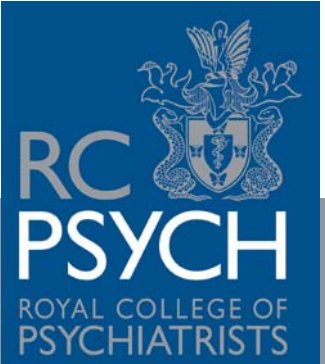


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# Eating disorders in the UK: service distribution, service development and training

Report from the Royal College of Psychiatrists' Section of Eating Disorders

March 2012

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Section of Eating Disorders

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# Contents

Working group	4
Executive summary and recommendations	5
Aims and objectives	8
Background	9
Training of specialists in the psychiatry of eating disorders	19
Main findings of the 2008 survey of eating disorders services in the UK and Ireland	20
Surveys of service providers and patients	27
Appendices	
A. Questionnaire for health professionals with a special interest in eating disorders (includes all CAMHS practitioners)	35
B. Eating disorders services: questionnaire for health professionals in general adult services	41
C. Eating disorders services: questionnaire for service users	46
D. Definitions	51
References	52

# Working group

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# Executive summary and recommendations

Eating disorders are serious mental disorders with high levels of physical and psychological comorbidity, disability and mortality. Two previous Royal College of Psychiatrists surveys of services for patients with eating disorders were published in 1992 (Council Report CR14) and 2000 (Council Report CR87). Both identified poor provision of specialist eating disorder services and that patients often had to travel long distances from home for treatment.

To review national provision for eating disorders, a further survey was undertaken of services providing specialist treatment for patients with eating disorders in the UK and the Republic of Ireland, including services for children, adolescents and adults in the National Health Service (NHS) and the private sector. Services for obesity were not surveyed. Overall, 83 services from all parts of the UK and Ireland participated; 62 (75%) were NHS services. This is an increase in the number of services compared with the earlier reports. Twenty-three services catered for both children and adolescents; 23 for adolescents only; 7 for children and adults (including one treating 13- to 25-year-olds); and 29 for adults only. One service did not provide information on the age range of people treated.

The majority of services were led by a consultant psychiatrist (82%). Multidisciplinary teams included a wide range of health professionals, most commonly specialist nurses (81%) and clinical psychologists (76%); 54% of teams had a dietician, 51% had a psychotherapist, 49% had a social worker and 47% an occupational therapist.

Therapeutic approaches used by services most often were:

- for anorexia nervosa – individual cognitive-behavioural therapy (CBT) (84%), nutritional advice and monitoring (82%) and family-based treatment (77%)
- for bulimia nervosa – individual CBT (79%), self-help literature (67%) and selective serotonin-reuptake inhibitors (SSRIs) (65%)
- for binge eating disorder – self-help interventions (58%), nutritional advice and monitoring (54%) and individual CBT (54%)
- for eating disorder not otherwise specified (EDNOS) – individual CBT (67%), nutritional advice and monitoring (62%) and self-help interventions (54%)
- for in-patients – nutritional advice and monitoring (63%), individual CBT (58%) and anxiety management/relaxation (54%).

Of 447 in-patient beds identified in the UK (226 NHS, 221 private sector), 330 (74%) were in specialist units (166 NHS, 164 private sector).

Of note, some parts of the UK had little or no NHS in-patient provision for eating disorders.

The average length of stay in specialist eating disorder units (EDUs) was 18.2 weeks (s.d.=8.4) and 18.4 weeks in child and adolescent mental health (CAMH) in-patient units (s.d.=12.9). This is on average more than a month longer than admissions in the early 1990s (Royal College of Psychiatrists, 1992). Severely medically ill patients were most commonly admitted to a medical ward with involvement of eating disorders staff (62%) or to a paediatric ward (47%), or treated in a specialist EDU with medical input (25%).

Outcome monitoring was undertaken by 75% of participating services. Outcome measures varied widely, with a mixture of eating disorder-specific and generic measures being employed. Only a minority of services met all four criteria for a specialist service (i.e. in terms of seeing >25 newly referred patients per annum, the multidisciplinary staff required, the provision of out-patient and in-patient treatment and the availability of both individual and family interventions).

This survey demonstrates a welcome increase in number of services since the previous College report. However, it appears that this increase is mainly explained by a growth in small services that do not fulfil all criteria of a specialist service. This has implications for the quality of care provided, for instance in terms of the confidence of services in dealing with severe or complex presentations, access to a range of evidence-based treatments and transitions between services.

## RECOMMENDATIONS

- 1 An integrated quality network for eating disorder services across the age range covering all service components of eating disorders services and involving patients and carers should be set up to provide external quality control and accreditation of services.
- 2 A national audit of eating disorder services should be conducted. This should:
  - a look into care pathways and transitions between services, both from community to more intensive treatments and across the age range; this needs to include an evaluation of patient and carer experience of treatment and of care pathways
  - b explore the reasons for lengthy in-patient admissions, both for children/adolescents and for adults
  - c evaluate adherence to the MARSIPAN guidelines (Royal College of Psychiatrists & Royal College of Physicians, 2010), given that a substantial group of individuals with eating disorders receive in-patient treatment in medical or paediatric units.
- 3 All eating disorders services should conduct outcome monitoring. The Eating Disorders Section of the Royal College of Psychiatrists should produce a list of recommended outcome measures to be used. In addition, an eating disorders-specific glossary/adaptation of Health of the Nation Outcome Scales (HoNOS), HoNOS-eating disorders should be developed.

- 4 The availability of evidence-based psychological treatments in in-patient eating disorders settings is limited and needs to be improved. It must include access to both individual and family-focused psychological interventions.
- 5 Eating disorders services seem to be mainly using traditional models of care, including out-patient and in-patient care, with other service components being available more rarely. Innovative ideas for service models and configurations should be developed in collaboration with colleagues in primary and secondary care services and tested, with the aim of reducing fragmentation of eating disorders services and care pathways.
- 6 All areas should have access to a specialist eating disorders service with in-patient beds. We stand by our previous recommendation (Royal College of Psychiatrists, 2000) that specialist eating disorders services should be led by a consultant psychiatrist and need to be multidisciplinary. Adding up consultant sessions available at present gives a total of about 33 whole-time equivalent (WTE) consultant sessions, with a proportion of the sessions in the private sector. This suggests that at least another 39 consultant WTEs are required to bring the country average up to 1.2 WTE per 1 million population.<sup>1</sup>
- 7 The broad composition of a specialist eating disorders service for a population of 1 million people should be 1.2 WTE 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.

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<sup>1</sup> CR87 (Royal College of Psychiatrists, 2000) specified 1 WTE eating disorders consultant per 1 million population. This figure has been scaled up owing to the significantly increased demands on consultant time. For further details see pages 24–25 of this report.



# Aims and objectives

## BROAD AIMS

- 1 To conduct a review of service provision for eating disorders (with emphasis on quantity and quality) in the UK and Ireland.
- 2 To assess need for training posts in eating disorders.

## SPECIFIC OBJECTIVES

- 1 To conduct a mapping exercise of eating disorder service provision for children, adolescents and adults within the NHS and private sector across the whole of the UK and the Republic of Ireland.
- 2 To get a measure of adherence to key National Institute for Health and Clinical Excellence (NICE) recommendations within eating disorder services.

# Background

The eating disorders (anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise specified (EDNOS)) are biologically based serious mental disorders which individuals typically acquire in mid-adolescence at a developmentally sensitive time (Klump *et al*, 2009). About 90% of those affected are female. Lifetime prevalence rates for full and partial anorexia nervosa in the general population range from 0.9 to 4.3% for females (Hudson *et al*, 2007; Wade *et al*, 2006), and from 4 to 7% for full and partial bulimia nervosa (Favaro *et al*, 2003). The lifetime prevalence of binge eating disorder is 3.5% in women and 2.0% in men (Hudson *et al*, 2007). The overall incidence and prevalence of anorexia nervosa and bulimia nervosa is stabilising in Western countries (Currin *et al*, 2005; van Son *et al*, 2006), but increasingly younger people are affected. The incidence of EDNOS and binge eating disorder continues to rise, as does the combination of eating disorders and obesity (Darby *et al*, 2009; Hay *et al*, 2008).

Eating disorders have major psychological, physical and social sequelae (Hjern *et al*, 2006) with poor quality of life (De la Rie *et al*, 2007; Pohjolainen *et al*, 2009) and high health burden (Mond *et al*, 2009). The mortality in anorexia nervosa is high (Papadopoulos *et al*, 2009; Button *et al*, 2010), although introduction of specialist services appears to have improved survival (Lindblad *et al*, 2006). Less is known about the mortality rates of bulimia nervosa and EDNOS, although a relatively recent large study suggests this may be as high as that of anorexia nervosa (Crow *et al*, 2009a). Eating disorders also exert a high burden on families and other carers (Haigh & Treasure, 2003; Winn *et al*, 2007). Given these features, the provision of services is complex. Patients' pathways through care are often not straightforward, as there are typically a number of transitions, including those between general and specialist services, child/adolescent and adult services, student health and home services, paediatric/medical and psychiatric services (Treasure *et al*, 2005).

This report is a revision of Council Report 87 (Royal College of Psychiatrists, 2000), which focused on provision of specialist services for eating disorders and training of eating disorders specialists. That publication was itself based on an earlier Council Report on eating disorders (Royal College of Psychiatrists, 1992). In the intervening 10-year period, the landscape and policy context of the NHS have changed considerably. In what follows we will set the scene by briefly reviewing the findings of the two previous Royal College of Psychiatrists reports and will then describe the policy and research context which forms the background to the present survey and report.

## PREVIOUS ROYAL COLLEGE OF PSYCHIATRISTS' SURVEYS ON EATING DISORDERS

In 1992, the Royal College of Psychiatrists surveyed 21 specialist services for eating disorders in the UK. The survey showed that 1560 new patients were treated at these centres. Of these, 239 were admitted as in-patients, most of them for anorexia nervosa. The average duration of hospital stay was 13 weeks (Robinson, 1993). There were few local specialist services and patients had to travel long distances for treatment. A second survey was conducted in 1998; it focused on the provision of eating disorder services and the availability of training for specialists. The survey found that the number of NHS units for the treatment of eating disorders had increased from 21 to 39 (Royal College of Psychiatrists, 2000). In addition, 18 private eating disorders services were identified. However, in many areas of the UK eating disorders service provision remained poor. Only about half of health authorities had a specialist service within their area, whereas under two-thirds had a consultant psychiatrist with at least three sessions devoted to eating disorders. Training positions at senior house officer or specialist registrar level were only available in half the clinics. Services for children and adolescents with eating disorders tended to provide a wider range of therapies, but were even more unequally distributed, with four regions, containing 25% of the UK population, having no available specialist service. The report concluded that in large parts of the UK services for the assessment and treatment of severe eating disorders were inadequate. The 1998 survey did not provide information on service user opinion, the number of in-patients, or the average length of stay.

