

Lynch Screening Practices: Preliminary Data from NCCCP and the NSGC Cancer SIG

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Basis for survey

- NCCCP inquiries
 - Centers struggling to set up programs
 - Data to help identify best practices, support to begin screening, resources
- Multiple inquiries on NSGC listserv

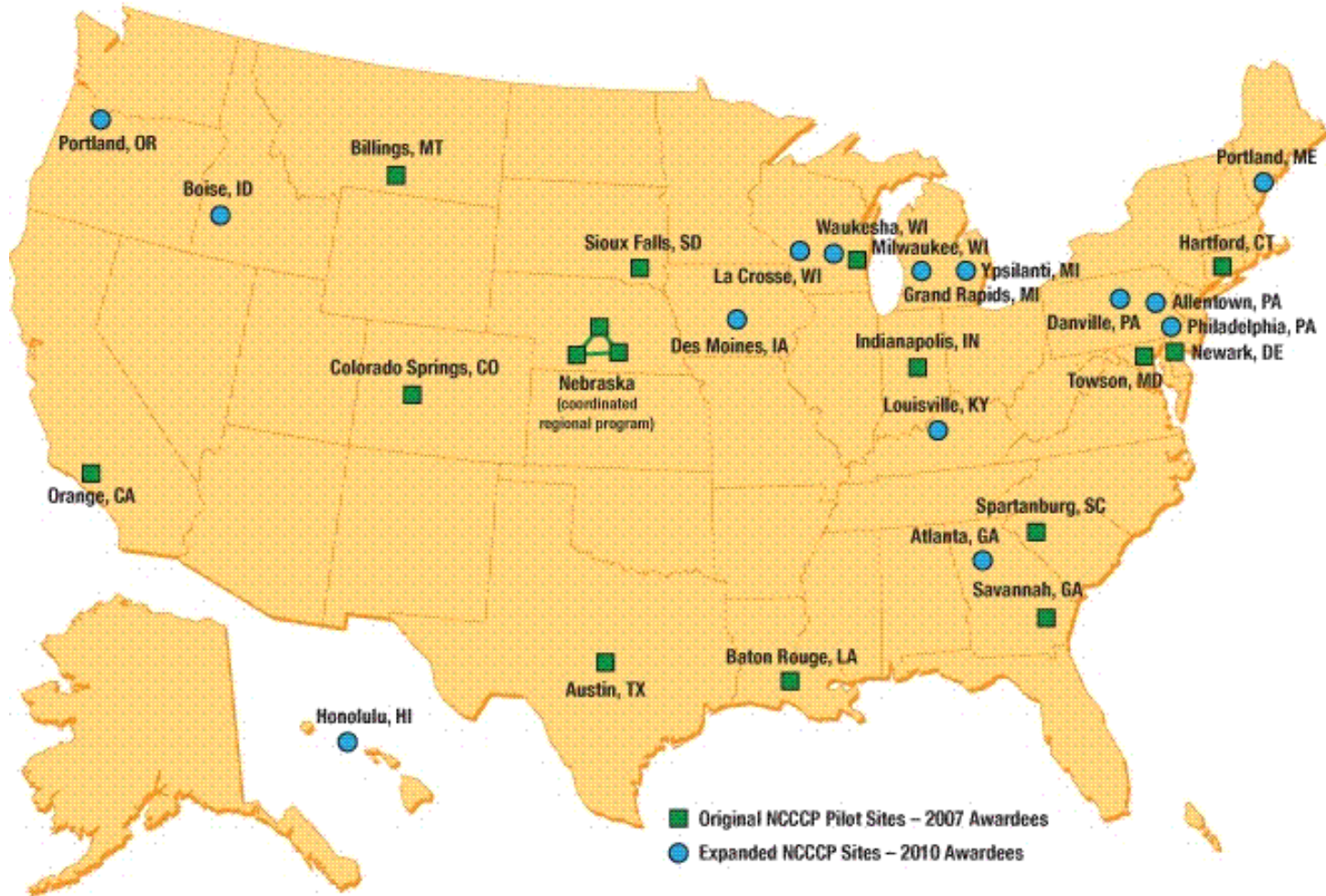


NCCCP



- National network of community cancer centers
<http://ncccp.cancer.gov/>
- The NCCCP seeks to:
 - Bring more Americans into a system of high-quality cancer care
 - Increase participation in clinical trials
 - Reduce cancer healthcare disparities
 - Improve information sharing among community cancer centers

NCI Community Cancer Centers Program
NCCCP Hospitals



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Survey results



- Survey Monkey in May 2011
- NCCCP sites (N=30)
- 22 states
- 100% response rate
- 8/12 have CGC on-site



