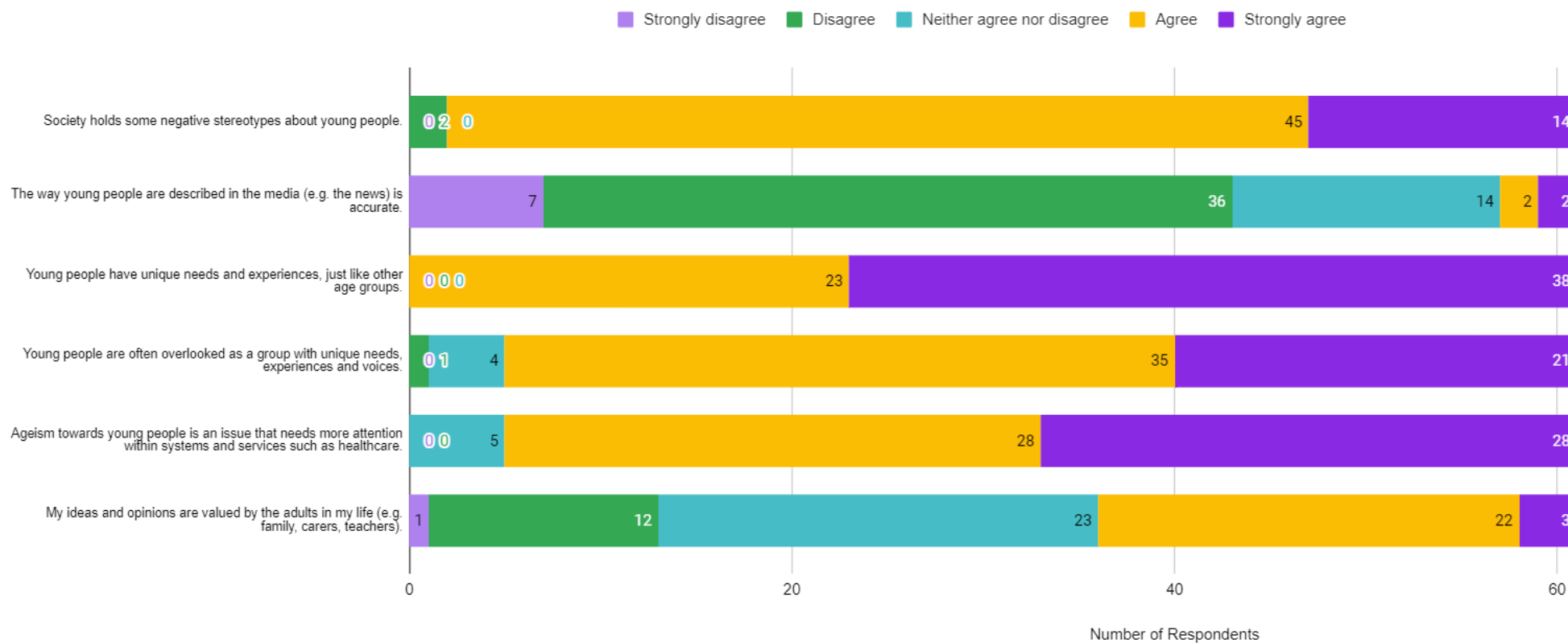


Figure 3

Question: Please tell us how often, if at all, you have experienced the following...

See Table C9 for detailed results.

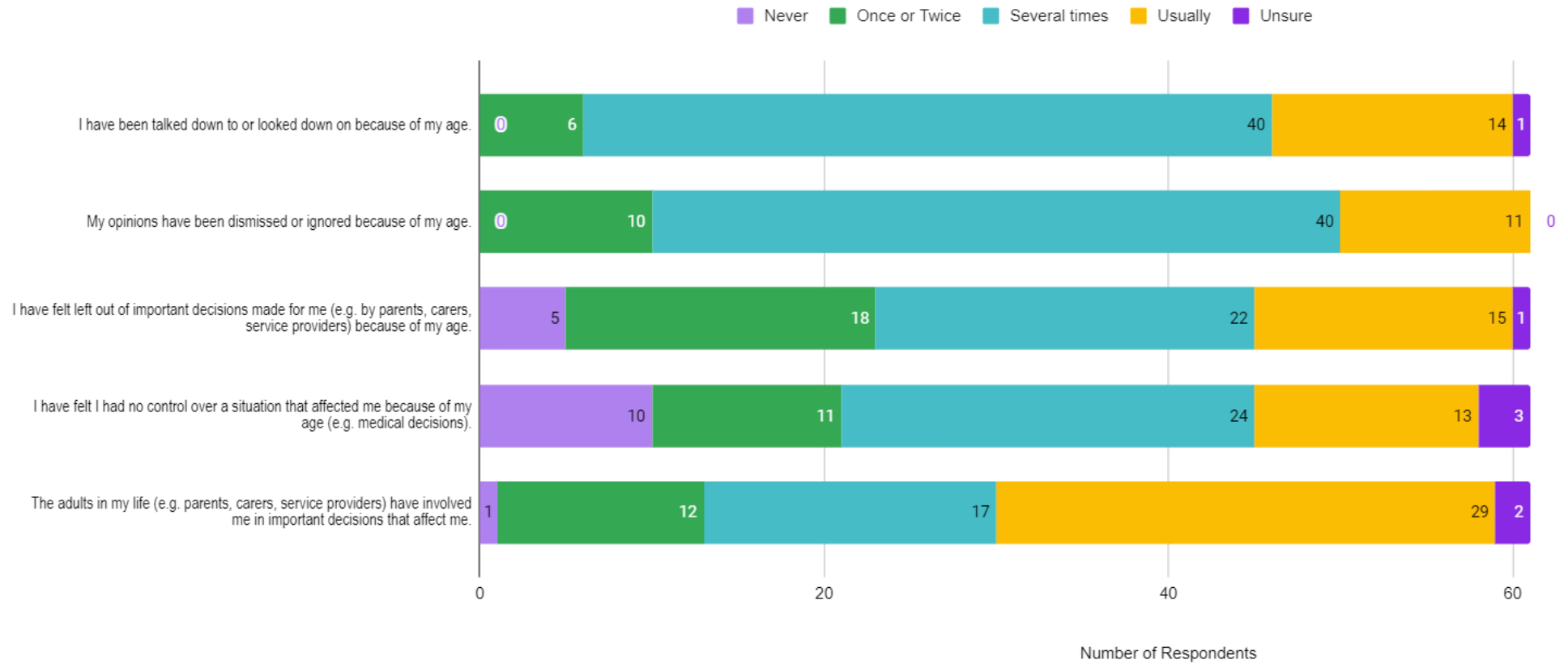


Figure 4

Figure 4 exhibits the frequency of certain experiences as reported by survey respondents.

## AGEISM IN HEALTHCARE

Respondents were asked to rate their overall experience within the healthcare system on a scale of 1 to 10 (with 1 being the worst and 10 being the best). The results indicated a mean of 5, and mode of 7. See Table C10 for detailed results.

Question: On a scale of 1 to 10 (1 being the worst and 10 being the best), please tell us your overall experience with the healthcare system as a young person.

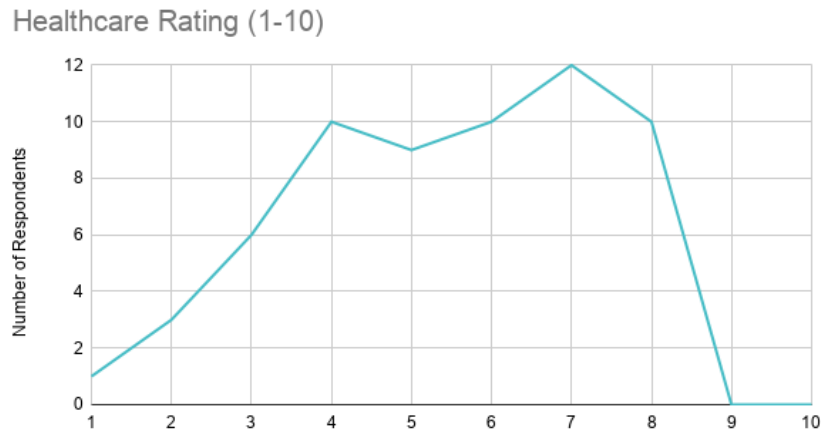


Figure 5

Respondents were then asked if they believed they had experienced ageism within the healthcare system (see Figure 6).