The report made a number of recommendations.

- 1 Each health authority, health board or primary care trust should identify local need for services for people with eating disorders at all ages, taking into account the views of user and carer groups.
- 2 Purchasers should establish adequate local services led by consultant psychiatrists to meet locally identified need. A ratio of 1 full-time equivalent consultant post per 1 million population should be secured for eating disorders in adults.
- 3 Services for eating disorders should be planned together with services for patients with psychiatric disorder in both primary and secondary care.
- 4 Six beds (or a combination of fewer beds and intensive day care places) per 1 million population, together with two or three local out-patient clinics, should be provided for patients over 16 years of age.
- 5 Recommendations for the treatment of children under 16 years of age should be developed under the auspices of the Royal College of Psychiatrists' Faculty of Child and Adolescent Psychiatry.
- 6 With regard to workforce implications, the report recommended that around 40 WTE consultant psychiatrists would be required to fill the identified need for the treatment of adults (over 16 years of age) with eating disorders.

## POLICY CONTEXT

Since the publication of CR87 (Royal College of Psychiatrists, 2000), a number of documents have been published which are of relevance to the present report.

### *NICE GUIDELINES FOR EATING DISORDERS*

The NICE guidelines (National Collaborating Centre for Mental Health, 2004) apply to England, Wales and Northern Ireland; in Scotland separate guidance has been published (NHS Quality Improvement Scotland, 2006). The NICE guidelines make 102 clinical recommendations and contain recommendations for audit and implementation. Key priorities for implementation are as follows.

#### ANOREXIA NERVOSA

- Most people with anorexia nervosa should be managed on an out-patient 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 refeeding with careful physical monitoring (particularly in the first few days of refeeding) in combination with psychosocial interventions.
- Family interventions that directly address the eating disorder should be offered to children and adolescents with anorexia nervosa.

#### BULIMIA NERVOSA

- As a possible first step, patients with bulimia nervosa should be encouraged to follow an evidence-based self-help programme.
- As an alternative or additional first step to using an evidence-based self-help programme, adults with bulimia nervosa may be offered a trial of an antidepressant drug.
- Cognitive-behavioural therapy for bulimia nervosa (CBT-BN), a specifically adapted form of CBT, should be offered to adults with bulimia nervosa. The course of treatment should be for 16–20 sessions over 4–5 months.
- Adolescents with bulimia nervosa may be treated with CBT-BN, adapted as needed to suit their age, circumstances and level of development, and including the family as appropriate.

#### ATYPICAL EATING DISORDERS

- In the absence of evidence to guide the management of atypical eating disorders (EDNOS) other than binge eating disorder, it is recommended that the clinician considers following the guidance on the treatment of the eating problem that most closely resembles the individual patient's eating disorder.

- CBT for binge eating disorder (CBT-BED), a specifically adapted form of CBT, should be offered to adults with binge eating disorder.

#### ALL EATING DISORDERS

- Family members, including siblings, should normally be included in the treatment of children and adolescents with eating disorders. Interventions may include sharing of information, advice on behavioural management and facilitating communication.

Many of the recommendations have considerable resource and training implications for services. The guideline (National Collaborating Centre for Mental Health, 2004) states:

'There are insufficient data about the health service utilization patterns of patients with eating disorders and about the currently available health care resources for the treatment and management of eating disorders; hence at present it is impossible to calculate the estimated cost impact of the implementation of this guideline for the NHS.

However, it is anticipated that the recommended shift towards CBT in the management of bulimia nervosa would impose a great need for health care professionals trained in bulimia nervosa specific CBT. The NHS cost of bulimia nervosa specific CBT training per person was calculated using the resource use information provided by the [guideline development group]. The estimate is based on the teaching programme of the Department of Psychiatry, University of Oxford, UK including a two-day workshop, 20 four-hour long meetings and the additional time required by the trainer for a group of five trainees...The total training cost per trainee was estimated to be £4326 in year 2002-2003' (p. 179).

This estimate did not include qualification costs, travel costs and the cost of time spent travelling related to training. Moreover, although prescription of antidepressants for bulimia nervosa has become widespread, evidence on their long-term efficacy, particularly on the likelihood of relapse after drug withdrawal, is lacking (Berkman *et al*, 2006).

#### *NATIONAL SERVICE FRAMEWORK FOR CHILDREN AND ADOLESCENTS*

Central themes of this document (Department of Health & Department for Education and Skills, 2004) are the principle of early intervention and the delivery of evidence-based, high-quality care in age-appropriate facilities for young people up to the age of 18. Standard 4 focuses specifically on transition to adulthood and states:

'All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.'

Key aims of Standard 9 include that 'multi-agency services, working in partnership...provide early intervention and also meet the needs of children and young people with established or complex problems'; and that 'all children, young people and their families have access to mental health care based upon the best available evidence and provided by staff with an appropriate range of skills and competencies'.

Children and young people who require admission to hospital for mental health care have access to appropriate care in an environment suited to their age and development.

## *EQUITY AND EXCELLENCE: LIBERATING THE NHS*

This White Paper emphasises: giving patients greater choice and control and equipping them to make decisions through the provision of a greater range of data; focusing on clinical outcomes and quality rather than targets and reducing bureaucracy; empowering clinicians and other healthcare professionals to use their judgement and innovate (Department of Health, 2010).

## RESEARCH CONTEXT

A number of surveys relevant to the aims and objectives of the present review have appeared. These can be subdivided into studies mapping service provision, those focusing on healthcare utilisation and cost of eating disorders care, those examining pathways through care and those assessing service user and carer views on eating disorders services.

## *NEEDS ASSESSMENTS AND STUDIES MAPPING EATING DISORDER SERVICE PROVISION*

### ENGLAND AND WALES

There were two studies of note in England and Wales, the National In-patient Child and Adolescent Psychiatry Study (NICAPS) (O’Herlihy *et al*, 2003) and the *National Map of Feeding and Eating Disorders*, an unpublished study by Dasha Nicholls *et al* (details available from the author on request).

The aim of the NICAPS study was to describe the distribution and characteristics of NHS and private child and adolescent units in England and Wales. Out of a total of 80 child and adolescent units (providing 900 beds), 9 were eating disorder units, providing 98 beds. Seven of these were in the private sector, providing 80 beds. On the census day (19 October 1999), 20.1% of all child and adolescent beds were occupied by eating disorder patients. About half of these were in general child and adolescent units, whereas the other half were in specialist eating disorders units. No comparable figures for adults exist and it is unknown what proportion of adult patients with eating disorders is treated within specialist or generalist in-patient settings. The study did not systematically include paediatric facilities.

The *National Map of Feeding and Eating Disorders* had two aims, to identify services across England and Wales which offer assessment and treatment for children and adolescents with eating and feeding disorders and to determine the nature of these services. Paediatric services were not included in the survey. Services were identified via a number of different routes, including contact with commissioners, conference delegates and clinicians. The study was conducted in 2003. A total of 48 services identified themselves as offering specialist eating disorder care; of these, 12 were in-patient only, 18 offered both in-patient and out-patient (usually outreach) services, and 18 were out-patient only. Many of these would not meet the criteria for a specialist service outlined in CR87 (Royal College of Psychiatrists, 2000). Approximately half of the eating disorders services were within generic CAMHS and half were eating disorders only. Most of the latter were in the independent sector, where the proportion of patients who were NHS funded was over 90%. The mean length of in-patient stay was 6.3 months (range 3–20).

## SCOTLAND

A study from Scotland (Lemouchoux *et al*, 2001) highlighted that over 20% of the Scottish population had no access to any specialist services for eating disorders within the NHS. At the same time an estimated £1.9 million per annum was spent by the 15 health boards in Scotland commissioning care through private sector providers (Carter & Millar, 2004). The findings from this study led to a needs assessment at the national level and the outlining of a five-tiered model for service development.

## NORTHERN IRELAND

In Northern Ireland, the Review of Mental Health and Learning Disability (2005) identified that most service users were managed within primary care and generic adult and child and adolescent mental health services. Voluntary groups played an important part in supporting service users and carers. As there was no local specialist in-patient unit people requiring such treatment were sent outside Northern Ireland. These extra-contractual referrals were costly. For example, within the Eastern Health and Social Services Board (Northern Ireland's largest local health authority responsible for a population of about 665 000 patients) in the financial year 2003/2004, 9 patients were sent to England at a cost of around £ 500 000.

The Department of Health, Social Services and Public Safety therefore made the development of eating disorders services a priority. A Regional Eating Disorders Working Group was set up to oversee this work. As part of a local needs assessment the Group commissioned qualitative research which sought the views of patients, carers and service providers. Key issues identified from this were problems with awareness and early detection, primary care intervention, the paucity of integrated and equitable specialist services as well as the need for good health promotion strategies.

## STUDIES ON HEALTH SERVICE UTILISATION AND COST OF EATING DISORDERS CARE

### COST OF EATING DISORDERS CARE

The economic burden and health service use of eating disorders have received little attention, although such data are necessary to estimate the implications of any changes in clinical practice for patient care and healthcare resource requirements. As part of the NICE guideline development a systematic review was conducted reviewing the literature from 1980 to 2002 to report the current international evidence on the resource use and cost of eating disorders (Simon *et al*, 2005). Two cost-of-illness studies from the UK and Germany (Krauth, 2002), one burden-of-disease study from Australia (Vos *et al*, 2001) and fourteen other publications with relevant data from the UK, the USA, Austria, Denmark and The Netherlands could be identified. In the UK, the healthcare cost of anorexia nervosa was estimated to be £4.2 million in 1990. In Germany, the healthcare cost was €65 million for anorexia nervosa and €10 million for bulimia nervosa during 1998. The Australian study reported the healthcare costs of eating disorders to be AUS\$22 million for year 1993/1994. Other costing studies focused mostly on in-patient care, reporting highly variable estimates. There was a dearth of research on non-healthcare costs,

although one study suggests that financial costs of bulimia are significant (Crow *et al*, 2009b).

