

Reviewer Responses

We would like to thank the expert Peer Reviewer for the thoughtful review of our manuscript as well as the excellent and insightful recommended changes. Through incorporation of these recommendations, we believe we have significantly strengthened our manuscript.

Reviewer #1:

Median age - specify units (I presume years) and ideally IQR or range in parenthesis.

We greatly appreciate this comment. We have clarified that the median age was indeed in years in both the results section and tables, and we have added the IQR for age to the results section, as well.

I understand, there were three physicians who discussed risks / benefits of extracolonic cancer surveillance. Was there any association between physicians and people choosing to undergo surveillance?

Thank you very much for this insightful suggestion. We have added a breakdown of the cohort by provider, and we performed statistical analysis to look for any associations between different providers. This analysis demonstrated that there were statistically significant associations between providers and surveillance behaviors, and this data was added to Tables 2-4, with corresponding text added to both the Results and Discussion sections.

How do you explain MSH2 patients choosing to undergo SIC surveillance and not UTC surveillance, an effect not seen with MLH1 patients?

This is a great question. As you mention, this difference may have been related to a Type I error, or it could also have been due to factors that were not captured in our current study. We have added additional language addressing these possibilities to the discussion section.

The statement - 'race or ethnicity was not associated with choosing or completing surveillance' contradicts the previous paragraph where people of Jewish ancestry were found to be more likely to complete UTC surveillance.

Thank you for pointing this out. We clarified this statement by specifying that neither race nor Hispanic ethnicity was found to have any significant association with surveillance behaviors.

The statement 'Individuals with Lynch syndrome prefer transparent and personalized discussions pertaining to their management that include information regarding extra-colonic cancer surveillance' - I am not sure how helpful this is. While such a statement does not need a reference cited, more importantly, one would argue that every patient prefers transparent and personalized discussion pertaining to their health needs.

We appreciate this comment and agree with the sentiment. This statement has been removed from the manuscript as it can be assumed most patients would prefer a transparent and personalized discussion.

What were the findings in those 5 VCE cases which were deemed as false-positives?

Thank you for this question. The 5 false-positive video capsule endoscopy cases were initially suspicious for a polyp, however follow-up procedures for all of these cases showed no significant small intestinal neoplasia, thus leading us to deem these video capsule endoscopies false positives.

Positive predictive value / sensitivity & specificity of the test has been discussed in the manuscript. It would be useful to have PPV / Sensitivity / specificity etc with 95% CI for your cohort.

This is a great suggestion, thank you. Given data collection limitations, we are unable to calculate sensitivity and specificity as we do not have gold standard comparison data for those who tested negative on the surveillance exams. However we did calculate PPVs, and have added these as well as the 95% confidence intervals and 97.5% one-sided confidence intervals for our studied surveillance methods.