# Eating Disorders –

# A Framework for Wales

## June 2009

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# 1. Introduction

## 1.1. Background

In 2006, at the request of Welsh Assembly Government (WAG), the National Public Health Service for Wales (NPHS) prepared a draft "Eating Disorders Care Pathway / Model of Care" setting out the principles which might provide a framework for Wales.[1]

The 2006 document has been used by many health bodies in Wales as a source of good practice advice, but it was not formally issued by the Assembly as a model which providers and commissioners had to follow.

In discussion with the National Assembly for Wales' Cross Party Group for Eating Disorders in July 2008, it was agreed to review and update the original guidance taking account of the proposed changes to the NHS in Wales. This review should take account of:

a) co-morbidity with other conditions (depression, personality disorder, substance misuse etc)

b) medical stabilisation and refeeding

c) any best practice issued since 2006.

This current document builds on the 2006 NPHS advice, and the term "Eating Disorders: Framework for Wales" has been used to distinguish it from the early draft.

It represents the Assembly's expectations for the NHS in Wales.

## 1.2. Structure of Framework

This Framework has been prepared at a time of significant change within the NHS in Wales, so it has been designed to be applicable to both current and emerging health bodies. For this reason, the document defines roles generically, such as Primary Care, local mental health services etc, rather than specific elements of the organisation. Where it is intended that a role or function needs to be formally defined as falling to the proposed unified health bodies which will replace NHS Trusts and Local Health Boards, the phrase Local Health Board (or abbreviation LHB) has been used.

After this introductory section, Section 2 provides background information on eating disorders. Section 3 sets out the Welsh Assembly Government's approach and discusses the key strands which run throughout the Framework.

Section 4 draws these strands into the 4-tier model which is widely used for mental health services for children and young people, and increasingly for services for adults. A summary table of the issues at each tier is included within Section 4.

As current and emerging health bodies will need to assess themselves against this Framework, the standards are set out in Section 5. These will be developed through discussion with relevant professional bodies and patient/carer groups during 2009 as part of an ongoing process to ensure that they both reflect good practice and are backed up by more detailed practice guidelines.

In the light of the health minister's announcement (October 2008) of additional funding to develop specialist community support for eating disorders, a possible approach to establishing tertiary eating disorders teams is set out in Appendix B.

## 1.3. Methodology

To produce this draft Framework, the NPHS was asked to review the available evidence and strategies produced since their 2006 document.

NICE guideline *Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and eating disorders,* issued in 2004[2], remains the formal advice on clinical practice, and there are no arrangements yet in place for NICE to undertake the review which had originally been scheduled for 2008. NPHS therefore undertook a literature search using the original NICE search criteria to identify any relevant evidence which should influence this review.

As the focus of the NICE guideline was formal clinical trials (which predominantly look at highly intensive tertiary centres), NPHS also undertook broader literature searches to identify research and reports dealing with recent practice in secondary and primary care settings both in the UK and in other countries with comparable health care systems.

NPHS has also sought views from relevant policy leads in WAG and from practitioners across Wales (via the All Wales Eating Disorders Special Interest Group[3]) on aspects of the 2006 document which needed strengthening or clarification.

## 1.4. Key features

Based on the research undertaken by the NPHS, the responses to the consultation, on input from the National Assembly for Wales' Cross Party Group and from the All Wales Special Interest Group, WAG has adopted the following approach as a basis for addressing eating disorders in Wales:

a. Effective services for people with eating disorders are reliant as much on community, primary care, local mental health services and access to physical health expertise as they are on highly specialised services or facilities;

b. For staff in community, primary and secondary care to feel confident and competent in fulfilling their legitimate assessment and treatment roles, they need to know that they have the support of other tiers. They also need a readily available source of specialist advice and expertise;

c. In most cases, the roles set out in this Framework are not new or additional expectations – they are based on fundamental principles embodied in the relevant Assembly strategies and related documents. Despite this, there are major weakness and gaps across Wales which can result in individuals not receiving the care their condition requires.

d. It is necessary to reaffirm that eating disorders are mental disorders as defined within the International Classification of Disease (ICD) definitions[4], with severe forms involving potentially life-threatening complications.

e. This Framework therefore explicitly reinforces the roles of primary care teams, generic psychiatric and physical health services in identifying, assessing, intervening with and monitoring people who have an eating disorder. These services (Tiers 1 & 2) cannot operate adequately without each LHB having a defined Tier 3 resource or without access to flexible highly specialised Tier 4 expertise.

# 2. Background information and principles

## 2.1. Summary of underlying principles

a. Eating disorders are serious and may be enduring mental disorders that require appropriate responses from healthcare planners and providers[2].

b. Early identification and appropriate intervention improves the clinical outcome for many people who have an eating disorder[5]. Studies demonstrate that prognosis is better with early intervention. Thus, any referral protocol that applies diagnostic criteria too narrowly risks delays in particular patients receiving the attention that they require, and can restrict the benefits of early intervention[6]. Decisions need to be based on appropriate assessments of overall risk, not solely body mass index (BMI) thresholds etc[7].

c. Public and media attention is often focussed on the small number of people who require high cost tertiary inpatient care, but the overwhelming majority of cases should be handled by local generic services with access to specialist advice and support[2].

d. The four-tier strategic model used within child and adolescent mental health services provides an effective framework for future service commissioning for all age groups and is flexible enough to be the basis for designing services and for effective development of locality-specific pathways that run from local services through to the most specialised of services.

e. Acceptance of this four-tier approach would implicitly mean that attention would be focused on the development of a continuum of services across the range of ages and severity. The intention is to enable patients to receive the level and intensity of care that each requires, without forcing patients and staff to rely on highly specialised services. This change could potentially:

- increase access to early intervention provided by local services, i.e. those that offer the functions of Tiers 1 and 2;

- reduce the time spent in inpatient care or other residential admissions, unless they are unavoidable or required on the basis of a strategic understanding of intervention;

- reduce the likelihood of relapse after inpatient treatment and care;

- improve cost efficiency and quality of service provision.

f. Robust and equitable local services are only likely to be set up where there is a common national framework that defines the contribution to be expected from the agencies and professions involved.

g. Improvements will only be achieved if there is an acknowledgement that there are currently significant barriers to patients needing access to effective local services, and that a coordinated local approach is required which actively involves patients and carers.

## 2.2. Definitions and characteristics of eating disorders

For the purposes of this framework, the eating disorders considered are anorexia nervosa, bulimia nervosa and other related disorders as set out in section F50 of the 10th edition of the International Classification of Disease[4]. These disorders fall within the Welsh Assembly Government's definition of mental disorders for which people may require a mental health service for adults or a child and adolescent mental health service[8, 9]. This document does not deal with obesity.

It has been firmly established in reviews across the UK and the Republic of Ireland that the treatment available and offered to people who have an eating disorder is likely to be extremely variable[10, 11, 12, 13]. There is uneven provision and application of both generic and specialist mental health services, and many of the specific treatments identified as effective in the NICE guideline are not routinely available across NHS Wales[14].

There are a number of difficulties with the definitions used to describe eating disorders, and this can introduce misunderstanding. The term 'eating disorders' is used generally by the public and health professionals to cover a very broad range of problems of a great range of severities and duration, many of which do not reach the criteria set by ICD 10 for a disorder[4]. In the popular view, the term includes mild or transitory problems, attitudes and behaviours as well as eating disorders as defined in this document. When used as described in the NICE guideline, the term covers those disorders that meet specific diagnostic criteria, namely anorexia nervosa, bulimia nervosa and related disorders.

This divergence can create difficulties in interpretation that permeate into the expectations of the public, planners, primary care agencies, the specialist mental health services and the responses delivered by providers. For example, some local mental health teams decline to accept patients with eating disorders on the basis that they do not consider eating disorders per se to meet their criteria for severe and enduring mental disorders. This is despite the fact that eating disorders are clearly included in relevant definitions of mental disorders. Information from practitioners[3] suggests that this is an issue for some providers of mental health services for adults, whereas eating disorders are normally accepted as a core part of Child and Adolescent Mental Health Services (CAMHS).

In other cases, first level specialist mental health teams for adults such as Community Mental Heath Teams (CMHTs) are reported[3] to decline to accept referrals for people with an eating disorder on the basis that they do not have the requisite skills for such a complex condition. This may reflect concern that anorexia nervosa (as opposed to eating disorders generally) has been identified as having the highest mortality rate of all psychiatric conditions[15].

The low levels of confidence, experience and availability of clinical supervision identified through an all-Wales skills audit[16] will inevitably lead practitioners to refer to more specialist facilities when the intervention might appropriately be expected to be within the competence of local first level specialist services. LHBs need to develop clearer thresholds which define at what point to pass a patient on to more specialist services.

## 2.3. Characteristics and natural progression of eating disorders

The pattern of eating disorders is a complex one, and the characteristics differ considerably between younger people and adults.

National and international studies demonstrate that the majority of cases of eating disorders begin to develop during adolescence[2]. While some young people may recover from mild conditions that respond to interventions that are usually available within the first level Specialist CAMHS (these functions are at Tier 2), others have much more serious disorders. At this stage, they can do great damage to young people's long-term physical and emotional heath if they are not tackled appropriately, effectively and quickly. They can also have a significant negative impact on academic attainment and subsequent careers and life choices[2].

It is possible that it is this variation in severity that may support the erroneous portrayal of eating disorders in younger people as reflecting a passing life-style choice that is embraced by some young people during their passage through adolescence. Misunderstandings such as these that are sometimes portrayed in the media may result in the disorder not getting the priority its seriousness requires.

**It is important to emphasise that the effects of eating disorders can be devastating and, in a smaller number of cases, life-long or life-threatening.**

Early identification of and intervention with children and young people, and appropriate interventions for their families, can prevent the condition from escalating and can avoid long-term damage or the condition continuing into adulthood.

When people with eating disorders present for the first time in adulthood, the disorder may turn out to be already of some years' duration and may require longer periods of intervention and monitoring. At the transitional phase in late adolescence, young people may present with eating disorders that match either the adolescent or the adult patterns, making it especially important that services are responsive to people at this vulnerable stage. Unfortunately, this stage coincides with the time of greatest uncertainty and variation with respect to service responses.

Some people may develop a chronic condition in which they maintain employment, family and other activities but they may require long-term low level monitoring with additional intervention when they recognise that their condition is entering a more acute phase. The fact of a condition becoming 'chronic' does not mean that people in those circumstances do not need or are unable to benefit from appropriate intervention at relevant times, in the same way as other patients who have other chronic diseases or disorders may need long-term or episodic access to healthcare.

Anorexia nervosa has the highest mortality rate of any psychiatric illness through suicide and direct physical effects.[17] Additionally, patients who suffer with an eating disorder are very likely to also have other mental health problems or disorders[2,18,19].

## 2.4. Diagnostic and needs-led approaches

Research demonstrates that prognosis is far better with early intervention. However, many referral protocols or acceptance procedures insist on patients having met very specific diagnostic criteria over a prolonged period before considering a referral.

Such an approach can result in people being refused or excluded by teams until their problems have developed to a sufficiently serious or complex level to meet the team's referral criteria. This is not in the interests of either patients or service providers.

It is understandable that services need to prioritise their attention to those in greater clinical need, but referral protocols must allow for speedy assessments to identify risks and indicate where early intervention or advice on care management could prevent an individual's physical or mental health deteriorating.

Such an assessment will also help both the patient and staff to establish whether the patient is able to benefit from intervention – account has to be taken of the fact that some individuals need to reach a certain stage of motivation before certain interventions are beneficial. It is critically important however to ensure that an assessment of whether an individual is able to benefit from treatment should be made by staff with the relevant expertise in assessment.

In conclusion, as in other fields of mental health, it is important to operate a needs led assessment and care management service that does not require peoples' problems to meet set criteria but is based on an holistic assessment. This concentrates scarce resources on those who have particular needs and those people who present substantial risks.

The focus therefore needs to be on identifying the overall level of risk, taking in to account not only the formal diagnostic criteria used in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)[20], but also assessing the other factors which affect the risk level such as any other physical or psychological problems or vulnerabilities.

A range of guidelines and tools to help in assessing risk is readily available for use with patients with eating disorders in primary and secondary outpatient settings, medical inpatient care, general psychiatric inpatient care and more specialised eating disorders inpatient facilities. There is a need for LHBs to agree on which tools to use locally and to implement the use of such tools in their health community.

