



Butterfly

Community Insights Research

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Research report prepared by Kantar Public Division for Butterfly Foundation

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Table of contents

1.	Executive summary	3
2.	Introduction	6
2.1	Methodology	7
2.1.1	Qualitative Stage	7
2.1.2	Community survey	7
2.1.4	Interpreting the findings	9
3.	What is the level of community understanding of eating disorders?	11
3.1	Awareness and understanding of eating disorders is typically low	11
3.2	Knowledge of signs and symptoms also low	12
3.3	Eating disorders are not considered to be as prevalent as other types of mental health issues	13
3.4	Community interest in learning more	14
4.	How prevalent are stigmatising views, and how do these manifest?	16
4.1	Personal stigma	17
4.2	Perceived stigma	22
4.3	Self-stigma	23
5.	How do knowledge and attitudes vary across the population?	27
6.	What are the barriers to help seeking for those at risk of or with lived experience?	39
6.1	Role of external and environmental factors in driving negative body image and eating disorders	39
6.2	Role of personality and internal factors	43
6.3	Barriers to help seeking	44
6.4	Support needs	47
6.5	Effective and ineffective approaches to support	49
7.	Conclusions & recommendations	51
7.1	Conclusions	51
7.2	Recommendations	51

1. Executive summary

Kantar Public Division was commissioned by Butterfly Foundation in 2020 to conduct research exploring the knowledge and attitudes of the community around body image issues and eating disorders. Broadly, the research objectives sought to uncover:

- Existing **community perceptions** on the prevalence, presentation and impacts of eating disorders/body image issues and the stigma surrounding these issues; and

The **drivers and barriers** to seeking support for those at risk of/experiencing an eating disorder; This project consisted of both qualitative and quantitative research, to ensure a comprehensive insight into the outlined objectives.

1. An initial qualitative stage, comprising individual in-depth interviews with people who were at risk of or had lived experience of eating disorders; the parents and carers of those affected; health professionals and educators. As part of this stage, Kantar also engaged a specialist research agency, Cultural Partners, to conduct qualitative research with Indigenous people¹ who had lived experience or were at risk of eating disorders, and their family members or carers. Findings from this stage have been incorporated into this final report and are also available in full as a separate document.
2. A 15-minute online survey with a nationally representative sample of the general population, with a sample size of n=3,030. The data was weighted to represent the Australian population using ABS 2016 Census data.

The research was conducted in July-September 2020.

A summary of the findings from this research appears below.

❖ Awareness and understanding of eating disorders is typically poor

The research reveals that awareness and understanding of eating disorders is limited across the community, particularly compared with knowledge of other mental health conditions. There is a large degree of uncertainty about many aspects of eating disorders, including whether or not it constitutes a mental health condition, signs of risk, and who is affected. For instance:

- One in four people believe that eating disorders only affect a very small proportion of the population [with a further 41 per cent either not knowing or undecided].
- One in five people think that you can tell someone has an eating disorder by looking at them.
- One in three people think eating disorders mainly affect teenagers.
- One in ten people feel confident in recognising the signs of an eating disorder.

❖ A sizeable minority of the population tend to minimise the seriousness of eating disorders

- One in ten people believe that eating disorders 'are not all that serious'

1. For ease of reference, throughout this report Aboriginal and Torres Strait Islander peoples are often referred to as 'Indigenous people'. We recognise that there are differences of opinion with regard to this terminology and no disrespect is meant should this language be considered inappropriate.

- One in four people believe that people with symptoms of eating disorders would only need to seek professional help if they became dangerously underweight.
- Younger people (aged 18-44) are more likely than older people to minimise the seriousness of eating disorders. Only 5% of people aged 45-64 believe that eating disorders are not serious, while 17% of people aged 25-44 believe that eating disorders are not serious.
- Women are more likely than men to believe that eating disorders are serious. 7% of women think that eating disorders are not serious, compared with 12% of men.

❖ **There is strong recognition of the links between body image and eating disorders within the community**

- The majority of people (84%) believe that body image issues affect health and wellbeing.
- The majority of people (84%) believe that body image issues can lead to an eating disorder.

❖ **A significant minority of people subscribe to common myths about eating disorders**

- One in four people perceive disordered eating as a sign of weakness.
- One in five people believe that people who binge eat 'just lack willpower'.
- One in four people believe that eating disorders are a choice, and that people 'could stop their behaviour if they really wanted to'.
- One in seven people believe that people with eating disorders 'just want attention'.
- Just over one in six people associate eating disorders with attention seeking, or a lifestyle choice for vanity
- A majority of respondents (57%) agreed that most people think only young girls are affected by eating disorders.
- Between 13-18 per cent of people believe that eating disorder behaviours are normal
- Stigma is evident across all types of eating disorders, though tends to be stronger in relation to males who are living with an eating disorder
- Younger males are more likely than others to hold stigmatising views.

❖ **Stigmatising views are evident among people living with or at risk of developing eating disorders, who tend to minimise their seriousness and impact**

Self-stigma is strong among many people with eating disorders or at risk of developing eating disorders.

For instance:

- Around one quarter believe that eating disorder behaviours are 'not all that serious'.
- Around one third believe that people with disordered eating will simply grow out of the behaviour and/or could stop what they are doing if they really want to.
- Around one third believe that disordered eating behaviours are 'pretty normal'.
- Half believed that eating disorder behaviours are common [with the exception of bingeing among males (38% thought this was common)].

❖ **The community is open to a range of non-clinical initiatives and interventions to improve awareness, decrease stigma and promote help-seeking** such as school-based workshops, fact-sheets and educational programs. As Butterfly already has an existing suite of school and community-based programs, a key challenge is how to expand the reach of these programs.

Drawing on the research findings, a series of recommendations are put forward for Butterfly Foundation's consideration. These are detailed in Section 9, but include:

- Increasing community awareness and understanding of eating disorders through broadly targeted communications and PR activities;
- Challenging misconceptions and stigmatising views held by specific groups, further developing and promoting education-based activities to correct engrained assumptions;

- Increasing help seeking behaviour amongst those at risk of/ experiencing an eating disorder, particularly through messaging that focusses on listening to, understanding and addressing the emotions and mental anguish underlying disordered eating, rather than on the behaviours themselves.

2. Introduction

Eating disorders are serious mental health conditions involving an unhealthy preoccupation with eating, exercise or body image issues. In Australia, a country with a population of more than 25 million, they affect approximately 4 in every 100 people², while only between 5-15% of those living with an eating disorder receive treatment³.

Eating disorders can have a significant physical and emotional impact on the person affected, and their family. Many people who live with an eating disorder keep their condition a secret or won't admit they have a problem. Stigma is a significant barrier to help seeking and early intervention, with evident ambivalence amongst the community around the severity of the disorder and misconceptions around those affected. It is largely viewed as something affecting young women only. For the increasing numbers of men living with the disorder, this creates additional stigma, and reinforces barriers to seeking help.

The reality is that eating disorders are very complex, serious psychological disorders that cause significant physical, mental, emotional, and social impairment. The overall mortality rate for an eating disorder is 20% – with anorexia nervosa having the highest fatality rate of any psychiatric disorder⁴.

Butterfly Foundation (Butterfly) was established in 2002 to provide support for people living with eating disorders and their families and carers. Butterfly runs national communication campaigns to build awareness, encourage help-seeking, and reduce stigma, while providing services to support early intervention, treatment and recovery.

Butterfly commissioned Kantar Public Division to further its understanding of community awareness and barriers to service access and utilisation. More specifically, the research objectives sought to uncover:

- Existing **community perceptions** on the prevalence, presentation and impacts of eating disorders/ body image issues and the stigma surrounding these issues; and
- The **drivers and barriers** to engaging with the services and support for eating disorders.

This report details the findings of this research and provides a series of conclusions and recommendations for consideration by Butterfly.

1 <https://www.healthdirect.gov.au/eating-disorders>

3 <https://www.nationaleatingdisorders.org/blog/what-treatment-usual-costs-australia>

4 <https://mhaustralia.org/general/stigmas-surrounding-eating-disorders-devastating-reality>

2.1 Methodology

This project comprised both qualitative and quantitative research, to ensure a comprehensive insight into the outlined objectives. This was undertaken in two stages as follows:

1. An initial qualitative stage, comprising individual in-depth interviews with people who were at risk of or had lived experience of eating disorders, the parents and carers of those affected, health professionals and educators. As part of this stage, Kantar also engaged a specialist research agency, Cultural Partners, to conduct qualitative research with people of Aboriginal or Torres Strait Islander backgrounds, who had lived experience or were at risk of eating disorders, and their family members or carers.
2. A 15-minute online survey with a nationally representative sample of the general population, with a sample size of n=3,030. Survey results were also used to inform the development of a segmentation model of the population around their perceptions and attitudes towards eating disorders.

More detail around each methodological component appears below.

2.1.1 Qualitative Stage

The qualitative research comprised a total of n=42 in-depth interviews, as follows,

Mainstream interviews

Kantar conducted n=33 in-depth interviews with a range of audiences, including:

- Seven participants classified as at risk of experiencing an eating disorder (not diagnosed but experiencing behaviours and/or concerns related to an eating disorder within the last 30 days) and consisted of n=7 females
- Seven participants identified as having a lived experience of an eating disorder (previously been diagnosed with an eating disorder), including n=4 males and n=3 females
- Seven family/friends/carers of people who had a lived experience of an eating disorder
- Six health professionals, including 2 mental health nurses, 2 psychologists, and 2 dietitians/nutritionists
- Six educators, including 3 counsellors and 3 teachers.

The interviews ranged from 60 to 75 minutes and a \$80-\$90 incentive was provided to thank participants for their time. Interviews were undertaken from 1 – 17 July 2020.

Aboriginal or Torres Strait Islander interviews

A series of nine additional in-depth interviews were undertaken with people of Aboriginal or Torres Strait Islander background, including:

- Six Aboriginal/Torres Strait Islander women aged 18 to 25 who were classified as at risk of experiencing an eating disorder or identified as having a lived experience of an eating disorder
- Three Aboriginal/Torres Strait Islander women who are mothers or carers of younger teenage women (aged 14-17 years) who were at risk of eating disorders or had lived experience of an eating disorder.

These interviews were conducted by Cultural Partners across three locations (Perth, Sydney and North Coast Region of NSW) from 18-27 August 2020.

The interviews were 1 hour and a \$100 incentive was provided to thank participants for their time.

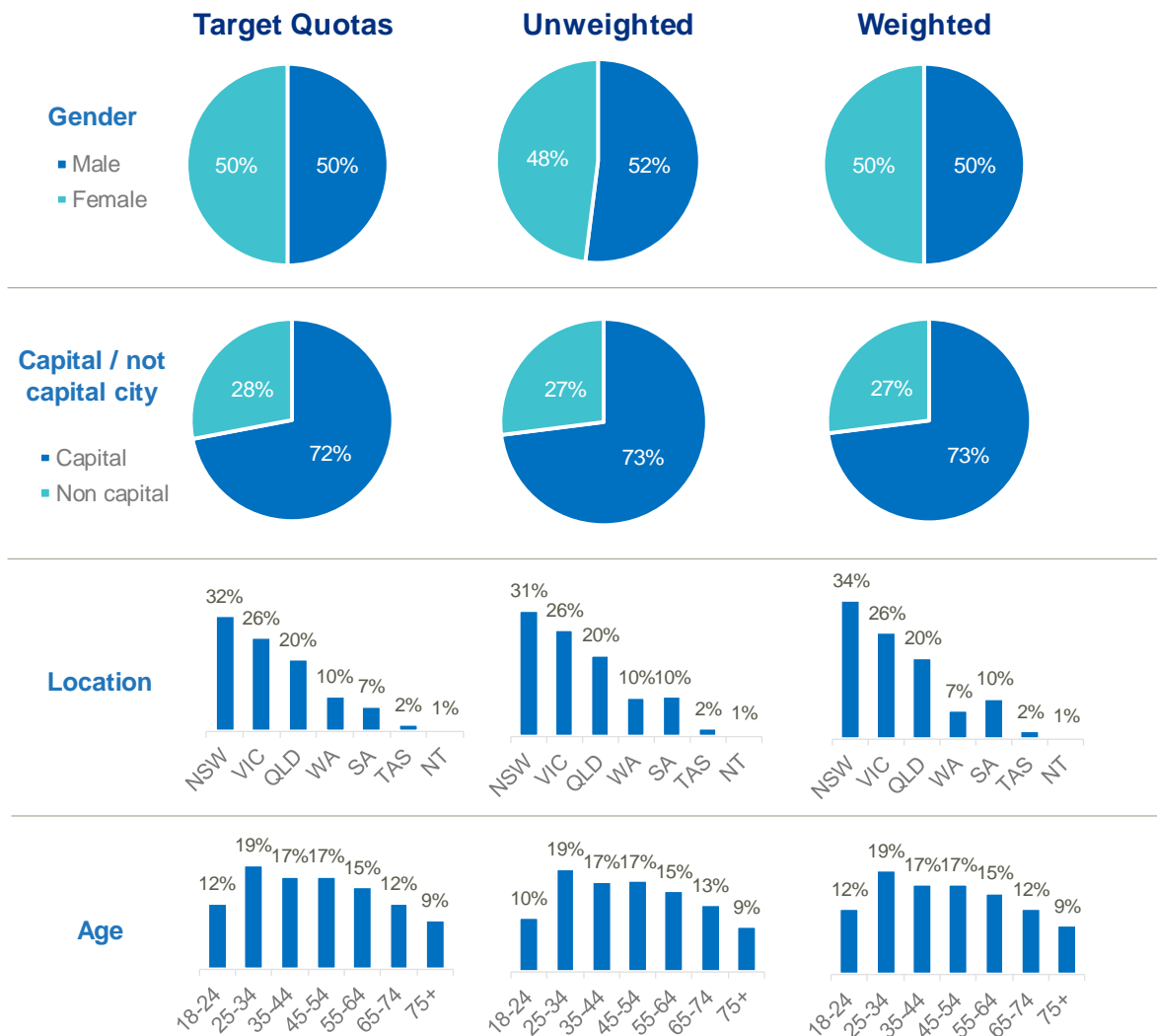
2.1.2 Community survey

An online survey was conducted with a representative sample of n=3,030 members of the general Australian population. The survey was 15 minutes in duration, and fieldwork was undertaken from 7-19 August 2020. The sample was provided by Lightspeed Research (LSR).

The following table provides a detailed outline of the final completes for each interest group.

