RECTAL CANCER OUTCOME MEASUREMENT IN ILLAWARRA SHOALHAVEN LOCAL HEALTH DISTRICT

CLINICIAN INFORMATION SHEET – DATA COLLECTION

The aim of this project is to introduce outcome measurements into routine clinical care for rectal cancer patients in the Illawarra Shoalhaven Local Health District (ISLHD). Outcome measurements allow us to measure the quality of care we provide and identify areas where we can improve.

WHY ARE WE COLLECTING PATIENT OUTCOMES?

We are seeking to answer questions such as:

- How does rectal cancer and its treatments affect our patients' quality of life and daily functioning
- How many rectal patients experience side-effects of treatment
- How do our services and our patient outcomes compare with those around the world

WHAT TOOLS ARE WE USING TO COLLECT PATIENT OUTCOMES?

ISLHD Cancer Services has implemented a comprehensive suite of outcome measures for rectal cancer using the ICHOM (International Consortium for Health Outcomes) framework.

<table>
<tr>
<td rowspan="2"> 
</td>
<td>Survival and Disease Control: These are measures which evaluate success against the overall goals of cancer treatment: freedom from recurrence / progression and survival.

Disutility of Care: These measures quantify the short-term complications of treatment. These measures will be collected while the patient is undergoing treatment or within 90 days of starting treatment.

Degree of Health: These measures evaluate the extent to which patients are able to lead productive lives, free of the effects of disease and treatment.</td>
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<tr>
<td>Co-morbidity (note this is not part of the ICHOM standards but clinicians wanted to see how co-morbidities affected outcomes longer-term and how this might inform decision-making at the MDTs).</td>
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WHO ARE WE COLLECTING PATIENT OUTCOMES FROM?

All current and future rectal cancer patients.

HOW ARE WE COLLECTING PATIENT OUTCOMES?

All patients will be provided with an initial survey pack, which will include:

- Information sheet with an opt-out consent form
- Preference for future surveys to be provided electronically (web-form) or paper form
- Patient reported outcome surveys for patients to complete (EORTC QLQ C30 and CR29)
- Comorbidity questionnaire to also be completed by the patient

Follow-up surveys at 6 months, and then annually for five (5) years will be sent out electronically to patients (of course, the option of completing via paper form is also available).

When will Outcome Collection Take Place?

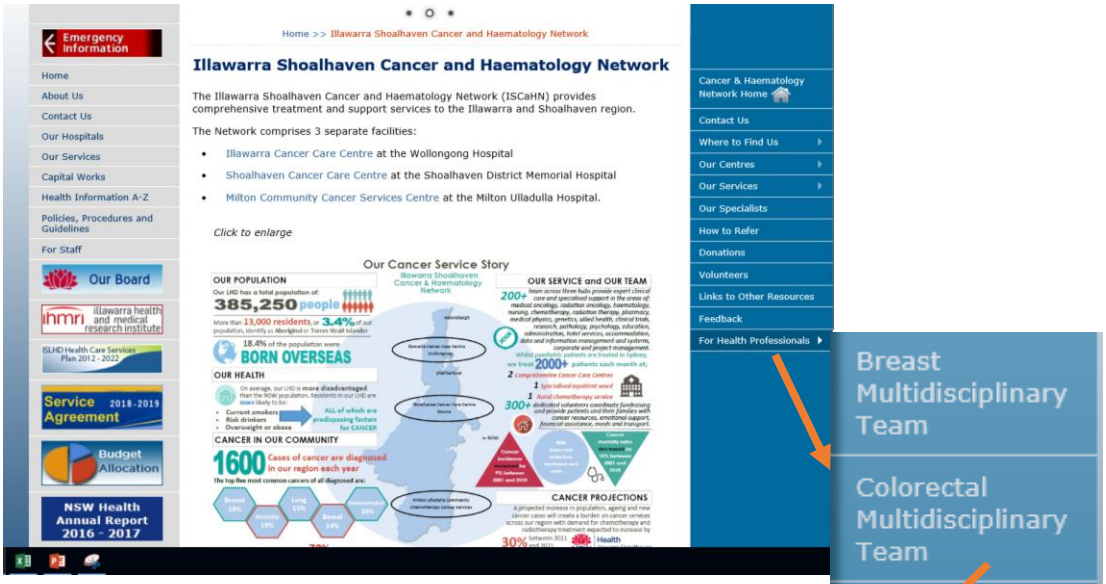
When	What	Who	How	Process for Incomplete forms
Initial Appointment or on referral to Colorectal MDT	- EORTC C30 and CR29 - Self-administered comorbidity questionnaire	Patient	Paper surveys will be sent out by the Outcome Measurement Coordinator following confirmation of diagnosis at the Colorectal MDT	Clinician to provide survey pack to patient. Outcome Measurement Coordinator will follow-up with electronic reminder after 1 month
At the first appointment following completion of treatment	Short Term Complications	Surgeon	Web-form (Figure 1) or email to project email address	Outcome Measurement Coordinator will follow-up with reminder to surgeon's private rooms after 2 weeks
		Radiation Oncologist	MoSAIQ (Figure 2)	Outcome Measurement Coordinator will follow-up with Radiation Oncologist after 2 weeks
		Medical Oncologist	MoSAIQ (Figure 2)	Outcome Measurement Coordinator will follow-up with Radiation Oncologist after 2 weeks
6 months	EORTC C30 and CR29	Patient	Electronic	Outcome Measurement Coordinator will send electronic surveys to patients (where requested)
12 months and annually to 5 years	EORTC C30 and CR29	Patient	Electronic	Outcome Measurement Coordinator will send electronic surveys to patients (where requested)
	Survival & Disease Control: Document local / regional / distant recurrence	Surgeon / Medical/Radiation Oncologist	Through follow-up consults in public / private rooms. Include ISLHD Cancer Care in all follow07p consult correspondence	Clinical Data Manager to follow-up missing data and maintain Rectal Cancer database

