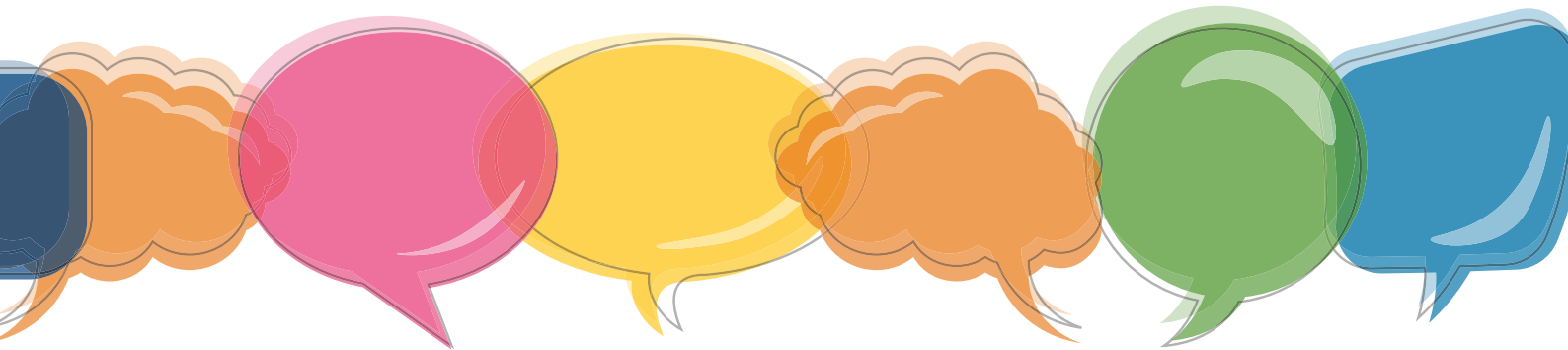


# National Specification for the Care and Treatment of Eating Disorders in Scotland



# Contents

<b>Introduction</b>	<b>3</b>
<b>Background</b>	<b>3</b>
<b>Implementation and Quality Assurance</b>	<b>5</b>
<b>What the Specification Covers</b>	<b>5</b>
<b>Who the Specification Applies To</b>	<b>6</b>
<b>Principles and Values</b>	<b>6</b>
<b>Mental Health and Wellbeing Strategy</b>	<b>8</b>
<b>Core Standards</b>	<b>9</b>
<b>Glossary</b>	<b>10</b>
<b>Summary of Outcomes</b>	<b>11</b>
Outcome 1: Leadership and Governance	12
Outcome 2: Service structure	16
Outcome 3: Access to Care	20
Outcome 4: Supporting people with Co-occurring Considerations and Comorbidities	23
Outcome 5: Assessment and Physical Risk Management	27
Outcome 6: Transitions	32
Outcome 7: Discharge	35
Outcome 8: Education and Training	38
Outcome 9: Shared and Supported Decision Making	41
<b>Appendix 1: Development of the Specification</b>	<b>43</b>
<b>Appendix 2: Membership of the Group</b>	<b>44</b>
<b>References</b>	<b>45</b>

# Introduction

Eating disorders are serious mental health conditions that involve abnormal eating behaviour and preoccupation with food, accompanied in most instances by prominent body weight or shape concerns (ICD-11, 2022). Eating disorders can have a significant impact on an individual's physical health, psychological wellbeing and associated functioning. ICD-11 classification (2022) includes several eating disorder categories including Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), and Other Specific Feeding and Eating Disorders (OSFED). It is estimated that around 1.25 million people in the UK have an eating disorder (Beat, 2022).

## Background

The National Specification for the Care and Treatment of Eating Disorders in Scotland has been developed in response to the National Review of Eating Disorder Services (2021), with a working group forming to develop them (see Appendix 2 for membership of the group). The aim of the National Review was to provide an overview of the current system of support for people with eating disorders, and their families and carers in Scotland. This built upon a previous report by the Mental Welfare Commission for Scotland (2020) which included a mapping of national eating disorder service provision. A significant number of stakeholders contributed to the review including individuals with experience of an eating disorder, their families, and clinicians. People with living/lived experience noted that while many services provide excellent care, there are areas for development and improvement:

- It can take a long time to access care;
- People can experience barriers to accessing the right treatment;
- People experience variability in services across the county;
- People often experience the transition between child and adolescent services and adult services as being very difficult;
- There appears to be a focus on services for Anorexia Nervosa and people with other eating disorders may find it difficult to access appropriate treatment, and
- Carers do not always feel well informed or included in treatment, especially in adult services, even though they provide significant support.

National Review of Eating Disorder Services (2021)

The National Review of Eating Disorder Services (2021) identified two main issues: lack of consistency in service provision, and confusion as to whether physical health monitoring was the responsibility of General Practitioners (GPs) or eating

disorder services. It was also identified that more training was needed for healthcare professionals to enable earlier detection, prompt referral, and appropriate treatment. (National Review of Eating Disorder Services, 2021). These findings were mirrored by the Mental Welfare Commission for Scotland (2020) who also noted the impact eating disorders can have on the whole family; concern about services using Body Mass Index (BMI) alone as a criterion for access to services; and inequalities in the national provision of eating disorder services.

In parallel to these national reports on eating disorder care, there have been two further prominent published guidelines that have informed the national specification for eating disorder care and treatment. The Scottish Intercollegiate Guidelines Network (SIGN) Guidelines for Eating Disorders (2022) provides recommendations based on the evidence for best practice in the management of people with eating disorders of all ages and gender groups, in any health or social care setting. The Medical Emergencies for Eating Disorders (MEED; 2022) provides comprehensive guidance on the recognition, assessment, and management of all eating disorders that people can present with as a medical emergency. Both documents are referenced throughout the Specification.

The Specification should be read alongside relevant legislation, policies, national health and well-being standards and health, and social care standards including:

- Core Mental Health Strategy (Scottish Government, 2023) [Available from: [Core mental health standards – gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/core-mental-health-standards-2023/)]
- Mental Health and Wellbeing Strategy (Scottish Government, 2023) [Available from: [Scotland’s Mental Health and Wellbeing: Strategy \(www.gov.scot\)](https://www.gov.scot/publications/mental-health-and-wellbeing-strategy-2023/)]
- National Health and Wellbeing Outcomes Framework (Scottish Government, 2015) [Available from: <https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/>]
- Health and Social Care Standards: My support, my life. (Scottish Government, 2018) [Available from: [Health and Social Care Standards: my support, my life – gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/health-and-social-care-standards-my-support-my-life-2018/)]
- Getting it Right for Every Child (GIRFEC National Practice Model) (Scottish Government, 2016) [Available from: <https://www.gov.scot/publications/girfec-national-practice-model/>]
- The Promise (Independent Care Review. The Promise. 2020 [cited 2021 Nov 1]; [Available from: <https://www.carereview.scot/wp-content/uploads/2020/02/The-Promise.pdf>]
- Realistic medicine, (Scottish Government 2016) [Available from: <https://www.gov.scot/publications/realistic-medicine-2016/>]
- **Mental Health Act (Scottish Government, 1983)** [Available from: [Mental Health Act 1983 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/1983/36/contents)]

# Implementation and Quality Assurance

The Specification supports national consistency in the delivery of eating disorder treatment. It has been developed to support local implementation by services, for example, to reflect local models of delivery and partnership working.

Each outcome within the Specification includes a section that outlines examples of evidence of achievement, and what it means for organisations and staff. These have been included to support internal quality assurance against the outcome. The Specification can also be used to inform organisational self-evaluation and improvement.

It is recognised that some elements of the Specification will involve structural changes to services. It is therefore recommended that implementation occurs over a ten-year period and is initially supported by the National Eating Disorder Network, the development of which has been recommended by the National Review of Eating Disorder Services (2021). This will enable national learning and cross service support on the practical implementation of the Specification in a phased and planned manner. Implementation will need to include local, regional and national elements.

## What the Specification Covers

The Specification outlines a national baseline of eating disorder service provision for the delivery of person-centred, safe, and effective care. It focuses on an optimal model of delivery to improve access to treatment, care, and support. The Specification applies across all levels of service provision from community outpatient teams to more intensive services, including inpatient and day services and the independent sector.

# Who the Specification Applies To

The Specification applies to the full developmental range of individuals who may present with eating disorders including children, young people, adults, and older adults. It also incorporates the full range of ICD-11 eating disorder presentations including AN, BN, BED, and Other Specified Feeding and Eating Disorder (OSFED) (ICD-11, 2022).

The Specification also includes ARFID, characterised by either: avoidance or restriction of food resulting in significant weight loss; clinically significant nutritional deficiencies; dependence on oral nutritional supplements or tube feeding; compromised physical health; or significant impairment in functioning (ICD-11, 2022). ARFID is not underpinned by a preoccupation with body weight or shape and as a result, is classified as a Feeding Disorder in ICD-11. However, it has been included in the Specification as it is recognised that the expertise of eating disorder professionals may be required to support comprehensive multi-agency treatment pathways in collaboration with a range of other organisations and services to provide the support required to meet patients' needs. This is a position mirrored by SIGN (2022), the National Review of Eating Disorder Services (2021), and MEED (2022).

## Principles and Values

The Specification is underpinned by principles and values aligned with quality healthcare provision.

