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A closed door to an open future

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Genetic self-tests can provide information about kinship, genetic traits and the risk of future illness. The Norwegian Government is not protecting the rights of children to decline such knowledge.

Photo: Einar Nilsen

January has a magical quality to it: a new beginning. Then the spring will come, and flag-hoisting, the summer holidays and Christmas. We know a bit about the rest, but much is uncertain. Just like life itself.

Genetic testing can provide the opportunity to learn a bit more about what is to come, and enable us to plan accordingly – for those of us who wish to do so. For a mere NOK 1000, the Israel-based company MyHeritage can offer polygenic scores that give a risk profile for heart disease, breast cancer, type 2 diabetes and hypertension, testing for single-gene variants (single-nucleotide polymorphisms) that predispose to, for example, Alzheimer's disease, and carrier status for a variety of recessively inherited conditions, such as cystic fibrosis (1). MyHeritage's American competitor, 23andMe, can also test genetic predisposition for features such as hair colour and preferences for ice-cream flavours (!) (2). Both companies offer testing to identify genetic origins, and social networks are available for tracking down (or being tracked down by) distant relatives.

Genetic self-tests are a hotbed of controversy. First, the results can be difficult to interpret. Second, the quality and comprehensiveness of the tests vary. The testing of single-nucleotide polymorphisms covers only a limited range of pathogenic variants (3). A woman who tests negative for BRCA-associated breast cancer may nevertheless have a pathogenic mutation. The probability of a false negative test will be particularly high if the woman belongs to a minority population. Last but not least, sending DNA to international, commercial companies is not advisable (4). DNA is regarded as particularly sensitive personal data that can never be fully anonymised (4).

> ***«At-home genetic testing of children is a large, international market aimed at parents who want the best for their children»***

Monitoring the use of genetic self-testing within the public health service presents professional, ethical and financial challenges. Several countries that allow such testing have produced guidelines for doctors on how to deal with this patient group (3, 5, 6). The British Royal College of General Practitioners and its members recommend ignoring genetic test results and call for genetic testing referrals within the public health service to be made solely on the basis of family history and clinical examination (7, 8).

Genetic testing within the public health service is strictly regulated in Norway. Persons to be tested predictively, i.e. for the risk of developing an illness in the future, should always be given personal counselling (9). Children under 16 years of age can only be predictively tested if their condition is serious and can be prevented. Private use of genetic self-tests, on the other hand, is not subject to any such regulation. At-home genetic testing of children is a large, international market aimed at parents who want the best for their children. In addition to health-related testing, it offers the questionable screening of children for their 'genetic talents' (10).

In March 2019, the Norwegian Government announced major changes to the Biotechnology Act, and its proposal is now being considered by the Storting. The only mention that the proposal makes of genetic self-testing is in its clarification that the ban on testing others or on 'requesting, receiving, possessing, or using genetic data on another person' also includes private individuals. However, this ban does *not* apply to parents of children under 16 years of age (11), despite the explicit request of the Norwegian Biotechnology Advisory Board, the Norwegian Directorate of Health and the Centre for Medical Ethics in the consultation process to ban the genetic self-testing of children (11), and the fact that the Norwegian Society for Medical Genetics wants the entire field to be regulated by law (12).

The Norwegian Government's argument concerns the parents' 'right and duty to make decisions for their child in relation to personal matters'. But why should this right be applied to genetic testing *outside* the health service when it is not applied *within* it. After all, neither parents nor healthcare personnel can make a decision on testing within the public health service unless other criteria under the Biotechnology Act are met.

The Minister of Health refers to problems in applying the legislation and difficulties entailed in policing a possible ban (13). However, such a ban is already in place in countries such as Germany and France, and the Norwegian Biotechnology Advisory Board is adamant that it is fully possible to implement (13).

Instead of a ban, the Government intends to focus on raising awareness through information campaigns and improving knowledge. I doubt that information alone is enough to curb the intensive marketing we are now seeing from companies offering genetic self-testing, and hope that the Storting will reject the proposed law, which gives well-meaning parents too much authority.

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