A framework for diabetes documentation and quality management in Germany: 10 years of experience with DPV

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Abstract

The DPV approach for quality management and documentation of diabetes in Germany consists of three basic modules: the diabetes documentation software DPV, semi-annual benchmarking for diabetes units (QC-DPV), and a data pool for diabetes research (DPV-SCIENT). The documentation system is available for general practices as well as for hospitals, and it supports the daily routine work of the diabetes team. The system covers a superset for all important data sets of quality initiatives in Germany. Longitudinal analyses of quality indicators related to diabetes are integrated. Twice a year, nation-wide benchmarking for pediatric diabetic units are performed, evaluating the outcome of their diabetes therapy. An improvement in completeness of control examinations could be observed during the last years in QC-DPV. The DPV-SCIENT data pool contains about 251 000 single examinations of 21 000 patients with diabetes. At least 53% of all patients with Type 1 diabetes in Germany who are less than 20 years of age are documented in DPV-SCIENT. © 2002 Elsevier Science Ireland Ltd. All rights reserved.

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1. Introduction and background

The basic impulse to implement a documentation system for patients with Type 1 diabetes at the Department of Pediatrics of the University of Ulm resulted from the memorable conference of St. Vincente in 1989. In St. Vincente, a significant decrease of diabetic related complications, such as blindness and amputations, had been demanded [1]. In order to be able to evaluate the success of the ongoing efforts, it was initially mandatory to record the current state of diabetes therapy in the early 1990s. Several quality initiatives in Germany started to collect diabetes data, mostly using standardized paper forms such as the Diabcare Basic Information Sheet. The Diabcare Initiative itself did not succeed in setting a commonly accepted standard in the process of documentation and evaluation in Germany [2]. Thus, several spin-offs of the Diabcare Initiative started to adapt and extend the Basic Information Sheet for their own needs, later designing computer programs repre-
senting electronic versions for their data sets [3,4]. Special requirements for the documentation of Type 1 diabetes in childhood led to the implementation of the DPV computer program in 1990. In the beginning, DPV was focused on pediatric patients [5] and was later extended to the needs of adult patients, never using paper sheets as an input medium. The benefits of paper documentation (e.g. easy to implement and easy to fill out) were obviously outperformed by the advantage of electronic documentation (e.g. one source serving several purposes such as patient report, quality documentation and research). Since 1990, DPV has been developed in a team cooperation between computer scientists and physicians at the University of Ulm.

3. DPV development history

The work on DPV started in 1990, and 2 years later, a first version was deployed as a stand-alone DBASE IV program to four pediatric hospitals in Germany. It allowed to collect inpatient and outpatient data and to write patient reports and data summaries. In 1993, several statistical functions were added to support internal quality monitoring for the hospitals. Two years later, the German Pediatric Working Group on Quality Control (AGPD) agreed upon approximately 200 outcome quality indicators for diabetes treatment in young patients [5]. These indicators were all integrated in DPV and could be evaluated at each center with the program. For 1995, a first nationwide benchmarking (called QC-DPV) was performed, based on aggregated quality data of 2300 patients collected in 23 pediatric hospitals using DPV. The number of patients in the benchmarking increased to 10 100 for the year 2000, treated at 103 hospitals. External benchmarking has been required in the German Social Code of Law since 1989. In 1996, DPV migrated to a MS Windows version based on MS FOXPRO 2.6, and in 1997, the system was extended to the documentation of adult patients with Type 1 and Type 2, fulfilling the needs of GPs as well as those of departments of internal medicine. Two years later, the GP version and the hospital version of DPV were separated, both based on a common data set, but each focused on different requirements such as integration in general practice software systems or hospital information systems. Since then, the GP version has been maintained by a small start-up company, a spin-off of the University, and the hospital version is still being developed at the Department of Applied Information Processing.

In the spring of 2001, there were about 160 systems installed in pediatric units, about 180 in departments of internal medicine, and about 1400 in general practices all over Germany. Since 1998,
anonymous examination records have been collected from 118 hospitals in a central data pool in Ulm (DPV-Scient). The data pool now contains about 251,000 examinations of 21,000 patients. Data are checked for integrity before they are read into the database. Hospitals receive a report for missing or inconsistent data.

This data pool mainly serves for scientific and epidemiologic research of diabetes in Germany [7–11,17]. Current estimations of the number of pediatric patients in Germany with Type 1 diabetes less than 20 years of age range from 14,000 [12] to 24,000 [13]. In the spring of 2001, we found data for 12,640 patients of this age class in DPV-Scient. This means that we have registered 51–90% of all young diabetic patients in Germany in our central database.

