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ABSTRACT

Importance: The development of colorectal cancer outcome registries internationally has been organic, with differing datasets, data definitions and infrastructure across registries which has limited data pooling and international comparison. Currently there is no comprehensive data dictionary identified as a standard. This study is part of an international collaboration that aims to identify areas of data capture and usage which may be optimised to improve understanding of colorectal cancer outcomes.

Objective: This study aimed to compare and identify commonalities and areas of difference across major colorectal cancer registries. We sought to establish datasets comprising of mutually collected common fields, and a combined comprehensive dataset of all collected fields across major registries to aid in establishing a future colorectal cancer registry database standard.

Design and Methods: This mixed qualitative and quantitative study compared data dictionaries from three major colorectal cancer outcome registries: Bowel Cancer Outcomes Registry (BCOR) (Australia and New Zealand), National Bowel Cancer Audit (NBOCA) (United Kingdom) and Dutch ColoRectal Audit (DCRA) (Netherlands). Registries were compared and analysed thematically, and a common dataset and combined comprehensive dataset were developed. These generated datasets were compared to data dictionaries from Sweden (SCRCR),

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Denmark (DCCG), Argentina (BNCCR-A) and the USA (NAACCR and ACS NSQIP). Fields were assessed against prominent quality indicator metrics from the literature and current case-use.

Results: We developed a combined comprehensive dataset of 225 fields under seven domains: demographic, pre-operative, operative, post-operative, pathology, neoadjuvant therapy, adjuvant therapy, and follow up/recurrence. A common dataset was developed comprising 38 overlapping fields, showing a low degree of mutually collected data, especially in preoperative, post operative and adjuvant therapy domains. The BNCCR-A, SCRCR and DCCG databases all contained a high percentage of common dataset fields. Fields were poorly comparable when viewed form current quality indicator metrics.

Conclusion: This study mapped data dictionaries of prominent colorectal cancer registries and highlighted areas of commonality and difference The developed common field dataset provides a foundation for registries to benchmark themselves and work towards harmonisation of data dictionaries. This has the potential to enable meaningful large-scale international outcomes research.

1. Introduction

Pooled data from international cancer registries provides important health demographic information [1,2]. Large broad-based national cancer registries have been present for many decades, providing epidemiological data across many cancer subtypes using strict global standards, such as those set by the International Association of Cancer Registries (IACR) that govern collection, codification, and presentation principles [3]. IACR-affiliated registries are used for high-level population-based epidemiological purposes with data providence, codification and communication processes generally affiliated with official government departments. Other initiatives include European Network of Cancer Registries (ENCR), and the Australasian Association of Cancer Registries that exist similarly in smaller regional jurisdictions[4,5].

These population-based registries generally lack the richness and complexity of field-specific and more technical data when compared with field-based clinical outcomes registries. Clinical outcomes registries have become increasingly prevalent across the past two decades, often developing in partnership with universities, medical training colleges and hospital collaborators to enable capture of surgical, epidemiological, oncological, pathological and general patient information that exceeds what is captured in larger broad-based national registries [6]. They are increasingly used to inform patient care, including through registry-based clinical trials, as they provide more numerous and specific data fields across relatively large numbers of patients.

Having a clearly defined data dictionary is essential for collecting high quality robust data and facilitates analyses and interpretation between clinical outcome registries nationally and internationally and provides opportunities to boost samples sizes in large collaborative studies. Furthermore, surgical oncology research and day-to-day operations are becoming increasingly driven by key quality indicator (QI) metrics from these outcome registries as a method to apprise effectiveness of services and to adapt and improve processes to improve patient care as an ongoing cause. It is therefore vital that the data that these quality indicators are based on be reliable and comparable between jurisdictions.

The development of colorectal cancer registries has occurred organically in different countries, and within the constraints and administrative infrastructure of each country's individual settings without the same degree of international oversight bodies such as IACR. Furthermore, data dictionaries may be constrained by national data standards or local data-linkage practices, making international harmonisation more challenging. This has led to vastly different data dictionaries between various national surgical colorectal datasets.

Despite the efforts of standardisation initiatives targeting the large population-based cancer registries (including those IACR-affiliated), there still exists inconsistency and confusion regarding basic data items such as date of diagnosis [7] and use of tumour staging systems [8]. This is despite the fact that these registries are used for applications including national statistics measures, government policy creation and global benchmarking exercises. Inconsistency in these data collection standards have been attributed to skewing breast cancer survival statistics in the UK for example [9,10]. Given that these population-based registries collect fewer and theoretically less-complex data fields, it could be concluded that the task of unifying data for field-specific outcome registries will be an even more difficult endeavour, especially given ongoing evolution in colorectal cancer surgical techniques, genetic markers, pre and post-operative care pathways and with the integration of patient-reported outcome measures (PROMS).

Outside of cancer registries there are general guidelines for use of metadata, with standards outlining the definitions and use of fields for defined contexts. There is currently no standardised international core outcome set for registry data on colorectal cancer. Agreement on a core outcome set would enable pooling of international data and would maximise data utility. Large scale cancer datasets provide the ability to generate important public health information to answer clinically relevant questions, for example in demonstrating the impact of screening on colorectal cancer outcomes [11]. There exist several initiatives to promote collaboration between outcome registries. For example, the International Consortium for Health Outcomes Measurement (ICHOM) have evaluated candidate topics for inclusion in an ideal colorectal cancer dataset[12].

