



Association of Coloproctology of Great Britain & Ireland

data-set for national bowel cancer audit

revision of dataset version 3

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SECTION A: UNIT DETAILS

Details in this section need only be entered once, when the unit first registers with Clatterbridge

- A1. Unit name** *This number identifies the site uniquely. Each copy of the database should have it's own Unit ID number. If you do not know what this identifier is contact the helpdesk at the Clatterbridge Centre for Oncology and they will provide you with the correct number.*
- A2. Unit's address**
- A3. Unit's postcode**
- A4. Unit's Phone number**
- A5. Unit's Fax number**
- A6. E-mail address of data-base contact**
Contact may be data collection person, Clinical Nurse Specialist, Cancer Services Co-ordinator, clinician etc.
- A7. Name of the lead clinician for bowel cancer**
- A8. E-mail address of lead clinician for bowel cancer**

SECTION 1 : PATIENT & REFFERAL DETAILS

- 1.1 Patient's NHS Number ***
patient's unique, 10 digit , new format NHS number. This is an essential identifier for linkage with cancer registries and ONS for validation and survival information.
- 1.2 Unit Patient Number**
The number or code assigned by the unit to identify the patient **uniquely** throughout the unit/organisation, also called the hospital number, case-sheet number, case number or registration number. This field is included for local use only, it is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.
- 1.3 Forename / Surname**
Used as an alternative local identifier for database searching. This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.
- 1.4 Postcode of patient's usual address ***
Full postcode of patient's usual address. This is used for deprivation analysis. Patients with no fixed abode should be assigned a pseudo-postcode of ZZ99 3VZ.

1.5 Date of birth

The date of the patient's birth. This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.

1.6 Sex *

- 1 Male
- 2 Female

1.7 Consultant/Surgical Firm

The Surname of the Consultant with overall responsibility of the patient. In some cases this will be after an internal referral to a member of the MDT. This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.

1.8 Height in cms *

1.9 Weight in Kg *

Collect 1.8 & 1.9 to calculate BMI

1.10 Source of referral

1. Elective Elective referral by GP to secondary care (to consultant of any speciality).
2. Emergency Emergency (from GP or hospital consultant) or patient self-referral to A/E
3. Internal From another consultant but not emergency.
4. Screening National programme, trial, surveillance.
5. Other

1.11 Colorectal Unit ID Code *

The unique code identifying the Trust, (NHS data dictionary & manual). The trust at which the MDT with principal care for the patient is based.

1.12 Date of receipt of referral *

The date of receipt by the hospital of an elective referral either by fax, mail or phone.

1.13 Priority of referral to outpatients *

To identify patients referred under the "two week rule" deemed to have a high risk of bowel cancer based on the primary care referral. In Wales, the estimate of priority is by the colorectal surgeon, in England it is that of the GP.

1. non urgent
2. urgent

1.14 Was this first referral to a member of the Multi Disciplinary Team

To track patterns of referral Y/N

1.15 Date of first hospital attendance (contact). *

Date of the first outpatient attendance, date of emergency admission, date of OP visit when cancer was first considered (eg on an OP visit for some other condition), date seen by specialist team for in-hospital referrals, date of first diagnostic procedure if this precedes the first OP appointment or date patient first seen following recall by screening unit.

1.16 Was this the first appointment offered?

For outpatient referrals, to identify if the delay in outpatient appointment was due to patient choice Y/N)

1.17 Colorectal or stoma therapy nurse seen ?

yes / no / not known (default)

1.18 Date seen by colorectal nurse or stoma therapist.

Date format (leave blank if not seen)

SECTION 2 : DIAGNOSIS, STAGING & CANCER DETAILS

2.1 Date of colonoscopy

date format.

