

Medicare Item Numbers for Eating Disorders

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Executive Summary

Thank you to butterfly and the Aus. government for implementing these changes. It has helped enormously and has lifted a huge weight off my shoulders. Its stressful enough getting treatment without the added financial pressures and its helped ease that.

Background and methodology

An online survey aimed at understanding the experiences of accessing treatment under Medicare item numbers for eating disorders among eating disorder sufferers and their carers has shown the Medicare Benefits Schedule items (MBS items) to be of incredible benefit.

In November 2019 the Commonwealth Government introduced 64 new MBS items numbers to provide care for eligible patients living with an eating disorder. The aim of this survey was to understand the experiences of individuals who have accessed treatment under this scheme and to gain insights into any barriers/challenges experienced in accessing the benefits.

An anonymous online survey comprising both open-ended and forced-choice questions was distributed through Butterfly Foundation's social media platforms, organisational networks and lived experience community.

Key findings

A total of 237 respondents who completed the survey had lived experience of an eating disorder or were carers of individuals who have/had a lived experience of eating disorders. Almost all participants were female (99.3 per cent) and identified as Australian. Most (63 per cent) lived in a metropolitan suburban area. People with Anorexia Nervosa were also over-represented.

A very high level of awareness of the MBS items exists

The majority of the sample were aware of the new MBS items with only 15% of the total sample being unaware or unsure if they were aware of the new items.

Media stories and Butterfly's communications played a critical role in driving awareness

Both the media and Butterfly Foundation have played a critical role in creating awareness of the MBS items among eating disorders sufferers and their carers; 29 per cent of respondents said that they heard about the items from the media, while 24 per cent cited Butterfly as the source of information.

Butterfly was also mentioned as an important source for recommendation to participants in accessing allied health care professionals who had specialised knowledge in treating eating disorders

The first mental health professional did not identify an eating disorder after at 4 visits when my daughter was in desperate need. Once we contacted the Butterfly Foundation and received a recommended psychologist we were thankfully on the right track.

Widespread improvements in accessibility

The findings from this survey suggest that the MBS items have provided significant benefits to many individuals suffering from eating disorders and those that care for them. The scheme has made treatment more accessible and affordable. Just over 95

per cent of those respondents who were able to access Eating Disorder Management Plans (EDMPs) perceived the new MBS items as helpful to them or the person for whom they care.

Respectful, empathic care supporting recovery

The vast majority of those who had obtained an EDMP (87.7 per cent) believed their values, needs and preferences had been respected in the development of their EDMP. A smaller, but substantial majority (60 per cent) found the development of the EDMP had helped them to better understand their ED and treatment goals. Only 20 per cent believed it had not helped them.

The majority of respondents (83 per cent) reported receiving empathic and competent care. Some commented that the Plan had been instrumental in their journey towards recovery:

This new scheme has provided me with the support I really needed and could never have accessed before. I'm forever grateful. I just hope I can keep accessing treatment until I'm truly ready, without it being cut short.

I cannot express enough how much it changed my life.

Most Eating Disorder Management Plans are developed by GPs

Under the new MBS items only general practitioners, psychiatrists and paediatricians are allowed to provide an Eating Disorder Management Plan (EDMP). The vast majority of respondents (93 per cent) reported a GP had completed the EDMP.

Lack of awareness among GPs is a significant barrier to care

While many had benefited from the scheme there were still barriers to access for a number of the participants. One of the biggest barriers to accessing the scheme was gaining access to general practitioners who are aware of the scheme and have the knowledge needed to fill out the forms.

When I went to get the Medicare plan, the GP had no idea what it was and had to contact 3 other GPs before finding someone who knew about it.

Out-of-pocket costs remain a barrier to care

Another big barrier is that even with the MBS items, treatment for some is still unaffordable.

Other challenges and barriers

Other barriers mentioned included the need for psychiatrist reviews, the eligibility criteria, and the narrow range of therapies covered.

For some respondents, geographic location and lack of access to health professionals who specialise in eating disorders created a barrier to accessing the MBS items:

Overall great but could be improved with improved clarity re developing plans, difficulties getting specialist review due to costs and wait lists, very restricted "content" as to what can be discussed or worked on when billing under this MBS number as ED treatment is not a one size fits all.

Recommendations

Recommendation 1: Commission additional research to assess the impact of the MBS items on underrepresented cohorts

As a sample derived through Butterfly's existing community of supporters and followers, it is not necessarily reflective of experiences overall, and findings should be read in conjunction with other research. One particular limitation is that the sample in this survey overwhelmingly identified as female, had a low representation of people identifying as non-binary or male, and had limited representation of people identifying as Aboriginal and Torres Strait Islander and from a range of cultural and

linguistic backgrounds. As such, Butterfly recommends that additional research be carried out in partnership with community organisations that can assist in eliciting survey responses from these cohorts.

Recommendation 2: Promote the MBS items on a recurring basis in order to maintain current levels of awareness over time

Widespread media coverage and dedicated promotion by Butterfly was effective in driving awareness of the MBS items, facilitating improved access to treatment. To continue the current high level of awareness among people with eating disorders and their families and carers, ongoing promotion is required.

Recommendation 3: Invest in targeted awareness raising of MBS items among GPs

Given that GPs are the most likely source of referral, Butterfly, other eating disorder organisations and GP professional bodies should work to improve awareness among GPs. Potential interventions include the development of clear step-by-step instructions on how to complete an EDMP, and advertisements and editorial in industry publications.

Recommendation 4: Continue to engage people with eating disorders and their families and carers

The views of people with lived experience situate administrative data within real world contexts and provide a critical counterweight to clinical perspectives. An eating disorder can be a disempowering experience, and person-centred care that values the individual and understands treatment from the patient's perspective helps tailor care that will support long term recovery (Butterfly Foundation, 2016). Butterfly recommends that the views of people with current or previous experience of eating disorders continue to be sought in relation to the impact of the MBS items.

Introduction and background

This report outlines the findings from a survey undertaken in Australia in June 2020, six months after 64 new Medicare Benefits Schedule (MBS) item numbers were introduced to support a model of evidence-based care for eligible patients living with eating disorders. The main aim of this survey was to understand the experiences of individuals in accessing these new Medicare provisions, so Butterfly Foundation can better understand their needs and advocate on their behalf. The survey focused on individuals with a current eating disorder, individuals who have previously experienced an eating disorder, and carers. Results from forced-choice questions and open-ended questions are outlined in the findings below.

Methodology

An anonymous online survey comprising both open-ended and forced-choice questions was sent throughout Butterfly Foundation's social media and organisational networks. The survey contained 31 questions. The quantitative results were analysed through SPSS. The qualitative results were analysed by a researcher who utilised a thematic approach.

The Sample

The overall sample comprised of 246 respondents. The data from nine respondents could not be included in further analyses as they did not have lived experience of an eating disorder. The remaining respondents (n=237) could be divided into three separate cohorts:

1. Individuals currently experiencing an eating disorder (80.2%, n=190)
2. Individuals who have previously experienced an eating disorder (7.2%, n=17)
3. Carers of individuals who have/had a lived experienced of eating disorders (12.7%, n=30)

The sample overwhelmingly identified as female (99.2%, n=235), with two respondents identifying as non-binary (0.8%, n=2). From Table 1 it can be seen that three-quarters of the sample, identified as 'straight/ heterosexual' (78.9%, n=183), 11.4% as 'bisexual' (n=27) and 4.2% as 'gay or lesbian' (n=10). Eighteen respondents (6.7%) chose to self-describe their sexuality or indicated they 'preferred not' to complete this question. One person stated they thought this question was 'not relevant' to the subject matter of the survey.

Gender Identity	Number of respondents	Percentage of respondents
Straight/ Heterosexual	183	78.9
Gay or Lesbian	10	4.2
Bisexual	27	11.4
Asexual	2	0.8
Pansexual	2	0.8
Queer	4	1.7
Prefer not to say	8	3.4

Table 1. Self-reported sexual-identity of sample

The majority of respondents were aged between 18-30 years of age (see Figure 1). Nobody over the age of 60 completed this survey.

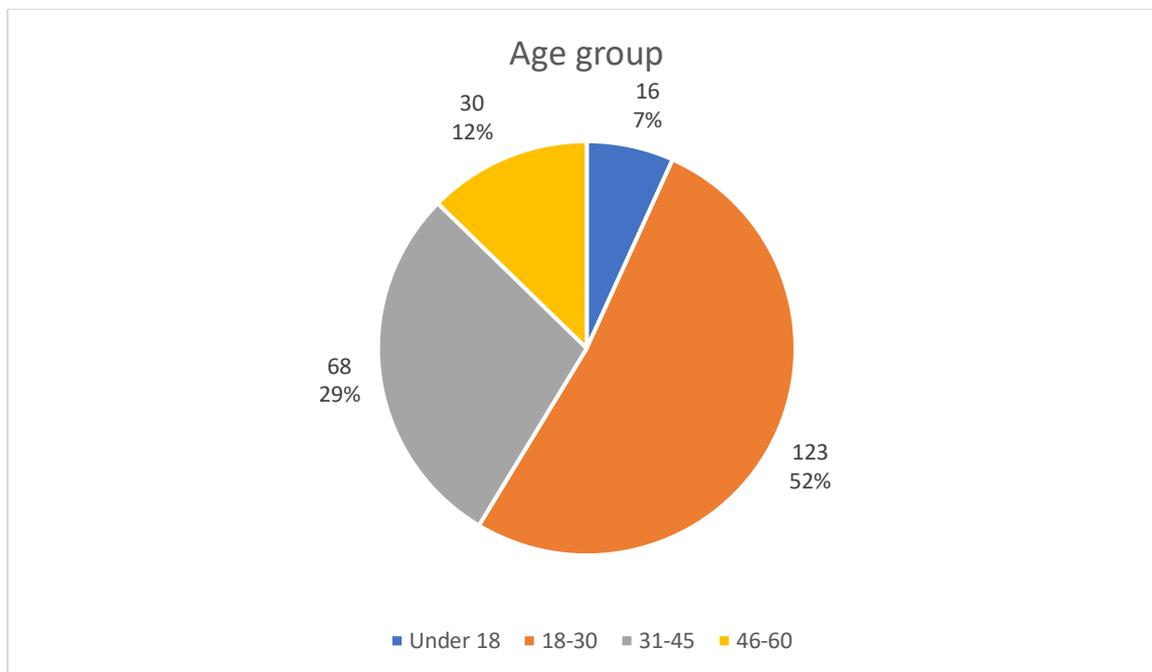


Figure 1. The percentage and number of the sample in the different age groups

The majority of the sample selected 'Australian' as their ethnic identity (n=214, 90.3%), with a small minority indicating they identified with different ethnicities (see

Table 2).

Ethnic Identity	Frequency	Percentage
Australian	214	90.3
Aboriginal or Torres Strait Islander	4	1.7
Asian	3	1.3
Indian	2	0.8
Middle Eastern	2	0.8
European	7	3.0
North American	2	0.8
European- Asian	1	0.4
White Zimbabwean	1	0.4
Prefer not to say	1	0.4

Table 2. Self-reported ethnic identity – frequency and percentage

The majority of the sample reported living in a metropolitan suburban area (n=149, 62.95) (see Figure 2).

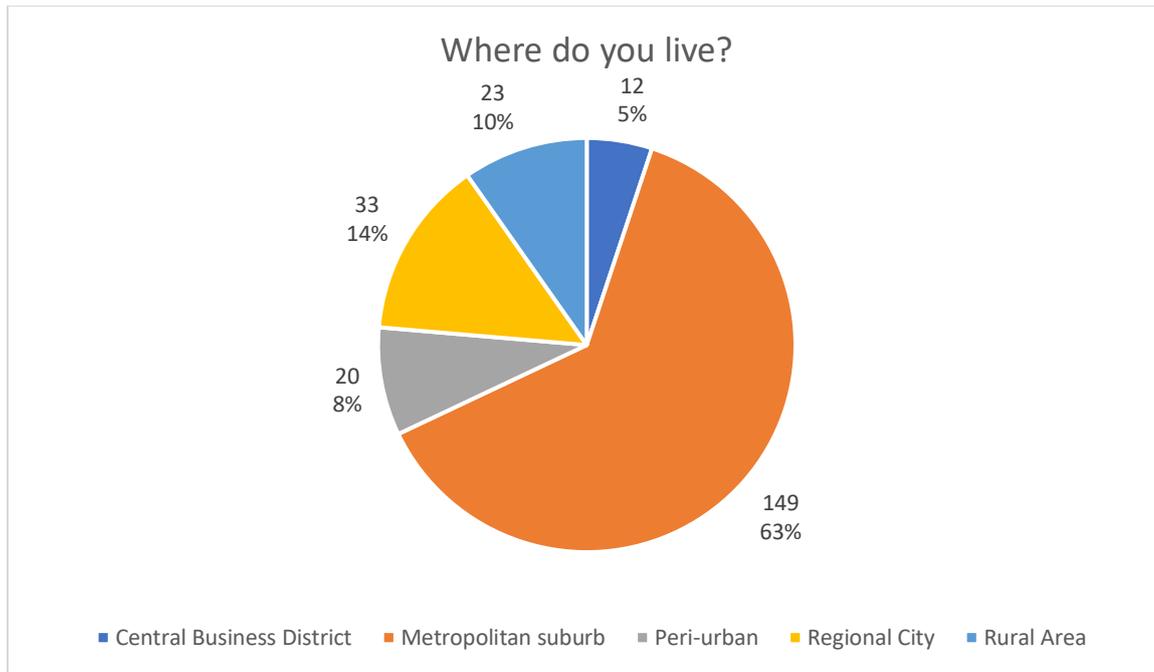


Figure 2. The frequency and percentage of respondents who live in different area classification

Results – Quantitative and Qualitative Findings

CEDs, PEDs and Carer Cohort characteristics

The overall sample was predominantly female (99.2%), which means it was not possible to explore differences between groups based on gender identity. In terms of age (see Table 3), there was no significant association between age groupings for the CEDs and PEDs ($\chi^2=2.70$, $p>0.05$).

	CEDs	PEDs	Carer
Under 18	14 (7.4%)	0	2 (6.7%)
18-30	109 (57.4%)	12 (70.6%)	2 (6.7%)
31-45	56 (29.5%)	5 (29.4%)	7 (8.6%)
46-60	11 (5.8%)	0	19 (63.3%)
Over 60	0	0	0
Total	190 (100%)	17 (100%)	30 (100%)

Table 3. Cohort demographic characteristics

No significant differences associations were found between the cohorts and other demographic characteristics (i.e., area where they live, sexual identity or ethnic identity (Australian/ other identity)).

Diagnosis of an ED

The respondents who either currently or previously reported experiencing an eating disorder, were asked if they had ever been diagnosed with an eating disorder. For those who reported currently (CEDs) or previously (PEDs) experiencing an ED, the majority had been diagnosed with an eating disorder by a professional (see Table 4). There was a significant association between the currency of the eating disorder and the presence/absence of being diagnosed with an eating disorder ($\chi^2=7.31$, $p<0.05$). Respondents who previously reported experiencing an eating disorder, were significantly less likely to report receiving a diagnosis from a health professional than those who were currently experiencing an eating disorder ($\phi=0.18$). Those who care for someone with an ED were not asked about the presence/absence of the diagnosis but were asked about the actual diagnosis.