- **Person-centred.** Providing care that is responsive to individual personal preferences, needs, and values and assuring that patient involvement/engagement guides and informs all clinical decisions (Healthcare Quality Strategy, NHS Scotland, 2010). The Specification supports patients to uphold their rights, for example through active engagement of individuals with lived/living experience in the design and evaluation of eating disorder services. The Specification has been informed by living/lived experience feedback from the National Review of Eating Disorder Service (2021).
- **Safe.** Patient safety is fundamental to the delivery of eating disorder treatment and care. Safe treatment for eating disorders addresses all aspects of the illness including physical, psychological, nutritional, and functional. The service structure and underlying protocols and pathways play an essential role in the delivery of safe care.

Several patients' deaths and other near-miss incidents have occurred following transfer between services at all levels. This includes child to adult mental health services, between two inpatient units, between medical units and specialist inpatient services, and between primary and secondary care (MEED, 2022). Similarly, transitions have been highlighted by stakeholders in the National Review of Eating Disorder Services (2021) as being particularly problematic. This led to the SIGN Guidelines for Eating Disorders (2022) to develop specific recommendations on managing transitions to supplement the existing Royal College of Psychiatrists (2017) Transition Guidelines for Patients with Eating Disorders.

An aim of the Specification has therefore been to reduce and prevent gaps in care via the provision of clear protocols and service agreements where essential transitions take place (e.g., differing levels of intensity of service provision within eating disorder services) and to change service structure to minimise unnecessary transitions where possible.

- **Effective.** The recommendations within the Specification are underpinned by scientific knowledge and include the provision of evidence-based interventions as recommended by SIGN (2022) and MEED (2022). The use of person-reported outcomes should be implemented in parallel with the national specification, following guidance by the National Eating Disorder Network.
- **Equitable.** Equitable healthcare involves providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, or socio-economic status. Stakeholders in the National Review of Eating Disorder Services (2021) and the Mental Welfare Commission (2020) report described variability in the availability of services, referring to a “postcode lottery”. The Specification aims to reduce this variability while acknowledging the diverse population needs of Scotland and the need for responsive implementation aligned with local models of delivery and partnership working.
- **Timely.** The need for early identification and intervention has been reinforced by the SIGN Guidelines for Eating Disorders (2022) which highlighted the potential accumulation of harm that can take place during an untreated eating disorder. This is partly a consequence of many eating disorders being more likely to develop during adolescence and early adulthood, a sensitive period for brain development (Schmidt, et al., 2016) and a time when an eating disorder can have a significant impact on physical health, social functioning, and educational attainment (Allen, et al., 2020). Treatment outcomes appear to be best during the first three years of illness (Treasure et al., 2015), yet most individuals do not access treatment for their eating disorder until many years after they first develop symptoms, if they access treatment at all (Allen, et al, 2020). SIGN (2022), highlights that our current NHS systems and pathways can compound delays in accessing treatment. Therefore, this Specification will support timely access to specialist eating disorders services, reduce barriers to care, and promote a culture of proactive engagement.

- **Efficient.** An efficient approach to eating disorder care and treatment is aligned with early intervention due to the significant impact this can have on health care use, psychological wellbeing, and quality of life. Initial evidence from First Episode Rapid Intervention for Eating Disorders (FREED) a service model designed to give young people rapid access to evidence-based treatment for eating disorders, suggests that the proportion of FREED patients that went on to require day or inpatient admissions was lower than typical service delivery models, giving cost savings (Allen et al., 2020, Austin et al., 2022; Fukutomi et al., 2020). This is replicated by international modelling analyses that have highlighted the long-term savings from early intervention for eating disorders (Butterfly Foundation, 2014; Bode et al., 2017).

Efficiency is also aligned with minimising duplication and reducing repetition. The ethos underpinning the Specification has been to change service structure to minimise unnecessary transitions and where possible to reduce obstacles in accessing specialist care e.g., unnecessary gatekeeping and/or multiple assessment processes leading to repetition of a patient's story.

- **Supportive relationships.** The Specification recognises the impact that eating disorders can have on the support networks around an individual including friends, family, and carers and the essential supportive function that extended interpersonal networks play in supporting recovery. The Specification mirrors the SIGN Guideline (2022) recommendations for the appropriate inclusion of family and/or carers in the support of individuals with eating disorders.

## Mental Health and Wellbeing Strategy

This Specification has been published in the context of the new Mental Health and Wellbeing Strategy. The Scottish Government and COSLA published its long-term vision and approach to improving the mental health and wellbeing of everyone in Scotland in June 2023. The Strategy is ambitious and describes what the Scottish Government and COSLA think a highly effective and well-functioning mental health system should look like – with the right support available, in the right place, at the right time, whenever anyone asks for help. ([Scotland's Mental Health and Wellbeing: Strategy \(www.gov.scot\)](https://www.gov.scot)).

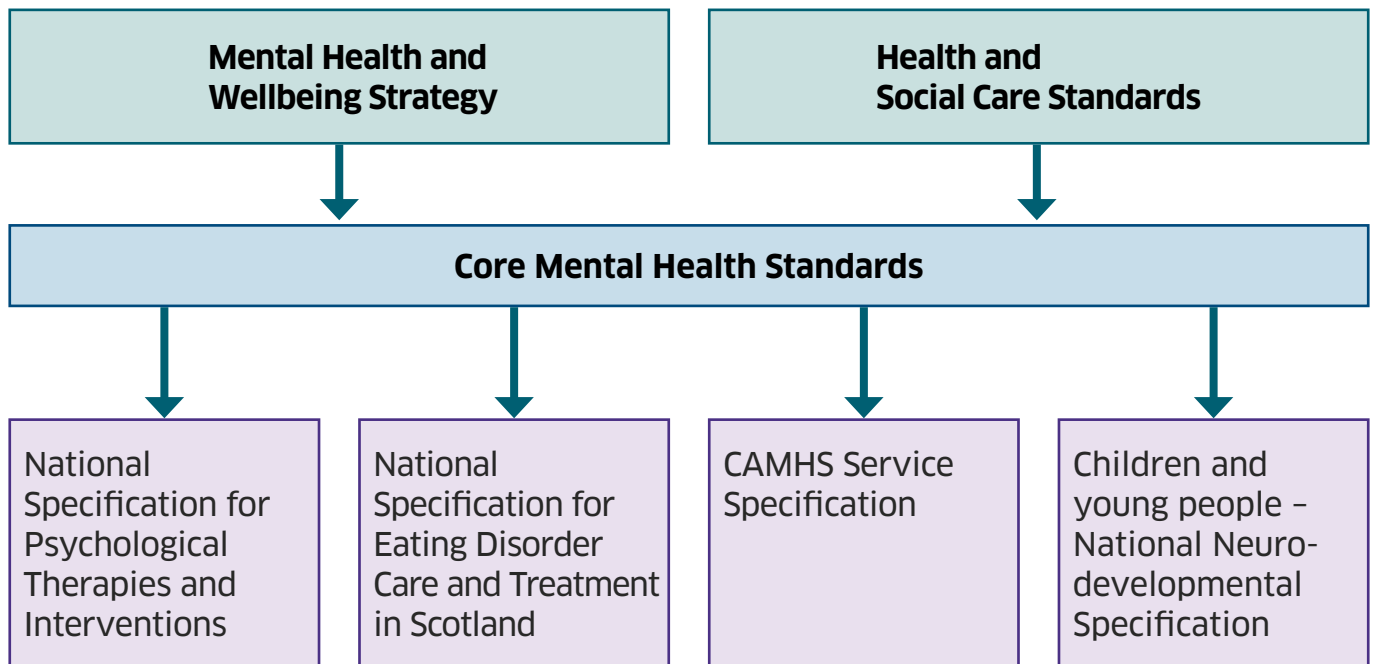


# Core Standards

As part of the Scottish Government's wider work to improve mental health services and care, we have developed new core mental health standards, which stem from the Mental Health and Wellbeing Strategy. These standards set out clear expectations for what services will provide, whilst recognising the need for local flexibility, and how we will provide assurance of high-quality care. These standards are designed to be aspirational about what good mental health services should look like. We know that many of these standards will already be being implemented by services but we also recognise that some of these may take longer for services to fully deliver in the face of ongoing systems pressures. We are therefore taking a phased approach to the measurement and implementation of the standards (see Annex A). This will include a pilot that will examine the feasibility of implementing the current set of standards which will inform any future refinements.

The standards have been developed in line with the vision of a Scotland, free from stigma and inequality, where everyone fulfils their right to achieve the best mental health and wellbeing possible. The core mental health standards can be accessed by clicking here: [Core mental health standards - gov.scot \(www.gov.scot\)](http://www.gov.scot).

The diagram below shows the Core Mental Health Standards and their relationship to the Health and Social Care Standards, Mental Health and Wellbeing Strategy and different specifications, including eating disorders.



# Glossary

This Specification, wherever possible, uses generic terminology that can be applied across all eating disorder providers and services.

Throughout the document, we refer to **organisations** implementing the Specification which is inclusive of NHS boards and where relevant these apply to third and independent sector too.

The term **representative** refers to any person that an individual experiencing care chooses to be involved in their care and support. This includes but is not limited to, next of kin, a power of attorney, carers, family, parents, or an independent advocate.

The term **family and/or carers** is inclusive of parents, carers, family, friends, and partners.

The term **co-occurring considerations** has been purposely used to acknowledge that this may be a more appropriate descriptor than comorbidity for some populations such as pregnancy, autistic individuals, etc.