Since then, a study comparing patients with eating disorders, those without eating disorders and a depression comparison group found healthcare costs for eating disorders patients to be higher than those for the non-eating disorders comparison group and similar to the depression comparison group; these costs remained high in the years following diagnosis (Mitchell *et al*, 2009). In the context of a randomised controlled trial the annual healthcare costs for anorexia nervosa in adolescents have been estimated as £34000 in the early stage of the illness (Byford *et al* 2007). These costs are likely to be higher for adults, because of the often lengthy hospital treatment (see below).

#### LENGTH OF HOSPITAL STAY

A study on NHS hospital admissions for adult psychiatric illness in England between April 1999 and March 2000 (Thompson *et al*, 2004) found admissions for patients with eating disorders to constitute 0.7% of all psychiatric admissions. Out of all diagnoses considered, patients with eating disorders had the highest proportion of admissions, the longest median length of stay (36 days), with 26.8% remaining in hospital >90 days. This study did not consider patients younger than 16, those admitted to psychiatry following an in-patient episode in a medical unit (e.g. medical admissions for self-harm) and those admitted to the private sector. A comparable study from Switzerland (Warnke & Rössler, 2008) found individuals with eating disorders to have the second longest duration of stay in hospital (after those with organic disorders).

## RESEARCH ON PATHWAYS THROUGH CARE AND IMPLEMENTATION OF THE NICE GUIDELINES

Several studies have addressed these issues from different and complementary perspectives, including those of various healthcare professionals and patients and their carers.

### *SURVEYS OF SERVICE USERS AND CARERS BY THE EATING DISORDERS ASSOCIATION*

The report *Getting Better?* prepared by the Eating Disorders Association UK (currently Beat) in 2005 was published to coincide with the 1-year anniversary of the publication of the NICE guidelines (National Collaborating Centre for Mental Health, 2004). In total, 1700 members of the Association and other people affected by eating disorders, including patients, carers and professionals, completed a health-check card. As much as 42% of respondents endorsed the item that early diagnosis by general practitioners (GPs) was unsatisfactory; 55% agreed that availability of specialist care was unsatisfactory and 34% felt that involvement of families was unsatisfactory. A second report, published in 2008, *Choice or Chance* reinforces the points already made: 1500 people were surveyed; of these, only 15% reported their GP understood eating disorders and knew how to help.



## *PATHWAYS THROUGH PRIMARY CARE STUDY*

This study (Currin *et al*, 2006) aimed to improve knowledge about the kind of services patients with eating disorders get in primary care and the decision-making processes involved in making a referral to secondary and tertiary care (Currin *et al*, 2006, 2007). A three-stage survey of all GPs in the South Thames Region ( $n=3783$ ) was conducted. On average, each individual GP saw two new patients with eating disorders per year. A quarter of all eating disorders patients were managed exclusively in primary care. Only 4% of GPs reported using a published guideline or protocol for managing eating disorders, mainly following the recommendation to measure patients' weight and height. In contrast, only 24.7% of GPs reported providing every patient with an eating disorder with information about their illness. Between 58 and 65% of GPs did not use the recommended body mass index (BMI) criterion to guide referrals. In-depth qualitative interviews with primary care physicians revealed a number of themes:

- GPs' concerns focused almost exclusively on anorexia nervosa, despite epidemiological evidence which suggests that the incidence and prevalence of bulimia nervosa is considerably greater
- the perceived role of primary care is to identify eating disorders cases, offer patients a supportive environment and refer them on for treatment to specialist services
- although GPs often mentioned the impact of anorexia nervosa on family members, especially at first presentation, they expressed uncertainty in how best to deal with this
- there was considerable frustration about referral pathways which often require GPs to refer patients with eating disorders to generic community mental health teams (CMHTs) as a prerequisite to specialist care
- many GPs are dissatisfied with the care they are able to give to patients with eating disorders and feel inadequately trained in effective treatment strategies
- GPs have many conflicting clinical and service priorities and feel overwhelmed by the number of guidelines distributed to primary care, resulting in low levels of awareness and utilisation of formal guidance on eating disorders.

## *PATHWAYS THROUGH SECONDARY CARE*

Very little is known about pathways of patients with eating disorders through secondary care. Many people with eating disorders are treated within CMHTs and in some areas this may be the majority of those presenting, even if a specialist service is available.

As there are often significant competing priorities in general adult psychiatry, the issue of capacity and competence for dealing with individuals who have an eating disorder in secondary care is important. If secondary care has problems of either capacity or competence, then stepped-care/patient pathway or hub-and-spoke models of care will have a gap and will be compromised.

## *PATHWAYS THROUGH SPECIALIST CARE*

This study prospectively followed pathways through care of over 1000 patients referred to the St George's Hospital and the South London and

Maudsley NHS Trust's eating disorders units (Waller *et al*, 2009a). Key findings were: 41% of patients referred for specialist treatment did not take up treatment and of those who did start treatment, about half dropped out. Those who entered treatment showed significant improvement in the eating disorder and comorbid symptoms and quality of life. People from minority ethnic groups were under-represented among eating disorder patients (Waller *et al*, 2009b).

## VIEWS ON EATING DISORDERS SERVICES FROM SERVICE USERS AND CARERS

The NICE guidelines on eating disorders emphasise the importance of the patient and carer experience in building a good therapeutic relationship and improving engagement with treatment goals. Research on the views of service users and carers has been a neglected area in the field of eating disorders (Bell, 2003). Only a handful of relatively large-scale studies exist (De la Rie *et al*, 2007; Escobar Koch *et al*, 2010; Nishizono-Maher *et al*, 2010). A survey of over 1800 individuals with eating disorders and other interested parties (i.e. carers, health professionals) conducted by the Academy for Eating Disorders asked participants to name the essential features of a high-quality eating disorder service and list their concerns about eating disorder treatments/services as practised currently (Escobar-Koch *et al*, 2010). A content analysis comparing the views of 144 US and 150 UK eating disorder service users was carried out. Both US and UK service users identified the following as essential aspects of care: a good therapeutic relationship; a holistic approach; individual psychotherapy or counselling; specialised treatment; client-centred care; support. In the US sample the main concerns involved lack of financial accessibility to services and problems with insurance coverage. In the UK sample, lack and inequity of availability of services were highlighted and several barriers to accessing care were identified. These concerned the gate-keeping role of GPs and long waiting lists in specialist services. Participants expressed concern about GPs' lack of knowledge of eating disorders and failure to perform timely diagnoses, which result in marked delays in referring patients to specialist services. This survey culminated in the development of the *Worldwide Charter for Action on Eating Disorders* (Academy for Eating Disorders, 2006), an aspirational document specifying what patients and carers can reasonably expect from an eating disorders service.

A survey of 200 adolescents with anorexia nervosa and their carers revealed higher rates of satisfaction in the carers than among young people themselves and higher rates of satisfaction with specialist (in-patient and out-patient) services than general CAMHS (Roots *et al*, 2009).

## SUMMARY

Previous reports from the Royal College of Psychiatrists and more recent mapping studies and needs assessments of specialist service provision for eating disorders have shown a picture of at best patchy and at worst non-existent provision of specialist services in many parts of the UK and Ireland. Training posts in eating disorders are few and far between. To date, no single

mapping exercise exists that has assessed eating disorders service provision in the UK and Ireland across the whole age range (childhood through to adulthood), including the NHS and the private sector and also including paediatric and general psychiatric services. Thus, only a fragmented picture of service provision is available, leading to serious underestimates of service provision and utilisation and making it difficult to plan for the future.

The recommendations of NICE guidelines on eating disorders provide a clear template against which the quality of services can be judged. Although the guideline applies to England and Wales, it is likely that it will inform clinical practice in other parts of the UK, too. As yet nothing is known about how the guideline is being implemented in specialist eating disorders services and the cost and training implications of this.

Finally, very little is known about whether or not NICE guidance has made a palpable difference for patients and their carers in terms of accessing high-quality evidence-based care. In designing the survey underpinning the present report a balance had to be struck between striving for comparability with the previous reports and also aiming to focus on additional areas, such as NICE guidance.

# Training of specialists in the psychiatry of eating disorders

Assessment and treatment of young people with eating disorders and their families forms part of the core child and adolescent psychiatry curriculum, and is everyday practice for specialist tier 3 CAMHS services in most areas. Increasingly, however, eating disorders teams are being established within specialist CAMHS, requiring child and adolescent psychiatrists to subspecialise. Specialist training opportunities for child and adolescent psychiatrists in eating disorders remain sparse owing to the paucity of highly specialised eating disorders services for young people within the NHS. This training need is unlikely to be adequately addressed without significant changes to service organisation for young people with eating disorders. The term 'specialist eating disorders service' within CAMHS can mean very different things, with wide geographical variation. Central to this is the fact that, within CAMHS services, in-patient and out-patient services are rarely integrated.

Training of psychiatrists in the assessment and management of adults with eating disorders has been developing over the past few years. A curriculum for the emerging specialty of eating disorders psychiatry (adults) has been written and is under consideration by the General Medical Council (GMC), with a view to establishing Eating Disorders Psychiatry as a recognised subspecialty of general and community psychiatry. We hope to hear from the Royal College of Psychiatrists and the GMC about these developments.

# Main findings of the 2008 survey of eating disorders services in the UK and Ireland

Eighty-three services participated in the survey of eating disorders specialists in all parts of the UK and Ireland; 62 of these (75%) were NHS services. Twenty-three services catered for both children and adolescents; 23 for adolescents only, 7 for children and adults (including 1 treating 13- to 25-year-olds), and 29 services for adults only; one service did not provide information on the age range of people treated. The majority of services were led by a consultant psychiatrist (82%). Multidisciplinary teams included a wide range of health professionals, most commonly specialist nurses (81%) and clinical psychologists (77%); 54% of teams had a dietician, 51% had a psychotherapist, 49% a social worker and 47% an occupational therapist.

The number of new referrals per annum varied widely. Only 32 (53%) of the 61 services that responded to that question saw more than 25 new referrals per annum. Seventy per cent of participating services assess urgent cases within 1 week of referral.

Therapeutic approaches used by services most often were:

- for anorexia nervosa – individual CBT (84%), nutritional advice and monitoring (82%) and family-based treatment (77%)
- for bulimia nervosa – individual CBT (79%), self-help literature (67%) and SSRIs (65%)
- for binge eating disorder – self-help interventions (58%), nutritional advice and monitoring (54%) and individual CBT (54%)
- for EDNOS – individual CBT (67%), nutritional advice and monitoring (62%) and self-help interventions (54%)
- for in-patients – nutritional advice and monitoring (63%), individual CBT (58%) and anxiety management/relaxation (54%).

