

Title: Addressing unwarranted variation in clinical cancer practice

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Dedication

This thesis is dedicated to my wife, Quan Bee and my son Sonjay. They made huge sacrifices to make this endeavour and journey possible for me. I remain forever grateful to them.

Deep Appreciation

I also sincerely thank both my supervisors. I was lucky to have David Kerr as my primary supervisor and Chris Cunningham as my co-supervisor. David as promised made my whole experience as a graduate student fun. He gave me space to grow and always encouraged a camaraderie-based approach towards seeking solutions.

Despite of his busy surgical practice, Chris was generous with his time and thoughts. He grounded my stratospheric graduate student like thinking onto addressing practical challenges confronting clinical practice.

Most valuably, both David and Chris made me delve deeper into issues, where we gathered there are many layers to the art of decision making in clinical practice that made it look deceptively simple.

As a result of both my supervisors, I came to appreciate three important criterias for science: (i) is the problem real, (ii) is there a candidate mechanism and (iii) the 'so-what ' criteria (are there large implications?).

It was a privilege to have had David and Chris as my fellow journeymen and be a part of University of Oxford - a venerable institution.

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Abstract

In the clinical setting, the term 'unwarranted variation' refers to variations in patient outcomes that cannot be explained by the patient's illness or medical needs, or the dictates of evidence-based medicine. These variations persist even after adjusting for patient-related factors. Unwarranted variation depends on a mix of disparities, including inequalities in access to appropriate care in a wide variety of geographical and cultural settings, in the uptake and application of clinical knowledge, in the prioritisation and allocation of resources, and differences in organisational and professional culture. Nevertheless unwarranted variation has been inexorably linked with clinical practice. The Multidisciplinary team (MDT) is an important component of cancer care and is analysed as one of the two strands of clinical practice. Temporal trends in colorectal cancer care, resource utilisation and MDT workings are analysed using mix-method approaches. Colorectal cancer and Liver MDTs in Oxford and Gothenburg were observed and its members interviewed. The framework on unwarranted variation is reviewed with the view of assessing its utility in colorectal cancer care while the implication Cancer Drug Fund has on variation in clinical practice is also explored. Results indicate significant mortality amongst the elderly with colorectal cancer and a significant number of patients not receiving surgery within one-year of diagnosis. However 90-day post surgical mortality has improved. No association between colorectal cancer spend and patient outcomes were found. Members of MDTs were observed to have diverse views on the roles and responsibilities of their MDT. Potential antecedents to unwarranted variation were identified through MDT workings. This study makes a distinction between professional uncertainty and clinical uncertainty to address the potential source of unwarranted variation. Recommendations on issues MDTs need to address such as defining its core purpose and developing reporting standards are made. A modification to the definition of unwarranted variation is also suggested. This study also proposes a conceptual risk scoring approach based on clinical pathways for addressing unwarranted variation. Several research areas have also been suggested.

Chapter 1: Introduction

Introduction

This research primarily attempts to address unwarranted variation. It does so by assessing the applicability of Wennberg's framework on unwarranted variation on cancer care and uses colorectal cancer (CRC) as the disease model. It reviews Wennberg's theory on practice variation and suggested causes that render unwarranted variation. CRC multidisciplinary teams (MDT) workings are deconstructed to understand its impact on variation.

Wennberg defines unwarranted variation as "care that is not consistent with a patient's preference or related to their underlying illness" (Wennberg 2002) .

Independent of disease stage, patients' genetic predisposition and associated prognostic factors such as age, gender, health status and tumour heterogeneity provide considerable scope for variation in colorectal cancer care. These risks alter and affect responses to treatment and survival. Nevertheless evidence from risk-adjusted studies as shown in this study indicates unwarranted variation remains recalcitrantly present. Regardless of close to 90 years of research and publications highlighting (unwarranted) variation, patients continue to receive variable care that affects preventable morbidity and mortality and are subjected to practices that have doubtful clinical value. Thereby diminishing quality and value of healthcare services.

It seems ameliorating unwarranted variation can be challenging as Mulley states (Mulley 2010):

"If all variation were bad, solutions would be easy. The difficulty is in reducing

the bad variation, which reflects the limits of professional knowledge and failures in its application, while preserving the good variation that makes care patient centred. When we fail, we provide services to patients who don't need or wouldn't choose them while we withhold the same services from people who do or would, generally making far more costly errors of overuse than of underuse."

The use of the Internet by patients and clinicians, the increase use of multidisciplinary teams (MDTs), resource constraints, excess capacity, changes in policy and advances in treatment are associated with practice variation. Several measures were undertaken to address such variation and one of it was the introduction of MDTs to diagnose and suggest treatment. On the face of it MDTs are logical and relevant, and the prevailing assumption is that if a MDT is consulted especially one based at a tertiary centre, good cancer care will follow. However MDTs its current structure and functionalities are not necessarily geared to mitigate unwarranted variation let alone consistently. As this research suggests MDTs could, albeit inadvertently, expose and/or initiate latent unwarranted variation. While measuring outcomes is pertinent, in the case of MDTs measuring and monitoring its processes and structure, as this research would suggest are relevant to addressing unwarranted variation.

Variation

The literature on variation with regard to cancer care as indicated throughout this research is extensive. These show undesirable variation range from outputs to outcomes e.g. avoidable deaths (Richards 2009) . Variation in clinical practice especially those affecting patient outcomes are important policy and operational issues to address. However not all variation is unacceptable e.g. when care takes into account patient-related risks and

preferences. Nevertheless there is little evidence to support that the current form of showcasing variation is an effective method of reducing it.

A couple of key studies (Glover, Wilson 1932, McArdle, Hole 1991) highlighted below highlight the salient points of variation.

Studies on variation date as early as the often-cited Glover and Wilson's 1932 study on tonsillectomies and Glover's subsequent presentations of their observations at the Royal Society of Medicine in 1938 (Wennberg, Gittelsohn 1973, Wennberg, Barnes et al. 1982, Glover 1938, Glover, Wilson 1932).

Glover's 1932 study showed in spite of the Chief Medical Officer of the Board of Education warning that tonsillectomies should be undertaken only when absolutely necessary there was an approximately 2.4-fold increase in the number of tonsillectomies in elementary school children from 1923 – 1930. In public elementary school children in London it rose from 7,656 to 18,119 and 47,685 to 109,738 in England and Wales. The then estimate according to their study for England and Wales the number of school children before the ages of 14 being tonsillectomized was 14% while it exceeded 33% in London. It was more than 65% in wealthier public schools. In contrast Glover finds through the medical officer in Munich that their rate in the spring of 1932 in Munich city was 0.5% and hardly any for the country districts. The School Medical Officer for London apparently claimed that the larger than necessary referral for operation was influenced by the availability of better surgical facilities. This in particular highlights clinical decisions (clinical practice) being affected by external factors. Meanwhile the study also showed an 8-percentage point difference between boys and girls receiving the surgical treatment even

though the incidence of rheumatism and tonsillitis was higher amongst girls in similar environment.

Glover, using the Great Ormond Street Hospital series of 500 patients, showed school children that were ill were more likely to undergo preventive tonsillectomy. Review of end-results provides no evidence that tonsillectomy accorded protection from measles and other common complications such as otitis media, mastoiditis and pneumonia. By reviewing end-results Glover showed an overuse of a medical procedure that provided little or no value.

Glover highlights the difficulty in defining what is an “appropriate case” beyond unequivocal indications such as clear obstruction or recurrent tonsillitis that would justify the procedure. Chapter 4 and 5 of this thesis discusses the issue of clinical uncertainty.

Therefore Glover retrospectively classified the cases, as (i) patients whom for certain tonsils are diseased, (ii) there is reasonable doubt that the tonsils are diseased and (iii) tonsillectomy is performed as a preventive measure. In doing so Glover highlighted divergence in clinical practice when clinical certainty is doubtful; as he remarked there have been great changes in opinion towards the criteria for tonsillectomy.

The study also showed more than half across a population of 14,000 school children were tonsillectomized randomly between those who had symptoms of “being ill” and those who were not “ill”. Influenza was the predominant determining factor.

In summary, Glover's 1932 study shows surgical rates could not reliably be attributed to medical evidence or the extent of the patient's illness. These rates seem to be associated to external factors such as clinical uncertainty, gender, socio-demographics and the availability of healthcare resources. It draws an association between variation and the subjective nature of clinical practice. Such factors as discussed in chapter 4 are the cornerstones of Wennberg's framework on unwarranted variation.

Since then many risk-adjusted studies on variations in treatment indicate similar undesirable variation (Wennberg 2002, Raine, Wong et al. 2010, McArdle, Hole 1991, Morris, Quirke et al. 2008, Goodman 2009, Morris, Taylor et al. 2011, Ghaferi, Birkmeyer et al. 2009, , NHS Atlas of Variation in Healthcare – 2015 § NHS Right Care - Population healthcare - improving value for patients and populations). As a method of drawing out variation risk-adjusted statistical models allow a fairer comparison between service providers against a set of patient outcomes.

Chapter 2 discusses CRC care trends from 2001 to 2010.

Unwarranted variation

Care not consistent with patient's underlying illness or preference is deemed as 'unwarranted variation', a term made popular by Wennberg in particular through the publication of the Atlas of Variation indicating variations in care in the United States (Wennberg, Cooper 1996). He classified unwarranted variation by providing a definition and a framework. His definition is **"Variation that cannot be explained on the basis of illness, patients'**

preferences or dictates of scientific medicine” (Wennberg 2002) .

Wennberg’s proposition rests on the association between patient preferences, availability of resources and clinical uncertainty and their impact on clinical practice. This respectively is based on three categories he sets out: preference-sensitive care, supply-sensitive care and effective care. Central to Wennberg’s framework is clinical practice. This definition and the ensuing framework are discussed in detail in Chapter 4, elucidating the challenges in applying existing frameworks, given the multifaceted aetiology of unwarranted variation, particularly against complex diseases such as cancer.

Clinical practice

This research will discuss the counterpoints on Wennberg’s postulation on unwarranted variation in and around the clinical practice. Practice-style factors, Wennberg claims, give rise to unwarranted variation. Doctors’ biases and clinical uncertainty he asserts impinge on clinical practice. In this study the multidisciplinary team (MDT) viewed as clinical practice was studied vis-à-vis its role and responsibilities to address unwarranted variation within the CRC pathway. Some of its findings, a working definition of ‘clinical practice’ and how clinical uncertainties could arise within CRC MDTs were recently published (Menon, Cunningham et al. 2016). Chapter 3 carries the details of the CRC MDT interviews conducted in Oxford, UK and Gothenburg, Sweden. While the term ‘unwarranted variation’ is used to highlight (sensationalise) variation in healthcare resources and patient outcomes (Carter 2016), results shown in Chapter 3 suggests its definition may not be adequately known or understood amongst clinicians. This chapter also observes the evolving nature of clinical practice. Meanwhile a paper published based on this thesis

discusses possible antecedents MDTs could observe to address unwarranted variation and its related challenges in clinical practice (Menon, Cunningham et al. 2016) .

Patient preferences

The issue of addressing patient preferences is central to clinical practice. According to Wennberg's framework adhering to patient preferences is an important element of addressing unwarranted variation. However this research will show this is not as easily as implied especially in cancer care where the patient is confronted with several and difficult trade-offs that can confound the clinician-patient encounter. Preferences are also subject to changes along the care pathway depending on how patients respond to treatment. By extension it would seem inadequate and inappropriate to approach 'patient preference' in cancer care as a one-off exercise, even though in doing so arguably no unwarranted variation was committed.

Also preference presumes choice, which is based on the patient's knowledge and understanding of their illness possible outcomes and quality of life trade-offs they may need to decide on. Likewise a patient's preferred option may be unavailable or inappropriate.

These issues raise the question of the nature of interactions within clinical practice (including MDTs).

Effective care

Effective care is a fundamental point in Wennberg's framework, i.e. if a patient does not receive treatment when indicated that would be classified as an

unwarranted variation. Specifically this category rests on underuse of effective treatment. However this research will show that the term 'effective care' does not and cannot automatically suggest appropriate or effective treatment, especially since Wennberg argues the utility of his framework extends towards managing healthcare costs where effective care can also mean cost-effective care. This issue is highlighted in the Cancer Drugs Fund case study in chapter 4. Further discussions will also show the term 'care' has broader implications than being confined to 'treatment' alone. Chapter 5 will also touch on the issue of 'effective treatment' against the backdrop of inappropriate use of drugs e.g. thalidomide.

Supply-sensitive care

In this category Wennberg posits external factors affecting the course of action a clinician determines in clinical practice. This is based on 'small area analysis' (SAV) Wennberg uses as his primary method of determining variation at practice level. Others have proposed alternatives e.g. resource demand and clinician induced demand models to explain these phenomena. Here Wennberg argues excess supply induces an *overuse* of resources, which can lead to over treatment. Thus overuse affects value. Others have challenged this conjecture. Chapter 4 as a whole provides a detailed discussion of Wennberg's framework.

Cancer care in England

National Cancer Policy

Many studies have shown unacceptable variation in cancer outcomes and these subsequently inform policy and service provisions. Poorer cancer

outcomes in England in comparison to similar health systems in Europe drove the impetus to address such variation. It specifically in 2000 introduced the National Cancer Policy (NCP) (Department of Health, London (United Kingdom) 2000). The NCP was to improve screening, prevention, community services, reduce waiting times for diagnosis and treatment, improve palliation and facilitate research – funded by an additional £570 million (Kerr 2000).

As part of its aims to reduce / eliminate unacceptable variation in patient outcomes, the NCP looked to facilitate better referral from general practitioners (GPs) to specialist teams for diagnosis and treatment. The NCP rode on the back of a set of pivotal recommendations found in the Calman-Hine report (Calman, Hine et al. 1995) and the first national audit of cancer waiting times by Kerr et al. (Spurgeon, Barwell et al. 2000). These reports essentially led the reconfiguring of cancer services in England and Wales where a system of integrated care and concentration of specialist services within tertiary centres was rolled out.

Cancer Reform Strategy

In 2007 Department of Health (DH) published The Cancer Reform Strategy (CRS) which primarily focused on efficiency and productivity, and launched the National Awareness and Early Diagnosis Initiative (NAEDI) with Cancer Research UK in 2008 (Richards 2009). The CRS identified six areas where action was needed to improve outcomes and services (UK Department of Health 2008) :

- I. Prevention
- II. Reducing cancer inequalities
- III. Improving patients experience
- IV. Earlier diagnosis and treatment

- V. Access to cost effective treatments
- VI. Delivering care in the most appropriate setting

It also identified four areas needed to ensure delivery:

- I. Better information
- II. Appropriate funding
- III. Building for the future
- IV. Stronger commissioning

Cancer survival

The gap in cancer survival between England and other comparable countries highlighted through the 1995 Eurocare study (Berrino, Sant et al. 1995) led the impetus to set targets, reconfigure services and increase resources. The NCP and CRS related measures were initiated to address these comparable survival differences (UK Department of Health 2008).

Thus in 2009 DH established the International Cancer Benchmarking Partnership (ICBP) with the primary objective of trying to understand survival differences between UK and five other developed countries i.e. Australia, Canada, Denmark, Norway and Sweden (Walters, Benitez-Majano et al. 2015). The comparatively low one-year survival in the UK was suggestive of late and/or advanced stage on diagnosis (Butler, Foot et al. 2013). With the exception of breast cancer, ICBP found no evidence to suggest UK was 'catching-up' with the other countries (Coleman, Forman et al. 2011). Results from the Concord-2 study indicate cancer survival has been broadly improving in the UK but remains lower when compared to similar high-income health systems (Allemani, Weir et al. 2015). The results show 5-year survival in the UK for patients diagnosed between 2005 and 2009 with stomach, colon, rectum, liver, lung, breast, cervix, ovary, prostate and leukaemia is still lower

than the five ICBP partner countries. A study using more recent 2010-2012 data again found England was not closing the international gap with Australia, Canada, Norway and Sweden in one- and five-year survival from stomach, colon, rectum, lung and ovarian cancers (Walters, Benitez-Majano et al. 2015).

DH recognises England's poor one-survival rates is reflective of late diagnosis especially since about 23% - 30% of diagnosis occur at emergency admissions (, House of Commons - Delivering the Cancer Reform Strategy - Public Accounts Committee, McArdle, Hole 2004). In their retrospective study of 3200 CRC patients, McArdle and Hole found proportionately more elderly patients (aged over 75 years) and women presented as emergency. More patients with left-sided colonic lesions and lower rectal patients were treated as emergencies. And advanced disease was more prevalent at emergency presentations too (McArdle, Hole 2004). Chapter 2 of the thesis shows the age related time trends in CRC care.

Overall the poor cancer survival rates indicate approximately 11,000 'avoidable' deaths if England were to match the best in Europe (Richards 2009). Around half of these avoidable deaths are related to breast, colorectal and lung cancers (Richards 2009). However there is little evidence to identify the relative impact on survival due to delays associated with patients, GPs, hospitals or any other part of the care pathway in England. Thus making it difficult to prove linkages between delays and poor survival from observational studies (Richards 2009).

2020 Cancer strategy

The National Health Service (NHS) in England reiterated through its 2020 Cancer Strategy that closing the international gap in survival rates is a significant benefit it aims to achieve (, Cancer Taskforce | Cancer Research UK). This report contains a long-list of 96 recommendations, and six strategic priorities. It predicts cancer diagnosis in the UK will rise from 2 million (2015) to 3.4 million by 2030. According to the report it expects the following benefits if its initiatives are implemented:

- Additional 30,000 patients per year will survive cancer for 10 years or more
- Close the gap in survival rates between England and comparable countries in Europe and elsewhere
- Better integrated care especially at transition points
- Patients better informed and empowered in decision making around their care
- Improvement in the quality of life including end-of-life care
- A reduction in cancer incidence
- A reduction in the variability of access to optimal diagnosis and treatment, and inequalities in outcomes
- Significant savings

Broadly, their action plan is:

- (i) Spearhead a radical upgrade in prevention and public health
 - Develop a new tobacco strategy – reduce adult smoking to less than 13% by 2020
 - Develop national action plan on obesity
- (ii) Drive a national ambition to achieve earlier diagnosis

- By 2020 95% of patients referred by GPs to receive a definitive diagnosis with cancer or otherwise within four weeks
 - Test new models of diagnostic pathways to reduce burden on GPs
- (iii) Establish patient experience as being on par with clinical effectiveness and safety
- Communicate with patients using digital technologies
 - Provide patients online access to all their tests and communications with hospitals
 - Systematise patient access to Clinical Nurse Specialist (CNS) or others to help coordinate their care
- (iv) Transform support for people living with and beyond cancer
- Develop stratified follow up pathways and “Recovery Package”
 - Develop national quality of life measure by 2017
 - Clinical Commissioning Groups (CCG) to commission appropriate end-of-life care
- (v) Make the necessary investments required to deliver a modern high quality service
- Upgrade linear accelerators
 - Access to new cancer treatments building from the Cancer Drugs Fund
 - Roll out nationally commissioned molecular diagnostics service
 - Address critical workforce shortages in deficit areas i.e. radiology, radiography, endoscopy, clinical oncology, medical oncology and CNS
 - Support cancer research
- (vi) Overhaul processes for commissioning, accountability and provision

- Establish Cancer Alliances to drive and support integrated care pathways
- Use dashboard of key metrics to elucidate variation and support service redesign

Colorectal cancer

Global epidemiology

The incidence of CRC is expected to rise as life expectancy increases and lifestyles change. In 2012, according to the International Agency for Research on Cancer (IARC) CRC is the third most common cancer in men and the second in women worldwide where 55% of cases occur in developed regions (, GLOBOCAN Cancer Fact Sheets: All Cancers). Figure 1 shows worldwide estimates on CRC incidence and mortality rates. A wide geographical variation in incidence but similar geographical patterns between sexes worldwide is shown. Overall CRC incidence is higher in males than in females. As indicated in figure 1 there is six-fold variation in men, four-fold in women in mortality rates worldwide, with the highest estimate in both sexes seen in Central and Eastern Europe (20.3 per 100,000 for men, 11.7 per 100,000 for women), while less developed regions are estimated to have poorer survival.

Colorectal cancer in England

Colorectal cancer is the third most common cancer in the UK with approximately 41,000 cases reported annually (, Bowel cancer incidence statistics | Cancer Research UK). According to the Office for National Statistics (ONS) a total of 34,025 (18,789 male (55%), 15,236 female (45%))

CRC cases were registered in England in 2014. This, it states represents 12.5% males and 10.4% females of the total number of cancers registered. Overall England has > 82% of the total CRC index admissions within the UK.

Figure 2 shows 84.5 cases per 100,000 males and 56.4 per 100,000 females were diagnosed with CRC in 2014 alongside incidence and mortality time trends from 1995 to 2014. It shows neither incidence nor mortality in both sexes has reduced appreciably over time.

Survival according to stage of disease differs (Table 1). It can suggest differences in quality of CRC care and patients' health status. Survival rates can be affected by differences in staging procedures and stage migration (Menon, Cunningham et al. 2016, Maringe, Walters et al. 2013). In an international study England was shown to have suboptimal CRC staging where fewer lymph nodes were examined pathologically compared to elsewhere in Europe and performed lower liver imaging (Gatta, Capocaccia et al. 2000). The parliamentary committee noted its concerns over the close to 5-fold variation in completeness of staging data among the eight regional cancer registries(, House of Commons - Delivering the Cancer Reform Strategy - Public Accounts Committee).

	One-year CRC survival (Adults)			
	Stage 1	Stage 2	Stage 3	Stage 4
2012	97.2% (96.4-97.9)	92.4% (91.8-93.0)	87.4% (86.7-88.0)	40.3% (39.5-41.1)
2013	97.8% (96.9-98.4)	92.8% (92.2-93.4)	87.8% (87.1-88.4)	41.3% (40.5-42.1)
	97.8%	92.0%	87.1%	39.9%

2014	(97.0-98.4)	(91.4-92.5)	(86.5-87.7)	(39.1-40.6)
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Table 1: One-year net age standardised survival for in England by stage, adults (aged 15 to 99), 2012-204 followed up to 2015. Numbers in brackets denote 95% confidence interval. Data source: National Cancer Registration and Analysis Service (NCRAS).

Care pathways and waiting times

Patients with CRC symptoms can be initially assessed by either their general practitioner (GP) or through bowel screening – for asymptomatic patients. Patients with acute symptoms are likely to be seen at Accidents & Emergency (A&E). Figure 3 is a schematic representation of CRC care pathway. Cancer waiting times represent time taken for patients either suspected of cancer or with cancer to be seen and treated. These were first introduced in the National Cancer Plan 2000 and subsequently refined through the 2007 Cancer Reform Strategy (, Going Further on Cancer Waits). Accordingly patients with CRC need to be first seen in the cancer hospital within 14 days of receipt of GP's urgent referral and be treated within 62 days of the GP's referral where specifically patients must be treated within 31 days of decision to treat. Specialists have the right for patients with suspected symptoms though not urgently referred by their GPs, to be treated within the 62-day pathway. Figure 4 shows an overview of cancer waiting times.

Patient outcomes

Wide variations exist in 5-year overall survival of patients with colon or rectal cancer. These are seen across regions and countries in Europe and within the UK (De Angelis, Sant et al. 2014). The differences in these variations have been discussed elsewhere (Menon, Cunningham et al. 2016). Studies show

variation in patient outcomes can be attributed at various levels of care services e.g. at the clinician level (McArdle, Hole 1991, Birbeck, Macklin et al. 2002, Porter, Soskolne et al. 1998), between hospital trusts (Appleby, Raleigh et al. 2011, Morris, Taylor et al. 2011), and at healthcare systems (De Angelis, Sant et al. 2014, Allemani, Weir et al. 2015). Even risk-adjusted studies show unwarranted variation in outcomes are associated across common themes i.e. screening (Hetzl, Huang et al. 2010, Bowles, Leicester et al. 2004), access to treatment (Raine, Wong et al. 2010, McCaffery, Wardle et al. 2002), range and quality of treatment (Miller, Woosley et al. 2004, Almoudaris, Burns et al. 2011, Baxter, Virnig et al. 2005) and socioeconomic status (Downing 2013). The National Bowel Cancer Audit in England and Wales too highlighted the need to investigate the number of patients with CRC not receiving surgery (, National Bowel Cancer Audit - Health & Social Care Information Centre).

Study on the variability of postsurgical morbidity and mortality by McArdle et al. highlights variation of care at the practice level (McArdle, Hole 1991). A total of 645 patients diagnosed with CRC treated at the Royal Infirmary, Glasgow between 1974 and 1979 (inclusive) were part of this retrospective study. Thirteen consultant general surgeons – none with specific interest in colorectal surgery, managed these patients. Irrespective of surgical intent all patients were followed up at three monthly intervals for two years, followed by six monthly intervals for subsequent three years and thereafter yearly up to ten years. Patients primarily underwent surgery for either curative or palliative care. 52.4% of resections were curative, 18.6% palliative, 20.5% palliative diversion and 8.5% either had only laparotomy (n=21) or no surgery (n=34). There was a > 4-fold difference in the number of patients cared for by

individual surgeons. Notably 23% of patients had their operation performed by surgeon in training.

Overall postoperative mortality between the surgeons irrespective of surgical intent varied from 8% to 30%. Meanwhile postoperative mortality ranged between 0% to 20% after curative resection and likewise 20% to 63% on 10-year survival. Two-year survival post palliative resection ranged from 7% to 100%.

On the basis of their multivariate analysis McArdle et al. identified besides patient-related risks, operating surgeons and their case volume as factors associated with postoperative mortality and survival. Their analysis points towards caseload associated outcome where surgeons with higher casemix volume, were found to have lower recurrences and considerably lesser postoperative complications. Likewise clear differences in technical capabilities, based on the incidence of technical complications e.g. wound dehiscence rates, anastomotic leakages and local recurrences, are shown to compromise patient survival. The paper sets out in detail how these variables differ amongst the surgeons.

In summary this study points out caseload, technical competency and the need for closer supervision of surgeons in training as salient factors for patient survival. By extension it lends weight for CRC surgery to be undertaken by surgeons trained to address this condition specifically. This therefore has relevance on how cancer services are configured and in addressing avoidable mortality and poor long-term survival rates. The wider implication is the

association between surgeon volume and outcomes. The 'volume' related issue has been discussed elsewhere (Menon, Cunningham et al. 2016).

Patient related risks

Family history or other medical conditions can predispose prospective patients to developing CRC. The risk of developing colon cancer than rectal cancer is higher due to inherent genetic predispositions (Wei, Giovannucci et al. 2004). Familial adenomatous polyposis (FAP) and hereditary non-polyposis colon cancer (HPNCC) are two genetic syndromes known to cause colon cancer (Kinzler, Vogelstein 1996). However most CRCs develop from sporadic adenomatous polyps, and generally polyps are asymptomatic (Young, Hobbs et al. 2011) prior to transforming into a carcinoma that 'drives' severity (Vogelstein, Kinzler 1993).

Some of the risks CRC patients face are asymptomatic early stages which are also not necessarily severe. CRC is a disease that develops over time as Vogelstein's 'multistep nature of cancer' theory suggests (Vogelstein, Kinzler 1993). Therefore late onset of specific symptoms such as blood in stools, rectal bleeding, change in bowel habit, anaemia, weight loss and others can delay referral to specialist care (Elliss-Brookes, McPhail et al. 2012). A systematic review suggests initial misdiagnosis, inadequate examination and inaccurate investigations can result in practitioner delay (Mitchell, Macdonald et al. 2008). It also found patient delay was greater for rectal than colon cancer where patients' non-recognition of symptoms contributed towards delays. The effects of such delays are further exacerbated if waiting times are long. Study by Spurgeon et al. suggest 90% of urgent CRC patients wait 35

days for their first outpatient appointment while non-urgent patients wait 60 days (Spurgeon, Barwell et al. 2000). Thus clinical uncertainties where CRC cannot be either confirmed or excluded and inefficient processes can induce delays in obtaining accurate and timely diagnosis - compromising quality in CRC care. The issue of clinical uncertainty is central to Wennberg's expositions on unwarranted variation – taken up further in Chapter 4.

For preventing CRC, the public have their share of avoidable risks: smoking, overweight and obesity, Type 2 diabetes, physical inactivity, alcoholism and high intake of animal fat and processed meat, and low uptake of bowel screening (Huxley, Ansary-Moghaddam et al. 2009, Larsson, Orsini et al. 2005, Wei, Giovannucci et al. 2004).

Operative risks

As mentioned above CRC patient-related characteristics can be independent of their operative risk. Increase in disease stage, ASA (American Society of Anaesthesiologists) category, urgency of operation, out-of-hours surgery, absence of excision, type of surgical procedure and volume of cases have been suggested as risk factors for 30-day operative mortality (Tekkis, Poloniecki et al. 2003). Also “hospital effect” as an indirect measure of the structure and process of cancer care in a hospital has been shown to affect patient risk (Tekkis, Poloniecki et al. 2003).

Surgical management of low-lying rectal tumours has evolved over the years with evidence suggesting the use of neoadjuvant treatment (Sauer, Becker et al. 2004, Frykholm, Glimelius et al. 1993) and anterior resection as surgical choice over abdominoperineal resection of the rectum (APER) (Heald, Moran

et al. 1998, Heald, Ryall 1986, MacFarlane, Ryall et al. 1993) . APER results in permanent stoma formation and has implication on patients' quality of life (Sprangers, Taal et al. 1995, Williams, Johnston 1983) and considerable risk for wound complications (Christian, Kwaan et al. 2005, Bullard, Trudel et al. 2005). As an extension, permanent stoma following low rectal surgery has been suggested as a surrogate marker of surgical quality (Tilney, Heriot et al. 2008). In England patients with higher deprivation are more likely to undergo APER and risk poor quality of care (Tilney, Heriot et al. 2008).

Therefore mitigating operative risks is expected to address unwarranted variation.

Thesis

This thesis has two interlinked strands i.e. (i) assessing temporal CRC care trends and MDT workings and (ii) addressing unwarranted variation.

The first strand follows that since the inception of NCP in 2000, the government and the NHS have concertedly tried to improve cancer care through increased funding, innovations and being evidence-based. These efforts have also seen the needs and preferences of patients and prevention becoming a central part of quality in cancer care. In 2004 the CRC MDT was introduced to manage CRC care. Based on all these it would seem reasonable to expect improvement in CRC care processes and patient outcomes. And these being associated with expenditure.

Studies on variation in clinical care have been made available to practioners and others for more than eighty years. From this a separate body of

scholarship on unwarranted variation developed. Though not as widely known as expected, Wennberg's theory and conceptual framework underpins the scholarship on unwarranted variation where clinical practice is central. However unwarranted variation remains difficult to mitigate. Nevertheless this thesis viewing unwarranted variation as a correlate of variation suggests the idea of addressing unwarranted variation through its antecedents. This may have practical value in clinical practice.

This second strand reviews the utility of Wennberg's theory and framework in clinical practice. CRC MDTs were the clinical practice of choice. As mentioned above based on the observations of MDT workings the idea of addressing unwarranted variation using an antecedent based framework was suggested and published (Menon, Cunningham et al. 2016).

MDT workings were deconstructed to identify possible antecedents of unwarranted variation with links to clinical outputs. In doing so, as part of the framework a conceptual 'toolkit' that may assist MDTs to address unwarranted variation on real-time basis is formulated. These findings are then extended onto hospital based CRC patient pathways where provisional risk scoring along conceptual 'critical clinical nodes' is suggested. These should provide a provisional framework for testing various hypotheses regarding clinical practice and unwarranted variation.

Specific aims, methods and discussions pertinent to this study are provided within the relevant chapters. As part of its conclusions this thesis highlights some of the gaps and challenges in addressing unwarranted variation. It also looks in some detail how MDTs may require closer scrutiny to address its

ability to ameliorate unwarranted variation. Potential future research is also suggested.

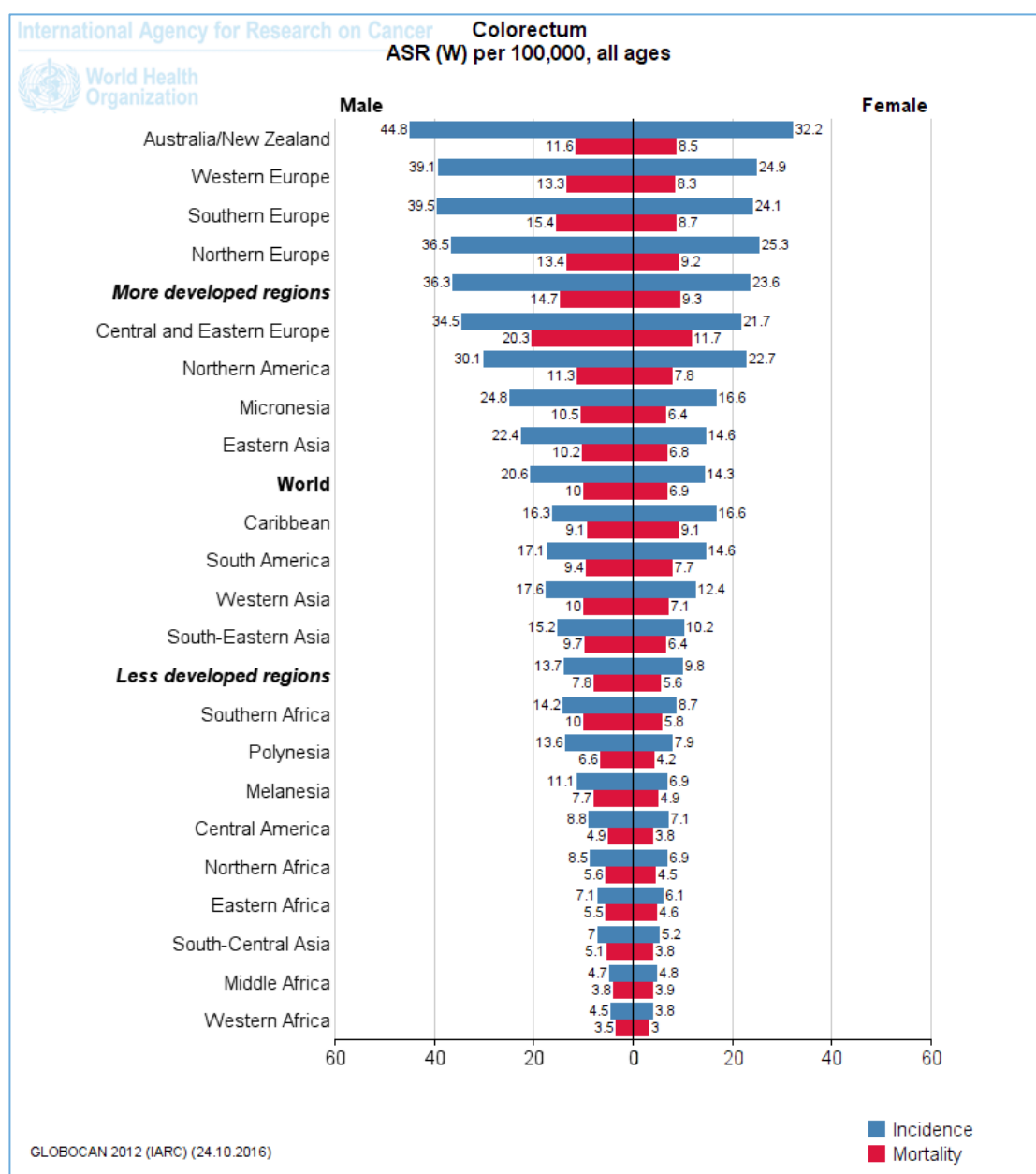


Figure 1: Estimated world CRC incidence and mortality estimated age-standardised rates (ASR-W) per 100,000, all ages. Source: GLOBOCAN 2012 (IARC).

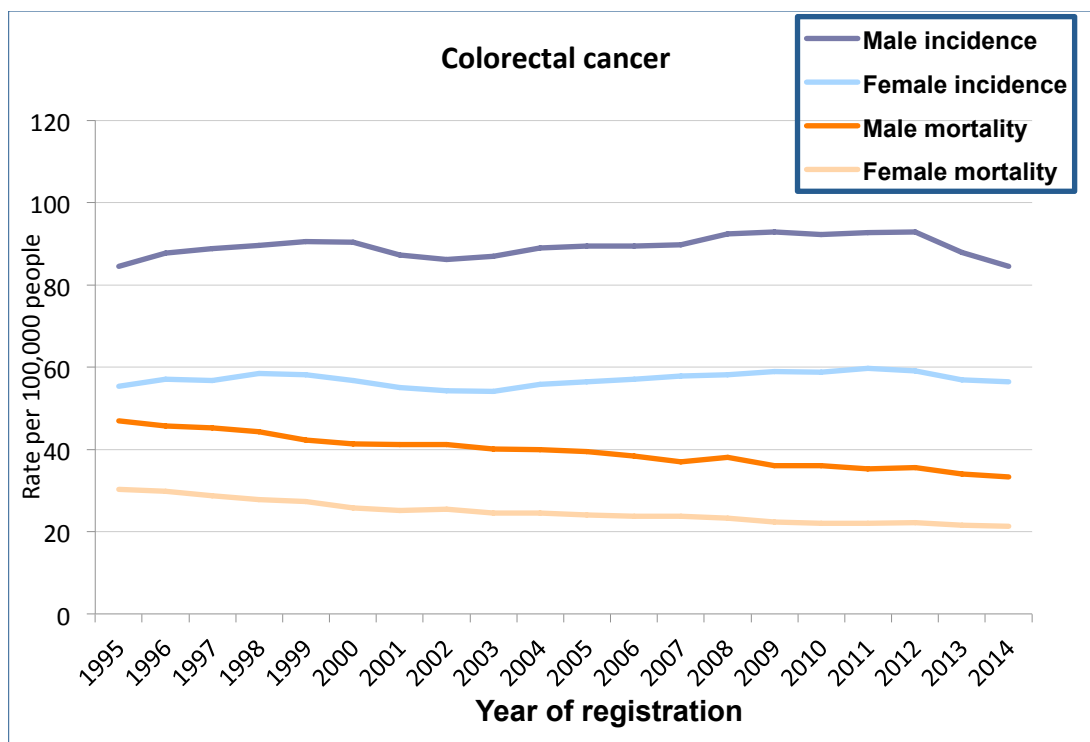


Figure 2: CRC incidence and mortality in England. Source: Office for National Statistics.

Primary referral pathways to CRC specialist centre

Treatment pathway within CRC specialist centre

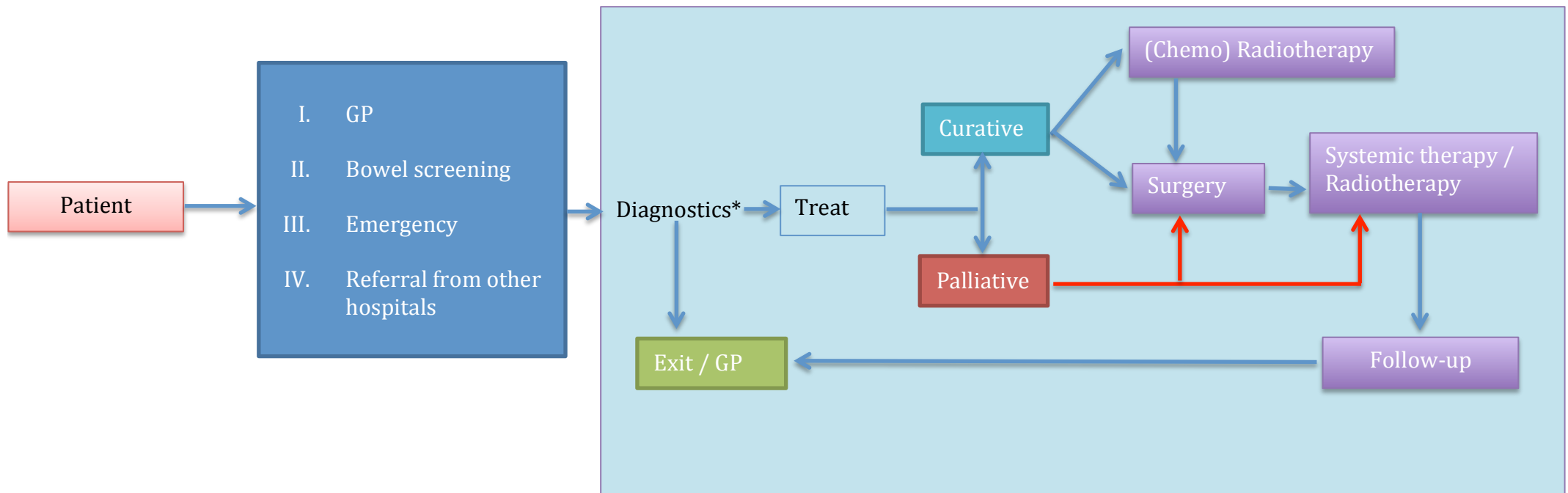


Figure 3: Overview of CRC referral and care pathways in England. * Patients diagnosed positive for CRC undergo treatment.

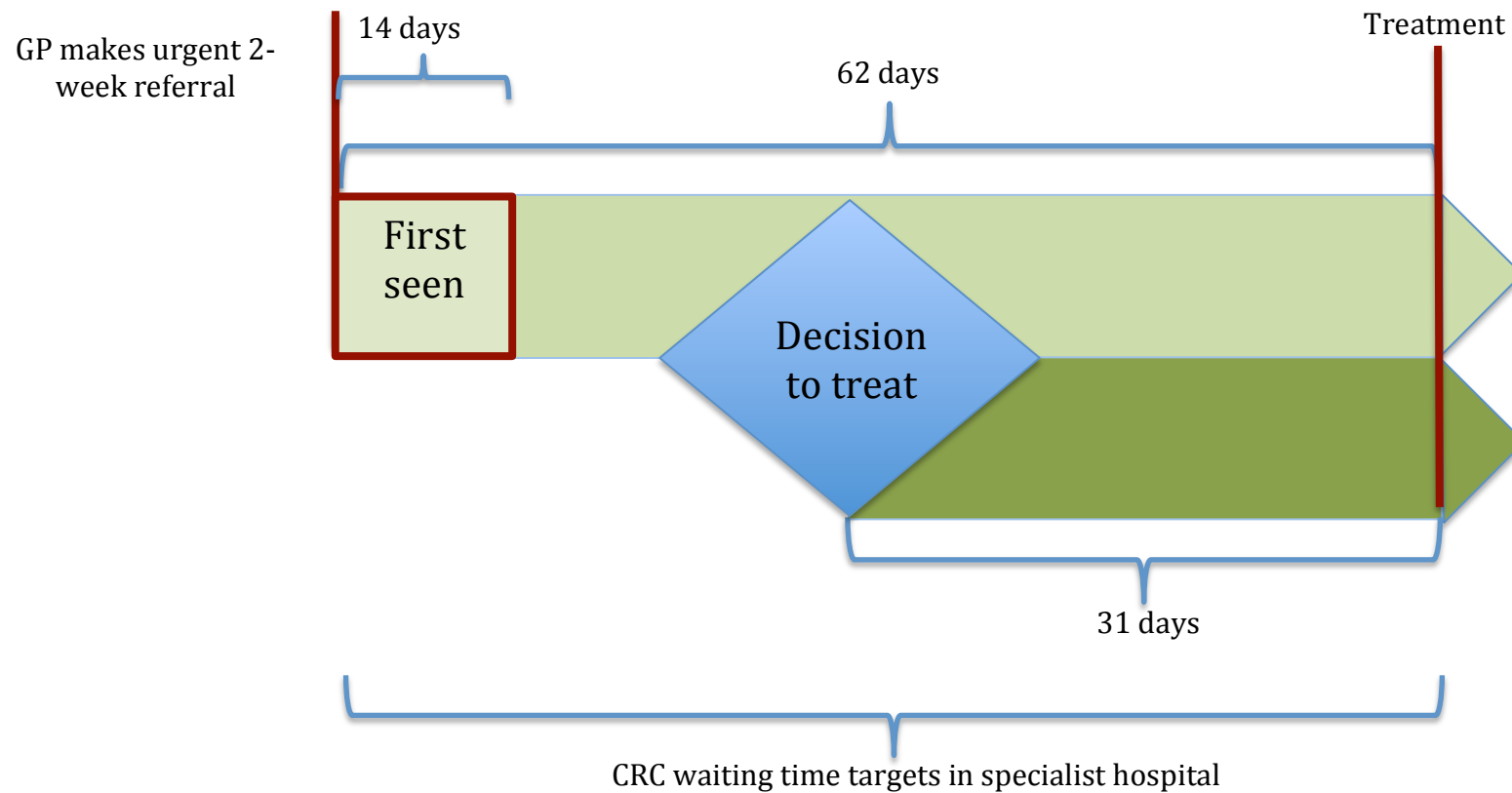


Figure 4: Cancer waiting times in the UK except for acute leukaemia, testicular and paediatric referrals.

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Chapter 2: Colorectal cancer care trends in England 2001-2010

Introduction

In 2000 the Department of Health (DH) published *The NHS Cancer Plan* (Cancer Plan) – a 10 year strategy to improve cancer care (Department of Health, London (United Kingdom) 2000) . The Cancer Plan introduced additional diagnostic services to improve access to care, cancer networks to improve diagnosis, created multidisciplinary teams (MDT) to provide consistent specialist care and reduce waiting times and GP led urgent referrals to ensure care is received in a timely manner. The Cancer Plan committed additional £570 million for cancer care. DH estimates that between 2000-01 and 2003-04 cancer services received additional £640 million besides the £540 million made available through the Cancer Plan. The overall expenditure for cancer services increased from £3.4 billion to £6.3 billion from 2003 to 2009. Since 2000, several initiatives underpinned by policy and funding were undertaken towards improving cancer services (Table 1). Such efforts have also seen the needs and preferences of patients and carers (Department of Health 2010), and prevention becoming important strands of quality in cancer care (Britain 2010). The UK continues to strive to improve its long-term cancer outcomes, which are lower than comparable European and other countries (Coleman, Forman et al. 2011, UK Department of Health 2008). In part, by reducing unwarranted variation which is defined as “Variation that cannot be explained on the basis of illness, patients preferences or dictates of scientific medicine” (Wennberg 2002) .

Colorectal cancer (CRC) is the third most common cancer in the UK and the second most common cause of cancer death (, Bowel cancer statistics | Cancer Research UK). Surgery is its main treatment and generally expected to be provided within 3 months of diagnosis (Morris, Taylor et al. 2011). Early post-surgical mortality has been suggested as an indicator of surgical quality and by extension MDTs (Morris, Taylor et al. 2011). Surgeons working in England performing bowel cancer surgery are expected to publish their case related mortality data as part of an overall attempt to improve quality (, Individual Surgical Outcomes for 2016 | The Association of Coloproctology of Great Britain and Ireland).

Studies have shown unwarranted variation exist in the management of CRC. Cavalli-Bjorkman et al. show that 5-year relative and overall survival was associated with the level of education patients had. Also patients with higher education were more apt to receiving pre-treatment diagnostic CT scans and had lower colostomy rates compared to those with lower education (Cavalli-Björkman, Lambe et al. 2011) . Morris et al. showed in comparison to Sweden and Norway, England had the greatest excess mortality amongst CRC patients aged ≥ 80 years at diagnosis and was at its maximum in the first 3 months after diagnosis (Morris, Sandin et al. 2011) .

