Health Care Needs Assessment
Severe Eating Disorders

North East and Cumbria 2015

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Specialty Registrar Public Health
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Executive Summary

The focus of this Health Care Needs Assessment (HCNA) is on defining the cohort of patients that require admission to adult specialised inpatient eating disorder services and/or admission to intensive day care provision in the North East and Cumbria. The purpose is to ascertain whether the current service provision is meeting the needs of this population and to understand if variation in service usage exists and to also identify any unmet need.

Aim

To assess the population health care need for specialised eating disorder services in the North East and North Cumbria.

Objectives

1. Understand the characteristics of the cohort of patients using NHS commissioned specialised eating disorder services in the North East and Cumbria
2. Map the patterns of the patient journey through NHS commissioned specialised eating disorder services in the North East and Cumbria
3. Estimate the prevalence and incidence of severe eating disorders in the North East and North Cumbria
4. Provide a map of current NHS commissioned service provision and compare the services to the national specialised commissioning service specification and other relevant national standards
5. Understand the demands, wishes and alternative perspectives of interested parties including professional and public views on the provision of specialised eating disorder services in the North East and Cumbria
6. Identify cost effective and evidence based practice in the treatment of severe eating disorders
7. Identify unmet need
8. Synthesise the information and data collected and make recommendations for future service provision and service improvement initiatives

Key Drivers

Hospital admissions for eating disorders have increased over the previous two years (2012-2014). The North East had the highest rate of admissions for an eating disorder (6.5 per 100,000 of the population) in England. Anorexia nervosa accounted for 76% of all admissions (Health and Social Care Information Centre 2014).

Whilst there has been an overall increase in the incidence of eating disorders (2000 – 2009), the incidence of anorexia nervosa at a population level has remained stable. However for women age 15-19 years old there has been an increase (Micali et al 2013). The annual prevalence rate for young women is 0.29% (Smink et al 2012).
Eating disorders are often associated with other psychiatric conditions and carry a high risk of suicide. The overall mortality rates are elevated as well (Preti et al 2009). The cost of treating eating disorders is substantial (Stuhldreher et al 2012).

Methodology
An analysis of data on the patient cohort utilising specialised eating disorder outpatient and inpatient services was used to inform service usage, patient demographics and clinical quality/patient outcomes. Included within the scope of this work is to understand what would have prevented an admission to hospital from the perspective of those who have experienced specialised services.

Focus groups and interviews were facilitated with key stakeholders; including providers, patients and carers/relatives. A survey was designed and disseminated to patients and carers/relatives. The comparative element of the HCNA was undertaken by comparing local configuration of service provision to published guidelines. A visit to the Regional Eating Disorder Service in Leicester provided an alternative perspective on service configuration. A review of literature focused on patient outcomes for the treatment of severe eating disorders based upon the treatment setting (outpatient and inpatient).

Results
The North East and Cumbria has an excess of more than 5 specialised inpatient eating disorder beds.

There appears to be a higher level of use of inpatient beds, but there is a lack of community based eating disorder provision. It is unknown how the lack of a community-based service contributes to the higher demand for beds.

The majority (61%) of patients remain as inpatients for longer than the commissioned care package of 126 days (4 months). A significant number of patients have hospital stays in excess of 12 months with 30% of all episodes of care exceeding 12 months.

A high proportion of patients (84%) are not admitted under the Mental Health Act and 83% of all inpatient admissions were planned.

The region places more demand on the use of out of area commissioned beds than the number of beds within the region that are used by patients that do not reside in the North East and Cumbria.

There is significant geographical variation in the use of inpatient and outpatient services. This highlights under use of services by some Clinical Commissioning Groups (CCGs) and over use by others. Populations closest to specialised services make greatest use of both services. Residents of Cumbria do not use intensive day care services.

There is limited data on the effectiveness of inpatient and intensive day care services, and there is little known about the patients, in particular how many recover
from a severe eating disorder and the proportion of patients with chronic and acute eating disorders.

Patients and carers/relatives express the need for more beds, quicker access into services and that services are specialised eating disorder services.

Currently the intensive day services have been commissioned as an alternative to hospital admission. The analysis of service use data identified 430 patients that were accessing outpatient provision (2013-2015). It is not known how many of these patients are now being treated within community mental health services.

The structure of the intensive day services and the number of places available cannot meet the demand of the volume of patients reported to be accessing outpatient care. Alternative treatment options for this group need to be defined, these need to be evidence based and cost effective.

There is a tension between delivering a recovery-focussed model of care and challenging the expectation from patients and carers/relatives that there is a need for long-term and continued engagement in specialised services.

Patients, carers and relatives reported poor communication and coordination of care between inpatients and day services and between specialised eating disorder services and community mental health services.

Patients, carers and relatives reported long delays in accessing an assessment, this was particularly important for young people aged 16-17 years old who were caught between child and adolescent and adult mental health services.

There are significant deficits in certain staff groups such as the number of junior medical staff and psychological therapists. However the annual spend by NHS England on specialised eating disorders is above the Royal College of Psychiatrists recommended minimum allocated budget (an excess of £500K above the minimum spend per year).

Currently there is support for carers/relatives who have family members admitted to the intensive day care provision and admitted into specialised eating disorder inpatient units. Carers/relatives want continued support across the entire care pathway, including primary care and secondary mental health services.

A minority (19%) of carers have had a formal assessment of their needs.

**Recommendations**

**Priority 1:** Cumbria patients are not accessing outpatient or day care provision. A focussed time limited piece of work is required to understand the service provision in Cumbria.

**Priority 2:** Commissioning more beds in specialised eating disorder units will not address the needs of those with a severe eating disorder. Alternative solutions to
treatment need to be identified. These alternative treatment options need to be evidence based. There needs to be a greater emphasis on treating patients on an outpatient basis.

**Priority 3:** Stakeholders should together define a recovery-focused model of care for the treatment of severe eating disorders in the North East and Cumbria. This needs to address the perverse incentive around low BMI and admission thresholds.

**Priority 4:** A resource exploration exercise needs to be undertaken in order to ensure that the right level of service is in the right place. Crucial to this is involvement of the CCGs in defining their requirement to develop community-based provision.

**Priority 5:** The care pathway for eating disorders needs to include community-based specialised eating disorder services and formal support for carers/relatives.

**Priority 6:** Increase the number of carers/relatives receiving a formal assessment of their needs as a carer.

**Priority 7:** Undertake a marginal analysis of the current intensive day care programme and establish if it is possible to increase the number of places available by addressing service efficiencies.

**Priority 8:** There are significant gaps in certain professional groups; including psychology and junior medical staff. Health Education North East need to lead a workforce forward planning exercise, in order to address these deficits and to actively promote training in eating disorders across all staffing levels to develop expert teams and ensure succession planning.

**Priority 9:** Design a data collection specification that provides all stakeholders (patients, providers and commissioners) with an overview of the quality of the services in the North East and Cumbria.

**Priority 10:** Given the significant gaps in knowledge on the patient population in contact with specialised eating disorder services; an audit of patient records is required in order to identify the following:

- Recovery rates for severe eating disorders in the North East and Cumbria
- Proportion of chronic and acute patients in contact with services
- Identification of avoidable admissions
- Number of planned/emergency admissions
- Number of new patients not previously known to services
- Attrition rates

This information would provide a valuable insight into the patient cohort and also provide a baseline from which progress can be measured.
1. Background

Eating disorders are divided into the following diagnostic categories: anorexia nervosa, bulimia nervosa, binge eating disorder (BED) and atypical eating disorders which is also referred to as eating disorders not otherwise specified (EDNOS).

Over the last decade there has been a significant increase in the incidence of all eating disorders, in particular for women aged 15-19 years (Micali et al 2013). The incidence of anorexia nervosa and bulimia nervosa has remained stable, but the incidence of atypical eating disorders and EDNOS has increased. Early detection and identification of eating disorders has improved, how much this has contributed to the increase in incidence of eating disorders is not known.

The Health and Social Care Information Centre has reported an increase in eating disorder hospital admissions for the last two years 2012 – 2014. Anorexia nervosa accounted for 76% of all admission, bulimia 5% and 19% were for other eating disorders. The North East had the highest rate of admissions for an eating disorder (6.5 per 100,000 of the population) in England (HSCIC 2014).

Eating disorders comprise a range of syndromes encompassing physical, psychological and social features (NICE 2004). People with eating disorders often experience acute psychological distress, as well as severe physical complications such as gastrointestinal problems, problems with blood chemistry and cardiac abnormalities and osteoporosis. Eating disorders often co-exist with other mental health problems, particularly depression and anxiety. Eating disorders frequently develop into chronic conditions, with poor rates of recovery and in some cases the resulting medical complications are fatal. This complex combination of physical and mental health conditions alongside an increased risk of mortality mean that treating eating disorders is not straightforward.

All eating disorders have an elevated mortality risk; however this is further increased with anorexia nervosa. A study in the 1990s reported that anorexia nervosa was associated with highest rate of mortality among all mental health disorders (Harris and Barraclough 1998). A more recent study has estimated a mortality rate of 0.51% for anorexia nervosa and 0.17% for bulimia nervosa per year. (Smink 2012).

The impact of an eating disorder on an individual’s relationships at home and family life as well as their employment, study and social pursuits is considerable. A study that explored recovery rates for eating disorders reported that within the 7.5 years follow-up period for those with a diagnosis of bulimia nervosa 74% fully recovered and for those with anorexia nervosa 33% fully recovered (Steinhausen 2002). For those that do not achieve recovery over time the severity of physical and social difficulties associated with eating disorders may increase. This can result in losing personal autonomy and increased social isolation, which in turn can promote a further reliance on the eating disorder as an emotional coping mechanism to deal with this loss of personal autonomy and social isolation.

Anorexia nervosa is characterised by low weight, body image distortion, an avoidance of perceived fattening foods and engaging in specific activities to reduce weight (self-induced vomiting, excessive exercise and use of appetite suppressants).
Bulimia nervosa is characterised by being a normal weight or overweight, a preoccupation with eating at specific times and engaging in specific activities to reduce weight, or to counteract effects of overeating (self-induced vomiting and use of laxatives). Bulimia nervosa is often preceded by anorexia nervosa.

BED is diagnosed when binge eating occurs in the absence of ‘compensatory behaviours’. As a consequence people with BED are usually overweight/obese. The prevalence of obesity is increasing and the cost to the individual in terms of quality of life, and to NHS resources, is high.

Atypical eating disorders or EDNOS is a diagnosis given when the general symptoms of eating disorders exist, but without fitting the exact criteria for one of the above diagnoses. This is the most common form of eating disorder identified in clinical practice accounting for 60% of all cases (Fairburn 2005). It should be noted that EDNOS is not a milder form of eating disorder, and can be as severe in presentation as any other diagnostic category.

All of these conditions are more common in females than males and usually start in adolescence and young adulthood (Hoek 2003, Smink 2012).

The Kings Fund published a report on the projected costs of providing eating disorder service in 2016. Service costs for eating disorders in 2007 were estimated to be £15.7 million, with 95 per cent of this related to anorexia nervosa. Costs are projected to increase to £23.8 million by 2026. Including lost employment costs brings the total to £50.6 million in 2007 and £76.4 million in 2026. Lost employment accounts for 69% of total costs (Kings Fund 2008).

Eating disorder services generally offer a stepped care model with more intensive support offered to more severely unwell patients. While most patients will receive treatment in community services, some (mainly those with anorexia nervosa) will require an inpatient hospital stay (JCPMH 2013).

National Institute for Health and Care Excellence (NICE) clinical guidance highlights that most eating disorders should be treated on an outpatient basis (NICE 2004).
1.1 Table 1: Stepped Model of Care – Eating Disorder Services

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<tbody>
<tr>
<td>Identification and detection of eating disorders</td>
<td></td>
</tr>
<tr>
<td>Monitoring and on-going assessment of patients discharged from community and secondary mental health services and specialised eating disorder services.</td>
<td></td>
</tr>
</tbody>
</table>

1.2 Aim

To assess the population health care need for specialised eating disorder services in the North East and North Cumbria.

1.3 Objectives

1. Understand the characteristics of the cohort of patients using NHS commissioned specialised eating disorder services in the North East and Cumbria
2. Map the patterns of the patient journey through NHS commissioned specialised eating disorder services in the North East and Cumbria
3. Estimate the prevalence and incidence of severe eating disorders in the North East and North Cumbria
4. Provide a map of current NHS commissioned service provision and compare this to the national specialised commissioning specification and other relevant national standards
5. Understand the demands, wishes and alternative perspectives of interested parties including professional and public views on the provision of specialised eating disorder services in the North East and Cumbria

6. Identify cost effective and evidence based practice in the treatment of severe eating disorders

7. Identify unmet need

8. Synthesise the information and data collected and make recommendations for future service provision and service improvement initiatives

1.4 Health Care Needs Assessment Framework

Health care needs assessment (HCNA) is a systematic review of the health issues facing a population leading to agreed priorities and resource allocation that will improve health and reduce inequalities within a particular health care setting. The overall aim of HCNA is to provide information to plan, negotiate and change services for the better and to improve health in other ways (Stevens 2015).

Health care needs assessment is about engaging people in thinking about health care provision, and planning what can be done to improve health and reduce health inequalities (Hooper and Longworth 2002).

There are four key components to a HCNA:

1. Epidemiological
   The assessment of incidence and prevalence (how many people need eating disorder services for the treatment of severe eating disorders)

2. Evidence based
   What is the current evidence base on the provision of interventions to treat severe eating disorders?

3. Comparative
   The effectiveness and cost-effectiveness of eating disorder services in the North East and Cumbria and how baseline service information compares with other services and national guidelines

4. Corporate
   What are the views and opinions of the key stakeholders on the provision of eating disorder services for the treatment of severe eating disorders?

The figure below presents these four components and how they relate to need.
1.5 Defining the Scope
The focus of this HCNA is on defining the cohort of patients that require admission to adult specialised inpatient eating disorder services and/or admission to intensive day care provision in the North East and Cumbria. The purpose is to ascertain whether the current service provision is meeting the needs of this population and to understand if variation in service usage exists and to also identify any unmet need.

It is anticipated that further work will build upon this HCNA and focus on the needs of children and young people accessing Child and Adolescent Mental Health Services (CAMHS).

This HCNA explores the access into community mental health services, CAMHS and primary care as experienced by the cohort of patients that have also experienced adult specialised inpatient eating disorder services and/or intensive day care provision. As a result the health needs of those with a mild or moderate eating disorder are not represented in this needs assessment.

The majority of hospital admissions are for the treatment of anorexia nervosa, therefore the focus of this HCNA has been on this patient group.

Included within the scope of this work is to understand what would have prevented an admission to hospital from the perspective of those who have experienced specialised services. Identifying population level interventions on preventing the onset of eating disorders is not within the scope of this health needs assessment.
1.6 Defining Severe Eating Disorders
Severe Anorexia Nervosa is defined in weight terms as an individual with a BMI of <15. Other factors such as rapidity of weight loss and metabolic disturbance due to starvation or purging behaviours in addition to BMI determine medical risk and therefore consideration for admission. Men can be physically compromised, e.g. hypothermia, weakness at a relatively higher BMI and therefore there should be a lower threshold for consideration for possible admission. (NICE 2004).

NICE also highlights that the majority of people suffering from anorexia nervosa including those with a BMI of <15 can be successfully treated in community by outpatient eating disorder services. Only a small minority of those suffering from severe anorexia nervosa require inpatient treatment.

The NHS National Service Specification for eating disorder services uses the same definition as NICE. In the absence of a definition of severity for other eating disorders such as bulimia and EDNOS, the following guidance is provided:

Patients with eating disorders who require inpatient care generally fall into one of four categories:
1. Rapid weight loss with evidence of system or organ failure, which is potentially life threatening.
2. Outpatient psychological treatment has not been sufficient to effect a change or improvement.
3. Those at low weight (usually chronically unwell), who are not able to manage in daily life, who require help with weight stabilisation or modest weight restoration, often in the context of medical instability. These patients frequently have severe psychiatric co-morbidity and/or difficult social/ family circumstances.
4. In exceptional circumstances it may be appropriate to admit a patient suffering from severe and medically unstable Bulimia Nervosa for a symptom interruption admission, e.g. a patient with diabetes, pregnancy, or not responded to intensive community treatment.
2. National Policy Context
There are a number of national policy drivers that are directly relevant to the commissioning, configuration and the day-to-day delivery of specialised eating disorder services for adults.

In 2004 NICE issued clinical guidelines for the identification, management and treatment of eating disorders. These guidelines were reviewed in 2010 but left unchanged. NICE is currently in the process of updating these clinical guidelines with an anticipated publication date of April 2017.

The 2004 NICE clinical guidance made the following recommendations for implementation:

- Most people with anorexia nervosa should be managed on an outpatient basis with psychological treatment provided by a service that is competent in giving that treatment and assessing the physical risk of people with eating disorders.
- People with anorexia nervosa requiring in-patient treatment should be admitted to a setting that can provide the skilled implementation of re-feeding with careful physical monitoring (particularly in the first few days of re-feeding) in combination with psychosocial interventions.
- Family interventions that directly address the eating disorder should be offered to children and adolescents with anorexia nervosa.

The Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) was devised in response to a number of deaths due to non-adherence to nutritional treatment regimens because of psychiatric problems, and medical complications, such as re-feeding syndrome. The scope of MARSIPAN guidance includes acute medical wards, general psychiatric wards and specialised eating disorder units. In 2010 the MARSIPAN guidance was updated. The main implication for service configuration was on defining the care pathway between acute medical wards and specialised services.