For anorexia nervosa, 74% of services were able to offer in-patient care, 78% offered out-patient care and 49% day care. Of 447 in-patient beds identified in the UK (226 NHS, 221 private sector), 330 (74%) were in specialist units across 30 specialist services, with 166 beds in the NHS (in 18 services) and 164 in the private sector (12 services). Of note, some parts of the UK have little or no NHS in-patient eating disorders provision.

The average length of in-patient stay in specialist EDUs was 18.2 weeks (s.d.=8.4) and 18.4 weeks in CAMHS in-patient units (s.d.=12.9). Severely medically ill patients were most commonly admitted to a medical ward with involvement of eating disorders staff (62%) or to a paediatric ward (47%), or treated in a specialist EDU with medical input (25%).

The proportion of in-patients detained under the Mental Health Act was on average 8%.

Follow-up post-discharge from in-patient treatment was offered by the majority of services (49 out of 57) and in 32 out of 43 services this was specialist follow-up. Outcome monitoring was undertaken by 75% of participating services. Outcome measures varied widely, with a mixture of eating disorder-specific and generic measures being applied.

Only a minority of services met all four criteria for a specialist service (i.e. in terms of seeing > 25 new referrals per annum, the multidisciplinary staff required, the provision of out-patient and in-patient treatment and the availability of both individual and family interventions).

This survey demonstrates a welcome increase in number of services since the previous College report (Royal College of Psychiatrists, 2000). However, it appears that this increase is mainly explained by a growth in small services that do not fulfil all criteria of a specialist service.

## SERVICE DEVELOPMENT SINCE 2000

The 2008 Royal College of Psychiatrists' survey underpinning the present report was designed in part to map on to the previous report. In addition, it focused on new areas, not addressed in the previous publication.

Recommendations of the 2000 report are in italics.

- a *Each health authority or health board and/or primary care group (PCG) or primary care trust (PCT) should identify local need for services for adults and for children and adolescents with eating disorders, taking into account the views of users and user groups.*

The observed increase in services suggests that this objective has been at least partially met.

- b *Purchasers should establish adequate local services, shared with other purchasers when appropriate, led by consultant psychiatrists, to meet locally identified need. A ratio of one full-time equivalent (FTE) consultant post per million population should be provided for eating disorders in adults.*

Many of the services participating in the 2008 survey did not fulfil the criteria for a specialist service and nearly 20% were not led by a consultant psychiatrist. Therefore, the adequacy of existing services needs to be questioned.

- c *Services for eating disorders should be planned together with services for patients with psychiatric disorder in both primary and secondary care. Some conditions can be dealt with partly or fully by generic services, with support from local specialist services.*

This has not been the focus of the present report.

- d *We recommend the provision of six beds (or a combination of fewer beds and intensive day places) per million population, together with two or three local out-patient clinics, for patients over 16 years of age.*

Of 447 in-patient eating disorders beds for children, adolescents and adults (226 NHS, 221 private sector) identified in the UK, 330 (74%) were in specialist units (across 30 specialist services), with 166 beds in the NHS (in 18 services) and 164 in the private sector (12 services). A more fine-grained analysis separating child and adolescent beds from

adult beds was not possible as a number of units catered for all ages. Of note, some parts of the UK have little or no NHS in-patient eating disorders provision.

- e *Recommendations for the treatment of children under 16 years of age should be developed under the auspices of the College's Faculty of Child and Adolescent Psychiatry.*

Since the 2000 report, the age cut off for referral has changed so that many child and adolescent units accept referrals up to the age of 18. The needs of children and adolescents have been considered in separate reports – NICAPS (O'Herlihy *et al*, 2003) and *National Map of Feeding and Eating Disorders* (D. Nicholls *et al*, details available from the author on request).

- f *Consultant numbers: around 60 whole-time equivalent consultant psychiatrists will be required for the treatment of adults (over 16 years of age) with eating disorders.*

Adding up consultant sessions available at present gives a total of about 33 WTEs, with a proportion of the sessions in the private sector. This suggests that at least another 39 consultant WTEs are required to bring the country average up to 1.2 WTE consultant per 1 million population.<sup>2</sup>

## RECOMMENDATIONS – WHAT NEEDS TO HAPPEN NOW

- 1 An integrated quality network for eating disorder services across the age range, covering all service components of eating disorders services and involving patients and carers, needs to be set up to provide external quality control and accreditation of services. The Section of Eating Disorders, in collaboration with Beat and the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI), is currently developing such a network. The aim is that over time this will provide accreditation for eating disorder services. This is the first quality network to cover in-patient and out-patient services and also to span the whole age range from childhood to adulthood. As such, it serves as a model for other quality networks to be developed. This will allow production of the data set out in the NHS White Paper (Department of Health, 2010) that will inform patient choice in care (see p. 13, this report).
- 2 A national audit of eating disorder services should be conducted. An expression of interest should be submitted to Healthcare Quality Improvement Partnership (HQIP) for such an audit. The audit should address the following topics.
  - a Care pathways and transitions between services, both from community to more intensive treatments and *vice versa* and across the age range. This needs to include an evaluation of patient and carer experience of treatment and of care pathways.

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<sup>2</sup> CR87 (Royal College of Psychiatrists, 2000) specified 1 WTE eating disorders consultant per 1 million population. This figure has been scaled up owing to the significantly increased demands on consultant time. For further details see pages 24–25 of this report.

Eating disorders have a peak age of onset in mid-adolescence. Thus, many individuals start treatment in child and adolescent services and are handed over to adult services. Transitions from child/adolescent to adult services or from community to in-patient services are difficult and disruptive for patients and families owing to time delays between assessment and treatment, duplication of information, disruption in bonds with healthcare professionals, and differences in philosophies of care (Treasure *et al*, 2005). Gate-keeping and bottlenecks between different service intensities also are disruptive.

Very little is known about patient and carer experience of different eating disorder treatments and settings and in particular different care pathways. One study (House, 2011) has evaluated different care pathways for children and adolescents with anorexia nervosa in and around London from the perspectives of patients, carers and service providers, using a mixed-methods approach (quantitative and qualitative). A funded national audit could build on this approach and extend it.

- b In-patient admissions are lengthy, both for children/adolescents and adults. Attempts should be made to explore this.

Criteria for in-patient admission in people with eating disorders vary considerably between different countries. In Britain, in-patient treatment is reserved exclusively for those with a very severe form of the illness. The substantial increase in duration of in-patient treatment compared with data from the first Royal College of Psychiatrists' report on eating disorders (1992) is of concern and needs to be evaluated to understand the reasons for this. In fact, the reported average 18-week duration of in-patient admissions in the present report may even be an underestimate as a recent study of in-patients in 11 specialist UK eating disorders units showed an average duration of stay of 25 weeks (J. Treasure, 2011, personal communication).

- c Given that a substantial group of individuals with an eating disorder receive in-patient treatment in medical or paediatric units, adherence to the recommendations of the MARSIPAN report (Royal College of Psychiatrists & Royal College of Physicians, 2010) should be evaluated.

The MARSIPAN report on the treatment of severely ill patients with anorexia nervosa was prompted by serious concerns about the care of such patients in medical units and a number of deaths of young people with anorexia nervosa in these settings. An audit of mortality from anorexia nervosa (starvation-related reasons and suicide) should form part of an audit of MARSIPAN recommendations.

- 3 All eating disorders services should conduct outcome monitoring. The College's Section of Eating Disorders should produce a list of recommended outcome measures to be used. In addition, HoNOS for eating disorders needs to be developed. An Eating Disorders Section group on this topic has met and has drafted an eating disorders-specific glossary of HoNOS. The next steps are now to get this agreed by the College, develop accompanying training vignettes and disseminate this to all eating disorders services for use.



- 4 The availability of evidence-based psychological treatments in in-patient settings is limited and needs to be improved. All in-patient services must have access to both individual and family-focused psychological treatment approaches.
- 5 Eating disorders services seem to be mainly using traditional models of care, including out-patient and in-patient care, with other service components such as day care, community outreach and crisis response and resolution being available more rarely. Innovative ideas for service models and configurations should be developed in collaboration with colleagues in primary and secondary care services and tested with the aim of reducing fragmentation of services and care pathways. Consideration should be given to development of integrated eating disorder services across the age range, training of expert patients and carers, developing rehabilitation using a recovery focus, intensive community outreach, etc.

In areas where the provision of eating disorders services is limited or inadequate, primary and secondary care services will need to be willing to take on the role of providing assessment, treatment and support to certain groups of eating disorder patients. Thus, patients with uncomplicated bulimia nervosa or binge eating disorder might be managed using evidence-based guided self-help and CBT for eating disorders in primary care owing to the increased access to psychological services now available in primary care. This will require training of primary care mental health practitioners in these techniques as well as supervision that could be provided by eating disorders specialist services. Second, vulnerable patients with severe and enduring eating disorder (SEED) might be managed by their GPs and secondary psychiatric care under the Care Programme Approach, with access to specialist services for training and supervision as well as referral should a patient deteriorate. Advanced methods for training and supervision using electronic media such as e-learning tools and telemedicine may well form part of these arrangements.

- 6 Based on the data from the present survey, adding up available consultant sessions gives a total of about 33 WTEs nationwide, with a proportion of the sessions in the private sector. This suggests that at least another 39 consultant WTEs are required to bring the country average up to 1.2 consultant psychiatrist per 1 million population. Recommendations for the training of consultants in this field have been developed by the Eating Disorders Special Interest Group and Eating Disorders Section of the Royal College of Psychiatrists. A training curriculum for eating disorders has also been created in preparation for recognition of eating disorders psychiatry as a subspecialty of general and community psychiatry, which is currently being applied for. In future it is envisaged that additional routes into the subspecialty of eating disorders psychiatry will be via child and adolescent psychiatry, psychotherapy and possibly also addictions psychiatry.
- 7 We stand by our previous recommendation (Royal College of Psychiatrists, 2000) that eating disorders services should be led by a consultant psychiatrist and that to qualify as a specialist service there needs to be a multidisciplinary team with expertise in the delivery of a range of evidence-based treatments and a sufficient number of new cases. Commissioners of new eating disorders services need to take note of this.

