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- Care of Children and Adolescents with Gender Dysphoria

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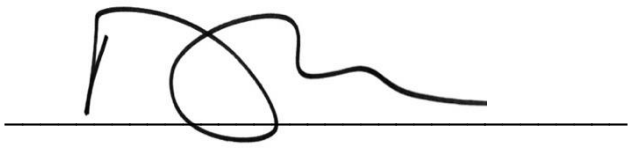

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This document is an unofficial English translation of a document prepared in Swedish.

Care of children and adolescents with gender dysphoria*[1]

National knowledge support[1] with recommendations for professionals and decision-makers

Socialstyrelsen

* Unofficial translation prepared for purposes of litigation. The Swedish government did not translate this document.

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Foreword

The National Board of Health and Welfare[i] has been commissioned by the Swedish government (S2019/02042/FS, S2019/03899/FS) to update the national guidelines, *Good Care of Children and Adolescents with Gender Dysphoria,*[ii] which were published in 2015.

In order to provide guidance to relevant agencies with the least possible delay, some sections of the guidelines were updated in stages, as the knowledge base and overall assessments became finalized. The sections on support and evaluation were published in March 2021 and the section on hormone therapy in February 2022. This December 2022 report contains the updated guidelines in their entirety.

Appendices to the report include a list of contributors and a glossary of terms.[iii] The knowledge base with methods description is presented in a separate report.[iv]

These guidelines are aimed at professionals working with this patient population and decision-makers responsible for the quality of care. The ongoing gender dysphoria-related initiatives at the National Board of Health and Welfare need to be reflected in the revisions of the information in reports, "For those with gender dysphoria" and "For those who meet people with gender dysphoria in their work." [v] The revised reports will, therefore, be published at a later date.

The updated guidelines contribute to Sweden's efforts to meet the goal of ensuring healthy lives and promoting well-being for people of all ages in Agenda 2030. They also contribute to meeting the goal of the national strategy for sexual and reproductive health and rights; good, equal, and equitable sexual and reproductive health in the entire population. Maria Bodin has been the project manager for the work with the guidelines and Anders Fejer and Anders Berg have been the responsible unit managers.

The National Board of Health and Welfare would like to thank the experts who contributed to the revision of the sections in question, as well as the patient, family and stakeholder organizations and managers who provided comments on the working versions of the documents before publication. The final assessments of the National Board of Health and Welfare on puberty-suppressing and hormonal treatments were not shared by all participating experts.

Olivia Wigzell
Director General

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Summary

The National Board of Health and Welfare has been commissioned by the Swedish government to update the guidelines, *Good Care of Children and Adolescents with Gender Dysphoria*, which was published in 2015 [1]. Sections of the guidelines have been updated and published in stages. This final report contains the updated guidelines in their entirety, and thus supersedes both previous interim reports and the guidelines from 2015.

Key terms are explained in the introductory section and in the appendix.[vi] A separate appendix, *Knowledge Base with Methods Description,* describes how the different sections have been developed.[vii]

For decision-makers

For several years now, care for people with gender dysphoria has been characterized by a lack of access and a lack of knowledge about the outcomes of the care. The National Board of Health and Welfare emphasizes to the decision-makers in healthcare regions that both of these issues need to be improved in the near future.

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. Good psychosocial care is essential. The patient group is heterogeneous and psychosocial care needs to be clearly inclusive of young people with non-binary gender identities. Various gender affirming treatments need to be offered when they have been deemed indicated.

The 2015 guidelines stressed the importance of monitoring and evaluating the healthcare interventions offered in the context of clinical work. The quality registry (gender dysphoria registry) that was planned for at the time has so far been unable to meet the need. It is urgent that the healthcare regions act to ensure that systematic documentation and monitoring of care at a national level is realized.[viii] Longitudinal data are needed to provide a coherent picture of the patient population, from referral to eventual diagnosis of gender dysphoria, with follow-up of patients offered different care interventions.

The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) concludes that there is insufficient scientific evidence to assess the effects of puberty suppressing and cross-sex hormone therapy on gender dysphoria, psychosocial health, quality of life for adolescents with gender dysphoria, and other factors [2]. The knowledge gaps need to be addressed and the National Board of Health and Welfare recommends that these treatments be provided within the context of research. Here too, the healthcare regions have a responsibility to provide support

so that relevant research can begin in the near future. The research questions that need to be answered for the field are listed in the SBU's database of knowledge gaps. Priority needs to be given to study designs that can answer the important questions to the greatest extent possible.

Caution with hormonal and surgical treatment

At a population level, i.e., for the population of adolescents with gender dysphoria as a whole, the National Board of Health and Welfare currently assesses that the risks of puberty-suppressing and gender-affirming treatment likely outweigh the expected benefits of these treatments. The National Board of Health and Welfare therefore gives the following weak, negative recommendations as guidance to the health care system:

- that treatment with GnRH analogues, gender-affirming hormones and mastectomy can be provided in exceptional cases.

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 that the efficacy and safety of treatments, benefits, and risks are not proven [2] and that three factors have shifted the balance between benefits and risks in a negative direction:

- the uncertainty resulting from the lack of clarity about the causes to the continued increase in the number of people diagnosed with gender dysphoria, particularly between the ages of 13 and 17 and especially among people whose registered gender at birth was female, since the guidelines were published in 2015
- the documented occurrence of medical detransition among young adults, which refers to the process of discontinuing gender-affirming medical treatment for any reason or seeking to reverse the medical effects of completed gender-affirming treatment [3, 4]. According to SBU, it is not possible to determine how common it is for adolescents to subsequently change their perception of their gender identity or to discontinue gender-affirming treatment [2].
- the experience-based knowledge of participating experts is less uniform than it was in 2015.

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Decisions on treatment for an individual case

For guidance in deciding on puberty-suppressing treatment for an adolescent in Tanner stage 3 and for gender-affirming hormone therapy, the National Board of Health and Welfare recommends using the criteria documented and monitored in the framework of the "Dutch protocol" [5-7]. These criteria include the presence of gender incongruence from childhood, a stability of gender identity over time, clear distress brought upon the onset of puberty, and an absence of factors that complicate the diagnostic assessment. According to the participating experts, puberty-suppressing treatment can, in some cases, be considered to be of great benefit even at Tanner stages 4 and 5, in particular for young people registered as male at birth whose masculinization in later puberty will make it very difficult to pass in adulthood.

The documented experience in the Dutch protocol includes only adolescents with binary gender identity, and the participating experts lack clinical experience with puberty-suppressing and gender-affirming hormonal treatment for adolescents with non-binary gender identity. The National Board of Health and Welfare concludes that there is a lack of knowledge to guide decisions on hormonal treatment for adolescents with non-binary gender identity but continues to consider that gender dysphoria, rather than gender identity, should guide access to care and treatment. An urgent task yet to be performed in connection with updating the guidelines *Good Care of Adults with Gender Dysphoria* [8] is to map the experience of assessment and gender-affirming treatment for non-binary gender identity that is used to care for adults.

Other recommendations

Other recommendations are that healthcare services:

- should offer psychosocial support for an open exploration of gender identity during the diagnostic assessment. As in 2015, the National Board of Health and Welfare emphasizes exploration as a prerequisite for good and safe care.
- should systematically investigate for signs of autism spectrum disorder (ASD) and ADHD/ADD before or at an early stage of the assessment. In the case of signs of ASD, neuropsychiatric assessment should be initiated.

The recommendations of the National Board of Health and Welfare remain as before, that the healthcare system should offer the following measures to adolescents with gender dysphoria:

- sexuality and sexual health counseling and treatment
- fertility preservation
- voice and communication treatment

- hair removal

The expected patient benefit from these measures is considered high and the risks comparatively low. It is important that when offered, these measures are documented for follow-up to enable increased and comprehensive knowledge about this patient population and their care.

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Introduction

This report contains an updated version of the guidelines, *Good Care for Children and Adolescents with Gender Dysphoria,* published in 2015. The update was commissioned by the government and has been carried out in stages. The sections on support and assessment were published in March 2021, the section on hormonal treatment in February 2022, and the remaining sections and the guidelines in their entirety in December 2022. Two new sections have been added: *New recommendations for hormonal treatment - basis and consequences* and *Non-binary gender identity - knowledge and need for clarification*.

Purpose and target group

The aim of the guidelines is to contribute to good and equitable care for children and adolescents with gender incongruence and gender dysphoria. The primary target groups are health professionals in the healthcare sector and decision-makers with responsibility for the respective healthcare activities.

About the recommendations of the National Board of Health and Welfare

The National Board of Health and Welfare's recommendations related to issues such as treatments are based on the state of knowledge at the time the recommendations were developed. The recommendations provide guidance for professionals and decision-makers, i.e., they are not binding statements about appropriate treatment measures for individual patients. It is always the responsibility of the treating health professional to assess the needs of the individual patient on a case-by-case basis to ensure - based on science and proven experience - that the patient receives adequate treatment.

Terms

The meaning of some key terms is explained here, otherwise please refer to appendix 2 *Terms and abbreviations*.[ix] The guidelines apply to children and adolescents, which refers to persons under 18 years of age. Legally, children are defined as any persons under age 18. Wherever there is a reference to legislation, only the term child is used.

In sections related to medicine, children refers to persons under the age of 18 who have not yet entered puberty, while adolescents refers to persons under the age of 18 whose puberty has started. The term youth is sometimes used in [the report] sections to refer to both children and adolescents.

Gender identity refers to a person's self-identified gender, the internal experience of being man/boy, woman/girl, or belonging to no gender or to another gender.

Gender incongruence refers to a perceived mismatch between gender identity and the sex registered at birth. Gender dysphoria refers to distress that may be linked to gender incongruence. People with gender incongruence do not necessarily experience gender dysphoria, but gender dysphoria is common among those who seek care and undergo assessment. To simplify language, the guidelines will mainly use the term gender dysphoria. In the context of clinical diagnosis and statistical classification, the terms gender incongruence and gender dysphoria have more specific meanings.

Clinical diagnosis and statistical classification

Diagnostic assessment

Diagnostic assessment is done according to guidelines and practices, with psychiatry often using the Diagnostic and Statistical Manual of Mental Disorders (the DSM system). The current fifth version (DSM-5) includes a diagnosis for gender dysphoria in children (302.6) and a diagnosis for gender dysphoria in adolescents and adults (302.85). For children, adolescents and adults, the diagnosis is made when:

- A. there is a marked incongruence between the person's perceived/expressed gender and registered sex that has lasted for at least 6 months; and
- B. the condition is associated with clinically significant distress or impairment in social, school or other important areas of functioning.

For adolescents and adults, the main criterion A is considered present when 2 out of 6 symptom criteria have been met. In order for the main criteria A to be considered present in children, several symptom criteria must be met (6 out of 8), and one of them must be criterion A1, i.e., "a strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one’s assigned gender)." Symptom criterion A1 can be understood as a requirement that the child has repeatedly expressed a desire to belong, or repeatedly insists on belonging, to the opposite sex (or other gender identity different from the sex registered at birth).

The requirement of symptom criterion A1 means that the diagnosis of gender dysphoria in children is not made solely on the basis of symptom criteria A2-A6 (nonconforming gender role behaviors in relation to dress, play, toys, activities, and playmates), or A7-A8 (dislike of own anatomy, strong desire for sex characteristics consistent with perceived gender identity).

A similar distinction is made in the description of the code HA61 (Gender incongruence of childhood) adopted in 2019 in the latest version of the International Classification of Diseases and Related Health Problems (ICD-11). See further *Gender-variant behavior insufficient for diagnosis and coding* below.

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Coding according to the ICD classification

The International Statistical Classification of Diseases and Related Health Problems (ICD) is the basis for cause-of-death statistics and statistics on diseases and other health problems. The ICD codes are used to provide a uniform way to indicate the diagnosis code when reporting to the National Board of Health's health data registries (e.g., the patient registry). For all inpatient care and some outpatient specialist care visits, the diagnosis or diagnoses that led to the care contact must be reported to the patient registry using ICD codes. Coding is done in accordance with the coding instructions accompanying the classification. When there is no confirmed diagnosis, ICD code for symptoms or other reasons for the health care contact used instead.

The coding of a health condition according to the ICD has no direct link to the care measures deemed justified and appropriate, i.e., the code should be applied once the diagnosis has been made, regardless of the measures that follow. For many conditions, there may be clinical reasons not to provide certain treatment in an individual case, which are made clear in the medical record.

In May 2019, the WHO adopted ICD-11, replacing ICD-10, which was published in 1992. The National Board of Health and Welfare is working on the introduction of a Swedish version of ICD-11.[1] Translation work is underway and is expected to be completed in 2025, after which implementation in the health care system will begin.

New chapter and new codes in the new classification

With ICD-11, the codes related to gender identity in the ICD classification have been moved from the psychiatry section ("Mental, Behavioral and Neurodevelopmental disorders") to a completely new section ("Conditions related to sexual health").

The following ICD-11 codes should be used:

- HA60 (Gender incongruence of adolescence or adulthood)
- HA61 (Gender incongruence of childhood)
- HA6Z (Gender incongruence, unspecified – “unspecified” residual category)

The code "Gender incongruence of adolescence or adulthood" (HA60) will thus replace the three codes related to gender identity in ICD-10-SE: transsexualism (F64.0), other specified gender identity disorders (F64.8), and gender identity disorder unspecified (F64.9) in ICD-10-SE.

The move to a new section and the introduction of the new codes in ICD-11 indicates that trans identity is not a psychiatric condition [9].

[1] See https://www.socialstyrelsen.se/statistik-och-data/klassifikationer-och-koder/icd-11/

The new codes in ICD-11 differ from the F64 codes in ICD-10-SE in several ways. One difference is that the distinction of binary gender identity made by the code Transsexualism (F64.0) in ICD-10-SE will disappear because the HA codes describe gender incongruence without specifying the gender identity. Another difference is that ICD-11 may include the code related to children (HA61).[2]

The English-language code descriptions for ICD-11 are provided below.

