



The Association of Coloproctology  
of Great Britain and Ireland

# ACPGBI Enquiry

## Colorectal Cancer Outcomes in Wales

**5 December 2016**

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# Table of Contents

1.	Foreword	4
2.	Executive Summary	5
3.	Patient Commentary	7
4.	Enquiry Panel	9
5.	Background to Enquiry	14
	i. History of NBOCA	
	ii. Reasons for Enquiry	
	iii. Objectives of Enquiry	
	iv. Process	
	v. Stakeholders	
6.	Context	21
	i. Geography	
	ii. Demographics of Welsh Population	
	iii. Epidemiology of Colorectal Cancer in Wales	
	iv. Choice of Comparators	
7.	Data	30
	i. Acquisition of data	
	ii. Process	
	iii. Data quality	
	iv. Analysis	
	v. Adjustment for socio-economic deprivation and use of an imputational model	
	vi. Publication and interpretation of results	
8.	Further Analyses and Reflections	37
	i. Temporal Comparison of 2-yr Survival by English and Welsh MDTs	
	ii. Comparisons of Institutional Performance	
	A. Case ascertainment	
	B. Data quality and completeness	
	iii. Comorbidity and how it is measured	
	iv. Confounding effect of deprivation on cancer outcomes	
	v. System-level differences between England and Wales	
	vi. Acknowledgement of unattainable goals	
	vii. Future directions and impact of NBOCA	



9.	Key Messages from Welsh MDTs	48
	i. Common themes	
	ii. Specific themes for each MDT	
10.	Conclusions	68
11.	Recommendations	70
	Audit Support:	
	Data Accuracy:	
	Audit Systems:	
	Analysis of Audit Data:	
12.	Response from Dr Tom Crosby, Medical Director of Wales Cancer Network	73
13.	Acknowledgements	74
14.	Glossary	75
15.	References	79
	Appendix A: Responses from Welsh MDTs following Consultation on Draft Report	81
	Appendix B: Terms of Reference	89
	Appendix C: Agenda for Meeting 12 April 2016	94
	Appendix D: Healthcare Systems and Cancer Care in Wales	96
	Appendix E: Attendance List at All Wales Meeting on 12 April 2016	102
	Appendix F: Summary of Welsh MDT Organisational Reports Submitted to NBOCA 2015	104



# 1. Foreword

The mission of the Association of Coloproctology of Great Britain and Ireland is to promote the prevention, care and cure of colorectal disease. To this end, the support of our members, who deliver this mission, is a central activity of the Association.

Thus, when we were asked by the Welsh surgeons to investigate the reasons underlying the low observed survival at two years after diagnosis for bowel cancer patients in Wales diagnosed between 2008 and 2011, we were very willing to do so. The enquiry upon which we embarked as a result involved an extremely detailed examination of audit processes and the organisation of colorectal cancer services in Wales and we were delighted at the level of cooperation that we received from everyone concerned. We very much hope that the report will prove to be a useful tool in addressing the deficiencies that were found, and both the clinical community and colorectal cancer patients in Wales may be assured of the ongoing support of the Association.

I should like to express my sincere thanks to the whole review team and particularly to Nicola Fearnhead who, as Chair of the Research and Audit Committee, has shouldered the vast majority of the work involved in producing this report.

I should also like to extend my gratitude to the Welsh clinicians who provided an unparalleled level of engagement with the process.

**Professor Robert Steele**  
**Chair, ACPGBI Invited Enquiry into Colorectal Outcomes in Wales**  
**Immediate Past President ACPGBI**  
**October 2016**



## 2.Executive Summary

The 2014 Annual Report of the National Bowel Cancer Audit (NBOCA) reported lower observed survival at 2 years after diagnosis for all bowel cancer patients diagnosed in Wales between 2008 and 2011 as compared to patients treated in English Strategic Clinical Networks (SCNs). This effect was also shown for observed and risk-adjusted survival after surgical treatment for bowel cancer.

The purpose of this invited review was to determine the basis of these differences in patient outcome. The prime factor considered was that poorer outcomes in Wales might have been seen because of problems with the data supplied to NBOCA and associated methodological compromises in analysis. In addition, differences in the health and the economic status of the Welsh population and possible differences in healthcare pathways between Wales and the English SCNs were considered.

The Invited Review found that the quality and methods of data collection in Wales and upload into NBOCA may have a central role in compromising a true like for like comparison between Wales and the English SCNs. While clinician and multidisciplinary team (MDT) professional commitment to audit was universal, several individual MDTs were severely compromised in the level of administrative and technological support available for complete and timely data collection. Crucially, clinician ability to check and verify the Cancer Network Information System Cymru (CaNISC) upload to NBOCA was lacking. Many MDTs were unable to recognise the clinical practice supplied to NBOCA from their respective units.

The use of a unified data collection system CaNISC has advantages for some who use a real-time data collection module. Upload of data from CaNISC to the National Bowel Cancer Audit is carried out as a single data transfer which means that clinicians are not checking individual data on NBOCA's Clinical Audit Platform to provide validation of data entered.

For the relevant audit period, there were also specific concerns about case ascertainment in Wales and whether it was feasible to undertake robust risk-adjusted comparisons of colorectal cancer care between England and Wales. An imputation model was used but was imperfect due to differences in the data it was based on, for example relating to social deprivation in England and Wales.

It is the case that patients in Wales have significant differences in levels of health problems, deprivation and per capita health spending when compared to patients in England. However, concerns over data accuracy and methodology ultimately mean that it has not been possible to



establish whether the differences in colorectal cancer outcome are true, and much less what factors might be responsible for these differences.

Reassuringly, two-year survival for colorectal cancer patients diagnosed in Wales was not significantly different from that in England in the later 2015 and 2016 NBOCA Annual Reports, albeit that these more recent reports looked at shorter time periods and so included fewer patients.

Investment in new technology to provide a successor to CaNISC is essential. Selection and commissioning of a modern system should involve all relevant stakeholders to ensure that it is fit for audit purposes and sufficiently adaptable to be able to respond to changes in audit collection requirements in a timely fashion.

Change in current practice to identify responsible surgeon by General Medical Council (GMC) number for each patient treated would allow individual Welsh surgeons to check their personal data in NBOCA by Clinical Audit Platform sign up and thus provide a valuable means of rigorous quality assurance of colorectal cancer outcome data.

Good audit data is key to ensuring high quality care for Welsh patients with bowel cancer to help drive quality improvement programmes. Detailed recommendations have been made about improving and underpinning good audit practices in Wales which will have lessons for all cancer services.



### 3. Patient Commentary

The aim of the National Bowel Cancer Audit (NBOCA) is to measure the quality of care and survival of adult patients diagnosed with bowel cancer in England and Wales. The Audit collects data on key items identified as determining good outcomes for patients, and analyses and compares these between Strategic Clinical Networks and NHS Trust/hospital sites.

Data protection and privacy are an important part of the Audit. The data are anonymised, so that no individual patient can be identified in the results. The data is collected as fairly as possible as some hospitals serve different populations, who may be older or with other additional illnesses, and this is called risk adjustment.

The Audit has a high participation rate so that almost all patients in England and Wales are included in the Audit, and it has become highly respected and valued as a source of important information in improving care for patients with bowel cancer.

Audit data collection is highly complex and relies on the inclusion of a number of data sets collected nationally outside the Audit, as well as information from either individual doctors who deliver care or administrators, which is uploaded directly into the Audit database. If data are not available or believed not to be accurate, it can undermine the Audit.

The 2014 National Bowel Cancer Audit Report reported what appeared to be poorer results for Wales with regard to outcomes at 2 years after diagnosis, whatever the type of treatment, when compared with English Networks delivering cancer care. Lack of the relevant national data items meant that the results could not be risk adjusted to reflect the different hospital patient populations.

Outcomes also appeared poorer at 2 years following an operation to remove bowel cancer, although these results could be adjusted for the variation in risk across different patient populations.

There was concern as to whether this was due to a series of problems with data collection or actually reflected problems in the way in which bowel cancer care is delivered in Wales. Certainly a major database vital for risk adjustment was not made available to the Audit, and this had a major impact.

Various factors come together to ensure optimal care for patients, and these include sufficient resources and the way care is organised, as well as good clinical care.

As a result of the uncertainty, this Enquiry was suggested by Welsh surgeons who are members of the Association of Coloproctology of Great Britain and Ireland, the professional organisation



which represents surgeons who care for patients with bowel cancer. The invitation to undertake this Enquiry was then made by the Medical Director of Wales Cancer Network.

The Enquiry Panel travelled to Wales in April 2016 to undertake direct consultation with Welsh multidisciplinary teams, composed of the various professionals who care for bowel cancer patients, and audit support services, as well as analysing data held by the NBOCA (Audit) and also the Welsh Cancer Intelligence and Surveillance Unit (WCISU) which is the national cancer registry for Wales.

Unfortunately, the conclusions of this detailed report are such that problems with data collection, both in quality and accuracy, as well as the lack of Welsh national data enabling risk adjustment, mean that no firm conclusions can be arrived at as to whether the differences in the care of Welsh patients with bowel cancer are actual or whether the data is at fault.

For those who wish to read further, detailed recommendations are outlined in Section 11 of this report.

From a patient perspective, it remains important that those involved at all levels, from those responsible for providing permission and provision of national data to the Audit to those who care directly for patients in hospital, cooperate and coordinate to give future clarity on the quality of bowel cancer care being provided to Welsh patients. It is a duty of care to these patients, who are currently disadvantaged and poorly served, when compared with patients in England, by virtue of lack of Audit information, and therefore the means by which improvements to their care can be identified and initiated.

**Mrs Jo Church**  
**Chair, Patient Liaison Group**  
**Association of Coloproctology of Great Britain and Ireland (ACPGBI)**





## 4. Enquiry Panel

### Chair:



**Professor Robert Steele** obtained his initial surgical and academic training in Edinburgh, Hong Kong and Aberdeen and was appointed as Senior Lecturer in Surgery at the University of Nottingham in 1990. He was then appointed Professor of Surgical Oncology at the University of Dundee in 1996 and as Professor of Surgery and Head of Academic Surgery in 2003. His main interests are the treatment of and screening of colorectal cancer. Having led the UK demonstration pilot that was used to inform the decision to introduce national screening programmes throughout the United Kingdom, he is at present the Clinical Director of the Scottish Colorectal Cancer Screening Programme, and has published extensively in this area.

He has chaired several NHS QIS and HIS groups related to colorectal cancer and colorectal cancer screening and he chaired the SIGN group that developed the latest set of colorectal cancer guidelines. He is a past member of Council of the Royal College of Surgeons of Edinburgh and the Edinburgh editor of “The Surgeon”. He is co-founder and co-director of the Scottish Cancer Prevention Network, Chair of the Health Services Research Committee of the Scottish Government’s Chief Scientist’s Office, Chair of the Board of Directors of the Scottish Cancer Foundation and immediate Past President of the Association of Coloproctology of Great Britain and Ireland, having been President at the start of the Enquiry.



## Panel Members:



**Professor Paul Finan** recently retired from his NHS post as Consultant General and Colorectal Surgeon in Leeds. He remains active in research and holds an honorary chair in colorectal surgery within the University of Leeds.

Professor Finan qualified in medicine from Bristol in 1974 and, having completed his pre-registration posts in Bristol, taught anatomy in both Cardiff and Iowa, USA. His surgical training was completed in Bristol, Oxford, Leeds, and St Mark's Hospital in London. He was awarded an MD after a period of research in Cambridge. He was appointed as a consultant in general and colorectal surgery in 1986.

Professor Finan's research has been primarily related to colorectal cancer. He is the author of over 130 peer-reviewed papers and has lectured widely in the field. He served as Hon Treasurer, and Hon Secretary of the Association of Coloproctology of Great Britain and Ireland and was President in 2006/7. He was also clinical lead for the national bowel cancer audit for four years and has served as Chair of the colorectal site specific clinical reference group of the National Cancer Intelligence Network for six years. His on-going research, with Professor Eva Morris is to investigate differences in management of colorectal cancer at a national level and to look at variance in outcomes at a population level throughout England.



**Professor Eva Morris** is Professor of Cancer Epidemiology and leads the Cancer Epidemiology Group within the Institute of Cancer and Pathology and the MRC Medical Bioinformatics Centre at the University of Leeds. Her research centres on the linkage and exploitation of routine NHS datasets to investigate the processes and outcomes of cancer care.





**Professor Alastair Munro** is a recently retired clinical oncologist. Following expulsion from school in Dundee, he went to work on a farm before studying medicine at St Andrews. He trained in oncology at the Hammersmith Hospital and The Western General in Edinburgh. Subsequently he held consultant posts at the Hammersmith Hospital in London, the Princess Margaret Hospital in Toronto, and St Bartholomew's Hospital in London.

For the past 18 years he has been back in Dundee as a clinical academic. His interests include: medical decision-making; the influence of socio-economic deprivation on outcomes for patients with cancer; intraoperative radiotherapy; the role of MDT meetings in the management of cancer. Currently he is working with Macmillan Cancer Support on developing a virtual MDT for managing the late consequences of treatment for cancer.



After A levels in Classics, **Mr Adam Scott** studied Medicine at St Bartholomew's Hospital, London with an intercalated year in Physiology. His surgical training began in Leicester, London and St Mark's where he obtained his MS and has continued since becoming a Consultant Colorectal Surgeon in Leicester in 1993.

Over the years he has held various management positions including Clinical Director of Gastroenterology, Surgery and Urology and was Honorary Secretary of the Association of Coloproctology of Great Britain and Ireland between 2011 and 2014. He is a member of the clinical governance panel of the ACPGBI and has led invited clinical reviews for the Royal College of Surgeons of England. He is actively involved in teaching and training in Leicester where he is a Clinical Teacher for the university and has an interest in appraisal and clinical assessment. He chairs the colorectal cancer MDT and has a particular clinical interest in the local excision of rectal cancer.





**Mr Nigel Scott** is a Consultant Colorectal Surgeon at Lancashire Teaching Hospitals Trust, a post he has held since 2006. He trained in Manchester, the Mayo Clinic MN and was Lecturer in Surgery at the University of Wales College of Medicine. As Senior Lecturer and then Consultant Colorectal Surgeon for 15 years at the Hope Hospital Intestinal Failure Unit, his interests included surgery of inflammatory bowel disease and the management of tertiary referral surgical catastrophes.

A move to the Cancer Centre at the Royal Preston Hospital includes a practice in laparoscopic colorectal surgery, complex pelvic resection, anal cancer salvage and the development of neoadjuvant rectal cancer complete response protocols. Nigel Scott was President of the Association of Coloproctology of Great Britain and Ireland between 2011 and 2012 and was Clinical Lead for the National Bowel Cancer Audit between 2012 and 2015.



**Mr Graham Williams** is a Consultant Colorectal Surgeon at the Royal Wolverhampton Hospitals Trust. He trained in colorectal surgery in Minneapolis and St Paul, Minnesota.

He is Co-editor of *Contemporary Coloproctology* and an Associate Editor of *Diseases of the Colon and Rectum*. He is a member of the Court of Examiners for the Intercollegiate Board in General Surgery (FRCS part III). He is Past President of the Association of Coloproctology of Great Britain and Ireland and was responsible for the first publication of surgeon specific outcomes in colorectal cancer surgery in September 2013.





**Professor Steven Brown** has been a Consultant Colorectal Surgeon in Sheffield for the past 14 years. He was Honorary Secretary of the Association of Coloproctology of Great Britain and Ireland 2014 - 2016.



**Miss Nicola Fearnhead** is a Consultant Colorectal Surgeon at Addenbrooke's Hospital in Cambridge. She chairs the ACPGBI Research & Audit Committee and the National Bowel Cancer Audit (NBOCA) Clinical Advisory Group. She has led Clinical Outcome Publication for Bowel Cancer for the past two years and sits on the National Cancer Research Institute Colorectal Clinical Studies Group Surgical Subgroup.



## 5. Background to Enquiry

### i. History of NBOCA

The National Audit of Bowel Cancer (NBOCA) may be considered, by any measure, a success but this has only been achieved through the hard work of many individuals and organisations. As the Audit moves through to its next phase, it is worth remembering just how far it has come in the past fifteen years.

A national audit was stimulated by the success of several regional audits throughout the United Kingdom. Amongst these were the Lothian, Wessex and Trent/Wales audits. Enthusiastic individuals, keen to ensure the highest possible standards of care were being delivered to their patients, worked closely together to derive a minimum data set and to agree a suitable platform on which to gather and analyse their data. This early work was under the auspices of the Association of Coloproctology of Great Britain and Ireland (ACPGBI) but gathering of data was left to individual surgeons and case ascertainment was clearly not truly population-based.

Recognition of the limitations of the audit, and the increasing costs incurred with the whole process of data collection, analysis and production of reports, led to the agreement to apply for, and receipt of, central government funding. This was through the Healthcare Quality Improvement Partnership (HQIP) and what was then the Information Centre. Acceptance of the funding brought with it a set of conditions, two of which were to increase case ascertainment and to proceed to the publication of MDT-identifiable outcomes. Both of these were met over the next few years. Case ascertainment increased to such a degree that by 2012 all MDTs in England and Wales were registered with the audit and case ascertainment (using Cancer Registry data and later HES data) increased to over 90%.

This wealth of data led to the production of annual reports and the analyses contained within the “silver books” were met with enthusiasm by clinicians. The extension of analyses in recent years has led to publication of MDT-identifiable data and these have been of use to both clinicians and commissioners alike. The rapid uptake of laparoscopic procedures for colorectal cancer, prompted by national initiatives (LAPCO), and the increasing use of colonic stents to minimise acute surgery are just two areas where the audit recognised changes in practice. Nevertheless further political developments were to engage clinicians even more.

The use of audit data to inform public reporting of individual surgeon outcomes with respect to 90-day post-operative mortality was to see a major change of direction. Whilst many would, and have, argued that publication of outcomes at an individual level was ill-advised until sufficient



data was collected to allow robust statistical analysis of these data, the exercise probably did more to engage clinicians in the process of audit than any other initiative. Data, submitted by MDTs “on behalf of their clinicians” was scrutinised to a level that had previously been just an aspiration. Not all MDTs seized this opportunity but, by linking the audit to the activities of colorectal MDTs, clinical engagement and validation of individual data improved markedly.

The most recent Audit report has addressed other issues of importance. By virtue of the initial enthusiasm of surgical involvement, the audit could be, and was, criticised as being a “surgical” audit rather than an audit of the whole colorectal cancer pathway. The most recent audits have looked at the use of radiotherapy in rectal cancer and the reasons for non-resection (currently around 30%). It is planned to conduct further, in-depth, audits of many aspects of colorectal cancer care, using linkage to other available data sets and these plans are covered later in this report where the future direction is discussed.

## **ii. Reasons for Enquiry**

The National Bowel Cancer Audit (NBOCA) analysed and published results of colorectal cancer treatment at the level of Strategic Clinical Networks (SCNs), rather than the smaller Cancer Networks, in 2014. Wales was assessed as a single network and compared with SCNs in England, which meant that Welsh outcomes were being compared with similar size population units of around 3 million people for the first time.

In the 2014 report, Wales was an outlier for two major outcomes relating to survival:

- Observed all cause mortality rate at 2 years for all patients diagnosed with bowel cancer.
- Observed and risk-adjusted mortality rates at 2 years after surgical resection of bowel cancer.

The observed two-year all cause mortality for all patients (including those who did not undergo surgery) was significantly worse than expected in Wales (see Figure 1). Risk adjustment was not possible for all cause mortality as risk adjustment data items were not available for patients who had not undergone surgery. Analysis demonstrated significantly worse observed and risk-adjusted two year outcomes after previous colorectal cancer resection surgery in Wales when compared to the English SCNs (see Figures 2 and 3).



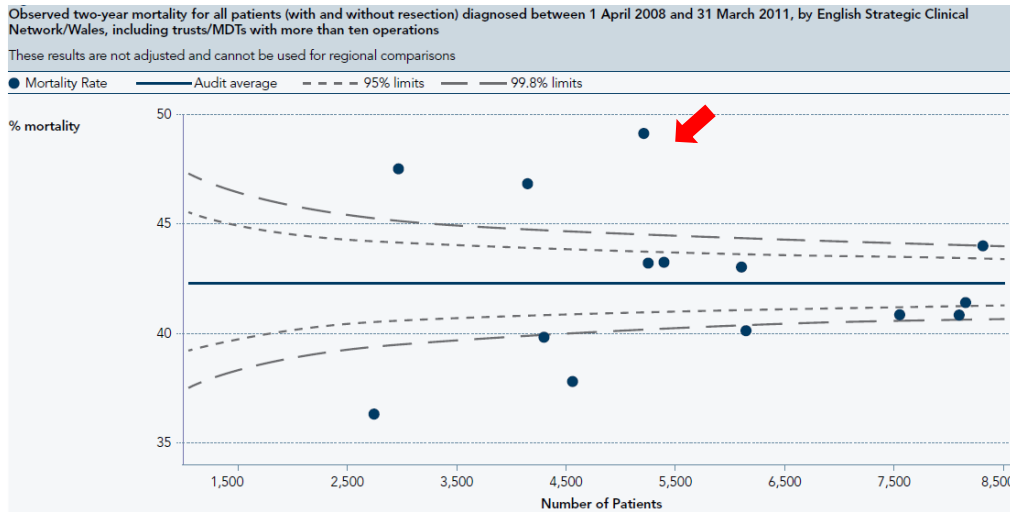


Figure 1: Two year mortality from all causes for patients treated for bowel cancer (both with and without surgery) in Wales (marked with arrow) as compared to the English Strategic Cancer Networks. The two English SCNs that are also outliers in this plot are not outliers for 2 year observed or risk-adjusted mortality after surgical resection. Reproduced with permission from Figure 4.4 in NBOCA 2014 Annual Report (<http://www.hscic.gov.uk/catalogue/PUB16021/nati-clin-audi-supp-prog-bowe-canc-2014-rep1.pdf>).

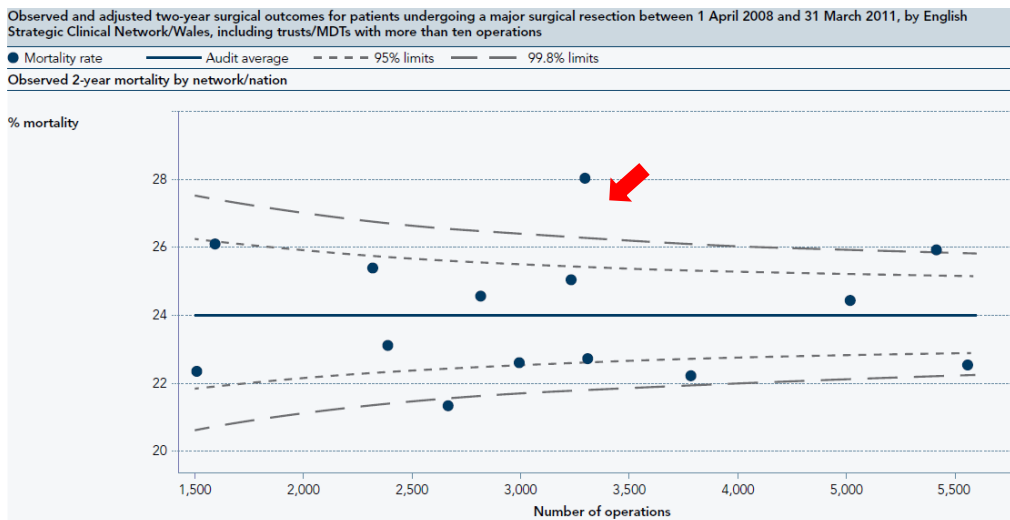


Figure 2: **OBSERVED** two year post-resection **all cause mortality** for Wales (negative outlier at 28% marked with arrow) as compared to the English Strategic Cancer Networks. Reproduced with permission from Figure 4.5 of NBOCA 2014 Annual Report (<http://www.hscic.gov.uk/catalogue/PUB16021/nati-clin-audi-supp-prog-bowe-canc-2014-rep1.pdf>).