Group	Breakdown	Population - ABS (n)	Population proportion (%)	Sample size (n=3,000)	Achieved (n=3,030)
Age	18-24 years	2,333,712	12%	300-375	308
	25-34 years	3,681,876	19%	525-600	586
	35-44 years	3,264,828	17%	450-525	516
	45-54 years	3,183,795	17%	450-525	518
	55-64 years	2,838,812	15%	375-450	462
	65-74 years	2,151,469	12%	300-375	381
	75+ years	1,639,196	9%	225-300	259
Gender	Female	12,484,673	50%	1425-1575	1562
	Male	12,286,036	50%	1425-1575	1468
State	NSW/ACT	7,915,000	32%	825-975	933
	VIC	6,385,800	26%	675-825	793
	QLD	4,965,000	20%	525-675	609
	SA	2,584,800	10%	225-375	300
	WA	1,728,100	7%	150-300	295
	TAS	524,700	2%	30-75	66
	NT	246,700	1%	30-75	34
Location	Greater Capital Cities	16,551,151	72%	2100-2250	2226
	Rest of Australia	8,047,782	28%	750-900	804
Special Interest groups	Indigenous	649,168	3%	75-150	92
	*LGBTQIA+	*750,000+	4-6%	120-180	198

The figure below outlines the target quotas set and achieved in the online survey. The data was weighted to represent the Australian population using ABS 2016 Census data.



Questions pertaining to eating disorder experience or risk drew on a validated scale, with additional questions to identify the full range of eating disorders.

2.1.3 Interpreting the findings

Significance testing

Where applicable, significance testing has been carried out at the 95% confidence level in relation to survey data. This means that there is a less than 5% probability that a difference occurred by chance. Significance testing has been primarily undertaken against the 'Total' population. Where sample sizes allow (minimum n=30) significance testing was undertaken between smaller subgroups such as gender, location, age etc.

Statistically significant differences in data between groups in the tables of results have been highlighted using the following arrows within and below the table and/or chart:

▲▼ Significantly higher/lower than total population at 95% c.i

A survey result is reported as being 'significant' if it is unlikely to have occurred as a result of chance due to only a portion of the population being sampled rather than the population as a whole. This means that if 100 different samples of the population were surveyed, one could be confident that the same result would be achieved in at least 95 of these samples. This definition of 'significance' is beneficial when searching for noteworthy results to report, in particular when results for certain subsamples are significantly higher or lower than the overall sample average.

Reporting notes

When interpreting the findings throughout this report please consider the following:

- ❖ Some percentages do not add up to 100%. This may be due to rounding (percentages are represented to the nearest integer), the exclusion of answers such as "don't know" or "not applicable" or multiple response questions.
- ❖ Regarding in-text references: where a statistic is referenced in relation to a 5-point scale e.g. 64% agree that 'xxx' – this 'agree' is referring to a NET result of 'agree' and 'strongly agree'. Conversely, 'disagree' will refer to a NET result of 'disagree' and 'strongly disagree'. This applies for all 5-point scales.
- ❖ Some stacked bar charts do not display the data label when the percentage is 1% or less to minimise clutter on the chart and aid readability.
- ❖ Survey respondents were asked a range of attitudinal and belief statements with which they were asked to agree or disagree. Statements which are phrased in a similar manner or share a similar theme have been grouped accordingly.
- ❖ Survey respondents were asked some questions with an open-ended response frame. In order to analyse and summarise results, a thematic analysis was undertaken on all responses to 'code' similar responses into a code frame. Some respondent responses can qualify for multiple codes.
- ❖ The base size below each figure describes the respondents who were eligible to answer the question and indicates the actual number (n) who responded to the question. Where the base is a subset of the total response, due to unique questionnaire 'pathways', the meaning of the base is explained (e.g. 'those aware of reablement').
- ❖ In order to facilitate analysis and comparison of findings across subgroups, all charts and tables have been presented using percentages (as opposed to number of mentions).
- ❖ Direct quotes from the qualitative research have been used to illustrate key points.
- ❖ This report was produced in accordance with ISO 20252 standards.

3. What is the level of community understanding of eating disorders?

The research reveals that awareness and understanding of eating disorders is limited across the community, particularly compared with knowledge of other mental health conditions. There is a large degree of uncertainty about many aspects of eating disorders, including whether or not it constitutes a mental health condition, signs of risk, and who is affected. In the main, males and older people tended to be least well informed.

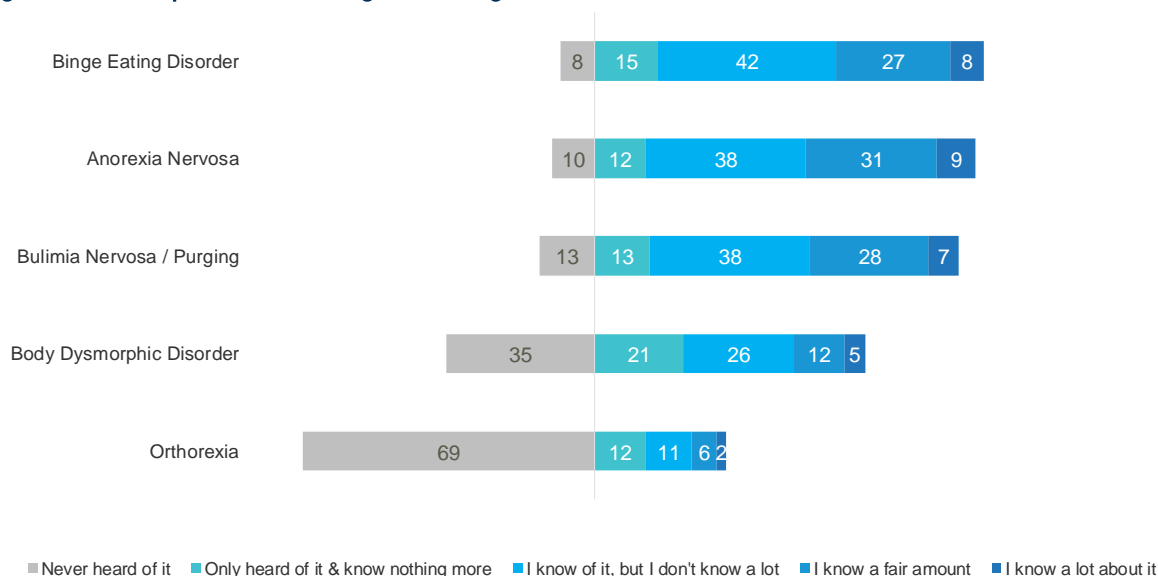
Nonetheless, on a broad level, there is interest in finding out more, with various educational initiatives in the area holding appeal for many.

3.1 Awareness and understanding of eating disorders is typically low

The research demonstrates very low levels of understanding of eating disorders across the general population. While around nine in ten were at least aware the three most common types of eating disorder (92% aware of Binge Eating Disorder, 90% aware of Anorexia Nervosa, 87% aware of Bulimia), very few felt that they knew a lot about these conditions. Awareness and understanding of other conditions were notably lower, with around a third of the population never having heard of Body Dysmorphic Disorder, and one in seven never having heard of Orthorexia.

Overall, awareness and understanding tended to be greater amongst females and young people than amongst males and older people.

Figure 1: Self-reported knowledge of eating disorders

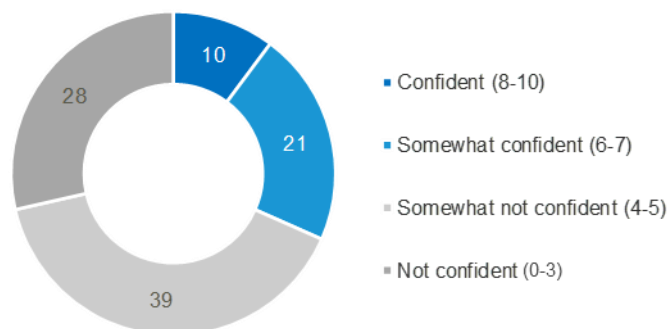


Q3. Which of these statements best describes your knowledge with each of these types of disorders...
 Base: All respondents (n=3,030)

3.2 Knowledge of signs and symptoms also low

In view of the relatively low levels of knowledge of eating disorders, it is unsurprising that only one in ten respondents felt confident in recognising the signs of an eating disorder.

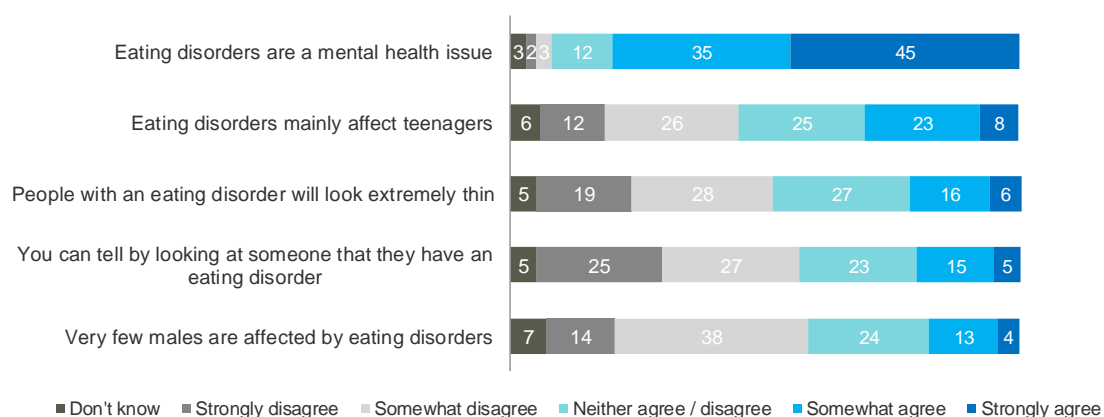
Figure 2: Confidence in recognising the signs of an eating disorder



Q20. And overall, how confident are you with the following...
Base: All respondents (n=3,030)

Indeed, the research showed a high degree of uncertainty about how eating disorders manifest and who they affect. As Figure 3 below shows, respondents put forward high 'undecided' and 'don't know' scores in relation to a number of statements reflecting a range of misconceptions about eating disorders, including that they mainly affect teenagers, that people who have an eating disorder look extremely thin, that you can tell by looking at someone that they have an eating disorder, and that very few males are affected by eating disorders.

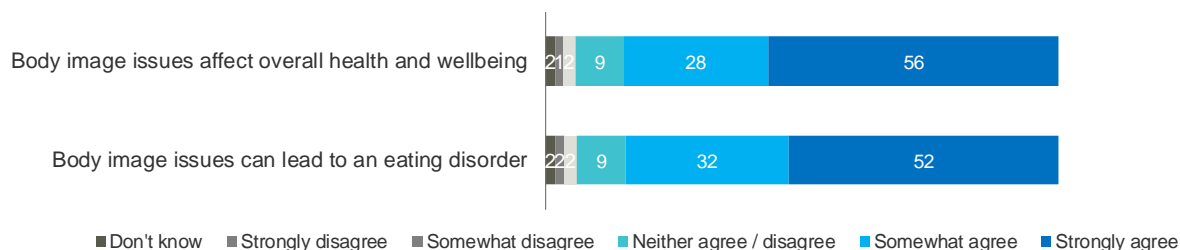
Figure 3: Understanding of eating disorders



Q15. And thinking more specifically around some of the things specific to eating disorders or body image. To what extent, if at all, do you agree or disagree with each of the following...
Base: All respondents (n=3,030)

Interestingly, there was stronger recognition of the links between body image and eating disorders, with relatively high levels of agreement that body image is a health concern, and can lead to an eating disorder.

Figure 4: Understanding of body image issues



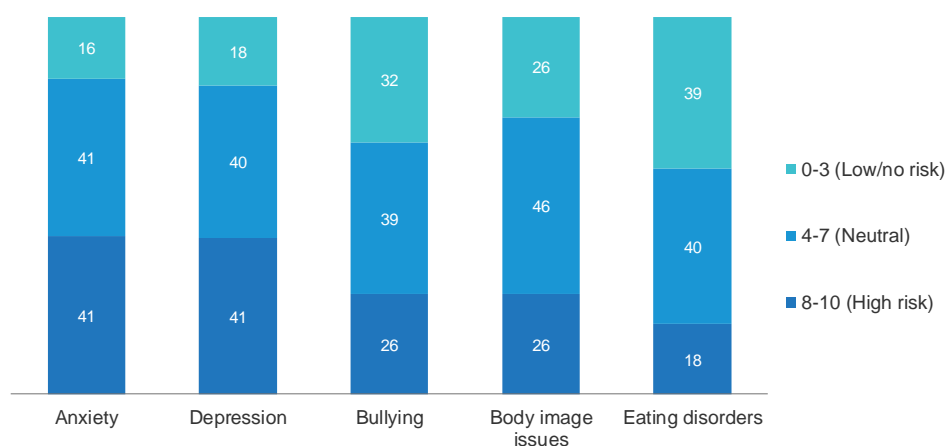
Q15. And thinking more specifically around some of the things specific to eating disorders or body image. To what extent, if at all, do you agree or disagree with each of the following...

Base: All respondents (n=3,030)

3.3 Eating disorders are not considered to be as prevalent as other types of mental health issues

The research suggests that many people underestimate the prevalence of eating disorders within the community. Overall, a quarter of the respondents agreed that 'eating disorders affect a very small proportion of the population', with a further 41% either not knowing or undecided. A comparison with other mental health issues demonstrates that the perceived risk of experiencing an eating disorder is considered relatively low. Only 18% saw eating disorders as a potentially high risk for affecting someone they know, contrasting with some 41% of respondents who saw anxiety and depression as being of high risk in this regard. Perhaps unsurprisingly, females and younger people were more likely than others to attribute high risk to experiencing an eating disorder.

Figure 5: Perceived prevalence of experiencing mental health conditions



Q1. Below are some different types of conditions that can affect a person's mental or physical wellbeing. To what extent, if at all, do you think there is a risk of each affecting somebody you know?

Base: All respondents (n=3,030)

3.4 Community interest in learning more

Potentially reflecting typically low levels of awareness and understanding of eating disorders, it was suggested by participants in the qualitative interviews that the issue is rarely a focus in the media or in public discourse, particularly compared to other mental health issues such as anxiety and depression. Some older participants perceived a reduced focus on eating disorders compared to ten or more years ago, when there was concern about the influence of very thin models on young people's perceptions around body image and weight. Some teachers also observed a reduced focus on body image and eating disorders in schools and suggested these topics had perhaps been superseded by other issues, including climate change and mental health more broadly (especially anxiety and depression). Teachers noted that the inclusion of specific issues in the school program tended to be driven by individual staff members, so eating disorders may only be an area of focus if a teacher is willing to champion it.

Some participants speculated that eating disorders may not be as prevalent as they had been 5-10 years ago. Some attributed this to change in feminine beauty ideals from 'thin' to 'curvy'.