Gender incongruence of adolescence or adulthood (HA60)

Description: Gender incongruence of adolescence and adulthood is characterized by a marked and persistent incongruence between an individual´s experienced gender and the assigned sex, which often leads to a desire to 'transition', in order to live and be accepted as a person of the experienced gender, through hormonal treatment, surgery or other health care services to make the individual´s body align, as much as desired and to the extent possible, with the experienced gender. The diagnosis cannot be assigned prior the onset of puberty. Gender variant behavior and preferences alone are not a basis for assigning the diagnosis.

Gender incongruence of childhood (HA61)

Description: Gender incongruence of childhood is characterized by a marked incongruence between an individual's experienced/expressed gender and the assigned sex in pre-pubertal children. It includes a strong desire to be a different gender than the assigned sex; a strong dislike on the child's part of his or her sexual anatomy or anticipated secondary sex characteristics and/or a strong desire for the primary and/or anticipated secondary sex characteristics that match the experienced gender; and make-believe or fantasy play, toys, games, or activities and playmates that are typical of the experienced gender rather than the assigned sex. The incongruence must have persisted for about 2 years. Gender variant behavior and preferences alone are not a basis for assigning the diagnosis.

Gender incongruence, unspecified (HA6Z)

HA6Z in ICD-11 is an unspecified residual category. During the update process, the question of whether HA6Z will be used as a provisional diagnosis after the first visit was raised.[x] However, HA6Z is intended to be used only if gender mismatch is known but there is not enough information to determine whether HA60 or HA61 should be used. Examples of such situations are if the coder is a different person from the clinician and the information is missing, or if for some reason it would be difficult to determine whether or not the person has entered puberty.

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[2] Several codes in ICD-10-SE were discontinued on 1 January 2009 following a decision by the National Board of Health and Welfare, including "Gender identity disorder in childhood" (F64.2).

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Gender-variant behavior insufficient for diagnosis and coding

The ICD-11 code descriptions for adolescents and adults (HA60) and children (HA61) indicate that variations in gender role behaviors (alone) do not provide a sufficient basis for coding. In addition, the code description for gender incongruence in children is more detailed than that for adolescents and adults and specifies that three signs (relating to the wish, sex characteristics, and activities) must be present for at least two years in order for the code to be used. According to WHO experts, the aim of requiring the presence of all three signs was to avoid the code being used for children who are nonconforming in the sense that they prefer activities that are more often associated with a gender other than the one registered for the child at birth [10].

Corresponding requirements apply to the diagnostic assessment of gender dysphoria in children in the DSM-5, where more symptom criteria must be met for diagnosis in children compared to diagnosis in adolescents and adults, and where criterion A1 must be met (See *Diagnostic assessment* above). Similarly, the purpose of the A1 criterion requirement for children in the DSM-5 has been to avoid overdiagnosis (false positives) of children with gender-variant behavior who do not have a desire to belong to a different gender [11, 12].

Questions about ICD coding in specific situations

Questions about which diagnosis should be coded in some specific situations have been raised during the revision of the guidelines. One is the situation where an endocrinologist cares for a patient who started gender-affirming treatment and who (after age 18) received a legal gender change and no longer meets criteria for the diagnosis of gender dysphoria. Another concerns the code to be used when a person who has undergone gender-affirming treatment later seeks care with a wish to reverse the effects of the gender-affirming treatment and no longer meets the DSM criteria for gender dysphoria. At present, there are no definitive answers to these questions. As a basic principle, when a condition requires treatment, it is coded as that condition, even when the treatment continues over a long period of time. A discussion on coding in situations such as these needs to be conducted jointly by the units authorized to provide national highly specialized care and, if necessary, may involve the National Board of Health and Welfare.

Age limits for gender-affirming treatments

Gender-affirming treatments for gender dysphoria include voice and communication therapy, hormonal and surgical treatments, and hair removal (the latter for people registered male at birth). The aim of the treatments is to change the voice and body to be more in line with gender identity (reduced gender dysphoria) and to make it easier for the person to be perceived by others in accordance with their gender identity (increased quality of life).

Gender-affirming surgery of the genitals and removal of gonads (ovaries and testicles) are regulated by the act (1972:119) on the determination of gender in certain cases ("the Gender Identity Act"). Persons over 18 years of age may apply for these surgical procedures when applying for a change of legal gender under the Gender Identity Act.

Hormone therapy and gender-affirming surgery for secondary sex characteristics (e.g., mastectomy) are not covered by any specific legislation but can be performed under the Health and Medical Services Act (2017:30), HSL. This means that there are no legal age limits for when these treatments may be performed in cases of gender dysphoria.

Prescription of medicines for persons under 18 years of age

The National Board of Health and Welfare has been commissioned by the government to survey the prescription of puberty-suppressing and gender-affirming medicines for persons with gender dysphoria. The survey includes people who were newly diagnosed with gender dysphoria and prescribed the drugs between 2006 and 2018. Among the 1381 people newly diagnosed before age 18, more than half had not received either puberty-suppressing or cross-sex hormone treatment before age 18. Forty percent of those registered female at birth and 53% of those registered male at birth initiated puberty-suppressing treatment within five years of diagnosis. Treatment with cross-sex hormones was started within five years of diagnosis by 66% of those registered female at birth (testosterone) and 59% of those registered male at birth (estrogen) [13].

The child rights perspective

The Convention on the Rights of the Child in Swedish legislation

The UN Convention on the Rights of the Child, known as the CRC, sets forth the rights of children. Since 1 January 2020, the CRC applies as Swedish law.[3]

There are four so-called foundational principles in the CRC. These are the right of the child to non-discrimination (Article 2), the best interests of the child (Article 3), the child's right to life, survival, and development (Article 6) and the child's right to express his or her views and be heard (Article 12). The views of the child shall be given due weight in accordance with the age and maturity of the child. The

[3] See the Act (2018:1197) on the United Nations Convention on the Rights of the Child.

convention also contains other important articles, such as the right of the child to the enjoyment of the highest attainable standard of health and access to health care (Article 24), parental responsibility (Articles 5 and 18), and the right of the child to protection of privacy and personal integrity (Article 16).

The principles of the CRC have been expressed in a number of Swedish statutes, including the Patient Act (2014:821), PL, which contains provisions on the best interests of the child, the right to information and the importance of a child's position in relation to care and treatment.

The best interests of the child must be considered

In the case of health care provided to children, the best interests of the child must be taken into special account.[4] The preparatory work for the Patient Act states that in the difficult decisions that need to be made in healthcare activities, the best interests of the child must be the guiding principle. The assessment of the best interests of the child is a multi-step process. Health professionals must take into account science and proven experience and, depending on the age and maturity of the child, seek a basis for the decision from guardians. The starting point of the best interests of the child is respect for the child's full human value and integrity. What is in the best interests of the child must therefore be determined on a case-by-case basis.

Furthermore, it is stated that the process of arriving at the best interests of the child requires active consideration of each individual case. The life and health of the child must be protected.

However, the child's integrity,[xi] right to express their opinion, and right to influence [matters concerning them] must also be considered when assessing what is in the best interests of the individual child in a particular situation. The child's attitude towards care should be clarified as far as possible and the child's attitude should be given due weight in relation to his or her maturity.[5] The work of caregivers in this area is complex because, depending on the child's age and maturity, they must take into account the child's wishes and desires, interact with the child's guardians and protect the child in vulnerable situations. The preparatory work also states that to the extent possible, both long-term and short-term consequences of decisions such as providing or withholding certain care or treatment from the child should be considered. [6]

[4] Chapter 1, Section 8 of the Patient Act and Chapter 5, Section 6 of the HSL

[5] Chapter 4, Section 3 of the Patient Act

[6] See prop. 2013/14:106 p. 63

Children's right to self-determination and guardians' responsibility

Legal clarifications of children's right to self-determination and the responsibility of guardians are provided in the National Board of Health and Welfare's bulletin *Children seeking healthcare*, number 8/2020.[xii] As a starting point, it is the guardian who has the right and obligation to decide on matters of health care for the child.

However, as the child grows older and more mature, the child's wishes must increasingly be considered. A child may be considered mature enough to decide on his or her own about a particular care or treatment alone if he or she can assimilate the relevant information and understand the consequences of the decision. However, considerable maturity is required for a child to be able to consider more extensive treatments and interventions.[7]

According to the National Board of Health and Welfare's assessment, the support and consent of the guardians is a prerequisite for offering an adolescent with gender dysphoria puberty-suppressing and cross-sex treatment (See *Hormonal treatment for gender dysphoria in adolescents*). Greater emphasis on the child's willingness and maturity to make decisions alone can more often be placed on other types of care, such as psychosocial support. It should be noted that the preamble to the Patient Act emphasizes that even when a child is mature enough to decide on a particular care or treatment, the staff should still endeavor to involve the guardians, unless the child objects, or if doing so cannot be considered to be in the child's best interests.[8] However, it also appears that, for example, in the case of psychiatric care, there are instances where it has been considered acceptable for children under age 15 to seek and receive care without prior consultation with their guardians.

Regardless of the outcome of healthcare providers' assessments of the best interests of the child in relation to various healthcare interventions, all children have a right to their identity and integrity. The fact that children with gender expression and/or gender identity that falls outside the cis-norm are at increased risk of psychological and physical violence and that guardians are sometimes the perpetrators needs to be taken into account [14]. Discomfort with non-cis-heteronormativity may be the basis for guardians to subject their children to "conversion therapy" [15]. If healthcare professionals become aware of, or suspect that, a child is being harmed, they have a duty to immediately report it to social services.[9]

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[7] Cf. prop. 2013/14:106 p. 119

[8] Prop. 2013/14: 106 p 66.

[9] Chapter 14, Section 1 of the SoL.

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Ethical issues in the care of youth with gender dysphoria

A report submitted to the government by the Swedish National Council on Medical Ethics (Smer) in 2020 identified several ethical issues related to the care of children and young people with gender dysphoria [16]. Some of these issues are directly relevant to clinical work and are addressed elsewhere in these guidelines:

- how far youth self-determination should extend
- information that enables informed decision-making
- limitations of the knowledge base
- balancing the expected benefits and risks in the individual case.

Also see the section on hormonal therapy, section *Basic requirements for hormonal therapy*.

In its report, Smer also raises ethical issues at the systemic level, including the importance of care on equal terms, and the [healthcare] prioritization, both within the [patient] group, and in relation to other care needs. A need for care is considered to exist when there is a gap between the individual's current state of health and the state of health that science and evidence suggest can reasonably be achieved with various forms of care [17, 18].

Another issue discussed by the council [16] is whether healthcare today is moving towards more demand-driven care in several areas. Smer concludes that demand-driven care clashes with current priority-setting principles, according to which healthcare providers should prioritize according to need. The Health Care Act does not imply the right of the patient to receive a particular treatment. According to health legislation, care should be based on respect for the patient's autonomy and integrity and should be shaped and carried out to the extent possible in consultation with the patient.[10] In cases where there are several treatment options that are consistent with science and proven experience, the patient should be given the opportunity to choose the option he or she prefers. The patient shall receive the chosen treatment if this appears justified in view of the disease or injury in question and the cost of the treatment.[11] However, the patient cannot dictate which care is to be provided, and the patient's participation can never imply that the requirements for care and treatment provided in accordance with science and proven experience should be lowered (prop. 2013/14:106 p. 72 and 1981/82:97 p. 50). In cases where the care provider and the patient do not agree on the needs assessment, the care provider's interpretation is,

[10] Chapter 5, section 1 of the Health and Medical Care Act [2017:30], HSL, Chapter 4, section 1 and Chapter 5, section 1 of the Patient Act [2014:821], and Chapter 6. Section 1 of the Patient Safety Act [2010:659], PSL

[11] Chapter 7, Section 1 of the Patient Act (2014:821)

according to the preparatory works to the Health and Medical Care Act (HSL), the applicable interpretation.[12]

[12] The preparatory work for the old HSL states that "the patient's right to self-determination and privacy cannot be absolute but must be limited for several reasons. It is not possible to let the patient determine the content and scope of care. Such decisions must always be made by the health care provider and the person who has medical responsibility for the care." (prop. 1981/82:97 p. 118)

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Changing Care Area

The evolution of the diagnosis of gender dysphoria

In a report published by the National Board of Health and Welfare in 2020 [19], the evolution of the diagnosis of gender dysphoria in the population between 1998 and 2018 is presented. In figures 1-4 below, the years 2019 - 2021 are also included. The calculations are based on the number of persons registered in the Patient Registry (PAR) with any of the ICD codes F64.0, F64.8 and F64.9.

It has been noted that coverage in PAR has increased over time and that trends in the prevalence of gender dysphoria may therefore be overestimated [20]. The National Board of Health and Welfare's assessment is that under-coverage may be driving some of the increase in the early part of the time series but that it has little bearing on the increase that occurred in the 2010s.[13]

Figures 1 and 2 show the incidence rate, i.e., the number of new cases of persons with a diagnosis of gender dysphoria per 100,000 broken down by registered sex at birth and by age group. In the 2020 report [19], the National Board of Health and Welfare noted a marked increase in the number of new cases seen between 2013 and 2018. Figure 2 shows that the increase in the number of new cases between 2013 and 2018 was more pronounced among people younger than 30 than among people in the older age groups. The increase was greatest among children aged 13-17, and particularly among children aged 13-17 with a registered gender of female at birth. After 2018, a decrease in the number of new cases is seen for both sexes between 2018 and 2020, followed by a slight increase in 2021 (Figure 1). The decrease in the number of new cases is most pronounced among young people whose registered sex at birth is female. However, for those registered as female at birth in the 13-17 age group, the increase in 2021 brought the incidence rate this year to the same level as in the peak year of 2018 (Figure 2).

Several possible explanations for the decrease in the number of new cases in 2019 and 2020 were submitted in draft comments, including that the clinic in Stockholm, which receives a large proportion of the country's patients, had reduced activity in 2019. Another possible explanation, according to one study, is that media coverage of the care of young people with gender dysphoria led to a reduction in referrals.

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[13] The coverage of the registry is believed to be high, but there is a lack of complete comparative data. Specialist outpatient physician visits began to be collected in 2001, and the coverage rate is assessed to have gradually increased over time, particularly around 2011. Private providers, especially in specialized outpatient care, are estimated to account for most of the non-response.

According to the study, the media coverage that was negatively framed was most intense in 2019 [21].

