Rhaglen Endosgopi Cenedlaethol
National Endoscopy Programme

Interim Guidance for the Risk Stratification of Patients on the Surveillance Waiting List

For Welsh Health Boards

Version 1

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Core Writing Group: Dr Sunil Dolwani (NEP), Dr Sunnia Gupta (Cardiff University Division of Population Medicine), Dana Knoyle (NEP), Hattie Cox (NEP)
Review Group: Dr John Green (NEP), Dr Phedra Dodds (NEP), Dr Neil Hawkes (NEP), Hayley Heard (NEP)
Additional Contributors: Dr Tom Pembroke (Consultant Hepatologist, Cardiff and Vale UHB)

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INTRODUCTION

Since the beginning of March 2020 the COVID-19 pandemic has caused serious delays for endoscopy services and, for many Health Boards (HBs), capacity has been reduced with the majority of surveillance work being paused as services focus on USC and emergency work. With some historic backlog of surveillance prior to the pandemic, which continues to increase, this risk stratification guidance has been developed to aid prioritisation of the surveillance waiting list.

Please note:

- This guidance is only relevant for use **in surveillance patients during the pandemic** and is not intended for prioritisation of other waiting lists.
- There is also a pre-requisite for endoscopy services to have **implemented the BSG post-polypectomy and post-colorectal cancer resection surveillance guidelines (2020) prior** to using this guidance.

GENERAL PRINCIPLES

In general, there should not be any reason to remove a patient from the waiting list unless this has been explicitly discussed with the patient and reasoning for this has been discussed. Patient preference and full understanding must be obtained and confirmed. Reasoning for removal from the surveillance waiting list could be: as a result of either patient preference or a change in the patient's condition, change in national/international guidelines or change in circumstances from the time of being added to the waiting list, making the procedure inappropriate or unfeasible.

All decisions (mostly prioritisation/deferment rather than removal) should include communication to the patient's primary care/medical team.

Key points to remember:

- **No patient's care should be delayed** by the validation process: those HBs that have started to clinically validate their waiting list should continue.
- **Arrangements to support patients** who change their mind about having their endoscopic procedure or would like to defer the procedure when offered after the initial conversation must be in place.
- **Appropriate consultation** to meet a patient's needs: remote or face to face.
- **Narrowing of health inequalities:** e.g. support for people with communication difficulties, including those whose first language is not English; appropriate arrangements for those with a learning or behavioural difficulty or a mental health problem that may impact on their capacity to make an informed decision.

(Adapted from NHS England – C0760 guidance on clinical validation of surgical waiting lists link here)

The aim is to make the best mutually agreed decisions with patients and is not an exercise to reduce numbers on waiting lists.

Waiting lists should be validated in two or three stages:

1. Technical validation (administrative and clinical): ensure the waiting list is accurate and up to date.
2. Patient discussion: patients are contacted by a locally determined appropriate member of the team to establish their wishes.
3. Remote clinical consultation: for patients who wish to discuss their situation in more detail using shared decision making (SDM).

RISK STRATIFICATION PROCESS

This risk stratification guidance is based on a comprehensive assessment of risk for an individual on a surveillance waiting list based on -

- The indication for the procedure (inherent risk of the condition)
- Length of time overdue
- The health status of the patient (Comorbidity and COVID consequences/risk)
- Patient preference

The assessment should be undertaken by a clinician/appropriate members of the team, using the tables below, with pre-populated scores. The higher the score the higher the risk/priority.

- **Stage 1** is to determine each patient's overall surveillance priority by adding together a score for their indication for the surveillance procedure (Table 1) and a score for the length of time that they are overdue their procedure (Table 2). A higher score equals a higher priority.
- **Stage 2** includes contacting patients (in order of their surveillance priority score from Stage 1) to determine their comorbidities (Table 3) and COVID risk score (Table 4), and using this to understand their overall health status. A higher health status score equals a higher risk.
- **The overall additive score from Tables 1 and 2 are the primary prioritisation mechanism for practical use prior to using Tables 3 and 4 which relate to feasibility and appropriateness and then table 5 which is patient preference.**
- The flowchart on page 4 provides a step by step process for you to follow.

RISK STRATIFICATION PROCESS FLOWCHART

Prior to undertaking the process ensure that the new BSG surveillance guidelines (2020) have been applied for any patients on the surveillance waiting list post-polypectomy or post colorectal cancer resection.