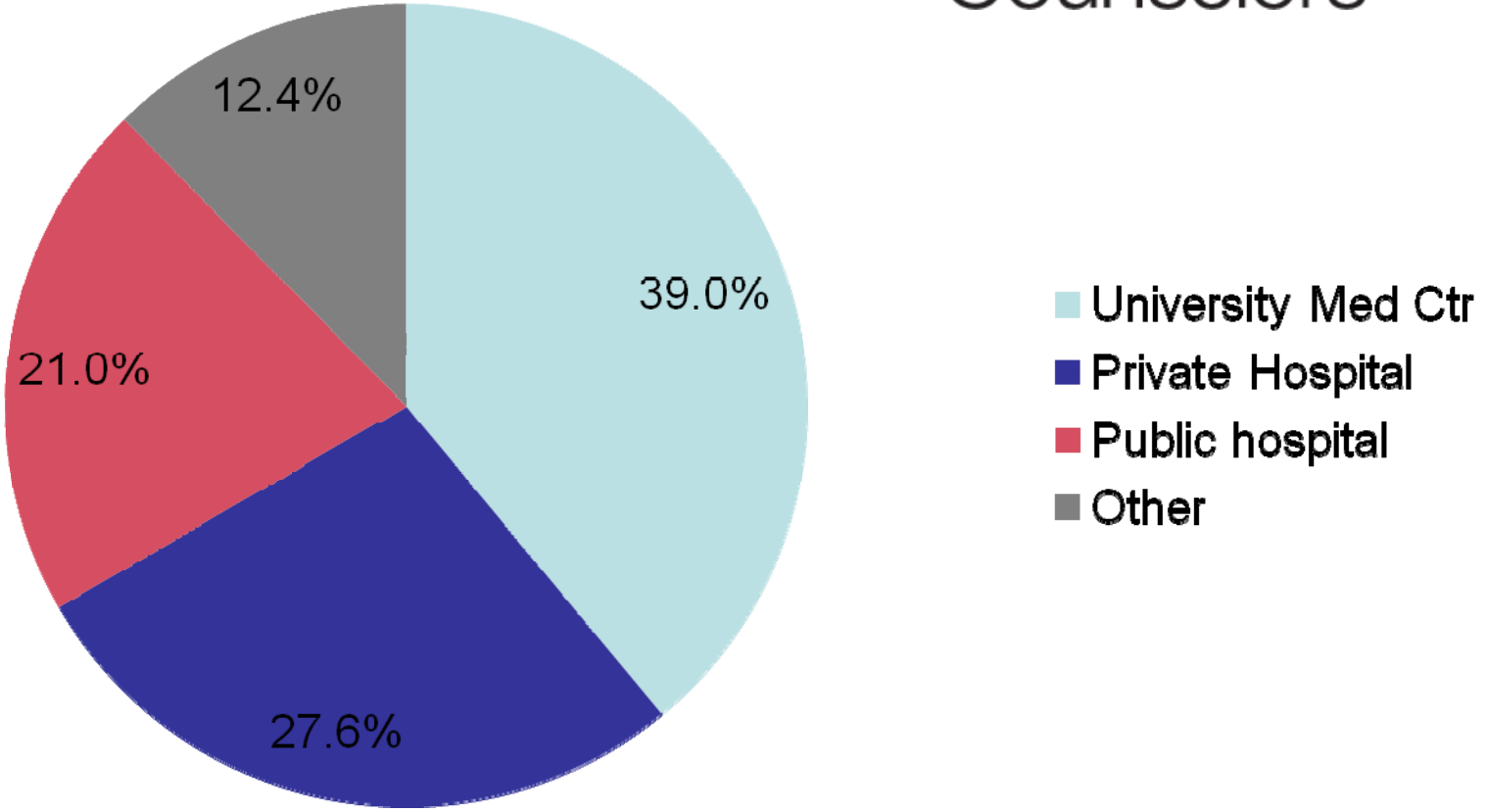
Survey results

- Survey Monkey in July 2011
- 128 responses (membership=633)
 - 20% response rate
- 32 states