- 45 (73.77%) selected 'yes'
- 12 (19.67%) selected 'maybe'
- 4 (6.56%) selected 'no'

Question: Do you think you have experienced ageism while using a healthcare service?

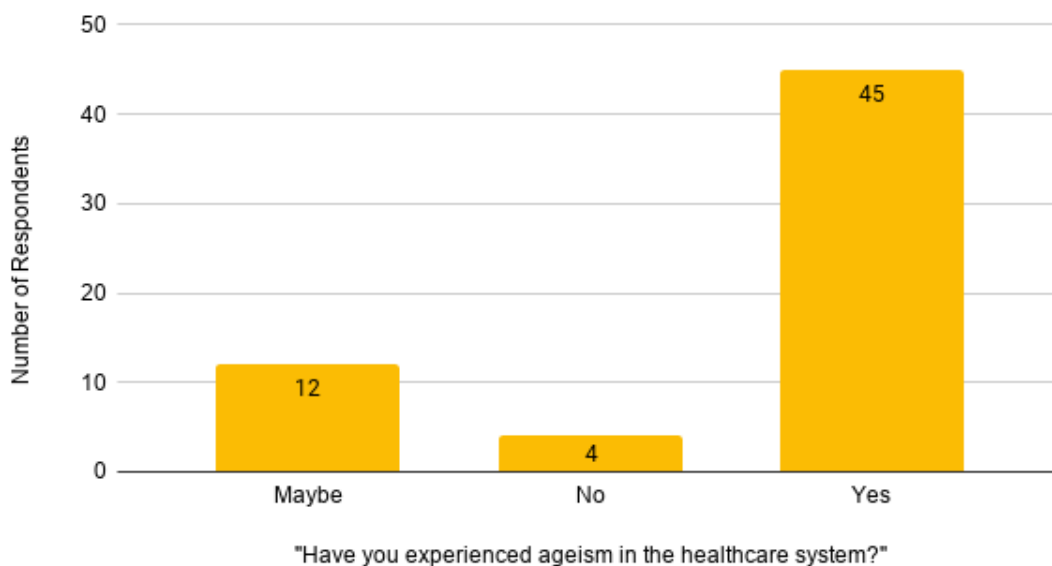


Figure 6



Of those who responded 'yes' or 'maybe', the most frequent healthcare settings in which ageism occurred were:

- At a GP/doctor (indicated by 69.64% of respondents)
- At a specialist (indicated by 51.79% of respondents)
- At a mental health service (indicated by 51.79% of respondents)
- At a hospital (indicated by 42.86% of respondents)

Question: Where has this happened to you (you can select more than one option)?

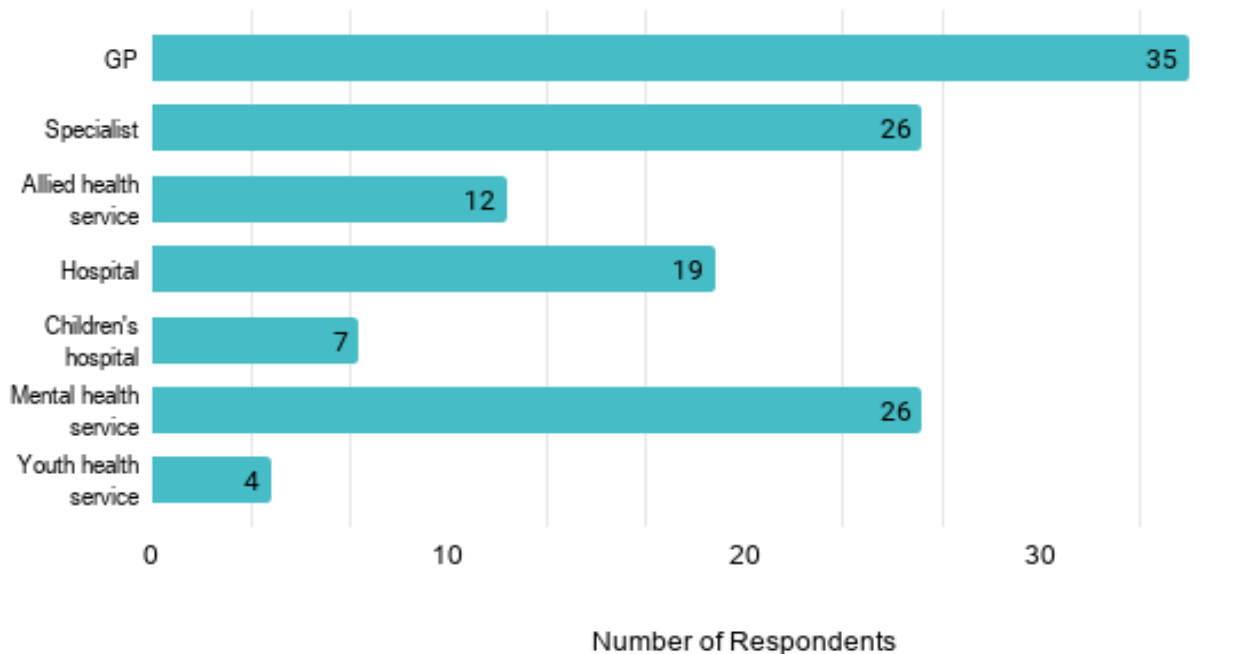


Figure 7

See Tables C11 & C12 for detailed results.

### Opinions and Experiences of Ageism in the Healthcare System

Figure 8 shows the levels of agreement among survey respondents on several statements regarding ageism and related topics within the healthcare system. Agreement was varied, though the overall results indicate difficulty navigating the healthcare system, and a perceived lack of understanding of young people among healthcare professionals.

Over half of respondents agreed or strongly agreed that healthcare professionals, overall, do not understand young people well enough. Further, over 80% of respondents either disagreed or felt neutral towards the statement regarding healthcare settings being welcoming to young people. (See Figure 8 & Table C13 for full results).

Question: Please tell us how much you agree with the following statements...

See Table C13 for detailed results.