Figure 1. Incidence of gender dysphoria since 1998

Incidence (new cases) of persons diagnosed with gender dysphoria since 1998. Registered sex at birth.

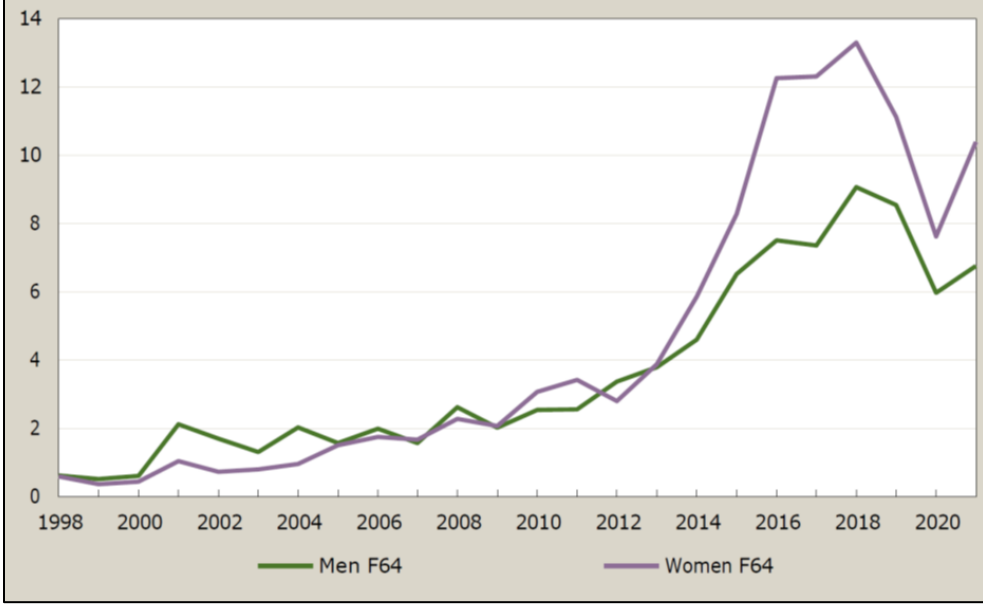

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Figure 2. Incidence of gender dysphoria by age and registered sex

Incidence (new cases) of persons diagnosed with gender dysphoria (F64) since 1998. Registered sex and age at time of diagnosis.

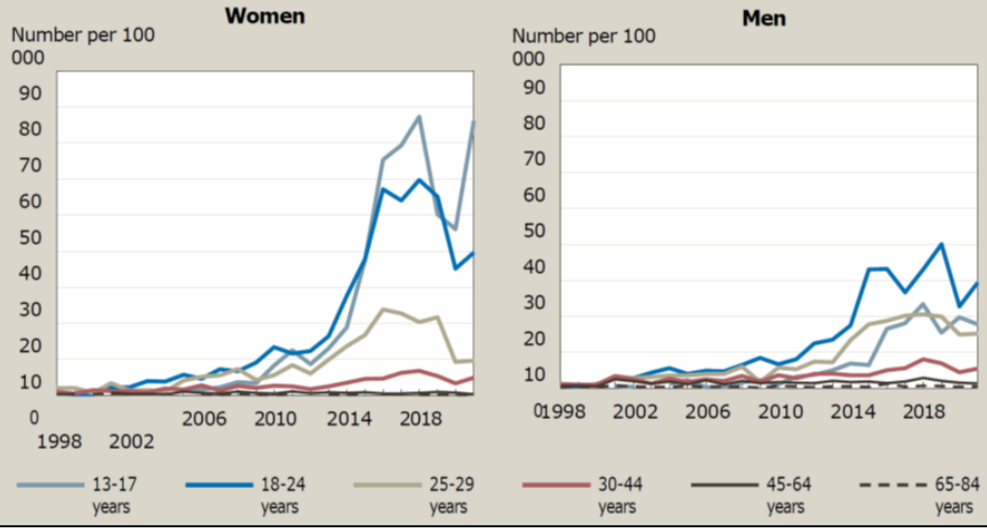


Figure 3 shows that the prevalence of gender dysphoria, i.e., the number of people per 100,000 who had a gender dysphoria diagnosis in a given year, continued to increase after 2018. This is partly explained by the high incidence among young people in the previous year. Figure 4 shows the prevalence over time in different age groups. Until 2018, the prevalence of a gender dysphoria diagnosis increased most among younger persons, both for young people with registered male at birth and those registered female at birth. Between 2018 and 2020, a decrease in prevalence is seen in the13 - 17 years age group, while a continued increase was seen in other age groups. In 2021, however, the incidence of a diagnosis of gender dysphoria was higher than in 2018, even in the 13 to 17 age group.

Figure 3. Prevalence of gender dysphoria since 1998

Prevalence of persons diagnosed with gender dysphoria since 1998 among persons registered in Sweden. Registered sex at birth.

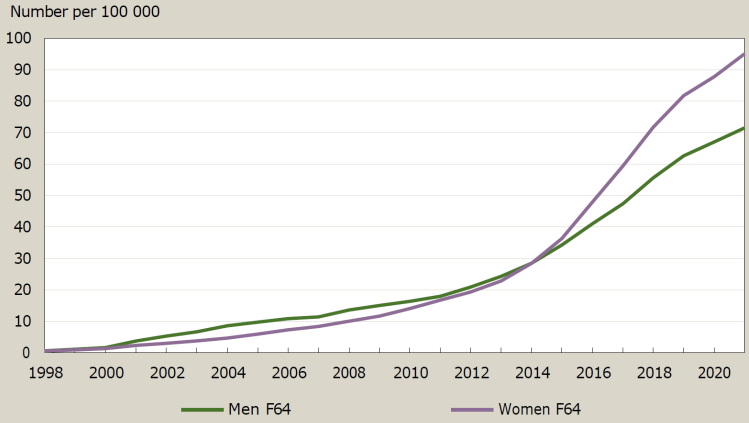
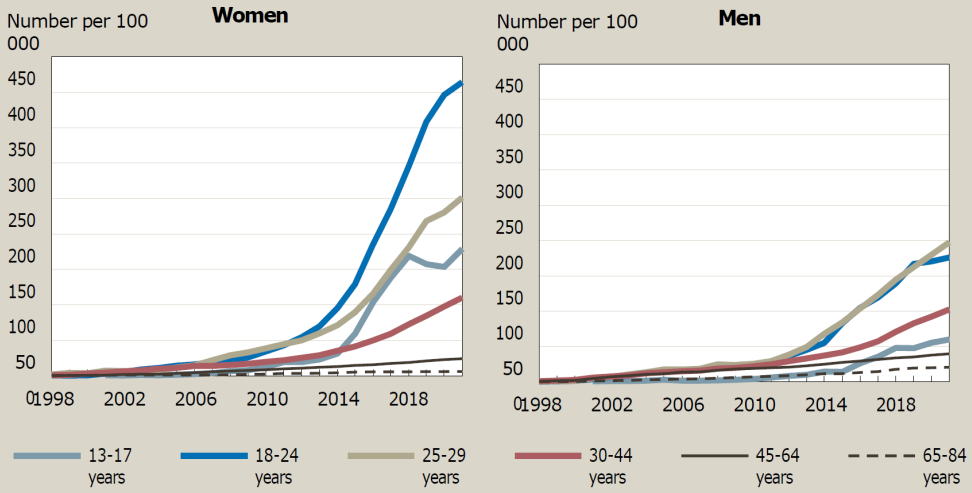


Figure 4. Prevalence of gender dysphoria by age and registered sex

Prevalence of persons diagnosed with gender dysphoria (F64) since 1998 among persons registered in Sweden. Registered sex and age at time of diagnosis.



Transition to national highly specialized care[xiii]

In December 2020, the National Board of Health and Welfare determined [22] that certain gender dysphoria-related care will constitute national highly specialized care and will be provided by three units. Multidisciplinary decisions on gender dysphoria care are to be made under a single operational responsibility within units that are authorized to provide national, highly specialized care.[14]

This 2020 decision means that a national unit will be contacted in cases of suspected gender dysphoria, regardless of the age of the patient. This unit will be responsible for psychiatric and diagnostic evaluation and assessment, as well as decisions about follow-up and further treatment. Endocrinological evaluation, assessment, and treatment initiation shall also be provided by the national units. However, all regions still need to carry out some evaluation and assessment before and after referrals. The allocation of responsibilities and resources will be determined by the national units in dialogue with regional health care providers and decision-makers. Who has the right to refer and what is required for referral needs to be described by the national health units.

[14] At the time of publication of the knowledge-support, no authorization to provide national highly specialized care had been granted to any organization. As granting authorization depends on the preparation process, it is unclear when authorization may be expected to be granted.

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Authorizations to provide national highly specialized care are regulated by law (Section 7, Section 5 of the Health Care Act [2017:30] and Section 2, Section 2 of the Health Care Regulation [2017:80]) and in the National Board of Health and Welfare's regulations (HSLFFS 2018:48) on national highly specialized care. These set out general and specific conditions, including that the units providing national highly specialized care must cooperate with one another and with referring units, and must promote research in the field.

Competence for good care and good treatment[xiv]

Competence of practitioners

Reasons for the decision to designate this care as national highly specialized care [22] include the fact that some care for gender dysphoria is deemed complex and infrequent, requiring a certain volume and multidisciplinary competence. This care requires close collaboration between professionals such as psychiatrists, psychologists, sociologists, endocrinologists, speech therapists, reproductive medicine specialists and plastic surgeons, all with specific competence for the patient group.

Some of the measures mentioned in the guidelines are not included in the definition of national highly specialized care but remain at the regional level (e.g., mastectomy and hair removal). Multidisciplinary assessment and close cooperation between the evaluation team and plastic surgeons in the regions is also required for mastectomy (See *Surgical treatment*).

Competence that enables good treatment is needed in all activities where health professionals meet people with gender dysphoria.

Competence for good treatment

All health care must be provided with respect for the equal value of all people and for the dignity of the individual (Section 3, Section 1, Article 2 of the HSL). It is essential that healthcare professionals who encounter young people with gender dysphoria are familiar with issues relating to gender identity and gender expression and have knowledge of the living conditions, health, and rights of transgender people. Healthcare professionals also need to be aware of cis- and heteronormative assumptions and language and be sensitive and respectful in their contact with the young people and their families.

Once a license to provide national highly specialized care has been granted, the region must cooperate with other regions that provide care in the same licensed care area. Methods of cooperation between national units and the regional level of care

may therefore need to be worked out. Since some evaluation and assessment will continue to be provided at regional level according to the decision, competence-enhancing efforts are important in to enable good care that is fair and equitable and provides good treatment to people with signs of gender dysphoria throughout the entire healthcare pathway. Knowledge building activities and knowledge translation may need to be adapted based on the mission of the regional health services.[15]

When caring for young people with gender dysphoria, it is important for staff to affirm the person's gender identity [15, 23]. One measure that has a significant impact on the individual is for health staff to ask for the person's preferred name and pronouns and then use them, even when they do not match the civil registration data. This applies both in direct contact with the person and in the documentation of the healthcare contact (See appendix 3 for legal clarifications on documentation).

According to participating experts, the fact that the healthcare system affirms the young person's gender identity in this way is also a prerequisite for being able to create a trusting and functioning relationship with the patient during the evaluation.

Many young people with gender dysphoria have a more complicated relationship with their bodies than other young people and may need more time and consideration than is usual for a physical examination. In these situations, it is important that one uses respectful and inclusive language that draws on the terms for naming body parts that the individual prefers, if the person has such preferences. It is also important to provide information about upcoming physical examinations in advance so that the young person has the opportunity to prepare mentally.

[15] Here, regional care refers to care that is not covered by national highly specialized care.

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New Recommendations on Hormonal Treatment – Basis and Consequences

In 2012, the National Board of Health and Welfare was commissioned by the government to produce a guideline for the health care profession, with recommendations on care and treatment of transsexualism and other gender identity disorders. The commission was preceded by a study that had revealed issues such as significant regional differences regarding access to care and the content of care [24]. The guidelines *Good Care of Adults with Gender Dysphoria* and *Good Care of Children and Adolescents with Gender Dysphoria* were published in 2015[1, 8].

When the guidelines for children and adolescents underwent updates in 2020-2022, there were facts, which, according to the National Board of Health and Welfare's overall assessment, have led to the recommendation that puberty-suppressing treatment with GnRH analogues and gender-affirming hormone therapy for adolescents need to be restricted.

The basis of the recommendations

In the context of research

According to the assessment of the National Board of Health and Welfare, there is a need to start generating knowledge about puberty-suppressing and gender-affirming hormone therapy for adolescents with gender dysphoria in the near future. The importance of follow-up and evaluation of the care interventions offered as part of clinical work is emphasized in the 2015 guidelines [1]. At the time, the healthcare system was planning the introduction of a quality registry (the Gender Dysphoria Registry), which has not yet been able to respond to the needs. Longitudinal data are needed to provide a coherent picture of the patient population, from referral to possible diagnosis of gender dysphoria and with follow-up of patients offered different treatment options. The National Board of Health and Welfare urges decision-makers in the relevant healthcare regions to facilitate the registry so that it can reach full functionality as soon as possible.

Eventually, data from the gender dysphoria register could be used for registry studies, but this will take time. The knowledge gaps identified by the SBU, for instance, the impact of treatments on gender dysphoria, mental health, and quality of life [2], also need to be addressed by initiating clinical trials that can answer these research questions to the extent possible given conditions in the field. Here too, healthcare

regions have a responsibility to facilitate the initiation of relevant research in the near future.

Given the uncertainties described in the sections below, clinical trials will also ensure that all relevant information is conveyed to caregivers and young people and that consent is obtained before treatment is initiated.

From "should" to "may in exceptional cases"

The SBU literature review from February 2022 [2] states that for adolescents with gender dysphoria, there is insufficient evidence to assess the effects of puberty-suppressing and cross-sex hormone therapy on most patient-oriented outcome measures (gender dysphoria, psychosocial health, and quality of life). It is also not possible to assess the effects of the treatments on cognitive function, body measurements, body composition, or metabolism.[16] SBU finds some support at the population level that adolescents who have received puberty-suppressing hormone treatment recover bone density during subsequent cross-sex hormone treatment with estrogen or testosterone (low certainty), but that it is not possible to determine whether bone density will eventually fully recover to a level comparable to adolescents in the general population. For details of the study, see the SBU report [2].

