NICE National Institute for Health and Care Excellence

DIAGNOSTICS ASSESSMENT PROGRAMME

Molecular testing strategies for Lynch syndrome in people with colorectal cancer

Diagnostics Consultation Document – Comments

Diagnostics Advisory Committee date: 23 November 2016

THEME: Tumour sample for MSI/IHC testing

Comment number	Name and organisation	Section number	Comment	NICE response
1	NHS Professional	1.1	The phrase "when first diagnosed" should be further clarified. Does this mean testing of all biopsied CRC (i.e. testing of biopsy material) or all resected CRC. The first is a larger group than the latter. What sort of patient groups (all biopsied CRC patients or just resected cases) had been investigated in the studies considered in the analyses? If the recommendation is indeed to test all biopsied CRC (i.e. testing of biopsy material), it is accepted that such material will, due to better fixation, increase the success rate of MMR and MSI analyses. However, compared to resection material, endoscopic biopsies are more likely to contain a component of just adenoma or non-neoplastic tissue. The concordance of mismatch repair or MSI status between adenoma and its subsequent carcinoma is far from absolute. Macrodissecting biopsy material to enrich for carcinoma tissue (especially for MSI testing) is much more difficult than with resection material.	Thank you for your comment which the committee considered. The committee discussed which tissue should be used for testing. It heard from clinical experts that the results of tests using tissue obtained from biopsies and from resections correlate well and concluded that the material to be tested should be determined by clinical judgement and the tissue available for testing when colorectal cancer is diagnosed. This can include cancers diagnosed in polyps. The committee's considerations of this are described in section 5.16 of the guidance document. The committee also discussed synchronous colorectal cancers, and heard that sporadic tumours can occur in people with Lynch syndrome. Because of this, the committee concluded that testing for Lynch syndrome should be considered for each primary cancer. This

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			What is the recommendation if there are synchronous colorectal carcinomas? Should both carcinomas be tested? Finally, should all polyp cancers (i.e. carcinomas found in polypectomy/EMR specimens) also be tested?	committee consideration is described in section 5.16 of the guidance document.

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THEME: Population tested for Lynch syndrome

Comment number	Name and organisation	Section number	Comment	NICE response
2	Bowel Cancer UK	General comment	As this guidance focusses on identifying Lynch syndrome in new bowel cancer patients, we ask that the committee also address, through this guidance, retrospective testing for people who have already been diagnosed with bowel cancer. At present there is no guidance available to clinicians as to how this testing should be carried out. Those patients without a strong family history of the disease may not qualify for testing unless the test has already taken place on the resected tumour. Clinicians have informed us that this can take place on a case by case basis but that provision currently varies across the country. Bowel Cancer UK is regularly contacted by patients who tell us that they were not tested at diagnosis of bowel cancer but have since asked their GP/clinician about testing and have been told that this cannot happen. Including retrospective testing under this guidance will reduce variation in testing for these patients too and identify more people with Lynch syndrome.	Thank you for your comment which the committee considered. The committee heard that in practice retrospective testing would likely be done on request rather than testing being offered systematically. Although it agreed that retrospective testing would be beneficial, it noted that the testing of people previously diagnosed with colorectal cancer was outside the scope of this assessment. The committee therefore decided that no changes to the guidance document were needed.

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THEME: Recommended strategies

Comment number	Name and organisation	Section number	Comment	NICE response
3	NHS Professional	1.1	It is not feasible to recommend "using immunohistochemistry for mismatch repair proteins **OR** microsatellite instability testing" when subsequent recommendations are completely dependent on which protein is aberrant. In other words, MSI analysis alone will not indicate which MMR protein is aberrant. Therefore, MMR immunohistochemistry will always be needed to further triage MMR deficient or MS unstable CRC cases as per the recommendations. One way to account for this would be to submit only MSI-H cases for IHC testing. However, if so, this needs to be made more explicit in the recommendations and it also adds further complexity to the testing pathway.	Thank you for your comment which the committee considered. The committee noted that the recommended testing strategy for MSI does not depend on identifying which MMR gene is mutated. This is described in the recommendations which state that MSI positive cases should be subsequently tested for *BRAF V600E* followed by *MLH1* promoter hypermethylation testing when *BRAF V600E* is negative. The committee decided to emphasise that the recommended testing strategies involve the use of sequential tests in section 1 of the guidance document.
4	Royal College of Pathologists	1.1	Strongly disagree with the recommendation to use BRAF V600E to differentiate sporadic and Lynch associated colorectal tumours where IHC is abnormal for MLH1 or MSI is positive. • BRAF V600E is found in Lynch syndrome mutation carriers • There are other activating mutations besides BRAF V600E	Thank you for your comment which the committee considered. The committee noted that the recommended strategies do not involve the use of *BRAF* V600E testing alone to

