National Clinical Programme
for Eating Disorders

Eating Disorder Services

HSE MODEL OF CARE FOR IRELAND

Clinical Strategy and
Programmes Division

HSE Mental Health Services

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Eating Disorder Services

HSE MODEL OF CARE FOR IRELAND

ENDORSED BY:

College of Psychiatrists
of Ireland
Wisdom • Learning • Compassion

BODYWHYS
The Eating Disorders Association of Ireland

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- Ms. Harriett Parsons Bodywhys for co writing the chapter on patient experience.

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Foreword

On behalf of the HSE National Clinical Programme for Eating Disorders, I am very pleased to present this Model of Care document, which outlines the HSE plan for its eating disorder services in Ireland into the future. Eating disorders have the highest mortality and morbidity within mental health and they pose significant health, social and economic cost to people with eating disorders, to their families and to society. Early intervention, evidence based care, and consistent support make a profound difference to the clinical and personal recovery of people who are affected by eating disorders, including to those in adolescence when so many eating disorders begin.

Through its support of the National Clinical Programme for Eating Disorders, the HSE has prioritised the provision of high quality, accessible and value for money eating disorder services in Ireland. In the absence of a pre-existing dedicated eating disorder infrastructure or strategy, this Model of Care document has been developed in order to guide the delivery of those aims.

Key recommendations include the development of a national network of dedicated eating disorder teams embedded within the mental health service, a stepped model of outpatient, daypatient and inpatient care provision based on clinical need, and the development of a skilled, trained workforce. In the context of the significant physical morbidity associated with eating disorders, this Model of Care also recommends a strong integration between primary care, mental health services and medical teams, including the bridging of the acute hospital and mental health service divide through mutual clinical commitments and shared pathways. A formal and ongoing collaborative working relationship with Bodywhys, our partners in the eating disorder working group, is also proposed. While it may seem ambitious, all of these strategies are needed in order to deliver a high quality and safe eating disorder service in Ireland.

I would like to express gratitude to all of the multidisciplinary members of the HSE eating disorder working group for their dedication, insight and collaboration in the development of this Model of Care, as well as to Bodywhys, who strongly represented the voice and values of people with eating disorders within our work. On behalf of the National Clinical Programme for Eating Disorders, I also express sincere appreciation to the Clinical Advisory Group and to the College of Psychiatrists of Ireland, whose members dedicated significant time and expertise in an external review of this Model of Care. Finally, my thanks to the Clinical Leads and managers of the other HSE National Clinical programmes who reviewed the document, met with us and provided advice and support on the clinical areas where this eating disorder programme interfaces with their own services. We all hope that this was just the beginning of an ongoing collaborative relationship between our respective clinical programmes in improving HSE services for those with eating disorders.

Dr Sara McDevitt
National Clinical Lead for Eating Disorders
January 2018

Foreword

On behalf of the HSE Mental Health Division, and the Clinical Strategy and Programmes Division, I am delighted to present and endorse this Model of Care document as part of the National Clinical Programme for Eating Disorders. This document has been developed in close partnership with Bodywhys, and the College of Psychiatrists of Ireland.

The National Clinical Programme for Eating Disorders is part of a family of mental health and other health related Clinical Programmes, created by the HSE Clinical Strategy and Programmes Division in an effort to develop high quality health services, based on a programmatic approach, with an emphasis on a strong evidence base, improving patient safety, value and equity.
This Clinical Programme and Model of Care is a good example of integrated care planning across the health service, with mental health, acute hospital and primary care at the centre of service delivery, with the aim of improving patient safety and outcomes.

This Model of Care is a based on interdisciplinary training and working, with clinicians developing skills in response to patient need, with a clear focus on optimising patient and clinical outcomes. The Model was developed with a clear evidence base, with a designed supervision and support structure to support clinicians to develop competencies in delivering interventions. In this regard, the Clinical Programme has already developed training initiatives for clinical staff in specialist Cognitive Behavioural Therapy, Family Based Therapy and MARSIPAN training for people with eating disorders with severe physical illness.
In anticipation of this publication, the HSE Mental Health Division is prioritising investment in the implementation of this Model of Care with significant service development for eating disorders likely in 2018 and beyond.

I would like to thank Bodywhys and the College of Psychiatrists of Ireland for their leadership and commitment to this Clinical Programme, and in particular I would like to thank Dr Sara McDevitt, Clinical Lead, and Ms Rhona Jennings, Programme Manager for their relentless desire and efforts to improve services for people with eating disorders.

Dr Philip Dodd
National Clinical Advisor and Clinical Programmes Group Lead-Mental Health
January 2018

Endorsement from Bodywhys

On behalf of Bodywhys – the Eating Disorders Association of Ireland, I welcome this HSE's Model of Care Programme and acknowledge the opportunity for the organisation to have collaborated on same. It is to be welcomed that this Clinical Programme is designed to support better access, good governance, innovation and improvement in quality care as key drivers of service development in eating disorders.

Since its foundation in 1995, Bodywhys has been passionate about advocating for an eating disorder service in Ireland. When a Vision for Change (AVFC) was published, it was greatly welcomed, as the policy detailed a comprehensive model of mental health service provision, including specific recommendations for the treatment of eating disorders.

In striving to make this vision a reality, Bodywhys welcomes this Clinical Programme, which sets out clearly developed pathways to support timely access to developmentally appropriate services that respond to all levels of clinical need. In line with this commitment, a dedicated multidisciplinary service, mediated through a stepped care model, is being developed. To achieve this aim, there has been a welcome considerable investment in the training of a skilled workforce in the assessment and management of eating disorders.

The impact an eating disorder has on those who are affected, cannot be understated. In this regard, the Bodywhys support ethos has emerged from the understanding built up about this serious and complex issue from many perspectives, and most importantly from what we hear from people affected, and from the family and friends who are supporting a person through recovery. The recognition of the patients' perspective, as being at the heart of this development, is to be welcomed. This Model of Care recognises as crucial, a committed collaborative partnership between Bodywhys, the HSE and the mental health services, in developing structures to support recovery, at all levels of the stepped care model as detailed within this document, while recognising the complexity of the recovery journey.

Those who are affected by eating disorders have clearly identified the three main aspects that are crucial for their recovery – expertise and consistency; appropriate and individualised treatment and support; and time to enable recovery. Responding to this expressed need will progress the core values of the patients' experience to address the complexity and challenges associated with this complex issue.

This document is a clear reflection of what can be achieved when we work collaboratively to effect change. In Bodywhys we look forward to continuing to work in partnership to ensure this Model of Care is realised.

Jacinta Hastings
CEO – Bodywhys

BODYWHYS
The Eating Disorders Association of Ireland

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HSE Clinical Programme Consultations

National Clinical Programme for Paediatrics and Neonatology

National Clinical Programme for Acute Medicine

National Clinical Programme for Palliative Care

Glossary of common acronyms

AMHS	Adult Mental Health Service
AN	Anorexia Nervosa
AFT	Adolescent-Focused Treatment
ARFID	Avoidant Restrictive
BED	Binge Eating Disorder
BN	Bulimia Nervosa
CAMHS	Child and Adolescent Mental Health Service
CAT	Cognitive Analytic Therapy
CBT–E (BN)	Cognitive Behaviour Therapy – eating disorders
CBT-ED	CBT for eating disorders
CBT-SE	Cognitive Behaviour Therapy for severe and enduring eating disorders
CMHT	Community Mental Health Team for adults
CREST	Cognitive Remediation and Emotional Skills Training
CRT-ED	Cognitive Remediation Therapy for eating disorders
DSM V	Diagnostic and Statistical Manual – diagnostic classification system
EDs	Eating Disorders
EDT	Eating Disorder Team
FPT	Focal Psychodynamic Therapy
HIPE	Hospital In-Patient Enquiry System
ICD	International Classification of Diseases (WHO)
PT	Interpersonal Psychotherapy
IPE	Interprofessional education
NCPED	National Clinical Programme for Eating Disorders
MANTRA	Maudsley Anorexia Nervosa Treatment for Adults
MARSIPAN JMARSIPAN	Management of Really Sick Patients with Anorexia Nervosa
MFT-AN	Multifamily Therapy for Anorexia Nervosa
OSFED	Other Specified Feeding and Eating Disorders
PiLaR	Peer-Led Resilience programme (Bodywhys)
SE-ED, SE-AN	Severe and enduring eating disorder or anorexia nervosa
SSCM	Specialist Supportive Clinical Management
SFT	Systemic Family Therapy
TAU	Treatment As Usual
WHO	World Health Organisation

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Introduction

This Model of Care document describes the HSE's strategic vision for its provision of eating disorder services in Ireland in the future. It also represents the cornerstone of the HSE National Clinical Programme for Eating Disorders (NCPED) and is the HSE's commitment to providing services for people with eating disorders.

Eating disorders have the highest mortality and morbidity all of the mental disorders. They affect a relatively young section of the population and have enormous socioeconomic cost. However, effective treatment can substantially improve clinical outcomes and promote sustainable recovery. The HSE has, therefore, prioritised eating disorder (ED) services as part of its National Clinical Strategy and Programme Division (CSPD), which aims to develop high-quality, person-centred, integrated care through a clinician-led, evidence-based approach to service reform.

In keeping with this strategy, this HSE Model of Care for eating disorder services has been designed to help the HSE to improve patient outcomes and safety by delivering the three main objectives of its clinical strategy:

- Improved quality of care delivery to all those with eating disorders
- Improved access to assessment and treatment
- Improved value for money and cost effectiveness

This approach is consistent with the Mental Health Commission's framework, 'A Recovery Approach within the Irish Mental Health Services' (MHC, 2008), the HSE's 'Framework for Improving Quality' (2016) and the Commission on Patient Safety and Quality Assurance 'Building a Culture of Patient Safety (2008). It is also aligned with the International Academy of Eating Disorders' (AED) Worldwide Charter for Action on Eating Disorders (2008). HSE is not alone in its current prioritisation of ED service improvement; similar programmes of ED service reform are being implemented across the UK, Australia, Canada and New Zealand, to name just a few countries.

A HSE national working group was established in late 2015 and charged with the task of developing the HSE's future national Model of Care for its eating disorder services. The group was comprised of multidisciplinary clinicians with experience in working with adults and children with eating disorders and those who were nominated by their professional bodies. It included representation from Bodywhys, the national support organisation for people in Ireland who are affected by eating disorders.

The working group reviewed all of the available data on national ED provision in Ireland and also consulted with stakeholders, professional bodies and service users on current practice. It reviewed international models and guidelines of best practice and service provision for eating disorders, and examined recent and Irish-based research. Four subgroups within the working group were formed focused on: adult services, child services, evaluation, and training. Internal papers were presented for discussion. External ED experts and advisors were also consulted, including an Eating Disorder Clinical Advisory Group (EDCAG) from the College of Psychiatrists of Ireland.

What follows in this HSE Model of Care, therefore, represents a comprehensive and evidence-based roadmap for the future development of HSE eating-disorder services in Ireland. It includes recommendations for local and national delivery of ED treatment and care pathways, and outlines the resource implications. This includes an integrated approach to service delivery across mental health, primary care and hospital settings. It includes proposals for a national eating disorder register with a clinical and service national dataset, so that it is possible to evaluate the NCPED and steer its effectiveness. The Model of Care also outlines recommendations on workforce development, training and governance. The aim is to guide HSE managers, CHO management teams, hospital managers, commissioners, executive clinical directors and lead clinicians in the effective planning, delivery and evaluation of ED services in Ireland.

When implemented, the National Clinical Programme for Eating Disorders will enable the HSE to achieve its objectives of providing quality, safe, accessible, and cost-effective eating disorder services, and in doing so, will assist people with eating disorders to achieve their best clinical outcomes and meaningful recovery.

Clinical Background

What are eating disorders?

Eating disorders are a group of mental disorders that are characterised by serious disturbance in eating behaviour and weight regulation as a result of core psychopathology around eating and body image. Although descriptions of this group of conditions were in evidence from as early as the 12th and 13th centuries, the term anorexia nervosa (AN) was first formally coined by Sir William Gull in 1873 and classified as a disorder by Gull and Lasègue in the same year. Anorexia nervosa is now the third most common chronic condition in adolescent females after obesity and asthma (Whitaker et al, 1992; Golden, 2003; Lucas, 1991). Bulimia nervosa (BN) was subsequently defined by Russell in 1979, and since then there has been growing recognition and refinement of what are now known to be a class of mental health disorders that have the highest mortality and morbidity risk of all (Arcelus, 2011).

2.1: Classification

Eating disorders are clinically diagnosed using one of the two main diagnostic classification systems for mental disorders: ICD-10 (WHO, 1992) and DSM-5 (APA, 2014). In Europe, including Ireland, ICD-10 is conventionally used by most mental health services and has been used to classify and diagnose eating disorders until recently. However, as ICD-10 is now 24 years old and under review (ICD-11 is due out in 2018), DSM-5 currently presents the most up-to-date and widely used system for diagnosing eating disorders. It differs substantially from its predecessors in the introduction of a new eating and feeding disorder category: Avoidant Restrictive Food Intake Disorder (ARFID). Additionally, the previously largest category of eating disorder, Eating Disorder Not Otherwise Specified (EDNOS), has now been removed in order to encourage more specific classification, with other descriptions refined. Based on the current research evidence, the DSM-5 work group decided that obesity did not merit classification as an eating disorder (Marcus & Wildes, 2012).

It is expected that ICD-11 will be closely aligned with the new DSM-5 (NCCMH, 2015), and thus DSM-5 is being used in this Model of Care document. This will be reviewed when ICD-11 is published in 2018. Details of the DSM-5 diagnostic criteria for eating disorders are displayed in Table 2.1.

2.2: Epidemiology

To date, no Irish study has comprehensively researched the epidemiology of eating disorders in Ireland across the age range, and only one prevalence study on eating behaviour and attitudes in adolescents has been undertaken in Ireland (McNicholas, 2010). Therefore, estimations for Irish levels of eating disorders in the population as a whole are generally extrapolated from international sources.

Prevalence

Prevalence is a measure of the number of cases in the population at a single point in time (point prevalence), or within a given year (one-year prevalence), or at some point over their lifetime (lifetime prevalence). It is therefore a useful measure for service planning as it includes cases at different stages and times. Table 2.2 summarises the prevalence ranges for eating disorders from a number of international epidemiological studies. Prevalence estimates for the newly defined ARFID are currently unknown. Overall, the lifetime prevalence of the three main eating disorders is approximately 4% (NIMH, accessed 2016). This equates to an estimated 188,895 people having experienced an eating disorder at some point in their lives in Ireland (based on an Irish census population in 2016 of 4,722,364). Internationally, 2.7% of 13-18 year-olds develop severe eating disorders (Merkinagas, 2010), and 0.1% of the 8-15-year group were estimated to meet the full DSM 4 criteria for an eating disorder in that study (CDC, 2013).

Subclinical forms of eating disorders are also common and are potentially equally disabling in terms of impact on function (Schmidt, 2008). The recent STEDI (Stigma and Treatment of EDs in Ireland) study highlighted a high presence of eating psychopathology among Irish youth. Half of that sample revealed dissatisfaction with their body, with approximately one-third (n=99) expressing concern about their eating habits (O'Connor, 2016). The EPICA study of prevalence of 3,031 secondary school students from across Ireland found a self-reported prevalence rate of

Table 2.1: DSM-5 diagnostic criteria for eating disorders (APA, 2014)

(feeding disorders not included here as they do not fall within remit of this clinical programme)

Anorexia Nervosa (AN)

A. Persistent restriction of energy intake, leading to significantly low body weight (in the context of what is minimally expected for age, sex, developmental trajectory, and physical health).

B. Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though at significantly low weight).

C. Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation or persistent lack of recognition of the seriousness of the current low body weight.

Subtypes

1. Restricting type,
2. Binge/purging type (based on last 3 months).

Bulimia Nervosa (BN)

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:

1. Eating, in a discrete period of time (e.g. within any 2-hour period) an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances
2. A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).

B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics or other medications, fasting or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa

Binge Eating Disorder (BED)

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:

1. Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances and
2. A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating)

B. Associated with three or more of:

- Eating much more rapidly than normal
- Eating until uncomfortably full
- Eating large amounts of food when not feeling physically hungry
- Eating alone because of embarrassment over how much one is eating
- Feeling disgusted with oneself, depressed or very guilty afterwards

C. Marked distress regarding binge eating is present.

D. Binge eating occurs, on average, at least once a week for three months.

E. Binge eating is not associated with the recurrent use of inappropriate compensatory behaviours and is not occurring exclusively during the course of Bulimia Nervosa, Anorexia Nervosa or ARFID.

Note: Binge Eating Disorder is less common but much more severe than overeating. It is associated with more subjective distress regarding the eating behaviour, and co-exists commonly with other psychological problems.

Avoidant Restrictive Food Intake Disorder (ARFID)

A. An eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:

1. Significant loss of weight (or failure to achieve expected weight gain or faltering growth in children)
2. Significant nutritional deficiency
3. Dependence on enteral feeding or oral nutritional supplements
4. Marked interference with psychosocial functioning

B. The behaviour is not better explained by lack of available food or by an associated culturally sanctioned practice.

C. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is experienced.

D. The eating disturbance is not attributed to a medical condition or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behaviour exceeds what is usually associated, and warrants additional clinical attention.

Other Specified Feeding or Eating Disorder (OSFED)

A. Significant distress and impairment in areas of functioning, but does not meet the full criteria for any of the other feeding and eating disorders.

B. A diagnosis might then be allocated that specifies a specific reason why the presentation does not meet the specifics of another disorder (e.g. Bulimia Nervosa – low frequency).

The following are further examples of OSFED:

- Atypical Anorexia Nervosa: All criteria are met, but, despite significant weight loss, the individual's weight is within or above the normal range.
- Binge Eating Disorder of low frequency and/or limited duration: All of the criteria for BED are met, except that they occur at a lower frequency and/or for less than three months.
- Bulimia Nervosa of low frequency and/or limited duration: All of the criteria for Bulimia Nervosa are met, except that the binge eating and inappropriate compensatory behaviour occurs at a lower frequency and/or for less than 3 months.
- Purging Disorder: Recurrent purging behaviour to influence weight or shape in the absence of binge eating.
- Night Eating Syndrome: Recurrent episodes of night eating, eating after awakening from sleep, or excessive food consumption after the evening meal.

The behaviour is not better explained by environmental influences or social norms. The behaviour causes significant distress or impairment. The behaviour is not better explained by another mental health disorder (e.g. BED)

Unspecified Feeding or Eating Disorder (UFED)

This category applies to where behaviours cause clinically significant distress or impairment of functioning, but do not meet the full criteria of any of the other feeding or eating disorder criteria. This category may be used by clinicians where a clinician chooses not to specify why criteria are not met, including presentations where there may be insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

American Psychiatric Association (2014)

Table 2.2: Prevalence of eating disorders

	AN	BN	BED	EDNOS
Point prevalence	Adolescent Females 0.39–0.64% [5]	Females 1% [2]	2% [9]	2.4% [5]
1-year prevalence	Females 370/100,000 [1, 2]	Females [2] 1000/100,000		
Lifetime prevalence – females	Females [2, 3, 4] 0.9–2.2% (Narrow) 2.4–4.3% (Broad) Males [3, 2] 0.1–0.3%	Females 0.9–2.3% [2, 3, 4, 8] 1.3% (age13–18) [7] Males 0.1–0.5% 0.5 (age13–18) [7]	Females 0.9–3.5% [3, 4, 2] Males 0.3–2% [2, 3, 4]	

1 Hoek (2006), 2 Stice (2012), 3 Hudson (2007), 4 Preti (2009), 5 Machado (2007), 6 Hoek (2003), 7 Swanson (2011), 8 Keshi-Rahkonen (2009),9 RANZCP (2014)

'caseness' of 10.9% of adolescent girls. This was similar to international levels. The figure for Irish adolescent males was lower in that study, at 2.4%. Approximately one-third of adolescent girls reported dieting or feeling dissatisfied with their bodies (McNicholas, 2010).

Although the gender gap has narrowed, eating disorders remain more common in females, particularly for AN, and for BN where prevalence rates are three times higher than for males (NIMH, 2012). This gender gap is lower for BED and for younger children, at a ratio of 2:1 female-to-male cases. Male eating disorders are now considered to have been traditionally under-recognised and under-diagnosed. They are estimated to account for 25% of AN/BN cases and 36% of BED cases (Hudson, 2007).

Eating disorders have been found to occur independent of socioeconomic class and family income. Family history of education has been associated positively with the development of eating disorders, particularly for eating disorders in females and for males with AN (Goodman, 2014). Eating disorders occur across all ethnic groups, cultures and countries, although research has mainly focused to date on those in Western countries and amongst females.

Incidence

'Incidence' means the number of new cases of a disorder that develop within a particular timeframe. In the UK, an analysis of the General Practice Research Database has estimated that the annual incidence rate of eating disorders had risen from 32.3 in the year 2000 to 37.2 in 2009, per 100,000 of the population aged between 10-49 years (Micali, 2013). Based on the provisional Irish CSO census data for 2016, this would equate to 1756.72 new cases per annum in Ireland in the same year of 2009. Micali (2013) also found that the highest overall incidence rates were in the 15-19 female age group (164.5/100,000), while the highest incidence for males occurred in the 10-14 age group (17.5/100,000). The average age of onset of eating disorders is reducing (Favaro, 2009). For AN, the peak incidence of onset is now 14-18 years and for BN it is 14-22 (Lock, 2015a). BED most commonly presents in the late teens or early 20s.

2.3: Causes of eating disorders

The causes of eating disorders are complex and include biological, environmental and psychosocial factors. From a biological perspective, it is estimated that additive genetic factors account for 40-60% of the liability of an individual to developing AN, BN and BED (Duncan, 2017; Pinheiro, 2010). The impact of dietary restriction and subsequent physical starvation then plays a significant biological role in the maintenance of restrictive eating disorders through the effects of malnutrition on cognitive, emotional and physical functioning (Trace, 2013; Lock, 2015a). Other risk factors that combine towards a vulnerability to developing an eating disorder include: being female, a premorbid tendency towards anxiety and perfectionism, difficulty managing emotions, low self-esteem, onset of puberty, severe life events (70%), dieting, and trying to lose weight (Lock, 2015a, NIMH, 2015). People with diabetes, coeliac disease and other medical conditions where treatment requires strict dietary control are at increased risk (Colton, 2015), as are those who have undergone gastric bypass surgery (Conceicao, 2015). A survey of Norwegian elite athletes in 2004 found that 13.5% of male athletes reported clinical or subclinical eating disorders, and that the rate of disordered eating in female athletes was up to 42% in some sport specialties (Sundgot-Borgen, 2004); one-third of US female athletes described symptoms (Female Athlete Triad) and attitudes consistent with anorexia nervosa (Johnston, 1999).

While sociocultural factors such as westernisation and media and social pressures around physical appearance are contributory factors to the development of eating disorders, they alone do not cause eating disorders (AED, 2015). Eating disorders are associated with psychological risk factors such as body dissatisfaction (McNicholas, 2009). This group of conditions are recognised as serious mental health disorders and are not a matter of choice (AED, 2015).

2.4: Mortality and prognosis

Mortality

A systematic review of 36 studies found that the standardised mortality ratio (i.e. the increased risk of dying prematurely from a condition) for all eating disorders is three times that of the general population, and it is 5.86 times higher for anorexia nervosa (AN), the highest rate of all mental disorders (Arcelus, 2011). For adolescents with AN, this figure rises to 10 times that of their peers, and current data indicates that 10% of those who present with AN will die prematurely from it within 10 years of onset. The causes of death from AN are commonly physical, with one-third of people dying from cardiac dysfunction resulting from the direct impact of starvation. Other medical causes of death include diabetic hypoglycaemia, oesophageal tears and rupture (Derman, 2006). Twenty percent will die by suicide.

Prognosis

Despite the relatively higher levels of mortality associated with eating disorders, much has changed in the prognosis of eating disorders in the last decade. Current first-line evidence-based treatments such as FBT (Family-based Treatment) and CBT-E (Enhanced CBT for Eating Disorders), have been found to enable 40-45% of patients with EDs to achieve remission, with a further 30% having a clinically significant partial recovery (Lock, 2015; Fairburn, 2013). A full recovery can typically take between two and five years for adolescent AN (Lock, 2015a). However, adolescent patients have better prognosis with early intervention, resulting in 73% recovery reported in the British National Surveillance Study (Nichols, 2011; Barrett, 2015). BN has higher remission rates, but relapse is more common. Vos (2001) estimated that the average duration of AN for adults in the community is eight years, and five years for BN.

It has been estimated in countries that only 5% to 15% of patients with EDs seek treatment (Butterfly Foundation, 2012), and indeed uptake of services seems to be lower than estimated in Ireland. This has significant implications both at individual and socioeconomic level (see Section 2.5 below). The severity and duration of an untreated eating disorder can have a devastating effect on psychosocial outcomes such as the ability to engage in relationships, continue in education and take up employment opportunities. This in turn impairs personal recovery even further.

For some people, even with treatment, their eating disorder will have a more chronic course, with significant associated mortality and morbidity, particularly for AN. Early intervention has been shown to reduce this likelihood, and is thus the focus of many ED specialist services. However, people with severe and enduring EDs (SE-ED) are also a subgroup of adults with particular service, treatment and support needs. Even at this later stage of an eating disorder, good ED services can increase and maximise the chances of optimal recovery (Robinson, 2015).

2.5: Comorbidity

Physical comorbidity

The physical effects on the body of eating disorders, and in particular anorexia nervosa, are extensive with a negative impact on every bodily system. Longstanding endocrine, cardiac and metabolic complications are often seen, with impact such as osteoporosis, delayed growth and ovarian damage being potentially irreversible in this relatively young age group. Table 2.3 summarises the physical complications of eating disorders. Common reasons for physical instability and acute hospitalisation include severe or rapid weight loss (> 25% normal weight), dehydration, circulatory failure, (e.g. collapse, slow or rapid pulse, low BP, poor peripheral circulation), hypoglycaemia, persistent vomiting or vomiting blood, severe depression and suicidal behaviour.

Table 2.3: Acute and chronic physical comorbidity of eating disorders

General	Core hypothermia, dehydration
Cardio-respiratory	Hypotension, bradycardia, heart failure, Up to 1/3 of hospitalised patients with AN have mitral valve prolapse and pericardial effusion; increased risk for cardiomyopathy due to muscle wasting, purging) Arrhythmias and QTC elongation Emphysema-type lung changes
Gastrointestinal	In AN: reduced gastric motility and emptying, constipation, superior mesenteric artery syndrome In BN: oesophagitis – when severe leads to oesophageal tears (Mallory-Weiss), rupture and pneumomediastinitis In BED: gastric dilatation or rarely gastric rupture Acute pancreatitis (caused by purging) Raised liver enzymes; dyslipidaemia (uncommon); fatty liver (uncommon)
Electrolyte disturbance	Purging is associated with hypochloraemic metabolic alkalosis, low K+, PO4, Mg2+, Cl,- Na+ Laxative abuse is associated with hyperchloraemic metabolic acidosis Hypoglycaemia, hypoalbuminemia
Renal	Renal insufficiency secondary to severe fluid restriction or vomiting
Endocrine	Hypoglycaemia; impact on diabetic control Hypothalamic suppression with low gonadotropic and sex hormones > hypogonadism; pubertal delay, amenorrhoea low thyroxine, low IGF-1
Haematological	Nutritional deficiencies: anaemia; B12, folate, ferritin and Vitamin D stores depleted, Leucopenia
Neurological and muscular	Abnormalities in brain structure (large ventricles) have been associated with very low bodyweight and cortisol Organic brain syndrome: cognitive effects; seizures (acute) Peripheral neuropathy (chronic) Proximal muscle wasting
Skin and teeth and other	Peripheral oedema Osteopenia, osteoporosis and stress fractures; decreased linear bone growth in adolescents, Stature Hair loss (TE) and lanugo hair Skin changes: Russell's sign, xerosis (dry skin); hypercarotinemia; acrocyanosis; oedema; acne; dehydration; other deficiencies Vomiting: dental erosions and perimylolysis; swollen parotid and submandibular glands

For children and adolescents, physical comorbidity can also include delays in pubertal developmental and growth (Campbell, 2014). In addition, the reduced proportion of body fat in pre-pubertal children can lead to rapid medical deterioration and risk of chronicity despite a ‘pseudo healthy’ appearance. Hudson (2012) studied the under-13 year-old group in the British Surveillance Study, and found that over one-third of ED cases were medically unstable at presentation (60% bradycardia, 54% hypotension, 34% dehydration, 26% hypothermia). Over 50% of these cases had required admission to hospital shortly after diagnosis, 73% to a paediatric ward, and 41% of those cases with medical instability had not been underweight.

Psychiatric comorbidity

From a mental health perspective, people with EDs also have a much higher lifetime risk of having another mental health disorder and 56.6% of adults with AN and 94.5% of adults with BN also meet lifetime criteria for second psychiatric disorder (Hudson, 2007). The same study also found higher rates of mood disorder, especially depression (42.1%), anxiety disorder -particularly phobias (47.9%), substance-use disorder (27%) and impulse-control disorders (30.8%) in those with AN. For BN, these figures were 70.7%, 80%, 36.8% and 63.8% respectively. There is also a higher rate of axis two (ICD-10) disorders in people with eating disorders. Increased risk of self-harm and suicidality are also significant risks associated with both AN and BN.

In children and adolescents, the odds ratio of having another axis one diagnosis is 1.5 (CI = 0.5-4.4) for AN, 8.6 (CI = 2.7-27.3) for BN, and 5.9 (CI = 2.5-13.8) for BED (Swanson, 2011). AN was particularly associated with oppositional defiant disorder in that study, with BN and BED being more particularly associated with anxiety and depression. Some children also present with underlying conditions such as Asperger syndrome, or early feeding disorders. This has implications for service provision, and mental health professionals who treat EDs they must also have expertise in the recognition, diagnosis and treatment of co morbid mental health conditions.

2.6: The cost of eating disorders

Given the severity, complexity and duration of eating disorders, together with a rising incidence in the context of limited resources, the issue of the socioeconomic cost of EDs has been investigated internationally in some detail. In the absence of Irish research on economic impact, international research therefore provides an insight into the economic implications of EDs and for the delivery of ED services in Ireland.

1. Australia

The Butterfly reports: ‘Paying the Price’ (2012) and ‘Investing in Need’ (2014)

These two reports were commissioned by the National Eating Disorders Collaboration (an Australian government-sponsored body) to evaluate the economic and social costs of EDs in Australia and to plan more cost-effective services. The context was that the studies estimated that only an 5-15% of people in Australia with ED were recieving treatment, and that 85% reported difficulty in accessing treatment. Deloitte Access Economics carried out a cost-effectiveness analysis (CEA) in 2012. They established that the total cost of EDs in Australia that year was 69.7 billion Australian dollars and that expenditure on ED treatment in the same year was 99.9 million Australian dollars (Table 2.4). The population of Australia in that year was 22.72 (approx. 4.77 times that of Ireland today). The implications of EDs in Ireland can be extrapolated from this study as being much higher than usually recognised.

From a clinical perspective, the first Butterfly report subsequently led to a second Deloitte report in 2014, which recommended that ED services be prioritised by the Australian government. It concluded that early intervention with best-practice treatment was likely to be more cost-effective and efficient than treatment as usual (TAU) (the latter cost was estimated at 6,000 AUS dollars for BN and 84,000 AUS dollars per person for AN, the latter due to increased inpatient costs). Specialist eating disorder multidisciplinary teams, a stepped care model, and longer-term follow-up to prevent relapse were all recommended. While Deloitte acknowledged that this was more expensive than current practice and service funding, the report concluded that the economic benefits of extra years of education

Table 2.4: Costs of eating disorders in Australia in 2012 (Aus. $m)
Deloitte Access economics/Butterfly foundation, 2012

	Individual	Family/ friends	Government	Employer	Society/other	Total
Health system costs	10.4	7.9	69	0	12.6	99.9
Productivity costs	9378.1	0.0	4841.9	843	0	15063
Carer costs	0	5.7	2.8			8.5
Other financial costs	585.2	8.8				594.0
Deadweight loss*					1414.8	1414.8
Transfers		7.2	7.2			0
Total financial	9973.8	15.2	4921	843	1427.4	17180.2
Burden of Disease (Bod)**	52554.9	0	0	0	0	52554.9
Total with BoD	62528.7	15.2	4921	843	1427.4	69735.2

* Deadweight losses are administrative and efficiency impacts of levying taxation to fund government payments. ** BoD equals years of healthy life lost (DALYs) multiplied by value of a statistical life year (VSLY). (Source: Butterfly Foundation, 2012 & 2014)

and employment due to the faster recovery of this relatively young population, as well as improved access for those who had not previously received treatment, substantially outweighed current financial concerns from an overall socioeconomic perspective. They estimated the benefit to cost ratio at 5.38 to 1.

2. UK

'Costs of Eating Disorders in England' (2012), Beat, Pro Bono Economics, DOH).

'The Costs of Eating Disorders: Social, Health and Economic Impacts' (2015), Beat and Pricewaterhouse Coopers

The first of two Beat (National Eating Disorder Association, UK) reports in (2012) estimated the cost of eating disorders to UK society and to the NHS and focused particularly on young people in England. This study used research literature data and NHS data ,where available, to estimated that the overall cost of eating disorders in young people in England in 2011 was between £1.26 and £9.6 billion per year. This included:

- £80-100 million in direct healthcare costs
- £0.23-3.9 billion in lost GDP
- £0.95-6.6 billion in costs of reduced health and length of life

In 2015, Beat commissioned a second study from Pricewaterhouse Coopers (PWC) in order to complete a more detailed socioeconomic estimation, and this was based on the direct experience of adults with eating disorders. This report estimated that the average annual cost to each person was:

- £8,850 per person for mental health treatment (excluding treatment of the physical aspects) – in some cases, with inpatient treatment up to £100,000
- £1,500 direct financial burden for the individual
- £2,800 direct financial burden for their carer
- £9,500 for time off work or education for person over 20 (£650 if under 20)
- £5,950 for time off work or education for carers

Table 2.5: Costs of eating disorders in the UK per annum (£)

(Source: Beat 2012, 2015)

	COST
Health sector	£3.9–4.6 billion (+ £0.9-1.1bn private)
Direct financial cost (sufferer/carers)	£2.6–3.1 billion
Economic (lost income to economy	£3.9–4.6 billion (+ £0.9-1.1bn private)
Total financial	£3.9–4.6 billion (+ £0.9-1.1bn private)
Wider social (lost education, productivity, social, family)	£3.9–4.6 billion (+ £0.9-1.1bn private)

- Additional impact on quality of life (relationships, productivity, etc.)

Table 2.5 summarises the projected overall cost of EDs in the UK, based on this study. PwC concluded that early and faster referral of suspected EDs, unlocking delays in access to treatment, and the funding of holistic supports to cater for the wider impact of EDs on individuals and carers would enhance recovery.

To this end, in 2014 the UK government announced NHS funding of £150 million (£30m annually over five years) to move the focus on resourcing inpatient care for children and adolescents with eating disorders to developing dedicated specialised national community ED services, in addition to day programmes, training and services for adults.

2.7: Stigma and obtaining treatment

As mentioned earlier, in Australia in 2012, only 5% to 15% of people with EDs were estimated to access treatment. It is widely accepted that people with EDs often do not seek help. Even in the context of social stigma around mental illness, EDs have been found to arouse more stigmatic attitudes in the general public than depression (Roehrig, 2009). Misconceptions – such as believing that anorexia is the person's own fault, that they are looking for attention or that biological factors play a lesser part (therefore less 'real 'illnesses) – have all been suggested as causal (Stewart, 2006).

Within healthcare, clinicians from a variety of disciplines have also been found to hold more negative attitudes to EDs than other conditions (Thompson-Brenner, 2012). A recent survey of UK psychiatrists found that 61.7% of them viewed AN as being a 'neurotic mental disorder' and thought that such patients are less likely to recover (Jones, 2013), a much older view that seems to have endured. It has been suggested that a key factor relating to clinician discomfort is perceived lack of clinical competence and worry.

In Ireland, the STEDI study found that even experienced health professionals with moderately good knowledge of EDs show poor recognition of the symptoms and tend to view EDs as a group of chronic, female-based conditions. Additionally, participants believed that clinicians preferred working with other conditions such as depression or diabetes (McNicholas (2016).

Stigma is a barrier to people in seeking help or continuing in treatment because it interferes with therapeutic relationships and trust. It also has a negative impact on screening and recognition, patient engagement, collaborative-care planning and recovery goals. This has implications for the effectiveness of the HSE's National Clinical Programme for Eating Disorders. It has economic implications as those who do not get help or seek treatment are less likely to recover with the personal and socioeconomic cost as described above. Both of these concerns underline the need for the NCPED to ensure that public and professional training and education about EDs is a focus within this Model of Care, so that stigma can be addressed, understood, managed and reduced.

Box 2.1: Summary – 10 key facts about eating disorders from the literature

- An estimated 188,895 Irish people will experience an eating disorder at some point in their lives (based on epidemiological projections[1]).
- Approx. 1,757 new ED cases develop each year in Ireland in the 10-49 age group.[2]
- Females are at least 2-3 times more likely than males to develop an eating disorder.
- The causes of EDs are a complex mixture of biological, psychological and social factors; 40-60% of the estimated causality of AN and BN is heritable or genetic.
- Eating disorders are diagnosable mental health disorders (World Health Organisation, 1992). They are not a lifestyle choice.
- Eating disorders have the highest mortality and morbidity risk of all the mental health disorders.[4] The mortality rate in adolescents with EDs is 10 times that of peers. Much of this is caused by the physical consequences of starvation.
- Most people can and do recover from EDs if they get effective, evidence-based treatment from ED-trained staff.
- Only 5% to 15% of people with EDs seek help; 85% report that it is hard to access treatment.[3]
- The socioeconomic cost of EDs in the general population is estimated to run to between £13.3bn and £15.7bn in the UK, and up to AUS$69.7bn in Australia, when the long-term burden of disease is included.[3, 5, 6]
- Economic studies recommend that outpatient, early intervention, stepped care, and specialist ED teams will reduce the overall socioeconomic cost through reduced inpatient stays, faster recovery and relapse prevention.[3, 6]

1. Estimated from NIMH, 2. Estimated from Micali, 2013, 3. Butterfly Foundation (2014), 4. Arcelus (2011), 5. Butterfly Foundation (2012), 6. Beat (2012, 2015).

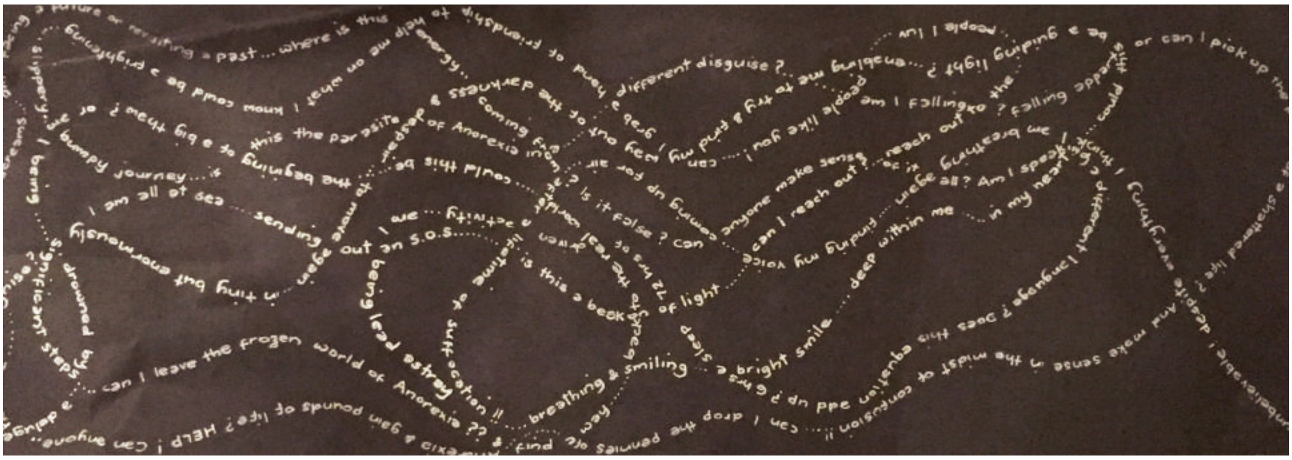
Rationale

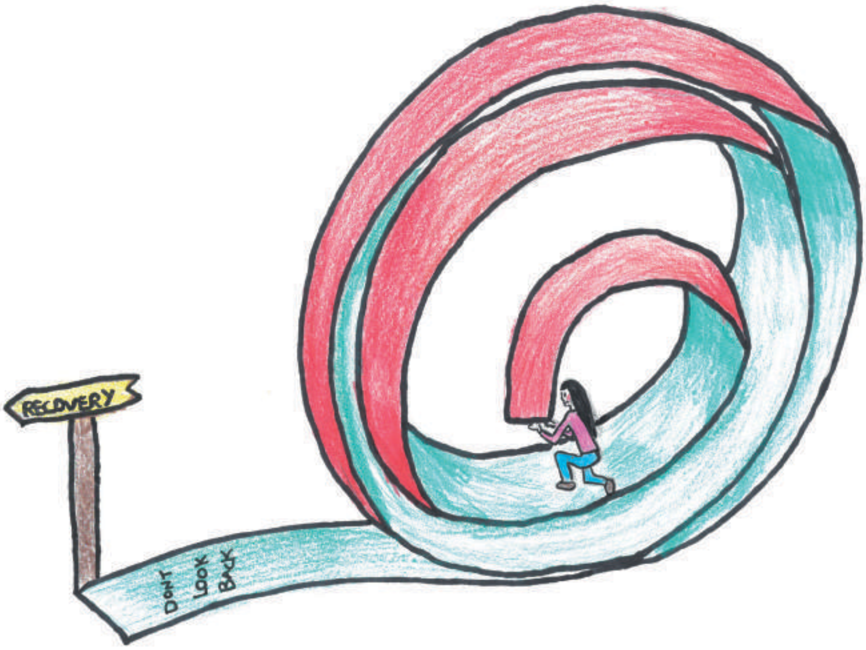
The HSE has an ongoing commitment to improve and reform health services in Ireland. Its Clinical Strategy and Programmes Division aims to improve the quality, access and value for money of its services through the use of evidence-based approaches. It plans to do this by focusing on key clinical areas of high risk or widespread concern, and by bringing clinical leadership into the heart of decision-making around their strategic development. In addition to the integrated care programmes, there are now approximately 33 national HSE clinical programmes in development or implementation across HSE, including the National Clinical Programme for Mental Health.

Clinical governance and patient safety are central to this HSE approach. In 2008, the Commission on Patient Care and Quality Assurance noted that *“knowledgeable patients receiving safe and effective care from skilled professionals in appropriate environments with assessed outcomes”* is the key to achieving a culture of patient safety. Within mental health, this is particularly relevant for eating disorders because they have the highest mortality, morbidity and cost per admission of all of the mental health disorders, with significant acute and chronic risk and safety implications (see Section 2).

A Vision for Change (2006), the Department of Health’s national strategy for mental health, identified ED services as an area of future development. However, since its publication, much has changed in terms of our knowledge and understanding of what works best in ED treatment and in how ED disorder services can best be delivered. Internationally, this has resulted in a drive towards new ways of delivering ED services and a focus on outpatient care. New service frameworks have developed across the UK, Canada, Australia, New Zealand and other European countries over the last decade (see Section 7).

In Ireland, there has never been a comprehensive national eating disorder service. This has resulted in wide variation and inequality of access, treatment and outcome across the country. The HSE has therefore prioritised ED services for development at this time. By developing a National Clinical Programme for Eating Disorders and by implementing this HSE Model of Care, it is envisaged that all patients with EDs who attend HSE will be able to obtain the timely, evidence-based and high-quality level of care that they need so that they can achieve personal recovery and better clinical outcomes when they develop this challenging group of disorders.




RECOVERY
DON'T
LOOK
BACK

Aims and Objectives

Safety and Quality

- Improve clinical outcomes by providing evidence-based treatment
- Reduce mortality and morbidity through earlier recognition, early case finding and recognition, consultation and diagnostic assessment.
- Improve clinical outcomes through early intervention and multidisciplinary care
- Reduce medical crises, mortality and morbidity by implementing clinical risk pathways, management frameworks and physical monitoring
- Use clinical outcome evaluation data to inform individual patient care planning, as well as for local and service planning
- Improve safety through formal integrated care pathways and better communication between services and teams.

Access

- Early access to advice and clinical assessment
- Early access to psychosocial and medical treatment
- A range of levels of care appropriate to level of clinical need of patients – more service options for clinicians to consider
- A national network of services and training so that service gaps can be managed strategically.

Cost-effectiveness

- Reduce the number and duration of inpatient psychiatric admissions through:
    - The provision of alternative settings: enhanced outpatient, day and group programmes
    - Evidence-based practice to increase outpatient efficiency and capacity
    - Early management of deterioration.
- Reduce the duration of outpatient treatment and increase capacity through:
    - Staff who are experienced and trained to work with people with eating disorders
    - Provision of supervision and consultation to clinicians through the ED teams and network
    - Evaluation and clinical audit through a national and local dataset.
- Reduce the number and duration of acute medical admissions through:
    - Collaborative integrated care pathways to and from medical assessment and consultation
    - Use of best practice risk-assessment tools to determine clinical need
    - Development of multi-agency ‘virtual’ teams to assist urgent decision-making around medical risk – e.g. MARSIPAN or JMARSIPAN teams
    - Enhanced number of discharge options through a stepped care structure and approach to service provision (Section 9).

