



## Butterfly Foundation

Consumer Experience  
Pathway User Research

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### Butterfly Foundation

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# Executive Summary

U1 has been engaged by Butterfly Foundation to conduct user research that explores the consumer journey. The research aims to elicit feedback that helps identify existing gaps and pain points encountered when accessing eating disorder/body image resources and services.

Participants consist of 9 segments (Previous users of Butterfly services, Current Butterfly consumers, Recovered people with lived experience, Health professionals, Industry bodies, Sporting and community organisations, School or Education professionals, General public and people at risk/carers of people at risk) and provide reflections on their current behaviours and attitudes to the resources they use and where opportunities exist to better support consumers of eating disorder and body image concern resources.

### Aim and Approach

- The findings presented in this report relate to research undertaken across multiple days, from Monday the 31<sup>st</sup> of October to Thursday the 17<sup>th</sup> of November
- 45 in-depth moderated interviews, 60-minutes long, were conducted remotely via Zoom
- 2 group workshops, 90 minutes long, were conducted remotely via Zoom



# 1

## Where do consumers from this cohort typically come from?

For all participants, an online browser search was the intuitive first step when seeking resources for help and they described being more inclined to look for academic or government sources because they felt more authentic and trustworthy. Examples include: Inside Out, BetterHealth and NSW health. Commentary from participants in the sporting and community organisation segment indicated that having resources like the Butterfly posters on their office wall, or within the workplace, are often catalysts for conversations with young people and their parents

# 2

## Butterfly is the intuitive first place to go

Typically, Butterfly was found to be the most informative resource and gave the impression of a trusted information provider. Participants often described using Butterfly as their only source of information, not needing to look at any other resources or tools. Commentary considered Butterfly as the gold standard for representation compared to other resources available locally. When reflecting on the language of Butterfly resources, participants commented that they feel current and inclusive. This observation was of particular relevance for participants who did not have a formal or singular diagnosis, as it addressed their concerns and made them feel validated

# 3

## I don't know what I don't know

In most segments, the participant's initial steps were to undertake self-directed learning-phase research to get more knowledge about the issue, symptom matching, identify behaviour and understand the next steps and what to do themselves (either as an individual or supporter). Commentary indicated that a barrier to researching available support is difficult when 'you don't know what you don't know'. After the initial research, they may then want to talk to someone with expertise so that they could ask more specific questions about their situation

# 4

## Content inclusivity could be better

Male identifying participants found that whilst Butterfly has the most diverse resources of those available, most online resources were targeting young girls and were unrelatable to them. Participants that do not fit the 'stereotype of an eating disorder' have typically experienced bias due to gender, age and body size. eg, a 40-year-old male described feeling isolated and unable to relate to any online resources or support groups as they tended to target teenage girls. Subsequently, this left him feeling uncomfortable and vulnerable in those group situations, which he felt were not designed for him. Similarly, this applies to gaps in nuanced cultural behaviours around food

# 5

## Consumers expect that GPs will know the answers

Participants from segments with lived experience expressed a previous expectation that GP's have a standardised level of understanding/ experience with disordered eating. However, participants described gaps in their GP's general understanding of disordered eating which they find highly frustrating and has resulted in some clinician bias and the subsequent impact on their diagnosis and the support they receive

*"GPs have a lot of learning to do. I'm lucky that I fit the stereotype of what an ED looks like...white, thin female"*

# 6

## Ongoing connection with Butterfly makes consumers feel secure

Having an ongoing connection with a resource like Butterfly was described as being very impactful. For several participants, this was represented through the regular e-newsletter. Whilst the newsletter was often not engaged with or read in full, it was a helpful and tangible connection to Butterfly, and a reminder that help was available when and if it was needed, a safety net. Consider ways to set up a connection with individuals and supporters when they first visit the Butterfly website e.g. an opt-in email/text support service with a periodic 'just checking in' message. Messaging may differ, depending on which stage of their journey a consumer identifies they are at

Segment 4

### 7 | Participants want to see Butterfly increase its visibility

Participants often expressed wanting to see Butterfly as more prominent in public, to raise collective awareness of ED and Body image concerns. Based on their own experiences, participant suggested touchpoints include: waiting room posters at all medical and allied health clinics, at the entry of fast food venues, bathroom posters in gyms and nightclubs positioned alongside existing alcohol and mental health campaigns

*"For me there was a strong link with grief (after traumatic still birth)...if I could have come across Butterfly resources in my obstetrician's office that would have been beneficial...touchpoints in those services, both private and public" Segment 4*

### 8 | Characteristics of social media use and preferences is mixed

Social media engagement was not consistent amongst the cohort. Some participants expressed a preference to avoid all platforms in order to block triggering content. Alternatively, other participants still expressed a preference for platforms like Instagram because it provided them with some positive body image content to follow. These participants who preferred to engage with social media platforms still acknowledged that they encountered highly triggering and negative content on the platform but did their best to avoid it

### 9 | A wait when seeking support may lead to a dropout

The website chat was a highly regarded feature for anonymous support by all participants. However, whilst they appreciated that immediate assistance may not always be available, the wait experienced was frustrating and could likely lead to a drop-out because the consumer is seeking to connect with someone immediately. This correlates to a more general experience that participants described as commonplace outside of Butterfly services - the wait time for clinical appointments is often long and elongates their recovery journey



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# Background and Approach

U1 has been engaged by Butterfly Foundation to conduct user research that explores the consumer journey to identify existing gaps and pain points encountered when accessing eating disorder/body image resources and services.

The research aims were to:



Discuss participants' experiences of accessing resources and support about eating disorders and body image concerns



Discover how and why participants decided on specific resources, what their requirements were and how they located them



Determine what the consumer journey may look like for participants across the various segments and what role the support and resources played at different touchpoints of the consumer journey

Provide reflections on their current behaviours and attitudes to the resources they use and where opportunities exist to better support consumers of eating disorder and body image concern resources



52 participants:

- 6 x People at risk and their carers
- 8 x People who have used Butterfly
- 6 x General public
- 8 x People currently using Butterfly
- 8 x Recovered people with lived experience
- 3 x Educators
- 8 x Health professionals
- 2 x Industry bodies
- 3 x Sporting and Community organisations



Depth interviews:  
60-minute one-on-one interviews discussing participant experiences with the research topic, preferences and attitudes regarding resource and support services

Workshops:  
Group workshops were 90-minute sessions (and where not possible, shorter one-on-one individual interviews were conducted) to reflect on their experiences with the topic within their chosen professional setting



The interviews were conducted using Zoom, an online meeting tool

All participants used their own desktop or laptop computer to join the sessions



Depth interviews were conducted from 31<sup>st</sup> of October to 14<sup>th</sup> November 2022

Workshop interviews (group and individual) were conducted from 15<sup>th</sup> November to the 17<sup>th</sup> of November 2022

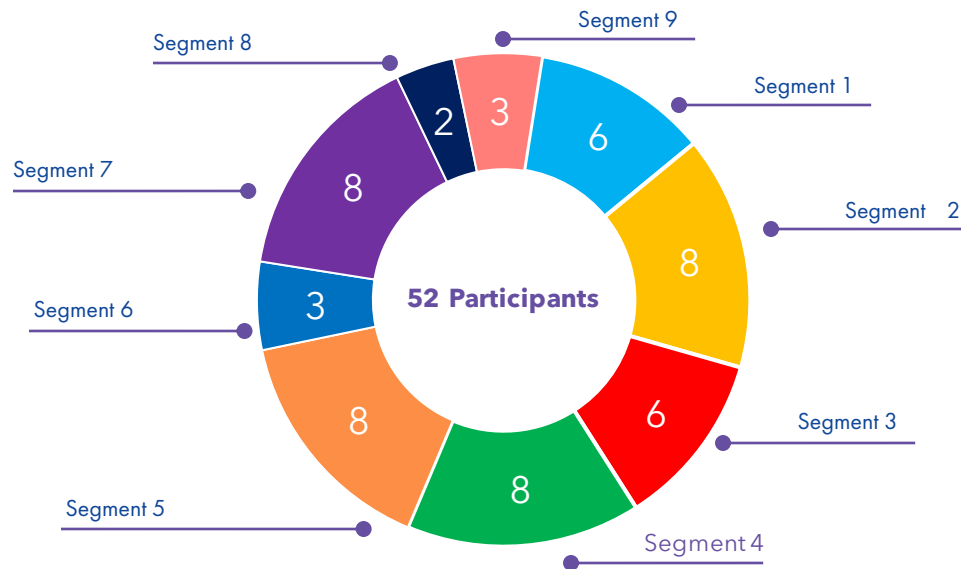
### In depth interview (60-minutes)

- Welcome and introduction
- Moderated discussion to explore experiences, behaviors and attitudes of the participants regarding their current approaches and resources utilised
- Explore current understandings of Butterfly resources, existing familiarity, frequency of access and effectiveness of resources .  
Butterfly Foundation touchpoints survey  
(where applicable)
- Participants are asked to reflect on their overall experiences of what they have experienced in the session and discuss their key takeaway and 'magic wand' opportunities
- Wrap-up

### Workshop (90-minutes)

- Welcome and introduction Icebreaker activity: Quick activity to ease participants into session content and identify themselves individually
- Moderated discussion to explore experiences, behaviours and attitudes of the participants regarding their current approaches and resources utilised
- Explore current understandings of Butterfly resources, existing familiarity, frequency of access and effectiveness of resources.  
Butterfly Foundation touchpoints survey  
(where applicable)
- Participants are asked to reflect on their overall experiences of what they have experienced in the session and discuss their key takeaway and 'magic wand' opportunities
- Wrap-up

## Participant Overview – Segment breakdown



- Segment 1** - People at risk and their carers
- Segment 2** - People who have used Butterfly
- Segment 3** - General public
- Segment 4** - People currently using Butterfly
- Segment 5** - Recovered people with lived experience

- Segment 6** - Educators
- Segment 7** - Health professionals
- Segment 8** - Industry bodies
- Segment 9** - Sporting and Community organisations

**Aware of BF** N=40

**Unaware of BF** N=12



37 x female identifying



1 x Non Binary identifying



16 x male identifying

Age ranges	N=
19-29	8
30-39	16
40-49	10
50-59	16
60-79	4

## Participant details

Participant number	Gender	Age	Member segment	Moderator
1	Male	33	Segment 1	1
2	Male	51	Segment 3	1
3	Female	62	Segment 1	1
4	Female	67	Segment 3	1
5	Male	52	Segment 5	1
6	Female	41	Segment 2	1
7	Male	55	Segment 1	2
8	Female	33	Segment 7	3
9	Male	40	Segment 5	2
10	Female	57	Segment 5	3
11	Female	59	Segment 5	1

