

Scottish Eating Disorder Services Review

Full Report

May 2021

Scottish Eating Disorder Services Review

Full Report

Table of Contents

| | |
|--|-----------|
| Scottish Eating Disorder Services Review | 1 |
| Full Report | 1 |
| Context of the review | 3 |
| Background | 3 |
| Policy Context | 5 |
| Clinical Aspects | 6 |
| Terms of reference for the review | 8 |
| How the Review was conducted | 11 |
| 1. Public engagement | 11 |
| 2. Engaging with clinicians | 13 |
| 3. Consultation with NHS Boards and relevant organisations | 14 |
| 4. Third Sector organisations | 16 |
| 5. Build on the Mental Welfare Commission for Scotland’s Scoping of Services 16 | |
| 6. Consider a range of guidance | 17 |
| Recommendations | 18 |
| Recommendation 1: Covid-19 response | 18 |
| Recommendation 2: Implementation planning | 18 |
| Recommendation 3: Coordination of national activity and data collection ... | 20 |
| Recommendation 4: Lived Experienced Panel | 21 |
| Recommendation 5: Public health | 21 |
| Recommendation 6: Self-help resources available to all..... | 22 |
| Recommendation 7: Early Intervention | 23 |
| Recommendation 8: Primary care | 23 |
| Recommendation 9: Safe medical care | 24 |
| Recommendation 10: Investment in specialist eating disorder services..... | 25 |
| Recommendation 11: Workforce | 28 |
| Recommendation 12: Education and Training..... | 28 |
| Recommendation 13: Families and carers | 31 |
| Recommendation 14: Inpatient eating disorder services | 31 |

Recommendation 15: Eating disorders Research in Scotland..... 31

References..... Error! Bookmark not defined.

“If we can get support in place before inpatient I do think that would make a really big difference.” (Workshop, person with lived experience)

“Working in Eating Disorders is stressful and there is high turnover and burnout!” (Workshop, healthcare professional)

“I’ve been in and out of different units because in Scotland if you have comorbidities you go in and out of different units.” (Workshop, person with lived experience)

“I’m very aware that it wasn’t put in the NICE guidelines about diagnosing Binge Eating Disorder or anything until very recently even though it’s the commonest diagnosis.” (Workshop, person with lived experience)

“People are quite scared to go to their GPs because they don’t fit the stereotype.” (Workshop, person with lived experience)

Context of the review

Background

In 2006, NHS Quality Improvement Scotland published a report, 'Eating disorder services in Scotland: recommendations for management and treatment' (1). The recommendations in this report were developed by a group led by Drs Chris Freeman and Harry Millar and incorporated NICE Guideline 9 (2004) on Eating Disorders where applicable to the Scottish context, as well as published evidence and current best practice within NHS Scotland.

Since then, a number of substantial developments have taken place in eating disorder services. This includes the first NHS adult specialist eating disorder inpatient unit opening in Aberdeen in 2009 to serve the population of the north of Scotland together with a Managed Clinical Network serving the same population. A further regional unit for adults opened in 2012 in south east Scotland to serve the populations of NHS Lothian, Borders, Fife and Forth Valley. There have been developments in specialist community eating disorder teams across the country in adult services, often with very different models of care and different referral criteria. Some areas have provided intensive home treatment to reduce the need for inpatient treatment, and some areas have 'all-age' eating disorder services. Within services for children and young people under 18, those with eating disorders tend to be seen within generic child and adolescent mental health services (CAMHS) rather than specialist children and young people's eating disorder services which have been commissioned across all areas in NHS England (2).

Even with the developments noted, there is a lack of adequate service provision to ensure that anyone in Scotland can access timely, safe, person centred, effective, efficient and equitable care for an eating disorder when they need it which is the ambition of the Scottish Government's mental health strategy 2017 – 2027.

The National Institute for Health and Care Excellence (NICE) updated its guidance in 2017, 'Eating Disorders: recognition and treatment'(3). Clinicians in Scotland raised some concerns about the applicability of the guideline to the specific context of eating disorder services across Scotland, and it was agreed that a SIGN guideline (Scottish Intercollegiate Guideline Network) would be appropriate. It had originally been hoped that the guideline, chaired by Dr Jane Morris, would be published around April 2021, but this has been delayed due to the Covid-19 pandemic. It is hoped that the guideline will be published later in 2021. Two of the leads of this review (SA & CO) are also on the SIGN Guideline Group.

In light of concerns raised by people with lived experience of having an eating disorder, or caring for someone with an eating disorder, as well as reports from clinicians and other work, the Mental Welfare Commission for Scotland undertook a national themed visit of eating disorder services in 2018 and 2019 (4,5). The Commission made a number of recommendations for integration authorities, as well as recommendations for Scottish Government and Healthcare Improvement Scotland. This report, titled 'Hope for the Future,' together with a mapping of services

across Scotland were published in September 2020. The Commission's recommendations were as follows:

Recommendations for integration authorities

An integration authority can be a local authority, a health board or an integration joint board, according to the model of integration adopted locally.

We recommend that integration authorities:

- have clear and detailed operational guidance and policies relating to services that look after people with eating disorders and ensure care transitions are coordinated;
- have a comprehensive range of services available across all ages and gaps in provision are identified and addressed; have clearly defined access to inpatient mental health beds for people with eating disorders, across the age range;
- ensure support is maintained following discharge from hospital and specialist community services including support for families/carers;
- develop protocols about physical health monitoring, including the assessments and investigations that should be undertaken by primary and secondary care providers and clear guidance on how different services are expected to work together;
- put in place protocols outlining how the provision of medical care for 16-17 year olds, who require medical inpatient treatment, will be supported by mental health and eating disorder services;
- ensure that there is access to the appropriate level of training in ED for their staff;
- have in place a range of supports, in relation to all aspects of health, for people with an eating disorder;
- family/carers should be involved, where appropriate, in the planning of treatment, and have access to a range of information and support that can provide help when caring for a person with an eating disorder, or when in a crisis situation.

Recommendations for Scottish Government

While undertaking this themed visit, we were told that eating disorder services will be subject to a national review by the Scottish Government, designed to assess and improve support for people with eating disorders.

We recommend that Scottish Government:

- use this report to help inform the work of their national review;
- look to establish a managed network in relation to eating disorders; this would help to address issues of inequality in access to services, public education, staff education and the sharing of best practice.

Recommendations for Healthcare Improvement Scotland (HIS)

We recommend that HIS prioritise a review of the Scottish Intercollegiate Guidelines Network (SIGN), which requires review, revision and update of the efficacy of treatments and therapies to support people with eating disorders in Scotland.

In March 2020, Clare Haughey, Minister for Mental Health announced that a national review of eating disorder services would be undertaken <https://www.gov.scot/news/review-of-eating-disorder-services/> The review was launched on 16th October 2020 with the aim of reporting to Scottish Government by the end of March 2021.

Policy Context

The Scottish Government is committed to delivering high quality eating disorder services. It wants to ensure that people with an eating disorder receive the treatment and support they need, when they need it, regardless of who they are, where they live, or what type of eating disorder they have. Scottish Government is committed to ensuring that people with lived experience of an eating disorder, or of caring for someone with an eating disorder are actively involved in reviewing and developing support and treatment services.

In announcing the review in March 2020, Scottish Government stated that ‘it forms part of the programme of work to improve performance in mental health waiting times and support early intervention in community settings and across the third sector, local government and the NHS.’

The Scottish Government Mental Health Strategy 2017-2027 (6) has the ambition to ‘prevent and treat mental health problems with the same commitment, passion and drive as we do with physical health problems.’ The strategy states that this means working to improve:

- Prevention and early intervention;
- Access to treatment, and joined up accessible services;
- The physical wellbeing of people with mental health problems;
- Rights, information use and planning.

In her introduction to the Strategy, the then Minister for Mental Health stated that “We want to see a nation where mental healthcare is person-centred and recognises the life-changing benefits of fast, effective treatment. We want a Scotland where we act on the knowledge that failing to recognise, prioritise and treat mental health problems costs not only our economy, but harms individuals and communities. In short, we share the ambition that you should only have to ask once to get help fast.” The strategy has a large focus on services for children and young people and the only specific mention of eating disorders is in relation to the development of a digital tool to support young people with eating disorders. Although eating disorders typically emerge in mid to late adolescence(7), we know that half of presentations to services occur in the adult (>18 years) setting and that eating disorders can emerge at any age.