5

Scope of this Model of Care

This Model of Care applies to HSE service provision for adults and children with eating disorders (EDs) in Ireland. While focusing on mental health services, it also makes reference to eating disorder service provision in primary care and acute hospital settings. It outlines a plan to work collaboratively with other national clinical programmes in that context, so that its aims and objectives can be achieved.

The HSE National Clinical Programme for Eating Disorders and its Model of Care are focused on the following DSM-5 eating-disorder categories:

- Anorexia Nervosa (AN)
- Bulimia Nervosa (BN)
- Binge Eating Disorder (BED)
- Avoidant/Restrictive Food Intake Disorder (ARFID)
- Certain other Specified Feeding and Eating Disorders (OSFED) – e.g. Atypical AN, BN, BED – where mental health treatment is clinically indicated

Feeding disorders fall outside the scope of the National Clinical Programme for Eating Disorders. ARFID is included when there is a clinical indication and evidence base for mental health intervention.

In the development of this Model of Care, the National Clinical Programme aims to encompass the different stages and levels of severity of EDs, from early case recognition and assessment though to early intervention and recovery, as well as for people who have severe and enduring eating disorders (SE-ED).

6

Mission, Vision and Core Values

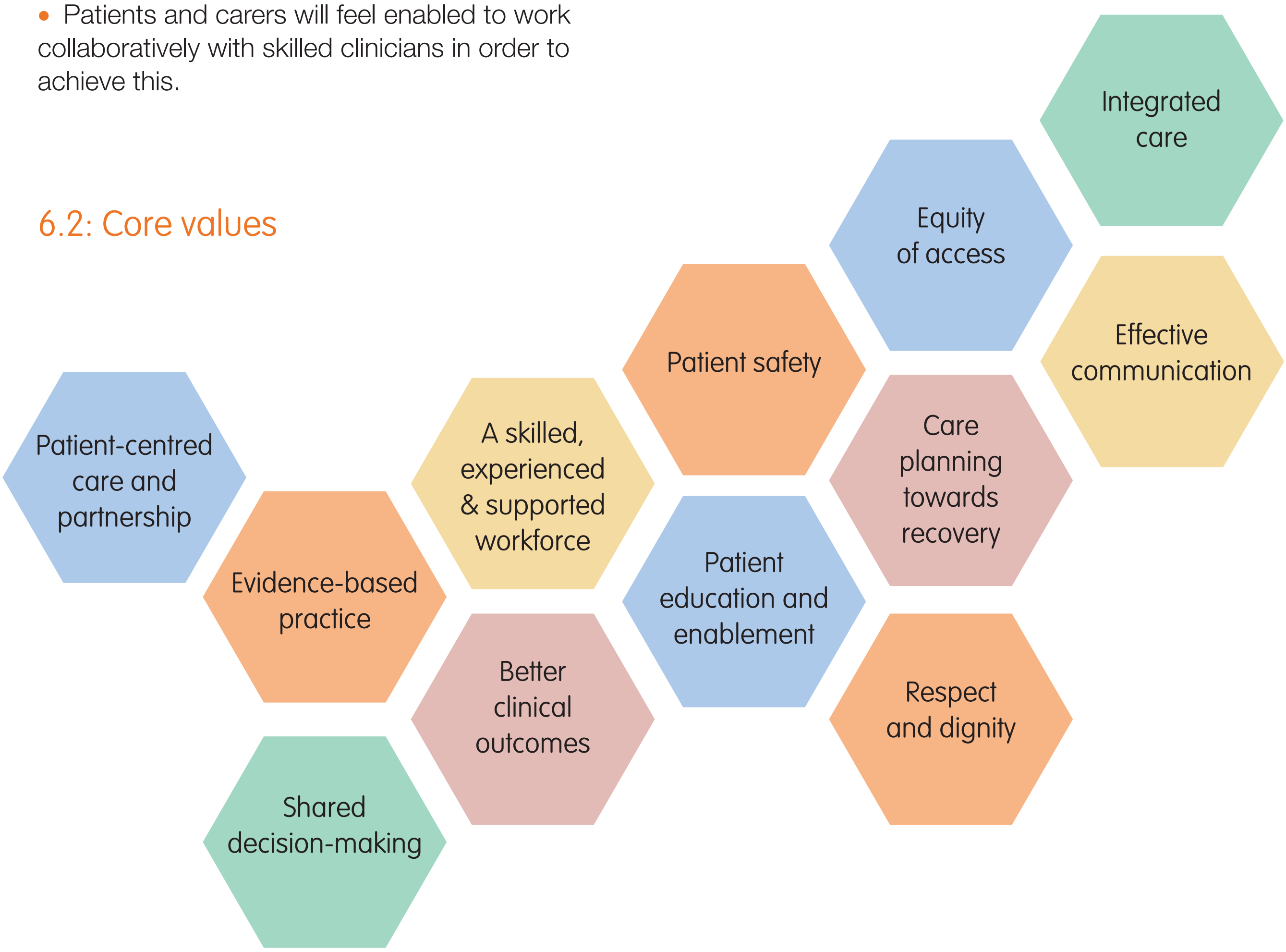
6.1: Mission and vision

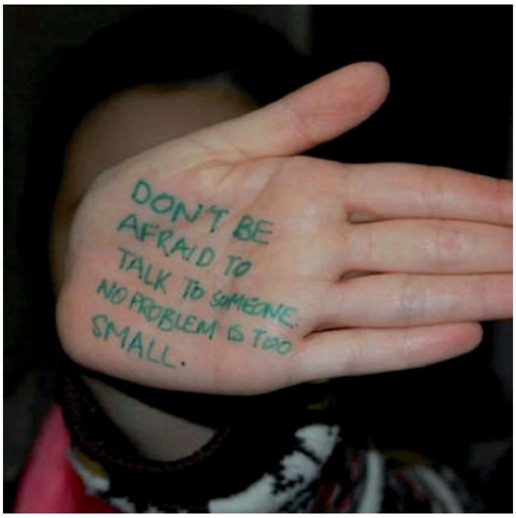
The mission of the HSE National Clinical Programme for Eating Disorders (NCPED) is to develop an evidence and values based Model of Care for HSE eating disorder services in Ireland that is sustainable and effective from the perspective of patients, clinicians and health managers.

The vision of this programme is that:

- People with eating disorders will receive the optimum level of accessible, comprehensive and evidence-based care that they need, so that they feel supported in their individual recovery from eating disorders.
- Care will be accessible, equitable and ethical in terms of resource management.
- Patients and carers will feel enabled to work collaboratively with skilled clinicians in order to achieve this.

6.2: Core values




DON'T BE
AFRAID TO
TALK TO SOMEONE.
NO PROBLEM IS TOO
SMALL.

International Best Practice in ED Service Delivery

Methodology

In order to develop an evidence base for HSE eating-disorder services into the future, the working group conducted a search of the published literature using the Pubmed/Medline and Cochrane databases. Keywords included 'eating disorders', 'anorexia nervosa', 'bulimia nervosa' 'EDNOS', 'guideline' 'systematic review', 'meta-analysis', 'treatment', 'evaluation', and 'service provision'. The purpose was to identify Level 1 international best practice and clinical guidelines published between 2005 and 2016. A similar search was conducted to identify other recent metanalysis and randomised controlled trials, using the same keywords, because some of the guidelines identified had predated more recent research. A manual search though Medscape and the ED websites of key international professional bodies was also completed in order to gather further evidence. Irish research on eating disorders was reviewed. Some key international experts in eating disorders were also consulted. A consultation process with an external Clinical Advisory Group for Eating Disorders from the College of Psychiatrists of Ireland also took place

Twenty eight key guidelines and documents on clinical international practice became the focus of more detailed review as listed in Appendix 1.

7.1: International recommendations for ED service delivery design and treatment setting

To date, formal research on ED service setting and design has been limited, and therefore, the international service and clinical best-practice guidelines that were reviewed were mainly based on expert consensus or on consensus with a formal literature review (identified by 'C' and 'R' respectively in Table 7.1 below). Despite this limitation, the international recommendations on the design and delivery of ED services are broadly consistent. The recommendations of 17 key reports that include service delivery are summarised in Table 7.1. The conclusions that can be drawn concerning the planning of future Irish eating disorder services are summarised in Box 7.1.

7.2: Evidence-based eating disorder teams

Based on the review of the literature, the following conclusions can be made:

- Comprehensive eating disorder care requires a multidisciplinary, multiagency approach involving primary care, mental health, and medical services.

- The core mental health team working directly or indirectly with each ED case includes at minimum a therapist, psychiatrist and dietitian (RANZCP, 2014). The role of the eating disorder dietitian, is outlined in Box 7.2. as dietetics is a relatively new profession within mental health services in Ireland,

- The specific professional discipline of the ED therapist has not been specified in international models of care, but should be a mental health professional with a experience and training in the delivery of psychosocial interventions for mental health, in addition to specific training in ED interventions. The use of guidelines and manualised treatment is recommended (NICE, 2017).

- 'Virtual' MARSIPAN teams are now being established across the UK, consisting of a consultant physician, paediatrician, gastroenterologist, consultant psychiatrist and senior dietitian, in addition to a medical nursing team. Such models of acute physical care are also being developed elsewhere. These 'virtual' teams form around a specific ED case when the case presents to an acute hospital with possible medical instability. A collaborative treatment plan is then agreed, charted in the patient's notes and communicated to all clinicians, the patient and family.

Table 7.1: International recommendations on the delivery of eating disorder services

Country (& document)	Age range	Model of care	Levels	Additional information
AUSTRALIA / NEW ZEALAND **RANZCP (2014)** (C, R)[1] **Future Directions (NZ, 2008)** (C)[1] **People with EDs (NSW, service plan 2013)** (C)	All	**'Stepped and seamless care ... range of options' RANZCP** Specialist ED service and generic MHS where access to it is not available[2]	– Outpatient – Intensive outpatient with meal support – Day programme – Inpatient	Outpatient setting recommended – least restrictive. Pathways to facilitate transitions between services. Medical admission: for stabilisation or if OPD treatment not working. Medical criteria given for this. Includes detailed nursing, feeding guidelines. If psych. admission is needed, to SEDU or if unavailable to general unit with specialist ED team/liaison support.
USA **AACAP (2015)** (C, R)	Under 18	**Stepped-** Specialist ED trained multidisciplinary teams	– Outpatient – Intensive/day – Inpatient	Outpatient recommended – ED skilled staff. Inpatient if outpatient is unsuccessful or unavailable. Disadvantages noted. If admitted>> short stay, involve families. SAHM guidelines for this
AED (2012, 2015 and website) (C)	All	Mentions stepdown from residential/ inpatient but does not address models Note: US model of care is generally ED-specific standalone services or within broader provision		Gives medical and psychiatric criteria for admission.
APA (2006 & 2012) (C, R)	Adults and YP	**Stepped-** – Specialist ED service – generic MHS where access not available specialist and non	1. Outpatient regular 2. Outpatient-intensive 3. Day-patient/partial hosp. 4. Residential psych. 5. Full hospitalisation – medical	Level of care is needs-based. Notes that BMI <85% requires highly structured programme. Notes one Korean study where day programme was superior to outpatient for BN in adolescents.
UK **NCCMH/ NHS1 (2015)** (C)	Under 18	**Stepped** -Specialist ED teams mainly unless in remote areas – Day-patient/ – minimum catchment population 500,000.	– Outpatient – Day programmes	Outpatient-focused services, intensive OPD involves weekly physical monitoring. Psych. inpatient: specialist ED programmes. Aim weight restoration. AN <70% BMI BN – required by <5% Specific care pathways and timeframes included. Specific clinical criteria for medical admissions; refers to NICE 2004 (which predates MARSIPAN/JMARSIPAN guidelines).
Quality improvement Scotland (2006) (*predates a number of studies on setting*) (C)	All ages	**Stepped** Outpatient-generic / specialist ED Other levels specialist ED services	– Outpatient (Generic and ED) – Day-patient/assertive outreach – Inpatient	MARSIPAN/JMARSIPAN guidelines to guide admission decision-making.
NICE (2004) **NICE (2017)** (focused on clinical rather than service structure) (C, R)	All ages	Refers specifically to ED services; staff with access to supervision NICE (2004 Non-ED specialists 'seek advice from ED specialists'	– Outpatient – Day-patient – Inpatient	Outpatient for most patients Specific criteria for referral to ED day and inpatient care NICE 2004 Includes specific clinical pathways – specific guidance for SE-ED care
JCPMH/ NHS (2015) (C)	All	**Stepped** Specialised Multidisciplinary ED teams at all tiers where available	– Outpatient – Day care – Inpatient	Children - outpatient care appropriate for 80% of cases. Approx. 20% will need more intensive levels of care. Formal local referral pathways recommended. MARSIPAN/JMARSIPAN congruent.
CONTINENTAL EUROPE **ESCAP (2015)** **Review of Spanish, German, Dutch and UK guidelines for Anorexia** (C, R) **Kenniscentrum (2015);**	Under 18	**Stepped or needs-based access** MDT with ED experience Dutch guide: ED centres	– Outpatient – Day-patient – Inpatient	No consensus on thresholds for inpatient/day/outpatient across 4 European countries (Germany, Spain, Netherlands, UK): Germany & Netherlands have lower thresholds. Common to all 4 guidelines for inpatient admission: – Insufficient response at OPD – Suicidality/DSH – Acute medical stabilisation – Severe social or psychiatric comorbidity

Germany (Herpertz, 2011) (C, R)	All	ED skilled staff	– Outpatient – Inpatient – Day-patient	AN: Lack of research on which setting is optimal is noted. Some with AN may need to go straight to inpatient (lower threshold for admission to IP). BN: admit when outpatient/day fails or no clinical change
Spain (2009) (under review) (C)	8+	**Stepped** Specialist ED services	– Outpatient – Day-patient – Inpatient	BN: mostly outpatient AN: outpatient, with day/inpatient if no improvement at OPD; inpatient as near home as possible BN: mostly outpatient If attending generic services, seek advice of specialist ED service if planning to admit.
CANADA **British Columbia MOH CPG (2010)** (C, R)	All ages	Continuum of stepped care Lower levels of care from generic or Specialist ED teams Higher level of care from ED services	1. Low-intensity outpatient 2. High-intensity recovery day/inpatient specialist ED teams 3. Variable intensity-out/inpatient QoL-focused 4. High-intensity inpatient – medical stabilisation 5. Inpatient – medical stabilisation	Uses APA (2006 framework) Outpatient first Criteria to choose intensity of care include: medical acuity, symptom/QoL interference, engagement with treatment
CPA **(2010) (Findlay, 2010)**	Under 18	**Stepped** Specialist ED where available	– Outpatient – day programme – Inpatient	Outpatient is first line – includes weekly medical review

1. C = Consensus guideline; C, R = Consensus and literature review mentioned. 2. RANZCP notes that many people may not be able to access specialist service locally.

Box 7.1: Key conclusions on service delivery

- **A specialised ED services infrastructure is needed**

The NCCMH (2015) and RCPsych (2012) have noted that a minimum of 25-50 new patients a year is needed for mental health teams to sustain specialist ED skills. Specialist ED teams have been associated with faster recovery, higher patient satisfaction, lower costs, lower rates of inpatient admission and better case identification and access (Gowers, 2010; Hay for Cochrane, 2015; House, 2012). Where eating disorders are treated by generic mental health teams, specialist ED consultation and support are essential to those teams.

- **Stepped care model**

ED treatment should be provided through outpatient, intensive/day, and inpatient settings. Day services have good potential as a second-line alternative to inpatient or as stepdown from it (AACAP, 2015; APA, 2012; ESCAP, 2015; Espie, 2015; NICE, 2017). Few randomised controlled trials (RCTs) are available, but research indicates that day services for young people are associated with decreased costs and decreased number of inpatient admissions (Herpertz-Dahlman, 2014; Ornstein, 2012). The treatment setting should be based on patient clinical presentation, with patients stepping up and down in intensity of care as needed.

- **Community-based outpatient care**

There is consensus that outpatient is the most appropriate treatment setting for both adults and children with eating disorders if the patient is medically stable with support, though research in the area of location of care is limited (Watson, 2013). For BN, BED and ARFID, there is no evidence for the benefit of inpatient admission unless the patient is medically unstable. For AN, inpatient psychiatric admission for adolescents' risks disempowering parents, separating children from families, and counters some treatments (e.g. FBT) being provided effectively (Espie, 2015; AACAP, 2015). It is also associated with higher relapse rates (Lock, 2015; Gowers, 2010). However, some patients with very low weight, lack of treatment response or comorbidity may need a more highly structured setting than outpatient can provide (ESCAP, 2015; Herpertz, 2011). Psychiatric admission, when required, should be focused on weight restoration and short duration of admission.

- **Multidisciplinary team approach**

The core team consulting or working with each ED case includes at minimum an ED therapist, psychiatrist and dietitian. The specific professional discipline of the ED therapist is not defined, but they should have specific training, expertise and experience in working with eating disorders.

- **Medical risk evaluation and medical admission**

Medical admissions to acute hospitals are required for physical stabilisation in severe restricting EDs and sometimes BN (5% of BN cases). When needed, this should be brief and focused on medical safety and refeeding. Specific patient care pathways, risk and decision algorithms are included in most guidelines focused on this area (see Section 7.5 below for further detail on refeeding, and RCPsych 2012, 2014).

- **Formal integrated care pathways**

Seamless transitions and integrated care are a key focus of all the documents, and the national service documents that were reviewed include formal care pathways. The complexity and nature of eating disorders means that patients must navigate across different levels of setting (mental health & medical teams, CHO and acute hospital structures), and must make age-related transitions in service. Formal care pathways assist collaborative working and improve patient safety (RCPsych, 2012).

Box 7.2: Role of the dietitian in Eating Disorders treatment

Primary care dietitian

- Initial recognition and advice for those at risk in primary care.
- Provision of nutrition education and support to those at risk.
- Provision of dietetic assessment to support GP decision-making on referral for ED assessment.

Specialist dietitian

- Identification and assistance to the team in the management of refeeding syndrome and clinical complications such as hypoglycaemia, gastrointestinal dysfunction, hyponatraemia, growth, etc.
- Physical risk of malnutrition – assessment and management.
- Assessment and recommendations of the need for nutritional support and supplements.
- As a member of the MDT, support to people with EDs in making changes to their eating by working collaboratively with them to develop a nutritional care plan.
- Empowering family, carer and staff with meal coaching strategies and knowledge.
- As a source of evidence-based nutritional expertise within the MDT.
- As a member of the MARSIPAN/JMARSIPAN team during medical admissions (also good practice for hospital-based dietitian to liaise with ED dietitian).
- Contribution to the education and training of other health professionals working with EDs.

7.3: Assessment and diagnosis

All of the clinical practice guidelines that were reviewed recommend that patients receive a detailed and comprehensive initial assessment of their mental and physical health. This is the key to patient engagement and risk management. Domains that are specifically recommended for inclusion in the first assessment are summarised in Tables 7.2 to 7.4. A key component of case recognition and assessment is the exclusion of medical conditions that may mimic eating disorders such as thyroid disease, diabetes, coeliac disease, Crohn's disease, Addison's disease, craniopharyngoma and other neoplasms, autoimmune disorders, as well as mental health disorders such as depression, psychosis, somatoform and feeding disorders.

A common criticism of ED services in Ireland and abroad is that waiting times for assessment and then for treatment are too long (Beat, 2015; Fursland, 2016). In that context and with patient safety in mind, many of the guidelines we reviewed have attempted to address this through the development of specialist teams and clinics. In the UK, the National Collaborating Centre for Mental Health (2015) and Royal College of Psychiatrists (2016) recently set some key timeframe targets for the new NHS ED teams for children and adolescents. The latter timeframe addresses the issue of internal waiting lists for psychosocial treatment, which is an ongoing issue in mental health services in Ireland

- from referral to assessment: 15 days routine, 1 week urgent, 1 day emergency.
- from referral to treatment: 4 weeks

Table 7.2: Summary of recommendations on assessment and diagnosis – all ages*

	RANZ CP (2014)	BCMOH/Canada (2010/11)	NICE[1] (2017): Tx, focussed	AED (2015)	Spain[1] (2009)	Wales (2012)[2]	Scot. (2006)	MARS**. (2014)	APA (2006/12)	AACAP (2015)	ESCAP (2015)	JMARS** (2014)
Age range covered	**All**	**All**	**All**	**All**	**8 +**	**All**	**All**	**18+**	**All**	**To 18**	**To 18**	**To 18**
Use formal diagnostic criteria	DSM 5	DSM 4 TR	Not mentioned	DSM 5	DSM 4 ICD 10	Refers.		NA	DSM 4	DSM 5	DSM 5	NA
Screening tool		SCOFF	Not alone	x	x		x	x		x		x
Person-centred	x	x	x	x	x	x	x		x	x	treatment	x
Motivational/engagement stance	x	x				x				x	focussed	
Involve families & carers	x	x	x	x	x	x		x	x	x	only	x
Multidisciplinary assessment	x				x					x		x
Core ED symptomatology	x	x	x	x	x	x		NA	x	x		x
Cognitive/confusion	x	x			x							x
Comorbidity	x	X	x	x	x		x	Medical	x	x		x
Physical/medical Hx assessment	x	x	x	x	x	x	x	x	x	x		x
Risk	x	x	x	x		MARS	x	x	x	x		x
Investigations	x	x	Not mentioned	x	Exam-based		x	x	x	x		x
Dental erosions[3]	BN	x	x	exam			x		Hx	x		NA
Nutritional assessment	x	x	x	x		x		x	x	X5		x
Psychosocial assessment	x	x	x	x	x	x	x	NA		Partly addressed		Part
MSE/ psychiatric	x	x	x	x	x	x		x	x	x		x
Dietary records[3]		x							x			
Self-report measures		x	x		x	Link		NA	x	x		
Structured interview		EDE but not full			x	Link		NA		x		NA

Initial assessment may involve such cases and so they are included here. NA = not relevant to the context of that document;
1. Guideline is under review at present; 2. References MARSIPAN/ JMARSIPAN; 3. Dietary review may involve clinician consulting with dietitian or more direct dietetic consultation,[4] including substance abuse.

* This table summarises the domains specifically mentioned in the guideline. There was substantial variation between service and clinical focus in the documents; some provide more detail than others. Blank box indicates that no mention was made in the document of this domain.** MARSIPAN and JMARSIPAN are specific guidelines for severely at-risk AN (see Section 7.5).

Table 7.3: Summary of recommendations on baseline physical examination – all ages

	RANZ CP (2014)	BCMOH/Canada (2010/11)	NICE[1] (2017)	AED (2015)	Spain[1] (2009)	Wales (2012)	Scot. (2006)	MARS. (2014)	APA (2006 & 2012)	AACAP (2015)[2]	ESCAP (2015)	JMARS (2014)
Age range covered	**All**	**All**	**All**	**All**	**8 +**	**All**	**All**	**18+**	**All**	**To 18**	**To 18**	**To 18**
Weight	x	x	x	x	x	As for MARS/JMARS	x [2]	x	x	x	Treatment focused only	x
Height	x	x	x	x	x		x [2]	x	x	x		x
BMI calculation	x	x	x	x	x		x [2]	x	x	NA		x
Respiratory rate					x							x
Pulse rate: seated/standing	x	x	Cardiac	x	x		x	x	x	x		x
BP seated/standing	x	x	x	x	x		x	x	x	x		x
Core temperature	x	x	x	x	x		x	x	x	x		x
Peripheral oedema	x		Assmnt. of physical + mental risk						x			x
Peripheral circulation							x		x			x
Muscle weakness (SUSS)[1]		x					x	x				x
Skin exam, Russell's, DSH		x			x				x	x		x
Head and neck – parotids, teeth		x dental			x dental					x		x
Hydration status		x			x							x
Mid upper arm circumf.												x
History-specific: assumed in some documents but not specifically mentioned												
Cardiac	x		ECG?						x			x
Menstrual	x								x			NA-
Neurological					x							
Child-specific								NA				
Use of growth centile charts		x	Growth monit.	x						x		x
% BMI calculation	x	x		x					Charts	x		x
Developmental growth/puberty		x					x		x	x		NA

1 Primary care guidance; 2 if patient is agreeable. This document then refers to the Society of Adolescent Health and Medicine guidelines for decisions on medical risk

7.3.1: Best-practice guidance on anthropometric measurement

(compiled from NICE, 2004; RCPsych, 2014); Boland, 2013 and working group)

7.3.1.1: Weight measurement

- Ideally weigh at same time of day, and document fluid and food intake prior to weight
- Ensure empty bladder
- Weigh in light clothes (e.g. leggings and light vest)
- No footwear
- Ensure objects removed such as jewellery, wallet, phones
- Ensure hair is dry
- Record weight in kg

7.3.1.2: Height measurement

- Individual should be barefoot or in thin socks
- Remove ponytails, etc that may interfere with accurate measurement
- Ensure heels, bottom, back and head are touching the apparatus with eyes and ears at 90° (the Frankfort Plane)
- Don't allow to stretch up
- Measure on expiration – best of three
- Record height in cm to the nearest 0.1cm (do not record in ft/inches)
- Use a non-wall-based stadiometer

7.3.1.3: BMI calculation

- BMI is a case recognition tool to indicate how heavy a person is relative to their height and is the simplest indicator of thinness and fatness
- BMI can be calculated as in Table 7.1, below.

7.3.1.4: Growth and % BMI calculation in under-18s

compiled from NICE, 2004; SAMH, 2015; RCPsych, 2012; Boland, 2013)

- Height and weight in those under-18 are both plotted on standard growth charts for comparison to Irish population norms and parental heights (e.g. UK RCPCH growth centile charts).
- Previous information about the child's growth will give a more complete picture of their trajectory and the impact of the ED. The GP may have these details.
- Body mass index (BMI) is not a linear constant in childhood, and so is not a reliable indicator of physical stability or growth.
- BMI should be adjusted for the young person's age and gender by use of a BMI centile chart.
- The child's BMI is plotted and the median weight for height is marked.
- The difference between the child's BMI and the median (50th centile) for age and gender is calculated.
- This can be expressed as a standard deviation score (SDS), or as a percentage of the median BMI (% weight for height), as in table 7.5, over.

Table 7.4: Calculating BMI and adult health weight ranges

Calculation	Range	CDC (2015)
Weight ÷ Height (m)^2 = BMI e.g. A 50kg woman; Ht 170cm = 1.7m $\frac{50}{1.7 \times 1.7}$ = 17.3 (underweight)	< 18.5	Underweight
	20–25	Healthy range
	25-30	Overweight range
	30 +	Obese range

Table 7.5: Calculating % BMI and medical risk in under-18s

Calculation	BMI %	JMARSIPAN risk tool
Actual BMI ÷ by Median BMI 50th (Centile Chart) = % BMI	>70%	High risk
	70–80%	Alert to high risk
	80–85%	Moderate risk
E.g. 15-year-old boy, Ht 165cm, Wt 40kg. Has BMI of 14.7.	>85%	Low risk
So, $\frac{14.7 \text{ x } 100}{19.8} = 74\%$ BMI	95–100%	Target range for recovery

(Ref. Junior MARSIPAN, RCPsych, 2012; SAHM, 2015)

Box 7.3: Summary of recommendations for the assessment of eating disorders

- Use of case finding and recognition questionnaires to guide professionals on whether a full ED assessment or referral is recommended but not as the sole method of screening.
- Use of a formal diagnostic classification DSM-5 or ICD-11 (due 2017) for ED diagnosis.
- Comprehensive initial assessment includes a detailed assessment of the weight and growth trajectory, eating psychopathology and behaviour, comorbidity, family, psychosocial, nutritional and mental state examination.
- Use of patient-reported measures and questionnaires is recommended at assessment in order to support the clinical interview.
- Comprehensive assessment involves comprehensive baseline physical examination.
- Comprehensive assessment involves comprehensive baseline medical investigation.
- A developmental approach to the physical assessment of children and adolescents is essential (e.g. %BMI, centiles, growth, etc.
- Risk assessment includes mental, physical and social risk.
- For both adults and children, family involvement (parent/carer) is highly important in order to gather collateral history and to engage understanding and support for the refeeding process.

Table 7.6: Summary of recommendations for initial baseline physical investigation of eating disorders – all ages[1]

	RANZ CP (2014)	BC MOH/Canada (2010)	NICE[2] (2017)	AED (2012)	Spain (2009)	Wales (2012)	Scot. (2006)	MARS.[3] (2014)	APA (2006/2012)	AACAP (2015)	ESCAP (2015)	JMARS [3] (2014)
Age range	**All**	**All**	**All**	**All**	**8 +**	**All**	**All**	**18+**	**all**	**To 18**	**To 18**	**To 18**
Electrolytes (K+P04, Mg2+, Na, Cl bicarbonate)	x	x	Assess fluid and electrolyte balance	x	x	As for MARS. / JMARS	x	x	x	x	Treatment focus only	x
Urea and serum creatinine		x	Relevant blood tests	x	x			x	x	x		x
Ca 2+		x		x	x			x		x		x
CRP								x				
Blood glucose	x	x		x	x		x	x		x		x
LFTs (AST/ALT /bilirubin/ alk phos.)	x	x		x	x		x	x	x	x		x
Amylase, lipase				?					If vomiting	x		
ESR				?					x	x		Inflammatory markers
Total/serum albumin	x	x		x	x			x		x		
FBC and differential	x	x		x	x		x	x		x		
Coagulation screen					x							
B 12								x		x		
Folate								x				x
Serum ferritin								x	x			
Vitamin D								x				
ECG	x	x	x	x	x		If indic.	x		x		x
Thyroid function tests		x	As above	?	x		x	x	x	x		x
FSH/LH/ oestradiol – girls		x		?	x				Non-routine	x		
Testosterone – boys		x		?					>6/12			
Lipids					x					x		
HCG if indicated										x		
Urinalysis		x			x			x	x			
DEXA	>6/12 Hx	>6/12	>1 yr children >2 years adults				x		>6/12	>6/12		
Abd. Ultrasound		>6/12	As above									
Coeliac screen												x
Toxicology									If indicated / AN			

1 Escalate to a more detailed physical risk assessment such as MARSIPAN if clinically indicated. 2 NICE 2004 gave more detailed recommendations on assessment. 3 Focus on the acute management of severe anorexia only.

7.4: Evidence-based treatment of eating disorders

- Research on eating disorder treatment has focused on three main areas:
  - psychosocial treatment
  - pharmacological treatment
  - nutritional therapy refeeding.
- Underlying all of the research on evidence-based treatments is that weight restoration is the key goal and that early refeeding and physical risk management underpin recovery. This ‘food is medicine’ approach means that the most effective psychosocial approaches include regular weighing and monitoring as part of treatment, sharing the persons weight with them unless unsafe to do so
- Early intervention is associated with better outcomes, and early weight gain in the first four weeks of therapy indicates better prognosis.
- There is currently a limited but growing evidence base regarding the most effective psychosocial treatments for AN and BN. However, the evidence base for BED and ARFID is more poorly understood at this time as these diagnoses have only been formally defined relatively recently.
- Older guidelines that were reviewed by the working group (e.g. NICE, 2004 and QIS Scotland, 2006) are more general in their treatment recommendations as they preceded much of the research in this area.
- Randomised controlled trials (RCTs) have concluded that certain psychological treatments for EDs can yield recovery rates for 40-50% of patients with (i.e. minimal or no symptoms/restored BMI) and result in a substantial reduction in symptoms in a further 30-40% of cases (Kass, 2013; Fairburn 2015; Waller, 2016a). This compares with much lower chances of full remission with non-evidence-based treatments (Poulson, 2014) and with treatment as usual (TAU) in CAMHS (Gowers, 2010). In some studies, this difference between therapies in clinical outcome has been two to threefold.
- Time to remission varies substantially between treatment approaches. For example, FBT and SFT-AN for AN in adolescents are equally effective, but the latter may take more sessions and so, a longer timeframe. The same difference has been seen for CBT-E and IPT for BN in adults, with the latter taking twice as long to reach remission. This is a key factor to consider given the importance of early remission and duration of illness in recovery.
- To date, there are few treatment studies that have focused on male eating disorders or on people with severe and enduring eating disorders (SE-ED).

7.4.1: Evidence-based psychosocial treatments

Tables 7.7 and 7.8 summarise the current state of play in 2017 with regard to best-practice recommendations on psychosocial interventions for EDs in adults and children respectively. Some of the older guidelines that were reviewed pre-dated some important studies. Two broad paths have generally been taken regarding the research of psychosocial treatments for eating disorders. The first involves specific eating disorder focused psychological treatment such as:

- CBT-E (Fairburn, 2008): Cognitive Behaviour Therapy-Enhanced for Eating Disorders (Use: adults – all eating disorders; adolescents – BN/BED). This is a manualised CBT-ED treatment with 20 or 40-session format starting with twice weekly sessions. The patient is weighed by the therapist as part of therapy. It is an outpatient treatment.
- FBT (Lock, 2010): Family-Based Treatment for Anorexia Nervosa in children and adolescents. This is a manualised first-line treatment, usually of 15 to 20-session duration. The patient is weighed as part of treatment. It is delivered in an outpatient setting, initially on a weekly basis.
- Focal Psychodynamic Psychotherapy (FPP-ED). A manualised treatment for adults with anorexia nervosa – 40 sessions.
- FT-AN (Eisler, 2000 & 2005; Le Grange, 2008): systemic family therapy for anorexia nervosa. This is a first-line treatment for children and adolescents with anorexia nervosa and is delivered in an outpatient setting. It is a precursor to FBT- AN, and has continued to evolve, with less structured sessional format. The patient is weighed as part of treatment.
- MFT-AN (Eisler, 2005, 2016): Multiple Family Therapy for Anorexia Nervosa. (Use: adolescents and young adults with AN). Partly manualised. This is an intensive systemic group format of FT-AN (9-10 days over 9 months) which is attended by 5-6 families together. Family group meals.
- Focal Psychodynamic Psychotherapy (FPP-ED). A manualised treatment for adults with anorexia nervosa – 40 sessions

- AFT (Fitzpatrick, 2010; Lock, 2010, 2015b): Adolescent-Focused Therapy (Use: Adolescents with AN); also related to ego-oriented psychotherapy. A second line for adolescents with anorexia nervosa. Manualised. Outpatient setting.
- CRT (Dahlgren, 2014): Cognitive Remediation Therapy (adults and adolescents – AN). Manualised. This is an add-on treatment for anorexia nervosa which is focused on thought process rather than content. It aims to improve insight and is associated with enhanced engagement and lower case dropout from services. It is not BMI-focused. Individual or group formats. Inpatient, day-patient, outpatient settings – 6-10 sessions.
- CREST (Tschanturia, 2015): Cognitive Remediation and Emotional Skills Training. A variation of CRT encompassing emotional regulation skills. Research to date is on adults with AN and mainly in inpatient setting.
- IPT–BN (Fairburn, 1993, 2015; Murphy 2012): Interpersonal psychotherapy for BN/EDs (use: adults with BN). A manualised weekly sessional programme. Outpatient setting. Patient is weighed as part of treatment.
- UCAN (Bulik, 2011): Uniting Couples in the Treatment of Anorexia Nervosa (use: adults – AN).

Further RCTs are ongoing for many of the above interventions. Other specific psychological treatments such as radical openness, DBT and Internet-delivered CBT are undergoing research at present, but evidence is not currently robust enough to be included in the clinical practice guidelines that were reviewed at this stage.

The second approach of the research has been a focus on broader 'wraparound' approaches to treatment which includes, but is not limited to, specific psychological treatments. For adult anorexia nervosa, this has included the following:

- MANTRA (Schmidt 2014, 2016) – Maudsley Model of Anorexia Nervosa Treatment for Adults. This is a second-line treatment for adults with AN. A manualised modular programme of 20-30 sessions' duration, depending on BMI, including sessions with dietetics and carers. 8 Modules, Recovery focused.
- SSCM (McIntosh, 2006), Specialist Supportive Clinical Management.

Both of these programmes are now recommended as second-line treatments for adult AN (RANZCP guidelines 2014; NICE 2017). In 2016, a follow-up of the multicentre MOSAIC randomised controlled trial which compared MANTRA and SSCM found no difference in outcome between these treatments at two years, though there was higher patient preference for the latter (Schmidt, 2016).

Some other wraparound approaches in research at present and which may have a role when first and second-line treatments have been ineffective or for patients with SE-ED/AN include the ANITT (Anorexia Nervosa Intensive Treatment Team) approach (Munro, 2014) which has been described in an open study, but has not yet been evaluated in an RCT.

It is important to note that the majority of the psychosocial therapies mentioned in Tables 7.7 and 7.8 are delivered by qualified and ED-experienced mental health clinicians from a variety of psychotherapeutic backgrounds (e.g. psychiatrists, psychologists, psychiatric nurses, mental health social workers, family therapists, CBT therapists, etc.). The key is that they have training/experience in that particular model of treatment (e.g. Lock, 2015).

Day programmes/inpatient-based psychosocial treatment programmes

There is currently no RCT or consensus guidance on which particular psychosocial treatments work best within day and inpatient programme settings (with the exception of CRT), and there is limited guidance on how best these interventions can be adapted and incorporated into non-home-based settings (Loeb, 2015). Pragmatic evaluation studies on Multiple Family Therapy for Anorexia Nervosa (Eisler, 2016) day programmes and Radical Openness inpatient programmes for adult anorexia (Lynch, 2013) suggest the potential of these two approaches within an intensive day programme for eating disorders.

In summary, whilst the evidence base for specific psychosocial treatments for EDs is growing, significant gaps in high-quality studies remain: particularly for ARFID, for males, for children and adolescents with bulimia and for those with SE-ED (Bailey, 2014). Clinical training provided by the HSE National Clinical Programme for Eating Disorders will aim to target the most current evidence-based treatments and will be subject to regular updates as part of HSE commitment to patient quality and safety.

Table 7.7: Summary Table of international recommendations for psychosocial treatment of adults with EDs

	RANZCP (2014)	BC MOH/Canada (2010)	NICE (2017)	AED (2014)	Spain[1] (2009)	Scotland (2006)	APA (2006/12)	Cochrane (2006, 09, 15)
Age range	**All**	**All**	**All**	**All**	**8 +**	**All**	**All**	
Anorexia nervosa	Individual: 1st CBT? 2nd Line SSCM? or MANTRA Involve families if living at home and < 3 yrs ? FTx> IT	Individual[2] no type specified CBT noted MANTRA and UCAN also described	1st line CBT-ED MANTRA SSCM 2nd Line FPT	No consensus	Not specified (PPT – see footnote)	Variety available		
SE-ED								
Bulimia nervosa	1st CBT/ CBT-E 2nd IPT (same efficacy, takes longer than DBT?	1st line BN focused self-help, with supportive sessions 2nd line CBT-ED	1st CBT-E 16-20 sessions 2nd then IPT/other	1st CBT	1st? Self-help 2nd CBT-BN[1] (16-20 sessions) 3rd Another individual/IPT[1]	1st Line: CBT-E 16-20 sessions 2nd Line: IPT/other	1st CBT 2nd Indiv. 3rd?Online GSH as adjunct	1st CBT-BN specific 2nd IPT[1] 3rd ?SH
Binge ED	1st CBT/CBT-E	1st CBT-BN[1]/E 2nd IPT DBT as adjunct if BPD	1st BED guided self-help prog. 2nd Group CBT-ED 3rd Individual CBT-ED	1st CBT	1st CBT – adapted 2nd IPT-BED[1]	1st Line: Self-help 2nd Line: CBT-E 3rd: IPT or modified DBT	1st CBT – indiv. or group ?Internet 2nd ?IPT or ?DBT	
Other EDs		EDNOS- CBT 1st line						

Notes: 1. IPT has similar efficacy to CBTE-E/BN but takes twice as long, which means CBTE is offered first. 2. Motivational interviewing mentioned. 3. This RCT evidence more recently suggests CBT> PDT.

Table 7.8: Summary Table of international recommendations for psychosocial treatment – children and adolescents with eating disorders

	RANZCP (2014)	**BC MOH/Canada (2010)**	**NICE (2017)**	**RCPsych (20i5)**	**AED (2015)**	**Spain[1] (2006)**	**Scot. (2015)**	**AACAP (2015)**	**ESCAP[2] (2015)**
Age range	**All**	**All**	**All**		**All**	**8 +**	**All**	**< 18**	**< 18**
AN	1st FBT or SFT 2nd if family not available/ older- ?CBT-E/AFT Not TAU	1st line: FBT AN Or MFT – alone or adjunct (group) Separate FT if high criticism	1st line FT-AN – single or group 2nd line: CBT-ED or AFT-AN	1st FBT-SFT 2nd IPT –some 3rd EOIT 4th Combined?	1st Family Therapy 2nd CBT when weight restored	1st Family Therapy	1st; Family interventions	1st Family therapy partic. FBT (10-20 sessions) 2nd Individual if not possible (AFT) 3rd ?CBT-E	FBT. Involve family. May supplement with individual therapy: ?AFT/ ?CBT/?SSCM CRT
BN	CBT CBT-E	CBT-BN[3]? FBT-BN?	1st line: FT-BN 2nd line: CBT-ED	CBT FBT	CBT	CBT – BN but add family / adapt for developmental age	CBT-E 16-20 sessions then IPT/other		Not covered
BED	CBT CBT-E	Behavioural or family-based treatment 2nd Group CBT-ED	1st: BED guided 2nd: Group CBT-ED self-help prog. 3rd: Individual CBT-ED		CBT	Psychological treatments adapted for age	Self-help then CBT-E or IPT or modified DBT	? IPT – v limited research	Not covered
ARFID								?CBT ?Family	Not covered
Notes		In general: behaviour/family							

1. Being revised; 2. ESCAP (European Society for Child and Adolescent Psychiatry – Herpertz-Dahlmann, 2015; 3. CBT BN is now developed into CBT-E

Box 7.4: Summary of key principles of effective psychosocial treatment

- All of the evidence based treatments are underpinned by supportive, motivational, empowering, psycho-educational, and recovery-focused clinician attitudes and skills.
- However, these strategies do not replace an active ED-focused, evidence-based treatment. Treatment as usual (TAU) has not been found to be effective.
- A key component of successful treatment is that the clinician has ED experience and specific training, and is aware of the dynamics of the therapeutic relationship. This is essential in order to manage setbacks quickly and collaboratively and to enhance fidelity to the treatment model being used.
- Weight restoration and refeeding are the key initial goals and steps towards recovery. ‘Food is medicine’. Refeeding may precede psychological work when the patient is too unwell cognitively or physically to engage in psychological work Therefore, regular weight monitoring is part of psychosocial treatment and the weight is usually shared with the patient.
- Although the therapeutic discipline of the clinician is not generally specified in the guidelines (experience and training in EDs is), complex cases may need to work with staff from specific clinical backgrounds; e.g. some comorbidities or complexities may specifically benefit from work with the psychologist, social worker or psychiatrist on the team as a key therapist.
- Families and carers are a key support to recovery and should be included in all treatment plans, for both adults and children. Family interventions are the core focus of therapeutic work with adolescents and children.
- Early intensity of treatment improves outcomes and this in turn predicts prognosis. Progress is closely monitored in the first 4-6 weeks.
- Those with SE-ED require additional functional recovery-focused goals.
- Evaluation of clinical progress is an important part of effective treatment, and the regular use of clinical outcome evaluation measures is recommended (NICE, 2017)
- See Section 16.

7.4.2: The role of self-help

Self-help strategies, such as information-sharing, bibliotherapy and use of internet resources, are a key part of any treatment and have been shown to improve patient satisfaction, enablement and recovery across all medical disorders. From an ED perspective, these strategies have been found to be superior to placebo and to decrease the distress of adults waiting for assessment or treatment (Perkins for Cochrane, 2006). Structured online self-help programmes have also been found to produce significant reductions in expressed emotion and distress in patients with EDs, as well as a reduction in depressive symptoms in carers (Grover et al., 2011). Supported self-help approaches have been found to be effective as a standalone treatment for BED (Iacovino, 2012; Streigel-Moore, 2010), and to be acceptable to many patients.

Most ED guidelines that were reviewed included reference to self-help, particularly at community and primary care level (Table 7.3). However, with the exception of adult BN (NICE, 2017), self-help in itself is not an effective treatment for eating disorders. It is an adjunct to evidence-based treatment that may improve engagement and motivation as well as self-care (e.g. dental advice for people who are purging). Self- help has not yet been robustly researched in children or adolescents with EDs.

7.4.3: Evidence-based pharmacological treatments for EDs

Overall, current guidance on the pharmacological treatment of EDs is that medication is not an effective standalone treatment for eating disorders, and that it should be seen as an adjunctive treatment to refeeding and psychosocial interventions, or used to treat comorbidity if clinically indicated (BC, 2010; RANZCP, 2014; AACAP, 2015; NICE, 2017; Maudsley Guidelines (2015).

