

of diagnosed gender dysphoria in the 13-17 age group decreased in 2019 and 2020 and increased again in 2021 (also see *Introduction*).

The SBU noted in 2019 that it is unclear how prevalent gender dysphoria is in the population and whether it has changed over time [25]. Factors that have been discussed as contributors to the increase include increased access to care and awareness of gender identity issues in society, reduced stigma, and social influencing factors [26].¹⁷ Furthermore, the experience of the evaluation teams in recent years is that the patient population is also more heterogeneous than before. Young people whose gender incongruence emerges in childhood and for whom the onset of puberty causes marked distress are described as a smaller proportion of the young people they encounter. Until there is more clarity of the extent to which factors such as social influence play a contributing role, these changes represent an uncertainty that affects the assessment of the benefit-risk balance of the hormonal treatments.

Medical detransition documented among young adults

According to SBU [2], the scientific evidence is not sufficient to determine how often young people change their perception of their gender identity later or discontinue an initiated puberty-suppressing and/or gender-affirming treatment.¹⁸ In recent years, cases of young adults who detransition after undergoing gender affirming treatment have been documented [3, 4].

The concept of detransition is multifaceted and can refer to medical, social, and legal aspects of a gender-affirming process. In some of the scientific publications that have addressed the topic so far, medical detransition is defined as the process by which a person discontinues a gender-affirming medical treatment, such as treatment with sex hormones, or seeks to reverse the medical effects of undergoing gender-affirming hormonal or surgical treatment [4, 27].

Studies that have investigated the reasons for medical detransition have found that some people find it easier to identify with their natal sex for various reasons and that this is the primary reason for the decision to detransition. In an American study, 60% of respondents reported that a change in their own definitions of male and female had made them more comfortable seeing themselves as their natal sex [3]. Others choose medical detransition despite still identifying as transgender. In these cases, the decision may be primarily related to factors that make it difficult to continue treatment and/or difficult to live in accordance with their gender identity, such as

¹⁷ See for example, <https://www.umo.se/jag/sexuell-lagging-och-konsidentitet/konskorrigering/>

¹⁸ In this context, it should be noted that discontinuation of puberty-suppressing treatment with GnRH analogues during the evaluation is not considered a problem but rather a valid outcome of the evaluation.

medical side effects, societal pressure, discrimination, or dissatisfaction with the results of treatment [28, 29].

Psychological and medical care needs that may arise in the context of medical detransition include the need for support to manage emotions that may arise during the process, support with tapering hormonal treatment, and assessment of the possibility of seeking to reverse the effects of surgical procedures [4]. It is important that healthcare services are prepared to respond to any needs for care that arise. Depending on the primary reason for the decision, individuals' needs for care related to medical detransition may vary [29].

Less consistent experience-based knowledge

The recommendations and treatment criteria in the 2015 guidelines were largely based on recommendations published by The World Professional Association for Transgender Health (WPATH): Standards of Care, version 7 (SoC-7) [30], and on the experience of the experts who participated at the time. The experience of participating experts in the review work of the National Board of Health and Welfare is less uniform than it was in 2015, in that there are also questions and concerns about hormonal treatments and the conditions under which they are provided. It is the National Board of Health and Welfare's determination that the updated treatment criteria should be more clearly tied to the treatment criteria that were evaluated in the Dutch protocol. Key criteria in the Dutch protocol for puberty-suppressing treatment with GnRH analogues and for (possible) subsequent gender-affirming treatment, is that a clear cross-sex identification with the opposite sex has existed since childhood and persisted over time, and that the onset of puberty has caused clear distress. In view of the fact that in the vast majority of cases gender incongruence observed in childhood disappears over time [31], the importance of applying caution when treating with GnRH analogues was stressed in early descriptions of the Dutch protocol [5, 6].

The studies reporting longitudinal treatment outcomes using these criteria [5, 6] cannot answer questions about the efficacy and safety of treatments, but (still) represent the most robust source of experience-based knowledge about the conditions under which treatments can produce good outcomes.

The Consequences of the Recommendations

Desired, intended consequences

The intended consequence of the recommendation to offer puberty-suppressing and gender-affirming treatment in the context of research is

- increased knowledge for appropriate and safe care.

The intended consequence of the recommendation to offer hormonal therapy in exceptional cases, in accordance with the criteria set out in the evidence base, until such time as a study with ethics board approved inclusion and treatment criteria is in place, is

- safe treatment in a more uncertain state of knowledge, in particular minimizing the risk that an adolescent will wish to have the treatment undone later in life.

Possible negative consequences

Risks and possible negative consequences that may result from the two recommendations have been partly identified and taken into account during the course of the work in dialogue with participating experts, and most importantly by patients, relatives and interest groups (in draft comments and at a stakeholder meeting in April 2022). The recommendations are based on existing knowledge and ethical considerations (See also *The National Board of Health and Welfare's overall assessment*). On the part of the National Board of Health and Welfare, the study of negative consequences has been aimed at gathering information that is important to convey to decision-makers in the healthcare regions responsible for the healthcare activities in question.

The recommendation on research

Two risks and possible negative consequences of the recommendation that puberty-suppressing and gender-affirming treatment should be given in the context of research have been pointed out:

- even longer waiting times to get to an evaluation
- compulsion to participate in research in order to receive treatment.

The risks/consequences expressed and, in some cases, related clarifications are described below.

Even longer waiting times for evaluation

In its 2022 report, the Swedish Agency for Youth and Civil Society (MUCF) states that access to gender-affirming care is not working satisfactorily in terms of waiting times [15]. In the case of people under the age of 18, the Swedish National Council on Medical Ethics 2020 [16] describes that waiting times of up to two years to start an evaluation are not uncommon and notes the seriousness of the fact that this is a vulnerable group of young people whose needs for care need to be investigated. Patients, relatives and interest groups have pointed out that waiting times risk being

further extended if resources continue to be needed for the implementation of research as well.

The National Board of Health and Welfare stresses the importance of the timely allocation of resources that enable good and accessible care and facilitate the conduct of relevant research.

Compulsion to participate in research in order to receive treatment

Another consequence that has been pointed out is that patients may feel forced to participate in research in order to access the treatment they feel they need. However, it is common that patients with serious health conditions can only receive a certain treatment, the benefits and risks of which are not yet clear, by participating in research studies. The patient always has the right to opt out. If a patient does not wish to participate in a research study, the healthcare system has a responsibility to offer the patient a treatment other than the one provided in the study to meet the need for care, if such treatment is available.

Recommendation on treatment in exceptional cases

Until a research study with ethics board approved inclusion and treatment criteria is in place, the National Board of Health and Welfare's assessment is that puberty-suppressing and gender-affirming hormone treatment can be given in exceptional cases, in accordance with the criteria in the updated guidelines. The following risks and possible negative consequences of the recommendation have been pointed out:

- continued dysphoria and increased distress due to endogenous puberty
- increased risk of suicide due to gender dysphoria and endogenous puberty
- increased need for future surgery due to undergoing endogenous puberty
- increased self-medication
- manipulated patient histories^{xv}
- reduced trust in healthcare and reduced propensity to seek help
- upholding the two-gender norm when non-binary people are excluded.

The risks/consequences expressed and, in some cases, related clarifications are described below. The knowledge base on the risks of not offering the treatments (but providing psychosocial care) is insufficient. However, the risks of increased suffering, suicide, and self-medication need to be taken seriously by the healthcare system and are important to address and prevent (See *For decision-makers* for further information).

Continued dysphoria, increased suffering, and suicide risk

One risk that has been expressed is that adolescents who feel a strong need for puberty-suppressing and/or gender-affirming treatment but are not offered it, may be at increased risk of mental health problems.

It is important that the healthcare system provide adequate psychosocial care for these young people. See *For decision-makers* for further information below.

Increased need for future surgery and reduced quality of life

One consequence of not offering puberty-suppressing treatment to an adolescent with gender dysphoria is that the effects of natal puberty will persist for the rest of his or her life. Any gender-affirming surgical interventions will not be able to fully compensate for this and the person will find it more difficult to be perceived by others in accordance with their gender identity in adulthood. For the individual whose gender dysphoria persists over time, this will have a lifelong and significant negative impact on quality of life.

Increased self-medication and use of international online services

Another possible negative consequence is an increase in self-medication with sex hormones that adolescents buy themselves or through others on the Internet. More general risks of buying medicines online include the presence of counterfeit medicines and the negative consequences that can occur when taking them.¹⁹ Self-medication among adolescents with gender dysphoria has been described previously [23, 32] and it is unclear how commonly it occurs. In addition to the risk of increased self-medication, the use of international online services that are not subject to Swedish laws may also increase in cases where guardians believe that the child needs puberty-suppressing or gender-affirming hormone treatment but is not offered it.

