



mental welfare
commission for scotland

Hope for the future

A report on a series of visits by the Mental Welfare Commission looking at care, treatment and support for people with eating disorders in Scotland

Themed visit report

September 2020



Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

A report on a series of visits by the
Mental Welfare Commission for Scotland
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Hope for the future

*"I want to find release from the obsession with food/body as a way of avoiding everyday life. The ability to live life to the full without the mental torture of an eating disorder, the exhaustion, desperation and hopelessness of it all.
I am very hopeful however."*

"I want to be able to enjoy myself again, have a milkshake and not feel like I'm a failure. I want to be able to have the memory and focus to work well, and no longer have to use an eating disorder because I can't control how I feel. I want to feel normal."

"I hope for more peer roles within services. Often those with lived experience are dismissed as being able to be on the other side, however, often it can be easier to relate to others with lived experience and can encourage recovery. A huge part of recovery is connection and friendships."

"I hope when I leave that I will be stronger and able to follow up the development gained in the intensive therapies work. I am a mum and a wife and I don't want to miss out on those things."

Executive summary

Eating disorders are serious mental illnesses and potentially life threatening conditions. Anorexia nervosa has the highest mortality rate of any mental illness and can have a devastating lifelong impact¹. For a full description of eating disorders and their wider implications, please refer to Appendix A.

This is the first time that the Mental Welfare Commission for Scotland ('the Commission') has carried out a themed visit in relation to people with eating disorders. We were aware from our contact with people with eating disorders, their families and carers, the staff who provide treatment and support, and others, that access to general and specialist treatment and support could vary across the country.

During 2018 and 2019, we consulted with a number of people and organisations to understand priority topics and develop questions, which we then took forward into our themed visit, delivered in two phases over 2019 and 2020. We heard from 74 people with an eating disorder and 30 carers. We also carried out an exercise to identify the provision of care and treatment across NHS health boards in Scotland. We also consulted 103 health professionals using online surveys.

The aim of our themed visit was to gain a closer understanding of the current situation in relation to the care and treatment of people with eating disorders in Scotland.

We have written this report for a number of different audiences:

- People with eating disorders and the families/carers who support them may find it helpful to hear about the experiences of others and also to know what to expect from services.
- People who provide care, treatment and support for people with eating disorders should read this report and use it to reflect on their current practices.
- Commissioners and managers of health and social care services should review this report and consider aspects of current practice and service provision that can be improved.

We also make recommendations and will be sending this report to those noted in the recommendations. We will follow up formally on their responses and report publically on those responses.

Key findings

We found that early intervention in the course of an eating disorder, support through CMHTs (community mental health teams) and eating disorder services, access to psychological interventions and therapies, and a positive and engaging relationship with the professionals providing care were said to be critical to people with eating disorders.

However, people with eating disorders and their families/carers felt there could often be a lack of support available and delays in accessing that support. Some felt excluded from the diagnostic process and experienced prejudice connected with the stigma attached to eating disorders.

While many of the family/carers who took part in our themed visit reported positively about excellent care, they also talked about the difficulties they could face. Without

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4102288/>

exception, they all told us that caring for someone with an eating disorder had devastating and long-lasting effects on the whole family. The impact on families can be traumatic and we heard that many families/carers were sometimes left feeling helpless and unsupported.

A number of concerns were raised about the focus on using BMI (body mass index) alone as a criterion for referral and access to services – and also as an indicator of recovery – with less attention paid to other critical factors including co-existing mental health conditions. For GPs too, this can be felt to act as a barrier to referral to specialist services if symptoms are present but BMI is still within acceptable limits.

We noted inequalities in the provision of services, including the availability of psychological therapies, with some people accessing support privately. We also found confusion and conflict over the responsibility for physical health monitoring between GPs and psychiatrists.

Compliance with and awareness of guidelines on waiting times for assessment and referral varied. We heard about gaps in care provision between services following transitions from one service to another, and also from inpatient to community care.

Our mapping exercise (Appendix B) provided an overview of the widely differing organisation of services caring for people with eating disorders in Scotland. This is the first time such an overview has been achieved and the process of information gathering highlighted differences in health boards' approaches to describing details of the services they provide.

Feedback on dietary management from patients in inpatient settings raised questions regarding the quality, choice and presentation of meals, as well as the structure and management of mealtimes.

Finally, we noted the need for more specialist training, knowledge acquisition and skills development for some professionals involved in the diagnosis, care and treatment of people with eating disorders. Where this is not present, it can create a lack of confidence and trust.

Recommendations

Recommendations for integration authorities

An integration authority can be a local authority, a health board or an integration joint board, according to the model of integration adopted locally.

We recommend that integration authorities:

- have clear and detailed operational guidance and policies relating to services that look after people with eating disorders and ensure care transitions are coordinated;
- have a comprehensive range of services available across all ages and gaps in provision are identified and addressed; have clearly defined access to inpatient mental health beds for people with eating disorders, across the age range;
- ensure support is maintained following discharge from hospital and specialist community services including support for families/carers;
- develop protocols about physical health monitoring, including the assessments and investigations that should be undertaken by primary and secondary care providers and clear guidance on how different services are expected to work together;
- put in place protocols outlining how the provision of medical care for 16-17 year olds, who require medical inpatient treatment, will be supported by mental health and eating disorder services;
- ensure that there is access to the appropriate level of training in ED for their staff;
- have in place a range of supports, in relation to all aspects of health, for people with an eating disorder;
- family/carers should be involved, where appropriate, in the planning of treatment, and have access to a range of information and support that can provide help when caring for a person with an eating disorder, or when in a crisis situation.

Recommendations for Scottish Government

While undertaking this themed visit, we were told that eating disorder services will be subject to a national review by the Scottish Government, designed to assess and improve support for people with eating disorders.

We recommend that Scottish Government:

- use this report to help inform the work of their national review;
- look to establish a managed network in relation to eating disorders; this would help to address issues of inequality in access to services, public education, staff education and the sharing of best practice.

Recommendations for Healthcare Improvement Scotland (HIS)

We recommend that HIS prioritise a review of the Scottish Intercollegiate Guidelines Network (SIGN), which requires review, revision and update of the efficacy of treatments and therapies to support people with eating disorders in Scotland.

How we carried out this visit

Pre-visit consultation

In early 2019, we undertook consultation to gain insight into the current care and treatment of people with eating disorders in Scotland.

Our engagement and participation officers met people with eating disorders and families/carers and also met support organisations, including BEAT Scotland (a charity specialising in support for people with eating disorders). They asked what they felt our priorities should be and what we should focus on in our questionnaires. Some took part through group meetings while others took part in individual interviews. Altogether 44 people were involved.

Over 30 different topics were identified, with the most common being services using BMI (body mass index) as a criterion for admission, and the lack of support in the community for people with eating disorders and their families/carers. Difficulties in achieving access to early intervention, specialist service input where there is a dual diagnosis, and challenges around transitions from CAMHS (children and adolescent mental health services) to adult services, were also highlighted.

We then considered all of the information gathered, and used it to inform our questionnaires aimed at people with eating disorders, their families/carers, and professionals involved in care and treatment.

Visit methodology and data collection

We carried out the themed visit over two phases. In phase 1 we visited ten eating disorder services in different health boards across Scotland. During these visits we conducted staff questionnaires, reviewed case notes and met with patients and families/carers to hear about their experiences. Those not able to meet us on visits were given the opportunity to take part by completing questionnaires.

During phase 1 we also requested information from health boards about the provision of services for people with eating disorders in their area.

In phase 2 we were able to consult more widely, using online surveys. People with eating disorders and their families/carers completed online questionnaires, mirroring those used on our visits. We also surveyed GPs, psychiatrists, dietitians and therapists with regard to the provision of care for people with eating disorders.

Impact of COVID-19

Unfortunately, due to the implications of the COVID-19 pandemic, we have not been able to include all of the information we collected through our visits in this report.

Phase 1 relied on paper copies, but missing entries had not yet been corrected and input into the database. With our offices closed, hard copies could not be accessed and checked against digital records that had data missing, nor could those awaiting input be entered onto the system. With uncertainties around when copies could be accessed, we proceeded without the missing data from phase 1.

This will be reviewed at a later date and is estimated as 24% of the total number of individuals visited, 27% of the total number of families/carers we met and 20% of the staff questionnaires of the services we visited. This report should therefore be read with this unexpected missing data taken into consideration.

Phase 1 methodology

The ten eating disorder services we visited included seven inpatient units, of which three were generic CAMHS units and one, The Priory in Glasgow, was non-NHS. Armadale Ward at Stobhill Hospital is a general adult mental health ward but has four beds reserved for the treatment of people with eating disorders. The remaining three visits were to specialist community eating disorder services.

We received staff questionnaires from the eight out of the ten services we visited. We also gathered information from 48 people with eating disorders who were receiving care from these services. Over one third of our respondents were being treated under the Mental Health (Care and Treatment)(Scotland) Act 2003, with most of those under a compulsory treatment order, and some under a short-term detention certificate. We received completed questionnaires from 10 carers.

We gave people the choice of completing a questionnaire independently or with us. As a consequence, some data is missing from questionnaires completed due to pandemic-related work or respondents not answering all questions.

As we were already aware that specialist eating disorder services vary across the country, we wrote to all health board chief executives in July 2019 with a list of questions to find out more about their services, and followed this up in early 2020 with a request for more information. The responses to our questionnaire to chief executives (and the content and clarity of responses) varied. Although we received a good response from many boards, the impact of the COVID-19 pandemic delayed our ability to follow up missing data initially, however we were able to finalise our data gathering in May 2020 and sent out drafts to health boards for final feedback in June 2020.

The information provided in Appendix B represents the first completed mapping exercise of eating disorder services across Scotland and the variation in eating disorder services that exists.

Phase 2 methodology

We created six online surveys: one to gather insight from people with eating disorders (with or without a formal diagnosis), one to gather insight from families/carers supporting people with eating disorders and four to gather insight from a range of professionals involved in the care and treatment of people with eating disorders. We distributed our surveys through the Commission's Twitter account, website and also through a number of collaborating stakeholders.

A total of 26 people with a diagnosed eating disorder who were living in Scotland and/or receiving care and treatment from a Scottish health board responded to our online survey. An additional 14 responses were received from individuals who thought they had an eating disorder but had not received a formal diagnosis or treatment. We analysed responses from this group separately.

Twenty family members/carers from nine different health board areas responded to our phase 2 questionnaire.

The online surveys for professionals working with people with eating disorders were designed to gather knowledge from the different professional groups that people with eating disorders may come into contact with. We distributed these surveys through the Commission's Twitter account and through a number of collaborating stakeholders, including the Royal College of Psychiatrists. We received responses

from 21 GPs, 27 dieticians, 24 psychiatrists and 31 clinicians delivering psychological therapies for eating disorders.

Among the 24 psychiatrists who participated, the majority (nine) were general adult consultants, six were eating disorder specialists, four worked in child and adolescent mental health (CAMHS) and three in liaison psychiatry. The two remaining psychiatrists worked in other specialties. We asked about the setting each participant worked in, directing them to questions relevant to that setting: six psychiatrists treated people with eating disorder in the community, four provided inpatient care only and seven treated patients across both settings. Seven psychiatrists did not routinely manage patients with an eating disorder and we asked these respondents about their experience of local services for people with eating disorder as well as education and training.

A total of 74 people with a diagnosis of eating disorder who were aged 12 years or older² (48 people during phase 1 and 26 during phase 2) participated in the themed visit. Of these, 68 were female and 6 were male.

Although eating disorders can affect children under the age of 12, issues relating to capacity and consent to take part in this themed visit, and in the relation to compulsory treatment, meant that they were not included.

Table 1. Characteristics of individuals with eating disorder consulted during themed visit (n=74)

Characteristic		Total N=74	Phase 1 N=48	Phase 2 N=26
Gender	Female	68	41	26
	Male	6	6	-
Age	12-15	9	8	1
	16-17	17	15	2
	18-24	15	8	7
	25-34	17	10	7
	35-39	7	4	3
	40-49	5	1	4
	>50	4	2	2
Health board	Borders	2	2	-
	Dumfries and Galloway	2	1	1
	Fife	4	2	2
	Forth Valley	4	1	3
	Grampian	6	5	1
	Greater Glasgow and Clyde	11	5	6
	Highland	3	3	-
	Lanarkshire	4	3	1
	Lothian	27	19	8
	Shetland	1	1	-
	Tayside	7	4	3
	Other/England	2	1	1
	Missing	1	1	-
Setting cared for	Home/community	42	16	26
	Inpatient	29	29	-
	Missing	3	3	-

Chapter 1

Accessing support and understanding impact

The vast majority of people with eating disorders are treated in the community by their local CAMHS, primary care team or CMHT with links to other support services where appropriate. Many will turn to their GP as a first step and, while some will go on to support themselves at home with the help of family/carers, others may require specialist support either within their community or in an inpatient setting.

People with eating disorders, those with a diagnosis and those without, told us about the difficulties they can experience when trying to access support in the community – including issues around resources, service criterion and stigma – and many told us that they'd like to see improvements to the services offered to people with eating disorders, particularly in community settings.

They told us that some treatments were only available in specialist inpatient services, rather than in the community where people may be better placed to engage. And they told us that not getting support at a time when it's needed can lead to a deterioration in physical, mental and emotional wellbeing, sometimes resulting in hospital admission.

Tackling stigma

“Spoke to family and friends initially and then sought anonymous online advice - too embarrassed and ashamed to approach GP.”

Adult reporting binge eating disorder

Although the Scottish Government's *Mental Health Strategy 2017-2027* highlights the need to create a Scotland where all stigma and discrimination relating to mental health is challenged, and where we adopt a collective understanding of how to prevent and tackle mental health problems, many people told us that, due to a lack of knowledge and understanding of eating disorders, they were subject to prejudice from friends, family and members of the public.

Among the 14 survey respondents who told us they thought they had an eating disorder but had not received a diagnosis or sought treatment, stigma and feelings of shame featured prominently. Negative attitudes from family, friends, colleagues and health professionals had sometimes deterred individuals from seeking help.

