

Implementing initiatives to support equitable and knowledge-based healthcare for victims of sexual violence

On 9 March 2023, the National Board of Health and Welfare was given the assignment of implementing initiatives to support equitable and knowledge-based healthcare for victims of sexual violence (Ref. no. 5.7–17179/2023). The assignment included conducting an in-depth survey and analysis of healthcare for victims of sexual abuse and sexual violence and proposing appropriate and cost-effective initiatives for developing care. This also included analysing the need for, and producing, clinical practise guidelines and training initiatives for the healthcare sector as well as analysing the need for a national support function.

The results of the National Board of Health and Welfare's survey and analysis show that care is inequitable across the country and between different groups. Cohesive chains of care do not exist in all regions, which means that patients do not always know what care is available and healthcare staff do not always know where these patients should be referred, especially in the non-acute stage. The survey shows that there is a lack, among other things, of clinical practise guidelines following sexual violence, specialised clinics in all regions, and clarity in the regulation of evidence collection.

The survey also shows that there is a need to make the clinical practise guidelines and training initiatives that already exist more easily accessible to healthcare staff, not least in primary care. The need is particularly great for more knowledge about online sexual violence against children. The National Board of Health and Welfare has therefore produced new clinical practise guidelines that are aimed primarily at staff in student health services and youth clinics. As yet another way to develop care so that it is more appropriate and cost-effective, the Board proposes, in accordance with the EU directive, that a National Knowledge Centre (NKC) be established. According to the EU directive, the member states must designate or establish a public body to be responsible for coordinating, implementing, monitoring and evaluating the measures for preventing and combating all forms of violence covered by this directive.

Our conclusion is that an NKC tasked with disseminating knowledge and information to healthcare professionals, addressing research and

methodological development needs, and strengthening coordination between existing actors can increase the conditions for more equitable, knowledge-based and individualised care in the regions. This would also bring the possibility of addressing the identified needs and improvement proposals described in Report 1. In conclusion, the National Board of Health and Welfare has therefore prepared a cost estimate for the establishment and operation of a national knowledge centre. The Board does not take a position on organisational domicile but presents two possible proposals. The cost estimates may need to be adjusted based on the centre's assignment description, operational content and organisational domicile, but according to the template, an NKC would cost SEK 20 million the first year.

The government assignment is presented in three different parts:

Report 1 – “Survey and in-depth analysis of healthcare for victims of sexual abuse and sexual violence”

In this report, the Board presents the results of a survey and in-depth analysis of care for victims of sexual violence, which consists of:

- Survey of the care of patients treated for sexual violence,
- Description and analysis of the chain of care for children and adults, in both acute and non-acute stages, with a focus on person-centred care and accessibility,
- Description and analysis of knowledge-based care and the need for clinical practise guidelines and training initiatives,
- Description and analysis of collaboration between relevant actors and equability.

Based on these results, proposals have been made for training initiatives and support to develop the care for this patient group. The proposals for training initiatives form the basis for what is drawn up in the clinical practise guidelines that the Board has produced (Report 2 – Supporting equitable and knowledge-based care – Clinical practise guidelines for healthcare staff who encounter victims of sexual violence). The Board also proposes initiatives that the regions can implement to develop care.

Report 2 – Supporting equitable and knowledge-based care – Clinical practise guidelines focused on online sexual violence and on people with harmful substance abuse and addiction who are subjected to sexual violence

Based on the proposals for training initiatives in Report 1, the Board has produced two clinical practise guidelines:

1. Clinical practise guidelines on online sexual violence aimed at healthcare staff in student health services and youth clinics.
2. Clinical practise guidelines for talking to people with harmful substance abuse and addiction and people experiencing homelessness who have been subjected to sexual violence. The clinical practise guidelines are primarily aimed at staff in primary care.

Report 3 – “The need for a national support function that can serve as a knowledge centre (NKC) and provide support for the healthcare sector in matters related to sexual violence – The National Board of Health and Welfare’s assessments and proposals”

In this report, the Board presents the results of analyses on the need for an NKC for healthcare in matters related to sexual violence.

The Board presents its assessments and makes some proposals.