STAGE 1 – OVERALL SURVEILLANCE PRIORITY SCORE

Collate list of all patients that are overdue their surveillance procedure

↓

Undertake administrative and clinical validation to ensure waiting list is accurate and up to date

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Use the indications for surveillance procedures (Table 1) to assign corresponding priority score for each patient and capture in Table 6

↓

Using the patient's length of time overdue (Table 2), assign a corresponding score and capture in Table 6

↓

Add the two scores together to provide overall surveillance priority score

↓

Repeat this process for all patients that are overdue their surveillance procedure and capture in Table 6

↓

Order the list of patients as per their overall surveillance priority score (from highest to lowest)

↓

Contact patients to discuss their procedure, starting with those with the highest overall surveillance priority score*

↓

STAGE 2 – COMORBIDITY + COVID RISK SCORE & OUTCOME

Work through Tables 3 and 4 with the patient to understand their comorbidity and COVID risk and capture scores in Table 6

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Agree with the patient whether to proceed or defer their procedure (taking into account Stage 1 and Stage 2 scores)

↓

Document the agreed outcome in Table 6

↓

Send a letter to the patient detailing the agreed way forward (templates in Appendix 2 can be used to help with this process)

* We appreciate that contacting each patient will be a time consuming process, however current guidance from NICE regarding arranging planned care during the pandemic recommends the best strategy is to share decision making with patients (NICE - COVID-19 rapid guideline). Welsh Government and BSG also recommend that patients are fully involved in decision-making processes when endoscopic tests are being considered (BSG - Patient Experience GI Endoscopy, Welsh Government - Prudent Healthcare).

TABLE 1 – INDICATION FOR THE SURVEILLANCE PROCEDURE

This is a condensed version of the table in order to facilitate its use. The full version of the table (including the evidence base and risks) can be found in Appendix 1 with references.

REASON FOR SURVEILLANCE	SUGGESTED SURVEILLANCE INTERVAL	SCORE
Post polypectomy and post cancer resection		
High risk findings (two or more premalignant polyps including at least one advanced colorectal polyp OR five or more premalignant polyps)	3 years	**3**
Polyps but no high risk findings (10 years younger than lower BSW age limit)	5 years	**2**
LNPCP with histological R0 en Bloc Excision	Yes: 3 years No: Site check 2-6 months then after further 12 months	**Yes – 2** **No - 3**
Previous colorectal cancer	1 year	**3**
Polyp cancer follow up		
Piecemeal resection of polyp – histology confirming polyp cancer	3 month and then 12 month check colonoscopy, if normal then 3 year surveillance	**4**
Piecemeal resection of polyp – histology confirming polyp cancer – further surgery for polyp cancer	12 month check colonoscopy and then 3 year surveillance	**3**
Resected En Bloc (endoscopic or surgical)	If R0 according to pathologist- • 3 years If R1 according to pathologist – • Individualised in consultation with the surgical team	**R0 – 3** **R1 - 4**
Family history/hereditary colorectal cancer		
Lynch syndrome:		**5**
• MLH2 and MSH2 variants	2 yearly from 25 years old	
• MSH6 and PMS2 variants	2 yearly from 35 years old	
Moderate risk (one FDR diagnosed with CRC under 50 years or, two FDRs (in first degree kinship) diagnosed with CRC at any age, of whom the patient under assessment is an FDR of at least one affected individual)	Colonoscopy at 55 years old – • Polyps: surveillance as per post-polypectomy guidelines • Normal: National screening	**2**
High risk (families with a cluster of at least three affected FDRs with CRC diagnosed at any age, across at least two generations, of whom the patient under assessment is an FDR of at least one affected individual)	5 yearly from 50 years old until 75 years old	**3**
Familial adenomatous polyposis (FAP)		
• APC pathogenic variant carriers	• Colonoscopy: 12 to 14 years old, 1-3 yearly depending on phenotype • Gastroscopy and duodenoscopy: 25 years old, as per Spigelman classification • Sigmoidoscopy/pouchoscopy: From time of colectomy, 1-3 yearly dependent on phenotype	**5**
• Individuals with an FDR with a clinical diagnosis of FAP (i.e. "at-risk") and in whom a constitutional pathogenic variant has not been identified	• Colonoscopy: 12 to 14 years old, 5 yearly until national screening age • Gastroscopy and duodenoscopy: Commence only if clinical diagnosis made of colorectal polyposis phenotype, as per Spigelman classification	**4**