"We were hearing about it more a few years ago than we are now. I remember it being a huge thing. It was really big and then it's gone quiet. I don't understand why because we now have social media... Maybe like big butts are in fashions, and maybe it's shifted like what the idea of true beauty has really changed. It's not the super skinny kind of model anymore. It's fat lips, fat butts, big hair extensions and long lashes." (Counsellor)

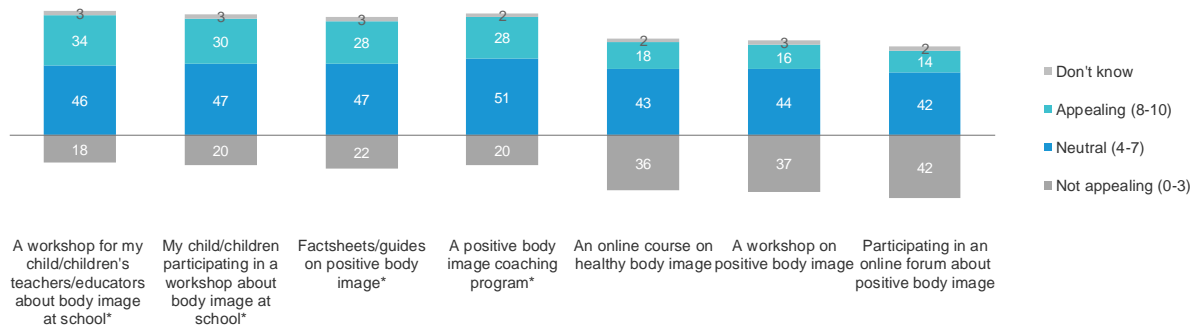
Health professionals also commented on the lack of awareness and understanding of eating disorders. Overall, there was a sense that the compulsive nature of eating disorders was generally not well understood by sections of the broader community.

"I don't think people realise the severity in this and the scary intensiveness of what an eating disorder can be like. I think that there's a lot of.... not misinformation, but perhaps, lack of education around what it actually can be like, the fact that it's all encompassing. It's not as simple as just eat. It's very scary and very intense and I don't think that the general population really realise that". (Psychologist).

"I think it's a lack of education, perhaps, or a lack of information and knowledge, because a lot of parents, when they do enter into a therapy program for any disorders because of their children, there's a lot of shock, and there's a lot of misunderstandings that need to be cleared up... (Psychologist)

A positive finding given the limited understanding of eating disorders across the community was a high degree of openness to learn more. This was particularly evident amongst parents, who showed interest in school-based workshops, fact-sheets and educational programs (of the kind delivered by Butterfly). While interest in initiatives was comparatively lower across the total sample, approximately six in ten indicated that online forums, courses and workshops on the issue held appeal.

Figure 6: Appeal of educational initiatives



Q21. Below are some more initiatives related to positive body image or eating disorders. For each initiative please tell me how appealing/interested these initiatives are for you personally. Base: All respondents (n=3,030)

*Only asked of parents or carers (n=1006)

4. How prevalent are stigmatising views, and how do these manifest?

There is clear evidence of stigmatising perceptions of eating disorders among sizeable sections of the community. A majority of survey respondents perceived that 'most people' view bingeing/purging as disgusting. Also, that 'most people' think 'only young girls are affected by eating disorders', which minimises the seriousness of eating disorders and potentially presents a barrier to help-seeking for males and adult women.

In addition, around one-quarter personally perceived disordered eating as a sign of weakness.

A similar proportion believed that people experiencing disordered eating are in control of their behaviour and, related to this, just over one-in-six associated eating disorders with attention seeking and/or lifestyle choice/vanity.

These views were most prevalent among males and younger people (aged 18-44).

Stigma pertaining to eating disorders can be conceptualised in three ways:

- Personal stigma – a person's stigmatising attitudes and beliefs about other people;
- Perceived stigma – beliefs about the negative and stigmatising views that other people hold; and
- Self-stigma – the stigmatising views that individuals hold about themselves.

A key mechanism by which stigma was explored was through the presentation of vignettes – short case studies illustrating a fictional character at risk of or living with an eating disorder. The vignettes provided a means to explore potentially negative attitudes and values in a more controlled, sensitive manner than asking respondents about these directly. Four vignettes were used, in order to facilitate separate understanding of attitudes towards different types of disorders, and to explore gender related stigma. The vignettes used were as follows:

- *Jane was in Year 12 when she started bingeing and purging. She had become increasingly self-conscious over the past year. She felt a lot larger than her friends, and felt sure that people talked about her appearance behind her back. Someone had told her that purging meant that you could eat whatever you wanted and not put on weight. She started doing it after eating a big meal, but soon it became a way to allow her to binge on 'bad foods' because she was feeling emotional or if something was getting her down.*
- *Brooke has been doing Dance since she was a kid. She really loves it. She has classes three times a week, and goes to the gym twice a week to keep her fitness levels up. A few months back Brooke started to feel that she looked bit heavier than some of the women in the class. She also noticed a lot of posts on Facebook about the 'ideal weight' for dancers. Brooke thought it might be an idea to lose a bit of weight, so decided to follow a low calorie diet – at first limiting her intake to 1000 calories a day. She did this for a couple of months, but then dropped to 700*

calories a day and for the past couple of weeks she's been doing 500 calories a day. Brooke weighs herself twice a day.

- Tom always felt a bit slight compared to his mates. As he got older, he started to notice loads of posts on Instagram of ripped guys. He really wanted to bulk up, so started going to the gym – at first once a week, but then more often, doing more and more sets every time. No matter how much he did though, he didn't seem to gain as much muscle as some of his friends. Despite working harder and harder, Tom still feels small. He now takes steroids and spends all his free time at the gym, determined to get the body he wants.
- Ever since he was a kid, Joe had worried about his weight – he'd been on loads of different diets, losing weight, only to put it back on again a few months later. When he started a new school/ university, he found it pretty hard to settle in. He knew no one, and really struggled to make friends. As the 'new guy', Joe felt extremely self-conscious. He would never eat in front of anyone at school/ university. Instead, he'd come home every day and hide himself away in his room, bingeing on chocolate and chips, unable to stop even when he felt completely full.

All survey respondents were asked direct questions about people with eating disorders, and asked to respond to these vignettes. Survey findings are reported for the general population and for those living with an eating disorder.

This approach was also undertaken qualitatively with people at risk/ living with/ recovered from an eating disorder. The vignettes were presented to participants and their responses sought through open ended discussion.

This section details the prevalence and manifestation of each type of stigma as evidenced within this research. It suggests that stigma is widespread at all three levels, in many ways lying at the foundation of the way eating disorders are viewed, both by the general public and those at risk of/ living with one, as described below.

4.1 Personal stigma

The research draws attention to a range of views indicative of high levels of personal stigma directed at those living with an eating disorder amongst the general public. The beliefs and attitudes observed most commonly through the research were as follows:

Eating disorders associated with weakness of character

There were also relatively high levels of agreement with statements suggesting that eating disorders are caused by some sort of character weakness. Around one-quarter (23-27%) agreed that 'if they [the people in the vignettes] were stronger people they wouldn't be doing this to themselves' and one-in-five (19-22%) agreed that the people who were bingeing 'just lack willpower'. This perception was more common among males than females and less common among those aged 45-64, in comparison to younger and older age groups, as shown in Table 1 below.

Table 1: Perceived weakness of character

	Vignette (% agreement rating 6-10)			
	Bingeing and purging (female)	Severe calorie restriction (female)	Muscle building, using steroids (male)	Bingeing (male)
'If [name] was a stronger person he/she wouldn't be doing this to him/herself'				
Total	23	23	27	25

Male	28	29	33	32
Female	18	17	21	19
18-24	24	27	25	29
25-44	27	24	30	30
45-64	18	19	23	19
65+	24	24	29	25
'[name] just lacks willpower'				
Total	19	-	-	22
Male	24	-	-	29
Female	14	-	-	16
18-24	19	-	-	23
25-44	22	-	-	28
45-64	14	-	-	16
65+	20	-	-	23

Perception of control

The perception that people experiencing eating disorders are choosing to engage in disordered eating patterns, rather than it being a symptom of a serious mental health condition, was relatively common.

Around one-quarter agreed that the people exhibiting disordered eating in the vignettes 'could stop their behaviour if they really wanted to'. This particularly applied in relation to the male muscle building example (29% agreed vs. 22-24% for the other vignettes).

A slightly smaller proportion agreed that the people described in the vignettes 'just want attention' (at least 14%). Again, this perception was more common in relation to the male muscle building example (24% agreed that he could stop what he was doing if he really wanted to, compared to 14% for the other two vignettes).

Just over one-in-six believed that people with eating disorders in general 'are trying to get attention' (17% agreed) and that 'eating disorders are a lifestyle choice or about vanity' (19% agreed). Nonetheless, an additional one in five neither agreed nor disagreed with each of these statements (20%, 21% respectively), indicative of some amount of acceptance (or at least lack of rejection) of this sentiment.

Again, a larger proportion of males than females agreed to each of the statements indicating that people with eating disorders should be able to control their behaviour. Younger people (aged 18-44) were also more likely to believe this (apart from with regards to eating disorders being considered 'a lifestyle choice or about vanity') as shown in Table 2 and Table 3 overleaf.

Table 2: Perception of control (% agreement rating 6-10)

	Vignette			
	Bingeing and purging (female)	Severe calorie restriction (female)	Muscle building, using steroids (male)	Bingeing (male)
'[name] could stop what he/she was doing if he/she really wanted to'				
Total	22	24	29	24
Male	27	29	36	30

Female	16	18	22	17
18-24	25	27	33	24
25-44	29	30	34	31
46-64	15	18	24	18
65+	18	21	25	21
'[name] just wants attention'				
Total	14	14	24	-
Male	18	18	32	-
Female	10	10	16	-
18-24	15	15	25	-
25-44	18	20	28	-
45-64	10	9	19	-
65+	13	9	22	-

Table 3: Perception of control (% somewhat/strongly agree)

	'People who have an eating disorder are trying to get attention'	'Eating disorders are a lifestyle choice or about vanity'
Total	17	19
Male	21	25
Female	13	14
18-24	18	17
25-44	20	24
45-64	13	13
65+	17	22

Minimisation of the seriousness of eating disorders

A sizeable minority of the community gave responses which indicated minimisation of the seriousness of eating disorders.

Around one-in-ten (9%) indicated that eating disorders 'are not all that serious' when asked directly, with a further 9% neither agreeing nor disagreeing with this statement. Similar findings were observed in relation to each of the behaviours described in the vignettes (10-12% indicated agreement that the behaviours were 'not all that serious' as shown in Table 4 below).

A larger proportion (at least 16%) believed that people are likely to simply grow out of disordered eating behaviours, and two-in-five (40%) felt that this type of perception was prevalent in the broader community (40% agreed that 'most people think eating disorders are just a phase', with a further 26% undecided).

Perhaps most concerning, because of the potential implications for help-seeking, was the belief held by almost one-quarter, that someone trying to lose weight by purging and/or severely limiting their calorie intake would only need to seek professional support if they became dangerously underweight (21% gave an agreement rating of 6-10 in relation to the binge/purge vignette, 24% in relation to the restrictive diet vignette).

Approaching three-in-five (57%) agreed that ‘most people in the community think only young girls are affected by eating disorders’ with a further 16% neither agreeing nor disagreeing. This minimises the seriousness and prevalence of eating disorders and potentially presents a barrier to help-seeking for males and adult women.

Minimisation of the seriousness of eating disorders was more common among males than females. For example, a higher proportion of males than females agreed that ‘eating disorders are not all that serious’ (12% vs. 7% of females). A similar pattern applied across responses to all of the vignettes, as shown Table 4 below. Younger people (aged 18-44) also tended to be more likely than older people to minimise the seriousness of eating disorders, again as shown in Table 5.

Table 4: Seriousness of eating disorders (% agreement rating 6-10)

	Vignette			
	Bingeing and purging (female)	Severe calorie restriction (female)	Muscle building, using steroids (male)	Bingeing (male)
‘[name] is likely to grow out of this type of behaviour’				
Total	16	17	19	16
Male	19	20	23	18
Female	12	13	15	13
18-24	20	21	24	18
25-44	23	23	26	22
45-64	10	11	14	12
65+	9	12	10	10
‘[name] would only need to seek professional support if he/she becomes dangerously underweight’				
Total	21	24	-	-
Male	24	29	-	-
Female	17	20	-	-
18-24	20	26	-	-
25-44	24	27	-	-
45-64	17	20	-	-
65+	22	24	-	-
‘What [name] is doing is not all that serious’				
Total	10	12	12	11
Male	12	14	16	13
Female	8	9	9	9
18-24	14	15	19	17
25-44	15	19	19	16
45-64	6	8	8	7
65+	4	5	5	6

Table 5: Seriousness of eating disorders (% somewhat/strongly agree)

	'Eating disorders are not all that serious'	'Most people think eating disorders are just a phase'	'most people in the community think only young girls are affected by eating disorders'
Total	9	40	57
Male	12	39	53
Female	7	42	60
18-24	13	46	61
25-44	17	45	59
45-64	5	35	57
65+	2	36	49

Normalisation of disordered eating

Closely related to the minimisation of the seriousness of eating disorders, and indicative of the normalisation of people pursuing the 'ideal' weight or physique, was the perception that the behaviours described in each of the vignettes were 'pretty normal' (13-18%, across the four vignettes, as shown in Table 6 below).

Normalisation of the severe calorie restriction and male binge eating behaviours described in two of the vignettes was more prevalent among males than females (6-10 agreement rating given by 19% of males vs. 14% of females and 16% of males vs. 12% of females respectively). There were no statistically significant gender differences in relation to the normality of each of the behaviours for the other two vignettes.

Younger people (aged 18-44) were more likely than those aged 45 years or more to perceive the descriptions of disordered eating behaviours as 'pretty normal', as shown in Table 6 below.

Table 6: Normalisation of disordered eating (% agreement rating 6-10)

	Vignette			
	Bingeing and purging (female)	Severe calorie restriction (female)	Muscle building, using steroids (male)	Bingeing (male)
'What [name] is doing is pretty normal'				
Total	13	17	18	14
Male	14	19	20	16
Female	11	14	16	12
18-24	17	22	25	19
25-44	19	23	23	21
45-64	8	12	14	9
65+	6	10	11	9

4.2 Perceived stigma

Bingeing/purging perceived as 'disgusting'

Perhaps the most striking finding in relation to stigma, was the consistency of the perception that 'most people think that bingeing/purging is disgusting'; three-in-five (59%) believed this to be the case, with a further 25% neither agreeing or disagreeing, and little difference by age or gender.

Unsurprisingly, the research suggests that those living with eating disorders are, themselves, conscious of stigmatising views within the broader community. Both qualitative and quantitative findings draw attention to high levels of perceived stigma amongst this cohort, with potentially harmful impacts on help seeking behaviours.

