



**The views of Children and
Young People in
Northamptonshire about
Eating Disorders**

**August
2016**





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“It’s not something I thought about a lot but I always considered an eating disorder as just bulimia and anorexia but actually seeing this and thinking about it I guess any form of unhealthy eating habits could meet this classification. Eating disorders just exist at the extreme end of the continuum of unhealthy to healthy.”

Male, 23 - response to the question ‘Please tell us what you think an eating disorder is’



Introduction

The Northamptonshire Children and Young People's Future in Mind Local Transformation Plan for Emotional Wellbeing and Mental Health (here after referred to as the Transformation Plan) aims to improve the emotional wellbeing and mental health of Children and Young People (CYP) across the county and sets out the actions that need to be taken in the next five years to do this. Healthwatch Northamptonshire (HWN) has been commissioned to engage with CYP to inform the objectives of the Transformation Plan. The starting point was to establish the views and awareness of CYP across the county about eating disorders.

From January to April 2016, Young Healthwatch Northamptonshire (YHW) carried out a survey asking CYP aged 9 to 24 across the county about:

- their knowledge and awareness about eating disorders
- if they had one themselves or knew someone who did
- if they knew where to go for help and which wellbeing services they were aware of



2,017 CYP completed the survey, which was five times the forecasted number of response. This report summarises the findings.



Key Findings

- Over three quarters (78%) of respondents said they knew what an eating disorder was, with most thinking it related to food intake in some way.
- More female respondents (84%) said they knew what an eating disorder was than male respondents (65%).
- Anorexia was the most well-known eating disorder, recognised by 86% of respondents.
- 136 respondents (7%) thought they had an eating disorder and there was little difference between the proportion of male and female respondents.
- Nearly one third (31%) of the respondents said they knew someone with an eating disorder.
- 53% of respondents did not know where to go for help with an eating disorder.
- Significantly more male respondents (60%) did not know where to go for help compared to female respondent (48%).
- Most respondents said they would go to a doctor or other medical professional for help and many said they would go to their family members or friends. Only 2% said they would go to a school nurse/counsellor.
- Over a third (39%) of respondents had not heard of any of a list of local services for CYP.
- More female respondents had heard of the services listed than male respondents. Only The Lowdown was known by a higher proportion of male respondents.
- Those reporting they had an eating disorder were more aware of most services.
- Many respondents thought that there was a need for more education about eating disorders and awareness-raising.
- Five times as many people responded to the survey as forecast.



Recommendations

Based on these findings HWN recommends that:

- More resources are put into raising awareness of eating disorders, what they are, and where to go for help and information, particularly targeting males and those aged 12 or under.
- More information about eating disorders is disseminated through schools, that schools have appropriate mechanisms to support young people needing help or advice, and that students know about them.
- Young people are involved in co-producing information and services for people with eating disorders and the wider population (co-production of services is recommended by the Education Policy Institute's Mental Health Commission¹, who rated the Northamptonshire Transformation Plan² as requiring substantial improvement in August 2016).
- Further work is undertaken to determine the prevalence of diagnosed and undiagnosed eating disorder in Northamptonshire, particularly among young men, and whether the prevalence is higher than in other areas of the country.
- Further work is undertaken to see if there is a link between those who identify their gender as 'other' and the prevalence of eating disorders.

¹ Progress and challenges in the transformation of children and young people's mental health care - a report of the Education Policy Institute's Mental Health Commission, August 2016

² Children and Young People's Future in Mind Local Transformation Plan for Emotional Wellbeing and Mental Health - NHS Nene Clinical Commissioning Group (CCG) is working together with local partners across the NHS, local authority public health, children's services, education and youth justice sectors and voluntary and community sectors to develop Local Transformation Plans for delivering improvements in children and young people's mental health and wellbeing in Northamptonshire over the next 5 years. The CCG will take guidance and approval from NHS England Specialised Commissioning and the local Health and Wellbeing Board in developing a vision for the future - to ensure that every child or young person gets the help they need when and where they need it.



Method

Survey design

A team of YHW volunteers, HWN staff and HWN volunteers worked together on this project to engage with CYP across the county from the ages of 9 to 24.

The project was designed in December 2015 and began with an Eating Disorders Workshop for YHW in January 2016.

At the workshop YHW developed a survey to gather young peoples' opinions, awareness and experiences about eating disorders and information and advice services.

The survey was designed to engage with CYP and explore their opinions. The survey (Appendix) was composed of short open and closed questions on one side of A4 for ease of completion.

Survey distribution

The survey was sent to all schools in Northamptonshire and to partner organisations to include in their newsletters, was shared in HWN's newsletter, website and social media. 2,017 responses were received in total - 1,966 surveys from three colleges and seven schools, as well as from various youth groups in Northamptonshire (see 'Thanks and Acknowledgements' for a full list), and 51 online responses.

All survey and workshop participants were told that their responses would be confidential.

Data analysis

Data from open text question was manually coded into categories derived from the data.

To maintain confidentiality, no-one is referred to by name or is identifiable by others throughout this report.



Eating Disorders Workshop

In January 2016, HWN organised a workshop for young people aged 9 to 16 to discuss and create the survey. Nine CYP attended the workshop. The day was split into an hour and a half workshop about eating disorders, followed by a two hour rock climbing activity to reward the young people for their hard work. At the workshop the CYP talked about what they thought an eating disorder was and created sample questions that were used as a starting point to create the survey.

The first activity at the workshop was to ask the CYP to answer the following questions in pairs (pairs were used so that everyone's opinions could be heard):

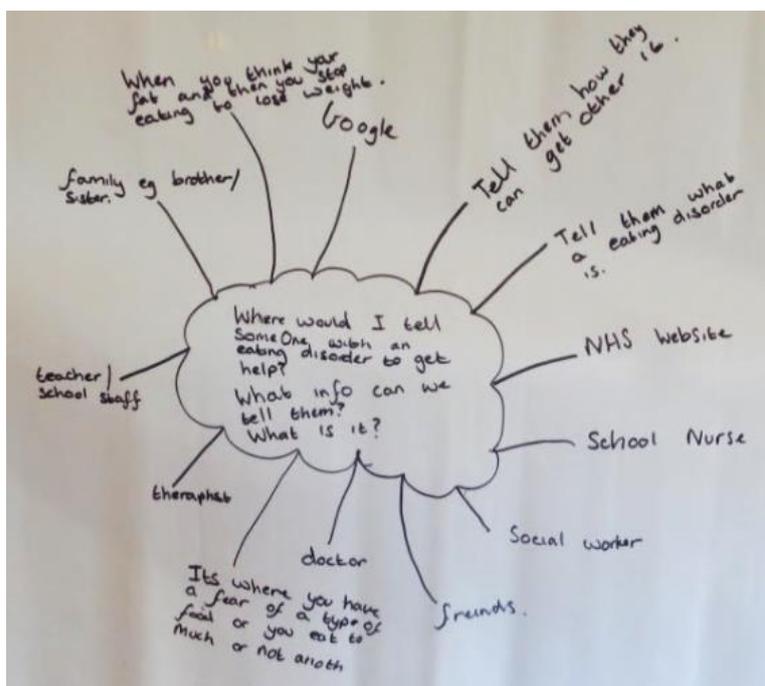
- What is an eating disorder?
- Where should these individuals go for help?
- What information would they need?

The responses to the questions showed that the CYP understood the purpose of the task and were aware of key issues. One pair had an interesting discussion about how to define an eating disorder, e.g.:

[An eating disorder is] “a lack of or excess of food for the body, creating deficiencies, changing body shape and state of mind in a person”

During the discussions the CYP developed their understanding of what an eating disorder is and talked about the different places to which people could go for help. Almost all of the groups had similar suggestions such as “doctor” or “school nurse”, “family” and “friends”.