4. Three modules for diabetes documentation and quality management

Our approach to improve the quality of care in diabetes comprises the following modules:
- a widely used diabetes documentation and information system to collect data and to support the diabetes team in their routine work;
- semi-annual nation-wide benchmarkings for pediatric diabetes units;
- a central data pool for epidemiologic and medical research on diabetes.

4.1. The documentation program DPV

A necessary requirement for all quality management is a well-structured and standardized documentation. The computer program DPV today contains a superset of all important diabetes data sets in Germany: the Diabcare Information Sheet [14], the FQSD data sheet [3,15], the dataset used by ASD as well as the dataset required for pediatric patients in Germany [5]. Export functions for all three quality initiatives are integrated in DPV, as well as the common data exchange format for general practice software systems called ‘BDT’. Thus, the user of the program is free to choose where to send diabetes data for quality monitoring. To support pediatric as well as internal medicine departments, we created automatically adapting user screens and printouts which show different parameters for adults (≥ 20 years) or adolescents and children (< 20 years). Since the hardware requirements for the underlying 16 bit Foxpro database of DPV are very low, it is sufficient to use an IBM PC Pentium 133 MHz with 32 MB RAM and about 13 MB of free disk space for the base system, running Win 3.11 or higher. DPV supports multi-user data handling in Novell or Win NT network environments using record locking. Currently, at the largest hospital, 1100 patients with about 20,000 examinations are documented in DPV, and data are entered and accessed at five client stations. This can even be handled with the old Foxpro database based on technology of the year 1995. Due to the old-fashioned Windows GUI of Foxpro 2.6 and the restricted possibilities to access the 32-bit Windows API, we migrated DPV to Visual Foxpro 6.0, which was completed by the middle of the year 2001.

The major system components to support routine care are listed in Table 1.

Data entered into DPV can be longitudinally evaluated by each diabetes unit. Summaries of the following areas are calculated by DPV and are serving for local quality monitoring as well as for reimbursement negotiations (Table 2).

4.2. External benchmarking for pediatric diabetes units (QC-DPV)

The results from the statistical calculations are aggregated data and therefore completely anonymous—no individual patient can be identified.

A further advantage of this procedure is that the calculation is running in the hospital and must not be performed for more than 100 hospitals in Ulm. The aggregated statistical results (see also Table 2) are collected twice a year for benchmarking. The results are encrypted in each hospital and sent by e-mail or on a floppy disk to the Department of Applied Information Processing. Participating hospitals later receive printouts for each of the 68 selected quality indicators, showing the overall calculated median in a specific parameter
Table 1

<table>
<thead>
<tr>
<th>Major system components of the documentation system DPV</th>
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<tbody>
<tr>
<td>Value</td>
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<tr>
<td>Generation of patient reports (integrated report or report via MS Word)</td>
</tr>
<tr>
<td>Data summaries</td>
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<tr>
<td>Data charts including normal ranges in children</td>
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<tr>
<td>Comprehensive database queries</td>
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<tr>
<td>Serial letters</td>
</tr>
<tr>
<td>Printout of prescribed insulin doses</td>
</tr>
<tr>
<td>Data exchange interfaces</td>
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<tr>
<td>Adaptable user screens and printouts</td>
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and the hospital’s ranking among the others as well as a trend analysis for the last years. The distribution of values is separated into good (green), medium (yellow) and poor (red) allowing a quick overview of the current situation in Germany. The HbA1c values and the numbers of hypoglycemic episodes are drawn on a bivariate chart, showing the difficult balance between the two most important parameters in insulin therapy (Fig. 1).

Finally, an ultimate ranking is performed, taking into account 22 quality indicators listed in Table 3. It is calculated how often a hospital is on the ‘good side’ of a parameter, i.e. below the median of all hospitals in this specific indicator. In 2000, the best hospital managed to have 20 out of 22 (91%) parameters ‘on the good side’.

The printouts are anonymous, so no participant can identify the others. This has been wished and agreed upon by the majority of hospitals, fearing their results might be used to make the public to turn against them. Two times a year, the results of the nation-wide benchmarking are discussed in a symposium with all participants. On a regional level, there are currently six quality circles which openly discuss their outcome results. Special non-anonymous printouts are produced for their reviews.

Table 2

<table>
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<tr>
<th>Overview on statistical summaries integrated in DPV</th>
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<tbody>
<tr>
<td>Area</td>
</tr>
<tr>
<td>High risk potential</td>
</tr>
<tr>
<td>Acute complications</td>
</tr>
<tr>
<td>Chronic complications</td>
</tr>
<tr>
<td>Completeness of examinations</td>
</tr>
<tr>
<td>Diabetes education</td>
</tr>
<tr>
<td>Level of metabolic control</td>
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</tbody>
</table>
Outcome improvement over the years can be mainly found for the parameter ‘completeness of required control examinations’ (Table 4).

