healthwatch Together

Bath and North East Somerset, Swindon and Wiltshire

Eating Disorders

An investigation into Eating Disorders in Bath, North East Somerset, Swindon, and Wiltshire, and the support available locally

Contents

Report summary

What is this report about?

This report looks into eating disorders in B&NES, Swindon and Wiltshire and the support available locally.

This report primarily focuses on people who suffer with an eating disorder or struggle with food. To gather feedback, we had an online survey and carried out interviews. The survey was also completed by parent/carers of individuals as well as parent/carers of younger children. Professionals working with children, young people and adults also participated in this project.

What did we do?

This project began in September 2023 and was completed in May 2024 with an online survey running from November 2023 to March 2024. We also attended engagement sessions and carried out interviews during this time. As a result, we have two in-depth case studies regarding two individuals' experiences of eating disorders and the failures of services to support them.

Looking at the Strategic Evidence Base for Bath and North East Somerset highlighted that in Bath, hospital admissions, where eating disorders are the primary diagnosis, are higher than the national average. Swindon and Wiltshire are below the average but still have gaps in support for eating disorders.

The survey ran from November to March with engagements being attended during this time. These engagements allowed for networking with organisations, resulting in the survey being spread further.

What were the key findings?

Across Bath and North East Somerset, Swindon and Wiltshire (BSW), the key findings included:

- Many patients reported that they did not feel listened to by professionals and support, if they received any, was felt to be not enough.
- The feedback showed that Individuals with an autism diagnosis are not given adequate support for eating disorders.
- Communication is a big issue facing services particularly communication between services and the patient.
- We heard that transitioning from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services is not a smooth process.
- The majority of people expressed the view that eating disorders are not stand-alone struggles. Individuals struggle with their mental health and require support for this alongside their eating disorder.

Conclusions and recommendations

Conclusions:

To conclude, the feedback we have collected, though based on a small number of individuals with diagnosed eating disorders (ED), indicates that eating disorder services across Bath and North East Somerset, Swindon, and Wiltshire (BSW) require improvement and are not currently meeting the needs of those struggling with an eating disorder or disordered eating.

Recommendations

Based on the feedback we have collected; we recommend the following:

• Improve communication between services by ensuring all those involved with a case are aware of the individual's circumstances and struggles.

• Enhance communication with the patient by ensuring they are being informed of the support available to them as well as being aware of who they are being referred to.

• Improve transition from Child and Adolescent Mental Health Services (CAMHS) to Adult support. This can be improved by ensuring all organisation are aware of the individual's case and appropriate support is put in place and that the individual is aware of this.

• Ensure that patients feel comfortable and trust their caregivers to receive the necessary support

• Provide clear pathways for parents/carers regarding how they can access support in their local area

• Provide more training for professionals, GPs and school staff with regard to recognising symptoms of eating disorders and a better understanding of where people can access support.

• Personalise treatment by involving the individual in their treatment plan, allowing them to have input, and viewing them as a person rather than defining them by their disorder.

• Improve mental health and psychological support provided to individuals struggling with an eating disorder.

• Take action to improve support for individuals with Avoidant and Restrictive Food Intake Disorder (ARFID), an eating disorder experienced by many individuals, particularly those with additional needs.

My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

This report is primarily the work of Jasmine Fawcus-Smith who was on placement with us from the University of Bath

Introduction and Background:

Introduction

Who are Healthwatch?

Healthwatch is your independent champion for people who use health and social care services. We're here to make sure that those running services, put people at the heart of care. As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

We are here to listen and understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that people's worries and concerns about current services are addressed. We are totally independent and can provide you with impartial and independent signposting advice. We are part of a network of 150 local Healthwatch across England and cover the whole of Swindon, Bath and North East Somerset, and Wiltshire.

Report:

This report focuses on the prevalence of eating disorders within Bath and North East Somerset (B&NES), Swindon and Wiltshire. By attending engagements and creating a survey, we were able to gather people's perspective on the causes of eating disorders and the support available locally.

Throughout this report, when referring to an eating disorder, we are using the NHS definition of eating disorders.

This survey was completed by individuals with a diagnosed eating disorder, individuals who struggle with food, parent/carers of individuals with food struggles and professionals working with those who struggled with an eating disorder/disordered eating.

Throughout this project, Healthwatch B&NES, Healthwatch Swindon and Healthwatch Wiltshire worked with different charities and organisations in order to be as inclusive and accessible as possible.

The list of organisations we contacted are in appendix 1.

What are Eating Disorders?[1]

Types of Eating Disorders:

The NHS defines an eating disorder as a mental health condition in which food is used as a way to cope with an individual's feelings and circumstances. The most common eating disorders are:

- Anorexia Nervosa- controlling weight through overly exercising, not eating enough food, or a combination of both.
- Avoidant/restrictive food intake disorder (ARFID)- this is when an individual avoids certain foods or restricts how much they consume. This can be due to a dislike of the smell, taste or texture of the food. ARFID is a relatively new eating disorder having only been added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) in 2013.
- Bulimia- taking action to avoid gaining weight after losing control over how much individual eats.
- Binge Eating Disorder (BED)- eating until the individual is uncomfortably full.
- Other Specified Feeding or Eating Disorder (OFSED)- where an individual's symptoms do not entirely align with any specific disorder. This is the most common eating disorder.

Who is more likely to be affected by an eating disorder?

According to the NHS, individuals between 13 and 17 years old are most likely to experience an eating disorder. However, eating disorders can affect any age group. Risk factors for eating disorders include:

- Family history of eating disorders, depression or alcohol/drug misuse.
- Bullying regarding an individual's weight, body shape and eating habits.
- Societal pressure.
- Sexual assault/abuse.
- Other mental health issues (e.g. anxiety, obsessive-compulsive disorder (OCD), low self-esteem).

[1] https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/

Disordered eating

What is disordered eating?

Individuals who struggle with food but do not meet the criteria to be diagnosed with an eating disorder may have disordered eating. Disordered eating is a term used to describe abnormal eating/food behaviours. Similar to eating disorders, disordered eating can often be a coping mechanism for individuals struggling with other aspects of their life.[2]

Background to research

A summary of the research that has been carried out nationally as well as in B&NES, Swindon and Wiltshire, and which influenced this project is set out below.

Data analysis and review of factors that impact young people's health and wellbeing in Bath and North East Somerset[3]

- This was the driving factor of our project as it clearly highlighted the need for more awareness around eating disorders.

How did people living with mental ill health access services during the pandemic?[4]

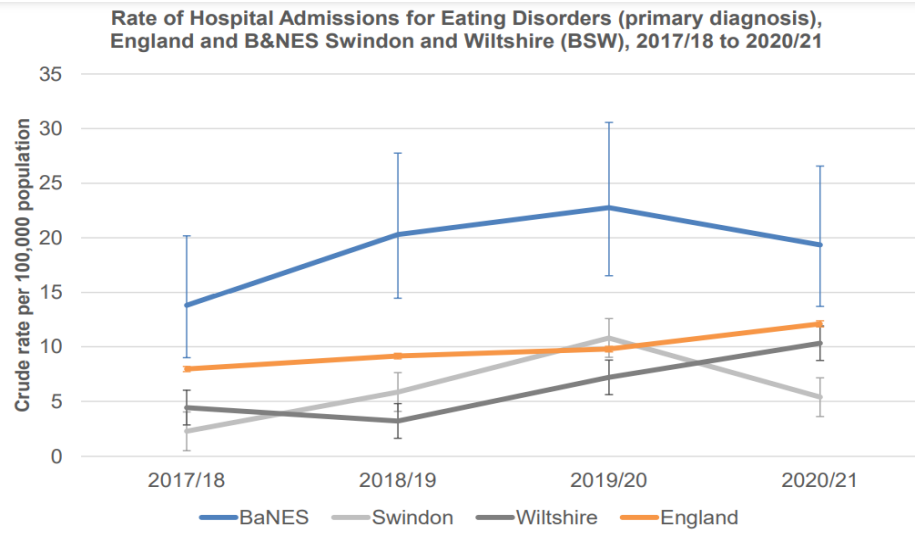
- This report, produced and published by Healthwatch B&NES, Healthwatch Swindon and Healthwatch Wiltshire, found that there was a lack of support for individuals for eating disorders.
- This lack of support included difficulties accessing services, a general lack of eating disorder services in B&NES and limited training for professionals regarding providing support for those with an eating disorder.

Strategic Evidence Base for Bath and North East Somerset[5]

- This document presents a summary of evidence and information which is used to inform decision making.

[2] Difference Between Disordered Eating and Eating Disorders (verywellmind.com)
[3] My Voice Matters: Data analysis and review of factors that impact young people's health and wellbeing | Healthwatch Data
[4] How did people living with mental ill health access services during the pandemic? | Healthwatch Data
[5] PowerPoint Presentation (bathnes.gov.uk) page 154

- Through internal analysis, this document shows that for hospital admissions, where eating disorders are the primary diagnosis, B&NES is significantly higher than Swindon, Wiltshire and England.
- Bath and North East Somerset- 19.4 per 100,000
- England- 12.1 per 100,00
- Wiltshire- 10.3 per 100,000
- Swindon- 5.4 per 100,000



B&NES Wellbeing and Mental Health Needs Assessment 2022[6]

- The findings of this research support the Strategic Evidence Base for B&NES as it also found that eating disorders and alcohol use were the most common reasons behind hospital admissions among young people, particularly girls.
- This report also found that 'in 3 of the past 4 years, Eating Disorders has been the highest observed primary diagnosis reason for admissions' (p.23).
- In 2021/22 eating disorders accounted for 28% of mental health primary diagnosis hospital admissions.

Joint Strategic Needs Assessment (JNSA) for Swindon 2024[7]

- This report found that for Swindon registered GP patients, the most common referral reason for hospital admissions in regards to mental health was 'In Crisis', followed by Eating Disorders.

Health Survey for England 2019 Eating Disorders[8]

- This survey found that for individuals aged 16 and over, 16% had a positive screen for a potential eating disorder.
- They also found that women were more likely to have an eating disorder and the most common age being between 16 and 24 (28%).

Mental Health of Children and Young People Surveys[9]

- This report, published in 2023, was a follow up to the 2017 survey looking at children and young people's mental health, published by the NHS.

[6] Mental Health Needs Assessment - 20220707.pdf (batnes.gov.uk)
[7] PowerPoint Presentation (swindonjsna.co.uk)
[8] HSE 2019 eating disorders (digital.nhs.uk)
[9] Mental Health of Children and Young People in England, 2023 - wave 4 follow up to the 2017 survey - NHS Digital

- This survey found that, on average, 20% of 8- to 25-year-olds have a probable mental disorder.
- 12.5% of 17- to 19-year-olds had eating disorders. ED rates among girls aged 11-16 were 4 times the rates of boys this age. 5.9% of 20- to 25-year-olds had an ED.

Children and Young People with an Eating Disorder: Waiting Times[10]

- This publication looks at how quickly patients start treatment, by weeks, since their referral.
- For the Avon and Wiltshire Mental Health Partnership NHS Trust, 96% of urgent cases are seen within 1 week and 96% of routine cases are seen within 4 weeks.

[10] CYPED-Publication-Q3-2022-23-Provider-CCG-new-codes-broken-links-to-publish-1.xlsx (live.com)

List of Abbreviations:

Abbreviation	Meaning
ADHD	Attention deficit hyperactivity disorder
AWP	Avon and Wiltshire Mental Health Partnership
ARFID	Avoidant and Restrictive Food Intake Disorder
A&E	Accident and Emergency
ASD	Autism Spectrum Disorder
BEAT	Eating Disorders Association
BED	Binge Eating Disorder
BSW	Bath and North East Somerset, Swindon and Wiltshire
B&NES	Bath and North East Somerset
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive behavioural therapy
CYPN	Children and Young People's Network
CQC	Care Quality Commission
DSM-V	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating Disorder
EUPD	Emotionally unstable personality disorder
FREED	First Episode Rapid Early Intervention for Eating Disorders
GP	General practitioner
NQT	Newly qualified teacher
PCLS	Primary Care Liaison Service
OCD	Obsessive-Compulsive Disorder
OFSED	Other Specified Feeding or Eating Disorder

PSHE	Personal, social, health and economic education
RUH	Royal United Hospital
SEED	Support and Empathy for people with Eating Disorders
SEND	Special Educational Needs and Disabilities
STEPS	AWP Eating Disorder - Support, Treatment, and Education Programme
SWEDA	Somerset and Wessex Eating Disorder Association

What did we do?

Timeline

This project was carried out between September 2023 and May 2024 with the survey running from November to March. Feedback was gathered via an online survey, a printed survey and direct communication with individuals in the community through engagement sessions and interviews across Bath and North East Somerset, Swindon, and Wiltshire (BSW).

Creating the survey

Findings pulled out from national and local research contributed to the creation of the survey as it provided an idea of the topic areas we wanted to research. From this, the survey was designed to gain an insight into individuals' perspectives on the causes of eating disorders as well as looking at which services people have heard of or have used.

The primary method used was a survey, ran both online and in-person. The survey included qualitative and quantitative data due to the inclusion of both open and closed questions. The survey is available in appendix 2.

Due to the high rates of hospital admissions resulting in an eating disorder diagnosis, the survey focused on recognising the potential causes of eating disorders and the struggles people with eating disorders face in accessing services.

Spreading the survey

As this project was also focused on looking at the support available locally, it was important to contact organisations who provide support to individuals who experience eating disorders.

Not all organisations who aided in spreading the survey work specifically with children and young people with eating disorders. Instead, we chose to contact a range of organisations who work with children and young people more generally and parent/carers of children and young people. Professionals were also welcomed to complete the survey.

For this project we used snowball sampling, convenience sampling and purposive sampling. These sampling methods were used to spread the survey to individuals and organisations who would be able to provide an insight into eating disorders either through their own experiences or through someone close to them.

Collecting findings

Once the survey was closed, data was collected and analysed. Key findings and patterns are presented in this report. Findings from interviews with individuals are presented as a case study which is included in appendix 3 in this report.

Who did we hear from?

Participants

Participants for this project included:

- Young people with a diagnosed eating disorder
- Young people with disordered eating/food struggles
- Students from the University of Bath
- Parent/carers of children and young people with an eating disorder or disordered eating
- Adults who either currently struggle with an eating disorder or struggled with an eating disorder as a young person
- Professionals working with young people

The survey was also open to anyone who wanted to share their experiences.

Survey

The survey was available online and in a printed format. In total, the survey received 230 responses.

Engagements

We also interacted with people and organisations at engagements which provided valuable qualitative feedback. Below is a list of the engagements attended:

- Bath Parent/Carer Forum café
- Kelly Foundation
- Mental Health Forum ran by Healthwatch Wiltshire
- Children and Young People SEND Network meeting
- My Future Event at New College
- Community Services Framework Eating Disorders Sub Group
- Bath College Careers Fair

Report findings: overview

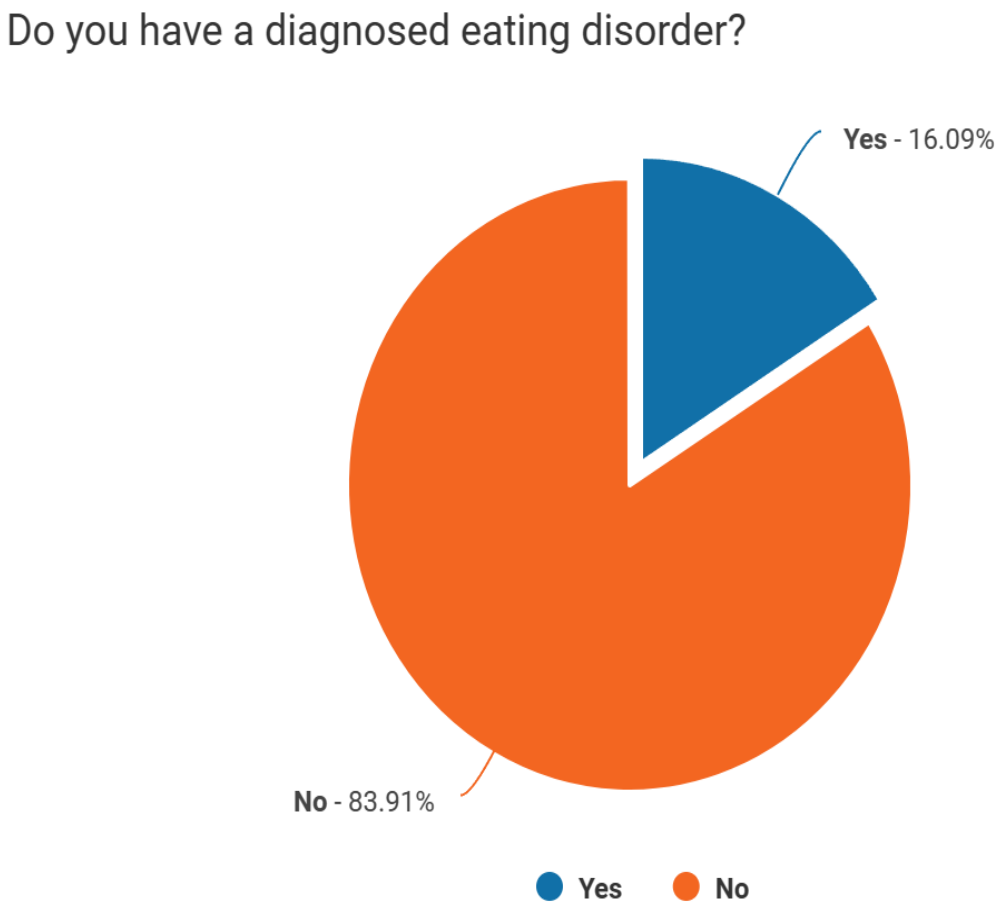
As this research project was run across Bath and North East Somerset, Swindon, and Wiltshire (BSW), we have created an overview of the findings below. We will be explaining and presenting evidence of these findings in more detail across the three areas in BSW.

The findings have been split into three key areas: diagnosis, causes, treatment and support. Within these areas key themes have been highlighted. Whilst many key themes have been found there has been one key theme that has stood out and is embedded in all three key areas. This is the opinion that *individuals feel they have to been at crisis point before their illness and struggles are acknowledged and support is provided.*

Full demographic information can be found in appendix 4,5,6and 7.

General feedback from survey

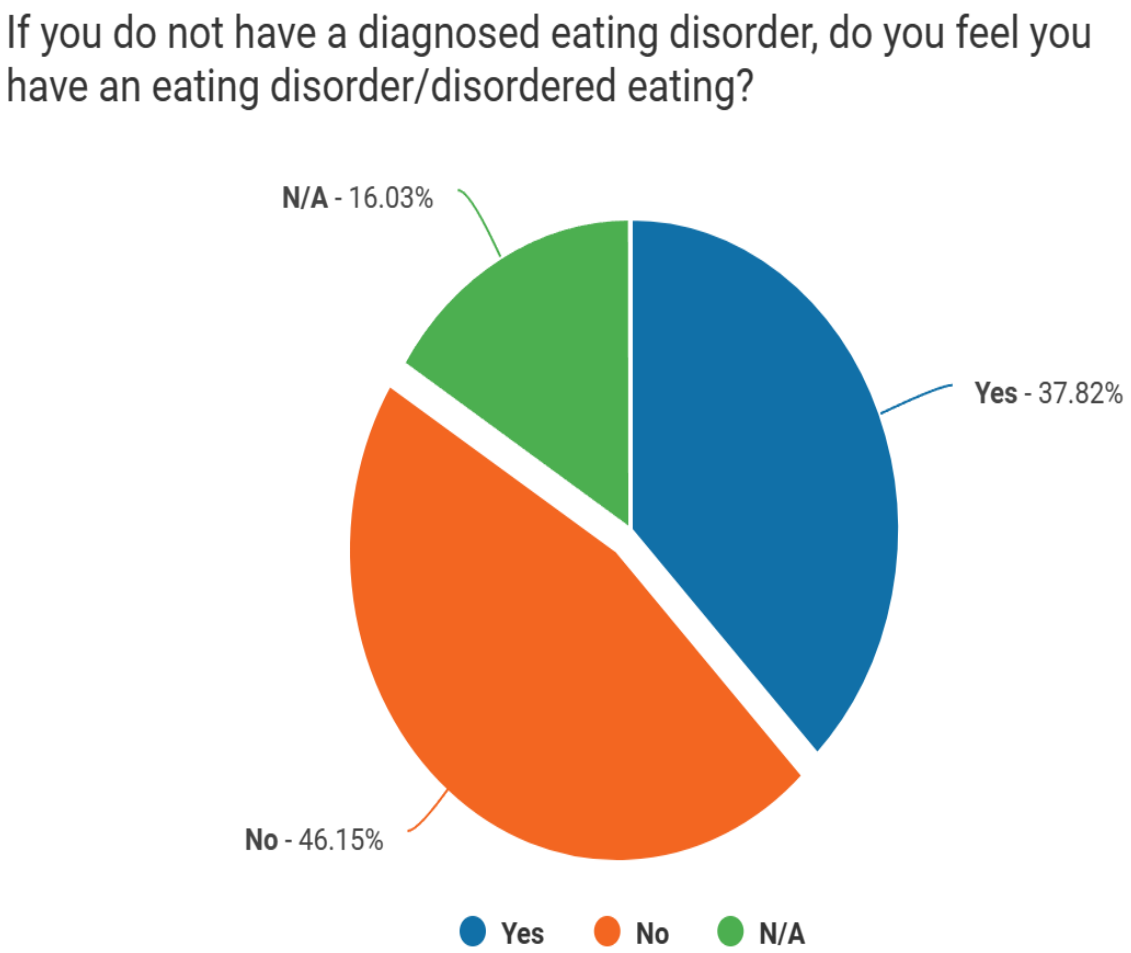
Diagnosis



- 37 of our respondents had a diagnosed eating disorder and 193 reported not. However, for those who answered yes, 1 respondent commented that they are

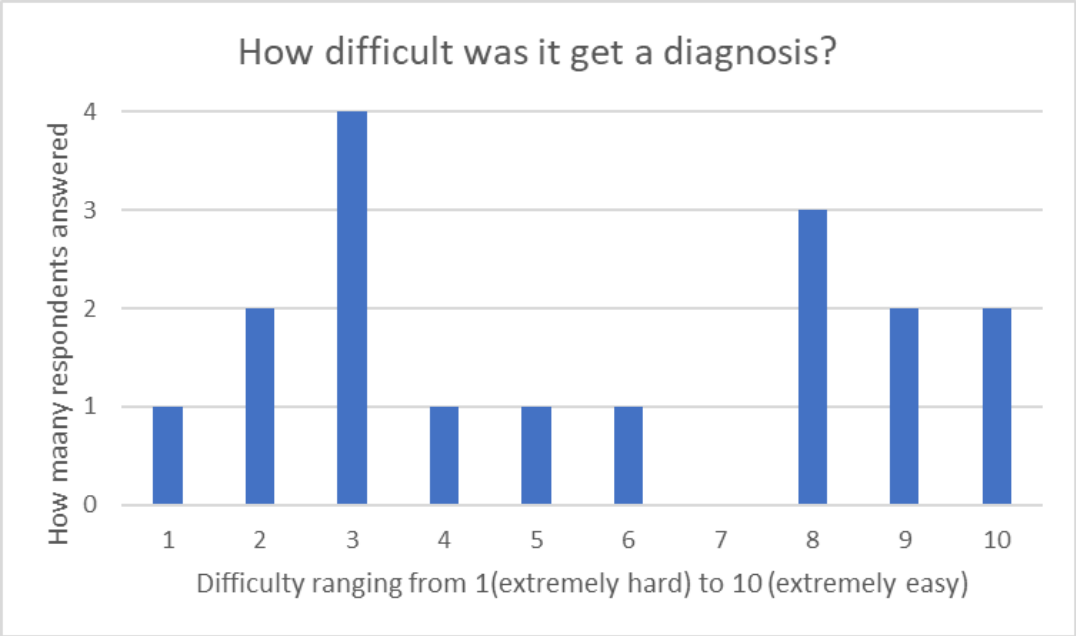
a parent of a child with Avoidant and Restrictive Food Intake Disorder (ARFID). Another respondent commented their son is 'not diagnosed but Avoidant and Restrictive Food Intake Disorder (ARFID) has been suggested.'

- Of those who responded no to the above question, 13 reported being a parent/carer of an individual with an eating disorder.
- 10 of these reported their loved one having a diagnosed eating disorder and 3 of these respondents reported their loved one having an undiagnosed eating disorder.
- 4 respondents reported themselves as having an undiagnosed eating disorder but have not been able to access support.
- 3 respondents also reported working within eating disorder services.



- The graph above shows that 59 respondents felt they, or their loved one, has an eating disorder.

On a scale of 1 (extremely hard) to 10 (extremely easy), respondents were asked how easy it was to get a diagnosis. We received 17 responses which varied across the scale. The most common answer being 3.



- When discussing diagnosis individuals reported the below struggles:

  No clear pathways to receiving a diagnosis or accessing support resulting in parents and individuals feeling lost and isolated.

> *"I don't know who to turn to"*

  Parents have reported finding it difficult to receive an eating disorder diagnosis particularly when their child has attention deficit hyperactivity disorder (ADHD) or Autism. This is reportedly due to professionals viewing their food struggles as part of this diagnosis.

> *"We are just told it is part of their diagnosis'*

- Patients feel like they are not listened to when they speak to professionals about their struggles. This has resulted in patients feeling as though they need to be at crisis point before their struggles are acknowledged. Others have reported being misdiagnosed as a result of not being listened to. This is combined with a lack of knowledge and understanding around eating disorders.

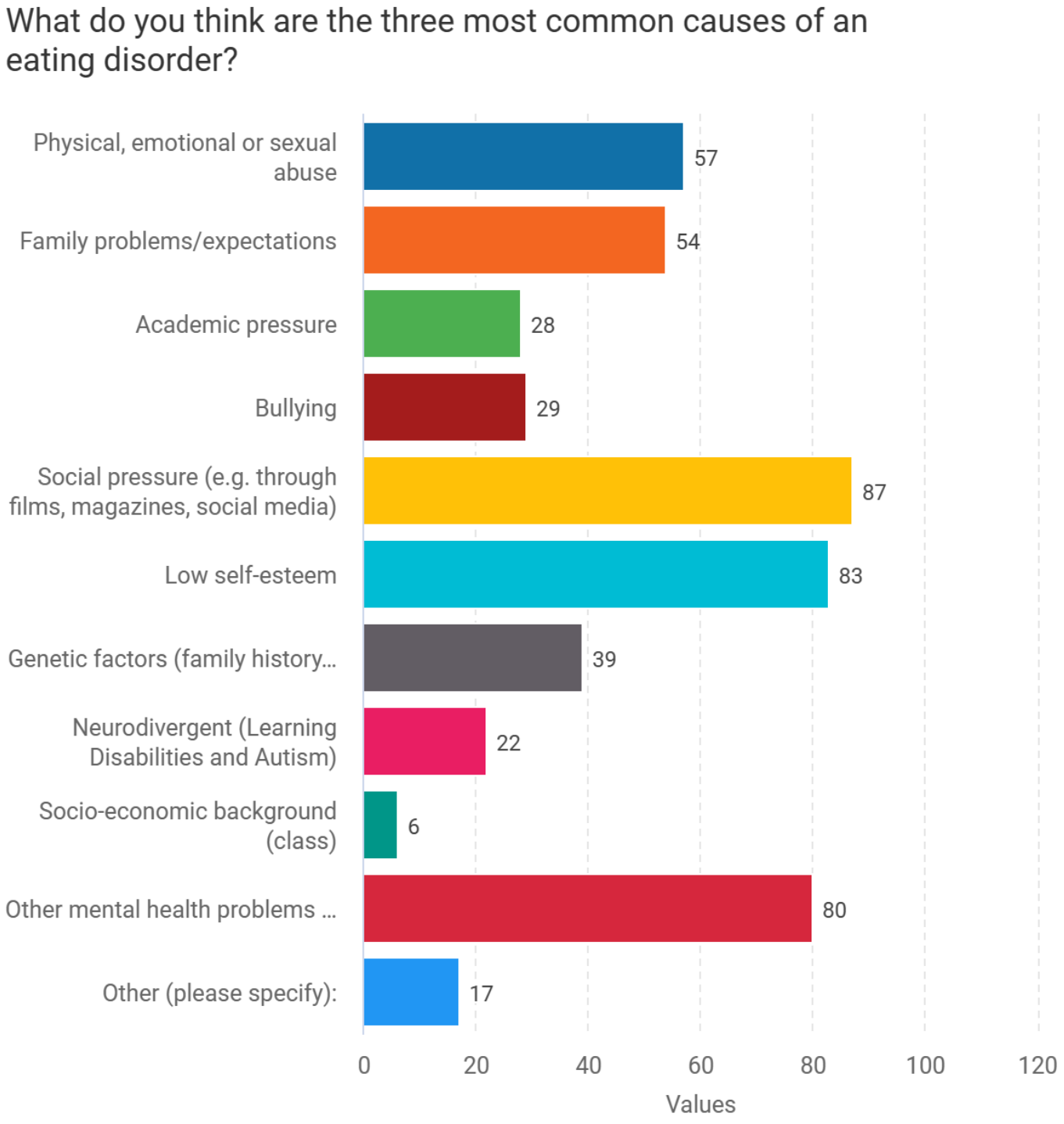
'I was initially misdiagnosed by the unit which felt like I wasn't being seen or listened to as a person'

"why do we have to wait until we are in a crisis?"