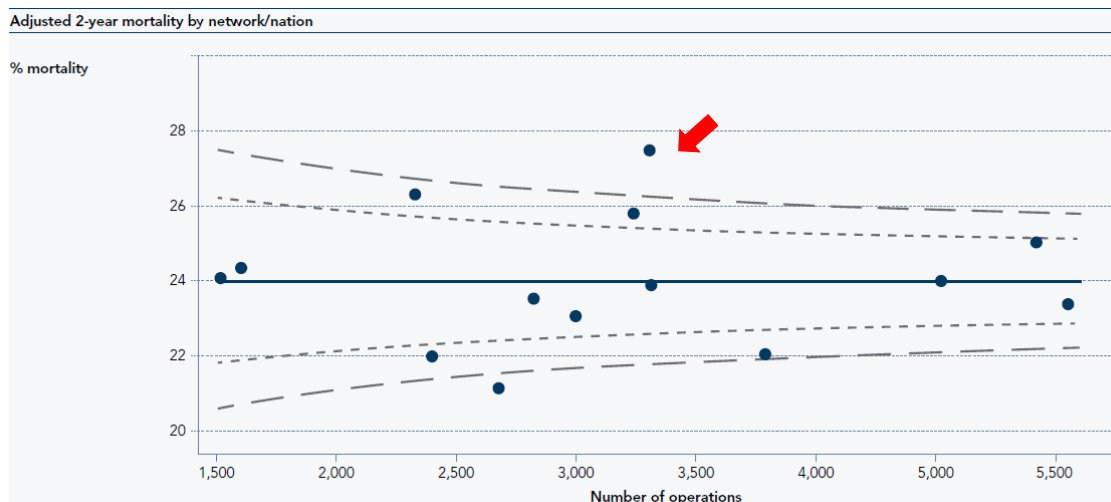


Figure 3: **RISK-ADJUSTED** two year post-resection **all cause mortality** for Wales (negative outlier at 27.5% marked with arrow) as compared to the English Strategic Cancer Networks. Reproduced with permission from Figure 4.5 of NBOCA 2014 Annual Report (<http://www.hscic.gov.uk/catalogue/PUB16021/nati-clin-audi-supp-prog-bowe-canc-2014-rep1.pdf>).

Potential reasons for these observed differences are disparities between patient groups and background mortality rates, variations in management pathways and differences in data quality. Risk adjustment processes can allow for differences in patient mix but also rely on mode of admission and level of comorbidity. This information is derived from Hospital Episode Statistics (HES) in England and from the Patient Episode Database for Wales (PEDW). PEDW data was not available to NBOCA in 2014 as it had been switched off due to concerns about accuracy.

The 2014 NBOCA Annual Report reported on short term outcomes of patients diagnosed with bowel cancer in England and Wales between April 2012 and March 2013. As survival was assessed at two years, the patient cohort reported in 2014 were those diagnosed with bowel cancer during the three year period of April 2008 to March 2011. Risk adjustment processes had taken in to account age, sex, American Society of Anesthesiology (ASA) grade, T stage, nodal status, the presence or absence of distant metastases, and the site of the primary tumour within the colon or rectum (Walker et al 2015).

Risk adjustment for the mortality comparison also takes in to account the mode of admission of each patient and their level of comorbid disease. This is usually derived in England from Hospital Episode Statistics (HES) which is a dataset that holds information on every inpatient stay in the English NHS. The equivalent Welsh dataset is Patient Episode Database for Wales (PEDW) but information from this resource was not available to the audit in 2014. This meant the audit team



had to 'impute' the missing values for each Welsh patient based on the survival experience and other characteristics of English patients.

The 2014 NBOCA Annual Report discussed potential reasons for the apparent outlying status of Wales with respect to colorectal cancer survival at two years. This may have been due to differences in data completeness and accuracy, to differences in patient characteristics including socioeconomic differences, differences in the quality of surgical resection or differences in the quality of care for patients with colorectal cancer in the peri-operative period. It may also have been the result of high case ascertainment or differences in data quality.

The recommendation from NBOCA at that time was that the data accuracy should be established, processes of data collection should be audited, the risk adjustment imputation model should be checked and PEDW data should be made available. There was also the recommendation that changes should be monitored over time.

Indeed the 2015 NBOCA Annual Report reported that Wales was no longer an outlier for either two year all cause or post-operative mortality. While these findings seemed reassuring, there was a caveat about a possible Type 2 error, due to the smaller number of patients included as only outcomes for a two (rather than three) year cohort of patients diagnosed with bowel cancer between April 2011 and March 2013 were analysed. The same data issues also prevail in later analyses and so subsequent comparisons may still be misleading.

In early 2015, the Welsh Chapter representatives on the Association of Coloproctology of Great Britain and Ireland (ACPGBI) Council raised the matter for discussion and requested help in assessing the quality and accuracy of the data. In view of this, members of the ACPGBI Executive and the National Bowel Cancer Audit entered into conversation with Dr Tom Crosby, Medical Director of the South Wales Cancer Network at the time and now Medical Director of Wales Cancer Network. After a number of discussions, terms of reference were agreed for an ACPGBI led enquiry in to the Welsh cancer outcomes and terms of reference were drawn up (see Appendix B *Terms of Reference*). The terms of reference were subsequently presented to the ACPGBI Council in June 2015 and approved unanimously.

### **iii. Objectives of Enquiry**

The Enquiry was established to provide an independent quantitative review of colorectal cancer outcomes in Wales. The specific aim was to assess the validity of the Welsh data used to assess colorectal cancer outcomes, provide qualitative assessment of data entry and risk adjustment processes, and allow comparison with other countries in the United Kingdom. Additional information gained during the process was intended to be shared.



#### **iv. Process**

The Enquiry process involved review of the data held by the National Bowel Cancer Audit, not just for the 2014 report but for the period of 2012 to 2015. This was supplied to the Welsh MDTs along with specific questions about their particular outcomes with respect to not only mortality but also other outcome measures.

The ACPGBI convened a panel of nine members under the chairmanship of Professor Robert Steele, President of the Association of Coloproctology of Great Britain and Ireland from 2015 - 2016. The other panel members included Professor Paul Finan (past President of ACPGBI), Professor Alistair Munro (recently retired Consultant Oncologist), Professor Eva Morris (Professor of Epidemiology), Mr Adam Scott (former Honorary Secretary ACPGBI), Mr Nigel Scott (past President of ACPGBI), Mr Graham Williams (past President of ACPGBI), Mr Steven Brown (Honorary Secretary 2014 - 2016), and Miss Nicola Fearnhead (Chair of the Research and Audit Committee).

In addition to preliminary and subsequent teleconferences and meetings, the Enquiry panel visited Wales over the period of the 11<sup>th</sup> - 12<sup>th</sup> April 2016. Meetings were held with the Welsh Cancer Registry on the 11<sup>th</sup> April 2016 and with representatives of all the Welsh Multi-Disciplinary Teams (MDTs), WCISU and CaNISC on the 12<sup>th</sup> April 2016. The format of the consultation was individual interviews with each MDT followed by group presentations and discussions in the afternoon. Appendix C includes the agenda for the meeting on the 12<sup>th</sup> April 2016 at the Life Sciences Hub Wales in Cardiff Bay.

Additional sources of information were sought from public data repositories and the Welsh Cancer Registry.

#### **v. Stakeholders**

The major stakeholders are patients in Wales with colorectal cancer and the multidisciplinary teams caring for them. The North and South Wales Cancer Networks which previously existed have since been amalgamated into a single network under directorship of Dr Tom Crosby. The Welsh Cancer Intelligence and Surveillance Unit (WCISU) is under the Directorship of Dr Dyfed Huws. Interactions in this enquiry took place with the following stakeholders and representative organisations:



<b>Organisation</b>	<b>Affiliation(s)</b>
Clinical Effectiveness Unit	Royal College of Surgeons
National Bowel Cancer Audit	Health Quality Improvement Partnership
North Wales Cancer Network	
South Wales Cancer Network	
Betsi Cadwaladr Local Health Board	
Hywel Dda Local Health Board	
Abertawe Bro Morgannwg University Local Health Board	
Cwm Taf Local Health Board	
Cardiff and Vale University Health Board	
Aneurin Bevan Local Health Board	
Bronglais MDT <sup>#</sup>	South Wales Cancer Network
Cardiff MDT	South Wales Cancer Network
Nevill Hall Hospital MDT	South Wales Cancer Network
Prince Charles Hospital MDT	South Wales Cancer Network
Princess of Wales MDT	South Wales Cancer Network
Royal Glamorgan Hospital MDT	South Wales Cancer Network
Royal Gwent Hospital MDT	South Wales Cancer Network
Swansea MDT	South Wales Cancer Network
West Wales General & Prince Phillip MDT	South Wales Cancer Network
Withybush General MDT	South Wales Cancer Network
Ysbyty Glan Clwyd MDT	North Wales Cancer Network
Ysbyty Gwynedd MDT	North Wales Cancer Network
Ysbyty Maelor MDT	North Wales Cancer Network
Welsh Cancer Intelligence and Surveillance Unit (WCISU)	
Cancer Network Information System Cymru (CaNISC)	

Table 1: Stakeholders in the ACPGBI National Enquiry into colorectal cancer outcomes in Wales.



## 6. Context

### i. Geography

The population of Wales was just over 3 million in mid-2014 as compared to just over 54 million in England and just under 5.5 million in Scotland. In 2014, there were just under 2 million adults aged between 16 and 64 in Wales and 615 000 adults aged over 65 years (Source: Stats Wales <https://statswales.wales.gov.uk/catalogue>).

There are seven local Health Boards in Wales that oversee delivery of healthcare. Six of these local Health Boards (LHBs) are involved in delivery of colorectal cancer care.

- Betsi Cadwaladr University Health Board is the largest health organisation in Wales, providing services for just under 700 000 people across the six counties of North Wales (Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham) as well as some parts of mid Wales, Cheshire and Shropshire. The Board is responsible for Ysbyty Gwynedd in Bangor, Ysbyty Glan Clwyd in Rhyl and Ysbyty Maelor in Wrexham.
- Hywel Dda Local Health Board provides healthcare services to around 383 000 people throughout Carmarthenshire, Ceredigion and Pembrokeshire. The Board is responsible for Glangwili Hospital in Carmarthen, Withybush Hospital in Haverford West, Prince Philip Hospital in Llanelli and Bronglais Hospital in Aberystwyth.
- Abertawe Bro Morgannwg University Health Board is one of the largest in Wales with responsibility for 525 000 people in the Swansea, Neath Port Talbot and Bridgend areas. It is responsible for Morriston Hospital in Swansea, Singleton Hospital in Swansea and the Princess of Wales Hospital in Bridgend.
- The Cwm Taf Local Health Board is responsible for just under 300 000 people and runs the Prince Charles Hospital in Merthyr Tydfil and the Royal Glamorgan Hospital in Llantrisant.
- The Cardiff and Vale University Health Board runs the University Hospital of Wales in Cardiff. It serves both its local population of 485 000 and offers regional services for Wales.
- The Aneurin Bevan Local Health Board is responsible for the delivery of health care services to 581 000 people living in the Gwent area and runs the Royal Gwent Hospital in Newport and Nevill Hall Hospital in Abergavenny.
- Powys Teaching Health Board covers a large rural area from Machynlleth in the north to Ystradgynlais in the south but does not offer colorectal cancer services. Patients from this



area have access to colorectal cancer services elsewhere in Wales and in Shrewsbury, England.

<b>MDT</b>	<b>Network</b>	<b>Hospital(s)</b>	<b>Location</b>	<b>Health Board</b>
Bronglais <sup>#</sup>	SWCN	Bronglais Hospital	Aberystwyth	Hywel Dda
Cardiff	SWCN	University Hospital of Wales	Cardiff	Cardiff and Vale University
Nevill Hall Hospital	SWCN	Neville Hall Hospital	Abergavenny	Aneurin Bevan
Prince Charles Hospital	SWCN	Prince Charles Hospital	Merthyr Tydfil	Cwm Taf
Princess of Wales	SWCN	Princess of Wales Hospital	Bridgend	Abertawe Bro Morgannwg
Royal Glamorgan Hospital	SWCN	Royal Glamorgan Hospital	Llantrisant	Cwm Taf
Royal Gwent Hospital	SWCN	Royal Gwent Hospital	Newport	Aneurin Bevan
Swansea	SWCN	Morriston Hospital Singleton Hospital	Swansea	Abertawe Bro Morgannwg
West Wales General & Prince Philip*	SWCN	Glangwili General Hospital Prince Philip Hospital	Camarthen Llanelli	Hywel Dda
Withybush General*	SWCN	Withybush Hospital	Haverford West	Hywel Dda
Ysbyty Glan Clwyd	NWCN	Ysbyty Glan Clwyd	Rhyl	Betsi Cadwaladr
Ysbyty Gwynedd	NWCN	Ysbyty Gwyneth	Bangor	Betsi Cadwaladr
Ysbyty Maelor	NWCN	Ysbyty Maelor	Wrexham	Betsi Cadwaladr

Table 2: Mutidisciplinary teams delivering colorectal cancer care in Wales in 2014. (MDT – multidisciplinary team, SWCN – South Wales Cancer Network, NWCN – North Wales Cancer Network). <sup>#</sup>Elective colorectal cancer services are no longer offered at Bronglais. \*These MDTs have since merged into a single MDT.



## ii. Demographics of Welsh Population

There are some important differences between the population in Wales and that in the other countries of the United Kingdom (Figure 4). Wales has the highest proportion of the population over the age of 75 in the UK (Figure 5) and a significantly higher proportion of adults under retirement age living with a disability. Average household incomes are lower in Wales than in other UK countries, but a lower proportion of the population drink alcohol or smoke.

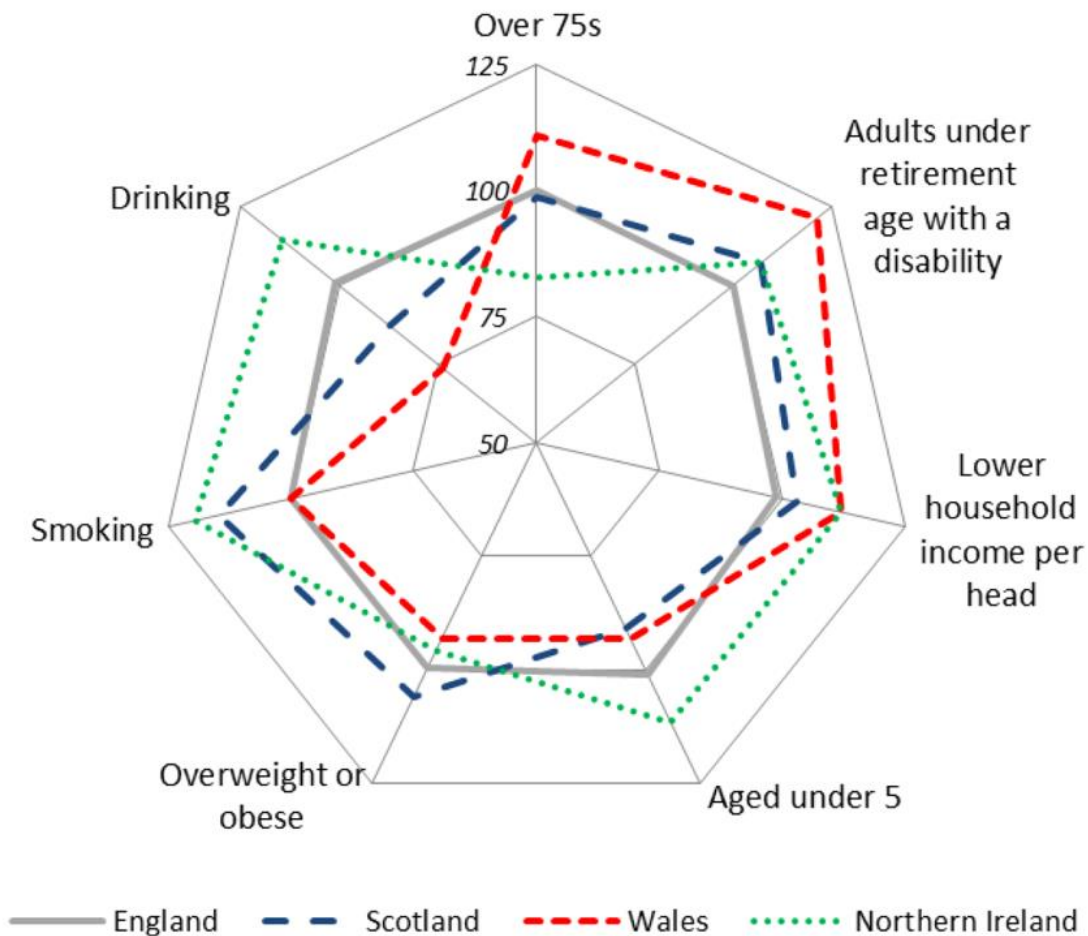
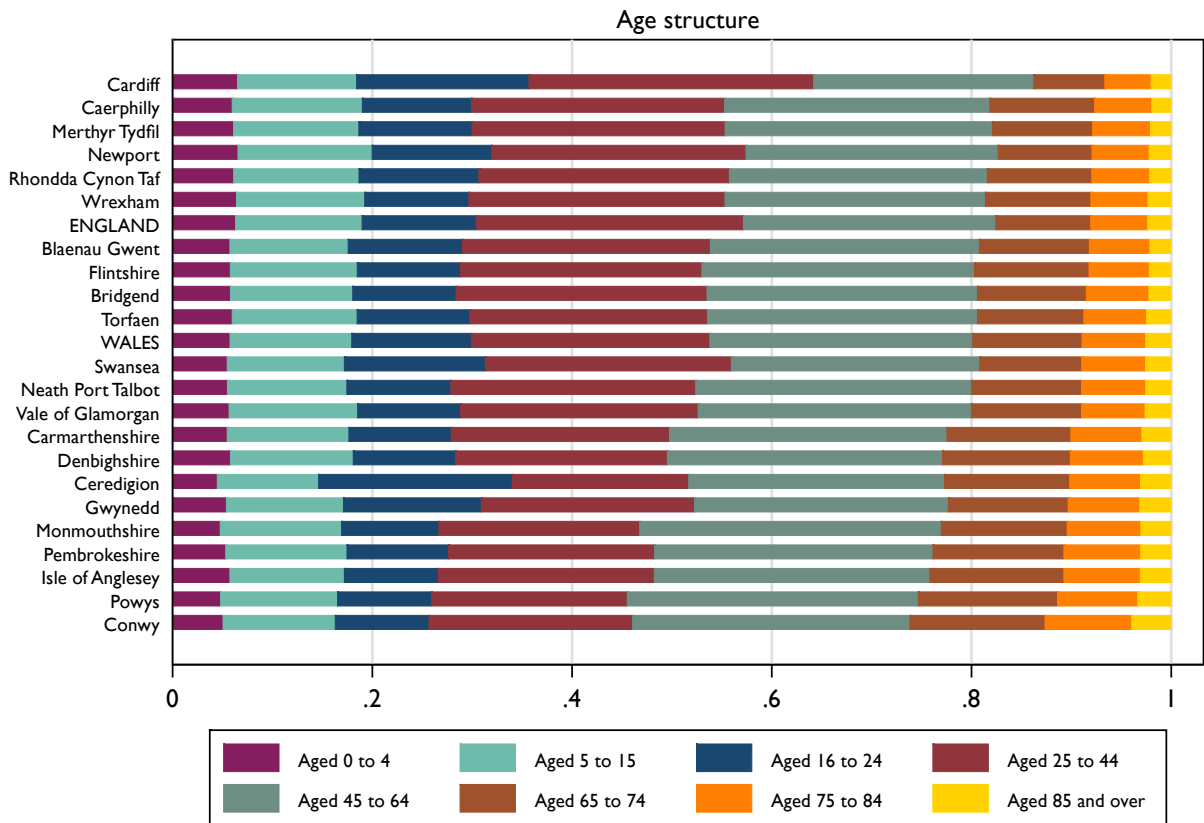


Figure 4: Health map illustrating differences among populations of the countries in the United Kingdom (source: *Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland* by Jamie Hart, William Palmer and Lee Summerfield under the direction of Laura Brackwell, with assistance from Richard Alcorn, Thibault Dornon, Rachael Foster, Joe Perkins and Jack Sharples. The National Audit Office 2012. [www.nao.org.uk](http://www.nao.org.uk)).





Source: Stats Wales year 2014

Figure 5: Breakdown of age structure of populations served by Welsh Local Authorities showing variation in population age. Age is accounted for in European Age Standardised Rates per 100 000 population (EASR). (Source: *National level population estimates by year, age and UK country*. Data from Statistics Wales published in 2014 <https://statswales.gov.wales/Catalogue>).

There is wide variation in socio-economic deprivation in Wales (Figure 6) with the most recent analysis available being published in 2014 (<http://gov.wales/docs/statistics/2015/150812-wimd-2014-summary-revised-en.pdf>). This indicated pockets of high relative deprivation in the valleys and large cities of South Wales, and also in North Wales, particularly in some coastal towns and those on the English border. There had been little change in the most deprived areas of Wales compared to an earlier analysis in 2011.

The average health need of the Welsh population is 1.07 compared to 0.91 for England and 0.93 for the UK as a whole (NAO data based on a commissioned but unpublished report by Deloitte). This is an indication that, overall, Welsh citizens are less healthy than the English but have a





similar level of health to populations in the North East of England. There is also some indication that when preventative services are available, people in Wales are less likely to use them.

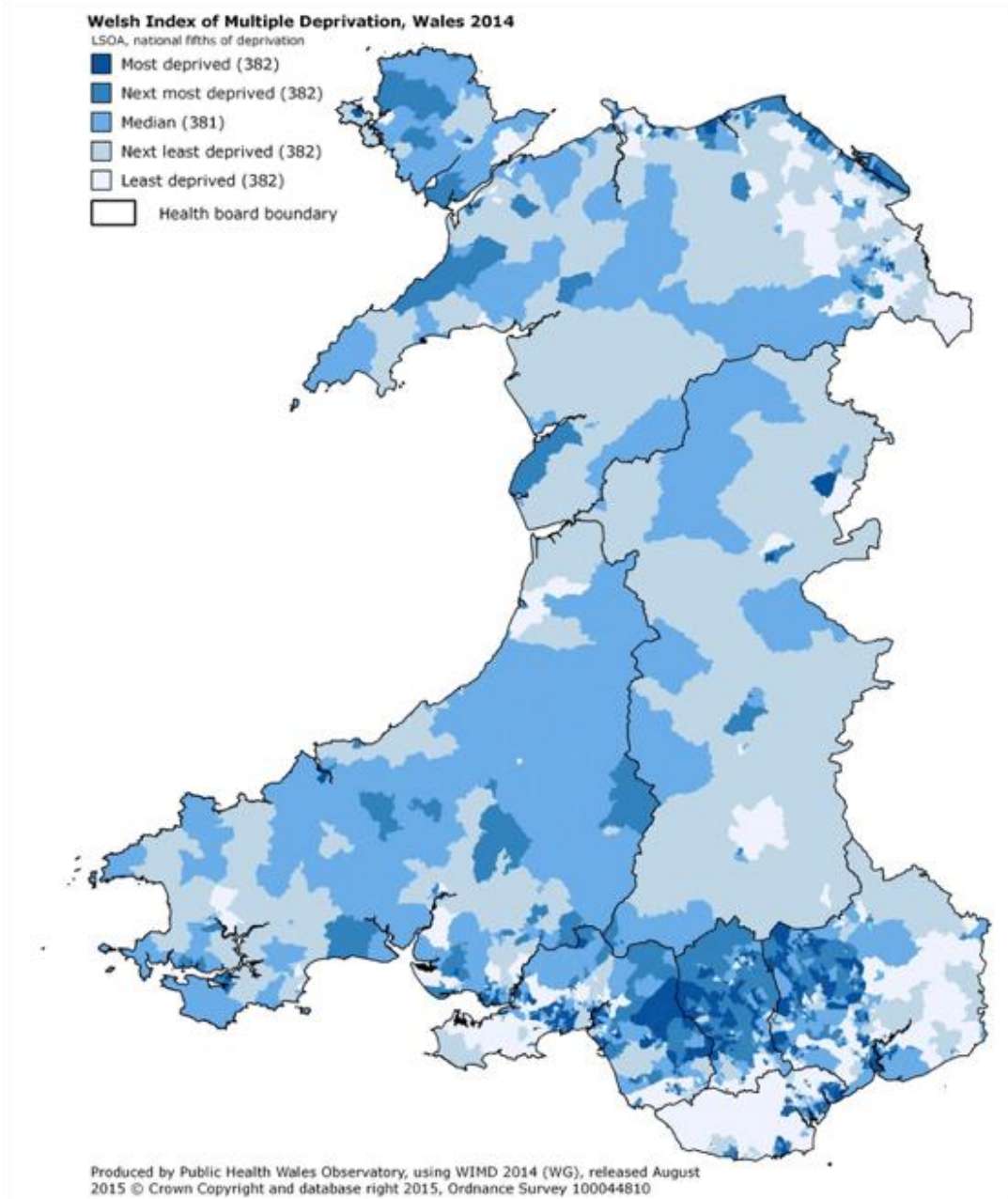


Figure 6: Health Board map of Wales illustrating level of deprivation as measured by Welsh Index of Multiple Deprivation in 2014 (source: Public Health Wales Observatory, <http://gov.wales/docs/statistics/2015/150812-wimd-2014-summary-revised-en.pdf>).