The section on self-medication in the 2015 guidelines [1] has been deleted in the 2022 update. According to the experience of the current experts, the previous wording on harm reduction and the need for rapid contact with an evaluation team, combined with the long waiting times for treatment, has in some cases led to adolescents starting self-medication.

It is important that adolescents and their guardians are informed about the medical risks of self-medication and how the healthcare provider views the possible

¹⁹ See 1177 on the risks of buying medicines online.

assumption of [responsibility for] medical treatment already started. According to Section 3, Section 2 of the PSL, the healthcare provider must take the measures necessary to prevent patients from suffering harm. When care is to be provided to an adolescent who is self-medicating or where medications have been prescribed by international online services with the involvement of a guardian, the healthcare provider may need to consider the risk of harm, in assessing the need for care. If the healthcare provider deems that the treatment needs to be indicated by a medical professional, and that the healthcare provider cannot assume responsibility for the treatment, it is important that the adolescent and the guardians are informed about this eventuality.

Furthermore, the healthcare service always has a responsibility to report concerns to social services if it considers that there is a risk of harm to the child.²⁰ Whether self-medication constitutes a basis for a report of concern may vary, according to the experts involved, depending on the circumstances of the individual case. If the healthcare provider deems that self-medication is always a reason for concern, this policy may be applicable and needs to be communicated to the adolescents and guardians.

Decreased trust and propensity to seek help in healthcare

Another possible consequence is that the proportion of young people with gender dysphoria who avoid contacting healthcare services despite feeling the need for care increases. Several government reports [15, 33] indicate that trust in society is low among young LGBTQI people, and especially among young trans people. Powers and authorities are perceived not to act to ensure the rights of trans people, but sometimes to directly oppose them [15]. To the extent that patients perceive that the fundamental right to live in accordance with their gender identity also includes a right to gender-affirming treatment, the revised recommendations may reinforce this lack of trust.

Perceived need for treatment may complicate care assessments

From both professional and patient perspectives, it has been suggested that some adolescents who do not meet the revised treatment criteria may feel compelled to adjust their narrative during the assessment in order to access the care they feel they need. The perception that transgender care is based on a template that one must fit into in order to receive (gender-affirming) care has been described previously [32]. There are also descriptions in government reports and scientific articles that the evaluation team has the role of "gatekeeper" [24, 34, 35], deciding whether patients

²⁰ Chapter 14, Section 1 of the SoL

should receive further treatment, and that this often contributes to limiting the transparency between the evaluation team and the patients. Patients, relatives and interest groups point to a risk that such "gatekeeping" will increase as a result of the updated recommendations.

The fact that healthcare decisions about gender-affirming treatments can sometimes be based on incorrect information can be viewed as a patient safety issue in principle, which is also relevant for the care of adults. In the evaluation of young people with gender incongruence, the involvement of caregivers means that the descriptions of several informants can be weighed together and form the basis for assessment.

When the evaluation starts after age 18, assessments are often based solely on the patient's own description.

Maintaining the two-gender norm

According to the Dutch treatment criteria, which the National Board of Health and Welfare considers should be used as a guide for individual cases, there is no documentation about puberty-suppressing and gender-affirming treatment for young people with non-binary gender identity. One consequence noted from the patients' perspective is that in this way, healthcare contributes to the maintenance of the two-gender norm. At present, there is a lack of documented experience, as well as a lack of experience among participating experts, of hormonal treatment for adolescents with non-binary gender identities.

The scope for including people with non-binary gender identities in care and treatment has increased as a result of the revisions to the DSM system and ICD classification that have taken place over the last ten years. The 2015 National Board of Health and Welfare guidelines [1, 8] also state that care interventions can generally be relevant for youth and adults with gender dysphoria regardless of the ICD-10 classification, and that the person's needs and situation should be the determining factors when deciding on each individual intervention.

During the revision work, the National Board of Health and Welfare noted that the clinical judgements and decisions about medical treatment for adult patients can be particularly difficult when the patient's gender identity is non-binary. Some of the factors that may contribute to this are the great heterogeneity within the population and the lack of knowledge to guide the assessment of when certain treatments may be beneficial for an individual patient (See *Non-binary gender identity - knowledge and need for clarification*). The available experience in adult care needs to be gathered and compiled in connection with the updating of the guidelines *Good Care of Adults with Gender Dysphoria* [8].

Overall assessment by the National Board of Health and Welfare

The expected benefits and potential side effects and risks of puberty-suppressing treatment with GnRH analogues and gender-affirming hormone therapy are described in the section *Hormonal treatment for gender dysphoria in adolescents*. In this section, possible negative consequences of the updated recommendations of the National Board of Health and Welfare have been described, some of which have been identified and taken into account during the course of discussions with participating experts, and others that were expressed by patients, relatives, and interest groups. On the part of the National Board of Health and Welfare, the survey has aimed to gather information that is important to convey to decision-makers in the health and medical regions who are responsible for the care activities in question. In the light of the comments regarding the draft, stating that the survey was done only after the recommendations had been decided upon and that the risks of not giving treatments have not been taken into account, the National Board of Health and Welfare would like to clarify the overall assessment and the basis on which recommendations on care measures have been given.

In the risk-benefit assessment that healthcare services make in the case of an individual young person, the expected benefits of the treatment in question need to have been made clear, and the benefits must be judged to outweigh the risks (See *Hormonal treatment for gender dysphoria in adolescents*). In the individual assessment, the expected benefits and risks of not providing the treatment in question also need to have been clarified and considered. In contrast, the recommendations of the National Board of Health and Welfare provide guidance at the population level. They are based on scientific and experience-based knowledge of the efficacy and safety of the treatment measures concerned, and on an ethical analysis.

The revised recommendations reflect the assessment that at the population level, the risks of the treatments are likely to outweigh the benefits, and are based on the uncertainties of knowledge and the factors previously mentioned in this section. The section shows that the evidence base in 2022 is unchanged compared to 2015 in that the scientific evidence is still considered insufficient to comment on either the benefits of the treatments or on the risks of the treatments for adolescents with gender dysphoria [2]. Although adolescents and young adults interviewed described access to the treatments as crucial to their mental health and sometimes as directly lifesaving [15, 36], there is (still) no evidence to conclude that the treatments have such benefits for the patient population [2]. Similarly, there is also no scientific evidence to draw conclusions about the risks that have been pointed out, such as the risk of offering psychosocial care but not puberty-suppressing and hormonal treatment.

Care must be provided on the basis of science and proven experience and the principle of doing good and not harm. In revising the recommendations, the National Board of Health and Welfare has taken into account the fact that the efficacy and

safety of treatments, benefits, and risks are not proven, and that three factors have shifted the balance between benefits and risks in a negative direction:

- the increased prevalence of gender dysphoria among young people [19], particularly among young people registered female at birth, and that the reasons for the increase and the relative shift between the sexes are not yet known
- that medical detransition among young adults has been documented [3], and it is not known how commonly it occurs
- that the experience-based clinical knowledge among participating experts is less uniform than it was in 2015.

For decision-makers

Young people suffering from gender dysphoria need to be able to promptly begin evaluation and be offered appropriate care based on needs assessments by the healthcare service. The various gender-affirming treatments listed in the different sections of the guidelines need to be offered once they have been deemed indicated. Good psychosocial care is essential. The patient population is heterogeneous and psychosocial care must be clearly inclusive of young people with non-binary gender identities.

Psychosocial care

In accordance with child psychiatric practice, the psychosocial care of young people with gender dysphoria needs to be adapted to the needs of the individual adolescent. Psychosocial support that helps the adolescent deal with natal puberty without medication needs to be the first option when choosing care measures. For those suffering from mental health problems, measures such as supportive counselling, psychotherapy, child psychiatric treatment and suicide prevention need to be offered and adapted to the nature and severity of the mental health problem and the young person's overall situation.

Regardless of the causes, healthcare services have a general mandate to seek to prevent suicide, as well as a specific responsibility to offer the best possible care, treatment, and support to people with thoughts or plans of suicide. The suicide risk of young transgender people is elevated compared to the suicide risk of young people in the general population (See *Support for young people and their families*). Healthcare professionals encountering young people with gender dysphoria need to be continuously vigilant to detect serious mental health problems, and suicidal thoughts in particular. It is important that procedures are in place to concretize suicide prevention work, in line with the forthcoming national strategy for mental health and

suicide prevention. Support for suicide prevention can be found on the National Board of Health and Welfare's website.²¹

Include measures to promote mental health

In addition to interventions aimed at reducing mental health problems, several reports point to the importance of care interventions that promote mental health in young transgender people [15]. Some are described and exemplified elsewhere in the guidelines:

- psychosocial support aimed at promoting resilience and self-esteem and at reducing the effects of minority stress
- psycho-educational interventions provided in a validating context and aimed at providing a greater knowledge and understanding of one's own situation.

See also Support for young people and their families.