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			See 5.4.1 of **Association of Clinical Genetics Science (ACGS) Best practice guidelines for genetic testing and diagnosis of Lynch syndrome** 'Analysis of MLH1promoter methylation is recommended over tumour testing of BRAF activating mutations (e.g. BRAF p.Val600Glu) as such mutations are detected in Lynch syndrome mutation carriers (i.e.the predictive value of BRAF testing is lower). MLH1promoter methylation testing is the more specific test and will also detect cases of constitutive epimutations. See 4.1.4 of ACGS guidance. Further if an MLPA approach is used, the kit will also detected cases of MHS2 promoter hypermethylation. http://www.acgs.uk.com/media/998715/ls_bpg_approved.pdf Also see the Best practice guidance **Association of Clinical Genetics Netherlands, 2016** http://www.oncoline.nl/index.php?language=nl English Translation https://translate.google.co.uk/translate?sl=nl&tl=en&js=y&prev=_t&hl=en&ie=UTF-	differentiate sporadic and Lynch syndrome associated tumours, but rather the use of both *BRAF* V600E and *MLH1* promoter hypermethylation testing. The wording of the recommendation has been amended to clarify that testing to differentiate sporadic and Lynch syndrome associated tumours includes the use of sequential *BRAF* V600E and *MLH1* promoter hypermethylation testing. The committee discussed the ACGS guideline on testing for Lynch syndrome. It noted that while the guideline does not recommend the use of *BRAF* V600E testing alone (section 5.4.1; page 18), it states that combined testing of the *MLH1* promoter and *BRAF* V600E alongside consideration of tumour content may improve reliability, though at additional cost (section 4.14; p13). The committee also noted additional sensitivity analysis carried out by the external assessment group, in which the

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			8&u=http%3A%2F%2Fwww.oncoline.nl%2Ferfelijke-darmkanker&edit-text=	specificity of *BRAF* V600E was decreased in the model and the effect on the cost effectiveness of strategies that included *BRAF* V600E and *MLH1* promoter methylation testing alone and in combination were assessed. The committee noted that unless the specificity of *BRAF* V600E testing was reduced substantially in the base case model, a strategy which included *BRAF* V600E and *MLH1* promoter hypermethylation testing remained cost effective compared to a strategy which involved *MLH1* promoter hypermethylation testing alone. The committee further discussed the accuracy of *BRAF* V600E testing and concluded that this test should remain in the recommended strategies to test for Lynch syndrome, when used in sequence with *MLH1* promoter hypermethylation testing.

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5	Royal College of Pathologists	4.28	Assumptions are contrary to **Association of Clinical Genetics Science (ACGS) Best practice guidelines for genetic testing and diagnosis of Lynch syndrome** a) MSI-L should NOT be considered a negative results See 4.1.2 http://www.acgs.uk.com/media/998715/ls_bpg_approved.pdf b) The sensitivity of MSI and IHC is known to be dependent on which MMR gene is mutated. See 4.1.3 http://www.acgs.uk.com/media/998715/ls_bpg_approved.pdf	Thank you for your comment which the committee considered. The committee discussed the results of MSI testing for Lynch syndrome and heard from clinical experts that MSI-L results are generally considered to be a positive result for Lynch syndrome. The committee also noted a scenario analysis in the diagnostics assessment report which modelled MSI testing when both MSI-L and MSI-H were considered as positive results. This suggested that including MSI-L as a positive result did not affect the cost-effectiveness of the MSI-based testing strategies. The committee concluded that both MSI-L and MSI-H should be considered as positive results. The committee decided to change section 5.11 of the guidance document to reflect this.

