The process of implementation of the diabetes register in Primary Health Care

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Abstract

Quality problem or issue. According to Swedish law, all health care units must have a system for quality improvement. The aim of this study was to follow an implementation process of a uniform routine for quality control of diabetes care in Primary Health Care in one county.

Initial assessment. Primary Health Care had a decentralized organization and patients with type 2 diabetes were served at 42 different Primary Health Care Centres.

Choice of solution. As the Swedish Diabetes Register (National Diabetes Register, NDR) holds the most important quality indicators, implementation of the NDR registration at all centres was chosen to be the best way to follow up quality in diabetes care.

Implementation. The process of implementing the NDR went through different phases and the main way to encourage commitment to the process was to reward performance in a progressively more differentiated way.

Evaluation. During the implementation process (2001–05) there was an increasing rate of registration. When the programme ceased, the registration rate had reached a level of 75%, which has remained stable and was still in 2010 one of the highest rates in Sweden.

Lessons learned. Important factors for success were the initiative taken by the profession itself and strong support from the leaders of the county council. It was also important to let the process develop gradually in order to get all staff involved. Among the outcomes was an increase in computer use in clinical practice among the diabetes nurse specialists and a structured way of encouraging the patients’ participation in self-care.

Keywords: quality improvement, quality management, endocrine disorders including type 2 diabetes, Primary Health Care/general practice, quality registers, implementation process

Quality issue

According to Swedish law, all health care units have to maintain a system for quality evaluation and improvement [1]. One such nationwide system is the National Quality Registers.

National quality registers in the health service

The Swedish Quality Registers have been recognized as valuable for building up databases by continuously reporting data from everyday clinical work [2]. The registers are based on personal identification numbers that have made it possible to cover a whole population and to study developments in diseases and treatments over time. The purpose of the national registers is to provide the medical care with data that show areas in need of improvement, and to present register data to enable the evaluation of improvement work and use the data in research projects. In 2010, there were 71 Swedish Quality Registers, most of which provide data for use in somatic care in hospitals. Primary Health Care is still a field where only a few registers are applicable [2] one of which is the Swedish Diabetes Register (National Diabetes Register, NDR).

Diabetes registers

There are 31 million people with diabetes in the European Union. Each country has different frameworks for planning treatments and routines for follow-up and evaluation. The NDR is described as being the most comprehensive Diabetes Register in Europe [3]. In 2008, the NDR was combined with SWEDIAKIDS, a register listing all children with diabetes in Sweden. Thereby, it is possible to follow the course of the patient’s disease throughout life [4].

In Europe, Denmark also keeps a Diabetes Register with data about prevalence, incidence and mortality but with no
quality indicators reflecting achievement of medical goals [5]. Outside Europe, there are countries with different kinds of Diabetes Registers, e.g. The Caritas Christi Health Care System, which established a unified American Diabetes Association (ADA) [6]. The Caritas Diabetes Register has a central role in an educational programme containing information between patients and their caregivers as well as self-management education. Another example is the NDR in Australia [7], a database that collects information about people using insulin. The register is used in epidemiological and clinical studies and provides health service providers and planners at commonwealth, state and local levels with information.

Local quality improvements

In the late 1990s, the process of creating quality improvement systems in Sweden had advanced faster in hospitals than in Primary Health Care Centres (PHCC). As the prevalence of diabetes during the studied period was estimated as 4% of the population, there were \( \approx 350,000 \)–\( 400,000 \) persons with diabetes in Sweden (9 million inhabitants) and about 16,000 in the county studied (424,000 inhabitants). Type 2 diabetes was predominant (85–90%) and the patients with diabetes type 2 were taken care of at the PHCCs [8].

Initial assessment

Primary Health Care in the county is organized in a decentralized way. Patients with type 2 diabetes—adult and elderly patients, often with other chronic diseases or health problems—are treated and followed up at 42 PHCCs ranging in size from 4000 to 20,000 inhabitants, where the staff consists of general practitioners (GPs), nurse practitioners, diabetes nurse specialists, other nurses and medical secretaries. There is also access to paramedical and laboratory personnel organized differently depending on the size of the PHCC.

