Eating Disorders

Care for People of All Ages





Scope of This Quality Standard

This quality standard addresses care for people of all ages with anorexia nervosa, bulimia nervosa, or binge-eating disorder. It applies to all care settings.

Although many statements may apply to avoidant/restrictive food intake disorder (ARFID), as well as other specified and unspecified eating disorders, this quality standard does not directly address the management of these conditions. This quality standard also does not address pica or rumination disorder.

Ontario Health's <u>Transitions from Youth to Adult Health Care Services</u> and <u>Transitions Between Hospital and Home</u> quality standards provide further guidance on transitions in care and may be applicable to people with an eating disorder.

What Is a Quality Standard?

Quality standards outline what high-quality care looks like for conditions or processes where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They:

- Help patients, families, and caregivers know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

Quality standards and their accompanying patient and caregiver guides are developed by Ontario Health, in collaboration with health care professionals, patients, and caregivers across Ontario.

For more information, contact QualityStandards@OntarioHealth.ca.

Quality Statements to Improve Care

These quality statements describe what high-quality care looks like for people with an eating disorder.

Quality Statement 1: Comprehensive Assessment

People with signs and symptoms of an eating disorder have timely access to comprehensive mental and physical health assessments. The assessment is used to determine whether they have a specific eating disorder, the severity of their symptoms, the degree of impairment, and whether they have any comorbid conditions, and to establish a plan of care.

Quality Statement 2: Level of Care

People with an eating disorder receive the most appropriate level of care, which takes into consideration their needs, goals, and experience with previous treatment.

Quality Statement 3: Transition From Youth to Adult Health Care Services

Young people with an eating disorder who will transition out of youth-oriented services to adult-oriented services receive transitional care that focuses on continuity and helping the young person develop independence.

Quality Statement 4: Psychotherapy

People with an eating disorder receive timely access to evidence-based psychotherapy that considers their individual needs and preferences.

Quality Statement 5: Monitoring and Medical Stabilization

People with an eating disorder receive ongoing medical monitoring to prevent and address adverse events and complications. They are offered acute medical stabilization when indicated.

Quality Statement 6: Support for Family and Caregivers

Families and caregivers of people with an eating disorder are offered resources, structured support, and education in a way that meets their needs.

Quality Statement 7: Physical, Mental Health, and Addiction Comorbidities

People with an eating disorder who have physical, mental health, or addiction comorbidities are offered treatment for their eating disorder and other conditions as part of a comprehensive plan of care.

Quality Statement 8: Promoting Equity

People with an eating disorder experience care from health care providers and a health care system that uses an anti-racist, anti-discrimination, anti-stigma, and anti-oppressive approach. Health care providers promote a culture that is compassionate, trauma informed, unbiased, and respectful of people's diversity. They build trust with people with an eating disorder and their families and caregivers, work to remove barriers to accessing care, and provide care equitably.

Quality Statement 9: Care for People Who Are Not Receiving Active Treatment

People with an eating disorder who are not receiving active treatment are offered medical monitoring, support, and follow-up that meets their needs and preferences.

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A Note on Terminology

The use of "family and caregivers" in this quality standard includes anyone in the person's support network, including parents, a significant other, children, siblings, friends, or personal supports, who will be involved in their care.

Due to its negative association with residential schools for the children of Indigenous communities throughout the colonization of Canada, the term "residential treatment" is not used in this quality standard. For treatment that requires 24-hour care in a facility that is not in an acute care hospital, "live-in treatment" is used for children, youth, and adults.

Why This Quality Standard Is Needed

Eating disorders are severe illnesses with significant medical and mental health complications, and can be difficult to treat. Eating disorders include anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder, and other specified and unspecified eating and feeding disorders, such as purging disorder, and atypical anorexia nervosa.¹⁻³

This quality standard will focus on anorexia nervosa, bulimia nervosa, and binge eating disorder because there is a lack of clinical practice guideline evidence for other types of eating disorders. Among young females, eating disorders carry the highest mortality rate of any mental health disorder. Suicide is the second leading cause of death among individuals with anorexia nervosa, and there is increased suicidal behaviour among people with bulimia nervosa and binge eating disorder relative to the general population.

Untreated eating disorders can become chronic and can lead to short- and long-term medical complications, including cardiovascular and renal problems, gastrointestinal disturbances, fluid and electrolyte abnormalities, menstrual and fertility problems, osteoporosis and osteopenia, dental and dermatological problems, and severe disability.¹ Individuals with eating disorders commonly experience low self-esteem, anxiety, body image issues, low mood, substance use, self-injury, social isolation, and other concurrent mental health conditions.².³

Prior to the COVID-19 pandemic, eating disorders were a common and severe health condition, affecting up to 4% of the population.^{4,5} From March to December 2021, emergency department visits increased by over 60% and hospital admissions increased by 37% for children and adolescents with eating disorders in Ontario.^{7,8} Children's hospitals have reported an unprecedented increase in

referrals for eating disorders, with lengthy waitlists for assessments and inpatient treatment (ranging from 7 to 12 months).9 Further, Canadian data showed children and young people with severe eating disorders were more medically unstable, displayed increased levels of functional impairment and food restriction, and were more likely to require hospital admission within four weeks of their initial assessment in 2020 compared to 2019 (prior to the pandemic).¹⁰ In addition, the National Eating Disorder Information Centre reported a doubling in the number of requests for support in November 2020 compared with 2019.9 These data highlight the urgent need for increased eating disorder services in Ontario.

Accessing timely and appropriate treatment for eating disorders can be challenging in Ontario for many reasons. There are few programs that provide a coordinated continuum of care from child and youth services to adult services, and transitions between levels of care are often disjointed and difficult to navigate. High-quality, evidence-based treatments (such as specific psychotherapies for eating disorders) are known to work, but are not consistently available across Ontario. Geographic, demographic, and individual variables may also affect access, wait times, and quality of care. These variables can include access to a medical provider, inclusion and exclusion criteria for treatment programs, the types of available psychotherapy and treatment options that address comorbid mental health and addictions, and the level of support from family and caregivers.

Although eating disorders have been found to be present among people with diverse racial/ethnic, cultural, and socioeconomic backgrounds, eating disorders have commonly been viewed as a condition that primarily affects wealthier, White, adolescent, cisgender females.¹¹ Ethnic minorities and immigrants are less likely to be identified as having an eating disorder in hospital contact data, and people from racialized communities are often underdiagnosed and typically untreated.^{8,9,12} Furthermore, transgender communities face substantial health inequities, including increased risk for eating disorders. 13 Recent studies have found that young people and adults who identify as two-spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations and gender identities (2SLGBTQIA+) are at high risk for eating disorders and that the lack of needed health care for this community can increase body dissatisfaction and further exacerbate this risk.¹⁰ Concerns with underdiagnosis of eating disorders in both young people and adults across Canada also suggests room for improvement in assessment, diagnosis, and ongoing monitoring of eating disorder symptoms and their associated comorbidities.14

With the growing incidence of eating disorders in Ontario, this is an urgent issue with many opportunities for improvement. This quality standard includes nine

quality statements that address areas identified by the Eating Disorders Quality Standard Advisory Committee as having high potential to improve care for people with an eating disorder in Ontario.

Measurement to Support Improvement

The Eating Disorders Quality Standard Advisory Committee identified four overarching indicators to monitor the progress being made to improve care for people with eating disorders in Ontario.

Indicators That Can Be Measured Using Provincial Data

- Rate of emergency department visits for an eating disorder in the past year
- Rate of hospital admissions for an eating disorder in the past year
- Percentage of people with an emergency department visit for an eating disorder in the past year for whom the emergency department was the first point of contact for mental health or addictions care

Indicator That Can Be Measured Using Only Local Data

 Percentage of people with an eating disorder who report an improvement in their quality of life

Quality Statements to Improve Care



Comprehensive Assessment

People with signs and symptoms of an eating disorder have timely access to comprehensive mental and physical health assessments. The assessment is used to determine whether they have a specific eating disorder, the severity of their symptoms, the degree of impairment, and whether they have any comorbid conditions, and to establish a plan of care.

Sources: American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Signs and symptoms of an eating disorder can include but are not limited to 2.3.15:

- Severe dieting or restrictive eating behaviours
- Other behaviours such as laxative, diuretic, or diet pill misuse, self-induced vomiting, and/or excessive exercise
- Rapid weight loss or fluctuating weight
- An unusually low body mass index (BMI; weight in kilograms divided by height in metres squared) or body weight that is considered low for the person's height and age, developmental trajectory, and physical health

Note: BMI should not be the sole factor in assessing for an eating disorder

- Family or caregivers reporting a change in eating behaviour or social withdrawal, particularly from situations that involve food
- A disproportionate concern about body weight or body shape
- Problems managing a chronic illness that affects diet, such as diabetes mellitus or celiac disease
- Menstrual or other endocrine disturbances
- Otherwise unexplained gastrointestinal symptoms and/or abdominal pain



- Physical signs of malnutrition, such as poor circulation, dizziness, palpitations, fainting, or pallor
- Unexplained electrolyte imbalance or hypoglycemia

Timely access to assessment: People with signs and symptoms of an eating disorder should be assessed as early as possible; ideally, soon after symptoms emerge. Assessments should occur within 4 to 8 weeks of the first point of contact with a health care provider (advisory committee consensus). If a person is medically unstable, they may require more emergent care. Assessments may take place over several visits and results of the assessment are communicated to the person and their family and caregivers when appropriate, including considerations of relevant cultural factors and language needs.

