Treatment of type 1 diabetes in the specialist health service – data from the Norwegian Diabetes Register for Adults

BACKGROUND The Norwegian Diabetes Register for Adults was established in 2005. The aim of the study is to assess the quality of treatment for adult patients with type 1 diabetes in the specialist health service based on register data.

MATERIAL AND METHOD We included patients ≥ 18 years with type 1 diabetes in the specialist health service for whom the register has data for the period from 1 July 2010 – to 31 December 2011. The patients were asked to consent to the transfer of data to the register when they attended a routine consultation. As of 31 December 2011, 95 % of the patients asked gave their consent. It is not known how large a proportion of patients were asked.

RESULTS We included the last registered data for 3 697 patients (46.8 % women) from 24 outpatient clinics and specialist centres. The average age was 41.8 years and the average duration of diabetes was 20.8 years. Median HbA1c, systolic blood pressure and LDL cholesterol were 8.0 %, 126 mm Hg and 2.8 mmol/l respectively. 9.8 % achieved all treatment targets set out in the national guidelines for diabetes. 18 % had HbA1c ≤ 7.0 %, while 22 % had HbA1c ≥ 9 %. 39 % of patients on statin therapy achieved the treatment target for LDL cholesterol. 19.6 % smoked on a daily basis. 14.9 % had received treatment for retinopathy and 5.8 % had experienced coronary heart disease. There was no record of foot examination or ophthalmoscopy being performed in 33 % and 29 % of patients.

INTERPRETATION The preliminary register data indicate that diabetes treatment should be improved both with respect to the implementation of recommended procedures and the proportion of patients who achieve the treatment targets.

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MAIN MESSAGE

Preliminary data from the Norwegian Diabetes Register for Adults show that 22 % of patients registered with type 1 diabetes had poor glycaemic control, with HbA1c ≥ 9.0 %

Only 10 % of patients achieved the treatment targets for HbA1c, LDL cholesterol and blood pressure

20 % of patients with type 1 diabetes were registered as daily smokers

The follow-up of patients was unsatisfactory, especially in relation to foot examination and eye status

The incidence of diabetes is increasing in Norway and the rest of the world (1). Figures for 2011 from the Norwegian Prescription Database indicate that there are approximately 200 000 persons diagnosed with known diabetes in Norway (2), and approximately 25 000 of these have type 1 diabetes. Good diabetes treatment reduces the frequency of macrovascular and microvascular subsequent complications (3–5).

In 2006 the Minister of Health and Care Services launched a national diabetes strategy for 2006–2010, which called for national data on the quality of diabetes treatment. In 2009 the Norwegian Directorate of Health issued national guidelines for the prevention, diagnosis and treatment of diabetes (6). These guidelines also put focus on the need for data on the quality of diabetes treatment. Quality of care in general practice has been assessed previously in a few cross-sectional surveys dealing mainly with people with type 2 diabetes (7, 8). There are no publications from the specialist health service in Norway about the quality of diabetes treatment for adults with type 1 diabetes. In connection with the Coordination Reform of the Norwegian health service it may be of special importance to monitor the quality of treatment for type 1 diabetes to ensure that patients are treated at the appropriate level in the health service.

The Norwegian Diabetes Register for Adults was established in 2005 in accordance with the recommendation of the Ministry of Health and Care Services. It is a consent-based national quality register with a mandate to collect data from both the primary and the specialist health service. Bergen Hospital Trust owns the register, but the Norwegian Quality Improvement of Primary Health Care Laboratories (Noklus) in Bergen is responsible for the day to day management of the register. In the first years the register variables were defined and an electronic registration tool (Noklus Diabetes) was developed, which also functions as a diabetes electronic medical record. This is in accordance with the commissioning document to the hospital trusts, which requires them to use diabetes electronic medical records with the aim of achieving a continual quality assurance of diabetes treatment.

The number of hospital outpatient clinics and specialist clinics that report data to the Norwegian Diabetes Register for Adults has increased from three in 2009 to 24 in 2011. The participants receive annual feedback where their own data are compared with data from other hospitals.