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				Further, the committee heard from the external assessment group that a previous review (Palomaki et al. 2009) reported evidence that the sensitivity of MSI testing varies depending on which MMR gene is mutated. However, none of the studies reporting this met the inclusion criteria for this review.

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THEME: MMR status and treatment

Comment number	Name and organisation	Section number	Comment	NICE response
6	Royal College of Pathologists	5.14	Lack of clarity and consistent consideration of utility of MMR status in directing chemotherapy. The consultation document says that MMR gene status may be useful in determining treatment options for colorectal cancer. Is this meant to be the constitutional status? The MSI tumour analysis that has been suggested for use in clinical practice is a somatic biomarker test not to be confused with the constitutional analysis.. 1.1.4.3 of the DAP evaluation report quotes a recent systematic review and meta-analysis did NOT find evidence that chemotherapy response was determined by MSI status. The European Society for Medical Oncology guidelines suggest that MSI should be evaluated in stage II colorectal cancer patients in order to contribute to treatment decision-making regarding chemotherapy administration. Saridaki, Z., Souglakos, J. & Georgoulias, V. Prognostic and predictive significance of MSI in stages II/III colon cancer. World J Gastroenterol 20, 6809-6814, (2014).	Thank you for your comment which the committee considered. The committee heard that knowing a person's MMR gene status may be used in determining treatment options, for example, to direct surgical decisions. Further, it heard that MMR tumour status may be used guide the selection of chemotherapy, but acknowledged that the clinical utility of this is not fully understood at present. Additional explanation has been added to section 5.15 of the guidance document.

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THEME: MMR status and treatment

Comment number	Name and organisation	Section number	Comment	NICE response
7	Private Sector Professional	General Comment	This is a comprehensive review that has delivered a balanced assessment of the knowledge to date and drafted sensible recommendations for testing. However the usefulness of testing for mismatch repair goes beyond syndromic patients and is important also for a much larger population of patients that has sporadic MMR defects. There are implication for prognosis and treatment strategy, including use of different conventional chemotherapy, use of different targeted therapy and use of immunomodulation (specifically modulation of checkpoint inhibitors). This review misses the opportunity to comment on these very important issues which are currently extremely topical and I would recommend that you consider extending slightly the scope of the review so that at least you could recommend that these points need to be addressed in another review.	Thank you for your comment which the committee considered. The committee noted that the assessment of tumour MMR status to inform decisions about chemotherapy, or other treatments, was beyond the scope of this guidance. The committee therefore decided that no changes to the guidance document were needed.

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THEME: Implementation

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8	NHS Professional	1.1	With a testing pathway which includes multiple steps (particularly if BRAF V600E and/or MLH1 promoter hypermethylation testing is required), it is crucial that there is clear clinical ownership of the testing and, particularly, its results. Otherwise, cases may be either not tested or insufficiently tested or their results may not be appropriately acted upon. Will NICE suggest who should take such ownership? Also for whoever that suggested profession or body (e.g. local colorectal MDT) is, will NICE acknowledge the need for extra resource for this increased workload and responsibility?	Thank you for your comment which the committee considered. The committee agreed that effective implementation of the recommended Lynch syndrome testing strategies will require good communication between colorectal cancer multidisciplinary teams and genetics or pathology laboratories to ensure that testing and reporting of results is co-ordinated. This consideration is described in section 5.20 of the guidance document. Further, it heard that the decision on who should lead on co-ordinating testing would be taken locally depending on local preferences. The NICE Adoption and Impact team are working with stakeholders to develop an adoption support pack to help organisations implement this guidance.
9	NHS Professional	1.1	These recommendations, as they are, will considerably increase the workloads to all Histopathology departments in England. This is at a time when these departments are already struggling	Thank you for your comment which the committee considered.

