A Bowel Cancer Framework for Wales

May 2008

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Foreword

Bowel cancer is a common disease in Wales with around 2,000 new cases and 1,000 deaths each year. The incidence of bowel cancer rises with age which means that, with an increasingly aging population, the NHS in Wales will need to plan for an increasing number of bowel cancer patients. Wales has a higher mortality rate than most European countries and within Wales there are variations in incidence and mortality. We need to address these health inequalities by targeting and co-ordinating resources from prevention through to treatment.

The Assembly Government recognised the need to reduce mortality levels when it set the Health Gain Target in 2004 requiring a reduction in cancer deaths in those under 75 by 20% by 2012[1]. Improved prevention, as a result of healthier lifestyles, and improved detection and treatment for those with bowel cancer will all contribute to meeting the Health Gain Target. Strategies, including population screening, are now needed to ensure these individual programmes of work are taken forward without delay and in a co-ordinated way. As part of this project, work has been carried out to analyse the causes, symptoms, diagnoses, and treatments for bowel cancer and the trends in incidence and mortality seeking to identify future prospects and potential benefits[2]. Clinical trials data show that mortality from bowel cancer can be reduced by 15% in the screened population[3,4] and by 8% overall[2].

This document, in considering the broad spectrum from prevention to palliative care, has endeavoured to consider the issues of public and patient choices and healthcare services. It further supports the implementation of the National Cancer Standards for Colorectal Cancer published in 2005. This is an ambitious programme involving collaboration across all sectors and involvement of both statutory and non-statutory organisations. However, to provide the world class service by 2015 as outlined in Designed for Life[5] and Designed to Tackle Cancer in Wales[6], each aspect of the proposed programme is of critical value.

Summary of Key Recommendations

The following are the main actions now required. The rationale for these actions and additional next steps are found within each Topic.

Topic 1 Prevention, patient awareness, decision aids and lifestyle choices

- Easily accessible **information[7] for the public** needs to be available so that individuals can be aware of early symptoms which should lead them to request professional advice without delay.

Key Responsibilities: Welsh Assembly Government, Wales Centre for Health, Informing Healthcare

Topic 2 Patient Access to Services

- Work to establish and develop a bowel **screening programme** should be taken forward as the first priority within the overall Framework.

Key Responsibilities: NHS Bodieser/Provider

Topic 3 Diagnosis and pre-operative staging

- The **national endoscopy training programme** set up in 2006 needs to ensure, as a first priority, that both medical and non-medical staff are trained to meet the needs of the bowel screening programme.

Key Responsibilities: Welsh Assembly Government, National Leadership and Innovation Agency for Healthcare [NLIAH]

- **Recruitment of radiology personnel and capacity problems associated with lack of equipment need to be addressed** to deal with the increased use of imaging in the diagnosis, staging and follow up of colorectal cancer.

Key Responsibilities: Welsh Assembly Government, NHS Bodies and Providers

Topics 4 and 5 Treatment and Palliative Care

- **Colorectal cancer multidisciplinary teams** focusing on diagnosis, treatment and palliative care should comply with the National Cancer Standards of 2005 by March 2009.

Key Responsibilities: NHS Bodies and Providers through their Cancer Networks

- Formal multidisciplinary training for colorectal teams in Wales should be promoted by a National Training Programme.

Key Responsibilities: Welsh Assembly Government, NLIAH

- Development and roll out of CANISC (Cancer Information System Cymru) should facilitate comparative clinical audit and monitoring compliance with cancer standards.

Key Responsibilities: Informing Healthcare, Cancer Information Framework Board, Regional Cancer Networks

Framework Methodology

1. The membership of the steering group and all contributors are listed in Appendix 1 and comprised individuals with specific expertise in prevention, screening, diagnostics, treatment and palliative care. The Terms of Reference is at Appendix 2. A number of individuals and organisations made contributions as either working papers or verbal advice.

2. The group considered similar work on bowel cancer undertaken in Scotland and England to ensure that this report reflected the broad consensus in approach across the UK. The intention from the start was to keep the document as simple and clear as possible and to highlight the gaps in current provision as well as to note the existing elements of good practice.

3. Each group member was allocated a topic area appropriate to their expertise and was tasked with working in collaboration with other specialists to prepare a report detailing the current service, priorities for the future and estimates of cost where possible. Work to provide a baseline of service provision was completed in 2005. Each Topic within this document contains a summary of outcomes required and next steps in relation to the 2005 baseline position.

4. In addition, all groups were requested to consider quality improvements, communication and potential for research. Topic priorities are included in each section and have also been collated in Appendix 3. All working papers are listed in Appendix 1 and are available on the Cancer Services Co-ordinating Group's (CSCG) intranet site[8].

5. The Draft Framework was circulated extensively as part of a formal consultation process. Users' views were sought via the CSCG Patient Forum, the Community Health Councils (CHCs) and national bowel cancer charities. The CSCG Patient Forum has worked with the Editorial Group to produce an information leaflet summarising the Framework for the general public.

Framework Context

6. A number of recent policy documents have been issued that provide a background for the Bowel Cancer Framework.

7. As part of the overall health system, cancer services are shaped by overarching policies such as Improving Health in Wales[9], Better Health Better Wales[10] and Health Challenge Wales[11] and the recently published Designed for Life[12] and Designed to Tackle Cancer in Wales[13] which updates the previous policy and describes the kind of health and social care services that the people of Wales can expect by 2015.

8. In relation to specific guidance relating to bowel cancer, the CSCG Strategic Development Plan [SDP] of 2002 flagged up as a potential new development the need to consider a programme for bowel cancer screening. This now needs to move centre stage.

9. The SDP also emphasised that pathology, radiology, non-surgical oncology and a strong research and trials-based culture needed to be adequately supported to maximise outcomes for patients and ensure effective cancer team working. The need for comprehensive, all-Wales clinical audit is central to improving outcomes and is being developed within the Cancer Information Framework. These generic themes are clearly evident in the respective working papers.

10. Moving from strategy to practice, the drivers for change have been the Cancer Minimum Standards and National Institute for Health and Clinical Excellence [NICE] technology assessments, service guidance and clinical guidelines. The Minimum Standards for Cancer Services of 2000 have been revised with the National Cancer Standards for Colorectal Cancer Services published in 2005 which take account of NICE service guidance.

11. The timeline for implementation of this Framework lies principally within phase 2 of Designed for Life. The Framework endorses the implementation of the National Cancer Standards and is therefore an early deliverable identified in Designed for Life with compliance required by March 2009. The National Cancer Standards do not include bowel cancer screening as the introduction of new screening programmes is

covered by the National Screening Committee [NSC] however, in line with the NSC guidance; the Assembly Government is committed to introducing screening for bowel cancer with the set up phase initiated in 2007.

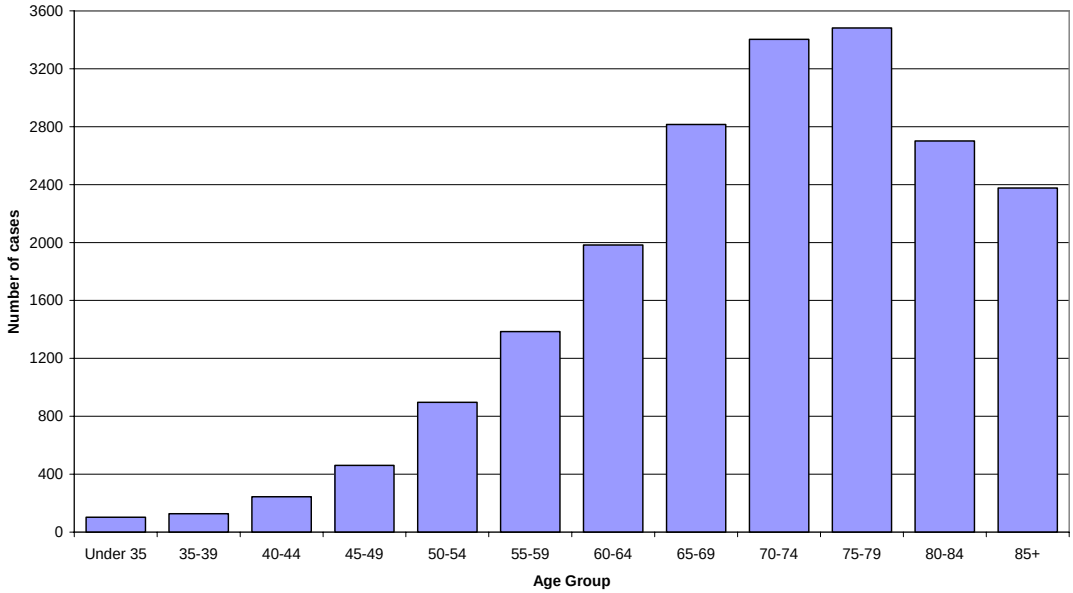
12. Improved access to services with a reduction in the time to be initially seen, diagnosed and treated is a key priority in each of the home countries. Prompt access to specialist care plus uniform high management standards by clinical teams, monitored by clinical audit, are expected to contribute to achieving the reduction in mortality in the under 75s, as detailed in the Health Gain Target[14]. Waiting times to the start of definitive treatment for patients diagnosed with bowel cancer are detailed in the National Cancer Standards and have been included as targets for the NHS in the Service and Financial Framework with compliance required from January 2007.

