The EURECCA project: Data items scored by European colorectal cancer audit registries

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Abstract

Aims: The EURECCA (European Registration of Cancer Care) consortium is currently formed by nine independently founded national colorectal audit registrations, of which most already run for many years. The cumulative experience of EURECCA’s participants could be used to identify a ‘core dataset’ that covers all important aspects needed for high quality auditing and at the same time lacking needless data items that only consumes administrative effort. The aim of this study is to compare the data items used by the nine registries participating in EURECCA to identify a core dataset and explore options for future research.

Methods: All colorectal outcome registrations participating in the EURECCA project were asked to supply a list with all the data items they score. Items were scored ‘present’ if they appeared literally in a registration or in case they could be calculated using other items in the same registration. The definition of a ‘shared data item’ was that at least eight of the nine participating registries scored the item.

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Introduction

In 2006, colorectal cancer caused over 200,000 deaths in Europe, making it the second most common cause of cancer-related death, while its incidence is still increasing. In developing countries, the rise in incidence is even higher, while they have the worst outcome. Although surgery is the cornerstone for curative treatment, there is great variability in outcomes among surgeons and institutions.

Quality of health care has a high priority on the political agenda of most European countries. Universal health care improvement initiatives, such as the development of a preoperative surgical checklist by the World Health Organization, reflect the contemporary global commitment to prioritizing high quality care within surgery.

Surgical quality assurance program, also called surgical audit, is a quality instrument that collects detailed clinical data from different health care providers, which can be adjusted for baseline risk and subsequently fed back to individual hospitals or surgeons. Major improvements have been achieved with national audits. However, although all the national audits achieved excellent results, differences in treatment and outcome remain between European countries and cannot be easily explained.

To reduce those differences by identifying and spreading best practice, the European CanCer Organisation (ECCO) initiated an international, multidisciplinary, outcome-based quality improvement program: European Registration of Cancer Care (EURECCA). The goal is to create a multidisciplinary European registration structure for patient, tumour, and treatment characteristics linked to outcome registration. Many important topics that are unanswered by randomised controlled trials could be researched using the data of EURECCA project. The EURECCA project makes use of existing national audit registrations and started with colorectal cancer, but in the future other solid tumour types, such as breast cancer, gastric cancer, and oesophageal cancer, will follow.

Unfortunately, clinical auditing comes with a price. Despite rapid development in medical information technology, clinical auditing still is a considerable administrative burden from medical professionals. A beautifully designed but very detailed registry that turns out to be too time consuming to complete is worthless. Therefore, it is important only to register those items that really matter. When a new audit is set up, dedicated professionals might be tempted to develop a very complete, although unnecessary large dataset. Instead of reinventing the wheel, a ‘core dataset’ distilled from existing audits could save much energy.

The EURECCA consortium is currently formed by nine independently founded national colorectal audit registrations, most of whom already run for many years. The cumulative experience of EURECCA’s participants could be used to identify a core dataset that covers all important aspects needed for high quality auditing and at the same time lacking needless data items that only consume administrative effort.

Even more important than being used as a template for other audits, an EURECCA core set will give the consortium insight in what research can be performed in the near future.

The objective of this study is to compare the data items used by the nine registries participating in EURECCA to identify a core dataset and explore options for future research within the EURECCA project.

Methods

All colorectal outcome registrations participating in the EURECCA project were asked to supply a list with all the data items they score. These data items were entered in a database and assigned to a main category and a subcategory. Items were scored ‘present’ if they appeared literally in a registration or in case they could be calculated using other items in the same registration. Secondly, the type of data (categorical, number, yes/no, free text) was scored. Software used for data input and analyses was SPSS 17 (PASW, Chicago). After all the items were entered in the database, a report was sent back to the national data managers to check for errors or incompleteness. The corrected lists were returned and processed in the database. In the corrected and completed database, shared data items between the registries were identified as well as resemblances in data type and categories. The definition of a ‘shared data-item’ was that only one registry was allowed not to score the item, so at least eight of the nine participating registries scored the item.

Results

All nine participating EURECCA registries (Table 1) supplied lists with all recorded data items, which were entered into a database and checked for accuracy as described.
in the methods section. The number of registered data items varied between 254 (Belgium) and 83 (Norway) (Fig. 1). A total of 45 items were collected by 8 or more of the participating registries and subsequently met the criteria for a shared data-item (Table 2). Among the 45 variables were patient data such as date of birth, gender, cancer type and ASA score. Furthermore, variables to score the use of endoscopy, rectal ultrasound, CT or MRI scan for preoperative staging met the shared data item criteria together with cT-stage and cM-stage. Items about the surgical treatment that met the criteria for a shared data item included date of surgery, main procedure, open or laparoscopic, the creation of an anastomosis and/or stoma and the important postoperative complication; anastomotic leakage. Eight or more out of the nine participating registries scored pTNM stage, radicality and distance of the tumour to the surgical resection plane. Registrations of administered pre- or postoperative radio- and or chemotherapy were also shared data items. Regarding follow-up, death status and date of death were shared data items. Items about tumour recurrence or quality of life were scored too little to become shared data items.

Fig. 1 shows the number of recorded data items scored by all nine EURECCA participants on the Y axis and the number of years since first registration on the X axis. There was no relation between time since first registration and the number of scored data items.

Discussion

After comparing the datasets of EURECCA’s nine participating registries, a list of 45 data items could be identified as a shared, core dataset. A strong variation between the number of data items collected by different registries was found, ranging between 83 by Norway and 254 by Belgium. Despite the fact that the oldest registry (Norway) used the fewest data items, there was no relation between time since first registration and slimness of the dataset.

Although many important items can be mentioned that are not listed in the core dataset, the most vital variables about patient, disease, preoperative staging, operation, pathology and survival are all part of the core dataset. Furthermore, data about pre- and postoperative adjuvant treatment are also part of the core dataset.

Worldwide and also within Europe, there are many differences in the use of (neo)adjuvant treatment for cancer. For instance, for rectal cancer with an unthreatened circumferential resection margin, many patients will receive short term (5 × 5 Gy) preoperative radiotherapy while others will get long course radiochemotherapy and sometimes this is administered postoperatively. Using the shared data items in combination with the impressive and unprecedented amount of patients supplied by EURECCA, an inventory about differences in (neo)adjuvant treatment can be made.
and linked to other data such as anastomotic leakage, surgical radicality and long term survival. The EURECCA core dataset offers enough patient data to perform statistical corrections for patient and tumour factors, necessary for a fair comparison between different treatments.

While the share of elderly in the incidence of colorectal cancer is increasing every year, elderly are remarkably enough excluded from most clinical trials concerning colorectal cancer. Again, the extensive data of EURECCA’s core dataset should be able to answer vital questions about the optimal treatment for elderly. Differences in treatment can be identified as well as differences in first presentation of disease, whether this is tumour stage, age, gender or incidence of a disease.

In conclusion, a valuable core data set is identified. This study shows a lean and easy to register core dataset that can help starting clinical audits setting up their database and help minimize administrative burden for existing audits. Most importantly, vital research questions will be answered in the near future using the power of EURECCA’s merged data.

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References