- See Appendix 1 for Outcome Measures Timeline
- See Appendix 2 for Summary of Measures
- See Appendix 3 for Follow-up protocol: colon and rectal cancer

FIGURE 1: HOW SURGEONS ACCESS STC FORMS VIA ISLHD INTERNET

http://www.islhd.health.nsw.gov.au/

Our Services → Cancer and Haematology Network → for Health Professionals



ISLHD Colorectal Cancer Multidisciplinary Team (MDT)

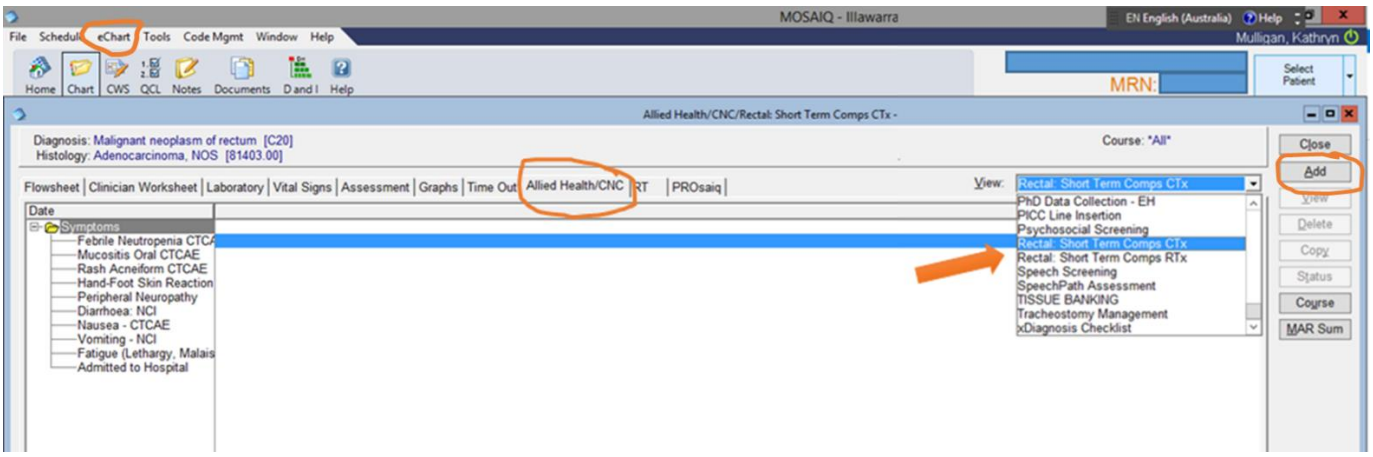
The Colorectal Cancer MDT is an expert team which oversees the diagnosis, treatment and evidence based management of colorectal cancers within ISLHD. Members of the ISLHD Colorectal Cancer MDT include specialist Colorectal Surgeons, Upper GI Surgeons, Medical Oncologists, Radiation Oncologists, Radiologists, Pathologists, Nuclear Medicine Specialists, Nurse Specialists and Allied Health Professionals.