Table 1 Overview of diabetes outpatient clinics that report to the Diabetes Register as of 31 December 2011 and of the number of patients from the various outpatient clinics included in this study

Diabetes outpatient clinic	Number of patients
Stavanger University Hospital	796
Norwegian Diabetic Centre	698
Haukeland University Hospital	601
Østfold Hospital Trust, Fredrikstad	399
Sørlandet Hospital, Arendal	293
Nordland Hospital Bodø	289
University Hospital of North Norway, Tromsø	159
Sørlandet University Hospital, Kristiansand	105
Helgeland Hospital, Mo i Rana	72
Innlandet Hospital Trust, Lillehammer	47
Helgeland Hospital, Mosjøen	42
Nordland Hospital, Stokmarknes	40
Haugesund Hospital	28
Hammerfest Hospital	19
Nordland Hospital, Lofoten	18
Innlandet Hospital Trust, Gjøvik	17
Innlandet Hospital Trust, Hamar	17
Oslo University Hospital, Ullevål[1]	14
Stord Hospital	13
University Hospital of North Norway, Narvik	11
Diverse[2]	19
Total	**3 697**

[1] All have reported data via Noklus Diabetes with the exception of Ullevål which reported via MRS

[2] Diakonhjemmet Hospital in Oslo, Diabetes Outpatient Clinic in Trondheim, Helgeland Hospital, Sandnessjøen, and Haraldsplass Hospital in Bergen

The purpose of this study is to assess the quality of treatment for patients ≥ 18 years with type 1 diabetes who have been monitored by the specialist health service, based on register data mainly from 2011.

Table 2 Age and sex distribution for patients with type 1 diabetes in the specialist health service for whom data were registered in the period from 1 July 2010 to 31 December 2011

Age, year	Number	(%)	Proportion of women (%)
18–19	124	(3.4)	46.8
20–29	767	(20.7)	47.1
30–39	803	(21.7)	50.3
40–49	918	(24.8)	45.5
50–59	596	(16.1)	44.1
60–69	353	(9.5)	47.3
70–80	120	(3.2)	52.5
≥ 81	16	(0.4)	62.5
Total	**3 697**	**(100)**	**47.2**

Table 3 Registered treatment procedures since 2009 for patients ≥ 18 years with type 1 diabetes for hospitals using the Noklus Diabetes electronic medical record. N = 1 378 patients unless otherwise indicated

	Procedure registered[1] (%)
Height recorded	96
Measurement of HbA1c	94
Measurement of LDL cholesterol	92
Mapping of coronary heart disease in the family previously	92
Weight recorded	82
Measurement of blood pressure	81
Measurement of microalbumin	75
Smoking habits indicated	73
Ophthamoloscopy (diabetes duration ≥ 5 years) (n = 1 206)	71
Examination with monofilament and/or tuning fork (diabetes duration ≥ 5 years) (n = 1 206)	67
Examination of foot pulse (diabetes duration ≥ 5 years) (n = 1 206)	66

[1] For HbA1c, blood pressure, smoking habits, microalbumin, weight, and foot examination only data from 1 October 2010 to 31 December 2011 are included (15 months back in time). Measurements of cholesterol/LDL and ophthalmoscopy are included if there are results from between 1 July 2009 and 31 December 2011 (30 months back in time). Height and previous coronary heart disease in the family are included regardless of the date.

Material and method

We included patients over 18 with type 1 diabetes monitored in the specialist health service for whom data had been registered for the period 1 July 2010 to 31 December 2011. The last registration of the different variables was used. For some variables, such as ophthalmoscopy, the registration could be prior to 1 July 2010. However, we excluded patients with no registered data in the period from 1 July 2010 to 31 December 2011. The data were delivered in a de-identified form.

The treating doctor's diagnosis forms the basis of the classification. Patients were asked on a continuous basis whether data could be sent to the register when they attended for a regular follow-up appointment. 95 % of the patients asked as of 31 December 2011 gave their consent. We do not know the proportion of patients asked among those who attended a regular check-up. Several of the hospitals were at an early stage of submitting data to the Diabetes Register and had therefore only registered data for a relatively small percentage of their patient population. The register variables include duration of diabetes, performing of different procedures, risk factors, treatment and diabetes-related complications. A complete overview of the variables can be found on Noklus' webpage (9).