MUTYH-associated polyposis (MAP)	• Colonoscopy: 1 yearly from 18 to 20 years old • Gastroscopy and duodenoscopy: From 35 years old, as per Spigelman classification	**5**
Juvenile polyposis syndrome (JPS)	• SMAD4 and BMPR1A pathogenic variant carriers: From 15 years old, 1-3 yearly dependent on phenotype • SMAD4 pathogenic variant carriers: From 18 years old, 1-3 yearly dependent on phenotype • BMPR1A pathogenic variant carriers: From 25 years old, 1-3 yearly dependent on phenotype	**5**
Individuals with an FDR with a clinical diagnosis of FAP and in whom a constitutional pathogenic variant has not been identified	From 12 to 14 years old, 5 yearly until national screening age	**4**
Peutz-Jeghers syndrome (PJS)	From 8 years old, small bowel surveillance 3 yearly.	**5**
Serrated polyposis syndrome		
:Affected individuals	From age of diagnosis, 1-2 yearly until 75 years	**5**
:FDRs of affected individuals	40 (or 10 years earlier than the index case) years old, 5 yearly until age 75 years	**2**
IBD surveillance:		
Low risk	5 years	**3**
• Extensive but quiescent ulcerative colitis or		
• Extensive but quiescent Crohn's colitis or		
• Left-sided ulcerative colitis or Crohn's colitis of a similar extent		
Intermediate risk	3 years	**4**
• Extensive ulcerative or Crohn's colitis with mild active inflammation that has been confirmed endoscopically or histologically or		
• Post-inflammatory polyps or		
• Family history of colorectal cancer in a first-degree relative aged 50 years or over		
High risk	1 year	**5**
• Extensive ulcerative or Crohn's colitis with moderate or severe active inflammation that has been confirmed endoscopically or histologically or		
• Primary sclerosing cholangitis (including after liver transplant)		
• Colonic stricture in the past 5 years		
• Any grade of dysplasia in the past 5 years		
• Family history of colorectal cancer in a first-degree relative aged under 50 years		
• Dysplasia/cancer at time of pouch surgery PSC		
• Type C mucosa of pouch (persistent atrophy & severe inflammation)		
Upper GI		
Barrett's oesophagus	Patients with LGD should have a repeat endoscopy in 6 months' time. If LGD is found in any of the follow up OGDs and is confirmed by an expert GI pathologist, the patient should be offered endoscopic ablation therapy after review by the specialist MDT. If ablation is not undertaken, 6-montly surveillance is recommended	**LGD SURV - 3** **HGD AFTER THERAPY* - 4**
• Shorter than 3 cm, with intestinal metaplasia, but no dysplasia	3-5 years	2
• Longer than or equal to 3 cm – no dysplasia	2-3 years	2
Varices		
• Grade I Varices	1 year	**4****
Risk factors for gastric cancer:	High risk CAG: 3 yearly endoscopic surveillance	**2**
• Polyposis		
• Extensive gastric atrophy		
• Extensive gastric intestinal metaplasia		

***Ablation therapy of HGD in Barrett's should be categorised as Priority 1 / suspected cancer and not a surveillance procedure**

****Clinical condition of the patient in cases of recent bleed/banding etc. may necessitate a higher score of 5 and will be up to treating clinician recommendation**

TABLE 2 – LENGTH OF TIME OVERDUE

This table indicates that any patients that are 6 months or more past their intended surveillance procedure date are the highest priority. **The rationale for not adding a point for every month that a patient is overdue past 6 months is because we do not want the length of time overdue to outweigh their indication risk score in Table 1.**

Length of Time Overdue	Score
<1 month	1
1-3 months	2
>3 but < 6 months	3
>6 months	4

TABLE 3 – THE PATIENT'S OVERALL HEALTH AND COMORBIDITY

The corresponding score should be added for each comorbidity that the patient may have. **Please see note below the table regarding age adjustment.** Charlson Comorbidity Index

Age-adjusted charlson comorbidity index (N = 567)

Score	Comorbidity	n (%)
1	Diabetes mellitus without end-organ damage	27 (5%)
	Cerebrovascular disease	10 (2%)
	Myocardial infarction	14 (2%)
	Congestive heart failure	0 (0%)
	Peripheral vascular disease	9 (2%)
	Dementia	2 (0.4%)
	Chronic pulmonary disease	55 (10%)
	Connective tissue disease	37 (7%)
	Peptic ulcer disease	16 (3%)
	Mild liver disease	5 (1%)
2	Diabetes mellitus with end-organ damage	2 (0.4%)
	Moderate/severe renal disease	0 (0%)
	Hemiplegia	0 (0%)
	Solid tumor without metastasis (exclude if >5 years from diagnosis)	32 (6%)
	Leukemia	2 (0.4%)
	Lymphoma	9 (2%)
3	Moderate/severe liver disease	0 (0%)
6	Metastatic solid tumor	0 (0%)
	AIDS (not just HIV positive)	0 (0%)

Age adjustment: For each decade after 40 years, add 1 point to total score (i.e. 1 point for age group 50–59 years, 2 points for age group 60–69, etc)

TABLE 4 - RISK OF COVID AND POTENTIAL CONSEQUENCES

BMA - COVID-19 risk assessment tool.

