Pilot study – Automated calculation of Quality Indicators from hospital data, to analyze guideline adherence in a pancreatic cancer network

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Project Information

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Topic:	EU4H-2021-JA-03
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Abbreviations and Acronyms

CCC	Comprehensive Cancer Centre
CCCNs	Comprehensive Cancer Care Centers or Networks
EC	European Commission
EU	European Union
KPI	Key Performance Indictaor
QI	Quality Indicators
WP	Work Package

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Executive Summary

Europe is resolved to provide equal access to high quality cancer care for its citizens across the European Union (EU). To establish high quality Comprehensive Cancer Care Centers or Networks (CCC(N)s), measuring quality of cancer care in a way that is unambiguous, transparent, evidence-based and enables caregivers to improve their quality of care, is an indispensable prerequisite.

Current initiatives to measure Quality Indicators (QI) rely on manual reporting, which is resource-consuming and error-prone.

In this pilot project, we deliver the proof-of-concept that QI for pancreatic cancer can be measured based on automated data extraction from routinely-collected hospital data, thus paving the way for scalable, unambiquous QI monitoring and value-based healthcare.

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1. Introduction

Europe is resolved to provide equal access to high quality cancer care for its citizens across the EU. To establish high quality Comprehensive Cancer Care Centers or Networks (CCC(N)s), measuring quality of cancer care in a way that is unambiguous, transparent, evidence-based and enables caregivers to improve their quality of care, is an indispensable prerequisite.

Several initiatives to measure quality of cancer care already exist (e.g. the European Cancer Center certification plan, EUSOMA for breast cancer). However, these rely on manual double entry of clinical data resulting in a high maintenance effort, while hospitals across the world are struggling with severe personnel shortages. Not surprisingly, only a minority of European hospitals take part in QI monitoring initiatives. Furthermore, manual data extraction relies to some extent on human interpretation and does not provide data lineage, which can result in differing datasets from different centers, impeding benchmarking. When standard of care changes, these laboriously developed datasets, containing only a handful of selected datapoints, may not be capable of answering new questions.

Therefore, an automated approach that minimizes the registration burden on hospitals, and that is transparent, unambiguous and flexible is necessary to scale actionable quality measurement across disease contexts and hospitals, and pave the way for value-based healthcare.

This pilot aimed to deliver proof-of-concept of automated real-time QI calculation in a single hospital. It builds on validated guideline-derived QIs for pancreatic cancer, as defined in the iPAAC EU joint action (based on the iET-QI).

2. Methods

We follow a multi-step approach, illustrated in figure 1. We maximize scalability of the methodology for other centres (blue tiles, steps 1-2;5-7). Only the green tiles (steps 3-4) need to be developed locally, which can be done using fully, partly or no automated data extraction, depending on local data maturity.

Respecting the time and budget constraints of this pilot, we add for every step what is in scope of CraNE Work Package 6 (WP6). The rest of the work will be continued after finalizing the CraNE Joint Action.

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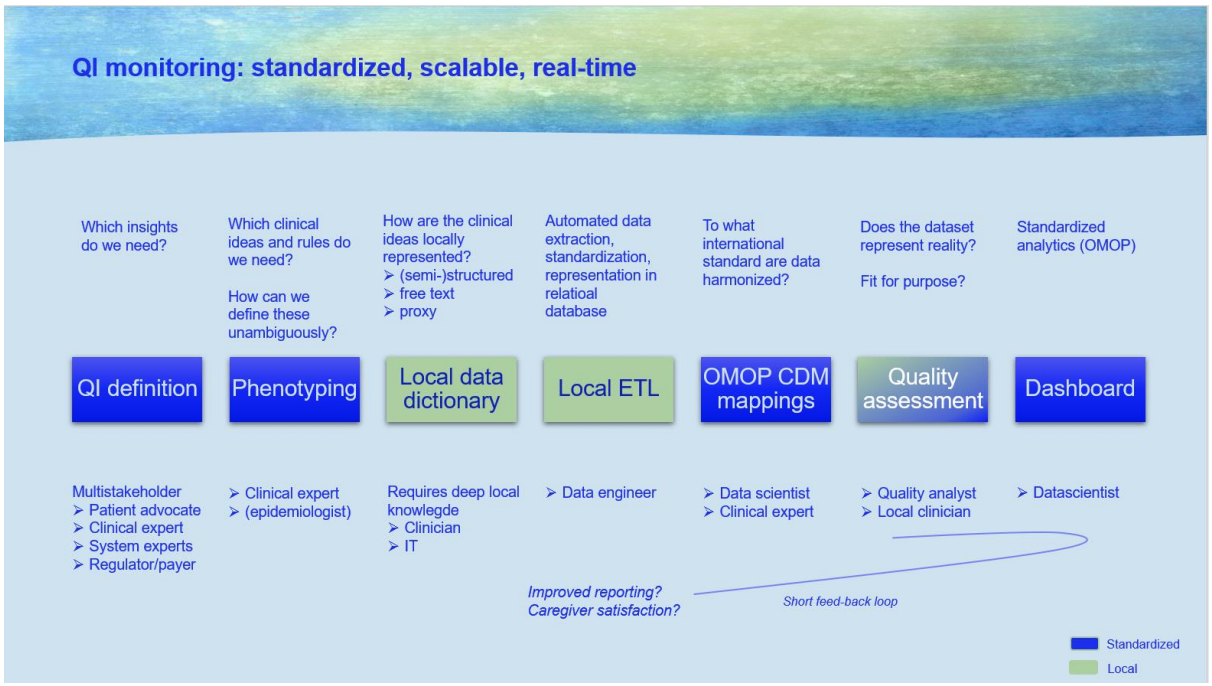

Figure 1: step-wise approach to automated QI calculation. ETL = extract, transform, load. OMOP CDM = Observational Medical Outcomes Partnership Common Data Model.

2.1. QI definition

The complex insights necessary to estimate quality of care are defined. Here, we use the QIs validated in the iPAAC joint action (appendix 6.1 "Set of Indicators for Pancreatic Cancer_updated2023").

➢ In scope: QIs directly related to pancreatic cancer (omitting QIs for endoscopic retrograde cholangiopancreatography and pancreatic surgery).

2.2. Phenotyping

The QI are broken down in clinical ideas and calculation rules. Unambiguous (machine-readable) definitions are made, allowing for reproducible datasets across institutions, regardless of manually vs automated data extraction.

➢ In scope: all selected QIs.

2.3. Local data dictionary

The clinical ideas are broken down further into datapoints that are present in the routinely-collected local data. The correct data sources are defined. If no fit-for-purpose data are identified for a certain QI, a no go for that QI is called.

➢ In scope: all selected QIs

2.4. Local ETL

Raw data are extracted and represented in a local database. Ideally, data are standardized towards an international format that allows for standardized analytics across datasources (in this case, an OMOP CDM datawarehouse).