Next, we asked the CYP to come up with questions relating to the design of the eating disorder survey. The CYP engaged well with this activity, thinking of questions which were relevant and well thought out. Examples of these questions include:





-
- “Do you think you have an eating disorder?”
 - “Do you know where to go if you need help?”
 - “How do you feel most of the time?”
 - “Which of these have you heard of/contacted? The Lowdown, CAN, ChildLine, Ask NORMEN, Young Minds, CAMHS, Young Minds, Talk out Loud”

The young people also suggested that we should aim for 300-400 responses and suggested places to distribute the survey to, such as: PSHE classes, break and lunch times at schools, GP surgeries, online, members of HWN, hospital school schemes, youth counselling agencies, shopping centres, Ask Normen, Talk Out Loud and many other suggestions.

HWN also received many positive comments from the CYP about the day it self, such as:

“I had so much fun”

“Thank you”

“You made the activity more hands on.”

“Well planned out”

“Cool”



After the workshop, the CYP were invited to take part in the rock climbing activity, which they all really enjoyed.

“I just wanted to drop you a line to extend a compliment to [the staff] for an excellent engagement event on eating disorders affecting children and young people [...] The environment was very relaxed, and once the ice was broken, it was a lot of fun too. Most of all, the young people worked to develop the questionnaire and I look forward to seeing this work progress.”

David Loyd-Hearn (Children and Young People Commissioning Manager Emotional Health and Wellbeing)





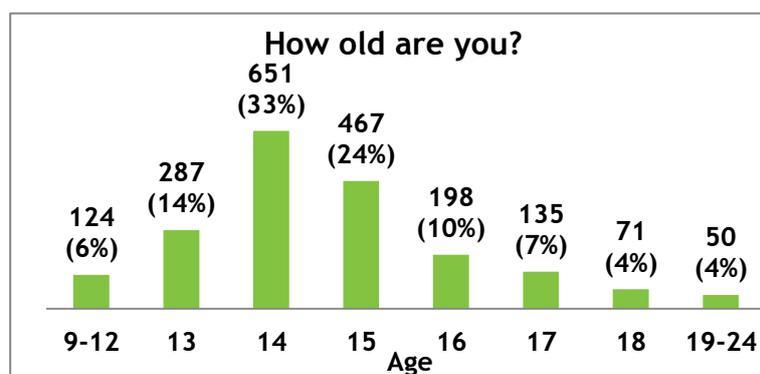
What CYP told us

- All figures given are percentages of all the answers received for a particular question, unless specified otherwise.
- Overall HWN received responses from 2,017 CYP within Northamptonshire. At least 1,956 of these were from 10-19 year olds. This represents approximately 2.4% of the CYP in the county aged 10-19, from 2015 estimates³.

Demographics

Age:

1,992 (99%) answered this question but nine said they were between the ages of 26 and 84. It was assumed that some of these answers were ‘tongue in cheek’ and so they were discounted in the calculations.



The majority of respondents were age 14-15 (57%) and 1,931 (97%) were between the ages of 11 and 18.

The relatively high proportion of 14 year old respondents is accounted for in part by the schools that took up the offer of HWN to talk to pupils requesting this was part of PSHE sessions for Years 9 and 10.

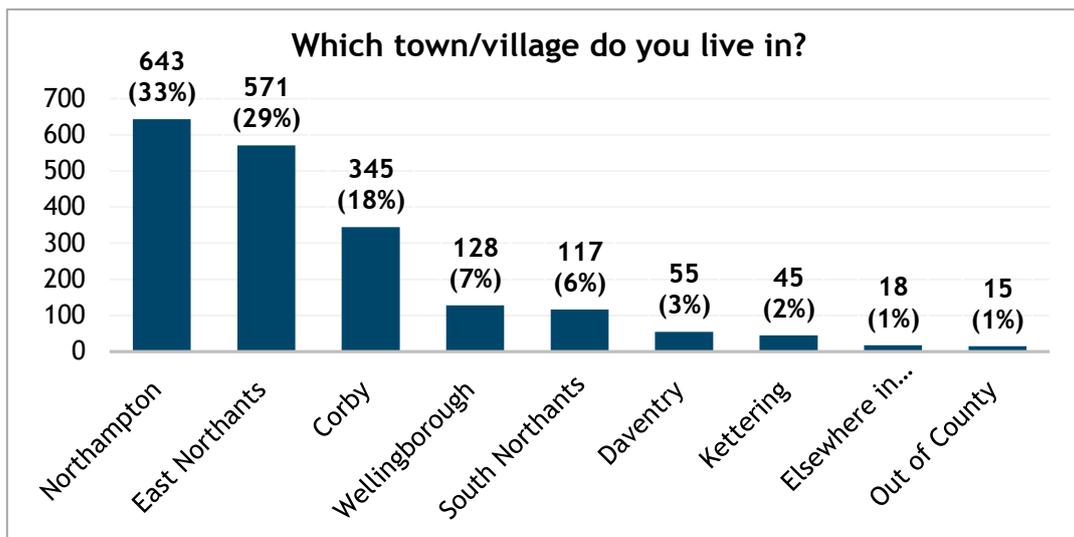
Location:

The surveys were received from across the seven different localities of Northamptonshire. 1,937 (96%) answered this question.

The majority of responses were from Northampton, East Northamptonshire and Corby.

The variation in responses from the different districts can be partly explained by the locations of the schools HWN visited and by variations in the amount of surveys returned by the schools.

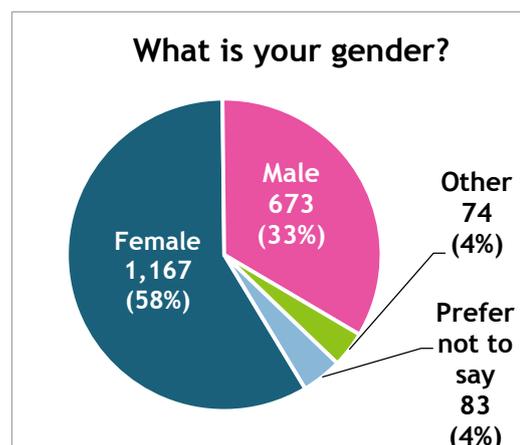
³ Office of National Statistics (ONS) 2015 Mid-Year Estimates (MYE) based on 2011 Census data. Northamptonshire Analysis, Census & MYEs : Population in Other Adhoc Age Bands/Groups, www.northamptonshireanalysis.co.uk



Gender

1,997 (99%) answered this question, the majority of whom were female.

The apparent over-representation of girls is in part because over 200 surveys were completed at Northampton School for Girls, an all-girls school (before sixth form).

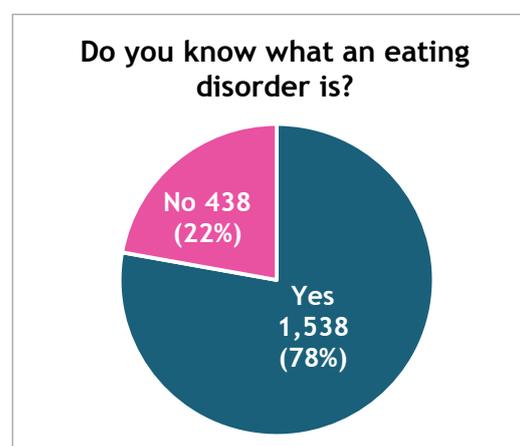


Knowledge of eating disorders

Do you know what an eating disorder is?