Choice of solution

In 2001, the NDR was in use in hospital clinics but hardly anywhere in primary health care in the whole country, though most diabetes patients were taken care of at the PHCCs. Therefore, it was decided to implement NDR registration as a mandatory routine at every PHCC in the county studied. The Research and Development (R&D) Department of Local Health Care was instructed to plan, organize and follow the entire implementation process.

To encourage the implementation of the NDR, the county council decided in 2002 to financially support the PHCCs’ registration. This was done according to a Payment-for-Performance (P4P) programme [9]. The programme stated that each PHCC was paid an initial financial incentive, \( \approx €5000 \), when officially starting the NDR registration. After this first incentive, differentiated and progressive amounts related to the number of patients being registered were paid out annually until 2005. The county council annually reserved \( \approx €650,000 \) for the implementation of the NDR. To get any reimbursement 50% of the diabetes patients at the PHCC must be reported and to get the maximum payment 75% must be reported. This was the threshold values throughout the programme and in 2005 the financial incentives ranged in size from \( \approx €2000 \) to \( €40,000 \).

Establishment of the goal levels of registration rates

After the decision to report to the NDR, the next step was to establish a level of registration rate where the new routine was considered successfully implemented.

To get an exact number of diabetes patients, a statistical extract from the electronic record database was needed. “Diagnosis” according to the ICD 10 [10] was a keyword used exclusively in the physician’s medical records and not in the nurse’s, which proved to be a weakness. It was necessary to go back 3 years in the electronic patient record database to retrieve all the patients, as many of them did not have an annual appointment with the physician, but visited the diabetes nurse specialist for regular check-ups once or twice a year. Having considered this, the percentage of the patients identified by the electronic record database, who were also identified by the NDR registration process, could be calculated.

The researchers and physicians in the Quality Committee considered 75% registration rate to be a reasonable level for maximal reimbursement. In principle, all patients with diabetes are listed in a PHCC, but to reach 100% registration rate would be difficult for most of the centres, depending on the organization and that populations served by different PHCCs differ in age distribution. The prevalence of diabetes increases with age [11] and some elderly patients live in nursing homes where most health care is provided by a municipal nurse [12]. The diabetes nurse specialists are situated at the PHCCs and see all patients living in their own homes, whereas people with diabetes who live in nursing homes are checked up by the municipal nurse. As the NDR registration was done only by the diabetes nurse specialists at the PHCC, some of the elderly patients were not being reported, despite their inclusion in the population of patients with type 2 diabetes. Multi-disease problems also affect some elderly patients [11] and this may sometimes lead to care in hospital and not in primary health care. Another obstacle to achieving 100% participation was that 5–6% of the population annually move out or into the county. Approximately 3% of the patients also moved between PHCCs within the country. All this affects the full-year statistics.

Implementation

Quality analysis

Quality analysis of improvement work can be done on three levels: Structure–Process–Result [13]. As the aim of this
study was to follow the implementation of a new routine, the focus was on the process level.

**Steps of implementation**

The structural level of quality in diabetes care includes a surgery staffed with a diabetes nurse specialist. In 2001, this demand was fulfilled in most PHCCs in the county. The predominant portion of the diabetes patients was also taken care of in the PHCCs, but reporting to the NDR was almost non-existent in primary health care. As an action on the process level of quality development, the county council decided to introduce the NDR in primary health care. This was the first step of the implementation process (exploration and adoption) [14]. As a first incentive the county council reserved ~€5000 per PHCC the first year of the programme when completion of technical equipment and staff training started at all PHCCs (Program Installation) [14].