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➢ In scope: building of a relational database from untransformed raw hospital data, as defined in the data dictionary.

2.5. OMOP-CDM mappings

See 4.

➢ Not in scope

2.6. Data quality assessment

A) *Clinical "sanity check"*

Assess whether the database reflects clinical reality (e.g. number of patients, stage at diagnosis, median age etc.)

➢ In scope

B) A formal data quality assessment on the following dimensions:

B1. Uniqueness

- Identifying completely duplicated rows
- Identifying identical visit identifiers with different values
- Identifying duplicate values with different visit identifiers

B2. Consistency by type

This part of the methodology assesses the consistency of data types within the dataset. Ensuring that each column adheres to the expected data type is crucial for maintaining the quality of the structured datasets. Inconsistencies in data types can lead to errors in data processing, analysis, and interpretation. This section focuses on verifying that each variable in the dataset conforms to its predefined format, as specified in a data dictionary of available.

B3. Completeness

- Essential completeness (e.g. every patients needs a diagnosis of "pancreatic cancer")
- Conditional completeness (e.g. every patient with pancreatic cancer resection needs to have a pancreatic resection)

B4. Consistency by range

Consistency by range involves ensuring that data values fall within expected ranges. This is particularly important for maintaining the qualitey of both numeric and categorical data. By verifying that data valies are within acceptable limits, we canidentify anomalies and potential errors that may affect data analysis and decision-making.

- Categorical
- Numerical
- Datetime

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B5. Consistency by multivariate rule

Temporal consistency is crucial for ensuring that the chronological order of events or measurements is logical and follows the expected sequence. This can be assessed both within a single data frame and across multiple data frames. Conditional consistency ensures that the presence or value of one variable logically depends on another variable. For example, if a drug is recorded, there should be a corresponding drug type.

- Temporal
- Conflicting information

B6. Correctness

➢ Out of scope. An assessment algorithm has been developed in collaboration with i-HD and will be run.

2.7. Dashboarding

Develop a dashboard based on OMOP, providing real-time QI visualisation for care teams, including time trends, KPIs and aberrant results for exploration.

➢ In scope: proof-of-concept dashboard for selected QIs

➢ Out of scope: OMOP-based dashboard for all QIs

2.8. Feed-back loops

Present the QI dashboard to the care teams. This allows for detection of unnoticed data quality issues, and we hypothesize that access to clinical insights will (1) motivate clinicians to improve qualitative routine data registration and (2) empower care teams to define, implement and monitor care quality improvement strategies.

QI that cannot be calculated due to lack of fit-for-purpose data are discussed in the team, to identify ways of enhanced routine reporting of selected datapoints.

➢ Out of scope

3. Results

3.1. QI definition

See appendix 6.1.

3.2. Phenotyping

Appendix 6.2 describes clinical ideas that based on a composition of raw datapoints (e.g. “tumour stage” derived from TNM, “incomplete resection” derived from R-status).

Appendix 6.3 describes full phenotypes for three QIs, based on a selection of clinical ideas and calculation logic. These are QIs that have finished a full validation process.

The preliminary phenotypes for all other QIs have been defined. However, we expect them to change slightly after planned feed-back loops with the entire care team. One

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example to illustrate this: we discovered an issue with the QI "pretherapeutic tumour board", because the preliminary phenotype required a tumour board between date of diagnosis and date of pancreatic cancer resection. For several patients however, the date of pancreatic cancer resection is the first tissue-based diagnosis (= formal date of diagnosis), resulting in a false negative "pretherapeutic tumour board". The final documentation will therefore be published after validation by the multidisciplinary team (step 8).

3.3. Data dictionary

Appendix 6.4 describes raw datapoints to be extracted from different hospital sources.

3.4. Local ETL

Built, based on appendix 6.4. The generated (patient-level) dataset is not shared because of privacy reasons.

3.5. OMOP mapping

Out of scope for CraNE WP6.

3.6. Data Quality Assessment

A) Clinical "sanity check":

Done in several iterations. The final check by the entire team, based on the dashboard, is pending. Lessons learned for centres attempting automated QI calculation will be published after the final check.

B) Formal data quality assessment.

Ongoing. The methodology and results will be published.

3.7. Dashboarding

The proof-of-concept dashboard of three QIs that have undergone the full validation process is shown below.

KPIs are shown in purple. The clinical team also has access to a pseudonymized table with patients who do not meet the QI, to allow for prompt assessment of improvement possibilities. For privacy reasons, only the table headers are shown.

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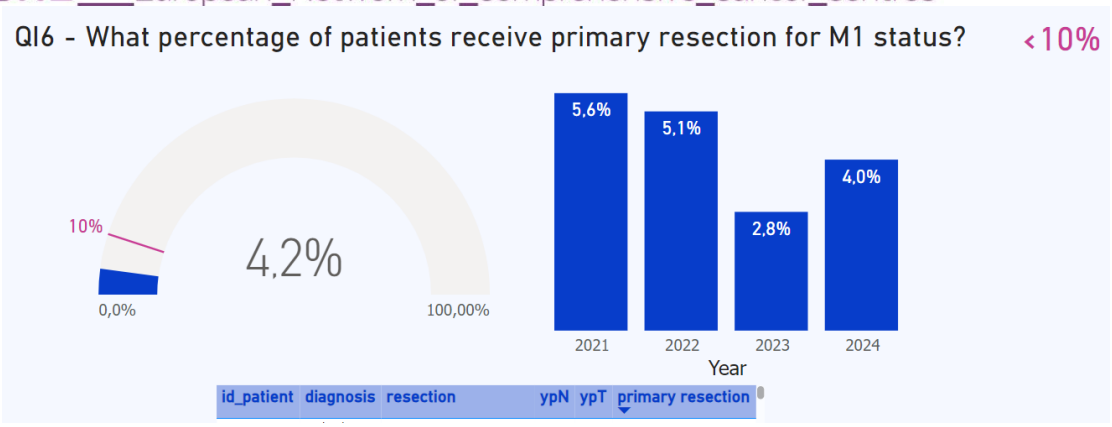
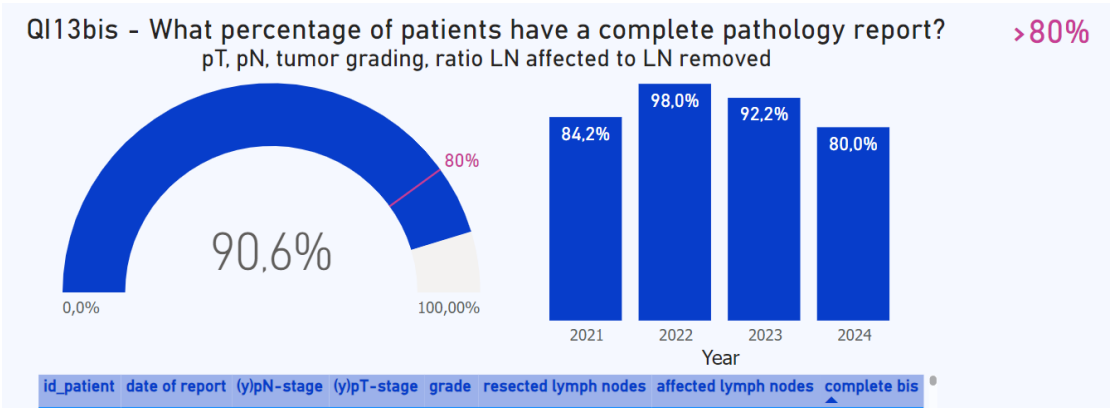
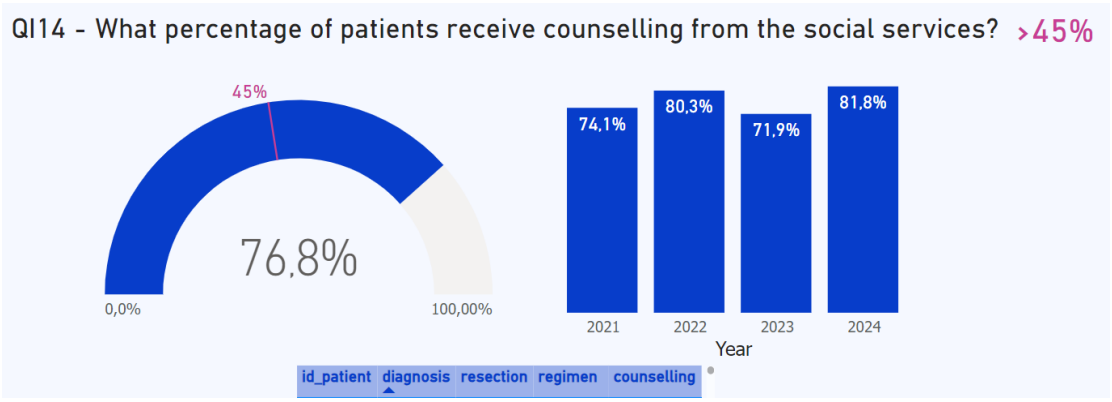