Causes

- The top three most common causes selected by respondents were: Social pressure/social media (87 respondents), Low self-esteem (83 respondents) and Other mental health problems (80 respondents).
- For B&NES, social pressure was selected the most. For Swindon, physical, emotional or sexual abuse was selected the most. For Wiltshire, low self-esteem was selected the most.
- It has been reported that there is limited early intervention available which as a consequence can result in eating disorders becoming more ingrained.

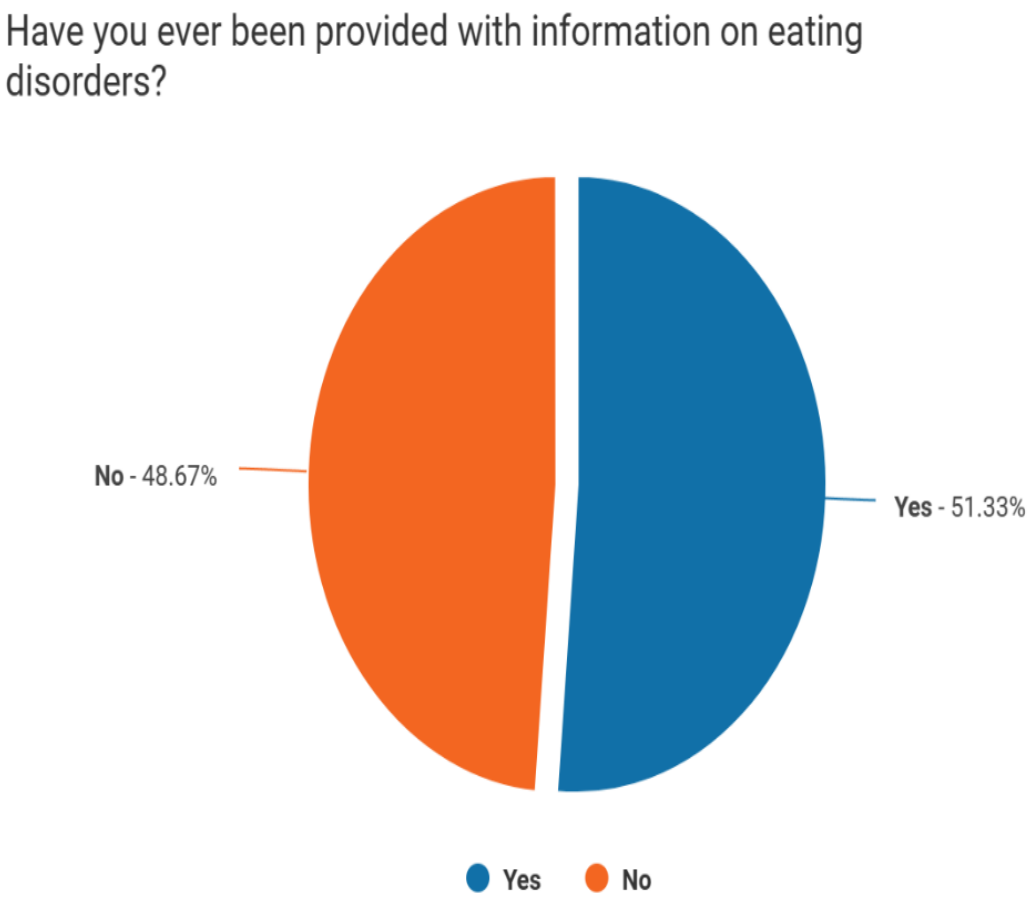
'Prevention/early intervention not provided at all'



Examples of other suggested causes included: 'all the above', 'control', 'family attitudes to food', 'procrastinating', 'work pressure', 'emotional dysregulation, due to lack of ability to'

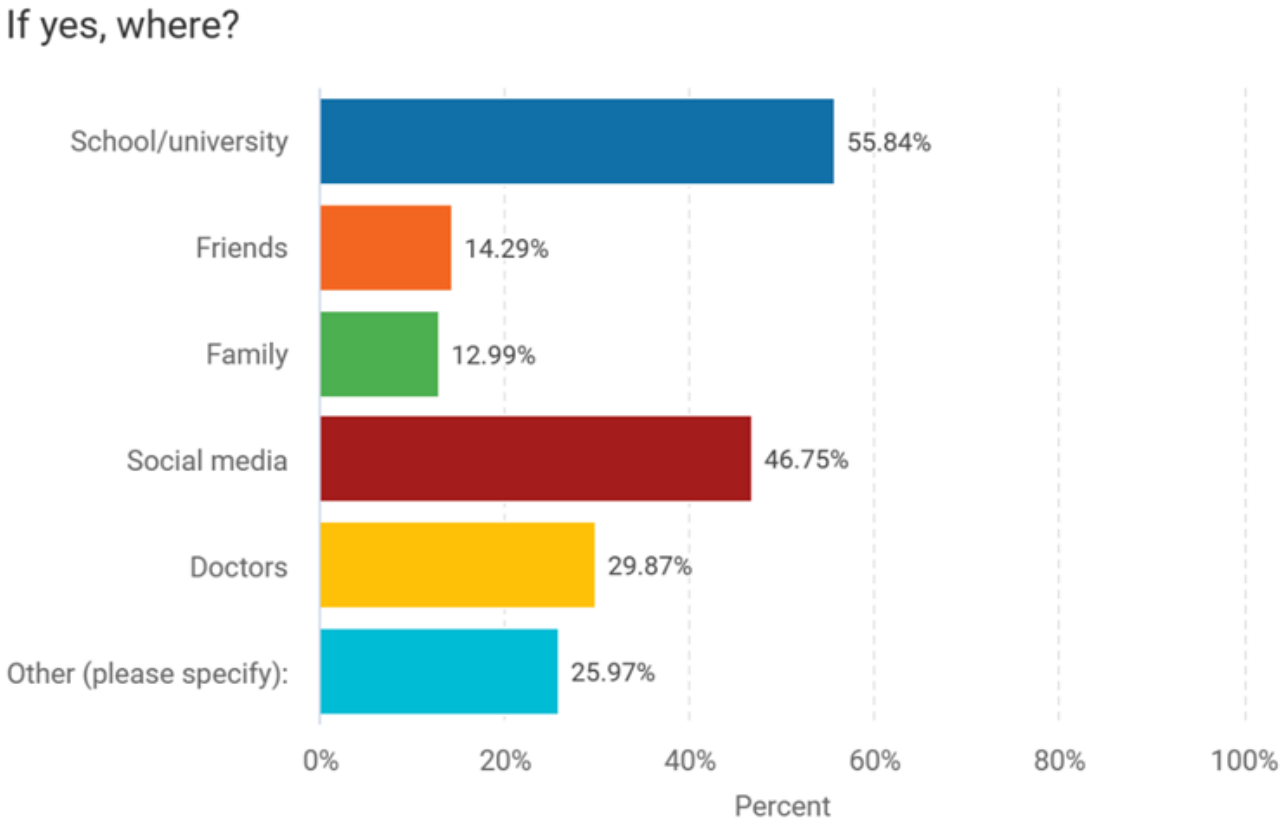
Information about eating disorders

73 respondents reported not having been provided with information on eating disorders and 77 reported they had.



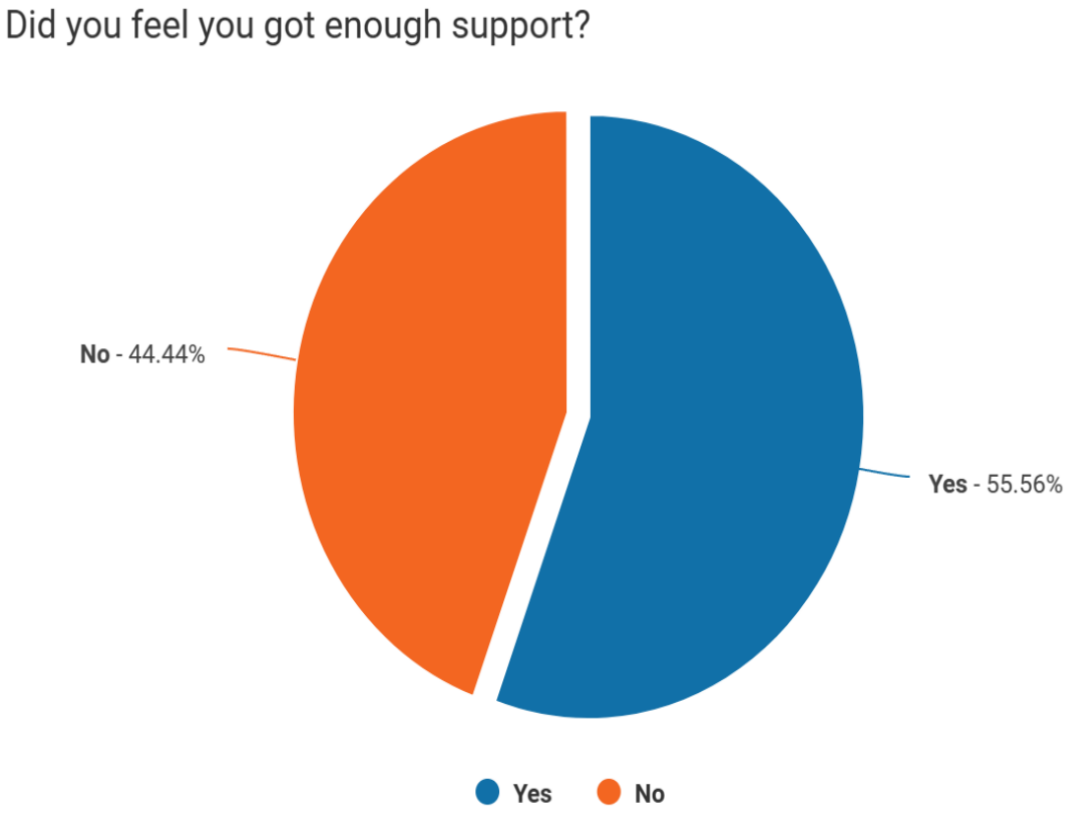
Whilst, 43 survey respondents reported schools/university providing them with information, individuals at the Bath College Fair reported not being provided with enough information about eating disorders.

> *"College provides information about mental health but not about eating disorders"*



Treatment and Support

- Out of those who reported having a diagnosed eating disorder, 8 felt like they did not receive enough support and 10 felt they did.



- Many respondents held the opinion that there is an overall lack of support across Bath and North East Somerset, Swindon and Wiltshire (BSW) particularly for Avoidant and Restrictive Food Intake Disorder (ARFID).

'My son should be diagnosed with ARFID but GWH Dietician confirmed they do not diagnose in our area and no support for it.'

- When accessing support, it was reported that support is primarily online. Specifically, respondents reported being directed to Eating Disorders Association (BEAT) and Somerset and Wessex Eating Disorder Association (SWEDA). However, for many respondents this is not the preferred method and they would prefer to access support face to face.

'I am just sent a leaflet that doesn't help.'

- Individuals felt they are not provided with adequate mental health support to aid with the recovery.

'I never got psychological help'

- Respondents reported that the transition from Child and Adolescent Mental Health Services (CAMHS) to adult services is fragmented.

'on transition into adult services was woefully poor.'

- Respondents had mixed views on the efficiency of communication between services and the patient.

'I think communication with the team and between health services has impacted at times on how supported I felt'

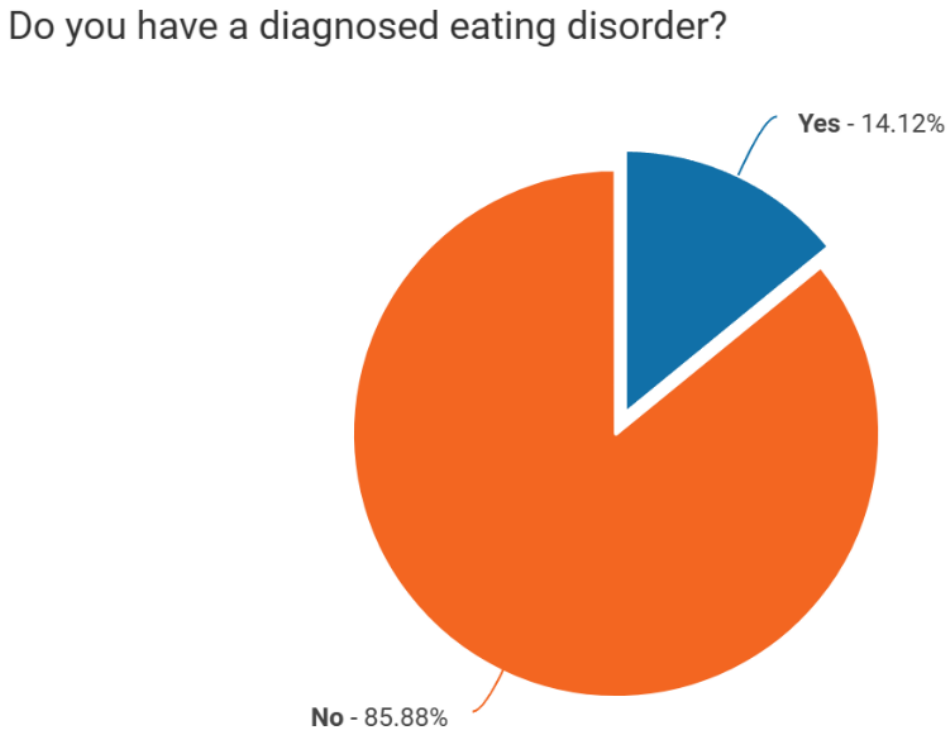
- Our case studies and respondents have provided various reports of failings by services. Overviews of one of these case studies are available in the locality available in appendix 3.

What did people in B&NES tell us?

Feedback was provided via our survey and engagement sessions. These included attending a café meeting run by the Bath Parent carer Forum and a careers event run by Bath College.

Feedback from our survey

85 people in B&NES responded to our survey. Full demographic information for B&NES can be found in appendix 5.



- 12 had a diagnosed eating disorder and 32 felt they either had disordered eating or an eating disorder which had not been diagnosed.
- 8-24 years old was our most common age with 56 respondents, followed by 25-49 years old with 12 respondents.
- 56 respondents were women, 26 were men and 2 were non-binary.
- 67 respondents were White British and 10 respondents were White (any other background)
- 61 respondents in Bath were students, 8 were part time, 12 work full time, 1 is a carer and 2 respondents selected other and described themselves as a 'student but also doing part time work' and 'parent of a child who is 13.'
- 62 respondents reported being heterosexual and 10 respondents reported being bisexual. 3 respondents preferred not to a say and 10 respondents preferred to self-describe.

Key findings across B&NES

Mixed routes of referral

B&NES had 12 respondents with a diagnosed eating disorder. Out of these 12 respondents, 5 reported referring themselves and 7 reported being referred by someone else. This includes GPs and parents. 2 individuals reported being referred after a hospital admission, suggesting that they had not received/accessed support until they needed to be admitted.

'Someone else (AWP professional (Avon and Wiltshire Partnership)) referred me, whilst I was receiving support for generalised anxiety disorder at the time.'

'Parents referred me when I was 14. I did not know/admit I had an eating disorder so it was helpful that my parents recognised the problem'

'I referred myself but only after several years of suffering and with the stipulation that if I changed my mind about receiving help at any point I could back out.'

Mixed opinions whether respondents felt listened to

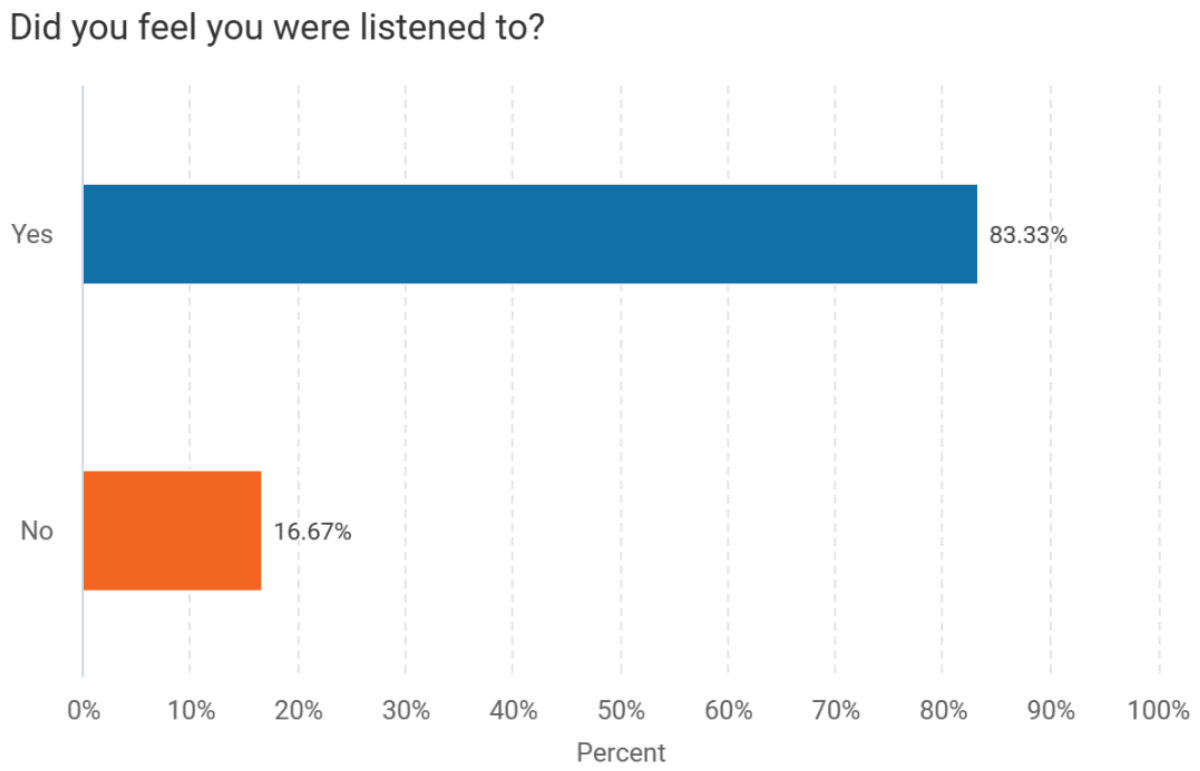
Respondents provided mixed opinions on services which provide eating disorders. Services respondents provided feedback on included: General practitioner (GPs), STEPs, Primary Care Liaison Service (PCLS), Eating Disorders Association (BEAT) and Child and Adolescent Mental Health Services (CAMHS).

'tried to get support but did not feel listened to'

'it was very hard to get anyone to listen or take my condition seriously'

'sometimes they would listen to what my parents were saying more than what I was'

'I was initially misdiagnosed by the unit which felt like I wasn't being seen or listened to as a person'



Mixed opinions on how supported respondents felt

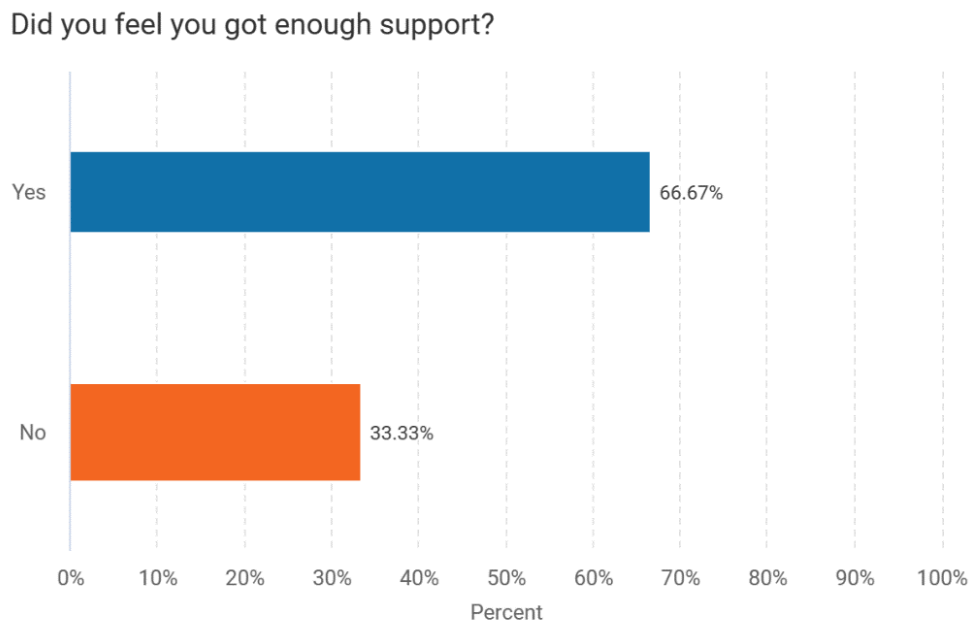
Respondents also provided mixed responses on how supported they felt. 2 respondents provided positive opinions on the support they viewed whilst 7 other respondents highlighted negative experiences of accessing support for an eating disorder.

'I felt that they were under time pressure and trying to pigeon hole my symptoms to fit a diagnosis which made me feel like just a case to be categorised.'

'I did not get help from a dietician which I feel I really needed'

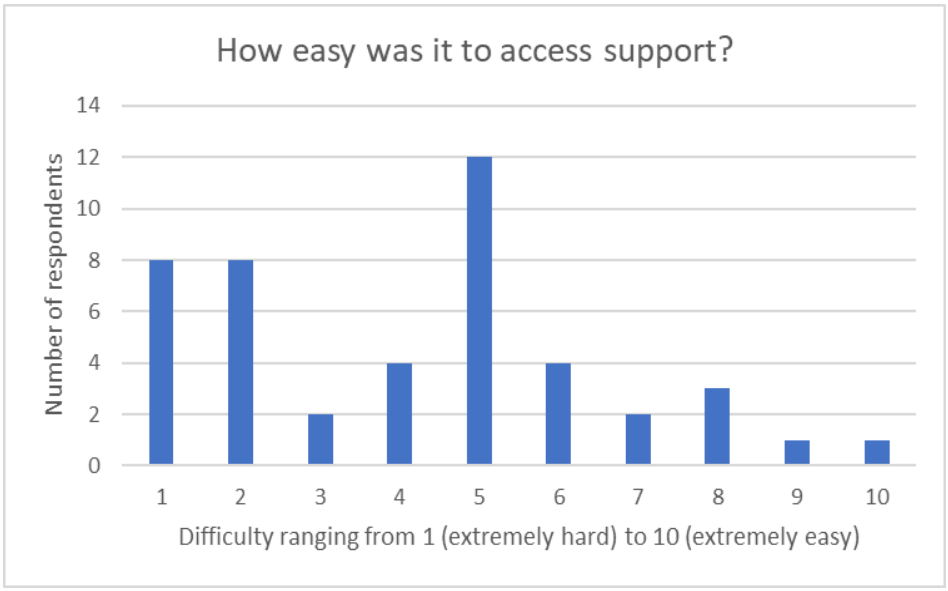
'I received essentially no guidance'

'It has taken a long time to get support which I believe has made my health deteriorate faster.'



Only one respondent found it extremely easy to access support

We asked respondents how easy was it to access support, if it was needed, on a scale of 1 to 10. 1 being extremely hard and 10 being extremely easy. The graph below presents the responses to this question.



This highlights that the majority of respondents had not found it easy to access support, and is backed up by respondents' comments below:

'for people I know with an Eating Disorder (ED) it was extremely hard and not always believed if not severely underweight.'

'there's not enough awareness of eating disorders (EDs) in the public domain'

'1 -none available in B&NES'

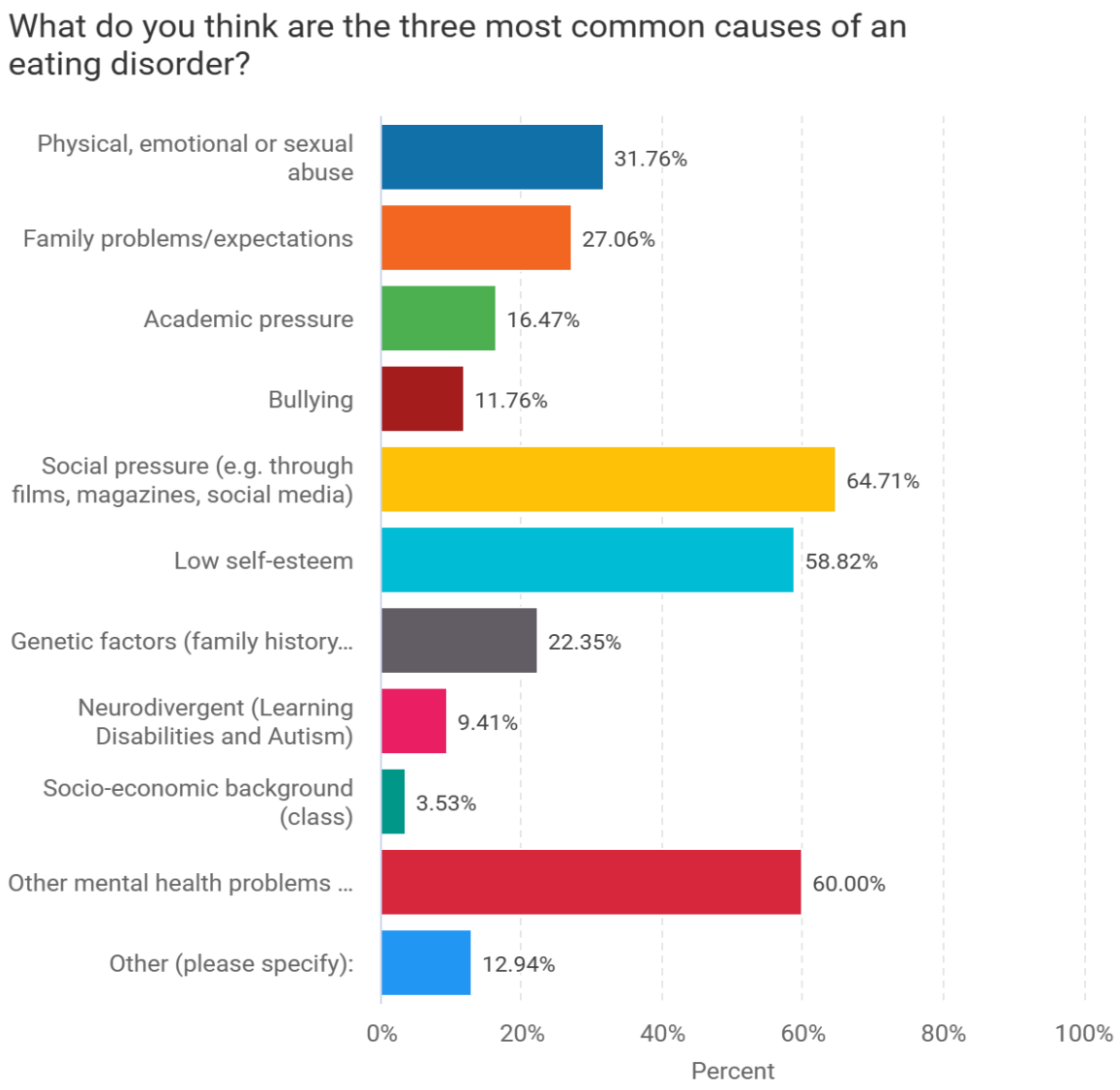
Social pressure was the most common cause of eating disorders selected

Social pressure such as pressure through films, magazines and social media, was selected the most regarding causes of an eating disorder.

The impact of social pressure/social media was also highlighted through engagements, particularly at the Bath College Career fair.

"There are pages promoting being skinny but if are skinny you are shamed for not being curvy"

Social pressure was closely followed by other mental health problems, such as depression, anxiety and bipolar disorder, and low self-esteem.