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			with rising diagnostic workloads compounded by a shortage of medical staff. Further, while Histopathology departments may be able to set up immunohistochemistry for MMR locally, it is much less likely that genetic-based analyses (BRAF V600E mutation analysis and MLH1 promoter hypermethylation studies) will be available at each Histopathology department or its host hospital. The subsequent need to test CRC cases off site and to track these cases will add further complexity to the testing pathways mentioned above.	The committee heard from clinical experts who considered that many histopathology departments already offer immunohistochemistry tests, and noted that testing for MMR proteins could be carried out alongside existing histopathology tests already carried out on colorectal tumour samples. Further it agreed that MSI testing, *BRAF* V600E and *MLH1* promoter hypermethylation may need to be carried out in specialist centres and noted that good communication will be required between laboratories if all tests in the recommended testing strategies cannot be carried out on one site; in terms of both organising testing and also the reporting of results. The committee considerations of this topic area are described in section 5.20 of the guidance document. The NICE Adoption and Impact team are working with stakeholders to develop an adoption support

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				pack to help organisations implement this guidance**.**
10	Bowel Cancer UK	6	Should these recommendations be adopted, they will have implications for the cellular and molecular pathology laboratories involved in the testing and for clinical genetics services who advise patients and families. So we welcome NICE's intention to develop tools in association with relevant stakeholders to help organisations put this guidance into practice. Findings from our Freedom of Information request (FOI), which looked at adherence to Royal College of Pathologists Colorectal Cancer Dataset, found that hospitals had difficulty with performing this test automatically as a reflex test, with only 56% carrying it out automatically. The majority of hospitals also faced challenges with carrying out molecular testing at diagnosis, with only 7 hospitals in England doing so. All other hospitals perform the test after treatment of bowel cancer. Our FOI also found that there are still 40 hospitals in England who are not performing molecular tests at all. These hospitals reported a number of barriers to implementing molecular testing including financial,	Thank you for your comment which the committee considered. The NICE Adoption and Impact team are working with stakeholders to develop an adoption support pack to help organisations implement this guidance.

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			resources and a lack of NICE guidance. However some hospitals did inform us of innovative ways that they have developed to overcome such barriers, including the development of regional approaches to streamline testing via the use of a singular pathology department. The development of tools and strategies to enable those hospitals who may struggle with implementing this new guidance of testing all colorectal patients for Lynch syndrome would be welcome and we would be happy to work with NICE to develop these.	
11	Bowel Cancer UK	General comment	While the Committee noted that good communication between colorectal MDTs and genetics or pathology laboratories is important it does not recognise the importance of good communication between health care professionals and the patient. The draft recommendations do not take into account a patient's need for effective communication and information in relation to the results of the molecular test. Our FOI found that 29% of hospitals do not do this unless there is a positive result or that the decision is made after referral to the genetics team. We recommend	Thank you for your comment which the committee considered. The committee discussed the impact that testing for Lynch syndrome can have on people with colorectal cancer and their families, and heard from patient and clinical experts about the importance of effectively communicating the results of testing. This committee consideration is described in section 5.2 of the guidance document.

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			that the result of the molecular tests are communicated to all colorectal patients regardless of the outcome – knowing that they could have inherited Lynch syndrome can affect people in different ways and sharing this result, regardless of the outcome could help to alleviate some of the anxiety that people experience during this time.	
12	Bowel Cancer UK	General comment	Our research has shown that knowledge of Lynch syndrome can be very low amongst some healthcare professionals. We understand that Lynch syndrome is a rare condition so it is possible that many healthcare professionals may not have heard of the condition but a number of our survey respondents reported that they were in fact the ones to inform their clinician about Lynch syndrome. 73% of our survey respondents told us that a knowledgeable GP could have improved their experience of being diagnosed and managed for Lynch syndrome, but we know that GPs in particular, may not have heard of the condition. Educating all healthcare professionals to at least a basic understanding of what Lynch syndrome is, and how to manage and support people with the	Thank you for your comment which the committee considered. The committee considered that increased implementation of testing for Lynch syndrome will help to drive greater awareness of the condition among patients and also medical professionals. The NICE Adoption and Impact team are working with stakeholders to develop an adoption support pack to help organisations implement this guidance.

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			condition, could ultimately help to identify more people and prevent more deaths from cancer. We urge NICE to consider adding to this guidance that all healthcare professionals involved in the diagnosis, management and care of people with Lynch syndrome should receive an appropriate level of education and training in order to provide adequate support to their patients.	