## 2.5. Incidence, prevalence and implications for services

Epidemiological studies into incidence and prevalence of eating disorders, both across the UK and internationally, offer very variable results. They are difficult to translate into useful indicators of need or demand for primary care, local mental health or specialist services.

To some degree, this uncertainty is unavoidable given the secretive nature of the condition and most patients' reluctance to seek help. Patients may also be reluctant to acknowledge the extent to which they are affected by their eating disorder because they fear the effects of treatment more than those of the disorder[21].

### a. *Methodological issues.*

There are also many methodological problems inherent in extracting robust epidemiological data for a condition for which randomised control trials are not practical or ethical[22]. The current categorisation of different forms of eating disorder also presents major difficulties, and the tendency has been for studies to focus on aspects of eating disorders which are capable of fine measurement because of their fixed diagnostic criteria, rather than addressing clinical significance.

Of particular significance is the fact that such rates as are available concentrate on epidemiological studies which are limited to patients who meet the full DSM IV[20] diagnostic criteria of either Anorexia Nervosa or Bulimia Nervosa. Of equal significance[23], both numerically and in terms of clinical severity and therefore implications for service responses, are the less well defined 'Eating disorders not otherwise specified' category described in the DSM IV[20] definitions. These are normally referred to within the UK as 'Atypical eating disorders'.

Patients who meet this category may be suffering from a clinical condition which is as severe and long-lasting as one which exactly matches the anorexia or bulimia nervosa definitions[23].

Studies of levels of clinically significant eating disorders in the UK[24] and Europe[25] consistently demonstrate that atypical eating disorders represent over a third of total clinically significant cases. Commentators also consistently stress that the slight variation from the formal, potentially artificial (and shortly to be amended)[26] DSMIV definitions should not be taken as indicating that these patients have minor levels of risk or need for support. NICE[2] guidance recommends that such patients should be treated in accordance with the diagnostic grouping which they most closely match.

Taken together, these factors result in significant problems for health organisations seeking to improve their response to eating disorders – after all, their aim is to try, through early identification and intervention, to help patients not to progress to the severity and risks which are associated with the full 'DSMIV' diagnoses required for entry to such studies.

### b. *Demographic issues*

Another important and consistent feature of epidemiological studies is the indication that there are much higher rates of all clinically significant eating disorders in females aged between 15 and 24, with some studies indicating that half of the total number of cases will be within this group[27]. The number of cases likely to need assessment, intervention and monitoring in any particular locality will be significantly influenced by its demographic profile. Estimates based on total population rates can therefore be misleading, and several parts of Wales have a sufficiently high proportion of their total

population within this risk group to merit enhanced consideration of the service profile appropriate to their locality.

Accurate figures on the scale and severity of eating disorders within each locality can only be established when there are local services in place operating robust registers within a Care Programme Approach. In preparing indicators for use in this Framework, the National Public Health Service for Wales is not claiming that they will be entirely accurate, but they are intended as an initial guide for LHBs.

For the purposes of this framework, the rates adopted in policy development in Scotland[28], Northern Ireland[11], New Zealand[29], and recommended in publications by the Eating Disorders Association[30] (now B-eat) and the Royal College of Psychiatrists[31] have been used to provide LHBs with some guidance on the levels of need at different levels of intensity. They have been increased proportionately to take Atypical Eating Disorders / EDNOS into account, and adjusted to take into account the percentage of each LHB's population falling in the higher risk group, namely females aged between 15 to 24 years.

### c. *Application of published rates to Wales*

LHBs will need to convert these estimates of incidence and prevalence into indicators of likely demand for their local services. These will vary across Wales for any particular element of service / profession depending on how local mental health services etc are organised. In relating these rates to their local circumstances to give an indication of the number of people likely to needing support at each level, LHBs may find it helpful to note the experience in Leicester[24] and the ANITT[32] service in Lothian, together with the profile of referrals experienced by the Royal Free Hospital[33].

The attached table suggests some initial working assumptions derived by applying published incidence and prevalence rates to LHB populations. The underlying rates used for these estimates are:

- Anorexia nervosa <u>incidence</u> rate of 8 persons per 100,000 total population per year, increased to 31 persons per 100,000 for each UA's population of females aged 15-24 (ONS Population estimates 2007 used).

- Anorexia nervosa <u>prevalence</u> rate of 29 per 100,000 among young females aged 15-24, estimated to represent half of all cases.

- Bulimia nervosa <u>incidence</u> rate of 11 persons per 100,000 total population per year, weighted as for anorexia nervosa above.

- Bulimia nervosa <u>prevalence</u> rate of 100 persons per 100,000 among females aged 15-24, estimated to represent half of all cases.

- As identified in expert commentaries[34], community population studies[25] and service referral studies[24], atypical eating disorders can be estimated as representing approximately 40-45% of total presenting and actual cases. The overall incidence and prevalence rates calculated for each LHB have been extrapolated accordingly.

Table 1 uses the available published rates to show:

a) the number of new cases of clinically significant eating disorders which could reasonably be expected to present per year in each LHB (ie, the incidence).

b) the likely total number of known cases of clinical significance, for each LHB whose condition is severe enough (namely moderate/high risk or severity) to need to be on the caseload of the respective tiers described in this Framework (ie, the prevalence rate).

| Table 1: Estimated rates of clinically significant eating disorders |
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Estimated rates of clinically significant eating disorders, all-Wales and individual Local Health Boards (LHBs).

| Local Health Board | Total new cases per year (incidence) | Estimated caseload within each tier (prevalence) | | | |
|---|---|---|---|---|---|
| | | Tier 1: | Tier 2: | Tier 3 | Tier 4 |
| North Wales (Pop 745k) | 234 | 712 | 162 | 101 | 17 |
| Powys (Pop 132k) | 46 | 117 | 27 | 17 | 3 |
| Hywel Dda (Pop 375k) | 130 | 426 | 97 | 61 | 10 |
| Abertawe Bro Morgannwg (Pop 600k) | 173 | 595 | 136 | 85 | 15 |
| Cwm Taf (Pop 330k) | 100 | 349 | 80 | 50 | 9 |
| Cardiff (Pop 500k) | 154 | 695 | 158 | 99 | 17 |
| Gwent (Pop 550k) | 194 | 637 | 145 | 91 | 16 |
| WALES | 1029 | 3532 | 805 | 502 | 86 |

*Source: National Public Health Service for Wales, October 2008*

d.  *Implication for services*

The implications of the estimates in table 1 for primary, secondary and tertiary services may more readily be understood in terms of impact at a General Practice level.

It is often cited that 'an average General Practice list of 2000 patients can expect to have 1 or 2 patients with anorexia nervosa at any particular time'.  This is only a small part of the picture, and it can be misleading as the term 'anorexia nervosa' as used in the source studies refers only to those patients who have graduated to the full diagnostic definition of Anorexia Nervosa.  In terms of clinically significant cases of eating disorders of sufficient severity to require intervention, monitoring or referral, the average practice is likely to have far more patients of varying severity, with the majority being of mild to moderate severity, who may be supported entirely at Tier 1 level with adequate advice and support.  In the case of practices with a high student population, this figure will certainly be higher.

With a total Wales population of just under 3 million and with 530 GP practices across Wales, the average practice size is 5660.  Such a practice might expect to have 2 <u>new</u> patients each year with a clinically significant eating disorder of a moderate or high severity.  They are also likely to have 7 patients registered with them at any one time who should be known as being at risk from an eating disorder.  The challenge is to be able to identify and support these individuals

Some (approximately 2) of these 7 will be at sufficiently severe risk as to need the additional expertise of local mental health services or other Tier 2 facilities.  The practice will still have a role for these patients in terms of their physical health care and ongoing coordination and support.  The arrangements and limits of this continued role should be set out in a shared care protocol agreed between the relevant services and the patient and carers where appropriate.

On average, such a practice will have 1 patient at any one time who has been referred to a Tier 3 service such as the proposed Tertiary Eating Disorders Team.  This patient will still remain involved with both the primary care team and local community health services etc during their involvement with the tertiary team.  This involvement will increase as part of a stepped approach towards the least intensive level possible.

Statistically, this notional average practice would expect to have a patient requiring highly intensive (i.e. Tier 4) intervention every 5 years or so.  Alternatively, one practice in five would expect this to occur at any one time.

# 3.  **Key strands**

This section sets out the key strands which are apparent from the research into the experience elsewhere, and which have influenced the development of the Framework. The purpose of including them here is to help LHBs to understand the rationale behind the roles and expectations built into the detailed sections which follow.

These strands focus solely on the intended NHS response to eating disorders.  This must not be taken as undervaluing the crucial contribution of non-NHS organisations and activities such as self-help, community and voluntary sector and the roles of school or university based counselling and support staff.

Inevitably, the issues are closely intertwined and feature in more than one tier - each relies on progress in other fields. The strands discussed in this section are:

a.  Screening and Risk Assessment. This is a theme which needs to run through all levels, and needs a comprehensive approach to avoid gaps/duplication.

b.  Primary Care. Discussion of what might be reasonably expected from primary care teams and what support they need to be able to meet those expectations.

c.  Local mental health services. There is inconsistency across Wales in the extent to which community and inpatient psychiatric services respond.

d.  Co-morbidity. A very significant proportion of people with an eating disorder also suffer from other forms of mental disorder, but the impact of this is not recognised in the way some services currently respond.

e.  Physical health risks. There are very severe physical health risks and consequences arising from eating disorders which need to be taken into account at all tiers.

f.  Workforce, capacity and training issues. These also run throughout the framework, and need to be considered from an all-Wales perspective.

## 3.1.  Screening[A] and risk assessment

There is strong evidence[42,2] that patients who go on to develop very serious eating disorders are likely to have attended their general practitioners (GP) or other generic health services on a number of occasions without their disorder being reported by the patients or detected by the practitioners.  There is a need to develop a greater awareness amongst GPs and other front line health care staff of suitable screening tools and to encourage their wider use. to help them to differentiate between patients with transient or self-limiting problems and those at greater risk.

As many people with an eating disorder will not readily acknowledge or admit (either to themselves or to others) to having a problem, it is important for staff who provide services to teenagers and young adults to maintain a high level of awareness of the possibility of eating disorders and to have a low threshold for requesting further assessment by Tier 1 services.

Screening is the "systematic application of a test or inquiry to identify people at sufficient risk of a specific disorder to benefit from further investigation or direct preventive action"[35].  Screening operates at a '*population*' level for target populations such as university students and those in vulnerable age groups. If opportunistic screening of this nature points to the probability of a serious or complex eating disorder, the next stage is assessment, which is focussed on *individual people*.  One simple screening tool, SCOFF[36], has been validated for use with adults[37].  An alternative has also been identified as being potentially more sensitive for use with primary care and university populations[38] and is particularly suited to opportunistic use in primary care settings.  Guidance on use of such tools and other assessment techniques can be found in the series of leaflets issued by the Eating Disorders Unit of the Institute of Psychiatry (details in Appendix A).

Assessments vary considerably in depth.  Following on from the line taken by NICE in respect of managing people who harm themselves[39], it is recommended that assessments are cumulative and build one upon another.  At the levels of primary care teams and generic community health services (which deliver the functions of Tier 1), assessment will be, appropriately, limited.  Its focus covers general psychiatric and psychological dimensions and the core intent is to determine the extent, duration and impact of any disorder on patients and decide on the next course of action.  In cases in which eating disorders are being considered, thorough physical examination is essential both in order to provide an assessment of immediate risk to life and to obtain baseline recordings.

Depending on the outcome of the initial assessment at this generic level, a more comprehensive assessment may be needed which covers physical health and more specialised mental health, psychiatric and psychological dimensions.  An assessment of this nature is usually undertaken by a mental health professional or someone with relevant training.  In some cases, this first level secondary assessment will be sufficient to point the way forward for the interventions that individual patients require.  These interventions include advice and access to self-help programmes, agreement on monitoring by primary care teams, or a period of therapeutic intervention provided by primary or secondary care staff (Tiers 1 and 2).

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[A] NB. The term 'Screening' is used in this Framework in its generic sense as used in NICE guidance on eating disorders[2].  It should not be interpreted as being a formal Programme as defined by the Collaborative Commissioning of National Screening Programmes.