Anorexia nervosa

For adults, a recent meta-analysis of 18 RCTs found, with caution, that antipsychotic and antidepressants achieved no difference in clinical outcome when compared with placebo for AN, although some weight gain with hormonal treatment was noted (De Vos, 2014). Other guidance suggests a limited role for certain antipsychotic medications (RANZCP, 2012; AACAP, 2015). Generally, the current advice with regard to AN in adults is to reserve medication for refractory cases, those who are severely unwell, and those who have significant comorbidity (British Columbia MOH, 2010). Serotonin levels are decreased during starvation, and this may have a negative impact on the efficacy of SSRI antidepressants.

There is currently no strong evidence base around the use of psychotropic medication or hormonal treatments for anorexia nervosa in adolescents (Lock, 2015; NICE, 2017).

Bulimia nervosa and Binge Eating Disorder (BED)

High-dose SSRI medication (Fluoxetine, up to 60mg) is licensed for use in adults with BN and BED in Ireland, and it appears to have some effectiveness in reducing the urge to purge and binge (RANZCP, 2014; BC MOH, 2012). Topiramate has also been found to be effective as a second-line treatment in this group (McElroy, 2012), though it is not licensed for this purpose in Ireland. RANZCP (2014) guidelines suggest that pharmacological treatments can be used alone for adults when psychological treatment (in this case CBT-E) is not available. Other pharmacological agents are not supported in the clinical guidelines that were reviewed by the working group.

There is at present little evidence on the use of psychotropic medication to treat childhood BN or BED. CBT has been found to be superior to pharmacological treatment alone in adolescents (Lock, 2015; BC MOH, 2012).

Box 7.5: Key principles of pharmacological treatment in people with EDs

- Poor to low evidence base for AN in adults.
- If medication is used for BN/BED, it is as an adjunct to other evidence-based treatments.
- Treat comorbidity as per the clinical guidelines for that condition.
- Ensure that starvation is not mimicking the symptoms of other conditions such as anxiety, depression, Asperger syndrome, emotional regulation, rigidity or distress.
- Because of the high risk of medical instability in this clinical group, closer physical risk monitoring is required for all patients with EDs who are prescribed psychotropic medications.
- No evidence base for pharmacological treatment for ARFID, OSFED.
- No robust evidence base around pharmacological treatment of EDs in adolescents and children.

Table 7.9: Summary table of current best-practice recommendations on pharmacological treatment of EDs

	RANZCP (2014)	BC MOH/Canada (2010)	NICE (2017)	APA (2016 & Yager 2012)	DE VOS (2014) meta-analysis	Maudsley Guidelines (12th, 2015)	WFSBP meta-analysis (Aigner, 2011)	Cochrane (2006, 9, 15)	AACAP (2015)	ESCAP (2015)
Adults										
AN	Limited APT if no response Comorbidity	Comorbidity only & not first-line? OLZ/SGA is experimental so use only if severe	Not sole treatment	Adjunct only Refers to WFSBP	ADT/APT no effect? ? hormonal tx	Not recommended Comorbidity only	Olanzapine Zinc (B) Other APT (C)	ADT: inconclusive	NA	NA
BN	1. High-dose SSRI/FLX (to 60mg) 2. Topiramate	FLX 60 mg 'gold standard Then another SSRI, then Topiramate	Not sole treatment	Not alone ADT/ SSRI Combine with CBT	NA	Fluoxetine trial	TCA Fluox* Topiramate	NA	NA	NA
BED		Not alone	Not sole treatment		NA	SSRI	SSRI, Topiramate	NA	NA	NA
EDNOS		Not alone unless no other tx available. ? silbutrine if wt loss needed								
Children and adolescents										
AN		No evidence so use only as an adjunct/significant comorbidity Use those that are effective for adults	Not sole treatment	Adjunct only Refers to WFSBP		As above	Does not specify – mainly adult studies reviewed	As above	Limited e.g. comorbidity	Not as primary tx for comorbidity only
BN			Not sole treatment	• Not alone • ADT/ SSRI • Combine with CBT	NA			NA	No research	NA
BED			Not sole treatment		NA			NA	No research	NA

WFSBP = World Federation of Societies of Biological Psychiatry (Aigner,2011); Maudsley Guidelines (Taylor, 2015).

7.4.4: Medical interventions in ED treatment

The National Clinical Programme for Eating Disorders aims to work collaboratively and on an ongoing basis with the National Clinical Programmes for Acute Medicine, Paediatrics, Primary Care and Emergency Medicine, as well as with Consultants in liaison psychiatry and their teams. This is essential in order to ensure that people with EDs will have their medical needs met and to maintain their safety and recovery. This includes the collaborative development of integrated clinical pathways, guidelines, training and resources for professionals.

In reviewing the literature, the following guiding principles were noted in relation to the physical health of people with EDs.

- People with severe EDs are at substantial risk of physical harm and/or death, and may require urgent refeeding and medical stabilisation (See Section 2).

- Medical intervention has a central role in both the recognition and management of risk in EDs. Doctors who are likely to meet such patients include GPs, general and liaison psychiatrists, emergency medicine physicians, acute medical physicians, gastroenterologists, endocrinologists, adolescent health physicians and paediatricians, in addition to mental health clinicians in specialist ED services.

- The physical complications of ED treatment may be acute (e.g. medical destabilisation) and/or chronic (e.g. impaired growth, gastrointestinal, osteoporosis, delayed puberty, endocrine, anaemia, renal, fertility, etc.).

- For the majority of people with EDs, regular monitoring of their physical wellbeing can be conducted safely in primary care, outpatient psychiatric or medical settings, through regular weighing and monitoring of key physical parameters (see Table 7.3 and 7.4). They may also need support for any chronic comorbidity through outpatient medical, gastroenterology, endocrinology or paediatric clinics.

- A smaller proportion of people with EDs, particularly anorexia nervosa, will require medical admission in order to be medically stabilised, to initiate refeeding (including nasogastric refeeding) for acute malnutrition, or less commonly as a form of intensive treatment.

- A systematic integrated approach by clinicians to the physical risk management of patients with EDs, and particularly anorexia nervosa, is recommended in all of the clinical practice guidelines that were reviewed. The majority included specific care pathways and guidelines to assist clinical decision-making on when and where to admit (RANZCP, 2014; AACAP, 2005; Society of Adolescent Health and Medicine, 2015; RCPsych, 2012 & 2014; BCDOH, 2010, etc.).

- In terms of AN, the most widely known risk-management guidelines at this time are the MARSIPAN guidelines for adults (RCPsych, 2015) and the Junior MARSIPAN guidelines (2012) for under 18s. These guidelines use a checklist (and an additional traffic-light system for under 18s) in order to estimate risk assessment of acute medical instability and safety in a standardised way. This in turn supports collaborative and evidence-based decision-making by the various clinicians and teams e.g. where and when to admit (e.g. ICU, AMU, ward or psychiatric unit) and discharge. Such risk guidelines also provide direction on the initial assessment of people with anorexia nervosa, including the rapid exclusion of other conditions that can cause rapid weight loss e.g. diabetes mellitus, hyperthyroidism, coeliac disease, IBD, malignancy, etc.

- In the UK, trained ‘virtual’ MARSIPAN teams are now being established across the NHS, consisting of a consultant physician/paediatrician/gastroenterologist, consultant psychiatrist/consultant in liaison psychiatry and a senior dietitian, in addition to the medical nursing team. Such clinicians form as a ‘virtual’ team when an anorexia nervosa case presents to hospital as medically unstable. The team agrees a collaborative treatment plan that is communicated to the patient, family and staff, and charted in the patient’s notes. The principle of this model is to provide a comprehensive, integrated, multi-agency, and responsive approach to risk management, with clear patient pathways and close collaboration between clinicians, patient and parents/carers. The goal is patient safety and a reduction in deaths from EDs.

7.4.5: Refeeding of patients with restrictive EDs

- The refeeding process is the most essential part of treatment for restrictive EDs such as anorexia nervosa, and the 'food is a medicine' approach is a cornerstone of medical stabilisation and ED recovery.

- People with severe AN usually have poor cognitive function due to their starved state, and this often limits their ability to engage in psychological treatments.

- When there is no obvious other underlying physical illness, it is imperative that refeeding is not delayed. Box 7.6 summarises key principles of safe refeeding for adults, and Box 7.7 summarises those for children and adolescents.

- The clinical goals of refeeding are medical stabilisation and to achieve weight gain to a level that will enable healthy bodily functioning in order to recommence growth or menstruation, avoid ovarian or osteoporosis complications, etc. Table 7.4 displays healthy and unhealthy BMI categories for adults, and Table 7.5 displays the BMI % risk categories for under 18s. The healthy ranges in these tables are considered to be targets for refeeding, although some individual variance does occur (CDC, 2015; RCPsych, 2014).

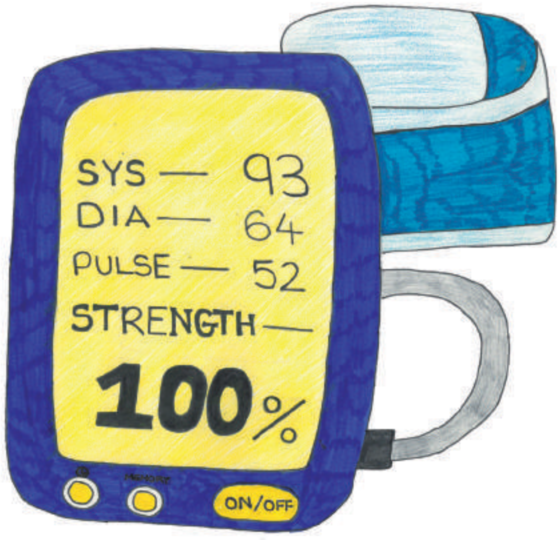
Children and adolescents

- In this age group, height as well as weight should increase during the treatment period because the child is still developing. Therefore, the child's target weight range will also change and increase over time and will need to be recalculated.

- The target BMI % is that needed for normal growth and for development to be restored. Lai (1994) found that menses resumed at an average of 96% weight for height but, as for most biological parameters, there is a normal distribution and therefore variation in this.

- Pelvic ultrasound scan can show whether uterine size and ovarian maturation has progressed (Allan, 2010). This may be a more sensitive marker than BMI% of return of hypothalamic-pituitary axis function in someone recovering from the effects of starvation. When pelvic ultrasound is not available, a target weight range of approx. 95% to 100% weight for height is generally recommended.

- Premorbid weight trends prior to the onset of illness area are useful in conjunction with estimated healthy weight range, in helping to determine when healthy bodily functioning is likely to recommence for each individual (Lask, 2007).



7.4.5.1: Refeeding syndrome

Refeeding syndrome is a rare but potentially fatal condition that can affect malnourished patients who have engaged in prolonged fasting in the early stages of refeeding. The person's metabolism switches from a catabolic to an anabolic state and, as a result of this flux, they may experience severe shifts in their fluid and electrolyte balance, particularly with regard to phosphate, potassium, magnesium and sodium, as well as glucose and other electrolytes (Mehanna, 2008). The drop in phosphate in particular can result in severe cardiopulmonary, neuromuscular and cognitive dysfunction. Symptoms include arrhythmia, cardiac failure, confusion, seizures and coma. Death can occur as a result of cardiac arrhythmia and failure, multiorgan failure and acute respiratory distress (Vignaud, 2010; SAHM, 2015). Refeeding syndrome also occurs in non-eating-disordered conditions that cause starvation.

Treatment of refeeding syndrome

The MARSIPAN (2014), Junior MARSIPAN (2012) and Society for Adolescent Health (2015) guidelines include detailed and specific recommendations on the identification and management of refeeding syndrome in severe anorexia nervosa and EDs. The NCPED recommends that the most up to date versions of these international guidelines be used as a reference by clinicians when refeeding care plans are being put in place.

7.4.5.2: Route of feeding

The preferred route for refeeding for all patients with EDs is the oral route (RCPsych, 2012 & 2014; AACAP, 2015; SAHM, 2015; RANZCP, 2014). It is therefore recommended in the first instance that all attempts be made to encourage the patient to re-establish their oral intake through a stepped, supported and managed eating plan.

7.4.5.3: Nasogastric feeding

Although oral feeding is the route of choice for refeeding of restrictive EDs, there is consensus that refeeding by a non-oral method may need to be considered in a small number of patients who have been unable to tolerate oral refeeding for physical or emotional reasons and who are medically unstable. The nasogastric ('tube') feeding route is the recommended route for non-oral refeeding for patients with anorexia nervosa (NICE full draft guidelines, 2016). Patient and parent/carer consent for this is crucial and, in the absence of either of these an appropriate legal framework should be considered (see Section 13). Key to this issue is the treatment setting and the training of nursing and medical staff. Appendix 2 contains references to key resources on nasogastric feeding and medical management of refeeding.

Box 7.6: Summary of International recommendations for the refeeding for adults with restrictive eating disorders

(See MARSIPAN Guidelines 2014 for complete advice; IRSPEN, Boland, 2013)

Outpatient

- Aim for a gain of 0.5kg per week (ESCAP 2015 reports 0.2-0.5kg).
- Use diaries and reference tables to calculate the person's calorie expenditure and make recommendations.
- Check baseline calorific intake, refeeding bloods and physical parameters including weight in order to determine the calorific increases that are needed.
- Monitor physical parameters for signs of instability, and refeeding syndrome.
- Weigh weekly to ensure that weight gain is on target, and graph progress.

- Monitor bloods as indicated by baseline results.
- For those at lower risk of refeeding syndrome, empower the patient to refeed in collaboration with their doctor/therapist and as part psychosocial treatment e.g. CBT.
- If not gaining weight over the first few weeks, consult with MDT/consultant. Consider a supplementary dietitian consultation.
- Avoid underfeeding (the person should aim to regain 0.5kg per week each week).
- Empower carers with meal coaching strategies and education so that they can support the refeeding.
- Even when physically stabilised, the person with the ED will require regular physical risk reviews by their doctor as part of their recovery plan so that signs of relapse and longer-term sequelae can be monitored (see Table 7.7 below).
- Encourage the patient to take an oral multivitamin and multimineral supplement until their diet is adequate to meet reference values (NICE, 2017). Consider the need for thiamine supplementation.

Intensive / inpatient / high risk of refeeding syndrome

- Aim for 0.5-1kg weight gain per week (RCPsych, 2014).
- MARSIPAN (2014) recommends an increase in intake of 20 kcal/kg/day in a specialist inpatient psychiatric setting (SEDU).
- Patients at high risk of refeeding syndrome or requiring medical settings may need to start at 5-10/kcal/kg/day, with a clinical and biochemical review every 12 hours (MARSIPAN, 2014).
- Use the hospital refeeding plan. Consult with hospital dietitian as soon as possible.
- Monitor for refeeding syndrome by:
  - Checking baseline physical parameters and monitoring daily for first 5 days.
  - Checking baseline refeeding bloods and monitoring them daily for first 5 days and then three times weekly until stable (Boland, 2013).
- Monitor weight twice weekly.
- Start supplementation of thiamine (200-300mg/day) and multivitamin immediately and for first 10 days of refeeding (Boland, 2013).
- Calorific increments are based on baseline intake and physical parameters, with dietetic consultation where available.
- Avoid underfeeding or overfeeding.
- Specific diet plans are recommended in consultation with specialist dietitian and responsible physician/psychiatrist.
- Consider the need for oral nutritional supplementation or NG feeding if patient is not restoring weight adequately.
- Continue to monitor for physical comorbidity as it arises. Once stabilised, empower the patient with meal coaching strategies to support their refeeding after discharge.

Box 7.7: Summary of international recommendations for the refeeding of children and adolescents with restrictive eating disorders

(See Junior MARSIPAN Guidelines, 2012, SAHM, 2015, ESCAP, 2015)

Outpatient

- Aim for a gain of 0.5kg per week (see review by ESCAP, 2015 which ranges 0.2-0.5) – 0.5kg gain may require up to 1,000 excess kcals per day in some cases.
- No clear consensus on starting calorie intake (international ranges are from 10- 40mg/kg/day). SAHM (2015) recommends a more aggressive approach.
- Avoid underfeeding and overfeeding (refeeding syndrome risk).
- Check baseline intake, refeeding bloods and physical parameters including weight to determine dietary intake.
- Monitor physical parameters for stability and refeeding syndrome, and weigh weekly to monitor whether weight gain is on target. Repeat bloods if indicated by baseline.
- Recommend multivitamin and multimineral supplement until intake is adequate.
- For those at lower risk of refeeding syndrome, empower parents to refeed their child, with doctor and as part of FBT/SFT/CBT-E programme.
- If not gaining weight over first few weeks, consult with MDT/consultant. Consider specialist dietitian consultation. For under-18s, consultation is initially with parents.
- Avoid underfeeding.
- Empower parents/carers with meal coaching strategies to support refeeding.
- Even when stabilised, children and adolescents will require a physical risk review by their doctor/psychiatrist every 6/52 as part of their biopsychosocial treatment plan to monitor for relapse and longer-term sequelae (QNED, RCPsych, 2016).

Intensive / inpatient / high risk of refeeding syndrome

- Aim for 0.5-1kg gain per week when admitted to inpatient/intensive treatment setting (RCPsych, 2012).
- No clear consensus on starting calorific intake. International ranges are from 10 to 40mg/kg/day. It should not be less than intake at admission.
- Obtain a dietetic plan/referral as soon as possible.
- Refeeding syndrome is most likely to occur within the first 4 days, but may occur up to a week. Monitor for refeeding syndrome by:
  - Checking baseline physical parameters and monitoring daily for first 5 days (J. MARSIPAN, 2012)
  - Checking baseline refeeding bloods and monitoring them daily for first 5 days and then three times weekly until stable
- Avoid underfeeding or unnecessary delays. Monitor weight twice weekly.

- Supplementation of thiamine (200-300mg/day) and multivitamin immediately before and for first 10 days of refeeding.
- Calorific increments are based on baseline intake, physical parameters, with dietetic consultation where available.
- Avoid underfeeding or overfeeding (review 12-hourly – MARSIPAN).
- Specific diet plans are recommended in consultation with specialist dietitian and responsible physician/psychiatrist.
- Consider the need for oral nutritional supplementation or NG feeding if patient is not restoring weight adequately.
- Continue to monitor for physical comorbidity as it arises.
- Once estabilised, empower parents and carers with meal coaching strategies to support ongoing refeeding after discharge.

Box 7.8: Identification of high risk of refeeding syndrome

(Ref: RCPsych,2012, SAHM, 2015, NICE 2016 (Draft)

- Very low weight (BMI <16) for adults or weight for height (<80% BMI) for <18 years
- Minimal or no intake for 3-5 days (<400-600kcals/day), exacerbated by compensatory behaviours
- Weight loss of >15% in last 3 months or fast rate of weight loss (0.5-1kg/week)
- Abnormal electrolytes (potassium, magnesium, phosphate) before refeeding begins (i.e. baseline bloods)
- Prior history of refeeding syndrome
- Neutropenia

7.4.6: Nutritional supplementation: vitamin and mineral supplements and meal supplementation

In general, nutritional supplementation is used on a case-by-case basis when clinical indicated following a full physical risk assessment including blood parameters with evaluation of fluid and electrolyte balance. Table 7.10 summarises the international consensus on the use of vitamin and mineral supplementation.

Oral nutritional supplementation (ONS) can be part of a refeeding plan, particularly in the following situations:

- When a patient is transitioning from nasogastric feeding
- During the early stages of refeeding (fluids may be more manageable for the patient initially but intake should also include solid food)
- When meals are not completed (the patient has the option to make up for lost calories with nutritionally complete ONS)
- When energy requirements are such that it is difficult to ingest a sufficient volume of food to continue weight regain (e.g. when the patient is approaching a healthy weight range)

It is recommended that the use of nutritional supplementation be discussed with a dietitian. Specific paediatric ONS should be used in the case of children.

Table 7.10: Summary table of current best-practice recommendations on the use of nutritional supplements for eating disorders

	RANZCP (2014)	Junior MARSIPAN	APA (2006 & 2012)	NICE guidance (2017)	AACAP (2015)	ESCAP (2015)	MARSIPAN (2014)
Age range	**All**	**<18**	**All**		**<18**	**<18**	**As clinically indicated**
Multivitamin		As clinically indicated		All	Consult dietitian	Lack of evidence noted	
Zinc			Grade B evidence	Multimineral supplement recommended for all patients with AN			
Phosphates	Adults: 500mg bd for 1 week						
Thiamine	Adults:100mg for 1 week						
Calcium							

7.4.7: Nutritional counselling

Nutritional counselling is recommended as a supplementary treatment to the psychosocial therapies as summarised above, but it is not an effective standalone treatment for eating disorders (RANZCP, 2015; BCMOH, 2010; NICE, 2017). However, expert consensus recommends that dietitians are a core part of ED teams and services as they can provide specialist nutritional counselling and support both to the multidisciplinary team and to people with EDs. For children and adolescents with non-complex EDs, dietitians may initially work indirectly via consultation and advice to the doctor and ED therapist who is providing FBT/CBT-ED. In the case of complex or severe EDs, inpatient and intensive daypatient settings, and for those at high risk of refeeding syndrome, or who are failing to gain weight or grow, etc., dietitians take on a more direct role in educating, supporting and empowering parents and advising them on the child's nutritional and growth needs.

Similarly, for adults with EDs, dietitians often work indirectly through the therapist e.g. during CBT-E, but they may also work directly with the person to help them to make changes and develop a collaborative nutritional care plan. Again, this nutritional counselling is done as part of a collaborative and comprehensive treatment plan. Specialist nutritional counselling is essential for anyone admitted to an acute medical setting for medical stabilisation and refeeding (see Box 7.6 and 7.7).

7.4.8: Treatment of osteoporosis

The consensus is that routine oestrogen therapy to treat low mineral density in children is not recommended, but that it may be appropriate in some cases for older adolescents and adult females. The use of bisphosphonates in adults has also been researched, with no overall consensus reported in the best practice guidelines at this time.

7.4.9: Other somatic treatments

- No clinical guideline that was reviewed recommended the use of other somatic treatments for EDs, based on the available research (e.g. Light therapy) (APA, 2012).
- The NICE guidelines (2017) do not recommend physical therapy such as transcranial magnetic stimulation, acupuncture, eye-movement desensitisation, weight training, yoga or warming therapy as part of treatment for EDs, based on the evidence available.

7.4.10: Physical exercise

Understanding the role of physical exercise in relation to eating disorders during treatment and managing exercise in the recovery of people with EDs is one of the challenges faced by treating clinicians. The pathological use and risk associated with excessive exercise as a symptom of the eating disorder must be balanced with the mood regulation and health benefits of exercise when patients are nearing normal weight.

In terms of treatment, a systematic review of the literature suggests that managed exercise may have a role in the later recovery from anorexia nervosa (Moola, 2013, Cook, 2016). However, no consensus on this role of exercise was addressed in the guidelines that were reviewed. The 2016 NICE draft guidelines made no recommendations in this area, although they suggest that the role of exercise in BED and BN be an area for future research. Weight training and yoga are not recommended in the 2017 NICE guidelines. The UK's Royal College of Psychiatrists has produced guidance for physiotherapists who encounter adult patients with anorexia nervosa and bulimia nervosa (Bentley et al for RCPsych, 2011), and this is recommended as a reference point for clinicians. For clinicians working with athletes with EDs, international consensus guidelines on 'return to play' are also available to assist in clinical decision-making in this area (Joy, 2014).

Current Service Description

The HSE's current model of service is that its eating disorder services are provided through its community mental health services.

8.1: Outpatiemt treatment

People with EDs currently receive their outpatient treatment through community AMHS (Adult Mental Health Service) and CAMHS (Child and Adolescent Mental Health Service) teams. There are also a few HSE clinicians with ED-specific roles nationally, for example in Sligo and in Dublin. The community AMHS and CAMHS teams are multidisciplinary, with every patient with an eating disorder having a named consultant psychiatrist. Recently, a small number of mental health dietitians have been recruited to specific AMHS and CAMHS teams. Their caseload includes, but is not specific to, ED treatment. ED-specific psychosocial treatments are available in some CAMHS and AMHS teams. However, while waiting lists for ED assessment have reduced in recent years, in many areas internal waiting lists have developed for psychosocial treatment including for EDs. This is a significant access barrier for patients in many areas of the country.

The HSE does not currently collect a comprehensive national clinical dataset on mental health or ED activity within the mental health service in Ireland on a regular basis. Therefore, comprehensive data on the national number of ED referrals, assessments, treatments offered, outcomes and waiting times is not available. However, It is known that access, services, treatment, waiting times and risk management vary widely across the country. A number of local ED service initiatives and examples of good practice are summarised in Appendix 3.

There is no activity data available on HSE outpatient services for over 18's with eating disorders. A HSE follow-up survey undertaken in 2016 of 62 clinicians who had completed HSE CBT- E training, two-thirds of whom were working in AMHS, found that 91% of those who participated reported that their AMHS team was treating five or fewer ED cases at that time.

In terms of under-18s, the annual HSE CAMHS survey undertaken each November provides the only indication of the amount CAMHS outpatient work with people with EDs, and this is taken only at a single point in time each year. In November 2015, 60 of the 62 HSE CAMHS teams who had returned data reported that EDs accounted for 278 (0.03%) of the patients who attended CAMHS nationally that month (Table 8.1). In 2016, a follow-up survey of training of 71 CAMHS clinicians from across the country found that multidisciplinary CAMHS clinicians reported a median of three current ED cases (range = 0-6 cases) that were open to their CAMHS team.

Table 8.1: Number of patients with EDs attending HSE community CAMHS in November 2014 & November 2015

	2014	2015
DML	85	80
DNE	48	48
South	82	68
West	106	82
Total no. of cases	321	278

Source CAMHS desk, 2016

8.2: Intensive, day, outreach and group programmes

There are no dedicated day, intensive treatment or outreach programmes for eating disorders currently in operation within HSE. A small number of local day/intensive-treatment programme initiatives take place nationally (see Appendix 3). In 2015, a number of HSE services in Dublin, Limerick and Cork collaborated with Bodywhys in providing PiLaR support groups for carers (see Section 11). A 10-day intensive multifamily group for anorexia nervosa (MFG-AN) also took place in 2015, and was attended by six families. These initiatives were supported from within existing AMHS and CAMHS services.

8.3: Inpatient treatment

The current model of care within HSE is that, when more intensive treatment and refeeding is needed than outpatient services can provide, the only other setting available for ED treatment is an inpatient setting.

Psychiatric admissions to HSE inpatient units

There are currently three dedicated psychiatric ED beds based at St Vincent's University Hospital for adults with eating disorders who are in need of psychiatric admission. In other parts of the country, adult patients are admitted to local general adult mental health units and attend generic inpatient treatment programmes. Nasogastric refeeding is not currently provided in psychiatric units in Ireland. The number of adult people with eating disorders who were admitted to inpatient psychiatric units in 2016 is displayed in Table 8.2.

For children and adolescents with EDs, inpatient psychiatric care is provided in the four regional inpatient adolescent units nationally in line with *A Vision for Change* (DOHC, 2006). There are no minimum or maximum numbers of ED beds in these units. EDs accounted for approximately 20.7% of cases admitted in 2016. In addition to access to generic inpatient group therapy and education programmes, specialised refeeding, dietetic, individual and family ED treatments are provided as part of ED programmes in these settings, including adapted forms of FT-AN, SFT, CBT-E and CRT. Nasogastric refeeding is not currently provided in the adolescent inpatient psychiatric units.

Table 8.2 provides data on inpatient admissions to the four HSE adolescent units in 2016. All but one were of voluntary status. Excluding those who were still admitted at the end of 2016 and so where it could not be calculated, the median age at admission in the 4 units was 15 (range = 12-17 years), and the median length of stay was significantly longer than for people with other psychiatric diagnoses at 112.5 days versus 49 days.

Other psychiatric admissions funded by the HSE

In addition to psychiatric admissions to HSE units, the HSE Treatment Abroad Scheme (TAS) approved funding for 12 out of 14 applications that it received between 2015 and 2017 to date. However, some of these may refer to more than one referral per case and the majority did not subsequently go ahead. The total cost to date of TAS for eating disorders is £1,596,733.21 between 2015-2017. Reasons given for TAU application by Consultants included the need for a specialised feeding programme and a specialised ED unit.

In some cases, treatment abroad for eating disorders is funded directly through local CHO mental health services rather than TAS. In 2015, this involved five patients (4 adolescent, 1 adult). Whilst final figures on cost are awaited, feedback from 5 CHO areas indicated a cost of 900,017 with €58,174 in family travel costs in that year.

Local CHO services also occasionally provide funding for admission to private/ independent inpatient eating disorder providers in Ireland when demand exceeds capacity. In 2015, this amounted to 12 cases, and 846 bed days. Figures for 2016 are awaited.

Medical admissions

People with EDs who are medically unstable and require medical admission for acute medical stabilisation, and those who require intensive initial refeeding, including nasogastric feeding, are admitted to HSE acute and general hospitals. There are currently no medical or paediatric consultant physicians or hospital-based dietitians with dedicated special-interest time in EDs in the HSE. There is no national care pathway in operation for transitions in and out of acute care, though some local initiatives based on MARSIPAN/JMARSIPAN are in operation or being piloted at St Vincent's Hospital Dublin, the National Children's Hospital, Sligo General Hospital, Wexford General Hospital and Cork University Hospital.

Table 8.3 summarises HIPE data for discharges of people with an ED (primary or secondary) from acute hospitals in Ireland in 2015. Figures 8.1 to 8.3 display the 10-year trends for discharge and length of stay of inpatients with eating disorders. There has been an increase in the annual number of children and adolescents under 18 with a primary diagnosis of an ED who are discharged from acute hospitals in the last decade: from 46 in 2006 to 93 in 2015 and 95 in 2016. The numbers for adults were stable until 2016, but rose from 62 in 2015 to 80 in 2016.

The median length of stay of under 18's with eating disorders in acute hospitals has been stable over the last decade, with a peak in 2010-2011. However, while the average length of stay for all ages has also been stable over the last decade (23.8 days in 2006 and 23.1 days in 2015), it is significantly longer than for other acute hospital diagnoses at discharge which was 12.3 days for other mental and behavioural disorders in 2015, and 5.7 days for all ICD dignoses (Table 8.4). The mean duration of admission in acute hospitals is generally longer for adults with EDs than for children, but the duration of admission for under-18s has risen in the last decade.

Table 8.2 Inpatient Psychiatric admissions and discharges of Adolescents with a Primary Diagnosis of an Eating Disorder in 2016

	No. of admissions (primary ED Diagnosis)	No of discharges	No. of Bed days* (all cases discharged in 2016)	Length of stay in 2016*
Facility	***Under 18 years (4 regional HSE units)***			
HSE child and adolescent units	34** (32 Female: 2 Male) (secondary ED Dx for 4 others)	30	4268	Eating disorders Median = 112.5 days Range = 1-319 days Mean = 125.52 days
General hospital psychiatric unit (adult)	1		Included in adult figures below	
HSE Total	35		4268*	All disorders Median = 49 days Mean = 66.52 days
Private Units	25			
Total (both)	60 (47 1st admissions) 4 M; 56 F			Median = 57 (all Dx) Mean = 54.96 (all Dx)

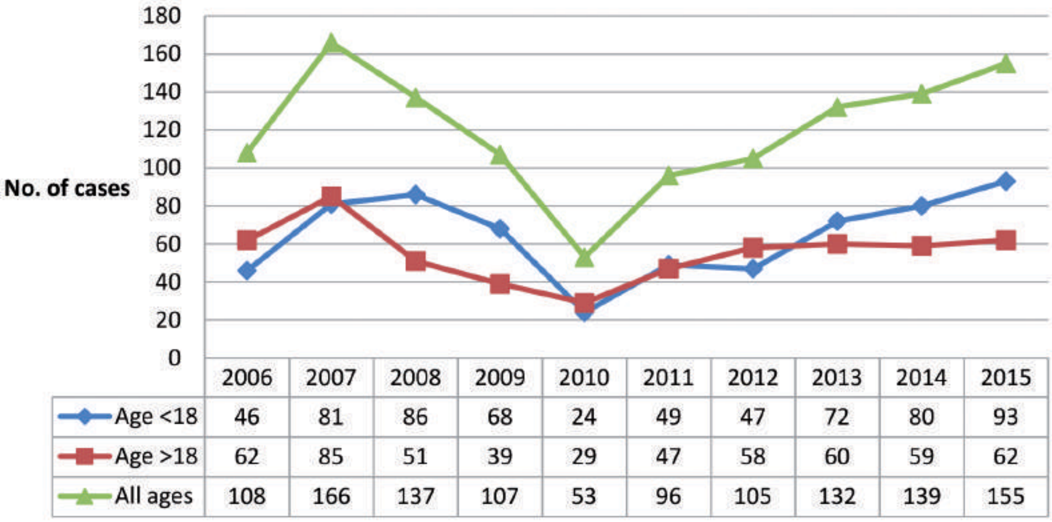
1 Source HSE CAMHS Audit, 2016 and HRB, 2016. * Bed days for patients not yet discharged were not included in this calculation.

Table 8.3: Inpatient Psychiatric admissions and discharges of Adults with a Primary Diagnosis of an Eating Disorder in 2016

	No. of admissions	No of discharges	No. of Bed days (all discharges)	Length of stay (all discharges)
	Private and HSE Hospitals			
General hospital psychiatric unit (adult)	149 (13 Male, 137 Female)	143 (129 of those who had been admitted in 2016)	6340	**Eating Disorders** Median = 34.3 days Mean = 44.3 days for all discharges Mean = 40 days for discharges of people admitted in 2016 **All Diagnoses** Median = 15 days Mean = 57. 7 days all discharges (Mean = 23 days for discharges of people admitted in 2016

Source HRB, 2017

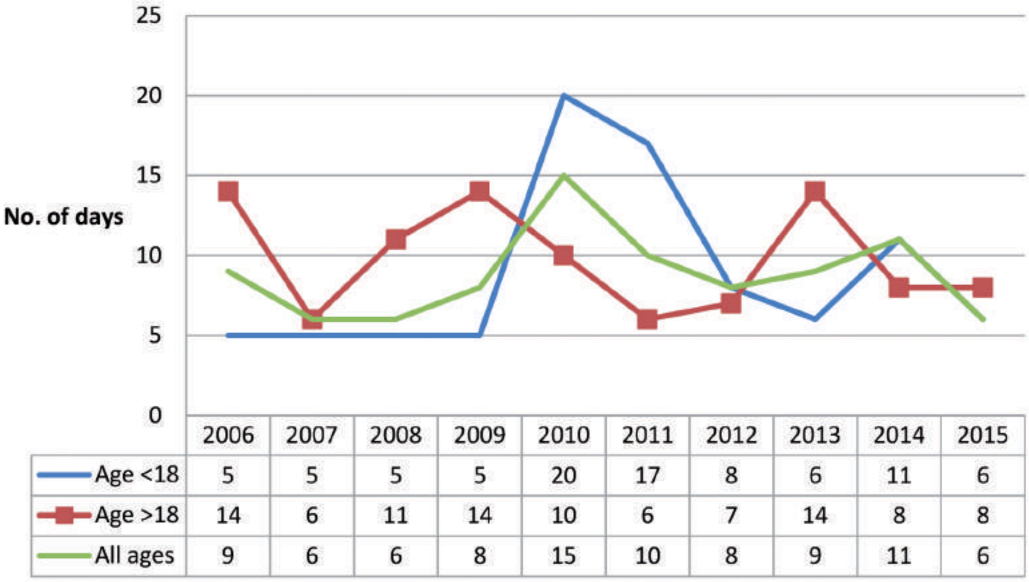
Figure 8.1: Number of discharges from acute hospitals of patients with a primary diagnosis of an eating disorder: 2006–2015



	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Age <18	46	81	86	68	24	49	47	72	80	93
Age >18	62	85	51	39	29	47	58	60	59	62
All ages	108	166	137	107	53	96	105	132	139	155

Source HIPE 2016

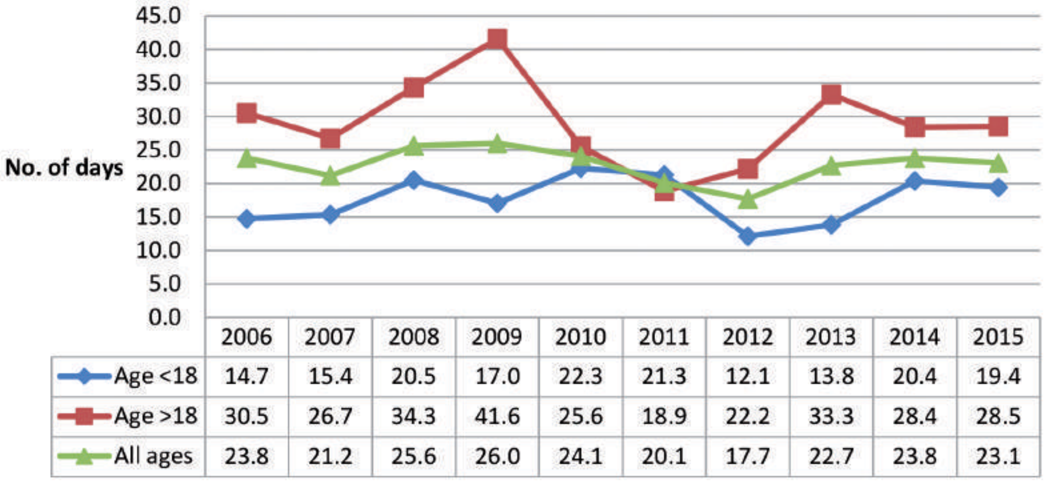
Figure 8.2: Median length of stay of patients with a primary diagnosis of an eating disorder in acute hospitals: 2006–2015



	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Age <18	5	5	5	5	20	17	8	6	11	6
Age >18	14	6	11	14	10	6	7	14	8	8
All ages	9	6	6	8	15	10	8	9	11	6

Source HIPE 2016

Figure 8.3: Mean length of stay of patients with a primary diagnosis of an eating disorder in acute hospitals: 2006–2015



	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Age <18	14.7	15.4	20.5	17.0	22.3	21.3	12.1	13.8	20.4	19.4
Age >18	30.5	26.7	34.3	41.6	25.6	18.9	22.2	33.3	28.4	28.5
All ages	23.8	21.2	25.6	26.0	24.1	20.1	17.7	22.7	23.8	23.1

Source HIPE 2016

Table 8.3: Total HSE Acute hospital discharges -any eating disorder (Primary and secondary diagnosis) (HIPE 2015)

All ED diagnoses

Age: < 18 years

Hospital	No. of discharges
OLHSC, Crumlin (<16 years)	25
Cork University Hospital	20
Mayo University Hospital	20
Temple Street Children's Univ Hosp (<16 years)	17
Tallaght Hospital	8
Wexford General Hospital	7
Beaumont Hospital	6
University Hospital Galway	6
Other HIPE*	36
Total	**145**

Primary diagnosis of ED

Age: 18+

Hospital	No. of discharges
Cork University Hospital	14
St Vincent's University Hospital	10
Other HIPE hospitals*	38
Total	**62**

Secondary/additional ED

Age: 18+

Hospital	No. of discharges
Cork University Hospital	19
St James's University Hospital	15
Tallaght Hospital	14
St Vincent's University Hospital	13
Midland Regional Hospital (Portlaoise)	7
Mater Misericordiae University Hospital	6
Beaumont Hospital, Dublin	6
Other	63
Total	**143**

* 'Other HIPE' includes HIPE hospitals that reported <5 discharges for EDs.

** Primary diagnosis is that recorded as chiefly responsible for the admission; secondary/additional is that coexisting or which arose during the admission.

8.4: Current HSE policy

In 2006, *A Vision for Change* recommended that the following resources be provided by HSE for patients with EDs:

- Adult services: 4 regional eating disorder teams; 24 inpatient beds nationally, located in association with those teams
- Child and adolescent services: 8 national inpatient ED beds in the National Children's Hospital. Other ED psychiatric admissions to the 4 regional inpatient adolescent units.

As outlined previously, in the intervening decade the landscape regarding best practice in ED service provision has changed substantially in line with the evidence that improved outpatient treatments for patients that lead to better clinical recovery. The *Vision for Change* proposals were inpatient-focused, and the purpose of this National Clinical Programme for Eating Disorders is to update the HSE vision for its ED service provision in line with international best practice, research and patient needs.

8.5: Workforce development and training

Since the establishment of the National Clinical Programme for EDs, a number of training initiatives have taken place with the aim of developing a workforce of clinicians within HSE who have specialist skills, experience and training in working with people with eating disorders.

Box 8.1: HSE workforce development strategy to date

1. FBT training: Progress

- 72 CAMHS clinicians: core training with Prof. J. Lock (2015)
- 1 CAMHS FBT supervisor trainee commencing in 2017
- National FBT training day for all of the above in 2016
- FBT group supervision network established in 2016 (8 groups nationally)
- Formal evaluation of the FBT training programme is ongoing

2. CBT-E training: Progress

- 63 CMHT and CAMHS clinicians completed CBT-E accreditation in 2013-4
- 2 advanced CBT-E training days were held for all with Prof Fairburn in 2015
- CBT-E supervision groups (7groups nationally) with CREDO supervision commenced in 2016
- National CBT-E training day 2016 for all CBT-E therapists
- Formal evaluation of the CBT-E training programme ongoing

3. ED CPD hubs: Progress

- 6 HSE ED CPD hubs are in operation nationally (Cork, Cavan/Monaghan, Limerick, Galway, Portlaoise and Sligo) since 2013

Box 8.2: Evaluation of the current HSE approach to ED service delivery

Strengths

- Local CAMHS/AMHS team provision enables local geographical access.
- ED services are built within the existing mental health infrastructure (staff, pathways, management). This requires less change or adaptation.
- Generic service may be better in cases of high comorbidity.
- Where FBT/CBT-E/ SFT is provided effectively in community teams, it works well for patients and families.

Weaknesses

- Poorer clinical outcomes for EDs are generally found in generic mental health services: longer duration, more expensive, less satisfaction, higher overall cost (Gowers, 2007).
- This has an impact on access for ED patients and for other patients – external and internal waiting lists.
- No existing day, outreach or intensive programmes – rapid escalation to medical or psychiatric admission leads to delayed access to bed and risk, delayed hospital discharges and increased cost.
- The local catchment areas in A Vision for Change are well below the recommended population threshold for teams to develop adequate ED expertise (25-50 cases per annum*).
- HSE staff who have taken FBT/CBT-E training report a lack of cases to develop their skills on, a lack of dedicated time, co-workers, and completing demands as barriers to developing expertise.
- There are long internal waiting lists for ED-specific psychosocial treatment in some areas.
- Practice varies around ED prioritisation, access, and admission thresholds.
- Practice around the choice of treatment offered varies (20-30% of variation in clinical outcome is known to depend on what is offered)**

* RCPsych 2012/NCCMH 2015; ** Waller (2016c, b)

A Stepped Model of Care

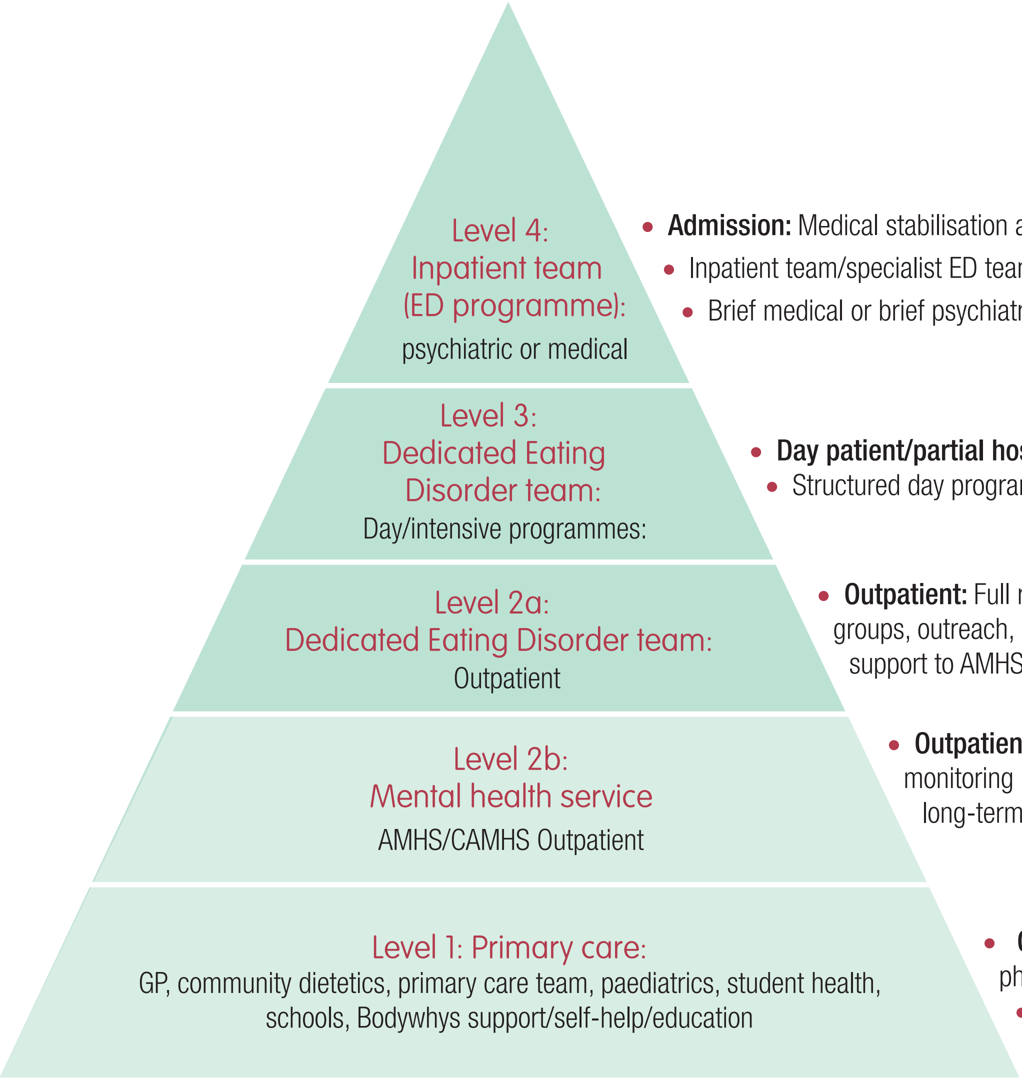
The right treatment for the right patient at the right time to achieve the best clinical outcomes

9.1: A stepped care model of service delivery

As summarised in Section 8, our examination of the international research and best practice indicates that a stepped care model provides the HSE with the best model for its delivery of services for those with EDs. Stepped care will enable the delivery of evidence-based care to patients with EDs when and where they need it.