The Strategy emphasises the need to build on lower, less intensive levels of care (Tiers 1 and 2) to prevent people becoming so unwell that they require more highly specialist and intensive treatment. This is highly relevant to eating disorder treatment where we know that early intervention improves outcome and reduces the risk of illnesses becoming more entrenched (8,9).

Clinical Aspects

Eating disorders include anorexia nervosa (AN), bulimia nervosa (BN), avoidant restrictive food intake disorder (ARFID) and binge eating disorders (BED), and variants which are classified under other specified feeding or eating disorders, and Feeding or Eating Disorders, Unspecified (ICD-11 classification) (10). They are mental disorders with serious medical consequences as well as risks of suicide. Eating disorders have the highest mortality of all mental disorders.

There have been recent advances in treatments as well as changes and expansions of diagnostic categories for eating disorders. There is a trend towards inclusive services for treatment of all people with eating disorders, regardless of age and severity, with the development of all age services and early intervention approaches.

Eating disorders typically develop in early to mid-adolescence but can emerge at any age (7). There can be long periods of time before people seek or receive help and half of all first presentations are to adult (18 years and over) services. The prevalence of anorexia nervosa in the general population is approximately 1% among women and 0.5% among men. There has been a significant increase in the annual incidence in 10 to 14 year olds in the last 7 years. It is reported that half of those who meet diagnostic criteria in the community do not access treatment. Bulimia nervosa is reported to have prevalence of about 2%, and binge eating disorders up to 4%. The population prevalence of ARFID is not known, largely because it is a relatively new diagnosis and still not well known. The overall lifetime prevalence of eating disorders is estimated to be 8.6% for females and 4.07% for males. Changes in diagnostic categories and criteria affect estimates of prevalence rates but prevalence has been increasing over time. The overall one-year prevalence is estimated to be 1.66% (2.62% for females and 0.67% for males) (11–14).

Data from the 2019 NHS-England health survey reported that 16% of people over the age of 16 screened positive for a possible eating disorder (15). This is up by 277% over the preceding 12 years. This included 4% of people who reported that their feelings about food interfered with their ability to work, meet personal responsibilities or enjoy a social life. Eating disorders have significant impacts on functioning. These figures are likely to be an underestimate due to stigma and the fact that eating disorders can be seen by the person as part of themselves and not

an illness so go unrecognised even by people themselves who have them. We do not have equivalent data from Scotland but there is no reason to be believed that the data would be any different. (Note that Improved data collection/population audit is urgently needed and included in the recommendations, see Recommendation 3).

The costs of eating disorders both to society and to the NHS are very high. In the Global Burden of Disease Study, of 306 physical and mental disorders, anorexia nervosa and bulimia nervosa combined ranked as the 12th leading cause of disability-adjusted life years (DALYs) in females aged 15–19 years in high-income countries, responsible for 2.2% of all DALYs (16). In Wales, individuals with eating disorders within a population database case cohort had total hospital admission costs of £17,254,751 per 1000 individuals over 20 years (17,18). Yearly hospitalisation costs of adult specialist inpatient eating disorder treatment are £2 million in Wales. The cost of GP contacts in Wales over 27 years was £37,689,894 per 1000 individuals for the eating disorder cohort compared to £17,069,401 per 1000 individuals for patients in a control group (19). NHS costs of eating disorders in Scotland have not been calculated.

In Scotland, the number of patients admitted with an eating disorder has increased from 434 in 2013 to 556 in 2018, an increase of 28% in the 5-year period. We do not yet have full data for changes in admission rates during the pandemic, however, inpatient colleagues report an increased number of referrals, and a significant increase in the complexity and severity of illness in people being referred for in-patient treatment. The two regional adolescent psychiatric units able to provide data report a combined 161% increase in eating disorder admissions between 2019 and 2020 (26 in 2019, 68 in 2020).

Hospital admissions for eating disorders in England have increased from 4,849 in 2007/2008 to 19,116 in 2018/19, an almost four-fold increase in demand, with no increased investment in specialist eating disorder in-patient units (20). The number of children and young people admitted with anorexia nervosa has doubled in the same period in England, but this was not reflected, at least prior to the pandemic in Scotland due to good access to appropriate Family Based Therapy (anecdotal evidence). [Awaiting data from ISD]

Eating disorders have the highest death rate among all mental disorders affecting young people and adults of working age (21). The rate of suicide is 23 times higher than in the general population. There is no system in place in the UK to correctly report these deaths, which can be due to both medical and psychiatric consequences of eating disorders. In Wales 6% of patients of all ages diagnosed by their GPs as having eating disorders had died within 16 years of diagnosis, a rate that was significantly higher than matched controls particularly for anorexia nervosa and also bulimia nervosa.

In 2017, the Parliamentary and Health Service Ombudsman (PHSO) report “Ignoring the alarms: How NHS Eating disorder services are failing patients” (22) made a number of recommendations following their review of the care and treatment of Averil Hart who died in 2012. The recommendations included reviewing medical education, improving the workforce, ensuring the parity of funding of services across the age range, and strengthening coordination of care for people with eating disorders. The Cambridgeshire assistant coroner has recently overseen 5 inquests into the deaths of people with anorexia nervosa, including Averil Hart (23,24). He highlighted a number of failings, and noted that in each case, there was an absence of formally commissioned provision for monitoring patients with anorexia nervosa. The issues highlighted in these reports are equally applicable to Scotland and must be taken into account to improve the safe management of people with eating disorders and prevent further avoidable deaths.

The coroner noted, “GP practices are trying to wrestle with one of the most challenging combinations of physical and mental ill health and are doing so, in my view, often with one hand tied behind their backs. It is that lack of a formal commissioned monitoring service for this cohort of mental health sufferers that causes and contributes to the miscommunication between primary and secondary care.”

Terms of reference for the review

The terms of reference were published on 16th October 2020 and can be found below, or at <https://www.gov.scot/publications/national-review-of-eating-disorder-services-terms-of-reference/>

Purpose of the Review

The purpose for this review is to provide a full picture of the current system of support that is available for those with an eating disorder, and their families and carers, in Scotland. This includes eating disorder support from primary care through to inpatient services, and the third sector and local support services.

The review will then provide Scottish Ministers and the Scottish Government with detailed recommendations on how services and the wider support system should be constructed to ensure that the right treatment and support can be provided to those with an eating disorder, and their families.

The review will ultimately be a first step in a phased programme of work to improve the outcomes for people living with an eating disorder in Scotland. A second phase of improvement work will be guided by the review’s findings and recommendations.

Scope of the Review

The scope of the review should include, but is not limited to, the following areas:

- The review should cover all eating disorder services for children, adolescents and adults, and consider the transition points between these services. This should also include inpatient provision and any private provision in Scotland.
- The review will build on the findings of the MWC report which includes a scoping of services that are provided by the third sector, generic community support and specialist services to ensure that we understand what needs are being met.
- The review should cross-reference its findings with the findings of the MWC report, so that we have a full picture of the current system of support that is available for those with an eating disorder and their families and carers.
- Make recommendations for how specialist eating disorder services can best be provided in urban, semi-urban and rural areas. This should include how early intervention can be achieved through early referral systems in primary care, schools, third sector, etc.
- Make recommendations on the implementation of a public health approach to the prevention of eating disorders with Public Health Scotland.
- Make recommendations as to how data for eating disorders can be collated consistently across services in Scotland. This should include recommendations for a minimum data set to assess eating disorder referrals and diagnosis, referral to treatment time and outcome data.
- Make recommendations of numbers and disciplinary mix of staffing that should be provided per 100,000 population.
- Make recommendations for what age range, if any, an eating disorder service should cover. This should take into consideration the views of individuals who have had an eating disorder and their families, and be outcomes-focused.
- Make recommendations about training and education.

The following overarching questions should be addressed:

1. What have we learnt from the Covid-19 pandemic that can inform our recommendations?
2. Are services accessible and serving the needs of people with eating disorders irrespective of stage, duration or severity of illness?
3. What support is provided in primary care and what role should primary care have in the detection and treatment of eating disorders across the range of severities?
4. What barriers are there to individuals and families accessing help and support for an eating disorder or suspected eating disorder across Scotland?
5. Does gender, sexual orientation, culture, ethnicity, religion, age or any other protected characteristic play a factor in barriers to treatment and support, and if so how can this be addressed to achieve equity of access?
6. How can early intervention be achieved through early referral systems in areas such as primary care, schools and the third sector?