Risk factor	Indicator	Adjustment
Age	>50	1
	>60	2
	>70	4
	>80	6
Sex at Birth	Female	0
	Male	1
Ethnicity	Caucasian	0
	Black African descent	2
	Indian Asian descent	1
	Filipino descent	1
	Other (including Mixed race)	1
Diabetes and Obesity	(Type 1 or Type 2) uncomplicated*	1
	(Type 1 or Type 2) complicated*	2
	BMI≥35kg/m^2	1
Cardiovascular disease	Angina, previous MI, stroke or cardiac intervention	1
	Heart failure	2
Pulmonary disease	Asthma	1
	Non-Asthma chronic pulmonary disease	2
	Either above requiring oral corticosteroids in previous year	1
Malignant neoplasm	Active malignancy	3
	Malignancy in remission	1
Rheumatological conditions	Active treated conditions	2
Immunosuppressant therapy	Any indication	2
Interpretation	**Score**	
Low Risk	<3	
Medium Risk	3-5	
High Risk	≥6	

*Complicated diabetes = presence of microvascular complications or HbA1c≥64mmol/mol

TABLE 5 – PATIENT PREFERENCE

Patient preference		Category
Discussed and agreed with the patient:	Yes - proceed now*	A
	Yes – proceed but defer time	B - communicate with GP and document reasons for deferral – maintain on waiting list
	No – inappropriate/unfeasible	C - communicate with GP and document reasons for taking off waiting list
Patient preference to come off waiting list after discussion of pros and cons		D - communicate with GP and document reasons for taking off waiting list

*If a patient develops new symptoms whilst waiting for their procedure and contacts the endoscopy unit (as instructed in Letter 1 Appendix 2), a Standard Operating Procedure (SOP) must be in place to ensure that it is dealt with appropriately (e.g. the coordinator discusses with the endoscopy lead who decides on the way forward).

TABLE 6 – FINAL PRIORITISATION SPREADSHEET

An Excel spreadsheet has been developed in which teams should record the scoring from the process above.

USE OF FIT TO TRIAGE PATIENTS ON THE SURVEILLANCE WAITING LIST

We are aware of some use of the Faecal Immunochemical Test (FIT) for triage of patients on a Colonoscopy waiting list. Currently for the post-polypectomy and post colorectal cancer cohort there is little evidence to suggest that this would be a helpful strategy for this surveillance patient cohort and some evidence that it would miss colorectal cancers (Robbins et al, 2018). Therefore, we currently cannot recommend its use in this group of patients.

USE OF FIT IN LYNCH SYNDROME PATIENTS ON SURVEILLANCE

In relation to the use of FIT for Lynch syndrome patients on a surveillance waiting list, we are aware of a service evaluation pilot being undertaken in England through the Southern England screening hub with the intention to assist in triage of patients in this very high risk cohort. As far as the National Endoscopy Programme (NEP) are aware the evidence for use of FIT to guide surveillance in this group is still emerging, though this pilot may help in gathering useful data on its utility. If your organisation is participating in this pilot then you will be aware of the process involving requesting FIT kits from the Southern England hub as well as sending copies of colonoscopy and histology results to them. Our understanding is that the pilot is running until December 2020. We consider Lynch syndrome patients to be the highest risk category on the surveillance waiting list and they should be appropriately prioritised and procedure undertaken as soon as possible and as close to their surveillance interval as possible. The implications for patients with Lynch syndrome being overdue for surveillance are far more adverse than almost any other category.

SUPPLY OF FIT TESTING KITS

Services have currently informed us that there is a degree of challenge in the supply of FIT kits across the UK due to supplier issues. If this is a local constraint then it would be helpful to prioritise use of FIT to areas where there is stronger evidence for its use. If your HB does intend to use FIT for any groups of cases on your surveillance waiting list then please ensure that the appropriate risk stratification as above has already been applied to them.