In addition, numerous studies have investigated which quality indicators are perceived to be providing insight and clinical value, which may offer guidance to which clinical data should be prioritised [13–15]. However, no study to date has compared the data dictionaries of current major colorectal cancer registries to identify common fields between them and to in-turn offer a basis for registry compatibility.

This project leverages partnerships from a new multi-national registry collaboration initiative, the International Colorectal Cancer Outcome Registry Collaboration (ICORC), in order to highlight areas of difference and commonalities between three major colorectal cancer outcome registries in Australia/New Zealand, England/Wales, and the Netherlands, especially with reference to evidence-based and consensus-based quality indicators and case-use indicators. We sought to identify a set of fields that are common between these registries currently to demonstrate the extent of direct compatibility that currently exists, prior to any harmonisation processes. We also aimed to develop a comprehensive set of all current fields collected as a basis for future Delphi consensus processes. We also sought to compare these three registries to other national outcome registries to gain a broader understanding surrounding the wider extent of heterogeneity in data dictionaries beyond those three included for more in-depth analysis.

2. Methods

2.1. Included databases and registries (Table 1)

2.1.1. National Bowel Cancer Audit (NBOCA) - England and Wales

NBOCA is the National Bowel Cancer Audit for England and Wales and forms a part of the Gastrointestinal Cancer Audit [16]. It is run jointly by the Clinical Effectiveness Unit at the Royal College of Surgeons of England, NHS digital, and the Association of Coloproctologists of

Table 1
Characteristics of selected Colorectal Cancer Clinical Outcomes Registries.

Outcomes Registry	Abbreviation	Country	Years Active	Cases Included	N° of Total Cases (Approx.)	New Cases Annually (Approx.)	Data Collectors	Case Ascertainment	Registry Establishment and Maintenance
American College of Surgeons National Surgical Quality Improvement Program	**ACS NSQIP**	USA (predominantly)	1989 to present	Colorectal Cancer	N/D	N/D	Certified tumour registrars at specific Commission on Cancer–approved hospitals	722 Sites (70 % of all new CRC cases in USA)	American College of Surgeons (ACS)
Base Nacional de Cáncer Colorrectal en Argentina	**BNCCR-A**	Argentina	2022 to present	Colorectal Cancer	1000	N/A	Clinicians	28 sites	Argentinian Colorectal Cancer Consortium
Bowel Cancer Outcomes Registry	**BCOR**	Australia, New Zealand	2007 to present	Colorectal Cancer	53,000	4140 (2022)	Clinicians	21.7 % of all CRC patients (82 % of these form public hospitals)	Colorectal Surgical Society of Australia and New Zealand (CSSANZ); Monash University
Danish Colorectal Cancer Group Database	**DCCG**	Denmark	Rectal cancer 1994 to present: Colon Cancer 2001 to present	Colorectal Cancer	70,000	3953 (2836 colon, 1117 rectal) (2022)	Clinicians	99 % CRC patients (All hospitals in Denmark)	Danish Colorectal Cancer Group (DCCG)
Dutch ColoRectal Cancer Audit	**DCRA**	Netherlands	2009 to present	Colorectal Cancer	108,000	9132 (2019)	Clinicians	95 % CRC patients (All hospitals in the Netherlands)	Association of Surgeons of the Netherlands (ASN); Dutch Institute for Clinical Auditing (DICA)
National Bowel Cancer Audit	**NBOCA**	England, Wales	2002 to present	Colorectal Cancer	450,000	28, 523 (2021)	Representatives of National Health Service Trusts	89 % (All NHS trusts and Health Boards in England and Wales)	Clinical Effectiveness Unit (CEU) - Royal College of Surgeons of England (RCS); National Health Service (NHS) digital; Association of Coloproctologists of Great Britain and Ireland (ACPGBI); Healthcare Quality Improvement Partnership (HQIP)
North American Association of Cancer Registries	**NAACCR**	USA, Canada	1987 to present	All cancer types including: Colorectal Cancer, Anal Cancer	N/D	N/D	Varies	All central cancer registries in USA are members	American Cancer Society; American College of Surgeons (ACS) Cancer Programs; Canadian Partnership Against Cancer; Centers for Disease Control and Prevention (CDC); College of American Pathologists; National Cancer Institute; National Cancer Registrars Association; Public Health Agency of Canada
Swedish Colorectal Cancer Registry	**SCRCR**	Sweden	Rectal cancer, 1995 to present; colon cancer, 2007 to presen	Colorectal Cancer	125,000	5097 (2021)	Clinicians	99 % (All hospitals in Sweden)	Swedish Cancer Society

N/A = Not applicable; N/D = Not Disclosed; CRC=Colorectal cancer.
Table adapted from: MacCallum C et al. (2018)[2].

