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## **Report on a review of the Eating Disorders Framework for Wales**

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### **Publication/ Distribution:**

This document describes a rapid review of the Eating Disorders Framework for Wales to inform a refresh of the Framework by Welsh Government. It considers the evidence, the results of engagement with service users and clinicians and a discussion of the relevant policy directives/guidance.

**Review Date:** NA

### **Purpose and Summary of Document:**

The distribution of this document is restricted to Welsh Assembly Government, for their consideration.

**Work Plan reference:** NA

# 1 Introduction

In 2008 the National Public Health Service for Wales produced a discussion document that described a proposed model of care for Eating Disorders in Wales<sup>1</sup>. The proposed model was submitted to and accepted by the Welsh Government in 2009<sup>2</sup> with their publication of the Eating Disorders Framework for Wales.

In 2015 Welsh Government asked Public Health Wales to review the Framework and advise on any revisions that may be appropriate within a refresh of the Framework. The remit for the work included the need to take account of the findings in the Tier 4 review; the expansion of community treatment in recent years; and the investment, since 2013, in improving Child and Adolescent Mental Health Services (CAMHS) provision for eating disorders. The Minister also committed that the review would include consultation with both the National Assembly Eating Disorder Cross Party Group and service users and providers.

This report provides a summary of the review undertaken by Public Health Wales. The report covers:

- an overview of relevant policy and strategy since 2009
- a summary of evidence based reviews since the strategy
- a brief overview of changes to clinical guidelines and treatment regimes since 2009
- a summary of the findings from an engagement process with service users, carers and health professionals.
- an estimate of the level of need in the population of Wales
- a description of current patient experience and outcome measures

This paper will draw together the various strands described above and makes recommendations for Welsh Government to consider in relation to the Eating Disorders Framework. It is accompanied by separate and detailed appendices on the Engagement Process and Service Outcome Measures.

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<sup>1</sup> Peter Boyle. "Eating disorders: Framework for Wales" 2009, Cardiff, National Public Health Service for Wales. Accessed Sept 2015

[http://www.rcpsych.ac.uk/pdf/Eating%20Disorders%20Framework%20for%20Wales%20Technical%20Consultation%20Document%20\(PDF\).pdf](http://www.rcpsych.ac.uk/pdf/Eating%20Disorders%20Framework%20for%20Wales%20Technical%20Consultation%20Document%20(PDF).pdf)

<sup>2</sup> Welsh Assembly Government. Eating Disorders – A Framework for Wales June 2009. Cardiff, WAG. Accessed Sept 2015

<http://www.wales.nhs.uk/sitesplus/documents/866/Eating%20Disorders%20-%20A%20Framework%20for%20Wales.pdf>

## 2 Background

The following section provides a brief summary of the 2009 Framework for Eating Disorders. The detail relating to the tiers of service provision are described in Appendix A.

The tiered model of care described in 2009 is consistent with the current Welsh strategy for mental health – ‘Together for Mental Health’<sup>3</sup>.

The framework describes a layered service provision across 4 tiers. Each tier provides a defined service appropriate for the needs of the patient with an eating disorder at stages of their condition. The most complex and severely affected individuals will require the support of specialised service providers (tiers 3 and 4), whereas cases with milder severity are supported either at primary care (tier 1) or perhaps generalist mental health community providers (tier 2). The agencies or teams that are involved in the provision of services include those providing interventions in community settings, primary care, primary care mental health teams, community mental health teams, community intensive treatment teams and finally specialist CAMHS providers.

Access to services beyond general practice is by referral and in general, the higher the tier, the more restricted the access is to ensure that only appropriate cases are seen by the relevant specialists, consistent with the principles of Prudent Healthcare.

The framework addresses specific actions required by Local Health Boards (LHBs) and also describes key issues and barriers to implementation of the Framework at each tier.

Public Health Wales contributed to the production of a guide<sup>4</sup> for the implementation of the Framework in 2012. This was as part of a work programme for the Welsh Government ‘National Core Group for Mental Health Intelligent Targets’.

This guide was produced to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive. It also provided an audit tool to assess service improvements.

<sup>3</sup> Welsh Government Website  
<http://gov.wales/topics/health/nhswales/healthservice/mental-health-services/strategy/?lang=en>

<sup>4</sup> NHS Wales Website  
<http://www.1000livesplus.wales.nhs.uk/eating-disorders>

### 3 Strategic Context

There have been a number of developments in policy and strategy relating to mental health since the original framework was implemented in 2009. The implications for the current framework have been considered in the context of these changes. Service quality, health outcomes and meeting service user needs are recurrent themes in the areas described below.

#### 3.1 Together for Mental Health

'Together for Mental Health'<sup>5</sup> is the current Welsh Government strategy for Mental Health and was issued in 2012. The strategy superseded the 2001 Strategy for Adult Mental Health Services, the 2009 Mental Health National Service Framework (NSF) and the previous 10 year Strategy 'Everybody's Business'. Together for Mental Health covers a period of 10 years and has an associated 3 year delivery plan. The Delivery Plan for the period 2016-2019 is currently the subject of consultation by Welsh Government.

The strategy covers a number of areas and aims to address the following:

- Improve the mental health and wellbeing of the whole population;
- The impact of mental health problems and/or mental illness on all individuals, families, carers, communities and the economy is recognised and reduced;
- The inequalities, stigma and discrimination experienced by people experiencing mental health problems and mental illness are reduced;
- Individuals have better experience of the support and treatment they receive and have an increased feeling of input and control over related decisions;
- The access to, and the quality of, preventative measures, early interventions and treatment services is improved and more people recover as a result;
- The values and attitudes and skills of those treating or supporting individuals with mental health problems or mental illness are improved.

Central to the introduction of the Strategy was the Mental Health (Wales) Measure, which places legal duties on health boards and local authorities to improve support for people experiencing mental ill-health.

<sup>5</sup> Welsh Government Website  
<http://gov.wales/topics/health/nhswales/healthservice/mental-health-services/strategy/?lang=en>

## 3.2 Social Services and Wellbeing Act 2014

The Social Services and Well-being (Wales) Act came into force on 6 April 2016 and describes changes in the way in which young people and their carers interact with services<sup>6</sup>. In particular, the Act changes the way people's needs are assessed and how services are delivered. The Act promotes community based help to reduce the need for formal, planned support. Particular aspects of this includes ensuring services provide the right support at the right time; easier access to relevant, clear information and advice; simpler assessments undertaken in consultation with the young person; equal rights for carers support to be assessed and stronger powers to keep people safe. In addition, the Act extends support for looked after children up to the age of 21 and educational support up to the age of 25. One of the aims of the Act is to improve wellbeing of people who need care and support.

The Act seeks to enable local authorities to work more closely with other organisations. It requires public sector organisation to produce joint needs assessments, focus on prevention, enshrines a duty to report at risk children (and adults), strengthens complaints systems and provides clarity on information for services users and carers.

## 3.3 Together for Children and Young People

The Together for Children and Young People (T4CYP) Programme is a multi-agency, multi-professional programme aimed at improving the emotional and mental health services provided for children and young people in Wales. The programme was launched at the end of February 2015 and is being led by the NHS in Wales with the support of Welsh Government.

Previous reviews of specialist CAMHS in Wales have identified that the service is under more pressure than ever before, and in spite of additional investment and staffing, does not have the capacity to meet demand<sup>7</sup>. Over the last 4 years it is reported that there has been over 100% increase in referrals to CAMHS<sup>8</sup>. Many of the children and young people who are then assessed do not need highly specialist interventions, but add to the waiting times for those children and young people who do need such support.

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<sup>6</sup> Welsh Government Website : *Care and support in Wales is changing*  
<http://gov.wales/topics/health/socialcare/act/?lang=en>

<sup>7</sup> Public Health Wales 2011 Child and adolescent mental health services (CAMHS) in Wales: a review of highly specialised services

<sup>8</sup> Personal communication Dr David Williams.

It is important that there is timely access for children who need specialist CAMHS. Early identification is the key to providing additional support when it is most needed - particularly for Tier 1 services where children and young people can experience long waits.

The aims for the T4CYP Programme are as follows:

- To provide strategic leadership, direction and support to ensure that high quality services can be delivered;
- To make sure that real change is delivered at pace across Wales;
- To make sure that emotional and mental health services for children and young people are delivered in line with the principles of prudent healthcare.

### 3.4 Prudent Healthcare

Professor Mark Drakeford, the then Minister for Health and Social Services, declared 2014 to be the 'year of prudent healthcare'<sup>9</sup>. Professor Drakeford defined this as, 'Healthcare that fits the needs and circumstances of patients and actively avoids wasteful care that is not to the patient's benefit.'

The Welsh Government describe prudent healthcare as delivering three objectives:

- Do no harm.
- Carry out the minimum appropriate intervention.
- Promote equity between professionals and patients.

The main driver behind prudent healthcare in NHS Wales is to ensure that the people of Wales receive the best possible care from the available resources.

### 3.5 The Review of the Financial Ringfencing Arrangements for Mental Health Services in Wales

A review of the financial ringfencing arrangements for mental health services was undertaken in 2015 by Price Waterhouse Cooper<sup>10</sup>. The Review concluded that the purpose of the ringfence – to protect spending

<sup>9</sup> Welsh Government Website : *Prudent healthcare*

<http://gov.wales/topics/health/nhswales/prudent-healthcare/?lang=en>

<sup>10</sup> Welsh Government Website: *Written Statement - Welsh Government Response to PricewaterhouseCoopers Review of the Financial Ring Fencing Arrangements for Mental Health Services in Wales Report to the Minister for Health and Social Services.*

<http://gov.wales/about/cabinet/cabinetstatements/2016/ringfence/?lang=en>

on mental health services in Wales – had largely been achieved. The report confirmed that the ring fence has helped protect expenditure on mental health services. It recommended that the arrangements should be retained and strengthened by the adoption of an outcomes-based approach, supported by enhanced accountability, mental health needs assessment and a suite of new financial indicators. Once an outcomes based approach has been put in place and those outcomes secured, the report suggests that a ring fence may no longer be required.

The Welsh Government agreed to take this forward through the NHS Planning Framework under which health boards produce Integrated Medium Term Plans (IMTP) covering a three year period. These are underpinned by a population health needs-based commissioning clinical and service plan. Welsh Government will require health boards to strengthen the mental health component of the IMTPs, with mental health needs assessments and issues fully incorporated into the planning process, thereby ensuring that needs are identified, along with the planned service, workforce and financial requirements to meet these needs. As the IMTP process develops over time, it will move towards the outcomes-based approach recommended in the report.

### **3.6 Welsh Community Care Information System**

The Welsh Community Care Information System (WCCIS) is a single integrated data solution available to all health and social care organisations across Wales<sup>11</sup>. This system will bring information together in one secure point so that it is available wherever people are being treated or cared for.

This system was developed in response to the awareness that synchronous health and social care optimised patient care. WCCIS has been nationally procured to support the transformation of community, social care, mental health and therapy services across Wales to promote person centred care.

WCCIS is currently being rolled out across Wales in 2016. One particular aspect of WSSIC is that the system will support the recording of outcome measures. This will help examine quality and safety of current and future services. The single electronic patient record will be the community 'glue' that brings services together around an individual patient. WCCIS will provide a firm basis upon which service reconfiguration can be undertaken taking into account severity of conditions, treatment undertaken and outcomes relating to services provided.

<sup>11</sup> NWIS Website : *Welsh Community Care Information System*  
<http://www.wales.nhs.uk/nwis/page/66175>

### 3.7 Implications for the Eating Disorders Framework

The strategic developments outlined above are each consistent with and should support the delivery and implementation of the Eating Disorders Framework. The approach to a tiered model of care resonates strongly with objectives of Prudent Health Care, Together for Mental Health, the Together for Children and Young People programme and current models of service provision. However, there are important messages for service providers in particular to ensure that outcomes are routinely recorded and collated. These services are traditionally poorly supported by routine data on activity and outcomes and developments in this area through WCCIS should be beneficial. This will help inform the outcomes based approach to funding as described by Welsh Government. Any examination of whether services meet the needs of the patients must be confirmed by clinical outcomes and patient experience measures.