Figure 9.1 illustrates the recommended stepped care model of care for HSE ED service provision in the future. It includes four levels of care setting, running from primary through to tertiary/inpatient care, with the aim of taking the patient from case finding and early recognition through treatment and then into stabilisation and recovery. This model is recommended for both HSE child and adult ED services. It envisages a lifespan approach to ED care, with both services working in parallel clinically (in line with Mental Health Commission guidelines), but collaborating closely on ED clinical pathways, supports, transitions, education and training, evaluation, clinical governance and research, both at CHO level and nationally. Sample pathways for adult and under-18s services are displayed in Figures 9.3 and 9.4 at the end of this section. Box 9.2 summarises the benefits and challenges of the stepped care model.

Figure 9.1: HSE stepped model of care for eating disorders



- **Admission:** Medical stabilisation and/or refeeding including NG
- Inpatient team/specialist ED team/liaison psychiatry team
- Brief medical or brief psychiatric admission

- **Day patient/partial hospitalisation**
- Structured day programmes, groups

- **Outpatient:** Full range of outpatient treatments, groups, outreach, supervision, consultation, advice, support to AMHS/CAMHS/GP as needed

- **Outpatient:** First-line treatment and monitoring in some locations, comorbidity, long-term support, stepdown

- **Outpatient:** Case recognition, physical risk monitoring
- Support, self-help, education

Box 9.1: Key components of the stepped care model

- Appropriate, personalised evidence-based advice, treatment and support is accessible to patients at each level of care
- Access to higher levels of care is dependent on risk and the effectiveness of previous levels in terms of sustainability. This is done through shared care, early intervention, consultation and timely access to treatment in order to minimise deterioration and escalation to inpatient care.
- The levels are not mutually exclusive; e.g. the GP remains involved as part of the team as patients move up and down the steps, as does the keyworker. Access to consultation is available from other levels (see below).
- Day programmes, groups and partial hospitalisation offer a structured but more enabling alternative to inpatient care.
- Specialist ED teams operating at levels 2a, 3 and 4 provide advice, support, and consultation to AMHS/CAMHS and to primary care. Care may be shared, for example, when a person is attending a local CAMHS/AMHS, but also requires dietetic or group intervention from the ED team
- Patients move up and down the levels of care according to their level of need, and remain at higher levels (e.g. day service) for the period that is clinically necessary.

Box 9.2: Benefits and challenges of the stepped care model

Benefits

- This model is supported by the current international best practice guidelines for ED treatment and services.
- Access to each level of care is guided by the assessment of physical risk and clinical need.
- The model promotes access to evidence-based treatment in a timely fashion in the most efficient setting in order to improve outcomes.
- It promotes recovery principles and provides for shared decision-making with service users on treatment options.
- It provides an opportunity for access to evidence-based interventions within a comprehensive, wraparound ED service.
- It provides the opportunity to develop seamless and fluid transitions between levels of stepped care.
- It alleviates service pressure at three key areas: in often overstretched generic AMHS/CAMHS where ED treatment takes much longer (e.g. external and internal

waiting lists), acute and psychiatric inpatient bed capacity demand, and delayed discharges.

- It allows for the development of sustainable expertise in EDs within HSE mental health services through the involvement of ED teams with larger catchment areas.
- Day/intensive treatment options are a less expensive step-up/down than extended inpatient care.

Challenges (see Section 12)

- As in other countries, the equitable provision of specialist services across Ireland is challenging in terms of geographical access and dispersed population areas (see Section 10).
- Additional staffing and resources are required, including some redeployment and backfilling of experienced staff with existing ED skills.
- It requires sustained leadership and negotiation with stakeholders at local and national level to ensure integration into other HSE programmes, strategy and services.
- It requires an adequate catchment area population size to develop workforce expertise and to be sustainable.
- Development of collaborative integrated care pathways with other stakeholders is needed – e.g. CAMHS/AMHS, primary care, paediatrics, acute hospitals, etc.
- It needs to be embedded within the mental health infrastructure.

9.2: Level 1: Primary care

Early case finding and identification of eating disorders is essential to improving clinical outcomes. The most common first point of contact with the health service for patients with EDs is through their GP. Given that internationally, most people with EDs never reach mental health services, GPs have traditionally had a key role to play, by default, in eating disorder care. In the comprehensive development of the HSE eating disorder service this must be taken into account; i.e. that Level 1 of any ED service provision is at primary care and community service level.

Collaboration with primary care will therefore be a key component of the provision of ED services. It will be a priority for the HSE Clinical Programme for Eating Disorders to jointly develop care pathways, resources and supports with colleagues in primary care and the National Clinical Programme for Primary Care. As well as the GP, Level one also includes community dietetics, the primary care team, student health services, psychology and community support organisations. The range of ED care provided at primary care level is outlined in Box 9.3.

It is essential that GPs and primary care teams are linked in with the other levels of the stepped care model of ED service delivery in an integrated fashion, and that they are supported by the ED network in their area so that their effectiveness can be enhanced. Integrated care will be supported though the availability of case consultation, toolkits and electronic supports, collaborative pathways, joint education and CPD initiatives, and opportunities for participation in local ED service development at CHO and national level.

Box 9.3: Level one: the key roles of the GP and primary care team

- Promoting and raising ED awareness in the community by displaying information on EDs and support groups (Bodywhys) in clinics, surgeries, etc.
- Consulting and case recognition of patients who presenting with possible EDs, including those presenting initially with secondary or comorbid physical issues.
- Providing basic education and advice, including referral for community dietetic advice and education on healthy eating, if appropriate.
- Shared decision-making with the patient on the risks and benefits of ED service and treatment options depending on patient needs, and making evidence-based recommendations.
- Monitoring of borderline or at risk cases.
- Supporting the patient to engage in self help which is evidence based.
- Onward referral to ED team, AMHS, CAMHS, acute medicine or paediatrics when clinically needed.
- Shared care with mental health services on physical risk components of the ED; GP knows the patient medical history, family, has access to lab, etc.
- Follow up when the recovered patient has been discharged from mental health services back to primary care.
- Liaison and consultation around patients with ED team and local community mental health services.
- Community supports to patients with SE-ED who are living alone and need home support.

Onward referral

- **When?**
  - Case recognition and physical parameters indicate that a full ED multidisciplinary assessment is now required (by ED-focused consultation, SCOFF questionnaire, physical parameters, risk assessment, etc.).
- **How?**
  - Liaison with coordinator of local ED or mental health service.
  - Use of a standardised referral form with key clinical risk information is recommended.

9.3: Level 2: Outpatient treatment

As indicated in Section 7, research indicates that the majority of patients with DSM-5 EDs can be treated at least as effectively in an outpatient setting as in an inpatient one. Key to this is having timely access to evidence-based treatment from outpatient clinicians and teams who are experienced in working with EDs (Gowers, 2006). Conversely, treatment as usual (TAU) at generic CAMHS has been associated with delayed recovery, longer attendance, more referrals onward, and therefore higher costs. After the acute phase of treatment, outpatient treatment for EDs is appropriate for patients who were previously at high medical risk, but are now in a stage of recovery or stabilisation. The core clinical recommendations for outpatient care for ED across the age range are outlined in Box 9.4 and 9.5.

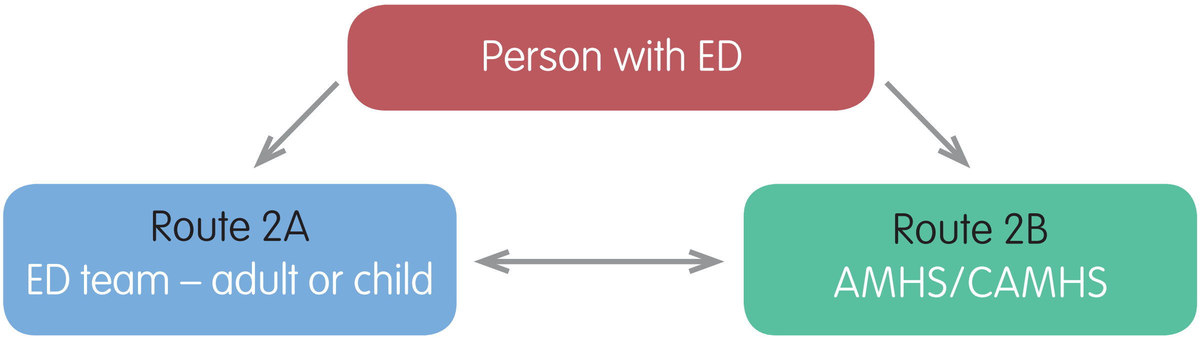
Taking into account the differences in catchment area size in Ireland between the average *A Vision for Change* AMHS/CAMHS team sector of 25,000 to 50,000, and the estimated catchment area population of 500,000 required for an eating disorder team to have enough numbers of clinical casework to develop expertise and run programmes (RCPsych, 2012; NCCMH, 2015), as well the issue of staff retention and geographical access, we recommend that outpatient treatment for EDs be available for patients via two routes: 2A and 2B below (Figure 9.2).

9.3.1: Level 2b: AMHS/CAMHS outpatient care

Where a CAMHS/AMHS team includes clinicians who have ED experience as well as training in first line evidence-based treatments for eating disorders (e.g. CBT-E and FBT etc.), local AMHS or CAMHS teams may be the appropriate and accessible service setting for patients with mild/moderate EDs or for those with comorbidity. This may also be the suitable option for people living in geographically remote regions of low population, who would otherwise have long distances to travel. In these cases, consultation and support will be available to the CAMHS/AMHS team from their section ED team (see below and Section 10).

Sustainability is a major limitation of this generic CAMHS/ AMHS model of service delivery for eating disorders. Feedback from clinicians to the working group indicates that issues such as retention and movement of ED-experienced staff, gaps in key clinical roles and a lack of referral volume have to date resulted in this route becoming untenable or unsafe in some HSE areas. The result is patchy services, delays in access to treatment or no treatment being available. This in turn can lead to escalation in patient risk, poorer outcomes, increased admissions, delayed inpatient discharges and inconsistent communication amongst clinicians. The practice of individual clinicians working alone on ED cases, however skilled, is not recommended due to the complexity, level of risk and variety of clinical needs with which people with EDs present.

Figure 9.2: Referral options for access to Level 2 outpatient ED treatment



To manage risk, it is recommended that, where a local CAMHS/AMHS team is providing a service for people with EDs:

- A key senior clinician from the AMHS/CAMHS team who has ED training and experience becomes the keyworker for the team for ED cases, and continues to co-work with the rest of their team to deliver treatment.
- If fewer than 10 cases are attending an AMHS/CAMHS team per annum and there is also no nearby ED team (see below), it is recommended that 2-3 AMHS or CAMHS teams co-work the ED caseload across a larger sector of the population than individual team catchment area size in order to retain expertise.
- In these two scenarios, clinicians are recommended to link formally with their nearest ED team (see Section 11) in order to access extra advice, consultation, resources, supervision, training and support.

9.3.2: Level 2a: Specialist ED teams – outpatient care

A number of dedicated adult and child ED teams will be established at key locations nationally in order to support the stepped care model of ED service delivery in HSE. These ED teams will operate at Levels 2, 3 and 4 of the stepped model of care – i.e. providing specialised outpatient, day-patient and inpatient care/support to people with eating disorders. In addition to this core clinical work (as described in Tables 9.1 and 9.2), these ED teams will support generic AMHS and CAMHS teams by:

- Providing consultation and support to CAMHS/AMHS and primary care in their sector (as described above).
- Enabling patients who are attending AMHS/CAMHS for treatment to gain access to 'add-on' groups, dietetic advice and other specialist ED initiatives in the area, although the patient in this case remains under the responsibility of CAMHS/AMHS for their overall care planning.
- Providing an alternative setting for specialist outpatient ED treatment if it is not otherwise available, when first-line outpatient treatment at CAMHS/AMHS has been ineffective, or when there is a high level of risk, complexity or severity.

The roles and responsibilities of the ED team at outpatient level are the same as those for AMHS/CAMHS (2b), but with an enhanced range of treatment options. Key to the effectiveness of this route will be the close collaboration between the ED team and generic AMHS/CAMHS team, through keyworker, consultant psychiatrists and at times, shared care arrangements around complex cases and those with comorbidity.

9.3.3: Early intervention

Early intervention is a cornerstone of this HSE model of care in terms of reducing the mortality and morbidity associated with EDs. A core component of the programme will therefore include the use of timeframes in order to ensure that services meet this need.

Recommended timeframes

- The ED team coordinator (Section 10.4.3) contacts the referrer and patient within 72 hours of receiving the referral.
- A decision is made on the level of risk and urgency based on the information gathered:
  - Assessment within 2-4 weeks depending on the clinical severity and risk in the individual case
  - Treatment starts within 2-4 weeks of assessment.
  - Information and advice about local support services, Bodywhys, useful books and information literature are provided for all cases while waiting for assessment or treatment – i.e. active waiting list management and empowerment of the person with an ED and/or their family.
- ***Risk advice: the ED team should be contacted and an earlier appointment be given if the patient deteriorates.***

Box 9.4: Level 2 a and b recommended guidelines for the outpatient care of adults with eating disorders (CAMHS & ED team)

Referral Stage

- Consultation provided to primary care as needed
- Coordinator contacts referrer within 72 hours
- Active waiting list support
- Screening for EDs within generic CMHT caseload
- Liaison within ED teams on case-by-case basis
- Liaison with acute medicine, emergency medicine, liaison psychiatry service, GP and AMHS services in transitions – e.g. medical admission, turning 18, etc.

Assessment Stage

- Multidisciplinary assessment within 2-4 weeks (Table 7.2)
- Involvement of family, carers, with permission
- ED-focused assessment – e.g. duration, severity, fears, methods, drive, body image, etc.
- Psychiatric assessment and mental state examination
- Screening for comorbidity
- Diagnosis based on DSM-5/ICD-11 criteria
- Comprehensive ED-focused physical examination and investigations (Tables 7.3 and 7.4)
- Evaluation of risk using MARSIPAN parameters
- Feedback/psycho education
- Signpost to support/Bodywhys

Treatment Stage

- Appoint keyworker
- Treatment starts within 2-4 weeks of assessment
- Evidence-based outpatient psychosocial, pharmacological, nutritional treatments available as per current standards (e.g. CBT E, CBT-ED, MANTRA, SSCM, IPT- BN, etc.) See section 7.
- Weekly weights initially
- Core team includes therapist, consultant psychiatrist, dietetic consultation, GP
- Regular core team case reviews
- Regular clinical outcome evaluation, including BMI
- Regular physical exam and risk monitoring MARSIPAN)
- Access to medical OPD/GP assessment when needed – physician
- Work with carers/family – coaching, support
- Home care – e.g. living alone, SE-ED and not able to travel
- Treat comorbidity – rest of MDT access

Discharge Planning Stage

- No ED: discharge back to Level 1
- Has ED – which setting?

  ? Severity

  ? Supports

  ? Local infrastructure

  ? Location
- If outpatient Tx is suitable: attends ED team or AMHS as per local arrangements
- Request enhanced support from ED team as clinically needed – e.g. dietetic consultation, group access, consultation, etc.
- Move to next level up if:
  - First-line treatment ineffective after adequate trial
  - Needs more structure than 1-2 appointments per week
  - Deteriorating

Box 9.5: Level 2 a and b recommendations for the outpatient care of EDs in children and adolescents (CAMHS & ED team)

Referral Stage

- Consultation to primary care as needed
- Coordinator contacts within 72 hours
- Active waiting list support
- Screening for EDs within generic CAMHS caseload
- Liaison within ED teams on a case-by-case basis
- Liaison with paediatrics, acute and emergency medicine, liaison psychiatry service, GP and CAMHS and AMHS services in transitions – e.g. medical admission, turning 18, etc.

Assessment Stage

- Multidisciplinary assessment within 2-4 weeks (Table 7.2)
- Involve family/carers, with permission
- ED-focused assessment – e.g. duration, severity, fears, methods, drive, body image, etc.
- Psychiatric assessment and mental state examination
- Screening for comorbidity
- Diagnosis based on DSM-5/ICD-11 criteria
- ED-focused physical examination and investigations (Tables 7.3 and 7.4)
- Evaluation of risk using Junior MARSIPAN parameters
- Feedback/psycho education
- Signpost to support/Bodywhys

Treatment Stage

- Appoint keyworker
- Treatment starts within 2-4 weeks
- Evidence-based outpatient psychosocial, pharmacological, nutritional treatments available as per current best practice (Section 7) – FBT, SFT, CBT-E etc.)
- Weekly weight initially
- Core team includes therapist, psychiatrist, dietetic consultation, GP
- Regular core team case review
- Clinical outcome evaluation, BMI
- Regular physical exam and risk monitoring (Junior MARSIPAN)
- Access to medical outpatient assessment when needed – paediatrician/medicine
- Work with carers/family – coaching, support
- Home care – not able to travel
- Treat comorbidity – rest of MDT

Discharge Planning Stage

- No ED: discharge back to Level 1
- Has ED – which setting?

  ? Severity

  ? Supports

  ? Local infrastructure

  ? Location
- If outpatient is suitable: attends either ED team or CAMHS team as per local arrangements
- Request enhanced support from ED hub as clinically needed – e.g. dietetic consult, group access, consultation, etc.
- Move to next level up if:
  - First-line treatment ineffective after adequate trial
  - Needs more structure than 1-2 per week
  - Deteriorating
- Refer to AMHS adult ED team well in advance of 18 years as per model of care recommendations

9.4: Level 3: Intensive treatment and day care

Day or partial hospitalisation programmes offer a more cost-effective alternative to inpatient treatment and are an effective step-up to more structured intensive treatment for patients for whom outpatient care has been ineffective after a trial of weekly sessions, or due to their level of illness severity (Section 7). Such programmes are also useful as a step-down from inpatient medical and psychiatric admission, and can thus assist in discharge planning.

In the HSE stepped model of care for ED services, Level 3 ED care will involve day and intensive treatment programmes. These will be delivered by the same dedicated ED team that provided care at Level 2a. Attendance at such programmes may be part-time or full-time, and programmes are generally time-limited, structured and intensive. Boxes 9.6 and 9.7 display details of such Level 3 programmes for adults and children. Group programmes are not evidence-based for younger children, and at this time it is recommended that Level 3 day programmes for under 18s be focused on adolescents. As treatment at this level may be short-term (e.g. a weekly group, or time-limited programme), it is recommended that the original AMHS/CAMHS team retain the lead role as primary service for their patient, if that patient is receiving their outpatient treatment from that service.

9.5: Level 4: Inpatient treatment

Level 4 is the most intensive treatment setting within the HSE Model of Care for people with eating disorders. It involves both psychiatric and medical inpatient admissions.

- Although there is good evidence that inpatient psychiatric care is not required for most patients with EDs, it is recognised that a small number of people, mainly with restrictive EDs, require inpatient care for short periods during their illness, for structured refeeding and/or stabilisation.

- In guiding the clinical decisions in such situations, based on the current literature, the HSE NCPED has endorsed the MARSIPAN and Junior MARSIPAN guidelines for adults and children with anorexia nervosa respectively. (RCPsych 2014, 2012). These risk-management guidelines help doctors determine an objective level of medical risk, and therefore to decide collaboratively which setting is most appropriate for the patient – inpatient acute medical/paediatric, psychiatric or outpatient.

- In the HSE Model of Care for eating disorders, each adult and child ED team in the HSE network will be linked with an acute medical or paediatric hospital in terms of medical admissions of patients with EDs.

- Psychiatric inpatient beds for EDs be collocated with acute hospitals in order to ensure smooth transitions and manage patient safety more effectively. Where this is not possible (e.g. the regional adolescent units), medical input to patients with EDs on the psychiatric ward will be formalised through sessional input from a paediatrician, youth health physician or physician with an interest in EDs.

- This clinical programme supports the formation of MARSIPAN and Junior MARSIPAN type ‘virtual teams’ in each hub of the ED network so that critical decision-making around medical stabilisation is rapid through local care bundles and pathways, including transfer arrangements. Such teams include the patient keyworker (plus an ED team member if the local ED team was not previously involved), ED psychiatrist, liaison psychiatrist (where available), physician or paediatrician/adolescent health physician, hospital dietitian and medical nurse managers or advanced nurse practitioners.

9.5.1: Medical admission of people with EDs

Medical admission is required when patients are identified as being at substantial risk of physical harm and/or death due to the physical causes of starvation and when urgent refeeding under medical observation is required. People with severe anorexia nervosa of very low weight or severe dietary restriction and high risk of refeeding syndrome, medically unstable bulimia nervosa, or comorbid physical disorder such as diabetes fall into this category (Box 9.8 and 9.9).

Box 9.6: Level 3: recommendations for day/intensive treatment programmes for adults with eating disorders

Assessment

- Assess as previously described (Section 7)
- Discharge to Level 2a or 2b if patient does not require or want an intensive treatment programme
- Requirements
  - Outpatient treatment has been inadequate in intensity or deterioration
  - High structure is needed
  - The patient is eating and commits to do so
  - Medical risk does not suggest inpatient admission is required (MARSIPAN)
  - Referral has come via ED outpatient or AMHS team on referral form and discussion has taken place on clinical appropriateness, goals and responsibilities
- As these programmes are time-limited (e.g. 8-10 weeks), case remains open to original team and keyworker in a shared care model
- Original keyworker continues to liaise with and support the patient and ED team

Treatments provided at level 3

- Time-limited programmes usually have up to 10 places (maybe more if part-time)
- Intensive refeeding programme/partial hospitalisation to include:
  - Some meals onsite in group
  - Weekly core team meeting
  - Weekly individual patient goals and therapeutic outcome evaluation
  - Weekly psychiatric review and risk management, including physical parameters and lab work
- Consultant physician consultation and review as needed (sessional)
- Dietitian consultation and advice
- Individual psychotherapeutic treatment based on most current evidence-based models (currently CBT-E, MANTRA, SSCM, CRT, IPT-ED, etc.)
- ED-focused group programme may include:
  - Psychoeducation
  - Cooking/meal preparation
  - Shared meals/coaching
  - Cognitive and emotional strategies – e.g. CBT, CRT, Mindfulness, RO, CREST
  - Body-image work
  - Occupational recovery goals, incl. return to school
- Individualised occupational therapy (e.g. for those with SE-ED)
- Carer interventions, incl. groups and carer-focused models (e.g. MANTRA)
- Treatment of some comorbidity related to the ED – e.g. anxiety, depression – or may be done via AMHS team through shared care
- Pharmacological treatment as appropriate
- For some EDs a once-weekly group programme to support outpatient care may be more appropriate (e.g. BN)
- Other less intensive group programmes to enhance outpatient work may be also co-facilitated or supported through Level 3 – e.g. SE-ED, carer workshops, etc.

Box 9.7: Level 3: Recommendations on day/intensive treatment programmes for adolescents with eating disorders

Assessment

- Assess as previously described (Section 7)
- Discharge to Level 2A or 2B if patient does not require or want an intensive treatment programme
- Requirements
    - Outpatient treatment has been inadequate in intensity or deterioration
    - High structure is needed
    - The patient is eating and commits to do so
    - Medical risk does not suggest inpatient admission is required (J.MARSIPAN)
    - Referral has come via ED outpatient or CAMHS team on referral form and discussion has taken place on clinical appropriateness, goals and responsibilities
- As these programmes are time-limited (e.g. 8-10 weeks), case remains open to original team and keyworker in a shared care model
- Original keyworker continues to liaise with and support the patient and ED team

Treatments provided at level 3

- Time-limited programmes usually have up to 10 places (may be more if part-time)
- Intensive refeeding programme/partial hospitalisation to include:
    - Some meals onsite in group
    - Weekly core team meeting
    - Weekly individual patient goals and therapeutic outcome evaluation
    - Weekly psychiatric review and risk management, including physical parameters and lab work
- Consultant physician consultation and review as needed (sessional)
- Dietitian consultation and advice
- Individual psychotherapeutic treatment based on the most current evidence-based models (FBT, FT-AN CBT-E (CBT-ED), CRT, MFT-AN, etc.)
- ED-focused group programme may include:
    - Psychoeducation
    - Cooking/meal preparation
    - Shared meals/coaching
    - Cognitive and emotional strategies – e.g. CBT, Mindfulness, RO, CRT
    - Body-image work
    - Occupational recovery goals, incl. return to school
- Individualised occupational therapy where needed
- Parent/carer interventions including groups
- Treatment of some comorbidity related to the ED (e.g. anxiety, depression) – or may be via CAMHS through shared care
- Pharmacological treatment as appropriate
- For some EDs a once-weekly group programme to support outpatient care may be more appropriate (e.g. BN)
- Other less intensive group programmes to enhance outpatient work may be also co-facilitated or supported through Level 3 – e.g. parent/carer workshops, etc.

Box 9.8: Level 4 – Recommendations for the inpatient medical admission of adults with eating disorders

Admission

Goal: Admit those who need it

GP, consultant psychiatrist, ED team or medical team recognise potentially severe medical risk

- Medical risk assessment using MARSIPAN guidelines – physical examination, bloods etc.
- Same-day consultation with ED team and MARSIPAN team (including liaison psychiatrist)
- Decision to admit, how and where – e.g. ward/AMU/ICU, (collaborative pathways – to be agreed by local subgroup)

Treatment

Goal: Medical stabilisation

- Composition of core MARSIPAN team agreed as previously described
- Collaborative care plan agreed
  - with patient/family
  - in the notes
- Immediate evidence-based refeeding plan instituted and scheduled
- Oral refeeding trial if at all possible (NG if needed)
- Daily medical review of risk of refeeding syndrome including bloods x 5 days (see Section 7)
- Biweekly weight and BMI calculation
- Minimum of weekly MARSIPAN core team meeting to update this plan and risk
- Daily dietetic consultation
- Regular consultant psychiatry, psychiatric reviews
- 1:1 support: keyworker sessions
- Support of the medical nursing staff by ED team to support and coach patient in refeeding
- Psychoeducational materials and activity given to patient appropriate to their cognitive ability (keyworker)

Discharge

Goal: Discharge as soon as patient is stable

- Decision to stay or discharge is under daily review by MARSIPAN team, based on medical stability
- Parameters for discharge are agreed, based on patient risk/safety in each setting
- Options: which level to discharge to?

  ? Level 2A: regional ED team
  - Is outreach needed?
  - General day hospital
  - Supported accommodation
  - 2B support?

  ? Level 3: Intensive ED programme

  ? Level 4: Inpatient psychiatric eating disorder bed

Box 9.9: Level 4 – Recommendations for the inpatient medical admissions of children and adolescents with eating disorders

Admission

Goal: Admit those who need it

- GP, consultant child psychiatrist, ED team or medical team recognise potentially severe medical risk
- Medical risk assessment using J.MARSIPAN guidelines – physical examination, bloods etc.
- Same-day consultation with ED team and J.MARSIPAN team including paediatric liaison consultant
- Decision to admit, how and where – e.g. paeds/IICU (collaborative pathways, to be agreed by local subgroup)

Treatment

Goal: Medical stabilisation

- Composition of core J.MARSIPAN team agreed as previously described
- Collaborative care plan agreed
  - with patient/family
  - in the notes
- Immediate evidence-based refeeding plan instituted and scheduled
- Oral refeeding trial if possible (NG if needed)
- Daily medical review of risk of refeeding syndrome including bloods x 5 days (see Section 7)
- Biweekly weight and BMI calculation
- Minimum weekly JMARSIPAN core team meeting to update this plan/risk
- Daily dietetic consultation
- Regular consultant child psychiatry/ psychiatric reviews
- 1:1 support: keyworker sessions
- Support of the medical nursing staff by ED team to support and coach patient in refeeding
- Psychoeducational materials and activity given to patient appropriate to their cognitive ability (keyworker)

Discharge

Goal: Discharge as soon as patient is stable

- Decision to stay or discharge is under daily review by MARSIPAN team, based on medical stability
- Parameters for discharge are agreed, based on patient risk/safety in each setting
- Options: which level to discharge to?

  ? Level 2A: regional ED team
  - Is outreach needed?
  - General day hospital
  - Supported accommodation
  - 2B support?

  ? Level 3: Intensive ED programme

  ? Level 4: Regional adolescent unit or NCH ED bed

9.5.2: Inpatient psychiatric admissions

- When treatment has been unsuccessful at outpatient (Level 2) and day-patient (Level 3) levels of care, a period of inpatient psychiatric admission may be the most appropriate setting for the patient to obtain ED treatment.

- This includes patients with:

  - severely low weight (e.g. < 75% BMI) but who don't require medical admission

  - comorbidity that requires inpatient psychiatric treatment

  - those who require 24 hours' structured refeeding and stabilisation

- The aim is to provide a short period of intensive refeeding and treatment so that the patient can stabilise enough to live safely at home and engage in a day or outpatient care plan.

- Brief admissions are particularly important for children and adolescents, where some of the most effective treatments such as FBT and CBT-E can only be delivered effectively when children are living at home and where parents are empowered to lead in supporting the refeeding and recovery of their child on a daily basis.

- Shorter psychiatric admissions protect family relationships more than longer admissions, and thus are important for the psychological development of adolescents.

The recommendations for inpatient psychiatric treatment are displayed in Box 9.10 and 9.11.

9.5.3: Eating disorder 'champions'

The National Clinical Programme for Eating Disorders (NCPED) has proposed a model of integrated service delivery in the HSE approach to ED service provision, which is new in involving acute hospitals and primary care as well as mental health services. The programme will require both national and local support to achieve its objectives and to be implemented effectively across the HSE.

In collaboration with other HSE clinical programmes, the NCPED plans to identify ED 'champions' or leads from across paediatrics and adolescent health, acute medicine, and primary care, at acute hospital network and CHO level. Their role will be to collaboratively support, educate, promote best practice and lead a focus on excellence in ED treatment in their respective departments at both clinical and at management level (see Section 12).

Box 9.10: Level 4 – Recommendations for inpatient psychiatric admissions of adults with eating disorders

Admission

Goal: Admit those who need it

GP/consultant psychiatrist, ED team or medical team recognise potential need for psychiatric admission:

- Failure of outpatient & day-patient treatment – more structure needed
- Psychiatric comorbidity requires admission
- Medically stabilised (MARSIPAN) but need 24-hour refeeding programme
- Brief respite
- Discuss with ED consultant
- Decision to admit if eating and medically stable, how and where (e.g. ED beds in the specified adult uni for this hub), formal pathways to be developed locally – see Section 10)

Treatment

Goal: Refeeding and psychiatric stabilisation

Composition of patient core team for this stay also includes the patient's original keyworker.

- Minimum of weekly core team meeting
- Collaborative care planning
- Recovery and discharge-focused weekly goals
- Early dietetic assessment and individualised structured refeeding plan
- Meal coaching
- Consider capacity for brief period of NG at mealtimes where needed and patient is medically stable
- Regular physical risk review including physical observations, examination and lab work (MARSIPAN)
- Access to physician consultation
- Weekly psychiatric review and MSE
- Carer support and engagement – access to Level 3 support group, meal coaching
- Keyworker support visits
- Individual evidence-based, ED-focused therapy if cognitively suitable – e.g. CREST, CRT, psychoeducation
- Groups – generic and specific if appropriate
- Treat any comorbidity

Discharge

Goal: Discharge to day programme as soon as ready

- Discharge is under daily/weekly review
- Parameters agreed by core team, based on patient need, bloods, safety in each setting
- Options: which other level of stepped care?

  ? Level 2a: Back to AMHS OPD treatment:

  – Is outreach needed?

  – Regional day hospital

  – Supported accommodation

  ? Level 2b: regional ED team – outpatient care

  ? Level 3: Intensive day programme, partial hospitalisations

  ? Level 4: Inpatient medical

Box 9.10: Level 4 – Recommendations for inpatient psychiatric admissions of children and adolescents with eating disorders

Admission

Goal: Admit those who need it

GP/consultant child psychiatrist, ED team or medical team recognise potential need for psychiatric admission:

- Failure of outpatient & day-patient treatment – more structure needed
- Psychiatric comorbidity requires admission
- Medically stabilised (J.MARSIPAN) but needs 24-hour refeeding programme
- Brief respite
- Discuss with ED consultant child psychiatrist
- Decision to admit if eating and medically stable, how and where (e.g. ED beds in regional unit or NCH 8-bedded ED unit), formal pathways to be developed by local hub – see Section 10)

Treatment

Goal: Refeeding and psychiatric stabilisation

Composition of patient core team for this stay also includes the patient's original keyworker

- Minimum of weekly core team meeting
- Collaborative care planning
- Recovery and discharge-focused weekly goals
- Early dietetic assessment and individualised structured refeeding plan
- Meal coaching
- If NG needed, consider NCH or paediatric/adolescent health physician, AMU transfer
- Regular physical risk review including physical observations, examination and lab work (J.MARSIPAN)
- Access to paediatric and physician consultation
- Weekly psychiatric review and MSE
- Parent support and engagement through SFT, meal coaching and prep for FBT at discharge
- Keyworker support visits
- Individual evidence-based, ED-focused therapy if cognitively suitable – e.g. CREST, CRT, psychoeducation
- Groups – generic and specific if appropriate
- Treat any comorbidity

Discharge

Goal: Discharge to day programme as soon as ready

- Discharge is under daily/weekly review
- Parameters agreed by core team, based on patient need, bloods, safety in each setting
- Options: which other level of stepped care?

  ? Level 2a: Back to CAMHS OPD treatment:

  – Is outreach needed?

  – Day hospital

  – Other community supports

  ? Level 2b: ED team – outpatient care

  ? Level 3: Intensive ED day programme, partial hospitalisation

  ? Level 4: Inpatient medical

  ? Level 4: NCH admission needed

Figure 9.3: Proposed care pathway for adults

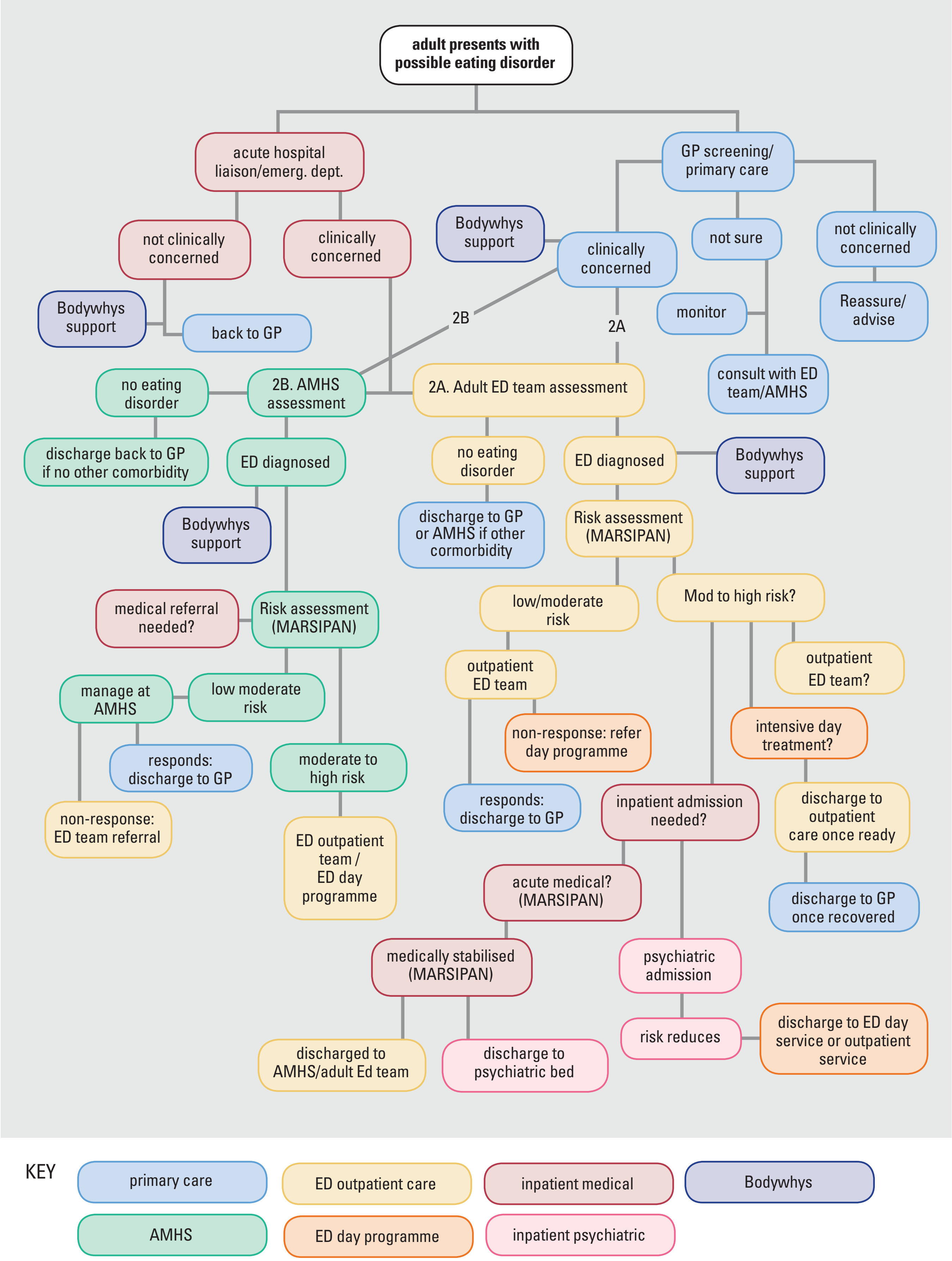
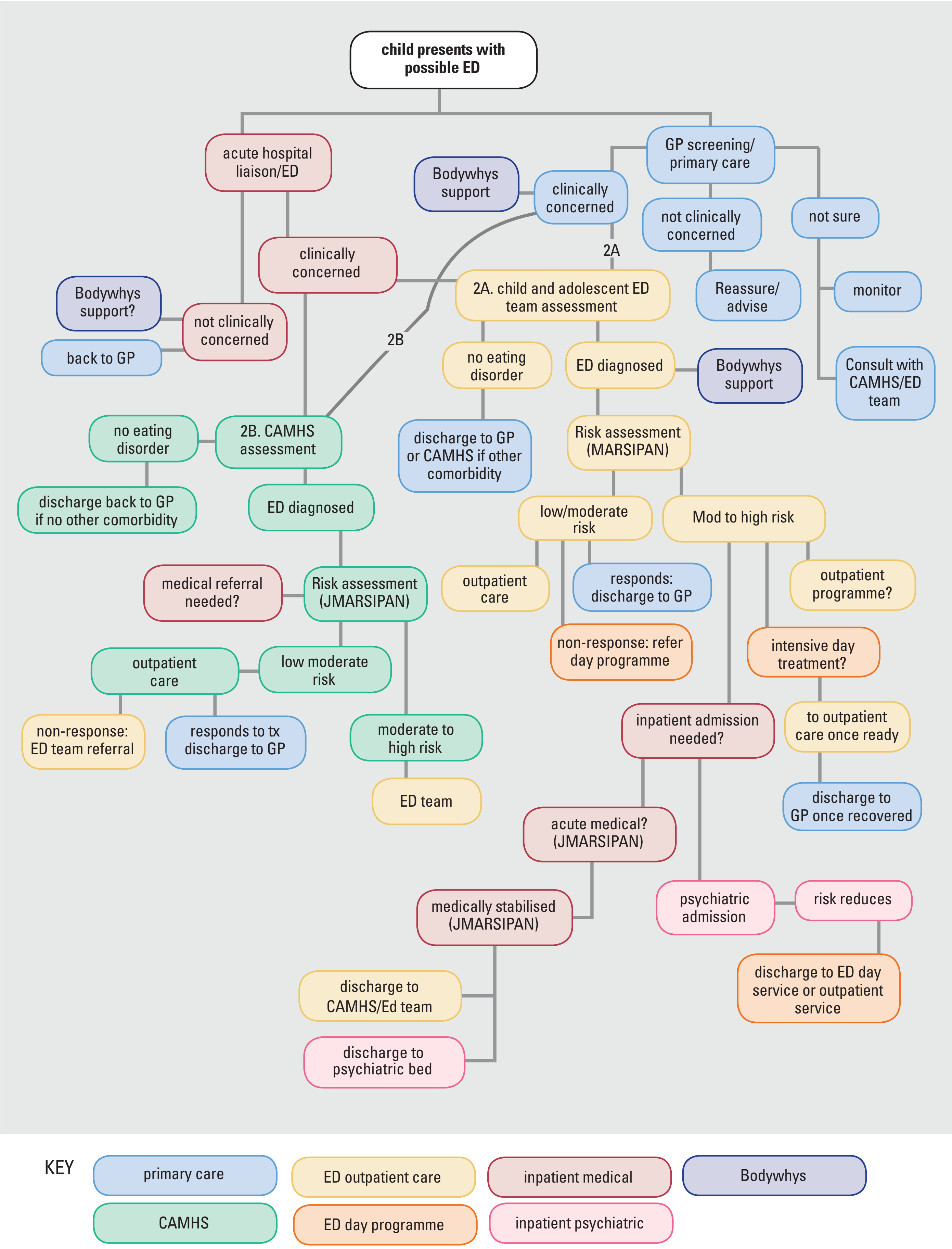


Figure 9.4: Proposed care pathway for children and adolescents



A National Clinical Programme for Eating Disorders

10.1: National ED network

The purpose of the HSE National Clinical Programme for Eating Disorders (NCPED) initiative is to ensure that people in Ireland with eating disorders receive evidence-based, accessible care from services that are sustainable in the long term. Therefore, it is recommended that the dedicated ED teams in each CHO area (adult and child) also form a local hub within a national ED network of HSE eating disorder teams in their area. This network is tasked with leading the delivery of the NCPED across the country. It will ensure a consistent approach to service delivery, so that people with EDs will have reliable access to evidence-based treatment at the level of care that they need, wherever they live. This approach also will also include national strategies on how to support community and inpatient CAMHS and AMHS teams at local and national level.

10.1.1: ED hubs and minihubs

All of the ED teams will be organised as follows:

- **ED hub teams:** These teams are located in large population centres with designated inpatient psychiatric ED beds, and comprise of a full adult and a full child ED team (Section 12). All levels of the stepped model of care for EDs are delivered by these hub ED teams – i.e. levels 2a (outpatient), 3 (day/intensive), and 4 (inpatient support and consultation).

- **ED minihub teams:** These teams are located in CHO areas which have less than the recommended population of 500,000. They do not have designated inpatient ED programmes or beds, and they refer to regional centres when an inpatient treatment programme is needed. The teams are proportionately smaller, and provide Levels 2a and 3 of ED care (outpatient and day-patient) on a full-time or part-time basis depending on need. Cases that require inpatient psychiatric admission have pathways to a linked inpatient unit with ED beds. However, the minihub ED teams otherwise operate independently of the hub teams, and take the lead for ED services in their own sector.

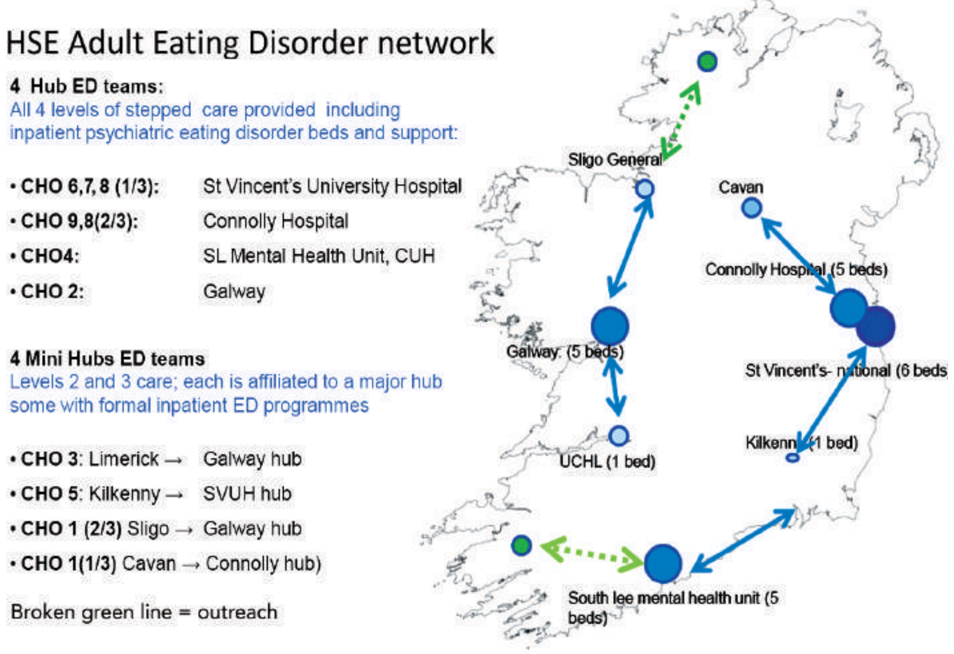
For adult services, each dedicated eating disorder team is therefore linked with the hub ED team that supports a unit with adult ED inpatient beds. For adolescent services, ED teams have direct links are through the regional adolescent units, as is currently the case for CAMHS teams. The reason that all hubs do not have psychiatric ED beds is that an adequate cohort of patients is required in order to deliver an effective eating disorder inpatient programme and to allow for inpatient staff to develop expertise.