Great Britain and Ireland (ACPGBI). It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of National Health Service (NHS) England and Welsh Government. It has operated since 2002, and national data collection has been mandatory since 2010. It includes approximately 30,000 patients with newly diagnosed colorectal cancer each year. The data dictionary used in this study was the core NBOCA dataset, although it does link to various other clinical and national health databases (not included in this study).

2.1.2. Bowel Cancer Outcomes Registry (BCOR) - Australia and New Zealand

(Formerly known as Binational Colorectal Cancer Audit - BCCA)

The Bowel Cancer Outcomes Registry (BCOR) is supported by the Colorectal Surgical Society of Australia and New Zealand (CSSANZ) and records surgical outcomes for colorectal cancer in Australia and New Zealand [17]. Case ascertainment is compulsory for all surgical trainee cases in Australia training under Royal Australasian College of Surgeons programs.

BCOR has collated data on over 50,000 patients since 2007. Other colorectal cancer databases within Australia include a quality improvement registry operated by Cabrini Health and Monash Health which record an extended dataset, whilst also incorporating the BCOR dataset (not included in this paper).

2.1.3. The Dutch ColoRectal Audit (DCRA) – Netherlands

The Dutch ColoRectal Audit was founded in 2009 by the Association of Surgeons of the Netherlands (ASN). The DCRA is an obligatory multidisciplinary registration which records results from all colorectal surgery patients in the Netherlands and is used to monitor and improve national quality standards [18]. Between 2009 and 2019, data from 107, 785 patients were included in the registry. The DCRA was used as a model for the initiation of other audits by the Dutch Institute for Clinical Auditing (DICA).

2.1.4. The Swedish Colorectal Cancer Registry (SCRCR) - Sweden

The Swedish Colorectal Cancer Registry (SCRCR) has reported on rectal cancer outcomes since 1995 and colon cancer outcomes since 2007 and contains data from over 125,000 patients[19].

2.1.5. The Danish Colorectal Cancer Group Database (DCCG) - Denmark

The Danish Colorectal Cancer Group Database (DCCG) has recorded data from all patients with newly diagnosed colorectal cancer since 2001 and is a population based clinical quality outcome database[20].

2.1.6. North American Association of Cancer Registries (NAACCR), and ***American College of Surgeons National Surgical Quality Improvement Program (ACS NSQIP) – USA and Canada***

USA colorectal cancer surgical outcomes data is split between cancer (NAACCR) and surgical (ACS NSQIP) databases. The landscape of colorectal cancer outcome data in the USA differs from many other countries as multiple databases exist with different remits, rather than a single colorectal cancer outcome registry[21].

2.1.7. ***Argentinian Colorectal Cancer Consortium Registry Project – Base Nacional de Cáncer Colorrectal en Argentina (BNCCR-A) - Argentina***

The Argentinian Colorectal Cancer Consortium registry project is in foundation-stage development aiming to establish a national database of colorectal cancer surgical outcomes in Argentina[22,23].

2.2. Comparison of international colorectal databases

Data dictionaries from BCOR, NBOCA and DCRA, were systematically compared using Microsoft Excel and Google Sheets programs to manually identify common and unique fields, and to identify differences and similarities in data dictionary definitions within these fields. These three databases were selected for analysis due to their consensus recognition as being well-run, having sufficient longevity, capturing large patient enrolment and ease of access to database-specific expert guidance during the analysis process.

Fields from these registries were grouped into domains aligned with patient treatment stages/events for easier interpretability. These domains included: demographic, pre-operative, operative, post-operative, pathology, neoadjuvant therapy, adjuvant therapy and follow-up/recurrence domains.

Only current registry data dictionary versions were used for comparison (Details regarding versions used available in *supplementary information*). Fields contained within other databases that registries may link to (for example linkages to national health registries or hospital administrative databases) were out of scope for this current analysis and were not included.

2.3. Mapping to quality indicators and clinical outcome metrics

Fields were then mapped to colorectal cancer outcome quality indicators that have been proposed in the literature. There is no single source of widely accepted and validated quality-outcome measures in colorectal cancer care. However, two systematic reviews capturing literature between 1966 and 2005 (Patwardhan et al.) [24] and 2006–2016 (Keikes et al.) [25] demonstrated a comprehensive list of evidence-based, consensus-based and validated quality indicators which we have used as a basis for this mapping exercise. Quality indicators from Patwardhan et al. were selected from those with the highest appraisal rating. Indicators from Keikes et al. were selected from a list of those evidence-based or validated measures or consensus measures where indicators were mentioned in 4 or more separate peer-reviewed published consensuses.

Fields were also mapped to the Queensland Cancer Quality Index (CQI) to offer an insight into a current real-world application of QI measures [26]. The CQI was developed by Cancer Alliance Queensland, a part of the Queensland Department of Health in order to provide information into the safety and quality of cancer treatment. Its development process involved throughout interrogation of indicator metrices in the literature, clinical practice guidelines, consensus measures and pilot trials. It is applicable to Queensland, Australia's third most-populous state, and is a representative sample of key benchmarking indicators used internationally.

2.4. BCOR, NBOCA and DCRA common dataset

These registries were used to obtain a 'common dataset' of fields mutually found in all three registries. Differences in fields were identified by consulting accompanying registry-specific data dictionaries and were further resolved into three classes:

1. Differences whereby one or more registries completely lacked a datapoint,
2. Differences whereby data point definitions contain conflicts that may affect meaning and interpretability between registries, and
3. Differences in data point definitions unlikely to affect meaning or interpretability between registries.