The tiered model was introduced in 2001<sup>12</sup> by the National Assembly for Wales. Over time, the model has been iteratively refined in 'Together for Mental Health' and the current Eating Disorders version is embedded in the Eating Disorders Framework. Appendix A describes this in detail. The commissioning of Tier 4 services on behalf of Local Health Boards (LHBs) was initially undertaken by Health Commission Wales and latterly the Welsh Health Specialised Services Committee (WHSSC) in 2010<sup>13</sup>. WHSSC commissions, plans and funds highly specialised mental health services for those living with Eating Disorders. The commissioning of services is based on a service specification which is periodically reviewed and updated by WHSSC<sup>14</sup>. LHBs directly fund and provide services for the majority of children and young people with Eating Disorders in the community and where relevant inpatient services.

## 4 Guidelines and Treatment Regimes

A critical component of this Review is to identify any changes in clinical guidelines or evidence based treatment regimes. Clinical guidelines typically are derived from the following sources:

- National Centre for Health and Care Excellence (NICE)

<sup>12</sup> National Assembly for Wales. "Child and Adolescent Mental Health Services. Everybody's Business, Strategy Document September 2001". 2001, Cardiff, NAW.  
<http://www.wales.nhs.uk/publications/men-health-e.pdf>

<sup>13</sup> National Archives Website : *Health Commission Wales*  
<http://collections.europarchive.org/tna/20061023100523/new.wales.gov.uk/topics/health/hcw/?skip=1&lang=en&ts=4>

<sup>14</sup> WHSSC. Specialised Services Policy: CP19 Specialised Services Policy for Tier 4 Child and Adolescent Mental Health Services. 2014, Caerphilly, WHSSC  
<http://www.whssc.wales.nhs.uk/sitesplus/documents/1119/CP19%20CAMHS%20v6.01.pdf>



- Professional bodies/Royal Colleges i.e. Royal College of Psychiatrists
- Systematic reviews of treatments and interventions e.g. Cochrane Reviews, National Collaborating Centre for Mental Health (NCCMH).

The approach used was based on examining published evidence provided by the Public Health Wales Knowledge Service. International comparisons have been described in relation to user experience<sup>15</sup> but not service provision or models of care.

## 4.1 Clinical Guidelines

NICE published guidance on the management of Eating Disorders in 2004<sup>16</sup>. This document played a significant part in informing the Eating Disorders Framework for Wales 2009. The NICE guidance resonates with the Scottish guidance on management and treatment issued in 2006<sup>17</sup> and recommendations from the Royal College of Psychiatry (RCP) report on service provision in 2012<sup>18</sup>. NICE undertook two reviews of the evidence informing the 2004 guidance - in 2008 and 2011. Since then, a review undertaken by NICE in 2014 concluded that there was insufficient new evidence to warrant a revision of the 2004 document<sup>19</sup>. At the time of writing this paper, NICE is consulting on guidelines relating to recognition and treatment of Eating Disorders<sup>20</sup> (to be finalised by 2017).

The RCP report concluded that whilst there had been an improvement in terms of access to services across the United Kingdom, there was still room for improvement in terms of more specialist provision. The College also reiterated the need for better outcome measurement with a National Audit of Outcome Measures.

<sup>15</sup> Escobar-Koch T, Banker JD, Crow S, Cullis J, Ringwood S, Smith G, van Furth E, Westin K, Schmidt U. "Service users' views of eating disorder services: an international comparison." *Int J Eat Disord*. 2010 Sep;43(6):549-59. doi: 10.1002/eat.20741.

<sup>16</sup> NICE. Eating disorders in over 8s: management NICE guidelines [CG9] Published date: January 2004. <https://www.nice.org.uk/guidance/cg9>

<sup>17</sup> Health Improvement Website : *Eating Disorders in Scotland - Recommendations for Management and Treatment*

<http://www.healthcareimprovementscotland.org/default.aspx?page=12439>

<sup>18</sup> RCP. Eating disorders in the UK: service distribution, service development and training. Section of Eating Disorders College Report CR170 Report from the Royal College of Psychiatrists' 2012, RCP, London

<http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf>

<sup>19</sup> NICE. Clinical Knowledge Summaries: Eating disorders. Revised 2014.

<http://cks.nice.org.uk/eating-disorders#!changes>

<sup>20</sup> NICE Website: Eating disorders - recognition and treatment. NICE in development [GID-CGWAVE0703] Anticipated publication date: April 2017

<https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0703>

The RCP report on the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) was published in 2010 and was revised in 2014<sup>21</sup>. This document addressed a perceived need to clarify good practice for the interdisciplinary management of extremely ill patients with anorexia nervosa in both medical and psychiatric units. A Junior MARSIPAN guideline was also been produced for children. This document sought to plug a gap in the original NICE guidance and was initiated by the deaths of anorexia patients on general medical wards.

The National Collaborating Centre for Mental Health (NCCMH) was commissioned by NHS England to produce a Commissioning Guide for Children & Young People with Eating Disorder in 2015<sup>22</sup>. The commissioning guide affirms the NICE Guidance as the approach that should be taken and also recommends that outcome monitoring of all services by commissioners. The report emphasises the need for early interventions and for ensuring that individual and family support are part of the service provided.

## 4.2 Summary

Therefore, having looked at the evidence and policy context, in respect of the 2009 Framework, there is little to be changed in relation to the model of care apart from the strengthening the monitoring of process outcomes (through the use of WCCIS) as well as patient and family experience.

The publication of revised NICE Guidelines in 2017 may necessitate a further consideration of the framework.

## 5 The Engagement Process

In setting out to review the Eating Disorder Framework, it was essential to include the views of service users and their carers. The engagement process received views from service users, carers and service providers using face to face meetings and written submissions. The key findings from these are described below. A more detailed description of the engagement process is described in Appendix B.

<sup>21</sup> RCP. College Report CR189: MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa 2<sup>nd</sup> Version. 2014, London, Royal College of Psychiatrists. <http://www.rcpsych.ac.uk/files/pdfversion/CR189.pdf>

<sup>22</sup> NCCMH. Access and Waiting Time Standard for Children and Young People with an Eating Disorder. Commissioning Guide. Version 1.0. London, NCCMH, 2015.

The engagement process undertaken by Public Health Wales was a two phase approach encompassing a web based consultation and service user engagement events.

## **5.1 Web Based Consultation**

The web based consultation was undertaken in August 2015. This was undertaken by contacting chairpersons and leads of committees relevant to Eating Disorders service provision, namely:

- Cross Party Group on Eating Disorders,
- Eating Disorders Subgroup of the CAMHS/ED Steering Group
- Eating Disorders clinical leads group
- All Wales Clinical Leads Group
- A voluntary sector charity that works with people with Eating Disorders (Gofal).

These respective groups were asked and agreed to disseminate information relating to the web based consultation with a covering letter describing how individuals could register their views. The web based consultation tool were designed and developed by Public Health Wales specifically for this consultation. Suitable governance arrangements ensured that no identifiable data was collected and consultees were encouraged to express their views anonymously using a structured template based on the current Eating Disorders Framework.

The web based responses fell into one of two types:

- Matters that related to the Framework itself
- Observations relating to variations in the implementation of the Framework

The responders to the web based consultation numbered 26 were a mixture of service users and providers: 7 service users, 4 carers and 15 service providers.

There appeared to be consistent concerns raised in relation to implementation across the whole pathway and in different tiers. In particular there are some repeated concerns regarding the following;

- Lack of dietetic provision and also variations in approaches to re-feeding.
- Lack of care co-ordination and support for carers
- Particular services cited as needing improvement were primary care and community teams.

- Rural service provision – Powys and North Wales were repeatedly flagged as parts of Wales where implementation of the Framework was not considered to be robust.

It is important to remember however that these are the views of a small self selecting sample and may not be representative of the wider body of service users, carers and professionals.

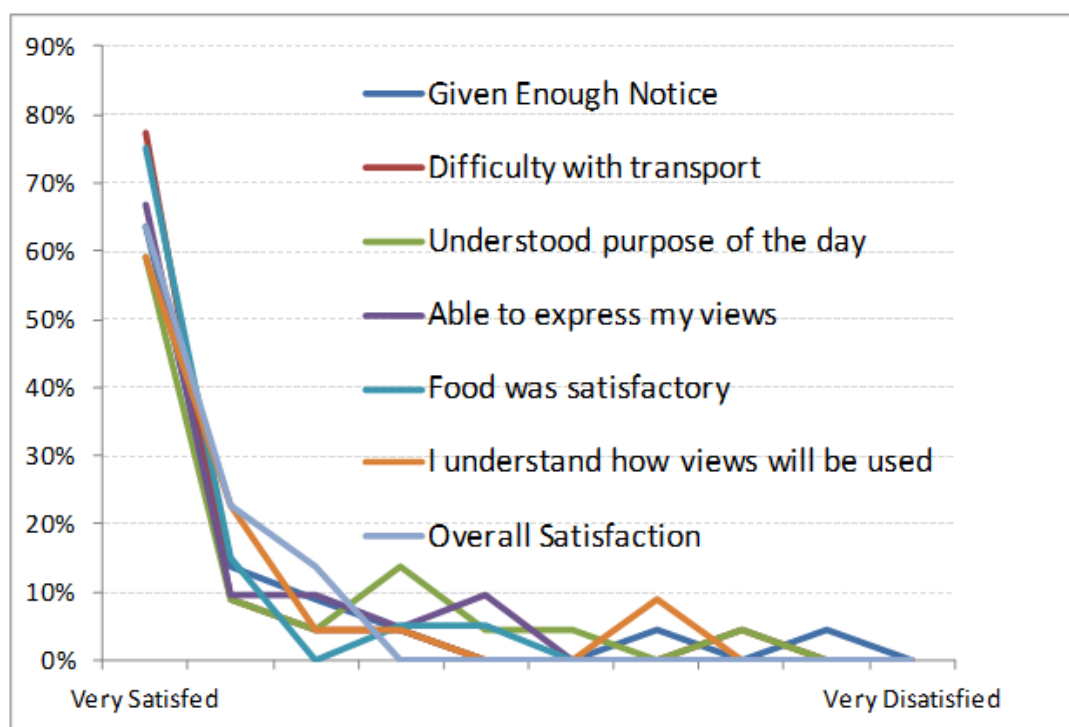
#### 5.1.1 Service User Engagement

The web based consultation was a technical approach to seek an understanding the views of service users and providers. Respondents remarked that service users may not easily understand the Eating Disorders Framework and as such a different method of engagement was needed. Moreover, as service users and their families are experts in their own right, it was important to learn from their experiences in an appropriate manner.

Two service user events were arranged and promotion of these events was undertaken via all main clinics throughout Wales and known service users groups (e.g. Gofal). Service providers were not invited to attend. Care was taken to ensure that attendees did not become duly upset by the discussion and careful consideration was given to the types of food on offer. A very well informed carer was one of the speakers and was able to open up the discussion. Facilitators ensured that attendees were able to describe their experiences of care at different tiers of the service.

The events were organised so as to ensure that the venues were accessible to a geographical spread of attendees (North Wales and South Wales), close to transport hubs and travel costs were reimbursed. Individuals who could not attend either event submitted written responses (3). The events were attended by a total of 50 people - the majority being carers (32). The majority of attendees came to the South Wales event, with 10 people attending the North Wales event.

Their views on the events are described in the figure below. It can be inferred that the attendees were satisfied with the overall process.



**Figure 1 Responses from attendees**

The attendees expressed a wide variety of views. These were initially collated by tier on a standardised response questionnaire. On reading the responses, it became apparent that there were themes that were repeatedly mentioned. One striking example is that *good experiences* of care were mirrored with the same issues when they were described as *bad experiences* of care by many attendees. An example of this was that often attendees stated that a single person made all the difference to the care pathway, either improving it or making the experience far worse. The reasons for this are given below, but include the knowledge, attitudes or behaviours of staff. These two exact opposites of experience gave considerable face validity that the views expressed were not only common but found across all levels of service.

Details of the responses are found in Appendix B but the service users made important references to the following areas for all tiers:

- Limited specialist knowledge, poor attitudes and inadequate skills of staff
- Hardly any information readily available to empower carers and individuals
- There should be a holistic approach to the management of treatment
- There are a number of system facilitators and blockers - particularly post discharge planning and in respect of the provision of advice

The main conclusion from the engagement processes was that *implementation* of the Framework was the main concern of both service users and providers.