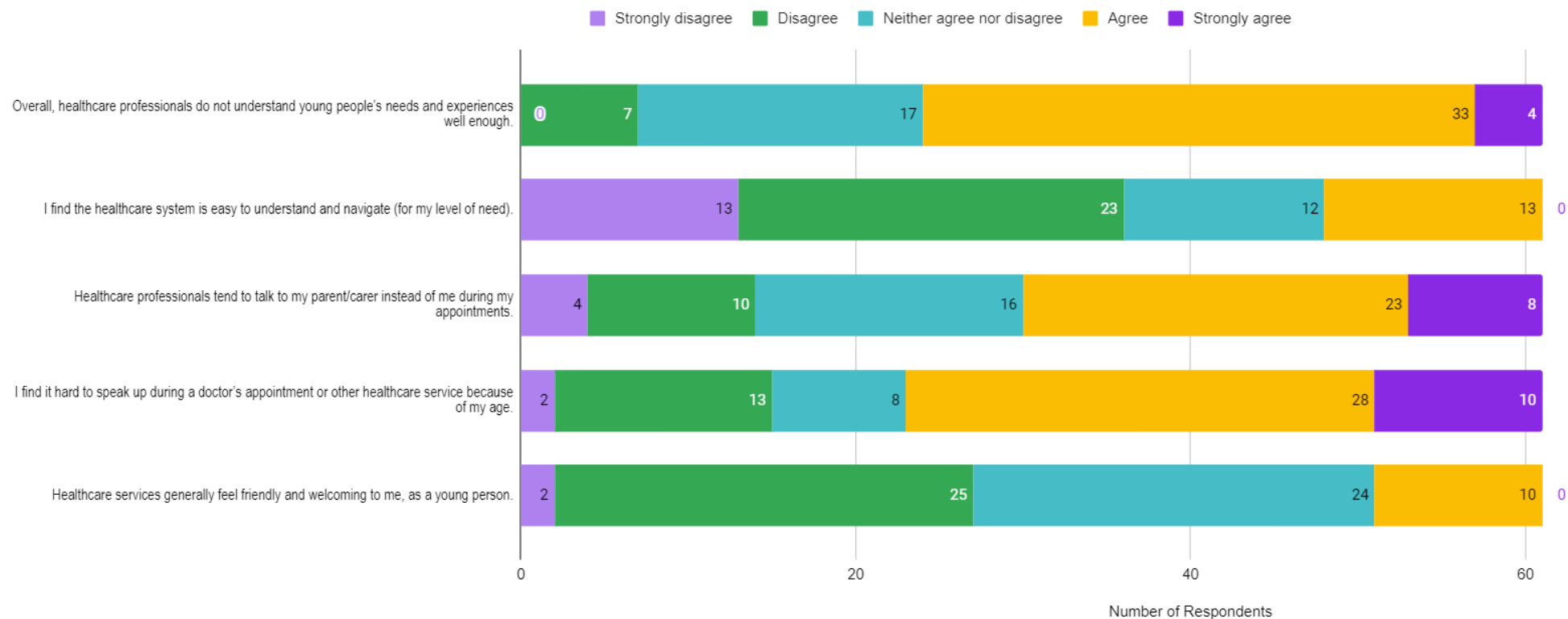


Figure 8

Question: Please tell us how often, if at all, you have experienced the following...

See Table C14 for detailed results.

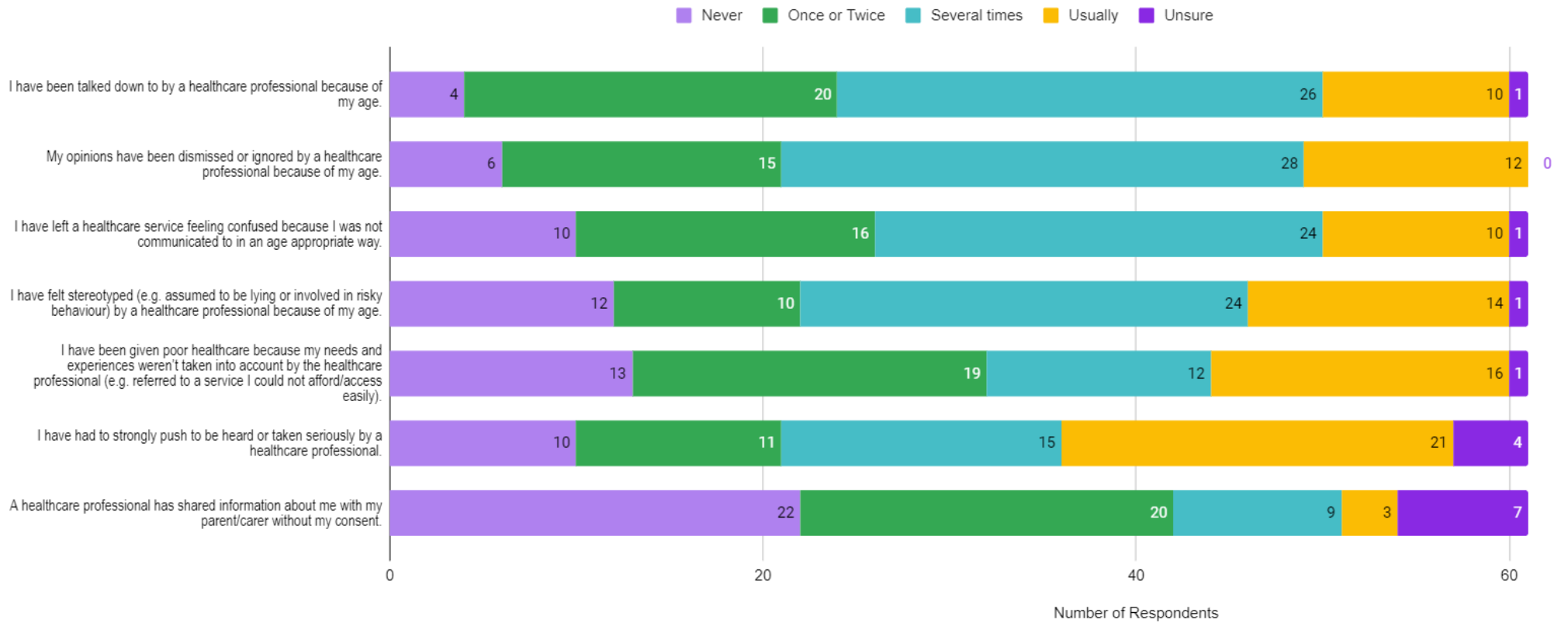


Figure 9 indicates the frequency of various experiences as reported by survey respondents.

Figure 9

## KEY THEMES

Respondents were offered the opportunity to share any experiences or elaborate on their overall experience with the healthcare system in an open-ended response question at the end of the survey. Over a third (n=26, 42.6%) of respondents took the time to share their experiences which allowed for a significant thematic analysis of the responses. The emerging themes present in the responses from participants follow a clear parallel to previous research regarding adultism, age stereotyping and implicit bias. The following are the key themes present in the responses received.

### “TOO YOUNG”

One of the most significant themes to emerge from the research was the notion of young people being deemed by healthcare professionals as “too young” to be experiencing certain issues, to understand their health, and to understand what they need. This theme encapsulates the experiences of young people as they attempt to access effective healthcare and are dismissed due to ageism. This experience appeared particularly prominent among respondents who indicated experiences of chronic health conditions.

When asked to elaborate on their experiences of ageism within the healthcare system, one respondent reported hearing explicitly that they were “too young” to be experiencing what they were expressing to a healthcare professional:

*“Hearing ‘you’re too young to be this ill’ from a doctor” (Non-binary person, 21-24)*

Similarly, one respondent reported:

*“...doctors seem to think that only if I’m old would it really be bad.”*

It appears that the more complex a young person’s healthcare needs are, the less likely they are to receive respectful and adequate healthcare. This directly parallels findings by the Australian Institute of Health and Welfare (2020). Many respondents reported hearing that they were “too young” to be as ill as they were reporting to their healthcare professionals. This notion embodies the impacts of age, stereotyping, and implicit bias on young people’s access to effective healthcare.

A teenage respondent, who reported having a chronic illness, stated:

*“I’ve been told that people my age don’t get chronically ill.” (Female, 15-17)*

Another respondent reported the explicit use of the phrase “too young” by a healthcare professional:

*“Healthcare professionals think I’m “too young” to have the problems I do.” (Female, 21-24)*

Interestingly, many respondents indicated experiencing pushback from specialist doctors. This is noteworthy, as health consumers, especially young people who may be less familiar with the

healthcare system, tend to expect the best quality and expertise from specialists due to the highly specialised nature of their education and practice, and the high fees charged for access to such. However, within the quantitative data we see numerous respondents indicating experiences of ageism in specialist healthcare settings (see Figure 6).

As outlined by Robards et al. (2019a), young people with chronic health conditions, disabilities and mental health conditions are more likely to face all barriers to care. Therefore, this data is particularly compelling, paralleling the findings of Robards et al. (2019a) and indicating the need for more inclusive and age-appropriate health care for young people. A young adult respondent discussed their experience with specialists:

*“I have found specialists to be particularly dismissive of my experience because I’m too young and ‘don’t know what I’m talking about.’” (Female, 21-24)*

This experience is echoed by another respondent, self-reported as having chronic conditions:

*“Specialists often believe that I am ‘too young’ to have chronic medical problems.” (Female, 18-20)*

These findings parallel those found by the Australian Institute of Health and Welfare (2020) who reported that “younger patients with one or more chronic conditions were less likely to report that their specialists always listened carefully, showed respect for what they had to say and spent enough time with them” (p. 17).

## MISDIAGNOSIS & MISSED DIAGNOSIS

Several respondents indicated significant delays in treatment and diagnosis of various illnesses and issues due to being “too young” to be experiencing such symptoms and issues. Again, this was a prominent issue for young people living with chronic conditions and/or disabilities. Healthcare professionals’ unwillingness to acknowledge chronic issues in young people has led to many forgoing care due to negative experiences, delaying diagnosis of serious medical conditions due to having to see several doctors before one will listen, financial stress of managing multiple healthcare appointments as a young person, and health conditions impacting one’s ability to work.