Other causes suggested by B&NES respondents included:

'family attitudes to food in how weight correlates to worth'

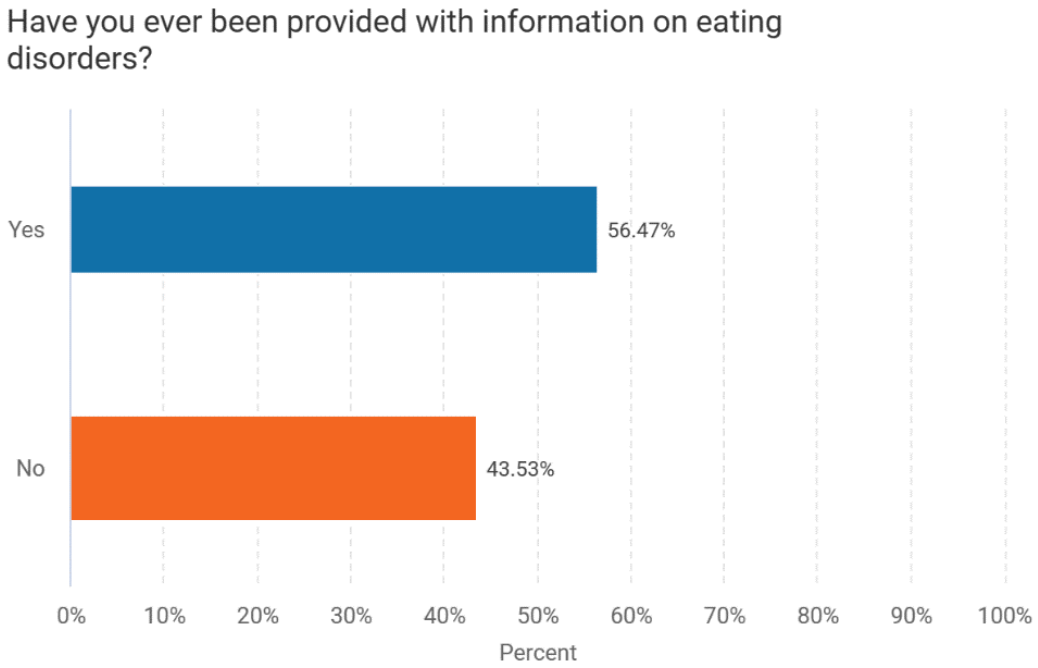
'control'

'I think they are all contributors'

Other respondents commented on their difficulty to pick just three of the suggested causes:

'I think all of the identified factors can impact on an individual developing an eating disorder'

School/university is the most common place to have been provided with information on eating disorder



48 respondents reported that they have been provided with information regarding eating disorders whereas 37 individuals have not. Of those who have been provided with information, school/university was the most common response. This was followed by social media and doctors.

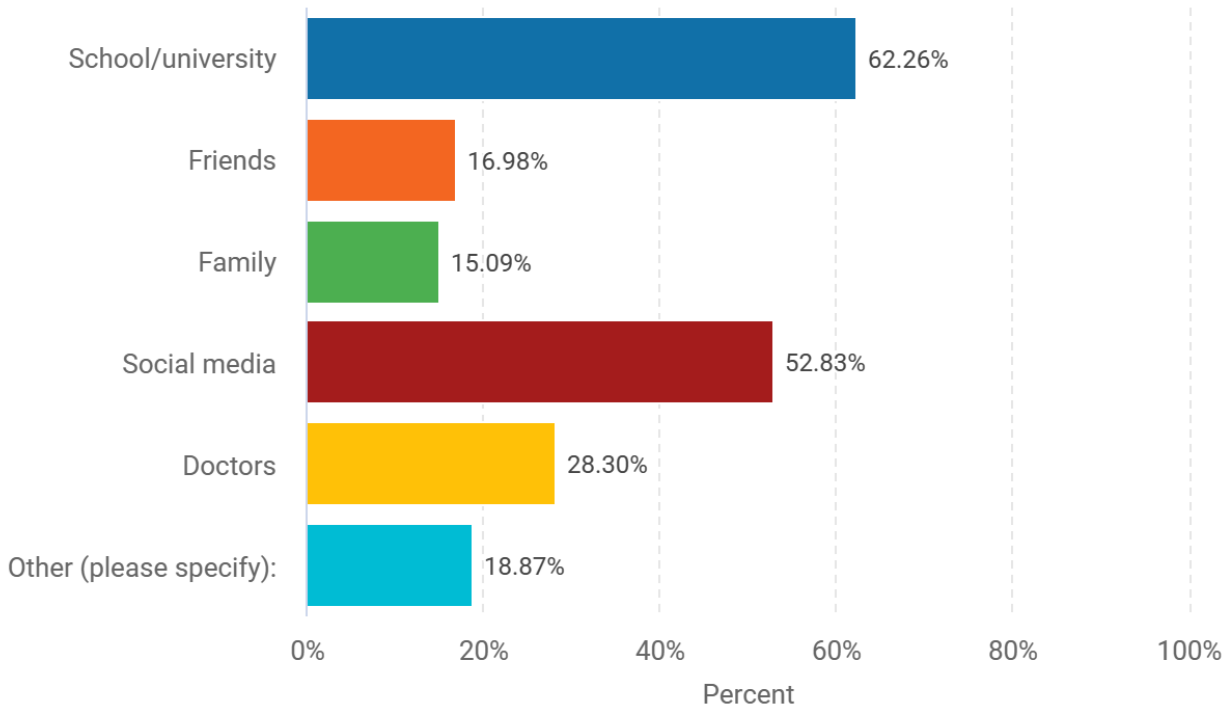
Respondents also commented on other places in which they have been provided with information. Examples of these include: STEPs team, staff when a

loved one was an inpatient, workplace, Eating Disorder (ED) training and via paediatrician

One respondent also provided information regarding information accessible for carers.

'Child and Adolescent Mental Health Services (CAMHS) offered a 6 week course for carers'

If yes, where?



Issues and gaps

Lack of third sector organisations

From a discussion with Bath Mind, it was highlighted that there is no third sector organisation which solely focuses on providing support for individuals suffering with an eating disorder in B&NES.

This results in other third sector organisations, such as Bath Mind, providing support where possible. Bath Mind can provide face to face support for those who have an eating disorder as well as a diagnosed mental health illness such as Emotionally unstable personality disorder (EUPD).

Whilst this support is beneficial, it was suggested that having a third sector organisation focused on eating disorders would provide more effective support to individuals with an eating disorder.

Communication between services and patients

As adult eating disorder services within B&NES are run by Avon and Wiltshire Mental Health Partnership (AWP) and eating disorder services for under 18s are run by Child and Adolescent Mental Health Services (CAMHS), Oxford Health, communication between these two organisations is extremely important in providing effective and efficient support. However, feedback from our survey suggests that communication has been an issue for many individuals in B&NES resulting in individuals feeling less supported and delays in support.

'communication with the team and between health services has impacted at time how supported I felt'

'STEP's team have one direct email address and contact number there have often been delays in communication or responses not received.'

'Difficulties in communication between the teams also meant that the STEP's team didn't have information before or following the admission that could have meant this could have been anticipated or avoided.'

Lack of knowledge by professionals

Respondents have reported feeling misdiagnosed due to professionals not understanding the individuals suffering and not being aware of the support available. This has resulted in individuals feeling as though they are not supported or listened to.

My general practitioner (GP) at the time of my struggles had no idea how to support me or that STEPs even existed'

'there's a lack of eating disorder awareness and treatment knowledge by medical professional (i.e. GPs)'

'I was initially misdiagnosed by the unit which felt like I wasn't being seen or listened to as a person.'

'I felt that they were under time pressure and were trying to pigeon hole my symptoms to fit a diagnosis which made me feel like just a case to be categorised which led to my being initially misdiagnosed with Avoidant and Restrictive Food Intake Disorder(ARFID). I still feel uneasy about my new diagnosis and that *it doesn't always fit my experiences'*

Lack of mental health support

Many individuals with an eating disorder also struggle with their mental health. However, participants have reported receiving limited mental health or psychological support to help understand the reasons behind their eating disorder. This has resulted in individuals reporting that their physical health is considered more important than their mental health. With the psychological reasons behind their eating disorder not being treated, individuals will continue to struggle with their eating disorder.

'I never got psychological help, I was just given a meal plan and lots of frequent physical tests. They were focused on my physical health and then discharged me once my observations were safe enough so all of the cognitive processes behind it have never been addressed'

'no psychological treatment for eating disorder (ED)'

'the mental health input was minimal and I felt very on my own while I was struggling'

Lack of prevention and early intervention

Individuals have been able to access support when they are experiencing severe struggles however, there has been reports of limited early intervention/ prevention in place for eating disorders.

'lack of awareness of support in the community to aid early intervention'

'I never really realised that I had an eating disorder until it was so engrained that I had to go into hospital for intensive support'

Lack of support available

Feedback from our survey highlighted that individuals feel there is a lack of support available within B&NES, particularly regarding access to dieticians. For the support that is available in B&NES, respondents held the opinion that support was only available when the individual had hit crisis point. This has resulted in individuals feeling as though organisations do not want accept responsibility for the individual.

'even if they listen and acknowledge it as a problem, they just put you on a waiting list. I also often felt that I was being pawned off onto different services and no one actually wanted to take responsibility for me.'

'my recovery was almost entirely down to me with little input from the team that was supposedly helping me'

'the main issue is access in the first place.'

'they don't support me until I reach a crisis point and then they step in'

'general practitioner (GP) referred to therapies who had nothing in B&NES. Did not get support.'

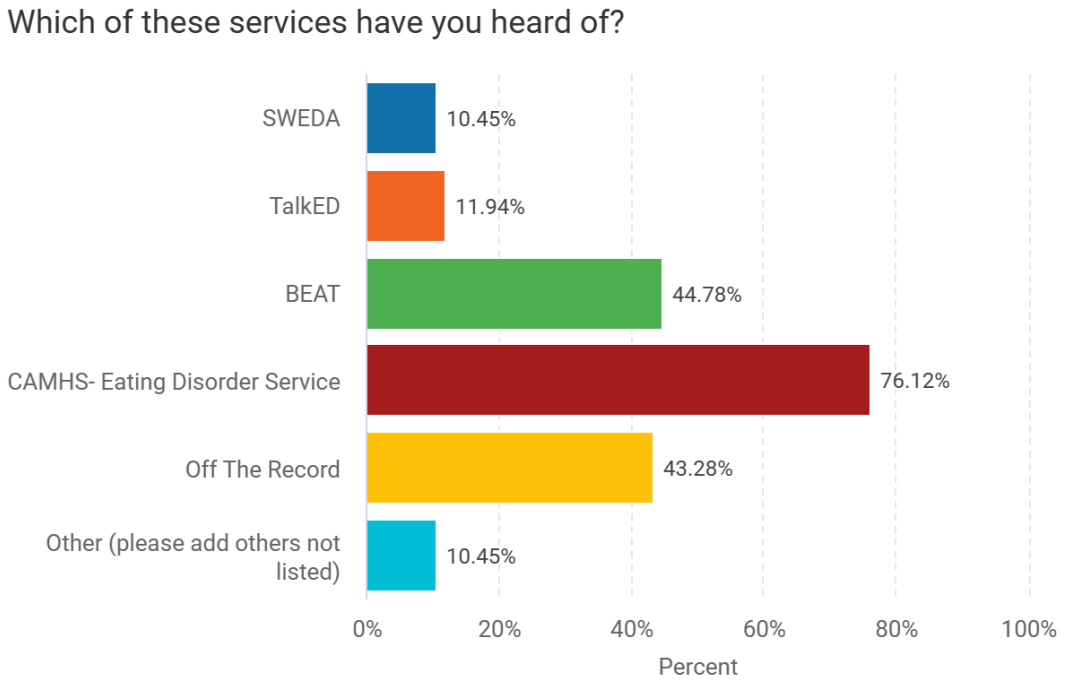
'I still cannot get a dieticians input despite still being dangerously underweight'

Feedback on Services

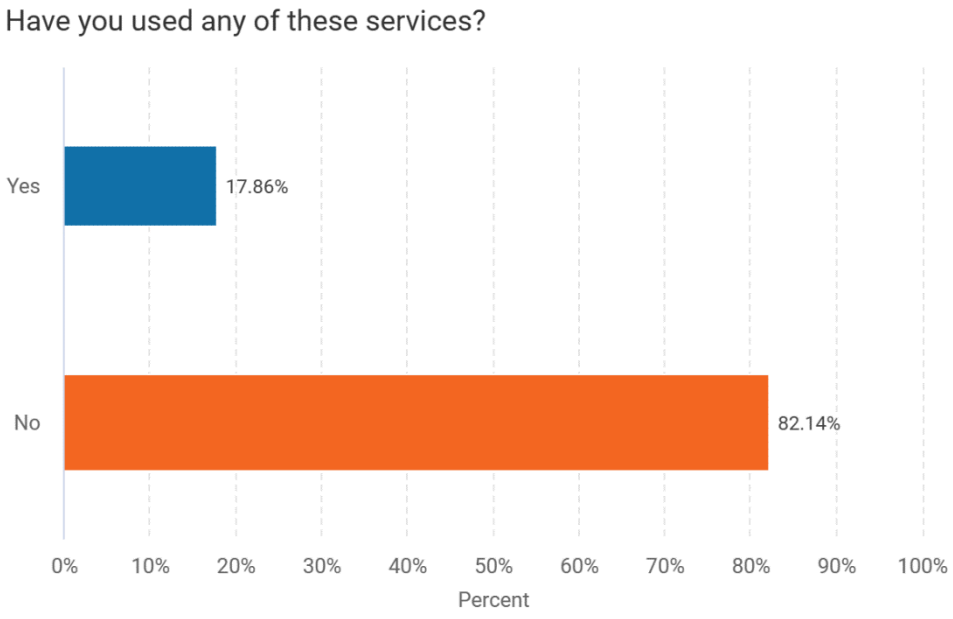
The graph below shows the responses, given via our online survey, about organisations who provide support for eating disorders.

Feedback from our survey showed that many respondents were aware of organisations that can provide support to individuals with an eating disorder.

2 respondents have not heard of any of the services and 2 respondents stated they knew of these services through their employment. 2 out of the 7 respondents who selected 'other' provided other services they have heard of. This includes: *STEPs, Oxford Health eating disorder service and Bath eating disorder support group.*



However, the majority of respondents have not used these services.



What services have people used and did they help?

We asked respondents to provide feedback on the services they have used. Respondents' positive and negative comments are provided below:

Primary Care Liaison Service (PCLS)

'with the Primary Care Liaison Service (PCLS) I didn't feel listened to and the follow up referral letter contained numerous mistakes'

Avon and Wiltshire Mental Health Partnership (AWP) and STEPs

POSITIVES	NEGATIVES
'Royal United Hospital (RUH) staff and STEPS were both amazing'	'communication with the team and between health services has impacted at times on how supported I felt'
'I cannot fault the care and communication from individual support workers at STEPs'	'there have often been delays in communication or responses not received'
'Great service, caring, compassionate and really recovery focussed. Excellent service when you get referred and are offered help.'	'Difficulties in communication between the teams also meant that the STEP's team didn't have information before or following the admission'
'immensely helpful for Cognitive behavioural therapy (CBT), occupational therapy & dietetic support'	'the support from Bristol STEPS does not feel like enough; they don't support me until I reach a crisis point'
'My general practitioner (GP) and the STEPs team have been good, and I have felt supported and listened to.'	'it has taken a long time to get support which I believe made my health deteriorate faster.'
	'I also feel that due to the pressure the team are under I have not been given access to the correct therapy/treatment for my needs'

Child and Adolescent Mental Health Services (CAMHS)

POSITIVES	NEGATIVES
'I think it helped in terms of not speaking to someone who was not a family member or friend'	'no psychological treatment for the Eating Disorder (ED)'
'very helpful in my experience'	

‘really helped me through a difficult time, gained a lot from their counselling services’	‘didn’t feel as though the therapeutic techniques used were necessarily helpful’ ‘referred to Child and Adolescent Mental Health Services (CAMHS) but discharged as unable to help’ ‘Difficulties in communication between the teams also meant that the STEP’s team didn’t have information before or following the admission’ ‘Sometimes they would listen more to what my parents were saying than what I said’

GPs

POSITIVES	NEGATIVES
‘My general practitioner (GP) and the STEP’s team have been good, and I have felt supported and listened to.’ ‘My doctor at my university medical centre game me lots of time and I felt she listened intensively to my experiences’	‘my family had to be quite forceful with general practitioner (GP) as they were initially unwilling to take blood/weight measurements or refer me to hospital’ ‘My GP never picked it up […]. He didn’t know the right questions to ask or how to signpost me to support that could have helped’ ‘there’s a lack of eating disorder awareness and treatment knowledge by medical professionals (i.e. GPs)’ ‘My GP at the time of my struggles had no idea how to support me or that STEPs even existed’

Eating Disorders Association (BEAT)

POSITIVES	NEGATIVES
‘were good in providing a lot of insightful information’ ‘the support groups were helpful through the initial stages of realising I was sick’	‘BEAT helpline- didn’t really help’ ‘I used BEAT. I found the emergency phone line wasn’t very helpful, if I called them distressed or struggling

they couldn't really offer any support or advice'

Feedback from engagements

Experiences of parent/carers of young people with additional needs

This engagement involved attending the Bath Parent/Carer Forum and speaking to parent/carers of individuals with Special Educational Needs and Disabilities (SEND) and/or eating disorders/disordered eating. From this, these parents provided valuable insight into their own experiences and their child's experiences with accessing eating disorder support for a child with additional needs.

Key points

- Expanding diet- Parents struggle to include new things into their child's diet due to their primary diagnosis. Certain foods reflect their mood. Some foods are more comforting to them. Difficulty is increased as their children often only like certain makes/brands of food, such as McDonalds. This can cause financial strain.
- Accessing treatment- When trying to access treatment, parents feel they receive no help and experience parent-blaming from themselves and other people. They don't know where to receive help and are often told they need to be stricter with their child.
- Lack of consistency- Parents reported being told different outcomes by different paediatricians despite using the same form each time.
- Schools- parents held the opinion that the training and knowledge of teachers needs to be improved regarding food struggles particularly for children with additional needs. Teachers are also included in completing assessment forms; one parent's experience included their school asking a newly qualified teacher (NQT) who had little knowledge of the child to complete the form.
- Child and Adolescent Mental Health Services (CAMHS)- Overall, the parents felt there is a lack of support from CAMHS and frustrations arose regarding cancelling appointments, sometimes at very short notice, just hours before the appointment was due to take place.

Feedback

"Eating is connected to my mental health"

"Food is a control issue which is linked to autism"

"Individual with attention deficit hyperactivity disorder (ADHD) are rigid, when they decide on a diet, that's it"

"The guidance we are given is 'they'll eat if they are hungry', this is not helpful"

"Schools only deal with overweight children"

"The level of support given to young children is far less than the support given to 18 year olds"

"B&NES do not offer support"

"We are told we coddle our children too much"

Young people's perspectives on eating disorders

By attending the Bath College Career Fair, we gathered young people's opinions on eating disorders. We had an interactive activity which asked three questions. Within this activity we had individuals place a sticker indicating 'yes' or 'no' for the first two questions and left the third question open for groups/individuals to provide their answers.

Individuals we engaged with were aged 16-18 and upper age.

Are eating disorders normalised?

25 individuals answered yes. 3 answered no

"They are increasing amongst men. Some people don't speak about it as much but guys are starting to talk about it more"

"They should be normalised. People should be comfortable speaking about it"

"Nobody judges you for having one so in that sense it is normalised"

"If you have one, people are supportive and try to help"

"Mental Health and Eating Disorders are normalised so people might not know if they have one because there is a lack of information about it"

"It is more socially acceptable. People are more comfortable to speak about it but some still might be scared they will get judged"

"People talk about them but there could be more awareness"

"There is lots of stigma. People think people do it for attention and it isn't seen as a mental health problem"

"Eating disorders are still taboo"

"Talking about them might make people have one or encourage people to have one"

Does your school/college provide information on eating disorders?

1 individual answered yes. 27 answered no.

"School does not provide enough information about eating disorders"

"It should be included in personal, social, health and economic education (PSHE)"

"There is some information but not enough"

"Group tutorials would be a good place to get information to students"

"There should be more information about eating disorders in all schools and colleges"

"PSHE does not focus on eating disorders, they should include it. They only focus on drugs and alcohol"

"The support is there but it takes a long time to access it. This information should be included in lessons"

What do you think are the primary causes of eating disorders?

"Social media influences body image"

"Social media promotes it"

"People think it is cool. They brag about not eating but also brag about how much they eat"

"Social media now promotes eating disorders amongst boys"

"Parents can cause it. They control what you eat and you learn behaviours from them. They can make bad comments"

"Other pupils and bullying. Schools have a flock mentality"

"People brag about not eating"

"They are encouraged by friend groups, particularly girls, they influence each other"

"Mental health and social media impact it. When I am anxious, I don't eat. When I am depressed, I over eat"

"People want to look like influencers which isn't helpful"

"Social norms and society influence body image. Lots of people want to be skinny because that's the norm but that doesn't mean it is always healthy"

Case Studies

'Escaping Anna'

A woman, who was exploited by an individual claiming to treat vulnerable women with eating disorders, contacted us to tell her story. We are aware this clinic closed in 2008 but she felt her experiences are still happening today based on her outreach work she carries out.

- The individual, who struggled with emetophobia (a fear of vomiting) and an eating disorder, met a therapist in the early 2000s. This individual did not appear to be registered with a professional mental health authority or have her private clinic registered with the Care Quality Commission (CQC).
- As a result, the clinic was not assessed. The individuals who attended this live-in-clinic reported to experience sexually inappropriate behaviour by the practitioner and deterioration in their mental and physical health.
- In 2008 the clinic closed. Patients reported their experiences to the police.
- More information on this study is available on this link: Eating disorder psychologist 'made patients sicker' - BBC News

ARFID: avoidant and restrictive food intake disorder

A parent of a young child with Avoidant and Restrictive Food Intake Disorder (ARFID) who is part of the Bath Parent Carer Forum spoke to us about her experience with accessing support.

- Poor eating started when her child was three years old. The parent noticed gagging and food and drink refusal. When she queried this with professionals, she was told the child was just being fussy despite her son going from the 97th centile to the 20th centile (for weight) in 6 months.
- The parent and child received no support until the child had to be admitted to the hospital and was placed on a feeding tube for three weeks. This was extremely traumatic for the parent who also had previously experienced a traumatic birth.

- During the hospital stay, the family were assigned a paediatrician, but the parent felt they were not helpful. Parents were told to stick with a dietician and if they needed a paediatrician they would have to go back to the GP and be referred again. The child was sent home and referred to Child and Adolescent Mental Health Services (CAMHS) but the referral was withdrawn as the child was under 5 years old
- Despite being based in B&NES, the child was referred to Great Ormond Street Hospital. Parents asked if they could go to a hospital in Bristol but they were told there were no dieticians available. Parent also phoned her health visitor but received no support.
- As Avoidant and Restrictive Food Intake Disorder (ARFID) is a relatively new eating disorder, the parent felt the school nurse and staff were not informed in this disorder.
- Overall, this parent felt they received no support and were left to find help themselves.

Recommendations for B&NES

Below are recommendations suggested by individuals from B&NES who have provided feedback.

- Reduce cancellation of appointments especially at late notice or on the day.
- Provide teachers and health professionals with training regarding eating disorders, particularly how eating disorders present themselves for individuals with additional needs.
- Recognise eating disorders are not only present in people who are underweight but can also affect people who are not underweight.
- Improve referral processes by ensuring referrals are being completed in a time effective manner thus reducing the need for parent/carers to follow referrals up.
- Improved connections and transitions between services, particularly children and adolescent services and adult services.
- Provide information and support for individuals with Avoidant and Restrictive Food Intake Disorder (ARFID) and parent/carers of individuals with ARIFD.
- Improve information provided to students. Feedback provided by students suggested that eating disorders should be a topic taught about in personal, social, health and economic education (PSHE).
- Improve knowledge of GPs in recognising symptoms of eating disorders and their knowledge around the support available locally.
- Increase availability of dieticians in order to reduce individuals having to travel out of area to access support.

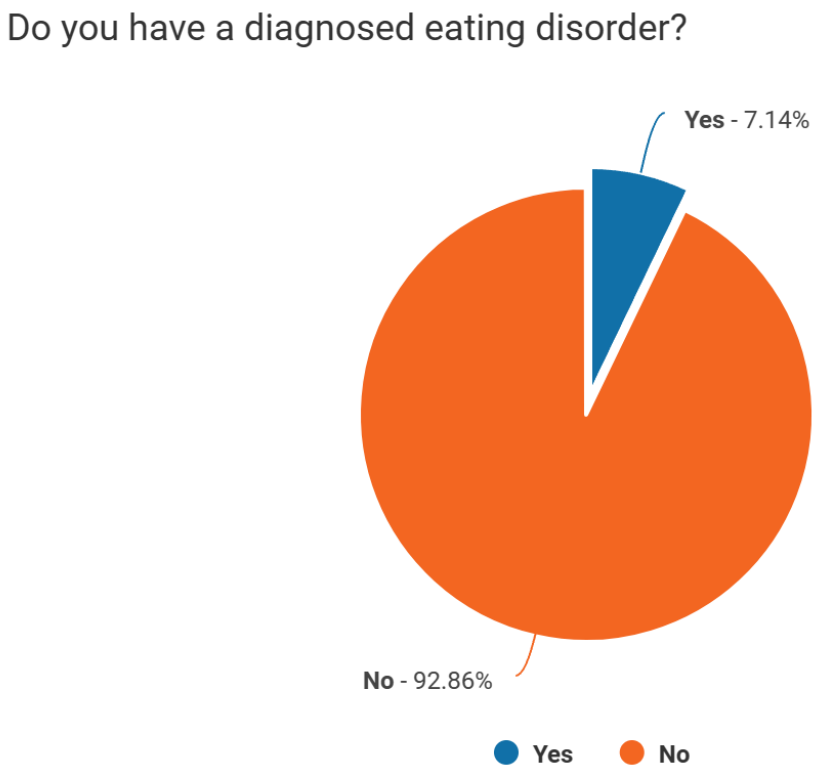
- Provide psychological and mental health support for individuals with an eating disorder.
- Introduce a third sector organisation dedicated to providing support to individuals struggling with an eating disorder.

What did people in Swindon tell us?

Feedback from Swindon was given via our survey, discussions, and engagements with third sector organisations and the NHS. These discussions resulted in two in-depth case studies involving two young women who have struggled with eating disorders for many years. Their case studies highlight failures by services, unfortunately resulting in one of these young women taking her own life in August 2023.

Feedback from our survey

28 respondents reported being based in Swindon. Full demographic information for Swindon can be found in appendix 6.



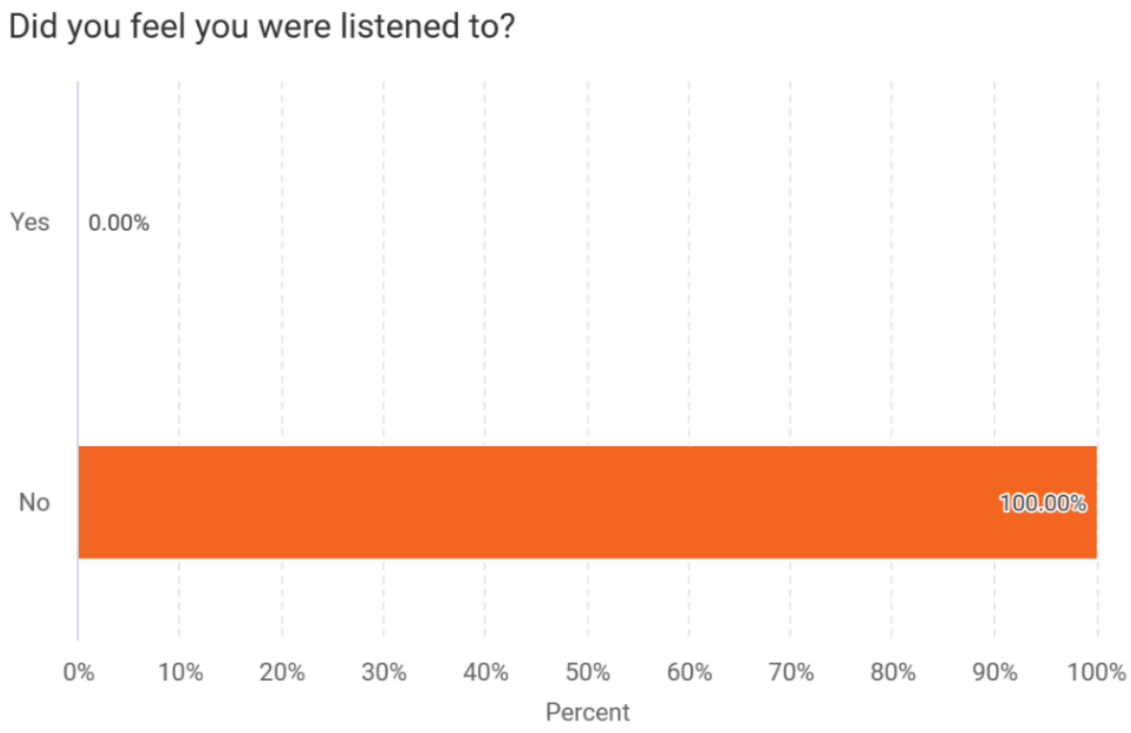
- 2 respondents reported having a diagnosed eating disorder and 26 reported not having a diagnosed eating disorder. However, of those who reported not having an eating disorder 6 stated they were parents/carers of an individual with an eating disorder.
- 13 felt they either had an eating disorder/disordered eating.