## Participant details

Participant number	Gender	Age	Member segment	Livestream Group
12	Male	65	Segment 3	2
13	Male	39	Segment 5	1
14	Female	38	Segment 7	3
15	Male	19	Segment 2	1
16	Female	44	Segment 5	2
17	Female	79	Segment 5	3
18	Female	47	Segment 7	3
19	Female	41	Segment 1	1
20	Female	51	Segment 7	2
21	Female	38	Segment 2	3
22	Female	30	Segment 2	1

## Participant details

Participant number	Gender	Age	Member segment	Livestream Group
23	Male	33	Segment 5	2
24	Female	51	Segment 7	3
25	Female	30	Segment 7	1
26	Female	42	Segment 7	2
27	Female	52	Segment 2	1
28	Female	38	Segment 3	1
29	Male	20	Segment 4	3
30	Female	26	Segment 4	3
31	Female	35	Segment 7	1
32	Female	54	Segment 4	3
33	Female	30	Segment 4	1



## Participant details

Participant number	Gender	Age	Member segment	Livestream Group
34	Female	28	Segment 2	2
35	Female	52	Segment 2	1
36	Female	23	Segment 4	2
37	Non-Binary	49	Segment 4	1
38	Male	25	Segment 2	1
39	Male	35	Segment 4	1
40	Female	36	Segment 4	1
Workshop 1 (a)	Male	58	Segment 1	1
Workshop 1 (b)	Female	53	Segment 2	1
Workshop 1 (c)	Male	46	Segment 1	1
Workshop 1 (d)	Female	56	Segment 2	1

## Participant details

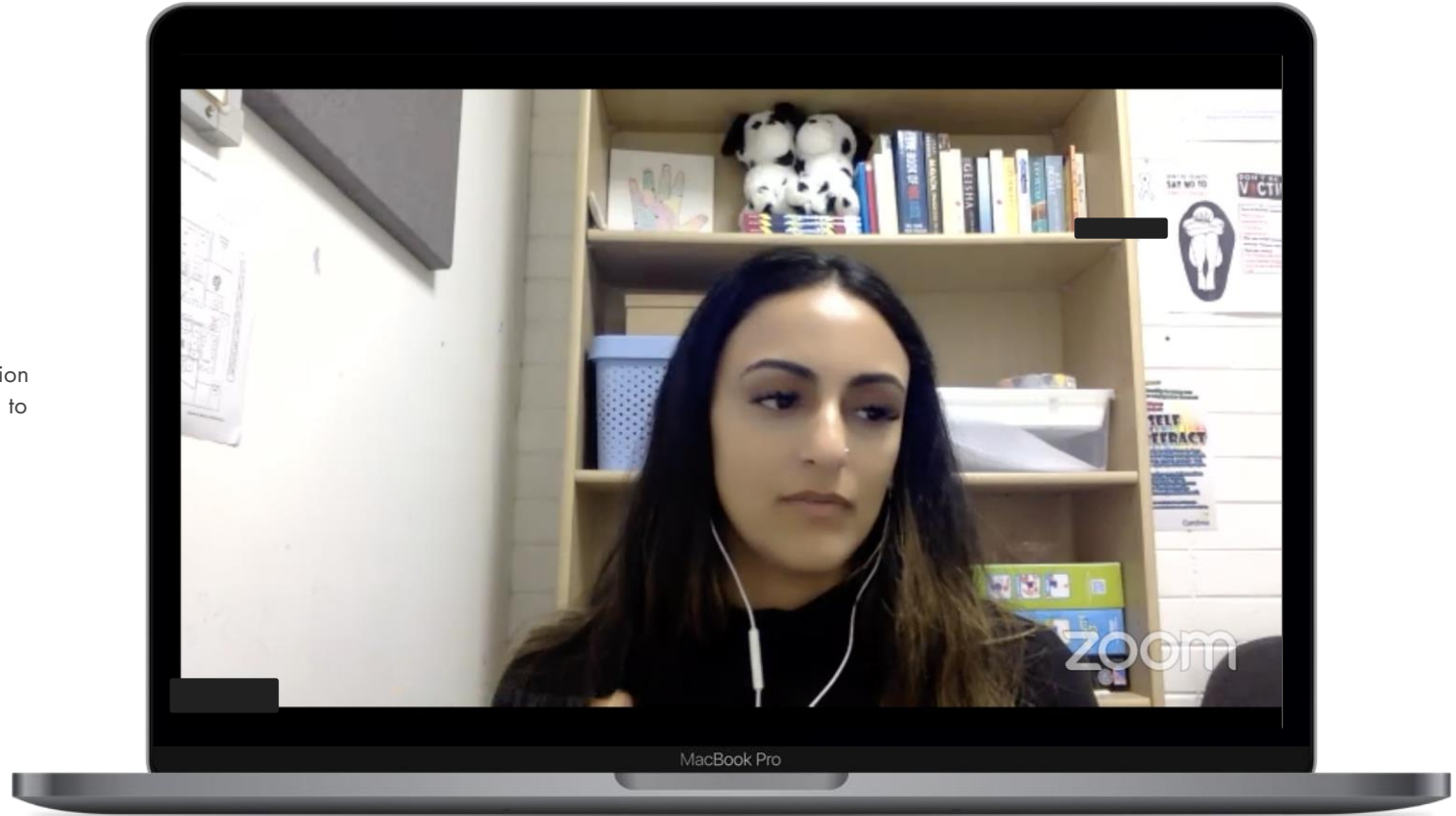
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Participant number	Gender	Age	Member segment	Livestream Group
Workshop 2 (a)	Female	38	Segment 6	1
Workshop 2 (b)	Male	40	Segment 6	1
Workshop 2 (c)	Female	26	Segment 6	1
Workshop 3 (a)	Female	n/a	Segment 8	1
Workshop 3 (b)	Female	38	Segment 8	1
Workshop 4 (a)	Female	50	Segment 9	1
Workshop 4 (b)	Female	42	Segment 9	1
Workshop 4 (c)	Female	29	Segment 9	1

### Session test setup (Depth interview)

Researcher view:

Participants attended the session using their desktop computers to engage with the research discussion



### Session test setup (Workshop)

Researcher view:

Participants attended the session using their desktop computers to engage with the research discussion



## Interpreting qualitative research

This research was exploratory and qualitative in nature and hence the results and findings are presented in a qualitative manner

- Qualitative research techniques used for this project enable the identification and in-depth exploration of issues relating to participants' experiences, opinions and attitudes
- They do not enable statistical estimates to be made of the proportion of the target population holding a particular view on an issue
- The reports, therefore, provides an indication of occurrences and themes rather than the exact proportions of participants who had a particular experience or opinion

Quotes have been provided throughout the report to illustrate and /or support the main results or findings under discussion



## Terminology

Where a participant has used a specific term or language to self-describe their experience, that terminology has been maintained and repeated (where possible) to ensure that their authentic experience is relayed as best as possible. There are some instances where different terms have been used interchangeably by a participant whilst referring to the same example i.e. 'their disordered eating' and 'their eating disorder'

Additionally, this report uses a number of abbreviations to aid with readability, these include:

BF	Butterfly Foundation
Butterfly	Butterfly Foundation
ED	Eating Disorder Binge
BED	Eating Disorder
DE	Disordered eating Subject
SME	Matter Expert General
GP	Practitioner



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# Findings and Recommendations

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# Participant experience summary

Segment One – People and carers of people with, or at risk of, an eating disorder/  
body image concern



### Findings

- Concern for a loved one and wanting to ensure the use of appropriate language and approach was the first research step described by most participants in this segment. It should be considered that at this time, participants expressed that they would likely be overwhelmed and in shock that this unforeseen hurdle was happening within their family/sphere and anticipated not knowing what to do or who to talk to.
- Typically, participants described that they would intuitively search online, looking for a reputable website such as a government health or peak body that specialises in the subject matter (e.g..gov, .org). After some initial background research (self-education), participants described they would look for an expert, someone like a counsellor to talk to so they can ask more specific questions i.e. symptoms, case studies related to levels of symptoms, gauge urgency and severity, and then talk to someone in person (phone, chat, f2f) after that.

*"I am doing this out of love... I am out of my depth,  
this is very complicated"*

#### Segment 1

*"Some guidance is what I would be after...show me how I can be the most helpful I can be right now."*

#### Segment 1

*"I would seek the professionals...Google search 'body image disorder Australia', I'm sure something would pop up. I would go to the government ones (websites) first because I think they are funded by the government and will have the most leading advice, the most official and best resources...not biased or profit-driven"*

#### Segment 1

*"How do I broach this subject with this person in a way that is not patronising and displays empathy and sympathy? How do I frame my advice to this person in a way that they won't feel like I'm being threatening and accusatory and that it's coming from a place of me wanting to help? How to go about this as a complete layperson, with no formal training, in the same way, you might show someone how to give first aid for the first time, it's essentially the same thing"*

#### Segment 1

### Findings

- Whilst brand recognition of Butterfly Foundation was low in this cohort, a very clear understanding of the diversity and prevalence of disordered eating was apparent in the discussion for all participants
- A clear expectation exists that consumers may only need to access the website in the initial phases to kick start the journey unless the situation escalated quickly, in which case return visits for additional resourcing and support may be required

*"I think it is more common than people think...I think it's more visible and openly spoken about now via social media"*

#### Segment 1

*"Depends on how the situation plays out. If the circumstances change you might have different resources. Like if it escalated to a crisis. I suppose at the start, when you first became concerned. And then as it progresses then it's kind of like a new situation to revisit and access different resources for. You'd hope that if it was an organisation that specialised that they'd have a pretty comprehensive or broad set of tools or info for different situations."*

#### Segment 1

*"For simple research maybe a one-off visit to a website would suffice. If it's really serious and what I had tried didn't work, I might need to return to try again – it's a process"*

#### Segment 1

*"The first thing that comes to mind is how prevalent it is... a lot more recently with the effects of social media, there is a lot more openness about, and how people portray themselves in the editing of social media.. i.e. false expectations about how someone looks. I think it affects 99% of the population"*

#### Segment 1

*"I think the early stages would be the most important gathering (information) phases. It would be helpful to be able to look back at them down the track if things don't change"*

