The Regulation and Quality Improvement Authority

Review of Eating Disorder Services in Northern Ireland

December 2015

Assurance, Challenge and Improvement in Health and Social Care

www.rqia.org.uk

The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for monitoring and inspecting the quality, safety and availability of health and social care (HSC) services in Northern Ireland.

RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest.

Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on the RQIA's website at www.rqia.org.uk.

Acknowledgements

We are grateful for the cooperation from individuals and agencies, both voluntary and statutory, who met with us to discuss issues, highlight areas of good practice and suggest areas for improvement. We also thank those who attended our focus groups and our summit event, many of whom shared their personal experiences of eating disorder services.

Contents

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Executive Summary

This review of eating disorder services in Northern Ireland was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS).

Eating disorder conditions include anorexia nervosa, bulimia nervosa, other specified or unspecified feeding or eating disorders; avoidant restrictive food intake disorder; and binge eating disorders.

The eating disorder service in Northern Ireland is on a journey of transformation. Professional groups and teams in health and social care (HSC) trusts demonstrated they are building systems and structures that have the potential to provide better quality services for people with eating disorders. The direction of travel is clearly influenced by DHSSPS policy and guidance, which promotes integration, early intervention and a model of stepped care provision.

While much has been done in terms of investment, to help establish community teams, both in children and adult services, the increasing referral rate and current capacity of the trusts to respond, requires to be reviewed by the HSC Board.

This report is informed by the insights and experiences of service users, parents, carers and voluntary organisations involved in supporting people with eating disorders and the professionals who provide services to them.

Some parents and carers stated that advice was not consistently available to help them cope with living with someone with an eating disorder. There is a need for early intervention, and the development of eating disorder pathways for both young people and adults. More treatment options provided by trusts would be helpful, for example, individual therapy, parent counselling and family support groups.

Given the increase noted in the numbers of younger people presenting with eating disorders over the past few years, staff working in education services require a range of information about how best to respond to their needs. Good quality information and easy to read booklets for young people explaining eating disorders are available. However, adult patients, carers and service users told us that finding appropriate and easy to read information about eating disorders can be difficult. Most carers stated they had to source relevant material from the internet.

The experiences of service users’ initial contact with general practitioners (GPs) and of their subsequent referral to other essential services were mixed. The review team did not meet with individual GPs, but in discussions with the HSC Board Directorate of Integrated Care, a proposal was made that each trust identify a specialist consultant or staff grade physician, who the GP can contact for advice.

The review team noted a small number of children aged under 12 required admission to paediatric wards. Established cooperative relationships with paediatric consultants were evident in these cases, and resulted in early intervention and positive risk management.

There are no specific designated eating disorder beds at Beechcroft Child and Adolescent Mental Health Service, Belfast. Admissions for treatment of eating disorders to this facility have more than doubled from 12 patients in 2011-12 to 26 patients in 2014-15.

The review team recommends that the HSC Board should review the current services available for patients with eating disorders in Beechcroft, and review the effectiveness of the delivery of all inpatient level 4[1] services for both young people and adults with eating disorders.

The development of a day care model for young people and adults would appear to be effective, but difficult to develop in each trust without a sufficient number of patients. The HSC Board should discuss with trusts the best use of resources in the development of intensive day treatment services.

Complex cases may require additional care and treatment in hospital, and can exceed the ability of trusts to manage the risk. The HSC Board advised that from 1 July 2012 to 30 September 2015, 52 patients were referred to hospitals to Great Britain and the Republic of Ireland (these are known as extra contractual referrals (ECRs)). The review team noted that the HSC Board did not have any outcome measures to evaluate the effectiveness of these arrangements.

RQIA recommends that there should be a feasibility study to determine if a specialist eating disorder unit should be developed in Northern Ireland, and welcomes the Health Minister's statement in October 2015 on this matter[2]. A potential option could be for such a unit to be established on an All-Ireland basis. Further engagement with patients who have been subject to ECRs is critical in the future development of eating disorder services.

Partnership working with voluntary organisations, involving service users and their families was evident in all trusts. A number of families indicated they wished to play a greater part in how services are developed, reviewed and commissioned, with the principles of user engagement embedded in everyday practice.

This review makes 11 key recommendations and 15 supporting recommendations for improvement in eating disorder services in Northern Ireland.

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[1] Level 4 services are specialist/inpatient treatment services for patients who have failed to respond to treatment offered at level 3.

[22] https://www.dhsspsni.gov.uk/news/hamilton-announces-eating-disorders-move

1.0 Terms of Reference

1. Profile the eating disorder services in Northern Ireland (to include input from acute medical and psychiatric services, where relevant) in terms of meeting the needs of adults and children/young people, including the organisational structure, staffing levels, skills and capacity available to respond to assessed needs.

2. Establish an understanding of the range of support services provided by organisations contracted by HSC trusts, for young people and adults with eating disorders, and report on the accessibility, flexibility and responsiveness of these services.

3. Assess the effectiveness of the communication and information sharing with service users and carers and how this informs the commissioning arrangements by the HSC Board and the provision of services by the HSC trusts.

4. Review the efficiency and effectiveness of the performance of the HSC trusts in relation to the delivery of a four level model of service provision for young people under 18 and adults with eating disorders in Northern Ireland.

5. Examine the effectiveness of the arrangements made for patients from Northern Ireland to access specialist services in other jurisdictions.

6. Identify any learning or recommendations for improvement to ensure the efficiency and effectiveness of the future delivery of the eating disorder services in Northern Ireland.

1.1 Exclusions

Eating disorder services dealing with obesity were excluded from this review.

Circulars, guidance, standards, reviews and reports which were published during the course of this review were not assessed as part of this review and may be highlighted for consideration in the future.

2.0 Review Methodology

RQIA used a range of methods to carry out this review:

1. A literature review on eating disorders, and the standards and guidelines available for these services.

2. Self-assessment questionnaires were sent to service providers, one for adult services and one for child and adolescent eating disorder services, addressing the following areas:

    i. Information on the mental health care pathway and levels of intervention available to adults, children and young people with an eating disorder in each HSC trust, at levels 1, 2, 3 and 4, in accordance with stepped care model of service provision.
    ii. The rights, views and choices of those using services.
    iii. The types of interagency approaches used to assess and review adults, children and young people under 18 with an eating disorder.

3. Focus group discussions were held with a range of service users and carers, from all five trust areas.

4. Meetings with senior managers and clinicians from each HSC trust and the HSC Board, responsible for commissioning and providing eating disorder services in Northern Ireland.

5. Meeting with staff from the HSC Board Directorate of Integrated Care about access and support from GP services.

6. A visit to the regional child and adolescent regional mental health inpatient unit at Beechcroft to review its provision of inpatient eating disorder services.

7. Information was also obtained from a GP working in the Marino Therapy Centre, Dublin regarding the role of the GP in eating disorder services in the Republic of Ireland.

RQIA's review team convened a number of focus groups of service users and carers across the trusts, throughout the course of the review. The team also met the Eating Disorders Association (EDA), the HSC Board, Public Health Agency (PHA) and HSC trusts.

A stakeholder summit event was held in October 2014 involving DHSSPS, PHA, HSC Board and trusts. A range of eating disorder support groups involving service users and carers also attended this event. A service programme manager and senior nurse involved in managing eating disorder services from St Patrick's Mental Health Eating Disorders Service, Dublin, also made a presentation regarding the specialist services provided in the Republic of Ireland.

3.0 Introduction

Eating disorders[3] comprise a range of syndromes encompassing physical, psychological and social features. The physical complications of these disorders may cause great difficulties for individuals experiencing them, family members and health service staff. Anorexia nervosa and bulimia nervosa can both be longstanding conditions, with substantial long-term physical and social effects.

Long-term disabilities exert negative effects on employment, relationships and parenting. The impact of a person's eating disorder on home and family life is often considerable and family members may carry a heavy burden over a long period of time. Family members are often at a loss to know how to help or offer support to an affected relative.

While anyone can develop an eating disorder, regardless of age, sex or cultural or racial background, the most commonly affected group are young women between the ages of 15 and 25. An eating disorder may also appear in middle age. One of the most common symptoms of eating disorders in both women and men is an exaggerated concern about fitness as a weight reducing behaviour, body weight/shape or health concerns, leading to weight loss in some cases and weight gain in others. The three main categories of eating disorders are anorexia nervosa, bulimia nervosa and binge eating disorder.

There are many factors that may contribute to the likelihood of an eating disorder occurring. These include a family history of an eating or anxiety disorder; perfectionist personality characteristics; social and cultural aspects such as exposure to western body ideals; family attitudes; and a genetic predisposition. A focus on controlling weight and shape through restriction of food, over-exercise or binge eating, in certain cases, is used to manage worries or stress. Bereavement, bullying, abuse, family problems, long term illness, or concerns over sexual identity may also trigger an eating disorder.

Anorexia Nervosa

Anorexia nervosa is defined as loss of appetite for nervous reasons. It often starts with a person attempting to control their body weight and shape through a restriction of food intake (dieting).

The disorder itself takes control and distorts thinking, which can lead to impaired decision making about adequate food intake and overestimation of body weight and size.

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[3] (Eating Disorders in the UK: Service Distribution, Service Development and Training: Report from the Royal College of Psychiatrists, Section on Eating Disorders, 2012)

Anorexia nervosa is diagnosed when a person refuses or is unable to maintain his or her body weight over a minimal normal weight for age and height, such as 15% below that expected. Sufferers have a body mass index (BMI) of less than 17.5 in adults, an intense fear of gaining weight, a disturbed body image, and, in women, primary or secondary amenorrhea.

The diagnostic criteria for anorexia nervosa include[4]:

- Restriction of energy intake relative to body requirement, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health.
- Intense fear of gaining weight or of becoming fat or persistent behavior that interferes with weight gain, even though at a significantly low weight.
- Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Research indicates that 46% of patients with anorexia nervosa can be expected to recover; 33% make a partial recovery; and 20% remain chronically ill[5].

Bulimia Nervosa

Bulimia nervosa is around five times as common as anorexia nervosa, and is defined as[6]:

- Recurrent episodes of binge eating.
- Eating, in a discrete period of time, an amount of food that is larger than most people would eat during a similar period of time and under similar circumstances.
- A sense of lack of control over eating during the episode.
- Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; excessive exercise at least once a week for three months.
- Self-evaluation is unduly influenced by body shape and weight.

Bulimia nervosa is more likely to develop in late teens to early 20s. This can occur in a belief that bulimia will help one to diet successfully, where other attempts to lose weight have failed. It is also often associated with low self-esteem, or a lack of self-confidence. A patient may have previously had anorexia nervosa.

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[4] Diagnostic criteria for Anorexia Nervosa from the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V)

[5] Source http://www.b-eat.co.uk/about-beat/media-centre/information-and-statistics-about-eating-disorders

[6] DSM V criteria for Bulimia Nervosa

Bulimia nervosa is more difficult for others to notice, as patients have normal body weight, or their weight may fluctuate. For this reason the condition may remain undetected for many years. In common with anorexia nervosa, people who develop bulimia nervosa become reliant on the control of food and eating as a way of coping with emotional difficulties in their lives. They are often highly preoccupied by their weight or shape.

Bulimia nervosa tends to run a relapsing and remitting course, with about two-thirds of those with the condition recovering within five years. Treatment is most effective when provided early, to help minimise the long-term physical and psycho-social disabilities associated with this condition.

Binge Eating Disorder

Binge eating is an eating disorder where a person feels compelled to overeat on a regular basis. People who binge-eat do not purge themselves to control weight, but may try to limit weight gain by having periods of eating very little food between binges.

Psychiatric and Physical Complications of Eating Disorders

Eating disorders are associated with high levels of psychiatric and physical complications, which are often irreversible, lead to multiple medical investigations and have significant resource implications in their management. Psychiatric and medical complications may arise:

Psychiatric

- Over half of patients with anorexia nervosa or bulimia nervosa have an episode of depression at some time during their lives.
- Rates of personality disorder are considered to be higher in anorexia nervosa than in the general population.
- Almost two-thirds of those with anorexia nervosa suffer from anxiety disorders during their lifetime, with obsessive compulsive disorder and social phobia being the most common. In bulimia nervosa there is a higher rate of alcohol and drug misuse.

Medical

- Malnutrition can lead to vitamin deficiencies, reduced bone marrow function, leading to reduced immune function and infections and changes in the electrolyte levels in the blood. This can lead to increased risk of cardiac arrhythmia and seizures, loss of muscle tissue (including heart muscle), and changes in liver function. Due to osteoporosis and osteopenia, 30 - 40% of patients with anorexia are three times more likely than the general population to suffer a bone fracture.

- Female patients with anorexia have markedly reduced fertility rates and seven times the average perinatal mortality rate for children[7].
- With appropriate treatment and recovery from the eating disorder, the majority of the physical effects are reversible. However, some, such as loss of tooth enamel, osteoporosis and problems with fertility, can be irreversible, if not addressed early enough.

If a patient loses a significant amount of weight, it can affect their ability to think clearly and this can make any rational decisions about their own treatment or circumstances difficult. In such situations an admission for assessment, under the Mental Health (Northern Ireland) Order 1986, may be required prior to beginning treatment.

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[7] Eating Disorder Services/ DHSSPS Consultation Paper May 2002

4.0 Prevalence of Eating Disorders

Incidence and prevalence rates for anorexia nervosa and bulimia nervosa vary among published studies[8]. However, it is estimated that eating disorders affect around 1% of the population. Incidence is 10-12 times higher among females than males. Around 1 in 250 women and 1 in 2,000 men will experience anorexia nervosa at some time in their lives.

On average, the length of illness in anorexia nervosa is seven years, and bulimia nervosa can take several years of treatment.

The peak age of onset is 13-18 years. Overall, around 1-2% of adolescents/young adults develop some form of eating disorder. Female teenagers have the highest rates of new cases of anorexia nervosa each year, at 51 per 100,000. Most cases develop between 13-25 years, however, an increasing number are now being reported among those under 10 years of age[9].

About 10% of people diagnosed as having an eating disorder are men. However, these conditions often go undetected in male sufferers. Many men find it hard to ask for help, particularly when the doctor or counsellor does not recognise their symptoms. There are also a high proportion of treatment resistant cases within this client group, which can result in a high cost of treatment.

There has also been an increase in the number of new cases of eating disorders that do not meet the criteria for a diagnosis of either anorexia nervosa or bulimia nervosa. These are classified as eating disorders not otherwise specified (EDNOS) and binge eating disorder.

Prevalence of Eating Disorders in Northern Ireland

Each year in Northern Ireland, some 50-120 people develop anorexia nervosa and around 170 people develop bulimia nervosa. There are around 100 admissions to acute hospitals for eating disorders annually. This excludes patients requiring inpatient treatment outside Northern Ireland. Between July 2012 and September 2015, the HSC Board advised that 52 referrals were made for ECRs to other hospitals or clinics in Great Britain or the Republic of Ireland. Two of these were young people under the age of 18.

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[8] The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database Nadia Micali1, Katrina W Hagberg2, Irene Petersen3, Janet L Treasure4

[9] Eating Disorders, core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders, published by capital British, capital psychological society and Gaskell 2004

Admissions of Young People Under 18 to Acute Medical Wards

The behaviours associated with eating disorders can cause serious medical problems. The number of admissions of children and young people for medical treatment to acute hospital wards between 2013 and 2015, with an underlying eating disorder is outlined in Table 1.

