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Establishing an Internet-Based Paediatric Cancer Registration and Communication System for the Hungarian Paediatric Oncology Network

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Abstract. Cancer registration has developed in Europe over the last 50 years, and in the last decade intensive joint activities between the European Cancer Registries, in response to the need of pan-European harmonization of registration practices, have taken place. The Hungarian Paediatric Cancer Registry has been functioning as the database of the Hungarian Paediatric Oncology Network since 1971, aiming to follow the incidence and the treatment efficacy of malignant diseases.

The goals of this globally unique open source information system are the following: 1) to raise the quality of the registration system to the European level by developing an Internet-based registration and communication system, modernizing the database, establishing automatic statistical analyses and adding an Internet website, 2) to support clinical epidemiological studies that we conduct with international collaborators on detailed analyses of the characteristics of patients and their diseases, evaluation of new diagnostic and therapeutic methods, prevention programs, and long-term quality of life and side effects.

The benefits of the development of the Internet-based registration and communication system are as follows: a) introduction of an Internet-based case reporting system, b) modernization of the registry database according to international recommendations, c) automatic statistical summaries, encrypted mail systems, document repository, d) application of data security and privacy standards, e) establishment of a website and compilation of educational materials.

The overall objective of this scientific project is to contribute towards the improvement of cancer prevention and cancer care for the benefit of the public in general and of cancer patients in particular.

1. The Organizational Background

The Hungarian Paediatric Cancer Registry has been functioning as the database of the Hungarian Paediatric Oncology Network since 1971, aiming to follow the incidence and the treatment efficacy of malignant diseases. The Hungarian Paediatric Cancer Registry has a history of over 30 years of tradition and accumulated know-how. The registry has been audited by a review team of the International Agency for Research on Cancer. We practice population-based registration covering the whole country. High quality data on leukaemia incidence, and data on solid tumours have been gathered by the Hungarian Paediatric Oncology Network. We have close and productive contacts with clinicians, based on traditions and over 30 years of experience. A wide range of clinical information is accessible through the registry. Long-term follow-up has always been emphasized, therefore follow-up data are available from the earliest times. The registry operates with a fully motivated and qualified young staff. Recently, tender applications have been assembled for the funding of our projects, and moderate governmental support has been awarded for infrastructure improvements. The Ministry of Education and the Ministry of Information and Communication have announced our project as a leading initiative towards adopting the eEurope standard of the European Community.

We conduct clinical epidemiological studies with international collaborators (IARC – International Agency for Research on Cancer) through active data collection, detailed analysis of characteristics of patients and their diseases (SIOP – Société Internationale d'Oncologie Pédiatrique, BFM Berlin-Frankfurt-Münster Study Group), evaluation of new diagnostic and therapeutic methods, and their long-term follow-up. Therefore, we promote better understanding of tumorigenesis and improvements of treatment results.

We perform epidemiologic research to ensure the completeness of the data in the registry with active data collection and collaborating partners (National Cancer Registry, Hungarian Central Statistical Office, National Health Insurance). We analyze the incidence and possible causes (both retrospectively and prospectively), risk factors (spatially and temporally), and the efficacy of new therapeutic procedures. We actively follow up long-term survivors to assess their quality of life and long-term side effects.

2. The Difficulties of Paper-Based Cancer Registration

Since the early 1970's, the Hungarian Paediatric Oncology Network has been using a paper-based cancer registration system. Four kinds of registration forms were in use: an initial form for new leukaemia cases, an initial form for new solid tumour cases, a follow-up form for leukaemia cases and a follow-up form for solid tumour cases. All kinds of forms were filled in by physicians at treatment centres, towards the end of a year – usually using a typewriter or by hand. The forms were then sent to the registry by post, where they were verified and ordered into files. In 1982, computerized data storage commenced. As the computational power of personal computers grew and as better software for data analysis and visualisation appeared, the expectations towards the database increased as well. The coding system and the database structure have undergone three major overhauls and many smaller changes.

Filling in the forms with a typewriter and later typing the data into a computer is a waste of resources – at the same time there are no resources for recording detailed patient histories and disease courses.

The administrative burden on the reporting physicians was moderate in the earliest times: a relatively constant number of new patients were reported each year, together with the follow-up data of a few survivors. However, as the proportion of surviving patients increased due to the adoption of more successful treatments – more and more patients were followed up for longer and longer periods of time. Although the diversity of the collected follow-up data was reduced, by the end of the 1990's the quality of the follow-up data, one of the major strengths of the registry, was at risk. It became an everyday necessity for the registry staff to actively collect data.

Although the registry has always provided data for medical science and health research - often back to the reporting physicians themselves, they were still separated from the contents of the database by complicated access procedures.

The international studies aiming to improve cancer therapy, in which the Hungarian Paediatric Oncology Network participates, demand more and more detailed information on the progress of treatment, therapy toxicity and late effects. Genetic research also requires patients past their active therapy, i.e. it calls for long-term follow-up together with genetic information.