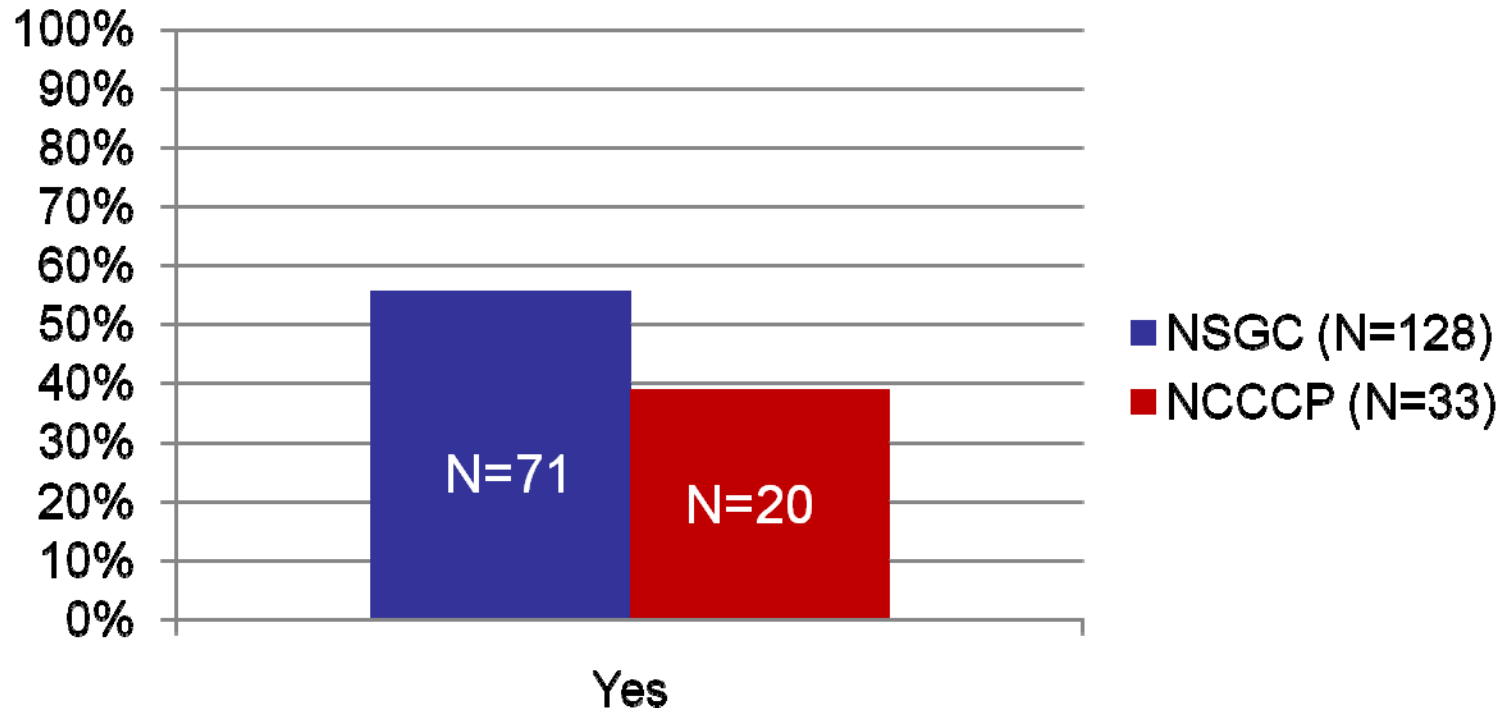
Possible that there is some overlap



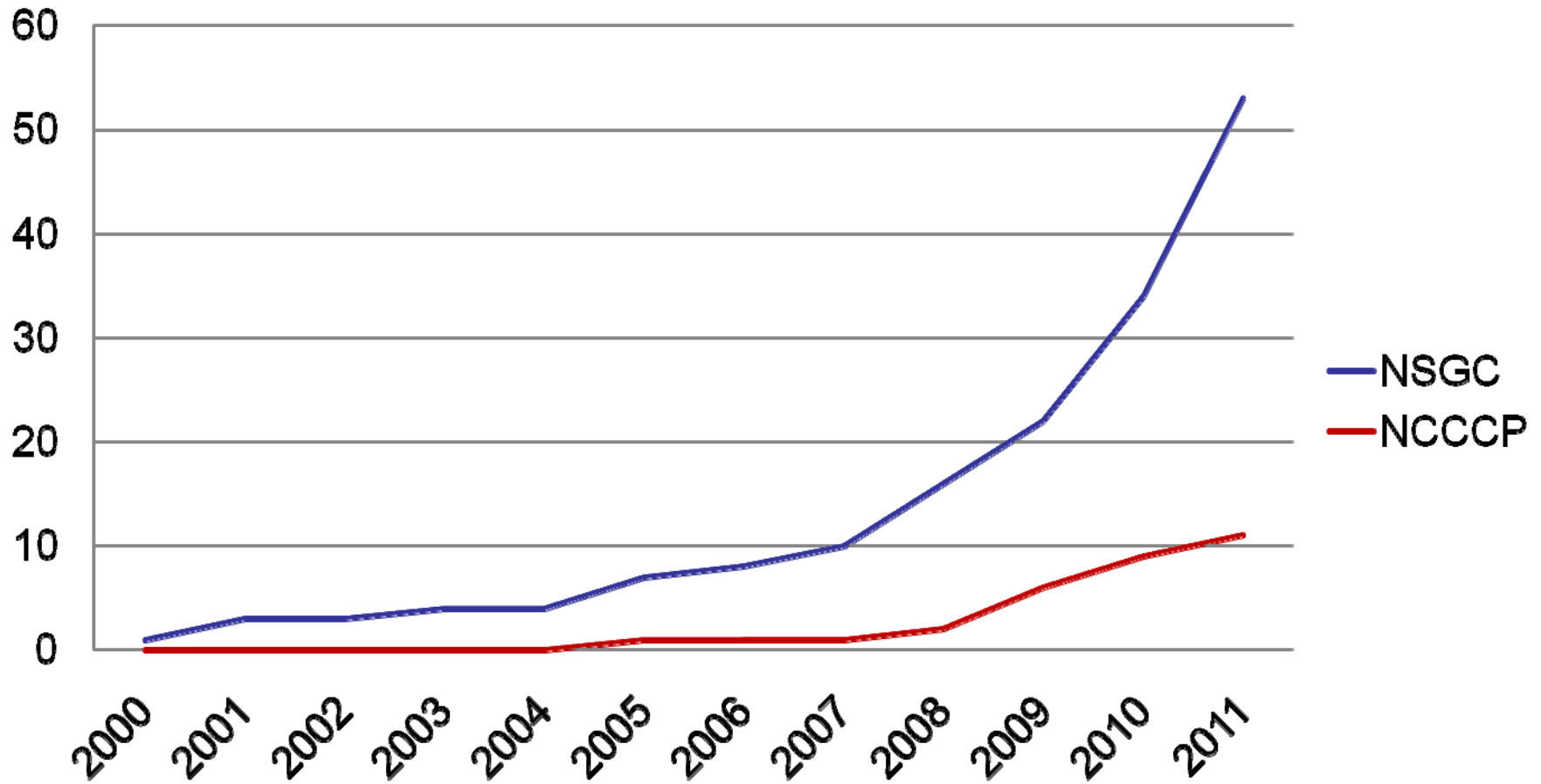
Work setting



Do you have a routine screening program for Lynch Syndrome?