### iii. Epidemiology of Colorectal Cancer in Wales

There were just under 20 000 newly diagnosed patients with cancer in Wales in 2014 (<http://www.wcisu.wales.nhs.uk/sitesplus/documents/1111/WCISU%20Statistical%20report%20%28bilingual%29%20rotated.pdf>). In 2014 there were 1327 men and 1008 women reportedly diagnosed with colorectal cancer. Colorectal cancer was the second most common cancer in men and the third most common cancer in women. There has been a gradual but steady increase in incidence of bowel cancer over the past ten years. In 2014, bowel cancer accounted for just under 1000 deaths in Wales, the second most common cause of cancer death after lung cancer.

There is some variation in incidence of colorectal cancer in different health boards with the European age standardised rate per 100 000 of the population, being lowest in West Wales where the incidence is 69.4 and highest for Cwm Taf at 87.3 in 2014. Cwm Taf had the highest reported bowel cancer mortality rate of all the Welsh Health Boards and Powys had the lowest, although case ascertainment is questionable in the latter region as most patients are treated elsewhere.

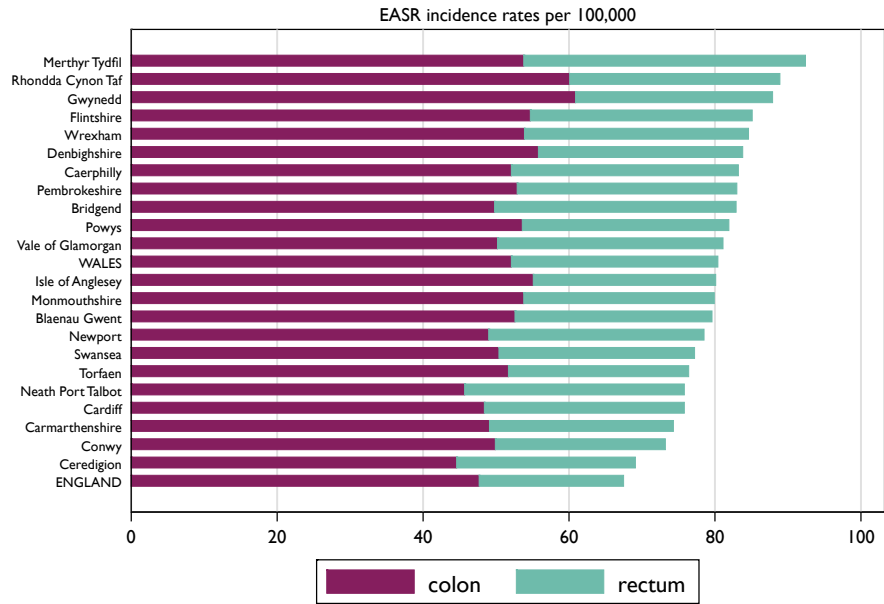
Bowel cancer incidence increases with area deprivation but there is less inequality than with other cancers such as lung cancer. There are, however, inverse inequality gaps with breast and prostate cancer incidence rates tending to be higher in more affluent areas. Although the gap in one year survival from all cancers has decreased between the least and most deprived areas of Wales, it has increased slightly for five year survival. In contrast to this, the gap in one year and five year survival rates between the least and most deprived areas has widened considerably for bowel cancer (*Cancer in Wales*, WCISU).

The age standardised rates for incidence and mortality for cancers of the colon and rectum are compared with the English rates in Table 3 and the rates by Welsh local authority are shown in Figures 7 and 8. The incidence and mortality rates for colorectal cancer are higher in Wales than England, particularly for rectal cancer.

Site	Measure	Wales	England
Colon	Incidence	52.1	47.7
	Mortality	19.2	16.5
Rectum	Incidence	28.3	19.8
	Mortality	11.7	7.0

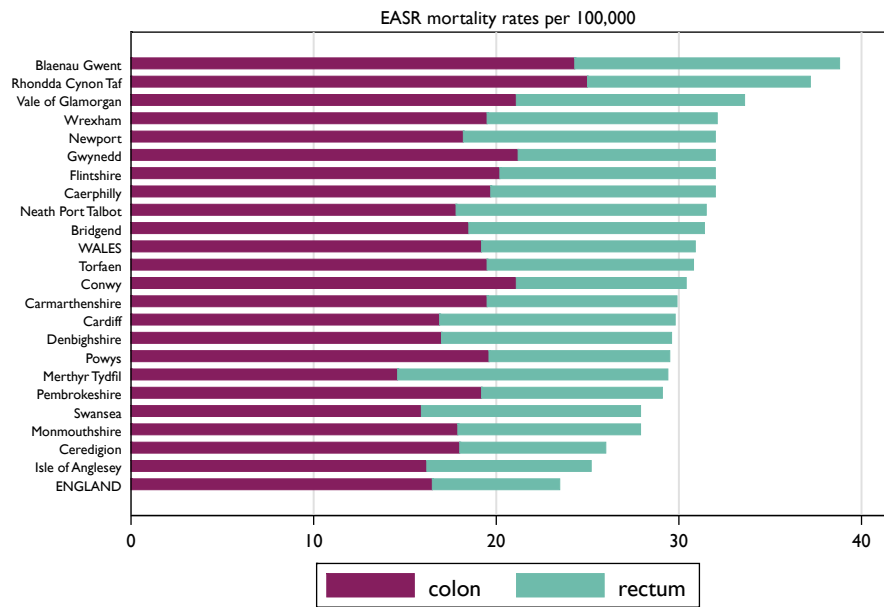
Table 3: European age standardised rates per 100,000 (EASR) for incidence and mortality in colorectal cancer in England and Wales (Source: WCISU and NCRAS).





Source: WCISU <http://www.wcisuwales.nhs.uk/official-statistics-exel-files-of-trend-April-2016> & NCRAS

Figure 7: European age standardised rates per 100,000 (EASR) for incidence of colorectal cancer in England and Wales, with breakdown by local authority in Wales (Source: WCISU and National Cancer Registration and Analysis Service (NCRAS)).



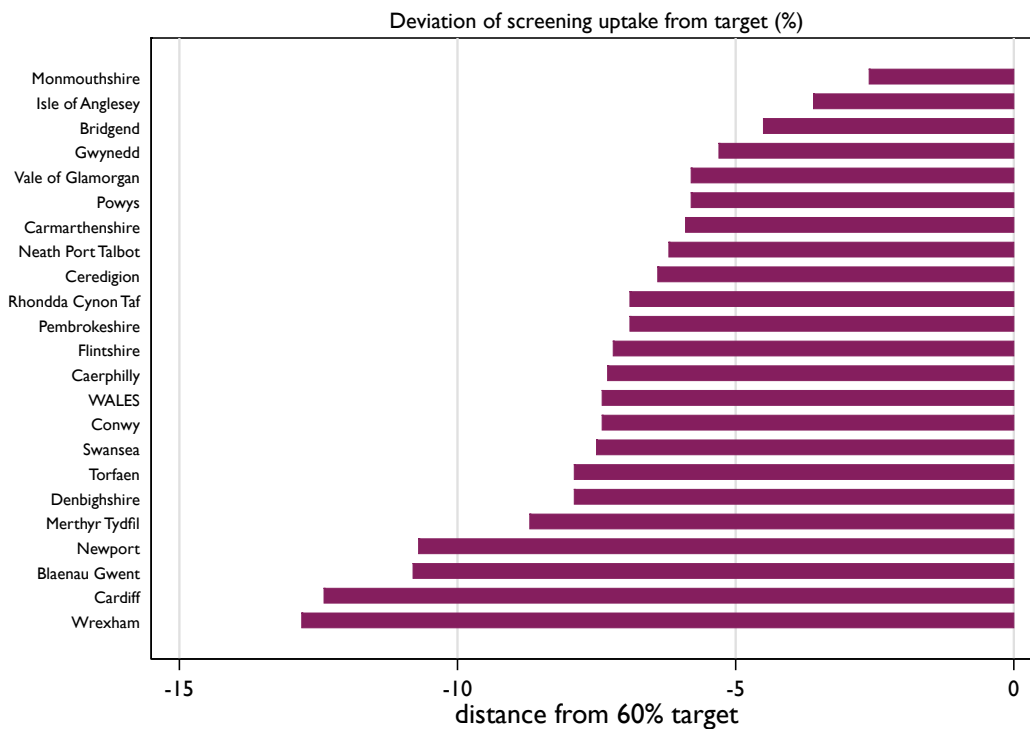
Source: WCISU <http://www.wcisuwales.nhs.uk/official-statistics-exel-files-of-trend-April-2016> & NCRAS

Figure 8: European age standardised rates per 100,000 (EASR) for mortality from colorectal cancer in England and Wales, with breakdown by local authority in Wales (Source: WCISU and NCRAS).



The Bowel Screening in Wales Campaign offers screening to men and women resident in Wales between the ages of 60 and 74 years old with faecal occult blood screening. The overall uptake rate for bowel screening in Wales is low (52.5% in 2014 as compared to 58% in England) and there are significant differences in uptake rates amongst local authorities as illustrated in Figure 9.

Although Wales may have poorer screening uptake than England overall, rates in Wales are similar to some of the more deprived SCNs in England, against which Wales was compared in the 2014 NBOCA Annual Report.



Source: PHW Bowel screening uptake by Unitary Authority and Health Board 2013/2014

Figure 9: Percentage deviation of screening uptake from target for screening, by local authority (Source: Bowel Screening Wales Annual Statistical Report 2013-14, published 2015, Screening Division of Public Health Wales <http://www.wales.nhs.uk/sitesplus/888/news/36504>).



#### iv. Choice of Comparators

In the 2014 National Bowel Cancer Audit Report, Wales was compared to the English Strategic Cancer Networks. It was suggested after publication that it may have been preferable to only compare Wales to SCNs in the North of England where there was more similarity in population demographics, and not to all English SCNs. There is also considerable variation in outcomes within Wales itself and the Panel were asked whether it would have been an option just to provide intra-Wales comparisons. Wales has, however, always been presented in NBOCA as a single entity and was previously compared to much smaller networks of around a million rather than much larger and arguably more comparable SCNs.

Welsh MDTs largely faced comparable problems in service delivery and had similar levels of service provision as illustrated by the information submitted to NBOCA in 2015 (see Appendix F: *Organisational Reports*).

It was highlighted to the Panel that access to subspecialist services for colorectal cancer was not comparable between Wales and England:

- Resection of colorectal cancer metastases was not offered widely in Wales with North Wales referring patients to Aintree.
- Cetuximab had only recently been introduced in Wales.
- Recurrent rectal cancer patients were managed in Swansea but North Wales MDTs referred patients to the Christie Hospital in Manchester.
- Heated intraperitoneal chemotherapy (HIPEC) for advanced intraperitoneal malignancy had not been funded by commissioning bodies.
- Patients with pseudomyxoma peritonei had to be transferred to England for management.

Although these differences exist and there may be logistical difficulties and financial burden for patients needing access to these specialist services, it would be misleading to attribute a significant numerical impact on colorectal cancer outcomes overall due to the small proportion of patients affected. It is important not to overstate the importance of these services when trying to explain overall differences in Welsh outcomes.



## 7. Data

This enquiry arose because of the perception that outcomes for patients with colorectal cancer were, when compared with English SCN data, worse in Wales. Context is crucial here: the outcome experienced by any individual patient is not simply dictated by the competence and skills of those members of the healthcare team with whom that patient comes into direct contact. The technical competence of teams is but one factor amongst many.

The context within which a treatment for cancer is delivered is important (see Appendix D: *Healthcare Systems and Cancer Care in Wales*). Disparate factors may influence outcomes and, if we are to compare results between systems or countries, then we need to be able, using numbers, to assess the extent to which contexts differ. Inferior results do not necessarily indicate bad practice but, unless any epidemiological, socio-demographic and organisational differences are objectively scrutinised, the line of least resistance will be followed and institutions and individuals may be unfairly blamed. True comparisons may only be made with similar data from the differing areas to allow appropriate risk adjustment.

The principal remit of this Enquiry was, however, to assess the quality and accuracy of data, and the systems used in acquisition and analysis.

### **i. Acquisition of data**

Data acquisition in most instances was carried out either during or after multidisciplinary team (MDT) meetings, but there was wide variation in use of paper or electronic recording of data entry, with the majority of sites choosing to enter data afterwards. Support in terms of MDT coordinators was variable with a few long-serving coordinators but a common theme was of high turnover. Cover for MDT coordinators while on leave was also variable with a colleague usually attending the meeting but not always recording data items for the audit or not entering the data on central databases until the usual postholder returned from leave.

Data are then entered onto the Cancer Network Information System Cymru (CaNISC) directly, or – in the case of some of the North Wales MDTs – submitted to another hospital for upload or via a local electronic system called Myrddin, specific to North Wales where it had been introduced by Ysbuty Maelor.



Some MDTs reported using the MDM module on the CaNISC website in real time for data entry during the MDT. There were mixed opinions on the utility and ease of the MDM module on CaNISC, and a more general acknowledgement that it took additional time while still ensuring data accuracy and completeness. Limited clinician time, insufficient allocation of time to MDTs in job planning and split site MDTs were also raised as potential barriers to best practice in data collection. Appropriate resources for good quality data collection and submission are essential elements underpinning effective audit.

CaNISC is a purpose-built system originally designed to allow all Wales to have access to the same system on a single platform. Its primary purpose is to report cancer waiting times and allow scheduling of cancer treatments including chemotherapy and radiotherapy. With respect to data collection, there was concern that CaNISC may not be functioning appropriately for the service. Much discussion revolved around whether a new system should be commissioned and about the functionality of that system.

The option of using Somerset, a platform widely used in England, had been considered but duplication of data entry on multiple platforms was not thought to be judicious. Concern was expressed that CaNISC may not reflect the data that has been entered, and may be less fit for audit processes than Somerset. CaNISC does not allow duplicate entries with the consequence that sometimes entries were deleted rather than combined, and that data may potentially be lost due to this. The options for information technology upgrades discussed at the open meeting included adoption of Somerset or a scratch build of a new Wales-specific CaNISC-like system. The decision on updating CaNISC was yet to be taken by the Welsh Government.

There was variation in the application of advice about coding of ASA status and whether a patient was undergoing an emergency or an elective procedure. A repeated theme in small group discussions was how TNM status should be assigned for each patient, with many clinicians believing the radiologist alone was responsible for TNM staging. It was advised that TNM is ultimately an MDT function and that clinical staging should be recorded including the use of M0 or M1, reserving Mx for those situations where there was real uncertainty. Reassurance was given that it is not necessary for a radiologist to alter a CT report in order for an M stage to be included. If a radiologist has scored the M stage as Mx, then it is still possible for the MDT to assign an M0 or M1 following MDT discussion.

It is also important to note that the circumferential resection margin (CRM) status needs to be recorded as this was particularly poorly reported across most Welsh MDTs despite its potential for significant impact on outcomes. In summary, accurate pre-operative staging and integrated clinico-pathological staging at completion of treatment are essential to guide good treatment and therefore must be recorded faithfully as audit data items.

Although CaNISC was designed as a system for planning oncology treatments, almost every MDT highlighted the fact that preoperative radiotherapy use in rectal cancer patients appeared disproportionately high when considering local policies. It was not clear whether rates of



radiotherapy use were particularly high or if this too was a data entry problem (as rates have varied substantially in the NBOCA reports for Wales over time).

## **ii. Process**

It is also important to be satisfied that data were correctly uploaded and any discrepancies addressed. CaNISC offers reports on uploads at regular intervals with some MDTs reporting checking these 3-monthly for clinical sign-off and others unaware of this facility. Sign-posting of areas of concern that needed to be addressed, e.g. incomplete data sets especially relating to risk factors used in risk adjustment, was not widely used.

The Welsh data from CaNISC was transferred in a single national download to the Open Exeter platform for transfer to NBOCA.

Clinical sign-off is a fundamental aspect of good audit data collection, and involves not just entry but verification of downloaded data. Frequent and repeated mention was made of discrepancies between data seen on CaNISC and what then appeared in the NBOCA report, despite earlier clinical sign-off. It was proposed that the CaNISC upload be reviewed by Welsh clinicians on the Clinical Audit Platform.

Length of stay, which would have been derived from HES data for the rest of the audit, is collected in CaNISC but had not been transferred as it was not understood that this data item was required. Addition of new data items to CaNISC was perceived as a time-consuming and laborious process, limiting the ability of CaNISC to collect any new data items introduced by NBOCA.

## **iii. Data quality**

The case ascertainment rate of the Welsh data raised some concerns. There were 2159 registrations with the Welsh Cancer Intelligence and Surveillance Unit (WCISU) of patients with colorectal cancer in Wales for the audit period covered in the 2014 NBOCA Report but only 2042 patients were included in the NBOCA audit. It is possible that new cancer patients from Powys were excluded if they received treatment in England but they should have been captured if treated by other Welsh MDTs.





Full comparisons of NBOCA and WCISU data may be found in Section 8 under the heading “Comparisons of Institutional Performance” and in Table 4. Full discussion of the impact of case ascertainment on analysis is discussed in that section of the report.

Separate concerns were raised about the future collection and accuracy of PEDW data. PEDW data had not been available for risk adjustment of comorbidity in the 2014 analysis. As PEDW has only recently been switched back on, it will remain to be seen in the future whether the data collected in PEDW are sufficiently robust to offer a valid risk adjustment process.

#### **iv. Analysis**

Analysis of data was carried out using validated statistical methods and peer-reviewed and published risk adjustment processes. Risk adjustment models depend on availability of data items for risk adjustment including age, sex, TNM stage, site of tumour within colon or rectum, ASA grade, comorbidity and mode of admission (Walker et al 2015).

Data presentation was standard in tabulated form and funnel plots as appropriate. The comprehensive analysis undertaken by NBOCA is felt to be useful in assessing outcomes and facilitating quality improvement initiatives. Lack of PEDW data undoubtedly caused problems with analysis in the 2014 report.

There are valid comparisons to be made between MDT outcomes within Wales with wide variation. Some of this variation will be due to relatively low case numbers which again argues for the collective assessment of all Welsh data.

Ideally cancer specific survival would be a better outcome measure than all cause mortality and this remains a goal for future reports.

#### **v. Adjustment for socio-economic deprivation and use of an imputational model**

The measures of socio-economic deprivation used in the UK are based on information provided by households to the national census. The most recent data are based on the 2011 census, with older data from the 2001 census. Personal information on income, employment and education is aggregated and combined with neighbourhood data on access to services, crime, and other



environmental factors. This is used to produce an index based on the information relevant to a specific geographical location with weighted contributions from each factor used in the index.

The English Index of Multiple Deprivation (EIMD) is based on seven factors and the Welsh Index of Multiple Deprivation (WIMD) is based on eight factors; the weightings are also different between the two scores (see Figure 10). Thus, although the Welsh and English indices are superficially similar there are, in fact, fundamental differences between them. Deprivation as measured in Wales is not the same as deprivation measured in England.

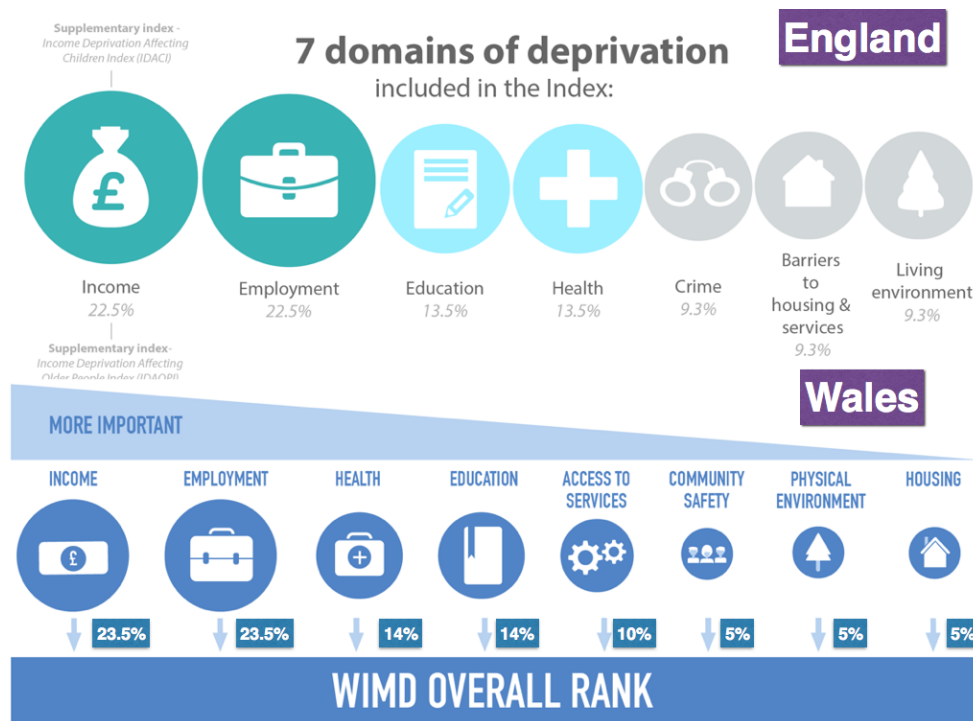


Figure 10: Comparison of measures of socio-economic deprivation as used in England (English Index of Multiple Deprivation) and Wales (Welsh Index of Multiple Deprivation) (Sources: EIMD [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/464431/English\\_Index\\_of\\_Multiple\\_Deprivation\\_2015\\_-\\_Infographic.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/464431/English_Index_of_Multiple_Deprivation_2015_-_Infographic.pdf) and WIMD graphic is derived from <http://gov.wales/docs/statistics/2014/141112-wimd-2014-guidance-en.pdf>).

There are also more general problems associated with the use of composite indices, particularly when used in health services research. Both the Welsh and English indices contain health as a determinant. The overall score in both indices gives it significant weight: 13.5% of the total in



England; 14% in Wales. This can lead to circular arguments. When the composite index uses an item containing a measure of poor health it is bound to “predict” poorer health. Even if only the income domain of Index of Multiple Deprivation (IMD) is used for risk adjustment purposes in analysis, the proportion income contributes is again different in the English and Welsh indices.

Access to health services may also be confounding. Patients with poor access to health services may, provided they actually obtain treatment, enjoy better outcomes on average than those with easier access to services. This is a variant of stage shift. If access is difficult, then only the fitter and more determined patients (those who are likely to fare better) will obtain access to treatment. Thus, if results achieved by hospitals and specialist services are being compared, outcomes may be better for those centres serving more widely dispersed communities. This may lead to countermanding effects within the components of a composite index: lower income associated with worse outcome and yet difficult access associated with better outcomes.

Given these problems, it is better to use a single measure, income deprivation, when assessing the effects of socio-economic deprivation on patients treated for cancer. The adjustments in the NBOCA analysis used income deprivation for the English data and the WIMD for the Welsh data. These differences in measuring deprivation may have had some effect on the reliability of the imputational procedures used to compensate for the absence of PEDW data, and hence information on the mode of admission and on comorbidity for the Welsh patients.

Although methodological differences in measuring deprivation may hinder comparisons between England and Wales, comparisons within Wales are still valid but may in turn be confounded by small numbers.

## **vi. Publication and interpretation of results**

The Panel was asked to address the question of whether the outcome data for Wales should have been published, in light of concerns about the lack of PEDW data and need for imputational methods to allow risk adjustment. Analysis was undertaken on the Welsh data provided to the audit. It should be noted that a draft of the NBOCA 2014 analysis was made available to the Welsh Government prior to publication and no request for withholding of data was made. If there had been a request for non-publication, the reason for the basis of such a request would be included in the Annual Report.