In several instances, diagnosis appears to have taken several years from respondents’ first engagement with the healthcare system regarding their symptoms. One respondent reported the following:

*“It took 8 years for me to get the care that I needed. I believe my opinions, demands (that eventually led to the right solution) and experiences were dismissed largely due to me being a teenager at the time.” (Female, 21-24)*

Delay in diagnosis due to care not being received or a misdiagnosis being made can lead to a myriad of negative health consequences, lowered quality of life, and adverse emotional and relationship impacts (Thorpy & Krieger, 2014). As we see in responses, for many young people, diagnosis is delayed due to the healthcare professionals’ unwillingness to listen to their concerns, believe the severity of their symptoms, or believe certain chronic conditions can occur in younger people at all.

This is again paralleled by the findings of the Australian Institute of Health and Welfare (2020) with regard to chronically ill young people's experiences with healthcare professionals. Another respondent indicated their experiences with both GPs and specialists:

*"It took six years and countless appointments with different GPs and specialists to confirm a diagnosis because no one would take me seriously due to my age." (Female, 21-24)*

Another respondent stated:

*"My chronic migraines went untreated and undiagnosed for 20 years." (Female, 21-24)*

Here we see the consequences of healthcare professionals' dismissal of young peoples' symptoms and experiences. Delays in diagnosis can lead to negative perceptions of healthcare, as well as significant health consequences, both physical and mental.

## AGE STEREOTYPING & ACCUSATIONS

Several young people reported being accused of lying by healthcare professionals. Types of accusations included those of drug seeking and lying about symptoms or conditions in order to avoid school attendance. Several respondents indicated experiencing explicit accusations made by healthcare professionals, leading to critical delays in diagnosis and care.

When asked to share any experiences of ageism, one respondent reported:

*"Having to make a case to convince doctors that I actually do need these drugs for chronic pain and that I'm not just looking for a 'high'" (Female, 18-20)*

This experience of being accused of drug seeking was echoed by another respondent:

*"[Healthcare professionals] saying that I am seeking pain relief medication because I am addicted and that I just want to party." (Female, 21-24)*

Research regarding age stereotypes has tended to focus on the experiences of older people, however previous research, in conjunction with the current findings, indicate a trend of stereotyping of young people. Stereotypes of young people as risk takers, rebellious, and irresponsible, while founded in some truth regarding adolescence, may contribute to the experiences of those accused of drug seeking while seeking healthcare. Similarly, multiple respondents reported being accused of lying about their health in order to avoid attending school. One respondent reported this experience, despite their noted enjoyment of school:

*"...my whole life doctors found 'nothing wrong' or said I was lying to get out of school even though I enjoyed school." (Female, 21-24)*

Similarly, one respondent reported being told this by multiple doctors:

*“I’ve been told I was faking being sick, and I just had anxiety as I was a high achieving student... Many doctors I saw said I wasn’t sick and I just didn’t like going to school” (Female, 15-17)*

These experiences speak to a need for further research regarding age stereotyping of young people and the impacts of such on their healthcare.

## EXPLICIT DENIAL OF CARE

Several respondents indicated having explicitly asked for investigation of symptoms and for access to particular treatments and supports and being outright denied by their healthcare providers. One respondent stated:

*“I asked to see an OT [occupational therapist] for help choosing an appropriate mobility aid. I was told I was too young and would become reliant on a mobility aid. I had to buy one with no OT input.” (Non-binary person, 21-24)*

Another respondent discussed their experience with medication side effects:

*“I was coming to her [doctor] with symptoms that I later found out to be associated with overdose of the medication... [she] didn’t take anything I said seriously.” (Female, 21-24)*

Multiple female respondents reported being denied reproductive care due to their age, despite explicit requests to receive routine testing. One respondent stated:

*“I was told I did not need a pap smear as I was too young even though my family has a history of cervical cancer. Provider argued with me while I insisted on a pap smear... was provided one but was made to feel uncomfortable during the procedure by the provider who kept saying ‘everything is normal’ in a condescending way as if my concerns were invalid.” (Female, 21-24)*

Another respondent stated:

*“I complained of severe period pain for several years and nobody took me seriously. Eventually I found a doctor who believed me... I had stage 4 endometriosis.” (Female, 21-24)*

These responses indicate the, often explicit, nature of healthcare professionals’ dismissal of young people. Despite specific and explicit complaints and requests, many young people find themselves disbelieved, dismissed and without adequate healthcare. Further, some responses indicate the importance of intersectionality within healthcare. Both age and gender bias may contribute to the disbelief of young women with regard to reproductive conditions and care.

## THE COST OF HEALTHCARE AGEISM

The issues outlined in this section have significant implications on the young people experiencing them. Several respondents reported the various impacts and consequences of not being taken seriously by their healthcare providers, having a diagnosis delayed, or being accused of lying by healthcare professionals. With regard to the years of trying to be heard within the system, one respondent stated:

*“... It’s exhausting having to justify and advocate for myself all the time, after all these years.”  
(Female, 21-24)*

Another respondent described the emotional toll of their experience:

*“I’ve found that having a neurological disorder in my 20s has been extremely isolating... doctors generally don’t give me the accessible resources to understand my condition.”  
(Non-binary person, 21-24)*

Multiple respondents reported financial impacts of healthcare and how this affects their healthcare experiences. One respondent reported receiving condescending remarks from a medical receptionist when their mother helped pay for their specialist appointment. The respondent indicated why this was such a negative experience:

*“I was 20, the appointments cost \$380, and I was recovering from surgery.” (Female, 21-24)*

Lastly, one respondent described their experience with an eating disorder treatment program for people under 18. They describe various instances of negative experiences and the impact this had on her:

*“... It created enormous tension and left me feeling disempowered. Doctors treated me with suspicion and disbelief and spoke almost exclusively to my parents (including sharing information against my will).” (Female, 21-24)*

These responses indicate the significant impacts of substandard practice on young people’s health, trust in the healthcare system, and personal relationships. Not only does mistreatment and dismissal lead to delays in diagnosis or misdiagnosis, the mental health, financial and emotional costs are also high.



## DISCUSSION

The aim of this report was to explore the experiences and opinions of young people with regard to ageism, particularly within the healthcare system. While exploratory in nature, the study found several clear areas of consideration. Young people are experiencing incidents of ageism in various areas of society, but notably within interactions with the healthcare system. Results of the study indicate a high prevalence of experiences of ageism, as well as a general agreement across respondents, agreeing that ageism towards young people is a significant issue, and one that requires more attention than is currently being provided. Further, respondents agree that young people are a unique and often overlooked group, leading to the issues and experiences faced. Lastly, findings indicate high rates of ageist experiences in healthcare among young people living with chronic conditions and/or disabilities. Further differences were found in comparison of responses across genders.

When we consider the previous research, as outlined in this report, the presence of ageism towards young people within healthcare is not surprising. Much of the results of this study parallel findings and notions put forth by previous research. Robards et al. (2019a) discuss the integral nature of marginalisation on the experiences of young people within healthcare. The findings of the current study support this, with comparisons of results showing lower reported ratings of healthcare experiences among non-binary respondents, compared to those identified as 'male' or 'female' (see Figure A6). As Robards et al. (2019a) outline, young people belonging to marginalised groups such as sexuality and/or gender diverse young people, are more likely to experience considerable barriers to healthcare and system navigation. While the results of the current study are small, in conjunction with previous research, I believe this is a significant finding requiring more in-depth ageism-related research with marginalised young people, and an essential focus on intersectionality within age related research.

The results also indicate that a significant number of the reported experiences of ageism in healthcare occurred in a general practice setting. This may be due to many young people not having engaged with other healthcare services. However, this is important to consider as GPs are the first port-of-call for most health consumers, especially those who may not be familiar with the system such as young people. If young people are encountering negative experiences in general practice settings, they may be discouraged from engaging with other services or with the system at all in the future. Thus it is critical that these experiences are heard and taken into account in order to effectively address ageism within healthcare.