Number of Centers screening by Year

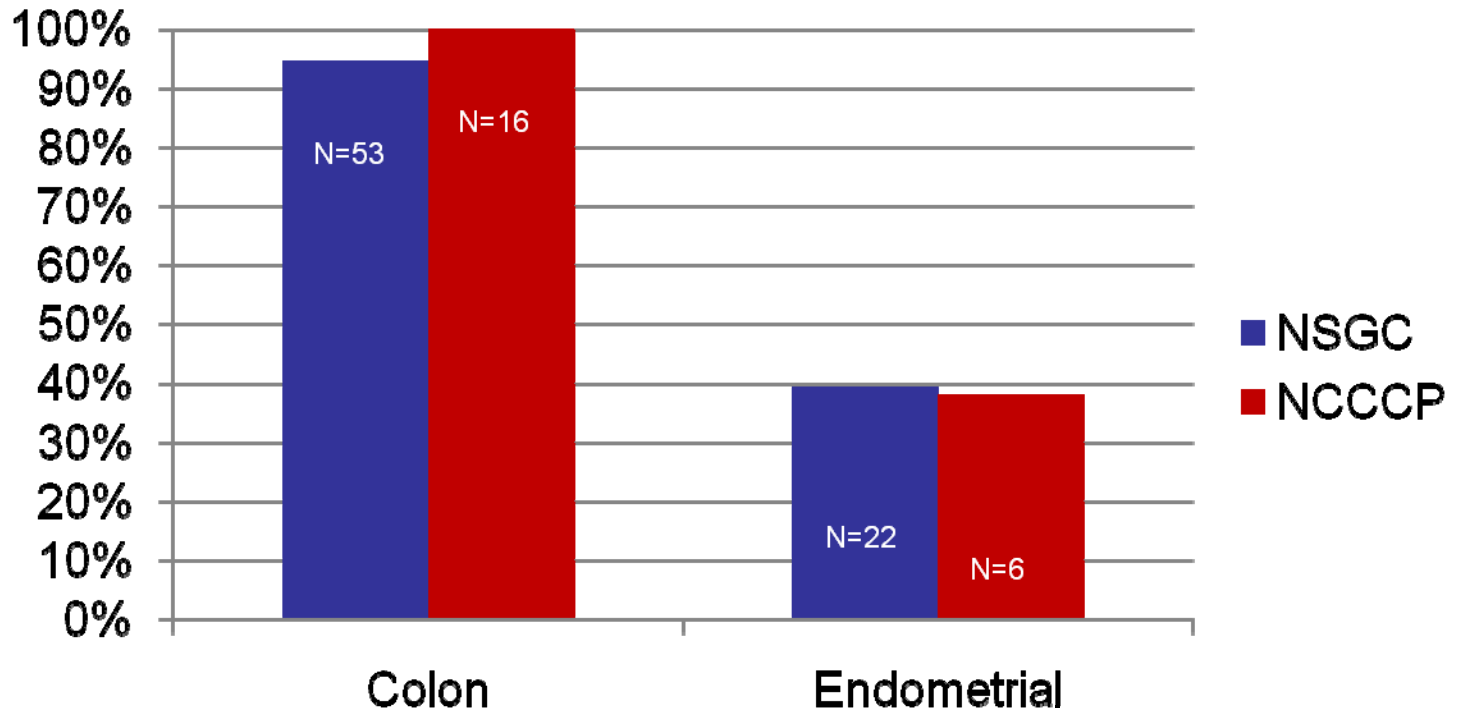


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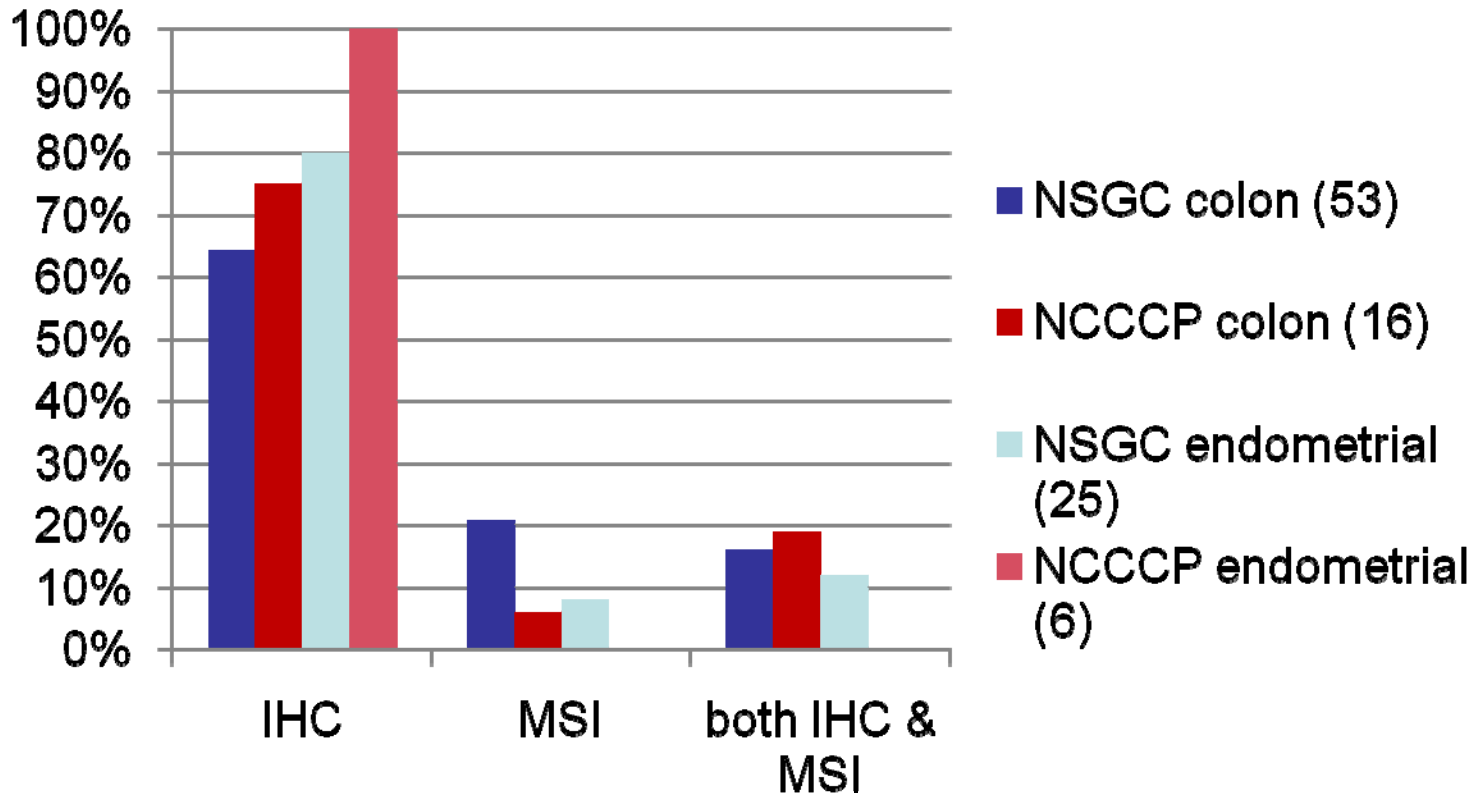