The definition of “audit” is an examination of accounts and the word is derived from the Latin word "audire" meaning “to hear”. Reporting unexpected findings is a critical aspect of the function of any Audit, especially a national one where the “accounts” are not purely financial but potentially have real impact on patient care and outcomes.



While perhaps imperfect, the risk adjustment processes were the best available at the time in a situation which was not ideal and where, importantly, the crude observed analyses also suggested an effect. There would be a much greater cause for concern if the officers of NBOCA had elected to suppress the analyses rather than publish them with caveats about validity. Nevertheless it is also accepted that if data processes and collection are poor, then the 'GIGO' (*garbage in, garbage out*) principle will apply.

Differences in the risk adjustment model might impair comparisons between English SHAs and Wales as a whole, but there is still validity in investigating differences within Wales.

Publishing national audit data requires adherence to strict quality controls and regulations, and there is always the possibility that a potential problem may be highlighted. Good audit provides data but not information about reasons for the findings. There may be clues within the data but subsequent outlier processes then become essential, namely a two-stage outlier process of checking accuracy and validity of data followed by investigation of reasons for outlier status.



# 8. Further Analyses and Reflections

## i. Temporal Comparison of 2-yr Survival by English and Welsh MDTs

Funnel plots of observed survival and adjusted survival at 2 years for Welsh MDTs compared to English MDTs (based on published NBOCA data) are shown respectively in Figures 11 and 12:

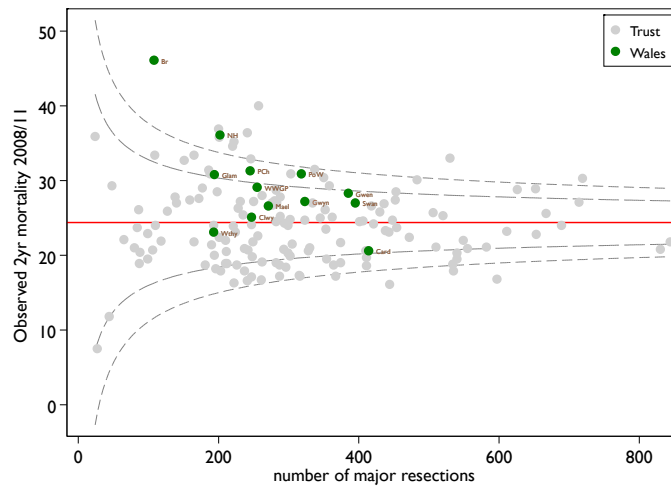


Figure 11: Observed 2 year mortality following treatment for colorectal cancer showing Welsh MDTs as green dots and English MDTs as grey dots (data from NBOCA 2014).

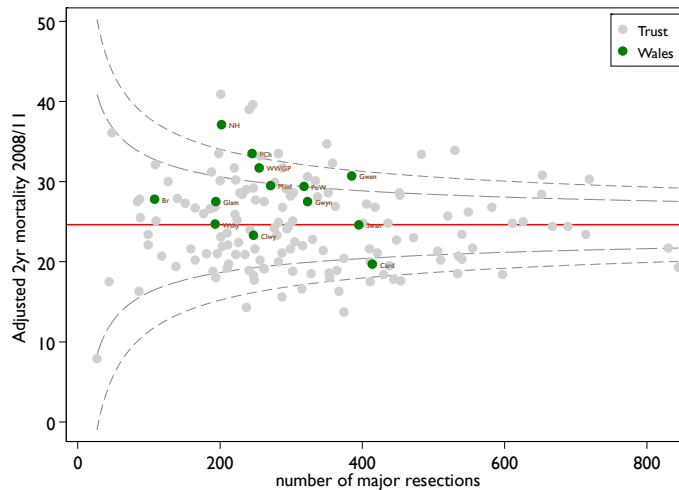


Figure 12: Adjusted 2 year mortality following treatment for colorectal cancer showing Welsh MDTs as green dots and English MDTs as grey dots (data from NBOCA 2014).



In a direct comparison of English and Welsh MDT outcomes, Nevill Hall MDT is an outlier in both the observed and the adjusted 2 year mortality plots. Prince Charles MDT becomes an outlier after adjustment. Although Bronglais MDT is an outlier in observed survival, adjustment brings its outcomes within the funnel plot. It is noteworthy that Nevill Hall and Prince Charles MDTs serve some of the more deprived communities in Wales.

For the majority of Welsh MDTs, 2 year mortality decreased between the audit periods covered by the 2014 (a three year audit period covering patients treated between 2008 to 2011) and 2015 (a two year audit period covering 2011 to 2013) Annual Reports. Data from MDTs in the North of England, which is demographically most similar to Wales, are included in the following analyses using funnel and Forest plots.

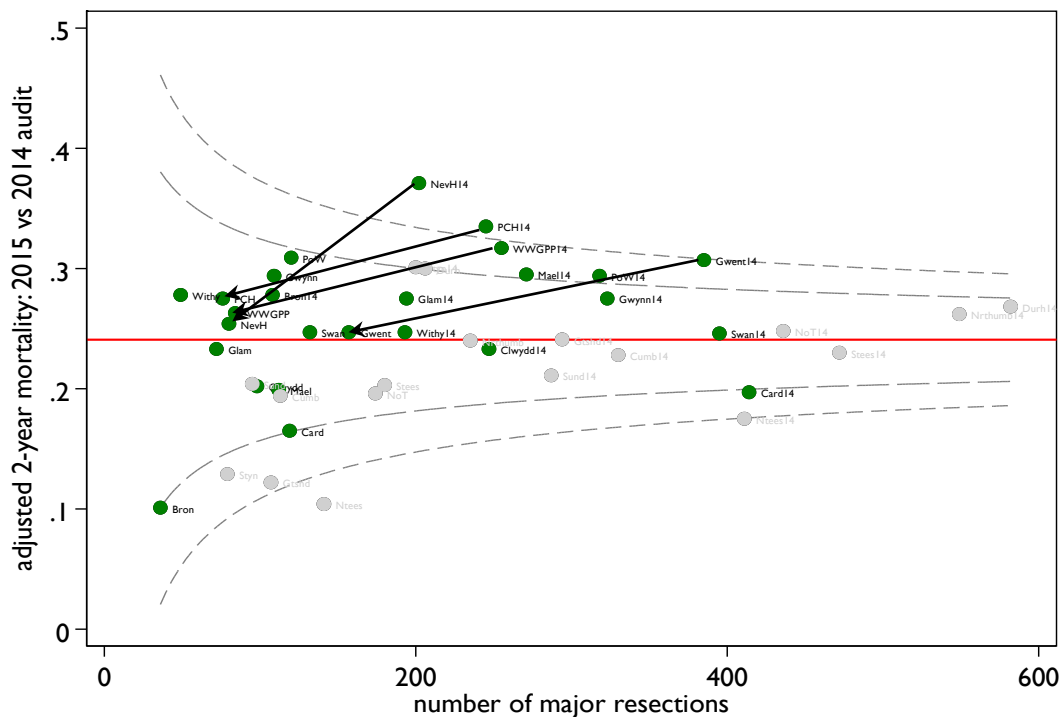


Figure 13: Funnel plot showing changes for Welsh MDTs (green dots) between the 2014 and 2015 Reports as compared to Northern England MDTs (grey dots) (data from NBOCA 2014 and 2015). The number of resections falls proportionally for the consecutive time periods as the 2015 report included data for two years rather than three years as in the 2014 report. Two Welsh MDTs (Nevill Hall and Prince Charles Hospital) were clear outliers in the 2014 audit and another (Gwent) was borderline. In the 2015 audit, all the Welsh MDTs were within the funnel. These changes are illustrated by the black arrows on the plot.



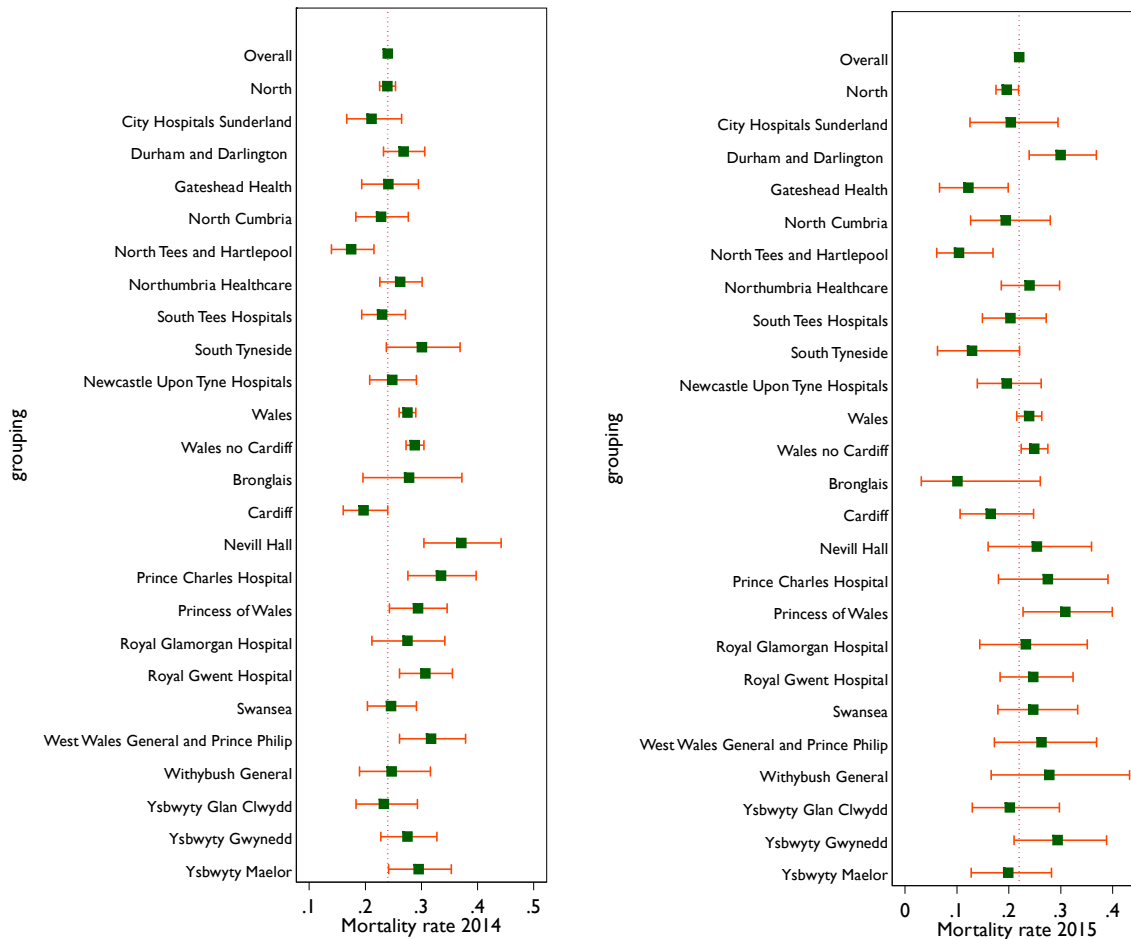


Figure 14: Forest plots showing 2 year mortality rates for Wales and Welsh MDTs published in the 2014 and 2015 Annual Reports as compared to the overall results and Northern England MDTs in the same time periods (data from NBOCA 2014 and 2015).

These results, obtained using different analytical techniques, suggest that the increased 2 year mortality rates seen in cancer patients treated in Wales between 2008 and 2011 were no longer apparent for those treated between 2011 and 2013. Although welcome, these findings should, however, be interpreted with some caution, given the smaller numbers involved in the shorter time period of the later report and therefore the possibility of introducing a type 2 error.



## ii. Comparisons of Institutional Performance

Comparing institutional performance in the management of colorectal cancer is challenging. Robust comparisons must take into account A) case ascertainment and B) data quality and completeness.

National comparisons of outcome require complete national data. Incomplete case ascertainment may adversely affect the results of such work as analyses based on only a proportion of a unit's caseload may not be representative of that unit's practice. Units with a small caseload are more likely to have apparently outlying practice arise simply by chance.

Data quality and completeness must be high to provide consistent data to produce robust comparative results. Data must be recorded and coded uniformly to make analyses valid. Different populations will pose different risks. For example, young patients with early stage disease will have very different outcomes to elderly frail people with advanced disease. The data captured must be rich enough to enable analyses to take into account these differences in patient case mix and support risk adjustment.

The statistical approaches and analytical methods used by NBOCA are strong. However, the data being used in NBOCA analyses has limitations and these data quality issues limit the conclusions that can be drawn, particularly regarding institutional comparisons, from these analyses.

### A. Case ascertainment

NBOCA has incomplete case ascertainment of the colorectal cancer population. This limits the strength of any institutional comparisons made as results drawn from a proportion of a unit's caseload may not be representative of a unit's overall practice. The NBOCA team attempt to account for this in the interpretation and application of the Audit's findings. For example, they estimate each Unit's level of case ascertainment as a marker of quality.

In England, this is done by comparing new cases in each audit submission to the number of new cases appearing in the Hospital Episode Statistics (HES) dataset. Comparisons are then made between the cases submitted to the audit and those found in HES. HES effectively forms the gold standard denominator of the number of new cases.

This is not an ideal method as HES is not the most robust or complete source of information regarding diagnoses of colorectal cancer. There are well characterised data quality issues in HES





that include the duplication of cases and incorrect diagnostic coding (leading to some non-cancers being included in the denominator and some real ones omitted). The incomplete case ascertainment in HES significantly limits the validity of case ascertainment reported in the audit.

For Wales, NBOCA had previously used the Patient Episode Data for Wales (PEDW) to calculate case ascertainment. This dataset is the Welsh equivalent of HES. PEDW was not available to the NBOCA team at the time of the 2014 Annual Report and so no case ascertainment figures were available for the Welsh audit data.

To inform this review, comparisons of case ascertainment of the NBOCA data from Welsh MDTs have been made with data held by the Welsh Cancer Intelligence and Surveillance Unit (WCISU) and are presented in Table 4. These analyses illustrate the large differences in observed cancer rates when the base datasets have differences in case ascertainment. Case ascertainment for Welsh MDTs in NBOCA for the 2013, 2014 and 2015 audit periods was 94.7% overall.

	2013 audit		2014 audit		2015 audit		3 year period	
	WCISU	NBOCA	WCISU	NBOCA	WCISU	NBOCA	WCISU	NBOCA
Bronglais	56	51	52	48	29	35	137	134
Cardiff	279	247	296	242	280	247	855	736
Nevill Hall	132	117	118	103	134	131	384	351
Prince Charles	120	116	110	108	121	117	351	341
Princess of Wales	158	171	165	173	147	159	470	503
Royal Glamorgan	110	104	150	146	127	124	387	374
Royal Gwent	246	272	229	236	215	239	690	747
Swansea	245	190	254	238	265	200	764	628
West Wales & Prince Philip	163	160	159	146	179	168	501	474
Withybush	86	80	129	121	112	86	327	287
Ysbyty Glan Clwydd	204	174	165	157	189	166	558	497
Ysbyty Gwynedd	166	173	153	146	191	191	510	510
Ysbyty Maelor	170	178	179	178	151	155	500	511
Wales	2 135	2 033	2 159	2 042	2 140	2 018	6 434	6 093

Table 4: Comparison of results obtained from the NBOCA audits for Welsh MDTs from the 2013, 2014 and 2015 reports with those derived from the dataset maintained by the Welsh Cancer Intelligence and Surveillance Unit.



Using data held by the English National Cancer Registration Service (NCRS) and the Welsh Cancer Intelligence and Surveillance Unit (WCISU) provides a stronger method of determining case ascertainment than comparison with HES or PEDW data. NCRS and WCISU both use multiple data sources to identify all new cancer diagnoses in their jurisdictions and are recognised as providing the most reliable data on cancer diagnoses and outcome. As such, they provide data upon which all official national cancer statistics are based.

## B. Data quality and completeness

The comparisons in Table 4 show significant differences in results derived from two different datasets. Before it is possible to make institutional comparisons, it is essential to determine if these differences are a result of variation in clinical practice or variation in data quality and coding practice.

NBOCA recognises that any apparent variation in practice may be accounted for by variation in patient case mix and so uses robust statistical methods to ensure outcomes are appropriately risk adjusted. NBOCA has demonstrated that important factors to consider when undertaking such risk adjustment include the Charlson comorbidity and mode of admission variables. These are derived in England by patient-level linkage of NBOCA data to HES but, for Wales, they have been completely absent in recent datasets as there has been no access to PEDW. It is worth noting that, even if PEDW data had been available and these variables derived from PEDW, they may not have been directly comparable to those derived from HES, as PEDW is a separate dataset with different coding detail and rules to HES. Other variables used in risk adjustment (such as TNM stage, performance status, ASA grade, etc) may also be missing across the English and Welsh populations due to incomplete data capture.

NBOCA runs a multiple imputation model to try and overcome this problem. Multiple imputation works by using the data that are present to predict the values of the missing data. Models are run several times to predict the missing values and then these are combined to give the best estimate for each absent variable. Outcomes are then assessed using these best estimate imputed values. Such imputation models are only valid if the data they impute are missing at random i.e. there are no systematic differences between the observed and missing values.

In Wales, it is not possible to account for systematic differences between the missing values and the observed values using the observed data. For example, as there is no comorbidity or emergency admission data available for Wales, the imputation model must predict based on English values for 'comparable' patients. But, Welsh patients may be systematically different to their English counterparts (with higher comorbidity rates or more likely to present urgently) so imputing them from English data may be misleading.



A similar issue relates to the comparability of variables in the risk adjustment model. To strengthen the imputation model, the NBOCA team has correctly included many factors that are predictive of outcome. One of these is socioeconomic deprivation which they have defined using the Index of Multiple Deprivation (IMD). As socioeconomic status is strongly associated with negative prognostic factors for colorectal cancer (e.g. presence of multiple comorbidities, emergency presentation, advanced stage of disease), it is important to include it in the analysis.

The specific issues relating to assessment of comorbidity and social deprivation are considered in more detail in the next sections.

### **iii. Comorbidity and how it is measured**

Comorbidity is defined as diseases that affect a participant in a study in addition to the condition that is the subject of the study. In studies of patients with cancer, any coexistent disease that is not the cancer of interest would be included in the assessment of comorbidity. Comorbidity rises with age and, at any given age, socio-economically deprived individuals have more comorbidity.

The most widely used comorbidity scales are the Charlson score and its close relative, the ACE-27. The NBOCA audit in 2014 adjusted underlying risks using Charlson scores derived from HES data. The lack of PEDW data meant that no such direct adjustment was possible for the Welsh patients and the risk adjustment was performed using imputational techniques.

The Charlson score has evolved since it was first published in 1987. In its most recent form, it combines information on 19 comorbidities with an age-related factor to produce a total comorbidity score (Charlson et al 1987). It includes cancer as a comorbidity. Localised malignancy, lymphoma or leukaemia score 2 points, whilst metastatic cancer scores 6 points. When using the Charlson score for patients with malignant disease, the cancer scores should be omitted, unless the patient has more than one type of cancer. The only mental health condition that contributes to the Charlson score is dementia.

The ACE-27 (adult comorbidity evaluation 27) is based on a matrix of 27 conditions divided into 12 main groups. There are 4 degrees of severity:

- 0 absent
- 1 mild impairment
- 2 moderate impairment
- 3 severe impairment



Calculating the ACE-27 score is simple. Take the highest individual impairment score and this is the ACE-27 score, unless there are two or more conditions scoring 2 in which case the ACE 27 score is 3.

The ACE-27 also includes cancer amongst the conditions to be scored but, unlike the Charlson score, has more comprehensive coverage of mental health conditions (schizophrenia, bipolar disorder, suicide attempts, dementia, and substance abuse). Given the adverse effect of mental health problems on outcomes in patients with cancer, the ACE-27 may be the more useful instrument.

#### **iv. Confounding effect of deprivation on cancer outcomes**

The effect of socio-economic deprivation on cancer survival may be mediated in a number of ways. Any interpretation must take heed of the problem of confounding. Confounding occurs when two or more variables may influence an outcome, and when it may not be possible to decide whether or not their effects are entirely independent of each other. The problem of potential confounders bedevils any study of cause and effect.

As a practical example, consider the relationship between comorbidity and socio-economic deprivation. Both these factors adversely affect the survival of patients with cancer but their effects are unlikely to be independent. People who have multiple comorbidities are often unable to work and therefore are likely to be unemployed or on low incomes. Employment and income are both factors used to construct indices of deprivation and therefore by definition comorbidity and socio-economic deprivation cannot be considered independent variables. Conversely, people living in poor housing and on low incomes are more likely to suffer ill-health and so the confounding may occur in each direction: comorbidity causing socio-economic deprivation; deprivation causing comorbidity.

One solution is simply to accept these difficulties and use socio-economic deprivation as a proxy measure for comorbidity, as well as for several other factors that might adversely affect survival in patients with cancer. At both health board and local authority level, there are significant differences in the percentages of patients who are socio-economically deprived.

Socio-economic deprivation is associated with significantly lower survival for patients in Wales (Figure 15). The adverse impact on five-year survival for colorectal cancer is 10% when the most affluent are compared with the most deprived. This is well in excess of any survival benefit associated with the use of adjuvant chemotherapy, where the overall benefit at the population level is under 5%.



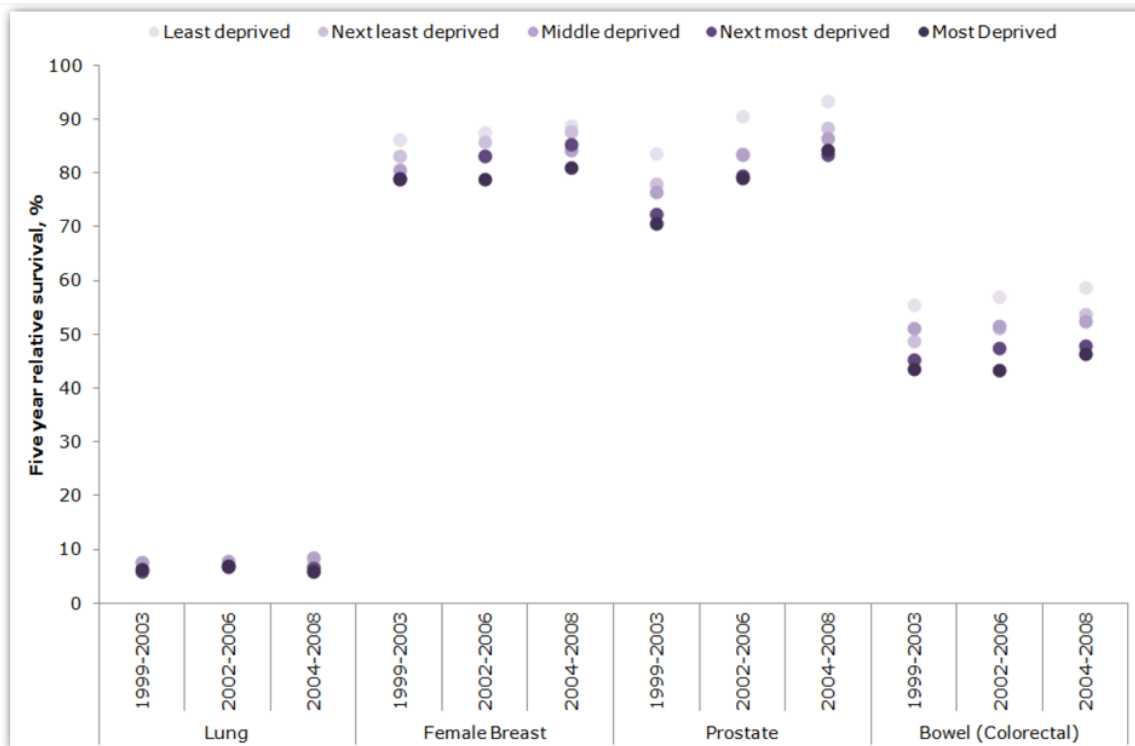


Figure 15: Variation in 5 year survival (%) in Wales according to level of socio-economic deprivation for common cancer types (lung, breast, prostate and colorectal) indicating wide variation in colorectal cancer outcomes between least and most deprived quintiles of population (Source: *Cancer in Wales: A summary report of the population cancer incidence, mortality and survival*, including new 2013 data released as Official Statistics on 3 February 2015, [www.wcisu.wales.nhs.uk](http://www.wcisu.wales.nhs.uk)).