Treatment targets and selected procedures used as quality targets in this survey are based on recommendations in the national guidelines from 2009 (6), i.e. target achievement for HbA1c (≤ 7 %), for blood pressure (systolic ≤ 135 mm Hg, diastolic ≤ 80 mm Hg) and for lipids (LDL cholesterol ≤ 2.5 mmol/l without known cardiovascular disease, ≤ 1.8 mmol/l with known cardiovascular disease) as well as on the performing of procedures to detect risk factors and early complications. The guidelines recommend that the majority of procedures are carried out annually, but some should be carried out every second year (6). It is not always possible to carry out check-ups at exactly one or two-year intervals, therefore we have extended the time period for the performing of procedures to 15 and 30 months respectively.

Noklus Diabetes software, used by most of those who supply the data, is both a clinical tool providing decision support and a data collection tool for the register, and constitutes an almost complete diabetes medical record. The registration is carried out by a doctor and/or nurse in connection with the consultation. The program communicates with the outpatient clinic's record system so that the data registered there are easily exported to the main electronic record, while other data (patient identification data and laboratory data) are imported from the main

record to the diabetes medical record. Therefore the register also contains information about some examinations that were conducted before the patient was included. In addition, a Medical Registration System (MRS) has been developed that can be used for the manual entry of register variables via the Norwegian Health Network. This is a solution for hospitals that cannot yet install, or choose not to install, Noklus Diabetes software.

All health regions delivered encrypted electronic data via Noklus Diabetes with the exception of Oslo University Hospital, Ullevål, which used MRS. Descriptive statistics were performed using the statistics program SPSS version 20. We calculated confidence intervals based on binomial distribution for the percentage of women and men registered for each complication. The survey was assessed by the Regional Committee for Medical and Health Research Ethics and was found to be exempt from the notification requirement.

Results

The results are based on patient data from 22 hospital outpatient clinics and two specialist centres, altogether 3 697 patients (Table 1). Table 2 shows age and gender distribution in the different age groups. The average age was 41.8 years and the average duration of the disease was 20.8 years. 3.6 % were over 70 years of age. Average Body Mass Index (BMI) for men and women was 26.3 kg/m^2 and 25.9 kg/m^2 respectively. 19.6 % of patients were registered as daily smokers, and this percentage was approximately the same for men and women and among patients over and under 40 years of age.

Table 3 shows registered procedures at hospitals that have used Noklus Diabetes since the first quarter of 2009, i.e. sufficiently long to carry out procedures that were recommended to be carried out every second year. The percentage of registered procedures was 66–96 %.

Table 4 shows the proportion receiving medication with an insulin pump, antihypertensives, statins, acetylsalicylic acid, or warfarin in 2011. The proportion receiving treatment with antihypertensives, statins and acetylsalicylic acid was highest in the age group ≥ 40 years.

Table 5 shows the distribution of values for HbA1c, blood pressure and lipids, and Table 6 shows the percentage who achieved the treatment targets. 18 % of the patients achieved the treatment target of HbA1c ≤ 7 %, while 22 % had HbA1c ≥ 9 %. Median HbA1c was approximately 8.0 % in the majority of age groups for both sexes and 8.4 % in the youngest groups (18–24 years). Patients with an insulin pump had median HbA1c of 8.3 % and patients with other types of insulin treatment HbA1c of 8.0 %. HbA1c-values were median 7.2 % for > 63 blood glucose measurements/week (n = 80), 7.7 % for 29–63 measurements/week (n = 626), 8.1 % for 15–28 measurements/week (n = 492) and 8.4 % for 1–14 measurements/week (n = 410).

Median systolic and diastolic blood pressure for men was 130/80 mm Hg, while women had median values of 122/78 mm Hg. 57 % of patients on antihypertensives achieved the treatment target for systolic blood pressure ≤ 135 mm Hg. Of patients on statin treatment, 39 % achieved the treatment target for LDL cholesterol: 42 % of patients with no known cardiovascular disease and 33 % with known cardiovascular disease. We had no information about statin dosage in patients who did not achieve the treatment target. 9.8 % of the patients reached all the treatment targets for HbA1c, systolic blood pressure and LDL cholesterol.