The term **living/lived experience** refers to individuals with current or past experience of an eating disorder.

The term **all-age** refers to the full age range, from birth through to older adults.

The term **holistic assessment** refers to an assessment process which takes into consideration the overall health of an individual including physical, psychological, social, spiritual needs and levels of associated risk and functioning.

The term **multi-disciplinary** is used to describe a care team involved in the support and/or treatment of individuals that is made up of a variety of professionals.



# Summary of Outcomes

## **Outcome 1: Leadership and Governance**

Organisations demonstrate effective leadership, governance, and partnership working in the management and delivery of eating disorder services.

## **Outcome 2: Service Structure**

Organisations deliver a range of services which are safe, effective, and person-centred. High-quality treatment and support are delivered by multi-disciplinary teams working in partnership.

## **Outcome 3: Access to Care**

All individuals have equitable, consistent, and timely access to effective eating disorder health care and services. Services should be flexible and responsive to individual needs.

## **Outcome 4: Supporting People with Co-occurring Considerations and Comorbidities**

All individuals with co-occurring considerations and physical/psychiatric comorbidities have equitable, consistent, and timely access to effective eating disorder services and ongoing treatment and support.

## **Outcome 5: Assessment and Physical Risk Management**

All individuals have a holistic assessment and where clinically appropriate receive ongoing physical risk management.

## **Outcome 6: Transitions**

Clear transition protocols are in place and used routinely to support safe and coherent care.

## **Outcome 7: Discharge**

Discharge from eating disorder services is planned, collaborative, and based on individualised goals of treatment.

## **Outcome 8: Education and Training**

Organisations demonstrate commitment to the education and training of all staff involved in eating disorder services, appropriate to roles and workplace settings.

## **Outcome 9: Shared and Supported Decision Making**

All individuals receive inclusive information to facilitate informed choice and shared and supported decision making.

## Outcome 1: Leadership and Governance

### Outcome Statement

Organisations demonstrate effective leadership, governance, and partnership working in the management and delivery of eating disorder services.

### Rationale

Effective leadership and governance are critical to ensuring safe, person-centred, and high-quality health and social care services. Individuals accessing eating disorder services should have confidence that their care and support is of the highest quality. Services should understand people's needs and experiences by undertaking meaningful consultation and facilitating codesign.

People accessing services should benefit from partnership working at a local, regional, and national level. Effective planning and partnership work should be underpinned by arrangements and information sharing that facilitate the delivery of high-quality, equitable care.

Public health and clinical leadership should support effective planning and continuous quality improvement. To allow for effective planning and management, organisations must ensure the effective collation, analysis, and review of eating disorder data, such as local and national epidemiological and improvement data.

### Outcome in Action

- 1.1 Organisations can demonstrate robust governance arrangements, with clear lines of accountability, covering all aspects of the patient journey.
- 1.2 Organisations can demonstrate a commitment to quality planning and assurance through:
  - effective data collection, including data on health inequalities
  - involving people with living/lived experience at both multi-disciplinary team and leadership level to meaningfully shape service design and delivery
  - local and national benchmarking against agreed outcomes, and
  - clear alignment of strategic policy objectives and implementation strategies, and routine monitoring of patient outcomes to inform interventions.
- 1.3 Organisations can demonstrate a commitment to international human rights conventions by:
  - taking a rights-based approach to service planning and delivery, and
  - routinely informing people of their rights and providing comprehensive training to staff on upholding people's rights, which is updated when necessary and appropriate to their role and setting.

- 1.4 People are given meaningful opportunities to participate in the design and evaluation of eating disorder services, and organisations can demonstrate where this feedback has resulted in change.
- 1.5 There are clear and structured risk management and adverse events processes, which include:
  - accountability and responsibility arrangements for reporting any risks, including monitoring people at risk
  - accountability and responsibility arrangements for reporting adverse events
  - a consistent approach to reporting adverse events
  - a documented escalation process for adverse events, and
  - organisational learning from adverse events.
- 1.6 Information management structures and governance processes are in place to support:
  - national data collection (CAPTND), benchmarking, and performance to improve patient safety and quality of care, where appropriate, and
  - the routine sharing, with fully informed consent, of identifiable personal healthcare data between care providers, and the effective collation of anonymised data in support of care governance.
- 1.7 Organisations support and encourage service evaluation, audit, and research to develop and share best practice.
- 1.8 There is regular review and audits of clinical environment and resources, making sure these are accessible for those with protected characteristics, sensory, and communication differences.
- 1.9 There are agreed pathways and processes, developed with people with living/lived experience, to ensure:
  - accessible and responsive care, including self-referral options
  - information is shared appropriately between public health and primary care, secondary care, laboratories, third sector, local authority, and independent healthcare sector services
  - there are resilience plans for service disruption
  - there is clear communication of physical risk assessment and test results and onward referral for management and support as necessary
  - prioritisation of those most in need
  - individuals with co-occurring considerations such as pregnancy, diabetes, mental health concerns, and neurodivergent individuals are adequately and appropriately supported, and
  - appropriate signposting to additional areas of support, including the third sector, as necessary.

**1.10** There are systems in place to ensure that all medical equipment used in the provision of eating disorder care have:

- planned preventative maintenance, and
- a mechanism for routine checks and testing, and rolling replacement schedules.

### **What does this mean for the person receiving care?**

You can be confident that:

- you will receive a safe, equitable, and high-quality service that is personalised to meet your needs and which will include members of your support network as appropriate
- services are committed to quality improvement, have effective leadership and governance, and are engaging effectively with people with living/lived experience of eating disorders and using services
- you will be given meaningful opportunities to participate in decisions about how services are shaped
- information about you and your care will be shared with your consent, where appropriate, and in line with national guidance, and
- that while you wait for access, there will be a process in place to support escalation of concerns in the event of significant deterioration while waiting.

### **What does this mean for staff?**

Staff:

- understand and can access care pathways, standards, and guidance relevant to their role
- actively participate in the multi-disciplinary team and are supported by their organisations to understand their role
- are aware of how to report and escalate adverse events
- are proactive in raising and responding to identified concerns which may impact on patient safety and care, and
- are encouraged and supported to work collaboratively with allied services.

### **What does this mean for the organisation?**

The organisation:

- has governance arrangements in place to determine roles, responsibilities, and lines of accountability, including adverse event management
- supports a culture where concerns can be raised and appropriately acted upon
- ensures co-ordinated person-centred pathways for access and delivery of care are developed and implemented including alignment with other mental health pathways, guidelines reporting and IT

- performs routine monitoring of outcomes to inform health interventions and improve service delivery, including experience of service delivery
- monitors and responds to areas of concern
- engage with staff, patients, and carers to identify areas for improvement
- record and monitor data in line with CAPTND
- undertake quality improvement and assurance activities to ensure performance against the Specification
- has planned preventative maintenance, quality assurance checks, and a rolling replacement schedule in place for all equipment and peripherals
- encourages research and clinical excellence where research is undertaken and has processes in place to monitor people awaiting services, including how risk and reassessment are managed, and
- support a professional Network to deliver the regional and national implementation of the Specification.

### **Practical examples of evidence of achievement**

*(NOTE: this list is not exhaustive)*

- Documentation describing lines of accountability, roles and responsibilities, and escalation of adverse event reporting.
- Documentation describing monitoring and reporting systems for local strategic aims and objectives, quality improvement, and service delivery objectives.
- Care pathways and local and national standard operating procedures demonstrating multi-disciplinary working.
- Improvement work, including action plans, data collection and review of data, such as feedback from service users, staff members, national benchmarking, and evidence of timeliness of processes.
- Documentation describing preventative maintenance, quality assurance checks, and rolling replacement schedules for equipment and peripherals.
- A management system for reporting, reviewing, and learning from all types of adverse events.
- Evidence of research activity.
- Evaluation of clinical effectiveness against national or local standards.
- Evidence of codesigned service plans, innovative engagement with local communities, and good communication with service users.

## Outcome 2: Service Structure

### Outcome Statement

Organisations deliver a range of services which are safe, effective, and person-centred. High-quality treatment and support are delivered by multi-disciplinary teams working in partnership.

### Rationale

Patient safety is fundamental to the delivery of eating disorder treatment and care. The service structure and underlying protocols and pathways play an essential role in the delivery of safe care. The aim of the Specification is to reduce and prevent gaps in care via the provision of clear protocols and service agreements and to change service structure to improve patient safety where possible. This includes consideration of the implementation of the recommendations of all-age eating disorder services across Scotland (National Review of Eating Disorder Services, 2021) while making sure that the developmental needs of younger populations, and associated assessment of risk and specialist intervention, are not lost in the potential merging of services.

International clinical practice guidelines recommend that most individuals with an eating disorder should be treated in outpatient care (Hay et al., 2019). This is led by the need for efficient use of healthcare resources, patient preference, and greater adherence to outpatient treatment in clinical trials (Freeman, 1992; Gowers, et al., 2007). However, when individuals cannot be managed in the community due to physical or psychiatric risk, there is a need for a range of more intensive service structures inclusive of day patient, intensive outreach, and inpatient treatment.

Stakeholders in the National Review of Eating Disorder Services (2021) described variability in the availability of services. This Specification aims to reduce this variability while acknowledging the diverse population needs of Scotland including remote and rural locations where different models of service delivery, such as regional multi-disciplinary teams and services, may be more appropriate.