Categorisation of these differences was conducted by consensus between two reviewers including a colorectal surgeon and a junior doctor and was screened by three independent reviewing representatives affiliated with each of NBOCA, BCOR and DCRA.

Related fields were combined into 'key data areas' with qualitative analysis and further comment conducted regarding specific differences.

2.5. BCOR, NBOCA and DCRA comprehensive dataset

These three registries were also used to generate a 'comprehensive

dataset', a combined amalgamation of all fields collected across all registries.

2.6. Mapping common and comprehensive datasets to other international registries

The 'common dataset' and 'comprehensive dataset' were quantitatively compared with the ACS NSQIP, SCRCR, DCCG, BNCCR-A and NAACCR data registries.

3. Results

3.1. Key differences between BCOR, NBOCA and DCRA

There are differences in the level and breadth of detail recorded for some data themes (Supplementary Table 1). The DCRA contained nearly twice the number of preoperative fields and three times the number of neoadjuvant fields of either BCOR or NBOCA. NBOCA contained a very small number of fields relating to operative and post-operative domains. NBOCA and DCRA had more pathology fields (20 and 22 fields respectively) than BCOR (9). BCOR contained substantially more follow-up/recurrence data fields (22) versus NBOCA (3) and DCRA (1).

There are differences in the level of detail recorded for colon versus rectal cancer. There are several fields which are currently specified as rectal cancer only in the BCOR registry. For example, neoadjuvant therapy is recorded for both colon and rectal cancer in NBOCA and DCRA, while it can only be recorded for rectal cancer in BCOR (Supplementary Table 1).

There are technical differences in definitions for some fields. For 'distance from the anal verge', there are differences in the modality of how it is assessed. The DCRA records radiological distance, whereas the BCOR records this endoscopically and for NBOCA it is either (Supplementary Table 2, Row 16).

NBOCA and DCRA include fields relating to molecular status, while BCOR does not record molecular status fields (Supplementary Table 2). The version of American Joint Committee on Cancer (AJCC) TNM staging system [27] used also differs. NBOCA uses 5th or 8th version with a field to specify version, BCOR uses 5th and DCRA uses 8th· . Discussion of surgical risks is included as a data field in DCRA only. CPEX testing results are recorded in NBOCA but not BCOR or DCRA. DCRA records more detail on previous interventions than NBOCA or BCOR. For example, DCRA records whether there was a previous attempt at colonoscopic resection, whether there was a preoperative stoma or a preoperative appendicectomy.

BCOR has more detail on post-operative surgical outcomes including complications. The BCOR and DCRA also contain significantly more detail on postoperative complications than NBOCA.

3.2. Mapping BCOR, NBOA, DCRA to quality indicators and outcome metrics

Out of panel of 25 selected consensus, evidence-based and cohort-validated quality indicators (QIs) only 9 are able to be assessed and directly compared across all three registries with current data dictionaries (Table 3A). The DCRA reported on 18 QIs, followed by BCOR (14) and NBOCA (10). Similarly, only 6 of the 15 Queensland Cancer Quality Index (CQI) measures were able to be directly compared (Table 3B). The results suggested that where a registry does capture QI data, they tend to be well aligned with other registry data dictionaries that also capture it. Therefore, it appears that a lack of reporting of QIs, leads to lack of compatibility, rather than intrinsic data definition differences. There appears to be a lack of pre-surgical coloscopy data available in the BCOR and NBOCA. NBOCA also failed to capture TME completeness despite the association with disease-free survival, and also did not record the rate of permanent stoma formation, despite featuring a part in ICHOM patient-centred outcome measures [12]. CEA levels were not measured by any registry, however their exclusive use as a screening tool has been questioned [28]. With regard to the CQI notable fields lacking data comparability were regarding socioeconomically disadvantaged population care and well as time to systemic/radiation therapy. Other metrics regarding survival and hospital stay are present as linkages to NBOCA but are not included in the core registry.

3.3. BCOR, NBOCA and DCRA common dataset

Thirty-eight common fields were identified across these datasets, with most fields arising from demographic (10 fields), preoperative (11), operative (6) and pathology domains (6) (Table 2). Common demographic fields included data such as gender, age, and postal code at diagnosis. Common preoperative fields included date of diagnosis, pre-treatment clinical AJCC Node (N) and Tumour (T) TNM system staging, tumour location and distance from the anal verge for rectal cancer. Operative fields included date of surgery, surgical procedure and surgical approach and conversion. Pathology fields included lymph node counts and AJCC TNM staging. There were no common fields within the follow-up/recurrence domain. Differences were observed in 19 fields, though only one field, date of diagnosis, contained differences likely to affect meaning. The date of diagnosis definition used in NBOCA and DCRA is from the date of first biopsy confirmation, while BCOR takes the data of diagnosis from the date the patient was first seen (Supplementary Table 2, Row 6).