7. Would the establishment of an Eating Disorders Managed Clinical Network help to address issues of inequality, public education, staff education and support the sharing of best practice? Or is there another format that would deliver this more efficiently?
8. Are services meeting the needs of people with comorbidities such as ASD, trauma, personality disorders and anxiety and depression, etc. ,and how can this be improved?
9. Are services meeting the physical health needs, comorbidities and sequelae of patients (such as obesity, diabetes, gastrointestinal, bone and endocrinological problems) across the age ranges, and how can they better ensure medically safe treatment?
10. How can we build workforce capacity by increasing the number of trainees and training opportunities for eating disorders across all disciplines?
11. How can we promote education, service development, innovation and research in eating disorders across Scotland?
12. How can we ensure that all frontline medical personnel can identify and safely manage patients with eating disorders who may present in non-specialist settings, for example in GP surgeries, school nurses, A&E, and acute medical or paediatric wards?

Engagement

Ensuring that key stakeholders, clinicians and those with lived experience are fully engaged with the review is crucial to the review providing recommendations that are realistic for all those working to improve the lives of those with eating disorders.

The review should engage with key stakeholders and networks across Scotland such as, but not limited to: the CAMHS Eating Disorder Steering Group, the Scottish Eating Disorder Interest Group, the Royal College of Psychiatrists, the Royal College of General Practitioners, the Royal College of Paediatrics and Child Health, the Royal College of Emergency Medicine, third sector organisations, diabetes and neurodevelopmental clinicians/networks , paediatrics and those with lived experience and their families.

The review will take into consideration the development of the Scottish Intercollegiate Guidelines Network (SIGN) guidelines on eating disorders that are currently being developed. These guidelines will cover referral, management of medical and mental health risks, choice of treatments and management of transitions.

Due to the time-limited nature of this review, it is unlikely that full engagement with every area in Scotland will be possible. Instead, the review may wish to consider engaging with a sample of urban, semi-urban, and rural areas.

Outputs

The Leads should provide a report which seeks to address the issues listed above. Recommendations should be evidence-based and proportionate, with consideration given to their implementation, for example recommendations could

span short, medium and long term actions for improving eating disorder support in Scotland. We expect that all recommendations are agreed with clinicians and those with lived experience to ensure that they are practical and meet their expectations.

Timescales

The Leads will present an outline report containing initial findings, issues and priorities to the Scottish Government by early 2021. The final iteration of the review should be presented to Scottish Ministers in March, to allow for the Scottish Government to publish the report before the elections in May.

The Leads of the Review will keep the Scottish Government fully informed of progress in delivering the scope and outcomes of the review as set out in this Terms of Reference and the previous Review Specification. Any revisions to the agreed scope, outcomes and timescales for delivery shall be subject to agreement with the Scottish Government and Scottish Ministers.

October 2020

How the Review was conducted

The Service Review was conducted between 16th October 2020 and 8th March 2021. There have been several broad overlapping phases of the review:

1. Public engagement

Gathering views and creative suggestions from the public, both people with eating disorders of all types and severities and their families, concerning their views about the current services and suggestions for improving treatment for people with eating disorders. This was done via engagement events and by online surveys.

Three engagement events were arranged via Zoom with booking via EventBrite because of the ongoing Covid-19 pandemic and associated restrictions. Information about these events was sent to all eating disorder services to distribute. We also enlisted the help of various third sector organisations to reach out to people using their services. These included Beat Scotland, SEDIG (The Scottish Eating Disorder Interest Group), The Linda Tremble Foundation, Male VoicED, SAMH, Penumbra, LGBT Youth Scotland, Enable Scotland, Scottish Trans Alliance, SWAN (Scottish women's autism network), Scottish Autism. We are very grateful to Beat Scotland who kindly set up all workshops via their Zoom account.

We set up a review Twitter account [@ScotEDReview](#) and information was regularly updated on this account. We had some information in a BBC Radio Scotland news report.

We acknowledge the difficulty in ensuring that everyone who may have been interested in contributing to this review were aware of it and are grateful to a number of organisations for their support in raising awareness of the review.

We acknowledge that online events may not be available to, or accessible to everyone. We wanted to consult as widely as possible and ensure that anyone who wanted to take part could get involved. Those not able to join Zoom events were encouraged to make contact with us.

We tried to have events in the early evening or on a weekend to ensure that people could attend without changing work or other commitments.

At each event which lasted two hours, we had a brief introduction, then used breakout rooms with smaller groups, each with two facilitators – one to scribe and one to facilitate discussion. Facilitators were mostly from outside of Scotland and not directly involved in the review. We hoped this would reduce the risk of bias from people who had experience of Scottish services. Breakout rooms were arranged for each event depending on the range of people who had signed up, for example, as follows:

- Mothers of people with an eating disorder
- Fathers of people with an eating disorder
- People with a short duration of illness
- People with a longer duration of illness

Although we had a number of males with eating disorders sign up, none attended the events. Further work needs to be done to adequately engage with men with eating disorders in reviewing and developing services.

Events took place on the following dates, each for 2 hours.

- Tuesday 24th November 2020 at 5pm – 65 participants booked
- Thursday 26th November 2020 at 7pm – 55 participants booked
- Saturday 28th November 2020 at 10am – 37 participants booked

Not everyone who booked was able to attend and because of the online nature of the meetings, we unfortunately do not have an accurate list of attendees.

Events were recorded to develop a thematic analysis. Themes are provided in detail in Appendix 2.

Surveys produced in SurveyMonkey were sent to everyone who booked an event. These were also distributed via social media, via third sector originations, and via eating disorder services. Details of the survey are included in Appendix 3.

We are grateful to the following facilitators who gave their time to support the review:

- Helen Missen, FEAST board member and mother of someone with an eating disorder
- Lorna Collins, lived experience, campaigner and support worker
- Peter Missen, father of someone with an eating disorder
- Suzanne Baker, FEAST board member and mother of someone with an eating disorder
- Gemma Johns, evaluation manager Technology Enabled Healthcare (TEC) Cymru and lived experience
- Poppy Wright, research assistant at TEC Cymru
- Bridget Taylor, retired nurse, and lived experience of having an eating disorder
- Bethan Whistance, research assistant at TEC Cymru
- Jessica Williams, research assistant at TEC Cymru
- Adrian King, senior business analyst
- Emma Broadhurst, Beat Scotland
- Stephanie Harris

2. Engaging with clinicians

Gathering views and creative suggestions from clinicians across Scotland from a range of disciplines and backgrounds and services who may see people with eating disorders whether as part of or all of their practice, concerning their views about the current services and suggestions for improving treatment for people with eating disorders.

Four events were arranged via Zoom, with bookings thought EventBrite and information distributed via social media as well as via other networks, including: The Royal College of Psychiatrists in Scotland mailing list; eating disorder services; ScotFED (the Faculty of Eating Disorders of the RCPsych in Scotland); the Scottish Eating Disorder Dietitians Group; the CAMHS Eating Disorder Steering Group; the Scottish Society for Gastroenterology; via Primary Care leads; and via direct contact with the Royal College of General Practitioners in Scotland, the Royal College of Paediatrics and Child Health and the Royal College of Emergency Medicine.

We were delighted to have bookings from across all areas of Scotland, and from a wide variety of clinical backgrounds, including paediatrics, paediatric dentistry, autism services, acute medicine, intensive care medicine, general practice, school nursing, liaison psychiatry, general psychiatry and mental health services as well as from the full range of the specialist eating disorder service multidisciplinary team.

We are very grateful to a number of external facilitators who have significant experience of either eating disorder services, or other mental health services and service review and development work. As with the public workshops, we invited clinicians who do not work in Scotland to facilitate these meetings, and had two facilitators per breakout room.