Table 1: Acute Medical Admissions of Young People Under 18 by Trust from 1 April 2013 – 31 March 2015

HSC Trust	Hospital	Number of Admissions
Belfast	Belfast City Mater Hospital Royal Victoria	11
Northern	Antrim Area Causeway Hospital	19
South Eastern	Ulster Hospital	14
Southern	Craigavon Area	9
Western	Altnagelvin	14
Total		67

Between 1 April 2013 to 31 March 2015, 67 young people were admitted to medical wards with symptoms of an eating disorder.

Number of Admissions to Acute Medical Inpatient Wards for Adults with Eating Disorder Related Health Issues

Table 2: Number of Admissions to Acute Medical Inpatient Wards for Adults with Eating Disorder Related Health Issues (July 2012 - September 2015)

Trust	July 2012 - June 2013	July 2013 - June 2014	July 2014 - June 2015	July 2015 - Sept 2015	Total
Belfast	9	3	7	3	**22**
Northern	23	3	16	3	**45**
South Eastern	11	3	5	3	**22**
Southern	2	0	5	0	**7**
Western	6	0	1	0	**7**
Total	**51**	**9**	**34**	**9**	**103**

Health and Social Care Board – Nov. 2015

A reduction in the number of admissions for eating disorder beds to medical inpatient wards was noted in the period July 2013-June 2014.

5.0 Profile of Eating Disorder Services in Northern Ireland

5.1 Treatment Guidelines for Eating Disorders

The treatment of eating disorders in Northern Ireland is based on the National Institute for Health and Care Excellence guideline CG9[10], published in 2004. DHSSPS recognises this as a key source of evidence-based, cost-effective guidance on which to operate services. In addition to the treatment guideline, NICE also publishes information for patients and their carers.

The professional support offered to patients depends upon their disorder, the availability of services in their area or the arrangements that the HSC Board has made to purchase ECRs, outside Northern Ireland.

The NICE guideline emphasises that most people with anorexia nervosa should be managed on an outpatient basis, with psychological treatment provided by a service that is competent in giving treatment and assessing the physical risks of people with eating disorders.

5.2 Types of Treatment

Patients may be offered a range of different forms of therapy. If patients are at a very low weight, it may be appropriate for them to restore body weight before engaging in psychological therapy. The therapy offered should be based on discussions between the patient and the healthcare professionals. They will be offered a talking therapy such as: counselling; cognitive behaviour therapy; psychotherapy; cognitive analytic therapy; group therapy; or family therapy. Within more intensive forms of treatment such as inpatient or day patient units, group therapies and experiential therapies should be offered alongside individual talking therapy. The goals of the treatment are:

- To correct any medical problems which may occur as a result of an eating disorder
- To help the person reach a healthy weight and to develop healthy eating patterns
- To help the person to talk about their feelings and learn healthier ways of coping with problems.

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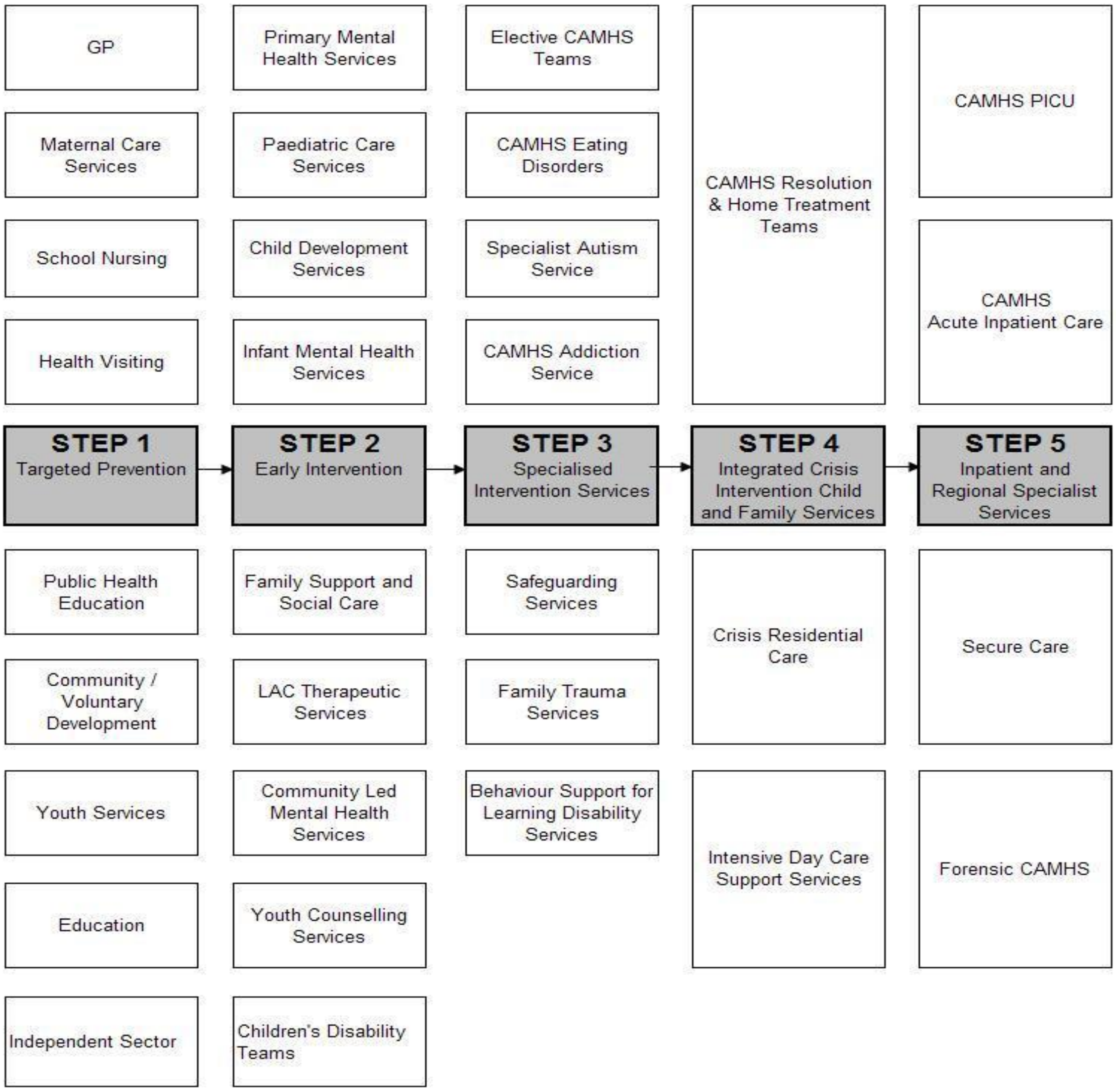
[10] https://www.nice.org.uk/guidance/CG9

5.3 Children Under 18 with Eating Disorders

NICE guidance and clinical practice recommendations suggest that young people with eating disorders should be assessed and receive treatment at the earliest opportunity. The review team met with a range of staff that provide services across the stepped care assessment and treatment model of service provision in each HSC trust. In 2012, DHSSPS developed a five step model, which outlines the relationship between care steps and service provision.

Figure 1: Five Stepped Care - Matched Care Services[11]



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[11] CAMHS A Service Model. July 2012. DHSSPS

Across all HSC trusts, children under 18 have access to an eating disorders service under the umbrella of the child and adolescent mental health service (CAMHS), which includes primary mental health workers and community-based specialist CAMHS teams. Crisis assessment and intensive treatment teams are also available.

In 2014, Northern Ireland's total investment in CAMHS was £19.3 million[12]. This represents 8% of total mental health expenditure, compared to a national average of 10%.

Table 3: Staff Employed within CAMHS Eating Disorder Services

CAMHS	Staff Eastern Region[1] Whole time Equivalent (WTE) Funded Posts	Northern Trust Whole time Equivalent (WTE) Funded Posts	Southern Trust Whole Time Equivalent (WTE) Funded Posts	Western Trust Whole Time Equivalent (WTE) Funded Posts
Consultant Psychiatrist	0.1		0.1	0.2
Staff Grade Psychiatrist	0.2			
Dietician	0.8	0.5	0.6	0.2
Social Worker				1.0
Team Leader	1.0	1.0	1.0	
Clinical Nurse Specialist	1.0		1.0	1.0
Band 6 Nurse Practitioners	2.0			
Family Therapist	0.1		0.5	
Eating Disorder Therapist		1.0		2.0
Total	**5.2**	**2.5**	**3.2**	**4.4**

RQIA's review team noted that due to differences in investment by trusts, the teams are at different stages of development.

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[12] The Rees Review of Child and Adolescent Mental Health (NI). September 2014

Where necessary, eating disorder teams, refer children and young people who may require hospital admission for intensive care, support and treatment to Beechcroft. This is a specialist facility, which offers a range of services and is located in Belfast.

Greater Belfast (including South Eastern Trust)

The Eating Disorder Youth Service (EDYS) for under 18s in the South Eastern Trust, offers a comprehensive assessment, treatment and preventative mental health service to children and young people aged up to 18 years of age. Staff also provide support to parents and carers.

The South Eastern Trust accepts patients with mild eating disorders (Step 2). Only those with severe eating disorders (Step 3) can be referred to the specialist eating disorder teams.

Referrals are generally received from GPs, but can also be made by the CAMHS team, in line with the stepped care model.

The community team indicated that it was moving towards early intervention and prevention involving GPs, schools, nursing staff, school counsellors and practice nurses delivering services at a primary care level.

The trust indicated that young people referred to the service and their families are offered a comprehensive eating disorder assessment, including the use of standardised self-rating questionnaires; a CAMHS network assessment; a specialist eating disorder clinician rated questionnaire; and a dietetic assessment.

This information helps to provide feedback to the young person, and their family. This includes the shared development of a care plan and recommended interventions, including intensive support at home, involving the crisis assessment and intervention team.

On referral to the team, while the waiting time for an appointment varies, at the time of the review did not exceed nine weeks. Cases are prioritised in line with the Integrated Elective Access Protocol (IEAP)[13] and clinical need.

At this initial meeting staff assess the child/young person to consider the best course of treatment/intervention/support service to meet their needs. The trust endeavours to provide a service in partnership with the child or young person, and parents or carers.

The treatment plan used by trusts to treat patients with anorexia nervosa is a recovery based model, which may involve: feeding; weight restoration; physical monitoring; family-based interventions, including psycho-education and parental management; and, individual interventions.

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[13] An Integrated Elective Access Protocol DHSSPS 2008

It may also include cognitive behavioural therapy and motivational enhancement, multi-family group therapy and, on occasion, prescribed medication.

The treatment offered by both Belfast and South Eastern trust staff for bulimia nervosa is based on family-based interventions and individual cognitive behavioural therapy.

Belfast Health and Social Care Trust

The Belfast Trust reported that it has developed robust cooperative relationships with paediatric consultants. The team offered inreach support to young people in acute hospital settings.

Support and training to help increase awareness and understanding of eating disorders and how teams can help is offered to school staff, youth workers, GPs and others who work alongside children and young people.

Northern Health and Social Care Trust

The Northern Trust CAMHS eating disorder service is located at Alder House at Antrim Area Hospital. Referrals are accepted from many sources, such as GPs, paediatricians, dieticians and school nurses. It provides a comprehensive assessment and diagnosis service to establish the severity of a patient’s eating disorder problem. The eating disorder team consults with both primary care and specialist CAMHS in relation to patients presenting with anorexia nervosa or bulimia nervosa.

The CAMHS team provides a range of therapeutic treatments, including: family-based treatments; multi-family therapy; motivational interviewing; and interpersonal adolescent focused therapy. The team also provides psychoanalytical work, supervised intensively by an accredited child and adolescent psychoanalytical psychotherapist, and cognitive behavioural psychotherapy, as required.

Clients presenting with mild eating disorder symptoms, with no physical risk, are managed within the primary mental health team. Young people presenting with moderate eating disorder symptoms, where there are no specific risks, are treated within specialist CAMHS. Those with moderate to severe eating disorder presentations are treated within the specialist eating disorder team.

The eating disorder team primarily offers an outpatient service, with a paediatric inpatient service, where severely malnourished patients require naso-gastric tube feeding. The Northern Trust has two beds at Antrim Area Hospital dedicated to acute admissions of children under 16 with an eating disorder. This has demonstrated beneficial outcomes for younger people due to earlier intervention. This has also helped reduce admissions of young people to Beechcroft.

Following an assessment, a treatment plan is discussed and agreed with the young person and their family. Young people receive intensive daily support and psychological intervention from the eating disorder team.

Psychiatric support is provided by the specialist CAHMS team as required. The senior psychology staff consult with the team/leader and clinical services manager for advice and management in relation to treating service users who meet the diagnostic criteria for an eating disorder.

The clinical services team leader carries a full caseload, involving supervision referrals, management and clinical time. Clinical nurse specialists are accredited in cognitive behavioural psychotherapy.

Southern Health and Social Care Trust

In 2013 the trust opened an eating disorder service for young people under 18 at the Longstone Centre, Armagh. This newly refurbished centre offers an open, bright, comfortable space with excellent facilities and a full range of treatment options available.

The Southern Trust assesses and treats young people who present with anorexia nervosa, bulimia nervosa and other eating disorders. Referrals are accepted from GPs, paediatricians (hospital and community), medical physicians, emergency department consultants and from the generic CAMHS team.

The eating disorder team offers a range of therapeutic interventions including: individual work; motivational work; group work; family therapy; multi-family therapy; and dietetic input/education/group work.

The team works in close collaboration with GPs, and staff in both paediatrics and acute wards, to share information and provide advice on the management of eating disorders. This involves face-to-face contact with ward staff and meetings between Craigavon Area Hospital and CAMHS**.**

Western Health and Social Care Trust

The Western Trust CAMHS team provides eating disorder services at three sites, Londonderry, Omagh and Enniskillen. This ensures local access to CAMHS services and promotes multidisciplinary and interagency collaborative working at a local level.

The approach of the Western Trust eating disorder team is based on the individual assessed need of the young person and family. Therapeutic inputs include multifamily cognitive behaviour therapy - enhanced (CBT-E) and systematic family therapy, motivational interviews, body image work and group work.

At the time of the review, the Western Trust CAMHS team, did not have a psychologist, consultant psychiatrist, occupational therapist or a family therapist.

Clinical supervision of cases is provided within a multidisciplinary context as an integral part of the intensive therapy-eating disorder (IT-ED) service framework. CAMHS staff have access, on a contractual basis, to consultation from Great Ormond Street Hospital, London, funded by the HSC Board.

Inpatient treatment may be required to assess clinical risk involving medical stabilisation in Altnagelvin Hospital or the South West Acute Hospital. In such cases, there is liaison between the CAMHS team and the acute paediatric ward.

5.4 Beechcroft

The review team visited Beechcroft, managed by the Belfast Trust, a 31 bedded facility for children and young people with mental ill health. Its function is to provide a safe and containing therapeutic environment where intensive assessment can be provided and the child can be stabilised. Eating disorder specialists from Beechcroft provide advice to medical staff in acute hospital wards as required. Similarly, medical specialists support and advise CAMHS staff on medical issues during an inpatient admission to Beechcroft.

The staff profile for Beechcroft includes a cognitive behavior nursing therapist, social workers, occupational therapists, clinical psychologists and consultant psychiatrists employed on a full and part-time basis.

There are no dedicated eating disorder beds in Beechcroft for patients who require additional treatment modalities/family therapy. Children under 12 can be admitted to Beechcroft when their level of risk indicates that admission is the only option.