Table 7 provides an overview of complication frequency. Median diabetes duration in patients with complications was approximately 30 years regardless of type of complication. Peripheral neuropathy was registered in 13.8 % (95 % KI 11.3–16.3) of men and in 7.2 % (95 % KI 5.2–9.2) of women, ulcers in 5.4 % (95 % KI 4.3–6.5) of men and 2.3 % (95 % KI 1.5–3.1) of women, and amputations in 1.3 % (95 % KI 0.7–1.9) of men and 0.2 % (95 % KI 0–0.4) of women. Microalbuminuria or proteinuria were found

Table 4 Proportion of registered patients ≥ 18 years with type 1 diabetes who were treated with an insulin pump, antihypertensives, statins, acetylsalicylic acid and warfarin in 2011. The proportions are calculated based on the number of patients with data on medication, varying from the lowest, 2 508 (warfarin), to the highest, 2 944 (insulin pump), for the various medications

Treatment (data available)	%	% < 40 years	% ≥ 40 years
Insulin pump (n = 2 944)[1]	30.0	32.3	28.0
Antihypertensives (n = 2 530)	28.6	10.1	41.7
Statins (n = 2 531)	26.7	6.7	42.6
Acetylsalicylic acid (n = 2 524)	14.2	1.6	24.5
Warfarin (n = 2 508)	1.8	0.4	2.8

[1] Patients who did not use an insulin pump, receiving other forms of insulin treatment.

Table 5 Distribution of values for HbA1c, blood pressure and lipids in patients ≥ 18 years with type 1 diabetes followed up in the specialist health service and with data recorded in the Data Register in the period from 1 July 2010 to 31 December 2011

Risk factors (data available)	Median and (10–90 percentiles)	
HbA1c (n = 3 573)	8.0	(6.7–9.7)
Systolic blood pressure (n = 2 829)	126	(110–149)
Systolic blood pressure with treatment (n = 544)*	134	(115–160)
Systolic blood pressure without treatment (n = 1 446)[1]	124	(110–142)
Diastolic blood pressure (n = 2 829)	78	(65–90)
LDL cholesterol (n = 3 422)	2.8	(1.8–3.9)

[1] Data are available on any medicament-based treatment of hypertension in 1 990 of 2 829 patients whose blood pressure has been recorded

Table 6 Percentage who achieved the treatment targets for HbA1c, blood pressure and LDL cholesterol among patients ≥ 18 years with type 1 diabetes who were followed up in the specialist health service and have data registered in the Diabetes Register in the period from 1 July 2010 to 31 December

Treatment target (data available)	Percentage
HbA1c ≤ 7 (n = 3 573)	18
Systolic blood pressure ≤ 135 (n = 2 829)	74
Systolic blood pressure ≤ 135 without treatment (n = 1 446)[1]	81
SBT ≤ 135 with treatment (n = 544)[1]	57
Diastolic blood pressure ≤ 80 (n = 2 829)	73
LDL cholesterol ≤ 3.5 (with no known cardiovascular disease and no statin therapy, n = 1 285)[2]	79
LDL cholesterol ≤ 2.5 (with no known cardiovascular disease and statin therapy = 403)[2]	42
LDL cholesterol ≤ 1.8 (with known cardiovascular disease, n = 224)[2]	33

[1] Data are available on any medication-based treatment of hypertension in 1 990 of 2 829 patients whose blood pressure has been registered

[2] Data are available on any cardiovascular disease in 1 912 of 3 422 patients whose LDL cholesterol has been recorded

Table 7 Number and percentage distributed according to sex of patients ≥ 18 years with type 1 diabetes followed up in the specialist health service with registered complications in 2011