The Royal College of Psychiatrists published guidance on feeding and the nutritional management of patients with anorexia nervosa (2005). The guidance provides a provisional set of recommendations rather than being a definitive statement on practice.

The commissioning and service configuration of specialised eating disorder service for adults is supported by two key documents.

2. Joint Commissioning Panel for Mental Health; Guidance for commissioners of eating disorder services.

Both documents outline in detail a description of what good and effective eating disorder services look like and the required care pathway that is needed in order to treat patients with severe eating disorders.
2.2 Quality standards and eating disorder services
There are specific quality standards for eating disorder services. These standards have been designed by the College Centre for Quality Improvement (CCQI) which is linked to the Royal College of Psychiatrists and the Quality Network for Eating Disorders (QED). These standards incorporate the Royal College of Psychiatrists Accreditation for Inpatient Mental Health Services (AIMS). The Care Quality Commission (CQC) set out essential standards, which are expected for healthcare services to ensure quality and excellence. An overview of the themes covered by these quality standards is outlined in appendix i.

2.3 Quality assurance arrangements in the North East and Cumbria
The Specialised Commissioning Team, NHS England, has responsibility for a range of specialised mental health and learning disability services across Cumbria, Northumberland Tyne and Wear. The ambition of NHS England is to bring equity and excellence to the provision of specialised care and treatment, which is patient-centred and outcome based, placing the patient at the centre of planning and delivery.

There is a robust contract monitoring and review process in place between commissioners and providers. To complement this, an annual schedule of quality visits are carried out (a schedule of quality visits is listed in appendix i).

The visits are intended to complement existing formal contract monitoring processes, providing better qualitative information and understanding of patient experience. They allow commissioners the opportunity to see the environments that people are living in and ensure that individuals, their families and ward staff have the ability to meet and speak to them to ensure good quality service provision.

The Specialised Commissioning Team NHS England, also complete more in-depth reviews in the form of a service review. The purpose of a service review is to give assurance to commissioners that current service providers are meeting the requirements of the national service specification and the needs of the current population. A service review will compare the requirements of the specification with actual service delivery and gives an outline of current service provision. Additionally it highlights good practice and service gaps in line with the service specification and proposes recommendations for future developments.
3. Epidemiology of Severe Eating Disorders

The focus of this HCNA is on the adult population (over 18s) that require admission to hospital for eating disorders.

There are several ways of expressing the frequency of eating disorders in the population. Incidence rate is defined as the number of new detected cases per year for eating disorders, normally expressed per 100,000 population. Prevalence includes new and existing cases.

Lifetime prevalence estimates of DSM-IV anorexia nervosa, bulimia nervosa, and binge eating disorder are 0.9%, 1.5%, and 3.5% among women, and 0.3% 0.5%, and 2.0% among men (Hudson 2008). There has been little research done on the distribution of the atypical eating disorders (Fairburn 2003).

The management of most eating disorders will be done within primary care and secondary (community) mental health services, which is not an indicator of severity. Those requiring specialised eating disorder services such as access to inpatient or intensive day care will do so in response to acute medical risk as a result of the eating disorder, this acute medical risk is associated more with anorexia nervosa than with other eating disorders (Treasure 2010).

Establishing the prevalence and incidence of anorexia nervosa is difficult as at a population level, anorexia is a relatively rare condition. Another consideration is that many people with anorexia nervosa may not come to the attention of service providers and those that do may be incorrectly diagnosed. Therefore studies that have used data from clinical records will not identify the entire population with anorexia nervosa. Community surveys have been identified as the best source for prevalence data. However large-scale studies are rare or the definition that has been used to define anorexia nervosa differs significantly between studies.

The epidemiological studies that have been conducted on anorexia nervosa have identified that anorexia nervosa affects more women than men; it is estimated that 10% - 25% of clinical cases of anorexia nervosa are male (Hoek 2003 and Woolridge 2012).

Young people have been identified as being at a particular risk of developing anorexia nervosa in comparison to the whole population, with the peak age of onset of anorexia nervosa at 15-19 year (Micali 2013).

There is a lack of studies that have been conducted at a whole population level. The majority of published epidemiological studies have concentrated on young women (under 25 years old). These studies have their limitations including: being small-scale, having limited age ranges, and being setting-specific i.e. hospital or GP based registers, which will not capture those not accessing services.
3.1 Projected Incidence of Anorexia Nervosa

This section aims to provide an estimated annual incidence rate of new cases per year for anorexia nervosa for the North East and Cumbria. The data used to provide this estimate is based upon the findings from a study that used GP based medical records to identify the number of new cases of anorexia nervosa by age and gender over a ten-year period (2000 – 2009) for the age group 10-49 years old (Micali 2013). At a population level the overall incidence rate for anorexia nervosa has not changed significantly over this ten year period. The graph below plots the annual incidence of new cases within primary 2000 – 2009 (Micali et al 2013).

Using the above incidence rates an annual average incidence rate for men (0.98 per 100,000) and women (13.49 per 100,000) was calculated based upon the rates reported for 2000 – 2009.

This annual estimate was then used to calculate the expected number of new cases for men and women aged 10-49 years reported in primary care within a one year period, using the 2013 mid-year population estimates for the North East and Cumbria aged 10-49 years.

The authors highlight that this data does not pick up cases that have not presented to primary care (Micali et al 2013). In the Netherlands, on average 40% of the community cases of anorexia nervosa are detected by general practitioners (Hoek, 2003). Assuming that 40% of new cases of anorexia nervosa are detected in primary care, an estimate has been calculated for the number of people presenting with anorexia nervosa that are in the community and have never accessed primary care per year for the North East and Cumbria region.
Figure 3: Annual expected new cases of anorexia nervosa by sex for the North East and Cumbria

It is estimated that a total of 112 new cases of anorexia nervosa would be identified within primary care each year and there would be 169 undetected cases within the community.

In the UK, an epidemiological study using the general practice research database found that 80% of cases of anorexia nervosa were referred on to secondary care (Turnbull et al. 1996). Assuming that this proportion is replicated in the North East and Cumbria there would be 90 new cases of anorexia nervosa being referred into secondary care in the North East and Cumbria each year.

There are no applicable studies that present incidence or prevalence rates in relation to severity and hospital admission for severe eating disorders. There is one study that estimated an incidence rate for severe anorexia nervosa that required hospital admission at 1.2 per 100,000 person-years (women aged 12 – 25 years) (Milos 2004). However this study was based on the population of Switzerland and is not transferrable to the UK healthcare system.

3.2 Prevalence of Anorexia Nervosa

There are a number of ways to express prevalence. This includes point prevalence, which is the number or rate per 100,000 population at a particular time that have an eating disorder. Period prevalence is the number of cases of an eating disorder within a given time period, normally one year expressed as an ‘annual prevalence rate’. Lifetime prevalence is the proportion of people that have an eating disorder at any point in their lives.
Prevalence data on anorexia nervosa for over 18s is scarce or not appropriate as it is often out of date, based upon small numbers or conducted in healthcare settings that are not applicable to the UK. As previously mentioned the main published papers have focused on women aged 15-24 years (Hoek 2003, Smink 2012). Although these prevalence rates for ‘young women’ have also been described in other papers as relating to women aged under 35, direct correspondence with the authors of the original epidemiological studies has confirmed the age as 15 – 24 years old.

Table 2: Annual estimated number of women aged 15-24 years old with anorexia nervosa in the North East and Cumbria

<table>
<thead>
<tr>
<th>Level of Morbidity/Care</th>
<th>Estimate for one-year prevalence rates for Anorexia Nervosa per 100,000 women aged 15-24 years</th>
<th>Estimate numbers of women aged 15-24 years with Anorexia Nervosa per year (lower and upper range based upon 95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>95% CI</td>
<td>North East</td>
</tr>
<tr>
<td>Community</td>
<td>370</td>
<td>333 - 410</td>
</tr>
<tr>
<td>Primary Care</td>
<td>160</td>
<td>136 - 187</td>
</tr>
<tr>
<td>Mental Health</td>
<td>127</td>
<td>106 - 151</td>
</tr>
</tbody>
</table>

*Based upon 2013 mid-year population estimates for women aged 15-24 North East and Cumbria.

Assuming that the North East and Cumbria has the same prevalence rates for anorexia nervosa; the above table highlights that there is potentially each year between 209 – 297 women aged 15 – 24 in the North East and Cumbria accessing mental health services (community and secondary care) for anorexia nervosa.

3.3 Comparing utilisation with estimated prevalence rates for anorexia nervosa

The above estimates for the number of women aged 15 – 24 years old with anorexia nervosa in contact with mental health services (community mental health and secondary mental health services) has been compared to actual service usage within secondary care for women in the same age group in the North East and Cumbria. This has included data on adult (>17 years) and CAMHS (<18 years) admitted to specialised eating disorder units in the North East and Cumbria. There are some limitations as this only provides a comparative estimate for women aged 15-24 years old.
3.31 Inpatient utilisation

Table 3 Estimated percentage of population with anorexia nervosa aged 15-24 accessing inpatient eating disorder services in one-year period

<table>
<thead>
<tr>
<th>Expected annual number of women with AN aged &lt;25s in contact with mental health services</th>
<th>Estimated &lt;25s accessing inpatient care within a one year period*</th>
<th>% Women with AN aged 15-24 accessing inpatient eating disorder services within a one year period</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>216</td>
<td>80</td>
</tr>
<tr>
<td>Cumbria</td>
<td>34</td>
<td>10</td>
</tr>
<tr>
<td>North East and Cumbria</td>
<td>250</td>
<td>90</td>
</tr>
</tbody>
</table>

*This will be an over estimation as CAMHS data includes young women <15 years old

The above results indicate that there are lower numbers accessing commissioned inpatient services from Cumbria. The data set above does not include out of area placements, annually there is approximately 15 out of area placements only a small proportion of these are residents of Cumbria.

Based upon the comparison between prevalence rates and inpatient usage for women aged 15-24 years old; in the North East and Cumbria it is estimated that 36% of all women aged 15 – 24 years old who are known to mental health services each year are admitted to specialised eating disorder inpatient units.

A study in the USA estimated that 21.5% of patients with anorexia nervosa required hospitalisation each year (Streigel-Moore 2000). A ten-year retrospective study of service usage within adult eating disorder services in Leicester recorded 25.2% of adults with anorexia nervosa required hospital admission at some point during their treatment with the average length of treatment 2.5 years (Wales et al 2013).

3.32 Outpatient utilisation

NICE clinical guidance on the treatment and management of eating disorders highlights that in the UK it is the norm for the majority of patients to be treated on an outpatient basis (NICE 2004).

A comparison between the expected number of women and 15 – 24 years old with anorexia nervosa in contact with mental health services (specialised and secondary care) and the actual numbers of women aged 15-24 years old accessing intensive day services and outpatient care within a one-year period is presented in the table below.
The above table highlights that there is very little outpatient and intensive day care provision accessed by young women residing in Cumbria.

As previously mentioned there is little data on service utilisation and severity of eating disorder. A study conducted in specialised eating disorder services in Leicester highlight that around 75% of patients are seen on an outpatient basis (Palmer 2000).

Another study in specialised eating disorder services in South London that explored the care pathways identified that 75% of patients were managed as outpatients and 4% (23/530) engaged in intensive day services and 40% (16/40) of patients that had been inpatients were stepped down into intensive day care (Waller 2009).

Comparing these proportions to the North East and Cumbria less women aged 15-24 years old are managed on an outpatient basis, there is a similar percentage that access intensive day care services.

### 3.4 Challenges in interpreting the data

There are real methodological challenges when attempting to ascertain whether the numbers actually reached by the specialised inpatient and outpatient services are too few or too many.

There are numerous epidemiological studies on the age distribution in relation to the age of onset of anorexia nervosa; however there are few studies that explore the age and gender distribution within specific treatment settings.

The above data only provides a snapshot for women aged 15 - 24 years old, given this only represents 59% of the inpatient population and 50% of the outpatient population the analysis presented only provides part of the whole picture.
This means that there are some significant questions that cannot be answered:

1. Are the existing numbers that are using inpatient and outpatient care within an acceptable range?
2. There appears to be under use of outpatient and day care services for residents of Cumbria.
3. Is the proportion of patients utilising the different levels of services within an acceptable range?
4. Does the age profile of inpatients in the North East and Cumbria differ to that experienced in other areas i.e. is there a higher prevalence rate of anorexia nervosa amongst young women?
5. Is there better early detection and identification of anorexia nervosa in primary care and therefore there are more women at a younger age being referred into specialised eating disorder services?
6. Does the population in the North East and Cumbria have a higher level of morbidity and complexity so therefore require more frequent admission and longer admissions to inpatient services?
4. Summary of evidence
A systematic review of the evidence relating to the treatment of anorexia nervosa within outpatient and inpatient settings was undertaken. The aim of the literature review was to identify the current evidence base and to compare the effectiveness of treatment within these settings. The search strategy is in appendix ii.

One systematic review of studies comparing inpatient and outpatient care identified two small randomised, controlled trials (RCTs) [Meads et al, 2001]. One RCT (n = 90) compared inpatient treatment with two different outpatient treatments or assessment interview only [Crisp et al, 1991]. All patients “had to be sufficiently ill that inpatient treatment was a possibility but not essential”.

Although no differences were reported between the group for psychometric (Morgan-Russell scores) or weight-related outcome measures at 2 or 5 years, the validity of this finding is limited owing to the possibility of the lack of difference being due to small sample size (type 2 error) and other methodological issues (for example lack of blinding).

The second RCT (n =42) that was included in the systematic review compared inpatient with day patient treatment for people with anorexia nervosa [Freeman & McFarlane, 1993. This was published only as a conference proceeding and, despite efforts to contact the authors by the reviewers, there was insufficient information to establish the validity of the finding that, at 2 years follow up, there were no significant differences between the two groups in terms of weight gain or “general psychopathology”.

One further small RCT was identified in the database search [Kong et al, 2005]. This RCT compared day patient with outpatient treatment for 43 women with anorexia nervosa already receiving outpatient treatment in South Korea. Although participants in the day treatment group showed significantly greater improvements in their Eating Disorder Inventory-2 score, frequency of binging and purging, BMI, depression and self-esteem score compared to the outpatient group, this finding is limited due to methodological problems. These included lack of allocation concealment and lack of blinding. Because outcome measures were self-reported and participants were not blinded to allocation, there is a high possibility of ascertainment bias.

The systematic review identified numerous other case series, which showed worse outcomes following inpatient treatment compared with day or outpatient treatment, in terms of mortality and psychometric score. However, this is likely to be due to confounding. One further study (identified in the database search) of 75 consecutive adolescent cases of anorexia nervosa found that during the follow up, being an inpatient was associated with worse outcomes (in terms of Morgan-Russell Global Assessment Scale) compared to never having been an inpatient, even after adjusting for severity at onset [Gower et al, 2000]. However, although the study might be described as a cohort study, it is unclear how the two groups compared, this comparison was not the main objective of the study, the study participants had variable follow-up duration (from two to seven years) and it is likely that unmeasured confounding factors account for the difference.
The database search did not identify any studies that compared specialised and non-specialised care. However, a follow-up study identified in commissioning guidance [Joint Commissioning Panel] found shorter duration of admission and lower rate of relapse among inpatients treated in specialised hospitals compared to non-specialised hospitals in Germany [Richard et al, 2005]. Given that this was not the main research question and the risk of confounding, this finding should be viewed with caution. It is also unclear if it is applicable to an English healthcare context.

In summary, evidence on the relative effectiveness of inpatient, day patient or outpatient care, or of specialised compared to non-specialised care, is either lacking or at high risk of bias or confounding. There is some suggestion that, where inpatient care is not considered essential, outpatient care may be equally effective. And day patient treatment may be more effective than usual outpatient care. However, both of these findings need to be confirmed in larger, well-conducted randomised controlled trials.
5. Perspectives from Patients and Service Users and their Relatives and Carers

5.1 Methods
The remit of this HCNA was to understand the needs of the population in the North East and Cumbria in relation to the provision of specialised eating disorder services. Focus groups were arranged within both of the specialised service providers (NTW and TEWV), with separate focus groups facilitated within the intensive day services and within the inpatient services. Three focus groups were organised with relatives and carers.

The format of the focus groups was a semi-structured facilitated session, which explored the following areas:

1. Identifying which services and approaches had been helpful in the early stages of developing eating disorders, and what aspects of care had been lacking in the early onset of eating disorders.
2. What are the aspects of care provided within specialised services (intensive day care and inpatient) that help recovery, and what aspects of care are lacking in aiding recovery and discharge from specialised services?
3. What needs to be in place to prevent readmission back into specialised services (intensive day care and inpatient)?

In order to gain the views and perspectives from those not currently in treatment services and from carers and relatives that did not engage in the support groups two surveys were designed to capture their experiences and perspectives on service provision in the North East and Cumbria. The survey for patients/service users is appendix iii and the survey for relatives is appendix iv.

The surveys were accessed by PHE Select Survey an online survey tool. The hyperlink to the surveys were distributed to current and past service users and to their carers/relatives via mailing lists held by the providers.

The structure of the survey incorporated the three questions asked within the focus groups as well as some demographical and clinical information. No demographical or clinical information was collated on the participants engaging in the focus groups.