pM is not included in the QI, as this is not part of pathology reporting in Belgium.



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3.8. Feed-back loops

Out of scope for CraNE WP6. First feed-back loop discussions are planned in October 2024.

4. Conclusion

We show that automated real-time calculation of complex clinical insights (QIs) is feasible based on routinely-collected hospital data. Presence of fit-for-purpose data and data quality are crucial. We develop a methodology that is largely scalable to other hospitals, and can be implemented regardless of the level of data maturity. This pilot paves the way to access to high quality healthcare for citizens across Europe.

5. Future directions

Future work needs to address:

- On the short term:
    - Perform structured data quality assessment & share methodology
    - Map data to OMOP CDM & share ETL
    - Develop real-time dashboard based on OMOP CDM & share code
    - Identify crucial missing data & improve routine clinical reporting
    - Discuss QI results in multidisciplinary care team & develop care quality improvement strategies

- On the mid-long term:
    - Implement clinical feed-back loops and monitor evolution of QI performance over time
    - Scale pilot to other centres

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6. Appendix

6.1. Set of Indicators for Pancreatic Cancer

See attached PDF document “Appendix 6.1. Set of Indicators for Pancreatic Cancer_updated 2023”

6.2. Data Dictionary Composite

See attached PDF document “Appendix 6.2. Data Dictionary Composite”

6.3. Phenotypes

See attached PDF document “Appendix 6.3. Phenotypes”

6.4. Data Dictionary Raw

See attached PDF document “Appendix 6.4. Data Dictionary Raw”

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INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Co-funded by
the Health Programme
of the European Union

Updated Quality Indicators for Pancreatic Cancer to monitor and improve oncological care within Comprehensive Cancer Care Networks (CCCN)

Author(s):	Lead author: German Cancer Society e.V.
Version:	4.0, final
Date:	22.02.2023

Content

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Abbreviations

CCCN	Comprehensive Cancer Care Network
CRM	Circumferential Resection Margin
CT	Computed Tomography
ERCP	Endoscopic Retrograde Cholangio-Pancreatography
GIN	Guideline International Network
IET	Ipaac Evaluation Tool
iPAAC	Innovative Partnership for Action Against Cancer
TME	Total Mesorectal Excision
QI	Quality Indicator
US	Ultrasound
VAC	Vacuum-Assisted Closure
WP	Work Package

Background

The Comprehensive Cancer Care Networks (CCCNs) represent innovative approaches for the management of cancer patients consisting of multiple cooperating health units with specific expertise in the different steps of care. Quality Indicators (QIs) constitute valid and reliable tools that allow to measure the quality of oncologic care among similar structures belonging to different health systems. Objective of Work Package 10, Task 3 was to develop a standardized tool (the iPAAC Evaluation Tool for Quality Indicators in Oncology – iET-QIs) in order to define a multi-step process for the selection of QIs for the evaluation of CCCNs, and to assess its efficacy by applying this instrument.

The iET-QI was developed as a methodological tool describing an 8-step process that leads to the selection of QIs feasible for the CCCN setting (see document "Methodology Paper iPAAC"). The tool was implemented accordingly with the reporting standards for guideline-based performance measures of the Guideline International Network (GIN).

In this report the final set of quality indicators for pancreatic cancer are presented.

Quality Indicators for Pancreatic Cancer

Quality Indicator	Reference	Further supporting reference
QI 1 Pancreatic: Pretherapeutic case presentation		
Numerator: Patients of the denominator who were presented at the pretherapeutic tumor board **Denominator:** All patients with pancreatic cancer	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	van Rijssen LB, van der Geest LG, Bollen TL, Bruno MJ, van der gaast A, Veerbek L et al.National compliance to an evidence-based multidisciplinary guideline on pancreatic and periampullary carcinoma. Pancreatology, 16 (2016) http://dx.doi.org/10.1016/j.pan.2015.10.002
QI 2 Pancreatic: Post-operative case presentation		
Numerator: Patients of the denominator who were presented at the post-operative tumor board **Denominator:** All patients with pancreatic cancer and resection	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

Quality Indicator	Reference	Further supporting references
QI 3 Pancreatic: Pancreatitis after ERCP		
Numerator: ERCP´s of the denominator with endoscopy-specific complications (= Pancreatitis, bleeding and perforation) after ERCP **Denominator:** All ERCPs for each endoscopy unit	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	
QI 4 Pancreatic: Adjuvant chemotherapy		
Numerator: Patients of the denominator with adjuvant chemotherapy **Denominator:** All patients with pancreatic cancer and resection (UICC Stad. I-III and R0 resection w/o NET/NEC)	van Rijssen LB, van der Geest LG, Bollen TL, Bruno MJ, van der gaast A, Veerbek L et al.National compliance to an evidence-based multidisciplinary guideline on pancreatic and periampullary carcinoma. Pancreatology, 16 (2016) http://dx.doi.org/10.1016/j.pan.2015.10.002	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf Karl Y. Bilimoria, David J. Bentrem, Keith D. Lillemoe, Mark S. Talamonti, Clifford Y. Ko, on behalf of the American College of Surgeons' Pancreatic Cancer Quality Indicator Development Expert Panel, Assessment of Pancreatic Cancer Care in the United States Based on Formally Developed Quality Indicators, JNCI: Journal of the National Cancer Institute, Volume 101, Issue 12, 16 June 2009, Pages 848–859;

