When is 'enough' data really enough?
Data capture in the CIC Cancer Project

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Continuous Improvement in Care cancer

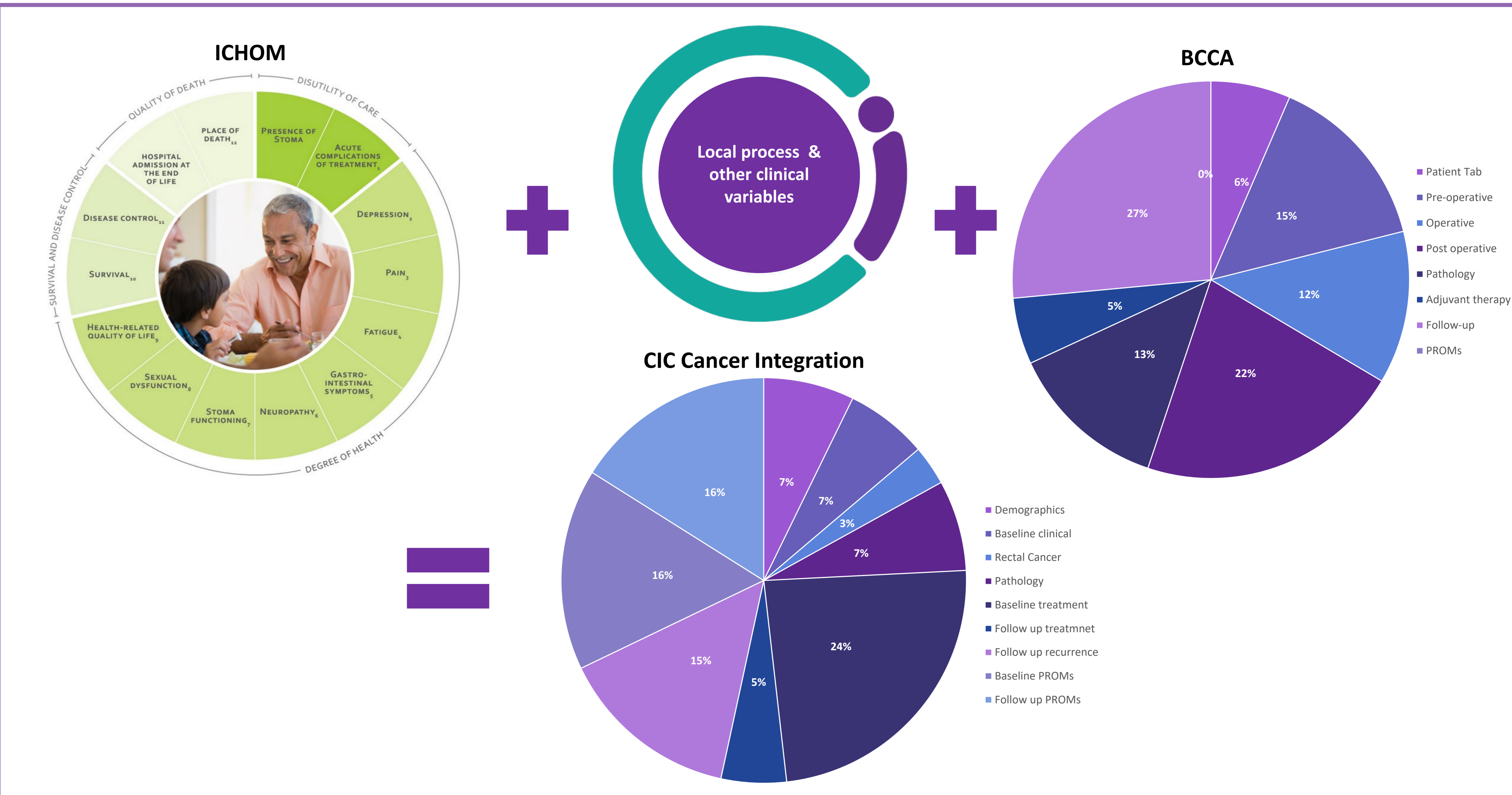*Contact – ciccancer-smed@uwa.edu.au; www.ciccancer.com*

Project Methodology…

◎ The Continuous Improvement in Care – Cancer (CIC Cancer) Project aims to explain variations in health outcomes, which at present cannot be understood with conventional health outcome measures. To achieve this, the project is collecting data to not only look at disease and clinical outcomes but also to assess processes and systems and their efficiencies in the delivery of care from prevention, diagnosis, treatment, and survivorship to end of life care.

◎ Importantly, the data will include Patient Reported Outcome Measures (PROMS) which will enable the capture of patients' perspectives on how health service interventions during their cancer journey have impacted on their quality of life, daily functioning, and symptom severity. This will enable an understanding of the value of healthcare interventions on patients' lives.