5.2 Participants and Responses

Table 5: Focus group participants

<table>
<thead>
<tr>
<th>Focus Groups</th>
<th>Inpatient</th>
<th>Intensive Day Care</th>
<th>Carer/Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>15</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>
Table 6: Survey responses

<table>
<thead>
<tr>
<th>Survey Responses</th>
<th>Completed</th>
<th>Partially Completed</th>
<th>Incomplete (no answers)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients and service users</td>
<td>29</td>
<td>6</td>
<td>19</td>
<td>54</td>
</tr>
<tr>
<td>Relatives and Carers</td>
<td>28</td>
<td>4</td>
<td>34</td>
<td>66</td>
</tr>
</tbody>
</table>

There were a significant proportion of incomplete questionnaires with no information in any of the fields. Only completed or partially completed questionnaires were analysed.

5.3 Patient and Service User – demographical information
- 89% (31/35) responses were from women and 11% (4/35) male respondents.
- 97% (34/35) respondents described their ethnic background as White British and 3% (1/35) as Black African.
- All 35 respondents were residents of CCGs within the North East and Cumbria region.

5.4 Patient and Service User – clinical information
The reported peak age of onset of eating disorder was aged 10 – 20 years old with 86% (30/35) experience of onset within this time-frame.

The majority of respondents 86% (26/30) had initially accessed their GP for help.

Just under a half 43% (13/30) of respondents reported that they had been admitted to inpatient services and 46% had used the intensive day care provision. The thirteen respondents that had been admitted to inpatient care 54% (7/13) had experience of being placed out of area.

80% of respondents had been under the care of community mental health teams.

Respondents were asked if they had received any other mental health diagnosis.
- Twenty-four (80%) had a diagnosis for depression
- 67% (20/30) had a diagnosis for anxiety
- Just over half of respondents (16/30) had a dual diagnosis of depression and anxiety

5.5 Carers and Relatives - demographical information
There were a total of 32 completed or partially completed returned questionnaires, all of the respondents lived in the North East and Cumbria region. The majority of responses were from women 84% (27/32) and 5 (16%) were from men. All respondents described their ethnic background as White British.
Most respondents 81% (26/32) were caring for a daughter, 3/32 (9%) providing care for their partner. The other three respondents were caring for a son, parent or sibling.

A total of 30/32 (94%) were caring for a female relative.

The age range for carers was 31 – 66 years old and the age range for the person they are caring for was 14 – 65 years old.

5.6 Carers and Relatives - clinical information

Nearly half (47%) of all respondents had cared for someone who had accessed CAMHS eating disorder services.

Two thirds 21/32 reported having engaged in family therapy as part of the treatment programme.

Only 19% (6/32) reported having received an assessment of their needs as a carer.

Nearly three quarters (23/32) respondents had cared for a relative who had been admitted as an inpatient, 44% (16/23) of carers had experienced their relative being admitted to a hospital that was out of area.

78% of respondents had experience of care from the community mental health teams.

A full overview of the demographic profile for the entire survey respondents’ appendix v.

5.7 Results

Both of the surveys have had responses from patients and their carers who have had direct experience of managing the complexity of eating disorders alongside other co-existing mental health conditions as well as experience of secondary and tertiary care.

The respondents of survey and the participants in the focus groups are not a representative sample of the population that have experience of eating disorders so therefore there are limitations that need to be taken into account when analysing and reporting on the information provided from these sources.

It is important to reiterate the purpose of the survey and the focus groups, which was to elicit the views and experiences of those who have had contact with services in order to explore and highlight the aspects of care that contribute to providing specialised eating disorder services that prevent admission to hospital, facilitate recovery within the community, and when unavoidable hospital admission is required that this period of admission is for as short as possible.

This section presents the perceptions and opinions of patients and carers/relatives on the services in the North East and Cumbria.
5.71 Thematic analysis
The following section provides an overview of the discussions from the focus groups and the survey responses. The results from the survey and focus groups have been themed into what has worked and which aspects of care have helped at each level of care, which are:

- Primary care and community mental health services
- Assessment
- Inpatient
- Intensive day care

The responses have been categorised into the following themes:

- Therapeutic
- Service Structures, Environment and Processes
- Staffing, Knowledge, Skills and Approach

5.8 Summary and key points
Below is a summary of the key themes that emerged from the focus groups and survey. This is followed by a more in-depth presentation of these themes and how these are expressed at the different levels of service provision.

Relatives and carers reported that it feels as though services are only available when the individual is dangerously ill and can no longer cope and that there is a ‘spiral’ of either going up into services or down out of services and nothing else.

Patients and relatives/carers all expressed that once an admission to hospital had been facilitated there was a feeling of not having to hold the responsibility for the eating disorder anymore, this was described as a huge relief, a sense of being absolved of all responsibility and finally being looked after, taken care of and not being at fault. There was a very real sense of finally feeling safe.

Therapeutic

- Patients and carers thought that there is a need for therapeutic processes that do not just focus on weight but acknowledge the underlying causes and addresses other mental health conditions
- Therapy that facilitates discharge i.e. develops independent living and social skills
- Access to individual and group based therapy in the community and not just through specialised services
- Closed therapeutic groups in the day service prevent newly admitted patients from participating
- There is a need for intensive training packages for carers so that they can be educated on eating disorders and be skilled up participate in recovery plans
Service Structures, Environment and Processes

- Quick access to assessment and diagnosis. Once an eating disorder has been detected there needs to be speedy access to specialised eating disorder services, rather than referral to community mental health teams where there can be long delays in receiving an assessment.
- The current referral criteria into specialised eating disorders has established a perverse incentive which is based upon having a low BMI.
- There is poor transition processes between the different levels of care.
- Being able to access services near to home is important.
- There was a perceived lack of trust in the ability of community mental health teams to effectively manage and treat eating disorders.
- Currently there is poor care coordination and communication between inpatients and day services and between specialised eating disorder services and community mental health teams.
- There is a lack of continuity of care when discharged to community mental health teams.
- There is a need for quick and easy access back into specialised services after discharge.
- Support group for carers that are not just open to current patients/service users.

Staffing, Knowledge, Skills and Approaches

- Staff that are able to challenge and work collaboratively with the patient.
- Staff that are trained and knowledgeable in detecting, treating and monitoring eating disorders.

5.9 Accessing help early and preventing an admission to hospital

Initial Contact with GP/Primary Care and Community Mental Health Services

The GP or university counselling services were generally the first point of contact, followed by a referral into community mental health teams or CAMHS.

There was mixed experience of the care provided by GPs, with some reporting that the GP was very understanding and tried to access support, whilst others reported that the GP was not helpful and either dismissed the urgency of the situation or said unhelpful things which exacerbated the situation.

The importance of accessing an eating disorder expert or specialised early was expressed. There was a perception that community mental health teams and GP/primary care did not have the skills and knowledge to treat eating disorders and this often meant that the initial focus for treatment was solely on food intake and food diaries rather than addressing the underlying causes.

However respondents also highlighted that they had experienced high levels of confusion as a result of their anorexia nervosa deteriorating. Participants reflected that they were aware that their behaviours and that their relationship with food was
altered, this state of confusion was described as resulting in a real lack of being able to fully understand what was going on in terms of interactions with healthcare professionals. This confused state was highlighted as a real barrier to accessing psychological interventions. This lack of engagement increased the tension between the individual and their parents/family and health care professionals. This tension then raised the levels of anxiety in the individual, which contributed to the reliance on the known coping mechanism i.e. the anorexia nervosa.

A number of participants also discussed that they were in denial and did not share the concerns for their physical and mental health that had been expressed by their family and health professionals.

The above points pose a real challenge to the implementation of early interventions as in order to engage in psychological interventions such as CBT and DBT, the individual is required to have a level of awareness to psychologically engage.

**What worked in accessing help early and preventing an admission to hospital?**

**Therapeutic**
- Intensive home support and specialised therapy in the community
- Group work and group therapy
- Treatment of other mental health conditions such as depression and anxiety.

**Service Structures and Processes**
- Quick access to assessment and a diagnosis
- New referral process, so that someone already known to services can be assessed by the Eating Disorder community team without having to go back to GP
- Access to specialised eating disorder services
- Good care coordination with regular meetings and consistent monitoring or bloods and weight. Maintaining a stable BMI
- Contact with social worker and provision of family support

**Staffing, Knowledge, Skills and Approach**
- Caring and empathetic approach
- Staff who are trained and knowledgeable regarding eating disorders

**Issues reported**

**Therapeutic**
- The psychological input was too late
- A focus on self-help and food dairies was not useful and when these approaches failed the individual feeling at fault for this failure

**Service Structures and Processes**
- Delays in receiving an assessment or long waits (over six months) before accessing an assessment
- The long waits resulted in emergency admissions to medical wards
- Poor communication between services and a lack of communication with patients and carers/relatives.
- Inconsistent care provided by community mental health teams
- Transition from CAMHS to Adult services was difficult
- Those aged 17 years at diagnosis having to wait until they were 18 years old in order to receive treatment
- Being discharged from services too soon

**Staffing, Knowledge, Skills and Approach**
- Staff apologising for not knowing about eating disorders
- Staff providing poor or harmful advice
- Staff not detecting that there is an emerging eating disorder

### 5.10 The Assessment Process
Participants in the focus group and responses from the surveys highlight a perceived perverse incentive i.e. that the access to inpatient care requires the individual to have a BMI of <15. A number of individuals discussed a notion of being ‘sick enough’ to warrant a bed. In order to meet the admission threshold required the patient to lose more weight. This was predominant theme throughout the focus groups and in the survey responses. The context in which this was cited was when individuals had had contact with their GP or with the community mental health team and being informed that they did not meet the admission criteria by the health professional. Many discussed how harmful this message was.

This message of not being ‘sick enough’ and not having a low BMI (<15) further perpetuated the following messages:
1. That the individual was fat as their BMI was too high
2. That the individual was a failed or unsuccessful anorexic and unable to achieve their ideal BMI
3. That they could still lose weight and not be ill enough to require hospital admission
4. That there was nothing wrong with them and parents/GP were making a fuss about nothing.

All of these messages resulted in a further weight loss, which in turn for most facilitated admission to eating disorder inpatient care or admission to a medical ward.

Likewise, being given a number for their category of urgency (1,2,3,) indicated how long the individual was going to have to wait for admission to specialised care. There was perception of being given a grade. A number of individuals talked about how there was the potential for the competitive and anorexic self to need to achieve a higher category of urgency, and in order to do this meant further food restriction and/or purging.
The above issues represents a very real challenge to services as currently there is an admission criteria that directly relates to BMI. However it is important to acknowledge that BMI is not the only indicator of requiring an admission.

5.11 The aspects of hospital based inpatient care that supports recovery

Patients and relatives/carers all expressed that once an admission to hospital had been facilitated there was a feeling of not having to hold the responsibility for the eating disorder anymore, this was described as a huge relief, a sense of being absolved of all responsibility and finally being looked after, taken care of and not being at fault. There was a very real sense of finally feeling safe.

This sense of relief was not described in the same intensity when talking about experiences of day services or community based provision.

**Therapeutic**

- Having a care plan that is tailored to the individual and that addresses more than just the weight and BMI.
- A range of therapy including group therapy
- Preparation for discharge that includes developing independent living skills and building on social skills and maintaining relationships

**Service Structures, Environment and Processes**

- Access to staff 24hrs
- Good communication – knowing where you are and what is being planned
- A care plan that addresses the other mental health issues like anxiety and depression.
- Maintaining regular contact with Community mental health services (CPN or Social Worker) whilst still in hospital
- Being in a hospital close to home
- A homely environment
- Support for the carer/family and actively preparing for discharge

**Staffing, Knowledge, Skills and Approach**

- Being challenged to engage
- A team and collaborative approach (working together on your eating disorder)
- Acknowledgement that the treatment may take a long-time and that there may be further hospital admissions in the future; this helped to alleviate a sense of failure.

**Issues reported:**

**Therapeutic**

- Too much focus on weight gain and too quickly
- Therapy sessions and group work being cancelled
• Being too ill in the inpatient service and not being able to engage in psychological therapy

Service Structures, Environment and Processes
• Being placed out of area resulted in missing family and pushing to be discharged too soon, resulting in readmission.
• Large units with too many people
• Discharged too soon and a feeling of the safety net being pulled and not fully prepared to deal with the anorexia nervosa back in the community.
• BMI too low on discharge
• Discharge plan of care not being followed up in the day service
• Real issues with the word DISCHARGED, this being interpreted as either being well and therefore not needing to access any other services or as being fat and needing to try harder at the anorexia/purging.
• A lack of communication and not knowing what is happening or being planned
• Parents/carers expected to maintain recovery with no or very little support e.g. dietary plans.
• No contact with CMHT/community services

Staffing, Knowledge, skills and approach
• Under staffed and a reliance on inexperienced bank nurses meant that patients could ‘run rings round them’

It is relevant to note that there were a number of comments on the competitive tendering process that occurred in 2010 which resulted in the tender being awarded to TEWV. There were responses from both patients and carers and from the focus groups and the surveys.

A number of respondents made comments on this decision and how it had impacted upon the services provided by NTW.

5.12 Intensive day care services
The intensive day service was highlighted by patients and service users in the focus groups and via the survey responses as a really useful package of care that was accessed as an alternative to hospital admission thus preventing hospitalisation and as a step-down from being an inpatient aiding in skilling up the individual in the long-term recovery and management of their anorexia. It was noted though that in order to fully engage in the day service the individual needed to be motivated.

Carers and relatives on the other hand expressed a level of anxiety and a lack of confidence in the function of the day service. Some of this anxiety was due to the Newcastle service being very new and no longer located on the RVI site and being relocated to Walkergate Hospital. Other expressions of concern included experience of increased compensatory behaviour at home in the evenings and at weekend with a sense that the relative/carer is unprepared, or not supported in enabling the recovery of their family member and that the communication that relatives and carers
had with professionals in the inpatient service is not replicated when discharged to the day service.

The aspects of intensive day care that support recovery

Therapeutic
- Personalised care from a holistic and multi-disciplinary team approach, which looks at all aspects of your life.
- It’s not just about putting weight on but enables the individual to cope with the anorexia in the real world
- Works best when in good place and when motivated
- Being motivated to change and able to work with the care plan
- A gradual programme which encourages social eating whilst allowing the patient to maintain control over how this happens
- A care plan that meets the needs of the individual
- Peer support
- Maintaining access to therapist (post discharge)

Service Structures, Environment and Processes
- A homely environment not too clinical where you can bring in your own stuff to make it feel more homely
- That it is not in a hospital, you are not walking into a hospital everyday
- Works best as a step up (has been the one thing that has stopped from being hospitalised)
- Flexible and easy access back into the service when needed
- Support after leaving the day service (good care coordination)
- Free travel
- Being local and easy to get to
- Flexibility to attend different sessions and a sense of you doing things for yourself

Staffing, Knowledge, Skills and Approach
- Recognition that anorexia nervosa is part of a bigger picture (other mental health issues) and now that these have been addressed the eating disorder has been addressed and there has been a change in eating behaviour
- Really good at noticing when start to become unwell and prevents this from becoming worse

Issues:
Therapeutic
- Discharge for patient from the day service can be perceived as ‘recovered’ or ‘fat’ or as now ‘well’ when the reality is there is still much work to be done towards recovery.
- Closed therapeutic groups which means if you have been admitted after the start of a group you sit around with nothing to do
• Groups and sessions being cancelled at short notice
• Being left to do everything and feeling overwhelmed

Service Structures, Environment and Processes
• One size fits all a lack of tailored treatment
• Being around people that are too ill for the day service and are not motivated, or are sabotaging the progress of others.
• BMI colour categorisation on reports meant that patients compete over colour categories and intentionally lose weight.
• Having to go to the day service as a means of accessing the other specialised support i.e. dietician and therapy, perceiving the day service as a waste of a day.
• Every day is the same and is just structured around meals and snacks
• Little structure, not knowing what’s happening and this impacting upon anxiety
• What happens at weekend and evenings (compensatory behaviour)
• There needs to be better planning for transition to community services/back to GP
• Taxis not arriving to collect or being very late.

Staffing, Knowledge, Skills and Approach
• Better communication and care planning
• Staff not being around

5.13 Experience of Community Mental Health Services
In the carers and relative support groups there was an issue of access to skilled staff who have expertise in eating disorders, this was raised on a number of occasions and was of particular concern during in the early stages and development of anorexia nervosa and after discharge from specialised services.

There was a lack of confidence in community mental health teams to manage patients with eating disorders the following explanations were given by relatives/carers:

Service Structures, Environment and Processes
• Relatives and carers had an expectation that a referral to the community mental health services or CAMHS would mean they would have access to specialised help and this was not the case.
• Lack of work with the parents and the patient together
• Dealing with a number of different CPNs in quite short periods of time or not being notified when named key workers are no longer working within the community mental health services.

Staffing, Knowledge, Skills and Approach
• Generic mental health staff are not skilled in working with eating disorders
• Staff giving wrong information/dangerous information to patients which results in a deterioration in weight and thus admission to hospital
• High staff turnover so did not see the same person and did not have the opportunity to develop a relationship

Although a number of these themes were echoed by the patients/service users. Carers and relatives were more concerned with the following:

Therapeutic
• On discharge there is an expectation that in the community service that you can do it on your own and you may need some extra therapeutic support

Service Structures, Environment and Processes
• A lack of contact with community mental health services whilst in specialised services
• Not following up care plans or diet/meal plans
• Not knowing who your care coordinator is (lack of a named person)

Staffing, Knowledge, Skills and Approach
• Staff apologising for not being specialists in eating disorders
• Poor communication between specialised services and community resulting in poor care

There were positive experiences of the community services from both patients and relatives/carers:

Therapeutic
• The remit of the community service to focus on the other mental health issues such as anxiety, depression meant that the underlying causes were addressed. Relatives and patients reported that when this was done right, then on going recovery and long-term management improved.