Many of those living with/ recovering from an eating disorder were cognisant of a range of prevailing misconceptions around eating disorders – with their assertions in this regard broadly aligning with the views held by the community as reported above. These included the assumption that people experiencing an eating disorder have the ability to control or stop what they are doing (as discussed) or that having an eating disorder (or mental health issue more broadly) is a sign of weakness. Also, that it might be form of attention seeking and, related to this, that eating disorders are in some way self-inflicted.

"...they definitely don't want to talk about it because they are immediately seen as being almost weaker than the others or having something wrong with them, you know, and they don't want to be seen like that." (Parent)

A comparison with the general population reveals that those at risk, or with lived experience, of an eating disorder are more likely than others to believe that stigmatising views are common among the broader community. For example, the majority agreed that:

- 'most people think that bingeing/purging is disgusting' (66% vs. 59% of the total population)
- 'most people think eating disorders are just a phase' (58% vs. 40% of the total population)
- 'most people think only young girls are affected by eating disorders' (68% vs. 57% of the total population).

Perceived stigma could present as a barrier to help seeking. The stories of those living with/in recovery from an eating disorder indicated that parents often hold damaging misconceptions, with a tendency towards victim blame and minimisation. Some felt that their parents had not taken their concerns about weight and body image seriously; for example, their parents had tried to reassure them that it was normal to feel the way they did or seemed to expect them to be able to change how they felt.

This appeared to deter many of those with lived experience or at risk of developing an eating disorder from disclosing their behaviour, while potentially contributing to the disorder by shaping and reinforcing negative body image.

"There's all this stigma at the moment about mental health and this definitely falls into that umbrella and I feel like she, and any kids that are dealing with any mental health issues, depression or anxiety, they definitely don't want to talk about it because they are immediately seen as being almost weaker than the others or having something wrong with them, you know, and they don't want to be seen like that." (Parent)

"I think that part of it is just potentially, you know, there's a lot of stigma around it, you know, and would get thrown around in households. And in the media, about the kind of person that has an eating disorder or body image issue, or even the kind of person that needs therapy."
(Bulimia, Anorexia)

"Depending on your relationship with your parents and other people in your family, could be until grandparents or whatever. Depending on the type of person they are, I definitely think that

they can be they coming from a place of caring and concern and wanting you to feel better and not be in that place. But it's very much just met with that. 'Stop'. 'Clearly, you know, you made these bad decisions and you need to just stop it and get it right'. (Bulimia, Anorexia)

Despite these assertions, there were high levels of concern about the seriousness of eating disorders among the parents/carers who participated in the qualitative elements of this study. They had witnessed first-hand the impacts of eating disorders on their children's mental and, in some cases, physical health. They also understood how hard it could be for a person living with/at risk of developing eating disorders to change their behaviour and underlying thought processes, as well as the challenges involved in supporting someone to achieve this.

"I think they're very serious because it starts with an eating disorder, but it becomes a mental health issue. It isolates you from having fun in life, enjoying simple things, it just overtakes your brain so you pretty much obsess about the same thing over and over again, so your mind is not free to just be a teenager, to go and relaxing and just have fun. Because you are constantly worrying about how much did you eat today. Is that too much? Did you work it off? So I think it's huge because it harms. This is why young people have a lot of mental health issues. It might start with the eating disorder, but it could end in a really serious depression. They are linked together anyway." (Parent)

4.3 Self-stigma

Those living with an eating disorder also showed high levels of self-stigma. This included:

- a sense of failure or embarrassment, having to 'resort to' 'abnormal' behaviours to try to achieve a desired or 'normal' weight or body shape
- self-loathing and shame associated with a perceived lack of self-control or 'gluttonous' behaviour (for those experiencing bingeing and purging shame was sometimes more associated with the bingeing aspect, as they felt the purging in some ways was to atone for the binge)
- feeling abnormal and alone in their behaviour
- believing their disordered eating patterns were a sign of weakness and/or not a 'real' problem, suggesting some internalisation of the idea that they should be able to stop their behaviour.

"In my experience, it feels like you have, which is ridiculous, but it's just it feels like we should have more control over that [an eating disorder]. You know, not that it should just be able to go away, but if you have enough willpower, if you have enough whatever, you can fix it... I also think that part of it for me anyway has been 'I'm doing these things' or 'I'm not doing these things', whatever the case might be, to achieve this [desired weight], but I'm still not looking like what I think I should look like, that other people can achieve without doing this. I think it's almost like you failed at it..." (Bulimia, Anorexia)

Very similar themes were noted in the qualitative research with Indigenous young people, with many indicating negative self-perceptions which ranged from identifying as somewhat of a loner and "a little bit weird" through to an extreme of self-hatred and feelings of being overweight and ugly, disgusting and unworthy.

"She [female vignette] already feels judged and different, so I would think she would think people would hate her even more if they knew [about her disordered eating]." (Indigenous female)

"She thinks she is ugly, and no one likes her." (Indigenous female)

"She thinks others would think she's disgusting, and she does it because she's a nobody."
(Indigenous female) The quantitative research shows that stigmatising views of eating disorders were more likely among those at risk, or with lived experience, of an eating disorder than the population as a whole, indicating self-stigmatisation. For example, among those at risk, or with lived experience, of an eating disorder:

- three-in-ten (30%) agreed that people who have an eating disorder are 'trying to get attention' (vs. 17% of the total population)
- around three-in-ten agreed that eating disorders are a 'lifestyle choice or about vanity' (31% agree vs. 19% of the total population)
- around three-in-ten agreed that the people described in the vignettes who were bingeing and/or purging 'just lack willpower' (vs. around two-in-ten of the total population).⁵
- around one-third agreed that if the people described in the vignettes were 'stronger' they wouldn't be doing this to themselves (vs. around one-quarter of the total population)⁶

➤ *Minimisation*

In addition to these self-stigmatising views, the qualitative research revealed a strong tendency among those at risk of experiencing eating disorders to downplay the seriousness of their own behaviour. They tended to feel that what they were doing was not serious enough to be considered an 'eating disorder' and/or that they were not doing enough to cause physical harm – for example, because they were 'only' purging occasionally or had not lost a dangerous amount of weight.

The impact of the negative feelings they were having about their weight and/or body image on their mental wellbeing was perhaps their most pressing concern, along with their preoccupation with these issues taking up time they would rather be spending with family or friends. They typically wished they could be more confident and content, rather than feeling such a strong compulsion to change themselves. This mental pre-occupation seemed to remain even among those who felt they had overcome their disordered eating behaviours to some degree – and they still faced a constant mental battle to resist the compulsion to re-engage in these behaviours.

However, others felt that they personally had at least some control in terms of being able to prevent their disordered eating habits from developing to the point that they would become seriously ill. Some believed that they would stop their disordered eating behaviours at some undefined stage in the future. A few though appeared to be aware that they might be over-estimating their own control. For example, one young woman explained that she might advise a hypothetical friend in a similar situation to her own to seek help as it could become a slippery slope.

"...if it's not really unhealthy, and if it's not really, really damaging. There are people who have actual conditions and people might just think that it's like attention seeking or that it's not that unhealthy if it's not that extreme kind of thing.... I think she probably judges herself about it a little bit more harshly, and so it's like, you know, if one of her friends was doing the same things, she'd be more like this is a slippery slope. This is dangerous. You shouldn't be doing this kind of thing, but for herself, it's like, well, people who are seriously ill and have a problem are doing a lot more than you." (Bulimia)

⁵ Agreement (6-10 rating), in response to the vignettes, that XX person 'just lacks willpower': female bingeing & purging: 28% vs. 19% total sample, male bingeing: 34% vs. 22% total sample.

⁶ Agreement (6-10 rating), in response to the vignettes, that 'if XX was a stronger person he/she wouldn't be doing this to him/herself': bingeing & purging by females: 34% vs. 23% total sample, severe calorie restriction by females: 30% vs. 23% total sample, muscle building, including use of steroids, by males: 35% vs. 27% total sample, bingeing by males: 36% vs. 25% total sample

This minimisation of the seriousness of eating disorders was identified among a sizeable minority of the survey respondents identified at risk of/having lived experience of an eating disorder in the quantitative survey, as follows:

- Around one-quarter believed that eating disorders, and the behaviours described in each of the vignettes, was 'not all that serious'.⁷
- Around one-third believed that the people described in each of the vignettes would simply 'grow out of this type of behaviour' and/or could stop what they were doing 'if they really wanted to'.⁸
- Around one-third believed that the behaviour of the people described in the vignettes was 'pretty normal'.⁹
- Around half or slightly more - believed that each of these behaviours were 'common', with the exception of bingeing among males (38% thought this was common).¹⁰

In all of these instances, minimising the seriousness of eating disorders was more common among those at risk/with lived experience than among the population as a whole.

"But she's very ashamed of her behaviour and just wants them [friends] to think that she's slim because she's, you know, exercising like crazy or just has a fast metabolism rather than she's actually got a disorder...she thinks that it's OK if you're doing lots of exercise to stay thin. But if you're, you know, if you're making yourself sick, then that's something to be ashamed of in her in her mind." (Binge eating)

"And the feelings of loss of control, of like shame or whatever, it is in the bingeing that leads to the purging...there's an element in purging or in restricting or whatever that feels the opposite of shameful because, even though you know that it's not true, there's still that part of you that's like, oh, this is the right behaviour because I am too big, therefore, I congratulate myself, and that's not something to feel ashamed of, it's something to feel proud because I'm making myself better by doing this." (Bulimia)

Based on the qualitative findings, it is probable that a larger proportion of those with lived experience would be critical of themselves and their own behaviour than would be critical of others having similar experiences.

It is hypothesised that this reflects a tendency towards self-criticism amongst those experiencing an eating disorder, underpinned by a sense of shame and weakness, particularly in finding it difficult to stop what

⁷ Agreement that eating disorders are 'not all that serious' (26% vs. 9% total sample). Agreement (6-10 rating), in response to the vignettes, that what XX person is doing is 'not all that serious': female bingeing & purging: 26% vs. 10% total sample, female severe calorie restriction: 26% vs. 12% total sample, male muscle building, including use of steroids: 27% vs. 12% total sample, male bingeing: 26% vs. 11% total sample.

⁸ Agreement (6-10 rating), in response to the vignettes, that XX person is 'likely to grow out of this type of behaviour': female bingeing & purging: 31% vs. 16% total sample, female severe calorie restriction: 30% vs. 17% total sample, male muscle building, including use of steroids: 35% vs. 19% total sample, male bingeing: 31% vs. 16% total sample. Agreement (6-10 rating), in response to the vignettes, that XX person could stop what they were doing 'if they really wanted to' female bingeing & purging: 34% vs. 22% total sample, female severe calorie restriction: 31% vs. 24% total sample, male muscle building, including use of steroids: 36% vs. 29% total sample, male bingeing: 35% vs. 24% total sample.

⁹ Agreement (6-10 rating), in response to the vignettes, that what XX person is doing was 'pretty normal': female bingeing & purging: 29% vs. 13% total sample, female severe calorie restriction: 31% vs. 17% total sample, male muscle building, including use of steroids: 33% vs. 18% total sample, male bingeing: 31% vs. 14% total sample.

¹⁰ Agreement (6-10 rating), in response to the vignettes, that what XX person is doing is 'common among men/women': female bingeing & purging: 49% vs. 33% total sample, female severe calorie restriction: 57% vs. 44% total sample, male muscle building, including use of steroids: 51% vs. 39% total sample, male bingeing: 38% vs. 21% total sample.

they recognise is a harmful behaviour. A correlation between experience of an eating disorder and depression may also explain the prevalence of self-stigma amongst this cohort.

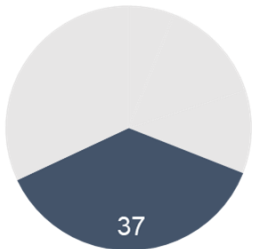
This highlights the importance of addressing negative stereotypes and misconceptions when communicating with this audience. Such beliefs are likely to shape a negative self-image, thereby potentially acting to reinforce the behaviour, and/or serving as a barrier to seeking help. In addition, these findings point to a need for extreme sensitivity when relaying messages to this audience, ensuring that any attempt to encourage help-seeking does not inadvertently perpetuate or reinforce self-stigma by applying too much pressure, or suggesting that an inability to stop is a sign of weakness. Further discussion around the implications of these findings for Butterfly Foundation appears in Section 9 of this report (recommendations).

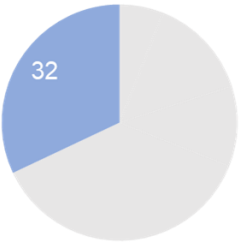
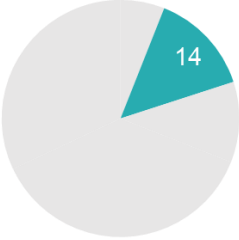
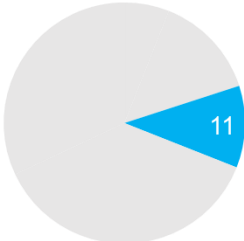

5. How do knowledge and attitudes vary across the population?

The key themes underpinning knowledge and attitudes around eating disorders as described in the preceding Sections were evident to varying degrees across the population. To understand the relative influence of these themes, and how they relate to different sections of the population, a segmentation analysis was completed. The technique groups the population together such that within each cluster (or segment), attitudes and behaviours are as similar as possible, and that between segments are as different as possible.

Overall, the two largest segments were the least likely to subscribe to stigmatising views. Progressive Advocates, representing around a third of the population show high levels of awareness and understanding of eating disorders, while Concerned Believers, at 37%, also see the issue as highly serious, though lack confidence in their ability to identify signs or seek appropriate support. The Judgmental Cynic segment are those most likely to subscribe to negative misconceptions, though show some openness to learning more about the issue. The two remaining segments are largely disengaged with the issue – the larger of the two, Distracted Indifferents, show little understanding of the issue and struggle to see its relevance, though show some interest in learning more. By contrast, the smallest segment, Detached Deniers tend to be more dismissive and unlikely to change.

An overview of the segments appears below, with more detail around the profile and characteristics of each segment following.

