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Development Of An Oncology Data Network In Germany

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Abstract. In the 1990ies, an oncology data network has been set up mainly in the New States of Germany. Although not formally planned and established as a whole, it consists of a number of initiatives, that co-operate well and gain added value from this co-operation. From the technological view, the centre of the network is the Gießener Tumordokumentationssystem (GTDS), that was developed at Gießen University. We present important basic conditions in which this development took place, show some results and describe future directions of the development.

1. Introduction

Already in the 70ties, a large number of Comprehensive Cancer Centres including hospital cancer registries (HCR) has been founded in the former FRG. Several cancer registry computer systems (CRCS) like KRAZTUR, HIT etc. were developed to support in particular the collection and storage of data of tumour patients defined in the "Basisdokumentation für Tumorkranke" [1]. With these data stored in the CRCS treatment and follow-up of tumour patients as well as research should be improved. In the former GDR the tumour documentation was very well organised and included the social and medical care but was mainly done on paper. The related infrastructure was changed completely after the reunification. Therefore it was necessary to consider and develop a new infrastructure comparable to the solutions already implemented in the Western part of Germany. The new comprehensive cancer centres needed immediately technical equipment for diagnosis and treatment, and, for the cancer registries powerful CRCSs. Since nearly all of the systems available at that time were more than ten years old, they could not easily been transferred. Therefore it was decided, to develop a new CRCS which is now well-known under the name GTDS (Gießener Tumordokumentationssystem) and which is now in use in more than 30 cancer registries in Germany.

2. Gießener Tumordokumentationssystem (GTDS)

GTDS was designed following two integrated concepts. First it was decided to use the most recent available technology, entity relationship models and relational data bases as development frameworks. Using the development tool IEF, a comprehensive data model for cancer registries was developed which was transferred into the relational GTDS data base. This model still fits the requirements of data processing in hospital cancer registries and has been extended only marginally during the last ten years. The design process was intensively supported by a working group of experts from cancer registries in Germany.

Second we were convinced, that tumour documentation that should really satisfy patient care and also the requirements of research and quality assurance has to collect more data than in the mentioned version of the Basisdokumentation were included. Therefore a new version of the "Basisdokumentation" was assembled, which contained more clinical and follow up data than the previous version. We were also convinced that the extension of the size of the data set would only be accepted by clinicians and registrars, if the collected data itself was used wherever possible to support the management of patient care within the hospital and after discharge during follow up. Therefore GTDS [2] offers functions not only for documentation and registry management but also for the support of clinical care. The latter comprises scheduling functions for therapy plans and follow-up care, calculation of chemotherapy and support of communication between physicians and departments by automatically generating discharge letters, consulting and treatment reports and summaries.

Several scheduling functions are integrated which are continuously adaptable by the user to the requirements of the registry and the actual situation of the patient. They enable the registry to give organisational support to care givers in and outside the hospital, e.g., by printing schedules and eligible medical procedures. Documentation expense is reduced since available information is printed on individual documentation forms, and the registry can actively keep track of the patient's history. The hospital cancer registries can hold a long-term electronic patient record of cancer data. By these tools implemented in GTDS the registry becomes a central information resource. The tumour documentation can be integrated into the process of patient care and could provide apparent benefits. It is no longer thought of as an additional and useless burden. By the immediate use of the data for patient care the quality of the collected data can be increased extensively since wrong or insufficient data in reports and summaries could seriously influence the care process.

The comprehensive set of tools and functionalities provided by GTDS is used in different intensity. In 1999, an evaluation of GTDS applications showed that 17 of 27 registries regularly or frequently use overview reports which are sent out to attending physicians. Management of follow-up care was used in 7 registries. Other functionalities that are used only in some registries are chemotherapy planning and calculation and the regular writing of discharge letters. Since some of the registries are still in the starting phase the application rate of the provided functionalities is continuously increasing.

Another aspect that became important during the development of GTDS was the integration of data. All the required data should be collected only once and should be provided to as many as necessary purposes. It should be possible to import data that are already available elsewhere in a hospital information network, like administrative data from administrative systems or clinical findings from the clinical laboratory, the radiology or the pathology departments. On the other hand, data that are needed elsewhere, e.g., in physicians offices and in population based registries, should be exported. Newer developments are dealing also with the exchange of more complex data like components of or complete registry patient records among registries. For this purpose, an interface has been implemented in GTDS which can receive HL7 messages i.e. from administrative, laboratory or pathology systems and which can export messages to physicians office systems (POS) according to the "Behandlungsdatenträger (BDT)" standard used in German POS. [3]

The frequent contact that physicians have with their registry underlines the network character of the system and will result in an extended online access to registry data that currently is available mainly in hospitals where the registry system is located.

In the age of internet and telemedicine, the registries have to intensify their efforts for integration. In the last years, a pilot project at Dresden Technical University investigated the conditions for an online access to registry data by GP physicians and implemented it in prototype installations (RegKom project) [4]. One of the main results was the implementation of authentication and encryption techniques that will be generally available in the short future. An other aspect is the exact definition of services that can operate on registry data and provide a protected interface for systems that want to integrate registry functions. This ongoing project is realised as a prototype for the GTDS where the services will be accessed by an HTML-client. The services, that include overview reports and entry of follow-up data for the first phase, will be available via an Intra-/Internet connection. Combined with authentication and encryption techniques, physician office systems can be integrated into the network in an online instead of a paper based way.