To help improve services provided across Northern Ireland, at the time of the review the HSC Board had commissioned a separate review of Acute CAMHS[14].

Admissions to Beechcroft

The review team noted that admission rates more than doubled from 12 in 2011-12 to 26 in 2014-15. Between 1 April 2011 and 31 March 2015 a total of 83 young people were admitted for treatment of eating disorders to Beechroft. The majority of admissions are in the 15 to 16 year old age group.

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[14] The Rees Review of Child and Adolescent Mental Health (NI). September 2014

Table 4: Admissions of Young People under 18 years to Beechcroft from 2011 - 2015 by Trust

HSC Trust	Number of Admissions
Belfast	27
Northern	7
South Eastern	18
Southern	6
Western	25
Total	**83**

The Belfast, South Eastern and Western trusts have more admissions to Beechcroft, whilst the Southern and Northern trusts manage most patients within their CAMHS eating disorder services.

The lack of a psychologist, psychiatrist or family therapist in the Western Trust CAMHS eating disorder service may be a contributory factor to their higher admission rate to Beechcroft.

The review team noted an increasing number of young people under 12 being cared for in acute wards who do not fit the eligibility criteria for admission to Beechcroft.

The review team noted there was no system in place for the HSC Board to monitor the number of children admitted to acute wards.

KEY RECOMMENDATION 1
The HSC Board should review the assessed need for services against the capacity and current level of funding in HSC trusts to ensure that trusts can offer early intervention and further develop their community based teams.

5.5 Adult Services

There are four adult eating disorder teams in Northern Ireland. The Belfast Trust provides the eating disorder service on behalf of the South Eastern Trust.

Adult specialist eating disorder teams plan and deliver treatment in line with a model involving four levels of stepped care, as recommended by the Bamford Review[15], NICE guidelines[16] and the psychological services model for mental health services endorsed by the DHSSPS[17].

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[15] The Review of Mental Health and Learning Disability (Northern Ireland). A strategic Framework for Adult Mental Health Services. DHSSPS. June 2005. P38 & P108-110. Recs: 100-102. http://www.dhsspsni.gov.uk/adult mental health report.pdf

[16] NICE. Eating Disorders. National Clinical Practice Guideline Number CG9.2004

[17] A Strategy for the development of psychological therapy services. June 2010. DHSSPS.

Trust staff stated they follow Clinical Guideline 9, Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders, (NICE 2004), and other mental health service standards relevant to Northern Ireland.

Trusts use a stepped care approach to match patients' needs with the right treatments and interventions, and to assess the correct level of support required. Decisions about the right treatment setting in which to manage a person with an eating disorder currently depend on: the nature of the disorder; the level of risk; physical and psychological complications; and, patient preference.

Every step reflects a recovery model, and the recovery principles contained in the model inform the delivery of eating disorder services in Northern Ireland. This includes supporting patients to recover aspects of their lives prior to the onset of their disorder and to improve quality of life.

The aim of this stepped care model is to provide treatment in the community and prevent hospital admissions. The review team noted developed links and co-working arrangements with relevant services, to address physical health needs of service users. It is of particular importance that prevention, early detection and prompt treatment and support are available to pre-empt long-term complications. The contribution, made by appropriately informed family members and carers, was raised by families, and this should be considered by practitioners.

Adult trust teams include consultant psychiatrists who specialise in eating disorders; specialist nurse therapists; dieticians; and clinical service managers/team leaders. However, no evidence was provided to the review team of social workers being employed as part of adult eating disorders teams.

The majority of adult patients are treated within their local community mental health teams, where professionals have a range of training and skills to respond to assessed need. More intensive and complex interventions may require access to specialist services, which varies within and between trusts.

Care pathways for eating disorders are in the process of development by the HSC Board, to ensure a coherent strategic approach across the regional teams in delivering the stepped care model of intervention.

KEY RECOMMENDATION 2
The HSC Board should progress, as a priority, the development of care pathways for eating disorders for CAMHS and adult services.

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http://www.dhsspsni.gov.uk/a-strategy-for-the-development-of-psychological-therapy-service-june-2010.pdf

5.6 Use of Integrated Elective Access Protocol

A key objective for HSC trusts is to ensure that services to treat and care for people with mental health needs are responsive and accessible to all who need them.

Integrated Elective Access Protocol (IEAP)[18] has been agreed by the HSC Board. This sets out systematic principles and processes for the management of patients/clients from the point of referral to the point of discharge. These principles apply across all mental health care services, but some specialist areas of mental health need to tailor the guidance to reflect the specific needs of their patient/client group.

Trusts are required to ensure that patients wait no longer than nine weeks from referral to the commencement of treatment. For psychological therapies patient should wait no longer than 13 weeks.

At the time of the review, some young people with eating disorders were on a waiting list for CAMHS. However, all were seen within the required nine week timeline in accordance with the regional integrated elective access protocol. The review team did not note any robust system in place to monitor the experiences of these young people. It is essential that commissioners engage regularly with young people and their families, to better inform commissioning decisions.

Any individual who presents at an emergency department and is considered to be high risk of self-harm is usually offered an urgent mental health assessment, either in the emergency department, or on the ward, if they are admitted for medical treatment. An arrangement for a Card Before You Leave[19] referral has been put in place for a next day appointment, which can be used in low risk cases, or where a patient refuses the urgent assessment**.**

Promoting Quality Care (PQC) Guidance (DHSSPS, May 2010)[20] on risk assessment and management in mental health services has been adopted by all trusts. A review of the PQC guidance was undertaken by the HSC Board who was involved in launching the regional Mental Health Care Pathway in 2014. Its intention was to have new risk assessment and management procedures in place through developing tools to support the You in Mind[21] implementation.

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[18] An Integrated Elective Access Protocol DHSSPS 2008

[19] HSC Board has carried out an evaluation of the Card Before You Leave scheme in emergency departments 24 April 2013. Findings are now available HSC Board Publications.

[20] Promoting Quality Care - Good Practice Guidance on the Assessment and Management of Risk in Mental Health and Learning Disability Services. DHSSPS. 2010

[21] New Regional Mental Care Pathway developed jointly by HSC Board and Public Health Agency, You in Mind – October 2014

5.7 Stepped Care Model of Intervention for Adults

	Level 1	**Level of Intervention**	**Client Group**
SUPPORT FROM VOLUNTARY SECTOR	Primary Care (GP Health Visitors, Practices Nurses etc.)	•Recognition and watchful waiting. Weight monitoring and bloods checked. •Mental Health Promotion. •Information and low level help, Dietary service	•For those with atypical eating patterns, recent onset eating disorder without severe weight loss or physical symptoms or people who require support and monitoring.
	Level 2	Level of Intervention	Client Group
	Community Mental Health Team	•Facilitated self-help and guidance in work and community settings •Brief psychological interventions and counselling in primary and community setting	•For those that have failed to respond to level one •For those mild to moderate •Eating disorders with concurrent other mental health problems •For those mild to moderate •Eating disorders who do not present physical risk
	Level 3	Level of Intervention	Client Group
	Eating Disorders Service Specialist Outpatient Service	•Close clinical monitoring both psychological & physical – through the shared care with the relevant agency •Combined treatments •Intensive psychological interventions using motivational and engagement work, CBT-E, IPT, Psychodynamic therapies. •Intensive key working with other agencies to ensure service users are involved in all aspects of their treatment to provide a safe enrolment to facilitate recovery.	•For those not responding to intervention at Level 1 or 2. •For those with severe and complex eating disorders •For those with rapid weight loss or long term low weight •For those presenting with high physical risk or other medical complication
	Level 3A	Level of Intervention	Client Group
	Intensive support and re feeding in reach service in acute medical and Psychiatric wards	•Re-feeding •Treatment of Co-Morbid Psychiatric illness •Level 3 Community Services operating on an in reach service spaces	•For those not responding to intervention at level 3 •For those with severe and complex eating disorders •For those with rapid weight loss or long term low weight •For those presenting with high physical risk or other medical complication
	Level 4	Level of Intervention	Client Group
	Specialist Inpatient Treatment (Currently ECR to preferred providers in England and Republic of Ireland)	•Complex psychological treatments within specialist services •Developments of care packages with additional input from specialised services	•For those that have failed to respond to level 3 •For those acutely ill in need of robust day programmes

5.8 Investment in Eating Disorder Services in Northern Ireland

Investment was provided during 2005-08 to allow for the development of specialist community eating disorder services across all trusts. Trusts also received additional investment to establish a specialist eating disorder practitioner resource within CAMHS teams.

In 2008, accepting that community-based eating disorders were under-resourced, DHSSPS provisionally identified £1 million funding, with a plan for second year funding to develop eating disorder services. However, £0.5 million of this funding was not allocated. As a consequence, eating disorder teams were unable to develop the service levels agreed with commissioners, and capacity is currently considerably less than required.

Table 5: Staff Employed within Adult Eating Disorder Services

Staff Profile by trust (Adults) Whole Time Equivalent (WTE) Funded posts	Eastern Region	Northern	Southern	Western
Consultant Psychiatrist	1.0	0.08	0.5[2]	0.08[5]
Consultant Physician	0.1			
Staff Grade doctor	0.6			
Dietician	1.0	0.8	1.0	0.6
Eating disorder practitioners	6.0	5.0	3.8 2.0	2.5
Clinical services manager	1.0	1.0		
Team Leader Band 7			1.0	1.0
Nursing staff Band 5/6	1.0			
Nursing staff Band 5	1.0			
Clinical Psychologist				
Specialist Occupational Therapist				0.4
Healthcare Assistant	1.0			
Administration Staff	2.0	1.0	1.0	1.0
Total	**14.7**	**7.88**	**9.3**	**5.58**

Eastern Region Adult Eating Disorder Service

The Eastern Region Adult Eating Disorder Service (AEDS) provides treatment for people with severe and complex eating disorders within both Belfast and South Eastern trusts. The team, based at Woodstock Lodge offers patients a choice of venues at satellite clinics in the South Eastern Trust. GPs refer patients through the respective HSC trusts agreed points of access for all adult mental health referrals.

Woodstock Lodge is the single point of referral for patients living in Belfast; another mental health assessment centre has been identified for patients living in South Eastern Trust area.

Services are designed along a stepped model of care. A comprehensive assessment of need and a risk assessment is undertaken, in line with PQC guidance on the Assessment and Management of Risk (DHSSPS, May 2010) and the new regional mental health pathway. Staff assess the presenting needs of patients, triage the referral, and refer the patient to the appropriate service. This can include referral to a psychologist, a psychiatrist, a specialist practitioner in a community mental health team, or the specialist eating disorder team. Hospital doctors can access mental health services through agreed psychiatric liaison arrangements, or the agreed single point of access in the trust, depending on circumstances. Patients can also be seen at home where there is a particular clinical need.

The team also provides support, training and supervision to staff delivering care at all other steps in the model. This helps to ensure that people with an eating disorder obtain the appropriate level of services for their condition.

Psychological interventions are considered to be crucial in addressing the core attitudes that underline eating disorders, and in influencing the longer term outcomes.

Individualised, structured psychological therapies offered include:

- comprehensive assessment of need
- a risk assessment in line with PQC
- cognitive behaviour therapy (CBT)
- specialist supportive clinical management (SSCM) and
- physical monitoring of patients’ conditions in collaboration with their GP.

The AEDS team offers individualised and structured psychological therapies including:

- CBT; CBT-E interpersonal therapy
- multi-family group work (initiative with CAMHS Eating Disorder Youth Service (EDYS)
- motivational enhancement work
- body image work
- physical and psychiatric review
- psycho education groups
- carers’ support

The team also provides intensive nutritional rehabilitation and community support for patients attending day care and an in-reach service during any period of inpatient treatment, ensuring a seamless transfer from hospital to community.

Support is also provided to families and carers and the team work closely with Eating Disorder Association (EDA). The AEDS staff have taken an active role in developing recovery colleges[22] in both the Belfast and South Eastern trusts as part of the Implementing Recovery through Organisational Change (ImROC) programme, which is a new approach to helping people with mental ill health[23].

The Belfast Trust has taken a lead in developing a regional eating disorder care network across Northern Ireland. This has enabled practitioners regionally to share concerns and highlight areas of good practice. All eating disorder teams indicated that they attend monthly clinical network meetings where regional evidence-based practices are shared, and new developments in treatments are presented for learning.

Northern Health and Social Care Trust

The Northern Trust AEDS provides a trust-wide service, based at Holywell Hospital Antrim. It also has clinics in Coleraine, Ballymena, Ballymoney, Magherafelt and Whiteabbey. The service treats adult patients with anorexia nervosa, bulimia nervosa and other specified or unspecified feeding or eating disorders.

This service works closely with Arts Care[24], occupational therapy and The Wellness Hub to provide arts imagery, creative imagery, writing groups, reading groups and wellness recovery action planning (WRAP) training specific to eating disorders. The reading group published The Rain Before the Rainbow in 2015.

The Northern Trust has a website used by schools, colleges, patients and members of the public. Information leaflets with advice for sufferers and carers are sent to all GP practices and hospitals in the area.

Southern Health and Social Care Trust

The Southern Trust (provides an eating disorder service for adults based in Lurgan, with satellite clinics in Armagh, Dungannon and Newry. It treats individuals suffering from anorexia nervosa, bulimia nervosa and other feeding or eating disorders.

The Southern Trust employs a consultant psychiatrist in psychotherapy and a range of eating disorder specialist staff. No family therapist post was included in the staffing profile submitted to the review team. The trust has access to a consultant psychiatrist, who is not part of the eating disorder team.

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[22] South Eastern HSC Trust Recovery and Wellbeing College was launched in March 2015 and is the fifth college of its kind developed in Northern Ireland. It builds on the national drive to create a society where people with mental health difficulties have access to the same opportunities in life as everyone else to help them focus on the recovery from their illness

[23] http://www.knowledge.hscni.net/Content/Uploads/file/ImROC%20Presentation.pdf

[24] Arts Care, in partnership with Health and Social Care Trusts throughout Northern Ireland, aims to make all forms of art accessible to patients, clients, residents and staff

Psychiatrists provide in-reach support to two hospitals and to its psychiatric wards, where they co-work with the core team, and provide training to ward staff.

The eating disorder service provides supported body image work groups which it intends to roll out across the trust, and has received positive feedback from patients. The service provides a number of treatments:

- CBT (specific to eating disorders)
- interpersonal psychotherapy
- motivational enhancement therapy
- body image work
- physical monitoring, in conjunction with GP
- psycho-education

Since 2011 as a result of the CAWT[25] eating disorder project and funding from the Southern Local Commissioning Group (SLCG) the trust's eating disorder care pathway has developed. This allows the treatment by the specialist outpatient and inpatient eating disorder teams of patients with all levels of severity of anorexia nervosa, bulimia nervosa and EDNOS.

Two practitioners are based within the adult eating disorder team who offer assessment and treatment to patients with mild to moderate eating disorders. This ensures that referrals are triaged appropriately and allocated promptly to the eating disorder team.

SLCG agreed to provide funding to mainstream the CAWT project from 1 January 2015. This has ensured a seamless and efficient referral process and care pathway. Patients are treated earlier, and can continue to be treated locally, remaining in their own communities. The trust believes that providing targeted specialist eating disorder treatment by trained professionals is essential in view of the poor prognosis for those with chronic, severe or complex eating disorders, particularly in the diagnosis of anorexia nervosa.

Patients who require inpatient care are admitted to the Bluestone Unit, Craigavon Area Hospital, where staff are experienced in the treatment of eating disorders. The community eating disorder service works alongside the inpatient team and provides dietetic and therapeutic input to patients as part of their care plans.