Introduction to bowel cancer

13. Bowel cancer is a common disease in Wales with around 2,000 new cases and 1,000 deaths each year [Table 1][15]. In men, bowel cancer is the second commonest new cancer after lung and in women, it is the third commonest after breast and lung. There is a different incidence in men and women, mainly because cancer of the rectum is more common in men than women, with a 20-50% higher incidence[16].

14. Figure 1 shows the rapid increase in incidence with age for bowel cancer based on Welsh data for all bowel cancers registered over the 10-year period 1994-2003. The bar chart indicates the frequency by age-group and reflects the actual caseload for clinicians.

Figure 1 Numbers of new patients, by age, diagnosed with bowel cancer over the 10-year period 1994 to 2003

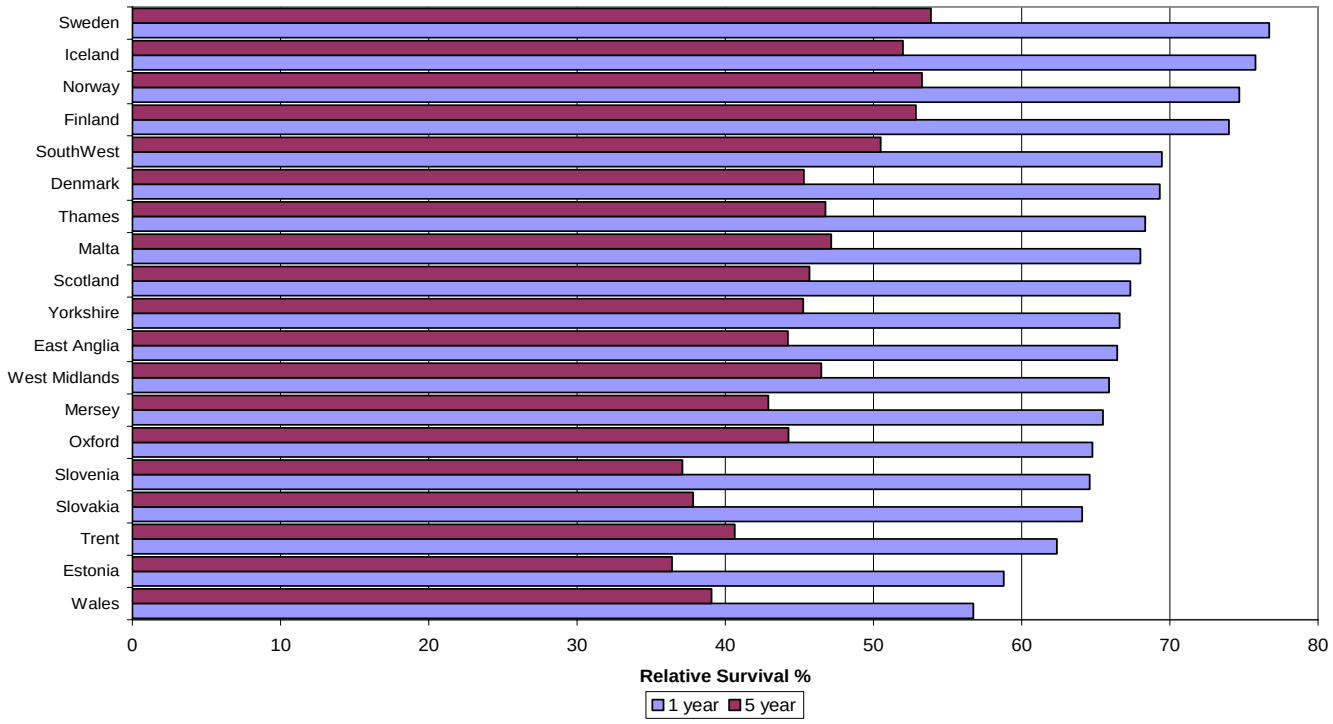


15. There are variations in both incidence and survival from colorectal cancer between the LHB areas of Wales with some definite ecological associations discernible[17]. The

incidence of colon cancer appears to be highest in areas of rural west and north Wales as well as urban areas such as Merthyr Tydfil. Dietary factors are likely to be important. Survival is highest in relatively affluent areas such as Vale of Glamorgan and lowest in more deprived areas such as Merthyr Tydfil and Rhondda Cynon Taf. This may be related to general poorer health and factors relating to public awareness which may delay presenting to the GP.[4]

16. There is some evidence for higher rates of incidence and mortality for large bowel cancer in Wales *vis à vis* England[18]. There is also evidence from the Eurocare-III study that in 1990-1994 Wales had a lower survival both at 1 year and 5years than the rest of the UK and many other countries in Europe [Figure 2]. The Eurocare-III study showed an association with expenditure on health and cancer survival outcomes[19].

Figure 2 Relative Survival for bowel cancer at 1 and 5 years - ranked by 1 year relative survival



17. Table 1 summarises data on incidence, survival and mortality. In 2005 there were 2,024 newly diagnosed bowel cancers in Wales[20]. Based on historic data, it is reasonable to expect as more people live into their 80s and beyond that the NHS will need to plan for an increase in the numbers of bowel cancers.

Table 1 Registration, mortality and survival data for bowel cancer

	Colon Cancer		Rectal Cancer	
	Men	Women	Men	Women
New cases in 2005	677	568	473	306
Predicted cases in 2010*	749	593	521	321
Deaths in 2005[21]	317	278	202	118
Relative Survival % at 1 year after diagnosis in years 1990-1995	61.1	57.8	70	66.2
Relative Survival % at 1 year after diagnosis in years 1996-2000	65.9 (+4.8)	63.0 (+5.2)	73.2 (+3.2)	74.9 (+8.7)
Relative Survival % at 5 years after diagnosis in years 1990-1994	41.8	38.1	40.2	41.8
Relative Survival % at 5 years after diagnosis in years 1995-1999	47.6 (+5.8)	44.9 (+6.8)	46.9 (+6.7)	52.7 (+10.9)

* using age specific rates by 5 year age band for 2005 and projecting forward to 2010

18. The situation is changing and the improving survival seen on comparison of data for patients diagnosed between the years 1990 to 1994 and 1995 to 1999 (Table 1 see brackets) can be attributed to a combination of more specialised surgery, advances in chemotherapy and multidisciplinary team working[22]. However there remain clear challenges to improve survival including tackling problems relating to late presentation of nearly half of all patients and the co-morbidities associated with many new cases in people aged more than 75 years[23] .

19. It stands to reason that the outcome after the treatment of most diseases should be improved by earlier diagnosis. This is a particularly logical argument in bowel cancer where outcome is intimately related to the stage of the disease when treated. For example, 5-year survival in bowel cancer falls from nearly all patients to approximately 1 in 5 when patients are grouped into those treated with early or advanced disease. Unfortunately, too many patients with bowel cancer present late in the natural history of the disease with subsequent low potential for cure[24].

Topic Area 1 – Public Awareness and Prevention

Topic Lead: Dr Iain Robbé, Clinical Senior Lecturer, Cardiff University and Honorary Consultant in Public Health Medicine, National Public Health Service for Wales. Group members are acknowledged in Appendix 1.

Introduction

20. Some 75% of bowel cancers are sporadic indicating that the origin of these tumours is related to lifestyle issues including diet. The public need to be aware of this situation and, coupled with appropriate information, offered help to adopt healthier lifestyles. High consumption of total fats and saturated fats, red meat particularly processed and heavily smoked, as well as alcohol and smoking act as promoters of colorectal cancers. There is good evidence that physical activity and a diet rich in vegetables, fibre, starch and non-starch polysaccharides amongst others act as inhibitors of colorectal cancers[25].

21. Health promotion therefore has an important part to play in offering people the choices that could reduce the risks of developing bowel cancers. Not all bowel cancers however occur sporadically with 15 % probably having a genetic basis and examples include familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC). The recognition of these genetic abnormalities imposes an increasing responsibility on the medical profession for recognizing those patients who are at risk from the various forms of inherited colorectal cancer. The Cancer Genetics Service Wales (CGSW) uses evidence-based guidelines for the referral of individuals at high risk of FAP or HNPCC to the three Cancer Genetics Centres.

22. Outcome after the treatment of many diseases should be improved by earlier diagnosis. This is a particularly logical argument in colorectal cancer where outcome is intimately related to the stage of the disease when treated.

Key Priorities

The immediate priority is to develop easily accessible decision aids for the public so that people can be aware of early alarm symptoms and request professional advice without delay. This will build on the current emphasis on the importance of a healthy diet and exercise exemplified by Health Challenge Wales.

Summary of findings and next steps

The following areas are summarised in Table 1.