- 25-49 years old was our most common age with 17 respondents, followed by 50-64 years old with 7 respondents.
- 27 respondents were women and 1 respondent a man.
- 27 respondents were White British and 1 respondent was from mixed/multiple ethnic groups: Black African and White
- 10 respondents worked full time, 8 part time, 3 were unable to work due to health issues/disability, 3 were students, 2 retired, 1 was a carer for someone with long term health conditions/disability, and 1 engaged in unpaid work/volunteering.
- 21 respondents reported being heterosexual and 4 respondents reported being bisexual and 1 reported being a gay man.

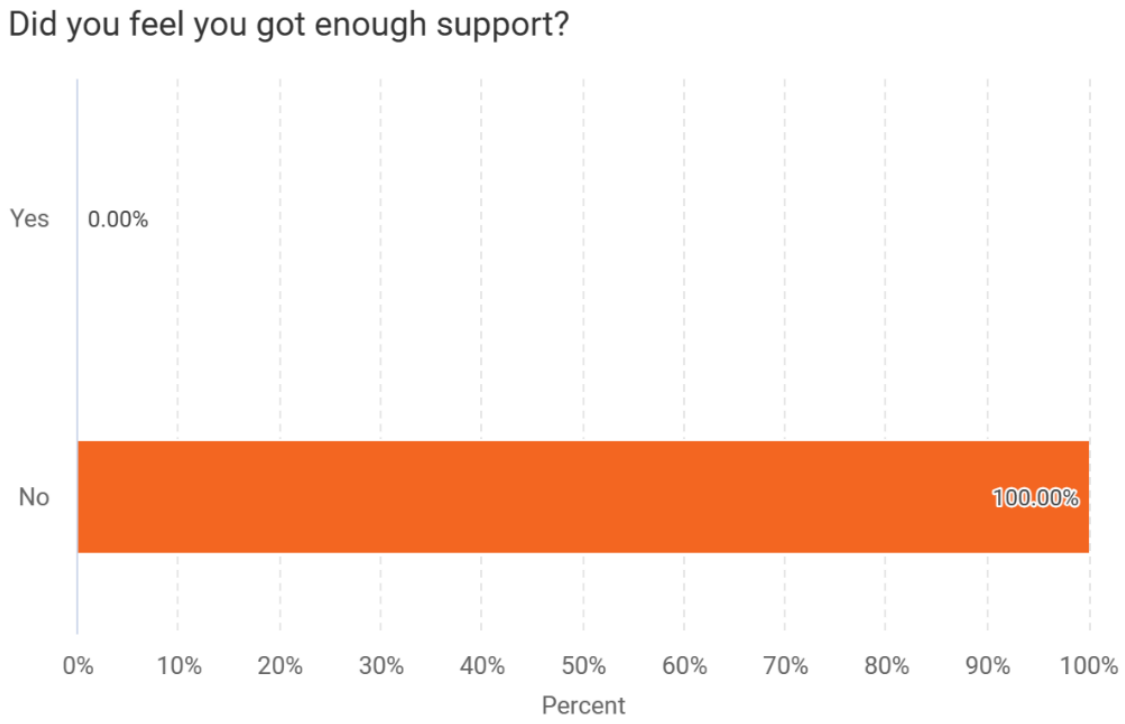
Key findings across Swindon

Respondents reported not feeling listened to

2 of the respondents with a diagnosed eating disorder did not feel listened to and did not feel they have enough support.



The organisations these individuals were referred to are Child and Adolescent Mental Health Services (CAMHS) and their GPs.



One respondent provided the below comment:

> *'They did not understand physical and mental needs.'*

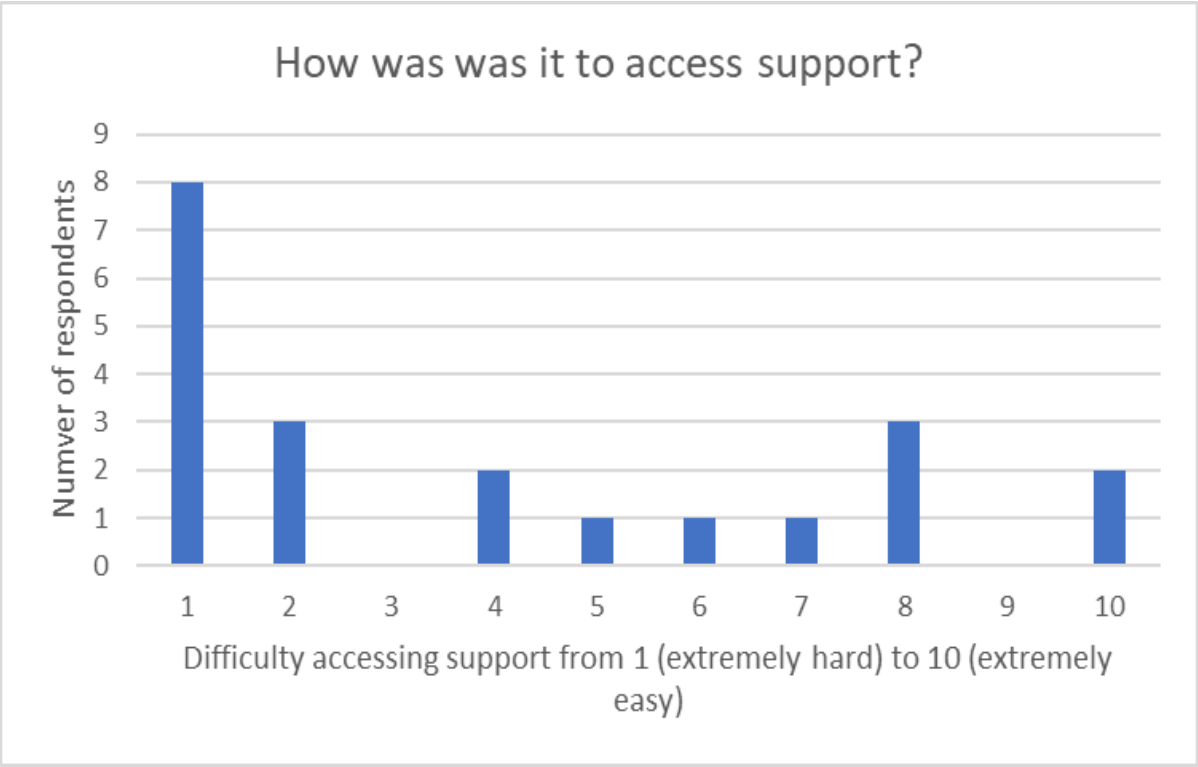
This is a key issue that has been highlighted throughout Bath and North East Somerset, Swindon and Wiltshire (BSW) and within our case studies from Swindon.

Achieving diagnosis and accessing support

Respondents were asked how easy they found achieving a diagnosis on a scale of 1 (extremely hard) to 10 (extremely easy). For the respondents who reported having a diagnosed eating disorder, the responses were: 1, 8, 10.

When asked how easy respondents found accessing support if it was needed, on a scale of 1-10, we received 23 responses which are presented below.

One respondent provided a score of 0 and another stated n/a.



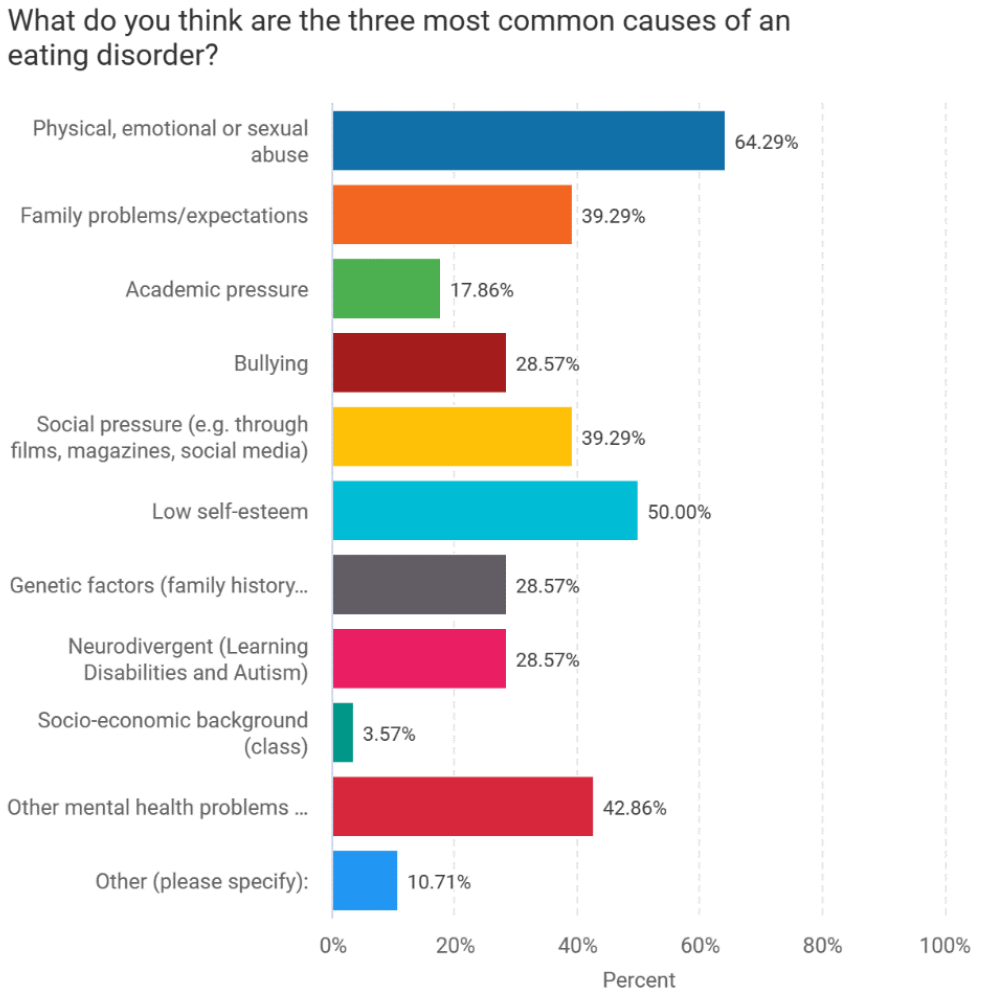
Abuse was reported as the most common cause of an eating disorder

18 respondents felt physical, emotional or sexual abuse was one of the most common causes of an eating disorder. This was followed by low self-esteem and other mental health problems.

Similar to B&NES, one respondent provided the below comment.

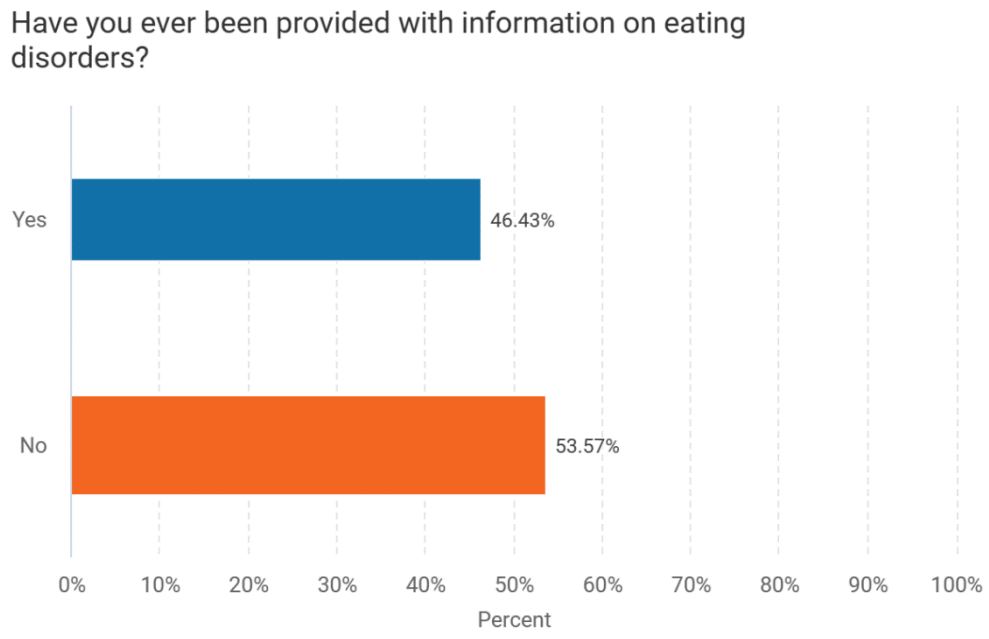
> *'I think there are complex and multiple causes which may include several of the above.'*

This shows that eating disorders are a complex issue and are unlikely to have a single cause. Due to this, recognising the reasons behind an eating disorder is an important part of providing treatment for the individuals struggling with an eating disorder. Without acknowledging these causes, individuals will continue to struggle with their eating disorder.

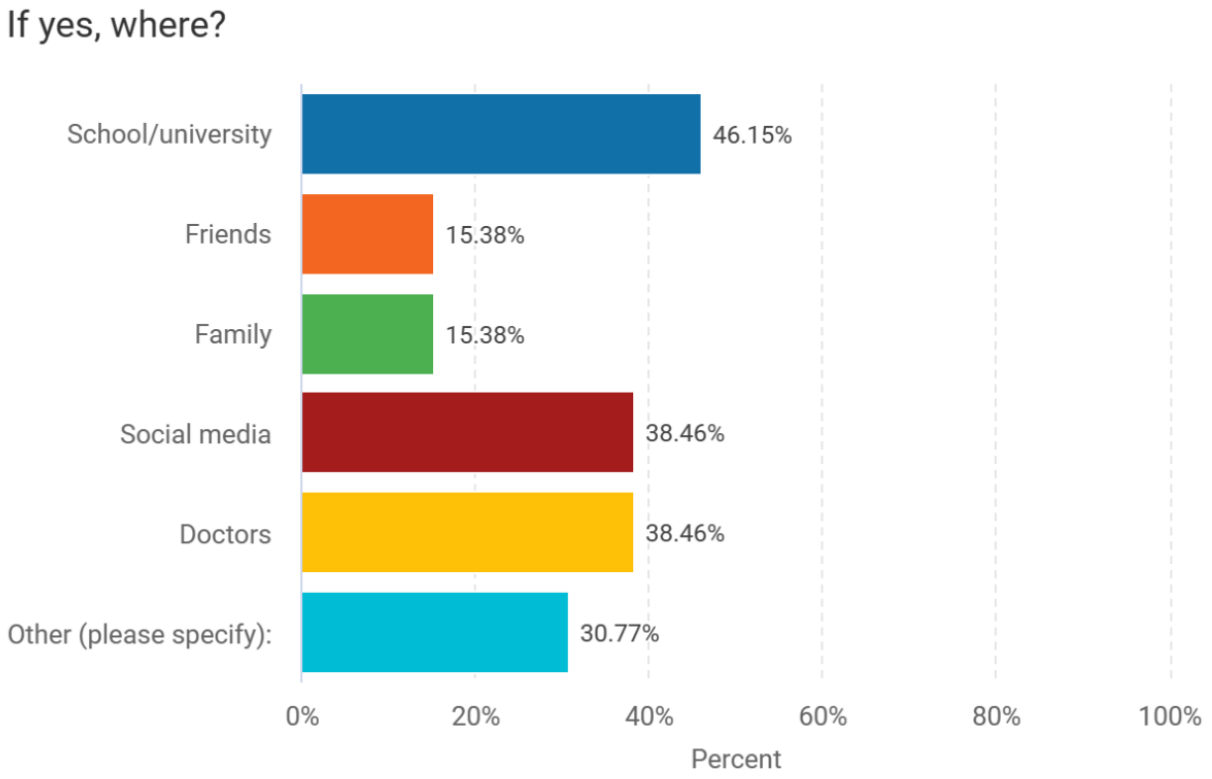


Mixed reports regarding being provided with information about eating disorders

When asked if they have ever been provided with information on eating disorders, responses were mixed. For those who have received information about eating disorders, school/university was the most common option selected. Similar to B&NES, this was followed by social media and doctors.



Other places respondents have been provided with information include: *workplace, charities, Mental Health for England and Child, and Adolescent Mental Health Services (CAMHS).*



Issues and Gaps

Mental health support

Similar to B&NES, respondents reported on the lack of mental health support individuals with an eating disorder receive. With the focus being on the physical symptoms of an eating disorder, the causes behind an individual's eating disorder (ED) is not acknowledged or treated. Without this acknowledgement and support for mental health, individuals are unable to address the root causes of their eating disorder (ED), making it more difficult for them to overcome their struggles.

> *'Many are confused by the fact the support offered is only treating/interested in the symptoms and not the cause with a disjointed approach Eating Disorder V Mental Health.*

> *'They did not understand physical and mental needs'*

Issues surrounding the use of the term 'disordered eating'

Disordered eating refers to abnormal eating behaviours that do not fulfil the criteria for an eating disorder. Feedback suggests that this term can be distressing and dismissive to individuals struggling with food.

> *'This is confusing and causes a lot of distress. Many families have said to me and my own experience is "it is a weight trigger". When told their loved one have disordered eating rather than an eating disorder, they feel their loved one has to become worse to be seen as having an issue.'*

Outdated views on eating disorders

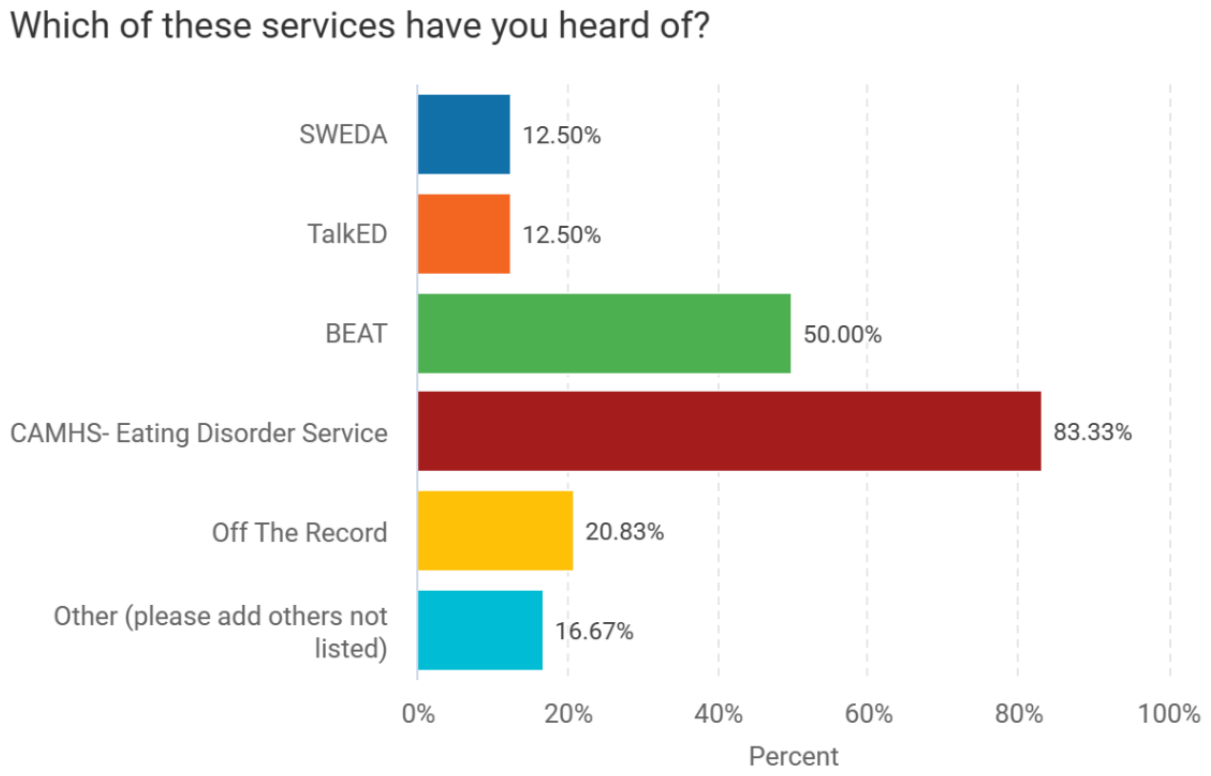
Acknowledging that eating disorders are not exclusive to anorexia or being underweight is an essential part of ensuring all those with an eating disorder receive the appropriate support. Feedback has shown that professionals may still be continuing to view eating disorders in an outdated manner, holding the view that eating disorders only occur at a certain age and if you are underweight. This can result in individuals not receiving the support they need.

> *'being in my late 30s, the doctors don't want to listen'*

> *'I overeat due to anxiety but this is not classed as an eating disorder so I get no support, even though I need it. I am just told I am overweight and it's my fault'*

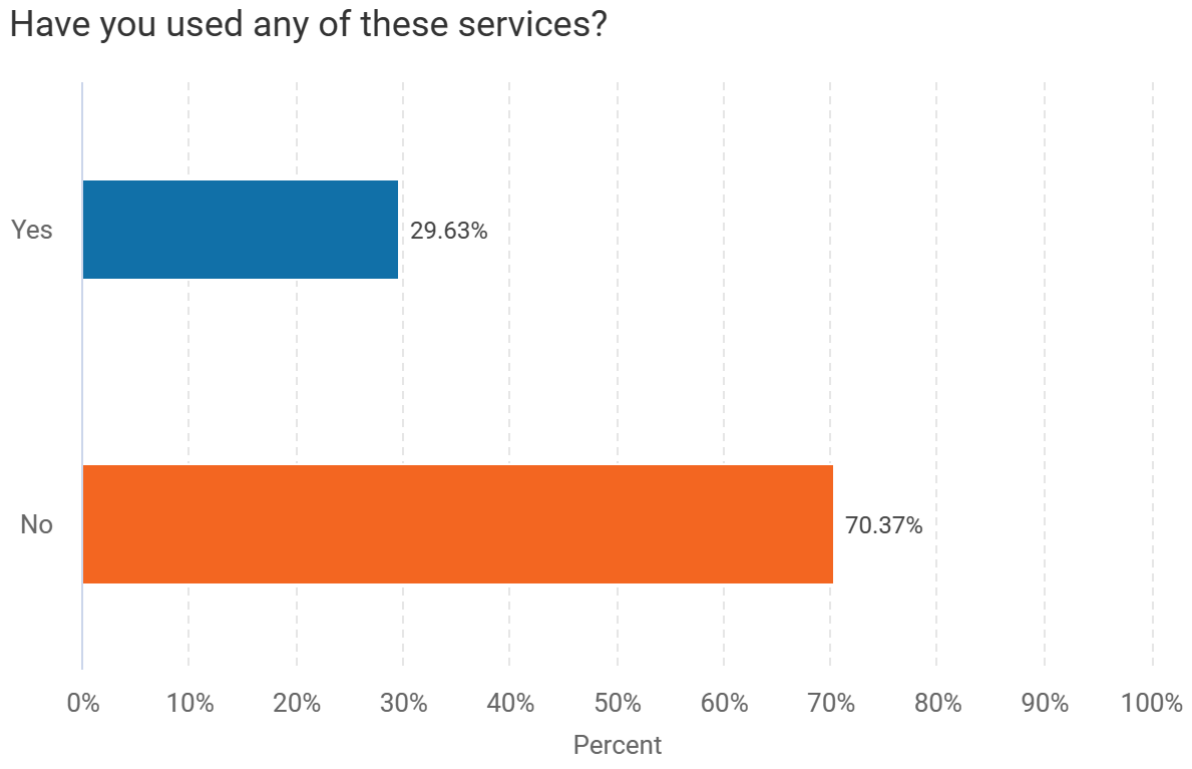
Feedback on Services

Below is feedback given via our online survey. Respondents were asked which services they have heard about and if they have used these services.



2 respondents who selected 'Other' referred to Cotswold House in the comments. 1 respondent stated they had heard of none of the services, and 1 respondent mentioned Support and Empathy for people with Eating Disorders (SEED).

However, the majority of respondents have not used the services above.



What services have people used and did they help?

We asked respondents to provide feedback on the services they have used. Respondents' positive and negative comments are provided below:

Child and Adolescent Mental Health Services (CAMHS)

POSITIVE	NEGATIVES
'It did some good' 'Yes, they did help'	'Transition into adult services was woefully poor. It felt as if the approach was "you are an adult now, so grow up and get off the books as soon as possible"' 'CAMHS-no' 'They were not helpful to an autistic female who needed support with Avoidant and Restrictive Food Intake Disorder (ARFID), which is not understood.'

Cotswold House

POSITIVES	NEGATIVES
	'Cotswold house Oxford health very poor' 'Cotswold house were awful. My daughter died in August because of lack of support'

Feedback from organisations

Access to Services

From speaking to a Public Health Specialist, we were put in touch with a Live Well Project Lead. This discussion highlighted gaps in services and treatment available. Regarding the 18- to 25-year-olds referred to this service, anxiety and eating disorders are the most prevalent reasons behind referrals. However, speaking to a project lead, eating disorders are often included as an additional diagnosis rather than being the primary reason for referrals.

When signposting, it was highlighted that there are a limited number of services available for receiving support for eating disorders. This created a discussion around access to these services. Services can be difficult to access and due to limited capacity individuals are encouraged to pay privately for counselling which can create barriers to accessing support.

Whilst there are various online support services, it was suggested it is easier to not engage with online services whereas in-person services can be more effective.

Improving awareness at all levels and across all ages is an important change needed to improve support. With eating disorders becoming normalised, many do not realise they are struggling until later in their life. In this discussion, women in their mid-30s are realising how far back their food struggles go, with it now impacting their fertility and other aspects of their life. Therefore, it is important to improve awareness and preventative measures within schools as well as adult care services.

Feedback from engagements

Kelly Foundation:

The Kelly Foundation offered practical support to adults In Swindon who are experiencing mental health Issues. They are a charity and offer well-being support, general advocacy, counselling, life coaching and signposting

From discussions with the General Manager of the Kelly, whilst there were some positive experiences, these discussions showed that the system often failed individuals who were now receiving help from the Kelly Foundation.

To understand system failings further, we held discussions with the families of individuals struggling with eating disorders. Summary of the case study is below the full case study can be found in appendix 3.

Case Study

19-Year-Old Girl

This is the experience of a 19-year-old girl who has suffered with an eating disorder since the age of 13.

- At age 13, her parents and school noticed she was losing weight and her parents found food hidden away in her room. After finding the hidden food, her parents took her to her doctor who referred her to Child and Adolescent Mental Health Services (CAMHS). Her parents praised CAMHS for their support. She restored her weight until she was 18 years old.
- At age 18, she began self-harming and attempted suicide on two occasions with the second attempt occurring after being treated by the Crisis Team and being referred to Avon and Wiltshire Mental Health Partnership (AWP). She also relapsed with her eating disorder at this time. As a result, she was referred to Cotswold House by AWP. At this time, she was diagnosed with a personality disorder however she was not given any explanation of what this diagnosis meant. This was brought up to her Care Coordinator who apologised and stated that she should have been told about the diagnosis.
- When being referred to Cotswold House, the family felt that the staff did not have any knowledge of the previous support she received at Child

and Adolescent Mental Health Services (CAMHS). This lack of communication has been an area of frustration for her and her family.

- Initially, she was told she did not have to go to Cotswold House for breakfast as this was her easiest meal of the day. However, she was then informed she had to attend four days a week from 8am to 6pm. Highlighting another occasion of poor communication.
- During her time as a day patient, she was regularly blind weighed as it was not beneficial for her to see her weight. Despite this, the individual received a letter with her weight written on it. She was also told she would have two 1:1 discussions a day and have someone help with her food diary. These did not happen more often than they did, further highlighting flaws in the support and gaps in communication. She was also publicly told off for cutting her food up as staff deemed her to be taking too long.
- Prior to her admission as a day patient, her family informed Cotswold House of a family holiday and was told she could go and return as a day patient. However, the day before the family holiday, the individual was informed during her visit to Cotswold House that this was her last day and she was going to be discharged. This was extremely distressing to the individual. The individual has not returned as a day patient since August 2023.
- In January 2024, a professional review meeting was held due to the individual informing the Kelly Foundation of her suicidal thoughts. Her Care Coordinator was unaware of these thoughts as the individual did not trust her. Within this meeting, the Care Coordinator stated, *'Kelly Foundation might mother them but we don't work like that'.*
- Since this meeting, it is believed her self-harm has increased.

For more information on this case, please read the full case study available in appendix 3.

Recommendations

Below are recommendations based on feedback provided by organisations, our survey respondents and our case studies.

- Acknowledge eating disorders do not only occur in young people who are underweight. Eating disorders can affect people of any age and does not only present itself in people who are underweight. This means it is important to ensure everyone who is struggling with an eating disorder feels supported and listened to.
- Improve mental health support for individuals with an eating disorder. Feedback has suggested that treatment is focused on the individual's physical symptoms rather than their mental health needs and the root causes behind their eating disorder. Addressing these root causes is necessary in order for an individual to overcome their eating disorder.
- Improve knowledge around eating disorders, particularly Avoidant and Restrictive Food Intake Disorder (ARFID). This requires ensuring there is support available to individuals suffering with this form of an eating disorder.
- View individuals as a person rather than as their disorder. This is extremely important in ensuring the patient feels listened to and supported. Eating disorders effect everyone differently therefore it is important to acknowledge the person as an individual and provide personalised treatment with the input of the patient.