2.2 Result of colonoscopy.

1. Normal: no evidence of cancer.
2. Abnormal: cancer detected whether complete or not
3. Inadequate: no cancer but incomplete examination
4. Not done
5. Not known

2.3 Reason for incomplete colonoscopy

1. Obstructing cancer
2. Poor bowel preparation
3. Patient intolerance
4. Technical reasons
5. Other

2.4 Colonoscopy complications

1. Bleeding
2. Perforation

2.5 Date of barium enema

2.6 Result of barium enema

1. Normal: no evidence of cancer
2. Abnormal: defined as cancer or polyp.
3. Inadequate or equivocal: bowel not fully visualized or report unsure (usually means further investigation by CT, colonoscopy, flexible sigmoidoscopy or repeat barium study)
4. Not done
5. Not known

2.7 Date of CT scan

2.8 Result of CT SCAN

Record scan result for liver only

1. Normal liver
2. Liver metastases
3. Liver uncertain

2.9 Date of first MRI Scan (rectal cancer only)

1. date format
2. scan not done

2.10 Result of first MRI scan (rectal cancer only) *

1. T stage
2. N stage

2.11 Date of second MRI scan

2.12 Result of second MRI Scan *

This would usually be done to assess response of rectal cancer to oncological treatment.

1. No change to bulk
2. Increase in bulk
3. Reduction in bulk

5.3 Date of endoanal ultrasound scan (Rectal cancer only)

Date of scan (date format)

2.14 Result of EUS

T stage

2.15 Date of abdominal ultrasound scan

1. date format
2. scan not done

2.16 Result of Abdominal USS

1. No metastases
2. Liver metastases
3. Liver uncertain

2.17 Pre treatment TMN stage

T stage: based on MRI and / or EUS for rectal cancer

N stage: based on MRI for rectal cancer

M stage: based on CT scan or other investigation not recorded in dataset such as bone scan, CXR etc.

Liver

1. none
2. uncertain
3. certain.

Bone

1. none
2. uncertain
3. certain

Lung

1. none
2. uncertain
3. certain

Other

1. none
2. uncertain
3. certain

2.18 Date of diagnosis *

Date on which cancer was first diagnosed at operation, histology, colonoscopy, sigmoidoscopy (flexible or rigid), barium enema or other means. Use the date that the biopsy or investigation was done, not when reported.

2.17 Cancer Site by ICD10 code *

The major site as identified by the clinician at presentation.

- | | |
|---------------------|-------|
| 1) Caecum | C18.0 |
| 2) Appendix | C18.1 |
| 3) Ascending colon | C18.2 |
| 4) Hepatic Flexure | C18.3 |
| 5) Transverse colon | C18.4 |
| 6) Splenic flexure | C18.5 |
| 7) Descending colon | C18.6 |
| 8) Sigmoid colon | C18.7 |
| 9) Recto-Sigmoid | C19 |
| 10) Rectum | C20 |

Definition of rectal cancer: Lower margin of cancer 15cm or less from anal verge at sigmoidoscopy.

2.19 Synchronous cancer? [multiple responses possible]

1. None
2. Caecum C18.0
3. Appendix C18.1
4. Ascending colon C18.2
5. Hepatic Flexure C18.3
6. Transverse colon C18.4
7. Splenic flexure C18.5
8. Descending colon C18.6
9. Sigmoid colon C18.7
10. Recto-Sigmoid C19
11. Rectum C20

2.20 Height above anal verge for rectal cancer only *

Cms measured by digital examination, rigid or flexible sigmoidoscopy.

2.21 Modified Dukes' Stage *

Final clinico-pathological staging. Dukes D = distant, metastatic spread distant or local, residual disease after surgery. It is accepted that a small number of "D" cases are cured by further treatment, such as liver resection, but for the purpose of the database, spread distant from the primary should always be recorded as "D".

1. A
2. B
3. C1
4. C2
5. D
6. Not known

SECTION 3: PRIMARY OPERATION DETAILS

3.1 Date of start of first definitive procedure *

This may be surgery (including stoma alone), radiotherapy or chemotherapy but not examination under anaesthetic, which is considered part of as staging.

3.2 Was surgery carried out *

Although stent is coded below as a procedure, it should not be considered as an operation in 3.2.

YES / NO

3.3 Reason no surgery performed. *

1. Patient refuses treatment for whatever reason
2. Patient unfit
3. Advanced disease
4. Other

3.4 **ASA Grade ***

1. I (Fit)
2. II (Relevant disease)
3. III (Restrictive disease)
4. IV (Life threatening disease)
5. V (Moribund)

3.5 **Thrombo prophylaxis y/n**

3.6 **Antibiotic prophylaxis y/n**

SURGERY DETAILS

3.7 **Date of surgery ***

Date of any definitive surgery for this cancer, may be a palliative procedure such as Stent insertion.

3.8 **Start time of Surgery**

(24 hour clock).