1.1 Public awareness of early signs and symptoms

1.2 Changes in lifestyle behaviours

- a) increase physical activity
- b) encourage healthy eating
- c) reduce smoking
- d) reduce excessive alcohol consumption

1.3 Genetic surveillance of individuals with an increased risk

1.4 Topics for Research

Topic 1.1: Public awareness of early signs and symptoms

Outcomes Required	2005 Baseline position	Next Steps
a) Earlier presentation leading to prompt access to treatment and thereby reduced mortality.	A wide variety of LHB-led initiatives were in-progress including**:** • Materials distributed to support the European Cancer Code. • Posters on bowel cancer and other cancers developed by Specialist Health Promotion Service and distributed via Health Promoters in the field. • Communities First Partnership where members of the public were designated to help increase awareness of cancer. A number of voluntary organisations provided information, education, awareness raising and campaigning initiatives. Interactive decision aids for individuals concerned about bowel cancer symptoms did not exist.	Public Health Teams to • Work in partnership with other health promotion initiatives/staff and to contribute to a central directory to record projects in progress, and the outcome of evaluation. • Ensure printed materials are updated, or newly developed, and freely available to the public utilising existing networks. • Provide training/briefing sessions for health professionals/promoters to support the dissemination of materials. • Increase media coverage to inform public awareness where there is evidence of the effectiveness of this approach Welsh Assembly Government to • Explore with voluntary organisations opportunities for collaboration in raising public awareness of bowel cancer using a targeted approach based on areas of increased incidence. • Development of an interactive decision aid.

Topic 1.2: Changes in lifestyle behaviours – physical activity		
Outcomes Required	**2005 Baseline position**	**Next Steps**
a) Increased physical activity.	There were many innovative projects underway directed either centrally or at the community LHB level. The following are examples. The Welsh Assembly Government was targeting young people. Projects included: • Food & Fitness – Promoting Healthy Eating and Physical Activity for Children and Young People in Wales[26]. • Those in Climbing Higher Next Steps, including support for Sports Council schemes such as Dragon Sport and the PE and School Sport programme. Community-based projects included[27]: • The Food & Fitness Health Promotion Grant Scheme. • Inequalities in Health Fund projects with a nutrition or physical activity element. Initiatives addressing the needs of at risk groups and older people include: • Development of a national exercise referral schemes. • Piloting of the British Heart Foundation "Move More Often" resource aimed at promoting physical activity among frail older people in care settings.	To take forward Climbing Higher – Next Steps[28].

Topic 1.2: Changes in lifestyle behaviours – healthy eating

Outcomes Required	2005 Baseline position	Next Steps
b) Increased consumption of fruit, vegetables, fibre; reduced consumption of saturated fats, salt, processed meat. Increased public awareness of the benefits of healthy food choices. Reduced obesity.	Various initiatives were in progress to improve diet Welsh Assembly Government • Development of a Quality of Food Strategy • Welsh Network of Healthy School Schemes, including promotion of fruit tuck shops, healthy vending machines, water coolers/water bottles. • Primary School Free Breakfast Initiative. LHB-led initiatives include • Healthy Schools and Young peoples' health promotion included initiatives such as fruit tuck shops, water coolers/water bottles, and development of schools nutrition strategy. • Childhood obesity project 2004-2007 with a family centred approach provided by a psychologist, dietician and sports developer. • Health promotion (community) included nutrition and exercise sessions for sheltered housing, get cooking schemes and promotion of the five a day message. • Training on obesity management and weight reduction given to key community workers e.g. Re-enablement team and Extend. • A Nutrition Action Plan had been produced as part of the Health and Social Care Well Being Strategy. Many initiatives were targeted through workplace, preschool, school, college, hospital and community settings, and also sub- population groups.	• To implement the Quality of Food Strategy

Topic 1.2: Changes in lifestyle behaviours – reduce smoking

Outcomes Required	2005 Baseline position	Next Steps
c) Reduced number of young people who start smoking. Increased number of smokers who give up smoking. Extended smoke-free environments.	The Assembly Government initiatives included targeting young people. Examples of smoking prevention and cessation initiatives were • Teaching resources for primary and secondary school, Smokebugs clubs for 8-11 year olds and a Smokefree Class competition for 11-13 year olds. • Approaches to adolescent smoking cessation with other European countries through an EU-funded project. • Smoking cessation initiatives included funding of all Wales Smoking Cessation Service through the National Public Health Service. • Production and dissemination of information and self-help materials. • Support for No Smoking Day. • The Welsh Assembly Government had made a commitment to implementing a ban on smoking in public places[29] In addition to the above, LHB initiatives include • Children's Smoking Prevention Project funded by the Big Lottery targeted at school years six and seven. • Cessation of smoking programme targeted at the adult population in deprived areas.	Adolescent Smoking Cessation to be consolidated into the all Wales Smoking Cessation Service. • Healthy Schools to maintain level of work around smoking prevention. • Continued funding for Smokebugs. • Increased and mainstreamed investment in smoking prevention initiatives based on multi-component approaches.

Topic 1.2: Changes in lifestyle behaviours – reduce excess alcohol intake		
Outcomes Required	**2005 Baseline position**	**Next Steps**
d) Reduced alcohol intake to that required in national guidelines for sensible drinking.	The following were examples of LHB-led reduction in alcohol initiatives are in-progress. • Harm reduction, treatment, counselling, group work provided by statutory and voluntary sector. • Illegal-availability-stifling initiatives, including test purchasing and validate proof of age scheme. • Community Safety Partnership Substance Misuse co-ordinating actions through a three year Action Plan. • Counselling and motivational interviewing to individuals who have a problem with alcohol. • Projects that offer information and advice as support for people undergoing detoxification. • Initiatives targeted through workplace, school, college, hospital and community settings, and also targeted through specific sub population groups.	• Welsh Assembly Government to develop and implement a revised Substance Misuse Strategy[30]

Topic 1.3: Genetic surveillance of individuals with an increased risk

Outcomes Required	2005 Baseline position	Next Steps
Appropriate referral of individuals and families with a family history of colorectal cancer allowing for identification of those at increased risk and accurate risk stratification.	The CGSE, based on three Cancer Genetics Centres, is established with all Wales referral guidelines[31] issued and used by GPs and appropriate hospital clinicians	The CGSW to ensure that referral guidelines are kept in line with new UK or international recommendations
Appropriate surveillance of individuals and families at increased risk, according to their level of risk.	Individuals assessed at moderate risk were referred for 5 yearly colonoscopic surveillance[32]. Individuals assessed at high risk were referred for appropriate surveillance [33] and/or surgery. This was ideally to a consultant with a particular expertise in managing these high risk families.	Surveillance regimes for those at increased risk should be rationalised according to the level of risk, in line with current guidelines. This may involve increasing the frequency of screening for those at the highest risk and decreasing it for some individuals with only a moderate risk. The genetic register for HNPCC and Polyposis families in Wales should be maintained and developed to facilitate appropriate surveillance and multidisciplinary management of the extra-colonic manifestations of these disorders.

Topic 1.3: Genetic surveillance of individuals with an increased risk (continued)

Outcomes Required	2005 Baseline position	Next Steps
Appropriate investigation and genetic testing of individuals and families at increased risk of developing colorectal cancer.	The molecular genetic laboratory, in collaboration with pathology services, offered MSI (Microsatellite Instability) and IHC (Immunohistochemistry) testing of pathology samples from affected individuals, both deceased and surviving.	To expand MSI and IHC testing to all moderate risk families in order to identify atypical HNPCC families and in the rest (the majority) exclude HNPCC. This will allow more appropriate use of colonoscopy resources. Where evidence of clinical and cost effectiveness is shown, NHS Bodies should support further development of the mutation detection service.

Topic 1.4: Topics for Research

1. Effectiveness of programmes that seek to raise public awareness of bowel cancers' symptoms.
2. Evaluation of initiatives that seek to change lifestyle factors, for example, physical activity, healthy eating, smoke free environments and alcohol consumption.
3. Effectiveness of aspirin and non-anti-inflammatory drugs in the prevention of bowel cancers.
4. Use of genetic markers for increased risk of cancers and their effectiveness in enabling earlier diagnoses, better targeting of treatments, knowledge of prognosis and of side effects/toxicities.

Topic Area 2 – Patient access to services

Topic Lead: Dr Hilary Fielder, Director of Screening Services, Velindre NHS Trust. Group members are acknowledged in Appendix 1.

Access to Services

Access to services is considered from three routes.

A) via a national screening programme

B) via referral from a GP

C) via the Cancer Genetics Service – refer to Topic Area 1

A. Access via a national screening programme for bowel cancer

23. The aim of a bowel cancer screening programme is to reduce the incidence of and mortality from bowel cancer by 15% as achieved in the randomised controlled trials.

24. The 'Polyp-Cancer Sequence' was established many years ago. Seventy-five percent of colorectal cancers are spontaneous and mature from pre-existing polyps over a period of 10 to 35 years. Colorectal polyps (the pre-malignant lesion) have a very predictable natural history and may remain completely asymptomatic. Hence the reasons for offering a screening programme.

25. The National Screening Committee [NSC] has reviewed the evidence on bowel cancer screening and found that population screening of people over the age of 50 for non-visible (occult) blood in the faeces can reduce the mortality rate for bowel cancer by detecting pre-malignant polyps or early cancers. The NSC recommended to Ministers that a pilot screening project be organised to test the acceptability and feasibility of achieving the necessary levels of quality required to reduce mortality without significant adverse effects. These pilots have reported and the NSC has advised that a national bowel cancer screening programme be implemented for people aged 50 to 74 years.

26. In February 2007, the Assembly Government announced funding to establish the phased implementation of a national bowel cancer screening programme for Wales.

27. Health Commission Wales has instructed Velindre NHS Trust to set up and implement the bowel screening programme as per NSC advice. A national Steering Board has been established in July 2007, to oversee this work. The Team acknowledges, with thanks, the time and practical help given thus far by staff of both the English and the Scottish programmes.