In the report *I am not alone, there are others like me*^{xvi} [15], MUCF provides an updated picture of the living conditions of young LGBTQI persons and suggestions for continued measures to reduce the vulnerability of transgender persons. Among the measures proposed in the report are:

- provision of "safe spaces" where young LGBTQI people can meet others in the same situation
- increased resources and competence for youth clinics, school health, primary care, and psychiatry to meet and create forums for young trans people in need of professional support.

The report also describes the experiences of sixteen young transgender people regarding what has worked to strengthen their mental health [37]. The interviews show that opportunities to meet other transgender people, as well as to feel safe, supported and accepted by family, friends, school, and work, are important for mental health. Participating in activities and contexts where one can freely explore oneself (e.g., through role-play), as well as physical activity and freedom of movement in comfortable settings are also perceived as strengthening.

²¹ <https://www.socialstyrelsen.se/kunskapsstod-och-regler/omraden/psykisk-ohalsa/>

Information about why the recommendations have changed

According to the participating experts, adolescents today come to the clinic with a great deal of suffering that has worsened due to long waiting times. Consistent with the testimonies above, some adolescents are firmly convinced that medical treatment is the only thing that can make them feel better. Even guardians may sometimes question why the only (as perceived by individuals) effective treatment for gender dysphoria is not offered to the adolescent who feels a strong need for it. It is important that young people and families are provided with information that helps paint a more nuanced picture and facilitate the understanding of why the recommendations regarding medical treatments have become more restrictive.²²

Such information may state, for example that:

- young adults detransition and sometimes regret gender affirming treatment, despite their previous conviction that treatment was the right solution [3, 4], and that we do not currently know how commonly this occurs [2]. This is a problem because care measures must be provided based on science and proven experience and on the principle of doing good and not harm.
- results from various types of correlation studies, which are sometimes cited as support for the benefits of treatments, generally have low reliability because the study designs do not allow to draw conclusions about efficacy and safety.

²² The information above and other key information in the knowledge support will be considered when updating the information material "For those with gender dysphoria".

Non-Binary Gender Identity – Knowledge and Need for Clarification

During the revision process of the section on hormonal treatment (October 2021), comments were received from the patient's perspective, including comments on the fact that a cross-gender identity was put forward as a criterion for puberty-suppressing and gender-affirming hormone treatment. The responses pointed out that gender dysphoria and the need for treatment should be the guiding principle, not the pronoun or gender identity of a person. Furthermore, it has become clear during this work that the participating experts are not entirely united on this issue and that there are also related issues concerning the care and treatment of adults with non-binary gender identity. The aim of this section is to provide an initial picture of the state of knowledge about the care and treatment of people with non-binary gender identity and issues that the National Board of Health and Welfare believes need to be addressed and clarified.²³

Background

Non-binary gender identity refers to a gender identity outside the binary division of man/woman, boy/girl. The group is heterogeneous and includes, for example, people who identify as both masculine and feminine, somewhere between masculine and feminine gender identities or as gender neutral. Others may identify as a specific third gender, as multiple genders or as all genders (pangender) [38]. The terms people use to describe their nonbinary gender identity vary among individuals, and an individual's nonbinary gender identity can sometimes vary over time and depending on the context [39].

The proportion of people with non-binary gender identity varies in different studies, depending on factors such as the population studied and how study participants are recruited. A 2020 literature review based on international studies [40] found that 11-15% of young people enrolled in gender identity clinics had non-binary gender identities. Similarly, a Swedish publication from 2021 found that 26 people in a total

²³ The inventory of the state of knowledge has included the referral version of the Standards of Care version 8 (SOC8) from WPATH ("Chapter draft for public comment - Nonbinary") that was made available in December 2021 and scientific publications that the National Board of Health and Welfare identified during a survey in September 2020 (See the separate appendix Knowledge base with methods description).

patient group of 232 (11.2%) stated that they preferred a pronoun other than she/he; the median age in the group was 24 [41].

The scope for including people with non-binary gender identities in care and treatment has increased as a result of the revisions to the DSM system and ICD classification that have taken place over the last decade. Since the 2013 publication of the DSM-5, the diagnosis of gender dysphoria (302.85) may be made regardless of whether the gender identity is binary or non-binary. The ICD-11, adopted by the WHO in 2019, allows for the use of the code Gender Incongruence (HA60) regardless of whether the gender identity is binary or non-binary. See *Clinical diagnosis and statistical classification* in the *Introduction* section for more information.

In line with the DSM-5, the recommendations of the 2015 guidelines [1] were for young people with gender dysphoria in general, i.e., including young people with non-binary gender identity.

Knowledge of care needs

Two literature reviews published in 2019-2020 compiled studies examining the health and social situations of people with non-binary gender identities [40, 42]. One literature review looked at people up to age 25 [40], while the other looked at people of all ages [42]. The authors of both reviews concluded, that among other factors, it is (also) important that young people with non-binary gender identity are offered psychosocial support in order to reduce the consequences of marginalization and minority stress (See also the previous section and section *Support for young people and their families*).

A 2021 Swedish study suggests that the majority of healthcare seekers with binary and non-binary gender identities feel a need for gender-affirming hormonal treatment and some form of surgical treatment [41]. People with non-binary gender identity have varying needs and desires for physical changes. Some have no need for gender-affirming treatment and some describe needs and desires similar to those of people with binary gender identity, i.e., a clear feminization/masculinization in relation to the registered sex at birth. Others may have needs and desires for an increased or decreased, relative to their registered sex at birth, degree of feminization/masculinization of, for example, hair, body shape, and vocal pitch [43].

Knowledge of care and treatment

In recent years, assessment instruments have been developed that can be used as a basis for discussion or to support assessments during the diagnostic evaluation, regardless of the person's gender identity (See *Evaluation of young people with gender incongruence*). One instrument was developed specifically for non-binary gender identities and is intended to support diagnostic assessment when gender-

affirming treatment is being considered for this group [44]. Psychological support specifically for people with non-binary gender identity has also been described [45].

Regarding GnRH analogue and gender-affirming hormone therapy, there appears to be a complete lack of documentation for the group of youth with non-binary gender identities. In the Dutch protocol, cross-gender gender identity is a criterion for both puberty-suppressing and gender-affirming hormone therapy [5, 6]. According to participating pediatric endocrinologists, there is a lack of experience in treating youth with nonbinary gender identity, both in the Nordic countries and internationally. The "Non-binary" section in the WPATH version of SoC8 states that an individual's need for gender-affirming treatment cannot be determined on the basis of gender role behaviors, gender expression, or gender identity. The section also states that knowledge is limited with regard to adults, while explicit references to "adolescents" are missing.²⁴

An article from 2020 [43] suggests how hormonal treatment in particular can be adapted to people with non-binary gender identity. Suggestions for treatment pathways for people registered as male and female at birth are described in a flowchart, however the article makes no reference to adolescents.

A 2019 US study [46] reported that 58 of 458 (13%) of patients with gender dysphoria who underwent gender-affirming breast surgery from 2012 to 2017 had non-binary gender identities. All 58 persons with non-binary gender identity were persons registered female at birth who had undergone mastectomy; the mean age was 29.5 years (sd=7.60).

Need for clarification

At present, descriptions of puberty-suppressing and gender-affirming hormonal treatment for adolescents with non-binary gender identity appear to be completely lacking in the literature, and very little is available on gender-affirming treatment for the adults. The National Board of Health and Welfare concludes that the experience, questions, and considerations related to the assessment and treatment of this patient population need to be discussed at the national level. For example, important questions concern the possibilities and limitations of health care to meet different types of wishes for bodily changes in the adult patient population based on medical and surgical considerations, and how the indication for treatment is determined. For the adolescent population, a pressing issue is to clarify the conditions under which adolescents with non-binary gender identities can be offered hormonal treatment in the context of research.

²⁴ The National Board of Health and Welfare was able to access the consultation version of SoC8 as preliminary information in December 2021. The conditions remain in the final version of SoC8 published in September 2022.

Support for Young People and Their Families

The number of young people referred for gender dysphoria assessment has increased significantly over the past decade. The increase is seen both nationally and internationally and is particularly evident among adolescents registered female at birth [25, 26]. The experience of the evaluation teams in recent years is that [currently], the young people being evaluated are also a more heterogeneous group than in the past.

Young people whose gender incongruence begins in childhood and for whom the onset of puberty causes clear distress are a smaller group. In these cases, the child's exploration and the evaluation team's contact with the family often extends over many years. Time is an important factor in the certainty of assessments, and the diagnosis is relatively straightforward once evaluation begins. It is usually relatively easy for the young person, guardians, and the evaluation team to reach a consensus on care needs and treatment measures in these cases.

