



Data exchange in radiotherapy

## Creating a data exchange strategy for radiotherapy research: Towards federated databases and anonymised public datasets



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### ABSTRACT

Disconnected cancer research data management and lack of information exchange about planned and ongoing research are complicating the utilisation of internationally collected medical information for improving cancer patient care. Rapidly collecting/pooling data can accelerate translational research in radiation therapy and oncology. The exchange of study data is one of the fundamental principles behind data aggregation and data mining. The possibilities of reproducing the original study results, performing further analyses on existing research data to generate new hypotheses or developing computational models to support medical decisions (e.g. risk/benefit analysis of treatment options) represent just a fraction of the potential benefits of medical data-pooling. Distributed machine learning and knowledge exchange from federated databases can be considered as one beyond other attractive approaches for knowledge generation within “Big Data”. Data interoperability between research institutions should be the major concern behind a wider collaboration. Information captured in electronic patient records (EPRs) and study case report forms (eCRFs), linked together with medical imaging and treatment planning data, are deemed to be fundamental elements for large multi-centre studies in the field of radiation therapy and oncology. To fully utilise the captured medical information, the study data have to be more than just an electronic version of a traditional (un-modifiable) paper CRF. Challenges that have to be addressed are data interoperability, utilisation of standards, data quality and privacy concerns, data ownership, rights to publish, data pooling architecture and storage. This paper discusses a framework for conceptual packages of ideas focused on a strategic development for international research data exchange in the field of radiation therapy and oncology.

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## Background and rationale

Clinical and pre-clinical radiotherapy study data represent one of the most valuable assets for academic radiation therapy and oncology research institutions. Rapidly pooling research data via the process of data exchange has become beneficial and a necessary requirement for conducting large multi-centre radiotherapy studies [1]. Resulting data pools represent the primary input for generation of medical knowledge bases with a broad range of applications, including predictive models for decision support systems based on clinical data [2] and discovery of prognostic features in radiomics [3]. Predictive model research has potential to not only improve quality-of-life but also increase survival, for example by using isotoxic strategies [4]. Fig. 1 depicts the process of an application-specific knowledge discovery from large scale multi-centre data pools.

Integrated radiotherapy research data (originating from multiple data sources) represent a powerful research tool to evaluate dose, volume and time parameterised responses in tumours and normal tissues. Such data are fundamental for generating novel multivariable prediction models for tumour control probability (TCP) and normal tissue complication probability (NTCP). These prediction models can be translated into innovative studies on personalised radiotherapy, e.g. for biologically based intensity modulated dose distributions which may reduce the risk of treatment toxicity or increase the probability of local tumour control. As such they can also be used to inform and involve patients in treatment decisions through shared decision making [5]. Reliable estimates of treatment consequences are a prerequisite for discussing patients' preferences and for assessing their personal trade-off between the risks and benefits of treatment options. Conversely, data on patient values and preferences can also be added to the database to incorporate the patients' perspectives.

The data also are extremely useful for comparative analyses of treatment approaches, e.g. particles vs. photons or different treatment combinations [6,7], and have the potential to decrease health care costs with a more rational use of expensive medical

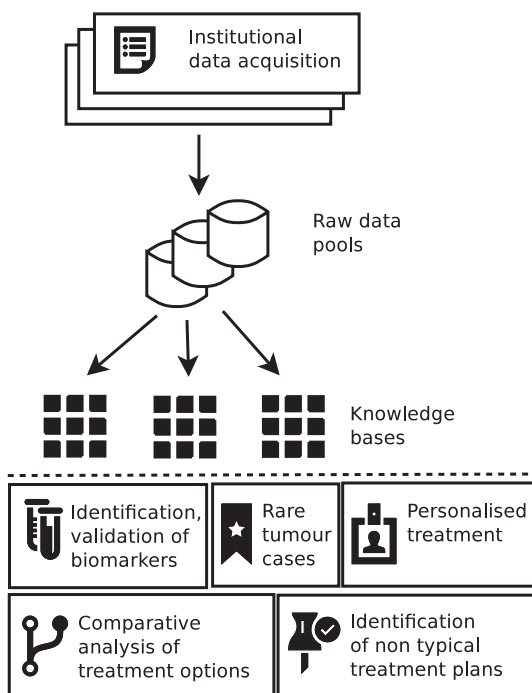


Fig. 1. Large scale multi-centre studies produce raw data pools, which can be used to generate application-specific prediction models or knowledge bases.

technology [8]. By linking them to investigations on tissues of the corresponding patients, they may also provide a backbone for the identification and validation of (imaging) biomarkers for radiation oncology. Sharing research data can accelerate the process of medical quality assurance, including checks for consistent contouring, dose (re-)planning and protocol adherence in prospective radiotherapeutic studies. Finally, sharing research data may speed up the adoption of research results into day to day clinical practice.

It is the concern of translational research informatics to provide an appropriate software solution for managing integrated research datasets, enabling the broader collaboration of research institutions.

On 26th November 2013 a workshop organised by the German Cancer Consortium (DKTK) and EurocanPlatform was hosted in Dresden, Germany to examine radiotherapy-specific IT solutions developed within Europe. Existing projects within the European Society for Radiotherapy and Oncology (ESTRO) and several regional, national and international initiatives were presented. The workshop resulted in two important conclusions. Firstly, the presented platforms, as diverse as they are, focus on the same set of problems mostly on an institutional level with few examples on a national and international dimension. Secondly, a strong interest was stated in setting up a collaborative effort to accelerate and harmonise the ongoing data collection activities and to promote open access to radiotherapy research datasets.

The main goal of this paper is to initiate the development of a radiotherapy-specific data exchange strategy preventing disconnected institutional level solutions and move towards international data interoperability. This can be achieved by the implementation of well-chosen concepts, without the need for unnecessary reinventions.

The following major challenges that currently hamper effective collaboration and data exchange efforts were identified:

- Interoperability between clinical IT solutions: systems differ in their acceptance/support of internationally standardised protocols, formats and semantics.
- Maturity of radiotherapy information standards: incomplete development of radiotherapy specific data element dictionaries, controlled vocabularies and ontologies.
- Uniformity of data collection: data are collected using different scoring systems (e.g. scoring of radiation-induced toxicity) and at different time points, which may render data merging complicated or even impossible.
- Data completeness: data are often represented without sufficient meta-data, causing the risk of information loss after exchange.
- Data quality: the quality of collected information can vary from project to project and from institution to institution, making it necessary to establish quality assurance work-flows.
- Data bias: difference in practice, protocols and equipment may cause a systematic difference between data from different institutes.
- Patient privacy: the protection of privacy and the relation to informed consent as well as secondary use of research data have to be considered seriously, also in view of the very different interpretation and application of confidentiality and privacy rules and laws between different countries, different states of one country and sometimes even between different ethical committees.
- Open source data: in disciplines like genetics there is the tradition to rely on published public repositories data. This is not the case with most of the clinical disciplines.

These challenges impede the realisation of large scale multi-centre exchange of medical data and leads to unnecessarily high costs. It is unrealistic to expect an immediate and conclusive solu-

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