1,976 (98%) answered this question and the majority (78%, 1,538) said they did know what an eating disorder was.

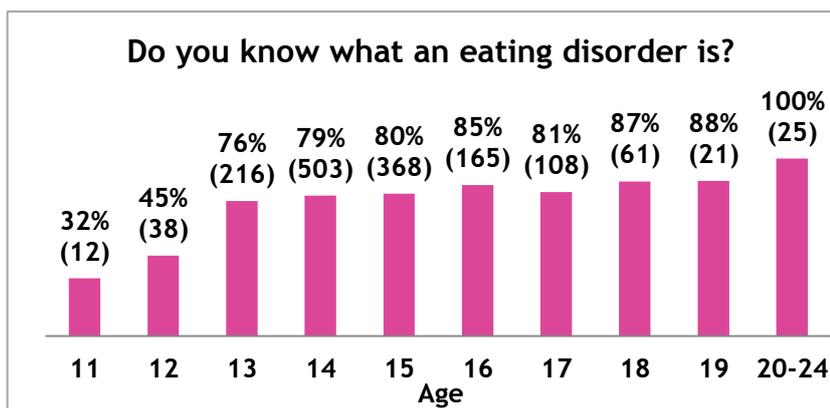
Significantly more female respondents (84%, 981) said they knew what an eating disorder was than males (65%, 440)⁴.



⁴ P<0.0001 Chi-square test



Knowledge of what an eating disorder is increased with age, with most respondents over the age of 12 saying they did know what an eating disorder was.



Those that said they did know what an eating disorder was were asked to tell us what they thought it was in order to explore their understanding and perceptions.

1,348 (67%) made 1,705 separate suggestions that were grouped into the following themes:

| Please tell us what you think an eating disorder is | Number of response | Percentage of answers |
|---|--------------------|-----------------------|
| Answers relating to food intake: | 686 | 40% |
| Eating too much or too little | 314 | 18% |
| Eating too little | 270 | 16% |
| Eating too much | 36 | 2% |
| Lack of control over food intake | 44 | 3% |
| Fear of food | 16 | 1% |
| Over-controlling eating | 6 | <1% |
| 'Problems' with eating or poor eating habits: | 387 | 23% |
| Problems about eating (generic/unclear) | 297 | 17% |
| Eating the wrong things/poor eating habits/unhealthy eating | 90 | 5% |
| Named examples and body issues: | 342 | 20% |
| Body image/low self-esteem | 155 | 9% |
| Named examples, inc. Anorexia, Bulimia | 90 | 5% |
| Vomiting | 69 | 4% |
| Changes to eating that cause excessive weight loss or gain | 28 | 2% |
| Mental health related answers: | 218 | 13% |
| A mental illness/problem affecting eating | 127 | 8% |
| Food/eating problems that affect our mental/physical health | 67 | 4% |

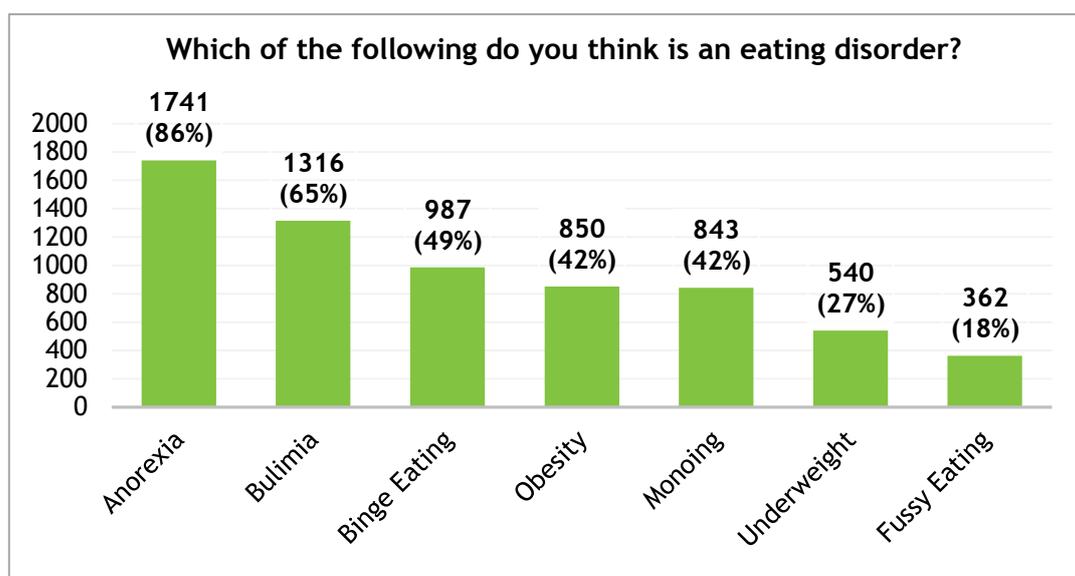


| | | |
|-------------------------------------|-----------|-----------|
| Emotions/stress affecting eating | 24 | 1% |
| Physical 'problems' | 72 | 4% |
| An illness/problem affecting eating | 38 | 2% |
| Can't eat certain foods/fussy eater | 30 | 2% |
| Allergies/Diabetes | 4 | <1% |

It is difficult to distinguish between the different themes respondents emphasised in their answers but it is clear that most respondents told us that eating disorders were to do with the amount of food eaten. Many, particularly older respondents, had a broader understanding of the term and highlighted the link to body image/self-esteem and mental health.

Which of the following do you think is an eating disorder?

Respondents were asked to circle which of the following they thought were eating disorders: Bulimia, Anorexia, Obesity, Binge Eating, Monoing⁵, Underweight and Fussy Eating. They could circle more than one and circled three each on average. 3% did not circle any and 6% circled all seven.



The following were suggested when we asked if there were any other eating disorders that we had not mentioned:

⁵ Monoing: only eating one type of food.



| Suggestions | Number suggesting it |
|---|----------------------|
| Eating Disorder Not Otherwise Specified (EDNOS) | 6 |
| Orthorexia ⁶ | 3 |
| Purging | 3 |
| Eating non-food items | 2 |
| Eating not enough or too much | 2 |
| 'Extreme diets' e.g. Ana diet, liquid only | 2 |
| Body Dysmorphic Disorder | 1 |
| Not being able to eat properly/not being hungry enough to eat | 2 |
| Avoidant/Restrictive Food Intake Disorder (ARFID) | 1 |
| ProAna ⁷ | 1 |
| Allergies | 1 |
| Obesity | 1 |

Some respondents also gave additional comments in response to this question:

“Anything that surrounds or is affected by negative thoughts, you could be under/overweight or fussy, but it doesn't overtake your life”

“Technically, any form of unhealthy eating could be an eating disorder”

“Being overweight can be seen as an eating disorders because of the stigma fat people binge eat. Likewise being underweight can sometimes be seen as an eating disorder. But you don't have to be either extreme to have an eating disorder”

“These can all be related to other illnesses”

“Fussy eating, only if it becomes a problem”

“You can binge and not have a disorder”

⁶ Orthorexia: obsessive focus on “healthy” eating, exaggerated emotional distress in relationship to food choices perceived as unhealthy.

⁷ ProAna: the promotion of behaviours related to the eating disorder anorexia nervosa.

