

# Swedish diabetes register, a tool for quality development in primary health care

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**Introduction:** In Sweden, quality indicators in health care have been the basis for developing National Quality Registers. The Swedish National Diabetes Register (NDR) – one of the largest diabetes registers globally – was introduced in primary health care (PHC) in the county of Östergötland by an implementation project, 2002–2005. **Aim:** The aim of the present paper was to investigate, by using the results of the NDR, whether the registration led to sustained outcomes of medical results of diabetes care in PHC in the county during the period 2005–2009. **Method:** HbA1c, blood pressure (BP), albuminuria and low-density lipoprotein-cholesterol were registered online in the NDR. In 2005 and 2006, goal achievement for HbA1c was measured and compared between PHC centres (PHCC) within the county. In 2007, achievements to national goals were compared between the PHCCs within the county and with those Swedish counties that had attained a sufficiently high registration rate. In 2008 and 2009, the average county results were compared with the corresponding national average measurements for all 21 Swedish counties combined. **Result:** In 2005, a clear improvement trend for HbA1c and BP was shown within the county. In 2007–2009, goal achievements in the county studied were slightly better than the other counties measured and the country as a whole in almost every comparison. **Discussion:** The present study has shown association between medical results and registration in the NDR. As the project was primarily a quality improvement work, the results have continuously influenced the development of diabetes care. Both the health professions and the county council now have – in the NDR – an effective and rapid method for evaluation and follow-up of diabetes care. The systematic documentation, followed by comparisons and analyses, create ideas for care improvements.

**Key words:** diabetes care; medical result; primary health care; quality improvement; quality register

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## Introduction

In 1993, the Swedish Board of Health and Welfare stated that quality assurance should be

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implemented in the Swedish health care service and referred to the need for comparison, the basis for which should be national indicators. In 2005 and 2011, the regulation was revised and patient security and responsibility of management and professional obligations clarified (The Swedish National Board for Health and Welfare, 2011).

Though quality of care has been defined in different ways, the Donabedian model of

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Structure–Process–Result is still the dominating theoretical basis for describing and measuring quality in health care (Donabedian, 1966). At first, there was a tendency to equate quality of care with conditions, such as modern equipment and the availability of health care, geographically and financially, to all inhabitants (ie, the structure level), whereas quality measuring of medical indicators were regarded as an internal material for the medical professions (Garpenby, 1997). However, on demand of the authorities it has in recent years become a greater openness and transparency.

Questions about the best outcome of care and treatments have resulted in definitions of quality indicators. In Sweden, quality indicators for treatment and care of patients with different diagnoses have been the basis for developing National Quality Registers. There were 71 national quality registers in the Swedish health and medical service in 2010 (SALAR (Swedish Association of Local Authorities and Regions), 2010). The registers, which are annually monitored and approved for financial support by an Executive Committee, contain individualized data recording patient problems, medical interventions and outcomes after treatment. Most of the Swedish national registers keep data concerning specialities in hospitals, for example, stroke and hip replacement surgery, whereas there has been less reporting to national quality registers in primary health care (PHC). One reason could be that quality improvement processes in family medicine are complex and often lead to increasing workload for general practitioners, whose work has to be conducted so that certain patient groups are not neglected. (Tapp *et al.*, 2009). However, as the registers reflect ‘real-world’ management – unlike clinical trials – they can show differences in patient outcomes in different clinics/centres, and thereby make a valuable basis for comparisons, learning and quality improvements (SALAR, 2007).

Studies of a large-scale, multicentre register of adherence to Heart Failure Quality-of-Care Indicators in the US hospitals showed a great variety in conformity with the quality indicators (Fonarow *et al.*, 2005). The study consequently revealed that treatment and care frequently did not follow guidelines. One important conclusion was that development of an educational and quality improvement programme should have the potential to considerably reduce variability in care and improve the outcome for patients (Fonarow *et al.*, 2005).

In a study of implementation of quality measures in children’s health care, Shaller (2004) emphasizes the importance of standardization of quality measures. The standardization may sometimes conflict with the need for innovation and flexibility, but Shaller stresses that this tension must be managed by quality leaders to maintain a balance between the two.