Clinical consensus indicates that the optimal model of service delivery for people with an eating disorder is a dedicated, multi-disciplinary eating disorder services (NHS England, 2019).

### Outcome in Action

- 2.1 Organisations ensure a range of services, with varying intensities of provision, are developed. These should be based on individual assessment and clinical risk, and available to all people who have been assessed as requiring treatment and support.
- 2.2 Consideration will be given to a specialist all-age ED service. All organisations will ensure continuity of specialist care to individuals across ages and areas while meeting the full range of developmental needs of children, young people, adults, and older adults.



- 2.3 Organisations ensure a range of options in the delivery of care are offered which are person-centred, responsive and trauma-informed. These include:
- inpatient care
  - outpatient care
  - day services
  - outreach including intensive outreach services
  - digital and online technology, and
  - freely available evidence-based self-help materials.
- 2.4 Different models and intensity of service provision are integrated with transparent pathways and protocols to enable safe provision of treatment at points of transition and to support individuals to experience their care as connected, coherent, and recovery-focused.
- 2.5 Clear protocols are in place to manage:
- risk and safety, and
  - unattended appointments.
- 2.6 Assertive and proactive follow-up protocols are in place that are designed to prevent inappropriate discharge and support engagement in treatment and care.
- 2.7 Organisations ensure that services are delivered by multi-disciplinary teams who work in effective partnerships with other agencies and the third sector.
- 2.8 Where health boards have smaller populations, creation of regional specialist eating disorder multi-disciplinary teams may be appropriate. Appropriate protocols should be developed to ensure seamless information exchange (within the parameters of information governance and informed consent) and consistency in care and treatment.
- 2.9 As a minimum, essential outpatient care should include:
- psychiatric assessment and review
  - SIGN and **The Matrix** (A Guide to Delivering Evidence Based Psychological Therapies and Interventions in Scotland) recommended psychological practice
  - physical risk management
  - medication, and
  - dietetic intervention.

**2.10** An ideal staffing mix for a comprehensive eating disorder all-age service should include:

- administrative staff
- dietitians
- family therapists
- medical professionals (e.g. clinical nurse consultant, GP, physician, paediatrician)
- nursing staff
- occupational therapists
- peer support workers
- physiotherapists
- psychiatrists
- applied psychologists (including assistant psychologists)
- psychological therapists
- social workers, and
- support workers.

Where appropriate, people are supported to access speech, language or communication assessment and support, and art and creative therapies.

### **What does this mean for people?**

You:

- will receive safe and high-quality eating disorder treatment from a multi-disciplinary team
- can be confident that while the majority of eating disorder treatment is provided on an outpatient basis, you can access a range of higher intensity eating disorder services if required, and
- will have an opportunity to feedback on the service you have received without any negative impact on your care and treatment.

### **What does this mean for staff?**

Staff:

- are well supported in a multi-disciplinary eating disorder team
- receive appropriate training and receive effective clinical supervision appropriate to their role and workplace setting, and
- understand and can access care pathways, standards, and guidance as appropriate

## What does this mean for the organisation?

The organisation:

- considers developing an all-age range specialist eating disorder service and ensures continuity of care across the age range and across contexts
- routinely assesses service capacity to implement the Specification, and develops associated staff training plans to meet the need for evidence-based care
- participates in national reporting of routine outcomes
- can access higher intensity specialist eating disorder service provision including day services, intensive treatment services, and inpatient, and
- has clear protocols in place to manage risk and safety, and transition between services that are assertive and proactive in nature.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Development of an all-age eating disorder service.
- Regional specialist eating disorder multi-disciplinary teams in health boards with smaller populations.
- Cross-health board protocols to facilitate seamless information exchange and consistency in care and treatment.
- Details of staff mix and referral pathways.



## Outcome 3: Access to Care

### Outcome Statement

All individuals have equitable, consistent, and timely access to effective eating disorder health care and services. Services should be flexible and responsive to individual needs.

### Rationale

The need for early identification and intervention has been reinforced by the SIGN Guidelines for Eating Disorders (2022). It highlighted the potential accumulation of harm that can take place during an untreated eating disorder and that our current NHS systems and pathways can compound delays in accessing treatment.

This has also been reiterated by stakeholder feedback to the National Review of Eating Disorder Services (2021) that identified several areas of concern around access to care in Scotland. Specifically:

- stakeholders drew attention to how long it can take to access specialist eating disorder care
- individuals reported experiencing barriers to accessing the right treatment
- stakeholders highlighted a predominant service focus on Anorexia Nervosa, meaning individuals with other eating disorders could find it difficult to access appropriate treatment.

There is therefore a clear need for this Specification to be underpinned by the values highlighted in the Scottish Government's Mental Health Strategy (2017-2027) including a focus on early intervention and equal access to the most effective, evidence-based, and safest care and treatment for individuals experiencing a range of eating disorder presentations.

### Outcome in Action

- 3.1 Organisations ensure equitable and consistent access to services, treatment, and care regardless of a person's protected characteristics.
- 3.2 Eating disorder services are accessible to individuals with the full range of eating disorders including OSFED, BED and as part of a multi-agency pathway for ARFID, and access is equal and consistent irrespective of the episode of presentation.
- 3.3 Individuals with a primary diagnosis of BED will be offered an evidence-based pathway in specialist eating disorder services which will include effective links with weight management services.

- 3.4 Organisations should reduce barriers to care and promote a culture that enables outreach, proactive engagement, and enhances accessibility.
- 3.5 Specialist eating disorder services are supported to accept self-referrals and referrals from any relevant professional, including counsellors, school nurses, and the third sector.
- 3.6 Each service has clear accessible information in a range of languages and formats that include:
- accessible contact details that are easy to find
  - clear instructions on how to contact the service or submit an online self-referral form, and
  - 'first line advice' while individuals wait to be seen.
- 3.7 A range of methods of self-referral are available for those unable to access online referral forms. Clear and accessible guidance on alternative methods of referral should be available.
- 3.8 People have access to services and treatment as soon as they are needed with immediate access to treatment and support, where appropriate. This includes people who present:
- early in the development of the illness
  - early in help-seeking, or
  - early in recurrent episodes of illness or relapse.
- 3.9 Organisations ensure that decisions on accepting a referral (including self-referral) should be based on a holistic assessment and review of an individual's circumstances, needs, and preferences and not based solely on clinical measurements such as BMI and taking into account vulnerability and risk.
- 3.10 Individuals with an eating disorder should receive SIGN concordant treatment in specialist eating disorder services within appropriate timelines:
- maximum of four weeks from receipt of a referral for routine cases, and
  - within one week from referral for urgent cases.
- 3.11 All eating disorder services are accessible and safe for individuals in larger bodies including access to specialist equipment for monitoring physical health and the clinical environment.

## What does this mean for the person receiving care?

You will:

- be able to see the right person in the right place at the right time
- be able to self-refer to specialist eating disorder services, if think you might have an eating disorder, and
- be seen by people with appropriate skills, knowledge, and competencies.

## What does this mean for staff?

Staff:

- in collaboration with those with living/lived experience, develop an action plan to reduce barriers to accessing specialist services and implement associated mechanisms, including the use of self-referral, and
- have the skills and capacity to deliver timely evidence-based interventions for the full range of eating disorders.

## What does this mean for the organisation?

The organisation:

- assesses service capacity to embed the national specification, and develop associated staff training plans to meet the need for evidence-based care
- supports services to accept self-referrals
- undertakes regular audits of referral data to understand representation aligned with prevalence rates and local population demographics, with associated action plans to reduce inequalities, and
- participates in national reporting of standardised waiting time data.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- An annual audit of eating disorder referrals to a local specialist eating disorders team using standardised data collection.
- Comparison of referral data nationally and with prevalence rates and local population demographics.
- Identification of potential areas of health inequalities (e.g. lack of males being referred) and an action plan developed, in partnership with individuals with living/lived experience including individuals from that particular demographic, to reduce inequalities.
- An easily accessible website with clear information on service criteria and accessible first link advice.
- Information is available in a range of languages relevant to the local population and in accessible formats.

## Outcome 4: Supporting people with Co-occurring Considerations and Comorbidities

### Outcome Statement

All individuals with co-occurring considerations and physical/psychiatric comorbidities have equitable, consistent, and timely access to effective eating disorder services and ongoing treatment and support.

### Rationale

Individuals with eating disorders frequently experience a high level of co-occurring considerations in addition to the physical health problems experienced because of the disordered eating symptomatology. The term **co-occurring considerations** has been purposely used to acknowledge that this may be a more appropriate descriptor than comorbidity for some populations including people who are pregnant or autistic.

It has been estimated that over 70% of individuals with an eating disorder experience at least one other psychiatric disorder and that this is linked with increased severity of eating disorder symptoms (Spindler and Milos, 2007). Eating problems are twice as common in people with type 1 diabetes than in people without diabetes (SIGN, 2022). Research indicates that 20-30% of individuals with AN display diagnostic features characteristic of autism (Westwood et al, 2017). Individuals who report more autistic features are more likely to present with more severe ED psychopathology (Kerr-Gaffney et al, 2019); are more likely to require inpatient or intensive day programme treatment (Stewart et al., 2017), and report poorer global outcomes post treatment (Nazar, et al., 2018; Nielsen et al., 2022).