Comprehensive mental and physical health assessment: A comprehensive assessment includes both a comprehensive mental health assessment and a comprehensive physical health assessment:

Comprehensive mental health assessment: For people with signs and symptoms of an eating disorder, the comprehensive mental health assessment includes but is not limited to an assessment of^{2,3}:

- Restrictive eating behaviours, food avoidances, or other changes to pattern of eating (e.g., reduced food variety, elimination of food groups)
- Preoccupation with food, body weight, and/or body shape
- Presence of binge eating, purging (i.e., self-induced vomiting, misuse of laxatives and/or and diuretics), excessive or compulsive exercise, or other disordered eating behaviours (e.g., rumination, regurgitation, chewing and spitting, use of medication to change body weight)
- Eating-related fears (e.g., fear of food and weight gain)
- Psychosocial impairment secondary to eating or body image concerns or related behaviour
- Family history of eating disorders, or other mental health or addiction conditions
- Prior treatment for an eating disorder and response to that treatment
- Presence of self-injury behaviours, suicidality, trauma-related symptoms/post-traumatic stress disorder, substance use, and/or other mental health comorbidities

Comprehensive physical health assessment: For people with signs and symptoms of an eating disorder, the comprehensive physical health assessment includes but is not limited to^{1,2}:

- Vital signs, including temperature, resting heart rate, blood pressure, orthostatic pulse, and orthostatic blood pressure
- Height
- Weight history (i.e., lowest and highest weights, recent weight changes)
- Determining the degree to which the person is under weight/weight suppressed (BMI or percent median BMI, BMI percentile for adults, and growth curve trajectories for children and young people are an important part of the assessment)
- o Note: BMI should not be the sole factor in determining the need for care
- Physical appearance, including signs of malnutrition, purging behaviours, and/or problems with teeth and gums
- Laboratory tests, including a complete blood count
- Comprehensive metabolic panel, including but not limited to:
 - Extended electrolytes (includes calcium, magnesium, and phosphate)
 - Liver enzymes and renal function tests
- Hormones (i.e., estrogen, follicle stimulation hormone, luteinizing hormone, testosterone)
- Screening for celiac disease and inflammatory bowel disease
- Electrocardiogram for people with a suspected restrictive eating disorder, people with severe purging behaviours, and people taking medications known to alter electrocardiogram results
- Bone mineral density for those with amenorrhea for 6 months, or males underweight for 6 months

Comorbid conditions: People with an eating disorder may have other physical health or mental health or addiction conditions, and these might affect their presenting symptoms and response to treatment. It is important to assess for comorbid conditions and presence of self-injury and risk of suicide.



Physical conditions to assess for may include but are not limited to:

- Diabetes mellitus
- Inflammatory bowel disease
- Celiac disease

Mental health and cognition conditions to screen for and assess (if needed) include but are not limited to:

- Anxiety disorders
- Mood disorders (such as depression or bipolar disorder)
- Obsessive-compulsive disorder
- Substance use disorders
- Attention-deficit/hyperactivity disorder
- Autism spectrum disorder
- Post traumatic stress disorder
- Personality disorders
- Schizophrenia and other psychotic disorders

Rationale

Early assessment and treatment can prevent long-term negative physical and psychological outcomes,^{5,16,17} and it is important that people with signs and symptoms of an eating disorder have a comprehensive assessment as soon as possible—especially if the person is at risk of serious physical harm. For those who are underweight or have lost a significant amount of weight, it is important to understand the severity of the person's low weight or weight loss as part of the assessment. Physical and mental health assessments can take several visits to complete and should be done in-person, if possible.^{1,18} However, people in Ontario often wait several months to over a year for an assessment, depending on their location.⁹ Access to a comprehensive assessment can be particularly challenging for people in rural and remote areas of Ontario. Furthermore, people with an eating disorder may not have insight into the presence or severity of their own signs and symptoms,^{4,19,20} and eating disorders commonly go undiagnosed and undetected unless identification and assessment occur.¹

Eating disorders can develop at any age; however, the typical age of onset is young adulthood. Pediatricians and primary care providers should ask all children and young people about their eating patterns and body image and be alert to potential signs and symptoms of an eating disorder.²¹ People experiencing food



insecurity can also show signs of an eating disorder and there can be trauma associated with feeding and eating. Steps should be taken to identify appropriate supports and provide trauma-informed care.

Additional information from family and caregivers to inform the assessment may help identify eating disorder symptoms, behaviours, and comorbidities as people with an eating disorder may underreport and conceal symptoms (e.g., amount of food consumed, time spent exercising, frequency of binge eating and/or purging), or conceptualize symptoms differently.¹ People can develop an eating disorder, including anorexia nervosa.

For children and young people, it is important to involve families, caregivers, support networks, school personnel, coaches, and health professionals who are in close contact or routinely work with the person. Some symptoms of an eating disorder are cognitive in nature (e.g., fear of weight gain, overvaluation of weight and body shape) and depend on abstract reasoning ability. Children may not have the capacity to articulate such symptoms and more information on behaviours may be necessary from other sources.²²

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

Your health care providers should ask you questions about your thoughts, feelings, behaviours, and physical health. They will do this to find out whether you have an eating disorder, and to make a plan for your care as soon as possible. Your family, caregivers, or other supportive people in your life can be involved in these steps too.

For Clinicians

When a person seeks care for their eating disorder symptoms, assessment should occur as soon as possible—ideally within 4 to 8 weeks of their initial contact. When a person presents with signs and symptoms that you suspect could indicate an eating disorder, conduct comprehensive mental and physical health assessments to determine the severity of symptoms, degree of impairment, and nature of the eating disorder, and to identify any comorbid conditions and determine a treatment plan, if needed. Racism and discrimination can undermine a comprehensive assessment for eating disorders. Ensure that the care delivered is inclusive, affirming, welcoming, and culturally sensitive for Black, Indigenous, and racialized people, people who identify as 2SLGBTQIA+, and other equity-deserving groups where there are known barriers to care.



For Organizations and Health Services Planners

This care may not be currently available across Ontario, but it is important to ensure that systems, processes, and resources are in place for clinicians to identify and properly assess people who may have an eating disorder as soon as possible. Assessments for eating disorders should be locally available and accessible. Ensure health care professionals in primary care and community-based settings are aware of locally available assessments for eating disorders.

Ensure health care providers have the necessary training, knowledge, and skills to accurately assess for eating disorders

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with signs and symptoms of an eating disorder who receive the following:
 - A comprehensive mental health assessment
 - A comprehensive physical health assessment
- Percentage of people with signs and symptoms of an eating disorder who have the following initiated within 8 weeks of the first appointment with their health care provider:
 - A comprehensive mental health assessment
 - A comprehensive physical health assessment
- Local availability of assessments for eating disorders within 8 weeks of a first appointment with a health care provider for signs and symptoms of an eating disorder

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Level of Care

People with an eating disorder receive the most appropriate level of care, which takes into consideration their needs, goals, and experience with previous treatment.

Sources: American Psychiatric Association, 2023¹ | Couturier et al., 2021¹⁸ | National Institute for Health and Care Excellence, 2017²

Definition

Level of care: Levels of care for eating disorder treatments include self-directed interventions, group therapy, individual therapy, outpatient, day treatment, live-in treatment (formerly referred to as residential treatment), and acute inpatient treatment programs. Care may also include medical hospitalization where the focus of care is medical stabilization.¹ Care at all levels can involve multidisciplinary teams. Day treatment and live-in/bedded treatment includes care from a multidisciplinary team made up of health care professionals, such as psychotherapists, registered dietitians, and other allied health professionals. Outpatient treatments may be provided in a hospital or community setting, including primary care.

The least intensive treatment that is likely to be effective and appropriate to the individual's needs should be provided first.²³ "Least intensive" refers to the intensity of the treatment, such as the number of treatment hours, level of monitoring, and the notion that treatment should disrupt the person's life as little as possible (e.g., in terms of proximity to home and school or work attendance). Level of care should be guided by the comprehensive assessment, including severity of symptoms, experience with previous treatment in terms of the effectiveness and tolerability of previous treatments (if applicable). Care planning should involve collaborative discussions between the health care team and the person and where appropriate, their family and caregivers. People's preferences, and those of their family and caregivers (when appropriate), should be taken into account when multiple options for levels of care are considered appropriate.



