

EGAPP Data from 91 Lynch Syndrome Screening Network (LSSN) applications as of 5.17.12

1. Which of the following best describes your institution with respect to Lynch Syndrome screening?

	Number	%
Currently providing routine tumor screening for Lynch syndrome on all or a subset of colon, endometrial or other cancers	52	57.1
Planned implementation of existing protocol for routine tumor screening for Lynch syndrome on all or a subset of colon, endometrial or other cancers within the next 6-12 months	10	11.0
Developing or plan to develop protocols for routine tumor screening for Lynch syndrome on all or a subset of colon, endometrial or other cancers	17	18.7
Involved in the care of patients with colon and/or endometrial cancer and interested in resources or research regarding routine tumor screening for Lynch syndrome	18	19.8
A federal/state agency or professional society with interest in universal screening for Lynch syndrome	5	5.5
Other‡	5	5.5
Total Institutions*	91	

**Some institutions checked multiple options*

‡Starting in less than 6 months; assisting another hospital with implementing protocols; pilot project for endometrial screening only; agency that provides genetic counseling for several hospitals; IHC ordered on all endometrial cancers by gynecological oncologist for those under 50, but consent required, varies by practitioner

7. Would your institution be willing to enter data from your screening program into the LSSN database on a regular basis?

Yes = 43/91, 47.3%

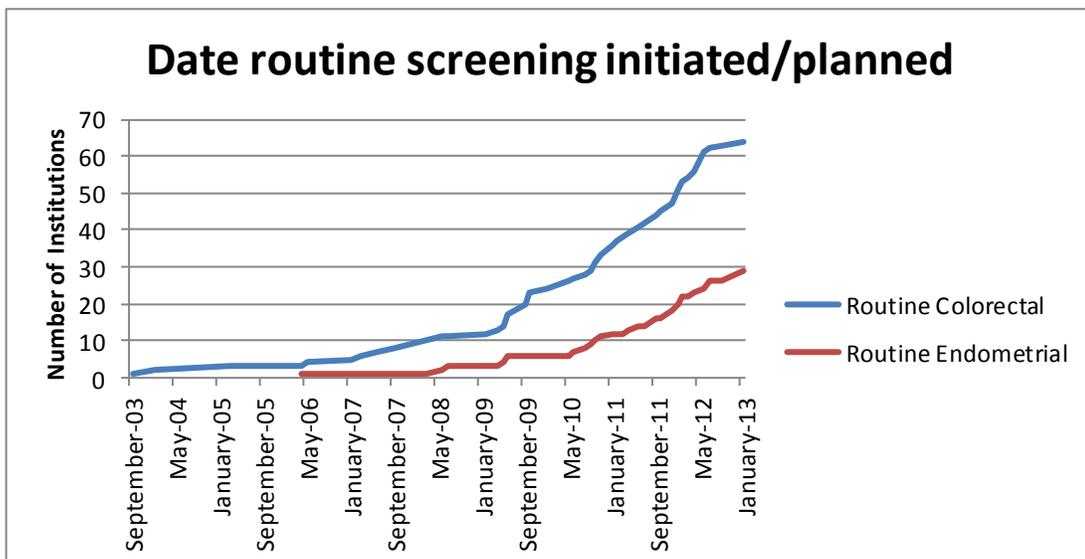
No = 0 (data entry does not apply to all LSSN applicant institutions)

Unsure = 41/91, 45.1%

8. Please indicate how the 2009 EGAPP recommendation influenced your institution's protocol regarding universal screening. **Select all that apply:**

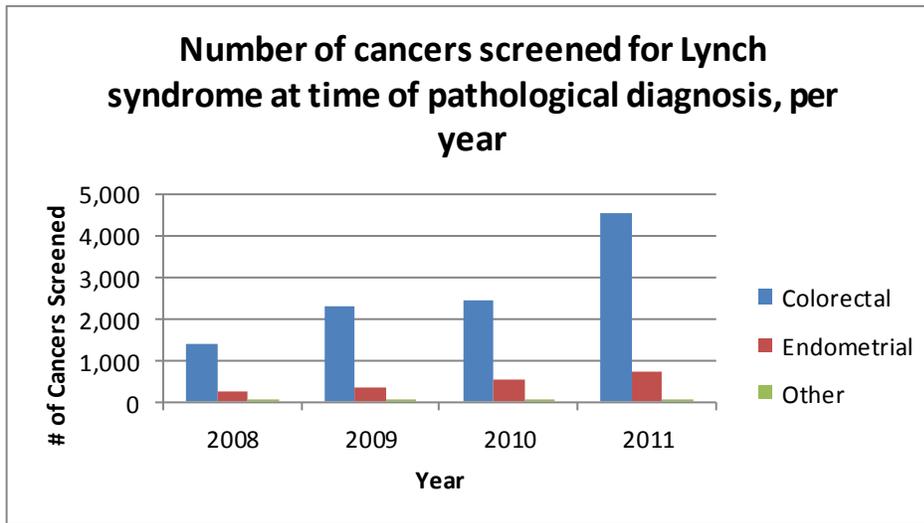
	Institutions Number (%)			
	Current routine Screening	Planned routine in 6-12 mo	Others	Total
Supported/justified existing screening protocols	22	2	0	24
Altered existing protocols with regards to type of tumor testing performed	3			3
Altered existing criteria for screening by moving from subset of CRCs to all CRCs	11	1	0	12
Provided basis for initiating a Lynch screening protocol at our institution	18	5	5	28
Is being used to justify developing a Lynch screening protocol at our institution	5	5	20	30
Not applicable	1	0	4	5
No impact	4		2	6
Total	52	10	29	

9. Date routine screening initiated or planned to start (if applicable)



This is out of 62 institutions with current/planned implementation of routine screening.

10. Please estimate the number of cancers which were screened for Lynch syndrome at the time of pathological diagnosis in each year, regardless of your institution's protocol at the time.



Year	Cancer Type		
	Colorectal	Endometrial	Other
2008	1,373	240	21
2009	2,305	331	25
2010	2,460	530	36
2011	4,516	750	44

Not all institutions were able to estimate their numbers. For 2008, 28 institutions provided a number for their colorectal cancers, 32 for 2009, 35 for 2010 and 45 for 2011.