Diabetes mellitus is one of the common national diseases and most of the patients in Sweden with type 2 diabetes are taken care of in PHCs. The Swedish National Diabetes Register (NDR) is one of the largest diabetes registers globally. It is a Result Register (all data are related to the degree of achievement of national targets) of Quality Indicators concerned with diabetes care. The NDR was initiated in 1996 by the Swedish Society for Diabetology as a response to the demands of the St. Vincent Declaration for Quality Assurance in Diabetes Care in 1989. National guidelines for diabetes care were established at the same time (Gudbjörnsdottir *et al.*, 2003).

The Quality Committee in PHC in the county of Östergötland in Sweden was commissioned to follow and stimulate quality improvement, especially in the care of the major national diseases and primarily diabetes. The Structure–Process–Result model was used to follow and analyse the development of quality in diabetes care (Donabedian, 1966). On the structure level, there were the conditions at the PHC centres (PHCC), such as guidelines for diabetes care and a surgery with a university-educated diabetes nurse specialist. On the process level, there were the control and treatment actions that took place and, finally, on the result level, the medical results. The NDR contained aggregated data on both treatments and results. Therefore, the Quality Committee initiated an implementation project with the aim to get all PHCCs in the county to start continuously recording their patients’ visits to the diabetes nurse specialists in the NDR. The stages of the implementation programme were described as: (1) Exploration and Adoption, (2) Programme Installation, (3) Initial Implementation, (4) Full Operation, (5) Innovation and (6) Sustainability (Fixsen *et al.*, 2005). The project had significant support from the management, allocated resources and specialized personnel – factors of importance for successful implementation (Lukas *et al.*, 2008) – and from 2002 to 2005, the stage of full operation

had been reached. During that period, the county council financially supported the PHCCs reporting to the register by the Pay for Performance concept (P4P; AHRQ (Agency for Healthcare Research and Quality) Resources, 2006).

In Sweden, there were about 8.9 million people in the first year of the implementation project (2002), and in the studied county there were 424 000 inhabitants. According to the estimated diabetes prevalence of 4%, there were about 360 000 patients with diabetes in the whole country and 16 000–17 000 in the county. Type 2 diabetes was predominant (85–90%) and these patients were treated and followed up at the PHCCs. In the year 2002, the registration rate in PHC in the county rose from 12% to 49% (from 2000 to 8000 patients), whereas the increase in the country went from 8% to 11% (30 000 to 39 000 patients). The coverage continued to increase in the following years, and in 2005, the average registration rate in NDR in the county was 75%.

## Aim

The aim of the present paper was to investigate, by using the results of the NDR, whether the registration led to sustained outcomes of medical results of diabetes care in PHC in the county during the period 2005–2009.

## Method

When the patients in the present county studied visited the diabetes nurse specialist, the variables that were followed up, HbA1c, blood pressure (BP), albuminuria and low-density lipoprotein (LDL)-cholesterol, were registered online in a standardized NDR formula. The Research and Development unit annually collected data from the NDR, compiled, analysed and presented the result to the county council and the PHCC managers. The study included the total number (and no sample) of patients consecutively registered by their visit to the diabetes nurse.