- Dr Agnes Ayton, Chair of the Faculty of Eating Disorders, Royal College of Psychiatrists
- Dr Alex Thomson, Consultant Liaison Psychiatrist
- Dr Kiran Chitale, Consultant Psychiatrist in Eating Disorders
- Dr Caz Nahman, Consultant Psychiatrist in Eating Disorders
- Dr Ashish Kumar, Vice Chair, Faculty of Eating Disorders, Royal College of Psychiatrists
- Dr Andrea Brown, Consultant Psychiatrist in Eating Disorders
- Adrian King, Senior Business Analyst
- Menna Jones, National Eating Disorders Lead, NHS Wales
- Sarah Fuller, Specialist Dietitian in Eating Disorders
- Ursula Philpott, Specialist Dietitian in Eating Disorders
- Dr Michael Lim, Consultant Anaesthetist

As with the public workshops, these events were recorded, and thematic analysis is presented in Appendix 2

Following a brief introduction, participants were taken to breakout rooms which aimed to ensure a wide range of geographical and clinical backgrounds in each room. Breakout discussions lasted for around one hour prior to a 30-minute feedback session.

Events, and booking numbers were as follows:

- 27th November 2020 – 35 participants booked
- 9th December 2020 – 65 participants booked
- 17th December 2020 – 63 participants booked
- 12th January 2020 – 64 participants booked

Surveys were sent to all participants and also distributed through the networks noted above. Detailed responses are available in Appendix 4.

We were very grateful to Drs Alastair McKinlay, Francesca Moroni and Gillian Leggett, Consultant Physicians in NHS Grampian for meeting with us to discuss their particular expertise in nutrition and anorexia nervosa.

We also met with Dr Agnes Ayton, Chair of the Royal College of Psychiatrists Faculty of Eating Disorders, and Dr Phil Crockett, Chair of ScotFED, the RCPsych in Scotland Faculty of Eating Disorders to discuss the review.

3. Consultation with NHS Boards and relevant organisations

Consulting and discussions with chief executives, or chief officers and others in leadership in the 14 Health Boards.

We wrote to all Boards in November 2020 inviting them to meet with us to discuss the review and to help us think about issues that may be relevant in relation to their Board. Some meetings have had to be rearranged due to

other priorities for the Boards. Meetings which have taken place, and those that are planned are noted below.

| | | |
|-----------------------------|--|--|
| NHS Ayrshire & Arran | John Burns, Chief Executive | 7 th December 2020 |
| NHS Borders | Simon Burt, General Manager, Mental Health & Learning Disability Services | 1 st March 2021 |
| NHS Dumfries & Galloway | | To be held 1 st April 2021 |
| NHS Fife | Carol Potter, Chief Executive | 18 th January 2021 |
| NHS Forth Valley | | Postponed on 16 th February |
| NHS Grampian | Caroline Hiscox, Chief Executive & Jane Fletcher, Head of Mental Health & Learning Disability services | 16 th March 2021 |
| NHS Greater Glasgow & Clyde | Katrina Phillips, Head of adult services | 17 th January 2021 |
| NHS Highland | Louise Bussell, Chief Officer | 11 th January 2021 |
| NHS Lanarkshire | Ross McGuffie, Chief Officer, and colleagues | 8 th December 2020 |
| NHS Lothian | Prof Alex McMahon, Executive Director of Nursing and colleagues | 25 th January 2021 |
| NHS Tayside | | Awaiting response |
| NHS Orkney & Shetland | Michael Dickson, Chief Executive | 25 th January 2021 |
| NHS Western Isles | | Awaiting response |

In addition, we met with:

- Dr Stewart Irvine, Acting Chief Executive of NHS Education Scotland on 18th January 2021
- Dr Jane Morris, Chair of the SIGN Eating Disorders Guideline Group on 27th January 2021
- The Scottish Child & Adolescent Mental Health Service Eating Disorders Steering Group on 21st January 2021
- Dr Alastair Cook, Principal Medical Officer for Psychiatry, 19th February 2021
- The Scottish Dietitians' Eating Disorder Clinical Forum, 26th November 2020

4. Third Sector organisations

Discussions with third sector organisations concerning their views about current services and suggestions for improving treatment for people with eating disorders, and the potential role for the third sector.

As noted earlier, we attempted to contact a wide range of charities that work in Scotland and may have contact with people who have eating difficulties or eating disorders. We invited these organisations to meet with us and met with representatives of the following organisations on 12th January 2021 via Zoom. Further information is contained in Appendix 2.

- Supported (Formerly The Linda Tremble Foundation)
- Beat Scotland
- Scottish Association for Mental Health
- YouthLink Scotland
- Scottish Recovery Network
- Anorexia Bulimia Care

We also met separately with Andrew Radford, Chief Executive of Beat.

5. Build on the Mental Welfare Commission for Scotland's Scoping of Services Gathering information regarding referral numbers, staffing levels and other indicators of existing services for people with eating disorders.

The Mental Welfare Commission provided detailed information on services available in each Board area (5). One of the leads of this review (SA) has previously collated data on service staffing and referral criteria. We have written to all services to attempt to confirm the information we already had and to add to this by gathering information on referral numbers, service specification etc but have had little response. Information that has been provided is detailed in the service scoping Appendix 1. We are aware that clinicians from each service attended our clinician workshops, and we also met with managers, however, we have not been able to fully complete a scoping exercise within. The short timescale of this review. It is hoped that this work can continue in future phases.

6. Consider a range of guidance

Considering a range of guidelines, Scottish Government documents, and legislation relevant to the Service Review. The following publications and reports are relevant in addition to those already mentioned above.

- i. As noted, the SIGN guideline for eating disorders is currently in progress but their recommendations are not sufficiently ready to be shared and considered as part of the recommendations in this report.
- ii. NICE Guideline NG69 (May 2017) Eating Disorders: Recognition and Treatment (3)
- iii. NICE Quality Standard QS175 (September 2018) Eating Disorders (25)
- iv. Royal College of Psychiatrists (2014) CR189. MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa (2nd edn) (26)
- v. Royal College of Psychiatrists (2012) CR168. Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa (27)
- vi. Royal College of Psychiatrists (2012) CR170. Eating Disorders in the UK: Service Distribution, Service Development and Training (withdrawn from website).
- vii. National Collaborating Centre for Mental Health, commissioned by NHS England (2015) Access and Waiting Time Standard for Children and Young People with an Eating Disorder: Commissioning Guide (2)
- viii. Parliamentary and Health Service Ombudsman (2017) Ignoring the alarms: How NHS eating disorder services are failing patients (22)
- ix. Beat (2017) Delaying for years, denied for months: the impacts on sufferers of delaying treatments for sufferers in England (28)

The full report was submitted to the Minister on 17th March 2021.

Recommendations

The following 15 recommendations will ensure that Scotland meets the Vision, using the principles articulated above, within 10 years.

Short term recommendations are numbers: 1, Covid-19 response; 2, implementation planning; 4, lived experience panel; 6, self-help resources; and 13, families and carers.

Medium term recommendations are numbers: 3, co-ordination of national activity; 8, primary care; 9, medical care; and 12, education and training.

Longer term recommendations are numbers: 5, public health; 7, early intervention; 10, specialist care; 11, workforce planning; 14, in-patient care; and 15, research.

Recommendation 1: Covid-19 response

Emergency funding should be provided to rapidly meet the urgent needs of eating disorder patients and services as a direct result of an increase in the number and severity of eating disorder presentations related to the Covid-19 pandemic. Funding should prioritise physical health stability, risk reduction, support inpatient discharge and prevent admission to hospital.

Ownership: Scottish Government providing funding, individual health boards responsible to Scottish Government.

- 1.1 This urgent funding is to enable expansion of medical, nursing, dietetic and therapist time and additional support workers (including peer and carer support workers) within a rapid time frame for the next 12 months. Specific requirements are likely to vary in each area.
- 1.2 Additional funding for adaptation of facilities may be included if facilities need to be made Covid-safe or adapted to provide the same level of care during the pandemic as would normally be expected.
- 1.3 The third sector could be contracted to provide support services to work alongside NHS eating disorder services. (For example, Beat are able to provide training for carers, support for adult patients while waiting for therapy and support for families.)
- 1.4 Training on a national basis (for example, through virtual training days) is recommended for all newly recruited staff; this could be done together with third sector organisations.
- 1.5 Fair allocation of funding should take into consideration population density.

Recommendation 2: Implementation planning

An Implementation Group should be set up by Scottish Government. This short-term group will be responsible for the implementation of these service review recommendations, planning for and setting the strategic direction,

vision and ethos for improvement and service delivery over the next 10 years. This group should report directly to Scottish Government.