For most of the young people encountering evaluation teams [currently], the situation is different. Many seek care later in puberty, largely describing longstanding gender incongruence that was noticeable before and worsened with puberty. There may be aggravating circumstances to consider, which make life challenging for the young person and complicate diagnosis and certainty of assessment for the evaluation team. In the experience of the evaluation team, psychosocial support of various kinds needs to be provided over a longer period of time for most young people, before a consensus on care needs and interventions is reached by the young person, guardians, and the evaluation team. The psychosocial support described in this section is often an integral part of the evaluation.

The content of this section applies generally to youth with gender incongruence and includes people with non-binary gender identities.

Broad psychoeducational approach to initial support

Often, evaluation teams see a need to initially offer support with psychoeducational elements that relate not only to gender identity but also to identity development more

generally.²⁵ The content of the interventions and the form in which they are delivered are individualized. The aim of the interventions is both to provide a safe and validating context, and to provide information that can help the person to gain a better knowledge and understanding of their own situation and how they can deal with it. The themes addressed vary and may include:

- teenage years
- friends (past, present, and future)
- well-being (physical and mental health)
- the body
- the family and the context in which you grow up
- fears, uncertainty, and ambivalence
- the Internet (is its use supportive or not?)
- difficult life experiences
- autism/ADHD/ADD
- other psychiatric conditions
- gender norms, and their impacts
- relationships, sexuality, sexual orientation
- what it means to them to be transgender
- values, e.g., how I see myself and others, dare to fight/dare to back down
- transphobia and minority stress (See below).

The experience of the evaluation teams is that this approach facilitates continued unconditional exploration of gender identity during the evaluation. Some young people reassess their situation over time and choose to end the evaluation at a relatively early stage.

Minority stress and protective factors

Several government reports and literature reviews show clear differences in health between young LGBT people and young people in general [47, 48]. The differences are most evident in the area of mental health, where anxiety, depression, and stress are more prevalent among LGBT people compared to the general population.

According to a FORTE evidence review on health and living conditions among young LGBT people [48], growing research supports the notion that the increased risk of ill health among LGBT people can be at least partly explained by the minority stress model [49, 50].²⁶ The theory describes increased psychosocial stress

²⁵ According to the description of the participating experts, in some regions this type of intervention can be provided by youth clinics, before the young person is referred for gender incongruence assessment.

²⁶ The model was originally developed to explain differences in mental health based on sexual orientation [5, 6] but has since been extended to understand the increased risk of ill-health in other minority groups.

specifically associated with a person's sexual orientation or gender identity deviating from the norm, which is an additional contributor to general life stress. Sources of minority stress are external: being discriminated against, rejected and subjected to prejudice and violence; and internal processes that arise as a result: living in a state of readiness and fear of being discriminated against, rejected or subjected to violence, feeling the need to keep one's identity secret from those around them, and internalized homophobia, biphobia and transphobia, i.e., the negative attitudes of the environment becoming part of the person's self-image [50].

Research in this area shows that young LGBTQ people are at increased risk of being exposed to violence and other types of bullying, both in physical and digital contexts [48]. Results from the Public Health Agency's 2015 survey [33] also suggest that the high rate of suicidal ideation among transgender people is linked to specific negative life conditions with experiences of abuse, discrimination and violence, as well as low trust in social institutions such as healthcare and schools.²⁷ Similar conclusions are drawn in the 2020 report on Public Health Agency's qualitative interview study about mental health, suicidality, and self-harm among young transgender people [36].

According to the theory, minority stress can be countered by various methods aimed at creating change at the structural and policy, as well as individual levels [50]. For example, psychosocial support aimed at promoting resilience and self-esteem of individuals is thought to contribute to reduced minority stress and improved mental health.

Knowledge about promotion methods and protective factors

In 2017, the Public Health Agency stated that the state of knowledge regarding effective methods to promote good health and prevent poor health among LGBTQ people was unclear [51]. At the time, the number of studies was small, and the majority had weak study designs. Studies suggested that school-based interventions that include LGBTQ people and increase the visibility of different identities related to gender and sexuality could counter suicidal behavior. Studies also suggested that the mental health of LGBTQ people might be improved by participating in support groups with other LGBTQ people and by cognitive behavioral therapy with a focus on affirming their LGBTQ identity. However, the evidence in the review was not

²⁷ A total of 796 transgender people aged 15–94 responded to the survey. A total of 36% reported that they had seriously considered taking their own lives at least once in the past year. Among young transgender people aged 15–19, this proportion was 57%, compared to 7% among young people in general in the 16–29 age group according to the National Health Survey. These results need to be interpreted with caution, particularly because the transgender survey respondents were recruited via a self-selected web-based survey.

sufficient to conclude these effects. Subsequent reviews of the literature have also reported similar findings [52].

For children, adolescents, and their families, support groups and activities organized by interest groups or health services can be important. According to FORTE's literature review [48], research shows that social support from friends and family can act as a protective factor against poor mental health among young LGBTQ people. Other reported protective factors include a positive LGBT identity, positive experiences of 'coming out,' belonging at school and in families, and feeling safe at school.

The Public Health Agency's 2020 interview study [36] and MUCF's 2022 report [15] also highlight protective factors that can reduce psychological distress and promote mental health among young transgender people. Examples include receiving support from relatives and school, receiving adequate care for their gender dysphoria and/or psychiatric diagnoses, and being seen and affirmed in their gender identities.

Information, support, and advice for families

It can be overwhelming for family and friends when a child or adolescent shows signs of gender incongruence or gender dysphoria. At first, family and friends may not know what it means. It is common to worry about the reactions of the community and that the young person will be harassed or harmed.

Relatives and friends may also face lack of understanding and negative reactions from the environment in relation to the child, sibling, peer, or partner transgressing gender norms or showing signs of gender incongruence. Interventions to promote the resilience and coping skills, similar to those offered to the affected young person may be needed by family and friends.

Information, support, and counselling may be needed for shorter or longer periods of time, depending on the needs of the family and the development of the child's or adolescent's gender incongruence. Psychosocial support for family members and friends may be provided together with the child or adolescent. They can also be provided individually or in groups with other family members and friends.

The issue of social transition in children

Some children with signs of gender incongruence or gender dysphoria express early on that they want to start living in accordance with their gender identity at school and in other contexts, for example by changing their first names, hairstyles, and style of dress. The ability to express oneself is important for children in general, and there is

research supporting the observation that the ability to socially transition is associated with good mental health in children [53].

At the same time, caregivers need to be informed about research suggesting that for many children, early signs of gender incongruence and gender dysphoria disappear before or around puberty. In a 2016 review [31], the proportion of "persisters" (people whose gender dysphoria is deemed to have persisted since childhood) in the ten studies included ranges from two to 39 percent. In a 2021 publication [54], 17/139 (12%) of participants registered male at birth were reported as "persisters".

The advice to guardians currently is to continue to pay attention to the development of the child's gender incongruence and how the child is doing, and to be open to the fact that the child may change their mind over time. An important task for healthcare services is to support guardians in finding strategies and contexts where the child is free to be him or herself which are appropriate to the young person's individual circumstances and needs, and to frame them such that the child feels free to change should the gender incongruence later cease.

Children who show early signs of gender incongruence or gender dysphoria and their families are regularly followed by the assessment teams at varying intervals based on the family's support needs. Guardians are also encouraged to make contact if concerns about the child arise in the interim. If signs of gender incongruence or gender dysphoria persist as puberty approaches, an evaluation needs to be considered. It is important to start an evaluation when there is a need for care, and it is deemed to be to the child's benefit.

Guardians may also need support liaising with societal functions and social contexts in which the child participates, for example to inform or coordinate approaches with school staff, or to facilitate the everyday life of young people who already live in accordance with their gender identities (See also *Assisting the young person in liaising with community functions* below).

As with other care, the recommended measures on information, support, and counselling for families require the availability of health professionals with the right competence for the task. (See also *Competences for evaluation*, section *Evaluation of gender incongruence in children and adolescents*).

Recommendations on psychoeducational interventions, support, and counseling for families

Legal guardians of children and adolescents admitted to healthcare services for signs of gender incongruence or gender dysphoria should be provided with psychoeducational measures, support, and counselling.

Relatives and those in the immediate environment of children and adolescents admitted to healthcare services for signs of gender incongruence or gender dysphoria should be provided with psychoeducational measures, support, and counselling.

Reasons for the recommendations

Background: People with gender incongruence and gender dysphoria are generally a vulnerable group in society. For young people with signs of gender incongruence and gender dysphoria, it is particularly important to feel support and acceptance from guardians and others in their immediate environment. In turn, guardians, other relatives, and friends may need information, support, and counselling themselves in order to support the child or adolescent in the best possible way.

The expected benefit (purpose) of the measures is that family and relatives will be supported as needed and enabled to support their child, sibling, partner, or friend so that the young person can develop with a positive self-image. The aim is also to enable guardians to make informed choices about the issues that arise, and to support the child's exploration in the best possible way.