Several respondents reported living with chronic illness and/or disability, and through thematic analysis, it is clear that young people living with chronic illness and disability face a plethora of barriers and opposition from healthcare professionals in their pursuit of diagnosis and management. This is of immense importance as, currently, approximately 9.8% of 15-24 year olds in New South Wales alone live with a chronic condition, and 7.8% live with a disability (NSW Ministry of Health, 2017). These results, in combination with a recent report from the Australian Institute of Health and Welfare (2020) indicate a critical need to address young chronically ill and disabled people's access to, and experience with, the healthcare system. This is necessary, both to ensure best health outcomes, as well as development of trust in the healthcare system and the professionals working within it, for many young Australians living with chronic conditions and/or disabilities.

The study provides new insight into the opinions of young people, the prevalence of negative experiences in healthcare among young people, and the need for an intersectional lens within age

and healthcare related research and practice. While previous research has focused on the barriers to healthcare present for young people, very little was known regarding explicitly age specific issues and experiences among young people. Previous research found that barriers such as cost, accessibility, and confidentiality concerns were among the most frequently cited by young people, while the current study explored experiences of explicit and implicit *ageism*. Results build on the existing research by expanding on young people's experiences with age, the power relations between young people and healthcare professionals, the attitudes of young people towards ageism in general society and media, and the prevalence of explicitly ageist experiences in healthcare among young people. The importance of this research is exhibited in the number of respondents who chose to share more about their experiences of ageism in healthcare. Over a third of respondents shared their specific experiences, indicating an eagerness to discuss this issue and a desire to share personal stories of ageism in healthcare.

## STUDY LIMITATIONS

The most significant limitation of this study was the time constraint necessary. As this project was developed for a Field Placement by a university student, a specific and small amount of time was available to complete the project. This meant that the online survey was available to respondents for a short amount of time (3 weeks), leading to a small sample size.

The generalisability of the data is impacted by the overrepresentation of certain demographics, such as female respondents and respondents aged 21-24, and the underrepresentation of others such as those living in rural and remote areas, and those identified as male or non-binary. The overrepresentation of female respondents in this study may be due to several reasons, including the potential impact of the intersection of sexism and ageism leading to more explicit experiences among young women compared to men.

It was beyond the scope of this research to account for all potential demographics in order to analyse for significant correlations between demographics and experiences of ageism. Despite this, the broad nature of this study allowed for an exploration of general attitudes among young people and allows one to begin to develop an idea of ageism in healthcare as it applies to young people.

## CONCLUSION

This report found compelling results within young people's responses. Respondents overwhelmingly reported having experienced ageism within the healthcare system, and reported surprisingly low overall ratings of the healthcare system.

The main themes found through young people's experiences were:

- Young people were often dismissed by healthcare professionals for being 'too young' to experience certain health issues, and 'too young' to know what care they require
- Young people seeking healthcare were often met with accusations rather than treatment, support, and care
- Healthcare professionals' mismanagement of young people due to ageism can lead to delayed diagnosis and forgone care
- Intersectional identities such as gender and age groups may play a significant role in healthcare experiences
- Young people living with chronic conditions and disability face significant challenges when seeking healthcare

The experiences shared through this research show that many young people experience ageism when engaging with the healthcare system, and, when given the opportunity, are eager to discuss such issues. Young people face many barriers to access, navigation, and ongoing engagement with the healthcare system, and, through this research, it is clear that ageism plays a role in this.

## RECOMMENDATIONS

### Future Research

Future research is required in this area in order to establish a deeper understanding of ageism in healthcare, as faced by young people. A larger sample size would allow for future research to expand on the findings of this study and improve the generalisability of results. Future areas of research should include the intersection of ageism, sexism, and LGBTQI+ identity and its impact on healthcare access, engagement, and navigation among young people. The results of this research indicate potential disparities in healthcare ratings and outcomes among those belonging to more marginalised gender identities. In combination with previous research regarding marginalisation, this is a compelling area of research with the potential to improve many young people's lives.

Similarly, the results of this research indicate significant barriers to effective healthcare for young people living with a chronic condition and/or disability. In conjunction with the recent findings of the Australian Institute of Health and Welfare (2020), this speaks to a need for research in this specific area. This appears to be a rich area of experiences and could provide integral data that may improve our understanding of both ageism and ableism within the healthcare system.

As outlined earlier in this report, youth can be conceptualised as a marginalised group in society (DeJong & Love, 2015). In order to address the results of this study, and deeply understand any future research, we must deconstruct the notion of youth subordination and adult domination and begin to address the core of this issue. By understanding youth oppression at its foundation, we may begin to see shifts in healthcare experiences and journeys of young people.

## **Organisational Involvement**

Organisations such as the Association for the Wellbeing of Children in Healthcare (AWCH) can play a critical role in young people's healthcare journeys. The exploration of ageism experiences among young people provided in this study indicate a need for increased advocacy for young people's rights in healthcare, as well as an increased understanding of young people's needs among healthcare providers.

AWCH advocates for children and young people's rights within the healthcare system and is thus in a unique position to work alongside young people in order to begin addressing the issues outlined in this report. Additionally, AWCH is in a position to work closely with other youth advocacy and healthcare-related organisations to further improve our understanding of young people's experiences within the healthcare system and to address issues such as ageism and any other barriers to healthcare for young people.

Advocacy work such as running focus groups with young people to gather further insight into healthcare experiences, advocating for youth participation within other organisations, as well as the design and implementation of services may be effective actions for AWCH and other youth and healthcare focused organisations in order to strengthen the findings of this report.

## **Collaboration & Codesign**

Codesign of services, models and frameworks is necessary to ensure inclusivity and effectiveness. Several studies document effective and empowering methods of youth participation within healthcare service design (Thabrew et al., 2018). In order to ensure any change is effective, collaboration with young people should be employed. This will not only work to empower young people to be engaged in systems and services but will also help to ensure that changes will be useful and effective for the demographics they will benefit.

Participation in codesign with young people should be active and enthusiastic, with aspects such as power relations, and critical reflection being considered actively and consistently throughout the design process (Farr, 2017). Any overhaul or change to healthcare systems and services should utilise the insight of consumers, including young people. Without this, any change made may be in vain.

Again, organisations such as AWCH are in a position to utilise the insight gained from this report to advocate for the importance of youth participation in healthcare. Effective codesign comes from true collaboration between parties; youth advocacy organisations may assist services to ensure their collaboration with young people is respectful, effective and non-tokenistic.

## **System Overhaul**

Currently, the Australian healthcare system is highly fragmented and difficult to navigate, particularly for young people (Robards et al., 2018). While this study focused on the experiences of age discrimination among young people, the structural barriers present within the system also contribute heavily to the engagement of young people. In order to begin addressing the negative experiences of young people within the healthcare system, we must also address the structures that constrain the accessibility of services. The noted disconnect between services, both public and private, such as specialists, is responsible for much of the fragmentation of the system, and much of the financial barriers experienced by young people. This disintegration of systems must be addressed, as well as the attitudinal issues as outlined in this report, in order to improve young people's experiences with the healthcare system.

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APPENDIX A – KEY FIGURES

Figure A 1 – Responses to the statement “Ageism towards young people is an issue that needs more attention within systems and services such as healthcare.”

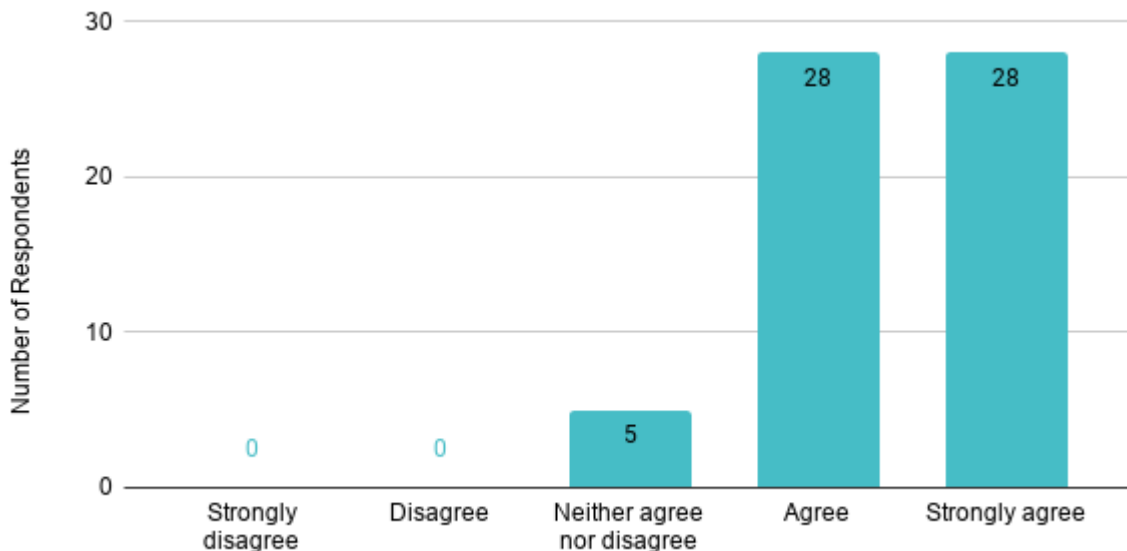


Figure A 2 – Responses to the statement “Young people have unique needs and experiences, just like other age groups.”