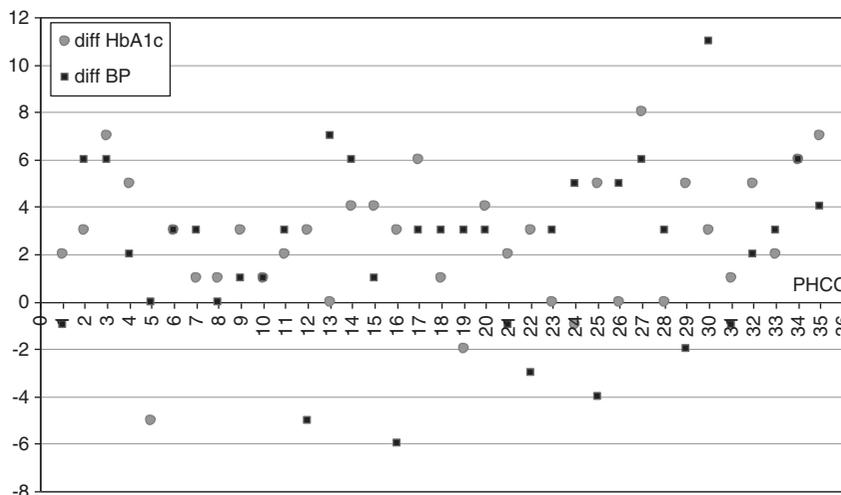
The medical goals in the NDR are stated by national guidelines, which have, for some indicators, been revised during the study period. As this project was to follow up diabetes care in clinical practice, the current values of the revised targets have been used in most of the results reported.

For example, on national level, the goal value for HbA1c was set to 6% from the year 2007. During the implementation project, the goal value was 6.5%, and in the county there has been great interest in following the development on a similar basis, that is, the same medical goals, even after 2007. This has only been possible with data generated within the county, which might complicate comparisons, but the project was in the first place a retrospective study in clinical practice and not a research project. Therefore, the access to data concerning other counties has been limited to what the NDR has presented in their national reports.

To get a sufficient sample size for comparisons both within the county studied and between counties, the study group set a 50% registration rate as the target where experience and learning could take place. This level (50%) was reached at each one of the 42 PHCCs in the county of Östergötland in 2005, and medical results, in terms of quality indicators, have since then been studied and compared between PHCCs within the county.

The project was predominantly a quality improvement work. Consequently, some variables have been studied just for a couple of years in order to follow up special improvement works, whereas HbA1c and BP have been followed up annually. Year-to-year planning of the study was based on needs and questions from the clinical practice and discussions in the Quality Committee. There were continuous measurements of goal achievements during the project years as the basis for the reimbursements. In 2005, the last year of the P4P programme, there were two occasions of measurements (April and October) of goal achievements for HbA1c and BP. A comparison was made between those 36 PHCCs that participated on both occasions. After 2005, there has been only one compilation of results each year. In 2006, the goal achievement for HbA1c was measured and reported, both for all treatment groups together and patients treated only by diet. In 2008 and 2009, all treatment groups, that is, insulin, oral and insulin combined, oral alone and diet treatment were reported separately.

The county of Östergötland was the first in Sweden to start a compulsory NDR registration in PHC, but gradually other PHCCs in the country started recording their diabetes patients in the NDR. Comparisons on national level have been published in annual reports since 2007



**Figure 1** Differences in goal achievements at each primary health care centres in the county studied for HbA1c  $\leq 6.5\%$  and systolic blood pressure (BP)  $\leq 140$  mmHg at two measurements in 2005, the last year of the Pay for Performance programme. Difference calculated as achievement to goal (%) in October minus achievement to goal (%) in April. Difference  $>0$  = improvement, difference  $<0$  = worsening.

(The Swedish National Board for Health and Welfare, 2010a). A registration rate of 50% was at that time achieved in PHC in eight Swedish counties, the county studied included, and a comparison of goal achievements for HbA1c and BP between those counties was made. In 2008–2009, the registration rate in the whole country had reached a level of meaningful comparisons. The average measurements of the county studied of goal achievements for HbA1c, BP, LDL-cholesterol and the absence of albuminuria were compared with the corresponding national average measurements for all 21 Swedish counties combined.

The results were presented in descriptive, aggregate statistics (Excel, 2007) showing percentages of patients, achieving national goals for different quality indicators in diabetes care.

The project did not involve any interventions in the regular diabetes treatment or use of confidential individual data, which is why ethical approval was not needed.