## 6 Patient Experience

At the time of this review, neither providers nor commissioners collected patient experience data in a consistent, comparable and routine manner. This task is made more difficult as patient experience measures need to be robust and valid for adults, children and cognitively impaired individuals. The refresh of the current Framework could therefore not be informed by current measures of patient experience.

## 7 Level of Need

The existing Eating Disorders Framework described the estimated prevalence of Eating Disorders. The following tables provide updated prevalence estimates of Anorexia and Bulimia Nervosa in Wales. The recording of Service provision is in the process of being improved across all Tiers with the introduction of the Welsh Community Care Information System (WCCIS). Once data is available, LHBs will be able to compare the types of service provision (i.e. in-patient admissions to hospitals or clinics) with the estimated population of people with Eating Disorders in their locality. The collection of data will also give a better understanding of the relative needs of people with Eating Disorders – i.e. different levels of severity.

It should be noted that there are very small numbers of individuals affected in certain Health Board populations. As a result, the values have been rounded to the nearest 5. The following tables display the revised population prevalence's for the numbers of people with anorexia and bulimia nervosa aged 15 – 34 years. These figures include all levels of need, not just those who might be expected to access specialist services.

**Estimated number of adults with anorexia nervosa, males and females aged 15-34, Wales health boards, 2014**

	<b>Males</b>	<b>Females</b>
Betsi Cadwaladr UHB	25	230
Powys tHB	5	40
Hywel Dda UHB	15	130
Abertawe Bro Morgannwg UHB	20	195
Cardiff & Vale UHB	25	225
Cwm Taf UHB	10	115
Aneurin Bevan UHB	20	215
<b>Wales</b>	<b>120</b>	<b>1,150</b>

Produced by Public Health Wales Observatory, using MYE (ONS) and prevalence estimates from McCrone et al (2008)  
Numbers have been rounded to the nearest 5 to reflect the imprecision of the estimates

**Estimated number of adults with bulimia nervosa, males and females aged 15-34, Wales health boards, 2014**

	<b>Males</b>	<b>Females</b>
Betsi Cadwaladr UHB	80	775
Powys tHB	15	125
Hywel Dda UHB	45	430
Abertawe Bro Morgannwg UHB	70	645
Cardiff & Vale UHB	75	750
Cwm Taf UHB	40	385
Aneurin Bevan UHB	70	715
<b>Wales</b>	<b>400</b>	<b>3,825</b>

Produced by Public Health Wales Observatory, using MYE (ONS) and prevalence estimates from McCrone et al (2008)  
Numbers have been rounded to the nearest 5 to reflect the imprecision of the estimates

## 8 Changes to Service Provision

In 2013, the Health and Social Services Minister announced his intention to provide recurrent funding of £250,000 to enhance the provision of care for young people with eating disorders. The Minister wanted to ensure that funding should lead to service redesign enabling more young people with a range of complex needs, not just eating disorders, to be treated closer to home at Ty Lydiard. The Minister asked for additional sessions of psychiatry, nursing, psychology and dietetics with specific expertise in eating disorders, to expand the existing South Wales Eating Disorder clinic on a hub and spoke basis.

WHSSC allocated the funding for training (£42,650) and service provision (£207,350)<sup>23</sup>.

#### 8.1.1 Service Provision

Service provision was improved by the creation of new posts i.e. Consultant Child and Adolescent Psychiatrist (0.5wte), Psychologist (0.4wte), Dietetics (1wte), Specialist Nurse (1wte) and Administration Support (0.5wte). The new Eating Disorder Outreach service has been operational since January 2015. This service is a combination of the previous Eating Disorder Clinic set up by Cwm Taf University Health Board and the newly established Specialist Outreach Team. Recruitment to the posts took place in 2015 and the Team was fully operational by November 2015.

The new Outreach Service has:

- Set up Consultant sessions for South and Mid Wales and these have been held across the six health boards.
- Offered supervision sessions
- Developed Operational Guidelines and a referral form.
- Offered assessments/second opinions for young people from across Wales.

During the period January 1st to 31st December 2015 a total of 84 Consultant sessions were offered on an outreach basis as well as 23 Supervision sessions. A total of 28 new referrals were received by the service and 27 patients have been assessed in the Specialist Outpatient Clinic in Ty Llidiard. Eighteen patients with a Primary diagnosis of an Eating Disorder were admitted to Ty Llidiard, one of whom was repatriated from England.

#### 8.1.2 Training

Training has been highlighted as one of the most important areas to be taken forward by the new Outreach Service. A consultation event was held in March 2014 with the South London and Maudsley NHS Foundation Trust, to develop a robust training programme and to decide the way forward for the Health Boards across Wales.

The South London and Maudsley NHS Foundation Trust provide a two year training programme for child and adolescent eating disorders.

<sup>23</sup> Personal Communication ; Caroline Winstone, WHSSC



The key aim of the programme is to support the development of a comprehensive specialist service for child and adolescent eating disorders that is able to provide effective treatment based on the most up to date research evidence. The training includes modules on both inpatient and outpatient interventions with the aim of supporting a service model that is able to provide effective treatment on an outpatient basis for the great majority of patients.

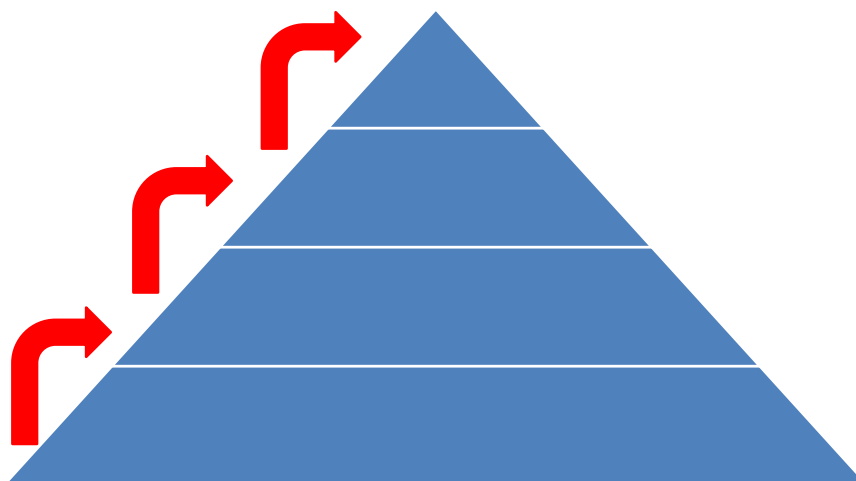
The training has a strong emphasis on practice and skill development and a focus on multi-disciplinary working. One of the aims of this programme is to build on existing skills of the multidisciplinary team and to develop a strong family oriented team approach with specific expertise around specialist working with eating disorders. The training also focuses on medical assessment and risk management issues relating to both outpatient and in-patient management.

A training programme for Wales, based upon the above, has been developed by the South London and Maudsley NHS Foundation Trust in conjunction with all Health Boards and is tailored to the training needs of both specialist mental health services and partner agencies. The training programme commenced in January 2015. The training covers Medical Assessment and Risk Management in In-Patient and Outpatient Settings, Meal Planning and Dietetics. Seventy one clinicians attended the training programme from across Wales from a variety of disciplines. To further enhance and develop skills it was proposed that an All Wales MARSIPAN (management of really sick patients with Anorexia) group be formed to establish best practice across Wales.

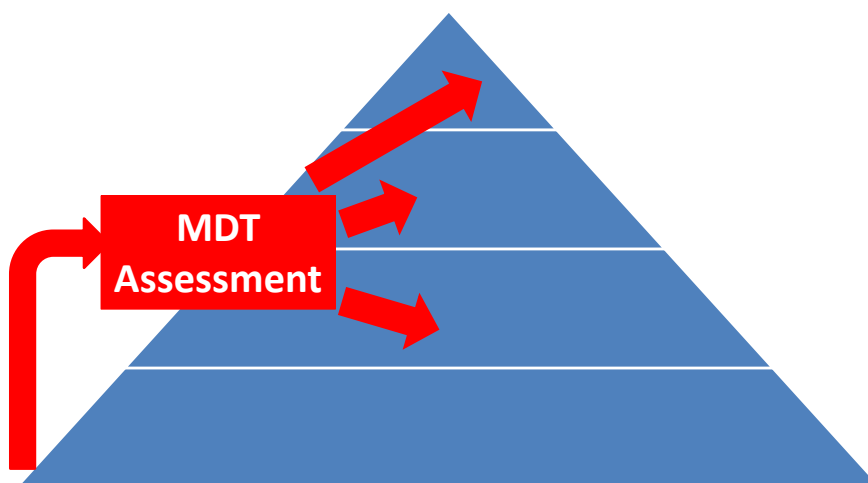
Further training days have been held and have covered various forms of Family Therapy across the year.

The key feature of the training programme is that early intervention results in a more cost-effective service with better outcomes<sup>22</sup>. This has been of interest to a recent Parliamentary Select Committee hearing<sup>24</sup> and NICE. NICE is currently consulting on the recognition and treatment of Eating Disorders and will be making recommendations in 2017. The Maudsley model changes service provision from a tiered referral approach towards a community eating disorders service being the entry point for assessment. The person and family with ED are referred to the relevant tier **after** this assessment. The diagrams below describe the changes in the model of provision.

<sup>24</sup> UK Parliament Website : *Children's and adolescents' mental health and CAMHS - Health Committee Contents*  
<http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/342/34203.htm>



**Figure 2 Current Tiered Referrals**



**Figure 3 Multi-disciplinary Team Assessment undertaken by a community eating disorders service (Maudsley Model).**

The Maudsley model offers an expert service from the point of first contact by a trained team. Staff in Wales are currently being trained to deliver this model.

Welsh Government funding was also agreed for twenty clinicians from across Wales to attend the International Eating Disorder Conference in March 2015. These attendees included Tier 2/3 Eating Disorder leads from each Health Board, with an expectation of cascading their knowledge and information throughout the generic teams.

## 9 Outcomes

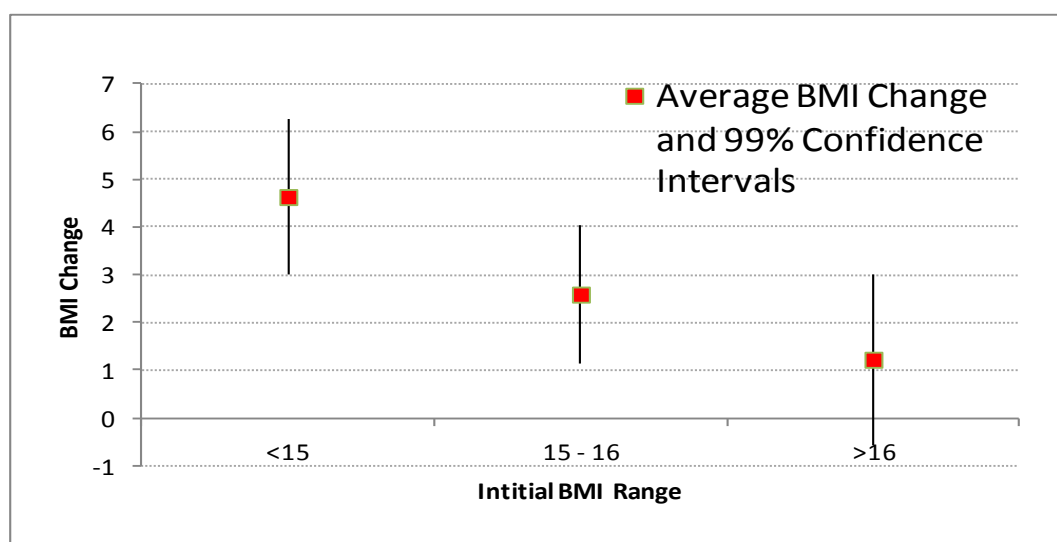
The original Eating Disorder Framework described a number of standards and the need for monitoring these standards at a local level. These standards are as relevant today as they were in 2009. However, the 2009 Framework had limited emphasis on the monitoring of outcomes and patient experience measures at a local and national level.

As part of this refresh, Public Health Wales examined clinical audit data relating to Eating Disorders – particularly outcome data from Children's Services (Tier 4) and Adult Services (Tiers, 2, 3 and 4). Details of this analysis are found in Appendix C. It should be noted that the author was not able to obtain outcomes data for all providers of Eating Disorder services across Wales.