	Current experience (CED)	Previous experience (PED)
Diagnosis	179 (94.2%)	13 (76.5%)
No Diagnosis	11 (5.8%)	4 (23.5%)
Total	190 (100%)	17 (100%)

Table 4. Presence/ Absence diagnosis of an eating disorder

From Table 5 it can be seen that for CEDs and Carers the most common diagnosis was Anorexia Nervosa, with 57.5% of CEDs and 76.7% of CEDs reporting this diagnosis. For PEDs the most common diagnoses were Anorexia Nervosa (38.5%) and Bulimia Nervosa (38.5%). There was no association between the group (CED, PED and Carer) and the nature of the diagnosis ($\chi^2=16.85$, $p>0.05$).

Diagnosis	CED	PED	Carer
Anorexia Nervosa (AN)	103 (57.5%)	5 (38.5%)	23 (76.7%)
Bulimia Nervosa (BN)	28 (15.6%)	5 (38.5%)	1 (3.3%)
Binge Eating Disorder (BED)	15 (8.4%)	1 (7.7%)	3 (10.0%)
Other Specified Feeding and Eating Disorder (OSFED)	20 (11.2%)	0	2 (6.7%)
Rumination Disorder	1 (0.6%)	0	0
Avoidant/ Restrictive Food Intake Disorder (ARFID)	2 (1.6%)	0	0
Body Dysmorphia	1 (0.8%)	0	0
Disordered Eating	3 (1.7%)	1 (7.7%)	1 (3.3%)
Other	6 (3.4%)	1 (7.7%)	0
Total	179 (100%)	13 (100%)	30 (100%)

Table 5. Eating Disorder Diagnosis by Cohort (CED, PED and carer)

Recommendation 1: Commission additional research to assess the impact of the MBS items on underrepresented cohorts

As a sample derived through Butterfly's existing community of supporters and followers, it is not necessarily reflective of experiences overall, and findings should be read in conjunction with other research. One particular limitation is that the sample in this survey overwhelmingly identified as female, has a low representation of people identifying as non-binary or male, and limited representation of people identifying as Aboriginal and Torres Strait Islander and from a range of cultural and linguistic backgrounds. As such, Butterfly recommends that additional research be carried out in partnership with community organisations that can assist in eliciting survey responses from these cohorts.

Awareness of the new Medicare Item Numbers

On 1 November 2019, the Federal Government implemented new MBS item numbers for the management and treatment of eating disorders. The new items introduced were designed to enable patients with complex eating disorders to access up to 40 sessions with a mental health professional and up to 20 sessions with a dietitian annually under an Eating Disorder Management Plan (EDMP). In the survey, respondents were asked whether they were aware of these new items. The majority of the sample were aware of the new Medicare Eating Disorder Scheme (84.6%, n=198).

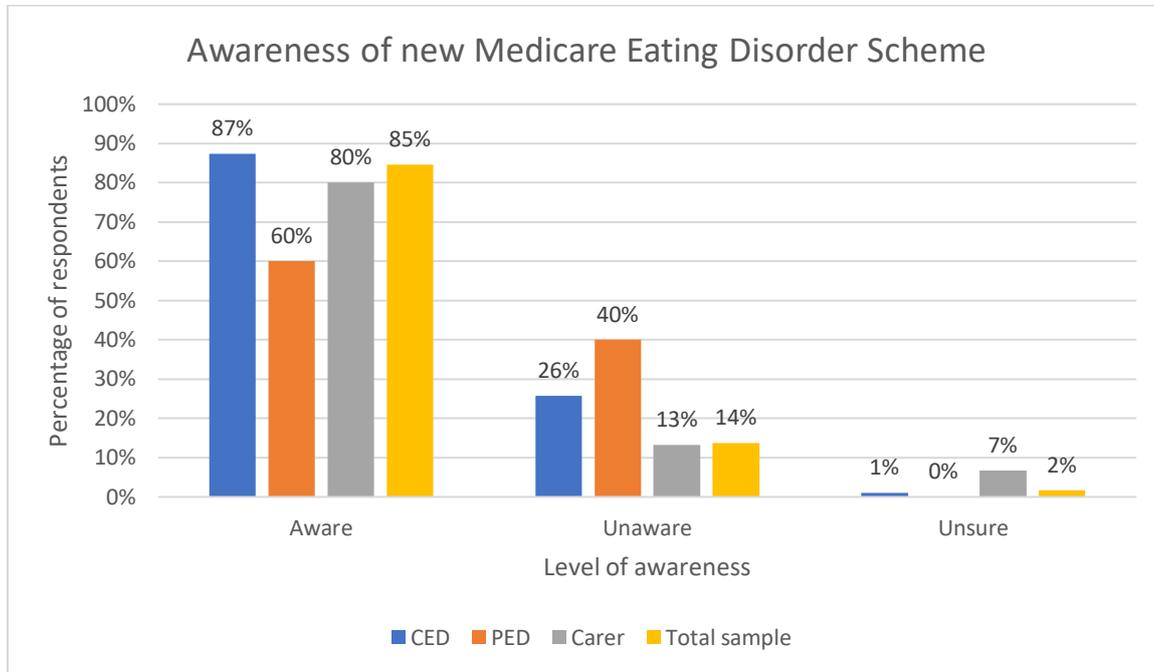


Figure 3. Awareness of the new Medicare Eating Disorder Scheme for the total sample and by cohort

From Figure 4 it is evident the total sample endorsed a number of different sources whom had made them aware of the new scheme. The two sources with the greatest number of endorsements were the media (29.3%, n=58) and Butterfly Foundation (23.7%, n=47). Those respondents who were made aware by 'other' source listed: Social media (n=3) and recovery coach – Mia Findlay (n=1).

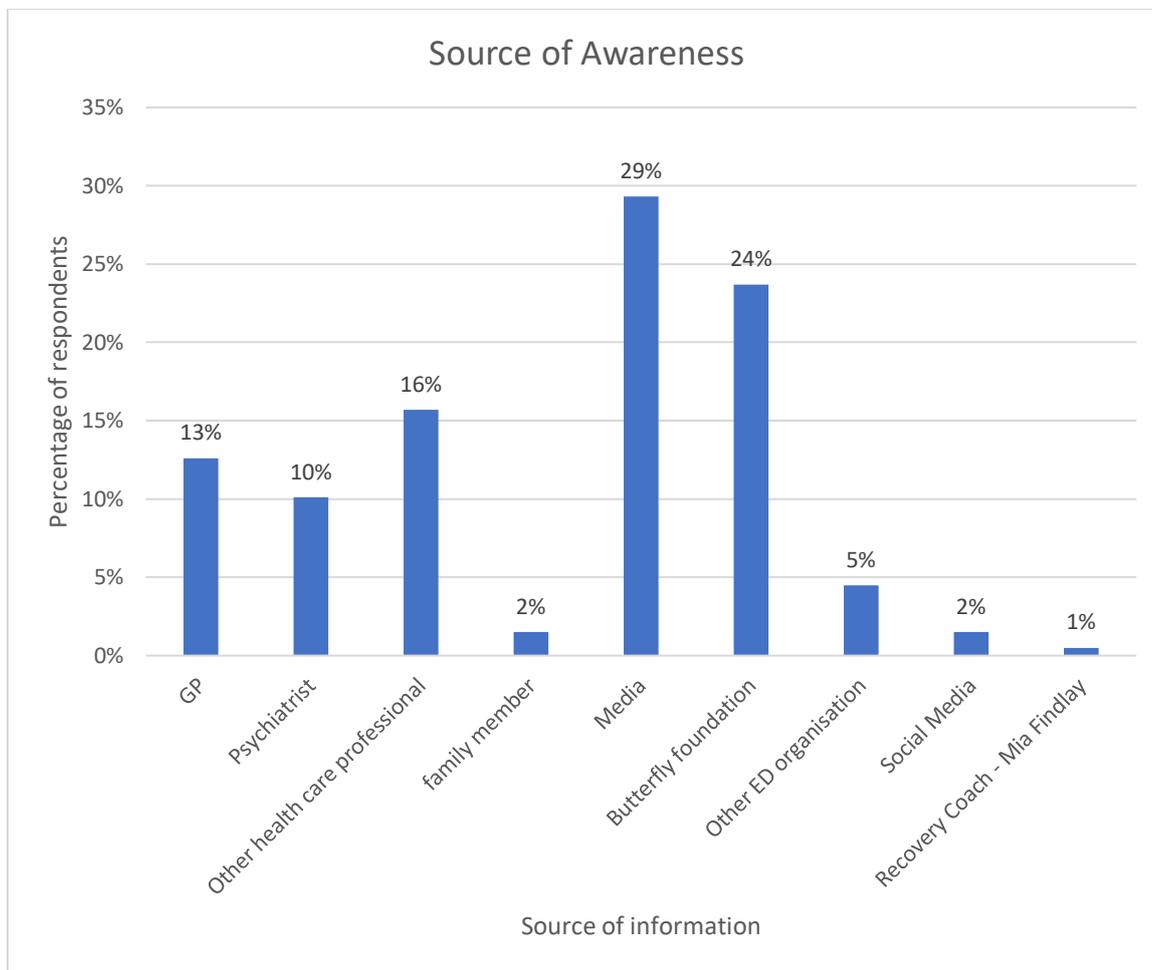


Figure 4. The percentage of respondents who endorsed each source for providing their awareness of the new MBS Eating Disorder Scheme.

For the following analysis, two groups were created. The first group 'current' was made up of CEDs and carers who are currently caring for someone with an ED (n=219). The second group 'past' was made up of PEDs and carers who have in the past cared for someone with an ED (n=15).

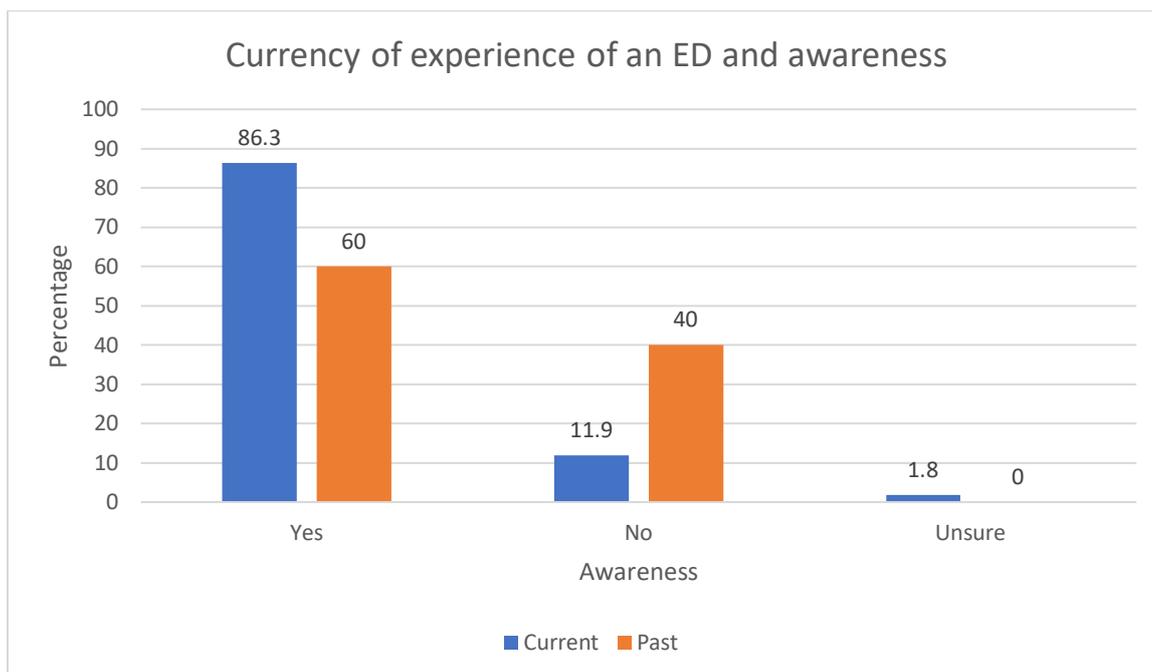


Figure 5. Currency of experience with an ED (current versus past) and awareness of the new Medicare ED Scheme.

A significant association was found between the currency of the experience with an ED and level of awareness of the new Medicare ED Scheme ($\chi^2=7.32, p<0.05$), with those who have current experience being significantly more likely to be aware of the scheme than those with previous experience of an ED ($\phi=0.20$).

Increasing awareness

Thirty-six respondents (15% total sample) indicated they were either 'not aware' or 'unsure' if they were aware of the new MBS ED Scheme. These respondents were asked what they believed would be the best ways to make them aware of the new scheme. The responses of those experiencing an ED and carers were collapsed into one group, as the group of carers who were unaware was too small (n=6) to make any interpretation of differences meaningful.

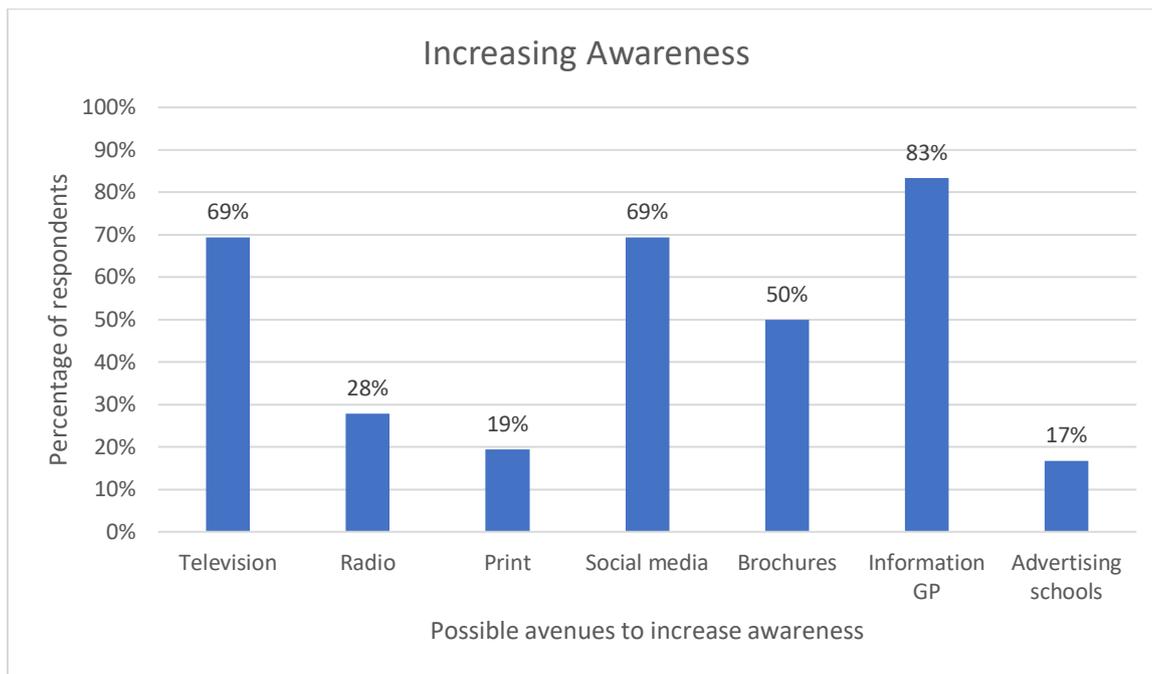


Figure 6. Respondent/s who were unaware of the new MBS ED Scheme endorsement of different ways in which they could be made aware of the scheme.

Figure 7 is can be seen that the most frequently endorsed avenues for increasing awareness of the MBS ED Scheme are information from the GP (83%, n=30), television (69%, n=25), social media (69%, n=25) and brochures in health care settings (50%, n=18).