4.3. Diabetes data pool DPV-SCIENT

There are still a lot of unanswered questions related to therapy and epidemiology of diabetes in Germany. The request for a central data pool to enable statistical research based on single patient examinations came soon after establishing QC-DPV. Since 1998, DPV has been able to make the data completely anonymous and export the whole database content. The central DPV-SCIENT database server is located at the University of Ulm. In the spring of 2001, we had collected the results of about 251 000 examinations of 21 000 patients recorded in 118 hospitals in Germany, which were mainly of pediatric patients (12 600). The data pool is available for researchers who are contributing patient data. Several working groups are currently active, focusing e.g. on ‘Non-Type-1-diabetes in childhood’ or on ‘diabetes and overweight’. Since data is not collected in context of prospective randomized control studies but mainly result from daily routine work, one has to be very careful with the interpretation of analyses. Epidemiologic questions (e.g. the hospitalization rate in diabetic children in Germany [17]) can be answered more precisely from the data than e.g. the effect of new therapy modalities. The question of a precise estimation of diabetes Type 1 prevalence in childhood in Germany will be better answered with the help of DPV-SCIENT. Currently, a study is being run using DPV-SCIENT as a second source for a capture–mark–recapture procedure in the federal state of Nordrhein-Westfalen. For Germany as a whole, we find 12 640 patients with Type 1 diabetes in the data pool who had been in spring 2001 less than 20 years old. When this is compared with a population of \( n = 17\,674\,008 \) people being less than 20 years of age in Germany (based on an estimation from 1997 [18]), this means that the diabetes prevalence
Table 3
Twenty-two selected quality indicators for a final ranking used in QC-DPV

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Average inpatient days</th>
<th>Admissions due to ketoacidosis</th>
<th>Control of blood pressure</th>
<th>HbA1c check</th>
<th>Urinary albumin check</th>
<th>HbA1c-MOM in remission</th>
<th>Post-puberty: HbA1c-MOM</th>
<th>BMI-difference after diabetes education</th>
</tr>
</thead>
<tbody>
<tr>
<td>hypoglycemic episodes</td>
<td>Severe</td>
<td>Retinopathy</td>
<td>Height and weight measured</td>
<td>Cholesterol check</td>
<td>Questioned for smoking</td>
<td>Pre-puberty: HbA1c-MOM</td>
<td>Percent cholesterol &gt;6.5 mmol/l</td>
<td></td>
</tr>
<tr>
<td>episodes with coma</td>
<td>Severe</td>
<td>Microalbuminuria</td>
<td>Examination of insulin injection marks</td>
<td>Eyes examined</td>
<td>Median of all HbA1c-values (MOM)</td>
<td>Puberty: HbA1c-MOM</td>
<td>Inpatient days per patient</td>
<td></td>
</tr>
</tbody>
</table>

MOM, multiple of the mean [21]; BMI, body-mass-index.

in Germany for this age class must be greater than 0.07%. This is only a lower limit of the real prevalence rate because there are a lot of federal states not sending much data to DPV-SCIENT, especially in the eastern part of the country.

5. Lessons learned

We have seen many diabetes software systems come and go within the last 10 years. They often have mainly been dedicated to filling out basic information sheets on computer screen, but were not constructed to help physicians and nurses in their daily routine work. This is not enough to be successful as a software system, as there must be additional benefit for the team to use a program over a longer period of time.

It was and still is mandatory for DPV to keep hardware and software resources as low as possible to fit in the small hardware environments of small hospitals. Again and again, there has to be found the balance between nice-to-have high expert features and basic mainstream requirements in diabetology. Often it is easier to communicate a big vision for quality management in diabetes, than to do the nasty work of implementing report generators fulfilling the requirements for demanding design. Thus, we had to change the focus from ‘our vision of diabetes software’ to ‘what are the needs of the customers’. Our difficult decision was whether to build a research software system full with smart functionality (such as control charts for HbA1c [19] or context sensitive expert help) that only a few people really use due to time constrictions; or should we aim for a broad distribution by supporting the basic needs of daily work. We decided for the latter and were well accepted in German hospitals and practices specialized in diabetes. This, on the other hand, turned out to be fundamental for building a data pool on diabetes patients like DPV-SCIENT, which now opens new perspectives such as using e.g. datamining technology in diabetes research. Currently, we are working on a prediction algorithm for the level of metabolic control using collaborative filtering [20].
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