3. Integration of epidemiological cancer registries.

Another partners in the current network is the former "National Cancer Registry", now called the common registry of the new states ("Gemeinsames Krebsregister", GKR). It was primarily considered that the physicians have to transmit data sets to the epidemiological as well as to the hospital cancer registries. Most of the physicians objected since they did not understand why they should write down nearly the same data on different sheets and mail these sheets to different institutions. In the Cancer Registry Law it was already considered that hospital cancer registries can also transmit patient data to the epidemiological cancer registries on behalf of the attending physician. Epidemiological cancer registries need only a very small data set describing the patient and the tumour disease since they have to investigate alterations of the incidence only. All this data are available in hospital cancer registries and as a rule in a high quality.

Therefore it was decided to implement also an interface to the data processing unit of the GKR into the GTDS to transmit the required epidemiological data out of the hospital registries electronically. Meanwhile this route has become the most important data source of the GKR. In some States more than 90 % of the reports are transmitted electronically – today still via diskette – out of GTDS centres.

By a new law an important additional pathway is now becoming operational. Epidemiological registries report also the death certificates and can allocate these data to the patient data base which allows a lifetime follow up of tumour patients. These data can now be transmitted to the hospital cancer registries which improves the importance of their data base in particular for quality assurance analysis and investigations quite extensively. Also this pathway is now provided electronically by the GTDS.

4. Integration of quality insurance investigations and analysis

Another important task of hospital cancer registries is to support quality assurance investigations. Three different approaches have already been established which are either partly completely dependent on the hospital registries, or, partly supported by the registries by providing related data. The Central Database of Hospital Registries (CDHR) which has been built up at Gießen University from the mid 1980ies, is another partner in this network. It collects anonymous data about diagnosis, treatment and follow up out of the hospital cancer registries according to the "Basisdokumentation". The CDHR is comparable to the National Cancer Data Base (NCDB) of the Commission on Cancer in the US. First results of the CDHR have been published in the Internet (http://www.med.unigiessen.de/akkk/spez/) in 1995. After five years of operation of GTDS in most of the associated centres, a new CDHR is now built up. The new results have shown a much better quality of data, in particular of follow-up information. Several analyses of clinical data are currently carried out which show already differences in the quality of care in different centres. The results are currently carefully evaluated and will be published soon. But it can already be seen, that hospital cancer registries (HCR) can play an important role in care management and quality evaluations.

A further important part in this network are special quality management programs, like the "Feldstudien" in which also GTDS registries took part during the last years. An additional concept where HCR can be involved in are the Patient Care Evaluation Studies (PCES) that are carried out in co-operation with the Commission on Cancer in the US where PCES have been established for a long time. Each year two tumour entities are evaluated by PCES. Findings and tumour stages at diagnosis, treatment and follow-up are investigated more extensively than in the Basisdokumentation, almost always on a random sample of patients. One PCES on thyroid cancer has already successfully carried out which has shown distinct differences between US and Germany. A second study on bronchial cancer is currently under preparation in which the HCRs should be centrally involved. It is considered to introduce the PCES as a continuous applicable quality assurance tool also in Germany mainly carried out by the hospital cancer registries and in particlar the GTDS centres.

5. Results

The following results are exemplary for the efficiency, that could be achieved in the network.

As mentioned above, the number of paper based reports to the GKR decreased dramatically shortly after the reunification. With the introduction of electronic communication, the completeness of data in the population based GKR increased from 16-57% in 1992 to 57-80% in 1996 (Berlin excluded) with a DCO percentage of 16% in Brandenburg and Saxonia. More than 90 % of reports are transferred electronically from hospital cancer registries, and they are almost completely exported from GTDS-systems.

As an example for the possibilities enabled by analysis of the central tumour database, we currently investigate differences in breast-preserving surgery / mastectomy ratio between registries with comparable stage distributions. Another phenomenon that we detected is the development of the early stage / advanced stage ratio in breast cancer between the US National Cancer Database NCDB (1986 to 1992), the central tumour database with data from the Western states (1986 to 1992), and new data from 1995 to 1997 for the new states. The ratio in the new states is much more similar and sometimes even better compared to the NCDB and much more better than it was in the Western states in former years. Like every time in quality management, these indicators are only first hints, that have to be discussed with the clinicians before they are accepted as clinically significant differences.

6. Future Directions

By the implementation of the GTDS in HCR a comprehensive network has been established which now shows first and impressive results in improving healthcare and quality assurance investigations and analyses. As the already mentioned evaluation has shown, the GTDS is well accepted by the user even if there are complaints about necessary improvements. The development of a new graphical user interface is nearly completely finished.

New technologies like the application of web-browsers and XML for improving the user interface, the storage and retrieval of text documents or the organ-specific documentation and for facilitating the report functionality of the system are under investigation. In a project sponsored by the Federal Ministry of Health, we are defining services for the open access to registry systems, and we are implementing prototypes that demonstrate the access to the services by an HTML interface. The communication with the services is done in XML. It is our intention to improve the communication between and the functionality which is provided for the different partners in the network as much as possible.

7. Conclusions

In the 1990ies, a new cancer registry computer system has been introduced mainly in the Eastern states of Germany which has now become the basis of an oncology data network. Although not formally planned and established as a whole, it consists of a number of initiatives, that co-operate well and gain added value from this co-operation. This development was promoted by a couple of conditions, that can be generalised:

- The multiple use of data (clinical, epidemiological, scientific, quality control) raises acceptance of documentation, thus increasing data completeness and quality.
- The unified registration reduces data capture effort and proves to be very successful.
- The legal conditions favour the intensive co-operation between hospital and population based registries
- Data standards (basic and organ specific data sets) consider the requirements of all types of data use.
- The acceptance of documentation is increased by a direct feedback of data through useful services provided by registries
- The predominant use of one documentation system (GTDS) reduces development costs and facilitates changes resulting from changing requirements

Finally, an infrastructure has been formed, on which additional programs for quality management or clinical trials can build.

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