Although the state of research has remained largely unchanged since the guidelines were developed in 2015, the previously strong, positive recommendations on puberty-suppressing and gender-affirming treatment have been revised to weak, negative recommendations.

The new assessments are based on the continuing uncertainty of knowledge and the three factors described below (See also *The National Board of Health and Welfare's overall assessment*). Comprehensive descriptions of the expected benefits and risks of the treatments are provided in the section *Hormonal treatment for gender dysphoria in adolescents*.

The patient population has changed

The 2015 guidelines [1] already noted that the number of people with diagnosis codes related to gender identity was increasing. A continued increase in the number of care-seekers and young people with these diagnostic codes has subsequently been seen both nationally and internationally, particularly among young people and especially among young people registered female at birth [19, 25, 26]. Between 2008 and 2018, the number of new cases of diagnosed gender dysphoria among persons aged 13-17 years registered female and male at birth multiplied, from 4 to 77 per 100,000 and

[16] The SBU uses the term "cross-sex", which in the knowledge support corresponds to the term "gender confirmation".

from 2 to 23 per 100,000, respectively [19]. Subsequently, the number of new cases 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-laggning-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).

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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/

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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

[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.

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adolescents with non-binary gender identities can be offered hormonal treatment in the context of research.

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 be partly explained by the

[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.

minority stress model [49, 50].[26] The theory describes increased psychosocial stress 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

[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.

[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.

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 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)*.

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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 counseling 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]

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[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.

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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.

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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.

This document is an unofficial English translation of a document prepared in Swedish.

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.

This document is an unofficial English translation of a document prepared in Swedish.

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.

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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

[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

assessments, in order to provide structure to the assessments and facilitate discussions within the evaluation team.

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.

This document is an unofficial English translation of a document prepared in Swedish.

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

ultimately make it impossible for an adolescent to try to live in accordance with their gender identity during the evaluation. It is important that the adolescent's needs for assistive devices or aids are assessed and that the authorities offer aids that enable the adolescent to try to live in accordance with their gender identity.

Recommendation on assistive devices

> Following an individual assessment, but no sooner than the preliminary diagnosis of gender dysphoria is made, healthcare services should provide adolescents with aids to facilitate their living in the social role that corresponds to their gender identity.

Reasons for the recommendation

Background: The fact that the body reflects the gender registered at birth can make it difficult for an adolescent to be perceived by others in accordance with their gender identity. Aids that can help include bindings used to hide the breasts or penis, wigs, breast prostheses and various types of penile prostheses.

The expected benefit (purpose) of the measures is to facilitate adolescents who want to live in accordance with their gender identity, and to contribute to an increased quality of life for the individual.

Possible risks: One possible risk is that the measures, if offered too early in the education process, may risk entrenching a gender identity that is not grounded in the individual. This risk can be mitigated by offering aids after a preliminary diagnosis of gender dysphoria at the earliest, and after an individual assessment. The assessment team also needs to alert the adolescent to the fact that regular binding of breasts and penis can have negative physical consequences and help to prevent these consequences should the adolescent choose to use these devices.

The knowledge about expected benefits and risks is based on experience, gathered from the experts who participated in the guidelines work and publications describing young people's experiences of using aids (i.e., binders) [73, 74]. 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.

Hormonal treatment for gender dysphoria in adolescents

This section includes updated recommendations about treatment with gonadotropin-releasing hormone analogue (GnRHa) and gender-affirming hormone treatment, as well as decision support to guide treatment decisions.

Content and extent

This section focuses on fundamental aspects and ethical considerations. For medical issues, reference is made to consensus-based guidelines for endocrine treatment of gender incongruence in adolescents [55]. This refers to issues of evaluation of physical health, testing, preparations and dosing, monitoring, and transition to adult care. Other hormonal treatments such as progestins (low and moderate dosages) and combined contraceptive pills are mentioned but not described in detail.

Basic conditions for hormonal treatment

The National Board of Health and Welfare's assessment is that both GnRH analogue treatment and gender-affirming hormone therapy may be offered under certain basic conditions, which are described in more detail below. Conditions (criteria) specific to each treatment are then described in connection with the specific recommendation.

In the context of research

The National Board of Health and Welfare's assessment is that treatment with GnRH analogues and sex hormones for adolescents with gender dysphoria should be provided within the framework of research. Until a research study with ethically tested inclusion and treatment criteria is in place, the National Board of Health and Welfare's assessment is that the treatment can be provided in accordance with the updated recommendations and criteria in the guidelines. In terms of the research questions that need to be answered, the National Board of Health and Welfare refers to the knowledge gaps for the area of care listed in the SBU database. For more information, see *New recommendations for hormonal treatment - basis and consequences.*

Thorough diagnostic evaluation

Recommendations for conducting the child psychiatric and diagnostic assessment are described in the section *Evaluation of gender incongruence in children and adolescents*. The evaluation places stringent requirements on the psychiatric,

psychological, and psychosocial assessments, and must be tailored to the medical, psychological, and social circumstances of the adolescent.

Multidisciplinary assessment

The decision to initiate GnRH analogue or gender-affirming hormone therapy must be based on a balanced multidisciplinary assessment that considers the adolescent's whole situation. At a minimum, the decision needs to be taken jointly by the multidisciplinary team responsible for the child psychiatric and diagnostic assessment and the pediatric endocrinologist responsible for physical health considerations (For further information, see *Evaluation of gender incongruence in children and adolescents*).

Support and consent from guardians

Legal clarifications of children's right to self-determination and the responsibility of guardians are provided in the National Board of Health and Welfare's bulletin, *Children seeking health care*, number 8/2020. As a starting point, it is the guardian who has the right and obligation to decide on matters of health care for the child. However, as the child grows older and more mature, the child's wishes must increasingly be taken into account. A child may be considered mature enough to decide alone on his or her own about specific care or treatment if he or she can assimilate the relevant information and understand the consequences of the decision. However, considerable maturity is required for a child to be able to contemplate more extensive treatments and interventions.[37]

According to the Gender Dysphoria Registry's 2020 annual report, a consensus between the adolescent, guardians, and health care providers is a prerequisite for offering treatment with GnRH analogue and/or gender-affirming hormone treatment [75]. This treatment should be viewed in the light of the pervasive and lifelong consequences of treatment for the individual.

The support and involvement of guardians is also important for adherence to treatment and for the overall psychosocial situation of the adolescent.

Information that enables an informed decision

Health care providers should seek to achieve the best possible shared understanding with the patient on important issues of care and treatment. A prerequisite for this is that the patient is well informed about his or her health condition and the different

[37] Cf. prop. 2013/14:106 p. 119

treatment options that may be available based on the patient's life situation and personal circumstances.[38]

Legal provisions in the healthcare system's obligation to provide information are set out in Section 3 of the Patient Act. When the patient is a child, the child's guardian must also be informed.[39] The preparatory work for the Patient Act states that in order to be able to make an informed decision, one of the requirements is that the patient should receive scientifically based information about the advantages and disadvantages of the various treatment options for the condition in question. Furthermore, it states in situations where the patient's treatment regimen includes the possibility of waiting before initiating interventions, the patient must also be informed about this, along with the possible consequences of a decision to wait. This information should be provided as early as possible in the care process.[40]

There is no section in health legislation that explicitly states that health care has an obligation to also provide information about the uncertainties and gaps in the knowledge base. However, such information is considered necessary from an ethical and moral perspective, to enable patients and caregivers to make informed decisions [16]. Such information can also be considered consistent with the legal requirements of objectivity and impartiality in public administration.[41]

The responsible pediatric endocrinologist should provide information about the treatment to the child and guardians early in the diagnostic evaluation and then repeatedly, based on the needs that arise as the evaluation progresses (See also *Evaluation of gender incongruence in children and adolescents*).

Assessment of expected benefit-risk for individual

For each individual adolescent, the expected benefits of the treatment in question need to have been made clear, and the benefits must be assessed to outweigh the risks. The expected benefits and risks of not providing the treatment also need to have been made clear and considered [16]. When healthcare is provided to children, the best interests of the child must be carefully considered (Section 1, Section 8 of the Patient Act).[42]

The provision of GnRH analogues to adolescents with gender dysphoria under certain conditions is a practice that has emerged in the Netherlands in recent decades.

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[38] Prop. 2013/14:106 p. 72.

[39] Chapter 3, Section 3 of the Patient Act.

[40] Prop. 2013/14:106 p. 48.

[41] See Chapter 1, Section 9 of the Instrument of Government (RF) and Section 5 of the Administrative Procedure Act (2017:900).

[42] See further the section on the <Child rights perspective> in the <Introduction> chapter.

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Important cornerstones in the development of the "Dutch protocol" have been the clear distress of some adolescents at the onset of puberty and the observation that gender dysphoria was rarely amenable to psychotherapy for these adolescents [76-78]. The importance of applying caution when treating with GnRH analogues is reflected, among other things, in the criteria that the gender incongruence should have started in childhood, persisted until puberty, and that the onset of puberty should have caused clear distress [5, 79].

According to literature reviews by SBU and NICE [2, 80, 81], it is currently not possible to draw firm conclusions about the efficacy and safety of GnRH analogue and gender-affirming hormone therapy for adolescents with gender dysphoria (See separate appendix *Knowledge base with methods description*).

The expected benefits and possible risks of the treatments are described in the following sections.

Treatment with GnRH analogue

Treatment with gonadotropin-releasing hormone analogues has been used since the early 1980s to slow puberty in children with *central precocious puberty* (CPP), i.e., pubertal development that starts before 8 years of age in girls and before 9 years of age in boys. GnRH analogue is also used in various conditions that inhibit growth during adolescence, and in gender dysphoria in adolescents [82].

Endogenous puberty in boys and girls is well described in the literature, including by Nordic research groups, in terms of the gradual increase in sex hormone levels and the timing of these changes [83-93]. Pubertal development is usually considered to have ended when the person reaches their final height. Continued masculinization and feminization of the body occurs for several years after puberty.

Expected benefit of the treatment

Treatment with a GnRH analogue for gender dysphoria is primarily aimed at lowering the distress associated with the development of puberty and reducing the risk of poor mental health. The goal of treatment is to prevent the body from physically developing in a direction that is not consistent with gender identity. If treatment is initiated in early puberty, it also reduces the risk of developing (more or less irreversible) sexual characteristics that are difficult to change or eliminate later in life such as voice pitch, height, hips, jaw and face features and facial hair. In this way, the aim is also to make it easier for the person to be perceived in accordance with their gender identity by the environment, and to contribute to a better quality of life. The need for subsequent hair removal, speech therapy,[xviii] and gender-affirming surgery is thus reduced.

Even in later puberty (Tanner stage 4-5), treatment aims to reduce the distress associated with endogenous development, lower the risk of poor mental health, and to inhibit further masculinization and feminization of body shapes and body composition (further growth of breasts and hips, respectively, additional body hair, roughening of features and lowering of voice, and growth of chest, feet, and hands). Another purpose in later puberty is to reduce the emotional stress that often accompanies erections and menstruation.

Finally, the treatment aims to reduce distress that may facilitate further exploration of gender identity during the course of the evaluation, and thus also has a diagnostic purpose.

Possible side effects and risks of the treatment

In both early and late puberty, weight gain is a common side effect of GnRH analogue. For adolescents who are already severely overweight, treatment may further increase the risk of future health problems and worsen the prospects for possible future gender-affirming surgery (see *Physical health consideration* below).

Withdrawal symptoms such as hot flashes can occur if levels of sex hormone are high enough when treatment with GnRHa is started and are relatively common among adolescents in late puberty. Decreased energy levels and low mood may occur [94]. Decreased sex drive may be noticed when treatment is started after completed puberty.

Available treatment studies and clinical experience suggest that menstruation in girls treated with CPP returns on average one year after treatment ends, but it may take as long as two years. Longer time to menstruation at discontinuation or after completion of treatment can be expected if treatment is started before menarche has occurred [95]. The few, small studies of boys with CPP suggest that testosterone levels and testicular volume are recovered one year after completion of treatment, and that full pubertal development may be reached by late teenage years [96]. These findings are also consistent with sperm recovery in studies of "contraceptive pills for men" in which GnRH analogues were used in combination with high (supraphysiological) doses of testosterone [97].

For young people treated with GnRH analogues in early puberty, there are clear difficulties in offering fertility preservation, especially for young people registered female at birth who have not yet had menarche [98-100]. For young people in early puberty and those registered male at birth, reportedly there are experience-based difficulties producing semen samples for freezing. Descriptions related to fertility preservation are given in the section *Sexual and reproductive health*.

Absence of sex hormones over a long period of time can lead to a risk of reduced bone mineralization and, in the long run, increased risks of osteoporosis and bone fracture in adulthood. No certain conclusions about the risks can be drawn at this

stage from the existing scientific evidence (See the separate appendix *Knowledge base with methods description*).

The extent to which height growth is affected has not yet been studied systematically and is largely dependent on the physical development of the adolescent. If treatment is started early in the development of puberty then remaining height growth will be delayed. Final height is only reached when sex hormone levels have been sufficiently high for a sufficiently long time, and the growth zones are closed. This can be positive or negative for the adolescent and must be considered on an individual basis.

The absence of sex hormones over a long period of time can lead to a risk of negative effects on cognitive development. No certain conclusions about the risk can be drawn from existing scientific evidence (See the separate appendix *Knowledge base with methods description*).

Delayed puberty in gender dysphoria causes the adolescent to be physically and psychologically out of sync with his or her peers.

When treatment is started in early puberty, it results in stunted penile growth, and the growth of the scrotum decreases. Any vaginal construction in adulthood may therefore need to be carried out using methods other than what is currently considered the "gold standard" (constructing a vagina using only skin from the penis).

Finally, if the adolescent does not go through puberty, there is a possible risk that treatment with GnRH analogues may consolidate a gender incongruence that could have proven to be transient over time [31].

Recommendation

Treatment with GnRH analogues for adolescents with gender dysphoria should be provided in the context of research. Until a research study with ethics board approved inclusion and treatment criteria is in place, it is the National Board of Health and Welfare's assessment that treatment with GnRH analogue may be given in exceptional cases, in accordance with the updated criteria in the medical guidelines.