#### Segment 1

### Findings

- There is limited existing brand recognition of Butterfly for the participants we spoke to in this cohort, as they expressed having not yet needed to engage with resources or support in this space
- General research was described as being typically preferred on a desktop device due to screen size and the ease of being able to have multiple browser tabs open

*"If I needed to access multiple things, it's easier with the tabs open on the laptop. And for images or reading it's harder on the phone."*

**Segment 1**

*"I use my desktop. it's easier for me. I use the phone for calling or email. I have multiple windows open, it's a lot easier on a desktop. Comfort, time and privacy"*

**Segment 1**

*"All I know is that they are related to eating disorders...they've been mentioned on television before"*

**Segment 1**

*"Everyone knows beyond blue, cancer council....I'm unfamiliar with BF"*

**Segment 1**

*"To do a bit more digging/researching ... a laptop or desktop is always the best platform"*

**Segment 1**

### Recommendations

- Knowing how to approach a sensitive situation was something that was sought out by participants and some compared it to first aid training. They would be looking for advice specific to themselves, friends/relatives, warning signs, how to talk to a loved one, what to say/not say and how to verbally acknowledge that it won't be an overnight fix. While there is information about what to do/say on the Butterfly website, a consumer's ability to self-identify the type of information they need and locate it in a period of duress may be reduced;
  - 1) Consider ways to take individuals/carers/supporters by the hand when they first arrive on the website i.e. with a 'Where do I start' decision support tool (customised to key needs of different segments/personas and what stage they are at in their journey)
  - 2) Consider ways to set up a connection with individuals/carers/supporters from when they first visit the Butterfly website e.g. an opt-in email/text support service with a periodic 'just checking in' message. The frequency could be every two weeks for the first month, then monthly for three months, then every two months - this would ensure an ongoing connection that wasn't intrusive but maintained that contact. Messaging may also differ depending on which stage of the journey a user indicates that they are at. This could be something that is asked when they first opt-in and could be revisited at points in the future

### Recommendations

- Both the supporter of and the individual at risk wanted more public exposure to the issue and more awareness raising about Butterfly. Consider alternative ways to get Butterfly more 'in the face' for at-risk cohorts, particularly for those in regional areas to access support e.g. posters in changeroom at gyms and clothing stores, partnerships with gym apps (see similar participant suggestion on page 39,43)

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# Participant experience summary

Segment Two – People who have used Butterfly services (themselves, for a client or someone else)

### Findings

- Participants from this segment typically described that knowledge of disordered eating, prior to experiencing it firsthand, was limited, and the learning curve was steep because 'you don't know what you don't know'. Knowing where to go for assistance was not initially intuitive to them

*"In my own experience, I was unaware of the scope of eating disorders before I was diagnosed, then when I was sick I didn't see it as a problem"*

#### **Segment 2**

*"I wasn't aware how prevalent it was. I didn't realise how common our story was... my family were very distressed"*

#### **Segment 2**

*"Trying to find information to help ourselves... I don't know what I need to find out. I knew when it became a problem, I know I'm having an issue but when I access the information...nothing fits"*

#### **Segment 2**

*"For years, when anyone said 'eating disorder' I would immediately think of anorexia and bulimia ..."*

#### **Segment 2**

### Findings

- Participants described experiencing concern from their family that their behaviour around food wasn't 'normal' and described supporters or carers taking the initiative to 'Google' and find the Butterfly website. This was a common theme where individuals didn't take any action until they were 'found out' or approached by those close to them
- Often participants from this segment described that their disordered eating was likely bubbling under the surface for many years until a significant traumatic event occurred (starting high school, death of a family member, miscarriage) which provided the catalyst to begin their journey to seek help

*"She used to eat small meals and then went from that to skipping meals and then outright refusing to eat, that combined with her losing quite a bit of weight.. that's when I realised we needed help"*

#### Segment 2

*"Initially it was the catalyst for me learning about the signs of an ED I was probably in denial for quite a while... once I got to that Butterfly website, it was like oh shit....yeah my daughter needs my help...it was really confronting, there was no magical cure"*

#### Segment 2

*"It became apparent to me, the lack of male representation in mainstream and social media and television. I don't see people like myself being adequately represented."*

#### Segment 2

*"When I was sick I didn't see it as a problem"*

#### Segment 2



### Findings

- Typically, Butterfly was found to be the most informative resource and gave the impression of a trusted information provider. Participants often described using Butterfly as their only source of information, not needing to look much further to any other resources or tools because they found it to be the most comprehensive and credible. Commentary considered Butterfly as the gold standard for representation compared to other resources available locally
- The frequency of visits to the website is clustered around the initial crisis phase or discovery of disordered eating - articles/info and personal stories were all they typically wanted to engage with at this early stage. Facebook groups for carers of people with ED's also provided insights into what other people were experiencing, which was seen as positive peer support, particularly for parents

*"I only ever saw male representation of eating disorder through Butterfly, which is odd because it's clearly not a gendered illness"*

#### **Segment 2**

*"It's something BF does well is the wide range of representation and stories and being able to relate to them"*

#### **Segment 2**

*"Facebook groups for mums with children with ED's, I found them really, really, useful... it's (support for daughter) constantly in the back of my mind... I might just go into the group and put a post in there to hear other people's input"*

#### **Segment 2**

### Findings

- Similarly to other lived experience segments, participants discussed their encounters with GP bias and/or misdiagnosis, typically occurring if the GP involved is not familiar with the intersection of multiple diagnoses (PTSD, Chronic pain, Anxiety)
- Lack of continuity of care and wait times was commonly raised by participants whilst at the same time acknowledging the limited resources available. The requirement to explain themselves and their symptoms/ diagnosis every time they saw a new expert was described as exhausting, with some participants offering workarounds they had devised to conserve energy in these moments i.e. bringing written notes or journals to show a clinician

*"They have a module where you can share your story, which I have found really helpful, I have done that, and if I can help in some way that's something I really want to do"*

**Segment 2**

*"It can be challenging to know where to reach out to next..."*

**Segment 2**

*"Mums on the Facebook group are great but I don't want to lean on them too much"*

**Segment 2**

*"I tried to access stories of other people, all social media has an anorexia community and it's not the most helpful when you're in recovery, it can lead to comparison"*

**Segment 2**

### Recommendations

- Carers and supporters of people at risk routinely seek reassurance about the perceived 'urgency' or 'seriousness' of their situation from the website. A common request from this cohort was to see mealtime strategies included on the website to assist carers or supporters in times of crisis and reduce the stress around this regular occurrence. Consider surfacing strategy resources for carers on how best to support someone at mealtime. Participants also felt it's very important to learn and know the 'right' terminologies before seeking out support or approaching someone about concerns for their welfare

*"We didn't know if it was an ED or mental health, we were directed to the website because of their presentation... what do we do with this situation? ... I needed some reassurance about meals and who to go to next"*

### Segment 2

*"I would like support to know how to support her!"*

### Segment 2

*"The handouts about disordered eating, that is the only reason I went to the website. When we spoke to the helpline the information they provided was fabulous and the counsellors were so helpful"*

### Segment 2

*"Some strategies for me to use at mealtime to best support my daughter, that's the main thing I struggle with. Words or phrases to use to show her that I get it and understand what she is going through and to avoid the constant battles. It's very stressful for everyone"*

### Segment 2

### Recommendations

- As flagged previously, providing a way for users to opt-in for a 'connection/check-in' service by text or email would allow Butterfly to have an ongoing relationship with users - a way for their present selves (who aren't yet willing to seek help) to possibly secure help and support for their future selves. This service could be targeted based on personal/segment/stage
- There is a tendency to ebb and flow in motivations, to dip into a resource like the Butterfly website, then retreat and then come back again. If an individual can be encouraged to opt-in for a discrete 'connection/checking in' service, then they have a gentle but continuing reminder that help is available when they are ready to take it. They may not take it up but the connection to support for the future self remains
- Consider investigating a way to use cookies to recognise first-time users that would trigger a pop-up 'Where to start' decision-support questionnaire to give users specific, targeted information depending on their circumstances. This could also be where they could opt in for the 'connection/checking in' service

*"Numerous times that she has been admitted to hospital, the children are the focus... which they should be ... there is not a lot of support for parents. I have just found it really difficult how to know how best to support her and avoid the constant confrontations about food"*

### Segment 2

*"Ongoing support for parents who are involved... my own mental health has suffered because of this"*

### Segment 2

*"It would be really great if a doctor could give you a mixed bag/toolbox (resources), there is not one size fits all.. i.e. meetings are good but not if you are going to go if you have anxiety...it would ensure that there is no one left behind"*

### Segment 2

### Recommendations

- Participants often felt that if there was more exposure about the issues and where to get help that this would raise awareness and make people understand that negative behaviours around food and body aren't 'normal'. Like Segment 1, consider looking for opportunities for Butterfly to partner with organisations like gyms, clothing stores and schools to get awareness-raising info into change rooms and toilets (refer to similar recommendation on page 31)

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# Participant experience summary

Segment Three – General Public

### Findings

- Similar to most other segments, participant initial steps were to undertake 'self-directed learning phase' research to get more knowledge about the issue, symptom matching, identify and learn about various disorders, then understand next steps and what to do themselves (either as an individual or supporter). Commentary indicated that a barrier to researching available support is difficult when 'you don't know what you don't know'. After the initial research, they may then want to talk to someone with expertise so that they could ask more specific questions about the situation. Whilst reaching out and communicating to an expert was the next step, there was no clear preference across the cohort for communicating by text, chat, phone or face-to-face  
*"What is it? What are the consequences of it? What will happen? Is there a treatment or forms of help available? Dig a bit deeper"*

#### Segment 3

*"I would google 'symptoms of a person suffering from eating disorder'... mainly because I have no previous experience with this kind of thing"*

#### Segment 3

*"I would want to know what you say... it would be easy to say unhelpful things. What can I do to support them? Do we not meet up for coffee and have a walk instead? Who could I refer them to? I don't think its something I could manage on my own..."*

#### Segment 3

*"From the Google search there would be a range of sources and websites, I would tend to favour those sites that look more medical focused over like a Reddit chat... more authority"*

#### Segment 3

*"The first point of call would be a google search and type in ED issues or BI issues... there is nothing directly that comes to mind. I would be looking for .gov or medical body website or institute... I would trust"*

#### Segment 3

### Findings

- For people in this segment who typically expressed little to no lived experience, there is an assumption that things will get better after an acute situation occurs, there was little comprehension or discussion of journey length or possible occurrence of relapse

*"At the outset, support from a service would be more often, contact via email or phone, and then it would improve over time"*

