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Original article

A national approach for automated collection of standardized and population-based radiation therapy data in Sweden ☆

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ABSTRACT

Purpose: To develop an infrastructure for structured and automated collection of interoperable radiation therapy (RT) data into a national clinical quality registry.

Materials and methods: The present study was initiated in 2012 with the participation of seven of the 15 hospital departments delivering RT in Sweden. A national RT nomenclature and a database for structured unified storage of RT data at each site (Medical Information Quality Archive, *MIQA*) have been developed. Aggregated data from the *MIQA* databases are sent to a national RT registry located on the same IT platform (INCA) as the national clinical cancer registries.

Results: The suggested naming convention has to date been integrated into the clinical workflow at 12 of 15 sites, and *MIQA* is installed at six of these. Involvement of the remaining 3/15 RT departments is ongoing, and they are expected to be part of the infrastructure by 2016. RT data collection from ARIA®, Mosaiq®, Eclipse™, and Oncentra® is supported. Manual curation of RT-structure information is needed for approximately 10% of target volumes, but rarely for normal tissue structures, demonstrating a good compliance to the RT nomenclature. Aggregated dose/volume descriptors are calculated based on the information in *MIQA* and sent to INCA using a dedicated service (*MIQA2INCA*). Correct linkage of data for each patient to the clinical cancer registries on the INCA platform is assured by the unique Swedish personal identity number.

Conclusions: An infrastructure for structured and automated prospective collection of syntactically interoperable RT data into a national clinical quality registry for RT data is under implementation. Future developments include adapting *MIQA* to other treatment modalities (e.g. proton therapy and brachytherapy) and finding strategies to harmonize structure delineations. How the RT registry should comply with domain-specific ontologies such as the Radiation Oncology Ontology (ROO) is under discussion.

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Technical developments during the last decades have increased the possibilities to deliver complex radiation therapy (RT) dose distributions to patients. To make full use of the technical advances and truly individualize treatments (personalized RT), details on various treatment approaches need to be recorded and evaluated [1]. The key to clinical optimization of RT is a comprehensive understanding of the relationship between patients, tumour and treatment characteristics, and treatment outcomes, where *Radiation Oncology* informatics plays a key role [2–4]. RT is one of the most digitalized disciplines in modern healthcare. However,

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creation of sufficiently large databases is challenging. Dose distributions stored in treatment planning systems (TPSs) and oncological information systems (OISs), often in separate databases, are represented according to local conventions, and kept at the treating clinics unless extraction of RT data is required for a specific purpose. Recording these data in a systematic and prospective manner is difficult but would facilitate comparisons and evaluations of new RT approaches on a larger scale. This has the potential to improve cancer treatments in the longer perspective.

Data collection has to be straight-forward and resource-light for the busy clinic [3]. To minimize errors in data recording, data types and formats need to be standardized and information in separate databases needs to be linked [5]. Typically, institution-specific solutions are needed, and among others, Jani et al. presented an integrated outcome-study database by linking the record-and-verify database for RT with the global hospital database through a bioinformatics database solution [6]. A larger scale open-source based infrastructure was presented by Roelofs et al. in which data sharing between two university clinics in two European countries was facilitated in projects developing predictive models for various cancer diagnoses [3]. A solution on a national scale is the DICOM-based RT plan database for research collaboration and reporting in Denmark by Westberg et al., which enables secure sharing of non-anonymized DICOM-RT data and also provides solutions for foreign countries to connect [7]. In the United States, a pilot project to suggest an infrastructure solution for collection of treatment and outcome data across American radiation oncology and hospital information systems, "the National Radiation Oncology Registry", is pursued in collaboration with RT system vendors [8]. So far, none of the abovementioned solutions or any other system have proven sufficiently efficient to support systematic RT data collection on a large scale.