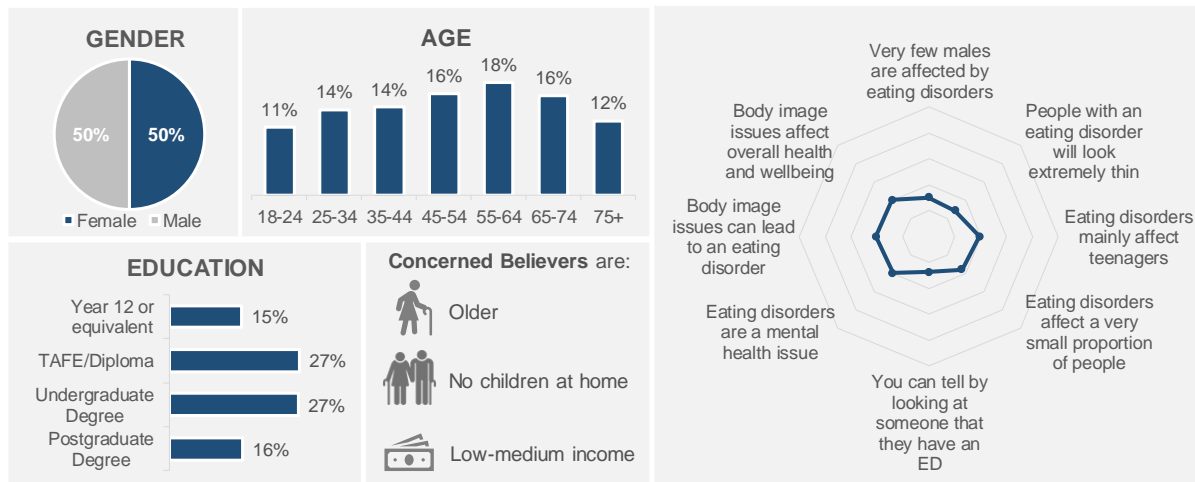
Segment	Size	Demographic skew	Description
1. Concerned Believers		Female Retired / Empty nest Slight skew to mothers Non-CALD	Concerned Believers show high levels of awareness of the 'traditional' eating disorders, anorexia, bulimia nervosa and binge eating disorder. Concerned Believers display good understanding about body image and how unhealthy relationships with food can develop into an eating disorder. However, they are not confident in recognising the signs of an eating disorders or reaching out to support services.

<p>2. Progressive Advocates</p>		<p>Female Younger Share house or living at home At risk group Slight skew to mothers Non-CALD</p>	<p>Progressive Advocates are the most well-informed segment. They reject common misconceptions about Eating Disorders and have a good understanding of the factors that can result in an eating disorder, as well as signs and symptoms. This segment is typically more socially conscious.</p>
<p>3. Judgemental Cynics</p>		<p>Male Fathers with children at home High SES CALD Indigenous</p>	<p>Judgemental Cynics are largely ill-informed about eating disorders. Uncertain about whether or not eating disorders are a mental health condition, they hold a range of stigmatising views. Nonetheless, members of this segment are open to learning more, and show interest in education in this regard.</p>
<p>4. Distracted Indifferents</p>		<p>Middle aged male Living with partner Lower SES</p>	<p>Distracted Indifferents also shows limited awareness of knowledge of eating disorders, with less than half recognising that they are a mental health issue. Typically preoccupied with other aspects of their lives, Distracted Indifferents lack the time to give the issue serious consideration. Despite this lack of engagement, Distracted Indifferents are not completely dismissive of opportunities to attend workshops or receiving material about positive body image.</p>
<p>5. Detached Deniers</p>		<p>Male Older Retired Lower SES</p>	<p>Detached Deniers are typically unengaged with the issue of eating disorders, seeing them as having very little relevance to themselves or their lives. Generally ignorant about the issue, they show very little interest or motivation to find out more.</p>

37%

Concerned Believers

This group shows high levels of awareness of the 'traditional' eating disorders, anorexia, bulimia nervosa and binge eating disorder. Concerned Believers display a good understanding about body image and how unhealthy relationships with food can develop into an eating disorder. However, they are not confident in recognising the signs of an eating disorders or reaching out to support services.



Concerned Believers make up of just over a third (37%) of the total population. This group shows high levels of awareness of the 'traditional' eating disorders, anorexia, bulimia nervosa and binge eating disorder. Concerned Believers recognise that eating disorders are a mental health condition, and display a good understanding around body image issues and how unhealthy relationships with food can place people at risk.

Concerned Believers are more likely to be older without children at home, and from lower socioeconomic backgrounds. There is also a slight, but not statistically significant skew towards mothers within this segment.

► Concerned Believers reject common misconceptions

Overall, this segment does not subscribe to the misconceptions that exist around eating disorders. They understand eating disorders are a serious mental health issue, not a lifestyle choice taken up by teenage girls. Similarly, they recognise that you cannot tell someone has an eating disorder just by looking at them – people suffering from eating disorders come in all shapes and sizes.

Eating disorders are a significant mental health issue and can affect anyone.

► Concerned Believers lack confidence in their knowledge of eating disorders

While Concerned Believers have some level of understanding of eating disorders and reject stigmatising views, they are not overly confident in their knowledge of eating disorders. In particular, they are not certain that they would recognise the signs of an eating disorder or mental health issue, or how they would help a friend suffering from an eating disorder.

► Concerned Believers have little awareness of Butterfly, but are open to supporting the charity

The segment has high awareness of mainstream mental health organisations including Beyond Blue and the Black Dog Institute. Despite this, they have relatively low awareness of Butterfly Foundation compared to the other segments. While they are not overly involved in charitable activities, they are concerned about the issue of eating disorders and open to supporting Butterfly.

► **As a target for education and awareness raising, Concerned Believers could be convinced to become more active supporters of Butterfly Foundation**

Concerned Believers see the issue as important, but lack confidence in their understanding or ability to take action to support those in need. Nonetheless, they are attitudinally open and supportive so represent a key target group for attention.

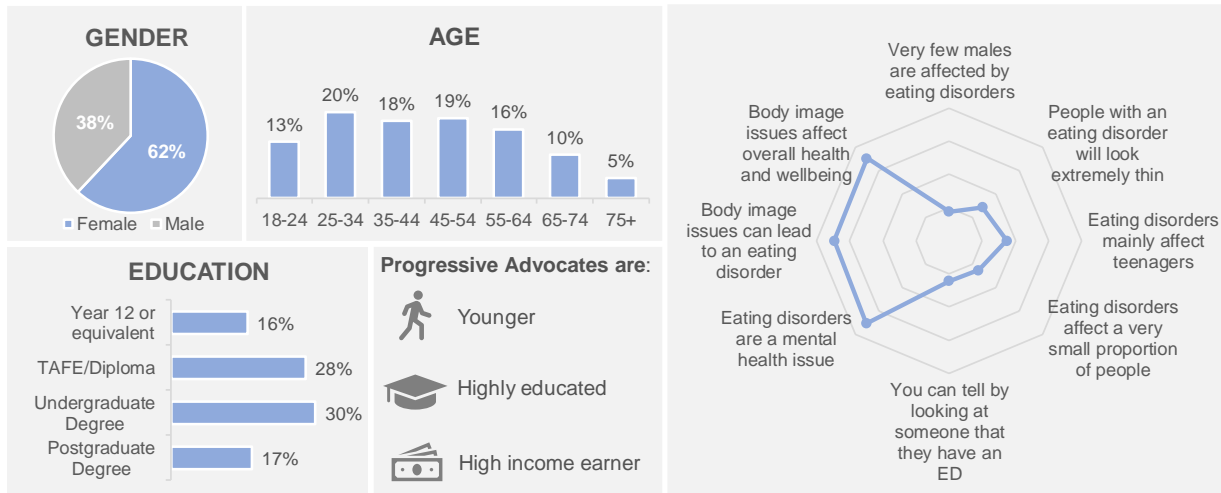
The Convinced Believer segment are likely to be receptive to awareness-raising and educational initiatives. Communications should aim to equip this segment with the knowledge and skills required to recognise the signs of someone affected by an eating disorder and to offer appropriate support.

In addition, initiatives that can build the profile of Butterfly Foundation and its work could help to shift this segment from being generally concerned about the issue to more active in supporting Butterfly, noting that they are more inclined to become occasional donors rather than brand champions.

32%

Progressive Advocates

Progressive Advocates are the most well informed segment, showing a high level of understanding of eating disorders, risk factors, signs, and appropriate support approaches. For this group, the issue is often personal and considered extremely serious. Progressive Advocates are most likely to be aware of Butterfly, and hold positive associations with the brand.



Of all segments, Progressive Advocates are best informed about the issue, showing high levels of understanding that eating disorders are a serious mental health issue, rather than symptomatic of a lack of willpower or control. Progressive Advocates are not afraid of stepping in to help contact a support service to help those around them, and are more likely to be aware of support services compared with other groups.

This segment forms approximately one third (32%) of the total population – they represent young to middle aged people, and include a relatively high proportion of those at risk of developing an eating disorder. While not statistically significant, there is a slight skew towards mothers with children living at home within this cohort.

► Progressive Advocates show high levels of awareness and understanding

Progressive Advocates show a high level of confidence in their understanding of eating disorders, and are highly unlikely to exhibit stigmatising view or misconceptions associated with the condition.

They reject the notion that:

- ✗ People who have an eating disorder are attention seekers
- ✗ You can tell by looking at someone that they have an eating disorder
- ✗ Eating disorders are a lifestyle choice or about vanity
- ✗ Eating disorders are not all that serious

Rather, they are informed and acknowledge that:

- ✓ Eating disorders is not just a phase
- ✓ Disordered eating can affect anyone – not just young girls.

► Progressive Advocates are most likely to see the issue as personally relevant

This is a highly relevant and in some cases personal issue for many Progressive Advocates. They are conscious of the risk of developing an eating disorder, including amongst people they know, and are mindful of the seriousness of this occurring. They demonstrate awareness of the role of social and cultural factors in perpetuating negative body image, and recognise the links between this and eating disorders.

2 in 5 believe there is a high risk of body image issues affecting someone they know.

► **Progressive Advocates are aware of Butterfly Foundation and hold positive brand perceptions**

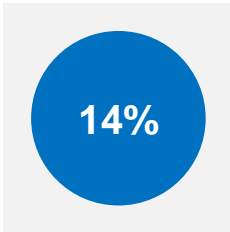
Progressive Advocates show high awareness of mainstream mental health initiatives, and Butterfly Foundation is relatively top of mind. Of all segments, Progressive Advocates are most well informed of the function and remit of Butterfly Foundation, and consider it a trustworthy and important provider of support services and education on eating disorders.

Advocates regularly donate to charities and are likely to advocate for Butterfly.

► **Communication activities should leverage the positive attitudes evident amongst this segment**

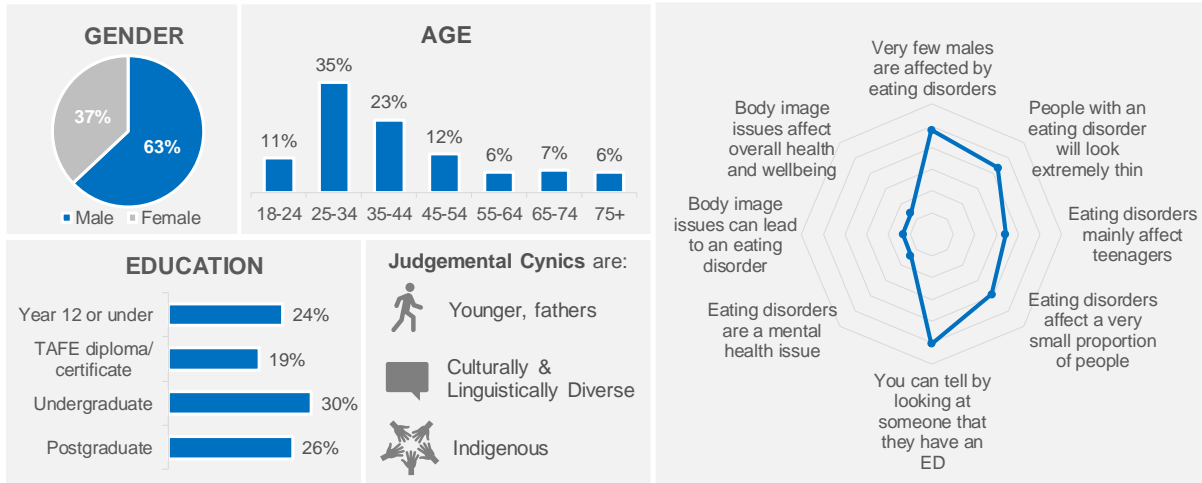
Advocates view the issue as highly important, and are confident and equipped to share their knowledge with others. They essentially act as standard bearers and, as such, could be valuable to harness in challenging preconceptions and biases relating to the issue and promoting positive messages through their networks.

Progressive Advocates are therefore a key audience for Butterfly's initiatives and communications. Messaging should focus on leveraging their already supportive attitudes, encouraging them to be part of an 'anti-stigma movement': calling out negative views and misconceptions, while promoting Butterfly Foundation to others.



Judgemental Cynics

Judgemental Cynics hold a range of negative and stigmatising views around eating disorders. Despite being typically well educated and affluent, this segment shows poor understanding of the various types of eating disorders, or their seriousness. Nonetheless, they tend to open to understanding more and show some interest in initiatives and programs to this end.



Constituting 14% of the total population, Judgemental Cynics are largely ill-informed about eating disorders. Uncertain whether or not eating disorders are a mental health condition, they hold a range of highly stigmatising views. Nonetheless, this segment are socially conscious and open to learning more, showing interest in education in this regard.

This segment are skewed male, and contain a high representation of parents, and high income earners, as well as those with CALD backgrounds, and Indigenous people.

► **Judgemental Cynics are poorly informed about eating disorders and holds highly stigmatising views**

Judgemental Cynics demonstrate poor understanding of eating disorders, subscribing to a range of stereotyped notions about what they are and who they affect. For instance, they are more likely to believe that eating disorders only affect girls, that you can tell someone has an eating disorder by their appearance, that those affected are typically attention seekers, and that they will eventually grow out the behaviour. Cynics believe that most people think that bingeing and purging is disgusting, and that this behaviour is a sign of weakness and lack of will power.

► **Judgemental Cynics accept that social factors contribute to Eds**

Judgemental Cynics also share many misconceptions about what contributes to eating disorders. They believe that dieting is a normal part of life for most people and that eating disorders are a lifestyle choice mainly affecting teenage girls.

Nonetheless, this segment acknowledges the impacts of societal factors such as influencer/celebrities/athletes, advertising and social media affecting the way people feel about their body.

Bullying (32%), anxiety (34%) and depression (36%) are considered more of a risk than eating disorders (24%)

► **Judgemental Cynics are eager to learn more**

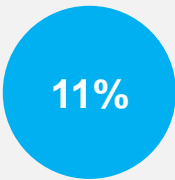
Despite their ill-informed views, this segment has high awareness of mainstream mental health organisations including Butterfly Foundation, and, to some extent, are likely to have accessed mental health support for either themselves or family. They are socially conscious individuals and more inclined to donate, volunteer or display public support for initiatives they believe in.

Reflecting an eagerness to learn, Judgemental Cynics show receptiveness to initiatives for positive body image and eating disorders such as positive body image coaching programs for parents, online courses and works shops on healthy body image.