Recommendation 2: Promote the MBS items on a recurring basis in order to maintain current levels of awareness over time

Widespread media coverage and dedicated promotion by Butterfly was effective in driving awareness of the MBS items, facilitating improved access to treatment. To continue the current high level of awareness among people with eating disorders and their families and carers, ongoing promotion is required.

Access to the Medicare Eating Disorder Scheme

Of the total sample, n=136 reported they had been able to access the new MBS Eating Disorder Scheme. Of those, 86% (n=117) were CEDs, 13.2% (n=18) were carers and 0.7% (n=1) was a PED.

Of those with a 'current' experience of an eating disorder (CEDs and current carers) who were aware of the new scheme (n=189), 71.4% (n=135) had accessed the scheme, 24.3% (n=46) had not experienced the scheme, and 4.2% (n=8) were unsure. There was no significant association between whether the person was a CED or current carer and their reported ability to get an EDMP to access to the new ED scheme ($\chi^2=1.81, p>0.05$) (see Figure 7).

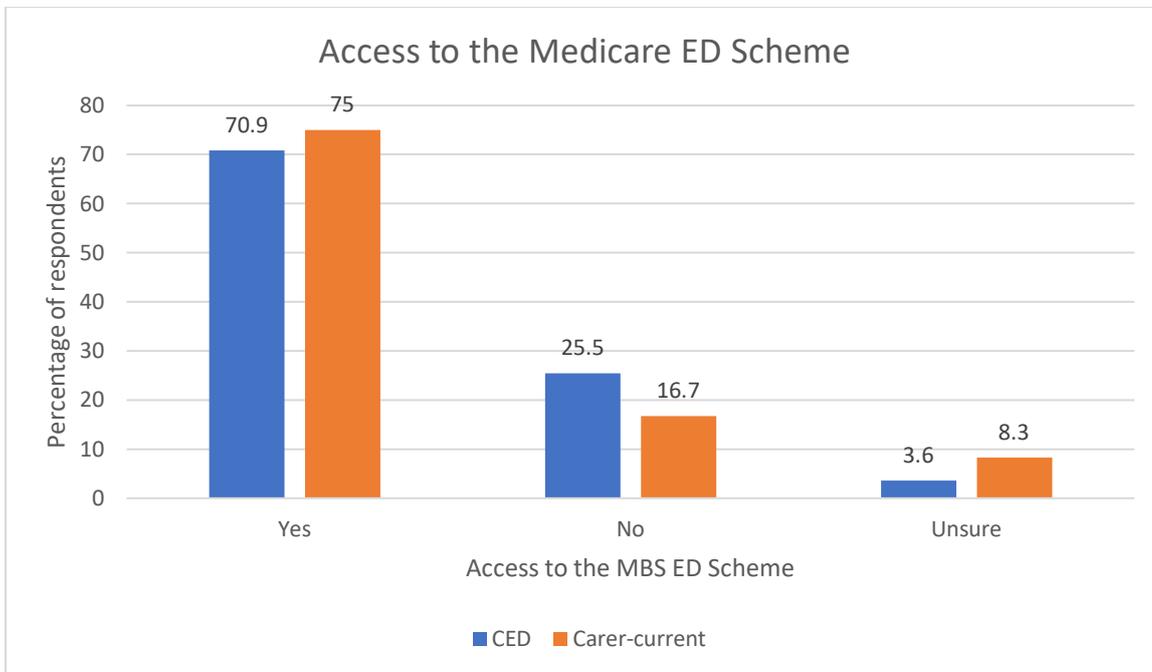


Figure 7. Reported access to the new MBS ED scheme by 'current' (CEDs and current carer)

Experiences of those who have accessed the new Medicare items

1. Referral Source / Source of EDMP

Under the new MBS Eating Disorder schedule only general practitioners, psychiatrists and paediatricians are allowed to provide and Eating Disorder Management Plan. Of those who had obtained an Eating Disorder Management Plan (n=136), they were asked which of these health professionals had completed the plan. From Figure 8 it is clear, the vast majority reported a GP had completed the Eating Disorder Management Plan (93.3%, n=127).

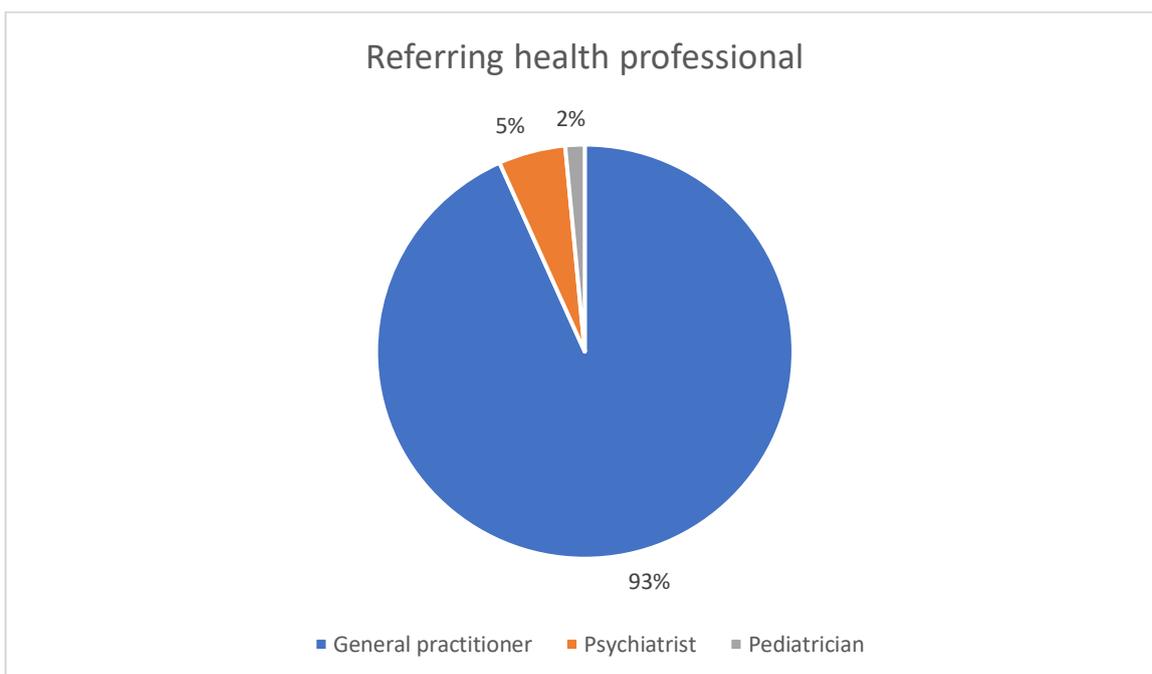


Figure 8. The percentage of respondents who had obtained an Eating Disorder Management Plan from the eligible health care providers.

2. Experience with obtaining the ED Management Plan

Quantitative findings

To gain a greater understanding of the respondents (n=136) experience with obtaining the Eating Disorder Management Plan (EDMP), they were asked to rate the professional who completed the EDMP on four 5 point Likert scales, which were anchored from 'very true' to 'not at all true':

1. It was easy to find a health care provider who was **knowledgeable about the Eating Disorder Management Plans**.
2. My **values, needs, and preferences were respected** in the development of the plan.
3. The development of the Eating Disorder Treatment Plan has helped me to **better understand my eating disorder and treatment goals**.
4. The support I (or the person I care for) received was of **high quality and from a competent doctor**.

Given the small number of psychiatrists and paediatricians who completed the EDMP, meaningful comparison of the experience with the different providers was not possible from the available data; hence data across the three health providers was collapsed.

Ease of finding a health care provider who was knowledgeable about the EDMP

Approximately half the sample (51.8%, n=70) rated that it was 'easy to find a health care provider who was knowledgeable about the EDMP' as 'somewhat' or 'very true'. Just over one-third (35.6%, n=48) rated it as 'somewhat' or 'not at all true' (See Figure 9).

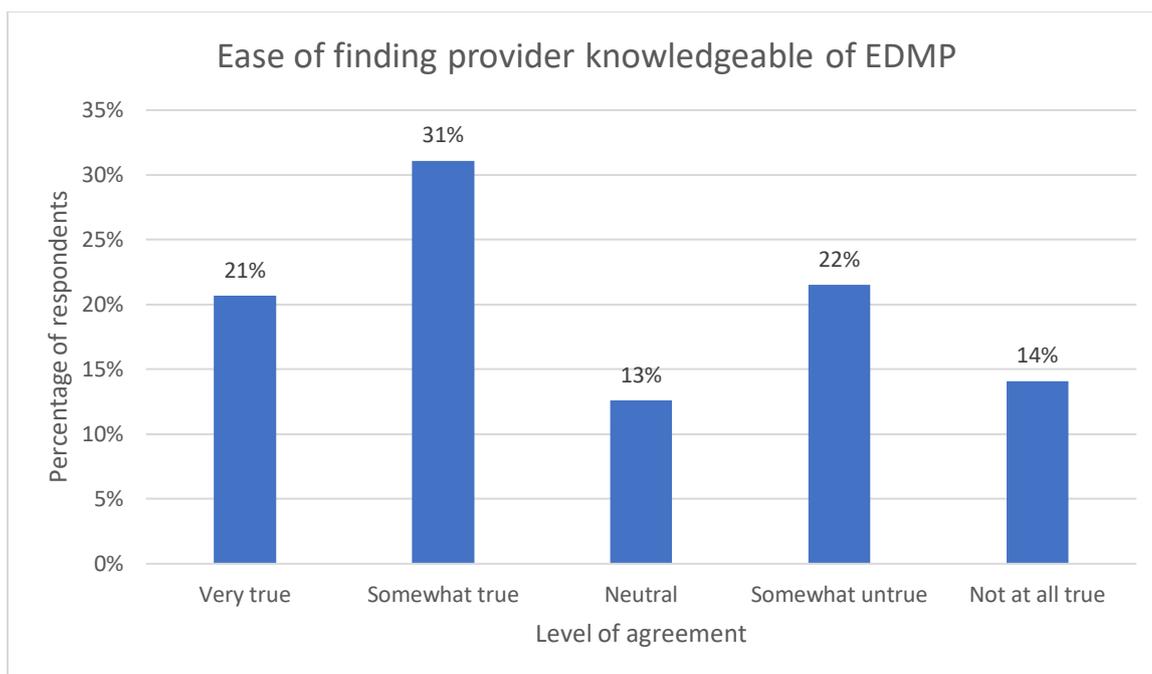


Figure 9. Ease of finding a health care provider who had knowledge of EDMP

My values, needs and preferences were respected in the development of the plan

The vast majority of those who had obtained an EDMP believed their values, needs and preferences had been respected (86.7%, n=117) in the development of the plan. With very few believing this was not the case (7.4%, n=10) (see Figure 10).

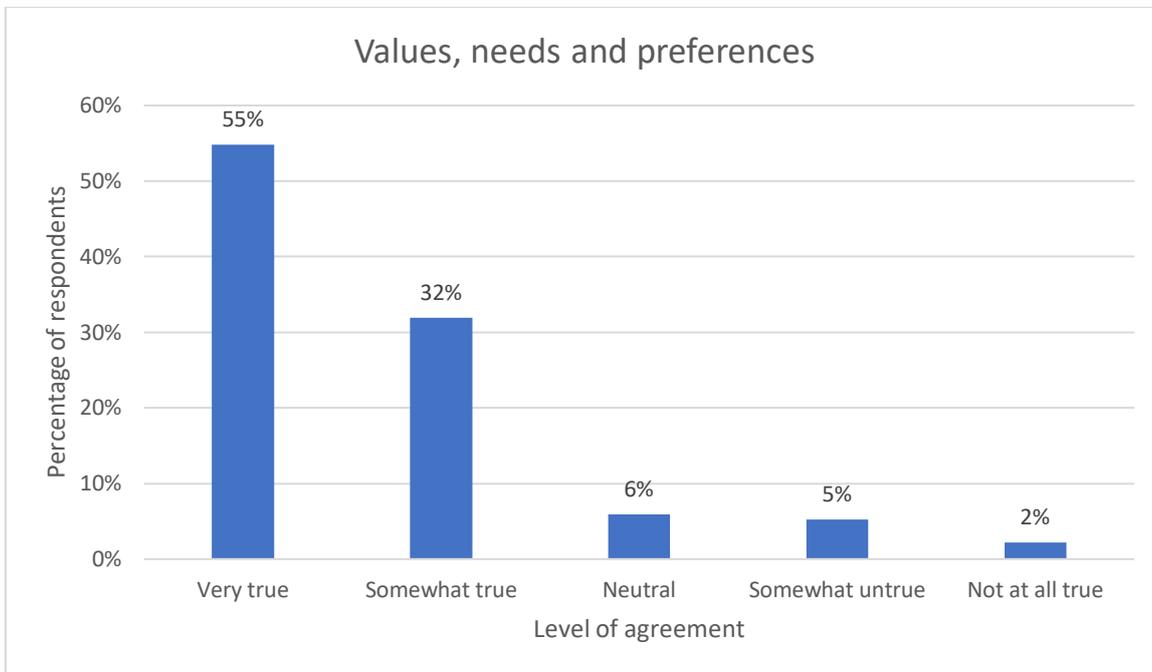


Figure 10. The percentage of respondents who believed their values, needs and preferences were respected in the development of the EDMP

The development of the EDMP helped me to better understand my ED and the treatment goals

A smaller, but substantial majority (60%, n=81) found the development of the EDMP had helped them to better understand their ED and treatment goals. Only 20% (n=26) believed it had not helped them (see Figure 11).

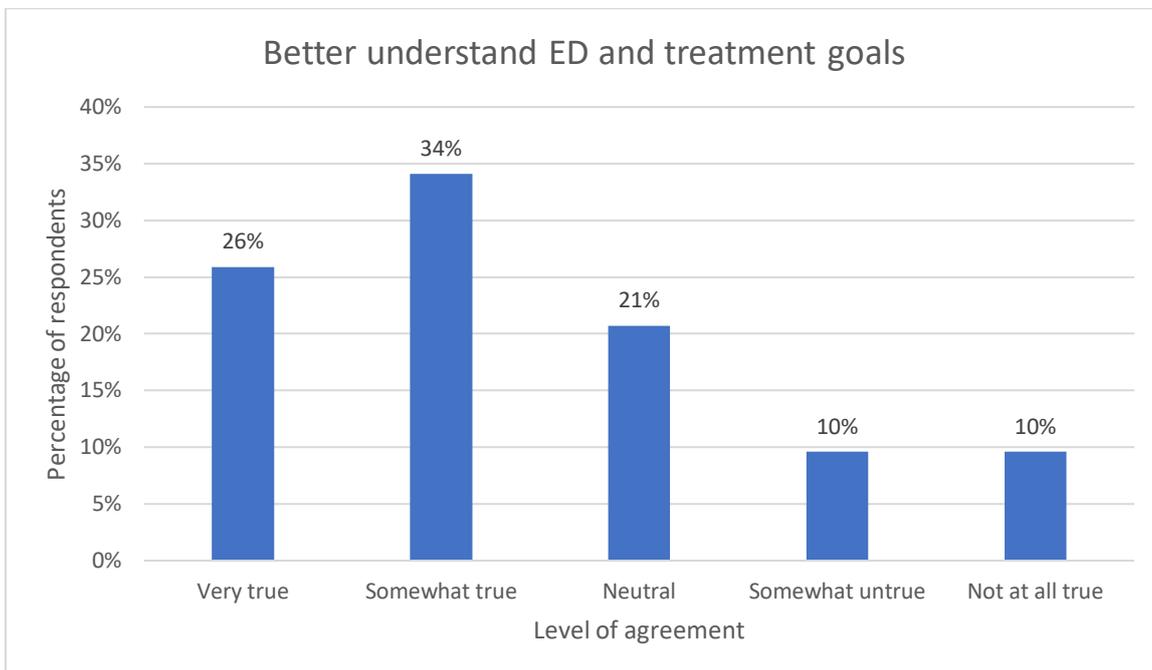


Figure 11. The percentage of respondents who believed the development of the EDMP had helped them to better understand their ED and the treatment goals.