- ISLHD Colorectal Cancer MDT Referral Form (PDF Fillable Form)
- ISLHD Colorectal Cancer MDT Referral Criteria
- ISLHD Lower Gastro-Intestinal Tract Cancers Model of Care
- ISLHD Colorectal Cancer Follow-up Protocol

ISLHD Rectal Cancer Outcomes Measurement Project

FIGURE 2: HOW ONCOLOGISTS ACCESS STC FORMS VIA MOSAIQ

eChart → Assessments → Allied Health/CNC → Rectal Short Comp CTx (or RTx) → Add



WHERE TO SEND PAPER-BASED SURVEYS / QUESTIONNAIRES?

Please Scan and Send to:

ISLHD-RectalCancerOutcomes@health.nsw.gov.au

NEED HELP?

Outcome collections and documentation can be found on the Colorectal MDT website

OR

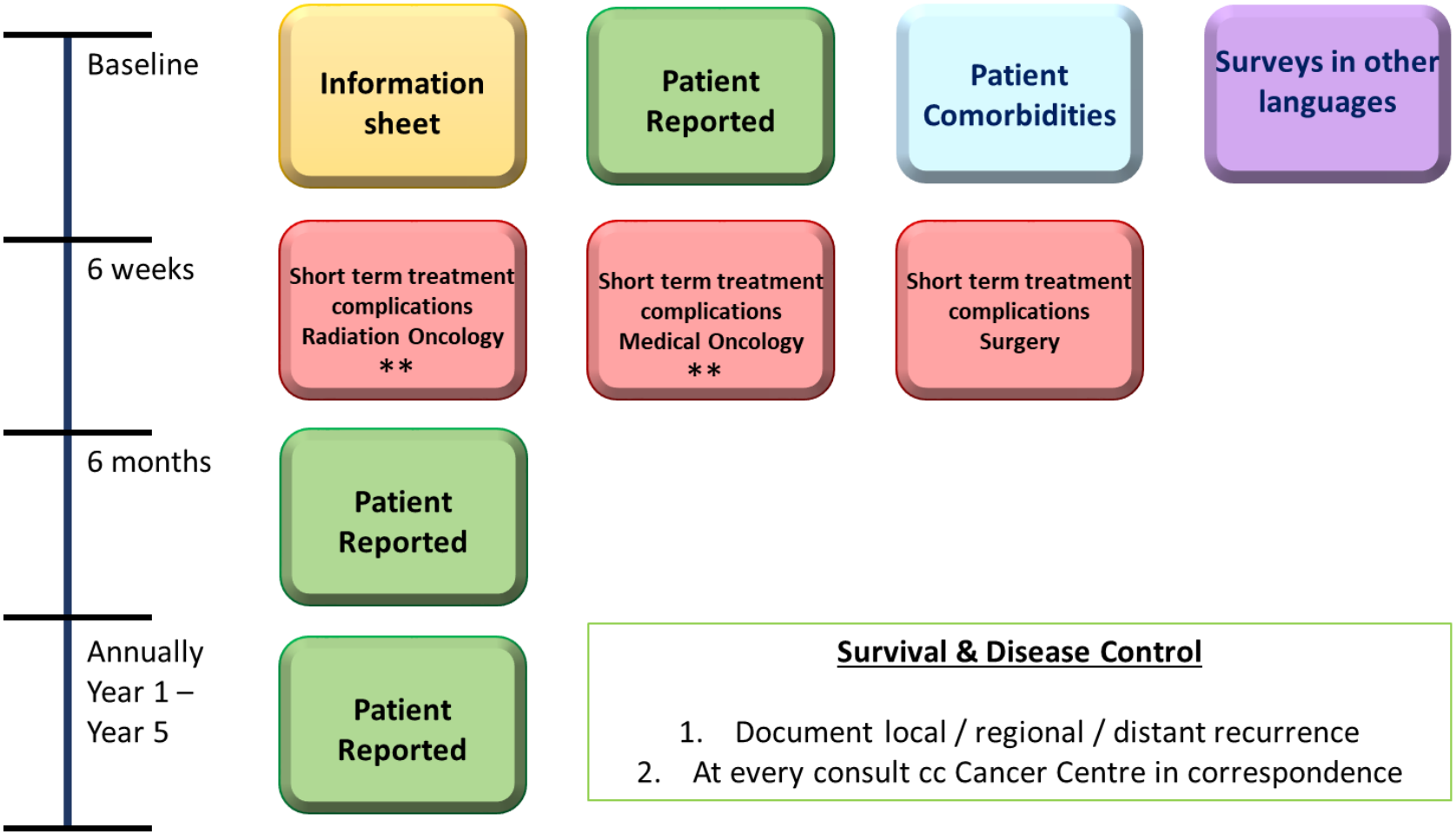
Please do not hesitate to contact the Outcome Measures Project Coordinator at