Quality Indicator	Reference	Further supporting references
QI 5 Pancreatic: Palliative chemotherapy		
Numerator: Patients of the denominator with palliative chemotherapy **Denominator:** Non-surgical patients with pancreatic cancer and ECOG 0-2; Patients with pancreatic cancer and secondary metastasis (M1) without metastasis resection and ECOG 0-2 (w/o NET/NEC)	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	Karl Y. Bilimoria, David J. Bentrem, Keith D. Lillemoe, Mark S. Talamonti, Clifford Y. Ko, on behalf of the American College of Surgeons' Pancreatic Cancer Quality Indicator Development Expert Panel, Assessment of Pancreatic Cancer Care in the United States Based on Formally Developed Quality Indicators, JNCI: Journal of the National Cancer Institute, Volume 101, Issue 12, 16 June 2009, Pages 848–859
QI 6 Pancreatic: Primary resection for metastatic pancreatic cancer (new)		
Numerator: Patients of the denominator with primary resection of the tumour **Denominator:** Patients with pancreatic cancer (w/o NET/NEC) with distant metastases, peritoneal carcinomatosis, LN metastases, considered as distant metastases (M1))	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

Quality Indicator	Reference	Further supporting references
QI 7 Pancreatic: Second-line therapy (new)		
Numerator: Patients of the denominator with second-line therapy **Denominator:** Patients with pancreatic cancer (w/o NET/NEC), ECOG 0-2 and progression under palliative first-line therapy	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	
QI 8: Local R0 resections		
Numerator: Patients of the denominator with local R0 resesectoins after completion of surgical therapy **Denominator:** All patients with or without pancreatic cancer with pancreatic surgeries	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

Quality Indicator	Reference	Further supporting references
QI 9 Pancreatic: Revision surgeries		
Numerator: Patients of the denominator with revision surgeries after peri-operative complications within 30d of pancreatic surgery **Denominator:** All patients with or without pancreatic cancer with pancreatic surgeries	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

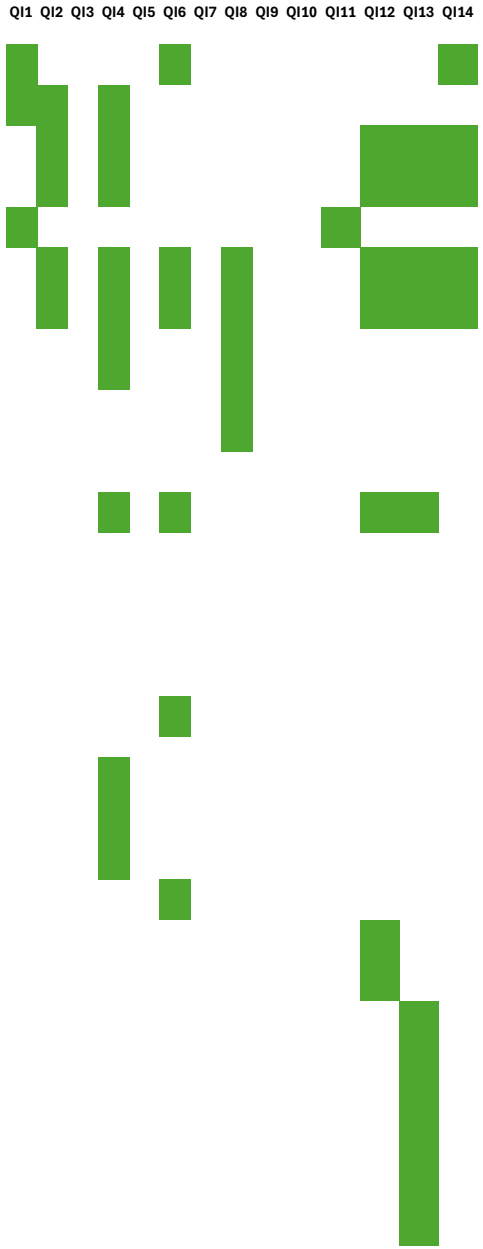
Quality Indicator	Reference	Further supporting references
QI 10 Pancreatic: Post-operative wound infections		
Numerator: Patients of the denominator with post-operative wound infection within 30 days from pancreatic surgery with need for surgical wound revision (flushing. opening. VAC dressing) **Denominator:** All patients with or without pancreatic cancer with pancreatic surgeries	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

Quality Indicator	Reference	Further supporting references
QI 11 Pancreatic: Post-operative mortality		
Numerator: Patients of the denominator who died within 30 days from pancreatic resection **Denominator:** All patients with pancreatic resections	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	Bilimoria, K. et al (2009): Assessment of Pancreatic Cancer Care in the United States Based on Formally Developed Qulaity Indicators, JNCI, Volume 1010, Issue 12, pages 848-859. https://academic.oup.com/jnci/article/101/12/848/2515610 Agency for Healthcare Research and Quality https://www.qualityindicators.ahrq.gov/Downloads/Modules/IQI/V2019/Ver-si-on_2019_Benchmark_Tables_IQI.pdf
QI 12 Pancreatic: Lymph node examination		
Numerator: Patients of the denominator with ≥ 12 regional lymph nodes in the surgical specimen after completion of surgical therapy **Denominator:** All patients with pancreatic cancer and resection who have undergone a lymphadenectomy w/o NET/NEC	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	Agency for Healthcare Research and Quality https://www.qualityindicators.ahrq.gov/Downloads/Modules/IQI/V2019/Ver-si-on_2019_Benchmark_Tables_IQI.pdf Kowalski, C., Graeven, U., von Kalle, C. et al. Shifting cancer care towards Multidisciplinarity: the cancer center certification program of the German cancer society. BMC Cancer 17, 850 (2017)

Quality Indicator	Reference	Further supporting references
QI 13 Pancreatic: Complete pathology report after resection		
Numerator: Patients of the denominator with a complete pathology report containing: pT, pN, M. tumor grading, ratio LN affected to removed LN **Denominator:** All patients with pancreatic cancer and resection w/o NET/NEC	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	
QI 14 Pancreatic: Social services counselling		
Numerator: Patients of the denominator who received counselling from the social services **Denominator:** All patients with pancreatic cancer (incl. patients with new recurrence and/or distant metastases)	European Cancer Centre Certification Programme Annual Report Pancreatic Cancer Centres (2022) http://ecc-cert.org/wp-content/uploads/2022/10/panc_annualreport-2022-A1_220531.pdf	