Summary of Report 1 – Survey and in-depth analysis

Survey – Care of patients subjected to sexual violence

Data in the patient register for the 2020–2022 period shows that a total of 6,735 people received care with one of the diagnosis codes linked to sexual violence. In most cases, this concerned care in the acute stage. However, there is a large dark figure in these statistics because many people do not seek care and because the responsible healthcare staff do not always use the relevant diagnosis codes. The vast majority of patients are young women and girls. For patients over age 18, a slight increase in numbers can be seen during the 2020–2022 period. This may be because healthcare staff have become better at registering the codes, because more people are seeking care for sexual violence, or because sexual violence has increased. The majority of the patients were born in Sweden and have a pre-upper-secondary or upper-secondary education. This confirms that it is primarily young victims of sexual violence who seek care in an acute stage. In 2022, Region Kronoberg had the lowest number of people per 100,000 residents with one of the relevant diagnosis codes. Regions Uppsala, Stockholm, Örebro and Västernorrland had the most people. This may be because these regions have clinics for victims of sexual violence. The patient register does not include psychiatric care resulting from sexual violence, but we can monitor the number of people with the relevant codes who were prescribed medication for psychiatric conditions for the first time. The survey does not show any change in this number during the 2020–2022 period. Diagnosis codes linked to sexual violence are set mainly within gynaecological care, obstetrics and gynaecology, paediatrics, hospital admissions and emergency services, emergency clinics, and surgical care. It is thereby likely that the victims turned to these services in the acute situation. Interviewees also confirm that most people who seek care in non-acute stages have complaints such as pain, anxiety and depression, and the visits have therefore not been registered with codes linked to sexual violence.

The chain of care in acute and non-acute stages with regard to person-centred care and accessibility

The chain of care for adults

The analysis shows that the chain of care is deficient in several ways, for example in relation to non-acute treatment. It is also evident that the care offered is not equitable across the country and does not always reach the most vulnerable groups, such as patients subjected to repeated sexual abuse in childhood, human trafficking, aggravated rape or prostitution. The results also show that there are shortcomings in the chain of care for victims of sexual violence. Many people struggle for a long time to be taken seriously and to receive the proper care. Medical care, evidence collection and help coming into contact with a counsellor in the case of “minor trauma” seems in the acute stage to function relatively well in parts of the country. However, psychosocial follow-up and response seem to have potential for improvement, and should be more equitable. Care in the non-acute stage also has major shortcomings and seems to not be adapted to the most vulnerable patients.

Chain of care for children

The chain of care for children seems to function best for those in the acute stage, and who have not developed complex trauma. In some parts of the country, emergency care is reported to function relatively well, especially where there are specialised clinics for rape and for children who have reached the age required to access these. However, specialised clinics do not exist in all regions, and the chain of care is less clear for children seeking non-specialised care or who are too young for the specialised clinics. In most places in Sweden, children who have not reached puberty end up in a paediatric clinic or paediatric surgery. According to our interviewees, there is great variation in reception, knowledge and experience. It is difficult for children and young people (or relatives trying to support them) to know where they can turn for non-acute care needs following sexual violence. Other thresholds to entering care are limited telephone hours and long queues. Non-acute care for children is often fragmented and underdimensioned, and in many places in the country does not exist at all. At present, it is unclear to what extent questions about sexual violence are asked, and what is done to identify children who do not talk about the sexual violence themselves. This needs to be addressed, especially for the children who are particularly vulnerable. There is also a need for more resources and specialist expertise. The compilation provides extremely scant material on the medical follow-up of children. We did not have the opportunity to go into more depth into this part of the chain of care, and there are few studies about care for young children subjected to sexual violence. The results must therefore be interpreted with caution.

Need for clinical practise guidelines and training initiatives

The National Board of Health and Welfare's analysis shows that healthcare professionals should ask questions to identify the patients, who rarely speak about the violence voluntarily. This is not done to a sufficient extent, and healthcare staff need more knowledge about how to identify and treat patients who have been subjected to sexual violence. They also need to know how to handle the information they receive in conversations about sexual violence, and where the patient can be referred if the healthcare staff identifies that they have trauma-related symptoms as a result of sexual violence. There is also a lack of knowledge about sexual violence against children and about gender perspectives. Child and gender perspectives should therefore be included in existing clinical practise guidelines and training initiatives. These training initiatives and clinical practice guidelines should be repackaged with consideration to different groups of patients, such as LGBTQI people, people with disabilities, people with substance abuse or addiction problems, and people experiencing homelessness. Sexual abuse of children that is carried out and spread via the internet can have consequences just as severe as physical assault. Healthcare professionals working with children and young people describe a great need for increased knowledge about online sexual violence. The analysis also shows that there is a need for training about this type of sexual violence, as well as more research on treatment methods for severely traumatised patients with comorbidities, and training on trauma-informed person-centred care for doctors and nurses. Care for victims of sexual violence should be adapted to each individual and situation. This would provide systematically improved symptom assessment, referral, treatment planning, follow-up and care. Furthermore, clinical practise guidelines are needed on different types of tools that support cooperation between relevant actors, such as cooperation between nurses and social services or between emergency medical care and psychiatry. These clinical practise guidelines could be developed within the scope of a new government assignment.