APPENDIX 1: EVIDENCE BASE FOR TABLE 1 PRIORITY SCORING

REASON FOR SURVEILLANCE	EVIDENCE BASE AND RISKS	SUGGESTED SURVEILLANCE INTERVAL	SCORE
Post polypectomy and post cancer resection			
• High risk findings (two or more premalignant polyps including at least one advanced colorectal polyp OR five or more premalignant polyps)	Rutter MD, East J, Rees CJ, et al. British Society of Gastroenterology/Association of Coloproctology of Great Britain and Ireland/Public Health England post-polypectomy and post-colorectal cancer resection surveillance guidelines. Gut 2020;69:201–223. doi:10.1136/gutjnl-2019-319858	3 years	**3**
• Polyps but no high risk findings (10 years younger than lower BSW age limit)		5 years	**2**
• LNPCP with histological R0 en Bloc Excision		Yes: 3 years No: Site check 2-6 months then after further 12 months	**Yes: 2** **No: 3**
• Previous colorectal cancer	**76.9% (10/13) of postoperative colorectal cancers occurred within the first 2 years**. Wang T, Cui Y, Huang W-S, et al. The role of postoperative colonoscopic surveillance after radical surgery for colorectal cancer: a prospective, randomized clinical study. Gastrointest Endosc 2009;69:609–15.	1 year	**3**
Polyp cancer follow up			
Piecemeal resection of polyp – histology confirming polyp cancer	**Recurrence rate for malignant polyps:33.3% (not annual risk)** Seo GJ, Sohn DK, Han KS, et al. Recurrence after endoscopic piecemeal mucosal resection for large sessile colorectal polyps. World J Gastroenterol. 2010;16(22):2806-2811. doi:10.3748/wjg.v16.i22.2806 M**ean risk of recurrence for non- pedunculated polyps 20% (95%CI 16%–25%**). Belderbos T, Leenders M, Moons L, et al. Local recurrence after endoscopic mucosal resection of nonpedunculated colorectal lesions: systematic review and meta- analysis. Endoscopy 2014;46:388–402.	3 month and then 12 month check colonoscopy, if normal then 3 year surveillance	**4**
Piecemeal resection of polyp – histology confirming polyp cancer – further surgery for polyp cancer		12 month check colonoscopy and then 3 year surveillance	**3**
Resected En Bloc (endoscopic or surgical)	**Mean risk (not annual risk) of recurrence 3% (95%CI 2%–5%)**. Belderbos T, Leenders M, Moons L, et al. Local recurrence after endoscopic mucosal resection of nonpedunculated colorectal lesions: systematic review and meta- analysis. Endoscopy 2014;46:388–402.	If R0 according to pathologist- • 3 years 3 If R1 according to pathologist – • Individualised in consultation with the surgical team 4	**R0: 3** **R1: 4**
Family history/hereditary colorectal cancer			
Lynch syndrome:	Monahan KJ, Bradshaw N, Dolwani S, et al. Guidelines for the management of hereditary colorectal cancer from the British Society of Gastroenterology (BSG)/Association of Coloproctology of Great Britain and Ireland (ACPGBI)/ United Kingdom Cancer Genetics Group (UKCGG). Gut 2020;69:411–444. doi:10.1136/gutjnl-2019-319915		**5**
• MLH2 and MSH2 variants		2 yearly from 25 years old	