Locations of the HSE ED hubs and minihubs have been chosen with reference to the following factors:

- Accessibility
- Size of population served
- HSE ED capacity and specialism in the CHO area
- Current referral patterns and pathways
- Geographical size and spread of the population served
- CHO area and configuration
- Acute hospital network configuration
- Presence of other independent sector providers of ED services

The locations of the adult ED teams are displayed in Figure 10.1 and in Table 10.1. The locations of the child and adolescent ED teams are displayed in Figure 10.2 and in Table 10.2. The child and adolescent ED network will also include eight national ED inpatient beds that were proposed in A Vision for Change (2006), and which will be located in the adolescent psychiatric unit in the new National Children's Hospital.

Figure 10.1: Dedicated eating disorder service network for adults



HSE Adult Eating Disorder network

4 Hub ED teams:
All 4 levels of stepped care provided including inpatient psychiatric eating disorder beds and support:

- **CHO 6,7,8 (1/3):** St Vincent's University Hospital
- **CHO 9,8(2/3):** Connolly Hospital
- **CHO4:** SL Mental Health Unit, CUH
- **CHO 2:** Galway

4 Mini Hubs ED teams
Levels 2 and 3 care; each is affiliated to a major hub some with formal inpatient ED programmes

- **CHO 3**: Limerick → Galway hub
- **CHO 5**: Kilkenny → SVUH hub
- **CHO 1** (2/3) Sligo → Galway hub
- **CHO 1**(1/3) Cavan → Connolly hub)

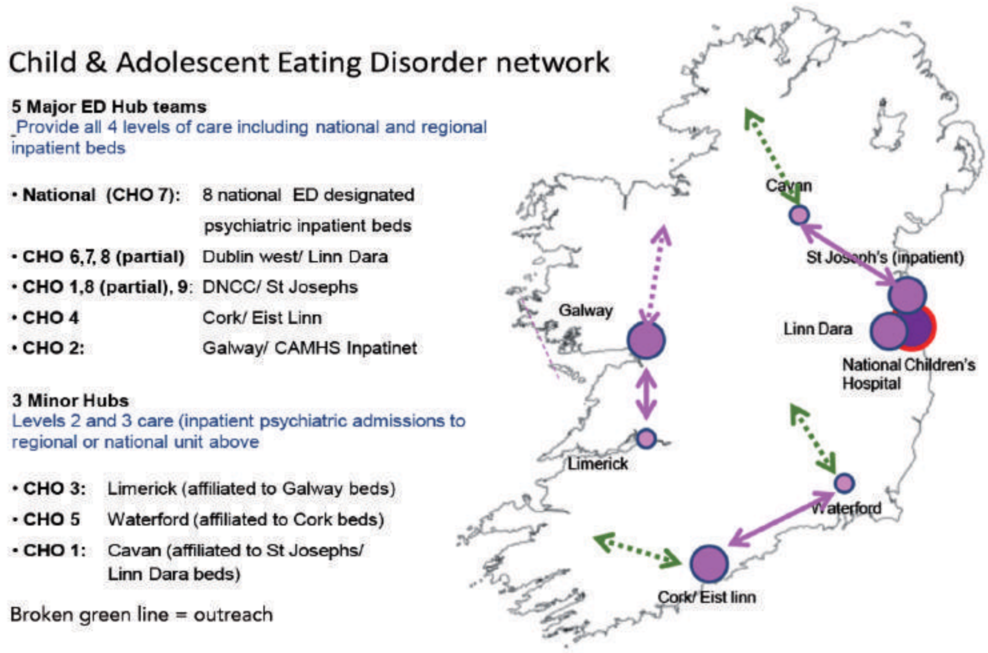
Broken green line = outreach

Table 10.1: National adult ED network by CHO

ED hub or minihub team	**Total pop. AMHT 18-65 yrs** (2016 census)	**Psychiatry beds (acute hospital)**
CHO 1: Sligo/Leitrim/Donegal/Cavan-Monaghan • **Sligo ED minihub** • **Cavan minihub with outreach to CHO 9**	394,333	GUH (5 beds) Connolly Hospital
CHO 2: Galway/Roscommon/Mayo • **Galway ED hub**	453,109	GUH (5 beds) (Acute hospital link: GUH)
CHO 3: Limerick/Clare/North Tipperary • **Limerick ED minihub**	384,99	1 short-term bed at LUH ** Long term >> GUH
CHO 4: Cork and Kerry • **Cork ED hub**	690,575	5 beds at SLMHU (Acute hospital link: CUMH)
CHO 5: South Tipp/Carlow/Kilkenny/Wexford/Waterford • **Kilkenny ED minihub**	510,333	1 short-term bed ** Long-term >>(SVUH or SLMHU)
CHO 6: Dublin South-East and Wicklow (SVUH) • **ED hub –extended team** also covers CHO 7 and part of 8	445,590	6 at SVUH (Acute hospital link: SVUH)
CHO 7: Dublin South-West and Kildare • Covered by the CHO 6-based extended ED hub team	645,293	SVUH
CHO 8: Laois, Offaly, Longford, Westmeath • Laois/Offaly to be covered by CHO 6 ED hub • Longford/Westmeath, Meath and Louth to be covered by CHO 9 ED hub	616,229	SVUH Connolly Hosp.
CHO 9: North Dublin and Dublin North City MHS • **North Dublin ED hub** also covers part of CHO 8 North Dublin also covered by CHO 1	621,405	5 beds at Connolly Hospital (Acute hospital link: Connolly)

* All psychiatric beds are collocated with an acute hospital with AMU/ICU.** The beds in LUH and SLH are for local respite/short-term use. If longer-term admission is needed, transfer to a psychiatric unit with an inpatient ED programme is recommended. Attendance at local intensive day programme may also be an option. CHO 5: if Kilkenny, link with Dublin; if Waterford, link with Cork.

Figure 10.2: Dedicated eating disorder service network for children and adolescents



Child & Adolescent Eating Disorder network

5 Major ED Hub teams
Provide all 4 levels of care including national and regional inpatient beds

• **National (CHO 7):**	8 national ED designated psychiatric inpatient beds
• **CHO 6,7, 8 (partial)**	Dublin west/ Linn Dara
• **CHO 1,8 (partial), 9:**	DNCC/ St Josephs
• **CHO 4**	Cork/ Eist Linn
• **CHO 2:**	Galway/ CAMHS Inpatinet

3 Minor Hubs
Levels 2 and 3 care (inpatient psychiatric admissions to regional or national unit above

• **CHO 3:**	Limerick (affiliated to Galway beds)
• **CHO 5**	Waterford (affiliated to Cork beds)
• **CHO 1:**	Cavan (affiliated to St Josephs/ Linn Dara beds)

Broken green line = outreach

Table 10.2: National child and adolescent ED network by CHO (under 18 years)

Hub/Minihub Sector	Total pop. CAMHS (2016 census)	Psychiatry beds (acute hospital)
National: Psychiatric unit in NCH (Linn Dara**) • ED hub team- service to Dublin sectors 8 national beds	National CHO 7/all	National ED beds Up to 18 years 8 ED-dedicated beds (Acute link: onsite NCH)
CHO 1: Sligo/Leitrim/Donegal/Cavan-Monaghan • Outreach to Donegal from Galway minihub • Cavan/Monaghan ED minihub	394,333	CAMHS Inpatient Unit Merlin Park (GUH link)
CHO 2: Galway/Roscommon/Mayo • Galway ED hub	453,109	CAMHS Inpatient Unit Merlin Park (Acute link with GUH)
CHO 3: Limerick/Clare/North Tipperary • Limerick ED minihub	384,998	CAMHS Inpatient Unit Merlin Park
CHO 4: Cork & Kerry • Cork ED hub	690,575	Eist Linn adolescent unit (Acute hospital link: CUH)
CHO 5: South Tipp/Carlow/Kilkenny/Waterford/Wexford • Waterford ED minihub	510,333	Eist Linn adolescent unit
CHO 6: Dublin South-East and Wicklow* • Covered by the CHO 7 Linn Dara ED hub (below)	549,531	Linn Dara adolescent unit
CHO 7: Dublin South-West and Kildare* • Linn Dara ED hub team- extended** Also covers CHO 6 and part of 8	541,352	Linn Dara adolescent unit (Acute hospital link NCH, Connolly)
CHO 8: Laois, Offaly, Longford, Westmeath • Laois/Offaly to be covered by Linn Dara hub • Longford/Westmeath, Meath and Louth to be covered by CHO 9 hub	616,229	Linn Dara / St Joseph's (Tallaght/NCH)
CHO 9: North Dublin and Dublin North City MHS • North Dublin ED hub (also covers part of CHO 8) North Dublin also covered by CHO 1 minihub	621,405	St Joseph's (NCH, Beaumont)

* The variance in the total populations CHO 6 & CHO 7, reflects the current coterminous anomaly between specialities.
** Linn Dara ED team will also be supported by NCH-based HSE hub. NCH unit is an approved centre linked with Linn Dara Services.

10.2.1: People living in remote areas

- People living in isolated areas or at distance from large population centres have more difficulty accessing any type of specialist service. This can be particularly difficult for patients with EDs because they may be physically compromised whilst also requiring weekly or twice-weekly acute treatment. For adolescents, it may not be feasible for the entire family to travel long distances regularly for FBT or SFT treatment sessions.

- In such cases, the balance of risk and feasibility may mean that their outpatient treatment for EDs should be delivered by the local AMHS/CAMHS team so that they can receive accessible, regular, safe care (Level 2b care).

- In such cases, it is essential that the CAMHS/AMHS team have access to support from their local ED team. This may be in the form of consultation, training, telemental health, virtual medicare (see below), access to ED groups, and outreach clinics such as dietetics, etc.

- In such cases, the core team and keyworker for the case will be from their local generic CAMHS/AMHS team (Level 2b care).

10.2.2: Telemedicine, telemental health and virtual medicare

- A key role of the ED team will be to support generic AMHS and CAMHS where they are delivering ED care.

- Telemedicine and virtual medicare maximise the opportunity for clinicians working in generic mental health services to 'meet' remotely and be supported by the ED hub team for clinical, supervision and other support. It maximises access for clinicians and minimises non-clinical time used in travelling. It is also useful for communication with teams in acute hospital and distant inpatient facilities about referral, care and discharge planning (Vaitheswaran, 2012).

- Telemental health has been enacted effectively for some new mental health initiatives for remote communities in Scotland (Millar, 2009). Although research is limited, from a patient perspective feasibility and acceptability are reportedly high, and some patients prefer it to long commutes. It has also been associated with lower financial costs and clinical time commitment due to reduced need for the clinician to travel.

- However, telemedicine may not be suitable for some people with EDs when frequent weighting, monitoring, etc are essential. Local arrangements may therefore be needed in such cases, including with GP's in primary care.

- The National Clinical Programme for EDs (NCPED) will explore the feasibility and cost of telemedicine/virtual medicare for key geographical areas of low population density (e.g. Donegal, Kerry). Both local CAMHS/AMHS and ED teams will require training and infrastructure in order to maximise its potential for regular effective use.

10.3: ED hub/minihub working

- The core units for delivering the model of care for EDs in each area/CHO will be the ED adult and child eating disorder teams (Figures 10.1 and 10.2).

- To maximise the effectiveness and development of the NCPED in each CHO, it is recommended that adult and child ED teams work collaboratively and in an integrated fashion, as an 'eating disorder hub' in each area. This will also assist transitioning of adolescents from child to adult services. (Figure 10.3).

- It is recommended that the adult and child ED teams in each hub or minihub hold a business meeting regularly (at least quarterly) to discuss and develop ED services in their area or CHO in the following areas of clinical governance:
    - ED service strategic planning within their CHO/sector in collaboration with the Executive Clinical Director, Mental Health Lead, and area management team
    - Development of consistent care pathways with other services and referrers (primary care, acute hospitals, inpatient and between adult and child services) where feasible.
    - Involvement and collaboration with service users, including with the national ED support group, Bodywhys.
    - Development of MARSIPAN and J.MARSIPAN teams in collaboration with staff in the local nominated acute hospital – there should be consistency of framework where possible, particularly in the context of the 16/17-year-old age group.
    - Local communication strategies about EDs for service users: leaflets, website and resource development

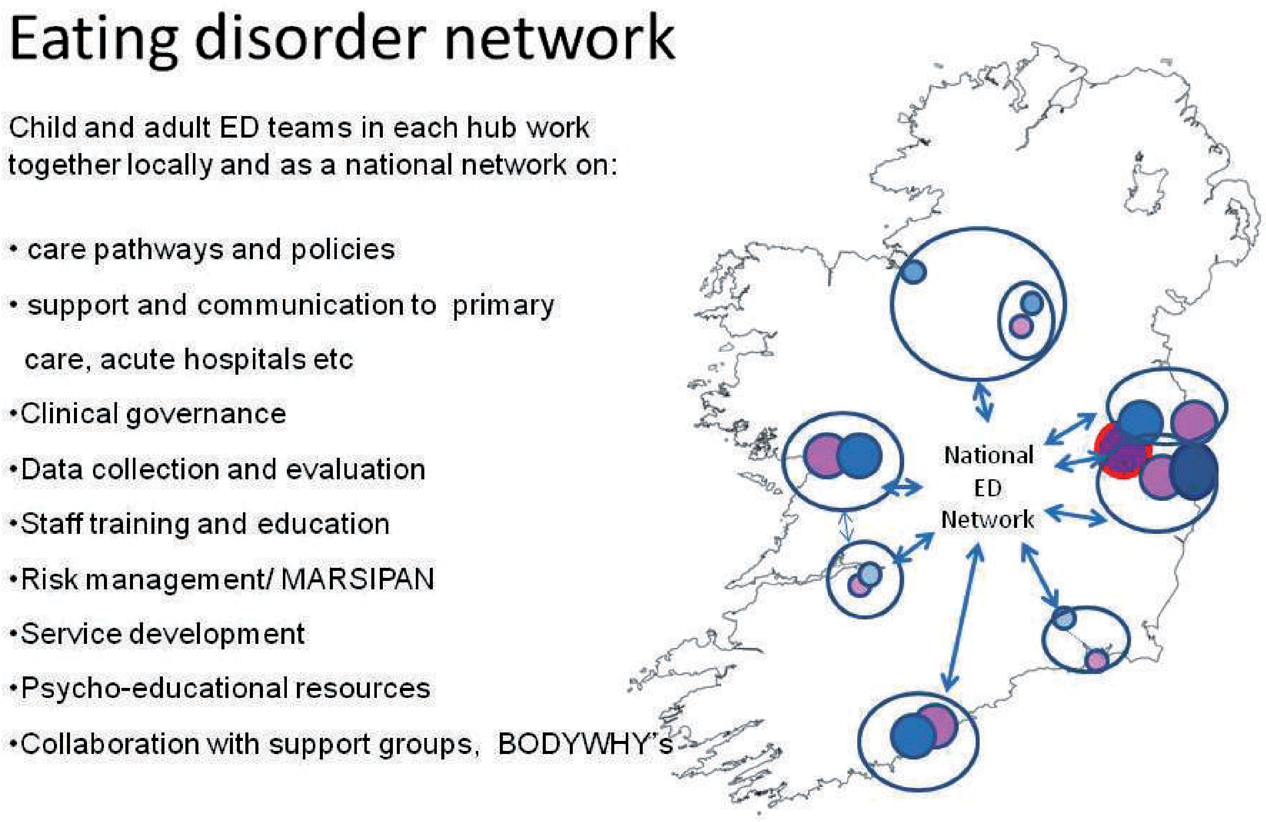
  - Metrics and evaluation of the ED service/hub: shared learning and improved reliability though local experience and data
  - Risk-management strategies
  - ED service innovation and projects
  - Collaboration with the national ED network
  - Research initiatives

- It is also recommended that teams hold a monthly meeting to discuss transfer of upcoming cases from child to adult services. This process should be commenced at 17.5 years, in order to plan for seamless and strategic transfer and handover at 18th birthday.

- To optimise collaborative care, it is recommended that adult and child ED teams collaborate in interprofessional education, training initiatives and CPD activities where they overlap (see Section 15). A monthly internal ED CPD session is recommended as a minimum for each hub.

- Community AMHS and CAMHS teams who are also delivering ED treatment in their area should be included as part of this extended ED hub in each CHO area in terms of attendance at such educational meetings and CPD initiatives (Figure 10.4).

Figure 10.3: National adult and child network of ED hubs and teams



Eating disorder network

Child and adult ED teams in each hub work together locally and as a national network on:

- care pathways and policies
- support and communication to primary care, acute hospitals etc
- Clinical governance
- Data collection and evaluation
- Staff training and education
- Risk management/ MARSIPAN
- Service development
- Psycho-educational resources
- Collaboration with support groups, BODYWHY's

Figure 10.4: Eating disorder 'hubs' and their interfaces

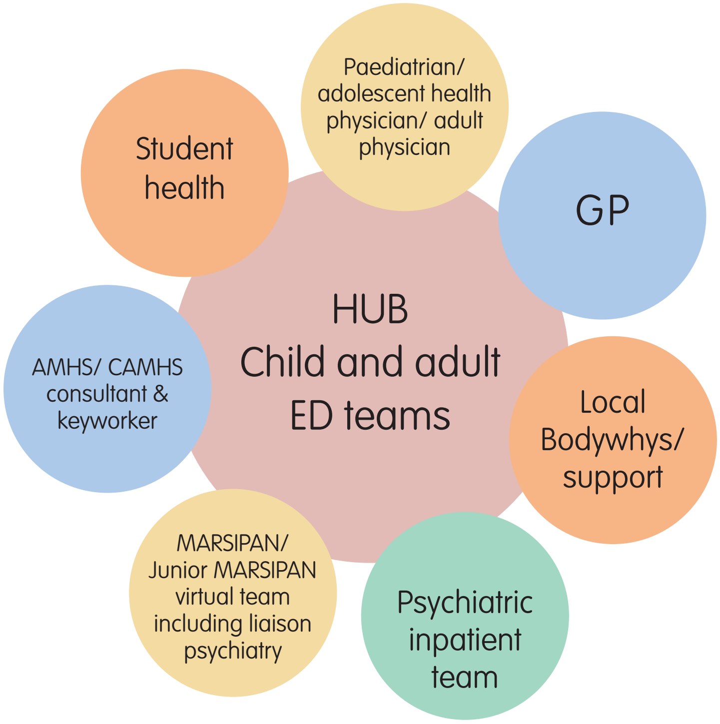
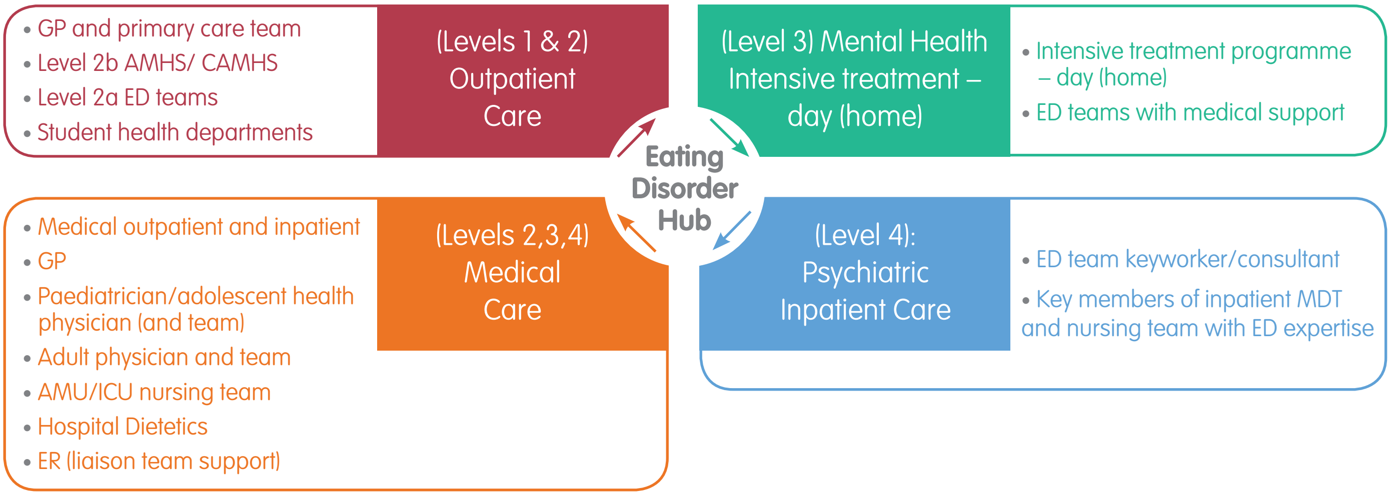


Figure 10.5: ED hub roles and responsibilities in each CHO area

- Develop local ED care bundles, procedures and pathways
- ED advice, consultation & support
- Clinical assessment, diagnosis and treatment
- Risk management
- Collaboration with local AMHS/ CAMHS
- Liaison with local services
- Service user participation
- Evidence-based approach
- Support ED training and clinical supervision for EDs
- Service and clinical outcome evaluation, data collection and audit
- Clinical governance
- Case management
- Research
- Constructive collaboration with national ED network
- Maintain a recovery ethos

Figure 10.6: Clinicians delivering the model of care



Box 10.1: Key components of each ED hub (minihub)

- Each ED hub consists of the adult and child ED teams working in a particular geographical area, and also includes other key service providers such as paediatricians, physicians, liaison psychiatrists, local GP lead or representative, Bodywhys representative, service user representative, etc.
- The ED hub aims to work seamlessly across the different levels of the stepped care model
- The ED team works in an interdisciplinary way where feasible and safe – i.e. in addition to their profession-specific skills, all clinicians will have a range of essential ED clinical skills in order to flexibly manage clinical demand, minimise internal waiting lists, and respond effectively to crisis.
- The ED team has situational awareness and is trained to be responsive to crisis.
- The ED hub functions as part of the national ED network in terms of development, pathways, evaluation, data collection, training and governance (as described above).
- Child and adult ED teams adopt a shared and collaborative approach to ED service development and delivery within their area. This will assist service users, referrers and colleagues to access and understand the service (Figure 10.4).
- Where local AMHS/CAMHS clinicians are delivering first and second-line ED treatment, they are understood to be part of the extended ED hub in terms of access to support, consultation, clinical supervision, and other initiatives. This will ensure standardisation, equal access, and staff support in the provision of ED care.

10.4: ED team competencies

Key to the implementation of this model of care is the successful functioning of each ED team within the wider mental health and acute hospital system. Section 12 outlines the resource requirements to fully implement this ED programme. Additionally, certain key team competencies are required to enable an ED team to function effectively (Table 10.3).

Table 10.3: Competencies within each dedicated eating disorder team

Clinical competencies

- Experience, training and expertise in working with people with EDs
- Range of assessment, risk management and treatment skills for EDs and their common comorbidity including but not limited to the following evidence-based treatments:
  - Child and adolescent: Family Based Therapy, FT-AN, Systemic Family Therapy, CBT-E (CBT-ED), IPT-ED, MFT-AN, RO, SSCM, DBT, CRT, meal coaching etc
  - Adults: CBT-E/ED, CBT-SE, IPT-ED, MANTRA, CRT, SSCM (including for SE-ED), Focal psychodynamic, MET, meal coaching

Risk management

- Situational awareness and flexibility: CRM crisis skills to respond quickly
- MARSIPAN and J.MARSIPAN training and competencies
- HSE open-disclosure training

Communication and interpersonal skills

- Interprofessional communication, consultation and negotiation skills to enable collaborative working
  - across all levels of the model of care, settings, variety of professionals and with service users
    - within the team
    - to prioritise communication and collaboration around case management
    - to ensure mutual understanding of roles and clinical responsibilities
    - to prioritise team meetings for the purpose of communication and collaborative care planning
- Clear and timely verbal and written competency to MHC and international ED quality standards
- Collaboration on the development of ED services nationally and locally

Patient-centred focus

- Personal and clinical recovery is prioritised
- Collaboration with patient, shared decision-making and communication of risk information
- Empowering patient, including carer/family
- Acting on patient and stakeholder feedback

Leadership and strategy

- Project management and outcome-focused skills to:
  - develop ED services within the catchment area – e.g. care bundles and shared pathways, training
  - collaborate with other local stakeholders
  - contribute to the National Clinical Programme for Eating Disorders

IT skills and data skills

- Data-collection and core analysis skills to enable clinical outcome evaluation/KPI interpretation
- Audit and evaluation at regional and national level
- Telemedicine

Education, supervision and academic

- Clinical supervision, consultation training skills to provide consultation and support within the catchment area
- Education and teaching skills to develop local ED training initiatives both within the team and in overlapping services
- Clinical research capacity – data-collection and analysis skills to evaluate outcomes, improve service functioning

10.5: Key ED team roles

In order to sustain the work of the ED team, the working group has identified three key roles within the team.

10.5.1: Clinical leadership

In line with A Vision for Change and the Mental Health Act 2001, each ED team will be clinically led by a consultant psychiatrist or consultant child psychiatrist, and be under the clinical leadership of the executive clinical director in the CHO area in which they are based.

10.5.2: Clinical keyworker

"Each service user has an individual care and treatment plan that describes the levels of support and treatment required in line with his/her needs and is co-ordinated by a designated member of the multi-disciplinary team, i.e. a key-worker"

– MHC Quality Improvement Framework (2007): Standard 1.1.

- Communication and transitioning between services has been particularly associated with high clinical risk for people with eating disorders (RCPsych, 2012).

- In that context, every person with an ED who is attending the ED hub team will be allocated a **keyworker**, who may be any clinical member of the multidisciplinary team.

- The clinical keyworker will usually be the person working most closely clinically with the service user and their family or carer, and may change over time as a result of transitions – it is often the person's key therapist.

- The aim is to provide continuity and consistency for the service user as they negotiate their way through the many interfaces and transitions across services as they receive treatment and care.

- Details of the clinical keyworker role and responsibilities are outlined in Box 10.2.

10.5.3: Referrals and ED team coordinator

The role of the referrals co-ordinator is:

"... an intrinsic part of the mental health team... fulfilling clinical and administrative function... the administration and triage of referrals in consultation with the consultants and other team members, managing the waiting lists, organisation of team meetings, and liaising with GPs and primary care professionals, local community agencies, self-help and other community"

– A Vision for Change (DOHC, 2006): p82

"*... The team coordinators serve as a single point of access to the team, a function that brings them into close relationships with general practitioners and other referring agencies...*" – Mental Health Commission (2006)

- We recommend that each ED team have a referrals coordinator who has a key role as a common point of contact for referrers and as a source of initial information and advice.

- It is recommended that this person be a senior clinician of any discipline who fulfils this role in a part-time capacity (while also working clinically so as to maintain their clinical role and retain clinical competency).

- As clinical lead, the consultant psychiatrist provides oversight regarding clinical decision-making about incoming referrals processing and waiting-list prioritisation.

- The line management of the referrals coordinator is within their profession.

Box 10.2: Proposed role of the clinical keyworker

In addition to their clinical role on the team, clinical keyworker roles will include:

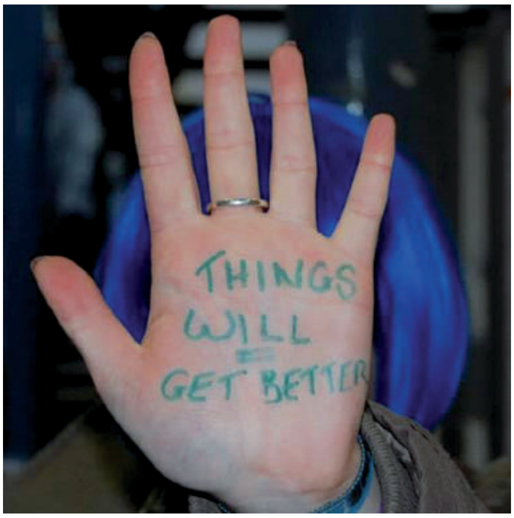
- Introducing their keyworker role to the service user and their family, carer or advocate (clarify consent if over 18).
- Serving as a point of contact for the service user and for their family, carer or advocate throughout their treatment.
- Serving as the link person between the ED team and any other service or professional that the service user is involved with such as school, GP, Bodywhys, etc.
- Listening to service user and family to understand their ideas, concerns, expectations, values and questions.
- Providing information on the HSE ED programme, local ED hub team, support groups and self-help resources in a way that service users and families can understand, etc.
- Supporting shared decision-making in collaborative treatment planning between the service user/family and the consultant psychiatrist and multidisciplinary team.
- Ensuring that care plans are regularly reviewed by the MDT (e.g. through team meetings, professionals meetings) and that the service user is fully informed.
- Working with other members of the MDT to ensure that liaison with relevant agencies takes place.
- Providing information and support on likely next steps at each stage of treatment.
- Coordination and support at all steps and levels of the service user's treatment, including to inpatient care as follows:

  – When the service user is hospitalised on a medical ward, the key worker attends weekly care planning meetings with hospital MDT, provides ongoing support to the service user/family on the ward, and is a link between hospital staff and ED team (as well as consultant to consultant).

  – When the service user requires psychiatric admission, the keyworker is a consistent link between the hospital and ED team, attends review meetings, provides ongoing support, and helps in discharge planning.
- Co-ordinating the discharge process with MDT and other relevant agencies and ensuring timely written communication
- When a young person is turning 18, the key worker and be part of the transition process and meeting between child and adult mental health services.
- Ensuring that all relevant documentation, including formal care plans, risk clinical outcome measures and data, have been completed for this service user in line with best practice, including standards of the HSE NCPED.

Box 10.3: Proposed role of the referrals and team coordinator

- Carries out administration and triage of referrals in consultation with the consultant psychiatrist and multidisciplinary team
- Acts as a single point of contact for referrers and queries
- Coordinates the waiting list and ensures that referrals are processed efficiently in accordance with clinical need, the team's operational policy and the NCPED
- Liaises with referrers, acute hospitals, CAMHS, local community agencies, self-help and other community resources (e.g. Bodywhys)
- Develops local professional relationships and establishes local ED training needs. Takes a lead role in the coordination of team meetings
- Together with the consultant psychiatrist and the rest of the ED multidisciplinary team:
    - Ensures that there is meaningful service user and carer involvement in both local ED service development and clinical decision-making
    - Helps facilitate equitable team workload distribution and appropriate level of service
    - Communicates any resources required to the consultant, CHO management team and NCPED
    - Helps coordinate team members' leave, in accordance with the protocols agreed with relevant consultants and line managers, so as to ensure that there is an adequate number of clinical and admin staff on duty to deliver the required level of service
    - Works with the ED consultant to help identify team training needs and support training days
    - Supports the ongoing audit of clinical records, integrated care plans and teamwork practice
    - Collaborates with the NCPED in the ongoing development of ED services: rollout of minimum standards, clinical governance and quality guidelines
    - Collaborates in evaluating clinical activity levels in line with nationally agreed key performance indicators and metrics of the NCPED, as well as any local requirements
    - Supports the ED team in ensuring that their service is planned, delivered and evaluated in a recovery-centred manner, and to the required standard of the HSE's organisational approach and this Model of Care
    - Co-develops and updates team policies and resources, in collaboration with the consultant psychiatrist and MDT (e.g. MHC frameworks and NCPED)


THINGS
WILL
GET BETTER

The Patient Journey

11.1: The patient perspective

A core value of the National Clinical Programme for Eating Disorders (NCPED) is that the HSE model of care will provide the opportunity, care and environment for people with EDs to recover. As well as evidence-based and timely treatment provided by trained staff, patients with EDs find that a number of other factors can assist, support and motivate them along their journey to recovery. Bodywhys, the national support organisation for those with EDs, and a collaborator in the development of this Model of Care, has provided the HSE working group with insights from the Irish patient perspective, in order that this too can guide the development of the HSE model of care for eating disorders. Box 11.1 and Figure 11.1 summarise their perspectives.

Box 11.1: What patients need from eating disorder services

(written by Bodywhys, the national service user support group for people with EDs)

The three main areas that people tell us are crucial for them are:

1. Expertise and consistency

- Specifically in relation to treatment for people with EDs, there needs to be continued focus on ensuring that all service providers, from the GP in primary care to the inpatient consultant psychiatrists and staff, understand the complexity of treating a person with an ED, and that anyone who enters the health system to access help can benefit from a pathway to recovery that is ***both expert and empathic***.

- We hear frequently that a lack of consistency in the provision of treatment proves problematic for patients with EDs, and often has a detrimental effect on a person reaching recovery. A main focus for the clinical programme should be ensuring consistency in:

  a. **Pathways** of treatment

  b. **Rationale, understanding and methodology** within each service, and connecting to the step up and step below

  c. **Personnel** – we cannot stress enough how obstructive it is for patients to see different clinicians on each visit, or not being able to work with one person throughout their treatment by any service

2. Appropriate and Individualised treatment and support

- Each person has an individual experience of EDs. It is important that the treatment pathway fits them, rather than they having to fit it. This means that the service would have the flexibility and expertise to be able to treat someone even if problems arise due to the nature of resistance and denial in an ED.

3. Time

- It takes time to recover, but often time is not considered as a vital part of the recovery process. That patients are given the time to recover and that the service they are part of is resourced to enable the patient to do so is a key to recovery.

Figure 11.1: What people have told us they need from clinicians and staff – Bodywhys

11.2: Patient support

The HSE National Clinical Programme for Eating Disorders has embedded these key concerns of people and patients with eating disorders as described above, into its model of care for eating disorder services. This includes a focus on systems and pathways to sustain:

- Engagement
- Continuity of care
- Seamless transitions
- Patient and family support
- Collaborative and shared decision-making
- Evaluation from the service-user perspective
- A flexible, person-centred system to respond to individual clinical needs
- Recovery focus
- Access to staff with expertise (see Section 15)

Figure 11.2 displays the ED care pathway from the patient perspective. A number of key factors in this HSE model of care have been are designed to address the issues of continuity of care and seamless transition for patients as they make their journey through treatment, as follows:

11.2.1: Keyworker

The clinical keyworker on the team is a key point of ongoing contact and support for every patient throughout their engagement in ED treatment and programme, and across the multiple settings that can take place in (see Section 10.4.2). This will help address anxiety and concerns that can occur regarding changes in clinical staff and doctors, as well as improving communication between professionals.

11.2.2: Core team

- From a patient perspective, in order for their mental and physical wellbeing to be comprehensively and consistently managed, they will mainly work with a core group of clinicians from the larger multidisciplinary team.

- Regular communication within the core team is important for ensuring patient safety and understanding. This includes weekly meetings and teleconferences/video conferences between professionals when patients are admitted to day/inpatient care.

- The core team for each patient includes:
  - Main therapist (also keyworker)
  - Consultant psychiatrist
  - General practitioner
  - Physician (paediatrician/adolescent health physician/acute medical/endocrine)
  - Dietitian as clinically indicated

11.2.3: Bodywhys and support services

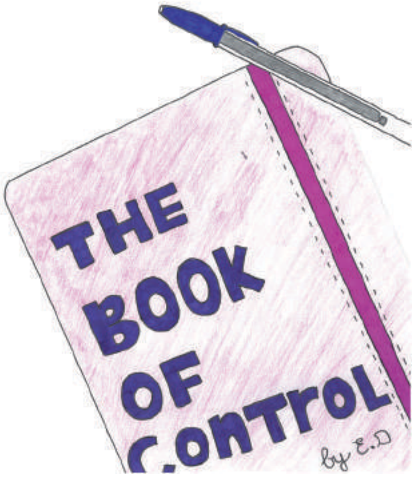
- Access to support is a key part of patient care at all stages of their clinical journey, from screening and assessment through to recovery, and this includes for the family. Support is particularly important at times of service engagement and transition.

- Access to formal support in parallel with treatment can enhance patient understanding and motivation, and thus improve engagement with treatment (which is often uncomfortable). This in turn improves outcomes and decreases disengagement and risk to the most vulnerable patients.

- Therefore, the national ED support service in Ireland, Bodywhys, is a partner organisation with HSE in the development of this Model of Care. The Model of Care includes a strong collaborative and shared commitment with Bodywhys and ED support services to ensuring that patients get the most effective advice and treatment. Box 11.2 describes the services currently provided by Bodywhys to complement each level of the Model of Care

- It is recommended that evidence based educational resources provided by organisations such as Bodywhys be actively recommended and available for access by people attending for eating disorder treatment at all levels of this HSE Model of Care and as a complement to their clinical services.

- Similarly to other aspects of the ED programme, it is important that support programmes for patients are also evaluated, so that they can be refined and developed in line with the needs and values of people with eating disorders.



Box 11.2: Bodywhys support services at each level of the HSE Model of Care

(by Harriet Parsons, Bodywhys)

Bodywhys can support the work of the HSE clinical programme by working with both the person with the ED and their carers. Essential to this stepped care approach is the collaboration between the HSE clinical programme and Bodywhys.

Level 1: Primary care: support, self-help, education

- For the person with an ED, Bodywhys can be both a confidential listening ear supporting and motivating the person in taking their initial steps towards recovery seeing a professional, encouraging initial and ongoing engagement with services and providing accurate information about EDs and treatment pathways.
- Patient resource pack, online, phone support.
- Bodywhys also, in partnership with the ICGPs, has developed a resource for GPs to enhance their knowledge, understanding and approach when seeing people with EDs for the first time.
- Bodywhys can support the education of professionals and the general public in the area of EDs. It works in schools, both primary and secondary, and at third level where requested.

Level 2a and 2b: Outpatient care

- Support for those engaged in the service and their family – support between appointments is sometimes essential to ensure that the person engages fully and is encouraged and motivated to see this part through.
- The PiLaR programme is one such initiative where Bodywhys works with parents and carers for four weeks to provide them with understanding of EDs, as well as tools and skills for supporting their loved one through the treatment process.

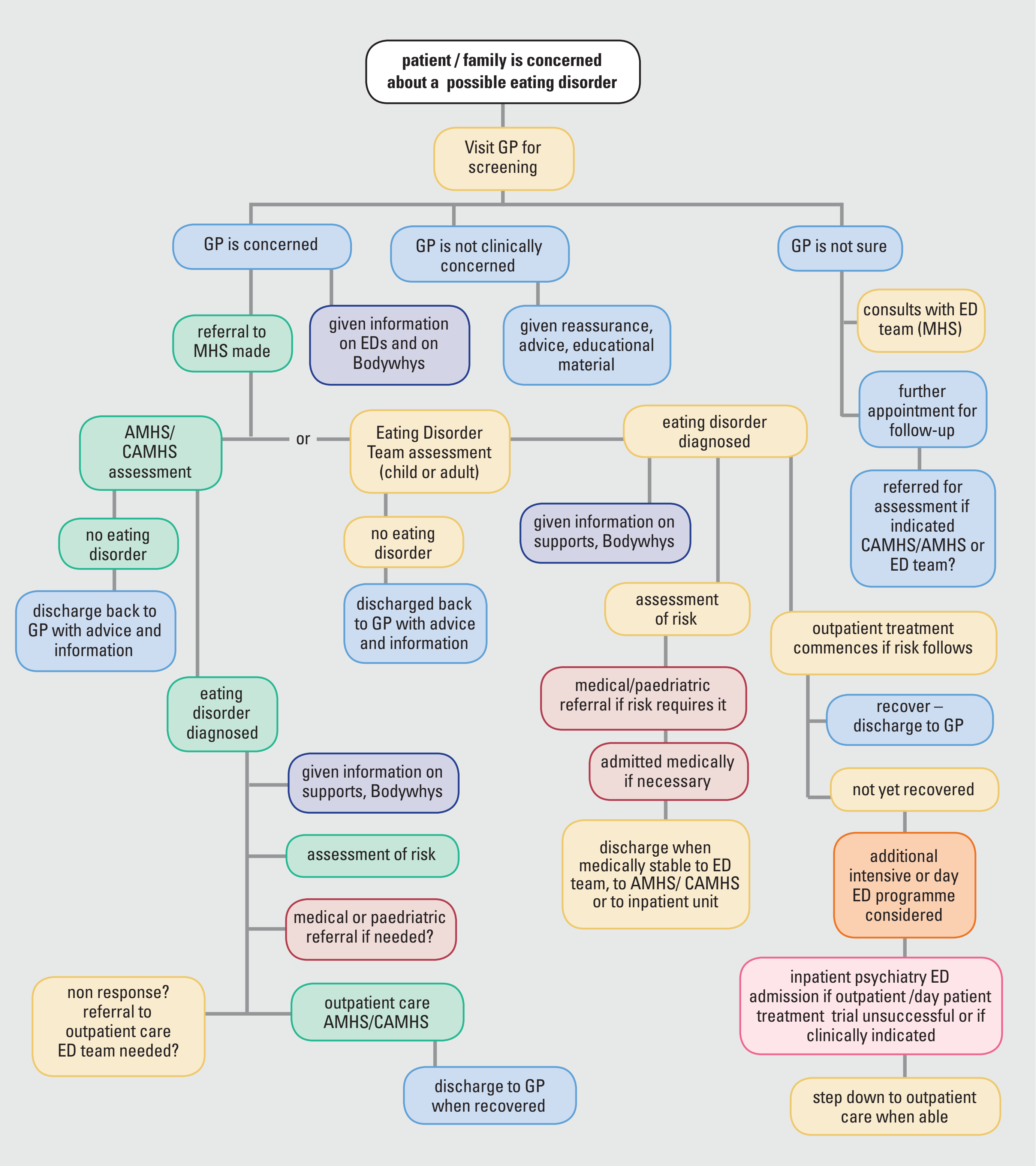
Level 3: Day and intensive treatment programmes

- At this level it is more often the family that requires support, as the person is fully engaged with the service. The family for the most part always play a huge role in the recovery process, and, depending on the age of the person with the ED, this can be more or less formal. Families need support to ensure they take care of themselves, and also that they understand the intricacies of recovery from an ED. This can be a slow process. Families need to be supported so that they can see it through as the person moves from Level 3 to Levels 2 and 1 in recovery.
- Bodywhys can also provide support to the person as they recover and descend from Level 3 to Levels 2 and 1, where they often look for aftercare-type support that is frequent and safe.

Level 4: Inpatient care – psychiatric or medical

- This can be an extremely distressing and difficult time for families. When a person requires this level of care, they are often reluctant and too unwell to engage in support themselves, but rather rely on the clinicians and family for support. It is crucial that families can receive support for themselves at this level. Recovery from this point will take time. To sustain good support for the person in question, they must also be supported.

Figure 11.2: Patient care pathway and journey to recovery



KEY

primary care	ED outpatient care	inpatient medical	Bodywhys
AMHS/ CAMHS	ED day programme	inpatient psychiatric	

11.3: Primary prevention and early recognition

- *A Vision for Change* (DOHC, 2006) recommended that awareness of EDs be increased through general publicity campaigns by national and voluntary bodies at primary and community mental health level.

- Early detection and diagnosis, prevention programmes and appropriate cost-effective treatments have been proven to greatly reduce the impact of an eating disorder, as outlined below.

11.3.1: School and college-based prevention programmes

Background

> ***"… general mental health education modules as part of positive mental health awareness rather than as a module devoted specifically to eating disorders, for example in the SPHE programme. "This education should stress positive healthy eating and positive body image following a general prevention model".***
>
> – *A Vision for Change* (DOH, 2006)

As mentioned in Section 2, approximately one-third of adolescent females in Ireland diet regularly and are dissatisfied with their body, with around 10% of being at risk of EDs (McNicholas, 2010). Of the primary prevention programmes that have developed over time, most are school or college based as described by Stice (2013) and summarised as follows:

- The earliest prevention programmes were largely taught formally and were and psycho-educational in content. These have not been found to reduce risk factors, symptoms or future onset of EDs (Pearson, 2002).

- The second generation of school-based programmes were also didactic, but they targeted empirically proposed risk factors such as body image and body dissatisfaction. They produced significant reductions in select EDs risk factors, but rarely affected the core ED symptoms or the onset of EDs (Stice, 2013).

- The third generation of school/ education-based prevention programmes also target empirically established risk factors, but do so with more interactive intervention, and often using motivational principles from social theory and positive psychology (Steck, 2004). They have tended to reduce ED risk factors and symptoms, and sometimes to reduce ED onset (Stice, 2013). Research has also shown that targeting protective factors that reduce the likelihood of developing an ED may also be effective in promoting self-esteem, confidence and positive body image in college students.