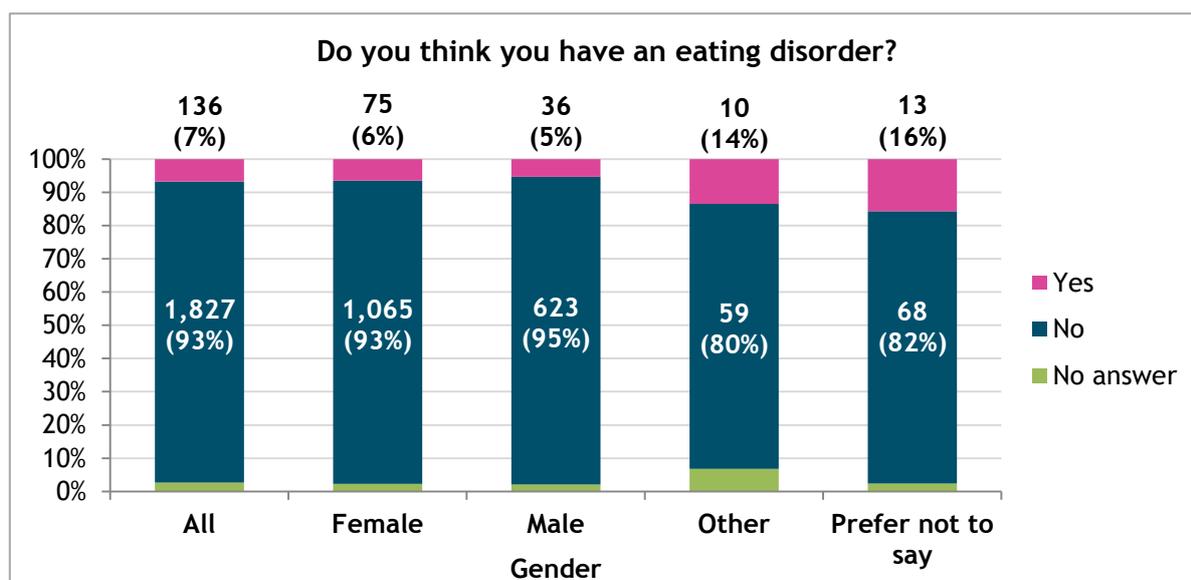


Prevalence of eating disorders

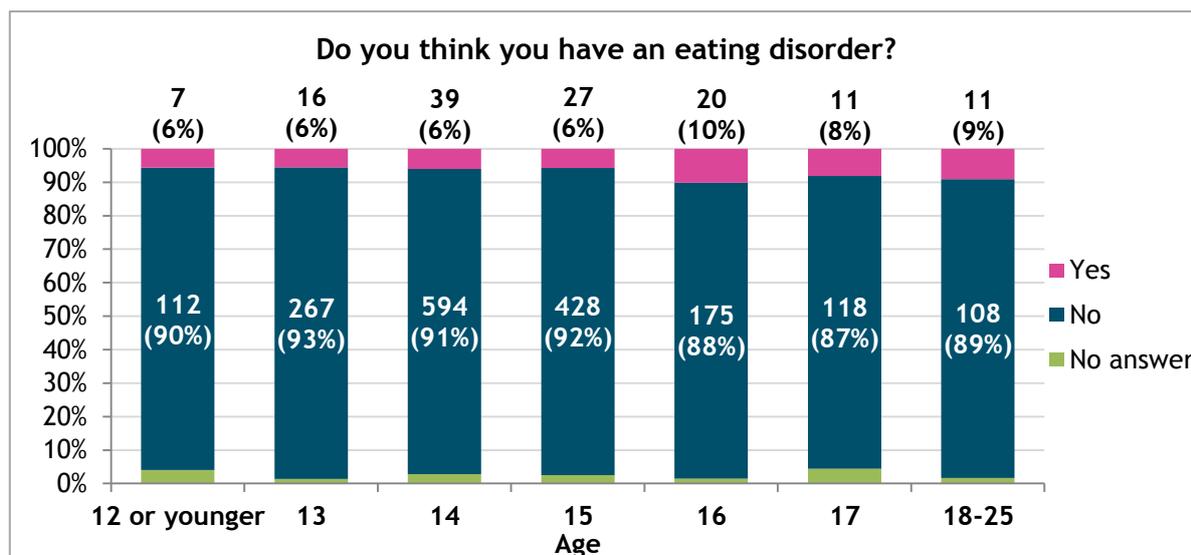
Do you think you have an eating disorder?

1,963 (97%) answered this question and 136 (7%) of these said they did have an eating disorder.

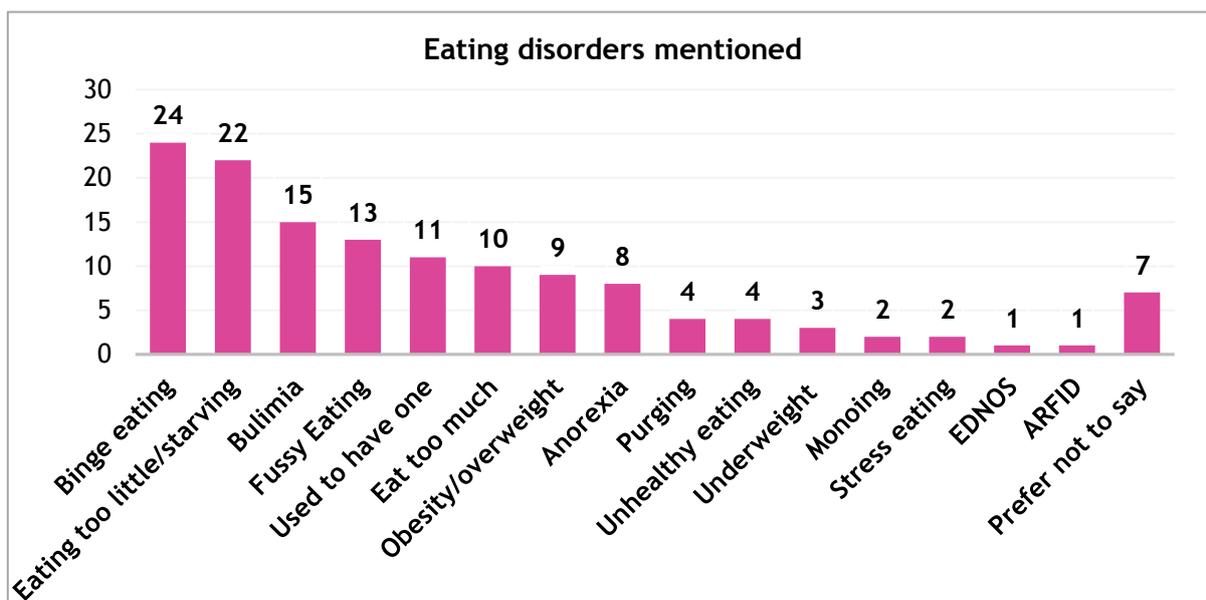
There was little difference between the proportion of female and male respondents saying they had an eating disorder. There may be a higher proportion of those who preferred not to tell us their gender or telling us they had an 'other' gender saying they had an eating disorder (although the numbers were small).



Eating disorders were reported by a greater proportion of those aged 16 or over (although again, the number in these age groups is relatively small).



