

Complaint and commentary regarding The Norwegian Healthcare Investigation Board (NHIB) report “Patient safety for children and youth with gender incongruence”. [“Pasientsikkerhet for barn og unge med Kjønnsinkongruens”]

On behalf of FRI - The Norwegian Organization for Sexual and Gender Diversity, POGI - Patient organisation for Gender Incongruence, and Queer Youth, we’re expressing our concern about the report and share our criticisms of selected aspects that we find particularly problematic or lacking.

This is an English summary of the full complaint, which will be made available in Norwegian on our web pages on Monday 15th of May.

Patient safety versus concerned parents

NHIB is an independent government agency whose mandate is to investigate serious adverse events and other serious concerns involving the Norwegian healthcare services. In this instance the instigating event was messages of concern from concerned relatives of persons aged 16-21 that had sought treatment for gender incongruence. The messages questioned the soundness of the treatment, stating a concern that there was no mental health follow up or enough questioning if gender-affirming treatment was the right approach, as well as expressing concern that the parents had not been closely involved in the assessments.

We have several concerns about the entirety of the investigation undertaken by NHIB. From the misrepresented evidence used to justify the recommendations, and a disregard for the soundness and integrity of major actors in the field, to the basis for the investigation and that the recommendations do not appear to address the problems stated. This is further complicated by the fact there has been no information to indicate the nature of the serious adverse events, or indeed if there were any negative consequences to the patients that could be of serious concern. It’s our view that these recommendations will do very little to prevent further incidents, and are instead likely to further reduce access to healthcare and increase othering of trans people. This has already shown itself to be true, as the regional health authorities in western Norway published a [press brief](#) on the 28th of March stating that the new regional services for gender incongruence is suggested to not provide medical care, citing NHIB’s report¹. This is in addition to the growing number of mentions of the report in the media, in attempts to argue against medical care for trans people.

¹ Original text: “I dei regionale sentera er det foreslått av det ikkje skal starte opp medisinsk behandling, berre ikkje- medisinsk behandling og utgreiing.

Children over the age of 16 are competent to make decisions regarding their healthcare in all other contexts, and NHIB fails to reflect over why parental involvement is recommended only as long as it's not damaging to the child. We find it very concerning that NHIB are in this instance helping the facilitation of familial abuse through threats of withdrawal of healthcare by non-supportive parents, even impacting their adult children. The fear that some may regret the treatment they undertake is used to argue that there's growing uncertainty around the efficacy of treatment. The concern is centred on imagined misdiagnosis, leading to treatments that will be regretted. The biggest factor for regret, as far as we know, is non-support from community and family.

Addressing discourse - "parts of current dialog from certain actors is dominated by ideology and an us-versus-them-rhetoric"². The choice to address the fact that current public debate impacts patient safety would be welcomed, were it not for the fact that no solution is suggested. Our organisations have regularly attempted to have reasonable debate only to be ignored, portrayed as being inconsequential or excluded.

Our concerns around the reports recommendations:

Reclassification to experimental treatment:

"NHIB recommends that puberty blocking agents, hormonal treatments and surgical gender-affirming medical treatment of children and young people be defined as experimental treatment. This is especially important for teenagers with gender dysphoria"³

The reclassification of gender-affirming medical treatment as an experimental treatment would be disastrous for young trans people. The following points are our main concerns with this:

1. Treatment classified as experimental is not covered by the legal concept "right to necessary health services" which ensures that all people in Norway are afforded the healthcare they need. Young trans people would no longer be entitled to receive this treatment.
2. Treatment would only be offered as part of research, for the purpose of gathering data on long term outcomes. Aside from the general ethical issues of forcing young people to take part in research, there has already been strong criticisms of research performed at the national treatment centre as seen in [sykepleien.no](https://www.sykepleien.no). People who participated in this past study expressed the

Den nye [Ukom-rapporten](#) støtter også disse tilrådingane."

² Original text: "deler av dagens dialog fra enkelte aktører er preget av ideologi og en oss-mot-dem-retorikk"

³ Original text: "Ukom anbefaler at pubertetsblokkere og hormonell og kirurgisk kjønnsbekreftende behandling for barn og unge defineres som utprøvende behandling. Dette er særlig viktig for tenåringer med kjønnsdysfori"

experience as deeply invasive and uncomfortable, and that they did not feel like they could decline participation or in several cases were not clearly informed that the questionnaires were part of a study.

In our complaint we have referenced quotes from several major medical organisations (including: World Professional Association for Transgender Health(WPATH), Pediatric Endocrine Society, & American Academy of Pediatrics) that have warned against the classification of puberty suppression as experimental treatment.