Where LHBs collect data, there is statistically significant evidence to show that the clinical outcomes confirm improvements in Body Mass Index, physical functioning and psychological well being for children and adults at various Tiers. More importantly, there are consistent and reassuring observations that the best outcomes, in terms of BMI, are found amongst those individuals that are most affected by the Eating Disorders.

One example of this is shown below – where children with the lowest initial BMI have the greatest improvement in their weight (

**Figure 4).**



**Figure 4 Changes in BMI in Tier 4 Children Service Users (N Wales) by differing initial BMI**

(Source: Clinical audit data, personal communication)

## 10 Summary and Recommendations for the revised Framework

In reviewing the Eating Disorders Framework, Public Health Wales has considered changes in the strategic context within which services are delivered; changes in clinical guidelines and treatment pathways; user, carer and service provider feedback.

This Review has identified that:

- Changes in policy and strategy since the publication of the Framework are both consistent with the Framework and should provide an environment in which implementation of the Framework is supported and enabled.
- There have been no significant revisions to clinical guidelines or clinical treatment of Eating Disorders since the publication of the Framework. However, this will require further reflection following the anticipated publication of revised guidance from NICE in 2017.
- There have been changes to the model of service delivery with the introduction of an initial specialist assessment and specialist outreach services to support delivery at each Tier of the model. This is consistent with good practice and is supported by carer and user feedback.
- Engagement with users, carers and service providers highlighted a number of areas which could be strengthened in relation to service provision.
- Implementation of the Framework requires further attention to ensure that there is consistency of approach across Wales.
- Further work is needed to strengthen data collection and recording of outcome measures.

### 10.1 Recommendations

- The Eating Disorders Framework is reviewed following publication of NICE Guidance on Recognition and Treatment of Eating Disorders expected in 2017
- Health Boards should review progress in the implementation of the Eating Disorders Framework using the standards described in the original Framework. This will inform the current state of implementation of the framework and identify the variation in access to services across Wales.

- Health Boards should utilise the service improvement model described by Public Health Wales 1000 Lives Improvement Service in 2012 to support continuous improvement in Eating Disorder Services.
- There should be work engaging all key stakeholders to develop and agree uniform outcome measures across Wales that include measures of severity, BMI, functional scores, psychological well being scores, complexity, co-morbidities, patient experience and family experience. The experience measures must be validated, evidence based, bilingual and capable of being used in children, adults, cognitively impaired individuals and carers. These measures should cover children and adults and thereby inform transition for services users from children to adult services.
- Health Boards should collect and submit all above outcome data as agreed with the current All Wales clinical audits. This includes an annual audit of the admissions to hospitals for re-feeding in line with the Eating Disorders Intelligent Targets Driver 4 for inpatient admissions for severe eating disorders to medical settings.
- Welsh Government should ensure that there is robust and periodic scrutiny of the implementation of the Framework across Wales.
- Health Boards and Local Authorities should ensure that the needs of service users and carers for information about Eating Disorders and what can be done by carers or families to support recovery of individuals affected, is made available on an All Wales basis in line with the requirements of the Social Services and Wellbeing Act. Access to support and advice is not only a basic right under the Act but also improves post discharge care for service users and thereby reduces the risk of readmission.
- The Framework needs to be refreshed with changes to the responsibilities of various organisations in keeping with the above recommendations.

## Extracts from the 20019 Eating Disorders Framework

## Appendix A

### 4.6. Tier 1: Characteristics and implementation issues

<p><b>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 &amp; access procedures will normally allow direct access by patient or parents (in the case of minors) dependent on local circumstances.</b></p>			
<b>Patients most likely to need service.</b>	<b>Probable interventions</b>	<b>Examples of agency or team</b>	<b>Key resources required to undertake role</b>
<ul style="list-style-type: none"> <li>• People with or without a diagnosed eating disorder who present with or display patterns of concern/risk.</li> <li>• Patients with low intensity and chronic eating disorders that need to be monitored.</li> </ul>	<ul style="list-style-type: none"> <li>• Education.</li> <li>• Screening</li> <li>• Initial identification &amp; assessment.</li> <li>• Referral for advice or assessment.</li> <li>• Health promotion.</li> <li>• Brief interventions.</li> <li>• Short term counselling.</li> <li>• Long-term monitoring, independently or as part of shared care with specialist services.</li> </ul>	<ul style="list-style-type: none"> <li>• General Practitioners and other staff of the Primary Healthcare Teams.</li> <li>• School / University health or welfare staff</li> <li>• Youth, Community and Voluntary Sector Services</li> <li>• Health care professionals working in general hospital and community settings.</li> </ul>	<ul style="list-style-type: none"> <li>• Screening/Assessment skills &amp; tools.</li> <li>• Designated contact point on Eating Disorders within CAMHS and CMHT.</li> <li>• Awareness of 'motivational' aspects of eating disorders and consequences for engaging/avoiding help.</li> <li>• Guidance on medical risk implications &amp; appropriate investigations.</li> </ul>
<p><b>Key implementation issues &amp; barriers</b></p> <ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> <li>• Early identification and sensitive early support are needed to reverse the tendency for patients to have to develop severe symptoms before receiving care.</li> <li>• 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.</li> </ul>			
<p><b>Actions required by each Local Health Board (LHB):</b>            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.</p>			

#### 4.7. Tier 2: Characteristics and implementation issues

<p><b>Tier 2 services</b> 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:</p> <ul style="list-style-type: none"> <li>• <b>Specialists in mental health services</b>, 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.</li> <li>• Additionally, <b>paediatric and adult physicians</b> 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.</li> </ul>			
<b>Patients most likely to need service.</b>	<b>Probable interventions</b>	<b>Examples of agency or team</b>	<b>Key resources required to undertake role</b>
<ul style="list-style-type: none"> <li>• Patients whose behaviour / condition indicate the possibility of an eating disorder of sufficient severity to require assessment and/or ongoing intervention.</li> <li>• 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.</li> </ul>	<ul style="list-style-type: none"> <li>• General mental health assessment as part of the Unified Assessment process / CPA.</li> <li>• Interventions &amp; therapy.</li> <li>• Relapse prevention &amp; monitoring.</li> <li>• Managing transition between teams &amp; tiers</li> <li>• Consultancy to T1, including pre-referral advice</li> <li>• Comprehensive investigation &amp; monitoring of physical health together with GP etc</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist Child &amp; adolescent mental health service (Specialist CAMHS) teams.</li> <li>• Community Mental Health Teams (CMHTs)</li> <li>• Staff in Tier 1 services with enhanced expertise, e.g. Primary Mental Health Care Workers</li> <li>• Paediatric and general medical teams.</li> </ul>	<ul style="list-style-type: none"> <li>• Suite of assessment tools.</li> <li>• Guidance on medical risk implications &amp; appropriate investigations.</li> <li>• Sufficient range of disciplines, expertise and experience.</li> <li>• Access to specialists for training, advice and support.</li> </ul>
<p><b>Key implementation issues &amp; barriers</b></p> <ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> <li>• Eating disorders 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</li> <li>• 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.</li> </ul>			
<p><b>Action required by Local Health Boards (LHBs):</b> 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.</p>			



#### 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.**

<b>Patients most likely to need service.</b>	<b>Probable interventions</b>	<b>Examples of agency or team</b>	<b>Key resources required to undertake role</b>
<ul style="list-style-type: none"> <li>• Patients who have not responded to Tier 2 interventions or who are seen to require the expertise of Tier 3</li> <li>• Patients with particularly complex needs and/or co-morbidity.</li> <li>• Some patients returning from inpatient treatment.</li> </ul>	<ul style="list-style-type: none"> <li>• Structured interventions and therapy.</li> <li>• Intensive home-based day-care or family interventions.</li> <li>• Structured relapse prevention.</li> <li>• Intensive community-based outreach &amp; day care therapy programmes.</li> <li>• Consultancy to T2</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Community Intensive Treatment Teams (as operating in Specialist CAMHS).</li> <li>• Tertiary/Regional Eating Disorders Teams.</li> </ul>	<ul style="list-style-type: none"> <li>• Multidisciplinary team spanning appropriate range of skills.</li> <li>• Access to clinical supervision.</li> <li>• Resources to enable them to undertake assessments and interventions in wide range of settings and locations for outreach activity, including meal support.</li> <li>• Strong pathways to/from to acute medical services</li> </ul>

#### 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. .**

<b>Patients most likely to need service.</b>	<b>•Probable interventions</b>	<b>•Examples of agency or team</b>	<b>•Key resources required to undertake role</b>
<ul style="list-style-type: none"> <li>•Patients who have not responded to interventions through T1-3 or who are seen to require the expertise of Tier 4,</li> <li>•or whose physical condition makes inpatient care essential.</li> <li>•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.</li> </ul>	<ul style="list-style-type: none"> <li>•Inpatient treatment for life-threatening cases</li> <li>•Inpatient treatment for highly complex cases which have not been resolved following community interventions.</li> <li>•Highly complex assessment where there is significant co-morbidity.</li> </ul>	<ul style="list-style-type: none"> <li>•Hafod Newydd Unit and Cedar Court (both Tier 4 generic CAMHS units)</li> <li>•External NHS and Independent Sector provision.</li> <li>•Community-based intensive teams (to be developed)</li> </ul>	<ul style="list-style-type: none"> <li>•Defined range of professional expertise and interventions appropriate to designation as Tier4.</li> <li>•Access to appropriate settings to provide community based intensive interventions.</li> <li>•Pre-arranged pathways to relevant facilities and expertise to ensure smooth stepped transitions.</li> </ul>

#### 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

## **The Engagement Process and Key Findings      Appendix B**

### **1      Introduction**

This Appendix is part of the Review of the Eating Disorders Framework that was undertaken by Public Health Wales (PHW) in 2015. This document specifically describes the Engagement Process and the key findings. The engagement process undertaken by PHW was a 2 phase approach encompassing a web based consultation and two service user engagement events

Public Health Wales has consulted and engaged widely with professional and service users to consider how the services for Eating Disorders are delivered and received from different perspectives.

#### **1.1      Web based consultation**

The Web based consultation was undertaken in August 2015 for a period of a month. The approach taken is described below.

Leading individuals with an interest in Eating Disorders were engaged prior to the consultation to raise awareness. This was undertaken by contacting chairpersons and leads of committees relevant to Eating Disorders service provision, namely:

- Cross Party Group on Eating Disorders,
- ED Subgroup of the CAMHS/ED Steering Group Eating Disorders clinical leads group
- All Wales Clinical Leads Group
- A voluntary sector charity that works with people with Eating Disorders (Gofal).

All these respective groups were asked and agreed to disseminate information relating to the web based consultation with a covering letter describing how individuals could register views.

An approach to this engagement process was designed by Public Health Wales in close discussion with Welsh Government.

The web based consultation tool and database were designed and developed by Public Health Wales specifically for this consultation. Suitable governance arrangements were put in place to ensure that no identifiable data was collected through this approach. Consultees were assured that they could express their views anonymously and linked via a web page to the 2009 Framework.

The database and website provided a template for respondents to indicate their demographic characteristics (i.e. service user/provider/carer, provider of services, and LHB of residence). Importantly, the website enabled free text responses from the consultees express their views. This was intended to ensure an *open* means of capturing views and opinion limiting the risk of bias that could arise through closed questions. Views expressed in writing by the respondents were collated into sections that mirrored the structure of the Framework;

## 1.2 Results

Each response was collated into the sections outlined above. The responses appeared to be of two types:

- Matters that related to the content of the Framework itself
- Observations relating to variations in the implementation of the Framework

The respondents to the web based consultation were a mixture of service users and providers: 7 service users, 4 carers and 15 service providers. Of the 11 respondents that were service users or carers, these were drawn from North and South East Wales.

The following tables display the collated responses from the web based consultations. These have been aggregated to the different sections of the Framework. To maintain the accurate 'voice' of the respondents the text below is as it was written and has not been corrected for typographical or spelling. Italic sentences have been added by the author to explain particular acronyms for the lay reader.

## Introduction

CAEDS (*Children and Adolescent Eating Disorder Services*) have initiated the development of a MARSIPAN bed to support the tier 3 service and reduce tier 4 (out of area) admissions with a view to promote effective more locally based treatments. (*Marsipan is a protocol for managing severely affected Eating Disorders patients*). This hasn't yet been implemented or agreed by commissioners and is considered a significant unmet resource. CAEDS have no formal contract with Specialist eating disorder units in England and there are none available in Wales. This creates an ongoing problem for ED patients in Wales as they often have to wait to receive urgent and necessary treatment. CAEDS are consistently working to ensure inpatient treatment is supported by community services and provided to the highest standard. For example, we devised an inpatient care plan proforma especially for ED patients in North Wales to ensure all medical colleagues could provide consistent and excellent care whilst being aware of all the key risk indicators and advice on how to manage these for each individual patient needing inpatient treatment on both medical and psychiatric wards.

