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Online Transmission of Clinical Data for Disease Management and Registers

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Abstract

There is growing demand for collection of structured clinical data for administrative and medical purposes such as quality management, registers and health care system planning. Especially integrated care concepts for chronic diseases put higher requirements on the availability of longitudinal common data. The aim of this work was to provide a flexible system to collect clinical data from routine care, available area-wide across institutional borders in Austria and Germany. It was our goal to implement plausibility checks and manual data revision while keeping the technical entry-barrier as low as possible. Data could be collected from various sources: a) paper forms made available electronically using an OCR scanner, b) online data entry through a web browser, c) data extracted from EPRs. A text-based comma separated file format was defined for data import from scanner and EPRs and made public. Until February 2007 more than 275.000 data-sets have been collected. Online data import was widely accepted: Between 2002 and 2006, 78 % of data were imported online by 34 different centres for 206 participating centres. EPR data import gained importance recently due to a physician incentive by a certification programme, which lead to an escalating increase of transmitted data sets.

Keywords:

data collection, quality assurance, health care, information systems

Introduction

Administrative and medical purposes such as quality management, registers and health care system planning create a growing demand for collection of structured clinical data in primary and ambulatory care, especially in the management of chronic diseases. Effective quality improvement strategies have been identified and published [1,2]. Many of these strategies such as audit and feedback [3] rely on clinical data collected by physicians. We report experiences with data acquisition implemented in our online web application Healthgate BARS over 5 years.

The aim of this work is to provide a flexible system to collect clinical data from routine care for quality management and patient registry in diabetes care, available area-wide across institutional borders. Plausibility checks and manual data revision had to be provided to make structured data available at a required minimum quality level to sub-

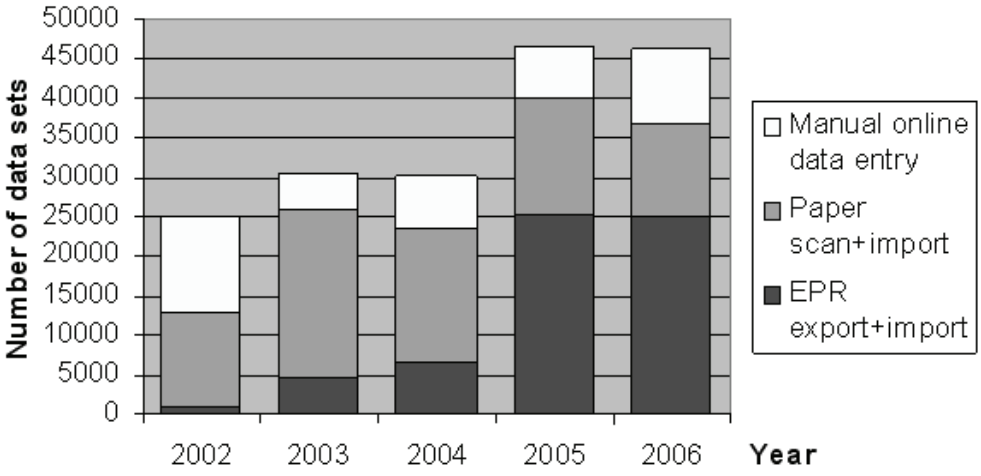

Figure 1- Data entry per year by input method

sequent data analysis. As the system was introduced in 2002 in Austria and Germany, common infrastructure such as electronic health record systems or health information networks were not available. In both countries, electronic patient records (EPR) in GP (general practitioner) practices often were available in very basic form only or not present at all. It was therefore our intention to fulfil the above requirements while keeping the technical entry-barrier as low as possible.

Material and methods

Data could be collected from various sources: a) data from paper forms made available electronically using an OCR (optical character recognition) scanner, b) online data entry through a web browser, c) data extracted from EPRs. A text-based comma separated file format was defined for data import from scanner and EPRs and made public. Data import was carried out through a Java 2 Enterprise web application and split into two sequential steps: Upload and revision. Files were uploaded and imported asynchronously using Message Driven Beans. All records passing plausibility checks were immediately stored in the database and remaining records marked for revision. Users were notified by email about import status. All data-sets not yet imported could be revised online and saved to the database. Data extracted from EPRs typically required only minor or no revisions. For this study, changes in data entry behaviour and data sources were analyzed over time.

Results

Until February 2007 more than 275.000 data-sets have been collected. Since 2002, 78 % of data have been imported online by 34 different centres for 206 participating centres in Germany and Austria (Figure 1). The web-based approach made the system easy to reach, use and administer. Data collected on paper was scanned and imported in two centres and could be revised locally in physicians' offices. The system was used in Austria and Germany by the voluntary quality management initiative “Forum for Quality Systems in Diabetes care”, as well as in routine care in Diabetes education projects in four Austrian provinces (Styria, Salzburg, Carinthia, Vienna). Since 2005 a certification programme introduced by the German Diabetes Association is supported by Healthgate, which increased demand for EPR interface development and lead to a dramatic increase of data imported from EPRs in Germany. Particularly specialized centres (9 hospitals, 22 diabetes clinics and 1 GP) managed to adopt EPR data extraction. These 32 centres contributed more than 40 % of overall data.

Discussion and conclusion

Our experiences show, that data acquisition tools for quality management are required and accepted by physicians. Automatic extraction of data entered in EPRs is the most practical solution to establish regular and high volume data transmission. However, this alternative has the highest entry barrier, because it requires development and modification of existing software systems in physician’s offices, achievable only by regulations or incentives for physicians.

In Germany, the HL7 based Sciphox (Standardized Communication of Information Systems in Physician Offices and Hospitals using XML) standard [4] is currently used in a follow-up project, to make data collected in the nation-wide Disease Management Program available for open benchmarking. In Austria, health information network and health smartcard, which have been rolled out about a year ago, provide a promising infrastructure for secure and high-performance data transmission and seamless system integration. In both countries, especially on the GP level, standards for data transmission only exist for administrative purposes and separation of healthcare sectors is prevalent. Introduction of a national Electronic Health Record (EHR) is discussed [5], which could reduce many of the existing barriers. However, presumably several years will pass until the fragmented market for EPR software on GP level will be penetrated by these initiatives. Meanwhile, as a step by step approach towards common EHR standards for connectivity and semantic interoperability, in both countries there is a strong need for harmonization and standardisation of data transmission as well as for algorithms to extract structured data from EPRs. Harmonization and Standardization on a national level as well as incentives and support for clinics and physicians are more important than technical innovation to achieve positive short and medium term results.

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