In the case of younger people, their first level specialist assessments should usually involve a paediatrician as well as specialist mental health services (Tier 2) in the light of the immediate and longer-term consequences of eating disorders for young people's physical health.

Some patients, namely those who have complex or enduring problems, require assessments to be made by more specialised Tier 3 or Tier 4 services. This may be aimed at providing advice to Tier 2 specialist practitioners on the management of their cases, or to assess whether a period of more intensive and specialised intervention is required.

Many referral algorithms use measures such as the Body Mass Index (BMI) to define thresholds of risk. The use of BMI in this way masks some extremely important risk factors for patients at all stages and ages. There are particular concerns over its use in children, where plotting changes over time for both weight and height on centile charts provides a more useful indicator[2, 40].

For all patients however, BMI should not be the only measure used to assess risk as there are many other factors which will affect the level of risk, for example the rate of weight loss, intensity of vomiting or laxative use, cardiovascular abnormalities or electrolyte imbalances. As noted elsewhere, co-morbidity in terms of other psychiatric or psychological disorders are very likely to be present (particularly depression, Obsessive Compulsive Disorder-like behaviours and suicidal ideation or self harming behaviours), and can greatly increase the level of risk from both the eating disorder and the other disorders.

The impact of family/social support (or its absence) should not be underestimated and should be taken into account in assessments at all tiers.

In view of the forthcoming changes in NHS structures, early work will be required to achieve a consistent series of categorisation of risks based on a sufficiently broad range of factors. These categories should be linked to the type and intensity of service responses which can be expected from each of the tiers, so that problems of transition and gaps between tiers are addressed systematically and equitably. This needs to be supported by clinical audit to assess the appropriateness of patient flows.

To ensure that appropriate factors are taken into account in forming a comprehensive assessment of risk, a series of assessment tools is available for use in different settings, and can be incorporated into local protocols.

## 3.2. Primary Care Teams

The issues regarding the role of primary care in the identification, assessment, support and treatment of people with eating disorders is complex, but real improvements cannot be achieved in responding to eating disorders in Wales without them being addressed. There is clear evidence of the value of early identification and intervention before an eating disorder can develop into a life-threatening condition such as severe anorexia nervosa, and primary care teams have a unique and crucial part to play.

Experience of both patients and practitioners in Wales demonstrates that there is no universal acceptance of the contribution which should be expected from primary care, despite the probability that 50% of sufferers will have attended their GP surgery on several occasions before identification/diagnosis[41, 42].

Audits have shown that the majority of general practitioners in some localities are unaware of the basic assessment and screening tools available, and some are unwilling to undertake routine weight and blood monitoring.

These factors have been identified in a large-scale survey of GPs in SE England by the Institute of Psychiatry[43] and they also feature significantly in evidence to the Scottish Parliament[44] and in a review within the Republic of Ireland[13].

An audit of GPs within Cardiff & Vale NHS Trust[45] area has demonstrated that these issues are also valid in Wales, with 96% of responding GPs saying that they were unaware of the screening tools available.

The problems identified in such research cannot be resolved without an understanding of the factors which contribute to the low rate of identification and engagement by many GPs.

One of the contributory factors leading to the current position will be the fact that individual GPs do not routinely receive training in this field[46], either in their initial, postgraduate training or as part of their continuous professional development[47], and most do not see enough cases to develop expertise.

Commentaries in several countries identify the duration of GP consultations as being a significant factor[48]. It is noted for example that the type of interaction required to build up rapport and confidence in the face of a sufferer's ambivalence over treatment is not readily going to be achieved within a short consultation

An additional factor is the absence of readily available sources of advice and support from local teams such as some CMHTs, as few localities have dedicated Eating Disorders Services for GPs to approach for advice.

The SCOFF[49] screening tool has been validated as robust for use in primary care settings, being sensitive enough to indicate the potential need to investigate further. Studies in GP surgeries[50] have however shown that many practice staff place little value on such screening on the basis that they have nowhere to refer a patient on to if the results indicate the probability of an eating disorder.

A further challenge in securing robust primary care involvement has been the exceptionally low level of awareness and use of practice guidelines on dealing with eating disorders. This has been apparent in studies in Wales[45] as well as elsewhere in the UK[51] and in Canada[52], Australia and New Zealand[53] which decided to issue guidelines similar to those issued by NICE but which provide more detailed manuals for primary care staff. As few as 5% of GPs in some studies followed the sort of referral or investigation thresholds recommended in national guidelines, or those produced by Royal Colleges and specialist centres[54].

17.

Some localities in Wales have issued local guidance for primary care teams on identification, assessment and management, but there is no Wales-wide approach. Elsewhere in the UK, Scotland has issued detailed guidelines[55] to supplement NICE, but the Scottish Parliament established[44] that these guidelines had not been taken up within primary care teams.

The conclusion reached by the Quality Improvement Scotland (QIS) is that change is only likely at general practice level where undertaking this activity is included in formal performance management and outcome frameworks, and has been the subject of locally agreed protocols. The NHS in Scotland also recommends to GPs that they should include patients with severe chronic eating disorders on the registers they are required to maintain of patients 'with schizophrenia, bipolar disease and <u>other psychoses</u>'[55]

The NICE Guideline for eating disorders was issued in January 2004[2]. The essential elements behind the NPHS recommended pathway are consistent with the NICE guideline as follows:

a. Chapter 5 of the full NICE guideline deals with the implications for primary care, and fully supports the role set out in the pathway in terms of identification, assessment and monitoring. It notes that over half of clinical cases of eating disorders go undetected by GPs, despite the fact that sufferers are far more likely than the general practice population to have attended surgeries in the few years prior to diagnosis.

b. Building on the information from NICE on the variability of referrals from primary care to specialist centres, the Institute of Psychiatry's research[56] showed that GPs in the South East of England do not follow the recommended thresholds for referral, and do not routinely follow the guidance regarding physical monitoring. Within Wales, a very high majority of GPs in a recent baseline audit state that they did not have access to screening and assessment tools, and some indicated a reluctance to participate in the weight monitoring and routine blood checks which are so important.

c. The most relevant items related to primary care in the proposed pathway are the following recommendations included as sections 5.2.5.1 and 5.2.5.2 in the full NICE guideline[2]:

> *"For people with eating disorders presenting in primary care, GPs should take responsibility for the initial assessment and the initial co-ordination of care. This includes the determination of the need for emergency medical or psychiatric assessment.*
>
> *Where management is shared between primary and secondary care, there should be clear agreement amongst individual health care professionals on the responsibility for monitoring patients with eating disorders. This agreement should be in writing (where appropriate using the care programme approach) and should be shared with the patient and, where appropriate, his or her family and carers."*

d. Further work is needed to explore and develop the role of primary care, non-NHS front line health care staff, social care staff and voluntary sector staff in relation to eating disorders.

## 3.3. Community mental health services and general psychiatric inpatient care

This section considers the role of local generic mental health services in the identification, assessment, intervention and monitoring of people with eating disorders.

It applies to the entire range of local mental health services settings (community, outreach, outpatient, day care or inpatient), ages (child, adolescent or adult) and to all disciplines.

As described in the Framework for Mental Health Services for Scotland:

> *Many people with eating disorders have severe and/or enduring mental disorders which must give them the priority and access to services equal to other groups with severe and/or enduring mental disorder.*

> *There should be local guidelines to assist generic staff in the management of mild to moderate uncomplicated cases and guidelines on who to refer to for more specialised services for eating disorders.[28]*

The fundamental principle underlying the Welsh Assembly Government's position is the unequivocal reinforcement of eating disorders of relevant severity as being mental disorders. The fact that they are not necessarily referred to in relevant mental health guidance or policy issued by the Assembly does not mean that patients with these disorders are excluded.

At no time has the Assembly authorised NHS Trusts or Local Health Boards to exclude eating disorders from their responsibilities to ensure that patients with mental disorders obtain assessment, interventions and monitoring in accordance with their clinical needs. Unfortunately, it is clear from representations made to the Cross Party Group and to the All Wales Eating Disorders Special Interest Group that the absence of specific reference to eating disorders in some policy documents has been interpreted in some localities as indicating exclusion. This issue seems to arise primarily in adult mental health services, as child and adolescent mental health services will have been required to ensure that eating disorders are specified as included in their core functions under the relevant circulars.

Exclusion of patients with an eating disorder from access to local mental health services is not only inappropriate and unacceptable in terms of equity, it is also clinically unsound in the light of the extremely high levels of psychiatric co-morbidity and the confounding effect of eating disorders on many of the disorders.

All the expectations set out in the revised National Service Framework for Adult Mental Health *Raising the Standard*[8] and in the Supplement Guidance prepared for the NHS by the National Public Health Service[57] apply to eating disorders as to other mental health disorders. LHBs therefore need to ensure that they have taken steps to ensure that the four underpinning principles set out in the relevant strategies apply as much to patients with eating disorders as to other disorders, namely that they are Equitable, Empowering, Effective and Efficient.

In its baseline review of adult mental health service provision[14] across Wales, the Wales Audit Office noted that there were particular concerns over the limited focus which had been given to early intervention. It also noted that the transition between child and adolescent and adult mental health services was problematic.

From the point of view of the NSFs dealing with both adult mental health services[8] and children and young people[58], there are several very important implications for LHBs to address in respect of eating disorders:

a. Where local mental health services have not fully fulfilled their responsibilities in respect of eating disorders, this will have had an impact on primary care and other 'Tier 1' services who would have been deprived of the appropriate source of advice on assessment methods etc. for patients being seen at that level.

19.

b. Where local mental health services teams or staff do not currently have sufficient understanding of eating disorders to be able to undertake relevant risk assessments, care planning or interventions to a degree and depth appropriate to their role, it is incumbent on them to rectify this deficit, not to refer inappropriately to more specialised services.

c. When considering the referral arrangements and severity thresholds for access by patients with eating disorders to adult mental health services, account must be taken of Child & Adolescent Mental Health services which feed into these adult services. This relates particularly to incompatible age thresholds used by some CAMHS/Adult agencies. This issue was identified in Everybody's Business (section 6.6) but which is still a major operational issue despite the clear guidance issued by the Welsh Assembly Government[59]. These variations in referral thresholds can mean that patients suddenly become ineligible for support on reaching 17 or 18 years of age. Such artificial barriers need to be addressed jointly to ensure that there are coherent procedures based on assessed need and agreed, phased transition, not unilaterally imposed thresholds.

## 3.4. Co-morbidity with other conditions

Co-morbidity is the presence of two or more disorders, physical or mental, in an individual. The relevance of this in terms of care pathway is related to both co-morbidity with other mental health problems and its impact on services; and co-morbidity of physical health conditions. Physical health issues are discussed in section 3.5.

### a. *Psychiatric co-morbidity*

Studies have shown that a very high proportion of patients suffering from a moderate or severe eating disorder will also have elements of other serious psychiatric difficulties at some time during the course of their illness.

Despite this, practitioners across Wales have identified that there are degrees of segregation or exclusion in the way mental health services respond to eating disorders which suggest that the interaction between an eating disorder and other psychiatric conditions is not being adequately taken into account.

In terms of mental health co-morbidity, the research and professional guidelines demonstrate that psychiatric co-morbidity with anorexia and bulimia nervosa is present in key areas, including depression, bipolar disorder, anxiety disorders (obsessive-compulsive disorder, panic disorder, social anxiety disorder and other phobias, and post-traumatic stress disorder) and substance misuse.

There are four key dimensions to this co-morbidity:

a. Firstly, the effects of starvation and unstable eating can affect both the diagnosis and response to treatment of the comorbid disorder. Starvation in particular will have a profound effect on mood and cognition[60] .

b. Secondly, guidance suggests that, for patients with anorexia nervosa (and, to a lesser but still significant extent, bulimia nervosa) minimal change can be expected in the treatment of the comorbid condition if the patient is still starved.

c. Thirdly, treatment of the eating disorder itself will have to take into account the effects of the comorbid psychiatric problems – yet some services are reported to be reluctant to accept referrals for patients whose primary diagnosis is an eating disorder.

d. Finally, even issues as fundamental as absorption of medication used in some comorbid psychiatric disorders will be affected, either due to the patient's electrolyte imbalance or to purging behaviour such as vomiting or laxative abuse.