Change of care from one area to another. Pls have to rejoin a long waiting list which is dangerous and unacceptable.

General update on service development across Wales and across the age span. some achievements and further challenges i.e. managing 16-18 year old with eating disorders, paediatrics currently will not see and adult medicine say they do not have the skills., issues around transition especially so when the young person is resistant but at high risk.. Introduction of the Mental Health Measure. include marsipan and junior marsipan

Holistic support should be offered to patients in the community to enable them to re engage with education, work or social activities.

Treatment should involve psychological intervention & not just weight restoration. Anorexia is a MENTAL illness & focusing on weight (symptom-side effect) will not enable the patient to recover.

I feel as a parent of a 19 year old who currently suffers with anorexia nervosa there needs to be much more support to both patient and parent/carer .... As it stands my daughter has now been 'discharged' and every day is still a daily struggle.

We 'cope' daily without ANY support at all.

I have no idea about the Framework. Where do I find it? I don't really care about being academic about this. I approach it from a personal perspective. Our experience with CAHMS for my daughter was brilliant but Adult Services leaves very much to be desired. Things have to change for adults from the Patient centered to the family centered. Anorexics at 18 are not 'adults' in the sense of being able to make decisions for themselves; they are still like children and children with a mental illness, at that. At the moment I see my daughter failing FAST and Adult Services just keep dragging their feet.

I would like to see recognition that the input of Dietitians' is vital at an early stage, but that there is little funding for dietitians to provide input, particularly not the targeted funding that allows them to work collaboratively with CAMHS colleagues

Increased acknowledgement of role of dietetics in the refeeding and weight recovery process and medical stabilization process.

It may be helpful to patients to work more closely to their local GP. For example, as a patient myself, all medicines prescribed to me (including vitamins and glucose tablets) were not recorded as part of my treatment unless I mentioned it during a session. This would also allow important information needed (for example, low blood sugar) to be used in preparing a meal plan.

No it gives a clear detailed description of the background and principles of the service

Since the original framework came out the Mental Health Measures have been enacted which have seen the introduction of Primary Mental Health Support Services (PMHSS) which have improved services at PC level. The CAMHS / ED network is also now in place.

p7 1st paragraph, final sentence 'This document does not deal with obesity' could helpfully be cross -referenced to the All Wales Obesity Pathway.

The new diagnostic categories in the DSM5 need to be referenced.

The background information and principles remain sound. However, what requires addressing is the adherence of services for people with eating disorder to these principles. Particularly early identification of emerging eating disorders and effective diagnosis is not being achieved consistently in primary care across areas of Wales. Where appropriate intervention is available, it is often following a lengthy wait during which time people's eating difficulties deteriorate further and become more entrenched and treatment-resistant. Early identification and screening needs to keep pace with new classifications of eating disorders and new evidence of high-risk groups such as sufferers of diabetes and hard-to-diagnose groups such as boys/men, and older clients. The principle of the 4-tier

approach highlights the need for services to be fully integrated and span the range of needs. However with the services at those tiers being under-resources, there are significant gaps within this model, such as in the funding of full-time ED specialist staff at Tier 2 in all Health Boards for both CAMHS and adult mental health services, a significant gap of provision between Tiers 3 and 4 for adults, and rising waiting times for Tier 4 specialist eating disorders adult inpatient services. The principles indicate that the ED Framework provides clear descriptions of expectations for services at all levels, however greater clarity is needed in the document to highlight primary care's responsibility to undertake ongoing physical monitoring for patients once they have been referred on to Tier 2 and above of the services.

The background information is general to Eating Disorders but feels very adult orientated. As a CAMHS professional (Tier 4 Outreach service for South Wales for children and adolescents) I would like to see more mention of children and young people, particularly as early intervention is so important.

The health board doesn't treat people as individual with their specific needs. They treat us like everyone with an eating disorder has the same characteristics when this is not the case.

The new framework needs to include a reference to Prudent Health Care Principles - Do only what is needed, no more, no less and do no harm. Too many review appointments can be 'iatrogenic' for some eating disorder patients.

The framework needs to include NICE (National Institute of Clinical Excellence) do NOT do approach - emphasis on dietary counseling NOT being the sole treatment for adults with Anorexia Nervosa (NICE 2004)

The section on relating to primary care needs to include a point on GP's having the role of monitoring patients with eating disorders from the medical / physical health perspective. (Bloods, BP etc).

CMHT - adult patients with Anorexia Nervosa need to be under CMHT (Community Mental Health Team) in order to see the dietitian. There have been times when CMHT has said they will not accept patients back onto their books - capacity issues. Dietitian capacity issues at Tier 1 / Tier 2 also needs to be addressed - patients with eating disorders are complex patients.

The underlying principles remain valid however the four tier strategic model relies heavily on skills and expertise at every Tier. For clinical presentations that have lower incidence and prevalence rates such as Eating Disorders there is evidence that regional specialist teams develop more effective expertise to deliver services rather than relying on local services.

The update to diagnostic categories for eating disorders published in 2014 as contained in DSM (DSM is a coding system used to record patient data) V. The ICD-11 is out for consultation at the moment and is also likely to be amended (ICD is a coding system used to record patient data),

It would be helpful to include a reference to the Mental Health Measure 2010

and how this will impact on those defined within the Framework i.e. that those with an eating disorder will receive a service at Primary Care appropriate to their presentation and that a Care and Treatment Plan will include an assessment and treatment interventions for their eating disorder.

## KEY STRANDS

### Implementation

Again an update of where we are highlighting progress. More description with action points for each strand which informs on approaches and evidence.

More support - I cannot emphasize this enough.

Primary care and GP monitoring remains a challenge and ongoing need for engagement from GPs needs to remain on the agenda. The role of shared care between mental and physical health needs to be revisited and joined up.

Training in schools and colleges, appropriate emphasis is placed on obesity but this needs to be balanced with educating pupils and staff about eating disorders, body image, balanced eating.

Enhanced training for the acute sites involved in the refeeding process to ensure care plans and aims and objectives are clear and transparent to all involved

Primary care should highlight the role of monies supplied by WG for the implementation of mental health services at Tier 1 and how this should impact on early assessment and ultimately prognosis.

Refeeding needs to be supervised by a Registered Dietitian with the appropriate competencies

P27 The reason that community mental health teams/CAMHS/psychiatry often cannot access dietetics is that they have not commissioned services from them. Without funding, dietetics does not have the capacity to take on often time consuming patients with eating disorders. Urgent attention should be given to appropriately funding dietetic posts for all Tiers of eating disorders. Many times dietitians receive referrals from GPs and CAMHS, expecting them to advise ED patients in isolation which is neither appropriate, nor effective

Screening and risk assessments on referral via SPOAA (Single Point of Access and Allocation – the way in which mental health service users are seen by services) need further education and training to identify accurate risk and signpost to appropriate service or care team. Better links needed between services and SPOAA teams in order to determine best form of intervention. Further training for Primary and Secondary care teams on assessing and treating individuals with Eating Disorders. CAEDS offer consultation, supervision, and training to all professionals working with eating disorders in North Wales as part of our service remit. This are often poorly attended and unwelcomed by staff and service managers and is certainly an ongoing issue in North Wales. There appears to be a lack of infrastructure in the model and its implementation to the lower tiers and service staff. CAEDS is too small a service to effectively promote the model to others tiers. This creates disparity across the tiers in North Wales



and often leaves significant gaps in services in terms of what they offer. Physical Risks are often overlooked and not appropriately managed in the community. Co-morbidity is a problem and often there is an uneven response in terms of providing treatment when a person's co-morbidity is an Eating Disorder.

The key strands remain valid in particular the workforce, capacity and training issues. There remains a gap in the expertise of primary care and secondary care services. Tier 3 services have developed significantly but are under resourced and are often taking on patients that should be managed in secondary care but aren't due to a lack of expertise. This is sometimes due to the small numbers, going through the local secondary care services and therefore health professionals do not have the opportunity of developing skills, sometimes it is due to the lack of interest in the clinical presentation. Tier 3 services have provided extensive training and supervision to try to overcome this problem.

Where young people are mentioned it is stated that a pediatrician as well as specialist mental health services (Tier 2). In the scoping exercise undertaken in 2014 it was clear that this is not happening in many areas and it would be useful to try to give this more emphasis so that Health Boards realize that this is an important element of assessment and care of young people who have an eating disorder. Again in Medical stabilization and refeeding it would be useful to stress that admission to a Pediatric ward needs to focus on acute medical care and it would be good to try to establish Junior MARSIPAN guidelines in all Health Board areas, with a contribution from Pediatricians. Again, this is in place in some areas but not in others. The fact that it is in the framework but not yet taken on board is the issue to address. Many young people do not have, as is recommended rigorous monitoring of their physical health and I believe that there needs to be a named Pediatrician in each Health board who would be the link for Eating Disorders, which works well in some areas.

The other issue for CAMHS is the lack of Dietetics in the treatment of Eating Disorders in some Health Boards. There is currently no CAMHS Dietetics in Cwm Taf, ABMU and Cardiff and Vale which means that young people in these areas do not have this valuable input. There is some Dietetic input in the Tier 4 service but this to serve the in-patient Unit and the Tier 4 Outreach team. This does not address the deficit in accessing a specialist Dietitian in the community.

There is also a growing evidence base for family based interventions for young people who have eating disorders and training in Wales has been geared to skilling staff up in family/ systemic therapy. It is important to emphasis this and to highlight the ongoing need for both training and for staff who can deliver family based interventions. There is also growing evidence for CBT for older adolescents and this also raises a training and workforce issue.

Workforce planning and commissioning requires a more robust response to the delivering of care throughout the ED Framework as it does through the implications set out by Welsh measures.

## Tiered Model

**Implementation**

All the tier services require more investment especially in T2 and 3 services to enable support to T1 services. In addition T4 service provisions for Wales are inadequate and requires greater investment to function for the rurality of Wales

Care Coordination is an issue as a good number of patients seen in Cwm Taf who require CC (Care Coordinator) are not always appropriate to the CMHT service in general and would be better CC'd by an Eating Disorder Team Member.

Early intervention teams need more support with implementing this model. No definite acceptance of four tier approach across North Wales, Inconsistent implementation of this model between tiers in different geographical areas of North Wales.

In CAMHS, again in some but not all areas there has been a failure to appoint a member of the Tier 2 service to be the designated person for Eating Disorders. In areas where this has happened, there is a clear benefit. Again, it would be useful if this could be emphasized to try to get implementation in all the Health Board areas.

In the CMHTS we are having to care coordinate someone with an eating disorder that we may never see just for paperwork purposes

Increased emphasis on the need for appropriate and timely transitions from CAMHS to adult services.

Acknowledgement of lack of specialist dietetic expertise within CAMHS CIT teams. Serious concerns about transition patients holding inaccurate ideas about food received from non dietetic staff.

No I think each tier is described well and carried out effectively by the service

Struggles exist in terms of timely access to specialist dietetic support owing to limited available staff. Lack of specialist Dietetics across Wales remains an issue. Dietetics has a key role in all Tiers 1-4. Some Tier 3/4 services have dietetic support without any infrastructure in place at Tiers 1/2 and hence the effectiveness is limited and inequity exists across the geography of Wales

Physical health care monitoring remains a problem at primary care level. Some GP practices are loathe doing this stating that this should be done at secondary care level. Secondary care services are variable, some teams have invested in the development of individuals in regards to their expertise and skills others due to the demands of other mental health presentations struggle to meet the needs of individuals with eating disorders. It is felt that a health board wide secondary care service specific for eating disorders would go a long way in ensuring equitable services are delivered by skilled individuals.

In regards to Tier 3 services there needs to be further investment in this area to ensure a more stepped down approach for individuals when being discharged from hospital this would enable tier 3 services to provide more intensive home treatment to ensure the effective transition from hospital to the community. Intensive home treatment would also potentially prevent admission.