Ownership: Scottish Government, Scottish Government's appointed chair of Implementation Group

We suggest that core tasks of the Implementation Group could be to:

- 2.1 Take note of the data generated by the Mental Welfare Commission and this Service Review in Phase 2 (provided in Appendices).
- 2.2 Finalise the costing of the recommendations of this Service Review including the specific manpower needs are once the recommendations of this review are accepted.
- 2.3 Operationalise the recommendations of this Service Review across Scotland taking into account the context, needs and constraints of different health boards.
- 2.4 Conduct project planning for the implementation of all aspects of the recommendations as led by the implementation group.
- 2.5 Develop further and plan for implementation of quality standards of care across Scotland for all levels of treatment for eating disorders, in line with SIGN, MARSIPAN, and Scottish Government's Mental Health Transition and Recovery Plan (<https://www.gov.scot/publications/mental-health-scotlands-transition-recovery/pages/22/>) Scottish Mental Health Strategy and policy, GIRFEC and other relevant policy documents.
- 2.6 Develop a skills and competency framework, and training strategy in partnership with NHS Education Scotland (NES) and Eating Disorders Education and Training Scotland (EEATS), for all staff, including third sector, who may see or work with people who have eating disorder symptoms or diagnosis, see recommendation 12.1-12.3 for more detail.
- 2.7 Build a public health strategy for Scotland with Public Health Scotland and other agencies that makes eating disorder prevention everyone's business.
- 2.8 Design as a priority a comprehensive plan for systematic data collection and ongoing analysis across Scotland, to address current lack of data. This needs to include planning and funding for appropriate staffing and IT infrastructure to be able to collect, analyse and report the data systematically across Scotland. Datasets should include annual audit of the prevalence of all eating disorder diagnoses, nationally agreed measures to evaluate service delivery and outcomes, and collation of Significant Incident Reviews together with local medical leads to report annually to the National Eating Disorder Group.

Recommendation 3: Coordination of national activity and data collection

A National Eating Disorder Network should be established and funded by Scottish Government. This permanent Network will take over from the work of the Implementation Group to support the implementation of the recommendations on an ongoing basis. It will also be responsible for the coordination of national functions including training, national level service development, setting quality standards, and coordinating research and innovation networks for eating disorders.

Ownership: Scottish Government, Implementation Group with stakeholders, all Health Boards

Responsibilities of the National Eating Disorders Network may include:

- 3.1 Implementation across Scotland of the all the plans for change designed by the Implementation Group with ongoing further development as appropriate.
- 3.2 Working with Public Health Scotland and other agencies to continue to build, implement and evaluate a public health strategy for Scotland that makes eating disorder prevention everyone's business.
- 3.3 Collating national data and providing on an ongoing basis annual audits of the prevalence of all eating disorder diagnoses, analysis of nationally agreed datasets to measure service delivery and outcomes, collation of Significant Incident Reviews to report annually to Scottish Government.
- 3.4 Support and lead on training for healthcare and other stakeholder professionals, see recommendation 12 for more details.
- 3.5 Hosting a Scottish Eating Disorder Network website with signposting, educational material, and providing access to online self-help/management programmes, as well as providing a platform to host any Scottish information gathering, research and sharing activity.

We suggest that the National Eating Disorder Network could be staffed by:

- A National Eating Disorder lead who leads and manages the Network.
- A core staff team comprising both child and adolescent and adult multi-disciplinary professionals at Consultant grade who are national level leaders – this could include nursing, allied health professionals, psychology, psychiatry, physical medicine and 3rd Sector membership. Each core staff team member will have responsibility in leadership and development for their profession/sector/geographic location, as well as allocated responsibilities for the Networks work plan.
- A lived experience panel comprising people with a range of lived experiences which advises and works alongside the Network.
- In addition, there should be adequate administrative and data analyst support for the remit of the Network to be carried out.

Recommendation 4: Lived Experienced Panel

There should be a lived experience panel set up who will advise the Implementation Group and work alongside the National Eating Disorders Network. The lived experience panel should include patients, families and loved ones, and third sector representatives and there should be diversity in the panel, for example, including all eating disorder diagnoses, men with eating disorders, LGBT representatives and people from ethnic minorities. The panel will advise on all eating disorder national changes.

Ownership: Implementation Group then National Eating Disorders Network, Scottish Government

- 4.1 The Lived Experience panel will help ensure equality and diversity and parity of esteem is central to the implementation.
- 4.2 Panel members should be reimbursed for their time and travel.
- 4.3 Panel membership should be on a fixed term basis to ensure diversity.

Recommendation 5: Public health

The Scottish Government should fund and support development of a comprehensive public health strategy for Scotland that makes eating disorders prevention everyone's business.

Ownership: Scottish Government, National Eating Disorders Network and Public Health Scotland

We suggest that this may include:

- 5.1 Support from eating disorder national lead for engagement of government and other agencies with industry (fashion, advertising, sports and fitness, food industry, social media) in how they can work to promote a positive body image culture in Scotland.
- 5.2 Provision of evidence-based parenting advice on promoting positive body image for all, sensible healthy eating and exercise, emotional literacy, risk factors for and signs of eating disorders. This could be done via the National Eating Disorder Network website or in conjunction with existing evidence-based parenting programmes delivered by schools and parent organisations, 3rd sector, or primary care (for example, via health visitors).
- 5.3 Support from eating disorder national lead for engagement of Scottish Government and relevant health agencies with the fitness sector (gyms, sports teams and clubs, personal trainers, dance schools and elite as well as grassroots sports organisations) in developing standards in the industry that promote health at all shapes/weights, prevent eating disorders and increase awareness to enable early identification of emerging eating disorders and Relative Energy Deficiency in Sport (<http://health4performance.co.uk/healthcare-professionals/>) with signposting to treatment.

5.4 Developing with NES, Public Health Scotland and the education sector, evidence-based, school-based (state and independent sector) prevention packages which include mental wellbeing, emotional resilience, social media literacy, moderating anti-obesity public health messages, and dealing with precursors of eating disorder such as body image issues, and compliant with the SHANARRI indicators (<https://www.gov.scot/policies/girfec>).

5.5 Engaging with Public Health Scotland on the delivery of “Healthier future: Scotland’s diet and healthy weight delivery plan” (2018) to ensure joined up thinking in relation to obesity and eating disorders.

(<https://www.gov.scot/publications/healthier-future-scotlands-diet-healthy-weight-delivery-plan/>)

5.6 The National Eating Disorder Network providing eating disorders expertise to existing programmes tackling mental health stigma, such as <https://www.seemescotland.org/about-see-me/> and in mental health wellbeing resources such as <https://young.scot/campaigns/national/aye-feel>.

Recommendation 6: Self-help resources available to all

Scottish Government should provide funding to the Third Sector to build platforms and a range of community services to enable the Scottish public to have free access to evidence-based self-help/management programmes and supports, including peer support networks.

Ownership: Scottish Government, the National Eating Disorder Group, Public Health Scotland and the Third Sector

We suggest that this could include:

6.1 The Third Sector working with the National Eating Disorder Network to create and host evidence based self-help and early intervention programs as recommended by SIGN, for example for Binge Eating disorders.

6.2 Developing peer support networks with the Third Sector to provide peer support to people with eating disorders and their families irrespective of the stage of the illness or whether they are in treatment.

6.3 The Scottish Government increasing the Scope of www.caredscotland.co.uk to include eating disorders across all ages and link it to the National Eating Disorder Network so that CaredScotland can serve as an information point for all family and carers with loved ones across the age range and all eating disorder diagnoses.

6.4 Developing online support for family and carers, which could be coordinated between the National Eating Disorder Network and the Third Sector, to provide additional practical and emotional support for people with eating disorders and their families to augment services provided by the NHS.

6.5 Peer support networks which can be developed with the Third Sector to provide support for all carers and adapted to meet the needs of all, including fathers/partners and siblings.

Recommendation 7: Early Intervention

Key Stakeholders and Healthcare professionals should be able to identify the signs and symptoms of all eating disorders including at early stages and know how to support and sign post people into treatment.

Ownership: Implementation Group, National Eating Disorders Network, Key stakeholder organisations, healthcare professional organisations

We Recommend:

7.1 Key stakeholders in the early identification of eating disorders should include, school staff, youth services, sports, and fitness sector.