#### v. System-level differences between England and Wales

There are significant differences between England and Wales in overall spending on health, in the proportion of the budget that is spent on specific conditions (including cancer) and in the per capita spending on each patient with cancer. There are also important differences in the disposition of resources. These differences are summarised and illustrated in Appendix D: *Healthcare Systems and Cancer Care in Wales*.



In broad terms, when compared to England, Wales is a poorer country with lower Gross Value Added (GVA), which is a metric of economic activity, measuring the contribution to the economy of each individual producer, industry or sector in the United Kingdom. There is a lower rate of per capita spending on health and a higher rate of per capita spending on social services. Wales spends more of its health budget on trauma and musculoskeletal conditions, and has fewer GPs and more hospital beds serving a dispersed population which may cause problems with access to specialist services. Overall Wales spends less money on the care of each patient with cancer than England.

There are also broad differences in health outcomes between Wales and England with lower healthy life expectancy in Wales, higher amenable mortality rates (measure of mortality that might have been prevented with optimally organised and delivered health services), longer inpatient lengths of stay, higher emergency admission rates and longer waiting times. Overall survival rates for cancer are lower in Wales than in England.

Factors other than the performance of individual MDTs will influence outcomes in colorectal cancer. If Welsh patients are truly different from English patients, and if the differences are the explanation for the inferior outcomes in Wales, then we need to know much more about each set of patients. Statistical legerdemain cannot adequately compensate for missing or inaccurate data. At the very least, we need to have uniform assessment of comorbidity and socioeconomic deprivation across both jurisdictions.

There are sufficient system-related differences between Wales and England to account for some of the observed differences in outcomes. Given planned decreases in funding for healthcare, and given the projected increases in the proportion of patients over the age of 75 in Wales, the concern is raised that future outcomes for patients with colorectal cancer in Wales may lag further behind the results achieved in England.

## **vi. Acknowledgement of unattainable goals**

No enquiry can deliver precisely what it ideally would like to see done. The Panel would like to acknowledge that the following aspirational goals could not be achieved given limitations on availability of information, time constraints and limitations on data sharing:

- Cancer specific survival
- Comparable index of deprivation



## **vii. Future directions and impact of NBOCA**

To flourish the national audit must appreciate the world of data gathering, interpretation and widespread dissemination. That having been said, a national audit, answering important clinical questions, has a definite role within this field. The challenge for the audit, going forward, is to consolidate its position and work with other agencies to improve outcomes through better information.

Future plans for the audit have already been discussed at team and Board level and include several “deep dive” audit reports on relevant clinical questions. Clearly focused topics, with complete clinical engagement, will be of enormous value both to patients and clinicians alike. In addition, there are plans to link the data derived from the national audit to other, well established data sets e.g. national radiotherapy (RTDS), systemic chemotherapy (SACT), emergency laparotomy audit etc. Such links will widen the remit of the audit and are to be encouraged.

Whilst the national audit, in past years, was the main source of data capture for colorectal cancer, the inception of the National Cancer Intelligence Network (NCIN) has provided population based data which is of increasing value. Change in management of this resource, that now resides within Public Health England as the National Cancer Registration and Analysis Service, does not alter the fact that these data can be complementary to clinician-owned and clinician-verified data held within the national audit. Indeed, most MDTs in attempting to avoid duplication of effort, use the same systems to populate the national cancer registration service and the national audit. A major area to be developed is the degree of national coverage by these systems. The audit, despite many efforts in the past, covers mainly England and Wales whereas the NCRAS covers just England. There are, however, approaches at a Government level to extend the population data set to Scotland, Wales and Northern Ireland.

The concept of a National Colorectal Cancer Data Repository is not new and is supported by many bodies. Linkage of data from a variety of sources, robust risk adjustment and statistical analysis, and clinical engagement at all phases of the process is surely a goal worth pursuing. The opportunity to have the very best data set can only serve to improve our management of patients with colorectal cancer.



## 9. Key Messages from Welsh MDTs

### i. Common themes

There were a number of key themes that emerged during face-to-face discussions with individual MDTs. Most teams were aware of the Palmer Report from 2014 which recommended participation in national audits and clinical sign-off (Palmer Report 2014). However there was poor understanding of the audit pathway, and some aspects of best practice in audit had either not been communicated or implemented e.g. importance of including risk adjustment items within data set, coding of mode of admission, ASA grade. Performance status was also particularly poorly collected.

Resource issues with potential impact on audit data collection and upload were also common. Lack of audit personnel support due to limited availability, rapid changeover, and lack of cross-cover during leave or absence were shared.

Resources for all patients accessing cancer diagnostics, and not just cancer care, were limited with frequent mention of limited access to endoscopy, and long waiting times for routine investigations.

Particular pressures on service delivery due to geography and patient demographics was another key issue, and this often resulted in multi-site decision-making and delivery of cancer care. Complex patient pathways with access to elective and emergency care across different sites are common, especially with acute oncology and elective radiotherapy on separate sites.

Similar problems arose when patients needed subspecialist treatment e.g. resection of metastases, organ-sparing techniques including transanal endoscopic microsurgery or Papillon brachytherapy, HIPEC, and treatment for recurrent pelvic malignancy.

Concerns about whether CaNISC was fit for purpose were raised several times, especially due to bureaucracy surrounding amendments to allow the platform to be more responsive to central changes in audit requirements.

The disconnect between clinicians delivering healthcare services and the Welsh Government and Department of Health Wales was another frequent topic of debate.





## ii. Specific themes for each MDT

One of the principal reasons for visiting Wales during this Enquiry was to meet with clinicians on the ground and to hear their views. This section concentrates on what we heard in the face-to-face meetings with individual MDT members and representatives of CaNISC and WCISU on 12 April 2016. The representatives from each MDT are listed in Appendix E *Attendance*. The individual MDTs are reported in alphabetical order, followed by CaNISC and WCISU.



## Cardiff and Vale

Represented by Mr Simon Phillips, Consultant Surgeon and MDT Lead, and Mr Michael Davies, Consultant Surgeon.

*Audit data items are loaded on to CaNISC in real time at the MDT meeting and corrected contemporaneously. It was felt that there was good support from local data management. Performance status had not been part of the minimum data set until very recently. Length of stay was not well recorded. There was definite enthusiasm for improving the gaps in data collection and efforts had already been made to address this.*

*There was a high proportion of patients who were classified as “not operated” or “unknown”. This was felt to be due to poor information about how to upload data on to the CaNISC form and a default to the system to “unknown” if data fields were incorrectly filled.*

*It was agreed that the neoadjuvant therapy proportion was incorrect but it was not clear why this was the case. Local estimates of use of radiotherapy were around 30% with a standard policy for delivery of radiotherapy.*

*It was noted that there was a very low proportion of ASA 1 patients at just 1%. Local representatives agree that this was due to a local bias towards listing patients as ASA 2 if they had a diagnosis of cancer.*

*Laparoscopic surgery rates were good overall.*

*The questions raised by representatives were whether patients who died before MDT meeting discussion should be excluded from analysis (as currently they are included) and whether the mortality risk adjustment process used for Wales based on derivation of English figures was correct.*

*A surgical meeting held separately from the MDT checked that data was entered prospectively. There are only 1.5 whole time equivalent specialist care nurses which meant limited support for patients. Cardiff provides expertise in transanal endoscopic microsurgery and is the regional referral centre for early rectal cancer.*

*Emergency service provision had been an issue until quite recently, with lack of access to critical care and delays to NCEPOD theatres felt to be the main barriers. Considerable effort had been made in order to address these issues and improve emergency surgery provision. Cardiff had the fifth largest number of patients in the National Emergency Laparotomy Audit (NELA) in the UK, and this had been a useful driver for change.*

*The Panel acknowledged that overall outcomes from Cardiff were good, and that colorectal cancer survival, in particular, was the highest in Wales.*



## **Nevill Hall**

Represented by Mr Graham Sturgeon, Specialist Nurse Practitioner and Ms Nicola Rogers, MDT Coordinator with support from Mr Michael Davies, Consultant Surgeon, in his capacity as South Wales Chapter Representative for ACPGBI, as no surgeon was available.

*All surgery for colorectal cancer takes place at a single hospital, Nevill Hall Hospital in Abergavenny.*

*Data collection was carried out with CaNISC being run during the MDT as the local team felt this was the best way to ensure that all the data fields were completed during the MDT. Any corrections were made contemporaneously and then signed off. Length of stay was recorded in CaNISC but taken from PEDW and therefore was often incomplete. A particular problem for the MDT was lack of recording of ASA grades – this was due to the automatic default to ASA 1 in CaNISC – resulting in inaccurate risk adjustment.*

*In terms of data support, cover for the MDT coordinator was provided for holidays. The colorectal MDT co-ordinator also managed the skin, neuroendocrine and colorectal cancer MDTs. Line management consisted of the Lead MDT coordinator.*

*It was felt that emergency surgery workload was high and that late presentation of colorectal cancer was not uncommon. It was noted that there was wide disparity within the catchment area in terms of socio-economic variation with some areas being quite prosperous while other areas were more deprived. The on call system consisted of one surgeon being on call for a week and they would potentially carry out some elective cancer surgery during that time. The emergency NCEPOD list was routinely used in 2013-2014 for elective colorectal cancer cases in order to meet targets. There were two colorectal surgeons who carried out the elective resections.*

*Radiotherapy was used in rectal cancer treatment on the recommendation of Oncology. The majority of rectal cancer patients with a threatened margin would have radiotherapy. Radiotherapy was delivered at Velindre in Cardiff and oncologists from Velindre attended the MDT. However it was noted that Velindre was a separate Trust and there was some uncertainty how the radiotherapy data was uploaded into the audit. It was reported that there was 30 minutes travelling time each way for radiotherapy which had an impact on compliance from patients.*

*Chemotherapy was available both locally at Nevill Hall Hospital and at Velindre, but with facilities for infusional and oral chemotherapy being delivered locally.*



## Prince Charles Hospital

Represented by Professor Puthucode Haray, Colorectal Surgeon and MDT Lead, Mr Ashraf Masoud, Colorectal Surgeon, Mr Kamal Asaad, Medical Director of Cwm Taf Health Board, and Mr Wayne Jenkins, Senior Manager of Cancer Services.

*MDT data collection was carried out in the MDT with a paper proforma (sample supplied to Panel) and was later loaded in to CaNISC. The MDT Coordinator covered both the colorectal and upper GI MDTs, including cover for illness. It was reported that CaNISC does not upload everything in to the National Bowel Cancer Audit including deaths (although the Panel noted that death data were retrieved from the Office of National Statistics rather than CaNISC). Performance status was not recorded as there was no mechanism for Payment By Results and no link to outcomes, but efforts had been made to improve this. PEDW data had been lacking and it was felt that this had resulted in inadequate local risk adjustment for case mix.*

*It was felt that the emergency case load locally was very heavy and that this was a contributor to relatively high mortality rates. It was not entirely clear what proportion of cases were carried out as emergencies.*

*There were conflicting views locally about the indications for use of radiotherapy in rectal cancer, although all patients with threatened margins would usually be treated with long course chemoradiotherapy. The team pointed out that there was a high rate of locally advanced rectal cancer at first presentation, and that this factor probably contributed to high rate of local radiotherapy use. However it was also acknowledged that radiotherapy uptake was reduced by patients preferring not to travel for treatment and in those wishing to avoid poor functional outcomes. The local MDT preference was for long course chemoradiotherapy. Radiotherapy was delivered at the Velindre Suite in Cardiff and chemotherapy was administered at the MacMillan Unit at Prince Charles Hospital.*

*The high rate of abdominoperineal excision of rectum was thought to reflect the small denominator.*

*There was a local policy of encouraging laparoscopic surgery for rectal cancer.*

*The Prince Charles MDT presented their own analysis in a slide show: it was suggested that the relatively high two year mortality was due to inaccurate loading of data into the National Bowel Cancer Audit due to problems with data collection. It was also suggested that local mortality was inappropriately risk adjusted upwards, and that the Welsh Index of Multiple Deprivation was not equivalent to English deprivation scores. It was felt that more weight should be given to Professor Stephen Palmer's Report on deprivation and the need for risk adjustment, and a copy of the report was supplied to the Panel.*



*The Prince Charles Group had carried out an extensive review of 246 patients and had found a number of discrepancies between their review and NBOCA:*

- *Eight patients should not have been included within their data set for a variety of reasons*
- *Analysis of risk adjustment items had noted a high proportion of patients presenting with metastatic disease and this was the main reason for the negative impact on survival.*



## Princess of Wales Hospital

Represented by Mr Barry Appleton, Consultant Colorectal Surgeon, Miss Joanna Hilton, Consultant Colorectal Surgeon, and Mrs Lisa Wilkins, MDT Co-ordinator. \*

*The local team was disappointed in the data gaps as they felt they had a robust system and that it was probably subsequent processes for uploading data that were responsible for the number of gaps. There had been no obvious change in the data collection process in recent years.*

*MDT data was entered live during the MDT. There was frequently an issue within the MDT meeting about recording of pre-treatment TNM staging. It was reported that their local radiologists felt that CT was not an appropriate tool for T staging of colonic cancer and therefore an accurate radiological T stage could not be given. They did feel that CT was an appropriate tool for identification of metastases, and therefore the M stage was provided accurately. Nevertheless data collection on TNM status was relatively poor.*

*Performance status had not been collected until recently as they were unaware of the need. There had been issues over the definition between emergency and urgent surgery.*

*Laparoscopic access was noted to be relatively low but this was felt to improve with recent appointments.*

*It was felt that the radiotherapy rates were simply wrong and that local rates were around 45%. Patients with advanced pelvic cancers were referred to Swansea and with complex polyps or early rectal cancer to Cardiff. It was thought that the high local abdominoperineal excision of rectum rate was a transient feature, but also that the permanent stoma rate may reflect patient choice and perhaps this factor should be recorded in CaNISC.*

*There was some concern from the team about what outcome data should be used for. While it was fine if used for research or reassurance, data should also be used for quality improvement.*

\* Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.



## Royal Glamorgan Hospital

Represented by Mr Kamal Asaad, Medical Director, Miss Debbie Clements, Consultant Surgeon and MDT Lead, and Mr Wayne Jenkins, Head of Business and Operational Support.

*The Royal Glamorgan representatives thought that there were real issues with Audit data analysed due to missing data which was not the case in terms of their local collection. As a team, they appeared committed to data collection and were disappointed that their efforts had not been recognised.*

*There had been an issue with support from data clerks. An experienced clerk had left the MDT in 2013 and been replaced with a junior inexperienced member who had required significant mentorship. It was felt that this problem had now been resolved.*

*Performance status was collected vigorously but not recorded within the CaNISC system. Length of stay was also not being recorded. There was a high proportion of “not operated, unknown” cases that was perceived as a data upload issue with lack of clear instructions on how to complete the CaNISC form and a presumed default to the “unknown” option.*

*High rates of use of radiotherapy were felt to be incorrect but it was felt that about 60% of patients with a rectal cancer would be recommended to undergo radiotherapy. It was suggested that most of their rectal cancer data was inaccurate. CaNISC captures the first treatment and not necessarily any major operation. Stoma rates were felt to be inaccurate as temporary ileostomy reversal had not been captured within the CaNISC system.*

*The emergency surgery rate was felt to be under representative of what was seen in local practice. This was because of a tendency to accommodate emergency cases on elective lists and then report those patients as elective cases rather than emergencies. Local data indicated that 20% of colorectal cancer patients were presenting as an emergency.*

*Laparoscopic surgery rates had improved with the appointment of three new colleagues trained in laparoscopic colorectal surgery. The laparoscopic rate had improved to about 50%. The local surgeons worked a 1 in 7 on call rota. There was good local access to preassessment but cardiopulmonary exercise testing was not available.*



## Royal Gwent Hospital

Represented by Mr Brendan Murphy, MDT Co-ordinator, Mr Keshav Swarnkar, Consultant Colorectal Surgeon, and Mr Gethin Williams, Consultant Colorectal Surgeon.

*Real time data collection allowed high data completeness. The data was collected during the MDT straight on to CaNISC with completion of a proforma and data entry at the same time. There was a strong local ethos to validate all of their data on a three monthly basis.*

*It was noted that performance status was not routinely collected but that they had only recently been made aware of the need to collect it. Length of stay data was being recorded but not registered as a result of a glitch in uploading on to the National Bowel Cancer Audit Platform.*

*It was felt that the high level of emergency cases was a realistic representation of local practice.*

*There was no problem with access to radiology resources for staging CT but PET availability was much more restricted as patients needed to travel to Cardiff. The very high reported rate of preoperative radiotherapy was thought to be due to a reporting error with estimates of use of radiotherapy in rectal cancer patients at only 30-40%. The recent increase in abdominoperineal excision rates was acknowledged as high but thought to be only a temporary blip due to small numbers.*

*Local policy was quite aggressive in terms of taking on high risk patients. The ASA grade was decided by the anaesthetist and recorded.*

*It was agreed that the laparoscopic surgery rate was low with only three of five colorectal surgeons offering laparoscopic surgery. The high proportion of emergency cases also had an impact on a lower laparoscopic surgery rate.*

*It was reported that there was no local access to HIPEC where this was indicated for patients with a high risk of peritoneal disease and that access for patients to Basingstoke was particularly difficult. Cetuximab chemotherapy was not available locally.*

*A potential solution to improving data was suggested: to offer a data checking process following data collection, much as is carried out for consultant outcome publication in England. There was a recommendation that there should be engagement from the ACPGBI to enable this process and allow a joined up audit policy between England and Wales.*





## Swansea

Represented by Mr Chandra Sekaran, Colorectal Surgeon and MDT Lead for Swansea, Professor John Beynon, Colorectal Surgeon, Marisa Bennet, MDT Co-ordinator, and Martyn Evans, Wales Colorectal Cancer Audit Lead. \*

*The team reported that data submission was made to CaNISC but the feeling was that CaNISC was slow to respond to changes that were necessary in a functional audit tool. There was some concern that the technology infrastructure was rather dated, particularly in view of site architecture and difficulty in use. Concern was also raised about the national lack of high quality PEDW data and the impact of this on the Audit's ability to carry out risk adjustment.*

*Data collection was carried out manually and then uploaded on to the MDM module of CaNISC with completion of data sets being carried out at a later date. A largely electronic system was in place. The team reported a 90 minute MDT meeting to cover 50 patients and felt that they were better served with a whole morning being devoted to MDT. It was hoped that this would be possible from June 2016.*

*The upload of data from CaNISC to Open Exeter appeared to result in disappearance of some data fields and it was not clear why this was happening.*

*It was reported that there were high emergency surgery rates locally, partly due to late presentation and partly due to delayed treatment while on waiting list for elective surgery. National Emergency Laparotomy Audit data had indicated that they were dealing with a large number of emergency cases.*

*The Swansea MDT covered Morrison, Singleton and Neath Port Talbot Hospitals but colorectal cancer services are based at Morrison Hospital. Swansea area has a catchment of 450,000 population, but there is also a regional referral practice in advanced rectal malignancy.*

*It was reported that waiting times were long in Wales overall, with Endoscopy services being inundated and postoperative cancer patients having surveillance procedures delayed. The routine wait for colonoscopy was reported to be 10 months. In contrast, access to radiology was reported to be excellent.*

*The rates of preoperative radiotherapy use in rectal cancer treatment between 2012 and 2014 were 10-20% and it had been a surprise to the local audit team to see the reported jump in NBOCA in 2015 which was felt to be a reporting error. Local policy prefers long course chemoradiotherapy where indicated and this is delivered in Swansea.*

*The Swansea team pointed out that the reported number of rectal cancer cases in NBOCA was an underestimate of the actual case numbers. This was felt again to be a recording issue as a result of assignment of cases to other MDTs when they had been referred in for regional expertise. It*



*was also felt that they had a high case load of high risk patients. The relatively high abdominoperineal excision rate was felt to be representative of referral practice and the fact that they were the only MDT with availability for plastic surgery to assist in perineal reconstruction after abdominoperineal excision of rectum. (The Panel noted that referral practice may increase numbers of permanent stomas but this implies that the case numbers are in fact accurate.)*

*The team was keen to see PEDW data turned back on, despite ongoing concerns about the quality of the data. The Swansea team keep their own local research data base and have undertaken work looking at a scatter plot of postcodes and the impact of this on outcomes.*

*It was particularly mentioned that the role of ACPGBI should be to provide resources to both assist with data collection and also with dissemination of information.*

\* Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.



## **West Wales, Withybush and Bronglais**

Represented by Mrs Joy Singh, Consultant Surgeon and MDT Lead, Mr Jegadish Mathias, Consultant Surgeon, Mrs Melanie Guy, MDT Co-ordinator, and Linda Roberts, Information Specialist, CaNISC.

*This group pointed out that they covered a third of the area of Wales, originally across four hospital sites. The West Wales and Prince Phillip Hospitals had been amalgamated for about five years. They now worked across three sites but have had a single MDT since 2012. The team produced three reports, one for each of the three sites. The oncologist supporting the MDT was based in Singleton and all other MDT members were linked in by videoconference.*

*No elective colorectal cancer surgery is carried out at Bronglais or Prince Phillip Hospitals, although some colorectal cancer patients are diagnosed in Bronglais where three general gastrointestinal surgeons carry out emergency surgery and outpatient diagnostics. The MDT starts with cases from Bronglais to allow clinicians there to only attend the part of the meeting relating to their patients. There were three colorectal surgeons at each of the West Wales and Withybush Hospitals.*

*The local team thought that the case numbers in the Audit were inaccurate. Withybush thought that their numbers were artificially low as patients may be treated elsewhere in Wales. Similarly, patients who had neoadjuvant treatment elsewhere did not always have surgery locally. Linda Roberts reported that it was difficult to differentiate between where patients were diagnosed and where they were operated on and this may have an impact on data.*

*Data collection was carried out by a Coordinator who supported all the cancer MDTs (not just colorectal) and needed to work with different people across different sites. Proformas were available for data collection. The MDT starts at 8.15am on Wednesday mornings by teleconference with Bronglais who leave at 9.00am. The rest of the patients from West Wales and Withybush are then discussed.*

*Emergency surgery is carried out across all three sites. Bronglais has 2-3 emergency admissions per day with a 1 in 3 on call consultant cover, Withybush has 6-7 emergency admission per day with 1 in 5 cover, and West Wales has around 12 admissions per day with 1 in 8 cover. The majority of colorectal cancer surgery is done by colorectal surgeons, even if presenting as an emergency.*

*Radiotherapy is delivered by the Singleton Hospital in Swansea. Criteria for radiotherapy were that any low rectal cancer should receive radiotherapy, and mid rectal cancer with involved nodes or threatened circumferential resection margins would also have neoadjuvant long course chemoradiotherapy. It was felt that local radiotherapy rates were probably around the order of 70%.*



*ASA data was often dealt with post-hoc due to difficulty of gleaning the information from anaesthetic charts. No cardiopulmonary exercise testing is available on site.*

*There are two dedicated gastrointestinal pathologists supporting the MDT but it was felt that the quality of reporting was poor. CRM reporting had improved after introduction of double reporting by pathologists but it was suggested that use of locum pathology cover locally had led to an erroneously high CRM rate due to local processing and reporting practices.*

*Readmission rates were noted to be high, particularly at Withybush in 2013. It was felt that this reflected the older population undergoing resection, but may also reflect relative lack of specialist nursing support. There are four full time Specialist Cancer Nurses (SCNs) in West Wales at Carmarthen, but only one in Withybush and two part time nurses in Bronglais. It was noted SCNs had long travelling distances on poor roads to visit patients in rural areas.*

*The MDT team acknowledged a sense of functioning poorly, the need for improvement and the impact of local tensions across MDT sites. A longer MDT session lasting a whole morning was under consideration. Discussions had taken place about the options of either centralizing colorectal cancer surgery on a single site or of continuing the current “hub and spoke” model of care.*

*It was felt that the use of CaNISC was helpful in terms of capturing data and that this would help support increased input and performance status in the future. It was also suggested that the Association of Coloproctology should provide appropriate benchmarks for care.*

*A copy of a March 2016 publication of a report on colorectal cancer outcomes in the financial year April 2013-April 2014 was supplied. This report indicated that there were different case numbers between the National Bowel Cancer Audit report and the local report. It was clear that a lot of effort had been made in collecting data locally and it would be useful to see this level of information loaded in to the National Bowel Cancer Audit platform.*



## Ysbyty Glan Clwyd

Represented by Mr Andrew Maw, Consultant Colorectal Surgeon, and Miss Shirley Wainwright, MDT Co-ordinator. \*

*There was very limited clerical support for data collection within the MDT and for the audit. The team was unsure why their data completeness had not been good recently as it had always been high in the past.*

*Within the MDT meeting, it was noticed that TNM staging was not always included in the CT reports by some of the local radiologists, and so TNM stage had to be clarified in the MDT meetings with the MDT radiologists present. Performance status had not been collected until recently because they were unaware of the need.*

*It was felt that there was a high rate of emergency surgery which was reflected within the data. This was felt to relate to an elderly population. This was currently being audited following Peer Review recommendations. There was an additional impact in terms of emergency work as the population in the area increased significantly for several months of the year due to transient population in caravans and tourists.*

*It was felt that deprivation locally was very high and that this had an impact on outcomes. The proportion of ASA 1 patients was low and this was felt to be a true reflection of the local situation. The team suggested that reported readmission rates were not reflective of their practice and that perhaps some patients were doing so well that they were being recorded as a readmission when they attended for early adjuvant chemotherapy.*

*There was concern about risk adjustment processes, the lack of availability of PEDW data and the impact of this on accuracy of risk adjustment. The MDT had no opportunities to check the PEDW data for accuracy.*

*Local geography had an impact on ability to deliver good care with poor access to stenting and to cardiopulmonary testing (now available at Wrexham 40 miles away). Although there was a new high dependency unit, it was understaffed and this was having impact in terms of access of patients to high dependency care for both emergency and elective colorectal cancer surgery. Planned colorectal cancer surgery was frequently cancelled on the day for this reason.*

*Lack of access to specialist pseudomyxoma and HIPEC services disadvantaged Welsh patients. Local referral practices included going to Liverpool for brachytherapy, but there was limited access to treatment at Basingstoke. There was also willingness to join the English system.*

*Three colorectal surgeons were participating in a 1 in 8 on call rota. There was lack of succession planning for colorectal specialist nurses. Their local peer review had also recommended an extra surgical post and computer for live data input but neither of these had been achieved.*



*It was reported that there was lack of support and a degree of disengagement by management, and noted that Betsi Cadwaladr University Health Board was currently in special measures.*

\* Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.