In regards to Tier 4 services we believe that this should be delivered within mid/South Wales to ensure more effective transition and also to ensure more timely access to beds. Current Tier 4 provider manages less complex cases well however for those individuals who have significant co-morbid difficulties often their needs are not met within this unit.

The way this section is split up and the wording used does not really cover the joint working aspects. It is set out as if the services work independently of each other and does not describe the ongoing roles of each tier if a patient is referred on e.g. ongoing role of GP in physical health monitoring when patient is under care of Tier 2 / 3.

Tier 1 - PMHSS to be outlined Tier 2- on-going training needs remain significant across both Tier 1 and 2.

The 'designated contact' role envisaged in CMHTS has been difficult to implement due to lack of financial 'backfill' of role and other pressures on CMHT practitioners. Tier 2 Lead Clinician roles have been helpful in driving this level of implementation and liaising with Tier 1 and 3 colleagues.

Specialist dietetic support at Tier 2 remains patchy across HBs.

The need for a more intensive community based service to supplement Tier 3 services in facilitating step down / up to Tier 4 has become apparent.

Tier 3: In description of the function of Tier 3 services, there needs to be an additional commitment stated that the Tier 3 service needs to provide a viable and credible community-based alternative to inpatient admissions for all patients who may be treated safely in the community. This needs to include adequate provision for physical monitoring protocols for patients with severe eating disorders, and high intensity supervision of mealtimes to ensure that adequate levels of support are available for people with severe eating disorders to be managed effectively indiscreet periods of time.

## Standards

### Implementation

All standards need to be reviewed to consider the reviewing and responsibility of compliance to the standard so this can be considered in the new document and action plans put in place to achieve during specific timeframes.

Standards of care are inconsistent across North Wales. Primary Care teams report to be unequipped with the correct skills to work with mild ED patients and rarely seek support from other tiers. Secondary Care teams report to have a lack of training and are unable to work with ED patients. CAMHS services do not

adequately communicate with Adult services to ensure streamlined transfer of care to Adult ED Services.

Waiting list times need to be reduced drastically.

### 1.2.1 Summary of feedback received

There appeared to be consistent concerns raised in relation to the implementation across the whole pathway and in different tiers. In particular there are some repeated concerns regarding the following;

- Lack of dietetic provision and also variations in refeeding approaches.
- Lack of care coordination and support for carers
- Particular services cited as needing improvement were primary care and community teams.
- Rural service provision – Powys and North Wales were repeatedly flagged as parts of Wales where implementation of the Framework was not considered sufficiently robust.

## 1.3 Engagement events

The engagement process received views from service users, carers and service providers using face to face meetings and written submissions. The key findings from these are described below.

The web based consultation was a very technical approach to understanding the views of service users and providers. Respondents remarked that service users may not easily understand the Eating Disorders Framework and as such a different method of engagement was needed. Moreover, as service users and their families are experts in their own right, it was important to learn from their experiences in an appropriate manner.

Service users were invited to one of two events; one in North Wales and another in South Wales. Attendees from West Wales were offered a similar meeting, but uptake was low and West Wales attendees agreed to attend the event in South Wales event. A number of individuals (3) who could not attend either event submitted written responses.

Venues for the events were selected which were readily accessible by public and private transport. The Swalec Stadium and Glyndwr University were chosen as they fulfilled these criteria.

Reimbursements for travel costs were provided for attendees with funds made available by Gofal.

The events were described as *service user events* and service providers were excluded unless they had a lived experience of eating disorders. A number of carers attending were also employed by the NHS.

Promotion of the events was achieved via all main clinics throughout Wales and known service users groups (e.g. Gofal).

The venues had a separate room made available for attendees to take time out as there was a risk that the discussion might be traumatic for some. An experienced individual was identified prior to the events as the lead person who would be able to support distressed attendees if required.

It was agreed that the chairperson for each event would be a senior clinician from the *opposite end* of the country. This ensured that service users could ask technical questions from an unbiased senior clinician who they would never have met before nor would they meet again. Dr Robin Glaze and Dr Menna Jones agreed to this in South Wales and North Wales respectively.

Facilitators were available at the meetings to ensure that a consistent approach was used during the discussion on different tables.

A very well informed carer for a person with an Eating Disorder was one of the speakers and was able to open up the discussion.

The author spoke at the meetings in a non clinical fashion and made it very clear that his role was to learn from the attendees.

The attendees were asked to describe what went well during their experiences of care at different tiers of the service. They also were asked to describe what did not go well during different levels of the service. This was recorded on a questionnaire using open text fields. Round table discussion took place where individuals were able to describe their views in an open fashion.

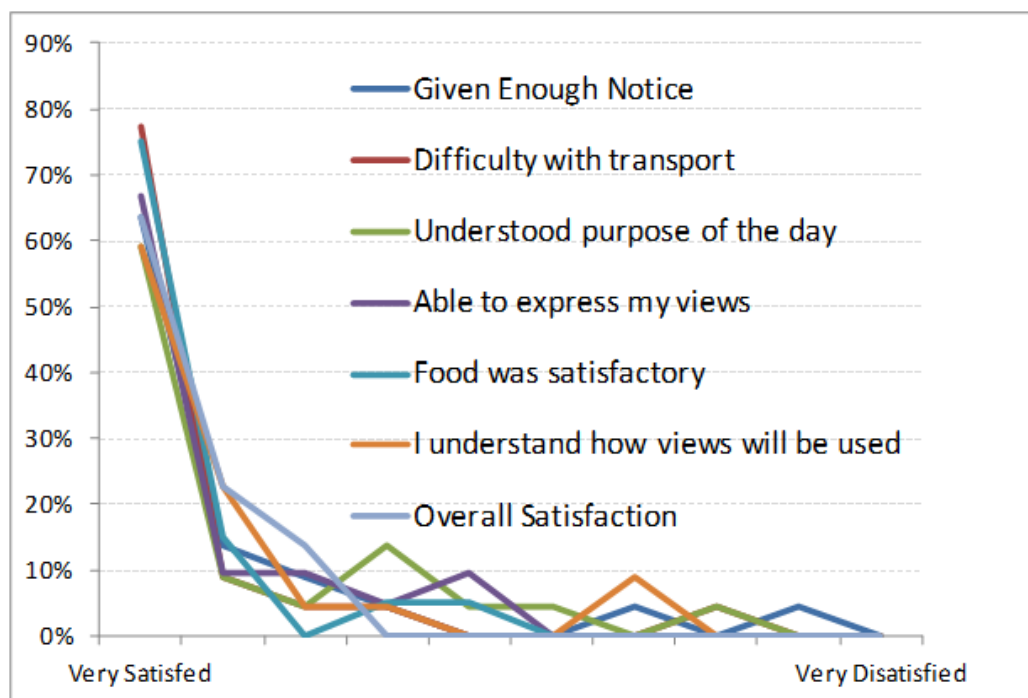
At the beginning of each event, the author made sure that attendees knew the purpose of the day, how their views were going to be used, that the ground rules were of *anonymity* and *confidentiality*. Chatham House rules were reiterated; what was said on the day would not be repeated outside the room.

Considerable thought was given to the food to be provided. The agreed approach was to provide healthy options with finger food and small plate sizes. This would ensure that service users did not become unduly upset at the sight of large plates.

## 1.4 Results

The events were attended by a total of 50 people, some of whom could only attend during parts of the day. The majority of these attendees were carers. The ratio of carers to people with Eating Disorders was approximately 2:1. The majority of attendees came to the South Wales event (40) and 10 people attended the North Wales event.

Their views on the events are described in the figure below. It can be inferred that the attendee's were satisfied with the overall process.



**Figure 1 Responses from attendees**

The attendees expressed a wide variety of views. It was particularly striking that *good experiences* of care were mirrored with the same issues when they were described as *bad experiences* of care by many attendees. An example of this was that often, attendees stated that a single person made all the difference to the care pathway improving, and conversely, they also stated that a single person made the whole process far worse. The reasons for this are given below, but included knowledge, attitudes or behaviours. These two exact opposites of experience gave considerable face validity that the views expressed were not only common but found across all levels of service.

The areas of care discussed are as below and relate to all tiers of the Eating Disorders Framework:

- Knowledge and skills (of staff)
- Information for carers
- Treatments
- System facilitators / blockers

#### 1.4.1 Facilitators of good care

The following four tables describe the comments received when Service Users were asked 'what went well?'. The numbers in brackets relate to the number of times the issue was raised.

<b>Primary Care / Tier 1</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	Clinicians understood the situation (7)
Information for service users	
Treatments	Quick referral (7) Maintained follow up appointments (4) In surgery blood tests
Inherent system facilitators	Clinician Showed understanding and empathy (8) A Single person made the difference (11) The School nurse excellent (4) The GPs providing a sick note
<b>Outpatients / Tier 2</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	Aware of EDs Given diagnosis Listening skills
Information for service users	Information and phone advice (2) Sources of information – voluntary sector
Treatments	Holistic approach (3) Rapid referral process (6) Family based therapy (8) Good communication within the team (4) MDT (Multi Disciplinary Team) sessions organised into one day to ensure joined up approach Home based telephone support (3)

	Parents counselling (5) Multi family therapy Out of hours advice (2) Knowledge of how to re-enter service
Inherent system facilitators	Good Rapport with therapist / team (6) Staff showed Empathy (2) A Single person made the difference (6) Pressure from Ombudsman and AM
<b>Tier 3</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	Made the difference
Information for service users	Information given and shared (2) FEAST (voluntary association providing support for Eating Disorders Service users) 5
Treatments	Family therapy worked Transport to clinics Good communication with local team
Inherent system facilitator	Professional non judgemental staff (5) Local clinician made effort to maintain contact with team Single person made the difference (3)
<b>Tier 4</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	
Information for service users	Parents given hope and information (3) Support from other sufferers
Treatments	Parents part of the team (2) Family oriented therapy (2) Good links with education for school aged children Discharge planning Short term respite (2)
Inherent system Facilitators	Empathetic team (3)



### 1.4.2 Barriers to 'good care'

The following tables describe service users views of what did not go well. The numbers in brackets relate to the number of times the issue was raised.

<b>GP / Tier 1</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	Staff saying the wrong things actually made things worse (11) GP lack of knowledge (19) Clinical focus on physical and not psychological (3) Clinical Ignorance of tests and results (6)
Information for service users	No guidance for carer on next steps (4)
Treatments	Limited access to dietetics (3) Uncertainty when to refer (6) Delayed referral (10) Reluctant to approve sick leave Staff turnover and continuity of care (6) Out of hours – limited knowledge Difficult to get Complan No communication from Tier 2 (3)
Inherent system blocks	Perverse incentives to lose weight (4) Carer exclusion for adult patients Saying the wrong things actually made things worse (11)
<b>Outpatient / Tier 2</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	Lack of knowledge was counterproductive and dangerous (12) Care coordinator ignorant of EDs Care plan did not have clear goals
Information for service users	Bed rest & walking not explained (3) No information about diagnosis, instructions, advice or support on what to do and how to react (17) Patient did not interact with service (3)
Treatments	Travel distance Variability of staff and poor communication between staff (6) Focus on physical and not psychological (6) Reluctant to refer on (3) Long waiting times for referrals (6)

	<p>Poor dietetic support (3)</p> <p>No number to call for advice out of hours and difficult to contact in hours (2)</p> <p>Not enough counselling for carers and families (12)</p> <p>Awful environment (3)</p> <p>Difficult to get Complan</p>
Inherent system blocks	<p>Parental blame (6)</p> <p>Staff saying the wrong things actually made things worse (12)</p> <p>Carer / Parental exclusion for adult patients (7)</p> <p>General hospital completely indifferent and treated with disdain (5)</p> <p>Perverse incentive for critical weight to be achieved to trigger services (3)</p>
<b>Tier 3</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	<p>Staff saying the wrong things actually made things worse (10)</p> <p>Temporary staff / locums / trainee staff were ignorant and unhelpful (6)</p> <p>General staff unable to cope with child with severe mental health problems (10)</p>
Information for service users	<p>Better links with education for children in full time education</p> <p>Parents felt ostracised and blamed</p> <p>Impacts of restraint not explained</p> <p>Information on how to deal with crises (5)</p> <p>Information on bed rest (4)</p> <p>Lack of carer support (1)</p>
Treatments	<p>Distance (3)</p> <p>Non available dietitian (2)</p> <p>Limited psychologist input (4)</p> <p>Infrequent therapy sessions</p> <p>Welsh language provision in English hospital</p> <p>Discharge at BMI 15 is too early when limited community support</p> <p>Section used as a threat (3)</p> <p>Too much emphasis on weight (6)</p> <p>Ignorance on refeeding approaches (6)</p> <p>Environment not clean (2)</p> <p>Lack of communication with tier (2)</p>
Inherent system blocks	
<b>Tier 4</b>	
<b>Theme</b>	<b>What was said (number of times commented on)</b>
Knowledge and skills	<p>Unsuitable general ward admission – not enough skill with ED counterproductive (16)</p>