#### Segment 3

*"I know I need to have really great empathy. The feeling is very real for them, the anxiety or the issue"*

#### Segment 3

*"It risks your personal relationship with them... you are stuck between a rock and a hard place"*

#### Segment 3

*"The person's needs might change over time so the support and resources would need to change over time...perhaps the bulk of research up front but there would be things I would want to know as I go through that journey,"*

#### Segment 3

*"Empathy for the person and wanting to understand their point of view... It's important to understand them in order to help them"*

#### Segment 3

*"A bit anxious for the person, but researching would feel empowering..."*

#### Segment 3



### Recommendations

- When probed about their thoughts of where they expected to learn about Butterfly, participants commented that if they were to know about Butterfly earlier in the journey (before a crisis point) it would enable them to share information by word of mouth within existing networks and friendship circles, normalising the topic. Touchpoints suggested; posters at a clinic or medical waiting room, targeted online advertising, placement of BF information in the entry of a fast-food venue, bathroom posters in nightclubs-positioned alongside alcohol and mental health campaigns so it's more visible and to sow the seeds into patrons' minds, increasing BF awareness (see similar participant suggestion/recommendations on page 31, 39)
- As discussed previously, participants expect that when typing in an initial search using their web browser, Butterfly would come up as a top result, being Government funded and a website with authenticated information

*"It needs people to talk about it, billboards, Facebook pop-up ads... once people start talking and normalise it then we can start to know how to have those conversations"*

### Segment 3

*"I wasn't aware of that organisation, I'm hoping that they do their SEO really well. I'm hoping they pop up really high on the list"*

### Segment 3

*"I don't think money should be spent on BF awareness, but I think it's important when people do a google search that it comes up immediately". "I would expect my GP to direct me to BF if I needed help for myself or my kids or my friend"*

### Segment 3

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# Participant experience summary

Segment Four – People currently using Butterfly services

### Findings

- Participants in this segment typically described their journey beginning as teenagers, with their condition continuing into adulthood - which for many could manifest again in traumatic or stressful situations
- Similar to recovered people with lived experience, there is an expectation that GPs have a standardised level of understanding/experience with this topic, and participants have found that gaps in their GP's general understanding impacted on their diagnosis and the support they receive
- Access to resources at the beginning of the journey, outlining next step strategies and what to expect made the journey much smoother for the participants we spoke to. Early intervention and knowing about a resource like Butterfly would have likely avoided years of unnecessary and damaging hospitalisations according to participant reflections

*"GPs have a lot of learning to do. I'm lucky that I fit the stereotype of what an ED looks like....white, thin female "*

**Segment 4**

*"My GP who has a specialisation in women's health hadn't even heard of the Butterfly Foundation"*

**Segment 4**

*"There is a higher mortality rate for men due to clinician bias, which I have experienced myself"*

**Segment 2+ 4**

*"I'm always learning... there is always more to learn."*

**Segment 4**

*"I expected her to know about this, but I had to educate her on what she needed to do. My first GP was the same. I felt like I had to take the lead there in looking after my health, it's my responsibility I get that but I expect when I go and see a practitioner that they can offer me something I can't offer myself"*

**Segment 4**

### Findings

- Ongoing support that is flexible and allows a person to dip in and out as required is preferred, engagement may depend on other health factors (or diagnoses) being experienced at the time and how overwhelming that feels for participants
- Additional resources used by and cited by participants within this segment include:
  - 'Rehabilitate, Rewire, Recover' by Tabitha Farrar
  - Butterfly Foundation 'Emerge' program
  - Australian New Zealand Eating Disorders Association
  - Inside out - [database]
  - National Eating Disorders
  - Eating disorders Victoria - Peer Support program
  - Day-program St. Vincent's Hospital
  - Maudsley centre (UK)
  - BF podcast

*"It's been immensely challenging and heartbreaking.. the worst"*

#### **Segment 4**

*"You don't know what you don't know... I think I'm across it all but I don't know"*

#### **Segment 4**

*"That was tough... I didn't want that to happen to us and it was in my face. On the flip side, there were some families coming out the other side"*

#### **Segment 4**

*"It's something that always looms in the back of my head... it's always there"*

#### **Segment 4**

### Findings

- The stress and anxiety experienced by carers of people with disordered eating were described by some participants as being ongoing, consuming and having a significant impact on themselves and other members of the immediate family living under the same roof. Typically, primary carers of younger people we spoke to with disordered eating are restricted to working part-time due to the medical needs of their child

*"How can I support my child to start eating adequately again? How do I navigate this?"*

#### Segment 4

*"Rollercoaster ride of emotion. The desperation of some way of shifting things for your loved one so that they are not suffering. It's all-consuming"*

#### Segment 4

*"It's quite simplistic, which could be helpful for first-time people but each element of the overall approach needed to be fleshed out more with people who actually demonstrated how to be a dolphin etc... the option to delve more deeply or additional readings and references for those who want to immerse themselves in it. Because you are living and breathing it 24/7, everything else is on hold"*

#### Segment 4

*"When things have been very difficult it really is so hard, knowing there is support there (carers support group and training) and despite accessing that help often still feel very alone when things feel hopeless and inadequate"*

#### Segment 4

### Findings

- Upon finding the Butterfly website via Google, participants described it as being a helpful launchpad during the initial phase of their journey. A basic overview of conditions and overall facts is what is immediately required, and this was described by participants as being immediately and easily achieved
- The website chat was a highly regarded feature for anonymous support by all participants and whilst they appreciated that immediate assistance may not always be available, the wait experienced was frustrating and could likely lead to a drop out –because the consumer is seeking to connect with someone immediately
- Having an ongoing connection with a resource like Butterfly was described as being very impactful. For several participants, this was represented through the regular e-newsletter. Whilst the newsletter was often not engaged with or read in full, it was a helpful and tangle connection to Butterfly, and a reminder that help was available when and if it was needed

*“Great I'm not alone, you can help me. It was really helpful and actually naming the problem is a gamechanger”*

#### Segment 4

*“The moment you start digging and you find resources, you get familiar with the system. It really is on the person to seek that out actively. For example, I have not seen a single pamphlet or flyer at any GP or medical centre, marketing or comms around that at all.... You wouldn't know about them or the resources they offer. I think that's a missed opportunity”*

#### Segment 4

*“For me, there was a strong link with grief (after traumatic still birth]....if I could have come across it (Butterfly resources) in my obstetrician's office that would have been beneficial...touchpoints in those services, both private and public”*

#### Segment 4

*“Every now and then when I have a lapse in my own self-directed thought process... The website allows me to break the cycle and get reinforcement... it's a great resource, they should be commended”*

#### Segment 4

### Findings

- Support groups were perceived as helpful by participants who 'fit the stereotype' of an eating disorder, but were described as a double-edged sword because they can trigger newly learned negative behaviours, and seeing other long-term experiences of other families can leave carers/supporters feeling helpless
- Some participants commented that if Butterfly support groups were focused towards a specific disordered eating or body image concern, it would be more relevant and feel more supportive for the attendees to be engaging with and sharing similar experiences
- When reflecting on the language of Butterfly resources, participants commented that they feel current and inclusive. This observation was of particular relevance for participants who did not have a formal or singular diagnosis as it address their concerns and made them feel validated

*"Some of the practical strategies would be better targeted to specific ED's rather than more general ones"*

#### Segment 4

*"Nervousness (about the BF support group), I wasn't sure... I felt worried about judgment because I'm in the middle, I'm not morbidly obese that I'm homebound... that's when you start to doubt yourself... it's obvious I'm not there for undereating. If they think they're fat, then what are they going to think about me?"*

#### Segment 4

*"I think it would be good to separate Binge Eating Disorders from the others... most of the content (in the Emerge program) was geared to undereating disorders. Even if I had to wait sometime to have some more focused information I would prefer that"*

#### Segment 4

*"Not everyone has a diagnosis...eating disorders vs disordered eating, they are both the same thing, but different words or flipped differently, so I think that the language used makes you feel validated, even if you don't have the diagnosis."*

#### Segment 4

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# Participant experience summary

Segment Five – Recovered people with lived experience



### Findings

- The relationship between the patient and GP was described to have a big influence on the success of the outcome for the person with DE, ED or BIC. Participants described a strong link between a more successful outcome through a trusting relationship with a GP, particularly if the GP had a thorough and up-to-date knowledge of the subject matter and resource references
- Typically for all participants, an online browser search was the intuitive first step when seeking resources for help and they described being more inclined to look for academic or government sources because they felt more authentic and trustworthy, examples include Inside Out, BetterHealth and NSW health
- Male identifying participants found that whilst Butterfly has the most diverse resources of those available online, most online resources appeared to cater to young girls and were unrelatable to them, particularly as an older adult male
- Participants that do not fit the 'stereotype of an eating disorder' have experienced GP bias due to gender, age, diagnosis, and body size. For example, a 40-year-old male described feeling isolated and unable to relate to any online resources or support groups that tended to target teenage girls. Subsequently, this left him feeling uncomfortable and vulnerable

*"I didn't think it would last... as life progressed and circumstances changed so did it"*

#### **Segment 5**

*"EDs are all about secrecy, it pushes everyone away"*

#### **Segment 5**

*"Finding 'people like me' and resources for 'people like me' is very important"*

#### **Segment 5**

*"Seeing myself through someone else experiences"*

#### **Segment 5**

### Findings

- For those participants who were very young when their condition developed, parents typically managed the whole process as they were unable to take the initiative for themselves and typically at the time were unaware that they had a problem
- When referring to being in recovery with lived experience, participants often reflected that their disorder 'never really goes away', rather it stays dormant. A life event, stressful moment or past trauma can be the catalyst for their disorder to become prominent in their life again. However, these participants shared that they feel they now have the adequate tools to confidently look after themselves in periods of flare-up
- Social media engagement was not consistent amongst the segment. Some participants expressed a preference to avoid all platforms in order to block triggering content. Alternatively, other participants still expressed a preference for platforms like Instagram because it provided them with some positive body image content to follow. These participants who preferred to engage with social media platforms still acknowledged that they encountered highly triggering and negative content on the platform but did their best to avoid it

*"Feels like a frog in boiling water.... you just don't know in the moment"*

#### **Segment 5**

*"It would be really bad for me. I stay away from all of them (social media platforms)"*

#### **Segment 5**

*"I imagine there would be outreach on bulletin boards at the hospital and community centres. I would google it obviously. I would hope that your GP would tell you"*

#### **Segment 5**

*"I'm a researcher, I'm a fixer, I would google and then go down the rabbit hole. I presume there is a lot of information on Facebook"*