In a narrative review of the literature by Stice in 2013, of the 60 or so school-based programmes that were reviewed, significantly larger intervention effects had tended to emerge for those that targeted high-risk individuals versus a universal population, were interactive in nature, that focused on targeted risk factors and that used a multi-session format (Stice, 2013). Only two such programmes produced a statistically significant and clinical meaningful reduction in DSM-4 EDs at three-year follow-up: the Body Project Intervention (Seidel et al., 2009) and Healthy Weight (Stice, 2008 and 2012). Body and shape concern programmes have more recently been researched through internet-based school and college-based programmes, with some potential benefit (Jones, 2014).

In summary, it seems that the best place in which to promote the mental health of children and adolescents is in the school, and the best approach to addressing the issue of EDs at this level of primary prevention is not to make EDs themselves the specific focus of the intervention programme, but to focus on risk factors in a multimodal approach (Borresen et al., 2003). This is also in line with the recommendations in *A Vision for Change* (DOHC, 2006). The most effective aspects of ED prevention programmes with adolescents are displayed in Box 11.3.

Box 11.3: Recommendations for prevention programmes for adolescents

- Use a health promotion approach, focusing on building self-esteem and positive body image.
- Use interactive approaches – young people learn more this way.
- Develop social and recreational practices that incorporate the person's support network.
- Use developmentally appropriate materials.
- Focus on strengthening protective factors.
- Follow a multi-session structure, allowing for both direct experience and time between sessions for reflection (necessary to reinforce learning).
- Include a long-term follow-up.
- Include media literacy and advocacy components.
- Take a balanced approach to nutrition and physical activity, challenging the social pressures to be thin and emphasising the negative outcomes of pursuing the thin muscular ideal (e.g. the body project intervention).

Ref: Stice 2013

11.3.2: Community-based prevention programmes

There is also a need for greater general public awareness regarding EDs so that people at risk of developing EDs can be identified and supported to seek help more quickly, and so that general misconceptions and stigma about EDs can be addressed and reduced.

- Campaigns such as Eating Disorders Awareness Week, Bodywhys' 'Be Body Positive' and, internationally, the Academy for Eating Disorders' 'Nine Truths about Eating Disorders' (now translated into Irish) provide opportunities for people with EDs to feel supported in coming forward to seek help, as well as to empower those who have recovered to collaborate with the HSE Clinical Programme and Bodywhys in promoting accurate and recovery-focused views about EDs and ED treatment.

- In third-level education settings, the Healthy Body Image programme, trialled with US college students, is an example of a combined IT and community-based approach, which screens and targets students at risk of EDs and aims to change community culture (Jones, 2014). The Body Project Collaborative (Stice, 2011) uses a trained peer led cognitive dissonance programme approach and has been widely researched, and introduced to 140 college campuses in 25 countries.

- However, although such selective dissonance-based ED prevention programmes have been found to have a long-term impact on ED risk factors, sub threshold symptoms and psychosocial impairment, they have not been found to alter the timing of onset, BMI or service use of college students with EDs (Stice, 2015).

11.4: Patient self-management and self help

As summarised in Section 7.4.2, self-help, self-management and health literacy are well known to be key components of illness recovery and improved clinical outcomes, either as a primary or as a supporting intervention. For example, patient education and shared decision-making has been associated with patient enablement, satisfaction, better coping and adherence to treatment both across healthcare (Adams, 2010) and specifically in mental health (Hamann, 2006). This may in turn help services to manage their resources more effectively.

In relation to the evidence base for self-help in ED care, one of the most effective first-line treatments for BED is a supported self-help programme and manual (Fairburn, 2008 & 2013), and is a first-line intervention for that condition (RANZCP, 2014). The same manual also supports the CBT-E programme for anorexia nervosa and bulimia nervosa. Use of a parent self-help manual is also a key support to the FBT approach in empowering parents (Lock, 2015b).

There is also now a growing research base that suggests that in the future, online treatment programmes and evidence-based App programmes may support clinical treatment, enhance patient enablement and improve access to treatment for those living far away from services or working, where attendance is more challenging. For example, the study by Jones (2014) mentioned above, used an online programme to screen college students and identify those at risk, and who were then invited to targeted interventions.

However, at this time, the majority of web-based apps and programmes have not been formally evaluated and are not evidence-based.
In addition, searches through the plethora of ‘pro-ana’ and ‘pro-mia’ internet websites yield vastly more accessible and strongly negative material that promote ED motivation and behaviours (Borzekowski, 2010). Such websites are extremely destructive, if not deadly for people with EDs, as can be the overuse of social media where body type is compared and discussed to extreme levels.

This Model of Care will support the enablement and education of people with EDs and their families by:

- Recommending educational, bibliotherapy self-help resources to patients that are accurate, safe, well researched, recovery-focused and relevant.
- Encouraging people with EDs to become enabled and actively involved in their care plan through shared decision-making around care, and the active use of any patient manuals that accompany treatment programmes.
- Providing information about additional supports and supporting theirinvolvement in same e.g. Bodywhys, PiLaR.
- Warning patients and parents/carers of the risks of accessing pro-ana and pro-mia websites and advice on the safe use of social media such as Facebook and instagram for adolescents.
- Involving service-user representatives in the development of ED services in their region and nationally through the HSE service user engagement initiatives.
- Collaborating with patients and researchers in developing and evaluating resources that can support self-management and empower people with eating disorders towards optimal recovery.

Resources Required to Deliver the Service

The HSE will require additional multidisciplinary staff and infrastructure resourcing in order to deliver the Model of Care and to meet and manage the clinical needs of this complex, high-risk population. The development of the National Clinical Programme for Eating Disorders (NCPED) was driven by a recognition that Ireland currently lacks the services needed to meet the needs of people with EDs, and that additional specialist ED services are needed.

The NCPED supports the recommendations for adult, child and liaison psychiatry services as outlined in A Vision for Change (DOHC, 2006). However, whilst specifically addressing the need for ED service improvement and resourcing, A Vision for Change focused on an older understanding of ED provision – i.e. inpatient beds, generic teams and mainly adult-focused services. As outlined in Sections 2 and 7 of this document, ten years later we now know that that vision for eating disorders is inadequate in meeting the quality, access and safety needs of this population. The need for specialist ED services in Ireland has also been outlined previously by the Royal College of Psychiatrists (2003).

In the absence of existing services and comprehensive data, there are no current Irish recommendations as to the level of resources needed to deliver a national ED service in Ireland. When estimating the requirements to deliver this Model of Care, the working group therefore looked to international staffing recommendations from other countries with large public health systems, as well as to Irish epidemiological projections. This included reference to documents from the UK's Joint Commissioning Panel for Mental Health (2013), National Collaborating Centre for Mental Health (NCCMH) (2016), the Royal College of Psychiatrists (RCPsych, 2012, 2013) and NHS (2014), and from the Royal Australian and New Zealand College of Psychiatrists (RANZCP, 2014). Common to all the resource documents reviewed is a typical range, experience and ratio of healthcare professionals within the specialist ED teams that is needed to provide an accessible, quality and cost-effective ED service.

12.1: Staffing and HR requirements

Existing services

- This Model of Care is designed to enhance the quality of HSE ED service provision rather than to replace the work of existing AMHS/CAMHS where high-quality ED care is currently being provided.

- It is expected that any existing ED capacity within AMHS and CAMHS will continue to be dedicated to EDs. It is also recognised that some people with EDs will prefer to attend local CAMHS and AMHS teams for reasons of geography, access or preference, as well as for treatment of co morbid conditions.

- The Clinical Programme will continue to provide support and training to clinicians working in generic AMHS/CAMHS teams through the ED network of hubs and supervision groups. It has to date trained 73 and 62 clinicians in FBT and CBT-E, respectively, in this regard.

- This section will therefore not address existing primary care or community AMHS/CAMHS team resources that are already in operation.

- A quality national ED service cannot be provided without additional resources for EDs being funded.

12.1.1: Specialist ED team staffing requirements

- The recommended team composition and requirements for each full adult and child eating disorder team are displayed in Tables 12.1 and 12.2. Together with CAMHS/AMHS, they represent the clinical capacity needed to manage projected demand for ED intervention based on the current population in Ireland. In the absence of existing services and comprehensive adult and adolescent ED data in Ireland, they should be viewed as a starting point.

- Each ED team provides outpatient, day programme/partial hospitalisation and inpatient, where appropriate. However, it is recommended that each team initially focuses on developing specialised outpatient and day-patient capacity in order to bridge the gap between inpatient and outpatient services within mental health services nationally.

- The grades of post mentioned below are the minimum requirements to deliver ED-specialised treatment effectively and also to provide consultation, supervision and support to local AMHS/CAMHS clinicians when needed. Eating disorder experience is essential for all clinicians.

Box 12.1: Recommendations for mental health staffing

- HSE services nationally already include a small number of ED-specific posts, special-interest sessions or clinicians, and ED therapists, teams and beds. In the context of clinical governance under the NCPED, it is recommended that these be aligned with the ED network teams and hubs, and be included as existing ED posts in ED capacity calculations in each CHO.

- It is recommended that the ECD and CHO management teams in each area complete a needs assessment and gap analysis to determine the extent of ED service staffing and skill in their area.

- Specialist ED services should be staffed appropriately by mental health clinicians with experience in EDs. Therefore, staff who are experienced in working with EDs may be redeployed where feasible, with backfilling of their original posts.

- Separate ED recruitment panels may need to be created, as it is essential that staff working with EDs have the necessary experience, expertise and skill in EDs to work safely and effectively with patients with EDs and provide a Tier 2, 3, and 4 specialist service. This is in addition to having a solid background of general mental health experience.

Table 12.1: Adult ED team staffing: base capacity (per 500-600,000 population)

Discipline*	Whole-time equivalence (WTE)	Minimum grade
Consultant psychiatrist	1	Consultant
Psychiatric nursing**	3	At least 1 CNS, 1 CMHN
NCHD	1.5	1 registrar (OP/DH)*** 0.5 senior registrar (SR supports team liaison with inpatient teams)
Clinical psychologist	1	Senior
Consultant physician	0.2 +0.1	Consultant
Dietitian	1	Senior
Dietitian – acute hospital	0.1	Senior
Occupational therapist	1	Senior
Social worker	1	Senior
Creative therapist	1	Senior
Clinical coordinator (clinician)	0.5	Senior
Admin	2	1 x grade 4; 1 x grade 3
Ancillary staff for day programme	Sessional	
Total	**13.4**	

* Includes a trained family therapist in the team from among these disciplines. ** Nurse numbers reflect key role in supporting the day programmes, meals and hospital liaison. *** OP = Outpatient; DH = Day Hospital.

Table 12.2: Child & adolescent ED team staffing- base capacity (per 500,000-600,000 pop)

Discipline*	(WTE)	Minimum grade
Consultant child psychiatrist	1	Consultant
Senior registrar/registrar	1.5	1 registrar (OP/DH)*** and 0.5 senior registrar (supports team liaison with inpatient teams)
Clinical psychologist	1	Senior
Social worker	1	Senior
Dietitian with ED specialism	1	Senior
Dietitian – acute hospital	0.1	Senior
Psychiatric nursing**	3	CNS/CMHN
Occupational therapy	1	Senior
Paediatrician/adolescent health physician/acute physician	0.2 +0.1	Consultant
Co-coordinator	0.5	Senior
Admin	2	1 grade 4
Ancillary (staff for day programme/ education/ creative)	2	Department of Education
Total	**14.4**	

* Includes a trained family therapist in the team from among these disciplines. ** Nurse numbers reflect key role in supporting the day programmes, meals and hospital liaison. *** OP = Outpatient; DH = Day Hospital.

12.1.2: Staffing for the inpatient beds

The HSE's National Clinical Programme for Eating Disorders is prioritising the development of the specialist ED teams, with a goal of reducing the need for inpatient psychiatric ED beds and length of stay as a result of these teams. However, for a small percentage of people with eating disorders, psychiatric inpatient admission and access to dedicated beds will be required.

- **Adult psychiatric inpatient staffing**

The development of the 20 adult inpatient ED-focused beds nationally, in addition to the three ED beds already in place in St Vincent's Hospital, Elmpark, Dublin, will require additional nursing and staffing in line with standard HSE inpatient staffing levels. Inpatient access to specialist ED dietitian and the consultant physician linked with the ED team is also essential.

- **Child and adolescent psychiatric inpatient staffing**

The four regional adolescent inpatient units are currently staffed to include provision for ED admissions, and so no new ward staffing is required here. Extra MDT input may be needed to provide more ED-specific inpatient programmes, and day attendance at the local ED day programme is also a possible way of in delivering this level of care. Staffing for the planned eight psychiatric inpatient beds in the psychiatric unit of the National Children's Hospital is part of the *A Vision for Change* (2006) framework and staffing projections. The NCPED will support the National Children's Hospital and HSE in their planning of this unit so that it aligns with the NCPED and its model of care. Additional extra staffing for these child and adolescent ED beds will include access to paediatrician/ adolescent health physician, specialist ED dietitian and teaching staff.

Table 12.3: National staffing requirements to support the NCPED Model of care

Discipline*	WTE	Grade
National programme manager	0.2	TBC
National clinical – other	0.2	Consultant
Data analyst	0.2	5
Admin	0.2	5
Total	**0.8**	

12.2: Facility and infrastructure requirements

The NCPED is a new service development within HSE acute services in Ireland. It also proposes innovative methods of service delivery in Ireland, for example through telemedicine in mental health and regularising collaborative working across mental health and acute care. As such it will require additional facility infrastructure in order to support clinicians in delivering the model of care. Tables 12.4 and 12.5 summarise the core estimated requirements for each hub in order deliver the model of care in each sector.

Table 12.4: Adult ED Team : Estimated facility requirements per hub team

Level of Model of Care	Requirements
Level 2a	No new requirements
Level 2b: Outpatient	One clinical facility per CHO
Level 3: Day/intensive treatment programme	Individual therapy/outpatient rooms/office space (capacity of 1 per WTE clinician) Group rooms x 2 Viewing room and facilities Patient quiet room Kitchen Dining/meal area Admin office Meeting room Physical examination room and equipment – ht/ wt/ ECG etc. Accessible location: physical exercise an issue in travelling in this clinical group Formal IT links to acute hospital: electronic access to lab results IT infrastructure to collect data for evaluation IT infrastructure for videoconferencing & teleconferencing Access to training facilities for staff and public
Level 4: Inpatient psychiatric	23 inpatient beds nationally* St Vincent's, Dublin – 6 Connolly Dublin – 5 CUH – 5 GUH – 5 LUH – 1 SLK – 1 * Overall reduction in demand for inpatient beds (HSE and external) is expected once outpatient and day services are developed
Level 4: Medical beds	No extra requirements over the Vision for Change numbers. A reduction in demand for inpatient beds expected once outpatient and day services are developed.

Table 12.5: Child and adolescent ED team: Recommended facility requirements per hub team

Level of Model of Care	Requirements
Level 2b: Outpatients	One clinical facility per CHO
Level 3: Day Programme	Individual therapy/outpatient rooms (capacity 1 per WTE per clinician) Family rooms x 3 Group rooms x 2, 1 Viewing room and viewing/recording equipment for family therapy Kitchen Dining/meal area Patient quiet room Admin office Meeting room Physical examination room and equipment – ht/ wt/ ECG etc Accessible (physical exercise an issue) Direct IT links: electronic access to lab results, etc IT infrastructure to collect data for evaluation and audit IT infrastructure for videoconferencing & teleconferencing Training facility access for public and staff training
Level 4: Inpatient psychiatric	National Children's Hospital – 8 national beds No extra requirement for the other regional inpatient units* A reduction in demand for inpatient beds is expected once outpatient and day services are developed
Level 4: Medical beds	No extra requirements A reduction in demand for inpatient beds is expected once outpatient and day services are developed

12.3: IT requirements

12.3.1: National IT requirements

- In order to enable the HSE National Clinical Programme for Eating Disorders to measure its impact and progress in relation to its aims of quality, access and cost-effectiveness, it requires the ability to evaluate the programme at local, CHO and national level. To do this effectively will require the systematic, comprehensive and feasible collection of activity and clinical data across both CHO and acute hospital settings (Section 16).

- Given the flow of patients between services in this population, the working group recommends the establishment of a national electronic eating disorder register in order to enable staff from these different settings to record anonymised data for the evaluation of the programme.

- The working group also recommends the development of a dedicated HSE ED website to provide evidence-based resources and information to both staff and patients.

12.3.2: ED hub IT requirements

- **Database and supporting infrastructure**

Each team will require access to IT, a database and software in order to collect and analyse clinical outcome data at local and hub level for performance planning. This infrastructure is also needed to enable teams to collect activity and KPI data that will be developed nationally for evaluation of the NCPED. Formal links to HRB regarding access to acute hospital (HIPE) activity data is also required.

- **Video and teleconferencing facilities**

In order to enable access to the ED service by service users who are living far away or who are unable to travel to the hub, in addition to fulfilling the consultation, supervision and supportive commitments of the ED teams to AMHS and CAMHS, it is essential that videoconferencing and teleconferencing facilities be available at each ED hub. This will also allow for communication and effective management within the ED network.

- **Training**

Each ED hub will require regular access to audiovisual training equipment and space in order to fulfil its roles as a provider of clinical supervision, training and support for clinicians in AMHS/CAMHS, primary care and acute hospitals who are caring for people with EDs.

- **Lab IT links**

Given the high level of physical monitoring required in order to manage clinical risk in people with EDs, the ED teams require direct IT links in order to access hospital lab results efficiently, and act upon abnormal results as soon as possible (acute risk management)

Box 12.2: Recommendation for local needs assessment and planning

- A needs assessment and gap analysis should be carried out by each CHO mental health Lead, ECD and area management team in order to determine and plan for the staffing, facilities and IT requirements they need in order to implement the HSE Model of Care for EDs.

12.4: Training budget requirements

A key requirement of the ED hub is that the teams can work effectively and collaboratively across settings in an integrated care model. As discussed below in Section 15, interprofessional education has been shown to improve patient outcomes and safety, to enhance collaborative teamwork and to manage access and resources more efficiently (WHO, 2010). Therefore, each ED team hub will require annual funding to resource interprofessional team-based training programmes in their sector, maintain their expertise and to address gaps. This includes joint training – e.g. MARSIPAN training and primary care – with acute hospital clinicians. The working group recommends that an education budget be ring-fenced to the ED programme and its hubs and managed by the NCPED at CHO and national level so that joint or national team-based training initiatives can be undertaken, where cost-effective. Funding of an induction programme for all staff will also require resourcing and collaboration (see Section 15).

12.5: Interdependency with other clinical programmes

The NCPED will require collaboration with other HSE clinical programmes in order to deliver this integrated model of care for patients with EDs, including training requirements (Figure 12.1). It is planned that ED care pathways and bundles will be developed in collaboration with HSE and primary care programmes as well as key stakeholders, such as liaison psychiatry services. A key focus of these early working groups will be on access and discharge pathways to and from primary care, acute hospitals and the eating disorder teams and on training. It is also recommended that specific subgroups be formed to develop best-practice service guidelines/ consensus on the management of nasogastric feeding and refeeding, services and care for those with intellectual disability and eating disorders, and on the management of severe and enduring EDs (Table 12.6).

Figure 12.1: A collaborative and integrated model of care

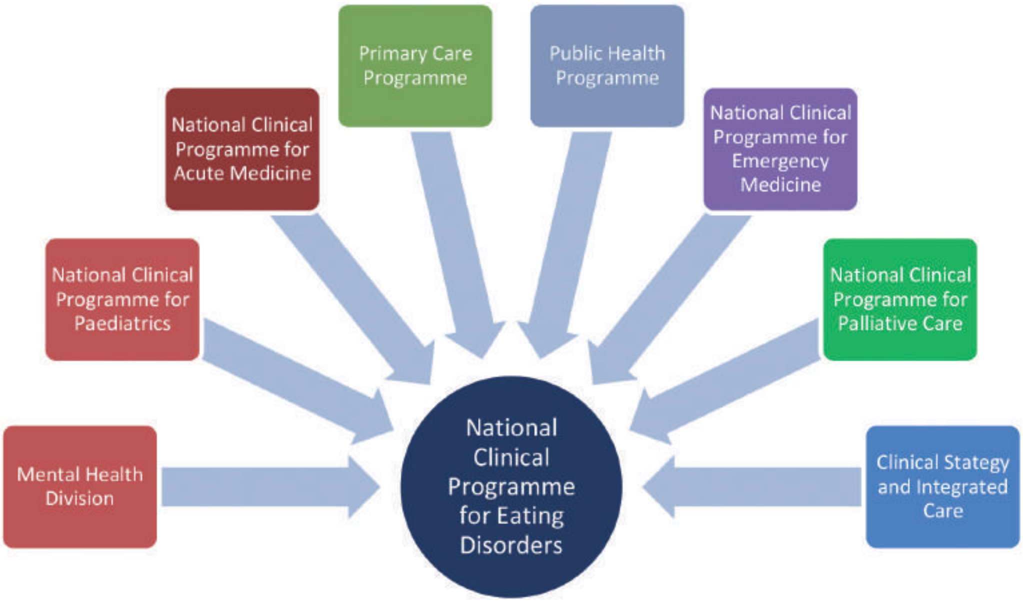


Table 12.6: Recommended clinical pathways and working review groups within the National Clinical Programme for Eating Disorders- first steps

National and local Clinical Guidelines and Pathways

- To and from primary care
- To and from acute hospitals, accessing medical care
- Shared care models of working – e.g. GP and psychiatrist, psychiatrist and physician, etc.

First Review Groups

- Nasogastric Feeding
- MARSIPAN/JMARSIPAN Implementation
- Severe and Enduring EDs
- ED Care in people with Intellectual Disability
- Education and Training Group

Legal and Ethical Considerations

From a legal perspective, the HSE National Clinical Programme for Eating Disorders will operate under the following legislation and frameworks so that it fulfils its legal and ethical obligations towards people with EDs and ensures that their clinical needs, safety and rights are respected in line with their best interests at all times.

- Mental Health Act 2001, its reviews and codes of practice
- The Mental Health Commission's Judgement Support Framework and publications (where relevant)
- Any upcoming capacity legislation
- Children First Act (2015)
- Data Protection Acts
- Any other relevant Irish legislation

The National Clinical Programme for Eating Disorders will collaborate with other key stakeholders such as the Mental Health Commission and College of Psychiatrists of Ireland in order to clarify common ethical and legal issues that arise specifically in relation to the clinical management of people with EDs. This will also include facilitation of the sharing of resources and support to frontline HSE clinicians on a case-by-case basis, when legal dilemmas or queries arise in connection with patients with EDs, if this is available, and in association with HSE solicitors.

13.1 :Consent to treatment

Under 18's

1. Psychiatric treatment

- Children and adolescents with EDs who are under their 18th birthday must have the consent of their parents or legal guardian in order to access psychiatric or mental health treatment (Table 13.1). This is a legal requirement and includes the mental health treatment of EDs.
- In the case of adolescents aged 16 and 17, it is additionally considered good practice to obtain adolescent 'assent' to treatment. Although this is not essential from a legal perspective, in practice psychiatric treatment is much more likely to be successful where an adolescent is in agreement with treatment so this approach is is also clinically sound. Finally, the ethical prerogative is to collaborate with competent, autonomous, informed patients where possible.
- The MHA 2001 applies to children and adolescents with eating disorders in Ireland.

2. Medical treatment

- In terms of medical treatment, parental/guardian consent must be obtained for children and adolescents under the age of 16.
- Adolescents aged 16 and over can provide their own consent for medical treatment, and parental consent is not legally required (Non-Fatal Offences Against the Person Act, 1997).

This anomaly in Ireland concerning the age of consent to psychiatric and medical treatment, between the 16th and 18th birthday, is particularly challenging in the management of EDs, where refeeding, though not a psychotropic or psychosocial intervention, is part of eating disorder treatment by mental health teams. In practice, where uncertainty arises and time allows, legal advice may be sought on a case-by-case basis (see Table 13.1).

Adults

1. Medical and psychiatric treatment

All adults over the age of 18 with an ED may consent to medical and/or psychiatric treatment for an eating disorder once they are fully informed and have capacity to do so. Where capacity is lacking or if they meet the criterion for mental disorder under the MHA 2001, the appropriate legislation or legal advice should be sought (see Sections 13.2 and 13.3 below) and family should be involved where possible.

Table 13.1: Consent to treatment before 18th birthday

	Medical treatment is needed (refeeding)	**Medical treatment is needed (refeeding)**	**Psychiatric treatment is needed**	**Psychiatric treatment is needed**
	Child agrees	**Child refuses**	**Child agrees**	**Child refuses**
Parent agrees	Treatment goes ahead. Parent consent is not needed if over 16.	Under 16, parental consent is adequate. Over 16, get legal advice	Treatment goes ahead with Parental consent and child assent.	Under 18, parental consent is legally adequate, but work to try to gain assent. Get legal advice/court if unsure.
Parent disagrees	If under 16, parental consent is required. If over 16, child can consent. Consideration of Children First/ court/ Guardian ad litem.	Consider common law if acute risk; seek legal advice-High Court regarding court order. Consideration of Children First guidelines./court Guardian ad litum	Consider Mental Health Act 2001 (District Court) Consideration of Children First / Guardian ad litum	Consideration of Children First / Guardian ad litum Consider MHA 2001

Box 13.1: Definition of mental disorder (MHA 2001)

Person has a ‘mental illness’ under the act (‘*a state of mind affecting their thinking, perceiving, emotion or judgement which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons*) and because of the illness either:

- poses a risk of immediate and serious harm to themselves or others (3a),

or

- judgement is so impaired that failure to admit them would lead to a serious deterioration or prevent the administration of appropriate treatment that could only be given by such an admission (3B1)

and

- admission would be likely to benefit or alleviate the condition to a material extent (3B2)

13.2: Mental Health Act 2001

The Mental Health Act 2001 is the legal framework in Ireland under which psychiatric patients may be admitted for involuntary psychiatric treatment to an approved centre under the care of a consultant psychiatrist. Key to this framework is that the person is suffering from a ‘mental disorder’ as defined under section 3 of the MHA 2001. (See Box 13.1).

The best interest of the patient is paramount. The MHA 2001 offers legal protection and formal reviews for those admitted under this legal framework. For adults, this involves a tribunal panel. For children, reviews of detention take place in the district court. The different processes and pathways used to detain adults and children under the Act are clearly described in the Act and in its codes of practice.

For a small number of people with eating disorders, their clinical condition will meet the above criteria for a mental disorder under section 3 of the MHA at a certain time, and they will require detention in their best interests. This includes, for example, people with severe anorexia nervosa or bulimia nervosa who require inpatient psychiatric treatment where outpatient treatment is inadequate or has failed. It is important to note that the current MHA and Mental Health Commission guidelines governing restraint do not include the coercive feeding of patients with EDs who are detained under the MHA.

International research suggests that people with EDs who are detained on an involuntary basis tend to be more unwell, and have a longer duration of admission than their voluntary counterparts. They have been found to achieve higher weight gain but to have poorer long-term prognosis (Ramsey, 2009). Smaller studies that have researched the experience of involuntary admission suggest a variable outcome. Some patients get angry as they feel that they were not so unwell as to warrant involuntaty admission, while others describe feeling 'saved' (Colton, 2004). An adolescent case series of 12 participants found that some of those admitted on an involuntary basis went through a series of psychological stages as they progressed through involuntary treatment ('battle', 'bubble', 'stepping out of the bubble',' the anorectic self') (Seed, 2015).

13.3: Capacity and refeeding

As outlined above, children under 18 in Ireland lack the legal capacity to consent to psychiatric treatment (Box 13.2). This also holds true for children under 16 in terms of consenting to medical treatment. However, it is important to note that even adults with severe EDs, especially anorexia nervosa, often have poor cognitive function due to their starved state. Together with the anorectic cognitions inherent within the disorder, this can be associated with a lack of clinical capacity to make decisions about consenting to refeeding.

Box 13.2: Clinical capacity in decision making

Clinical capacity includes the ability to:

- Understand information
- Retain information
- Understand the balance of risk,
- Make and communicate a decision
- Reflect on the implications of a decision to accept or reject refeeding and treatment

While immediate lifesaving treatment can be provided under common law in Ireland, once the patient is acutely medically stabilised, a decision must be made quickly regarding further treatment.

Some individual cases have been referred to the High Court in order to seek an individual Treatment Order when there is uncertainty about the legal status of refeeding as an intervention. In most of these cases, the family, legal team and medical team have all been in agreement about obtaining a court order in order to feed the patient. On the rare occasions where there is no such agreement, the court may appoint a guardian ad litem to act for the patient. During the High Court process, the Mental Health Act process continues in parallel.

In the absence of current capacity legislation and clarity, and when there is doubt as to the course of action, it is recommended that the consultant psychiatrist, clinical director of the service, director of nursing and senior hospital administration seek advice from HSE solicitors on a case-by-case basis.

13.4: Child protection legislation

All clinicians and staff members working within the ED programme should be trained in the principles of the Children First national guidance on the protection and welfare of children. This includes having awareness of child protection concerns and procedures for reporting them and in collaborating with Tusla (the Child and Family Agency) where such issues arise.

13.5: End-of-life decisions and care

(Developed in collaboration with the National Clinical Programme for Palliative Care)

This section considers issues regarding the management of patients with EDs, mainly anorexia nervosa, who are dying from their illness.

- While psychiatric practice often involves chronic, severe illness, and also sudden death from suicide, it can be difficult to manage patients who are starving to death as a result of a mental health condition, and particularly young patients.
- Unfortunately, there is a paucity of evidenced-based literature to guide clinicians in what can be a very challenging part of caring for patients with severe EDs.

- Much of the existing literature revolves around the use of involuntary admission, including coercive feeding, to treat severely ill patients as described above. In many jurisdictions, this is now accepted practice (e.g. Ireland, United States, Australia, New Zealand, UK) and is considered life-saving.

Treatment of refractory anorexia nervosa

As previously noted, more than 10% of patients of with anorexia nervosa will die as a consequence of their illness. This means that treating clinicians will inevitably encounter patients whose illness is refractory to all available treatment. There is no agreed definition of what treatment refractory anorexia nervosa actually means. However, there is a general acceptance that patients who continue to deteriorate despite having received evidence-based treatment, and for whom further treatment is believed to be futile, can be considered to have reached the point of being described as treatment-resistant. Treatment is considered to be futile if 'recovery is impossible or virtually impossible' (Lelie, 2003).

People with treatment refractive disease may be grouped into two broad categories:

- People with EDs who have had lengthy unsuccessful treatment, and who make a decision to refuse further distressing treatment in the knowledge that this (refusal) will lead to their imminent death.
- People with treatment refractive EDs, who refuse further treatment but do not believe that they will die as a result of this decision.

In other branches of medical practice, a palliative care approach is adopted by the primary team in the management of patients who are considered treatment refractive. Additionally, specialist palliative care teams may be requested to assist in the management of complex physical, emotional, psychosocial or spiritual issues related to the life-limiting condition.

For the first group of patients, adopting a palliative care approach and involving the specialist palliative care team, has been found by some teams to be a helpful intervention. Lopez, published on their experience of this (2010) and found that their patient benefitted from palliative intervention, and ultimately hospice care.

However, the timing and value of involving the specialist palliative care team in the management of the second group of patients remains a topic of debate, nationally and internationally. Some argue that the specialist palliative care team have a role in promoting patient understanding of the realities of their situation, providing relief from distressing symptoms or responding to staff or family distress. Others point to a concern that providing palliation of symptoms before a 'point of no return' may inadvertently support the patient's denial of the serious nature of their illness and limit opportunities for interventional management.

As stated, there is no agreed care pathway for managing ED patients who are considered by the multidisciplinary team to be approaching the end of life. However, certain general principles can be considered as outlined in Box 13.3.

Box 13.3: Principles of end of life care for patients with treatment refractive anorexia nervosa

- A decision that a patient is refractory to treatment is made by the treating consultant psychiatrist with expertise in managing EDs, and in collaboration with the MDT and physicians.
- In certain cases, if there is doubt about whether the patient would benefit from further treatment, a second opinion from another consultant psychiatrist specialising in eating disorders can help to clarify the situation.
- Multidisciplinary team management is a cornerstone of treatment in caring for patients with EDs, even for those patients who are considered to be refractory to treatment and who are approaching the end of life.
- The multidisciplinary team should possess palliative care approach skills (*Palliative Care Competence Framework, 2014*) and regular assessment of palliative care need should be conducted (*Palliative Care Needs Assessment guidance, 2014*).
- In addition to the patient's usual team, there is likely to be medical physician involvement to support the patient's physical care at this time.
- As above, there is some evidence that referral to specialist palliative care (SPC) can be helpful. In those patients who recognise that their illness is terminal, the palliative care team can provide support, if needed (*National Eligibility Criteria for Palliative Care, 2014*). For those patients who do not believe that their illness is terminal, inviting the patient to have SPC assessment can signpost the seriousness of the situation for some, and enable the patient to make choices about their care. The value of further engagement of the SPC team following initial assessment should be made on a case-by-case basis, with input from consultants in psychiatry, physicians and palliative care.
- As in other end-of-life situations, family is an important consideration. Not only can the family assist the patient in making choices about their care, they will often have struggled for years with a very ill loved one, and find the terminal process difficult and distressing. Palliative care can be a useful support for them.
- It is important to be aware of the stress that staff who have been caring for a patient may experience when providing care towards the end of life, and after the patient dies. Staff should be supported and facilitated in managing this stress. SPC staff may need training and supports to manage the specific psychological aspects of caring for those with EDs; ED clinicians may need training and supports to manage the palliative aspects of care. A group opportunity to discuss what is happening, or has happened, can also be helpful.
- The HSE offers a specific confidential, facilitated debriefing service for staff, which some clinicians have reported as beneficial. This service can be accessed by contacting the Employee Assistance Programme, Dr Steevens' Hospital, Steevens Lane, Dublin 8. Telephone number: 00 353 1 6352319.

- In light of the limited evidence base and experience in this area, ED and SPC teams should reflect upon and share their learning from experiences of collaborating in the provision of care.

References

Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan, Rowe D, Wynne M, Palliative Care Competence Framework Steering Group (2014). Palliative Care Competence Framework. Dublin: Health Service Executive. http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/competencyframework.pdf

The National Clinical Programme for Palliative Care (2014). Palliative Care Needs Assessment Guidance. Dublin: Health Service Executive. http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/pall%20care%20needs%20assessment%20guidance.pdf

The National Clinical Programme for Palliative Care (2014). National Eligibility Criteria for Palliative Care. Dublin: Health Service Executive. http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/refer%20specialist%20palliative%20care%20services.html

Clinical Governance of the HSE National Clinical Programme for Eating Disorders

Clinical governance has been defined as:

"A framework through which … organisations are accountable for continuously improving their services and safe-guarding high standards of care by creating an environment in which excellence of clinical care will flourish" (Scally, 1998).

Figure 14.1 displays the seven key pillars of clinical governance on which this programme will focus in relation to quality improvement and implementation. In doing so, the programme will also develop its governance structure, with reference to the following national frameworks.

- Best Practice Standards for Mental Health services (HSE, 2017)
- National Clinical Programmes: Checklist for Clinical Governance (HSE, 2011)
- Framework for Improving Quality in our Health Service (HSE, 2016)
- Standards for Clinical Practice Guidance. National Clinical Effectiveness Committee (DOH, 2015)
- Achieving Excellence in Clinical Governance: Towards a Culture of Accountability (HSE, 2010)
- Quality Framework for Mental Health Services in Ireland (Mental Health Commission, 2007)
- Excellence in Mental Healthcare Records (Mental Health Commission, 2007)
- Code of Governance Framework for the Corporate and Financial Governance of the HSE (HSE, 2011)
- Draft HSE National Framework for Developing Policies, Procedures, Protocols and Guidelines (PPPG) (HSE, 2016).
- MHC Guidance Document on Individual Care Planning Mental Health Services (2012).

Figure 14.1: Clinical governance pillars of the National Clinical Programme for Eating Disorders

14.1: Clinical governance practice and procedures

- In line with the goals of quality and safety that underlie the HSE Clinical Programme's Strategy Division and the Mental Health Division, this Model of Care has a number of components embedded in its core framework in order to ensure that clinical governance is maintained and developed as the National Clinical Programme for Eating Disorders is implemented. These are summarised below.

- It is recommended that the clinical leadership within the individual ED teams and national network collaborate with CSPD, the HSE Mental Health Division and HSE CHO area management teams in order to evaluate the National Clinical Programme for Eating Disorders on a regular basis so as to review progress towards standards and KPI's, identify barriers and trends, support progress and plan strategic development.

- We recommend that this process happen through quarterly meetings at both CHO and national level, so that the ED network can evolve as a learning organisational network in the broadest sense.

- All eating disorder teams will participate in the HSE Best Practice Guidance for Mental Health Services, though self assessment in relation to its five themes and the use of the GAIT tool.

14.2: Risk management

- Eating disorder teams within the NCPED will operate within the existing risk management structures of the HSE and Mental Health Division.

- The NCPED will be subject to the HSE Safety Incident Management Policy (2014) in terms of its reporting and management of critical incidents.

- This programme will operate under the ethos and principles of the HSE Open Disclosure policy when adverse outcomes arise, so that such incidents can be recognised, managed and resolved promptly (Proposal for Health and Social Care Services: a change management approach to implementing an open disclosure programme. HSE, May 2015).

- Quarterly governance meetings, risk register, and the collection of key outcome data will assist in the monitoring of potential patient risk at both local hub and network level (see Section 16).

- From a clinical perspective, the programme supports the MARSIPAN and Junior MARSIPAN clinical risk management guidelines and the development of related local clinical pathways and virtual crisis teams so that services can provide an early collaborative response to clinical risk escalation. The development of frameworks and local integrated clinical pathways will be enhanced at national level though formal collaboration with key clinical stakeholders in the development of these patient safety pathways (National Clinical Programmes in Paediatrics, Acute Medicine and Emergency Medicine, etc).

- The prioritisation of clinical supervision and training in evidence-based intervention within the Model of Care, will reduce patient risk through the development of expertise and support within clinical teams.

- All team members will be supported through the clinical leadership of a consultant psychiatrist.

- Core national training for staff in their first year of working on the programme will include modules on clinical risk management, open disclosure, crisis team management and clinical risk management as part of the risk management strategy in working with eating disorders (see Section 15).

14.3: Clinical effectiveness and evidence-based practice

- In formulating the standards and content of this HSE Model of Care, the working group referenced the most up-to-date international guidelines and research available on clinical and service best practice (Appendix 1, Section 8).

- Consultation with the Eating Disorder Clinical Advisory Group (College of Psychiatrists of Ireland) and other external advisors in the development of this Model of Care has ensured that the recommendations made are robust in their potential to ensure clinical effectiveness.

- At its initial three-year review and as this programme develops, the role of the ED network and its clinical leadership will be to ensure that the NCPED continues to operate on the basis of up-to-date, high-quality research evidence when delivering HSE eating disorder clinical services effectively and efficiently to patients, to the level of international best practice standards.

- The design of the national programme as a network will improve the dissemination of clinical knowledge, training and expertise on the ground at national level, though the sharing of good practice in a learning culture. This includes impact at acute hospital and primary care services.
- A dedicated HSE ED web resource for professionals will be developed.
- Individual teams will be responsible for developing their own internal CPD and training events, and identifying local training gaps and needs

14.4: Service-user involvement and experience

Service users will be actively involved in the National Clinical Programme for Eating Disorders in a number of ways:

- At national level, through the participation of Bodywhys, the national patient support organisation for EDs, in the working group that developed this Model of Care. Bodywhys will also be involved in its further reviews and meet regularly with the NCPED as the programme is implemented.
- At CHO level, through collaborative and complementary working relationships between HSE ED services and Bodywhys (e.g. complementing PiLaR and other supports with local demand for support groups).
- At team and clinician level, through the case-by-case evaluation of the patient experience of HSE services – through Patient Reported Experience Measures (PREMs) and feedback forms (see Section 16). These will be evaluated in the core data that will be collected for every patient and reviewed by the team and hub as part of quality improvement.
- By including service users in the delivery of the core training curriculum for every clinician, so that the patient experience is understood by clinicians.
- By using service-user feedback in the planning of local ED service initiatives, highlighting and learning from feedback, etc.
- By sharing feedback to patients who attend the ED programme in order to improve trust and manage patient expectations at CHO and national level – e.g. results of audits, activity, etc.
- By developing a dedicated HSE ED website with information for service users.

14.5: Clinical audit and evaluation

- Evaluation of both the clinical and training components of the NCPED is an essential part of its clinical governance. Detailed descriptions of the approach that will be used in the programme are outlined in Sections 15 and 16. This 360° approach to clinical evaluation will ensure that the programme will meet international best-practice standards in clinical outcome evaluation (CORC, 2014).
- The clinical metrics recommended for use in this Model of Care will enable robust clinical audit so that clinicians, teams and the ED network can evaluate, reflect and improve the clinical effectiveness of the programme as part of their standard practice at clinician level. This includes metrics for acute hospital admissions.
- Activity metrics will enable resources to be used most effectively in order to maximise access and efficiency at service and clinical programme level.
- A specific clinical audit skills module will be included in the core training curriculum for this programme so that all clinicians have the skills to regularly audit their own clinical practice as well as the competency to contribute and collaborate with larger clinical audits within their hub and across the ED network.
- Service goals that are set each year will include the completion of a team-based audit and quality-improvement initiative.
- A key requirement for evaluation and clinical audit is to have adequate capacity, training, administrative support and IT infrastructure in order to complete the data analysis. The working group has recommended access to a national data manager, IT resources and collaboration within a proposed research network so that audit and evaluation can be supported nationally (Section 17).

14.6: Staff training, development and support

- As outlined in Section 15, the NCPED will include a robust and comprehensive education and training programme to support and train HSE staff to deliver high-quality ED treatment and care effectively and safely. This will include the development of a core training programme for all clinicians during their first year of working in the ED hubs.

- This education programme will require dedicated development and training time and support, particularly in the initial years of the programme, and while a national and local HSE ED staffing infrastructure is being established.

- This Model of Care recommends that funding be provided on a national and local team basis so that interprofessional education (IPE) initiatives can enhance collaborative care and integrated team working on the ground (Section 15). This includes IPE initiatives with services such as primary care and hospital-based teams. To date, this approach has been effective in shaping the national HSE FBT and CBT-E training strategy, as well as in other team-based ED training initiatives.

- Oversight of the training and development programme for staff working with EDs will take place both at team level and nationally at the quarterly meetings. This will include a process of regular staff and team feedback so that gaps can be identified and addressed, and so that clinicians and other staff are confident, informed and skilled in meeting the quality standards of the NCPED and HSE.

- In their role within each CHO, the ED teams will also provide and collaborate in education and training initiatives with partner services also working with people with EDs, such as local mental health and liaison psychiatry services, paediatrics, medicine, emergency, primary care, education. This includes supporting staff in acute hospitals where people with EDs are admitted and MARSIPAN/Junior MARSIPAN training programmes.

- As with the rest of AMHS and CAMHS, all staff should have access to
  - Professional supervision within their discipline
  - Peer CPD on a team/hub level
  - Clinical supervision on cases from the clinical lead on the team (consultant psychiatrist) so that clinicians feel supported and safe in their work

- As noted in Section 2, working with EDs can be challenging, Clinicians are recommended and will be supported to develop and attend process/reflective groups (e.g. Ballint, Schwartz Round etc.) in order to maintain their resilience. Ideally, these should be independently facilitated.

14.7: Staffing and management

Line and service management

- Each ED team is an integrated part of their local mental health service. They will therefore operate under the clinical leadership of the local Executive Clinical Director in that CHO, and under the management of the Head of Mental Health Services and area management team for that sector. This includes involvement in local on-call roster arrangements with other mental health teams in the sector.

- It is recommended that in each ED Hub, the ED consultant clinical lead and coordinator meet with their local ECD, risk manager, and local management team formally on a regular basis in order to develop and integrate the ED service in each CHO area. This will be supported by the NCPED within each CHO.

- Each ED team is also part of the integrated NCPED and its network. It is therefore recommended that the ED lead and coordinators meet quarterly on a national basis with other hub teams in order to progress the quality of their ED service within the Clinical Programme, share innovation and improve its quality.

- Finally, at local level, it is recommended that key members of both adult and child hub teams, acute hospital leads, primary care and a service user representative meet quarterly to develop the clinical aspects of the programme locally (e.g. pathways, care bundles, checklists, etc) and to evaluate progress. This will be supported through the national website for the programme.

- Local line management for individual clinicians is similar to other staff working in HSE AMHS/CAMHS in each area.

Clinical management

- In line with both the Standards for Mental Health Services in Ireland (MHC) and the Mental Health Act 2001, each ED team will be led by a consultant psychiatrist or consultant child and adolescent psychiatrist.

- The consultant psychiatrist retains overall clinical responsibility and leads care planning for patients attending the ED service in collaboration with the MDT. This includes the provision of clinical consultation and clinical supervision on these cases to other clinicians on the team.

- In terms of consultant clinical responsibility for each patient with an ED who is attending the MHS:

    - When the person is attending their local AMHS/CAMHS team for ED treatment, the clinical lead for their care will be the local AMHS or CAMHS consultant psychiatrist or consultant child and adolescent psychiatrist.

    - This arrangement will also apply where the patient and local AMHS/CAMHS team are accessing short-term ED treatment from the ED service e.g. weekly group or consultation from individual members of the ED team.