When supporting individuals with co-occurring considerations and/or comorbidity, eating disorder services should work with individuals to deliver responsive and person-centred care. Staff should also work in partnership with other services, agencies, and the third sector to provide joint integrated care. Where possible, a lead service should be identified/nominated to coordinate care. A focus should be on continuity of care, with supported information sharing to enable shared treatment. NHS eating disorder services should ensure specialist pathways for individuals with comorbidities and/or co-occurring considerations to promote person-centred care, and treatment should be flexible to ensure that individual needs and goals are of utmost consideration.

It may be appropriate for support to be provided on a longer-term basis to ensure that individuals can maintain progress made in treatment. Clinical expertise would suggest that pathways to support people with co-occurring considerations should include the capacity to access diagnostic pathways, multi-disciplinary assessments (including sensory assessment, communication assessments, and medical assessments), and adaptations to treatment delivered by appropriately trained staff.

In September 2021, the Scottish Government published the **National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care** which sets out seven standards for service providers to ensure that children and young people, who have neurodevelopmental profiles with support needs, receive support that better meets their needs. These standards should be considered in parallel with the Specification.

## Outcome in Action

- 4.1 People with co-occurring considerations and/or comorbidity have equitable access to care, treatment, and support. In addition, there should be no delay to referral or treatment.
- 4.2 Organisations ensure that eating disorder services follow SIGN (2022) and MEED (2022) guidelines for the assessment and treatment of eating disorders for individuals with co-occurring considerations and/or comorbidity.
- 4.3 Patients with diabetes and eating disorders receive shared care from diabetic professionals and mental health specialists and appropriate physical risk assessment as recommended by SIGN (2022) and MEED (2022).
- 4.4 Eating disorder services have specialist pathways, that include joint working with other services such as weight management if appropriate, developed in partnership with people with living/lived experience, for individuals with specific considerations including but not limited to:
  - diabetes
  - obesity
  - pregnancy and those in the postnatal period
  - individuals with long standing eating disorder presentations
  - other mental health conditions
  - autism and neurodivergence (whether formally diagnosed or not), and/or
  - ARFID.
- 4.5 Organisations ensure that when joint working takes place between services, that service provision is integrated with transparent pathways and protocols, including a clear agreement on clinical responsibility and information sharing (with appropriate consent).



## **What does this mean for the person receiving care?**

You will:

- receive a comprehensive assessment
- be supported to consider different treatments or options, including joint working with other services appropriate to your needs
- be fully involved in developing your treatment plan which will take into account your personal views and preferences, and
- be seen by people with appropriate skills, knowledge, and competencies, including staff who have specialist training aligned with your needs.

## **What does this mean for staff?**

Staff:

- will receive appropriate training and support to effectively assess common comorbidities and co-occurring considerations as part of a holistic eating disorder assessment, and
- can understand and can access specialist pathways for individuals with common co-occurring considerations, and
- support people to access health, social care, and third sector support, and
- will receive appropriate training to develop skills in the treatment of individuals with eating disorders and comorbidities/co-occurring considerations.

## **What does this mean for the organisation?**

Organisations:

- have clear protocols in place for joint working between services including diagnostic assessments
- ensure specialist pathways are developed in partnership with people with living/lived experience, for individuals with co-occurring considerations, and
- perform regular audits of adherence to protocols and pathways.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Pathways (co-produced with people with lived/living experience) to support joint working to facilitate early identification and intervention, appropriate assessment, and suitably adapted and effective intervention led by trained staff.

For example:

- pathway for people with diabetes which integrates with diabetes services
  - pathway for autistic individuals (whether formally diagnosed or not) using best practice principles recommended by the PEACE pathway including adaptations to the clinical environment, adaptations to treatment and care, screening, and associated referral pathways for neurodevelopmental assessment if required.
- Regular audit of adherence to pathways including patient experience feedback.



## Outcome 5: Assessment and Physical Risk Management

### Outcome Statement

All individuals have a holistic multi-dimensional assessment and where clinically appropriate receive ongoing physical risk management.

### Rationale

This outcome is aimed at the generic assessment process within specialist eating disorder services and associated risk assessment, including ongoing physical risk assessment and management, including physical monitoring in both primary care and specialist services.

Assessment in specialist eating disorder services should be holistic, covering physical health, mental health (including comorbidities), social factors, and co-occurring considerations. This should be completed by an experienced and appropriately trained clinician. An assessment should not be based on single measures (for example BMI) and instead should identify the full range of eating disorder symptomatology and comprehensively review an individual's circumstances. Screening tools and physical observations should never be used in isolation to determine whether someone has an eating disorder.

A holistic, multi-dimensional assessment should result in a shared understanding of the presenting problem and the person's needs. This will enable a review of available evidence-based treatment options to support the individual in making an informed and collaborative decision about their treatment and care. Assessment is a continuous process and any changes to an individual's presentation should be monitored and reviewed with care plans regularly updated to reflect current needs.

Assessment in eating disorder services should be proactive, using an outreach approach to support engagement. Clinicians should be prepared that they may at times support individuals with some uncertainty about engaging in treatment. Although patients may have a good understanding, reasoning, and appreciation of their illness, the change in values and sense of identity that can result from their illness can impact on decision making. The issue of treatment acceptance and patient autonomy is therefore complex and not static. MEED highlight that the common factors in successful services seem to be cooperation, trust, shared protocols, regular networking, and intensive, proactive (rather than reactive) care (MEED, 2022).

Responsibility for outreach and follow up to support engagement with assessment lies with the service, and clear time frames and service expectations should be set to support this. This approach should be person-centred supporting appropriate service flexibility in times and locations of assessment appointments. As part of this engagement and assessment process, family and carer support can be provided without breaching patient confidentiality and should be offered to families or carers, when appropriate, even if an individual is not accessing services (SIGN, 2022). Peer support workers could also be used as a tool for supporting engagement with treatment for adults with eating disorders.

Multi-dimensional risk assessment includes both psychiatric and physical health monitoring. It is essential that eating disorder services have the capacity to manage the physical risk which will include physical monitoring. It is essential that eating disorder services are having the skills, equipment and systems to support physical monitoring as part of an individual's care plan. Along with physical monitoring it is essential that the clinician assesses risks in psychological and social domains while paying attention to matters of insight, motivation, consent, and the legal framework for intervention. When a patient is very unwell or highly distressed, they may lack capacity/competence in relation to particular decisions. Also, the nature of the illness and associated eating disorder cognitions may affect the capacity to provide an accurate account of presentation; this can also falsely assure clinicians of risk. Teams should document the nature and level of risk, and the nature of the best interest decision and act to reduce risk and preserve life (MEED, 2022). The need for emergency medical or psychiatric admission for anyone at risk of serious physical complications, suicide or serious self-harm should also be considered.

Initial physical and psychiatric risk assessment in primary care allows specialist eating disorder service to prioritise referrals and for a referrer to indicate the urgency of care that is required. Clear guidance should be in place for primary care based on MEED (2022) and access to consultation with specialist services when required. In some instances, a shared care approach may be used between specialist eating disorder services and primary care. If this has been formally agreed, clear protocols should be in place for physical monitoring based on the detailed guidance supplied by MEED (2022). This protocol should be collaboratively developed at an organisational level including clear documentation of the responsibilities for each service in the undertaking of physical monitoring, checking results, and actioning any escalation that may be required in a timely manner. Clear service protocols should also be in place detailing the process and clinical responsibility for physical risk assessment and management, while an individual is waiting to be assessed or being supported to engage in this process. This should include documenting who holds clinical responsibility at this time, and the associated processes for monitoring changes in presentation and risk. All individuals involved in physical risk assessment and management should have the necessary skills and training to identify monitor and manage eating disorder behaviours, symptomatology and knowledge of eating disorder physical risk assessment guidance.

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.

## Outcome in Action

- 5.1 Holistic assessments are completed by an experienced and appropriately trained clinician.
- 5.2 Clear service protocols and pathways are in place while an individual is waiting to be assessed or is being supported to engage in this process detailing:
  - who holds clinical responsibility, and
  - associated processes for monitoring changes in presentation or risk, who is responsible for this and how this is escalated if appropriate.
- 5.3 Clear clinical practice guidelines for physical risk assessment and management including physical monitoring are in place and easily accessible for referrers and clinicians within the service that:
  - align with MEED (2022)
  - are followed by risk assessment and documented escalation processes, as appropriate, and
  - detail potential challenges to accurate risk assessment.
- 5.4 Where a shared care approach is used between specialist eating disorder services and primary care for ongoing physical risk assessment and management including physical monitoring, a clear protocol exists including:
  - agreement and documentation of which service holds clinical responsibility, and
  - associated expectations for physical monitoring, including who undertakes the physical health assessment, checks and interprets results and has ownership of the overall physical risk assessment results, and associated risk assessment. There should be protocols for escalating concerns if required.
- 5.5 Organisations ensure health care professionals have the necessary training and skills appropriate to their role, responsibilities, and workplace setting, to identify, monitor and manage eating disorder behaviours.
- 5.6 Organisations ensure that staff have the appropriate skills and competencies to predict and monitor early biochemical signs of refeeding syndrome and how to manage physical risk in line with MEED (2022).
- 5.7 Organisations ensure services use protocols for refeeding within acute and community settings that emphasise the need to avoid under-nutrition and refeeding syndrome.
- 5.8 Organisations ensure that there are protocols in place to establish baselines as part of physical health monitoring. Baseline data should be considered in the context of, and following discussion with, the person.