The following should be considered when deciding on the appropriate level of care^{1,24}:

- The person's current physical health, medical comorbidities, body mass index (BMI)/body weight, and whether their health is declining
 - Note: BMI should not be the sole factor in determining level of care
- Whether medical hospitalization is needed to actively monitor medical risk parameters (e.g., through laboratory assessments, physical observation, electrocardiogram)
- Comorbid conditions (e.g., diabetes, substance use disorder) that would affect treatment needs, leading to the need for a higher level of care
- The likelihood of the person reducing or stopping their eating disorder behaviours (e.g., dietary restriction, binge eating, purging, excessive exercise) without meal support or monitoring
- For the consideration of outpatient and day treatment in children and young people, whether the person can be supported by family or caregivers at home
- Psychosocial context, including the level of environmental and psychosocial stress, and the person's support systems (e.g., family and caregiver supports)
- Experience with previous treatment
- Accessibility of care and how appropriate it is to the person's needs and preferences (e.g., geographical and/or financial considerations, access to transportation, housing, school, work, childcare needs)

When transitions occur between levels of care, multidisciplinary coordination and collaboration between health care teams are needed to ensure a timely transition and the continuity of care, to support the person's treatment, and to prevent symptom relapse. This may involve coordinated case conferences and robust team handovers to ensure transfer of accountability in care.

Rationale

The most appropriate level of care for a person with an eating disorder is determined based on the findings of comprehensive physical and mental health assessments, their experience with previous treatment, and consideration of the person's needs and preferences for their care. Outpatient, evidence-based psychotherapy is likely to be the most appropriate and effective treatment for



most individuals. However, some people need to initiate treatment at a higher level of care.¹

Eating disorder treatments typically focus on changing eating disorder thoughts, behaviours, and other symptoms through psychotherapy. Medical stabilization and nutrition interventions may also be part of eating disorder treatment, depending on individual needs. Nutrition interventions include nutrition education, dietary recommendations, meal planning, and meal support. Virtual treatment can also be beneficial and appropriate, depending on the needs of the person and the resources available.

Symptoms of the eating disorder, comorbid conditions, and overall physical health may change over time, and can require a reassessment of the diagnosis or most appropriate level of care. A higher level of care may be needed if a person has not responded to outpatient treatment. It is crucial that sufficient evidence-based outpatient treatments are available and accessed first before more intensive treatments are explored (if appropriate for their care). It is important that care is coordinated when people transition to different levels of care to minimize disruptions to their treatment and daily routines. For information on transitions from hospital to home, see the <u>Transitions Between Hospital and Home</u> quality standard.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

Your health care providers should offer you the treatment option that has the best chance of helping you and is the least disruptive to your life (for example, is as close to home as possible). If your symptoms don't improve with this treatment, your health care providers should offer you the next most appropriate treatment option for you. This should be done in a coordinated way.

For Clinicians

Collaborate with people with an eating disorder to determine the most appropriate level of care based on the severity of their eating disorder, experience with previous treatment, and their individual needs and preferences. Offer the least intensive treatment option that is likely to be effective first.

For Organizations and Health Services Planners

For people with an eating disorder, ensure that systems and processes are organized to enable access to evidence-based treatment. Ensure that the balance of services and appropriate levels of care are available, free of cost, to



meet the needs of the population. Transitions need to be supported and well resourced for people to move between levels of care based on their needs.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with an eating disorder who receive the most appropriate level of care (see Definition: Level of care for a list of level of care considerations)
- Percentage of people with an eating disorder who report there was good collaboration between health care teams during a transition between levels of care
- Percentage of people with an eating disorder whose symptoms are not improving under current treatment who are reassessed by a health care provider and are offered the next most appropriate treatment option (see Definition: Level of care for a list of level of care considerations)

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Transition From Youth to Adult Health Care Services

Young people with an eating disorder who will transition out of youth-oriented services to adult-oriented services receive transitional care that focuses on continuity and helping the young person develop independence.

Sources: National Institute for Health and Care Excellence, 2016²⁵ I National Institute for Health and Care Excellence, 2017² I Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Transitional youth-to-adult care: This prepares people between the ages of 15 and 24 years^{26,27} and their family and caregivers to transition to an adult model of care. This should involve:

- A written care plan that outlines the current treatment, its timeline and duration to avoid disruptions to treatment and gaps in care. It should include the treatment plan and a plan for the eventual transition to adult care. The person should have a copy of the plan, and it should be reviewed and updated as necessary^{28,29}
- An identified clinician who will take the lead on coordinating the transition (transition coordinator), ideally selected by the young person, and who has consented to the role. The transitions coordinator serves as the contact person for issues relating to the transition and the person's care and is the main link with other providers. The transition coordinator may help arrange appointments, act as a support person and/or advocate, help mitigate disruption to treatment, and guide the young person to other services and sources of support that fits with their treatment plan and needs/life circumstances.^{28,29} This may be a provider already involved in the care of the young person, or may be a provider specifically appointed to coordinate the transition.
- A collaborative transition meeting (or meetings) held virtually or in-person that include the young person, their youth provider(s), and key adult



provider(s) to review the written care plan and discuss the details of transitioning to adult care. Their primary care provider and family or caregivers attend the meeting, as appropriate²⁸

Developing independence: Preparing the young person for an adult approach to eating disorders care is important. This might include elements specific to their eating disorder, such as eating unsupervised and changes to their treatment (e.g., family-based treatment to cognitive behavioural therapy). This might also involve promoting self-advocacy, autonomy, practising skills (such as how to book appointments), access to information, and changes in decision-making, privacy, and consent.

Rationale

Transitioning out of child and youth services can be overwhelming and difficult for young people with an eating disorder and their families and caregivers. Early planning and continuity of care provided through youth services, such as having a written care plan, a transitions coordinator, and a meeting with adult services is important for the young person to transition to adult services without gaps in their monitoring or treatment. A course of treatment should not be interrupted due to a transition in care. When possible, the transition should be determined by biopsychosocial readiness and not just chronological age.

A written transition plan that documents what care will be continued, who will provide the care, and any potential care gaps, and how to address them, can help young people and their parents and caregivers know what to expect and feel more confident in the process. This transition plan can help ensure continuity of care and that their transition from youth to adult services meets their needs. A transitions coordinator to oversee the transition planning and coordination can lead to a more positive experience, better attendance in adult services, and better outcomes.²⁸ Meeting and engaging with new health care providers who will take a role in their future care can help reduce concerns about the transition and can increase their confidence about transitioning to an adult service or another provider. Being part of the communication between current and future health care providers creates a collaborative transition—a transfer of care where the patient is present and involved in the conversation. As part of this process, the person may learn new skills, take on more responsibility for their health care, and be introduced to new treatments. Families and caregivers may also benefit from added support when the person with an eating disorder is transitioning to adult care.

Specialized services for youth with eating disorders can ease the transition from youth to adult care. Specialized services can include developing a care plan,



preparation for transition, an introduction to adult care and specialized individual or group treatment services. Ontario Health's <u>Transitions From Youth to Adult</u> <u>Health Care Services</u> quality standard provides further guidance on transitions in care and may be applicable to people with an eating disorder.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

If you are moving from care for young people to care for adults, you should receive support that helps you become more independent. You should be involved in your own care, and you should not notice any interruptions in your treatment.

For Clinicians

Work with the person (and their family and caregivers, where appropriate) to support their transition to adult services, including identifying a transition coordinator, developing a written care plan to assist with the process, and facilitating an introduction to adult services. It is important to fully involve the young person, and where appropriate, their family and caregivers.

For Organizations and Health Services Planners

Ensure systems, processes, and resources are in place for people with an eating disorder to receive appropriate transitional services to maintain continuity of care between health care providers. This includes appropriate transition planning, coordination, and an introduction to adult services.

Ensure that health care providers have sufficient resources and training to provide care for youth transitioning to adult services. Ensure that mechanisms are in place to prevent gaps in care and unnecessary delays in care.

QUALITY INDICATOR: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

 Percentage of people with an eating disorder who will transition out of youth-oriented services to adult-oriented services and who receive transitional care that focuses on continuity and helping the young person develop independence

Measurement details for this indicator, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Psychotherapy

People with an eating disorder receive timely access to evidence-based psychotherapy that considers their individual needs and preferences.

Sources: American Psychiatric Association, 2023¹ | Couturier et al., 2021¹8 | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Timely access: People with an eating disorder should be offered evidence-based psychotherapy delivered by a regulated health care professional as soon as possible. Psychotherapy ideally begins within 4 to 8 weeks of the comprehensive assessment (advisory committee consensus).