Efforts were made to provide earlier diagnosis to improve morbidity and mortality. Bowel screening was shown to be effective in reducing disease-specific mortality (Faivre, Dancourt et al. 2004). The national bowel-screening programme in England was initiated in 2006 for all adults aged 60-69 and subsequently extended to up to ages 74 (Morris, Whitehouse et al. 2012).

This element of the thesis aims to describe the temporal trends at a population level in the number of CRC diagnoses, one-year mortality from time of diagnosis, 90-day post-surgical mortality, and the number of patients not receiving a major resection within 12 months of diagnosis.

	Initiatives
1995	Calman-Hine report – “Policy Framework for Commissioning Cancer Services”
1997	Department of Health (DoH) publishes “Improving Outcomes in Colorectal Cancer” – clinical practice guideline
2000	DoH launches “The NHS Cancer Plan” (10 year plan) NICE issues guidance on the use of liquid based cytology for cervical screening
2002	Breast screening extended to older women – up to age 70
2004	National Institute for Health and Care Excellence (NICE) updates ‘Improving Outcomes in Colorectal Cancers’. Introduces composition of colorectal cancer MDT
2006	Pilot - NHS Bowel Screening Programme – achieved nationwide coverage in 2010 (for ages 60-74)
2007	NHS launches - Cancer Reform Strategy (5 year plan). Also publishes impact assessment for the strategy
2008	The National Cancer Intelligence Network (NCIN)
2009	National database for radiotherapy treatment and outcomes
2010	DoH publishes “Equity and Excellence- Liberating the NHS” Cancer Drugs Fund
2012	Health and Social Care Act 2012 is enacted

Table 1: Select key initiatives related to cancer services

Methods

Others have described the HES database in detail (Faiz, Warusavitarne et al. 2009). Briefly, it contains patient level demographic, diagnosis and surgical data of all patients admitted to the National Health Service hospitals in England. Information was extracted from HES on all patients diagnosed with a first primary colon (International Classification of Diseases Version 10 (ICD10) code C18-19) or rectal (ICD10 code C20) cancer in England between Jan 1 2000 - 31 December 2010. This database was accessed at the Unit of Healthcare Epidemiology, Nuffield Department of Population Health, University of Oxford. Information based on inpatient care was extracted on age, date of admissions, date of surgery, date of death, diagnostic codes and surgical codes. Patients were checked for the existence of a primary CRC resection as defined by Classification of Interventions and Procedures version 4 (OPCS4) within 12 months of the date of their first admissions. Cases were included if the relevant diagnosis and surgical codes appeared in the records fell within the study period i.e. 2001-2010.

Patients were analysed based on three age groups i.e. ≤ 59 years, 60-74 years and ≥ 75 years and time to an event in three intervals i.e. 0-29 days (1 month), 1-3 months (30-89 days) and 3-12 months (90-364 days). The events were (i) time from diagnosis to death (ii) time from diagnosis to surgery and (iii) time from surgery to death. These were calculated and tabulated separately for patients with colon and rectal cancers. Patients were categorised as “no surgery within 1 year” if no primary resection was identified within one year from the date of admissions. Data were analysed using chi-square test and coefficient of determination. For tests of significance, p values

<0.05 were considered significant. Statistical analyses were carried out using SPSS Version 16.0 (SPSS Inc.) and Microsoft Excel.

Results

Diagnosis

This study indicates overall for every 3 persons diagnosed with colon cancer there are 2 persons diagnosed with rectal cancer (Figure 1). By proportion an average of 61% are diagnosed with colon cancer and 39% with rectal cancer. This trend has remained stable from 2001-2010. Within the study period 203,641 and 124,531 individuals had a first inpatient admission with primary diagnosis of colon or rectal cancer respectively (Table 2). As Table 2 shows there has been a 20.8% increase in the combined total colon and rectal cancer diagnoses over the study period. There has been an overall rise in both cancers since 2003 (Figure 2).

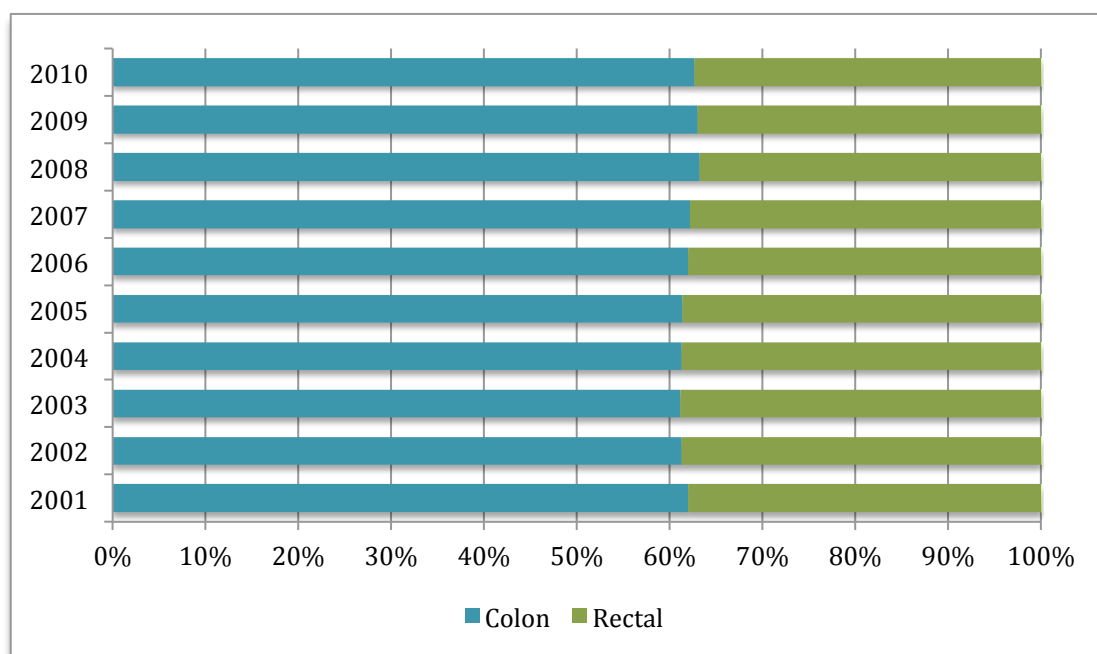


Figure 1: Proportion of colon and rectal cancer diagnosis in England, 2001 - 2010.

Year	Colon	Rectal	Total
2001	18634	11444	30078
2002	18514 (-0.64%)	11707 (2.3%)	30221 (0.48%)
2003	18519 (0.03%)	11753 (0.39%)	30272 (0.17%)
2004	19132 (3.31%)	12098 (2.93%)	31230 (3.16%)
2005	19701 (2.97%)	12406 (2.55%)	32107 (2.81%)
2006	20483 (3.97%)	12564 (1.27%)	33047 (2.93%)
2007	21064 (2.84%)	12823 (2.06%)	33887 (2.54%)
2008	22399 (6.34%)	13023 (1.56%)	35422 (4.53%)
2009	22418 (0.08%)	13166 (1.10%)	35584 (0.46%)
2010	22777 (1.60%)	13547 (2.90%)	36324 (2.10%)
Total	203641	124531	328172

Table 2: Colon and rectal cancer population. Numbers in parenthesis denote percentage change in comparison to previous year.

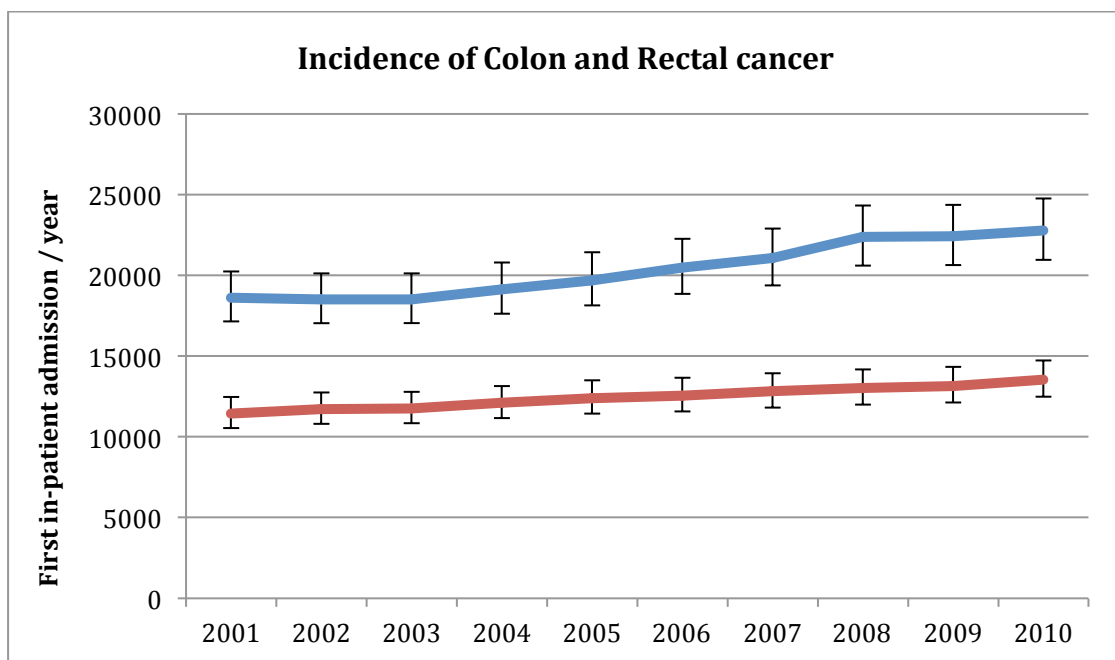


Figure 2: Colon and rectal cancer diagnosis in England, 2001-2010.

Table 3 shows 83.2% of patients diagnosed with CRC are aged 60 and above. And within these the largest portion (45.3%) of patients diagnosed with colon cancer lies in the ≥ 75 years age group and 43% within 60-74 years old for rectal cancer. See Appendix 1 for details on age-related diagnoses.

	≤ 59 years	60-74 years	≥ 75 years	Total
Colon	31,078 (15.3%)	80,423 (39.4%)	92,140 (45.3%)	203,641 (100%)
Rectal	24,209 (19.4%)	53,427 (43%)	46,895 (37.6%)	124,531 (100%)
Total	55,287 (16.8%)	133,850 (40.8%)	139,035 (42.4%)	328,172 (100%)

Table 3: Age related colon and rectal cancer diagnosis, 2000-2010.

Figure 3a shows there was a significant rise in the number of patients diagnosed with colon (10%) and rectal (14%) cancer aged ≤ 59 years for the study period (colon $\chi^2(9) = 69.56$; $p < .001$, rectal $\chi^2(9) = 51.41$; $p < .001$).

There was also a significant increase in incidence for both colon (27%) and rectal (27%) cancers for patients aged 60-74 years (colon $\chi^2(9) = 842.14$; $p < .001$, rectal $\chi^2(9) = 329.71$; $p < .001$) (Figure 3b). Likewise Figure 3c indicates a significant trend over time for colon (23%) and rectal (11%) cancers in patients aged ≥ 75 years (colon $\chi^2(9) = 548.28$; $p < .001$, rectal $\chi^2(9) = 54.77$; $p < .001$).

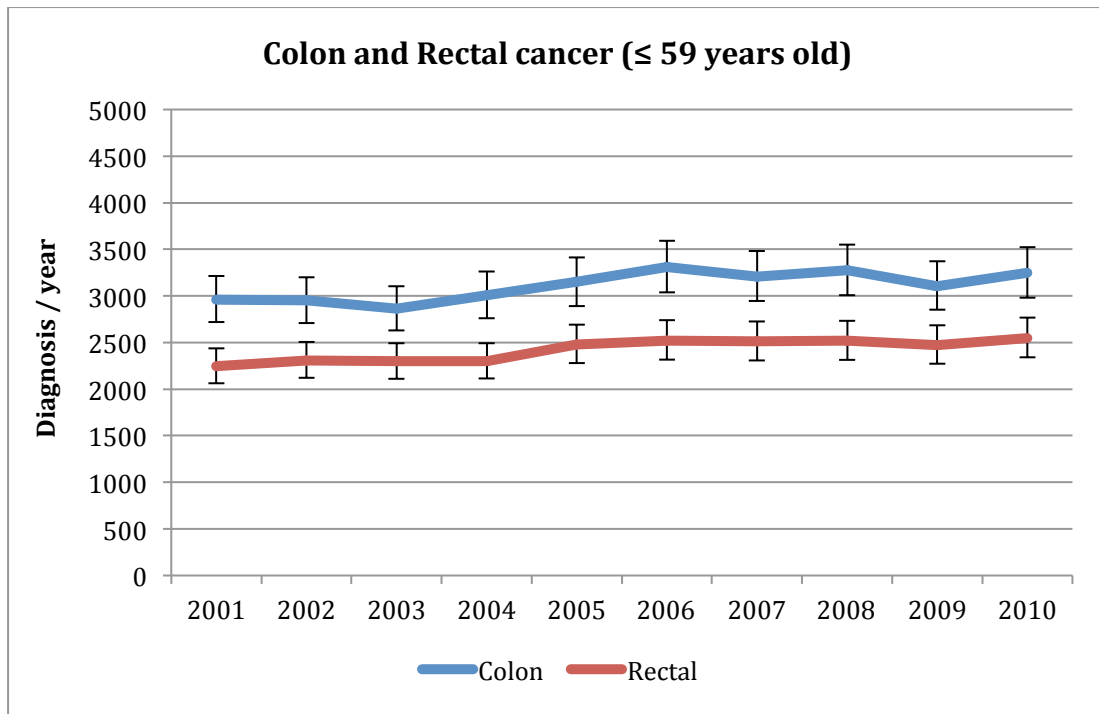


Figure 3a: Patients aged ≤ 59 years diagnosed with colon and rectal cancer, 2001-2010.

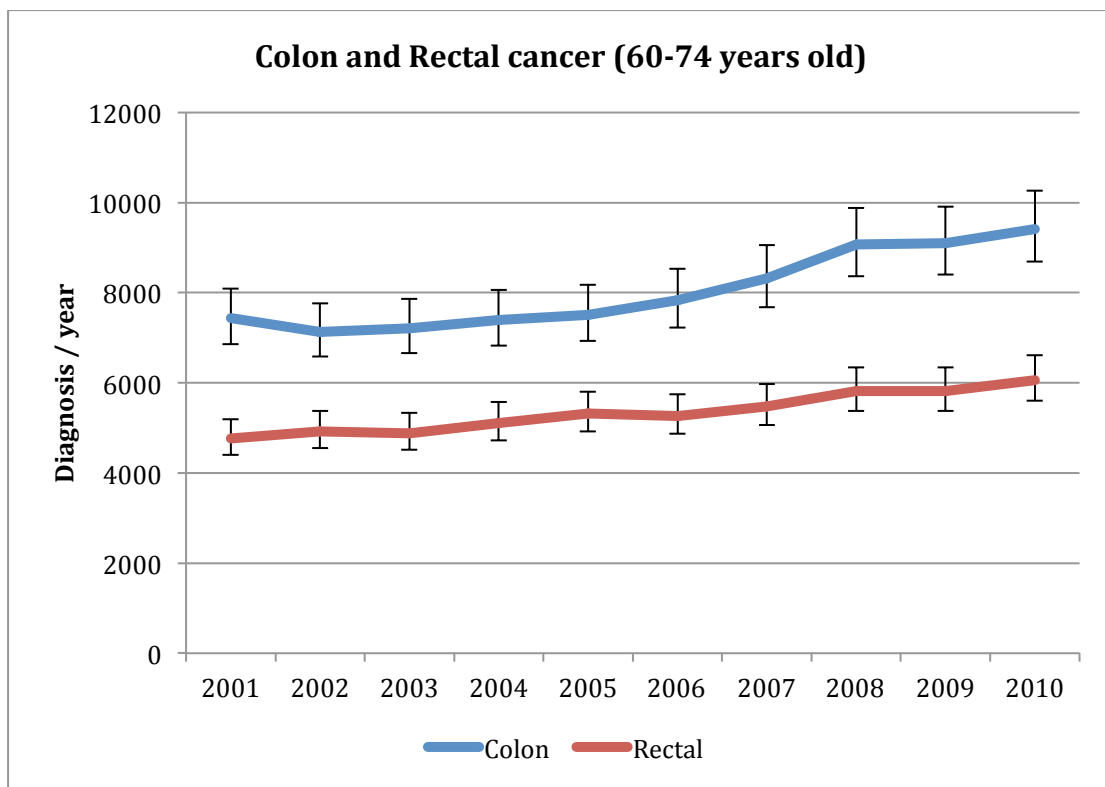


Figure 3b: Patients aged 60-74 years diagnosed with colon and rectal cancer, 2001-2010.

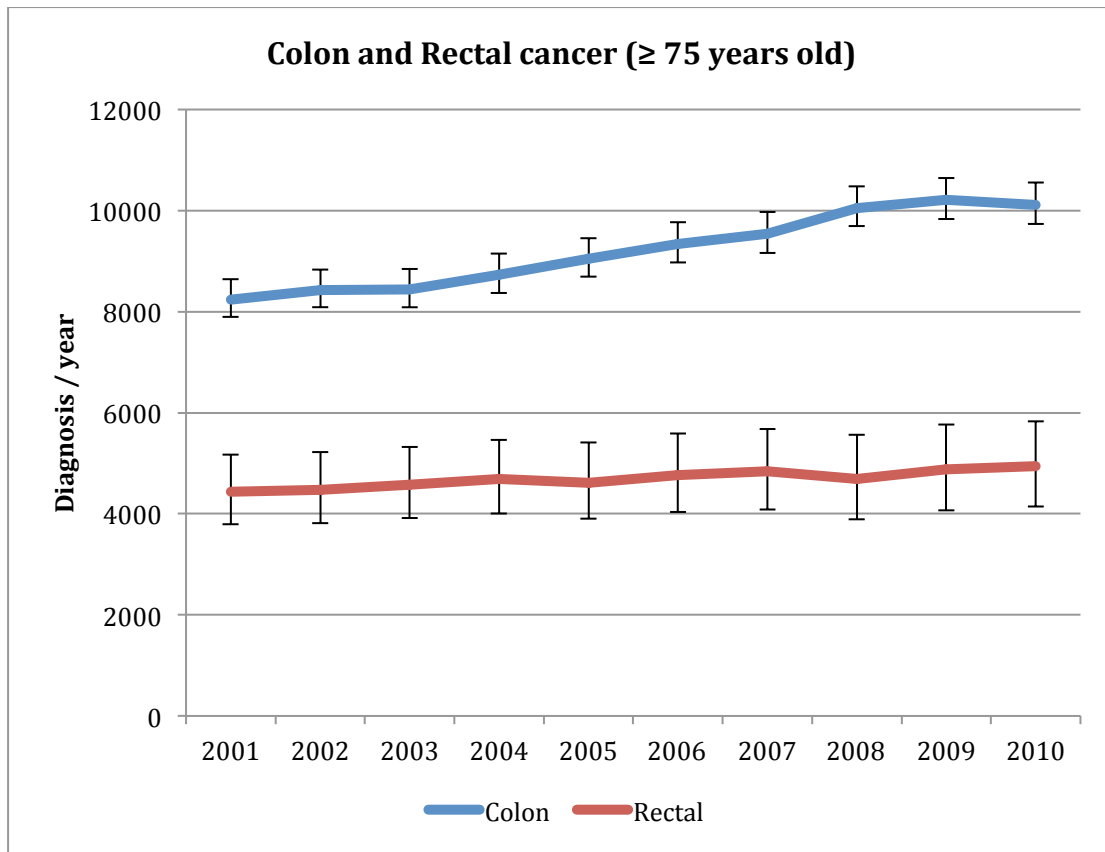


Figure 3c: Patients aged ≥ 75 years diagnosed with colon and rectal cancer, 2001-2010.

1-year mortality from diagnosis

Over the study period there was a significant rise in 1-year mortality from the time of diagnosis for both colon (23%) and rectal (11%) cancers (colon $\chi^2(9) = 456.27$; $p < 0.05$; rectal $\chi^2(9) = 40.94$; $p < 0.05$) (Figure 4). See Appendix 2 for details on patient count.

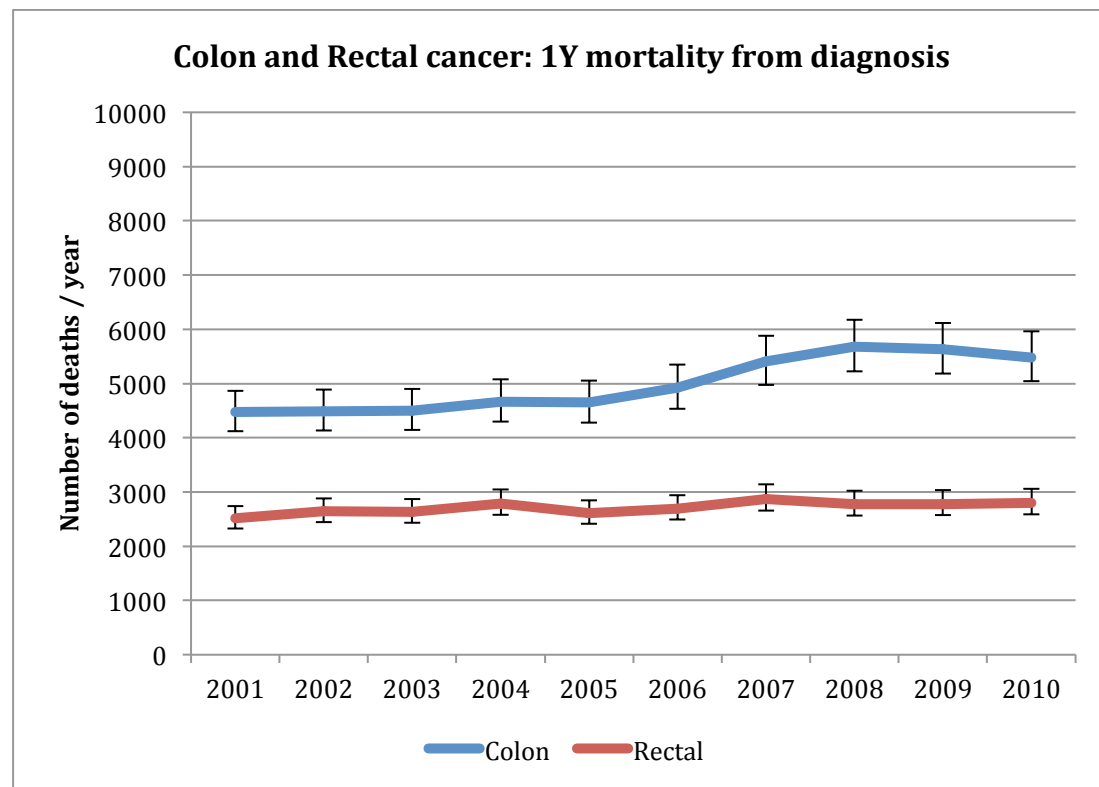


Figure 4: Mortality within 1-year from the time of colon and rectal cancer diagnosis, 2001-2010.

Age-related

Figure 5a shows that over the study period there was no significant increase in mortality within 1-year from diagnosis for patients with colon and rectal cancer aged ≤ 59 years (colon $\chi^2(9) = 13.32$; $p > .05$, rectal $\chi^2(9) = 3.91$; $p > .05$).

Figure 5b shows over time mortality was significant in patients aged 60-74 years diagnosed with colon and rectal cancer (colon $\chi^2(9) = 44.14$; $p < .05$, rectal cancer $\chi^2(9) = 21.25$; $p < .05$). Also there was a significant rise in both colon (41%) and rectal (15%) cancer mortalities for individuals aged ≥ 75 years (colon $\chi^2(9) = 543.62$; $p < .05$), rectal $\chi^2(9) = 38.98$; $p < .05$) (Figure 5c).

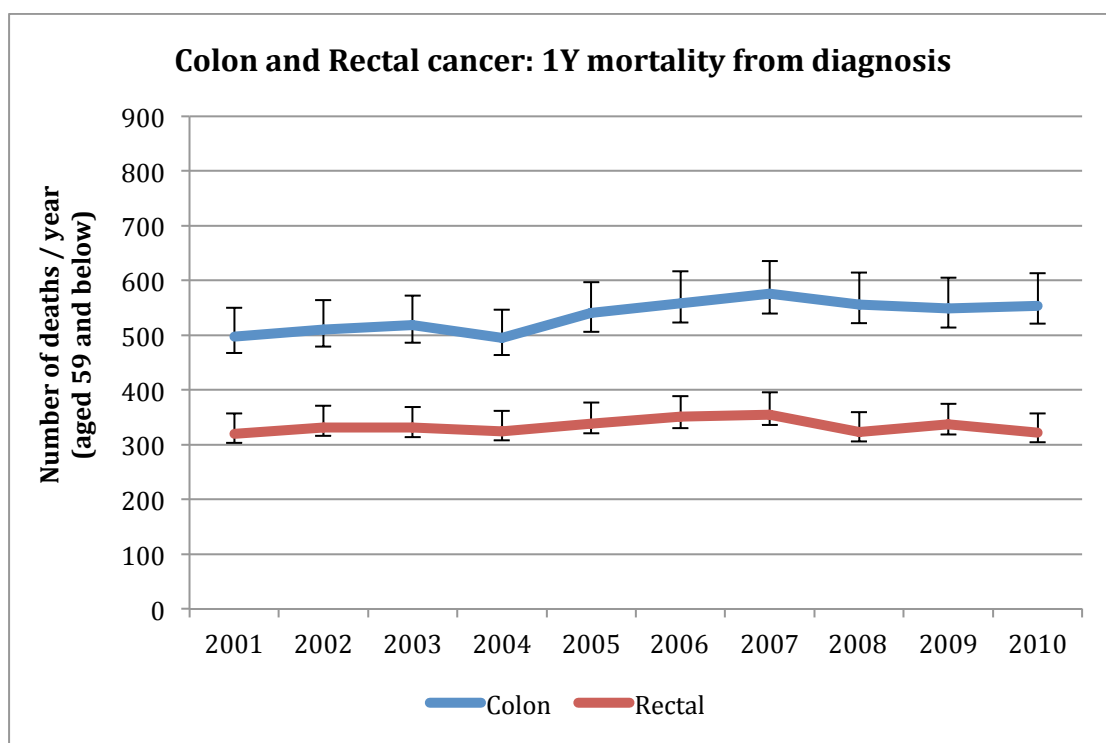


Figure 5a: Mortality within 1-year from colon and rectal cancer diagnosis in patients ≤ 59 years, 2001-2010.

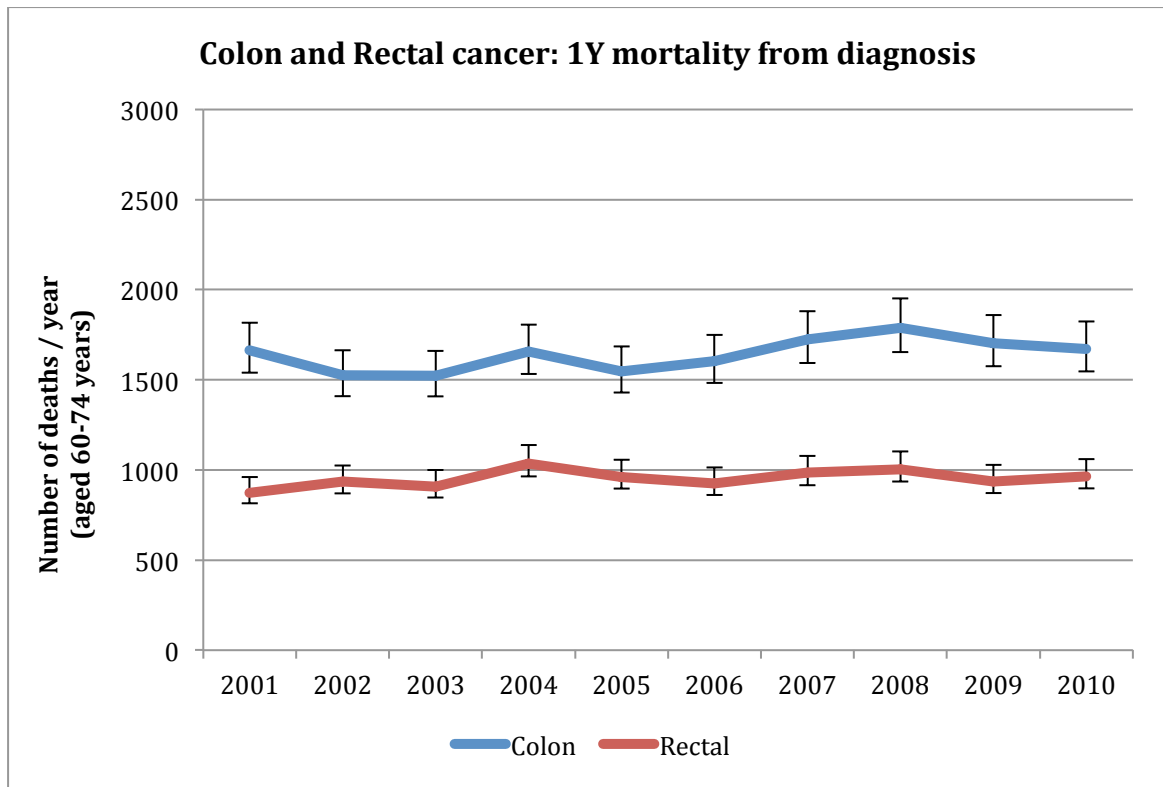


Figure 5b: Mortality within 1-year from colon and rectal cancer diagnosis in patients aged 60-74 years, 2001-2010.

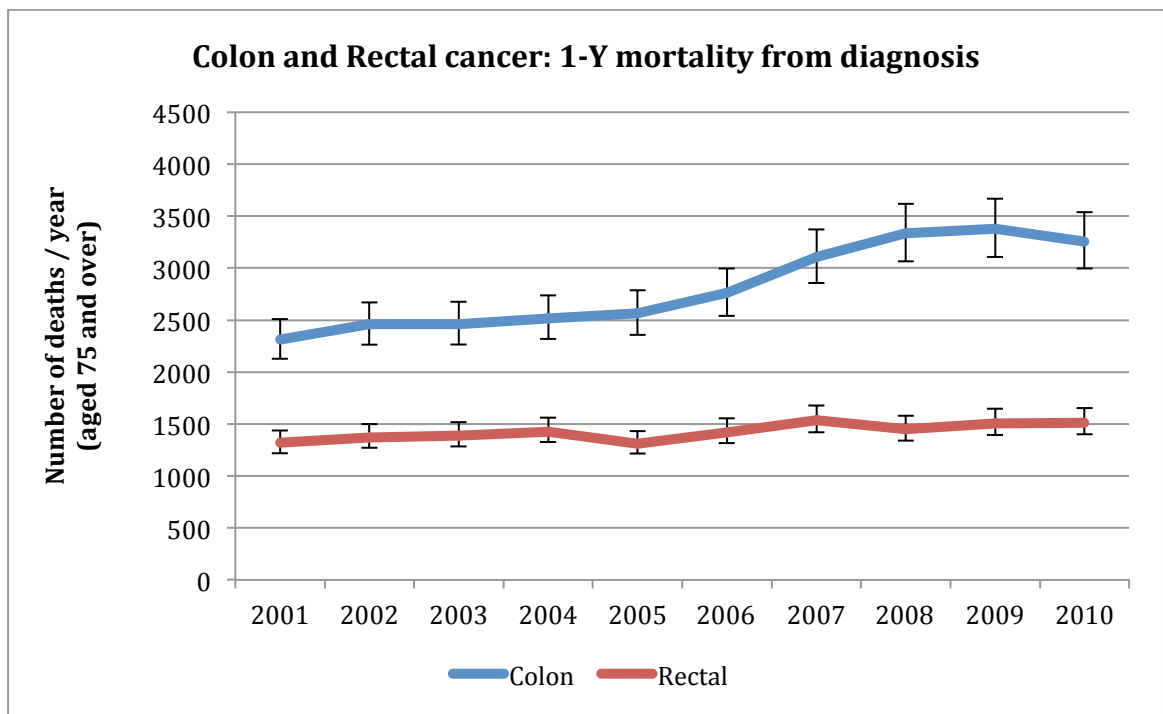


Figure 5c: Mortality within 1-year from colon and rectal cancer diagnosis in patients ≥ 75 years old.

Surgical care

Not receiving surgery

Table 4a shows only 42% of colon cancer patients undergo a major resection within 12 months from diagnosis and 47% for rectal cancer. No significant difference is observed in the proportion of patients not receiving surgery across all age groups for both cancers (Colon χ^2 (2) = 0.76; $p > .05$, Rectal χ^2 (2) = 3.75; $p > .05$) (Appendix 3).

Over time there was a significant age-related increase in the number of patients with colon cancer not receiving a major resection within 1-year of diagnosis (≤ 59 years - 10% increase; χ^2 (9) = 212.49; $p < .05$, 60-74 – 19%; χ^2 (9) = 205.58; $p < .05$ and ≥ 75 years – 28%; χ^2 (9) = 308.12; $p < .05$) (Figure 6a). The results for rectal cancer showed similar significant age-related increase (≤ 59 years – 24% increase; χ^2 (9) = 57.85; $p < .05$, 60-74 years – 25%; χ^2 (9) = 116.95; $p < .05$, and ≥ 75 years – 24%; χ^2 (9) = 108.20; $p < .05$) (Figure 6b).

Surgeries performed

A total of 118,059 major colon cancer and 66,277 rectal cancer surgeries were undertaken within one year of diagnosis (Table 4a). Of these, major colon cancer resections are taken earlier than rectal resections (colon χ^2 (2) = 12107; $p < .001$, rectal cancer χ^2 (2) = 3732; $p < .001$). 76% of colon cancer resections are performed ≤ 1 month from diagnosis and correspondingly 54% for rectal cancer.

Results in Table 4b reveal no significant difference between age and the time taken to undergo major colon or rectal resection.

Colon cancer					
	≤ 1month	1-3 month	3-12 month	No surgery w/in 1 year of diagnosis	Total
≤59	14314	3216	503	13045	31078
60-74	37235	11571	1246	30371	80423
≥75	37925	10899	1150	42166	92140
Rectal cancer					
	≤1 month	1-3 month	3-12 month	No surgery w/in 1 year of diagnosis	Total
≤59	7193	3348	3702	9966	24209
60-74	16610	8500	6713	21604	53427
≥75	11840	5687	2684	26684	46895

Table 4a: Colon and rectal cancer population in relation to time from diagnosis to surgery.

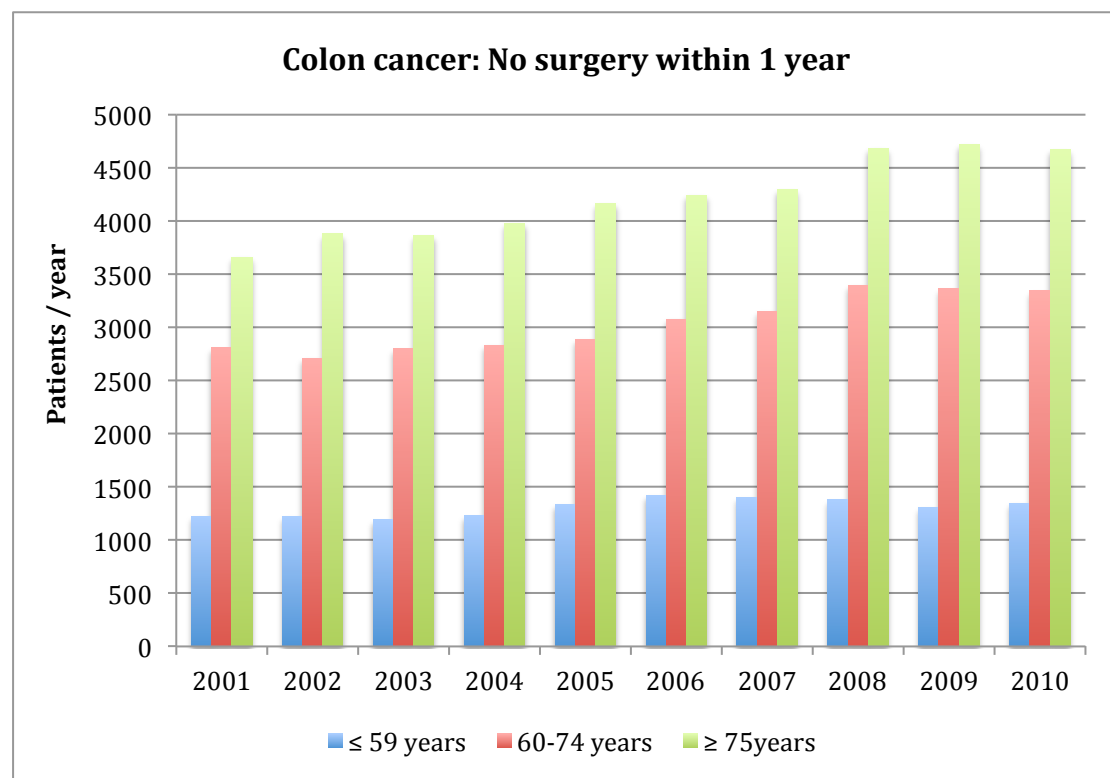


Figure 6a: Patients with colon cancer not receiving major surgery within 1-year of diagnosis, 2001-2010.

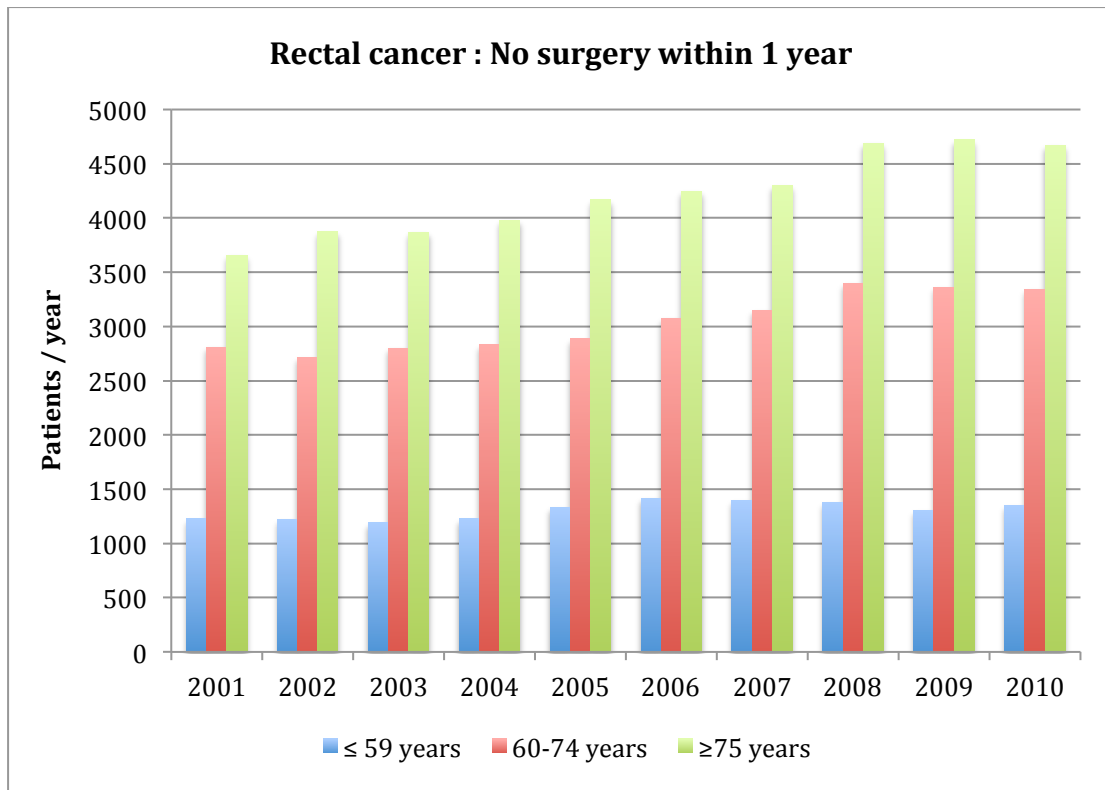


Figure 6b: Patients with rectal cancer not receiving major surgery within 1-year of diagnosis, 2001-2010.

*Colon cancer proportions				
	≤ 1month	1-3 month	3-12 month	Significance
≤59	46.1	10.3	1.6	$\chi^2 (2) = 0.32, p > .05$
60-74	46.3	14.4	1.5	$\chi^2 (2) = 0.60, p > .05$
≥75	41.2	11.8	1.2	$\chi^2 (2) = 0.55, p > .05$
Significance	$\chi^2 (2) = 0.4, p > .05$	$\chi^2 (2) = 0.7, p > .05$	$\chi^2 (2) = 0.1, p > .05$	
*Rectal cancer proportions				
	≤1 month	1-3 month	3-12 month	Significance
≤59	29.7	13.8	15.3	$\chi^2 (2) = 1.83, p > .05$
60-74	31.1	15.9	12.6	$\chi^2 (2) = 1.79, p > .05$
≥75	25.2	12.1	5.7	$\chi^2 (2) = 3.18, p > .05$
Significance	$\chi^2 (2) = 0.7, p > .05$	$\chi^2 (2) = 0.5, p > .05$	$\chi^2 (2) = 4.4, p > .05$	

Table 4b: Colon and rectal proportions in relation to time from diagnosis to surgery.* Proportions based on figures in Table 4a.

Post-surgical mortality

The decline in 90-day post-surgical mortality in colon (40%) and rectal (35%) cancer was significant (colon $\chi^2(9) = 95.49$; $p < .05$; rectal $\chi^2(9) = 69.18$; $p < .05$) (Figure 7). See Appendix 4 for details on patient count.

Table 5 shows there are no significant differences in 1-year post-surgical mortality amongst patients with colon and rectal cancer. Highest percentage of case fatalities for both cancers occurs within 3-12 months of surgery.

Table 6 shows there is significant age-related difference in mortality in the ≤ 1 month for both cancers and at 3-12 months for colon cancer. Post-surgical mortality is highest amongst the oldest group of patients.

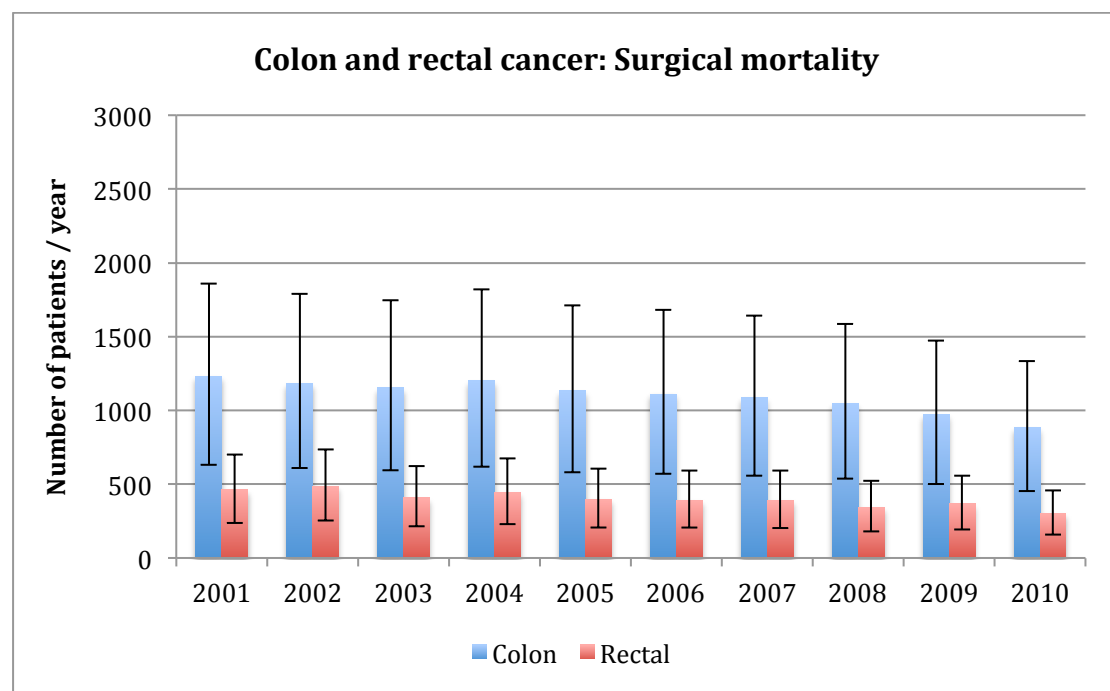


Figure 7: Colon and rectal cancer - 90-day post-surgical mortality, 2001-2010.

	≤1 month	1-3 month	3-12 month	Total post-surgical death (TD)	Total surgeries (TS)
Colon	7286 (6%)	3709 (3%)	10809 (9%)	21804	118541
Rectal	2581 (4%)	1406 (2%)	4236 (6%)	8223	66244
Percentage (TD/TS)	Colon = 18%		Rectal = 12%		$\chi^2 (2) = 1.91$, p > .05

Table 5: Colon and rectal cancer patients in relation to post-surgical mortality. Figures in parenthesis are percentage of deaths against total surgeries performed.

	≤ 1 month		1-3 months		3-12 months			
	Colon	Rectal	Colon	Rectal	Colon	Rectal	Total "colon deaths"	Total "rectal deaths"
≤ 59	297 (15%)	157 (17%)	337 (17%)	125 (14%)	1392 (69%)	632 (69%)	2026 (100%)	914 (100%)
60-74	1962 (27%)	835 (27%)	1239 (17%)	515 (17%)	4026 (58%)	1748 (56%)	7227 (100%)	3098 (100%)
≥ 75	5027 (40%)	1589 (38%)	2133 (17%)	766 (18%)	5391 (43%)	1856 (44%)	12551 (100%)	4211 (100%)
Total	7286 (33%)	2581 (31%)	3709 (17%)	1406 (17%)	10809 (50%)	4236 (52%)	21804 (100%)	8223 (100%)
χ^2	11.4	8.07	0	0.53	6	5.6		
p value	p < .001	p < .01	p > .05 non-sig	p > .05 non-sig	p < .05	p > .05 non-sig		

Table 6: Colon and rectal cancer patients in relation to time from surgery to death.

Colorectal cancer spend

As mentioned earlier in the chapter, cancer care has received substantial funding to improve its services since the implementation of the Cancer Plan in 2000. As an adjunct to the above study data, observations between CRC spend and patient outcomes were undertaken. Public Health England (PHE) provided the data on reported CRC spend by Primary Care Trusts (PCTs) for periods 2007 to 2012 alongside with reported 1-year relative survival for 2005-2009.

Figure 8 shows for six years, 2006/7 to 2011/12, the difference in reported CRC spend (PCTs are ordered from low to high for each year). The shifts in the curves reflect changes in the level of spending on CRC over time. Appendix 5 details each PCTs reported CRC spend.

Table 7 shows variation in CRC spend in all years across all PCTs. A 134-fold variation in spend is seen in 2006/07, reduced drastically to 21-fold by 2011/12. The table also shows spending data is normally distributed with approximately 82% of PCTs within one standard deviation above or below from the arithmetic mean spend. Figure 9 shows the highest 1-year survival rate observed was 81% and 66% the lowest. (Appendix 6 provides details on 1-year relative survival as per PCTs). Figure 10 and those in Appendix 7 show there is absolutely no correlation between CRC reported spend and 1-year relative survival.

These measures suggest that utilisation of financial resources is a poor predictor of either CRC survival or clinical practice. It is also difficult to gauge

from these data the optimal spend, since the spread in expenditure is substantially larger than the difference in 1-year relative survival.