Appendix 6.2. Data Dictionary Composite

Datapoint	Description	Possible values (type varchar)	obs_dt	info	Source	Remark
Date of diagnosis	Date of diagnosis of pancreatic cancer (registratie_type = 'Nieuwe incidentie')	YYYY-MM-DD	datum_incidentie	Topography code	Cancer register	
Date of relapse	Date of relapse of pancreatic cancer (registratie_type = 'Follow-up')	YYYY-MM-DD	datum_incidentie	Topography code	Cancer register	
Pancreatic cancer	Cancer arising primarily in the pancreas	true	datum_incidentie	Topography code	Cancer register	Includes special histologies (e.g. NET) Only includes invasive cancers Does not include metastases to the pancreas. Includes patients who get only part of their treatment in UZA
Pancreatic resection	Complete or partial resection of pancreas	true	datum afname	CODAP code for location	davinci	CODAP code for location = 47.X Pathology_type = “operatiestuk”
Pancreatic cancer resection	Complete or partial resection of pancreas, containing malignancy	true	datum afname	diagnose_cod	davinci	CODAP code for location = 47.X Pathology_type = “operatiestuk” CODAP code for diagnosis indicates malignancy (see sheet 'CODAP codes pancreas')
R0 resection	Resection of pancreatic cancer with negative resection margins	true	datum afname	CODAP code for location	davinci	Pancreatic cancer resection AND R stage = 0 All R stage free text values that are not 0 or 1 or 2 are considered missing values (e.g. “x”, “is”, “1?”)
Incomplete resection	Resection of pancreatic cancer with positive resection margins, microscopically (R1) or macroscopically (R2)	true	datum afname	R stage	davinci	Pancreatic cancer resection AND R stage = 1 or 2 All R stage free text values that are not 0 or 1 or 2 are considered missing values (e.g. “x”, “is”, “1?”)
date of tissue retrieval		YYYY-MM-DD	datum afname	Order descriptions of tissue retrieval	davinci	
neuro-endrocrine histology	Neuro-endocrine tumor or neuro-endocrine carcinoma	true	datum_incidentie	Histologische diagnose	Cancer register	
cT	Clinical T stage	T0, T1, T2, T3, T4, Tx	datum_incidentie	cT	Cancer register	
cN	Clinical N stage	N0, N1, N2, Nx	datum_incidentie	cN	Cancer register	
cM	Clinical M stage	M0, M1	datum_incidentie	cM	Cancer register	
pT	Pathological T-stage	T0, T1, T2, T3, T4, Tx	datum afname	pT	davinci	Sometimes a resection is incorrectly labeled as “biopsy”, so do not include pathology_type = resection Date of pathology report is later than date of tissue retrieval
pN	Pathological N-stage	N0, N1, N2, N3, Nx	datum afname	pN	davinci	
pM	Pathological M-stage	M0, M1, MX	datum afname	pM	davinci	
ypT	Pathological T-stage after neo-adjuvant treatment	T0, T1, T2, T3, T4, Tx	datum afname	ypT	davinci	
ypN	Pathological N-stage after neo-adjuvant treatment	N0, N1, N2, N3, Nx	datum afname	ypN	davinci	
ypM	Pathological M-stage after neo-adjuvant treatment	M0, M1, MX	datum afname	ypM	davinci	
pancreatic cancer stage	UICC stage of cancer of the exocrine pancreas	1, 2, 3, 4	date of TNM, or if Stadium form kkr, datum_incidentie	TNM or 'Stadium'	davinci, Cancer register	Sources, in order of priority for use: -Davinci, specimen “pancreatic cancer resection”. Fields: pT, pN and pM -Cancer Register C25.X/3. Fields: pT, pN and pM -Cancer register C25.X/3. Fields: cT, cN and cM -Cancer register C25.X/3. Field: Stadium
Upfront metastatic pancreatic cancer	M1 status at diagnosis (stage 4)	true	date of Pancreati cancer	M1	davinci, Cancer register	Pancreatic cancer stage = 4
Lymphadenectomy done		true	First diagnostic date	Date of surgery	Oncobase	“HadLymphadectomy” = 1 Exclude entries where “NumberOfLymphNodesRetrieved” = 0
Number of lymph nodes retrieved		Integer (0<)	First diagnostic date	Date of surgery	Oncobase	Exclude entries with empty field, or 0 as value
Oncobase (y)pT-stage	Is pathological T-stage reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If any of the fields “pT” or “ypT” has content, return: present If none of the fields “pT” or “ypT” has content, return: absent
Oncobase (y)pN-stage	Is pathological N-stage reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If any of the fields “pN” or “ypN” has content, return: present If none of the fields “pN” or “ypN” has content, return: absent
Oncobase (y)pM-stage	Is pathological M-stage reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If any of the fields “pM” or “ypM” has content, return: present If none of the fields “pM” or “ypM” has content, return: absent
Oncobase grade	Is tumor grade reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If the field “DifferentiationCode” contains a value 1, 2, 3 or 4, return: present. If any other value, return: absent
Oncobase number of affected lymph nodes	Is the number of affected lymph nodes reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If the field “NumberOfLymphNodesWithTumoralInvolvement” contains an integer, return: present. If not, return: absent



Oncobase number of resected lymph nodes	Is the number of resected lymph nodes reported?	Present, Absent	First diagnostic date	Date of surgery	Oncobase	If the field “NumberOfLymphNodesRetrieved” contains an integer, return: present. If not, return: absent
start date of systemic therapy regimen	Start date of a new regimen of antineopastic systemic therapy	YYYY-MM-DD	First date of administration of the regimen	therapie_naam	Chemo Pro	
systemic therapy regimen	Administration of antineoplastic systemic therapy	therapie_naam	Date of administration	'Island_id'_'Number in administration cycle'	Chemo Pro	
tumor board	Case discussion at tumor board	appointment, verslag	date of tumor board	MOC type	schapptbook or EPD	If 1 is present: date of tumor board If 2 are present with 1-6d interval: date of “appointment" type (if both "verslag" type, first) If 2 are present with >6d interval: consider as 2 tumor board events, each with their own timestamp
social	Did the patient receive social counselling at any time point after diagnosis?	true	Date of contact	Subcategory	Millenium EHR	Time window: after date of diagnosis
last follow-up	Date last seen in the hospital (before or on date of death)	YYYY-MM-DD	Date of last encounter	Department of last contact	EPD encounters	Date of last patient contact in the hospital, regardless of the type (consultation, day clinic, hospitalization…) or medical service (oncology, cardiology, emergency…)
date of death	Date of death	YYYY-MM-DD	datum_overlijden	/	onco_patientinfo	