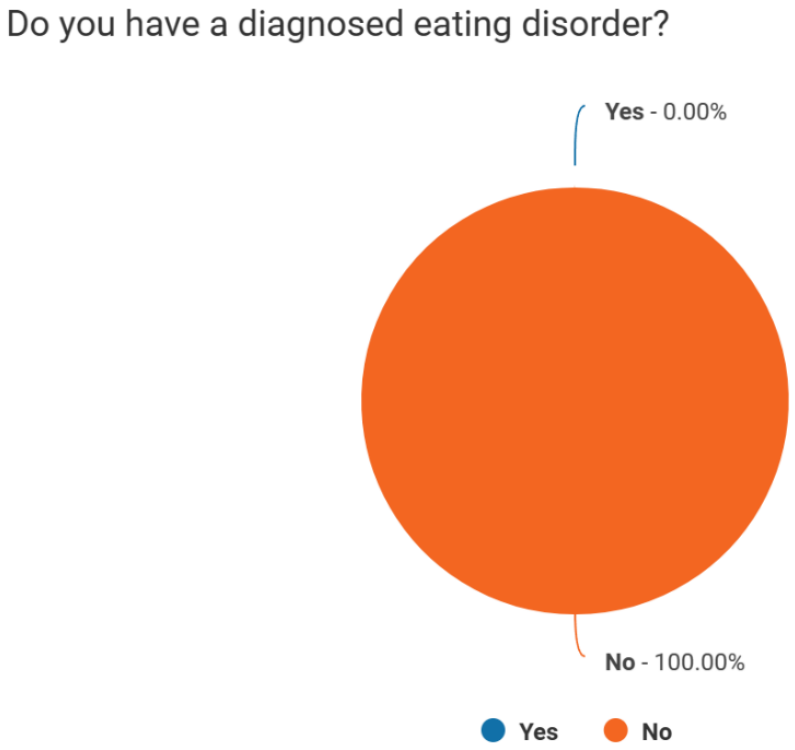
What did people in Wiltshire tell us?

Feedback from Wiltshire was provided via our survey. Healthwatch also attended the Mental Health Forum. As the survey was available for less time than B&NES and Swindon, we received fewer responses than the other localities.

Feedback from survey

We received 17 responses from Wiltshire.

- 0 respondents had a diagnosed eating disorder. 2 respondents reported previously struggling with an eating disorder (ED). 1 respondent is an assistant psychologist in an adult eating disorder service and Child and Adolescent Mental Health Services (CAMHS) eating disorder service.



- 1 respondent reported their friends thinking they have an eating disorder (ED). 1 respondent is the parent of an individual with an eating disorder.
- 7 respondents felt they do have an eating disorder that has not been diagnosed.
- 25-49 years old was our most common age with 8 respondents, followed by 50-64 years old with 6 respondents, 2 responses for 18-24 years old and 1 response for 65-79 years old
- 14 respondents were women and 3 respondents were men.
- 15 respondents were White British, 1 respondent was White (any other background) and 1 respondent was White Irish.
- 11 respondents in Wiltshire worked full time, 3 part time, 1 was retired, 1 was a carer for someone with a long-term health condition/disability and 1 was training for a new career.
- 13 respondents reported being heterosexual, 3 reported being bisexual and 1 respondent reported being a gay man.

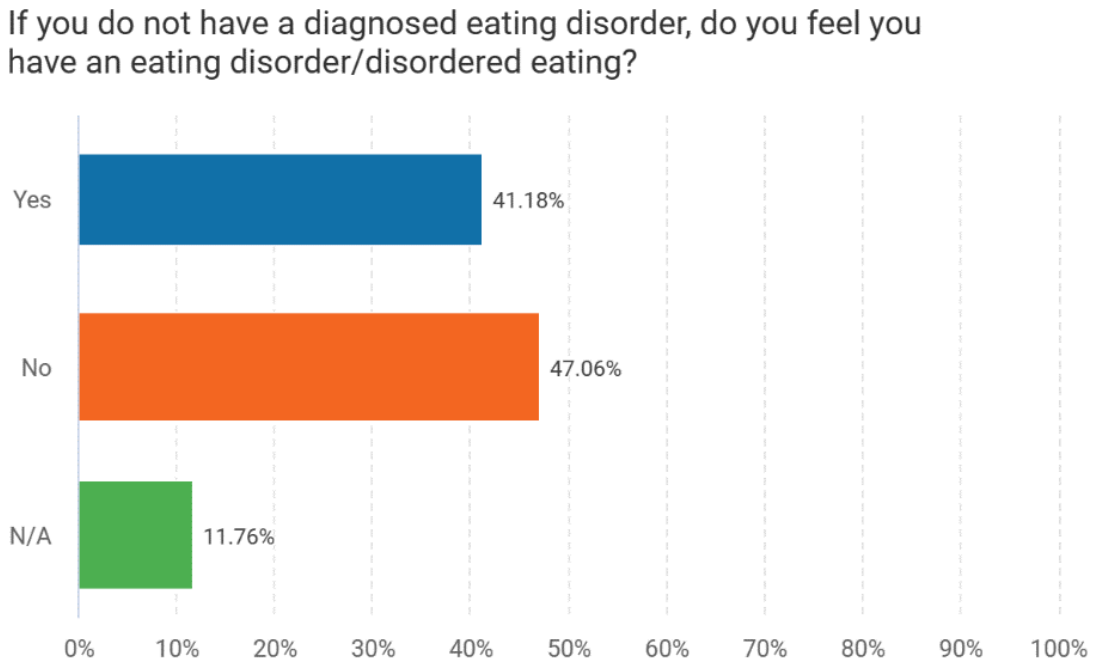
Key findings/themes

Awareness of disordered eating

70% of respondents were aware of the term disordered eating with one individual commenting on how this term reflects their experiences.

> *'It has only just occurred to me that the term would probably be the correct term for the times when I wouldn't eat as a teen/young adult. I was never formally diagnosed with an eating disorder but I definitely had disordered eating.'*

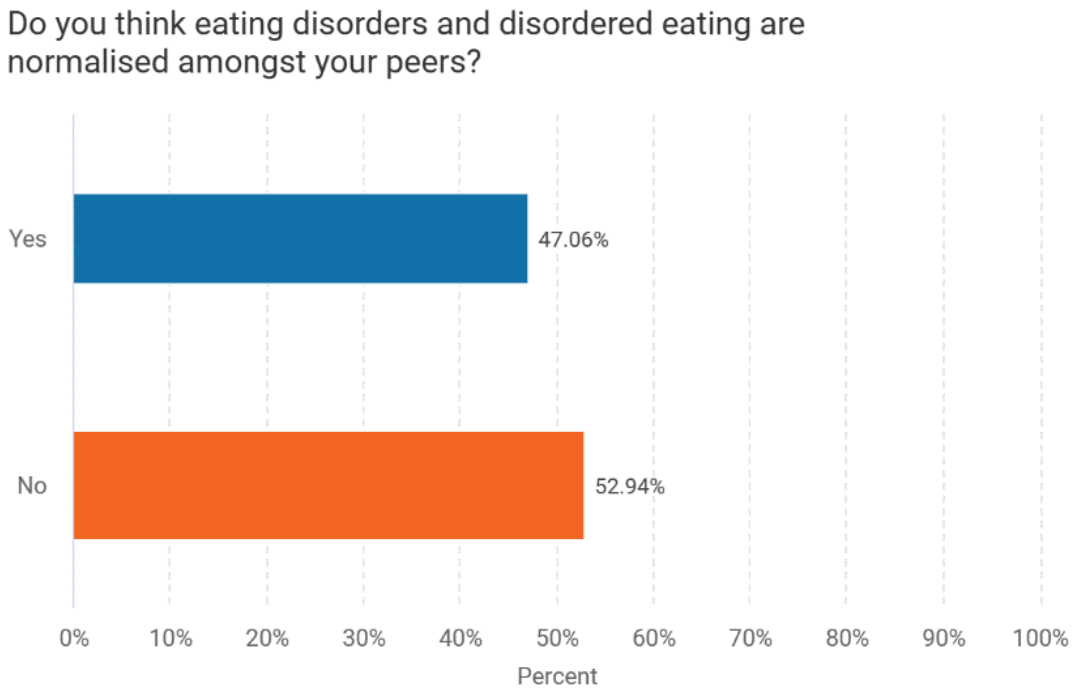
The below graph shows that 41% of respondents felt they do have an eating disorder/disordered eating.



Normalisation of eating disorders/disordered eating

For B&NES and Swindon, many students reported eating disorders being normalised amongst their peers. However, as we did not hear from students in Wiltshire, we received the perspective of parent/carers and older adults. From these respondents there was a mixed response.

8 respondents felt eating disorders are normalised and 9 felt they are not.



Low self-esteem is the biggest cause of eating disorders

Low self-esteem was selected the most for causes of eating disorders with 10 respondents selecting this cause. Low self-esteem was followed by family problems/expectations and physical, emotional or sexual abuse. One respondent commented:

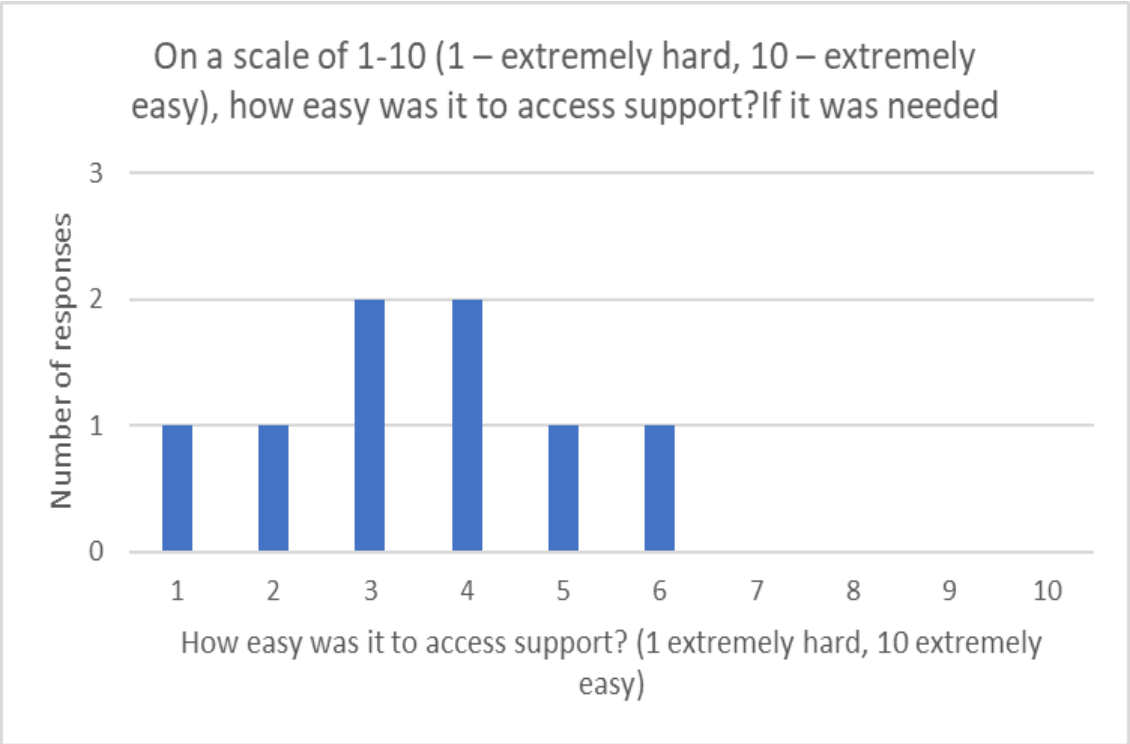
> *'Most of the above!! I can't choose just three as I think so many of them are common causes. The only one I'd never considered before is socio-economic but that doesn't mean it's not also the case. Certainly abuse, family problems, mental health issues and neurodivergence, low self-esteem and social pressure or social issues, family history, all of these!'*

Zero respondents reported finding it extremely easy to access support

10 respondents provided feedback on how easy it was for an individual to access support if support was needed. None of the respondents reported finding it extremely easy to access support.

One individual commented:

'I never sought support as I tried to hide my difficulties.'



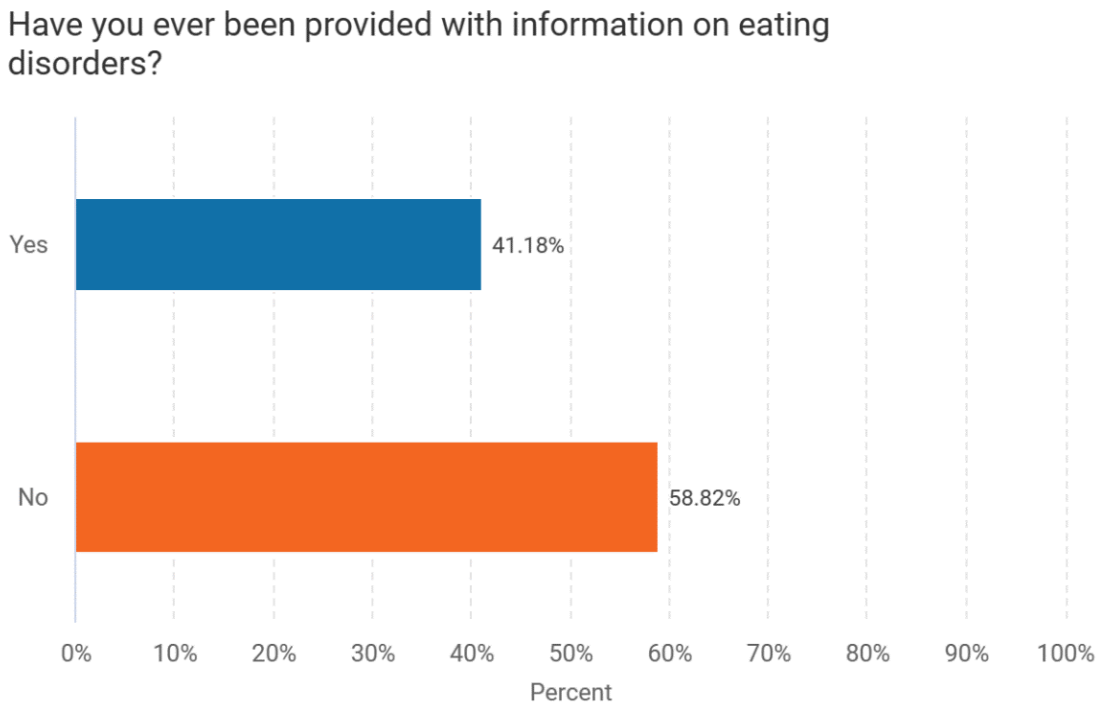
Child and Adolescent Mental Health Services (CAMHS) was the most common service respondents had heard of

The two most common services individuals had heard of were CAMHS and Eating Disorders Association (BEAT). However, 94% of respondents have not used these services. Despite this, one respondent provided feedback on their experience in CAMHS.

'CAMHS helped, but only able to access once in extreme crisis, very high threshold and have to be in crisis to access, my daughter was hospitalised very shortly after accessing CAMHS'

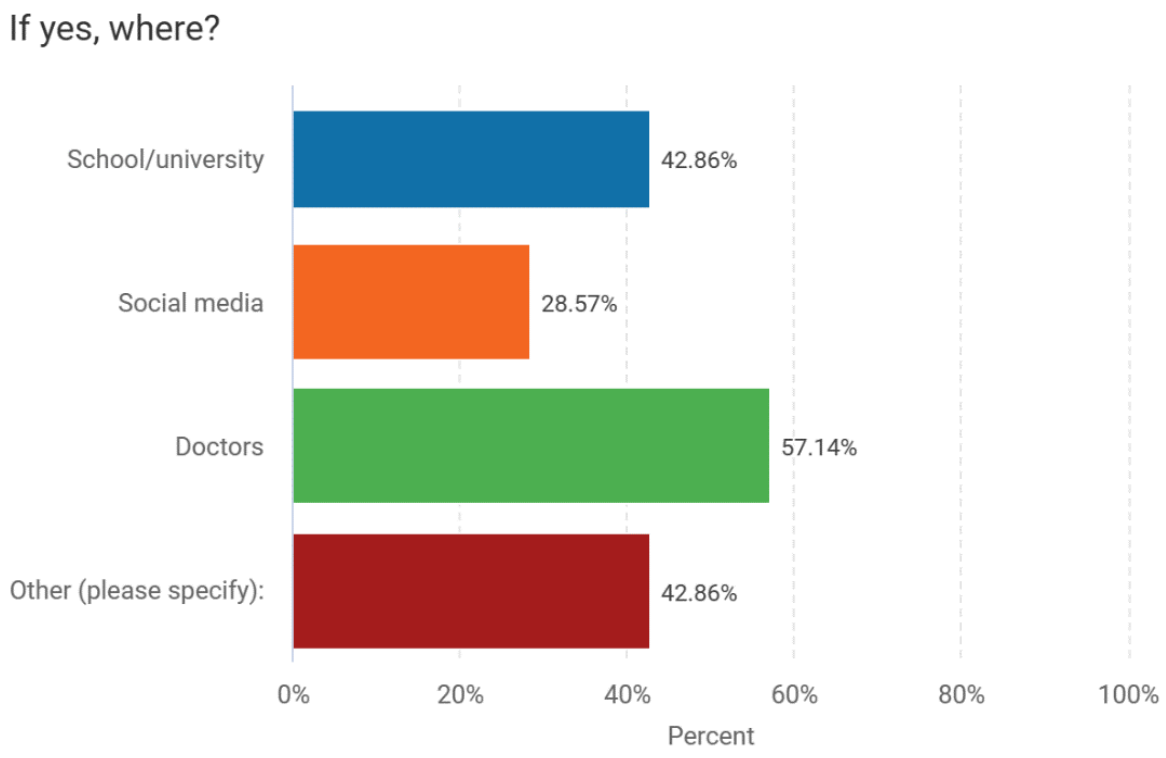
Limited access to information

10 respondents reported not being provided with information on eating disorders. Below highlights where 7 respondents have received information about eating disorders.



Regarding information provided at school. One respondent commented:

> *'At school the information was pretty poor- very limited'*



Issues and Gaps

Lack of information/misinformation

Whilst completing this project, we used recent research provided by the local council. However, when researching statistics in Wiltshire there was very little information available. This includes having limited information available on Wiltshire Council's website and the Wiltshire Joint Strategic Needs Assessment.[11]

Outdated views of eating disorders were also suggested by one respondent who commented:

> *'made me believe you had to be underweight to have an eating disorder.'*

Access to services

Respondents also reported finding it difficult to access services within Wiltshire. Two respondents provide experiences of difficulty accessing services and the reasons behind this.

> *'I never sought support as I tried to hide my difficulties'*

> *'Child and Adolescent Mental Health Services (CAMHS) helped, but only able to access once in extreme crisis'*

Recommendations

Below are recommendations for Wiltshire based on feedback provided via our online survey.

- Ensure information regarding where to access support is easily accessible and available to individuals across Wiltshire.
- Improve prevention and early intervention support for individuals with an eating disorder. From this, individuals should feel they do not need to be in crisis point before they are acknowledged and receive support.

[11] JSNA Wiltshire Intelligence

Analysis of NHS Eating Disorder Services in Bath and North East Somerset, Swindon and Wiltshire (BSW)

Input from NHS services

To understand the formal NHS eating disorder services provided across Bath and North East Somerset, Swindon and Wiltshire (BSW), we contacted and met with the Senior Service Manager for Eating Disorders at Avon and Wiltshire Mental Health Partnership (AWP).

We also contacted Child and Adolescent Mental Health Services (CAMHS), so that we could include their feedback in the report but were disappointed not to receive any feedback or input.

Avon and Wiltshire Mental Health Partnership Eating Disorder Services

Our aim in meeting with Avon and Wiltshire Mental Health Partnership (AWP) was to understand who provides the various services across Avon and Wiltshire Mental Health Partnership (BSW).

For Bath and North East Somerset, AWP covers mental health and eating disorder services for individuals over 18. Oxford Health Child and Adolescent Mental Health Services (CAMHS) covers eating disorders for those under 18 in B&NES.

For Swindon and Wiltshire, AWP covers the mental health services but Oxford Health covers eating disorder services.

How does AWP provide support for eating disorders?

Within the meeting we were informed of some of the support AWP provides to individuals with eating disorders and support for organisations:

- Weekly physical health clinics
- Weekly risk clinics
- Occupational therapy
- Peer support worker who has lived experience

- Family therapy
- Psychological therapist
- Recovery teams- for individuals with additional needs such as self-harming
- Crisis team- operates 24/7. For individuals who are experiencing a severe mental health crisis such as suicidal thoughts
- Pathways for different eating disorders such as Binge Eating or Bulimia
- STEPs Eating Disorder Service
- Face to face appointments at Blackberry Hill Hospital Bristol, Bath NHS House, Paulton Hospital as well as home visits.
- Dieticians
- Duty Support- third sector organisations and GPs can contact this service for assistance and advice.

Despite this range of support, a key gap was recognised around the support available for Avoidant and Restrictive Food Intake Disorder (ARFID). Avon and Wiltshire Mental Health Partnership (AWP) is not commissioned to provide this specialist support resulting in limited support for this type of eating disorder.

While there had been some discussion between Avon and Wiltshire Mental Health Partnership (AWP) and Child and Adolescent Mental Health Services (CAMHS) regarding CAMHS support for young people with Avoidant and Restrictive Food Intake Disorder (ARFID), the outcome of these discussions remained unclear.

It was noted that AWP Eating Disorder Service is not a 24-hour crisis service, and that if an individual was in crisis they should contact the crisis team, 999 or visit Accident and Emergency (A&E). This reflected their view that for an individual with an eating disorder, a crisis will be related to their physical health rather than mental health which requires urgent medical support.

How to access support from AWP?

For eating disorders, Avon and Wiltshire Mental Health Partnership (AWP) provides support to individuals over 18. They take referrals from GPs, universities, third sector organisations and the Primary Care Liaison Service. The recommended pathway to access Avon and Wiltshire Mental Health Partnership (AWP) is to go to the GP as they can carry out necessary checks prior to referral. AWP have provided GPs with a flow chart outlining who they should refer individuals to. This document can be found in appendix 9. Avon and Wiltshire Mental Health Partnership (AWP) is also working to introduce self-referral forms as a method of accessing their services.

For students moving to B&NES for university, their local/*home* team can arrange a transfer to AWP's services. It was reported that Avon and Wiltshire Mental Health Partnership (AWP) works closely with universities and carries out meetings to new cohorts to highlight services available to students.

In the circumstance where an individual has been admitted to hospital, they will be assessed by the Mental Health Liaison team who should then contact AWP. However, it was noted that this can sometimes be fractured as AWP reports not always being informed of these individuals in a timely manner.

STEPs:

Avon and Wiltshire Mental Health Partnership (AWP) provides inpatient eating disorder services through STEPS. This service supports individuals in Bath and North East Somerset, Bristol, North Somerset and South Gloucestershire, Devon, Cornwall and Somerset. Whilst STEPs provide inpatient support with 10 beds at Blackberry Hill Hospital, these are not available to residents in Bath and North East Somerset. Instead, these individuals will be referred to Cotswold House in Marlborough.

Inpatient Admissions:

If an individual from B&NES requires an inpatient admission, Avon and Wiltshire Mental Health Partnership (AWP) will refer them to the Hope Spa Provider Collaborative who would then decide if an inpatient admission is appropriate. From there, they will decide where the patient will be admitted depending on bed availability and urgency.

Transitioning from Child and Adolescent Mental Health Services (CAMHS) to adult mental health services:

As Avon and Wiltshire Mental Health Partnership (AWP) covers individuals over 18, CAMHS, run by Oxford Health, provides support for individuals under 18. However, if an individual is seen to need continuous support as they turn 18, they will need to be transferred from CAMHS to AWP. To provide a smooth transition, there is a transition worker within CAMHS who begins working on the individual's transition when they are 17 and a half years old. This is to ensure the appropriate support is in place for when individuals turn 18. When being transferred to AWP, information regarding previous support given should also be transferred.

Discharge from service:

Patients should be included throughout the discharge process. Their care coordinator should also be involved in this process. Oxford Health have a 'stepped care' team on discharge from inpatient care to help support a smooth transition back into the community. If a patient needs to be readmitted for inpatient care, this should be supported by the STEPs community team. If they require support following a discharge from the service, they should see their GP who can support with a referral.

Mental health and eating disorder support:

If an individual requires mental health support and eating disorder support, AWP state they provide these alongside each other, where possible, to prevent fragmentation in treatment. However, it was recognised that when it comes to therapy, it may not be beneficial to access two different forms of support at the same time. They aim to have joint care reviews across different teams.

Changes made by Avon and Wiltshire Mental Health Partnership (AWP):

In the last three years, AWP's eating disorder service has increased significantly in size, moving from 8 members of staff to 50.

This is as a result of an increase in funding for eating disorder services due to the Community Mental Health Framework programme.

Introduction of First Episode Rapid Early Intervention for Eating Disorders (FREED). This is for anyone under 25 years old who has suffered with an eating disorder for less than three years. It aims to provide quicker and earlier support to prevent an eating disorder from becoming ingrained in the individual.

AWP are aiming to introduce a self-referral form and process, and are developing this in a more 'co-produced' way.

AWP are also aiming to introduce and implement a standard agreement with GPs regarding physical health monitoring tests such as blood tests. Their experience is that whilst some GPs are happy to take on this monitoring, others are not.

Recommendations made by Healthwatch for Avon and Wiltshire Mental Health Partnership (AWP) based on this meeting:

AWP to have a member of staff attend the Children and Young People's Network (CYPN) as a representative.

AWP to ensure their website clearly outlines services available for eating disorders and how to access them.

AWP to ensure transition from Child and Adolescent Mental Health Services (CAMHS) to adult support is smooth and the appropriate support is in place for the patient.

Conclusions and Recommendations

Conclusions:

To conclude, the feedback we have collected, whilst based on a small number of people with a diagnosed ED, indicates that eating disorder services across Bath and North East Somerset, Swindon and Wiltshire (BSW) require improvement and are not currently meeting the needs of individuals struggling with an eating disorder or disordered eating.

Whilst there were some reports of positive experiences, the support available is not consistent or easy to access. Drawing from the positive experiences, it is important to ensure that individuals feel listened to and that they feel their struggles are taken seriously.

Recommendations

Based on the feedback we have collected; we recommend the following:

- Improve communication between services by ensuring all those involved with a case are aware of the individual's circumstances and struggles.
- Improve communication with the patient by ensuring they are being informed of the support available to them as well as being aware of who they are being referred to.
- Improve transition from Child and Adolescent Mental Health Services (CAMHS) to Adult support. This can be improved by ensuring all organisation are aware of the individual's case and appropriate support is put in place and that the individual is aware of this.
- Ensure that patients feel comfortable and trust their caregivers to receive the necessary support
- Provide clear pathways for parents/carers regarding how they can access support in their local area
- Provide more training for professionals, GPs and school staff with regard to recognising symptoms of eating disorders and a better understanding of where people can access support.
- Personalising treatment- include the individual in their treatment plan. Allow them to have input. View people as an individual not as their disorder
- Improve mental health and psychological support provided to individuals struggling with an eating disorder.
- Take action to improve support for individuals with Avoidant and Restrictive Food Intake Disorder (ARFID), an eating disorder experienced by many individuals, particularly those with additional needs.

- Develop services tailored to their requirements, as highlighted in a study by Inoue *et al* (2021), which revealed that 12.5% of their participants with Avoidant and Restrictive Food Intake Disorder (ARFID) also had autism spectrum disorder (ASD).[12]
- Ensure information is being provided throughout Bath and North East Somerset, Swindon and Wiltshire (BSW) and that this information is easy to access such as through AWPs website. Information availability can also be improved with colleges as suggested by Bath College students.

Next Steps

This report provides an important overview of local peoples' experiences of eating disorders in B&NES, Swindon and Wiltshire. This report will be shared with commissioners for each area, statutory bodies including the Care Quality Commission (CQC), Bath and North East Somerset, Swindon and Wiltshire NHS Integrated Care Board (BSW ICB, formerly the Clinical Commissioning Group), NHS England and NHS Improvement, and third sector providers of health and social care in the Bath and North East Somerset, Swindon and Wiltshire (BSW) region.

We will share our findings with people who took part in the survey via our website and will keep them updated on what has happened as a result of sharing their experiences with us.

We will share this report with the organisations who contributed, publish it on our websites and share key messages about our findings on our social media channels.

Each Healthwatch will work with local services and organisations to ensure our recommendations are considered, monitor how they implemented, and provide updates on their progress. We are committed to carrying out any follow-up work required to support local services in delivering the best experience possible for everyone.