3.4. BCOR, NBOCA and DCRA comprehensive dataset

Combining and amalgamating the BCOR, NBOCA and DCRA databases produced a comprehensive dataset of 225 currently collected fields (Table 4, Supplemetary Table 1). The DCRA was the largest contributing database (contributing to 150 fields), followed by BCOR (125 fields) and NBOCA (78 fields). The largest domain was preoperative (52 fields), followed by postoperative (50 fields), operative (30 fields) and pathology (30 fields). Of the comprehensive dataset fields 60.0 % of fields were only found in a single registry, 23.1 % across 2 registries only, and only 16.9 % were common in all three registries analysed (Table 4). There was the least commonality in the follow-up/recurrence domain (81.8 % fields were unique to only 1 registry), followed by adjuvant therapy (80.0 %), and postoperative (65.4 %) domains.

3.5. Comparing the common and comprehensive datasets to the DCCG, SCRCR, ACS NSQIP, NAACCR and BNCCR-A

The greatest differences were noted with USA-based where it was more difficult to directly identify colorectal cancer-specific fields (Table 5). The ACS NSQIP database contained 32 fields within the comprehensive database, mainly in the post-operative domain, whilst the NAACCR contained 83 fields from the comprehensive dataset, mainly regarding pathology. The SCRCR and DCCG registries were broadly comparable to the comprehensive and common dataset, containing 36 and 30 fields respectively out of the thirty-eight-field common dataset. The BNCCR-A contained 24 fields within the common dataset, and 51 fields within the comprehensive dataset spread relatively evenly across all domains. This demonstrates some validity that the core dataset is captured more generally in outcome-based registries beyond those assessed (see Table 5).

4. Discussion

This study used a data-driven approach looking at the data dictionaries that are currently in use, as previously utilised by Mayer et al. [29]. Analysis has shown that a common datasetis relatively limited with a small number of fields able to be directly compared amongst three recognised preeminent colorectal outcomes registries. Those common

Table 2
Comparison of Common Dataset field definitions between NBOCA, DCRA and BCOR.

Data point	Comparison of field definitions: No difference	Differences unlikely to affect meaning	Differences likely to affect meaning
Patient/Demographic Domain			
Country-Level ID or National database-Level ID	☐	☑	☐
Patient Hospital Number	☑	☐	☐
Hospital or Hospital ID	☑	☐	☐
Date Of Birth	☑	☐	☐
Given Name(s)	☑	☐	☐
Surname	☑	☐	☐
Patient Initials	☑	☐	☐
Sex	☑	☐	☐
Postal Code at Diagnosis	☑	☐	☐
Country	☐	☑	☐
Preoperative Domain			
Date of Diagnosis	☐	☐	☑
Multidisciplinary Team Meeting - Case Discussed	☑	☐	☐
Location of Tumour Site(s)	☐	☑	☐
Distance from Anal Verge - Rectal Cancers	☐	☑	☐
Pretreatment Clinical T Staging (cT)	☐	☑	☐
Pretreatment Clinical N Staging (cN)	☐	☑	☐
Number of Tumours	☑	☐	☐
Synchronous Tumour	☐	☑	☐
Synchronous Tumour - Site	☑	☐	☐
ASA Score (American Society of Anesthesiology Score)	☑	☐	☐
BMI (or Height and Weight)	☑	☐	☐
Operative Domain			
Date of Primary Surgery	☑	☐	☐
Surgical Urgency	☐	☑	☐
Primary Surgical Procedure Performed	☐	☑	☐
Surgical Access	☐	☑	☐
Surgical Access - Conversion Type	☐	☑	☐
Stent Placed	☑	☐	☐
Post-Operative Domain			
Additional Operation/Return to Theatre	☐	☑	☐
Pathology Domain			
Pathological T Stage	☐	☑	☐
Pathological N Stage	☐	☑	☐
Pathological/ Radiological M Stage	☐	☑	☐
Number of Lymph Nodes Examined	☑	☐	☐
Number of Lymph Nodes Positive	☑	☐	☐
Circumferential Resection Margins	☑	☐	☐
Neoadjuvant Therapy Domain			
Neoadjuvant Therapy Received	☐	☑	☐
Neoadjuvant Therapy Received - Modality	☐	☑	☐
Adjuvant Therapy Domain			
Adjuvant Therapy Received	☑	☐	☐
Adjuvant Therapy Received - Modality	☐	☑	☐
Follow-up and Recurrence Domain			
No common fields in Follow-up/Recurrence domain			

Table 3A
Mapping Selected Quality Indicators to NBOCA, BCOR and DCRA.