The support I (or the person I care for) was of high quality and from a competent doctor

The vast majority (83.7%, n=113) believed the support they received was of high quality and from a competent doctor. Very few (7.4%, n=10) believed this not to be the case (See Figure 12).

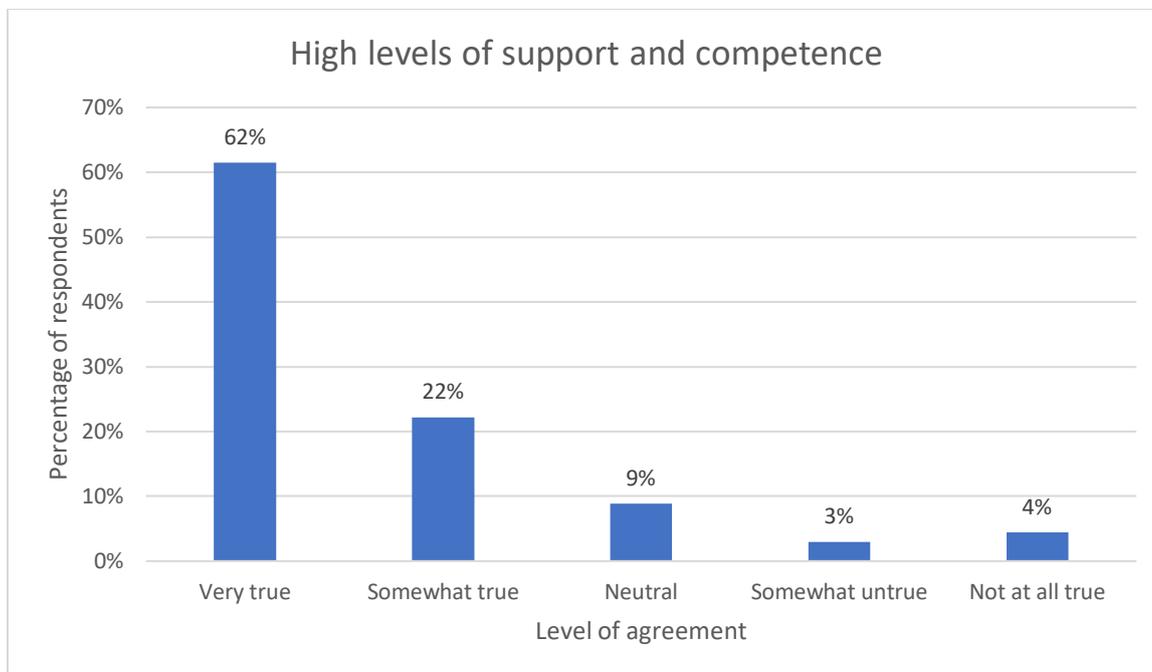


Figure 12. The percentage of respondents who believed the support they received was of a high quality and from a competent doctor.

In terms of 'current' respondents (i.e. CEDs and current carers) there was no significant difference in their ratings of (1) the ease of finding a health care provider who was **knowledgeable about the Eating Disorder Management Plans** ($F(1, 132)=0.247$, $p>0.05$), (2) the belief their **values, needs, and preferences were respected** in the development of the plan ($F(1, 132)=2.34$, $p>0.05$), (3) their belief the development of the EDMP had helped them to **better understand the ED and treatment goals** ($F(1, 132)=1.53$, $p>0.05$), or (4) the perception of the support received being of a **high quality and from a competent doctor** ($F(1, 132)=3.64$, $p>0.05$). There were also no significant differences in the endorsement of these items by the different age groups, or locations where people resided (i.e., metropolitan suburb, regional city etc.).

Qualitative findings

Those who had obtained an EDMP were also given the opportunity to provide any further comments on whether they had on the development of the EDMP.

Has allowed me/the person I care for to get the needed help

Many participants mentioned that as a result of the plan they were able to get the help that they needed either for themselves or for the person that they cared for. The plan for many had allowed them to afford the number of sessions that they required and had been instrumental in their journey towards recovery.

I am very grateful for the new Medicare ed plan, it has helped me so much, I am able to see an ED psychologist regularly and have made so much improvement/progress since November 2019.

The 40 sessions is ... AMAZING. My doctor had no idea what I was talking about but I still got what I needed for the rebates. so it was whatever.

I only started to show real progress when I switched to weekly sessions which was only possible due to ...more Medicare session[s].

Access to an adequate number of affordable Psychology appointments was incredibly necessary and appreciated in fighting toward recovery. Thank you.

This plan is vital & so very much appreciated, it allows us to help support our daughter in her long battle against AN. Such a relief for parents wanting to give their child the best possible chance to recover using more frequent treatment visits.

I feel really thankful to be able to see my psychologist more regularly due to this plan and have been able to link into a good quality dietitian.

This management plan has literally been a life saver for my daughter. We gave been able to access sessions fortnightly with her psychologist which has enabled her to get the support she needed.

The extra Medicare sessions have made a massive difference to me and my family. It's been much easier for me to see my psychologist weekly and dietitian fortnightly now that it's not as expensive. My team has been really helpful in terms of getting the plan. Overall, it's really helped me to make progress.

Having a knowledgeable health care professional helped

Participants commented on the importance of having a knowledgeable health professional who was familiar with the new items. They also mentioned the importance of being able to access a health professional who was knowledgeable about eating disorders.

We are lucky my daughter has a proactive GP who had familiarised herself with the new item numbers and what was required to develop the plan.

My GP is excellent. It was in November when this was all new when she developed my EDTP and there weren't many helpful resources through Medicare to assist her.

I was very lucky that my GP has an interest in eating disorders and had the cheat sheets provided by an eating disorder organisation ready to go.

I benefited greatly from being referred to a competent GP with experience working with people with EDs by EDV.

I started getting help about 4 years ago. It was really challenging finding a GP who was sensitive/caring enough and knowledgeable enough to refer the appropriate actions. I now have a brilliant team. My psychologist was actually the one who referred and pushed for ED plan...her specialty is in the area. Without her knowledge and understanding I don't think it would have been such a smooth and easy process.

Lack of General Practitioner knowledge of plan, how to complete it and eating disorders

Of those who commented, one of the most frequent comments provided by participants with regards to the development of the plan was the lack of knowledge of general practitioners both in terms of the existence of the plan and how to fill it in. Some participants indicated that there was very little information given to providers to help them to understand and develop the plans. Some mentioned having to help their GP's fill out the forms while others spoke of how their GP's had to muddle through and learn as they went. One of the difficulties that participants highlighted was that it was not a set form. A lack of knowledge about the plan and how to fill it out resulted in some participants having to make multiple visits to their GP resulting in delays to the development of the plan. While some of the general practitioners had difficulties accessing the plan and filling it in, other participants suggested that their general practitioners also had very little knowledge and understanding of eating disorders.

GP access to knowledge about the plan.

When I went to get the Medicare plan, the GP had no idea what it was and had to contact 3 other GPs before finding someone who knew about it.

Even my GP who is extremely knowledgeable about mental health and eating disorders really struggled to find the plan and everything. The first GP I went to was terribly invalidating and filled out a mental health care plan instead because she was confused.

All GPs should be given information about the new ED plan as or GP was unaware of the new Medicare plans.

My first doctor didn't know what to do, they charged me for multiple sessions because they didn't know how to find or fill out the application. I changed doctors when I had to get the 10 session review and it was great, they knew exactly what to do and was very helpful. I don't think that the plan was widely advertised as my gp and The whole clinic hadn't heard of it.

My GP didn't know what I was talking about had to find the form and what was involved.

Psychiatrist was very knowledgeable however GP who had to set up was not so knowledgeable and hence it required multiple weeks and visits to put into place. They found it hard to find the form for the application.

My psychologist knew all about it but my GP was hopeless - I had to google the item numbers on my phone during the consult. The extra sessions have been amazing though - I'm the best I've been for 15 years.

I had to print out information from your website as my GP was unaware of it.

Was a very lengthy process with my GP- I am comfortable with GP and health literate so understand the process, but I can imagine for a young person this process could be very draining.

Plans difficult to fill in and understand

Make it easier for doctors to complete.

GPs need greater guidance in developing a plan - my GP clinic had a very hard time understanding what the item included and how to develop a plan in alignment with requirements. There needs to be more information given to providers so they can effectively manage patient needs.

My GP had never completed a plan before, and had to learn as he went.

Maybe educate the GPs more about this and what they need for each set of 10 sessions.

My GP knew about the plan but did not know how to complete the requisite paperwork. He completed it on the wrong template. I then had to go in a second time and coach him through the process.

Unfortunately, I was the first client my GP had seen in regards to the eating disorder plan and she struggled to complete the required paperwork. She was not given any advice from the government about how to proceed. The referrals after every 10 sessions are tiresome and the psychiatrist appointment cost me \$540 dollars out of pocket which is not available for everyone.

I've heard many doctors have struggle with finding what to do as there isn't a set form.

It was my psychologist who referred me back to my GP. It was right as the new numbers were coming out so my Dr muddled through for me but since has got a better handle on it. So she didn't know the detail of how it worked but did not hesitate to learn and do some prep for me because she thought it would be a good treatment for me and it has really helped me.

Doctors need more education about eating disorders

GP poorly educated about Eating disorders.

We need better education for GPs, and for medical students and doctors in training.

My GP is fantastic although I think she has struggled to find lots of information about the process and the best way to treat eating disorders. I think GPs could benefit from more information on how to assist patients.

I am not sure a plan was actually created. My daughter was just provided with a referral to a psychologist and a referral to a dietitian. Both the psychologist and dietitian were booked for 6 weeks. My daughter ended up in hospital before we could see either. Since her stay in hospital we have been looked after by the CYMHS. I am worried about whether or not we will be able to access the funding once she has completed her treatment with CHYMS. From what I have read I have an understanding that my daughter may struggle for many years despite the fact that we have restored her weight. Will we be able to find a doctor that will understand that she has anorexia even though she is no longer underweight?

Recommendation 3: Invest in targeted awareness raising of MBS items among GPs

Given that GPs are the most likely source of referral, Butterfly, other eating disorder organisations and GP professional bodies should work to improve awareness among GPs. Potential interventions include the development of clear step-by-step instructions on how to complete an EDMP, and advertisements and editorial in industry publications.

Required review by psychiatrist pointless, expense and barrier to accessing plan

One participant highlighted that the required review by a psychiatrist was pointless and another spoke about the huge out of pocket cost as a result of the required psychiatrist review.

I think the required review by a psychiatrist after 20 sessions is pointless as they don't have to know you or have seen you before. How can they make an assessment after a single visit?

My GP, dietician, and psychologist have been phenomenal in terms of the plan. However, the psychiatrist who did the review charged me \$580 for the appointment, told me it required a higher fee because it was on the EDP, and used an item number that only gave me \$170 Medicare rebate leaving me significantly out of pocket. She also took over 6 weeks to provide the report to my GP and myself and my GP needed to call and email repeatedly to get the report in time to prevent my access to psychology sessions through the EDP from being cut off.

Have an excellent psychologist and dietitian. GP does not have a clue. There is no collaborative or MDT approach. If you have to get Drs to sign forms there should be collaboration and codes for a team and patient discussion. Having to have a psychiatrist sign the form mid way is a total barrier. My psychiatrist won't let me talk about eating disorders and refused to sign the form as she is not an ED psychiatrist. Other psychiatrists don't have disabled access and refused to see me by Telehealth even with the covid item numbers, other Telehealth services wouldn't see me because I was out of areas. General psychiatrists refuse to fill in ED paperwork and ED psychiatrists won't see people with complex comorbidities and disabilities. It is stupid having to find a dr to sign a form who won't be involved in the treatment of the person. The cost of psychiatrists are also a major barrier and they make no consideration for people who lost their home in the natural disaster and not able to work because they are trying to rebuild post natural disaster. Local mental health teams refuse to see people with eating disorders, if you are going to make a plan requiring a psychiatrist review there needs to be psychiatrists to do the reviews, I can't continue because I can't get a signature and my psychologist says I am more than eligible. NDIS won't cover medical and say I need to get Ed services through Medicare and I can't because I can't get a piece of paper signed for something I am eligible for.

Cost, distance and lack of specialised care

Two participants mentioned that the distance to access a health professional meant that they could not access the plan. Another spoke about a lack of health care providers who specialised in eating disorders in the area in which they lived. For some patients and their carers upfront expenses meant that they still struggled to afford treatment.

There's no psychologists or dietitians within 2.5 hours of me.

Even though the Medicare system allows more sessions, you actually have to find someone who specialises. Living in a regional area makes it hard to access support and the gap payment is still way too high. This service is a start but there's a long way to go to help people living outside major cities.

Extremely difficult to find a psychologist that specialised in eating disorders as well as all the other conditions I required therapy for. Especially in the western suburbs of Melbourne.

It is amazing to have access to so many more sessions with my therapist - however, if I only needed to pay the gap it would help me a lot. My only income is the DSP and I constantly need to use my rapidly depleting savings to pay the upfront cost of sessions. I know the cost of therapy is something many can't afford, even with the Medicare changes.

I am eligible for the Medicare Eating Disorder management plan however I am still paying \$300+ each week for my psychology and dietetic appointments that I am required to attend due to being under a Treatment Authority... I can't afford this each week twice a week and I was promised 40 free psychology sessions and 20 free dietician appointments? Seems like that isn't the case. What's the point of having a management plan when I am still spending a large amount out of pocket each session?

Still out of pocket \$70 per fortnight for psychology appointments even though she returned home from Uni for COVID and appointments are shorter and by phone. Also GP visits are not bulk billed in my rural home town so out of pocket there also. i.e. my daughter with ED is a uni student and doesn't receive Centrelink or has an income so financially relies on family, however we are not privy to info from either GP or psychologist so very left in the dark. She could not afford this treatment even with the extended mental health care plan due to upfront and out of pocket expenses.

Unsure of the eligibility criteria

Two participants mentioned being unsure if they fitted the criteria.

I'm not exactly sure I understand the criteria and worry that I'll gain weight too fast and no longer be eligible for EDTP because I do not require inpatient treatment (I did in the past, but I'm able to maintain stability now).

I just remember being scared that I wouldn't fit the criteria and that I would look stupid if I went to my GP and asked about it but didn't end up getting the plan, my dietitian said that I would fit the criteria but I was still scared.

Narrow access to therapies

For another participant by only offering certain therapies there was a failure to recognise the factors that often drive an eating disorder.

The fact that it HAS to be certain types of therapies completely neglects the fact that eating disorders are the tip of the iceberg of what is usually trauma or something that drives the ed.

ED questionnaire

While one participant was positive about the questionnaire that individuals were required to fill in to access the plan, another perceived it to be triggering.