## Result

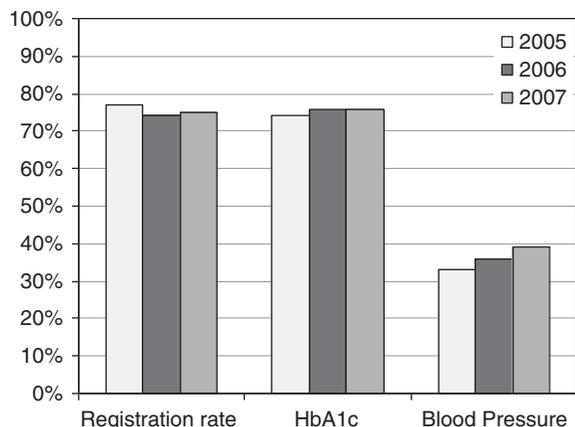
In the measurements in April and October 2005, the last year of the P4P programme, the county

average achievement for HbA1c ( $<6.5\%$ ) was 70% and 72%, respectively, and for BP ( $<140$  systolic) 61% and 63%, respectively. Comparisons between the measurement occasions were made on PHCC level and showed a clear improvement trend, as most of the PHCCs (27/36 respective 26/36) reached a better result in October than in April (Figure 1).

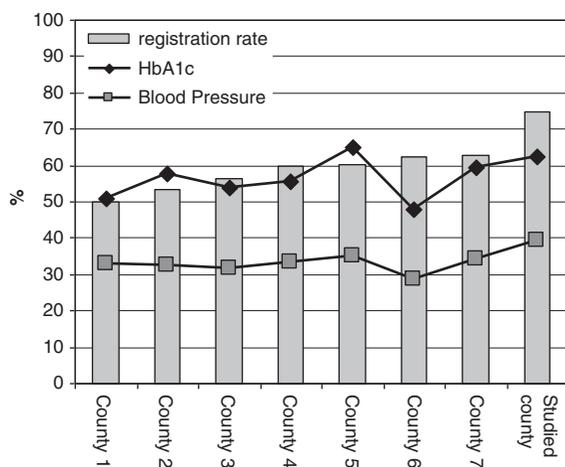
During 2005–2007, a little more than 12000 patients were registered annually. The measurements of the quality indicators for HbA1c ( $<6.5\%$ ), for all treatment groups together, and BP ( $<130$  systolic) showed a tendency of improved values (Figure 2).

In 2006, the goal achievement for HbA1c  $\leq 6.5\%$  was 76% for all patients collectively. According to the national guidelines, there was a target level of HbA1c  $\leq 5.5\%$  for diet-treated patients that was achieved by 72% of the recorded patients.

In the annual follow-up in 2007, the results were compared, as in previous years, between the PHCCs within the county of Östergötland, but there was also, on the basis of the NDR annual report, a comparison between those Swedish counties that had reached a registration rate of at least 50% – studied county included (Figure 3). In the NDR annual report 2007, 55% of the PHC patients in Sweden had reached a



**Figure 2** Registration rate and achievements to goal for HbA1c  $\leq 6.5\%$  and blood pressure (BP)  $\leq 130/80$  mmHg on average county level. Number of registered patients in the county studied in 2005:  $n = 12\,840$ , 2006:  $n = 12\,391$ , 2007:  $n = 12\,609$ .



**Figure 3** Comparisons between national goal achievement HbA1c  $\leq 6.0\%$  and blood pressure (BP)  $\leq 130/80$  mmHg for those eight counties in Sweden, which had reached a registration rate in the National Diabetes Register of 50% or more in 2007.

level of HbA1c  $< 6.0\%$  (NDR Annual Report 2007). This led to a new target of HbA1c = 6% in the national guidelines (The Swedish National Board for Health and Welfare, 2010b), which is also the target level in the graphs below.

During 2008 and 2009, there were still a bit more than 12 000 patients registered each year. The results showed goal achievements for BP

and, for the first time, goal achievement for HbA1c, in each treatment group (Table 1).

In 2008, there were 175 413 patients registered in the NDR in PHC throughout Sweden, that is, 50% of the calculated number of patients with diabetes. In 2009, most counties delivered data from the majority of their patients with diabetes, and the number of patients then registered in PHC in Sweden was 216 851. In the present county studied, there were 12 327 (2008) and 12 777 (2009) patients registered at all PHCCs combined. Results of measurements from the county studied and the country as a whole were compared. With one exception – HbA1c in 2009 – goal achievements in the present county studied were slightly better than in the country as a whole (the studied county included). In Figure 4, goal achievements for HbA1c, BP, LDL-cholesterol and the absence of albuminuria are illustrated.