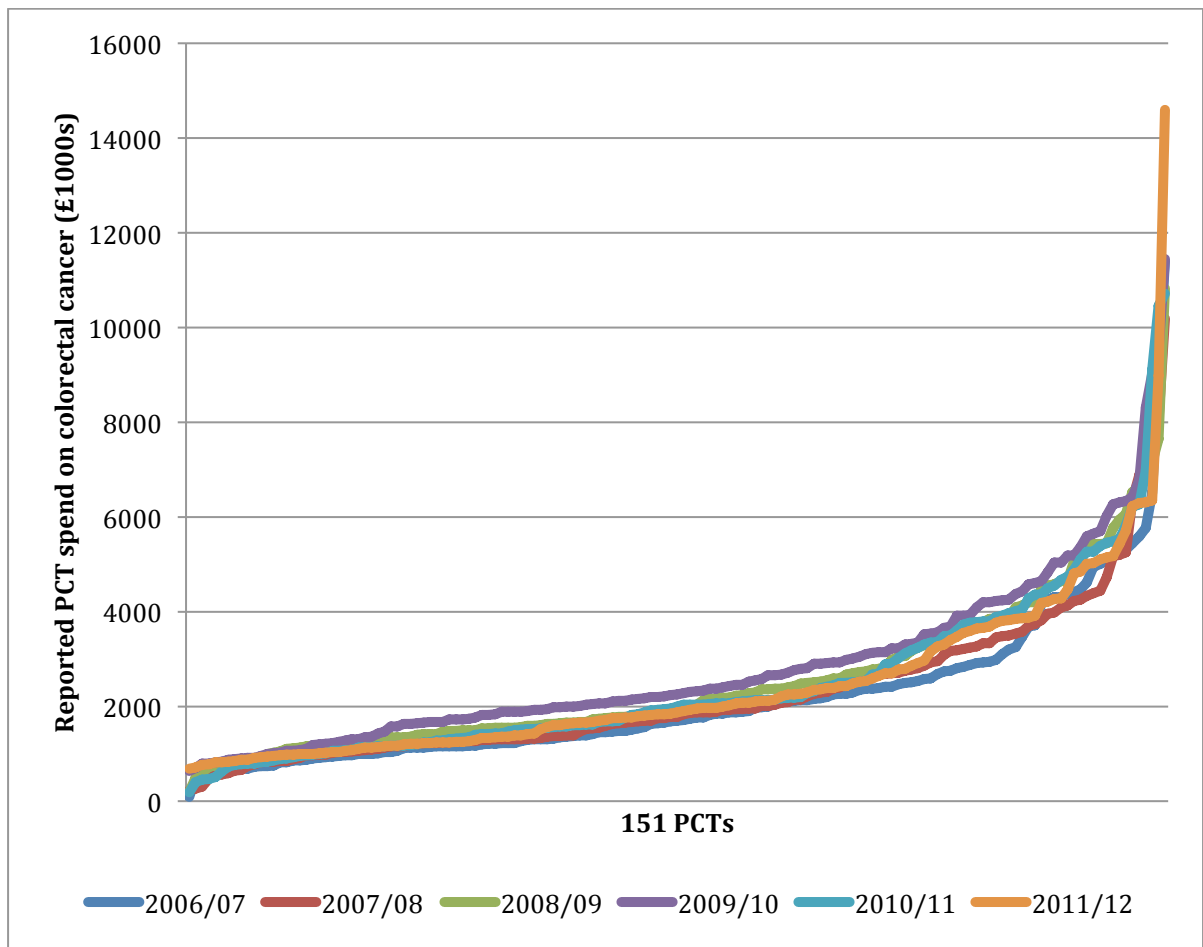


Figure 8: Colorectal cancer spend trend 2006/07 to 2011/12.

	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12
Total spend (£1000s)	326102	340000	382457	423851	372530	363589
Average	2160	2252	2533	2807	2467	2408
95% CI	2154 - 2165	2246 - 2257	2528 - 2538	2802 - 2812	2461 - 2473	2402 - 2414
Min (£)	85	231	197	638	187	680
Max (£)	11406	10193	10830	11447	10722	14600
Variation	134.2	44.1	54.9	17.9	57.3	21.5
Standard Deviation	1611	1595	1688	1810	1796	1777

Table 7: Colorectal cancer spend across 151 PCTs. Data source: PHE.

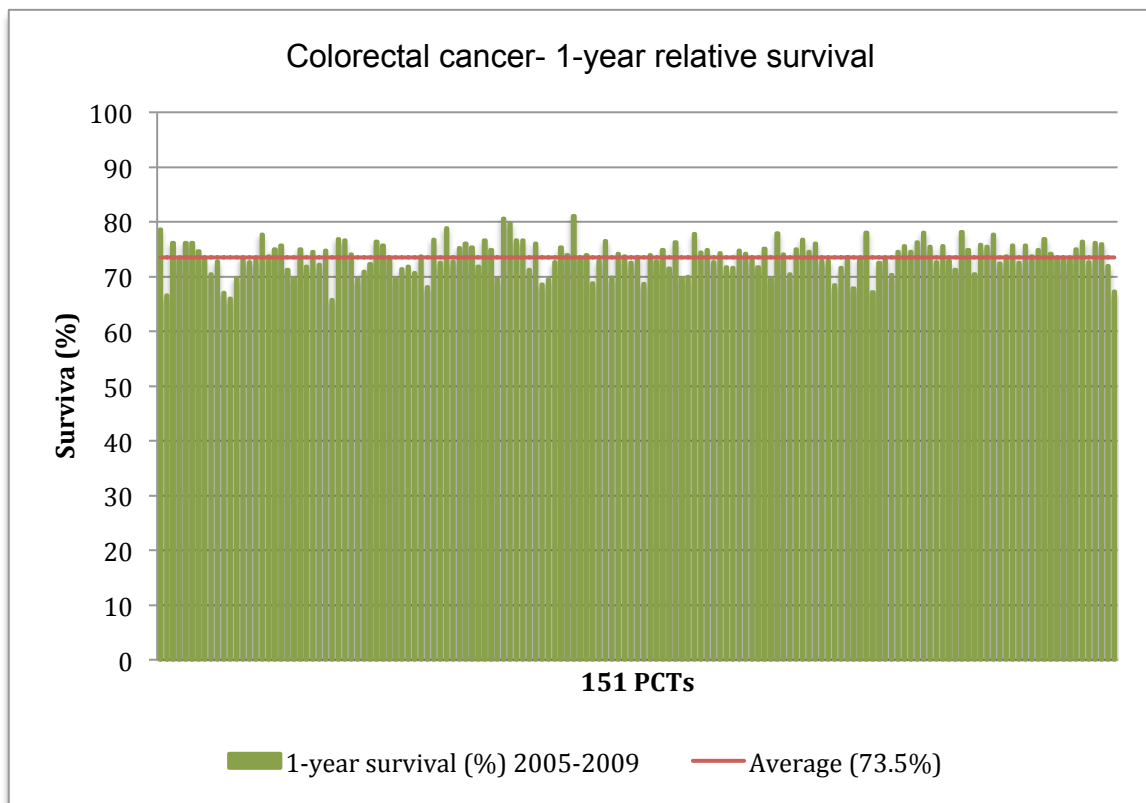


Figure 9: Colorectal cancer - 1-year relative survival (2005-2009) across 151 PCTs. Data source: PHE.

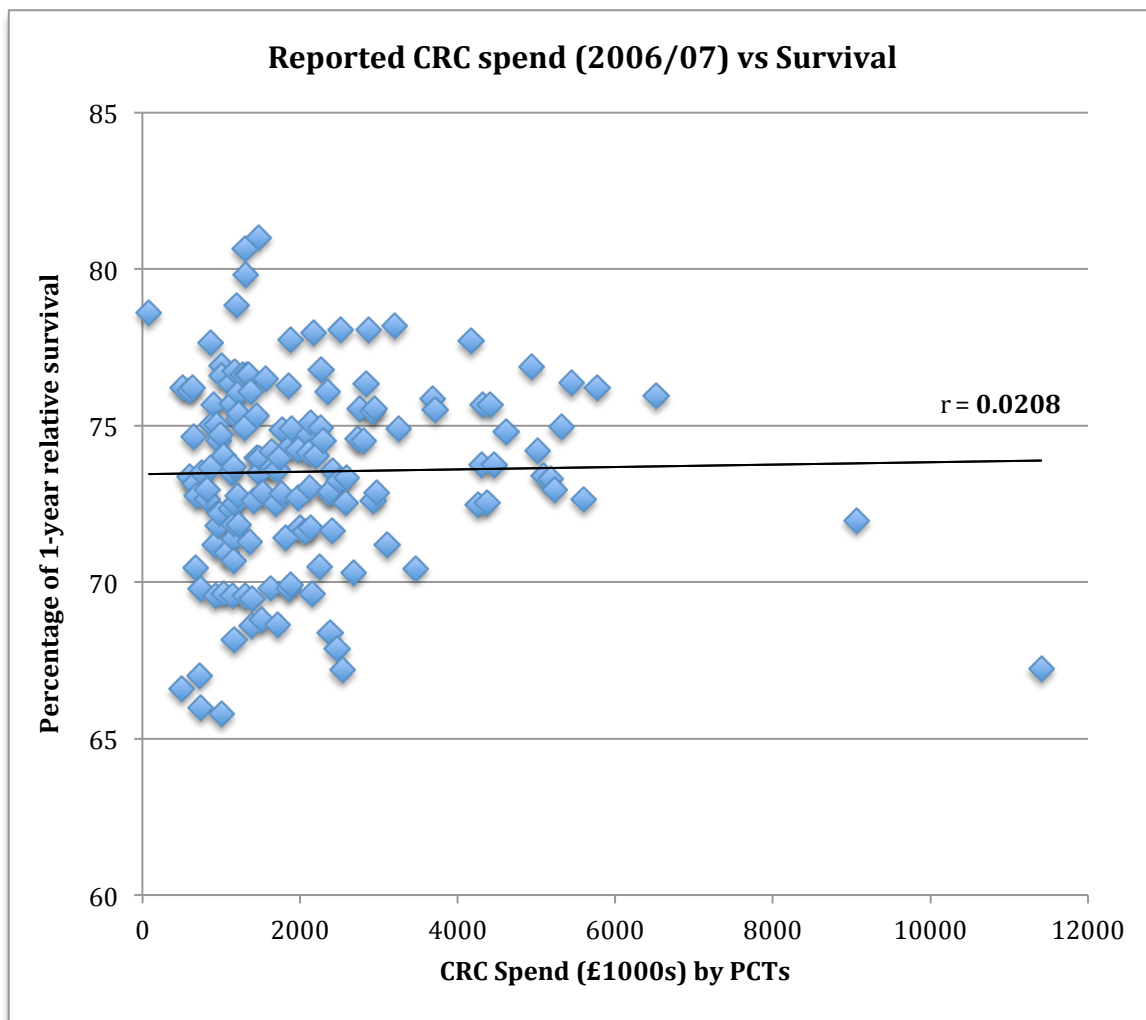


Figure 10: Reported 2006/07 CRC spend across 151 PCTs against 1-year relative survival. Data source: PHE

Discussion

There is a significant upward trend in the number of diagnoses of colon and rectal cancers across all age groups in the study period. The introduction of the Bowel Screening programme and CRC MDTs could have contributed to the increase in diagnoses. The post world war II baby boomers (born ca. 1946) ([\[ARCHIVED CONTENT\] UK Government Web Archive – The National Archives](#)) are also in the age group that could be affected by CRC, as the data above shows that the majority of patients are 60 years old and above. This age-related increase in diagnoses is also seen in other studies (Morris, Taylor et al. 2011, [Bowel cancer statistics | Cancer Research UK](#)) The proportion of patients diagnosed with colon cancer to rectal cancer remained largely consistent over the study period.

Overall approximately 20% of the combined CRC study population died within 1-year of diagnosis. Unsurprisingly this mortality is greatest in patients aged ≥ 75 since close to one third die within 1-year of diagnosis. Elderly CRC patients (aged ≥ 75) also have higher 30-day post-surgical mortality, which maybe explained in part by presentation with more advanced disease and perhaps compromised health status with multiple comorbidities (De Marco, Janssen-Heijnen et al. 2000, Janssen-Heijnen, Maas et al. 2007). Results from another study specifically looking at thirty-day postoperative mortality after CRC surgery in England showed that patients are more likely to die postoperatively if they were older (greatest if > 80 years), presented with advanced tumour stage, had multiple comorbidities, and came from greater socioeconomic deprivation (Morris, Taylor et al. 2011).

As the bowel-screening programme does not cover the elderly cohort, it increases the likelihood of them presenting with advanced disease which may affect their preferences and treatment decisions. The HES database does not have reliable stage at presentation information so it is not possible to provide further insights into the reason for this apparently increased mortality in the elderly.

Studies have demonstrated that approximately 20% of patients' diagnosed with colon or rectal cancer present with stage 4, advanced disease at their first diagnosis (Downing 2013, Hu, Bailey et al. 2015). Another study reviewing patients between 2006-2008 indicated 23% of both colon and rectal cancer patients did not receive any surgery (Downing 2013). The 2016 National Bowel Cancer Audit reports 37% of bowel cancer patients did not undergo major resection and suggest these patients can be divided into three broad categories: (i) Too little cancer (Stage 1), (ii) Too much cancer (stage 4) and (iii) Too frail. However the audit also reports that 16% of patients could not be classified (, National Bowel Cancer Audit - Health & Social Care Information Centre)

There is a significant increase in the number of CRC patients not receiving surgery within 1-year of diagnosis. This could be because of better patient selection and patient preferences. However it may also be suggestive of 'underuse of treatment' and as per Wennberg's definition it is an unwarranted variation (Wennberg, Gittelsohn 1973). (Note: Details of Wennberg's definitions and related areas are discussed in Chapter 4). Thus there is no indication that The Cancer Plan, and its subsequent funding and strategies

over the study period have ameliorated this potential underuse. This issue of patient selection within clinical practice requires further study, particularly amongst the elderly.

Although the dominant focus of these analyses has been on temporal trends of mean values, it is interesting to note that the standard deviations have not changed over time. One might predict that the Cancer Plan investments would have the dual effect of improving average clinical outcome figures and reducing the degree of variation around these, however there is no evidence of this.

A significant number of rectal cancer patients receive their surgery later than those diagnosed with colon cancer. Suggesting the possibility that these patients undergo neoadjuvant treatment e.g. radiotherapy and a wait and see approach to assess tumour response in line with clinical evidence (Habr-Gama, Perez et al. 2006, Maas, Beets-Tan et al. 2011, MERCURY Study Group 2006).

Other studies have shown advanced chronological age by itself should not be viewed as a negative prognostic factor for those fit for major CRC surgery (Basili, Lorenzetti et al. 2008, Puig-La Calle Jr, Quayle et al. 2000, Devon, Vergara-Fernandez et al. 2009, Chiang, Chen et al. 2003, Papamichael, Audisio et al. 2009). Results here have shown that there is no significant age-related difference when individuals receive their CRC surgery.

A substantial portion of 1-year post-surgical mortality takes place within 90 days of surgery across all age groups. However the 90-day post-surgical

mortality shows a downward trend. This may be associated with better diagnostics, improved selection of surgical procedures and more effective MDT working.

This study has shown that 1-year relative survival between 2005-2009 has remained stable across PCTs notwithstanding the substantial variation in spend. Since these are reported expenditures it is possible that it is under reported through inappropriate coding or by bundling costs where it becomes difficult to definitely allocate specific costs. Nevertheless the cancer spend data shows no links between financial resource utilisation and 1-year CRC survival. And by implication it suggest clinical practice is not necessarily associated with cancer spend.

One limitation of this study is the HES database itself. The quality and accuracy of coding data within the HES database has been previously raised (Audit Commission for Local Authorities and the National Health Service in England and Wales 2008, Garout, Tilney et al. 2008). Another possible limitation is that the study population is not case-adjusted. These may relate to factors pertaining the patient (e.g. disease stage or types of comorbidities) or the service provider (e.g. availability of specialised MDT, specialisation of operating team, quality and availability of post-surgical care). Another limitation was that data for 2011-2015 was not available for the study. This period would have shown the impact of the National Bowel Screening programme that went nationwide from 2010. However given the trends and possible underuse of treatment these results should not be dismissed.

Conclusion

This study has shown that ten years since the funding and implementation of The Cancer Plan the number of patients possibly undertreated i.e. not receiving surgery has not abated and requires to be monitored to make improvements.

The rise in mortality amongst the elderly patients and variation in spend unrelated to outcome requires to be assessed. Because the study could not exclude possible confounders in clinical case-mix, particularly stage, between age groups and tumour site, its primary value is in hypothesis generating. Nevertheless its findings have value vis-à-vis clinical practice with regard to the framework on unwarranted variation, which is discussed in Chapter 4 of this thesis.

Appendix 1

Colon cancer diagnoses across age groups			
	0-59 years	60-74 years	75 and over
2001	2962	7434	8238
2002	2950	7131	8433
2003	2863	7216	8440
2004	3007	7394	8731
2005	3149	7510	9042
2006	3310	7831	9342
2007	3208	8320	9536
2008	3275	9069	10055
2009	3107	9102	10209
2010	3247	9416	10114

Rectal cancer diagnoses across age groups			
	0-59 years	60-74 years	75 and over
2001	2246	4761	4437
2002	2309	4923	4475
2003	2298	4884	4571
2004	2299	5109	4690
2005	2479	5319	4608
2006	2523	5270	4771
2007	2513	5471	4839
2008	2520	5815	4688
2009	2472	5817	4877
2010	2550	6058	4939

Appendix 2: 1-year mortality counts from the time of colon and rectal cancer diagnosis

1-year mortality from diagnosis			
	Colon cancer	Rectal cancer	Total
2001	4474 (64%)	2514 (36%)	6988
2002	4493 (63%)	2640 (37%)	7133
2003	4504 (63%)	2629 (37%)	7133
2004	4669 (63%)	2789 (37%)	7458
2005	4650 (64%)	2611 (36%)	7261
2006	4923 (65%)	2698 (35%)	7621
2007	5409 (65%)	2876 (35%)	8285
2008	5680 (67%)	2775 (33%)	8455
2009	5632 (67%)	2780 (33%)	8412
2010	5481 (66%)	2801 (34%)	8282

1-year mortality from diagnosis (≤ 59 years)			
	Colon cancer	Rectal cancer	Total
2001	498 (61%)	320 (39%)	818
2002	510 (61%)	332 (39%)	842
2003	519 (61%)	331 (39%)	850
2004	495 (60%)	325 (40%)	820
2005	541 (62%)	338 (38%)	879
2006	559 (61%)	351 (39%)	910
2007	576 (62%)	355 (38%)	931
2008	556 (63%)	323 (37%)	879
2009	549 (62%)	337 (38%)	886
2010	554 (63%)	322 (37%)	876

1-year mortality from diagnosis (60-74 years)			
	Colon cancer	Rectal cancer	Total
2001	1665 (66%)	873 (34%)	2538
2002	1524 (62%)	935 (38%)	2459
2003	1523 (63%)	909 (37%)	2432
2004	1656 (62%)	1035 (38%)	2691
2005	1546 (62%)	962 (38%)	2508
2006	1603 (63%)	925 (37%)	2528
2007	1724 (64%)	984 (36%)	2708
2008	1789 (64%)	1004 (36%)	2793
2009	1703 (65%)	936 (35%)	2639
2010	1671 (63%)	965 (37%)	2636

1-year mortality from diagnosis (≥ 75 years)			
	Colon cancer	Rectal cancer	Total
2001	2311 (64%)	1321 (36%)	3632
2002	2459 (64%)	1373 (36%)	3832
2003	2462 (63%)	1389 (37%)	3851
2004	2518 (64%)	1429 (36%)	3947
2005	2563 (66%)	1311 (34%)	3874
2006	2761 (66%)	1422 (34%)	4183
2007	3109 (67%)	1537 (33%)	4646
2008	3335 (70%)	1448 (30%)	4783
2009	3380 (69%)	1507 (31%)	4887
2010	3256 (65%)	1514 (35%)	5040

Appendix 3

Colon cancer – No surgery w/in 1-year of diagnosis				
	≤ 59 years	60-74 years	≥ 75 years	Total
2001	1226	2810	3658	7694
2002	1223	2712	3879	7814
2003	1191	2798	3865	7854
2004	1227	2834	3977	8038
2005	1331	2885	4166	8382
2006	1417	3076	4243	8736
2007	1398	3150	4299	8847
2008	1377	3398	4686	9461
2009	1307	3364	4721	9392
2010	1348	3344	4672	9364
Total (A)	13045	30371	42166	
Grand total (B)	31078	80423	92140	
A/B (%)	42.0%	37.8%	45.8%	

Rectal cancer – No surgery w/in 1-year of diagnosis				
	≤ 59 years	60-74 years	≥ 75 years	Total
2001	891	1916	2378	5185
2002	919	2009	2472	5400
2003	883	1942	2502	5327
2004	944	2134	2650	5728
2005	1058	2190	2623	5871
2006	1020	2145	2712	5877
2007	1071	2206	2834	6111
2008	1037	2294	2740	6071
2009	1039	2367	2831	6237
2010	1104	2401	2942	6447
Total (A)	9966	21604	26684	
Grand total (B)	24209	53427	46895	
A/B (%)	41.2%	40.4%	56.9%	

Appendix 4: 90-day post-surgical mortality

	90-day post-surgical mortality	
	Colon cancer	Rectal cancer
2001	1231	464
2002	1181	485
2003	1153	407
2004	1201	444
2005	1132	398
2006	1111	389
2007	1085	388
2008	1047	344
2009	973	367
2010	881	301
Total	10995	3987

Appendix 5: Reported PCT spend on colorectal cancer 2006/7-2011/12

Name	Reported spend (1,000s) – colorectal cancer					
	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12
South Gloucestershire PCT	1004	1305	1417	1997	2132	1136
Havering PCT	1389	1652	1417	2003	1578	1908
Kingston PCT	930	1267	756	1102	1173	1023
Bromley PCT	1826	1942	1860	2246	1412	2257
Greenwich Teaching PCT	2736	1693	2506	4196	2060	1075
Barnet PCT	1294	1307	1476	3306	403	877
Hillingdon PCT	1221	2952	1552	1257	1493	1761
Enfield PCT	1851	2087	2591	2063	187	996
Barking and Dagenham PCT	1478	1158	1658	1303	767	1032
City and Hackney Teaching PCT	599	558	605	1013	1012	1146
Tower Hamlets PCT	1301	1226	1411	1073	1084	831
Newham PCT	865	829	732	1227	1063	868
Haringey Teaching PCT	2153	1671	1675	2207	455	776
Herefordshire PCT	1476	1364	2131	1354	2151	1664
Milton Keynes PCT	919	1158	1326	1060	1957	1600
Newcastle PCT	1715	231	2697	2659	2205	1695
North Tyneside PCT	1351	480	1770	1634	2117	2253
Hartlepool PCT	603	646	889	962	866	984
Stockton-on-Tees Teaching PCT	1067	1223	1316	1423	1869	1874
North Lincolnshire PCT	824	1022	850	2193	1188	1243
Nottingham City PCT	659	1836	1919	2174	3915	3264
Bassetlaw PCT	637	852	1174	1307	627	1221
Plymouth Teaching PCT	1153	1194	1541	1469	1826	1935
Salford Teaching PCT	2874	1756	2298	2772	1511	1812
Stockport PCT	2295	2015	2594	2902	1337	1362
Portsmouth City Teaching PCT	1308	985	845	1003	723	977
Bath and North East Somerset PCT	1200	1383	1175	1643	925	932
Luton Teaching PCT	1362	820	1120	1030	1311	1300
Hammersmith and Fulham PCT	1688	1302	197	793	830	846
Rotherham PCT	1000	1866	2040	2660	2035	1841
Ashton, Leigh and Wigan PCT	2495	2532	3064	3681	2052	2081
Blackpool PCT	679	302	1588	2199	899	1251
Bolton PCT	1377	2292	1196	2813	3342	4468
Ealing PCT	1174	2579	2285	3100	3122	2000
Hounslow PCT	1889	1939	1488	2283	1682	1632
Warrington PCT	1631	2713	2739	1205	1517	995
Knowsley PCT	1031	1046	822	1061	796	818
Oldham PCT	1218	1293	1817	2110	1543	1330
Calderdale PCT	905	1935	1027	1365	1148	951
Darlington PCT	1156	746	496	911	796	974
Barnsley PCT	999	2678	2189	2452	1241	1218
Bury PCT	958	1271	1368	2011	984	1385
Swindon PCT	1157	1292	1350	916	1060	1206
Brent Teaching PCT	1459	1872	1354	2374	2133	1761
Harrow PCT	863	591	772	823	1284	1342
Camden PCT	1383	829	1330	1727	471	719
Islington PCT	1533	1593	1787	1724	503	680

Croydon PCT	1741	1758	1607	1883	1467	2107
Gateshead PCT	2069	1324	1668	1213	1676	1832
South Tyneside PCT	1876	1473	2239	1837	963	1337
Sunderland Teaching PCT	2414	2546	3786	2908	2095	2425
Middlesbrough PCT	942	1038	1049	908	1199	1265
Southampton City PCT	1165	850	1544	1770	1416	919
Medway Teaching PCT	1223	1033	1193	1629	1433	2425
Kensington and Chelsea PCT	686	1377	1152	1574	816	770
Westminster PCT	990	2140	1890	3326	1345	1226
Lambeth PCT	1771	1227	1341	1941	781	1799
Southwark PCT	1486	1069	1106	1730	998	1602
Lewisham PCT	1267	973	1665	2427	1165	1390
Wandsworth PCT	1125	1083	1248	1672	1425	1749
Tameside and Glossop PCT	1324	2013	1400	2149	1562	1718
Brighton and Hove City Teaching PCT	517	1243	1627	1184	1554	2029
South Birmingham PCT	2803	2034	3470	2402	2284	2783
Shropshire County PCT	1877	1650	2371	1666	2446	2921
Walsall Teaching PCT	2352	5201	2799	3149	1682	2141
Richmond and Twickenham PCT	1033	265	850	638	1074	1131
Sutton and Merton PCT	2135	1786	2521	3222	2544	1956
North Somerset PCT	738	546	1351	1274	1941	1824
Coventry Teaching PCT	2203	1634	1750	2927	1618	1749
Telford and Wrekin PCT	649	658	1212	697	2067	1242
Wolverhampton City PCT	1706	916	1590	2057	1913	2080
Heart of Birmingham Teaching PCT	1209	1273	1000	1978	1132	1005
Leeds PCT	4615	3955	5448	5366	5532	5714
Kirklees PCT	2266	3583	2431	3354	2038	2356
Wakefield District PCT	749	2650	3550	3664	3310	2642
Sheffield PCT	2977	4096	4549	4832	2186	2477
Doncaster PCT	2575	4128	2982	3014	1617	1667
Derbyshire County PCT	5313	4396	4653	5041	6218	6233
Derby City PCT	1654	1538	3422	1885	1165	1166
Nottinghamshire County Teaching PCT	2838	3341	4089	6031	4744	3692
Lincolnshire Teaching PCT	11406	10193	10830	11447	5101	4288
Redbridge PCT	2127	1958	1650	2305	1277	1409
Waltham Forest PCT	2175	967	1964	1736	1173	1566
County Durham PCT	5179	4255	3851	6273	4504	5151
Cumbria PCT	5599	4340	4585	5036	3728	3308
North Lancashire PCT	2383	2262	2397	3921	2040	2298
Central Lancashire PCT	1897	3092	2732	3223	3761	3910
East Lancashire PCT	3713	2686	1939	2459	2496	1852
Sefton PCT	2263	3210	3167	2708	1992	1964
Wirral PCT	2247	2750	2381	2339	3192	2120
Liverpool PCT	2376	3168	2546	3142	3499	3470
Halton and St. Helens PCT	2470	2146	1737	2125	2064	2118
Western Cheshire PCT	1451	1694	1559	1924	1173	1359
Central and Eastern Cheshire PCT	3102	2925	3297	4428	3977	3663
Heywood, Middleton and Rochdale PCT	1133	1327	1500	1571	953	1168
Trafford PCT	1414	1385	2184	1888	1523	1965
Manchester PCT	3470	3267	3575	4237	1830	2214
North Yorkshire and York PCT	4259	3817	5413	6303	6264	6304
East Riding Of Yorkshire PCT	976	1883	2482	2675	2422	2069

Hull Teaching PCT	496	2379	1780	2583	2177	1521
Bradford and Airedale Teaching PCT	2372	2813	4199	4381	4017	3398
South East Essex PCT	85	1302	1478	795	2387	1968
Bedfordshire PCT	965	1871	2491	2551	2320	2794
Surrey PCT	5236	4723	6531	9028	9102	14600
West Sussex Teaching PCT	3684	5170	3780	6802	10457	4185
East Sussex Downs and Weald PCT	2104	1545	2231	2930	3895	3816
Hastings and Rother PCT	1640	1197	1625	1935	2530	2699
West Kent PCT	4940	4450	3433	4226	5274	6297
Leicestershire County and Rutland PCT	5014	3237	4471	3936	4275	5178
Leicester City Teaching PCT	2411	1242	1780	1672	1404	1655
Northamptonshire Teaching PCT	4306	3485	5435	5644	4052	3555
Dudley PCT	2944	2310	3237	3135	3783	2693
Sandwell PCT	1977	1960	3332	2796	2188	2394
Birmingham East and North PCT	4314	2787	4200	4091	3793	3878
North Staffordshire PCT	879	1308	1243	2119	1702	1069
Stoke On Trent Teaching PCT	1118	2218	2177	2911	3023	2263
South Staffordshire PCT	4376	3492	5765	6418	4364	5014
Worcestershire PCT	4169	3737	5072	4642	3795	3766
Warwickshire PCT	4464	3338	3880	5183	3483	3846
Peterborough PCT	821	1130	832	833	1604	824
Cambridgeshire PCT	2590	3541	3049	3916	5270	5030
Norfolk PCT	6515	8040	5950	4196	5458	1154
Great Yarmouth and Waveney Teaching PCT	2000	3454	2362	1977	1773	1427
Suffolk PCT	2929	3978	5170	5700	6991	6351
West Essex PCT	1304	1517	1834	1820	2107	2521
North East Essex PCT	2123	1337	1727	2316	2887	2856
Mid Essex PCT	1973	2405	2368	3055	2666	3592
South West Essex Teaching PCT	1563	1872	2006	2058	2689	2597
Eastern and Coastal Kent Teaching PCT	4410	6885	5424	5588	4671	5106
Hampshire PCT	9064	7566	7146	9515	10722	8983
Buckinghamshire PCT	2759	2865	4661	4577	5487	3812
Oxfordshire PCT	2684	2705	2785	3519	4356	4262
Berkshire West PCT	1764	1688	2154	2155	2128	3856
Berkshire East Teaching PCT	2103	1925	1499	1905	1605	2342
Gloucestershire PCT	5088	5251	7017	4602	4556	4210
Bristol Teaching PCT	1222	1786	2677	2985	2502	1258
Wiltshire PCT	2516	4228	3888	3567	3368	2531
Somerset PCT	2920	2675	6630	3539	3604	3153
Dorset PCT	2536	3702	4138	4248	3236	3650
Bournemouth and Poole Teaching PCT	3252	2080	2839	2373	2511	2383
Cornwall and Isles Of Scilly PCT	3202	3189	3867	5182	4895	4847
Devon PCT	5446	7214	7643	8316	5826	4810
Redcar and Cleveland PCT	739	1161	1495	869	1327	1245
Isle of Wight Healthcare PCT	1148	1097	1535	1815	1141	1109
Hertfordshire PCT	5771	6353	6062	6340	5395	5437
Northumberland Care Trust	1854	780	3629	2518	2900	2969
Bexley PCT	1510	1371	1549	2044	2032	948

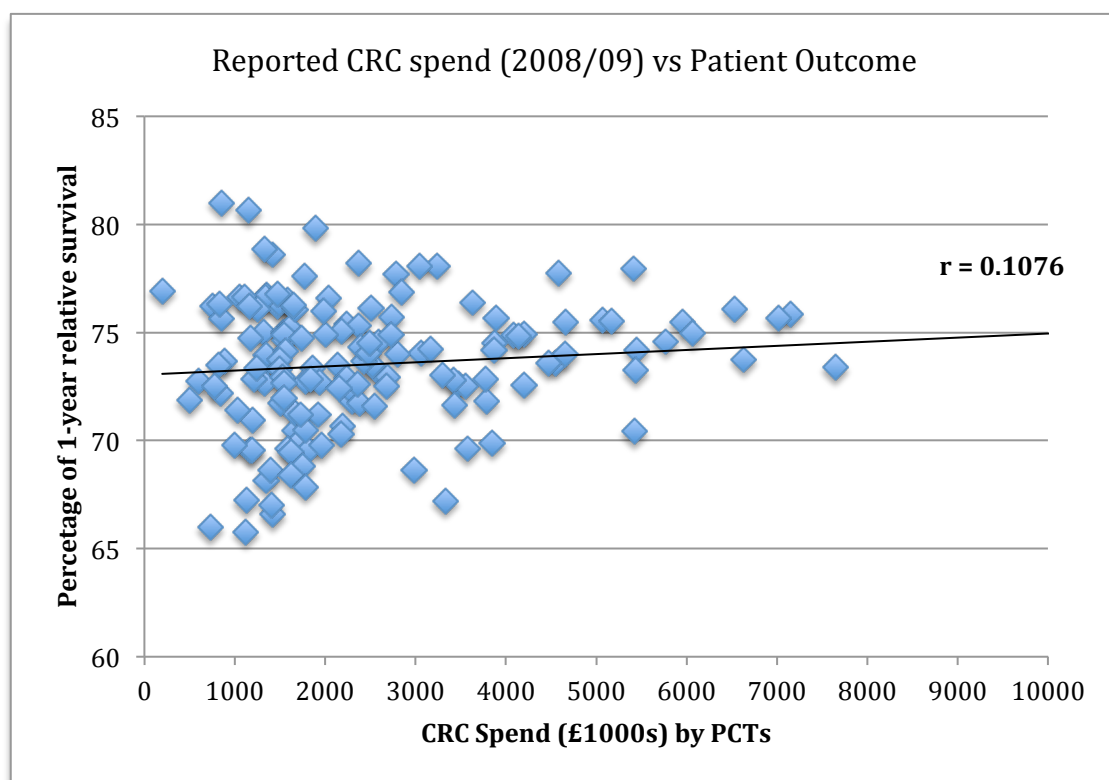
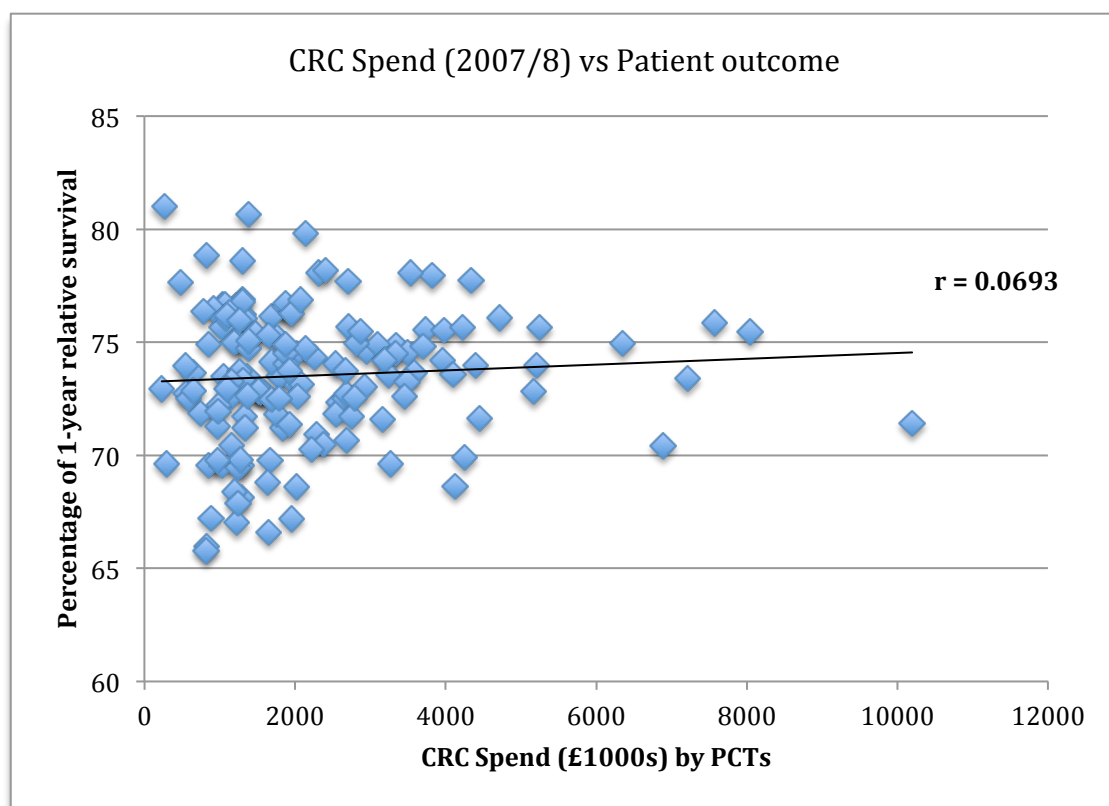
Torbay Care Trust	1158	1102	1167	1885	1245	1039
Solihull Care Trust	1130	1267	1984	2248	1576	1199
North East Lincolnshire PCT	726	980	1548	1652	1933	1641
Blackburn with Darwen Teaching PCT	1175	887	1130	887	888	990

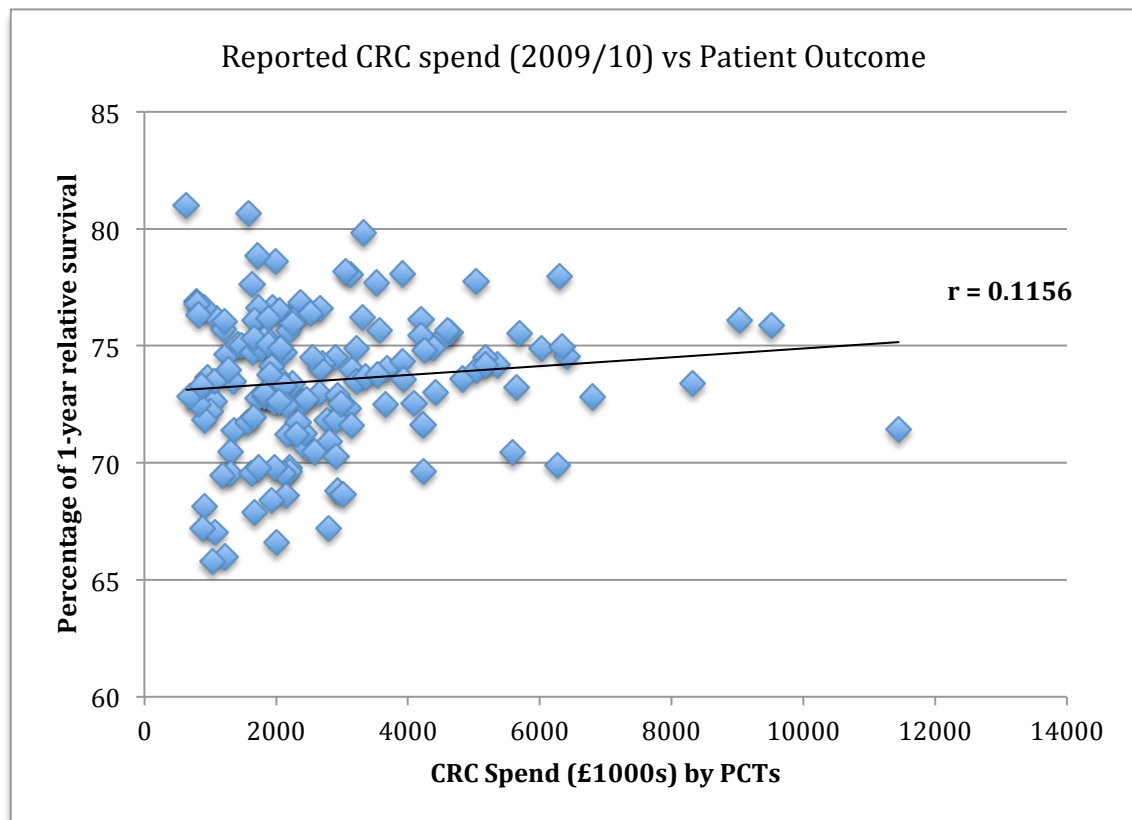
Appendix 6: 1-year relative survival 2005-2009 as per PCTs

Geog. code	Survival (%)	5K6	72.5	5NJ	74.24
5A3	78.6	5K7	78.84	5NK	71.73
5A4	66.59	5K8	72.77	5NL	71.59
5A5	76.2	Geog. code	Survival (%)	5NM	74.71
5A7	73.36	5K9	75.22	5NN	74.12
5A8	76.13	5KF	76.04	5NP	73.02
5A9	76.21	5KG	75.36	Geog. code	Survival (%)
5AT	74.62	5KL	71.83	5NQ	71.73
5C1	73.14	5KM	76.64	5NR	75.07
5C2	70.46	5L1	74.91	5NT	69.64
5C3	72.74	5L3	69.55	5NV	77.96
5C4	67.01	5LA	80.65	5NW	74.03
5C5	65.97	5LC	79.82	5NX	70.48
5C9	69.78	5LD	76.63	5NY	74.94
5CN	73.48	5LE	76.64	5P1	76.78
5CQ	72.64	5LF	71.27	5P2	74.5
5D7	72.95	5LG	76.07	5P5	76.07
5D8	77.63	5LH	68.61	5P6	72.82
5D9	73.65	5LQ	69.46	5P7	72.88
5E1	75.03	5M1	72.6	5P8	68.39
5EF	75.65	5M2	75.32	5P9	71.63
5EM	71.2	5M3	73.98	5PA	73.57
5ET	69.55	5M6	81.01	5PC	67.86
5F1	75.01	5M7	73.48	5PD	73.24
5F5	71.81	5M8	73.96	5PE	78.06
5F7	74.53	5MD	68.8	5PF	67.2
5FE	72.19	5MK	72.84	5PG	72.55
5FL	74.71	5MV	76.49	5PH	73.32
5GC	65.78	5MX	69.8	5PJ	70.28
5H1	76.91	5N1	74.18	5PK	74.56
5H8	76.6	5N2	73.66	5PL	75.55
5HG	74.03	5N3	72.5	5PM	74.5
5HP	69.63	5N4	73.59	5PN	76.32
5HQ	70.92	5N5	68.64	5PP	78.07
5HX	72.33	5N6	73.98	5PQ	75.45
5HY	76.34	5N7	72.8	5PR	72.61
5J2	75.69	5N8	74.87	5PT	75.52
5J4	73.48	5N9	71.42	5PV	72.84
5J5	69.55	5NA	76.27	5PW	71.2
5J6	71.39	5NC	69.78	5PX	78.18
5J9	71.85	5ND	69.9	5PY	74.89
5JE	70.67	Geog. code	Survival (%)	5QA	70.43
5JX	73.69	5NE	77.74	5QC	75.85
Geog. code	Survival (%)	5NF	74.34	5QD	75.5
5K3	68.14	5NG	74.9	5QE	77.69
5K5	76.74	5NH	72.7	5QF	72.45
				5QG	73.74

5QH	75.67
5QJ	72.52
5QK	75.66
5QL	73.74
5QM	74.82
5QN	76.87
5QP	74.19
5QQ	73.4
5QR	73.29
5QT	72.95
5QV	74.95
TAC	76.37
TAK	72.64
TAL	76.2
TAM	75.96
TAN	71.96
TAP	67.22

Appendix 7: Reported colorectal cancer spend vs. 1-year relative survival





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Chapter 3: Workings of MDTs in colorectal cancer care – data from two specialist centres in England and Sweden

Introduction

The 1995 Calman-Hine report was instrumental in configuring the commissioning of cancer services and the need for multidisciplinary consultations and management for cancer patients in England and Wales (Calman, Hine 1995). The advisory also outlined site specialist consultant surgeons should provide surgical management. It introduced the clinical nurse specialist responsible for specific cancer care. As a consequence of this paradigm-shifting advisory, cancer centres were expected to have a high degree of specialisation and comprehensive provision of all aspects of cancer care. Recommendations on how care should be provided became the catalyst for future multidisciplinary team (MDT) composition and workings. MDTs have been increasingly involved in cancer care in largely across Europe, the United States and Australasia (Taylor, Munro et al. 2010). The rationale for introducing MDTs was to ensure the collective and integrated involvement of multiple experts required for managing complex diseases is undertaken and done so in an efficient manner (Taylor, Munro et al. 2010). MDTs therefore are part and parcel of clinical practice. The impact of the Calman-Hine report on colorectal cancer (CRC) patients has been discussed elsewhere (Morris, Haward et al. 2006) and is not part of this research.

The guidance on improving CRC outcomes in England specified the core composition and operations of the CRC MDT (National Institute for Clinical Excellence 2004a). Some of its key recommendations were:

- All patients either suspected or newly diagnosed with CRC are promptly referred to, and managed by a CRC MDT.
- Ensure patients with potentially resectable liver metastases are referred to specialist MDTs for assessment.
- CRC MDT should involved in management and follow up of emergency patients.
- A team that has surgical expertise trained in all aspects of total mesorectal excision and clinical oncology should manage patients with rectal cancer.
- MDT meetings shall be held weekly.
- MDTs administrative head is usually the lead clinician.
- MDT should seek a distributed leadership for decision-making.

The guidance anticipated the following benefits of MDT working:

- Patients more likely to be offered a range of treatment options at appropriate times and receive seamless care through all stages of their disease.
- Patients are less likely to have lower recurrence rates and more likely to have better long-term survival rates.

Studies show corollary between higher utilisation of preoperative radiotherapy, adjuvant chemotherapy and improved five-year survival in rectal cancer patients and MDT workings (Morris, Haward et al. 2006). Likewise since the introduction of MDTs operative mortality in patients with oesophageal carcinoma fell over fourfold from 26% to 5.7% while 5-year survival improved fivefold, from 10% to 52% (Stephens, Lewis et al. 2006)

and improved two-year survival in head and neck cancer patients (Birchall, Bailey et al. 2004). A UK wide survey of MDT members on the MDT workings found close 90% of respondents agreed that effective teams improve clinical decision-making, take more evidence based approaches and provide improved quality of care (Taylor, Ramirez 2009). It follows that one of the objectives of the CRC MDT is to provide all CRC patients in the UK evidence based care options, irrespective of their disease stage or their place on their care pathway.

The MDT based approach is a paradigm shift in cancer management and it would not be surprising to observe variations in its development and management (Saini, Taylor et al. 2012). Saini et al. reported differences across 39 countries in breast cancer MDTs. Variations were reported in structure and functioning of MDTs, clinical decision-making, composition, and frequency.