◎ The project will utilise an extensive platform of data and evaluate how best to implement the system within both the public and private sectors for a range of cancer types. In some cancer groups established databases already collect much of the clinical data; however, process and systems data, as well as PROMS, is poorly captured.

◎ In order to implement a dataset capable of capturing all necessary information, data variables from several established databases need to be amalgamated and mapped. The International Consortium for Health Outcomes Measurement (ICHOM) standard sets of outcomes measures will be used with the addition of data and outcomes relevant to WA patients.

Data Mapping…

◎ Integration is underway for colorectal cancer and data variables from the National Bi-National Colorectal Cancer Audit (BCCA) and ICHOM standard set for colorectal cancer have been amalgamated.

◎ Although the PROMS variables from the ICHOM Set have been adopted as a whole, data mapping for the clinical variables was necessary to integrate these data models that employed different nomenclature for anatomical location categorisation, surgical techniques, and adjuvant treatment regimes. Furthermore, neither dataset accounted for local process variations and adherence to national/international best practice guidelines – necessitating incorporation of even further variables. Transformation of a large proportion of the variables was also required to enable ease of capture by either clinician or patient.

◎ Ongoing clinical data will be collected by clinicians. Wherever possible, data will be extracted electronically from existing data systems, securely transferred and then data items mapped to automatically populate the relevant dataset field within the 'Site System'. PROMs will be collected at designated time points by either the clinician, in consultation with the patient, or the patient will complete these via a web-based 'PROMS Platform' using a computer, tablet, or mobile telephone. The PROMs dataset will then be uploaded to the 'Site System'. De-identified data will be regularly transferred to the 'CIC Cancer Research Database' for evaluation and feedback to the hospital sites as part of a quality improvement cycle.

◎ This pilot in colorectal cancer will inform the model for data capture in four other cancers – lung, breast, prostate, and ovarian.

Mapped Variables…

PRIMARY TUMOUR LOCATION			COLORECTAL CANCER SURGERY	
ICHOM	BCCA	Mapping	ICHOM	Mapping
0 = Caecum 1 = Appendix 2 = Ascending colon 3 = Hepatic Flexure 4 = Transverse Colon 5 = Splenic Flexure 6 = Descending Colon 7 = Sigmoid Colon 8 = Rectum 999 = Unknown	0 = Appendix 1 = Caecum 2 = Ascending colon 3 = Hepatic Flexure 4 = Transverse Colon 5 = Splenic Flexure 6 = Descending Colon 7 = Sigmoid Colon 8 = Rectosigmoid 9 = Rectum upper third (>12cm) 10 = Rectum mid third (8-12cm) 11 = Rectum lower third (<8cm) 12 = Pending 999 = Unknown	ICHOM 0 = BCCA 1 ICHOM 1 = BCCA 0 ICHOM 8 = BCCA 8 or 9 or 10 Add BCCA 12 Pending	1 = Hemicolectomy Right 2 = Extended Colectomy Right 3 = Transverse resection 4 = Hemicolectomy left 5 = Subtotal Colectomy 6 = Total Colectomy 7 = Sigmoid Resection 8 = Anterior Resection 9 = Low Anterior Resection (LAR) 10 = Abdominoperineal Resection (APR) 11 = Proctectomy with Colo-anal 12 = Other 999 = Unknown	ICHOM 1 = BCCA 1 Right Hemicolectomy ICHOM 2 = BCCA 2 Extended Right Hemicolectomy ICHOM 3 = BCCA 15 Transverse colectomy ICHOM 4 = BCCA 3 Left hemicolectomy ICHOM 7 = BCCA 4 Sigmoid Colectomy ICHOM 6 = BCCA 5 Total Colectomy ICHOM 5 = BCCA 6 Subtotal colectomy ICHOM 11 = BCCA 7 Proctocolectomy or BCCA 14 Colo-anal anastomosis ICHOM 9 = BCCA 9 Low anterior or BCCA 10 Ultralow anterior resection ICHOM 10 = BCCA 11 APR ICHOM 12 = BCCA 12 Hartmann's or BCCA 13 Miscellaneous operation or BCCA 16 Local excision or BCCA 17 TEMS/TAMIS or BCCA 18 Laparotomy only or BCCA 19 other

ICHOM + Local process & other clinical variables + BCCA = CIC Cancer Integration

BCCA legend: Patient Tab, Pre-operative, Operative, Post operative, Pathology, Adjuvant therapy, Follow-up, PROMs

CIC Cancer Integration legend: Demographics, Baseline clinical, Rectal Cancer, Pathology, Baseline treatment, Follow up treatmnet, Follow up recurrence, Baseline PROMs, Follow up PROMs

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