28. NLIAH set up a managed endoscopy training network in 2006 which will support the increased demand for endoscopy as outlined in this Framework, though not the advanced training and accreditation currently advocated by the English programme.

B. GP referral of symptomatic patients

29. Currently, most patients are referred for endoscopy assessment from general practice. This route places demands on secondary care services that are not easy to predict, and waiting times have historically been difficult to manage, as demand has always outstripped supply. A review of endoscopy services has been undertaken as part of the NLIAH's Endoscopy Programme and a summary of the findings of this work is included in the working papers for Topic 3.

30. In the overall drive to provide prompt access for patients and pick up earlier stage disease the revised National Cancer Standards require urgent referrals with suspected cancer to start definitive treatment within 62 days of receipt of the referral. This subsumes the 'two week' wait from GP referral to first appointment and tests required confirm a diagnosis and has been incorporated into the 2005 - 06 Service and Financial Framework for the NHS in Wales for compliance from January 2007.

31. Evidence from monitoring the 'two week wait' has shown that only about a third of patients diagnosed with bowel cancer actually enter the service as 'urgent suspected cancer' referrals[34]. To address this, NICE has published recent guidance[35] on the criteria for referral of patients from primary care with suspected cancer.

32. In response to the need for more effective categorisation of patients a questionnaire and clinical decision support software have been developed to help identify which patients are likely to have disease and therefore require endoscopy and which may safely remain under clinical surveillance within general practice[36,37]. This questionnaire and pathway, developed by a team at Leighton Hospital, has been piloted in Wales at Ysbyty Glan Clwyd, Conwy and Denbighshire NHS Trust and Swansea NHS Trust. This and other innovative developments may improve access for patients and ensure appropriate use of bowel cancer services should further published research confirm the early studies.

C. Referrals from the Cancer Genetics Service

33. Colonoscopic surveillance services have been considered for patients with genetic pre-dispositions that are at a higher risk than the general population. It should be recognised that many of these patients are currently receiving surveillance, albeit not as part of a nationally planned and organised programme, and this should be factored in to any assessment of services.

34. Cancer Genetics Service Wales and the Bowel Cancer Screening Project should consider including people found to have a genetic predisposition for bowel cancer on the screening pathway for recall to colonoscopy.

See Topic 1 for further detail.

Key Priorities

To establish and develop a bowel cancer screening programme.

Summary of findings and next steps

The following areas are summarised in Table 2.

2.1 Introduction, establishment and development of screening programme

2.2 Referrals from Primary care

2.3 Topics for Research

Topic 2.1: Introduction, establishment and development of a Screening Programme		
Outcomes required	**2005 Baseline position**	**Next Steps**
Establishment of a national bowel cancer screening programme as advised by the NSC a) The programme to be supported by a robust organisational model.	No bowel cancer screening pilot sites were set up in Wales.	• The organisation principles of screening in Wales will be followed with a single all Wales screening programme having responsibility for the programme delivery – Bowel Screening Wales. • A Project Team at Screening Services, Velindre NHS Trust will establish the programme under the supervision of a Steering Board. The team will appraise the initial proposals below and make recommendations for implementation to the Steering Board. • One central Screening Office [SO] should be established. The SO should issue invitations, testing kit, and arrange for appropriate management including direct referral to the secondary care diagnostic teams. One centralised laboratory will be required for Wales and this should be sited with the SO. Referral should be made directly from the screening office to identified diagnostic departments and a lead in the diagnostic team responsible for arranging appropriate management • The programme should consider recalling all patients diagnosed within the programme requiring surveillance according to nationally defined protocols for immediate and high risk patients

Topic 2.1: Introduction, establishment and development of a Screening Programme [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
b) Information requirements for the programme to fit with Informing Healthcare's overall strategy		A screening computer system will be specified, appraised and procured. Bowel Screening Wales, via its IM&T sub group will work with Informing Healthcare to ensure the requirements for a bowel screening programme fits in with their overall strategy to establish an electronic patient record and demographic spine. Bowel Screening Wales will ensure that its systems support the cancer information requirements already identified for colorectal cancer MDTs and Trust statutory returns.
c) The programme to be supported by an appropriate staffing structure.		The Steering Board must ensure an appropriate staffing structure, supported by adequate on-going training to maintain defined quality standards.
d) The programme to be underpinned by appropriate diagnostic services.		Endoscopy services are being enhanced prior to commencement of a screening programme. The Global Rating Scheme, funded for three years from 2008, will provide a lever to improve standards in colonscopy services. Bowel Screening Wales will also help Local Health Boards and Health Commission Wales plan for additional treatments in the early years while the programme becomes established. Bowel Screening Wales will provide agreed performance monitoring reports for NHS Bodies. Sharing of individuals' data between the central programme and Trusts undertaking diagnostic assessments and treating cancers will be required to ensure proper evaluation of the service and to permit informed choice.

Topic 2.1: Introduction, establishment and development of a Screening Programme [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
Expanded endoscopy services in support of the bowel screening programme. See also Topic 3	No nationally supported endoscopy training programme	Ensure the training programme established in 2006 recruits adequate numbers of medical and non-endoscopists. The screening programme may need to consider additional training of colonoscopists to achieve the accreditation proposed by the English programme.
Designation of colonoscopy units linked to the screening programme and working to required quality standards.		Referral from the SO should only be to identified diagnostic departments, with a dedicated lead and providing information for QA and evaluation. The SO need to identify diagnostic departments that meet the required standards. This may need to take a phased approach. All elements of bowel cancer services should be enhanced and the programme will help provide information to help plan to cope with the increase in the temporary increase in demand as a result of the introduction of the screening programme.

Topic 2.2: Referrals from primary care

Outcomes required –	2005 Baseline position	Next Steps
a) Appropriate referral of patients with suspected cancer.	NICE service guidance provided criteria to be satisfied for urgent referral[38]. National Cancer Standards for waiting times from referral to start of definitive treatment were in place and being monitored as part of the SaFF process. Tools existed to capture information on symptoms to help either primary care or cancer specialists identify which patients require urgent referral for further investigation and which may be monitored in primary care.	NICE service guidance on referral for suspected cancers should be supported in primary care. Informing Health Care, working with the Cancer Information Framework, should plan to identify the clinical information needs of primary care. Decision-aid tools, as an additional support to identifying patients with suspected cancer whether utilised in primary or secondary care, should be further investigated.

Topic 2.3: Topics for Research

In relation to the proposed screening programme,

1. Research on differential uptake to the screening programme.

Research and audit will need to be undertaken to assess interventions aimed at maintaining or improving uptake in specific groups of individuals. In other screening programmes uptake has been lower in poorer socio-economic groups and in other potentially vulnerable groups. Uptake in bowel screening in Wales is likely to be lower in men if it follows trends in the pilots.

User satisfaction surveys will be undertaken.

2. Evaluation of outcomes.

The effect of the introduction of screening on the characteristics of polyps, tumour staging, incidence and mortality will be evaluated. Collaborations for evaluation will be sought with others in the UK.

Topic Area 3 – Diagnosis and pre-operative staging

Topic Lead: Mr Nicholas Carr, Consultant Surgeon, Swansea NHS Trust and Chair of CSCG Colorectal Cancer Steering Group. Group members are acknowledged in Appendix 1.

Introduction

35. Investigations of the large bowel fall into two categories, namely, endoscopy and imaging.

36. Endoscopy utilises a steerable fibre optic/video instrument for direct visualisation of the bowel and allows removal of small growths (polyps) and biopsy of suspected cancer. Flexible sigmoidoscopy is used to investigate the lower large bowel, primarily in patients with symptoms of fresh rectal bleeding and/or change in bowel habit. Colonoscopy is performed with a longer instrument with the intention of visualising the whole of the large bowel and is indicated in patients who are suspected of having colorectal cancer. Subsequent colonoscopy is required in some patients who are discovered to have significant abnormalities at flexible sigmoidoscopy.

37. The large bowel may be imaged in many ways but the two main methods currently employed in clinical practice are double contrast barium enema and computerised tomography (CT). Both techniques involve X ray exposure to generate an image. Barium suspension and air are introduced into the colon and a series of X-ray images are taken to show the whole of the large bowel. It is safe, well tolerated and requires no sedation. CT produces cross sectional images of the body, and using a dedicated protocol, can be tailored to specifically image the large bowel to produce a CT colonogram (CTC). Conventional CT is also useful to investigate patients with suspected intestinal obstruction or palpable abdominal masses. CTC is relatively new but experience is rapidly increasing throughout Wales.

38. Each type of investigation has specific advantages and disadvantages. Colonoscopy, in skilled hands, is the most accurate method for detecting colorectal cancer and

polyps, but it is invasive, requires sedation and carries the greatest risk, albeit small, of serious complication. Flexible sigmoidoscopy is less invasive, simpler to perform and is adequate to exclude serious disease of the distal colon in low risk patients. Barium enema is slightly less sensitive than endoscopic methods for detecting cancer but is safer, widely available and remains an effective diagnostic tool. CT colonography, at its best, is at least as accurate as barium enema and may be as accurate as colonoscopy in detecting larger polyps, though the evidence for this is not consistent. CTC is particularly useful for assessing the right side of the colon after incomplete colonoscopy, and also in patients with mobility problems as well as those who are unfit for colonoscopy. Both imaging techniques suffer from an inability to sample tissue for analysis so that patients subsequently require colonoscopy to investigate polyps or other suspicious findings.