The Southern Trust has not required any ECRs for treatment of eating disorders within the last two years. This is considered to be as a result of earlier interventions through the use of CAWT funding, and the upskilling of staff to deal with eating disorders.

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[25] Cooperation And Working Together (CAWT) is a partnership between the Health and Social Care Services in Northern Ireland and Republic of Ireland, which facilitates cross border collaborative working in health and social care

Western Health and Social Care Trust

The Western Trust's adult eating disorder team has bases in Londonderry and Omagh, and provides satellite clinics in Enniskillen, Strabane, and Limavady. At the time of the review there was no social worker or family therapist in eating disorder team. Psychology/ psychotherapy input is accessed through other services.

The trust provides information leaflets to service users at an initial assessment appointment, signposts people to appropriate websites and provides an eating disorder booklet. They offer a range of psychological interventions including: CBT; CBT-E, interpersonal psychotherapy; and family work.
Other interventions include specialist dietetics support, and a specialist occupational therapist assists with shopping, cooking and meal supervision support. Group work interventions are provided in relation to body image, craft skills work and preparation for independent living.

At level 2, the trust's primary care mental health teams offer assessment and treatment of mild to moderate eating disorders. It offers evidence-based psychological treatments, such as CBT-E, which has been delivered through the CAWT project. CAWT eating disorder therapists have, on a rotational basis, provided staff updates/training to GP practices. Trust staff have good working relationships and have developed shared care arrangements with GPs and the voluntary sector. In more complex cases GPs can access specialist biochemistry blood results through a consultant chemical pathologist, at Belfast City Hospital.

At level 3, a specialist outpatient eating disorder service is provided offering a psychological therapy service for those who have severe, enduring, complex and treatment resistant eating disorders. This service also provides assessment for all urgent referrals. Patients will be offered assessment and intervention from the specialist dietician and occupational therapist. If a patient does not respond to community interventions, an admission may be made to a medical ward at Altnagelvin Area Hospital or South West Hospital. The Western Trust indicated that staff are working beyond the original commissioned service, as they have to provide inreach services to the acute hospital sector and two psychiatric units.

The trust shares best practice initiatives at regional clinical network meetings every six weeks. The clinicians also provide advice and guidance for physicians on medical management of patients with eating disorders. Increasingly, trust staff indicated they are working with people who have mild to moderate eating disorders. Current facilities are limited as staff are unable to provide specific interventions such as body image therapy.

There is insufficient space to provide a resource library and kitchen/dining facilities to work with service users with regard to their eating patterns. A business case has been submitted to the HSC Board to develop a centralised base in Strabane to enable more intensive day care for service users and families. The trust considers that this will facilitate and improve links and support for the team, service users, and carers.

6.0 Support Services Provided by Voluntary Organisations

Members of the review team met with a number of voluntary organisations contracted by the trusts involved in supporting service users with eating disorders, their families and carers. Service users, families and carers attended focus groups run by a number of the voluntary organisations on behalf of RQIA, to present their views on the accessibility, flexibility and responsiveness of these services (See Appendix 1).

Some support groups are jointly facilitated by a HSC trust eating disorder professional and a volunteer. Other support groups are led solely by a volunteer. A mixed range of views, both positive and negative, were presented to the review team about the experiences of attendance at eating disorder support groups.

6.1 StampED – Eating Disorder Support Group

StampED[26] is an eating disorder support group, based in the Antrim area, which works closely with staff in the Northern Trust Adult Eating Disorder Service. In the Northern Trust, two eating disorder team members attend StampED meetings, as requested by the group, to facilitate two-way training. StampED also attends health fairs in schools, universities and community centres. The trust encourages StampED's attendance at all levels of treatment and also following discharge, to help prevent relapse.

The group comprises of current and recovered eating disorder sufferers, and families/carers who aim to raise the profile of eating disorders and its impact on them. StampED has devised and published posters and developed an information leaflet for GP practices in the trust area. This leaflet, providing information regarding indicators of eating disorders, and how to access the eating disorder services, is available on the StampED website. They also devised a cover letter, which is now sent out by the trust, to people with eating disorders, to assist them in understanding their illness and the treatment process.

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[26] http://stamp-ed.co.uk/

6.2 Adapt Eating Distress Association (Adapt EDA)

Adapt EDA operates in the Southern Trust area and works towards increasing understanding and awareness of eating disorders. ADAPT EDA has a contract with the trust to provide support to service users and carers. They attend the Southern Trust eating disorder project group meetings, and encourage patients and carers to comment on the care they receive, using this feedback to help the trust improve service development. The Southern Trust also shares information on service planning and development at meetings of Adapt EDA.

Adapt EDA provides support, information and understanding for people affected by eating disorders, their family, carers and friends, health professionals, teachers and others who request advice and support. Confidential support is provided through a helpline, a youth line, and one-to-one meetings are also offered. Monthly support and self-help groups are available for both people affected by eating disorders and their families/carers.

6.3 Eating Disorders Association Northern Ireland (EDANI)

The EDANI offers support and advice to people who are affected by anorexia, bulimia nervosa or binge eating disorder, and offers a 24 hour telephone support service for those who need assistance.

The Eating Disorders Association has a contract with the DHSSPS which is renewed on a yearly basis. They are also contracted by the HSC Board to provide a regional information service.

EDANI is run by a group of volunteers who have either experienced an eating disorder themselves, or have helped a family member affected by an eating disorder. They offer advice to the individual or the carer, and can listen with understanding and empathy. EDANI also provides an education awareness programme for young people. Its volunteers visit many schools and youth organisations to raise awareness of eating disorders. EDANI has produced a guide for carers, to help them provide support for someone experiencing an eating disorder.

EDANI holds anorexia and bulimia nervosa support groups twice monthly. The service refers those with binge eating disorder to a support group which meets in Belfast. This group is referred to as Over Eaters Anonymous.

A number of families indicated that the EDANI service forms an essential lifeline for many people, as there are often waiting lists for specialist treatment. The service aims to bridge the gap when specialist treatment is not immediately available. Although they are not an alternative to professional help, they provide a support service to people in the waiting period between referral and treatment appointments.

6.4 The Laurence Trust

This group provides support to men living with an eating disorder, mainly in the Northern Trust area, but in other parts of Northern Ireland as required. The Northern Trust has an informal arrangement with the Laurence Trust in relation to the service it provides, but no service level agreement is in place to deliver services. The Laurence Trust provides information for families, so that they can understand the impact of the condition on a male family member.

The volunteers use their experiences of having a sibling living with an eating disorder, to help young men and their friends and relatives, to become better informed about the effects of the condition.

The Laurence Trust help build the confidence of men living with an eating disorder, enabling them to talk about and face up to their problems. It supports and helps break down barriers, or stigma, that can exist for men with eating disorders.

The Laurence Trust also aims to give professionals a better understanding of eating disorders; to become more responsive to men's needs; recognise the barriers sufferers feel when facing treatment and recovery; and to suggest ways of overcoming difficulties.

6.5 Caring about Recovery from Eating Disorders (CARED)

CARED was launched as a voluntary charity in 2014. The primary aim of CARED is to support parents of children and young people to come to terms with, and recover from the issues surrounding eating disorders. It has introduced aspects of the New Maudsley Model of working with families across Northern Ireland in its training events for parents and carers. The New Maudsley Model has been available for over twenty years in England, and is used in many countries around the world. The model teaches parents about responding to eating disorders, provides families/carers with enhanced communication skills, identifies the psychology of change and provides information on how to promote recovery.

At the time of the review CARED had appointed 12 facilitators across Northern Ireland. It delivered its first carers course in September 2014 and continues to receive requests from parents for further training.

CARED had sent out letters about eating disorders and about training courses they offer to every GP surgery, mental health and counselling agency and secondary school. CARED met with review team members to discuss its vision for improving services. CARED suggests that a dedicated day outpatient centre should be established, which offers a drop in service, training for professionals, dietetic advice, psychotherapy, complimentary therapies and a weekly eating disorder therapy group.

CARED suggests that if a day care outpatient centre was developed, outpatients could be treated quickly and on a more cost effective basis.

This could potentially reduce hospital admissions, release beds, reduce the average length of inpatient stays, and the numbers of patients being treated outside Northern Ireland.

At the time of the review CARED was not contracted by HSC trusts to provide any services to families.

6.6 Men's Action Network (MAN)

The Western Trust meets regularly with Men's Action Network (MAN) to help understand key issues raised by men. MAN was founded in 1994 in Limavady, through the efforts of a group of local men. It seeks to provide a safe space and weekly self-help support group for men experiencing eating disorders, or other mental health and wellbeing issues. Its ethos is one of prevention and intervention, recognising and supporting men and boys' emotional, physical, mental health experiences while striving to develop their health and wellbeing.

6.7 Derry Well Woman Service

The Derry Well Woman Service provides a range of programmes to support the needs of women of any age. It links in with the Western Trust to identify issues requiring service improvement. It provides people with eating disorders individual support through counselling, one-to-one clinics and sign-posting to medical services provision. It also offers the opportunity, through support groups, to meet with other women experiencing a health crisis or lifestyle change.

6.8 Voice of Young People in Care (VOYPIC)

VOYPIC is a charity working across Northern Ireland, promoting the rights and improving the lives of children and young people cared for away from home. VOYPIC is contracted by all five HSC trusts to provide advocacy services and support for young people admitted to Beechcroft, or in care placements, as required.

When a young person with an eating disorder is admitted to Beechcroft, they are provided with a welcome pack containing details of the VOYPIC advocacy service. This information is also displayed around the wards. The advocate provides a continuous service to all young people in Beechcroft. Young people are provided with the opportunity to express their views through one to one meetings with their named nurse and by attending weekly multidisciplinary care planning meetings. They can involve the VOYPIC advocate if they wish to challenge any aspect of their care and treatment.

7.0 Findings

All HSC trusts highlighted the demand for eating disorder beds in both medical inpatient and psychiatric wards, but noted a reduction in admissions in 2014-2015.

Table 6: Number of Psychiatric Inpatient Admissions for Adults with Eating Disorder Related Treatment (July 2012 to September 2015)

Trust	July 2012 - June 2013	July 2013 - June 2014	July 2014 - June 2015	July 2015 - Sept 2015	Total
Belfast	7	3	2	0	**12**
Northern	7	17	12	5	**41**
South Eastern	7	11	8	0	**26**
Southern	9	15	6	1	**31**
Western	0	3	2	0	**5**
Total	**30**	**49**	**30**	**6**	**115**

7.1 Provision of Clinical Supervision and Guidance in Delivering Specialist Psychological Interventions in Adult Services

An awareness of evidence-based practice was evident across the trusts' multidisciplinary teams where considerable investment had been made in the provision of specialist training opportunities.

All therapists in the Eastern Region (Belfast and South Eastern trusts) AEDS are registered with a professional body and are eligible or are accredited with the British Association for Behavioural and Cognitive Psychotherapies (BABCP), Irish Council for Psychotherapy (psychoanalytic section) and the European Association for Psychotherapy.

The review team considers that regular provision of high-level clinical supervision and guidance from an identified senior lead supervisor is essential in delivering specialist psychological interventions.

The Belfast Trust stated that it does not have a senior clinician available to provide leadership, direction, clinical expertise, supervision and training. This is provided within the team by the consultant psychiatrist and clinical services manager.

The Southern Trust has a consultant medical psychotherapist who provides weekly clinical supervision, based on psychodynamic principles to the eating disorder team. A team leader, a cognitive behavioural psychotherapist, accredited with the BABCP, provides monthly clinical supervision to each member of the team.

All cases within the service are reviewed within this model of supervision. The trust considers this level of clinical expertise has helped staff to manage patients more effectively in the community.

Within the Western Trust, the nursing team lead provides leadership, direction, clinical expertise, supervision and training. There is a psychological therapy service for individuals who have severe enduring complex treatment with resistant difficulties. The Western Trust also avails of a regional consultant psychiatrist one day per month.

Within the Northern Trust, the clinical services manager is a trained psychiatric nurse who provides leadership, clinical expertise, clinical supervision, training and direction to staff within the eating disorder service. A consultant psychiatrist provides clinical input one day per month, and may be contacted by phone at any time, as can a staff grade doctor.

The review team was concerned about gaps in capacity in the provision of psychological services across trusts. All psychological treatments should be based on a range of evidence-based interventions and staff providing treatments should be trained in outcome measurement.

Some patients and carers stated they had not been advised by staff of the range of evidence- based psychological therapies available to patients.

It is essential that practitioners communicate this to patients. The Academy for Eating Disorders Worldwide Charter for Action on Eating Disorders (2008)[27] and the NHS England Eating Disorders Charter Mission Statement 2014 are a helpful benchmark for trusts in this respect.

The review team considers that a mapping of therapeutic skills across the service should be conducted, to identify existing knowledge and skills, and gaps that may affect the delivery of therapeutic interventions.

The review team was concerned that, in some cases, NICE recommended interventions were not being reviewed and were being allowed to continue past the recommended number of sessions.

In keeping with the Strategy for the Development of Psychological Therapy Services (DHSSPS, 2010), trusts should be offering evidence of both low and high intensity psychological interventions to patients with eating disorders in community and acute mental health settings.

SUPPORTING RECOMMENDATION 1

HSC trusts should ensure a system of appropriate clinical case supervision is in place to enable staff to review cases with a senior lead supervisor (champion) to ensure adherence to evidence-based practice.

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[27] http://aedweb.org/index.php/get-involved/get-involved-sigs-2/get-involved-sigs-5

7.2 Multidisciplinary Involvement in Eating Disorder Services

The review team noted a low number of occupational therapists and social workers employed in adult eating disorder services. A social work perspective in assessments and formulations is an essential component of a multidisciplinary assessment. The Belfast Trust advised that eating disorder therapist posts are available to occupational therapists, but stated that staff have not applied for these posts.

Occupational therapy is also helpful to individuals who are highly ambivalent about change. Specialist occupational therapy, psychological interventions, including experiential interventions (e.g. meal preparation, independent living skills) and motivational enhancement also support the process of recovery**.**

The review team recommend that the role and function of occupational therapy and social work should be strengthened, both in CAMHS and in adult services.

KEY RECOMMENDATION 3
The HSC Board should review the skill mix within eating disorder services to ensure that services can effectively meet the needs of service users.

7.3 Training and Supervision

Clinical supervision is a mandatory requirement for all professional staff engaged in the delivery of specialist management interventions. It should also be embedded in the governance structures of the trusts.

Belfast Trust stated that it is difficult to source professional development, as most of the relevant training takes place outside Northern Ireland.

The Northern Trust provides funding for supervision for four managers to enable them to present particularly complex cases. The clinical services manager is directly supervised by a specialist in eating disorders when dealing with complex cases and had attended a master class to ensure competency in delivering CBT-E and cascading/supervising this treatment option. The Northern Trust also has a professional nursing forum for specialist teams (including personality disorder/forensics), chaired by the clinical services manager.

At the time of the review, the Southern Trust had regular clinical supervision sessions via video link with a specialist in eating disorders in Oxford. The trust had visited specialist eating disorder inpatient units in London to view the infrastructure, skill mix and model of service provision. The service supports and develops practice and standards through its model of monthly clinical supervision by the training leader, based on CBT principles. The team also receives weekly group supervision, based on psychodynamic principles.

The Western Trust provides clinical supervision for the adult eating disorder team leader. All clinicians attend monthly clinical network meetings for continuing professional development and case presentation.