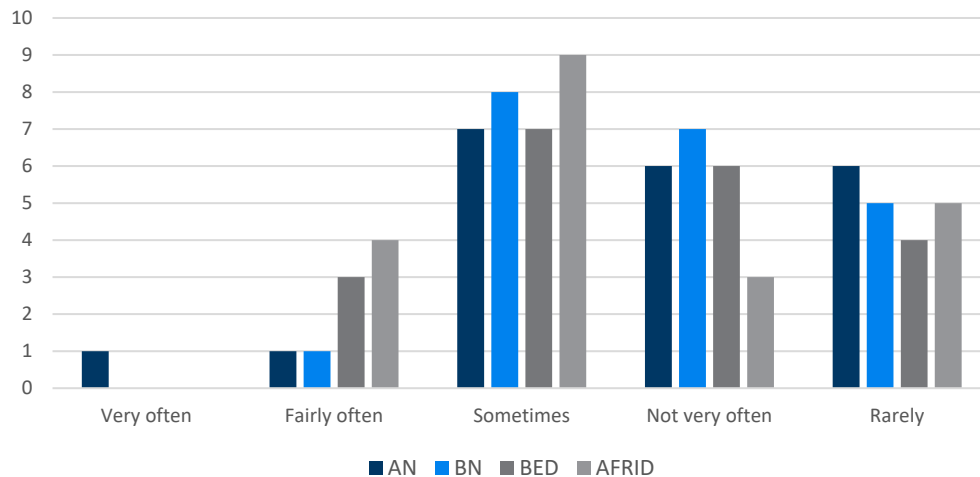
Geographical differences

Support for people with eating disorders varies across Scotland's different geographical regions as described in Appendix B. Where an individual lives can influence the types of service and resource available. People with eating disorders and their families/carers, told us that services are limited in some regions, even more so in rural areas. Some people told us that they had to seek private therapy in the absence of NHS Scotland provision locally.

The GP caseload for people with eating disorders

It is unlikely that GPs, in their usual caseloads, see people with severe eating disorders with great frequency. Figure 1 shows, of the 21 GPs who responded to this question, the highest frequency reported was for binge eating disorder and ARFID (avoidant restrictive food intake disorder).

Figure 1. Frequency of GPs seeing patients with eating disorders on caseloads (from Phase 2 survey, N=21)



AN: anorexia nervosa, BN: bulimia nervosa, BED: binge eating disorder, ARFID: avoidant restrictive food intake disorder.

GPs also told us that they seldom see patients under the age of 12 years, and most frequently see patients in the 12-17 year and 18-25 year age groups.

The dietician caseload for people with eating disorders

We asked dieticians how often they saw people with different eating disorders in their caseload - all but one of the 26 who responded to our phase 2 survey told us they very often saw people with anorexia nervosa. Fewer reported seeing people with bulimia nervosa, binge eating disorder or ARFID. Only two reported seeing 'other' conditions - one was atypical anorexia nervosa and the other was autism spectrum disorder.

1.1 Understanding where support comes from

"Although I can make an appointment to see my GP, this is not enough as she does not have much knowledge of eating disorders and she can only offer a short appointment."

Person with eating disorder

During phase 1, we asked the 48 people who were receiving support from an inpatient or specialist community service about the support they were receiving. Of those who responded, around a quarter told us they were receiving all the support they needed. The same amount were only receiving some of the support they needed, and a few said they were receiving very little support.

The remaining people (just under half) provided a broad range of views including that more support was needed, specifically within local communities, and that there was a lack of resources. "I get the support I need but from a private therapist, not NHS services," said one.

During phase 2, we asked people with eating disorders to tell us who was providing their current care. Of the 26 survey respondents there was a fairly even split between those receiving care from their GP and those receiving care from a specialist team.

Across both phases we asked families/carers if their relative was accessing support to help them manage their eating disorder. A third of the 30 family/carer respondents told us that there was no access to support.

1.2 Delays in receiving specialist support

“Early intervention is the best indication of recovery. People are most likely to accept help when they have asked for it. When they have been sent away after asking, they will eventually no longer accept it. That is why, in inpatient units, most patients are on sections. It is recovery to the bare minimum and go home. It is like a hellhole of soggy corn flakes to be discharged and back to a miserable life. It is just a battle of ‘let me live my life’ and them saying ‘we do not want to let you die just yet’.”

Person with eating disorder

The Scottish Government’s *Mental Health Strategy 2017-2027* highlights the need for improvement in prevention and early intervention for people with mental health issues. People with eating disorders told us that there was a great need for early intervention and early diagnosis. They felt that by the time they got help, their behaviours and attitudes were entrenched. They believe that if they had received help earlier, their chances of recovery would be better.

“After being referred to eating disorder services I was told I’d need to wait at least three months to access help. In this time my physical and mental health declined and I was really unwell. Earlier access to treatment would have helped to prevent a decline.”

Person with eating disorder

Delays in accessing help and support may involve two components: delays due to individuals having symptoms but not yet realising they have a problem or are not yet ready to seek help, and delays when the individual has sought help but is awaiting treatment.

During our phase 1 and phase 2 visits, some people told us that they had experienced lengthy delays for treatment, admission and access to specialist services – even to get into a support group. People told us that not being able to access support quickly was traumatic and consequently made it difficult to form therapeutic relationships when help was finally obtained.

In *Chapter 2, From referral to diagnosis*, we examine the reasons for delays in receiving support in more detail.

1.3 Reviewing crisis support

Crisis situations can occur at any given time and the way that people with eating disorders cope will vary from individual to individual and be influenced, - positive or negatively - by the length of time they spend in the crisis situation, the coping strategies available to them, and the level of support they need to manage the situation. Knowing where to access help or support in a crisis is vital for people with eating disorders and their families.

The family/carer perspective

"... there is no crisis support. We tried to get crisis support through NHS 24 but were advised we would have to wait until CAMHS [child and adolescent mental health services] reopened on Monday. And CAMHS are not resourced for crisis support; they are appointment driven. There is a clear lack of resources, meaning CAMHS are overstretched."

Family/carer

Around a third of families/carers told us they had a crisis plan in place, but many commented that they didn't have access to any specific advice on how to handle a crisis. Of the 30 relatives/carers who responded to this question in phase 1 and phase 2, a third told us they did not have access to help in a crisis. Some reported good access to crisis support, but others told us of calls not being answered and of having to go back to their GP for a further referral.

Accessing support at a time of crisis for a person with an eating disorder appeared to vary across geographical regions and while some areas had crisis intervention teams, a number told us that they would contact NHS24 or go to A&E. Insight from families/carers suggested that access to crisis support was often dependent on whether the person with the eating disorder was being supported by a specialist community eating disorder team as opposed to generic services such as CAMHS, the community mental health team or primary care services. Although some of these services have set up crisis support within their specialist eating disorder teams, this was not always available 24/7.

1.4 Understanding the impact on families/carers

"There is just not enough resource to assist in the community. When treating a loved one at home with an eating disorder, the impact on the family can be horrendous. More support in the home is needed; there is no real bridge between inpatient and home. We... needed more support on a practical basis than CAMHS could offer. I am sure that this lack of resource leads to inpatient care being required when it could be managed at home."

Parent

The majority of those with eating disorders who took part in our survey were aged between 16 and 35 years, so many were adults living independently or semi-independently. The vast majority of people with an eating disorder are cared for in the community, often by families.

To successfully support people with eating disorders, these families/carers need help to manage a very steep learning curve, and this support should be both psychological and practical. By helping family carers to maintain structure and routine, the person with an eating disorder may be able to stay at home and avoid admission to hospital. Around half the people we spoke to said there was no community support to facilitate this, although they acknowledged the need for it.

"I had to give up my job. The condition dominates everything the family does, every meal time is stressful, you can't go on holiday or eat out socially or go out as a couple."

Parent

We recognize that not all families/carers are able or want to be involved and sometimes may be prevented from being involved. The impact of eating disorders on families/carers is significant, and we asked families/carers to tell us more.

The responses were overwhelmingly negative with the situation most commonly described as 'devastating' as well as 'exhausting' and 'relentless'. Families/carers described feeling 'helpless' and talked of the enormous strain on all interpersonal relationships, as well as the negative impact on other siblings. Loss of meaningful relationships with extended family and friends was also mentioned, along with concerns over being judged on parenting skills. Some of the people we spoke to told us it was impossible to continue with employment and this resulted in financial pressures. Being unable to plan activities like holidays or meals out led to loss of social life and further isolation. One said simply: "It is a very destructive, all consuming and cruel illness."

The Carers (Scotland) Act 2016³ puts a duty on local authorities to provide an adult carer support plan to help families/carers meet their own needs while carrying out a caring role. However, during our themed visit we found that very few relatives/carers

³ <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>

had been directed to any support for themselves, although one had accessed BEAT online and one had attended support groups in the initial stages. Only one of the relatives/carers was aware of being offered an assessment although several said they would have appreciated it. According to one:

"This would be very helpful as, although I'm a resilient individual, this has caused more stress than I ever imagined I could handle."

Chapter 2

From referral to diagnosis

During the consultation phase, one of the most frequently voiced concerns from people with eating disorders, and their families/carers, was around services appearing to concentrate on weight alone as a threshold for accessing treatment. They said it meant that people who needed support did not get it and it also made people with eating disorders concentrate on the very thing that they should not concentrate on – in other words, low weight became a target to achieve, either in order to access services.

“There is a heavy focus on BMI. I had a patient who admitted to controlling their calories as they felt they were overweight. Their BMI was still acceptable, however, [weight] was decreasing dramatically and I had to send several letters to get them the help they needed.”

GP

“In her case her weight was not considered to be low enough, even though the doctor had suggested it would be too much of a strain on her heart to walk uphill to school.”

Family/carer

BMI is an essential diagnostic criterion for anorexia nervosa. The reasons for people developing eating disorders are complex, and we wanted to find out if families/carers felt that aspects other than weight restoration and BMI were being properly addressed.

Several mentioned that services, including GPs, put excessive focus on weight restoration and nutrition, while not addressing associated mental health issues and co-morbidities which would still be present even if weight and BMI were within acceptable ranges. Several families also mentioned other complicating conditions like autism, which they felt were impacting on the eating disorder but being ignored by services.

People with eating disorders often felt that a service’s focus on weight and BMI either prevented them from accessing support or delayed the provision of support until weight became dangerously low.

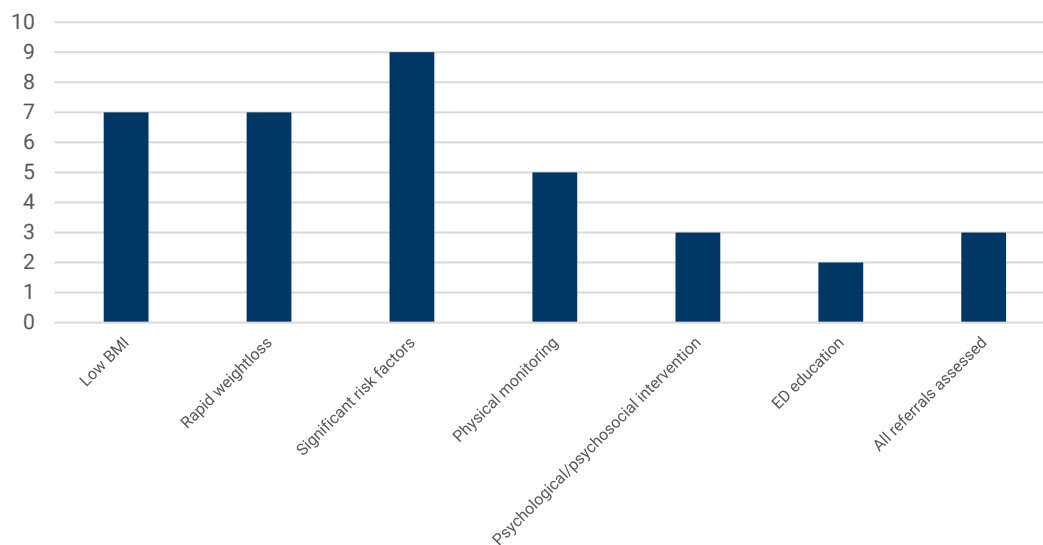
“There was nothing at all for anyone with a BMI over 13, even in the presence of excessive exercise (eight hours running/gym and 10 hours walking a week). When the eating disorder service referred me back to my GP there was no follow up. My weight plummeted because I felt like I was too fat to deserve care.”

Person with eating disorder

2.1 Referral and admission criteria for specialist services

For most services, the main admission and referral criterion were low BMI, significant risk factors and/or physical healthcare monitoring. For half of the services, identified needs for either psychological or psychosocial intervention also formed part of their referral criterion. Other specific criteria were also noted, some only applicable to inpatients, such as admission or referral directly from a medical ward. Additionally, some criteria were specific to CAMHS, where anyone with an eating disorder could be referred and low BMI was not a requirement.

Figure 2. Criteria for admission/referral acceptance to eating disorder services



We reviewed individuals' referral and admission processes with staff, to gather information about the route to referral or admission to the service for people with eating disorders. Thirty-six responses were recorded against nine categories identified as reflected in Table 2 below.

Table 2. Reason for referral/admission

Reason	Number of Responses
Physical deterioration	11
Weight loss	10
Deterioration in mental health	6
Reason for referral/admission unclear	6
Restricted diet	4
Medical stabilisation and nutrition	4
Treatment for eating disorder behaviours	3
Low weight	3
Self-harm	2

The psychiatric perspective

"We are funded for only moderate to severe eating disorder presentations, moderate presentations receive CMHT intervention in first instance but this may not be an eating disorder recognised psychological therapy. There is often a delay in CMHT making timely referrals to our service or not assessing risk accurately."

Psychiatrist

During phase 2, we asked consultant psychiatrists who provide inpatient care for people with eating disorders if there were any exclusion criteria for admission. Of the nine inpatient psychiatrists who responded, three reported there were. It was noted that if people required acute medical care due to physical health risks, they would be admitted to a general hospital medical ward instead.

The majority of psychiatrists told us that there were gaps to service provision and these included:

- services focusing only on patients with anorexia nervosa
- services having a set limit to the number of patients they can work with
- not being able to accept people under the age of 16 which is difficult when CAMHS is overstretched.

The GP perspective

"Our local CAMHS service actively looks to cancel referrals (although they wouldn't admit this) due to a lengthy waiting list. Referrals are often cancelled for spurious reason or downgraded because they don't have abnormal blood result for example. I would like to get the intervention started before they have abnormal blood results."