Possible risks: No clear risks associated with the measures have been identified, provided that the professional has the required competence and that the information provided is comprehensive. For example, information to guardians needs to highlight both research suggesting that the possibility of social transition is associated with good mental health for the child, and research highlighting uncertainty about the child's future gender identity.

Knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems that the expected benefits of these measures outweigh their possible risks.

Supporting young people interacting with societal functions

Young people with gender dysphoria who live in accordance with their gender identity report feeling excluded in social contexts, and they are at increased risk of bullying and exposure to violence [48]. Young people are also often limited in their opportunities to opt out of social contexts such as school and place of residence. Healthcare services can help to reduce psychosocial risk factors by assisting young people in their contacts and through collaboration and cooperation with, for example, schools, social services, and youth clinics. A prerequisite is that depending on the current situation and the child's age and maturity, guardians and/or the child consent to the collaboration and to the provision of information (see Sections 12, Sections 2 and 3 of the Public Access to Information and Secrecy Act [2009:400], OSL).

It is important that support is flexible and adapted to what the adolescent experiences as problematic in their everyday life. This can include, for example, informing school staff about gender dysphoria and treatment, and practical measures in the case of sex-segregated education, such as arranging changing rooms for sports.²⁸ The need to solve such problems can arise and re-emerge, for example, when the young person changes school or place of residence and during social transition/retransition. Strategies for schools to increase students' knowledge of different gender identities and to prevent bullying and harassment can also be addressed.

The young person and guardians may also need information and help with the practical details of a name change.²⁹

²⁸ The Swedish National Agency for Education's support material for sex and sexuality education in the later years of primary school states that schools need to consider how to facilitate participation in education for transgender people, for example by offering the possibility of separate changing rooms and by consistently avoiding working with gender-segregated groups (2013; p. 114).

²⁹ On 1 July 2017, the Personal Names Act (2016:1013) was introduced at the same time that the Names Act (1982:670) was repealed. Provisions on first names can be found in sections 26–28 of the Personal Names Act. The application for a change of name must be made to the Tax Agency.

Recommendation to assist the young person in contacts

Healthcare services should assist children and adolescents in their contacts with the relevant societal functions such as schools and social services, in order to prevent and reduce the problems that young people with signs of gender incongruence or gender dysphoria perceive as relating to their condition in their everyday lives.

Reasons for the recommendation

Background: Young people with gender dysphoria who live in accordance with their gender identities can experience problems in their everyday lives that affect their quality of life and self-esteem. In this context, health care should contribute to reducing psychosocial risk factors by assisting the young person in contacts and interacting with, for example, schools and social services.

The expected benefit (purpose) of the measures is to enable a functional everyday life for young people living in accordance with their gender identities, to reduce the risk of poor mental health and to contribute to a good psychosocial adaptation.

Possible risks: No clear risks have been identified with the measures, provided that the professional has the required competence for the task.

Knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge-base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems that that the expected benefits of the measures outweigh their risks.

Evaluation of gender incongruence in children and adolescents

This section describes what an evaluation of gender incongruence in children and adolescents should include, based on science and proven experience from the perspective of patient safety.

The content of the section applies generally to the evaluation of gender inequality in young people and includes people with non-binary gender identities.

Purpose of the evaluation

The purpose of a gender incongruence evaluation is to decide whether there is a need for care and which interventions are justified and appropriate for the individual young person. This includes assessments of the young person's gender incongruence and gender dysphoria and whether there are co-occurring conditions and factors to consider.

A longer period which involves support measures

The term "evaluation" in health care often refers to a relatively short and limited period of time. Evaluation of gender incongruence in young people, who are in a period of intense physical and mental development, usually needs to last for several years and is prolonged when there is a high degree of uncertainty in the assessment. The time between initial support measures and the start of the evaluation is not always clearly delineated, for example when the family has made contact at an early age with the child. See also the section on *Support for young people and their families*.

General considerations

Competencies for evaluation

Where health care activities are conducted, there must be the staff needed to provide Good Care (Section 5, Section 2 of the Health Care Act [2017:30], HSL). Health care staff must carry out their work in accordance with science and proven experience. A patient must be given expert and caring healthcare that meets these requirements (Section 6, Section 1 of the Patient Safety Act [2010:659], PSL).

In December 2020, the National Board of Health and Welfare made a decision [22] that certain gender dysphoria-related care, including evaluation, will constitute “national highly specialized care” and will be provided at three units. According to

the decision, multidisciplinary competence, and collaboration between different professions, with special expertise for this patient population, is required. See also *Competence for Good Care and treatment* in the section *Introduction*.

In terms of assessment of children and adolescents, according to proven experience, it is important that the diagnostician has developmental psychological and child and adolescent psychiatric competence, as well as the ability to recognize and diagnose co-occurring psychiatric conditions and differential diagnoses in children and adolescents [30, 55].

Individualized evaluation

Health care activities must be carried out such that the requirements of Good Care are met. This means, among other things, that the care must be of good quality, meet the patient's needs for security, continuity, and safety and be based on respect for the patient's self-determination and integrity (Chapter 5 § 2 Health Care Act [2017:30], HSL^{xvii}). According to preparatory work on the previous HSL, good care means, among other things, that it must be adapted to the individual patient's particular circumstances. The preparatory works also states that it must be assumed that the care meets people's needs for security and safety in medical terms (prop. 1981/82:97 on the Health and Medical Care Act etc. p. 56).

The content and duration of the evaluation need to be adapted to the medical, psychological, and social circumstances of the child or adolescent. The type of evaluation needed varies from one young person to another, depending on:

- the age and physical and mental maturity of the young person at the time when the evaluation is initiated
- whether the gender incongruence started during childhood, at the onset of puberty or later in puberty/after puberty
- the extent to which healthcare services have had prior awareness of the young person's gender incongruence of the family
- whether there are co-occurring conditions or aggravating factors that need to be evaluation and considered
- the stability of the gender identity
- the young person's maturity and ability to understand the long-term consequences of gender-affirming treatment (if it is being considered)
- the extent to which information needed for the evaluation is provided in the referral.

The evaluation needs to last as long as necessary to meet its purpose and ultimately minimize the risk of mistreatment. Ultimately, the young people themselves, the guardians, and the evaluation team all need to feel confident about the outcome of the evaluation.

Long evaluation times can be psychologically stressful for the young person. Collaboration with other health care providers involved, e.g., for the evaluation and treatment of co-occurring conditions, needs to be efficient so that the evaluation is not delayed. It is important that, when deemed appropriate, interventions for co-occurring conditions or aggravating factors are carried out in parallel with the evaluation of the gender incongruence.

Information about the evaluation

Each patient shall be provided with individually tailored information including their health condition, and the methods available for evaluation, care, and treatment. The patient must also be informed about when he or she can expect to receive care and about the expected course of care and treatment (Section 3, Section 1 of the Patient Act [2014:821]). The information must be provided to the young person and to the guardian, provided that provisions on confidentiality or professional secrecy do not prevent this (Sections 3 and 5 of the Patient Act).

Although it is not possible to say in advance exactly how long an evaluation will last, or which support and treatment interventions will be involved in the individual young person's case, it is important that the evaluation team explains the following to the young person and the guardians:

- the different parts of the evaluation and their aims
- what the evaluation will answer
- what the evaluation team needs to rule out
- that other child and adolescent psychiatric interventions may need to be initiated if the assessment team identifies a need for them
- that the evaluation team collaborates with others, including child and adolescent psychiatry, social services, and physical health professionals
- which rules, guidelines, and care practices the evaluation team has to consider
- that the aim is to work with the young person and guardians to determine the best course of action if gender dysphoria persists throughout the evaluation.

The information detailed above must be provided at the beginning of the evaluation and then continuously as the need arises.

Finally, it is important to inform young people and their guardians about the possibilities and limitations of different gender-affirming treatments during the evaluation [30]. Often, the person under evaluation has their own ideas about what gender-affirming treatment means.

Even when it is unclear that gender-affirming treatment will be an option, it is essential that the young people and their caregivers have a realistic picture of what the treatments will mean in the short and long term, and time to process this information.

In cases where gender affirmation treatment is later deemed indicated and appropriate, the young person and guardians must be informed again. The information must be given by the person directly responsible for the type of care under consideration, e.g., information on hormone treatments is given by the child's endocrinologist.

Evaluation methods and informants

As a rule, guardians are involved in the evaluation.³⁰ Close relatives should also be given the opportunity to participate if the child or adolescent so wishes.

Recommendation on evaluation methods and informants

Healthcare services should carry out the psychological, psychosocial, and psychiatric components of gender incongruence evaluation using valid assessment methods, investigative interviews, and life histories obtained from the child or adolescent and from the guardians.

Reasons for the recommendation

Background: As with all evaluation, it is important that the health service gets as good and complete a picture of the patient and their situation as possible.

