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## **Equality under the Health Research Act**

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**When information on your health is collected, you should have equal protection under the law whether you are a source in a newspaper report or a patient in a research project.**



Photo: Sturlason

During the last cross-country skiing season, the *Dagbladet* newspaper published a series of articles on eating disorders among Norwegian athletes [\(1\)](#). Under the collective title 'A sick skiing nation', the findings caused a stir and led to 'public apologies, changes in coach training and investigative initiatives' [\(2\)](#).

It is commendable that the press has provided broad coverage where other social actors (namely, sports and research) have failed to do so. *Dagbladet* received an anonymous tip-off that eating disorders are rife in the cross-country skiing community, but found little research in the field. The lack of up-to-date knowledge was confirmed by experts in the area, and *Dagbladet* decided to document 'the extent of eating disorders and disordered eating behaviour in our national sport' [\(2\)](#).

As part of the investigative journalism, medical examinations were carried out and health data obtained from current and former athletes. Under the headings 'Qualitative survey', 'X-ray examinations', 'Hormone blood tests' and 'Psychological tests', with the subheading 'Psychometric and statistical analysis', the journalists explained in the SKUP method report from 2021 [\(2\)](#) why and how they gathered health data from the sources. In addition, they sought expert assessments from professors in geriatrics, nutritional physiology,

sports psychiatry and sports science [\(2\)](#). These experts did not contribute to the data collection, data storage or publication. However, some of them questioned whether the 'investigation' constituted health research [\(3\)](#).

Health research is regulated in the Act on Medical and Health Research (the Health Research Act) and must be submitted for assessment to the Regional Committees for Medical and Health Research Ethics (REC) prior to data collection [\(4\)](#).

Several healthcare researchers reacted to *Dagbladet's* series of articles [\(5\)](#). There was a swift call for a research ethics assessment, and the Science Ombud at the University of Oslo contacted the National Committee for Medical and Health Research (NEM) [\(6\)](#). Over a year later, the Norwegian Board of Health Supervision received the committee's unequivocal assessment, which concluded that the series of articles 'constitutes research covered by the Health Research Act' [\(3\)](#).

***«If a research project does not obtain approval from REC, can the protection that the Health Research Act was intended to give individuals be bypassed by redefining the project as journalism?»***

*Dagbladet* quickly responded with a counter-argument. The editor-in-chief emphasised that 'where research communities fail to prioritise important areas of significant societal relevance, the press should be able to step in and investigate the field themselves' [\(7\)](#). The managing editor referred to consultations with lawyers and stated that 'we were crystal clear – both to the researchers and the readers – that this was a journalistic project' [\(8\)](#), and argued that if the law can be used to control journalism, it has to be changed.

Both argued that the press cannot and should not be controlled by a research committee. NEM pointed out that this was a diversion in the debate, and that the committee has no wish to limit the independent role of the press but to ensure that health research is ethical [\(9\)](#). At the time of writing, a final jab at NEM can be seen in the headline 'Attempted Strangulation in Norway' in *Dagbladet's* own coverage of the article series winning a top prize at this year's AIPS Sport Media Awards [\(10\)](#).

Newspapers often write about health, thereby providing valuable public information. 'A sick skiing nation' shone an important spotlight on female and young athletes and the possible long-term effects of low nutritional intake in relation to training volume. The articles attracted the attention of politicians, and the series has received several awards [\(2, 8, 10\)](#). It is undoubtedly a good series of articles, but is it *more* than just good journalism?

Journalists and researchers play an important role in society, and freedom of the press and academic research are highly valued. Freedom of the press should not be taken for granted in Norway either. Nor should we ignore the fact that the press and researchers mutually benefit from each other.

The upcoming decision by the Norwegian Board of Health Supervision is expected to help clarify the distinction between health research and journalism. There must be equality before the law.

The Health Research Act does not apply to specific professions or groups; it applies to everyone. If the Norwegian Board of Health Supervision finds that *Dagbladet's* coverage does not constitute health research, it could be perceived as source protection and freedom of the press trumping research ethics. If a research project does not obtain approval from REC, can the protection that the Health Research Act was intended to give individuals be bypassed by redefining the project as journalism? This, in turn, would result in research, regardless of its quality and significance, evading peer review and scientific publishing.

Regardless of the Norwegian Board of Health Supervision's decision, journalists and researchers must be able to highlight threats to press freedom and academic freedom. Where the law is clear but not workable, efforts can be made to change it as permitted by our democracy. By the same token, we must avoid a situation where the pursuit of new knowledge comes at the expense of those whom the legislation intends to protect, whether it be patients who consent to participate in research or sources that shed light on the darker aspects of our national sport.

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