GP

Just over half of the GPs who responded to our survey experienced barriers when making referrals for people with eating disorders. These included lack of services, long waiting lists, lack of psychiatrists, lack of support for patients to use online tools, lack of resources for under 18s, rejection of referrals, little or no support for bulimia nervosa and restrictive disorders, BMI cut off points and rapid weight loss not being seen as an appropriate criterion for some patients.

2.2 Lived experience of referral and admission

"I kept being referred to the next level - I kept feeling it was... more complicated. I thought: "Am I that bad?" The GP thought I needed specialist input, so referred me to the dietician. The dietician said 'it is more complicated' and 'your difficulties aren't manageable in this service'. The psychiatrist thought that I needed 'somebody more specialised'. Eventually, about a year ago, I got an appointment as my eating was going out of control – I got offered individual or group therapy."

Person with eating disorder

Reasons for referral

During both phases, we asked people with eating disorders about their understanding of the reasons for their referral and/or admission and a range of themes emerged.

In addition to those reasons identified in Table 2 we noted further themes including the recurrence of unhealthy repetitive behaviours, difficulties with self-management of an eating disorder, relapse, stabilisation and continuing treatment having moved on from CAHMS.

We wanted to explore the concerns that people with eating disorders might have had at the point of being referred or admitted to an eating disorder service, and received 39 comments in response to our questionnaire. A number of common topics around concerns at the point of being referred/admitted emerged, including:

- negative or unhelpful experience while in contact with the service and the staff
- lengthy waiting times to access a service
- variations in service provision and
- weight as the main focus.

Comments included a 'lack of compassion' and 'they told me I didn't look that skinny'. We were also told that 'waiting lists are shocking'. A number of people with eating disorders told us that their condition had worsened considerably due to delays in being able to access support on the one hand, and uninformed or unsympathetic treatment from staff in both primary and secondary care settings on the other.

Experience of accessing inpatient care

"She did have a wait of six weeks when her BMI was critically low, and was on a general psychiatric ward, not a specialist ward."

Parent

2.3 The assessment and diagnosis processes

We wanted to find out more about how specialist services assess and formally diagnose people with eating disorders. We also wanted to understand the experiences of individuals going through this process.

Assessment process timeframes

During phase 1, we asked each service how long they took to establish a diagnosis of an eating disorder. This varied across the eight units that responded. Some indicated that if there was an existing or prior diagnosis, then the assessment would be completed in one session. A few responded that an assessment would be conducted over two sessions, with the second session including a more generic psychiatric review. A few of the services also indicated that an assessment could take longer than two sessions if there was diagnostic complexity or a longer review was required to support the formulation and development of a treatment plan.

Screening and nutritional assessment

On receiving a referral, all services reported using a screening process which mainly included an initial review by the team leader and/or consultant. Nearly all the services requested an indication of urgency. We asked at what stage in the admission/referral journey a dietician would conduct a nutritional assessment. All of the adult inpatient units indicated that this would be completed on the day of admission (if that was a week day) while for community services, this was carried out 'early on', especially where there was a requirement for re-feeding.

Diagnostic assessment

Specialist services told us that when carrying out an assessment for eating disorder they all used diagnostic criteria set out in ICD-10 (the International Classification of Diseases, World Health Organisation) or DSM-V (the Diagnostic and Statistical Manual, American Psychiatric Association) with the majority using ICD-10. The use of additional assessment tools, such as the Eating Disorder Examination Questionnaire (EDE-Q) was mentioned by some services. When assessing weight, child and adolescent specialists noted that Weight for Height (WfH) was a more appropriate measure for some young people than body mass index (BMI).

Advising a diagnosis

When we asked who was involved in advising the person with an eating disorder (and their family/carer if appropriate) of a formal diagnosis, all the services told us that this was given by the consultant psychiatrist involved in the team. In one service, a psychologist was involved and in another, an occupational therapist. For some of the community-based eating disorder services, the focus on providing a formal diagnosis depended on whether the person with the eating disorder wished to know this; whether there was a clinical indication that giving the diagnosis was required; and whether it would help the individual access mainstream psychiatric services.

Involving family, friends and carers

The involvement of family/carers in the assessment process can be helpful and services we visited told us that where possible, and with consent, families were encouraged to be involved. When this didn't happen, it was mainly due to the person with the eating disorder being over the age of 18 and not giving consent.

In our phase 2 survey, we asked consultant psychiatrists how often relatives/carers were involved in the assessment process, provided patient consent was given. The majority of psychiatrists who responded said this happened very often – this included all the CAMHS consultants who took part in the survey. The remaining psychiatrists said this happened often or sometimes, with just one reporting that family/carers were rarely involved.

Table 3. Characteristics of eating disorder diagnosis among individuals (n=74)

Characteristic		Total N=74	Phase 1 N=48	Phase 2 N=26
Age first noticing symptoms	<12	15	6	9
	12-15	28	15	13
	16-17	4	3	1
	18-24	4	3	1
	25-34	2	2	-
	35-39	1	-	1
	40-49	2	1	1
	No diagnosis yet	1	1	-
	Rather not say	1	1	-
	Missing	16	16	-
	Age when diagnosis received	<12	4	1
12-15		17	8	9
16-17		7	4	3
18-24		16	11	5
25-34		4	2	2
35-39		3	1	2
40-49		3	2	1
>50		1	-	1
No diagnosis yet		4	4	-
Missing		15	15	-
Diagnosis*		Anorexia Nervosa	46	25
	Bulimia Nervosa	8	3	5
	Binge eating disorder	2	1	1
	Avoidant restrictive food intake disorder (ARFID)	2	-	2
	Other	1	-	1
	Not sure	4	3	1
	Rather not say	1	-	1
	No diagnosis yet	4	4	-

*Self-reported, separate variable from records not shown here

2.4 Lived experience of assessment and diagnosis

“Our initial experience of getting recognition of the eating disorder and of my child’s difficulties was poor and damaging, which made it difficult to trust the service. A more obvious coordinated team approach with regular appointments at the same time and designated times for health checks and support in the same appointment would make things easier.”

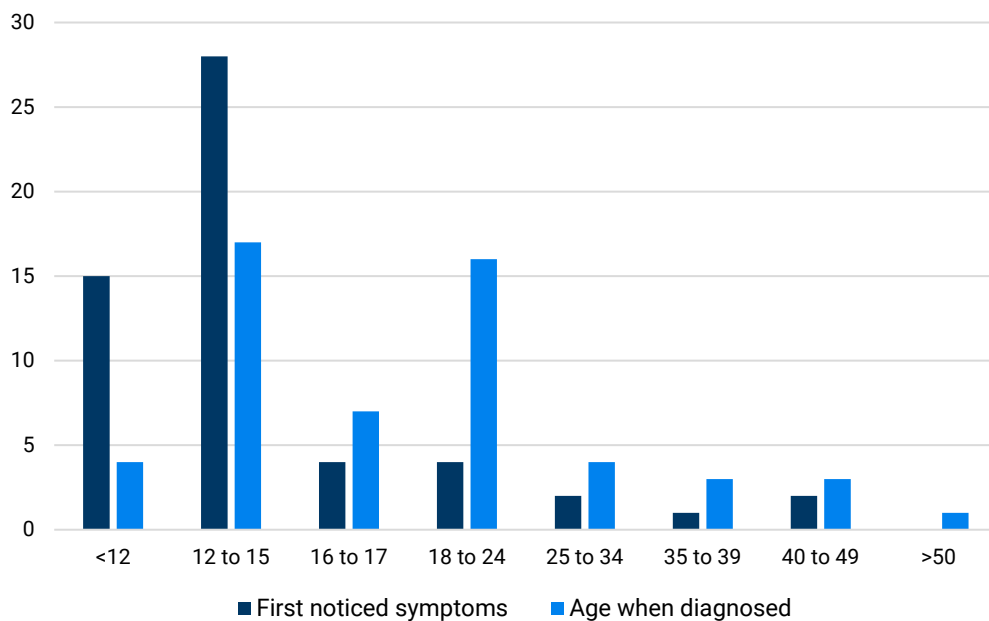
Parent

The early phase of an eating disorder is a potentially critical period for preventing or modifying the onset of illness, as well as its course and duration. We wanted to know more about people’s experience of receiving an eating disorder diagnosis, about their involvement in the process, if family/carers had been consulted and what information had been provided or offered at this crucial time.

Age range for recognition and diagnosis of symptoms

56 respondents told us what age they were when they first noticed symptoms associated with an eating disorder, and at what age they were diagnosed.

Figure 3. Age of onset of symptoms and diagnosis for people surveyed in Phase 1 & 2 (n=56)



Prevalence of eating disorder types

BEAT's 2015 report, *The Costs of Eating Disorders: Social, Health and Economic Impacts*, indicates that eating disorders such as bulimia nervosa and binge eating are more prevalent than anorexia nervosa. However, anorexia nervosa was the main diagnosis for more than half (62%) of the people with eating disorders we reviewed because our main source of information was those accessing specialist eating disorder services, and therefore at the more severe end of the eating disorder spectrum.

Involvement and consultation in the diagnostic process

Of the 74 people with eating disorders who were involved in both phases, 54 responded about their involvement in the diagnostic process. While the majority felt that they been *fully or partially involved*, a significant number told us they were *not involved* in the diagnostic process.

2.5 Co-existence of eating disorders with other mental health issues

"I get no support with autism – my psychiatrist and psychologist and me are just figuring it out as we go along but such a massive overlap for people with eating disorders, this needs to be improved!"

Person with eating disorder

It is well known that that people with eating disorders often present with or have co-morbid mental health issues⁴. This can complicate both diagnosis and treatment options, often resulting in the person either falling between services or feeling that one part of their health is being addressed and the other is not.

During both phases we asked family/carers if they had experienced any difficulties in getting appropriate 'joined up' treatment for their relative, and if recognition had been given to other (co-morbid) conditions present. Of the family/carers who responded, a third said no recognition was given, while less than a third told us they were satisfied that recognition had been given.

We examined case files for each individual whose care we reviewed in person in phase 1 to identify if there were any co-existing diagnoses for mental illness. This was true for 27 out of 48 individuals, among whom a mood disorder (depression or bi-polar affective disorder) was present in ten. A range of 'other' diagnoses including EUPD (emotionally unstable personality disorder), other personality disorders, anxiety, obsessive compulsive disorder and autism spectrum disorder were noted in the other 17 individuals.

⁴ <https://pubmed.ncbi.nlm.nih.gov/16738079/>

2.6 Waiting times and waiting lists

“During the last six months we have been continuously full and the demand outstrips the resource – patients are waiting on average two weeks for a bed and are being cared for safely in an interim facility – these are the sickest patients. Less sick patients are waiting many weeks, (it is a) regret we cannot help less obviously sick patients who want to come into the higher intensity support to continue recovery for short spell.”

Psychiatrist

Given the severity of symptoms, the physical and mental health risks associated with people who have eating disorders, we wanted to look at the waiting times from referral to admission and/or treatment. All of the services who provided data during phase 1 indicated that, from the time they received a referral, the person with the eating disorder would wait for no longer than eight weeks until they were admitted or assessed.

Table 4. Waiting times from referral to admission/treatment (data from Phase1, N=48)

Waiting time	n
No wait	19
Waiting time noted	7
Unclear waiting time	10
Waiting time not recorded	12

The psychiatric perspective

During phase 2, we asked psychiatrists about waiting times for assessment for both young people and adults in their area. Two of three CAMHS psychiatrists said the four-week timeframe for young people was met locally, with another saying young people with suspected anorexia were usually seen within a week. When we asked about adults with an eating disorder, half the psychiatrists surveyed answered (12 out of 24) and seven said there was a locally agreed timeframe for adults, three said there was not and two didn't know. Timescales quoted were between two to 18 weeks. Where a locally agreed referral time was in place, six of the seven psychiatrists said adults were seen within this timeframe, some noting that, in practice, adults would be seen more quickly.

The GP perspective

Just over half of the GPs in our survey reported that children and young people being referred to an eating disorder service don't start their assessment within the four weeks of referral outlined in the NICE Quality Standard^{5, 6}.

NICE also recommend that adults with suspected eating disorder, who are referred to a specialist eating disorder service, should start assessment and treatment within a locally agreed timeframe. The majority of the GPs who responded were not sure of the timeframe within which adults should start assessment following referral. Only two GPs reported knowledge of a local timeframe with one reporting it as being four weeks and the other as 16 weeks. One of them advised that patients were not seen within the timeframe.

The psychologist and therapist perspective

Thirteen respondents told us there was a waiting list for therapies for people with eating disorders and eleven of those went on to tell us that this ranged from one to 40 weeks (with a median of 25) while 11 said no waiting list was available and seven didn't know.

Waiting times for young people

The NICE quality standard for eating disorders⁷ states that young people should begin assessment within four weeks of referral. When we spoke to inpatient and specialist community services, about half reported that this usually happens in their area. Individual comments suggested that those presenting with rapid weight loss were usually seen within the standard waiting time set by NICE.

Just over half of the GPs in our survey reported that children and young people being referred to an eating disorder service don't start their assessment within the four weeks of referral outlined in the NICE Quality Standard.

The family/carer perspective

Around a third of family/carers were not happy with their initial contact with services and a few felt that although help had come quickly this had been because of the poor physical condition of the person with the eating disorder.

⁵ <https://www.nice.org.uk/guidance/qs175/chapter/Quality-statement-1-Early-assessment-and-treatment>

⁶ Although NICE standards do not have formal status in Scotland, they have influence. Clinicians should have regard for NICE guidelines, evidence based recommendations and quality standards, particularly in areas where SIGN guidance is not currently available.

http://www.healthcareimprovementscotland.org/our_work/technologies_and_medicines/nice_guidance_and_scotland.aspx

⁷ <https://www.nice.org.uk/guidance/qs175/chapter/Quality-statement-1-Early-assessment-and-treatment>

They expressed concern about the level of understanding shown by GPs with regard to symptoms and the need for prompt referral. Several felt that GPs relied too heavily on BMI and would not refer until a certain figure was reached. In some cases, a lengthy wait to access CAMHS was an issue and several families report that, even under CAMHS, they felt the seriousness of the situation was not appreciated.