According to the Normalization Process Theory [15], it is of great importance that new ways of working become routinely embedded in everyday practice. Therefore, it was important that all diabetes nurse specialists started recording their patients at their regular visits. The heads of the PHCCs were responsible for creating the educational and technical conditions needed. There were some difficulties getting started in some places, but after some start-up problems, the number of patients recorded in the NDR significantly increased.

The financial support (a total of €650 000 annually) was a strong incentive throughout the implementation programme. After the first-year bonus, the reimbursements became more and more differentiated and finally turned into a sliding scale where the PHCC was paid in relation to the exact percentage of their diabetes patients that they reported. From 2002 until 2005, the P4P programme was carried out and the implementation had reached a stage where the registration routine was embedded in everyday practice [15].

P4P programmes had been introduced in health care in other countries and there was an increasing enthusiasm for linking payment with performance [16, 17]. However, not only positive effects but also some unintended effects of the financial incentives have been found, for example, so-called adverse selection, which means avoiding the most severely ill patients when improving measures get a higher level of reimbursement, or ‘gaming behaviour’ whereby the incentives produce improvements in documentation rather than in the quality of health care [18]. Neither adverse selection nor gaming behaviour observed in this study.

Whether to focus on measurements of process or measurements of outcome when defining the goals is important, as is whether to design the incentive target as an absolute or a relative performance goal. Still, the size of the financial incentive provided by a P4P scheme seems to be the key factor in motivating changes in behaviour [19].

**Support from the NDR**

Registration was initially carried out on paper forms and sent to the NDR administration to be inputted into a national database. Statistical summaries were done by the NDR administration and sent to the project leader once a year or on request. After online registration was initiated in all PHCCs in 2003–04, statistics could be taken out of the system at any time. Although the local nurses had begun to use electronic patient records in 2002 and thereby had started to use keywords in computerized documentation [20], the NDR also financially supported a specially educated nurse to supervise the local diabetes nurse specialists in online NDR registration.

During the project there was a continuous dialogue between the project leader and the NDR. There were also internal meetings with the county council. One physician, who was the NDR coordinator for primary health care, participated actively in the project and served as an intermediary to GPs and diabetes nurse specialists at all the PHCCs.

**Evaluation**

There was already an effect of the implementation programme in the first years—a much larger relative increase in the number of NDR-reported patients in the county than in the country in general (Table 1).

In most Swedish counties during the studied period, registration in the NDR increased in hospitals, whereas in primary health care only sporadic PHCCs started reporting. However, in the county studied, most PHCCs soon reached a registration rate of 50%, but in September 2004 there was still a variation from 16 to 98%. Between the measurement occasions in September 2004 and in April 2005, there was an average increase of registration rate from 62 to 78% but still a variation from 21% to nearly 100%. In 2006, the registration rate from 2005 remained (Fig. 1).

However, most of the PHCCs which at first remained on a lower registration rate gradually increased their number of registered patients and the registration rate among the units thereby became more even. The PHCCs are compiled below after the September 2004 ranking and the development of the registration rate is shown for every separate PHCC (Fig. 1).

By comparison with Sweden as a whole, it can be seen that in 2005—the last year of the P4P programme—the registration rate in the county studied had increased much more than the rate in the country overall (studied county included) (Fig. 2).

**Table 1** Annual numbers of primary health care registrations in the NDR

<table>
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<th>Year</th>
<th>Number of patients</th>
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| The county | 2664 | 6783 | 8273 | 12 777 |
| Sweden     | 32 501 | 34 652 | 49 289 | 216 851 |
Although the reimbursement for registration ceased in 2006, the National Report of Regional Comparisons 2009 revealed that the registration rate in the county studied was still one of the highest in Sweden [21]. The good results themselves also served as incentives for sustainability and the activity is now embedded in everyday practice [14, 15].