Evidence-based psychotherapy that focuses on eating disorders: Psychotherapy for eating disorders is typically provided in individual or single-family sessions. However, they can also be provided in group and multi-family formats. The length of evidence-based psychotherapies for eating disorders varies but is typically around 20 sessions. More sessions may be provided to individuals who are significantly underweight to support the weight restoration process.¹ In Ontario, psychotherapy is a controlled act and should only be preformed by certain regulated professionals who are authorized to provide it.³0

The following are examples of psychotherapies that focus on eating disorders and are considered first-line treatments:

Psychotherapies for children and young people under the age of 18

Family-based treatment (FBT) is a treatment for children and young people with anorexia nervosa or bulimia nervosa and typically consists of 18 to 20 sessions over a 1-year period. The needs of the child or young person should be reviewed 4 weeks after treatment begins and then every 3 months to establish the appropriate frequency of sessions and length of treatment²



If FBT is ineffective or unsuitable, other therapeutic approaches can be considered, such as cognitive behavioural therapy for eating disorders (CBT-ED) for children and young people with anorexia nervosa, bulimia nervosa, and binge eating disorder. Adolescent-focused psychotherapy is also appropriate for young people with anorexia nervosa.

Psychotherapies for adults age of 18 and over

• Cognitive behavioural therapy for eating disorders targets binge eating, compensatory behaviours, dietary restriction, low weight, and excessive concern with body shape and weight. CBT-ED also helps individuals to establish a regular pattern of eating and an appropriate and therapeutic plan for weight monitoring, and includes psychoeducation, self-monitoring of eating and related behaviours, exposure to avoided foods, and strategies to reduce concerns about shape and weight. CBT-ED also includes strategies to prevent relapse in the future and can be delivered individually or in a group setting.¹ The treatment is typically about 20 sessions, although fewer sessions may also be effective³¹

CBT-ED should be offered for 1-3,15:

- Adults with anorexia nervosa or bulimia nervosa
- Adults with binge-eating disorder
- Interpersonal psychotherapy (IPT) involves identifying and working on specific interpersonal problem areas currently affecting the individual, including role disputes, role transitions, interpersonal deficits, and unresolved grief. IPT focuses on ways in which binge-eating behaviours are related to current interpersonal problems and includes relapse prevention. The treatment is typically about 20 sessions and can be delivered individually or in a group setting¹

IPT for eating disorders is recommended for 1.3:

Adults with binge-eating disorder

Other therapeutic approaches are included for consideration in clinical practice guidelines, depending on the person's situation. There are lower levels of evidence for these approaches depending on the population and type of eating disorder. Examples include:

 Focal psychodynamic therapy (FPT), Maudsley Anorexia Nervosa Treatment (MANTRA), and specialist supportive clinical management (SSCM) for anorexia nervosa¹⁻³



- IPT, integrative cognitive-affective therapy (ICAT), and schema therapy for bulimia nervosa^{1,3}
- Brief strategic therapy, dialectical behaviour therapy, ICAT, and schema therapy for binge eating disorder³

For many psychotherapies, the evidence base comes from a limited population and may not have been studied in all people who may benefit from these treatments. It is important that all psychotherapies for eating disorders be traumainformed and culturally sensitive.

Rationale

Evidence-based psychotherapies for eating disorders are recommended as interventions for all age groups¹⁻³ and are appropriate in all stages of treatment, including weight restoration and relapse prevention. Medical monitoring during psychotherapy is an important part of care for people with an eating disorder. Accessing evidence-based psychotherapy can be challenging due to the lack of programs that offer these treatments, high demand for these services, the cost of psychotherapy, and long waitlists. Most evidence-based psychotherapies focus on establishing a pattern of regular eating, stopping weight control behaviours, restoring weight, and improving body image.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

You should be offered a type of treatment called psychotherapy. It should be available as soon as possible after your assessment. Psychotherapy can:

- Help you establish regular eating patterns
- Provide education about eating disorders and how to get better
- Improve your thoughts and feelings about eating and your body shape and weight

If you agree to psychotherapy, you should not need to wait too long to start treatment.

For Clinicians

Offer evidence-based psychotherapy to people with an eating disorder in alignment with their needs and preferences. They should begin evidence-based psychotherapy that focuses on eating disorders as soon as possible, ideally within 4 to 8 weeks after the comprehensive assessment.



For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place for people with an eating disorder to access, timely, evidence-based psychotherapy free of charge, appropriate to their type of eating disorder and their needs and preferences. Ensure health care providers have the necessary training, knowledge, and skills to deliver psychotherapy for people with an eating disorder. Ensure health care professionals in primary care and community-based settings are aware of the locally available psychotherapies for people with an eating disorder.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with an eating disorder who receive evidence-based psychotherapy by a health care professional within 8 weeks of the completion of their comprehensive assessment
- Local availability of evidence-based psychotherapy delivered by a health care professional within 8 weeks of the completion of their comprehensive assessment

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Monitoring and Medical Stabilization

People with an eating disorder receive ongoing medical monitoring to prevent and address adverse events and complications. They are offered acute medical stabilization when indicated.

Sources: American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Monitoring: People with an eating disorder should be monitored by their health care team based on the severity of the eating disorder. This can involve monitoring of vital signs, laboratory tests and growth parameters (height and weight). For those who are underweight or have lost a significant amount of weight, it is important to understand the severity of the person's low weight or weight loss. Based on an assessment of the person's premorbid measured height and weight, menstrual history (for people with secondary amenorrhea), current pubertal stage (for children and young people), and psychosocial wellbeing. Depending on the clinical situation, it may be important to set an individualized goal weight.

Medical stabilization: People with an eating disorder with low weight may require medical stabilization in an acute inpatient setting when they are at risk of hemodynamic instability, significant electrolyte abnormalities, nutritional deficiencies, and various organ dysfunction. Any of these may contribute to morbidity or mortality.^{2,3,15} The goals of medical stabilization for people with an eating disorder who are underweight, malnourished, or medically unstable are to restore medical stability and to normalize vital signs, electrolytes, and fluid balance. People of any size or weight can experience hemodynamic instability if they are below their biologically appropriate weight or have lost a large amount of weight in a short period of time.

Adverse events and complications: People undergoing acute nutritional rehabilitation are at risk of medical complications, especially during the first week of renourishment. Refeeding syndrome is the most serious acute complication and can include a range of clinical symptoms, such as seizure, cardiac arrhythmias, cardiac failure or arrest, coma, and sudden death. However, refeeding syndrome can be prevented by close monitoring. This monitoring must include a protocol for measuring electrolytes, daily weight fluctuations, and vital signs.¹ Health care providers who treat people with an eating disorder should be trained to recognize symptoms of refeeding syndrome. Normally, weight gain helps to improve most of the physiological complications of starvation, and the risk of medical complications declines over the subsequent weeks of renourishment.¹²

A common chronic complication from eating disorders includes low bone density. People of all genders with eating disorders can experience a loss of bone mineral density. To reduce the risk of osteopenia, osteoporosis, and bone fractures (e.g., in hips or spine), it is important for people to reach and maintain a medically appropriate body weight for their age and height. Where appropriate, bone mineral density should be measured.^{1,2}

Rationale

Monitoring will ensure that people with eating disorders whose health is at risk are identified and connected with the care they need. People with eating disorders whose health is at serious risk may need emergency care and/or admission to hospital. Signs that a person's health may be at serious risk include, but are not limited to rapid substantial weight loss, unstable vital signs, electrolyte disturbances, cardiac abnormalities, hemodynamic instability, medical complications of malnutrition, suicidal thoughts or behaviours, risk of death or imminent risk of serious medical complications. Medical stabilization is an important component of treatment that focuses on restoring medical stability. People with severe weight loss may experience cognitive impairment resulting in loss of decision-making capacity. Medical stabilization is an important first step of an intervention to restore cognitive function for further treatment decisions. Monitoring is an ongoing process that should be tailored to meet the needs of the individual.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

Your health care providers should check in with you regularly to see how you are feeling (physically and emotionally). Your health care providers may also suggest medical stabilization to manage your eating disorder. This involves being admitted



to a hospital until you are physically healthier. They should check on you regularly while you are in the hospital.

For Clinicians

Monitor people with an eating disorder to help prevent complications. Offer medical stabilization for people with an eating disorder who are malnourished, medically unstable, or very underweight, and monitor them for complications and adverse events. People of any size or weight can experience hemodynamic instability and require medical stabilization.

For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place so that people with an eating disorder receive appropriate ongoing monitoring and medical stabilization, if indicated. Ensure the presence of adequate community resources and outpatient treatment options to support people before medical stabilization is required and after it is complete.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with an eating disorder who receive ongoing medical monitoring at every appointment with their health care provider
- Percentage of people with an eating disorder who are medically unstable and subsequently receive acute medical stabilization

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Support for Family and Caregivers

Families and caregivers of people with an eating disorder are offered resources, structured support, and education in a way that meets their needs.