Reasons for the recommendation

At present, no certain conclusions can be drawn about the efficacy and safety of this treatment for young people with gender dysphoria based on existing scientific evidence. There is a small number of studies and most have small numbers of participants and lack comparison groups. For further information, see separate appendix *Knowledge base with methods description*.

For population of adolescents with gender dysphoria as a whole, the National Board of Health and Welfare currently concludes that the risks of treatment with a GnRH analogue are likely to outweigh the benefits of treatment. The basis for this assessment is presented in the section *New recommendations for hormonal treatment - basis and consequences*. The basis for the recommendation to provide treatment with GnRH analogues in the context of research is also presented in the section *New recommendations for hormonal treatment - basis and consequences*.

The basis for the criteria in the guidelines for young people who have reached Tanner stage 3 is experience-based knowledge documented in scientific publications of the "Dutch protocol" [5, 7, 79, 101], the clinical experience of the participating experts and ethical considerations.

The basis for excluding young people in Tanner stage 2 in the recommendation, who are covered under the "Dutch protocol", is the assessment of the participating experts that the adolescent needs time to be exposed to endogenous puberty before starting treatment, which is in line with ethical considerations.

The criteria used in the guidelines for young people who have reached Tanner stage 4-5 are based on the experience of the participating experts.

For information about how experience-based knowledge was gathered and otherwise implemented, see the separate appendix *Knowledge base with methods description*.

Decision support - guidance on treatment decisions

Criteria to consider for adolescent in Tanner Stage 3

- Basic conditions of thorough diagnostic evaluation, multidisciplinary decision-making, consent from guardians, provision of information, and expected benefit/risk assessment are met.
- The adolescent has a stable psychosocial situation and there are no factors that obscure the certainty of the clinical assessments (neuropsychiatric or intellectual disability, untreated psychiatric problems including suicidal risk and trauma, substance use).
- Gender incongruence has existed since childhood and gender identity has remained stable over time.[43] There is a lack of evidence about how long gender incongruence should have existed; a UK publication from 2021 has set the limit at a minimum of 5 years [102].
- The onset and progression of puberty has brought clear suffering.
- DSM-5 diagnostic criteria for gender dysphoria (302.85) are met.

[43] The Dutch protocol was developed for young people with binary (“cross-gender”) gender identities.

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- The adolescent should be between 12 and 15 years old. In a Dutch publication reflecting the "Dutch protocol", treatment with GnRH-analogue was started on average at 14.75 years of age (SD=1.92, range 11.3-18.6) [103]. During the guidelines update process, comments were received both that 12 years is too low a cut-off, and that treatment with extended follow-up may in exceptional cases be justified before the age of 12.

Criteria to consider for adolescents in Tanner stage 4-5

Treatment with GnRH analogue for adolescents whose gender incongruence or gender dysphoria does not appear in childhood but only at puberty is not described in publications of the "Dutch protocol." In the experience of the participating experts, the treatment can in some cases be deemed to be of great benefit, particularly for young people registered male at birth whose masculinization in later puberty makes it very difficult to pass as an adult.

In Sweden, for young people registered female at birth, progestins (low and moderate dosages) and combined contraceptive pills have in recent years become a first-line choice over GnRH analogues.

If treatment with GnRH analogue is offered at Tanner stage 4-5 as described above, then

- the basic prerequisites of thorough diagnostic evaluation, multidisciplinary decision-making, consent from guardians, provision of information, and expected benefit/risk assessment have been met
- DSM-5 diagnostic criteria for gender dysphoria (302.85) are met
- the adolescent, for ethical reasons, must have a stable psychosocial situation and there are no factors that obscure the certainty of the clinical assessments (neuropsychiatric or intellectual disability, untreated psychiatric problems including suicidal risk and trauma, substance use).

Criteria relating to the process

- Treatment with GnRH analogue requires that psychosocial support enabling open exploration of gender identity is provided in parallel. For further information, see sections *Support for young people and their families* and *Evaluation of young people with gender incongruence*.
- Treatment with GnRH analogue is initiated for a limited time. There is no evidence to indicate the maximum duration of treatment. A maximum period of 2-3 years has been mentioned during the update process.
- Adolescents and guardians have been informed about the possibilities, limitations, and uncertainties of fertility preservation measures, as well as about different gender-affirming treatments.
- Growth rate and expected final height are monitored during treatment, and follow-up is otherwise adjusted based on physical health considerations.

- Adolescents and guardians understand that adolescents sometimes choose to discontinue treatment (e.g., because their gender identity changes or because of side effects), that healthcare services sometimes deem that treatment must be discontinued (e.g., if absolute bone density decreases during treatment), and that treatment is not a promise of gender-affirming hormone treatment.

Physical health considerations and possible contraindications

- physical disease with risk of osteoporosis (DXA measurement before starting treatment, consultation with treating physician)
- ongoing cortisone treatment (assessment based on indication, dose, and duration of treatment, DXA measurement before starting treatment, consultation with treating physician)
- being severely overweight (watchful waiting, guidance on dietary habits and support for weight loss is provided as early as possible in the contact)
- other physical disease and ongoing treatments, e.g., malignant disease, catabolic conditions with significant loss of muscle mass (watchful waiting until the condition is stabilized consultation with treating physician).

Gender-affirming hormone treatment

Gender-affirming hormone treatment involves the administration of sex hormones to develop secondary sex characteristics in a feminizing direction (for those registered male at birth), or in a masculinizing direction (for those registered female at birth). When administered to adolescents with gender dysphoria who have not undergone full pubertal development due to previous puberty-suppressing treatment, gender-affirming hormone treatment is intended to induce pubertal development in accordance with one's gender identity. Hormone replacement with estrogen or testosterone often continues for life.

The treatment regimen differs for adolescents vs adults with gender dysphoria [55]. For adults, treatment starts at the full doses of testosterone and estrogen, respectively, while adolescents start treatment at lower doses that are gradually increased. As the dose of the cross-sex hormone is increased, GnRH analogue may be given in parallel to block the endogenous sex hormone.

Adults registered male at birth will continue to need medicines that inhibit the secretion of sex hormones by the congenital gonads, as long as the testicles are not surgically removed. Such "testosterone blockade" for adults is usually achieved with an anti-androgen drug. Adults registered female at birth do not usually need a similar drug in the future, as testosterone itself is often an effective block to estrogen production.

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Expected benefit of the treatment

The aim of gender-affirming hormone treatment is to change the body to better reflect the person's gender identity, thereby reducing gender dysphoria and improving quality of life. The effects of treatment are dose-dependent and vary from person to person [104]. For adolescents registered female at birth, the following physical effects of testosterone treatment are expected [105]:

- lowered voice
- increased facial and body hair
- loss of ovulation and menstruation
- reduced breast tissue
- enlarged clitoris
- increased muscle mass
- reduced proportion of subcutaneous and body fat.

Androgenic alopecia (hair loss) can occur after long-term treatment with testosterone [104]. The androgenic effects on voice, facial and body hair become permanent after approximately six and 12 months of treatment, respectively [104]. Any effects on jaw, height and body proportions are irreversible, with the degree of effect depending, among other things, on the physical development of the adolescent at the start of treatment.

For adolescents registered male at birth, the following physical effects of estrogen treatment are expected [105]:

- breast growth
- reduced erectile function and sexual desire
- reduced testicle size and sperm production
- softer skin
- reduced (not eliminated) facial and body hair
- redistribution of body fat and increased ratio of body fat to muscle mass.

It takes about two years before maximum breast growth is achieved [104]. If treatment is stopped, some breast growth will remain permanent. Any effect on body height is irreversible, with the degree of effect depending on the physical development of the adolescent at the start of treatment.

Possible side effects and risks of the treatment

Oily skin and acne are side effects that can occur mainly during the first six months of testosterone treatment [104]. "Chafing" problems of a growing clitoris may also occur. Individuals registered male at birth may experience decreased sex drive resulting from estrogen treatment (due to the reduced testosterone levels) [105].

Gender-affirming treatment with both testosterone and estrogen has negative effects on reproductive ability. The extent of the effects and the extent to which reproductive

function can be restored if treatment is discontinued are currently unknown [105]. There is no guarantee that an adolescent undergoing fertility preservation will be able to become a genetic parent in the future either. For further information, see *Sexual and reproductive health.*

Individuals registered male at birth who are treated with estrogen are at increased risk of venous thrombosis [104, 105] (See also below on *Physical health considerations*).

Finally, there is a risk that the person may later wish to discontinue or reverse the effects of the treatment, for example because the effects were not as expected or because the person has changed their perception of their gender identity [3].

Recommendations

> Gender-affirming hormone treatment with testosterone or estrogen for adolescents with gender dysphoria should be provided in the context of research. Until a research study with ethics board approved inclusion and treatment criteria is in place, it is the National Board of Health and Welfare's assessment that gender-affirming hormone therapy can be given in exceptional cases, in accordance with the updated criteria in the guidelines.

Reasons for the recommendation

At present, no certain conclusions may be drawn about the efficacy and safety of the treatment for young people with gender dysphoria based on existing scientific evidence.

The studies are few in number, most have small numbers of participants and lack comparison groups. See further the section *Knowledge-base* in appendix 4.

For the group of adolescents with gender dysphoria as a whole, the National Board of Health and Welfare currently deems that the risks of cross-sex hormone therapy are likely to outweigh the benefits of the treatment. The basis for this assessment is presented in the section *New recommendations for hormonal treatment - basis and consequences*.

The basis for the recommendation to provide gender-affirming hormone treatment in the context of research is also presented in the section *New recommendations for hormonal treatment - basis and consequences*.

The basis for the decision support criteria is the evidence-based knowledge documented in scientific publications of the "Dutch protocol" [5, 79, 101], the clinical experience of participating experts, and ethical considerations. For information about how experience-based knowledge was obtained and

implementation in general, see the separate appendix *Knowledge base with methods description*.

Decision support - guidance on treatment decisions

Criteria to consider relating to the adolescent

- Basic prerequisites for thorough diagnostic evaluation, multidisciplinary decision, consent from guardians, provision of information, and risk/benefit assessment have been met.
- The adolescent has a stable psychosocial situation and there are no factors that obscure the certainty of the clinical assessments (neuropsychiatric or intellectual disability, untreated psychiatric problems including suicidal risk and trauma, substance use).
- Gender incongruence has existed since childhood. Gender identity has been stable over time and unchanged during treatment with GnRH-analog.[44]
- DSM-5 diagnostic criteria for gender dysphoria (302.85) are met.
- The adolescent has started to live socially in accordance with their gender identity.
- The adolescent demonstrates mental maturity, including a knowledge and understanding of the outcomes expected from gender-affirming hormone treatment, and from possible future gender-affirming surgery as well as the medical and social risks of the treatments.
- The adolescent is at least 16 years old.

Criteria relating to the process

- The adolescent and guardians are aware of the risk that reproductive capacity may be negatively affected by the treatment, and of the conditions for procurement of gametes for freezing.
- The adolescent understands that fertility preservation does not guarantee that they will be able to become a genetic parent in the future.
- Where fertility preservation measures are possible, the adolescent has been offered such measures.
- The adolescent understands the importance of adherence to treatment and that in adulthood there will be a need for continued regular contact with the endocrinologist and physical health examinations if necessary.

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[44] The Dutch protocol was developed for young people with binary ("cross-gender") gender identity. A pressing issue is to clarify the conditions under which adolescents with non-binary gender identity can be offered hormonal treatment in the context of research.

- Psychosocial support is offered when needed during treatment, for example, for changes in social interactions with the environment, or to manage mood swings and other side effects of medication. Sexual health counselling may also be needed (See the section *Sexual and reproductive health*).

Physical health considerations and possible contraindications

Some risks or medical conditions may be exacerbated by gender-affirming hormone treatment. Healthcare providers need to take these into account before starting hormone treatment. For example, for people registered male birth, it is important to consider thromboembolic risk and the risk of breast cancer before treatment with estrogen. For people registered female at birth, erythrocytosis and effects on the liver are important conditions to consider prior to testosterone treatment. For further information, see the SBU literature review (2022) on hormone therapy for adults with gender dysphoria [106].

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Surgical treatment

Unlike aesthetic plastic surgery, surgical procedures for gender dysphoria are reconstructive in nature since they are performed on medical grounds. The procedures aim to adapt the body to the individual's gender identity, reducing the psychological distress caused by gender dysphoria and helping the individual to achieve a level of functioning as comparable as possible to that of cis-persons.

In light of comments received about a draft version of this section, the National Board of Health and Welfare would like to begin by describing the work that formed the basis for the update. The 2015 guidelines on the care of children and adolescents [1] contained recommendations on five different gender-affirming surgical procedures that required consideration: mastectomy, breast augmentation with implants, reduction of the larynx, liposuction of the hip, and facial surgical procedures.[45] In preparation for the update, the National Board of Health and Welfare identified the extent to which the five procedures have been performed for gender dysphoria before age 18, their expected benefits and risks, and the scientific and experience-based knowledge available when the recommendations were revised. The results of the survey for the five interventions and the ethical evaluation that was carried out are presented in the separate appendix *Knowledge base with methods description*.

Overall ethical analysis

As with gender-affirming hormone treatment, gender-affirming surgical procedures have profound and, in some cases, lifelong consequences for the individual. Many of the uncertainties that have prompted the agency's more restrictive recommendations on hormonal treatment for underage patients also apply to a great extent to gender-affirming surgical procedures.[46] The National Board of Health and Welfare's principal conclusion when revising the evidence base is that gender-affirming surgical procedures should not be performed before the age of 18.

[45] See the chapter <*Introduction*> regarding age limits for gender affirmation treatments

[46] See the chapter <New recommendations for hormonal treatment - basis and consequences>

Ethical analysis of mastectomy and other procedures

The abovementioned survey revealed that 85 operations were performed before the age of 18 for the indication of gender dysphoria between 2004 and 2021; 84 of these are mastectomies and one was breast augmentation with implants.