Complication (data available)	Total number of registered complications	% for women	% for men	% for all
Coronary heart disease (n = 2 789)	162	4.6	6.8	5.8
Cerebral stroke (n = 2 789)	36	1.0	1.5	1.3
Amputation (n = 2 789)	23	0.2	1.3	0.8
Vascular surgery (n = 2 789)	33	0.6	1.7	1.2
Ulcers below the ankle (n = 2 789)	111	2.3	5.4	4.0
Retinopathy without laser treatment (n = 2 789)	394	13.2	14.9	14.1
Retinopathy with laser treatment (n = 2 789)	415	14.3	15.3	14.9
Mikroalbuminuria (n = 2 789)	195	5.6	8.1	7.0
Proteinuria (n = 2 789)	53	1.4	2.3	1.9
Lack of foot pulse (n = 1 341)	53	3.2	4.6	4.0
Peripheral neuropathy (n = 1 382)	148	7.2	13.8	10.7
eGFR (n = 3 594):				
< 15	3	0.1	0.1	0.1
15–29	25	0.5	0.9	0.7
30–44	54	1.5	1.5	1.5
45–59	95	3.4	1.9	2.6
≥ 60	3 417	94.5	95.6	95.0
At least one episode of serious hypoglycemia during the past year (n = 1 812)	299	18.2	15.1	16.5
Hospitalised at some time for ketoacidosis (n = 1 700)	307	21.7	15.1	18.0

in 9 % with estimated glomerular filtration rate (eGFR) ≥ 60 ml/min/1.73m^2 and in 18.3 % with eGFR < 60 ml/min/1.73m^2.

Discussion

Age distribution

Based on data in the Diabetes Register, patients with type 1 diabetes constitute a relatively young patient group, with two-thirds under 50 years of age and only 4 % who are 70 years or older, as against 10 % of the population as a whole (10). Several factors may contribute to the low number of patients ≥ 70 years: a greater number of older patients are probably monitored by their own GP and are not included in this study. This explanation is backed by the Scottish and Swedish diabetes registers (11, 12), which also incorporate considerable reporting from GPs, showing that approximately 7 % of patients with type 1 diabetes are 70 years of age or older. The incidence of type 1 diabetes has increased in recent decades with the result that a relatively large proportion of patients with type 1 diabetes are still young. It is also likely that patients with type 1 diabetes have reduced life expectancy. At the time of diagnosis, Type 1 diabetic patients under 15 years of age and born in Norway in the period 1973–1983 had four times higher mortality than the general population (13). In a recently published US study, life expectancy was 15 years shorter for diabetic patients diagnosed in the period 1950–1964 compared with patients diagnosed in the period 1965–80 (14). A study from Scotland in the period 2005–07 showed more than twice as high mortality in patients with type 1 diabetes compared with the general population (15).

Procedures conducted

It is a matter of concern that recommended ophthalmoscopy (6) is only documented in 71 % of patients at the hospitals that have used the diabetes electronic medical record since 2009. It is uncertain whether this is because the patients have not in fact been examined by an ophthalmologist or whether there is a lack of communication between ophthalmologists and doctors at the diabetes outpatient clinics. In comparison 86 % of patients with type 1 diabetes in Scotland (in the past 15 months) and 96 % in Sweden (in the past two years) had undergone eye screening (11, 12). The national diabetes guidelines recommend annual foot examinations for all people with diabetes. We find that foot examinations have been performed in line with the current recommendations in only two-thirds of patients – this is better than in Sweden (58 %), but poorer than in Scotland (93 %) (11, 12). There are also deficiencies in the implementation of simpler routines, including measurement of HbA1c and blood pressure (Table 3). In a review of patient records at one of the hospitals, it transpired that the main reason for the lack of HbA1c in the data set was that the patient had not been followed-up at the outpatient clinic due a shortage of doctors (unpublished data, Stavanger University Hospital).

Treatment of risk factors and achievement of goals

Based on the Diabetes Control and Complications Trial (DCCT) and other studies (3, 16–18), treatment targets for patients with type 1 diabetes are that they should have approximately normal blood sugar levels. This may be difficult to achieve because intensified insulin treatment can produce an unacceptably high risk of hypoglycemia. Nevertheless, it is disturbing that 22 % of the patients have poor glycaemic control with HbA1c ≥ 9 %, while only 18 % have good control with HbA1c ≤ 7 %.