Sources: American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definition

Resources, structured support, and education: These should include information about the nature and risks of the person's specific eating disorder diagnosis, the treatments available, and the likely benefits and limitations of those treatments in a format that meets the needs of families and caregivers (e.g., reading level, language preference, format [verbal, written, or video]). If applicable, resources and education should be provided to address misconceptions about eating disorders. Where appropriate, written information and resources should be provided for family and caregivers who do not attend assessment or treatment sessions with the person with an eating disorder.² Transitions in care can be an especially challenging time for families and caregivers. They may require additional support and resources during transitions.

Support groups may be beneficial and can be offered where appropriate and available; for example, moderated online caregiver forums, peer support,¹ or the Experienced Caregivers Helping Others (ECHO) model.²,³,¹8 Other resources should be offered if desired, such as guided CBT-based self-help and unguided caregiver psychoeducation self-help interventions for families and caregivers of children and young people with an eating disorder.²,¹8

Rationale

Family and caregivers of a person with an eating disorder can experience severe distress and may benefit from an assessment of their own needs to help determine what supports should be offered.^{2,35}



Family and caregivers should be given comprehensive information (both verbal and written) about the person's eating disorder, its likely causes, the planned course of treatment, and the plan for treating any comorbid physical health or mental health or addiction conditions, if appropriate. It is especially important to assess and support the needs of family and caregivers of children and young people, including practical support and an emergency plan if the person with an eating disorder is at high medical or mental health risk or at risk of suicide. For adults, the involvement of family and caregivers is determined by the person's preferences, values, and needs, acknowledging that not everyone may want to involve their family and caregivers in their care.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

If your family and caregivers are involved in your care, your health care providers should ask them how they are doing and offer them support if they want it. Support could include:

- Offering them information about your eating disorder, in the language of their choice, if possible
- Helping them find a support group where they can talk with other people who are supporting a person with an eating disorder
- Guided and unguided self-help interventions for family and caregivers of people with an eating disorder based on cognitive behavioural therapy techniques

For Clinicians

Ensure that families and caregivers are offered resources, structured supports, and education about eating disorders. They may benefit from a psychosocial assessment depending on their needs. Families and caregivers should be included in care and treatment planning, especially for children and young people. For adults, involvement of families and caregivers occurs according to the wishes of the person with an eating disorder.

For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place so that families and caregivers of people with an eating disorder can be offered resources, structured support, and education in a way that meets their needs. Ensure that health care providers have the necessary skills and resources to assess and address any unmet psychosocial needs of family and caregivers. Ensure relevant information and support are available and accessible to family and caregivers.



QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of children and young people with an eating disorder whose families and caregivers receive resources, structured support, and education by a health care provider
- Percentage of people with an eating disorder whose families and caregivers are involved in their care and whose families and caregivers report feeling supported and informed about eating disorders

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Physical, Mental Health, and Addiction Comorbidities

People with an eating disorder who have physical, mental health, or addiction comorbidities are offered treatment for their eating disorder and other conditions as part of a comprehensive plan of care.

Sources: American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Physical, mental health, or addiction comorbidities: Comorbid health conditions, such as depression and anxiety disorders, are common in people with an eating disorder, and some comorbidities can present as a result of an eating disorder. It is important to identify comorbidities as part of the assessment of a person who may have an eating disorder (see quality statement 1).

Treatment: Treatments for an eating disorder and a comorbid health condition can take place at the same time or one after the other. Treatments may include medical (e.g., medication) and psychological treatments and should be in line with appropriate clinical practice guideline recommendations for the condition. The following factors should routinely be taken into consideration when making treatment decisions:

- The type and severity of the eating disorder
- The type and severity of the comorbid health condition
- The person's degree of impairment
- Available treatment options for the comorbid health conditions
- The person's treatment preferences, and, where appropriate, those of their family and caregivers



Health care providers should collaborate to support the effective treatment of the person's eating disorder and their comorbid health condition(s). When collaborating, teams should use outcome measures for both the eating disorder and the comorbid health condition(s) to monitor the effectiveness of each treatment and the potential impact each may have on the other(s).^{2,3,15} Strong multidisciplinary coordination may be needed to adequately address the person's eating disorder needs and any comorbidities.^{1,2}

Rationale

Comorbid physical, mental health, or addiction conditions are common and important to identify as part of the assessment of a person who may have an eating disorder (see quality statement 1).¹ The presence of comorbid health conditions should not prevent people from receiving eating disorder treatment and should not exclude them from care for their comorbid conditions. Some physical comorbidities may be an outcome of an eating disorder (e.g., gastroesophageal reflux disease, irritable bowel syndrome, other gastric motility disorders), whereas others may affect eating behaviours and intake (e.g., diabetes mellitus, celiac disease, inflammatory bowel disease). In some cases, dietary restrictions can increase the likelihood of developing an eating disorder.³6.37 Even if a comorbid health condition is unrelated to an eating disorder, it can influence the choice of treatment or the need for medical stabilization.

Identifying comorbid health conditions and assessing their relationship to the eating disorder and its severity are important for treatment planning. When another mental health condition is present, the outcomes for both the eating disorder and the other mental health condition can worsen.³⁸⁻⁴⁰ A comprehensive mental health assessment is important for determining if symptoms and behaviours such as substance use, depression, anxiety, obsessive thoughts, or compulsive behaviours represent an independent co-occurring disorder or have developed as a result of or in response to the eating disorder. It is important to consider the whole person when planning treatment for an eating disorder and any comorbidities.

What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

If you have other physical, mental health, or addiction conditions, your health care providers should offer you treatment for both your eating disorder and any other condition you have. If they are not able to treat your other conditions, they should connect you with another care provider who can, and work with that provider. Your health care providers should involve you (and your caregiver, depending on the circumstances) in decisions about your care.



For Clinicians

Determine the most appropriate course of treatment for the eating disorder and any comorbid physical, mental health, or addiction conditions, considering the severity of each condition and the person's needs and preferences. Care for all conditions should be part of the same treatment plan. Care for each condition can be provided concurrently or sequentially.

For Organizations and Health Services Planners

Ensure that systems, processes, and resources are in place so that people with an eating disorder are able to receive treatment for both their eating disorder and any comorbid physical or mental health or addiction conditions they may have. This may require multidisciplinary collaboration.

QUALITY INDICATOR: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

 Percentage of people with an eating disorder who have physical, mental health, or addiction comorbidities who are offered treatment for their eating disorder as part of the same treatment plan

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Promoting Equity

People with an eating disorder experience care from health care providers and a health care system that uses an anti-racist, anti-discrimination, anti-stigma, and anti-oppressive approach. Health care providers promote a culture that is compassionate, trauma informed, unbiased, and respectful of people's diversity. They build trust with people with an eating disorder and their families and caregivers, work to remove barriers to accessing care, and provide care equitably.

Sources: Advisory committee consensus | American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017² | Scottish Intercollegiate Guidelines Network, 2022³

Definitions

Health care system that uses an anti-racist, anti-discrimination, anti-stigma, and anti-oppressive approach: A health care system that acknowledges the historic and current intersections of race, colonization, gender, and the impacts on health care access must address the structural factors of racism, discrimination, bias, and stigma that disproportionately limit care for certain groups of people (see Appendix 4, Guiding Principles, Social Determinants of Health). Such a health care system ensures safe, accessible, and equitable care for people with an eating disorder, as well as their families and caregivers. This includes building a traumainformed practice of care and actively addressing structural racism, discrimination, and biases (specifically weight biases), impacting access and engagement in treatment. Care is provided to all people regardless of age, weight, body size, gender, sexual orientation, socioeconomic status, religion, race/ethnicity, cultural practices, geographical location, and any comorbidities or disabilities. Health care practices validate people with an eating disorder and their lived experiences. Health care providers working in such a health care system take proactive steps to eliminate the impact of bias on the care they provide and to ensure equitable quality-of-life outcomes for all people.



Culture that is compassionate, trauma informed, unbiased, and respectful of people's diversity: A culture in a health care setting that is:

- Compassionate: Care is provided by health care providers whose care is not influenced by biases, who have knowledge of eating disorders, and who actively listen to their patients, work to understand their needs, and provide timely, high-quality care
- Trauma informed: Care is provided by health care providers who understand the potential impact of trauma on people's thoughts, beliefs, and behaviours, as well as on their relationships with eating disorders and the health care system⁴¹
- Respectful of people's diversity⁴²: Care is provided by health care providers who look beyond preconceived notions and stereotypes of people with an eating disorder (e.g., weight bias, gender bias) to see the person for who they are as an individual. Providers seek to:
 - Understand the person's life circumstances (e.g., gender-affirming care)
 - Respect the person's identity
 - Respect the person's cultural or faith traditions, mealtime and food practices, values, and beliefs
 - o Ensure that care is provided in the person's preferred language
 - Ensure care is culturally sensitive
 - Respect the person's wishes to involve family or caregivers in their care

Equitable care: Equitable care requires that all people with an eating disorder are provided an equal opportunity to attain their fullest health potential through barrier-free access to high-quality clinical care. Ensuring equitable care requires addressing barriers in and beyond health care settings, including addressing the social determinants of health (e.g., racism, discrimination, economic prejudice). Equitable care is attained when people with an eating disorder receive appropriate, timely interventions and no longer experience preventable complications due to stigma or discrimination.