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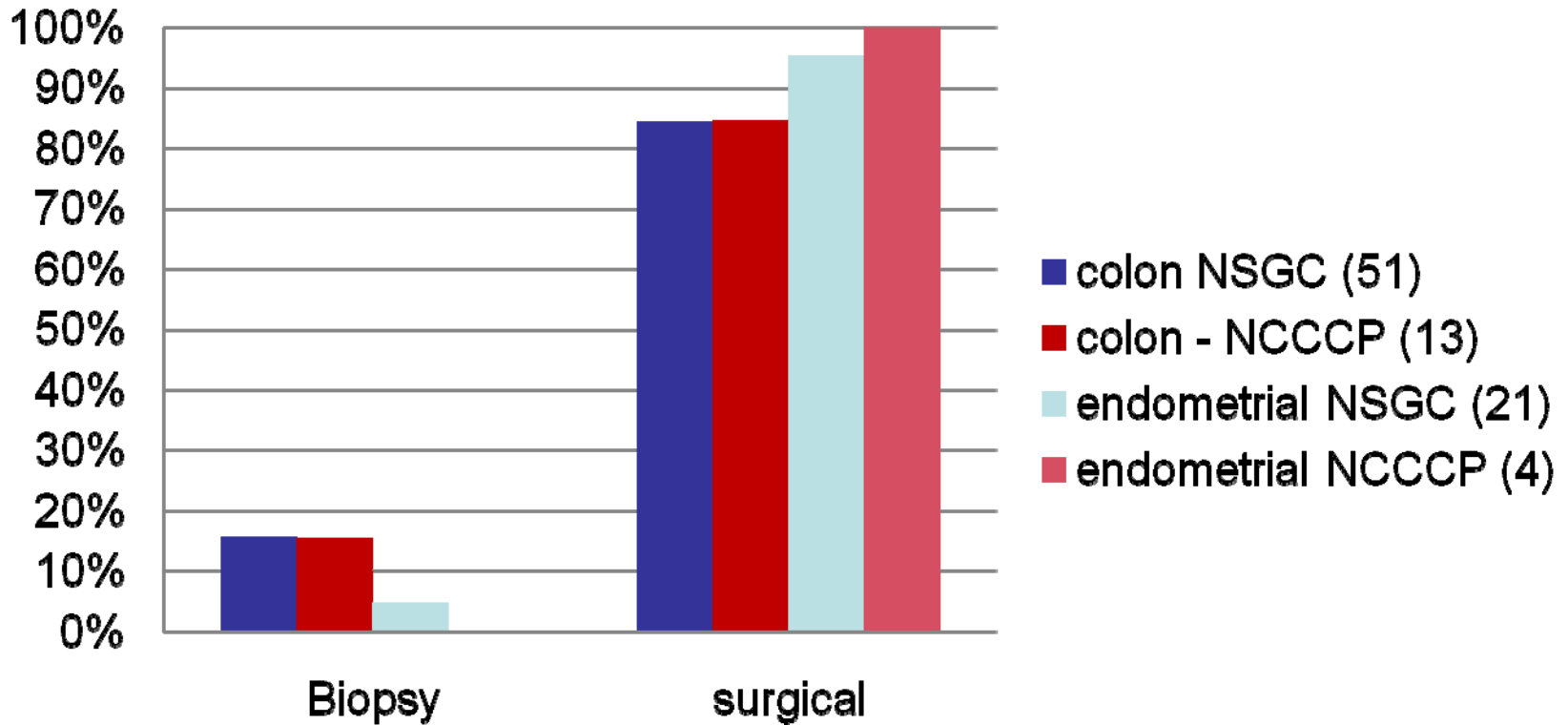
Routine screening performed currently



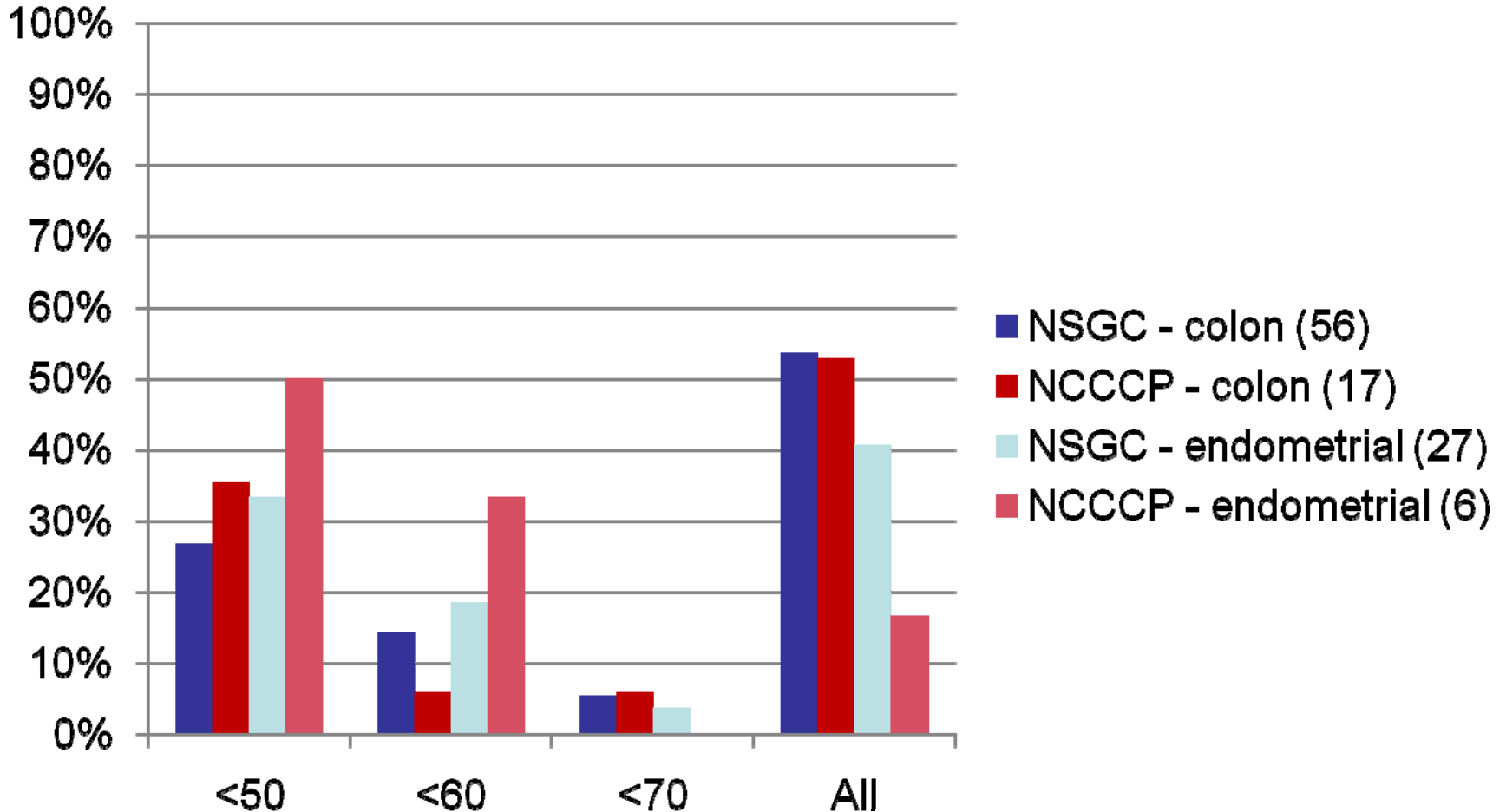
What type of screening to you initially do?