We asked respondents to tell us what eating disorder they had. 118 answered and gave 136 definitions:



Although the numbers were small for each group, there was a difference in the most common categories given by male and female respondents. Most male respondents mentioned fussy eating, eating too much/binge eating or eating badly whereas most female respondents mentioned eating too little, binge eating, bulimia and anorexia.

| Eating disordered mentioned (in descending order) | | | |
|--|------------|---|----|
| Male | | Female | |
| Fussy Eating | 6 mentions | Eating too little/starving oneself/skipping meals | 16 |
| Eat too much | 5 | Binge eating | 15 |
| Binge eating | 4 | Bulimia | 12 |
| Eating too little/starving oneself/skipping meals | 4 | Anorexia | 8 |
| Obesity/overweight | 3 | Used to have one | 8 |
| Unhealthy eating | 2 | Fussy Eating | 5 |
| Bulimia | 1 | Purging | 4 |
| Monoing | 1 | Eat too much | 4 |
| Underweight | 1 | Obesity/overweight | 3 |
| Used to have one | 1 | Underweight | 2 |
| Stress eating | 1 | Monoing | 1 |
| | | EDNOS | 1 |
| | | Unhealthy eating | 1 |
| | | Stress eating | 1 |



A number of respondents explained more about their thoughts and issues about eating, such as:

“I got diagnosed with anorexia by CAMHS. I have a meal plan but I purge it”

Female, 16

“I tend to deliberately not eat anything throughout the day so that I can lose weight, if I do happen to eat something I always try and get it out by making myself sick”

Female, 15

“Recovering bulimic eating less than I should”

Other gender, 14

“I do not eat hardly anything, my parents force me to eat”

Female, 13

“I will starve myself then binge eat then starve myself”

Other gender, 14

“I don't like to eat because I'll get fat”

Female, 14

“I don't eat breakfast that often. I don't eat enough”

Male, 13

“When I eat, I eat too much”

Male, 15

“I get upset about it sometimes, but I wouldn't say I have one”

Female, 13

“Potentially, as I eat excessively when nervous”

Male, 17

“I eat a lot when I get sad but I haven't really eaten much”

Female, 13

“I always count calories, I refuse to let myself eat throughout the day and only have one meal. I get nervous eating around people and if I do I eat slowly and try not to let them see me eating”

Female, 15



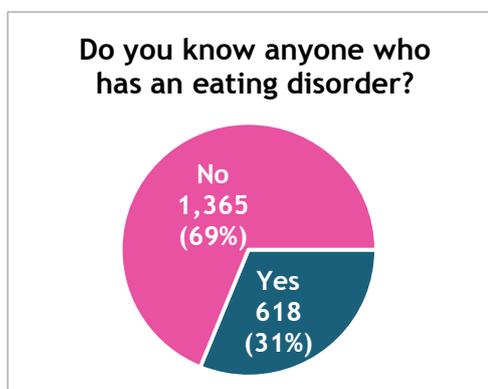
“I eat normally and I don't think about weight”

Female, 13

Do you know anyone who has an eating disorder?

1,983 (98%) answered this question. Nearly a third of respondents (31%, 618) reported that they knew someone with an eating disorder.

We asked those who said they did know someone to tell us who that was (e.g. a relative, friend, etc.). 454 respondents told us details of 471 people they knew, with three quarters saying the person they knew with an eating disorder was a friend (for confidentiality reasons, we did not ask for more information about the person they knew with an eating disorder):



| Person | Number of respondents | Percentage of respondents | Percentage of answers |
|--|-----------------------|---------------------------|-----------------------|
| Friend | 341 | 75% | 72% |
| Relative | 93 | 20% | 20% |
| A named person, fictional character or celebrity or unspecified person | 31 | 7% | 7% |
| Prefer not to say | 6 | 1% | 1% |

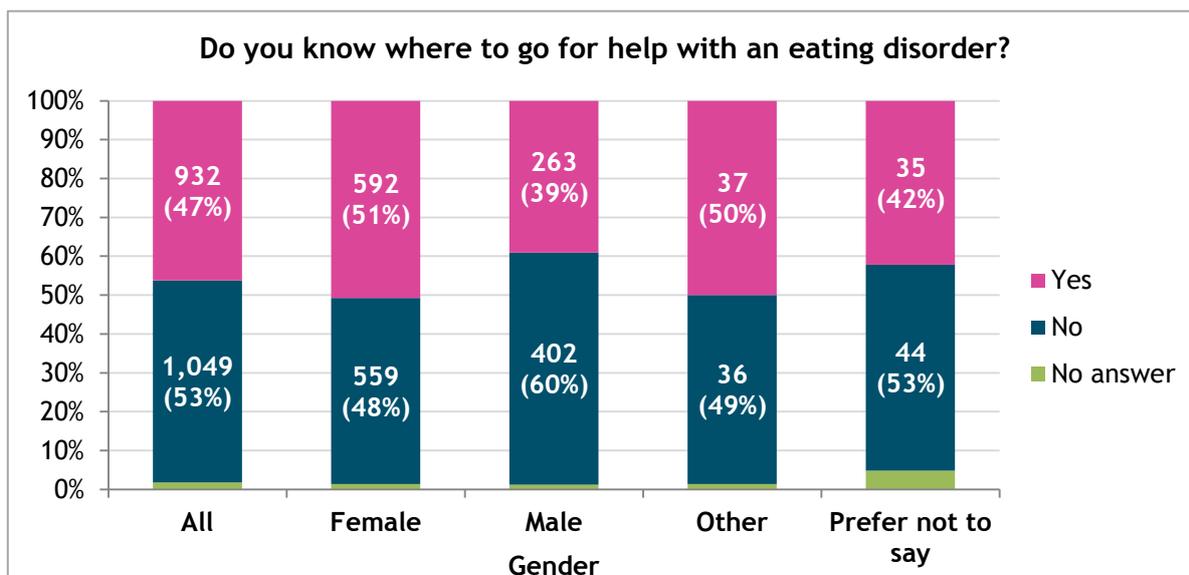
Help and information

Do you know where to go for help for an eating disorder?

1,981 (98%) answered this question. More than half (53%, 1,049) reported that they did not know where to go for help with an eating disorder.

Overall, significantly fewer male respondents knew where to go for help than female respondents⁸.

⁸ P<0.0001 Chi-square test



Of the 136 who told us they had an eating disorder, 52% (71) said they knew where to go for help. Looking at female and male respondents separately, 56% (42 of 75) of females reporting an eating disorder knew where to go for help compared to 44% (16 of 36) of males reporting an eating disorder.

Where would you go for help for an eating disorder?

In the follow-up question they were asked to tell us where they would go for help with an eating disorder. 738 answered with 952 different answers:

| Where they would go for help | Number of respondents | Percentage of respondents | Percentage of answers |
|--|-----------------------|---------------------------|-----------------------|
| Doctor or other medical professional | 521 | 71% | 55% |
| Family or friends | 146 | 20% | 15% |
| Advice organisations and support groups | 91 | 12% | 10% |
| Teacher, school, or another trusted adult | 90 | 12% | 9% |
| Mental health professional, counsellor or a specialist | 57 | 8% | 6% |
| Online | 19 | 3% | 2% |
| School nurse/counsellor or social worker | 18 | 2% | 2% |
| Dietician or nutritionist | 10 | 1% | 1% |

Most respondents said they would go to a doctor or other medical professional and many said they would go to their family members or friends. Only 2% said they would go to a school nurse/counsellor.



Advice organisations and support groups specified included:

- Healthwatch Northamptonshire - 38 (probably because it was conducting the survey)
- Childline - 26
- The Lowdown - 6
- Service Six, Young Minds, Beat⁹ - 1 each

Some respondents also gave additional quotes in response to this question:

“Doctors, CAMHS, Lowdown, the internet (various websites like Beat⁷)”

Female, 16

“Anyone who has that power to help. Family, GPs, local youth centre etc...”