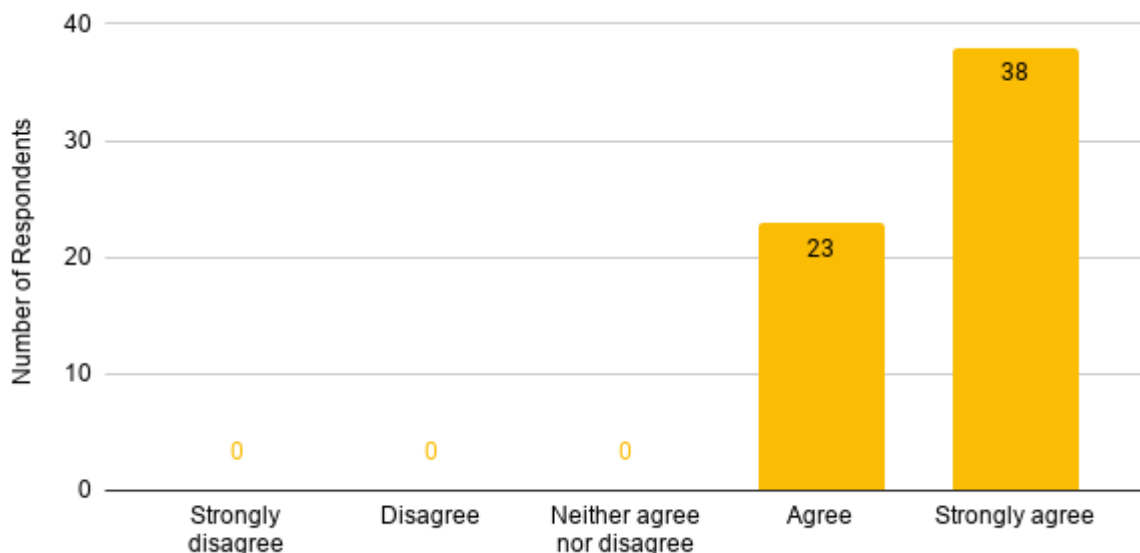


Figure A 3 – Responses to the statement “Young people are often overlooked as a group with unique needs, experiences and voices.”

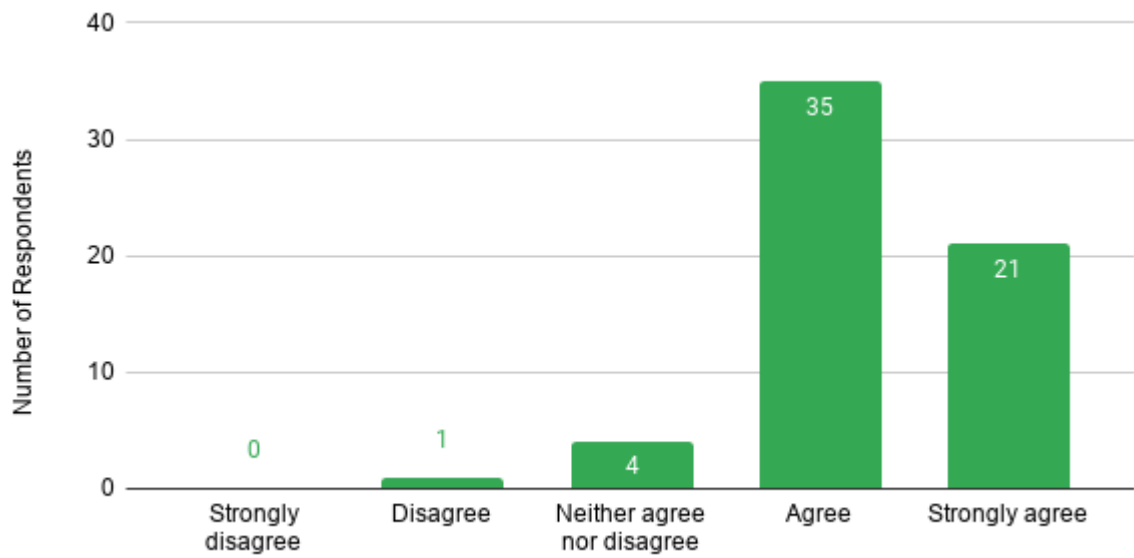


Figure A 4 – Answer to Question 5, “Do you believe you have experienced ageism as a young person?”, (see Appendix B) by gender of respondents.

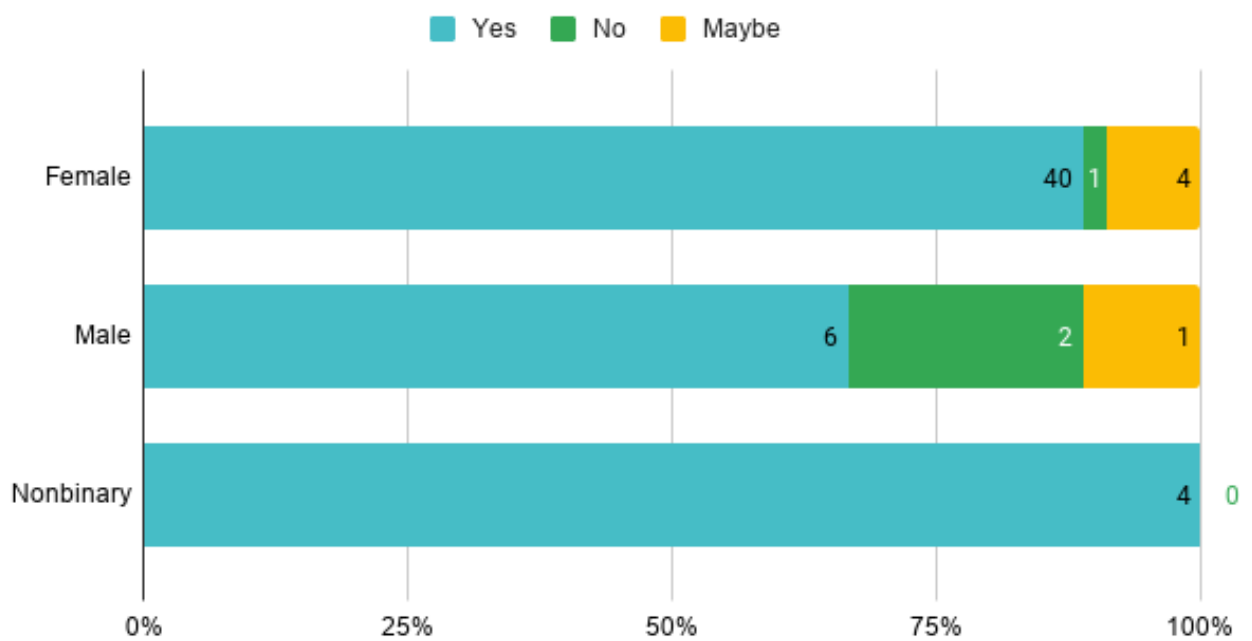




Figure A 5 — Answer to Question 10, “Have you experienced ageism while engaging with the healthcare system?” (see Appendix B) by gender of respondents