[12] Prevalence of autism spectrum disorder and autistic traits in children with anorexia nervosa and avoidant/restrictive food intake disorder | BioPsychoSocial Medicine | Full Text (biomedcentral.com)

Appendices

Appendix 1- Organisations contacted

Organisations contacted in B&NES include:

- Bath Mind
- Children and Young People's Network
- University of Bath
- Community Wellbeing Hub
- Bath Parent Carer Forum
- Mentoring Plus

Organisations contacted in Swindon include:

- Kelly Foundation
- Swindon Carers Centre
- Swindon SEND Family Voice
- Swindon Public Health
- Swindon Senior Mental Health Lead Network
- STEPS
- Team Smash
- Youth voice

Organisations contacted in Wiltshire include:

- Wiltshire Council
- Children and young people mental health network
- CAMHS
- Wiltshire Parent/Carer Council
- BBC Wiltshire
- Wiltshire Times
- Mental Health Forum

Other organisations contacted include:

- Eating Disorder Health Integration Team (EDHIT)
- Avon and Wiltshire Mental Health Partnership (AWP)
- Oxford Health

We contacted other third sector groups across BSW including members of the CYPN in B&NES but did not receive any response.

We also contacted Child and Adolescent Mental Health Services (CAMHS) for input but did not receive a response.

Appendix 2- Eating Disorder Survey

Eating Disorder Survey Questions

1. Do you have a diagnosed eating disorder? *

- [ ] Yes
- [ ] No

Comments:

2. If yes, did you refer yourself or did someone refer you?

Referred yourself or Someone referred you (please specify)

3. Did you feel you were listened to?

- [ ] Yes
- [ ] No

Comments:

4. Who were you referred to?

5. Did you feel you got enough support?

- [ ] Yes
- [ ] No

Comments:

6. On a scale of 1-10 (1 – extremely hard, 10 - extremely easy), how easy was it to get a diagnosis?

7. Are you aware of the term disordered eating?
Disordered eating is a term used to describe abnormal eating behaviours that do not qualify or fulfil the criteria for an eating disorder.

- [ ] Yes
- [ ] No

Comments:

8. If you do not have a diagnosed eating disorder, do you feel you have an eating disorder/disordered eating?

- [ ] Yes
- [ ] No
- [ ] N/A

9. Do you think eating disorders and disordered eating are normalised amongst your peers?

- [ ] Yes
- [ ] No

10. What do you think are the three most common causes of an eating disorder?

- [ ] Physical, emotional or sexual abuse
- [ ] Family problems/expectations
- [ ] Academic pressure
- [ ] Bullying
- [ ] Social pressure (e.g. through films, magazines, social media)
- [ ] Low self-esteem
- [ ] Genetic factors (family history of eating disorder/mental health disorders)
- [ ] Neurodivergent (Learning Disabilities and Autism)
- [ ] Socio-economic background (class)
- [ ] Other mental health problems (depression, anxiety, bipolar disorder)
- [ ] Other (please specify):

11. On a scale of 1-10 (1 – extremely hard, 10 – extremely easy), how easy was it to access support? If it was needed

12. Which of these services have you heard of?

- [ ] SWEDA
- [ ] TalkED
- [ ] BEAT
- [ ] CAMHS- Eating Disorder Service
- [ ] Off The Record
- [ ] Other (please add others not listed)

13. Have you used any of these services?

- [ ] Yes
- [ ] No

14. If Yes which service have you used and did they help?

15. Have you ever been provided with information on eating disorders?

- [ ] Yes
- [ ] No

16. If yes, where?

- [ ] School/university
- [ ] Friends
- [ ] Family
- [ ] Social media
- [ ] Doctors
- [ ] Other (please specify):

17. Please tell us your age

- [ ] 13 to 15 years
- [ ] 16 - 17 years
- [ ] 18 - 24 years
- [ ] 25 - 49 years
- [ ] 50 - 64 years
- [ ] 65 to 79 years
- [ ] 80+ years
- [ ] Prefer not to say
- [ ] Not known

18. Please tell us your gender

- [ ] Woman
- [ ] Man
- [ ] Non-binary
- [ ] Prefer not to say
- [ ] Prefer to self describe:

19. Please tell us which sexual orientation you identify with

- [ ] Asexual
- [ ] Bisexual
- [ ] Gay man
- [ ] Heterosexual/straight
- [ ] Lesbian/Gay woman
- [ ] Pansexual
- [ ] Prefer not to say
- [ ] Prefer to self describe:

20. Please select your ethnicity

- [ ] Arab
- [ ] Asian/Asian British: Bangladeshi
- [ ] Asian/Asian British: Chinese
- [ ] Asian/Asian British: Indian
- [ ] Asian/Asian British: Pakistani
- [ ] Asian/Asian British: Any other Asian/Asian British background
- [ ] Black/Black British: African
- [ ] Black/Black British: Caribbean
- [ ] Black/Black British: Any other Black/Black British background
- [ ] Mixed/multiple ethnic groups: Asian and White
- [ ] Mixed/multiple ethnic groups: Black African and White
- [ ] Mixed/multiple ethnic groups: Black Caribbean and White
- [ ] Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background
- [ ] White: British/English/Northern Irish/Scottish/Welsh
- [ ] White: Irish

- [ ] White: Gypsy, Traveller or Irish Traveller
- [ ] White: Roma
- [ ] White: Any other White background
- [ ] Prefer not to say
- [ ] Other (please specify):

21. Which of the following best describes your current employment status?

- [ ] Working full time (employed or self employed)
- [ ] Working part time (employed or self employed)
- [ ] Unemployed and looking for work
- [ ] Unable to work due to health issues or a disability
- [ ] Retired
- [ ] Stay at home parent
- [ ] Caring for someone with long term health conditions or a disability
- [ ] Student
- [ ] Doing unpaid work/volunteering
- [ ] Prefer not to say
- [ ] Other (please specify):

22. Where are you based?

- [ ] Swindon
- [ ] Bath and North East Somerset
- [ ] Other (please specify):

Appendix 3- Case Study

19-year-old girl

Background:

This individual, who will remain anonymous, is a 19-year-old girl who has struggled with an eating disorder since the age of 13. Within this time period, she has attempted to take her life on multiple occasions and more recently has written a plan to take her life.

This account details events, issues and struggles after receiving care from the Avon and Wiltshire Partnership (AWP) and Cotswold House Marlborough.

At age 13, she began losing weight which was noticed by her parents and her school. After finding food being hidden away in her room, her parents took her to the GP who referred her to Child and Adolescent Mental Health Services (CAMHS) as an outpatient. The support from CAMHS was praised by the parents and her weight restored until she was 18 years old.

At age 18, she began self-harming. Initially creating superficial wounds, her self-harming escalated to a suicide attempt. From this, she was treated by the Crisis Team and was then referred to AWP. Within this time, a second attempt to end her life occurred. As a result, she was referred to Chatsworth House as an outpatient for mental health support. During this time, the individual relapsed with her eating disorder. Due to this relapse, she was referred to Cotswold House Marlborough by AWP. During this referral process, the individual was diagnosed with a personality disorder.

Referral and Treatment at Cotswold House Marlborough:

As she was over the age of 18, she was discharged from CAMHS and was now receiving care at Adult Mental Health Services. However, the family felt that Cotswold House did not have any information regarding the support and treatment she received whilst with CAMHS. This lack of communication and information sharing has been an area of frustration for the individual and her family.

The referral to Cotswold House was initially for four weeks, with her being seen once a week. Her parents expressed concern about what support she would receive after these four weeks and were unsure if she would just be discharged. As it was deemed the individual needed support past four weeks, her Community Care Worker extended the referral. Parents also had to push for their child to receive support more than once a week. However, parents were told they had to wait for a review to assess what support she could be given, causing delays in the individual receiving treatment.

July and August 2023:

In July 2023, her parents pushed for Cotswold House to do home visits so they could see the struggles she was facing. Two home visits were carried out which resulted in the individual becoming a day patient. At this time, the individual was given a diagnosis of Emotionally Unstable Personality Disorder (EUPD). The individual was not informed of her diagnosis and instead found out via a letter from AWP to Cotswold House. The individual was not sat down and given an explanation of what this diagnosis meant, how it could be managed or how it manifests. The individual proceeded to question this with her Care Coordinator at AWP who apologised and told the individual she should have been told about her diagnosis.

Despite her disagreement, the individual was told her eating disorder was a result of her personality disorder. Having struggled with an eating disorder prior to her personality disorder diagnosis, the individual felt she struggled with her eating disorder and mental health separately.

Due to her reluctance to attend as a day patient, the individual had discussions with her Community Care Worker who informed the individual that she did not have to go in for breakfast as this was her easiest meal of the day. However, on attendance to Cotswold House, a ward care officer told her she had to be there from 8am to 6pm, four days a week. This negatively affected the individual as this was not part of the agreement she had made. Parents also pushed for the visits to be reduced to three times a week.

Prior to the individual becoming a day patient, the family had booked a holiday for the middle of August. Cotswold House, as well as her Community Care Worker, were aware of this holiday and the family were told it was okay for the individual to go on the holiday and return as a day patient. Within these discussions, there was no mention of discharging her as a patient.

In August 2023, the day before her family holiday, the individual attended Cotswold House and was told by a member of staff she was being discharged that day. As this had not been discussed, this was extremely distressing to the individual who was now unsure of whether she would continue to be supported. From this, she experienced a break in treatment and was once again informed she had to wait for reviews to receive support. The individual has not returned as a day patient since August 2023.

As part of the individual's treatment at Cotswold House, she was blind weighed due to it not being beneficial for her to see her weight. Despite this, the individual received a letter which had her weight written in it. This was extremely distressing to the individual as this was something that was agreed would be not be shown to her.

During her time as a day patient, she was supposed to have two 1:1 discussions a day. However, this did not happen more often than it did. Despite her parents expressing concern about the lack of 1:1 discussion, they continued to not consistently occur. The individual was also left alone to complete her food diary despite being told someone would help her fill it out.

The individual was also not checked on during the day. This resulted in occasions where she would be sat alone crying with no one offering help or speaking to her.

Due to strict rules regarding food, the individual was publicly told off, in front of other patients, for cutting up her food. Despite trying to eat her meal, she was told she was taking too long to cut up the food.

Professional Review Meeting:

In January 2024, a meeting was held between the Kelly Foundation, Avon and Wiltshire Mental Health Partnership (AWP), Cotswold House, Family Therapy Unit, the individual and her parents. The purpose of this meeting was to expand on a letter sent by the Kelly Foundation to the AWP regarding the individual's plan to end her life, which she showed to a trusted worker at the Kelly Foundation. When asked why she did not talk to her Care Coordinator regarding her suicidal thoughts, the individual stated *she does not trust her Care Coordinator.*

Within this meeting, AWP did not want to agree to providing the individual with psychology support as she is currently receiving support at Cotswold House, despite this only being four sessions. During this meeting, the individual was not asked what she needs or would like and was spoken about as if she was not present at the meeting. Furthermore, there was the opinion that AWP did not want to take responsibility for the individual's case.

After the professional review, the individual's parents contacted the Care Coordinator to request details from the meeting. The Care Coordinator did not respond and instead brought up the parents' email during their next meeting with the individual, rather than responding to the parent. The Care Coordinator also stated 'we do things differently, Kelly Foundation might mother them but we don't work like that'.

Since this meeting, the Kelly Foundation believe the individual's self-harm has increased.

Key Issues:

From discussions with the individual's parent and their worker at the Kelly Foundation, a key issue with communication has been highlighted. Communication issues are outlined below:

- The transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services highlighted a lack of communication between the two services as Cotswold House did not have any information or history about the individual's treatment whilst she was with CAMHS.
- Where the individual was initially informed, she did not have to attend Cotswold House for breakfast but was later told she did have to attend at 8am, it was suggested that there was a lack of communication between the Community Care Worker at Cotswold House, other members of staff, the individual and her family.
- There is also the view that communication was neglected regarding the discharging of the individual prior to her family holiday. Prior to the holiday,

the individual and her family were not informed, nor was there any discussion, regarding discharging the individual at that stage. There was also a lack of communication regarding the next steps in providing support after discharging her.

- Issues of communication also arose when AWP sent a letter to Cotswold House outlining the individual's personality disorder diagnosis, rather than informing the individual herself. As a result, the individual was not sat down and informed of her personality disorder diagnosis by her Care Coordinator at AWP
- The individual experienced frustration when she had to repeat her experiences to multiple professionals. There was the opinion that frustrations would not occur if all those involved in the individuals case communicated with each other as to provide the best care possible.

Furthermore, it was the opinion of individuals involved in this case that AWP view individuals as the disorder rather than as a person, resulting in the issue of treatment being viewed as a blanket approach.

In addition, there is the view that Avon and Wiltshire Mental Health Partnership (AWP) is more concerned with an individual meeting deadline and a timeline rather than taking a personalised approach dedicated to helping the individual recover. When these timelines are not met, it is the opinion that AWP view the individual as not wanting to get better.

Another key issue is the lack of acknowledgement regarding relapses. Eating disorders are not a curable disease, individuals require consistent on-going support and techniques to manage their disorder. However, in this case, an understanding of relapses is not evident in the treatment provided by AWP or Cotswold House.

Placement Student's Feedback

From discussions with the individual's family and a worker at the Kelly Foundation, I observed communication as the biggest frustration facing the individual's involved in this case. Fragmentation between CAMHS and adult mental health services, as well as fragmentation between mental health services and eating disorder services, have resulted in the individual feeling not listened to and not trusting those responsible for ensuring she receives effective treatment and support.

We hope that the struggles faced by this individual can be used to highlight areas that need be improved in order to provide the best support possible. Despite the struggles they have faced, the family had a positive opinion regarding the treatment received through Child and Adolescent Mental Health Services (CAMHS) and towards their Community Care Worker.

Recommendations

- Enhance communication between the services involved in an individual's care.
- Strengthen communication with the individual and their family

- Recognising the needs of individuals and viewing them as people rather than as their disorder. From this, more personalised approaches to treatment can be made. For example, asking the individual what food they like and ensure the food included in their food plan is food they actually like.
- Provide clear pathways for individuals and their parents after a diagnosis.
- Limit delays in reviews and recognise the impact these delays have on an individual's mental health.

Next Steps

This case study will be part of a wider report looking into eating disorders, more specifically the support available locally and people's perspectives on the causes of eating disorders among children and young people.

Thank you to the Kelly Foundation for their support on this project and to the individual and her family for sharing her story.

Appendix

Avon and Wiltshire Mental Health Partnership- Our services :: Avon and Wiltshire Mental Health Partnership NHS Trust (awp.nhs.uk)

Child and Adolescent Mental Health Service- Bath & NE Somerset | Oxford Health CAMHSOxford Health CAMHS

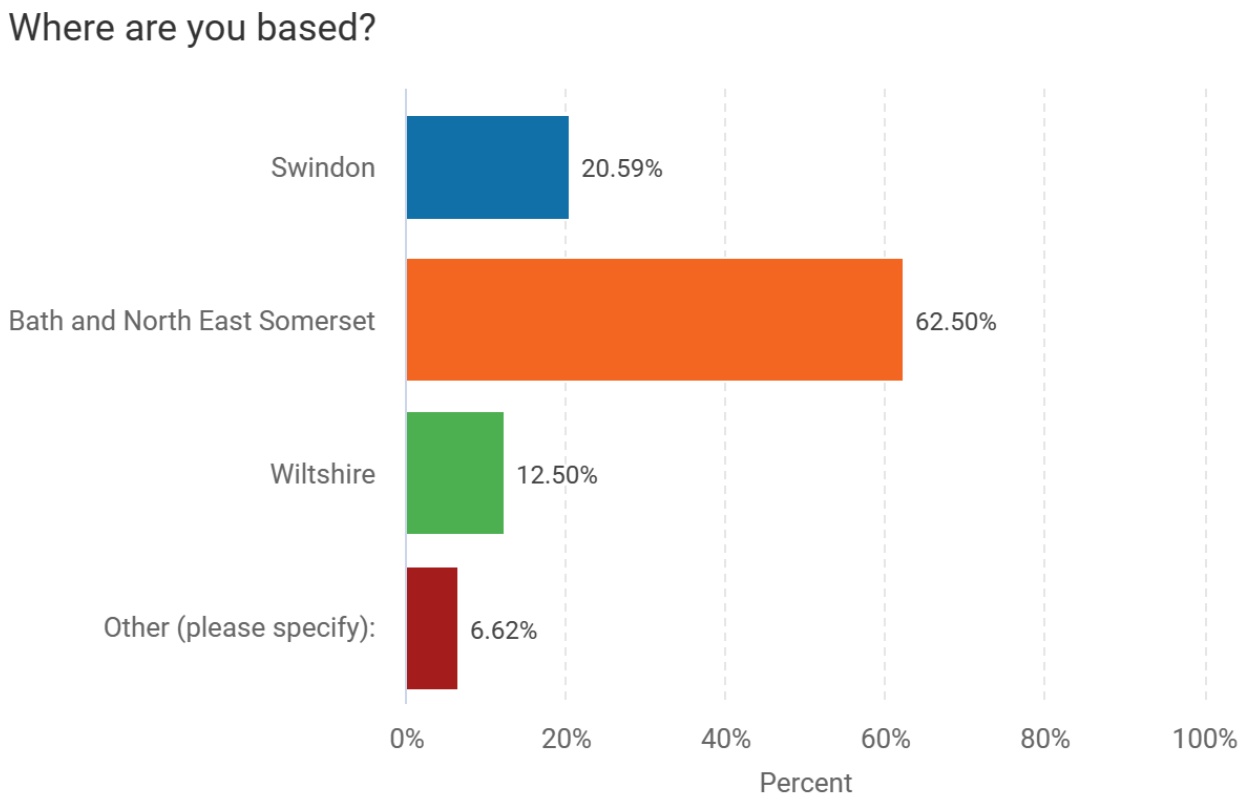
Chatsworth House- Overview - Chatsworth House - NHS (www.nhs.uk)

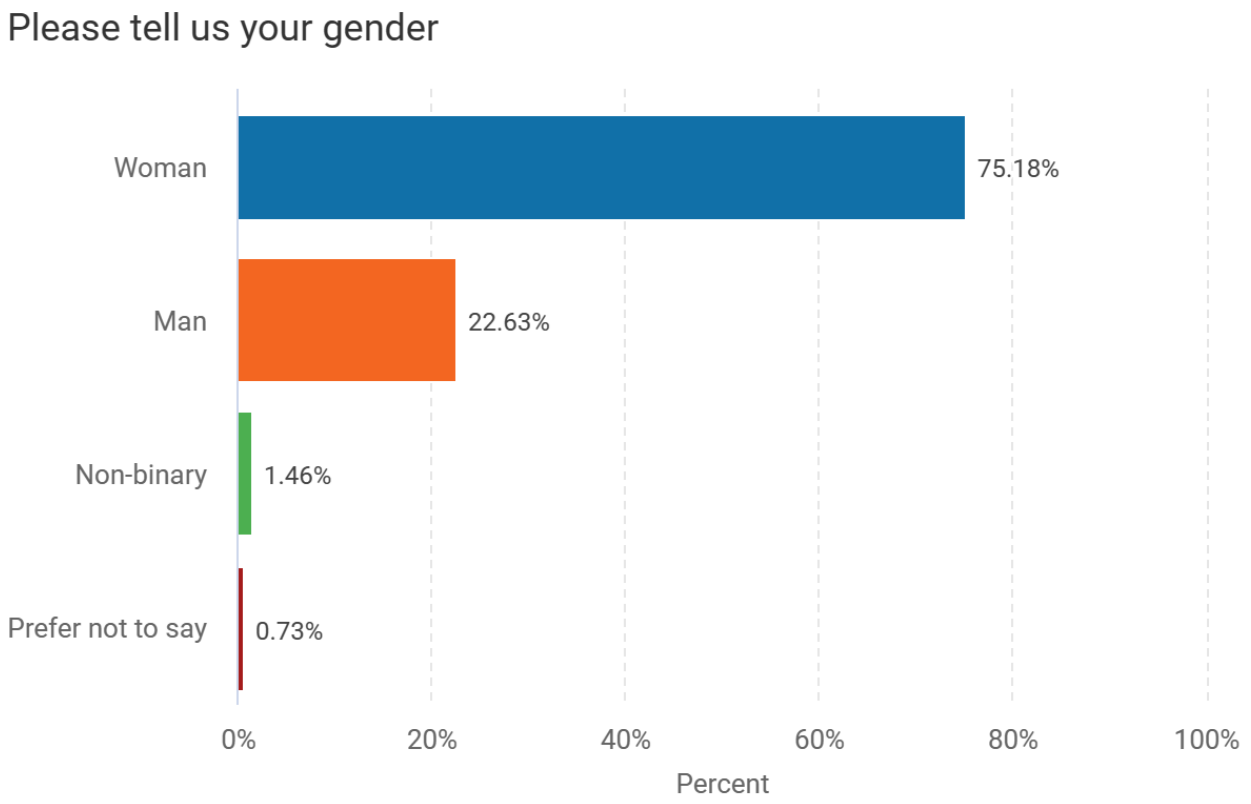
Cotswold House Marlborough- Cotswold House Marlborough Inpatient & Day Unit | Cotswold HouseCotswold House (oxfordhealth.nhs.uk)

Kelly Foundation- The Kelly Foundation - Home (4kelly.org)