We have updated the recommendations from CR87 (Royal College of Psychiatrists, 2000) with a suggested distribution of staff across a team serving a population of 1 million (Table 1). Rather than being too prescriptive about the type of psychological therapist, it is assumed that there should be mixed expertise and appropriate seniority. The figures from 2000 have been scaled up owing to the significant increase in time pressures (added treatment requirements as per NICE guidelines) and increases in documentation and administrative requirements.

**Table 1 Suggested distribution of whole-time equivalent (WTE) staff in a team serving a population of 1 million: comparison of two Royal College of Psychiatrists reports**

Type of professional	WTE	
	2000 report	2012 report
Consultant psychiatrist	1	1.2
Senior trainee (ST5, ST6)	1	1.2
Junior trainee (ST3, ST4)	1	1.2
Psychological therapist (including clinical and counselling psychologists, CBT and family therapists)	4.5	5.4
Nurses	24	28.8
Dietician	1	1.2
Occupational therapist/creative therapist	3	3.6
Administrator	3.5	4.2
House-keeper	0.5	0.6

CBT, cognitive-behavioural therapy.

## CONCLUSIONS

Although significant progress has been made since the 2000 Royal College of Psychiatrists report in that there has been an increase in the number of services, all too often these seem to be small services that do not fulfil criteria for a specialist eating disorders service. The number of consultants in eating disorders remains significantly below the 2000 College recommendations. This has implications for the quality of care provided, for instance in terms of the confidence of services in dealing with severe or complex presentations, access to a range of evidence-based treatments and transitions between services. Our recommendations therefore focus on innovation in service developments and on a broad range of other quality improvement and management measures.

Some additional points deserve mentioning.

- Additional qualitative data (not included in this report) were obtained as part of the survey of specialist eating disorders teams and concerned the question of what participating centres considered the strengths of their service were (Koskina *et al*, 2011). Five main strengths of a service were identified:
  - quality of treatment/provision of evidence-based treatments
  - staff skills
  - continuity of care
  - family involvement
  - accessibility and availability.

This suggests that the key messages from the NICE eating disorder guidelines have been absorbed by services and are suitably prioritised. Having said that, complex resource limitations are identified by eating disorders staff as frustrating their efforts in meeting patient need (Reid *et al*, 2010).

- We had hoped to conduct a parallel patient and carer survey. Unfortunately, this did not take place and we therefore only have the provider perspective on the type and quality of service available. As outlined in the recommendations, it will be vital for future Royal College of Psychiatrists reports and eating disorders quality initiatives to firmly include patient and carer perspectives.
- We call upon the College, service commissioners and the government to continue to improve the quality of training and care in eating disorders throughout the UK, to reduce fragmentation of care and care pathways and to facilitate the development of integrated services.

# Surveys of service providers and patients

## SURVEY METHOD

To prepare the present report, a working group was formed from the members of the Section of Eating Disorders of the Royal College of Psychiatrists. Three integrated questionnaires (see appendices A–C) were developed: one for psychiatrists in the UK and Ireland with a special interest in eating disorders, including all child and adolescent psychiatrists, one for adult general psychiatrists and one for patients and carers. All questionnaires focused on service provision for eating disorders in the area, including access to NICE-recommended evidence-based treatments, and waiting times. Questionnaires for specialists were distributed by mail to all members of the Section of Eating Disorders and the Faculty of Child and Adolescent Psychiatry of the Royal College of Psychiatrists, together with a covering letter outlining the purpose of the questionnaire. Participants were given the option of completing the paper version or accessing the survey online on the Beat website.

A large-scale nationwide survey of CMHTs was beyond the scope of this report. Instead, a small-scale survey of CMHTs in the Newcastle conurbation was conducted. The survey for patients and carers was accessible on the Beat website. As it yielded a very small number of responses, this was deemed to be unrepresentative and the results are not included in the analysis.

These surveys were conducted in 2008.

## MAIN FINDINGS

### *SURVEY OF EATING DISORDER SPECIALISTS*

We received 89 questionnaire responses in total. Of these, three were invalid (retired responders, no data provided) and there was duplication of data from the same service in three cases. Thus, the total number of valid questionnaires was 83.

### *SERVICES LOCATED*

Table 2 shows the distribution of services by health service sector. Of the 83 responding services, 62 were in the NHS and 15 were privately run. Table 3

shows the geographical distribution and status of participating services. Data suggest that London is host to the largest concentration of services in England, although overall the distribution has improved since 1998 – a trend particularly evident in the north of England. Scotland has also seen an increase in services, where the total number has risen to 13 from 4 in 1998. However, despite some areas of improvement, provision remains inadequate in Wales, Northern Ireland and many parts of the Republic of Ireland.

**Table 2 Distribution of services according to service sector**

Sector	Frequency, <i>n</i> (%)
NHS	62 (75)
Independent sector	15 (18)
Voluntary sector	2 (2)
HSE	4 (5)
Total	83 (100)

HSE, Health Service Executive; NHS, National Health Service.

**Table 3 Distribution of services by geographical region**

Region	NHS	Independent	Voluntary	HSE	Total
England					
North East	3	0	0	0	3
North West	6	2	0	0	8
Yorkshire and the Humber	4	1	0	0	5
East Midlands	1	1	0	0	2
West Midlands	8	1	0	0	9
East of England	5	0	0	0	5
London	7	4	0	0	11
South-East Coast	2	0	0	0	2
South Central	4	2	1	0	7
South West	2	1	0	0	3
Wales	1	0	0	0	1
Scotland	12	1	0	0	13
Northern Ireland	1	0	0	0	1
Other	4	0	0	0	4
Republic of Ireland					
Eastern	–	1	0	0	1
South Western	–	0	1	0	1
Mid Western	–	0	0	1	1
Southern Area	–	0	0	3	3
Other	–	1	0	0	1
Total					81 <sup>a</sup>

HSE, Health Service Executive; NHS, National Health Service.

a. Information missing for two participants.

## DIFFERENT PROFESSIONS

The vast majority of services (82%) were led by a consultant psychiatrist, the remainder (18%) by a variety of professionals (Table 4). Multidisciplinary teams included a wide range of health professionals (Table 5), most commonly specialist nurses (81%) and clinical psychologists (76%). On top of that, 54% of teams had a dietician, 51% had a psychotherapist, 49% a social worker and 47% an occupational therapist. Specific criteria for a specialist service, outlined in the 1998 report, established that

a multidisciplinary staff team requires at least one consultant psychiatrist, one specialist nurse and one therapist. Table 6 shows that 22 services have all three multidisciplinary team members, meeting criteria for a specialist service.

**Table 4 Profession of lead clinician**

Lead clinician	Frequency, <i>n</i> (%)
Consultant in adult psychiatry	40 (48)
Consultant in child and adolescent psychiatry	27 (33)
Clinical psychologist	4 (5)
Consultant psychiatrist and psychologist	1 (1)
Nurse specialist	1 (1)
Psychotherapist	1 (1)
Dietician	1 (1)
Other	1 (1)
Not known	7 (8)
Total	83 (100)

**Table 5 Health professionals in the multidisciplinary team**

Professional	Frequency, <i>n</i> (%)	WTEs dedicated to eating disorders
Specialist nurse	58 (81)	2.58
Clinical psychologist	55 (76)	0.77
Consultant psychiatrist (non-specialist in eating disorders)	49 (67)	0.14
Senior house officer in psychiatry	39 (57)	0.22
Consultant psychiatrist (specialist in eating disorders)	33 (56)	0.82
Dietician	39 (54)	0.59
Psychotherapist	37 (51)	0.59
Social worker	35 (49)	0.11
Specialist registrar in psychiatry	33 (47)	0.17
Occupational therapist	34 (47)	0.35
Staff grade in psychiatry	26 (36)	0.33
Physiotherapist	13 (18)	0.43

WTE, whole-time equivalent.

**Table 6 Multidisciplinary teams meeting the criteria for a specialist service**

Mandatory multidisciplinary team members, <i>n</i>	Frequency, <i>n</i> (%)
0	21 (33)
1	10 (16)
2	11 (17)
3 (criterion met)	22 (34)

## WAITING TIMES

Waiting times for assessments and treatment are often a problem. Table 7 shows waiting times for assessments. The majority of patients needing to be seen urgently are seen in less than 1 week.

With regard to routine assessments these are offered within 4 weeks by 57% of services, the remainder is spread through the other categories. Factors cited as reasons for the assessment waiting time include resource issues (e.g. staff availability, bed availability – cited by 23 services) or increased demand on services (cited by 2 services).

**Table 7 Assessment waiting times**

Waiting time	Frequency, <i>n</i> (%)
Urgent assessment	
< 1 week	58 (70)
1–4 weeks	21 (26)
4–8 weeks	1 (1)
8–12 weeks	1 (1)
> 12 weeks	1 (1)
Missing	1 (1)
Routine assessment	
< 1 week	5 (6)
1–4 weeks	42 (51)
4–8 weeks	17 (21)
8–12 weeks	11 (13)
> 12 weeks	6 (7)
Missing	2 (2)

Further waits are usually incurred between assessment and treatment (Table 8). Services are clearly trying to prioritise anorexia nervosa with 37% of services offering treatment within a week and 87% offering treatment within a month.

About 83% of NHS services offer treatment of anorexia nervosa within a month compared with 100% of independent and voluntary sector services. For bulimia nervosa the respective figures are 60% *v.* 100%, for binge eating disorder 58% *v.* 100% and for EDNOS 63% *v.* 100%.

**Table 8 Time to treatment**

Waiting time	Frequency, <i>n</i> (%)			
	Anorexia nervosa ( <i>n</i> =79 services)	Bulimia nervosa ( <i>n</i> =65 services)	Binge eating disorder ( <i>n</i> =59 services)	EDNOS ( <i>n</i> =68 services)
< 1 week	29 (37)	11 (17)	7 (12)	11 (16)
1–4 weeks	40 (51)	35 (54)	34 (58)	38 (56)
4–8 weeks	5 (6)	9 (14)	6 (10)	10 (15)
8–12 weeks	2 (3)	6 (9)	6 (10)	5 (7)
> 12 weeks	3 (4)	4 (6)	6 (10)	4 (6)

EDNOS, eating disorder not otherwise specified.