Rationale

People of all ages, genders, and cultural backgrounds can develop an eating disorder, and the clinical presentation of an eating disorder may be influenced by cultural factors. ⁴³⁻⁴⁵ To ensure equitable health outcomes, it is important to determine the ways in which people with an eating disorder experience inequity in access, assessment, treatment, and outcomes owing to factors such as age, gender, sexual orientation, race/ethnicity, culture, weight, and body size, as well



as the social determinants of health, including socioeconomic status. For example, transgender and gender nonbinary youth may adopt disordered eating behaviours as means of interrupting unwanted body changes, such as the onset of puberty. Gender-affirming interventions help prevent food restriction and related behaviours. For young people and adults who identify as two-spirit, lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations and gender identities (2SLGBTQIA+), the impact of external stressors such as discrimination, stigma, and violence can accumulate over time and lead to a greater risk of developing an eating disorder compared to their heterosexual and cisgender counterparts. Subsequently, the stress accumulated from external stressors can compound the impact of internal stressors. It is important to learn whether people with an eating disorder have had gender-affirming medical interventions, such as hormone therapy or surgical interventions.

Health care providers caring for people with an eating disorder should strive to provide accessible and equitable services for the populations most impacted by the social determinants of health by taking the following steps:

- Ensuring regular team training on diversity, equity, inclusion, and antiracism—and in particular, understanding the impact racism, colonialism, homophobia, sexism, and transphobia can have on accessing safe and culturally responsive care for people with an eating disorder. Training should also include a focus on serving Black, Indigenous, and racialized people, and people who identify as 2SLGBTQIA+
- Ensuring all clinical materials are written with consideration for people more commonly affected by the social determinants of health—preferably with input from those groups
- Ensuring discussions of meal planning and food choices are culturally appropriate and relevant
- Including people from diverse backgrounds on advisory committees or boards
- Incorporating trauma-informed principles into programming and care and providing people with an opportunity to give feedback on their care delivery experience



What This Quality Statement Means

For People With an Eating Disorder and Their Family and Caregivers

You should feel like you are being treated with respect, dignity, and compassion by your health care providers. You should receive care in a manner that respects your identity and is free from bias. Your care providers should work with you to understand your eating disorder and how treatment is affected by your unique identity. They should be respectful of, and attentive to, cultural differences (among other things). You should be able to get high-quality health care when you need it, no matter where you go (for example, at your doctor's office or at the hospital).

For Clinicians

Treat people with an eating disorder (and their families and caregivers, where appropriate) with respect, dignity, and compassion, and work to establish trust with them. Ensure that you are equipped with the appropriate education, knowledge, and skills needed to provide trauma-informed care in a culturally sensitive, anti-racist, and anti-oppressive way that recognizes intersectional (see Appendix 4, Guiding Principles, Intersectionality) identities of people with an eating disorder. See the person for who they are as an individual, actively listen to them, work to understand their needs, and provide timely, high-quality care.⁵² Be an advocate and an agent of change if structural factors of discrimination are observed and need to be addressed.

For Organizations and Health Services Planners

At the provincial and local levels, ensure that health care and other services are provided by a knowledgeable workforce capable of addressing the many needs of people with an eating disorder. This includes engaging with other sectors, such as education and community-based services. Health care organizations have a responsibility to implement changes to care delivery that reduce structural barriers to care and engagement.

Ensure that providers across health care settings receive ongoing education and training, that the workforce represents the diversity of the population being served in terms of their racial/ethnic and cultural backgrounds, and that care practices are trauma informed, culturally sensitive, anti-racist, and anti-oppressive.

Ensure eating disorder services are developed in partnership with the groups most impacted by the social determinants of health, including racialized populations, to address their concerns and develop culturally sensitive health



care and community and social services. This process should be accompanied by a review of policies and procedures that aims to remove intrinsic systemic barriers to accessing care and services, to advance equity, and to address interlocking systems of social oppression and to recognize the intersectional identities of people with an eating disorder (see Appendix 4, Guiding Principles, Intersectionality). For more information, please see Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework. In addition, to support the development of tailored services, consider the use of Ontario's Health Equity Impact Assessment Tool as a practical decision-making tool to support your equity analysis to address racism and anti-Black racism.

QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with an eating disorder who report receiving care from health care providers and a health care system that uses an anti-racist, antidiscrimination, anti-stigma, and anti-oppressive approach
- Local availability of resources and training for health care providers of people with eating disorders to provide them with the knowledge and skills needed to provide care that is compassionate, trauma informed, unbiased, and respectful of people's diversity

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.



Care for People Who Are Not Receiving Active Treatment

People with an eating disorder who are not receiving active treatment are offered medical monitoring, support, and follow-up that meets their needs and preferences.

Sources: American Psychiatric Association, 2023¹ | National Institute for Health and Care Excellence, 2017²

Definitions

Not receiving active treatment: People with an eating disorder may not be receiving active treatment because they are waiting for treatment, it has ended, it has not helped in the past, or they have declined it.² Those who are not receiving active treatment should be connected to primary care and community supports for ongoing monitoring and referral back to eating disorder treatment as indicated.

Medical monitoring, support, and follow-up: Medical monitoring is described in quality statement 5. Support can involve guided self-help interventions^{2,18} (e.g., workbooks, e-interventions), peer support, and interventions to support readiness for treatment. Regular check-ins and follow-up for a person's eating disorder behaviours are provided by a health care provider.

Rationale

Eating disorder treatment can be a physically and psychologically challenging experience. Some people may find intensive forms of treatment to be intolerable or unacceptable. Other people may not have benefited from eating disorders treatment despite multiple attempts and may decline further treatment. People with eating disorders whose health is at serious risk may need emergency care and/or admission to hospital. For people with eating disorders whose health is at serious risk but decline care, their capacity to make this health care decision should be considered according to Ontario's Health Care Consent Act⁵⁴ and the Ontario Substitute Decisions Act.⁵⁵ Signs that a person's health may be at serious



risk include, but are not limited to rapid substantial weight loss, unstable vital signs, electrolyte disturbances, cardiac abnormalities, hemodynamic instability, medical complications of malnutrition, suicidal thoughts or behaviours, and risk of death or imminent risk of serious medical complications. Strengthened primary care and community-based health care can support people in achieving their health goals for those who are not engaged in active treatment. People with an eating disorder and their families and caregivers may access helpful information through websites, chat rooms, and social media. However, in some instances, misinformation exists and professional guidance is important. Health care professionals should inquire about the use of peer- or internet-based support and discuss the information, ideas, and approaches that have been gathered from these sources and the level of evidence to support informed decisions.

What This Quality Statement Means

For People With Eating Disorders and Their Family and Caregivers

You may not be receiving active treatment for your eating disorder for any of the following reasons:

- You are waiting for treatment
- You have finished treatment
- Treatment hasn't helped in the past
- You don't want it or aren't ready for treatment

If this is the case, your health care providers should continue to offer you other support that meets your needs and preferences, and connect you with other available resources.

For Clinicians

Support and collaborate with people with an eating disorder who are not receiving active treatment and their family and caregivers to determine what ongoing follow-up and support best meets their needs.

For Organizations and Health Services Planners

Ensure that systems, processes, and resources are organized so that people not receiving active treatment for an eating disorder receive appropriate ongoing medical monitoring, follow-up, and support based on their needs.



QUALITY INDICATORS: HOW TO MEASURE IMPROVEMENT FOR THIS STATEMENT

- Percentage of people with an eating disorder who are not receiving active treatment, but receive ongoing medical monitoring at every appointment with their health care provider
- Percentage of people with an eating disorder who are not receiving active treatment, but report feeling supported by their health care provider

Measurement details for these indicators, as well as indicators to measure overarching goals for the entire quality standard, are presented in Appendix 2.

Appendices

Appendix 1. About This Quality Standard

How to Use This Quality Standard

Quality standards inform patients, caregivers, clinicians, and organizations about what high-quality care looks like for health conditions or processes deemed a priority for quality improvement in Ontario. They are based on the best evidence.

Guidance on how to use quality standards and their associated resources is included below.

For People With Eating Disorders and Their Families and Caregivers

This quality standard consists of quality statements. These describe what high-quality care looks like for people with an eating disorder.

Within each quality statement, we've included information on what these statements mean for you, as a patient, family member, or caregiver.

In addition, you may want to download the accompanying <u>patient and caregiver</u> <u>guides</u> on eating disorders to help you have informed conversations with your health care providers. Inside, you will find information and questions you may want to ask as you work together to make a plan for your care.