2.7 Provision of support materials and signposting

"I was informed of a self-help group with the service. I think some of the materials were from BEAT, otherwise I felt well informed of my disorder."

Person with eating disorder

When people with eating disorder symptoms are being assessed for diagnosis, we would expect a range of materials to be provided.

Availability of information on eating disorders

Among the phase 2 survey respondents who told us they thought they had an eating disorder but had not received a diagnosis, almost all (13 out of 14) identified as having a specific eating disorder (these varied and included anorexia nervosa, bulimia, ARFID and overeating). In this small group, binge eating disorder was most often mentioned, with five of 14 respondents reporting this.

We asked if individuals had looked for information about eating disorders and all but one said they had. Sources of information varied, with online resources most frequently referenced and the BEAT website in particular mentioned by several people as being useful. One respondent commented: "BEAT, Mind, Young Minds... these resources were helpful, especially BEAT." However, less helpful sources were also mentioned with one young adult commenting:

"I looked online at BEAT and NHS. However I also had access to Pro-Ana and Pro-Mia which were unregulated sites with promotion of eating disorder behaviours."

Some people told us they had a difficult experience when trying to source information and a few struggled to access information on binge eating disorder in particular, with one person commenting: "I have looked online but most resources are related to specific conditions such as bulimia nervosa and purging which is not my issue."

When we asked respondents what might have helped them to seek support, the availability of better information was mentioned a number of times.

An electronic resource has been developed and is available at:

<https://caredscotland.co.uk/>

Support at the point of assessment

We found that while some people with eating disorders said they received no information, most said that they were given leaflets, information from websites or signposted to peer group organisations. A few said they were given advice about books to read, and some mentioned gaining an understanding of their diagnosis through admission to hospital or attending a support group.

For those using specialist services, all were provided with a verbal explanation, most were provided with leaflets, information from websites and books; a few were provided with signposting to peer group organisations.

Each service also explained their different approaches to providing information at the time of an assessment. We heard that one service did not give materials out routinely

but would provide relevant information depending on the needs of the person/family who had been referred while one CAMHS unit, whose staff were BEAT ambassadors, signpost people with eating disorders and their families/carers towards the BEAT website, printing off the leaflets when required. Another CAMHS service used leaflets along with helpful videos.

Psychiatrists reported that they didn't have dedicated staff to provide support for the relatives/carers of people with eating disorders, but did provide information packs and did signpost relatives/carers to local support groups.

Support at the point of diagnosis

In addition to materials provided at the point of assessment, we wanted to find out what was provided at the point of formal diagnosis. Comments from people with eating disorders were generally positive with regard to leaflets and signposting, although some were negative, with individuals commenting that they were 'left in the dark' or 'googled it myself' or 'didn't receive any information'.

About a third of the families/carers who had been involved in the diagnosis process felt they had been given enough information and advice, while a few felt overwhelmed. Of those who were unhappy, a lack of practical advice when back at home was cited, along with a lack of support when other issues such as autism are present. One relative/carer pointed out that the majority of advice is for parents of young people and that there is little available for those caring for adults with eating disorders. Another suggested that more proactive information would be helpful, telling parents about warning signs to look out for in the first place. Some families/carers commented that they had educated themselves from websites and books, while several families felt that far too much was left for them to pick up by themselves with knowledge and support secured via peers and online forums rather than through specialist service provision.

Support on admission to inpatient services

We asked whether a welcome or introduction pack was given at the point of coming into the service. Around half of the people with eating disorders responded, with the majority indicating that they did receive information, however some told us they did not and a few were not sure. We also asked if the information had been helpful and the majority said it had been either very, or fairly, helpful with only a few saying it was not.

We asked psychiatrists during phase 2 what information inpatients were given about their diagnosis. The most common response was a verbal explanation, followed by signposting to online information and to other support services.

Chapter 3

Care and treatment delivery and experience

Based on the 2004 NICE standards⁸, in 2007 NHS Quality Improvement Scotland (QIS) developed a guide for people with eating disorders⁹. The guide set out in detail what people with eating disorders could expect from the NHS and what support and treatment they should be offered.

QIS stated that, for children and young people, most of the care provided should be the same as that given to anyone else with an eating disorder although age, circumstances and stage of development should be taken into consideration. The main difference noted is that it can be helpful to involve family members in a child or young person's treatment.

The report recognised the difficulties faced by families/carers and advised them to ask for help from a healthcare professional or support group. It also recognised the help and support families/carers could offer people with eating disorders in accepting their problem.

In 2014, the Royal College of Psychiatrists in Scotland produced a briefing paper that highlighted improvements in the provision of specialist eating disorder services¹⁰. The report noted that the first specialist adult NHS inpatient unit had opened in Aberdeen in 2009 to serve the north of Scotland, and a second adult unit had opened in West Lothian in 2013. Some specialist adult eating disorder beds has been made available in Glasgow (although these did not constitute an individual unit) and The Priory in Glasgow continued to offer a specialist private facility for adults.

The report also noted that a number of services had been developed to provide alternatives to hospital admission, or shorter admissions where possible, and these included anorexia nervosa intensive treatment teams in Lothian and Fife, the day programme in Aberdeen, a specialist team in Glasgow and ED Connect, and a consultation-based service for children and adolescents in Glasgow. Under-18s with eating disorders continued to be treated within general child and adolescent mental health services (CAMHS) where clinician expertise and patient outcomes had been enhanced by the introduction of evidence-based family therapies.

⁸ National Institute for Clinical Excellence, *Understanding NICE guidance: a guide for people with eating disorders, their advocates and carers, and the public* (2004) <https://www.rcpsych.ac.uk/docs/default-source/members/divisions/scotland/scotland-faculties-ed-management-of-eating-briefing-paper>

⁹ NHS Quality Improvement Scotland, *Eating Disorders in Scotland - A Patient's Guide* (2007) https://www.moodcafe.co.uk/media/19636/Eating_disorders_patientguide.pdf

¹⁰ The Royal College of Psychiatrists in Scotland, *Management of eating disorders in Scotland – briefing* (Royal College of Psychiatrists, 2014)

3.1 An overview of specialist service provision

"... we aim to be innovative, creative and adaptable in meeting the needs of our clients – for example, offering intensive community input as an alternative to hospital (when deemed safe enough to do so). The team have a shared culture and values... and are highly committed, enthusiastic and passionate about delivering compassionate care to people with eating disorders."

Specialist community team

During our visits to specialist adult and CAMHS inpatient and community services, we asked the senior charge nurse or clinical lead to describe in advance what was available for people with eating disorders and their families, and what worked well. Of the eight responses we received, a number of common themes emerged:

- well motivated, structured and supported staff
- one-to-one time with patients
- patient-centred treatment – flexible and evidence-based
- standardised evaluation of outcomes
- multi-disciplinary team (MDT) working
- good links to other services and clear, seamless pathways of care and
- use of feedback to provide insight.

Opportunities for improvement

We also asked the specialist services to tell us about any improvements that would make a positive difference to the care and treatment of people with eating disorders. This is what they told us.

- Address gaps in service.
- Create clearer, agreed pathways across health board areas.
- Establish eating disorder day and inpatient services locally which are appropriately resourced to offer a high standard of clinical care
- Become a FREED (first episode early intervention for eating disorders) service to further enhance and develop work on early intervention.
- Increase staffing resource to meet clinical demand.
- Increase resources to support expansion of the SEED (severe and enduring eating disorders) pathway and develop pathways from hospital to community.
- Implement feedback mechanisms for people with eating disorders, their families and carers.
- Increase access to CBT ED (cognitive behavioural therapy for eating disorders) and FBT (family based therapy) plus CRT (cognitive remediation therapy) and DBT (dialectical behavioural therapy) for those with poor prognostic features.
- Have time to target early stages and improve entry into specialist service care with more capacity to develop.
- Provide staff with the facilities they need so that they feel confident in their skills to help people with eating disorders.
- Create a model of care that is consistent over all ages.
- Provide more psychologically-led training for staff.

The benefits of a multi-disciplinary approach

We asked services to tell us about the input from multi-disciplinary professionals and if they were satisfied with the input; more than half told us that they were. Where the response was only 'somewhat satisfied', the score was based on capacity and stretched resources, preventing everyone involved from being able to attend multi-disciplinary team meetings. We also asked about specialist community staff availability to attend multi-disciplinary team meetings – again, most services commented positively on this, indicating that community staff would be involved in an individual's review and again at pre-discharge stage.

Thirteen of the 24 psychiatrists who responded to our online survey (in phase 2) were delivering care to people with eating disorders in the community (seven were general adult psychiatrists, three were eating disorder specialists and three were CAMHS consultants). Most eating disorder specialists and CAMHS consultants indicated that within the multi-disciplinary team (MDT) they had expertise from specialist eating disorder nurses, dietitians and psychologists. The community general adult psychiatrists had better access to psychology than to specialist eating disorder nursing and dietetic input, with four saying psychology input was available within the team and two on referral. Social work support within community MDTs was only reported among general adult consultants surveyed (4 of 7). Other specialist input such as speech and language therapy appeared more available on referral by consultants in CAMHS and some general adult teams than by eating disorder specialists.

3.2 Helpful points of contact and support

We asked people with eating disorders which services they came into contact with, what treatments they found most helpful, and what types of support they were receiving.

The lived experience perspective

"I found the social support very helpful when I was in treatment. This was with an assistant psychologist."

Person with eating disorder

During both phases, we asked people with eating disorders what was helpful in terms of their care treatment and support and a number of key themes emerged.

- Staff engagement, including a consistent point of contact and regular contact or appointments, as well as joined up care from different professionals involved.
"It's helpful having a regular point of contact, non-judgemental staff, somebody there for me and regularly, weekly contact."
- Availability of therapies and support for help with staying on track and achieving goals.
"I currently have a sponsor at Overeaters Anonymous and attend a support group once a week and am going through a 12 step programme."
- Care plans to refer to.
"I find the fluidity of care plan and availability of inpatient staff helpful when I'm struggling."

We also asked what one thing people with eating disorders would change about their care, treatment and support to make it better. We received 52 comments with some clear themes emerging.

- Increased and earlier support from staff in eating disorder services.
"I would like weekly support from my CPN (community psychiatric nurse) and daily support with meals/snacks"
- Consideration of different approaches including group and activity therapies, more gradual implementation of eating plans, more opportunities to be at home, more support for those who have had an eating disorder for many years and more community support.
"Being quickly brought into the environment of having to be weighed and work in boundaries and baselines was particularly hard. . . I would have liked this to be more gradual."
- More eating disorder support, particularly around meals and BMI focus.
"I was turned away from the community eating disorder service with a BMI of 14. Absolutely no other help available. Was left entirely on my own, no follow up from anyone, not even GP. I continued to lose weight and became really scared."

Only a few people had contact with and support from a range of other services such as social workers, peer support workers, speech and language therapists, mindfulness therapy, alternative therapies, drop in facilities and one-stop shops. Of these, one-stop shops in particular were considered mainly helpful.

- Friends were seen as most helpful with people feeling content with the network they had.
- Family was also most helpful to many, although some found family not very/not at all helpful.
- Contact opportunities through work, education and volunteering were helpful to many.
- Getting access to a psychologist, a dietician and community mental health support were all contact opportunities that people with eating disorders said they would like to see more of.

3.3 Family/carer perspectives on care and treatment

Throughout the themed visit, we spoke to families/carers to ask them about their experiences of caring for people with eating disorders – and also their concerns. As the majority of people with eating disorders are cared for in the community, we expected family involvement to be sought out and welcomed, and that they would be fully involved in decisions around care and treatment where appropriate. Working in partnership with families/carers can be important to aiding recovery, preventing admission to hospital and maintaining progress in the community setting.

Involvement and relationships with service staff

"I was looking for advice on how to handle this refusal to eat and violent outbursts but was told I should just call the police for violent outbursts, and I had several different medical opinions on how to encourage her to eat before the hospitalisation. None of them were successful and in fact some of them (such as aggressively pushing her to finish meals) made things worse."

Parent

Just under half of the families/carers we spoke to made positive observations about care and treatment, although around a third had mixed views and a few made negative comments.

Families/carers supporting people with eating disorders in an inpatient setting were overwhelmingly positive about their relationship with staff and said they were happy that their concerns were being listened to and that their views were respected. Positive words used in reference to care included 'exceptional', 'extremely beneficial' and 'empathetic'.

However, in community settings, some were satisfied but some felt excluded with two commenting specifically that their GP hadn't taken their concerns seriously and one that services had dismissed their opinions.

About a third of those who commented from a community setting said that they were not completely happy with care and a few said that, on occasion, they felt dismissed and patronised and had concerns about the staff's attitude to the person with the eating disorder. Several families cited a lack of resources and felt progress was limited due to staff shortages, especially in community support.

Highlights of care

"We feel that the care my relative has received is exceptional. The specialist eating disorder service team have always been there even in crisis times. The FBT session we found extremely beneficial for us as a family to express our feelings and thoughts regarding the situation as a whole."

Parent

We asked families/carers what they felt were the most helpful aspects of care, and the most common answer was the benefit of psychology input, and FBT (family based therapy) in particular. However, lack of psychology input and long waiting lists for CBT

(cognitive behavioural therapy) were an issue. Dietetic advice was also appreciated as was ongoing support for other conditions like anxiety. Continued support after discharge and specific input into the home was also said to be useful, with a dedicated consistent team with different skillsets cited and several families mentioned very useful peer support from BEAT.

Opportunities for improvement

We asked families/carers if they had any suggestions on how services could be improved and have noted the most recurrent themes below.

- Improved access to services in the early stages.
- Improved training for GPs or new and improved protocols that can be followed and monitored (one relative/carer suggested a self-referral system to a specialist team to bypass GPs altogether).
- Triage by phone immediately after referral and a means of communication with the team while on the waiting list to provide safeguards.
- Reduced waiting times to get to CAMHS and for CBT and an increase in resources available to teams to set up specialist services.
- FBT should be more widely available.
- A move away from BMI (body mass index) or WFH (weight for height) measurements as evidence of the severity of the condition.
- Earlier focus on co-morbid mental health issues as the driving force behind eating disorders alongside weight restoration measures
- Better recognition of co-morbid conditions and alternative pathways to support individual needs, including a more person-centred approach to people with eating disorders with co-morbid conditions like ASD to fully benefit from treatment.
- Provision of 'step down' facilities after discharge such as a day hospital or intensive home treatment teams to increase the ability of families to continue to support their relative.
- Provision of tools (and support to use them) to support people with eating disorders who are living at home with their families, along with psychological support to cope with the immense pressure that home care and treatment puts on the whole family.
- Moving to an 'all age' approach to remove the disruption of transition and the break in treatment that can occur at that point, as well as making treatments available to everyone.
- Monitoring of recovery rates across different areas and approaches to provide much needed data and help formulate more stringent, evidence based, treatment guidelines that can be used nationally.