3.9 **Mode of operation; CEPOD classification ***

1. **Elective:** Operation at a time to suit both patient and surgeon e.g. after an elective admission
2. **Scheduled:** An early operation but not immediately life-saving. Operation usually within 3 weeks
3. **Urgent:** As soon as possible after resuscitation. Operation within 24 hours
4. **Emergency:** Immediate and life-saving operation, resuscitation simultaneous with surgical treatment. Operation usually within 2 hours

3.10 **Surgeon**

Name of surgeon that performed procedure, for APER operations the perineal surgeon may be recorded below. This field is included for local use only, it is automatically excluded by the extraction tool when data is sent to Clatterbridge for analysis.

3.11 **GMC code of principal operating surgeon**

The code is an eight character alphanumeric code based on the GMC registration number: the first character will be the letter 'C': characters 2-7 will be the doctors GMC number; character 8 is a check digit. The default code for Code 'not known' is C9999998. This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.

3.12 Grade of principal operating surgeon

- 1. Consultant**
- 2. NCCG**
3. SpR
4. SHO
5. Other specify

3.13 Assistant.

Name of the scrubbed assistant in theatre. This field is included for local use only, it is automatically excluded by the extraction tool when data is sent to Clatterbridge for analysis.

3.14 Second assistant if any.

Name of the scrubbed second assistant in theatre. This field is included for local use only, it is automatically excluded by the extraction tool when data is sent to Clatterbridge for analysis.

3.15 Perineal surgeon if operation is APER

Name of surgeon, this field is included for local use only, it is automatically excluded by the extraction tool when data is sent to Clatterbridge for analysis.

3.16 Grade of perineal surgeon

- 1. Consultant**
- 2. NCCG**
3. SpR
4. SHO
5. Other specify

3.17 GMC number of perineal surgeon

This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.

3.18 Anaesthetist grade.

Grade of most senior anaesthetist present in theatre during the operation

1. Consultant
2. NCCG
3. SpR
4. SHO

3.19 Was anastomosis done. ^Δ

Y/N.

3.20 Was stoma done ^Δ

1. no
2. ileostomy temporary
3. ileostomy permanent
4. colostomy temporary
5. colostomy permanent

3.21 Date stoma closed

date format

3.22 Procedure: OPCS4 code *

1. Right Hemicolectomy H07.9 Excision of right hemicolon
2. Extended right hemicolectomy H06.9 Extended excision of right hemicolon
3. Transverse Colectomy H08.9 Excision of transverse colon
4. Left Hemicolectomy H09.9 Excision of left hemicolon
5. Sigmoid colectomy H10.9 Excision of sigmoid colon
6. Anterior Resection H33.4 Anterior resection of rectum and anastomosis nec
7. APER H33.1 Abdominoperineal excision of rectum and end colostomy
8. Hartmann's proceduce H33.5 Excision of part of left colon with end colostomy and closure or exteriorisation of the distal remnant.
9. Trans Anal Resection of Tumour H41.9.Operations on rectum through anal sphincter
10. Total excision of colon and rectum:
H04.1 Panproctocolectomy and ileostomy
H04.2 Panproctocolectomy and anatomosis of ileum to anus and creation of ileal pouch.
11. TEMS H41.2 Peranal excision of lesion of rectum by Transanal Endoscopic Microsurgery
12. Stent H24.3 Endoscpcic insertion of a stent in obstructing cancers.
13. Polypectomy: H20.1 Endoscopic resection of lesion of colon (excluding sigmoid)
H23.9 Endoscopic resection of lesion of lower bowel using fiberoptic sigmoidoscope
14. EUA only H44.4 With/without biopsy
15. laparotomy only T30.9 No procedure other than a biopsy
16. laparoscopy only T43.9 Diagnostic endoscopic examination of the peritoneal cavity with or. without a biopsy
17. Stoma only G74.9 ileostomy, .9 colostomy
18. OTHER state OPCS4 Code(s)

3.23 Surgical Access: Laparoscopy or open operation? *

1. Open operation
2. Laparoscopic operation, regardless of conversion to open or not. **If this field is selected, other laparoscopic fields below, 3.24 to 3.27, and 4.04 to 4.05, become compulsory.**

3.24 Surgical Access: laparoscopy *

1. Laparoscopy then open surgery (targeted incision after laparoscopic assessment)
2. Laparoscopy converted to open – definition of conversion is inability to complete the intra-abdominal resection laparoscopically.
3. Laparoscopic completed (includes lap assisted)

3.25 Reason for conversion *

1. Bleeding
2. Perforation
3. Adhesions,
4. Other

3.26 Type of bowel division *

1. Intracorporeal
2. Extracorporeal

3.27 Type of anastomosis *

1. Intracorporeal
2. Extracorporeal
3. None

3.28 Curability *

The surgeons' opinion of the completeness of the excision based on clinical findings at the time of operation **which should not be revised** in the light of subsequent histopathology reporting.