    - When the patient is attending the ED team for all of their care, the clinical lead for their care is the ED consultant psychiatrist or consultant child and adolescent psychiatrist.

    - When the patient is admitted to a medical setting, they will be admitted under the care of their medical consultant or paediatrician with consultation from their ED (or sector) consultant psychiatrist, consultant child and adolescent psychiatrist or liaison psychiatrist in the acute hospital.

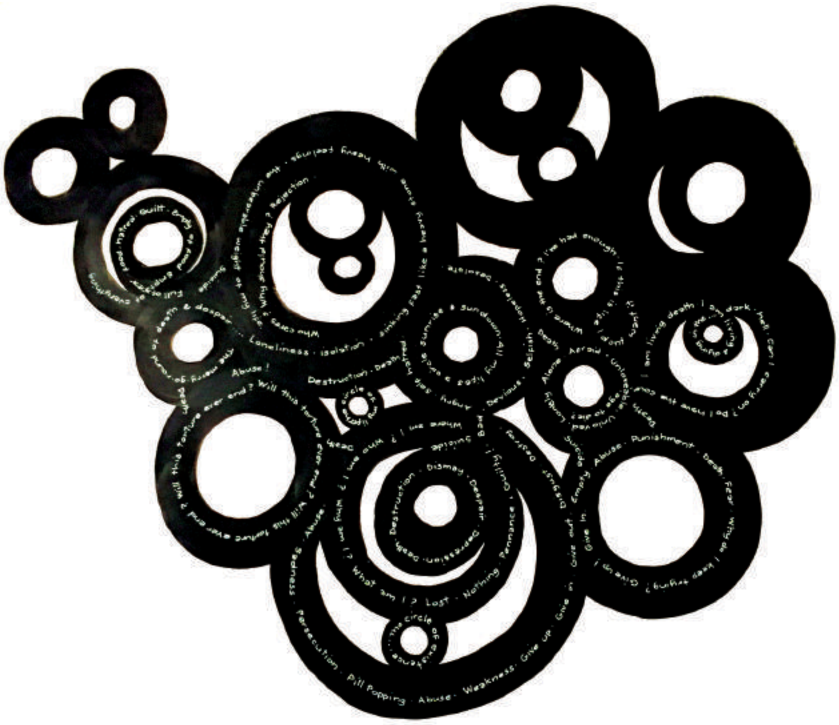
    - When adult patients are admitted to mental health inpatient settings, they will remain under the care of their consultant psychiatrist (generic or ED team)

    - When children or adolescents are admitted to inpatient psychiatric settings, they will come under the care of the consultant child and adolescent psychiatrist for that inpatient unit, with consultation with their ED consultant (unless the latter has admitting rights).

    - All patients admitted medically or to inpatient settings will have the option of specialist case consultation with the ED consultant psychiatrist or consultant child psychiatrist, and ED team for that area.

14.8: Research and development

See Section 17 regarding research network.


Food. hatred. Guilt. Empty
Full of everything
death & despair
Loneliness . isolation . sinking fast like a heavy stone
Who cares
Why should they ? Rejection
Abuse !
Destruction . Death
Will this torture ever end ? Will this torture ever end ?
Where am I ?
Suicide
Destruction . Dismay . Despair
Depression . Death
What am I ? Lost . Nothing . Pennance . Guilty
The circle of existence
Persecution . Pill Popping . Abuse . Weakness . Give up . Give in . Give out
Sunrise & Sundown
Devious . Selfish
Alone . Afraid . Unloved
Death
Empty . Abuse . Punishment . Death . Fear
Why do I keep trying ? Give up !
Give in
I am living death
I've had enough

Education, Training and Workforce Development

15.1: Background

One of the common themes that emerges from the literature on the provision of ED care is that a lack of specialized ED training and clinician skill is associated with poorer outcomes, longer recovery times, higher costs and higher hospital admission rates (Gowers, 2010). Inexperience and clinician self-perception of lack of confidence has also been associated with stigmatized and negative attitudes among staff regarding those with EDs (Thompson Brenner, 2012). Disengagement with services and dissatisfaction with care are likely to be inevitable consequences.

To address this issue at international level, there have been three broad approaches to the training and development of an ED-skilled workforce:

- First, there has been an explosion in the number of short ED clinical training courses being offered in recent years. Virtually none of these have been formally evaluated in terms of educational effectiveness or patient outcome, and many are narrowly focused on one aspect of therapeutic approach, which is inadequate to address the broader complexity of needs of people with EDs.

- A second approach has been to provide training placement opportunities in specialist ED teams for longer periods, with ongoing supervision. This is sometimes accredited by postgraduate training bodies and networks (e.g. RCPsych). In countries with an ED infrastructure, this has worked well and expertise is then brought to other services. The downside is the limit in placement opportunities and high cost of sending staff for away training for long periods.

- A third approach has been to develop longer programmes providing core training in EDs. Again, the literature review indicates a lack of comprehensive evaluation of the quality of these courses to date, and most are not accredited by a recognised education or training body. More recently in international settings, the university sector has stepped into this area in other countries through the development of CPD modules/postgraduate qualifications. Additionally, in NHS England and Scotland, where there has been a formal switch in provider from generic AMHS/CAMHS to specialist ED services, and the NHS is working with a number of collaborating ED specialists to develop a core training programme for all NHS staff working in their dedicated eating disorder teams. This model is of a comprehensive interprofessional induction and CPD programme, including follow-up casework and supervision.

15.2: The role of interprofessional education (IPE)

In addition to the challenge of training up a workforce skilled in ED care, two further challenges will affect the HSE's ability to develop a sustainable, safe and effective ED service, and both can potentially be addressed through training:

- First, the current recruitment and retention crisis in international and Irish health services particularly in relation to mental health comes at a time of rising population, clinical chronicity and diminishing mental health resources. This has led to depleted services, lengthy internal and external waiting times, and an overreliance on inpatient eating disorder care.

- Secondly, people with EDs in particular are likely to encounter a wide variety of doctors, allied health professionals, and teams from across primary care, acute and mental health settings. They will therefore usually encounter great complexity in the health system and require greater formal cross-service collaboration and integrated care pathways. Greater complexity breeds increased risk and safety concerns when it comes to healthcare, especially for those with EDs (RCPsych 2012).

In 2010, the World Health Organisation, in its 'Framework for Action on Interprofessional Education and Collaborative Care', endorsed the view that, to address these twin global issues, interprofessional educational (IPE) was the essential key to increasing workforce capacity and improving collaborative practice (WHO, 2010). IPE is defined in Box 15.1 and differs from traditional 'unidisciplinary' and 'multidisciplinary' educational approaches, the latter of which involves parallel learning.

Across mental health, effective team-based collaborative care has been associated with increased patient satisfaction, reduced error and safety incidents, and increased patient engagement, including for those with severe and enduring mental illness (Malone, 2007). However, it is not without its challenges in the context of the multiple professional boundaries in healthcare (Ferlie, 2005). Studies on the impact of training on health professionals have found that IPE is associated with higher team satisfaction, improved implementation of evidence-based practice, fewer errors, and lower need for inpatient stays (Hammick, 2007; Sargeant, 2011; Morey, 2002; Bleakley, 2012; Lee, 2013; Brock, 2013; WHO, 2010). IPE and collaborative care do not replace the specialist skills of individual professional disciplines, but enhance them while improving clinician and team flexibility, which in turn improves access to care.

Box 15.1: Definition of interprofessional education (IPE)

> ***“Interprofessional Education occurs when two or more professions learn, with, from and about each other, to improve collaboration and the quality of care”*** (CAIPE, 2002)

15.3: The Irish context

15.3.1: Current undergraduate and postgraduate ED training

- **Undergraduate education**

Undergraduate students report that EDs have not traditionally been included in most of the undergraduate curricula for medical and allied health professional degree courses in Ireland. When included, ED education has generally been limited to a single lecture or tutorial, with no patient involvement or clinical opportunities.

- **Professional postgraduate training**

Eating disorders have traditionally been included minimally in generic professional training programme curricula (e.g. psychiatry, psychology, nursing), if at all. Due to their complexity and the small case distribution across generic teams, in practice, most mental health professionals have therefore treated few or no people with EDs by the time they have attained their professional qualification.

- **Post-professional qualification**

After qualification, and in line with current uniprofessional funding steams within HSE, any interested clinicians seek out individual short courses or training opportunities funded by their departments or through independent self-funding. Many such formal training programmes for FBT, CBT-E, IPT, etc are accessible to any qualified, experienced mental health clinician once they have a background in psychotherapeutic work as part of their training and the opportunity to work with enough people with eating disorders

15.3.2: Recent ED education and training initiatives in Ireland

HSE Clinical Programme

Recently, there have been a number of new initiatives within HSE to address these training gaps and to lay foundations for the implementation of the NCPED Model of Care.

- Since the NCPED was first announced (in 2013), a number of interprofessional CPD groups focused on eating disorders have been developed in Cork, Cavan, Kilkenny, and Dublin. These meet regularly for CPD, peer supervision and case discussion and, in some cases, run group or sector-wide clinical initiatives.

- Since 2014, the HSE NCPED has collaborated with both CREDO at Oxford University and the FBT Training institute at Stanford University in order to begin the development of its future ED workforce. Training has been provided in the two most evidence-based first-line treatments for EDs as these have the best outcomes in terms of early intervention: FBT and CBT-E. To date:

  - 63 mental health clinicians nationally from five clinical disciplines have been accredited in CBT-E from across child and adult mental health teams nationally, and through an innovative online and case supervision-based formal research evaluation. A further 33 are currently accessing online training.

- 73 clinicians from CAMHS have received basic training in FBT. From this, a three-year workforce development programme towards accreditation for key clinicians is being rolled out. An Irish FBT supervisor is also being trained in addition to some other clinicians being accredited and the development of an FBT supervision group network.

- 8 CBT-E supervision groups are now in place nationally, facilitated though CREDO.

- 8 FBT peer supervision groups are in place nationally.

- National FBT and CBT CPD days were held in 2016 and 2017.

- An ED annual update for all mental health teams was piloted in Cork in 2016, with 55 attendees from adult and child teams Cork/Kerry. This took an interprofessional, adult learning workshop approach.

To date, formal educational evaluation of the above initiatives suggests that key protective factors for clinicians working with eating disorders are ongoing supervision groups, clinician prior experience with EDs, and having a designated role in the team in providing ED care. Barriers to implementation have been low levels of referrals in small sectors, working in isolation, lack of confidence, and competing clinical demands (McDevitt, 2014, 2015). Evaluation of these programmes is ongoing.

Other professional body and support initiatives

- The College of Psychiatrists of Ireland (CPsychI) has commissioned two-day training in EDs for basic and higher specialist psychiatry trainees since 2015 as part of its core training curriculum. In 2014, it established an ED special-interest group (EDSIG) in order to promote and support ED training, standards and CPD within Irish psychiatry for both trainees and consultant psychiatrists. All consultant psychiatrists are currently registered in one of the four psychiatric specialist divisions of the Medical Council . The CPsychI and EDSIG plan to develop specific guidelines on additional experience and competencies that would be recommended for future consultants leading the dedicated ED teams. Specialist ED placements will also be developed in collaboration with the Postgraduate Training Department. The CPsychI is collaborating with the HSE in the development of these future ED training initiatives.

- The Nursing and Midwifery Planning and Development Unit (HSE Dublin North) is currently developing a national guidance document to equip both medical and psychiatric nurses in Ireland with a holistic understanding of EDs. This will provide them with knowledge and skills to assist them in the assessment, management and therapeutic engagement with individuals who are experiencing an eating disorder. It is envisaged that this will align with the educational aims of the NCPED, with both programmes being in active communication and collaboration.

- A number of interprofessional training initiatives now take place regularly for medical staff working with EDs – e.g. National Children's Hospital, St Vincent's Hospital, and nationally.

- Bodywhys takes an active and collaborative role in the delivery of professional training and CPD in EDs through their work in presenting at HSE training events for professionals on the patient perspective, their research and services, and also through the provision of psycho-educational material.

15.4: Education and training strategy of the NCPED

- Based on the clinical requirements of patients with EDs, the published literature on EDs, IPE, ED training and workforce development, and on the evaluation of HSE's own ED training programme to date, it is essential that this clinical programme develops an evidence-based strategy for the development of its ED workforce that is comprehensive, evidence-focused, effective and sustainable. A goal for the NCPED in 2017/18 will be to develop a comprehensive and detailed educational strategy.

- Key to the effectiveness of the HSE's training strategy is an acknowledgement that clinicians coming to work in the HSE ED programme will have benefited greatly from other ED training they have received elsewhere through their professional bodies, universities and other organisations. The focus in the NCPED educational strategy and its Model of Care is not to replace other initiatives, but to focus on ensuring that the HSE supports its clinicians and teams to meet the overall goals of the NCPED: quality and safety, value for money and access in ED service provision.

Box 15.2 summarises the 10 key principles and five components that will underlie the HSE education and training strategy for its ED network.

Box 15.2: HSE education, training and workforce development strategy

10 principles

- Interprofessional education approach
- Includes a focus on collaborative care/ team training
- Areas of greatest clinical need to be prioritised first for training
- Focused on evidence-based treatment
- Common evaluation standard for all training programmes
- Sustainability of learning through clinical supervision
- Experienced mental health staff, in order to maximise retention of learning, deliver more specialised ED treatments and to supervise others
- National strategic approach to training: training priority for those with high clinical ED workloads and need
- Service-user collaboration in training programmes
- Knowledge translation: passing on the learning

5 components

Training in the HSE ED network

- Core interprofessional clinical training programme for all ED staff
- Clinical supervision structures
- Any specific ED training will focus on treatments recommended in current CPG/BPG

Training of others (Mohanna, 2011)

- Provide education to others: collaboration with other clinical programmes, ICGP etc. in the co-delivery of training at CHO level

Supporting others in their ED training:

- Support ED staff to support discipline-specific undergraduate and postgraduate training initiatives within HSE, professional bodies, universities, etc.

15.4.1: Core interprofessional clinical training

- The HSE Clinical Programme will establish an interprofessional education and training advisory subgroup comprised of key experts in eating disorders and in education in order to advise on developing a collaborative IPE core training curriculum.

- This curriculum will include the key competency areas identified by the working group and which are based on the literature to date (see Figure 15.1). The purpose of training is to enable the ED hub to function effectively, flexibly and safely and provide patients with EDs with the treatment they need, when they need it.

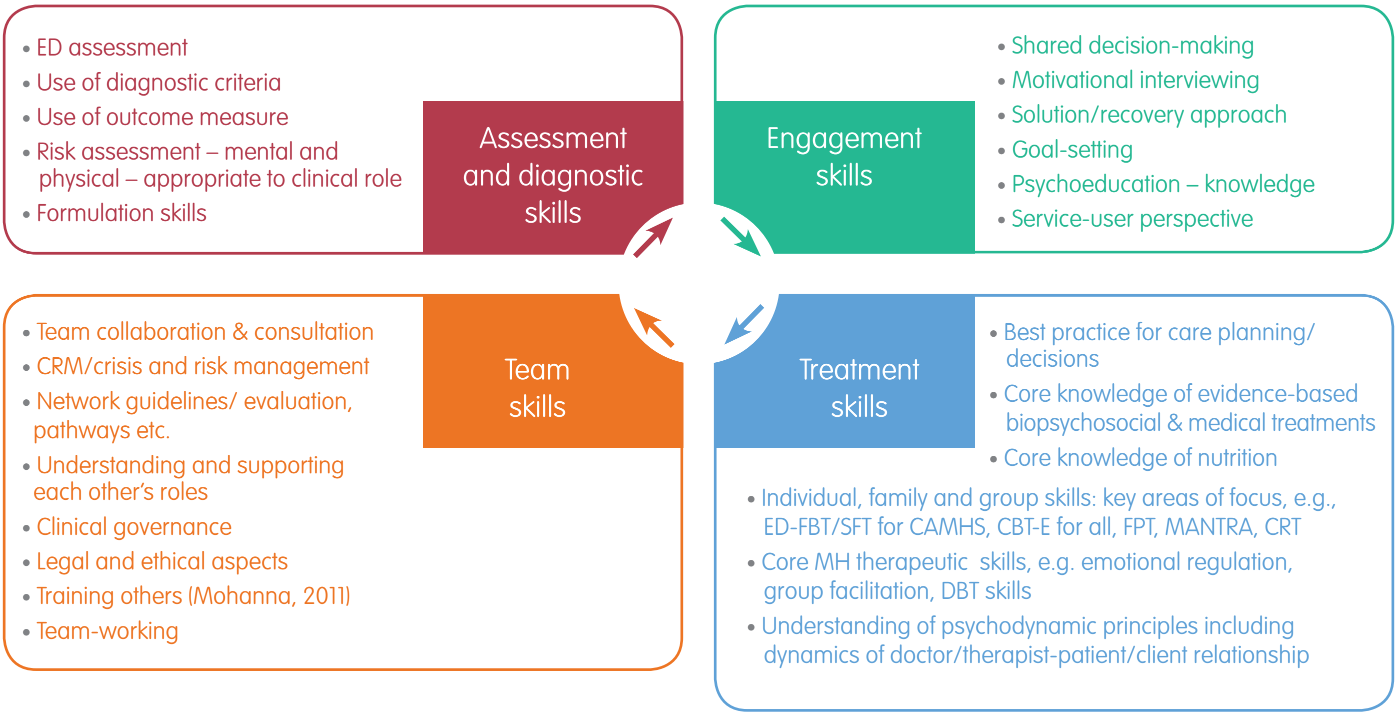
- Many of the uniprofessional educational initiatives mentioned above in section 15.3.2 are likely to include content that can be adapted easily for an interprofessional audience.

- The development and delivery of the core training may also involve collaboration with third-level institutions and professional bodies in terms of shared accreditation, CPD modules, and resources.

- In the context of staff turnover and sustainability, any such programme is likely to require a strong online and clinical case supervision component in order to ensure that new staff in the future will not have to wait long to access programmes and so that that learning is translated as soon as possible into clinical practice.

- The HSE core training will also need to be supported by annual CPD updates on new developments in ED care and to be aligned with other staff CPD requirements.

Figure 15.1: Current recommendations of focus in the core curriculum for the NCPED



Assessment and diagnostic skills

- ED assessment
- Use of diagnostic criteria
- Use of outcome measure
- Risk assessment – mental and physical – appropriate to clinical role
- Formulation skills

Engagement skills

- Shared decision-making
- Motivational interviewing
- Solution/recovery approach
- Goal-setting
- Psychoeducation – knowledge
- Service-user perspective

Team skills

- Team collaboration & consultation
- CRM/crisis and risk management
- Network guidelines/ evaluation, pathways etc.
- Understanding and supporting each other's roles
- Clinical governance
- Legal and ethical aspects
- Training others (Mohanna, 2011)
- Team-working

Treatment skills

- Best practice for care planning/ decisions
- Core knowledge of evidence-based biopsychosocial & medical treatments
- Core knowledge of nutrition
- Individual, family and group skills: key areas of focus, e.g., ED-FBT/SFT for CAMHS, CBT-E for all, FPT, MANTRA, CRT
- Core MH therapeutic skills, e.g. emotional regulation, group facilitation, DBT skills
- Understanding of psychodynamic principles including dynamics of doctor/therapist-patient/client relationship

15.4.2: Clinical supervision

When run effectively, clinical supervision programmes build on formal training programmes, sustain skills, enhance efficacy, and improve safety and collaboration on clinical cases. This will be particularly important for clinicians not working directly within a dedicated ED hub team. Such clinicians should have the opportunity to avail of educational supervision of their ED work, though teleconferencing/videoconferencing if needed. Any clinician working regularly with EDs in a given CHO or hub areas should be included when planning clinical supervision networks.

Clinicians working in the HSE ED teams will have access to supervision through the following:

- Professional supervision provision through existing arrangements with their local line management professional structure
- Case supervision via the clinical leadership of the consultant psychiatrist on the ED team to whom they can go for consultation, advice or support
- The working group also recommends that clinicians on the ED teams have access to regular peer clinical supervision groups through their ED team/network
- Any formal supervisory component required for their training in a particular therapy – the existing FBT and CBT-E clinical supervision groups may be examples of such programmes

15.4.3: Specific ED-focused training

The NCPED will continue to focus its training strategy on prioritising internationally evidence based specialist training in EDs for clinicians so that the model of care can be delivered. As well as its ongoing support for the FBT and CBT-E programmes, the next treatments of focus will include MARSIPAN/Junior MARSIPAN training at national level, , SSCM, MANTRA and IPT- BN, and a focus on intensive treatment and day/group intervention programmes.

15.5: Provision of education to others

A key role of the local ED hub teams and the NCPED will be to support the development and sustainability of clinicians and services who encounter patients with EDs in the broader HSE services, such as AMHS/CAMHS, acute hospitals and primary care. This will include collaborating and supporting ED training initiatives with ICGP, local primary care, hospital departments and universities. Bodywhys has already taken a role as a collaborator in this area, having a history of engaging in such educational initiatives. The national and local ED network will collaborate in the development of educational material about EDs for referrers, GPs and primary care services in their area (e.g. how to screen, access help and appropriate care pathways for patients with EDs, self help support etc.). Pilot projects on Irish GPs has suggested that simple, electronic dashboards and toolkits can improve GP case recognition, risk management and confidence in caring for people with eating disorders in an Irish setting (O'Callaghan, 2015; O'Sullivan, 2013).

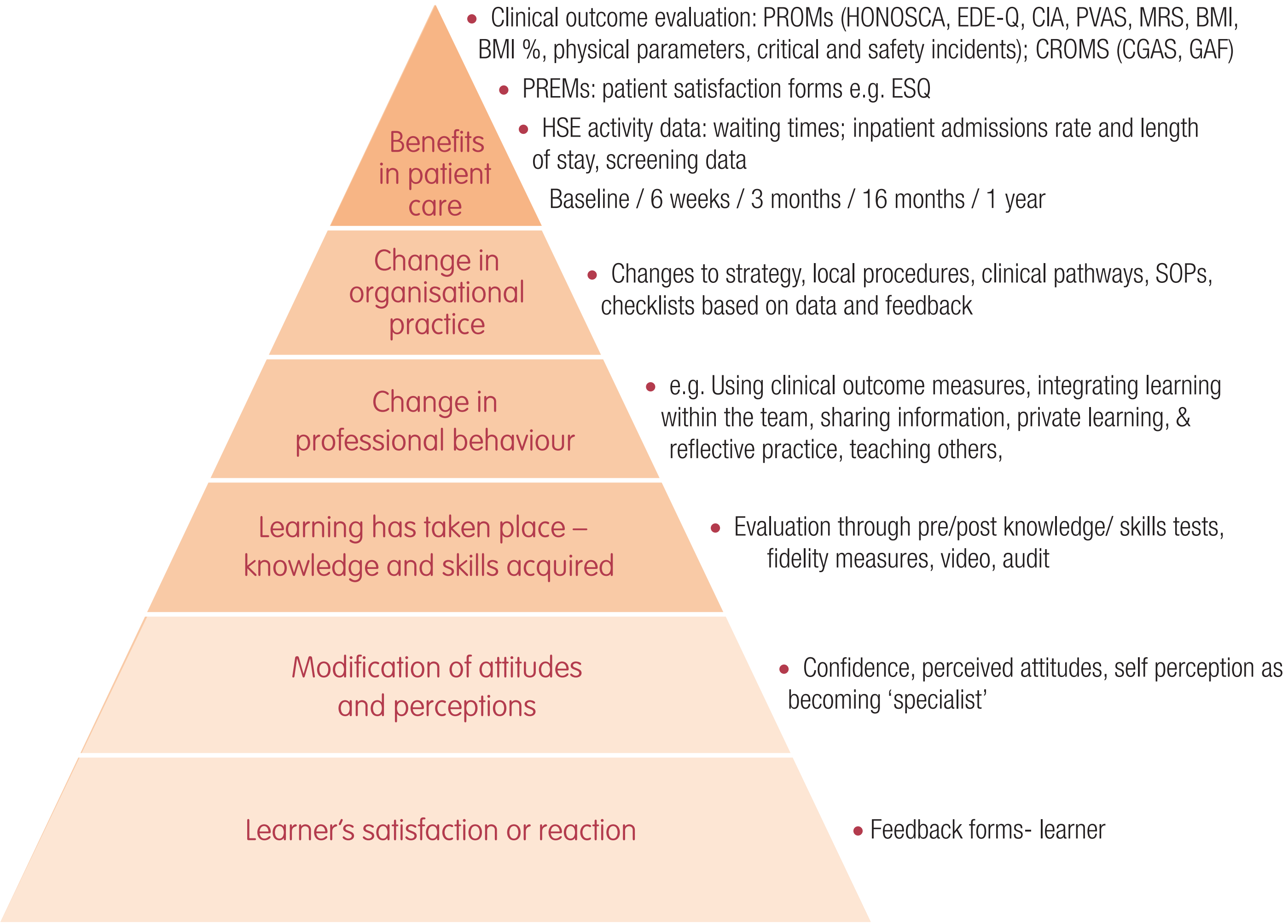
15.6: Evaluation of training and education programmes under the NCPED

In order to ensure that all the training initiatives that are supported or endorsed by the HSE NCPED present value for money and benefit for patients, clinicians and HSE, all of the education, training and staff development programmes supported through HSE will be subject to formal educational evaluation.

Figure 15.2 displays an example of an established evaluation framework for training which is adapted here for illustration of how it may work in an eating disorder training context. The proposed dataset for the clinical and service evaluation of the NCPED itself will also assist in providing data on the effectiveness of future clinician training programmes (see Section 16).

Figure 15.2: Kirkpatrick's hierarchical model adapted for evaluation of the effectiveness of a clinician training programme for eating disorders

(Adapted from Kirkpatrick's levels of evaluation, and Barr, 2001)



- Clinical outcome evaluation: PROMs (HONOSCA, EDE-Q, CIA, PVAS, MRS, BMI, BMI %, physical parameters, critical and safety incidents); CROMS (CGAS, GAF)
- PREMs: patient satisfaction forms e.g. ESQ
- HSE activity data: waiting times; inpatient admissions rate and length of stay, screening data

Baseline / 6 weeks / 3 months / 16 months / 1 year

- Changes to strategy, local procedures, clinical pathways, SOPs, checklists based on data and feedback

- e.g. Using clinical outcome measures, integrating learning within the team, sharing information, private learning, & reflective practice, teaching others,

- Evaluation through pre/post knowledge/ skills tests, fidelity measures, video, audit

- Confidence, perceived attitudes, self perception as becoming 'specialist'

- Feedback forms- learner

Evaluation and Metrics

As the National Clinical Programme for Eating Disorders (NCPED), through this Model of Care, evolves to deliver the HSE's three goals of quality and safety, good access and value for money, it will require a robust, formal, and evidence-based approach to its evaluation from the outset.

The working group referenced international best-practice standards on mental health, ED services and outcome evaluation in order to formulate an initial strategy and minimum dataset for the NCPED. This included a review of recommendations by the International Academy of Eating Disorders (2012), National Collaborative Centre for Mental Health (UK) (2015), Child Outcomes Research Collaborative (CORC, 2015), and the RCPsych (2015), in addition to the broader literature on service evaluation. Specifically, the systematic evaluation of this programme will be based on the principles outlined in Box 16.1.

Box 16.1: Principles underlying the evaluation model of the NCPED

- Enables monitoring of the key goals, including patient access to services, external access waiting times to assessment, internal waiting-list times to access evidence-based treatment; access to medical consultation and inpatient admission when clinically needed, DNA rates etc (Bjork, 2008).
- Includes a component that is clinically meaningful and useful to clinicians on the ground. By obtaining timely feedback on clinical outcomes, clinicians can evaluate their clinical impact and performance with their patients, individually, as a team and as an ED network. This enables adjustment where needed, or can reassure if on track (Boswell, 2015). This helps to improve patient outcomes (Davidson, 2014; Knaup, 2009).
- Includes information on clinician and team caseload, level of care and cost, so that managers and teams can be accountable for their decision-making in allocating clinical resources at national, CHO and team level. The aim is to use the most evidence-based interventions efficiently and effectively.
- Enables barriers and gaps at local and national level to be identified and addressed in a systemic and evidence-based manner; e.g. evaluating the translation of knowledge from training into patient care and which training has had most impact for patients.
- Includes data on the ED programme though the 360° use of multiple reflective lenses: clinician, service user, family, hub team, manager, national ED network – i.e. fully evidence-based.
- Is feasible and acceptable for patients: this means striking a balance between 'questionnaire overload' and in patients providing information that will help them personally (recovery curve, safety, collaborative feedback on their progress) as well as to improve their services. A number of studies indicate that clinical outcome evaluation is associated with improved experience and outcomes for patients at risk of treatment failure and that it enhances collaboration and shared decision-making (Wolpert, 2014; Moran, 2012; Davidson, 2014; Bjork, 2008).
- Is feasible and acceptable for clinicians. This means that the evaluation model:
    - Includes data which is clinically in use where possible, albeit informally

- Is clinically relevant for work in tracking progress, focusing on problem areas, enabling difficult conversations with patients (Law, 2014)
- Can be also used in supervision and reflective professional development, individually and within the clinical team (Law, 2014)
- Includes that PROMs (Patient Reported Outcome Measures) and CROMs (Clinician Reported Outcome Measures) have a track record as being psychometrically and practically sound and collaborative (Wolpert, 2014)
- Is easy to interpret clinically
- Acts as a support to clinicians, but does not preclude use of other measures and clinician judgement. (Van Noorden, 2012)
- Is efficient and easy to use

- Includes a process of review, including feedback from clinicians and patients to ensure the evaluation component of this Model of Care is working optimally. Formal review of the evaluation model at 1 and 3 years.
- Researchs and shares findings to enhance confidence in the National Clinical Programme for Eating Disorders with the public, clinicians, HSE and other agencies.
- Is sensitive to cost. Where clinical measurement tools are approximately equal in psychometric properties and value, the ED programme will first use those which are freely available.

16.1: Evaluation metrics

Table 16.1 summarises the minimum clinical dataset that is recommended in order to evaluate the effectiveness of the ED programme in terms of its impact for adults and children with EDs who attend HSE services. This is not exhaustive. ED clinicians may well decide to use additional screening instruments (e.g. EAT/ChEAT) or more formal interview-based measures (EDE, EDI-3, etc). Table 16.2 summarises the activity metrics with measures mapped onto the HSE aims and objectives for its clinical programmes (Section 4).

16.2: Data collection

Much of the activity data in the activity dataset is already collected by HSE from generic AMHS/CAMHS teams, though not by diagnosis as in the case of this programme.

- Many of the clinical measures are being collected routinely by FBT and CBT-E clinician networks on a case-by-case basis to track progress and for supervision, However, their use is often not comprehensive or consistent enough to track wider progress of a clinicians caseload.
- A key role of the team clinical coordinator will be to centralise data collection and collation within the hub, as well as to work with the national ED programme and team in developing systems to assist in the evaluation and audit process.
- The ongoing use of paper-based questionnaires in the mental health service requires substantial clinician time for data entry and analysis. In practice, much of this data also becomes unused beyond the immediate clinical session, and this can be a waste from a clinical, audit, evaluation and service improvement perspective. An electronic format for data collection and entry is recommended in order to enable efficient analysis in clinical services. The costs of this are likely to be much lower than the time taken by clinicians to do this work manually.

- **National Eating Disorder Register**

People with eating disorders present and transition between primary care, mental health and acute hospital settings, all with different data and IT infrastructure. Together with the lack of a unique patient identifier, this inhibits communication and the comprehensive evaluation of mental health services and the ED programme. The working group therefore recommends the establishment of a National Eating Disorder Register, similar to that used for other specified medical conditions, so that the patient journey can be properly monitored and understood for the purpose of improving services, patient outcomes and safety.

Table 16.1: Recommended clinical outcome and quality evaluation metrics (each case)

Purpose

- To enable the individual clinician and local ED team to clinically audit their work
- To enable 360° progress tracking and collaborative care planning for individual patients with their clinician and at team level
- To assist the clinical team in collaborative decision-making around service improvement, professional development and learning
- Broader recovery focus than just weight

Each Case

When?	**What?** *Which clinical tool or instrument?*	**Why?** *Domain being considered*	**How often? How to gather?**
Baseline assessment 6 weeks 3 months 6 monthly At discharge	DSM 5/ ICD 11 Diagnosis	Diagnostic classification	Collected by individual clinicians to evaluate progress on case-by-case basis Anonymised team data is then collated by team coordinator monthly for local clinical evaluation, clinical audit, service improvement
	EDE-Q[1]	ED Psychopathology- (PROM)	
	CIA[3]	Quality of life measure (PROM)	
	HONOS/HONOSCA[2] (consider MFQ[7].)	Comorbidity	
	CGAS[5] (child) or GAF[4] (adult)	Clinician-rated outcome measure (CROM)	
	ESQ[8]	Patient experience (PREM)	
	BMI if over 18, %BMI if <18 years	Physical parameter (risk and safety)	
	Physical risk severity	Monitoring of risk (CROM)	
	DSH category (NCP-DSH metric)	Suicidality (PROM)	
	Psychotropic medication	Other treatments needed	
	PVAS[6] (if < 18)- consider SCORE 15	Measure of carer functioning	
	Main therapeutic approach (multiple)	Measure of evidence base	
	Bodywhys engagement (yes/no)	Receiving support services	
	Substance use	Comorbidity	
At baseline	Gender	Demographics	
At baseline	Age category – range	Demographics	
At baseline	Electoral area	Demographics	

1. Eating Disorder Examination Questionnaire (EDE-Q); 2. Health of the Nation Outcome Scales/Children and adolescents (HONOS/HONOSCA); 3. Clinical Impairment Assessment 3.0 (CIA); 4. Global Assessment of functioning scale (GAF) 5. Children's Global Assessment Scale (CGAS), 6. Parent Versus Anorexia Scale (PVAS), 7 Mood and Feelings Questionnaire; 8. Experience of Service questionnaire

Table 16.2: Recommended – access, quality and cost metrics for the NCPED

Purpose

National evaluation of HSE ED programme to ensure its goals of: access, safety & quality, and value for money

Each Team **When?**	**What?** **Which domain?**	**Why?** **How to gather?**	**How often?**
Assessment	No. of cases referred and referrer	Access to assessment	Collated by team administrator and coordinator Submitted monthly by the coordinator to leadership/management for purpose of evaluation, service improvement and reflection
	Source of referral	Access to assessment	
	No. of consultations (i.e. FtF or by phone)	Access to advice	
	No. of assessments offered	Access to assessment	
	No. of assessments declined	Access and value	
	Time from referral to assessment	Access to assessment	
	No. of assessment DNAs	Access, value for money	
MH treatment	Total no. of clinical appointments offered and by type (individual or group)	Value for money	
	No. of first treatment appointments offered	Access to treatment	
	Time from assessment to 1st treatment session	Access to treatment	
	No. of treatment appointments declined	access, value for money	
	No. of clinical sessions provided	Access, value for money	
	No. of clinician sessions	Value, access,	
	No. of inpatient admissions	Safety, access, value for money	
	No. of day-patient admissions	Safety, access, value for money	
	No. of open cases, by how long open	Effectiveness; value	
	Type of psychosocial intervention	Quality	
	No of discharges	Effectiveness, value	
	Referrals to private treatment	Value for money, access	
	Referrals abroad for treatment	Value for money, access	
Acute Hospital	No. of admissions	Access, safety	
	Dietitian reviews	Access, safety	
	Length of stay	Access, safety, value	
	Special nursing	Safety, value	
	ICU	Safety, quality	
	NG feeding	Safety, quality	
	Deaths	Safety, quality	
Inpatient Psych	TBA		

16.3: Timeframes in the NCPED model of care

- The timeframes that are recommended for the collection of the clinical outcome data (Table 16.1) are based on literature review, on knowledge that improvement in the early weeks of treatment is a key predictor of progress (Waller, 2014), and on the clinical experience of both the working and clinical advisory groups. Baseline, three months, six months, then six-monthly and at discharge have been identified as key timeframes for the tracking clinical progress during the patient journey. The dataset and timeframes summarised in Table 16.1 will be piloted and reviewed within one year of commencement in order to evaluate the feasibility and utility of the data that is being measured.

- It is noted that some of the clinical measures mentioned above are used even more frequently by clinicians. For example, the ED-15 is a session-by-session measure to map progress more closely in the early stages of treatment, and at four weeks many clinicians would then repeat the longer EDE-Q and CIA. The timeframes in the model of care are as a minimum standard, and other monitoring is at the clinicians discretion.

- Similarly, the physical risk score and BMI (%) timeframes mentioned here are for evaluation purposes only. Clinically, it is recommended that weight be measured weekly in the early months of treatment until the patient is stable, and that full physical risk be reviewed regularly; e.g. weekly or daily in the case of severely unwell/inpatient status. The RCPsych recommends that even for stable patients, a 6 weekly full review of physical status with a psychiatrist every six weeks is required (RCPsych, 2016).

16.4: Data protection act

Clinical data collected through evaluation of the programme, whether in paper or electronic form, is part of the patient record and will come under the remit of the Data Protection Amendment Act (2003) in terms of access, safety, storage, rights, etc.

16.5: Use of data for evaluation, clinical audit and research

Where clinical evaluation and audit is being undertaken by the ED hub team or network as part of its ongoing quality improvement and service development , data will be anonymised and collated in order to protect individual patient confidentiality.

Where ED research is planned within the team, by the ED network or in collaboration with external researchers/universities that involves access to clinical data, this will be subject to the usual formal ethical approval by the relevant local ethics committee(s), so that that appropriate ethical standards on patient confidentiality, anonymity and rights are maintained. (Section 17).

16.6: Review period

Formal review of the effectiveness of the HSE NCPED and this Model of Care in terms of quality, access and value for money will take place initially at three years, and then as an annual ongoing process of evaluation. These review will include:

- A review of the programme activity and benefit to people with eating disorders: the metrics, measures, timeframes and patient outcomes, as outlined above.

- Feedback from clinicians and patients on the ground in terms of their experiences of the clinical programme, of the outcome metrics and with the goal of iterative and reflective learning cycles of service improvement.

Research Network

As mentioned in Sections 2 and 7 of this Model of Care, there are many gaps in our knowledge and understanding of eating disorders and their effective treatment, particularly relating to:

- Treatment: some conditions which still have quite a limited research basis
- Aetiological basis of eating disorders
- Variable definitions of recovery and good outcome for patients
- Treatment effectiveness in a real-world, non-university setting
- Patient experience of recovery – cognitive, emotional and functional
- Impact on carers and families
- Treatment of patients with comorbidity
- Eating disorders in males
- Severe and enduring EDs
- Socio economic cost of eating disorders and eating disorder care in Ireland
- Intensive treatment: what and for whom
- The role of exercise

The National Clinical Programme for Eating Disorders offers a unique and powerful opportunity to contribute to the global understanding of patients with EDs and the development of better treatment programmes for their care through clinical and service research partnerships. It has the benefits of being a national public service, with a centralised network of teams working together, a robust clinical evaluation programme, has an integrated service model across the age range, and a newly trained, skilled clinical workforce.

In the same way that collaborative clinician-researcher partnerships have enhanced cancer research and treatment in Ireland and abroad, the NCPED will aim to support clinical and service research in EDs in Ireland where it can. A key challenge will be to ensure that the research is robust enough to be meaningful in terms of study power, impact and relevance for patients.

The research strategy of this clinical programme is to:

- Promote a research culture that involves partnership between clinician, researcher and people with eating disorders
- Collaborate with the HRB and other large funders of research, and advocate for a focus on the funding of ED research by those groups
- Maintain a register of research projects that are undertaken within the NCPED in order to avoid duplication, enable hubs to link, ensure research governance is maintained, and support feasibility, sample power, acceptability, completion and publication.
- Collaborate with universities and relevant third-level institutions in providing opportunities for medical and allied health students with undergraduate, Master's or doctorate-level research requirements, and to collaborate with clinicians on important, clinically relevant ED research questions and projects.
- Support research by HSE-ED clinicians in relation to research into patient recovery and experience, clinical outcomes, and treatment effectiveness.
- Ensure that such clinicians have access to software for analysis such as SPSS and NVIVO in order to complete this clinical research, with links to supports where needed.
- Actively support patient involvement in research through leaflets and posters when research projects are robust, supervised and ethically approved, while also clearly separating research involvement from issues of clinical care.
- Disseminate the results of evaluation and research projects to people attending the service and to the wider public.

Appendices

Appendix 1: Key international clinical practice standards

International service and clinical practice standards reviewed by the working group

Table 1: Key clinical practice service standards used in formulating HSE Model of Care

- Clinical Practice Guidelines for the Treatment of Eating Disorders (adult and child) (2014). Royal Australia and New Zealand College of Psychiatrists (RANZCP).
- Practice Parameters of the American Academy of Child and Adolescent Psychiatry(2015) (AACAP
- Clinical practice recommendation for residential and inpatient ED programmes. (2012).Academy of Eating Disorders (AED), 2012.
- Worldwide Charter for Action on Eating Disorders (2008) AED, 2008.
- MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa (2014), 2nd edition. RCPsych.
- Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa CR 168 (2012) RCPsych.
- Access and Waiting Time Standard for Children and Young People with an Eating Disorder. (2015) National Collaborating Centre for Mental Health, NHS.
- Practice guideline for the treatment of patients with eating disorders (2006) APA.
- Guideline Watch: Practice Guideline for the Treatment of Patients with Eating Disorders (2012), 3rd edition, APA, Yager, 2012.
- Eating Disorders in the UK: Service distribution, service development and training. (2012) RCPsych.
- Future directions for Eating Disorder services in New Zealand. (2008) MOH.
- NSW Service Plan for People with Eating Disorders 2013-2018.(2013) NSW government
- Eating Disorders in Scotland: Recommendations for management and treatment. (2006) NHS, Quality Improvement Scotland
- Guidance for commissioners of eating disorder services. (2013) Joint Commissioning Panel for Mental Health, UK.
- Position of the Academy of Nutrition and Dietetics: Nutrition intervention in the treatment of eating disorders (2011) Academy of Nutrition and Dietetics
- Clinical Practice Guidelines for the BC Eating Disorders Continuum of Services (2011). BC Ministry for Health.
- Position Paper of the Society for Adolescent Health and Medicine: Medical Management of Restrictive Eating Disorders in Adolescents and Young Adults. (2015) SAHM.
- NICE Guidelines- Eating Disorders in Over 8's (2004) – NICE
- NICE Guidelines- Recognition and Treatment of Eating Disorders (2017) NICE and draft (2016)
- ESCAP Expert Paper: New developments in the diagnosis and treatment of adolescent anorexia nervosa – a European perspective, 2015.
- Individual psychological therapy in the outpatient treatment of adults with anorexia nervosa – Cochrane Reviews (2015), Hay et al.
- Meta-analysis on the efficacy of pharmacotherapy versus placebo on anorexia nervosa (2014). De Vos, JED.
- Clinical Practice Guideline for Eating Disorders – Madrid: Quality Plan for the National Health System of the Ministry of Health and Consumer Affairs (2009).DOHCA.
- The Diagnosis and Treatment of Eating Disorders. Clinical Practice Guideline of the following societies: DGPM, DKPM, DGKJG, DGPPN, DJPS and AWMS. German Eating Disorder guidelines (2011).
- Maudsley Guidelines (2015) 15th edition.
- Eating Disorder Service Operational Policy: Delivering across the age range (2012). Wales – Aneurin Bevan Health Board/NHS.
- Family-based treatment of children and adolescents with anorexia nervosa: Guidelines for the community physician (2010). Findlay et al. Canadian Paediatric Society.
- World Federation of Societies of Biological Psychiatry (WFSBP), Guidelines for the pharmacological treatment of eating disorders. (2011) Aigner et al, WFSBP Task Force on Eating Disorders.