3.4 Psychological therapies and other treatments

We sent out questionnaires to the ten specialist adult and CAMHS inpatient and community services we visited during phase 1, asking about psychological therapies provided for people with eating disorders.

In addition, we noted other therapies offered by just a few of the services including cognitive behavioural therapy (CBT) for bulimia nervosa, cognitive analytic therapy (CAT), adolescent focused therapy (AFT), acceptance and commitment therapy (ACT) and specialist supportive clinical management (SSCM) as well as decider skills, EMDR (eye movement desensitization reprogramming), Schema therapy and pet, music and art therapies.

Table 10: Perceived benefit of eating disorder treatments and therapies as reported by people with an eating disorder

Treatment/therapy	Very helpful	Fairly helpful	Not very helpful	Not at all helpful	Total
Medication	12	20	9	1	42
Individual therapy	13	14	3	1	31
Group therapy	4	13	6	1	24
Cognitive behaviour therapy	3	11	11	3	28
Family therapy	6	4	3	2	15
Family based treatment	7	3	2	2	14
Dialectical behaviour therapy	1	3	1	2	7
Cognitive analytic therapy	2	1	0	0	3

In general, access to psychological therapies was reported to be limited and the range of different therapies and interventions equally so.

We were interested to see that medication was reported as being helpful as medication has not been shown to be effective for anorexia nervosa although there is some evidence for bulimia nervosa¹¹.

¹¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000192/>

3.5 Physical healthcare interventions and medication

We asked the eating disorder services we visited during phase 1 about physical health monitoring. All said they carried out regular monitoring of patients' blood pressure, heart rate, weight and BMI, as well as regular blood tests and ECGs.

When we reviewed the case files of people we visited in hospital, almost all had received physical health screening within 24 hours of admission. We also looked at co-morbid health conditions and the incidence of diabetes in particular, this was only clearly reported in one person.

In the phase 2 survey we asked psychiatrists who were treating people with eating disorders in the community about pathways to assess and manage co-morbid conditions such as diabetes. Of the 13 who responded, five reported that there was a pathway in place, four said there was not and four didn't know. We discuss physical health monitoring further in *Chapter 4.5*.

Practices around prescribing medication

Of the 48 people with eating disorders we consulted with during phase 1, we were able to review the case files of 37. We looked at medication prescribing and found that over two thirds (27 of 37) were prescribed medication. All but one of this group had a diagnosis of anorexia nervosa. Antidepressants were the most commonly prescribed medication (in 23 of 27), followed by antipsychotics (in 17 of 27, with Olanzapine being most often prescribed). Thirteen people were prescribed a combination of both antidepressant and antipsychotic medication.

When we looked at co-morbid mental health conditions, 16 of the 27 people prescribed medication had a co-morbid diagnosis. Nine had an anxiety or mood disorder, six had co-morbid personality disorder and one had autism spectrum disorder (ASD). Among those prescribed a combination of antidepressant and antipsychotic medication, just over half (7 out of 13) had a co-morbid diagnosis.

3.6 Care plans

Prior to our phase 1 visits to the specialist services, we asked about the involvement of the person with an eating disorder in their care plan. Nearly all of the services indicated that individuals were involved in a number of ways.

Most of the inpatient services reported that they provided a copy of the care plan to the individual and also discussed and agreed whether this should be shared with family/friends/carers. When we asked about the frequency of care plan reviews, some indicated that care plans were reviewed weekly, some at the multi-disciplinary team meeting and others at timescales of between four to six weeks.

When visiting the specialist adult and CAMHS inpatient services it was possible to review care plans and, of those we reviewed, we considered half to be fully satisfactory, in line with our good practice guidance on person-centred care plans¹²; 12 were satisfactory with some issues; and one was unsatisfactory.

“Electronic care plans for mood, discharge plans, nutrition and meal time, NG and ECT. There are personalised sections relating to situation, goals and interventions all clearly relating to the patient.”

Mental Welfare Commission Officer

“Not satisfactory - no evidence of patient involvement in care plan preparation. Care plan is generic without patient's name. It is not updated weekly. Content is about meal plans, mealtime management, skin viability. No clear risk update.”

Mental Welfare Commission Officer

¹² https://www.mwscot.org.uk/sites/default/files/2019-08/PersonCentredCarePlans_GoodPracticeGuide_August2019_0.pdf

3.7 Engaging in activities

"I live my life like a siege. I need something that de-stimulates me – there's no channel to get rid of all the negativity – something like a women's group, book club or, as there was today, someone from a local walking group."

Person with eating disorder

For most people, how they spend their day is important to socialisation and self-esteem, and is therefore a core focus of mental health care planning. Meaningful activity can involve hobbies, socialising with family and friends, exercising, sport and other leisure activities, as well as more structured educational and vocational courses. While some of these activities can be provided, mental health services are increasingly making links with mainstream community resources to develop collaborative approaches.

Giving people the opportunity to take part in meaningful activity can help to provide structure to their day and reduce stress, frustration and boredom as well as increase social interaction, relieve anxiety and generally improve wellbeing. Being engaged in meaningful activities can help to foster an atmosphere of hope and optimism, which can enhance recovery and help to maximise therapeutic benefit.

We explored this across both phases. Only a few who responded told us they had access to all the activities they wanted. We asked about the activities that they found most helpful and nearly a third of the responses cited arts, crafts, colouring in and puzzle books. In addition, people told us they would like regular groups – painting, music, lunch for example – to share experiences and learn more about their eating disorders.

During our phase 1 visits to specialist adult and CAMHS inpatient and community services, we noticed positive examples of a range of activities such as music and art groups, daily journals, cooking, shopping and visits with families. However, we also noted the challenges to participation for people on bed rest and also those not willing to engage in scheduled activities.

More than half of the services had, or had previously had, input from outside organisations such as BEAT, and 'pet therapy' was the activity most frequently organised.

When we asked about gaps in activity provision, the key themes emerging from staff included more focus on group work and peer support worker involvement.

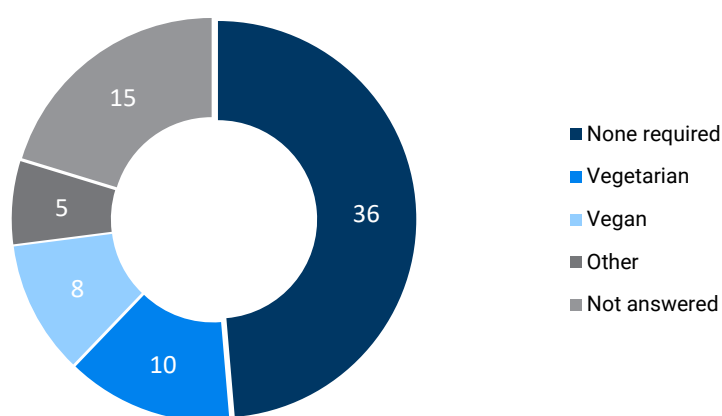
3.8 Dietary requirements, inpatient meals and artificial nutrition

“When I was an inpatient, meal times were very structured, rigid and formal which I think created an unhelpful atmosphere. It also did not teach tolerance of flexibility which is needed for real life – quite often outside of hospital it is not always possible to eat at a set time every day.”

Person with eating disorder

We asked respondents across both phases to tell us about their specific dietary requirements. See figure 4:

Figure 4. individual responses to identification of dietary requirements (n=74)



We also received 10 specific comments from people in inpatient settings about accessing a specialist diet. Half indicated that their needs were met while others commented that their choices (particularly vegan) were sometimes over-ruled by the dietician.

When we asked about changes that could be made to meal times in inpatient settings, the most common theme to emerge was around routines, but this included conflicting feedback on whether separating people at different stages of treatment, or with different eating disorders, was a good or a bad thing. Respondents also commented on the need for more staff (and more support from staff) at supervised meals and on the poor quality, choice and presentation of food.

Nutrition by artificial means (Naso-gastric (NG) feeding)

When people with anorexia nervosa are not able to eat due to their eating disorder their body can become so malnourished that their health and life is at significant risk. In these cases nutrition by artificial means, which commonly takes the form of NG feeding, can prevent further deterioration and provide the person with essential nutrition as a step towards them being able to eat more normally.

We reviewed the use of NG feeding in specialist adult eating disorder and CAMHS inpatient units and nine people told us they had been fed in this way. Eight of them

commented on the experience and the majority described it as negative using words such as 'distressing', 'painful', 'uncomfortable', 'inhumane' and 'traumatic'.

"Kept her alive, so good. But six year on, illness still dominant and the mental health aspect of it not really tackled."

Family/Carer

"Done very well. I was told what would happen and what to do beforehand. I can remember holding a nurse's hand and squeezing, so it didn't feel too restrictive. I did feel overpowered and scared to talk though."

Person with eating disorder

NG tubes were inserted by trained staff in all of the specialist inpatient units. The clinical plan for when artificial feeding would stop varied. In two instances, it was still authorised but no longer required, in a further two it was time limited and in three it was BMI dependent. The remaining two detailed that individuals had to have gained weight and be accepting oral nutrition.

Treatment under the Act

When a person is being treated under The Mental Health Act 2003, nutrition by artificial means can only be given if one of the following criteria applies:

- the person has capacity to consent and gives consent in writing
- a designated medical practitioner (DMP) authorises the treatment or
- urgent medical treatment provisions apply.

The relevant forms under the 2003 Act are, respectively:

- T2c (certificate of consent to treatment)
- T3b (certificate of the designated medical practitioner) and
- T4 (record of notification following urgent medical treatment).

Where there is consent, a person must be considered capable of giving valid and informed consent and this must be given in writing. Best practice guidance regarding assessing capacity is covered in the Commission's guide, *Consent to Treatment*¹³ and guidance to support decision making for artificial nutrition is provided in the Commission's *Nutrition by Artificial Means Guide*¹⁴.

Where the person is incapable of consenting or refuses consent, a designated medical practitioner (DMP) must certify that the treatment is in the person's best interests. A DMP is an independent doctor appointed by the Commission.

¹³ https://www.mwscot.org.uk/sites/default/files/2019-06/consent_to_treatment_2018.pdf

¹⁴ <https://www.mwscot.org.uk/sites/default/files/2019-06/mhc-guides-nutrition-revised.pdf>

With regard to the lawful authorisation of NG feeding, we found only one issue where the T3b (the form which must be completed and sent to the Commission) wasn't present as required and we followed this up on the day of our visit.

3.9 Observing rights and restrictions during treatment

In line with the principles of the Mental Health (Care and Treatment) (Scotland) Act 2003, any restrictions on an individual's freedom should be proportionate and the least necessary. We have produced guidance and information for clinical staff to follow when restrictions are being considered¹⁵ as well as advice about people's rights^{16,17}.

Awareness and understanding of rights, advocacy and advance statements

Of the 74 people with eating disorders who took part in phase 1 and phase 2 of our themed visit, 25 people were detained under the Mental Health (Care and Treatment) (Scotland) Act 2003. We asked if they had been told about their rights, been made aware of advocacy and had prepared an advance statement (AS). An advance statement is written by someone who has been mentally unwell and sets out the care and treatment they would like, or would not like, if they become ill again in future.

- The majority who had been detained under the Act reported that they had been told about their rights but of those, nine said they didn't understand them.
- The majority who had been detained under the Act reported that they had been made aware of advocacy with around half of those opting to use this service.
- Five who had been detained under the Act reported that they had an advance statement in place.
- Of both those detained and non-detained, around half told us that they hadn't heard of advance statements and five said they would like one.

Lived experience of restrictions and reasons for restraint

During phase 1, we asked the 48 respondents about restrictions that might have been put in place when they came into contact with specialist services, particularly inpatient units. We wanted to know if restrictions had been placed on their access to electronic devices and social media, as well as physically through increased observation or restraint.

- Seven people advised that restrictions had been placed on access to their mobile phone and the internet with four reporting that they didn't agree with this.
- Eleven people advised that they'd been placed on an increased level of observation during an episode of care, seven recently and four some time ago.
- Six people told us they'd been physically restrained during an episode of care.

When physical restraint was used during an episode of care, this was in connection with attempting to leave the inpatient unit, to prevent self-harm or for NG feeding. Some found the experience negative, using words and phrases including 'no privacy', 'isolated' and 'didn't like it' while others spoke more positively about helpful nursing support and feeling safer.

¹⁵ https://www.mwscot.org.uk/sites/default/files/2019-06/rights_risks_2013_edition_web_version.pdf

¹⁶ https://www.mwscot.org.uk/sites/default/files/2019-07/rights_in_mind_1.pdf

¹⁷ https://www.mwscot.org.uk/sites/default/files/2019-06/human_rights_in_mental_health_services.pdf

Specified persons

Despite there being restrictions in place for seven people, only one individual was specified. Sections 281 and 286 of the Mental Health (Care and Treatment) (Scotland) Act 2003 provide a framework within which restrictions can be placed on people who are detained in hospital.

Where a patient is a 'specified person' in relation to these sections of the Act, and where restrictions are introduced, it is important that the principle of least restriction is applied. We would therefore expect restrictions to be legally authorised and the need for specific restrictions to be regularly reviewed. *Our Specified Persons Good Practice Guide* is available on our website¹⁸.

The family/carer perspective

We asked families/carers about concerns over restrictions. Most advised that they were satisfied and recognised that restrictions were imposed in the best interests of the person with an eating disorder. One commented: "Any rules imposed were for the purpose of keeping her from further harm." However, a few felt that some of the rules had negative effects in terms of the lowering of mood.

¹⁸ http://www.mwcscot.org.uk/media/216057/specified_persons_guidance_2015.pdf

3.10 Step down and discharge

"Eating disorders are always there, even if they are 'dormant' and the people who suffer are always in recovery so they should be treated like cancer patients and brought in regularly for follow-up care and treatment if necessary."