► **Judgemental Cynics appears to be a key target for communications and education**

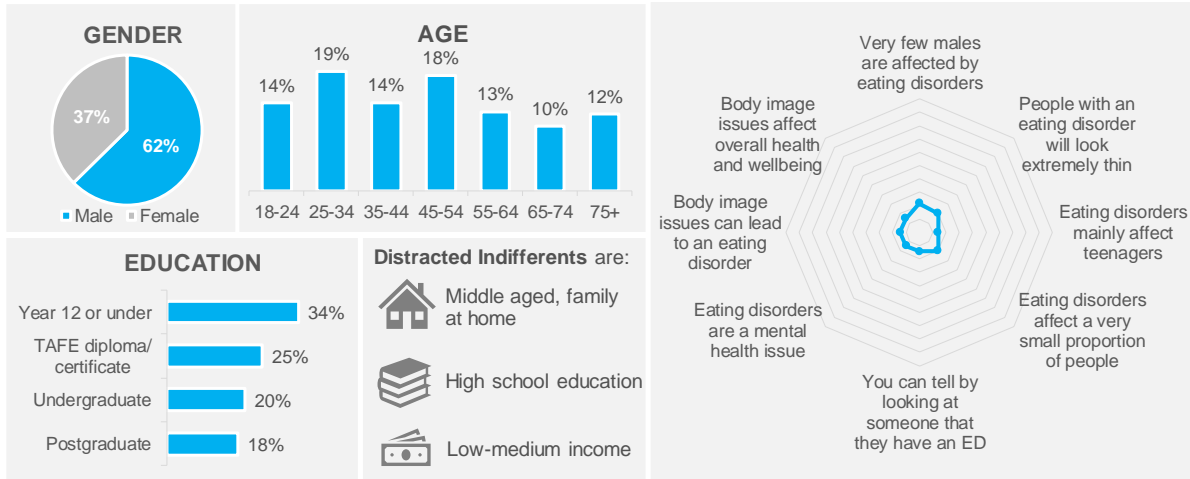
The Judgemental Cynics segment is a potentially primary target audience for communications aiming to educate the population around eating disorders, challenging common misconceptions and stigmatising attitudes. Despite their highly ill-informed views, Judgemental Cynics show readiness to learn more, suggesting that targeted communications may be effective in increasing their understanding of eating disorders, exposing the fallacy of stereotypes that underpin the way this segment are currently conceptualising the issue.

As a segment that skews towards parents, focussing on risks and impacts for younger people may help to generate relatability, in particular drawing attention to the role of parents in potentially sowing the seeds of negative body image among children from an early age.



Distracted Indifferents

Distracted Indifferents have little sense of personal connection with eating disorders, and very low awareness or understanding of what they are and who they affect. Currently, they see no reason to engage with the topic– though they are open to finding out more.



Distracted Indifferents represent a small proportion of the population, at just over one in ten of the Australian community (11%). Similar to Detached Deniers, Distracted Indifferents shows little awareness or understanding of eating disorders, and are generally unengaged with the issue. Unlike Deniers, however, Indifferents show openness to learning more.

Distracted Indifferents skew male, and tend to be from lower socioeconomic backgrounds.

► Distracted Indifferents feel little connection with the issue

While Distracted Indifferents show more awareness of the risks of anxiety and depression, very few regard eating disorders or body image issues as likely to affect either themselves or others they know.

Rather than holding stigmatised views, this segment are largely disconnected from the issue – they have no real opinion or interest in the topic, and are largely uncertain about who is affected by eating disorders, and what the signs may be.

Less than 1 in 4 believe there is a risk that someone they know will be affected by anxiety and depression, while less than 10% see themselves or others they know as being at risk of an eating disorder or body

► Distracted Indifferents have low awareness of Butterfly but is open to finding out more

Distracted Indifferents have little to do with organisations or initiatives for mental health, and are significantly less likely than others to be aware of service providers for eating disorders. Among the very few who are aware of Butterfly Foundation, one in four have only heard of the name, and about one half don't know very much about the organisation.

There is a sense that Distracted Indifferents are focussed on other priorities in life. While they are not particularly community minded, they are not completely dismissive of opportunities to attend workshops or receiving material about positive body image.

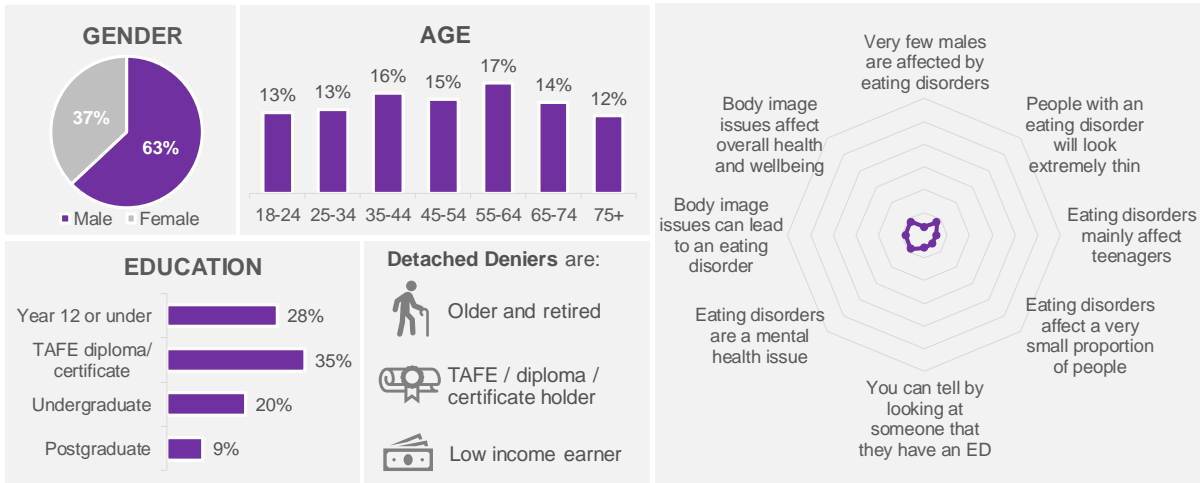
▶ **Distracted Indifferents may respond to awareness raising and educational initiatives**

Distracted Indifferents are likely to respond to communications as long as they can attract their attention and effectively 'cut-through'. In order to do so, any approach must elicit interest by demonstrating a reason for this segment to care about this issue, positioning eating disorders as a mental health condition equally serious as depression and anxiety.



Detached Deniers

Detached Deniers have very little understanding of eating disorders and largely regard them as irrelevant to themselves or the people they know. This segment holds minimising and dismissive attitudes to mental ill-health generally and eating disorders specifically. They tend to be set in their ways and uninterested in learning more.



The Detached Deniers segment makes up of just 6% of the total population. This group display very low degree of engagement with the issue, predominantly driven by a lack of interest and understanding about eating disorders, and more broadly – mental wellbeing. This attitude appears also to reflect little reported exposure to people living with an eating disorder, in addition to weak engagement with social issues generally, and a mindset largely closed to learning anything new about the issue. Detached Deniers tend not to be particularly community minded, and are unlikely to have volunteered, displayed public support for an initiative, nor made a donation for a NFP or charity group in the last year.

Detached deniers are an older, male segment with lower socioeconomic backgrounds.

► Detached Deniers minimises the risk, prevalence and impact of mental health issues

Detached Deniers are largely unconcerned about mental health issues in a broad sense. They show considerable scepticism about the likelihood that someone they know would be affected by mental ill-health, including an eating disorder or body image issue. Following on from this, Detached Deniers are generally dismissive about the seriousness of eating disorders, with high proportions seeing little risk that a body image or eating disorder would influence mental/ physical wellbeing.

There is 'no risk at all' of eating disorders (31%) and body image issue (25%) affecting mental/physical wellbeing

► Detached Deniers shows poor understanding of eating disorders

Detached Deniers find it difficult to grasp the idea of mental health and eating disorders. These are not health issues they have been educated on or 'grown up with'. They do not believe these to be serious health issues.

Close to a third of this segment (29%) believe that dieting is a normal part of life for most people, while just over half (58%) agree that eating disorders are a mental health issue versus 79% of the total population. They report high levels of uncertainty around most aspects of eating disorders, including who they affect, how they manifest, and what might contribute to them. Despite this lack of knowledge, Detached Deniers are generally unmotivated to find out more.

► Detached Deniers have little interest in learning more or seeking support

Detached Deniers are by far the segment least engaged with support services for eating disorders, this extends to organisations that operate under the wider mental health umbrella. Among the very few who are aware of Butterfly Foundation, most have only heard of the organisation and know nothing more.

Detached Deniers show considerable disinclination to ask for help. Very few Detached Deniers have contacted a support service, either to seek information for themselves or someone else, nor have they referred someone they are concerned about.

► Detached Deniers are unlikely to be receptive to communications/ education

It is highly unlikely that this group will engage in any communications or initiatives on the issue of eating disorders. This, together with the very small size of this segment, calls into question their suitability as a target audience for any form of intervention.

6. What are the barriers to help seeking for those at risk of or with lived experience?

The pressure to conform to idealised depictions of beauty and body shape is strong, even though the 'ideal' body shape for women is perceived to have changed from thin to 'curvy', with social media playing a key role. This appears to be a key contributor to the onset of body image concerns and disordered eating, along with family relationships with food.

Strong self-stigmatising views were expressed by people at risk, or with lived experience, of eating disorders, with the perception that eating disorders are a sign of weakness being particularly prominent.

There was also a tendency to minimise the seriousness of their behaviours, and/or over-estimate their ability to control them, particularly in the absence of physical symptoms or extreme weight loss. Linked to this minimisation, there was a fear that the 'risks' of getting support to address disordered eating, such as uncontrolled weight gain, would outweigh the potential benefits.

This fear was a key barrier to help seeking, along with not identifying as someone with an eating disorder and/or a belief that their behaviour was not serious enough to warrant this.

The research with people at risk of or living with an eating disorder sheds considerable light on the way at-risk groups conceptualise the disorder, and the internal and external factors that may deter help-seeking. The interviews provided insight into the beliefs and attitudes that may underpin resistance to help-seeking, and preferred sources of support and advice.

6.1 Role of external and environmental factors in driving negative body image and eating disorders

The research draws attention to an ongoing and strong influence of external and environmental factors in contributing to body image and eating disorders. Key themes from the research in this regard were as follows:

❖ *Pressure to conform to socially desirable body shapes*

People at risk, or with lived experience, of eating disorders reported feeling intense pressure to try to conform to **culturally acceptable body shapes**. Key among the reasons cited for the development of body image issues and disordered eating were the narrow images of beauty portrayed in advertising, music videos, TV, films and social media. There appears to have been a shift in recent years away from the depiction of extreme thinness as the ideal body shape for women towards a 'curvier' ideal. However, the images portrayed were still perceived to conform to a particular aesthetic, for example, 'toned' in the 'right' places, with flawless skin etc. Males also felt there was increasing pressure for them to have toned and muscular bodies, which may require them to simultaneously lose weight (fat) and 'bulk up' (with muscle).

Participants described being 'bombarded' with images of physical perfection, particularly via social media. It was suggested that, in this cultural climate, significant concern with appearance was the norm,

especially among young people, although to varying degrees. There was awareness that images across all these platforms are curated and may have been altered using filters, photoshop or other enhancements, but this did not seem to negate their negative impact on body image and self-esteem.

"...wherever you look they get bombarded with a certain image, and there's not enough talk about how this may be affecting them, to do with body disorders, with eating disorders. There used to be years ago, but I honestly haven't heard anything for the last 10 years, which is when everything amped up with the social media. And that's when kids are having these issues a lot more, but it's not really talked about enough." (Parent)

❖ ***Thinner is better and dieting norms***

The belief that 'thinner is better' appears to remain as a pervasive social norm. Some of those interviewed reported being complimented for losing weight, even when they had not indicated they had been trying to do so. Conversely, despite some acknowledgement of shifts in the acceptability of being openly critical about weight or appearance, this behaviour was still considered relatively common. Remarks and comments, whether positive or negative in tone, were often considered particularly significant when made by the opposite sex.

"Some things that are considered normal that I probably don't think should be considered normal. So, I think she probably had, you know, an uncle who would like pinch her stomach when she's in a bathing suit and like make a joke about it or something like that. Just things that are small but that like probably kind of planted seeds in her head." (Bulimia)

Reflecting this, dieting was perceived as a social norm among most of those identified as being at risk of or with lived experience in the quantitative survey (i.e. 62% agreed that dieting is a normal part of life for most people vs. 50% of total surveyed).

Pressure to be thin was thought to be amplified in **activities with a focus on physical form**, including dance and some sports.

❖ ***The conflicting representation of a 'healthy lifestyle'***

The often conflicting representation of a 'healthy lifestyle' within the media may have contributed to confusion around the 'healthiness' of disordered eating. Some of those whose behaviour and/or attitudes indicated that they may have been at risk of developing an eating disorder believed that they were engaging in a healthy lifestyle choice or trying to achieve a healthy body shape in a healthy way. For these participants, there seemed to be genuine confusion about what it means to be 'healthy' and they did not associate their behaviour with eating disorders. Although the number of males interviewed in the qualitative phase was relatively small, this type of confusion appeared to be more prominent for them, and there was a sense that some did not want to 'admit' that they might have experienced an eating disorder, perhaps because of the association with young females.

❖ ***The role of family***

A range of other environmental factors were also identified as contributors to the development of body image and eating disorders. While it has been shown that supportive families are helpful for recovery from eating disorders, interview participants raised family dynamics or family relationships with food as contributors to the development of body image concerns and eating disorders. Aspects which were identified included the following:

- **family expectations/family pressure to be successful**

- poor (or not close) **relationships with parents and/or siblings**
- comments on or **criticism of weight or body shape** from family members
- competition with **peers or siblings**
- unhealthy **relationship with body image** or food within the family

"I think my family was definitely like there's good foods and there's bad and it's not about having a balance in your life, it's just about there are good and there are bad." (Bulimia)

"Her (female vignette) relationship with her parents and siblings is not that great. Her brother ignores her, and her sister pushes her away." (Indigenous female)

"[A person without an eating disorder would have] a good family life and good friends. She does well at school, but she has no real negatives in her life. There's no part of her life that makes her sad." (Indigenous female)

Mothers in particular were seen as a key influence on female children; both in terms of being a role model (their own relationship with food, body image etc) and in terms of making direct comments about their children's weight or body shape.

"I think a lot of mothers care a little bit more about their daughter's weight rather than their sons. They have themselves grown up in a society that said that they needed to look a certain way and that is just kind of like a mentality that they pass on." (Bulimia)

The role of family in contributing to the development of an eating disorder was also a prominent theme within the research with **Indigenous people**. Participants pointed to a range of factors reflecting an unstable home-life, including unsupportive relationships with parents, friction between siblings, and a sense of being ignored, misunderstood, and rejected.