Increasingly cancer MDTs can expect to be under further demands to manage more patients given the expected rise in cancer incidence (Ferlay, Shin et al. 2010). Ferlay et al. reported CRC is the third most common cancer in men and second in women worldwide. It accounts for almost 8% of all cancer deaths worldwide, making it fourth most common cause of death from cancer. Close to 60% of cases occur in developed countries. The expected rise in the incidence of CRC and advances in surgical and non-surgical interventions in managing CRC can lead to uncertainties as to the best therapeutic approaches for clinically different patients, and what is considered optimal can differ between countries, institutions and individual clinicians (Rougier,

Neoptolemos 1997a). Nevertheless a MDT based approach is justified in managing CRC given the key ongoing contributions surgery, oncology and radiotherapy provide in evaluating optimal treatment options (Rougier, Neoptolemos 1997a). A recent systematic review on the impact of MDTs found patients discussed at CRC MDTs had (i) better coverage of preoperative staging (ii) a two-fold chance of receiving adjuvant therapy (iii) better 3-year survival rates for Dukes C patients and (iv) higher utilisation of magnetic resonance imaging for staging and (v) TNM staging was more complete (Pillay, Wootten et al. 2016). This review also observed CRC studies did not show details about the structure, frequency and participants of MDT meetings. However given extraneous effects such as organisational structures, streamlining of clinical pathways and others, some circumspection is required when trying to interpret causal links between MDT workings and patient outcomes (Patkar, Acosta et al. 2011). On the other hand MDTs have been suggested to improve coordination of services and be levers of improvement in clinical quality (Fleissig, Jenkins et al. 2006). Nevertheless as mentioned earlier, variations on how MDTs function have been reported. There is no report on how or whether CRC MDTs address unwarranted variations be it within the MDT meetings or treatment pathways. There is little evidence of MDTs addressing unwarranted variation in CRC outcomes (Menon, Cunningham et al. 2016).

Study aims

This mix-method qualitative study tried to understand CRC MDTs workings and their views on unwarranted variation in clinical care. Observations on the workings and interviews of members of CRC MDTs took place at the Churchill

Cancer Hospital, Oxford (OUH) and Sahlgrenska University Hospital (SUH), Gothenburg. Both hospitals are CRC referral centres. The study had the following aims:

- I. To understand the role of MDTs**
- II. To understand MDT workings in providing effective clinical care**
- III. To identify possible drivers of unwarranted variation**

Methods

Development of the questionnaire

A series of discussions between key stakeholders through emails, face-to-face meetings and Skype calls helped develop the questionnaire. After a few iterations, the questionnaire was developed (Appendix 1). It was in English and consisted a total of 12 questions in two parts. One part consisted of 10 fixed open-ended questions and the other two fixed questions required participants to use 1-3 rating scale to answer. The questionnaire was finalised once it was assessed to have face validity based on published literature supporting the relevance of the proposed themes and current MDT functions and structures. Semi-structured interviews approach was taken as an initial basis to explore if MDTs appreciated and accepted the concept of unwarranted variation.

Participants

A purposive non-random sampling of participants was initiated. Participants were members of CRC and Liver MDTs in both hospitals. A total of 30 representative participants took part in this study. Statistical representativeness was not sought in using this sampling approach. This is a common approach in qualitative studies (Britten 1995). Research supervisors

initially contacted all respondents at OUH while Head of Department of Surgery at SUH initiated contact with respondents there. The researcher (Muralee Menon, interviewer) subsequently followed up with the respondents. In all, the participants consisted of eight CRC surgeons, six liver surgeons, six oncologists, three radiologists, one pathologist, three nurses and three administrative assistants/coordinators. All of them participated voluntarily.

Procedure

The study method consisted of two parts; (i) unstructured observations of MDT sessions and (ii) semi-structured interviews. Informal unstructured observations of MDTs enabled the interviewer to develop a better understanding of MDT workings, its participants and structure. This facilitated development of relevant and meaningful open-ended questions for the semi-structured interviews.

The semi-structured interviews approach was taken to enable respondents to give their full opinions, as the topic discussed was deemed complex. In addition there was only one chance to interview the respondents due to their heavy work commitments. Open-ended questions are the preferred method when topics are largely unknown or complex, and can yield accurate data (Bowling 2009). No respondent was given the questionnaire beforehand; only at the time of the interview. This reduced potential bias by respondents. All respondents, when answering questions 10-12 were provided with the same written definitions of unwarranted variation (Appendix 2). All interviews were conducted in English and took place at respondents' choice of location and time. They were made to feel at ease prior to the start of the interview. The

interviews lasted approximately one hour. The interviewer was particularly conscious not to influence responses by either providing personal views, being judgemental or alluding to how respondent's colleagues had answered.

The interviews began with a brief list of questions about the respondent's full name, post in the hospital, type of MDT involvement, how long respondent has been attending the MDT and frequency of the MDT meeting. All answers were manually recorded and read back to the respondent for clarity and confirmation. Interviews were not audio taped, since participants were not comfortable with this. All respondents protected the time they made available for the interview hence there were no interruptions or distractions.

Thematic content

Since this was an observational study the conventional content analysis approach was used to identify emerging themes (Burnard, Gill et al. 2008, Hsieh, Shannon 2005, Pope, Ziebland et al. 2000) In stage 1, interview transcripts were transcribed verbatim and analysed identifying initial emerging themes within the data. Either short phrases or a word that sums up each answer discussed in the transcript is viewed as "initial themes" (Burnard, Gill et al. 2008). Responses that are off topic are uncoded. In stage 2, for purposes of refining the initial themes, informed by analytical and theoretical ideas they are worked through and duplications omitted, resulting in a consolidated set of final themes.

Calculating combined responses for questions 9 & 10

Comparison scores (CS) for questions 9 & 10 are calculated based on total score of a category over maximum possible score (i.e. $CS = \text{total score} / \text{max.}$

possible score). Total score is the sum (Σ) of ratings by all respondents on a category. Maximum possible score (MPS) is the total number of respondents multiplied by maximum rating (i.e. number of respondents * max. rating). For OUH (n=14) its MPS is 42 (14 *3) and for SUH (n=16) it is 48 (16*3). A percentage of their CS provides equivalence.

Calculating individual responses for questions 9 & 10

The percentage of individual response is calculated for each type i.e. Type 1 to 3. These percentages are calculated by adding the number of respondents per their rating divided by total number in the cohort. For example if 7 OUH respondents had given a rating of 1 for a category, then the percentage claiming Type 1 would be 7 / 14 i.e. 50%.

Results

Analysis of the transcripts for Q1 for both cohorts provided the initial emerging themes from the data and is shown in Appendix 3. Three main final themes were identified i.e. (i) expertise and present cases, (ii) clinical quality and (iii) provide expert treatment plan (Tables 1a and 1b).

OUH Q1: How would you define the role of the MDT and your role and responsibilities within it?	
Initial themes	Final themes
• Expertise • Multispecialty expertise	1. Expertise and present cases
• Provide quality control • Clinical assessment and guidance • Discuss diagnosis • Consistent quality • Integrated approach • Robust discussion • Reduce variation	2. Clinical quality

• Multispecialty discussion • Discuss all cases • Provide expert based review • Discuss evidence-based treatment options	
• Treatment options • Oncology treatment options • Optimal treatment • Provide best standard of care • Assess best care approaches	3. Provide expert treatment plan

Table 1a: Final themes of Q1 based on OUH interviews.

SUH Q1: How would you define the role of the MDT and your role and responsibilities within it?	
Initial themes	Final themes
• Provide expertise • Clinical expertise • Present cases • Expert discussion	1. Expertise and present cases
• Sufficient clinical data • Structured approach • Advice • Check data • Assess patients • Provide diagnosis • Clinical discussion • Reduce variation • Confirm diagnosis • Integrate care	2. Clinical quality
• Treatment plan • Recommendations • State treatment • Consensus on treatment • Treatment options • Optimal treatment	3. Provide expert treatment plan

Table 1b: Final themes of Q1 based on SUH interviews.

Analysis of Q2 and its initial themes are shown in Appendix 4. Final themes for both cohorts were derived from these. OUH's final themes were (i) modulate variation, (ii) better treatment, (iii) discussion and consensus and (iv) clinician keeping up to date (Table 2a) and SUH shared all the same four themes as OUH with one additional theme i.e. efficiency (Table 2b).

OUH Q2: How does the MDM contribute towards maintaining and/or improvement of quality (clinical effectiveness) in clinical care?	
Initial themes	Final themes
• Modulates variation • Reduce variation • Check and balance • Highlight information required • Better patient safety • Integrated care • Timely care	1. Modulate variation
• Patient's health status in treatment plans • Up to date patient information for decision making • Focus on treatment when meeting patient • Up to date treatment • Improve treatment • Treatment planning	2. Better treatment
• Discuss all treatment options • Enable full discussion • Multiple experts discussion • Collective decision • Expert discussion • Consensus on diagnosis • Expert opinions	3. Discussion and consensus
• Nothing overlooked • Set benchmark • Stay up to date • Question colleagues	4. Clinician keeping up to date

Table 2a: Final themes of Q2 based on OUH interviews.

SUH Q2: How does the MDM contribute towards maintaining and/or improvement of quality (clinical effectiveness) in clinical care?	
Initial themes	Final themes
• Modulates variation • Reduce variation • Evidence based	1. Modulate variation
• Optimise treatment options • Best treatment options • Improve patient management	2. Better treatment
• Collective approach • Better discussion • Consensus approach • All patients discussed • Structured discussion • Expert feedback	3. Discussion and consensus
• Educational • New knowledge • Continuing medical education	4. Clinician keeping up to date
• Quicker decisions	5. Efficiency

Table 2b: Q2 - final themes based on SUH interviews.

Question 3 essentially has two parts i.e. strengths and weakness of the MDT. Their results are shown in Appendix 5. Table 3a shows MDT strengths as seen by OUH. It shows five final themes i.e. (i) multiple high quality experts, (ii) reduce variation, (iii) team based patient care, (iv) educational and (v) nursing. Meanwhile SUH had four themes i.e. (i) quality, (ii) decision making, (iii) educational and (iv) patient consultations.

OUH Q3a: What are 2-3 main strengths of the MDT?	
Initial themes	Final themes
• Varied expertise with quality • Varied expertise • Multiple experts	1. Multiple high quality experts
• Reduce variation • Consistency in treatment	2. Reduce variation
• All patients reviewed • Teamwork • Improve patient care • Image guided treatment • Quality input • Relevant expertise • Team based care • Transparency in decision making • Integrated care • Clinical discussion • Experienced clinical team • Multi expert based care	3. Team based patient care
• Learning opportunity • Clinical trials	4. Educational
• Nursing voice • Nursing quality	5. Nursing

Table 3a: Q3 - final themes based on OUH interviews.

SUH Q3b: What are 2-3 main strengths of the MDT?	
Initial themes	Final themes
• Reduce variation • Consistency in treatment • Facilitate quality • Look at various treatment options • Structured approach • Improve data quality • Multiple expertise • Manage risk • Complex cases • Specialist care • Reduce risk • Quality decisions • Integrated care	1. Quality

• Make tough decisions • Discuss with experts • Communications between experts • Collective decision making • Quicker decision making • Definitive diagnosis • Consensus approach	2. Decision making
• Learning environment • Educational • Teaching session	3. Educational
• Easier to talk to patients • Whole care process	4. Patient consultations

Table 3b: Q3 - final themes based on SUH interviews.

The second part of Q3 relates to MDTs weaknesses. OUH had five final themes i.e. (i) communications and teamwork, (ii) accountability, (iii) clinical information (iv) efficiency and (iv) decision-making process (Table 3c). Meanwhile SUH had four themes, which were the same as OUH except for clinical information (Table 3d).

OUH Q3c: What are 2-3 main weaknesses of the MDT?	
Initial themes	Final themes
• Poor communications between hospitals • Poor teamwork • Team management • Registrars excluded • No trainees	1. Communications and teamwork
• Lack 'ownership' of patients • No review of decisions • Poor feedback on outcomes • Some surgeons never attend • Pre-MDT inertia • No decision outside MDT	2. Accountability
• Patchy clinical information and on patient preferences • Clinical uncertainty • Clinical input	3. Clinical information
• Multiple reviews	

• High turnover of coordinators • Attendance • Time management • Access to patients before MDT meets • Clashes with OT timing • Poor case preparation • Delays in treatment • Time consuming • Variable attendance • Equipment failure • Not all cases reviewed	4. Efficiency
• Lack of decision • Erratic decision making • Patient list management • Individual opinions • No check and balance on decisions • Bias in treatment choices	5. Decision making process

Table 3c: Q3 - final themes based on OUH interviews

SUH Q3d: What are 2-3 main weaknesses of the MDT?	
Initial themes	Final themes
• Intimidating • Passive involvement	1. Communications and teamwork
• No 'responsibility' • No patient advocate • Poor compliance of guidelines	2. Accountability
• Delays • Rubber –stamping • Lack of beds • Time management • Interruptions • Variations • Treating clinician absent • Variable attendance • Faulty technology • Lack senior doctors • Poor preparations by clinicians • Oncologist absent • Insufficient time • Variable attendance	3. Efficiency
• Lack of decisions • Variations on how guidelines upheld • List management • Unstructured decision making • Can be rigid	4. Decision making process

Table 3d: Q3 - final themes based on SUH interviews.

Analysis of Q4 and its initial themes for both cohorts are shown in Appendix 6. In Q4 both cohorts had same three final themes i.e. (i) clinical evidence and information, (ii) administrative and clinical support and (iii) list and meeting management (Tables 4a and 4b).

OUH Q4: What type of assistance or resources would be needed to improve multidisciplinary meetings (MDMs)?	
Initial themes	Final themes
• Clinical trials • Clinical guidelines • Access to / sufficient clinical information • Improve data collection • Get second opinions when evidence is weak • Feedback on patient outcomes • Info on patient preferences	1. Clinical evidence and information
• Stable administrative support • Better trained coordinators • Reliable IT equipment • Other clinical expertise • Be part of managing coordinators • Be clear on coordinator's post • More time for case preparation • IT and admin support	2. Administrative and clinical support
• Better list management • Nurses to stratify cases • Registrars to present cases • Time constraints • Variation in chairing • More time allocation • Core e.g. surgeon and radiologist to make decisions on easier cases • Better proforma • Filling in proforma	3. List and meeting management

Table 4a: Q4 - final themes based on OUH interviews.

SUH Q4: What type of assistance or resources would be needed to improve multidisciplinary meetings (MDMs)?	
Initial themes	Final themes
• Clinical trials • Clinical guidelines • Access to / sufficient clinical information • Improve data collection • Get second opinions when evidence is weak • Feedback on patient outcomes • Info on patient's preferences • Feedback on multimodality treatment	1. Clinical evidence and information
• Access to high quality technology • Nursing input • Support for prep and presentation • More prep time for complex cases • Protect MDT time • Reliable infrastructure • More coordinators • Relevant / more experts	2. Administrative and clinical support
• Time for OT and MDT • Have checklist • More structured meeting • What and way cases discussed is key • Nurses to attend • Active engagement • Keep current timings	3. List and meeting management

Table 4b: Q4 - final themes based on SUH interviews.

Initial emergent themes based on Q5 for both cohorts are shown in Appendix 7. In Q5 OUH had two final themes i.e. (i) manage clinical quality and (ii) provide expertise (Table 5a). SUH had similar themes as OUH, but with an additional theme i.e. process management (Table 5b).

OUH Q5: How do you think you contribute towards clinical care quality through MDMs?	
Initial themes	Final themes
• Rectify deficiencies • Chair important when evidence is weak • Provide accurate clinical info • Ensure clinical quality • Balance clinical risk • Can better manage patients • Help reduce variation • Can offer integrated care • Clinicians are up-to-date	1. Manage clinical quality
• Expertise • Represent patient • Provide expertise • Provide expertise and balance on oncological treatment	2. Provide expertise

Table 5a: Q5 - final themes based on OUH interviews.

SUH Q5: How do you think you contribute towards clinical care quality through MDMs?	
Initial themes	Final themes
• Ensure imaging quality • Review clinical decision if patients are seen before MDT • Sufficient clinical data • Patient safety • Prepare for MDT • Promote discussion	1. Manage clinical quality
• Expertise • Question treatment • Provide patient preferences • Patient liaison • Offer different perspective • Show scan and explain disease	2. Provide expertise
• Impress on waiting times • Patient consultations	

• Document recommendations • Present cases and receive feedback • Coordination • Communicate key points • Encourage active engagement	3. Process management
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Table 5b: Q5 -final themes based on SUH interviews.

Initial emergent themes based on Q6 for both cohorts are shown in Appendix 8. In Q6 OUH had three final themes i.e. (i) consultations with patients, (ii) improve clinical knowledge and (iii) helps decision-making (Table 6a). SUH also had three themes i.e. (i) consultations with patients, (ii) improve clinical knowledge and (iii) managing care processes (Table 6b).

OUH Q6: How do you use the information / knowledge gathered through MDMs to help with your day-to-day clinical practice?	
Initial themes	Final themes
• Informed discussions with patients • Provide treatment options • Discussions with colleagues helpful when dealing with patients	1. Consultations with patients
• Better knowledge • Improve clinical knowledge • No outcomes audit • Know limitations	2. Improve clinical knowledge
• Confirm treatment plan • Help interpret scans • Spread burden of decision making • More definitive diagnosis and treatment plan • Informs decision making	3. Helps decision-making

Table 6a: Q6 - final themes based on OUH interviews.

SUH Q6: How do you use the information / knowledge gathered through MDMs to help with your day-to-day clinical practice?	
Initial themes	Final themes
• Informed discussions with patients • Provide treatment options • Can present to patient collective decision • Helps with patient's anxiety • Patients feel better its MDT decision • Discuss MDT findings with patients • Know how to deal with patient	1. Consultations with patients
• Increase knowledge • Up todate • Learn • Transferable knowledge	2. Improve clinical knowledge
• Inform treatment plan and practical issues • Explain to pts and family about Rx • Do bookings • Prioritising patient list • Inform patients of prep and doctor's appointment • Coordinate all treatment • Use checklist • Useful to refer to MDT notes before surgery	3. Managing care process

Table 6b: Q6 - final themes based on SUH interviews.

Appendix 9 shows the initial emergent themes based on Q7 for both cohorts.

In Q7 both cohorts had same two final themes i.e. (i) effective care and (ii) efficiency (Table 7a & 7b).

OUH Q7: How do patients benefit from the MDT? What would be the possible difference in clinical care if their case were not discussed at the MDT?	
Initial themes	Final themes
• Better informed choices • Reduce variation in care • Better clinical quality • Balanced approach • Reduce variation • Integrated care • Best available review of experts	1. Effective care
• Otherwise slow • Efficiency in time to treatment • Patient care can be haphazard if not through MDT	2. Efficiency

Table 7a: Q7 - final themes based on OUH interviews.

SUH Q7: How do patients benefit from the MDT? What would be the possible difference in clinical care if their case were not discussed at the MDT?	
Initial themes	Final themes
• Manage risk of poor competence • Reduce variation • Better quality decision • Reduce chance / risks • Reduce unwarranted variation • Reduce errors • Useful for complex cases • MDT changes initial Dx and Rx	1. Effective care
• Quicker care process	2. Efficiency

Table 7b: Q7 - final themes based on SUH interviews.

Initial emergent themes on Q8 for both cohorts are shown in Appendix 10. Both cohorts had two same final themes i.e. (i) patient's preferences not captured and (ii) treating / primary clinician (Table 8a & 8b)

OUH Q8: How is a patient's preference towards clinical care discussed and captured at MDMs?	
Initial themes	Final themes
• Patient's preference largely not captured • Not easily captured • Limited capture at MDT • Not known before MDT meets	1. Patient's preferences not captured
• Through treating clinician • Primary clinician otherwise not captured • Referral letter • Patient notes • Nurses and surgeons	2. Treating / primary clinician

Table 8a: Q8 - final themes based on OUH interviews.

SUH Q8: How is a patient's preference towards clinical care discussed and captured at MDMs?	
Initial themes	Final themes
• Not at all, very little at best • Mostly not discussed • Not captured	1. Patient's preferences not captured
• Captured at outpatient clinic • Depends if Dr has met the patient • Captured through nurses • Through referral doctors and nurses	2. Treating / primary clinician

Table 8b: Q8 - final themes based on SUH interviews.

For questions 9 and 10, respondents were requested to provide a numerical rating score (1-3) to indicate the level of significance MDTs and drivers of unwarranted variation have respectively on several themes. These ratings specifically were:

1 = None to minimal (Type 1 effect / driver)

2 = Minimal to Moderate (Type 2 effect / driver)

3 = Moderate to Significant (Type 3 effect / driver)

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?

This question focuses on the role of MDTs, primarily in effective care based on surgical and non-surgical care. A total of seven themes were used. Four themes were related to quality in surgery i.e. (i) 30-day mortality, (ii) 90-day mortality, (iii) 1-year mortality and (iv) readmissions. Three other themes addressed non-surgical care i.e. (v) long vs. short course radiotherapy treatment, (vi) adjuvant chemotherapy and (vii) managing chemo-toxicity.

Comparison scores

Figure 1 shows Q9 comparison scores (CS) between OUH and SUH on MDTs role in reducing variation on the above-mentioned categories. Both cohorts based on their CS, had the following similar responses:

Type 1

- Managing chemo-toxicity

Type 2

- 30-day mortality

Type 3

- 1Y mortality
- Long vs. short course radiotherapy
- Adjuvant chemotherapy

Appendix 11 shows how OUH and SUH rated MDTs against the seven categories.

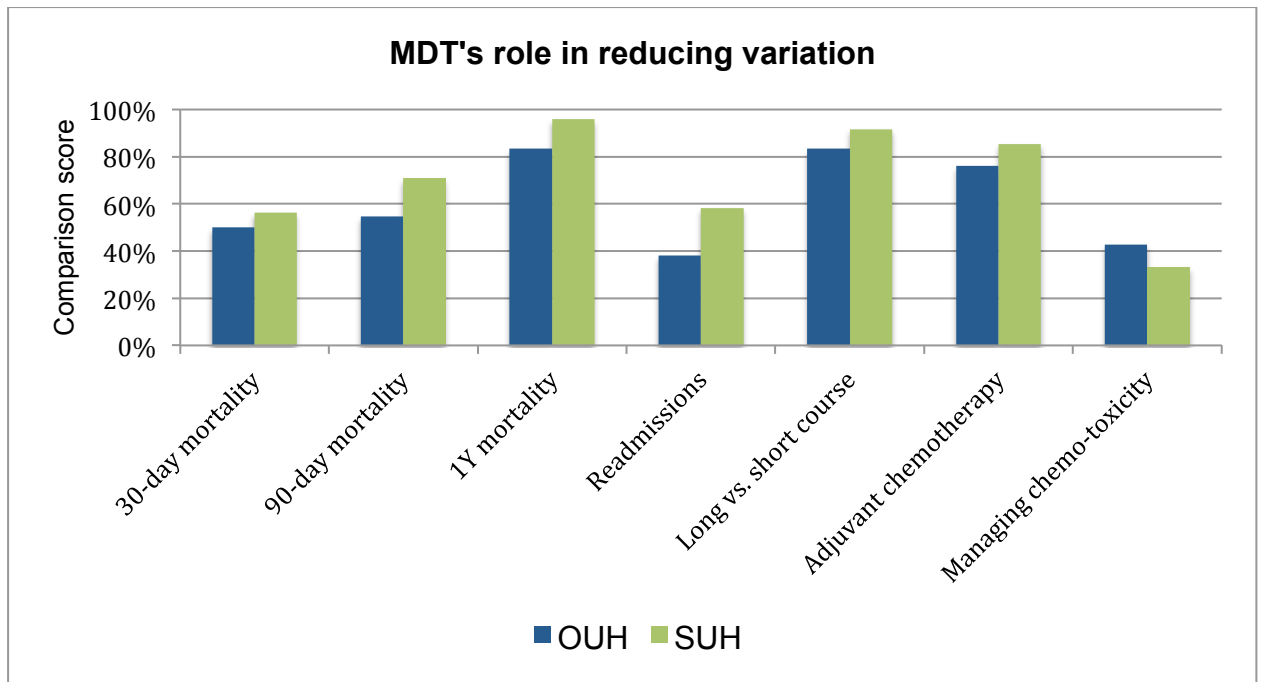


Figure 1: Comparison between OUH and SUH on effects on MDTs on variations on CRC outcomes and care

30 & 90-day mortality

Majority of the respondents (OUH, 64%; SUH, 50%) reported MDTs had Type 1 effect on 30-day mortality (Table 9a). Overall less than 20% reported a Type 3 effect. This is in line with both cohorts during the interviews suggesting 30-day mortality was more linked with perioperative care e.g. care at the intensive care unit, rather than necessarily with MDTs. However results indicate a difference in opinions with regards to 90-day mortality (Table 9). OUH seems to rate MDT role mostly between Type 1 and 2 while almost a third of SUH suggest MDTs bear a heavier responsibility with regards to 90-day mortality.

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
30-day mortality			
Type 1	64% *(9)	50% *(8)	14
Type 2	21% (3)	31% (5)	10
Type 3	15% (2)	19% (3)	4
90-day mortality			
Type 1	50% (7)	19% (3)	31
Type 2	36% (5)	50% (8)	14
Type 3	14% (2)	31% (5)	17

Table 9a: MDT's putative role on reducing risk in 30-day and 90-day CRC. * Parenthesis indicate number of respondents

1-year mortality

Majority (57% OUH; 87.5% SUH) rated MDTs as having a Type 3 role on 1-year mortality (Table 9b). Results indicate both cohorts leaning towards MDTs having an appreciable role on 1-year mortality.

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
1Y mortality			
Type 1	7% (1)	0% (0)	7
Type 2	36% (5)	12.5% (2)	24
Type 3	57% (8)	87.5% (14)	31

Table 9b: MDTs role on 1-year mortality.

Readmissions

Majority (86% OUH and 50% SUH) reported a Type 1 role (Table 9c). This 36% point difference is the largest for Q9. Notably OUH was clear (0%) that MDTs did not have a Type 3 role, while 25% SUH presented otherwise. OUH respondents suggested readmissions was mostly a surgical quality issue and not related to MDTs.

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
Readmissions			
Type 1	86% (12)	50% (8)	36
Type 2	14% (2)	25% (4)	11
Type 3	0% (0)	25% (4)	25

Table 9c: MDT's role in CRC readmissions.

Radiotherapy (long course versus short course)

A small percentage indicate Type 1 role in radiotherapy treatment, while 36% OUH and 13% SUH indicate Type 2 role (Table 9d). Majority support a Type 3 role. Both cohorts acknowledged oncologists are highly relevant within the MDT and as such the MDT provides an important platform for clinical discussions between surgeons, oncologists and other experts. Respondents emphasised the relevance and importance of this formalised clinical MDT discussion in particular when there are treatment options that require clinical discussions.

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
Long vs. short course radiotherapy			
Type 1	7% (1)	6% (1)	1
Type 2	36% (5)	13% (2)	23
Type 3	57% (8)	81% (13)	24

Table 9d: MDTs role in reducing variation in radiotherapy treatments

Adjuvant chemotherapy

Majority of both cohorts report MDTs having a Type 3 effect on adjuvant chemotherapy rates. SUH was unequivocal (0%) ruling out Type 1 effects, in contrast 21% OUH reported otherwise (Table 9e).

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
Adjuvant chemotherapy			
Type 1	21% (3)	0% (0)	21
Type 2	29% (4)	44% (7)	15
Type 3	50% (7)	56% (9)	6

Table 9e: MDT's role in adjuvant chemotherapy.

Chemo-toxicity

SUH was unequivocal (100%) that MDTs had only Type 1 effect on managing chemotoxicity while 79% OUH thought likewise (Table 9f). There was a small spread within the OUH cohort indicating Type 2 and Type 3 effect (14% and 7% respectively).

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (Rounded off)
Managing chemo-toxicity			
Type 1	79% (11)	100% (16)	21
Type 2	14% (2)	0% (0)	14
Type 3	7% (1)	0% (0)	7

Table 9f: MDTs role in chemotoxicity.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?

All respondents were provided a same written definition of unwarranted variation (Appendix 2) to answer this question. Aim of the question was to assess if respondents appreciated the concept of unwarranted variation and its possible drivers. Respondents were asked to rate 1 to 3 (same rating as Q9) 16 possible drivers. Appendix 12 shows how OUH and SUH rated these putative drivers.

Comparison score

Figures 2a and 2b show the comparison scores between OUH and SUH on how they rated the putative drivers of unwarranted variation for 30-day mortality. The results below indicates the similarities in their ratings:

Type 1 driver:

- National Cancer Policy
- Elective care

Type 2 driver:

- Underuse of effective treatment
- Adverse drug interactions
- Premature discharge from hospital
- Either non adherence to or not seeking patients preferences

Type 3 driver:

- Emergency cases
- Low volume of cases
- Limited specialist care at hospital
- Quality of post-operative care at hospital
- Uncertainty of scientific evidence leading to practice variation

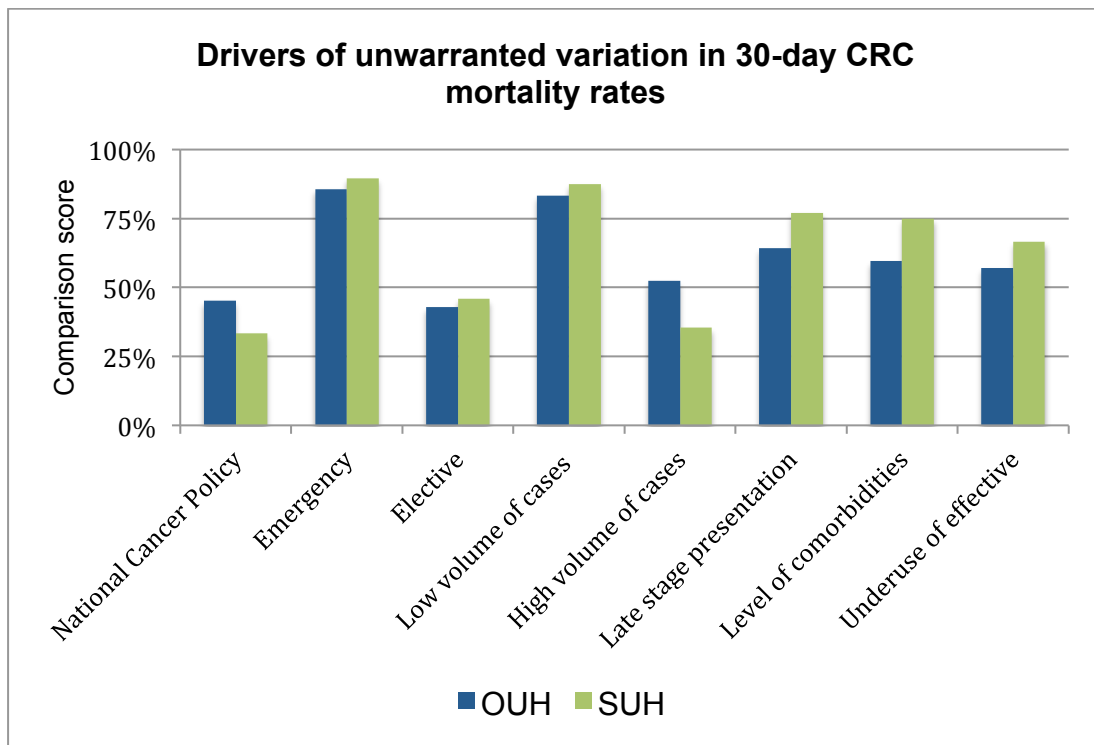


Figure 2a: Putative drives of unwarranted variation

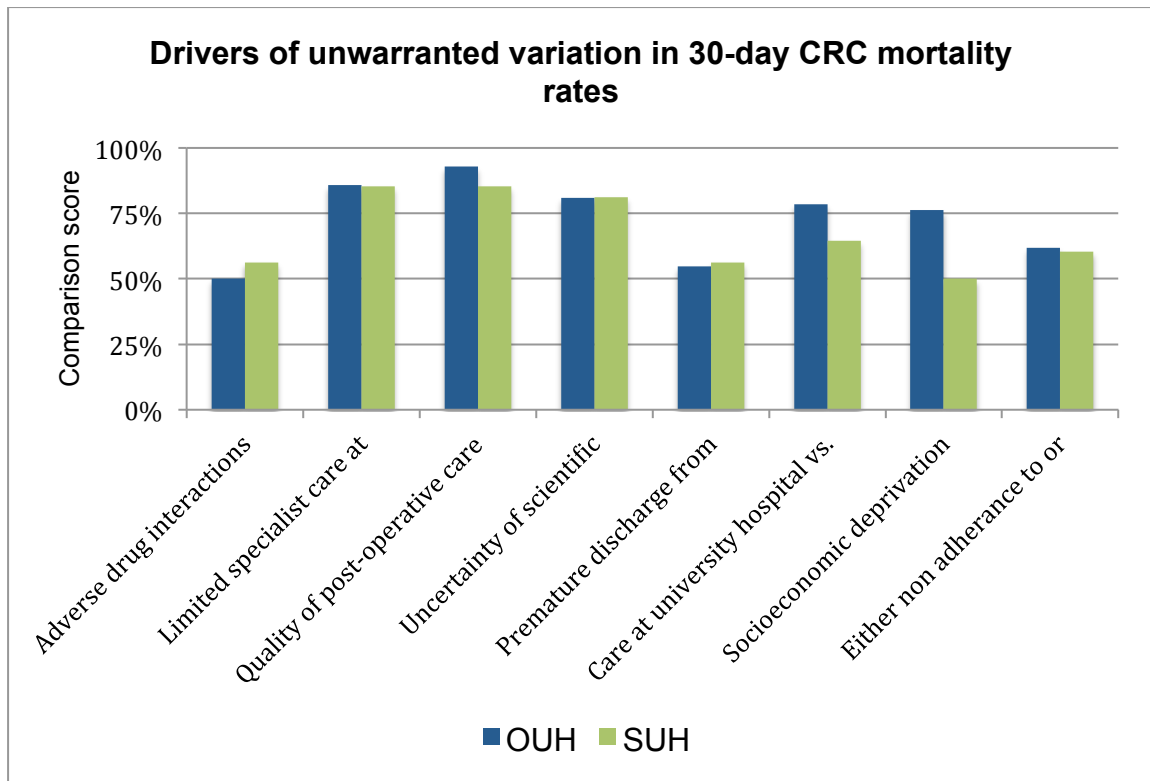


Figure 2b: Putative drivers of unwarranted variation in 30-day CRC mortality.

National Cancer Policy

79% OUH and 100% SUH suggested National Cancer Policy as a Type 1 driver (Table 10a). While SUH was very clear that National Cancer Policy at worst had only minimal effects as a driver of unwarranted variation, however close to one fifth of OUH respondents believe policy does have a larger impact.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
National Cancer Policy			
Type 1	78.6%	100%	21
Type 2	7.1%	0%	7
Type 3	14.3%	0%	14

Table 10a: National Cancer Policy as a possible driver of unwarranted variation.

Emergency admissions

64.3% OUH and 75% SUH reported emergency admissions played a Type 3 role (Table 10b). Both cohorts reported patients being at risk when diagnosed and treated at smaller district hospitals that lack necessary expertise. OUH results show an intra-cohort difference of 35.7-percentage points between Type 2 and Type 3 and 56-percentage points within SUH.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Emergency admissions			
Type 1	7.1%	6%	1
Type 2	28.6%	19%	10
Type 3	64.3%	75%	11

Table 10b: Emergency admissions as a possible driver of unwarranted variation.

Elective admissions

OUH rated elective admissions ranging from 1 to 3 while SUH gave it 1 to 2 rating (Table 10c). However majority viewed it as a Type 2 driver. SUH was unequivocal (0%) that it was not a Type 3 driver.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Elective admissions			
Type 1	78.6%	62.5%	16
Type 2	14.3%	37.5%	23
Type 3	7.1%	0%	7

Table 10c: Elective admissions as a possible driver of unwarranted variation.

Volume

The respondents viewed hospital caseload as an important factor where both cohorts mostly saw low volume as a Type 2 and Type 3 driver, while high volume was mostly viewed as a Type 1 driver (Table 10d).

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Low volume of cases			
Type 1	0%	6%	6
Type 2	50%	25%	25
Type 3	50%	69%	19
High volume of cases			
Type 1	57.1%	94%	37
Type 2	28.6%	6%	23
Type 3	14.3%	0%	14

Table 10d: Hospital volume as a possible driver of unwarranted variation.

Late stage presentation

With regards to late stage presentation, both cohorts largely differed on how they viewed it as Type 1 and Type 2 driver (Table 10e). 42.9% OUH and 6% SUH reported it as Type 1 driver. This is a 37-percentage points difference in their views as Type 1 and 35-percentage points difference as Type 2. OUH saw it mostly as Type 1 (42.9%) and SUH as Type 2 (56%).

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Late stage presentation			
Type 1	42.9%	6%	37
Type 2	21.4%	56%	35
Type 3	35.7%	38%	2

Table 10e: Late stage presentation as a possible driver of unwarranted variation.

Comorbidities

Majority (92.9%) of OUH participants reported comorbidities as Type 1 and Type 2 drivers while a combined 100% of SUH participants viewed it as Type 2 and Type 3 driver (Table 10f). One of the striking differences was 29% of OUH participants and 0% SUH viewed it as Type 1 respectively.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Comorbidities			
Type 1	28.6%	0%	29
Type 2	64.3%	75%	11
Type 3	7.1%	25%	18

Table 10f: Comorbidities as a possible driver of unwarranted variation.

Underuse of effective treatment

Majority in both cohorts reported underuse of effective treatment as Type 2 driver (Table 10g). SUH cohort (75%) mentioned a likelihood of patients not receiving effective care especially when clinicians either refuse or defer seeking MDT's opinion on treatment options. SUH also reported the likelihood of care meeting national guidelines and the use of best current evidence when MDTs are involved in care options.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Underuse of effective treatment			
Type 1	35.7%	12.5%	23
Type 2	57.1%	75%	18
Type 3	7.2%	12.5%	5

Table 10g: Underuse of effective treatment as a possible driver of unwarranted variation.

Adverse drug interactions

Majority (57.1%) of OUH reported adverse drug interactions as Type 1 driver, while 31% SUH did likewise (Table 10h). The largest difference was in how each cohort viewed it as a Type 2 driver, i.e. 35.7% OUH and 69% SUH. This is a 33-percentage point difference. None (0%) in the SUH cohort found it to be a Type 3 driver. Majority of respondents from both cohorts said this aspect is further complicated when patients have had extensive surgery and comorbidities and were treated at the hospital with limited specialist care.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Adverse drug interactions			
Type 1	57.1%	31%	26
Type 2	35.7%	69%	33
Type 3	7.2%	0%	7

Table 10h: Adverse drug reactions as a possible driver of unwarranted variation.

Limited specialist care

Majority (57.1% OUH and 63% SUH) of the respondents reported limited specialist care as a Type 3 driver (Table 10i). OUH was unequivocal (0%) in its view limited specialist care as a Type 1 driver. This result of being a Type 3 driver is also mirrored in their views on the quality of postoperative care at hospital, where both institutions (78.6% OUH, 68.7% SUH) primarily favour it as a Type 3 driver.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Limited specialist care			
Type 1	0%	6%	6
Type 2	42.9%	31%	12
Type 3	57.1%	63%	6

Table 10i: Limited specialist care as a possible driver of unwarranted variation.

Quality of postoperative care

Majority (78.6% OUH, 68.7% SUH) rated quality of postoperative care as Type 3 driver (Table 10j). OUH was unequivocal (0%) that it was not a Type 1 driver while 12.5% of SUH reported otherwise.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Quality of postoperative care			
Type 1	0%	12.5%	13
Type 2	21.4%	18.8%	3
Type 3	78.6%	68.7%	10

Table 10j: Quality of postoperative care as a possible driver of unwarranted variation.

Uncertainty of scientific evidence

Both cohorts had 1-percentage point difference (57.1% OUH, 56% SUH) in their views on ‘uncertainty of scientific evidence leading to practice variation’ being a Type 3 driver (Table 10k). Close to 90% of total respondents rated it either as Type 2 or Type 3 driver. Some respondents from both cohorts suggested variations in 30-day mortality were unlikely due to clinical uncertainty but more so attributed to postoperative care quality.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Uncertainty of scientific evidence			
Type 1	14.3%	13%	1
Type 2	28.6%	31%	2
Type 3	57.1%	56%	1

Table 10k: Uncertainty of scientific evidence as a possible driver of unwarranted variation.

Premature discharge

Majority of respondents (64.3% OUH, 56% SUH) reported premature discharge as a Type 2 driver, while slightly more than a third (35.7% OUH, 38% SUH) reported it as Type 1 (Table 10l). OUH was unequivocal (0%) that 'premature discharge' was not a Type 3 driver.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Premature discharge			
Type 1	35.7%	38%	2
Type 2	64.3%	56%	8
Type 3	0%	6%	6

Table 10l: Premature discharge as a possible driver of unwarranted variation.

Care at university hospital vs. non-university hospital

Majority (50% OUH, 68.7% SUH) rated this category a Type 2 driver (Table 10m). A high proportion of OUH respondents (42.9%) rated it as Type 3 driver, thereby close to 93% OUH rating it as either Type 2 or 3 driver. There is a 12-percentage point difference between cohorts on how they rated it as either Type 2 or 3.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Care at university vs. non-university hospital			
Type 1	7.1%	18.8%	12
Type 2	50%	68.7%	19
Type 3	42.9%	12.5%	30

Table 10m: Care at university hospital vs. non-university hospital as a possible driver of unwarranted variation.

Socioeconomic deprivation

Of all themes 'socioeconomic deprivation' had the largest difference between cohorts on how they scored the putative drivers (Table 10n). 50% OUH and 6% SUH scored this a Type 3 driver. This is a 44-percentage point difference.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Socioeconomic deprivation			
Type 1	21.4%	56%	35
Type 2	28.6%	38%	9
Type 3	50%	6%	44

Table 10n: Socioeconomic deprivation as a possible driver of unwarranted variation.

Non-adherence or not seeking patient's preference

Majority of OUH respondents (71.4%) reported this as a Type 2 driver (Table 10o). This cohort said patient's preferences would be adhered to. 7.2% OUH and 18.8% SUH scored it Type 3 with the view there are times patients' preferences are not actively sought.

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (Rounded off)
Non adherence or not seeking patient's preference			
Type 1	21.4%	37.5%	16
Type 2	71.4%	43.7%	28
Type 3	7.2%	18.8%	12

Table 10o: Non-adherence or not seeking patient's preference as a possible driver of unwarranted variation

Question 11 has two parts i.e. being familiar with the term 'unwarranted variation in outcome' and its implications on patient outcomes. The interview results are shown in Appendix 13, while results summary is shown below in Tables 11a and 11b respectively.

Familiar with the term 'unwarranted variation in outcome'		
	OUH (n=14)	SUH (n=16)
No	11/14 (78.5%)	14/16 (87.5%)
Yes	3/14 (21.5%)	2/16 (12.5%)

Table 11a: Results on the familiarity of the term 'unwarranted variation.

Possible implication on patient outcomes		
	OUH (n=14)	SUH (n=16)
No	9/14 (64.3%)	5/16 (31.3%)
Yes	5/14 (35.7%)	11/16 (68.7%)

Table 11b: Results on the possible implication of unwarranted variation on patients.

Interview transcripts for question 12 and its initial themes are shown in Appendix 14 while its final themes are shown below in tables 12a (OUH) and 12b (SUH). Both OUH and SUH have the same four final themes i.e. improve quality, (ii) be up to date, (iii) team management and (iv) patient management and preferences.

OUH Q12: How could your MDT address unwarranted variation in clinical care?	
Initial themes	Final themes
• Optimal clinical information • Show guidelines • Review decisions, complications and mortality • Compare with other MDTs • Be aware of 'unwarranted variation' at MDTs • Standardise presentation • Measure unwarranted variation • Measure quality • Monitor and receive feedback • Evidence based care	1. Improve quality
• Be current • Audit on treatment opinions against guidance	2. Be up to date
• Improve team dynamics • Reach consensus • Better team dynamics	3. Team management
• Be aware of patient's preferences • Insist on knowing patient preferences • Present options to patients • Evidence based treatment options • Reduce practice variation • Seek second opinion when relevant	4. Patient management & preferences

Table 12a: Q12 final themes based on OUH results.

SUH Q12: How could your MDT address unwarranted variation in clinical care?	
Initial themes	Final themes
• Reduce overuse of harmful treatments • All patients to be reviewed at MDT • Encourage MDTs in hospitals without resources • Check if relevant information or issues are discussed • Address gaps in clinical information • Reduce practice variation	1. Improve quality
• Have real-time feedback • Feedback on outcome of surgery	2. Be up to date
• Consensus approach • Reduce bias • Allocate more prep time	3. Team management
• Patient centric approach • Pt list management	4. Patient management & preferences

Table 12b: Q12 final themes based on SUH results.

MDT observations

The following are the main observations:

(i) *Purpose* – The MDTs seems to operate on an ‘automated’ basis. Whilst participants through their interview results suggest they are at the MDT to provide their expertise, it seems majority come to ‘attend’ (not necessarily participate) a common activity rather than a purpose. The core purpose of the MDT beyond a general descriptive statement in the UK i.e. ‘The management of all patients with colorectal cancer should be the responsibility of colorectal multidisciplinary teams’ (National Institute for Clinical Excellence 2004b), does not exist anywhere, including for MDTs in Sweden. This statement of responsibility is a broad and opaque ambit. As the interview results suggest MDT participants specifically feel that MDTs have no real ‘responsibility’ for any specific patient.

(ii) *Enthusiasm* – From discussions some simply don’t look forward to attending the MDTs. Some of the common reasons mentioned during discussions were “ Oh! We are just rubber stamping”, “its intimidating”, “have nothing to learn”, “why should I when others don’t bother”, “some people are just bullies, so why bother” and “it takes too long because people are not focused”. On the other hand, some reasons to attend are, “I want to know what the others feel about my patient’s care”, “here to observe and learn” “here for the patients, so that they get the best shot at treatment”, “going through the process” and “can question some treatment decisions”.

Some have moments when they enthusiastically engage in the discussions but then return to an indolent state rather rapidly. A few clinicians maintain their enthusiasm and a sense of engagement throughout. In discussions with them, it seems their engagement in the MDT is driven by a sense of purpose and responsibility. However MDT participants who attend other tumour MDTs had indicated variations in MDT workings and how it can affect one's participation.

(iii) *Highest level of expertise* – The MDTs bring together some of the highest level of clinical expertise in one sitting to discuss cases in ways that are not replicated anywhere else within clinical practice. The development and management of such a clinical practice seems to have not taken into consideration what motivates high calibre individuals and the best approaches to engage them. For example attendees have remarked about the need to have their attendance taken. Some said, “we are being treated like school children”, “so unprofessional” and “so what does it really mean to the patient scientifically”. Notwithstanding in wanting to assess attendance, one of the hospitals could not provide attendance records, as it was lost.

(iv) *Feedback* – All attendees seek feedback and receive none, let alone any they feel useful. Some of their comments are, “Only God knows what happens to our recommendations after the MDT especially in the outlying centres”, “are we sure we are not making the (patient's) situation worse, or are we and no one tells us either”, and “what's the point of reading prosaic outcome stats when we should know about patients we discussed and in real-time, isn't that

what so-called surveillance can do.....so much money and effort with almost no sense if we are getting it right early on in order to inform practice”.

While data on patients and their treatment are entered and used for on-going patient management and reporting, none are relayed back to the MDT. It appears the MDT is a ‘closed system’. In reviewing the database it appears data entered reflects outputs, with no links to outcomes and guidelines nor is why certain decisions taken captured.