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THEME: Other Lynch syndrome associated cancers

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13	Royal College of Pathologists	2.2	General lack of acknowledgement, due and consistent consideration of other Lynch associated tumours, specifically endometrial cancer. Whilst it is appreciated that endometrial cancer was out of the original scope of the consultation the utility of including early onset (under 50 years) endometrial cancer in the incusion criteria could be added to the research recommendations. Approximately 2.5% of all newly diagnosed endometrial cancer patients have Lynch syndrome. Hampel, H., Frankel, W., Panescu, J., Lockman, J., Sotamaa, K., Fix, D., Comeras, I., La Jeunesse, J., Nakagawa, H., Westman, J. A., Prior, T. W., Clendenning, M., Penzone, P., Lombardi, J., Dunn, P., Cohn, D. E., Copeland, L., Eaton, L., Fowler, J., Lewandowski, G., Vaccarello, L., Bell, J., Reid, G. & de la Chapelle, A. Screening for Lynch syndrome (hereditary nonpolyposis colorectal cancer) among endometrial cancer patients. Cancer Res 66, 7810-7817, (2006).	Thank you for your comment which the committee considered. The committee noted that testing for Lynch syndrome in people diagnosed with endometrial cancer was outside the scope of this guidance, which focussed on people diagnosed with colorectal cancer. However, the impact of gynaecological surveillance for endometrial cancer in people identified as having Lynch syndrome through tumour based or cascade genetic testing was included in the modelling for this assessment. This is noted in sections 4.18, 4.25, 4.28 and 4.48 of the guidance document.

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THEME: Further data collection

Comment number	Name and organisation	Section number	Comment	NICE response
14	Bowel Cancer UK	5.17	We urge NICE to consider recommending the development of a registry of people identified as having Lynch syndrome. Collecting this anonymised data, in a registry, at point of diagnosis of cancer or at identification, can help increase our knowledge and understanding of Lynch syndrome and how many people are affected. It could also facilitate research into any regional differences in treatment and care and lead to improvements in outcomes. Many clinicians have come forward in support of a national registry, including the Mallorca Group who stated that a regional or national registry is needed to guarantee the continued surveillance of people with Lynch syndrome. Patients have also come forward expressing their support – 87% of people who took our patient experience survey in the summer would consent to be part of a registry to help further research, ensure there is greater coordination of care services and to raise the profile of the condition.	Thank you for your comment which the committee considered. The committee discussed the development of a national registry for people identified as having Lynch syndrome. It heard that a national registry could be of value provided that it is developed alongside clear research questions, but noted that recommending such a registry was beyond the remit of this assessment.

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THEME: General

Comment number	Name and organisation	Section number	Comment	NICE response
15	NHS Professional	1.1	A testing pathway presented as a flowchart/algorithm may be a useful supplement to this document.	Thank you for your comment which the committee considered. The committee considered that a flowchart illustrating the recommended testing strategies could be a useful resource for clinicians. The NICE team will work to develop this resource to publish alongside the guidance.
16	Bowel Cancer UK	General comment	Bowel Cancer UK is the UK's leading bowel cancer research charity. Improving the identification and management of high risk patients for bowel cancer is one of our top policy priorities and we welcome this opportunity to comment on the NICE DCD on molecular testing strategies for Lynch syndrome in people with colorectal cancer.	Thank you for your comment which the committee considered.
17	Bowel Cancer UK	General comment	We strongly support NICE's recommendation of testing all colorectal tumours for mismatch repair proteins in order to identify patients for Lynch syndrome. We believe the draft recommendations for expanding this testing to all bowel cancer patients are sound and provide suitable basis for guidance to the NHS for the following reasons:	Thank you for your comment which the committee considered.

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THEME: General

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			• This will help to reduce the risk of patients falling through the diagnostic net. Clinicians will no longer need to adhere to restrictive criteria such as the cancer dataset from the Royal College of Pathologists or the Amsterdam/Bethseda guidelines to identify people with Lynch syndrome. • While Lynch syndrome is usually suspected in people who are diagnosed with bowel cancer under age of 50, it also commonly affects older people too. This means people over 50 with Lynch syndrome are potentially being missed under current guidelines. Expanding testing to all patients diagnosed with bowel cancer will mean more people and their families can be identified and placed in a surveillance programme to receive regular colonoscopy. • Testing everyone will not only save lives but also save the NHS money as universal testing has proven economic benefit.	