Service Structures, Environment and Processes
• Continuity of relationship (maintaining weekly contact whilst in specialised services)
• Having the same worker to monitor (on a weekly basis) this builds up the relationship and ensures that if someone is deteriorating it is picked up quickly

5.14 What needs to be in place to prevent readmission to hospital
Patients and service users described how at a subconscious level they were aware that there is a direct relationship between losing weight and receiving support. Therefore there does need to be some mechanism for continued support that provides monitoring of weight and identifying at an early stage when weight is beginning to be lost and addressing this quicker.
Relatives and carers reported that it feels as though services are only available when the individual is dangerously ill and can no longer cope and that there is a ‘spiral’ of either going up into services or down out of services and nothing else.

A number of patients and carer/relatives highlight that this continued support, needs to be provided by eating disorder specialists rather than in generic community mental health services. Whereas others highlight that this on-going support can be provided in the community in services like NIWE and the community mental health teams.

The key components of care that need to be in place include:

**Therapeutic**
- More group support (October 2015 there is a 7 month waiting list for NIWE)
- Quick access to psychological therapies
- Support groups for carers/relatives that are open to all and not just cares/relatives of those that are currently in specialised eating disorder services
- Intensive training programmes for carers/relatives to provide coping mechanisms, education on eating disorders and an overview of what to expect and the reality of what recovery looks like.

**Service Structures, Environment and Processes**
- Quick and easy access back into specialised services when needed
- Consistency and regular contact with the same worker
- Services that are available out of normal office hours
- Services are local and easy to access
- More beds locally to prevent out of area admissions.

**Staffing, Knowledge, Skills and Approach**
- Staff who are confident and knowledgeable in working with eating disorders

The data from the surveys and the focus groups is incredibly rich and highlights a number of issues regarding the provision of eating disorder services. These primarily relate to the care pathway and the provision of high quality and accessible therapeutic interventions.
6: Provision of Specialised Eating Disorders in the North East and Cumbria
The purpose of this chapter is to describe the local specialised eating disorder service configuration in the North East and Cumbria. Compare how services are structured in the North East and Cumbria to the national service specification and NICE clinical guidance (2004) and the Royal College of Psychiatry National Review of Eating Disorder Service Provision (2012).

6.1 Methodology
The commissioned service providers were requested to provide a range of documents such as copies of standard operational procedures, CQC inspections etc. A full copy of the documents requested and provided is appendix vi.

Interviews were conducted with the managers of the intensive day services and the inpatient services. All commissioned services were visited and discussions were had with staff.

The aim of the visits and interviews were:
1. To understand how the services were delivered
2. To capture the range of intervention offered
3. To map out the staffing structures and the range of professionals employed within the services.

Table 7: Overview of specialised eating disorder services within a stepped care model for the North East and Cumbria

<table>
<thead>
<tr>
<th>Stepped Care</th>
<th>Eating Disorder Service Provision - Adults</th>
<th>Treatment and Interventions</th>
<th>Referral Method</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 5</td>
<td>Regional inpatient Care: Specialised Eating Disorder Services 20 beds</td>
<td>Defined by NHS National service specification (inpatient services)</td>
<td>Referral from Secondary Mental Health or CAMHS</td>
<td>NTW TEWV</td>
</tr>
<tr>
<td></td>
<td>Intensive Day Services: Specialised Eating Disorder Services 15 places per session</td>
<td>Defined by NHS National service specification (outpatient services)</td>
<td>Referral from Secondary Mental Health or CAMHS</td>
<td>NTW TEWV</td>
</tr>
<tr>
<td>Step 4</td>
<td>Community mental health teams Community eating disorder team Outpatient management of eating disorders Anorexia Nervosa Intensive Community Service</td>
<td>Psychological and pharmacological interventions Access to MDT</td>
<td>GP Referral</td>
<td>NTW TEWV Cumbria Partnership</td>
</tr>
<tr>
<td>Step 3</td>
<td>High intensity therapeutic interventions for eating disorders</td>
<td>CBT: mild to moderate eating disorders</td>
<td>Self-Referral</td>
<td>IAPT</td>
</tr>
<tr>
<td>Step 2</td>
<td>Low intensity therapeutic interventions for eating disorders</td>
<td>Computerised CBT Guided self help Support groups Counselling</td>
<td>Self-Referral</td>
<td>IAPT NIWE</td>
</tr>
<tr>
<td>Step 1</td>
<td>Primacy Care</td>
<td>Support groups and access to primary mental health worker</td>
<td>Self-Referral</td>
<td>GP</td>
</tr>
</tbody>
</table>
6.2 Service Structures and Staffing Composition

The Royal College of Psychiatrists recommend that the broad composition of a specialised eating disorders service for a population of 1 million people should be 1.2 WTE (Whole Time Equivalent) consultant psychiatrists, 2.4 WTE senior and junior psychiatric trainees, 5.4 WTE psychological therapists, 28.8 WTE nurses, 1.2 WTE dieticians, 3.6 WTE occupational and creative therapists, 4.2 WTE administrators and 0.6 WTE house-keepers. (RCPsych 2012)

At a population level the Royal College of Psychiatrists recommends that there should be 6 eating disorder beds per million population aged over 16 years (this level may be reduced in conjunction with the provision of intensive day care services). There should also be two or three local outpatient clinics. The cost of providing this per million population is £1m (£1 per person over 16 years old in a population). This cost should be regarded as a minimum expenditure (RCPsych 2000).

The Royal College of Psychiatrists provide in detail the staffing composition and costs, the evidence base that underpins these assumptions is not clear. Likewise the recommended 6 beds per million and the reduction of this allocation in conjunction with the provision of intensive day services is has not been defined in exact numbers of intensive day care places and how many beds this replaces.

The cost of £1 per person was published in 2000, the worth of this £1 in 2000 is estimated to represent £1.38 in 2014 this is using a historical opportunity cost model (Officer and Williams 2014).

The size of the population aged over 16 years in the North East and Cumbria is 2,571,021 (2014 Mid-Year Population estimates) (ONS 2015). The minimum expenditure as outlined by the Royal College of Psychiatrists for the North East and Cumbria based upon 2014 costing is £3.5m. The Actual budget for the provision of adult inpatient and outpatient care in 2013 was £4m.

The table below outlines the recommended staffing levels applied to the North East and Cumbria. When comparing the recommended staffing levels and actual levels there is lower levels for all staffing components with the exception of consultant psychiatrists and dieticians, which were both within the expected staffing levels. A full breakdown for each of the services providers and staffing structures is appendix vii.
Table 8: Comparison of recommended staffing levels and actual staffing levels 2015

<table>
<thead>
<tr>
<th>Recommended Service Compositions (per million population)</th>
<th>Applied to North East and Cumbria Population</th>
<th>Actual for the North East and Cumbria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.2 WTE consultant psychiatrists</td>
<td>3 WTE consultant psychiatrists</td>
<td>3.2 WTE consultant psychiatrists</td>
</tr>
<tr>
<td>2.4 WTE senior/junior psychiatric trainees</td>
<td>6.2 WTE senior/junior psychiatric trainees</td>
<td>2 WTE senior/junior psychiatric trainees</td>
</tr>
<tr>
<td>5.4 WTE psychological therapists</td>
<td>14 WTE psychological therapists</td>
<td>7.2 WTE psychological therapists</td>
</tr>
<tr>
<td>28.8 WTE nurses</td>
<td>75 WTE nurses</td>
<td>57.7 WTE nurses</td>
</tr>
<tr>
<td>1.2 WTE dieticians</td>
<td>3 WTE dieticians</td>
<td>3 WTE dieticians</td>
</tr>
<tr>
<td>3.6 WTE occupational and creative therapists</td>
<td>9 WTE occupational and creative therapists</td>
<td>6.8 WTE occupational and creative therapists</td>
</tr>
<tr>
<td>4.2 WTE administrators</td>
<td>11 WTE administrators</td>
<td>8 WTE administrators</td>
</tr>
<tr>
<td>0.6 WTE house-keepers</td>
<td>1.6 WTE house-keepers</td>
<td>0.2 WTE Gastroenterologist</td>
</tr>
<tr>
<td>Other posts:</td>
<td></td>
<td>1 WTE Psychology assistant</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 WTE Physiotherapist</td>
</tr>
</tbody>
</table>

The budget for adult specialised eating disorder services for the population of the North East and Cumbria is in excess of the recommended minimum; however the staffing components across most of the levels is below the expected numbers.

There are a total of 20 adult inpatient beds commissioned alongside two intensive day care services located in the South and the North of the region. The Royal College of Psychiatrists recommend 6 beds per million population. It is also recommended that less beds are required if there is access to intensive day care services. Based upon this recommendation 15 beds would meet the needs of the population. At present 5 extra beds are available as well as the intensive day care provision.

The Royal College of Psychiatrists survey does not report on how many adult eating disorder services meet the above staffing level, it is highlighted only a minority of services met all four criteria (number not reported) for a specialised service:

1. Seeing > 25 new referrals per annum
2. Multidisciplinary staff teams
3. Provision of out-patient and in-patient treatment
4. Availability of both individual and family interventions

In terms of service configuration the services provided by NTW and TEWV meet the above criteria. The number of new referrals per year has not been ascertained as the data sets did not identify new or existing referrals.
6.3 Interventions provided by Specialised Eating Disorder Services in the North East and Cumbria

There is clear and consistent guidance on the types of interventions that a specialised eating disorder service needs to provide. This guidance is outlined in the following documents:

- NHS England National Service Specification – Eating Disorders
- NICE Clinical Guidance: Eating Disorders core interventions in the treatments and management of anorexia nervosa, bulimia nervosa and related eating disorders.
- Joint Commissioning Panel for Mental Health: Guidance for commissioners of eating disorder services.

The commissioned service provision in the North East and Cumbria meets the above specifications. An overview of the key aspects of service delivery is detailed in appendix viii.

6.4 Staff perspectives on Specialised Eating Disorder Services

Perspectives from staff were gained during the site visits, discussions in team meetings and from the interviews with managers. There were a number of issues identified that potentially impact upon services.

6.41 Patient Cohort

The patient profile was changing with an increase of younger people entering into services at an earlier age alongside an increase in older people who were managing their eating disorder in the community; however still required readmission.

There were higher levels of complexity in the cohort utilising specialised services including; trauma, PTSD (Post Traumatic Stress Disorder) as well as depression, OCD (Obsessive Compulsive Disorder), anxiety and personality disorders.

There is a need to ensure that the model of care is recovery focussed and not solely facilitating harm reduction and maintenance. Regardless of the number of times that a patient has been admitted there is still the possibility that recovery can be achieved.

For the patients that have early onset of eating disorders there needs to be the ability to treat this group with assertive and intensive outreach.

6.42 Carers/Relatives

It was acknowledged that there were tensions in managing the expectations of carers and relatives and the clinical needs of the patients. These tensions were especially heightened when discharge from inpatient care into day services or community mental health provision was being planned.
6.43 Service Structure
A number of staff expressed a view that there should not be time limitations placed upon treatment regimes.

There needs to be an outpatient option, whether this is provided in tertiary care or within secondary care, this team needs to be a multi-disciplinary team that has the ability to work at a specialised level. The team needs to comprise of psychological therapists, dieticians and be recovery focussed as well as providing a monitoring role.

In terms of the intensive day service there were a number of concerns. It was felt that day service was better suited as a step down from inpatient care rather than as a step up from community mental health services. Central to this concern was the fear that the day service would be holding high-risk patients that were not motivated enough to fully engage and that this group of patients then had a detrimental impact upon those patients that were motivated.

6.5 Service Comparison – Leicester Eating Disorder Services
In conjunction with the HCNA a visit was made to the regional eating disorder service in Leicester. It is important to note that the service configuration in Leicester is useful as a comparative and alternative model, rather than a definitive model of care that North East and Cumbria need to replicate.

The service structure in Leicester eating disorder services covers a wider geographical area (geographically smaller that the North East) and serves a higher population. This population is more concentrated than the North East and Cumbria. The Leicester regional eating disorder service is a maximum one-hour travel from any of the counties served by the service.

There is an inpatient unit and intensive day service. The inpatient unit has fewer beds (16) than the North East and Cumbria; these beds are rarely fully occupied.

Sitting beneath the inpatient and intensive day care is an outpatient service, which is delivered centrally from the main hospital site. The majority of patients are managed within the outpatient service. The outpatient service has a multi-disciplinary team.

Leicester eating disorder service covers five counties. Within each of these counties there is a community eating disorder team that provides psychological therapies, dietary and nutritional interventions as well as support for carers/relatives.

The key differences between the North East/Cumbria and Leicester is the lower number of beds used and the support and management of patients within the community. The day service has been adapted to meet the different needs of those stepping down from inpatient care and those stepping up from the community services.
7: Overview of use of Adult Eating Disorder Services in the North East and Cumbria

7.1 Introduction
The purpose of this section is to provide a retrospective snapshot of service utilisation and to describe the cohort accessing specialised eating disorder services for adults aged 18 years and over.

The service utilisation descriptors used to provide an overview of usage include:
- Number of individual patients accessing inpatient and outpatient services
- Number of contacts with outpatient services
- Emergency or planned admission
- Number and proportion of episodes of completed care within inpatient services
- Number and proportion of episodes with no discharge
- Length of stay
- Number and proportion of bed days used within expected commissioned packages of care (<126 days)
- Geographical variation in service usage across the North East and Cumbria

The descriptors of interest used to define the cohort accessing specialised adult eating disorders include:
- Age
- Gender
- Ethnicity
- Socio-economic status
- CCG of residence
- Secondary diagnosis and comorbidities
- BMI on admission and discharge
- Legal status
- Admission history (previous admission or first admission)

In order to inform future planning and resourcing of eating disorder services in the North East and Cumbria the expected prevalence and incidence of anorexia nervosa was calculated.

7.2 Data Sets
Three data sets were used to analyse service utilisation and to define the characteristics of the cohort accessing services. All data sets provided pseudonymised data; this meant that for each data set an individual patient was provided a unique identifiable number. This enabled the analysis of service utilisation at a patient level, rather than solely from an episode of care perspective i.e. a patient journey through inpatient and outpatient services was mapped for each patient. There was no patient identifiable information in any of the data sets provided.

An overview of the data set used and the methodology for each of the tables and charts is provided as an appendix (Appendix ix).
1. Hospital Episode Statistics for completed episodes of care for residents of the North East and Cumbria with a primary or secondary diagnosis of anorexia nervosa (F500) or atypical anorexia nervosa (F501) for the period 2011-2015. A bespoke data request was designed and submitted to Public Health England Knowledge and Intelligence team (appendix x).

2. Contract management data for all patients utilising NHS England commissioned specialised eating disorder services in the North East and Cumbria 2013-2015. The contract management data set consisted of information routinely submitted by the two providers in order to process payment for the commissioned services for both the adult and children and young peoples commissioned services.

3. The commissioned providers; Tees Esk and Wear Valley NHS Foundation Trust (TEWV) and Northumberland Tyne and Wear NHS Foundation Trust (NTW) supplied data on all patients accessing inpatient and outpatient provision. The data set included clinical presentation and previous eating disorder service usage (2012 – 2015). A bespoke data request was submitted to both providers and included data available from existing case management systems (PARIS and RIO) and data extraction from clinical notes (appendix xi).

7.3 Data Limitations
This section briefly outlines the key limitations to the data sets and how these limitations impact upon the interpretation of the results.

7.31 Hospital Episode Statistic (HES) data:
This data set only refers to completed hospital admissions for the two providers of specialised eating disorder services in the North East and Cumbria. The HES data set does not include any lengths of stay that are continuous for the period 1\textsuperscript{st} April 2011 to 31\textsuperscript{st} March 2015.

The data set did not include any data from NTW for the financial years 2011-2012 and 2014-2015 therefore the results from this data set will be an under-representation of actual service usage.

HES data reports on all ages.

The data provided for outpatient episodes was incomplete and not robust enough for statistical analysis.

There are a number of widely recognised limitations to HES data, this includes coding inconsistencies as information is collected directly from NHS organisations.
and the definition of speciality codes is not consistent between trusts. HES data does not include any information on case mix or the complexity of the patient population accessing services. Episode level data is not a measure of patient admission rates and, finally Information relating to mental health is often not as complete as other elements of HES data.

7.32 Contact management data:

This data set provided a two-year snapshot of service usage for the period 1st April 2013 – 31st March 2015 and this included patients that had been admitted prior to 1st April and those still admitted on 31st March 2015.

The inclusion of an admission and discharge date enabled a bed day usage to be calculated for each patient that had been admitted prior to the 1st April 2013.

Data for the periods January – March 2014 and December 2014 – March – 2015 were missing for TEWV and there was no data provided for March 2015 from NTW for inpatient services. Data from CAHMS and outpatient appeared to be complete.

The data sets did provide admission and discharge dates. In order to create a complete data set for the missing periods the data set supplied by both providers were searched for matching admission dates that were prior to the missing periods and matching discharge dates, this enabled a calculation to be made for the missing bed days. Dates could not be matched for 2/68 patients.

The contact management data did not contain any information relating to demographical descriptors, other than the CCG of residence and an age indicator that identified which service (adult or CAMHS) the patient was accessing.