The percentage of patients reaching the treatment target is similar to that achieved in Sweden where 15.2 % had HbA1c < 6.9 % in 2011, and better than in Scotland where only 22 % had HbA1c < 7.5 % and 37.3 % had HbA1c > 9 % in the same year (11–12).

Type 1 diabetes is associated with considerably higher risk of cardiovascular disease (19, 20, 21), but it is unclear whether hyperglycemia per se also contributes to this. In Scotland the risk of cardiovascular disease was found to be 3.0 and 2.3 times greater in women and men respectively with type 1 diabetes compared with the general population (15).

It is also worrying that so few achieve the treatment targets for lipids. 19.6 % of the patients with type 1 diabetes were registered as daily smokers in 2011 compared with 17 % (aged 16–74 years) in the general population (10). In 2011, 25 % and 12 %

respectively of patients with type 1 diabetes in Scotland and Sweden smoked (11, 12). This indicates that we must have a greater focus on smoking cessation and the treatment targets for HbA1c and lipids in patients with type 1 diabetes.

Complications

Overall the incidence of retinopathy with or without laser treatment is the same – probably indicating under-reporting of retinopathy without laser treatment, perhaps due to a failure of communication between ophthalmologists and diabetes outpatient clinics. It is important to improve screening of changes in the eye fundus since retinopathy is also associated with four times higher mortality (22). In comparison, retinopathy without laser treatment is more frequently reported in Scotland (12). Serious renal failure is almost certainly somewhat underestimated because such patients are often monitored by nephrologists. The Diabetes Register should endeavour to include these patients as well to acquire an overview of the number and course of renal complications.

Limitations

The patient base constitutes approximately 15 % of the 25 000 people assumed to have type 1 diabetes in Norway, and in addition not all the data sets are complete. We do not have exact figures for how many patients attend each outpatient clinic, and how many of those who have had a check-up were asked about inclusion in the register. We cannot therefore calculate the percentage of patients included. Several outpatient clinics are at an early stage of delivering data to the register and have therefore only recorded data for a relatively small proportion of their population. Therefore we cannot rule out a degree of selection of patients in our study. Despite these limitations, we believe that the data are representative since the patients are registered as far as possible on a continuous basis when they report for a routine check-up, and 95 % of the patients have consented to having their data sent to the register.

The use of a standardised diabetes electronic medical record and the automatic collection of laboratory data indicate that the data are valid, but we have not conducted systematic studies confirming whether the data are transferred correctly to the Diabetes Register. The only laboratory sample in which the designation is not currently standardised is albumin in the urine, which may result in a rather low registration of this procedure (Table 3).

The proportion of patients for whom complications have been registered is generally high, with the exception of examinations for foot pulse and neuropathy and of information about hypoglaecemia and ketoacidosis. With the exception of retinopathy, our reporting of complications is fairly similar to the Scottish survey (given in parentheses) (12): coronary heart disease 5.8 % (6.4 %), foot ulcers 4.0 % (4.3 %), cerebral stroke 1.3 % (2.1 %), amputation 0.8 % (0.6 %) and retinopathy 29.0 % (51.2 %). This also indicates that our data are representative and valid. The Swedish diabetes register has not published comparable data on complications in 2011.

Conclusion

The collection of data for the Norwegian Diabetes Register for Adults is progressing well. Data on the quality of diabetes treatment are available, and participating outpatient clinics can compare their own data with that of others for the first time. This offers ample opportunity for quality improvement measures locally. However, the Diabetes Register lacks data from certain parts of Norway and the basis for comparison will be improved when the eastern part of Southern Norway and Central Norway contribute their data.

The preliminary results show that there is room for improvement especially regarding the treatment of hyperglycemia and dyslipidemia, and only 10 % of the patients achieve all the treatment targets for HbA1c, LDL cholesterol and blood pressure. The patients must be motivated to stop smoking, and the recommended procedures must be followed to a greater extent. We are of the opinion that the use of a dedicated diabetes electronic medical record that facilitates systematic follow-up and regular reporting to the Diabetes Register will be important factors in meeting these challenges.

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