The review team considers that regular provision of high-level clinical supervision and guidance is essential in specialist supportive clinical management intervention.

SUPPORTING RECOMMENDATION 2
HSC trusts should review the delivery of high-level clinical supervision arrangements to ensure that specialist clinical management interventions are appropriate across CAMHS and adult services.

It was unclear to the review team whether HSC trusts had suitably qualified and experienced staff available to treat more complex eating disorder cases. The review team noted that not all therapists who deliver evidence-based psychological interventions had training and qualifications to masters or doctorate level and/or accreditation with a relevant body.

KEY RECOMMENDATION 4
HSC trust therapists delivering evidence based psychological interventions should have training and qualifications in a recognised therapeutic model, in accordance with recommended guidance, overseen by an accredited body.

7.4 Dependence on External Peer Supervision from Great Britain

All HSC trust eating disorder teams use a regional eating disorder network for peer supervision**.**

Four trusts demonstrated evidence of dependency on external peer supervision from specialist clinicians in England and Scotland. After nine years of dependency on external supervision, the Southern Trust eating disorder team had gained the necessary expertise to provide its own clinical supervision of complex cases. The inclusion of a medical psychotherapist in the eating disorder team has assisted staff in treating more complex cases.

The Northern Trust avails of peer supervision via an agreed regional network, where complex cases are presented. The clinical services manager is one of five individuals who participates in video links with a specialist in eating disorders in Oxford. Five members of the eating disorder team have video link supervision with other eating disorder experts in England and Scotland.

Staff in the Northern and Western trusts have completed the CBT/ CBT-E [28] training delivered by the University of Oxford.

Eating disorder therapists, dieticians, psychiatrists and nurse practitioners had attended CBT-E training. The clinical services managers from the trusts have been receiving direct supervision from an external specialist since 2006.

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[28] Transdiagnostic CBT For Eating Disorders“CBT-E”- Christopher G Fairburn 2009

The clinical services manager in the Belfast Trust, a BABCP accredited therapist, has attended extra training in England to ensure competency in cascading the training and supervision. The team lead in Western Trust has also attended a master class (training for trainers in England) to maintain competencies to deliver/cascade this modality of treatment.

The Belfast and Western trusts indicated that it remained a challenge to continue to resource external supervision on an ongoing basis, much relevant training takes place outside Northern Ireland.

SUPPORTING RECOMMENDATION 3
The HSC Board should review the cost of external supervision and explore how trust staff can be supported to provide regional clinical and supervisory expertise in complex cases.

7.5 Monitoring of Outcomes

All eating disorder services should undertake monitoring and auditing of the outcomes of their interventions. All trusts agreed questionnaires regionally to measure outcomes of service provision within adult eating disorder services. Trusts are expected to issue these questionnaires to patients before and after treatment.

Some service users indicated they currently complete eating disorder evaluation questionnaires, and a goal attainment form at the end of therapy.

A number of trusts indicated that they had been monitoring outcomes, but were unable to report clearly on the outcome measures used. The review team were advised by trusts that their capacity to undertake clinical audits is sometimes constrained by their need to attend to clinical priorities of patients.

The review team noted the intention of the HSC Board to develop a framework for trusts to report on outcomes, using a CORE tool, to ensure that outcomes are consistent and comparable across trusts.

KEY RECOMMENDATION 5
The HSC Board should develop and review outcome measures used by HSC trusts for assessing the clinical effectiveness of particular treatments and interventions.

SUPPORTING RECOMMENDATION 4
The HSC Board, in establishing an outcome framework, should ensure trusts audit and report on outcomes following a period of treatment.

7.6 Transition Arrangements

The review team notes that there is a regional transfer protocol which sets out the criteria for young people transferring from CAMHS to adult services. It applies to any young person currently in receipt of CAMHS with an eating disorder. Where it is likely that a child/young person will require future input from specialist eating disorders services, a referral is made to an adult mental health team, who are involved in making preparations for the transition to adult services.

The Southern Trust has a transfer protocol between child and adolescent services and adult mental health services, in cases of patients with comorbidity, who require treatment.

It was unclear to the review team that all trusts are following the regional transfer protocol. The review team was unable, without auditing files, to determine the adequacy of the existing protocols for transition, or examine if they were properly adhered to in practice.

Some carers expressed concerns about the arrangements for their child's transition to adult services, and when and how the transition arrangements would be planned. A number of parents considered that adult services do not deliver the same level or type of services that young people receive in a CAMHS environment, and were concerned about maintaining their child's progress following transition.

Case Example 1 – Transitional Planning from CAMHS to Adult Services

"My parents had to put a lot of pressure on the consultant in eating disorders to enable me to transfer from children/young people to adult services. I felt that follow up care has been a let-down, as I really hadn't any".

SUPPORTING RECOMMENDATION 5
HSC trusts should monitor that the regional transfer protocol is being adhered to by staff to ensure a smooth transition from CAMHS to adult eating disorder services.

When patients move between services, such as adolescents moving to adult services, or where patients move to another area, liaison is required to ensure services are maintained, or reciprocal arrangements between specialist services are agreed. Patients emphasised that these arrangements must not rely solely on referral via primary care, as this can lead to delays.

A number of service users said they found it more difficult to access services, having transferred from CAMHS to adult services, particularly if they had relapsed and required further intervention.

Some service users and carers talked about the delay in accessing support services after they had been discharged from mainstream services.

Case Example 2 – Difficulty in Accessing Services Once Discharged

"My wife suffered from an eating disorder for many years. To get on the right path following her relapse, I had to make endless phone calls to receive help for her and felt helpless. A direct path back into the service by the trust would have helped."

One young person advised the review team that when she left home to study in Belfast, it was very difficult to access services in another trust.

Case Example 3

"I've been back in university for four years and haven't been able to get back in the service."

SUPPORTING RECOMMENDATION 6
HSC trusts should review the effectiveness of referral pathways to ensure patients who relapse are fast tracked into appropriate assessment treatment and support services.

7.7 Views of Service Users, Families/Carers - Support and Provision of Information

A range of support groups and services have been developed in Northern Ireland in response to the needs of service users and their families/carers. Most parents and carers indicated that they had been informed of support groups and offered the opportunity to participate in such groups by the trust. All five trusts had engaged with voluntary eating disorder groups in their areas. Whilst various levels of intervention are required for patients, a complex number of communication interfaces existed, involving professionals including primary care, acute care, mental health and eating disorder teams.

RQIA met with parents and carers who stated that focus groups were an effective and efficient way to receive information. Whilst most carers indicated that they benefited by hearing how other parents had coped, or handled similar situations, others stated that they required more immediate professional help to deal with their situation than the support offered by attending voluntary groups.

Some carers stated that they could not handle listening to others who were distressed about not receiving prompt access to services, when they were experiencing so much difficulty themselves.

A number of parents described the "*wear and tear*" on everyone in the family, and repeatedly emphasised that the person with the eating disorder is not the only one in need of support.

"We discovered we are not the only ones having an eating disorder in the family".

Other parents/carers found that support groups helped them to draw on the experiences of people to help understand, comfort, and, when necessary, challenge each other. Parents indicated that they often received ideas and support for handling new or difficult situations by meeting other parents in the support groups who had similar experiences.

They found it helpful to "*call on the collective wisdom and experience of members who've already been through it*". "*Recovery from an eating disorder can be a long road filled with setbacks and you need support".*

A number of parents considered it helpful to be part of a support group, as support groups can lobby for improvements to services.

Service users and carers stated they have specific needs that must be met to help them cope with living with a child/adult with an eating disorder. These include:

- good information and guidance
- emotional support
- pathways to treatment

Service users and carers presented mixed views on the adequacy of communication and information sharing, but more so in adult services.

Parents of children who relapse or who have long-term struggles with their disorders said they "*get hit particularly hard*". They stated that *"services provided by the trusts cannot be seen in isolation from the services required by families and carers, given the consequence for the whole family".*

Each HSC trust indicated that they offer families support, through an identified eating disorders therapist, assigned to a service user and their family.

A number of parents stated that information and advice was not consistently available for all parents about the range of options available to help families cope with a family member with an eating disorder. They also considered that more families should be offered this type of training and that people who have recovered from eating disorders should be more involved in the recovery colleges. One carer commented that more information is required for young men with a learning disability with eating disorders.

The review team commended the Northern and Southern trusts in respect of their publications for young people with eating disorders. The Western Trust has developed an information book for adults with eating disorders.

The Belfast Trust is developing leaflets and information booklets in consultation with service users and carers.

The parents who attended the CARED training programme said they had found it very beneficial, in terms of the clarity of information provided about how they should best approach coping with a family member with an eating disorder.

SUPPORTING RECOMMENDATION 7
HSC trusts should consider providing a wide range of options in helping families cope with eating disorders, ranging from individual therapy to family support groups.

SUPPORTING RECOMMENDATION 8
HSC trusts should review the nature and type of information about eating disorders provided for service users and families, to ensure that it is easily accessible.

7.8 Effectiveness of the Communication and Information Sharing with CAMHS Service Users and Carers

The need for the provision of high quality information and improved communication was highlighted by service users and carers throughout the review. The review team explored how information from service users and carers informs commissioning arrangements and the provision of services by the trusts.

The review team considered the effectiveness of communication and information sharing with service users and carers. Information was obtained from a series of meetings with staff from the five HSC trusts, the HSC Board and the PHA. All trusts highlighted their meetings with support groups run by voluntary organisations and their interface with the Regional Eating Disorders Network Group (REDNG) group (ref 7.10) in terms of strategically trying to influence the development of eating disorder services. The PHA also described their investment in training and development of specialist community-based teams and the establishment of the regional eating disorder clinical network.

The views of service users, parents and carers on the effectiveness of communication and information sharing were also obtained through a series of focus groups facilitated by EDANI. One to one meetings were held with a number of service users and families who requested to meet the review team.

Carers reported mixed experiences of communication, and provided examples of what they considered to be insufficient information sharing. Communication is clearly a two-way process. A number of parents said that they believed there was no recognition of their role as experts in their own children’s care, at primary care and other professional levels. Some positive comments on interventions and provision of support services by Beechcroft staff were provided by parents.

Case Example 4 – Positive comments about Beechcroft staff

"Beechcroft was a lifesaver. My daughter saw the psychologist, dietician and had a family therapist who helped the family."

Some parents were negative about the communication and approach taken by eating disorder teams in sharing details about their relative's condition and the treatment pathway.

Case Example 5 – Not Listening to Service Users / Carers

"My daughter of 15 years had serious weight loss and a low BMI. My GP referred her to Beechcroft as a day patient. My daughter considered that Beechcroft staff concentrated more on the eating plan. Whilst it was important, I felt they were not listening to my view that she needed help with her emotional state."

Case Example 6 – Lack of any Robust Information

"*I went to see my GP in February because my daughter's weight was low. The GP said she was not dangerously low and to come back in six to eight weeks.*

I refused to leave until the GP referred her for help. She was referred to the outpatient team at Beechcroft Adolescent Unit. She was given a diet plan which she did not stick to. I was not provided with any information. Most of the information I received was from the internet or books I bought. I was not shown a care plan for her until November when I asked to see the doctor, some nine months later."

Case Example 7 – Communication about Therapy

"The intensive intervention team from Beechcroft had to come to our house to watch my daughter eat. We never saw a psychiatrist or psychologist, only a few nurses.

When eventually she was offered a therapeutic counselling session, it lasted 10 minutes. The therapist said she could not do much for her as she would not open up. Is it not the job of a therapist to try and encourage her to do so? How could you do therapy in 10 minutes?"

Another parent of a young adult expressed frustration about the poor communication by staff at Beechcroft.

Case Example 8 – Lack of Feedback at Outpatient Clinic

"We ended up taking our own minutes of meetings with Beechcroft staff as the information was not shared with us about the agreed actions. When we returned to appointments, we ended up giving the consultant the minutes of action we recorded".

A carer suggested more help could be given to support other siblings in the family who find the situation difficult.

Case Example 9 – More Support for Family Members/Siblings

Family members, including siblings should normally be included in the treatment of children and adolescents with eating disorders.

"The type of interventions that would have helped are sharing of information, advice on behavioural management and on facilitating communication".

Poor communication can result in delay, frustration and anxiety for service users, parents, and carers who may be unsure as to what to do next. Service pressures may lead to insufficient time being available to discuss issues of concern. While the review team recognises the demands and pressures in the system, this can mean that opportunities for early intervention may be missed. These communication issues require review and further discussion involving the HSC Board and service providers.

KEY RECOMMENDATION 6
HSC trusts should consider the welfare of family members as part of the treatment of children and adolescents with eating disorders, including provision of advice on behavioural management and advisable methods of communication.

7.9 Confidentiality

Eating disorders can involve and affect families and carers in a profound way and often involve issues of medical safety. For some carers, continuing involvement when a young person reaches the age of 18 was proving difficult. Some carers said they did not know what was being planned, or their family member chose not to keep them informed.

To provide care adequately, families need the support of professionals in advising them of the best way of responding appropriately in these circumstances. Healthcare professionals need to be sensitive to this, while maintaining the patient's confidentiality.

7.10 Service User Involvement in Commissioning

The Regional Eating Disorders Network Group (REDNG) was established by DHSSPS in 2005, to advise on the development of services within Northern Ireland. The priority was the development of community based specialist teams in each trust over the short to medium term who have the capacity to treat more people than inpatient services and offer greater opportunities to manage eating disorder cases at an earlier stage. The development of a community based service model was proposed to limit future need for inpatient services. The regional group include representatives from the DHSSPS, PHA, HSC Board and trusts; and involves a number of the eating disorder voluntary groups.

The review team was not provided with terms of reference for REDNG. REDNG is chaired by a public health doctor, meets bi-monthly. Twice a year, senior operational managers are invited to attend this meeting. Standards and guidelines are discussed, shared and considered by all members of the group.

The eating disorder clinical network has been successful in securing funding for the development and collation of psychometrics for eating disorder services to help evaluate and audit their interventions. The review team was advised by trusts that further funding is required to analyse relevant information to inform future service developments.

As a result of a number of concerns raised by professionals and carers this group funded training for staff in the management of really sick patients (MARSIPAN[29]) and also provided opportunities for HSC trusts to visit specialist eating disorder units in England and Wales.

A number of service users expressed concerns that eating disorders are a growing problem in Northern Ireland, and while much has been done, there are concerns about the capacity of the trusts to respond adequately to increasing demand on the service. This should be reviewed by the HSC Board in terms of targeting future investment.

It is critical that service users and carers perceptions are taken into account in the delivery of the service. The review team noted that at a REDNG meeting in June 2014, attended by service users and carers, it was agreed that this may not be the best forum for them to raise their individual concerns. It was considered that preparation and support for individuals to be able to participate effectively in business meetings would be helpful. It is important that REDNG in its future terms of reference outlines its methodology for service user involvement in service development and improvement, along with their proposed methods of communication with service users.

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[29] MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa. CR 162. October 2010. Royal College of Psychiatrists and Royal College of Physicians.

SUPPORTING RECOMMENDATION 9
The Public Health Agency should agree the terms of reference for the Regional Eating Disorders Network Group (REDNG) with all relevant stakeholders and their methodology for engaging with service users in service improvement.

7.11 Level 1 – Primary Care Services

Early intervention is important, as the clinical outcomes for patients presenting with a mild to moderate illness are better than those for patients with a severe and enduring eating disorder. At level 1, people with eating disorders may present to midwives, obstetricians, dentists, diabetes specialists and primary care staff. Patients with eating disorders can deteriorate quickly or already be unwell. Risk assessments must consider physical, psychological and social issues, to identify those for whom early intervention and referral would be most beneficial.