Family/Carer

The 'step down' from hospital to home

Some of the relatives/carers we spoke to commented that they felt that professional support can be withdrawn too soon. Having no 'step down' between hospital and home was cited as a real difficulty in maintaining positive progress on discharge with one relative/carer commenting: "She didn't get enough support and certainly not enough after discharge."

"At discharge, even though I raised many concerns, these were dismissed and I was told it was OK to keep hiding food from my daughter, that it was OK she will still not eat in front of anyone and that her body issues were normal teenage anxieties! All red flags for eating disorders."

Parent

It was also felt that once weight was restored, then discharge followed even if other issues remained unresolved and one parent commented that despite raising mental health concerns, their child was discharged with no follow up once they'd reached an appropriate BMI. Others commented that they felt they'd been prematurely discharged from CAMHS without being referred onto adult services, leaving them to cope along with ongoing problems and, as one parent commented: "... we felt in limbo with no support..."

Discharge planning

Most psychiatrists who worked in community services reported that there was, or mostly was, pre-discharge planning for people with eating disorders moving from inpatient to community care; that there was/mostly was good communication; that information was shared in a timely manner; that responsibilities for monitoring were made clear; and that family/carers were kept informed about decisions.

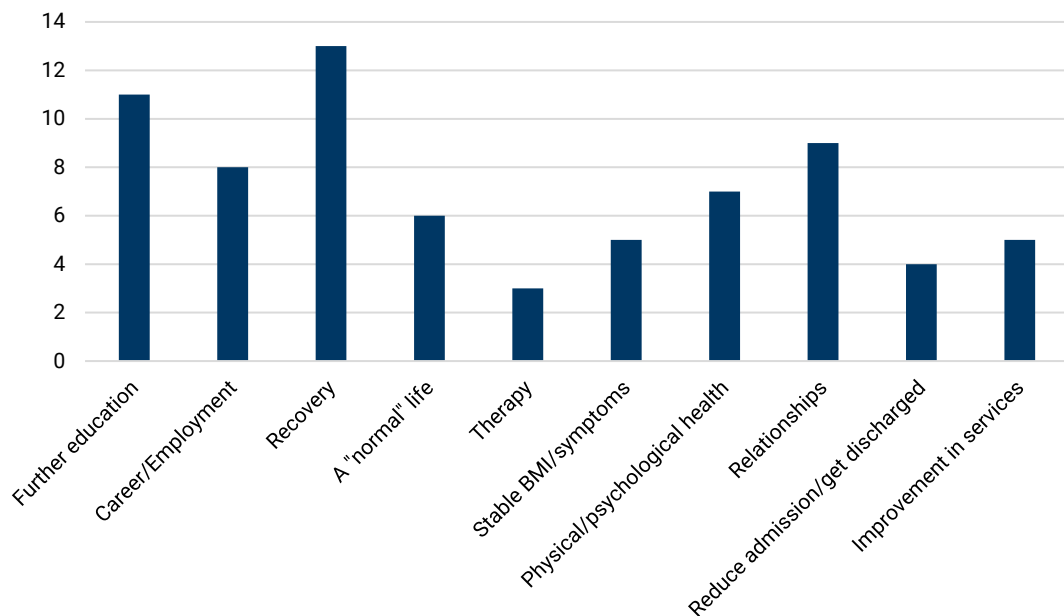
3.11 Hopes and aspirations for the future

"I have recently been discharged from the adult eating disorder service. They were extremely helpful, and my hope for the future is to maintain my progress and to build on it further. I would one day like to be fully recovered."

Person with eating disorder

The final question that we asked was about hopes and aspirations for the future. We received 57 comments covering a range of themes of which recovery was the most recurrent, followed by moving forward with further education. Relationships and career or employment opportunities were also noted and many people spoke of their hope of leading a 'normal life' including improved physical and psychological health, and having a stable BMI. A few mentioned improvements in services, reduced admissions and therapy.

Figure 5. Hopes and aspirations for the future



Chapter 4

Transitions, pathways, monitoring and protocols

The nature of an eating disorder requires assessment, treatment and monitoring, not only in relation to mental health, but also in relation to physical health. This can present challenges for services because it often requires a number of services to work together to provide good patient care. Critical elements of care require focus being kept on complex details while ensuring that the wider perspectives of an individual's needs are not lost. Additionally, many eating disorders develop during adolescence, which is a time of great change.

It was particularly striking, as we collected our mapping data, to see how health boards differed in their readiness to describe services for people with eating disorders in their areas. Some boards were able to provide very detailed descriptions of services with well-delineated and detailed care pathways, outlining standards and expectations of care provision between different elements. Others were much less equipped to respond with several describing services in CAMHS but not in adult services, or vice versa.

The coordination of care for people with eating disorders has been included as a standard by NICE, especially the transitions associated with young people moving from child to adult services, transitions where more than one service is involved, and transitions for people who need care from different areas at different times – for example, university or college students living away from home.

When we asked GPs and psychiatrists about improvements to be made in relation to services, many commented on the need to improve joint working and improve transitions. We heard about staffing shortages, especially among psychiatrists, and were told that informal rather than formal relationships are often what enables things to work in practice between services; this can lead to problems when one clinician leaves or retires and the replacement does not share the same role.

Common themes emerging, when we discussed transitions and joint working, were the need to clarify roles within primary care, the need to develop pathways with transition and supervision (particularly for the transition from CAMHS to adult services), more shared care and support and specific eating disorder resources for physical healthcare monitoring.

4.1 Types of transition

"The transition from CAMHS to adult services is very, very challenging!"

Parent

There are a number of types of transition that people with eating disorders might experience during their journey from diagnosis to recovery.

- From GP referrals (primary care) to secondary (mental health) and tertiary (inpatient) care (whether this is specialist, generic, medical or paediatric) and vice versa.
- From secondary mental health outpatient care to tertiary mental health inpatient care (whether specialist or generic) and vice versa.
- From mental health services of whatever type to acute medical inpatient services (including paediatric) and vice versa.
- From CAMHS to adult mental health care (whether inpatient or outpatient and whether specialist or generic service in both).
- From specialist adult eating disorder services to generic adult mental health services and vice versa.
- Between dual places of residence for students in further education living away from home.
- Between independent and NHS service provision.
- Between one geographical or health board area and another (and also between Scotland and England).

The report, *Ignoring the Alarms; How NHS Eating Disorder Services are Failing Patients*,¹⁹ describes the risks and poor service provision that patients with eating disorders can be exposed to, particularly in relation to joint service working and relations. It argues for improved quality, availability and coordination of eating disorder services. NICE describe the significant geographical variations in the provision of eating disorder services and this is mirrored in the summary of service provision in Scotland, provided at Appendix B of this report.

The transition from inpatient care to community services

When asked about transition in care, few GPs reported good communication between services – this included a lack of timeline information sharing, a lack of clarity around responsibility for ongoing monitoring and a lack of information for family/carers around decision making. Overall, a relatively large proportion of psychiatrists reported that they didn't know about the various aspects of transition from inpatient to community.

¹⁹ Parliamentary and Health Service Ombudsman, *Ignoring the Alarms: How Eating Disorders Services Are Failing Patients* (House of Commons, December 2017)

4.2 The transition from CAMHS to adult services

“Though we have very good transition processes we are faced with the challenge of philosophy of services – adult services run a motivation-based individual focused service while CAMHS runs a supported change, often lead by parents (implicit consent of young person) service.”

CAMHS psychiatrist

The GP perspective

“Transitions are very poorly managed in health board area – often there is no communication between the service and the GP has to refer, meaning the patient goes to the bottom of the waiting list for adult services.”

GP

The transition between children’s and adult mental health services has been recognised for some time as one that commonly causes difficulties. This is for a number of reasons. NICE refers to this specific transition, in one of its standards for eating disorders and coordination of care, and has also produced guidance around the transition from children’s to adult services more generally²⁰.

The Scottish Government’s *Mental Health Strategy 2017-2027* has published guidance around the transition from CAMHS into adult services as part of Action 21²¹.

When we asked GPs about their experience of transition between children’s and adult mental health services for young people with eating disorders, three of the 21 GPs who responded said they thought there had been good planning, while six did not, and the remainder didn’t know. Comments included that ‘transitions are poorly managed’ and one GP told us they had to write to CAMHS as CAMHS had not initiated the process themselves.

The psychiatric perspective

“We have a clear transition protocol... and I attend the CAMHS eating disorder resource meeting monthly. We still run into problems with transitions not happening in a timely manner and this causes difficulties for patients and their families. We have surveyed recent transition patients to try to assess their thoughts on the process so that we can improve this.”

Adult eating disorder psychiatrist

By contrast, the data we received from psychiatrists during phase 2 revealed that all four CAMHS psychiatrists believed there was good planning around transitions and

²⁰ Transitions from children’s to adults’ services for young people using health or social care services.NG43.2016.<https://www.nice.org.uk/guidance/ng43>

²¹ Transition Care Planning.Scottish Government 2018.<https://www.gov.scot/publications/transition-care-planning-action-21-principles-transition/>

three reported that the transition period was flexible and could last for up to six months. Three believed that good communication was in place and all felt that transitions centred around young people's needs and that family/carers were involved.

However, only two of the nine general adult psychiatrists thought that good planning was in place in their area, with three stating it was not, and only four agreeing that the transition was led by young people's needs. Three of the six specialist adult eating disorder psychiatrists thought that transitions from CAMHS involved good planning and the same three thought communication was good.

The family/carer perspective

"At that point her care fell into a black hole - there just wasn't any!"

Parent

Although transition from CAMHS was only relevant to six of the thirty respondents across both phases, it was universally felt to be unsatisfactory with comments including 'very, very challenging' and 'shockingly bad and almost negligent'. Additionally, family/carers described being abandoned or excluded from the care process on reaching adult services.

4.3 Transition issues for students living away from home

"It is difficult – depends on their preferences and how often they return home. We prefer services local to where they are most to handle this and if very unwell they often return home and have treatment locally."

GP

We wanted to find out how services responded to providing care for people with eating disorders who are also students living away from home. This provides challenges in respect to coordinating care since an individual's GP may change several times over the course of a year and services may vary greatly from one health board area to another.

Thirteen GPs responded to our question around the care and monitoring of students with eating disorders who are registered with a different GP during term time. Of those, only three had come across the issue and all three told us there was poor communication in place, particularly as registration with a GP during the holidays may be temporary.

Sixteen psychiatrists responded to our question regarding the coordination and management of care for students who live in different places during term time and holidays. Although four said that they had not come across this as an issue, the remainder gave varied responses including that this was challenging, depended on GP registration and how often the person was back at home, but comments included that it was done to the best of the service's ability with attempts made to liaise with the other location.

4.4 Integrated care pathways

“Reasonably well managed given the all-age nature of the service. I have also been involved in transitions to other areas which have gone fairly smoothly as I know most eating disorder psychiatrists in west and central Scotland.”

GP

The issue of transitions and shared or joint working in eating disorders is substantial and we asked GPs and psychiatrists working within NHS Scotland about their knowledge of integrated care pathways (ICPs).

- One third of GPs said they were aware of ICPs for services that look after people with eating disorders in their area, a third were not and a third thought there weren't any.
- Three of the four CAMHS psychiatrists who responded were aware of ICPs in their area, but not for adults.
- Four of the nine general adult psychiatrists who responded were aware of ICPs in their health boards for adults (this relates to three health boards) but none were aware of ICPs for CAMHS in their area.
- Of the six specialist adult eating disorder psychiatrists who responded, only four knew of ICPs in their area for adults (this related to four health boards) and only two knew of an ICP for CAMHS.

4.5 Who's responsible for physical health monitoring?

"This is a major problem and is generally managed on an ad hoc basis. Patients will usually have physical health monitored by dedicated medical staff but when they are off or otherwise unavailable that falls to CMHT. Local GPs vary hugely in their attitudes to this with some completely refusing to do any physical health monitoring."

Psychiatrist

Responsibility for the physical health monitoring of patients with anorexia nervosa seemed largely uncertain, and the monitoring of patients being looked after by mental health services was found to be an area of significant difficulty for all respondents to our survey, despite physical health monitoring being a fundamental and core element of eating disorder care.

Only a very small number of mental health services said they were able to undertake their own physical health monitoring, with most health boards relying on this taking place between mental health and primary care GP services working together. We were told that few boards had formalised this joint working protocol – not just in terms of who decides what investigations should take place and how frequently – but, critically, around who is responsible for acting on the results and ensuring that information is available to inform ongoing and holistic assessment of the health of people with eating disorders.

The GP perspective

"For the patients I have seen in the past there has been no decision about monitoring, it was just left up to me as a GP."

GP

When we asked GPs if there was an agreed protocol for physical health monitoring, which set out responsibilities between primary and secondary care, four GPs from four different health boards confirmed that there was, but a further nine said there wasn't and four didn't know. Although one GP commented that arrangements were agreed, others described the situation as 'an absolute mess' and 'an absolute disaster'.