- 5.9 Patients with purging behaviour, are supported to access regular dental visits for dental monitoring and treatment.
- 5.10 Clinicians should consider whether the Mental Health (Care and Treatment) (Scotland) Act 2003 needs to be invoked when a patient (of any age) declines treatment. There may be a responsibility to provide compulsory treatment if there is a risk to the person's life or to prevent significant deterioration health and wellbeing (SIGN, 2022).
- 5.11 Organisations ensure services have access to psychiatric and/or acute inpatient treatment for stabilisation when indicated for those at immediate risk. Specialist eating disorders teams should establish close links and shared care during inpatient admission for continuity of patient care.
- 5.12 Organisations ensure that services provide robust physical health monitoring and appropriate referral during antenatal, perinatal and postnatal periods.
- 5.13 Organisations ensure the provision of accurate, reliable, and responsive information and support on dysfunctional activity and exercise and misuse of steroids.
- 5.14 Organisations ensure that patients with a long-standing eating disorder, experience a person-centred approach to for physical risk assessment and management.
- 5.15 Organisations demonstrate they are implementing MEED (2022) and SIGN (2022).

### **What does this mean for the person receiving care?**

You:

- will receive a comprehensive assessment by a specialist eating disorder clinician to support a shared understanding of the presenting problem and your individual needs
- will be supported to engage in the service to meet your needs
- are safely physically assessed throughout the course of your wait, assessment, and treatment with the service.

## What does this mean for staff?

Staff are:

- provided with the necessary training to support the provision of a holistic assessment and safe and effective for physical risk assessment and management
- can access physical health monitoring equipment to safely and effectively provide for physical risk assessment and management within the service, and this is regularly audited and maintained
- supported to take a proactive outreach approach to support individuals to engage with/in the service, and
- aware of service protocols for physical risk assessment and management and shared care clinical responsibilities of each service if appropriate.

## What does this mean for the organisation?

The organisation ensures:

- there is clear and easily accessible guidance on for physical risk assessment and management for primary care colleagues to support risk management
- physical risk assessment and management protocols are based on MEED (2022) guidance, and
- that if shared care with primary care is used, that this is agreed at an organisational level, with clear documented protocols detailing clinical responsibilities
- will ensure that appropriate governance around physical risk assessment and management is in place

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Shared care agreements between the specialist eating disorder service and primary care to support for physical risk assessment and management in a remote and rural location.
- Protocol detailing who holds clinical responsibility and associated processes for each step of the for physical risk assessment and management.
- Protocol outlining outreach approaches to support engagement.
- Details of training and support available to staff.
- Evidence of implementation of SIGN and MEED guidance.
- Evidence of information (in a range of languages and formats) to support patients in their decision making including the use of steroids.

## Outcome 6: Transitions

### Outcome Statement

Clear transition protocols are in place and used routinely to support safe and coherent care.

### Rationale

Transitions are points of increased risk for individuals with eating disorders and can adversely affect quality of care and patient safety. Transitions have been highlighted as being a significant problem for individuals with eating disorders (National Review of Eating Disorder Services, 2021). The ethos underpinning transitions should be to remove gaps in care and delays in treatment for the benefit and safety of the patient, rather than protocols based on service needs. Consideration of the development of all-age community eating disorder services in Scotland (as recommended by the National Review of Eating Disorder Services, 2021) will minimise transitions due to age. However, individuals with eating disorders will still experience essential transitions of care, e.g. differing levels of intensity of service provision depending on the provider, and/or geographical moves.

Transition protocols should be in place to support good communication between and within services and providers with clear lines of responsibilities to support safe and coherent care. Careful consideration should be made to reduce repetition and/or unnecessary service barriers (e.g. a transfer of care needing to be assessed by a primary care mental health team prior to specialist eating disorder services).

SIGN Guidelines for Eating Disorders (2022) propose specific recommendations on managing transitions to supplement the existing Royal College of Psychiatrists (2017) Transition Guidelines for Patients with Eating Disorders. This is in addition to existing guidance from Healthcare Improvement Scotland on Transition Planning from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (2018). In 2018 the Scottish Government published the Transition Care Plan (TCP) Guidance, describing the standards required in the planning of good transitions for young people moving from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services. This approach allows flexibility for those aged 18-25 to continue their care and treatment with CAMHS where this is in their best interests rather than automatic transfer to adult services.

When a transition of care takes place, the transition should be identified early, prepared, managed, and followed up by clinicians in both services (SIGN, 2022). Where appropriate, services should work collaboratively for six months before the planned transition to ensure seamless care (Royal College of Psychiatrists, 2017). A written transition plan should be drawn up in collaboration with the patient (and representative, where appropriate) and clinician(s). This plan should be readily accessible and shared appropriately, following consent (SIGN, 2022). Transition plans should include physical risk management (MEED, 2022) with clear lines of clinical responsibility documented.



## Outcome in Action

- 6.1 Organisations ensure that transition protocols are in place to support effective communication between services. This includes external and internal service transitions with clear lines of responsibilities to support safe and coherent care.
- 6.2 Organisations ensure that transfers of open and active cases to other eating disorder services, will not be placed on a waiting list again and should be seen immediately without delay.
- 6.3 Eating disorder services should collaboratively develop a written transition plan with an individual and where appropriate their representative. Where appropriate, services should work collaboratively for six months before the planned transition and written plans should include risk assessment and consider medical monitoring, with clear lines of clinical responsibility documented.
- 6.4 For patients in, or moving to Higher Education, eating disorder services should work closely with primary care and University/College mental health services to support consistent and integrated care and minimise delays in treatment.  
  
The option to retain treatment with services in an individual's home board could be considered while an individual attends Higher Education in another locality if this supports consistency in care, with clear risk assessment and medical monitoring responsibilities agreed.
- 6.5 Eating disorder services should provide the person's representative with information and advice around the transition where appropriate and with consent.

## What does this mean for the person receiving care?

You:

- will experience continuity and consistency in your care
- will develop a joint plan with your clinicians which will support you if you move between services and this plan will be accessible to you to share, and
- will not be put back onto a wait list when moving between services in Scotland within or between Health Boards if you are receiving active eating disorder treatment or if you are moving from elsewhere in the UK to Scotland including for Higher Education.

## What does this mean for staff?

Staff:

- understand and can access transitions protocols for within and between services, and
- will know who is responsible for medical monitoring and has clinical responsibility for care at all points of the transition.

## What does this mean for the organisation?

The organisation:

- considers developing an all-age range specialist eating disorder service and ensures continuity of care across the age range and across contexts will not put individuals back onto a wait list when moving between services in Scotland within or between Health Boards and will prioritise continuity of care
- ensures clear protocols are in place for transitions within and between services
- has transition protocols which are person-centred and reduce repetition and/or unnecessary service barriers, e.g. individuals being placed back on a waiting list or needing to be assessed by a primary care mental health team prior to accessing their new specialist eating disorder service)
- ensures transition protocols stipulate clinical responsibility for care and medical monitoring for each point of service transition, and
- performs regular audits of adherence to transition protocols.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Clear transition protocols for each level of common transition pathways within and between services.
- Standardised information is available for individuals with eating disorders and their carers or representatives, where appropriate, to explain the transition process and relevant information on the services they are transitioning to.
- Audit to demonstrate regular transition meetings between services that experience frequent transitions with each other to support good working relationships and to resolve any areas of concern or unmet needs.
- Feedback from individuals who have recently experienced service transitions to support learning and continued development of co-produced transition protocols.

## Outcome 7: Discharge

### Outcome Statement

Discharge from eating disorder services is planned, collaborative, and based on individualised goals of treatment.

### Rationale

Effective and person-centred discharge from services is important for people experiencing services, as well as for staff and organisations. Discharge can be a point of anxiety for individuals with eating disorders and their representatives and wider support networks. It can also be influenced by service pressures and clinical demands, meaning discharge processes have the potential to become service-led rather than person-centred.

In parallel to the requirements to access eating disorder services, discharge should never solely be based on a person's BMI, weight, or frequency of binge and purge episodes. Instead, discharge should be planned and based on a continuous holistic assessment of an individual's needs and person-centred treatment goals. A co-produced discharge plan should include a detailed relapse management plan, advice on the process and expectations of re-entering treatment if required, and signposting for ongoing support in the community from health, social care, and third sector on discharge. For individuals who have had a long duration of illness, it might be preferable for services to provide flexible 'light touch' contact as a means of maintaining the quality of life they have reached, rather than full discharge to external community support. This is of particular importance for patients who have been involved with services for many years and for whom the transition from services will require support.

### Outcome in Action

**7.1** Organisations ensure that discharges from care are:

- based on a holistic assessment and review of an individual's circumstances, needs, and preferences
- not be based solely on clinical measurements such as BMI
- planned following informed decision making involving patients and their representatives where appropriate, and
- phased with the ability to re-engage directly with the same service if there is a need to do so
- offering collaborative discharge and relapse prevention plans including physical risk management, and
- where there is disagreement about discharge or unplanned discharge then clear communication should be provided with the primary care and the person receiving care.

- 7.2** Organisations consider options for ongoing support to ensure that there are options for ongoing support with the service as an alternative to full discharge to the community which are responsive to need, for example, for individuals who have had a long-standing eating disorder and who may benefit from alternative/further supports.
- 7.3** NHS services work with social care and third sector organisations to facilitate any ongoing support that may be required post discharge from specialist eating disorder services.