#### **Segment 5**

### Recommendations

- There is no one-size-fits-all approach, with each participant describing the path of their individual journey differently. Participants discussed needing support and resources that can be dipped into and revisited when they are ready to receive it. Joining a support group is a big step and it is important that those who are outside the bell curve, particularly older men, aren't deterred because of fears that they won't relate, don't fit in, or worse, that their intentions for attending could be misconstrued
- Feeling that culture, faith or ethnicity was a barrier to finding support was raised as a concern for some participants who believed that it may be difficult for a person unfamiliar with their cultural relationships around food to understand or empathise with their situation. Consider including other filtering criteria to the Referrer Database e.g. 'gender', 'age', 'faith', 'ethnicity', 'sexual identity'

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# Participant experience summary

Segment Six – Education professionals

### Findings

- Participants in this segment described sometimes feeling ill-equipped when presented with situations in which students were discussing disordered eating or body image concerns at school. The varying levels of expertise and lack of accredited learning in this area were cited as factors in their decision to typically flag their concern about a student with more senior or better-qualified staff members
- Educators we spoke to described observing behaviour at school that may differ from what a parent has informed them is happening at home, which can lead to them feeling overwhelmed with responsibility
- Concern about their students is experienced as being twofold; the human connection and worry for the student wellbeing whilst simultaneously having concern for their own administration and 'covering bases' worry, making sure that they have crossed T's and dotted the I's themselves

*"As a teacher, I don't turn off at night and reflect....you are worried"*

### Segment 6

*"I wouldn't handle it, seek to flag it with the wellbeing team (if the school is resourced enough to have one), or the principal (someone more senior) or at a staff meeting. Do it in a sensible way"*

### Segment 6

*"You can't really do a lot... it's a hard balance to find, it's about building trust"*

### Segment 6

*"We are becoming more like social workers rather than teachers to be honest"*

### Segment 6

*"I was sort of limited, I'm only a beginning teacher! That behaviour is happening at home, you wouldn't see that behaviour necessarily at school"*

### Segment 6

### Findings

- When seeking in-class resources, all participants from this segment commented on the value that the Butterfly toolkit (website) provides them. Participants described having linked students to Butterfly in the past and having had them out to speak in both regional and metro schools. Additionally, the Betterhealth.vic.gov website is often relied upon when creating in-class resources
- Participants described friends of the student for whom there is concern are the best resource, "they often spill the beans" and provide accurate information about the situation at hand
- When probed about how they became aware of BF, participants generally described a brand awareness that went back further than their professional life

*"I guess I found out about them from my designing health coursework, I had never heard of them... revisited it when I had students in need"*

#### **Segment 6**

*"You go into teaching because you care, you worry about them generally, there is turmoil"*

#### **Segment 6**

*"I like the fact they come up and speak to students because you never know, a student might be sitting there quietly and taking it in... I find it really helpful, and then we will revisit it later in class"*

#### **Segment 6**

*"Really trying to get that message across, they are brainwashed...we only have them for an hour a day compared to 7 hours a day on TikTok"*

#### **Segment 6**

*"It gave me tips on how to talk to him... I didn't want to trigger him. I want to make allowances but I'm restricted in the allowance I can make. What do I need to do on my end?"*

#### **Segment 6**

*"I've known about them since primary school... a girl on the bus was wearing a bracelet and I swear Dolly and Girlfriend magazine, there used to be advertising in there"*

#### **Segment 6**

### Recommendations

- Consider increasing the marketing of education modules for teachers to skill up and surfacing these modules better on the website; Participants discussed that hearing other teachers' stories and shared experiences shed more light on the resources and strategies available for themselves to ponder, enabling them to better assist students and more confidently deal with situations as they may arise. However, participants from this segment were unaware of the resources that Butterfly offers

*"Butterfly come and speak to our students, but I think they could do more work with teachers, a compulsory training unit or a tick-off program to keep it at the forefront of your mind... we have the curriculum in place to tackle some of these things but we need to skill up the adults in these kids' lives"*

#### **Segment 6**

*"Hearing other teachers' stories makes you realise you're not alone and it's ok that I don't know everything"*

#### **Segment 6**

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# Participant experience summary

Segment Seven – Health professionals



### Findings

- Generally, Butterfly forms part of the 'care plan' devised by all participants from this segment, when patients present with eating disorders/body image-related concerns
- The Butterfly website is a key source of modules, fact sheets and questionnaires that are used as a basis for developing age-appropriate teaching materials for use with high school students
- Participants discussed speaking to and seeking advice from other peers in their field that specialise in eating disorders/body image-related concerns. If patients are seeking support, generally they would be advised to access the Butterfly website initially and then be referred to other specific clinicians that can support them
- Often patients may present with other issues and then body image-related concerns/eating disorders come through as the underlying issue. Participants believe in building a relationship with their patients so that they feel safe to speak with them, and providing support, resources and/or referrals if the patients choose to take the step to treatment

*"General information, workshops and training, pre covid there was some professional development for service providers, it's a one-stop shop that we point families to, to see if there is something they are interested in"*

#### **Segment 7**

*"It is really case by case depending on how they present...we get info from Dove, Butterfly, Monash Health, adolescent health nurse that we connect young people and their families with"*

#### **Segment 7**

*"It's mixed gendered, in the last 2 years we have noticed a really high number of males presenting with body issues.... previously it has been more dominated by females presenting... bit of a contagion effect"*

#### **Segment 7**

*"Language is so vital, good food vs bad food, trying to scaffold or shield my boys from the language of older people in their life"*

#### **Segment 7**

### Findings

- Participants described that much of the current resources or support material available to them is geared towards females with under-eating disorders, which may often be addressing very specific issues and motivations that are not as represented for people outside of that target group, eg weight restoration
- Similarly to complaints from other segments, content felt culturally biased, and whilst there is some diversity present it was felt that it is not apparent enough in the existing resources available to the professionals that we spoke to

*"It's rare to come in at a crisis level, it's more early intervention"*

#### **Segment 7**

*"I'm not sure where to look for how to talk about age-appropriate phrases (kid specific) eating, how much.... how do we locate best practice?"*

#### **Segment 7**

*"Definitely there is a gap of resources for male-identifying, how to have the conversation with the student and also the parents. i.e. the names Butterfly and Dove are associated with female toiletries... doesn't lend itself to being approachable to all individuals. Cultural differences around food, I gained more knowledge around this by working with the young people - they have taught me a lot"*

#### **Segment 7**

*"It's more openly spoken about and targeted to by providers towards female presenting... It's a lot harder to pick up with those who identify as male"*

#### **Segment 7**

*"I find most clients are not very familiar with them, not like Beyond Blue which most of my clients would know what services they provide"*

#### **Segment 7**

### Recommendations

- Participants commonly expressed some concern that individuals with lived experience are unlikely/unable to reach out when they are at their worst - yet this is when they may need help the most. It was suggested that outreach resources would be helpful for people needing help rather than expecting them to be proactive when they are feeling unwell/vulnerable/in denial etc. This is an opportunity that Butterfly could enhance by creating more segment/age/situation-specific resources and surfacing these via a 'Where to start' decision-support tool/questionnaire that serves up targeted info and resources to users. Additionally, confidence in the currency of resources was of particular interest. As practitioners, there is a desire to understand if the content reflects current thinking/understanding.

*"Dove were able to give workshops/ books to use with students to work through as a cue ... that has been really helpful... I haven't been able to get those resources from Butterfly, as a health professional the practical tools that I can use and implement and work on with a young person (is preferred and more helpful)"*

#### Segment 7

*"Having tactical tools for services providers to use as you need them, i.e. questions for professionals to ask, about males and how they present and what to look for"*

#### Segment 7

*"I don't watch or read anything if its older than 12 months old"*

#### Segment 7

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# Participant experience summary

Segment Eight – Industry bodies

### Findings

- Participants from this segment were typically partners of, or have worked closely with, Butterfly in the past, so familiarity with resources and touchpoints that are available were very thorough
- Participants generally expressed that they became aware of Butterfly prior to working in their chosen professional field
- Typically, consumers would contact the relevant organisation or industry body as the starting point of their journey. Participants commented that if they needed to find more specific content for a consumer they would be directed to Butterfly as the experts, rather than assist them with internal resources
- Some commentary indicated that a shift of attitudes has been noticed within the mainstream around Eating Disorders and Body Image concerns, with an increase in seeking help 'slowly progressing'

*"Eating disorders is not something people need to know about until they need to know about them.... and then they are not sure where to turn for help or how to get through it"*

#### **Segment 8**

*"We have worked with BF closely... they are the leading expert"*

#### **Segment 8**

*"I knew about them before working in this space...they are a well known brand"*

#### **Segment 8**

*"Butterfly Foundation is the leading voice for ED's in Victoria, there is real name recognition, most people I feel like have heard of the Butterfly Foundation"*

#### **Segment 8**

### Findings

- Some of the complications encountered by participants working in this segment are the lack of demographic diversity, the intersectionality of diagnosis, gender, additional mental health concerns and other cultural aspects and approaches around food

*"It's quite monocultural, female, Anglo or western background cohort that maybe looks and sounds the same... this is where you can miss a lot of the intersectionality within this space... hence why the same demographics are reflected"*

#### Segment 8

*"Unsure of where the plan is to address the inclusivity"*

#### Segment 8

*"It's hard in terms of messaging, you don't want to alienate people who most engaged with you whilst still engaging the other key groups"*

#### Segment 8

*"There are some that feel that their ED is more socially acceptable and then there is those that don't and feel shame often binge eating"*

#### Segment 8

### Recommendations

- From a media perspective, it was suggested that additional initiatives and campaigns to highlight the different service streams available for people with eating disorder or body image concerns would be advantageous, as would making the service offerings and pathways between each organisation really clear. This may allow young people to identify the most appropriate organisation that they may need to engage with

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# Participant experience summary

Segment Nine – Sporting and Community organisations

### Findings

- As professionals working in sporting organisations, participants were familiar with Butterfly as an organisation and general awareness of the resources offered were very high
- Participants generally expressed that they became aware of Butterfly prior to working in their chosen professional field
- Participants in this segment described their roles to include:
  - Listen, hear what they have to say
  - Equipping them better for life
  - Empowerment for more healthy decision making
  - Making a safe space for young people
  - Provide pre-emptive support for young people
  - Create an understating of what body care looks like
  - Establishing nice relationships with food
  - Mitigate trauma and expectations placed on young people
- Commentary from participants in this segment indicates that resources like Butterfly posters on their office wall or within the workplace, are often catalysts for conversations with young people and their parents