1. Curative: removal of the primary tumour in which there is no macroscopic evidence of local residual disease or at distant metastases.
2. Palliative: residual disease in the opinion of the surgeon, either locally or at distant metastases.
3. Uncertain:

3.29 If palliative, due to:

1. Local disease
2. Distant disease

3.30 If uncertain, due to:

1. Local disease
2. Distant disease
3. Other (please specify)

3.31 Local complications of cancer *

Was there a local complication of the cancer at the time of operation.

- 0 None
- 1 Pericolonic abscess
- 2 Free perforation
- 3 Intestinal obstruction
- 4 Other.

SECTION 4: POSTOPERATION DETAILS

4.0 Post operative in-patient death * Y/N

4.1 Postoperative death < 30 days Y/N

4.2 *Date of Discharge or Death **

4.3 Major complication : leak / abscess / bleed / obstruction / other: *

Major complication definition: a complication that requires re-operation, interventional radiology, ITU/HDU care or delays discharge by more than 72 hours

1. none
2. leak: unequivocal clinical evidence of anastomotic breakdown with or without radiological confirmation
3. abscess: wound, intra abdominal or pelvic pus
4. bleed: gastrointestinal, intra abdominal or wound bleed
5. obstruction postoperative bowel obstruction.
6. readmission within 30 days of discharge
7. other eg. renal, respiratory, cardiovascular

4.4 Laparoscopic specific complications this item is still under discussion and the definitions are to be agreed*

1. None
2. Surgical emphysema
3. Pulmonary insufficiency
4. Significant intraoperative haemorrhage
5. Duodenal injury
6. Small bowel injury
7. Ureteric injury
8. Major vessel injury
9. Gross faecal contamination
10. Bladder injury
11. Injury by trocar
12. Injury by instrument

4.5 Early port-site complications *

1. no complication
2. port site sepsis (pus at port site or cellulitis treated by antibiotics)
3. port site bleeding / haematoma (definition as for major complications above)
4. other

SECTION 5 : HISTOPATHOLOGY DETAILS

5.1 Date specimen received *

Date specimen booked in by Pathology Dept

5.2 Date of report *

Date on the histopathology report.

5.3 Authorising pathologist

GMC code of Pathologist who authorises the report. This field is automatically excluded by the extraction tool, for confidentiality reasons, when data is sent to Clatterbridge for analysis.

5.4 Synchronous cancer

Yes / No

5.5 Cancer size

Record maximum cancer diameter in mms.

5.6 Positivity of cut colon or rectal margins *

If the macroscopic distance from the cancer to the nearest cut end of the bowel is less than 3 cms that cut end should be examined histologically and the presence or absence of cancer should be recorded. If the minimal distance from the cut margin is less than or equal to 1 mm the margin is considered "involved".

1. Yes
2. No
3. not applicable

5.7 Distance to cut margin *

1. Distance in mms
2. More than 3 cms

5.8 Positivity of circumferential margins *

circumferential margins refer to the completeness of the surgeon's resection margin in the opinion of the histopathologist. In parts of the colon or rectum covered by peritoneum, recording of the circumferential (surgical resection) margin is not appropriate. This should be recorded as Not Applicable (N/A). Involvement of this margin is different from serosal involvement.

Positivity of margin: When the tumour is 1mm or less from the surgical resection circumferential margin.

1. Yes
2. No
3. N/A

5.9 Distance from cancer to circumferential margin *

Measure in mms

5.10 Histological grade *

The histological grade of the invasive component of the lesion as reported by the pathologist.