It is therefore absolutely essential that referral, assessment and intervention protocols within all mental health services take the fact and impact of co-morbidity into account. In drawing up such protocols, LHBs will need to recognise that individual patients cannot simply leave one part of their disorder on hold while being referred to separate services for the other – there need to be robust arrangements for joint working between teams.

### b. *Common areas of psychiatric co-morbidity in eating disorders*

This summary table indicates the range and degree of co-morbidity which needs to be taken into account by LHBs in designing their local services:

| Condition | Lifetime prevalence estimate |
|---|---|
| **Depression** | *Co-morbid major depression or dysthymia has been reported in 50%–75% of patients with anorexia nervosa and bulimia nervosa* |
| **Bipolar disorder** | *4% - 6% in patients with anorexia nervosa or bulimia nervosa are usually around 4%–6% but have been reported to be as high as 13%).* |
| **Obsessive-compulsive disorder (OCD)** | *Some studies suggest up to 40%, most indicate 25% for anorexia nervosa cases, and obsessive-compulsive symptoms have been found in a large majority of weight-restored patients with anorexia nervosa treated in tertiary care centers. OCD is also common among patients with bulimia nervosa* |
| **Personality disorders** | *Comorbid personality disorders are estimated as ranging from 42% to 75%.among patients with eating disorders. It is also reported that eating disorder patients with personality disorders are more likely than those without personality disorders to also have concurrent mood or substance abuse disorders* |
| **Substance abuse).** | *Highest at 30%–37% for bulimia nervosa; 12-18% among patients with anorexia nervosa, primarily among those with the binge/purge subtype* |
| | *Source: Practice Guidelines produced by the American Psychiatric Association′* |

**Table 2: Common areas of psychiatric co-morbidity**

## 3.5. Physical health care

Eating disorders are defined as mental disorders and mainly managed within mental health services, but they have very important physical health dimensions which need to be taken into account at both the individual patient level in terms of assessment and treatment, and at a health care planning and service organisation level.

The framework for mental health services in Scotland summarises the issues in these terms:

> "Patients with severe eating disorders suffer major physical complications, some of which may be acutely life threatening.  These patients require access to acute general medical specialist services with expertise in the assessment and management of severe nutritional problems.  Some will present initially in general hospital wards and will require ready access to skilled mental health liaison staff and dieticians, all trained in the assessment and management of eating disorders."[28]

There are two main aspects related to the physical care of people with an eating disorder which have implications for the roles set out in the tiered Framework for Wales:

- *Medical stabilisation and refeeding*
- *General health care and monitoring at all stages.*

### a. *Medical stabilisation and refeeding.*

It is not generally understood by those responsible for planning and developing services that, for some patients suffering from severe eating disorders (e.g. low weight anorexia nervosa patients), admission to inpatient treatment will need to focus on acute medical care, rather than psychiatric intervention.

If the risk assessment shows that a patient's health is severely compromised, they may need to be admitted to a setting that can correct the nutritional deficits which will have developed, particularly where patients have restricted intake of fluids as well as food.

There are very great risks when beginning to re-feed a patient after a prolonged period of extreme abstention or starvation, mainly the complication termed Refeeding Syndrome.  This term refers to the severe electrolyte and fluid shifts associated with metabolic abnormalities in malnourished patients undergoing refeeding[61].  Refeeding can easily result in deficiencies in several nutrients, and some of these (particularly deficiencies of potassium, magnesium and phosphate) can rapidly result in heart failure and death.

Guidelines have been issued by the Royal College of Psychiatrists on nutritional management of anorexia nervosa[62], and LHBs must ensure that these are adopted and used both by their general physicians and across their psychiatric units.  All patients undergoing refeeding programmes should be cared for by multi-disciplinary teams with including appropriate expertise in the psychiatric/ psychological aspects of care and physical health (metabolic/ endocrine/ dietetic) aspects of care.

### b. *General health care and monitoring at all stages.*

There are three aspects related to the physical health care of patients with eating disorders which have influenced elements of this framework, and which are summarised below. It is beyond the scope of this framework to deal with such clinical matters in details, and there are many sources of research and clinical guidance available for practitioners to refer to. They are highlighted here as factors which must be included in reviews and service specifications by LHBs.

- *Factors related to the physical damage which can results from failure to diagnose or treat eating disorders.*

Eating disorders are psychiatric conditions where medical complications are common and can have long term consequences. Most of the conditions summarized below will resolve with timely and intensive treatment and resolution of the eating disorder[63].

Without such timely identification and robust attention however, young people in particular can be left with chronic medical conditions. Some stages of development amongst children and young people are absolutely critical for early identification and intervention because of the limited period when some organs or tissues develop. The potential long term consequences of anorexia nervosa amongst children and adolescents can also include stunting of growth.

The restriction of food and fluid intake in anorexia nervosa leads to all the effects of starvation and dehydration including circulatory problems, gastric problems, electrolyte imbalance, heart failure, kidney failure, osteoporosis and possible epilepsy[64].

At later stages of anorexia, the effects of failing diagnose or treat patients can be far more immediate, and these have been referred to above in connection with refeeding.

- *The importance of routine monitoring at different levels of intensity.*

Research consistently identifies the importance of rigorously monitoring physical health, from the initial presentation at primary care through to intensive care units.

This has implications for all tiers, and needs to be included as a specific element in their specifications and resources. There are particular risks when longer term care is being shared between teams – in these cases, it is essential for the arrangements to be set out in writing and shared with all parties, including the patient.

There are examples of monitoring tools readily available from several sources, including a full suite used by the ANITT team in Lothian, Scotland[32] which includes protocols for long term, low-level monitoring as well as high risk scenarios.

- *Specific physical conditions where the existence of an eating disorder can have a confounding or co-morbidity impact.*

There are also other physical aspects of co-morbidity which need to be considered where risks can be increased or the options for treatment may need to be amended.

Recommendations from NICE[2] and other commentators[19] identify diabetes and pregnancy as requiring particular attention. Close liaison will be required between staff working in these fields and eating disorders specialists to develop appropriate awareness training and support protocols for obstetric patients or those diagnosed with diabetes who have eating disorders.

### 3.5.b..1. Diabetes

In the case of diabetes for example, NICE guidelines[65] on the diagnosis and management of diabetes in both adults and young people recommend that members of

multidisciplinary professional teams should be alert to the possibility of bulimia nervosa, anorexia nervosa and insulin dose manipulation in adults with type 1 diabetes.

These guidelines highlight that the risk of morbidity from the complications of poor metabolic control suggests that consideration should be given to early, and occasionally urgent, referral of adults with type 1 diabetes to local eating disorder services. They also recommend that all young people presenting with Type 1 diabetes and poor treatment adherence should be screened and assessed for an eating disorder. Other practice guidelines highlight the risk of diabetic patients with eating disorders under-dosing their insulin to lose weight[66], and studies have shown that mortality rates are higher with combined anorexia nervosa and type 1 diabetes then with either condition alone[67].

### 3.5.b..2.  Pregnancy

The potential for enhanced risks arising from eating disorders in pregnancy differ greatly between anorexia nervosa and bulimia nervosa[2, 19]. In the case of anorexia nervosa, the probability of becoming pregnant is greatly reduced, but there remains the risk of patients relapsing into anorexic behaviour during pregnancy. In the case of bulimia, there are additional factors concerned with unplanned pregnancy linked to ineffective contraception with purging behaviour.

Because of the potential for complications for both mother and child, pregnant women with eating disorders require careful monitoring throughout and following their pregnancy. This has implications for both obstetric staff, district nursing teams and for specialist eating disorders teams which will need to provide advice and support to these staff. Obstetric staff are also very well placed to identify potential problems with eating disorders in patients who have avoided seeing any other health care professionals[68].

### 3.5.b..3.  Substance misuse

As noted in section 3.4 above, research also shows that people with severe eating disorders are not only more likely to have problems with alcohol or substance misuse, but also that their eating disorders can result in such problems having far more damaging impact than other groups[66].

As with other conditions, the rate and impact of simultaneous eating disorders and substance misuse require formal links between relevant specialists and teams.

## 3.6. Workforce, capacity and access issues

The sections that follow describe each of the four tiers referred to in Section 1.2. While reference is made to some of the main features for workforce planning at each tier, it is suggested that the necessary development of the workforce should be on a 'whole system' basis.

The roles envisaged for the staff in primary care, for example, raise issues of capacity as they are most likely to have an impact both on general practitioners and on staff of the specialist mental health services (such as Primary Mental Health Care Practitioners) who are based within primary care services.

Establishing tertiary teams with the requisite skills to discharge the functions of Tier 3 arguably requires an all-Wales initiative that is planned together with local services that are the likely source of recruitment. The workforce challenges go far beyond these highly specialised teams as there are major implications for general health practitioners, such as those in primary care, and paediatric services, and staff in local specialist mental health services which deliver the functions of Tier 2.

The Cross Party Group has highlighted the fact that many of the health professions on which effective services depend have little or nothing in their core curriculum to equip staff with the awareness and skills required. This is a major problem which requires a concerted approach with relevant Universities and other training bodies, and which WAG will address in conjunction with the Cross Party Group.

Experience in other home countries of the UK has clearly demonstrated that it is necessary to develop the skill base already in place, rather than expecting to be able to recruit directly into most Tier 3 teams.

Some issues which have emerged during the NPHS's research for this Framework are outlined in the following sections.

There are two particular aspects of intervention where LHBs will need to undertake a structured review of their local arrangements, namely in respect of dietetics and access to psychological therapies and counselling.

Arrangements for these activities would benefit from all-Wales co-ordination to ensure that LHBs operate consistently, gain from expertise elsewhere and work together to build up an evidence base of what is effective.

## a. *Role of the Dietetics in the treatment of eating disorders*

Dieticians, with their expertise in assessing nutritional requirement and up to date knowledge, are an essential part of the multidisciplinary team approach required for the assessment and monitoring of patients with eating disorders.

There are however several aspects of the role of dieticians in the treatment of eating disorders which need to be clarified and taken into account in local protocols. These protocols will need to be informed by advice from relevant professional bodies and networks, but it is already apparent from representations made to the Cross Party Group that there are issues which need attention when LHBs review current practice.

Patients, carers and health professionals have reported that, in some NHS Trusts in Wales, there is no access to dieticians for psychiatric inpatients. In many cases, community mental teams cannot make direct referrals to dieticians, and have to ask GPs to make referrals to community dietetic services. Given that both patients with eating disorders (and those with other mental health problems) may need advice on nutritional issues, such exclusions need to be reviewed so that referrals are considered on the basis of assessed risk and clinical need.

It is also important for LHBs to make a distinction between the roles and expectations of non-specialist dieticians and those with additional expertise in either mental health or eating disorders.

NICE guidelines[2] on managing eating disorders specifically recommends that dietetics should not be the sole input for patients with anorexia nervosa or bulimia nervosa. This recommendation reflects the fact that dieticians will not have had formal counselling training as part of their syllabus, and very few will have taken more intensive training in psychological therapies. Many courses do not in fact include in-depth training on eating disorders or other mental disorders.

Patients with eating disorders are inevitably likely to be resistant to nutritional treatment which conflicts with their ideal body image[19], and it is not reasonable to expect a non-specialist dietician to achieve dietary change without the patient receiving appropriate psychological therapies.

Their expertise is however essential when used appropriately – providing an educational and advisory role for mild and early stage eating disorders and those who are motivated to act on such advice, and working as part of a team for patients with moderate/severe eating disorders.

Access to the skills and expertise of a specialist dietician will be crucial in any Tier 3 eating disorder service being developed by LHBs to provide accurate education about nutrition, weight gain, weight maintenance, the resumption or normal eating, and the nutritional methods of avoiding the refeeding syndrome[19].

27.

## b. *Psychological therapies and counselling*

A coordinated approach to the provision of psychological therapies and counselling is critical to the successful implementation of the Framework, and LHBs must take a proactive approach to defining the range and level of staff providing such support to people with eating disorders. This must be done in conjunction with patients and carers, and must take into account the resource implications of different models.

Many patients suffering from clinically significant eating disorders experience difficulty accessing specialist psychological treatments and patients in some areas are not offered meaningful alternatives to a prolonged wait[69]. Given the overwhelming evidence in favour of early identification and intervention in this field[2], this situation clearly needs to be addressed as a matter of urgency.