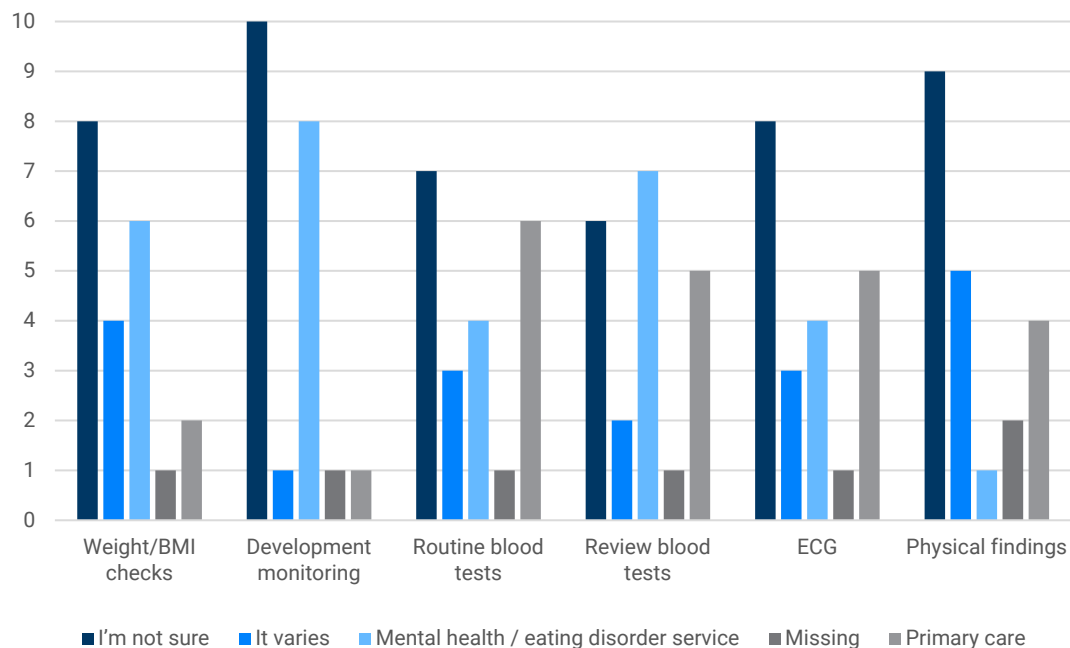
Many GPs reported that they didn't know whose responsibility it was, while the majority said it was the responsibility of the mental health or eating disorder service. Several GPs expressed concern that if physical health monitoring is left to primary healthcare services, then a lack of planning for monitoring, combined with increasingly nurse-led services, means that there is a lack of staff to interpret results and no good shared care.

"If someone is unwell enough to need weekly bloods/ECGs should they not also be seeing a specialist weekly rather than just attending for bloods/ECG – GPs are unlikely to have the capacity or specialist skills to undertake this."

GP

Figure 6 outlines GPs' understanding of the responsibilities for medical monitoring among different professionals when care is jointly managed between primary and specialist (secondary) services.

Figure 6. GPs understanding of responsibility for physical health monitoring of eating disorder patients



The psychiatric perspective

Six of the 13 psychiatrists (one CAMHS, two specialist eating disorder, three general adult) who responded to our survey during Phase 2 reported that their area had locally agreed protocols for physical health monitoring while five didn't have such protocols and two didn't know. Of the six who reported that they did have locally agreed protocols in place for medical monitoring, five reported the protocol set out care arrangements and responsibilities between primary and specialist (secondary) care with the same five reporting that the protocol outlined how the services should work together.

However, comments from the five psychiatrists who didn't have locally agreed protocols in place consistently pointed to the role of the GP in physical health monitoring.

Additionally, over half of the psychiatrists reported that their service does not have the capacity to provide at least weekly blood tests (which may be indicated for some patients); three reported that they did have capacity and two didn't know.

One GP practice told us that a member of their primary care team was specifically trained to provide eating disorder care.

In Dumfries and Galloway, the physical monitoring of people with eating disorders has been made a local enhanced service (LES); GPs monitor physical health as determined by risk level. A GP resource pack has been devised and biannual training in eating disorders for primary care staff is provided²².

²² The Royal College of Psychiatrists in Scotland, *Management of eating disorders in Scotland*

4.6 Protocol for admission to medical or mental health wards

It may often not be clear whether admission to hospital for people with eating disorders should be to a medical ward or a mental health ward. This issue forms an important part of the MARSIPAN and Junior MARSIPAN guidance developed by the Royal College of Psychiatrists, which contains a number of recommendations for services around the need for protocols and joint working²³.

Due to the regional nature of child and adolescent inpatient provision in Scotland, care closer to home versus care in a specialist unit often influences decisions. However, only two of the four CAMHS psychiatrists who responded to our survey told us that a local protocol existed around who should be looked after in a mental health ward and who in a medical ward. Three of the six specialist adult eating disorder psychiatrists told us that their health board had a protocol to guide this decision but only one of the nine general psychiatrists described this.

To support joint working between mental health and medical (including paediatric) services, the Royal College's MARSIPAN guidance makes a clear recommendation that forming working groups between mental health and physical health clinicians is an important way in which to develop protocols to support practices and joint working for individuals admitted to medical wards. However, only three of the psychiatrists (one CAMHS, two specialist eating disorder) who responded to our survey said there was a MARSIPAN or Junior MARSIPAN group in place locally to manage this medical/psychiatric interface as per MARSIPAN guidelines, while five said there was no such activity and five didn't know.

Specific protocols for 16-17 year olds requiring admission to a medical ward

When gathering information from health boards during our mapping exercise, we were given a small number of protocols that had either been developed or were being developed to support the care of children and young people under the age of 16 years in paediatric wards, but few that related to young people over the age of 16 being admitted to medical wards.

The differences in age division between medical specialties – where paediatrics care for the under 16s and adult medicine the over 16s – contrasts with mental health services which commonly see young people up to the age of 18, while those over 18 years are managed by adult services. Effectively this leaves a potential care complication for 16 and 17 year olds requiring medical input. One psychiatrist commented on problems associated with this, while another described working arrangements relating to the medical care of 16-17 year olds that were in direct conflict with the operational guidance on medical arrangements for their service, which they provided.

One children's mental health service shared a copy of their draft guidance with us and we noted that it did not make any reference to the distinction between paediatrics or acute medical services for the care of under 18s. Interestingly, when we reviewed the

²³ MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa. Royal College of Psychiatrists

Junior MARSIPAN: Management of really Sick patients with Anorexia Nervosa in under 18s. Royal College of Psychiatrists

case notes of one of their 17-year- old patients (where a clinician had sought advice from a paediatrician) the clinician had been promptly directed to adult medical services given the young person's age.

It is vital that the needs of young people, who might be looked after by both adult medical services and children's mental health services are not overlooked, and that work to develop protocols and joint working arrangements are not restricted to paediatric services only.

Chapter 5

Staff education and training

The 2017 report, *Ignoring the Alarms: How Eating Disorder Services are Failing Patients*²⁴ noted that NHS England eating disorder services are failing patients, and highlighted specific areas of focus to improve services. One of these highlighted the need for the General Medical Council (GMC) to conduct a review of training on eating disorders for all junior doctors to improve their understanding of these complex mental health conditions.

Collaboration and communication

Skilled early intervention can have a significant beneficial effect on the course of eating disorders, and creating resources within specialist eating disorder services should be considered. This could include providing wider training for other professionals around screening, and appropriate referral onto secondary care, as well as awareness initiatives with partner agencies such as education and ethnic minority groups. This would ensure that the expertise from specialist teams can be effectively used to support primary care, non-specialist services, education, social care and other agencies to work towards a truly integrated approach.

A research study, undertaken in 2017 with all UK medical schools, revealed that medical students receive less than two hours training on eating disorders over their four to six years of undergraduate study²⁵. We were interested in finding out what training was available for staff across various professional disciplines.

We would expect professionals working in specialist eating disorder services to have access to training to develop their knowledge and skills but, during our consultation phase, people with eating disorders reported that they believed many general mental health workers had limited knowledge of eating disorders and would not engage in discussion about them.

Opportunities

EEATS (Eating Disorder Education and Training Scotland) was developed in response to the need for improved training for professionals providing care and treatment for people with eating disorders. EEATS offers an accredited programme of training and theoretical knowledge designed to equip specialist eating disorders professionals of any discipline. Its syllabus currently includes awareness and knowledge of NICE Guidelines. NHS Education Scotland (NES) have supported the development of a curriculum and an accreditation system for multi-disciplinary training across the age range in eating disorders.

Half of the health boards areas involved in our survey had undertaken further accredited training via EEATS and NHS Education Scotland and had identified further staff to undertake this specialist training. Two health boards supported staff to undertake further training to enable them to be accredited supervisors in their service.

²⁴ Parliamentary and Health Service Ombudsman, *Ignoring the Alarms: How Eating Disorders Services Are Failing Patients*

²⁵ Agnes Ayton, Ali Ibrahim, *Does UK medical education provide doctors with sufficient skills and knowledge to manage patients with eating disorders safely?* (Postgraduate Medical Journal, Volume 94, Issue 113, 4 June 2018)

5.1 Specialist perspectives on confidence and training needs

During our consultation with people with eating disorders and their families/carers, we were told that they did not always feel that the professionals they were working with had sufficient knowledge and expertise.

The GP perspective

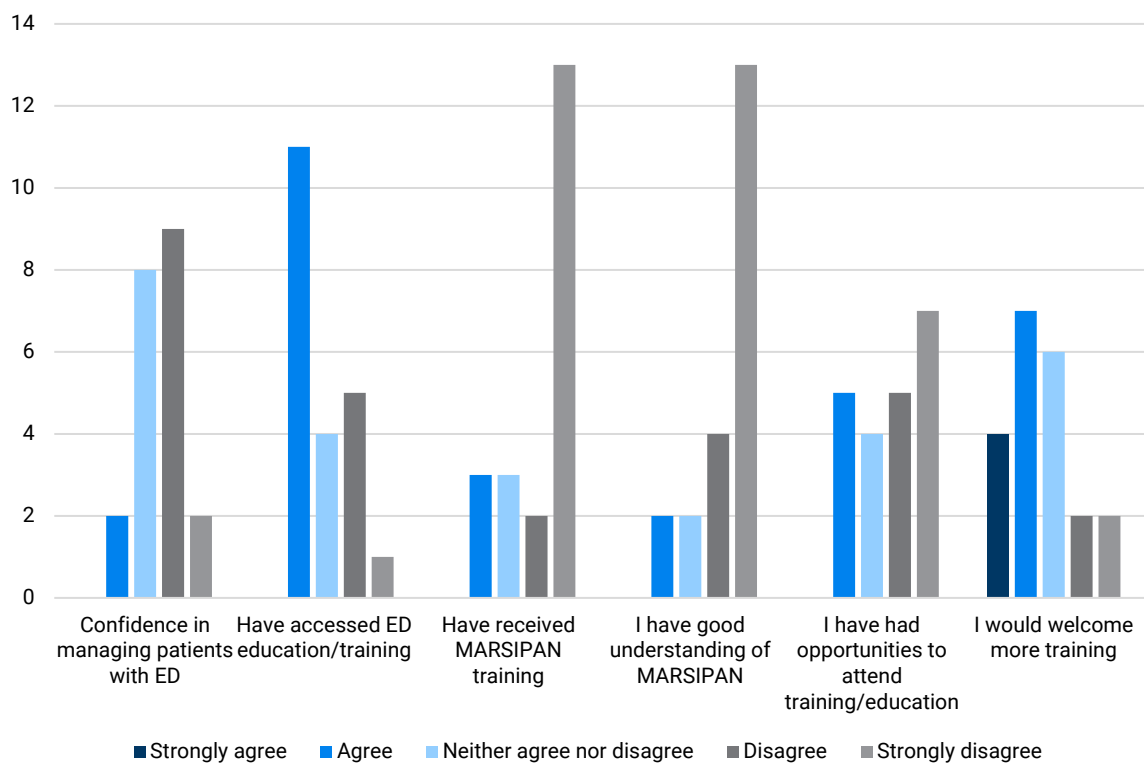
"Feel we are missing lots of diagnoses."

GP

GPs are likely to be the first port of call for people with eating disorders and we wanted to find out more about their training experiences; 21 GPs completed our phase 2 online survey and their involvement in providing eating disorder consultations varied from daily to six monthly.

Overall, GPs who responded to the survey did not express high confidence in managing patients with eating disorders and while just over half agreed they had accessed education and training, this was generally low with regard to MARSIPAN guidelines specifically. Only five GPs felt they had an opportunity to attend education or training, and 11 agreed that they would welcome more training.

Figure 6. GP confidence and training



The dietician perspective

Twenty-seven dieticians responded to our phase 2 survey and some worked across multiple settings. The majority reported feeling confident about managing patients with severe anorexia and while most either strongly agreed or agreed that they had received a good level of training, even more said they would welcome more training.

The psychiatric perspective

"I was lucky to be mentored by a colleague with longstanding experience in eating disorders when I started this job – a must, in my opinion."

Psychiatrist

Twenty-four psychiatrists from various clinical specialties responded to our phase 2 survey. While most either agreed or strongly agreed that that they were confident in managing people with eating disorders and had received a good level of training, nearly half said they would welcome further training.

Comments from psychiatrists on confidence and training including pointing to the need for 'a well-funded, well-supported national clinical network in eating disorders' and praise for the EEATS²⁶ accreditation programme.

²⁶ Eating disorder education and training Scotland <http://www.eeats.co.uk/>

5.2 Exploring training provision and opportunities for staff

We wanted to find out what training staff received to help them support people with eating disorders, including any specific psychological interventions.

Specialist inpatient and community services training

When we met with senior charge nurses (SCNs) and clinical leads across ten specialist services during phase 1, we asked about opportunities to develop their skills and knowledge. We have information on eight of these services who told us that there was a range of training options available across health boards, including e-learning, learn pro, access to training via psychological services and a training manager to oversee needs. Staff told us they had undertaken training in the following areas:

- nutritional/dietetic issues
- nasogastric (NG) tube feeding
- psychological formulation
- distorted perception of body image/food
- formal assessment of eating disorder
- giving diagnosis of eating disorder
- trauma
- value based care
- managing self harm/crisis and
- recovery principles/based care.

Training in psychological interventions varied across health boards but therapies included CBT (cognitive behavioural therapy), DBT (dialectical behaviour therapy), FBT (family based therapy), and SSCM (specialist supportive clinical management). While we heard about good examples of training, we also heard about a number of challenges. These included limited resources to support staff going off the ward for training, limited budgets and the lack of a psychologist to support nursing staff.

Opportunities

We found that all specialist services offered a range of training and development opportunities for staff, relating to individual and team continuing professional development (CPD).

5.3 Confidence and trust: the family/carer perspective

"On the day we went for our initial meeting (and to be given formal diagnosis) with the psychiatrist, my daughter, who refused to know her weight and got very anxious about it, was told by the psychiatrist that she had put on 'too much weight.' Sent my daughter into a meltdown!"

Parent

It's important that families/carers have confidence in the therapeutic team, trust professionals to know what they are doing, and believe them to be fully informed on the latest treatments.

During phase 1, the majority of family/carers engaging with specialist services told us that they felt staff had enough knowledge and training. Just over half in phase 2 said they felt staff had enough knowledge and training but highlighted issues including a lack of expertise or 'patchy knowledge' in the recognition of initial symptoms by their GP.