Organ	Diagnosis code	Diagnosis description	Malignancy (excl in situ)	Primary pancreatic malignancy (excl in situ)	Pancreatic adenocarcom (excl in situ)	Pancreatic NET or NEC	Other primary pancreatic malignanc (excl in situ)
47NS Pancreas, NOS	96KL	(Neuro)endocrine carcinoma (NEC), undifferentiated;Small cell (neuro)endocrine carcinoma (small cell NEC)	1	1	0	1	0
47ST Cauda of pancreas	99AC	Acinar adenocarcinoma;Acinar cell carcinoma;Acinic cell carcinoma	1	1	1	0	0
47KO Pancreas, head	93	Acinar prostatic adenocarcinoma;Adenocarcinoma, biliary type;Adenocarcinoma, gastric foveolar type;Adenocarcinoma, non-intestinal type;Adenocarcinoma, NOS;(Extrahepatic) cholangiocarcinoma (ECC);Parathyroid carcinoma	1	1	1	0	0
47WI Whipple resectie	93SA	Adenocarcinoma in serrated adenoma;Serrated adenocarcinoma	1	1	1	0	0
	93IN	Adenocarcinoma invasief (musculosa)	1	1	1	0	0
47ST Cauda of pancreas	93DU	Adenocarcinoma, mammary gland type;Carcinoma of no special type (NST) with apocrine differentiation;Carcinoma of no special type (NST), invasive (former invasive ductal carcinoma, NOS);Carcinoma of no special type (NST), invasive with medullary features;D	1	1	1	0	0
	93MG	Adenocarcinoma, moderately differentiated	1	1	1	0	0
47NS Pancreas, NOS	93WG	Adenocarcinoma, poorly differentiated	1	1	1	0	0
47NS Pancreas, NOS	93GG	Adenocarcinoma, well differentiated	1	1	1	0	0
47WI Whipple resectie	93AS	Adenosquamous carcinoma, NOS	1	1	0	0	1
47ST Cauda of pancreas	96AN	Anaplastic carcinoma	1	1	0	0	1
47NS Pancreas, NOS	79AT	Atypical carcinoid;(Neuro)endocrine carcinoma (NEC), intermediate differentiated;(Neuro)endocrine tumour G2 (NET G2) - (intermediate differentiated)	1	1	0	1	0
47KO Pancreas, head	79CA	Carcinoid, NOS;(Neuro)endocrine carcinoma (NEC), well differentiated / low grade;(Neuro)endocrine tumour G1 (NET G1) - (well differentiated);Testicular teratoma, monodermal (well differentiated neuroendocrine tumour);Typical carcinoid;Well differentiated	1	1	0	1	0
47NS Pancreas, NOS	80CA	Carcinoma, NOS	1	1	N/A	N/A	N/A
47NS Pancreas, NOS	93CC	Clear cell adenocarcinoma;Clear cell renal cell carcinoma	1	0	0	0	0
47WI Whipple resectie	93MU	Colloid adenocarcinoma;Colloid carcinoma (formerly mucinous cystadenocarcinoma of lung);Mucinous adenocarcinoma;Mucinous tubular and spindle cell carcinoma	1	1	1	0	0
47KO Pancreas, head	93CR	Cribriform adenocarcinoma;Cribriform comedo-type adenocarcinoma;Cribriform ductal adenocarcinoma	1	1	1	0	0
47KO Pancreas, head	93GA	Gastrin-producing NET (gastrinoma)	1	1	0	1	0
47NS Pancreas, NOS	79GI	Gastrointestinal stromal tumour (GIST), uncertain malignant potential	1	1	0	0	1
47NS Pancreas, NOS	94SH	High-grade serous carcinoma	1	1	0	0	1
	80CR	Malignant tumour, complete regression after induction therapy (ypT0)	1	1	N/A	N/A	N/A
47CY Cytology of pancreas	80DD	Malignant tumour, differential diagnostic problem	1	1	N/A	N/A	N/A
	80SN	Malignant tumour, negative resection margin	1	1	N/A	N/A	N/A
47CY Cytology of pancreas	80	Malignant tumour, NOS	1	1	N/A	N/A	N/A
	80SP	Malignant tumour, positive resection margin	1	1	N/A	N/A	N/A
47NS Pancreas, NOS	99CA	Mixed carcinoid-adenocarcinoma (MANEC) (at least 30 % of both components have to be present)	1	1	0	1	0
47KO Pancreas, head	93SR	Mucinous adenocarcinoma, signet-ring cell type;Poorly cohesive adenocarcinoma (including signet ring cell carcinoma and other variants);Signet ring cell adenocarcinoma	1	1	1	0	0
	93ME	Mucoepidermoid carcinoma	1	1	0	0	1
	96	Sinonasal undifferentiated carcinoma;Undifferentiated (anaplastic) carcinoma;Undifferentiated carcinoma	1	1	0	0	1
47NS Pancreas, NOS	93MS	Solid adenocarcinoma (with mucin production);Solid ductal adenocarcinoma	1	1	1	0	0
47KO Pancreas, head	91	Squamous cell carcinoma, NOS	1	1	0	0	1
47NS Pancreas, NOS	93TU	Tubular adenocarcinoma	1	1	1	0	0
	96OS	Undifferentiated carcinoma with osteoclast-like (stromal) giant cells	1	1	0	0	1

CraNE JA

Quality Indicators (QI) for pancreatic cancer care – calculation logic
Author: Annelies Verbiest, Antwerp University Hospital

QI6: Primary resection for metastatic pancreatic cancer

What percentage of patients with pancreatic cancer (not NET/NEC) receive primary resection for metastatic pancreatic cancer (M1 status as defined by distant metastases, peritoneal carcinomatosis or lymph nodes considered as distant metastases)?

Consider the data points:

- Upfront metastatic pancreatic cancer (= M1 status)
- Neuro-endocrine histology
- Date of diagnosis
- Pancreatic cancer resection
- ypT
- ypN

QI6 cohort definition:

Patients with:

- Upfront metastatic pancreatic cancer

Of these, exclude patients with:

- Neuro-endocrine histology

General remarks:

- The numerator (primary resection) includes both patients who receive a diagnosis of M1-disease pre-operatively AND peroperatively (e.g. peritoneal carcinomatosis) AND shortly post-operatively (the highest stage in the first 3 months after diagnosis is recorded as initial stage).
- The numerator excludes patients with a mention of neo-adjuvant treatment (ypTNM).
- The denominator includes patients who undergo an “open-close” surgical procedure (M1 disease is diagnosed peroperatively and resection is cancelled).
- We assume that primary resection for metastatic cancer would be carried out within 4 months (122 days) of diagnosis. This assumption is meant to avoid inclusion of patients who undergo pancreatic surgery for another reason at a later time point.