In respect of patients over 18, Raising the Standard[8] recommended the adoption of the guidance published by the Department of Health, *Treatment choice in psychological therapies and counselling*[69]. This guidance acknowledges that the evidence base for the use of specific psychological techniques is limited, and most studies have been undertaken in highly structured settings where the differences between techniques are likely to be less relevant than the overall regime and supportive environment[70]. In the case of children and adolescents, the evidence base is even less well developed in terms of being able to identify any particular formal techniques as significantly more effective than others[71].

Some commentators refer to summary reports of family-based interventions for younger patients and cognitive behavioural therapy (CBT) for older patients as having been definitively demonstrated to be effective, but the formal evidence base for these reports is in fact very limited[72]. This is demonstrated by reviews by such eminent commentators as Fairburn[18] and reinforced in a 2008 Cochrane Review[73].

What is less well reported is the evidence that guided self help can be as effective as formal psychological therapies from a qualified therapist, at least for bulimia nervosa, and is certainly more beneficial for many patients than merely placing them on a waiting list[74]. Where a patient can gain from approaches such as CBT, this can be provided by a range of staff with appropriate training, support and supervision[74].

As most of the published evidence arises from studies in highly intensive health care settings[70] they do not consider the very important contribution of counselling undertaken at primary care levels, or the highly structured counselling provided in some universities[75] across Wales.

The recent Cochrane Review[73] highlights the fact that there are significant resource implications involved depending on the model used to provide psychological therapies.

Public and patient engagement is a fundamental feature in relevant NSFs and in the proposals announced for changes in the NHS. It is essential for LHBs to ensure the full participation of all relevant disciplines as well as sufferers and carers in decisions on the range, type and setting for psychological therapies and counselling to be provided.

Following consultation on this Framework, the Assembly will consider mechanisms for ensuring that LHBs work together to develop proposals for how psychological therapies and counselling are to be made available and evaluated at each tier, and how support and supervision might operate between the tiers and with non-NHS activity such as school[76] and university based counselling.

# 4.	Proposed four-tier model of care for patients who have an eating disorder

## 4.1.	Outline of the model

The model proposed provides a strategic conceptual framework on which to base the planning and development of a comprehensive range of assessments and treatments for people with an eating disorder who live in Wales.  It achieves this by outlining the functions of each tier to enable LHBs to translate them into local action plans for delivering a continuum of assessment, treatment and care.

A four-tiered strategic approach to underpinning the planning and design of systems for delivering services has been in use within Child & Adolescent Mental Health Services (CAMHS) for some years.  This approach is based on the framework recommended by the NHS Health Advisory Service report 'Together We Stand'[77].  Essentially, it pragmatically sets out a way of describing the various service responses or functions that patients need at different times.  It is policy in England as in Wales and is now widely accepted across the UK as the basis for planning, commissioning and delivering services.

A similar tiered approach is evident in some adult mental health and substance misuse services, and it also features strongly in the new Welsh Assembly Government strategy for the NHS in Wales, 'Designed for Life'[78].

There is some variation in the way the tiers are described between CAMHS and mental health services for adults, particularly in respect of those activities and functions that are provided by local specialist mental health services.

It is important to note that the tiers set out in this Framework refer primarily to the contribution expected from the NHS in Wales.  The comparable framework in Scotland[28] describes an addition tier (Tier 0) which deals with the contribution from the community at large and from non-NHS organisations.  In focussing this Framework on the NHS contribution, the Welsh Assembly Government is not minimising the crucial importance of community and other activities, and LHBs will need to work with their partner agencies to develop robust and supportive local networks.

At a national level, Welsh Assembly Government has commenced discussion with leads for initiatives such as school-based counselling and mental health promotion to ensure that the implications for them of eating disorders are taken into account in their development and implementation.

It is also important to bear in mind that neither services nor people fall neatly into tiers. Patients may often require the facilities or functions of more than one tier at the same time or sequentially, and some patients require services from all of the tiers at the same time.

Similarly, staff may work within more than one tier – for example, many specialist practitioners work at both Tier 2 and Tier 3 levels, with their Tier 3 activities being discharged through a sessional input to a multidisciplinary team with a specific or specialist remit to review or work with more complex cases

*The tiered strategic framework should be seen as a tool for Local Health Boards (LHBs) to check that they have the full range of services in place.*

29.

As with other mental health problems, most people with an eating disorder should be seen at Tier 1 and most of those who require more specialist input than is reasonably available from Tier 1 services should be seen at Tier 2. Patients with more severe, complex or persistent disorders may require second-level specialist services (at Tier 3) and some may require admission to much more specialised inpatient facilities. This progression will apply to assessment activity as much as to monitoring and interventions.

The majority of people with an eating disorder will receive an initial assessment at Tier 1. Within that group many will require specialized assessment and intervention by Tier 2 services before they can be returned to primary care for monitoring. If they do need a more complex level of assessment or intervention than can reasonably be expected from Tier 1 services, they should be assessed and treated in the local first level specialist mental health services (Tier 2), namely the relevant CAMHS or Adult Community Mental Health Team / Service – or by a designated physical health unit with relevant expertise if there is a significant medical dimension or risk.

It is our intention that the majority of people with an eating disorder should be cared for through a combination of services that deliver functions that fall into Tiers 1 and 2. Some patients will require rather more specialised services from specialist eating disorders teams and others may require periods of admission if their physical health is at threat or if there are particular mental health and psychological matters to address.

It should be stressed however that, in recommending that staff who work in services that deliver the functions ascribed to Tiers 1 and 2 should be able to identify, assess and intervene with people with an eating disorder, the framework is not suggesting that they should have the total responsibility for complex cases. It suggests that this workforce is able to offer or secure meaningful assessment and intervention for people at a much earlier stage and before they develop severe anorexia nervosa etc.

The intention of this draft framework is to facilitate service developments by setting out the possible interventions that might reasonably be expected of them within a stepped approach to care.

Such an expectation inevitably brings with it the acknowledgement that each tier can only function with the readily available support of the more specialist tiers.

30.

## 4.2. Tier 1 service functions

The activities that comprise Tier 1 are generic services that are staffed by professionals who are not normally or necessarily specialists in eating disorders or mental health. Their roles do, however, frequently bring them into contact with a number of people who have eating disorders, whether or not those people acknowledge their problems or are actively seeking help with their disorder.

Staff who work within settings that offer the facilities of Tier 1 should have the skills to recognise potential and actual eating disorders, and should have ready access to colleagues with more detailed knowledge and expertise. *(It is important to stress that Tier1 does not simply equate to primary care as used in NHS terminology, but also includes other activities provided by health, social and community services).*

### a. *Functions and tasks, Tier 1*

Functions that are provided at Tier 1 include:

a. Monitoring by general practitioners and hospital and community health staff of the physical and mental health of people with eating disorders to identify any changes in condition and associated risk. This may either be as the main healthcare professionals where patients do not currently require more specialised interventions, or as part of a shared care arrangement with specialist staff who are able to offer the functions that fall into Tier 2 (e.g. local mental health teams) or Tier 3 (e.g. formal eating disorders specialist teams);

b. Health education, prevention and psycho-education to raise awareness, reduce the potential risks of some people developing severe eating disorders or to prevent people with an eating disorder developing other severe conditions;

c. Routine screening of vulnerable groups of people to improve early identification of patients with eating disorders (some of whom will try to mask their problems or be reluctant to initiate assessment and treatment), and application of basic assessment tools;

d. Working directly with people and families through short-term advice, counselling and guided self-help and use of book prescribing;

e. Knowledge of referral routes and thresholds that apply to criteria for entry to the more specialised services.

### b. *Workforce matters, Tier 1*

In order to deliver the necessary assessments and interventions, all professionals should have a good understanding of eating disorders, and have the skills and tools to help them identify and assess people who are at risk.

A number of tools are available for primary care staff and other staff who deliver the functions of Tier 1 to assist them to identify and carry out the initial assessments of people who may have eating disorders. There are also several tools and guidelines on the nature and extent of the monitoring and thresholds of physical health. A compendium of resources for staff who deliver the functions that are assigned to Tier 1

will be established and kept up-to-date in response to the changing evidence of effectiveness of a variety of interventions.

These tools will also be made directly available to primary care teams and other Tier 1 services through the Map of Medicine[79] protocols in due course.

Many practitioners feel that they have not had sufficient training or experience to be able to use these tools with confidence or competently, or to know which is the most effective in each of a variety of circumstances (e.g. at different ages or in the face of co-morbidity)[16]. They should have access to training and advice from staff who deliver the more specialised functions of, usually, Tier 2.

They should also be able to approach both Tier 2 and Tier 3 services for pre-referral consultations to obtain advice on potentially complicated cases. This both increases their expertise and confidence in handling cases directly, and avoids inappropriate referrals[24].

## 4.3. Tier 2 service functions

Services that deliver the activities and functions that are assigned to Tier 2 are mainly provided by staff who have had relevant training and have current expertise in assessing and working with people who have mental disorders. Therefore, they have expertise in methods of assessing and intervening with people who have a broad range of mental disorders and these general specialist skills are required by all patients who have an eating disorder.

Staff who deliver the functions of Tier 2 need to be able to apply their knowledge of mental disorders and expertise with patients who have eating disorders as with other mental disorders. They should be available to offer advice to staff who deliver the functions of Tier 1. They should be able to undertake more extensive assessments than staff in primary care and recognise cases and circumstances in which more intensive assessment or interventions are required. Additionally, they should be able to recognise when referral may be appropriate to a more specialist team for people with eating disorders (i.e. teams that are able to deliver the functions of Tier 3).

The expertise that falls into Tier 2 may also be available from particular members of primary level services who have undertaken additional training in mental health or eating disorders such as Primary Care Mental Health Practitioners.

Medical, nursing and other staff on paediatric or acute medical wards who need to have specific and relevant expertise in the physical health aspects of eating disorders would also be operating at Tier 2,

### a. *Functions and tasks, Tier 2*

The functions allocated to Tier 2 include all of the functions of Tier 1, plus:

a. Health education, prevention and psycho-education to raise awareness, reduce the potential risks of some people developing severe eating disorders or to prevent people with an eating disorder developing more severe conditions;

b. Provision of expertise in assessment using standard assessment techniques to identify the principal causes and risks;

c. Undertaking direct interventions to assist patients to deal with their eating disorders and comorbid disorders. The precise range of interventions will need to be agreed within each LHB, but it must include equitable access to adequate CBT and family therapies as set out in relevant Assembly targets.

d. Providing monitoring for patients with eating disorders in accordance with any care programme or shared care agreed;

e. Monitoring and reviewing patients who are receiving intensive/residential treatment according to agreed protocols and any reviews or monitoring visits to patients who are admitted to inpatient units out-of-area for which the commissioners have agreed contracts with identified providers;

f. Providing appropriate monitoring and interventions in respect of the effects on physical health that are within the expertise of mental health specialists and arranging for assessment by specialist physicians if that level of expertise in physical healthcare is required.

g. Provision of acute medical expertise (for example paediatricians and adult physicians) in the physical dimensions and effects of eating disorders, including nutritional implications and refeeding.

b. *Workforce matters, Tier 2*

Staff who deliver assessments and interventions that are designated as Tier 2 functions require formal acknowledgement of this being a core part of their roles. In the case of consultant medical staff, this role must be built into their formal work plans with appropriate sessions allocated and incorporated into their CPD and assessments.

Each specialist mental health team for adults that delivers the functions of Tier 2 should appoint one of its members to be the designated contact in respect of eating disorders for liaison with services that provide the functions of Tiers 1 and 3 (NB. the local Specialist CAMHS teams already are required to have Primary Mental Health Workers).

There is a significant difference between adult and younger people's mental health services across Wales in respect of the way they incorporate assessment, care management and intervention for people who have or who may have an eating disorder within their core activities. The local Specialist CAMHS services normally accept referrals of people who may have eating disorders of appropriate severity as part of their core business, whereas many mental health services for adults do not yet provide an equivalent response or expertise. The organisational, workforce and training implications of the role which is set out in this framework requires urgent attention.

## 4.4. Tier 3 service functions

The functions that constitute Tier 3 in the stepped model of care presented in this framework are those 'second line' specialist services that are provided by multidisciplinary teams that have particular expertise in working with people who have an eating disorder and who require that level of specialised expertise. Referral of patients to teams that deliver these Tier 3 functions may be required because the resistance of an individual's condition to less specialised interventions has prevented them from benefiting sufficiently, or because co-morbidities present diagnostic and management challenges.

