

Lynch Syndrome

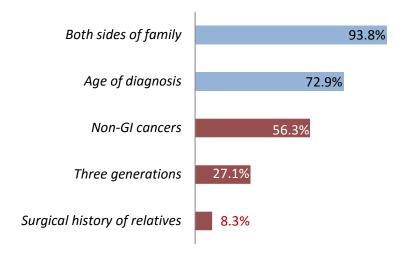
2014 Screening and Genetics Survey Results

Listed below are highlights from a 2014 survey completed by practicing gastroenterologists in Washington and Oregon about the current clinical practices related to screening and managing individuals and families with or at-risk for Lynch syndrome

A total of 274 surveys were distributed with 48 eligible participants responding for a 17.5% response rate, no incentives were offered for completing the survey.

Family Health History:

Items Physicians Reported Always Asking



While most respondents reported they collected information about both sides of their patient's family, <60% of responding gastroenterologists reported always asking about non-gastrointestinal cancer, and <30% of responding gastroenterologists reported always asking for family history up to three generations.

A **detailed family health history** that includes three generations of both sides of the family and all cancer diagnoses and ages at diagnosis is a useful tool in screening individuals for Lynch syndrome and other hereditary conditions. Asking about the surgical history of relatives can be helpful since early hysterectomies can prevent endometrial cancers among female family members.

Tumor Screening and Genetic Testing:

Items Physicians Reported Always Performing

33%

of responding Gastroenterologists screen all colorectal tumors using MSI or IHC

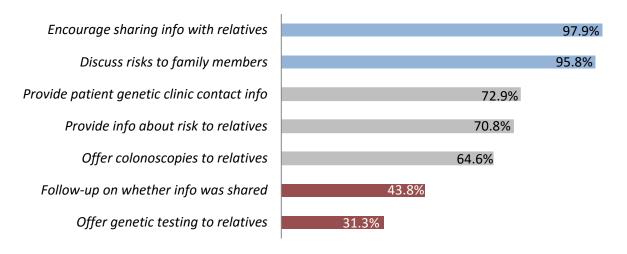
<65%

of responding Gastroenterologists offer genetic testing or referral to a genetics clinic to all patients suspected of having Lynch syndrome

Universal tumor testing using microsatellite instability (MSI) or immunohistochemistry (IHC) is now recommended as a clinical practice guideline by several organizations including the *American College of Gastroenterology* and the *American Gastroenterological Association* to help identify individuals at-risk of Lynch syndrome.

At-Risk Family Members:

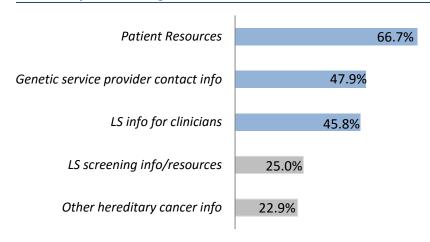
Items Physicians Reported Always Doing



Cascade screening is the process of testing at-risk family members of individuals diagnosed with Lynch syndrome so that they too may benefit from early screening and other health care options.

Clinical Resources:

Items Physicians Reported Would be Beneficial



The survey asked physicians what resources related to Lynch syndrome would be most useful to their clinics. **67%** indicated that resources to give to patients would be useful while almost **50%** requested genetic provider service contact information.

Resources and educational materials can support clinicians in caring for their patients.

Conclusion:

The study shows that gastroenterologists in WA State are doing well in many aspects of screening and managing Lynch syndrome. However, results also suggest areas for improvement such as documenting other cancers associated with Lynch syndrome in the patient's family history to improve the sensitivity of family history as a screening tool, greater adherence to the current practice guidelines of universal tumor testing, and greater accessibility of genetic services to improve the identification of individuals with Lynch syndrome.

This project is funded and distributed by the Washington State Department of Health, Screening and Genetics Unit. For people with disabilities, this document is available on request in other formats.

To submit a request, please call 1-800-525-0127 (TDD/TTY call 711).