A multidisciplinary approach to improve treatment strategies for patients with hepatic or pancreatic cancer

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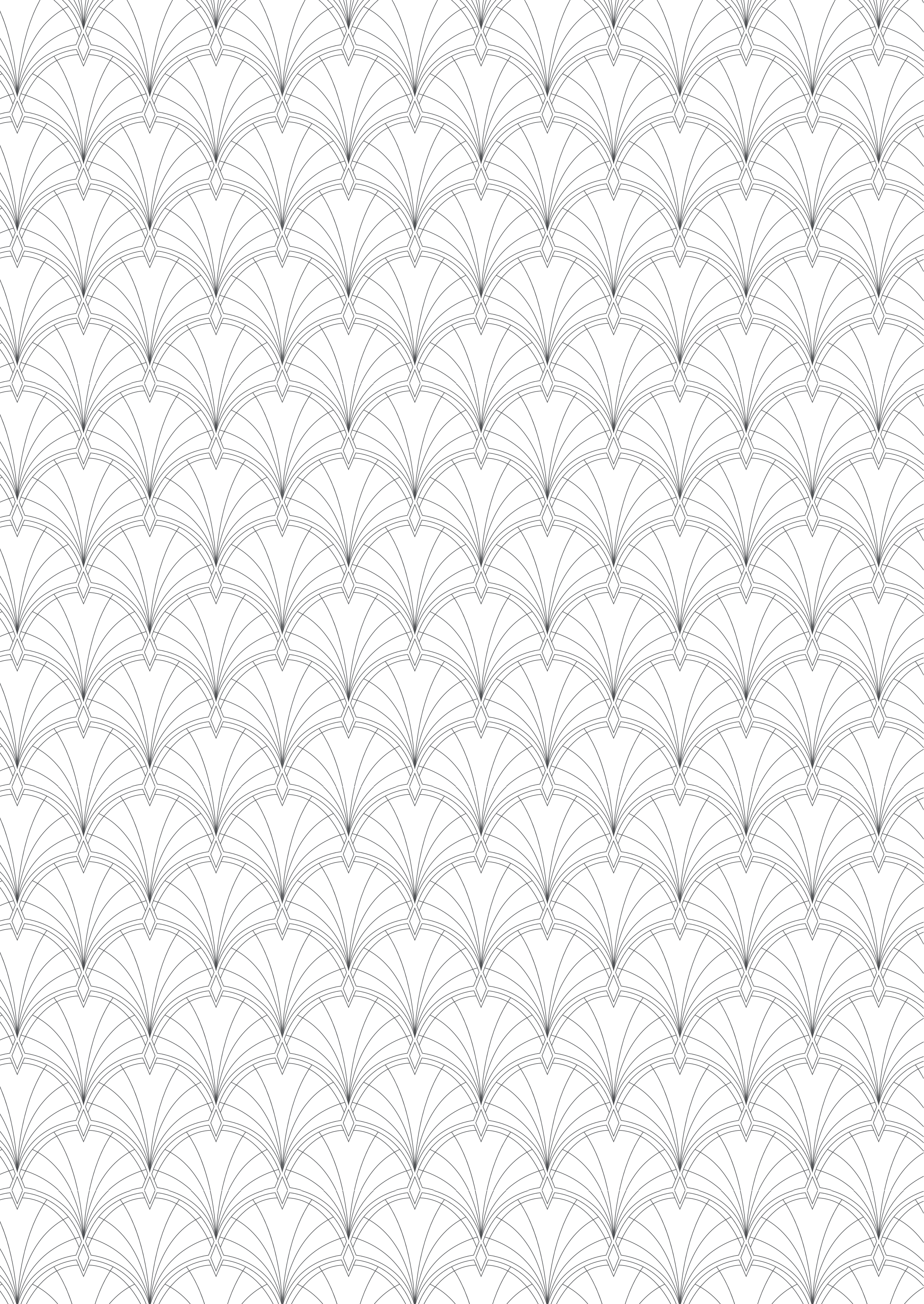
Citation

Leede, E. M. de. (2021, December 1). *A multidisciplinary approach to improve treatment strategies for patients with hepatic or pancreatic cancer*. Retrieved from https://hdl.handle.net/1887/3244234

[‘Baat het niet, dan schaadt het wel.’
Professor Emile Voest, NRC januari 2015]

PART II

Tailored care for patients with pancreatic cancer



CHAPTER 7

Common variables in European pancreatic cancer registries: The introduction of the EURECCA pancreatic cancer project

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European Journal of Surgical Oncology, September 2016

ABSTRACT

Background

Quality assurance of cancer care is of utmost importance to detect and avoid under and over treatment. Most cancer data are collected by different procedures between different countries, and are poorly comparable at an international level. EURECCA, acronym for European Registration of Cancer Care, is a platform aiming to harmonize cancer data collection and improve cancer care by feedback. After the prior launch of the projects on colorectal, breast and upper GI cancer, EURECCA's newest project is collecting data on pancreatic cancer in several European countries.