Mastectomy involves the surgeon removing breast tissue to give the chest a masculine appearance. Often the surgeon also needs to adjust the size and position of the nipples.[47]

Participating experts have pointed out that the benefits of mastectomy may outweigh the risks of the procedure even in the case of a minor, particularly for those with a high level of breast-related distress and who have started gender-affirming hormone treatment with testosterone. The development of secondary sex characteristics such as beard growth and deep voice may in these cases cause difficulties in passing in accordance with the gender identity and cause additional suffering for the individual. A similar risk/benefit ratio has not been assessed for breast augmentation with implants or the other procedures included in the 2015 guidelines (See the appendix *Knowledge base with methods description*). Based on this background, the National Board of Health and Welfare has developed a recommendation and decision support for mastectomy procedures for gender dysphoria before the age of 18, but this has not been done for the other surgical procedures included in the 2015 guidelines.

Expected benefits of mastectomy

Mastectomy is often the first and sometimes only surgical procedure that people registered female at birth choose to undergo. The expected benefits of mastectomy are improved quality of life in terms of reduced personal suffering (gender dysphoria), increased ability to participate in social contexts and activities, and an increased ability to be perceived by others in accordance with one's gender identity. A qualitative study [107] found that for young trans-masculine people, breasts evoke strong negative emotions such as depression, anxiety, shame, and self-loathing. The dysphoria leads to avoidance of social contexts, can cause difficulties in carrying out daily activities such as schoolwork and makes it difficult to participate in physical exercise. The option of binding the breasts may enable participation in social contexts but is less effective in sports. Binding can also have negative physical consequences and has not been found to reduce gender dysphoria by itself [74, 107].

[47] Other indications for mastectomy are breast cancer and increased risk of breast cancer.

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Possible side effects and risks of mastectomy

Serious complications that can occur include necrosis of nipples or residual breast tissue. Aesthetic problems such as asymmetries of the chest itself or the nipples may also occur, as well as visible scars that can sometimes widen. General surgical complications such as bleeding and infection may occur.

In the experience of the participating surgeons, the risk that it will not be possible to breastfeed a child after the procedure is high, but the magnitude of the risk varies depending on the surgical method used. Nipple sensation is adversely affected by transplantation and often disappears completely.

Finally, relating to gender dysphoria, there is a risk that the person may later wish to reverse the effects of the treatment, for example because of a change in their perception of their gender identity [3], and that this is not deemed possible to prioritize or to implement properly by the health care system. The feasibility of reversing the effects of mastectomy with breast implants for an individual case can only be predicted once the mastectomy has healed and other medical factors are known. General plastic surgical considerations are that previous scarring of skin in the surgical area, poorer tissue quality, and the risk of tissue deficit together impair the chances of successful tissue expansion. Reduced and displaced nipples will usually not be able to be repositioned without a further tissue deficit, which adversely affects the shape of the breasts. All in all, this makes it very difficult to achieve a good result with implants after mastectomy with nipple grafting.

Recommendation

> Mastectomy for adolescents with gender dysphoria should be carried out within the framework of research. Until a research study with ethically tested inclusion and treatment criteria is established, the National Board of Health and Welfare's assessment is that mastectomy can be offered in exceptional cases, for adolescents who meet the updated guidelines criteria for gender-affirming hormone treatment.

Reasons for the recommendation

At present, no definitive conclusions can be drawn about the efficacy and safety of mastectomy for young people with gender dysphoria based on existing scientific studies. For further information, see *Knowledge base with methods description.*

For the population of adolescents with gender dysphoria as a whole, the National Board of Health and Welfare currently deems that the risks of mastectomy are likely

to outweigh the benefits of the procedure. The basis for this assessment is presented in the introduction to this section.

The basis for the recommendation to offer mastectomy before age 18 in the context of research is the need to improve knowledge about the outcomes of treatment. Given the new knowledge and uncertainties described in previous sections, there is also a need to ensure that all relevant information is communicated to guardians and young people, and that consent is obtained before treatment is provided.

The basis for the decision support criteria is the evidence-based knowledge documented in scientific publications of the "Dutch protocol" [5, 6, 108, 109], the clinical experience of participating experts, and ethical considerations. See the separate appendix *Knowledge-base with methods description*. The documented, step-by-step approach of the Dutch protocol - where puberty-suppressing treatment, gender-affirming hormones and surgical interventions have been offered to adolescents according to clearly described criteria and where follow-up over time is documented - represents the best available knowledge and should therefore be used.

As for testosterone treatment more generally, according to the experience of the experts involved, it has relatively little impact on the plastic surgery outcome of mastectomy. However, according to the participating experts, it cannot be excluded that a period of hormone treatment for people with small to medium-sized breasts may reduce breast volume sufficiently to allow mastectomy to be performed in a way that leaves less scarring. Another reason for waiting until the testosterone has had time to take effect is to allow the person to adjust to the changes brought about by the hormone treatment. These conditions are highly variable and the benefit of waiting needs to be weighed against the suffering caused to the individual when the effects of hormone treatment become noticeable, and the breasts are difficult to conceal.

Adolescents who meet the criteria for hormone therapy but are unable to start it for any reason also need to be offered mastectomy if the other conditions are met.

Decision support - guidance on treatment decisions

Criteria to consider relating to the adolescent

- Basic prerequisites for thorough diagnostic evaluation, multidisciplinary decision, consent from guardians, provision of information, and risk/benefit assessment have been met. Clarifications on multidisciplinary assessment and information provision specific to mastectomy are provided at the end of the section.
- The adolescent has clear suffering linked to the breasts.

- The adolescent meets the guidelines criteria for gender-affirming hormone treatment (See *Gender-affirming hormone treatment - decision support*).
- In order to prevent the remaining mammary gland from growing and requiring a secondary operation, it is desirable that breast development is completed at the time of the mastectomy.

Criteria relating to the process

- The plastic surgeon has made sure that the adolescent has understood what the procedure entails and has realistic expectations of the results. As part of this, the surgeon has shown images of post-mastectomy surgical results in which the physical conditions match those of the patient as closely as possible, and which include both good and suboptimal results.
- In accordance with general plastic surgery considerations in public health, a BMI ≤ 30 and non-smoking before the procedure is recommended, to reduce the risk of complications during the healing process and for optimal plastic surgery outcomes. When justified, weight loss and smoking cessation have been supported prior to surgery.
- If the medical history has revealed risk for heritable breast cancer, the adolescent has been informed that the risk is not completely eliminated after the procedure, and that self-examination for breast cancer can sometimes be made more difficult due to scarring. In cases of a strongly increased risk of breast cancer, an in-depth oncological assessment is needed. The mastectomy will then be more complete than is usual in cases of gender dysphoria and is performed generally in the same way as a prophylactic mastectomy for cis-women.[48]

Physical health considerations and possible contraindications

- bleeding disorders, obesity, and smoking
- ongoing pregnancy or attempt to become pregnant
- other serious illness that increases the risk of complications
- medical conditions that pose an increased risk during surgery/anesthesia.

Multidisciplinary assessment

Unlike the diagnostic and child psychiatric evaluation and the hormonal treatment of gender dysphoria, mastectomy is not included among the care measures defined as

[48] The current version of *Good Care of Adults with Gender Dysphoria* (2015) recommends general breast cancer screening only for people registered female at birth who have intact breasts (pp 80–81).

national highly specialized care, but shall remain with the regions.[49] Forms of collaboration between the national units and surgical units in the home regions need to be developed to allow multidisciplinary assessments for this intervention for both adolescents and adults with gender dysphoria—a process that to date has often been lacking, according to participating surgeons. Continuity of contact, where surgeons and teams familiarize themselves with one another's assessments, is described as crucial to building a trusting, collegial network where indications and specific patients may be discussed.

For example, private health care providers who receive a request to perform mastectomy must assess whether the desired operation is part of a gender-affirming treatment (and thus is to be considered as healthcare with the relevant regulation in HSL, PSL, PL), [xix] or whether it is desired for purely aesthetic reasons. In the latter case, the procedure is instead regulated by the act (2021:363) on aesthetic surgical procedures and aesthetic injection treatments and is then not allowed before age 18. However, even in such a case, other requirements apply, including the requirements in the HSL[xx] that the procedure must be conducted in such a way that the requirements of Good Care are met and that the PSL[xxi] apply (see §§ 5 and 6). Based on the requirement in Section 6, Section 1 PSL that healthcare personnel must perform their work in accordance with science and proven experience, and that a patient must be given expert and caring treatment that meets these requirements, it is very reasonable that private health care providers who have not examined the patient themselves consult the evaluation team in order to decide whether mastectomy should be offered as part of gender-affirming care.[50]

Information that enables an informed decision

Provisions describing the healthcare system's information obligations may be found in Section 3 of the Patient Act. The person providing the information must, to the extent possible, ensure that the recipient has understood the content and significance of the information provided (Section 3, Section 7 of the Patient Act). When the patient is a child, the child's guardians must also be informed.[51] See also the corresponding text section in the section on *Hormonal treatment for gender dysphoria in adolescents*.

The adolescent needs to be informed about the operation with sufficient time to be able to consider and reflect on it. It is important that there is enough time for the discussion with the plastic surgeon. This may also mean that the information

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[49] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/nationell-hogspecialiserad-vard-konsdysfori-beslut.pdf

[50] Please note that there may be rules about confidentiality and secrecy that must be considered here.

[51] Chapter 3, Section 3 of the Patient Act.

sometimes needs to be given on repeated occasions. At the consultation, the adolescent and guardians are given information about:

- different surgical techniques in relation to the adolescent's individual characteristics
- advantages and disadvantages of each technique
- typical risks and potential complications of the different techniques.

At this consultation, it is also important to discuss the operation itself and give the adolescent the opportunity to ask questions and discuss aftercare in detail.

As young adults sometimes detransition and wish to reverse the effects of the operation [3], surgeons also need to clarify that it is not possible to determine in advance what the medical conditions for restoring the effects of mastectomy with breast implants will be in an individual patient's case, and whether such surgery will be offered to the individual as part of public healthcare.

Sexual and reproductive health

Sexual and reproductive health is a state of physical, emotional, psychological, and social well-being in relation to all aspects of sexuality and reproduction, and not merely the absence of disease, dysfunction, or injury [110].

Discussions about sexuality take place in several situations during the evaluation of adolescents with gender dysphoria; for example, in connection with exploring gender identity and while providing information about how treatment with sex hormones can affect issues such as sexual desire. An adolescent who is about to start hormonal treatment should also be informed about how the treatment may affect their chances of becoming a genetic parent in the future (See also *Hormonal treatment for gender dysphoria in adolescents*).

In addition, adolescent may have their own needs for sexology counselling, depending in part on their level of maturity and whether they have begun to engage in sexual relations. Some adolescents feel comfortable discussing their sexuality with others. Others do not, which is important to respect. The treating professional needs to be open to discussing sexology issues without forcing the adolescent to talk about them.

Sexology counseling and treatment

Adolescents with gender dysphoria may need to discuss their sexuality with a professional, such as a sexologist or other person with sexology competence. As with other adolescents, there is a wide range of sexual identities, sexual practices, and sexual problems among adolescents with gender dysphoria. Issues of sexuality specific to people with gender dysphoria may include management of gender dysphoria in a sexual relationship and changes in sexual orientation or sexual preferences as part of the exploration of gender identity. Other examples of topics to be addressed in sexology counselling and treatment may include:

- relationships and emotions
- violence and sexual abuse
- what characterizes good romantic or sexual relationships, such as being affirmed in one's gender identity
- sexual dysfunction
- how unwanted pregnancy can be prevented
- that hormonal contraceptives may be a treatment option for people who primarily experience menstruation dysphoria
- that cross-sex hormone treatment is not a safe contraceptive method
- how to prevent the transmission of HIV and other sexually transmitted diseases
- information about HPV vaccination.

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Adolescents who are about to start or have started hormonal treatment may need to discuss the effects this may have on sexual function and desire. The biological changes brought about by the treatment may require support around the ability to feel pleasure and to enjoy sexuality.

Discussing sexuality and sexology issues with adolescents with gender dysphoria places special demands on professionals. It is essential to use respectful and inclusive language based on the terms preferred by the adolescent if there are such preferences, or to suggest alternatives if the adolescent feels uncomfortable with traditional expressions.

When working with adolescents, it is particularly important that the professional shows sensitivity to and has competence in responding to experiences of sexual vulnerability, which may be more common among transgender people than among Swedish adolescents in general [33].

If sexology expertise is lacking within the team, or if these issues are not given sufficient attention during the evaluation or gender-affirming treatment, the adolescent should be referred to alternative care services, such as a sex and sexuality clinic with specific expertise in dealing with people with gender dysphoria. This may also offer the possibility of a gynecological or andrological check-up and testing, the procedures that require a special approach from the treating provider. Local youth centers may also have staff with sexology expertise. In larger towns, there may be clinics that work specifically with people who have had sex for compensation or who have lived with other forms of sexual vulnerability.

Recommendation

Healthcare services should offer sexology counselling and treatment to adolescents with gender dysphoria.

Reasons for the recommendation

According to the National Board of Health and Welfare's recommendation, the healthcare system should offer individualized sexology counselling and treatment to adolescents with gender dysphoria who want it. Such counselling or treatment should be adapted over time and take into account the unique social and medical conditions of the adolescent.

The scientific evidence is insufficient to assess the efficacy and safety of the measure. According to the experience of the participating experts, the measure contributes to an improved quality of life while not entailing any direct risks.

It is important that the counselor is a professional with specialist knowledge in the field. Where possible, counselling should be provided by the evaluation or treatment team. Otherwise, the adolescent should be referred to clinics and practitioners with experience and knowledge of the issues involved and of gender dysphoria. The local youth center is often a valuable resource in this context. In larger towns, there are sometimes clinics that work specifically with people who are or have been sexually vulnerable.

Fertility preservation measures

Fertility preservation is offered to people at risk of fertility problems related to medical treatment. These are usually various cancer treatments but also include other treatments, such as gender-affirming hormonal treatment for gender dysphoria.