*"Listen, hear what they have to say. Reassure them that it is a safe space"*

#### **Segment 9**

*"It's a very new area for sport generally, the awareness is common in gymnastics but our role is to unpack that and provide info for where to get help and support"*

#### **Segment 9**

*"I have known about them for a long time... when was a teenager I loved Sportsgirl... I think there was a link there"*

#### **Segment 9**



### Findings

- Some difficulty can be experienced by participants of this segment when determining which service or resource to turn to as there may be overlap in the services offered and it may not be immediately clear which is most relevant to the immediate need
- The helpline is a really useful resource for coaches, parents and athletes whilst the website is used as a one-stop-shop and often links are shared to specific parts of the website containing relevant information
- Specific Butterfly Podcast episodes are referred to athletes to hear about stories of lived experiences of relevant topics
- Bodykind 'schools' and 'families' were described as being 'really relevant in high-performance sport'
- Other key functional resources that are currently utilised in their roles include the AIS, the Eating disorder association (NEDC) and Inside Out Institute, and these are often used to get buy-in from the person they are supporting

*"Health vs performance... linking them both to get buy-in"*

#### **Segment 9**

*"Early on I was like...who do I need to go to for what?... we don't want to confuse people"*

#### **Segment 9**

*"... It's a challenge of who offers what.....what do I go to Inside Out for? What do I go to Butterfly for? What do I go to EDC for?"*

#### **Segment 9**

*"It's not about claiming turf it's about the user experience... avoiding duplication of resources....In everything we do in this space, how do we make it as easy as possible for people?... I feel like that's a really good lens to come at it with"*

#### **Segment 9**

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# Personas & Journey maps



## PERSONA // Care is motivated & managed by others

## PERSON NEEDING SUPPORT

### Francis

<b>Age:</b>	16
<b>Household:</b>	Mum, Dad, Sister, Dog named Benny
<b>Location:</b>	Outer Metro
<b>Occupation:</b>	F/T student, Casual after-school job
<b>Lifestyle:</b>	Playing video games, hanging out with friends, exercising, walking the family dog

### QUOTE

*"I was unaware of the scope of ED before I was diagnosed, then when I was sick I didn't see it as a problem"*

### ABOUT

Francis is experiencing disordered eating, a condition that may have started to bubble under the surface a year or two ago but as the stress of school life is being felt more, people around Francis have started to make comments about changes in Francis' behaviour, particularly around the approach to food and exercise.

Mealtime at Francis's house is often stressful as Francis may prefer to stay in their bedroom away from the family or leave the house for a jog.

Francis's Mum often sits down and initiates honest conversations to try and understand what is going on and how she can help, but Francis typically brushes the enquiry off.

Some months ago, Francis's health deteriorated to a point that Francis was hospitalized after seeing the family GP.

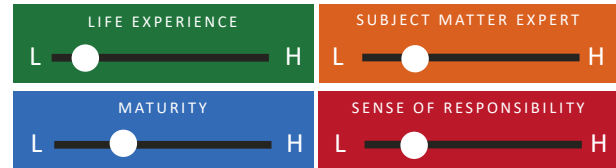
Since leaving the hospital after the most recent visit, Francis's Mum has linked Francis up to a Butterfly Foundation support group, dietician and psychologist, after some extensive research on the Butterfly Foundation website and a GP referral.

### ATTITUDES AND GOALS





- 'ED's are about secrecy, I push everyone away'
- Seeking engagement with people experiencing the same things as me
- Support from people around me throughout my recovery
- I want to see stories of recovered people with lived experience who look like me

### Characteristics:

Francis is low on life experience, due to still living at home. Francis attends school when they can and are heavily dependent on family for the management of their care. May be in denial of the problem or unaware there is an issue.



## Francis - Care is motivated and managed by others

Stage	Something is going on ...	I need some help...	(If) Hospitalization is required	Calmer seas & checking back in
 <b>Doing</b>	<ul style="list-style-type: none"> <li>Francis has received comments about their body in the past which made them feel anxious</li> <li>Has recently been focused more on the way they look and family/friends have expressed concern about behaviour around food and/or exercise</li> </ul>	<ul style="list-style-type: none"> <li>Francis' parent has a discussion with the family GP without Francis present</li> <li>Parent convinces Francis to see an expert (dietician/GP) to focus on their 'nutrition'</li> <li>Appointment with GP to arrange Mental health plan referral</li> </ul>	<ul style="list-style-type: none"> <li>Inpatient visit/s are a double-edged sword; medical assistance is urgent but being surrounded by other people with disordered eating is a competitive environment</li> <li>Avoiding triggering stimuli online where possible</li> </ul>	<ul style="list-style-type: none"> <li>Learning strategies to recognise and help when things start to feel uncontrolled</li> <li>Regular appointments with a Psychologist/ GP or preferred SME</li> <li>Avoiding triggering stimuli at school is important</li> </ul>
 <b>Thinking / feeling</b>	<p>"I think I'm fine"</p> <p>"I get validated for my thinness, the compliments are a rush"</p>	<p>"My family are really being impacted"</p> <p>"The GP gave me some hard truths about the seriousness of my health problem"</p>	<p>"At the hospital, it's so competitive in there"</p> <p>"I feel guilty for what I am putting my family through"</p>	<p>"The learning is ongoing"</p> <p>"I want to share my story"</p> <p>"I have one teacher who helped get me back to school, she was my ally, she got me through"</p>
 <b>Pain Points</b>	<ul style="list-style-type: none"> <li>Denial causes family tension and stressful living environment</li> <li>Fractious and forced conversations with family</li> </ul>	<ul style="list-style-type: none"> <li>Waiting times</li> <li>Finding a GP that is a SME</li> <li>Resources that are culturally relatable</li> </ul>	<ul style="list-style-type: none"> <li>Uncertainty</li> <li>Reflecting on the impact this has on the support network is difficult</li> <li>Instances of relapse</li> </ul>	<ul style="list-style-type: none"> <li>There is no one-size-fits-all approach, every individual moves through their journey differently</li> <li>Unsure if they will ever be 'fully' recovered</li> </ul>
 <b>Influence</b>	<ul style="list-style-type: none"> <li>Negative body image and 'wellness' content on social media</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation: Emerge program</li> <li>Dietician</li> <li>Difficult conversations with GP, family</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation facilitated program</li> <li>Conversations with Psychologist</li> <li>Podcasts: stories of recovered people</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly website; recovered people stories</li> <li>Butterfly</li> <li>Open conversations with Psychologist, family</li> </ul>



## PERSONA // Concerned about their own behavior

## PERSON NEEDING SUPPORT

### Jean

**Age:** 33  
**Household:** Partner  
**Location:** Metro  
**Occupation:** Web marketing, P/T Yoga teacher  
**Lifestyle:** Loves Yoga, Bushwalking, spending time in person with friends.

### QUOTE

*"I've never managed to do 'balance' well. I have disordered eating... I have experienced binge eating my whole teen/adult life"*

### ABOUT

Jean is experiencing disordered eating, which may have started to bubble under the surface when they were younger. As the stress and expectations of a busy life are being felt more, a traumatic life event has exacerbated these feelings, sparking people around Jean to make comments about changes in Jean's behaviour, particularly around Jean's approach to food and exercise.

Often Jean feels helpless, isolated and unsupported, but also feels terrible that family are impacted by Jean's own illness.

After doing a self-initiated web search, Jean finds the Butterfly Foundation website (a

trusted and authentic feeling resource) and over several visits explores the resources and links, some of which are helpful. When feeling well enough, the web chat and helpline are useful if Jean needs reassurance and support.

Jean has engaged with a few different GPs to find one who knows about disordered eating. Due to a lack of general knowledge amongst these GP's, Jean experiences some bias around gender, age, culture and physical appearance.

Once a suitable GP is settled upon, Jean is then provided a mental health plan and engages with a psychologist.

### ATTITUDES AND GOALS

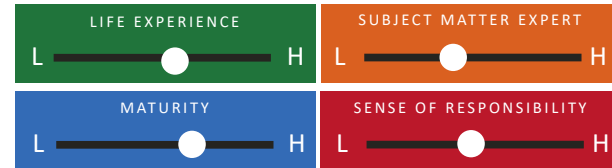
- Finding 'people like me' and resources for 'people like me' is very important. Much of Butterfly's resources feel geared to younger people or are somewhat culturally specific
- 'I need a 'where to start guide', I don't know what I don't know'
- Support specific to my kind of disordered eating, that I can dip in and out of as I am able/need to

### Characteristics:





Jean has mid-level life experience, due to being at a stage where some important lifestyle decisions are being made.

Jean typically self-manages their own care, with some additional support from friends and family.

Jean may have an additional diagnosis that sits alongside disordered eating, however, Jean may also be curious or concerned about their own behaviours but remains undiagnosed.



## Jean – Concerned about their own behavior

Stage	Stressful event triggers crisis....	I need some help...	Calmer seas...	Checking back in...
 <p>Doing</p>	<ul style="list-style-type: none"> <li>Traumatic life event occurs: (relationship breakdown, illness, moves city, miscarriage) which surfaces feeling that has been bubbling away for a few years</li> <li>Family/friends express concern about behaviour around food</li> </ul>	<ul style="list-style-type: none"> <li>Online research: heavy reliance on Butterfly Foundation services via the website</li> <li>Ask for help, anonymously via webchat, helpline</li> <li>Discussion with a GP to arrange Mental health plan referral</li> </ul>	<ul style="list-style-type: none"> <li>Learning strategies, to recognise and assist when things start to feel uncontrolled</li> <li>Regular appointments with Psychologist/GP or preferred SME</li> <li>Subject matter learning is ongoing</li> <li>Avoiding triggering stimulus</li> </ul>	<ul style="list-style-type: none"> <li>Email comms from Butterfly Foundation as a helpful safety net - knowing it's there</li> <li>Check back into the BF website regularly for updated resources and materials</li> </ul>
 <p>Thinking / feeling</p>	<p>"I have been found out"            "I recognise I am spiraling"            "I'm at a loss, how do I get out of this vicious cycle...obsessing over food, obsessing over calories, and feeling anxious in social situations"</p>	<p>"I don't know what I don't know-help!"            "How bad or urgent is my situation?"            "My family are really being impacted"</p>	<p>"Receiving newsletter and passive communication from Butterfly makes me feel connected"            "I'm getting things back on track but it's always in the back of my mind"</p>	<p>"I'm realistic and when I'm feeling like my thoughts are relapsing, I'll jump back onto the website to read some stories of recovered people"</p>
 <p>Pain Points</p>	<ul style="list-style-type: none"> <li>Energy levels and capacity to engage during a crisis is low</li> <li>Feeling shame and judgement from family &amp; friends</li> </ul>	<ul style="list-style-type: none"> <li>Waiting times</li> <li>Finding a GP that is a SME</li> <li>Resources for people that look like me; gender, culture, age</li> </ul>	<ul style="list-style-type: none"> <li>Reflecting on the impact this has had on support network is difficult</li> </ul>	<ul style="list-style-type: none"> <li>There is no one-size-fits-all approach, every individual moves through their journey differently</li> <li>Unsure if they will ever be 'fully' recovered</li> </ul>
 <p>Influence</p>	<ul style="list-style-type: none"> <li>Negative body image and 'wellness' content on social media</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation</li> <li>Inside Out</li> <li>Conversations with GP, family</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation facilitated program</li> <li>Conversations with Psychologist</li> <li>Podcasts: stories of recovered people</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly website</li> <li>Inside Out</li> <li>Read: 'Rehabilitate, Rewire, Recover' by Tabitha Farrar</li> <li>Watch: 'Embrace' movie</li> </ul>