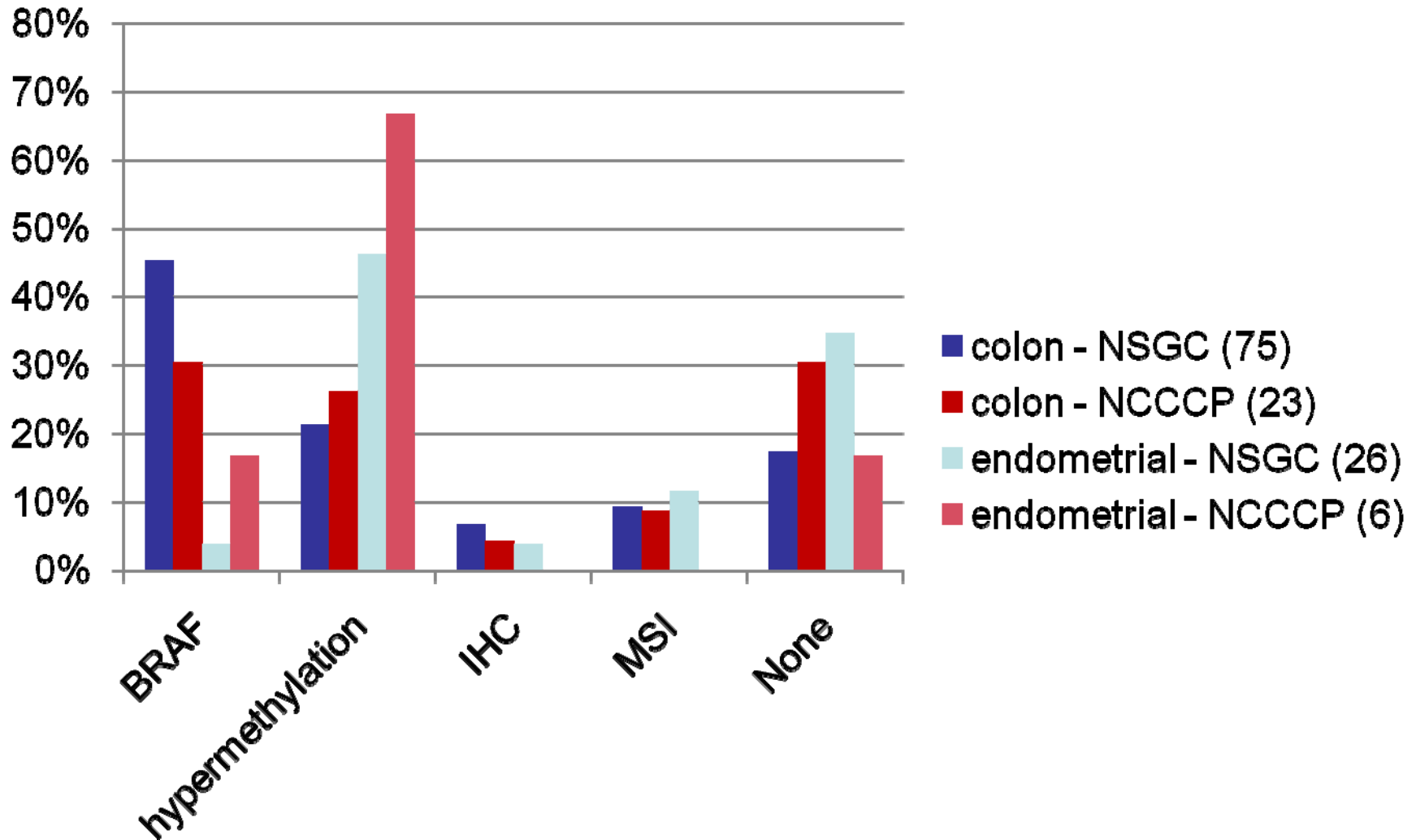
Do you screen biopsy or surgical specimens?



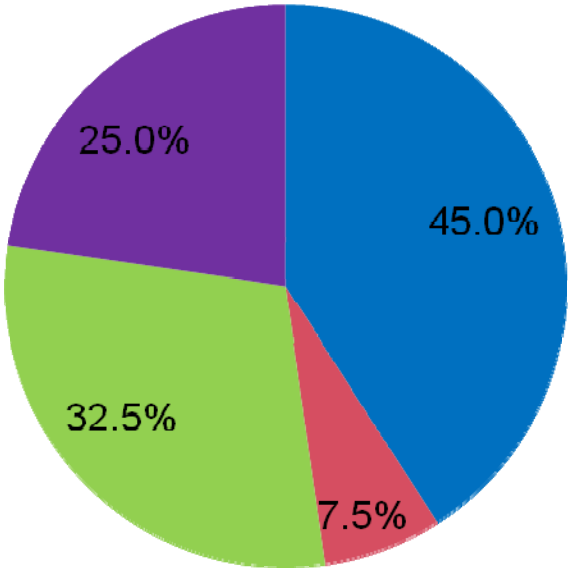
Under which circumstances do you test these tumors?