## TREATMENTS AND CARE AVAILABLE

Therapeutic approaches used by services most often were (Table 9):

- for anorexia nervosa – individual CBT (84%), nutritional advice and monitoring (82%) and family-based treatment (77%)
- for bulimia nervosa – individual CBT (79%), self-help literature (67%) and SSRIs (65%)
- for binge eating disorder – self-help interventions (58%), nutritional advice and monitoring (54%) and individual CBT (54%)
- for EDNOS – individual CBT (67%), nutritional advice and monitoring (62%) and self-help interventions (54%)
- for in-patients – nutritional advice and monitoring (63%), individual CBT (58%) and anxiety management/relaxation (54%).

**Table 9 Therapeutic approaches used in eating disorders**

Therapeutic approach	Frequency, <i>n</i> (%)			
	Anorexia nervosa	Bulimia nervosa	Binge eating disorder	EDNOS
Individual CBT	68 (84)	64 (79)	43 (54)	54 (67)
Nutrition advice and monitoring	66 (82)	52 (64)	44 (54)	50 (62)
Family-based treatment	62 (77)	40 (49)	31 (38)	37 (46)
Self-help literature	60 (74)	54 (67)	47 (58)	44 (54)
Individual counselling	49 (61)	37 (46)	31 (38)	40 (49)
Formal family therapy	47 (58)	26 (32)	19 (24)	26 (32)
Anxiety management and relaxation	46 (57)	37 (46)	29 (36)	36 (44)
SSRIs	44 (54)	53 (65)	29 (36)	30 (37)

CBT, cognitive-behavioural therapy; EDNOS, eating disorder not otherwise specified; SSRIs, selective serotonin reuptake inhibitors.

Table 10 indicates the type of care available. Out-patient care is most widely available for all types of eating disorders. In-patient care is available for anorexia nervosa and bulimia nervosa in 74% and 48% of services respectively. The mean number of beds available in in-patient care was 10.9.

Of these services that provided in-patient care, 41% used specialist eating disorders beds, 21% used beds on a general CAMHS ward, and 8% used general psychiatry beds. The average length of stay in specialist EDUs was 18.2 weeks and 18.4 weeks in CAMHS in-patient units (Table 11).

**Table 10 Type of service available**

Service	Frequency, <i>n</i> (%)			
	Anorexia nervosa	Bulimia nervosa	Binge eating disorder	EDNOS
In-patient care	61 (74)	39 (48)	21 (26)	36 (44)
Out-patient care	64 (78)	60 (72)	50 (61)	57 (70)
Day-care	40 (49)	31 (38)	20 (24)	29 (35)

EDNOS, eating disorder not otherwise specified.

**Table 11 Location of in-patient eating disorders beds and average stay**

Unit	<i>n</i>	Average (s.d.) stay, weeks
General adult psychiatry	6	12.6 (30.6)
General in-patient CAMHS	15	18.4 (12.8)
Paediatric ward	3	2.7 (2.8)
Specialist eating disorders unit	30	18.2 (8.4)

CAMHS, child and adolescent mental health service.

There were 447 in-patient eating disorders beds (for children, adolescents and adults) in the UK (226 NHS, 221 private). Of this total, 74% were found to be specialist EDUs, accounting for 330 specialist beds across 30 specialist services; 166 of these were in the NHS and 164 in the private sector (12 services).

The NHS specialist beds were located in the following areas: north-east (1 service, 4 beds), north-west (2 services, 6 beds in one, missing data for the other), East Midlands (1 service, 15 beds), West Midlands (4 services, 38 beds total), East of England (3 services, 25 beds total), London (3 services, 50 beds total), south-central (2 services, 14 beds in one, missing data for the other), south-west (1 service, 12 beds), Scotland (1 service, 2 beds). Thus, some parts of the UK have little or no NHS in-patient eating disorders provision.



## SEVERE ILLNESS

Severely medically ill patients were most commonly admitted to a medical ward with involvement of eating disorders staff (62%), to a paediatric ward (47%) or treated in a specialist EDU with medical input (25%) (Table 12). On average, 1.5% of patients received nasogastric feeding (Table 13). The proportion of in-patients detained under the Mental Health Act was on average 8%.

**Table 12 Treatment of severely medically ill patients**

Treatment pathway	Frequency, <i>n</i> (%)
Admission to a medical ward with involvement of eating disorders staff	38 (62)
Admission to a medical ward without involvement of eating disorders staff	10 (18)
Admission to paediatric ward	36 (47)
Medical backup within the eating disorders unit	19 (25)
Refer to other service	15 (20)

**Table 13 Proportion of in-patients fed by a nasogastric tube or percutaneous endoscopic gastrostomy (PEG) tube, or detained under the Mental Health Act**

Treatment option	Patients affected, estimated %
Patients fed by a nasogastric tube	5
Patients fed by a PEG tube	1.7
Patients detained	7.9

## OUTCOMES AND POST TREATMENT FOLLOW-UP

Outcome monitoring was undertaken by 75% of participating services. Outcome measures varied widely with a mixture of eating disorder-specific and generic measures being employed. The most common outcome measurements were weight monitoring/BMI and use of the EDE-Q.

Clinicians reported that on average, 78% of patients reached a BMI of 17.5 kg/m<sup>2</sup> on discharge from their service.

Follow-up post-discharge from in-patient or day-care treatment was offered by the majority of services and in most services this was specialist follow-up. Duration and type of follow up is detailed in Table 14.

**Table 14 Duration and type of follow-up post in-patient or day-care treatment**

Service	Follow-up duration, <i>n</i>			Follow-up type, <i>n</i>	
	None	Up to 1 year	> 1 year	Specialist	Non-specialist
Day patient	22	14	27	27	13
In-patient	8	12	37	32	11

## CRITERIA FOR A COMPREHENSIVE EATING DISORDERS SERVICE

The 1998 College Report (CR87) outlined criteria for a comprehensive eating disorders service. This concerned four main points:

- activity – the clinic needed to receive in excess of 25 new referrals per annum

- staff – a multidisciplinary staff team was required including at least one consultant psychiatrist, one nurse and a therapist, who could be a psychologist, psychotherapist or a well-trained counsellor
- intensity – at least out-patient and in-patient treatment were required
- treatment range – patients were required to be offered at least individual and family interventions.

In that report, just over half of clinics (56%) fulfilled all the criteria. Worryingly, however, in the present report just 12% of responding clinics fulfil all four criteria. Data in Table 15 suggest this is due to deficits in multidisciplinary staff teams. Just 34% of services have a multidisciplinary team that meets criteria for a comprehensive service. Low rate of referrals may also contribute to the level of unsatisfactory services in the UK, with only half of clinics meeting referral rate recommendations.

**Table 15 Clinics meeting Royal College of Psychiatrists' criteria for a comprehensive service (n=83) in 2008**

Criterion	Number of clinics (%) <sup>a</sup>
Activity	32 (52)
Staff	22 (34)
Intensity	54 (65)
Treatment range	64 (79)
All four criteria	10 (12)

a. Percentages adjusted for response rate.

## SURVEY OF GENERAL PSYCHIATRISTS

Three questionnaires, from one urban CMHT in each of the three major urban areas in the Newcastle conurbation were received. They all relate to the same specialist regional eating disorder survey.

### *RESPONSIVENESS*

Community mental health teams were able to respond to urgent assessments within a few days and were appropriately responsive to routine referrals. Allocation of a care coordinator was equally timely and responsive.

### *PERSONNEL AND EXPERTISE*

No teams had a psychologist and only one had dietetic input (for one session per week). Therefore, perhaps unsurprisingly, there was little expertise within the teams for psychological therapies. Two teams described having skills in guided self-help for bulimia nervosa to some degree, but otherwise there was no expertise in psychological therapies specific to eating disorders.

Some teams had expertise in more generic psychological treatment modalities: CBT, one team – yes, two teams – to some degree; cognitive-analytical therapy (CAT), three teams – no; dynamic psychotherapy, three teams – no. All teams reported expertise in assessing and managing psychiatric risk and comorbid conditions, but all three reported only some degree of expertise in assessing medical risk.

### *RELATIONSHIP WITH REGIONAL EATING DISORDERS SERVICE*

All teams had a 'hub-and-spoke' regional eating disorders service within a 10-mile distance. The teams received 34 eating disorders referrals in a 12-month period (a likely underestimate in view of the high comorbidity prevalence in secondary care). Ten referrals were made to the tertiary service (29%). Referral criteria to the regional eating disorders service were explicit and adhered to, and ongoing contact with a CMHT was expected. The CMHTs were also expected to provide crisis management, additional (including carer) support and social care.

### *FUTURE DEVELOPMENTS*

There were differing opinions regarding future developments. One team looked at developing a secondary care eating disorders team, another wanted additional training and supervision from specialists, and the third thought that an expansion of in-patient and community tertiary services was the most called for. Perhaps this is an interesting reflection on the lack of consensus nationally.

# Appendix A. Questionnaire for health professionals with a special interest in eating disorders (includes all CAMHS practitioners)

This survey, conducted by the Royal College of Psychiatrists and Eating Disorders Association, aims to identify eating disorders service provision in the UK and the Republic of Ireland. We are very grateful to you for taking the time to complete it. It should not take longer than 15 minutes. Please read the instructions for each question carefully and fill them in as best as you can. Quantitative answers can be your best guess. If you cannot, or do not wish to, answer a particular question, then please leave the question blank.

Your name:

.....  
Your profession and position in the unit:

.....  
Work address:

.....  
Your e-mail address:

.....  
Your telephone number:

.....  
Name of unit:

.....  
Address of unit:

.....  
Name of lead clinician:

.....  
Profession of lead clinician:

.....  
**Q1** Is this an NHS or an independent specialist service?

NHS

.....  
Independent (go to Q3)

.....  
Other (please specify)

.....  
**Q2** If this is an NHS service, which are the main organisations commissioning your service?  
Please write below:

**Q3a** If you work within the UK in which NHS region/country is the service located? Please mark below:

North East \_\_\_\_\_  
North West \_\_\_\_\_  
Yorkshire and the Humber \_\_\_\_\_  
East Midlands \_\_\_\_\_  
West Midlands \_\_\_\_\_  
East of England \_\_\_\_\_  
London \_\_\_\_\_  
South East Coast \_\_\_\_\_  
South Central \_\_\_\_\_  
South West \_\_\_\_\_  
Wales \_\_\_\_\_  
Scotland \_\_\_\_\_  
Northern Ireland \_\_\_\_\_  
Other \_\_\_\_\_

**Q3b** If you work within the Republic of Ireland in which Health Service Executive (HSE) region is the service located?