The use of 'bank' nursing staff without specialist knowledge in hospital settings was also mentioned, and one respondent noted the difficulty in staff connecting with her child who had ASD as well as an eating disorder. Some felt that 'bad advice' and unhelpful comments were made by staff who they felt should know better.

Appendix A

About eating disorders

Eating disorders are a group of serious mental illnesses, associated with significant morbidity and mortality. Often beginning in adolescence, people with eating disorders can be affected throughout their lives. The three main types of eating disorder are anorexia nervosa, bulimia nervosa and binge eating.

Anorexia nervosa is characterised by extremely low bodyweight, a distorted body image and an excessive fear of gaining weight. Low bodyweight is maintained through severely restricted calorie intake and may be accompanied by excessive exercising and/or purging through vomiting or the use of laxatives²⁷.

Bulimia nervosa is characterised by repeated uncontrolled binges during which excessive quantities of food are consumed in a short period of time, followed by compensatory purging²⁸.

Binge eating is characterised by repeated uncontrolled bingeing but without the compensatory purging seen in bulimia nervosa²⁹.

Although eating disorders can affect people of all ages, with children as young as six years old reported as having developed anorexia nervosa, symptoms of eating disorders start most commonly in adolescence³⁰. A recent report³¹ estimates that the total number of people with eating disorders in the UK is 724, 845 of whom 1% have anorexia nervosa, 50% have bulimia nervosa and 49% have binge eating disorder.

Contributory factors and prevalence

Like many illnesses, eating disorders are thought to be caused by a complex interaction of factors. For any individual, a combination of genetics, personality traits, thinking processes and societal pressures may be involved. Women are typically affected more commonly than men, at a ratio of 9:1, although this may under-represent the prevalence of male eating disorders³².

Psychological, physical and psychiatric implications

Eating disorders present both psychological and physical symptoms, and significant psychiatric comorbidity is found in people with eating disorders.

Psychological symptoms can include low moods, poor concentration, obsessional thinking, anxiety and sleep problems³³ while physical effects can be significant, impacting on all body systems and, at times, requiring acute medical treatment to

²⁷ S Zipfel, KE Geil, CM Bulik, P Hay, U Schmidt, *Anorexia nervosa: aetiology, assessment and treatment* (Lancet Psychiatry, vol 2, 2015) pp1099-1111

²⁸ J Treasure, AM Claudino, N Zucker, *Eating disorders* (Lancet, vol 375, 2010) pp583-593

²⁹ KM Culbert, SE Racine, KL Klump. *Research review: what we have learned about the causes of eating disorders – a synthesis of sociocultural, psychological and biological research* (Journal of Child Psychology and Psychiatry, vol 56(11), 2015) pp1141-1164

³⁰ D Wood, C Knight, *Anorexia nervosa in adolescence* (Paediatrics and Child Health, vol 25(9), 2015) pp428-432

³¹ BEAT/PwC, *The costs of eating disorders*

³² See 28

³³ See 31

prevent death³⁴. People with eating disorders can also experience long-term physical health issues – even once their eating disorder is under control. Anorexia nervosa has the highest mortality rate of any mental illness³⁵ with figures suggesting that up to half of those deaths are through completed suicide³⁶.

A recent review found that mood and anxiety disorders, including generalised anxiety disorder and obsessive compulsive disorder (OCD) were the most common co-morbid psychiatric disorders found in people with eating disorders³⁷. Alcohol and substance misuse are particularly associated with bulimia nervosa and binge eating disorder. Additionally, around a fifth of those with anorexia nervosa are affected by neurodevelopmental disorders, including autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD)³⁸.

Family and societal implications

The quality of life for people with eating disorders and their families can be significantly affected^{39,40} through disruption to education and work, and the impact on social and family life. Relatives of people with eating disorders exhibit higher rates of anxiety and depression than the general population⁴¹. In addition, financial costs associated with treatment, including paying for private care, can be significant and, alongside these individual costs, there are broader societal costs in terms of the economic burden of healthcare costs and the impact on workplace productivity⁴².

Treatment considerations and guidelines

In their guidance document of May 2017, *Eating Disorders: Recognition and Treatment*, NICE (the National Institute for Health and Care Excellence) recommends that treatment for people with eating disorders should be primarily psychological and community based and should include dietary advice; and that for children and young people, treatment should involve families⁴³. Although NICE does not recommend the use of medication for the treatment of eating disorders, the Royal College of Psychiatrists in Scotland, in their briefing paper *Management of Eating Disorders in*

³⁴ P Westmoreland, MJ Krantz, PS Mehler, *Medical complications of anorexia nervosa* (The American Journal of Medicine, vol 129, 2016) pp30-37

³⁵ HJ Hoek, *Incidence, prevalence and mortality of anorexia nervosa and other eating disorders* (Current Opinion in Psychiatry, vol 19, 2006) pp389-394

³⁶ The Royal College of Psychiatrists in Scotland, *Management of eating disorders in Scotland*

³⁷ A Keski-Rahkonen, L Mustelin, *Epidemiology of eating disorders in Europe: prevalence, incidence, comorbidity, course, consequences and risk factors* (Current Opinion in Psychiatry, vol 29(6), 2016) pp340-345

³⁸ See 28

³⁹ See 31

⁴⁰ T Agh, G Kovacs, D Supina, M Pawaskar, BK Herman, Z Voko, DV Sheehan, *A systematic review of the health-related quality of life and economic burdens of anorexia nervosa, bulimia nervosa and binge eating disorder* (Eating and Weight Disorders, vol 21, 2016) pp353-364

⁴¹ T Agh et al, *A systematic review of the health related quality of life and economic burdens of anorexia nervosa, bulimia nervosa and binge eating disorder*

⁴² See 31

⁴³ National Institute for Health and Care Excellence (NICE) guideline, *Eating disorders: recognition and treatment* (NG69, May 2017)

Scotland, notes that there is evidence for the use of high dose antidepressants in the treatment of bulimia nervosa⁴⁴.

Physical health monitoring is also recommended for people with both anorexia nervosa and bulimia nervosa and, in severe cases of eating disorder, day or inpatient psychiatric treatment may be appropriate and emergency medical admission may be required when physical health is severely affected⁴⁵. The MARSIPAN⁴⁶ (Management of Really Sick Patients with Anorexia Nervosa) and Junior MARSIPAN⁴⁷ guidelines provide recommendations for the management of people with eating disorders who are admitted to medical wards with anorexia nervosa, including guidance on a joint approach between physicians and psychiatrists.

Evidence from BEAT, the UK's leading eating disorder charity, suggests that just under 50% of those with anorexia nervosa or bulimia nervosa will go on to make a full recovery while 20% of those with anorexia nervosa and 23% of those with bulimia nervosa will remain chronically ill following treatment. BEAT also note that it is common for people with eating disorders to experience relapses during treatment and they report a relapse rate of 63% across all eating disorders⁴⁸. Prognosis is most positive for young people receiving treatment early on in their illness⁴⁹ and, for all people with eating disorders, longer waits for treatment are associated with poorer outcomes⁵⁰.

A UK-wide perspective

The UK Parliamentary and Health Service Ombudsman Report, *Ignoring the Alarms: How Eating Disorder Services are Failing Patients*⁵¹, focused on two deaths in England from anorexia nervosa and was extremely critical of eating disorder service provision. The report made a number of recommendations, including improving adult eating disorder services and increasing the provision of eating disorder specialists.

In 2019, the Welsh Government published a review of eating disorder services across Wales⁵², while in June 2019, a report on adult community eating disorder services in England was published by BEAT⁵³, which raised a number of concerns including long waiting times and variations in access to services across the country.

⁴⁴ The Royal College of Psychiatrists in Scotland, *Management of eating disorders in Scotland*

⁴⁵ NICE Guideline, *Eating disorders: recognition and treatment*

⁴⁶ The Royal College of Psychiatrists, *MARSIPAN: Management of really sick patients with anorexia nervosa* (CR189, 2nd Edition, The Royal College of Psychiatrists, 2014)

⁴⁷ The Royal College of Psychiatrists, *Junior MARSIPAN: Management of really sick patients under 18 with anorexia nervosa* (CR168, The Royal College of Psychiatrists, 2012)

⁴⁸ See 31

⁴⁹ S Zipfel et al, *Anorexia nervosa: aetiology, assessment and treatment*

⁵⁰ The Royal College of Psychiatrists, *Position statement on early intervention for eating disorders (PS03/19)*, The Royal College of Psychiatrists, May 2019)

⁵¹ Parliamentary and Health Service Ombudsman, *Ignoring the Alarms: How Eating Disorders Services Are Failing Patients* (House of Commons, December 2017)

⁵² <https://gov.wales/eating-disorders-service-review-2018>

⁵³ BEAT, *Lives at Risk: The state of NHS adult community eating disorders services in England* (BEAT, 2019)

In Scotland, the Royal College of Psychiatrists' briefing paper, *Management of Eating Disorders in Scotland*⁵⁴, summarised adult eating disorder services across the country at the time and noted that under 18s were well served by CAMHS (child and adolescent mental health services) who have experience in the management of eating disorders and access to inpatient units. A number of recommendations were made, including improvements in transitions between services and in clinician training.

The Scottish Government's *Mental Health Strategy: 2017-2027*⁵⁵ highlights eating disorders as a specific strategy area.

⁵⁴ The Royal College of Psychiatrists in Scotland, *Management of eating disorders in Scotland*

⁵⁵ The Scottish Government, *Mental Health Strategy: 2017-2027* (The Scottish Government, March 2017)

Appendix B

Eating Disorder Services across Scotland

As part of this themed visit we gathered information about services developed for individuals with eating disorders across Scotland. We are aware from our work that services that look after individuals with eating disorders are very varied across the country.

In July 2019 we wrote to all Health Board Chief Executives with a standard list of questions. The information we received was helpful but, for a number of boards, varied in content and clarity. In early 2020 we conducted a follow up request for information from those Health Boards where there was uncertainty over service provision. Unfortunately although we received a good response from many Boards overall, the impact of the Covid 19 pandemic delayed the chasing up of data to try and provide a complete data set initially. Prior to final publication we were able to gather further information and check with Boards the accuracy of the information we had collected. 11 of the 14 Boards gave us feedback on the information provided. The information contained in this appendix is based on the information provided to us by the Boards about their services in response to our enquiries.

We found the readiness with which Boards were able to respond to our enquiries about services for individuals with an eating disorder varied widely. The collated information demonstrates the wide variability of services across the country. Although the table provides a summary of services for the different health boards it is important to be aware that such a summary when read in isolation carries the risk of hiding the sheer variability and complexity of service provision it attempts to portray.

A full description of these services can be found on the Commission's website [here](#).

Glossary

In order to try and provide consistency in the representation of the information we received about the services for individuals with eating disorder across Scotland we used the following descriptions given below.

Inpatient mental health services are marked as specialist when the beds within the unit/ ward are dedicated for patients where their primary diagnosis is an eating disorder. Generic inpatient services are those which are designed to meet the needs of individuals with many different types of mental health difficulties and do not specialize in providing inpatient care solely for those with an eating disorder.

Community mental health services are services designed to look after individuals within the community and we have separated them into specialist services for eating disorders, generic mental health services and day services. We have defined specialist eating disorder community services as those services which specialize solely in the care of individuals with an eating disorder as the primary difficulty, and are separate from generic mental health services, and may be independently resourced. Generic mental health community services are those which are designed to look after individuals with a range of mental health difficulties and do not specialize in providing care for eating disorder alone. Some generic mental health teams may have an eating disorder pathway or even an eating disorder team within the generic service however these have been grouped within generic community services since they do not exist independently from the generic service and staff have shared caseloads. We defined day services as day facilities where individuals with an eating disorder may receive day care which may or may not be specialized for the treatment of eating disorders alone.

Specialist networks exist in some areas of Scotland and we defined them as networks which have been set up across health board boundaries to support complex case management for individuals with an eating disorder.

Summary Table of Health Board Responses

Health Board		Western Isles	Tayside	Shetland	Orkney	Lothian	Lanarkshire	Highland	Greater Glasgow & Clyde	Grampian	Forth Valley	Fife	Dumfries & Galloway	Borders	Ayrshire& Arran
Inpatient Mental Health	Specialist Adult	tbc	Eden	Eden	Eden	REDU	Priority	Eden	Stobhill	Eden	REDU	REDU	-	REDU	Priority
	Generic Adult	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Generic Child & Adolescent	tbc	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Community Health Services	Specialist Eating Disorder Service	Specialist Across Age range	-	-	-	-	-	-	-	-	-	-	-	-	✓
		Specialist Adult	-	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	-
		Specialist CYP	-	-	-	-	-	-	✓	✓	-	-	-	-	-
	Generic Mental health services	Generic Adult	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Generic CAMHS	✓	✓	✓	?	✓	✓	✓	✓	✓ ²	✓	✓	✓	✓
	Day services	Day Patient Adult	-	-	-	?	-	-	✓	✓	✓	-	-	✓	-
		Day patient CYP	-	-	-	?	✓	-	-	-	-	-	-	-	-
	Specialist network to discuss cases	Adult	tbc	✓ ⁵	✓ ⁵	✓ ⁵	✓ ⁴	-	✓ ⁵	-	✓ ⁵	✓ ⁴	✓ ⁴	-	✓ ⁴
		Children & Adolescent	-	-	-	-	-	-	-	-	-	-	-	-	-
	Medical Inpatient	Paediatric <16 yrs	✓	✓ ⁶	✓	✓	✓	✓	✓	✓ ⁶	✓ ⁶	✓ ⁶	✓	✓	✓
Adult Medical >16 yrs		✓	✓	✓	✓	✓	✓	✓ ⁶	✓ ⁶	✓ ⁶	✓ ⁶	✓ ⁶	✓	✓	

Notes on Summary Table of Health Board Responses

- tbc To be confirmed. Discussions underway regarding provision.
- √ service in place
- no service in place
- ? no information received
- 1 See separate Health Board entry
- 2 Eating disorder team sits within CAMHS
- 3 Eating Disorder development team is non-clinical
- 4 Quarterly meeting of South East Scotland network for adult eating disorder services
- 5 Monthly VC meetings of North of Scotland MCN for adult eating disorder services
- 6 MWCS told of additional work to support medical inpatient care of individuals with an eating disorder

Access to full details of this mapping exercise can be accessed on our website [here](#).



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