The expected benefit (purpose) is that the young people themselves, guardians and the evaluation team should feel confident about the outcome of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks of the measures are that they may create anxiety and feelings of suspicion, should differing views of the adolescent's suffering and needs emerge, or if guardians find it difficult to understand and accept the young person's gender incongruence. Since the support and understanding of guardians is of great importance for the mental health of the young person, risks can be reduced by providing appropriate psychosocial support to the young person, and by providing information, support, and advice to guardians when needed. Risks can also be

³⁰ The starting point is that it is the guardian who has the right and obligation to decide about matters of health and medical care for the child. However, as the child's age and maturity increase, greater consideration must be given to the child's wishes. A child may be considered mature enough to decide on his or her own about certain care or treatment if he or she can assimilate the relevant information and understand the consequences of his or her decision. However, considerable maturity is required for a child to be able to decide on more extensive treatments and interventions (cf. prop. 2013/14:106 p. 119).

reduced by the evaluation team by describing and justifying the purpose of the evaluation to the young person and the guardians (See *Information about the evaluation* above).

Knowledge on expected benefits and risks is based on experience gained from international publications on the subject [56, 57], as well as from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems that the expected benefits of these measures outweigh their risks and that the need for the measures is great. The patient safety aspect is the overriding reason for a strong recommendation.

Diagnostics

The diagnostic evaluation focuses on the young person's gender identity, how the gender incongruence has developed over time and how it affects the person's health and quality of life. Diagnosis is made and coded according to criteria in the DSM and ICD systems (See *Introduction*).

Examples of instruments that may be used as a basis for discussion or to support the assessments in other ways are:

- Gender Congruence and Life Satisfaction Scale (GCLS) [58]
- Transgender Congruence Scale (TCS) [59]
- Utrecht Gender Dysphoria Scale-Gender Spectrum (UGDS-GS) [60]
- Genderqueer Identity Scale (GIQ) [44]
- Body Image Scale (BIS) [61].

The first four instruments in the list above were developed in recent years. Unlike several earlier instruments, they cover the full range of gender identities, i.e., not just binary gender identity (female/male). One exception is the GIQ [44] that has been developed specifically for genderqueer (including nonbinary) gender identities and is intended to support diagnostic assessment when gender-affirming treatment is being considered for this group.

When these sections were first published (March 2021), the GCLS, TCS and BIS were translated into English and are available through the Gender Dysphoria Registry.³¹

Psychosocial support for exploration

As much of a young person's life can affect both the development of identity more generally, and the development of gender identity, it is important that psychosocial support for exploration is provided as part of the evaluation.

Properly designed support enables young people to openly explore experiences, thoughts, and feelings related to identity and gender identity in a safe and validating context. The key starting points are:

- there are many gender identities and ways of expressing one's gender identity
- there are many things in life that can affect identity and gender identity
- identity and gender identity can change over time
- reflecting and trying things out in the real world is important in order to gain personal experience on which to base decisions
- attention needs to be paid both to the situation here and now, and to well-being through the life-long perspective.

The unconditional nature of the exploration means that the young person's uncertainties and doubts are also included in the discussions. This requires a good alliance with the young person, a clear understanding that this is part of the evaluation and that any doubts are not seen as negative by the evaluation team. Psychoeducational interventions are normally used during the exploration (See *Broad psycho-educational approach for the initial support* in the section *Support for young people and their families*).

In order to support the young person's own exploration of gender identity, professionals need to be supportive yet neutral, thereby minimizing the risk that their own values or expectations will influence the young person in any specific direction. If the young person has a concurrent neuropsychiatric disability, good knowledge of autism spectrum disorders and ADHD/ADD is also required for the task (See also section *Specific conditions and factors to consider*).

³¹ GCLS dated 190521, translated by Dhejne C, Byström M, Görts-Öberg K & Södersten M. TCS dated 151201, translated by Södersten M, Johansson A, Beckman U, Östberg P & Dhejne C. The translations were completed according to WHO recommendations.

Recommendation on psychosocial support for exploration

Healthcare services should provide psychosocial support for the unconditional exploration of gender identity during the evaluation of gender incongruence in children and adolescents.

Reasons for the recommendation

Background: Providing space and psychosocial support for exploration in the context of the evaluation is fundamental, as identity development and gender identity can both affect, and be related to, a young person's life. The extent to which psychoeducational interventions need to be included, and the amount of time for exploration, depend on the conditions under which the evaluation is carried out for the individual (See *Individualized evaluation* above and *Broad psycho-educational approach for the initial support* in the section *Support for young people and their families*).

The expected benefit (purpose) of the measures is to allow the young person to reflect on what may have influenced the gender incongruence in their own case and what may influence it in the future, and thus to define their gender identity on a broader basis. From a healthcare perspective, research is necessary to obtain diagnostic certainty and to provide healthcare interventions that also will be beneficial for the young person in the longer term. In the longer term, the purpose is to give young people themselves, guardians, and the evaluation team confidence in the results of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks of the measures are that young people who do not feel they need exploratory talks may feel questioned and mistrusted. These risks can be mitigated by the professional clarifying the purpose of the measures, the neutrality of the investigative team in relation to the outcome, and the fact that the measures do not constitute questioning the young person's gender identity or experiences. Information about the experiences of the evaluation team and the fact that adolescents' gender identity and wishes for treatment sometimes change during the course of the evaluation can provide freedom in the exploration and prevent adolescents from feeling locked into what they have previously thought, felt, and verbalized. Furthermore, professionals need to be supportive and neutral, minimizing the risk of their own values or expectations influencing the young person in any direction. Attempting to change the young person's perception of their gender identity with so-

called conversion therapy is currently considered unethical [30] and, according to an American study [62] may contribute to poor mental health later in life.³²

The knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence about the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge-base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems the expected benefits of the measures to outweigh their risks, and that the need for the measures is great. The patient safety aspect is an overriding reason for a strong recommendation.

Special conditions and factors to consider

Neuropsychiatric conditions

Several international literature reviews show that neuropsychiatric disability is more common among young people with gender incongruence/gender dysphoria than among young people in the general population [63-66]. National statistics from 2016-2018 also show that autism diagnoses and ADHD/ADD diagnoses are very common among people with gender dysphoria diagnosis (F64) compared to the general population [19]. Among young people aged 13-17 and registered female at birth, 15% have a concurrent autism diagnosis (vs. 1% of the population) and 19% have a concurrent ADHD diagnosis (vs. 4% of the population). Among young people in the same age group registered male at birth, 12% have an autism diagnosis (vs. 2% of the population) and 13% have ADHD/ADD-diagnoses (vs. 8% of the population).

Implications of concurrent autism spectrum disorder (ASD)

A 2018 consensus document [67] describes the collective experience of a group of international experts about young people with gender incongruence and concurrent autism spectrum disorders (ASD). The document refers to young people with ASD from puberty to age 19, who do not have severe language impairment or intellectual disability. A related publication from 2018 describes the results of in-depth interviews with young people with gender incongruence and concurrent ASD [68].

The experience of the group [67] is that concurrent ASD needs to be considered from the very beginning of the evaluation. Because there is wide variation between people

³² A cross-sectional study by Turban et al. (2019) included 27,715 trans people. It found an association between psychological problems, suicidal thoughts and suicide attempts in adulthood, and having undergone conversion therapy in childhood.

with autism diagnoses, the evaluation team needs an ASD assessment to gain knowledge of the impact of the condition on the individual young person. This is done in order to gain a better understanding of the individual and to be able to adapt the evaluation and support measures accordingly.

Furthermore, in the group's experience [67], ASD-related ways of functioning can sometimes contribute to gender incongruence. For example, minor concerns about gender identity can sometimes lead the young person to the conclusion that complete gender-affirmative treatment is necessary.

Support interventions focusing on ASD may therefore be needed during the evaluation. If, in the course of the evaluation, it becomes clear that the young person's desire for transition has been caused by symptoms of ASD or some other concurrent condition, the team will need to assess the young person's possible need for further psychosocial support at the end of the evaluation.

Furthermore, ASD-related ways of functioning [67] can sometimes lead to the young person's gender incongruence not being taken seriously, e.g., because the person spends less or no time on their appearance to be perceived by others as a male or female, has no opinion about their name and cares less about the opinions of others more generally. The absence of such common outward signs may raise questions about the young person's credibility among parents and professionals. However, in the experience of the group [67], many such adolescents may have clear and persistent gender incongruence. In a related study [68], gender dysphoria and gender identity in 18 of 22 adolescents with concurrent ASD were unchanged at follow-up from baseline measurements; the duration of follow-up was 22 months.³³

According to the consensus document [67], the greater complexity of the assessments in concurrent ASD means that the diagnostic evaluation usually needs to last longer and that any decisions on medical treatment need to be taken at a slower pace. The consensus document [67] also stresses that ASD should not exclude an adolescent from a diagnosis of gender dysphoria or from relevant treatment when indicated.

