

LSSN Application

Welcome to the Lynch Syndrome Screening Network (LSSN). You are being asked to complete this application survey as you have expressed an interest in becoming a LSSN member. Each institution may name a primary and secondary contact; a second contact is optional, and the participation of the second contact in LSSN activities is at the discretion of each institution. Guidelines are currently being established with regard to the obligations and privileges of full and affiliate member institutions. Data collected in this application may be used to facilitate obtaining fiscal support and promotion of the LSSN.

If you do not have an existing protocol for routine (automatic at the time of pathological diagnosis) tumor screening, please disregard questions 10 – 14.

Date of Application

Month: _____ Year: _____

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

- *Currently providing routine tumor screening for Lynch syndrome on all or a subset of colon, endometrial or other cancers.*
- *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.*
- *Developing or plan to develop protocols for routine tumor screening for Lynch syndrome on all, or a subset of colon, endometrial or other cancers.*
- *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.*
- *A federal/state agency or professional society with interest in universal screening for Lynch syndrome.*
- *Other - please describe: _____*

2. Primary Contact

Primary Contact Name: _____

Institution: _____ Department: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Email: _____

Phone Number: _____

3. Secondary Contact

A second contact is optional; participation of the second contact in LSSN activities is at the discretion of each institution.

Secondary Contact Name: _____

Email: _____ Phone Number: _____

4. Which LSSN committee(s) does the primary contact wish to participate on?

Select up to two, only one member per institution on each committee

- Governance & Structure Education
- Database Funding
- Research None

5. Which LSSN committee(s) does the secondary contact wish to participate on?

Select up to two, only one member per institution on each committee

- Governance & Structure Education
- Database Funding
- Research None

6. What educational and/or protocol resources does your institution have available to share with the LSSN?

Select all that apply

- Screening protocol/algorithm
- Patient/provider education materials
- Sample pathology reports
- Sample patient/provider letters
- Other – specify _____
- None

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

- Yes
- No
- Unsure

8. The Evaluation of Genomic Applications in Practice and Prevention (EGAPP) published a recommendation in January 2009 endorsing screening for Lynch syndrome on all newly diagnosed colorectal cancers. Please indicate how this recommendation influenced your institution's protocol regarding universal screening. Select all that apply

- Supported/justified existing screening protocols
- Altered existing protocols with regards to type of tumor testing performed
- Altered existing criteria for screening by moving from subset of CRCs (e.g. under 50) to all CRCs
- Provided basis for initiating a Lynch screening protocol at our institution
- Is being used to justify developing a Lynch screening protocol at our institution
- Not applicable
- No impact

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

Colorectal Month: _____ Year: _____

Endometrial Month: _____ Year: _____

Other (Specify) _____ Month: _____ Year: _____

----- *Questions for institutions with existing protocols for 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.

2008:

Colorectal _____ Endometrial _____ Other _____

2009:

Colorectal _____ Endometrial _____ Other _____

2010:

Colorectal _____ Endometrial _____ Other _____

2011:

Colorectal _____ Endometrial _____ Other _____

11. Cancers included in routine screening:

Select all that apply

- All colorectal cancers
- Colorectal cancers under age ____
- Colorectal cancers with specified pathological features _____
- Colorectal cancers - other specified criteria _____
- All endometrial cancers
- All endometrial cancers under age ____
- Endometrial cancer with specified pathological features _____
- Endometrial cancers - other specified criteria _____
- Other cancers _____

12. Current tumor screening protocol:

More than one reflex option may be selected, if applicable

Strategy		Colon	Endometrial	Other : _____
MSI only				
MSI with reflex to:	IHC			
	BRAF			
	Hypermethylation			
IHC only				
IHC with reflex to:	MSI			
	BRAF			
	Hypermethylation			
MSI and IHC	No reflex testing			
	Reflex to BRAF			
	Reflex to hypermethylation			

13. Genetic counseling involvement:

Level of Involvement	Colon	Endometrial	Other: _____
Genetics reviews all screen results and follows-up on abnormal			
Genetics is advised of all abnormal screens to initiate follow-up			
Patients with abnormal screens are referred to genetics at the discretion of the ordering physician, pathologist, or other clinician involved in the patient's care			
Only patients with identified MMR mutations are referred for genetic counseling			
Genetic counseling is not routinely involved in our Lynch screening protocol			

14. Please list all hospitals/institutions under your routine tumor screening protocol.

Name	City	Zip Code