"Her childhood was filled with negativity about how she and her mother see women and how they are supposed to be." (Indigenous female)

"I think when she is at home, she is quiet and would not be showing her mother and brothers and sisters what she is doing. She is probably the one in the family that never gets in to trouble." (Indigenous female)

"Home is a place to hide." (Indigenous female)

"She was traumatised. It was hard to be accepted by the family as she feels that no one really accepts her or understands her." (Indigenous female)

"Her relationship with her parents and siblings is not that great. Her brother ignores her, and her sister pushes her away." (Indigenous female)

Similarly, among those classified as at risk of/having lived experience of an eating disorder in the quantitative research, family, friends and social media were rated as strongly influences on how they felt about themselves in terms of their looks and body image (i.e. rated as 8-10 in terms of influence on 10-point scale):

- Parents/ siblings (35%)
- Friends (35%)
- Social media (31%)

- Celebrities/influencers (25%)
- Advertising (23%)
- Colleagues (22%)
- Athletes (18%)

❖ *Bullying, trauma and stressful life events*

The experience of bullying or other types of trauma was also identified as a potential contributing factor, particularly amongst Indigenous participants. The seriousness and complexity of eating disorders when combined with existing trauma and disadvantage were readily apparent to Indigenous mothers and carers in particular, and they provided specific examples from their own experience to highlight a range of dangers. Bullying and lack of support were resonant themes and were perceived to be critical risk factors. There was a consistent view amongst young Indigenous people and family members alike that eating disorders often commenced, or worsened, during school, particularly around the period of 10 to 12 years of age. Participants felt that this was the age at which bullying was most likely to emerge, together with exposure to social media. Expectations of body size, whiteness, shape, and comparisons with other women were thought to be prevalent around these ages.

"I think girls tend to be more affected. Younger girls more so than older women who you would think would have a bit more sense or at least know who they could talk about if they did have body image or eating issues... If they have been tormented or bullied or made fun of. They may take drastic measures to try and change the way they look if someone has said something negative about them or a death in the family or another traumatic event or even got a new boyfriend." (Indigenous mother)

"I think a person is at risk if they are a little bit different in looks or personality or they don't fit the mould that most young people feel they should. Even if they have a supportive family, for young people these days other people's opinions and those of their peers really matter to them and this can hurt them if its negative. I know some kids that will not go to school as they do not want to get bullied or feel rejected. It is really sad. Kids can be withdrawn or quiet or stop doing things they used to enjoy, these are all early warning signs. I think kids these days often need professional support and strategies on how to get through this bullying." (Indigenous mother)

"About age 10-12 years old, she started to think more about what she looks like. She was probably eating a lot and influenced by what the media say about weight. Her eating behaviours started at this age and she was being influenced by media." (Indigenous female)

Significant, and in some cases, stress-inducing life events were also highlighted as potential triggers for specific episodes of disordered eating, including exams/study/work, starting college/university, moving to a new location or a relationship breakdown.

❖ *COVID-19*

Qualitative fieldwork for this study was undertaken in July 2020, at which time much of Australia had recently been in lockdown as a result of the COVID-19 pandemic, while participants were still facing various restrictions brought about to enforce social distancing. These measures were thought to have elevated stress for those at risk of or living with an eating disorder, given increased isolation, a lack of distractions, limited exercise options, and an opportunity to form rigid habits when spending more time at home and less time taking in part in spontaneous activities or events. These in combination were thought to risk the onset or exacerbation of an eating disorder.

"...because of everything that's happening with COVID is hard not to see if there's a bit of a link. I mean, people are at home, we're isolating... We are not distracted by life and other people, and so I guess it can be easy to get caught up in a bit of that, especially if we were told that while we're isolating, we should be exercising and looking after ourselves, and often eating disorders to start in that way; focusing on your health and fitness and it can kind of be a bit of slippery slope from there, so it's hard not to attribute blame to COVID and isolation..." (Psychologist)

"I think a lot of other people with histories of eating disorders have found the same thing with COVID; isolation just means that it's very easy to build habits again... Now we don't have any spontaneity because we're not allowed to do anything, and so you just have all of this time on your hands to exercise and do that kind of thing..." (Bulimia)

6.2 Role of personality and internal factors

❖ Personality traits considered more common among people with eating disorders

There was general agreement that any type of person could develop an eating disorder. It was considered common for people with eating disorders to put on a 'brave face' and therefore they could appear happy, outgoing and confident to the people around them. Having said that, there were some underlying personality traits that parents/carers, as well as people with disordered eating, and professionals, felt might be more prevalent in people experiencing eating disorders, including:

- perfectionist tendencies
- over-thinking
- a strong desire to be liked and to fit in
- low self-esteem (beyond weight and/or body image)
- relatively shy
- empathetic and caring
- being more guarded in their relationships with others, due to concerns about how others see them and, for some, a reluctance to be honest about their relationship with food
- possible preference for a smaller more trusted friendship group, linked to the above
- experience of anxiety, depression or other mental health issues.

"I guess just the pressure of wanting to kind of become the best or to be the right version of yourself, which I think is what the restricted eating and that stuff kind of is about." (Bulimia)

"I don't think there's necessarily any rhyme or reason, but generally speaking you do see, say, a lot of links between perfectionism and anxiety with eating disorders. I think because it does take quite a lot of determination to start on this kind of Journey of an eating disorder. Once it takes hold, it's really got a hold. But to get there in the first place, I think it takes a lot of determination and perfectionistic tendencies." (Psychologist)

A need for belonging and acceptance was particularly evident amongst the research with **Indigenous** people. Indigenous participants showed a high degree of concern around how they were perceived by others. Interestingly, this was not necessarily expressed in critical terms, but was rather seen as a reflection of diligence, desire to be successful, and concern with fitting in. Nonetheless, many felt that it was unlikely that someone living with an eating disorder would have many friends, reflecting a reluctance to share personal details, especially regarding eating behaviours.

“Wanting to be the best and looking the best and keeping up appearances with the social media.” (Indigenous female)

“She is dedicated and wants to be successful and achieve. She is worried about her appearance and keeping up with other people.” (Indigenous female).

“I think she [female vignette] is pretty similar to most girls but just far more reserved and shy.” (Indigenous female)

“She [female vignette] really wants to fit in and make friends but she is so self-conscious and eating seems like it’s the only way that she can feel good.” (Indigenous female)

Some parents/carers also felt there may be a genetic or inherent component, particularly if they themselves, or their other children had also experienced eating disorders or body image issues.

❖ *Changes in eating habits and personality*

Parents/guardians considered changes in eating habits to be the key warning sign for the onset of eating disorders, including picky/fussy eating, skipping meals, reducing portion size, calorie counting and eliminating certain foods entirely (e.g. sugar or fat). Personality changes were also cited, including increases in irritability, argumentativeness, missing school or getting into trouble at school. There was awareness among the parents/guardians interviewed that there may or may not be visible changes in weight or body shape.

❖ *Life stages*

Risk of developing body image issues or eating disorders were considered to be heightened at various life stages. The onset of puberty was thought significant, particularly for those developing earlier or later than peers, which could prompt heightened self-consciousness, and potential alienation. Further, increasing **independence in teenage years** could result in greater agency to control food choices, and increased privacy etc.

6.3 Barriers to help seeking

The qualitative interviews showed that there are many barriers that can deter those at risk, or with lived experience, of an eating disorder from seeking information and support.

❖ *The role of stigma as a barrier to help seeking*

As described in Section 4, those at risk of/ living with an eating disorder were more likely than others to hold a range of stigmatising views about the disorder. Stigma emerges as a prominent barrier to help seeking. For example, many participants reported not telling family members or friends about their behaviour out of concern they would not understand their experience or may view them more negatively if they knew about their disordered eating. Apprehension was also expressed about ill-informed, trite and/or potentially disempowering responses from friends and family members. Other reasons included not having a very close relationship with family members or friends and because of the self-stigma they felt about what they were doing/feeling.

"I guess like that initial in reaction would be is to be like why are you doing that? But you are beautiful, like you don't need to be skinny, you know, and that just disempowers her." (Binge eating)

"There's all this stigma at the moment about mental health and this definitely falls into that umbrella and I feel like she, and any kids that are dealing with any mental health issues, depression or anxiety, they definitely don't want to talk about it because they are immediately seen as being almost weaker than the others or having something wrong with them, you know, and they don't want to be seen like that." (Parent)

Perceptions around stigma and resulting fears about being judged or criticised by others also emerged as a strong barrier to help seeking in the research with Indigenous people.

"I think she is too embarrassed and has no self-respect or confidence left. She doesn't know how to bring it up. She may have told a friend, but I would be surprised if she told anyone." (Indigenous female)

"No, she would be doing it and keeping it private, so people don't judge her." (Indigenous female)

"No one else knows what she has been doing. She has not talked to others about it or sought any information or advice. She is self-conscious and worried and doesn't know how to talk about it with others." (Indigenous mother of teenage daughter and carer for teenage nieces)

❖ **Shame and embarrassment**

Reflective of self-stigma, another barrier to seeking support for some, was a **sense of embarrassment** that they did not look like 'someone who had an eating disorder', for example because they felt they looked overweight, or at least not 'skinny' enough. Similar perceptions were held by around one-third of the at risk, or lived experience, participants in the survey, as follows:

- 32% agreed (strongly or somewhat) that 'people with an eating disorder will look extremely thin' (vs. 22% of the of the total population)
- 33% agreed (strongly or somewhat) that 'you can tell by looking at someone that they have an eating disorder' (vs. 22% of the total population).

❖ **Fear about the consequences of seeking help**

When a person is suffering as a result of a mental health issue such as depression, they are likely to want the symptoms they are experiencing to stop. By contrast, those at risk, or with lived experience, of an eating disorder may not want their disordered eating to stop.

Some of those interviewed who appeared to be at risk of developing an eating disorder believed that the 'benefits' of their eating patterns, such as weight loss, building muscle or feeling a sense of control over themselves and their body, ultimately outweighed the costs and risks, particularly as the risks tended to be minimised (as described in Section 4).

A number of those at risk/ with lived experience of an eating disorder also described a conflict between their 'rational' thoughts and 'irrational' feelings about the prospect of seeking help. Rationally, they were aware that their thoughts about food and body image and the associated behaviours were not making them happy and were potentially physically and mentally damaging. There was also a desire to feel content and confident in the body they had. However, at the same time they felt a deeply ingrained fear

about what would happen if they were supported to stop their behaviour, such as uncontrolled weight gain or loss of comfort from bingeing.

"I think she still wants to be like the most slim version of herself that she kind of has in her head, but that she understands the toll that it takes to do that, and for the most part, she's not willing to sacrifice her health and you know whatever else to be like that, and so I think she still she still wants that version of herself but recognises that it's not viable. Yeah, and she probably wants their behaviour to go away for that reason, but also, I think she doesn't want to be like passing that on to her kids, if she has kids. Like she knows that it's wrong. Like it's kind of annoying that it's still there like she just wishes that it wasn't there but she probably still does have the desire to be skinny and therefore does have the desire to like take, all of those issues rather than trying really, really hard to get rid of them if they're not constantly a problem." (Bulimia)

"I think she [female vignette] does want to stop it but nothing else makes her feel good." (Indigenous female)

"She now wants to stop her eating behaviours. She is more of a stress eater and feels guilty about her eating behaviours. She would, but it is the only thing that makes her feels good or comforts her." (Indigenous female)

"Sometimes you're just worried that if you tell someone, you know, just because you need someone to hear, to understand, without trying make you stop. And sometimes the thought of that [being made to stop] is just horrific as well, you know. (Bulimia, Anorexia)

This fear, as well as fear of being judged, can result in people who are experiencing eating disorders actively hiding what they are going through.

"You can hide bulimia...and I'm trained. They are really, really good at maintaining their illness and highly skilled [at keeping their illness a secret] ... People with anorexia are normally highly motivated but really want to maintain the eating disorder." (Mental Health Nurse)

Internal conflict about stopping was also evident in the research with Indigenous people. Despite recognising a need to stop, many showed ambivalence about doing so, driven by an inner desire to continue – in order to meet goals, or 'feel good', as well as habitualisation of the behaviour, and low self-efficacy to change.

"I don't think she knows how to stop her sadness". (Indigenous female)

"She now wants to stop her eating behaviours. She is more of a stress eater and feels guilty about her eating behaviours. She would, but it is the only thing that makes her feels good or comforts her." (Indigenous female)

"I think she would want to stop but doesn't know how to stop without being overweight and feeling like she won't be a dancer. She is obsessed with keeping up with that image." (Indigenous female)

"I think she does want to stop it but nothing else makes her feel good." (Indigenous female)

❖ **Not recognising a need to seek help**

Not identifying as having an 'eating disorder' and/or feeling that their behaviours were not sufficiently serious or frequent enough to warrant seeking support (as discussed in Section 4) was another significant barrier to help-seeking. There was a feeling that many of the available supports and resources are targeted at people at the 'more serious' end of a continuum of disordered eating patterns, for example, those with diagnosed eating disorders, significant weight loss or other physical health problems.

Reflecting this, around one-third of survey respondents who appeared to be at risk, or with lived experience, of an eating disorder suggested, that a person who was bingeing and purging or severely restricting their calorie intake, as described in two of the vignettes, 'would only need to seek professional support if they became dangerously underweight' (32% gave a 6-10 agreement rating in response to the bingeing and purging vignette, 36% gave this rating in response to the calorie restriction vignette. Again, this view was less common among the population as a whole (21% and 24% respectively).

❖ *Questions around support services*

Other barriers to help-seeking pertained to perceptions of available support. This encompassed:

- Concerns about the **confidentiality of support services**. This particularly related to a fear that parents might be told or find out about that they were seeking support or about the nature of their problems.
- Scepticism about the **efficacy of treatment** or the availability of high-quality counsellors or psychologists.
- The **perceived cost and/or time investments** that may be involved in accessing support (particularly for counselling/therapy). One participant explained that it was particularly difficult to summon up the motivation and energy to seek support when they were experiencing significant difficulties, but when they were feeling somewhat better seeking support didn't feel like a priority.

"Something like seeing a psychologist or psychiatrist does take a lot of money and it takes time and it takes a lot of energy, it's very easy resource wise, not do that and to be like this is not worth it right now for the money that it is. And then when it is really hard, and it would be worth it, you don't have the like mental resources to do it. Yeah, so I guess it's kind of like because it's a hard thing then any kind of barrier could be enough just to almost give you a reason not to do it." (Bulimia)

- Related to the cost barriers, health practitioners interviewed for this study noted that GPs may not be aware of, or not adequately communicate, the subsidised support services that are available to those affected by eating disorders through Medicare (i.e. additional support available to those who fit the eligibility criteria for the MBS Eating Disorders Treatment Pathway).