Quality Indicator	Data Present in Registry			Able to compare quality indicators across all registries
	NBOCA	BCOR	DCRA	
Pre-operative				
Staging (cTNM) prior to treatment	Yes	No	Yes	No, DCRA uses TNM 8th edition, NBOCA uses 8th or 5th edition and BCOR uses 5th edition – may be difference in classification. BCOR does not record cM staging.
Complete colonoscopy (colon)	No	No	Yes	No
Colonoscopy to the ileocecal valve performed prior to surgical resection	No	No	No	No
Colonoscopy complication rate	No	No	Yes	No
Multidisciplinary meeting discussion	Yes	Yes	Yes	Yes
Pre-operative CEA level	No	No	No	No
Pelvic Imaging for rectal cancer	No	Yes	Yes	No
Percentage of patients with positive FOBT who underwent an appropriate evaluation	Yes	Yes	Yes	Yes
Operative				
Abdominoperineal resection (APR) rate	Yes	Yes	Yes	Yes, All registries record
Completeness of total mesorectal resection/ excision (TME)	No	No	Yes	No
Permanent stoma rate	No	Yes	Yes	No
Surgeon and hospital caseload	No	No	No	No
Post-Operative				
Anastomotic Leakage	No	Yes	Yes	No
Reoperation rate	Yes	Yes	Yes	Yes
30-day in-hospital mortality	No*	Yes	Yes	No* Not a part of NBOCA core database but may exist in linkage.
Pathology				
Mean number of lymph nodes	Yes	Yes	Yes	Yes
Circumferential resection margin (CRM) (rectum)	Yes	Yes	Yes	Yes
Neoadjuvant Therapy				
Radiotherapy for rectal cancer (if indicated)	Yes	Yes	Yes	Yes
Adjuvant Therapy				
Referral to a Medical Oncologist (if indicated)	Yes	Yes	Yes	Yes, Can be extrapolated from 'adjuvant therapy received'
Timeliness of adjuvant chemotherapy (stage II or III colon cancer)	No	No	Yes	No
Stage II and III rectal cancer, percentage receiving radiation therapy	Yes	Yes	Yes	Yes

Adherence of radiotherapy management treatment (adenocarcinoma of the rectum or sigmoid colon)	No	No	Maybe	No May be able to be extrapolated from DCRA 'radiotherapy details' field depending on data quality
Follow-up and Recurrence				
Follow-up CEA level	No	No	No	No
30-Day readmission after colectomy	No	Yes	Yes	No
Percentage of patients with colorectal cancer receiving postoperative (surveillance) colonoscopy	No	No	No	No

Adapted from Patwardhan et al. (2007) [24] and MacCallum et al. (2018)[25].

fields are also found more broadly in the DCCG, SCRCR and BNCCR-A which lends some validity to its use a basis for harmonisation.

Unsurprisingly date of diagnosis, a field which has many outcome measures derived, had differing methods of definition, which mirrors ongoing issues noted amongst the epidemiological population-based registries. Pre-operative tumour-related complications and pre-existing medical issues were are also areas requiring further improvement, especially in the development of pre-operative risk-stratification tools such as the ACS NSQIP Surgical Risk Calculator [30] which are valued by patients[12].

Post-operative complications are an area identified by ICHOM as an important patient-centred metric and enable insight into causes of in-patient mortality and increased length of stay data. The definitions and categorisation of these varied greatly, for example BCOR required fever, peri-wound cellulitis to record a diagnosis of wound infection (a common post-operative complication), whereas DCRA did not contain any guideline for diagnosis, and NBOCA did not record this complication at all. Similarly, post-operative bleeding (BCOR definition: bleeding requiring interventions, DCRA: nil definition, omitted in NBOCA) and ileus (>1 week in BCOR, and >5 days in DCRA, omitted in NBOCA) point to similar problems in fields that are fundamental to surgical-driven outcome registries. Some registries have attempted to patch this issue by introducing 'Frequently Asked Questions' sections related to complexity in definitions [31], however this does little to address the poor compatibility in what are very common, patient-concerning and surgically relevant post-operative complications.

Items such as FOBT screening program participation, adjuvant therapy, hospital-stay data and follow-up data in the UK does not fall under the purview of the NBOCA but may be derived from other database sources such as Hospital Episode Statistics, National Mortality Data and Systemic anti-cancer therapy datasets. Indeed, the UK has a complex linkage arrangement that draws information from various sources which we concede was unfortunately beyond the analysis conducted in this paper. Whilst data linkage contributes to efficiency, potential for tapping into other rich source of information and avoidance of duplication, it creates theoretical concerns regarding privacy and data sharing arrangements, especially where data is gathered and stored by different entities. There have been concerns raised, for example, regarding the effect of the European Union General Data Protection Regulation legislation on linkage arrangements and data[32].

Pathological data was an area with a large amount of asynchrony. Fields including mismatch repair, BRAF/RAS status and lymphatic/vascular invasion, all areas important to prognostication, were poorly captured, especially in BCOR. This may reflect the relatively rapid progression in cancer biomarker research, which continue to build in their validity as prognostic factors [33]. Traditionally TNM staging has been the classification system guiding prognosis, however a move toward precision oncology will bring the formerly mentioned marker and future candidates to the fore. Incongruity in capture of this data, especially in the BCOR, may also reflect the overarching registry operations organisation. BCOR is operated by the Colorectal Surgical Society of Australia and New Zealand – a surgical society, whilst NBOCA and DCRA both have non-surgical college related operators. Input from working groups beyond surgery may enhance the identification and capture of relevant fields related to pathology, or medical/radiation oncology for example. Other more minor issues concern method of recording AJCC TNM fields with each registry having a differing policy on which (5th vs 8th edition) nomenclature it accepts.