ISLHD-RectalCancerOutcomes@health.nsw.gov.au

VERSION CONTROL

Version	DATE	OFFICER	DESIGNATION
1	July 2018	Brooke Selby	Project Officer
2	Jan 2019	Kathryn Mulligan	Cancer Systems Innovation Manager

Appendix 1: Outcome Measures Collection Timeline



*** At the first appointment following completion of surgery, chemotherapy or radiotherapy**

**** Medical and Radiation Oncology STC can be completed electronically via MoSAIQ**

Appendix 2: Summary of Measures

Survival & Disease Control:
Overall Survival
Recurrence-free survival
Progression-free survival
Pathological complete response / tumour regression score
Margin status
Quirke score

Degree of Health – Patient Reported Measures:		
Overall wellbeing	Fatigue	Gastrointestinal symptoms
Emotional wellbeing	Mobility	Sexual functioning
Social functioning	Bowel functioning	Erectile dysfunction
Depression	Faecal leakage	Vaginal symptoms
Physical functioning	Stool frequency	Presence of stoma (colostomy or ileostomy)
Pain	Diarrhoea	

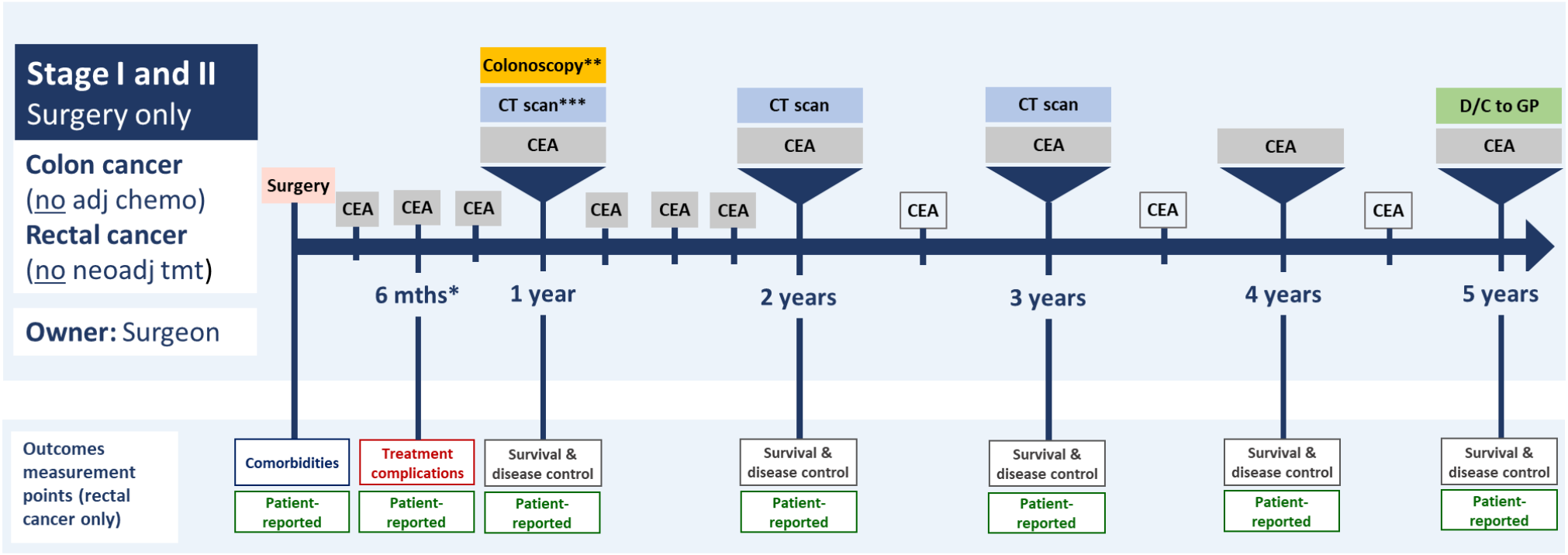
Disutility of Care – Short Term Complications of Treatment		
Radiation Therapy	Chemotherapy	Surgery
Skin desquamation	Febrile neutropenia	Anastomotic leak
Dysuria	Mucositis (oral)	Stoma-related complications
Diarrhoea	Acneiform rash	Incontinence post-op
Proctitis	Hand-foot syndrome	Wound complications
Mucositis	Neuropathy (sensory)	Thromboembolic event
Weight loss	Diarrhoea	Haematoma
Missed treatment	Dose reduction	Death within 30 days
Incomplete treatment	Missed / delayed cycle	Blood transfusion
Early cessation of concurrent chemotherapy	Incomplete treatment	Return to theatre
		Unplanned ICU stay
		LOS > 21 days
		Readmission < 30 days

Intended to quantify impacts of therapy complications. Only some impacts will be avoidable.

Follow-up protocol: colon and rectal cancer

ISLHD Colorectal Tumour Program

NSW Government Health Illawarra Shoalhaven Local Health District



* **Time period:** from surgery if disease-free; from CT scan if recurrence or disease progression

** **Subsequent colonoscopy interval:** if normal at 1-year post-surgery, repeat 5-yearly; adenomas- repeat as per adenoma chart; cancer- refer as appropriate.

*** **CT scanning for stage I patients:** not included in recommended routine follow-up in NCCN and Ontario guidelines – up to discretion of clinician.