The data set included individuals that were accessing NHS England commissioned services from outside the North East and Cumbria area. These individuals were not included in the analysis.

The outpatient data reflects a period when both providers (NTW and TEWV) were offering different models and care packages and therefore are not comparable. The quality and robustness of the data provided for outpatients is unknown.

7.33 Provider data set:

The data set provided by NTW and TEWV was pseudonymised patient level information which contained the following for adult (>16 years) inpatient and intensive day care.

- Patient demographics (age, gender, ethnicity)
- Clinical information (BMI on admission and discharge, legal status and diagnosis – including existing co-morbidities)
- Utilisation for 2012 - 2015 (admission and discharge date)
Data was requested for the following fields but were not supplied by either or both NTW and TEWV.

- Patient information for the period 2010 – 2015
- CCG area of residence
- Clinical outcome measures (EDQ6)
- Destination at discharge
- Previous admissions to inpatient care
- Referral route into inpatient care

The data set required some cleaning prior to analysis. This involved the following:

- NTW did not provide a unique pseudonymised number for each patient. The same patient had a different pseudonymised number for each financial year. These duplicates were removed, so the data set provided an overview of service usage based upon the number of individual patients rather than episodes of care.
- Calculating length of stay for each patient was done by using admission and discharge dates
- TEWV provided ICD-10 codes for diagnosis and NTW provided descriptive free text box for this field. The ICD-10 codes for other co-morbidities were grouped at a high level e.g. F42 (F42.0 – F42.9) categorised as OCD.
- The ICD-10 codes of interest were F00 – F99 (Mental and behavioural disorders) and Z00-Z99 (Factors influencing health status and contact with health services).

The provider data set provides very rich data on the patient population that accessed inpatient and day care services 2012-2013. There are limitations to this data set in that the analysis will include patients from outside the North East and Cumbria area.

7.4 Describing the cohort of patients that access specialised eating disorder services in the North East and Cumbria

This section provides an overview of the patient cohort that has used specialised inpatient and day care in the North East. The data used in this section is HES data and service provider data.

It is important to highlight that the HES data captures all finished admission episodes (FAEs) for patient’s resident in the North East and Cumbria with a primary or secondary diagnosis for anorexia nervosa or atypical anorexia nervosa, whereas the service provider data includes incomplete episodes of care.
7.41 Type of eating disorder and hospital admission

The table below presents the primary diagnosis for a hospital admission for the two data sets.

Table 9: Primary diagnosis for a hospital admission in the North East and Cumbria

<table>
<thead>
<tr>
<th>Data Set</th>
<th>Anorexia Nervosa</th>
<th>Atypical Anorexia Nervosa</th>
<th>Bulimia Nervosa</th>
<th>Other</th>
<th>EDNOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>HES</td>
<td>85%</td>
<td>6%</td>
<td>4%</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>Service Provider</td>
<td>91%</td>
<td>4%</td>
<td>1%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

The majority of patients are admitted to hospital with anorexia nervosa or atypical anorexia nervosa.

7.42 Age

Half of the patients using specialised inpatients services (50%) are aged 17 – 24 years old; this is based upon the data from the service providers as it includes completed and non-completed episodes of care.

![Figure 4: Age distribution patients accessing specialised eating disorder services in the North East and Cumbria 2012-2015](image)

7.43 Gender

In terms of gender 6% (8/145) are male and 94% are female (137/145). This is based upon the service provider data set.

HES data does give a slightly different breakdown in terms of gender 10% male and 90% women for the same age group. The HES data is within expected range for gender, the service provider data suggests that there are less men than expected within inpatient eating disorder units in the North East and Cumbria.

It is important to highlight that HES captures completed episodes and the service data set is for all patients. The time period is different (HES 2010 – 2015 and
service provider 2012 – 2015) and an increase or decrease in small numbers of men using eating disorder services will significantly impact upon the overall proportion.

7.44 Ethnicity
HES data and the data from service providers highlight that 93% of patients are White British or White other; these proportions reflect the ethnic profile of the North East and Cumbria (ONS CENSUS 2011).

![Figure 5: Ethnic profile inpatients 2010 - 2015](image)

7.45 Socio-economic status
The largest Quintile group is group one (least deprived group) with 24% of all FAEs falling within the least deprived quintile group with an IMD score ≤ 8.49.

![Figure 6: Quintiles of Social Economic Status for FAEs](image)
7.46 Co-morbidities

As previously highlighted the majority of people admitted to specialised eating disorder units have anorexia nervosa (91%) or atypical anorexia nervosa (4%). This section explores the range and number of other existing co-morbidities as identified in the service provider data set.

Most patients admitted to the specialised eating disorder inpatient units have more than one diagnosis. Only 30% (43/144) have a single diagnosis recorded on their records this diagnosis is either anorexia nervosa or atypical anorexia nervosa. This means that for 70% of the patient cohort there are other presenting mental health and physical conditions.

The graph below shows that in the patient cohort accessing services in the North East and Cumbria the largest diagnosis is for other diagnosis (this constitutes non mental health or behavioural diagnosis), followed by a diagnosis for depression and substance misuse.
The table below shows the total percentage of patients with a mental health or behavioural diagnosis or a diagnosis for factors influencing health status and contact with health services. This includes self-harm and non-compliance with medical treatment.

Table 10: Percentage of patients with comorbidities and other diagnosis

<table>
<thead>
<tr>
<th>Co-morbidity</th>
<th>% Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Diagnosis (non-mental health or behavioural diagnosis)</td>
<td>53%</td>
</tr>
<tr>
<td>Depression</td>
<td>25%</td>
</tr>
<tr>
<td>Substance Misuse</td>
<td>20%</td>
</tr>
<tr>
<td>Self-harm</td>
<td>13%</td>
</tr>
<tr>
<td>Non-compliance medical treatment</td>
<td>10%</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>8%</td>
</tr>
<tr>
<td>PTSD</td>
<td>5%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>4%</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>1%</td>
</tr>
<tr>
<td>OCD</td>
<td>1%</td>
</tr>
</tbody>
</table>

The majority 53% of patients have a diagnosis for a medical or physical condition. There are very low numbers of patients recorded with OCD and co-existing bulimia.
nervosa (1%), likewise there are low numbers with anxiety and other mental health conditions that are commonly associated with eating disorders.

Co-morbidity is not a robust indicator of complexity and an individual can have a severe and complex eating disorder without other mental health conditions.

7.47 Legal Status
Most patients admitted into specialised inpatient eating disorder services do so on a voluntary basis (84%), with 16% being detained under the Mental Health Act.

Table 11: Legal status recorded on inpatient records

<table>
<thead>
<tr>
<th>Legal Status – Recorded on Patient Records</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal</td>
<td>84%</td>
</tr>
<tr>
<td>Formally detained under Mental Health Act Section 2</td>
<td>1%</td>
</tr>
<tr>
<td>Formally detained under Mental Health Act Section 3</td>
<td>15%</td>
</tr>
</tbody>
</table>

7.48 BMI
This section presents BMI on admission and discharge and the difference between these two measures.

The graph above shows that 7% (10/136) of patients that are admitted at a very low BMI (<12) and 15% (20/136) patients admitted above BMI 15. The majority 78% are admitted with a BMI between 12 and 15.

BMI on discharge shows that 34% of patients have a BMI below 15 on discharge and in total 79% of patients are discharged with a BMI <17.
The graph below shows that most patients experienced an increase in BMI ranging from 0.1 to 7.4. Five patients experienced a decrease in BMI between admission and discharge.

It is important to note that the BMI on admission is only a snapshot of two time points and does not provide any detail on increases and reduction in BMI at other time points in treatment, nor does it provide any insight into other comorbidities or complexity.

The scatter gram above plots the difference in BMI between admission and discharge against total length of stay. There is no linear relationship between the length of stay and BMI and for the patient cohort accessing inpatient care the length of stay does not have a significant impact upon increasing BMI on discharge.
7.49 Length of stay

The majority of patients exceeded the 18 weeks commissioned package of care 61% (42/107) of patients with completed admission and discharge date were inpatients for more than 126 days.

![Figure 12: Length of stay inpatient 2012 - 2015](image)

It is difficult to directly compare the length of stay in eating disorder inpatient units nationally. The graph below shows the percentage of patients being discharged from the two local inpatient units in comparison to the proportion of patients being discharged across England for a hospital admission for an eating disorder. In the North East and Cumbria 16% of patients admitted to NTW and 11% of patients admitted to TEWV were admitted for more than 6 months, whereas nationally 6% of admissions were for more than 6 months.

It is important to highlight that the national data set does include emergency admissions to acute medical wards and will therefore have a higher number of shorter stays.
The chart above identifies that 16 episodes of care exceeded 6 months which equates to 12% of all HES episodes recorded for NTW and TEWV specialised eating disorder units. The chart below presents the length of stay for each of these 16 patients of which 3/16 have a length of stay longer than 12 months.

In the North East and Cumbria there are a number of patients that have significantly long stays as inpatients. The HES data will only capture length of stay for those patients that have been discharged.
An analysis of the contract management data highlights that there are a number of patients without discharge who have been admitted as inpatients for more than 12 months. The length of stay for this group with no discharge includes stays of more than 4 years. This is a small group of patients; however the stays in excess of 12 months place a high level of demand on provision.

### 7.5 Service Utilisation

This section provides an overview of the local care pathway for specialised eating disorder services and the number of patients accessing the different levels of provision for a two year period (2013-2015).

The proportion of patients accessing the different levels of specialised eating disorder services is presented in the chart below.

It is important to note that the different levels of care are not mutually exclusive and for those admitted as inpatients there is further use of outpatient and intensive day services.

This section also presents further analysis of the service usage data which compares the patient pathway and the numbers accessing the different levels of care in the North East and Cumbria to specialised eating disorder services in South London.
Table 12: Summary table - Service Utilisation

<table>
<thead>
<tr>
<th>Service Level</th>
<th>North East and Cumbria Residents 2013 – 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total number of individuals accessing services</td>
</tr>
<tr>
<td>Outpatient</td>
<td>430</td>
</tr>
<tr>
<td>Day Services</td>
<td>54</td>
</tr>
<tr>
<td>Inpatient (Adult)</td>
<td>68</td>
</tr>
<tr>
<td>Inpatient (CAMHS)</td>
<td>47</td>
</tr>
</tbody>
</table>
Patients accessing adult specialised eating disorder services 440 (100%)

Residents from North East and Cumbria accessing specialised eating disorder services 430 (98%)

- Seen on an outpatient basis 362 (84%)
- Admitted as an inpatient 68 (16%)

- Admitted to intensive day care 36 (8%)

Patients stepped down to intensive day care 18 (26%)

Out of area residents admitted to NE and Cumbria 10 (2%)

- Seen on an outpatient basis 5 (50%)
- Admitted as an inpatient 5 (50%)

Patients treated as an outpatient and inpatient 3 (75%)
Most patients referred into specialised eating disorder services were treated on an outpatient basis (84%) and 16% were admitted as inpatients within this two year period. There was a significant proportion (90%) of the inpatient population that were also seen on an outpatient basis.

Further analysis on this group of patients has identified that 75% (51) of patients over the two year period were simultaneously accessing outpatient care whilst being admitted as an inpatient.

It is difficult to assess whether the numbers of patients in contact with specialised eating disorder services is within an expected range. A study conducted in South London eating disorder services retrospectively tracked the patient journey through the various levels of care over a two year period (2002 – 2003). The population size covered by this service is 2.7 million (local population) and a further 3.8 million (tertiary care provision).

This service usage figures have been adapted to replicate the care pathway in the North East and Cumbria.

**7.52 Figure 17: Service Utilisation and Patient Pathway South London Eating Disorder Services (2002 -2003)**

(Waller et al 2009)

Comparing the patient flow in South London eating disorder units to services in the North East and Cumbria it would appear that there is less cross over between the different levels of care.
Particularly the numbers that received both an inpatient admission and treatment via the outpatient programme. In the North East and Cumbria a higher proportion of patients move between these two aspects of service provision whereas in South London there were a higher number of patients that were only treated on an outpatient basis without requiring an admission to inpatient care.

The other observation is that given the larger population size covered by South London (2 times larger than the population in the North East and Cumbria) proportionately the numbers accessing the South London services are lower. However, caution does need to be applied as the study conducted in South London covered a two year period 2002-2003 and services have changed significantly since this time, in particular the structure and delivery of intensive day services.
### 7.6 Geographical Variation and use of Inpatient services

Table 13: Overview of inpatient use and CCG of residence

<table>
<thead>
<tr>
<th>CCG Area of Residence</th>
<th>CCG Population size</th>
<th>Number of bed days used</th>
<th>Number of episodes</th>
<th>Number of re-admissions</th>
<th>Rate per 100,000 population of Accessing Inpatient</th>
<th>All bed days used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Total</td>
<td>&lt;126 days</td>
<td>&gt;126 days</td>
<td>&lt;126 days</td>
<td>&gt;126 days</td>
</tr>
<tr>
<td>South Tees</td>
<td>273,532</td>
<td>3,329</td>
<td>334</td>
<td>2,995</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Darlington</td>
<td>105,584</td>
<td>1,480</td>
<td>485</td>
<td>995</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Hartlepool and Stockton-On-Tees</td>
<td>283,912</td>
<td>1,325</td>
<td>507</td>
<td>818</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Northumberland</td>
<td>316,278</td>
<td>1,507</td>
<td>144</td>
<td>1,363</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Newcastle West</td>
<td>140,025</td>
<td>1,102</td>
<td>192</td>
<td>910</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>North Tyneside</td>
<td>201,206</td>
<td>699</td>
<td>43</td>
<td>656</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Durham Dales, Easington and Sedgefield</td>
<td>272,878</td>
<td>648</td>
<td>493</td>
<td>155</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>North Durham</td>
<td>240,116</td>
<td>1,107</td>
<td>85</td>
<td>1,022</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Newcastle North and East</td>
<td>139,067</td>
<td>721</td>
<td>199</td>
<td>522</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Gateshead</td>
<td>200,349</td>
<td>277</td>
<td>0</td>
<td>277</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>South Tyneside</td>
<td>148,164</td>
<td>170</td>
<td>170</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Sunderland</td>
<td>275,330</td>
<td>252</td>
<td>0</td>
<td>252</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Cumbria</td>
<td>505,902</td>
<td>203</td>
<td>203</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>310,2343</td>
<td>12,820</td>
<td>2,855</td>
<td>9,965</td>
<td>40</td>
<td>39</td>
</tr>
</tbody>
</table>

*Less than 5 patients
Table 13 provides an overview of service usage by CCG area of residence. There were 68 individual patients from CCGs in the North East and Cumbria accessing adult inpatient service 2013-2015. In total these 68 patients had 79 separate episodes of care of which 20 (26% were readmissions). These 11 readmissions were distributed amongst 8 patients. Within the two-year period 14% of admissions were readmissions.

There is variation in bed usage at a CCG level, with the greatest rate of usage at a population level for Darlington CCG at 1,440 (95% CI 1,368.1 – 1,513.8) bed days per 100,000 population followed by South Tees CCG at 1,212 (95% CI 1,171.4 – 1254.3) bed days per 100,000 population. Cumbria has the lowest bed use rate at 34 (95% CI 28.7 – 39.1).

Figure 18 presents the bed rate used per 100,000 population for all CCGs in the North East and highlights the variation in bed use between the CCGs.

**Figure 18: Rates of Adult Eating Disorder Specialised Beds used per 100,000 population (95% CI) 2013-2015**

Darlington CCG has the highest population rate accessing inpatient services at 6.63 per 100,000 population this is almost three times higher than the rate for the North East and Cumbria (2.19 per 100,000 population). Caution does need to be applied when comparing crude rates as differences in age structures of the population have not been accounted for, the prevalence of severe and enduring anorexia nervosa at a population level is relatively rare and therefore is disproportionately impacted by a small increase in numbers of patients.
Figure 19 presents the crude population rates per 100,000 for those accessing inpatient eating disorder services in the North East and Cumbria. This highlights that although there is variation in the crude rates for each CCG, this difference between rates is not statistically significant.

**Figure 19: Crude rates for population accessing inpatient eating disorder services North East and Cumbria 2013-2015**

Given the above geographical variation in overall bed usage by CCGs it is not surprising that there is a variation in the proportion of beds used that exceeds the 126 days of care package.
Cumbria, Sunderland, South Tyneside and Gateshead all have very low numbers of patients within inpatient eating disorder services, therefore these areas are more prone to reflect the extremes of these patients e.g. have one patient who was discharged prior to 126 days or have one patient who exceeded the 126 days of care threshold.

7.7 Out of Area Admissions
The available 20 beds provided by TEWV and NTW contribute to the total number of nationally commissioned eating disorder inpatient beds. This means that any individual can be placed in a NHS commissioned bed regardless of where in the country they reside. It is considered best practice to place an individual as near to their home as possible; however when a regional bed is not available an alternative NHS commissioned bed is sought.

An analysis of the contract management data has identified that over a two year period (2013 – 2015) there were 5 patients who were not residents of the North East and Cumbria admitted to either NTW or TEWV eating disorder inpatient units.

During the period January 2014 – July 2015 there were 27 patients from the North East and Cumbria that were placed in out of area beds. The majority (70%) were admitted to the Priory in Glasgow.

Cumbria residents used 7% of these out of area beds and residents of North East CCGs used 93% of the beds.
7.8 Readmissions

Figure 21: Proportion of repeat admissions to Commissioned Specialised Eating Disorder Services in the North East and Cumbria 2010-2015

An analysis of HES data has identified that over a five-year period 29% of the patient population accessing the specialised eating disorder inpatient unit required more than one admission.