We do not feel that NHIB have adequately explained their reasoning for dismissing the strong recommendations and guidelines provided by the largest international bodies in the field, and therefore we request that they either provide their evaluation of the available knowledgebase, and reconsider its current recommendations.

Establishing a quality assurance register & revising national guidelines:

"Our findings show that the evidence base is lacking, and we are therefore giving several recommendations that will contribute towards strengthening the knowledge base. It's our opinion that there is a need to establish a medical quality register with national status."⁴

The report outlines the need for a national register, in order to strengthen knowledge. This is something we fully support and in accordance with the National Professional Guidelines for Gender Incongruence from the Norwegian Directorate for Health. There has already been work initiated towards establishing a register previously, The municipal Health Center for Gender and Sexuality in Oslo invited our involvement as user-representatives in 2022, where NBTS were also requested as collaborators. NBTS declined to participate. We consider this part of their pattern of refusal to contribute towards the implementation of the National Professional Guidelines for Gender Incongruence, and a lack of willingness to work with others to improve the quality of the healthcare provided. The systematic refusal to follow the guidelines by NBTS, and by extension the lack of accountability exercised by Oslo university hospital, South-Eastern Norway Regional Health Authority and the Ministry of Health and Care Services, is a direct contributor to endangering the healthcare provided to young trans people.

Our critique towards NHIB report revolves around the seeming lack of awareness of the history in the field, and a complete lack of holding the responsible parties to account. The guidelines published by The Norwegian Directorate of Health have been harshly criticised in NHIBs report, but there is no mention of those responsible for implementing and enforcing those guidelines since 2020. Had there been an actual effort to implement these, much of the NHIBs concerns regarding the

⁴ Original text: "Våre funn viser at kunnskapsgrunnlaget er mangelfullt, og vi kommer derfor med flere anbefalinger som sammen vil bidra til å styrke kunnskapsgrunnlaget. Vi mener at det er et behov for å opprette et medisinsk kvalitetsregister med nasjonal status."

guidelines, the status of the national knowledge base, and level of competency in the health service would be resolved.

Concerning lack of critique of sources, inappropriate weighting of evidence bases, and poor understanding of trans people's healthcare.

A common theme throughout the report is the claim that the evidence surrounding gender-affirming medical treatment for young trans people is insufficient, and NHIB uses this claim to justify their assessments and recommendations. There are a few points of concern we feel undermine the apparent accuracy of their work.

1. Shallow conclusions and apparent poor overall understanding, potentially due to the short timeline for the project. The investigation was initiated in summer 2022, and published 6-9 months later on 9 March. Comparable reviews and reports in the field, like the Cass review, have spent considerably more time to ensure a thorough understanding of all factors involved in the healthcare and wellbeing of young trans people. This review has taken less time than some young people wait for their first assessment appointment at NBTS.
2. Dismissing WPATH's expertise, and undermining the integrity of the Standards of Care for the Health of Transgender and Gender Diverse People, Version 8 (SOC 8). NHIB refers to the organisation and the guidelines in terms that are dismissive of their actual professional expertise.
3. Uncritically comparing sources with vastly different quality and level of bias, exemplified by the vast amount of opinion pieces from online publications that are listed in the reports references.
4. Giving greater weight to publications developed with greater risk of bias, as exemplified by preferring the conclusions of Sosialstyrelsen to reduce access to gender-affirming medical treatment. A publication whose evidence base did not include thorough systematic reviews, and instead relies on consensus based recommendations by a comparatively small number of experts.
5. Insufficient efforts to include representatives from the groups currently undergoing, waiting for, rejected from treatment and their close relations. Skeiv Ungdom, the largest organisation that represents young people impacted by the report had to be invited by representatives from other organisations, as well as parents support organisations that have since publication expressed their disappointment in not being included in the investigation at all.
6. Use of imprecise language, the terms child, teenager, young person and youth are all used within the report but are never defined to clarify which age groups they refer to. This opens a risk of various biases by leaving it up to the reader to infer the maturity and age of the groups referred to, for example the age of children being offered medical treatments. This could have easily been avoided through adopting the definitions used in established treatment guidelines.

7. Discussing the increase in referrals to gender-affirming treatment, statements such as; "*Especially the number of children and youth that seek out, or are referred to, such treatment in their teens has increased considerably*"⁵, are made without adequate evidence, or at times with no citations at all. In chapter 3 "about gender incongruence", numbers reported by NBTS are presented as being evidence of this *considerable increase*. Unfortunately these numbers cannot prove this, as they are a convenient selection of yearly referral numbers for adults *and* youth, not separated by age group or assigned sex. The way the numbers are presented is deeply concerning, perpetuating an attitude of favouring fear over factual debate.

⁵ Original text: "*Spesielt har antallet barn og unge som søker seg til, eller blir henvist til, slik behandling i tenårene økt betydelig.*"