(v) *Resources* – As seen from the MDT interviews, the MDT coordinator seems a highly regarded resource. Coordinators are recruited and managed by another unit. Coordinators are responsible for coordinating all the interdependencies MDTs require to be effective. They also input data during MDT meetings. The Information Technologies (IT) used at these MDTs are nothing more than an electronic method of documenting paper work. It appears the picture archiving communication system (PACS) used to manage radiological images is not linked to the MDT database. In addition, separate logins are required to access patient records. The pathology IT system is also a silo by itself. In all, nurses, coordinators and MDT chairpersons need to navigate fragmented IT systems. In OUH CRC coordinators have different databases and these are not always coordinated with the national CRC database of the Association of Coloproctology of Great Britain and Ireland.

(vi) *Institutional support* – The impression is that MDTs are a ‘stick-on’ that hospitals need to have in order to comply with guidelines. The MDTs receive perfunctory support from within the organisation and don’t seem to receive the recognition it can be (is) high quality clinical practice that improves clinical

standards within the hospital. Observations suggest MDTs generally are not seen as a strategic fit within the organisation and usually find it a struggle to receive resources. Some commented, “If MDTs are so important then why is it CCGs don’t recognise their costs”, “MDT’s workload is ever increasing, but resources don’t keep up” “in trying to get resources it makes you feel in reality MDT is a tick box exercise” and a couple said “we can’t even have coffee served because MDT is not important for management”. Appendix 15 provides the list of interviewees from OUH and SUH.

Discussion

Questions 1-8 are discussed collectively and the others by themselves. As with the all the questions, by delving deeper on the interview comments provides a clearer and at times diverse picture as to the perceptions of the MDT's role and workings. Table 13 provides an overview of similar responses OUH and SUH cohorts shared for questions 9 and 10.

	Type 1 (None to minimal)	Type 2 (Minimal to moderate)	Type 3 (Moderate to significant)
MDT's role	Managing chemo-toxicity	30-day mortality	1Y mortality - Long vs. short course radiotherapy - Adjuvant chemotherapy
Drivers of unwarranted variation	- National Cancer Policy - Elective care	- Underuse of effective treatment - Adverse drug interactions - Premature discharge from hospital	- Emergency cases - Low volume of cases - Limited specialist care at hospital - Quality of post-operative care at hospital - Uncertainty of scientific evidence leading to practice variation

Table 13: Similar ratings by OUH and SUH cohorts.

Questions 1-8

Both cohorts viewed their own roles within the MDT chiefly was to provide their expertise, represent the patient and present cases. They broadly viewed the MDT's role as (i) ensure clinical quality and (ii) provide expert treatment plan. With regards to clinical quality OUH focussed on clinical assessment, treatment guidance, decision-making and integrated care approach. SUH

focussed on sufficient clinical data, assess patients sufficiently, verify diagnosis, integrate care, ensure equal care and reduce variation.

The National Health Service (NHS) Outcomes Framework provides five patient outcome domains to drive better quality through the NHS (Dept of Health 2012). These domains were derived from the 3-part definition of quality set in the NHS Next Stage Review report (Darzi 2008). Quality as defined by the NHS is now enshrined into the Health and Social Care Act 2012 (Great Britain. Department of Health 2012). Quality was viewed through three core areas: (i) keep patients as safe as possible (ii) ensure access to the most effective treatments and (iii) empower patients – this specifically takes into account patient preferences. In parallel according to Donabedian another approach to quality in healthcare is by examining structure and processes of care rather than just outcomes (Donabedian 1966, Donabedian 2002).

Besides quality, providing expert treatments plans were also viewed as the MDT's role. This fits into NHS's quality domains and Donabedian's framework. As such MDT's role would be to ensure and deliver clinical quality. However the broad scope of answers received suggest it would be prudent to discuss and decide the parameters of quality MDTs wish or need to address.

According to the interviews, MDT meetings could maintain quality by standardizing treatment plans thereby modulating variation. Reaching consensus in treatment plans amongst MDT participants and clinicians being up to date were seen as important factors towards ensuring quality. Having robust discussions and being able to question colleagues was seen as an important mechanism for achieving meaningful consensus. MDT meetings are

critical nodes on the care pathway when discussions on evidence takes place amongst experts. The participants viewed this was important for real-time learning. MDT meetings were also seen as an efficient mechanism for guiding good care in a timely manner.

A MDT by definition has multiple experts, and both cohorts see this in itself as strength. This particular observation lends credence that clinicians themselves see the need for a multiclinical approach towards diagnosing and treating patients with complex diseases such as colorectal cancer. Whilst there is no unequivocal empirical evidence suggesting MDTs' specifically are more effective in improving long-term survival outcomes, there is good evidence that MDTs do influence care processes e.g. assessing effective treatment for patients with rectal cancer through a MRI directed MDT that can help ameliorate positive circumferential resection margins (CRM) with appropriate preoperative treatments (Burton, Brown et al. 2006a). In their series Burton et al. show rectal cancer patients discussed at MRI directed MDTs were offered preoperative therapy and followed up with resection, zero (0) % had positive histological CRM, while more than a fifth of patients not discussed at MDT and had surgery alone had positive CRM (Burton, Brown et al. 2006a). Crucially this study also identified patients that were originally deemed inoperable underwent a CRM –ve resection following neoadjuvant treatment. This highlights the need for MDT discussions using appropriate diagnostic modalities can overturn an initial poor prognosis.

As a whole the cohorts believe it is conceivable that MDTs reduce (unwarranted) variation. Re-audits have found the need to have (preoperative)

MDT discussions as it catalyses improvements in clinical outputs e.g. better clinical staging enabling effective neoadjuvant treatment (Burton, Brown et al. 2006a).

One of the other strengths MDTs deemed to have is it enables clinicians to have more confident consultations with patients about their condition and suggest optimal treatment. Feedback from patients, according to the interviewees, was that patients felt they received best care when told the proposed treatment was based on MDT discussion. While this is certainly comforting for the patient, it is not necessarily the whole picture when evidence for treatment is weak. This point is picked up later under the 'uncertainty of scientific evidence' section below.

MDTs being educational were seen as strength too. MDTs observed during the course of this research certainly discussed a myriad of cases with differing complexities. However there was no obvious evidence that 'learning' was formalised either through feedbacks or that decision-making became better explicitly due to knowledge gathered during past MDTs. In fact as discussed later, lack of feedback is a telling point. Nevertheless it is conceivable that some passive learning takes place.

One of the potential 'down-sides' of having discussions between varying gradations of expertise is that it can affect teamwork. Poor teamwork and communications was identified as a weakness. Communications can be poor between main centre and referral hospitals. This can be either related to poor infrastructure and/or lack of understanding of expectations between both teams. Some have also indicated that communications within teams can also

be seen as dysfunctional. However no meeting during the 30 CRC and Liver MDT observations made during the research at OUH (limited observations were made at SUH), could be deemed dysfunctional where patients were put at risk. Discussions can be robust, but these seem more for cases where clinical guidelines seem inadequate or there is insufficient clinical information.

Patchy clinical information was recorded as a weakness. Radiologists from both cohorts indicate variations in the quality of images received in particular from referring hospitals. This can lead to over staging the tumour. The role of the radiologist vis-à-vis the surgeon and oncologists puts demands on the former. This was observed in both cohorts, and through feedback from radiologists i.e. wanting to better understand clinical information is required for treatment planning. Both cohorts also observed the need for a better understanding of the role of the pathologists with regards to MDT's expectations.

Physical MDT room layouts and lack of adequate equipment e.g. microphones did not render easier communications. Radiologists and pathologists do frequently sound muffled since the placement of their equipment reduces clear communications with the rest of the MDT. During the course of the research, the CRC MDT in OUH changed its layout from classroom style to U-shape. The latter facilitated face-to-face discussions that seem to encourage better participation in discussions leading to a more representative consensus. Some have considered the atmosphere in MDTs as intimidating. This is not necessarily off the mark, as MDTs sessions are

very 'business-like' and may not be suitable for all. That said it does not need to preclude a collegiate atmosphere.

The lack of accountability by the MDT was another weakness reported. This was primarily that the MDT is not directly responsible for the patient. This observation however is reflective of where MDTs are placed along the patient pathway. As such it would seem impractical for MDTs to have the same responsibilities and accountabilities for any particular patient, as would the patient's lead clinician. That said, it would seem inevitable that MDTs in due course be made accountable for their decisions given that MDTs are e.g. in the UK formally recognised into the care pathway.

MDTs are resource intensive given the volume and complexities of cases a CRC or Liver MDTs may need to handle especially at the main referral centres. Both cohorts have indicated challenges in managing the patient list. MDTs have limited time to address a disproportionately long list of patients. Thus patients may not get the full benefit of the MDT due to lack of time, incomplete or lack of case preparation and / or inconsistent ordering of the list which does not necessarily reflect the complexity or urgency of a case. Such factors have been described as 'order-effects' (Menon, Cunningham et al. 2016). Order-effects can render MDTs inefficient (time management) and affect their decision-making processes (e.g. unstructured, no decisions). According to observations and feedback from cohorts, late entrees and lack of clarity as to why patients are reviewed more than once further exacerbates the order-effects. Variable attendance either by being completely absent or attending a session intermittently was viewed negatively and affecting clinical

quality. The dominant view was that patients deserve consistency from the MDT and this requires clinicians to have their MDT time protected and attend MDTs responsibly. The consistent absence of surgeons whose patients are discussed at MDTs and lack of quorate of oncologists – both which happens, was deemed unacceptable.

Administrative support and reducing turnover of MDT coordinators and having better-trained coordinators are important assistance cohorts sought. More nursing input was also sought where currently at times only a small fraction of nurses attend and also that their attendance is not rotated. Both cohorts wanted more time for case preparation and complex cases and better Information Technology equipment. Equally they voiced the need for better management of the patient list. Independent of resources and assistance both cohorts emphasised the need for feedback, especially on patient outcomes.

By providing their expertise at MDTs, the cohorts by and large believe they contribute towards ensuring clinical quality. This is done by providing different perspectives on treatment, being adequately prepared and up to date and be able to voice out when clinical information is insufficient. The chair was deemed important particularly when there is clinical uncertainty or evidence is weak. Patient risks were seen to be balanced by promoting discussions and exploring treatment options. This balancing of risk is premised on having constructive and effective discussions. Observations of the MDTs indicate for such discussions to take place, it depends on several factors i.e. (i) the complexity of the case, (ii) the expertise and experience of participants at the

exact time of discussion, (iii) the encouragement to discuss and (iv) order-effects. Here it was observed the chair plays a strategic role in encouraging effective participation. Participation seems curtailed if participants sense a preference from the chair. A docile approach by the chair is also counterproductive as participants, according to interview discussions, equate this to lack of leadership. Thus it seems over time the role and responsibilities of the chair has become more expectant within MDT participants.

As alluded to earlier, MDT meetings help clinicians in their consultation with patients. Participants felt, armed with feedback from the MDT allowed them to manage the anxiety that may otherwise be present between patients and themselves. Providing a conclusive diagnosis and clear treatment options enabled the clinicians to better help patients focus on making treatment choices. A point to note here is that clinicians in both cohorts were unclear especially amongst the lesser experienced clinicians if they were allowed to address diagnosis and treatment options before receiving MDT's views. (Senior clinicians felt there was some inertia amongst junior colleagues while waiting for MDTs decisions.) The point being, what is the weight of the MDT's point of view i.e. is it an advice or guide which must be adhered to and made known to the patient or one left to the patient's lead clinician's discretion to accept in part, fully or totally discard. And is there a responsibility to inform the patient of the MDTs decision? In the UK, NICE guidelines clearly state the need to refer CRC patients to the MDT. The logical extension would be (arguably) MDT is the 'best' body to recommend a course of treatment. In *Rose vs. Thanet Clinical Commissioning Group* (2014) the administrative court ruled that it would be unlawful in failing to implement guidelines issued

by NICE even though there is no statutory duty to do so (Ranson, Cline et al. 2015). The ruling found that the patient has a right to approved drugs and treatments recommended by NICE and merely disagreeing with the guideline is not sufficient reason to not follow the guideline. As such, not discussing a patient with CRC disease at a CRC MDT can be seen to be flouting NICE guidelines. By extending the logic, does a clinician have the right to merely disagree with a MDT's recommendation without showing 'exceptional reasons' as required in *Rose vs Thanet*? As MDTs become standard clinical practice in cancer care it would be useful to clarify its role and powers. The implications of recognising a MDT vis-a-vis NICE guidelines should not be overlooked.

Both cohorts agreed that patients, through MDTs could receive effective care. In addition they state MDTs facilitate integrated care which otherwise would be haphazard and risky for patients, thereby indicating that by providing a MDT based approach clinical competency is enhanced and patients receive better-informed choices for treatment. Evidence for improved care and survival in CRC patients attributed to MDTs has been discussed elsewhere (Morris, Haward et al. 2006, Pillay, Wootten et al. 2016, Rougier, Neoptolemos 1997b, Taylor, Munro et al. 2010).

As shown in Appendix 2 and in Chapter 4, one of the fundamental tenets of unwarranted variation is not providing care in compliance to patients' preferences. This particular distinction is discussed in detail in Chapter 4. Nevertheless both cohorts state that patient preferences are largely not captured nor discussed at MDTs. The general assumption is that either the

nurses or primary clinician is aware of patient's preferences. Here it is useful to clarify according to the respondents, often patients discussed at MDT have not been seen by their specialist clinician yet. Hence the issue of patient preference becomes moot since the patient has yet to know the full clinical position they are in. However MDT observations show postoperative patients preferences are not systematically or consistently discussed either. There does not seem to be requirement per se to do so. However given the MDT's position and its *locus standi* in the care pathway it would be debatable if the MDT has committed an act of unwarranted variation by not considering a patient's preference. The recent expert consensus on the role of MDT remains silent about providing care with regards to patient preferences (Borras, Albrecht et al. 2014).

Question 9

As shown in Results both cohorts shared similar views on some of the categories. They viewed MDTs as having a Type 1 role with regards to chemotoxicity. This view is supported where throughout the period of observing MDTs there was no mention or discussion on the adverse effects related to any kind of systemic treatment. In fact the MDTs that were observed almost never discussed details of the systemic treatments. The focus was more on the overall treatment plan. Oncologists in attendance would quickly come to a broad consensus on what was the preferred treatment approach.

The cohorts rated MDTs playing a Type 2 role with regards to 30-day post surgical mortality. As mentioned in Results, 30-day mortality was generally

viewed as a postoperative issue and MDT discussions were more focussed on deciding if the tumour was operable and if surgery was curative or palliative. Respondents also commented that very few palliative cases are discussed. During the course of this research, respondents were asked to comment why despite surgery being one of the cornerstones of CRC treatment, only approximately 55% of CRC patients in England receive surgery (, National Bowel Cancer Audit - Health & Social Care Information Centre). Almost all were surprised at the low rate and could not offer a reasonable explanation besides speculating on the completeness of the Audit data. Nevertheless all were curious to know what happened to patients that did not receive surgery and if their outcomes were monitored. This remains unanswered.

MDTs are expected to play a more significant role in 1-year mortality and as expected in radiotherapy (RT) and systemic therapies. The MDT role on 1-year mortality was seen as such since MDTs discussed staging, surgical margins and pre and postoperative treatments. These discussions took considerations towards ameliorating local recurrence and advance disease. Equally MDTs would look to refining treatment strategy according to patient's response to treatment. MDTs discuss possible treatment sequences (e.g. first-line of treatment etc). Nevertheless the choice of long or short course radiotherapy seem subjected to local practices. Here the point to consider is that MDTs seem to pre-empt, albeit at times implicitly, treatment goals.

30 & 90-day mortality

Whilst both cohorts rated Type 2 role in 30-day mortality, they differ on 90-day mortality. Both cohorts indicated 30-day mortality was more reflective of technical quality of surgery and postsurgical care. SUH participants were in the opinion - from a prognostic point of view, 90-day mortality was relatively more linked to MDT discussions as is 1-year mortality.

1-year mortality and readmissions

The Type 3 role for MDTs is in line with evidence that MDTs facilitate better patient stratifications, targeted preoperative therapy and reduction of positive circumferential resection margins in patients with rectal cancer (MERCURY Study Group 2006, Burton, Brown et al. 2006b). Studies show improved clinical outcomes and CRC survival when managed by MDTs (Junor, Hole et al. 1994, Kesson, Allardice et al. 2012, Friedland, Bozic et al. 2011, Shah, Arora et al. 2014, Prades, Remue et al. 2015). Of note, risk-adjusted 1-year mortality for patients with colon cancer is more than twice for readmitted patients compared to non-readmitted patients (Greenblatt, Weber et al. 2010). This association is comparable to differences in 1-year mortality between stage I and III disease and patients older than 85 years against those between 66-70 years old (Greenblatt, Weber et al. 2010). A strong association between 30-day readmissions and one-year mortality and 3-year survival has also been reported (Greenblatt, Weber et al. 2010, Schneider, Hyder et al. 2012). Thus published evidence and responses to this research question clearly support the significant role of MDTs play in 1-year mortality. As such providing feedback on 1-year mortality to MDTs may be relevant and useful for assessing quality.

Data on early readmissions for patients with colon cancer supports the use of readmissions within 30 days as a surgical quality indicator (Greenblatt, Weber et al. 2010). Readmission has been associated with excess mortality and the Medicare Payment Advisory Commission in the United States estimates up to 75% of readmissions are preventable (Schneider, Hyder et al. 2012). Population based studies suggest readmissions related to colon cancer treatment are largely preventable surgical complications (Greenblatt, Weber et al. 2010). Most colon cancer readmissions cluster around the 3-7 days within discharge and a high proportion of readmitted patients treated are associated with higher levels of comorbidities, higher rates of preoperative bowel perforation and emergent operation (Schneider, Hyder et al. 2012, Greenblatt, Weber et al. 2010). Among the disease-related variables emergent admissions and poorly differentiated tumour were significantly associated with readmissions while treatment related variables include prolonged length of stay, perioperative blood transfusion, ostomy creation, receiving adjuvant chemotherapy within 30 days of postoperative discharge, and surgeon and hospital procedure volume (Greenblatt, Weber et al. 2010). The above evidence supports the view from this research that MDTs largely play a Type 1 role in readmissions since factors related to readmissions seem more linked to perioperative care and surgical competence. It could be useful to study the impact fast track discharge of elderly colon cancer patients' with multiple comorbidities undergoing open versus laparoscopic surgery may have on readmissions and mortality rates.

Radiotherapy (Long vs. short course radiotherapy)

Minsky B, in an overview on the use of short-course versus long-course RT treating rectal cancer states the evidence which treatment is preferred is equivocal, hence the approach would mainly be led by local guidelines (Minsky 2012). For example NICE clearly states not to offer short-course preoperative radiotherapy for low risk resectable rectal cancer, while the same should be offered for patients with moderate-risk operable cancer (, Colorectal cancer overview - NICE Pathways). Whereas in Sweden short course RT with delayed surgery as a treatment approach is used to treat resectable rectal tumours (Pettersson, Holm et al. 2012).

Minsky's overview shows both the competing pelvic radiation approaches are meant for reducing risk of local recurrences and shrinking the tumour. The primary end-point being R0 resection. As an aside, and as mentioned above Burton et al. showed the importance MDTs play especially in assessing objective evidence based on MRI findings for treating patients with rectal cancer (Burton, Brown et al. 2006b). These studies support the view that MDT plays a Type 3 role in assessing treatment sequences and options. This as shown above is in tandem with the view that one of MDT's role is to formulate treatment goals.

Adjuvant chemotherapy

The results from this research question where the view largely was that MDT has a Type 3 role in reducing variation in prescribing adjuvant chemotherapy is not surprising given the nature of the MDTs composition and duties. This result supports other studies on the increase uptake of chemotherapy in

patients discussed at MDTs (Forrest, McMillan et al. 2005, Back, Ang et al. 2007). This again intimates the role MDT's seem to play along the treatment continuum.

Managing chemotoxicity

The primary view held by respondents was that it was not the role of MDT to manage chemotoxicity per se, though it does take into account potential side effects and possible consequences recommended treatment(s) might cause. Nevertheless it would be important to note the difference between both cohorts, since SUH was unequivocal MDTs had only a Type 1 role, whereas OUH ranged from Type 1 to 3. Such distinctions may be relevant to address when trying to define roles and responsibilities of MDTs.

Notwithstanding the benefits of clinical and medical oncology treatments for CRC, acute and long-term toxicities related to these treatments have been well recorded. These can affect quality of life through a range of changes in physical appearances, impairment of bowel, bladder and sexual function (Van de Velde, Boelens et al. 2014, Aklilu, Eng 2011). However a large number of the respondents took a somewhat pedestrian approach to this question waving it off as though it does and should not concern the MDT. If MDTs generally took that approach, it is possible patients might not receive sufficient or appropriate care when their quality of life is significantly affected which in turn may dissuade them from continuing with their treatment. Improved communications between all stakeholders particularly between treating clinician and patient should be encouraged. Feedback to MDTs on

patient's progress and how they cope with toxicities could inform prospective MDT decision-making.

Question 10

Collectively both cohorts rated five key Type 3 drivers of unwarranted variation in 30-day mortality. Respondents suggested all five drivers are interlinked. Studies (discussed below) have shown variation in outcomes associated to these five drivers cannot be explained by either patient's illness or preferences. It is however less straightforward for viewing emergent admissions as a Type 3 driver. According to some respondents not having sufficient and appropriate resources at Emergency, particularly at out of hours drives unwarranted variation as opposed to the severity of the illness in itself. It would therefore seem an emergency CRC patient treated at a low volume hospital and/or one that lacks specialist care (e.g. out of hours) faces a higher risk of unwarranted variation. Evidence on emergent cases is discussed further below.

Underuse of effective treatment (Type 2 driver) according to respondents happens largely if comorbidities or response to drugs are not actively taken into consideration and notably if patients are not discussed at MDTs. According to SUH respondents, some clinicians from district or smaller hospitals still either refuse or only reluctantly seek MDT consults. Equally incomplete clinical information too was said to contribute to providing less than optimal care. This according to OUH respondents has at times led to up-staging the tumour and over-treatment. Respondents from both cohorts felt

that limited resources can affect bed availability, consequently causing some earlier than optimal surgical discharge, which can lead to readmissions.

National Cancer Policy

Some OUH participants opined that policies such as process targeting e.g. 2 week 'fast-track clinics', can have unintended consequences. This has been shown to encourage inappropriate referrals (Chohan, Goodwin et al. 2005). Another area cancer policy lays bare is the hub and spoke tiered approach (centralisation of care) to cancer commissioning in the UK as prescribed by the Calman-Hine advisory (Calman, Hine et al. 1995). This approach is predicated on an inference that high volume centres are associated with better outcomes across most cancer procedures and care. However the veracity of this association remains debatable (Menon, Cunningham et al. 2016, Halm, Lee et al. 2002). As discussed in detail in Chapter 4, the English government's policy on conjuring the Cancer Drugs Fund has shown to have significant implications on preference-sensitive care, clinician autonomy and value-based care. Based on these, unintended consequences as a result of cancer policy should not be underestimated.

Emergency and elective admissions

Bass et al. indicate index emergency CRC presentations predict significantly poorer outcomes (Bass, Fleming et al. 2009). Through a population based risk-adjusted study McArdle et al. show emergency CRC presentation in comparison to elective admissions is associated with excess postoperative 30-day mortality and poor 5-year survival (McArdle, Hole 2004). As shown above emergent colon cancer cases are also apt to readmissions affecting

postoperative survival. As such evidence supports the majority view that emergency admissions is a Type 3 driver.

Majority viewed elective admissions as Type 1 driver. Studies show postoperative mortality for elective admissions are significantly lower than emergency admissions (Anderson, Hole et al. 1992, McArdle, Hole 2004, Sjo, Larsen et al. 2009, Ascanelli, Navarra et al. 2003). It is relevant to note that there are many interrelated factors e.g. availability of specialist clinical team, bed management, availability of various treatment modalities, patient's health status and others which can affect postoperative mortality rates that are beyond this discussion.

Low and high volume caseloads

There are many studies on caseloads, be it institutional or surgeon related that have been adequately discussed elsewhere indicating an equivocal relationship between volume and outcomes (Menon, Cunningham et al. 2016). However evidence on rectal cancer care suggest low volume surgeons pose a higher risk to patients, regardless of institutional volume (Menon, Cunningham et al. 2016, Halm, Lee et al. 2002). Majority of respondents from both cohorts predictably suggest there is higher patient risk at low volume centres where for instance low volume surgeons have been shown to prefer abdominoperineal resection (APR) when total mesorectal excision (TME) was an option for treating rectal cancer when the former intervention is known to be associated with poorer outcomes and quality of life (Morris, Quirke et al. 2008). However through discussions with the cohorts, it is hard to discount the possibility that their views on 'volume' are not biased by prevailing

professional perception and policy. Nevertheless, it is unclear if the centralisation of cancer care policy has improved emergent CRC care at all times consistently throughout the year at specialist centres. This area may need more attention especially if the NHS intends to increase its care days and shorten the time taken to confirm cancer diagnosis.

Late stage

From discussions most of the OUH cohort viewed late presentation as *fait accompli* and as such clinical intervention has little impact on outcome, whereas majority in SUH cohort suggested possibilities of unwarranted treatment including withholding treatment. Notwithstanding OUH's views on it as a Type 1 driver, more than a third also viewed it as major (Type 3) driver. This gives a broader spread of views compared to SUH's i.e. confined between Types 2 and 3. Overall results indicate the need to address deeper issues of under treatment, overtreatment or inappropriate treatment in patients presenting late stage disease. There may be clinical challenges associated with operator related operational inadequacies (e.g. lack of out of hours care) and / or technical competencies (e.g. lack of CRC specialist surgeons, imaging facilities), and patient-related factors (e.g. tumour heterogeneity) to confidently ascertain what is deemed 'late stage' and its optimal care. Managing late stage CRC disease, in light of ever increasing knowledge in diagnostics and treatment, and the need for MDT based care does not seem like an 'open and shut' case (Borras, Albrecht et al. 2014).

Comorbidities

OUH respondents largely view comorbidities as either a Type 1 or Type 2 driver, while SUH sees it as Type 2 or Type 3. Overall SUH sees comorbidities having a larger impact as a possible driver. Most participants suggest there is a tendency for treating clinicians to under appreciate the impact comorbidities has on the patients' progress and outcomes during cancer treatment. Studies show comorbidities have a larger impact on outcomes for patients with less advanced cancers or cancers with longer mean survival, and are prognostically independent in cancers with poor survival (Piccirillo, Tierney et al. 2004, Read, Tierney et al. 2004). MDT observations indicate an inconsistent attention to comorbidities. Having a structured reporting proforma may be able to address this.

Underuse of effective treatment

This category is one of the core tenets of Wennberg's definition on unwarranted variation (Wennberg 2002). Evidence supports the interview results where this category is a Type 2/3 driver. As mentioned earlier respondents from both cohorts expect MDTs to modulate variation in ensuring provision of standardised effective care. Thus it is reasonable to suggest the variation in question is confined to the inputs and outputs of the MDT.

During the course of observing MDTs, no specific decision on surgical techniques e.g. APR or TME, nor neoadjuvant or adjuvant treatment regimes were specifically discussed. This could be on the assumption treatment protocols shall be as per guidelines. Nevertheless details of administered

treatments were not seen at MDTs when patient records are shown. However MDT discussions on the sequence of treatment was observed.

APR is generally associated with poorer outcomes, but may be the 'only' option for selected complex cases. In contrast in less complex cases TME / AR have led to better local disease control and overall survival (Kapiteijn, Putter et al. 2002, Martling, Holm et al. 2000, Wibe, Møller et al. 2002, Heald, Ryall 1986). In Sweden the introduction of TME, between 1994 to 1997 has seen a 60% to 27% reduction in APR rates (Martling, Holm et al. 2000) while in England between 1998 and 2004 there was substantial variation in surgical practice where surgeons with low caseload are most likely to perform an APR (Morris, Quirke et al. 2008). Independent of case-mix, significant variation was observed in the use of APR as opposed to AR when both procedures were a choice for patients in England (Morris, Quirke et al. 2008).

A systematic review shows a 39% - 71% variation on the use of adjuvant chemotherapy in patients with stage III colon cancer (Etzioni, El-Khoueiry et al. 2008). Notably, this review also showed whilst one of the reasons for underuse is not being referred to an oncologist by the treating surgeon (in a non-MDT based care model), but being seen by an oncologist does not necessarily assure patients would receive standard adjuvant chemotherapy either (Luo, Giordano et al. 2007). Study by Ayanian et al. found use of adjuvant chemotherapy for CRC varied substantially by age, marital status, race and hospital volume (Ayanian, Zaslavsky et al. 2003). Meanwhile McGory et al. suggest low socioeconomic status predicts underuse of chemotherapy or radiotherapy in CRC care (McGory, Zingmond et al. 2006).

None of the MDTs observed showed transparently links between treatment decisions and guidelines (by and large its assumed) nor comparisons against previous decisions. It would also seem modulation of variation within MDTs' is directly subjected to who is present at the exact time when a case is discussed.

Adverse drug interactions

Cancer patients receive numerous drugs aimed at addressing their cancer, comorbidities and need for supportive care. By and large both cohorts rated 'adverse drug interactions' as Type 1 and 2 drivers. Potential adverse drug interactions have been found to be common among cancer patients and most often comprised of drugs to treat comorbidities (Riechelmann, Tannock et al. 2007), likewise the length of stay and the number of prescribed drugs are risk factors (Riechelmann, Del Giglio 2009). The majority of the respondents viewed this aspect as becoming more complex when patients have had extensive surgery, suffer from multiple morbidities or are treated at hospitals with limited specialist care. The evidence in this category links up with the section above on 'comorbidities'. From observations it seemed while cohorts gave comorbidities deeper consideration they were possibly too sanguine about adverse drug interactions.

Limited specialist care and quality of postoperative care

It was unsurprising to find limited specialist care rated as a Type 3 driver. Studies show surgery undertaken by surgeons with interest / qualified in colorectal surgery or surgical oncology can achieve considerable improvement in clinical endpoints and overall survival (Schrag, Panageas et

al. 2003, McArdle, Hole 1991, Porter, Soskolne et al. 1998, Borowski, Bradburn et al. 2010, Schrag, Panageas et al. 2002, Martling, Holm et al. 2000). The results suggest links between limited specialist care and quality of postoperative care where the latter was also rated as Type 3 driver.

Uncertainty of scientific evidence

This category is another of Wennberg's tenets on unwarranted variation (Wennberg 2002). The majority of the respondents view this category rather seriously as a driver of unwarranted variation. MDT observations also showed different decision-making approaches occurring when a discussion ensues where evidence is weak on possible surgical options i.e. choice between radical surgery or local excision for patients with rectal tumour that has dramatically reduced subsequent to neoadjuvant treatment, but remnants of the tumour were observed at endoscopy (therefore 'wait and see' approach was not an option any longer). In the case of local excision the discussion centred on the quality of life issues versus the risk of leaving behind lymph node involved with cancer and risking recurrence.

The use of positron emission tomography (PET) scans for diagnosing rectal cancer has also provided grounds for robust discussions. PET scan is able to differentiate between fibrosis or desmoplastic reaction and tumour better than a MRI (magnetic resonance imaging) scan, and this is relevant e.g. in diagnosing recurrent rectal cancer (Van de Velde, Boelens et al. 2014).

The European expert review on CRC MDTs recommends, when faced with weak evidence especially in high-risk patients, referral to specialist centres is

highly advisable (Van de Velde, Boelens et al. 2014), and assumes the specialist centres would know how to address gaps in evidence.

The above MDT observations were made at a specialist centre. It would also seem that clinicians would need to extend the choices discussed at MDTs to patients especially in light of weak evidence lest, by act of omission, the clinician leads the patient to believe that the treatment of choice advised by the MDT was obvious. Be that as it may, practice variation linked to uncertainty of scientific evidence would seem a 'natural occurrence' but imposing a cancer treatment on to a patient without full disclosure about the absence of robust evidence seem inappropriate and unacceptable. Here the patient consent should be encouraged on the basis of such disclosure, which might prompt the patient and their clinician to discuss risk-benefits trade-offs. In parallel MDTs observed did not seem to have visible structured mechanisms on how it learns and retains knowledge. It was primarily participant dependent and interactional.

Premature discharge

Most respondents' viewed premature discharge, if it happened, was largely due to a bed management policy, which they needed to comply with.

A systematic review suggested accelerated recovery and shorten hospital stay showed increase in readmissions rates and increase in mortality in comparison to standard elective care after colorectal cancer surgery (Gouvas, Tan et al. 2009). A study of 149,622 patients who underwent colectomy between 1985 and 2005 showed readmissions rates had increased while length of stay for this procedure reduced (Schneider, Hyder et al. 2012). In

contrast another study suggested 'fast tracking' had not shown evidence of reduction in postoperative complications (Gustafsson, Hausel et al. 2011). Nevertheless hospital performance measures (e.g. bed management, length of stay) that may encourage premature discharge become blunt instruments if the complexity of the patient's postoperative status is not given due consideration. This however requires a fine balance given constraints on resources and capacity.

Care at university vs non-university

Respondents from OUH mentioned significant variation in cancer care affecting patient outcomes between university and non-university hospitals in England, in contrast to SUH respondents suggesting variations between hospitals in Sweden were not significant. Notably this result seems consistent with results on 'limited specialist care', and 'quality of post-operative care'. There was also concern amongst both cohorts about lack of effective care at non-university hospitals particularly if MDTs were not in place or ineffective. Studies show university hospitals had higher uptake of sphincter-sparing surgery and adjuvant chemotherapy than their non-university counterparts (Etzioni, El-Khoueiry et al. 2008).

Socioeconomic deprivation

OUH participants were clear that socioeconomic status was associated with unwarranted variations in cancer care in contrast with SUH cohort believing there is equality in the cancer care provided within Sweden. Regional Oncological Centres in Sweden were established in the 1980s to develop cancer care guidelines and equal access to best practices and treatment

(Cavalli-Björkman, Lambe et al. 2011). However evidence indicates social disparities in managing CRC particularly between those with low education to high education levels in Sweden (Cavalli-Björkman, Lambe et al. 2011). Studies suggest patients with CRC from deprived socioeconomic clusters are likely to present as emergency cases, have higher levels of comorbidities and have <12 lymph nodes examined, all of which lend towards a greater 30-day postoperative mortality and reduced long-term survival (Aarts, Lemmens et al. 2010, Oliphant, Nicholson et al. 2013, Morris, Taylor et al. 2011, Wrigley, Roderick et al. 2003). As such achieving equality in access and quality care can modulate mortality rates. It might be relevant to study how (e.g. structure, functions and accountabilities) Sweden implements its cancer care policy to achieve equality.

Non-adherence or not seeking patients' preferences

Both cohorts felt clinicians believe treatments they propose are in accordance with patients' wishes. In line with results from earlier questions, both cohorts have also indicated the difficulties or absence of obtaining patient's preferences at MDTs, where for example NICE encourages a MDT discussion prior to meeting with patients to discuss treatment options (, Colorectal cancer overview - NICE Pathways). A recent systematic review was undertaken to assess published patient preferences across the whole CRC treatment pathway (Currie, Askari et al. 2015). This review showed patients (especially those who had chemotherapy previously) value moderate survival benefit over the debilities from adjuvant therapy in order to minimise personal regret and concerns their dependents may have. Stomas are most viewed poorly, indicating quality of life seem to be driving patient preference. Studies

included did not show any particular patient characteristics that could predict patient preference for surgical treatment options. Wennberg and colleagues have also argued that patient preferences should be the dominant factor when choosing treatment plans (Barry, Mulley et al. 1988). It may not be implausible that clinicians who make treatment decisions (albeit vicariously) for the patients believe their decision-making approach is underpinned on principles of 'shared-decision making' model. 'Preference' presumes choice, which in turn is linked to a complex myriad health system-based and patient related factors (Menon, Cunningham et al. 2016). MDT observations did not indicate patients' preferences being discussed on a consistent basis. None of the electronic documents shown at (post surgical) MDTs indicated patient preferences being documented.

Question 11

As the results indicate almost all the respondents are unaware of the term 'unwarranted variation'. The results were mixed in terms of understanding the implications of unwarranted variation on patient outcomes. It seems from the interviews and observations, MDTs could do with some clear parameters as to what they see fit to demarcate as unwarranted variation. Some have suggested that unwarranted variation should be known on real-time basis, as it would inform decision-making. This seems a reasonable and responsible way forward.

Question 12

Both cohorts suggested the importance of feedback in order to address unwarranted variation. They also emphasised the need for evidence-based

care and the need to measure quality. Overall one of the final themes to address unwarranted variation is 'improve quality'. Here once again the issue of clinical quality is associated with the reduction of unwarranted variation. The participants' also viewed being up to date was important to ensure quality. This however is not a role MDTs were observed to play consistently nor reliably. Team dynamics were also seen to be important – this is consistent with the views expressed above where value is placed on the need for discussions within MDTs. Understandably catering for patient's preferences is expressed. Though it cannot be discounted that the participants may have been influenced to suggest so (about patient preferences) since they were shown the definitions of unwarranted variation a few minutes before answering this question. However, it may be useful to ask if MDTs need to factor in patient's preferences in their recommendations. This may allow an opportunity to mitigate preconceived bias by MDT and/ or treating clinician and patients.

A common point the cohorts raised was the need to reach consensus as a way of addressing unwarranted variation. 'Consensus' is commonly seen in the MDT related literature and spoken about amongst MDT participants, especially when an unpopular approach is expressed. It is important to ask what is meant by 'consensus' and in what circumstances is this relevant. For instance does reaching a consensus on APR make it correct when there was no surgeon skilled in sphincter-saving surgery to give an opinion and the MRI images were of poor quality? Or pressing for neoadjuvant treatment because that was the dominant opinion amongst oncologists present when the meeting had only few surgeons? In one of the MDTs a show of hand was used to

decide on a case. As such are all opinions to be weighted equally? Does 'consensus' mean evidence-based? These issues require some reengineering of MDT processes and rethinking of its accountabilities.

MDT observations

As mentioned earlier, the development of a team-based approach is an impetus towards a change in clinical practice on how patients with complex diseases such as cancer are managed. The term 'team' in MDT however, at least in practice, seems nothing more than having a group of specialists come together to discuss cases. Outside of an MDT they are not seen as a 'team'. The National Cancer Action Team (NCAT) in 2010 based on a survey of 2000 MDT members spelt out the characteristics of an effective MDT. This study is useful for MDTs to assess themselves against their counterparts. It however works on the concept of one MDT model can serve all types of cancer. This assumption, based on observations during this research, needs to be tested. Observations during this research showed variations in member's perception of their CRC MDT's role. This suggests there is a need to address an upstream gap i.e. defining a core purpose. A well-defined core purpose is relevant to building a cohesive team, the cornerstone towards long-term sustainability (Collins, Porras 1996). Collin and Porras in their seminal work provide a framework for developing a core purpose (Collins, Porras 2005). Notably they show that core purpose needs to go beyond mere description of an organisation's activities. Core purpose, they articulate, gets at the deeper reasons for an entity's existence. This should not be confused with specific goals or business strategies. While purpose itself does not change, it should inspire change. A core purpose is bigger than a charismatic leader, product,

service team or technology. The following are five important characteristics of a company's core purpose as identified by Collin and Porras adapted for CRC MDTs:

- (i) It's inspiring to those *inside* the MDT.
- (ii) It's something that remains for decades from now as it is today.
- (iii) It should help the MDT think expansively about what it *could* do but isn't doing.
- (iv) It should help MDT decide what *not* to do.
- (v) It is truly authentic to that specific MDT in a specific service provider.

Observations also suggest the CRC MDTs were not entirely clear on who their primary and secondary clients are. This can lead to a potpourri of activities sending mixed messages to MDT members on priorities. A point to note here is the discrepancy that may exacerbate the situation i.e. the aforementioned NCAT report (2010) states MDTs provide recommendations rather than decisions, while NICE's Guidance on cancer services (2004) states MDTs are responsible for the management of all colorectal cancer patients. Both these statements are not aligned to each other, thus collectively do not unequivocally identify who is CRC MDTs primary customer i.e. is it the patient or the treating clinician or the hospital itself? As suggested by Collin and Porras's study, identifying MDTs core purpose can be the impetus towards encouraging better attendance and being engaged in meetings. This can improve enthusiasm. As such having attendance taken as a punitive measure, albeit veiled, suggest lack of alignment between aspirations expert members may have against what the MDT is trying to achieve.

Receiving feedback is important for planning. That said it is important to know what feedback is relevant against targets and goals an organisation sets. A national survey shows communications between MDT coordinators and primary care is poor (Soukop, Robinson et al. 2007). Thus how does this correlate to its core purpose and is it a responsibility of all MDTs is not clearly shown anywhere.

While it is important to receive feedback on patient outcomes, the question is, is this more relevant if the MDT's primary customer is the treating clinician or if its core purpose for example is to improve clinical practice in cancer management?

Thus the question arises, what is the MDT's business? The answer based on this research observation is neither clear nor consistent since at an aggregate level the role MDTs play according to its members is highly diverse.

Lack of feedback is again suggestive of misalignment between members' expectations and MDT's business. Feedback to members needs to be aligned to areas the MDT wants measured to assess its progress and effectiveness. As such fragmentation of support systems e.g. IT, and challenges in obtaining resources are symptomatic of the lack of clarity of MDT's purpose and possibly relevance. The overburdened coordinators, nurses and chairpersons face could be symbolic of this. Logistical needs discussed during this research are retrospective, and do not necessary cater for the future. Therefore it would be reasonable to channel institutional resources especially during tough economic times towards areas that have clear links to targets and goals the institution deems as relevant measures of its progress and viability.

While the MDT is filled with clinical expertise, it seems to face gaps in the use of management and organisational theories that can help its advance. Given the calibre within MDTs, it would be reasonable to view MDT as a business unit providing strategic value to the institution and actually improve its clinical quality. Consolidating all cancer MDTs as a single unit could streamline business process (given its current interdependencies), possibly save costs and provide collective leadership. In doing so, it brings MDTs into the folds of mainstream clinical practice which can help address unwarranted variation.

In addition to the above, it is also important to appreciate contextual differences that could impact MDT workings and its leadership. In the UK pursuant to the Calman-Hine report specialist CRC services were centralised. However final decision-making it would seem still rests at the local service provider, unless the patient is cared for at the tertiary hospital. In essence the same was observed in Gothenburg where videoconferences between specialist MDTs and local hospitals took place on a weekly basis and decision-making rests finally on the local clinician. Thus these specialised MDTs worked more like consulting arms rather than decision-making entities.

With regard to centralisation of care (not just MDT consults), emphasizing hospital volume as opposed to just clinicians' volumes is likely a better approach towards improving patient outcomes. This way, the hospital is expected to cater for and provide better perioperative care. These specialist centres should undertake at least a 100-120 CRC related surgeries per year.

Conclusion

Is the team-based cancer care model collectively known as MDT needed? The evidence that cancer is a complex disease and as a result requires multiple specialists to help diagnose and treat patients is compelling. Therefore, it increasingly can be seen as being *negligent* if expert knowledge is not harnessed. The specialist centre model reflects the importance of expert intervention. MDTs have an importance that extends beyond its functional activities based around weekly meetings. Not only do they reaffirm the need for multispecialty approach in cancer care, they could affect clinical practice in particular amongst future specialists. Increasingly MDTs may be the fall-back quality position clinicians will come to rely on. Clinicians relaying MDT views as an entry point to engage their patients also send a message to patients that their clinician's opportunity and ability to discuss at an MDT is in the best interest of the patient. Thus the MDT is viewed as the 'best brains' on their illness. This becomes, albeit implicitly, a brand portraying quality. The rise in the number of MDTs and related entities symbolises this.

The question then arises: if not MDTs, then what? This question must not be confused between the idea of an MDT and how it currently operates.

MDTs are a service innovation – one that disrupts the status quo doctor-patient relationship. In doing so it shifts risks from individual clinicians to a collective group. This is relevant at several levels, let alone malpractices. MDTs will increasingly be seen as a necessary 'quality' mark to establish and maintain clinical legitimacy. As such it could – as is now – impinge on individual clinician's autonomy. This tension should not be underestimated particularly among specialities that traditionally exercised greater authority on

how patients are treated. The need for this 'authority' could affect MDT models. In theory, full autonomy of a single clinician and that of an MDT are mutually incompatible: we can never have both simultaneous and in full. If MDT decisions are binding, then the treating clinician is seen to have lesser freedom to change treatment plans. Alternatively if MDTs are merely advisory then this augments the clinician's autonomy to either choose the MDT's recommendation or to go at it alone. This also allows the clinician to circumvent MDTs.

CRC MDT in the UK arguably started from 2004 with the publication of 'Improving Outcomes in Colorectal Cancers – Manual Update' - 2004 by NICE. Point being it is a relatively new form of clinical practice. It sits at institutional crossroads between clinical practice and senior management. Recognised by government policy yet treated like an inconvenience for presumably not carrying its own weight, i.e. hospitals find it difficult to fully recoup MDTs time costs from commissioners according to senior management in one of the hospitals. By sitting on this crossroads it faces the danger of just drifting without making its desired impact on patients or its own members. An MDT without a clear core purpose, terms and accountability backed with sufficient corporate alignment will render it weak in the face of evolutionary challenges. On the other hand, letting MDTs drift is unwarranted.

There is little reason to believe policy makers and professional medical bodies can or will justify abolishing MDTs. Therefore it is reasonable to assume MDTs as a policy are here to stay. Broad guidelines are provided on its composition and operations, almost nothing touches on its business model. Its

business model needs to create and deliver value, which begs the question who is it creating value for? Christensen and colleagues suggest four interlocking elements within business models that need to come together to create value: customer value proposition, profit formula, key resources and key processes (Johnson, Christensen et al. 2008) that hospitals running MDTs could utilise. Such internal corporate alignment is also strongly emphasised by Collin and Porras based on their seminal study of visionary companies (Collins, Porras 2005). Meanwhile an MDT's business model and operational needs should be reviewed within the framework of the hospital's business plan and business model. Observations suggest MDTs show only marginal tendencies to cater for future needs. There was no indication either of a systematic approach towards innovation or comparable corporate level strategic planning that can help put MDTs in firmer footing. This renders MDTs into a state of facelessness. It is possible this predicament is similar across majority of MDTs. Presumably tripartite effects of increasing volume, faster diagnosis and advances in medical sciences will stress MDTs coping mechanisms and business model. Today's MDTs should explore if they require serious business planning if they are to be accountable, remain relevant and provide value.

Healthcare systems and policy makers continue to espouse about being patient centred. Yet MDT members admit patient preferences are hardly discussed due to one reason or another. Interestingly when probed further no interviewee explored ways patient preferences could (should) be sought, since it would be pertinent to being patient centred. From observations it would seem in practice MDTs are not patient centred as much as they are

disease oriented. Nevertheless since MDT members use MDT decisions to help with patient consultations, it could be a point for further research on how MDTs can empower patients. Considering how patients are armed with information from their Internet searches, it is reasonable to expect cancer patients (and their carers) to interrogate clinical decisions especially if these were made under duress when receiving the bad news. Moreover MDT members had indicated the need to revise initial staging and treatments plans initial clinicians propose.

MDTs in its current *modus operandi* conceivably cause friction between its need for resources and its perceived value. For a start the MDT needs to identify its core purpose. The Collin and Porras framework for developing the core purpose is suggested (Collins, Porras 2005). Based on its purpose it should then review its business model. At present it would seem MDTs operate as an activity within clinical services, hence its facelessness. Through its business model MDTs can, as part of its key processes seek to ameliorate variations in clinical practice and show their value proposition. In addition review and feedback are essential to evaluate if business practices (clinical practices) are relevant and appropriate lest poor practices become codified and perpetuated. The goal here is for MDTs to be sustainable, practical and solutions oriented.