ERHA-Eastern Region \_\_\_\_\_  
ERHA-East Coast Area \_\_\_\_\_  
ERHA-South Western Area \_\_\_\_\_  
ERHA-Northern Area \_\_\_\_\_  
HSE-Midland Area \_\_\_\_\_  
HSE-Mid Western Area \_\_\_\_\_  
HSE-North Eastern Area \_\_\_\_\_  
HSE-North Western Area \_\_\_\_\_  
HSE-South Eastern Area \_\_\_\_\_  
HSE-Southern Area \_\_\_\_\_  
HSE-Western Area \_\_\_\_\_  
Other \_\_\_\_\_

**Q4** What is the age range of patients with eating disorders that you treat?

\_\_\_\_\_

**Q5** Please comment if your service focuses on a particular age group:

\_\_\_\_\_

**Q6** How many patients were referred to the unit for assessment/treatment for each of the following types of eating disorders, in the calendar year 2007?

Anorexia nervosa \_\_\_\_\_  
Bulimia nervosa \_\_\_\_\_  
EDNOS \_\_\_\_\_  
Binge eating disorder \_\_\_\_\_  
Other (see below) \_\_\_\_\_

For 'other', please describe the type of eating problems you might be referred. These might be: selective eating; food phobias; functional dysphagia; food avoidance/weight loss in the context of depression, somatisation disorder, OCD, anxiety disorder; eating concerns in the context of parental eating disorders.

**Q7** For what area are you primarily commissioned to provide (if applicable)?

\_\_\_\_\_

**Q8** What proportion of your patients comes from outside the area in Q7 (if applicable)?

	Urgent cases	Routine cases
Less than one week		
From one to four weeks		
From four to eight weeks		
From eight to twelve weeks		
More than twelve weeks		

Please comment on any factors that influence this:

**Q10** On average, how long after assessment would treatment begin, for a routine case?

	Anorexia nervosa	Bulimia nervosa	Binge eating disorder	EDNOS
Less than one week				
From one to four weeks				
From four to eight weeks				
From eight to twelve weeks				
More than twelve weeks				

Please comment on any factors that influence this.

**Q11** Which of the following health professionals are in your multidisciplinary team? Please indicate in the first column the total amount of staff time in Whole Time Equivalents (WTE). Where possible please indicate in the second column the amount of time dedicated specifically to the treatment of eating disorders.

WTE eating disorders

Social worker		
Psychotherapist		
Physiotherapist		
Specialist nurse		
Dietician		
Clinical psychologist		
Occupational therapist		
Consultant psychiatrist (not specialist in eating disorders psychiatry)		
Consultant psychiatrist (specialist in eating disorders psychiatry)		
Specialist registrar in psychiatry		
SHO in psychiatry		
Staff grade in psychiatry		
Other (please add)		

**Q12** Which therapeutic approaches are characteristically used for the treatment of the following disorders? Please tick those that apply:

	Anorexia nervosa	Bulimia nervosa	Binge eating disorder	EDNOS	Available to in-patient
Individual cognitive-behavioural therapy					
Group cognitive-behavioural therapy					
Individual dynamic psychotherapy					
Group dynamic psychotherapy					
Formal family therapy					
Family-based treatment					
Cognitive-analytic therapy (CAT)					
Individual counselling					
Group counselling					
Self-help literature					
Self-help groups					
Guided self-care					
Carers' support group					
Nutrition advice and monitoring					
Anxiety management and relaxation					
Alternative therapies (e.g. homeopathy)					
SSRIs (e.g. Prozac)					
Other antidepressants					
Neuroleptics: low doses (equivalent to 100mg chlorpromazine daily)					
Neuroleptics: high doses (equivalent to >100mg chlorpromazine daily)					

**Q13** Are there any other therapeutic approaches that you use for the treatment of eating disorders? Please write below:

.....

.....

.....

.....

**Q14** Please indicate below which services are available for patients with anorexia nervosa, bulimia nervosa, binge eating disorders and EDNOS.

	Anorexia nervosa	Bulimia nervosa	Binge eating disorders	EDNOS
In-patient care				
Out-patient care				
Day care				
Domiciliary care				
Rehabilitation ward				
Liaison with non-specialist services				

**Q15** If you provide in-patient care, how many beds can you make available, at any one time, for patients with eating disorders?

N/a: go to Q18 \_\_\_\_\_

Beds: \_\_\_\_\_

**Q16** Where are these beds located? Please mark below:

In a general adult psychiatry ward

General CAMHS in-patient unit

Paediatric ward

Beds in a medical ward

In a specialist eating disorders unit (please name)\*

\*Definition: by specialist eating disorder in-patient unit we mean a unit where all or a high proportion of cases treated have an eating disorder and where a structured symptom-focused therapeutic programme is provided, with the expectation of weight gain and in order to achieve weight restoration. There should also be careful monitoring of the patient's physical status during refeeding. Psychological treatment should be provided which has a focus both on eating behaviour and attitudes to weight and shape, and on wider psychosocial issues and there should be provision for involving families and carers in the treatment.

**Q17** What is the average length of stay for in-patients?

	Weeks
In a general adult psychiatry ward	
General CAMHS in-patient unit	
Beds in a medical ward	
In a specialist eating disorders unit (please name)	
Paediatric ward	
Adolescent psychiatric unit	

**Q18** If you provide day care for patients, how many places are provided (i.e. the number that can be on your books at any one time)?

N/a: go to Q21

Places:

**Q19** Do you provide accommodation for day care patients if required?

Yes

N/a: go to Q21

No

**Q20** If yes, please give details of the type of accommodation provided:

**Q21** Please describe the follow-up offered after discharge from a) in-patient, and b) day-patient services and comment on type and duration:

Follow-up	None	Up to a year	More than a year	Specialist*	Non-specialist
Day-patient					
In-patient					

Definition: by 'specialist' we mean here a dedicated multidisciplinary team offering assessment and a range of therapeutic interventions aimed at eating disorders.

In-patient, please comment below:

Day-patient, please comment below:



**Q22** Do you measure the outcome of your treatments?

Yes \_\_\_\_\_  
 No – go to Q26 \_\_\_\_\_

**Q23** If yes, what method do you use to measure your outcome ratings and at what time points?

Method	Time points

**Q24** On discharge from the service what proportion of patients with anorexia nervosa are above BMI 17.5kg/m<sup>2</sup> (or 3rd BMI centile for children)?

\_\_\_\_\_ %

**Q25** How do you treat patients who are severely medically ill?

Admission to a medical ward with involvement of eating disorder staff \_\_\_\_\_  
 Admission to a medical ward without involvement of eating disorder staff \_\_\_\_\_  
 Admission to paediatric ward \_\_\_\_\_  
 Medical backup within the eating disorder unit \_\_\_\_\_  
 Refer to other service \_\_\_\_\_  
 Other – please describe what you do \_\_\_\_\_

**Q26** For the last calendar year 2006 give the number of patients on the unit who were PEG/NGT fed and your total number of admissions to that unit:

	Number of patients
NGT (nasogastric tube)	
PEG (percutaneous endoscopic gastrostomy)	
Total no. patients admitted to unit	

**Q27** In the last calendar year 2006 what proportion of patients were detained against their will?  
 \_\_\_\_\_ %

**Q28** If children were detained against their will, please indicate the relative proportions detained under the MHA, Children Act or using parental consent:

	Proportion of children admitted (%)
Mental Health Act	
Children Act	
Parental Consent	

**Q29** Please expand further on any particular qualities or advantages of the service you offer:

.....  
 .....  
 .....

**Q30** Please describe any way you would like to see the service develop:

.....

Thank you for your help with this research. Please return the completed questionnaire to:  
 Prof. Ulrike Schmidt, PO 59, Section of Eating Disorders, Institute of Psychiatry, De Crespigny Park, London SE5 8AF

# Appendix B. Eating disorders services: questionnaire for health professionals in general adult services

This survey, by the Royal College of Psychiatrists and the Eating Disorders Association, aims to identify eating disorders service provision in the UK and the Republic of Ireland. We are very grateful to you for taking the time to complete it. It should take no longer than 15 minutes to complete. Please read the instructions for each question carefully and fill them in as best as you can. We are sending a separate questionnaire to specialist eating disorders services. In this questionnaire we are interested in how eating disorders are managed in general adult psychiatric services only. If you cannot answer a particular question, then please leave the question blank. Please bear in mind that numerical answers only require a best guess.

Your name:

.....  
Your profession and position in the unit:

.....  
Work address:

.....  
Your e-mail address:

.....  
Your telephone number:

.....  
Name of unit:

.....  
Address of unit:

.....  
Name of lead clinician:

.....  
Profession of lead clinician:

**Q1** Which are the main organisations commissioning your service? Please write below:

**Q2** In which NHS region/country is the service located? Please mark below:

- North East \_\_\_\_\_
- North West \_\_\_\_\_
- Yorkshire and the Humber \_\_\_\_\_
- East Midlands \_\_\_\_\_
- West Midlands \_\_\_\_\_
- East of England \_\_\_\_\_
- London \_\_\_\_\_
- South East Coast \_\_\_\_\_
- South Central \_\_\_\_\_
- South West \_\_\_\_\_
- Wales \_\_\_\_\_
- Scotland \_\_\_\_\_
- Northern Ireland \_\_\_\_\_
- Other \_\_\_\_\_

**Q3** What is the age range of patients that you treat for eating disorders?

---

**Q4** Please comment if your service focuses on a particular age group:

---

**Q5** How many patients were referred to the service for assessment/treatment for each of the following types of eating disorders, in the calendar year 2006?

- Anorexia nervosa \_\_\_\_\_
- Bulimia nervosa \_\_\_\_\_
- Other (please describe) \_\_\_\_\_

For 'other', please describe the type of eating problems you might be referred. These might be: eating disorder in the context of a personality disorder, EDNOS, binge eating disorder, selective eating, food phobias, functional dysphagia, food avoidance/weight loss in the context of depression, somatisation disorder, OCD, anxiety disorder, eating concerns in the context of parental eating disorders.

**Q6** For what area are you primarily commissioned to provide (e.g. population size, by geographical area or by GP practice area)?

---

**Q7** What is the average waiting time for a patient with an eating disorder awaiting assessment? Omit and go to Q9 if your service does not see patients with eating disorders.

	Urgent cases	Routine cases
Less than one week		
From one to four weeks		
From four to eight weeks		
From eight to twelve weeks		
More than twelve weeks		

Please comment on any factors that influence this:

.....

.....

.....