Tier 3 teams are expected to provide structured treatment programmes that are focussed on people with serious and/or enduring mental disorders of a complexity or intensity that requires a referral from Tier 2.

The teams that deliver these functions of Tier 3 usually work in community settings to deliver specialist services to non-resident / ambulatory patients. Other Tier 3 functions include providing home-based intensive treatment and intervention programmes, and day-care facilities for people who require those additional intensities of intervention.

The nature of these Tier 3 functions is such that these services should usually be organised for populations larger than those of individual Unitary Authorities, and probably delivered on a 'regional' or well defined multi-LHB basis as formally agreed by relevant LHBs.

It is important to be clear that patients whose needs require their assessment or intensive interventions to be undertaken by specialist Tier 3 teams will almost certainly also continue to have needs that should be met by Tiers 1 and 2. In other words, referral of patients to teams that function at Tier 3 must not be taken as an indication that all of their needs will be met from Tier 3. Almost all such patients will need continued, coordinated and complementary investigations and interventions from colleagues in Tiers 1 and 2 for their physical health problems or coexisting mental disorders.

Similarly, in few instances is it wise that any member of staff should work solely at the Tier 3 level. Experience shows that most staff come together from CMHTs or other teams that deliver the functions of Tier 2 to work part-time as a team to deliver Tier 3. This works well and enables expertise gained in working at Tier 3 to be cascaded in other parts of the working week into teams and services that deliver the tasks of Tiers 1 and 2.

In some locations in Wales, Intensive Therapy Teams operate within CAMHS in community settings or through intensive day patient treatment and are also designated as supplying Tier 3 functions.

### a. *Functions and tasks, Tier 3*

The functions that are provided at Tier 3 include:

a. Working with staff who deliver the functions of Tiers 1 and 2 on an advisory and consultancy basis to enable those staff to continue their involvement in the direct treatment and care of particular patients;

b. Advice for staff in local/general inpatient settings such as paediatric or acute medical wards on appropriate treatment regimes and interventions;

c. Managing discrete caseloads for defined durations and purposes as part of a co-ordinated Care Programme Approach (where and when appropriate) where their therapeutic skills and a patient's assessed need make this appropriate;

d. Brief intensive out or day assessment to assist staff in Tiers 1 and 2 to provide local interventions;

e. More intensive assessment and therapy delivered by appropriately skilled staff of day care and day hospital services for patients who require them. The precise range of therapies will need to be agreed by each LHB, but it must include equitable access to adequate CBT and family therapies as set out in relevant Assembly targets.

f. Intensive treatment delivered by intensive therapy teams in community settings;

g. Facilitating successful discharge for patients following periods of specialist inpatient or day care, by providing continuing specialist treatment for patients in local services in accordance with an Enhanced CPA programme where and when appropriate. Particular patients who are being prepared for discharge may need such an enhanced intervention for a defined period to manage the transition from intensive inpatient and day care to lesser intensity of outpatient care in a community setting.

Access to services that deliver the functions of Tier 3 is usually through the relevant local CAMHS team or CMHT, rather than directly from primary care. This reflects the stepped model of care - it is not intended to create unnecessary barriers, but rather to ensure that patients are firmly embedded in the local network of services and that local interventions have been engaged. This is especially important when trying to re-introduce a patient into local services, when continuation of care is so important. There may be occasional exceptions to this restriction on referral routes in the case of crisis or rapid deterioration.

b. ***Workforce matters, Tier 3***

Unlike the services that deliver the functions of Tiers 1 and 2 (which will cover defined locations within a LHB), services that deliver the functions of Tier 3 may be more appropriately provided at an LHB-wide or multi-LHB level.

This will introduce important management and accountability issues to ensure that that teams that provide the functions of Tier 3 are adequately linked in to services arranged by individual LHBs and address transitional issues such as age and severity thresholds. It is at Tier 3 where there is greatest scope for overlap and gaps between local and 'tertiary' services. It is unlikely that sufficient staff will be immediately available to form Tier 3 services across Wales and hence there is a need for significant workforce development.

## 4.5. Tier 4 service functions

The functions that are ascribed to Tier 4 are highly specialised and intensive services for which specific referral and review criteria have been defined.

In most cases, services that deliver the functions of Tier 4 are delivered in an in-patient or residential setting because of the intensity of intervention required and the critical health status of the patients.

Services that deliver the functions of Tier 4 must not however be defined as automatically equating to a residential setting. Not all residential facilities can claim to have the expertise to be designated as Tier 4, and some activities needed in the community are of such intensity as to require expertise of a Tier 4 level.

Merely providing residential facilities does not make a facility a specialist one. Designation as a service that delivers the functions of Tier 4 must be based on meeting agreed levels and range of expertise and therapeutic input (i.e. providing certain key functions, with a defined range of health professional who have demonstrable expertise and experience in eating disorders.). Some units operate at Tier 4 level for some of their patients, but cannot be automatically considered to be Tier 4 facilities for eating disorders without these specific elements.

It should also be noted that intensive therapy teams may be available to work in community settings or through intensive day patient treatment. This is particularly

important where intensive work is required with a patient in their home setting or somewhere close to home.

Services that deliver the functions of Tier 4 are, usually, those that are designated as 'tertiary' in NHS terms and they require referral from secondary care services (which equate in broad terms to the functions of Tiers 2 and 3). Traditionally, they are considered on an all-Wales basis, and from 2003 responsibility for securing services that deliver the functions of Tier 4 was included in the portfolio defined by regulation for Health Commission Wales. Whatever the future arrangements for planning and arranging such intensive services, they will need to be planned in conjunction with LHBs to ensure that there is mutual recognition of respective roles and interfaces between Tier 4 activities and those outlined for Tiers 1-3.

### a. *Functions and tasks, Tier 4*

Interventions available at Tier 4 should include:

a.  The full range of capabilities of Tiers 1, 2 and 3;

b.  Intensive treatment for those whose health is severely compromised, who have not responded to intervention given the functions of Tiers 1 to 3 or whose weight loss is so rapid and severe as to require immediate intervention to save life and to promote prompt recovery;

c.  Brief intensive inpatient assessment to assist staff in Tiers 2 and 3 to provide local interventions upon discharge;

d.  Provision of advice to local secondary care services prior to patients' discharge and during agreed periods of follow-up;

e.  Providing training and development placements for staff from Tiers 2 and 3; and

f.  Providing case consultancy about potential treatment regimes.

Any patient receiving treatment from services that deliver the functions of Tier 4 could well be severely compromised in respect of their physical health, and adequate provision must be incorporated into each such service for appropriate diagnostic and treatment expertise and facilities.

Patients who are extremely ill or medically unstable may need to receive care in a setting for acute medical or paediatric patients. Such settings may well be designated as providing the functions of Tier 4 if they are also providing intensive psychiatric or psychological interventions through suitable staff of the psychiatric services being available to the staff of those wards. In most cases however, staff of those acute facilities will need to be able to call on Tier 3 or 4 specialists in eating disorders for expert advice on issues such as re-feeding regimes and other matters.

### b. *Workforce matters, Tier 4*

Services that deliver the functions of Tier 4 might be commissioned from NHS Trusts within NHS Wales, from the independent sector in Wales or from NHS providers or the independent sector outside Wales. This has major implications in terms of the ability of the NHS in Wales to influence the workforce planning that is required to enable it to commission services effectively. In most cases, the only scope for influence will be through service specifications, but HCW may not be able to dictate staff mix or levels of training.

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## 4.6. Tier 1: Characteristics and implementation issues

**Tier 1 services are generic services staffed by professionals who are not mental health specialists but who routinely come into contact with people who have an eating disorder. They may be community-based, and referral & access procedures will normally allow direct access by patient or parents (in the case of minors) dependent on local circumstances.**

| Patients most likely to need service. | • Probable interventions | Examples of agency or team | • Key resources required to undertake role |
|---|---|---|---|
| • People with or without a diagnosed eating disorder who present with or display patterns of concern/risk.<br><br>• Patients with low intensity and chronic eating disorders that need to be monitored. | • Education.<br>• Screening<br>• Initial identification & assessment.<br>• Referral for advice or assessment.<br>• Health promotion.<br>• Brief interventions.<br>• Short term counselling.<br>• Long-term monitoring, independently or as part of shared care with specialist services. | • General Practitioners and other staff of the Primary Healthcare Teams.<br><br>• School / University health or welfare staff<br><br>• Youth, Community and Voluntary Sector Services<br><br>• Health care professionals working in general hospital and community settings. | • Screening/Assessment skills & tools.<br><br>• Designated contact point on Eating Disorders within CAMHS and CMHT.<br><br>• Awareness of 'motivational' aspects of eating disorders and consequences for engaging/avoiding help.<br><br>• Guidance on medical risk implications & appropriate investigations. |

**Key implementation issues & barriers**

- Studies have clearly shown that many General Practitioners are not confident about taking an active role in assessing and monitoring the basic physical health of eating disordered patients, which can result in their condition developing adversely without detection or intervention.
- Staff will encounter patients with a very broad range of severity and risk, and sufferers will often mask their disorder as they often dread the likely treatment options more than the disorder itself.
- Early identification and sensitive early support are needed to reverse the tendency for patients to have to develop severe symptoms before receiving care.
- There is no consistency across Wales in respect of methods and approaches to screening those at high risk, or of targeting them with early short-term support.

**Actions required by each Local Health Board (LHB):**
Undertake needs/service assessment for their population. Ensure that their primary and secondary care arrangements are appropriate. Ensure that robust referral protocols are in place for their entire population. Identify any potential transitional gaps or anomalies across with services they interact with. Ensure that there are robust arrangements for local Tier 1 to support other tiers and agencies who will need access to generic health care or monitoring.

## 4.7.  Tier 2:        Characteristics and implementation issues

**Tier 2 services are those whose enhanced assessment and intervention skills are essential for addressing eating disorders, but which are not specific or exclusive to those disorders.  There are two main groups of activity:**

- **<u>Specialists in mental health services</u>, but not necessarily specialists in eating disorders.  Staff will have enhanced assessment and intervention skills across full range of mental health problems.  They may be part of local mental health provision, or be members of Tier 1 services who have obtained additional expertise in mental health generally and/or with people who have eating disorder.**
- **Additionally, <u>paediatric and adult physicians</u> responding to acute medical risks are defined as Tier 2 services for the purpose of this Framework in the light of their enhanced assessment and treatment skills.**

| Patients most likely to need service. | • Probable interventions | • Examples of agency or team | • Key resources required to undertake role |
|---|---|---|---|
| • Patients whose behaviour / condition indicate the possibility of an eating disorder of sufficient severity to require assessment and/or ongoing intervention.<br>• This may include inpatients in psychiatric wards where staff have concerns over their physical health, as well as liaison psychiatry input to general medicine/paediatric wards. | • General mental health assessment as part of the Unified Assessment process / CPA.<br>• Interventions & therapy.<br>• Relapse prevention & monitoring.<br>• Managing transition between teams & tiers<br>•  Consultancy to T1, including pre-referral advice<br>• Comprehensive investigation & monitoring of physical health together with GP etc | • Specialist Child & adolescent mental health service (Specialist CAMHS) teams.<br>• Community Mental Health Teams (CMHTs)<br>• Staff in Tier 1 services with enhanced expertise, e.g. Primary Mental Health Care Workers<br>• Paediatric and general medical teams. | • Suite of assessment tools.<br>• Guidance on medical risk implications & appropriate investigations.<br><br>• Sufficient range of disciplines, expertise and experience.<br><br>• Access to specialists for training, advice and support. |

**Key implementation issues & barriers**

- Eating disorders have both physical and psychiatric/psychological dimensions and consequences which can be of serious clinical risk.  Despite this, some services give less priority (or even exclude access) to people with eating disorders simply on the basis of the diagnosis.
- The physical effects of severe eating disorders can have grave consequences if they are not recognised, understood or addressed by medical and nursing staff on psychiatric, general medical or paediatric wards.
- Eating disordered cannot be separated from other psychiatric disorders.  Many patients will suffer from more than one disorder, and some aspects of eating disorders will have major effects on the presentation and treatment efficacy of other disorders. Despite this, carers, sufferers and practitioners report continued problems across Wales in accessing some Adult community health services
- The highest risk of developing serious eating disorders is between the ages of 15 to 24, yet carers, sufferers and practitioners report continued and extensive problems with gaps between CAMHS and Adult coverage.  Failure to act at the critical transitional stage can have life-long consequences.