Appendix 2: Medical risk management resources

FOR ADULTS:

RCPsych

1. MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa: CR 189.
   Accessible at www.rcpsych.ac.uk/pdf/CR189_a.pdf

2. MARSIPAN Checklist for Really Sick Patients with Anorexia Nervosa.
   Accessible at: www.rcpsych.ac.ik/pdf/CR189checklistXX.pdf

Irspen

3. Guideline document 1: Prevention and Treatment of Refeeding Syndrome in the Acute Care Setting.
   Accessible at www.irspen.ie

FOR PATIENTS UNDER 18YEARS:

RCPsych / RCPaeds / Nutrition

1. Junior MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa: CR 168
   - Summary accessible at www.rcpsych.ac.ik/pdf/cr168summary.pdf
   - Full version at www.rcpsych.ac.uk/files/pdfversion/CR168nov14

2. MARSIPAN Checklist for Really Sick Patients with Anorexia Nervosa.

   Accessible at: www.rcpsych.ac.ik/pdf/CR189checklistXX.pdf

Great Ormond Street Hospital

3. Clinical Practice Guideline on Refeeding of Children and Adolescents. Accessible at: www.gosh.nhs.uk/health-professionals/clinical-guidelines/refeeding-guidelines-children-and-young-people-feeding-and-eating-disorders-admitted-mildred-creak

4. Clinical Practice Guidelines: Nasogastric and orogastric tube management.

   Accessible at: www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasojejunal-nj-and-orojejunal-oj-management

Society of Adolescent Health and Medicine (SAHM)

5. Position paper on the Medical Management of Restrictive Eating Disorders in Adolescents, 2015.
   Accessible at: www.jahinline.org/article/S1054-139x%2814%2900686-7/pdf

6. Position statement on Refeeding Hypophosphatemia in Hospitalised Adolescents with Anorexia Nervosa (2014).

   Accessible at www.Adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/June-14-Refeeding-hypophosphatemia-anorexia.pdf

Appendix 3: Examples of good practice and service initiatives

A. A Student health (primary care) initiative to improve quality and effectiveness of ED screening and monitoring initiative: Student Health Services, University College Cork (O'Sullivan, 2014)

The aim of this project was to develop a clear, evidence-based care pathway for the multidisciplinary team management of Eating Disorders in a student health setting, in the context of a recognition of increased prevalence and impact of eating disorders in the student population. Referral pathways between student health physicians, counsellors, psychiatry and dietitians were agreed and a standardised Template Care Screen was developed based on NICE guidelines (2004) and KCL guidelines, and using the in-house clinical software package (Helix) for use in primary care consultations. This prompted all clinicians to have a consistent approach to the assessment, examination and recording at each attendance and facilitates reporting on outcomes for these students. The template was trialled by GPs in the department. Initial audit indicated that 16 patients had attended with a diagnosis of Eating Disorders (15 female, 1 male) prior to its introduction (2011/12). By December 2013 the total number seen had increased to 33 (3 male) indicating increased effectiveness of the screening. Of these, 15 had co-morbidities (depression, anxiety, stress, ASD and ADHD). 23 students (70%) had a BMI which was stable or improving. 2 students (6%) had BMI's which deteriorated, 1 student requiring leave of absence. 8 students (24%) graduated or were lost to follow-up. The medical team have concluded that the project has given clinicians a clear, time-efficient template to work with, in the screening, monitoring and evaluation of patients with eating disorders who present in a student health (equivalent of primary care) setting, as well as when to refer onward in terms of risk.

B. An ED specialist team and MARSIPAN pilot collaboration in a rural location: Sligo/Leitrim/West Cavan and South Donegal Adult Community Eating Disorders Service (Harron, 2016)

This ED service was started in July 2011 and serves an adult population of 107,659 in a geographically spread rural area across a number of AMHS sectors. The ED service was developed from a CAWT project for mild to moderate eating disorders. The service has also set up a 'virtual' MARSIPAN team in Sligo in 2014 for medically at-risk patients needing medical admission and drew existing staff from hospital, community and mental health settings to work in an integrated way to deliver evidenced-based treatment. This virtual team includes a consultant physician, consultant psychiatrist, eating disorders practitioner and senior dietitian who form and work collaboratively with the patient, as well as nursing and care staff, whilst the patient is in the hospital. Patients are admitted to the observation area of the medical ward which has now developed the greatest expertise in managing eating disorders. The team closely adheres to the principles of the MARSIPAN guidelines, including teamwork where senior decision-makers devise and revise treatment plans that are designed to minimise risk and improve outcomes for patients. Discharge planning is detailed, and one of the aims is to provide seamless continuity of care when the patient moves from the inpatient to outpatient setting. Key staff with ED experience were identified and received MARSIPAN training. Referrals for eating disorders have increased from 11 in 2011 to 46 per annum since the ED outpatient service started, indicating a higher degree of screening and awareness of eating disorders in the area. A total of 137 outpatient referrals have now been made, with pathways from AMHS. To date 7 patients who would previously have needed transfer to Dublin have gone through the local MARSIPAN programme and returned to outpatient care. Previously patients would have had a lower referral for private ED treatment in Dublin. The service has estimated that 376,600 euro has been saved in the first 2 years of the programme through treating patients at outpatient level and managing medical risk locally. Similar J MARSIPAN initiatives are also in operation or being piloted in the National Children's Hospital, Cork University Hospital and Wexford CAMHS.

C: A Bodywhys service user support group/mental health service collaboration to educate and support carers (Parsons, 2016) – adult and child

In 2014, based on the benefits of peer support and peer-led resilience, the PiLaR programme was developed by Bodywhys as a supportive adjunct to formal treatment services. PiLaR is a four-week (one evening per week) programme for family of a person with an eating disorder. Family members come together to improve knowledge, gain skills, and give and receive support from others in similar situations. The groups are facilitated and led by a trained clinician from Bodywhys. Topics covered include understanding eating disorders, managing mealtimes, how to have constructive and supportive conversations, helping siblings, managing anger, coping with relapse, and the recovery process. It has a strong supportive ethos. Thus far, the PiLaR programme has been run 18 times in collaboration with a local HSE mental health service (both AMHS and CAMHS) from across Cavan, Sligo, Dublin, Cork, Limerick, Kilkenny, Tralee, Athlone, Mayo, Waterford. A total of 343 carers of adults and children with eating disorders have attended. Registration is also open to carers from the general population of those not attending HSE, to encourage help seeking and resulting in the breaking-down of stigma and barriers to accessing treatment services. The PiLaR programme is a great example of a collaborative and integrated community-based programme, linking the public provision of HSE services to those in the community who need access to both services and support.

D. An adolescent intensive day treatment programme initiative for anorexia nervosa to support outpatient care – Multifamily Therapy for Anorexia Nervosa in adolescent (MFT-AN): Cork CAMHS

CAMHS in Cork covers a total catchment area population size of 542,196 and mental health services are provided by 8 community CAMHS teams and one regional inpatient unit with an inpatient ED programme. There is no dedicated ED team. In response to a clinical need for an intensive option as an alternative or step down from inpatient treatment, as well as in the context of limited ED resources and staffing in some sectors, the first MFG- AN group was commenced in 2011. Multifamily therapy for anorexia (MFT-AN) is an intensive form of FBT/systemic family therapy which is used for those who have not responded to first-line outpatient treatment, or as a step-down from inpatient care. Families (patient, parents, siblings, significant other relatives) attend for an initial psychoeducational session followed by a 4-day treatment group programme which ran from 9.30-5pm including snacks and lunch. Family, sibling, parent groups and activities are included. 5 follow-up full-day groups take place over the following 9 months to integrate skills into daily life, while the family also gets treatment from their local team. The programme is facilitated collaboratively by a consultant psychiatrist and two family therapists from across the service. MFG-AN has been suggested as an effective, empowering and cost-effective alternative to lengthy adolescent inpatient psychiatric treatment as have adolescent day programmes in general. The MFG-AN programme has now been run 3 times with a total of 16 families having completed the programme to date from across 6 teams. Evaluation indicates that the programme is associated with empowerment and enablement, improved family communication, externalisation of the disorder, acquisition of new skills to fight anorexia and patient satisfaction. It has provided a useful step down and alternative for some families to inpatient care.

Appendix 4: Useful sources of further information on eating disorders for the public and professionals

RCPsych: Patient leaflets and professional resources)

- http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/eatingdisorderskeyfacts.aspx
- http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/eatingdisorders.aspx

Bodywhys, Irish national support organisation

- www.Bodywhys.ie (lo-call 1890200444)

BEAT, UK national support organisation for EDs

- www.b-eat.co.uk

AED, the International Academy for Eating Disorders – US and international professional association, but also has information for people with eating disorders on its website

- www.aedweb.org

King's College London Institute of Psychiatry, Psychology & Neuroscience – resources for professionals and patients

- www.kcl.ac.uk/ioppn/depts/pm/research/eatingdisorders/index.aspx

References

Academy of Eating Disorders (2012). Clinical Practice Recommendations for Residential and Inpatient Eating Disorder programs. www.aedweb.org

Academy of Eating Disorders. (2014). Worldwide Charter on Eating Disorders. www.aedweb.org

Academy of Eating Disorders (2015) Nine Truths about Eating Disorders. www.aedweb.org

Adams RJ. Improving health outcomes with better patient understanding and education. *Risk management and healthcare policy*. 2010: 3, 61-72.

Aigner M, Treasure J, Kaye W, Kasper S and WFSBP Task Force on Eating Disorders (2011). World Federation of Societies of Biological Psychiatry (WFSBP), Guidelines for the pharmacological treatment of eating disorders. *World Journal of Biological Psychiatry*, 12: 400-443.

Allan B, Sharma R, Sangani B, Hugo P, Frampto I, Mason H, Lask B (2010). Predicting the weight gain required for recovery from anorexia nervosa with pelvic ultrasonography: an evidence based approach. *Eur Eat Disord Rev*, 18 (1): 433-8.

AND (2011). Position of the Academy of Nutrition and Dietetics: Nutrition intervention in the treatment of eating disorders.

American Academy of Child and Adolescent Psychiatry (2015). Practice Parameters for Child and Adolescent Eating Disorders.

American Psychiatric Association (APA) (2006). Practice guideline for the treatment of patients with eating disorders.

American Psychiatric Association (APA) (2012). Guideline watch: Practice Guideline for the treatment of patients with eating disorders. 3rd edition.

American Psychiatric Association (2014). Diagnostic and Statistical Manual of Mental Disorders, 5th edition: DSM-5.

Arcelus J, Mitchell AJ, Wales J. (2011). Mortality Rates in Patients with Anorexia Nervosa and Other Eating Disorders. *Arch Gen Psychiatry*, 68 (7): 724-731.

Bailey AP, Parker AG, Coulatti LA, Hart LM, Liu P, Hetrick SE (2014. Mapping the evidence for the prevention of eating disorders in young people. *J Eat Disorders*, 2(5): 1-12.

Barr H, Koppel I, Reeves S. Hammick M, Freeth D. (2005). *Effective Interprofessional Education: Argument, Assumption, Evidence*. Blackwell, Oxford.

Barrett E, Nicholls D. Eating disorders in children and adolescents. *BJPsych Advances,* May 2015, 21(3): 206-216.

Barrett E. (2016) Physical Care in eating disorders. Discussion paper for the National Working Group for Eating Disorders.

Barrett, E (2016). Eating disorders in Children and adolescents- an introduction to epidemiology and classification. Discussion paper for the HSE National Working Group for Eating Disorders.

Beat and Pro-Bono Economics, DOH (2012). Costs of eating disorders in England: Economic impacts of anorexia nervosa, bulimia nervosa and other disorders, focusing on young people.

Beat and Price Waterhouse Cooper (2015). The Costs of Eating Disorders: Social, health and economic impacts (2015).

Bentley J, Caddy P, Hammond L, Hull Yvonne, Ward M (2011). Physiotherapy Guidance Notes for Exercise and Physical Activity in Adult Patients with Anorexia and Bulimia. RCPsych.

Bjork T (2008). *Measuring Eating Disorder Outcomes – definitions, dropout and patient perspectives*. Orebro University.

Bleakley A, Allard J, Hobbs A (2012). Towards culture change in the operating theatre: Embedding a complex educational intervention to improve teamwork climate. *Medical Teacher*, 34: e635-640.

Bodywhys (2016). The PiLaR programme (Peer Led Resistance to eating disorders). Discussion paper presented to the HSE National Working Group for Eating Disorders.

Bodywhys (2016). The service user perspective. Discussion paper presented to the HSE National Working Group for Eating Disorders.

Boland K, Solonki D and O'Hanlon C (2013). IrSPEN Guideline document No.1. Prevention and Treatment of Refeeding Syndrome in the Acute Setting.

Borresen R, Rosenvinge JH (2003). From prevention to health promotion. In: Treasure J, Schmidt U, van der Furth E (Eds.). *Handbook of eating disorders*. London, Wiley: 435-453.

Borzekowski DLG, Schenk S, Wilson JL, Peebles, R (2010). e-ana and e- mia: A Content Analysis of Pro-Eating Disorder Websites. *American Journal of Public Health*. 100 (8): 1526-1534.

Boswell JF, Kraus DR, Miller SD, Lambert, MJ (2015). Implementing routine outcome monitoring in clinical practice: Benefits, challenges, and solutions. *Psychotherapy Research*, 25(1):6-19.

British Columbia Ministry for Health (2010). Clinical Practice Guidelines for the BC Eating Disorders Continuum of Services.

Brock D, Abu-Rish E, Chiu, CR, Hammer, D, Wilson S, Vorvick L, Blondon K, Schaad D, Liner D, Zierier B (2013). Interprofessional education in team communication: working together to improve patient safety. *BMJ Qual Saf*, 22:414-423.

Bulik CM, Baucom D, Kirby J, Pisetsky E (2011). Uniting couples in the treatment of Anorexia nervosa (UCAN). *Int J Eat Disord*, 44(1):19-28.

Butterfly Foundation (2012) Butterfly Report: Paying the price – The economic and social impact of eating disorders in Australia.

Butterfly Foundation (2014). Butterfly Report: Investing in need – Cost effective interventions for eating disorders.

CAIPE (Centre for the Advancement of Interprofessional Education) (2002). Defining IPE. Retrieved from https//www.caipe.org

Campbell K, Peebles P (2014). Eating Disorders in Children and Adolescents: State of the Art Review. Pediatrics, doi: 10.1542/peds2014-0194.

CDC (Centre for Disease Control) (2015). About Adult BMI. Retrieved from https://www.cdc.org/gov/healthyweight/assessing/bmi on 5/7/2016.

CDC (2013). Eating Disorders Prevalence for Children by Sex and Age. National Youth Fitness Survey. Retrieved from https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-children.shtm (accessed 10/02/16).

Colton PA, Olmsted MP, Daneman D, Farquhar JC, Wong H, Muskat S, Rodin GW (2015). Eating disorders in girls and women with type 1 diabetes; A longitudinal study of prevalence, onset, remission and recurrence. *Diabetes Care*, 38 (7): 1212- 1217.

Conceicao (2015). Eating Disorders and Problematic Eating Disorder Behaviours Before and After Bariatric Surgery: Characterisation, Assessment and Association with Treatment Outcomes. *Eur Eat Disord Rev*, 23 (8): 417-425.

Cook BJ, Wonderlich SA, Mitchell JA, Thompson R, Sherman R. Exercise in Eating Disorders Treatment: Systematic Review and Proposal of Guidelines. *Medicine & Science in Sports and Exercise*: 1408-1414.

McCallum K, Curtis-Tyler K (2012). Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes. *Diabet Med*, 29 (10): 1303-1310.

Dahlgren CL, Ro O (2014). A systematic review of cognitive remediation therapy for anorexia nervosa – development, current state and implications for future research and clinical practice. *Journal of Eating Disorders*, 2(26): 1-11.

Davidsen AH, Poulsen S, Waaddengaard M, Lindschou, Lau, M (2014). Feedback versus no feedback in improving patient outcome in group psychotherapy for eating disorders (F-EAT): protocol of a randomised clinical trial. Trials 15: 138

Department of Health and Children (DOHC) (2006). A Vision for Change: Report of the Expert Group on Mental Health Policy. Stationery Office, Dublin. 149-154.

Department of Health and Children, National Clinical Effectiveness Committee (2015). Standards for Clinical Practice Guidance.

Derman T, Szabo CP (2006). Why do individuals with anorexia die? A case of sudden death. *Int J Eat Disord*, 39 (3): 260-262.

De Vos J, Houtzager L, Katsaragaki G, van de berg E, Cuijpers P, Dekker J (2014). Meta- analysis on the efficacy of pharmacotherapy versus placebo on anorexia nervosa. J Eat Disorders, 2(27) 1-14.

Dunne D, Whyte A. (2016). Roles and Competencies of Clinical Psychologists within Eating Disorder Services. Discussion paper presented to the National Working Group for Eating Disorders.

Eisler I, Dare C, Hodes M, Russell G, Dodge E, Le Grange D. (2000). Family therapy for adolescent anorexia nervosa: the results of a randomised comparison of two family interventions. *J Child Psycho Psychiatry*, 41 (6): 727-36.

Eisler I (2005). The Empirical and theoretical base of family therapy and multiple family day therapy for anorexia nervosa. *J Family Therapy*, 27(2): 104-131.

Eisler I, Simic M, Hodsoil J, Asen E... Landau S (2016). A pragmatic randomised multi- centre trial of multifamily and single family therapy for adolescent anorexia nervosa. *BMC Psychiatry*, 16 (1): 422.

Espie J, Eisler I (2015). Focus on anorexia nervosa: modern psychological treatment and guidelines for the adolescent patient. *Adolesc Health Med Ther*, 6: 9-16.

Fairburn CG, Jones R, Peveler RC, Carr SJ, Solomon RA, O Connor ME, Burton J, Hope RA (1993). Psychotherapy and bulimia nervosa: The longer-term effects of interpersonal psychotherapy, behaviour therapy and cognitive behaviour therapy. *Arch Gen Psychiatry*, 48: 463-469.

Fairburn CG (2008). *Cognitive Behaviour Therapy and Eating Disorders*. Guilford Press.

Fairburn CG (2013) Overcoming Binge Eating (2nd edition). Guilford Press.

Fairburn CG, Bailey-Straebler S, Basden S, Doll HA, Jones R, Murphy R, O Connor ME, Cooper Z (2015). A transdiagnostic comparison of enhanced cognitive behaviour therapy (CBT-E) and interpersonal psychotherapy in the treatment of eating disorders. *Beh Research and Therapy*, 70:64-71.

Favaro A, Caregaro L, Tenconi E, Bosello R, Santonastaso P (2009). Time Trends in Age of Onset of Anorexia Nervosa and Bulimia Nervosa. *J Clin Psychiatry*: 70 (12): 1715-21.

Ferlie E, Fitzgerald L, Wood M, Hawkins, C (2005). The nonspread of innovations: the mediating role of professionals. *Academy of Management Journal* 48(1): 117-134.

Findlay S, Pinzon J, Taddeo D, Katzman DK, Canadian Paediatric Society (2010) Family-based treatment of children and adolescents with anorexia nervosa: Guidelines for the community physician (position statement): Canadian Psychiatric Association. *Paediatr Child Health*, 15 (1): 31-35.

Fitzpatrick KK, Moye A, Hoste R, Lock J, Le Grange D (2010). Adolescent Focused Psychotherapy for Adolescents with Anorexia Nervosa. *Journal of Contemporary Psychotherapy*. 40 (1): 31-39.

Furlong A, Sweeney M (2016). Role of Dietitians in Eating Disorders. Discussion paper presented to the HSE National Working Group for Eating Disorders.

Fursland A (2016). Presented at ICED 2016 and quoted in: New Protocol Aids Australian Patient Care. *Eating Disorders Review* (Ed: Crow, S) 27 (5): 5-6.

Geoghegan Gerri (2016). Discourse for National Policy for Eating Disorders Adult Working Group concerning Art Therapy inclusion in Multi Disciplinary Team approach Eating Disorder Treatment Plan. Discussion paper for the HSE National Working Group for eating disorders.

Gibson R (2016). Draft Psychotherapy skill set. Discussion paper submitted to the HSE Working Group for Eating Disorders.

Golden NH, Katzman DK, Kreipe RE, Stevens SL, Sawyer SM, Rees J... Rome, ES (2003). Eating Disorders in Adolescents, Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33, 496-503.

Goodman, A, Heshmati A, Koupil I (2014). Family history of education predicts eating disorders across multiple generations among 2 million Swedish males and females. PLoS One 2014: 9 (8): e106475.

Gowers SG, Clark AF, Roberts C, Byford S, Barrett B, Griffiths A... Roots P (2010). A randomised controlled multicentre trial of treatments for adolescent anorexia nervosa including assessment of cost-effectiveness and patient acceptability. The TOuCAN trial. *Health Technology Assessment*, 14 (15): 1-56.

Grover M, Naumann U, Mohommad-Dar L, Glennon S… Schmidt U (2011). A randomised controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychological Medicine*, 41: 1-11.

Gull W W (1873). Anorexia Nervosa (Apepsia Hysterica, Anorexia Hysterica): Paper to the Clinical Society of London.

Hamann J, Langer B, Winkler W, Busch R, Cohen R, Leucht S, Kissling W (2006). Shared decision making for in-patients with schizophrenia. *Acta Psychiatrica Scandinavica*, 114(4): 265-273.

Hammick M, Freeth D, Koppel I, Reeves S and Barr H (2007). A Best Evidence Systematic Review of Interprofessional Education. BEME Guide No. 9. 29 (8): 735-51.

Hay PJ, BacalJ, Claudino A, Ben-Tovim D, Yong PY (2009). Psychological treatments of Bulimia Nervosa and Binging. Cochrane Database of Systematic Reviews. CD000562.

Hay PJ, Claudino AM, Touyz S, Abd Elbaky G (2015). Outpatient psychological therapy for adults with anorexia nervosa. Cochrane Database of Systematic Reviews.

Herpertz-Dahnmann, B, Schwarte R, Krei M, Egberts, K, Warnke A, Wewetzer C... Dempfle A (2014) Day-patient treatment after short inpatient care versus continued inpatient treatment in adolescents with anorexia nervosa (ANDI): a multicentre, randomised, open-label, non-inferiority trial. *The Lancet*, 383 (9924):1222-1229.

Herpertz-Dahlmann B, van Elburg A, Castro-Fornieles J, Schmidt, U (2015). ESCAP Expert Paper: New developments in the diagnosis and treatment of adolescent anorexia nervosa – a European perspective. *Eur Child and Adol Psychiatry*, 24: 1153-1167.

Herpertz S, Haagenah U, Vocks S, Von Weiterscheim J, Cuntz U, Zeeck A (2011). The Diagnosis and Treatment of Eating Disorders. *Dtsch Arztebl Int*, 108 (40): 678-685.

Hoek HW, Van Hoeken D (2003). Review of the prevalence and incidence of eating disorders. *Int J Eat Disord*, 34 (4): 383-396.

Hoek HW (2006). Incidence, prevalence and mortality of anorexia nervosa and other eating disorders. *Curr Opin Psychiatry*,19(4): 389-94.

House J, Schmidt U, Craig M, Landau, S, Simic M, Nicholls D, Hugo P, Berelowitz M, Eisler I (2012). Comparison of specialist and nonspecialist care pathways for adolescents with anorexia nervosa and related eating disorders. *Int Journ Eating Disorders*, Vol. 45, No. 8, 12.2012, p. 949-956.

HSE (2008). Building a Culture of Patient Safety.

HSE (2010). Achieving Excellence in Clinical Governance: towards a culture of accountability.

HSE (2011). National Clinical Programmes: Checklist for Clinical Governance.

HSE (2011). Code of Governance Framework for the Corporate and Financial Governance of the HSE.

HSE (2016). Framework for Improving Quality in our Health Service.

HSE(2017).Best Practice Guidance for Mental Health Services. HSE.

Hudson JL, Hiripi E, Pope HG, Kessler RC (2007). The prevalence and correlates of eating disorders in the National Comorbidity Study Replication. *Biol Psychiatry*; 61 (3): 348-58.

Hudson LD, Court AJ (2012). What paediatricians should know about eating disorders in children and young people. *J Paediatr Child Health*, 48910):869-875.

Iacovino JM, Gredysa DM, Altman M, Wilfley DE (2012). Psychological Treatments for Binge Eating Disorder. Curr Psychiatry rep, 14(4): 432-448.

Irish Statute Book (2001). Mental Health Act 2001.

Irish Statute Book (199). Non-Fatal Offences Against the Person Act.

Joint Commissioning Panel for Mental Health, UK (2013). Guidance for commissioners of eating disorder services.

Johnson C, Powers PS, Dick R (1999). Athletes and Eating Disorders: The National Collegiate Athletic Association Study. *Int J Eat Disord*, 26 (1): 79-1 88.

Jones WR (2013). Knowledge and attitudes of psychiatrists towards eating disorders. *Eur Eat Disorders Rev*, 21(1):84-88.

Jones M, Taylor Lynch K, Kass AE, Burrows A, Williams J, Wilfley DE, Taylor CB (2014). Healthy weight regulation and eating disorder prevention in high school students: a universal and targeted web-based intervention. *J Med, Internet Res*, 16(2):e57.

Jones M, Kass AE, Taylor CB (2014). A Population-Wide Screening and Tailored Intervention Platform for Eating Disorders on College Campuses: The Healthy Body Image programme. *J Am Coll Health*, 62 (5):351-356.

Joy E, De Souza MJ, Nattiv A....Sundgot Borgen J (2014), 2014 Female Athlete Triad Consensus Statement on Treatment and Return to Play of the Female Athlete Triad. . Current Sports Medicine Reports: July/ August 2014,13:4, 219-232.

Kass AE, Kolko RP, Wilfley DE (2013) Psychological treatments for eating disorders. *Curr Opin Psychiatry*, 26 (6): 549-555

Kenniscentrum – Expert group on eating disorders in Adolescents (2015). The Dutch clinical practice guidelines. Accessible at www.kenniscentrum-kjp.nl

Keshi-Rahkonen A, Hoek HW, Linna MS, Raevouri A, Sihbola E, Bulik CM, Kaprio J (2009). Incidence and outcomes of bulimia nervosa: a nationwide population-based study. *Psychol Med*, 29 (5): 823-31.

Knaup C, Koesters M, Schoefer D, Becker T, Puschner B (2009). Effect of feedback of treatment outcome in specialist mental health care: a meta-analysis. *Br J Psychiatry*, 195: 15-22.

Lai KLC, de Bruyn E, Lask B, Bryant-Waugh R, Hankins M (1994) Use of pelvic ultrasound to monitor ovarian and uterine maturity in childhood onset anorexia nervosa. *Arch Disease Child*, 71: 228-231.

Las**è**gue EC (1873). De Anorexie Hystérique. Archives Générales de Médicine, Brumberg, Fasting Girls, pp 127.

Lask B, Bryant-Waugh R (2007). Eating Disorders in Childhood and Adolescence. Routledge.

Law D, Wolpert M (2014). A guide to using clinical outcome and feedback tools with children, young people and families. 2nd edition. CORC Ltd.

Lee L, Weston WW (2013). Developing Memory Clinics in Primary Care: An Evidence-based interprofessional program of continuing professional development. *Journal of Continuing Education in the Health Professions*, 33(1):24-32.

LeGrange D and Eisler I (2008). Family Interventions in Adolescent Anorexia Nervosa. *Child Adolesc Psychiatric Clin N Am*, 18: 159-173.

Lelie A, Verweij M. Futility without a dichotomy: toward an ideal physician-patient relationship. *Bioethics*. 2003.17,1: 21-31.

Lock J, Le Grange D, Booil J (2010). Randomised Clinical Trial Comparing Family Based Treatment to Adolescent Focused Individual Therapy for Adolescents with Anorexia Nervosa. *Arch Gen Psychiatry*, 67 (10):1025-1032.

Lock J, Le Grange D (2012). Treatment Manual for Anorexia nervosa: A Family Based approach. 2nd edition. Guilford Press.

Lock J, La Via MC, and American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI) (2015a). Practice Parameter for the Assessment and Treatment of Children and Adolescents with Eating Disorders. *J Am Acad Child Adolesc Psychiatry*, 54 (5):412-25.

Lock L, Le Grange D (2015b). Help Your Teenager Beat an Eating Disorder. 2nd edition. Guilford Press.

Loeb, KL, Le Grange D, Lock L (Eds). (2015). *Family Therapy for Adolescent Eating and Weight Disorders: New Applications*. Chapter 7, 116-145, Chapter 16, 375-397.

Lopez A, Yager, J, Feinstein, RE (2010). Medical futility and psychiatry; Palliative care and hospice care as a last resort in the treatment of refractory anorexia nervosa. *International Journal of Eating Disorders*. 2010. 43, 4: 372-377.

Lucas AR, Beard CM, O'Fallon WM and Kurland LT (1991). Fifty-year trends in the incidence of anorexia nervosa in Rochester, Minnesota: a population-based study. *American Journal of Psychiatry,* 148, 917-922.

Lynch TR, Gray KLH, Hempel RJ, Titley M, Chen EY, O'Mahen HA (2013). Radically open-dialectical behaviour therapy for adult anorexia nervosa: feasibility and outcomes from an inpatient programme. *BMC Psychiatry*, 13: 293.

Machado PP et al (2007). The prevalence of eating disorders not otherwise specified. *Int J Ear Disorder*, 69 (3): 2122-7.

Maher C, and the Adult Subgroup of the HSE National Working Group for Eating Disorders (2016). Stepped care. Secondary Services. Recommended model of care. Discussion paper presented to the HSE National Working Group for Eating Disorders.

Marcus MD, Wildes JE (2012). Obesity in DSM-5. *Psychiatric Annals*. 42 (11): 431-435.

Malone D, Newron-Howes G, Simmonds S, Marriot S, Tyrer P (2007). Community mental health teams (CMHTs) for people with severe mental illnesses and disordered personality. Cochrane Database of Systematic Reviews 2.

McDevitt SC (2014). The evaluation of an Interprofesisonal Education Programme in Eating Disorders for Specialist Clinicians using a Case-based Learning Approach. Master's Dissertation. University of Warwick.

McDevitt SC and Passi, V (2015). Evaluation of a pilot interprofessional education programme for eating disorder training in mental health services, *IJPM*, https://doi.org/10.1017/ipm.2015.61.

McDevitt SC, Furlong A, Comisky C, Whyte A, Larmer C (2016) Eating Disorder Services in the under 18's. Discussion paper presented to the HSE National Working Group for Eating Disorders.

McElroy SL, Guerdjikova O... Melia AM (2012). Pharmacological management of binge eating disorder: current and emerging treatment options. *Ther Clin Risk Manag*, 8: 219-241.

McIntosh VV, Jordan J, Luty SE, Carter FA, McKenzie JM, Bulik CM, Joyce PR (2006). Specialist Supportive Clinical Management for anorexia nervosa. *Int J Eat Disord*, 39 (8) 625-632.

McNicholas F, Lydon A, Lennon R, Dooley B (2009). Eating concerns and media influences in an Irish adolescent context. *European Eating Disorders Review,* 17(3):208-213.

McNicholas F, Dooley B, Keogh L, Lydon A (2010). Eating Problems in Irish Children and Adolescents – EPICA. *IJ Psych Med*, 27(4), 172-178.

McNicholas F, O'Connor C, O'Hara L, McNamara N (2016). Stigma and treatment of eating disorders in Ireland: healthcare professionals' knowledge and attitudes. *IJ Psych Med*, 33(1), 21-31.

McElroy SL, Guerdijkova A, Mori N, O'Melia AM (2012). Pharmacological management of binge eating disorder: current and emerging treatment options. *Ther Clin Risk Manag*, 8: 219-241.

Mehanna HM, Moledina J, Travis J (2008). Refeeding syndrome: what it is, and how to prevent it. *BMJ*, 338 (7659): 1495-1498.

Mental Health Commission (MHC) (2006). Multidisciplinary Team Working: From Theory to Practice: Discussion Paper. Mental Health Commission, Dublin.

Mental Health Commission (MHC) (2007). Quality Improvement Framework: Mental Health Services in Ireland. Mental Health Commission, Dublin.

Mental Health Commission (2007). Excellence in Mental Healthcare Records.

Mental Health Commission (MHC) (2008). A Recovery Journey: A Recovery Approach within the Irish Mental Health Services, Position Paper. Mental Health Commission, Dublin.

Mental Health Commission (MHC) (2012). Guidance Document on Individual Care Planning Mental Health services. the Mental Health Commission, Dublin.

Merkingas KR, He JP, Bursein M, Swanson SA, Avenevoli S...Swendsen J (2010). Lifetime Prevalence of Mental Disorders in US Adolescents: Results from the National Comorbidity Study. *J Am Acad Child Adolesc Psychiatry*, 49(10): 980-989.

Micali N, Hagberg KW, Petersen I, Treasure JL (2013). The incidence of eating disorders in the UK in 2000-2009: findings from the General Practice Research Database. *BMJ Open*, 3:e002646.

Millar HR (2009). Telemental health in Scotland. Scottish Centre for Telehealth .

Ministry of Health (MOH), New Zealand (2008). Future Directions for Eating Disorder Services in New Zealand.

Ministry of Health and Consumer Affairs (2009): Clinical Practice Guideline for Eating Disorders, Madrid: Quality Plan for the National Health System of the Ministry of Health and Consumer Affairs.

Mohanna K, Cottrell E, Wall D, Chambers, R (2011). Developing your teaching style and techniques. In Jones R, Jenkins F (Eds.). *Key tools and techniques in management and leadership of the allied health professionals.* London, Radcliffe: 119-128.

Moola FJ, Gairdner F, Amara CE (2013). Exercise in the care of patients with anorexia nervosa: a systematic review of the literature. *Mental Health and Physical Activity*; 6(2): 59-68.

Moran P, Kelesidi K, Guglani S, Davidson S, Ford T (2012). What do parents and carers think about routine outcome measures and their use? A focus group study of CAMHS attenders. *Clinical Psychology and Psychiatry*, 17(1): 65-79.

Morey JC, Simon R, Jay GD, Wears RL, Salisbury M, Dukes, KA, Berns SD (2002). Error Reduction and Performance Improvement in the Emergency Department through Formal Teamwork Training: Evaluation Results of the Medteams Project. *Health Serv Res*, 37(6): 1553-1581.

Munro C, Thomson V... Freeman CP (2014). A new service model for the treatment of severe anorexia nervosa in the community: the Anorexia Nervosa Intensive Treatment Team. *Psychiatr Bull*, 38 (5): 220-225.

Murphy R, Straebler S, Basden S, Cooper Z, Fairburn, CG (2012). Interpersonal Psychotherapy for Eating Disorders. *Clin. Psychol. Psychother*, 19(150-158).

National Collaborative Centre for Mental Health (2015). Access and Waiting Time Standard for Children and Young People with an Eating Disorder (version 1.0). Commissioned by NHS England.

NICE (2004): Guideline: Eating Disorders in Over 8s.

NICE (2016, draft, and 2017). Guideline 69. Eating Disorders: recognition and management.

NIMH (2012). Spotlight on Eating Disorders. Accessed July 2016. https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2012/spotlight-on-eatig-disorders.shtml

NIMH (2016). Eating disorder statistics for adults and children. Accessed June 2016. https://www.nimh.nih.gov/health/statistics/prevalence/eating-disorders-among-adults- anorexia-nervosa.shtml

New South Wales Government (2013). NSW Service Plan for People with Eating Disorders 2013-2018.

Nichols DE, Lynn R, Viner RM (2011). Childhood eating disorders: British National surveillance study. *BJPsych*, 198 (4): 295-301.

O'Callaghan A, McDevitt SC (2015). Piloting a toolkit for the early detection and management of eating disorders in primary care. Poster presented at the National Eating Disorders Conference, Dublin 2015.

O'Connor C, McNamara, N, O'Hara L, McNicholas F (2016). Eating disorder literacy and stigmatising attitudes towards anorexia, bulimia and binge eating disorder among adolescents. *Advances in Eating Disorders*, 4(2).

Ornstein RM, Lane-Loney SE, Hollenbeak CS (2012). Clinical outcomes of a novel, family centred partial hospitalisation program for young people with eating disorders. *Eat Weight Disord*, 17: 2170-77.

O' Sullivan C and O Malley C (2016). Core outcome measurements for eating disorders (literature review). Discussion paper for the HSE National Working Group for Eating Disorders.

O'Sullivan A, Buckley M, Byrne M (2014). Improving the health of patients with eating disorders in the student health setting using a customised care pathway and recording template. Poster presented at the ACAMH research day, Cork.

Pearson J, Goldklang D, Striegel-Moore RH (2002). Prevention of Eating Disorders: challenges and opportunities. *Int. J. Ear Disord*, 31(3): 233-9.

Perkins SS, Murphy RRM, Schmidt UUS, Williams C (2006). Self help and guided self help for eating disorders. Cochrane Database of Systematic Reviews.

Poulsen S, Lunn S, Daniel S, Folke S, Mathiesen BB, Fairburn CG (2014). A Randomised Controlled Trial of Psychoanalytical Psychotherapy or Cognitive- Behavioural Therapy for Bulimia Nervosa. *Am J Psychiatry*, 171: 109-116.

Preti A, De Girolamo G, Vilagut, G, Alonso J, de Graaf R, Bruffaerts... The ESEMeD-WMH Investigators (2009). The epidemiology of eating disorders in six European countries: results of the ESEMeD-WMH project. *J Psychiatr Res*, 43 (14): 1125-1132.

Quality Improvement Scotland – QIS (2006). Eating Disorders in Scotland: Recommendations for management and treatment (NHS).

Quality Network for Community Eating Disorder Services for Children and Young People (QNCC-ED)/RCPsych (2016). Service Standards. Editor Jasmine Harvey. Royal College of Psychiatrists.

Quality Network for Eating Disorder Services (QED) (2013). Standards for Adult Inpatient Eating Disorder Services, 1st edition. Royal College of Psychiatrists

Robinson PH, Kukucska R, Guidetti G, Leavey G (2015). Severe and enduring anorexia nervosa (SEED-AN): a qualitative study of patients with 20+ years of anorexia nervosa. *Eur Eat Disord Rev*, 23 (4): 318-28.

Roehrig J, McLean C (2009). A comparison of stigma toward eating disorders versus depression. *Int J Eat Disord*, 43:7, 671-674.

RANZCP (2014). Clinical Practice Guidelines for the Treatment of Eating Disorders.

RCPsych (2012) Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa (CR 168).

RCPsych (2012b). Eating disorders in the UK: service distribution, service development and training.

RCPsych (2012). Service Standards: Standards for Inpatient Eating Disorder Units – pilot edition.

RCPsych (2013). Building and sustaining specialist CAMHS to improve outcomes for children and young people (CR 182).

RCPsych (2014). MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa (2nd edition) (CR 189).

RCPsych (2016). Quality Network for Eating Disorders (QED): 1st National Report.

Rouhrig JP, McLean CP (2009). A comparison of stigma towards eating disorders versus depression. *Int J Eat Disord*, 43 (7): 671-4.

Ryan K, and the HSE National Clinical programme for Palliative care working group (2016). End of life Decisions and Care. Discussion paper submitted to the National Clinical Programme for Eating Disorders.

Ryan K, Connolly M, Charnley K ..... Wynne M (2014) Palliative Care Competence Framework Steering Group, Dublin, HSE.

Russell G (1979). Bulimia Nervosa: an ominous variant of anorexia nervosa. *Psychol Med*, 9(3): 429-448.

Sargeant J, MacLeod T, Murray A (2011). An interprofessional approach to teaching communication skills. *J. Contin. Educ. Health Prof.*, 31: 265-267.

Schmidt U, Lee S, Perkins S, Eisler I, Treasure J... Yi I (2008). Do adolescents with eating disorder not otherwise specified or full-syndrome bulimia nervosa differ in clinical severity, comorbidity, risk factors, treatment outcome or cost? *International Journal of Eating Disorders*, 41: 498-504.

Schmidt U, Renwick B, Lose A et al, (2013). The MOSAIC study: comparison of the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) with Specialist Supportive Clinical Management (SSCM) in outpatients with anorexia nervosa or EDNOS, anorexia type: study protocol for a RCT: Trials, 14: 160.

Schmidt U, Ryan EG, Bartholdy S et al (2016). Two-year follow up of the MOSAIC trial: A multicentre randomised controlled trail comparing two psychological treatments in adult outpatients with broadly defined anorexia nervosa. *Int J Eat Disord*, 49(8): 793-800.

Seidel A, Pressnell K, Rosenfield D (2009). Mediators in the dissonance eating disorder prevention program. *Behaviour Research and Therapy*, 47:645-53.

Slade M (2002). Routine Outcome Assessment in Mental Health Services. *Psychological Medicine* 32 (8):1345-56.

Smith E, O Riordan J, Crowe EM, Duffy I, Morrissey L (2016). The Role of Occupational Therapy in the Field of Eating Disorders. Discussion paper presented to the HSE Working Group for Eating Disorders.

Society of Adolescent Health and Medicine – SAHM (2015). Position Paper of the Society for Adolescent Health and Medicine: Medical Management of Restrictive Eating Disorders in Adolescents and Young Adults.

Stewart MC, Keel PK (2006). Stigmatisation of anorexia nervosa. *Int J. Eat. Disord*, 39:320-325.

Stice E, Marti CN, Spoor S, Presnell K, Shaw H (2008). Dissonance and healthy weight eating disorder prevention programs: Long term effects from a randomised efficacy trial. *J Consult Clin Psychol*, 76: 329-340.

Stice E, Rodhe P, Shaw H, Marti N (2012). Efficacy trial of a selected prevention programme targeting both eating disorders symptoms and unhealthy weight gain among female college students. *J Consult Clin Psychol*, 80: 164-170.

Stice E, Black Becker C, Yokum S (2013). Eating Disorder Prevention: Current Evidence- Base and Future Directions. *Int J Eat Disord*. 46(5): 478-485.

Stice E, Rohde P, Butryn ML, Shaw H, Marti CN (2015). Effectiveness Trial of a selective Dissonance-based Eating Disorder Prevention Program with Female College Students: effects at 2- and 3- year follow up. *Behav Res Ther*, 71:20-26.

Streigel-Moore RG, Wilson GT, DeBar L, Perrin N, Lynch F, Rosselli F, Kraemer HC (2010). Cognitive-Behavioural Guided Self-Help for the Treatment of Recurrent Binge Eating. *J Consult Clin Psychol*, 78(3): 312-321.

Sundgot-Borgen J, Torstveit MK (2004). Prevalence of eating disorders in elite athletes is higher than in the general population. *Clin J Sports Med,* 14 (1): 25-32.

Swanson SA, Scott ScM, Crow J, Le Grange D (2011). Prevalence and Correlates of Eating Disorders in Adolescents: Results from the National Comorbidity Survey Replication Adolescent Supplement. *Arch Gen Psychiatry*, 68(7):701-713.

Taylor D, Paton C, Kapur S. The Maudsley Prescribing Guidelines in Psychiatry, 12th edition. Wiley Blackwell.

Tchanturia K, Lock J. (2011) Cognitive remediation therapy for eating disorders: development, refinement and future directions. *Curr Top Behav Neurosci*, 6: 269-287.

Tchanturia K, Doris E, Mountford V, Fleming C (2015). Cognitive Remediation and Emotion Skills Training (CREST) for anorexia nervosa in individual format: self-reported outcomes. *BMC Psychiatry,* 15.53.

Thompson Brenner H, Satir DA, Franko DL, Herzog DB (2012). Clinician reactions to patients with eating disorders: a review of the literature. *Psychiatr Serv*., 63 (1):73-78.

Trace SE, Baker JH, Penas-Liedo E, Bulik CM (2013). The Genetics of Eating Disorders. *Annual Review of Clinical Psychology*, 9 (589-620.

Van Noorden, Van Der Wee, Zitman, Gitlay (2012). Routine outcome monitoring in psychiatric clinical practice: background, overview and implications for person centred psychiatry. *European Journal of Person Centred Healthcare*, 1(1):103-111

Vaitheswaran S, Crockett P, Wilson S, Millar H (2012). Telemental health: videoconferencing in mental health services. *Advances in Psychiatric Treatment*, 18 (392-398).

Vignaud, M, Constantin JM, Ruicard M... AZUREA group (2010). Refeeding Syndrome influences outcome of anorexia nervosa in intensive care unit: an observational study. *Critical Care*, 14: R172.

Vos, T, Mathers C, Herrman H, Harvey C, Gureje O, Bui D, Watson N, Begg S (2001). The burden of mental disorders in Victoria, 1996. *Social Psychiatry and Psychiatric Epidemiology*, 36(2):53-62.

Wales – Aneurin Bevan Health Board/NHS (2012): Eating Disorder Service Operational Policy: Delivering across the age range.

Watson HJ, Bulik CM (2013) Update on the treatment of anorexia nervosa: review of clinical trials, practice guidelines and emerging interventions. *Psychol Med*, 43(12): 2477-500.

Waller G, Gray E, Hinrichsen H, Mountford V, Lawson R, Patient E (2014). Cognitive- behavioural therapy for bulimia nervosa and atypical bulimia nervosa: effectiveness in clinical settings. *Int J Eat Disorders*, 47 (1)13-17.

Waller, G (2016a). Recent advances in psychological therapies for eating disorders. Version 1; 2 referees approved. F1000/Research 2016a, 5 (F100Faculty Rev: 702 (doi:10.12688/11000research.7818.1)

Waller G (2016b). Treatment Protocols for Eating Disorders: Clinicians' attitudes, Concerns, Adherence and Difficulties Delivering Evidence-Based Psychological Interventions. *Curr. Psychiatry Rep*, 18.36.

Waller G, Turner H (2016c). Therapist drift redux: Why well-meaning clinicians fail to deliver evidence based therapy, and how to get back on track. *Behav Res and Ther*, 77: 129-137.

Whitaker AH (1992). An epidemiological study of anorectic and bulimic symptoms in adolescent girls: implications for paediatricians. *Paediatric Ann,* 21: 752-9.

White S, Reynolds-Malear JB, Cordero E (2011). Disordered eating and the use of unhealthy weight control methods in college students: 1995, 2002 and 2008. *Eat Disord*, 19 (4): 323-334.

Wolpert, M (2014). The uses and abuses of patient reported outcome measures (PROMs): Potential iatrogenic impact of PROMS implementation and how it can be mitigated. *Admin Policy Mental Health*. 41:141-145.

World Health Organisation (WHO) (2010). Framework for Action on Interprofessional Education and Collaborative Care. WHO.

Yager J, Devlin MJ, Halmi, KA, Herzog DB, Mitchell JE, Powers P, Zerbe KJ (2014). Guideline Watch (August 2012). Practice Guideline for the Treatment of Patients with Eating Disorders, 3rd edition. Focus 12 (4): 416-431.

Notes

Notes

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