For Clinicians and Organizations

The quality statements within this quality standard describe what high-quality care looks like for people with an eating disorder. They are based on the best evidence and designed to help you know what to do to reduce gaps and variations in care.

Many clinicians and organizations are already providing high-quality evidence-based care. However, there may be elements of your care that can be improved. This quality standard can serve as a resource to help you prioritize and measure improvement efforts.

Tools and resources to support you in your quality improvement efforts accompany each quality standard. These resources include indicators and their definitions (Appendix 2). Measurement is key to quality improvement. Collecting and using data when implementing a quality standard can help you assess the quality of care you are delivering and identify gaps in care and areas for improvement.

There are also a number of resources online to help you, including:

- Our <u>patient and caregiver guides</u> on eating disorders, which you can share
 with patients, families, and caregivers to help them have conversations with
 you and their other health care providers. Please make the patient and
 caregiver guides available where you provide care
- Our <u>measurement resources</u>, which include our measurement guide of technical specifications for the indicators in this quality standard, and our "case for improvement" slide deck to help you to share why this standard was created and the data behind it
- Our <u>placemat</u>, which summarizes the quality standard and includes links to helpful resources and tools
- Our <u>Getting Started Guide</u>, which includes links to templates and tools to help you put quality standards into practice. This guide shows you how to plan for, implement, and sustain changes in your practice
- Quorum, an online community dedicated to improving the quality of care across Ontario. This is a place where health care providers can share information and support each other, and it includes tools and resources to help you implement the quality statements within each standard
- The <u>Health Equity Impact Assessment tool</u>, which can help your organization consider how programs and policies impact population groups differently. This tool can help maximize positive impacts and reduce negative impacts, with an aim of reducing health inequities between population groups

How the Health Care System Can Support Implementation

As you work to implement this quality standard, there may be times when you find it challenging to provide the care outlined due to system-level barriers or gaps. These challenges have been identified and documented as part of the development of the quality standard, which included extensive consultation with health care professionals and people with lived experience and a careful review of available evidence and existing programs. Many of the levers for system change fall within the purview of Ontario Health, and as such we will continue to work to address these barriers to support the implementation of quality standards. We will also engage and support other provincial partners, including the Ministry of Health or other relevant ministries, on policy-level initiatives to help bridge system-level gaps.

In the meantime, there are many actions you can take on your own, so please read the standard and act where you can.

Appendix 2. Measurement to Support Improvement

The Eating Disorders Quality Standard Advisory Committee identified four indicators for this quality standard. These indicators can be used to monitor the progress being made to improve care for people who have or are at risk for an eating disorder. Most indicators are provincially measurable, while one can be measured using only locally sourced data.

Using data from these indicators will help you assess the quality of care you are delivering and the effectiveness of your quality improvement efforts. We realize this standard includes a lengthy list of statement-specific indicators. These indicators are provided as examples; you may wish to create your own quality improvement indicators based on the needs of your population. We recommend you identify areas to focus on in the quality standard and then use one or more of the associated indicators to guide and evaluate your quality improvement efforts.

Organizations can use these indicators for quality improvement initiatives related to the types of eating disorders and age categories (children and young people, adults) their team is interested in. We do not intend for data to be collected about types of eating disorders and age groups that are beyond a team's focus.

To assess equitable delivery of care, you can collect data for locally measured indicators by patient socioeconomic and demographic characteristics, such as age, education, gender, income, language, race, and sex.

Our <u>measurement guide</u> provides more information and concrete steps on how to incorporate measurement into your planning and quality improvement work.

Measurement to support implementation

Indicators That Can Be Measured Using Provincial Data Rate of emergency department visits for an eating disorder in the past year

- Denominator: total population
- Numerator: number of people in the denominator who visited the emergency department for an eating disorder in the past year
- Data sources: National Ambulatory Care Reporting System (NACRS), appropriate population estimate (e.g., Registered Persons Database (RPDB), Statistics Canada population tables)

Rate of hospital admissions for an eating disorder in the past year

- Denominator: total population
- Numerator: number of people in the denominator who were admitted to hospital for an eating disorder in the past year
- Data sources: Discharge Abstract Database (DAD), appropriate population estimate (e.g., RPDB, Statistics Canada population tables)

Percentage of people with an emergency department visit for an eating disorder in the past year for whom the emergency department was the first point of contact for mental health or addictions care

- Denominator: total number of people with an emergency department visit for an eating disorder
- Numerator: number of people in the denominator for whom the emergency department was the first point of contact for mental health or addictions care in the past year
- Data sources: DAD, NACRS, Ontario Health Insurance Plan (OHIP) claims database, Ontario Mental Health Reporting System (OMHRS), RPDB

Indicator That Can Be Measured Using Only Local Data

Percentage of people with an eating disorder who report an improvement in their quality of life

- Denominator: total number of people with an eating disorder
- Numerator: number of people in the denominator who report an improvement in their quality of life
- Data source: local data collection

How to Measure Improvement for Specific Statements

Quality Statement 1: Comprehensive Assessment

Percentage of people with signs and symptoms of an eating disorder who receive the following:

- A comprehensive mental health assessment
- A comprehensive physical health assessment
- Denominator: number of people with signs and symptoms of an eating disorder
- Numerator:
 - Number of people in the denominator who receive a comprehensive mental health assessment
 - Number of people in the denominator who receive a comprehensive physical health assessment
- Data source: local data collection

Percentage of people with signs and symptoms of an eating disorder who have the following initiated within 8 weeks of the first appointment with their health care provider:

- A comprehensive mental health assessment
- A comprehensive physical health assessment
- Denominator:
 - Number of people with signs and symptoms of an eating disorder who have a comprehensive mental health assessment initiated
 - Number of people with signs and symptoms of an eating disorder who have a comprehensive physical health assessment initiated
- Numerator: number of people in the denominator who have this comprehensive health assessment initiated within 8 weeks of first appointment with their health care provider
- Data source: local data collection

Local availability of assessments for eating disorders within 8 weeks of a first appointment with a health care provider for signs and symptoms of an eating disorder

Data source: local data collection

Quality Statement 2: Level of Care

Percentage of people with an eating disorder who receive the most appropriate level of care (see Definition: Level of care for a list of level of care considerations)

- Denominator: number of people with an eating disorder
- Numerator: number of people in the denominator who receive the most appropriate level of care
- Data source: local data collection

Percentage of people with an eating disorder who report there was good collaboration between health care teams during a transition between levels of care

- Denominator: number of people with an eating disorder
- Numerator: number of people in the denominator who report there was good collaboration between health care teams during a transition between levels of care
- Data source: local data collection

Percentage of people with an eating disorder whose symptoms are not improving under current treatment who are reassessed by a health care provider and are offered the next most appropriate treatment option (see Definition: Level of care for a list of level of care considerations)

- Denominator: number of people with an eating disorder whose symptoms are not improving under current treatment
- Numerator: number of people in the denominator who are reassessed by a health care provider and are offered the next most appropriate treatment option
- Data source: local data collection
- Potential stratification: children and adolescents, adults

Quality Statement 3: Transition from Youth to Adult Health Care Services

Percentage of people with an eating disorder who will transition out of youthoriented services to adult-oriented services and who receive transitional care that focuses on continuity and helping the young person develop independence

- Denominator: number of people with an eating disorder who will transition out of youth-oriented services to adult-oriented services
- Numerator: number of people in the denominator who receive transitional care that focuses on continuity and helping the young person develop independence
- Data source: local data collection

Quality Statement 4: Psychotherapy

Percentage of people with an eating disorder who receive evidence-based psychotherapy by a health care professional within 8 weeks of the completion of their comprehensive assessment

- Denominator: number of people with an eating disorder
- Numerator: number of people in the denominator who receive evidencebased psychotherapy by a health care professional within 8 weeks of the completion of their comprehensive assessment
- Data source: local data collection

Local availability of evidence-based psychotherapy delivered by a health care professional within 8 weeks of the completion of their comprehensive assessment

Data source: local data collection

Quality Statement 5: Monitoring and Medical Stabilization

Percentage of people with an eating disorder who receive ongoing medical monitoring at every appointment with their health care provider

- Denominator: number of people with an eating disorder
- Numerator: number of people in the denominator who receive ongoing medical monitoring at every appointment with their health care provider
- Data source: local data collection.