The use of the EDQ is good as it focuses a lot on thoughts rather than behaviours which I think is really important considering it is a mental illness at its core.

I think the questionnaire required to be completed is very problematic and triggering.

Needs to be tailored to individuals needs

One of the participants mentioned that the plan was too long and intense for someone who was already in recovery.

It was very long and intense. could be trimmed down a little and shortened and accommodate to those already in recovery.

3. Experience/quality of care from psychologists and dietitians

The 64 new items under the new MBS for eating disorders allows up to 40 sessions with a mental health practitioner and up to 20 dietetic sessions of treatment from a certified dietitian over the span of a 12-month period.

In the survey, the 136 respondents who had been able to obtain an EDMP were asked whether they/or the person they care for had seen a mental health professional (psychologist, social worker, occupational therapist) or dietitian – under this scheme.

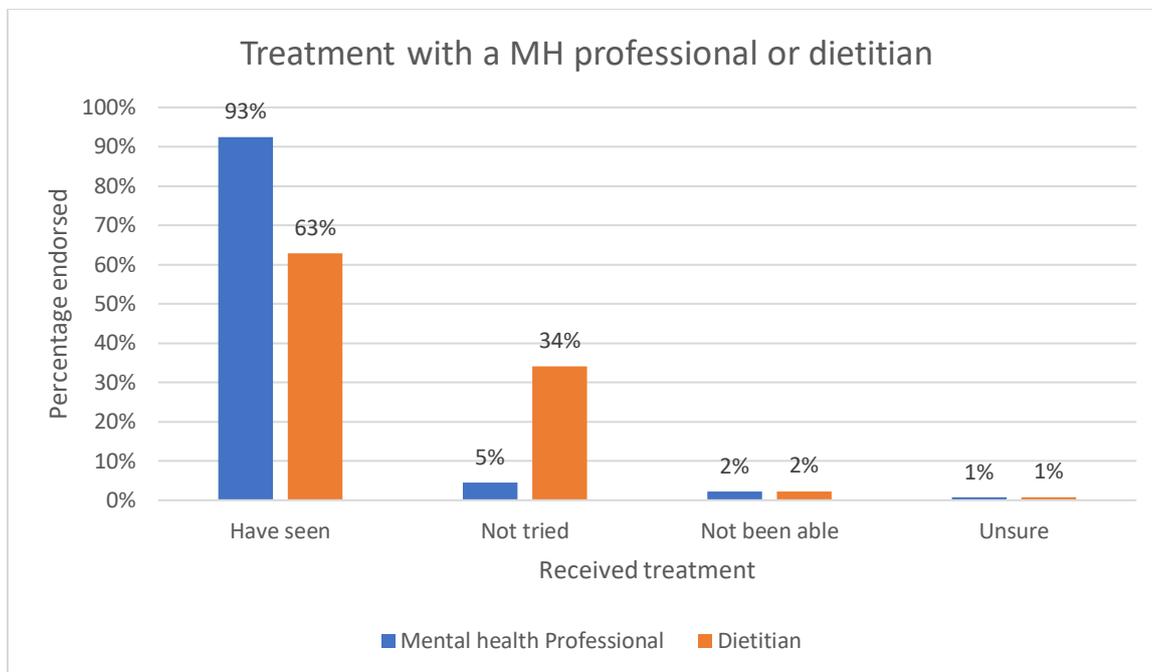


Figure 13. Percentage of sample seeking treatment with a mental health professional or dietitian

It can be seen from Figure 13 that the vast majority of the sample had seen a mental health professional (92.5%, n=124), with a smaller majority having seen a dietitian (62.9%, n=83). Over half the respondents (55%, n=75) had seen both a dietitian and mental health professional under the scheme. Only a very small percentage (2%, n=3) had not been able to get a referral to see a mental health professional or dietitian.

Mental Health Care Professional Experience– quantitative findings

The 124 respondents who had seen a mental health (MH) practitioner were asked to rate their experience by indicating how true or untrue a statement was on a five-point Likert scale. These statements were:

1. It was **easy to get a referral** to a mental health care professional who treats eating disorders.
2. There was a **long wait** to see a mental health care professional.
3. The out of pocket costs to see the mental health care professional were **difficult to afford**.
4. The mental health professional/s were **empathetic and caring**.
5. The treatment plan provided was/is **clear**.
6. The treatment plan provided was/is **effective**.
7. My care was **well coordinated** with **good communication** between my mental health care professional and others on my care team.
8. The support I (or the person I care for) received was of **high quality** and from a competent mental health practitioner.

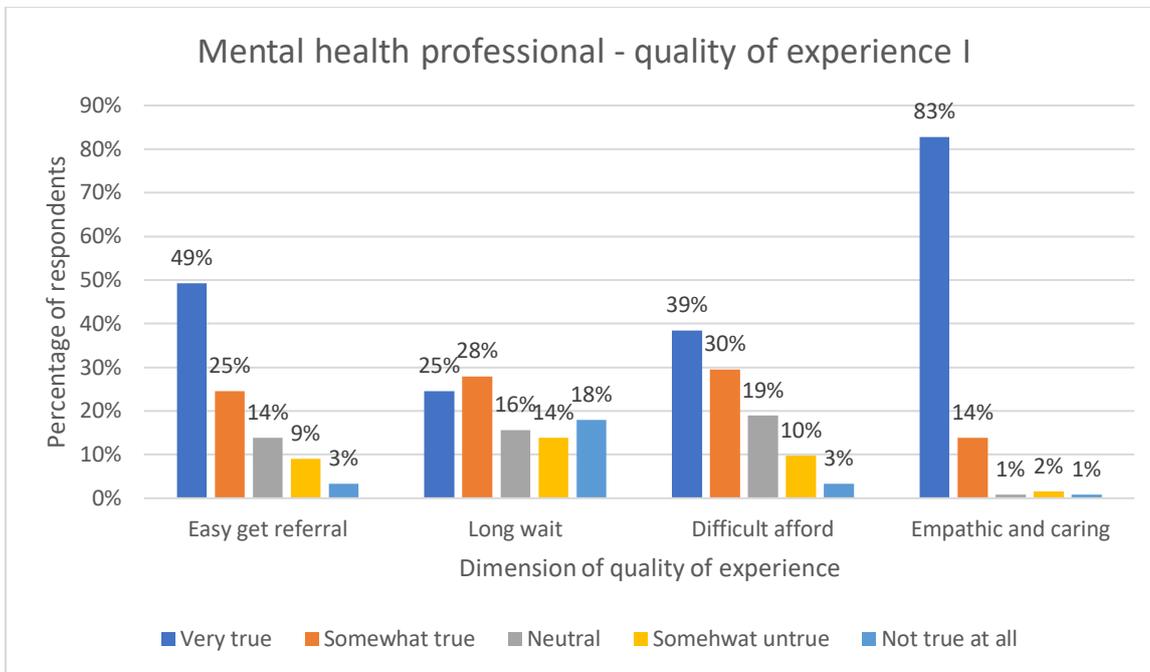


Figure 14. Ratings of the quality of experience - Mental health professional I

From Figure 14 it can be seen that 73.8% (n=90) respondents had found it easy to get a referral to see a MH professional. For just over 50% (52.5%, n=64) they had found there had been a long wait for an appointment and nearly 70% (68%, n=81) had found the out-of-pocket costs difficult to afford. For nearly all the people who saw a MH professional (96.8%, n=118) they found the professional to be empathetic and caring.

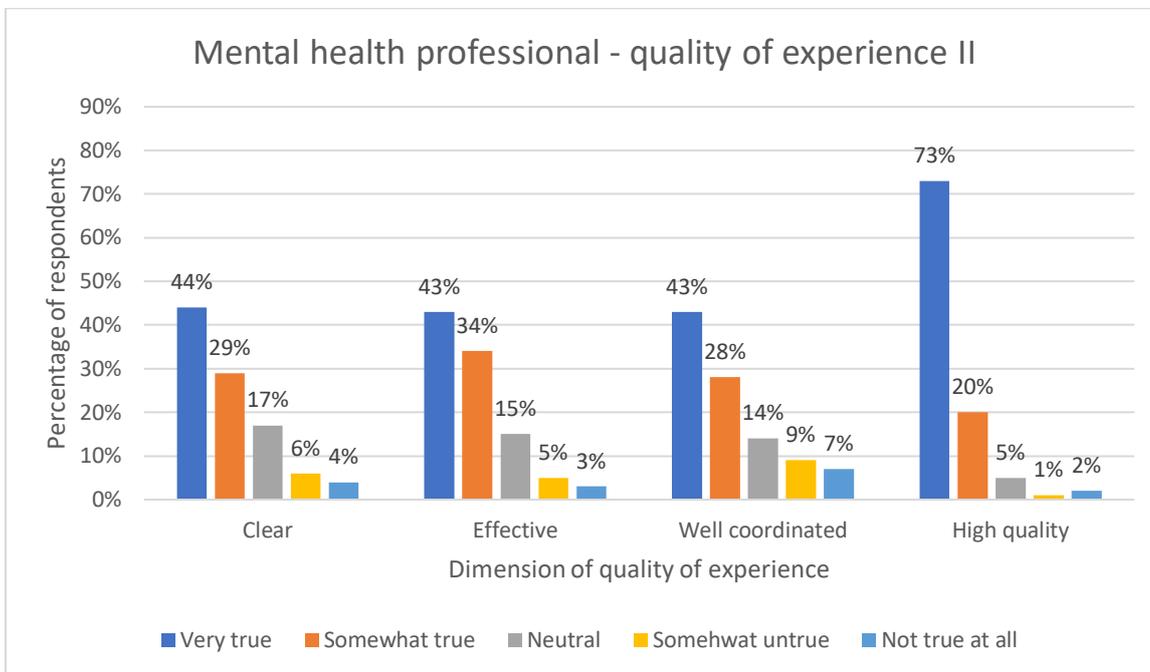


Figure 15. Ratings of the quality of experience - Mental health professional II

From Figure 15 it can be seen that the majority of respondents found the treatment plan they developed with the MH professional clear (73%, n=89) and effective (77%, n=94). They also found the communication and coordination of care with other treating professionals to be good (70.5%, n=86). Overall, the majority (92.7%, n=113) believed the support they (or their loved one) had received was of a high quality and from a competent mental health professional.

Dietitian Experience– quantitative findings

The 83 respondents who had seen a dietitian were asked to rate their experience by indicating how true or untrue a statement was on a five-point Likert scale. These statements were:

1. It was **easy to get a referral** to a dietitian who treats eating disorders.
2. There was a **long wait** to see a dietitian.
3. The out of pocket costs were **difficult to afford**.
4. The dietitian/s were **empathetic and caring**.
5. The treatment plan provided by the dietitian was/is **clear**.
6. The treatment plan provided was/is **effective**.
7. My care was **well coordinated** with **good communication** between my dietitian and others on my care team.
8. The support I (or the person I care for) received was of **high quality** and from a competent dietitian.

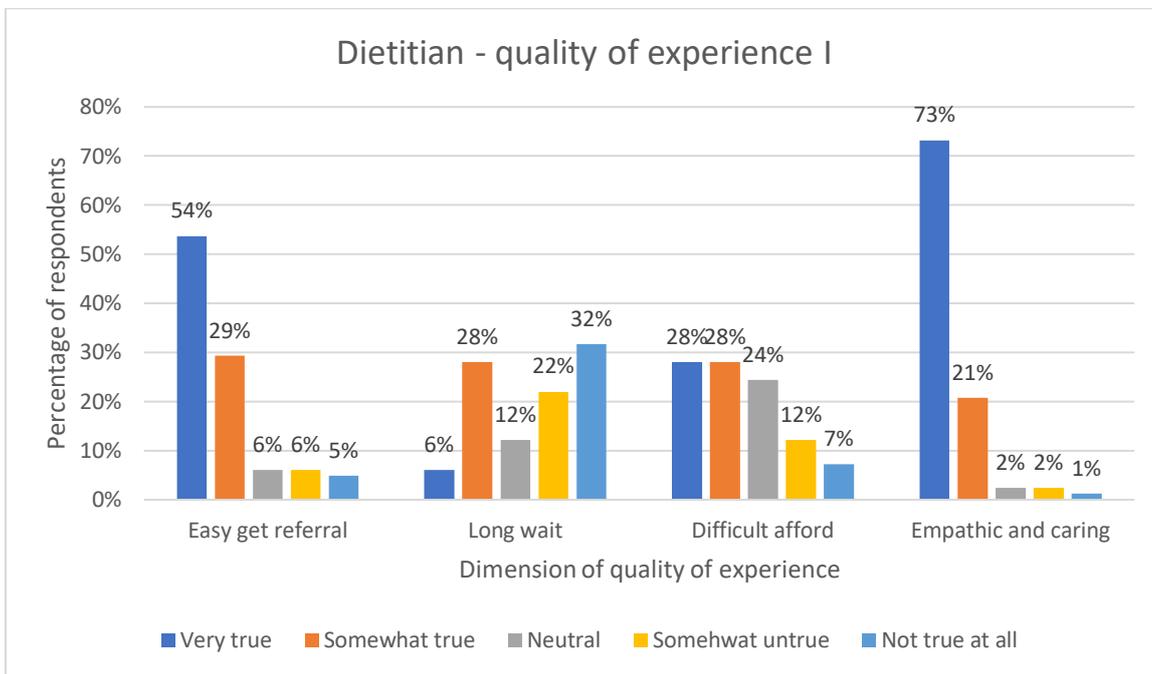


Figure 16. Ratings of the quality of experience - Dietitian I

From Figure 14 it can be seen that 82.9% (n=68) respondents had found it easy to get a referral to see a dietitian. Although one-third of the respondents (34.1%, n=28) found there was a long wait to see a dietitian, the greater majority (53.7%, n=44) did not find they had a long wait. Over half the respondents (56%, n=46) found the out-of-pocket expenses difficult to afford, but overwhelmingly (93.9%, n=77) found the dietitian they saw was empathetic and caring.

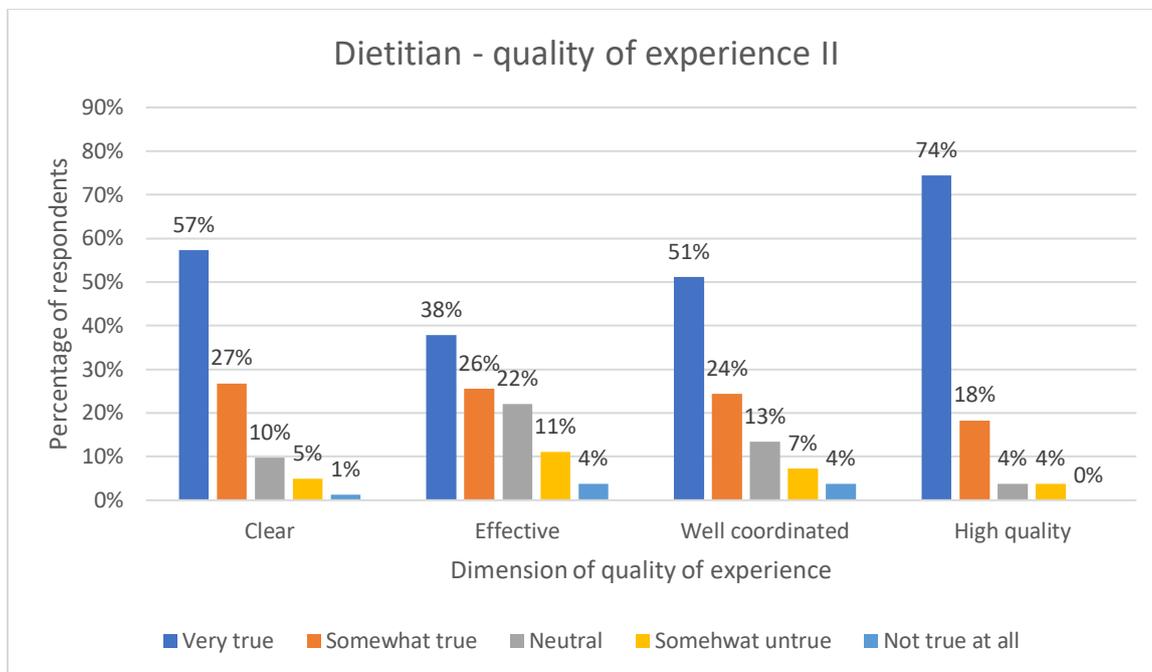


Figure 17. Ratings of the quality of experience – Dietitian II

From Figure 17 it can be seen that the majority of respondents found the treatment plan developed with the dietitian to be clear (84.1%, n=69). Three in ten respondents (63.4%, n=52) found the treatment plan to be effective. Overall, the majority of the sample (75.6%, n=62) were impressed with the communication and coordination of care between the dietitian and the rest of their care team. Just over 90% (92.7%, n=76) of the respondents believed the care they received from the dietitian to be of a high quality and provided by a competent dietitian.