What type of reflex testing do you do?

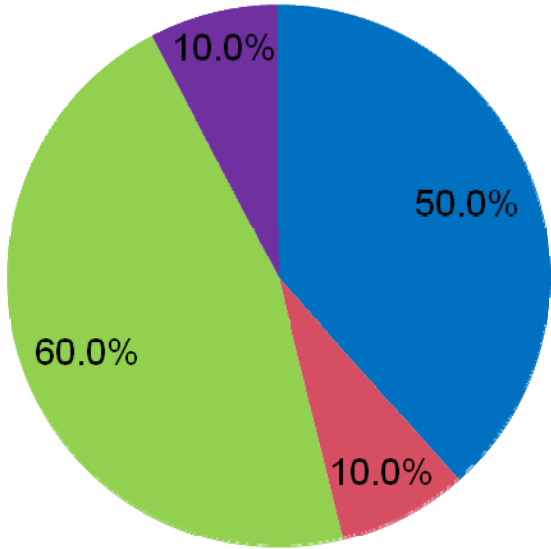


Who orders the reflex testing?



NSGC

- Pathologist
- Surgeon
- Genetic Counselor
- Automatic

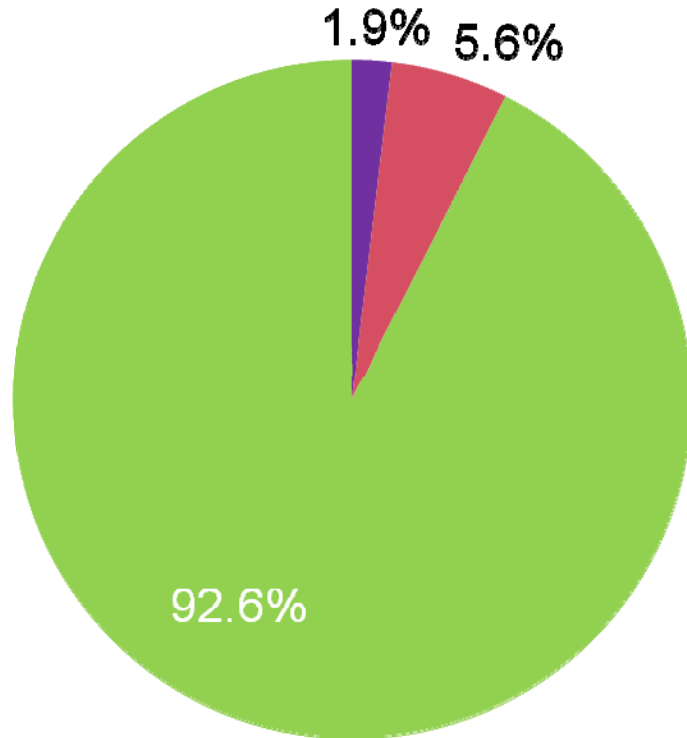


NCCCP



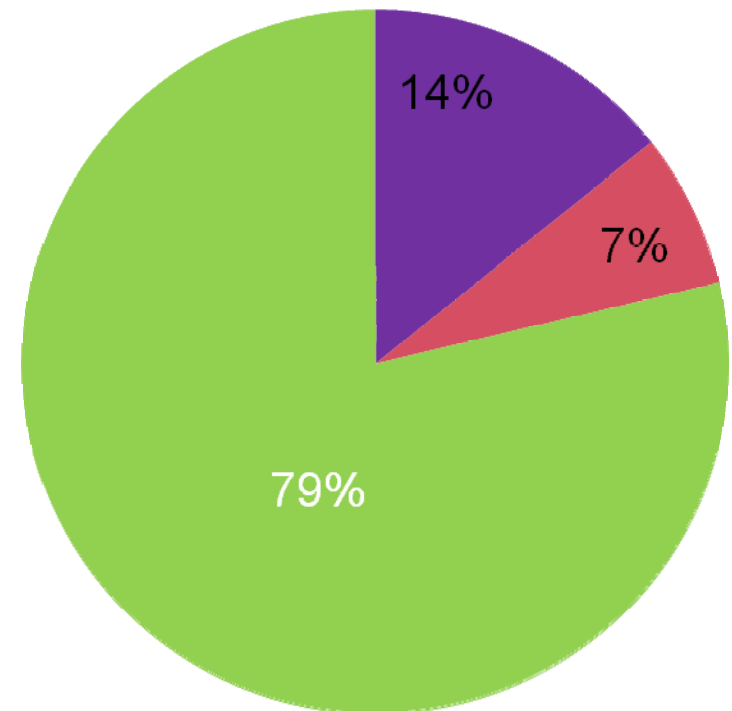
What type of consent do you obtain?