### **What does this mean for the person receiving care?**

You can be confident that:

- discharge from treatment will be planned with you, and your representative as appropriate, and with your consent
- discharge will be based on your need, not on your behaviour or clinical measures such as weight
- you will be able to request to re-engage directly with the same service within an agreed time frame rather than being referred and waiting to be assessed again, and
- if you have been involved with services for a long period of time and have experienced a longer-term eating disorder, any ongoing contact you have will be person-centred and agreed with you.

### **What does this mean for staff?**

Staff are:

- supported to co-produce discharge plans which are responsive and flexible to the person's individual needs, preferences, and goals
- able to signpost people for ongoing support in the community from health, social care, and third sector support, and
- supported to be creative in co-designing alternatives to full discharge to best support people who require person-centred and responsive ongoing support.

## What does this mean for the organisation?

The organisation:

- ensures that discharges are planned collaboratively with patients, and their representatives where appropriate, and with consent
- develops protocols to ensure discharge plans are person-centred, flexible, responsive to needs, and based on holistic assessment of preferences and individual goals
- has systems in place for people to re-engage directly with services within an agreed time frame after discharge according to their needs, and
- ensures there is a specific care pathway for people who require long-term support as an alternative to discharge into the community.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- An eating disorder service develops flexible and person-centred discharge pathways enabling individuals to be supported to re-engage with the service via self-referral within 6 months if they experience deterioration in their eating disorder symptoms.
- An eating disorder service develops pathways as an alternative to full discharge for individuals who have had a long duration of illness and who may benefit from irregular check-ins to support personalised recovery process.
- Clinical audit of discharge pathways with documentation of information and support to enable people to re-engage with services and have irregular check-ins.

## Outcome 8: Education and Training

### Outcome Statement

Organisations demonstrate commitment to the education and training of all staff involved in eating disorder services, appropriate to roles and workplace settings.

### Rationale

To ensure that eating disorder health care is safe, effective, and person-centred, all staff should have access to high-quality skills and competency-based training, supervision, and opportunities for personal development (National Review of Eating Disorder Services, 2021). This training should enable a specialist eating disorder team to effectively deliver evidence-based treatment and care aligned with SIGN (2022) and MEED (2022). Living and lived experience voices should be embedded at every level of training and its delivery via experts by experience. The National Eating Disorder Network would be well placed to deliver this training in collaboration with training and education providers.

High-quality care, treatment, and support should be delivered by an appropriately trained and well-supported multi-disciplinary team equipped to provide the diverse range of interventions required to support individuals with eating disorders.

### Outcome in Action

- 8.1 The organisation implements a comprehensive and multifaceted education and training programme that:
  - includes an assessment of staff training needs that is responsive to staff roles, responsibilities, and workplace setting
  - supports continuous professional development
  - promotes the use of quality improvement methods and tools
  - is aligned to professional development frameworks
  - embeds the voices of people with living and lived experience, and
  - includes an evaluation of the provision, quality, and uptake of training.
- 8.2 Comprehensive training plans are developed to ensure that continuous professional development for eating disorder services is available to clinical and non-clinical staff in public-facing roles.
- 8.3 Staff are supported to access and attend training and education (including continuous professional development) appropriate to their roles and are allocated appropriate time and resources to participate.

**8.4** Staff have access to training which includes:

- An overview of eating disorder presentations, risk factors, comorbid and co-occurring considerations, and treatment
- medical monitoring and risk assessment/management aligned with MEED (2022)
- SIGN (2022) recommended treatment and associated therapy-specific supervision
- The Matrix, a Guide to Delivering Evidence Based Psychological Therapies and Interventions in Scotland
- delivering person-centred care and support for individuals with comorbidity and co-occurring considerations
- the Mental Health Act (2003)
- trauma-informed care
- responsive engagement mechanisms for people and their representatives, where appropriate, and
- safeguarding vulnerable adults and children.

**8.5** Organisations support staff to attend and participate in relevant training, support, and supervision.

**What does this mean for the person receiving care?**

You can be confident that:

- you are receiving care from individuals with a high level of training in effective and safe treatment approaches, and
- you will be treated with respect and compassion, listened to, and fully supported to make informed choices.

**What does this mean for staff?**

Staff:

- can access and attend role appropriate training and supervision to enable the effective and safe delivery of treatment and care
- maintain the required competencies and qualifications for their roles and responsibilities, and
- know their role within multi-disciplinary teams and are supported to fulfil their responsibilities.

## What does this mean for the organisation?

The organisation:

- implements a comprehensive and multifaceted education and training programme that is aligned with the requirements of MEED (2022) and SIGN (2022) and supports staff to complete this training
- evaluates the provision, quality, and uptake of training, and supervision and ensures staff have capacity to undertake relevant training and supervision
- will resource appropriate cover where required to allow staff to access training and supervision.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Regular review and assessment of training needs and mapped to MEED (2022), the psychological therapies Matrix and SIGN (2022).
- Regular feedback and audit on the quality and uptake of provided training.
- Regional training events.





## Outcome 9: Shared and Supported Decision Making

### Outcome Statement

All individuals receive inclusive information to facilitate informed choice and shared and supported decision making.

### Rationale

The provision of high-quality, inclusive information is essential to empower and support people to make decisions, which are right for them about what matters to them. Decision making is an ongoing process and requires people to be fully informed and taken seriously, at all stages of their treatment journey and pathway. People accessing eating disorder services should be given appropriate time and resources to discuss their treatment in full, with their choices and concerns listened to and addressed. Organisations should provide high-quality, inclusive information on eating disorder services which is in a format and language responsive to their needs.

People should receive sufficient information about treatment options and reasonable alternatives. People should also have access to accurate information and choices on treatment and management, including digital or home treatment options.

The collection, use, and sharing of personal data should be fully explained to people accessing eating disorder services and be shared in line with national policies and procedures.

### Outcome in Action

- 9.1 People using eating disorder services are provided with inclusive information on all aspects of their care, including any onward referrals or interventions which is responsive to their individual needs.
- 9.2 People awaiting treatment and care are updated on anticipated timelines and delays.
- 9.3 People are listened to and are fully involved in all decisions about their health and care.
- 9.4 People receive information that is timely, relevant, and in a language and format that is accessible for them.
- 9.5 People can discuss risk, results, treatment, and management options with appropriately trained staff, and are supported to participate as equals in shared decision making.
- 9.6 Where appropriate and following consent as required, information should be sought from the person's representative when assessing risk.

## What does this mean for the person receiving care?

You will:

- be listened to and fully involved in all decisions about your care
- receive information to support shared and informed decision making in a language and format that is right for you
- be given information on a diagnosis if given, and any test results
- have your data treated with confidentiality and shared where appropriate to improve quality of care
- be offered support and time to discuss treatment options available to you, and
- be given an opportunity to discuss any aspect of your care, raise questions or concerns, and discuss how any results or ongoing treatment/referral will be communicated to you.

## What does this mean for staff?

Staff:

- offer a responsive, person-centred service
- are impartial, without judgement, and can demonstrate compassionate communication that is appropriate to the individual
- have access to evidence-based information in a range of formats and languages appropriate to the needs of the individual accessing support
- can support individuals to reach informed decisions, and
- have a clear understanding of any outcomes or results which can be communicated to individuals.

## What does this mean for the organisation?

Services and organisations have systems and processes in place to ensure:

- the availability of appropriate, easily accessible, and timely information access to consistent support resources including guided self-help materials, and
- access to accurate and reliable resources.

## Practical examples of evidence of achievement

*(NOTE: this list is not exhaustive)*

- Evidence of information provided in alternative formats and languages, taking account of the needs of people who may be digitally excluded.
- Clinical audit of consultations with documentation of signposting or written information being provided.
- Evidence of patient involvement in decision making, tools for shared decision making, and effective communication.
- Tailored resources for children and young people, representatives, and those with co-occurring considerations.

# Appendix 1:

## Development of the Specification

This Specification has been informed by current evidence and best practice and was developed by group consensus. The group was multi-disciplinary and multi-agency and included representation from people with lived/living experience. The working group was chaired by Ms Ellen Maloney and Dr Fiona Duffy. Membership of the Group is detailed in Appendix 2

### Evidence Base

A review of existing standards and underpinning research literature was carried out including Scottish Government, PHS, NICE, SIGN, NHS Evidence, and Department of Health websites. This was combined with stakeholder knowledge, including those with lived/living experience. This evidence was also informed by equality impact assessments.

### Quality Assurance

The working group members had individual and collective responsibility to sign off and provide relevant assurance, including clinical assurance of the Specification. All group members agreed to the working group's Terms of Reference.

Healthcare Improvement Scotland have been involved throughout the Specification development and have provided guidance and assurance on the processes for developing the Specification, including approaches to minimise bias.