MDTs could be organised according to severity of cases. For example early stage cases where diagnosis is straightforward and has protocolised treatment could be reviewed by a select few experts (e.g. Type 1 MDT) and perhaps done so using web-based platforms. Type 1 MDT can also be

responsible for stratifying the cases. And, a larger MDT (e.g. Type 2 MDT) specifically meets for complex cases where diagnosis and sequence of treatment is not necessarily straightforward. Type 2 MDTs too could meet virtually. Such virtual meetings however require appropriate IT systems. Customised software can help expedite MDT processes, patient reports and feedback to clinicians. Such software could also help in developing case studies for educational purposes.

Where MDTs have face-to-face meetings, the room's layout should be given due consideration. A U-shaped configuration has been observed to facilitate better communications between participants. More importantly a classroom style configuration should be discouraged. In addition, pathologists and radiologists should be clearly seen and heard – since currently either only their backs are seen or their computer screens block them from view. Participants should agree on the expected level and quality of clinical information and format of presentation. Type 1 MDT should be able to order the cases for presentation to Type 2 MDT. This could help mitigate 'order-effects' highlighted by Menon et.al. (Menon, Cunningham et al. 2016).

MDTs require leadership that facilitates communications and collective responsibility within MDT members and a 'collaborative' approach with non-MDT clinicians. The latter can help bridge the two parallel clinical practices (viz. MDT and single-clinician model) seen in CRC care.

One of the possible limitations of these conclusions is that only two MDT sites were explored. Further their socio-economic and cultural differences may also affect the generalizability of these conclusions.

As an on-going process, the science of management and clinical practice will need to act in lockstep to help MDTs face evolutionary challenges to address unwarranted variation in patient outcomes and costs that are unsurprisingly lighting rods of contemporary cancer care systems. Lastly, MDTs collectively as a 21st century cancer service innovation has global implications on patient care and outcomes.

Appendix 1

Title: Study of variations in colorectal cancer outcomes - Role of the MDT

The objectives of the semi-structured interview on Multi Disciplinary Team (MDT) and its meetings (MDMs) are:

- A. To understand the role of MDTs**
- B. To understand MDT workings in providing effective clinical care**
- C. To identify possible drivers of unwarranted variation**

Name of interviewee:

Post in the Trust:

Type of MDT involvement (e.g. lower GI):

How long has interviewee been attending the above MDT?

What is the frequency of the above MDT meetings?

Date of interview:

Questions:

1. How would you define the role of the MDT and your role and responsibilities within it?
2. How does the MDM contribute towards maintaining and/or improvement of quality (clinical effectiveness) in clinical care?
3. What are 2-3 main strengths and weaknesses of the MDT?
4. What type of assistance or resources would be needed to improve MDMs?
5. How do you think you contribute towards clinical care quality through MDMs?
6. How do you use the information / knowledge gathered through MDMs to help with your day-to-day clinical practice?
7. How do patients benefit from the MDT? What would be the possible difference in clinical care if their case were not discussed at the MDT?
8. How is a patient's preference towards clinical care discussed and captured at MDMs?

For questions 9 & 10 please use the rating score provided below as your answer:

- 1 = None to Minimal
- 2 = Minimal to Moderate
- 3 = Moderate to Significant

9. How would you rate a MDTs role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?

- (a) 30-day mortality
- (b) 90-day mortality
- (c) 1Y mortality
- (d) Readmissions
- (e) Long vs. short course radiotherapy treatment
- (f) Adjuvant chemotherapy treatment
- (g) Managing chemo-toxicity

10. How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?

- a. National Cancer Policy directives
- b. Route of admissions
 - a. Emergency
 - b. Elective
- c. Low volume of cases seen
- d. High volume of cases seen
- e. Late stage presentation
- f. Level of comorbidities

- g. Underuse of effective treatment ☐
- h. Adverse drug interactions ☐
- i. Limited specialist care at hospital ☐
- j. Quality of post-operative care at hospital ☐
- k. Uncertainty of scientific evidence thereby leading to practise variation ☐
- l. Premature discharge from hospital ☐
- m. Care at university hospital versus non-university hospital ☐
- n. Socioeconomic deprivation ☐
- o. Either non adherence to or not seeking patients' preference ☐

11. Are you familiar with the term 'unwarranted variation in outcome' and its possible implications on patient outcomes?

12. How could your MDT address unwarranted variation in clinical care?

Appendix 2

Unwarranted Variation

Unwarranted variation in healthcare refers to differences / variation in treatment that cannot be explained by evidence-based medicine, patient's illness or their preferences.

It can be caused by shortfalls in in three areas:

1. **Effective care** and patient safety, which includes services of proven clinical effectiveness, such as using lipid-lowering agents in patients with coronary artery disease (i.e. underuse of effective care).
2. **Preference-sensitive care**, treatment for conditions that have significant trade-offs in terms of risk and benefits for the patient, e.g. mastectomy vs. lumpectomy. The choice of care should be driven specifically by the patient's own preferences.
3. **Supply-sensitive care** is strongly correlated with healthcare system resource capacity and is generally provided in the absence of medical evidence and clinical theory e.g. patients undergo surgery or imaging due to excess capacity.

Appendix 3

Table 1a: Q1 OUH MDT interview – thematic analysis	
Q1: How would you define the role of the MDT and your role and responsibilities within it?	
Interview transcript	Initial themes
O1: Provide quality control of clinical assessment and guidance on treatment options.	Provide quality control Clinical assessment and guidance Provide Treatment options
O2: Present and discuss images.	Expertise and discuss diagnosis
O3: Oncology management – assess options	Provide oncology treatment options
O4: Offer thoughts on treatment options	Provide treatment options
O5: To bring together multispecialities viz. oncology, liver surgery, interventional radiology, and hepatologist inputs. In addition to radiology, cross-sectional radiology and therapeutic interventions e.g. ablation, image directed guided and u/s guided treatment.	Multispecialty expertise
O6: Ensure consistent high quality decision-making.	Consistent clinical quality
O7: Review all pathology being discussed including referrals	Provide expertise
O8: In one room bring together all clinical experts to handle complex cases (primary role). Secondary role – every case gets discussed. In place like CH good to get an ‘aggressive’ MDT to discuss clinical issues.	Integrated approach Provide multispecialty assessment Robust discussion
O9: Have discussion between experts and patients get similar and optimal treatment. Modulates variation.	Multispecialty discussion Patients receive similar and optimal treatment Reduce variation
O10: Discuss every patient with disease. Come to a view of optimal management of patients.	Discuss all cases Provide options on optimal treatment
O11: To have MDT discussion on patients and come up with treatment plan /recommendation.	Multispecialty discussion Provide treatment options

O12: Discuss all new cases and ensure best standard of care is given. Work out best steps of pathway to follow. Good that meeting is weekly as cancer is complex.	Discuss new cases Provide best standard of care Assess best care approaches
O13: Review patients according to expertise present.	Provide expert based review
O14: First contact for patients to discuss treatment management plans and obtain evidence-based options.	Discuss evidence-based treatment options

Table 1b: Q1 SUH MDT interview – thematic analysis

Q1: How would you define the role of the MDT and your role and responsibilities within it?	
Interview transcript	Initial themes
S1: Structured way of providing info on a case. Available background data (what comes in) then competence from the group to ensure clinical data is sufficient. Own role – HoD Dept. of Surgery, involved in 3 MDTs i.e. liver CRC-liver, and melanoma. Provide clinical input on surgical and medical oncology.	Structured approach Ensure sufficient clinical data Provide expertise
S2: Chair MDT and provide clinical experience. Role of MDT: Propose a treatment plan for the pt and get their consent. Coordinator will get the logistics ready	Provide expertise and chair MDT Propose treatment plan
S3: Role of MDT: Discuss patients amongst MDT colleagues Own role: Provide expertise as senior liver surgeon. Also present cases and summarize the MDT decisions and treatment planning.	Provide expertise, summarize MDT decisions MDT to enable expert discussions
S4: My role: Present my cases; go through all the data. Everyone gets all the info. Involve and engage on other cases too by providing my expertise. Role of MDT: Advisory board on treatment	Present own patients Provide expertise MDT provides advice on treatment
S5: Every patient should get same possibility of being discussed by several MDT experts. There are smaller MDTs with pathologists (once a month). Pathologists not involved in larger MDTs. My role: Present my cases and provide my views on other cases.	Present expertise and own cases MDT should discuss all patients
S6: MDT - Advisory board – gives suggestions/ recommendations. Has a role in ensuring quality of data. Own role – varies, though HoD, usually senior consultant will take the lead in the MDT. However will express clinical views when required.	Provide expertise MDT provides recommendations. Advisory
S7: Find best treatment for pt. Should be MDT based and not on single individual Dr. My role: Represent the patient at MDT.	Represent the patient MDT provide collective view on treatment
S8: Patients get a MDT based confirmation on treatment. Own role: Make sure there is a treatment plan and the patient confirms and understands it. Need to make sure all clinical data is provided to the MDT.	MDT provides treatment plan. Patient services Clinical data check
S9: MDT -To assess patients quickly (efficiently). Own role: coordinate and develop list of patients to be discussed.	Assess patients efficiently List management

S10: MDT - assesses patients quickly and provides common treatment decisions. Own role: coordinate referrals to be discussed at MDT.	Common treatment decisions List management
S11: MDT - To assess patient quickly and ensure clinical quality. Own role: Coordinate liaison between primary clinician and MDT clinicians. Register agreed treatment and inform patients	Efficiency in patient assessment Patient liaison
S12: MDT – provide diagnosis, status, staging and recommended Rx. Own role – as HoD involved in 3 types of MDTs (liver transplant, CRC, and liver mets). Coordinate / chair MDT, facilitate different opinions to ensure treatment suggestions are robust.	Provide diagnosis and treatment suggestions Coordinate MDT
S13: Have meetings with other experts to discuss about patients and hear different views. Some cases are complex therefore need MDT to agree on treatment plan. Own role: present images, describe the scans, show tumours and clarify the case.	Facilitate clinical discussion Provide treatment plan Provide expertise
S14: MDT - Main goal – get equal care and minimise variation in decision-making. Own role: involved in 3 MDTs i.e. general CRC, regional T4 MDT and liver. Make sure clinical decisions follow national guidelines and appropriate for patients. Now also facilitating junior clinicians to make decisions rather than always the seniors.	Reduce variation Leadership and clinical expertise
S15: Agreement on pts treatment. Need confirmation on Rx. Own role: present cases to MDT and clinical opinion	Consensus on treatment Present cases and expertise
S16: Pre-operative MDT role: Verify Dx and give Rx options. Start logistic process. Post-op MDT: Makes sure pt gets optimal adjuvant Rx. MDT makes suggestions only. MDT for complex cases: role to review complex cases and meet pts. Own role: provide surgical input	Verify diagnosis Optimal treatment Integrate care Provide expertise

Appendix 4

Table 2a: Q2 OUH MDT interview – thematic analysis	
Q2: How does the MDM contribute towards maintaining and/or improvement of quality (clinical effectiveness) in clinical care?	
Interview transcript	Initial themes
O1: The MDT plays a significant role as in the early days there were huge variations between clinicians on treatment plans. MDT modulated these variations towards the median and also took more notice of patients' health status etc in treatment planning.	Modulates variation Notice patient's health status in treatment plans
O2: Highlight if there are inadequate images, so that clinician responsible is aware that the patient may require additional imaging.	Highlight information required
O3: Improves quality by reducing variation when treatment is standardised. Modulates variation, can question colleagues.	Reduce variation Question colleagues
O4: Discussing a case through MDT allows patient to have better experienced colleagues to give their opinion. Check and balances against decisions, as patients do get rediscussed.	Expert opinions Check and balance
O5: Ensure most recent patient related factors are taken into account. Discuss all treatment options, in particular liver specific treatment. Enable full discussion to happen and agreement amongst all clinicians.	Up to date patient factors for decision making Treatment options discussed Enable full discussion
O6: Ensures nothing is overlooked. Bring people of varied skills / expertise. Cancer requires different treatment options.	Nothing overlooked Multiple experts discussion
O7: Complete agreement of diagnosis.	Consensus on diagnosis
O8: Make sure patient safety is adhered to. Errors are picked. Set benchmark for knowledge and judgement. Decision making too. Up-to-date / most informed – good drive to be abreast.	Better patient safety Set benchmark Stay up to date
O9: Modulates variation.	Reduce variation
O10: By discussing every pt and taking a collective view – adhere to protocol, reduce maverick behaviour, up to date treatment plans, help avoid error.	Patient safety Reduce variation Up to date treatment

O11: Tries to improve treatment	Improve treatment
O12: Collective decisions for best care. Hope there is an element of reflection.	Collective decision
O13: Full complement of expertise discussing the cases. So patients will get all aspects of care at a single point of time.	Expert discussion Integrated care
O14: Wide array of expertise, gives opportunity to discuss treatment options and in a timely manner. Good for planning especially if radical surgery needs to be undertaken.	Multiple experts discussing Timely care Treatment planning

Table 2b: Q2 SUH MDT interview – thematic analysis

Q2: How does the MDM contribute towards maintaining and/or improvement of quality (clinical effectiveness) in clinical care?	
Interview transcript	Initial themes
S1: Input more homogenous because of MDT and diminish variation.	Reduce variation
S2: Reduces variation – less tendency to do “my way”. More evidence based. There is tendency to provide a better discussion. Better to have MDM to reach consensus when evidence is poor.	Reduce variation Evidence based Consensus approach Better discussion
S3: Take time to prepare and summarise the case – then discuss with MDT. There are cases that may not be clear cut than try to reach consensus. Partly education (would not upstage tumour if no evidence)	Consensus approach Educational
S4: Provide guidelines for treating most patients.	Reduce variation
S5: Used to be pts were selected, now all pts discussed. Guidelines are used to guide Rx.	Evidence based All patients discussed
S6: No individual decisions; collective decisions, allows to manage risk and treatment options given. Optimising treatment.	Collective approach Optimise treatment options
S7: MDT approach – Primary Dr always follows MDT decisions.	Reduce variation
S8: MDT provides quality, i.e. best Rx options. Should be MDT based decisions.	Best treatment options
S9: Quicker decision therefore faster Rx and info provided to pts quicker.	Quicker decisions
S10: Quicker and more uniform decision.	Quick decisions Reduce variation
S11: Quicker Rx decisions. Also pts get decisions sooner.	Quicker decisions
S12: Good opportunity to have a structured discussion about pts with multiple experts. MDT discussions can create new info, therefore improve quality.	Structured discussion New knowledge
S13: MDT based decisions improve patient management.	Patient management

S14: Important part of continuing medical education – get team members to present their cases. Seniors to be present. Feedback from experts critical.	Expert feedback Continuing medical education
S15: Team based Rx decision. Good chance of obtaining optimal Rx options.	Optimal treatment options
S16: In maintaining compliance with national guidelines. Make sure there is limited variation.	Reduce variation Evidence based

Appendix 5

Table 3a: Q3 OUH MDT interview – thematic analysis	
Q3: What are 2-3 main strengths and weaknesses of the MDT?	
Interview transcript	Initial themes
Strengths	
O1: Wide variety of clinicians with experience Strong academic interest i.e. clinical trials – good recruitment possibilities Good quality radiologists	High quality expertise Clinical trials
O2: Every patient gets reviewed by different disciplines Reduce variation upto a point, variation due to lack of evidence	Reduces variation All patients reviewed
O3: Consistency of treatment towards particular conditions Get to know how colleagues work	Consistency in treatment Teamwork
O4: Bring varied clinical experience that can improve patient management Makes sure all information is present and reviewed by the correct experts. Good learning opportunities for junior doctors	Varied clinical experience Improve patient care Learning opportunity
O5: Level of commitment of all members to provide quality input. Multispecialities present All images reviewed Image guided treatment	Varied expertise Quality input
O6: Good mixture of expertise	Varied expertise
O7: Key consultants are present to provide their input Reduce variations in care	Relevant expertise Reduce variations
O8: Robust discussion especially on difficult cases Reduces variation No place for 'cowboys' Decision making becomes transparent	Transparency in decision making Reduce variation Team based care
O9: Opportunity to discuss patients at MDM. Patients get optimal treatment in agreement with other professionals. Integrated approach	Clinical discussion Integrated care

O10: Inclusion of varied specialists Prominence of nursing voice Every patient is discussed	Multiple experts Every patient discussed Nursing voice
O11: Vocal, different discipline will speak up Very experienced and qualified Nursing team holds the team together	Clinical discussions Experienced clinical team
O12: MDT Nurse prep very good All new patients discussed	Multi expert team All new patients discussed Nursing quality
O13: Patient getting benefit from all expertise	Multi expert based care
O14: Multidisciplinary nature gives an opportunity for evidence-based medicine. Involves allied healthcare personnel	Multiple experts

Table 3b: Q3 SUH MDT interview – thematic analysis	
Q3: What are 2-3 main strengths and weaknesses of the MDT?	
Strengths	
Interview transcript	Initial themes
S1: Structured way of how info is gathered Facilitates good clinical quality for patients from elsewhere Creates a learning environment	Structured approach Quality Learning environment
S2: Easier to make tough decisions Easier to talk to patients on diagnosis and treatment Looks at various Rx options probably not thought off earlier Standardisation is good	Make tough decisions Easier to talk to patients Reduce variation Treatment options
S3: Improve quality of clinical data received and summary Get to discuss with colleagues Educational	Improve data quality Discuss with experts Educational
S4: Intellectual capacity MRI presentation important – communications between surgeons and radiologists	Expertise Communications between experts

S5: Collective decision Can have MDT discussions on real-time Pts get decisions faster	Collective decision making Efficiency
S6: Multiple experts providing their opinions Diminishes risk for patients Teaching sessions for junior doctors Evidence based	Manage risk Teaching session Multiple experts
S7: MDT can discuss various angles for complex cases.	Complex cases
S8: As oncology nurses, understand the whole care process, so easier to deal with pts.	Whole care process
S9: Same care for all pts Teamwork Quicker decision making	Reduce variation Quicker decision making
S10: Good that regional hospital can get required expertise from main hospital Standardised care for all pts Specialists focused on cancer, so good for pts.	Reduce variation Specialist care
S11: Standard care for all pts Patients in regional centres also get expert MDT MDT has experience cancer experts	Reduce variation Expertise
S12: Provides a definitive Dx Reduces risk for patients	Definitive diagnosis Reduce risk
S13: Many specialists involved Good and quick decisions	Multiple experts Quality decisions
S14: MDT expertise can enable equal care Its educational	Reduce variation Educational
S15: MDT Have discussion – different points of view, and try and agree on Rx.	Multiple experts Consensus approach
S16: MDT Takes care of logistics – planning for the whole care	Multiple experts Integrated care

Table 3c: Q3 OUH MDT interview – thematic analysis

Q3: What are 2-3 main strengths and weaknesses of the MDT?	
Interview transcript	Initial themes
Weakness	
O1: Communications between main centre and referral hospitals are poor. There are process issues in referral centres that affect patient treatment and/or experience, e.g. patients are not given MDT decision if primary referring consultant is on leave etc. Lack of leadership – ‘ownership’ of patient. Opportunities to see the patient either directly or through remote communications e.g. Skype is highly variable. It is clinically useful to see the patient before MDT as clinical pathways for CRC are at times unclear in comparison to e.g. breast cancer. This helps with treatment decisions that could also incorporate patient’s choice. Clinical information is at times patchy and incomplete. Lack of clarity in who “owns” the patient. Weak lines of responsibility. Basic clinical work-up not done because clinician is waiting for MDT decision.	Poor communications between hospitals Lack of ‘ownership’ of patient care Lack of access to meet patients before MDT Patchy clinical information Pre-MDT inertia
O2: Time consuming Patients get reviewed multiple times Not all clinical information about the patient is available	Time consuming Multiple reviews Patchy clinical information
O3: Incomplete information, esp. from other hospitals Rapid changes in coordinators Don’t know the patient, their performance status, preferences.	Patchy clinical information and patient preferences High turnover of coordinators
O4: Sometimes some voices heard more than others. Dysfunctional teamwork Clinicians need to spend time out of clinic. Problem if certain expertise are lacking.	Poor teamwork Time constraints Attendance
O5: MDT may over run, affects clinic. MDT times now changed to after clinic, thus may not be optimal for clinic patients. Some images and reports not available. Images from outside not as good. At times medical report not available. At times images not uploaded timely because of lack of staff and volume heavy. At times external hospitals may not have seen post-treatment images.	Time management Patchy clinical information
O6: Time clashes with operating list Often decision making is deferred Decisions made are not reviewed. Should review quality Should review all CRC related mortality (3-6 months prior to	Clashes with OT timing No review of decisions Not all cases reviewed

death if any intervention was given) Insufficient palliative cases	
O7: Adding in too many cases Time keeping critical issue -> certain cases are at the end and may not have sufficient expert review No trainees	Patient list management No trainees
O8: Feedback not good People take things personal Decision making at times not truly evidence based; at times personal. Appetite for risk – lesser now No stratification of cases i.e. routine vs. difficult Inefficient preparation of cases	Poor feedback on outcomes Decision making erratic Not evidence based Poor case prep List management
O9: Happens only once a week. Could delay patients being treated and not discussed at MDT. Discussions not going anywhere w/o seeing the patient. Gray areas e.g. role of PET scans for rectal cancer	Delays in treatment Lack of decision Clinical uncertainty
O10: Dominated by individual opinions Pressure to go through list; no depth Pathology input - understanding the nature of the disease especially the rarer ones; be the authority. Reports on rarer subtypes not given.	Individual opinions List management Clinical input
O11: Some people not paying attention, therefore discussing the same thing Too many patients – problem to discuss all with quality Insufficient clinical info on some patients (these could be patients referred by DGH). No one sees the proforma being typed up and no checks.	Team management List management Patchy clinical information No check and balance on decisions
O12: Excluding registrars Time constraints Some surgeons don't attend, some never Meeting at times can be bullying Different agendas – not enough info on pts	Registrars excluded Time constraints Variable attendance Patchy information Some surgeons never attend
O13: Huge cost Not making decisions outside of MDTs	Costly No decision outside MDT
O14: Divergent views on treatment; opinions not always based on objective evidence especially when there are no guidelines. Too little time to discuss patients in depth as MDTs can take too long. IT equipment can fail, than difficult to discuss with referral centre.	Bias in treatment choices Time management List management Equipment failure

Table 3d: Q3 SUH MDT interview – thematic analysis

Q3: What are 2-3 main strengths and weaknesses of the MDT?	
Weakness	
Interview transcript	Initial themes
S1: Delay in decision-making – request for improved quality in data may take a long time No one takes responsibility if things go wrong MDT itself not responsible for the patient. Info is provided but have not interacted with patients	No “responsibility” No patient interaction Delays
S2: Can’t reach a decision “Rubber stamping” – have discussion but no value	Lack of decisions “Rubber stamping”
S3: Could cause a delay e.g. 7 days MDT decisions at times affected due to e.g. lack of beds	Delays Lack of beds
S4: Variations on how guidelines are upheld Length of MDT – too long, at times. People get interrupted	Time management Interruptions Variations on how guidelines upheld
S5: Don’t have every specialist in the room (is pathologist needed all the time?) Dr who presents the case might not be the Dr that treats the pt At times not much interaction i.e. collective decision.	Variable attendance Treating clinician absent Passive involvement
S6: Too long, can affect quality Can be intimidating	Time management Intimidating
S7: Not enough time on certain cases (too fast) Technology at times doesn’t work Participants leave and return and talk on the phone. Need the full board all the time every time.	List management Faulty technology Interruptions
S8: At times no liver surgeon, thus delay Pt discussed only once a week Discussion on pts should not be rushed through Participants should not attend to other things during MDT time	Delays – lack expertise List management Interruptions
S9: Lack of senior Drs Too many pts Drs not prepared Insufficient examination of patients	Lack senior drs List management Poor preparation

S10: Too many pts being discussed with not enough time Can't discuss some pts in detail because not enough time Clinicians not prepared At times oncologist can't attend	List management Poor preparation Oncologist absent
S11: Insufficient time as too many pts Insufficient examination of some complex cases because of time Some clinicians not prepared	List management Poor preparation by clinicians
S12: No patient advocate, therefore not sure of patient's preference Different professions take part, and don't work in a structured way, e.g. discuss Rx when Dx is not discussed fully or confirmed yet Nurses don't say much Not everyone is aware of the written decision is made. There are times there's discrepancies between radiologists and surgeons.	No patient advocate Passive involvement Lack transparency
S13: Not all cases need to be presented, but all are shown – takes time Not enough time to prepare	Time consuming List management
S14: Time consuming, many person-hours. Pre and post prep is time consuming Not structured enough – not time efficient, decision-making not formalised. More time needed for central issues i.e. prep of pt list, MDT notes that should be done immediately etc.	Time consuming Unstructured decision making Insufficient time
S15: Too many cases, so at times only focused on your cases, cannot engage on other cases. At times radiology not well prepared, than it would be problematic.	List management Poor preparation
S16: Too cook-bookish Dependent on which dr attends. Some don't follow guidelines at times even basic cases. Too few people attending – so may not have robust discussion. Variations in how MDTs managed and chaired	Can be rigid Variable attendance Poor compliance of guidelines

Appendix 6

Table 4a: Q4 OUH MDT interview – thematic analysis	
Q4: What type of assistance or resources would be needed to improve multidisciplinary meetings (MDMs)?	
Interview transcript	Initial themes
O1: More clinical evidence is required e.g. through clinical trials etc. Having guidelines, patient's preference and maybe cost-benefits displayed at MDTs are useful.	Clinical trials Clinical guidelines Info on patient's preferences
O2: Clerical staff for organisational purposes. Coordinators change rapidly.	Stable administrative support
O3: Having stable coordinators; at present it seems there's nothing encouraging them to stay.	Stable administrative support
O4: Some cases are unclear – access to clinical letters can be useful; MDT coordinators may need training as they need to pick up clinical matters. MDT outcomes should be made available to all and important to know patient outcomes.	Access to clinical information Better trained coordinators Feedback on patient outcomes
O5: Predictable availability of images and clinical reports. IT should be reliable.	Sufficient clinical information Reliable equipment
O6: Palliative care and gastroenterologist required.	Other clinical expertise
O7: MDT coordinator and IT support critical. No emergency helpline. Technology should be updated. Need better flow of how cases are presented. MDT coordinators have different line manager thus MDT has no idea of their future.	Be part of managing coordinators Reliable IT equipment Better list management
O8: Nurses to stratify routine vs complex cases. Need feedback mechanisms. Nurses to be trained to present relevant medical data for stratification. Coached to frame critical info. Maybe 1-2 registrars should present cases.	List management Feedback mechanisms Nurses to stratify cases Registrars to present cases
O9: Chairing – has variation amongst many MDTs. Volume and time an issue too. Need a better proforma for making sure there's a fruitful discussion. Need to decide who fills in the proforma.	Time constraints Better proforma Filling in proforma Variation in chairing

O10: Data collection to improve. 1.5 hrs per MDT would be better.	More time allocation Improve data collection
O11: MDT coordinator's post - not clear about the future	To be clear on coordinator's post
O12: More time for case prep and presentation. More time to check on patient info that was insufficient. Coordinator job satisfaction maybe an issue. Improve approach of meeting	More time for case preparation Clear about coordinators position
O13: Agreement on improving efficiency e.g. group of competent individuals to make decisions on easier cases. E.g. surgeon and radiologists could make some of the easier decisions.	Core e.g. surgeon and radiologist to make decisions on easier cases
O14: Better IT equipment and support. Good to get second opinions from other MDTs in cases where evidence is weak or lacking expertise.	IT and administrative support Get second opinions when evidence is weak

Table 4b: Q4 SUH MDT interview – thematic analysis

Q4: What type of assistance or resources would be needed to improve multidisciplinary meetings (MDMs)?	
Interview transcript	Initial themes
S1: Easy to access high quality technology e.g. presentation of radiology. Audio and visual quality is essential. Nursing input important	Access to high quality technology Nursing input
S2: More prep time needed. Someone to prepare and present	More prep time Support for prep and present
S3: Technically good. Need more prep time especially complex cases. Can clash with OT time.	Prep time for complex cases Time for OT and MDT
S4: Checklist to follow to present the info for presenting patients. Otherwise could miss things i.e. critical info e.g. clean colon before exam etc. Should put phones away – make MDT time protected.	Have checklist Protect MDT time
S5: Keep current time (good attendance)	Keep current timings
S6: Videoconferencing and imaging facilities must work well all the time. Need pathologist (not present at pre-op MDT)	Reliable infrastructure Relevant expertise
S7: Better and reliable technology	Reliable technology
S8: Lack of time. Time should be “secured”.	Protect MDT time
S9: More clinicians	More experts
S10: More time especially when workload is heavy	More time
S11: Need more coordinators that look into clinical data.	Coordinators
S12: Getting feedback and data sources on decision impact is useful. For CRC more info on biomarkers very important. Previously mtCRC – different instruments measure benefits from surgery (scoring systems). Now we can know if pt has responded to chemo etc. Now we need help of prognostic markers – very useful; just tumour reduction only is not enough. We need more targeted Rx.	Feedback on multimodality treatment
S13: Need more time to review cases.	More prep time
S14: Meeting should be more structured / standardised – what is discussed and way its discussed is important.	More structured meeting What and way cases discussed is key

S15: Important that everyone participates including nurses. Nurses should attend.	Active engagement Nurses to attend
S16: Have 2-3 experts available	More experts

Appendix 7

Table 5a: Q5 OUH MDT interview – thematic analysis	
Q5: How do you think you contribute towards clinical care quality through MDMs?	
Interview transcript	Initial themes
O1: Individuals and MDTs are up-to-date with relevant literature and through MDMs.	Clinicians are up-to-date
O2: Provide accurate presentation of the images. Rectify if deficiencies in image quality exist.	Rectify deficiencies
O3: By giving my clinical opinions, on how patient should be managed. The chair is important to help facilitate when clinical evidence is weak.	Expertise Chair important when evidence weak
O4: Providing accurate clinical info. Having seen the patient, can answer about their fitness and asking questions about treatment.	Represent patient Provide accurate clinical info
O5: By ensuring MDT runs smoothly by making sure that all images are received and reviewed accordingly. Would indicate if image quality is poor, may ask for patient to be rescanned.	Ensure clinical quality
O6: Providing surgical opinions and what's possible. Risk benefit analysis.	Provide expertise Balance clinical risk
O7: Confirm pathology. Emphasize if more biopsy is required.	Provide expertise Facilitate clinical quality
O8: Being able to provide surgical opinions, limits of surgery. Give professional opinions. Provide balance to the discussions.	Provide expertise and balance clinical risks
O9: Present the case in a more concise way to get questions answered.	Case presentation
O10: 25 years in the speciality. Balance between CT and RT. Strong research in the area, data to bear. Have the experience on how its done elsewhere.	Provide expertise and balance on oncological treatment
O11: Impact with patients. Feedback from patients that MDT reviewed their case is positive. Provide information to patients, address their fears.	Can better manage patients

O12: Contribute by being patient centric, standard treatment to be followed.	Help reduce variation
O13: Provide surgical input	Provide expertise
O14: Offering patient best-coordinated care. Work seamlessly for patient care.	Can offer integrated care

Table 5b: Q5 SUH MDT interview – thematic analysis	
Q5: How do you think you contribute towards clinical care quality through MDMs?	
Interview transcript	Initial themes
S1: Based on personal experience, competence and knowledge. Recommendations must be documented – I try and make sure this is done. I know what the 'rules' of MDTs are.	Expertise Document recommendations
S2: Impress on waiting time or radiologic imaging quality. See what is reasonable for patients; at times correcting enthusiastic pts	Ensure imaging quality Patient consultations Impress on waiting times
S3: Have the clinical background of patients. As presenting surgeon have the overview of pts and receive feedback	Present cases and receive feedback
S4: Help by following guidelines and question treatment suggestions, there is then introspection. Some pts are seen before MDT then Rx decided before MDT. MDT then looks into Rx plan and possibly change the plan (One example, 3 days before op). Forum for reflection / learning not really there.	Review clinical decision if patients are seen before MDT Question treatment
S5: Don't contribute much yet as have been away.	New
S6: Mainly in IBD (irritable bowel syndrome); get necessary information for Rx recommendation. Have good judgement on patients with comorbidity, so can give views on this.	Provide patient preferences
S7: Can be contact between pts and MDT. Patient preference taken into account real-time.	Patient liaison

S8: Understand patient preference because we are the contact between Pts and Drs / MDT.	Patient liaison
S9: Contact Drs at the unit and inform extra clinical needs	Coordination
S10: Ensure clinical data is sufficient and complete for MDT presentation	Sufficient clinical data
S11: Make sure data for operation is complete.	Patient safety
S12: Contribute by seeing different perspective from others participating. Take time to go through different alternatives. It takes time to calculate different possible outcomes based on different Rx options. By thinking optimally before MDT.	Offer different perspective Prepare for MDT
S13: Do our best to show the scans and explain the status of the tumour.	Show scan and explain disease
S14: Try to generalise what was discussed at MDT and capture salient points. Capturing the salient points is important, not necessarily easy for various reasons.	Communicate key points
S15: Try to listen to other cases but new to the system, so try and learn and give my best.	Try and learn
S16: Contribute by promoting the discussion and format of discussion. Get more people involved. That way quality can improve.	Promote discussion Encourage active engagement

Appendix 8

Table 6a: Q6 OUH MDT interview – thematic analysis	
Q6: How do you use the information / knowledge gathered through MDMs to help with your day-to-day clinical practice?	
Interview transcript	Initial themes
O1: Have better informed discussions with patients and possibly provide them with treatment options. MDTs enable quality discussions with patients.	Informed discussions with patients Provide treatment options
O2: Higher exposure to a particular disease, this helps with clinical management. This will provide better knowledge of which parts of the image are critical.	Better knowledge
O3: Should get proforma after decision is made at MDT, otherwise doesn't really help on the ground. 90% of the time rubber stamping – very costly.	Need post –MDT proforma
O4: Need MDT approval before patient can be treated. Able to ask if treatment is appropriate.	Confirm treatment plan
O5: Interpretation of images to be more fully informed, e.g. due to treatment there maybe changes that will show in the post treatment scans. Having the MDT helps with interpretation.	Help interpret scans
O6: Range of treatments made known. Hence giving patients a better choice. Spread the “burden” of clinical decision-making.	Spread burden of decision making
O7: By interacting with medical oncologist etc on treatment. Immunohistochemistry staging made very clear at MDT.	More definitive diagnosis and treatment plan
O8: By subscribing to the culture and mood of MDT – helps with patient safety.	Patient safety
O9: Useful to know how similar cases get treated. Also why certain decisions were made. Currently main role is to learn. Need outcomes proforma in the medical records.	Improve clinical knowledge
O10: Information on staging very useful – informs management decision. Generic knowledge gathered -> weakness about outcomes. No real audit about our practice is known.	Informs decision making No outcomes audit

O11: Transferring MDT decisions to the right people (MDT outcomes). Work out appointments esp. for urgent cases. Using proformas expedites appointments rather than letters.	Expedite patient management
O12: Inadequate outcome form. Discussions with colleagues helpful when dealing with patients.	Patient consultations
O13: Helps initially on the decision making process. Not hugely a knowledge enhancing activity.	Helps with initial decision making
O14: Helps plan treatment. Can extrapolate knowledge and experience from MDMs to other patients. MDMs also show what our limitations are.	Treatment planning Improve clinical knowledge Know limitations

Table 6b: Q6 SUH MDT interview – thematic analysis

Q6: How do you use the information / knowledge gathered through MDMs to help with your day-to-day clinical practice?	
Interview transcript	Initial themes
S1: MDT recommendations help discussions with patients. Patients feel we have taken a collective approach for care. Also helpful as it increases my knowledge, this helps with patients.	Informed discussions with patients Increase knowledge
S2: Get updated on clinical guidelines through MDMs. Some learning.	Up to date Learn
S3: Possible Rx already discussed, can present to patient as a collective decision. All patients are managed equally.	Can present to patient collective decision
S4: Use the info (do read a lot) by reflecting previous knowledge gathered at MDT. Can treat patients better now.	Improve knowledge
S5: Use it when with patient. Learn much from MDT discussions. Help with patient's anxiety.	Helps with patient's anxiety
S6: More up to date. Patients feel better that its MDT decision.	Up to date Patients feel better its MDT decision
S7: In contact with pts family. Can explain Rx plan and inform them of practical impact on pts. Can do bookings. (Note: 9 contact nurses, but only 2 attend MDTs).	Inform Rx plan and practical issues Do bookings

S8: Able to explain Rx plan to patients and their family.	Explain to pts and family about Rx
S9: Must call all pts; need to know which pt is urgent	Prioritising patient list
S10: Call pts – inform them of preparations they need to make and when their appointment with the doctor is.	Inform patients of prep and doctor's appointment
S11: Ensure all Rx is coordinated and prepare pt for surgery (pre-hosp prep). Use checklist on clinical evaluation. Order chemo if needed.	Coordinate all treatment Use checklist
S12: Helpful if patient is seen. Most times patient is seen for the first time after MDT. Discuss MDT findings with patient. When preparing for surgery useful to go back to MDT notes to see what was the Rx plan.	Useful to refer to MDT notes before surgery Discuss MDT findings with patients
S13: Learn how surgeons think and what's important for them.	Team work with colleagues
S14: Use either the patient related details to deal with patients or the salient points when dealing with other patients.	Transferable knowledge
S15: Know exactly what to say to patients. Given current experiences, can almost predict Rx recommendations.	Know how to deal with patient
S16: Receive guidance from MDMs and useful when dealing with patients.	Patient consultation

Appendix 9

Table 7a: Q7 OUH MDT interview – thematic analysis	
Q7: How do patients benefit from the MDT? What would be the possible difference in clinical care if their case were not discussed at the MDT?	
Interview transcript	Initial themes
O1: Patients can receive better informed choices. For patients who are 'standard' cases treatment plans would have minimal variation. However at times the MDT is able to spot reporting errors or other clinical problems that could have been missed.	Better informed choices Reduce variation in care Better clinical quality
O2: Every patient gets discussed. If not discussed in MDT clinician might miss out on providing appropriate treatment (non standard). Pre MDT days clinical decisions were sub-optimal.	Better clinical quality
O3: Patients benefit from having a balanced view, thus more rational approach.	Balanced approach
O4: Patient benefits from MDT expertise. If not discussed, patient may not get the expertise required. MDT makes patients treatment timelier.	Better clinical quality
O5: Patients benefit because all therapeutic options are discussed since very good set of experts are assembled. Otherwise patients may not get full range of options.	Better choices
O6: Get consensus (2 nd opinions) on their condition and treatment. If not they might not get 'full' options of possible treatments / care (practice variation)	Clinical quality Better choices
O7: Quality is audited; thus MDT has check and balance.	Clinical quality
O8: Time efficiency is given through MDTs for the patient. Improves decision making, otherwise slows down decision making and quality of diagnosis i.e. individualised practice variation.	Otherwise slow Improves decision making Reduce variation
O9: Patients get a team of specialists to provide care options as opposed to being treated by a single specialist.	Better treatment choices
O10: Patients are getting a MDT view on their treatment and in a timely manner. If not care can be fragmented	MDT based care options Efficiency in time to treatment Integrated care

O11: Benefit from their cases being discussed by room full of experts as opposed to one person. Patients feel reassured.	Best available review of experts
O12: Best standard of care. Yes there would be a difference if not discussed.	Better care
O13: Single point. Difficult to gauge the difference.	Integrated care
O14: If not discussed at MDT, patient care can be haphazard. Not planned thus not appropriate sequential treatment.	Patient care can be haphazard if not through MDT

Table 7b: Q7 SUH MDT interview – thematic analysis	
Q7: How do patients benefit from the MDT? What would be the possible difference in clinical care if their case were not discussed at the MDT?	
Interview transcript	Initial themes
S1: Patients benefit from MDTs as collective decisions and it manages risk of 'poor competence'	Manage risk of poor competence
S2: Pts benefit when variation is managed and not led solely by surgical inclinations. Previously we see the images, then patient, then MDT. Now its images at MDT then see pts.	Reduce variation Quicker care process
S3: Pts would have a better quality of decision i.e. MDT based quality.	Better quality decision
S4: Patients get a more standardised Rx plan now. Risk / chance is reduced. Previously (Pre MDT era) discussions were not as robust in addressing bias.	Reduce variation Reduce chance / risks
S5: Pts benefit by the MDT. Young pts - we want to do more, but not necessarily good. So MDT helps here. Opportunity for elderly patients too.	Reduce unwarranted variation
S6: Reduces risk of individual surgeons not being up to date where they may provide less than optimal care. Can overlook things at scans.	Reduce errors
S7: MDT most important for complex cases but all pts should be discussed.	Useful for complex cases

S8: More variation on clinical decisions if not discussed at MDT. Not sure if all pts will get equal care.	Reduce variation in treatment decisions
S9: Pts might get variations in Rx. Benefit from MDT – more standard care.	Reduce variation
S10: High risk for pts if no MDT.	Manage risk
S11: High risk for patients if there's no MDT based care.	Manage risk
S12: There might be lack of individualised data. Pt advocate required. Clinical care could differ by Dx, and Rx could not be validated or optimal. MDT often does change initial Dx and Rx options. Therefore big variation in outcomes if not discussed at MDT, which affects patients confidence. In Sweden no structured or efficient way (needs to be fast) of getting or providing 2 nd opinions. However Dr or patient can apply to 2 nd opinion board to get 2 nd opinion.	Can mitigate clinical errors Lack quality MDT changes initial Dx and RX
S13: Treatment might not be optimal.	Lack quality
S14: Variability greater if not discussed at MDT. Pts won't get optimal Rx.	Lack quality
S15: Some mistakes can happen, less optimal care and examinations.	Patient safety Quality
S16: Patient can receive poor Rx decisions if not reviewed by MDT.	Lack quality

Appendix 10

Table 8a: Q8 OUH MDT interview – thematic analysis	
Q8: How is a patient's preference towards clinical care discussed and captured at MDMs?	
Interview transcript	Initial themes
O1: At present patient's preference is largely not captured. There could be several reasons for this e.g. primary clinician has not discussed treatment options with the patient as they wait MDTs decision, MDT has not seen the referred patient or there is no single clinician whose responsible (or knows about the patient) for the patient. One way to mitigate this is to speak to the patient prior to MDM or have the patient's refereeing clinician present their patient's case.	Patient's preference largely not captured
O2: Primary clinician will present (if case is brought back to MDT). Not sure why some patients are being rediscussed.	Through treating clinician
O3: Only captured if the member of the MDT has a patient discussed, otherwise no info on patients preferences.	Primary clinician otherwise not captured
O4: Some clinicians may inform the MDT or referral letter may state. No specific box to tick.	Through clinicians Referral letter
O5: Clinicians would have discussed with patients prior to MDT. But now with the change in MDT times, clinicians discuss with patients after MDT. Hence preferences may be in patient notes.	Patient notes Not sure
O6: Not always able to meet patient or person who met the patient not at MDT. So may not be able to know patient's preference. Clinic letter is another possible method.	PP not easily captured Clinic letter
O7: Very little captured (perhaps a proforma is useful).	Limited capture at MDT
O8: Difficult for nurses to present patient's preference as not sure how to anticipate MDM would work on a particular day	Limited capture at MDT
O9: Patient's preference not necessarily captured.	Not captured
O10: Nurses are good at voicing patients preferences. Surgeon too will know.	Nurses and surgeons
O11: Tricky, because many pts have not been seen by the clinician and treatment options not clear yet. Sometimes GPs	Not known before MDT meets

will inform through their referral, at times patients will state their opinions.	Referral letter
O12: CNS's are patient advocates. At times patients are not seen as they come through screening.	Not captured at MDT
O13: At times receive patient letters indicating what they want (letter to Dr). Usually info is poor. Could be significantly improved.	Not captured Referral letter
O14: Likely that patient would have met with clinician or senior nurse before MDT meets. Patients given some options for treatment. Patients also given reassurance that their case is being discussed at MDT.	Through clinician or nurse

Table 8b: Q8 SUH MDT interview – initial coding framework

Q8: How is a patient's preference towards clinical care discussed and captured at MDMs?	
Interview transcript	Initial coding framework
S1: Not at all. Very little at best. At times pts inform their Drs. But MDT is the one that recommends but not decides per se. Dr dealing with the patient should be responsible for pts preference. Recommend on possible and appropriate option. Preferences lend subjectivity which can be another topic for research. Time is also critical for MDMs.	Not at all, very little at best
S2: In most cases pt preference are not seen before MDT. At times 2 nd MDT might capture (partly). Only minority of pts preferences are known.	Largely not captured, only minority of patients known
S3: Problem– might not have seen pt before MDT, so can't know preference.	Not seen before MDT
S4: Drs at O/Pt capture patient preferences. Patients most times have not expressed their preferences. Just want to be cured. (Note: Some non-university hosp surgeons feel there is no need to ask university hospital's MDT views)	Captured at outpatient clinic.
S5: Depends if Dr has met the patient. Usually if surgery is high risk than it is discussed. Mostly not discussed.	Depends if Dr has met the patient Mostly not discussed
S6: Aim: every pt to be seen before MDT. However at times no one knows the patient. Can overlook things at scans.	Not captured
S7: Drs often want to meet pts before MDTs. We provide the patient's preferences.	Captured through nurses
S8: Nurses provide pts preferences.	Through nurses
S9: MDTs contact referral Drs and assess pts's needs. Discuss different Rx and seek agreement with pt.	Contact referral doctor
S10: At times pt has informed Dr. If so then its in the medical record. Referring doctor can inform too, and contact nurses will also know.	Through referral doctors and nurses
S11: MDT can contact referring Dr. Contact nurses are also important as they may have discussed with pts.	Referral doctors and nurses
S12: Not enough. If patient is seen before MDT then pts preference is given but not formalised. It needs to be formalised.	Not captured
S13: Not much discussion on this.	Not captured

S14: Mostly not at all. At times discussed if preference is different from suggested Rx. Better if MDT meets before.	Not captured
S15: Usually Dr treating the patient will know	Through treating clinician
S16: Drawback except when pt is seen. So pt preference is not captured. Dr has to discuss with patient their preferences.	Not captured

Appendix 11

Q9: How would you rate a MDT's role on reducing variation in risk adjusted clinical decisions, outcomes and mortality rates?			
MDT's role	% of OUH respondents (n=14)	% of SUH respondents (n=16)	Difference in percentage points (rounded off)
30-day mortality			
Type 1	64% *(9)	50% *(8)	14
Type 2	21% (3)	31% (5)	10
Type 3	15% (2)	19% (3)	4
90-day mortality			
Type 1	50% (7)	19% (3)	31
Type 2	36% (5)	50% (8)	14
Type 3	14% (2)	31% (5)	17
1Y mortality			
Type 1	7% (1)	0% (0)	7
Type 2	36% (5)	12.5% (2)	24
Type 3	57% (8)	87.5% (14)	31
Readmissions			
Type 1	86% (12)	50% (8)	36
Type 2	14% (2)	25% (4)	11
Type 3	0% (0)	25% (4)	25
Long vs. short course radiotherapy			
Type 1	7% (1)	6% (1)	1
Type 2	36% (5)	13% (2)	23
Type 3	57% (8)	81% (13)	24
Adjuvant chemotherapy			
Type 1	21% (3)	0% (0)	21
Type 2	29% (4)	44% (7)	15
Type 3	50% (7)	56% (9)	6
Managing chemo-toxicity			
Type 1	79% (11)	100% (16)	21
Type 2	14% (2)	0% (0)	14
Type 3	7% (1)	0% (0)	7

*Parentheses indicate number of respondents.