In the section *Hormonal treatment for gender dysphoria in adolescents*, it is stated that one criterion for offering GnRH analogue is that the adolescent and guardian have been informed about the possibilities, limitations, and uncertainties of fertility preservation (See below *Fertility preservation that may be relevant for adolescents*). In order to offer gender-affirming hormone treatment with testosterone or estrogen to adolescents with gender dysphoria, the following criteria related to fertility should be met:

- The adolescent and the guardians are aware of the risk that reproductive capacity may be negatively affected by the treatment, and of the conditions for the procurement of gametes for freezing.
- The adolescent understands that fertility preservation is not a guarantee of becoming a genetic parent in the future.
- Where fertility preservation measures are possible, the adolescent has been offered such measures.

Information that enables an informed decision

According to the Patient Act, a patient must be given information about aspects such as their state of health, the methods available for evaluation, care and treatment, the expected course of care and treatment, significant risks of complications and side effects, aftercare, and methods of preventing illness or injury. When the patient is a child, the information must also be given to the child's guardians.

It is, therefore, important that adolescents with gender dysphoria and their caregivers are informed and counseled about the impact of puberty blockers and cross-sex hormones on the adolescent's future fertility before initiating hormone treatment. That also includes information about the possibilities and current limitations of healthcare services to help people become genetic parents.

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Impact of GnRH analogue treatment on fertility

Available treatment studies and clinical experience suggest that menstruation in girls treated with *central precocious puberty* (CPP i.e., puberty onset before 8 years of age in girls and before 9 years of age in boys) returns on average one year after GnRH analogue treatment is discontinued but may take as long as two years. Longer time to menstruation at discontinuation or after completion of treatment can be expected if treatment is started before menarche has occurred [95]. The few existing small studies of boys with CPP suggest that testosterone levels and testicular volume is recovered one year after completion of treatment, and that full pubertal development is attained by the late teenage years [96].

Impact on fertility of treatment with gender-affirming hormone

In adolescent and adults, sperm quality (e.g., number, motility) seems to be negatively affected by cross-sex hormone treatment [98-100, 111]. A 2021 Swedish study also shows that sperm quality in trans women who have received gender-affirming hormone treatment is worse than in trans women who have not received such therapy [112].

Suspension of hormone treatment seems to be able to restore sperm quality, but there is no clear evidence to say how long the suspension should be. Based on the fact that the formation of mature sperm in spermatogenesis in cis men takes about three months, a systematic review suggests this as the minimum-time limit for the interruption of cross-sex hormone therapy, in order to avoid adverse effects [100].

Furthermore, cross-sex hormone treatment with testosterone seems to have a negative impact on egg follicle maturation [111]. The length of time before menstruation returns after cessation of testosterone treatment appears to vary [99, 100]. The extent to which the effect of testosterone on reproductive organs and function is reversible or irreversible is unclear in the current state of knowledge, although there are self-reported cases where the effect appears to be reversible. However, information from longer-term follow-up is lacking [113].

Fertility preservation measures that may be relevant for young people

Fertility preservation in the context of gender-affirming hormone treatment is described in several systematic reviews [98-100, 111, 113], for further information see the separate appendix *Knowledge base with methods description*. It concerns different ways of obtaining and preserving gametes for possible future use in assisted conception. These procedures may also be relevant for young people.

For young people treated with GnRH analogues in early puberty, there are clear difficulties in offering fertility preservation, especially for those registered female at birth who have not yet had menarche [98-100]. According to the experts involved in the development of the guidelines, there are often both psychological and physiological difficulties for young people registered male at birth to produce semen samples for freezing.

Even when gametes can be procured, other conditions need to be in place later to achieve a pregnancy, such as a partner and/or a donor of opposite gametes, and access to various assisted conception methods. Retrieved gametes must be fertilized, an embryo created and developed and successfully implanted in the uterus. Assisted conception also involves legal provisions that may have an impact on the possibility of using procured gametes in practice (See separate section below). There is no guarantee that a person who has undergone fertility preservation treatment will be able to become a genetic parent in the future.

Sperm retrieval in the context of gender-affirming hormone treatment

For persons registered male at birth, sperm freezing is the most established fertility preservation measure [98-100, 111, 113] and may also be relevant for young people in the context of gender-affirming hormone treatment. A basic prerequisite for the possibility of sperm freezing is that the person has reached puberty and, normally, that the person is able to provide a sperm sample through masturbation [98-100].

Sperm can be preserved and frozen before, during, or after a certain period of suspension of treatment with cross-sex hormones [100, 111, 112]. A suspension of gender-affirming treatment may however produce undesirable masculinizing effects [100]. For young transwomen, there may be concerns about having to pause the gender-affirming treatment as well as psychological barriers to masturbating to produce sperm [98].

Egg retrieval in the context of gender-affirming hormone treatment

For people registered female at birth, it is possible to retrieve and freeze unfertilized eggs for possible later use in assisted conception. This may also be relevant for teenagers (after menarche) in the context of gender-affirming hormone treatment.

For example, freezing unfertilized eggs can be done in women who have cancer and where treatment could be harmful to the ovaries and eggs, or due to gender-affirming treatment. In Sweden to date, there have been relatively few unfertilized eggs that were frozen, and later thawed, fertilized, and transferred (in 2019, there were about 100 embryo retransfers, of which a dozen resulted in birth) [114]. According to a 2019 Swedish study [115], the trend among teenagers offered fertility preservation

for various medical reasons is that increasing numbers are opting for egg retrieval and freezing.

The egg retrieval procedure is an established practice for cis-women undergoing in vitro fertilization (IVF). The treatment is demanding, including stimulation with hormones, transvaginal ultrasound, and transvaginal retrieval of eggs from the ovaries. The treatment can potentially be perceived as even more challenging in trans men, and it may reinforce gender dysphoria [100, 116]. The same may be true for people with non-binary gender identity.

Egg retrieval can take place before testosterone treatment, or after a certain period of time off from the treatment [98-100, 111, 113]. However, a break in ongoing testosterone treatment may contribute to increased gender dysphoria in trans men, so early egg retrieval before starting any cross-sex hormone treatment may be preferable [111].

One option to discuss with young people registered female at birth before the initiation of gender-affirming hormone therapy, is the possibility of suspending testosterone treatment later in life in order to go through pregnancy. Trans men can potentially choose to undergo pregnancy either before or after testosterone treatment [99, 100].

Experiences of hormonal stimulation and egg retrieval among trans men

In a 2017 Swedish study [116], 15 trans men aged 19-35 years were interviewed about experiences of fertility preservation (hormonal stimulation and extraction of eggs for freezing). For people who needed to interrupt their testosterone treatment, this could be seen as draining and mentally stressful, as they felt, among other things, that their bodies became more feminine and their voices higher. People who experienced menstrual bleeding after discontinuing testosterone treatment found this to be one of the most difficult parts of fertility treatment, as the bleeding reminded them of something they did not want to be a part of (the gender they had left behind). A majority of the study participants reported that hormonal fertility treatment made them feel less comfortable with their bodies and that the treatment increased their gender dysphoria. Gynecological examinations, especially with transvaginal ultrasound, were perceived as uncomfortable situations because people felt that they were presenting themselves to others as women. The use of the wrong pronouns by the healthcare staff in this situation, referring to them as women, and the mention of gender-specific words such as egg and vagina were also perceived negatively. The same study also described different strategies that participants used to cope with the treatment, such as focusing on the purpose (i.e., the possibility of having genetic children in the future) and getting support from relatives during the treatment [116].

Legal conditions

Gametes (both eggs and sperm) can be frozen and stored for later use in fertility treatment (assisted reproduction). However, assisted fertilization can only be carried out in the Swedish healthcare system when the legal conditions for it are met. Assisted fertilization is regulated in Section 6 (insemination) and Section 7 (in vitro fertilization) of the Genetic Integrity Act (2006:351) and the National Board of Health and Welfare's regulations and general advice (SOSFS 2009:32) on the use of tissues and cells in healthcare and clinical research. There is no regulation stating how long unfertilized eggs or sperm may be kept frozen.

Since January 1, 2019, assisted fertilization with double donation is also allowed in Sweden, which means that both eggs and sperm are donated to the same recipient.

Recommendation

> Healthcare services should offer fertility preservation procedures to adolescents with gender dysphoria who are to undergo treatment that may adversely affect fertility, whenever possible based on the individual circumstances of the adolescent. This is provided on the condition that the young person requests these procedures after having received information on the impact of the treatment on fertility, its possibilities, and limitations.

Reasons for the recommendation

The procedure is primarily justified by ethical considerations and should be seen as part of providing equitable care to all patient groups undergoing treatment that may adversely affect fertility.

The scientific evidence is insufficient to assess the impact of fertility preservation procedures in terms of the rate of pregnancies or births, when offered to adolescents with gender dysphoria. However, egg and sperm retrieval for assisted fertilization is an established practice in other patient populations and can be expected to offer the possibility of genetic parenthood for people being treated for gender dysphoria as well. For further information, see the separate appendix *Knowledge base with methods description*.

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Voice and communication treatment

Voice and modes of communication play a central role in how people's gender expressions are perceived. For adolescents with gender dysphoria, the voice can be a factor that makes it more difficult to be perceived in accordance with their gender identities. This can cause great distress and lead to reduced quality of life [117]. The voice sending the wrong message about gender identity and/or creating uncertainty about how others perceive an individual can lead to anxiety, insecurity, and avoidance of speaking in different contexts. Therefore, adolescents with gender dysphoria may need help to adapt and develop their voices to match their gender identities.

The needs and goals of voice and communication treatment vary between individuals. Some aim to develop their voice and communication in a feminizing or masculinizing direction to the full extent possible, while others, for example those with a non-binary gender identity, may aim to be perceived as more gender-neutral.

Considerations during evaluation and treatment

The overall goals of gender-affirming voice treatment are to reduce adolescents' voice dysphoria, enable them to speak in a way they feel is comfortable, use their voices in the situations they choose and are able to use a favorable voice technique that does not fatigue the voice.

Pretreatment assessment includes taking a history and mapping the person's voice, speech, and communication. Voice and speech are recorded according to a standardized procedure and then analyzed perceptually (via listener assessment) and acoustically. Self-assessment questionnaires are used to document the person's subjective perception of their voice, how it works and any voice problems. Individual, realistic, and relevant treatment goals are established with the person based on their needs and circumstances. When indicated, the speech therapist may refer the patient to a voice specialist for vocal cord testing.

Speech therapy is not provided until the adolescent has been assessed and diagnosed with gender dysphoria. In cases where the diagnosis is not established but is preliminary, referrals may be made by the assessment team to a speech therapist, who will then meet with the person for information and counseling. It is desirable that adolescents registered female at birth are in contact with a speech therapist before starting testosterone treatment for information and documentation of voice [118].

Speech therapists who assess and treat people with gender dysphoria should, according to Swedish experts in the field, have at least two years of experience in speech therapy and documented competence in the field of gender dysphoria [119, 120].

Speech therapy

Speech therapy for people with gender dysphoria aims to help the person achieve a voice that better corresponds to their gender identity and to prevent and reduce voice problems. Treatment goals include several aspects such as changes in vocal pitch, resonance/voice tone, intonation/ melodic phrasing, and articulation [121-125]. Indications for speech therapy are:

- When the voice of trans people registered male at birth, who want the voice to be perceived in accordance with their gender identity, is perceived as too low and the voice tone/resonance too dark. The person may also have difficulty adjusting other aspects of voice and communication. In some cases, the person already speaks in a higher/more feminine voice, but the lower/deeper voice is temporarily noticeable, e.g., raspy, or coarse when coughing or laughing.
- When the voice of a trans person who was registered female at birth and wants the voice to be perceived in accordance with the gender identity is perceived as too high-pitched and the voice tone/resonance too bright. The person may also have difficulty adjusting other aspects of voice and communication. In the case of cross-sex hormone treatment with testosterone, vocal pitch lowers. Other aspects such as resonance, intonation, and articulation are not affected. In cases where the effect on voice is not sufficient, or a person is not treated with testosterone, or a person needs support to change resonance/intonation/articulation, gender-affirming voice treatment is an option.
- When people (both transgender people registered female at birth and transgender people registered male at birth) find it tiring to use their voice in the desired way and symptoms such as voice fatigue (so-called phonasthenia) occur. The voice may sound tense, hoarse, weak, unstable, and pressured.

Content, format, and duration of the treatment

There is no standardized model for the design of gender-affirming speech therapy, but several techniques and programs have been described for adults [121-125]. Speech therapy for adolescents addresses the same aspects of voice, speech, and communication as for adults. Treatment goals are primarily concerned with changing the tone of voice, but this is not enough to make a voice consistent with gender identity. Other variables also need to be changed, such as resonance/voice tone, vocal strength, intonation/sentence melody, and articulation.

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Vocal pitch depends on the rate of oscillation of the vocal cords, which gives the pitch frequency, and is measured in Hertz (Hz). An adult cis-man speaks in a vocal pitch averaging 116 Hz (+/- 15 Hz) and an adult cis-woman 188 Hz (+/-20 Hz) during reading [126]. Studies have shown that individuals registered male at birth need to raise their voice pitch to about 160 Hz for the voice to be perceived by others as a woman speaking [127].

Gender-affirming voice therapy is usually done on an individual basis and can consist of a single visit with counselling or a longer period of treatment. Shorter treatment periods may be appropriate when the person has only phonesthetic [voice fatigue] problems.

All or part of the treatment can take place via digital meetings. Group treatment may also be appropriate, usually after an initial period of individual treatment. The frequency and duration of treatment, as well as the design and goals of the treatment, are determined by the needs, circumstances, and motivation of the adolescent. A treatment period is rarely longer than the number of treatment sessions described below.

- For adolescents registered male at birth who have received GnRH analogue treatment, pubertal development in the masculine direction is halted. GnRH analogue thus prevents masculinization of the voice. In general, less adaptation of the voice is required among these adolescents. For those who have undergone a voice break and wish their voice to be consistent with their gender identity, voice treatment is often needed on a regular basis over a longer period of time, with about 10-15 treatment sessions.
- For adolescents registered gender female at birth who wish their voice to be consistent with their gender identity and who are not treated with testosterone, or where the effect of testosterone is not perceived as sufficient, voice therapy is often recommended on a regular basis with about 5-10 treatment sessions. Gender-affirming speech therapy cannot replace the effect of hormone treatment, i.e., it cannot lower the voice as much as testosterone treatment.
- For adolescents (both adolescents registered male and those registered female at birth) who are satisfied with the gender expression of their voice, but who need treatment for other voice problems, a shorter treatment period of about five treatment sessions is offered. This may be the case, for example, when adolescents registered female at birth develop problems such as hoarseness, unstable voice, or difficulty increasing vocal strength during testosterone treatment [128], or adolescents registered male at birth who have developed their voice on their own so that they are satisfied with their gender expression but become hoarse and vocally fatigued when they speak.