## Ysbyty Gwynedd

Represented by Mr Anil Lala, Consultant Surgeon, Dr Catherine Bale, Consultant Oncologist, and Miss Janine Morris, MDT Co-ordinator

*Data collection within the MDT was undertaken on a paper proforma and later entered on to CaNISC. They had already had feedback that this was “old fashioned” and “not intelligent” and had accepted that they would have to learn how to use the online function in CaNISC. The local IT system was called Myrddin and was specific to North Wales where it had been introduced by Maelor. They reported that the lack of guidance within the CaNISC form (which lacked drop down guidance menus) made it harder to use CaNISC.*

*It was noted that patients who had not had surgery needed to have a specific button selected which said that they had “no surgery” on the surgical pages which seemed counterintuitive.*

*Data entry on to CaNISC was complicated by an extra step that it was collected locally by the MDT Coordinator, transferred to Glan Clwyd and then uploaded from there to CaNISC. It was noted that there were discrepancies with local data and they would like the opportunity of a direct upload of their own data on to CaNISC.*

*They received bi-monthly validation from CaNISC. The team all agreed that there were source problems with respect to collection of TNM data and the seven audit items and that they had a low level of completion of CRM status.*

*Length of stay was completed within CaNISC but not downloaded on to the audit platform. They felt that there was no incentive to calculate length of stay as Payment By Results was not in use in Wales. Their local hospital IT system Myrddin did not allow date of discharge to be included. This was only done by hand at a later date.*

*There had been a high recent turnover of MDT coordinators. Within the MDT, cover was arranged by the MDT Team Leader. However the forms were completed by the Coordinator only on return from leave. The Coordinator was also responsible for tracking investigations.*

*In terms of emergency case load, there were low numbers. It was mentioned that the out of hours General Practice services locally tended to send patients to Glan Clywd.*

*Local Oncologists were reported to be keen on the use of radiotherapy, particularly long course chemoradiotherapy, although there had previously been high use of short course preoperative radiotherapy. A degree of need for locum surgical cover was thought to have resulted in a dependence on higher levels of radiotherapy but the MDT were confident that radiotherapy use was now falling. They also felt that there was a lack of standardisation of criteria for use of radiotherapy within their MDT. Indications for radiotherapy included threatened margins, lymphovascular invasion, or low rectal tumours. The radiotherapy was delivered in Glan Clwyd*



*(Marble Church) near Rhyl with hostel accommodation available for patients while adjuvant chemotherapy was delivered locally.*

*Patients with liver metastases are referred to Aintree, patients with pulmonary metastases are referred to English sites, anal cancer is referred to the Christie Hospital in Manchester and recurrent rectal cancer is referred to Leeds. Pseudomyxoma cases are referred to the Christie although it was noted that no funding is available for treatment of pseudomyxoma in Wales. Patients who were suitable for transanal endoscopic microsurgery were occasionally referred to Glan Clwyd. A local Gastroenterologist who was experienced in taking on patients for extended endoscopic resection meant that onward referrals for TEMS were not often required. Acute oncology services were available locally.*

*Surgical cover consisted of 5.5 whole time equivalents who also covered general surgery emergencies. There had been a recent slight increase in workload due to an increased load from Bronglais. A long-standing referral pattern of rectal cancer patients from Bronglais had recently started to include more complex colon cancer patients as well.*





## Ysbyty Maelor

Represented by Mr Michael Thornton, Consultant Surgeon, Mrs Fiona Davis, MDT Coordinator, and Linda Roberts (CaNISC).

*The MDT used a paper proforma with some of the information being derived from the local hospital information system (where only some data items are collected). Length of stay was derived from the date of discharge as recorded in CaNISC. They did not record comorbidity on CaNISC, although this is possible, as PEDW data was usually used for comorbidity recording. Complications were routinely recorded in CaNISC. There was discussion about the development of new data items within CaNISC: it was possible to do this with agreement but it would often take up to two years to actually change the data sets.*

*In terms of data support, there was only one MDT Coordinator with no back up. The MDT Coordinator also covered absences in other cancer specialties. When on leave, cover was provided to attend the MDT meeting and minutes were circulated after each MDT for clinical sign off, but the Coordinator was expected to deal with the backlog of data entry on return to work.*

*About 15% of the case load was due to emergency work and they felt that this did not really have an impact on overall outcomes within colorectal cancer surgery. The clinical team felt that they were well supported with intensive care facilities.*

*Radiotherapy rates were felt to be not as high as reported due to reporting errors. Local policy is that patients with threatened circumferential resection margins would have long course chemoradiotherapy but that clear margins would be identified as being suitable for a straight to surgery pathway. There was very little local use of short course radiotherapy. Patients received their radiotherapy in Glan Clwyd but adjuvant chemotherapy was delivered locally at Maelor.*

*Although the 3 MDTs within Betsi Cadwaladr were separate, there are biannual meetings between the three MDT sites in North Wales. Specialist referrals included sending patients to Glan Clwyd for transanal endoscopic microsurgery, exenteration surgery to the Christie Hospital, Manchester and to Leeds, and brachytherapy to Clatterbridge.*

*Twenty to thirty rectal cancer resections were carried out each year in Maelor with a range of between three and ten abdominoperineal excision of rectum cases. There had been a 25% increase in cancer workload overall with significant impact on colonoscopy and CT waiting times. Although these had been kept well controlled for patients on a 2 week cancer pathway, routine patients were waiting much longer as a result (for example up to 12 weeks for a colonoscopy). Consideration had been given to outsourcing to Chester to bring waiting lists under control. The lead endoscopist had instigated and led the outsourcing arrangements and the clinicians felt they benefited from a strong endoscopy Clinical Governance process.*



*Some of the increase in workload was felt to be due to the increase in geographical area covered by the MDT and some work from Glan Clwyd's catchment area as waiting list times were higher there than locally. In terms of surgeons available to deliver the workload, there were only two full time colorectal surgeons at the time of the meeting, as another was not currently operating and a locum had recently been appointed. The two surgeons were each delivering one and a half full day lists per week.*



## CaNISC and WCISU

NHS Wales Informatics Service (NWIS) supports Cancer Network Information System Cymru (CaNISC) and the Welsh Patient Administration System (WPAS) that was formerly known as Myrddin.

CaNISC is an in house system which is available to all of Wales and gives access to a single system. Its primary function is to report on cancer patient pathways and in particular on waiting times. The system has problems both with access and functionality. There is a MDT meeting module which allows CaNISC to be used for live data entry and validation. While this is laudable, the reality is that there must be sufficient clinical time for a MDT meeting (with secondary impact in terms of job planning) for CaNISC to be used for this purpose. However, if it is not used, then there is need for duplication of data entry whether using paper or electronic proformas as the information must be subsequently loaded onto CaNISC.

Historically other systems have been explored, including the Somerset system. However it is important to recognise that there has to be cross talk between multiple systems as well as the use of minimum data sets.

There has been repeated concern that CaNISC does not reflect data that has been entered. On exploring this issue, it was clear that it is important to ensure that there are no duplicate entries and that there is satisfaction that the correct data has been uploaded. Despite this, there are clearly ongoing discrepancies.

A number of issues were explored around the quality of data. The National Bowel Cancer Audit now has a clinical audit platform which allows clinicians in England to view their own unit data and in particular their own personal data. There is the additional issue of the impact of PEDW data and the fact that it has not been available for the past two years. This was initially reportedly due to concerns about the accuracy of this data but it is not yet clear whether or not the accuracy has now improved.

There are a number of decisions that need to be made around CaNISC in the future. The first is whether it is continuing to function. Secondly, consideration should be given to whether CaNISC remains fit for purpose and is sufficiently flexible to deal with changes in the future. The third important priority in terms of this Enquiry is to look for flexibility where important audit items may differ from one year to the next.

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) is the National Cancer Registry for Wales and is responsible for collecting and holding information about cancer care in Wales, as well as reporting on all cancers in the resident population of Wales, even if they receive treatment outside Wales.



## 10. Conclusions

High quality audit data is fundamental to ensuring quality of care for patients with bowel cancer in Wales. Welsh outcomes should continue to be scrutinized and compared at institutional level within Wales and at national level with the English Strategic Networks, given the comparable patient numbers.

The 2014 Annual Report of the National Bowel Cancer Audit (NBOCA) showed a difference in observed 2-year survival for bowel cancer patients in Wales when compared to patients treated in the English Strategic Clinical Networks. This difference was noted both for all patients irrespective of treatment but also for patients who had undergone surgical resection, in whom outcomes could be adjusted for risk by an imputational model.

The purpose of this Enquiry was to establish whether there was a true difference or not. Concerns over data accuracy and methodology ultimately mean that it is not possible to establish conclusively whether there was a true difference or not.

Two-year survival for colorectal cancer patients in Wales was not significantly different from that of the English Strategic Clinical Networks in the subsequent 2015 and 2016 NBOCA Annual Reports.

Data collection, access and clinical verification is lacking in some areas. The impression gained by the review panel was that all clinicians and their MDT colleagues are totally committed to ensuring high quality data collection; this is a fundamental component of good clinical practice. However, the resources required in terms of administrative support, allocation of clinician time and technological infrastructure vary considerably from MDT to MDT. Clinician ownership of data through linkage to General Medical Council (GMC) number and through timely checking of individual clinician data on the Clinical Audit Platform will allow real time validation of data and should be a priority for colorectal cancer care in Wales.

CaNISC has some advantages in audit collection, especially where its live module is used in MDTs for data collection. However, transfer of audit data as a single event means that currently clinicians do not have the opportunity to review and validate individual data in NBOCA's Clinical Audit Platform.

The successor to the CaNISC system requires engagement of all stakeholders and sufficient resources to build a modern data collection system that is both versatile and fit for audit purposes.



Lack of availability of Patient Episode Database for Wales (PEDW) has hampered risk adjustment processes to allow comparison of Welsh outcomes both within Wales but also with England. Attempts to carry out risk adjustment by imputational methods are laudable but not robust, given differences in measuring social deprivation between England and Wales. There is some question as to whether use of PEDW data, even if available, is valid to make the comparison as the Welsh and English Indices of Multiple Deprivation are weighted differently and comorbidity and emergency admission data from HES and PEDW may also not have been comparable.

There are undoubtedly wider issues beyond data collection and quality. The Enquiry had the opportunity to identify a number of issues pertinent to improving colorectal cancer care in Wales:

- The organization of the multidisciplinary colorectal cancer team, their meetings and practices are sub-optimal in some centres. The need for teleconferencing raises unique logistical problems that are not easily addressed.
- Some MDTs appeared overly reliant on reporting of radiological investigations for staging information without giving weight to clinical input.
- Providing clinical services across wide geographical areas has an impact on access to specialist treatment with long travelling times for some patients.
- Centralisation of oncology services provides expertise but needs to be balanced against patients needing to travel for treatment and local hospitals having to provide acute oncology services for complications arising from treatment.

Clinicians and audit support services should be congratulated for their willingness to engage and learn from this invited Enquiry from initial invitation and throughout.



# 11. Recommendations

Based on the findings detailed hitherto, the Reviewing Panel's recommendations are made on the following assumptions:

- A. The Minister of Health for Wales (and by extension the Welsh Government) fully supports the principles of national audit of cancer care and outcomes across all cancer sites and specifically for the purposes of this report, for Colorectal Cancer
- B. That this support is underpinned by full financial support for data gathering, submission and analysis.
- C. The newly formed All Wales Cancer Network also supports audit processes and participation in national audit programmes, which the Network and Welsh Government recognise should be a mandatory requirement.
- D. The Minister of Health for Wales (and by extension the Welsh Government) fully supports continued publication of audit results for Colorectal Cancer outcomes for Wales and comparison with outcomes for England.
- E. The NBOCA will continue to report on data submitted by Wales, even if Welsh Government support is not in place for best practice in risk adjustment.

The recommendations of the Panel of reviewers are as follows:

## **Audit Support:**

- 1. Audit is recognised as a key component of Supporting Professional Activities for clinicians engaged in the management of colorectal cancer and that this is factored into job planning to allow sufficient time for clinicians to engage in all stages of the audit process.
- 2. It is recognised that Multidisciplinary Team Coordinators are key personnel in the collection and entry of accurate data into the Audit platform. Each site undertaking colorectal cancer treatment should have adequately resourced and supported MDT coordinators who have sufficient cover for absences from colleagues to ensure timely entry of data.

## **Data Accuracy:**

- 3. An "all Wales" approach to best practice is agreed and implemented with respect to data acquisition, entry, validation, upload, feedback intervals and clinical sign-off.



4. An MDT coordinators Network is established across Wales to allow dissemination of information relating to audit, as well as mentoring of newly appointed coordinators by people familiar with this role.
5. As a minimum, an annual meeting of interested parties is instituted to define uniform standards for colorectal cancer audit across Wales and update newly introduced audit themes that require dissemination. In addition, there is integral involvement of the Welsh Representative of the NBOCA Clinical Advisory Group as well as the Welsh Cancer Registry and All Wales Cancer Network.
6. To ensure accuracy of information held on the Audit Platform, individual clinicians should have access to the Clinical Audit Platform to enable them to check the accuracy of data well before final analysis by NBOCA. It is accepted that the upload from CaNISC to NBOCA, previously via Open Exeter and now via the Clinical Audit Platform at NHS Digital, is done as a single upload. Opportunity for pre-upload review on CaNISC and post-upload review of individual data on the Clinical Audit Platform should be embedded.

#### **Audit Systems:**

7. Trusts are mandated to provide adequate Information Technology facilities to MDTs to allow real-time data entry of audit information during the MDT meetings as well as updating data out with the weekly MDT meetings.
8. The All Wales Cancer Network reviews the data collating systems in use and comes to an early decision as to which system will be used going forward, both in the short and long terms. The Review Panel has no opinion as to which system will be most suitable for Wales. Currently Welsh data is collated on CaNISC. Whichever system is selected should meet the following criteria:
  - Intuitive navigation through the various data entry fields.
  - Ability for data to be entered in real time during MDT meetings.
  - Flexibility in the system for rapid modification of the data entry platform to accommodate changes to the NBOCA minimum data set.
  - Rapid, accurate and easy upload of data from the audit platform to NBOCA.
  - Regular feedback to MDTs as to the data uploaded to the audit platform, highlighting missing data.
  - Ability for individual clinicians to access and review cancer data submitted in their name.



## Analysis of Audit Data:

9. Welsh mechanisms should be developed for identifying and dealing with observed discrepancy between different units across Wales. This will require understanding how data is collated and how risk adjustment is performed, as well as the importance of linked data from other sources such as PEDW and Cancer Registry data.
10. Where specific issues are identified, there should be systems in place to enable “deep dive” of the data by a Unit, giving a local opportunity for immediate internal assessment where problems are identified.
11. A major advantage of on-going audit is the ability to compare outcomes year on year. Annual review of local outcome data should facilitate local quality improvement programmes.





## 12. Response from Dr Tom Crosby, Medical Director of Wales Cancer Network

1 December 2016

### **ACPGBI Enquiry: Colorectal Cancer Outcomes in Wales**

Thank you for the opportunity to see and comment on the draft report. There are a couple of points that I would like to make from the Wales Cancer Network's perspective.

Firstly, we must not underestimate the importance of clinical engagement in data recording, sign off and submission. Validation reports are sent to MDTs at regular intervals and it must be noted that even using CaNISC, which we accept is an out-dated and inadequate information platform, the lung cancer community in Wales is able to demonstrate far higher participation and accuracy of data collection and reporting.

Secondly, whilst there is unanimous support from Welsh Government, NHS Wales and MDTs that we should participate in national audit and be able to compare performance between units in Wales as a country with Strategic Networks in England, we do not think we will have a fit-for-purpose information platform for several years. Mandating participation using systems that are not fit for purpose is challenging and we need to ensure that it does not lead to ongoing frustration and disharmony in the clinical service and between organizational structures in Wales.

We are extremely grateful to the ACPGBI for their incredible diligence in producing this report. We are determined that it will be used to lead the improvement in the reporting of patient outcomes and the quality of cancer services in Wales.

**Dr Tom Crosby**  
**Medical Director**  
**Wales Cancer Network**



## 13. Acknowledgements

The Invited Panel would like to acknowledge with gratitude the co-operation and assistance of the following during this Enquiry:

Dr Tom Crosby, Medical Director of Wales Cancer Network

Mr Martyn Evans, Lead Clinician for the Welsh Bowel Cancer Audit

ACPGBI Welsh Representatives, Mr Michael Davies (South Wales), Mr Anil Lala (North Wales) and Mr Ramesh Rajagopal (North Wales)

All members of Welsh Colorectal MDTs who contributed to the Enquiry

Dr Dyfed Huws, Director, Welsh Cancer Intelligence and Surveillance Unit

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Professor James Hill, Clinical Lead of NBOCA

Dr Kate Walker, Dr Angela Kuryba and Dr Abigail Vallance, Clinical Effectiveness Unit, Royal College of Surgeons of England

Mr David Waits, formerly Cancer Information Programme Manager, South Wales Cancer Network

Mr Hywel Morgan, Director, Wales Cancer Network

Cancer Network Information System Cymru (CaNISC)

Mrs Jo Church, Chair of Patient Liaison Group, ACPGBI



## 14. Glossary

**Adjuvant treatment** – An additional treatment (e.g. chemotherapy or radiotherapy) provided to improve the effectiveness of the primary treatment (e.g. surgery).

**American Society of Anesthesiology (ASA)** – A grading system to help determine how risky surgery is for a patient based on other medical conditions affecting their health.

**Association of Coloproctology of Great Britain and Ireland (ACPGBI)** – A professional association composed of surgeons and other clinicians who treat bowel diseases.

**Audit** – Systematic review and evaluation of data to determine the quality of clinical services.

**Bowel cancer screening** – The NHS Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 74. Those over 74 can request a screening kit from the Programme.

**Cancer Network Information System Cymru (CaNISC)** – A web-based computer system holding information about cancer treatment for patients in Wales. It is used for managing waiting times, scheduling appointments, planning multi-disciplinary care and supporting national cancer audits.

**Charlson score** – A scoring system that combines information on 19 comorbidities with an age-related factor to produce a total comorbidity score that may then be used in risk adjustment processes.

**Chemotherapy** – Drug treatment used to treat cancer. It may be used alone, or together with other types of treatment (e.g. surgery or radiotherapy).

**Clinical Nurse Specialists (CNS)** – These are experienced, senior nurses who have undergone specialist training. They play an essential role in improving communication with a cancer patient, being a first point of contact for the patient and coordinating the patient's treatment.

**Comorbidity** – Presence of one or more additional diseases or disorders that are also present in a patient with a medical condition e.g. bowel cancer. Comorbidity is important because it is associated with poorer outcomes from treatment.

**Computed Tomography (CT) scan** – An imaging system that uses X-ray radiation to build up a 3-dimensional image of the body.

**Curative care** – This is where the aim of the treatment is to cure the patient of the disease.



Forest plot – A graphical representation of results from multiple studies arranged around a vertical line of no effect. The results of several studies or centres are combined to give an overall effect.

Funnel plot – A graphical representation of outcomes plotted against number of patients treated with lines drawn on the graph to show limits of where variation should be expected and is normal. Institutions lying outside the expected funnel lines are “outliers” and need to examine why.

Heated Intraperitoneal Chemotherapy (HIPEC) – A highly concentrated, heated chemotherapy treatment that is delivered directly to the abdomen during surgery for more advanced bowel cancers.

Hospital Episode Statistics (HES) – A database which contains data on all in-patients treated within NHS Trusts in England. This includes details of admissions, diagnoses and those treatments undergone.

Imputation – The process of replacing missing data with substituted values based on previous data or extrapolation from other sources to allow statistical analysis.

Laparoscopic – Also called minimally invasive surgery or keyhole surgery, is a type of surgical procedure performed through small incisions in the skin instead of the larger incisions used in open surgery.

Lymph nodes – Lymph nodes are small bean shaped organs, often also referred to as lymph ‘glands’, which form part of the immune system. They are distributed throughout the body and can be one of the first place to which cancers spread.

Metastases – Deposits of cancer that occur when the cancer has spread from the place in which it started to other parts of the body. These are commonly called secondary cancers. Disease in which this has occurred is known as metastatic disease.

Magnetic resonance imaging (MRI) – A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Multidisciplinary team (MDT) – A group of medical and nursing colleagues from different healthcare professions with specialist expertise who collaborate to make treatment recommendations to ensure high quality patient care.

National Bowel Cancer Audit – A long-established, collaborative, national clinical audit run jointly by NHS Digital and the Association of Coloproctology of Great Britain and Ireland (ACPGBI). The Audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and analysis carried out by the Clinical Effectiveness Unit at the Royal College of Surgeons of England.



National Cancer Registration and Analysis Service (NCRAS) – A national cancer registration service run by Public Health England that aims to collect data on all cases of cancer that occur in people living in England for use in healthcare and research.

Neo-adjuvant chemotherapy – Chemotherapy given before another treatment, usually surgery. This is usually given to reduce the size, grade or stage of the cancer and therefore improve the effectiveness of the surgery performed.

Palliative care – The care given to patients whose disease cannot be cured. It aims to improve quality of life rather than extend survival and concentrates on relieving physical and psychological distress.

Patient Episode Database for Wales (PEDW) – Records of all episodes of inpatient and daycase activity in NHS Wales hospitals. This includes planned and emergency admissions, minor and major operations, and hospital stays for giving birth. Hospital activity for Welsh residents treated in hospitals in England is also included.

Risk adjustment – The process that takes into account differences or risk profiles between two groups of patients through statistical adjustment to allow legitimate comparison of the outcomes.

Socio-economic deprivation – Deprivation scores can be ascribed to an area or population to give a picture of its social and economic status. Deprivation is an important aspect to include in risk adjustment.

Stent – A flexible, hollow tube designed to keep a segment of the colon (large bowel) open when it has become blocked.

Stoma – A surgical opening in the abdomen through which the bowel is brought out onto the surface of the skin. Colostomy and Ileostomy are the two main types of stoma.

Strategic Clinical Networks (SCN) – A partnership of those who use, provide and commission a specialist clinical service in a large geographical area to make improvements in outcomes for complex patient pathways through an integrated, whole system approach.