Cooperation

The analysis shows that there are shortcomings in the cooperation between different actors in healthcare for victims of sexual violence, particularly between student health services and social services and between emergency medical care and psychiatry. Both the literature review and the interviews show that cooperation can be of great importance to the work to identify and examine victims of sexual violence. Cooperation and collaboration at the national, regional and municipal levels can also contribute to ensuring equitable care and knowledge dissemination, facilitating care in a non-acute stage, and facilitating police investigations. Cooperation can be formalised

through cooperation agreements to ensure that the parties have common procedures for referring and caring for these patients. The agreements may, for example, specify that regular cooperation meetings be held, and contain routines for the exchange of information, referral procedures, and clarifications of responsibilities.

Inequitable care

The results show that care is not equitable across the country and between different groups. Cohesive chains of care do not exist in all regions, leading to inequitable care in which patients do not know what care is available and healthcare professionals do not know where the patients should be referred. For patients who need something other than emergency care after physical sexual violence, care is often inadequate. Some regions have clinics that specialise primarily in emergency care following sexual violence. In these regions, it is clear for both patients and healthcare staff where the patients should turn in an emergency stage, and there are clear procedures and knowledge concerning response, medical and psychosocial reception, and follow-up. In other regions, it is less clear where one should turn, and these patients are often directed to an emergency ward. Women and transgender people with female genitalia then end up in a gynaecological emergency ward, and men and transgender people with male genitalia in a surgical emergency ward. According to register data for 2020–2022, there were comparatively few boys and men who sought care for being subjected to sexual violence, and among those who sought care, nearly half were born abroad, while the corresponding proportion for women was around one-fifth. This may indicate that men and boys subjected to sexual violence do not seek care and that there may be a large number of unreported cases. Among foreign-born boys and men, the higher number may be due to prostitution and sexual exploitation. Patients subjected to sexual violence sometimes have to endure long waiting times for mental health treatment, and according to interviewees, it is therefore common that they instead turn to non-profit and private actors instead. But not everyone can afford to pay for their mental healthcare themselves, and access to mental healthcare may thus be an income issue.

Summary of Report 2: Clinical practise guidelines focused on online sexual violence and on people with harmful substance abuse and addiction who are subjected to sexual violence

The needs assessment in Report 1 identified the following needs for clinical practise guidelines to make care more knowledge-based and equitable for victims of sexual violence:

- Develop clinical practise guidelines with associated training initiatives on the detection of, and care following, online sexual violence against children and young people aimed at healthcare staff in student health services and youth clinics
- Adapt existing training to the needs of different groups, e.g. LGBTQI people, people with disabilities, people with substance abuse/addiction problems, people experiencing homelessness, and children and young people.
- Package, update and structure the training that already exists, according to content and target group, and make it more easily accessible for healthcare professionals, especially in primary care.

This need for clinical practise guidelines is addressed in the form of the following products:

Need for Clinical Practise Guidelines	Clinical Practise Guidelines Product
Develop clinical practise guidelines with associated training initiatives on the detection of, and care following, online sexual violence against children and young people aimed at healthcare staff in student health services and youth clinics	Brochure aimed at healthcare professionals in student health services and youth clinics; see Appendix 1. Webinar focused on knowledge concerning different aspects of online sexual violence as well as proposals for concrete conversation tools.
Adapt existing training to the needs of different groups, e.g. LGBTQI people, people with disabilities, people with substance abuse/addiction problems, people experiencing homelessness, and children and young people.	Based on a needs analysis, a great need for supplementary clinical practise guidelines was identified, especially for healthcare staff in primary care who encounter people with harmful substance abuse and addiction and people experiencing homelessness.

<p>Package, update and structure the training that already exists, according to content and target group, and make it more easily accessible for healthcare professionals, especially in primary care.</p>	<p>The National Board of Health and Welfare's Communications Department is conducting a revision of the Board's external website "Kunskapsguiden" ("Knowledge Guide") to update and publish clinical practise guidelines and training focused on exposure to violence, including exposure to sexual violence.</p>
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Clinical practise guidelines: Online sexual violence

To increase the detection of online sexual violence, there must be increased knowledge of the phenomenon itself – knowledge that is lacking according to the survey.