**Action required by Local Health Boards (LHBs)**:  **1** Ensure that relevant eating disorders are included as core functions in CAMHS, CMHT and other local mental health services.  **2** Ensure that there are defined arrangements for the provision of appropriate physical health services.  **3** Identify any potential transitional gaps or anomalies across their area.  **4** Agree common 'Core Business' descriptions for all Tier 2 services they interact with.  **5** Ensure that services that provide the functions of Tiers 3 and 4 into their locality have the necessary access to local services.

## 4.8.  Tier 3:  Characteristics and implementation issues

**Tier 3 services are specialised services that focus on people who have serious and enduring mental disorders that require particular expertise through formal membership (possibly part-time) of designated multi-disciplinary teams.**

**Access to Tier 3 services is likely to be restricted to referrals from Tier 2 services, but there should also be provision for GP or Paediatric / Physician referral in emergency.**

| **Patients most likely to need service.** | •**Probable interventions** | •**Examples of agency or team** | •**Key resources required to undertake role** |
|---|---|---|---|
| •Patients who have not responded to Tier 2 interventions or who are seen to require the expertise of Tier 3 <br>•Patients with particularly complex needs and/or co-morbidity. <br><br>•Some patients returning from inpatient treatment. | •Structured interventions and therapy. <br>•Intensive home-based day-care or family interventions. <br>•Structured relapse prevention. <br><br>•Intensive community-based outreach & day care therapy programmes. <br>•Consultancy to T2 <br>• | •Community Intensive Treatment Teams (as operating in Specialist CAMHS). <br><br>•Tertiary/Regional Eating Disorders Teams. | •Multidisciplinary team spanning appropriate range of skills. <br>•Access to clinical supervision. <br>•Resources to enable them to undertake assessments and interventions in wide range of settings and locations for outreach activity, including meal support. <br>•Strong pathways to/from to acute medical services |

**Key implementation issues & barriers**

- As at September 2008, responsibility for Tier 3 activity is shared between Local Health Boards and Health Commission Wales, with no formal agreement on respective roles or funding for activity likely to be of a T3 level.
- There are no arrangements in place for 'regional' or 'Tertiary' Eating Disorders Teams/Services, and no agreement on the population size they would be appropriate to cover.
- Coverage of Intensive Community Teams is very limited, and those in place do not accept full range of ages or diagnoses.
- The existence of Intensive Community Teams must be seen as an essential element in a comprehensive service.  These will greatly reduce the need for inpatient care, but there will always be cases when individuals may require planned or emergency admissions so arrangements need to be in place for this.

**Action required by each Local Health Board (LHB)**: **1**_Define and monitor arrangements for the resident population which has not responded to Tier 2 interventions. **2**_Agree common 'Core Business' descriptions for all Tier 3 services operating within the LHB. **3**_Ensure that services that provide the functions of Tier 3 in their locality have defined access to relevant non-psychiatric health care. **4**_Together with other LHBs and relevant agencies, agree specification, working arrangements & referral protocols for Tertiary Eating Disorders Teams (TEDTs). **5**_Make arrangements for planning, managing, monitoring & evaluation of TEDTs.

## 4.9. Tier 4: Characteristics and implementation issues

**Highly specialised services involving intensive treatment regimes.  Access will be restricted to referrals from Tier 3 services, or in accordance with other agreed criteria set down. .**

| Patients most likely to need service. | • Probable interventions | • Examples of agency or team | • Key resources required to undertake role |
|---|---|---|---|
| • Patients who have not responded to interventions through T1-3 or who are seen to require the expertise of Tier 4,<br>• or whose physical condition makes inpatient care essential.<br>• Patients who are identified as high risk and for whom a short period of intensive assessment is required to facilitate treatment by Tiers 2/3. | • Inpatient treatment for life-threatening cases<br>• Inpatient treatment for highly complex cases which have not been resolved following community interventions.<br>• Highly complex assessment where there is significant co-morbidity. | • Hafod Newydd Unit and Cedar Court (both Tier 4 generic CAMHS units)<br>• External NHS and Independent Sector provision.<br>• Community-based intensive teams (to be developed) | • Defined range of professional expertise and interventions appropriate to designation as Tier4.<br>• Access to appropriate settings to provide community based intensive interventions.<br>• Pre-arranged pathways to relevant facilities and expertise to ensure smooth stepped transitions. |

**Key implementation issues & barriers**

* As at time of preparation of Framework, the future arrangements for securing highly specialised services such as Tier 4 are still under consideration.
* Irrespective of the final format of the arrangements and accountability, there will need to be a mechanism in place for securing services which need an all-Wales or 'supra-Local Health Board' approach.
* It is also essential that any such mechanism is established together with the mechanisms for Tiers 1-3, to avoid the creation or perpetuation of gaps, overlaps or uncertainties for patients and staff .  It will be essential therefore for formal agreement on the respective roles and inputs of these services and those secured and monitored directly by LHBs.

**Action required by each Local Health Board (LHB) together with Specialised interests**:
To be as defined in WHC(2003)53 or successor regulations, namely to secure and monitor:
1_Community-based intensive treatment & day care for CAMHS, 2_Equivalent intensity of community-based interventions for adults (described as 'tertiary' in guidance.
Commission range of inpatient and community-based intensive interventions in accordance with models agreed with relevant Networks

# 5.   Draft /Interim Standards for use as checklists

Standard 1

**Role of General Practitioners and primary care teams in identification, assessment and treatment of people with an eating disorder.**

Standard 2

**Role of local Mental Health Services in the provision of <u>advice and support</u> to primary care staff and community groups**

Standard 3

**Role of local Mental Health Services in the provision of <u>assessment and care planning</u>**

Standard 4

**Role of local Mental Health Services in the provision of <u>direct treatment interventions</u> for people suffering from an eating disorder**

Standard 5

**Provision of a range of Acute and general medical treatment and services.**

## 5.1. Standard 1: Role of General Practitioners and primary care teams in identification, assessment and treatment of people with an eating disorder.

**Description**

General Practitioners and their teams should have a clearly defined role in identifying the presence or possibility of an eating disorder in patients attending their surgeries and in following through with assessments and support.

**How would we know when practices are providing this role?**

For this standard to be met, it would be possible to demonstrate that the following were in place:

a. A document developed and agreed with local CAMHS **and** Adult Mental Health Services setting out the respective roles of primary care and other partners in the investigation, treatment and monitoring the physical health of people with an eating disorder. The following basic tasks have been recommended elsewhere as appropriate for primary care teams[80], [81]:

> - Early detection & establishment of seriousness of the patient's condition
> - Undertaking assessment and providing regular medical monitoring or physical status
> - Treating uncomplicated cases in primary care if possible
> - Deciding if referral or hospitalisation is necessary
> - Providing primary care support of outpatient specialist treatment
> - Acting as support & health educator for the patient and family
> - Prevention & health promotion
> - Management of chronic patients

b. Availability of protocols and guidance for practice staff on the use of SCOFF assessment tool and Map of Medicine guidance.

c. Availability of guidance on Risk factors and routine diagnostic tests.

d. For practices with a demographic profile indicating a relatively high proportion of patients in high risk groups, there should be a defined health professional to act as the primary contact and source of advice for patients, practice staff and external agencies.

e. Inclusion of severe eating disorders in practice registers of patients with serious & enduring mental illness.

f. Equitable access to any practice-based counselling services for patients whose have been identified as having mild / moderate eating disorders.

**Who is responsible for making it happen?**

A coordinated approach is required involving LHBs working with General Practitioners, together with Deaneries and training establishments.

**Who is monitoring compliance with the standard?**

To be defined by the LHB – but the process must involve robust user/carer input. Monitoring and reporting against this standard should be specifically included in the proposed remit of the vice chair of the LHB with specific responsibilities for mental health and community services.

### 5.2. Standard 2: Role of local community Mental Health Services in the <u>provision of advice and support</u> to primary care staff and community groups.

**Description**

Local Mental Health Services should provide a defined and appropriately resourced source of advice on Eating Disorders for both Children/Adolescents and Adults which is readily available to Primary Care Teams and other community-based groups.

**How would we know when it is achieved?**

For this standard to be met, it would be possible for a Trust to demonstrate that the following were in place:

a. A document issued by local CAMHS **and** Mental Health Services outlining who GPs etc can contact for advice on how they should treat and/or support people with eating disorders.

b. Inclusion of Eating Disorders as a 'Core Function' within each CAMHS and Community Mental Health Team, including performance of this advisory/support role, where possible specifying the number of sessions/hours for individuals within the Team to be allocated to Eating Disorders.

c. Programme of training for members of CAMHS and Mental Health Services which defines the spectrum from minimum awareness to professional qualification required to fulfil roles within team.

d. Protocols for how requests for advice are handled, including responses to non-medical approaches such as from colleges, schools and social services.

e. Clarity about the extent of support which may be given direct to families of sufferers of an eating disorder.

f. Catalogue of material and contact details of other sources of advice, to be offered both as a resource to Primary Care Teams and for the use of the team itself.

g. Defined level of time allocated from specified members of the team for providing awareness-raising training to appropriate groups, e.g. GP vocational training courses, INSET days, Registered Nurse and other local basic training courses.

**Who is responsible for making it happen?**

Each LHB as a core part of its responsibility for local mental health services

**Who is monitoring compliance with the standard?**

To be defined by the LHB – but the process must involve robust user/carer input and involve both internal monitoring arrangements and external reporting through its performance management frameworks. Monitoring and reporting against this standard should be specifically included in the proposed remit of the vice chair of the LHB with specific responsibilities for mental health and community services.

## 5.3. Standard 3: Role of local mental health services in the provision of <u>Assessment and Care Planning</u>.

**Description**

Local Mental Health Services should provide clearly defined and appropriately resourced **assessment services** for both Children/Adolescents and Adults which are readily available to Primary Care Teams and to non-psychiatric health services.

**How would we know when it is achieved?**

For this standard to be met, it would be possible for a Local Health Board to demonstrate that the following were in place:

a. A document issued by local CAMHS and Adult Mental Health Services outlining to whom GPs, Paediatricians, Adult Physicians etc can refer patients for **assessment** when an eating disorder is identified or suspected. Where there are geographical variations across the area served by the respective CAMHS/CMHT, these should be clearly identified.
b. The Assessment Service should be designated as a 'Core Function' of each Team with a defined number of sessions/hours built into the work programmes of named individuals of appropriate professional backgrounds. There should be a Core assessment/screening arrangement to respond to initial referrals with specified arrangements to broaden the scope of the assessing team dependent on an individual patient's circumstances.
c. Programme of training for all members of CAMHS and Adult Mental Health Services which defines the spectrum from minimum awareness to professional qualification required to fulfil roles within team.
d. Protocols for how referrals are handled, specifying target response times and including details of how the service responds to non-medical referrals such as those from colleges, schools and social services.
e. Catalogue of material and contact details of other sources of advice, to be offered both as a resource to referring bodies and for the use of the CAMHS/CMHT itself.
f. Defined level of time allocated into the work programme of specified members of the team for undertaking assessments and for maintaining knowledge of current issues in Eating Disorders.

**Who is responsible for making it happen?**

An identified Executive Director should be nominated in each LHB who is responsible for defining the local arrangements for all parts of the LHB's catchment area.

**Who is monitoring compliance with the standard?**

To be defined by the LHB – but the process must involve robust user/carer input and involve both internal monitoring arrangements and external reporting through its performance management frameworks. Monitoring and reporting against this standard should be specifically included in the proposed remit of the vice chair of the LHB with specific responsibilities for mental health and community services.

## 5.4. Standard 4: Role of local Mental Health Services in the provision of <u>direct treatment interventions</u> for people suffering from an eating disorder

**Description**

Local Mental Health Services should provide clearly defined and appropriately resourced **direct interventions** for both Children/Adolescents and Adults in accordance with assessed clinical need and in accordance with referral protocols which are consistent with partners' services.