Percentage of people with an eating disorder who are medically unstable and subsequently receive acute medical stabilization

- Denominator: number of people with an eating disorder who are medically unstable
- Numerator: number of people in the denominator who receive acute medical stabilization
- Data source: local data collection

Quality Statement 6: Support for Family and Caregivers

Percentage of children and young people with an eating disorder whose families and caregivers receive resources, structured support, and education by a health care provider

- Denominator: number of children and young people with an eating disorder
- Numerator: number of people in the denominator whose families and caregivers receive resources, structured support, and education by a health care provider
- Data source: local data collection

Percentage of people with an eating disorder whose families and caregivers are involved in their care and whose families and caregivers report feeling supported and informed about eating disorders

- Denominator: number of people with an eating disorder whose families and caregivers are involved in their care
- Numerator: number of people in the denominator whose families and caregivers report feeling supported and informed about eating disorders
- Data source: local data collection

Quality Statement 7: Physical, Mental Health, and Addiction Comorbidities

Percentage of people with an eating disorder who have physical, mental health, or addiction comorbidities who are offered treatment for their eating disorder as part of the same treatment plan

- Denominator: number of people with an eating disorder who have physical, mental health, or addiction comorbidities
- Numerator: number of people in the denominator who are offered treatment for their eating disorder as part of the same treatment plan as their physical, mental health, or addiction comorbidities
- Data source: local data collection

Quality Statement 8: Promoting Equity

Percentage of people with an eating disorder who report receiving care from health care providers and a health care system that uses an anti-racist, antidiscrimination, anti-stigma, and anti-oppressive approach

- Denominator: number of people with an eating disorder
- Numerator: number of people in the denominator who report receiving care from health care providers and a health care system that uses an anti-racist, anti-discrimination, anti-stigma, and anti-oppressive approach
- Data source: local data collection

Local availability of resources and training for health care providers of people with eating disorders to provide them with the knowledge and skills needed to provide care that is compassionate, trauma informed, unbiased, and respectful of people's diversity

Data source: local data collection

Quality Statement 9: Care for People Who Are Not Receiving Active Treatment

Percentage of people with an eating disorder who are not receiving active treatment, but receive ongoing medical monitoring at every appointment with their health care provider

- Denominator: number of people with an eating disorder who are not receiving active treatment
- Numerator: number of people in the denominator who receive ongoing medical monitoring at every appointment with their health care provider
- Data source: local data collection

Percentage of people with an eating disorder who are not receiving active treatment, but report feeling supported by their health care provider

- Denominator: number of people with an eating disorder who are not receiving active treatment
- Numerator: number of people in the denominator who report feeling supported by their health care provider
- Data source: local data collection

Appendix 3. Glossary

Adults: People aged 18 years and older.

Caregiver: An unpaid person who provides care and support in a nonprofessional capacity, such as a parent, other family member, friend, or anyone else identified by the person with an eating disorder. Other terms commonly used to describe this role include "care partner," "informal caregiver," "family caregiver," "carer," and "primary caregiver."

Children and young people: People under 18 years of age.

Culturally appropriate care: Care that incorporates cultural or faith traditions, values, and beliefs; is delivered in the person's preferred language; adapts culture-specific advice; and incorporates the person's wishes to involve family or community members.

Family: The people closest to a person in terms of knowledge, care, and affection; this may include biological family, family through marriage, or family of choice and friends. The person defines their family and who will be involved in their care.

Health care professional: Health care professionals as well as people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, recreational staff, and spiritual care staff.

Health care team: All providers, primary care providers, home and community care providers, as well as any other health care providers who give care and support to the person (and their parents and caregivers, where appropriate).

Primary care: A setting where people receive general health care (e.g., screening, diagnosis, and management) from a regulated health care professional whom the person can access directly without a referral. This is usually the primary care physician, family physician, nurse practitioner, or other health care professional with the ability to make referrals, request biological testing, and prescribe medications.^{56,57}

Primary care provider: A family physician (also called a primary care physician) or nurse practitioner.

Transitions in care: These occur when patients transfer between different care settings (e.g., hospital, primary care, long-term care, home and community care) or between different health care providers during the course of an acute or chronic illness.

Appendix 4. Values and Guiding Principles

Values That Are the Foundation of This Quality Standard

This quality standard was created, and should be implemented, according to the <u>Patient, Family and Caregiver Declaration of Values for Ontario</u>. This declaration "is a vision that articulates a path toward patient partnership across the health care system in Ontario. It describes a set of foundational principles that are considered from the perspective of Ontario patients, and serves as a guidance document for those involved in our health care system."

These values are:

- Respect and dignity
- Empathy and compassion
- Accountability
- Transparency
- Equity and engagement

A quality health system is one that provides good access, experience, and outcomes for all people in Ontario, no matter where they live, what they have, or who they are.

Guiding Principles

In addition to the above values, this quality standard is guided by the principles outlined below.

Acknowledging the Impact of Colonization

Health care professionals should acknowledge and work toward addressing the historical and present-day impacts of colonization in the context of the lives of Indigenous Peoples throughout Canada. This work involves being sensitive to the impacts of intergenerational and present-day traumas and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities, as well as recognizing their strength and resilience. This quality standard uses existing clinical practice guideline sources that may not include culturally relevant care or acknowledge traditional Indigenous beliefs, practices, and models of care.

French Language Services

In Ontario, the *French Language Services Act* guarantees an individual's right to receive services in French from Government of Ontario ministries and agencies in <u>26 designated areas</u> and at government head offices.⁵⁸

Integrated Care

People with an eating disorder should receive care through an integrated approach that facilitates access to interprofessional services from multiple health care providers from different professional backgrounds and across health care settings to provide comprehensive services. ^{59,60} Health care providers should work with patients, their families and caregivers, and communities to deliver the highest quality of care across settings. Interprofessional collaboration, shared decision-making, coordination of care, and continuity of care (including follow-up care) are hallmarks of this patient-centred approach. ⁶⁰

Intersectionality

Intersectionality refers to the differences in experiences with discrimination and injustice based on social categorizations such as race, class, age, and gender. These interconnected categorizations are known to create overlapping and interdependent systems of discrimination or disadvantage. ^{61,62} For example, stigma experienced by people with an eating disorder can vary depending on their racial/ethnic background, their age, any language barriers, gender, sexual orientation, presentation or their perceived class, but it can also differ depending on clinical and other demographic characteristics. Therefore, understanding how the various aspects of people's identities intersect can provide insight on the complexities of the processes that cause health inequities, and an understanding of how different people experience stigma and discrimination.

Recognition and Support of the Role of Parents, Family, and Caregivers

Recognition and support of the role of parents, family, and caregivers means creating the conditions and culture where they are respected for their expertise and welcomed as partners in the young person's care.^{63,64} This begins with acknowledging the positive impact they have on health outcomes at an individual and system level. Other key components in developing collaborative relationships among the young person, their family/caregivers, and health care providers include consistent involvement, mutual trust, and attending to the needs of parents, family, and caregivers.

Social Determinants of Health

Homelessness and poverty are two examples of economic and social conditions that influence people's health, known as the social determinants of health. Other social determinants of health include employment status and working conditions, ethnicity, food security and nutrition, gender, housing, immigration status, social exclusion, and residing in a rural or urban area. Social determinants of health can have strong effects on individual and population health; they play an important role in understanding the root causes of poorer health. People with a mental health issue or addiction often live under very stressful social and economic conditions that worsen their mental health, including social stigma, discrimination, and a lack of access to education, employment, income, and housing.

Trauma-Informed Care

Trauma-informed care is health care that reflects an understanding of trauma and the impact that traumatic experiences can have on people.⁴¹ This approach does not necessarily address the trauma directly. Rather, the approach acknowledges that a person may have experienced a previous traumatic event that may contribute to their current health concerns. It emphasizes understanding, respecting, and responding to the effects of trauma.⁶⁵

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About Us

Ontario Health

We are an agency created by the Government of Ontario to connect, coordinate and modernize our province's health care system. We work with partners, providers and patients to make the health system more efficient so everyone in Ontario has an opportunity for better health and well-being. We work to enhance patient experience, improve population health, enhance provider experiences, improve value and advance health equity.

Mental Health and Addictions Centre of Excellence

The Mental Health and Addictions Centre of Excellence was established within Ontario Health and is the foundation on which a mental health and addictions strategy is developed and maintained. This strategy recognizes that mental health and addictions care is a core component of an integrated health care system. The centre's role is to ensure that mental health and addictions care is:

- Delivered consistently across the province
- Integrated with the broader health system
- More easily accessible
- Responsive to diverse needs of people living in Ontario and their families

The centre will also help implement the Roadmap to Wellness, the province's plan to build a comprehensive and connected mental health and addictions system.

Equity, Inclusion, Diversity, and Anti-Racism

Ontario Health is committed to advancing equity, inclusion and diversity and addressing racism in the health care system. As part of this work, Ontario Health has developed an <u>Equity, Inclusion, Diversity and Anti-Racism Framework</u>, which builds on existing legislated commitments and relationships and recognizes the need for an intersectional approach.

Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society.

For more information: OntarioHealth.ca/about-us/our-people



Looking for more information?

Visit <u>hqontario.ca</u> or contact us at <u>QualityStandards@OntarioHealth.ca</u> if you have any questions or feedback about this quality standard.

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