Lessons learned

According to Fixsen et al. [14], the support of political and financial systems is of great importance all through the implementation stages. The county council’s decision to support registration in the NDR dramatically increased the share of patients reported in only 2 years. A broad approach and active individual support to help all diabetes nurse specialists start online registration has also been important for getting the method routinely incorporated in everyday work [15]. That this would also lead to improvement in diabetes care was an assumption. Before the project, there was no consistent picture of the quality of diabetes care in primary health care in the county. Today, comparisons between units and over time can be done at any moment. Improvements of diabetes care in terms of achievement of national medical goals have also been seen in a minor study [22]. However, following the implementation of a new routine was the aim of this study, and some observations are noticeable.

Diagnoses by the ICD 10 system [10] were registered exclusively in the physician’s electronic patient record. Many patients with type 2 diabetes were missing in the annual extract from the database because they did not have an annual appointment with a physician, but saw the diabetes nurse specialist once or twice a year. This finding highlighted the importance of including diagnosis registration in the nurse’s record as well and today this is a mandatory duty. Notes from every visit at the nurse-led diabetes practice can be found in the electronic record database [15].

It was important that the professions initiated the project. The heads of the PHCCs—most of them physicians—stated that the NDR was the most adequate instrument for evaluating diabetes care [4]. Consequently, there was a well-based decision of participation in the P4P programme, but each centre did not get started as easily. This showed the importance of gradual development of measurements and goals and the necessity to carry out the process in stages and adapt these stages to each individual [14].

The authorities’ objective of the implementation project was to incorporate the NDR registration in everyday clinical work [15]. The heads of the PHCCs were behind the decision, and the county council had expressed their will and
allocated money for the implementation, which of course was a strong incentive for the managers. A question of importance was, however, the size of the reimbursement. If the PHCCs got enough money to hire additional nurses for NDR registration during the project, the target had certainly been reached more quickly, but there would have been less sustainability. The purpose of the implementation project was to incorporate the NDR registration in the ordinary nursing routines [15]. Therefore, the reimbursement should be large enough as a bonus, but not to fund an entire budget line.

Studies have shown that establishing a fully implemented programme often requires 2–4 years [14]. In this project some of the PHCC very soon got a high NDR registration rate, whereas others needed more time to reach the target. One reason was that the diabetes nurse specialists must learn not only online registration in the NDR, but also how to collect data from the electronic record database and there were, at the time, two different electronic record systems in use. The ‘data maturation’ was also different among the diabetes nurses and so was the fear of changes. There was, however, a comprehensive and individual support in the form of supervision in the nurse’s workplace, templates to facilitate data collecting and availability of phone support. The data reported from the PHCCs to the R&D department and the NDR data extract were continuously compiled and presented in meetings and reports. If there were problems of delivering data from any PHCC, there was always a personal contact from the project leader in order to analyse and help solving the problems. Many of the diabetes nurses also soon realized the benefits of the NDR registration at their regular patient visits. This fact as well as the close contact between the project management and the PHCCs (heads and diabetes nurse specialists) was probably—of course together with the financial support—the most important reason why all 42 PHCCs gradually went through the implementation process and reached the stage of full operation [14].

Today, registration maintains about the same level as in the last year of the programme and is routine in everyday clinical work. The computerization of the patient records [20], together with the online NDR registration routine, has contributed to the diabetes nurse specialists’ use of the computer, not only for documentation. In the meeting with the patient, the diabetes nurse now uses the NDR registration variables as a structured, pedagogic instrument that creates good opportunities to help the patient participate in her/his self-care [23]. This benefit contributes most likely to the sustainability of the follow-up method [14].

Quality management in practice should lead to better care and well-being among the patients. Therefore, during the implementation programme and afterwards, compilations of medical results (HbA1c, blood pressure, cholesterol, etc.) have continuously been reported back to the PHCCs for analysis and improvements. We have, in an early minor study, as aforementioned, found a positive association between registration rate and achievement of medial goals for HbA1c and blood pressure [22]. An association between quality improvements in health care and the quality registers has also been shown by the Boston Consulting Group [24]. Of great interest is to follow the development some years after the financial support has ceased. The next step will be to compile and analyse the NDR statistics and compare performance over time between units and with the country average.

References