Male, 16

“I'm in an inpatient unit- any staff. Before admission, CAHMS or Childline”

Female, 17

“I would go to my GP and I'd hope they'd give the help that was needed, but from my understanding part of the nature of eating disorders can be denial about it being a problem. I think often family and friends would have to be aware and intervene and lead someone to getting the help they need”

Male, 23

“I would go online to find advice or speak to someone”

Female, 18

“You go to any responsible adult, like parents, teachers, the school nurse”

Male, 13

“To my parents, closest friends or your doctor”

Female, 13

“To a teacher or to someone who'd know what to do”

Female, 14

“They're not places I feel comfortable”

Female, 16

“You can get help from parent etc., but there are websites and helplines”

Female, 14

⁹ Beating Eating Disorders, The UK's Eating Disorder Charity - www.b-eat.co.uk



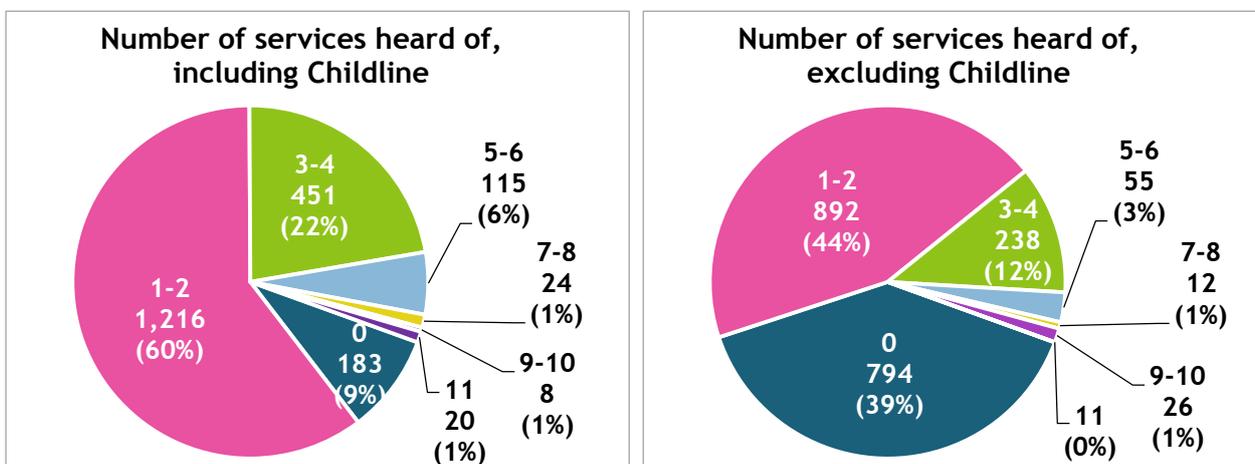
“Someone you trust - nurse, parent, etc.”

Female, 15

Which services have you heard of?

Respondents were asked to circle which of a list of services they had heard of.

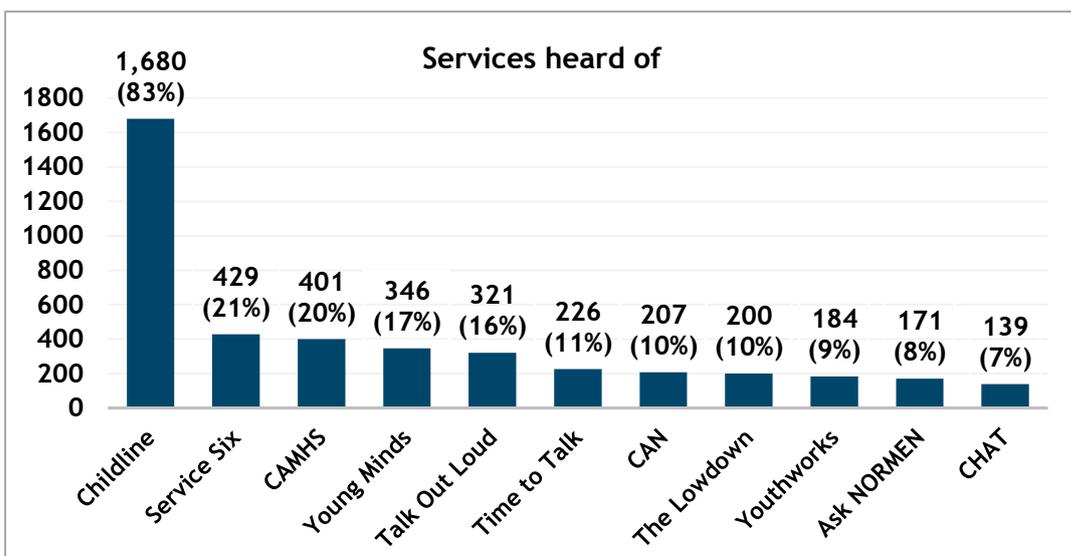
Most respondents (91%, 1,834) had heard of at least one of the services. 183 (9%) had not heard of any of them. The majority of respondents (83%, 1,680) said they had heard of Childline. If we exclude this national service and just look at local services more tailored to supporting CYP with eating disorders or mental health issues, a larger proportion, 39% (794) had not heard of any of the listed local services.



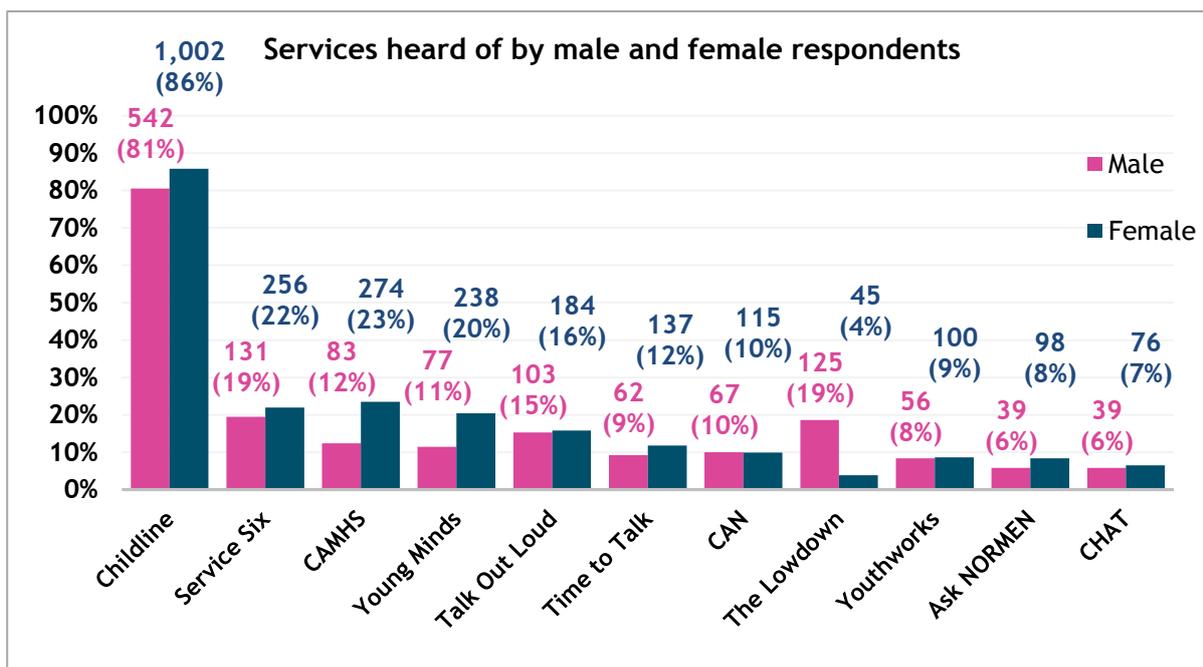
More female respondents had heard of the services listed than male respondents. 94% (1,093) of female respondents had heard of at least one service (included Childline) compared to 89% (596) of male respondents¹⁰. This gap was even bigger when comparing services other than Childline - 46% (311) of male respondents had not heard of any of the local services compared to 34% (400) female respondents⁷.

After Childline, Service Six and CAMHS were the services that most respondents had heard of.