The difference in care: MH Professionals and Dietitians

Seventy-five respondents had received care from both a MH professional and a dietitian. Comparisons using the Wilcoxon Signed Rank Test were conducted to compare MH professionals and Dietitians on the eight dimensions of quality care presented in the previous section. Three significant differences were found on the ratings for MH professionals and Dietitians. Respondents perceived the wait ($p < 0.001$) and the out-of-pocket costs ($p < 0.05$) associated with seeing a MH professional to be significantly greater than a dietitian. However, they perceived the treatment plan provided by the MH professional to be significantly clearer than the dietitian ($p < 0.05$). Keeping in mind, that all the ratings on this last variable were very positive for both classes of health care professional.

Mental Health Care Professional Experience - Qualitative findings

Respondents who had seen a MH professional were also asked whether they had any further comments.

Quality of Care

A number of participants stated that the care that they had received was of a very high quality and that this care had been instrumental on their road to recovery. One participant commented about the amount of research her psychologist did and how her psychologist had tried different approaches. Some participants mentioned that they did not initially receive the care that they needed but found the right health professionals in the end. Several participants already had established relationships with health care professionals, but the plan allowed them to see their health professionals more frequently. One participant stated that the plan allowed her to focus on her treatment without worrying about the expense. Several of the participants had poor health care experiences citing a lack of specialised care and empathy. One participant found the family method too rigid. A few participants found receiving care online/over the phone difficult.

Received great care

The Swan Centre in Perth is great, the staff there are amazing, I have made so much progress thanks to them.

Swan centre in Subiaco, Perth is outstanding for eating disorder treatment. Can't thank them enough.

Excellent HAES psychologist.

I was very lucky to be referred to an extremely competent psychologist several years ago and have been with her ever since. Psychologists who aren't skilled with eating disorders have so much potential to do that (and have done to me) and I think the EDP having key therapeutic interventions provided makes it easier to sort out who is and isn't skilled.

She has literally saved me. She has researched and tried new approaches with me, even doing some treatments usually used for trauma to dismantle some of my ingrained beliefs about myself that started when I was a child. I will never have words for how grateful I am for what she is teaching me and helping me learn about my ED and myself.

I am fortunate to have both an amazing psychologist and GP which has been such an asset to my recovery. I wouldn't be here if it wasn't for them.

Found the right health professionals in the end

We saw four different therapists before we found the perfect one, with excellent skills and a dietician who was amazing.

My daughter now sees a psychologist in a practice that specialises in ED's. We were initially referred to an adolescent psychologist (whom we only saw once) who did not understand ED's at all and basically just told my daughter she needed to go and eat. Practitioners without specific ED experience should be required to refer on whenever an ED is suspected.

The first mental health professional did not identify an eating disorder after 4 visits when my daughter was in desperate need. Once we contacted the butterfly foundation and received a recommended psychologist we were thankfully on the right track.

We have been so fortunate to get a psychologist who is a specialist in eating disorders. We had to wait 8 months to get into her but it was worth the wait. The public psych service was appalling, we had no psychiatrist to oversee medications etc. We are fortunate to be able to afford private sessions. I chose to leave the service and go to a private psychologist and our GP.

Already established relationships

Under the new plan I continued to see the therapist I had been seeing since 2015. It just meant we could try to schedule more frequent appointments to keep progress moving forward.

I was already seeing my treatment team (psychologist, psychiatrist and GP) so I had no trouble accessing ED specialists.

We had an established relationship which we were able to continue. If we didn't, I fear for the outcome.

I was already engaged with my psychologist for trauma work prior to ED diagnosis which meant there were no issues about access and I already had a strong therapeutic alliance with her.

I was already seeing my psychologist who specialises in ED so did not have waiting times etc. but it has made seeing her more frequently MUCH more accessible.

Medicare Plan allowed for a focus on treatment

The Medicare eating disorder plan allowed me to focus and engage in treatment without having to worry about how to financially fund it.

Poor experience – lack of specialised care and empathy

I'm not seeing an ED specialist because of previous poor experiences with such practitioners.

I didn't have a great experience with the psychiatrist and wish I don't have to see her. She prescribed me a dexamphetamine for binge eating which I wound up abusing for the appetite suppressant effect. When I explained, she wanted to prescribe me an anti-epileptic, even though my binge/purge behaviours are only about 1-3 times per week.

The family method was too regimented and doesn't take individual family circumstances into account.

While it was obvious that the mental health care professionals had a good textbook understanding of anorexia, it was obvious that they could not show empathy towards our daughter or family as a whole. The small amount of advice given was rarely useful. We

actually found our best support and coaching came from XX, a mother with lived experience who offers coaching to parents. She is based overseas, therefore we have paid for this service ourselves - no rebates. Without her compassion and wisdom I doubt we would have come as far as we have.

There are very few health professionals who are experienced and skilled in treating eating disorders.

Online health care/telehealth

I am far away so I've had zoom meetings with her. I don't think it's as beneficial as it could be.

I have found it quite difficult to get treatment with Telehealth and I know the professionals have found it hard too.

Barriers to accessing Care

A participant mentioned that a barrier to receiving good care was the lack of funding and support that inpatient services received. Several participants mentioned waiting times to both see professionals and to have their plans reviewed acted as barriers to treatment. For one participant, the psychologist that they found most helpful did not have the right qualifications to be able to provide the subsidised sessions. Travel and cost were also barriers for individuals accessing plans

Lack of funding and support

The service at 4gp inpatient in Adelaide is very underfunded and not much of a help in the end, but it's our only option here. They really need some help financially so the patients have a better chance at recovery. The nurses were overworked and it was difficult to get much support, I experienced a lot of judgment with medication and things weren't dealt with well. I was discharged too early and I went straight back to square one. It's a revolving door there because of the lack of funding and support.

Waiting list

The Dietitian so far has probably been the most valued source of help support & knowledge. Just on a waiting list to access a different psychologist through the ED mental Health plan as the last 7 months was all over the place with the first psychologist that my daughter accessed through the plan. I firmly believe that the best benefits have come from Family based therapy for Eating Disorders so we are waiting for an Appt with a psychologist who uses this method but this will mean travelling again to appointments for 1.5 hours each way.

It was very difficult to find a psychologist who didn't have a months long wait listing and I only got a spot by chance.

For a long time accessing treatment was hard to obtain because of long wait list periods.

I had to wait 5 months to get an appointment with my psychologist.

I waited almost 6 months for psychology. I've been very pleased with the care I've received but it was an agonising wait.

Wait time for review

The tricky bit is the review after 20 sessions as I didn't realise you could do that early. Currently waiting to find a psychiatrist to help get the next sessions.

Health professional not covered under the item numbers

I have seen a regular clinical psychologist for the last two years. He is incredibly helpful and uses a variety of techniques which work for me. Unfortunately he has not completed the appropriate eating disorder courses and is not eligible for the reimbursements. As a result, I have needed to see a different practitioner. Their approach is less helpful for me as it is the typical CBT-E approach to treating eating disorders. During COVID I have been unable to do Telehealth appointments which this psychologist due to appointment availability so I have gone back to see my previous psychologist but as I cannot use the MBS items to see him, I am paying for this myself at \$202 a session. I would have preferred to receive the subsidy to see my previous psychologist while I waited for appointments to become available post COVID.

Have to travel to find a health professional that aligns well

I have to travel 2 hours as the ones close by I didn't find fit well with me

Still not affordable

It is still really expensive to receive adequate treatment – i.e. weekly sessions are a large out of pocket cost.

Dietitian Experience - Qualitative findings

Respondents who had seen a dietitian were also asked whether they had any further comments.

Quality of care from dietitian

Several participants mentioned that they had received excellent care from their dietitian with a few indicating that the care they received had been life changing. One participant commented that they would not have seen a dietitian if it had not been for their ED plan. Another mentioned that their dietitian had made them aware of the plan. A few participants mentioned having poor experiences with dietitians with some commenting that they received a lack of specialised care. One participant stated that it was a waste of time seeing a dietitian. Some participant commented on a lack of collaboration between their dietitian and other health care professionals. For some participants treatment was still not affordable. For one participant, Covid had impacted their capacity to use the Medicare scheme and this had negatively impacted on their eating disorder.

Received excellent care from dietitian

My dietitian is amazing!

My dietitian is fantastic, XX, would highly recommend.

Lived experience too. She's excellent.

Finding a dietitian was tricky, but when we did she was life changing!

She is also amazing. She works out of an ED program and is caring and kind. She is the first dietitian I have seen who is yet to talk to me about meal plans and is working in the same way as my psychologist to break down beliefs around food first. I have been seeing her since January and we are only just starting to talk about specific foods and a new approach to what I eat. It has been immensely helpful.

My dietitian was my first ED specific treatment I received and (not exaggerating) he has saved my life.

Dietitian and the ED plan

I would not of seen one if not for the EDP.

She recommended the eating disorder plan to me.

Poor experience with dietitian/lack of specialised care

In the past, dietitians have been very aggressive with their information sharing and planning, often yelling at me. This is hard for me to cope with and often sends me into a meltdown from the sensory overload.

There are no specialist ED Dietitian's where I live. One was travelling up from Brisbane but that's now stopped. Accessing support is extremely frustrating and people are left in the public health system with high staff turnover and no specialist support.

Needs to be specifically Eating disorder Dietitian

There are almost no dietitians who understand eating disorders. The out of pocket cost is too high.

I thought, for my daughter, that we did not need a dietitian. Most of the information provided was googled right in front of us. Our own knowledge of food and nutrition was enough to get us through. We stopped after 3 sessions as we found it to be a waste of our time. One session would have been plenty.

Lack of collaboration between dietitian and other health professionals

She is great, but there's a big lack of communication between the doctors and her.

There is no treatment plan or collaboration it is more about trying to survive in the most unliveable conditions which has caused a massive relapse in my ED.

Too expensive

Unfortunately out of pocket costs seem to be higher since the introduction of this scheme. I'm in my late 40s and have been diagnosed with severe and enduring anorexia. I have qualifications in nutrition and went to specialist ED dietitian over many years. I found it futile. My fear of weight gain continues to override any support and guidance from a dietitian. I never went back for the second appointment.

EDTP impacted by Covid

During COVID I was unable to use my Medicare EDTP for a month or so because it wasn't covered. If I didn't have savings, this would have greatly impacted my recovery since COVID severely impacted my BED.

Recommendation 4: Continue to engage people with eating disorders and their families and carers

The views of people with lived experience situate administrative data within real world contexts and provide a critical counterweight to clinical perspectives. An eating disorder can be a disempowering experience, and person-centred care that values the individual and understands treatment from the patient's perspective helps tailor care that will support long term recovery. Butterfly recommends that the views of people with current or previous experience of eating disorders continue to be sought in relation to the impact of the MBS items.

4. Overall impressions of new Medicare Benefits Scheme for eating disorders

Quantitative results

The 136 respondents who reported they had obtained and EDMP were asked about their overall impression of the new Medicare Benefits Scheme for Eating Disorders. They were asked to rate on a 5-point Likert scale how true they believed the following statements to be:

1. Overall, the new Medicare Benefits Eating Disorder items were **helpful to me** (or the person I care for)
2. The new Medicare Benefits Eating Disorder items made it easier for me (or the person I care for) to **access support needed for an eating disorder**
3. The **greater number of sessions** provided by the new Medicare Eating Disorder scheme is more appropriate for the care and treatment of an eating disorder

4. The new Medicare Benefit Eating Disorder items have **eased the financial burden** of accessing support
5. The new Medicare scheme for Eating Disorders ensures that all the health care professionals involved are **competent with the care and treatment of eating disorders**

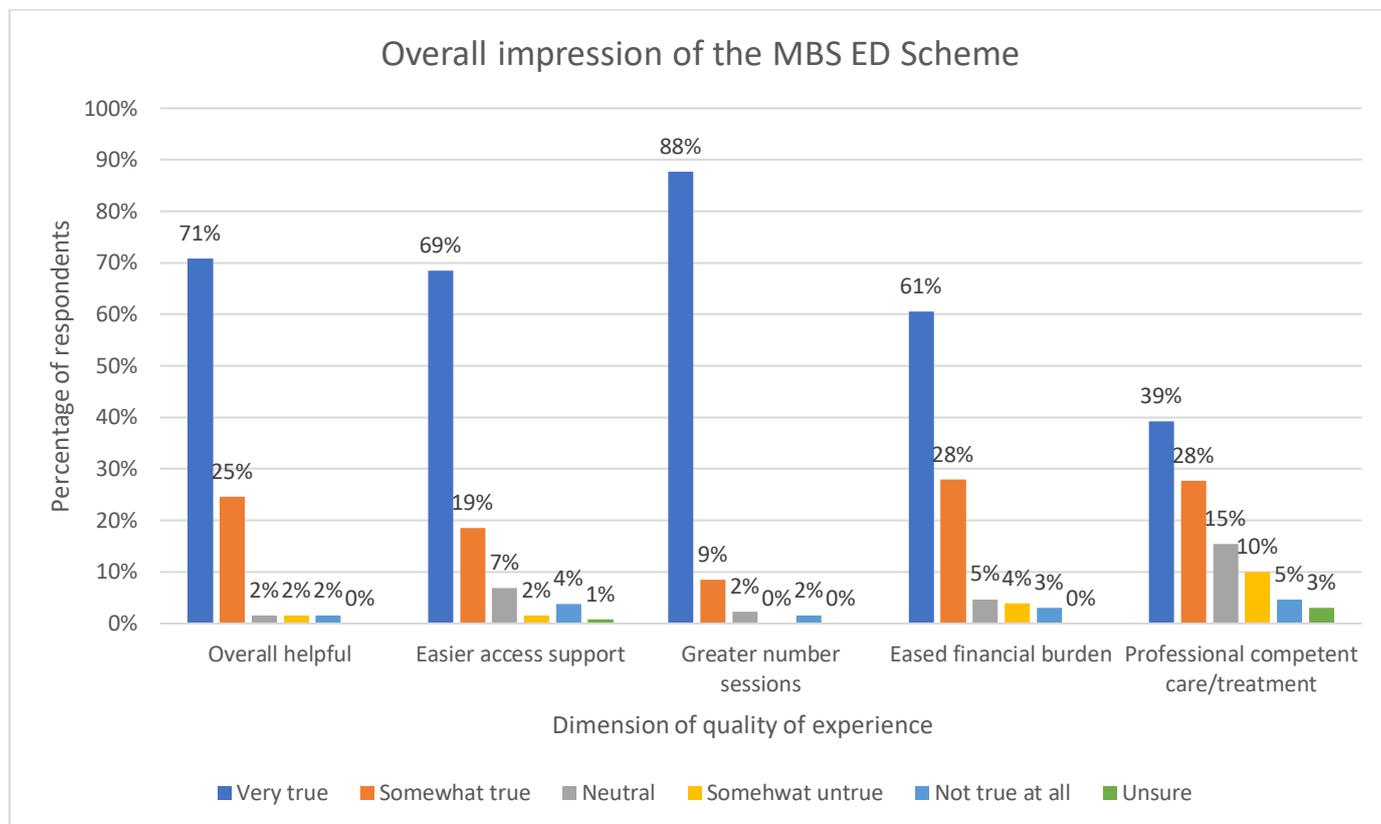


Figure 18. Respondent's ratings of their overall impressions of the new MBS ED Scheme

From Figure 18 it can be seen that 95.4% (n=124) held the overall belief that the new MBS ED Scheme was helpful to them or the person for whom they care. The vast majority believed it had made it easier for them to access the support they needed for an ED (86.9%, n=113), and believed the greater number of sessions provided was more appropriate for the care and treatment of ED (96.2%, n=125). For most respondents it had also helped to ease the financial burden of accessing support (88.4%, n=114). A lesser, but substantial proportion (66.9%, n=87) believed the new scheme ensures that all health professionals involved are competent with the care and treatment of ED. No significant differences were found between the three different cohorts (CEDs, PEDs and Carers) on these overall rating.