7.9 Emergency and planned admissions

Figure 22: Admission method FAEs 2010 - 2015

The majority of admissions for FAEs were planned with only 17% of admissions to TEWV and NTW coded as emergency admissions.
7.10 Out-patient Utilisation

A large proportion of patients 86% were seen on an outpatient basis. Many of these patients had short contact with outpatient care; with 45% (195/430) of patients having less than 10 contacts.

Figure 23: Range of contacts with Specialised Eating Disorder Outpatient/Day Services North East and Cumbria 2013-2015

![Graph showing range of contacts with Specialised Eating Disorder Outpatient/Day Services in North East and Cumbria 2013-2015.](image)

Figure 24 below presents the distribution of those patients having less than 10 outpatient contacts, 57 patients had one contact with outpatients.

Figure 24: Patients with <10 contacts with Specialised Eating Disorder Outpatient/Day Services in the North East and Cumbria 2013-2015

![Graph showing patients with less than 10 contacts with Specialised Eating Disorder Outpatient/Day Services in North East and Cumbria 2013-2015.](image)

Further analysis of this patient group receiving less than 10 outpatient contacts identified that most 81% (46/57) patients had no further contact with specialised eating disorder services. Eight patients (14%) were stepped up into inpatient care and 7% (4/57) were stepped down from inpatient care into outpatients.

Although many patients had limited contact with outpatients, a number of patients had extensive contact with outpatient provision, the maximum recorded was 589 contacts over two years.
There is geographical variation in relation to the use of eating disorder outpatient provision. To make a comparison between CCG areas a rate for contacts has been calculated per 100,000 population. The graph below shows that Cumbria residents have no contact with outpatient care and that residents of Newcastle North and East CCG and North Durham have a significantly larger use of outpatient care.

7.11 Summary
The demographics of the patient cohort in terms of age, gender, ethnicity and socio-economic status are similar to the national patient profile for eating disorders inpatient and outpatient services.
The recorded co-morbidities are surprisingly lower than expected, especially for other mental health conditions like depression and anxiety. The survey respondents reported that 80% had a diagnosis for depression however only 25% of patients had a diagnosis of depression recorded in the electronic case management system.

It was surprising that the majority (84%) of patients were inpatients on a voluntary basis and 83% of admissions were planned.

In terms of usage there are some extremes; with a small number of patients using a high level of resources in both the inpatient and outpatient settings. There is a significant cohort of patients that have been inpatients for between 12 months and 4 years. 30% (23/77) episodes of care exceeded inpatient stays of 12 months.

There are a substantial number of patients (45%) who has less than 9 outpatient appointments. The limitations of the data means that it is impossible to determine how many were screened out as being unsuitable for specialised eating disorder services and how many chose not to engage in services.

There is regional variation in use of inpatient and outpatient services, this suggests that some CCG areas are over using eating disorder services whilst other areas are under using services.
8: Discussion

The section presents a synthesis of the data collected for this HCNA. The synthesis has been broken down into the following themes:
- Service configuration
- Patient cohort
- Recovery focussed services
- Care pathway
- Variation

8.1 Service Configuration

Specialised eating disorder services in the North East and Cumbria operate within the national service specification and the Royal College of Psychiatrists’ recommended framework.

The services delivered within the North East and Cumbria meet the national quality standards outlined by the QED. Services at present offer the range of evidence based therapies and interventions recommended by NICE (2004). However, this may require reviewing when this guidance is updated and published (Anticipated April 2017).

The number of beds available to the population of the North East and Cumbria exceeds the Royal College of Psychiatrists’ recommended level by 5 beds. Currently there are 20 beds in eating disorder units.

The budget allocated to specialised eating disorder service exceeds the Royal College of Psychiatrists’ recommended level of spend by approximately £500k.

There are significant gaps in certain staffing groups within the North East and Cumbria specialised eating disorder services; in particular psychological therapists and psychologists and in junior medical staff.

The lack of psychological therapists and psychologists will impact upon the availability and range of evidence based psychological interventions.

There are few junior medical staff, in particular Specialty Registrars in Psychiatry. The North East already has difficulty in recruiting specialists from outside the region. This is particularly concerning as this will impact upon succession planning in the future.

8.2 Patient Cohort

The age and gender composition of the patients using service provision in the North East and Cumbria is similar to the national patient profile for severe eating disorders. The ethnic background of patients is representative of the population of the North East and Cumbria. The socio-economic status of the patient cohort is more or less equally distributed across the socio-economic groups.

In the North East there is a particularly high proportion of the prevalent population (women aged 15-24 years) admitted to inpatient services each year; 36% of those with
a diagnosis of anorexia nervosa in contact with mental health services are admitted to inpatient services each year. Use of outpatients for this population is 57%.

There is geographical variation in use of inpatient and outpatient/day services. Residents of CCGs that live in close proximity to the day services and inpatient units have a higher rate of use.

Residents of Cumbria CCG are less likely to be admitted (29% of the population in contact with mental health services are admitted as inpatients each year) their use of outpatient provision is extremely low (3%).

There are service utilisation extremes; with some patients having very short periods of contact with inpatient and outpatient care and another group of patients that have long lengths of treatment.

There is a significant cohort of patients that have been inpatients for between 12 months and 4 years. 30% (23/77) episodes of care exceeded inpatient stays of 12 months.

The majority of inpatients require stays that are longer than the commissioned care package of <126 days (61%).

Professionals working with this patient cohort describe an increase in number of younger people being admitted into hospital with acute severe eating disorders as well as a growing group of older patients with high levels of complexity. The data analysis was unable to confirm or refute this.

Most patients (84%) are treated on a voluntary basis rather than being detained under the mental health act. The Royal College of Psychiatrists Survey of Eating Disorder Services (RCPsych 2012) report that 8% of eating disorder patients were detained under the Mental Health Act. However this survey included paediatric and acute medical admissions and the report does not specifically identify if this 8% is exclusively related to specialised eating disorder services. It is not possible to directly compare this to the adult eating disorder population in the North East and Cumbria.

There is a lack of robust data on patients detained under the Mental Health Act in inpatient eating disorder units, this has meant that it is not possible to ascertain whether the number of patients detained under the Mental Health Act in the North East and Cumbria is within an acceptable range.

The majority of patients were admitted with a BMI <15 (78%).

The majority of patients were treated within 200 days and the difference in BMI between admission and discharge ranged from -0.8 to 7.4.

The available data sets had some limitations, which limited the analysis as follows:

1. **Individual contact with services**
   Surprisingly, there was insufficient data to accurately assess how many patients had been previously admitted to either inpatient eating disorder units and/or
CAMHS eating disorder services. There was insufficient length of data to assess readmission. The limitations of the data meant that it was not possible to calculate attrition rates.

2. Quality
There were no robust indicators of clinical quality and outcomes for patients. The providers routinely collected clinical outcome measures and followed up patients post discharge. However there was no evidence provided on how this data was used to measure clinical quality/patient safety or used to inform service improvement.

Although BMI and length of stay have been used within this analysis both of these measures are limited and do not represent clinical quality.

3. Recovery
46% of anorexia patients fully recover, with 33% improving and 20% remaining chronically ill (Steinhausen 2002). It was not possible to establish and compare recovery rates for the population in the North East and Cumbria.

4. Assessment
The Royal College of Psychiatrists recommend that in order to maintain an expert knowledge and skills base in eating disorders a specialised service would be expected to receive >25 new referrals per year. It was not possible to identify how many patients were new to services.

5. Severity and complexity
The range of diagnosis for other mental health conditions was based upon information retrieved from the electronic case management systems. The information recorded in these systems may not be an accurate reflection of comorbidity, as for some patients this information may be recorded within their clinical notes.

It was not possible to differentiate between patients with chronic (severe and enduring eating disorders) and those requiring a single acute admission.

8.3 Recovery Focussed Model of Care
A key message that emerged from all stakeholders was the need to move away from a model of care that was focussed on management of chronic eating disorders and harm reduction to a model of care that facilitated recovery.

Central to the realisation of a recovery focussed model of care was the need for multi-disciplinary teams. The composition of these teams needed to include psychological therapists as well as dieticians, occupational therapists, nursing and psychiatry.

The Royal College of Psychiatrists recommend that there are 5.4 psychological therapists per million population employed in the provision of specialised eating disorder services. Currently the North East and Cumbria is only operating with 50% of
the recommended number of psychological therapists. A further 6.8 WTE posts are needed.

To meet the Royal College of Psychiatrists recommended staffing level within the current budget would require a review of the service provision and the identification of existing resources that could be reallocated and prioritised to ensure that there is the right level of staffing required in the inpatient and intensive day service.

The effectiveness of the intensive day service in providing an alternative to hospital admission and to prevent further admissions is largely unknown. Psychological therapy input into both of the intensive day services appears to be very limited. However, given that the Newcastle service offers only 5 places and the Teesside service offers 10 places per session, a balance between effectiveness and efficiency does need to be established and a possible solution is to train and use more nursing staff in psychological interventions.

There are therapeutic sessions programmed into the weekly timetable some patients felt that the structure of the day service was not tailored to meet their needs and that the timetable dictated events rather than patients’ needs.

Some commented that group therapy programmes were closed, leaving newly admitted patients with nothing to do.

There appeared to be two different patient groups utilising intensive day services. There was a patient group that had been stepped down from inpatient and another group that had been stepped up from community services in order to avoid hospital admission. A number of patients and staff members highlighted that these two groups had very different needs and mixing these patient groups could be problematic.

These difficulties are not inevitable. For example the Leicester regional service made a very clear distinction between these two patient groups and ensured that those who were being stepped down had their own programme of care and when appropriate were integrated into the day service.

In the North East and Cumbria there is limited community based provision that is eating disorder specific. The community based eating disorder services that do operate are not multi-disciplinary and do not have psychological input.

There was an expectation expressed by patients, staff and carers/relative that once an individual is engaged in treatment for a severe eating disorder then that engagement could be for long periods of time and may involve repeat admissions. There was also a need expressed by both patients and carers/relatives to have continued access to services and that there were no restrictions applied to this. This presents a tension in establishing a recovery-focussed approach.

8. 4 Care Pathway

There was acknowledgement from patients and relatives/carers that detection of eating disorders within primary care had improved considerably. However patients and relatives commented on the time taken between the detection of an eating disorder in
primary care and being seen in secondary mental health services, and the subsequent impact this time delay had on the physical and mental deterioration of the individual.

The patient and relative experience of community mental health services in the treatment of severe eating disorders was poor.

Patients and carers/relatives expected that secondary care would have expertise in the treatment of eating disorders. Many experienced delays in accessing secondary care they felt that staff were not experienced or skilled in working with eating disorders and that there was a lack of continuity of care.

The care pathway from primary care into eating disorder services differs across the North East and Cumbria. Referrals from Northumberland and Tyne and Wear are directed to secondary care CMHTs for assessment and on-going treatment/monitoring. The CMHT will then refer into specialised eating disorder services.

In Durham, Darlington and Teesside there is a community eating disorder team that provides the CMHT function and referrals are direct to them. This community eating disorder team is funded by CCGs. There is no CCG funding for community eating disorder teams for Northumberland and Tyne and Wear. Although there is some CCG funding that supports NIWE a voluntary sector provider of eating disorder services.

At present the community service in Durham, Darlington and Teesside is not a multidisciplinary team comprising of psychological therapists, dieticians, occupational therapists and mental health nursing. The function of the community eating disorder team in Durham, Darlington and Teesside is limited to a monitoring function and when required providing speedy referral back into tertiary services.

In Cumbria eating disorders are managed within CMHTs with severe eating disorders having access to an intensive specialised team for the treatment of anorexia nervosa.

A consequence of the care pathway in the North East and Cumbria is that the only access to specialised multi-disciplinary eating disorder services is either as an inpatient or within the intensive day service.

The contract management data set identified an additional 430 patients using outpatient services. The intensive day services do not have the capacity to work with this volume. The provision of outpatient services is not within the national service specification. More information about this patient cohort is required in order to assess whether their needs are being met within community based services.

A number of patients and carers/relatives highlighted the perceived perverse incentive of the BMI threshold required in order to meet the admission criteria as an issue. The result of which included increased emergency admissions to acute medical beds and/or admissions into eating disorder inpatients units, with some requiring out of area placements.

An example of an alternative model of delivery is the service structure in Leicester. The Leicester regional eating disorder service covers a larger population. There is an
inpatient unit and intensive day service. The inpatient unit has fewer beds than the North East and Cumbria; these beds are rarely fully occupied. The key difference between Leicester and the North East and Cumbria is that the care pathway includes specialised eating disorder services within an outpatient services within the regional services and within community teams in secondary mental health services.

In order to reduce demand upon inpatient and intensive day services there needs to be a credible and evidence based alternative that responds quickly and is recovery focussed.

8.5 Variation in use
The causes of variation are complex and inter-related and may be affected by differences in population composition, patient decisions and attitude to risk; or can be a result of service configuration and clinical decisions (Kings Fund 2010).

There is a reliance on inpatient services. The North East has a higher rate of hospital admissions for eating disorders and has in excess of the expected number of beds to serve the population.

The North East and Cumbria place a high level of demand upon out of area beds. Over an 18-month period (January 2014 – June 2015) 27 patients were admitted to out of area specialised eating disorder units. Whereas over a two-year period (April 2013 – March 2015) 5 patients from outside the North East and Cumbria were admitted to the local specialised eating disorder units.

There is geographical variation in service usage. CCGs in close proximity to provision are over using services and others are under using services. Over use and under use is detrimental to patients and does not represent good use of resources.

There are extended stays in inpatient units, with 30% of all episodes of care exceeding 12 months.

These potential causes for variation in use of specialised eating disorder services are further explored below.

8.51 Population composition and demography
There are no obvious population based factors that would lead to an increase in the number of individuals with a severe eating disorder.

There are a number of factors that influence health inequalities in the North East and Cumbria. These mainly relate to differences in poverty and exposure to health damaging environments such as poorer living and working conditions and unemployment, differences in the chronic disease and disability left by including the legacy of heavy industry and its decline (Whitehead et al 2014).

These factors are not important determinants of severe eating disorders and would not be expected to increase the numbers of people with severe eating disorders.
The age structure of the North East and Cumbria, particularly for 15-24 year age group does not differ significantly to the age structure for England.

8.52 Patient decisions and attitude to risk
There are limited treatment choices available to patients with severe eating disorders. Patients and carers/relatives expressed a preference for specialised eating disorder provision rather than community based generic mental health provision. There was a hierarchy of preference with inpatient services being perceived as the most credible and best equipped to treat eating disorders. Many patients and carers/relatives requested that more beds were required in order to meet the current demand on out of area bed use.

Some patients and carers/relatives reported concern about the clinical threshold of BMI<15 for admission. This threshold was for some individuals interpreted as a target. This resulted in patients either attempting to manage their weight around or just above a BMI of 15 in order to avoid admission or for some patients further reducing their BMI in order to access services.

NICE guidance and commissioning guidelines for eating disorder services highlight those patients with a BMI<15 can be successfully managed within outpatient and day services. This was not the expectation of patients and carers/relatives.

This perceived hierarchy of treatment services alongside an expectation that a BMI <15 would result in an admission could possibly be placing an increased patient demand upon inpatient care.

It was surprising that the majority of patients were being treated on a voluntary basis and were planned admissions. Whilst collaboration is important, the high proportion of those admitted on a voluntary and planned basis may also reflect patient preference on treatment setting.

8.53 Resources availability and service configuration
The geographical availability of provision is a key driver. This HCNA has identified that there is geographical variation in service use at a CCG level and also at a regional level. The CCGs that are in close proximity to the provider sites have a higher ratio of use of both the inpatient and outpatient services. This higher level of use is a combination of having more individuals referred into these services and that a high proportion of patients stay within the services for a longer duration.

The North East and Cumbria has a higher number of recommended beds per population. Applying the Royal College of Psychiatrists recommendation of 6 beds per 1million adult population means that there is an excess of 5 beds. The Royal College of Psychiatrists also highlight that this notional 6 beds per 1million adult population can be further reduced if there are intensive day services. At present there are two intensive day services in the North East and Cumbria, suggesting the excess of beds is more than 5 for the populations served.
The lack of community based eating disorder services will influence inpatient and outpatient use; as currently these two services are perceived as the only available specialised services.

8.6 Summary
The North East and Cumbria has an excess of more than 5 specialised inpatient eating disorder beds.

There appears to be a higher level of use of inpatient beds, but there is a lack of community based eating disorder provision. It is unknown how the lack of a community-based service contributes to the higher demand for beds.

The majority (61%) of patients remain as inpatients for longer than the commissioned care package of 126 days (4 months). A significant number of patients have hospital stays in excess of 12 months with 30% of all episodes of care exceeding 12 months.

A high proportion of patients (84%) are not admitted under the Mental Health Act and 83% of all inpatient admissions were planned.

The region places more demand on the use of out of area commissioned beds than the number of beds within the region that are used by patients that do not reside in the North East and Cumbria.

There is significant geographical variation in the use of inpatient and outpatient services. This highlights under use of services by some Clinical Commissioning Groups (CCGs) and over use by others. Populations closest to specialised services make greatest use of both services. Residents of Cumbria do not use intensive day care services.

There is limited data on the effectiveness of inpatient and intensive day care services, and there is little known about the patients, in particular how many recover from a severe eating disorder and the proportion of patients with chronic and acute eating disorders.