	Focus on physical not psychological (3) Lack of knowledge ref: sectioning, restraint etc – (2) Lack of knowledge ref: measurement of weight, BP etc – (4) Need more time for counselling for carers and patients (3)
Information for service users	Not enough information for parents and patients during stay (2) Not enough information for parents and patients for discharge (5)
Treatments	Lengthy waiting time Difficult to access services – distance (2) No specialist service in Wales Unclean room and filthy ward in general psychiatric unit Parent required to be there during meal times (2) Parents had to restrain child Staff turnover(3) Limited and when available Poor dietetic input (7) Discharge at too low BMI (2) Poor communication with Tier 2 services (2) Poor university support when students are at University No education support whilst in day care or inpatient unit
Inherent system blocks	Hospitalisation used as a threat (2) Unsympathetic staff (3) Parental exclusion from decision making and post discharge care package (4)

### 1.4.3 Summary of Findings

#### **Knowledge and education of staff and service users**

This area of care was the issue that raised most comment; unsurprisingly the level of knowledge of the staff could make the difference between an excellent and a poor experience of the service. This could be in terms of the therapeutic approach, the taking of measurements and the clinical management. This information provided to and the knowledge level of the service user and their families were also highlighted as important issues. Training and development across the system should prioritise learning to:

- Support timely diagnosis – particularly in primary care
- Enable appropriate referral to specialist services – at all tiers but particularly in primary care.
- Improved consistency and continuity of clinical management in all tiers
- Recognise the importance of appropriate discharge arrangements
- Recognise the importance of parents and carers in supporting recovery and the role that timely and appropriate information relating to the diagnosis, treatment options and how best to manage crises at home, plays in recovery and preventing relapse

## Attitudes of staff

The views and experience of people expressed at these engagement events suggest that sometimes staff comments and attitudes to service users appear to not only be unhelpful but also counterproductive to the treatment and recovery of patients. Some of these comments will no doubt be addressed with better education but some reported instances described by service users would not meet the high standards of care that should be expected. There were consistent repeated examples of clinical staff in generalist settings who did not understand the clinical needs of the service users. More importantly, their attitudes appear to exacerbate disordered thinking by service users, sometimes by well meaning but often counterproductive comments. This appears to be associated with generalist (CAMHS and non-CAMHS) staff as opposed to specialist eating disorders staff. It was reported that less than positive experiences of care can lead to failure to seek help in future leading to further exacerbation of the condition.

## Holistic Approach

The need for a holistic approach to care was repeated many times as “it’s not just the weight change that matters”. Eating Disorders impact on all aspects of the individual and family life affecting education, employment, housing, recovery and most importantly family matters. Service users felt strongly that this should be at the forefront of the service model as it ensures a wider perspective than purely a weight loss or gain focus.

## Patients and Families Empowerment

This is a very important dimension which was described by a parent as “the elephant in the room”. This was namely that parents/ carers were seen in a number of ways:

- Part of the problem
- Part of the solution
- To be involved in the care plan
- To be excluded from care planning
- Not to be given information about their child once they are 18 years old because of patient confidentiality

This was thrown into further contrast by one particular service user and mother who had had a very favourable experience of care, primarily because both mother and daughter had good lines of communication which mitigated the challenges of the system. Moreover, a number of respondents found family group therapy, as well as meeting other parents, extremely beneficial. This appeared to be because they could learn from one another as well as having shared experiences that they could relate to

and draw support from. The difficulties associated with the position of the carer or family are particularly amplified during the period of transition from child to adult services.

### **Information and support**

All service users at the engagement events said, when asked, that when the diagnosis was made they were not given any information about the condition and what to do during difficult times. Through the discussion, the information sources identified by service users for how to manage in a crisis, included BEAT and other voluntary organisations, particular books, a paucity of "YouTube" videos and also advice from the Maudsley Hospital. This lack of information made discharge arrangements more difficult. Based on the above observations, it was commented that it is not hard to see why there are repeat admissions because post discharge support is difficult to obtain and the families/ carers are not prepared in terms of how best to support their family member in a crisis.

### **Post discharge planning and advice**

Parents/ families often mentioned that they were excluded from post discharge planning. It was said that when children, frail elderly and even people with dementia are discharged, the discharge care plan necessitates carer involvement and is seen to be an essential aspect of recuperation. Without this, "repeat admissions and the revolving door" would be more likely to take place. Eating Disorders, in sharp contrast, would from the experiences shared, seem to have distinct groups of families and carers that appear to be excluded from this process. This marked perception of parents/ carers is that this makes clinical and supportive care more difficult. The provision of information packs could in some way address this issue.

### **Other comments**

A notable number (8) of service users expressed gratitude for being asked about the service provision and felt the group discussions had been helpful in providing the opportunity to meet other service users, to share experience, to gain support and to learn from each other.

## Ideas from Service Users

In the parallel discussions, a number of constructive ideas were offered and the following received positive responses:

- Financial incentives for GPs to learn about Eating Disorders
- Information pack for service users
- Information pack for parents
- Post re-feeding counseling for parents and service users
- Crib sheets or “top 10 tips” for different groups of staff and parents/carers
- Web resources such as “YouTube” documentaries or helpful hints to enable service users cope with difficult situations

## 1.5 Conclusion

The two phases of the engagement approach were able to capture both the professional and the service user views. The approaches used were adapted to suit the audience. The main conclusion is that *implementation* of the Framework was the main concern of both audiences and not the Framework itself – with one exception. Service users were able to describe many examples of good experiences and practice that were mirrored when the service users more frequently described bad experiences. Knowledge, attitudes, supportive care and information were frequently raised by service users as areas to be improved. The professional respondents frequently cited the paucity of dietetic provision at all tiers and it was noted that this was the one major area that the previous model of care had not clearly described.

## Analysis of Available Outcomes data

## Appendix C

### 1 Introduction

This Appendix is part of the Review of the Eating Disorders (ED) Framework that was undertaken by Public Health Wales (PHW) in 2015. The original Eating Disorders Framework was written in 2005.

This Appendix specifically describes the analysis of the available outcomes data relating to Eating Disorders and the key findings. The analysis and presentation of data in this report has been undertaken with the kind permission of the Clinical Leads for these services. Information governance was addressed by released data being anonymised prior to being sent to Public Health Wales. No patient identifiable data was released. The purposes for release were purely on the basis of clinical audit and all clinicians have been closely involved with the inferences drawn from the data throughout the analysis. Clinicians have been given absolute control over the release of the data and the outcome measures shown below have been agreed by the clinicians involved.

#### 1.1 Background

After the 2005 Eating Disorders Framework was implemented, Welsh Tier 3 services collected service delivery data as recommended by the 1000 Lives programme for Eating Disorders. A decision was taken by the All-Wales Eating Disorders Special Interest Group (AWEDSIG) to monitor the clinical outcomes of patients receiving care from various Eating Disorders Service Providers in Wales. This commenced in 2011 and primarily records process and outcome measures relating to Tier 3 services for adults. Data is also collated in some Tier 2 and 4 adult services, and work is being undertaken to increase the spread of data collection at Tier 3 and Tier 2. In addition, efforts are being made to incorporate Tier 4 data from out-of-area services into the Welsh combined dataset.

The All-Wales Eating Disorders Special Interest Group (AWEDSIG) determined that the outcomes data collected relating to Eating Disorders should be a combination of psychological outcomes and Eating Disorder specific outcomes. These are recorded on the clinical outcomes dataset using the following measures:

**Body Mass Index (BMI)** – a measure which combines weight and height and is contained in the EDE-Q. The EDE-Q is a questionnaire used to

assess Eating Disorder Patients<sup>25</sup>. Tier 3 Services regularly collate BMI data for all users of their service but only those contained in the EDE-Q are analysed here.

**Core 34** – is a general psychological measure of distress based on 34 questions. Core 34 is a part of a family of well used and peer group validated measures of psychological distress. This score is an aggregate score based on “sub domain” measures of well being, functioning, problems and risk. The 4 sub domains are assessed and scored by specific questions - examples of which are given in the table below:

Domain	Example of Question
Well being	I have felt overwhelmed by my problems
Functioning	I have been able to do most things I needed to
Problems	I have felt despairing or hopeless
Risk	I have thought it would be better if I were dead

**Table 1:** The subdomains of the Core 34 measure

The answers to these questions are scored as numbers and are mathematically described as Wmean, Fmean Pmean and Rmean scores respectively. From a patient’s perspective, the Core 34 score is equivalent to a numerical “thermometer” reading of psychological distress in patients<sup>26,27</sup>.

**CIA (Clinical Impairment Assessment)** - is a 16 question instrument that specifically measures psychosocial impairment associated with Eating Disorders. CIA measures the severity of impairment using a numerical scale. From a patient’s perspective, this score is the equivalent to an Eating Disorders “blood test” that allows the clinicians use to understand the impact of the person’s eating disorder on their daily life<sup>28</sup>.

<sup>25</sup> Appendix in Fairburn CG. Cognitive Behavior Therapy and Eating Disorders. 2008, New York, Guildford Press.

<https://www.rcpsych.ac.uk/pdf/EDE-Q.pdf>

<sup>26</sup> Michael Barkham, Naomi Gilbert, Janice Connell, Chris Marshall, Elspeth Twigg. “Suitability and utility of the CORE-OM and CORE-A for assessing severity of presenting problems in psychological therapy services based in primary and secondary care settings”. The British Journal of Psychiatry Feb 2005, 186 (3) 239-246;

<sup>27</sup> Core CST Website : Information about the CORE-OM

<https://www.coresystemtrust.org.uk/instruments/core-om-information/>

<sup>28</sup> Kristin Bohn, Helen A. Doll, Zafra Cooper, Marianne O'Connor, Robert L. Palmer, and Christopher G. Fairburn. “The measurement of impairment due to eating disorder psychopathology”, Behav Res Ther. 2008 Oct; 46(10): 1105–1110.



The psychological scores described above are used in adult patients with Eating Disorders. The measurement of psychological well being in children is assessed using the Children's Global Assessment Score.

**CGAS (Children's Global Assessment Score<sup>29</sup>)** – is another measure of outcomes relates to levels of functioning. The higher the score, the better the levels of functioning and the CGAS scores are banded into groups of 10. These are described in the Table 2:

**Table 2:** The Children's Global Assessment Score- (CGAS) Scale and Scoring

<b>CGAS Functioning Scale and Score</b>	
<b>100–91</b>	Superior functioning in all areas (at home, at school, and with peers); involved in a wide range of activities and has many interests (e.g., has hobbies or participates in extracurricular activities or belongs to an organized group such as Scouts, etc.); likeable, confident; 'everyday' worries never get out of hand; doing well in school; no symptoms.
<b>90–81</b>	Good functioning in all areas; secure in family, school, and with peers; there may be transient difficulties and 'everyday' worries that occasionally get out of hand (e.g., mild anxiety associated with an important exam, occasional 'blowups' with siblings, parents or peers).
<b>80–71</b>	No more than slight impairments in functioning at home, at school, or with peers; some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g., parental separations, deaths, birth of a sibling), but these are brief and interference with functioning is transient; such children are only minimally disturbing to others and are not considered deviant by those who know them.
<b>70–61</b>	Some difficulty in a single area but generally functioning well (e.g., sporadic or isolated antisocial acts, such as occasionally playing hooky or petty theft; consistent minor difficulties with school work; mood changes of brief duration; fears and anxieties which do not lead to gross avoidance behaviour; self-doubts); has some meaningful interpersonal relationships; most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern.
<b>60–51</b>	Variable functioning with sporadic difficulties or symptoms in several but not all social areas; disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.
<b>50–41</b>	Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, poor to inappropriate social skills, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.
<b>40–31</b>	Major impairment of functioning in several areas and unable to function in one of these areas i.e., disturbed at home, at school, with peers, or in society at large, e.g., persistent aggression without clear instigation; markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal

<sup>29</sup> Royal College of Psychiatry Website : CGAS Rating Guide  
<https://www.rcpsych.ac.uk/pdf/CGAS%20Ratings%20Guide.pdf>

intent; such children are likely to require special schooling and/or hospitalisation or withdrawal from school (but this is not a sufficient criterion for inclusion in this category).