39. Radiological imaging techniques suffer from an inability to sample tissue for analysis so that patients subsequently require colonoscopy to investigate polyps or other suspicious findings. A National Health Technology Assessment is underway to assess the efficacy of CTC relative to barium enema and colonoscopy and the findings are due to be reported in 2008.

40. There has been rapid, enthusiastic but unregulated spread in the use of CTC, which will inevitably give rise to variation in performance. Training courses for CTC are now available but enrolment spaces are limited. Similarly, concerns have been raised in relation to colonoscopy competency, with low completion rates reported in a multi regional audit. The introduction of the national endoscopy training programme in 2006 and the implementation of the Global Ratings Scheme in 2007 will begin to address these issues.

41. For adequate disease staging, further imaging is usually necessary to assess local and distant spread of colorectal cancer. Patients with rectal tumours should undergo high resolution MRI scanning of the pelvis to determine who would benefit from adjuvant treatment or surgery alone. There is an important role for endo-anal ultrasound in identifying early stage rectal tumours amenable to highly specialised local excision. Distant spread of colorectal cancer is most effectively detected by CT scanning, and is essential for planning treatment. Recent guidance from the Royal College of

Radiologists states that staging CT should include the thorax, abdomen and pelvis for all patients diagnosed with colorectal cancer[39]. Positron Emission Tomography (PET) is an emergent technology, capable of identifying active tumour in the body and plays an increasingly important role in management of selected patients.

42. At present, the choice of investigation, either diagnostic or staging, will depend to a large degree on factors such as local waiting times, expertise and quality of diagnostic equipment. The National Innovations in Care Endoscopy programme produced dramatic improvement in waiting times in some units but success was not uniform, and reasons for failure must be identified.

43. Until recently training in endoscopy has largely taken place “on the job”, and the extent to which an endoscopist has been trained has depended on the approach of the consultants to whom they were allocated during their training period. The lack of uniformity in standards of training has been linked to evidence of poor procedure outcomes.

44. Traditionally, doctors have performed endoscopy but there is an urgent need to expand the personnel base for the provision of this investigation. Skill mix is essential to developing a future service within the modernisation frame work. Successful examples depend upon open and critical examination of the specific individual roles in the delivery of health care, coupled with professionals and their interactions together as a team. It allows some disciplines to focus their efforts on those skills they are best suited to perform and others to develop or extend their roles.

45. In the short to medium term, nurses and allied health professionals (AHP) should be trained to perform the low impact endoscopic investigations equating to clinically less risk i.e. upper GI endoscopy and flexible sigmoidoscopy. This approach would allow the nurse/AHP endoscopists to undertake a substantial number of the lower impact endoscopy lists allowing medical staff to concentrate on the increasing numbers of high level colonoscopies.

46. In the long term, experienced multi-skilled nurse/AHP endoscopies working at an advanced practitioner level would be able to assist with colonic surveillance and diagnostic programmes.

Key Priorities

1. The immediate priority is the continued support and development of a structured and accredited training programme for flexible sigmoidoscopy and colonoscopy. This programme should include the recruitment of nurses and AHP's. This is integral to the implementation of the screening programme for bowel cancer.

2. Recruitment of radiology personnel and capacity problems associated with lack of equipment need to be addressed to deal with the increased use of imaging in the diagnosis, staging and follow up of colorectal cancer.

Summary of findings and next steps

The following areas are summarised in Table 3.

3.1 Improved access to services

3.2 Training and skill mix

Topic 3.1: To provide reliable, accurate and readily available method for diagnosing and staging colorectal cancer		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) Improved access to colonoscopy and flexible sigmoidoscopy and appropriate imaging for patients with suspected colorectal cancer, in line with NICE guidance. Reduced colorectal cancer incidence by wider use of colonoscopy and polypectomy. b) Improved staging of patients diagnosed with colorectal cancer.	All 19 acute hospitals in Wales had endoscopy units with a small amount of gastrointestinal endoscopy carried out in community hospitals, this being especially prevalent in Powys. Endoscopists provided approximately 9,000 sessions accommodating 60,000 procedures annually. There were approximately 20 vacant posts for consultant radiologists. Most Welsh hospitals had some experience of CTC. Colonoscopy and double contrast barium enema were still the investigative modalities for the vast majority of patients. Radiographers performed most of the barium enemas with the images interpreted by radiologists. There was great variation in waiting times for both procedures. Most patients diagnosed with colorectal cancer had multi-slice CT of the abdomen and pelvis for staging purposes. MRI was used for local staging of most patients with rectal cancer.	The Endoscopy Managed Training Network to ensure training of both medical and non medical staff Trusts to support radiologists in attending approved courses for CTC[40]. To incorporate CT of thorax into staging protocols[41].

Topic 3.1: To provide reliable, accurate and readily available method for diagnosing and staging colorectal cancer (continued)		
Outcomes required	**2005 Baseline position**	**Next Steps**
c) Appropriate and well managed services for patients.	Waiting times for gastrointestinal endoscopy were very long in the most populated parts of Wales. In 2004 Innovations in Care and subsequently in 2005 NLIAH via the National Endoscopy Programme worked with the NHS to reduce waiting times. A service modernisation programme for imaging was underway with clear benefits for imaging of colorectal cancer.	Trusts to continue to streamline the diagnostic pathway.

Topic 3.2: Training and skill mix

Outcomes required	2005 Baseline position	Next Steps
a) An ongoing endoscopy training programme and quality assurance framework for all endoscopy units in Wales in line with guidance from the Joint Advisory Group [JAG].	**Medical endoscopy training courses** All trainees were expected to register with the JAG ▪ Two basic endoscopy courses. ▪ Two "training the trainers" courses, each accommodating eight experienced endoscopists. ▪ Commercially sponsored colonoscopy courses. ▪ Three courses in endoscopic ultrasound. **Radiology Training** There were a number of National Training Numbers in Wales for radiologists but no supporting funding.	Trusts should ensure training is be part of continual professional development for all members of the endoscopy workforce. Educational provision should be coordinated centrally by NLIAH with the training programme ensuring equality of access for doctors and nurses training in endoscopy in Wales, with provision of training at least as good as in England. A quality assurance programme should be put in-place so that all healthcare professionals performing endoscopy can be periodically assessed for competence and the existing workforce is trained in teaching and use of new technology.

Topic 3.3: Training and skill mix (continued)		
Outcomes required	**2005 Baseline position**	**Next Steps**
	Non-medical training: There was no provision for degree or master's level programme for nurses/AHP's wishing to work at an advanced level in endoscopic gastroenterology within Wales. There was, however, a programme run at diploma level through the University of Wales. There was a JAG approved training programme for medical staff at the Welsh Institute of Minimal Access Training (WIMAT).	NLIAH should support an appropriate educational programme leading to specialist practice for nurses and AHPs. The educational programme should be at degree/masters level and needs to be developed and dove tail with the JAG programme. This programme should be provided from a single educational provider. Once CTC is more established, appropriate staffing and skill mix should be reviewed.

Topic Area 4 – Treatment

Topic Lead: Mr Jeffrey Stamatakis, Consultant Surgeon, Bro Morgannwg NHS Trust, member of the CSCG Colorectal Cancer Steering Group, and Chair of the Cancer Information Framework Project Board. Group members are acknowledged in Appendix 1.

Introduction

59. Surgery is the mainstay of treatment for bowel cancer and, with very few exceptions, is the only treatment that can affect a cure. In the last 5-10 years, there have been very significant advances in assessing how far the cancer has spread and treatment options available to patients.

60. The surgical technique of Total Mesorectal Excision (TME) for rectal cancer is associated with a low local recurrence of the cancer and increased cure rates but this method requires specialist training and monitoring by audit. Such training workshops have been shown to improve the outcome of surgery[42].

61. There is increasing awareness that high quality imaging techniques can stage cancers with an accuracy that enables treatment to be tailored to the individual patient. This is particularly appropriate for rectal cancer, where MRI scans have transformed treatment planning. Preoperative staging using a CT scan of the thorax, abdomen and pelvis should be normal practice except in cases where information on cancer stage and metastatic spread would have no influence on management [43]. The use of modern staging methods is patchy and some patients do not have access to the quality of imaging required in modern bowel cancer treatment.

62. There has been a massive increase in the use of adjuvant radiotherapy and chemotherapy for bowel cancer, based on the results of sound clinical trials and supported by NICE. The benefit of preoperative radio / chemo-radiotherapy in rectal cancer has pressurised the resources available and the widespread use of postoperative adjuvant chemotherapy has over-stretched oncology clinics. Preoperative treatment will frequently produce a dramatic shrinkage and down-staging of rectal cancers and

postoperative chemotherapy increases survival, by up to 30%, in patients with cancer involvement of lymph nodes.

63. There have also been notable advances in palliative chemotherapy for patients who present with advanced disease or who develop recurrent cancer. Clinical trials have demonstrated that significant improvements in the quality and length of life compared with 10 years ago. These advances, as in other increasingly complex fields of medicine, demand the involvement of the specialist oncologist rather than the generalist.