Patients and carers/relatives express the need for more beds, quicker access into services and that services are specialised eating disorder services.

Currently the intensive day services have been commissioned as an alternative to hospital admission. The analysis of service use data identified 430 patients that were accessing outpatient provision (2013-2015). It is not known how many of these patients are now being treated within community mental health services.

The structure of the intensive day services and the number of places available cannot meet the demand of the volume of patients reported to be accessing outpatient care. Alternative treatment options for this group need to be defined, these need to be evidence based and cost effective.
There is a tension between delivering a recovery-focused model of care and challenging the expectation from patients and carers/relatives that there is a need for long-term and continued engagement in specialised services.

Patients, carers and relatives reported poor communication and coordination of care between inpatients and day services and between specialised eating disorder services and community mental health services. Patients, carers and relatives reported long delays in accessing an assessment, this was particularly important for young people aged 16-17 years old who were caught between child and adolescent and adult mental health services.

There are significant deficits in certain staff groups such as the number of junior medical staff and psychological therapists. However the annual spend by NHS England on specialised eating disorders is above the Royal College of Psychiatrists recommended minimum allocated budget (an excess of £500K above the minimum spend per year).

Currently there is support for carers/relatives who have family members admitted to the intensive day care provision and admitted into specialised eating disorder inpatient units. Carers/relatives want continued support across the entire care pathway, including primary care and secondary mental health services.

A minority (19%) of carers have had a formal assessment of their needs.
9: Recommendations
The key recommendations outlined have been themed into the following:

- Service configuration
- Service improvement
- Data collection and analysis
- Communication
- Further research

The recommendations for each of these areas have been set out in order of priority.

Recommendations - Service configuration

Priority 1: Cumbria patients are not accessing outpatient or day care provision. A focussed time limited piece of work is required to understand the service provision in Cumbria.

Priority 2: Commissioning more beds in specialised eating disorder units will not address the needs of those with a severe eating disorder. Alternative solutions to treatment need to be identified. These alternative treatment options need to be evidence based and cost effective. There needs to be a greater emphasis on treating patients on an outpatient basis.

There are a number of emerging models of care; for example FREED (First Episode and Rapid Early Intervention for Eating Disorders). FREED is a pilot programme delivered by South London and Maudsley NHS Foundation Trust. FREED aims to facilitate rapid assessment and flexible tailored treatment for young adults with anorexia or bulimia in the early stages of their illness by offering therapeutic interventions, including individual or group-based therapy, online supported treatment and university holiday sessions.

Initial results from the FREED programme showed that cutting long waiting times makes patients much more likely to engage with the treatment; reduces the high dropout rate from such care; helps patients recover more quickly than normal; and is hugely appreciated by patients and their parents.

Northamptonshire NHS Foundation Trust offers intensive home treatment as an alternative to hospital admission.

Recommendation – Service Improvement

Priority 3: Stakeholders should together define a recovery-focussed model of care for the treatment of severe eating disorders in the North East and Cumbria. This needs to address the perverse incentive around low BMI and admission thresholds.

Once established, this collaboration should:
a) Identify the steps required to achieve a recovery-focused model of care within the different treatment settings.

b) Design a set of outcomes that a recovery-focused model of care would be expected to achieve.

c) Identify which sources of data are most appropriate to measure progress against these outcomes.

d) Implement the changes required both in terms of service improvement and data collection.

e) Monitor and evaluate progress.

**Recommendation – Service Configuration**

**Priority 4:** A resource exploration exercise needs to be undertaken in order to ensure that the right level of service is in the right place. Crucial to this is involvement of the CCGs in defining their requirement to develop community-based provision.

**Priority 5:** The care pathway for eating disorders needs to include community-based specialised eating disorder services.

The community-based specialised eating disorder services need to be able to deliver recovery-focused models of care as well as being able to manage and monitor those with severe and enduring eating disorders. In order to fulfil this function, the community-based services must be resourced with multi-disciplinary teams that are to provide dietary and nutritional support alongside evidenced-based psychological therapies.

A whole pathway of care needs to be developed that spans CAMHS and adult eating disorder services.

The roles and functions of the different levels of services need to be defined, in particular the role and function of outpatient care and the remit of the intensive day service as a step up and step down from inpatient care.

The care pathway needs to include formal support offers for carers/relatives. A choice of individual/family support and/or group support needs to be routinely offered and available.

**Priority 6:** Increase the number of carers/relatives receiving a formal assessment of their needs as a carer.

**Priority 7:** Undertake a marginal analysis of the current intensive day care programme and establish if it is possible to increase the number of places available by addressing service efficiencies.

**Priority 8:** There are significant gaps in certain professional groups; including psychology and junior medical staff. Health Education North East need to lead a workforce forward planning exercise, in order to address these deficits and to actively
promote training in eating disorders across all staffing levels to develop expert teams and ensure succession planning.

Recommendations - Data Collection and Analysis

Priority 9: Design a data collection specification that provides all stakeholders (patients, providers and commissioners) with an overview of the quality of the services in the North East and Cumbria.

The data collection specification needs to include the following:

a) Quality assurance and evidencing clinical outcomes
Explore how discharge planning and care coordination assist patients that have an inpatient stay that extends beyond 126 days.

b) Patient safety
Identify key measures/markers that can be used to highlight/monitor patient safety. These may include:

- BMI on admission
- BMI on discharge
- The difference between BMI (admission and discharge) and length of stay

Use this information to produce an annual report that provides an overview of clinical quality and service usage. This report does not need to be extensively circulated, rather it is used within and between services and with commissioners to identify good practice and to recognise where there may be issues in the provision of specialised eating disorder services and how best to solve these at a regional level.

The table below outlines that data that is routinely collected and used by Leicester regional eating disorder service in the publication of their annual report.
Table 14: Data published in Leicester Regional Eating Disorder Service Annual Report

<table>
<thead>
<tr>
<th>Data Collected</th>
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<tbody>
<tr>
<td>Age</td>
<td>Patient cohort - demographic information</td>
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<td>Gender</td>
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<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Patient cohort - complexity and defining chronicity and acute eating disorders</td>
</tr>
<tr>
<td>Length of eating disorder history</td>
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<tr>
<td>Number of previous hospitalisations</td>
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<tr>
<td>BMI and weight on admission</td>
<td>Patient safety</td>
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<tr>
<td>BMI and weight tracked over admission</td>
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<tr>
<td>Length of stay</td>
<td>Quality assurance</td>
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<tr>
<td>Weight at 3 months and 1 year post discharge</td>
<td>Recovery</td>
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**Questionnaires – Clinical outcomes:**

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<thead>
<tr>
<th>Questionnaire</th>
<th>Clinical quality</th>
<th>Recovery</th>
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<tr>
<td>Eating Disorders Examination – Questionnaire version 6 (EDEQ-6)</td>
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<td>Recovery</td>
</tr>
<tr>
<td>Hospital Anxiety &amp; Depression Scale (HADS)</td>
<td>Clinical quality</td>
<td>Recovery</td>
</tr>
<tr>
<td>Clinical Outcomes in Routine Evaluation (CORE)</td>
<td>Clinical quality</td>
<td>Recovery</td>
</tr>
<tr>
<td>Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ)</td>
<td>Clinical quality</td>
<td>Recovery</td>
</tr>
<tr>
<td>Eating Disorders Quality of Life (EDQOL)</td>
<td>Clinical quality</td>
<td>Recovery</td>
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**Other questionnaires**

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<tr>
<th>Questionnaire</th>
<th>Clinical quality</th>
<th>Recovery</th>
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<tbody>
<tr>
<td>Entry to Ward &amp; Leaving Ward (questionnaire)</td>
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<td>Recovery</td>
</tr>
<tr>
<td>BMI 17.5 (questionnaires)</td>
<td>Clinical quality</td>
<td>Recovery</td>
</tr>
<tr>
<td>3 months post leaving (questionnaire)</td>
<td>Clinical quality</td>
<td>Recovery</td>
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</table>

**Priority 10:** Given the significant gaps in knowledge on the patient population in contact with specialised eating disorder services; an audit of patient records is required in order to identify the following:

- Recovery rates for severe eating disorders in the North East and Cumbria
- Proportion of chronic and acute patients in contact with services
- Identification of avoidable admissions
- Number of planned/emergency admissions
- Number of new patients not previously known to services
- Attrition rates

This information would provide a valuable insight into the patient cohort and also provide a baseline from which progress can be measured.
9.1 Recommendations for further research
There are a number of recommendations for further research on the treatment of severe eating disorders and outcomes for patients. In particular more research is required to assess whether a recovery-focussed model of care reduces inpatient admissions.

A number of the existing studies on service usage and care pathways are over 10 years old and do not reflect the national specification and current service configuration. This work needs to be updated in order to be able to quantify the expected flow of patients through eating disorder services. This information would be valuable to inform future service planning.

More robust research is required on length of stay and length of engagement in different treatment settings, the findings of this need to be presented in a meaningful way; length of stay in inpatient or outpatient is often presented as an average, which presumes a normal distribution, the data is affected by very long stays and very short stays and therefore an average is not an appropriate description.

There is robust prevalence data on the distribution of the different types of eating disorders for women aged 15-24 years old. There is limited evidence on the prevalence of severe eating disorders or the prevalence of chronic (severe and enduring) eating disorders. Establishing an evidence base for this will enable the identification of any changes relating to the chronicity of eating disorders and survival rates.

9.2 Next steps
The recommendations from this HCNA will be taken forward by an implementation group that will oversee the service improvement and data collection recommendations.

A rapid process improvement workshop will bring together key stakeholders that will explore the resourcing of community services.

This work is being co-ordinated by Dr James Brown email address: James.Brown@phe.gov.uk
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Royal College of Psychiatrists (2012). CR170 Eating disorders in the UK: service distribution, service development and training.


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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AIMS</td>
<td>Accredited Inpatient Mental Health Services</td>
</tr>
<tr>
<td>AN</td>
<td>Anorexia Nervosa</td>
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<tr>
<td>ANSOCQ</td>
<td>Anorexia Nervosa Stages of Change Questionnaire</td>
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<td>BED</td>
<td>Binge Eating Disorder</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<td>BN</td>
<td>Bulimia Nervosa</td>
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<td>Child and Adolescent Mental Health Services</td>
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<td>CMHT</td>
<td>Community Mental Health Team</td>
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<td>CORE</td>
<td>Clinical Outcomes in Routine Evaluation</td>
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<td>Eating Disorder Quality of Life</td>
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<td>Management of Really Sick Patients with Anorexia Nervosa</td>
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<td>Office National Statistics</td>
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<td>Electronic case management system - TEWV</td>
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<table>
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<tr>
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<td>Post-Traumatic Stress Disorder</td>
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<td>QED</td>
<td>Quality in Eating Disorder Services</td>
</tr>
<tr>
<td>RCPsych</td>
<td>Royal College of Psychiatrists</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>REDS</td>
<td>Richardson Eating Disorder Service</td>
</tr>
<tr>
<td>RIO</td>
<td>Electronic case management system - NTW</td>
</tr>
<tr>
<td>SOA</td>
<td>Super Output Areas</td>
</tr>
<tr>
<td>TEWV</td>
<td>Tees, Esk and Wear Valleys NHS Foundation Trust</td>
</tr>
<tr>
<td>WTE</td>
<td>Whole Time Equivalent</td>
</tr>
</tbody>
</table>
Appendix i: Quality Standards for Eating Disorder Services

There are specific quality standards for eating disorder services. These standards have been designed by the College Centre for Quality Improvement (CCQI) which is linked to the Royal College of Psychiatrists and the Quality Network for Eating Disorders (QED). These standards incorporate the Royal College of Psychiatrists Accreditation for Inpatient Mental Health Services (AIMS).

These standards are structured around care pathways (with specific modules for elements such as inpatient or outpatient care). They are grouped into the following areas:

- Environment and facilities
- Staffing
- Access admission and discharge
- Care and treatment
- Information consent and confidentiality
- Clinical governance
- Public health

The Care Quality Commission (CQC) set out essential standards, which are expected for healthcare services to ensure quality and excellence:

- Treating people with respect and involving them in their care
- Providing care, treatment and support that meets people's needs
- Caring for people safely and protecting them from harm
- Staffing
- Quality and suitability of management

These essential standards form part of the CQC quality inspections. Additionally and depending on services other quality standards also used to further ensure quality. For eating disorder services the following is asked:

- Are Eating Disorders Services safe?
- Are Eating Disorders Services effective?
- Are Eating Disorders Services caring? Good
- Are Eating Disorders Services responsive? Good
- Are Eating Disorders Services well-led?

Quality Visits by NHS Specialised commissioning team

- Richardson Intensive Eating Disorder Day service at Northumberland Tyne and Wear NHS Foundation Trust on June 2015
- Imperial Avenue Intensive day service Tees Esk and Wear Valleys NHS Foundation Trust June 2015.
- Birch August 2014 Tees Esk and Wear Valleys NHS Foundation Trust
- Evergreen February 2014 Tees Esk and Wear Valleys NHS Foundation Trust
- Huntercombe August 2015 The Huntercombe Group Edinburgh

During the visits there is a greater focus on the following issues:

- Safety
- Privacy and dignity
- Activities
- Choice
- Advice and information
- Staff establishment, training and development opportunities
- Access to advocacy services

A full service review took place at the Partial Hospitalisation Service at the RVI in 2013. NHS England have a quarterly clinical quality review meeting with providers which allow for further discussion and analysis of quality and safety information and identification of themes and trends.
Appendix ii: Literature review – Search Strategy

Population:
- People with anorexia nervosa

Intervention:
- Specialised eating disorders care including outpatient, day care and inpatient care

Control:
- Non-specialised mental health care or usual care, or inpatient compared to outpatient or day patient care, or day patient compared to outpatient care.

Outcomes:
- Mortality
- Weight or BMI
- Any validated clinical scale e.g. HONOS, EDEQ, SCOFF

Study:
- Randomised controlled trial
- Non-randomised controlled trial (quasi-RCT) or cohort study

Search strategy

Databases:
- Medline

Search terms for Medline
1. Exp Anorexia nervosa/
2. Exp Anorexia/
3. Exp Eating disorders/
4. Anorexia.tw.
5. Eating disorder$.tw.
6. Or/1-5
7. Exp “Referral or Consultation”/
8. (refer or referral$ or referred).tw.
9. (refer or referral$ or referred).ti.
10. consult$.tw.
11. (specialised or specialised or specialized).tw.
12. Tertiary.tw
13. (Outpatient or out-patient).tw.
14. (Inpatient or in-patient).tw
15. (“Day patient” or day-patient).tw
17. Or/7-16
18. and/6,17
19. exp Cohort Studies/
20. cohort.tw.
23. “Outcome Assessment (Health Care)”/
24. Treatment Outcome/
25. or/19-24
26. and/17,25

Search dates
1946 to present
Flow of studies through review

Records identified through database searching (n = 817)

Additional records identified through other sources (n = 4)

Records after duplicates removed (n = 821)

Records screened (n = 821)

Records excluded (n = 802)

Full-text articles assessed for eligibility (n = 19)

Studies included in qualitative synthesis (n = 5)

Full-text articles excluded, with reasons (n = 13)
Ten studies excluded based on study design
Two studies excluded because not patients with anorexia nervosa
One study excluded because not intervention of interest

No studies included in quantitative synthesis (meta-analysis)
Included Studies:


Appendix iii: Patient and Service User Survey

The link to the survey is below.

The survey is now closed (31st July 2015)


Appendix iv: Carer and Relative Survey

The link to the survey is below.

The survey is now closed (31st July 2015)

Appendix v: Demographic information from survey respondents

Patient and service user demographical information

The majority of respondents were working either part-time or full-time and 25% (8/32) were currently studying.
Patient and service user clinical history

The chart below presents the age of each respondent and the number of years that they have lived with their eating disorder.

The majority 90% (27/30) had received a diagnosis for their eating disorder and 27% (8/30) had been referred to CAMHS services for treatment of their eating disorder.

The majority 90% (27/30) had received a diagnosis for their eating disorder and 27% (8/30) had been referred to CAMHS services for treatment of their eating disorder.

Reported Eating Disorders

- Anorexia Nervosa: 60%
- Bulimia Nervosa: 30%
- Binge Eating Disorder: 23%
- EDNOS: 17%
Reported current and past service use

- No services: 17% current, 0% previous
- Inpatient: 43% current, 7% previous
- Day Services: 27% current, 20% previous
- Community Mental Health: 80% current, 60% previous
- NIWE: 43% current, 3% previous
- Private Therapy: 13% current, 3% previous
- Online support: 23% current, 0% previous

Reported co-morbidities

- Depression: 80% current, 67% previous
- Anxiety: 27% current, 17% previous
- Obsessive-compulsive: 13% current, 7% previous
- Personality disorder: 7% current, 7% previous
- None: 13% current, 7% previous
- PTSD: 7% current, 7% previous
- Substance misuse: 7% current, 7% previous
Carer and relative demographical information
There were a total of 32 completed or partially completed returned questionnaires, all of the respondents lived in the North East and Cumbria region. The majority of responses were from women 84% (27/32) and 5 (16%) were from men. All respondents described their ethnic background as White British.

Most respondents 81% (26/32) were caring for a daughter, 3/32 (9%) providing care for their partner. The other three respondents were caring for a son, parent or sibling. A total of 30/32 (94%) were caring for a female relative.

The age range for carers was 31 – 66 years old and the age range for the person they are caring for was 14 – 65 years old.