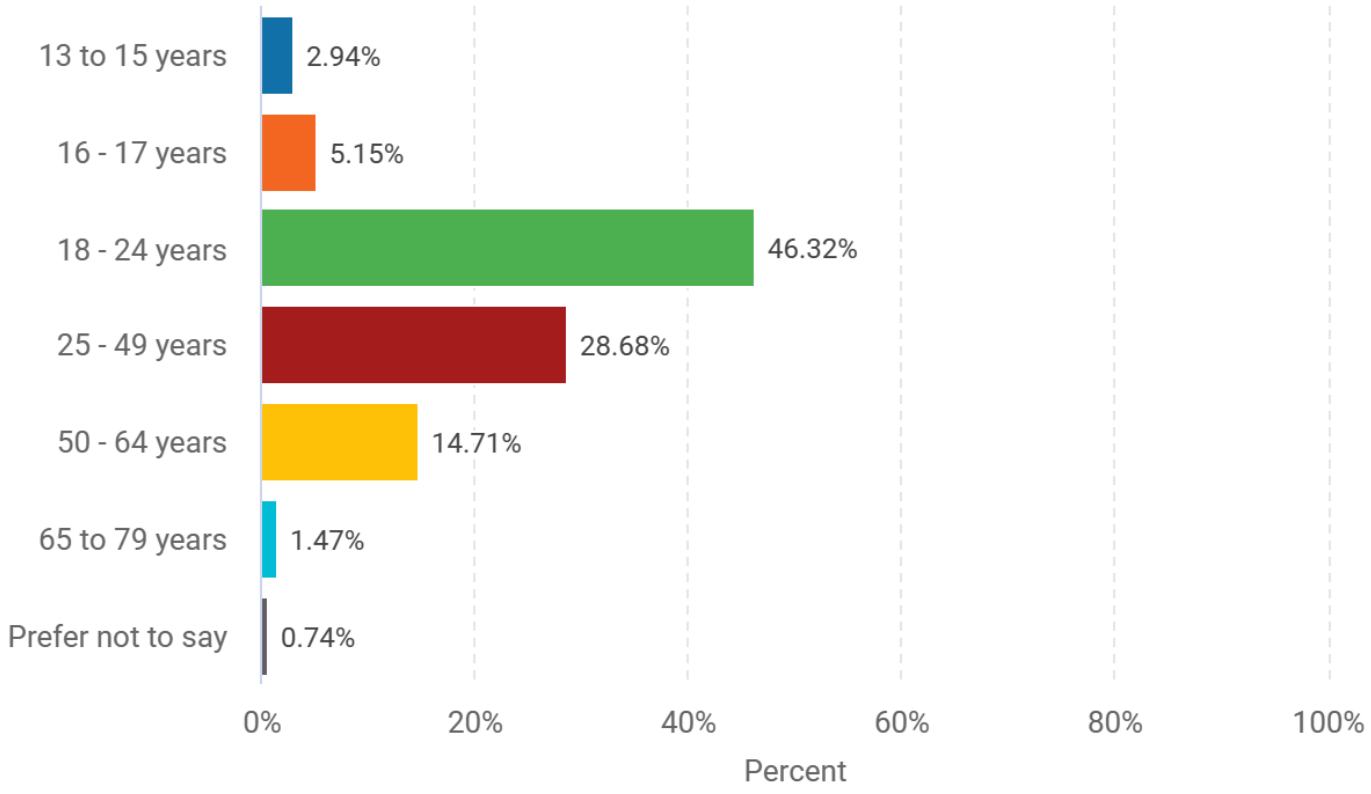
Appendix 4

Demographic Information for Eating Disorder Survey Respondents

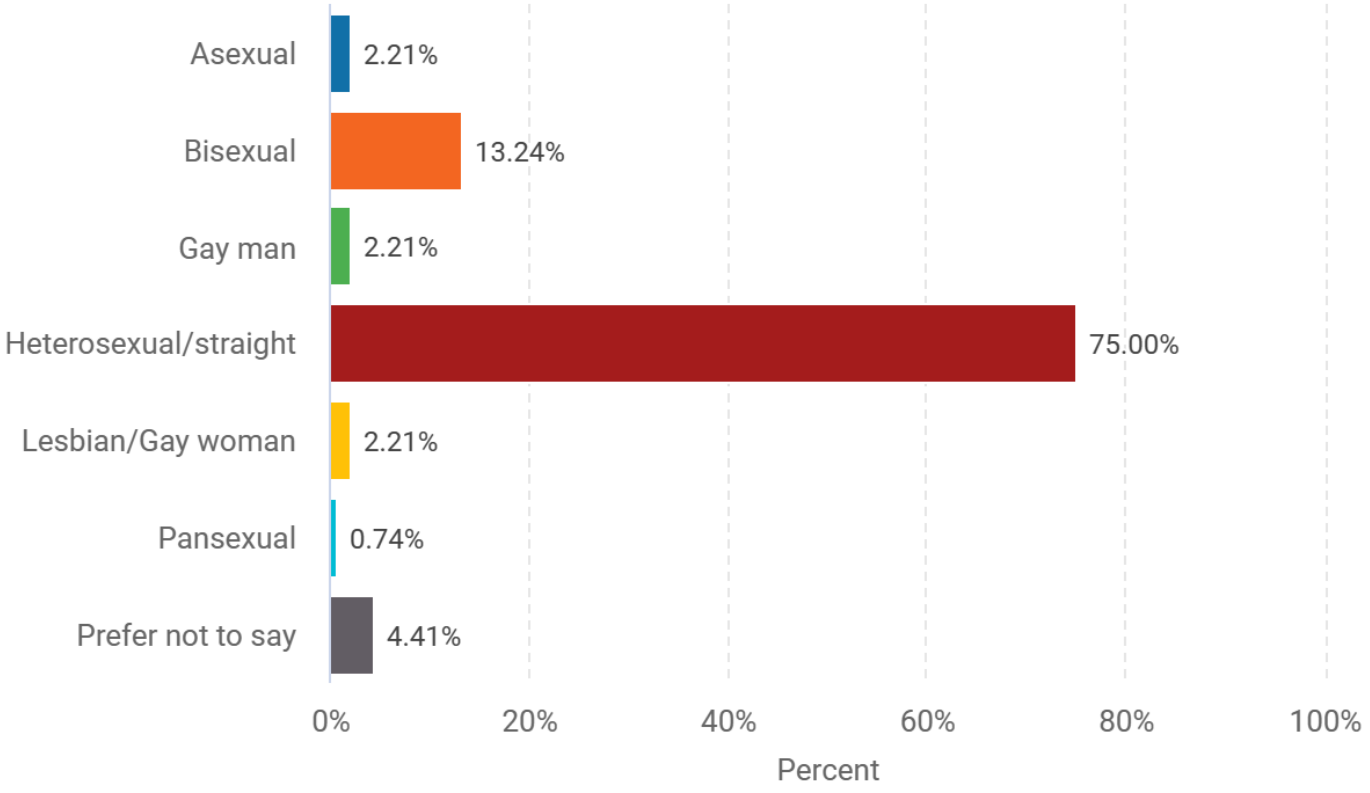




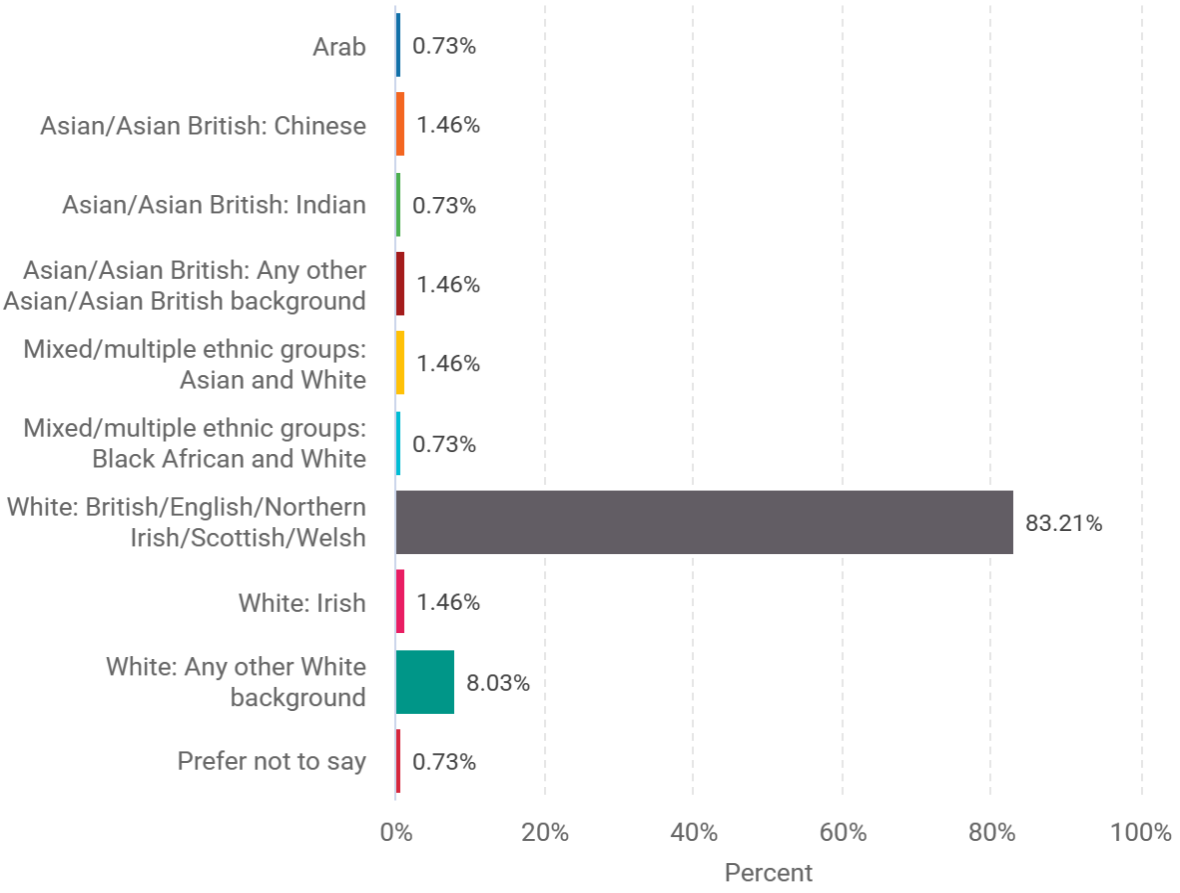
Please tell us your age



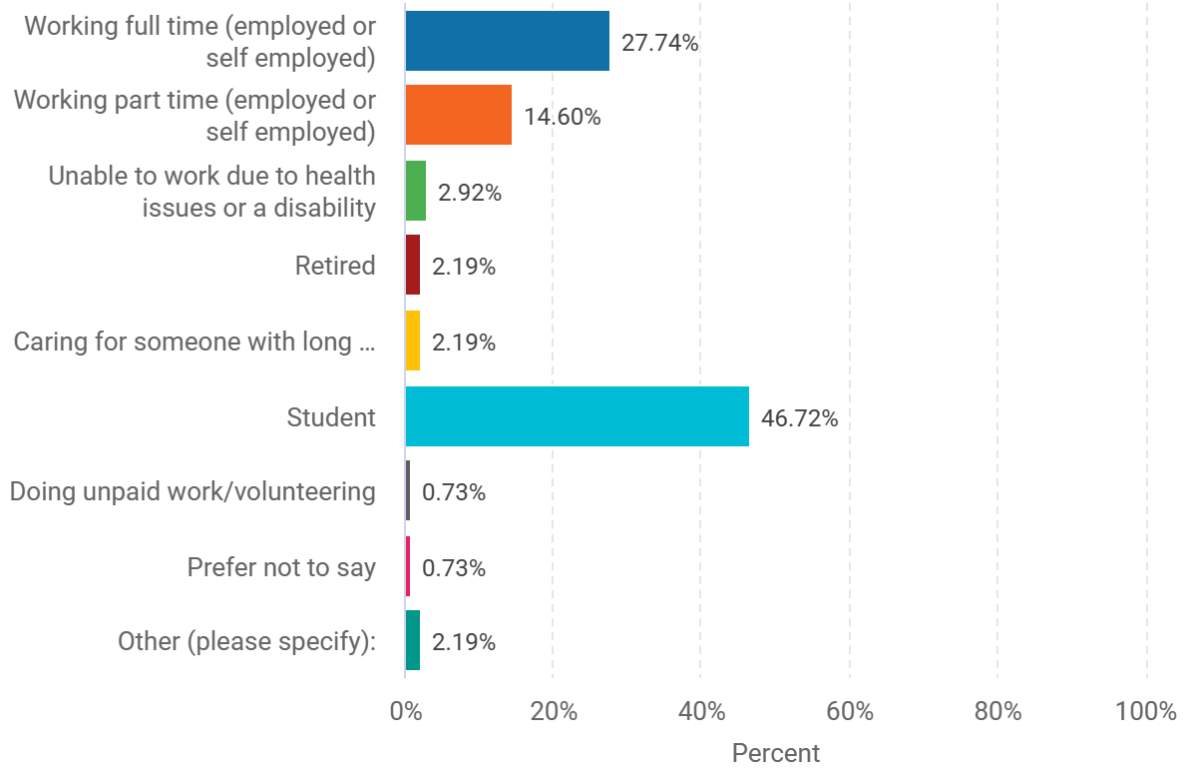
Please tell us which sexual orientation you identify with



Please select your ethnicity



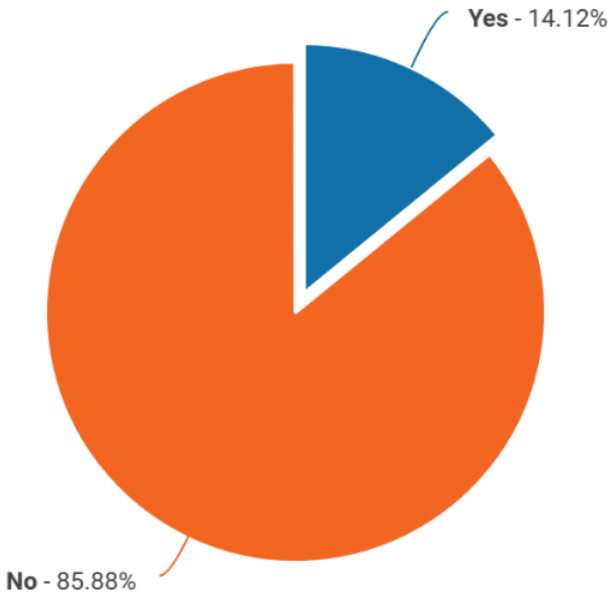
Which of the following best describes your current employment status?



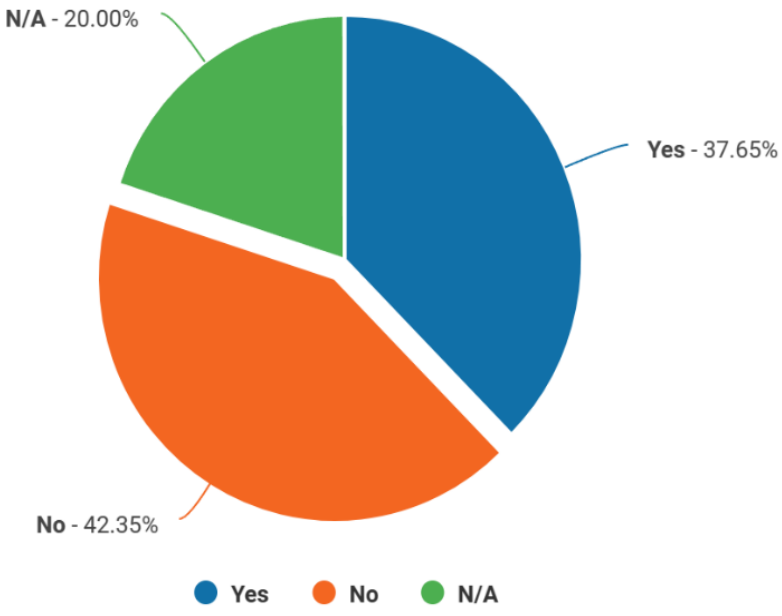
Appendix 5

Demographic information for Bath and North East Somerset

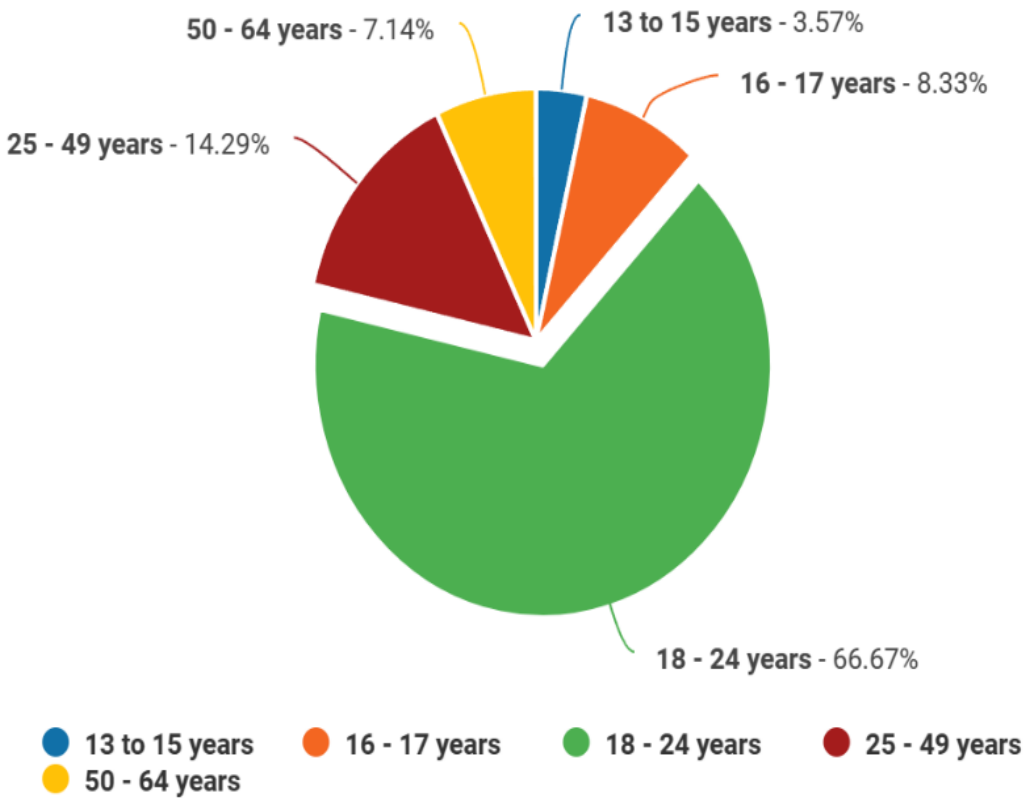
Do you have a diagnosed eating disorder?



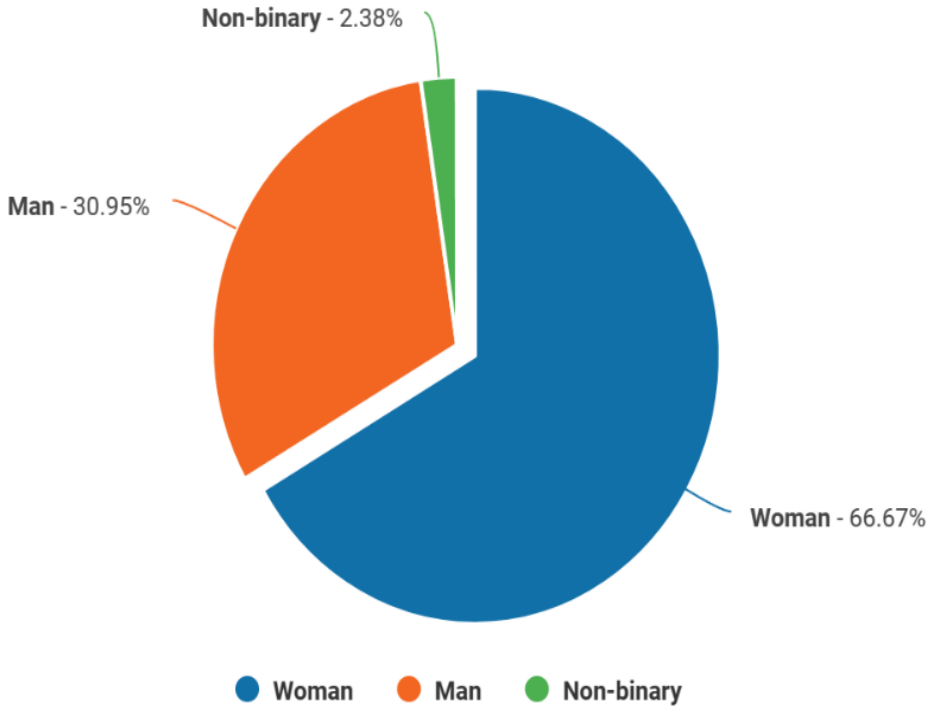
If you do not have a diagnosed eating disorder, do you feel you have an eating disorder/disordered eating?



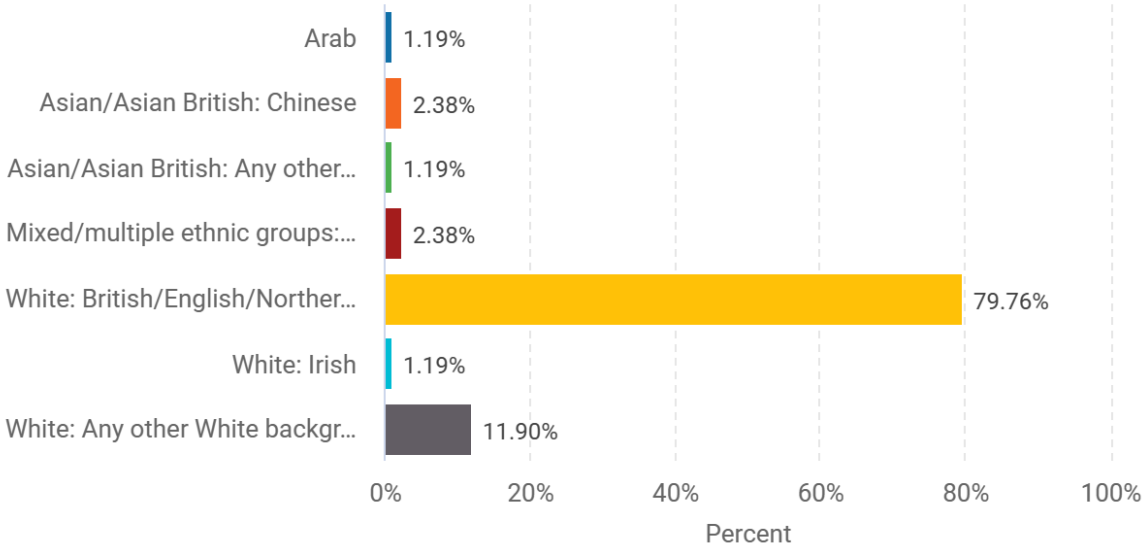
Please tell us your age



Please tell us your gender

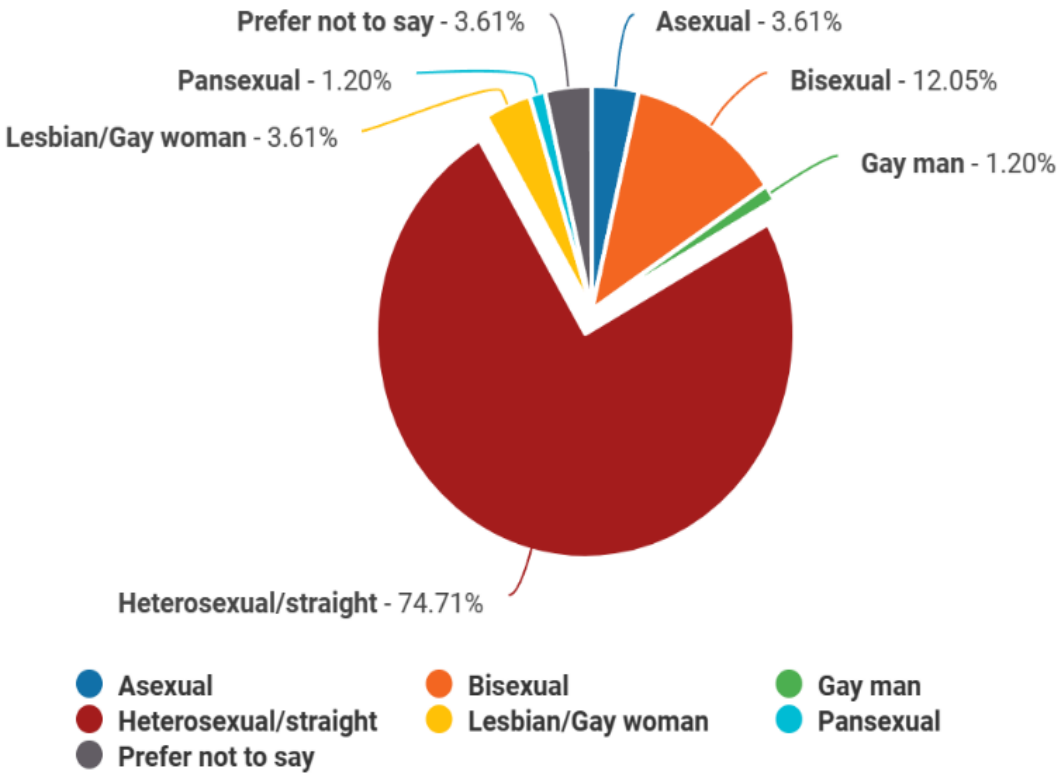


Please select your ethnicity

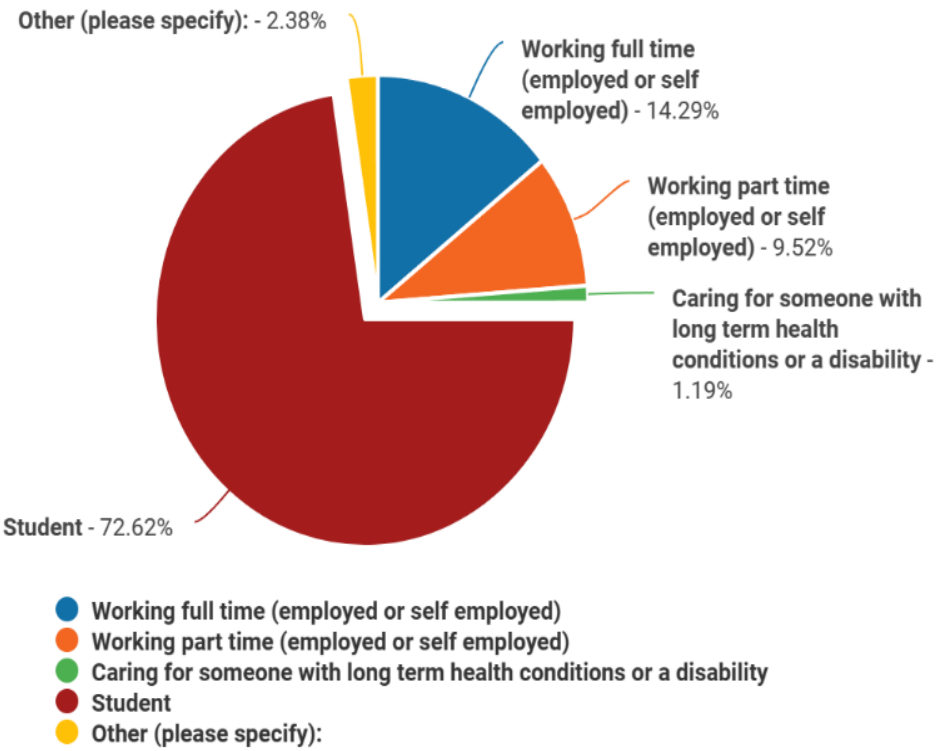


- **Arab**
- **Asian/Asian British: Chinese**
- **Asian/Asian British: Any other Asian/Asian British background**
- **Mixed/multiple ethnic groups: Asian and White**
- **White: British/English/Northern Irish/Scottish/Welsh**
- **White: Irish**
- **White: Any other White background**

Please tell us which sexual orientation you identify with



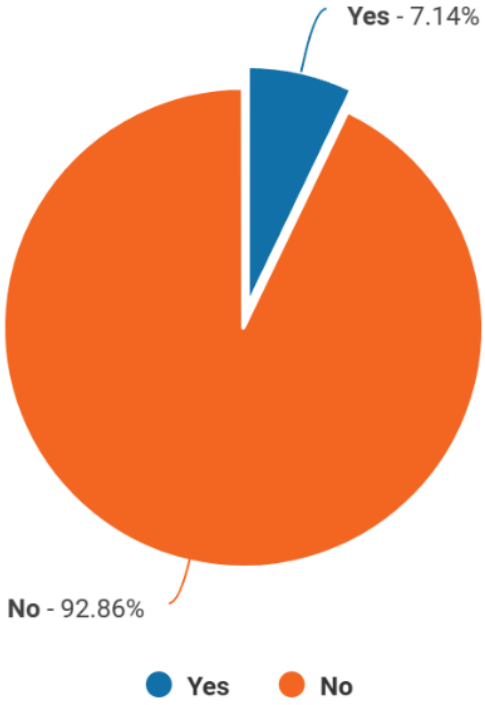
Which of the following best describes your current employment status?



Appendix 6

Demographic information for Swindon

Do you have a diagnosed eating disorder?



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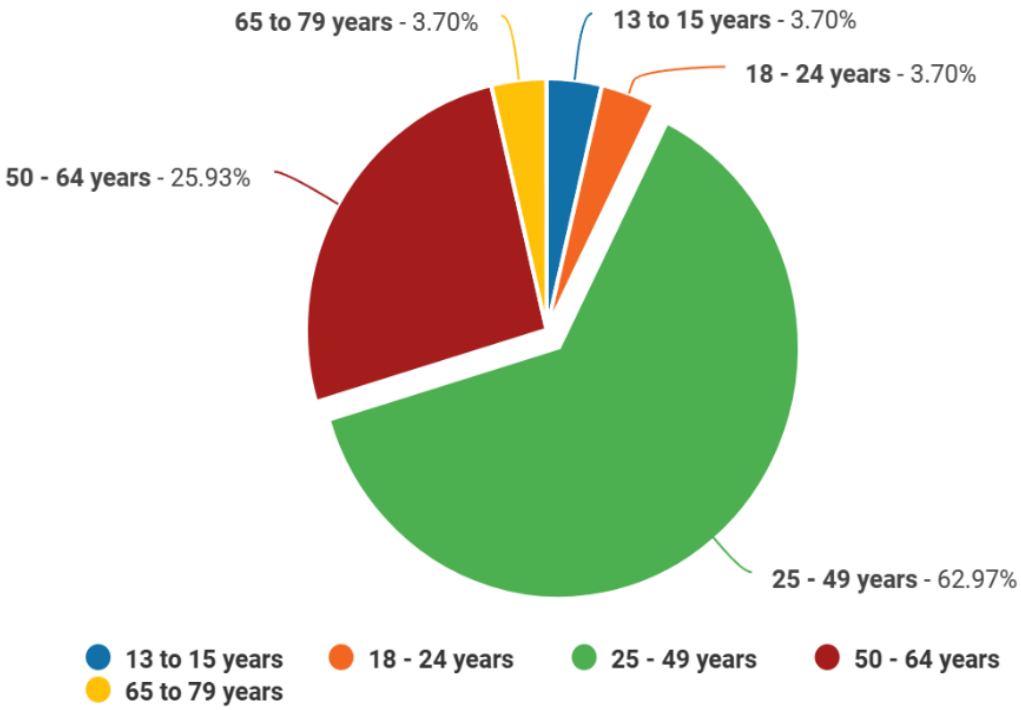
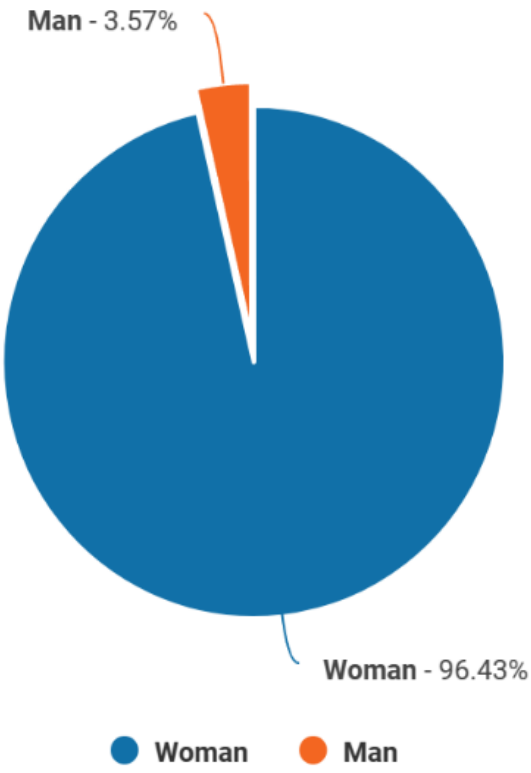
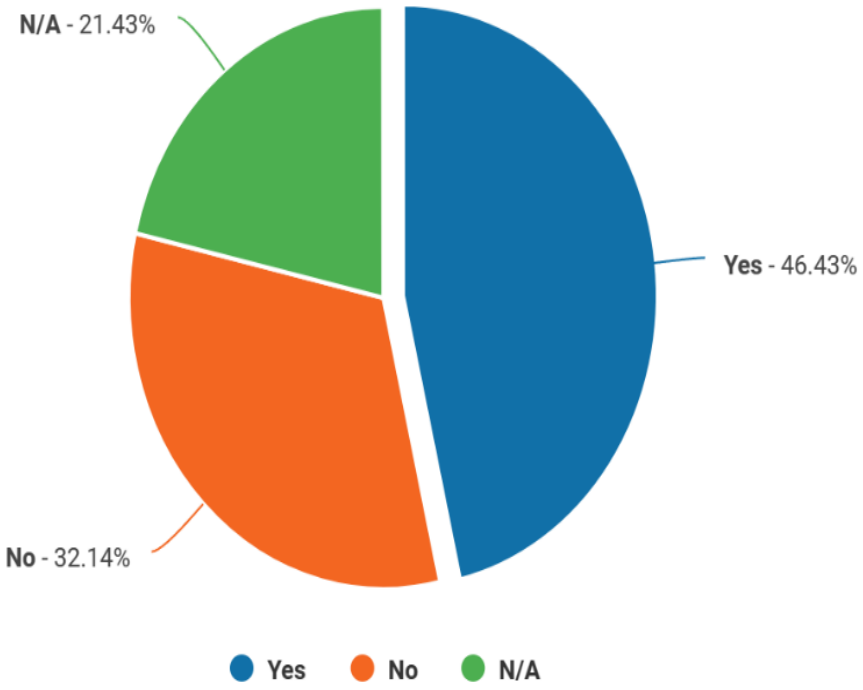


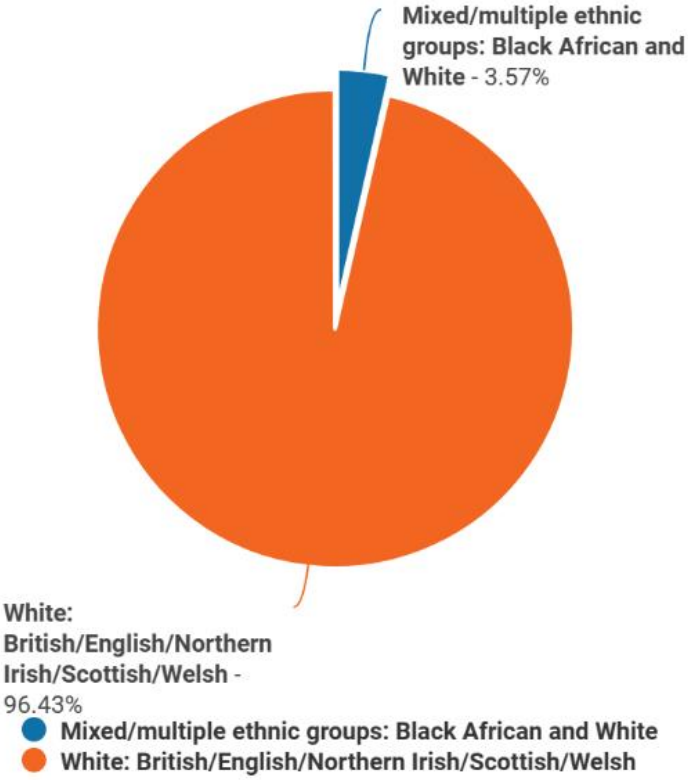
Please tell us your gender



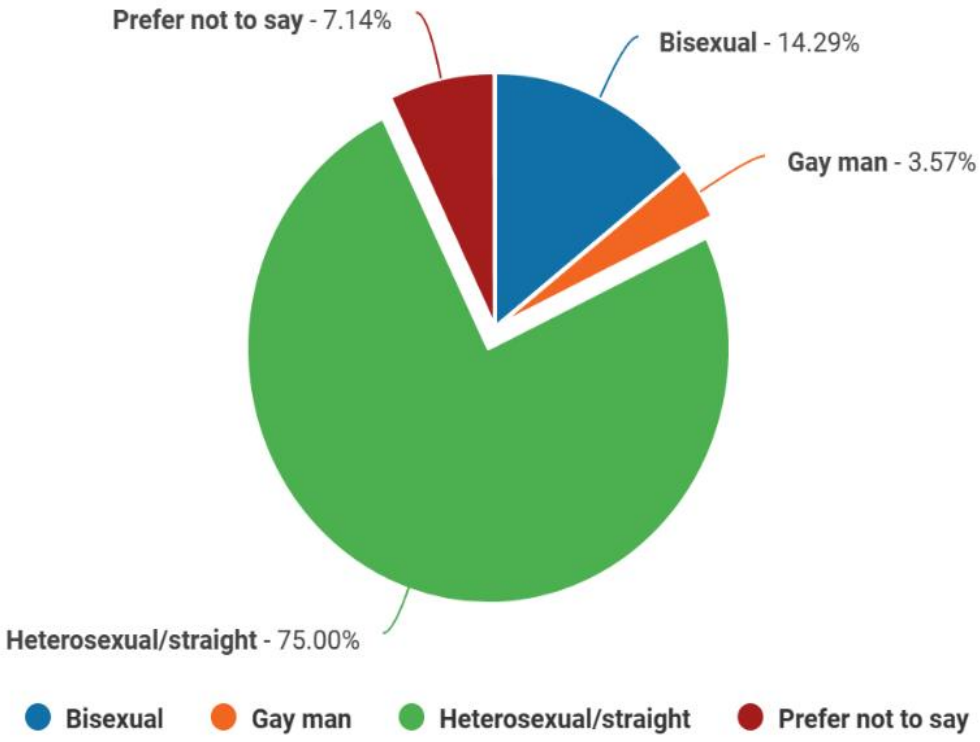
If you do not have a diagnosed eating disorder, do you feel you have an eating disorder/disordered eating?