• MSH6 and PMS2 variants			2 yearly from 35 years old	
Moderate risk (one FDR diagnosed with CRC under 50 years or, two FDRs (in first degree kinship) diagnosed with CRC at any age, of whom the patient under assessment is an FDR of at least one affected individual)	**FDR with CRC: 2.25 (95% CI = 2.00-2.53); >1 relative with CRC: 4.25 (95% CI = 3.01–6.08); relative diagnosed with CRC before age 45: 3.87 (95% CI = 2.40–6.22**).Johns LE, Houlston RS. A systematic review and meta-analysis of familial colorectal cancer risk. Am J Gastroenterol. 2001 Oct;96(10):2992-3003. doi: 10.1111/j.1572-0241.2001.04677.x. PMID: 11693338.		Colonoscopy at 55 years old – • Polyps: surveillance as per post-polypectomy guidelines • Normal: National screening	**2**
High risk (families with a cluster of at least three affected FDRs with CRC diagnosed at any age, across at least two generations, of whom the patient under assessment is an FDR of at least one affected individual)			5 yearly from age 50 years old until 75 years old	**3**
Familial adenomatous polyposis (FAP)				
• APC pathogenic variant carriers	**FAP to age of 21: 7% cancer risk; FAP to age 50: 93%** Gupta S, Provenzale D, Llor X, et al. NCCN Guidelines Insights: Genetic/Familial High-Risk Assessment: Colorectal, Version 2.2019. J Natl Compr Canc Netw. 2019 Sep 1;17(9):1032-1041. doi: 10.6004/jnccn.2019.0044. PMID: 31487681.	**A pathogenic APC mutation has almost 100 % penetrance toward the development of colonic polyposis. Colorectal cancer invariably develops in untreated FAP patients at a mean age of 36 years.** Septer, S., Lawson, C.E., Anant, S. et al. Familial adenomatous polyposis in pediatrics: natural history, emerging surveillance and management protocols, chemopreventive strategies, and areas of ongoing debate. Familial Cancer 15, 477–485 (2016). https://doi.org/10.1007/s10689-016-9905-5	• Colonoscopy: 12 to 14 years old, 1-3 yearly depending on phenotype • Gastroscopy and duodenoscopy: 25 years old, as per Spigelman classification • Sigmoidoscopy/pouchoscopy: From time of colectomy, 1-3 yearly dependent on phenotype	**5**
• Individuals with an FDR with a clinical diagnosis of FAP (i.e. “at-risk”) and in whom a constitutional pathogenic variant has not been identified			• Colonoscopy: 12 to 14 years old, 5 yearly until national screening age • Gastroscopy and duodenoscopy: Commence only if clinical diagnosis made of colorectal polyposis phenotype, as per Spigelman classification	**4**
MUTYH-associated polyposis (MAP)	**A cumulative lifetime CRC risk of 63% at 60 years**. Nieuwenhuis MH, Vogt S, Jones N, Nielsen M, Hes FJ, Sampson JR, Aretz S, Vasen HF. Evidence for accelerated colorectal adenoma--carcinoma progression in MUTYH-associated polyposis? Gut. 2012 May;61(5):734-8. doi: 10.1136/gut.2010.229104. Epub 2011 Aug 16. PMID: 21846783.		• Colonoscopy: 1 yearly from 18 to 20 years old • Gastroscopy and duodenoscopy: From 35 years old, as per Spigelman classification	**5**

Juvenile polyposis syndrome (JPS)	**40-50% Lifetime risk (NCCN)**	**9% to 50% risk of gastrointestinal tumors**. Cichy W, Klincewicz B, Plawski A. Juvenile polyposis syndrome. Arch Med Sci. 2014;10(3):570-577. doi:10.5114/aoms.2014.43750. **In patients with JP, the RR (95% CI) of colorectal cancer was 34.0 (14.4 to 65.7).** Brosens LA, van Hattem A, Hylind LM, Iacobuzio-Donahue C, Romans KE, Axilbund J, Cruz-Correa M, Tersmette AC, Offerhaus GJ, Giardiello FM. Risk of colorectal cancer in juvenile polyposis. Gut. 2007 Jul;56(7):965-7. doi: 10.1136/gut.2006.116913. Epub 2007 Feb 15. PMID: 17303595; PMCID: PMC1994351. **Risk of CRC 38%.** Howe JR, Mitros FA, Summers RW. The risk of gastrointestinal carcinoma in familial juvenile polyposis. Ann Surg Oncol. 1998 Dec;5(8):751-6. doi: 10.1007/BF02303487. PMID: 9869523	• SMAD4 and BMPR1A pathogenic variant carriers: From 15 years old, 1-3 yearly dependent on phenotype • SMAD4 pathogenic variant carriers: From 18 years old, 1-3 yearly dependent on phenotype • BMPR1A pathogenic variant carriers: From 25 years old, 1-3 yearly dependent on phenotype	**5**
Individuals with an FDR with a clinical diagnosis of FAP and in whom a constitutional pathogenic variant has not been identified			From 12 to 14 years old, 5 yearly until national screening age	**4**
Peutz-Jeghers syndrome (PJS)	**Cumulative risk: 39%** Syngal S, Brand RE, Church JM, et al. ACG clinical guideline: Genetic testing and management of hereditary gastrointestinal cancer syndromes. Am J Gastroenterol. 2015;110(2):223-263. doi:10.1038/ajg.2014.435	**Risk of CRC is 3%, 5%, 15%, and 39% at ages 40, 50, 60, and 70 years, respectively.** Hearle N, Schumacher V, Menko FH, et al. Frequency and spectrum of cancers in the Peutz-Jeghers syndrome. Clin Cancer Res May 15 2006 (12) (10) 3209-3215; DOI: 10.1158/1078-0432.CCR-06-0083	From 8 years old, small bowel surveillance 3 yearly.	**5**
Serrated polyposis syndrome				