### Consultation

A public consultation on the draft National Specification ran between 27 October 2023 and 9 February 2024. The consultation analysis report can be found here:

**[National Specification for the Care and Treatment of Eating Disorders in Scotland – Consultation Analysis Report – gov.scot \(www.gov.scot\)](#)**

If you have any questions, please contact: [EatingDisordersNationalReview@gov.scot](mailto:EatingDisordersNationalReview@gov.scot)

## Appendix 2: Membership of the Group

- Dr Fiona Duffy – Consultant Clinical Psychologist NHS Lothian, Senior Lecturer University of Edinburgh – Co-Chair of the national specification Working Group
- Ellen Maloney – Lived Experience – Co-Chair of the national specification Working Group
- Dr Marie Boilson – Consultant Psychiatrist, Clinical Director, NHS Fife
- Julie Coppola – Charge Nurse, NHS Ayrshire and Arran
- Kat Dixon-Ward – Clinical Advice Coordinator, BEAT
- Hazel Elliot – Advanced Dietetic Practitioner, NHS Lothian
- Dr Joy Olver – Consultant Psychiatrist, North of Scotland CAMHS Tier 4
- Amzu Parpia – Advanced Specialist Dietitian, NHS Fife
- Dr Annabel Ross – The Royal College of GPs
- Dr Fiona Wardell – Healthcare Improvement Scotland

# References

- Allen, Karina L., et al. "First episode rapid early intervention for eating disorders (FREED): From research to routine clinical practice." *Early Intervention in Psychiatry* 14.5 (2020): 625-630.
- Austin, Amelia, et al. "The first episode rapid early intervention for eating disorders-upscaled study: clinical outcomes." *Early Intervention in Psychiatry* 16.1 (2022): 97-105.
- Beat. (2022) Prevalence in the UK (Beat), URL: [Prevalence in the UK - Beat \(beateatingdisorders.org.uk\)](https://beateatingdisorders.org.uk) (cited 5/4/2023).
- Bode, K., Gotz von Olenhusen, N. M., Wunsch, E. M., Kliem, S., & Kroger, C. Population-based cost-offset analyses for disorder-specific treatment of anorexia nervosa and bulimia nervosa in Germany. *International Journal of Eating Disorders*, 2017; 50(3), 239- 249. <https://doi.org/10.1002/eat.22686>
- Butterfly Foundation. Investing in need: Cost-effective interventions for eating disorders, 2014. Cited 5/4/2023; available from: [FULL-REPORT-Butterfly-Foundation-Investing-in-Need-cost-effective-interventions-for-eating-disorders-report.pdf](https://www.butterflyfoundation.org.uk/wp-content/uploads/2014/07/FULL-REPORT-Butterfly-Foundation-Investing-in-Need-cost-effective-interventions-for-eating-disorders-report.pdf)
- Calderwood C. Chief Medical Officer's Annual report 2014-15 – Realistic medicine. Scottish Government, 2016, ISBN 9781785449475; Cited 5/4/2023; available from: <https://www.gov.scot/publications/chief-medical-officers-annual-report-2014-15/>
- Freeman, M. Removing rights from adolescents. *Adoption and Fostering*, 1992; 17, 14-19. <https://doi.org/10.1177/030857599301700105>
- Fukutomi, Akira, et al. "First episode rapid early intervention for eating disorders: A two-year follow-up." *Early Intervention in Psychiatry* 14.1 (2020): 137-141.
- Getting it Right for Every Child (GIRFEC National Practice Model). Scottish Government, 2016, ISBN 9781804357712. Cited 5/4/2023; available from: <https://www.gov.scot/publications/girfec-national-practice-model/>
- Gowers, Simon G. "Management of eating disorders in children and adolescents." *Archives of Disease in Childhood* 93.4 (2008): 331-334.
- Hay, Phillipa J., et al. "Inpatient versus outpatient care, partial hospitalisation and waiting list for people with eating disorders." *Cochrane Database of Systematic Reviews* (2019).
- Healthcare Improvement Scotland. Transition Planning from CAMHS to Adult Mental Health Services. Healthcare Improvement Scotland, 2018. Cited 5/4/2023; available from: [Transition care plans \(healthcareimprovementscotland.org\)](https://www.healthcareimprovementscotland.org/transition-care-plans)
- Independent Care Review. "The Promise", 2020. Cited 5/4/2023; available from: [The-Promise.pdf \(carereview.scot\)](https://www.independentcare.org.uk/wp-content/uploads/2020/06/The-Promise.pdf)

Inspectorate C. Health and Social Care quality standards: My support, my life. Scottish Government, 2018, ISBN: 978-1-78851-015-8. Cited 5/4/2023; available from: [Health and Social Care quality standards: my support, my life – gov.scot \(www.gov.scot\)](https://www.gov.scot/resources/documents/2018/04/Health_and_Social_Care_quality_standards_my_support_my_life.pdf)

Kerr-Gaffney, Jess, Amy Harrison, and Kate Tchanturia. “Cognitive and affective empathy in eating disorders: a systematic review and meta-analysis.” *Frontiers in psychiatry* 10 (2019): 102.

Mental Health (Care and Treatment) (Scotland) Act 2003. Scottish Government, 2003. Cited 5/4/2023; available from: [Mental Health \(Care and Treatment\) \(Scotland\) Act 2003 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2003/16/contents)

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. Mental Welfare Commission for Scotland, 2020. Cited 5/4/2023; available from: [Hope for the future – Exec Summary 03Sep2020.pdf \(mwscot.org.uk\)](https://www.mwscot.org.uk/03Sep2020.pdf)

Nazar, Bruno Palazzo et al. “An examination of the clinical outcomes of adolescents and young adults with broad autism spectrum traits and autism spectrum disorder and anorexia nervosa: A multi centre study.” *The International journal of eating disorders* vol. 51,2 (2018): 174-179. doi:10.1002/eat.22823

Nielsen, Søren et al. “Effects of autism on 30-year outcome of anorexia nervosa.” *Journal of eating disorders* vol. 10,1 4. 9 Jan. 2022, doi:10.1186/s40337-021-00518-1

NHS Education for Scotland. The Matrix: A guide to delivering evidence based psychological therapies and interventions in Scotland, 2023. Cited 1/8/2024; available from: <https://www.matrix.nhs.scot/>

NHS England with NICE and the National Collaborating Centre for Mental Health. Adult eating disorders: community, inpatient and intensive day patient Care Guidance for commissioners and providers. National Collaborating Centre for Mental Health, 2019. Cited 5/4/2023; available from: <https://cwlmcsc.co.uk/>

Schmidt, Ulrike, et al. “Eating disorders: the big issue.” *The Lancet Psychiatry* 3.4 (2016): 313-315.

Scottish Government. Mental Health Strategy 2017-2027 The Scottish Government’s approach to mental health from 2017 to 2027 – a 10 year vision. Scottish Government, 2017, ISBN 9781786526144. Cited 5/4/2023; available from: [Mental Health Strategy 2017-2027 – gov.scot \(www.gov.scot\)](https://www.gov.scot/resources/documents/2017/04/Mental_Health_Strategy_2017-2027.pdf)

Scottish Government. National Health and Wellbeing Outcomes Framework. Scottish Government, 2015, ISBN 9781785441103. Cited 5/4/2023; available from: [8. Improving outcomes – what people can expect – National health and wellbeing outcomes framework – gov.scot \(www.gov.scot\)](https://www.gov.scot/resources/documents/2015/04/National_Health_and_Wellbeing_Outcomes_Framework.pdf)

Scottish Government. National Review of Eating Disorder Services: report and recommendations. Scottish Government, 2021, ISBN: 978-1-80004-986-4. Cited 5/4/2023; available from: **National Review of Eating Disorder Services: report and recommendations – gov.scot (www.gov.scot)**

Scottish Government. The Healthcare Quality Strategy for NHSScotland. Scottish Government, 2010, ISBN: 978-0-7559-9323-9. Cited 5/4/2023; available from: **Healthcare quality strategy for NHSScotland – gov.scot (www.gov.scot)**

Scottish Intercollegiate Guidelines Network. Eating disorders A National clinical guideline SIGN 164. Scottish Intercollegiate Guidelines Network, 2022, ISBN 978-1-909103-89-4. Cited 5/4/2023; available from: **SIGN 164 Eating disorders Revised August 2022**

Spindler, Anja, and Gabriella Milos. “Links between eating disorder symptom severity and psychiatric comorbidity.” *Eating Behaviors* 8.3 (2007): 364-373.

Stewart, Catherine S., et al. “Impact of ASD traits on treatment outcomes of eating disorders in girls.” *European Eating Disorders Review* 25.2 (2017): 123-128.

The Royal College of Psychiatrists. Managing transitions when the patient has an eating disorder, Guidance for good practice. The Royal College of Psychiatrists, 2017. Cited 5/4/2023; available from: **Managing transitions when the patient has an eating disorder (CR208 Nov 2017) (rcpsych.ac.uk)**

The Royal College of Psychiatrists. Medical Emergencies for Eating Disorders: Guidance on recognition and management. The Royal College of Psychiatrists, 2022. Cited 5/4/2023; available from: **Medical emergencies in eating disorders (MEED): Guidance on recognition and management (CR233) (rcpsych.ac.uk)**

Treasure, Janet, Daniel Stein, and Sarah Maguire. “Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence.” *Early intervention in psychiatry* 9.3 (2015): 173-184.

Westwood, Heather, and Kate Tchanturia. “Autism spectrum disorder in anorexia nervosa: An updated literature review.” *Current Psychiatry Reports* 19 (2017): 1-10.

World Health Organization. “ICD-11: International classification of diseases 11th revision.” 2019. Cited 5/4/2023; available from: **ICD-11 (who.int)**



© Crown copyright 2024

**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](https://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](mailto: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](http://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: 978-1-83601-889-6 (web only)

Published by The Scottish Government, November 2024

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA  
PPDAS1515750 (11/24)