¹⁰ P<0.0001 Chi-square test



There were some differences in awareness of particular services between female and male respondents. Significantly more female respondents had heard of CAMHS⁷, Young Minds⁷, Childline¹¹, and Ask NORMEN¹². Significantly more male respondents had heard of The Lowdown⁷.

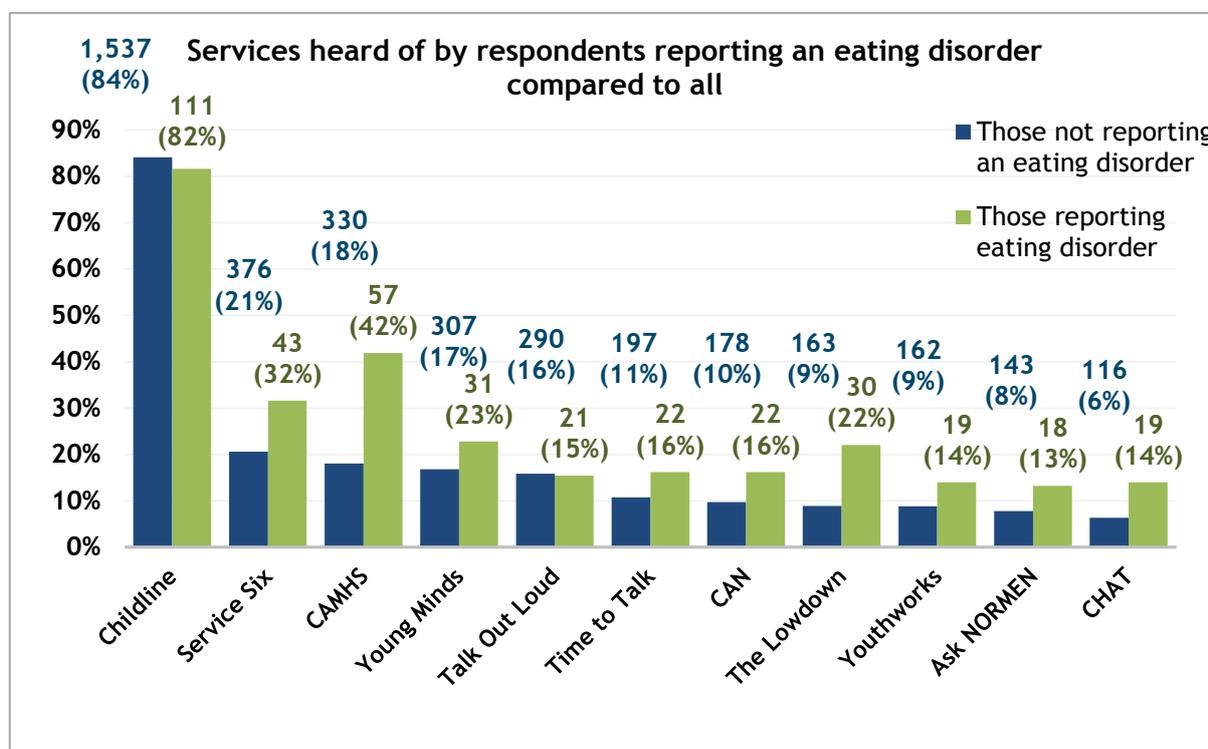


¹¹ P<0.01 Chi-square test

¹² P<0.05 Chi-square test



Unsurprisingly, those reporting they had an eating disorder were more aware of most services. Significantly more respondents reporting an eating disorder had heard of Service Six¹³, CAMHS¹⁰, The Lowdown¹⁰, CHAT¹⁴, Young Minds¹⁵, Time to Talk¹², CAN¹², Youthworks¹², and Ask NORMEN¹².



¹³ P<0.0001 Chi-square test

¹⁴ P<0.001 Chi-square test

¹⁵ P<0.05 Chi-square test



What other help/information should be available for young people about eating disorders?

Lastly, respondents were asked to tell us what other help or information they thought should be available for young people about eating disorders. 1,194 answered with 1,143 different answers (an additional 246 told us they did not know):

| Suggestions | Number of respondents | Percentage of answers |
|---|-----------------------|-----------------------|
| Education about eating disorders and where to go for help (awareness-raising), e.g. talks at school | 330 | 29% |
| Specific advice for those with eating disorders | 108 | 9% |
| Help at school/talking to teachers/youth clubs | 85 | 7% |
| Online information and support services, inc. apps | 78 | 7% |
| Access to clinicians, e.g. school nurses and doctors | 76 | 7% |
| Someone to talk to in general | 72 | 6% |
| Education/advice about eating well/dieting services/eating clubs/exercise | 69 | 6% |
| Support groups | 57 | 5% |
| Counselling/therapy | 51 | 4% |
| Information leaflets/booklets | 43 | 4% |
| Adverts (e.g.TV, posters, social media) | 38 | 3% |
| There is enough information already/nothing/nothing can help | 37 | 3% |
| Phone helplines | 31 | 3% |
| Family/friends | 26 | 2% |
| Eat/food/more food | 20 | 2% |
| Advice for parents/friends of those going through it | 10 | 1% |
| Free food, e.g. school meals, fruit and vegetables at school | 7 | 1% |
| Police | 5 | <1% |



The most common suggestion was for more education/general awareness-raising about eating disorders and where to go for help. The next most common suggestion was related to this but for more specific/detailed advice about eating disorders, such as how to spot the signs early, education about the consequences and advice for people with an eating disorder about how to improve their wellbeing or overcome the eating disorder. Together these categories account for 38% of the suggestions.

The top three suggestions were the same for 74 respondents reporting they had an eating disorder (education, 18 suggestions - 20% of answers, specific advice, 11 suggestions - 12%, help at school, 9 suggestions - 10%).

Many respondents explained their answers with additional, informative comments. The following comments are illustrative of these.

Education about eating disorders and where to go for help (awareness-raising):

“School presentations. We have ones on bullying and smoking. But eating disorders aren't discussed”

Female, 16

“Anything it's still something I don't greatly understand which would be catastrophic if I had one.”

Male, 19

“Educating young people about all different types of eating disorders not just the most common ones”

Female, 14

“Early symptoms, how to spot what's happening and what to do if you see something but are told to say nothing. REMOVE THE STIGMA”

Female, 15

“Workshops more readily available. School nurses being trained to help. More awareness in non-eating disorder people (education to help with the stigma associated with eating disorders)”

Female, 17

“To break stigma about the subject, openly show plans for help, correct help available is quite unknown, bring up awareness of symptoms”

Female, 15



“People need to be more educated on eating disorders, it’s not just because people want to be skinny”

Female, 16

“I think information about the conditions under which disorders are formed (which aren't necessarily under peer pressure) should be available, as magazines aren't often the cause of eating disorders despite what people say (although they do not help)”

Female, 19

“I think it should be talked about more in the media to make people aware. There's far too much 'this is perfect this is what you should look like' and not 'you're beautiful and amazing but if you do need help go here”

Female, 15

“I think people should be educated on mental disorders as a lesson to understand people better and treat things/people with respect”

Female, 14

“I think people should be told more information about eating disorders from an early age”

Male, 15

“People need to know more about different body types so they feel more confident about their weight”

Female, 14

“That eating disorders and other mental illnesses are not "trends" and you can't make yourself anorexic or decide to become depressed etc... Also that they are not something to be made fun of and people should not be driven to become ill over something someone else said”

Female, 15

“The long term and short term effects”

Male, 14

“What the causes are, how they occur and what damages they can have on your body”

Female, 16



Specific advice for those with eating disorders:

“I think that young people especially need information as to what they are actually suffering with, how they can improve their state and how they can overcome the disorder. Also, something should be put in place so that people suffering from an eating disorder can talk to somebody”

Female, 16

“Different methods on dealing with the feelings”

Female, 16

“Knowing how to recognise if you have a mental illness, the friend I mention hasn't realised she is ill”

Female, 15

“That it's not their fault. They can overcome it”

Female, 15

“That they aren't alone and there is always somewhere they can go to talk to someone”

Female, 19

Help at school/talking to teachers/youth clubs:

“I think it should be talked about in school and more info should be available from GPs as it is often brushed off, especially if the person is not extremely underweight”

Other, 16

“The chance to speak to someone, teachers or doctors in your school, without people judging or knowing about it (privacy!)”