64. Modern pathology can make a major contribution to improved bowel cancer outcomes by detailed examination of bowel cancer specimens and diligence in reporting vital prognostic criteria such as the number of lymph nodes and involvement of the cancer at the margin of the specimen. A median of 12 lymph nodes should be examined in order to state, with any degree of certainty, that there is no nodal involvement. Reporting a lower number of nodes may deny patients potentially-curative, adjuvant, chemotherapy and mis-inform on likely survival. Diligent pathology reporting is dependent upon specialist skill and increases the time that such examinations take.

65. In the UK, laparoscopic surgery for bowel cancer is in its infancy compared, for example, with Continental Europe, the United States and Australasia. In 2000 NICE recommended that open surgery should be the preferred operative method for patients with bowel cancer. However, there is now considerable evidence to support the use of laparoscopic techniques. Revised NICE guidance recommends that, with appropriate informed consent, the use of laparoscopic (including laparoscopically assisted) resection should be considered as an alternative to open resection providing the surgeon has completed appropriate training[44]. There is currently a shortage of trained specialist laparoscopic surgeons and recognized training programmes are in their infancy in the UK.

66. All of the above advances in care depend on the close working of a multiprofessional, multidisciplinary, team who consider the details and formulate a treatment plan for every patient with bowel cancer. The practice of multidisciplinary care is the basis of

improved bowel cancer management in the UK but is absolutely dependent on adequate resourcing.

67. Accurate population information on the process and outcome of treatment for patients with bowel cancer is thin and structured national audit is the only means by which the effect of new initiatives may be determined. National Audit also supports clinical governance and allows monitoring against standards.

68. Care of the bowel cancer patient typically takes place in a number of different locations, for example, it is possible for there to be an initial referral to one site, specialist imaging at a second, preoperative therapy at a third and surgery at a fourth. Conventional paper records are not suited to the provision of modern, networked cancer care and a single, electronic cancer record will optimise seamless care and avoid the risks inherent in moving paper records between hospitals.

Key Priorities

1. Colorectal cancer multidisciplinary teams focussing on diagnosis, treatment and palliative care should comply with the National Cancer Standards of 2005 by March 2009.

2. To set up a national MDT training programme for all colorectal cancer teams in Wales and to provide a suitable environment for successful MDT work.

3. Development and roll out of CANISC (Cancer Information System Cymru) should facilitate comparative clinical audit, monitoring compliance with the National Cancer Standards and provision of seamless care across different providers, e.g. cancer unit, cancer centre and palliative care.

Summary of findings and next steps

The following areas are summarised in Table 4.

4.1 Infrastructure

4.2 Surgery

4.3 Emergency Surgery

4.4 Laparoscopic Surgery and Enhanced Recovery Programmes

4.5 Rectal Cancer

4.6 Anal Cancer

4.7 Pathology

4.8 Chemotherapy

4.9 Radiotherapy in rectal cancer and interface with MRI, endorectal US and PET scanning

4.10 Oncology Research

Topic 4.1: Infrastructure		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) A single electronic cancer record for all patients to facilitate seamless network care.	Paper records and X-ray films moved between Trusts, resulting in delays in treatment, clinical risk from missing notes and poor communication between specialists in different Trusts. A national Welsh bowel cancer dataset and data collection system was under development (Cancer Information System Cymru - CANISC) as part of the Informing Healthcare Programme.	Trusts should implement the Cancer Information Systems Cymru (CANISC) in order to support the information requirements of colorectal teams in Wales.
b) All colorectal cancer MDTs to participate in a national bowel cancer service audit to benchmark the quality of care provided and to monitor the introduction of new management strategies. Optimal outcomes from the treatment of colon and rectal cancer using current best practice.	Only 7 of 13 Welsh Trusts that take part in the Association of Coloproctology of GB & I audit[45]. National Cancer Standards of 2005 required all MDTs to participate in both local Network level and all Wales clinical Audit[46].	The Cancer Information Framework Project should continue to advise on the roll out and training of CANISC to all colorectal MDTs with analysis of results, feedback to MDTs and closing of the audit loop. NHS Bodies should require participation in national audit by all MDTs that treat bowel cancer as set out in the National Cancer Standards using CANISC. Future planning of services should take account of quality clinical indicators defined by national clinical audit.

Topic 4.1: Infrastructure [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
c) Every patient with bowel cancer to be managed by a specialist MDT. d) Provision of adequate support for MDTs to allow for their efficient functioning.	There was a colorectal MDT currently in every Trust in Wales but it was not known if all bowel cancer cases were managed by the MDT.	Each Trust should ensure that: • all patients with a new diagnosis of bowel cancer are registered in CANISC • it's colorectal cancer MDT manages all patients with bowel cancer • it supports an adequately resourced and efficiently run team meeting. • it implements the CANISC MDT module.

Topic 4.2: Surgery		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) Waiting times for treatment to comply with National Cancer Standards.	National Cancer Standards of 2005 define the waiting times to start of definitive treatment. The SaFF process requires compliance with the targets from January 2007.	NLIAH, working with the Cancer Networks to ensure colorectal cancer MDTs implement and sustain best practice to achieve the cancer waiting times.

Topic 4.3: Emergency Surgery		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) Reduced mortality from emergency surgery.	UK data from the Association of Coloproctology Audit showed mortality of emergency surgery almost 1 in 5 – four times higher than after an elective operation. NICE Service Guidance and the National Cancer Standards of 2005 outline the services required. Very few units had an on-call rota for emergency bowel cancer surgery. It was not known how many patients admitted as emergencies were managed overnight by the on-call team and transferred to the MDT surgeon the following day.	CSCG to facilitate an all Wales audit of clinical teams operating on emergency cases in relation to NICE Service Guidance. Trusts to ensure availability of critical care beds in pre and post operative periods.
b) Increased availability of stenting for patients with left colon obstruction.	Availability of stenting was not known.	CSCG to facilitate an all Wales audit of availability of stenting.

Topic 4.4: Rectal Cancer

Outcomes required	2005 Baseline position	Next Steps
a) Clinical management plans to be tailored to individual patients by preoperative liver and pelvis imaging. b) Multidisciplinary management of all rectal cancer patients to be underpinned by preoperative imaging, high quality surgery and detailed histopathology. c) Minimal permanent stoma rates to be achieved by appropriate use of low anterior resection. d) The option of preoperative chemoradiotherapy should be considered in every case.	There was variability in relation to the methods and results of rectal cancer treatment. Permanent stoma rates and the use of neoadjuvant therapy were known to vary. Use of MRI and quality of reporting was unknown. Permanent stoma rates were generally unknown. Limited data was available from the Association of Coloproctology in GB and Ireland annual audits.	NLIAH to work with the CSCG Colorectal Steering Group to develop a training programme for MDT's to support patient management based on preoperative imaging (CT, MRI and EUS), surgery (TME and options for early and recurrent rectal cancer) and histopathology (methods and reporting). Networks to consider referral to a specialist MDT[47] within the Network for ultra low anterior resection, early rectal and recurrent pelvic cancer.

Topic 4.5: Anal Cancer

Outcomes required	2005 Baseline position	Next Steps
a) Network based specialist MDTs to manage patients with anal cancer as recommended by NICE.[48]	CSCG all Wales Audit of Anal Cancer[49] showed that only 26 cases per year were recorded with patients being managed in 17 hospitals. Of 23 oncologists 16 managed less than 3 patients over the 5 year period. Both staging investigations and data collection were inconsistent.	Each Cancer Network to identify one specialist MDT to coordinate care of patients with anal cancer probably based around an existing Colorectal team and including a sub-specialist gynaecologist with interest in HPV infection.
b) Improved staging with CT and MRI to be performed and reported by specialist radiologist.		
c) Adequate numbers of personnel and clinical resources to investigate, stage and treat patients within time frame recommended in the National Cancer Standards.	Time to radical radiotherapy treatment varied within Networks. Despite number of clinicians involved accrual rates clinical trials are up to 50%.	Sessional time/ job planning for no more than two clinical oncologists in each of the 3 cancer networks to manage patients with anal cancer and to discuss and supervise entry into appropriate clinical trials.

Topic 4.6: Laparoscopic surgery and enhanced recovery programmes		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) The controlled increase in availability of laparoscopic bowel cancer surgery. b) Improved quality of care for patients with laparoscopic surgery developed as part of an enhanced recovery programme providing faster recovery and shorter hospital stay.	Open rather than laparoscopic surgery was used for the treatment of colorectal cancer with laparoscopic surgery restricted to randomised controlled clinical trials as per NICE guidance published in 2000[50]. Laparoscopic bowel cancer surgery was carried out by a small number of surgeons in Wales with no central register or audit of these cases. There was no laparoscopic bowel cancer training or enhanced recovery courses in Wales.	The CSCG should advise NLIAH on implementation of a laparoscopic surgery training programme for colorectal cancer following the NICE technology appraisal of 2006. An all-Wales audit of all laparoscopic bowel cancer surgery should be undertaken using CANISC. A programme of visits to units with enhanced recovery programmes and study days in Wales for surgeons, anaesthetists, colorectal, theatre and ward nursing staff should be supported by NLIAH.