The clinical practise guidelines therefore focus on knowledge-raising information on the occurrence of different types of online sexual violence and include perspectives on both victims and perpetrators. Aspects to be considered for treatment purposes are addressed and concrete questionnaires for increasing detection are introduced. Legal aspects of online sexual crimes are also included.

The clinical practise guidelines have been designed in the form of downloadable brochures and are planned to be included in the platform for student health services guidance.

As a training initiative, a webinar will be held in spring 2025 in which the teaching programme SEXIT will be presented as a concrete tool for implementing detection. The webinar will be primarily aimed at staff in student health services and youth clinics.

Clinical practise guidelines: Talking to people with harmful substance abuse and addiction and people experiencing homelessness who have been subjected to sexual violence

The survey describes the need for supplemental clinical practise guidelines focused on people with harmful substance abuse and addiction and who may be experiencing homelessness. Above all, it describes the need to collect and raise awareness of existing knowledge to strengthen the implementation of existing knowledge and thereby increase the detection of exposure to sexual violence in this particularly vulnerable group. The clinical practise guidelines were designed as a supplement to existing training with a focus on the target group's unique needs. Aspects affecting the detection and treatment of sexual violence for this group are addressed. Further, existing quality-assurance measures are linked to these clinical practise guidelines.

The clinical practise guidelines are downloadable discussion and reflection materials that can be used individually but can also be advantageously used in a working group, e.g. at a workplace meeting.

Summary of Report 3 – The need for an NKC – The National Board of Health and Welfare’s assessments and proposals

The National Board of Health and Welfare’s survey and analysis found that there is a clear need for national support for healthcare professionals in matters concerning sexual violence. An overwhelming majority of the persons interviewed and those who responded to the Board’s survey indicate that there is a need to establish an NKC. The main reasons and desired functions for such a centre are summarised here.

The main reasons for the need of an NKC are for it to:

- function as a knowledge hub: to produce, compile and disseminate knowledge in order to reduce differences in how knowledge-based the care is
- conduct research and methodological development, with links to clinical activities to drive advancements
- strengthen the conditions for equitable access to care and individualised care
- offer consultation and expert support for professionals
- take responsibility for cooperation
- develop knowledge on initiatives to prevent sexual violence.

The National Board of Health and Welfare has also taken into consideration a number of criteria that have been set to establish an NKC as well as the European Parliament’s directive on combating gender-related violence and protecting the victims, especially women and victims of domestic violence.

Based on this, the Board finds that there is a need for an NKC that can contribute to victims of sexual violence receiving better care and to Sweden meeting the requirements in the European Parliament’s directive.

Several actors emphasise that an NKC needs to build on the knowledge available among existing actors in the area, complement these, and become a unifying actor. The National Board of Health and Welfare shares this assessment.

Such an NKC can be established in two different ways:

- within the scope of a university or a governmental authority
- as a new, independent NKC.

It is important that an NKC can be cost-effective. The cost is estimated at approximately SEK 19–20 million for start-up and establishment.

The National Board of Health and Welfare assesses that the centre should be tasked with:

- developing and compiling available clinical practise guidelines and disseminating knowledge and information within the healthcare sector
- working with methodological development and research and supporting the implementation of knowledge, with links to clinical practise
- identifying areas for development, including the need for research
- acting as a link between research, practise and decision-makers
- offering consultation to healthcare professionals
- acting as a coordinating national point of contact for matters in the area
- maintaining interdisciplinary cooperation with relevant actors.

Costs

The assignment included conducting an in-depth survey and analysis of healthcare for victims of sexual abuse and sexual violence and proposing appropriate and cost-effective initiatives for developing care. This also included analysing the need for a national support function and analysing the need for developing clinical practise guidelines and training initiatives for healthcare professionals.

Costs for training initiatives depend on the extent of the training and are estimated to vary between SEK 550,000 (PDF with text and images) and SEK 2,350,000 (advanced e-learning). In addition to this, the costs for healthcare staff to complete the training are estimated at between SEK 18.7 million and SEK 56.1 million, depending on the number of people in each staff category who complete the training and the length of the training. The costs for starting up and establishing a national knowledge centre are estimated at around SEK 20 million for the first year and SEK 19 million for the second year.