In all cases, adolescents are required to practice on their own between sessions with a speech therapist.

Follow-up

Follow-up takes place six months after the end of the speech therapy, and thereafter as needed.

Persons registered female at birth undergoing testosterone therapy are followed for up six to twelve months after starting hormone treatment [128].

Recommendation

> Adolescents with a preliminary or confirmed diagnosis of gender dysphoria speech therapy should be offered a consultation with a speech therapist, and, if necessary, healthcare services should provide gender-affirming speech therapy treatment.

Reasons for the recommendation

A voice that is perceived as too masculine or feminine for the person to be perceived in accordance with their gender identity causes great suffering and a reduction in quality of life. Furthermore, issues related to phonasthenia [voice fatigue] can occur when the voice is used to reflect the gender identity. In these cases, healthcare services should offer a consultation with a speech therapist and, if necessary, provide speech therapy to adolescents with a preliminary or confirmed diagnosis of gender dysphoria. The condition may have been coded as F64.0, F64.8 or F64.9 according to ICD-10.

The scientific evidence is insufficient to assess the efficacy and safety of this intervention. In the experience of the participating experts, this intervention contributes to a better correspondence between vocal pitch and tone and gender identity and thus to a reduction in gender dysphoria, a reduction in vocal strain, and an improvement in quality of life, while posing no direct risks.

The effects of the treatment are reversible and the risk of phonasthenia is considered less than when people try to change their voices on their own. For further information, see the separate appendix *Knowledge base with methods description*.

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Hair Removal

For adolescents with gender dysphoria registered male at birth, facial and other visible body hair can make it difficult to be perceived by others in accordance with their gender identity. It may therefore be important to get help to remove such hair permanently where possible.

Light- and needle-based hair removal methods

Today, two main methods are used to permanently reduce unwanted body hair. These are:

- Light-based methods (photoepilation): intense pulsed light (IPL) and laser.
- Needle-based methods: electrolysis, diathermy, and blending.

The goal of these hair removal methods is to destroy the hair follicles that produce unwanted hair and thus achieve permanent hairlessness. All hair follicles produce hair in cycles of growth and inactivity. Only hair follicles in the growth phase are susceptible to the damage attempted by the various hair removal methods. One course of treatment will therefore at most be able to destroy a proportion of the patient's unwanted hairs. The time between treatments depends on the length of the growth phase in the skin area in question. In clinical experience, between 5 to 10 regular treatments at least 4 to 8 weeks apart are usually required to reach all hair follicles in the treated area. The hairs that remain in the treatment area may sometimes be perceived as lighter and thinner.

Both light- and needle-based methods require a practitioner with sufficient skills and experience. This is especially true for needle epilation, which requires great craftsmanship to target the hair follicle correctly. Requirements for qualifications and professional competence of the practitioner of IPL and laser treatments are set out in the standard for aesthetic medical services[52].

Light-based methods - IPL and laser

Light-based hair removal means that the practitioner selects a wavelength of light that rapidly heats and destroys the pigment (melanin) present in the hair without affecting surrounding tissue (selective photothermolysis). Photoepilation can be done with IPL or with lasers of different wavelengths (alexandrite lasers, diode lasers, Nd:YAG

[52] 7 Standard SS-EN 16844:2017 Aesthetic medical services - Non-surgical medical procedures

lasers and ruby lasers). IPL uses a spectrum of light, while lasers use a specific wavelength. The practitioner chooses the IPL or laser and settings that are appropriate based on the patient's individual characteristics such as skin color, hair color, and hair thickness. In addition to the choice of laser type, parameters such as treatment area, pulse length, total energy, and type of cooling vary between devices and can be set manually according to the patient's individual circumstances.

With light-based methods, relatively large areas of skin can be treated in a short time. The handpiece of the device is moved over the entire area where the hair is to be removed.

Needle-based methods - electrolysis, diathermy, and blending

Needle epilation electrolysis involves inserting a thin current-carrying needle into the hair follicle for a few minutes, causing a chemical reaction and damaging the follicle. The main disadvantage is that it is a slow method; the needle has to stay in the hair follicle for a long time, sometimes several minutes, and the treatment can be painful. Often several needles are used at the same time to speed up the process.

Diathermy needle aspiration [thermolysis] involves heating body tissue with a high frequency alternating current. The practitioner inserts a current-carrying needle into the hair follicle, turns on the current and pulls out the hair with tweezers. It is a faster method than electrolysis, but with a greater risk of scarring and pigmentation.

All variants of needle epilation are relatively slow because they treat each hair individually. A common way to make electrolysis treatment faster is to mix the technique with diathermy. The treatment is called a blend and combines the efficiency of electrolysis with the speed of diathermy.

Recommendation

> Healthcare services should offer removal of hair from the face and neck, front and back of the trunk, arms, and hands to adolescents with gender dysphoria and registered male at birth, using light or needle-based methods depending on the individual's circumstances.

Reasons for the recommendation

When individuals registered male at birth have body hair that is considered to be too masculine for the individual to be perceived in accordance with one’s gender identity, it causes great suffering and reduced quality of life. In these cases, healthcare services

should offer hair removal with methods aiming at permanent hairlessness on the face and upper body (neck, front and back of the trunk, arms, and hands).

There are a limited number of controlled studies investigating the efficacy and safety of light-based and needle-based methods in comparison to no treatment, placebo, or temporary hair removal methods (e.g., shaving, plucking). The results suggest that laser treatment can reduce hair growth by up to about 50 percentage points in the short term, up to six months after completion of treatment. The results are considered to have low reliability. Other effects cannot be assessed based on the evidence, i.e., effects of laser treatment on hair growth in the long term, effects of IPL and needle-based treatment on hair growth in the short and long term, and the effects on mental health and quality of life (all methods). For further information, see the separate appendix *Knowledge base with methods description.*

According to clinical experience, light and needle-based methods provide a reduction in hair growth that is more pronounced and more lasting than other methods. In the experience of the participating experts, this intervention contributes to a reduction in dysphoria, greater opportunities for the person to be perceived in accordance with gender identity and to improved quality of life. The most common side effects for both light- and needle-based methods are mild and transient, such as pigmentation, skin redness, and swelling. Structural skin changes occur less frequently and can in rare cases become permanent. For further information, see the separate appendix *Knowledge base with methods description*.

A basic prerequisite is that the method and its implementation are adapted to the individual's circumstances. For this to be possible, both light and needle-based methods must be available at the clinics where hair removal is performed.[53]

Considerations during treatment

For people who produce androgens, it takes longer to reduce the hair coverage sufficiently in hormone-sensitive areas. It is therefore advantageous if hormone therapy with estrogen and anti-androgens (alternatively with GnRH analogue for adolescents) has been initiated before hair removal is started.

Following careful assessment of the person's conditions, the healthcare service can offer light-based or needle-based methods or a combination of these methods. To the extent appropriate in the individual case, the patient should be offered light-based methods as these are more accessible and more time- and cost-efficient than needle-

[53] Hair removal is not included among the care measures defined as national highly specialized care and will continue to be the responsibility of the regions.

based methods (See description of implementation above). To be able to remove hair using IPL or laser, it is necessary that:

- the patient has melanin in their hair follicles. Red, gray, or white hair does not respond to light-based treatment, so needle epilation needs to be used in these cases.
- the patient has less pigment in the skin than in the hair follicles. Individuals with darker, more pigmented skin are more likely to suffer from pain, pigment disturbances, and blistering of the skin when hair is treated with light-based methods.
- the dose is high enough, the practitioner has chosen the correct pulse length, there is a large treatment area, and there is adequate cooling of the skin.

Expected degree of hair removal and follow-up treatment

The aim of hair removal is to remove as much hair as possible. Hair growth can vary on different parts of the body during different periods of life. For example, hair growth on the chest and back of people registered male at birth tends to increase up to middle age. Thus, even under optimal conditions, it may be difficult to permanently maintain the achieved hairlessness.

Ongoing interventions to maintain treatment results varies between individuals and depends on the degree of biological maturity reached by the individual. After completion of treatment, there may be a need for one to several treatments per year. If an individual who had not reached full biological maturity at the time of previous treatment experiences the emergence of new hair follicles that started to produce hair in previously treated areas, more treatments may be needed.

This document is an unofficial English translation of a document prepared in Swedish.

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Translator's Notes

[i] [Translator's note: Healthcare in Sweden is decentralized – responsibility lies with the regional councils and, in some cases, local councils or municipal governments. The role of the central government is to establish principles and guidelines, and to set the policy agenda for health and medical care. The National Board of Health and Welfare (Socialstyrelsen) is a government agency under the Ministry of Health and Social Affairs that compiles information and develops standards to ensure good health, social welfare and high-quality health and social care for the whole population. The care is delivered though 21 county councils / regions https://sweden.se/life/society/healthcare-in-sweden]

[ii] [Translator's note: The Swedish term "god vård" is literally translated as "good care." This term came into existence in connection with the publication of the National Board of Health and Welfare's regulations on the management system for quality and patient safety (SOSFS 2005:12). Six areas are highlighted as important prerequisites for "good care" including: appropriate healthcare based on the best available knowledge, safe healthcare, patient-focused healthcare, effective healthcare, equitable healthcare, and timely delivery of healthcare. https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2009-11-5.pdf .

[iii] [Translator's note: Appendix 1-3, attached to the Swedish original report, are not included in this translation. They include:

1. Projektorganisation, a list of authors ("organization of the project").

2. Termer och förkortningar, a glossary of terms

3. Förtydliganden av juridiska förutsättningar, "clarifications of legal conditions"]

[iv] [Translator's note: The "knowledge base with methods description" is available at the following link:

https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2022-12-8302-kunskapsunderlag-med-metodbeskrivning.pdf].

[v] [Translator's note: These reports can be found at the following links: https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-1-6579.pdf

https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-1-6580.pdf].

[vi] [Translator's note: The appendix has not been translated.]

[vii] [Translator's note: The separate appendix, *Knowledge base with methods description*, has not been translated. It is available in Swedish at the following link: https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2022-12-8302-kunskapsunderlag-med-metodbeskrivning.pdf]

This document is an unofficial English translation of a document prepared in Swedish.

[viii] [Translator's note: Healthcare in Sweden is decentralized – responsibility lies with the regional councils and, in some cases, local councils or municipal governments. The role of the central government is to establish principles and guidelines, and to set the policy agenda for health and medical care. The National Board of Health and Welfare (Socialstyrelsen) is a government agency under the Ministry of Health and Social Affairs that compiles information and develops standards to ensure good health, social welfare and high-quality health and social care for the whole population. The care is delivered though 21 county councils / regions https://sweden.se/life/society/healthcare-in-sweden]

[ix] [Translator's note: The appendix has not been translated.]

[x] [Translator's note: The guidelines are referring to the difficulty of adjusting their current diagnostic process to the upcoming ICD-11 codes. The Swedish healthcare system has traditionally relied on the "unspecified" ICD-10 code of F64.9 as the provisional gender dysphoria code, pending the evaluation. The goal of the evaluation is to establish whether the person suffers from true gender dysphoria or whether other reasons better explain the experience of gender identity not matching the recorded sex. Patients who are confirmed as having true gender dysphoria (not secondary to other causes) are then assigned either a "binary" diagnostic ICD-10 code of F64.0, or a non-binary diagnostic code ICD-10 code F64.8. The report is pointing out that under the ICD-11 system, the "unspecified" code of HA6Z can no longer serve this provision purpose, complicating coding during assessment process. https://www.socialstyrelsen.se/om-socialstyrelsen/pressrum/press/vanligt-med-flera-psykiatriska-diagnoser-hos-personer-med-konsdysfori/]

[xi] [Translator's note: The concept of "child's integrity" involves physical health and mental health integrity. https://commission.europa.eu/aid-development-cooperation-fundamental-rights/your-rights-eu/know-your-rights/dignity/right-integrity-person_en#:~:text=Everyone%20has%20the%20right%20to,procedures%20laid%20down%20by%20law]

[xii] [Translator's note: See https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/meddelandeblad/2020-12-7117.pdf]

[xiii] [Translator's note: Highly specialized care is defined as care often requiring the most advanced technical equipment. In Sweden, such care is concentrated in university hospitals to ensure high quality and greater efficiency, and to enable research and development. https://www.commonwealthfund.org/international-health-policy-center/countries/sweden]

[xiv] [Translator's note: The Swedish term, "gott bemötande" is literally translated as "good treatment." This concept has a specific meaning in the Swedish healthcare system, the fundamental aspect of which is showing respect and interest in the person's situation. 'Good treatment" means showing personal care, acting on the basis of knowledge and experience, respecting the individual's autonomy and integrity and adopting a professional and humane approach. The goal of "good treatment" is to create trust and security in the provider-patient relationship. https://www.vardochinsats.se/missbruk-och-beroende/kommunikation-och-delaktighet/gott-bemoetande/]

[xv] [Translator's note: "Distorted patient histories" referees to the phenomenon of patients altering their medical history in order to qualify for the treatment.]

[xvi] [Translator's note: There appears to be an error in reference in the Swedish original, incorrectly referring to this report as "I am not alone, there are more like me." The actional name of the report says "I am not alone, there are others like me."]

[xvii] [Translator's note: This reference is to the Swedish Health and Medical Care Act https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30#K2]

[xviii] [Translator's note: the literal transition of the term used in the Swedish original is "logopedics," which refers to the speech therapy https://www.merriam-webster.com/medical/logopedics]

[xix] [Translator's note: "HSL" is the Health and Medical Care Act. "PSL" is the Patient Safety Act. "PL" is the Patient Act https://www.vardhandboken.se/arbetssatt-och-ansvar/ansvar-och-regelverk/patientens-rattsliga-stallning/lagstiftning/]

[xx] [Translator's note: "HSL" is the Health and Medical Care Act.]

[xxi] [Translator's note: "PSL" is the Patient Safety Act.]