Washington State Department of Health
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Lynch Syndrome

Fact Sheet for Healthcare Professionals

Colorectal cancer is the **second leading cause of cancer death** after lung cancer[1]

Lynch Syndrome is an **inherited condition** that increases a person's risk of developing colorectal and other cancers

About **3%** of patients with colorectal cancer **have Lynch syndrome**

It is crucial to **identify patients** with Lynch Syndrome **and their relatives** to allow them to take advantage of interventions that can significantly **reduce their risk** of cancer in the future

It is estimated that up to **98%** of Lynch syndrome cases with and without colorectal cancer are **undiagnosed**[2]

Lifetime Cancer Risks Associated with Lynch Syndrome:

10- 80% risk of colorectal cancer[3]

15-60% risk of endometrial cancer[4]

1-13% risk of stomach cancer[4]

4-24% risk of ovarian cancer[4]

2-4% risk of cancers of the hepatobiliary tract[4]

1-4% risk of cancers of the urinary tract[4]

Increased risks for cancers of small bowel, brain, and skin

Evidence-Based Clinical Recommendation for Lynch Syndrome Universal Tumor Screening

Several organizations recommend universal tumor screening to identify patients at risk for LS

The Multi-Society Task Force on Colorectal Cancer (2014)
American College of Gastroenterology, American Gastroenterological Association, American Society of Colon and Rectal Surgeons, American Society of Gastrointestinal Endoscopy

National Comprehensive Cancer Network (2015)
The NCCN recommends that all patients under the age of 70 years with colorectal cancer be tested for Lynch syndrome

The Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Recommendation (2009)[3]
The EGAPP Working Group found sufficient evidence to recommend offering tumor screening and genetic testing for Lynch syndrome to individuals with newly diagnosed colorectal cancer

Cascade Screening
Increasing Identification of Unaffected Individuals at Risk for Lynch Syndrome

For those patients who screen positive for Lynch syndrome on **universal tumor screening**, genetic testing can be performed to diagnose Lynch syndrome by identifying the patient's specific mutation. Other family members then can be tested for that mutation. This process is known as **cascade screening**.