## PERSONA // Non-professional Caregiver (family, friends)

## SUPPORT PROVIDER

### Frankie

**Age:** 52  
**Household:** Two Daughters aged 17 & 14  
**Location:** Regional  
**Occupation:** Nurse  
**Lifestyle:** Cycling, Gardening, Renovation TV shows and spending time with friends.

### QUOTE

*"How do I do this as a complete layperson with no formal training... show me how I can be the most helpful I can be right now"*

### ABOUT

Prior to supporting a family member (youngest child) with disordered eating, Frankie had a limited understanding of this concern and therefore the learning curve has been steep and stressful.

After noticing changes to their child's approach to food and exercise, Frankie initiates a web search and locates the Butterfly Foundation website whilst simultaneously visiting the family GP with/without the child present. Often Frankie feels helpless, isolated and guilty about the impact of their child's situation on the overall family dynamics. Frankie ensures that their child attends regular psychology

appointments and Butterfly group programs, however, right now is unfortunately unable to afford professional mental health services.

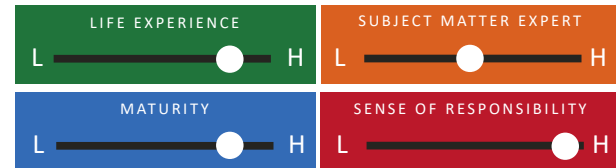
In the event that their child is hospitalised, Frankie will accompany them to minimize exposure to mimicking behaviour that may be encountered when staying alongside other patients with disordered eating. Whilst peer support groups can be intimidating and daunting to see extreme circumstances faced by other families, Frankie gets reassurance and helpful peer support from online community forums and groups.

### ATTITUDES AND GOALS





- Seeking strategies specific to mealtimes. There is so much learning to do
- I need a 'where to start' guide, I don't know how urgent or serious this situation is
- How do I broach discussions with a loved one
- Carers need ongoing support too

### Characteristics:

Frankie is a researcher, and feels confident they are up to date with all the resources currently available to them. In times of crisis, Frankie often needs to take time off work to support treatment for their child, this significantly impacts Frankie's capacity to earn income. Frankie's own mental health may suffer because of the stress incurred, specifically around mealtimes.







## Frankie – Non-professional Caregiver

Stage	Something is going on ...	I need some help...	(If) Hospitalization is required	Calmer seas & checking back in
 <b>Doing</b>	<ul style="list-style-type: none"> <li>Frankie starts to notice a change in behaviour related to food and exercise with one of their children, which causes some concern</li> <li>Online research: heavy reliance on Butterfly Foundation resources via the website</li> </ul>	<ul style="list-style-type: none"> <li>Discussion with a GP to plan the next steps</li> <li>Engaging with Butterfly website to understand what resources and support is available for their child</li> <li>Searching Facebook forums to get advice from other caregivers</li> </ul>	<ul style="list-style-type: none"> <li>Taking time off work and away from home</li> <li>Avoiding triggering stimulus</li> </ul>	<ul style="list-style-type: none"> <li>Email comms from Butterfly Foundation as a helpful safety net - knowing it's there</li> <li>Regular appointments with Psychologist/GP or preferred SME</li> <li>Subject matter learning is ongoing, checking back to BF website for new information</li> </ul>
 <b>Thinking / feeling</b>	<p>"I am worried and out of my depth"            "How urgent is this situation?"            "How do I broach this conversation in a respectful and empathetic way?"</p>	<p>"I blame myself"            "My family are really being impacted"            "I've become obsessed with getting food into this child"</p>	<p>"At the hospital, it's really triggering and frightening - it's so competitive in there. I try and keep them at home as long as possible"            "Exhausted and extremely stressed"</p>	<p>"It's always there, in the back of my mind"            "There is always more to learn"            "Still walking on eggshells"</p>
 <b>Pain Points</b>	<ul style="list-style-type: none"> <li>Feeling fear and confusion</li> <li>It's unclear where to start, first steps</li> </ul>	<ul style="list-style-type: none"> <li>Finding a GP that is an SME</li> <li>Waiting times between appointments</li> <li>Mealtimes</li> <li>Anguish for the whole household</li> </ul>	<ul style="list-style-type: none"> <li>Uncertainty</li> <li>Reflecting on the impact this has had on support network is difficult</li> <li>Multiple instances of relapse</li> </ul>	<ul style="list-style-type: none"> <li>Reflecting on the impact this has had on support network is difficult</li> <li>Worry for the child is ongoing</li> </ul>
 <b>Influence</b>	<ul style="list-style-type: none"> <li>Butterfly Foundation</li> <li>Inside Out</li> <li>Conversations with family and friends</li> </ul>	<ul style="list-style-type: none"> <li>Mental health plan referral</li> <li>Dietician</li> <li>Butterfly facilitated program</li> <li>Facebook caregiver community group</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation facilitated program</li> <li>Conversations with Psychologist</li> <li>Facebook caregiver community group</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly website</li> <li>Body positive social media sites</li> <li>Facebook caregiver community group</li> </ul>



## Frankie – Non-professional Caregiver (alternate)

Stage	Something is going on ...	I need some help...	Calmer seas & checking back in
 <p>Doing</p>	<ul style="list-style-type: none"> <li>Frankie starts to notice a change in behaviour related to food and exercise with one of their children, which causes some concern</li> <li>Online research: heavy reliance on Butterfly Foundation resources via the website</li> </ul>	<ul style="list-style-type: none"> <li>Discussion with a GP to plan the next steps</li> <li>Engaging with Butterfly website to understand what resources and support is available for their child</li> <li>Searching Facebook forums to get advice from other caregivers</li> </ul>	<ul style="list-style-type: none"> <li>Email comms from Butterfly Foundation as a helpful safety net - knowing it's there</li> <li>Regular appointments with Psychologist/ GP or preferred SME</li> <li>Subject matter learning is ongoing, checking back to BF website for new information</li> </ul>
 <p>Thinking / feeling</p>	<p>"I am worried and out of my depth"            "How urgent is this situation?"            "How do I broach this conversation in a respectful and empathetic way?"</p>	<p>"I blame myself"            "My family are really being impacted"            "I've become obsessed with getting food into this child"</p>	<p>"It's always there, in the back of my mind"            "There is always more to learn"            "Still walking on eggshells"</p>
 <p>Pain Points</p>	<ul style="list-style-type: none"> <li>Feeling fear and confusion</li> <li>Its unclear where to start, first steps</li> </ul>	<ul style="list-style-type: none"> <li>Finding a GP that is an SME</li> <li>Waiting times between appointments</li> <li>Mealtimes</li> <li>Anguish for the whole household</li> </ul>	<ul style="list-style-type: none"> <li>Reflecting on the impact this has had on support network is difficult</li> <li>Worry for the child is ongoing</li> </ul>
 <p>Influence</p>	<ul style="list-style-type: none"> <li>Butterfly Foundation</li> <li>Inside Out</li> <li>Conversations with family and friends</li> </ul>	<ul style="list-style-type: none"> <li>Mental health plan referral</li> <li>Dietician</li> <li>Butterfly facilitated program</li> <li>Facebook caregiver community group</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly website</li> <li>Body positive social media sites</li> <li>Facebook caregiver community group</li> </ul>



## Cee Jay

Age:	43
Household:	Two sons aged 9 & 13
Location:	Regional
Occupation:	Educator (high school)
Lifestyle:	Coaching junior sports team, camping and spending time with family/friends

## QUOTE

*"Butterfly could do more work with us teachers. We have the curriculum in place to tackle some of these things, but we need to skill-up the adults in these kids' lives"*

## PERSONA // Professional (Subject Knowledge - LOW)

## SUPPORT PROVIDER

### ABOUT

Cee Jay has no previous experience of disordered eating in their personal life, but is familiar with Butterfly Foundation from the in-school seminars that BF provide and from seeing students wearing BF-branded bracelets in the playground.

After becoming aware of changes in a student's behaviour, Cee Jay might typically flag the concern in a staff meeting or refer the issue to a more senior colleague if possible. However, Cee Jay is aware of maintaining a balance between the student relationship and trust whilst wanting to keep parents and senior staff informed of any concerning observations.

Cee Jay doesn't feel confident that they know enough about the subject matter or how to help young people they encounter, especially for those who present outside of a young, white, thin, female stereotype.

Cee Jay believes that Butterfly Foundation resources would be the instinctive key resource to guide any conversations they might have with parents and carers of students.

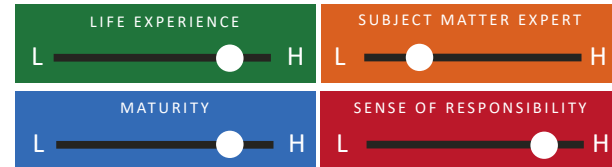
### ATTITUDES AND GOALS

- I need a 'where to start' guide, I don't know how urgent or serious this situation is
- How do I broach discussions with a student and or/ their parent
- Hearing stories from other professionals makes you realise it's ok to not know everything
- I got into teaching because I care, I worry about them





### Characteristics:

Cee Jay believes that as an educator their role is focused on early intervention and that crisis situations are less common in their school setting.

Cee Jay is not confident that they are up to date with current resources and best practice where these issues are concerned.