Topic 4.7: Pathology

Outcomes required	2005 Baseline position	Next Steps
a) Sufficient consultant histopathologists to provide a high quality pathology service to cancer MDTs. b) Access to specialist histopathologists for second opinion with difficult cases.	There was a national (UK-wide) manpower crisis in Histopathology with 11 of 56 Welsh posts vacant[51]. Specialists were in post in Swansea, Newport and Cardiff. There was no specialist gastrointestinal pathologist in North Wales.	Each Cancer Network to ensure a) MDTs have adequate histopathology input. b) the professional development of at least one specialist gastrointestinal consultant pathologist per Network.

Topic 4.7: Pathology [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
c) Pathology laboratory IT systems support on-screen template reporting of resection specimens according to the Royal College of Pathologists Minimum Datasets and allow seamless integration with CANISC.	Existing laboratory systems were inadequate and did not support state-of-the-art on-screen reporting. There was patchy local development by enthusiasts in a small number of laboratories with limited capacity for integration with other systems. Good products were becoming available commercially, licensed by the Royal College of Pathologists. These were available as "front end" applications that complement some existing generic Laboratory Information Management Systems [LIMS].	The Pathology Modernisation Project should continue to work with the Cancer Information Framework Project to ensure that the development of the all Wales LIMS takes account of cancer information requirements. Common software should facilitate data transfer between Cancer Units, Centres and WCISU using the infrastructure of CANISC.
d) All hospitals have appropriate facilities to support colorectal MDT working, including digital imaging. Availability of all-Wales telepathology system to facilitate diagnosis, second opinions, training and external quality assurance.	There was reasonable hardware support for MDTs in many hospitals. Telepathology networks were effective as evidenced by the all Wales Lymphoma Panel Service developed between Cardiff, Swansea and Bangor.	Cancer Networks need to ensure appropriate MDT facilities are available in all hospitals. Informing Health Care needs to support implementation of linked telepathology facilities for all Welsh histopathology laboratories.

Topic 4.7: Pathology [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
e) Training for consultant histopathologists in modern approaches to dealing with resection specimens in order to achieve high quality standards of reporting.	Training was last provided in 1997 for half of the consultants then working in Wales as part of the CROPS project. Data from some Trusts from the ACPGBI audit indicated that Quality standards, e.g. lymph node harvests were not being universally met.	Training for pathologists should be integral to MDT training as detailed in Table 4.4. Audit of pathology reporting should be undertaken using CANISC.
f) Access to specialist pathology investigation in relation to molecular diagnostics, integrated with laboratory genetics services.	An interim service for microsatellite instability was established in Cardiff jointly between UHW Histopathology and Institute of Medical Genetics.	Implementation of molecular diagnostics should be on an All-Wales basis to ensure high quality and value for money.

Topic 4.8: Chemotherapy

Outcomes required	2005 Baseline position	Next Steps
a) Sufficient numbers of appropriately trained Clinical & Medical Oncologists to support sub specialisation as recommended by the National Cancer Standards and NICE service guidance. b) Sufficient specialist registrars in Clinical and Medical Oncology to provide a pool of trainees for future consultant appointments. c) Adequately resourced chemotherapy day units (Pharmacists, Oncology Nurses, support staff). d) Clarity between Trusts and Cancer Centres about funding treatment and staff costs.	There were insufficient Clinical and Medical Oncologists to provide site specialised services across Wales. Cancer Networks were drawing up Action Plans for Colorectal Cancer services as a step towards ensuring compliance with Cancer Standards by March 2009. CSCG had established a Radiotherapy and Chemotherapy Advisory Group that have reviewed and updated the Non Surgical Oncology 10-year plan[52] . The updated Report[53] was published in 2006. Chemotherapy day units were reaching capacity. Clarity was required regarding planning responsibilities in relation to chemotherapy.	Cancer Networks to facilitate working arrangements so that Consultant cover is provided in Cancer Units. NHS Bodies to take forward the Welsh Assembly Government's 2006 Report on Demand and Capacity in Radiotherapy Each Network to review appropriateness of current chemotherapy service provision, patient numbers and clinical policies and on the basis of this calculate necessary capacity within chemotherapy day units.

Topic 4.8: Chemotherapy [continued]		
Outcomes required	**2005 Baseline position**	**Next Steps**
e) Appropriate use of effective drugs and timely reassessment of new chemotherapy agents by NICE and the All Wales Medicines strategy group (AWMSG).	CSCG was working with the Assembly Government, the Welsh Medicines Partnership and the Pharmaceutical NPHS to improve the process of implementation of new drugs into the NHS[54].	NHS Bodies supported by their regional Cancer Networks, to support implementation of national guidance from NICE and/or AWMSG.
f) Sufficient capacity within the Cancer Centres to deliver complex chemotherapy regimens and an IT infrastructure to allow the efficient prescribing of chemotherapy with audit against national guidelines.	The CSCG Radiotherapy and Chemotherapy Advisory Group was working to advise on service developments for chemotherapy.	Develop electronic links between CANISC and chemotherapy prescribing software to provide data transfer that will support all-Wales clinical audit.

Topic 4.9: Radiotherapy in rectal cancer		
Outcomes required	**2005 Baseline position**	**Next Steps**
a) Research into appropriate use of radiotherapy - clinical trials of adjuvant and palliative radiotherapy. b) Review of all rectal cancer patients pre-operatively by specialist MDTs. (see surgery for rectal cancer above)	In some centres, treatment was planned on the basis of tumour extent on high resolution MRI scan to enable high risk patients to be selected for long course pre-operative (Chemo-) radiotherapy.	Training needs of radiologists in undertaking and interpretation of high resolution phased array MRI scans of the pelvis should be assessed. Upgrading or cross referral to ensure MRI scans of the appropriate quality are available for all rectal cancer patients. Training should also be provided for MDT decision making in rectal cancer.
c) Endorectal ultrasound used for the evaluation of T stage in early lesions where local excision is being contemplated.	There was variable use of endorectal ultrasound which is available in one site for each of South East and South West Wales Cancer Networks.	All Wales clinical audit to be used to ensure endorectal ultrasound is used appropriately and available in all three cancer centres.
d) The use of PET scanning to assess recurrent disease and metastatic cancer.	There was no PET scanning facility in Wales	Welsh Assembly Government has committed to providing two PET scanners in Cardiff. NHS Bodies need to ensure that the evidence base underpinning the indications for PET scanning is regularly reviewed and acted upon.

Topic 4.10: Oncology Research

Outcomes required	2005 Baseline position	Next Steps
a) Each patient to be assessed for suitability for clinical trial entry. b) Infrastructure support to facilitate trial entry. An adequate number of research nurses and data management staff provided through the Welsh Cancer Trials Network. c) Sessional time for clinical trial work needs to be recognised in consultant oncologist's job plan. d) Facility for oncology trainees in Wales to undertake work leading to a higher degree.	The National Cancer Standards of 2005 required all patients to be assessed for trial entry. Support for clinical trial entry was via the Wales Cancer Trials Network (WCTN) who received funding from the Wales Office of Research and Development (WORD). There was variable trial entry in colorectal cancer across Wales. In 2004 there were 8 national trials open and active in Wales. Funding for specialist registrars to undertake research for either MD or PhD was not available.	MDTs should access training in communicating about clinical trials and raising awareness of trial portfolio. WCTN to discuss with Trust Chief Executives recognition of time for clinical trial work in consultant job plans. WORD to continue to support oncology research by providing funding for the WCTN, the Wales Cancer Bank and the Wales Gene Park through existing grant arrangements.

Topic Area 5 – Palliative Care

Topic Lead: Dr Andy Fowell, Consultant Palliative Care Physician, North West Wales NHS Trust, and Chair CSCG Steering Group for Specialist Palliative Care. Group members are acknowledged in Appendix 1.

Advisers:

CSCG Steering Group for Specialist Palliative Care

Introduction

69. Palliative Care[55] is an integral part of all health professional's work and as such is an important part of the care of some patients with bowel cancer. Palliative care needs may arise at any part of the patient's journey. Health professionals need to be able to recognise these needs and when there is a need to refer on to a specialist team. Whilst much of a patient's care takes place in the community under the supervision of General Practitioners and District Nurses, specialist services exist to provide input to those patients requiring enhanced input, as well as providing support, advice and educational resources to the generalist. Specialist Palliative Care should be available to all who require it.

70. The palliative care needs of bowel cancer patients are similar to other cancer groups, though there may be need for specialist skills in stoma care and dealing with the effects of local recurrence. Access to radiotherapy and anaesthetic pain relief skills are important. The need to address social care issues and to utilise the skills of the members of the wider team are pre-requisites of good care.

71. The Welsh Assembly Government set out its policy for palliative care in *A Strategic Direction for palliative care Services in Wales,* published in 2003. From 2003 to 2007, £10M was invested to develop and enhance palliative care provided by hospices including those in the voluntary sector. New Opportunities Fund provided £4.5M to

improve the facilities in which palliative care patients are cared for. A needs assessment of adult specialist palliative care for cancer patients in Wales was undertaken by CSCG in 2006 and the Welsh Assembly Government carried out a baseline review of services in 2007. The Welsh Assembly Government has committed £2 million a year from 2007-08 for voluntary services.

72. Since 2000, the Welsh Minimum Standards have been applied to Specialist Palliative Care teams and there has been evidence of increased membership of multidisciplinary teams and progress in auditing services. The new National Cancer Standards of 2005 require the core membership of all multidisciplinary teams to include a palliative care physician or nurse who is a member of a specialist palliative acre team. The National Cancer Standards for Specialist Palliative Care take account of the NICE guidance on Supportive and Palliative Care.