• Affected individuals	**Cumulative risk: 50%** Syngal S, Brand RE, Church JM, et al. ACG clinical guideline: Genetic testing and management of hereditary gastrointestinal cancer syndromes. Am J Gastroenterol. 2015;110(2):223-263. doi:10.1038/ajg.2014.435	**Prevalence of CRC in patients with SPS: 29.3%**. IJspeert JE, Rana SA, Atkinson NS, van Herwaarden YJ, Bastiaansen BA, van Leerdam ME, Sanduleanu S, Bisseling TM, Spaander MC, Clark SK, Meijer GA, van Lelyveld N, Koornstra JJ, Nagtegaal ID, East JE, Latchford A, Dekker E; Dutch workgroup serrated polyps & polyposis (WASP). Clinical risk factors of colorectal cancer in patients with serrated polyposis syndrome: a multicentre cohort analysis. Gut. 2017 Feb;66(2):278-284. doi: 10.1136/gutjnl-2015-310630. Epub 2015 Nov 24. PMID: 26603485. **Patients with SPS have an overall lifetime risk of CRC of approximately 7% at 5 yrs.** Boparai KS, Mathus-Vliegen EMH, Koornstra JJ, et al. Increased colorectal cancer risk during follow-up in patients with hyperplastic polyposis syndrome: a multicentre cohort study. Gut 2010;59:1094–100. doi:10.1136/gut.2009.185884	From age of diagnosis, 1-2 yearly until 75 years old	**5**
• FDRs of affected individuals	**SIR for CRC in first-degree relatives of serrated polyposis: 3.28 (95% CI, 2.16–4.77).** Egoavil C, Juárez M, Guarinos C, et al. . Increased risk of colorectal cancer in patients with multiple serrated polyps and their first-degree relatives. Gastroenterology 2017;153:106–12.10.1053/j.gastro.2017.04.003		40 (or 10 years earlier than the index case) years old, 5 yearly until 75 years old	**2**
IBD surveillance:				
	Among patients with UC, CRC developed in 24, for a cumulative incidence of 1% at 10 years (95% confidence interval [CI], 0%-2%), 3% at 20 years (95% CI, 1%-5%), and 7% at 30 years (95% CI, 4%-10%). Among patients with CD, 5 of 327 with colon disease developed CRC, with a cumulative incidence of CRC of 1% at 10 years (95% CI, 0%-2%), 1% at 20 years (95% CI, 0%-2%), and 2% at 30 years (95% CI, 0%-4%). Selinger CP, Andrews JM, Titman A, Norton I, Jones DB, McDonald C, Barr G, Selby W, Leong RW; Sydney IBD Cohort Study Group. Long-term follow-up reveals low incidence of colorectal cancer, but frequent need for resection, among Australian patients with inflammatory bowel disease. Clin Gastroenterol Hepatol. 2014 Apr;12(4):644-50. doi: 10.1016/j.cgh.2013.05.017. Epub 2013 May 23. PMID: 23707778.			
Low risk • Extensive but quiescent ulcerative colitis or • Extensive but quiescent Crohn's colitis or • Left-sided ulcerative colitis or Crohn's colitis of a similar extent	Laine L et al. SCENIC international consensus statement on surveillance and management of dysplasia in inflammatory bowel disease. Gastrointest Endosc 2015 Mar; 81:489. (http://dx.doi.org/10.1016/j.gie.2014.12.009)		5 years	**3**