5. Improvements to the new MBS ED Scheme

Respondents who had obtained an EDMP were asked if they believed there was any way in which the new scheme could be improved.

Less rigidity around eligibility and what the plan covers

Several participants suggested that there needs to be less rigid criteria around (1) who is eligible for the Medicare Benefits Scheme (2) type of eating disorders and (3) BMI. Participants recommended including more types of interventions under the scheme, covering early intervention and allowing psychologists that have established positive relationships with people with eating disorders to access the scheme regardless of their specialisations. One participant advised setting up a list of eligible practitioners across Australia

Weight and type of eating disorder

Less rigidity and vagueness around eligibility. Example - if I gain to a BMI over 17.5 am I still able to access the treatment, if I haven't been to hospital in the last year? Cognitive work really begins when you gain weight, and not much progress is generally made before a BMI.

Make the criteria include a larger group of people. And not biased to AN.

We were "lucky" that my daughter had anorexia which made it easier to access. The criteria for other eating disorders seemed harder to meet.

Less rigidity around types of psychological interventions

Less restrictions on the models used by clinical psychologists. Access in regional area. I am in mmm3 area which means no Telehealth so I can't access dietician or clinical psychologists who are experienced in eating disorders and there is no one local.

I have been in treatment for 7 years for anorexia and (diagnosed at 16, now 23) and I did maudsley which I didn't respond well to then tried CBT E and other therapies. Finally, I have a psychologist who really understands me, and I am responding amazingly well to treatment. I was so excited for the new MBS schedule to come because although my parents pay and can currently afford it (still a struggle) when I was younger we couldn't afford it and had to make hard decisions. I felt like this guilt would be lifted. However, although I am improving IMMENSELY (I never thought I'd recover but I really am!!!), the MBS doesn't fund the type of therapy that my psychologist is doing, as it only covers the more well known/ typical therapies that I tried and my family wasted a lot of money on because if anything I got worse in the process. I got so upset when I found out that my parents wouldn't, after so many years, have the help that they desperately needed 7 years ago when they really struggled and had to go without other things for something that didn't even help. Now that it is helping, Medicare still can't ease the financial burden because I think I'm doing like schema therapy or a mix of things not listed. I've had weird relationship with food even in kindergarten so I need therapy that goes pretty deep to childhood issues. I have been able to see a dietitian under it which has been great as therapy plus dietitian was too much to afford so we'd have to choose, but my dietitian has worked so well with my psychologist and GP. So in theory it is a GREAT scheme, but I just wish that it covered more types of therapies - if I did the ones it did cover it would be a waste of money, and I wouldn't want therapists feeling restricted to delivering particular types of therapy even if they don't think their client will respond well.

My psychologist doesn't specialise in ED's, but is fantastic. I can't use the MBS scheme with my psychologist because of the specified ED interventions required. It would be great if there were some flexibility/adjustment to allow a psych to be utilised under the scheme as a part of a treatment team (ie My dietitian specialises in ED).

Early intervention

The criteria to be eligible is very narrow and doesn't cover early intervention effectively

Provide a list of eligible practitioners across Australia

Providing a list of eligible practitioners across Australia for clients to access (psychologists, dietitians etc) to enable people to search for appropriate specialist care within their geographical location.

Need more sessions

A number of participants stated that the scheme needed to include more sessions with one participant commenting that one year was not enough to recover. A participant suggested that if required, the individuals should be able to access a repeat plan.

I anticipate for many people more sessions would be useful. I'm 6mths into my treatment and the end isn't in sight. The idea of the looming costs after I run out of Medicare funding is terrifying and daunting.

I'm likely to relapse if I don't have affordable and extensive therapy (which the new scheme has been provided - I'm extremely grateful, and have been able to move out of the public system and see specialised private clinicians!) because I hate gaining weight etc. - and with that added pressure of having to have a CURRENT AN diagnosis (which I assume means a low a weight), it makes it even harder to gain weight. I feel trapped. I don't want to go back to 10 sessions a year, I'll probably just end up back in hospital and the stuck in the public system and waste my life! Thanks for listening.

I know it seems absurd, but more sessions. I see a clinical psych 4 times a week and it's still an insane financial burden.

More sessions and less gap.

More appointments. I need to see a psychologist weekly due to the severity of my illness but it isn't enough on the plan.

Greater number of sessions or the ability to have a repeat once the EDP plan has reached the maximum number of sessions.

More sessions. GPs should offer it more.

More sessions with a dietician - these sessions have helped me more than my psychologist sessions, I wish I had more.

52 sessions would be great

Please continue it as one year is not long enough to recover.

Less gap in expenses

Numerous participants commented that treatment was still not affordable, with a number suggesting reducing or eliminating payment gap. Expenses appeared to be particularly high for dietitians. One participant suggesting making it easier for people to claim their expenses back.

It could be 100% rebated, no gaps (bulk billed) and include GP visits.

Actually making payment affordable.

The out of pocket costs are too high. There is no check on whether the professionals actually have the skills and experience.

Out of pocket gaps are still significant. The increased number of appointments available is amazing, but it also means more out of pocket that is challenging at times.

My experience has been that those psychologists who are eligible to provide the MBS subsidised sessions tend to charge a lot more (\$245 a session vs \$202 for my regular psychologist). This means that I am actually financially worse off per session in accessing care under the new scheme.

Smaller out of pocket costs/increased coverage. Medicare only covers half the cost of a session with my psychologist and with fortnightly treatment required, the costs are extremely high for a full-time student.

It still leaves me out of pocket \$116 per psych session which I have every week right now, plus having to go to a GP who specialises in ED for medical checks leaves me \$70 out of pocket and I have not yet accessed dietician rebates. So obviously the more medicare can cover the more people will be able to get help. I know without this Medicare scheme I would not have been able to access help but even then it is still financially difficult.

Higher rebates and more effort to get specialists into regional areas. Not everyone likes online consultations and they're still to expensive. Some Dietitian's are charging \$250 with only a \$50 rebate. How can anyone who is in need of weekly support supposed to afford that?

Seeing a dietician has been one of the most important things for me and my recovery but also the most expensive and least supported from the MBS items - I have had to stretch out my sessions a lot to afford them potentially impacting the rate of my recovery and it has been challenging to support myself in between sessions when I am not able to follow the plan. However I am grateful for any support and wouldn't have been able to access any appointments without the MBS.

Less dietician costs.

Lesser dietician costs.

More subsidised sessions. It's around half the amount needed.

Very low benefit available to see a dietician. Out of pocket expenses are \$140 each session, this is very high.

Make it easier to claim expenses back.

Can be difficult to claim as you have to manually lodge it through Medicare/myGov app but otherwise it's great.

More expedient reviews and less wait time

Participants suggested more expedient reviews and more oversight over how much psychiatrists charge for the reviews

Time, the speed in which referrals and reviews is a long time when in the midst of it all.

Having a review with a psychiatrist, if you aren't currently linked in with one can be a huge barrier, as many who specialise in eds have extensive wait lists, which often means paying out of pocket until the review can be done.

Smaller wait times (probably out of Medicare's control).

Greater clarity around item numbers particularly with regard to the review by the psychiatrist or pediatrician. Also, greater oversight of psychiatrists who do reviews to ensure they are not over charging and are providing the relevant report in a timely manner.

Need more awareness of the plan and how to complete it

Several participants commented that health professionals, particularly general practitioners need to be made more aware of the plan and be provided with more education on the steps required to develop the plan. Participants also suggested making sufferers and their carers more aware of it. One participant suggested that the plan needed to be more streamlined. Two participants stated that the questionnaire used to get the plan should be revised with one stating that responding to the questionnaire was a time consuming and emotional process.

Raise awareness about the scheme

Educate GPs on the scheme. The Dr we saw had to google everything when we needed the plan.

Have more GPs aware of it because a lot of them didn't know it even existed.

I think it just needs time to be better understood by both clinicians and suffers.

More awareness about the scheme by GPs.

Ensuring all GPs are aware of the new plans.

treatment providers can explain it, it would be good if we could access that information ourselves or be able to share it with others more easily (e.g. my family).

More knowledge around how to complete the plan

GPs to have a great knowledge of the processes - I had to go back to my GP twice as she wasn't sure of what to provide my psych and dietician. Without the support of a knowledgeable psych around this, and being in the right headspace to have motivation to change, it could have been really defeating.

Overall great but could be improved with improved clarity re developing plans, difficulties getting specialist review due to costs and wait lists, very restricted "content" as to what can be discussed or worked on when billing under this MBS number as ED treatment is not a one size fits all.

make it easier for GPs to set up.

The ease of reviews and issuing of the plan can be confusing.

Training for GPs so they understand the scheme.

GPs did not receive adequate training about it. Also, just because you got more sessions (which is amazing) didn't make it more affordable because the rebate was less than on a mental health care plan. Very few people have \$100-\$150 out of pocket that they can spare to see a psychologist every week/fortnight.

Needs to be more streamlined.

Less messing about with referrals to make it more streamlined. Too much organisation between doctors to get the right Medicare numbers etc.

Implementation of the plan/questionnaire.

The process of applying for it and the questionnaire should be revised.

It can be hard to find the time to see my GP to access each 10 sessions in the plan - the Psychologist should be able to have the power to do so. Also, the initial questionnaire / screening for EDP was very time consuming, emotional process and the process should be explained better to the consumer before proceeding (especially for young people). There should be a larger rebate per session - I still have to pay a large out of pocket cost each week and I am lucky to be still employed and able to finance this - for many this may not be an option.

More collaboration between health professionals

A few participants commented that there needs to be more collaboration and communication between health professionals to make the plan efficient and affordable.

Better comms to GP, psychiatrist etc about the stepped plan. I'm still trying to get the correct coded consult for my psychiatrist to review my original EDTP laid out by my GP.

Remove gap payments have psychiatrists who are able to sign the form and have collaborative team meetings where there is a plan, there is no communication between anyone. It is not cheaper than before because treatment means there is a gap no treatment is obviously cheaper.

Plan was great

Two participants said that the plan was great and it had been life saving for one of the participants.

I think it's great as it is.

It's life saving. If it had been around when I got really ill, I'd NEVER have gotten to such a terrible place. With Covid this year and a slight pay cut, I'm SO grateful. This is easily the best mental illness care plan in the world. I really feel like I can fully get my brain back and I am SO LUCKY to have this opportunity.

6. Feedback about the new MBS item number for ED

The 136 respondents who had been able to access an EDMP were asked if there was any further feedback they would like to provide on the new Medicare Benefits Item numbers for EDs. Twenty-six (19.1%) provided further comments.

Eating disorder plan has been a life saver

Numerous participants commented on how the Eating Disorder Plan had provided them with the help they needed and had allowed them to access better treatment. One participant stated that when the announcement was made there would be a Medicare subsidised scheme for eating disorders that they felt hopeful for the first time in the 27 years of experiencing an eating disorder. A few participants commented that the plan had allowed them to focus on their recovery instead of being stressed about the financial burden of getting treatment.

The EDP has been a life saver. Without it i would be unable to access treatment and potentially wouldn't be alive today. It's an essential.

It's fantastic we are able to access the help we need, in South Australia we need more help with eating disorder treatment. The public system needs funding.

Please keep!!!

This new scheme has provided me with the support I really needed and could never have accessed before. I'm forever grateful. I just hope I can keep accessing treatment until I'm truly ready, without it being cut short.

I cannot express enough how much it changed my life.

The additional sessions provided have honestly been lifesaving, I can now access sessions ongoing without having huge out of pocket expenses which has previously put strain on my mental health.

Fabulous that this now exists for us so that we can better access treatment.

Additional psychologist and dietician sessions under the new scheme have really helped me. I have had treatment in short spurts for so long – I've been living with AN for 27 years and I feel like now that I have consistent access to a psychologist I am making better progress than I ever have before. It is such a relief. I cried the day they made the announcement to say that there was going to be additional funding. I felt hopeful for the first time.

Thank you for making this possible. affordable, accessible and holistic.

Allowed me for a focus on recovery without stress about the financial cost.

Thank you to butterfly and the Aus. government for implementing these changes. It has helped enormously and has lifted a huge weight off my shoulders. Its stressful enough getting treatment without the added financial pressures and its helped ease that.

It has allowed me to engage and focus on my recovery from anorexia without having to worry about the financial burden. Previously I had to limit or cancel sessions with health professionals as I was unable to afford them which meant that my recovery was always stopping and starting.

People with eating disorders require ongoing support

Some participants expressed a concern that the subsidy might be cut off prior to a person being fully recovered.

This is so important for people to be able to access the services they need. Mental illness is a complex issue not solved in 10 psychology sessions. It requires coordinated and ongoing support from a range of professionals. So it has been life changing for many.

It has been really helpful for me. I have a couple of concerns though. My diagnosis is AN so I got it easily. It worries me that it is otherwise severity based in the sense that if you don't have AN then you have to be very sick to get it. Since one of the criteria is weight, as someone who knows how eating disorders think, I'm worried that people will lose weight in order to be able to access the support. I'm personally worried that now that I'm weight restored and doing better, that I may not have access to it for as long as I need. Mentally I still have a very long way to go and I feel like I still need the same amount of support to maintain my progress and may need it for some time. I'm worried that since I no longer fit the diagnosis of AN in terms of weight, that I might not be able to continue getting the same level of support, and that if I don't I might go backwards. Although I have a very good treatment team who will hopefully make sure I can still have it if I need it, I'm worried that other doctors, who maybe don't know eating disorders as well, may not recognise the need to have the same level of support after weight restoration. The actual scheme doesn't have any definition as to what is considered recovered. Given how it requires eating disorder sufferers without AN to be very ill to get it, it seems as though it will cut off when you get a bit better but are not actually recovered. It is just very unclear, which means that it's up to the practitioners to decide and that may mean some people don't get the support that they need.