Logic:

Define primary resection as:

- Pancreatic cancer resection within a time window of 0-122 days after date of diagnosis.
- If the pathology report of the pancreatic cancer resection indicates “pTNMType = yp” or “pTNMType = yN”, the patient is excluded from the “primary resection” group

Calculate the percentage:

- Numerator: number of patients in the patient cohort who receive primary resection
- Denominator: number of patients in the QI6 patient cohort

QI13: Complete pathology report after resection

What is the percentage of patients with resected pancreatic cancer (excl. NET/NEC), who have a complete pathology report (pT, pN, pM, tumor grading, ratio LN affected to removed LN)?

Consider the datapoints:

- Pancreatic cancer
- Pancreatic cancer resection
- Neuro-endocrine histology
- (y)pT-stage
- (y)pN-stage
- ~~Oncobase (y)pM-stage~~
- Grade
- Number of affected lymph nodes
- Number of resected lymph nodes

QI13 cohort:

Patients who meet both criteria:

- Pancreatic cancer
- Pancreatic cancer resection

Exclude patients with:

- Neuro-endocrine histology

General remarks:

- Because M-stage is not a pathological diagnosis, it is rarely explicitly reported in Belgium (pM1 is, pM0 is not). Therefore, we present "QI13bis", which omits M-stage from the requirements for a complete pathology report.

Calculation logic:

Define complete pathology report as:

- QI13bis: All 5 parameters are "present":
  - (y)pT-stage
  - (y)pN-stage
  - Grade
  - Number of affected lymph nodes
  - Number of resected lymph nodes

Calculate the percentage:

- Numerator: number of patients in the QI13 cohort with a complete pathology report
- Denominator: number of patients in the QI13 cohort
-

QI14: Social services counselling

What percentage of all patients with pancreatic cancer (incl. patients with new recurrence and/or distant metastases) receive counselling from the social services?

Consider the data points:

- Pancreatic cancer
- Date of diagnosis
- Pancreatic cancer resection
- Start date of systemic therapy regimen
- Social service counselling

QI14 cohort definition:

Patients who have

- Pancreatic cancer
  AND
- A date of diagnosis between the start of the observation period to 60 days before the end of the observation period
  AND *1 or 2 of the following treatment criteria:*

- Pancreatic cancer resection
  OR
- Start date of systemic therapy regimen

General remarks:

- A patient can enter the cohort only once, even when social service counselling is offered repeatedly.
- As social service counselling can be offered repeatedly, the current QI does not take into account a specific time window for social counselling after diagnosis of primary tumor or relapse.
- We include only patients who receive treatment (surgery and/or systemic therapy) in UZA, to avoid including patients who only consult for a second opinion. As such, patients who receive best supportive care only are not included.
- In UZA, counselling is provided both by social services and onconurses.

Logic:

Calculate the percentage:

- Numerator: number of patients in the QI14 cohort with social services counselling
- Denominator: number of patients in the QI14 cohort

Appendix 6.4. Data Dictionary Raw

Datapoint	Description	Possible values (type varchar)	obs_dt	info	Source	Remark
Date of diagnosis	Date of diagnosis of pancreatic cancer (registratie_type = 'Nieuwe incidentie')	YYYY-MM-DD	datum_incidentie	Topography code	Cancer register	
Date of relapse	Date of relapse of pancreatic cancer (registratie_type = 'Follow-up')	YYYY-MM-DD	datum_incidentie	Topography code	Cancer register	
Pancreatic cancer	Cancer arising primarily in the pancreas	true	datum_incidentie	Topography code	Cancer register	Includes special histologies (e.g. NET) Only includes invasive cancers Does not include metastases to the pancreas. Includes patients who get only part of their treatment in UZA
Pancreatic resection	Complete or partial resection of pancreas	true	datum afname	CODAP code for location	davinci	CODAP code for location = 47.X Pathology_type = "operatiestuk"
Codap	Codap code for location and diagnosis	Codap code for location	datum afname	CODAP code for diagnosis	davinci	CODAP code for location = 47.X
R stage	Resection margin	0,1,2,x,is,...	datum afname		davinci	CODAP code for location = 47.X Pathology_type = "operatiestuk" CODAP code for diagnosis indicates malignancy (see sheet 'CODAP codes pancreas')
date of tissue retrieval		YYYY-MM-DD	datum afname	Order descriptions of tissue retrieval	davinci	
neuro-endrocrine histology	Neuro-endocrine tumor or neuro-endocrine carcinoma	true	datum_incidentie	Histologische diagnose	Cancer register	
cT	Clinical T stage	T0, T1, T2, T3, T4, Tx	datum_incidentie	cT	Cancer register	topografie_code = C25.X Index Gedrag = 3
cN	Clinical N stage	N0, N1, N2, Nx	datum_incidentie	cN	Cancer register	topografie_code = C25.X Index Gedrag = 3
cM	Clinical M stage	M0, M1	datum_incidentie	cM	Cancer register	topografie_code = C25.X Index Gedrag = 3
pT_kkr	Pathological T-stage	T0, T1, T2, T3, T4, Tx	datum_incidentie	cT	Cancer register	topografie_code = C25.X Index Gedrag = 3
pN_kkr	Pathological N-stage	N0, N1, N2, Nx	datum_incidentie	cN	Cancer register	topografie_code = C25.X Index Gedrag = 3
pM_kkr	Pathological M-stage	M0, M1	datum_incidentie	cM	Cancer register	topografie_code = C25.X Index Gedrag = 3
Stadium_kkr	Cancer stage	Free tekst	datum_incidentie		Cancer register	topografie_code = C25.X Index Gedrag = 3
pT	Pathological T-stage	T0, T1, T2, T3, T4, Tx	datum afname	pT	davinci	Sometimes a resection is incorrectly labeled as "biopsy", so do not include pathology_type = resection Date of pathology report is later than date of tissue retrieval
pN	Pathological N-stage	N0, N1, N2, N3, Nx	datum afname	pN	davinci	
pM	Pathological M-stage	M0, M1, MX	datum afname	pM	davinci	
ypT	Pathological T-stage after neo-adjuvant treatment	T0, T1, T2, T3, T4, Tx	datum afname	ypT	davinci	
ypN	Pathological N-stage after neo-adjuvant treatment	N0, N1, N2, N3, Nx	datum afname	ypN	davinci	
ypM	Pathological M-stage after neo-adjuvant treatment	M0, M1, MX	datum afname	ypM	davinci	
Lymphadenectomy done		true	First diagnostic date	Date of surgery	Oncobase	"HadLymphadectomy" = 1
Number of lymph nodes retrieved		Integer	First diagnostic date	Date of surgery	Oncobase	
Number of lymph nodes with tumoral involvement		Integer	First diagnostic date	Date of surgery	Oncobase	
(y)pT-stage	Pathological T-stage (after neo-adjuvant treatment)	pT, ypT	First diagnostic date	Date of surgery	Oncobase	
(y)pN-stage	Pathological N-stage (after neo-adjuvant treatment)	pN, ypN	First diagnostic date	Date of surgery	Oncobase	
(y)pM-stage	Pathological M-stage (after neo-adjuvant treatment)	pM, ypM	First diagnostic date	Date of surgery	Oncobase	
Differentiation code		Integer	First diagnostic date	Date of surgery	Oncobase	
systemic therapy regimen	Administration of antineoplastic systemic therapy	therapie_naam	Date of administration	'Island_id'_'Number in administration cycle'	Chemo Pro	
tumor board	Case discussion at tumor board	appointment, verslag	date of tumor board	MOC type	schapptbook or EPD	1. Schapptbook. Include appointment types: • MOC Bespreking NET-werk • MOC Bespreking pancreas • MOC Bespreking digestieve 2. EPD Include "_Patient MOC verslagen" types: • MOC digestieve brief • MOC digestieve oncologie • MOC neuro-endocrien tumoren • MOC neuro-endocriene tumoren (NET) brief • MOC compl. Chir. Pancr/slokdarm bijdrage • MOC digestieve oncologie bijdrage
social	Did the patient receive social counselling at any time point after diagnosis?	true	Date of contact	Subcategory	Millenium EHR	Time window: after date of diagnosis
last follow-up	Date last seen in the hospital (before or on date of death)	YYYY-MM-DD	Date of last encounter	/	EPD encounters	Date of last patient contact in the hospital, regardless of the type (consultation, day clinic, hospitalization...) or medical service (oncology, cardiology, emergency...)
last follow-up per department	Date last seen per hospital deparment	YYYY-MM-DD	Date of last encounter	Department of last contact	EPD encounters	Can include dates after death (probably due to appointments)
date of death	Date of death	YYYY-MM-DD	datum_overlijden	/	onco_patientinfo	