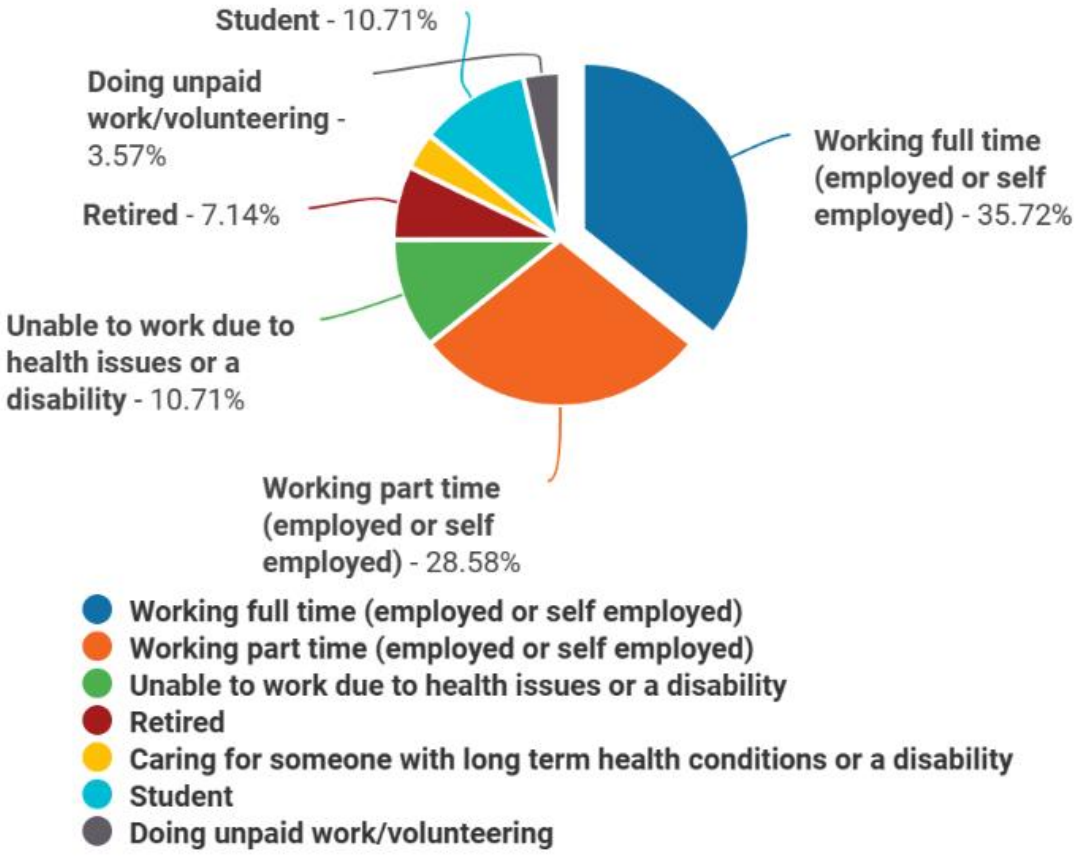
Please select your ethnicity



Please tell us which sexual orientation you identify with



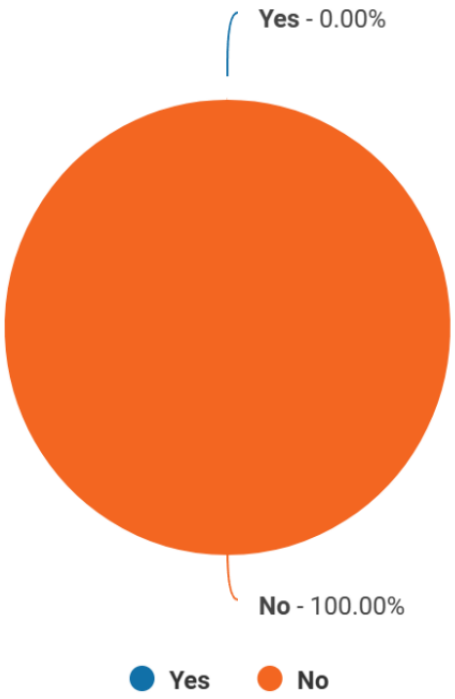
Which of the following best describes your current employment status?



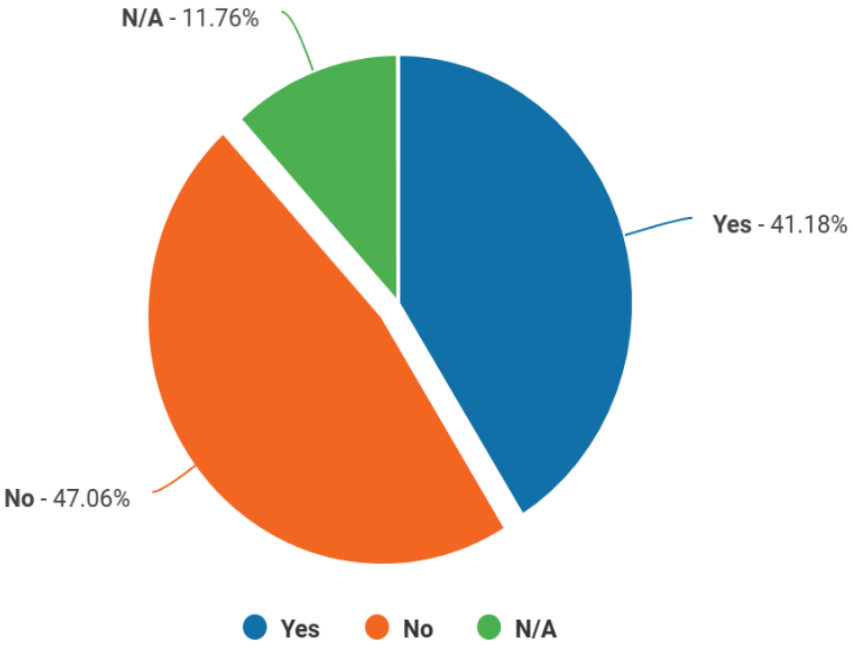
Appendix 7

Demographic information for Wiltshire

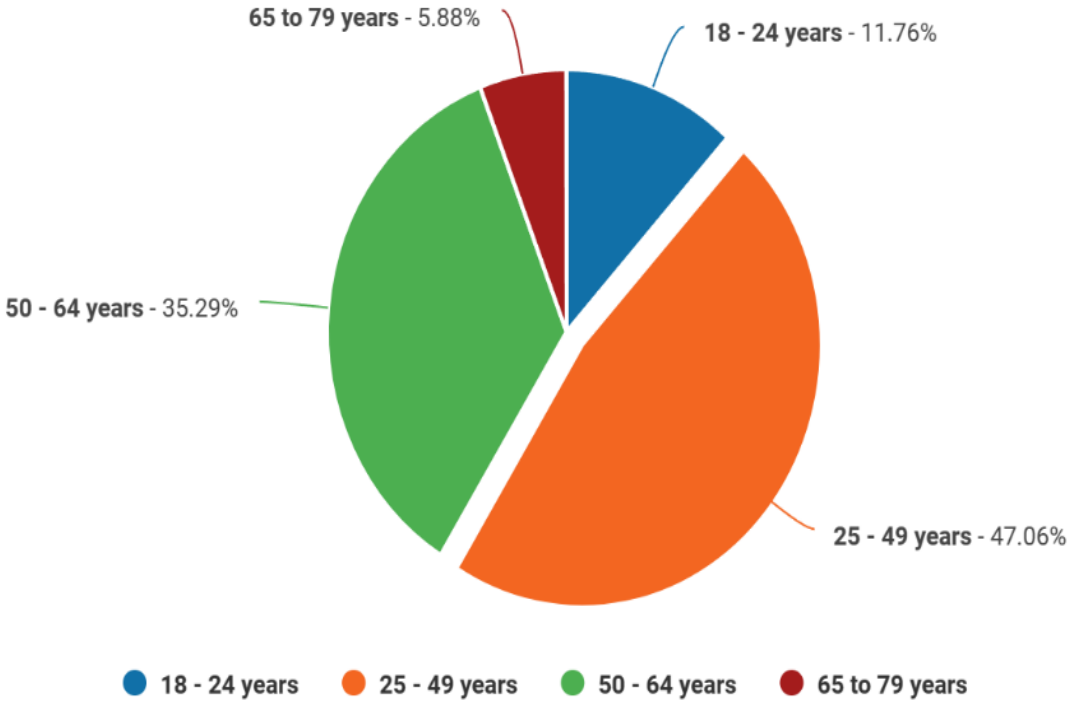
Do you have a diagnosed eating disorder?



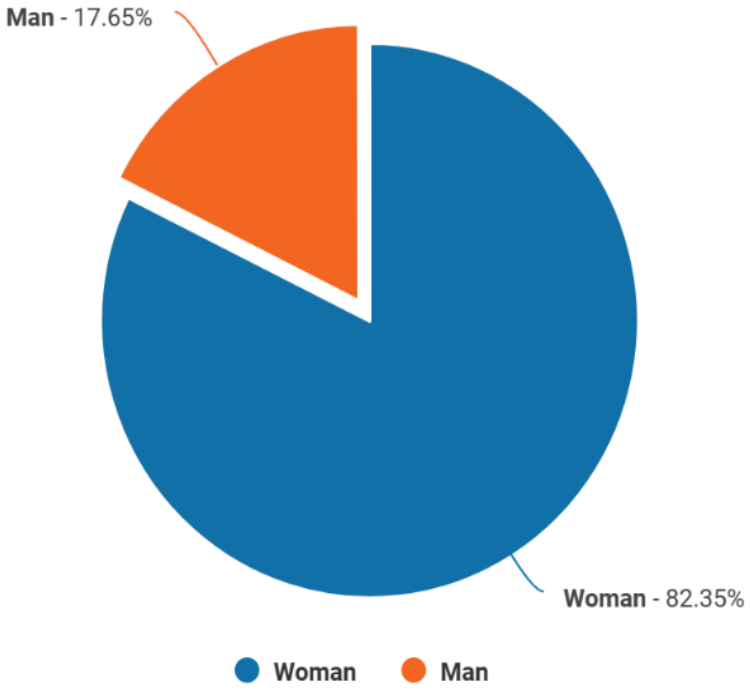
If you do not have a diagnosed eating disorder, do you feel you have an eating disorder/disordered eating?



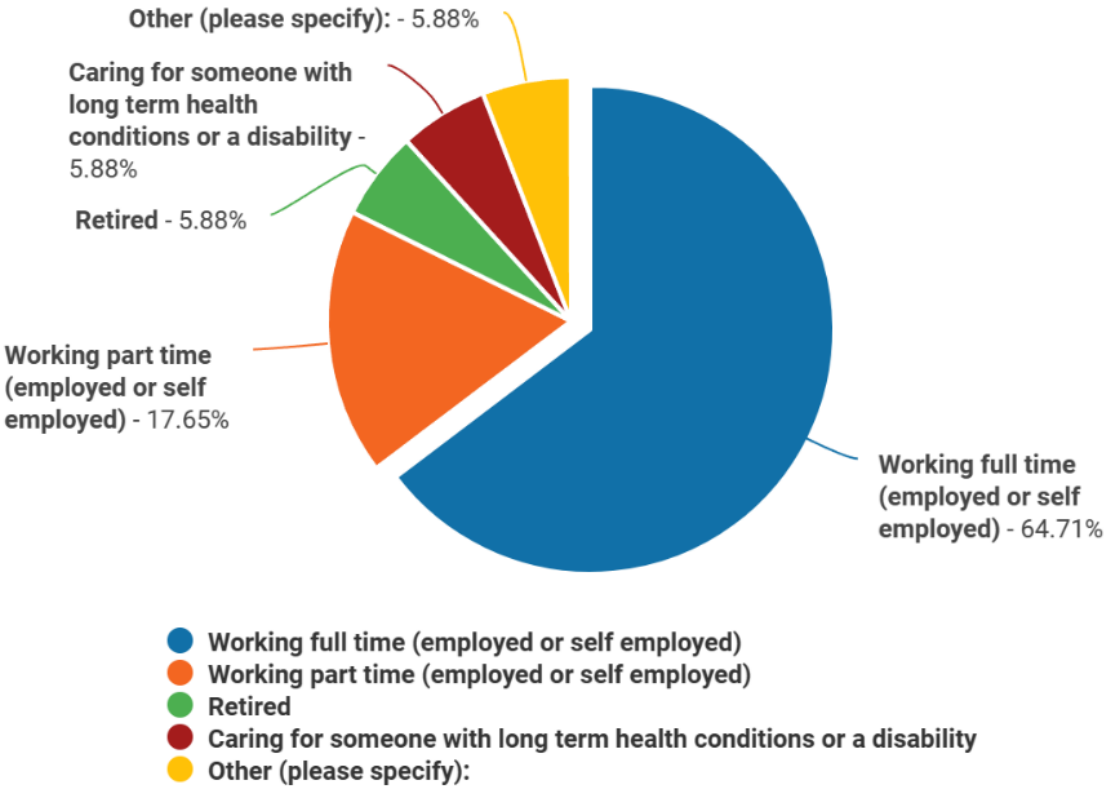
Please tell us your age



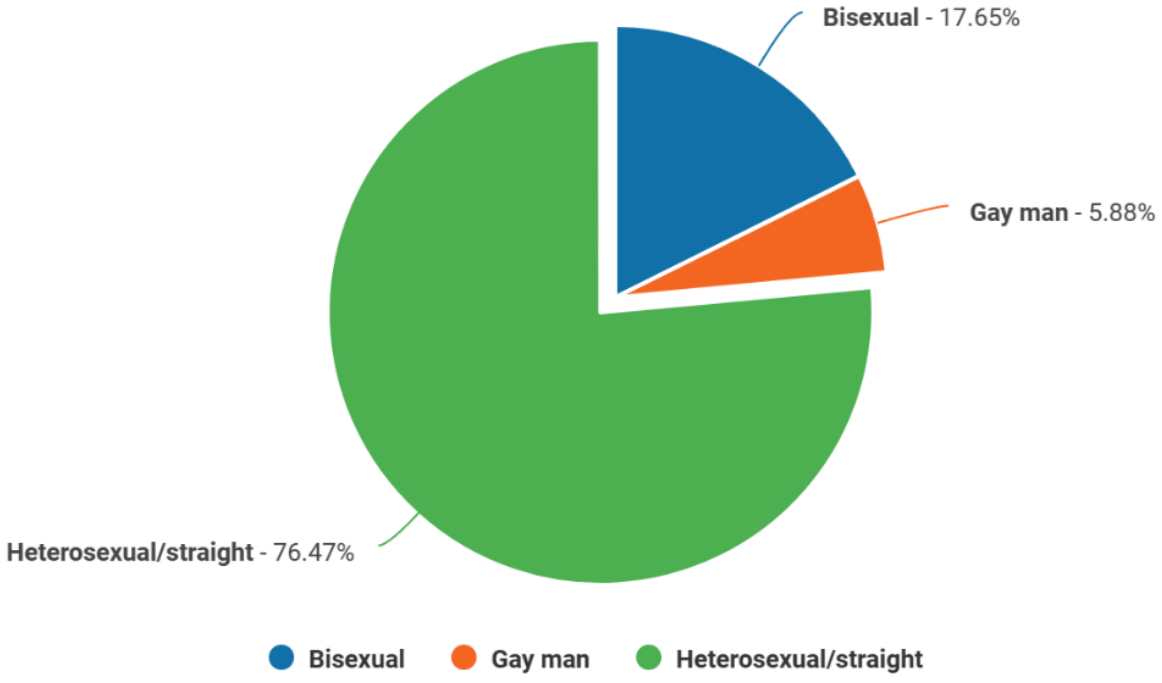
Please tell us your gender



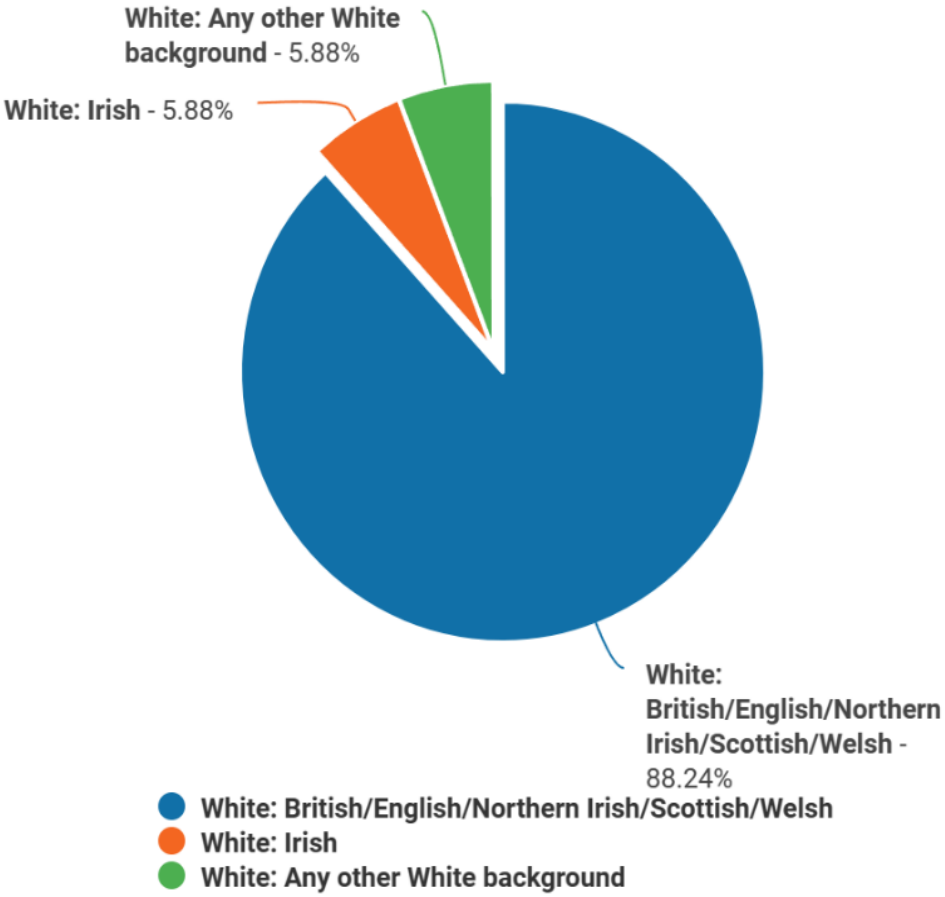
Which of the following best describes your current employment status?



Please tell us which sexual orientation you identify with



Please select your ethnicity



Appendix 8- eating disorder support in Bath and North East Somerset, Swindon and Wiltshire (BSW)

Child and Adolescent Mental Health Services (CAMHS):

- CAMHS is a specialist service for children and young people who are struggling with their mental health. This service is run by Oxford Health
- Bath and North East Somerset-Bath & NE Somerset | Oxford Health CAMHSOxford Health CAMHS
- Swindon- Swindon | Oxford Health CAMHSOxford Health CAMHS
- Wiltshire-Wiltshire CAMHS | Oxford Health CAMHSOxford Health CAMHS

SWEDA: Somerset and Wessex Eating Disorder Association

- Charity created by individuals with eating disorders and their loved ones operating in Somerset and Wessex.
- Provides support to those with a diagnosed eating disorder and those who struggle with food but do not have a formal diagnosis.
- More information available at - https://swedauk.org/

Eating Disorders Association (BEAT):

- A national charity which provides links to services local to the individual. They support those with eating disorders and provide information about eating disorders.
- Provides support to adults, children, young people, friends and family.
- They have a national helpline and an online peer support group.
- More information available at - Our services: Here to help. - Beat (beateatingdisorders.org.uk)

Bath Parent Carer Forum:

- This is a voluntary group of parent/carers of children and young people who believe parent/carers are experts in understanding their children and should be able to have a say in what happens in their local area.
- They provide opportunities to meet other parent/carers at cafes, short breaks for children and information valuable to parent/carers.
- Bath Parent Carer Forum allowed us to join a café and gather valuable information about the support available for eating disorders in Bath.
- More information available at -About us – BanesPCF

Mentoring Plus:

- This is a charity which supports children and young people in Bath and North East Somerset. They aim to ensure young people feel safe, heard and hopeful about their future.
- They provide primary volunteer mentoring, secondary volunteer mentoring, professional mentoring, student and family support as well as youth clubs.
- More information available at - About the charity | Mentoring Plus

Bath Mind and Swindon Mind:

- Mind is a national charity dedicated to supporting individuals experiencing mental health struggles. We contacted Bath Mind and Swindon Mind to help spread our survey.
- We discussed this project with Bath Mind who informed us of the services they provide. Bath Mind have a wellbeing team, breathing space, befriending service, counselling service and crisis support at Orchard House. Within this meeting, Bath Mind highlighted that there is no third sector group in Bath dedicated to eating disorders meaning there is a gap in the support available.
- Bath Mind- Our Services - Bath Mind
- Swindon and Gloucestershire Mind - Mental Health Support from Swindon & Gloucestershire Mind (sgmind.org.uk)

Swindon Carers Centre:

- This is an organisation who provide help and support to unpaid carers. They work with a range of services and partnerships with other organisations in Swindon.
- They provide support to adult carers, parent carers and young carers.
- More information available at - Home - Swindon Carers - Supporting Carers in Swindon

Kelly Foundation:

- This organisation was founded in 2022 and aims to provide support for adults and young people experiencing short or long-term mental health struggles. They provide support for anyone over 18 in Swindon.
- Whilst the Kelly Foundation is not an eating disorder service, they do provide support via a personalised support programme, advocacy support, life skills training, access to a life coach, counselling and support for friends and families.
- Through the Kelly Foundation we were able to speak to parents of two individuals who have suffered with an eating disorder. From this, we were given valuable insight into first hand experiences of failures in services and gaps in eating disorder support.
- More information available at - The Kelly Foundation - Home (4kelly.org)

Cotswold House Specialist Adult Eating Disorder Service

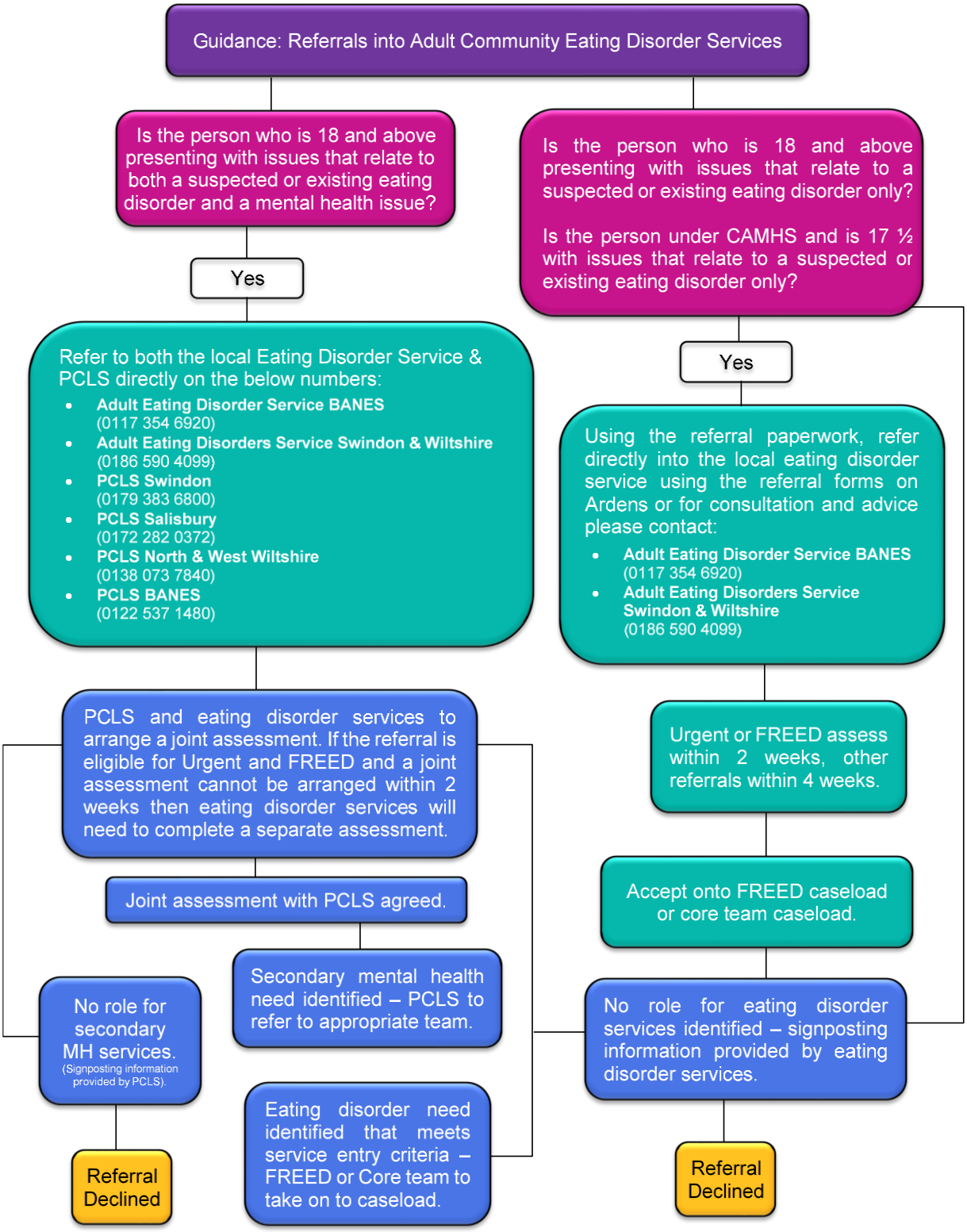
- Cotswold House is an award-winning specialist adult eating disorders service provided by Oxford Health NHS Foundation Trust. They operate from two modern eating disorders units in Oxford and Marlborough.
- Inpatient and day patient treatment programmes are run in both units and outpatient services are provided in locations across the counties of Oxfordshire, Buckinghamshire and Wiltshire.
- Cotswold House's work is to ensure that all young people and their families are informed about their services, treatment models and the shifting expectations regarding responsibility and confidentiality when they reach adult status.
- More information available at - https://www.oxfordhealth.nhs.uk/cotswoldhouse/about/

Appendix 9 – AWP flow chart

NHS Oxford Health NHS Foundation Trust

NHS Avon and Wiltshire Mental Health Partnership NHS Trust

BSW Eating Disorder Services Referral Flow Chart



healthwatch
Together

Bath and North East Somerset,
Swindon and Wiltshire

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Facebook.com/Healthwatchswindon