Methods

National cancer registries, as well as specific pancreatic cancer audits/registries, were invited to participate in EURECCA Pancreas. Participating countries were requested to share an overview of their collected data items. Of the received data sets, a shared items list (core data set) was made of items that are present in 7 out of 11 datasets. This common item list, creates insight in similarities between different national registries and will enable data comparison on a larger scale.

Results

Over 24 countries have been approached and up till now 11 confirmed participation: Austria, Belgium, Bulgaria, Denmark, Germany, The Netherlands, Slovenia, Spain, Sweden, Ukraine and United Kingdom. The number of collected data items varied between 29 and 130. This led to a shared items list of 25 variables divided into five categories: patient characteristics, preoperative diagnostics, treatment, staging and survival.

Conclusions

A list of 25 shared items on pancreatic cancer coming from eleven participating registries was created, providing a basis for future prospective data collection in pancreatic cancer treatment internationally.

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INTRODUCTION

Pancreatic cancer is associated with a poor prognosis for most patients. In trial populations a median survival of 23 months for initially resectable tumours in combination with neoadjuvant therapies was reached.[1] Over time, a clear increase of prescribed chemotherapy was observed in the Netherlands for patients with and without metastatic pancreatic cancer without any benefit of survival.[2] Capturing data on cancer outcome is crucial to detect over and under treatment in pancreatic cancer. Variations in incidence and mortality between European countries have been described previously.[3,4] Because survival might, besides lifestyle habits (such as smoking) and genetic differences, also be influenced by variances in treatment, structural international comparison would increase insight in 'best practices' in pancreatic cancer. Auditing cancer care with adequate case-mix adjustments is a very effective instrument to impact on outcome. For example, in rectal cancer, national audits were able to implement total mesorectal excision, (TME), reducing local recurrence and variation in other outcome parameters within countries.[5,6] Patterns of care can be identified and communicated to hospitals or physicians.[5,7,8] Feedback generates optimization of treatment standards and (neo)adjuvant therapy and avoidance of over and under treatment. Moreover, an important advantage of registries over clinical trials is that audit registries include the entire patient population which offers the opportunity to study patient groups that are usually excluded from clinical trials (e.g. elderly, high comorbidity).[5] However, registries across Europa differ and can therefore not easily be compared.[9] A 2013 EUROCHIP survey (European Cancer Health Indicators Project) showed that cancer registry data are a reliable source for evaluation and strategy planning, but not all data is available in every registry, impeding a complete comparison.[9] To create uniformity in the collected data and to enable a robust international comparison and report on outcomes, the European Society of Surgical Oncology (ESSO) and the European CanCer Organisation (ECCO) initiated an international, multidisciplinary, outcome-based quality improvement program: European Registration of Cancer Care (EURECCA). The EURECCA projects collaborates with existing national audits and cancer registries. [10,11,12] Following EURECCA Colorectal, Breast and Upper Gastro-Intestinal (GI), EURECCA Pancreas focusses on pancreatic cancer and is following the roadmap of the previous projects. The first step in the EURECCA Pancreas project is to describe a common data item list among the responding European countries. The data items will be the basis to design the future prospective international comparison EURECCA Pancreas project.

METHODS

From the start of EURECCA Pancreas, 36 (pancreatic) cancer registries have been approached and invited to join the EURECCA Pancreas platform and 44% responded (n=16). Reasons for not collaborating were the absence of a well-functioning cancer registry or no available data because the registry started recently. Eleven European countries agreed to participate in this comparison. An overview of variables that are collected on each patient, was requested. All recorded data items compared in a database and matching items were scored. If items were present in the database or could be calculated using other items in the database, they were marked ‘present’ in the shared items comparison. If an item was present in 7 or more datasets, it was marked as a ‘shared item’. 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. Most audit registries described in this article have given their full commitment to participate in the EURECCA framework by approval of the Call For Agreement.

RESULTS

Eleven complete lists of items were received from the collaborators; Austria, Belgium, Bulgaria, Denmark, Germany, The Netherlands, Slovenia, Spain, Sweden, Ukraine and the United Kingdom. Besides national or regional cancer registries (n=5), several pancreatic cancer specific cancer audits (n=6) in Europe supplied lists with recorded data items. Table 1 presents the eleven participating registries in this study. The number of collected items differs between the different countries, from 16-285. This is also depending on whether the registry is a national cancer registry or a specific registry on pancreatic cancer. Only four registries contain data on palliative treatment, the other seven registries are general cancer registries or surgical registries. Therefor it was decided that only data concerning surgically treated patients could be used.

A total of 25 items was marked present in seven out of eleven datasets, and thus form the common items data set, displayed in Table 2. These items were divided into five subcategories: patient characteristics, diagnostics, treatment, staging and survival.

