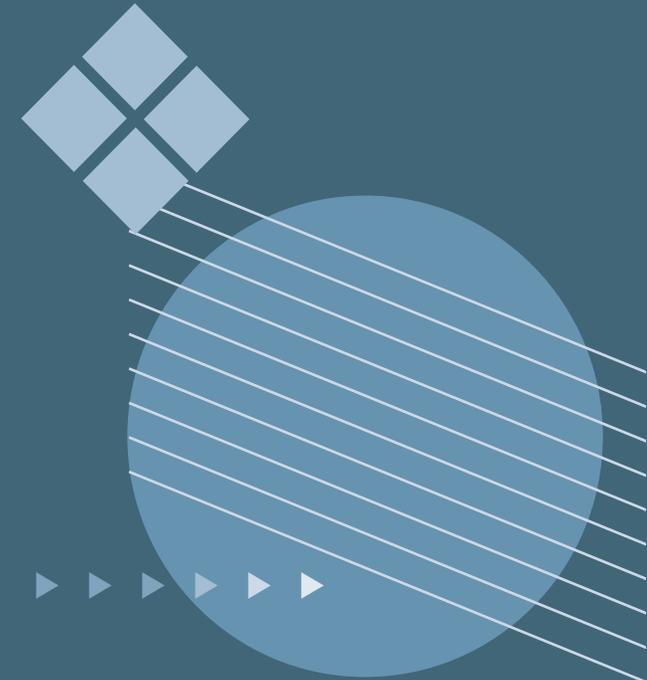


## *Esophageal Adenocarcinoma and Barrett's Esophagus Registry*



**Mayo Clinic  
Rochester, Minnesota**

If you would like to obtain more information about esophagus cancer or Barrett's esophagus please visit these Web sites:

[www.mayoclinic.com](http://www.mayoclinic.com)

[www.niddk.nih.gov/health/digest/summary/barretts/barretts.htm](http://www.niddk.nih.gov/health/digest/summary/barretts/barretts.htm)

[www.fhcrc.org/science/phs/barretts/](http://www.fhcrc.org/science/phs/barretts/)

### **Principal Investigator**

Yvonne Romero, MD  
Mayo Clinic

Thank you for taking the time to consider participation in the registry. If you have questions at any time, please contact our study coordinators:

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## About the study

A group of doctors and scientists at Mayo Clinic in Rochester, Minn., are working to advance the understanding of esophagus cancer and Barrett's esophagus. The main aim of our study is to collect blood and tissue for future testing. After collecting samples, we will perform tests to identify genes that may be involved in the development of esophagus cancer and Barrett's Esophagus.

**Esophagus Cancer** – there are two major types of esophagus cancer:

*Squamous cell cancer* usually arises in the upper part of the esophagus. This type of cancer is most common in older men who use tobacco and alcohol.

*Adenocarcinoma* commonly arises from Barrett's esophagus in the lower part of the esophagus. Although older men who smoke are at the greatest risk, Gastro-Esophageal Reflux Disease (GERD) is an additional risk factor for this type of cancer.

### **Barrett's Esophagus**

Barrett's esophagus is a complication of GERD. In Barrett's esophagus, reflux of gastric contents damage the normal lining of the lower esophagus, which is then replaced by a different type of lining. Patients with Barrett's esophagus have a much greater risk of developing esophagus cancer compared to the general population.

Adenocarcinoma of the esophagus, which usually arises in a Barrett's esophagus, has been increasing in incidence in the United States by four to ten percent per year in recent decades. The cause of the increase is unknown. Similarly, the role of genetic factors in Barrett's esophagus is not known.

### **Who should be involved?**

- People with either squamous cell cancer or adenocarcinoma of the esophagus.
- People with Barrett's esophagus of at least three centimeters length.

Your doctor, or the researchers at Mayo Clinic will be able to inform you if you meet criteria to participate in the study.

### **What is involved?**

As a registry participant, we ask you to:

- Answer questions about heartburn, difficulty swallowing, chest pain, history of previous cancer, tobacco use, beverage consumption and quality of life. These questionnaires may be answered at home. Pre-addressed and postage-paid envelopes are available.
- Donate approximately three and a half tablespoons of blood.
- Give permission to do research on a small amount of tissue removed during scheduled endoscopy or surgery. To use and study your tissue or blood, we need your informed, written consent.

### **What are the costs of participation?**

There are no monetary costs to you as part of your participation in the study. Some of your time will be spent completing questionnaires and having your blood drawn. If you chose not to participate, you will not jeopardize present or future medical care and treatment by your doctor or doctors at Mayo Clinic.

### **What are the benefits of participation?**

There may be no direct clinical benefit to participants in this important research project. Participants in this research project may assist researchers to improve their understanding of esophagus cancer and Barrett's esophagus. This knowledge could lead to new ways to help people at increased risk for esophagus cancer, as well as new treatments for treating and preventing esophagus cancer.

### **What about my privacy?**

All data from the registry will be used for research purposes only. Test results will not become a part of your medical record. Results may be published in a scientific journal, but your identity will not be released without your permission. This is in keeping with Mayo Clinic's policy of patient confidentiality

### **What happens next?**

Once you have given us your written permission we will obtain small bits tissue if you have an endoscopy or surgery as is necessary for your medical care. You will be asked to answer one or two questionnaires on an annual basis. We may contact you on your subsequent visits to the Mayo Foundation hospitals.

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