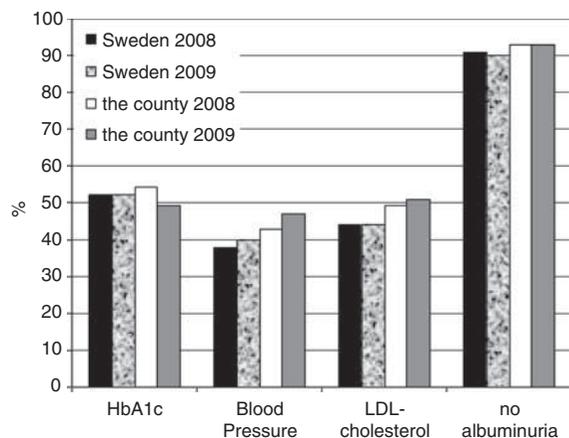
## Discussion

Although electronic patient records were introduced in PHC earlier than in hospital care, registration in national registers has been less applied in PHC than in hospitals. In this study, however, the implementation of a national quality register at every PHCC in the county was chosen to be the most appropriate way to follow up and evaluate diabetes care. The purpose was to describe whether there were medical results associated with registration rate in the NDR and how persistent they became. Before the implementation project in 2002, the current situation was not really known. There was no common tool or method for quality evaluation or follow-up in PHC. Every PHCC made their own follow-up and used their own separate quality indicators. With the implementation of the NDR there were standardized, evidence-based quality indicators introduced, which assured validity of the measurements and made it possible for comparisons within the county and also with other counties and country average (Hallgren Elfgrén *et al.*, 2012). The aim of the national quality registers is to collect and use data from everyday medical care, as the basis for research and development. One prerequisite is, however, that there must be data enough to be able to see and interpret trends and results. Diabetes is a major national disease with an estimated prevalence of 4% in

**Table 1** Number of patients with diabetes in primary care in the county studied and achievements to goal for HbA1c in different treatment groups and fulfilment of goal for blood pressure 130/80 mmHg for all treatment groups together during 2008–2009

Year	Number of patients with diabetes in the county (estimated, prevalence 4%)	Registration rate in the NDR	Insulin treatment, HbA1c $\leq$ 6.5%	Combined treatment, oral and insulin, HbA1c $\leq$ 6.5%	Oral treatment, HbA1c $\leq$ 6.5%	Diet treatment, HbA1c $\leq$ 5.5%	BP $\leq$ 130/80 mmHg
2008	16 906	73%	59%	55%	77%	68%	43%
2009	17 057	75%	53%	45%	74%	60%	47%

NDR = National Diabetes Register; BP = blood pressure



**Figure 4** Goal achievements for HbA1c < 6.0%, blood pressure (BP)  $\leq$  130/80 mmHg, low-density lipoprotein (LDL)-cholesterol < 2.5 mmol/l and patients with no presence of albuminuria in primary health care. Comparisons between the present county studied and Sweden as a whole (21 counties, studied county included) in 2008 and 2009.

Sweden, about 9 million people. In the implementation project, the goal was to cover at least 75% of the diabetes patients in the county (16 000–17 000), and no comparisons, within or outside the county, are made with <50% coverage of patients registered in the NDR.

Already after the first year of the county council's financial support during 2002–2003, improvements of medical results associated with an increasing registration rate in the NDR could be seen (Östgren *et al.*, 2005). After the financial support ceased, the registration rate was kept on the same level, that is, about 75%, and in this study (2005–2009), sustainability and even improvements of medical results as goal achievements for BP, cholesterol and HbA1c (with one exception in 2009) could be reported.