7.2 Key healthcare professionals who may see people with eating disorders should be trained and supported to be able to identify the signs and symptoms of all eating disorders including at early stages and know how to signpost people to treatment. See recommendation 12.4 – 12.8 for training details.

7.3 Key Primary healthcare practitioners should be enabled to become skilled in the early identification of people with eating disorders, and supported to signpost these people quickly into assessments and treatment.

7.4 Key Secondary healthcare practitioners, including in weight management and dentists should be enabled to become skilled in the early identification of people with eating disorders, and supported to signpost these people quickly into assessments and treatment.

7.5 The National Eating Disorder Network website outlined in Recommendation 3.5 should share information on early identification and early access to treatment and map service provision in Scotland and signpost the public to support and advice services offered across Scotland.

7.6 The National Eating Disorder Network website Recommendation 3.5 should also share information regarding relevant Third Sector organisations for people with eating disorders and their loved ones and the services these organisations offer, such as helplines, support groups and participation in advocacy programmes.

Recommendation 8: Primary care

Awareness, detection and early, effective treatment of eating disorders at primary care is important. There should be an ongoing training programme for all primary care clinicians to ensure consistent high standards are maintained in identification and management of patients who may have eating disorders, and their families. There should be increased support from specialist services when primary care is asked to assist with physical monitoring or support, for instance when patients live far away from specialist teams.

Ownership: Implementation Group, healthcare professional organisations, Eating Disorder Education and Training Scotland (EEATS) and NHS Education Scotland (NES)

Please refer to Recommendations 2 and 3 about the role of the proposed Implementation Group and National Eating Disorder Network. We recommend that:

8.1 The Implementation Group and National Eating Disorder Network should work with stakeholder organisations representing staff working in primary care settings

(General Practices, primary mental health and other community level healthcare) such as health visitors, midwives, community nurses and counsellors to agree training and care standards regarding eating disorders.

8.2 Primary care should be supported and resourced, where appropriate, to provide some aspects of care in conjunction with specialist teams depending on population and geography.

8.3 Primary care practitioners should NOT be required to hold medical responsibility for significant or severe eating disorders, except where this is appropriate for specific cases in partnership or agreement with specialist medical practitioners.

8.4 Scottish Government has committed to increasing the mental health workforce in 2021-22 by providing dedicated mental health professionals to work in all A&Es, all GP practices, police custody suites and prisons. These staff should all have training on identification and essential management of eating disorders.

8.5 Mental health workers and identified General Practitioners with special interests in mental health in all GP practices should be offered special training and support in eating disorder identification and the essential management of eating disorders.

8.6 Staff employed in the NHS 24 Mental Health Hub and in Mental Health Assessment Units developed in line with the Mental Health – Transition and Recovery Plan should have training on the identification and essential management of eating disorders.

Recommendation 9: Safe medical care

Medical aspects of care should be prioritized, with clear lines of responsibility and leadership from suitably trained medical experts. We recommend named eating disorder medical leads for every health board/region with oversight over the medical care of every patient with an eating disorder, who report data to the National Eating Disorder Network. This can be done in collaboration with General Practitioners, Acute Medicine and Paediatrics according to the local context of who has appropriate training in managing the medical aspects of eating disorders.

Ownership: National Eating Disorder Network, All health boards

We recommend:

9.1 Designing a sustainable training programme to develop and maintain medical expertise in eating disorders within and across Scotland is a priority, see recommendation 12.9 – 12.11.

9.2 There should be expert medical oversight ensuring safe medical management of all patients with moderate to severe eating disorders across Scotland. Every health board/region should have named pairs of medical leads, for adult eating disorders and child and adolescent eating disorders respectively. They should be: a named lead physician and adult eating disorder psychiatrist; and a named lead paediatrician and eating disorder child and adolescent psychiatrist. These named

medical leads should be responsible for oversight of the medical care of patients with eating disorders. These named health board/regional leads should have a day a week funded for this task on an ongoing basis and be specially trained to be expert in nutritional and medical aspects of eating disorders.

9.3 We recommend the named eating disorder medical leads for every health board/region should have oversight over the medical care of every patient with an eating disorder. The named leads should be able to provide input to local clinicians looking after patients, as well as be involved in training staff as required. This can be done in collaboration with Psychiatry, General Practitioners, Acute Medicine, Paediatrics according to context who have appropriate training in managing the medical aspects of eating disorders.

9.4 These leads should be tasked with collating data about every patient with eating disorders within their catchment, to report to the National Eating Disorder Network. They should receive all data from the area about any critical incidents and complaints, and also analyse and report all deaths amongst patients with eating disorders.

9.5 That the named psychiatric leads should be able to consult and share responsibility as appropriate with colleagues from other mental health services for patients who have complex mental disorders and neurodevelopmental disorders; similarly the named medical leads should similarly be able to consult and share responsibility with physician/paediatrician colleagues from other medical services for patients who have complex medical problems including diabetes, or medical consequences of eating disorders such as osteoporosis, and neurological, gastrointestinal, renal or endocrinological problems.

[Recommendation 10: Investment in specialist eating disorder services.](#)

The Scottish Government should commission and fund equitable provision of high-quality accessible specialist community-based services for eating disorders across Scotland for all ages, which see all types of eating disorders across the range of severity.

Ownership: Scottish Government, Implementation Group, National Eating Disorder Network, All health boards

We suggest that:

10.1 The Scottish Government should appoint an Implementation Group (see Recommendation 2) and provide funding for a programme of work to build a workforce with the skills and competencies to be able to provide specialist eating disorder treatment within specialist teams in Scotland as quickly as is possible to do so.

10.2 All specialist eating disorder services across the age range should accept self-referrals and referrals from any relevant professional, including counsellors, school nurses, third sector workers, as well as General Practitioners to enable rapid and equitable access regardless of age, severity and diagnosis.

Outcome: All eating disorder services should be reporting referral rates and sources to the National Eating Disorders Network lead for data collection by the end of 12 months, and thereafter on an ongoing basis. Furthermore, they should have appropriate resourcing of IT and administrative staff to enable this.

10.3 All eating disorder services should see patients fairly regardless of age, location and personal characteristics such as gender, sexuality, race, ethnicity, culture, language and religious beliefs. Duration of illness, age, type of eating disorder, body weight and presence of co-morbid medical or psychiatric disorders or neurodevelopmental disorders should not be used as barriers to treatment, and medically or psychiatrically unwell patients should be seen more quickly.

Outcome: All eating disorder services should be reporting demographics and characteristics (such as age, gender, diagnosis and severity) of all referrals, outcomes of referrals and all patients accepted into their services to the National Eating Disorder Network lead for data collection by the end of 12 months and thereafter on an ongoing basis.

10.4 All eating disorder services should ensure that they actively engage with service users to co-design and evaluate services. This would ensure that services are, and continue to be, environments that are accessible and welcoming to everyone and promote the formation of strong therapeutic relationships and recovery irrespective of gender, race, ethnicity, culture, sexuality, age or class.

10.5 We recommend an 'all age' approach to treating eating disorders. Initial changes could take the form of staff of current child and adolescent and adult eating disorder services forming virtual or face to face multidisciplinary teams to work together to provide seamless treatment which is developmentally appropriate to each patient.

10.6 Specialist eating disorder teams should hold responsibility for medical aspects of safe care for their patients. This can be done in collaboration with specific General Practitioners, Acute Medicine and Paediatrics as appropriate, however training in the medical aspects of eating disorders would be needed. We suggest that the Implementation Group should convene a working group to work with relevant stakeholders and all the named medical leads to discuss how this can be done.

10.7 Where health boards have smaller populations, creation of regional specialist eating disorder multidisciplinary teams may be appropriate. This could include having staff based in various health board locations and returning to a central base for multidisciplinary work, as well as utilising remote telehealth. This would ensure that people with eating disorders and their families are able to access the same range and quality of therapies and medical care wherever they live. We recommend that all health boards/regional teams should demonstrate that they can offer the entire range of SIGN-approved treatments and supports to their patients regardless of location of residence.