6.4 Support needs

Participants who were at risk of developing eating disorders sometimes struggled to identify their support needs, in part because of a reluctance to seek support for the reasons outlined above. However, some suggestions for the types of support that would be useful and that might help to address some of the barriers to help-seeking were suggested by parents, teachers and those at risk of or with lived experience of eating disorders, and other supports were implied by other feedback provided throughout the interview process including:

- **Workshops for parents** (likely via schools) and other information to help parents promote healthy relationships with food for their children and to effectively support children/young adults with body image issues or at risk of eating disorders. This might include how to respond to early warning signs, as much of the available information was perceived to focus on supporting people with diagnosed eating disorders.

"I wish they were mandates about parents going to workshops to learn about things that would be useful for them to know for their kids." (Bulimia)

- **Support groups for parents/guardians** of people experiencing eating disorders, as well as for those with lived experience, as both of these groups described feeling alone in their experience and sometimes unable to share what they were going through, because of a sense that only those with direct experience would fully understand.
- **Teacher training** on the subject of eating disorders and body image. Schools were reportedly open to external speakers talking to teachers about student welfare issues as part of staff development days on topics, but the time investment for teachers/school must not be too onerous given the high number of competing issues and causes.
- **Age-appropriate student programs** and/or guest speakers in schools, focusing on prevention, especially before puberty when participants told us feelings of low self-esteem related to body image often began to emerge, as well as for teenagers, when there could be more 'adult' discussions about some of the issues. Teachers noted that it is challenging to engage groups of young people in schools, so guest speakers must be skilled in this area.
- **Early intervention supports** for those exhibiting behaviours or feelings which put them at risk of developing an eating disorder, as well as information and support aimed at people who do not see themselves as having eating disorders or who believe they have relatively less serious disordered eating patterns.
 - There was interest in free specialised counselling or therapy, perhaps available in schools or via higher education providers, to allow easy access and drop-ins. The importance of confidentiality was stressed by younger people interviewed, specifically they indicated that parents must not be informed of attendance. One person explained that she would be unlikely to proactively seek out support or information, but may engage with this if it was proactively offered to her, for example through services in schools or higher education providers.
- **Testimonials** or advice from people who have experienced and recovered from eating disorders, for example via the media/social media, to counter that sense of being strange or alone in experiencing disordered eating, to show that treatments can be effective and to demonstrate that the benefits of recovery. Participants told us that they are more willing to take on board these messages from someone with personal experience.
- The provision of support by a **variety of channels**, as preference varied depending on circumstance and personality. For some of those with lived experience, webchat was favoured for its increased sense of anonymity and privacy, especially as conversations can't be overheard. This option was also considered less intimidating, particularly for first contact. However, telephone services were preferred by others for providing a stronger human connection when discussing a sensitive topic. Some would ideally want face-to-face support – again for a better sense of personal connection.

"I don't think she has talked to any of the above. If anyone it would be a professional or a counsellor, but it would have to be done anonymously, not in person or a way she may be identified so like on a website or over the phone. She would find it hard to talk to anyone of her friends or family. A stranger is easier as you don't mind what they think as much as you would mind someone you know." (Indigenous female)

"She [female in vignette] would be just wanting to make sure no one could identify her." (Indigenous female)

"A testimonial, like sometimes there's people who go on the radio or on the TV...People discussing things that have happened in their lives and then help people understand that they're not the only one." (Binge eating)

"I guess, just information about eating disorders and body image and all this stuff are like very common issues and that they're not, you know, something that you have to have in an extreme form for it to be an issue and like just reiterating that if it's not serious, that doesn't mean that it's not seriously affecting you." (Female, aged 21-24, lived experience, Bulimia)

Somehow having the ability to access people, to let them know that there are services available without you having to search the Butterfly Foundation to find those sorts of things (Bulimia)

Indigenous participants tended to put forward professionals, such as doctors, dieticians, counsellors, or other professionals as sources of support, and saw anonymous helplines as potentially appealing. Regardless of the source of support, a non-judgemental, empathetic and sympathetic approach was regarded as essential and the only likely successful pathway.

"I would tell her to go and see a doctor or dietician or speak to her parents about it." (Indigenous female)

When prompted about following Butterfly Foundation on **social media**, there was some interest in this, particularly if it featured useful information, testimonials and advice from people with lived experience, with representation from a range of positive body types. A number of the young Indigenous women interviewed stated a specific preference for Facebook as a potential source of information about eating disorders, rather than a website or other social media platforms.

"No, I would not look at website I would look at Facebook." (Indigenous female)

Interest in some of the initiatives that might be provided in relation to positive body image or eating disorders was tested in the quantitative survey. The results indicate that there is significant demand for these, particularly among those at risk, or with lived experience, of an eating disorder. At least one-in-ten indicated that each of these initiatives were very appealing to them (rating of 8-10 on a ten-point scale), as follows:

- **positive body image coaching program for parents/carers** (parents only: 43% vs. 28% of the total population)
- **workshop for my child/children's teachers/educators** about body image at school (parents only: 42% vs. 34% of the total population)
- **my child/children participating in a workshop** about body image at school (parents only: 39% vs. 30% of the total population).
- **factsheets/guides** on positive body image from my child/children's school (parents only: 36% vs. 28% of the total population)
- **online course on healthy body image** (34% vs. 18% of the total population)
- **workshop on positive body image** (31% vs. 16% of the total population total)
- **online forum about positive body image** (30% vs. 14% of the total population).

6.5 Effective and ineffective approaches to support

Those who felt that their disordered eating had improved (though not necessarily abated entirely) provided insight into the type of support they had found helpful and unhelpful, as follows:

Examples of effective support

- Counselling/therapy – some participants had accessed counselling/therapy for a range of mental health challenges (though not specifically for disordered eating) and had found this helped them to recognise and challenge unhelpful thought patterns and they were then able to apply this to how their thoughts about body image, eating and exercise.
- Talking to people who had personal experience of eating disorders, as this experience meant they were able to: fully understand, rather than minimise, their feelings; offer advice based on personal lived experience; and, in some cases, proactively check in to see how they were doing and warn them about the return of unhelpful behaviours, as well as help them to feel less alone in their experience. There was a sense that this type of direct advice and intervention was more likely to be accepted from those with lived experience or, perhaps, from health professionals with relevant professional experience.
- Family or friends listening to their thoughts and feelings, without judgement, and without trying to force certain behaviours or food types on them.
- Spending time and eating with people who had a healthy and positive relationship with food and exercise. This was particularly the case for those who has grown up with family members who appeared to have their own body image concerns or unhealthy relationships food and exercise.

Examples of ineffective support

Most of the examples of ineffective support centred around usually well-meaning friends or relatives not understanding of the seriousness of disordered eating or not understanding that the associated thoughts, feelings and behaviours are often experienced as all-encompassing and uncontrollable. Specific examples included friends or family:

- attempting to normalise or minimise the experience, thoughts and feelings of someone with disordered eating or body image issues, for example by reassuring them that everyone feels the same, that their body shape/weight is normal, or that how they are feeling will simply pass
- related to this, attempting to demonstrate empathy by comparing isolated experiences of eating too much or trying to lose weight to an eating disorder
- advising or expecting a person experiencing disordered eating to change their behaviour, thoughts or feelings.
- Suggesting 'healthier' ways to lose weight or alter body shape, such as exercise.

7. Conclusions & recommendations

7.1 Conclusions

While there has been significant media attention on the topic of eating disorders during the COVID-19 pandemic, for some interview participants the subject of eating disorders appears to have fallen from the public agenda in recent years, leading to a lack of awareness and understanding and some speculation that eating disorders might be less prevalent now. This is likely to impede people's ability to recognise that they or people they care about might be experiencing or at risk of developing an eating disorder.

A sizeable minority of the population held stigmatising perceptions of eating disorders, including minimising their seriousness, thinking that people experiencing them are in control of their behaviour, and believing that eating disorders only affect young girls. Eating disorders are also associated with weakness, attention seeking or vanity. These views tend to be more prevalent among males and younger people. Self-stigma was also common among people at risk of or with lived experience of an eating disorder. These perceptions present serious barriers to people seeking support, due to concerns about how they will be perceived if they reveal that they are struggling. Arguably even more importantly, those at risk of developing an eating disorder may not themselves realise the potentially serious implications of their behaviours and thought patterns. Some, particularly males, might also not want to admit to themselves that they are experiencing something that is associated with weakness or with young girls (this perhaps requires further investigation).

Fears about the consequences of stopping disordered eating such as uncontrolled weight gain or the loss of ability to obtain comfort from behaviours such as binge eating, are a key barrier to help-seeking. This perhaps implies a lack of understanding that treatment for eating disorders would aim to address underlying mental health issues driving disordered eating behaviours, rather than just trying to fix the behaviour.

Related to this, people at risk of, or experiencing eating disorders, appear more willing to accept advice and support from someone with personal experience.

The role modelling of unhealthy relationships with food within families appears to be a contributing factor to the development of eating disorders, suggesting a need for preventative educational interventions that target parents/carers. The constant stream of images of perfection presented by social media is another key driver of negative body image and unhealthy relationships with food and exercise that needs to be countered with more realistic and diverse depictions.

The Covid-19 pandemic has the potential to exacerbate, and contribute to the development of, disordered eating patterns as people experience heightened anxiety, isolation and a reduced ability to take-part in enjoyable/engaging activities. It may also present an opportunity to increase the profile of eating disorders in the public discourse, as addressing mental health issues is expected to be a key policy and funding priority over the coming years.

7.2 Recommendations

Drawing on the research findings, a series of recommendations are put forward for Butterfly Foundation's consideration. These are grouped around key objectives as follows:

- 1) *Raising the profile of eating disorders: Increasing community awareness and understanding of eating disorders*
- 2) *Challenging misconceptions and stigmatising views held by specific groups*
- 3) *Increasing help seeking behaviour amongst those at risk of/experiencing an eating disorder*

Suggested approaches for addressing each of these objectives are put forward below.

1. Increasing awareness and understanding of eating disorders

Key insight: There is a significant lack of awareness and understanding of eating disorders on a broad community level. Narratives around depression and anxiety appear to have dominated the media's focus for some time, and may be compromising cut-through of messaging on other mental health issues.

The research points to a need to raise awareness, increasing recognition of the prevalence, presentation, and impacts of eating disorders and clearly positioning them as a serious mental health issue. A lack of awareness and understanding may lie at the foundation of minimisation and stigma, perpetuating the belief that eating disorders are potentially not all that prevalent, serious or something to be concerned about.

Intervention: Given the lack of understanding evident across the population, a broadly targeted communications campaign is likely to be most effective both in boosting awareness and understanding, and in increasing awareness of Butterfly. The challenges of cutting through in the relatively crowded mental health landscape are noted, and point to potential benefit in leveraging PR as a means of 'injecting' the issue into the public discourse. The engagement of high-profile spokespeople may help to cut through in this regard, particularly if spokespeople can draw on personal experiences in a credible and authentic way.

Care should be taken to firmly position eating disorders as a serious mental health issue that affects a broad spectrum of people. Messaging should also aim to correct commonly held misconceptions about eating disorders, including that they only affect girls, that they are a choice rather than a health issue, and that they are not as serious as other types of mental health issues. In addition, when communicating on this issue:

- Frame the issue as a serious one, while using language that is supportive and positive.
- Messages must be sufficiently emotive to engage concern, but must not patronise, belittle, or evoke pity.
- Make use of real life, authentic stories across communications as a means of engaging audiences, strengthening empathy, and reinforcing credibility.
- Communications should place Butterfly front and centre, positioning the organisation as the primary source of education and support on eating disorders.

2. Challenging misconceptions and stigmatising views held by specific groups

Key insight: A cohort of the community (with a skew to young males – 'Judgemental Cynics') are more explicit in their stigmatising views of eating disorders. This group are most likely to subscribe to views such as that bingeing/purging is disgusting; that 'only young girls are affected by eating disorders'; that disordered eating is a sign of weakness; and that eating disorders are a form of attention seeking and/or a lifestyle choice/vanity.

Given their explicitly negative attitudes, this group may play a key role in reinforcing stigma around eating disorders amongst both the general population and self-stigma amongst those living with eating disorders. They are therefore a primary target for intervention. It is important to note, however, the complexity in challenging what are likely to be deeply held perceptions and attitudes amongst this group, in many cases

reinforced by peer and parental influences. Any intervention must be viewed as a long term and ongoing undertaking.

It is positive however to observe that this group show some openness to learning more about the issue.

Intervention: While a targeted communications campaign may help to draw attention to the issue, this group is likely to require education to demonstrate deeply engrained assumptions. As Butterfly already has an existing suite of school and community-based programs, a key challenge is how to expand the reach of these programs. Consideration could also be given to engaging high profile advocates with lived experience in speaking out against stigma, using public (or school-based) forums to challenge stereotypes and misconceptions.. In the longer-term and with sustained effort, this may help to build social disapproval and condemnation of stigmatising attitudes.

3. Increasing help seeking behaviour

Key insight: Strong self-stigmatising views were expressed by people at risk of, or with lived experience of eating disorders, with the perception that eating disorders are a sign of weakness being particularly prominent. There was also a tendency to minimise the seriousness of their behaviours, and/or over-estimate their ability to control them, particularly in the absence of physical symptoms or extreme weight loss. Linked to this minimisation, there was a fear that the 'risks' of getting support to address disordered eating, such as uncontrolled weight gain, would outweigh the potential benefits. This fear was a key barrier to help seeking, along with not identifying as someone with an eating disorder and/or a belief that their behaviour was not serious enough to warrant seeking help.

In order to increase help seeking amongst those at risk of/ living with an eating disorder, there is a need to counter the perception that only those who are experiencing serious physical problems need to seek professional help and provide resources and actively promote resources for people who don't see themselves as having an 'eating disorder' or a serious problem.

Intervention: Consider greater focus in communications relating to support services on listening to, understanding and addressing the emotions and mental anguish underlying disordered eating, rather than on the behaviours. It is important that communications avoid triggering fears about being 'forced' to stop their behaviours and/or the perceived negative consequences at having to stop their behaviours. Ideally utilise testimonials to convey and legitimise these messages (see below).

- Continue to engage with and share testimonials from people with lived experience to encourage help seeking, by providing hope that recovery is possible, reassurance that the consequences of seeking help will be positive, and by demonstrating a deep understanding of the fears underlying eating disorders.
- Provide information and support for parents, including:
 - how to encourage children to develop healthy relationships with body image, food and exercise from a young age (preventative), how to identify and address warning signs (early intervention) and how they can effectively support someone who has been diagnosed.
 - Aim to provide information directly to young people – e.g., via schools, social media, influencers etc – don't expect them to come to look for it.
 - Aim to make support services free and as easy to access as possible. Consider a focus on webchat as a first less intimidating step. Provide reassurances about confidentiality/anonymity.