The Norwegian Diabetes Register for Adults:
Why don't doctors make use of a helpful quality register?

Norway and the goat kid that refused to count

In this edition of the Journal of the Norwegian Medical Association, Cooper and his colleagues present the first nationwide survey that includes HbA1c, blood pressure, lipid values and the prevalence of subsequent complications among patients with type 1 diabetes. The study encompasses approximately 15 % of all those diagnosed with the disease in Norway. What is the status? Only 10 % reached the treatment targets defined in the national clinical guidelines (1) for HbA1c, LDL cholesterol and blood pressure. The average HbA1c was 8.0 %. HbA1c over 9.0 %, which constitutes a considerable risk factor for developing subsequent complications, was found in 22 % of the patients. The gravity of this is accentuated by the fact that 20 % smoked on a daily basis. In addition, a third had no documented foot examination in the past year, in spite of having suffered from the disease for a considerable time. Less than 60 % of those who were on treatment to reduce blood pressure and lipids reached the treatment target. Is this satisfactory? No. Can we substantiate our clinical impression that a gradual improvement is taking place in the quality of the treatment, and that the prevalence of vascular complications is declining? We don't know, since this is the first nationwide survey.

What is the situation for patients with type 2 diabetes, who make up more than 90 % of all those with diabetes in Norway? We don't know. Only 2,621 of the at least 160,000 who are treated by general practitioners, i.e. perhaps only 1–2 % of patients with type 2 diabetes, were registered in the Norwegian Diabetes Register for Adults (NOKLUS) in 2012 (2). This is in direct contrast to the Norwegian Childhood Diabetes Registry where more than 2,500 children with diabetes – more than 95 % of the total (3) – are registered. It is difficult to plan care for a patient group when we do not have satisfactory figures on status. One of the goals of the Coordination Reform of the Norwegian healthcare system is that the local authorities are to have a good overview of those with chronic diseases such as diabetes. This can be achieved by using NOKLUS Diabetes, which interacts electronically with the GPs' data system while at the same time assuring the quality of the treatment by showing the target values in the relevant medical guideline.

In Sweden, 347,000 patients with diabetes – i.e. almost 90 % of all those diagnosed with the disease – are registered in the National Diabetes Register (4). An improvement in reporting and treatment is documented for these patients from 2008 to 2012. The Swedish diabetes register has provided a substantial amount of new knowledge on diabetes, for example by the development of a risk calculator for cardiovascular incidents and by documenting that hospitalisation for heart failure in patients with type 1 diabetes is associated with HbA1c. This was recently published in *The Lancet* (5). In 2009 the Norwegian Ministry of Health and Care Services charged the regional health trusts with the task of putting electronic diabetes records to use in all health trusts. The task is clearly stated, but it is performed to only a small extent. As the medical officer in charge of a diabetes outpatient clinic, I am still waiting for this directive to be communicated to me through eight levels of more senior management.

Diabetes is an area of priority in the World Health Organization and in the outgoing government's strategy for non-contagious diseases (6). The goal is to reduce the mortality rate from non-contagious diseases by 25 % before 2025. It is difficult to see how this (over)ambitious goal can be reached without using a national diabetes register to the same extent as the Swedish register is used. This is also emphasised in the strategy, which includes the recommendation that the reporting of data to the National Diabetes Register/NOKLUS must be improved.

What must be done? In the recent government negotiations it was agreed that performance-based financing of the health trusts is to be increased. This will create the need for a special charge for inserting information in NOKLUS Diabetes at diabetes outpatient clinics. A charge of NOK 80 for this already exists for GPs – no.109: annual check-up of diabetes, cf. NOKLUS form (7). In the negotiations for GP charges, both parties should advocate an increase in this charge.

The study raises questions beyond the register aspect. For example, the prioritisation guide for endocrinology (8), compiled by the Norwegian Directorate of Health and the Norwegian Medical Association, gives patients with type 1 diabetes the right to prioritised health assistance. Is type 1 diabetes too complicated to be treated in the primary health service? A GP has perhaps four or five patients with type 1 diabetes. Insulin techniques have become more complicated: 20 % use insulin pumps, and a steadily-increasing number use tissue glucose measurement. Is such a small number of patients sufficient to gain adequate experience in the personalisation of insulin treatment? Or should the question be reversed: Does the GP know the patient better and is therefore more suited to personalise the treatment? My view is that the main responsibility should rest with the diabetes outpatient clinic.

Finally and most important: What do the patients think? This is not the Norwegian tale about all the animals that refused to be counted by the goat kid who could count. The Norwegian Diabetes Association is making efforts to persuade politicians that a non consent-based register should be introduced in line with the recently established cardiovascular register. This will require debate in the Norwegian parliament if the outgoing government's suggestion in the Norwegian Act relating to health registers that non consent-based registers can be established by regulation of the King in the Council of State is not approved. It is a paradox that the Norwegian Medical Association's reserved attitude represents the animals that refused to be counted, and that the user organisation represents the goat kid.

Things are getting better. The latest annual report from the Norwegian Diabetes Register for Adults shows that more than 7,500 patients at diabetes outpatient clinics have been registered. Keen diabetes nurses and doctors see the usefulness of a register they have established and updated themselves. Let us hope that GPs will also begin to use NOKLUS Diabetes. As most of us have perhaps forgotten, the goat kid saved the animals from drowning.

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The author has completed the ICMJE form and declares the following conflict of interest: He previously held the post of strategy director for diabetes in the Norwegian Directorate of Health, which has allocated project funds to NOKLUS diabetes.

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