4.1. *Application to quality indicator metrics*

Of the quality indicator measures selected there is overall a low degree of comparability of NBOCA, DCRA and BCOR to both those encountered in the literature, but a higher comparability with those in the case-use CQI example. NBOCA and BCOR did not capture any information regarding pre-surgical colonscopy, or follow-up surveillance rates despite studies demonstrating their inverse association with cancer mortality [34]. Completeness of total mesorectal excision and timeliness of adjuvant therapy were other areas lacking data despite associations again demonstrating mortality effect [35,36]. Most CQI and international benchmarking outcome metrics were captured in a comparible maner across the DCRA, NBOCA and BCOR. However, a notable exception includes date of diagnosis with each of the three registries defining separate threshold to establishing diagnosis. In a benchmark comparison this has this ability to warp data greatly in impacting screening/primary referral to diagnosis times given that the establishment of a tissue diagnosis (DCRA) is more lengthy than a pre-operative appointment (BCOR) or consensus date/pathological sample (NBOCA). Comparability in QI metrics allows for identification and diffusion of best-practices from well-performing regions to less well-performing regions.

These findings have utility in several contexts. This comparison provides a foundation for future work between these data registries to identify opportunities for harmonisation. This may be by modifying data dictionaries, and also by exploring data linkages within countries that may enable a more comparable dataset, for example, for those that lack follow up outcome data.

Secondly, in the short term, comparing a registry's data dictionary to other international data dictionaries is a useful audit exercise. This allows registries to compare themselves to current international benchmarks and see where they may need to evolve, develop new data fields, or modify existing fields. For example, for the BCOR, this mapping exercise currently highlights that neoadjuvant details are only recorded for rectal cancer, which differs from other cancer registries. Given changing treatment paradigms, this is clinically relevant.

Table 3B
Mapping Queensland Cancer Quality Index Indicators to NBOCA, BCOR and DCRA.

Queensland Cancer Quality Index	Data Present in Registry			Able to compare quality indicators across all registries
	NBOCA	BCOR	DCRA	
Effective				
Five-year survival	No	Yes	No	No
Received multidisciplinary review	Yes	Yes	Yes	Yes
Received cancer surgery within 30 days of diagnosis	Yes	Yes	Yes	No, Differing definition regarding 'date of diagnosis' between registries NBOCA: Cancer confirmed via pathology or date agreed upon BCOR: First Visit or preadmission consult DCRA: Date of first pathology record
Received radiation therapy within 30 days of diagnosis	No	No	Yes	No
Received systemic therapy within 30 days of diagnosis	No	No	Yes	No
Efficient				
Length of Hospital Stay	No*	Yes	No	No (Not included in core NBOCA database but data acquired via linkage)
Safe				
In-hospital mortality	Yes	Yes	Yes	Yes
30-day mortality after cancer surgery	Yes	Yes	Yes	Yes
90-day mortality after cancer surgery	No*	Yes	Yes	No* (Not included in core NBOCA database but data acquired via linkage)
1 year survival after cancer surgery	No*	Yes	Yes	No* (Not included in core NBOCA database but data acquired via linkage)
2 year survival after cancer surgery	No*	Yes	Yes	No* (Not included in core NBOCA database but data acquired via linkage)
Accessible				
Timeliness of cancer treatment in hospital	Yes	Yes	Yes	Yes
Timeliness of cancer treatment for rural and remote patients	Yes	Yes	Yes	Yes (Able to be extrapolated from postcode field)
Equitable				
Percentage of patients approx. 75 years of age receiving treatment within 30 days of diagnosis	Yes	Yes	Yes	Yes
Percentage of socioeconomically disadvantaged patients receiving treatment within 30 days	No	No	No	No

4.2. Harmonisation of data dictionaries

There is a recognition internationally that there are opportunities to increase the scope and the comparability of data across cancer registries. There are a number of international initiatives aimed to provide greater standardisation of data collected in biomedical data dictionaries. For example, a USA based initiative, PhenX toolkit aims to provide a standardised set of protocols and suggested data dictionaries for data collection in biomedical studies [37]. Similarly, Meteor in Australia is a Commonwealth initiative aiming to provide standardised demographic data [38]. For health-related data, international organisations like SNOMED and International Classification of Disease (ICD) provide

Table 4
Comprehensive Dataset fields present in 1, 2 or all 3 of NBOCA, BCOR and DCRA registries, stratified by domain.

	Comprehensive Dataset fields present in:		
Domain:	1 database only	2 databases only	all 3 databases
Demographic	4	1	10
	26.67%	6.67%	66.67%
Pre-Operative	33	8	11
	63.46%	15.38%	21.15%
Operative	14	11	6
	45.16%	35.48%	19.35%
Post-Operative	34	17	1
	65.38%	32.69%	1.92%
Pathology	15	9	6
	50.00%	30.00%	20.00%
Neoadjuvant Therapy	5	1	2
	62.50%	12.50%	25.00%
Adjuvant Therapy	12	1	2
	80.00%	6.67%	13.33%
Follow-Up/ Recurrence	18	4	0
	81.82%	18.18%	0.00%
Total:	**135**	**52**	**38**
	60.0%	**23.1%**	**16.9%**

Number of fields within domain present in 1, 2 or all 3 databases (top row), Percentage of datapoints within domain present in 1, 2 or all 3 databases (bottom row).

standardised definitions regarding health terminology [16,39,40]. Ideally, registries would align with these international data standards to improve harmonisation between datasets arising from different jurisdictions and countries. There have been attempts to standardise data dictionaries in clinical trials relating to colorectal cancer, for example, McNair et al. asked key stakeholders to rate the relevance of different datafields[41].