## Cee Jay – Professional (Subject knowledge – Low)

Stage	I think something is going on ...	I don't have the skills for this	I'm worried about them and me
 <p>Doing</p>	<ul style="list-style-type: none"> <li>Cee Jay is made aware that one of their students may be experiencing some disordered eating or body image concerns, which is worrying</li> <li>Butterfly Foundation has been out to speak to students at Cee Jay's school before but there has been no staff training</li> </ul>	<ul style="list-style-type: none"> <li>Seek guidance from other staff that may be more qualified to assist, i.e., counsellor, mental health practitioner</li> <li>Online research using the Butterfly Foundation factsheets</li> </ul>	<p>Concern about their students is experienced as being twofold; worry for the student's wellbeing whilst simultaneously having concern for their own administration and needing to 'cover bases', making sure that they have crossed T's and dotted the I's themselves</p>
 <p>Thinking / feeling</p>	<p>"I am worried and out of my depth" "Unsure what is best practice. What are the do's and don'ts?"</p>	<p>"I would escalate the issue, unless there was really good relationship with the student, in that case I might go directly to them" "How do I broach this conversation in a respectful and empathetic way?"</p>	<p>"As a teacher, I don't turn off at night, I reflect on things....you are worried" "We are becoming more like social workers rather than teachers to be honest"</p>
 <p>Pain Points</p>	<ul style="list-style-type: none"> <li>Concern about duty of care</li> <li>Concern about putting the student at risk or overstepping boundary</li> </ul>	<ul style="list-style-type: none"> <li>Feeling overwhelmed and out of their depth</li> </ul>	<ul style="list-style-type: none"> <li>Uncertainty about next steps and what actions are being taken at home</li> <li>Worry for the student is ongoing</li> </ul>
 <p>Influence</p>	<ul style="list-style-type: none"> <li>Butterfly Foundation website</li> <li>Dove self esteem project</li> <li>Conversations with peers during Staff meeting</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation website resources: factsheets (NEDC)</li> <li>Discussions with educator peers</li> </ul>	<ul style="list-style-type: none"> <li>Butterfly Foundation website resources and any relevant links provided</li> <li>Betterhealth.vic.gov for classroom course resources</li> </ul>

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# Key Recommendations

## Key recommendations

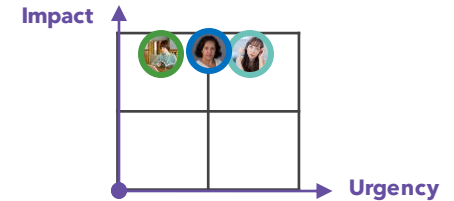
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Overall participant impressions of the Butterfly Foundation support resources were positive and received well. There are some opportunities that may improve the user experience in future service offerings and resource material:

- Having an ongoing connection with a resource like Butterfly was described as being very impactful. For several participants, this was represented through the regular e-newsletter. Whilst the newsletter was often not engaged with or read in full, it was a helpful and tangible connection to Butterfly, and a reminder that help was available when and if it was needed.

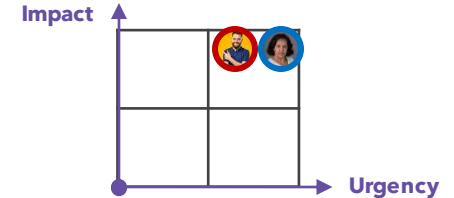
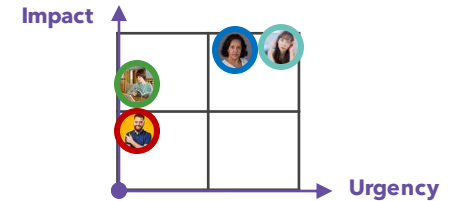
Consider ways to set up a connection with individuals/carers/supporters from when they first visit the Butterfly website e.g. an opt-in email/text support service with a periodic 'just checking in' message. The frequency could be every two weeks for the first month, then monthly for three months, then every two months - this would ensure an ongoing connection that wasn't intrusive but maintained that contact. Messaging may also differ depending on which stage of the journey a user indicates that they are at.

This could be something that is asked when they first opt-in and could be revisited at points in the future. There is a tendency to ebb and flow in motivation, to dip into a resource like the Butterfly website, then retreat and then come back again. If an individual can be encouraged to opt-in for a discrete 'connection/checking in' service, then they have a gentle but continuing reminder that help is available when they are ready to take it.



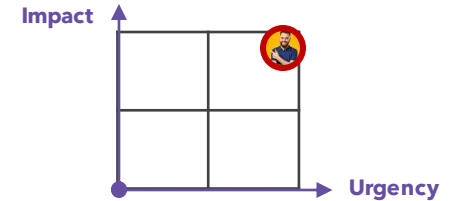
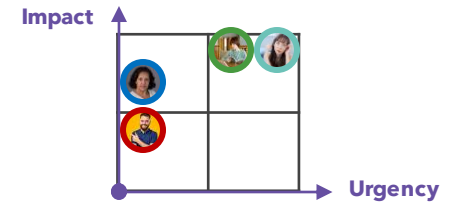
## Key recommendations

- Knowing how to approach a sensitive situation was something that was sought out by participants and some compared it to first aid training. They would be looking for advice specific to themselves, friends/relatives, warning signs, how to talk to someone at risk, what to say/not say and how to verbally acknowledge it won't be an overnight fix. While there is information about what to do/say on the Butterfly website, a consumer's ability to self-identify the type of information they need and locate it in a period of duress may be reduced; Consider ways to take individuals/carers/supporters by the hand when they first arrive on the website i.e. with a 'Where do I start' decision support tool (customised to key needs of different segments/personas and what stage they are at in their journey)
- Carers and supporters of people at risk routinely seek reassurance about the perceived 'urgency' or 'seriousness' of their situation from the website, especially around food consumption. A common request from this cohort was to see mealtime strategies included on the website to assist carers or supporters in times of crisis and reduce the stress around mealtimes. Participants also felt it very important to learn and know the 'right' terminologies before seeking out support or approaching someone about concerns for their welfare. Consider better surfacing existing and additional resource strategies of how best to support someone regarding these high-stress scenarios



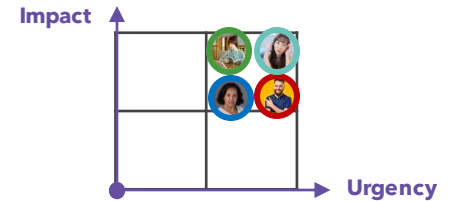
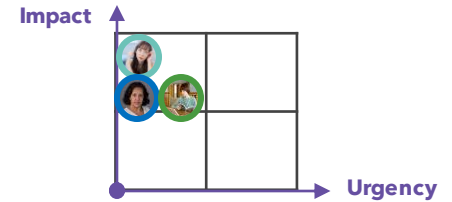
## Key recommendations

- Participants often felt that if there was more exposure about the issues and where to get help that this would raise awareness and make people understand that negative behaviours around food and body aren't 'normal'. Consider feasible opportunities for Butterfly to partner with organisations that increase brand awareness. Touchpoints suggested include; posters at a clinic or medical waiting room, targeted online advertising, placement of Butterfly information in the entry of a fast-food venue, bathroom posters in gyms or nightclubs positioned alongside alcohol and mental health campaigns – increasing visibility and to sow the seeds into a patron's mind
- Consider increasing the marketing of education modules for teachers to skill up and surfacing these resources better on the website; Participants discussed that hearing other teachers' stories and shared experiences shed more light on the resources and strategies available for themselves to ponder, enabling them to better assist students and more confidently deal with situations as they may arise. However, participants from this segment were unaware of the professional development resources that Butterfly offers



## Key recommendations

- While the 'Emerge' program is highly regarded, participant commentary suggested that what's missing is a shorter 'top-up' program for those who wish to revise or revisit the content as required. This may enable a consumer to receive some top-up short-term expert support and get back on track again during the recovery journey
- Feeling that culture, faith or ethnicity was a barrier to finding support was raised as a concern for some participants, who believed that it may be difficult for a person unfamiliar with their cultural relationships around food to understand or empathise with their situation. Consider including other filtering criteria to the Referrer Database e.g. 'gender', 'age', 'faith', 'ethnicity', 'sexual identity'





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Next Steps

1

### **Debrief findings**

Report to be delivered to Butterfly Foundation 7<sup>th</sup> December 2022

2

### **Further Research**

Butterfly Foundation team to consider the findings, journey maps and personas provided in this report to help inform future design iterations or enhancements to the support resources provided

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# Appendix

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# Survey responses

The following tables represent the distribution of participant\* responses when asked to rate their familiarity with examples of existing Butterfly Foundation touchpoints.

*\*Participants who were familiar with Butterfly Foundation prior to the research session*

## Responses – Familiarity with butterfly Foundation touchpoints

Touchpoint	Feels Familiar to me	I'm unsure	Feels Unfamiliar to me	n/a
Butterfly Foundation helpline	20	2	3	
Referral to Butterfly from another helpline service	13	4	5	2
Email marketing campaigns	12	5	7	
Butterfly Foundation website	22	1	1	
Primary School information flyers	3	1	13	7
Secondary School information flyers	7	3	9	5
Secondary school speaker sessions	8	1	10	5
Tertiary institution flyers	3	2	13	6
Presence at conferences	7	5	8	4
Digital marketing campaigns	14	3	7	

## Responses – Familiarity with butterfly Foundation touchpoints

Touchpoint	Feels Familiar to me	I'm unsure	Feels Unfamiliar to me	n/a
Fundraising events or initiatives	8	3	12	1
On the Fly e-Newsletter (for Lived Experience including carers)	6	4	14	
On the Fly e-Newsletter (healthcare professionals)	5		17	2
Butterfly Instagram account	7	2	14	1
Butterfly Facebook group	4	3	13	4
Butterfly Twitter account	2	2	15	5
Body Kind Schools	5	3	14	2
Body Kind Families	2	3	18	1
Body Kind Online	4	4	15	1
Butterfly: Let's Talk podcast	8		14	2

## Responses – Familiarity with butterfly Foundation touchpoints

Touchpoint	Feels Familiar to me	I'm unsure	Feels Unfamiliar to me	n/a
Youth Program (or Virtual Youth Program)	3	3	15	3
Support Groups - carers	11		9	4
Support Groups - individuals	15	3	6	
Wandi Nerida (residential centre on the Sunshine Coast)	8	1	10	5
Butterfly Collective (online Forum)	6	7	9	2
Butterfly Pathfinders (speakers' bureau)	2	3	17	2