To facilitate a nation-wide harmonization of treatment approaches for RT in Sweden, we developed a national infrastructure for prospective collection of interoperable RT data. Our infrastructure meets the requirements of all hospital departments delivering RT in Sweden, cancer diagnoses, and other intentions for RT. This includes: (1) a standardized national naming convention for RT structures to facilitate consistency in collected data, (2) a database solution for local storage of RT data to meet the requirements of automated data collection from TPSs/OISs on the national scale (Medical Information Quality Archive; *MIQA*), (3) a dedicated RT database on the existing IT platform that already hosts most of the Swedish clinical cancer registries specific to various cancer diseases (Information Network for CAncercare; *INCA*), and (4) a service for export of aggregated information including descriptors of structure doses and volumes from *MIQA* into the RT database on *INCA* (*MIQA2INCA*).

Materials and methods

There are 15 hospital departments delivering RT in Sweden, and they are geographically located in the more densely populated areas of the country. The work presented here was initiated at the seven University Hospitals in Sweden. Our suggested infrastructure evolved in three major steps with the first to get acceptance for a national standardized naming convention, the second to create a unified storage structure for RT data at each local data source, and finally to build a national database with aggregated RT data integrated with the clinical quality registries.

The technical solutions for data storage and data transfer were based on: (1) legal requirements for patient integrity, (2) the ambition to minimize manual interaction in the data collection process, and (3) the use of existing standards to increase flexibility in meeting future demands (*e.g.* changed data structures or data representations in the clinical systems). In the sections below, the technical solutions for the local and national databases are described in detail.

A national standardized naming convention

The naming convention was based on recommendations by Santanam et al. [9] and the ICRU report 83 with three minor modifications. Together, these offer terminology for the majority of relevant RT tumours (targets) and risk structures. They also provide directional terms for laterality and principles for structure margins for planning volumes. The recommended underscore-combined camel case expressions for organs at risk (OARs) were extended with additional terms and accompanied by Swedish names/expressions. A suggestion for how to truncate longer expressions for TPSs with a restricted number of characters in a structure name was introduced. The ICRU target descriptor and the treatment dose objective were extended with parentheses to provide a means to add comments. This national naming convention was presented to each participating clinic and was encouraged to be implemented as diagnosis or treatment-site-specific templates in each clinic's TPS. A national committee with representatives from all regions and relevant professions was also formed for maintaining and developing the nomenclature.

The naming convention has been published as a recommendation by the Swedish Radiation Safety Authority [10] (English version available at www.radiotherapy.se).

A unified local storage structure for RT data – MIQA

MIQA was initially developed as a local database solution for radiation oncology research with structured storage of DICOM-files at the University Hospital in Umeå (Fig. 1). The files are stored in a file database, which can be queried through metadata in an SQL database. *MIQA* allows for collection and storage of data from the most frequently used TPSs/OISs in Sweden and links information through each patient's unique 10-digit Swedish personal identity number which is given to each citizen at birth and used in all contacts with authorities including private and public hospitals. To adhere to national regulations on data protection, an explicit instance of *MIQA* is to reside locally within the firewalls of a hospital to ensure confidentiality of patient data. *MIQA* can also be set up as a research database where all patient identifying information is removed through full anonymization or pseudonymization.

MIQA Management is the user interface of *MIQA*. One of the overall goals with the project was to create a solution with minimal user interaction in the data collection process. Even with future complete compliance to the national naming convention there will be some need for manual interaction. For example, patients may be included in international trials with study-specific naming conventions, or specific planning information may be missing. *MIQA management* therefore provides intuitive tools for manual mappings of structure names onto the national nomenclature and, when appropriate, for the creation of general aliases. The treatment information for individual patients can be reviewed and simple corrections of incomplete or missing data can be made before submission to *INCA*.

A local MIQA database includes the original DICOM-RT-Dose, -Structure Set, -Plan, and when available, Treatment Summary Record files. Diagnosis codes (International Classification of Diseases, Version 10, ICD-10) are retrieved directly from the OIS (ARIA® or MOSAIQ®) and, in the MOSAIQ case, information about delivered fractions is retrieved directly from its database. The aggregation of RT information and transfer to the national RT registry is performed using a service called *MIQA2INCA*. Also, image

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