10.8 We suggest that telehealth should continue to be extensively used to enable treatment to be delivered anywhere in Scotland. This will enable co-working across geographic areas to occur across Scotland so that all patients can access the treatment they need. Scottish Government have already committed that 'we will

move to a position of “Near Me” as the default option where that is right for the person and they are happy to use the service.’ To promote digital inclusion, Scottish Government advocates creating innovation Hubs (included in the Mental Health Transition and Recovery Plan). Eating disorder services should ensure all health and care consultations are by Near Me or phone whenever clinically appropriate, using the Hubs as needed to support access and provide local community support. Scottish Government have committed to expanding a specific online Cognitive Behavioural Therapy (CBT) platform and enhanced internet based supported CBT; eating disorder specific enhanced CBT (CBT-E) is one of the few evidence-based treatments for eating disorders and we suggest this should be included in the Scottish online CBT resource.

10.9 Health Boards and Integrated Joint Boards should be held to nationally agreed levels of service provision, types of therapies offered and quality care standards (recommendations 2.5 above) and as recommended in the upcoming SIGN Guidelines. The National Eating Disorder Network should have oversight of compliance and conformity to SIGN Guidance and agreed Quality Standards, evaluated via collection of the national datasets.

10.10 For patients of all ages, it is crucial that eating disorder clinicians develop and maintain strong links and working relationships with other local specialist and generic services, so as to collaborate and work together to meet the complex needs that arise from comorbid mental health issues, such as personality disorders, addictions, post-traumatic stress disorder (PTSD). In turn, eating disorder services should work with these services to manage disordered eating and mild eating disorders amongst their patient group, which also prevents development of severe eating disorders. Eating Disorder Services need to develop improved links with services working with people on the autism spectrum, as well as training for ED and autism services on the appropriate management of eating disorders in people who have autism. The Implementation Group should convene a forum with Scottish leads for the different other specialties with eating disorder lead clinicians to enable consensus about how to work more closely together; this network of eating disorder lead clinicians should have ongoing meetings hosted by the National Eating Disorder Network to continue developing consensus and working relationships.

10.11 Eating disorder teams should develop and maintain strong working relationships with both national and local statutory and Third Sector agencies who are crucial in supporting all patients with eating disorders and their families. The presence of comorbidities increases the complexity and need for support in order to address all needs and achieve recovery.

10.12 The National Eating Network should host regular national Morbidity and Mortality meetings with lead clinicians across Scotland to review all critical events, near misses and deaths amongst patients with eating disorders. This data will be collated together with records of patient and family complaints and reported regularly to Scottish Government, together with the agreed learning points for improvement of patient care and safety.

Recommendation 11: Workforce

A comprehensive workforce plan will be developed that aims to build the workforce to be able it to meet the service standards over the next 10 years. This plan should emphasise staff retention and training within eating disorders services as well as recruitment.

Ownership: Scottish Government, Implementation Group, National Eating Disorders Network, All health boards.

We suggest that:

11.1 The comprehensive training plan described in recommendation 12 is prioritized in order to build a trained workforce for Scotland in the prevention, early identification and treatment of eating disorders.

11.2 Specialist teams should be created which have minimum numbers of essential disciplines, and advancement for all professionals. Teams should include therapists, medical and psychiatric staff, nurse practitioners, psychologists, dietitians and other allied health professionals; all of which could have a leadership role in these teams.

11.3 In addition to the creation of new posts, attention should be paid to the issue of retention of skilled staff once they are fully trained. This may include, equal training opportunities for all, roles determined by skills and competency and not limited by profession, role rotations, and the progression of staff through grades including in nursing and allied health professionals.

11.4 The National Eating Disorder Network should provide a forum where specialist teams actively work together to support staff, prevent burn out and provide research and other personal development opportunities.

Recommendation 12: Education and Training

A comprehensive training plan will be developed which will aim to equip the entire healthcare workforce which might see people with eating disorders and their families, to deliver high quality care for people with eating disorders in all settings ranging from early intervention to highly specialist care, and from community to inpatient. In addition, there should be appropriate education and awareness training for other relevant professionals, such as youth workers, counsellors, and sports coaches. Training should be appropriate to the role that each professional has with respect to prevention, identification, signposting, treatment and support of people with eating disorders.

Ownership: Scottish Government, National Eating Disorder Network, Eating Disorder Education and Training Scotland (EEATS) and NHS Education Scotland (NES)

We suggest the Implementation Group, prioritise:

12.1 The development of a skills and competency framework, in partnership with NHS Education Scotland (NES) and Eating Disorders Education and Training Scotland (EEATS), for all staff, including third sector, who may see or work with people who have eating disorder symptoms or diagnosis. The initial focus should be developing medical expertise in eating disorders within Scotland to ensure safe medical treatment of all patients with eating disorders, regardless of where they are seen.

12.2 Work in partnership with NES and EEATS and the third sector, to develop a training strategy that translates the NHS skills and competency framework into a framework suitable for non-healthcare/NHS professionals and supports appropriate training and awareness in schools, further education, third sector mental health workers and the fitness sector. This could include the use of digital technologies for training and supervision. Where possible and appropriate, resources already developed could be adopted and used. (For instance, training has already been created by Beat and the Royal College of Psychiatrists and can be rapidly implemented if desired.)

12.3 Enabling the National Eating Disorders Network to develop and host national remote training for all types of healthcare and other professionals.

In relation to early intervention, we suggest that:

12.4 The Mental Health Transition and Recovery Plan could make commitments to increase training for all school healthcare staff such as school nurses and school counsellors in conjunction with the Mental Health in Schools Working Group and the National Eating Disorder Network. This should include education on eating disorders. There is an existing commitment to increase college and university counsellors and we suggest these staff should have training on the identification and signposting of eating disorders.

12.5 There should be training in the identification and signposting of eating disorders for all staff in Mental Health and Wellbeing services, as part of the Scottish Government's Transition and Recovery Plan being rolled out in all local authority areas during 2021.

12.6 The National Eating Disorder Network, in partnership with EEATS and the third sector, as part of Recommendation 3.4, could train youth services workers to work with them to support early identification and signposting of young people with eating disorder symptoms to appropriate levels of support or treatment.

12.7 The National Eating Disorder Network, in partnership with EEATS and the third sector, should provide training to the sports and fitness industry concerning good practice in sports and fitness to prevent eating disorders, enable early identification and signposting of people with eating disorder symptoms to appropriate levels of support or treatment.

12.8 Primary care training should be an important part of the national training strategy and its implementation should be prioritised.

In relation to Medical aspects of care, we suggest that:

12.9 Designing a sustainable training programme to develop and maintain medical expertise in eating disorders within and across Scotland is a priority.

12.10 We suggest that this should include Scottish Government-funded fellowships in advanced nutrition for paediatric and acute medicine/gastroenterology higher trainees. These fellowships will enable medical higher trainees to have placements within both specialist eating disorder units and acute medical care settings, to develop advanced knowledge and skills in nutrition and eating disorders. These

trainees will be expected to become named consultant physicians and paediatricians who hold oversight of the medical aspects of treatment for eating disorders as part of their consultant roles, in addition to working as nutritional experts within their medical departments.

12.11 That a training programme is needed for staff of Weight Management Services in Scotland so that they are able to identify and manage patients in their services who have disordered eating, early eating disorders or established eating disorders, especially Binge Eating Disorder. These staff should co-work with eating disorder service colleagues to treat these patients.

In Relation to undergraduate training, we recommend:

12.12 Working with UK-wide organisations to increase the eating disorders content of curricula within medical school, dental school, general nursing, dietetics and clinical psychology training. This will require the National Eating Disorder Network and other eating disorder leaders to work at the UK level with the General Medical Council and General Dental Council, as well as organisations such as the Royal College of General Practitioners, Royal College of Psychiatrists, Royal College of Paediatrics and Child Health, Royal College of Physicians, Royal College of Nursing, and British Dietetic Association and British Psychological Society.

In Relation to Specialist care, we recommend that:

12.13 The National Eating Disorder Network should set up national specialist training and other programs which enable clinicians to have equal access to high quality skills and competency-based training, supervision, and opportunities for personal development irrespective of profession and location, in order to meet the nationally agreed quality standards.

12.14 The National Eating Disorders Network develops and provides remotely a training and education programme with accreditation for all specialist eating disorder clinicians to ensure consistent standards of training across Scotland and to enable all eating disorder services to provide the same level of evidence-based treatment and therapies to all patients as defined by the national quality standards. This should be done in partnership with the Eating Disorder Education and Training Scotland (EEATS) and NHS Education for Scotland (NES).