TNM Staging – The staging system for bowel cancer describes the extent of involvement of the primary tumour (T), whether any lymph nodes contain cancer cells (N), and whether the cancer has spread to another part of the body (M).

Transanal endoscopic microsurgery (TEM) – A minimally invasive technique to remove early cancers and large polyps in the back passage using specialist equipment.



Welsh Cancer Intelligence and Surveillance Unit (WCISU) – The National Cancer Registry for Wales responsible for collecting and holding information about cancer care in Wales, as well as reporting on all cancers in the resident population of Wales, even if they receive treatment outside Wales.



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# Appendix A: Responses from Welsh MDTs following Consultation

(Collated and submitted by Wales Cancer Network)

## Cardiff and Vale MDT

*The Cardiff and Vale MDT welcomes the report from the ACPGBI and acknowledges the substantial work in its preparation. We note the specific objectives were to assess the validity of Welsh data in comparing outcomes (between contributing MDTs in England and Wales) and to assess data entry and risk adjustment processes. This assessment was primarily for the data reviewed in the 2014 report (covering April 2008- March 2011 for 3 year outcomes, and April 2012- March 2013 for short term outcomes). This work covers preparation for, and visits to Cardiff on 11- 12 April 2016 and subsequent analysis and production of the Enquiry report.*

*The Enquiry report outlines thoroughly the demographic, epidemiological and socio-economic differences between areas of the UK. We note a focus on 2014 data (page 21, Geography; page 25, Deprivation; pages 26-28, Epidemiology) though this differs from the data covered by the Enquiry report.*

*A specific note is made of Fig 4, page 23 that appears to show lower household income and greater disability (higher deprivation) is negatively associated with obesity in Wales. The prevailing view and experience would suggest that affluent and fit patients are slimmer, not more obese.*

*A considerable proportion of the Enquiry report is dedicated to description of the data collection and analysis by NBOCA. In particular, the validity of adjustment for deprivation that is performed by an imputational model due to differences between HES and PEDW data and data quality.*

*Comparative analysis is presented of individual MDTs (page 38, 39) however, we are unclear whether this represents new assessment of the data in light of the ACPGBI enquiry, or simply presentation of the data already reported in the 2014 audit.*

*The robustness and use of an imputational model is defended by the enquiry, and yet PEDW data is criticised (and has been excluded) on account of its accuracy and ability to appropriately adjust for outcome. We find this contradictory unless PEDW data is so incomplete as to be worthless for audit (and by extension, use in health funding by the Welsh Government).*



Cardiff MDT valued the discussions on April 12 2016 (with common themes outlined in pages 48-67). It was disappointing that the enquiry was unable to determine why the data submitted to NBOCA appeared (at times) unrecognisable to several MDTs (specifically for example, the proportion of patients with rectal cancer receiving radiotherapy). We suspect that this reflects flaws in the information capture of the CaNISC dataset and subsequent (one time) upload. There does not appear to be an in depth assessment of this.

We note the importance of ASA to risk adjustment and the variability between MDTs in its assessment and recording. The report acknowledges this and the ACPGBI has recommended determination by anaesthetists alone (to mitigate bias by surgeons and individualised outcome data). We asked our anaesthetic department for clearer guidance, noting that the modifications to the original ASA score (Saklad et al. 1941) creates more inter-observer variability. In particular, no guidance is given as to whether malignancy should be considered to have systemic physiological impact on patients. We would value clearer direction from the ACPGBI in standardising this, noting for example the effect that neo-adjuvant treatment has on performance status and CPT physiological testing.

We highlighted that some hospitals may be excluding patients who die from emergency surgery prior to discussion at the MDT, as recommended by NBOCA ([http://content.digital.nhs.uk/media/17324/NBCA-FAQs/pdf/NBOCA\\_FAQs\\_2015.pdf](http://content.digital.nhs.uk/media/17324/NBCA-FAQs/pdf/NBOCA_FAQs_2015.pdf), accessed 19/11/2016) and raised the point that a deliberate delay of discussion at the MDT was possible with obvious effect on individual and MDT outcome. We are not aware that any comparison of ONS (colorectal cancer) deaths and reported MDT mortality has been performed.

We highlight that in 2008, a Welsh Government proposed Policy Aim was: “To provide diagnosis, treatment, and rehabilitation and palliative care services for people with cancer that match or surpass the best in Europe in terms of quality. In particular, to achieve and sustain comparable **one year and five-year survival rates** with the top European quartile by 2015.” (approximately that of NHS Central London (Chelsea) MDT) (<http://www.wales.nhs.uk/documents/Designed-to-tackle-Cancer.pdf>. Accessed 19/11/16)

In response, we note Fig. 18 page 98. Cardiff and Vale has the lowest per capita funding for cancer in Wales (approx. 14% below the mean) and over 20% below England.

In summary, we welcome the recommendations (pages 70-72) of the Enquiry which specify that time and resources are allocated to data and audit processes, and to validation by units and individual clinicians prior to submission.

We note that the Review Panel make their recommendations based on five core assumptions (page 70). We strongly request that the ACPGBI supports the Medical Director of the Wales Cancer Network in receiving written assurance from the Welsh Government that these five core principles are met. In addition, it would be valuable to have a framework from the Welsh Government for the financial and implementation commitments to support Colorectal Cancer Care in Wales.



## **Nevill Hall**

*At the time of submitting our MDT data for 2013 -2014, preliminary data was submitted but numerous data endpoints were highlighted as being absent. An extra data submission (within the allocated time frame) was prepared to cover the 21% missing data outlined in the report. This information was submitted through CaNISC from Cancer Services but was never uploaded. (An email confirming this was submitted to Wales Cancer Network.)*

*We have confirmation from CaNISC the information was sent from Cancer Services to the Cancer Network for submission, but have received no explanation as to why this was never added to our overall end results.*

*We contend that the missing data would affect our 90 day and 2 year mortality figures placing us within the Welsh national average as well as significantly reducing our missing data.*

*Areas of concern for our MDT are:*

- 1. Radiological staging of Mx/9 or Nx/9 are recorded as missing data , where they reflect an uncertainty on behalf of the reporting radiologist. This needs clarification or an agreed standard with a degree of uncertainty being able to be recorded.*
- 2. ASA grades are not universally applied with some MDTs having no ASA 1 patients. An argument that all colorectal cancer patients are automatically ASA 2 has an impact on expected outcomes.*
- 3. Adding new data collection criteria towards the end of a year will lead to absent data, confirmation of new data required should be at the beginning of the year, e.g. performance status.*
- 4. We have used a different interpretation for emergency / urgent surgery which would have an impact on our types of surgery performed as well as mortality and morbidity outcomes.*
- 5. Poor data collection and recording was highlighted in our Peer Review prior to this report. We addressed this issue by having a dedicated MDT Co-ordinator allocated. We were expecting to be within the normal percentile in all areas.*
- 6. The Cancer Network have admitted to using a different coding system to CaNISC where by data inputted can be mislabelled as missing data.*



## Princess of Wales Hospital

Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.

*The Princess of Wales Colorectal MDT is grateful for the work performed by the ACPGBI in conducting this review.*

- *CT is not an appropriate tool for T staging of colonic cancer and therefore an accurate radiological T stage cannot be given. It is an appropriate tool for identification of metastases, and therefore the M stage is provided accurately.*
- *In addition we also would like to expand on the important issue of the definition and recording of urgency of surgery. We feel that our MDT had been recording the urgency of surgery accurately according to NCEPOD definitions. However, during our discussions, it became clear that in general these definitions are applied more loosely (eg emergency admission = emergency operation, rather than urgent or scheduled if greater than 24hrs from admission) and that POW should alter our data recording. This will have a significant impact on our risk adjustment and adjusted mortality rates.*

Additional comments were received from Dr Siân Phillips, Consultant Radiologist , Princess of Wales MDT, Clinical Director Radiology (POWH and NPTH), Cancer Lead, POW, Head of Speciality School/ Associate Dean (Radiology), Wales Deanery:

*I am feeding back on the report from the POW with some specific comments on radiology staging made during the interview process with surgical colleagues.*

*The surgical review is welcomed as it has highlighted clear issues in anomalies and discrepancies across MDTs in Wales in the way data has been recorded. This report will hopefully focus minds on accurate data collection and validation, and the development of a robust informatics structure to collate quality data.*

*We welcome the comments regarding the TNM staging being an MDT decision, based on the full clinical picture presented at the meetings, not just based on a radiological report interpreted with limited clinical information in isolation of the MDT.*

*As three experienced radiologists, including the imaging lead for Bowel Screening Wales (GT), we often have an MDT discussion regarding the accuracy of T staging colonic tumours (not rectal) on the basis of CT imaging. At best this is a “best guess” as CT does not accurately delineate bowel wall architecture. From an imaging perspective, we stage all tumours based on standard radiological practice, utilising current TNM classification, being that CT, MR or EUS. The wording within the report would suggest that we do not stage colonic tumours. This is far from the truth.*



*We would be grateful if these comments could be modified to reflect the true picture.*

*Of note, there is also no comment regarding the increasing challenge of accessing Pathology and Oncology at MDTs. This is against a background of a dwindling workforce as also seen in Radiology.*

*Many thanks for the opportunity to feedback.*



## Royal Gwent Hospital

*Thank you for the opportunity to respond to the preliminary report into the above Invited Review. We are satisfied that the Report was fair, extremely thorough and well written and provides yet more stimulus for debate here in Wales. The conclusions of the enquiry are however predictably vague as to whether there is a genuine problem with substandard outcomes for our bowel cancer patients, or simply a problem with data submission. We feel however that the recommendations of this enquiry into the future of national audit in Wales are not explicit enough.*

*We hope that the visiting panel members discovered that most of the Welsh Colorectal MDTs they interviewed feel passionately that the highest possible standard of care they provide should be accurately reflected in the NBOCA report and not be let down by nationwide technological inadequacies. Whereas we acknowledge that there will be some deficiencies in data management (errors in quality and accuracy) by some Welsh MDTs, most MDTs supply the best possible data for review by NBOCA. For example, in Newport we enter data into CaNISC in real time at each MDT with clinicians reviewing what is annotated for each patient. Our Colorectal MDT Lead regularly meets with the (non-clinical) MDT coordinator to ensure the best possible validated data is submitted onwards. Clinicians ensure that any data finally sent to NBOCA has been verified as accurately as possible.*

*As clinicians, we are perplexed and exasperated by the inability of various Welsh agencies (Cancer Networks, WCISU, NWIS, Public Health Wales, WG) to prevent us from being unfairly compared to English outcomes. It is ironic that CaNISC is deemed 'not fit for purpose' yet we are encouraged to continue data collection on that platform. If PEDW cannot be used for accurate risk adjustment, then why can't another platform (eg Somerset) be used or created for this purpose? These important factors are outside the control of Colorectal MDT members.*

*In weekly multidisciplinary meetings across Wales, busy clinicians come together as a team to manage their patients whilst aiming for the best possible care for the individual. It behoves that all the relevant government bodies mentioned above come together and agree to appropriately resource and deliver the tools required so that we clinicians can present the best possible risk adjusted data for comparative national audit. This would represent a fair way forward with meaningful comparison of outcomes in Wales. Only then will patients in Wales know for sure if they are having second-rate care for bowel cancer.*

Keshav Swarnkar, Colorectal MDT Lead  
Gethin Williams, Clinical Lead for Colorectal Surgery



## Swansea

Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.

*May I just highlight a correction with relevance to Swansea MDT:*

*We discuss about 50 patients in our MDT and not 80 as mentioned in the report.*

Mr Chandra Sekaran, Colorectal Surgeon and MDT Lead, Swansea



## Ysbyty Glan Clwyd

Amendments have been made to the reported text after representation by the MDT and in agreement with the Panel.





## Appendix B: Terms of Reference



The Association of Coloproctology  
of Great Britain and Ireland

### **ACPGBI Enquiry Colorectal Cancer Outcomes in Wales**

#### **Terms of Reference**

##### **Background**

The National Bowel Cancer Audit (NBOCA) publishes an annual report examining outcomes from colorectal cancer treatment in England and Wales. In 2014, NBOCA analysed the results of colorectal cancer treatment at the level of Strategic Clinical Networks (SCNs) for the first time.

Wales was assessed as a single network. Analysis demonstrated significantly worse observed and risk-adjusted two year outcomes after colorectal cancer resection surgery in Wales when compared to the English SCNs (reference 1). The observed two-year all cause mortality for all patients (including those who did not undergo surgery) was also significantly worse than expected in Wales.

Potential reasons for these observed differences are disparities between patient groups and background mortality rates, variations in management pathways and differences in data quality. Risk adjustment processes can allow for differences in patient mix but rely on mode of admission and level of comorbidity. This information is derived from the Patient Episode Database for Wales (PEDW). PEDW data was not available to NBOCA in 2014.

##### **Purpose of Enquiry**

The Enquiry will provide an independent quantitative review of colorectal cancer outcomes in Wales. The principal role of the Enquiry will be to assess validity and



reliability of data used in outcome analysis for Welsh patients and to provide support for professional colleagues delivering healthcare services in Wales.

## Objectives

The Enquiry will aim to assess the validity of the Welsh data used to assess colorectal cancer outcomes, provide qualitative assessment of data entry and risk adjustment processes, and allow comparison with other countries in the United Kingdom.

It will not aim to investigate the underlying causes or reasons if true deficiencies are identified. This would potentially become the focus of a second enquiry if required.

## Representation

The Enquiry has been convened in response to requests from ACPGBI representatives on Council and with the co-operation of the Medical Director of the Wales Cancer Network who has responsibility for audit data collection. Formal permission has been sought for the ACPGBI to undertake this Enquiry, and granted by Dr Tom Crosby, All Wales Peer Review Clinical Lead and South Wales Cancer Network Medical Director.

The Enquiry will be chaired by Professor Robert Steele, ACPGBI President, and be conducted by an invited Panel with representation from colorectal surgery, oncology, statistical analysis and public health. All Panel members will be selected from outside Wales.

All communications in relation to the Enquiry will be conducted through official channels and will be primarily addressed to the Medical Directors of the Cancer Networks and Chairs of the Health Boards who will be responsible for dissemination to local services under their jurisdiction.

The Enquiry Panel will potentially have interactions with:

Organisation	Affiliation(s)
Clinical Effectiveness Unit	Royal College of Surgeons
National Bowel Cancer Audit	Health Quality Improvement Partnership
North Wales Cancer Network	Tony Shambrook, Executive Cancer Lead; Matt Making, Medical Director; Damian Heron, Director
South Wales Cancer Network	Tom Crosby, Medical Director
Betsi Cadwaladr Local Health Board	Ysbyty Gwyneth Hospital, Bangor Ysbyty Glan Clwyd in Rhyl, Wrexham Maelor Hospital in Wrexham



Hywel Dda Local Health Board	Glan Gwili Hospital in Camarthen, Withybush Hospital in Haverford West, Bronglais Hospital# in Aberystwyth
Abertawe Bro Morgannwg University Local Health Board	Morrison Hospital in Swansea, Singleton Hospital in Swansea, Princess of Wales Hospital in Bridgend
Cwm Taf Local Health Board	Prince Charles Hospital in Merthyr Tydfil, Royal Glamorgan Hospital in Llantrisant
Cardiff and Vale University Health Board	University Hospital of Wales in Cardiff
Aneurin Bevan Local Health Board	Royal Gwent Hospital in Newport, Neville Hall Hospital in Abergavenny
Bronglais MDT#	South Wales Cancer Network
Cardiff MDT	South Wales Cancer Network
Nevill Hall Hospital MDT	South Wales Cancer Network
Prince Charles Hospital MDT	South Wales Cancer Network
Princess of Wales MDT	South Wales Cancer Network
Royal Glamorgan Hospital MDT	South Wales Cancer Network
Royal Gwent Hospital MDT	South Wales Cancer Network
Swansea MDT	South Wales Cancer Network
West Wales General & Prince Phillip MDT	South Wales Cancer Network
Withybush General MDT	South Wales Cancer Network
Ysbyty Glan Clwyd MDT	North Wales Cancer Network
Ysbyty Gwynedd MDT	North Wales Cancer Network
Ysbyty Maelor MDT	North Wales Cancer Network
Welsh Cancer Intelligence and Surveillance Unit (WCISU)	Dr Dyfed Huws, Director, WCISU
Cancer Network Information System Cymru (CaNISC)	Janet Warlow, Information Specialist, SWCN
Cancer Network Information System Cymru (CaNISC)	Linda Roberts, Information Specialist, NWCN
National Cancer Intelligence Network (NCIN)	
Scottish Cancer Registry	

# No elective colorectal surgery is currently taking place in Bronglais.

## Scope

The Enquiry will focus on available data from the 2014 NBOCA report and will assess all aspects of audit processes, including accuracy of data, data input, risk adjustment processes and comparisons both with historical Welsh data and current English and Scottish outcomes. Data will be assessed against background mortality and deprivation scores, as well as attempting to establish if there are differences in colorectal cancer specific mortality. Access to PEDW data will be required and used if available.



## Timelines

	<b>Date due</b>
Teleconference to agree terms of reference	9 September 2015
Terms of reference	Draft to ACPGBI Executive 28 September 2015; presentation to Council & ratification 5 Oct 2015; final version December 2015
NBOCA response	December 2015
Enquiry Panel	Invited & confirmed December 2015
Invitations to Welsh MDTs and Medical Directors from Welsh Cancer Networks	December 2015
Face-to-face meeting	12 April 2016
Draft report to Welsh Cancer Networks and Health Boards for Consultation	3 November 2016
End of Consultation Period	1 December 2016
Publication of Enquiry Report	5 December 2016
Face-to-face meeting	9 December 2016

## Meetings

The Panel will meet with representatives of the Welsh Local Health Boards and MDTs for face-to-face discussions during the course of the enquiry. Other Panel meetings will be conducted by teleconference or convened in person as required.

## Reimbursement of travel expenses

The ACPGBI will reimburse reasonable day travel expenses, overnight accommodation and second class rail fares for Panel members. Any other costs must be agreed in advance. The ACPGBI will also fund costs of the face-to-face meeting to be held in Wales in January 2016. The South Wales Cancer Network will be responsible for travel expenses of Welsh representatives and for providing a venue for the face-to-face meeting in Wales.

## Report

The findings of the Panel will be published in a formal report. The draft report will be made available to the Welsh Cancer Networks and Health Boards four weeks prior to publication. The final report will include publication of comments or responses from these bodies.



## References

1. <http://www.hscic.gov.uk/catalogue/PUB16021/nati-clin-audi-supp-prog-bowe-canc-2014-rep1.pdf>

## Document History

Authors:	Nicola Fearnhead, Steven Brown, Robert Steele
Date:	19 September 2015
Approval by Council:	5 October 2015
Final version:	8 December 2015



## Appendix C: Agenda for Meeting 12 April 2016



### The Association of Coloproctology of Great Britain and Ireland

#### **ACPGBI Enquiry Colorectal Cancer Outcomes in Wales 12 April 2016**

##### **Background**

The National Bowel Cancer Audit (NBOCA) analysed and published results of colorectal cancer treatment at the level of Strategic Clinical Networks (SCNs) for the first time in 2014. Wales was assessed as a single network. Analysis demonstrated significantly worse observed and risk-adjusted two year outcomes after colorectal cancer resection surgery in Wales when compared to the English SCNs. The observed two-year all cause mortality for all patients (including those who did not undergo surgery) was also significantly worse than expected in Wales.

Potential reasons for these observed differences are disparities between patient groups and background mortality rates, variations in management pathways and differences in data quality. Risk adjustment processes can allow for differences in patient mix but rely on mode of admission and level of comorbidity. This information is derived from the Patient Episode Database for Wales (PEDW). PEDW data was not available to NBOCA in 2014.

##### **Purpose of Enquiry**

The Enquiry will provide an independent quantitative review of colorectal cancer outcomes in Wales. The specific aim will be to assess the validity of the Welsh data used to assess colorectal cancer outcomes, provide qualitative assessment of data entry and risk adjustment processes, and allow comparison with other countries in the United Kingdom.

##### **Panel Members**

The Panel will be chaired by Professor Robert Steele, President of ACPGBI. Other panel members include Mr Steven Brown, Miss Nicola Fearnhead, Professor Paul Finan, Professor Alastair Munro, Professor Eva Morris, Mr Adam Scott, Mr Nigel Scott, and Mr Graham Williams.



## Agenda for 12 April 2016

Venue: Life Sciences Hub Wales, 3 Assembly Square, Cardiff Bay, CF10 4PL

<https://www.lifescienceshubwales.com/>

Members of the Panel will meet representatives of each Welsh MDT during the morning. The afternoon session will consist of an open meeting with short initial background information presentations followed by structured questions and then free discussion.

8.30am	Panel briefing	
9.00am	Cardiff MDT	Prince Charles Hospital MDT
9.30am	Royal Glamorgan Hospital MDT	Swansea MDT
10.00am	Royal Gwent Hospital MDT	Nevill Hall Hospital MDT
10.30am	Break	
11.00am	Princess of Wales MDT	Ysbyty Maelor MDT
11.30am	Ysbyty Glan Clwyd MDT	Ysbyty Gwynedd MD
12.00 noon	West Wales General & Prince Phillip MDT, Withybush General MDT & Bronglais MDT#	
12.30pm	WCISU and CaNISC (combined Panel)	
1.00pm	Lunch	
2.00pm	Welcome, Introductions and Terms of Reference – Dr Tom Crosby/Prof Robert Steele	
2.10pm	2014 NBOCA Annual Report Outcomes for Wales – Miss Nicola Fearnhead	
2.20pm	National Overview of Bowel Cancer Outcomes – Professor Paul Finan	
2.30pm	Data Collection in Wales – Dr David Waits, Cancer Information Program Manager, Wales	
2.45pm	Structured Questions (Chair: Professor Steele)	
3.30pm	Break	
4.00pm	Open Discussion (Chair: Professor Steele)	
4.30pm	Concluding Remarks	
4.45pm	Meeting Closed	

# As these MDTs have now amalgamated, representatives will be interviewed together.

The Panel will present their findings in a written report which will be submitted to MDTs for comment prior to publication.



# Appendix D: Healthcare Systems and Cancer Care in Wales

## Healthcare Expenditure

Health spending in Wales is falling (see Figure 16). Historically, Wales has spent more per head on health than England, but in 2013 expenditures were equal. The projected expenditures indicate a continued fall for Wales and a slow increase for England. The part of England that, geographically and demographically, most resembles Wales is the North-East. As the figure shows, health spending in North-East England has consistently exceeded Welsh levels, particularly in the period 2007 to 2010.