The explosion of data demand undermines the motivation of physicians to report, which leads to a deterioration of data quality. In turn, the registry staff has to make extreme efforts to fix missing and erroneous data. Although many physicians already have e-mail accounts, they cannot serve as a communication medium for verifying patient data, because the e-mails flow unencrypted on the Internet, making it impossible to send sensitive information.

The annual reporting scheme has the added disadvantage in that it is not possible for physicians to remember exactly the details of the treatment process of each patients treated since the previous report. Additionally, cases emerging during the last month of the year may still lack diagnostic information at the time of their submission to the registry. The former obstacle leads to the inconveniences in retrieving patient documentation, while the latter leads to missing data items which need to be actively resolved later on, by the registrar.

3. The Benefits of the Electronic System

The first goal of the system is to reintroduce reporting motivation to physicians. Bi-directional data flow has a key role: the data stored in the registry becomes instantly accessible to treatment centres, helping them in their everyday work, in research activities and in healthcare planning. Keeping the database up to date is in the interest of every physician in the network. A treatment centre can download all available data on its patients at any time.

Besides raw data on patients corresponding to the treatment centre, simple statistical summaries are available as well, which makes the system even more useful for treatment centres. Database queries converted into spreadsheets ready for importing into statistical software are also programmed.

The handling of missing and erroneous data becomes much simpler. Instead of a long process of posting forms, checking their contents and contacting the reporters for corrections, many checks are automatic and instantaneous, the errors can be corrected interactively. Entry time checking is possible for many logical relationships among data pieces, arising from the pathophysiology of tumours. The checking rules are based on the Child-Check rule set of the International Association for Research on Cancer extended with logistic relationships. Detection of missing values is possible at the time of data entry, and the reporter can be warned immediately.

A more sophisticated type of handling of missing and erroneous data is the scope of the warning system. The warning system is a simple rule-based expert system keeping track of the data flow during patient registration, diagnostics, treatment and follow-up. Some international studies, like the Acute Lymphoblastic Leukaemia Intercontinental-BFM 2002 protocol, involve complex data flow structures, including revised diagnostics and conditionally-repeated treatment elements. The warning system knows when and who to warn if data are inconsistent or missing. For instance, it warns the responsible physician if a long-term survivor has not shown up for a control examination or if the status or the results of an examination are not entered into the system. Other examples are laboratory tests returning results long after taking the specimen (post-deadline warnings), or non-routine examinations requested by a research study (pre-deadline, keep-in-mind warnings).

If the warning system cannot solve a particular data problem, it forwards that problem to the registrar or to national study coordinators. They can issue manual warnings that are later handled by the warning system, or they can use encrypted e-mail to communicate with the person responsible for the problematic data.

The use of hierarchical selection lists for data entry spares the registry developer a lot of work. The developer can concentrate on the ICD-O-3 coding, which requires more experience than a typical reporting physician possesses. Instantaneous conversion between disease morphology and localization coding systems also becomes possible.

These features of the system fill in the gaps at many network centres, where electronic heathcare scheduling is not internally supported.

As the data entry process is of a continuous nature, individually adjusted to the treatment process of the patient, there is no need to send half-filled forms due to pending laboratory tests – and there is no need to retrieve old patient files, because the warning system notifies the physician to enter data when it's still at hand. It is much easier to enter fresh data than months-old documentation.

4. Additional Features of the Electronic System for the Users

As the physicians will log in to the system almost daily, additional features, aiding them in everyday work, are also worth implementing.

4.1 Automatic Data Extraction for the Needs of International Studies

The data format specified by the international data centres of international studies can be guaranteed by pre-programmed database queries and conversions. All that national study coordinators have to do is check the protocol-specific contents of the database, use secure e-mail for clarifications and use the protocol-wise data export function of the system.

4.2 Statistical Summaries

Basic statistical summaries on the whole database are available to all the users of the system. As said before, the staff of a treatment centre can view and download detailed and aggregate data on their own patients. Nationwide data in aggregate form is available to anyone. The results of national statistics are regularly copied to the website for general publication.

4.3 Research-Related Database Queries

With the electronic approval of the leaders of the network, requests for database queries can be sent to the server to gather data for research purposes. As these queries are subject to complex legal and ethical considerations, each transaction is logged with special verbosity.

4.4 Public Website Pursuant to the eHealth Code of Ethics

In addition to the isolated virtual private computer network of the Hungarian Paediatric Oncology Network that hosts the cancer registration and warning systems, the project also provides a website for the general public. The intended audience comprises young patients and their parents, professionals, supporters, sponsors and casual visitors. It contains articles about the paediatric tumour types and their treatment results; the institutions and the scientific results of the network, the registry, statistical summaries and announcements – in a uniform structure and appearance.

The website adheres to the eHealth Code of Ethics of the Internet Health Coalition [1] and the Health On the Net Code of Conduct [2]. Although both of these rule sets are formulated in self-regulatory terminology, the website of the Hungarian Paediatric Oncology Network is audited by an independent enterprise.