73. The development of the regional cancer networks has led to the formation of Palliative Care networks which have produced costed development plans in line with national guidance.

74. The CSCG formed an all Wales Advisory Group for Specialist Palliative Care in 2005. The need for improved access to psychological support for cancer patients has been highlighted and accepted by the CSCG as an important issue to address.

73. Work has been on going across Wales to improve the care of the dying patient in all care settings with the all Wales Care Pathway for the Last Days of Life being endorsed by the Welsh Assembly Government in 2006[56]. A Wales wide audit of use of the care pathway as well as the quality of documentation was completed in 2006.

74. *Designed to Tackle Cancer in Wales* (2006) calls for the integration of palliative care services, the need for patients to have a say in their place of care, and the planning of palliative care services and end of life care to be to a standard expected by the Welsh Care Pathway for the Last Days of Life.

75. The Health and Social Services Committee report on Cancer Services for the People of Wales[57] made a number of recommendations which are currently being taken forward.

76. There is a strong research base in Wales and a world leading medical educational programme.

Key Priorities

- CANISC should be further developed to support the collection of the palliative care dataset which can be accessed by all clinicians providing care in primary, secondary, tertiary care or in the voluntary sector.

Summary of findings and next steps

The key components of staffing, access to 24 hour services, education, research and patient representation are summarised in Table 5.

Table 5 – Topic Summary – Palliative Care

Outcomes required	2005 Baseline position	Next Steps
a) Fully staffed Specialist Palliative Care teams.	National Cancer Standards for Specialist Palliative Care in relation to Cancer Services had been published in 2005. Each Cancer Network had worked with its palliative care advisory group to prepare a costed network development plan for palliative care. An all Wales Needs Assessment and baseline review had been completed[58]. Many posts were funded on short term charity or Assembly Government funding.	To work towards the integration of voluntary and statutory providers of palliative care. Secure funding to continue beyond that provided by the present 3-year Assembly Government funding. The Welsh Assembly Government to increase the Specialist Registrar New Training Numbers. NHS Bodies to support an increased role for AHPs in cancer care. Cancer Networks to support compliance to the National Cancer Standards for Specialist Palliative Care by 2009.
b) Access to 24 hr services.	The Welsh Out of Hours Project is ensuring access to drugs and oxygen for critically ill patients.	There is a need to explore different models of care and match English End of Life Initiative. Work with Macmillan should consider how to implement the Gold Standards Framework as appropriate to Wales.

Outcomes required	2005 Baseline position	Next Steps
c) Increased provision of courses addressing the educational needs of the palliative care workforce.	There was a Diploma and Certificate level course based in Cardiff. Nursing modules and courses were available.	NLIAH to support a coherent approach to Education and Development of courses for Allied Health Professionals.
d) Development of evidence based research.	Pilot studies are in progress or completed and the WCTN Units were involved in the development of protocols	Support and develop research capacity in Wales.
e) Increased patient representation within the Cancer Networks.	Macmillan Cancer Support had funded a Patient User Involvement Programme in each cancer network.	NHS Bodies to develop further patient involvement within the cancer networks.

APPENDIX 1 – Acknowledgements

The CSCG Bowel Cancer Framework Sub Group and Editorial Group

Mrs Fiona Peel, Chair of CSCG and Sub Group

Mr Nicholas Carr, Consultant Surgeon, Swansea NHS Trust and Chair of CSCG Colorectal Cancer Steering Group – lead Topic 3

Dr Hilary Fielder, Director of Screening Services, Velindre NHS Trust – lead Topic 2

Dr Andy Fowell, Consultant Palliative Care Physician, North West Wales NHS Trust, and Chair CSCG Steering Group for Specialist Palliative Care – lead Topic 5

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Mr Jeffrey Stamatakis, Consultant Surgeon, Bro Morgannwg NHS Trust, member of the CSCG Colorectal Cancer Steering Group, and Chair of the Cancer Information Framework Project Board - lead Topic 4

The Editorial Group further acknowledge the essential contribution and support of the following individuals or organisations

<u>Introduction to Bowel Cancer</u>

Supporting papers:

Dr John Steward, Welsh Cancer Intelligence and Surveillance Unit

Projection of incidence and mortality for cancer of the large bowel to 2015, WCISU Occasional Report NO. S06/01

Dr Iain Robbe,

Cancer Scenario: Colorectal Cancer

<u>Topic 1 Prevention</u>

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Caerphilly

Bridgend

Swansea

Wrexham

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Topic 2 Patient Access to Services

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Dr Shantini Paranjothy, Specialist Registrar in Public Health

Mrs Nicola John, Pharmaceutical Public Health, National Public Health Service for Wales

Supporting paper:

2.1 Access to diagnostic services for bowel cancer services
Dr Hilary Fielder, Director Screening Services, Velindre NHS Trust.
2.2 Surveillance by colonoscopy for patients at higher risk than the general population
Dr Nicola John, Consultant in Pharmaceutical Public Health, NPHS, Velindre NHS Trust

Topic 3 Diagnosis, pre-operative staging

Dr Miles Allison, Lead Clinician for the Endoscopy Programme, NLIAH

Miss Ruth Lawler, Nurse Manager, Screening Services, Velindre NHS Trust

Ms Claire Lloyd, Senior Service Development Manager, NLIAH

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Dr Neil Warren, Manager, Welsh Institute for Minimal Access Therapy

Dr Tudor Young, Consultant Radiologist, Bro Morgannwg NHS Trust, and member of CSCG Colorectal Steering Group

Supporting papers:

3.1 *Current Options for the Radiological Diagnosis of Colorectal Cancer and Colonic Polyps*
Mr Tudor Young, Consultant Radiologist, Princess of Wales NHS Trust

3.2 Interim Report from Innovations in Care Endoscopy Programme 2004-05
Dr Miles Alison, Lead Clinician for the Endoscopy Programme
Ms Claire Lloyd, Manager Endoscopy Programme
3.3 Position statement for nurse and AHP endoscopy training
Mrs Ruth Lawler, Senior Nurse, Screening Services
3.4 Outline business case for an endoscopy training programme in Wales
Dr Miles Alison, Gwent NHS Trust
Dr Jill Swift, Cardiff and Vale NHS Trust,
Dr Nick Carr, Swansea NHS Trust
Dr Neil Warren, Manager, Welsh Institute for Minimal Access Therapy

Topic 4 Treatment

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Prof. Geraint Williams, Consultant Pathologist, Cardiff & Vale NHS Trust, and member of the CSCG Colorectal Steering Group

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Mr Gareth Popham, User Involvement Facilitator, South West Wales Cancer Network

APPENDIX 2 – Terms of Reference

The Cancer Services Co-ordinating Group was asked by the Welsh Assembly Government [Welsh Assembly Government] to submit, for consideration, a proposed national framework for development and co-ordination of measures which will help prevent and screen for bowel cancer, improve its detection, diagnosis and treatment.

The group has worked within the following terms of reference

- Chair of CSCG to establish an advisory task and finish group comprising relevant specialists to advise Welsh Assembly Government on developments for bowel cancer in Wales over the next 5 years.

- To ensure a methodology that was as inclusive as possible within the time frame and that included both representation from the NHS and Welsh Assembly Government.

- To ensure that recommendations took due note of:
    - similar initiatives in progress in the UK.
    - Welsh Assembly Government policy developments including new Cancer Standards and NICE Service Guidance.

- To determine outline costs where adequate information is available.
- To ensure a draft report is submitted to Welsh Assembly Government by the end of March 2005.

APPENDIX 3 – Topic Key Priorities

Topic 1 Public Awareness and Prevention

The immediate priority is to develop easily accessible decision aids for the public so that people can be aware of early alarm symptoms and request professional advice without delay. This will build on the current emphasis on the importance of a healthy diet and exercise exemplified by Health Challenge Wales.

Topic 2 Patient Access to services

To establish a bowel cancer screening programme.

Topic 3 Diagnosis and pre-operative staging

1. The immediate priority is the introduction of a structured and accredited training programme for flexible sigmoidoscopy and colonoscopy as has been established in England. This programme should include the recruitment of nurses and AHP's. This is integral to the implementation of the screening programme for bowel cancer.

2. Recruitment of radiology personnel and capacity problems associated with lack of equipment need to be addressed to deal with the increased use of imaging in the diagnosis, staging and follow up of colorectal cancer.

Topic 4 Treatment

1. Colorectal cancer multidisciplinary teams focussing on diagnosis, treatment and palliative care should comply with the National Cancer Standards of 2005 by March 2009.

2. To set up a national MDT training programme for all colorectal cancer teams in Wales and to provide a suitable environment for successful MDT work.

3. Development and roll out of CANISC (Cancer Information System Cymru) should facilitate comparative clinical audit, monitoring compliance with cancer standards and provision of seamless care across different providers, e.g. cancer unit, cancer centre and palliative care.

4. CANISC should further developed to support a palliative care dataset which can be accessed by all clinicians providing care in primary, secondary, tertiary care or in the voluntary sector.

FOOTNOTES & REFERENCES

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[30] Revised Substance Misuse Strategy expected publication date 2008

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