Appendix 12

Q10: How would you rate the following as possible drivers of unwarranted variation in 30-day mortality rates nationally?			
Drivers	OUH (n=14)	SUH (n=16)	Difference in percentage points (rounded off)
National Cancer Policy			
Type 1	78.6%	100%	21
Type 2	7.1%	0%	7
Type 3	14.3%	0%	14
Emergency admissions			
Type 1	7.1%	6%	1
Type 2	28.6%	19%	10
Type 3	64.3%	75%	11
Elective admissions			
Type 1	78.6%	62.5%	16
Type 2	14.3%	37.5%	23
Type 3	7.1%	0%	7
Low volume of cases			
Type 1	0%	6%	6
Type 2	50%	25%	25
Type 3	50%	69%	19
High volume of cases			
Type 1	57.1%	94%	37
Type 2	28.6%	6%	23
Type 3	14.3%	0%	14
Late stage presentation			
Type 1	42.9%	6%	37
Type 2	21.4%	56%	35
Type 3	35.7%	38%	2
Comorbidities			
Type 1	28.6%	0%	29
Type 2	64.3%	75%	11
Type 3	7.1%	25%	18
Underuse of effective treatment			
Type 1	35.7%	12.5%	23
Type 2	57.1%	75%	18
Type 3	7.2%	12.5%	5
Adverse drug interactions			
Type 1	57.1%	31%	26
Type 2	35.7%	69%	33
Type 3	7.2%	0%	7
Limited specialist care			
Type 1	0%	6%	6
Type 2	42.9%	31%	12
Type 3	57.1%	63%	6
Quality of postoperative care			
Type 1	0%	12.5%	13
Type 2	21.4%	18.8%	3

Type 3	78.6%	68.7%	10
Uncertainty of scientific evidence			
Type 1	14.3%	13%	1
Type 2	28.6%	31%	2
Type 3	57.1%	56%	1
Premature discharge			
Type 1	35.7%	38%	2
Type 2	64.3%	56%	8
Type 3	0%	6%	6
Care at university vs. non-university hospital			
Type 1	7.1%	18.8%	12
Type 2	50%	68.7%	19
Type 3	42.9%	12.5%	30
Socioeconomic deprivation			
Type 1	21.4%	56%	35
Type 2	28.6%	38%	9
Type 3	50%	6%	44
Non adherence or not seeking patients' preference			
Type 1	21.4%	37.5%	16
Type 2	71.4%	43.7%	28
Type 3	7.2%	18.8%	12

Appendix 13

Table 11: Q11 OUH MDT interview – results	
Q11: Are you familiar with the term ‘unwarranted variation in outcome’ and its possible implications on patient outcomes?	
Interview transcripts	
OUH	SUH
O1: Not totally familiar	S1: Now I am after reading the framework. We don't talk about unwarranted variation per se. Yes aware of impact on pts.
O2: No / No	S2: No / Not sure of the theory and implications on pts
O3: No / No	S3: No / Yes
O4: No / Yes	S4: No / No
O5: No / No	S5: No / No
O6: Yes / Yes	S6: No / Yes
O7: No / No	S7: No / Yes. Now we are looking into variations.
O8: Yes / Yes	S8: No / Yes
O9: No/ No	S9: No / Yes
O10: Not as defined. Yes	S10: No / Yes
O11: No/No	S11: No / Yes
O12: No / No	S12: Yes / Yes
O13: Only now.	S13: No / Yes
O14: Yes / Yes	S14: Yes / Yes
	S15: No / no
	S16: No / No

Appendix 14

Table 12a: Q12 OUH MDT interview – thematic analysis	
Q12: How could your MDT address unwarranted variation in clinical care?	
Interview transcript	Initial themes
O1: Have optimal clinical information available and have treatment guidelines available at MDTs	Optimal clinical information and show guidelines
O2: Be current with research, standard of care also patients preferences. Not sure of issues affecting referring centres.	Be current Be aware of patient's preferences
O3: Audit on treatment opinions against guidance. MDT should get patient's preferences if patient has been diagnosed with cancer.	Audit on treatment opinions against guidance Insist on knowing patient preferences
O4: Having consensus; present options to patients. Communications will help team dynamics.	Reach consensus Present options to patients Improve team dynamics
O5: Keep offering all possible treatments and ensure patient preference and evidence are taken into account. Consistency of clinical practice is important.	Evidence based treatment options Reduce practice variation
O6: MDT should review its decisions, complications and mortality. Morbidity and mortality meeting not sensitive enough to suboptimal treatment or changes. For example, +ve resection margin not picked up at M&M.	Review decisions, complications and mortality
O7: By comparing with other centres – outcomes and KPI	Compare with other MDTs
O8: Define unwarranted variation and measure as an outcome that could be measured, have benchmark. E.g. Top 10 sources of unwarranted variation and made aware of it at MDT.	Be aware of 'unwarranted variation' at MDTs
O9: Modulate variation. There have been attempts to standardize care between referral and hub. IT presentation should be standardised. Often-incomplete info from referral centres.	Clinical information Standardise presentation Modulate variation

O10: Need to have a measure, not aware of unwarranted variation in care advised by MDT.	Measure unwarranted variation
O11: Need to try and see what 'quality' to measure e.g. mortality, quality of life?	Measure 'quality'
O12: Better communications / effectively – open forum and get more info on patients.	Better team dynamics More information on patients
O13: Hospital in cancer network, should have strong protocols and be evidence based practice. Variation could be expected. National protocols could be modified for local needs. Encourage relevant clinicians and MDT to take decisions so long as protocol is followed. Local variation should be monitored. Feedback very useful.	Monitor and receive feedback
O14: Provide evidence based care. MDT short of expertise should confer with a MDT that has the relevant experience.	Evidence based care Seek second opinion when relevant

Table 12b: Q12 SUH MDT interview – thematic analysis	
Q12: How could your MDT address unwarranted variation in clinical care?	
Interview transcript	Initial themes
S1: A team based approach than single individual. Having better input on diagnosis and don't take premature decisions. Reduce overuse of harmful treatments.	Consensus approach Reduce overuse of harmful Rx
S2: Making sure all staff do what is best for patients. Reduce personal preference-based decisions.	Patient centric approach Reduce bias
S3: Lesser variations because of MDT. Seek equality in MDT decisions.	Consensus approach
S4: Account for relevant issues; all pts should be seen / discussed at MDTs. Not allow clinicians to choose not to present 'clear cut' cases.	All patients to be reviewed at MDT
S5: MDT for hosp that don't have resources to have their own MDT.	Encourage MDTs in hospitals without

	resources
S6: MDT should try and check if certain issues e.g. pt preferences are looked into.	Check if relevant information or issues are discussed
S7: Make sure consensus among MDT colleagues. All patients should get sufficient time in MDT.	Pt list management Consensus
S8: Must have consensus in MDT.	Consensus
S9: Seek help to address gaps in clinical information	Address gaps in clinical information
S10: Make sure clinical data is more complete.	Address gaps in clinical data
S11: Work with colleagues to ensure patient's data is complete.	Address gaps in patient data
S12: Difficult to have consensus, but important for patients. Lack of uniformity and patients would get variable care which is a huge problem.	Strive for consensus
S13: Need more time to review and prepare the scans (including pathology).	Allocate more prep time
S14: Feedback to MDT important. Need feedback on real-time basis.	Have real-time feedback
S15: Try to follow protocols more strictly.	Reduce practice variation
S16: No bias, as patient not seen. Try and get feedback on outcome of surgery.	Feedback on outcome of surgery

Appendix 15 – List of interviewees

OUH	Position
Zahir Soonwalla	HPB surgeon
Andrew Slater	Radiologist (CRC)
Andrew Weaver	Oncologist
Tessa Greenhalgh	Senior Registrar
Rachel Phillips	Radiologist (Liver)
Oliver Jones	CRC surgeon
Lai Mun	Pathologist
Ian Lindsey	CRC surgeon
David Bell	Oncology registrar
Tim Maugham	Oncologist
Jay Bradbury	Specialist nurse
Clare Jacobs	Oncologist
Srikanth Reddy	HPB surgeon
Wasir Saka	Oncologist
SUH	
Peter Naredi	HPB surgeon
Per Lindner	HPB surgeon
Christian Cahlin	HPB surgeon
Eva Angenete	CRC surgeon
Elinor Lindskog	CRC surgeon
Mattias Block	CRC surgeon
Kristina Danielson	Contact nurse
Matilda Oern	Contact nurse
Jolanta Rucinski	MDT coordinator
Lena Soderberg	MDT coordinator
Magdalena Granung	MDT coordinator
Magnus Rizelli	HPB surgeon
Rafid Al-Tahar	Radiologist (CRC)
Karl Kokeda	CRC surgeon
Petra Wieveg	CRC surgeon
Roger Bagge	General surgeon

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Chapter 4: Review the use of Wennberg's framework on unwarranted variation in colorectal cancer care

Introduction

In 2010 there was a 10% difference in 1-year cancer survival across 28 Cancer Networks of England for cancers of the stomach, oesophagus and lung (women) (Office for National Statistics, 2013). Wennberg defines unwarranted variation as variation that cannot be explained by patient's illness, patient's preferences or evidence-based medicine (Mullan 2004).

Variation in cancer care can diffuse across several themes. Studies on clinical quality show unwarranted variations in 30-day postoperative mortality rates after colorectal cancer (CRC) surgery (Downing 2013, Morris, Taylor et al. 2011), and male CRC patients receiving surgery more frequently than female patients (Morris, Quirke et al. 2008). However as mentioned in chapter 1 and elsewhere (Menon, Cunningham et al. 2016) patient-related factors can drive variation in CRC care.

CRC patient outcomes are also affected by organisational infrastructure of hospitals. Cornish et al. show NHS Trusts treating fewer than 190 cases per annum, less than 4 colorectal consultants, less than 4 HDU beds and less than 8 ITU beds were more likely to have a 30-day-risk-adjusted mortality twice than the national average (Cornish, Tekkis et al. 2011). This study also showed surgeons treating fewer than 35 cases per annum have increased postsurgical complications.

Though many studies have shown variation in cancer outcomes, none have applied Wennberg's framework to analyse these variations. The aim of this chapter is to apply Wennberg's framework on unwarranted variation and assess its utility on CRC care.

Wennberg's framework

Jack Wennberg's work on variation is widely acknowledged as the catalyst in bringing the issue of unwarranted variation in healthcare to the forefront (Stano 1993a, Mercuri, Gafni 2011, Birkmeyer, Reames et al. 2013, Appleby, Raleigh et al. 2011). Wennberg initially offered his definition of unwarranted variation in 2002 and refined it by 2004 (Table 1). His body of work (discussed below) highlights variation in clinical practice as a dominant source of unwarranted variation (Wennberg 2004, Wennberg, Gittelsohn 1973a, Wennberg 1984, Wennberg 2002, Wennberg, Cooper 1996, Wennberg 2011a). Variations are unwarranted, he argues, if they cannot be explained by either the patient's illness, preferences or scientific knowledge and after accounting for other external factors e.g. institutional capacity, he hypothesizes it is the clinician's idiosyncratic practice that renders such practice variations. Wennberg divides these unwarranted variations in clinical practice into three categories: (i) effective care, (ii) preference-sensitive care (iii) supply-sensitive care, and states that their proximate causes differ from each other (Table 2) (Wennberg 2002, Wennberg 2011a).

Wennberg hypothesizes that clinical practice inherently embodies the clinician's preferences and/or clinical uncertainties (Weinstein, Bronner et al. 2004b). Table 3 shows the two prevalent hypotheses. Wennberg regards

clinicians' preferences collectively as 'practice style factors' (Weinstein, Bronner et al. 2004b). While viewing unwarranted variation in supply-sensitive care as disproportionate uptake of healthcare resources per capita due to 'over supply' of these resources at the health system level (Wennberg 2002). He suggests such (supply-sensitive) rates of utilisation are supplier-induced rather than determined by patient needs (Wennberg 2002).

Effective care as a category of variation in clinical practice is further explored and discussed in the section below.

Year	Definitions	References
2002	Variation that cannot be attributed to the type or severity of illness or by patient preferences	(Wennberg 2002)
2003	Care that is not consistent with the patient's preference or related to patient's underlying illness	(Wennberg, Wennberg 2003)
2004	Variation that cannot be explained on the basis of illness, patients' preferences' or dictates of scientific medicine	(Mullan 2004)

Table 1: Wennberg's definitions of unwarranted variation in medical care

Unwarranted variation			
Categories of unwarranted variation	Effective care	Preference-sensitive care	Supply-sensitive care
Proximate cause	Underuse	Misuse	Overuse

Table 2: Wennberg's conceptual framework on unwarranted variation

Hypothesis	Details
Practice style	Clinicians as a result of their idiosyncratic practices are the source of medical practice variation.
Professional uncertainty	Physician uncertainty in diagnosing and treatment of a disease renders variation in care and utilisation of healthcare resources.

Table 3: Wennberg's hypotheses related to unwarranted variation

Over nine years (2002-2011) Wennberg provided several definitions of effective care (Table 4). He concludes that effective care is “restricted to interventions that all patients should want as part of the contract they make with their health care systems” (Wennberg, Fisher et al. 2002). In addition The Dartmouth Atlas of Variation, of which Wennberg is the founding member, adds that treatments should be backed by strong scientific evidence on efficacy and safety. In 2011 Wennberg states unwarranted variation in effective care is predominantly related to underuse of effective treatment that has been accepted based on randomised controlled trials or appropriately designed studies including professional consensus on patients who should receive any such treatment (Wennberg 2011b). He however does not necessarily preclude overuse.

‘Overuse’ has occurred when potential harm to a patient from a healthcare service exceeds possible benefit (Chassin, Galvin 1998). Prescribing antibiotics for a viral infection for which the treatment is ineffective is an overuse. ‘Underuse’ is – failure to provide healthcare service when it would have produced a favourable outcome for a patient (Chassin, Galvin 1998). Failures to provide immunisations to children, not treating hypertension are examples of underuse problems. However ‘misuse’ is deemed to have occurred when avoidable complications of treatment occur and consequently the patient does not receive the expected benefits of care (Chassin, Galvin 1998). A patient known to be allergic to penicillin continues to receive it is an example of misuse. Nevertheless misuse is not the same as error, because not all errors cause adverse events or injury (Chassin, Galvin 1998). However unmitigated errors can cause harm.

Year	Definitions of 'effective care'	References
2002	Effective care is said to comprise of the use of services that are supported by well-articulated medical theory and strong evidence for efficacy, as determined by clinical trials or valid cohort studies	(Wennberg, Fisher et al. 2002)
2002	Services whose effectiveness has been proved in clinical trials or well designed cohort studies and whose use does not involve substantial trade-offs that depend on patient preferences	(Wennberg 2002)
2004	Services of proven effectiveness that do not involve significant tradeoffs	(Wennberg 2004).
2007	Services that are proven value and have no significant trade-off – that is, the benefits of the services so far outweigh the risks that all patients with specific medical needs should receive them	(, Search Results - Dartmouth Atlas of Health Care)
2011	Interventions for which the benefits far outweigh the risks	(Wennberg 2011a)

Table 4: Chronology and definitions of Wennberg's category of 'effective care'

Evidence on unwarranted variation – Vermont study

Wennberg's method used to identify unwarranted variation is briefly discussed here before delving into his definitions. According to Wennberg, 'utilization rates' indicate quantity of clinical services delivered and types of cases treated (Wennberg, Gittelsohn 1973b). Wennberg and Gittelsohn's catalytic work in 1973 on variation (Vermont study) used small-area analysis (SAV) analysis on population-level data to quantify rates of utilisation (Wennberg, Gittelsohn 1973b). The authors state variations in healthcare services become more apparent when populations are divided into smaller groups, thereby grouping their study population into 13 distinct hospital catchment or service areas. Claiming the communities they studied were demographically similar; they examined variations in the use of hospital beds, human resources,

expenditure and treatment. The specificity of information in Vermont's data system was important to appraise comparisons between the hospital service areas.

The study observed close to a 2-fold difference in rates for nine surgical procedures. All variations were statistically significant. The most striking case was 10-fold difference in tonsillectomy rates and more than 18-fold difference in its related length of stay. However the study could not relate variation in tonsillectomy rates to prevalence of tonsillitis since no data on prevalence was available. Notwithstanding this, the authors surmised that these variations are most likely associated to differences in clinicians' interpretation of the indications for, and the efficacy of, tonsillectomy.

They observed a correlation between supply of clinicians, surgical rates and the complexity of surgery performed. Also where supply of physicians (as opposed to surgeons) was high, lesser surgeries took place. These observations they claim suggested a proclivity for utilising health services was based more so on clinicians preferences than patient needs. Variations were also observed in reimbursements for diagnostic services. Medicare reimbursements for laboratory services differed by 700 percent, electrocardiogram by 600 percent and x-ray services by 400 percent. In parallel there was a 3-fold difference in costs for physician services. These variations in reimbursements were not attributed to illness patterns. They claim no evidence either from medical literature or their data could substantiate higher reimbursements improved patient outcomes.

They also observed clinicians concentrated their practices in service areas with higher income per capita and tended to avoid those areas with larger proportions of persons age 65 and above.

The above differences, they argue, reflect supply-side induced variations. The quantity and quality of services rendered reflected on idiosyncratic clinical practices. Therefore they argued using rates of utilisation was indicative of variation in clinical practice. However they recognise normalising rate of utilisation is complex and difficult (Wennberg, Gittelsohn 1973b). Nevertheless rates need to be adjusted for patient and/or health system related circumstances to obtain comparable interarea rates. They also acknowledged that how health services are paid for affects clinical practice and consequently utilisation rates (Wennberg, Gittelsohn 1973b).

Other case-mix studies at various levels of aggregation also suggest variations in clinical practice. McArdle et al. reported 20-63% variability in 10-year overall survival after surgical resections with curative intent by one of the 13 surgeons within the same teaching hospital (McArdle, Hole 1991). Meanwhile Schrag et al. reported both hospital and surgeon specific procedure volumes predict outcomes following colon cancer resections, however hospital volume exerts a stronger effect (Schrag, Panageas et al. 2003). Miller et al. observed low volume hospitals are more likely to recover less than 7 lymph nodes and as such patients at low volume hospitals may have their tumour pathologically understaged compared to higher volume hospitals (Miller, Woosley et al. 2004). Nevertheless Burns et al. observed a large variation among institutions and surgeons in terms of colorectal cancer

(CRC) reoperation rates even within teams with high caseloads. They reported a threefold variation between highest and lowest performing trusts and a fivefold difference between surgeons (Burns, Bottle et al. 2011), meanwhile the National Bowel Cancer Audit of NHS hospitals in England and Wales identified a need to investigate the number of patients with colorectal cancer not receiving surgical treatment (, National Bowel Cancer Audit - Health & Social Care Information Centre).

Effective care

Several ideas within the definitions of *effective care* deserve elaboration. For purposes of clarity only Wennberg's contemporary i.e. 2011 definition of 'effective care' will be reviewed in this study. The term *effective* is defined as "the ability of an intervention to produce the desired beneficial effect in actual use" (Dorland 1901). The terms *care*, *interventions* and *services* require further probing, before proceeding to deconstruct the definition to aid in its analysis.

Care is defined as **"responsibility for or attention to health, well-being, and safety"** while *intervention* is defined as **"the act or fact or a means of interfering with the outcome or course especially of a condition or process (as to prevent harm or improve functioning)"** (Pease Jr 1995). As it happens, *care* is broader in scope, while *intervention* is specifically an act of treatment. Intervention is part of care. However 'intervention or treatment' is not necessarily interchangeable with 'care' as the latter includes elements of quality and patient safety, which are separate disciplines (Emanuel, Berwick et al. 2008).

Wennberg's emphasis is on interventions - known to be effective (scientifically accredited) - on the likelihood that it increases the chances of *beneficial outcomes*, thereby consistent on how quality in healthcare is defined (Chassin, Galvin 1998). It seems reasonable to view *beneficial outcomes* as clinical outcomes that patients' could value. For instance application of the total mesorectal excision surgical technique to treat patients with middle and lower third rectal cancer has seen 5-year survival raised from 45% to 75% and a considerable improvement in sexual and urological related quality of life (Enker 1997, Ridgway, Darzi 2003). While Morris et al. show patients with stage IV metastatic (liver) CRC amenable to liver resection after colorectal surgery can have a 5-year survival equivalent to patients with stage III (with nodal metastasis) compared to those not undergoing liver surgery (Morris, Forman et al. 2010).

Wennberg's codification of effective care, prior to 2011, alludes to *services* (as opposed to *intervention*). Though *services* is not explicitly elucidated, it would understandably refer to *health services*, which in turn refers to a broad spectrum of services that affect health including mental and physical illnesses, targeted to prevent and promote health and well being as well as acute, chronic, rehabilitative and palliative care (Chassin, Galvin 1998). These include an array of healthcare practioners e.g. physicians, surgeons, nurses and other healthcare professionals in various care settings (Chassin, Galvin 1998). Therefore given the congruency between 'care' and 'services' it is reasonable to conclude that 'effective care' as defined by Wennberg upto 2011 is related to health services. In contrast the 2011 definition mentions 'intervention'. It is not clear if this version was meant to be diminutive.

Intervention

In contrast to the previous definitions (Table 3) the 2011 definition does not allude to prequalified 'interventions' i.e. that it should be based on scientific evidence. The reason(s) for this specific omission is not known. Instead it includes a proviso i.e. 'for which the benefits outweigh the risks'. This prerequisite is open to interpretation. It can be interpreted as the determining factor for an intervention to be classified as 'effective'. Thus 'effective'-ness hinges on 'benefits' and it would seem patients are the primary beneficiaries. However as discussed below, the term 'benefits' in practice can be evaluated from a larger stakeholder base e.g. clinicians, payers and policy makers, and also with different units of analysis e.g. cost effectiveness, affordability and patient preferences.

Benefits

There is a need to clarify the issues about 'benefits' vis-à-vis costs since not offering the 'benefits' is a *prima facie* case of unwarranted variation (as per Wennberg's 2004 definition). As often observed across healthcare, benefits are often cross-referenced to costs (Brown, Riley et al. 2002, Winawer, Fletcher et al. 2003, Meyerhardt, Mayer 2005, Gyde 1990). As such, benefits and costs are linked to two other interrelated parties i.e. beneficiary and payer (Finkelstein, Trogon et al. 2009, Torio, Andrews 2006, Tangka, Trogon et al. 2010). In some cases both beneficiaries and payers are the same while in others they are different. Thus it would be challenging to approach direct patient-related benefits as suggested in 'effective care' in isolation of related costs, particularly as costs affect access to treatment too (Atun, Jaffray et al. 2015, Farmer, Frenk et al. 2010).

Likewise, benefits can mean different things to patients and clinicians alike especially during complex cancer care. For example two-thirds of cancer patients are willing to undergo therapies they do not want for the sake of their loved ones in particular at end-of-life stages (Gawande 2014). As such the patient acquiesces to the powerful chemotherapies with the hope of prolonging life whereby trading-off the remaining quality of life that may make a difference in end stages. At times it is simpler for the oncologist to just provide the medication than to try and change family's opinion, which at times is based on Internet searches (Gawande 2014).

Gawande also tells "wants are fickle" – doctors who listen to momentary desires their patients have may not be serving the patient's real wishes (Gawande 2014). Here Sessions states that when cancer clinicians take the path of least resistance it can albeit implicitly render false hope (Sessions 2012). This can lead to rapid deterioration of quality of life and painful demise (Sessions 2012). Given the complexities of assessing 'benefits' for and with cancer patients, Sessions asks "How important is quality of life and quality of death; and specifically, what is the cancer physician's role in the dying process?" He stresses the cancer clinician needs to take the role of a leader and have an honest dialogue based on realism and not avoid unpleasant news (Sessions 2012).

Trying to understand how cancer patients with varying degrees of severity and personal predicaments frame their benefits is certainly complex and complicated. How benefits are assessed and the possible reasons for either

withholding or providing a course of cancer treatment becomes relevant in assessing the application of Wennberg's framework in CRC care.

Risks

Definitions

The definition on unwarranted variation and related literature on *effective care* do not provide any clarification on the language used to underscore the definition. Hence it is useful to have a quick overview of related terms to set the scene. The World Health Organisation (WHO) defines *risk* as - "the probability that an unnecessary incident causing harm to a patient will occur" (World Health Organization, World Health Organization 2009). Relatedly WHO defines *patient safety* as - "reduction of risk of unnecessary harm to an acceptable minimum. An acceptable minimum refers to collective notions of given knowledge, resources available and the context in which care was delivered weighed against the risk of non-treatment or other treatment". WHO also views *safety and risk management* as: "Activities or measures taken by an individual or healthcare organisation to prevent, remedy or mitigate the occurrences or reoccurrence of a real or potential patient safety event" (World Health Organization, World Health Organization 2009).

Meanwhile healthcare organisational risk management is defined as: "The process of minimizing risk to an organisation by developing systems to identify and analyse potential hazards to prevent accidents, injuries and other adverse occurrences and by attempting to handle events and incidents which do occur in such a manner that their effect and cost are minimized. Effective risk management has its greatest benefits in application to insurance in order to avert or minimize financial liability" (MeSH, 2009).

From the above, it is reasonable to infer that there are different types of risks. These are borne by three interrelated parties i.e. patients, service providers (institutional and/or individual clinicians) and payers. And risk management encompasses patient safety i.e. reducing medical errors and adverse events (Shojania, Duncan et al. 2001).

Medical errors

In the course of their treatment in addition to inherent patient and treatment related risks, patients face unnecessary external risks that are systems related e.g. medical errors (Shojania, Duncan et al. 2001, Rogers, Gawande et al. 2006). The Institute of Medicine estimates close to 100,000 deaths in the United States annually are due to medical errors (Human 2000). A Dutch study over a ten-year period found patients faced a twofold risk of anastomotic leakage if their colorectal surgery was performed “after hours” i.e. between 15.30 hours and 07.45 hours (Komen, Dijk et al. 2009). The on-call team undertakes after hours surgeries. The authors also reported 14% mortality due to anastomotic leakage. However “in-hours” emergency CRC surgery does not automatically mean it is safer (personal communication C. Cunningham 2016).

Another study on medication error involving oral chemotherapy found errors occurred at every stage of the medication process i.e. ordering dispensing, administration and monitoring and follow-up. Errors in ordering were found to be the highest, followed by administration, dispensing and monitoring and follow-up (Weingart, Toro et al. 2010).

Caseload

Regardless of institutional caseload, surgeons with lower volume of procedures i.e. less than four per annum for colon cancer and 17 cases per annum for CRC pose a risk for patients (Schrag, Panageas et al. 2002, Van Gijn, Gooiker et al. 2010). Meanwhile surgical subspecialty in CRC or higher frequency of rectal resections by surgeon has been shown to be an independent prognostic risk for patient outcomes (Porter, Soskolne et al. 1998). Thus a 14.8 fold difference in annual caseloads observed across cancer networks in England and Wales poses a potential risk to patients (Menon, Cunningham et al. 2016). Reasons for these variations in caseloads and their possible effects on patient outcomes in England and Wales have not been clarified.

Delays

Delays in diagnosing or referring CRC are also known to affect patients' risks as shown through a systematic review by Mitchell et al. This study showed common and interrelated themes influencing practitioner delay – misdiagnosis due to failure to examine the patient, usually rectal examination, receiving negative or false negative tests results and practitioners in rural areas were less likely to refer (Mitchell, Macdonald et al. 2008). The review suggest at least a quarter and possibly up to three quarters of patients with lower gastrointestinal symptoms presented at primary care do not receive rectal examination. However the National Institute for Health and Care Excellence (NICE) guidelines on managing CRC is silent on encouraging digital examinations on patients suspected of rectal cancer at primary care

(, Colorectal cancer overview - NICE Pathways). Data analyses based on 41,299 patients with 24 different cancers in England who took part in the 2010 National Cancer Experience Survey found variations in the number of general practitioner consultations prior to referral to the hospital to diagnose cancer. Variations were related to age (older patients referred earlier), ethnic minorities (white patients referred earlier), gender (male patients referred earlier) and deprivation (affluent patients referred earlier) (Lyratzopoulos, Neal et al. 2012).

Given the above, the phrase ‘...far outweigh **the risks**’ in Wennberg’s definition is difficult to interpret. The immediate and broad assumption is that the ‘risks’ are confined to risks patients and patients’ only face. The difficulty is that risks attributed to cancer care providers and those independent of patient-related factors are broad ranging as some of the studies here suggest: wide variations in 5-year overall survival of patients with CRC across different regions and countries (De Angelis, Sant et al. 2014). Within the UK a 5.1% regional variation in 5-year overall survival exist for patients with colon cancer and 1.3% variation for patients with rectal cancer (De Angelis, Sant et al. 2014). In addition underuse of effective care places patients at risk e.g. under-provision of liver resections for treating metastatic CRC (Morris, Forman et al. 2010) or total mesorectal excision for low-lying rectal tumours (Heald, Moran et al. 1998).

Therefore patients face risks either through acts of commission or omission, which could delay and/or provide inappropriate diagnosis and likewise in treatment.

Financial

Patients with cancer face life-threatening risks. They also face risks of financial hardships due to high cancer care costs. Cancer patients in Washington State were found 2.65 times more likely to be bankrupt compared to people without cancer (Ramsey, Blough et al. 2013). This was due to cancer care bills. Actual cancer care costs can vary based on types of diagnostics, type and duration of intervention, type of provider, location of care and pre-existing financial protection (Ubel, Abernethy et al. 2013). Ubel et al. argue that discussing costs is a crucial component of decision-making as it allows patients to choose lower costs treatments that are viable alternatives and harbour them from financial distress (Ubel, Abernethy et al. 2013). A national survey of oncologists in the United States indicated that treatment costs influence their clinical practice and feel ill equipped to interpret issues on cost-effectiveness when making clinical decisions (Neumann, Palmer et al. 2010).

In summary the risks patients with cancer face are multidimensional (several themes and perspectives) and are not necessarily linear. Therefore in practice clinicians (and patients) may take 'simpler' approaches of weighing up benefits and risks. As such to put in practice the 'outweigh' concept simply based on clinical risks pose on patients seem inadequate. For example, assuming risks are based on patient's perspective, then the type of benefits to outweigh risks is unclear, where benefits could range from e.g. a short-term narrowly fixed clinical end-points or a continuum of trade-offs e.g. quality of life parameters.

The phrase ('...far outweigh the risks...') does not necessarily exclude risks other stakeholders face e.g. clinicians, hospitals or insurers. Costs affect clinical choices, therefore perception of value and clinical practice. As such, 'effective care' could mean providing an intervention deemed to be cost-effective. On the other hand, would providing treatment that is not cost-effective be classified as an unwarranted variation?

Cost-effectiveness

The main purpose of cost-effective analysis (CEA) is to compare the relative value of a proposed intervention in providing better patient outcomes against current practice (Drummond 1997). The CEA's denominator reflects potential health gain from the proposed intervention (e.g. in terms of quality-adjusted life year (QALY), years of life gained, premature births averted) and the numerator is the cost for obtaining that health gain (Drummond 1997). CEA is purported as a measure of efficiency in utilising financial resources in obtaining healthcare outcomes expressed as QALYs (Owens 1998). However it is not as straightforward, since the basic question remains - how much is the payer willing to pay towards the 'benefit' the payment may derive? Herein the concept of thresholds becomes relevant. CEA derived thresholds are value judgements that depend on (i) who is the decision maker (perspective), (ii) how the decision maker values health outcomes and money (trade-offs), (iii) views risks and (iv) availability of resources (Owens 1998, Weinstein, Stason 1977). Credibility of CEAs come into question when trade-off analyses calculating QALYs include quality-of-life factors which are important considerations in clinical practice when patients with cancer need to confront quality of life trade-offs, whilst payers evaluate resource allocation decisions

on difficult choices e.g. short-term versus long-term life-expectancy benefits (Weinstein, Stason 1977). A point to note is that CEA and cost-benefit analysis are two related approaches but not the same and confusion arises when one is loosely referred to as the other or vice-versa (Weinstein, Stason 1977). The use of economic parameters implicitly highlights the need to consider resource constraints in providing healthcare services. This is discussed further through case study below, meanwhile the pros and cons of CEA have been addressed elsewhere (Drummond 1997).

For purposes of completeness - the concept of “optimality” as introduced by Donabedian (Donabedian 2002) is briefly discussed. As a *priori* he defines optimality as ‘balancing healthcare gains against cost of such gains’ – suggesting an optimal point between health care *benefits* and costs; an inflection point beyond which paying more does not derive expected health gains, thereby representing ‘optimally effective’ care (Donabedian 2002). It is at this inflection point Donabedian argues that “maximally effective” care has been achieved (Donabedian 2002). It is important to highlight that concepts such as cost-effectiveness and optimality incorporate financial tools such as discount rates to evaluate future monetary value (Donabedian 2002, Drummond 1997). This makes QALY thresholds subjective. Alternatively the concept of optimality according to Donabedian can be applied where value is deemed at a maximum when optimality is achieved (Donabedian 2002) (Figure 1). Patient groups find optimality acceptable provided they are well informed of the potential harm of the intervention (Gray, Kerr et al. 2013).

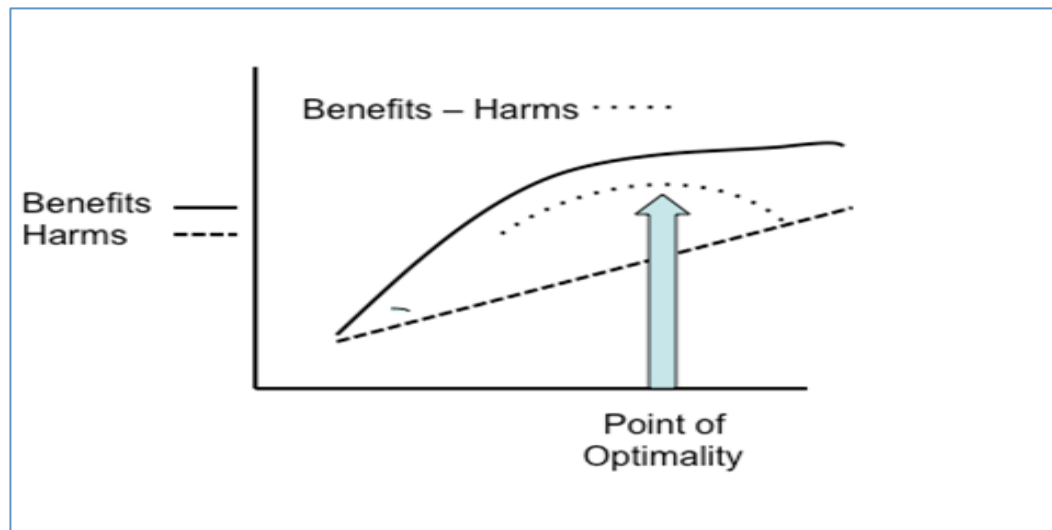


Figure 1: Conceptual treatment benefits vs. harm optimality model. Adopted from Donabedian, 2002.

Wennberg through his Vermont study showed spending more does not correlate to better patient outcomes. He argued that being consistent in providing effective treatment (as a factor of utilisation rates) is an approach towards managing healthcare related costs (Wennberg, Fisher et al. 2004). Thus his rationale for managing unwarranted variation also includes costs. Whilst Wennberg does not specifically argue on the basis of cost-effectiveness as a term, he does so on the basis of 'overuse' of treatment (Wennberg, Gittelsohn 1973a, Wennberg, Fisher et al. 2004). *Overuse* as defined above (Chassin, Galvin 1998) by default provides no-added value thus classified as waste (Berwick, Hackbarth 2012). Wennberg showed that high quality care was not necessarily high cost (Wennberg, Fisher et al. 2005). Likewise Neubauer et al. showed over 12 months a 37% lower cost to provide outpatient adjuvant chemotherapy for non-small-cell lung cancer (NSCLC) patients with no difference in overall survival (Neubauer, Hoverman et al. 2010). The costs difference was mainly due to significantly lower costs for chemotherapy and other medications, and notably less aggressive

approach was taken where chemotherapy beyond third line was not provided. Providing beyond third line demonstrated no additional benefits to patients. This study demonstrated how evidence based pathways can redress cost-effectiveness while maintaining equivalent outcomes and high-value cancer care, i.e. maximizing patient quality of life while minimizing economic burden of care.

Mitigating overuse and misuse saves costs, while mitigating underuse improves quality but also increases costs (Chassin, Galvin 1998). Trying to be cost-effective is an attempt to provide value to as many patients as possible with existing resources. Value is defined as health benefit per dollar spent, and the impact of remedying *underuse* based on value remains unclear (Chassin, Galvin 1998, Porter 2010). However, in practice it would seem that effective treatment is synonymous with cost-effective treatment.

Practice style

In 1984 Wennberg introduces the term “practice style factors” relating to treatment decisions taken by individual clinicians based on their subjective experience, which is not concordant with scientific evidence. And those ‘factors’ also disproportionately influence hospitalization rates (Wennberg 1984). This ‘excessive’ hospitalisation is seen, as ‘overuse’ which according to Wennberg, if addressed will help manage costs. These ‘factors’ are also claimed to create a ‘demand shift’ where rates of utilisation reflect more of clinicians’ set of subjective clinical practices rather than demand due to patient needs (Wennberg, Barnes et al. 1982). The phrase ‘practice’ and ‘practice style’ are not clearly defined (Mercuri, Gafni 2011, Stano 1993a).

Clinical practice

Practice is the appropriate spelling for the noun in both the US and British English and also as a verb in US English, while as a verb in British English its spelt as *practise* (Dictionary 1989). For consistency *practice* shall be used throughout this review. Some of the relevant definitions of *practice* as a noun are: “the actual application or use of an idea, belief or method; the customary, habitual or expected procedure or way of doing something”; the carrying out or exercise of a profession (Dictionary 1989). Thus as working definition for the purposes of this review, clinical practice at the individual clinician level is defined as: **“approaches clinicians take through their decision-making processes to diagnose and/or suggest methods of treatment or treat a patient”**. Thus practice style would relate to different clinical approaches clinicians may take in their practice. If so, a subtle and important point to highlight is the relevance of clinical decision-making approaches that might render differences in clinical practice styles. On the basis of the aforementioned definition, clinical practice can be reasonably assumed to be nodes along a patient’s clinical pathway where clinical decision-making takes place either between clinicians e.g. at multidisciplinary team meetings or between clinicians and patients in clinics. Different clinical practice styles have been observed in particular at the doctor-patient node (Flocke, Miller et al. 2002).

Practice style hypothesis

The practice style hypothesis suggests that clinicians, as a result of their idiosyncratic practices, are the source of medical practice variations and this

is reflected through variation in utilisation rates (Westert, Groenewegen 1999, Wennberg 1984). Wennberg suggested the practice style hypothesis to explain the practice variation phenomenon when age-adjusted studies failed to show correlation between utilisation rates and illness rates, insurance coverage, access and other patient or population related demands (Wennberg 1984).

There are two distinct yet interrelated parts to this hypothesis: (i) inter-practice variations and (ii) interarea variations (these areas maybe based on hospital catchment, post-codes etc). The first part suggests the subjective nature of clinical decisions (where it may not necessarily be evidence based) consequently giving rise to variations in treatment decisions i.e. clinical practice variation. Wennberg and Gittelsohn attribute these variations to clinical uncertainty - arising where there is a lack of professional agreement on a course of treatment (Wennberg, Gittelsohn 1982). However McClure argues that competent clinicians can employ a range of clinical practice styles to provide good patient outcomes – thereby suggesting that practice style variation with variable utilisation rates cannot and should not by default be seen in a negative light (McClure 1982). Differences in practice styles have also been attributed to the range of reactions clinicians' take when faced with clinical uncertainty (Gerrity, DeVellis et al. 1990), while Flocke et al. observed four distinct types of physician practice, namely (i) person-focused (ii) biopsychosocial (iii) biomedical and (iv) high physician control. Physicians with person-focused style have been shown to have the highest quality of physician-patient relationship and patient satisfaction (Flocke, Miller et al.

2002). The issues on clinical uncertainty are discussed further in the clinical uncertainty hypothesis section below.

Studies supporting practice style hypothesis do so on the basis of physicians cause overuse of resources (Salem-Schatz, Avorn et al. 1990, Feinglass, Martin et al. 1991), differences in practice styles (Flocke, Miller et al. 2002, Bertakis, Helms et al. 1995) and geographic variations in utilisation of resources (Welch, Miller et al. 1993, Davis, Gribben et al. 2002, Birkmeyer, Reames et al. 2013).

Birkmeyer et al. reviewed regional variation in 10 surgical procedures rates and found that (i) discretionary procedures for which clinical consensus was wide varied considerably (ii) surgical rates can vary substantially without infringing on clinical guidelines or scientific evidence (iii) procedure rates vary little when gaps between risks and benefits are large (iv) the extent effects of tradeoffs are incorporated into treatment decisions might be relevant in regional rates, (v) regional supply of specialists is a weak predictor of surgical rates (vi) financial incentives can affect regional variation especially common outpatient procedures e.g. cataract surgery, endoscopy and (vii) it is questionable the power scientific medicine can exert to reduce regional variation (Birkmeyer, Reames et al. 2013). These, the authors claim are indicative of clinicians' idiosyncratic practices at the practice level.

Rice offers another view. The clinician according to Rice induces demand when clinical decisions are made on the basis of economic incentives or fear of malpractice suits (Rice 1983). He defines demand inducement to have

occurred when “a physician recommends or provides services that differ from what the patient would choose if he or she had available the same information and knowledge as the physician”. The demand inducement model suggests that the clinician induces or reduces demand subject to reimbursement rates in relation to profit targets; the model predicts a negative relationship between changes in reimbursement and changes in inducing demand (Rice 1983).

Meanwhile Westert et al. (Westert, Groenewegen 1999) state that clinicians have more opportunities to induce demand when clinical “gold” standards are broad and subject to interpretation. In this circumstance there is lower risk of being criticised by peers for a course of action. And this is a critical factor since social ‘approval’ from colleagues is deemed necessary (Westert, Groenewegen 1999).

Equally there are other studies that provide alternative explanations as sources of variation in utilisation rates (Stano 1993b, Long 2002, Westert, Groenewegen 1999).

Stano argues that small area methodologies (i.e. SAV) are inappropriate for substantiating practice style effects through interarea variations in utilisation rates, as (i) it does not clearly distinguish between utilisation of an intervention from other population level determinants of variation e.g. deprivation or morbidity, and (ii) studies evaluating practice level variation do not use SAV thus attempting to use market area (e.g. hospital service areas) analysis to determine role of practice style differences and physician uncertainty is challenging (Stano 1993a). As such Stano’s position is that population based rates obscure practice styles, where for instance differences in rates can be due to same number of clinicians utilising a health resource at different rates

or a different number of clinicians using the health resource at a same rate. In addition since there are other determinants e.g. screening, disease prevalence, patient preferences, wide professional consensus on treatment, supply of healthcare resources and socio-economics that affect utilisation rates, it follows that differences in utilisation rates do not readily establish cause and effect vis-à-vis practice style factors. Thus attributing practice style factors to all or most of the unexplained variation according to Stano is a premature conclusion.

In light of the evidence, Stano argues that common inferences linking inappropriate or high utilisation rates to increase in spend, based on small area variation methods is unsubstantiated (Stano 1993a). This counters the 'area-based variation' approach towards managing healthcare costs by addressing *overuse* and the conjecture of a 'correct' utilisation rate. This is corroborated by a systematic review that found no evidence to support the hypothesis that overuse (suggesting clinical practice) of healthcare resources is a major source of regional variation (Keyhani, Falk et al. 2012).

As an alternative, Long provides the conceptual *resource demand model* to explain medical practice variation (Long 2002). In essence this model suggests that while the clinician calls on (demand) resources related to diagnosing and treating a patient, the clinician also makes the best clinical decision possible contingent upon the (exogenous) constraints they work under. A clinician's own temperament and abilities (endogenous factors), according to Long do also affect practice styles. Broadly exogenous constraints refer to (i) demands exerted by patients where patients expect

their health to be restored to an expected level, (ii) organisational – work environment constraints e.g. practice patterns that are loosely referred as ‘clinical policy’ and (iii) environmental – where clinicians are required to modify their practice to compete or match with other service providers. Long argues that exogenous factors have a large impact on clinical practice patterns. As part of this model, Long introduces the concepts of induced and innate variance. Induced variation is due to exogenous factors (independent variables) while innate variance is the residual variance in a regression analysis. Long presumes the innate variance will be small, and suggest that the innate variance is ‘style’ in the term ‘practice style’ (Long 2002).

Wennberg argues differences in practice style, in particular the propensity to rely on clinicians subjective decision-making is due to the presence of clinical uncertainties (Wennberg, Barnes et al. 1982) and “defensive medicine” (Wennberg 1984). While defensive medicine is unrelated to clinical uncertainties, the professional uncertainty hypothesis is aimed to address clinical uncertainty (Wennberg 1984). This hypothesis is discussed in the section below.

Professional uncertainty hypothesis

Wennberg introduces the professional uncertainty hypothesis to further interpret practice variation (Wennberg, Barnes et al. 1982). Wennberg provides two scenarios when professional uncertainty can occur:

- (i) When there is difficulty in reasonably assessing the patient’s illness, prognosis and treatment outcomes
- (ii) The clinician makes a vicarious decision on treatment that may not correspond with patient’s choice

The professional uncertainty hypothesis is premised on the rate utilisation model, where a statistically normal distribution of rates is expected if the probability of an operation is the same between areas. Wennberg's study utilising SAV across 62 individual hospital service areas observed larger variations (did not conform to statistically normal distribution) of care particularly in conditions without a clear criteria or consensus on treatment e.g. tonsillectomies, as opposed to conditions where professional diagnosis and treatment is without difficulty and disagreement respectively, e.g. paediatric inguinal hernias (Wennberg, Barnes et al. 1982). In brief, treatments that have low variation of utilisation are (i) where a patient's condition can be clearly defined and (ii) there is professional consensus on the value of a particular intervention (distinct from an alternative); on the other hand high variation procedures are to the contrary (Wennberg, Barnes et al. 1982).

Uncertainty in prescribing treatment stems in part from difficulties the clinician has early on in the diagnostic pathway to accurately compartmentalise the patient's illness where the extent of the disease and its treatment outcomes cannot be ascertained definitively (Eddy 1984, Balogh, Miller et al. 2016). However even when patients are appropriately diagnosed and likely outcomes ascertained, the clinician's preference for a particular treatment option might not align with the patient's preference (Wennberg, Barnes et al. 1982). Wennberg calls this misalignment 'demand shift' – a demand related to professional beliefs clinicians hold for an intervention rather than being driven solely by patients' needs (Wennberg, Barnes et al. 1982). He proposes *demand shift* as an alternative explanation lest clinicians' preferences be

misconstrued to be self-serving. Wennberg essentially demarcates his hypothesis into two albeit linked parts i.e. disease related uncertainties (i.e. scientific uncertainties) and clinician's preferences (i.e. demand shift).