A great challenge in the harmonisation of registry data dictionaries is that they need to be simultaneously consistent and adapt as data fields evolve. Furthermore, registry data dictionaries need to remain relatively consistent within countries to enable longitudinal analysis over time. Excessive change in the coding and definitions of fields may limit their utility when attempting to analyse multiple large datasets or temporal data trends. Altering data dictionaries in order to harmonise with international colorectal registries may have knock-on effects on existing data linkages within a country. For example, if a definition is used so as to be consistent with an oncology database within a country, attempting to change this definition may not be possible. Equally however, data dictionaries need to be able to adapt and change to reflect changing practice. This may include the introduction of new technology and surgical techniques, such as robotic surgery or TaTME, or evolving to reflect the introduction of new treatment paradigms, such as neo-adjuvant chemotherapy for locally advanced colon cancer which some centers have adopted in the wake of the FOxTROT study [42]. Developing a framework approach which allow databases to harmonise existing dictionaries whilst adapt to changing practice is key.

4.3. Data access and registry linkage

Cancer outcomes registries have significant value in stimulating quality improvement, feeding back data to individual hospitals and benchmarking performance [43]. They also provide an essential opportunity to evaluate results from new techniques and treatments when introduced in a population. Ideally, data dictionaries should not be duplicated, but should use those already in existence. Publication of data dictionaries in a freely accessible manner is important. This mapping exercise has highlighted the importance of open-source access to data dictionaries to ensure appropriate harmonisation of data dictionaries and avoiding undue duplication.

The USA has a complex arrangement of registry data. There have been projects linking the cancer and surgical outcome data, but to date no wholescale integration of the two types of databases. Collecting and maintaining registry data is a balance between collecting as much useful data as possible, while ensuring that the data collection is feasible with minimal burden to clinical staff, in order to maximise data validity and minimise missing data.

4.4. Integrating patient reported outcome measures (PROMs)

The complexity and utility of registries is increasing as patient reported outcome measures are given appropriate recognition as key metrics in cancer research. Integration of PROMS into cancer registries is an important part of future-proofing registry data. There are several practical limitations that need to be overcome including data collection and entry, but also harmonisation of PROMs used across datasets and methods of recording PROMs data in the dataset. The International Consortium for Health Outcomes (ICHOM) have formed an important foundation for developing a core set of patient centred outcomes by using an expert consensus approach including qualitative work with patients [44]. The present study adds to this by establishing which

Table 5
Mapping SCRCR, DCCG, NAACCR, ACS NSQIP and BNCCR-A registries to the Common Dataset: number of Common Dataset fields present within each registry, stratified by domain.

		Number of Common Dataset fields present within:				
	Common Dataset fields	SCRCR (SWE)	DCCG (DNK)	NAACCR (US/CAN)	ACS NSQUIP (US)	BNCCR-A (ARG)
Demographic	10	10	7	9	4	5
Pre-Operative	11	9	9	7	2	7
Operative	6	6	6	3	4	5
Post-Operative	1	1	0	1	1	1
Pathology	6	6	6	6	0	5
Neoadjuvant Therapy	2	2	2	2	0	1
Adjuvant Therapy	2	2	0	2	0	0
Follow-Up/Recurrence	0	0	0	0	0	0
Total	**38**	**36**	**30**	**30**	**11**	**24**

current non-PROMs fields exist and where areas for improvement are in harmonising the scope and data dictionaries of current registries. By identifying the non-PROM common fields and developing a standard common dataset, this provides further groundwork for the integration of PROMS into registries in a synchronised fashion.

4.5. Limitations and future directions

Information on how registry data is collected, entered, and verified within each jurisdiction was beyond the scope of the current manuscript. Further investigation of these areas would ellucidate how collection systems contribute to data quality and uncover what intrinsic data biases may exist to skew data. Within countries, there are often multiple different data registries that are of relevance to colorectal cancer. Linking databases and having multidisciplinary input to maximise data output is important. In-depth incorporation and analysis of registry data linkage was unfortunately beyond the scope of this study. Examining data linkages may lead to new avenues for international collaboration. More in-depth data providence, case ascertainment and completeness statistics were unfortunately not explored in this study and are not widely published in most registries. These metadata would add important contextual information regarding the usefulness of fields – there is little point in the presence of a field if it is not routinely measured. Qualitative work to examine the acceptability of data fields and prioritisation of fields by registries, patients and clinicians is ongoing, as is work investigating data linkage.

5. Conclusion

There are common elements that can be identified across international datasets in colorectal cancer registries particularly regarding demographic and operative data domains. However, significant differences exist in key fields and definitions regarding most other domains which limit comparison and pooling of data between international registries. Harmonisation of international datasets may lead to new opportunities for colorectal cancer outcome research.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejso.2023.107937.

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