



# LSSN Application & Database

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# Application Form

- Data capture
- Key elements
  - Who are you?
  - How will you be involved?
  - What is your protocol?
    - GC involvement
  - EGAPP impact?
  - Numbers
- Distribution
  - CGA
  - NSGC
  - Previous participants/interested organizations



## 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*

# Application Results

82 applications received as of 2/10/12

Institution LS Screening Involvement	#	%
Currently provide routine screening	49	59.8%
Plan to implement routine screening in 6-12 months	8	9.8%
Plan to develop protocols for routine screening	15	18.3%
Involved in care of patients and interested in research or resources regarding screening	16	19.5%
Federal/State agency or professional society with interest in universal screening	4	4.9%
Other^	5	6.1%

# Application Results

Cancers included in routine screening	#	%
Colorectal cancers (all)	35	42.7%
CRC under age 50	6	7.3%
CRC under age 60	8	9.6%
CRC under age 70	2	2.4%
CRC w/ specified path features	7	8.5%
CRC w/ other criteria	7	8.5%

# Application Results

Cancers included in routine screening	#	%
Endometrial cancers (all)	8	9.6%
Endometrial cancer under age 50	6	7.3%
Endometrial cancer under age 60	7	8.5%
Endometrial cancer under age 65	1	1.2%
Endometrial cancer under age 70	1	1.2%
Endometrial cancer w/ specified path features	4	4.9%
Endometrial cancer w/ other criteria	7	8.5%
Other cancers included*	4	4.9%

# Application Results - Protocols

Strategy		Colon	Endometrial
MSI only		2	1
MSI with reflex to:	IHC	6	1
	BRAF	7	0
	Hypermethylation	0	0
IHC only		10	9
IHC with reflex to:	MSI	6	2
	BRAF	21	0
	Hypermethyl	10	7
MSI and IHC	No reflex testing	4	1
	Reflex to BRAF	9	2
	Reflex to hypermethylation	5	4

# Application Results – GC involvement

<b>Level of Involvement</b>	<b>Colon</b>	<b>Endometrial</b>
Genetics reviews all screen results and follows-up on abnormalities	<b>24</b>	<b>12</b>
Genetics is advised of all abnormal screens to initiate follow-up	<b>14</b>	<b>5</b>
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	<b>25</b>	<b>12</b>
Only patients with identified MMR mutations are referred for genetic counseling	<b>1</b>	<b>1</b>
Genetic counseling is not routinely involved in our Lynch screening protocol	<b>0</b>	<b>0</b>





# LSSN Database

- Surveillance of routine LS screening on newly diagnosed CRC (HP 2020)
- Data to answer questions regarding efficacy, efficiency, utility
- Incentive for institutions to collect data
- Data to support institution infrastructure investment
- Incentive for new institutions to initiate screening
- Data to support mandate for insurance to cover LS screening/GC/testing

# LSSN Database

- Data on screening non-CRC LS cancers to support additional recommendations
- Data regarding test uptake by proband and relatives in “real world” settings
- Data regarding clinical and family history of mutation positive cases identified
- Identify “index” cases for further data collection via collaborative research efforts

# LSSN Database

- How much do we *need* to include to answer key questions

vs.

- How much we'd *like* to include to answer all the questions we have



# LSSN Database: Key Elements

- Demographics
  - Insurance info?
  - Past hx of LS/LS cancer?
- Index Cancer
  - Pathological features?
- Tumor Screening Performed & Results
- Screen Positive Individuals
  - Follow-up completed (GC, mutation analysis)
  - Results of mutation testing
  - Testing of family members?
  - Screening recommendations for family if mutation negative?

# Lynch Screening

Welcome maggie@greenwood.edu [Log Out] [change password]

Home    Data Entry    Data Extraction    Admin

Location1 ▾

User	
admin@transomdev.net	<a href="#">Edit</a>
dave@greenwood.edu	<a href="#">Edit</a>

Users:  ▾ [Add User to Location](#)

# LSSN Database Logistics

- Secure portal on CGA website
- Links to non-public log-in page on MPHI website
- HIPPA compliant
- Unique log-in for approved institutions
- Customized log-in for different purposes
  - Data entry
  - Data export
  - Site administration

# The Michigan Public Health Institute

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## MPHI DATA CENTER

The data center was designed from the ground up to house modern servers and network infrastructure for the health care community.

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