Weinstein et al. observed that discretionary clinical practices define who gets what type of surgery, more so since patient's preferences can be misinterpreted as patients commonly delegate decision making (particularly when faced with treatment options and difficult trade-offs) to their clinician (Weinstein, Bronner et al. 2004a). As such a particular pattern of treatment rates set in based on subjective clinical decision-making and personal preferences, which become the "norm" (Eddy 1984, Weinstein, Bronner et al. 2004a). Weinstein calls such rates a "surgical signature" phenomena (Weinstein, Bronner et al. 2004b). The 'surgical signature' is observed to be stable and constant over time (Weinstein, Bronner et al. 2004b, Stano 1993b). And that 'surgical signature' is reflective of interarea practice variation (Weinstein, Bronner et al. 2004b). Nevertheless Stano, as mentioned previously, argues 'surgical signature' phenomena does not necessarily capture practice / patient level factors (Stano 1993b).

The two distinct parts of the professional uncertainty hypothesis are discussed below.

Professional uncertainty

Uncertainties in medical diagnosis and care stem in part from patients presenting non-specific symptoms and inconsistent interobserver reliability (Koran 1975, Wennberg, Barnes et al. 1982, Harris, Lewin et al. 2008). In general it is perceived as where diagnosis is not difficult, variations are

curtailed by professional consensus (Weinstein, Bronner et al. 2004b). However Eddy argues that clinical uncertainty does not necessarily lie at a single point but lies on a continuum, ranging from defining a disease to consequences of different treatments, and is complex (Eddy 1984). This 'starting point' is further substantiated when most people will experience at least one diagnostic error in their lifetime, which could result in devastating harm (Balogh, Miller et al. 2016).

Eddy highlights the struggles in defining what is 'disease' and addressing it, where (i) clues to diagnose diseases can be obscure (contrary to suggestions in textbooks) prompting errors in either missing an existing disease or uncovering unrelated signs and (ii) the "disease" at the time of diagnosis may not be detrimental to the patient, however the condition is viewed as a disease since they presage a potential poor outcome, which requires the clinician to assess probabilities in real-time (Eddy 1984). This adds complexity at the doctor-patient consultation node since probability is not equivalent to certainty and treating the condition does not necessary mean cure either. Eddy remarks that the clinician acts on imperfect knowledge as the need to manage the patient requires synthesizing complex information about the disease, clinical symptoms, understanding the sensitivity and specificity of tests and significance of the test results. And correlate possible outcomes with treatment options and values the patient holds to when trade-offs need to be addressed (Eddy 1984, Eddy 2005). These in totality he states gives rise to wide variations clinicians place on the values of procedures. He adds however, given these clinical complexities, a clinician's tendency would be to draw on simplified heuristics, e.g. focus on quality of life, short vs. long-term

survival, financial costs. This approach overcomes the latent predicament of dealing with probabilities, where heuristically the clinician may take the approach “if there is a chance of the disease than the procedure should be performed”. In conclusion he remarks that given all the uncertainties, incentives and heuristics, clinicians will do what they are comfortable with and that is to “follow the pack” of colleagues which keeps them safe from criticism, free from having to explain their actions and are defended in their action through concurrence with colleagues. This tendency to follow the pack, Eddy argues, is the most important single explanation for regional variations in clinical practice. As mentioned earlier Eddy highlights that clinical uncertainties and their ensuing complexities can exist throughout the continuum of patient care (Eddy 1984, Eddy 2005).

In summary the above seem to argue that clinical lacunae lead to professional uncertainties, which affect clinical decision-making and renders practice variation. And ‘follow the pack’ is one-approach to provide care without necessarily addressing the prevailing uncertainty. Therefore at least conceptually it would seem conceivable that ‘follow the pack’ lends credence to ‘surgical signature’. In addition the more complex a disease is e.g. cancer, the greater the probability of practice variation. To reiterate, Wennberg corrals these subjective clinical leanings as “practice style factors” (Wennberg 1984).

It follows, independent of utilisation rates or access to care; professional uncertainty makes subjective clinical judgment a less reliable assessor of illness or patient outcomes.

Demand shift

Glover's seminal study (discussed in Chapter 1) indicating the inexplicable 10-fold variation in tonsillectomy rates associated to the change in the local Medical Officer (Glover 1938) is another example of clinician-induced demand. In addition, others have also suggested that clinicians induce demand by practicing "defensive medicine" (Wennberg 1984, Rice 1983) and for economic benefits (Rice 1983). Contrary to Wennberg's 'demand shift' Rice provides evidence suggesting clinicians induce demand for economic benefits, where demand inducement was measured as a function of changes in the intensity and quantity of surgical services and laboratory services respectively. Rice states that the demand inducement model predicts an inverse relationship between changes in reimbursement and changes in demand inducement. His interpretation is that the clinician will induce demand up to a desired level of profit. Thus suggesting (i) the increase implies the clinician is not necessarily acting in the best interest of the patient and (ii) the induced services may not necessarily be an effective course of diagnosis or treatment. His study showed decline in Medicare reimbursement rates in Colorado for surgery resulted an increase in the number of surgeries and their intensity, similarly declining reimbursement rates for laboratory services resulted in higher number of laboratory services per consultation (Rice 1983). He concludes by stating, "Demand inducement seems to occur in response to changes in physicians' economic environments". This according to his observation affected three aspects of clinicians' practices (i) intensity of services provided (ii) number of services provided and (iii) number of ancillary services (radiology and laboratory services) ordered. It will be recalled that

Wennberg suggested demand shift hypothesis as an alternative to demand induced for economic reasons. Rice's study (Rice 1983) using individual clinicians as a unit of analysis supports 'practice style factors' hypothesis but not necessarily 'demand shift' where the latter was suggested to distinguish practice variation due to personal economic gains. These findings lend credence to Stano's view that differences in interarea utilisation rates do not distinguish cause and effect with regards to practice style factors (Stano 1993a). Nevertheless professional uncertainty and clinician-induced demand can affect any decision-making node along the patient care pathway (McNeil 2001) and consequently quality.

It remains unclear if Rice's demand inducement model holds for clinicians who receive a fixed salary for their services.

Case study – Cancer Drugs Fund

The Cancer Drugs Fund (CDF) established in England primarily targeted inequities towards a class of cancer drugs that were available but not routinely accessible. The central point was *access*. This case study evaluates Wennberg's framework on unwarranted variation against the lens of access. It does so by looking through two components of access i.e. availability and affordability.

A pan European study revealed variations in the ability for cancer patients to access related drugs, with access varying according to country of residence (Wilking, Jönsson 2005). Countries differed in uptake of selected oncology drugs and the time taken for when these drugs were made available to patients. The Czech Republic, Hungary, Norway, Poland and the UK were

found to be laggards in adopting new cancer drugs in particular for treating breast cancer, colorectal cancer, lung cancer, non Hodgkin's lymphoma and supportive care. Ironically the study reports that UK ranks first in the amount of direct cancer research funding with the charitable sector contributing more than the public sector and yet lags behind other European countries in providing cancer patients access to new cancer drugs. Notably countries that lead health technology development (Sweden, Netherlands and the UK) are not the leading countries in providing access to cancer drugs (viz. Austria, Spain and Switzerland). Across Europe the UK had the most decisive economic evaluations where the National Institute for Health and Care Excellence (NICE) issues guidance for England and the All Wales Medicines Strategy Group and the Scottish Medicines Consortium (SMC) issue guidance for Wales and Scotland respectively. A NICE review takes 62 weeks while SMC takes 12 weeks. Besides the lengthy review period in England, the report indicates challenging budgetary allocations also hinder timely introduction of new cancer drugs at practice levels. This follows the effects on cancer survival rates in England in comparison to similar European countries or so the government argued.

Development of Cancer Drugs Fund

Public healthcare systems provide coverage for medications on the basis of clinical effectiveness and costs, but new cancer drugs are very expensive finding it difficult to meet cost-effectiveness criteria (Chafe, Dhalla et al. 2009). In 2011 the English government through its Department of Health (DH) introduced the £200m CDF as an interim measure till 2014 to improve patient

access to hitherto inaccessible cancer drugs (Stanton 2010, Maynard, Bloor 2011). Critically the government had set up CDF to address the lack of access to cancer drugs NICE deemed not cost-effective and therefore were not recommended for use (Stanton 2010). This lack of access to drugs was particularly notable for patients nearing the end of their lives and to newer drugs and since the set-up of CDF, NICE did not provide any further guidance on new cancer drugs (Stanton 2010). This lack of access or rationing, as it may seem, did not reflect the values society placed especially on access to end-of-life drugs (Stanton 2010). Hence through CDF cancer patients had access to drugs not routinely available through the National Health Service (NHS). As mentioned above CDF was an interim measure while a sustainable pricing mechanism with suppliers was being worked out (Stanton 2010, DoH 2010).

The government's white paper titled 'Equity and excellence: Liberating the NHS' expounded some of the circumstances leading to the formation of the CDF where it states "we are creating a new Cancer Drugs Fund; this fund will support patients to get drugs their doctors recommend" and "shared decision-making will become the norm: no decision about me without me" (DoH 2010). The government's rationale for setting up the CDF was as they claim to know: "patients and clinicians are frustrated and angry that they cannot access some effective cancer medicines on the NHS", and as such the existence of CDF empowers and enables clinicians to prescribe cancer drugs that would extend or improve patient lives (Stanton 2010). Fundamentally CDF started off by enabling oncologists and patients in England unprecedented rapid access to

expensive unfunded cancer drugs in publically funded hospitals that did not need to meet any cost-effective criteria. This seems to give unbridled access to selected patient benefits. Such access however can lead to 'drift' as discussed by Gray & Kerr – clinicians will always try to do more for patients once an intervention is widely used even if the criteria of the intervention does not necessarily fit the patient profile (as per clinical trials), thus causing the criteria to drift (Gray, Kerr et al. 2013). Such drifts affect clinical practice where increasing the resources available also increases the clinician's decision making threshold (Gray, Kerr et al. 2013).

Availability

Studies have shown unwarranted variations in accessing cancer treatment based on socioeconomic status (Aarts, Lemmens et al. 2010, Downing 2013, Raine, Wong et al. 2010, McCaffery, Wardle et al. 2002), age (National Cancer Equality Initiative 2010, Bouchardy, Rapiti et al. 2007, Bouchardy, Rapiti et al. 2003, Deandrea, Montanari et al. 2008) and ethnicity (Krakauer, Crenner et al. 2002, Bernabei, Gambassi et al. 1998). Patients in England have several methods of accessing cancer drugs (Stanton 2010, DoH 2010), but CDF specifically allowed access to cancer drugs that (i) have not been appraised or being appraised by NICE; (ii) not recommended by NICE and (iii) were used outside its marketing authorisation (off-label) (Stanton 2010, Chamberlain, Collin et al. 2015). In short it bypassed existing NICE mechanisms for recommending cancer drugs based on cost-effectiveness. In 2015, the National Audit Office (NAO 2015) reported CDF's total cost from October 2010 to March 2015 was £968m providing 74,380 patients with

cancer drugs however reflecting a 48% overspend. It states that 51% of patients received drugs previously appraised by NICE but were not recommended. Between 2012 and 2013 there was a 3.6-fold geographical variation between the north and south of England in accessing the CDF. This variation the report added was primarily attributed to the separate drug lists and drug priorities the 10 strategic health authorities were implementing, and access differed from one region to another. Regions with lower access spent less and the overall budget was underspent by 28%. In 2013 NHS England took over from DH the responsibilities to oversee the CDF, while four regional teams carried out day-to-day administration.

NHS England developed a single national list of 28 drugs – which could treat approximately 70 cancer conditions that would be routinely available through CDF (England 2014). Drugs not on the national list were made available through other mechanisms, e.g. NHS commissioning (England 2014). Since then coincidentally the geographic variations in accessing CDF drugs reduced significantly (England, All 2013, England 2014). The rise in cost since 2013 however was attributed to the increase in number of patients supported by the CDF and increase in the average cost per patient (£16,700) since access was also provided to new cancer drugs where previously there was no national purchasing arrangement (NAO 2015). Nevertheless there was more than 10-fold variation in costs across the regions (NAO 2015). In 2013, the government acknowledged one of the objectives of CDF was to provide patients with rare cancers access to effective treatment since their drugs due to low incidence are unlikely to be appraised by NICE (NAO 2015).

When NHS England had taken over from DH, the fundamental concept of CDF being 'unfunded' changed when its budget was subsumed into the NHS England's larger budget allocation. Which essentially meant if CDF overspent it affected resources available for other services NHS England was responsible for (Aggarwal, Sullivan 2014). By virtue of its overspend and the ever-rising cost of new cancer drugs CDF was deemed unsustainable (Edwards, Crump et al. 2015). As part of its reform CDF will fund drugs not cost-effective by NICE's standards if there is a chance it might prove to be otherwise within two years (Claxton 2016). NICE will be once again responsible for assessment of benefits and costs of new cancer drugs (Claxton 2016).

The CDF made expensive cancer drugs available by making it seem 'affordable' through a separate parallel budget, which was topped up when depleted. Hence it is conceivable at least in its early stages that overspend was taken as 'unmet demand' where topping up the fund would be justified. The rationale was, as mentioned above, patients would benefit in ways that were deemed as effective care and got their end-of-life preferences. Therefore the change in how the CDF is funded is an important distinction. Being incorporated into NHS England's budget CDF no longer could afford drugs deemed not cost-effective - a dramatic change from its *raison d'être*. This change now introduced a different threshold of 'affordability' from a value-for-money perspective. However how these changes may affect patient survival rates and clinical practice with regards to end of life choices needs further study.

Affordability

In this case study affordability is viewed as the availability of financial resources to procure intended purchase(s) taking into account opportunity costs. Purchases can be one off or on a sustained basis, and stakeholders tend to evaluate the value they derive from these procurements (Eichler, Bloechl-Daum et al. 2010). As mentioned above the government's position for introducing CDF was to achieve comparable survival rates with similarly developed countries. CDF is a parallel procurement mechanism, which provided a different threshold of affordability by essentially sidestepping established value-for-money thresholds other drug procurement policies adhered too. It is however conceivable stakeholders viewed this 'purchase' of additional survival as an outcome of higher value. It remains unclear what was the duration of additional survival benefits initially sought, by pursuing for example end-of-life strategies. Below the use of the drug Bevacizumab is presented as a case in point, highlighting the challenges in ultimately teasing out unwarranted variation using Wennberg's framework.

Bevacizumab

Like normal cells in the human body, tumour cells need to establish blood vasculature to meet their metabolic demands (Hanahan, Weinberg 2011). Tumour cells however through certain gene-based mechanisms chronically sprout tumour-associated neovasculature from existing vasculature - a process known as angiogenesis (Hanahan, Weinberg 2011). This pathological angiogenesis is recognised as one of the hallmarks of cancer that facilitates tumour growth and metastasis (Carmeliet, Jain 2000, Hanahan, Weinberg 2011). Thus one of the therapeutic strategies for cancer is to target tumour

vasculature, and in particular one of the inducers of angiogenesis i.e. vascular endothelial growth factor (VEGF) (Carmeliet, Jain 2000). Bevacizumab is a humanised monoclonal antibody targeting VEGF activities with the intention to disrupt tumour-associated angiogenesis (Hurwitz, Fehrenbacher et al. 2004, Kabbinavar, Schulz et al. 2005). Various clinical trials combining bevacizumab with other chemotherapeutic agents have been tested to treat metastatic colorectal cancer (mCRC) (Hurwitz, Fehrenbacher et al. 2004, Kabbinavar, Schulz et al. 2005, Saltz, Clarke et al. 2008, Tol, Koopman et al. 2009, de Gramont, Van Cutsem et al. 2012). In summary bevacizumab combined with other chemotherapeutic agents demonstrated clinical benefits for patients with previously untreated mCRC (Kabbinavar, Schulz et al. 2005, Saltz, Clarke et al. 2008).

However results including a systematic review show that the overall gains in survival has been modest ranging from an additional 1.4 months to 4.7 months (Eskens, Sleijfer 2008, Kabbinavar, Schulz et al. 2005, Saltz, Clarke et al. 2008, Messori, Conti et al. 2014, Goldstein, Chen et al. 2015, Tappenden, Jones et al. 2007) and data also suggest potential increase in adverse event for patients (de Gramont, Van Cutsem et al. 2012, Tappenden, Jones et al. 2007).

In 2014-15 CDF supported almost 1 in 5 patients starting a new chemotherapy treatment and the 10 most common cancer drugs accounted for 71% of the patients supported, while bevacizumab accounted for close to one fifth of patients - mostly colorectal cancer cases (Table 4). A recent study suggested that the implementation of CDF in England and not Wales provided

a natural experiment (Chamberlain, Collin et al. 2014). It found prescribing volumes for bevacizumab were similar in both countries the year before CDF was implemented. However post CDF it reported more than two-fold increase in prescription rates in England compared to 63.8% increase in Wales. Notably the report also suggested that since CDF provided a parallel mechanism of access it does not necessarily speed up the uptake of new cost-effective drugs. This poses a dilemma in terms of non-provision of effective care being viewed as unwarranted variation.

However in light of the above it would be relevant to reiterate several salient points on bevacizumab – (i) its an anti tumour angiogenesis drug used in a complimentary manner to treat advanced mCRC (ii) it has shown minimal clinical benefits in terms of oncological endpoints i.e. overall survival or progression free survival (Goldstein, Chen et al. 2015, Messori, Conti et al. 2014) and (iii) it has an unsustainable incremental cost-effectiveness ratio (Saltz 2015, Goldstein, Chen et al. 2015).

Notwithstanding the costs, the additional 1-2 months of survival selected patients receive should be assessed against how increased adverse events may affect quality of life. This raises the issue of effective use of limited resources. A cancer *policy threshold* that is higher than the mean cost of per QALY threshold can have consequences on population health in terms opportunity costs for managing other disease conditions (Claxton, Martin et al. 2015). When NICE issues a positive guidance its threshold takes into account the additional cost imposed on the health system which needs to forgo 1 QALY's worth of health through divestment from other interventions (Claxton,

Martin et al. 2015). Further thresholds would be expected to drift if discretionary decision-making is allowed on how resources can be spent (Claxton, Martin et al. 2015). Studies evaluating bevacizumab and its marginal benefits against its costs have argued the need to take a balanced approach to maintain sustainability (Saltz 2015, Goldstein, Chen et al. 2015).

The above case study suggests:

- I. Parallel access for cancer drugs may induce extraneous patient preferences and 'drifts' in clinical practice.
- II. Parallel funding can give rise to doctor-patient coupling type of decision-making.
- III. Doctor-patient coupling can foster drifts in clinical benefits thresholds.
- IV. Drifts in clinical benefits thresholds can be a potential source of practice variation.
- V. Parallel funding for improving access to expensive cancer drugs can paradoxically reduce access (Figure 2).

Cancer drug	Company	Cancer type	NICE decisions	Patients approved (%)
Bevacizumab	Roche	Breast cervical, colorectal, gliomas and ovarian	NR*	8,520 (19)
Abiraterone	Janssen-Cilag	Prostate	Recommended based on £2,300 for 12 tablets	4,940 (11)
Bendamustine	Generic	Leukaemia, lymphoma and myeloma	Approved for certain types of leukaemia	3,370 (8)

Cetuximab	Merck Serono	Colorectal and skin	NR	3,330 (8)
Enzalutamide	Astellas	Prostate	Recommended only if price is discounted	2,630 (6)
Everolimus	Novartis	Breast, pancreatic and renal	NR	2,310 (5)
Eribulin	Eisai	Breast	NR	1,840 (4)
Aflibercept	Sanofi	Colorectal	NR	1,580 (4)
Pemetrexed	Lilly	Lung	NR	1,300 (3)
Cabazitaxel	Sanofi	Prostate	NR	1,270 (3)
Total				31,090 (71)

Table 4: The 10 most common cancer drugs accessed through the Cancer Drugs Fund, 2013-15. Adapted from National Audit Office, 2015. *Not recommended.

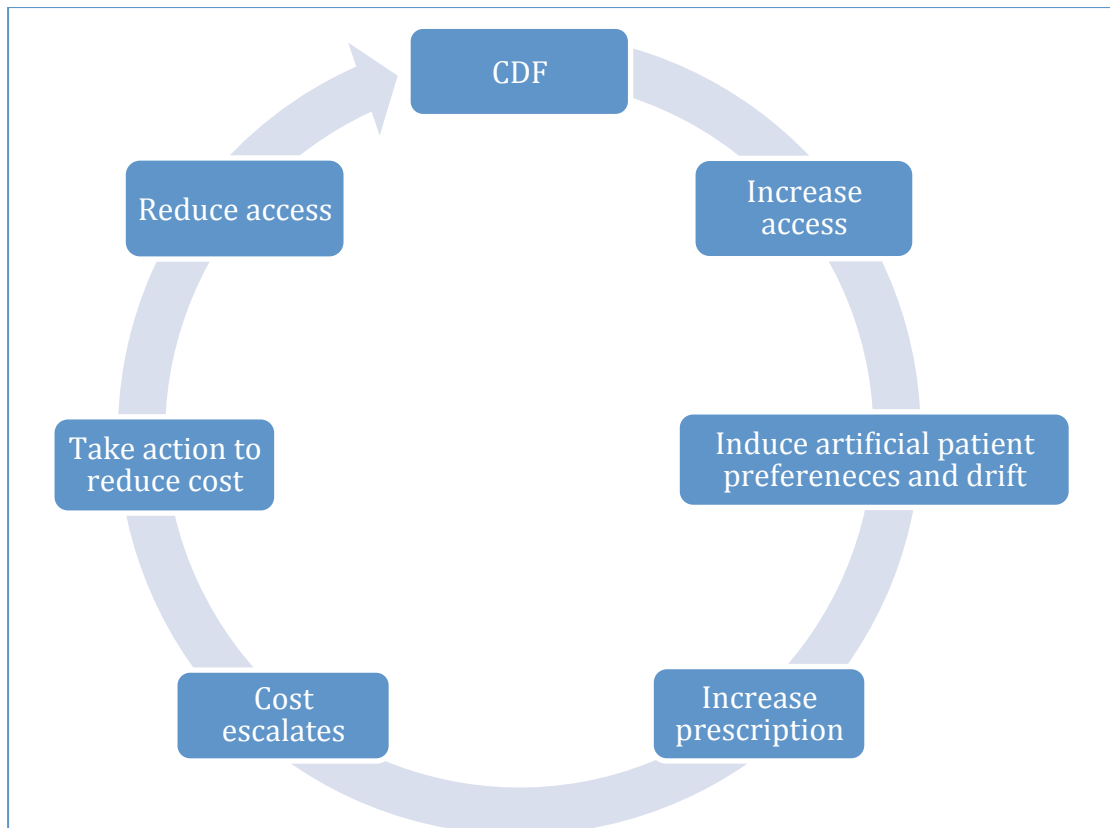


Figure 2: Conceptual CDF funding-access paradox.

Discussion

Wennberg's scholarship on variation led to the concept of unwarranted variation. Essentially statistical outliers equivalent to being 'bad' variation are considered as unwarranted. Thus Wennberg's definition suggests comparisons are made on whether patients are treated according to their underlying illness, preferences or by the dictates of scientific medicine. This is related to clinical care, however Wennberg and others have subsequently applied the compound term (unwarranted variation) to address healthcare costs and operational efficiencies. Therefore the term and the concept itself is used broadly and predominantly refers to issues that need to be rectified or avoided. But a broader use of the term and a clinically focused definition can send mixed signals that weaken its uptake that may explain such an observation amongst CRC MDT clinicians. The MDTs could not make any significant reference to Wennberg's body of work nor were aware if they could be contributing towards unwarranted variation (Chapter 3).

The key point of Wennberg's hypothesis and definition of effective care centres on clinical practice. Clinical practice is embedded within care pathways and can affect down stream processes and outcomes, i.e. quality. Wennberg shows clinical uncertainty and patient preferences are integral to clinical practice.

Conceivably another challenge affecting the appreciation of the framework is that the conceptual 'unwarranted variation' is seen as part of 'quality' and 'value'. Therefore improving quality or value by extension would be addressing unwarranted variation.

Patients with cancer can alter their preferences subject to their response to treatment and family expectations. As such in practice their preferences would seem more 'fluid' than fixed. As shown in the CDF case study, extraordinary availability of CRC drugs can induce variable therapeutic thresholds in practice. Patients are also known to transpose their preferences to their doctor where the latter may decide vicariously. Thus pinpointing 'patient preferences' can be a tricky exercise. Though Wennberg and others discuss the use of decisional aids to help patients with their treatment choice, his framework does not readily help with complex patient preferences experienced in cancer practices and in life altering conditions. MDTs play a vital role in CRC care, but as shown in chapter 3, do not necessarily take in patient preferences in their decision-making. That said the idea of placing importance on patient preferences is fundamentally essential and correct since cancer patients irrespective of stage of disease have important trade-offs to consider (Sessions 2012, Gawande 2014, Gearin-Tosh 2002).

Wennberg's focus on clinical uncertainty provides, albeit indirectly, the need for MDTs to address complex diseases where patient selection is one aspect of such uncertainty. For example the choice between transanal endoscopic microsurgery (TEM) i.e. a local excision (LE) and radical surgery for low-risk early rectal cancer can be challenging since the latter in such cases can be considered overtreatment (Hompes, Cunningham 2015). While the authors suggest the clinical parameters for selecting 'TEM-able' patients, they also indicate difficulties in obtaining relevant diagnostic data e.g. lymph node involvement. Surgeons may prefer radical surgery against LE due to

challenges on estimating the balance between the risk of recurrence and serious morbidity where patients and clinicians need to weigh these trade-offs (Hompes, Cunningham 2015).

Variation due to uncertainty can happen even a simpler level e.g. the arbitrary definition of the rectum itself, which varies across the world (Heald, Moran 2015). It becomes important to have consensus on such issues to have a better understanding of variation.

Other surgical specialities too have indicated complexities in decision-making towards treatment choices. Henry Marsh elucidates this in his book 'Do No Harm' (Marsh 2014).

The following MDT discussion is an excerpt on this point:

"What's his prognosis? I asked the registrar.

'Not good,' she said.

'But how much not good? I asked. Fifty percent? Ninety percent?

'He might recover.'

'Oh come off it! With both his frontal lobes smashed up like that? He hasn't got a hope in hell. If we operate to deal with the bleeding he might just survive but he'll be left hopelessly disabled, without language and probably with horrible personality change as well. If we don't operate he'll die quickly and peacefully.

'Well, the family will want something done. It's their choice,' she said.

I told her that what the family wanted would be entirely determined by what she said to them. If she said 'We could operate and remove the damaged brain and he may just survive' they were bound to say that we should operate. If, instead, she said 'If we operate there is no realistic chance of his getting back to an independent life. He will be left profoundly disabled. Would he want to survive like that?' the family would probably give a different answer. What she was really asking them in the first question was 'Do you really love him enough to look after him when he is disabled? And by saying this she is not giving them any choice. In cases like this we often end up operating because it's easier than being honest and it means that we can avoid a painful conversation. You might think the operation has been a success because the patient leaves the hospital alive but if you saw them years later – as I often do – you would realize that the result of the operation was a human disaster.

The room was silent for a while.

'The decision has been made to operate,' the registrar said stiffly.

Apparently the patient was under the care of one of my colleagues and one of the unwritten rules of English medicine is that one never openly criticizes or overrules a colleague of equal seniority, so I remained silent."

Such complexities suggest the three main items in Wennberg's definition i.e. treatment related to patient's underlying illness, patient preferences and scientific knowledge are interrelated and interlocking. Thus to tease one item out independent of the other(s) to assess variation can be misleading.

One parameter relevant to cancer care missing in Wennberg's framework is 'waiting time'. This is essential and as such is mandatory in the UK to report on this parameter. Delays in treatment can affect treatment options and outcomes.

With regard to 'scientific knowledge', as per Wennberg's framework the interpretation can be broad. For example senior clinicians could use anecdotal experience or information and not be challenged on the presumption it was 'scientific'. On the other hand, patients (and clinicians) can misconstrue contemporary clinical practice to be 'current' medical knowledge. In principle, by virtue of its composition and duties MDTs at least within tertiary hospitals are placed to address gaps in 'current' knowledge. Since waiting time and MDT consultations are relevant in CRC care these are two other parameters missing from Wennberg's framework (i.e. effective care).

One of the attempts to address (unwarranted) variation in cancer practice has been the formulation and broad access to treatment guidelines. Professional bodies such as the American Society of Clinical Oncology (Benson, Schrag

et al. 2004), National Comprehensive Cancer Network (Benson, Schrag et al. 2004, Benson, Bekaii-Saab et al. 2013), European Society of Medical Oncology (Glimelius, Tiret et al. 2013), European Society of Surgical Oncology (van de Velde, Cornelis JH, Aristei et al. 2013, Van de Velde, Boelens et al. 2014) and others publish such evidence-based guidelines (scientific knowledge) with the view of continuously establishing quality. Using evidence-based guidelines relevant to local settings can help address clinical uncertainty and decision-making. To do so, these guidelines may need to be supported by exemplar case studies that provide 'care solutions' in particular facing challenging treatment decisions involving patient (family) preferences. Under diagnosing early stages of cancer e.g. colorectal, could also be addressed through monitoring utilising telecancer approaches.

Conclusion

As seen, patients' conditions can render complex situations, which can be stressful and have wider implications affecting others. In such complex cases it may be challenging to reach consensus amongst clinicians on care solutions and therefore to try and elucidate unwarranted variation.

As shown Wennberg's framework is also used to address non-clinical issues i.e. cost-benefits. This dilutes its clinical focus and can affect its uptake in CRC practice.

In summary while Wennberg's framework and definitions are descriptive, its current form has limited use in CRC practice. However the concept of unwarranted variation and addressing it is certainly relevant in cancer care.

And to do so, antecedents of unwarranted variation in CRC care particularly within MDTs and risk scoring care pathways have been suggested elsewhere (Menon, Cunningham et al. 2016). A framework on unwarranted variation related to cancer care will need to cater for waiting time and the need for MDT based care based on relevant and consistent clinical data.

The use of digital technologies can play a strategic role in the uptake of best practices by providing relevant care solutions (besides guidelines) and real-time feedback on clinical practice e.g. MDTs.

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Chapter 5: Discussion and conclusion

Professional uncertainty

Clinical practice has been viewed as the main source of variation and in particularly unwarranted variation in clinical care (Wennberg, Barnes et al. 1982). There are two parallel clinical practices involving physicians that take place within the management of CRC. These are the single doctor-patient interaction and MDTs. The challenges and opportunities this dualistic approach fosters should not be underestimated. As discussed in Chapter 4 two strands i.e. professional uncertainty and supplier-induced demands are purported to affect clinical practice, and the dominant thinking is that the degree of professional uncertainty is proportional to the lack of evidence for either diagnosing and/or treating a clinical condition. In CRC this can lead to differential tumour staging as shown in Box 1 - an example of a common scenario encountered in CRC MDTs (personal communications, C. Cunningham, 2016):

Box1: Differential tumour staging in CRC MDTs.

The 'nervous' radiologist is afraid to under-stage in case it leads to under treatment, therefore stages it T3 N1 with threatened margin. The patient has radiotherapy and resection. The final pathology is ypT2 N0. We have no idea what the original pathology was and the T2 may be due to radiotherapy effect. The nodes are negative but they may have been positive before RT. So, the patient gets adjuvant therapy.

The same patient assessed with more confidence may be staged as T3N0 (or 1) with margin close but not threatened. That patient proceeds directly to surgery and the final pathology is T2 (or T3) N0. There is no need for adjuvant therapy.

Same patient and tumours, different MDTs, vast variation in treatment. Both are done in good faith.

By adding other variables into this example i.e. patient's age, health status and say possible breach of waiting times, the scenario becomes more complex. Whether these are taken into consideration or not when radiological evidence is sub-optimal is difficult to predict or assess. As in the course of observing CRC and Liver Cancer MDTs during this study all patients reviewed were given an opinion even though members of the MDT thought some of the images were of poor quality and in an ideal situation new images should have been sought.

It has been shown that reliance on heuristics and biases are characteristic of intuitive judgment under uncertainty and this applies to layman and experts alike (Tversky, Kahneman 1975). A physician's confidence and clinical uncertainties are inseparable components of clinical practice, and expecting the physician to reserve opinion in light of uncertainties conceivably runs contrary to patients or clinical colleagues expectations. Nevertheless the basis of a physician's confidence and its effects on decision-making would seem difficult to directly measure.

Both radiologists in the above example believe their decision is 'correct' in so far the patient is better off based on their bias. 'Availability' bias can occur in judging the frequency two events co-occurring (illusory-correlation effect) which is known to persist even when correlation between symptoms and diagnosis is negative (Tversky, Kahneman 1975). Availability bias is the assessment of the frequency an event or probability of an event based on the ease of recollecting similar instances or constructing relevant instances (imaginability) (Tversky, Kahneman 1975).

In this example unwarranted variation could be viewed possibly as over-treatment and done so post-hoc, without an appreciation of the context. This is one of the limitations of determining unwarranted variation based on statistics (e.g. small area variation) even if it is adjusted for patient-related risks. And in doing so potentially understates the inherent complexities of clinical practice. Further there is also no theoretical underpinning for Wennberg's assertion that professional uncertainty is a source of unwarranted variation. He also makes no distinction between professional uncertainty and clinical uncertainty. As such the following distinctions are suggested:

- Professional uncertainty is seen to have taken place when the clinician, independent of the quality and availability of clinical evidence, is not able to either diagnose or treat the patient or suggest the next course of action that would be deemed safe and appropriate by their professional bodies.
- Clinical uncertainty is deemed present when there is insufficient high quality clinical evidence to diagnose and / or treat a patient without placing the patient at undue risk of affecting their (preferred) outcome.

Observations made at MDTs during this study indicate clinical uncertainty rather than professional uncertainty is one of the drivers of variation in CRC care e.g. differential tumour staging (Menon, Cunningham et al. 2016) . Thus to address unwarranted variation in CRC clinical practice there is a need to be explicit regarding the standard of clinical evidence required for a MDT assessment. In not doing so the MDT, albeit inadvertently, perpetuates unwarranted variation.

Definition of unwarranted variation

The importance given to waiting times in cancer care clearly suggests the importance of receiving timely care. This mark of quality is congruent with Donabedian's framework for quality in healthcare quality that takes into account the triad of structure, process and outcome (Donabedian 1966). He defines 'process' as components of care delivered. Modern-day health systems amongst other things are meant to deliver care in a timely manner (Institute of Medicine (US). Committee on Quality of Health Care in America 2001). As discussed in Chapter 2, a proportion of CRC patients do not receive related major surgery in a timely manner.

Chapter 4 showed Wennberg's definition of unwarranted variation. His 2004 definition is repeated here for easy recall:

- "Variation that cannot be explained on the basis of illness, patients' preferences' or dictates of scientific medicine"

Since cancer waiting times are a measure of quality of care it may be useful to include this element into a definition to help address unwarranted variation in CRC care. A revised definition is suggested:

- "Colorectal cancer care that cannot be explained on the basis of illness, patients preferences, dictates of scientific medicine or not provided on a timely basis".

Clinical practice

As mentioned above the MDT is one of two stands of clinical practice. It is a service innovation that was introduced for colorectal cancer care in the England only as recently as 2004 (National Institute for Clinical Excellence 2004) . The MDT practice model shifts clinical decision-making from an

individual to the collective, namely from a single clinician's practice model to a MDT decision-making *process* where the 'ownership' rests with the organisation. The current MDT model separates decision-making from direct patient responsibility. This however cannot mean it has no responsibility and accountability towards the patient's effective and safe treatment. As expected there are some salient differences between MDTs and single clinician model (Figure 1).

Characteristics of single clinician model vs. MDT	
Single clinician model	MDT
• Single clinician decides on diagnosis based on clinical reports • Single clinician decides best course of treatment • Treatment approach related to clinician's clinical abilities and knowledge • Clinical decisions can be faster than MDT • Consultations with clinical colleagues is discretionary • Risk of individual bias • Lacks transparency in decision-making process • Single clinician may be different individuals at different times (depends on rota)	• Team of clinicians with different expertise discuss clinical reports to finalise diagnosis • Team of clinicians decide on best course of treatment • Treatment approach based on collective knowledge and experience of the team • Multidisciplinary consultation is compulsory • Difficult for individual bias, but groupthink bias possible • Clinical decisions can be slower as MDT meets at fixed times • Review clinical decisions • Transparent decision-making • Team dynamics can be dysfunctional

Figure 1: Comparison between single-clinician and MDT models of care

Role of MDTs

In essence MDTs are seen to better manage patient risks on the premise that cancer is a complex disease and therefore requires multiple experts to help diagnose and treat. However it is by no means uncertain that MDTs by themselves cannot give rise to unwarranted variation. This has been discussed in Chapter 3 and elsewhere (Menon, Cunningham et al. 2016) and it namely touched on several elements: composition of the team, continued presence of the team during the meeting and in terms of processes - data collection and presentation, patient list order and prioritisation, time allocated for individual patient discussions and decision-making. It also more importantly as a result of observing MDTs, raised the question of its *role*. This research has shown members of the MDTs have differing views and perceptions of this. This question of its *role* needs to be crucially answered to address unwarranted variation. In doing so its performance can be evaluated accordingly. Assessing MDTs based on patient outcomes, number of patients being reviewed by MDTs, clinician's attendance at MDTs etc without first establishing its role can be misleading. Point in case the National Cancer Peer Review Programme that reports on MDT assessment presupposes (albeit implicitly) every MDT has the same role and responsibility and performance is taken as per elements such as core MDT membership, not achieving 31 and 62 day cancer waiting time targets, number of brachytherapy treatments etc to name a few (, CQuINS V4 - National Cancer Review Programme 2009/10). Are MDTs responsible for timely care? Is it responsible for the number of treatments performed? Herein its role and

responsibilities vis-à-vis the single clinician strand needs to be studied and elucidated.

Information technology

The Oxford and Gothenburg MDTs use Information Technology (IT) for organizing their meetings, recording their decisions, reviewing radiology and pathology images. Treating clinicians have digital access to MDT decisions. However IT is not used to help their performance to make decisions. The data these MDTs collect does not immediately provide them information on the potential course correction that might be needed in a case. It seems these IT systems are used as though for 'accounting' i.e. business operational purposes rather than to improve and innovate clinical practice i.e. create value. IT could be used to address clinical uncertainties for example by assessing gaps in predetermined clinical reporting standards and guidelines that are enroute to MDTs and develop case studies to help with decision-making. Information systems that can give immediate access to previous decisions can help inform future decisions. Thus to address unwarranted variation, there is a need to define new information concepts in relation to the MDTs role and tasks. And within IT the emphasis should be more on 'Information' rather than 'Technology'.

MDT models

Several MDT models were suggested during the MDT interviews. One was status quo - where all CRC patients are discussed by the whole MDT (Type 1). Another was patients with 'straight forward' or simpler conditions are reviewed by a subset of the whole MDT whereas the more complex cases are

reviewed by the whole MDT (Type 2). And the third was for MDTs to review only complex cases (Type 3).

The question of the type of MDT model to be used is not a strategic matter but an operational one, i.e. a matter of efficiency rather than effectiveness. Once the MDTs values, goals and objectives are defined it will help determine the most relevant model to be used in order for it to be effective.

Decision-making

Decision-making approaches observed in the MDTs differed between MDTs and also between cases. Whilst this in itself is not seen in a negative light, it highlighted a lack of a consistent approach to evaluate evidence especially in cases where clinical uncertainty exists. Most times it was such cases that fostered most discussions and at times debate. The tendency then was towards seeking a consensus. There is no tangible reason to believe the consensus was more evidence based than those in the minority. And as mentioned in Chapter 3 not everyone's opinion at the MDTs can be taken as equivalent. It would seem paradoxical if the MDT was the bastion of scientific medicine than whatever the MDT wanted, provided enough of the members want it, must be granted. Equally it remains difficult to understand why some decisions cannot be deferred when it may be in the best interest of the patient that the MDT seeks additional opinion. Making clinical decisions without taking into account bias can place patients at risk.

The Gothenburg CRC MDT, at the tail-end of its MDT meetings immediately connects (remotely) to its Liver MDT to review cases. This seems to render efficiency and timely coverage, which is relevant especially since patients

discussed were with metastatic disease. In these instances the Liver team was a specialised subset of their larger team. MDT members agreed that this arrangement was efficient and effective especially as it enabled patients to be booked into immediately for treatment the day the CRC MDT meets.

Finally, MDTs carry a heavy responsibility and are by no means infallible. To this end new approaches are needed to assist and assess its decisions. These assessments need to be fed back to its members within a timeframe that makes clinical relevance if it is to have a chance to inform clinical practice.

MDTs should be seen as a consolidated form of clinical practice, one that is parallel to the single clinician model and both strands should be synergistic to each other.

Unwarranted variation

As shown above and in Chapter 4 Wennberg's framework on unwarranted variation requires some modification. To understand variation based on statistical analyses alone without taking into consideration the context on which clinical decisions had to be made e.g. based on poor clinical reports does not explain the drivers for unwarranted variation. Clinical practice in CRC care is not always a linear process thus placing clinical practice as a source of unwarranted variation without appreciating the inherent and on-going dynamics in prolonged patient care, is simplistic. As discussed in this thesis, variation studies do lack theoretical underpinning and present their findings on a post-hoc basis. However some of the findings in this research have led to a novel publication suggesting how potential drivers of

unwarranted variation CRC care could be addressed (Menon, Cunningham et al. 2016). The rise in life expectancies and the consequent changes in demographics will likely see an increase in the number of elderly individuals diagnosed with CRC. Clinical practice will need to take note of this cohort. Whilst clinical guidelines are present for managing the elderly with CRC (Papamichael, Audisio et al. 2009) some patients may prefer lesser intervention than more (discussed in Chapter 4). Hence just using rates of utilisation to assess variation may be inadequate if the context on how patients are selected for treatment is not elucidated.

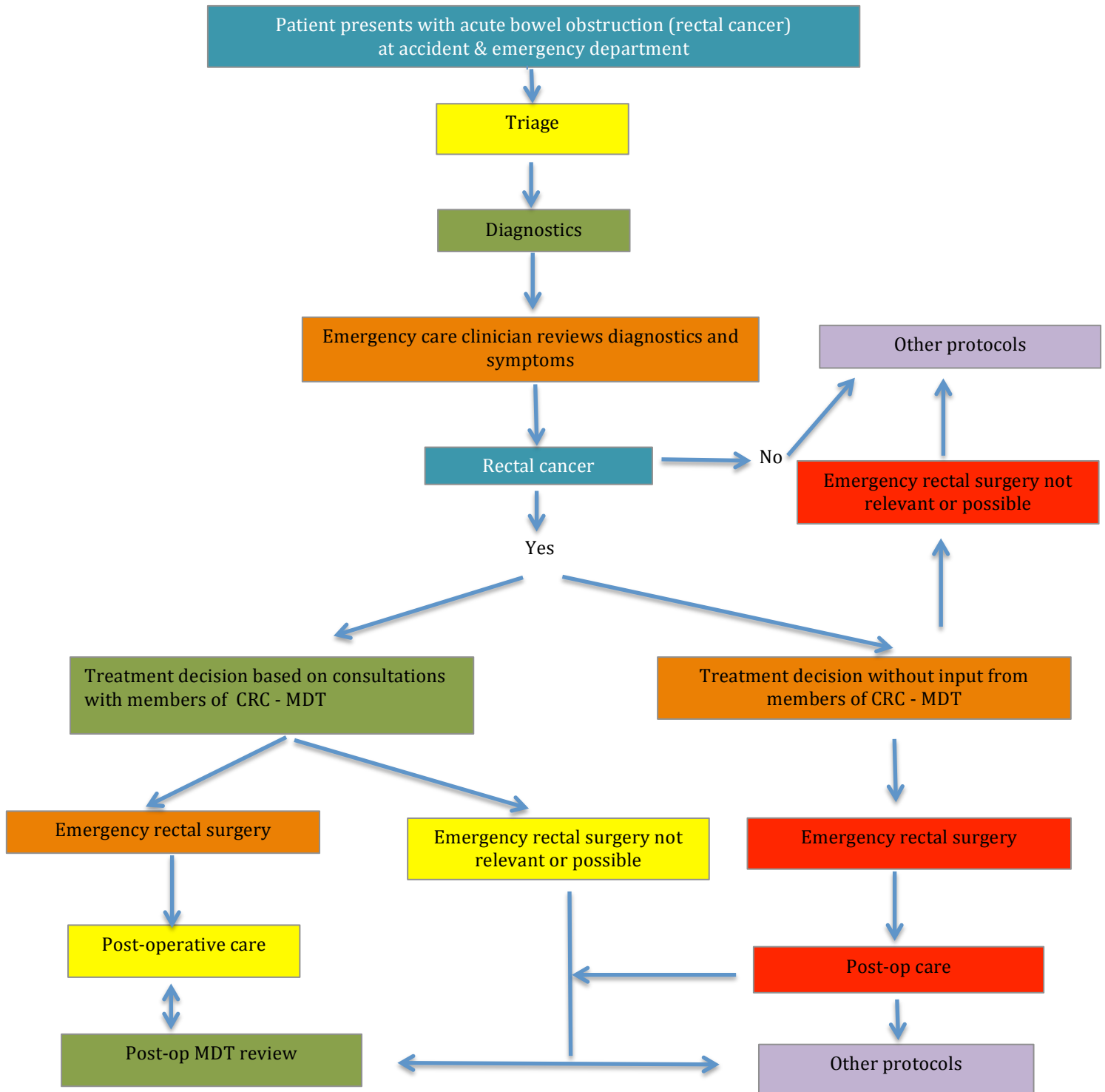
A conceptual approach to address unwarranted variation using clinical pathways is briefly discussed here as it has been highlighted in detail elsewhere (Menon, Cunningham et al. 2016). Evidence-based clinical pathways are taken as a readily available and as simple templates to identify and monitor potential unwarranted variation. Critical care nodes (CCNs) are identified on these clinical pathways. CCNs are defined as 'points in the clinical pathway at which a patient or their illness is examined, diagnosed or treated and/or clinical uncertainty could be evident'. CCNs are colour-coded to indicate risk levels and consequently be allocated related resources. CCNs in CRC care could be first clinical contact at diagnosis, emergency treatment, pretreatment MDT discussions or assessment at primary care. The idea of identifying and assigning a risk score provides a conceptual framework for CRC clinicians, hospital management and service commissioners to address unwarranted variation.

Unwarranted variation at different nodes is likely to have different consequences on patient outcomes. For example a patient presenting with rectal cancer as an emergency often requires an intervention without any opportunity for a preoperative MDT discussion. This poses a particular challenge on managing unwarranted variations in the care such patients receive. See Appendix 1 for conceptual risk scoring for emergency rectal cancer treatment pathway.

Conclusions

The value of addressing unwarranted variation in CRC care is indisputable. This thesis has suggested relevant definitions i.e. for clinical practice, professional uncertainty, clinical uncertainty and unwarranted variation. These can facilitate a better understanding of clinical practice factors that render unwarranted variation. There is a need to clearly define the role of the MDT. And in doing so MDTs should look towards new concepts of information and the use of IT to help address gaps in clinical uncertainty and decision-making processes to help address latent unwarranted variation. Equally, critical research should be taken to understand underlying mechanisms between clinical practice and patient selection for surgery in order to better understand practice variation.

Appendix 1



Conceptual risk scoring unwarranted variation in emergency rectal cancer treatment pathway

-  Imminent (e.g. affects immediate survival)
-  Urgent (e.g. affects 90-day survival, quality of life)
-  Highly likely (e.g. affects 2-year survival, patient's preferences)
-  Likely (e.g. affects treatment plan, quality of life)
-  Unknown

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