Intermediate risk • Extensive ulcerative or Crohn's colitis with mild active inflammation that has been confirmed endoscopically or histologically or • Post-inflammatory polyps or • Family history of colorectal cancer in a first-degree relative aged 50 years or over		3 years	**4**
High risk • Extensive ulcerative or Crohn's colitis with moderate or severe active inflammation that has been confirmed endoscopically or histologically or • Primary sclerosing cholangitis (including after liver transplant) • Colonic stricture in the past 5 years • Any grade of dysplasia in the past 5 years • Family history of colorectal cancer in a first-degree relative aged under 50 years • Dysplasia/cancer at time of pouch surgery PSC • Type C mucosa of pouch (persistent atrophy & severe inflammation)	**4.4% (95% CI 2.0–6.8) at 10 years, 8.6% (95% CI 4.0–13.3) at 20 years, and 12.7% (95% CI 6.0–19.3) at 30 years in patients with total colitis**. Eaden JA, Abrams KR, Mayberry JF. The risk of colorectal cancer in ulcerative colitis: a meta-analysis. Gut 2001;48:526–35.	1 year	**5**
Upper GI			
Barrett's oesophagus	**The annual incidence of OAC (Oesophageal Adenocarcinoma) was 0.19% (95% CI 0.08 to 0.34) in SSBO (short segment of Barrett's) as opposed to 0.33% (95% CI 0.28 to 0.38) overall** Desai TK, Krishnan K, Samala N, et al. The incidence of oesophageal adenocarcinoma in non-dysplastic Barrett's oesophagus: a meta-analysis. Gut 2012;61:970–6.	Patients with LGD should have a repeat endoscopy in 6 months' time. If LGD is found in any of the follow up OGDs and is confirmed by an expert GI pathologist, the patient should be offered endoscopic ablation therapy after review by the specialist MDT. If ablation is not undertaken, 6-montly surveillance is recommended	**LGD SURV - 3** **HGD THERAPY* - 4**
• Shorter than 3 cm, with intestinal metaplasia, but no dysplasia	0.19%	3-5 years	**2**
• Longer than or equal to 3 cm – no dysplasia	0.33%	2-3 years	**2**
Varices			
• Grade I Varices	**The annual progression of varices in cirrhosis patients was 12%. Cumulative incidence of varices at 10 and 20 years was 44% and 53%.** Merli M, Nicolini G, Angeloni S, et al. Incidence and natural history of small esophageal varices in cirrhotic patients. J Hepatol 2003;38:266–72.	1 year	**4****

Risk factors for gastric cancer: • Polyposis • Extensive gastric atrophy • Extensive gastric intestinal metaplasia		High risk CAG: 3 yearly endoscopic surveillance	**2**

***Ablation therapy of HGD in Barrett's should be categorised as Priority 1 / suspected cancer and not a surveillance procedure**

****Clinical condition of the patient in cases of recent bleed/banding etc. may necessitate a higher score of 5 and will be up to treating clinician recommendation**

APPENDIX 2: LETTERS FOR PATIENTS

All letters sent to patients will need to also be provided in Welsh. Please organise this within your Health Board in case you change the suggested text below.

Letter 1: Proceeding with test (Table 5 outcome A)

Dear ……..,

We are writing to you as you are currently on our waiting list for a surveillance ("check-up") endoscopy (a test that uses a thin flexible tube with a tiny camera on the end to look at an internal organ or tissue). The COVID-19 pandemic has unfortunately put a huge strain on endoscopy services and we therefore have to change the way in which we manage our surveillance waiting lists.

We telephoned you on … to discuss the situation with you. As per our conversation, we agreed to continue as planned with your surveillance test. We will be in touch in due course to arrange your procedure.

Should you develop any new symptoms in the meantime please contact the Endoscopy Unit on XXXXX XXXXXX.

Yours sincerely,

The Endoscopy Team
Copy to GP and Clinician

Letter 2: Deferring their procedure (Table 5 outcome B)

Dear ……..,

We are writing to you as you are currently on our waiting list for a surveillance ("check-up") endoscopy (a test that uses a thin flexible tube with a tiny camera on the end to look at an internal organ or tissue). The COVID-19 pandemic has unfortunately put a huge strain on endoscopy services and we therefore have to change the way in which we manage our surveillance waiting lists.

We telephoned you on … to discuss the situation with you. As per our conversation, we agreed that it is still in your best interest to have the procedure but due to current circumstances we have deferred your procedure until …. and we will be in touch in the future. If you have any further questions, please contact the Endoscopy Unit on XXXXX XXXXXX

Should there be any change in your health or circumstances that may affect you having your test please contact the Endoscopy Unit on XXXXX XXXXXX.

Yours sincerely,

The Endoscopy Team
Copy to GP and Clinician

Letter 3: Removing patient from the waiting list (Table 5 outcome C or D)

Dear ……..,

We are writing to you as you are currently on our waiting list for a surveillance ("check-up") endoscopy (a test that uses a thin flexible tube with a tiny camera on the end to look at an internal organ or tissue). The COVID-19 pandemic has unfortunately put a huge strain on endoscopy services and we therefore have to change the way in which we manage our surveillance waiting lists.

We telephoned you on … to discuss the situation with you. As per our conversation and your decision we have removed you from the surveillance waiting list. If you have any further questions, please contact the Endoscopy Unit on XXXXX XXXXXX.

Should you develop any new symptoms it is important that you report them promptly to your GP.

Yours sincerely,

The Endoscopy Team
Copy to GP and Clinician

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