More incentives for specialists to practice in regional areas

A couple of participants suggested that their needed to be more incentive for specialists to practice in rural areas and that there needed to be quality control over the specialists that did practice in rural areas.

It's ok for the government to provide the financial support but there needs to be more incentives for specialists to practice in regional areas. There aren't enough inpatient beds and people with ED's are stuck in the public system's general mental health units and that isn't helping.

I am as a parent very grateful to this scheme, however with the nature of eating disorders and the sometimes length in duration the financial burden is still extreme. What frustrates me is more the fact that there is no quality control with the psychologists that say they can treat eating disorders. From a regional area we are about to go back and see the very first eating disorder treatment team that we were referred too 2 years ago. My daughter has since seen 3 others in our regional area who have wasted our finances in saying they could treat eating disorders and yet they do not consult back occasionally with us the parents to so we are all on the same page. This is very frustrating as there has been no improvement in the eating disorder and the work that has been done by the Dietician is not backed up with the help from the psychologist. So we are now on a wait list to go back and see the original Psychologist that ever accessed but will need to travel to do this. This need to change psychologist was backed up by the Psychiatrist who we also had to access to get sign off for the extra visits to the extra visits to the psychologists on the plan.

Need the rebate to be higher

Rebate should be higher - at least \$150

Include other allied health services

Inclusion of other services like exercise physiology may be beneficial.

Need to upskill GP's to make sure people get this program.

I do feel like unless gps have a personal interest in this program then there is very little support for them to know how to use this plan correctly. My dr struggled to get up and going with it, and had it not been for my psychologist suggesting it, I wouldn't have known to ask. It was at the start of the scheme so hopefully that will change, but upskilling GPs in this area is still a huge gap in my opinion.

Barriers to Access

Fifty-three respondents who were aware of the new Scheme but had not been able to access the new MBS scheme were asked to nominate what, out of a list of factors, had stopped them from accessing the scheme. The factors included:

1. I (or the person I care for) am being cared for as an **inpatient** in a hospital
2. I can't find a doctor who can provide me (or the person I care for) with an Eating Disorder Management Plan (**referrer**)
3. I **don't know how** to gain access to these new Medicare Eating Disorder treatment Item numbers
4. I do **not want/ need** support at this time
5. I am **wary** of accessing support due to negative experiences with health professionals in the past
6. This scheme was **not available** when I (of the person I cared for) was experiencing an eating disorder
7. I am **no longer suffering** from an eating disorder

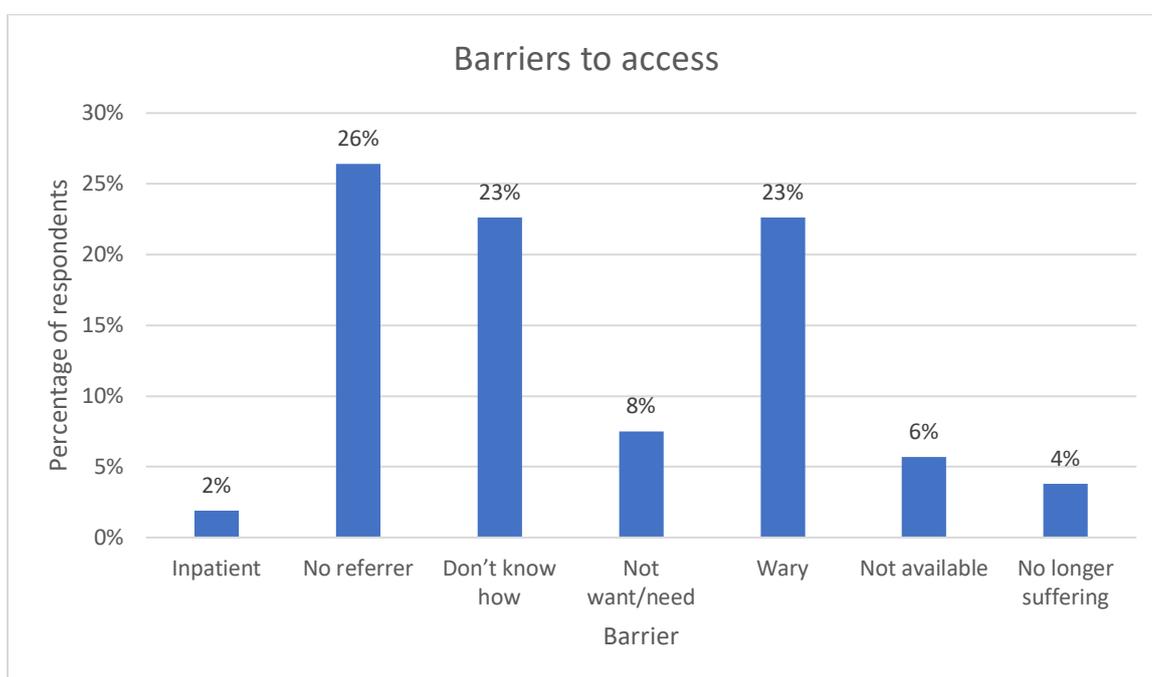


Figure 19. The percentage of the sample (aware of the new MBS Scheme) identifying barriers to being able to obtain an EDMP

The barrier most frequently identified by respondents who had not been able to access an EDMP was the inability to find a doctor who could provide them (or the person they care for) with an EDMP (26.4%, n=14) (See Figure 19). 'Not knowing how to gain access to the new MBS Scheme' (23%, n=12) and being 'wary of accessing support due to past negative experienced with professionals' (23%, n=12) were the next two most frequently endorsed reasons for not obtaining an EDMP.

The respondents were also asked where there were any other reasons for not obtaining an EDMP. Twenty-eight respondents provided other reasons, which have been summarised below:

Still not affordable

Several of the participants commented that even with the Medicare rebates that the cost of treatment was prohibitive.

Even with the Medicare rebates I still can't afford to pay for treatment.

Can't afford the treatment as they require full payment which is 3/4 my income.

There was still a gap payment per session and i couldn't afford that.

Still significant out of pocket expenses too see most psychologists who have ED experience.

I can't afford to pay the extra amount charged by psychologist and dietician. The Medicare rebate doesn't cover it all and I would be out of pocket \$110 per session which adds up to \$4400 for 40 sessions.

Doctor unaware of how to/won't develop plan

Another reason several of the participants had not accessed the plan was either because their GP was unaware or did not know how to develop the plan. One participant's GP would not develop a plan as they did not think the participant had an eating disorder and another GP perceived it to be a waste of time to do the training to get the extra sessions because the participant was his only patient with an eating disorder.

My doctor doesn't know how to provide me with the eating disorder plan

GP unaware of it.

After speaking with EDQ, I informed our GP of the plan. Unfortunately the GP, her nurse, her practice manager and her admin staff have had a lot of trouble understanding how and where to get the information and template from. I sent them several emails with attachments and even put a lot of info together myself but it took months for them to get the paperwork sorted out. I ended up paying over \$1000 for psychologist appointments for my daughter while she was waiting to be interviewed for a public outpatients FBT program after leaving hospital. I am now too exhausted and confused to ask whether the GP clinic has it sorted out. I think they might now because the dietician hasn't mentioned it to me again.

My daughter's GP hasn't done the required training to access the extra appointments. He said as she was the only patient he sees with an ED that he wasn't going to waste his time doing it! I was furious!!

My long term GP was unable to work out how to complete the plan.

My GP won't give me one as he doesn't believe I have an eating disorder due to my weight.

Don't meet the criteria

Three of the participants mentioned that they could not get a plan because they did not meet the criteria. A further two participants could not get a plan because their psychologists did not meet the eligibility criteria.

I do not meet the strict criteria to access the plan.

I am not deemed to be suffering severely enough.

Condition is not 'severe' enough to meet the requirements of the plan - more psychological at the moment rather than engaging in restrictive behaviour so I'm not in 'crisis.'

Psychologist not eligible to claim.

My psychologist who I have long term relationship with isn't eligible to claim.

My psychologist does not qualify as a specialist.

Finding the right professional

Participants mentioned that they were unable to find health professionals who specialised in eating disorders, one was looking for a new psychiatrist and another was unable to find a psychologist and dietician that would bulk bill.

There's no professionals nearby that treat eating disorders.

Looking for a new psychiatrist.

Unable to find psychologist/dietician that would bulk bill alongside the EDMP without an gap payments required.

Currently on a waitlist or in the process of developing a plan

One participant was on a waitlist and others were in the process of completing the plan.

*I have been unable to find a suitable clinician and am currently on a lengthy waitlist.
A few hiccups with the referrals and billing numbers. Hoping to sort through it.
I am looking into accessing treatment under this new plan.*

Found the paperwork required to do it triggering

I found the paperwork involved triggering to complete, so couldn't be accepted.

Fear of workplace discrimination

Wary of accessing due to potential discrimination at my workplace in relation to opportunities

Have other funding

I have NDIS funding which covers the full costs of my psychology appointments.

Assisting people to seek support using the new Scheme

Respondents who had not obtained an EDMP were asked if anything would have assisted or encouraged them to seek support using the new Medicare Benefit Scheme for ED.

Finding a GP that understands eating disorders

Several participants suggested that having a general practitioner who understood eating disorders would have encouraged them to access the new Medicare Benefits scheme. A participant mentioned that feeling shame had prevented them from telling their general practitioner about their eating disorder. A few participants also found it difficult to find a psychologist who specialised in eating disorders who was taking new patients.

Being able to see a gp that understands eating disorders. I've seen a few that made me feel uncomfortable because of their comments during a consultation. For this reason I'm very caution to reach out to a gp and get referrals that I actually need.

Medical professionals that don't just focus on the strict physical criteria that is seen in the Medicare benefit scheme. I'm scared of I ask about it I'll be laughed at and won't be considered sick enough.

A more knowledgeable GP on eating disorders.

A GP who understood eating disorders would have helped. I went to 2 different GPS. One attempted a referral to a psychologist. I saw her twice and she recommended I get another referral for someone specialised in the area. That same gp then said she didn't "feel comfortable" making the referral as she openly admits she doesn't understand. The next gp attempted to refer me to a psychologist recommended by the Butterfly foundation but the gap payment has made this impossible for me. I'm too disillusioned to keep trying only.

Not feeling as much shame in asking for help or telling your doctor you need help with your eating disorder. And also more availability of psychologists to see that specialise in eating disorders. I immediately get disheartened as there is no one who can fit me in or will be able to see me as a new patient.

Finding more evidence based treatments

More efficacious treatments and stronger evidence base.

Conclusion and discussion

A total of 237 respondents who completed the survey had lived experience of an eating disorder or were carers. They were almost all female, identified as Australian and most lived in a metropolitan suburban area. The participants were divided into three cohorts:

1. Individuals currently experiencing an eating disorder
2. Individuals who have previously experienced an eating disorder
3. Carers of individuals who have/had a lived experience of eating disorders

Respondents who previously reported experiencing an eating disorder, were significantly less likely to report receiving a diagnosis from a health professional than those who were currently experiencing an eating disorder.

Just over 95% of those respondents who were able to access the EDMP held the overall belief that the new MBS ED Scheme was helpful to them or the person for whom they care. The vast majority believed it had made it easier for them to access the support they needed for an ED and believed the greater number of sessions provided was more appropriate for the care and treatment of ED. For most respondents it had also helped to ease the financial burden of accessing support. Some commented that the plan had been instrumental in their journey towards recovery.

Just over half of the people who accessed the EDMP found it easy to find a health provider who was knowledgeable about the EDMP. The majority of the people who were able to access the EDMP found that their health professional respected their values, needs and preferences, helped them to better understand their ED and the treatment goals. Having plan had allowed them to focus on their recovery rather than the financial burden.

Just under three quarters of respondents had found it easy to get a referral to see a Mental health professional with just over half finding that there had been a long wait for an appointment and nearly three quarters finding the out-of-pocket costs difficult to afford. For nearly all the people who saw a Mental health professional they found the professional to be empathetic and caring. Overall, the majority believed the support they (or their loved one) had received was of a high quality and from a competent mental health professional.

Over three quarters of the respondents who saw a dietitian found it easy to get a referral to see a dietitian. Although one-third of the respondents found there was a long wait to see a dietitian. Over half the respondents found the out-of-pocket expenses difficult to afford, but overwhelmingly found the dietitian they saw was empathetic and caring. The majority of respondents found the treatment plan developed with the dietitian to be clear with 63.5 % finding the treatment plan to be effective. Overall, the majority of the sample were impressed with the communication and coordination of care between the dietitian and the rest of their care team.

Some participants already had established relationships with a team of health professionals but having the plans meant that they could see professionals more frequently.

The barrier most frequently identified by respondents who had not been able to access an EDMP was the inability to find a doctor who could provide them (or the person they care for) with an EDMP. 'Not knowing how to gain access to the new MBS Scheme' and being 'wary of accessing support due to past negative experiences with professionals' were the next two most frequently endorsed reasons for not obtaining an EDMP.

One-third of the sample had difficulty finding a health professional to complete the EDMP. One of the biggest challenges that participants experienced in accessing an EDMP was a lack of general practitioner knowledge of the plan and how to complete it. For some participants their out of pocket expenses still made treatment unaffordable. Having to access a psychiatrist to review the plan resulted for some in long waiting times as a result of both finding a psychiatrist and the length of time it took the psychiatrist to complete the review. Having to access a psychiatrist also led to extra costs that some participants could not afford. Some participants also found the eligibility criteria for accessing a plan, the types of psychological therapies covered by the plan and the health professionals covered by the plan too rigid and narrow.

A few participants made comments about a lack of competence and expertise from their health care professionals with one participant suggesting that having a dietitian who had special expertise in eating disorders was imperative to receiving relevant and helpful care.

A few participants suggested that the plan could be improved by making more sessions available under the scheme and allowing people to access it for longer period of time. More education was needed to raise awareness about the existence of the plan and then how to develop it (especially for GP's). Also, the rebate needed to be higher.

The findings in this survey indicate that the new MBS eating disorder items numbers have clearly been a positive step for people with ED and their carers. Given that GPs are the most likely source of referral, it would be helpful for Butterfly and other ED organisations to provide GP's with clear step by step instructions on how to complete an EDMF. It is often not possible for GP's to be 'fluent' in all the different processes. The MBS schedule is lengthy and would be difficult to digest in a single consultation.

The sample in this survey overwhelmingly identified as female. In order to obtain a more diverse sample, it would be valuable to also send the survey out through organisations that focus specifically on servicing people who identify as male as well as people who identify as gender diverse.

The majority of people with ED in Australia also present with one other lifetime psychiatric disorders. <https://www.nedc.com.au/eating-disorders/eating-disorders-explained/something/eating-disorders-in-australia/>. In future surveys it would be important to ask about comorbid diagnoses as these may be the issues that lead to respondents being more likely to seek help.

The high level of uptake of the scheme in this sample may be because the participants are already linked in with Butterfly foundation. We know they are linked in as they are completing this survey.

References

Butterfly Foundation. (2016). Insights in recovery: An overview of the research project informing the insights in recovery guide. Sydney: Mental Health Commission of NSW.

National Eating Disorders Collaboration Website nedc.com.au