Management of Physical Aspects of an Eating Disorder

Care for patients with eating disorders across HSC trusts should include:

- initial assessment by a GP
- general supportive care
- motivation enhancement alongside appropriate psychological treatments
- good medical management, and attention to nutritional care

It is expected that an initial assessment by a GP should include a general examination and baseline blood tests, with an ECG for those with BMI below 15. If weight loss is rapid, or BMI has fallen below 17.5 (the threshold for anorexia nervosa), referral to specialist services should be considered.

Urgent referral should be considered when BMI is 15. Height, weight and BMI should be measured, and plotted on a chart. BMI centile chart should be used for those aged under 18.

Voluntary organisations, self-help groups and families and carers have important roles to play in the delivery of level 1 services. The review team noted examples of leaflets being distributed by voluntary organisations to GP practices across Northern Ireland, advising of support and help available to sufferers of eating disorders.

Until a patient is seen at a specialist clinic, they should be reviewed regularly for weight monitoring and, if required, have a sit up-squat-stand, muscle strength (SUSS) test, bloods checked and an ECG performed.

All referrals should be triaged in accordance with the IEAP protocol[30] and classified as emergency (same day referral) or urgent (seen in less than five, up to a maximum of 10 days[31]).

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[30] Mental Health Services. Integrated Elective Access Protocol Addendum

HSC trusts reported that when a referral is accepted by an eating disorder team for children and adults, it is allocated to one therapist, with the exception of Southern Trust who make a multidisciplinary assessment, including a risk assessment in line with PQC guidance.

Service Users Views of GP Services – Level 1 Service

Patient experiences of initial contact with their GP and onward referral were reported as variable. During the RQIA focus group, 10 of the 12 attendees stated that they did not have a positive experience of attending their GP. RQIA did not validate these comments with individual GPs. The review team met with the HSC Board Directorate of Integrated Care staff to share the concerns raised by service users.

Case Example 10 – Insufficient Support from GP

"My daughter was 14 when she first went to see the GP. She was then told to go home and eat. Two years then went by and she ended up extremely ill and being admitted into an acute medical ward in hospital. Five or six years later she was required to have bloods taken by her GP".

The patient said that it wasn't something she had wanted to do every week, but that it had been requested by the eating disorders team. The GP *"refused to do bloods".*

Case Example 11 – Communication and Information Sharing in Adult Services

X explained how his relative has type 1 diabetes and an eating disorder. Around a year ago things got worse as she stopped eating. They went to the GP and were told that she needs help and a hospital referral. To get on the right path the relative indicated he had to make phone calls and try and find out information about his relative's condition himself as no information was openly available. X *"felt helpless as I didn't know where to go to seek help".* A direct path would have helped. I considered that the medical awareness surrounding eating disorders is poor.

Promoting Accessible, Safe and Effective Care. September 2010. Health and Social Care Board

[31] Mental Health Services Integrated Elective Access Protocol Addendum – Promoting Accessible, Safe and Effective Care, September 2010

Other comments from Service Users/Carers

Carers reported a range of experiences concerning GP diagnosis of eating disorder symptoms, referral to appropriate services and monitoring of ongoing physical risk.

One patient with diabetes said that all her care came from the hospital/diabetic clinic, and her GP was not involved at all.

A number of adult service users experienced a delay before being referred into the service.

"It takes a long time for referral. There is no support in between for patients."

Another service user said that the GP didn't listen until *"I got so ill that I had to be admitted into a psychiatric unit."*

Other service users "*not all GPs are on board. They cannot recognise a problem early before it escalates into a more major issue*. *Most doctors don't treat it as an illness. They label it as self-inflicted."*

Some carers stated that *"doctors are not listening…" "doctors are not diagnosing…". "It's not the professional; it's the attitude of the professional."*

All trusts raised a number of issues with the review team about GPs not carrying out physical monitoring in relation to blood investigations and the increased risk this can cause for some patients. In the Northern Trust this is always recorded as a serious adverse incident (SAI) and forwarded to the HSC Board.

"*There is no consistency whatsoever. If you get a good GP, you're on the pig's back, if not, it can be hell".*

"GPs should be better educated in eating disorders and be able to recognise it sooner".

The review team heard an account from a carer who could not get her GP to recognise how seriously ill her child was.

Case Example 12 – 11 Year old child – Lack of Awareness, Support and Communication from GP and Other Services

"After noticing some behavioural issues around food, we took X to see a GP in December 2013. Having tried to examine X, the GP printed out a BMI graph and told her to go home and eat, and the GP would see us again in three months.

We dropped X to school, then came home and rang the GP as we weren't satisfied with the off-hand way that X was treated. The GP didn't think there was a problem. The exact words to us were, "if you make an issue of this, it will become an issue."

After discovering that X had been regurgitating food, we contacted the hospital and were given an appointment with a paediatric doctor early in January 2014. The doctor agreed with our concerns and agreed to urgently refer X to the CAMHS eating disorder team.

After many phone calls to the hospital and the CAHMS team, a referral was eventually received some eight weeks later. X was then given an initial appointment for a further two month review. Meanwhile, X's condition continued to deteriorate and the behaviour became more volatile and erratic.

In April 2014, following a self-harming incident, we went to see our GP who had no idea what we should do about X. As it was Friday afternoon he prescribed an antihistamine and suggested we take X to an emergency department if X's condition continued to deteriorate over the weekend. We made the decision to take X to the emergency department the following Saturday morning. At the emergency department we were put in touch with the gateway team who arranged for X to be seen by the eating disorders youth service (EDYS) team the following Monday.

After the initial assessment by the EDYS team, it was decided to try to manage X's eating at home, with bloods and ECG being carried out by the GP. The first visit back to the GP for bloods and ECG resulted in no ECG being carried out. It was very traumatic and upsetting experience for X and my wife. The GP did not converse with X at all. After bloods were taken X felt unwell. The GP told my wife to take X outside for some air, X subsequently collapsed outside, and my wife carried X to the car and brought X home.

Our child continued to deteriorate and was admitted to a paediatric ward at the hospital. Beechcroft would not take X as X was under 12 years of age. A naso gastric tube was inserted and X remained in hospital for a further eight week period.

During X's time in hospital our main concern was support during meal times. Mainly, we were left to do this by ourselves".

SUPPORTING RECOMMENDATION 10
The HSC Board should review the services provided by primary care given the need for early intervention and prompt referral to appropriate eating disorder services.

7.12 Meeting with HSC Board Directorate of Integrated Care

The review team notes a wide disparity across the region in terms of medical input and in managing risk, particularly in monitoring the physical needs of patients. NICE states that most people with anorexia nervosa should be managed on an outpatient basis, with psychological treatment provided by a service that is competent in giving that treatment and assessing the physical risk of people with eating disorders.

The review team met with the HSC Board Directorate of Integrated Care to discuss the comments made by a number of service users and parents about access and support from GP services. They indicated that there are over 1,000 GPs in Northern Ireland, within 350 GP practices. The Qualities and Outcomes Framework (QOF), introduced in 2004 as part of the general medical services contract for GPs, includes indicators, with general practices receiving points according to their level of achievement, leading to payments. It accounts for approximately 18 per cent of GP income and is an important factor when considering funding of GP practices. Conditions such as diabetes and hypertension are included in QOF, but eating disorders are not. The HSC Board staff indicated that it is unlikely that GPs will see any more than one or two people with an eating disorder in any year.

If a patient has a low BMI and is physically very frail, blood tests should be carried out to detect any chemical abnormality. Following receipt of test results they need to be interpreted, however, GPs are not trained in interpreting such results.

All trusts have access to a consultant clinical pathologist in the Belfast City Hospital for analysis of any unusual blood results, and advice on subsequent treatment. The Northern Trust indicated at the time of the review, a concern in relation to five GP practices refusing to take bloods. Steps are being taken by the trust and HSC Board to come to a resolution**.** There needs to be an agreed system across all primary care services, to provide fast access for advice regarding patients suspected of having eating disorders who require this type of treatment.

HSC Board staff were aware that a number of problems existed in respect of GP monitoring of bloods. HSC Board staff proposed that to improve the service at primary care level, a specialist consultant or staff grade physician needs to be available, located in each trust, who the GP can contact for advice. A similar service is provided for patients who receive chemotherapy, or need the service of a diabetic nurse specialist.

A solutions proposed by the HSC Board Directorate of Integrated Care is that an eating disorder specialist consultant could give the patient an order form for bloods to go directly to the treatment room in their GP practice or laboratory in cases where this is a trust run service. A specialist physician in eating disorders in each trust could read the results and advise the GP of a proposed treatment plan.

The risk with this is that the patient who may be frail and unmotivated to seek help will not do this and may lead to a further deterioration in his/her condition. This matter requires further discussion between the HSC Board and trusts.

KEY RECOMMENDATION 7
The HSC Board should review the current arrangements to ensure that the physical monitoring of patients with eating disorders takes place in line with NICE guidelines[32].

7.13 Review of Level 2 – Secondary Care Services

Most patients with eating disorders are managed on an outpatient basis across the five HSC trusts, with psychological advice, medical monitoring and dietetic advice provided by a multidisciplinary team. Care is tailored to the individual needs of the patient, taking account of any comorbidity. The aims of specialist eating disorder services include: an understanding of their illness; improved psychological capacity to self-manage their illness; good physical health and lifestyle; healthy eating; and a healthy weight.

At level 2, the aim of outpatient treatment is to establish a therapeutic rapport with the patient, establish motivation for change and prevent further weight loss. For children and adolescents, the aims of treatment differ. As weight gain is crucial to development. Weight restoration takes priority over other educational and social needs and is often achieved by increased calorie intake or reduced energy output.

Professionals try to help patients to alter their abnormal thinking about food, weight and shape and to address other abnormal behaviours related to eating and weight. Trusts indicated that patients with more severe chronic treatment resistant illnesses are helped to try to maintain a safe weight and to improve their general quality of life.

The review team noted not all trusts approached the delivery of level 2 services in the same way.

At level 2 in the Belfast, South Eastern, Northern and Western trusts (depending on the circumstance), patients are assessed by: community mental health treatment teams; primary care mental health services; community paediatric teams; or child and adolescent mental health teams. These services provide more comprehensive mental health and physical assessments than at level 1.

Following assessment, short-term psychological treatments and longer term support are provided. Staff in the various teams with responsibility for provision of these services had all received training in the appropriate skills and competencies to manage patients at this level.

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[32] NICE. Eating Disorders. National Clinical Practice Guideline Number CG9.2004

In the Southern Trust, however, all referrals are directed to the eating disorder service at level 3. This enables the trust to capture overall referral activity and measure demand and capacity for the future development of the service.

7.14 Continuity of Care

Continuity of care is important for all patients with an eating disorder, so it is vital that they remain in contact with health services. Care is organised by trusts to provide this continuity and, wherever possible, for this to continue beyond weight restoration.

Current practice favours the treatment of the large majority of adult patients with anorexia within specialist eating disorder services, in line with NICE guidance.

In the Western Trust, the primary care mental health services offer assessment/treatment to people with mild to moderate eating disorders and also offer psychological treatment such as CBT-E. Referrals are triaged by experienced members of staff who are competent in the stepped treatment approach of eating disorders.

In more complex presentations, the eating disorder service is available for consultation and assistance in assessing the referral. Practitioners offering this treatment are supervised by the team lead of the eating disorder service on a monthly basis.

The Southern Trust had, as a result of CAWT eating disorder project funding, employed three additional practitioners, to help provide services for patients with mild to moderate eating disorders.

In September 2013, two CAWT staff transferred directly to eating disorder services. This has enabled more appropriate triaging and allocation ofcases of eating disorders. It has allowed for a greater enhancement of experiential learning for the team, a more secure clinical management process/supervision process, with a better ability to measure demand and capacity for the future development of the service. It has also provided easy access into services and a simple referral pathway for GPs with clear triage arrangements.

SUPPORTING RECOMMENDATION 11
The HSC Board should review the different treatment approaches used by trusts to determine the most appropriate treatment(s) offered at level 2.

7.15 Travelling Time to Appointments

In the Southern, Western and Northern trusts, service users complained about having to travel up to three hours to and from appointments. In complex cases, journeys often had to be made more frequently. The Northern Trust indicated they do not have the resources to set up satellite clinics, which could make the service more accessible for patients.

A number of service users stated they would have liked to have had an on-call service provided in evenings and weekends, as all trusts provide a 9am to 5pm week day service only.

7.16 Use of Food Diaries

Staff who work in eating disorder services indicated that food diaries are essential to treatment. The dietician reviews these with service users regularly as part of their treatment.

When use of food diaries was discussed with focus groups the views of service users were not positive, stating that they were not beneficial. A number of service users told the review team that whilst they completed their diaries, these were not followed up adequately by professionals. While balancing weight gain with psychological support is important in eating disorders, a number of service users said that professionals need to give more consideration to the cognitions and treatment of emotions.

"Food diaries just drew attention in my mind to what was going on and didn't help whatsoever."

"Food diaries are horrendous. Such a waste of time and professionals only have your word that what is included is true."

SUPPORTING RECOMMENDATION 12
The Public Health Agency (REDNG Group) should consider the views of service users regarding the effectiveness of the use of food diaries given the views expressed by service users regarding their usefulness.

7.17 Review of Level 3 – Dedicated Community Based Services

Specialist community teams for assessment, intervention and management of severe and complex eating disorders have been developed at level 3. These teams are responsible for:

- training and supervision of primary care and mental health professionals at levels 1 and 2.
- providing shared care arrangements with CAMHS, acute general hospital services and obesity clinics.
- undertaking research, monitoring and evaluation of eating disorder services.

Treatments provided at level 3 in every trust include psychological interventions based on CBT principles and offering specialist support to the more severe and enduring complex patients, by clinical managers. All trusts indicated they provided medical assessment, motivational interviewing, nutritional intervention, family work and psychotherapy. Some trusts offered group work sessions. In the case of patients with co-morbidity, for example, eating disorder and addictions, joint working arrangements are agreed with staff from other teams.

In the absence of an agreed regional eating disorder care pathway, all trusts had devised their own local level 3 pathway for patients who did not respond to community treatment. This included those who suffer from severe psychological distress, or those admitted to emergency departments or psychiatric hospitals. Trusts indicated that in-reach support services are provided to each inpatient setting where possible. The review team notes that this presented a challenge for all teams, due to the capacity of the current workforce to deal with increased workloads over the past four years and the complexity of cases and clinical management of risk. Trusts were particularly concerned about their ability to offer therapeutic support to patients who have more severe and enduring eating disorders, without additional staff.

In the Belfast Trust all referrals are sent to a lead consultant psychiatrist. The review team was concerned about the risk of placing all the responsibility for the coordination of services to one person, instead of a shared leadership arrangement. Difficulties may arise if the identified lead individual becomes ill or leaves the service.

In the Southern and Northern trusts, the services offered by the CAMHS eating disorder team were positively commented on by a number of carers. The high level of support offered by a small number of very dedicated and passionate practitioners, who had gone beyond the call of duty to support young people in distress because of their eating disorder, was noted by the review team. A range of information booklets has been devised by CAMHS staff for young people, to give them a better understanding of their illness.