Implications of concurrent ADHD/ADD

No guidelines or consensus documents describing the management of co-occurring ADHD/ADD during the evaluation of young people with gender incongruence have been identified. The National Board of Health and Welfare also learned that the

³³ The researchers followed 22 adolescents aged 13–21 with gender incongruence and concurrent ASD over a 22-month period. At follow-up, 18/22 were stable in their gender identity and gender dysphoria in relation to baseline measurements. For 4/22, a change in gender identity had occurred since baseline measurement: from transfeminine to non-binary (n=2), from transfeminine to cisgender (n=1) and from non-binary to cisfeminine (n=1). The four also no longer met the DSM-5 criteria for gender dysphoria.

clinical experience of evaluation teams regarding the impact of ADHD/ADD on young people's gender incongruence is not uniform, nor is the experience regarding the need for early knowledge from the neuropsychiatric evaluation for the subsequent assessment. Therefore, until such time as this information becomes available, the National Board of Health and Welfare's assessment is that knowledge of possible ADHD/ADD is primarily needed by the evaluation team so they have a broad understanding of the young person and can tailor information and support to the individual during the course of the evaluation. In accordance with child and adolescent psychiatric practice, a neuropsychiatric assessment with ADHD/ADD issues may be initiated later in the evaluation, if deemed justified.

Recommendation on early identification of signs of autism spectrum disorder (ASD) and ADHD

Healthcare services should, prior to or at an early stage of gender incongruence evaluation, systematically screen all children and adolescents for signs of ASD and ADHD. In cases where there are signs of ASD, neuropsychiatric assessment should be initiated.

Reasons for the recommendation

Background: Autism spectrum disorders and ADHD are more common among young people with a diagnosis of gender dysphoria than in the general population [19]. ASD and ADHD/ADD do not exclude a young person from a diagnosis of gender dysphoria or from treatment when indicated but are important to consider during the diagnostic evaluation. When signs of ASD are present and have not been previously assessed, a neuropsychiatric assessment needs to be conducted either by the evaluation team if the expertise is available, or by referral.

The expected benefit (purpose) of the measures related to ASD is to allow for possible concurrent ASD to be taken into account during the evaluation of gender incongruence in young people, as information and support need to be tailored to the individual during the evaluation. Because ASD-related ways of functioning can sometimes contribute to gender incongruence, and as there is a wide variability between people with autism diagnoses, the evaluation team needs to gain knowledge from the neuropsychiatric assessment of how the condition affects the individual young person early [in the process]. This is to gain a better understanding of the person and to be able to adapt the assessment and support interventions to the young person's circumstances and needs. In the longer term, the purpose is to give the young person people themselves, guardians, and the evaluation team confidence in the results of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks are that the measures may create anxiety among young people that gender incongruence is not taken seriously and feelings of suspicion among young people and their families. Experiences of not having been taken seriously by the health care system in the past can sometimes have an impact, e.g., for young people who have been refused a referral for an evaluation. Risks can be reduced by having the assessment team establish an alliance with the young people and their guardians, clarifying what concurrent ASD/ADHD/ADD means and that it is relatively common for them to coexist, and [explain] the purpose of the interventions. Another significant risk is that long evaluation times can be psychologically stressful for young people. Collaboration with other health care providers involved, e.g., for the evaluation and treatment of co-occurring conditions, needs to be efficient so that the evaluation is not delayed.

Knowledge base: The knowledge about expected benefits and risks consists of experience-based knowledge, gathered partly from an international consensus document [67], and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. (See separate appendix *Knowledge base with methods description*).

Benefit/risk balance: The National Board of Health and Welfare deems the expected benefits of the measures to outweigh their risks and that the need for the measures is great. Patient safety is an overriding reason for the strong recommendation.

Psychiatric conditions

A 2016-2018 survey by the National Board of Health and Welfare shows that psychiatric conditions are common among young people with a diagnosis of gender dysphoria (F64) and significantly more common than among young people in the general population. Among young people aged 13-17 and registered female at birth, 29% have a depression diagnosis, 32 percent had an anxiety diagnosis and 8 percent engaged in self-harm, including suicide attempts (compared to 3, 4 and 1 percent [respectively] in the same age group in the general population) [19]. Among young people aged 13-17 years and registered male at birth, 14% have a depression diagnosis, 21% an anxiety diagnosis, and 4% engaged in self-harm, including suicide attempts (compared to 1%, 2% and 0.5%, [respectively] in the same age group in the general population). Past trauma and eating disorders are also relatively common in the experience of the participating experts, and important to identify and consider during the evaluation.

The psychiatric conditions may:

- be a consequence of gender incongruence (gender dysphoria)
- be distinct from gender incongruence or gender dysphoria. In these cases, if the problems are not identified or remain untreated, they cause distress to the young person and may also complicate the diagnostic evaluation. It is

therefore important to pay attention to psychiatric conditions, self-harm, and suicidal tendencies and to offer adequate treatment when necessary. When treatment is provided by a healthcare provider other than the evaluating unit, it is important to offer guidance to practitioners who lack knowledge of gender incongruence [30].

- be a consequence of the vulnerability and discrimination that people who deviate from societal norms may experience (See *Minority stress and protective factors*, section *Support for young people and their families*). Psychosocial support that promotes the young person's resilience, self-esteem, and skills can therefore contribute to reducing poor mental health.
- in some cases, need to be considered continuously throughout the course of the evaluation. For the young person to have the courage to disclose sensitive information, such as sexual abuse, often requires more time and establishment of trust by the evaluation team.

Recommendations on identifying and reducing poor mental health

Healthcare services should:

- Systematically identify and assess any potential concurrent psychiatric conditions before or at an early stage of the evaluation of gender incongruence in all children and adolescents.
- Offer psychosocial support and psychiatric treatment to reduce potential poor mental health throughout the course of the evaluation of gender incongruence in children and adolescents.

Reasons for the recommendations

Background: There is a high co-occurrence of psychiatric conditions among young people with gender incongruence/gender dysphoria compared to young people in the general population. These may be unrelated to gender incongruence, a consequence of gender incongruence and/or a consequence of minority stress.

The expected benefit (purpose) of the measures is to be able to take into account any psychiatric conditions during the evaluation and to offer adequate help when they are present. The possibility that a concurrent psychiatric condition contributes to the gender incongruence for an individual needs to be considered, and if so, how this affects the evaluation. In the longer term, the primary aim of interventions is to give the young people, the caregivers, and the evaluation team confidence in the outcome of the evaluation. Otherwise, potential decisions on gender-affirming treatments otherwise risk being made on the wrong basis.

Possible risks of the "identify and assess" measure are that it may create anxiety and feelings of suspicion among children and adolescents and their families. Risks can be reduced by the evaluation team establishing an alliance with the young person and with guardians, making clear the relative prevalence of co-occurring psychiatric conditions, and the purpose of the measures. For the measures "psychosocial support and psychiatric treatment" no clear risks have been identified, provided that the professional has sufficient knowledge about gender incongruence for the task, or there is a possibility of supervision, if it is lacking.

Knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare assesses that the expected benefits of these measures outweigh their risks and that the need for the measures is great. Patient safety is an overriding reason for a strong recommendation.

Psychosocial aggravating factors

The evaluation includes consideration of whether there are any psychosocial factors that may hinder further evaluation or any gender-affirming treatment, and if so, which support measures are appropriate. These [factors] may include, for example, a lack of support from guardians, or a long absence from school and a lack of other social contexts that limit young people's opportunities for exploration. In these and similar situations, the evaluation team will need to consider what support is appropriate and whether liaison with schools, other care providers or social services should be initiated.

Recommendation to assess the psychosocial situation

Healthcare services should assess the psychosocial situation of the child or adolescent, including strengths and weaknesses in family functioning, support from guardians, the school situation and peer relationships, at an early stage of the gender incongruence evaluation.

Reasons for the recommendation

Background: When there are problems in the young person's or family's psychosocial situation, support measures may need to be initiated by the evaluation team, or in collaboration with entities such as schools, health care providers, and social services.

The expected benefit (purpose) is to assess how psychosocial factors affect the young person's ability to explore and access gender-affirming care, if deemed indicated, and to initiate support interventions if needed. In the longer term, the purpose of these measures is to give the young people themselves, the guardians, and the evaluation team confidence in the results of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks are that the assessment may create anxiety and feelings of mistrust among young people and their families, and that a prolonged period of evaluation when support is needed may place a significant strain on the young person. These risks can be reduced by clarifying the purpose of the measures and by offering psychosocial support where necessary. Collaboration with other health care providers involved, e.g., for the evaluation and treatment of co-occurring conditions, needs to be efficient so that the evaluation is not delayed.

The knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems the expected benefits of the measures to outweigh their risks and that the need for the measures is great. Patient safety is an overriding reason for a strong recommendation.