NSGC



31.5% have educational handouts for patients

NCCCP

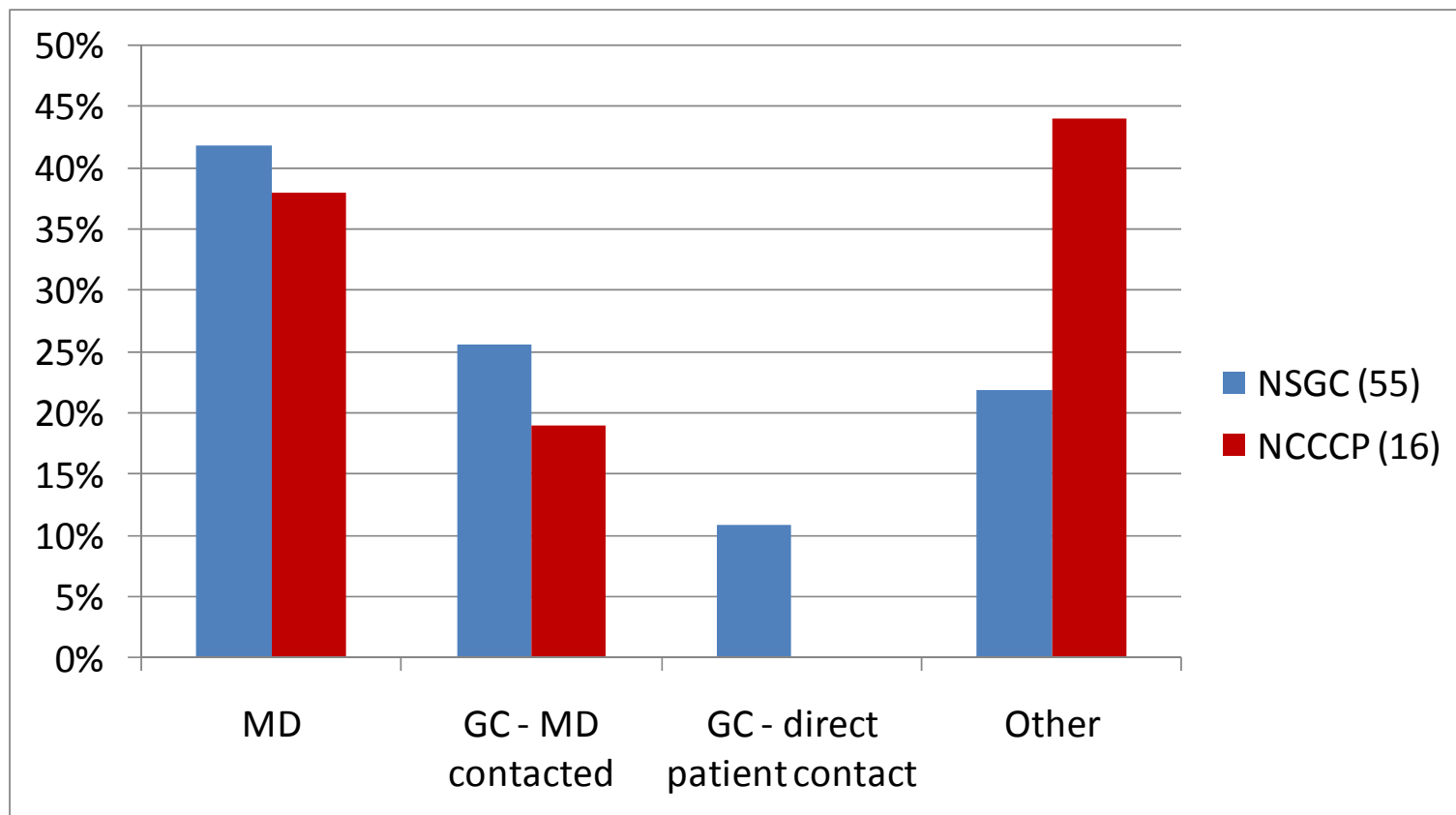


29% have educational handouts for patients

- Verbal
- Written
- None



How are results handled?



Other (NSGC):
Both MD/GC (8)
Case conference (4)

Other (NCCCP):
No systematic method (2)
Genetics gets reports (5)

Have you experienced a lack of patient compliance in follow-up?

	NSGC (N=54)	NCCCP (N=14)
Yes	33.3%	36%
No	51.9%	28%
Don't know/too early to tell	14.8%	35%

Problems with compliance include:

- Difficulty contacting and scheduling patient
- Patients do not show for appointment
- Some patients decline referral
- Not referred



What resources did you use to develop your algorithm*?

- Published literature
- EGAPP
- Other:
 - Input from pathologists and surgeons
 - Modeling after other centers, such as Ohio State
 - NCCN (cited by NSGC only)

*Both NSGC and NCCCP had similar responses



What barriers did you face as you implemented your screening protocol?

Barrier	NSGC (N=51)	NCCCP (N=15)
Convincing medical staff of the necessity	24	6
Getting the right people to the table	20	7
Concern for who was going to pay	18	7
Pathology was reluctant	10	2
Time	8	0
Other	19	6

Other barriers:

- Concern over patient consent
- Lack of results protocol
- Lack of educational resources

How did you overcome these barriers?

Response	NSGC (N=41)	NCCCP (N=13)
Getting support from certain physicians	11	2
Committee Meetings	10	4
Referencing published data	6	2
Education (presentation/course)	4	1
Persistence	4	0
Other	17	7

Other:

- Insurance reimbursement agreement
- Tie to research
- Talk to other centers who are screening
- Came up with firm proposal

If you do not do Lynch screening, select the barriers that apply:

Barriers	NSGC (N=50)	NCCCP (N=13)
Convincing medical staff of the necessity	29	9
Getting the right people to the table	28	9
Concern over who is going to pay	22	6
Pathology reluctant	20	4
Time	9	2
Not convinced it is necessary	0	2
Not interested	0	1
Other	13	4

What would be helpful as you attempt to implement screening for Lynch Syndrome?

Resource	NSGC (N=48)	NCCCP (N=13)
Algorithms	34	10
Journal articles	28	10
PowerPoint presentations	32	9
Other	13	4

Other:

- Funding
- Reassurance that 3rd party payers will reimburse
- Other doctors convincing physicians
- Practice guidelines
- Support from administration



Conclusions

- Screening is taking place
 - ~half (both studies) say they do some type of screening
- There is no unified approach to Lynch screening



Emerging trends

- IHC done most commonly, on surgical specimens
- ~Half are doing truly universal screening for colon cancer
- BRAF most common reflex for colon
- Hypermethylation most common reflex for endometrial
- Consent is not obtained
- Most common method of f/u requires MD to refer
- Follow-up appears to be an issue



Overcoming barriers

- Identify key players & get them to the table
- Educate them to get buy-in



NCCCP action items

- Create a hand-out describing Lynch screening
- Collect reimbursement data
- Suggested standard text in reports
- Study patient compliance/follow-up
- Create bibliography
- Identify key stakeholders
- Share algorithms/powerpoint slides

Thanks to:



- Claire Harwood

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