Tidsskriftet Tidsskrift for Den norske legeforening

A speck of blood

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The Norwegian government's proposal regarding the long-term storage of blood from neonatal screenings will soon be considered by the Storting. But has the government fully understood what it is proposing?

Photo: Einar Nilsen

From its humble beginnings well over 50 years ago, the purpose of neonatal screening has been unambiguous: to diagnose serious hereditary diseases that are easier to treat if detected early (1). The screening began with tests for phenylketonuria and congenital hypothyroidism, and in 2012 it was expanded to include 23 diseases. From 2018, Norwegian infants are being screened for 25 different diseases.

The screening has almost 100 % take-up, but many are unaware that they have the right to opt out. That participation is voluntary can scarcely be discerned from the (otherwise comprehensive) information on neonatal screening on the website of the country's largest hospital (2).

It is important to safeguard such high take-up against measures that could jeopardise support. This has been understood by many. 'Data from the neonatal screening contains very sensitive and private health information that, for privacy reasons, should not be linked to personal data,' wrote, for example, parliamentary representative Bent Høie in a parliamentary question to Anne-Grete Strøm-Erichsen, then Minister of Health and Care Services, in 2011 (3). At that point, samples were to be stored for six years.

The current government is now proposing long-term storage. Roles have changed, and the piper is playing a different tune: 'In connection with the diagnostic biobank, personal data may be processed if they are relevant and necessary,' states Minister of Health and Care Services Bent Høie's proposed legislation, which is currently awaiting review by the Storting's Committee on Health and Care Services (4). The proposal entails allowing blood from the neonatal screening programme as well as personal data to be stored indefinitely. The plan is for the Storting to consider the matter immediately after Easter 2018.

The government's desire for long-term storage of blood samples is not based on consideration of healthcare provision for the individual child. The reference group for neonatal screening has stated that storage of samples beyond 10–16 years has no clinical utility for the child, nor is it useful for neonatal screening per se (5). In common with several other consultation bodies, they point out that long-term storage has only one purpose, and that is research. Blood from the neonatal screening programme may also be used in research today, provided that informed consent is obtained. However, the Regional Committee for Medical and Health Research Ethics can grant exemption from this requirement 'if such research is of significant interest to society' (4). This arrangement will continue according to the proposal.

The problem is that 'significant interest to society' is far from a cohesive and context-independent measure. Over the course of a few decades, long-term storage would potentially result in a near complete DNA register of the Norwegian population. Such a register could be linked to a variety of other registers as well as to additional information about the individual. With storage for six years, the possibilities for research are limited. With indefinite storage, the possibilities for research are vast. With almost complete genetic information on an entire population, there is much that could be defined as 'of significant interest'. The most circumspect among us can easily envisage what a future totalitarian regime, or an invading foreign state, could accomplish by way of population surveillance, selection and control with such a tool in their hands.

And the rest of us need not look beyond our neighbouring countries to see how tempting it can be to use comprehensive DNA records for purposes other than those for which they were intended. In Sweden, the police have accessed the neonatal screening

register in association with murder investigations, and discussions are underway regarding use of the material in connection with paternity disputes and personal identification, and by insurance companies (6). In Denmark, samples from neonates are already used for genetic research without individual consent (7). At the time at which consent is granted it is impossible to foresee all of the possible ways in which such a register could be used or misused in the near or distant future (8).

It is therefore vitally important to understand the extent to which long-term storage will change the nature of the register. Clearly not everyone does. 'This is not a gene bank of Norway's population, it is a speck of blood on a piece of paper, and use of the samples is strictly regulated,' declared Høie, Minister of Health and Care Services to 'Dagens Medisin' ('*Medicine Today*') (9). Does the minister not know that a person's blood contains that person's DNA? A generous interpretation could be that the statement was a slip of the tongue, were it not also for the fact that similar wording is included in the final draft of the proposed legislation. There it states: 'It is important to emphasise that genetic information will not be collected and stored on all neonates'. (4).

Of course genetic information will be collected and stored, forever, on all neonates. 'Specks of blood' per se do have any value for research prior to extraction of the genetic information. It is this information that makes their long-term storage a matter of interest. And it is this information that could be linked to personal data (4). There is reason to question whether the government has fully understood what it is asking the Storting to approve.

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Publisert: 19 February 2018. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.18.0144
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