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Norway's guidance on paediatric gender treatment is unsafe, says review

Jennifer Block

Norway's national guidelines for the treatment of people with gender incongruence and gender dysphoria are inadequate and should be revised to protect patients and better guide health professionals, according to a report from the Norwegian Healthcare Investigation Board (Ukom) released earlier this month.¹ An English language version is expected in April.

Ukom found that the guidelines, which Norway's health directory published in 2020, do not offer a clear enough framework for patient evaluation, treatment, and informed consent, said Stine Marit Moen, Ukom's medical director. This has left too much room for interpretation among clinicians and unwarranted variation in care.

The board received notifications of concern from patients' family members, clinicians, and others, which prompted the investigation and report. "We're concerned that there may be undertreatment, overtreatment, and the wrong treatment, with variation in safeguarding and the extent of multidisciplinary involvement, posing a threat to patient safety," Moen told *The BMJ*.

The report found that there is insufficient evidence for the use of puberty blockers and cross sex hormone treatments in young people, especially for teenagers who are increasingly seeking health services and being referred to specialist healthcare. Ukom defines such treatments as utprøvende behandling, or "treatments under trial," said Moen.

National principles govern the delivery of investigational treatment—however, those principles have not been applied in the case of treatments for gender incongruence and dysphoria, said Moen. The board recommended that those principles are followed, and that Norwegian authorities document the outcomes of every young person treated in a national medical registry. "This will increase oversight, reduce unwarranted variation in patient treatment, and result in better quality care," said Moen.

Unlike other guidelines published by Norway's ministry of health, the 2020 guidelines for the treatment of gender incongruence and dysphoria were not based on a systematic review of the evidence.

"At the time, it was important to offer services to people with gender incongruity and dysphoria, and to state that they had a right to healthcare services," said Moen. "But it's our job to assess it from a medical point of view and patient safety, and the guidelines are insufficient in this regard."

Ukom has recommended that updated guidelines should be based on a new commissioned review or existing international up-to-date systematic reviews, such as those conducted in 2021 by the UK's National Institute for Health and Care Excellence. The board has published several other reports since its founding in 2020. Its recommendations are not binding, but Moen expects the report on the treatment of gender incongruence will have an impact.

"We've seen a marked increase in referrals to specialised healthcare services in Norway for teenagers, as seen in many other western countries, and nobody knows the reason. The stability of the gender dysphoria of these teenagers is not known, and the evidence of long term effects of gender affirming treatments for this young population is insufficient," said Moen. "It's not just a question of rights, it's a question of the requirements for our health system to ensure the best and safest treatment possible for everybody."

Norway's Directorate for Health and Social Affairs told *The BMJ* that its current guidelines acknowledge the limited evidence base on treatments for gender incongruence with recommendations "limited to the organisation and content of services on different treatment levels necessary to fulfil patient rights, as required by Norwegian health regulation." It said that it planned to start talks with clinicians and patient representatives to decide whether the guidelines needed to be revised.

On 23 March we added a comment from Norway's Directorate for Health and Social Affairs.

¹ Ukom. Pasientsikkerhet for barn og unge med kjønnsinkongruens. March 2023. <https://ukom.no/rapporter/pasientsikkerhet-for-barn-og-unge-med-kjonninkongruens/sammendrag>