7.18 Review of Level 4 – Regional/Sub-Regional Specialist Services

Inpatient Treatment – Level 4

The review team found that adult inpatient treatment is generally facilitated in acute general hospitals or in psychiatric hospitals. Inpatient treatment is aimed at recovery and usually leads to weight gain. All trusts indicated that for a minority of patients, admission to hospital may be necessary to stabilise their physical state or even save the life of a severely physically impaired patient.

The adult eating disorder provision in psychiatric or learning disability hospitals is reviewed as part of the RQIA inspection process. An admission to a psychiatric unit for a patient with an eating disorder can occur on an urgent/non urgent/planned/unplanned basis. Each psychiatric inpatient unit has an identified link nurse who receives ongoing training, support and supervision from adult eating disorder services.

The adult eating disorder service is available for consultation, support and where possible, provision of in-reach services.
They assist in the management of supervised re-feeding of severely malnourished patients, advice on the specialist psychological aspects of care, or are involved in decisions about compulsory treatment if required.

Depending on the patient's clinical presentation, a range of interventions are available with daily clinical supports offered in a more structured environment.

In Belfast and South Eastern trust areas, occasionally patients with severe eating disorders, not known to psychiatric services, may be admitted to one of seven general acute medical wards, as a result of severe physical risk to their health. The review team was advised that difficulties can occur, when trying to arrange planned and sometimes urgent inpatient care, due to constraints associated with general bed availability and the interface between medical and psychiatric units.

The review team was concerned that due to the use of multiple non-specialist units, there could be the potential to compromise treatment and prevent the development of eating disorder specialist expertise, as staff in general wards cannot all be trained to a specialist level in managing patients with complex eating disorders.

The Belfast Trust provides training and supervision to other professionals at each step of the model, or to any team who requests training, but indicated this presents resource implications.

High Turnover of Nursing Staff

The review team noted a high turnover of trained staff, particularly in the CAMHS service, who frequently move on to other positions, as there is no specific career pathway in the eating disorder service. This can disrupt the therapeutic relationship with patients. Staff in Beechcroft discussed their difficulties in retaining staff within a structure that provides few opportunities for career progression. The skill mix within eating disorder teams also needs to be considered to provide increased opportunity for career progression and the effective use of core competencies.

SUPPORTING RECOMMENDATION 13
HSC trusts should consider methods to improve recruitment and retention of the nursing workforce including incentivising staff through enhanced clinical roles e.g. advance practitioner or nurse consultant roles in order to develop a wider range of skills.

The review team spoke to a number of Beechcroft staff and found:

- A very dedicated and conscientious staff group
- Treatments focused on motivational enhancement, eating behaviour and attitudes to weight and shape and on underlying psychosocial issues
- Staff had a wide awareness of the importance of evidence-based practice for the young person and their family, and were supported with specific training and regular clinical supervision.
- If a child or young person in Beechcroft needs to be fed with a naso-gastric tube, they are transferred to the Royal Victoria Hospital or Belfast City Hospital.

A working group was established as a result of concerns that a number of patients with severe anorexia nervosa were being admitted to general medical units. This sometimes led to deterioration in their condition, due to, for example, psychiatric problems, non-adherence to a nutritional treatment, and medical complications, such as re-feeding syndrome. The review team noted insufficient access to psychology staff to meet the QNIC[33] standard in Beechcroft. As a result, staff said it was difficult to sometimes offer one to one interventions and psychology led therapeutic groups to all clients. This needs to be reviewed to ensure that treatment is delivered in accordance with evidence based care.

The review team noted that some staff guidelines contained no reference to the evidence base upon which the guideline was developed, which required to be reviewed by the trust.

SUPPORTING RECOMMENDATION 14
The HSC Board should review the model of service provision provided in Beechcroft in respect of evidenced based interventions and treatments based on NICE guidelines.

A number of parents expressed concern about the case mix of young people in the Beechcroft unit. The Rees Review also referred to the case mix of children at Beechcroft.

KEY RECOMMENDATION 8
The HSC Board should consider the recommendations of the Rees Review in respect of the design of the environment and services provided in Beechcroft in terms of facilitating the needs of young people with eating disorders.

The review team did not see evidence of the child care plans being shared with patients in Beechcroft.

The review team obtained views from service users and carers about their experiences of care in Beechcroft and the ability of the service to respond to their assessed needs. Some carers said they did not have an identified link person within the first week of the young person's admission.

SUPPORTING RECOMMENDATION 15
The Belfast Health and Social Care Trust should ensure that care plans are shared with young people and an identified link person is signposted for carers following admission of young people to Beechcroft.

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[33] QNIC - The Quality Network for Inpatient CAMHS

The following case example (information provided by a carer of a young person) demonstrates a positive experience of treatment in this unit.

Case Example 13 - Positive Support from Beechcroft Staff

“X was very ill with comorbid anorexia nervosa and secondary depression with suicidality requiring a number of referrals to the intensive treatment team.”

“Beechcroft offered us a lifeline in coping with the distress we all had to manage.”

A further case example demonstrates evidence of good practice in the management of a patient below the age of 12.

Case Example 14 - Good Practice

Patient X was a 10 year old girl who was initially assessed by the crisis assessment and intervention team (CAIT) following self-presentation to the emergency department, as the parents of X were struggling to manage food refusal. Clinicians in CAIT were very concerned and requested a medical review for the following Monday. The staff grade doctor was very concerned about X’s presentation, bloods were taken and a diet plan was initiated for X.

The CAIT team requested an initial referral to EDYS from the consultant paediatrician be expedited, in light of the amount of weight loss and high levels of distress. This was facilitated and patient X was first seen by EDYS in spring 2014. The initial aim was to implement the trust’s re-feeding plan orally at home, with twice weekly support from the team. Patient X tried very hard to engage with this but the eating disorder was very severe and was unable to fully comply and also began vomiting again. At this point admission to a paediatric bed was necessary as patient X was losing weight and refusing food and fluids.

Patient X was admitted to a paediatric ward in the general acute hospital. Over the first 48 hours X was unable to comply with a diet plan and a joint EDYS/paediatric decision was made to insert a nasogastric tube, in line with the Junior MARSIPAN guidelines.

Following insertion, patient X gained weight consistently. The weight for height increased in patient X from 80% to 94% over six weeks.

EDYS supported the admission through twice weekly visits, one of which incorporated a multi-disciplinary meeting with paediatric colleagues. During this meeting, a care plan was drawn up with goals for the forthcoming week. This was shared with parents and patient X received a child friendly copy.

Therapeutically, the trust focused on engaging with patient X, in the first instance due to low weight. However, despite the increasing weight of patient X, this proved a difficult process to continue, as X was very unwell and found it very difficult to verbalise distress. Various techniques were utilised to engage and as weight improved, the engagement of X improved. Parental support proved helpful as family based interventions are one of the cornerstones of treatment for anorexia nervosa in children and young people.

Despite making a physical recovery, patient X remained reluctant to move from naso gastric feeding to oral feeding. Referral was made to occupational therapy in an attempt to engage in activities that would distract and motivate the patient. This proved useful and patient X enjoyed having a set timetable of activities. Once weight was restored, patient X was prescribed low dose of medication, aiming to reduce distress, aggression and to reduce the intensity of anorexic thoughts.

Patient X’s mental state gradually improved and made the transition to oral diet over a short period of time. X continues to attend EDYS and has remained weight restored. X is now eating a varied and flexible diet plan and engaging well with the appointed individual worker.

EDYS provided training for paediatric nursing staff in the general acute hospital and has developed supported meals, to encourage staff to feel more confident in implementing this intervention. Nursing staff responded well to the training provided and used the multi-disciplinary team meeting as an opportunity to reflect on their practice.

Reflective learning on good practice:

- rapid response via Crisis Assessment and Intervention Team (CAIT) at the emergency department

- smooth transition and joint working from CAIT, EDYS and medical ward staff

- interventions based on NICE and Junior MARSIPAN

- an admission pathway was agreed with the paediatric consultant team in hospital, which ensured the efficient transition from community to hospital.

8.0 Extra Contractual Referrals for Treatment for Eating Disorders

This section examines the effectiveness of the arrangements made for patients from Northern Ireland to access specialist services in other jurisdictions. As there is no dedicated regional inpatient eating disorder service in Northern Ireland, each trust continues to provide local inpatient care within their existing medical/psychiatric wards in each trust.

When referrals exceed the capacity of local trust services, either in terms of complexity and in order to manage risk, patients may be transferred to specialist hospitals in England, Scotland or the Republic of Ireland, as an extra contractual referral (ECR).

The main reasons for a referral is when the patient does not respond to treatment locally and their physical health has been compromised to the extent of severe emaciation and dehydration. In most cases patients require skilled re-feeding in a specialist therapeutic environment that provide 24 hour close supervision.

Clear aims and objectives of the placement are agreed with the client and receiving unit prior to admission. Trust staff maintain contact via telephone, letter and video link with the specialist treating the patient. Family/carers, if appropriate, will be facilitated to visit. Discharge plans will be agreed with local services and when the patient is on leave therapy/intervention will continue. This helps promote a positive transition following the ECR period.

8.1 Extra Contractual Referrals: 2012 - 2015

Compared with other mental health conditions, eating disorders are a significant cause of death, with standardised mortality ratios five times the population average. Outcomes are worse for those who present to services late (National Collaborating Centre for Mental Health 2014[34]). The impact of these disorders is frequently long lasting and recovery takes place slowly.

From April 2012 to 30 September 2015, 52 patients were funded for extra contractual specialist eating disorders inpatient treatments. Table 7 include all costs which relate to new patient referrals and those requiring ongoing care and treatment for their eating disorders.

Patients were referred for treatment at a range of the locations in England, Scotland and the Republic of Ireland. These include: St Patricks Hospital, Dublin; The Priory, Glasgow; Cygnet Hospital and St Georges, London; Richardson Unit, Royal Infirmary, Newcastle; Cotswold House, Oxford; and The Dene, West Sussex.

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[34] Service user experience in adult mental health: Improving the experience of care for people using adult NHS mental health services. December 2011. NICE clinical guideline 136.

Table 7: Extra Contractual Referrals: July 2012 – September 2015

Year	Number of Referrals	Total expenditure on ECR
1 April 2012 - 31 March 2013	9 adults	£1.23 million
1 April 2013 - 31 March 2014	11 adults 1 young person under 18	£1.38 million
1 April 2014 - 31 March 2015	15 adults 2 young people under 18	£1.64 million
1 April 2015 - 30 September 2015	14 adults	£1.47 million (half-year cost)
	52 (49 adults and 3 young people)	**£5.72 million**

Trusts indicated their capacity to respond to referrals for eating disorder services is proving a challenge in terms of meeting existing needs. Without additional investment in eating disorder services trusts consider the current capacity to respond to assessed needs will be diminished, resulting in continued delays for patients in accessing treatment.

The review team did not find evidence of any evaluation carried out by the HSC Board of the effectiveness and value for money of ECRs.

KEY RECOMMENDATION 9
The HSC Board, in collaboration with the Public Health Agency and the REDNG, should review the benefits and effectiveness of ECRs in terms of outcomes for patients and value for money.

8.2 Patient Experiences of ECRs

The review team interviewed people who had experienced treatment in England through an ECR. One patient had experience of being an inpatient for a number of months. The service user had experienced previous care in general psychiatric units in Northern Ireland which were unable to treat her illness.

The parents of this service user also spoke of their frustration in persuading professionals to listen to the needs of their family and family member.

"The only way I can describe it is like being out on a boat at sea, with no oars and no shore, with a storm raging. It was a living hell every day." The family requested a transfer to a specialised eating disorder clinic in England.

Case Example 15 - ECR

"My weight had dropped to below six stone (5ft 10 inches) when I ought to have been nine and a half stone. My family did their own research to find the best unit and eventually I was transferred to the Maudsley Hospital in London where I spent X months. It was the Maudsley Hospital that saved my life."

A service user said that "*With the expert help in the London Hospital, I gained weight, confidence and reintegrated into society.*"

A major advantage of the ECR cited by the parent was that they were able to attend courses at the hospital to help them to cope on a day-to-day basis with living with their relative's eating disorder. This family are now actively involved in a voluntary organisation which provides training to help other families obtain the support they require.

Case Example 16 – Patient Requiring ECR

Patient in her 20s with a long standing history of eating disorders which has been particularly severe in the last seven years. X illness had reached life threatening levels on several occasions. X has had a number of specialist admissions between 2007 and 2013, preserving life, but not leading to any lasting recovery or even sustained periods of stability within the community.

The BMI of X fell to 12.5 and treatment was required in a medical ward as X needed naso-gastric feeding.

This case demonstrates that the management and treatment of patients with profound and life threatening eating disorders within local psychiatric/medical admission units remains an ongoing challenge for the service.

The treatment and admission of this patient was very challenging due to intense anorectic pathology. X was discharged with a BMI of 14 after refusing to return from a period of leave at home. X required detention under the Mental Health (Northern Ireland) Order 1986 and had to be naso-gastric fed on a medical ward.

Case Example 17 - ECR

Patient X aged 16 went with the mother to the GP as the patient had lost so much weight and had to be admitted into an acute hospital setting. X became very physically frail and required re-feeding. Neither the local medical or psychiatric units appeared to have the ability to provide adequately trained nursing staff to facilitate the compulsory re-feeding of this patient and to be able to use appropriate methods of restraint if required.

It was considered that Xs motivation to change would best be supported in a specialist inpatient setting. X was therefore transferred under an extra contractual arrangement to a hospital in London. X indicated to the team of feeling deeply unhappy in this unit. This impacted on the relationship that X had with the family. X felt that if the proper treatment had been given early on that X would not have become as ill. X has since made a full recovery from the illness.

8.3 Patients Views

Service users interviewed as part of the review process suggested that a day care unit is the best way forward in improving access to treatment and maximising client contact time for therapy. This would ultimately reduce the requirement for ECRs. It would reduce travelling time for service users and enable support services to be promoted locally in Northern Ireland.

A skill mix of staff would be required to develop this option, and, at a minimum, would require a consultant psychiatrist, staff grade doctor/physician, manager, mental health practitioners - including nursing staff, health care assistant, and occupational therapist services. Ongoing psychological therapies would need to be discussed and delivered by existing teams. Service users considered this would help ensure a seamless transfer back into community support.

A regional physical care pathway is required to address issues around the management of the physical risks associated with eating disorders, in particular, blood monitoring and shared care arrangements with general practitioners in the community. A further resource would be required to ensure patients could travel easily from home. Given the concerns expressed by service users and carers about the amount of time taken travelling to appointments, carer support and flexibility of service delivery may be enhanced by this type of model of day care. The model may also allow for further development of partnerships with the voluntary sector, primary and community care settings. The day care model would also enable education, training, help and therapeutic support to be provided by local statutory and voluntary services working together and help in building enhanced expertise in dealing with eating disorders regionally. More use of ex-patients who have recovered would also be helpful in terms of speaking to patients and acting as peer support workers.

This model has been piloted in the Belfast and South Eastern trust areas and has shown the potential for development as a community intensive support model. The Belfast Trust considered it would have needed a greater critical mass of patients likely to benefit from this approach but it could be tried as a regional pilot and run by two or three trusts as a service model and reviewed for effectiveness. The review team considered that setting up a number of such independent eating disorder day units could dilute the level of expertise available and ultimately prove to be a more costly approach.

KEY RECOMMENDATION 10
The HSC Board should discuss with all trusts how intensive day treatments could best be developed making best use of resources.