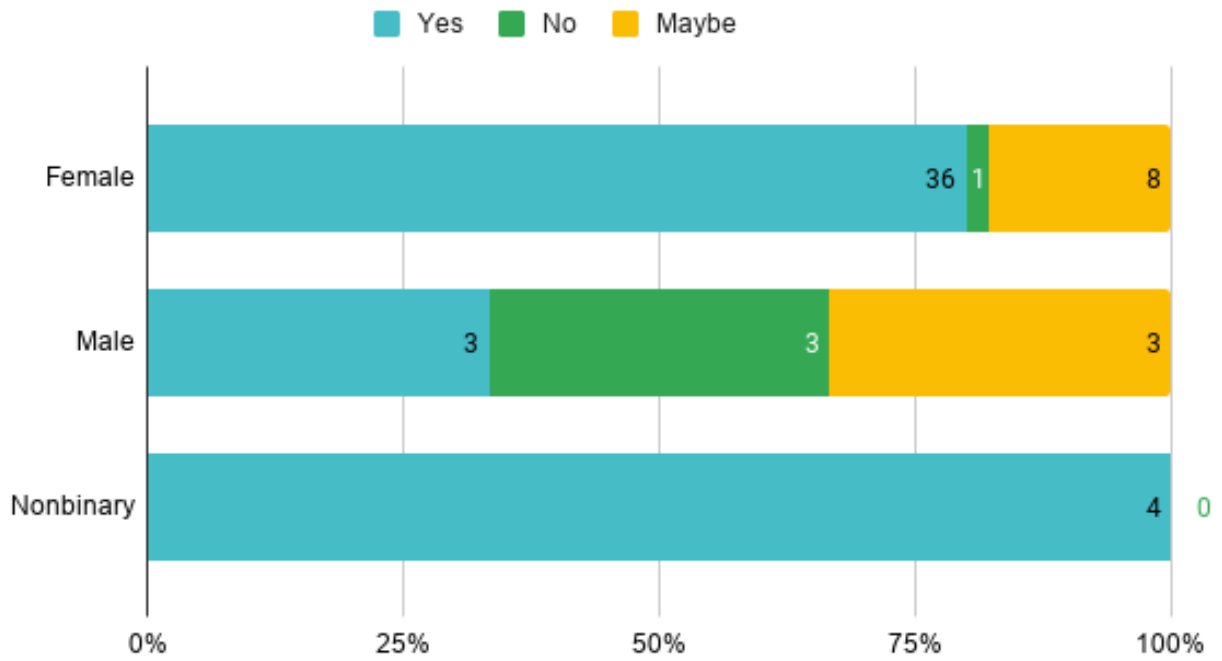
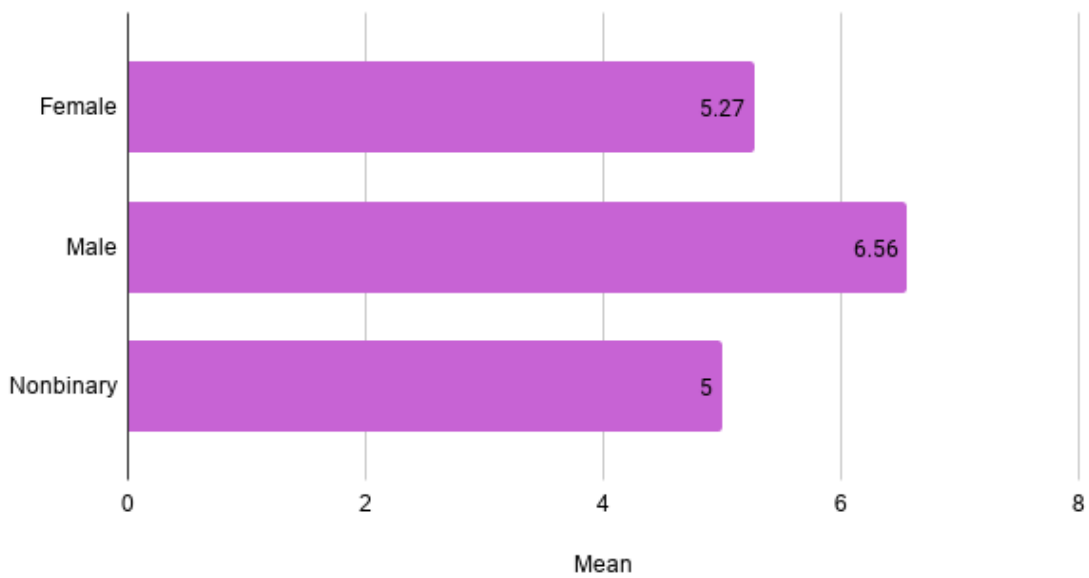


Figure A 6 – Mean rating of overall experience with healthcare system (see Table C10) by gender.



## APPENDIX B – ONLINE SURVEY

This research is being conducted by a fourth-year university student (Bachelor of Social Work) as part of their field placement in partnership with the Association for the Wellbeing of Children in Healthcare (AWCH).

The purpose of this survey is to explore young people's (12-24 years old) experiences of age discrimination, or 'ageism', particularly within the healthcare system.

This survey should take about 10 minutes to complete and all responses are completely anonymous.

If you would like to receive the final report based on the results of this survey, please contact [admin@awch.com.au](mailto:admin@awch.com.au) and you will be sent the final report once it is finished. Your email address will remain confidential and will not be kept or used for any other purpose.

Please contact Lizzy Harnett, CEO of AWCH, on [lizzy@awch.com.au](mailto:lizzy@awch.com.au) if you have any issues or concerns about this survey.

Thank you for participating!

Q1. How old are you?

12-14

15-17

18-20

21-24

Q2. Please select what applies to you (you can select more than one):

Female

Male

Non-binary

Prefer not to say

Prefer to self-describe/add more detail:

Q3. Which describes you best:

I live in a large city

I live on the edge of a large city

I live in a regional town

I live in a rural area

I live in a remote area

Q4. Where do you live?

New South Wales

Queensland

South Australia

Western Australia

Australian Capital Territory

Northern Territory

Tasmania

Victoria

I live in another country:

### **Ageism in General Society**

Q5. Age discrimination, or 'ageism', can be experienced by any age group, not just older people. Ageism can include treating someone differently to others because of their age, being rude to someone because of their age, ignoring or dismissing someone because of their age, and stereotyping age groups. Knowing this, do you think you have experienced ageism as a young person?

Yes

No

Maybe

Q6. Where has this happened to you (you can select more than one option)?

At home

At school

At work

At a healthcare service

At an extracurricular activity

In public (e.g. at a shop, on public transport)

Other (please specify)

Q7. Please tell us how much you agree with the following statements:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Society holds some negative stereotypes about young people.					
The way young people are described in the media (e.g. the news) is accurate.					
Young people have unique needs and experiences, just like other age groups.					
Young people are often overlooked as a group with unique needs, experiences, and voices.					
Ageism towards young people is an issue that needs more attention within systems and services such as healthcare.					
My ideas and opinions are valued by the adults in my life (e.g. family, carers, teachers).					

Q8. Please tell us how often, if at all, you have experienced the following:

	Never	Once or Twice	Several Times	Usually	Unsure
I have been talked down to or looked down on because of my age.					
My opinions have been dismissed or ignored because of my age.					
I have felt left out of important decisions made for me (e.g. by parents, carers, service providers) because of my age.					
I have felt I had no control over a situation that affected me because of my age (e.g. medical decisions).					
The adults in my life (e.g. parents, carers, service providers) have involved me in important decisions that affect me.					
My ideas and opinions are valued by the adults in my life (e.g. family, carers, teachers).					

**Ageism in Healthcare**

Q9. On a scale of 1 to 10 (1 being the worst and 10 being the best), please tell us your overall experience with the healthcare system as a young person.

[1] - [2] - [3] - [4] - [5] - [6] - [7] - [8] - [9] - [10]

Q10. Do you think you have experienced ageism while using a healthcare service?

Yes

No

Maybe

Q11. Where has this happened to you (you can select more than one option)?

At a GP/doctor

At a specialist

At a hospital

At a specialist children’s hospital

At an allied health service

At a mental health service

At a youth health service

Other (please specify)

Q12. Please tell us how much you agree with the following statements:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Overall, healthcare professionals do not understand young people’s needs and experiences well enough.					
I find the healthcare system is easy to understand and navigate (for my level of need).					
Healthcare professionals tend to talk to my parent/carer instead of me during my appointments.					