That structured guidelines and local division registers in general practice lead to improvements of quality in diabetes care has been suggested (Georgiou *et al.*, 2006; Taggart *et al.*, 2008), and today the majority of the PHCCs in Sweden use regional or local guidelines and also have a diabetes practice led by a nurse specialist, where all patients with diabetes are monitored (Adolfsson *et al.*, 2010). Another factor related to better outcomes in health care is high volume of medical procedures, especially in surgery but also in other treatments (Halm *et al.*, 2002; Urbach, 2004). As PHC is organized in a decentralized way with a heterogeneous patient base, a high volume at each centre is difficult to achieve. Therefore, documentation, in national registers, of care interventions and treatments in PHC is a way to gather experiences from large parts of the country. This was confirmed in a report in 2010 (SALAR, 2010), and in a widespread disease like diabetes, the national register is a prerequisite for taking advantage of the high volume of treatments and patient outcomes.

As this project was primarily a quality improvement work, the studied variables were guided by the needs in the clinical praxis. The medical results reported by the NDR statistics, formed the basis for different local projects. It was important, however, that the evaluations of these projects were always presented in forms of the standardized quality indicators established in the NDR, which made outcome comparisons possible (Shaller, 2004). The project has taken an action research approach, as the data of the results have been continuously considered and influenced the development of diabetes care. In a research design there would have been systematic selections of variables. In this project, the clinical practice has driven the development and this has

influenced both which and for how long variables have been followed up. Sometimes a single variable might have been followed for just a year or two, for example albuminuria, when treatment of patients at risk of kidney damage has been specially focused on. Others, HbA1c and BP, have been followed over the entire study. Regardless of changes in the target value, what was supposed to lead to improvement was the systematic documentation, comparisons, analyses and discussions – ‘measuring makes aware’ – among medical professional groups, which would create ideas for care improvements.

This project was a pioneering work concerning national quality registers in PHC. In the county studied, there was a rapid progress of the registration rate in the NDR and this aroused interest in other county councils in Sweden. Dissemination of experiences and results between PHCCs, within and among counties, has been important in the project and hopefully helped to take advantage of the benefits of the high volume. Today there is a high NDR registration rate in PHC in the whole country. The NDR is used as a tool for quality evaluation and follow-up of diabetes care in all counties (The Swedish National Board of Health and Welfare, 2010a). As there was no comparable documentation on a national level at the start of this project, all compared data are the results of the use of this ‘improvement tool’. In light of the developments in the county studied, there is reason to believe that there have been continuous improvements even in the other counties, associated with an increasing rate of registration in the NDR. Therefore, the differences in medical goal achievements between the counties must be assumed to be decreasing, as the differences in registration rates decrease. The results of the studied county also had a greater effect on the national outcome average during the first years as they were (and still are) included in the national basis. In 2007, there were, however, eight counties that reached at least 50% registration rate, and the first comparison between counties was presented and showed rather similar results. At that level (50% coverage), comparisons between PHCCs were considered to be associated with low risk of some centres reporting a selective sample of patients (with the best medical results). However, in the present county studied, the ambition still was that all PHC patients with diabetes should be reported to the NDR.

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There might, of course, be some slumps in sustainability of the registration rate or achievements of medical goals, which may be due to organizational changes or the needs of new educational initiatives when well-trained staff leave and must be replaced (Lukas *et al.*, 2008). Nevertheless, the aggregated NDR statistics highlights problems or trends to be analysed and discussed in professional teams. Although there is still a current debate about the interpretation of medical statistics and on what basis comparisons between PHCCs are to be made (Dagens Samhälle (in Swedish)), the quality registers and regional comparisons have resulted in a more open approach in health care and to the public (The Swedish National Board of Health and Welfare, 2010a).

In conclusion, the present study shows better and sustained medical outcomes associated with registration in the NDR. The study also indicates that both the health professions and the county council have, through the NDR, got an effective and rapid method for evaluation and follow-up of diabetes care at the aggregate level. Thereby, opportunities to take the necessary steps towards further improvements can be created, which could include testing alternative therapies/treatments, follow up subgroups of specific risk patients to assist them in handling their disease, developing patient education or revising local guidelines.

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