The site can be visited at *http://www.gyermekonkologia.hu*. The site is under continuous development regarding both content and appearance.

4.5 Document Repository

The members of the network can place all kinds of digital materials into the document repository and keep them ordered. These documents are accessible by all other members. Basic version management is available for documents in the repository and search is possible through metadata terms and inside document contents. The planned contents are international treatment protocol descriptions, ready-to-use presentations for the local media, useful documents and templates for everyday work, scientific results, application forms for events and multimedia presentations of instructive diagnostic results.

4.6 Encrypted e-mail System

Physicians can send and receive encrypted e-mails using their USB encryption devices. The level of encoding will ensures the security of transmitted data for many years to come.

4.7 Mailing Lists

Mailing lists are provided for physicians, leaders of the centres, stem cell transplantation board members, the staff involved in patient care throughout the network, research groups, physiotherapists and parents' associations. Some of these mailing lists work with encrypted traffic, which enables communicating sensitive patient data as well (e.g. minutes of stem cell transplantation board meetings).

4.8 Notice Board

The notice board is integrated with the mailing lists, and periodically sends announcements to the users.

4.9 Address Book

The address book stores the addresses, phone numbers etc. of physicians and leaders of the network, as well as collaborators. The address book is integrated with the mailing lists and a digest, containing filtered data, is periodically transferred to the contact section of the public website. Keeping the address book up-to-date is the duty of the warning system.

4.10 Internet Community

The above features splice the physicians of the Hungarian Paediatric Oncology Network into an Internet community, using the modern communication modalities offered by the system on a daily basis.

The daily routine occasionally involves an urgent need to provide consistent explanations for patients, especially under the age of 18. Therefore, onsite access allows the doctor to provide these facilities for patients. Overall, the communication between the members of the paediatric oncology team is rapidly improving through the use of this new, advanced technology. Once the project completes, daily interactive communication will be established. Due to the above mentioned achievements we believe that our patients will receive better treatment and significantly improved rehabilitation opportunities.

5. Technical Features

5.1 Centralized Server-Client Structure

The centralized server-client structure allows developments on the server side to become immediately available to all clients throughout the network.

5.2 Modern Database Structure

The database of the National Paediatric Cancer Registry has been converted from its previous, obsolete structure to a flexible and extensible object-relational database structure. The format of the database reflects the pathophysiological characteristics of childhood cancers and the regulations and recommendations on handling personal data and metadata. If a new national or international scientific study emerges, the registry database can be easily extended to serve its needs.

5.3 Archiving

Archiving of the registry database used to be manual and irregular. The new system secures valuable data regularly and almost automatically. If manual steps are necessary, the warning system issues warnings to the archiver. All manual steps are logged.

6. Information Technology Considerations

6.1 Software

Application server	Debian Linux	Java-based Web application running in the JBoss framework. PostgreSQL object-relational database system.
Firewall server	Debian Linux	ZORP packet filtering
Public web-server	Debian Linux	ZOPE web application server
Clients	Windows XP Professional	Mozilla. Aladdin eToken driver

6.2 Security

The system is implemented to the highest security standards possible. User access to the database is secured by the following components:

- strict security settings on the Windows XP client (including windows security settings, firewall, anti-virus programs),
- client-side password authentication,
- the firewall refuses connections from unknown IP addresses,
- the server accepts known x.509 certificates,
- the certificates are stored on the users' Aladdin eToken USB keys, password-protected,
- database access is restricted both at the application and the database level,
- administrative access is restricted for both the server and client computers,
- the servers are physically secured.

7. Summary of Project Benefits

The Internet Based Paediatric Cancer Registration and Communication System for the Hungarian Paediatric Oncology Network is globally unique in the sense, that in the absence of uniform treatment principles and a nationwide computer system, Hungary is the first country in the region developing such a nationwide system.

The development is primarily based on open source software, and the source code of our product will be available too. Multilingualism is supported throughout the application and other aspects of internationalization were also kept in mind during planning, to ease the development of a future international version. We believe that open source code carries the promise of delivering an extensively tested, bug-free system.

Launching the new system will lead to instantaneous improvement of data quality in many data groups. The administrative burden of cancer reporting will diminish for the physicians in the network, and the number of errors and missing values to be corrected by the registry staff will radically decrease, too. The motivation to maintain the cancer registry at a high quality will grow on both sides.

Internet communication strengthens the community working for paediatric cancer patients by "shortening the distance" between distant parts of the country. This enables us to perform detailed spatial and temporal analyses of the diseases and their causes, based on a globally-unique open source information system. The modernization of the registry will improve both professional and economic conditions of medical care and the planning of prevention programs, through up-to-date information. The overall objective of this scientific project is to contribute to improvement of cancer prevention and cancer care for the benefit of the general public and of cancer patients in particular.

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