KEY RECOMMENDATION 11
RQIA recommends that the HSC Board should undertake a feasibility study to determine if a specialist eating disorders unit should be developed in Northern Ireland. A potential option could be for such a unit to be established on an all-Ireland basis. Further engagement with patients who have been subject to ECRs should be considered as part of this process.

9.0 RQIA Summit Event

On 9 October 2014, RQIA held a Summit Stakeholder event to examine the strengths and the constraints of the service. Suggestions for improvement were invited from those attending. A range of service users, family members, voluntary organisations, professionals from the HSC trusts, the HSC Board and St. Patrick's Mental Hospital, Dublin were present.

Speakers included a service user; a carer; members of the Eating Disorders Association and the Laurence Trust; and staff from an independent eating disorder hospital service in the Republic of Ireland. The majority of participants welcomed what they perceived as the more supportive, informal and personal approach of the voluntary and community sector. Service users and parents said that relationships with individual professionals and the structure and levels of support offered, played an important role in their satisfaction and engagement.

A number of strengths and constraints within the service were raised, which have been considered in this review.

9.1 Strengths of the Service

Strengths of the service identified included:

- Information literature for service users particularly for those under 18 years provided by eating disorder services in Northern and Southern trusts, and for adult service users in the Western Trust.
- CAWT project in the Western and Southern trusts is reaching out to patients with mild/moderate eating disorders. This ensures patients are offered early intervention, and those in difficulty with an eating disorder are engaged before they become more acutely ill.
- The in-reach service provided by eating disorder teams both to acute units and psychiatric units, in three HSC trusts (Northern, Southern and Western). HSC trusts believed that use of inpatient beds should ideally be limited to one unit in each area. This would enhance the skills of the nursing team on the ward.
- Working with voluntary organisations such as Adapt, Bodywise, EDA and StampED, who, for example, have developed a leaflet for patients in the Northern Trust, which is provided to carers on first referral.
- Recording of outcomes for patients pre and post therapy (Western Trust).
- Good leadership in eating disorder teams with motivated, dedicated and compassionate staff, with high levels of training.
- Clear referral pathways developing across trusts to respond to clinical need, for example,. if urgent can be seen in 24 hours in most cases in Western and Southern trust areas.

- Active involvement in eating disorder groups by both service users and carers in both voluntary and statutory services. Motivation and energy for change/improvement is more evident between staff, family and carers when there is active involvement.
- Parent and carer involvement, and availability of multi-family therapy locally is increasing.
- Use of inpatient beds in an emergency in acute hospital paediatric units, with well trained staff. Good links with psychiatry/acute physicians and in reach to local medical/psychiatric units including, for example, the physical monitoring of bloods by a dedicated physician at Antrim Area Hospital.
- Clinical supervision in operation in different models with more evidence based treatments being used.
- More emphasis on family work in CAMHS services.

9.2 Areas for Improvement

Suggestions for improvement made by carers, service users and staff. These include:

- A lack of general awareness of eating disorders in Northern Ireland.
- Service users and carers consider that not enough is being done to ensure people are aware of signs/symptoms and risks of eating disorders. There is a concentration about healthy eating and nutrition, but some parents considered that the dangers of not eating at all are not as clear.
- A number of parents suggested that the services for young people with eating disorders are too fragmented, with little focus on prevention, and few links with schools.
- Visits to schools from people who have recovered from an eating disorder would help to raise awareness. This could help to remove the fear, anxiety and stigma and help complement other support services in the community.
- There is a need for the eating disorder service to use exit surveys for recovery.
- Health fairs to help those who are struggling with an eating disorder and are silent on this matter, to become more aware of assistance that can be offered.
- Review of funding, as there is a need for more consistency of resources across regions.
- Evaluation of the effectiveness of clinical interventions input and outcomes.
- Extend the range of therapies offered in line with NICE and the Royal College of Psychiatrists guidelines.
- Development of clearer child and adolescent mental health care pathways for acute services and Beechcroft. The HSC Board needs to review and strengthen the commissioning specification for Beechcroft (a review of Beechcroft was ongoing at the time of the review).
- Review the existing inpatient service at Beechcroft to assess the need for dedicated eating disorder beds.
- Improve communication between CAMHS and the adult regional network who could work more closely together.
- More flexibility with timing of appointments, as at times parents may not be able to take time off to attend during the day.

- Ensure there is good transition planning from children to adult services.
- Need to improve user feedback and analysis of outcomes, to improve practice and engage families in service developments, with more involvement of people who have recovered, to talk to others with eating disorders.
- More families trained in the use of the Maudsley Model with exploration of the use of recovery college, involving people who have recovered from an eating disorder.
- Consideration of a specialist inpatient unit supported with robust intensive day treatment services regionally to help prevent further ECRs.

10.0 Conclusion

Eating disorders are a growing problem in Northern Ireland**.** RQIA's review team noted the commitment and dedication demonstrated by all staff working with the complexity of eating disorders in Northern Ireland.

RQIA noted a process of meaningful engagement by the trusts in the review process.

A number of key themes emerge from this review:

People with eating disorders are not a homogenous group and often present with other disorders and issues. Eating disorders can be difficult to identify early and therefore more challenging to treat.

There is a need for a review of the physical health monitoring of patients and a review of the commissioning of this service to ensure early access to and greater parity of service provision across all trusts.

Care pathways need to be developed for young people and adults, by harnessing the views of experts by experience and professionals involved in commissioning and providing care.

The HSC Board should review the current staffing levels in HSC trusts and the skills and competencies available, particularly in complex cases, requiring high levels of clinical supervision. Further work is also required to develop clinical outcome measures that should be routinely recorded and used to inform clinical practice.

A disparity was noted across trusts with respect to provision of an appropriate skill mix and qualifications of staff, with a low level of employment of psychological and occupational therapy staff, particularly in adult services. The multidisciplinary staff team resource required to deliver early intervention and intensive programmes and particularly day care supports across the region requires to be reviewed.

Quality improvement is likely to be more effective if it is addressed at a whole system level, rather than as a number of disconnected initiatives in a number of trusts. This must be approached as a part of a regional long-term sustained change effort.

Across all of the services there is a need for clear and effective communication. HSC staff need to listen to the views and experiences of children and young people, their carers and volunteer support groups as they can offer suggestions that can act as drivers for effective change.

11.0 Summary of Recommendations

The Terms of Reference require the review team to identify any learning or recommendations for improvement and who should be responsible for these actions to ensure the efficiency and effectiveness of the future delivery of the eating disorder services in Northern Ireland.

Recommendations are noted as **Key Recommendations** or **Supporting Recommendations** each with its own number sequences. This allows the key recommendations to stand out as a broad picture of what the review seeks to achieve.

Key Recommendations

KEY RECOMMENDATION 1
The HSC Board should review the assessed need for services against the capacity and current level of funding in HSC trusts to ensure that trusts can offer early intervention and further develop their community based teams.

KEY RECOMMENDATION 2
The HSC Board should progress, as a priority, the development of care pathways for eating disorders for CAMHS and adult services.

KEY RECOMMENDATION 3
The HSC Board should review the skill mix within eating disorder services to ensure that services can effectively meet the needs of service users.

KEY RECOMMENDATION 4
HSC trust therapists delivering evidence based psychological interventions should have training and qualifications in a recognised therapeutic model, in accordance with recommended guidance, overseen by an accredited body.

KEY RECOMMENDATION 5
The HSC Board should develop and review outcome measures used by HSC trusts for assessing the clinical effectiveness of particular treatments and interventions.

KEY RECOMMENDATION 6
HSC trusts should consider the welfare of family members as part of the treatment of children and adolescents with eating disorders, including provision of advice on behavioural management and advisable methods of communication.

KEY RECOMMENDATION 7
The HSC Board should review the current arrangements to ensure that the physical monitoring of patients with eating disorders takes place in line with NICE guidelines.

KEY RECOMMENDATION 8
The HSC Board should consider the recommendations of the Rees Review in respect of the design of the environment and services provided in Beechcroft in terms of facilitating the needs of young people with eating disorders.

KEY RECOMMENDATION 9
The HSC Board, in collaboration with the Public Health Agency and the REDNG, should review the benefits and effectiveness of ECRs in terms of outcomes for patients and value for money.

KEY RECOMMENDATION 10
The HSC Board should discuss with all trusts how intensive day treatments could best be developed making best use of resources.

KEY RECOMMENDATION 11
RQIA recommends that the HSC Board should undertake a feasibility study to determine if a specialist eating disorders unit should be developed in Northern Ireland. A potential option could be for such a unit to be established on an all-Ireland basis. Further engagement with patients who have been subject to ECRs should be considered as part of this process.

Supporting Recommendations

SUPPORTING RECOMMENDATION 1
HSC trusts should ensure a system of appropriate clinical case supervision is in place to enable staff to review cases with a senior lead supervisor (champion) to ensure adherence to evidence-based practice.

SUPPORTING RECOMMENDATION 2
HSC trusts should review the delivery of high-level clinical supervision arrangements to ensure that specialist clinical management interventions are appropriate across CAMHS and adult services.

SUPPORTING RECOMMENDATION 3
The HSC Board should review the cost of external supervision and explore how trust staff can be supported to provide regional clinical and supervisory expertise in complex cases.

SUPPORT RECOMMENDATION 4
The HSC Board, in establishing an outcome framework, should ensure trusts audit and report on outcomes following a period of treatment.

SUPPORTING RECOMMENDATION 5
HSC trusts should monitor that the regional transfer protocol is being adhered to by staff to ensure a smooth transition from CAMHS to adult eating disorder services.

SUPPORTING RECOMMENDATION 6
HSC trusts should review the effectiveness of referral pathways to ensure patients who relapse are fast tracked into appropriate assessment treatment and support services.

SUPPORTING RECOMMENDATION 7
HSC trusts should consider providing a wide range of options in helping families cope with eating disorders, ranging from individual therapy to family support groups.

SUPPORTING RECOMMENDATION 8
HSC trusts should review the nature and type of information about eating disorders provided for service users and families, to ensure that it is easily accessible.

SUPPORTING RECOMMENDATION 9
The Public Health Agency should agree the terms of reference for the Regional Eating Disorders Network Group (REDNG) with all relevant stakeholders and their methodology for engaging with service users in service improvement.

SUPPORTING RECOMMENDATION 10
The HSC Board should review the services provided by primary care given the need for early intervention and prompt referral to appropriate eating disorder services.

SUPPORTING RECOMMENDATION 11
The HSC Board should review the different treatment approaches used by trusts to determine the most appropriate treatment(s) offered at level 2.

SUPPORTING RECOMMENDATION 12
The Public Health Agency (REDNG Group) should consider the views of service users regarding the effectiveness of the use of food diaries given the views expressed by service users regarding their usefulness.

SUPPORTING RECOMMENDATION 13
HSC trusts should consider methods to improve recruitment and retention of the nursing workforce including incentivising staff through enhanced clinical roles e.g. advance practitioner or nurse consultant roles in order to develop a wider range of skills.

SUPPORTING RECOMMENDATION 14
The HSC Board should review the model of service provision provided in Beechcroft in respect of evidenced based interventions and treatments based on NICE guidelines.

SUPPORTING RECOMMENDATION 15
The Belfast Health and Social Care Trust should ensure that care plans are shared with young people and an identified link person is signposted for carers following admission of young people to Beechcroft.

12.0 Glossary

Adult Eating Disorder Service (AEDS)	Clinical service for adults.
Cognitive Behaviour Therapy (CBT)	Discrete, time limited, structured psychological interventions, derived from the cognitive-behavioural model of affective disorders in which the patient: (1) works collaboratively with a therapist to identify the types and effects of thoughts, beliefs and interpretations on current symptoms, feelings states and/or problem areas. (2) develops skills to identify, monitor and then counteract problematic thoughts, beliefs and interpretations related to the target symptoms/problems. (3) learns a repertoire of coping skills appropriate to the target thoughts, beliefs and/or problem areas.
Counselling	Counsellors help to see the underlying emotional difficulties causing your unhappiness and eating distress. They will help work out why you are using this way of coping, and to discover new ways of coping. Counsellors should be properly qualified and receive regular supervision and training.
Crisis Assessment and Intervention Team (CAIT)	Crisis Assessment and Intervention Team (CAIT) provides rapid assessment and intervention to children and young people who present at Accident and Emergency or GP with acute mental ill health, self- harm or suicidal ideation. There is a partnership pathway with emergency departments for same day/next day assessment.
Dietician / nutritionist	Someone who has studied the scientific effects of food and nutrition on the body and is able to give advice on issues relating to food and eating habits.
Electrocardiogram (ECG)	A simple test that traces the electrical activity of the heart, also known as an ECG.

Family interventions	Interventions organised around the structure and function of the family system and on how interpersonal relationships determine behaviour in both individuals and families.
Incidence	The number of new cases of a condition per year.
Integrated care pathway (ICP)	An integrated care pathway is a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes.
National Institute of Clinical Excellence (NICE)	The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE produces guidance on health technologies and on clinical practice for the NHS in England and Wales.
Occupational Therapist	Someone who has professional training in assessing and treating people who have difficulties in participating in healthy, every day self-care, work or study and leisure activities using motivational, educational, experiential and creative activity.
Prevalence	The overall proportion of the population who suffer from a condition.
Prognosis	Prognosis refers to the possible outcomes of a disease and the frequency with which they can be expected to occur.
Psychiatrist	Someone who has initial training in general medicine as a doctor and has then specialised in the diagnosis, treatment and prevention of mental, emotional and behavioural disorders. Psychiatrists are qualified to prescribe medication.
Psychotherapist	There are different types of psychotherapists, who will have had advanced specialist training, usually to masters level, to work with people to help them to resolve their difficulties.

	They will listen and use a variety of therapeutic techniques to try and understand your emotional issues. The exact kind of therapy will vary, but they will give patients time to talk about feelings and eating problems.
Clinical Psychologist	A psychologist who will have an undergraduate and doctoral level degree as well as further clinical training. A psychologist is concerned with all aspects of behaviour and the thoughts, feelings and motivation underlying such behaviour.
Quality and Outcomes Framework (QOF)	The Quality and Outcomes Framework (QOF) is part of the new general medical services contract for general practices; it was introduced on 1 April 2004. The QOF provides financial rewards to general. practices for the provision of high quality care. The QOF measures achievement against a scorecard of 146 indicators, plus three measures of depth of care. Practices score points on the basis of achievement against each indicator, up to a maximum of 1050 points.

Appendix 1 – RQIA Eating Disorders Focus Group

Eating Disorders Review Meetings with HSC Trusts, Health and Social Care Board and Focus Groups

Meeting
Meeting with Anne McCann Eating disorders association Northern Ireland
Meeting Dr Maria Dowds, Medical Adviser, HSC Board and Dr Richard Orr
Meeting with CARED charity for eating disorders
Meeting with South Eastern Trust
Meeting with Belfast Trust
Meeting with Southern Trust
Meeting with Northern Trust
Meeting with HSC Board Primary Care Unit
Meeting with Western Trust
Site visit and meeting with Staff at Belfast Trust Beechcroft
Summit event at Antrim Civic Centre (50 attendees)

Focus Group Discussions

Meeting
Focus group discussion with service users and carers from Eating Disorders Association Northern Ireland (EDANI) held in RQIA Board room (n=16)
Focus group- Adult service users who avail of trust services (n=10)
Focus group- Young people who avail of trust services (n= 12)
Focus group- Young people from Belfast Trust who avail of trust services (n= 8)
Meeting with carer (Southern Trust) – a carer of family member who previously used eating disorder services (at carers request)

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