Filled box = *recommended* follow-up element

Empty box = *optional* follow-up element

Follow-up protocol: colon and rectal cancer

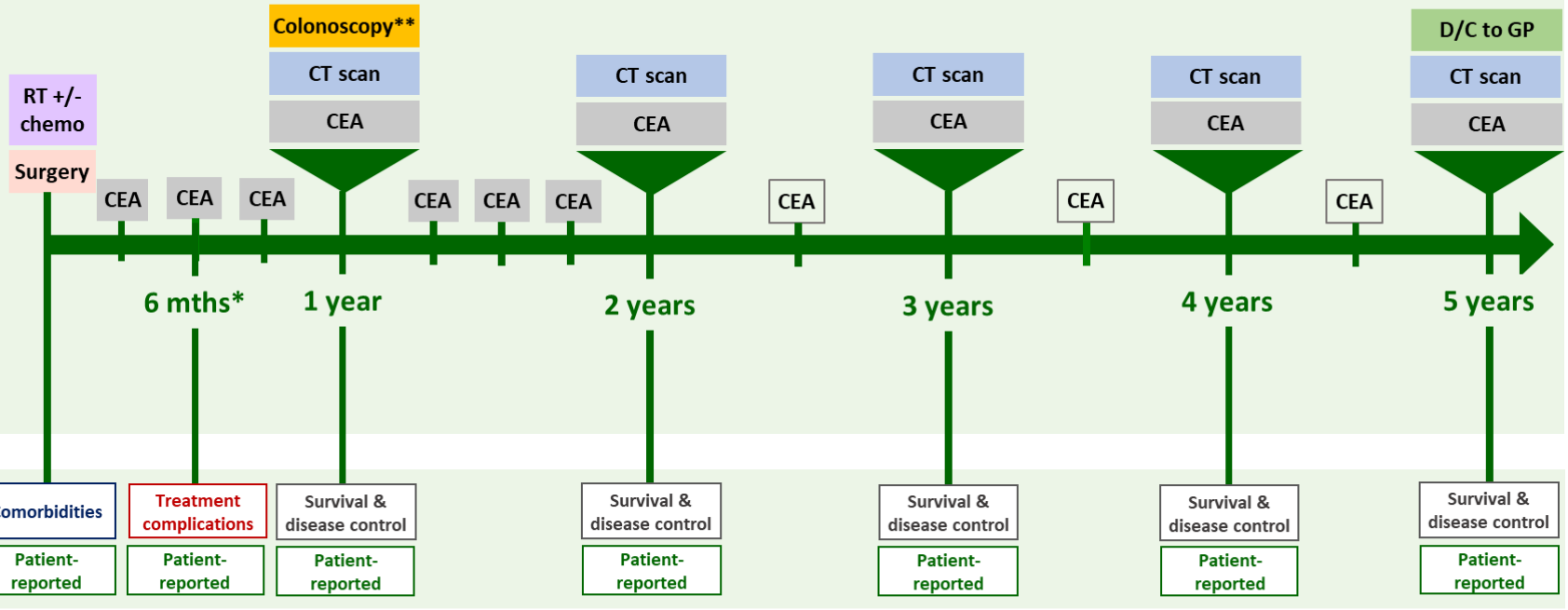
ISLHD Colorectal Tumour Program

NSW GOVERNMENT Health Illawarra Shoalhaven Local Health District

Stage II and III
With neo/adj tmt

Colon cancer
(with adj chemo)
Rectal cancer
(with neoadj tmt)

Owner:
Medical/ Radiation Oncologist



* **Time period:** taken from first treatment, then resets after second treatment; from CT scan if recurrence or disease progression

** **Subsequent colonoscopy interval:** if normal at 1-year post-surgery, repeat 5-yearly; adenomas- repeat as per adenoma chart; cancer- refer as appropriate.

Stage IV colon and rectal cancer **Owner:** Medical Oncologist **Frail patients >80yrs**: follow-up with GP

Filled box = *recommended* follow-up element

Empty box = *optional* follow-up element

Follow-up protocol: references

ISLHD Colorectal Tumour Program

Health Illawarra Shoalhaven Local Health District

1. National Comprehensive Cancer Network (NCCN), 2017. *Clinical practice guidelines in oncology: colon cancer*, version 2
2. National Comprehensive Cancer Network (NCCN), 2017. *Clinical practice guidelines in oncology: rectal cancer*, version 3
3. Cancer Care Ontario, 2013. *Colorectal cancer follow-up care patient pathway,* version 2013.5
4. National Institute for Health Care Excellence (NICE), 2016. *Surveillance report 2016 – colorectal cancer (2011) NICE guidelines CG131 and improving outcomes in colorectal cancer (2004) NICE cancer service guidance CSG5*
5. European Society for Medical Oncology (ESMO), Guidelines Working Group, Rectal Cancer, 2013. Clinical practice guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*; 24 (Supplement 6): vi81-vi88.
6. Rafferty J, et al. for the clinical practice guidelines committee of the American Society of Colon and Rectal Surgeons, 2015. Practice guideline for the surveillance of patients after curative treatment of colon and rectal cancer, *Disease of the colon & rectum,* 58: 713-725.
7. Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, *Follow-up of colorectal cancer survivors*.
8. Cancer Council Australia Surveillance Colonoscopy Guidelines Working Party, 2013. *Colonoscopic surveillance intervals – following surgery for colorectal cancer,* available at: http://wiki.cancer.org.au/australiawiki/images/3/34/Algorithm_for_Colonoscopic_Surveillance_Intervals_-_Following_Surgery_for_Colorectal_Cancer.pdf#_ga=2.21517435.1573391509.1500852300-1776091702.1498187560
9. Cancer Council Australia, 2017 *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer* (DRAFT for consultation), Wiki guideline.

Note: *This protocol contains evidence-based recommendations for follow-up, but should be tailored to individual patient needs*