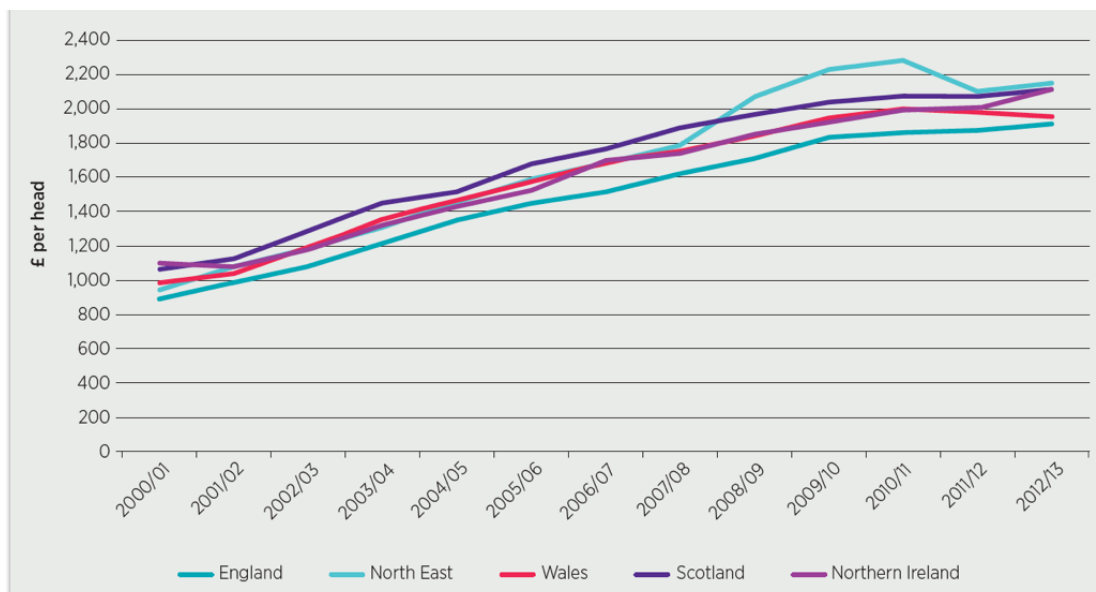


Figure 16: Government expenditure on health (£ per head) for countries in the United Kingdom and North East England, adjusted for current prices. (Source: Figure 14.3 in *The four health systems of the United Kingdom: how do they compare?* by Gwyn Bevan, Marina Karanikolos, Jo Exley, Ellen Nolte, Sheelah Connolly and Nicholas Mays, Health Foundation & Nuffield Trust, April 2014,

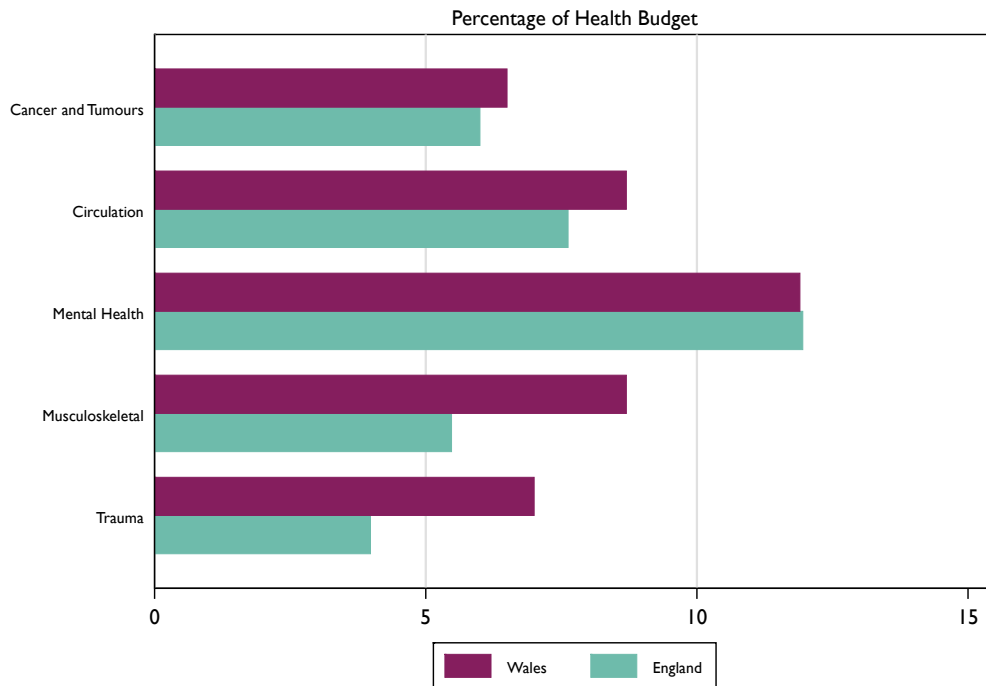
[http://www.nuffieldtrust.org.uk/sites/files/nuffield/140411\\_four\\_countries\\_health\\_systems\\_full\\_report.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/140411_four_countries_health_systems_full_report.pdf))

Wales spends slightly more of its health budget on cancer when compared to England, but considerably more on trauma and musculoskeletal conditions. This ties in with the higher proportion of adults under retirement age living with a disability and represents the long-term





effects of heavy industry on its workforce. The mines and mills are now closed or closing, but the effects of former harsh working environments persist.



Source: from health systems in transition (wales) and DoH 2003-04 to 2010-11 programme budgeting data

Figure 17: Proportion of health budget spent on different aspects of healthcare (Health Systems in transition (Wales) and Department of Health Programme Budgeting Data 2003/4 to 2010/11)

Although, at the population level, per capita spending on cancer is higher in Wales, the incidence of cancer is higher in Wales than it is in England. The net effect is that spending on cancer, per patient with cancer, is about 7.5% higher in England. The apparently low spending on cancer in Cardiff and the Vale is due to the “Velindre Effect”: the Velindre Cancer Centre is located in Cardiff and is a separately funded, directly accountable, health board with an annual allocated budget of £49 million.



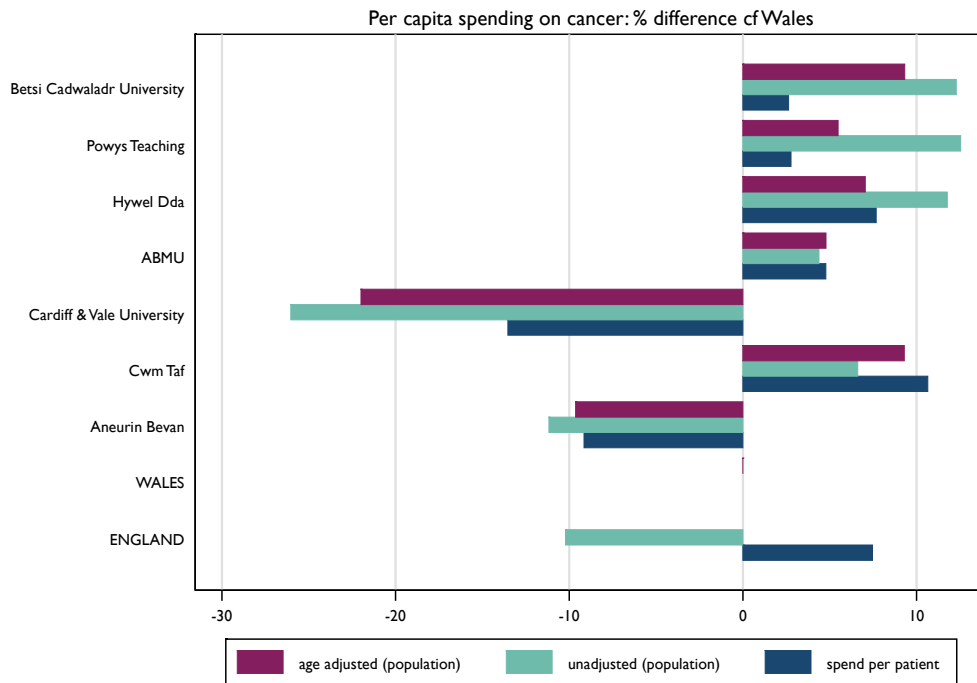


Figure 18: Differences in per capita spending on cancer care within Wales and for England in comparison to Wales as a whole. (Source: Data derived from Public Health Observatory Wales: NHS Expenditure and Health Tool [http://www2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf/85c50756737f79ac80256f2700534ea3/53e2856fdb8d975280257c0000448494/\\$FILE/20131002\\_NEHT\\_v2i.pdf](http://www2.nphs.wales.nhs.uk:8080/PubHObservatoryProjDocs.nsf/85c50756737f79ac80256f2700534ea3/53e2856fdb8d975280257c0000448494/$FILE/20131002_NEHT_v2i.pdf)).

Factors which might adversely affect outcomes for patients with colorectal cancer in Wales include: higher average health need in the general population; lower gross value added, consistent with lower income per head in Wales; lower number of GPs per 100,00 population.

### Cancer Care in Wales

The geography of Wales, and the concentration of non-surgical oncology into 3 centres affects the ease with which patients can access radiotherapy.



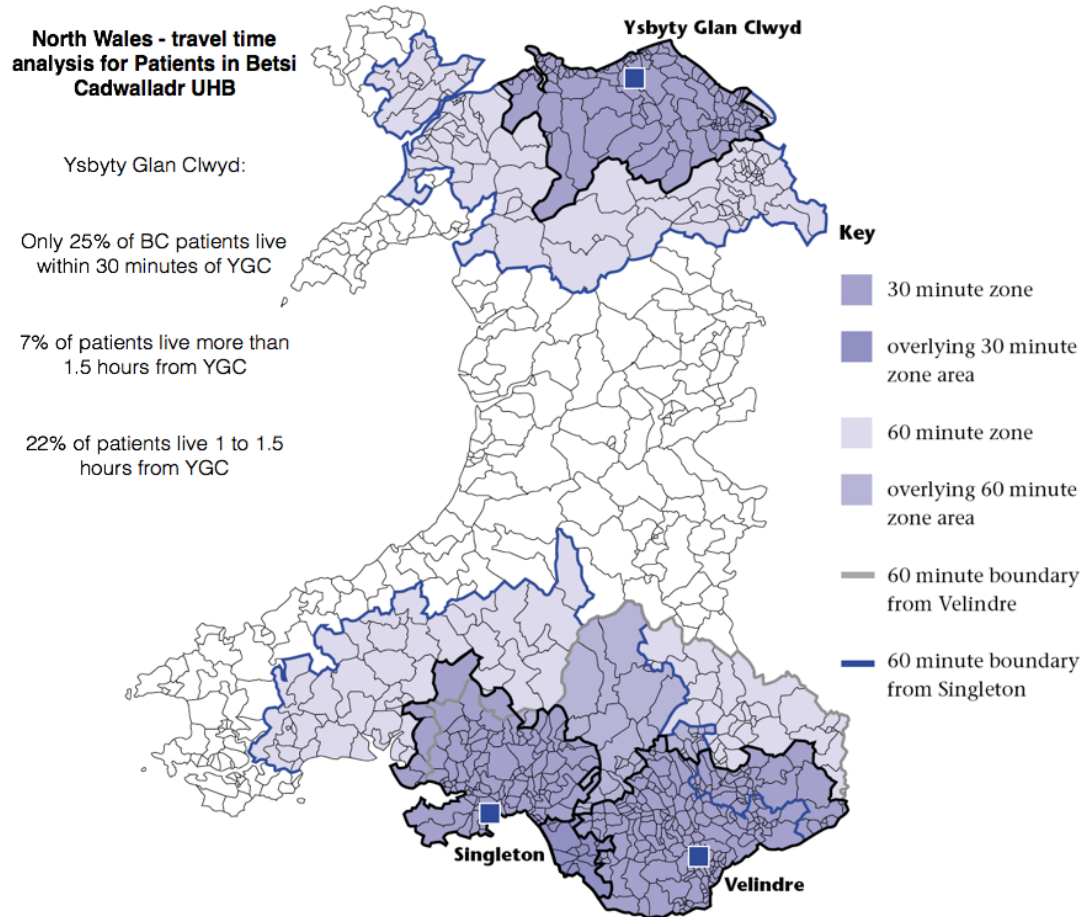


Figure 19: Travelling times for patients accessing radiotherapy services in Wales. (Sources: Cameron Report 1996 (travel times may now be out of date) and figures for Betsi Cadwalladr Health Board 2013).

Although Wales has historically had rather more oncologists per head of population than England, the distribution was uneven. There has been a concentration of resources at Velindre (Cardiff). The number of oncologists per million declined in Wales between 2011 and 2014 and slowly increased in England and the North-East. The net effect was that by 2014 the rates in Wales and England were similar.



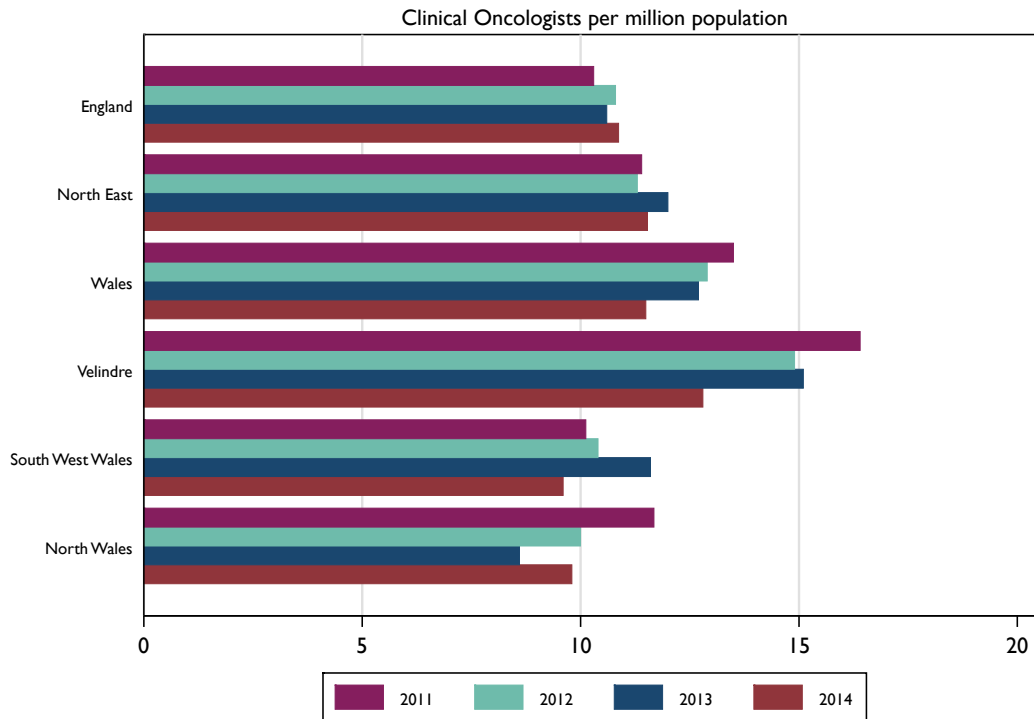
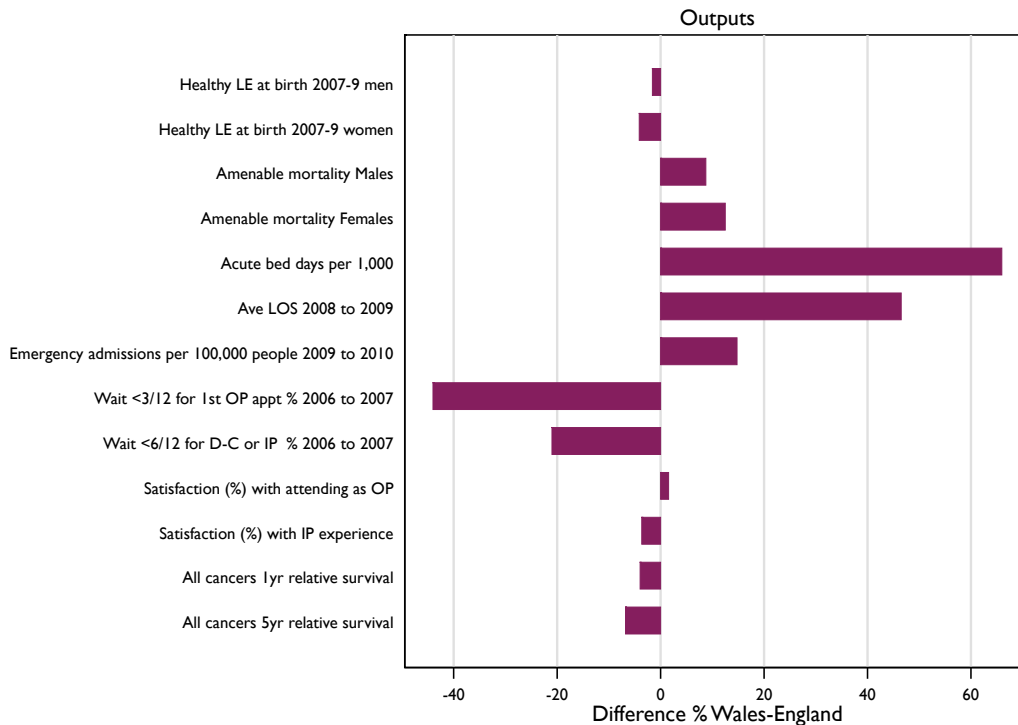


Figure 20: Clinical oncologists per million head of population from 2011 to 2014. (Source: Compiled from data published by the Royal College of Radiologists in its workforce census reports from 2011 to 2014. <https://www.rcr.ac.uk/clinical-oncology/service-delivery/rcr-workforce-census>).





Sources: NAO, OECD, 4 Countries Nuffield IFS 2016

Figure 21: Comparison of health service outcomes between Wales and England (Sources: data derived from *The four health systems of the United Kingdom: how do they compare?* Health Foundation & Nuffield Trust April 2014, [http://www.nuffieldtrust.org.uk/sites/files/nuffield/140411\\_four\\_countries\\_health\\_systems\\_full\\_report.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/140411_four_countries_health_systems_full_report.pdf); OECD (2016), *OECD Reviews of Health Care Quality: United Kingdom 2016: Raising Standards*, OECD Publishing, Paris. <http://dx.doi.org/10.1787/9789264239487-en>; *Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland* The National Audit Office 2012, [www.nao.org.uk](http://www.nao.org.uk))

Figure 21 summarises some relevant outcomes for health services in Wales compared with similar figures for England. Life expectancy is worse in Wales, amenable mortality rates are higher, there are more acute bed days consumed and patients have longer lengths of stay. There are more emergency admissions in Wales and waiting times for outpatient appointments and for treatment are longer. There are minimal differences in rates of satisfaction with care. Overall cancer survival rates at 1 year and at 5 years are worse in Wales.



## Appendix E: Attendance List at All Wales Meeting on 12 April 2016

Name	Title	Organisation	Base
Mr Barry Appleton	Consultant Colorectal Surgeon	Abertawe Bro Morgannwg University Health Board	Princess of Wales Hospital
Mr Kamal Asaad	Medical Director	Cwm Taf University Health Board	HQ, Ynysmeurig House
Dr Catherine Bale	Consultant Medical Oncologist	Betsi Cadwaladr University Health Board	Ysbyty Gwynedd
Professor John Beynon	Consultant Colorectal Surgeon	Abertawe Bro Morgannwg University Health Board	Singleton Hospital
Miss Debbie Clements	Consultant Colorectal Surgeon / cancer lead	Cwm Taf University Health Board	Royal Glamorgan Hospital
Mrs Fiona Davies	MDT Co-ordinator	Betsi Cadwaladr University Health Board	Wrexham Maelor Hospital
Mr Michael Davies	Consultant Colorectal Surgeon	Cardiff & Vale University Health Board	University Hospital of Wales
Mr Martyn Evans	Audit Lead and Consultant Colorectal Surgeon	Abertawe Bro Morgannwg University Health Board	Singleton Hospital
Mrs Melanie Guy	MDT Co-ordinator	Hywel Dda University Health Board	Glangwili General Hospital
Professor Puthucode Haray	Consultant Colorectal Surgeon	Cwm Taf University Health Board	Prince Charles Hospital
Miss Joanna Hilton	Consultant Colorectal Surgeon	Abertawe Bro Morgannwg University Health Board	Princess of Wales Hospital
Dr Dyfed Huws	Director	Welsh Cancer Intelligence and Surveillance Unit	Cathedral Road, Cardiff
Mr Wayne Jenkins	Head of Business and Operational Support	Cwm Taf University Health Board	Royal Glamorgan Hospital
Mrs Ceri Jones	Information Support	Cardiff & Vale University Health Board	University Hospital of Wales
Mr Anil Lala	Consultant Colorectal Surgeon	Betsi Cadwaladr University Health Board	Ysbyty Gwynedd
Mr Ashraf Masoud	Consultant Colorectal Surgeon	Cwm Taf University Health Board	Prince Charles Hospital
Mr Jegadish Mathias	Consultant Colorectal Surgeon	Hywel Dda University Health Board	Withybush General Hospital
Mr Andrew Maw	Consultant Colorectal Surgeon	Betsi Cadwaladr University Health Board	Ysbyty Glan Clwyd
Miss Janine Morris	MDT Co-ordinator	Betsi Cadwaladr University Health Board	Ysbyty Gwynedd
Mr Brendan Murphy	MDT Co-ordinator	Aneurin Bevan University Health Board	Royal Gwent Hospital
Mr Simon Phillips	Consultant Colorectal Surgeon	Cardiff & Vale University Health Board	University Hospital of Wales
Mr Gareth Popham	Audit & Governance Manager	South Wales Cancer Network	Morrison Hospital



Mrs Linda Roberts	Information Specialist	CaNISC	
Miss Nicola Rogers	MDT Co-ordinator	Aneurin Bevan University Health Board	Royal Gwent Hospital
Mr K A Saad	Medical Director	Cwm Taf University Health Board	Prince Charles Hospital
Mr Chandra Sekaran	Consultant Colorectal Surgeon	Abertawe Bro Morgannwg University Health Board	Singleton Hospital
Mr Andrew Simmons	MDT Co-ordinator	Cardiff & Vale University Health Board	University Hospital of Wales
Mrs Joy Singh	Consultant Colorectal Surgeon	Hywel Dda University Health Board	Glangwili General Hospital
Mr Graham Sturgeon	Surgical Practitioner		Nevill Hall Hospital
Mr Keshav Swarnkar	Consultant Colorectal Surgeon	Aneurin Bevan University Health Board	Royal Gwent Hospital
Mr Michael Thornton	Consultant Colorectal Surgeon	Betsi Cadwaladr University Health Board	Wrexham Maelor Hospital
Miss Shirley Wainwright	MDT Co-ordinator	Betsi Cadwaladr University Health Board	Ysbyty Glan Clwyd
Mr David Waits	Programme Manager	South Wales Cancer Network	Glanrhyd Hospital
Mrs Janet Warlow	Cancer Data Development & Quality Assurance Manager	Welsh Cancer Intelligence and Surveillance Unit	Cathedral Road, Cardiff
Dr Ceri White	Principle Statistician	Welsh Cancer Intelligence and Surveillance Unit	Cathedral Road, Cardiff
Mrs Lisa Wilkins	MDT Co-ordinator	Abertawe Bro Morgannwg University Health Board	Princess of Wales Hospital
Mr Gethin Williams	Consultant Colorectal Surgeon	Aneurin Bevan University Health Board	Royal Gwent Hospital



# Appendix F: Summary of Welsh MDT Organisational Reports Submitted to NBOCA 2015

Network/ Trust Name	Diagnostic/screening services								MDT services						Treatment				Other specialist services			
	Acute specialist colorectal take	Bowel screening by colonoscopy	Bowel screening by flexible sigmoidoscopy	Endorectal ultrasound (TRUS / ERUS)	Endoscopic ultrasound for colonic lesions more proximal to the rectum	MRI Liver with liver specific contrast for colorectal staging	PET-CT	Rectal contrast studies	HPB	Lung	Early rectal cancer	Locally advanced rectal cancer	Large or difficult polyps	Recurrent rectal cancer	Chemotherapy	External beam radiotherapy	Endoscopic mucosal resection (EMR)	Bowel stenting 5= Monday-Friday service, 7= Monday-Sunday service, AH= ad-hoc service, 24/7= day night night 7 days a week service	CPET	ERAS programme 5= Monday-Friday service, 7= Monday-Sunday service	Palliative care advice (24 hour access) o= unknown	
Bronglais MDT																						
Cardiff MDT	x	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓Off site	✓	✓	x	
Nevill Hall Hospital MDT	x	✓	x	x	x	✓	x	✓	x	x	✓	x	x	x	✓	x	✓	✓5	✓	✓7	✓	
Prince Charles Hospital MDT	x	✓	x	x	x	✓	x	✓	x	x	x	x	✓	✓	✓	✓	✓	✓Off site	x	✓7	✓	
Princess of Wales MDT	x	x	x	✓	x	✓	x	✓	x	x	x	✓	✓	x	x	✓	✓AH	✓Off site	✓7	✓		
Royal Glamorgan Hospital MDT	x	✓	✓	x	x	✓	x	✓	x	x	x	✓	✓	x	x	✓	✓5	✓Off site	✓7	✓		
Royal Gwent Hospital MDT	x	✓	x	x	x	✓	x	✓	x	x	✓	✓	✓	✓	✓	✓	✓5	x	✓5	x		
Swansea MDT	x	✓	x	✓	x	✓	x	✓	x	✓	✓	✓	✓	✓	✓	✓	✓5	✓	✓5	o		
West Wales General & Prince Phillip MDT	x	✓	x	x	x	✓	x	✓	x	x	x	✓	✓	✓	x	✓	✓AH	✓Off site	✓7	x		
Withybush General MDT																						
Ysbwyty Glan Clwydd MDT	x	✓	x	x	x	✓	✓	✓	x	x	✓	✓	✓	x	✓	✓	✓AH	✓Off site	✓	x		
Ysbwyty Gwynedd MDT	x	✓	x	✓	x	✓	✓	✓	x	x	✓	✓	✓	x	✓	✓	✓5	✓Off site	✓5	x		
Ysbwyty Maelor MDT	x	✓	x	x	x	✓	✓	✓	x	x	x	x	✓	x	✓	x	✓5	✓	✓	✓		