TABLE 1. *Characteristics of the participating registries; the EURECCA consortium*

Country	**Audit**	**Since**	**Type of registry**	**National/ regional data**	**Numbers of items**
Austria	ABCSG registry for pancreatic cancer[13]	2010	Pancreatic Cancer	National*	37
Belgium	National Cancer Registry	2005	Cancer	National	51
Bulgaria	National Cancer Registry	1952	Cancer	National	76
Denmark	Danish Pancreatic Cancer Database	2007	Pancreatic cancer	National	36
Germany	Halle/Magdeburg	2010	Pancreatic cancer	Regional	128
Netherlands	Dutch Pancreatic Cancer Audit	2013	Pancreatic cancer	National**	130
	Netherlands Cancer Registry	1989	Cancer	National	
Slovenia	Cancer Registry of Republic of Slovenia	1950	Cancer	National	50
Spain	Catalonian Pancreatic Cancer Audit	2013	Pancreatic cancer	Regional***	82
Sweden	National Quality Register for Pancreatic cancer	2010	Pancreatic cancer	National	285
Ukraine	National Cancer Registry Ukraine	1996	Cancer	National	16
United Kingdom	AUGIS HPB cancer registry	2009	Pancreatic cancer	National	54

*6 centres operating on pancreatic cancer **National audit, data from one high volume centre *** 6 parallel pancreatic cancer audits

DISCUSSION

Audit and registry structures have led to greater improvements in cancer care outcome than trial and drug development. EURECCA, the European cancer audit, is a valuable collaborative platform to increase our insights on performances in cancer care. Especially for pancreatic cancer with its aggressive biological behaviour it is crucial to collaborate on collecting data, from treatment to outcome. Capturing clinical relevant international benchmarks is not challenged before and would provide tools for feedback. Combining forces and population-based data will represent the actual patterns of care, more than results from clinical trials. International comparisons are the superlative measure to effectively benefit patients with pancreatic cancer.

Experience gained by all participants during years of setting-up (pancreatic) cancer registries and collecting data of patients, is combined in this new EURECCA project.

TABLE 2. *Shared items in eleven participating registries of the EURECCA Pancreas consortium*

Category	**Data item**
Patient demographics	Gender Patient number Patient name Age / Date of Birth ASA or ECOG or WHO performance status
Diagnostics	CT ERCP Date of diagnosis / Date of incidence Localization (Caput, Corpus, Cauda, etc.) Diagnosis cytology or histology (ICD-morfology) (Adenocarcinoma, Neuroendocrine, IPMN, etc.)
Treatment	Type of neoadjuvant therapy Date of surgery Type of surgery (PPPD, Whipple, distal/total, etc.) Vascular resection/reconstruction Complications Date of discharge / Duration of stay Postoperative radiotherapy Postoperative chemotherapy Postoperative radio-chemotherapy Date of start adjuvant therapy
Staging	pT pN pM Resection margin: R0/ R1/ R2
Survival	Date of death

A common dataset that covers all shared aspects concerning pancreatic cancer and its treatment is identified. A core dataset formation is the next step. For instance optimisation of the data set by adding ‘date of diagnose’, ‘clinical TNM stage’ and ‘CA19.9’ would form the template of future comparisons. Important information about the current common data set and the planned core dataset is that no individual physician or hospital data will be incorporated during future analysis; in no way it will be a name and shame report.

Not all audits or registries are population-based, containing data on all consecutive pancreatic cancer patients; 3 registries only collect data on surgically treated patients. In other registries, data from patients treated in a group of collaborating centers is collected. The coverage of the patients included in these audits might not be as complete as a national cancer registry, although several of them cover a majority of hospitals in a specific territory.

In EURECCA colorectal and EURECCA upper GI, common data items were included if present in 6 out of 7 respectively 8 out of 9 participating registries.[10,14] In EURECCA Pancreas presence in 7 out of 11 datasets was set as a limit, to achieve a more complete data set. A limitation of this dataset is that in contains no information on non-surgically treated patients. Often the data collections are surgical driven and no data on solely palliative treated patients is registered.

In the near future a retrospective analysis is planned with merged data from the collaborating registries. Differences in age, gender, incidence, tumour stage and differences in treatment can be identified. Also elderly patients are included in the EURECCA projects and consequently care patterns for the elderly pancreatic cancer patients can be analysed. The aggressive tumor biology and the late onset of complaints and consequently the late presentation of patients, results in high percentages of advanced stage disease and less therapeutic options. Only (borderline) resectable patients, the smallest group, are expected to be discussed in the tumour boards. Locally advanced pancreatic cancer patients, as well as metastasized patients are often directed to the medical oncologist. In future registry or audit structures of all stages should be combined to have a clear view of the medical decision making, clinical care pathways and treatment strategies in the different collaborating countries. By calculating with the date of diagnosis and date of surgery, waiting times for surgery or start of neoadjuvant treatment can be calculated. If patients are treated, neoadjuvant therapies impact on pathological responses, so it is very important to stratify for clinical stage before therapy starts. Pre-treatment TNM stages can then be compared to post-operative pathology reports on TNM stage, to unravel information about medical decision making in pancreatic cancer.

In conclusion, a common data set is identified for this new EURECCA Pancreas project. Establishing a core data set is the next step, and invitations for collection are planned in the near future. Among our future perspectives, a prospective international auditing of pancreatic cancer will be designed in a collaborative way respecting high data security and ethical analysis.

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