Organ	Diagnosis code	Diagnosis description	Malignancy (excl in situ)	Primary pancreatic malignancy (excl in situ)	Pancreatic adenocarcom (excl in situ)	Pancreatic NET or NEC	Other primary pancreatic malignanc (excl in situ)
47NS Pancreas, NOS	96KL	(Neuro)endocrine carcinoma (NEC), undifferentiated;Small cell (neuro)endocrine carcinoma (small cell NEC)	1	1	0	1	0
47ST Cauda of pancreas	99AC	Acinar adenocarcinoma;Acinar cell carcinoma;Acinic cell carcinoma	1	1	1	0	0
47KO Pancreas, head	93	Acinar prostatic adenocarcinoma;Adenocarcinoma, biliary type;Adenocarcinoma, gastric foveolar type;Adenocarcinoma, non-intestinal type;Adenocarcinoma, NOS;(Extrahepatic) cholangiocarcinoma (ECC);Parathyroid carcinoma	1	1	1	0	0
47WI Whipple resectie	93SA	Adenocarcinoma in serrated adenoma;Serrated adenocarcinoma	1	1	1	0	0
	93IN	Adenocarcinoma invasief (musculosa)	1	1	1	0	0
47ST Cauda of pancreas	93DU	Adenocarcinoma, mammary gland type;Carcinoma of no special type (NST) with apocrine differentiation;Carcinoma of no special type (NST), invasive (former invasive ductal carcinoma, NOS);Carcinoma of no special type (NST), invasive with medullary features;D	1	1	1	0	0
	93MG	Adenocarcinoma, moderately differentiated	1	1	1	0	0
47NS Pancreas, NOS	93WG	Adenocarcinoma, poorly differentiated	1	1	1	0	0
47NS Pancreas, NOS	93GG	Adenocarcinoma, well differentiated	1	1	1	0	0
47WI Whipple resectie	93AS	Adenosquamous carcinoma, NOS	1	1	0	0	1
47ST Cauda of pancreas	96AN	Anaplastic carcinoma	1	1	0	0	1
47NS Pancreas, NOS	79AT	Atypical carcinoid;(Neuro)endocrine carcinoma (NEC), intermediate differentiated;(Neuro)endocrine tumour G2 (NET G2) - (intermediate differentiated)	1	1	0	1	0
47KO Pancreas, head	79CA	Carcinoid, NOS;(Neuro)endocrine carcinoma (NEC), well differentiated / low grade;(Neuro)endocrine tumour G1 (NET G1) - (well differentiated);Testicular teratoma, monodermal (well differentiated neuroendocrine tumour);Typical carcinoid;Well differentiated	1	1	0	1	0
47NS Pancreas, NOS	80CA	Carcinoma, NOS	1	1	N/A	N/A	N/A
47NS Pancreas, NOS	93CC	Clear cell adenocarcinoma;Clear cell renal cell carcinoma	1	0	0	0	0
47WI Whipple resectie	93MU	Colloid adenocarcinoma;Colloid carcinoma (formerly mucinous cystadenocarcinoma of lung);Mucinous adenocarcinoma;Mucinous tubular and spindle cell carcinoma	1	1	1	0	0
47KO Pancreas, head	93CR	Cribriform adenocarcinoma;Cribriform comedo-type adenocarcinoma;Cribriform ductal adenocarcinoma	1	1	1	0	0
47KO Pancreas, head	93GA	Gastrin-producing NET (gastrinoma)	1	1	0	1	0
47NS Pancreas, NOS	79GI	Gastrointestinal stromal tumour (GIST), uncertain malignant potential	1	1	0	0	1
47NS Pancreas, NOS	94SH	High-grade serous carcinoma	1	1	0	0	1
	80CR	Malignant tumour, complete regression after induction therapy (ypT0)	1	1	N/A	N/A	N/A
47CY Cytology of pancreas	80DD	Malignant tumour, differential diagnostic problem	1	1	N/A	N/A	N/A
	80SN	Malignant tumour, negative resection margin	1	1	N/A	N/A	N/A
47CY Cytology of pancreas	80	Malignant tumour, NOS	1	1	N/A	N/A	N/A
	80SP	Malignant tumour, positive resection margin	1	1	N/A	N/A	N/A
47NS Pancreas, NOS	99CA	Mixed carcinoid-adenocarcinoma (MANEC) (at least 30 % of both components have to be present)	1	1	0	1	0
47KO Pancreas, head	93SR	Mucinous adenocarcinoma, signet-ring cell type;Poorly cohesive adenocarcinoma (including signet ring cell carcinoma and other variants);Signet ring cell adenocarcinoma	1	1	1	0	0
	93ME	Mucoepidermoid carcinoma	1	1	0	0	1
	96	Sinonasal undifferentiated carcinoma;Undifferentiated (anaplastic) carcinoma;Undifferentiated carcinoma	1	1	0	0	1
47NS Pancreas, NOS	93MS	Solid adenocarcinoma (with mucin production);Solid ductal adenocarcinoma	1	1	1	0	0
47KO Pancreas, head	91	Squamous cell carcinoma, NOS	1	1	0	0	1
47NS Pancreas, NOS	93TU	Tubular adenocarcinoma	1	1	1	0	0
	96OS	Undifferentiated carcinoma with osteoclast-like (stromal) giant cells	1	1	0	0	1