**How would we know when it is achieved?**

For this standard to be met, it would be possible for a health organisation with responsibility for local mental health services to demonstrate that the following were in place:

a. A document issued by local CAMHS and Adult Mental Health Services outlining the interventions which form its overall portfolio and which defines any limits it places on considering referrals or allocating resources. Where there are geographical variations across the area served by the respective CAMHS/CMHT, these should be clearly identified in the document/prospectus. This document will also specify the roles of all constituent parts of the community mental health services in respect of eating disorders (e.g. outreach, first access teams, etc, etc)

b. Confirmation in the prospectus that eating disorders are designated amongst the 'Core Functions' of each Team, and set out the interventions which are available. This will define the number of eating disorder-specific sessions/hours built into the work programmes of identified posts of appropriate professional backgrounds.

c. Procedures for staff on psychiatric inpatient units, setting out the particular risk assessments and other operational and clinical procedures they have established for the psychological and physical care of patients with eating disorders. These will include, but not be restricted to, protocols for supervised or assisted feeding, monitoring post-feeding activity and exercise etc.

d. A skills audit process and a programme of training for all members of CAMHS and Adult Mental Health Services which defines the spectrum from minimum awareness to professional qualification required to fulfil roles within team. This will include both inpatient and community based staff.

e. Protocols for how referrals are handled, specifying target response times and including details of how the service responds to non-medical referrals such as those from colleges, schools and social services.

f. Catalogue of material and contact details of other sources of advice, to be offered both as a resource to referring bodies and for the use of the CAMHS/CMHT itself.

**Who is responsible for making it happen?**

An identified Executive Director should be nominated in each NHS body with responsibility for mental health services, to be accountable for defining the local arrangements for all parts of the LHB's catchment area.

**Who is monitoring compliance with the standard?**

To be defined by the LHB – but the process must involve robust user/carer input and involve both internal monitoring arrangements and external reporting through its performance management frameworks. Monitoring and reporting against this standard should be specifically included in the proposed remit of the vice chair of the LHB with specific responsibilities for mental health and community services.

## 5.5. Standard 5: Provision of a range of Acute and general medical treatment and services.

### Description

Organisations responsible for non-psychiatric Hospital and Community Health Services must specify their arrangements for the provision of appropriate diagnostic and treatment responses from Paediatric, Adult General Medicine, Dietetics and other specialties to meet the physical health needs of both Children/Adolescents and Adults with eating disorders.

These should specify the extent of their responsibilities for providing expertise and direct intervention into psychiatric settings where appropriate as well as defining arrangements for direct treatment in non-psychiatric settings.

In particular, generic health services must identify and remove any barriers to people with eating disorders obtaining equitable access to services in accordance with their clinical needs.

### How would we know when it is achieved?

For this standard to be met, it would be possible for a health body to demonstrate that the following were in place:

a. A document developed and agreed with local CAMHS **and** Adult Mental Health Services outlining the protocols and mechanisms established to ensure that the physical health of people with an eating disorder can be adequately investigated and addressed. Where there are geographical or age-related variations across the area served by the respective CAMHS/CMHT, these should be clearly identified.

b. This document will make specific reference to the arrangements for urgent access to a physician with expertise in nutrition and refeeding. It is envisaged that each LHB will define a ward for each of child/adolescent and adult patients where this expertise can be developed, or to have written arrangements in place with an adjacent LHB's hospitals.

c. These arrangements must include the mechanism for the provision of advice to inpatient psychiatric staff on the management of complex cases where patients remain on a psychiatric ward. The protocols must specify referral and liaison arrangements for paediatricians and physicians etc to visit psychiatric inpatients when their physical health is compromised.

d. Non-psychiatric staff who are likely to have people with an eating disorder in their care must have defined arrangements in place for obtaining advice and support from someone with expertise in eating disorders. Where such situations are likely to be frequent, there must be a programme of awareness and skills training to ensure that there is a core of staff familiar with the presentation and complications caused by eating disorders.

### Who is responsible for making it happen?

An identified Executive Director should be nominated in each LHB, who is responsible for defining the local arrangements for all parts of the LHB's catchment area.

### Who is monitoring compliance with the standard?

To be defined by the LHB – but the process must involve robust user/carer input and involve both internal monitoring arrangements and external reporting through its performance management frameworks. Monitoring and reporting against this standard should be specifically included in the proposed remit of the vice chair of the LHB with specific responsibilities for mental health and community services.

# 6. Appendix A: Links to key guidelines

A number of key guidelines have been produced by South London & Maudsley NHS Foundation Trust's Eating Disorders Unit which has authorised their reproduction free of charge provided they are reproduced accurately and not used in a misleading manner or sold for profit.

Copyright remains with South London & Maudsley. They are listed here with appreciation, and can be located on the Institute of Psychiatry resources at http://www.iop.kcl.ac.uk/sites/edu/?id=73#item02.

**Downloadable resources from the Section of Eating Disorders/Eating Disorders Unit at South London and Maudsley NHS Trust**

**Student Counsellor Guide to eating disorders**
Download pdf

**The SCOFF questionnaire**
To aid early detection of eating disorders, developed by John Morgan at Leeds Partnerships NHS Foundation Trust.
Download pdf

**Could this be an eating disorder?**
A questionnaire to help establish whether there are sufficient reasons to be worried about a person's state possibly being an eating disorder.
Download pdf

**A Guide to the Medical Risk Assessment for Eating Disorders**
Designed for use with outpatients and inpatients with eating disorders.
Download pdf

**Guidelines for assisted feeding in patients displaying extreme dietary restraint**
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**Protocol for management of hypophosphataemia as part of the refeeding syndrome**
To be read in conjunction with *A Guide to the Medical Risk Assessment for Eating Disorders* and *Guidelines for assisted feeding in patients displaying extreme dietary restraint*.
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**Post discharge care and relapse prevention plan**
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**Maudsley Body Mass Index Table**
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**A GP's Guide to Eating Disorders**
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**Medical complications of anorexia nervosa**
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**Motivational Interviewing**
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# 7. Appendix B: Proposed framework for provision of specialist tertiary eating disorders teams

In setting out the Framework for Wales, the element which seems to be pivotal is the establishment of specialist teams working with appropriate professionals from their respective LHBs to create a robust service fulfilling the 'Tier 3' role set out in section 4 of this document.

Without this source of expertise in place, staff in primary care teams, local mental health services and relevant acute medical units would continue to have concerns about being able to fulfil their own roles, and patients would continue to experience delays or barriers in obtaining assessments and support.

The announcement by the Assembly of additional funding proposed for the establishment of specialist community eating disorders services[82] provides an opportunity for the NHS in Wales to create the sort of specialist service which practitioners, sufferers and carers have been seeking.

It is therefore proposed that there should be a new Tertiary Eating Disorders Team (TEDT) established for each of North Wales, Mid & West Wales and South East Wales. Each TEDT would be complemented by staff from the constituent LHBs as set out below to form a Tertiary Eating Disorders Service.

It is anticipated that the TEDTs would be formed with a multidisciplinary core of clinical psychologist, psychiatrist (sessional), dietician and consultant nurse/family therapist, all of sufficient seniority and skilled in eating disorders. This core would be augmented with other staff as appropriate, taking into account the existing skill base and gaps in the relevant LHBs.

In deciding on the range and grades of its staff, TEDTs will need to be mindful that their roles will include direct work with appropriate patients in a variety of settings as well as assessment, consultation and advice on care planning.

The Tertiary Eating Disorders Service would be completed by an appropriately senior clinical lead appointed by each of its constituent LHBs. In each case, LHBs would need to fund the appointment of two such clinicians, one each for its CAMHS and Adult Mental Health Services. It is proposed that these posts will need to have a 0.5WTE commitment to their TEDS role, the remainder being within the LHB's CAMHS/AMHS services. Their role within their LHB will include a responsibility to ensure that local mental health services fulfil their own Tier 2 and Tier 3 roles, and to ensure that the clinical skills and resources of people with eating disorders have equitable access to relevant diagnostic and treatment services in accordance with their clinical need.

As demonstrated in this Framework for Wales, it is of crucial importance for the successful operation of a specialist team such as the TEDT that each LHB puts in place robust mutually supportive arrangements between the specialist teams and relevant physical health services and primary care teams. To achieve this, and to ensure that the clinical lead from each LHB's CAMHS and Adult Mental Health Service has sufficient support to secure robust agreements, LHBs will need to formally designate responsibility for handling problems in this area to defined senior executive or director posts. This is particularly important where Child & Adolescent Mental Health services are organised and managed separately from other mental health services, as this can provide additional complications which will need to be actively addressed by the LHB.

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It is intended that the additional funding being made available for the core Tertiary Eating Disorders Teams will be dependent on constituent LHBs making the necessary commitment and arrangements for the posts and responsibilities specified above.

There are several aspects of eating disorders and the NHS response to them which encapsulate many of the concerns behind the current proposals for the NHS in Wales. For that reason, the establishment of specialist services linked to core LHB activity provides an opportunity for LHBs to develop systems of cooperation which will be essential in many other fields of health care.

In providing funding for the specialist Eating Disorders Teams proposed in this framework, the Assembly therefore intends to use this initiative to develop its approach on three key fronts.

Firstly, it is already a key feature of Assembly policy that health services should be far more influenced and responsive to patient, carer and public views and participation than has sometimes been the case. This is true both for the development of new services and for their monitoring and evaluation. LHBs will therefore be expected to demonstrate that they have actively engaged patients, carers and other parties in their development and ongoing monitoring of their services for people with eating disorders.

Secondly, the success of the TEDTs needs to be judged against patient-orientated criteria which are built into measurable performance targets. TEDTs will therefore be expected to work together to develop methods of activity and performance analysis which will allow judgements to be made on their effectiveness.

These methods of analysis will provide insight into the most effective combination and apportionment of time and resources to (for example) assessments, training to staff in Tiers 1 and 2, providing consultation or advice and direct clinical interventions.

Potential measures for consideration will be the proportion of patients for whom targets are set out through regularly reviewed CPA, and the proportion of such targets which have been met – this will enable patients and families to influence the perceived and reported performance of the teams against targets they have been party to setting.

Thirdly, as the success of the proposed TEDS relies on successfully establishing and maintaining links with community mental health, primary care teams and staff in non-mental health teams, they will be of particular value to the relevant LHB vice chairs as touchstones or benchmarks for their enhanced monitoring and reporting roles within the revised NHS in Wales.

## 7.1. Characteristics and scope of tertiary teams

The precise roles and operating arrangements for Tertiary Eating Disorders Teams and Services will need to be developed following the consideration of the overall Framework for Wales. In particular, the relationship between these teams and the Tier 4 activity currently arranged by Health Commission Wales will need to be considered when decisions on Tier 4 have been announced

The following recommendations have been drawn from experience in establishing and evaluating pilot regional eating disorders services in non-UK localities which have direct relevance to the situation in Wales.

They are reproduced here in full from the evaluation report[83] on the relevant Australian pilot as a valuable summary for use in establishing Tertiary Eating Disorders Teams in Wales.

- Eating Disorders Services need to be locally based.

- Communication pathways need to be established from the outset of the service, including feedback to those delivering the service.

- Eating disorders services should be delivered by a team of clinicians including clinical psychologist, psychiatrist, dietitian and family therapist.

- New services should be developed in consultation with both primary care and mental health services.

- The service model for eating disorders should be appropriate for the local context, geographical coverage and perceived needs.

- Clear guidelines should be developed for consumer participation at the initiation and development stages of a service.

- It is not realistic to expect an Eating Disorders Service to only provide assessment and care planning. This causes frustration both for those referring into the service and the service providers.

*With grateful acknowledgement to Prof Ruth Endacott and colleagues La Trobe University, Vic., Australia*

Subject to discussion following consultation on the overall Framework, it is envisaged that the Tertiary Eating Disorders Team will initially accept referrals for intervention for patients aged 18 and over.

Many specialist teams across the UK work with patients aged 16 and over, but the current proposal is for the TEDT formal clinical remit to start with 18+, with long term view of potentially extending downwards when expertise, resources and infrastructure (in both CAMHS and AMHS) have been adequately developed.

In proposing that TEDTs start with 18yrs+, one strongly influential factor is the fact that CAMHS teams should already be dealing with eating disorders as a core part of their role, and they will already have expertise in the field. CAMHS teams should already be moving towards a default age threshold of 18 in accordance with Assembly policy[59].

This does not reduce the critical importance of each LHB appointing a clinical lead link from CAMHS to become a member of the TEDS, as the transitional stage from CAMHS to adult services is highly complex.

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