I find it hard to speak up during a doctor's appointment or other healthcare service because of my age.					
Healthcare services generally feel friendly and welcoming to me, as a young person.					

Q13. Please tell us how often, if at all, you have experienced the following:

	Never	Once or Twice	Several Times	Usually	Unsure
I have been talked down to by a healthcare professional because of my age.					
My opinions have been dismissed or ignored by a healthcare professional because of my age.					
I have left a healthcare service feeling confused because I was not communicated to in an age-appropriate way.					
I have felt stereotyped (e.g. assumed to be lying or involved in risky behaviour) by a healthcare professional because of my age.					
I have been given poor healthcare because my needs and experiences were not taken into account by the healthcare professional (e.g. referred to a service I could not afford/access easily).					
I have had to strongly push to be heard or taken seriously by a healthcare professional.					
A healthcare professional has shared information about me with my parent/carer without my consent.					

Q14. Do you have any specific experience(s) of ageism in healthcare that you would like to share? If not, you're done! If yes, please share below.

## APPENDIX C – SURVEY RESULTS

Table C1 – Age Groups of Respondents

	N	%
12-14	10	16.39
15-17	4	6.56
18-20	10	16.39
21-24	37	60.66
Total	61	100

Table C2 – Gender of Respondents\*

	N	%
Female	45	73.77
Male	9	14.75
Non-binary	4	6.56
Prefer not to say	2	3.28
Other	2	3.28

\*Total may exceed 61/100% as respondents could select more than one option

Table C3 – Geographic Location of Respondents

	N	%
I live in a large city	37	60.66
I live on the edge of a large city	11	18.03
I live in a regional town	8	13.11
I live in a rural area	5	8.20
I live in a remote area	0	0
Total	61	100

Table C4 – State/Country of Residence

	N	%
New South Wales	33	54.10
Queensland	1	1.64
South Australia	0	0
Western Australia	3	4.92
Australian Capital Territory	4	6.56

Northern Territory	1	1.64
Tasmania	1	1.64
Victoria	9	14.75
I live in another country	9	14.75
Total	61	100

Table C5 – Countries of Residence of Non-Australian Respondents

Country	N
United States	3
United Kingdom	2
New Zealand	1
Finland	1
Germany	1
Indonesia	1

Table C6 – Respondents' Experience of Ageism

Have you experienced ageism?	N	%
Yes	52	85.25
No	3	4.92
Maybe	6	9.84
Total	61	100

Table C7 – Settings of Ageism Experiences\*

Where has this happened?	N	%
At home	24	42.11
At school	36	63.16
At work	29	50.88
At an extracurricular activity	10	17.54
At a healthcare service	42	73.68
In public	33	57.89
Other	1	1.75

\*Total may exceed 61/100% as respondents could select more than one option



Table C8 – Attitudes and Opinions of Ageism in General Society

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Total</b>
Society holds some negative stereotypes about young people.	0 0%	2 3.28%	0 0%	45 73.77%	14 22.95%	61 100%
The way young people are described in the media (e.g. the news) is accurate.	7 11.48%	36 59.02%	14 22.95%	2 3.28%	2 3.28%	61 100%
Young people have unique needs and experiences, just like other age groups.	0 0%	0 0%	0 0%	23 37.70%	38 62.30%	61 100%
Young people are often overlooked as a group with unique needs, experiences, and voices.	0 0%	1 1.64%	4 6.56%	35 57.38%	21 34.43%	61 100%
Ageism towards young people is an issue that needs more attention within systems and services such as healthcare.	0 0%	0 0%	5 8.20%	28 45.90%	28 45.90%	61 100%
My ideas and opinions are valued by the adults in my life (e.g. family, carers, teachers).	1 1.64%	12 19.67%	23 37.70%	22 36.07%	3 4.92%	61 100%

Table C9 – Experiences of Ageism in General Society

	<b>Never</b>	<b>Once or Twice</b>	<b>Several Times</b>	<b>Usually</b>	<b>Unsure</b>	<b>Total</b>
I have been talked down to or looked down on because of my age.	0 0%	6 9.84%	40 65.57%	14 22.95%	1 1.64%	61 100%
My opinions have been dismissed or ignored because of my age.	0 0%	10 16.39%	40 65.57%	11 18.03%	0 0%	61 100%
I have felt left out of important decisions made for me (e.g. by parents, carers, service	5 8.20%	18 29.51%	22 36.07%	15 24.59%	1 1.64%	61 100%

providers) because of my age.						
I have felt I had no control over a situation that affected me because of my age (e.g. medical decisions).	10 16.39%	11 18.03%	24 39.34%	13 21.31%	3 4.92%	61 100%
The adults in my life (e.g. parents, carers, service providers) have involved me in important decisions that affect me.	1 1.64%	12 19.67%	17 27.87%	29 47.54%	2 3.28%	61 100%

Table C10 – Rating of Overall Quality of Experience with Healthcare System

Rating (1-10)	N	% of sample
1	1	1.64
2	3	4.92
3	6	9.84
4	10	16.39
5	9	14.75
6	10	16.39
7	12	19.67
8	10	16.39
9	0	0
10	0	0
Total	61	100

**Table C11 - Respondents' Experience of Ageism in Healthcare**

Have you experienced ageism while using a healthcare service?	N	%
Yes	45	73.77
No	4	6.56
Maybe	12	19.67
Total	61	100

Table C12 – Healthcare Settings of Ageism Experiences\*

Where has this happened?	N	%
At a GP/doctor	39	69.64
At a specialist	29	51.79
At a hospital	24	42.86
At a specialist children's hospital	8	14.29
At an allied health service	13	23.21
At a mental health service	29	51.79
At a youth health service	4	7.14
Other	1	1.79

\*Total may exceed 61/100% as respondents could select more than one option

Table C13 – Attitudes and Opinions of Ageism in the Healthcare System

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	Total
Overall, healthcare professionals do not understand young people's needs and experiences well enough.	0 0%	7 11.48%	17 27.87%	33 54.10%	4 6.56%	61 100%
I find the healthcare system is easy to understand and navigate (for my level of need).	13 21.31%	23 37.70%	12 19.67%	13 21.31%	0 0%	61 100%
Healthcare professionals tend to talk to my parent/carer instead of me during my appointments.	4 6.56%	10 16.39%	16 26.23%	23 37.70%	8 13.11%	61 100%
I find it hard to speak up during a doctor's appointment or other healthcare service because of my age.	2 3.28%	13 21.31%	8 13.11%	28 45.90%	10 16.39%	61 100%
Healthcare services generally feel friendly and welcoming to me, as a young person.	2 3.28%	25 40.98%	24 39.34%	10 16.39%	0 0%	61 100%

Table C14 – Experiences of Ageism in the Healthcare System

	<b>Never</b>	<b>Once or Twice</b>	<b>Several Times</b>	<b>Usually</b>	<b>Unsure</b>	<b>Total</b>
I have been talked down to by a healthcare professional because of my age.	4 6.56%	20 32.79%	26 42.62%	10 16.39%	1 1.64%	61 100%
My opinions have been dismissed or ignored by a healthcare professional because of my age.	6 9.84%	15 24.59%	28 45.90%	12 19.67%	0 0%	61 100%
I have left a healthcare service feeling confused because I was not communicated to in an age-appropriate way.	10 16.39%	16 26.23%	24 39.34%	10 16.39%	1 1.64%	61 100%
I have felt stereotyped (e.g. assumed to be lying or involved in risky behaviour) by a healthcare professional because of my age.	12 19.67%	10 16.39%	24 39.34%	14 22.95%	1 1.64%	61 100%
I have been given poor healthcare because my needs and experiences were not taken into account by the healthcare professional (e.g. referred to a service I could not afford/access easily).	13 21.31%	19 31.15%	12 19.67%	16 26.23%	1 1.64%	61 100%
I have had to strongly push to be heard or taken seriously by a healthcare professional.	10 16.39%	11 18.03%	15 24.59%	21 34.43%	4 6.56%	61 100%
A healthcare professional has shared information about me with my parent/carer without my consent.	22 36.07%	20 32.79%	9 14.75%	3 4.92%	7 11.48%	61 100%