Female, 14

“Schools need to do more to educate people about eating disorders (and other mental illnesses) and offer more help and support”

Female, 14



Online information and support services:

“I don't know if it already exists but maybe someone to talk to online because it's not as personal”

Female, 17

“Websites that are more known, because I don't know any that have to do with an eating disorder and information about it”

Female, 15

“Apps - because people use their phones mainly”

Female, 14

“A questionnaire online to identify if you have one [an eating disorder]”

Female, 13

“Instagram accounts about it explaining what it is and how/if you're got it and how to help if you know someone with it”

Female, 14

Access to clinicians:

“Any health services, it shouldn't be something to have a stigma attached, people should always have access to help”

Female, 15

“It should be easier to contact a professional, which is more private and confidential than a phone call”

Female, 14

Someone to talk to in general:

“Actual nice people to talk to about it, not [profanity removed] that think it's okay to talk down on you :)”

Female, 16

“Easy places where you can talk to people anytime you need”

Male, 13



Education/advice about eating well/dieting services/eating clubs/exercise:

“A helpful meal list”

Male, 15

“A restaurant for people with eating disorders that helps them overcome it”

Female, 15

Support groups:

“They should be able to talk to other young people with eating disorders and try to get as much help as possible”

Female, 14

“More support groups to help people affected by eating disorders”

Female, 14

“They aren't alone and if they go to support groups they can make friends with people suffering similar problems”

Female, 14

Counselling/therapy:

“I feel like there should be a special clinic with psychiatrists and doctors specialising in the area of eating disorders”

Female, 15

Adverts (e.g. TV, posters, social media):

“A book, an advert on the TV (like the smoking one as it's memorable)”

Male, 13



Conclusions

Healthwatch Northamptonshire was commissioned as part of the Northamptonshire Children and Young People's Future in Mind Local Transformation Plan for Emotional Wellbeing and Mental Health, to engage with CYP across the county to find out if they knew what an eating disorder was, if they knew anyone with one, and if they knew where to get help and information.

2,017 surveys were completed from children and young people, most of whom were between the ages of 11 and 20. There was five times as many as expected. From our key findings, 78% knew what an eating disorder was, 31% said they knew someone with one, and 7% said they themselves had an eating disorder. Anorexia was the most recognised as an eating disorder (by 86% of respondents).

The NHS says that “a person with an eating disorder may focus excessively on their weight and shape, leading them to make unhealthy choices about food with damaging results to their health”¹⁶. Many of the definitions of an eating disorder given to us by the respondents agreed with this definition in part, mostly focusing on food intake. A few had a greater awareness, giving definitions more closely matching that from NHS England.

There are some stark gender differences in knowledge and awareness, with more female respondents knowing what an eating disorder is and knowing where to go for help and information, although overall only 47% of respondents did know where to go for help.

It is surprising that there was not any gender difference in the proportion telling us they had an eating disorder as national statistics suggest that only up to 20% of people in the UK affected by an eating disorder are male and that girls and young women aged 12-20 are most at risk¹⁷. The difference is likely explained by a difference in perception of what an eating disorder is between male and female respondents (with males respondents mentioning eating too much or poor diets and female respondents mentioning eating too little, bulimia and anorexia) and the fact we did not ask whether their eating disorder had been formally diagnosed. However, it may be worth investigating the prevalence of undiagnosed eating disorder, particularly among young men in Northamptonshire. There may be a link between identifying gender as 'other' or 'prefer not to say' and an increased prevalence of eating disorders but the numbers of these groups in this survey are too small for that to be determined.

¹⁶ <http://www.nhs.uk/conditions/Eating-disorders/Pages/Introduction.aspx>

¹⁷ Beat Guide to Understanding Eating Disorders, <https://b-eat.co.uk/about-eating-disorders/leaflet-library/1351-beat-guide-to-understanding-eating-disorders>



The UK's leading eating disorder charity, Beat (beating eating disorders) support anyone affected by eating disorders and offer training for young people and staff in schools. This was the most common other form of help or information that respondents wanted to be available with many suggesting some form of awareness-raising, including talks at schools. Beat report that eating disorders often start during adolescence, with growing numbers of younger children developing an eating disorder¹⁸. Some of the younger respondents to our survey reported that they thought they had an eating disorder (seven aged 12 or under) but only 32% of 11 year olds and 45% of 12 years olds knew what an eating disorder was. Many also suggested that awareness-raising should begin at a young age. It may then be important to increase education about eating disorders, particularly among younger children and young people.

¹⁸ <https://www.b-eat.co.uk/about-beat/media-centre/information-and-statistics-about-eating-disorders>



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Healthwatch Northamptonshire would like to particularly thank:

Schools:

- The Beehive
- Northampton School for Girls
- Champion School
- The Gateway School
- Higham Ferrers School
- Corby Business Academy
- Northgate School Arts College

Colleges:

- Northampton College
- Tresham College
- Huxlow Science College

Services:

- The Lowdown
- Young Healthwatch
- Shadow Board
- Talk Out Loud
- Service Six
- Nene CCG

HWN volunteers for delivering school assemblies and all others who took part in this survey.



About Healthwatch Northamptonshire

Healthwatch Northamptonshire (HWN) is the local independent consumer champion for health and social care. We are part of a national network of 148 local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. We will report our findings to health and social care decision makers to improve and influence the quality of care.

Our rights and responsibilities include:

- We have the power to monitor (known as 'Enter and View') health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.





Appendix - Survey

Young Healthwatch - Eating Disorder Survey **healthwatch** Northamptonshire

| | | |
|---|---|--|
| This short survey is designed to ask you your views about eating disorders. Everything you tell Healthwatch Northamptonshire is confidential and your details will not be shared with anyone else. | | |
| 1) How old are you: | 2) Which town/village do you live in? | |
| 3) Which gender are you? (Please circle answer) Male Female Other Prefer not to say | | |
| 4) Do you know what an eating disorder is? (please circle answer) Yes No If yes, please tell us what you think an eating disorder is: | | |
| 5) Which of the following do you think is an eating disorder? (please circles answers) Bulimia (being sick) Monoing (eating only one type of food) Anorexia (starving yourself) Underweight (being too thin) Obesity (being very overweight) Fussy eating (not eating certain foods) Binge eating (eating too much at one go) Other - please tell us: | | |
| 6) Do you think you have an eating disorder? (Please circle answer) Yes No If yes, please tell us what? | 7) Do you know anyone who has an eating disorder? Yes No If yes, please tell us who that is: (e.g. relative/friend etc.) | 8) Do you know where to go for help for an eating disorder? Yes No If yes, please tell us where you would go: |
| 9) Which of these have you heard of? (please circle) *The Lowdown *CAN *Childline *Ask NORMEN *Young Minds *CAMHS *Time to talk *Talk out Loud *Service 6 *Youthworks *CHAT | | |
| 10) What other help/information do you think should be available for young people about eating disorders? | | |

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Thank you for your time completing this today.



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