---

![Age of Relatives and Carers](image1)

![Age of person being cared for](image2)
Carer and relative clinical history
The majority of relatives had received a formal diagnosis for their eating disorder 97% (31/32). Nearly half (47%) of all respondents had cared for someone who had accessed CAMHS eating disorder services.

Two thirds 21/32 reported having engaged in family therapy as part of the treatment programme. Only 19% (6/32) reported having received an assessment of their needs as a carer.

The majority of carers have experience of caring for someone with anorexia nervosa alongside other mental health conditions such as depression and anxiety. It was reported that 84% (27/32) had experience of anorexia nervosa, of these 27 individuals only 4 had no other mental health diagnosis and for the 23 individuals with a co-existing mental health diagnosis the most common was depression 91% (21/23) followed by anxiety 70% (16/23).
Nearly three quarters (23/32) respondents had cared for a relative who had been admitted as an inpatient, 44% (16/23) of carers had had their relative admitted to a hospital that was out of area.
## Appendix vi: Documents Requested

<table>
<thead>
<tr>
<th>Document Requested</th>
<th>NTW</th>
<th>TEWV</th>
<th>NHS England</th>
<th>NIWE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Spec</td>
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<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>In patient outcomes</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>CQC inspection</td>
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<td></td>
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<td>AIMS</td>
<td>X</td>
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<tr>
<td>In patient referral</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schedule 4 Quality Requirements</td>
<td>X</td>
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<tr>
<td>Service review</td>
<td>X</td>
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<tr>
<td>Service pathway</td>
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<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>BEAT Accreditation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Service user satisfaction</td>
<td>X</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Costing day service</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Service usage</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Patient level data</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Service Directories</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Clinical pathways</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting times</td>
<td></td>
<td></td>
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<td>X</td>
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<tr>
<td>Service Timetables</td>
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<tr>
<td>Operational Policies</td>
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<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Staff structures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admission and discharge criteria</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Appendix vii: Staffing configuration

## Staffing structure Intensive Eating Disorder Day Care

<table>
<thead>
<tr>
<th>Imperial Avenue – TEWV (Middlesbrough)</th>
<th>Nursing</th>
<th>Medical</th>
<th>MDT</th>
<th>Psychology</th>
<th>Admin</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 WTE Manager x</td>
<td>1 WTE Consultant Psychiatrist</td>
<td>2 WTE OT</td>
<td>1 WTE Dietician</td>
<td>0.5 WTE Psychologist</td>
<td>1 WTE Medical Secretary</td>
</tr>
<tr>
<td>2 WTE Clinical Leads</td>
<td></td>
<td></td>
<td>0.4 WTE Physiotherapist</td>
<td></td>
<td>1 WTE Receptionist</td>
</tr>
<tr>
<td>3 WTE Staff Nurses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.6 WTE Support Workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benton House – NTW (Newcastle upon Tyne)</td>
<td>Nursing</td>
<td>Medical</td>
<td>MDT</td>
<td>Psychology</td>
<td>Admin</td>
</tr>
<tr>
<td>1 WTE Day Service Manager</td>
<td>0.2 WTE Consultant Psychiatrist</td>
<td>1 WTE OT</td>
<td>1 WTE Dietician</td>
<td>Psychological therapy provided by team from inpatient unit</td>
<td>Admin team shared with inpatient unit</td>
</tr>
<tr>
<td>2.5 WTE Staff Nurses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.3 WTE Support Workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Staffing structure Intensive Eating Disorder Inpatient units

<table>
<thead>
<tr>
<th>Birch Ward – TEWV (Darlington)</th>
<th>Nursing</th>
<th>Medical</th>
<th>MDT</th>
<th>Psychology</th>
<th>Admin</th>
<th>Catering</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 WTE Manager x</td>
<td>1 WTE Consultant Psychiatrist</td>
<td>2 WTE OT</td>
<td>1 WTE Dietician</td>
<td>0.5 WTE Consultant Clinical Psychologist</td>
<td>1 WTE Ward Secretary</td>
<td>Chef</td>
</tr>
<tr>
<td>3 WTE Clinical Leads</td>
<td></td>
<td></td>
<td>0.6 WTE Physiotherapist</td>
<td>1 WTE Psychologist</td>
<td>Catering Assistant</td>
<td></td>
</tr>
<tr>
<td>9 WTE Staff Nurses</td>
<td></td>
<td></td>
<td></td>
<td>0.65 WTE Psychological Therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.4 WTE Support Workers</td>
<td></td>
<td></td>
<td></td>
<td>0.5 WTE Psychology assistant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>REDS – NTW (Newcastle upon Tyne)</td>
<td>Nursing</td>
<td>Medical</td>
<td>MDT</td>
<td>Psychology</td>
<td>Admin</td>
<td>Catering</td>
</tr>
<tr>
<td>1 WTE Ward Manager</td>
<td>1 WTE Consultant Psychiatrist</td>
<td>0.8 WTE OT</td>
<td>0.5 WTE Dietician</td>
<td>0.5 WTE Consultant Clinical Psychologist</td>
<td>3 WTE Admin</td>
<td>Chef</td>
</tr>
<tr>
<td>9 WTE Staff Nurses</td>
<td></td>
<td></td>
<td></td>
<td>3.5 WTE Psychological Therapist</td>
<td>2 WTE Ward Clerks</td>
<td>Catering Assistant</td>
</tr>
<tr>
<td>8 WTE Support Workers</td>
<td></td>
<td></td>
<td></td>
<td>0.5 WTE Psychology assistant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix viii: Interventions provided within specialised eating disorder services in the North East and Cumbria

<table>
<thead>
<tr>
<th>Recommended Intervention</th>
<th>Provided within intensive day services</th>
<th>Provided within specialised eating disorder inpatient units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
<td>Yes - evidenced in site visits</td>
<td>Yes (within 24 hours of admission) evidenced in AIMS CCQI Accreditation for NTW Operational policy supplied for TEWV</td>
</tr>
<tr>
<td>On-going liaison with community mental health services</td>
<td>Community eating disorder team maintains contact with those in day services in Imperial Avenue Community mental health teams maintain contact with NTW patients accessing NTW day service.</td>
<td>Patients commented on the perceived lack of continuity of care from community mental health teams whilst being an inpatient at REDS. Patients and carers commented that communication between specialised services and community mental health services was poor.</td>
</tr>
<tr>
<td>Nutritional care plans (oral re-feeding)</td>
<td>Yes - evidenced in site visits</td>
<td>Yes - evidenced in site visits and in the weekly time-tables supplied from NTW and TEWV</td>
</tr>
<tr>
<td>Nasogastric tube re-feeding</td>
<td>NA</td>
<td>Yes evidenced in: AIMS CCQI Accreditation for NTW Operational policy supplied for TEWV</td>
</tr>
<tr>
<td>Intensive daily medical monitoring</td>
<td>Yes - evidenced in site visits</td>
<td>Yes - evidenced in site visits</td>
</tr>
<tr>
<td>Accept patients detained under the Mental Health Act</td>
<td>NA</td>
<td>Yes - evidence supplied in provider data on patients</td>
</tr>
<tr>
<td>Flexibility to accept 16 – 18 year olds</td>
<td>No evidence supplied</td>
<td>Yes (evidence supplied in provider data on patients)</td>
</tr>
<tr>
<td>Provision for men (access to own bathroom and sitting area)</td>
<td>NA</td>
<td>Yes - evidenced in site visits</td>
</tr>
<tr>
<td>Recreational and social activities</td>
<td>Yes evidenced in site visits and in the weekly time-tables supplied from NTW and TEWV</td>
<td>Yes - evidenced in site visits</td>
</tr>
<tr>
<td>Service Area</td>
<td>Evidence Provided</td>
<td>Notes</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>--------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Family therapy/intervention</td>
<td>No evidence supplied</td>
<td>Yes - evidenced in site visits</td>
</tr>
<tr>
<td>Information and support for carers</td>
<td>No evidence supplied</td>
<td>Yes - evidenced in site visits</td>
</tr>
<tr>
<td>Daily Group programme</td>
<td>Yes - evidenced in site visits/focus groups</td>
<td>Yes - evidenced in site visits/focus groups</td>
</tr>
</tbody>
</table>

**Evidence based psychological therapies:** provided by suitably qualified staff with regular clinical supervision.

<table>
<thead>
<tr>
<th>Therapy Type</th>
<th>Evidence Provided</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive behavioural therapy (CBT)</td>
<td>Yes evidenced in:</td>
<td>AIMS CCQI Accreditation for NTW</td>
</tr>
<tr>
<td></td>
<td>The weekly time-tables supplied from NTW and TEWV</td>
<td>Operational policy supplied for TEWV</td>
</tr>
<tr>
<td>Motivational Enhancement Therapy (MET)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive analytic therapy (CAT)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialectical behaviour therapy DBT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal therapy (IPT)</td>
<td>Yes - evidenced in site visits</td>
<td>No evidence supplied</td>
</tr>
</tbody>
</table>

**Clinical outcome measures:** All ED services should conduct outcome monitoring. As a minimum the following should be recorded:

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Evidence Provided</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight and Body Mass Index</td>
<td>Yes - evidenced in site visits</td>
<td>Yes - evidence supplied in provider data on patients</td>
</tr>
<tr>
<td>EDEQ</td>
<td>No evidence supplied</td>
<td></td>
</tr>
<tr>
<td>HONOS or HONOSCA</td>
<td>No evidence supplied</td>
<td></td>
</tr>
<tr>
<td>A measure of patient satisfaction/carer satisfaction</td>
<td>No evidence (TEWV)</td>
<td>Yes (NTW) evidenced in results of patient satisfaction</td>
</tr>
<tr>
<td>Public health interventions</td>
<td>No evidence supplied</td>
<td>Yes – use of Lester tool</td>
</tr>
</tbody>
</table>

*No evidence – no evidence was supplied this does not mean that this aspect of service provision is not in place.*
Appendix ix Overview of data presented in tables and figures

<table>
<thead>
<tr>
<th>Table title</th>
<th>Data source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 3 Estimated percentage of population with anorexia nervosa aged 15-24 accessing inpatient eating disorder services in one-year period</td>
<td>Contract management data Pseudonymised patient data 2013 - 2015</td>
</tr>
<tr>
<td>Table 4: Estimated percentage of population with anorexia nervosa aged &lt;25 years old accessing outpatient eating disorder services in one-year period</td>
<td>Contract management data Pseudonymised patient data 2013 - 2015</td>
</tr>
<tr>
<td>Table 9: Primary diagnosis for a hospital admission and data set</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
<tr>
<td>Table 10: Percentage of patients with comorbidities and other diagnosis</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
<tr>
<td>Table 11: Legal status recorded on inpatient records</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Figure title</th>
<th>Data source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 4: Age distribution patients accessing specialised eating disorder services in the North East and Cumbria 2012-2015</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
<tr>
<td>Figure 5: Ethnic profile inpatients 2010 - 2015</td>
<td>Hospital episodes statistics 2010 - 2015</td>
</tr>
<tr>
<td>Figure 6: Quintiles of Social Economic Status for FEAs</td>
<td>Hospital episodes statistics 2010 - 2015</td>
</tr>
<tr>
<td>Figure 7: Number of other diagnosis recorded on patient records</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
<tr>
<td>Figure 8: Type and order of diagnosis for other co-morbidities</td>
<td>Pseudonymised patient data 2012 - 2015</td>
</tr>
<tr>
<td>Figure 9: BMI on admission</td>
<td>Pseudonymised patient data 2012 - 2015</td>
</tr>
<tr>
<td>Figure 10: Difference between BMI on admission and discharge</td>
<td>Pseudonymised patient data 2012 - 2015</td>
</tr>
<tr>
<td>Figure 11: Scatter gram showing the relationship between length of stay and BMI on discharge</td>
<td>Provider data set (NTW and TEWV)</td>
</tr>
<tr>
<td>Figure 12: Length of stay inpatient 2012 - 2015</td>
<td>Hospital episodes statistics 2010 - 2015</td>
</tr>
<tr>
<td>Figure 13: Length of stay for eating disorders in the North East and Cumbria 2010 - 2015</td>
<td>Hospital episodes statistics 2010 - 2015</td>
</tr>
<tr>
<td>Figure 14: Length of stay for patients requiring &gt;6 months inpatient admission to Specialised Eating disorder services in the North East and Cumbria 2010-2015</td>
<td>Hospital episodes statistics 2010 - 2015</td>
</tr>
<tr>
<td>Figure 15: Length of stay completed and non-completed episodes care 2013-2015</td>
<td>Contract management data Pseudonymised patient data 2013 - 2015</td>
</tr>
<tr>
<td>Figure 18: Rates of Adult Eating Disorder Specialised Beds used per 100,000 population (95% CI) 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 19: Crude rates for population accessing inpatient eating disorder services North East and Cumbria 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 20: Proportion of beds used &lt; 126 days in Adult Eating Disorder Services per CCG North East and Cumbria 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 21: Proportion of repeat admissions to Commissioned Specialised Eating Disorder Services in the North East and Cumbria 2010-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 22: Admission method FEAs 2010 - 2015</td>
<td></td>
</tr>
<tr>
<td>Figure 23: Range of contacts with Specialised Eating Disorder Outpatient/Day Services North East and Cumbria 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 24: Patients with &lt;10 contacts with Specialised Eating Disorder Outpatient/Day Services in the North East and Cumbria 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 25: Patients with &gt;50 outpatient contacts 2013-2015</td>
<td></td>
</tr>
<tr>
<td>Figure 26: CCG outpatient contacts per 100,000 population (95% CI) .</td>
<td></td>
</tr>
</tbody>
</table>

Hospital episodes statistics 2010 - 2015

Contract management data Pseudonymised patient data 2013 - 2015
### Appendix x: Data requests HES

#### Time period (financial years)
- 2010 – 2011
- 2011 – 2012
- 2012-2013
- 2013-2014
- 2014 (Q 1, Q2 and Q3)

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>Geography</th>
<th>Demographics</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia Nervosa (F50)</td>
<td>NTW</td>
<td>Age</td>
<td>Inpatients or Outpatients</td>
</tr>
<tr>
<td>Atypical anorexia nervosa (F50.1)</td>
<td>TEWV</td>
<td>Gender</td>
<td>Length of stay</td>
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<tr>
<td>Bulimia Nervosa (F50.2)</td>
<td>Newcastle upon Tyne Hospitals</td>
<td>Ethnicity</td>
<td>Readmission (time period between discharge and readmission)</td>
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<td>IMD (ranked by SOA)</td>
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<tr>
<td>F50.4 Overeating associated with other psychological disturbances</td>
<td>National</td>
<td></td>
<td>Emergency admission</td>
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<tr>
<td>F50.5 Vomiting associated with other psychological disturbances</td>
<td>Local authority (area of residence of patient)</td>
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<td>Planned admission</td>
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<tr>
<td>F50.8 Other eating disorders</td>
<td>North East and Cumbria</td>
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<td>Voluntary admission or held under the 1983 Mental Health Act</td>
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<td>F50.9 Eating disorder, unspecified</td>
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<td>Treatment codes*</td>
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<td>Number of treatments per episode*</td>
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<tr>
<td>All diagnosis</td>
<td>Treatment providers:</td>
<td>Age</td>
<td>Inpatients or Outpatients</td>
</tr>
<tr>
<td>ICD codes (F50 – F50.9)</td>
<td>NTW</td>
<td>Gender</td>
<td>Length of stay</td>
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<td>Eating disorders</td>
<td>TEWV</td>
<td>Ethnicity</td>
<td>Readmission (time period between discharge and readmission)</td>
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<td>Newcastle upon Tyne Hospitals</td>
<td>IMD (ranked by SOA)</td>
<td>New referral</td>
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<td>Foundation Trust</td>
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<td>Emergency admission</td>
</tr>
<tr>
<td></td>
<td>Local authority (area of residence of patient)</td>
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<td>Number of treatments per episode*</td>
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### Appendix xi: Service Providers Data Request

<table>
<thead>
<tr>
<th>Patient Demographics</th>
<th>Admission</th>
<th>Number of Interventions delivered</th>
<th>Clinical</th>
<th>Clinical Outcome Measures</th>
<th>Assessments</th>
<th>Discharge</th>
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<tbody>
<tr>
<td>Age</td>
<td>Date of first diagnosis</td>
<td>CBT</td>
<td>Group programmes</td>
<td>NG</td>
<td>EDE-Q</td>
<td>Family/carers assessment</td>
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<td>Gender</td>
<td>Date of admission</td>
<td>IPT</td>
<td>Nutritional psych education</td>
<td>Blood testing (daily same day results)</td>
<td>Beck -Depression Inventory</td>
<td>Planned discharge (date)</td>
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<td>Ethnicity</td>
<td>Planned or emergency</td>
<td>MET</td>
<td>Emotional coping skills</td>
<td>ECG</td>
<td>Beck hopelessness scale</td>
<td>Nutritional care plans</td>
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<td>CCG</td>
<td>Number of prior admissions (dates)</td>
<td>CAT</td>
<td>Independent living</td>
<td>Drugs prescribed</td>
<td>Anxiety and depression scale</td>
<td>Risk assessment</td>
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<td>Employment and education</td>
<td>BMI on admission</td>
<td>Family interventions</td>
<td>Social skills</td>
<td>Self-esteem scale</td>
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<td>SAS-M</td>
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<td>Temperature</td>
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Time period: Financial Years
2010-11
2011-12
2012-13
2013-14
2014-15

Can this data be by individual patient and provide a transferable unique non-identifiable patient number/ID