1. Poor
2. Other

5.11 Histological type *

1. Adenocarcinoma
2. Mucinous tumours
3. Signet cell tumours
4. Other

5.12 Number of lymph nodes found *

5.13 Number of involved lymph nodes found *

The number of lymph nodes in the pathology specimen found to contain malignant tumour. Extramural tumour deposits measuring > 3mm are counted as involved lymph nodes even if no residual node structure can be identified.

5.14 Extramural vascular invasion y/n *

Record the presence of unequivocal tumour in vascular spaces

5.15 Perforation or serosal involvement for cancers at sites with serosal cover y/n *

5.16 Distance between the edge of the cancer and the nearer cut end of bowel in rectal and recto-sigmoid tumours *

Distance should be measured in the fixed specimen (mms).

5.17 Distance between lower end of cancer and dentate line in APER specimen *

Distance should be measured in the fixed specimen (mms).

5.18 TNM Staging *

Summary of TNM staging:

Tx	Minimum requirements for cancer assessment not met
pT0	No evidence of primary cancer
pT1	Cancer extends into the sub-mucosa
pT2	Cancer extends into the muscularis propria
pT3	Cancer extends through muscularis propria into subserosa or nonperitonealised pericolic or perirectal tissues
pT4	Cancer extends directly into the other organs or tissues, or cancer perforates the visceral peritoneum of the specimen
Nx	Minimum requirements for lymph node assessment not met (ie no lymph nodes found)
pN0	No lymph node mets
pN1	Cancer in 1 to 3 pericolic or perirectal lymph nodes
pN2	Cancer in 4 or more pericolic or perirectal lymph nodes
Mx	Minimum requirements to assess distant metastasis cannot be met
M0	No distant metastases
M1	Distant metastasis present

From: CANCER Principles and Practice of Oncology 5th Edition, Vincent T. DeVita Jr, Samuel Hellmann, Steven A. Rosenberg; Lippincott-Raven.

5.19 Pathological Dukes' Staging *

based on pathologists report, not known is included as the staging is a mandatory field

1. A
2. B
3. C1
4. C2
5. Not known. (.

SECTION 6: ONCOLOGY DETAILS

RADIOTHERAPY

6.0 Radiotherapy given *

1. none
2. short course preoperative
3. long course preoperative
4. postoperative
5. definitive (where radical RT/CRT given with no plan for surgical intervention)
6. palliative with or without surgery

6.01 Start date for radiotherapy *

Date format

6.02 Radiotherapy trial * YES / NO

CHEMOTHERAPY

6.2 Chemotherapy given *

1. none
2. neoadjuvant an adjuvant treatment given prior to potentially curative surgery.
3. adjuvant treatment given after curative surgery
4. palliative any treatment given to improve symptoms and possibly prolong life but where there is no prospect of long-term survival
5. other

6.4 Date chemotherapy started *

Date format

6.5 Chemotherapy trial * YES / NO

SECTION 7 FOLLOW UP DETAILS

7.0 Date of Follow-Up

either in the clinic, in endoscopy, by post or any other contact.

7.1 Mode of follow-up

1. Surgical outpatient
2. Endoscopy
3. Nurse specialist
4. GP
5. Postal

LOCAL RECURRENCE

7.2.1 Local Recurrence (within field of previously excised cancer)

YES / NO

7.2.2 Date of diagnosis of local recurrence

Date format.

7.2.3 Local recurrence diagnosed by

mode of diagnosis in following descending hierarchy

1. Histology
2. Imaging
3. Clinical
4. Other

7.3.1 Wound recurrence

YES / NO

7.3.2 Date of wound recurrence

date format

7.4.1 Port site recurrence

YES / NO

7.4.2 Date of port site recurrence

date format

DISTANT SPREAD

7.5.1 Distant spread

Metastatic disease occurring outside the field of operation

YES / NO.

7.5.2 Site of distant spread

- 1 Liver
- 2 Lung
- 3 Bone
- 4 Other

7.5.3 Date of diagnosis of distant spread

DEATH

7.6 Is the patient dead ?

- 1 Yes
- 2 No
- 3 Unknown

7.7 Date of death

7.8 Cause of death

- 1 Died of cancer
- 2 Died of other cause (cancer present)
- 3 Died of other cause (no evidence of cancer)
- 4 Unknown

7.9 Post-Mortem

Was there a post-mortem y/n

SECTION 8 : PALLIATIVE CARE

8.1 Referral to Palliative Care

YES / NO

8.2 Date referred to Palliative Care