Recommendation 13: Families and carers

Families and carers should be given a high level of support from the start of their loved ones eating disorder, and for as long as they need it. Experts by experience (both patients and families) should be involved in service design and implementation as well as quality improvement.

Ownership: Specialist eating disorder teams, the National Eating Disorder Network and the Third Sector

We suggest that:

13.1 The Government should increase the Scope of www.caredscotland.co.uk as an information point for all family and carers with loved ones across age range and diagnosis (See Recommendation 6.3).

13.2 Online support for family and carers should be coordinated by the Third Sector, these should include practical and emotional support.

13.3 Peer support networks should be developed with the Third Sector to provide support for all carers and adapted to meet the needs of all, including fathers/partners and siblings and other family members or loved ones who may be supporting patients.

13.4 Specialist eating disorder teams should ensure that all family and carers are given the opportunity for support and information about eating disorders.

13.5 Specialist teams should provide family and carers who are actively involved in providing care and support to their loved ones, with a high level of support and advise, irrespective of their loved ones age.

13.6 Advice and support for families and carers should be provided on employment rights and benefits.

Recommendation 14: Inpatient eating disorder services

Inpatient eating disorder provision is currently variable and inequitable across Scotland particularly for adult men. Inequitable access to inpatient care has significant impact on community services. Where there are inequalities, Health Boards should work together to ensure there are equitable access to services. We recommend a further, smaller review specifically of national inpatient provision across all ages in 5 years' time, after community service improvements have been implemented.

Ownership: The Scottish Government, Implementation Group and National Eating Disorder Network, all Health Boards

Recommendation 15: Eating disorders Research in Scotland.

Scottish Government should consider funding eating disorders research through NHS Research Scotland. Specific calls for eating disorder research should be made to support research which would fill gaps in knowledge and understanding of eating disorders in the Scottish population, and their treatment in Scotland. Particular note should be taken of gaps in the research base that SIGN identifies.

Ownership: Scottish Government, NHS Research Scotland, National Eating disorders Network, Health boards and eating disorder clinicians.

15.1 Developing a strong research culture should both make Scotland more attractive and able to recruit, train and retain high calibre research-oriented clinicians, and establish a culture of enquiry, innovation and accountability which will help drive up standards across all services.

15.2 Both the research agenda and the funded research should be co-produced by researchers with those with lived experience and clinicians working within the field.

15.3 This funded research should always aim to improve the treatment and welfare of people with eating disorders and their families.

References

1. NHS Quality Improvement Scotland. Eating Disorders in Scotland: Recommendations for healthcare professionals [Internet]. 2006. Available from: http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/eating_disorders_in_scotland_-1.aspx
2. NHS England. Access and waiting time standard for children and young people with an eating disorder: A commissioning guide [Internet]. 2015. Available from: <https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guid.pdf>
3. National Institute for Health and Care Excellence (NICE). Eating Disorders: recognition and treatment [Internet]. 2017. Available from: <https://www.nice.org.uk/guidance/ng69>
4. Mental Welfare Commission for Scotland. Hope for the future: A report on a series of visits by the Mental Welfare Commission looking at care, treatment and support for people with eating disorders in Scotland [Internet]. 2020. Available from: https://www.mwscot.org.uk/sites/default/files/2020-09/EatingDisorders_ThemedVisitReport_03Sept2020_0.pdf
5. Mental Welfare Commission for Scotland. Mapping of Eating Disorder Services across Scotland [Internet]. 2020. Available from: https://www.mwscot.org.uk/sites/default/files/2020-09/MappingOfEatingDisorderServicesAcrossScotland_Sep2020.pdf
6. Scottish Government. Mental Health Strategy 2017-2027 [Internet]. 2017. Available from: <https://www.gov.scot/publications/mental-health-strategy-2017-2027/>
7. Nicholls D., Lynn R, Viner R. Childhood eating disorders: British national surveillance study. *Br J Psychiatry*. 2011;198(4):295–301.
8. Fukotomi A, Austin A, McClelland J, Brown A, Glennon D, Mountford V, et al. First episode rapid early intervention for eating disorders: a two-year follow-up. *Early Interv Psychiatry*. 2020;14:137–41.
9. Brown A, McClelland J, Boysen E, Mountford V, Glennon D, Schmidt U. The FREED Project (first episode and rapid early intervention in eating disorders): service model, feasibility and acceptability. *Early Interv Psychiatry*. 2018;12(2):250–7.
10. World Health Organization. ICD-11 International Classification of Diseases 11th Revision. 2021.
11. Micali N, Martini MG, Thomas JJ, Eddy KT, Kothari R, Russell E, et al. Lifetime and 12-month prevalence of eating disorders amongst women in mid-life: a population-based study of diagnoses and risk factors. *BMC Med*. 2017;15(1):12.
12. Deloitte Access Economics. Social and economic cost of eating disorders in the United States of America: Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders. 2020.
13. Reas D., Ro O. Time trends in healthcare-detected incidence of anorexia nervosa and bulimia nervosa in the Norwegian National Patient Register (2010-2016). *Int J Eat Disord*. 2018;51(10):1144–52.
14. Galmiche M, Dechelotte P, Lambert G, Tavolacci MP. Prevalence of eating disorders over the 2000-2018 period: a systematic literature review. *Am J Clin Nutr*. 2019;109:1402–13.

15. NHS Digital. Health Survey for England [Internet]. 2020. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2019/health-survey-for-england-2019-data-tables>
16. Murray CJ., Barber RM, Foreman KJ. Global, regional, and national disability-adjusted life years (DALYs) for 306 diseases and injuries and healthy life expectancy (HALE) for 188 countries, 1990–2013: quantifying the epidemiological transition. *Lancet*. 2015;386(1009):2145–91.
17. Tan J, Humphreys I, Demmler J. The national economic burden of eating disorders in Wales: a clinical population study. *Lancet*. 2019;
18. Tan J, Humphreys I, Demmler J, Johns G, Lanceley C, Longo M, et al. The economic burden of patients with eating disorders to healthcare providers: A 27-year retrospective record linked electronic cohort study. Pre-print *The Lancet* [Internet]. 2019; Available from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3454702
19. Demmler J, Brophy S, Marchant A, John A, Tan J. Shining the light on eating disorders, incidence, prognosis and profiling of patients in primary and secondary care: national data linkage study. *Br J Psychiatry*. 2020;216(2):105–12.
20. NHS Digital. Finished admission episodes with a primary or secondary diagnosis of eating disorder. 2018.
21. Iwajomo T, Bondy SJ, de Oliveira C, Colton P, Trottier K, Kurdyak P. Excess mortality associated with eating disorders: population-based cohort study. *Br J Psychiatry*. 2020;197:1–7.
22. Parliamentary and Health Service Ombudsman. Ignoring the alarms: How NHS eating disorder services are failing patients [Internet]. London; 2017. Available from: <https://www.ombudsman.org.uk/publications/ignoring-alarms-how-nhs-eating-disorder-services-are-failing-patients>
23. Dyer C. Eating disorder services in England need urgent changes, says coroner. *Br Med J*. 2020;371:m4346.
24. Ayton A. Investment in training, evidence based treatment, and research are necessary to prevent future deaths in eating disorders. *Br Med J*. 2020;371:m4689.
25. National Institute for Health and Care Excellence (NICE). Eating Disorders: Quality standard [Internet]. 2018. Available from: www.nice.org.uk/guidance/qs175
26. Royal College of Psychiatrists. MARSIPAN: Management of really sick patients with anorexia nervosa [Internet]. 2014. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr189.pdf?sfvrsn=6c2e7ada_2
27. Royal College of Psychiatrists. Junior MARSIPAN: Management of really sick patients under 18 with anorexia nervosa [Internet]. 2012. Available from: <https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr168.pdf>
28. Beat. Delaying for years, denied for months. The health, emotional and financial impact on sufferers, families and the NHS of delaying treatment for eating disorders in England [Internet]. 2017. Available from: <https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-months.pdf>



Scottish Government
Riaghaltas na h-Alba
gov.scot

© Crown copyright 2021

OGL

This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80004-986-4 (web only)

Published by The Scottish Government, May 2021

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS878906 (05/21)

W W W . g o v . s c o t