**30–21** Unable to function in almost all areas e.g., stays at home, in ward, or in bed all day without taking part in social activities or severe impairment in reality testing or serious impairment in communication (e.g., sometimes incoherent or inappropriate).

**20–11** Needs considerable supervision to prevent hurting others or self (e.g., frequently violent, repeated suicide attempts) or to maintain personal hygiene or gross impairment in all forms of communication, e.g., severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.

**10–1** Needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect or personal hygiene.

## 1.2 Adults Services – Tiers 2, 3 and 4

The audit data collected contains a variety of measures for 412 patients. All LHB patients described are receiving Tier 3 services level but some data sets (e.g. ABUHB) also include Tier 2 and Tier 4 patients. This accounts for the larger numbers of patients on the data set as seen in. Of the 412 patients, a proportion had before and after outcome measurements that could be examined. The majority of patients only had one outcome measure recorded and therefore were excluded from the analyses below. It should be noted from a statistical perspective, small numbers of observations can make statistical comparisons difficult. Statistical analyses were initially undertaken using t statistics for comparison. However further analysis undertaken by colleagues from Public Health Observatory used non parametric ranking scores as the underlying data was skewed and non-normal. Details can be obtained from the author on request.

### 1.2.1 Place of Residence

Table 3 displays the LHB of residence of the service users recorded on the dataset.

**Table 3 LHB of Residence of Eating Disorders Patients recorded on the Audit Database.**

LHB	Number of Patients
ABMU	35
ABUHB	218
BCU	35
CVUHB	73
CTHB	32
HDHB	15
UNKNOWN	4
<b>Grand Total</b>	<b>412</b>

### 1.2.2 BMI

Patients BMIs show an overall increase following treatment on average of 1.06 at an all Wales level ( $p < 0.001$ ).

However it is important to note that the overall increase in BMI is not necessarily clinically meaningful. This is because BMI changes in severely ill anorexic patients are more significant than BMI changes in a normally thin person. Clinicians therefore look at the patients from a number of different perspectives and do not just use absolute BMI changes as a single measure of improvement.

One way of examining this is to focus on patients that have different initial BMIs on entering treatment. When patients lose weight and enter a treatment programme, they are weighed and this is described as the 'initial weight loss'. Clinicians will agree that severe initial weight loss (BMI of less than 15) is generally more clinically important than a person with a BMI of 17 and above. Table 4 compares changes in the BMI of patients with differing levels of initial weight loss. This shows that the patients with the most severe levels of initial weight loss (BMI of less than 15), have the greatest improvement (average increase) in weight whilst being managed by the service when compared to other groups. The number of patients in these groups is too small to undertake a robust statistical examination of the data. However, it is reassuring to see these results as it would be a greater concern if the greatest increase in weight was NOT in the most at risk group.

**Table 4 Average Change in BMI stratified by initial BMI weight band**

Initial BMI	Average change in BMI	Number of patients
<15	2.7	6
15-16	1.1	11
>17	0.5	24

The author is not able to undertake a LHB specific comparison of data because the numbers of patients from each LHB are too small for a meaningful statistical examination.

### 1.2.3 Core 34 and CIA scores

Core 34 and CIA scores also change when Eating Disorder patients are receiving care. These are described in Table 5 . It should be noted that all of these changes in scores are highly statistically significant at an all Wales level and show improvements in the psychological levels of distress amongst the Eating Disorders patients during and after treatment ( $P < 0.001$ ).

**Table 5 Changes in Psychological Scores of Eating Disorder Patients Receiving Care**

Values	Change in All Wales Score
Wellbeing score	1.18
Function score	0.92
Problems score	1.15
Core 34 score	1.06
CIA score	-0.09

Further examination of these scores by initial BMI shows improvements in all BMI groups but particularly in the patients with BMIs of less than 15.

**Table 6 Change in Scores for Key Measures by Initial BMI**

Initial BMI	Core 34	Wellbeing Score	Function Score	Problem Score	CIA
<15	0.70	0.87	0.67	0.68	-0.57
15-16	0.57	0.68	0.46	0.65	-0.29
>17	0.68	0.76	0.60	0.75	-0.09

Similar patterns were seen in improvements in the sub domains of the Core 34 which examined well being, functioning and problems (Table 6). None of these tables are suitable for statistical examination because of small numbers of patients.

The CIA score is a more specific score of psychosocial distress amongst Eating Disorder patients. This too showed improvements (indicated by a negative number) – particularly so amongst patients with the lowest BMIs (Table 4).

### 1.3 Children's in Patient Services (Tier 4)

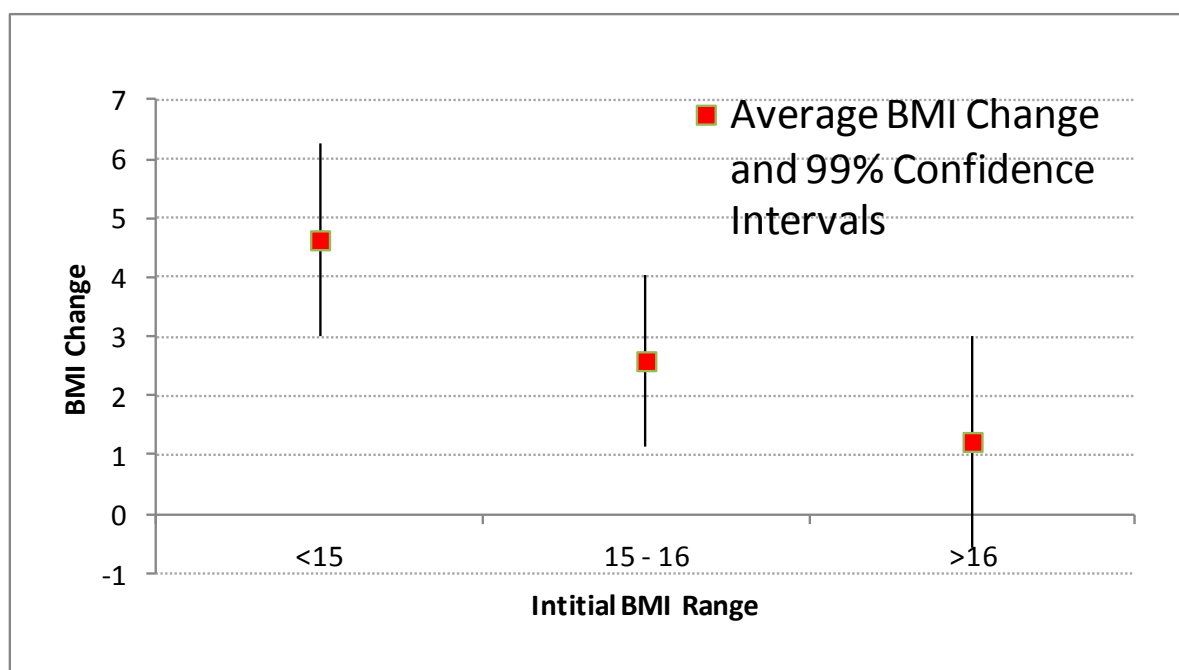
The following data is outcomes data for North Wales Tier 4 services and has been used with kind permission of Dr Robin Glaze.

The data in North Wales relates to children's Tier 4 services. This shows that for bulimia and anorexia patients, there is an improvement in weights and BMIs (Table 7). It should be noted that this is highly statistically significant for anorexic patients but not for bulimia patients. This is partly because of a small sample size for bulimia patients (4) and also because bulimia outcomes are not best described by using weight change alone.

**Table 7 Changes in weight and BMI in Tier 4 Children Service Users (N Wales)**

	Average Weight Gain	Average BMI Increase	Sample Size	Statistical Significance
Anorexia	8.21	3.17	47	Very Significant (99% CI)
Bulimia	2.50	0.95	4	Not Significant

This improvement in BMI is best examined with a stratified approach to differing levels of initial BMI. The following figure (Figure 1) shows that the improvements in BMI are most marked in the patients with the highest clinical risk– i.e. those with a lowest initial BMIs. These results are highly statistically significant (99% Confidence Intervals) for those with the lowest initial BMIs.

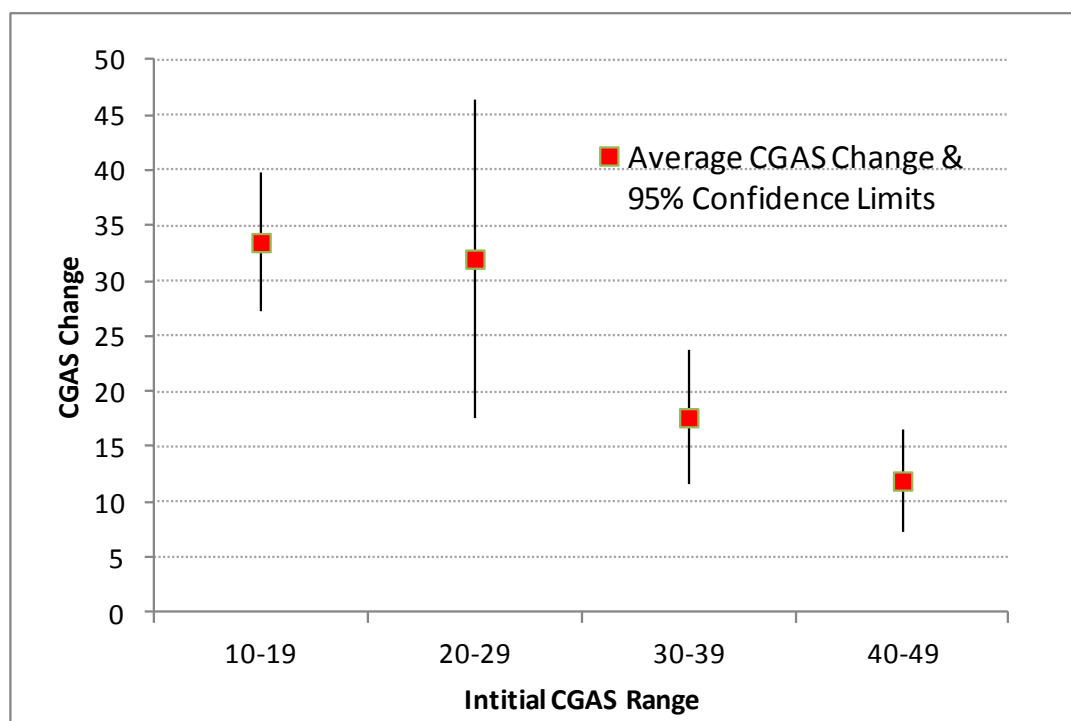


### Figure 1 Changes in BMI in Tier 4 Children Service Users (N Wales) by differing initial BMI

Source: Clinical Audit Data Personal Communication

North Wales Eating Disorders Team use the Children's Global Assessment Score to measure functioning. The higher the score, the better the levels of functioning and the CGAS scores are banded into groups of 10. These are described in the table above.

When the increases in CGAS are analyzed, it can be seen that the average increase in CGAS score is at least greater than 10 – i.e. one category or more on the scale described in the table above. The average increases in CGAS scores are greatest from those who had the lowest initial CGAS score (Figure 2). This result is statistically significant (95% Confidence Intervals) and resonates with the improvements in BMI – i.e. those that have the greatest need with the most severe manifestations of Eating Disorders have the greatest improvement in BMI and CGAS scores.



**Figure 2 Changes in CGAS in Tier 4 Children Service Users (N Wales) by differing initial CGAS**

## 1.4 Summary of Outcomes Data

It should be noted that the author was not able to obtain outcomes data for all providers of Eating Disorder services across Wales. However of those areas that were collecting data and where it was available, there is

statistically significant evidence to show that the clinical outcomes of these services confirm that there are improvements in BMI and psychological scores at a tier 2, 3 and 4 levels. More importantly, there are consistent improvements in outcomes which show that the best outcomes are found amongst those individuals that are most affected by the Eating Disorders.

There may be additional sources of information that the author has not been able to obtain.