Consider the need for external psychosocial support

It is common for the members of the evaluation team to have dual roles; they are expected both to investigate the person's gender incongruence, and to provide psychosocial support. The advantage of such an arrangement of roles is that the person providing support or counselling knows the young person and has specialist-level expertise in the area.

The disadvantage is that individuals may feel scrutinized in situations where they are primarily opening up to receive support. Young people may also feel hesitant to talk about sensitive issues because they are unsure whether the information will reach their guardians. An important part of building trust is informing the young person whether guardians have the right to know, or will be informed of, what the young person tells caregivers in one-to-one conversations.

Recommendation on external psychosocial support

During the evaluation of gender incongruence, healthcare services should monitor whether children and adolescents are able to access the psychosocial support offered by the evaluation team, and whether they feel it is adequate. If necessary, healthcare services should offer children and adolescents appropriate support or treatment contact outside the evaluation team.

Reasons for the recommendation

Background: The dilemma of the evaluation team's dual role of both investigating the young person's gender incongruence and providing psychosocial support can often be countered with a good alliance and information. If, in the case of an individual young person, it is deemed impossible to offer psychosocial support from within the investigative team in a manner in which the young person feels free from judgement, the healthcare service should instead offer it in a separate unit that can interact with the investigative team.

The expected benefit (purpose) is that all young people should have the space to explore their gender identity and related aspects without feeling judged. In the longer term, the purpose of these measures is to give the young people themselves, the guardians, and the evaluation team confidence in the results of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks: No clear risks have been identified, provided that the professional has sufficient knowledge of gender incongruence for the task or there is a possibility of supervision, if it is lacking.

Knowledge of the expected benefit/risk is experience-based knowledge, gathered from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems the expected benefits of the measures to outweigh their risks and that the need for the measures is great. Patient safety is an overriding reason for a strong recommendation.

Maturity assessment

As children grow older and more mature, more consideration should be given to their wishes.³⁴ In order to be able to consider treatment options and give consent for a healthcare intervention, children must be able to understand the information provided and consider the consequences of their decision.³⁵

One of the prerequisites for offering gender-affirming hormone therapy to an adolescent [is] that the person demonstrates mental maturity and an understanding of the outcomes that can be expected from gender-affirming hormone therapy, as well as the medical and social risks of the treatment (See also *Hormonal Treatment for Gender Dysphoria in Adolescents*).

Before deciding on gender-affirming hormone treatment, the healthcare service needs to carry out a maturity assessment. The publication *Assessing children's maturity for participation - Guidelines for social services, the health service and dental services* [69] describes physical, cognitive, and socio-emotional aspects of children's and adolescents' maturity, with executive function of particular importance for the ability to plan, assess risks, and consider consequences. At the population level, there are strong correlations between chronological age and maturity level, but there is considerable variation between individuals of the same age.

Continuous sensitivity to the child's abilities and experiences is of central importance when assessing the young person's maturity [69]. The various parts of the evaluation and interviews with the young person usually provide a sufficient basis for the assessment. If, for any reason, an in-depth examination of cognitive, emotional, or social aspects is justified for an individual, it should be carried out.

Internationally, there are assessment instruments that are specifically designed to support healthcare providers in assessing when adults' decision-making ability may be impaired [70]. Most of the instruments include assessment of the four abilities described by Appelbaum and Roth in 1982 as necessary for giving informed consent to participate in research [71]. These include the ability to understand information about the condition and about treatment options, the ability to recognize how the information applies to one's own situation, the ability to reason logically based on the information and arrive at a position, and the ability to express one's position. A manual describing how clinicians can structure assessment of a patient's decision-making ability when deciding on medical treatment is available in English [72]. This approach could also be considered for the conduct of adolescent maturity assessments, in order to provide structure to the assessments and facilitate discussions within the evaluation team.

³⁴ Chapter 6, Section 11 of the Parental Code (FB) and Chapter 4, Section 3 of the Patients Act.

³⁵ See prop. 2013/14:106 p. 119

Recommendation to consider psychological dimensions

Healthcare services should consider, and if necessary examine, psychological dimensions such as cognitive, emotional and social abilities of the child or adolescent when investigating gender inequality.

Reasons for the recommendation

Background: According to the National Board of Health and Welfare's 2015 guidelines, gender-affirming hormone therapy can be offered to an adolescent if it is indicated and otherwise appropriate based on the adolescent's situation and circumstances. An additional prerequisite is that the individual demonstrates mental maturity and an understanding of the results that can be expected from the treatment, as well as of its possible medical and social risks.

The expected benefit (purpose) of these measures is that the information on which the maturity assessment of an adolescent is based should be sufficient. In the longer term, the aim is that the young person, the guardians, and the evaluation team should feel comfortable with a possible decision about gender-affirming hormone therapy.

Possible risks of the measures are that they may create anxiety and feelings of suspicion among children, adolescents, and their families. These risks can be reduced by the evaluation team clarifying the purpose of the measure.

Knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems that the expected benefits of the measures outweigh their risks and that the need for the measures is great. Patient safety is an overriding reason for a strong recommendation.

The latter part of the evaluation

After the preliminary assessment, some young people may need further exploration through social transition and the need for assistive devices.

Trying to live in your gender identity

Some young people are already living socially in accordance with their gender identities when the evaluation starts. For others, living in accordance with their

gender identities may become part of further exploration, or later in preparation for gender-affirming treatment, depending on the preliminary assessment during the evaluation.³⁶ Trying to live in accordance with one's gender identity in preparation for gender affirmation treatment serves two main functions:

- It allows the person to explore what it is like to live in accordance with their gender identity and whether this corresponds to their expectations.
- This makes it easier for the health care staff to support the person optimally in a gender-affirming treatment process, based on the person's conditions, needs, and wishes.

The advantage of a person living in a social role consistent with their gender identity for a longer continuous period is that the person has many different opportunities to experience and adapt socially to the change. The social and psychological aspects of gender-affirming treatment can be more challenging than the physical aspects. Such a period also provides the best possible conditions for making sound decisions about gender-affirming treatment.

Minority stress can increase in the context of social transition, leading to an increased need for support measures. It is sometimes not possible or appropriate to socially transition, e.g., when the young person is at significant risk of exposure, bullying and violence from their environment. In situations like these, the evaluation team needs to consider a number of factors regarding how best to help the young person.

As with care in general, a prerequisite for the recommended action on counseling and support in matters of social transition is that there is access to health care staff with the appropriate competence. See also *Competences for evaluation*, section *Evaluation of gender incongruence in children and adolescents*.

³⁶ This has implications for anyone applying for a change of legal gender after age 18. According to section 1(2) of the act on the determination of gender identity in certain cases (1972:119), the "gender identity act," the person must have behaved in accordance with his or her gender identity for some time, i.e., have lived in accordance with his or her gender identity in everyday life for an extended period, usually at least one year (see prop. 2011/12:142 p. 33). It has been proposed to remove the requirement that the person has behaved in accordance with their gender identity for a period of time (see Draft proposal - Certain surgical procedures on the genital organs and change of sex as recorded in the population register 2021/07285).

Recommendation on advice and support on social transition issues

Children and adolescents with gender incongruence or gender dysphoria who are considering social transition or who have already started to live in accordance with their gender identities in social contexts should be offered counselling and support by the healthcare services.

Reasons for the recommendation

Background: Some young people already live in accordance with their gender identity when the evaluation starts. Others try it during the latter part of the evaluation as part of continued exploration of their gender identity. If gender-affirming treatment is being considered, this may be carried out in preparation over a longer continuous period. It is often gradual, with the person coming out to an increasingly wider circle, and eventually consistently behaving in accordance with the desired gender identity at home, school, and in all other social contexts.

The expected benefit (purpose) of the measures is to provide adolescents with support when planning how to proceed and what to do if they later decide not to proceed, and to deal with the social and psychological challenges that arise in the meantime. In the longer term, the purpose is to give the young people themselves, the guardians, and the evaluation team confidence in the results of the evaluation. Otherwise, potential decisions on gender-affirming treatments risk being made on the wrong basis.

Possible risks: No clear risks have been identified with these measures, assuming that the professional has the required competence.

Knowledge about expected benefits and risks is based on experience, gathered partly from an international consensus document [30] and partly from the experts who participated in the development of the guidelines. The National Board of Health and Welfare concludes that the scientific evidence on the expected benefits and risks of the measures is likely to be insufficient. See separate appendix *Knowledge base with methods description*.

Benefit/risk balance: The National Board of Health and Welfare deems the expected benefits of the measures to outweigh their risks and that the need for the measures is great.

Assistive Devices (Aids)

The fact that the body reflects the sex registered at birth can make it difficult for an adolescent to "pass" during a social transition, i.e., to be perceived by others in accordance with their gender identity. This is often emotionally stressful and may