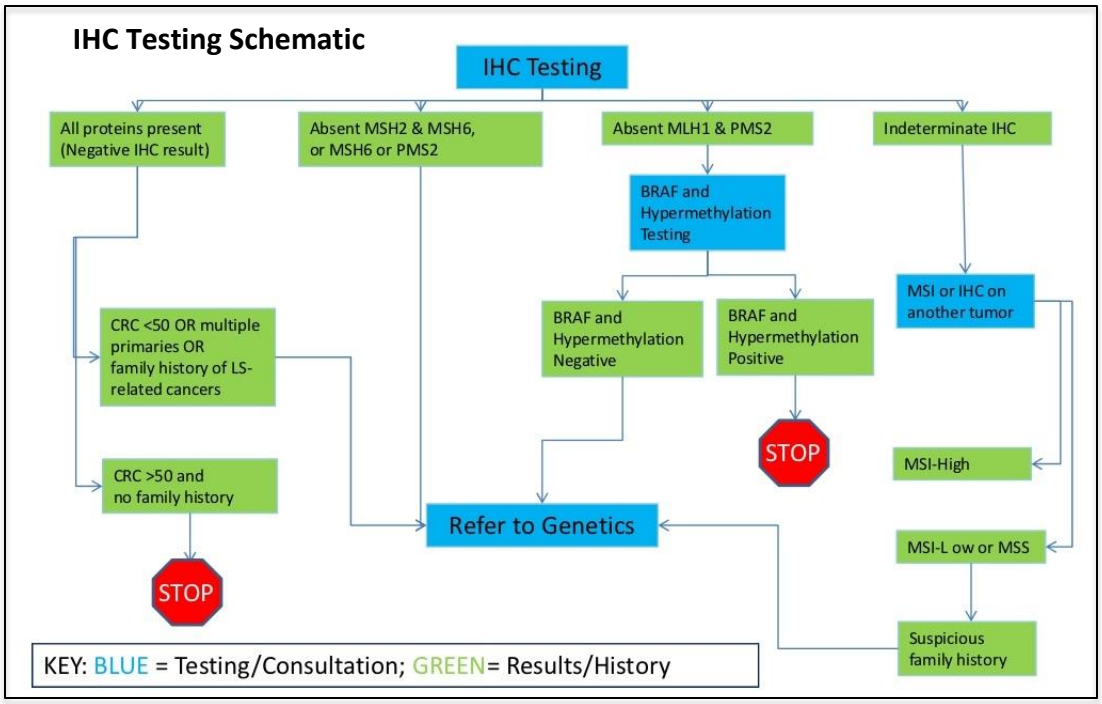
Potential Benefits of Genetic Testing

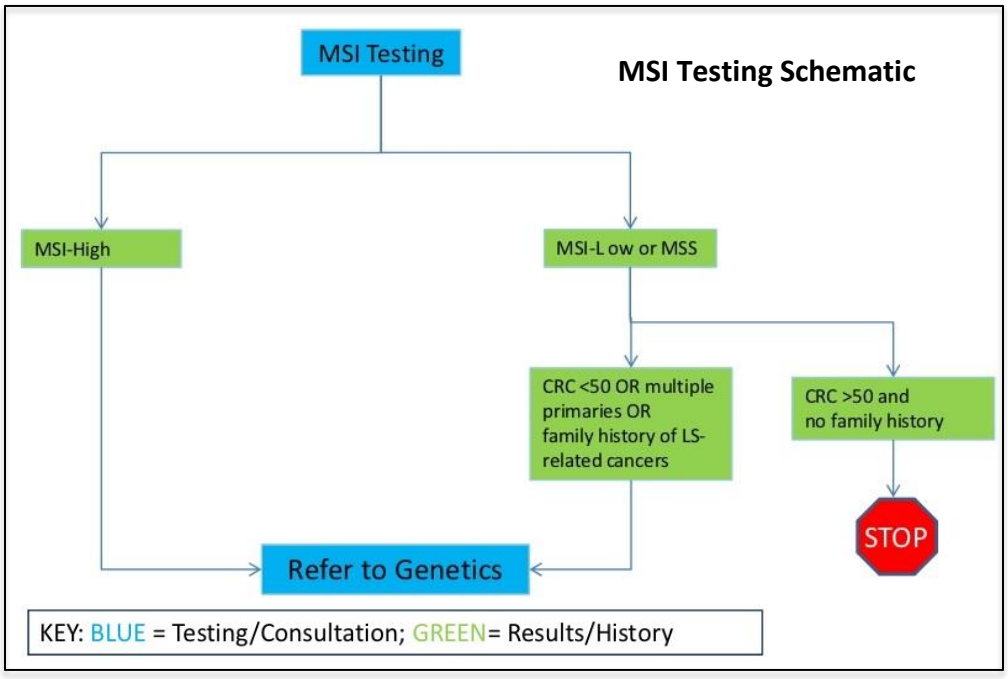
If a mutation is found, **increased tumor surveillance** can be implemented to detect cancer in the early stages or **prophylactic surgery** can be utilized to reduce risk.

Provide a patient's relatives with useful information, including **which mutation** relatives should be tested for.

For relatives, a negative test result may provide a **sense of relief** and will help them avoid **unneeded screening and surgeries.**

An employer **may never discriminate** against someone with respect to employment based on genetic testing information.





ǂ For IHC testing schematics visit: https://www.lynchscreening.net/wp-content/uploads/2012/04/IHC-+methylBRAF.jpg; For MSI testing schematics visit: https://www.lynchscreening.net/wp-content/uploads/2012/04/MSI-flowshart.jpg

References

1. American Cancer Society: Cancer Facts and Figures 2016. Atlanta, Ga: American Cancer Society, 2016. Last accessed June 14, 2016.
2. Cross et al., "Underutilization of Lynch Syndrome Screening in a Multisite Study of Patients with Colorectal Cancer." *Genetics in Medicine* 15, no. 12 (December 2013): 933–40.
3. Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group. Recommendations from the EGAPP Working Group: Genetic testing strategies in newly diagnosed individuals with colorectal cancer aimed at reducing morbidity and mortality from Lynch syndrome in relatives. *Genetics in Medicine* 2009; 11:35-41.
4. National Comprehensive Cancer Network. NCCN Guidelines Version 1.2015 Genetics/Familial High-Risk Assessment: Colon. MS3-7.

Adapted from the *Lynch Syndrome: Fact Sheet for Healthcare Providers* as part of the Tier 1 Genomic Applications Toolkit for Public Health Departments by the Centers for Disease Control and Prevention, Public Health Genomics in the U.S. Department of Health and Human Services.

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