**Q8** Once assessment is complete what is the average waiting time for a patient with an eating disorder to be allocated a therapist or care co-ordinator?

**Q9** Which of the following health professionals are in the multidisciplinary team? Please indicate the amount of staff time in Whole Time Equivalents (WTE):

WTE

	Social worker	
	Psychotherapist	
	Physiotherapist	
	Specialist nurse	
	Dietician	
	Clinical psychologist	
	Occupational therapist	
	Consultant psychiatrist (not specialist in eating disorders)	
	Consultant psychiatrist (specialist in eating disorders)	
	Specialist registrar in psychiatry	
	SHO in psychiatry	
	Staff grade in psychiatry	
	Other (please add)	

**Q10** Which of these areas of skill and expertise are available within your team?

	Yes	To some degree	No
Use of the Mental Health Act			
Use of the Mental Health Act in eating disorders esp. in anorexia nervosa			
Assessment and management of high level psychiatric risk (e.g. of suicide)			
Assessment of medical risk in eating disorders			
Psychosocial interventions (help with accommodation, welfare, finances, education, employment, etc.)			
Assessment and management of problems commonly comorbid with eating disorders (e.g. depression, impulsivity, personality disorder)			
Dynamic psychotherapy			
Family therapy for anorexia nervosa			
Family-based treatment for anorexia nervosa			
Cognitive-analytic therapy (CAT)			
Cognitive-behavioural therapy (CBT)			
CBT for bulimia nervosa			
Guided self-care for bulimia nervosa			

**Q11** Are there any other therapeutic approaches or specific skills available within your team? Please write in below:

.....

.....

.....

**Q12** Please indicate below which services are available for patients with anorexia nervosa, bulimia nervosa, binge eating disorder and EDNOS. Please tick those that apply:

	Anorexia nervosa	Bulimia nervosa	Binge eating disorder	EDNOS
In-patient care				
Out-patient care				
Day care				
Domiciliary care				
Rehabilitation ward				
Liaison with specialist services				

**Q13** If your general adult service provides in-patient care for patients with eating disorders, how many beds can you make available, at any one time, for these patients?

N/a: go to Q15

Beds:

**Q14** Where are these beds located? Please mark below:

In a general psychiatry unit

Psychiatric beds in a medical ward

Paediatric ward

Adolescent psychiatric unit

**Q15** Do you measure the outcome of your treatments?

Yes

No – go to Q19

**Q16** If yes, what method do you use to measure your outcome ratings and at what time points?

Method	Time points

**Q17** How does your general adult service treat eating disorder patients who are severely medically ill?

Admission to a medical ward with involvement of general adult mental health staff

Admission to a medical ward without involvement of general adult mental health staff

Admission to paediatric ward

Medical backup within the general adult psychiatric unit

Refer to other service

Other – please describe what you do

**Q18** Do you routinely refer to a specialist eating disorders service? Yes/No  
If 'Yes' please complete this table. If 'No' please go to Q.19.

How far away is it?

Approximate number of referrals in the last 12 months

Are referral criteria explicit?

Are referral criteria always adhered to?

Please add any comments on referral criteria

---

Are patients referred to you on discharge from the tertiary service?

---

Please describe this process

---

What sort of therapeutic interventions and support would you expect to provide in these circumstances?

---

For how long?

---

Do you have the facility to jointly manage cases with a specialist eating disorders service?

---

Please add any other comments on the nature of your relationship with the specialist service

---

**Q19** Please expand further on any particular qualities or advantages of the service you offer:

---

---

---

---

---

**Q20** Please describe any way you would like to see your service develop:

---

---

---

---

---

---

Completed by

---

Title

---

Thank you for your help with this research.

# Appendix C. Eating disorders services: questionnaire for service users

This is a survey for people with eating disorders who had treatment for this in the UK or the Republic of Ireland. Some of the questions appear to be directed specifically to the person with an eating disorder, 'the patient'. However, this questionnaire can be completed by either the patient or a person close to them such as a family member or a carer.

Please answer the questions as fully as you can, or feel able to. If you don't know the answer, or don't wish to give it, don't worry. It's fine to give a best guess! Any information you can give will be very helpful to us in conducting this important survey of services and treatment for people with eating disorders. This should take no longer than 15 minutes.

If you or your family member has had more than one referral for treatment of an eating disorder, please give your answers relating to the most recent referral.

Your name:

.....  
Please state whether you are a patient or a carer:

.....  
Name of unit where treatment was received:

.....  
Address of unit:

.....  
Name of lead clinician:

.....  
Profession of lead clinician:

**Q1** Did the treatment take place in an NHS or an independent specialist unit?

NHS

.....  
Independent (go to Q3)

.....  
Other (please specify)

.....

**Q2** In which NHS region is the service located? Please mark below. If you are not sure which category to tick feel free to write the name which you think best describes the area.

North East
North West
Yorkshire and The Humber
London
East of England
South East Coast
East Midlands
West Midlands
Wales
Scotland
Northern Ireland

**Q2** If you were treated within the Republic of Ireland in which Health Service Executive (HSE) Region was the service located? If you are not sure which category to tick feel free to write the name which you think best describes the area.

ERHA-Eastern Region
ERHA-East Coast Area
ERHA-South Western Area
ERHA-Northern Area
HSE-Midland Area
HSE-Mid Western Area
HSE-North Eastern Area
HSE-North Western Area
HSE-South Eastern Area
HSE-Southern Area
HSE-Western Area
Other

**Q3** How old were you (the patient) at the time of treatment?

Years
-------

**Q4** How long after the referral was made did an assessment take place?

	Please tick
Less than one week	
From one to four weeks	
From four to eight weeks	
From eight to twelve weeks	
More than twelve weeks	

**Q5** How long after assessment did treatment begin?

	Please tick
Less than one week	
From one to four weeks	
From four to eight weeks	
From eight to twelve weeks	
More than twelve weeks	

**Q6** What diagnosis (if any) was given?

Diagnosis	Please tick
Anorexia nervosa	
Bulimia nervosa	
EDNOS	
Binge eating disorder	
Other (please specify)	
No diagnosis given	



**Q7** As far as you know which of the following health professionals were involved in the treatment?

	Social worker	
	Psychotherapist	
	Physiotherapist	
	Specialist nurse	
	Dietician	
	Clinical psychologist	
	Occupational therapist	
	Consultant psychiatrist (not specialist in eating disorders psychiatry)	
	Consultant psychiatrist (specialist in eating disorders psychiatry)	
	Specialist registrar in psychiatry	
	SHO in psychiatry	
	Staff grade in psychiatry	
	Other (please add)	

**Q8** Which of these therapeutic approaches were offered?

	Please tick
Individual therapy	
Group therapy	
Family-based treatment	
Self-help literature	
Self-help groups	
Guided self-help	
Carers' support group	
Nutrition advice and monitoring	
Anxiety management and relaxation	
Alternative therapies (e.g. homeopathy)	
Antidepressants	
Other medication (write the name if you know it)	

**Q9** Were any other therapeutic approaches offered? Please write in below:

---

**Q10** In what type of setting did the treatment take place?

	Please tick all that apply
In-patient care	
Out-patient care	
Day care	
Rehabilitation ward or hostel	
Home care	

**Q11** If you have been offered in-patient treatments, please indicate in the table below where they took place and how many times you have been admitted there.

In a general adult psychiatry ward	
Beds in a medical ward	
In a special eating disorders unit	
Children's medical ward	
General child or adolescent psychiatric unit	

**Q12** How long was the most recent in-patient stay?

\_\_\_\_\_ Weeks

**Q13** If day care was given was patient accommodation offered?

Yes \_\_\_\_\_

N/a: go to Q15 \_\_\_\_\_

**Q14** If yes, please give details of the type of accommodation provided:

\_\_\_\_\_

**Q15** Please describe the follow-up offered after discharge from a) in-patient, and b) day-patient services. Please comment on type and duration of follow-up.

Follow up	None	Up to a year	More than a year	Specialist	Non-specialist
Day-patient					
In-patient					

In patient- please write in below:

\_\_\_\_\_

Day-patient – please write in below:

\_\_\_\_\_

**Q16** Were you aware of any measures such as questionnaires being used to assess the outcome of the treatments?

Yes \_\_\_\_\_

No – go to Q18 \_\_\_\_\_

**Q17** If yes, what method was used to measure outcome and when in the treatment did this happen?

Method – please write in below \_\_\_\_\_

Time points – please write in below \_\_\_\_\_

--	--

**Q18** Were you (the patient) asked to feedback your own views about treatments?  
Please comment:

.....  
 .....  
 .....

**Q19** If treatment was needed for severe mental/physical illness, where did that take place?

Admission to a medical ward with involvement of eating disorder staff \_\_\_\_\_

Admission to a medical ward without involvement of eating disorder staff \_\_\_\_\_

Medical backup within the eating disorder unit \_\_\_\_\_

Refer to other service \_\_\_\_\_

Admission to a children's ward \_\_\_\_\_

Other: \_\_\_\_\_

\_\_\_\_\_

**Q20** During admission were you (the patient) ever fed using an NGT or PEG?

NGT (nasogastric tube)

PEG (percutaneous endoscopic gastrostomy)

**Q21** Did the treatment ever involve using the Mental Health Act or Children Act? In other words were you, the patient, ever treated against your will?

**Q22** Please expand further on any positive qualities or advantages of the service that you were offered:

.....

.....

.....

.....

**Q23** Please describe any deficiencies or problems with the service:

.....

.....

.....

Completed by

Title

# Appendix D. Definitions

## SPECIALIST EATING DISORDERS SERVICE

CR 87 established criteria for a specialist service as follows:

- there will be at least 25 new referrals per annum
- the service will have a multidisciplinary staff team, including at least one consultant psychiatrist, one nurse and one therapist
- out-patient and in-patient treatment are provided
- patients are offered individual and family interventions

In light of NICE guidance and subsequent research evidence, the last criterion has been altered to: 'Patients are offered individual interventions, including CBT and family-based interventions'.

## SPECIALIST EATING DISORDERS IN-PATIENT UNIT

A unit where all or a high proportion of individuals treated have an eating disorder and where a structured symptom-focused therapeutic programme is provided, with the expectation of weight gain and in order to achieve weight restoration. There should also be careful monitoring of the patients' physical status during refeeding. Psychological treatment should be provided which has a focus both on eating behaviour and attitudes to weight and shape, and on wider psychosocial issues. There should be provision for involving families and carers in the treatment.

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